



Funded by the
Nordic Council
of Ministers

Nordic model for collaboration on the secondary use of health data: *steps towards implementation*

Report 5.0

Value from Nordic health data – VALO2 project

1 October 2026





Document info

0.1 Authors

Author	Partner
Rebekka Bjorg Gudmundsdottir	Directorate of Health, Iceland
Védís Helga Eiríksdóttir	Directorate of Health, Iceland
Sigríður Haraldsd. Elínardóttir	Directorate of Health, Iceland
Jenina Soimala	Finnish Institute for Health and Welfare (THL)
Mari Mäkinen	Finnish Institute for Health and Welfare (THL)
Michael Peolsson	Swedish eHealth Agency (SEHA)
Michel Silvestri	Swedish eHealth Agency (SEHA)
Mika Gissler	Finnish Institute for Health and Welfare (THL)
Mikael Rinnetmäki	The Finnish Innovation Fund Sitra
Persephone Doupi	Finnish Institute for Health and Welfare (THL)
Zuzana Nordeng	Norwegian Institute of Public Health (FHI)

0.2 Keywords

Keywords	Health data, Nordic, EHDS, Nordic Model, secondary use, governance, collaboration, VALO
-----------------	---

Disclaimer

The content of this report represents the views of the author(s) and do not necessarily reflect the views of the experts interviewed.

Copyright Notice

Copyright © 2026 The VALO2 Project – contributing parties and authors identified in this report.

This work is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License (CC BY-NC), (<https://creativecommons.org/licenses/by-nc/4.0/>). Other uses require the written permission of THL and Sitra.

Table of Contents

List of abbreviations	3
List of terms and definitions	4
Executive summary	5
Introduction	7
The VALO projects	7
The Nordic model for collaboration on the secondary use of health data	9
From project to long-term collaboration	12
Recommendation 1: Establish a Nordic Health Data Coordination Committee	14
Foundation	15
Action	15
Nordic Added Value, Impact and Efficiency	16
Proposed steps for Implementation	18
Recommendation 2: Establish a permanent Secretariat	19
Foundation	20
Action	20
Nordic Added Value, Impact and Efficiency	21
Proposed steps for Implementation	23
Recommendation 3: Endorse and resource a permanent Nordic Health Data Competence Forum	24
Foundation	25
Action	25
Nordic Added Value, Impact and Efficiency	26
Proposed steps for Implementation	28
Recommendation 4: Support an annual Nordic Health Data Summit	29
Foundation	30
Action	30
Nordic Added Value, Impact and Efficiency	31
Proposed steps for Implementation	33
A phased path forward	34
First phase	34
Second phase	35
Longer term development	35
Funding the Nordic Health Data Coordination Network	38
What needs to be funded	38
Funding options	39
Conclusion	41
References	42



List of abbreviations

Abbreviation	Full Term
CoP	Community of Practice
EEA	European Economic Area
EHDS	European Health Data Space
EHDS2	European Health Data Space, for the secondary use of health data
EHR	Electronic Health Record
EU	European Union
GDPR	General Data Protection Regulation
HDAB	Health Data Access Body
NCM	Nordic Council of Ministers
NordClass	The WHO-FIC Nordic Centre for Classifications in Health Care
NordDRG	Nordic Diagnosis-Related Groups
NOMESCO	Nordic Medico-Statistical Committee
NOSOSCO	Nordic Social Statistical Committee
TEHDAS2	Second Joint Action Towards the European Health Data Space
VALO	Value from Nordic Health Data
WS1/WS2/WS3	Workstream 1/2/3 (of the VALO project)



List of terms and definitions

Term	Definition
Nordic Health Data Coordination Network	The proposed permanent policy-alignment and implementation structure for Nordic collaboration on primary and secondary use of health data, led by a Nordic Health Data Coordination Committee (Recommendation 1), supported by a permanent Secretariat (Recommendation 2) and thematic expert working groups.
Nordic Health Data Competence Forum	A proposed permanent forum (Recommendation 3) bringing together authorities, experts, and practitioners to coordinate approaches, share experience, and support EHDS implementation across the Nordic countries — building on the Nordic EHDS2 Competence Forums.
Nordic Health Data Summit	A proposed annual convening event (Recommendation 4) bringing together the wider Nordic Health Data Ecosystem to share progress and strengthen collaboration.
Nordic Health Data Ecosystem	The overall system formed by the Nordic Health Data Coordination Committee, Secretariat, Nordic Health Data Competence Forum, and Summit together, plus the broader community of stakeholders who work with, contribute to, or benefit from the use of health data across the Nordic region — including researchers and research funding organisations (both national and Nordic), healthcare providers and workforce, public authorities, industry, patient organisations, and citizens.



Executive summary

This report is addressed to the Nordic Council of Ministers (NCM), concerned national ministries and authorities, and other Nordic health data stakeholders. The Nordic countries are in a strong position to make effective use of health data. Decades of investment in national health registers, the use of personal identity numbers that make linking data possible, and high levels of trust in public institutions provide a solid foundation. Together with the wider Nordic-Baltic region, this represents a population and research base at a scale no single country can achieve alone. Nevertheless, this advantage remains underused. Cross-border collaboration on health data continues to be fragmented. Researchers report that cross-border studies are often abandoned – not because relevant data is unavailable – but because accessing it is not feasible within practical timelines. Also, industry actors avoid cross-border data projects altogether due to the complexity and time involved.

The Value from Nordic health data (VALO) project was launched in 2024 and extended in 2025 (VALO2) to strengthen Nordic collaboration on the secondary use of health data, support joint preparation for the EU's European Health Data Space (EHDS), and test cross-border collaboration in practice. Through extensive engagement with stakeholders across all five Nordic countries, VALO has developed the Nordic model for collaboration on the secondary use of health data. The model is built around four key groups of actors (researchers; innovators; citizens and patients; and healthcare providers and workforce), supported by a common governance structure that enables coordinated collaboration.

This report focuses on the governance arrangements, since the other elements of the model depend on these arrangements being established. The focus of the VALO projects has been on the secondary use of health data, and the recommendations below reflect that focus. However, as the work developed, the close connection between primary and secondary use became increasingly clear. Thus, the proposed governance structure has been designed so that its mandate can extend to primary use. The report presents four recommendations that set out the initial steps required to move from project-based collaboration to a permanent and sustainable structure:

1. **Establish a Nordic Health Data Coordination Committee** – building on the existing NCM eHealth Group, with a rotating presidency aligned to the NCM cycle.
2. **Establish a permanent Secretariat** – to provide institutional continuity and knowledge maintenance across presidency rotations.
3. **Endorse and resource a permanent Nordic Health Data Competence Forum** – adopting the proven operational structure built through VALO, meeting regularly to support national authorities and expert working groups through EHDS implementation and beyond.
4. **Support an annual Nordic Health Data Summit** – a public forum convening the whole ecosystem, building on events already run under VALO.

None of these recommendations requires the creation of new structures from scratch. Each recommendation builds on the arrangements and partnerships developed and tested through VALO, as well as earlier Nordic collaboration and initiatives in health data. Together, they are designed to work as a single, coherent structure rather than separate,



project-based initiatives. The key requirement now is a commitment from the NCM and national authorities to formalise and sustain these structures with funding and political support, so that decades of national investment in health data can be translated into durable, shared Nordic – and increasingly Nordic-Baltic – advantage.



Introduction

The Nordic countries have a long tradition of using health data for research, development, and innovation. Rich national registers stretching back over fifty years, personal identity numbers enabling precise linkage across datasets, enabling legislation, and high public trust in institutions and research — these are the foundations that make the Nordic region genuinely distinctive in a global context. (1) For many years, the Nordic countries have systematically collected and structured a wide range of health data and were early pioneers in establishing legislation for its secondary use. Together, these complementary resources constitute unique research infrastructure that supports research and the knowledge-driven development of healthcare, forming a regional asset that no other part of the world can easily replicate. Combined, the Nordic – or Nordic-Baltic – countries also represent a population large enough to support health research and innovation at a scale no single Nordic country can achieve alone, approaching that of larger nations. (2)

Despite the Nordic advantages, they have not been fully utilised. Cross-border collaboration on health data has remained fragmented and difficult. Access timelines are long, the General Data Protection Regulation (GDPR) has been interpreted differently across countries, administrative processes are duplicated at every border, and transferring data between Nordic countries carries additional cost and complexity. Researchers describe abandoning cross-border studies not because the data does not exist, but because accessing it within realistic project timelines is not feasible. Industry actors describe avoiding cross-border data integration entirely. (3)

The experience of GDPR implementation, where the Nordic countries proceeded largely in parallel without coordinating their interpretations or approaches, illustrates what can happen when a shared legal framework meets five separate national systems with no Nordic-level coordination, resulting in fragmented compounds, and the collective advantage of the region is diluted rather than amplified.

The VALO projects

The Value from Nordic Health Data (VALO) project was established to address these challenges. Its aim is to strengthen Nordic collaboration in the secondary use of health data, to support joint preparation for EHDS implementation, to test cross-border collaboration in practice, and to help maintain a strong Nordic position in value-creating health data use. It was launched in 2024 as a collaboration between Finland, Iceland, and Sweden, with Denmark and Norway as observers. VALO2, began in April 2025, expanding the partnership to all five Nordic countries as full partners, with Estonia and Lithuania joining as observers and bringing a Nordic-Baltic dimension to the collaboration. No Nordic forum existed for active preparation and implementation of the EHDS regulation on the secondary use of health data. The NCM eHealth group (4,5) serves as an active forum for collaboration in the field of digital health. Its focus to date has been largely on the primary use of health data, approaching secondary use needs through the infrastructure built for primary use (see definitions on primary and secondary use in box 1).

The main focus of the VALO projects is on the secondary use of health data, and the recommendations in this document reflect the domains experiences and expertise.



However, as our work developed it became increasingly clear that the primary and secondary use of health data are closely connected and cannot be governed entirely in isolation from each other. The governance structure proposed in this report is therefore deliberately designed so that its mandate can also cover primary use as Nordic and European structures evolve in tandem.

The European Health Data Space (EHDS) Regulation has now entered into force, and EU and EEA countries are in the preparation phase for its implementation. The EHDS addresses many of the challenges created by fragmented legal frameworks, but no EU regulation can fully eliminate national variations. While EU regulations are directly applicable, their implementation still takes

place within existing national legal systems, administrative structures, and technical infrastructures. As a result, some differences in interpretation and practical implementation are likely to persist. The EHDS regulation itself explicitly leaves certain aspects of implementation open to national interpretation, reinforcing this expectation. National frameworks and infrastructures will therefore remain, to some extent, distinct. At the same time, European-level initiatives such as the Second Joint Action Towards the European Health Data Space project (TEHDAS2) (7) and the Community of Practice (CoP) (8) are necessarily designed to accommodate a wide range of national contexts and levels of digital maturity across EU and EEA countries. While this broad approach is essential at the European level, it also means that common solutions may not fully address all operational challenges related to cross-border data use in every setting. To

ensure that the full potential of the EHDS is realised in practice, complementary coordination at regional level is needed. For the Nordic and Baltic countries, this creates a clear policy imperative to strengthen collaboration, align implementation approaches where feasible, and develop shared solutions that facilitate efficient cross-border access and use of health data. Without such coordination, there is a risk that existing fragmentation will persist, limiting the overall impact of both national investments and European initiatives.

The VALO project builds on previous Nordic initiatives, including the Nordic Commons project. (9) Across VALO and VALO2, three interconnected workstreams have developed in parallel. The first workstream (WS1) focused on developing a Nordic model for collaboration on the secondary use of health data. The second workstream (WS2) has established and sustained a Nordic EHDS2 Competence Forum. (10) The third workstream (WS3) has piloted cross-border Nordic collaboration in health data reuse in practice.

Box 1. Primary and secondary use of health data

Health data originates primarily in the encounter between patient and healthcare provider, held under legal and ethical obligations that reflect that origin. As defined in the EHDS Regulation, *primary use* refers to the direct application of electronic health data in individual patient care — for example, a clinician accessing a patient's records, or data drawn from patient summaries and ePrescriptions to support healthcare delivery. *Secondary use* refers to the broader application of health data beyond direct patient care, encompassing individual-level or aggregated datasets used for research, innovation, policymaking, and regulatory activities, e.g. public health analysis and statistical reporting. (6) Not all data used for secondary purposes originates in patient care, e.g. cohort studies are also important sources of health data.



(11,12) Together, these workstreams have generated a set of practical outputs to support a coordinated cross-border use of health data. The following sections present the proposed Nordic model developed under WS1, along with recommendations for next steps and further implementation.

The Nordic model for collaboration on the secondary use of health data

The VALO project has developed a proposal for how the Nordic-Baltic countries can best collaborate on the secondary use of health data. This includes facilitating joint preparations for, and coordinated implementation of, the EHDS. The proposed Nordic model for collaboration on the secondary use of health data is presented visually in figure 1 and its development is described in detail in the interim report – *The Nordic model for collaboration on health data: Insights from an evolving process*. (13) The model identifies the main groups of actors involved and is based on the triple helix model of innovation which highlights the interaction between research, industry, and public institutions. (14,15) Additionally, it has been adjusted and refined through stakeholder research, workshops, and expert engagement across all five Nordic countries. (3) The model's underlying value proposition is summarised in Box 2.

The helix framework (15) is adapted here into a quadruple helix consisting of four interdependent components representing the main groups of actors who create and benefit from Nordic health data collaboration: Research Collaborations and Statistics, Innovation, Citizens and Patients, and Healthcare Providers/Healthcare Workforce. Research Collaborations and Statistics, and Innovation represent two complementary aspects of secondary use (described in Box 1). Citizens and Patients represent the individuals whose data is used and who stand to benefit from it, and Healthcare Providers occupy a dual role, recording the underlying data while also applying the outputs of research and innovation in care. At the centre sits the Driver, a coordinating function that aligns the components and maintains the governance architecture. Governance serves as an overarching layer that frames all components of the model and is the starting point for this report, as the other components depend on it. Without a shared governance structure in place, collaboration on research, innovation, patient and provider engagement cannot develop coherently. This governance structure provides the enabling condition that makes such collaboration possible in the first place. The four recommendations that follow, each address the establishment and operationalisation of this governance structure. Other parts of the model remain important but fall mostly outside the scope of this report, aside from elements such as the Nordic Health Data Summit, that cut across governance and the other components.

Box 2. The Nordic model's core value proposition

The model's core value proposition is to create a Nordic environment that empowers stakeholders to collaborate in advancing the use of health data for research, development, innovation, and policymaking, to benefit health, wellbeing, and economic prosperity. (3)

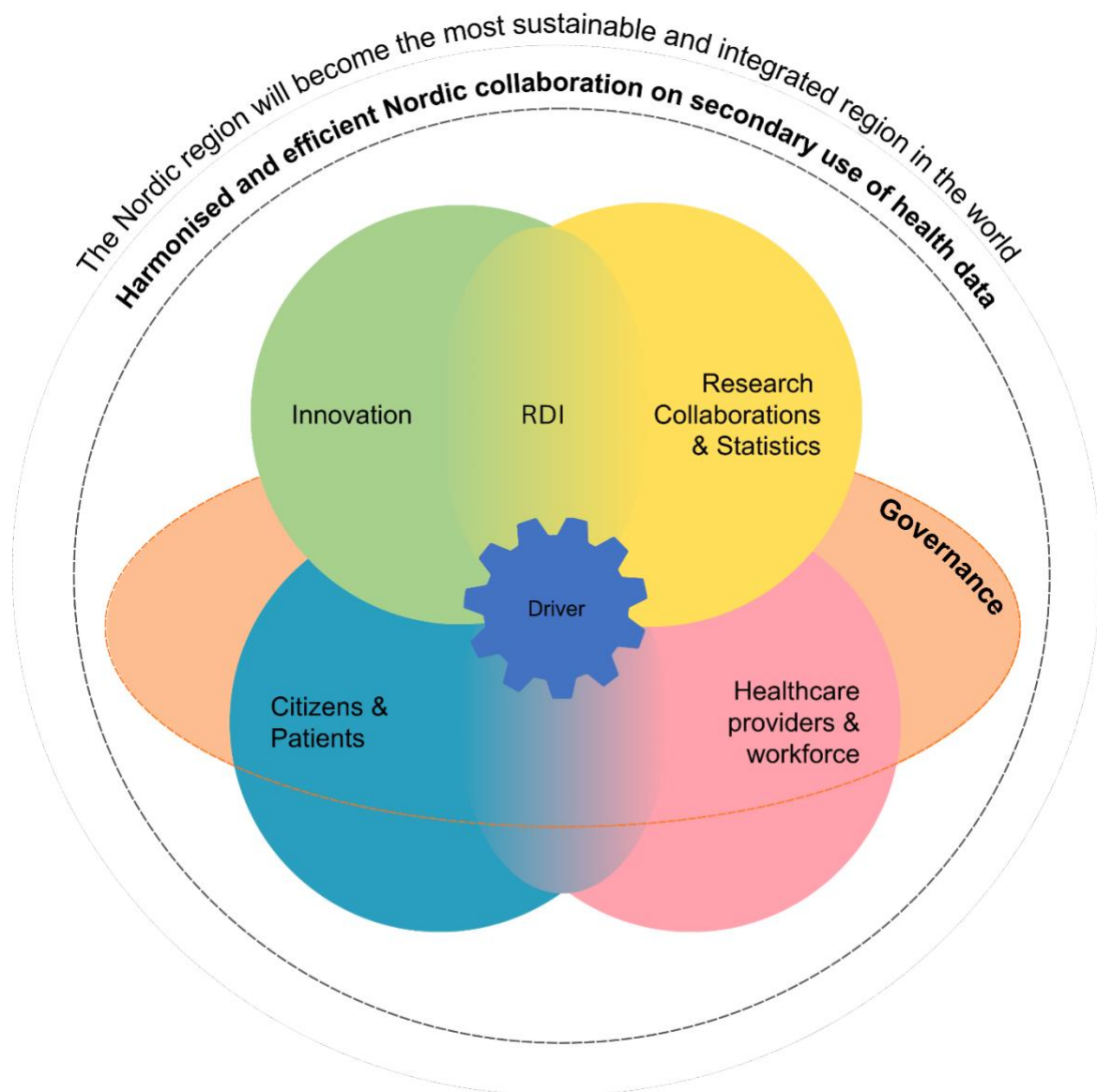


Figure 1. Nordic model for collaboration on secondary use of health data.

The proposed governance structure for the Nordic model consists of two interconnected levels: policy alignment and implementation level and thematic expert working groups, as illustrated in Figure 2.

The policy alignment and implementation level provides the strategic direction and coordination of the model. It comprises the Nordic Health Data Coordination Committee, the Secretariat and the representative(s) of the country holding the NCM presidency. Together these elements form the central driving force of the governance model, referred to as the Driver. The Committee sets priorities and provides stable coordination, and national ownership required for effective Nordic health data governance. The Committee sets priorities and makes decisions by consensus, while the presidency country holds overall responsibility for the annual work programme under the NCMs' rotating presidency cycle.



The Secretariat is intended to provide a stable operational support across the governance structure. Its role is to assist the Committee and the thematic expert working groups, facilitate coordination between strategic and technical work, and ensure continuity in the day-to-day work.

The thematic expert working groups (the area of work of which may vary over time) form the second level of the governance structure. These groups are tasked with developing and suggesting recommendations and practical solutions in defined areas, which the Committee is responsible for reviewing and acting on, e.g. by promoting the recommendations' advancement within each country.

Together, these two levels make up what this report refers to as the Nordic Health Data Coordination Network. The Network operates within the wider Nordic Health Data Ecosystem and serves as the coordinating mechanism between policy objectives and practical implementation (Figure 2). While the model initially focused on secondary use of health data, it is designed to include primary use.

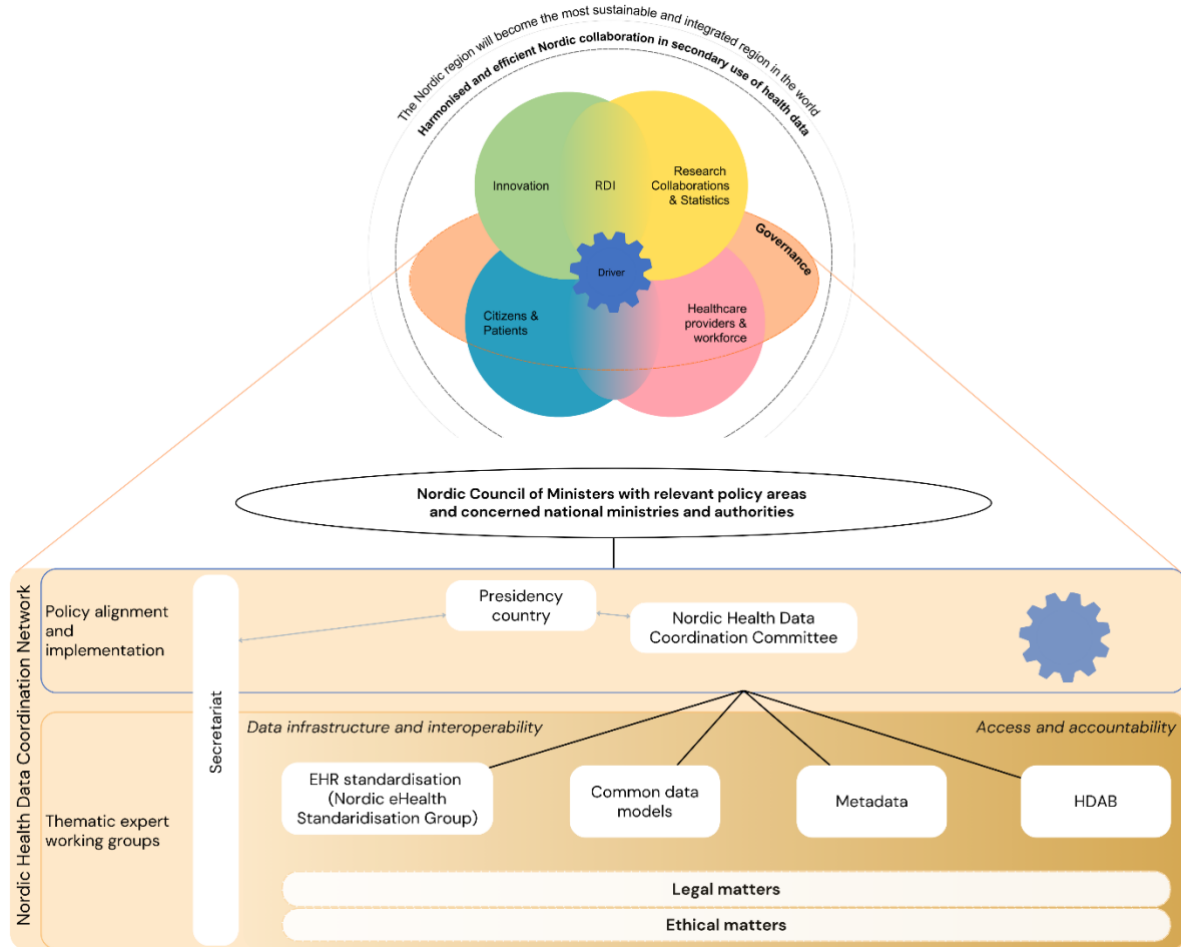


Figure 2. Governance layers of the Nordic model.

From project to long-term collaboration

The VALO projects has demonstrated that there is a genuine appetite for coordinated Nordic health data governance across the region – among researchers, permit authorities, industry actors, patient organisations, and policymakers. (3,13) What it has also made clear is that project-based coordination, however effective, has structural limits. The VALO projects are time-limited with a defined mandate, funding framework, and timeline. It cannot, on its own, provide the sustained political mandate, the formal NCM recognition, or institutional continuity for the Nordic Health Data Ecosystem to operate at the level necessary for EHDS implementation and to endure beyond individual project cycles.

To ensure continuity beyond individual projects and funding cycles, the proposed governance structure developed through WS1 of the VALO projects should be the first step towards the harmonised and efficient collaboration outlined in the Nordic model. Priority was therefore given to developing recommendations for these initial steps needed to establish a more coordinated Nordic Health Data Ecosystem.

This document presents four recommendations to the NCM, the ministries and relevant national authorities of the Nordic-Baltic countries, and other Nordic health data



stakeholders, on the initial steps needed to establish and operationalise the Nordic model for collaboration on secondary use of health data (Figure 1) on a permanent and sustainable basis. The recommendations build directly on the outputs and results of the VALO projects:

- **Recommendation 1: Establish a Nordic Health Data Coordination Committee** building on the existing NCM eHealth Group, with a rotating presidency aligned with the NCM cycle.
- **Recommendation 2: Establish a Permanent Secretariat** to provide institutional continuity and knowledge maintenance across presidency rotations.
- **Recommendation 3: Endorse and Resource the Nordic Health Data Competence Forum** building on the successful structure developed through VALO, meeting on a regular basis to support national authorities through the EHDS implementation period and beyond.
- **Recommendation 4: Support an Annual Nordic Health Data Summit** a public forum convening the whole Nordic Health Data Ecosystem, building on events previously organised under VALO and VALO2.

Recommendation 1:
Establish a Nordic Health Data Coordination
Committee

Foundation

With the EHDS now in force across the EU, the Nordic and Baltic countries are entering a critical phase of implementation. National decisions on interpretation and application will shape the health data landscape for years to come. As seen with the GDPR, limited coordination in implementing a shared European framework can lead to fragmentation across legal, administrative, and technical domains, with effects that persist over time. Central to this phase is the designation of national Health Data Access Bodies (HDABs), which each country is required to establish under the EHDS framework to oversee secondary use of health data.

The VALO project was established to address these coordination challenges in the context of EHDS implementation. Through the invitation-only Nordic EHDS2 Competence Forums, it has created a platform where Nordic authorities responsible for EHDS2 implementation can meet regularly, exchange experiences and seek alignment in their approaches. In practice, the Nordic EHDS2 Competence Forum met approximately three times per year, roughly four months apart. However, as noted above, a project-based platform cannot on its own provide the permanent political mandate or continuity Nordic Health data governance now needs.

Looking ahead, a more durable structure for Nordic collaboration in health data governance is required. The proposed governance structure of the Nordic model illustrated in Figure 2, outlines such an approach. In this model, a policy-alignment and implementation level, comprising the Presidency country, a Nordic Health Data Coordination Committee and a Secretariat, operates under the overarching framework of the NCM and relevant policy areas (e.g. Health and Social Affairs, Sustainable Growth, Digitalisation and Education, Research and Languages). This structure should also guide the thematic expert working groups. This recommendation focuses on aligning policies and supporting their implementation within each participating country.

A strong and practical foundation already exists on which to build. The NCM eHealth group (5) is an established forum within the existing NCM cooperation structures, with long-standing working relationships across all Nordic countries and a demonstrated ability to translate collaboration into concrete outcomes. Rather than creating new structures from scratch, there is a clear opportunity to build on and adapt this existing structure by expanding and updating its mandate to explicitly cover both primary and secondary use of health data. This approach was also a key conclusion of an internal VALO workshop on governance structures held at Vitalis in May 2026, where participants emphasised that existing structures such as the NCM eHealth group should be strengthened rather than duplicated, identifying it as a relevant governance reference model. (13)

Action

It is recommended that a committee be established as the permanent policy-alignment advisory and steering body within the policy layer of the Nordic Health Data Coordination Network (Figure 2). It is proposed that this is achieved by expanding and updating the mandate of the existing NCM eHealth group to explicitly cover both primary and secondary use of health data, including the EHDS framework, and to resource it accordingly. In the meantime, proposals specific to the secondary use of health data could be submitted for consideration in the NCM eHealth group's annual work plan.



The Committee should include two representatives from each Nordic country: one representing authorities responsible for the primary use of health data and one representing authorities responsible for secondary use. This would result in a core group of around 10–15 members. The Committee should meet at least twice a year, aligned with the NCM cycle and serve as the steering layer of the Network. Its responsibilities should include setting the annual work programme and providing clear mandate and direction to the working groups (Figure 2). As a first step, the Committee should develop a shared multiannual roadmap that sets out funding, defined deliverables, assigned responsibilities and measurable outcomes. The roadmap would be submitted for review by the relevant Committee of Senior Officials. Once endorsed the Nordic Health Data Coordination Committee is responsible for coordinating and monitoring with support of the Secretariat and drawing on recommendations developed through the Nordic Health Data Competence Forum and its working groups. This would help ensure that the four structures work together as a coherent and sustainable governance model rather than relying on a project-by-project collaboration. The Committee should also ensure accountability to NCM and relevant national ministries. To support this, designated ministry contacts should be established in each country at an early stage, with clearly defined roles and mandate.

The structure should be kept deliberately lightweight at the outset to support speed, flexibility and adaptability. Experience suggests that building on existing cooperation step by step, as trust and ways of working develop, provides a more sustainable foundation over time. The forthcoming designation of national HDABs offers a timely opportunity to establish a Nordic-level structure for policy alignment and implementation, bringing together a new set of institutional actors operating under a shared regulatory framework and with a clear interest in coordinated implementation.

It is recommended that the Committee operate under a rotating Presidency aligned with the NCM cycle. During its term, the Presidency country would coordinate the annual work programme and support the organisation of the annual Nordic Health Data Summit (Recommendation 4).

Rotation should be a core governance principle rather than simply an administrative arrangement. It promotes ownership and engagement across the Nordic countries, distributes responsibilities and follows the established NCM model in which each Presidency sets priorities at the beginning of its term and reports on progress at its conclusion.

Nordic Added Value, Impact and Efficiency

Establishing a Nordic Health Data Coordination Network creates a structured framework for addressing issues of common strategic importance. At its core, the Committee acts as the network's steering body, defining common priorities, guiding implementation efforts, and ensuring accountability.

The Committee provides a mechanism for bringing primary and secondary use of health data together within a common governance framework. As EHDS implementation progresses, an increasing number of issues span both domains (e.g. semantic interoperability, standardisation, data quality, intellectual property rights and trade secrets, as well as opt-out mechanisms' implementation). Addressing these within the same



structure supports coherent policy development, facilitates knowledge sharing, and reduces the risk of parallel or conflicting approaches across countries.

Building on existing Nordic cooperation structures enables the network to be established quickly and with limited additional administrative burden. The governance model strengthens the Nordic countries' ability to coordinate positions, exchange experience, identify common challenges, and develop shared approaches were beneficial.

Through this coordination, the Nordic countries strengthen their aligned voice in European discussions, support more consistent implementation of the EHDS, and reduce duplication of effort by building on shared expertise and experience. The network improves the effectiveness of national investments, increases the quality and consistency of implementation, and delivers outcomes that are more difficult and resource-intensive for countries to achieve individually.



Proposed steps for Implementation

- NCM extends the mandate of the NCM eHealth group to explicitly cover both primary and secondary use of health data, developing the group into a Nordic Health Data Coordination Committee.
- Terms of reference define the Committee's role, its relationship with the NCM.
- Membership should include two representatives from each country — one representing primary use and one representing secondary use. Each country also designates ministry contacts with clearly defined roles and responsibilities.
- A rotating Presidency is established, aligned with the NCM cycle, with an agreed handover process.
- The Committee holds its first meeting and agrees on its first annual work programme, including the actions outlined in Recommendations 2, 3, and 4.
- As its first task, the Committee establishes a shared multiannual roadmap — with dedicated funding, defined deliverables, assigned responsibilities and measurable outcomes — submitted for review and endorsement by the relevant Committee of Senior Officials. Once endorsed, the Committee is responsible for coordinating, monitoring and implementing the roadmap, with support from the Secretariat and drawing on recommendations developed through the Nordic Health Data Competence Forum and its working groups.
- The structure stays lightweight at the start, adjusted over time as needed.

Recommendation 2:
Establish a permanent Secretariat



Foundation

A Nordic Health Data Coordination Committee, with a rotating Presidency and workplan endorsement by the NCM, provides the strategic direction needed to guide Nordic health data governance. However, a governance structure that relies solely on the Presidency country to maintain day-to-day continuity creates a great risk to the work. At each rotation, relationships must be rebuilt, ongoing work handed over, administrative procedures re-established, and priorities agreed again. This reduces the time and capacity available to move forward. A permanent Secretariat, by contrast, would maintain these administrative and operational functions continuously between rotations, freeing the Presidency country to focus on political leadership and strategic direction rather than rebuilding the basic infrastructure of collaboration each time. Knowledge about ongoing activities, working relationships, emerging topics and lessons learned cannot be fully captured in written handover. Much of this knowledge is held by the individuals involved and can be lost when responsibilities move from one Presidency to the next.

This continuity is particularly important in the context of EHDS implementation, which will require ongoing coordination, shared learning and long-term follow-up over several policy cycle periods.

The NCM eHealth group has already recognised this challenge. During its discussions in early 2026, the group identified the need for a permanent Secretariat to maintain continuity during changes in Presidency and to support coordination over the longer term. The Nordic Centre for Classification in Health Care (NordClass) (16) already operates a comparable model. It has a permanent secretariat, a Board, and affiliated expert groups, and is financed directly by the participating countries rather than through NCM, showing this approach is not without precedent.

The experience of the VALO project and other Nordic initiatives further highlights this need. These projects have generated valuable outputs, strengthened networks and created new ways of working together. However, project-based collaboration is limited to a defined period. Without a permanent operational function, there is a risk that knowledge, relationships and lessons learned are lost or remain spread across separate initiatives instead of being built on and carried forward over time.

A permanent Secretariat would help preserve and build on the experience gained through previous projects and Presidencies. It would maintain institutional memory, ensuring that knowledge developed through Nordic collaboration remains accessible and actionable over time.

Action

It is recommended that NCM supports the establishment of a permanent Secretariat for the Nordic Health Data Coordination Network. The Secretariat should work under the direction of the Committee and provide ongoing support for coordination, continuity and implementation across Nordic health data collaboration.

Its core responsibilities should include:

- Maintaining knowledge and continuity when Presidency changes every year.



- Preparing agendas and meeting material for the Committee and help coordinate work between working groups within the Network.
- Facilitate the monitoring and collection of information on how the EHDS is being implemented across participating countries, drawing on input from national experts through the Competence Forum.
- Maintaining a shared knowledge base and online platform for the Nordic Health Data Ecosystem.
- Supporting the organisation of the annual Nordic Health Data Summit in collaboration with the country holding the Presidency.

The Secretariat should be staffed with dedicated personnel sufficient to carry out its functions. To ensure continuity and allow knowledge and expertise to build over time, staff appointments or contracts should extend beyond a single Presidency period. For the Secretariat to function effectively, all Nordic countries need to actively support it as a shared Nordic function operating on their behalf.

Unlike the Presidency, the Secretariat should not rotate between countries. It should have a fixed location, as this is what enables it to provide continuity, retain institutional memory and act as a stable point of contact over time.

The administrative location of the Secretariat should be determined through a structured process led by NCM in consultation with the Committee and the participating countries. No specific host organisation is proposed at this stage. Instead, the Nordic countries should jointly decide where the secretariat should be based, taking into account factors such as available capacity, ability to support the Secretariat's function, and organisational independence.

As the Secretariat matures, it could also take on a broader, outward-facing role, acting as a shared point of contact for Nordic collaboration on health data and helping establish Nordic health data as a recognised international brand for research, innovation and evidence-based policymaking (see Longer term development section below).

Nordic Added Value, Impact and Efficiency

A permanent Secretariat provides the operational capacity needed to turn the Network from a coordination mechanism into a sustainable governance structure. By providing a stable function across Presidencies, it allows the Committee to focus on strategic priorities and decision-making, while ensuring continuity in implementation, coordination and follow-up.

The Secretariat strengthens Nordic collaboration by maintaining a shared knowledge base and documenting the evidence, outputs and lessons learned generated through Nordic collaboration, ensuring that knowledge, methods and experiences from these initiatives can be shared through Competence Forums and reused across the region rather than developed in parallel.

By reducing duplication of effort, preserving institutional knowledge and enabling more effective use of existing expertise and resources, the Secretariat increases the value of national and Nordic investments in health data. The benefits generated through improved



coordination, stronger collaboration and more efficient implementation are likely to outweigh the operational costs of maintaining a permanent Secretariat.



Proposed steps for Implementation

- NCM leads a process with the Nordic Health Data Coordination Committee and participating countries to decide where the Secretariat is based.
- Countries agree on stable, multi-year funding, with an initial commitment of at least three years.
- The Secretariat has a fixed location and does not rotate with the Presidency.
- Dedicated staff sufficient to carry out its functions. Hosted within an administrative home.
- A clear process for transferring knowledge and responsibilities between Presidencies is developed and agreed.
- A shared knowledge base and website are set up early.
- The Secretariat's external role engaging international research and industry partners is defined and resourced from the start.

Recommendation 3:
**Endorse and resource a permanent Nordic Health
Data Competence Forum**

Foundation

When the VALO project was established in 2024, one of its main objectives was to create a forum for Nordic countries to prepare for and coordinate their implementation of the EHDS Regulation on the secondary use of health data. (10) This reflects the recognition that, even with common European legislation, countries may adopt different approaches to implementation. Such differences can make cross-border access of health data for secondary use more complex and difficult.

As part of VALO Workstream 2, the Nordic EHDS2 Competence Forum was established to support this coordination, meeting regularly throughout the project. The Forum brought together representatives from ministries, health authorities and other relevant organisations to share experience, compare national approaches, identify common challenges, and explore opportunities for alignment. This work has helped build a strong foundation for continued Nordic collaboration, including the development of professional networks focused on areas such as ethical review requirements and practices, metadata catalogues, (17) and coordination between the emerging Health Data Access Bodies (HDABs). (17) Over time, the Competence Forum has become the most established part of the VALO project, developing working methods, facilitating networking and creating a trusting environment for collaborative relationships that can continue to support dialogue, knowledge-sharing, and coordination as EHDS implementation progresses.

VALO2 has further expanded this collaboration by bringing all five Nordic countries into the project as full partners, with Estonia and Lithuania participating as observers. This has broadened both the scope and geographical reach of the discussions and created more opportunities for collaboration and exchange between the Nordic and Baltic countries.

Action

It is recommended that the NCM provide dedicated and sustainable funding to establish and maintain a permanent Nordic Health Data Competence Forum. This also requires participating countries to continue resourcing expert participation in the Forum. Building on the work of the VALO Nordic EHDS2 Competence Forum, this Forum would provide a lasting structure for Nordic collaboration on health data governance. How often this Forum meets should be determined by the participating countries, taking into account priorities, workload and available resources.

The Nordic Health Data Competence Forum should bring together the authorities, experts, and practitioners responsible for health data governance and EHDS implementation across the Nordic countries. Its role would be to coordinate approaches, share experiences as well as good examples, and address common challenges. The Committee and Secretariat should both participate in the Forum, creating a clear link between decision-making and implementation. Topics identified through the Forum could be brought to the Committee for strategic consideration, while priorities set by the Committee could be translated into Forum activities, working group initiatives, and work programmes with support from the Secretariat.

The Forum should be organised around thematic working groups in areas where Nordic coordination can provide the greatest value. These could include coordination between

HDABs/Digital Health Authorities, legal and regulatory matters, metadata standards and data exchange standards, common data models, electronic health record (EHR) standards, data holders, ethics, and engagement with citizens and patients. The thematic areas should remain flexible and be updated as priorities, implementation needs, and opportunities for collaboration change.

Given the limited resources available, the aim should not be to establish all working groups at once. Instead, a small initial set should be prioritised, based on where Nordic coordination is most needed and expanded as capacity and funding allow.

Close cooperation between national HDABs should continue through a dedicated HDAB working group. However, implementing the EHDS involves much more than the work of HDABs and requires input from different experts and authorities. Several focused working groups would bring together the right expertise for each area, while the Committee and Secretariat ensure that the work remains coordinated. The working groups should remain small and focused on practical needs-based outcomes. Their leadership could rotate between countries with strong links to the authorities and organisations responsible for health data governance and implementation in each country. The Secretariat should document the groups' work, including key outputs, methods, and lessons learned, ensuring that knowledge gained through Nordic collaboration remains accessible and can be used in future work.

Nordic Added Value, Impact and Efficiency

The Forum provides an important basis for collaboration at a time when countries are preparing for the implementation of the EHDS and addressing a range of related policy, legal, organisational, and technical questions. Although responsibility for implementation remains within each country, many of the challenges are shared. The Forum provides a structured setting for authorities, experts, and practitioners to exchange experiences, build a shared understanding of new and emerging issues, and consider common approaches where these provide value.

The Forum strengthens relationships between Nordic and Baltic HDABs, Digital Health Authorities, and other organisations involved in health data governance and implementation. These relationships support practical cross-border collaboration on issues such as permit procedures, legal requirements, data interoperability, and the development of technical solutions for health data exchange and use. Legal and regulatory matters remain a particular area of interest for Nordic collaboration and have been repeatedly identified through VALO stakeholder engagement and at the Vitalis workshop. (13) Researchers and industry representatives frequently point to differences in the interpretation and application of GDPR and other relevant legislations as barriers for cross-border research. The Forum provides a trusting setting for countries to share experiences, discuss common questions, and identify areas where common interpretation and understanding would be useful. (3)

By bringing together relevant authorities, experts, and practitioners on a regular basis, the Forum supports more efficient implementation of the EHDS through collaboration, knowledge sharing, and peer learning. It enables countries to build on each other's experiences, exchange practical solutions and emerging good practices, and avoid



addressing similar challenges independently. This is particularly valuable in areas where countries are working towards similar goals, including HDAB Health Authority development, metadata catalogues, interoperability, legal and regulatory questions, and common data standards.

The Forum also helps preserve and build on knowledge generated through Nordic collaboration. By documenting outputs, methods, and lessons learned and making them available for future use, it strengthens continuity across initiatives and helps maximise the value of both national and Nordic investments in health data governance. Over time, this contributes to more coordinated implementation, stronger Nordic collaboration, and a more consistent approach to health data governance across the region.



Proposed steps for Implementation

- NCM funds the Nordic Health Data Competence Forum, long-term basis, separate from funding allocated to the Secretariat.
- The Nordic Health Data Coordination Committee and Secretariat are formally involved in the Nordic Health Data Competence Forum activities.
- Initial thematic working areas are identified (e.g. HDAB/Digital Health Authority coordination, legal and regulatory matters, metadata and data interoperability, common data models, EHR standards, data holders, and ethics and engagement with citizens and patients) and reviewed regularly.
- Working groups stay small, with rotating leadership and regular meeting schedule.
- A transition plan to ensure continuity from the VALO Competence Forums, with the Secretariat maintaining a record of outputs and lessons learned.

Recommendation 4:
Support an annual Nordic Health Data Summit

Foundation

The Committee, the Secretariat, and the Competence Forum will together provide the core governance structure of the Nordic Health Data Coordination Network. They provide the strategic direction, coordination and operational support needed to sustain Nordic collaboration on health data over time. However, effective governance alone is not sufficient. To realise the full potential of the Nordic Health Data Ecosystem, the Network must also maintain an active dialogue with the broader community of stakeholders involved in or affected by health data use. This includes researchers, and research funding organisations (both national and Nordic), healthcare providers, public authorities, HDABs, data holders, industry, patient organisations, citizens, policymakers, and international partners. Citizens and patients in particular have a distinct stake in this work. Collaboration built on shared ethical principles, transparency, and responsible management helps maintain the public trust that continued use of health data for research, innovation and public benefits depends on. This trust is one of the Nordic region's greatest strengths, but it cannot be taken for granted. Collaboration should therefore be developed in a manner that promotes transparency, responsible data use and continued public trust. Bringing these groups together on a regular basis creates opportunities to share progress, exchange views, identify emerging needs, and strengthen collaboration across the wider ecosystem.

The Nordic Health Data Summit should build on activities already organised through the VALO project, including earlier event in Helsinki with the FinHITS project (13) and a planned event in Norway in collaboration with OMOPNorway. These events demonstrate strong interest across the Nordic health data community in a regular forum for exchange and collaboration. This was further confirmed at the Vitalis workshop in Gothenburg in May 2026 (13). Together, these initiatives have helped shape and test the concept of a recurring Nordic health data gathering. They have also explored a model in which the Summit is organised in partnership with relevant national projects and events. This approach has the potential to broaden the participation while reducing the organisational effort and costs involved.

Several common principles emerged from these events. The Summit should be inclusive and accessible to all, with both in-person and online participation. It should also rotate between countries to encourage local involvement and create opportunities for an interactive dialogue between stakeholders rather than functioning solely as a platform for presenting information. Participants also highlighted the value of co-locating the Summit with established national conferences and events, as well as presenting concrete project outputs and experiences from ongoing and completed Nordic initiatives.

The Summit provides a platform where these stakeholders can come together to share knowledge, discuss priorities, and strengthen engagement in Nordic health data collaboration. It also creates an opportunity to increase awareness of ongoing activities and showcase the value of Nordic collaboration to a broader audience.

Action

It is recommended that NCM formally endorse and support the Summit as a permanent annual event, and that the Presidency country takes responsibility for organising it each year. The Summit should be run in collaboration with the Secretariat and a relevant national



health data project or initiative, and where feasible, integrated into an established national health data or digital health conference in the host country. This approach would reduce the organisational burden for the Presidency, make use of existing infrastructure and audiences, and create a natural link between Nordic collaboration and national priorities. The experience from VALO stakeholder events and conferences such as Vitalis demonstrate the value of this model. Other similar opportunities exist across the Nordic countries.

The Summit should ideally serve as the main annual meeting for stakeholders involved in health data. Its programme should reflect the key components of the Nordic model, cover both primary and secondary use of health data, and include practical results from Forum activities and other Nordic initiatives. The Secretariat and the Committee should be responsible for developing and managing the agenda, drawing on input from the Forum's working groups where relevant. This allows the Committee to adjust the agenda as priorities and working group structure evolve, while sharing progress and gathering views from stakeholders to help shape future priorities.

The Summit should bring together a broad range of stakeholders described above. By providing a regular opportunity for dialogue, knowledge sharing, and presentation of Nordic work, the Summit can strengthen collaboration, increase engagement across the health data ecosystem and increase the visibility of Nordic health data initiatives both within the Nordic countries and internationally.

Nordic Added Value, Impact and Efficiency

The Summit provides a unique opportunity to connect stakeholders from across the Ecosystem who would not otherwise meet through the formal governance structures of the Network. By bringing together stakeholders from across the ecosystem, the Summit helps build a shared understanding of priorities and encourages dialogue across sectors.

The Summit offers an opportunity to exchange experiences, showcase emerging practices, and identify opportunities for collaboration. For researchers, it creates opportunity to connect with peers across the Nordic and Baltic countries, exchange methods and findings, and identify potential collaborators for cross-border studies. For healthcare providers and professionals, it provides insights into governance and technical developments that will affect clinical and administrative practice, while allowing them to raise practical concerns before decisions are finalised. For patient organisations and citizens, it provides a clear way to engage in discussion about how health data is governed and used across the Nordic region, helping to build transparency and public trust. For industry, it offers a clearer way to engage in Nordic health data collaboration and supports dialogue on innovation, partnerships, and investment opportunities.

The Summit also raises the Nordic region's international profile by highlighting Nordic capabilities, experiences and ongoing initiatives. By demonstrating a shared commitment to health data collaboration, it strengthens the Nordic region's role as a partner for research, innovation and cross-border health data initiatives.

As the annual meeting place for the Committee, Secretariat, Competence Forum, working groups and national initiatives, the Summit strengthens the effectiveness of the Nordic model by creating a recurring point of connection between its different components. It



provides a regular opportunity to present progress, discuss emerging priorities, gather feedback from stakeholders, and identify opportunities for coordination across countries and organisations, thus reducing the risk of fragmented efforts. It also creates a structured opportunity for strategic priorities to be discussed with a broader audience and informed by practical experience.

The Summit also helps maintain continuity in Nordic collaboration. Organised annually and supported by the Secretariat, it ensures that knowledge, experiences, and results from previous activities are shared from one Presidency to the next rather than recreated each year.

Finally, the Summit plays an important role in sharing and building on the results of Nordic pilot projects and other collaborative initiatives. By sharing experiences, methods and lessons learned across the Nordic region, it helps successful approaches to be reused and expanded and ensures that knowledge gained through Nordic collaboration continues to create value over time.



Proposed steps for Implementation

- NCM formally endorses the Nordic Health Data Summit as a permanent annual event.
- The country holding the Presidency, in collaboration with the Secretariat, picks a host conference and a co-organising national project.
- The Secretariat maintains a shared framework for running the Summit, handed over between presidencies.
- The programme is developed jointly by the Secretariat and the Nordic Health Data Coordination Committee, covering both primary and secondary use of health data.
- The Summit is designed for broad participation, from researchers and research funding organisations (both national and Nordic), healthcare providers, public authorities, HDABs, data holders, industry, patient organisations, citizens, policymakers and international partners.
- Feedback mechanisms are built in to inform future priorities.

A phased path forward

There is significant value in building on the current momentum created by the implementation of the EHDS and the strong level of engagement already established across the Nordic countries. Taking timely steps towards implementation helps maintaining commitment, make use of existing initiatives and expertise, and support faster progress towards a more coordinated Nordic approach.

The four recommendations in this report are designed to work together rather than as separate initiatives. Together, they provide a solid foundation for the Nordic Health Data Coordination Network with clear direction, support for implementation, continuity over time and opportunities for stakeholders to work together. While the recommendations are closely connected, they can be introduced in stages, gradually moving from project-based collaboration towards a lasting Nordic approach to collaboration on health data (Figure 3).

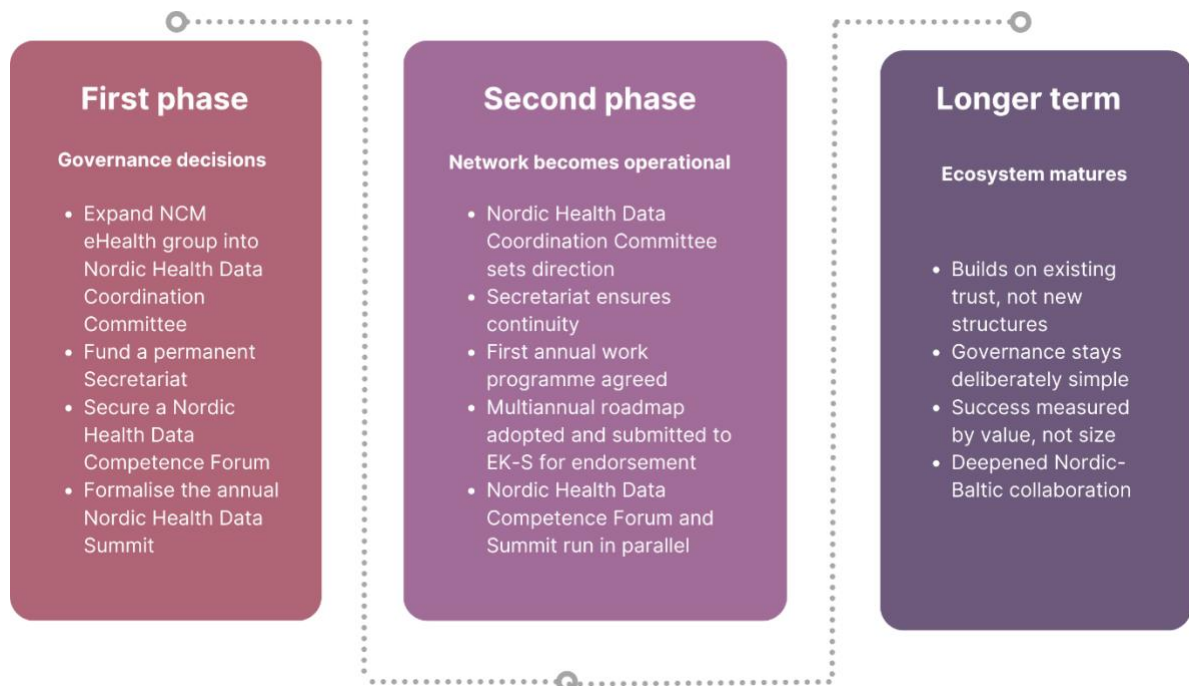


Figure 3. Phased implementation of the Nordic Health Data Coordination Network.

First phase

By the end of year 2026, NCM and the participating countries will need to take the key decisions needed to establish the Nordic Health Data Coordination Network. This includes expanding the mandate of the NCM eHealth group to establish the Committee, starting the process for establishing and funding a permanent Secretariat, securing the continuation of the Nordic Health Data Competence Forum beyond the VALO project period, and formally establishing the Nordic Health Data Summit as an annual event.

These are primarily organisational and governance decisions. They build on existing structures, networks, and ways of working, meaning they can be taken forward without creating entirely new organisations or governance arrangements.

Second phase

The formal process of establishing the Committee should begin in early 2027, with letters of appointment issued and participating countries invited to nominate their representatives. As these appointments are finalised, the Network becomes operational. The Committee begins to provide strategic direction, while the Secretariat provides continuity and retains knowledge and experience over time. The Committee holds its first meeting under its expanded mandate and agrees on its first annual work programme, including adopting the shared multiannual roadmap described under Recommendation 1 and bringing it forward for NCM endorsement. The Forum supports ongoing coordination and knowledge sharing across different areas relevant for the concerned ministries and authorities, while the Summit provides a regular opportunity to engage with the wider community. Thereby the closed Forum and the open Summit are complementing activities.

During this phase, the focus shifts from establishing the network to putting it into practice. Working methods are refined, collaboration between different parts of the network develops, and experience from ongoing work helps shape future priorities. The governance structure remains deliberately simple while building the capacity needed to support Nordic collaboration over time.

Longer term development

The Nordic Health Data Ecosystem is designed to build on existing structures, trust, and working relationships rather than replacing them. Its success should be measured not by the size of its governance structures, but by its ability to support effective Nordic collaboration where it creates added value. Over time, the combination of strategic direction, operational continuity, expert collaboration, and stakeholder engagement can provide a strong foundation for deeper and more ambitious forms of Nordic collaboration.

If the proposed structures are established and allowed to develop over time, the Ecosystem could evolve in several ways that go beyond the immediate goal of supporting EHDS implementation.

Nordic contribution to EHDS governance. A committee with a clear communication link with Nordic representations to the EHDS Board, and a coordinated Nordic position, would be well placed to contribute and help shape the implementation of the EHDS. The Nordic region's comprehensive registers, ability to link health data, and high level of public trust have built expertise and experience that could provide valuable insights. By speaking with a coordinated voice, the Nordic countries would be better positioned to contribute to future European approaches, standards, and practical guidance for implementation.

A recognised Nordic brand for health data research. With a well-established and adequately resourced Secretariat the Nordic region can strengthen its position as an attractive environment for responsible health data research and innovation. Over time, this could support stronger collaboration with international research organisations, pharmaceutical companies, and technology partners, while making Nordic health data



resources and opportunities for collaboration more visible and accessible. This ambition could eventually include the Secretariat acting as a shared point of contact for Nordic health data collaboration – maintaining up-to-date information on ongoing and completed work, including past pilot projects, along with available resources and opportunities for engagement. This would give researchers, public authorities and industry, both within the Nordic region and internationally, a clearer way to connect with Nordic health data initiatives. For data users, this could build on the “Data from the Nordics” web service proposed by VALO Workstream 2, a shared overview of access models, application routes and national entry points in each Nordic country. (18) The Secretariat’s role here would be one of documentation and signposting – keeping the knowledge base current and pointing others to relevant results – while the exchange of experience itself continues to take place within the Competence Forum.

Connecting existing Nordic structures. The Nordic countries have decades of experience in making health data comparable and usable across borders through groups and organisations under the NCM umbrella, including NOMESCO, NOSOSCO, NordClass, NordDRG, the NCM eHealth group, Nordregio and NordForsk. Over time, the Network could connect these existing bodies, bringing them together as part of a common Nordic Health Data Ecosystem and strengthening coordination across the field, while respecting their individual mandates.

Deepened Nordic-Baltic collaboration. Both Estonia and Lithuania participated as observers in the VALO2 project. However, their level of engagement varied with Lithuania taking a more active role than expected, while Estonia’s participation remained more limited. The Nordic EHDS2 Competence Forum has therefore begun sharing experiences across a wider region. As trust builds and the benefits of closer coordination become clearer, this relationship could grow into fuller participation and extend the reach of the Ecosystem to include broader Nordic-Baltic collaboration.

A harmonised technical and legal foundation. The Competence Forum’s expert groups’ work on metadata standards and legal interpretation could develop into a more comprehensive Nordic approach. This could include a shared Nordic metadata framework covering diverse health data types going beyond EHDS minimum requirements. More harmonised technical standards and shared understanding of the legal framework would make it easier for researchers and industry to work across the Nordic region as a single market, allowing the region to function more like a connected research environment rather than a group of separate countries working together.

Long-term HDAB cooperation. Close cooperation between national HDABs will remain important after the EHDS has been implemented. HDABs already have a heavy workload, and a permanent Nordic forum for practical cooperation would allow them to share work, learn from each other and develop common approaches over time. The HDAB working group within the Competence Forum could take on this role, providing a lasting platform for practical collaboration between Nordic and, potentially, Baltic HDABs.

A regular annual cycle of Nordic collaboration. Over time, the Summit will have rotated across all Nordic countries, building a broad network of participants from research, industry, patient organisation and healthcare providers, becoming a recognised and annual event in the Nordic health data calendar. It can also be complemented by smaller national or thematic events – such as established national health, policy, or industry forums – that can



develop over time to address the needs and interests of specific groups more closely. Such events help sustain engagement between the annual Summit and allow more specialised topics to be explored in depth.

None of this requires changing the principles that have guided the Nordic model from the outset. Building on what exists, respecting existing responsibilities, and coordinating rather than duplicating efforts. The long-term ambition is not to create heavier bureaucracy, but to help the Nordic countries turn decades of investment in health data into a lasting shared benefit. The Summit should remain open to those who want to contribute and should consistently create value for citizens, researchers, and institutions it is intended to serve.

Funding the Nordic Health Data Coordination Network

Sustainable funding is essential for implementing all these recommendations. Previous Nordic health data initiatives have often lost momentum not because ideas lacked value or commitment was lacking, but because they relied on project-based funding that ended before lasting structures could be established. The governance model proposed in these recommendations is intended to provide a permanent framework. To achieve this, it requires stable funding. (3)

Each of the four recommendations presented in this report has different funding requirements. The Nordic Health Data Coordination Committee, the Nordic Health Data Competence Forum, the Secretariat, and the Nordic Health Data Summit will all require dedicated funding. However, the amount of funding needed, the most appropriate funding arrangements, and the timing of these arrangements differ across the structures. The funding requirements for each recommendation are outlined below, followed by a discussion of the financing options available to NCM and the participating countries.

What needs to be funded

The Nordic Health Data Coordination Committee builds on the existing NCM eHealth group, which is already funded and meets regularly. Expanding the mandate of the group to form the Committee would require some additional funding to reflect its broader role, including coordinating and following up the work of the working groups. Compared with the other proposed structures, these additional costs are expected to be modest.

The Secretariat is the most significant new cost and the most urgent financing decision. It requires dedicated staff sufficient to carry out its functions, on a contract extending beyond a single Presidency cycle. Plus, the operational costs of maintaining a knowledge base platform. Secretariat costs are ongoing and recurring and the funding commitment must therefore be multi-year from the outset. A minimum three-year initial commitment is recommended to allow institutional memory and working relationships to accumulate to the point where they provide genuine value. (13)

The Nordic Health Data Competence Forum requires dedicated funding covering meeting organisation, facilitation, and the coordination of thematic working groups across borders. This should also include work carried out by these groups between meetings. The Metadata Network, for example, continued meeting in the period between the Nordic Commons project and VALO without any formal mandate to do so. The Legal/Ethical group, working under VALO's mandate from the outset, similarly began meeting between Competence Forum sessions on its own initiative, after participants identified the need for more space for dialogue. This funding currently comes from the VALO project. The transition from project-based to sustainable funding is time-sensitive: the Forum must not experience a gap in support during the EHDS implementation phase, when its coordination function is most needed. A transition plan is essential, ideally agreed upon before the end of the current VALO project.



The Nordic Health Data Summit could be held alongside existing national conferences allowing venue and logistics costs to be shared. The main financial requirements are facilitation, programme development, hybrid event infrastructure, and speaker support. A modest NCM contribution, complemented by funding and in-kind support from the Presidency country and co-organisers, would provide the continuity and reduce reliance on annual national budget decisions.

Funding options

No single funding model is recommended here. The most suitable approach will depend on political discussions among participating countries and NCM's budgetary frameworks. The following section outlines available options and the advantages and disadvantages of each.

Direct NCM contribution. Under this approach, the NCM would fund the Secretariat and Competence Forums through a dedicated item in its programme budget, in the same way it supports other permanent collaboration structures. A similar model is already used in Nordic cooperation using health and social data. The Nordic Medico-Statistical Committee (NOMESCO) and the Nordic Social Statistical Committee (NOSOSCO) are both funded by the NCM. These committees have a permanent secretariat within NordRegio in Stockholm and a board chaired by the country holding the NCM Presidency. (19) This is the simplest funding arrangement and provides the greatest level of stability, as NCM funding is predictable, and can be planned over several years. The disadvantage is that the full financial responsibility rests with NCM and funding may need to compete with other programme priorities. This could be partly addressed by drawing on funding from different policy areas. Health data and its infrastructure that supports it are relevant not only to health and social affairs, but also to other NCM policy areas, such as digitalisation and research, as well as initiatives such as New Nordics AI. (20) Contributions from several policy areas would reflect these shared interest and reduce the pressure on any one budget. It also means that because participating countries are not required to contribute directly, there are less opportunities for shared financial responsibility and ownership, which could affect long-term commitment.

National contributions from participating countries. Each participating country contributes to the funding of the Secretariat and Competence Forums. Contributions may be equal, based on factors such as population or GDP or according to an agreed formula, e.g. the NCM country index used for the operation of NordClass. (16) This approach shares costs across the region, reduces reliance on a single source of funding, and gives all countries a financial stake that may strengthen collective commitment. The eHealth Group is already an example of a funded structure within the NCM, and there is experience of countries contributing to shared Nordic infrastructure. The main challenge is that this model requires participating countries to agree on how contributions are determined. Reaching such agreements can take time, and continued support may be affected by changes in national priorities.

Membership or participation fees. Organisations that take part in the Ecosystem, such as research institutions, industry partners and permitting authorities — contribute through a fee-based arrangement. This approach can help generating financial ownership among participants beyond the five governments and linking contributions to the benefits received. It is, however, the most complex to option to develop and manage. It depends on having



enough participants willing to contribute and may raise concerns about equal access. Any fee structure should be designed to ensure that participation is not limited to organisations with greater financial resources. If adopted, this model is likely to be most appropriate as a complementary source of funding rather than the primary one.

EU project funding. Some part of the Ecosystem's work may be eligible for EU project funding, particularly activities related to metadata standards, legal alignment and the possible development of a Nordic metadata framework. This can provide a valuable additional source of funding to support specific activities. However, like all project-based funding, it is temporary and linked to clearly defined deliverables. While EU funding can help advance specific projects, it cannot replace the stable long-term funding needed for the ongoing work of the Secretariat and the Competence Forums.

A blended funding model. The most sustainable approach is likely a combination of several funding sources. A direct NCM contribution could provide a stable foundation, while national contributions would strengthen shared ownership and responsibility among participating countries. EU project funding could be sought for specific initiatives. Participation fees could also be considered for longer term, once the Ecosystem is established and its value has been demonstrated. A blended model spreads financial responsibility across multiple sources and reduces the reliance on any one source. It also reflects the different funding needs within the Ecosystem. The Secretariat requires stable and predictable funding, while the Summit and specific Competence Forum projects are better suited to time-limited project-based funding.

It is recommended that NCM and relevant national authorities give priority to initiating a dedicated funding dialogue with participating countries before the end of the year 2026. The discussion should consider all four recommendations together, ensuring that funding decisions are made as a part of a coherent framework rather than through separate processes. NCM's willingness to initiate and lead this dialogue, would demonstrate a clear commitment to the development and the long-term sustainability of the Nordic Health Data Ecosystem.

Conclusion

The Nordic countries are entering an important period in the development of health data governance. As countries prepare for the implementation of EHDS, there is a valuable opportunity to strengthen Nordic collaboration and build on the region's established strengths in health data, research, innovation and public administration.

The Nordic model developed through the VALO project provides a practical framework for organising this collaboration. The four recommendations presented in this report establish the key elements of a Nordic Health Data Coordination Network: strategic direction through the Committee, operational support through a permanent Secretariat, practical implementation support through the Nordic Health Data Competence Forum, and broad stakeholder engagement through the Nordic Health Data Summit.

The recommendations in this report build on existing Nordic initiatives rather than creating new structures from the ground up. The Nordic countries already have decades of experience in making health data comparable across borders through bodies under the NCM umbrella, and the proposed Network is designed to connect with and strengthen these existing structures. The NCM eHealth Group provides an established foundation for governance, while the Nordic EHDS2 Competence Forums developed through VALO have demonstrated the benefits of structured expert collaboration. The Nordic Health Data Summit has also proven to be an effective platform for bringing together stakeholders from across the health data ecosystem. Together, these initiatives provide a strong foundation for developing a more permanent and sustainable framework for Nordic collaboration on health data.

The proposed governance structure is designed to build on existing mandates, institutions, and established working relationships. Its aim is not to create additional administration structures, but to support coordination in areas where collaboration adds and creates value and to help countries address common challenges more effectively through joint actions than through separate efforts.

Over time, this model could support a stronger Nordic contribution to the continued development of the EHDS, closer collaboration between the Nordic and Baltic countries, greater visibility for Nordic health data initiatives, and the gradual development of more coordinated approaches to shared legal, organisational, and technical challenges. The long-term goal is to enable the Nordic region to build on decades of investment in health data and translate these strengths into a lasting collective value for researchers, public authorities, healthcare providers, industry, patients, and citizens.

What is needed now is a shared commitment from NCM and the Nordic countries to establish the structures, resources, and governance arrangements required to transition from successful project-based collaboration to a sustainable model for long-term Nordic collaboration. The foundations for this work have been established through the VALO project. The next step is to ensure that these foundations continue to generate value and support collaboration beyond the lifetime of the project.

References

1. Laugesen K, Ludvigsson JF, Schmidt M, Gissler M, Valdimarsdottir UA, Lunde A, et al. Nordic Health Registry-Based Research: A Review of Health Care Systems and Key Registries. *Clin Epidemiol*. 2021;Volume 13:533–54. doi: 10.2147/CLEP.S314959
2. Vad KH, Håvard Kolle R, Suomalainen K, Mäkinen M, Rautiainen MR, Kalliola M, et al. Secondary use of health data in Nordic co-operation [Internet]. Helsinki: Sitra; 2024. (VALO project, Workstream 1). Available from: <https://www.sitra.fi/en/publications/secondary-use-of-health-data-in-nordic-co-operation/>
3. Nordic model for collaboration on the secondary use of health data - a proposal [Internet]. 2025 Dec [cited 2026 Mar 17]. Available from: <https://www.sitra.fi/en/publication/nordic-model-for-collaboration-on-the-secondary-use-of-health-data-a-proposal/>
4. Nordic eHealth Benchmarking Towards a digitally supported health ecosystem [Internet]. Nordic Council of Ministers, The Nordic eHealth Research Network (NeRN); [cited 2025 Sept 23]. Available from: <https://www.norden.org/en/publication/nordic-ehealth-benchmarking-2>
5. Danielsen C, Virtanen T, Vuokko R, Hardardottir GA, Alsaker MA, Aksnes B, et al. eHealth standardisation in the Nordic countries [Internet]. 2019:537. Copenhagen: Nordic Council of Ministers; 2019 [cited 2024 Aug 20]. (TemaNord). doi: 10.6027/TN2019-537 Available from: <http://urn.kb.se/resolve?urn=urn:nbn:se:norden.org:diva-5668>
6. Regulation (EU) 2024/.... Of the European Parliament and of the Council of on the EHDS and amending Directive 2011/24/EU and regulation (EU) 2024/2847 [Internet]. Available from: https://www.consilium.europa.eu/en/press/press-releases/2025/01/21/european-health-data-space-council-adopts-new-regulation-improving-cross-border-access-to-eu-health-data/?utm_source=x.com&utm_medium=social&utm_campaign=20250121-health-data&utm_content=visual
7. TEHDAS2 [Internet]. [cited 2026 Sept 10]. Second Joint Action Towards the European Health Data Space – TEHDAS2. Available from: <https://tehdas.eu/>
8. Health Data Access Bodies – Community of Practice [Internet]. European Commission; [cited 2026 Sept 10]. Available from: https://health.ec.europa.eu/ehealth-digital-health-and-care/ehds-action/projects-supporting-ehds/health-data-access-bodies-community-practice_en
9. NordForsk [Internet]. n.a. [cited 2026 July 2]. Nordic Commons Sharing health data across the Nordic countries. Available from: <https://www.nordforsk.org/nordic-commons>
10. Silvestri M, Trocilo D, Vanhainen C, Mäkinen M, Liikala M, Soimala J, et al. Nordic EHDS2 Competence Forum – final report [Internet]. Helsinki: Sitra; 2025. (VALO project,



Workstream 2). Available from: <https://www.sitra.fi/en/publication/nordic-ehds2-competence-forum-final-report/>

11. Adam A. VALO NSCLC pilot study [Internet]. Helsinki: Sitra; 2025. (VALO project, Workstream 3). Available from: <https://www.sitra.fi/en/publication/valo-nsclc-pilot-study/>

12. Adam A. Lessons learned from multi-site federated analysis in VALO NSCLC pilot study [Internet]. Helsinki: Sitra; 2025. (VALO project, Workstream 3). Available from: <https://www.sitra.fi/en/articles/results-and-lessons-learned-from-a-federated-omop-study/>

13. Guðmundsdóttir R, Haraldsd Elínardóttir S, Eiríksdóttir VH, Silvestri M, Doupi P, Soimala J, et al. The Nordic model for collaboration on health data: insights from an evolving process [Internet]. Helsinki: Sitra; 2025 Dec. (VALO2 project, Workstream 1). Available from: <https://www.sitra.fi/en/publication/nordic-model-for-collaboration-on-the-secondary-use-of-health-data-a-proposal/>

14. Ranga M, Etzkowitz H. Triple Helix Systems: An Analytical Framework for Innovation Policy and Practice in the Knowledge Society. *Ind High Educ*. 2013 Aug 1;27(4):237–62. doi: 10.5367/ihe.2013.0165

15. Etzkowitz H, Leydesdorff L. THE TRIPLE HELIX---UNIVERSITY-INDUSTRY-GOVERNMENT RELATIONS: A LABORATORY FOR KNOWLEDGE BASED ECONOMIC DEVELOPMENT. 1995 Jan;14(1):14–9.

16. Helsedirektoratet [Internet]. Helsedirektoratet; [cited 2026 Sept 10]. The WHO-FIC Nordic Center for Classifications in Health Care (NordClass). Available from: <https://www.helsedirektoratet.no/digitalisering-og-e-helse/helsefaglige-kodeverk/nordclass>

17. Mäkinen M, Thinsz Z, Peolsson M, Wiklander P, Akcan D, Guðmundsdóttir R, et al. VALO_T2.6_Metadata_Final_Report 2025 [Internet]. Sitra; 2025. Available from: <https://www.sitra.fi/en/publication/valo-metadata-catalogues-final-report/>

18. Silvestri M, Mäkinen M, Soimala J. Towards a Nordic guide to efficient and secure access to health data for secondary use under the EHDS. Helsinki: Sitra; 2026 forthcoming. (VALO2 project, Workstream 2).

19. Nordic Health & Welfare Statistics [Internet]. [cited 2026 Sept 10]. Who we are. Available from: <https://www.nhwstat.org/who-we-are>

20. newnordicsAI [Internet]. Driving AI adoption across the Nordics and Baltics. Available from: <https://www.newnordics.ai/>