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The Nordic model for collaboration on health data: insights from an evolving process

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Value from health data – VALO project

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Executive summary

The Nordic countries possess exceptional assets for health data research: decades-long national registers, personal identity numbers enabling precise data linkage, enabling legislation, and high levels of public trust. Translating these advantages into effective cross-border collaboration has nonetheless proven difficult. Data access timelines, fragmented regulatory interpretations across countries, and a reliance on individual enthusiasm rather than formal mandates have all presented persistent challenges.

The VALO project, funded by the Nordic Council of Ministers, was set out to strengthen the foundation for cross-border health data collaboration in the Nordic region. Its aim was to establish common principles across the Nordic countries for implementing the European Health Data Space (EHDS) Regulation, to streamline research, development and innovation, and to demonstrate cross-border data use through concrete pilot studies. Work stream 1 (WS1) has been developing a Nordic model for collaboration on the secondary use of health data – a collaboration framework designed to make the Nordic region the world's most attractive destination for health data research and innovation.

This interim report documents the journey of that development from mid-2024 through May 2026. It traces the work through its major milestones: a situational analysis and structured stakeholder interviews that identified some of the core barriers; the first public presentation of the proposed Nordic model at the VALO Stakeholder Forum in Gothenburg in May 2025; successive refinements at Competence Forums and the Nordic Health Data Summit in October 2025; the transition from VALO to the expanded VALO2 partnership covering all five Nordic countries and Baltic countries' representatives as observers; an open unconference at the Radical Health Festival in Helsinki in January 2026; a dialogue with the secretariat of the Nordic Council of Ministers in February 2026; and an intensive governance design workshop at Vitalis in Gothenburg in May 2026.

The model has evolved substantially over this period. Its current form, informed by the triple helix model of innovation, is built around four interdependent components – Knowledge Sharing on Systems and Structures, Research Collaborations and Statistics, Innovation and Industry, and Citizens, Patients and Healthcare Providers – coordinated by a central Driver and framed by an explicit Governance layer. Crucially, citizens and patients are now positioned as core stakeholders in the governance structure, not as a background condition. This reflects a key insight from the Helsinki unconference: public trust in Nordic institutions is present but fragile, and meaningful patient and citizen involvement is essential to sustaining it.

A number of important questions remain open. These include how heavy the governance structure should be at the outset, how the model should be funded sustainably, and how it should relate to the EHDS governance architecture. These questions will be addressed in the final report – *Nordic Model for Collaboration on the Secondary Use of Health Data: Steps Toward Implementation* (working title) - due in September 2026.

What is clear is that the work has moved from aspiration to architecture. The model now has a concrete governance proposal, an active stakeholder base spanning researchers, industry, patient organisations, policymakers, and the Nordic Council of Ministers, and a clear set of questions to resolve. The foundation for a genuinely collaborative Nordic approach to health data can now be built.

1 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, legislation enabling the secondary use of health data, and high public trust in institutions and research – these are the foundations that make the Nordic region genuinely distinctive in a global context. Each country also brings complementary strengths: Denmark's prescription medicine register, Finland's biobank infrastructure, Iceland's isolated gene pool, and Sweden's quality registers. (1)

Despite these advantages, cross-border collaboration on health data has remained fragmented and difficult. Previously, no Nordic forum existed for active preparation and implementation of the EHDS Regulation in secondary use. There was no comprehensive understanding of what the Nordic countries needed to do to maintain their forerunner position. (1) The Value from Nordic health data (VALO) project was established to address this gap. Launched in early 2024 by Finland, Iceland, and Sweden, with Denmark and Norway as observers, the project expanded with VALO2 in April 2025 to include all five Nordic countries as full partners, while Estonia and Lithuania joined as observers, adding a Nordic-Baltic dimension. Both VALO and VALO2 built directly on previous Nordic work, including the Nordic Commons project. (2) VALO's project was divided into three work streams (WS) with concrete purpose:

- to develop a Nordic collaboration model for the secondary use of health data (WS1),
- to jointly prepare for the implementation of the European Health Data Space (EHDS) Regulation in Nordic EHDS2 Competence Forums (forums dedicated to the secondary use provisions of the European Health Data Space Regulation) and through collaboration on metadata catalogues (WS2), and
- to demonstrate Nordic collaboration through pilot research projects based on federated analysis and secure processing environments (WS3).

This interim report documents the journey of the development of the Nordic collaboration model for the secondary use of health data within WS1 in the entire VALO project (including both VALO and VALO2). A timeline for the work of VALO WS1 including tasks, events and milestones are presented in Figure 1. This report traces the work through the major milestones and events that shaped the model – showing how it has evolved, what each engagement contributed, and where the work stands now.



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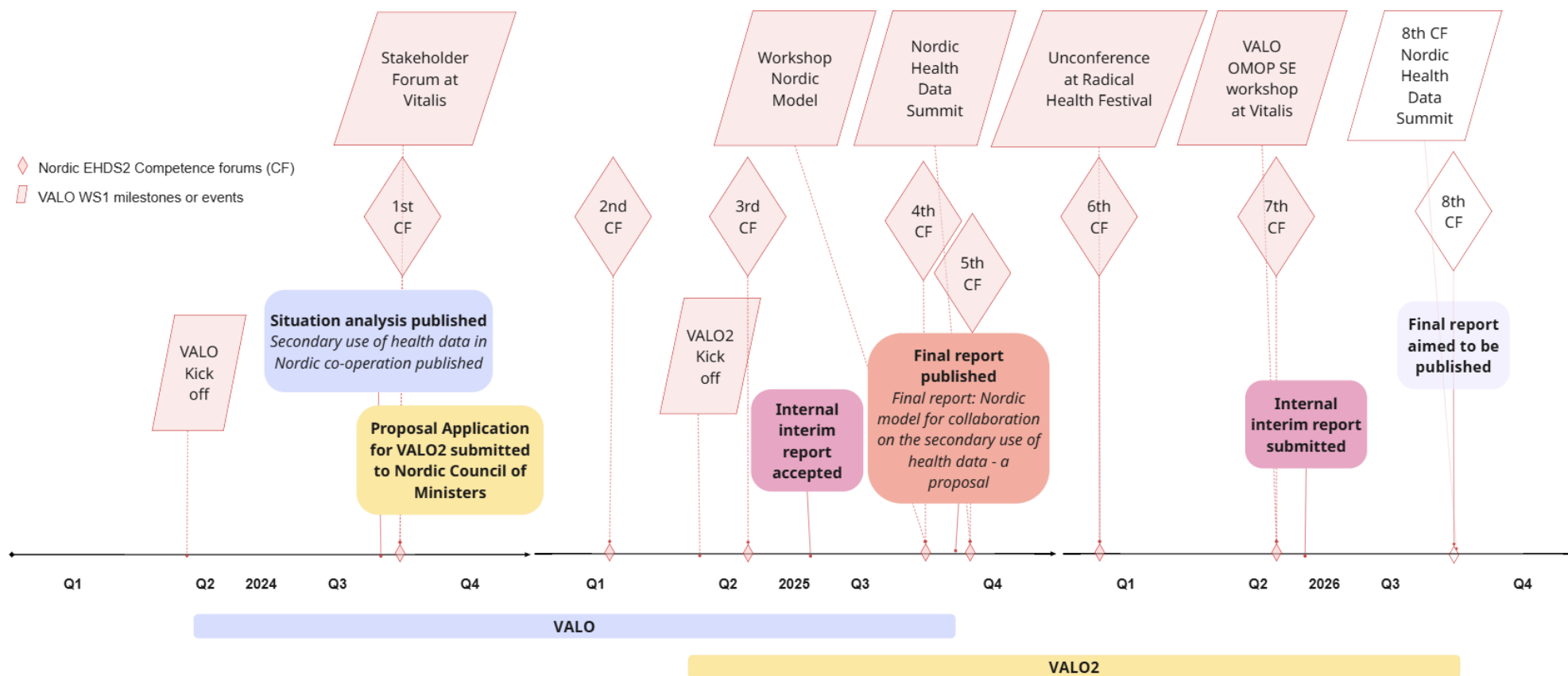


Figure 1. VALO work stream 1 timeline of tasks, events and milestones.



2 Building the foundation: Situational analysis and stakeholder interviews

The first task was to understand the landscape. A situational analysis (1) was conducted to examine existing initiatives, previous efforts, and their shortcomings. It mapped the regulatory environment across the Nordic countries, the state of technical and governance infrastructure, and the history of previous Nordic collaboration initiatives. The picture that emerged was consistent: initiatives launched with ambition, progressed through individual enthusiasm, and ultimately stalled when the enthusiasm ran out. Without formal mandates and dedicated resources, coordination could not be sustained.

The EHDS Regulation, approaching finalisation at the time, created both opportunity and urgency. It offers a common European framework for health data access that could reduce the regulatory fragmentation that had long complicated cross-border work – but it also raised questions about how Nordic collaboration would sit within European governance structures, and whether the high data quality and access standards that make Nordic registers valuable could be maintained.

To ground the work in real experience, the project conducted structured interviews with researchers and industry representatives across the region. (3) What they described was a fundamental paradox: the Nordic region possesses exceptional assets – a combined population of 27 million, decades-long registers, personal identity codes enabling precise cross-dataset linkage, high public trust – yet these advantages were consistently failing to translate into effective cross-border collaboration. Both stakeholder groups described adapting to the barriers rather than overcoming them by conducting studies in one country instead of combining Nordic data, defaulting to the lowest common denominator across countries, or avoiding cross-border data integration entirely because it was simply too complicated.

Three key findings became evident from the interviews: 1) Waiting time of one to two years for access to data were the most universally cited operational barrier, 2) regulatory fragmentation persisted despite a shared GDPR framework, with different national interpretations forcing researchers and companies to navigate multiple compliance environments even within the region. And 3) institutional commitment was identified as essential – previous Nordic initiatives had relied on individual enthusiasm rather than formal mandates and dedicated resources, and that approach had not worked. For a fuller account of the interview findings, see Annex 1 in the earlier report: Nordic model for collaboration on the secondary use of health data – a proposal. (3)

It should be noted that these structured interviews captured the perspectives of two stakeholder groups, i.e. researchers and industry representatives. Governmental stakeholders were not systematically represented through this interview process as their perspectives were intended to be captured during the Nordic EHDS2 Competence Forums. Citizens and patients were not represented in this phase of the work either. This is a recognised limitation of the evidence base underpinning the model's development.

3 A model takes shape

Drawing on these findings, the project developed its first proposal for a Nordic model for collaboration on the secondary use of health data (Figure 2). The model was presented to VALO participants at the 2nd Nordic EHDS2 Competence Forum in Copenhagen and then publicly at the VALO Stakeholder Forum on Nordic health data collaboration in Gothenburg at Vitalis in May 2025. The situation analysis and the stakeholder interviews with researchers and industry representatives, conducted as part of VALO and published in December 2025 (3), indicated a need for a platform for collaboration both within and across these groups. They also highlighted a need for cooperation and harmonised regulations among the Nordic countries. The resulting model had three components — a Nordic platform for knowledge sharing and harmonisation, a Nordic platform for research collaborations, and a Nordic platform for innovation and industry — operating within the EHDS and oriented toward the broader Nordic 2030 goals, supported by a central coordination function, the Driver, responsible for maintaining coherence and momentum across the three platforms.

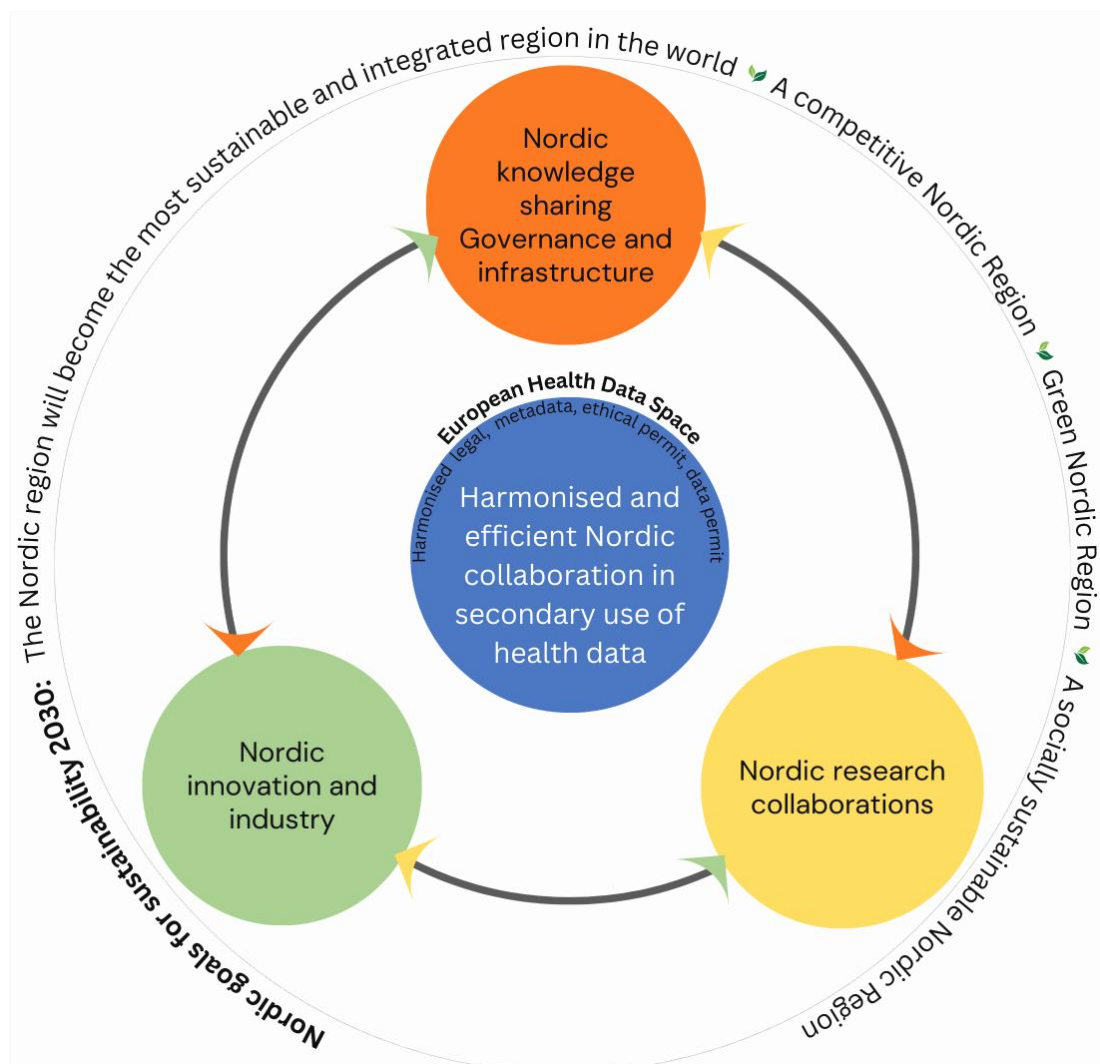


Figure 2. The Nordic model as presented at the 2nd Nordic EHDS2 Competence Forum, February 2025.

The three-platform structure reflected the interview findings directly. Researchers needed a structured space for knowledge sharing on systems and regulatory frameworks – a need reinforced by VALO partners and the Competence forums, which brought governmental and policy perspectives into the model's development. Research institutions needed infrastructure for cross-border studies. Industry needed a forum for collaboration and access to Nordic data assets. The Driver was the response to the institutional commitment finding: a dedicated entity with a formal mandate, rather than a reliance on voluntary coordination.

3.1 First external feedback: VALO Stakeholder Forum, May 2025

VALO convened a broader Stakeholder Forum on 20 May 2025 at Vitalis. This was the first occasion on which the developing Nordic model was presented beyond the project's own membership. A four-member panel brought diverse perspectives to the discussion. These included a Finnish entrepreneur who founded a startup for patients with diabetes, bringing both patient and industry perspectives; an Associate Professor from the Norwegian



University of Science and Technology, involved in the Nordic Health Data Spaces project (4) and assessing regional readiness for EHDS adoption as well as governance models for health data spaces; and a representative from the VALO project team, who presented the developing Nordic model.

The discussion broadly validated the overall direction. Panellists affirmed that the Nordic region's structural and cultural strengths, i.e. high levels of public trust, robust health systems, and pragmatic approaches to data sharing, provide a solid foundation for collaboration on which the model can build. The concept of a central coordination mechanism as a "one-stop shop" to reduce administrative burden for researchers, received strong support. Common data models, particularly OMOP, were identified as essential for making cross-border collaboration practical.

At the same time, the forum sharpened several tensions that would continue to run through the work. The question of equity in data access was raised directly: if access to Nordic health data requires resources that only large pharmaceutical companies can afford, the model risks serving commercial interests at the expense of independent researchers and smaller innovators. The importance of creating real incentives – not just structures – for data holders to provide high-quality data was emphasised. And the forum reinforced what the stakeholder interviews had already shown: that fragmentation within countries, not just between them, was a significant problem, with Sweden's regionalised systems and Finland's more centralised approach producing very different realities in practice.

The closing message from the panel captured the spirit of the moment well: the Nordics have unique advantages, but these must be translated into concrete collaborative frameworks. The work needed to be bold and ambitious and grounded in practical pilots that could demonstrate real value.

4 Refining the architecture

4.1 4th Nordic EHDS2 Competence Forum and Stakeholder Event, October 2025

By October 2025, the Model had evolved significantly (Figure 3). Presented at the 4th Nordic EHDS2 Competence Forum and internal workshop in September, as well as at the Nordic Health Data Summit (VALO and FinHITS Forum) (5) in October, the revised version replaced the three separate platform circles with a Venn diagram where the circles overlap, a visual change that carried conceptual weight. A Venn diagram, a widely used tool for visualising how distinct domains relate to and intersect with one another, represents areas that each retain their own logic and constituency while also sharing common ground with the others.

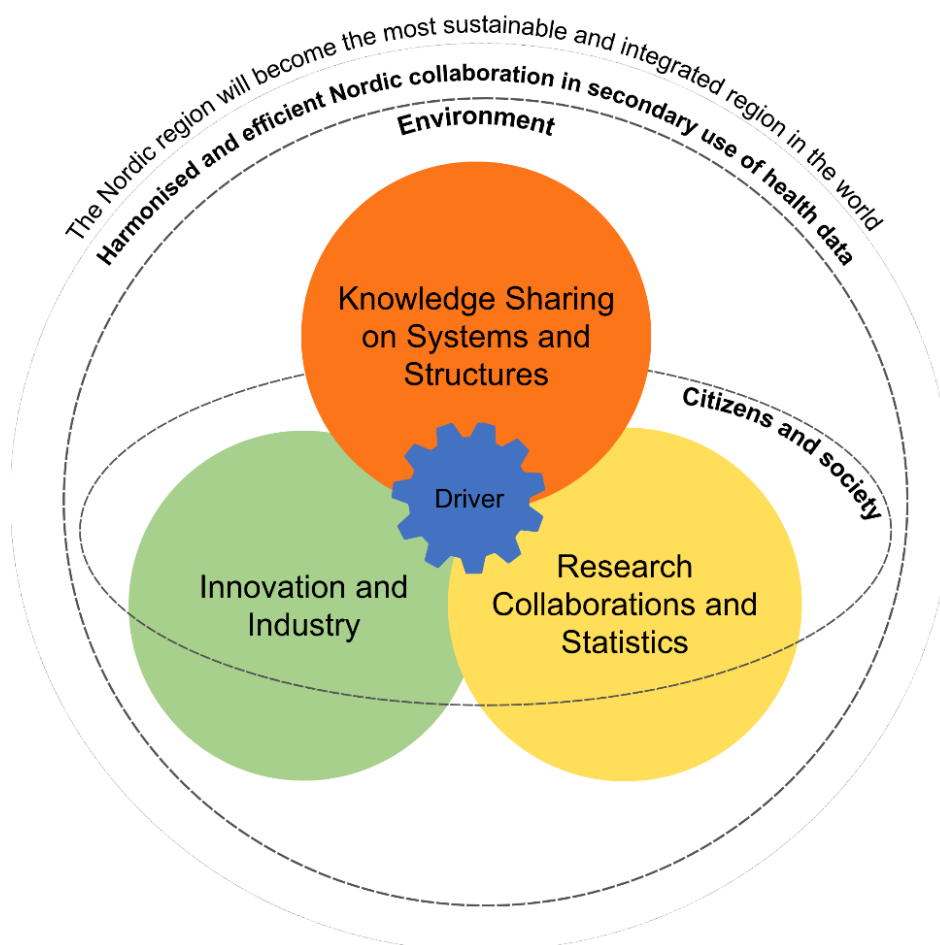


Figure 3. The Nordic model as proposed in *Nordic model for collaboration on the secondary use of health data – A Proposal*, published in December 2025. (3)

In the Nordic model, this means that Knowledge Sharing on Systems and Structures, Research Collaborations and Statistics, and Innovation and Industry each have a distinct purpose and stakeholder base, but they are not isolated from one another. Regulatory knowledge shapes what research is possible, and which innovations can reach the market, while research findings, in turn, inform how regulation should evolve. At the same time, industry innovation generates new questions that regulation must address. The model needed to reflect these interconnections clearly.

The structure in which the three platform circles overlap signalled growing recognition that the three domains cannot be treated as fully separate. Insights into systems and structures influence what kinds of research can be undertaken. Research outcomes, in turn, shape the direction and possibilities of industry development. Innovation then feeds back into the requirements for systems and organisational frameworks. Therefore, the model needed to evolve to make these relationships explicit rather than leaving them implicit.

The labels also became more specific. “Knowledge sharing and harmonisation” became “Knowledge Sharing on Systems and Structures” – grounding the component in the concrete work of mapping national EHDS implementation and identifying regulatory divergences. “Research collaborations” became “Research Collaborations and Statistics”. The inclusion of statistics in this component reflects the fact that meaningful analysis often requires demographic, social, and environmental data that is not held in health registers but in national statistics institutions. It also reflects the well-established collaboration on health and welfare statistics across the Nordic countries within NOMESKO and NOSOSKO, which are components of the Nordic health data ecosystem. However, the status of statistical bodies as data holders under EHDS remains an open question in some Nordic countries, a gap that has direct implications for the model’s ability to support its research ambitions. Taken together, these changes in labelling marked a shift, moving the components from aspirational categories toward descriptions of actual work.

The Nordic Health Data Summit brought together a broader and more international audience than any previous VALO event, with a three-member panel drawing perspectives from industry, prospective Health Data Access Bodies, and patient organisations, including representatives from outside the Nordic region for the first time. The industry representative, from a major pharmaceutical company, framed Nordic health data collaboration in explicitly commercial terms and highlighted the region’s exceptional value for real-world evidence studies. A representative involved in establishing Lithuania’s Health Data Access Body brought a Baltic perspective and made a strong case for expanding the model to include the Baltic states. A representative from a cancer research patient advocacy organisation introduced the theme of trust – arguing that it is not static but must be continuously cultivated through transparency and demonstrated benefit to patients.

From the industry side, the case for Nordic collaboration was articulated in explicitly commercial terms: Nordic health data represents exceptional value for real-world evidence studies, but lack of predictability was identified as the main challenge. This included differences in how similar laws are interpreted across countries and uneven quality in interactions with data controllers. Harmonised legal interpretations and a more solution-oriented approach between researchers and authorities were viewed as more critical than structural change alone.

The Lithuanian HDAB representative brought forward a perspective that would recur in later discussions: the value of expanding the model to include the Baltic states, which share similar levels of digital health maturity and face comparable implementation challenges under EHDS. A Nordic-Baltic model was framed not as a distant aspiration, but as a practical and logical next step.

The patient perspective introduced a theme that would prove equally enduring: trust is not static and must be continuously cultivated. Patients support data use when it is transparent, locally grounded, and demonstrably beneficial, but many citizens remain unaware that secondary use of their data supports research at all. Meaningful patient involvement was described as essential, alongside a caution against tokenistic participation in which input is collected but not acted upon.



Taken together, the October event reinforced the direction of the model while sharpening the questions it needed to address: how to achieve legal harmonisation in practice, how to integrate Baltic countries into the collaboration in a meaningful way, and how to make patient involvement genuinely substantive. These questions continued to shape the work that followed.

The work of this phase culminated in the report *Nordic model for collaboration on the secondary use of health data – A Proposal*, published in December 2025 (3), and presented at the Nordic Health Data Summit (VALO and FinHITS Forum) in October 2025. (5) The report set out a value proposition, a set of design principles, and a governance structure built around a central Driver and three interdependent components. It's concluding chapter clearly identified the remaining unresolved issues, providing direction for the subsequent stages of development.

5 The transition from VALO to VALO2

The concluding chapter of the report published in December 2025 (3), "Bridging over to VALO2", was explicit about what remained unresolved. The governance structure needed to be tested and refined, and the funding model had yet to be determined. Stakeholder engagement also needed to deepen, particularly with the Nordic Council of Ministers (NCM). In addition, the model needed to be grounded in practical experience, meaning that the pilots developed in parallel under Work Stream 3 were expected to provide important practical lessons for further development of the Nordic model.

VALO2 continued the work outlined in the previous report. The first task, a structured review of VALO across all the three Work Streams, examined what tangible goals could be used to measure progress toward a Nordic forerunner position in the use of health data, and what lessons could be drawn from the earlier project to inform the continued development of the Nordic model. This review, completed in December 2025, set the direction for the governance and stakeholder work that followed.

The review produced two outputs. The first, a set of recommendations on how to take the Nordic model forward, was developed within WS1 and would inform the presentation to the NCM the following month (see Chapter 7). The second was a proposal to adopt an Objectives and Key Results (OKR) framework as a way of giving the work concrete direction. Rather than tracking progress through abstract aspirations, OKRs set a clear shared objectives alongside specific, measurable key results over a defined period.

The OKR framework was introduced at the 6th Nordic EHDS2 Competence Forum in Helsinki in January 2026, where breakout groups were asked to formulate concrete objectives and key results for their respective areas of work (see Figure 4). The resulting OKRs, developed by the HDAB, metadata and legal breakout groups, will be reported on in full in the WS2 report. The aim of the OKR framework proposal was to anchor discussions in specific, actionable outcomes rather than general conversation.

At this stage, participants in VALO identified a strong alignment between the findings emerging from the situation analysis and stakeholder consultations and the theories developed by Etzkowitz and Leydesdorff in the Triple Helix Model of Innovation. (6) The literature on the helix model was therefore explored further. The Triple Helix framework, together with its subsequent extensions, provides a useful lens for understanding how key stakeholders can collaborate to foster innovation, advance research, and contribute to social and economic development. The model was then refined through continued engagement over the following months, and this framework became the theoretical foundation for the Nordic model.

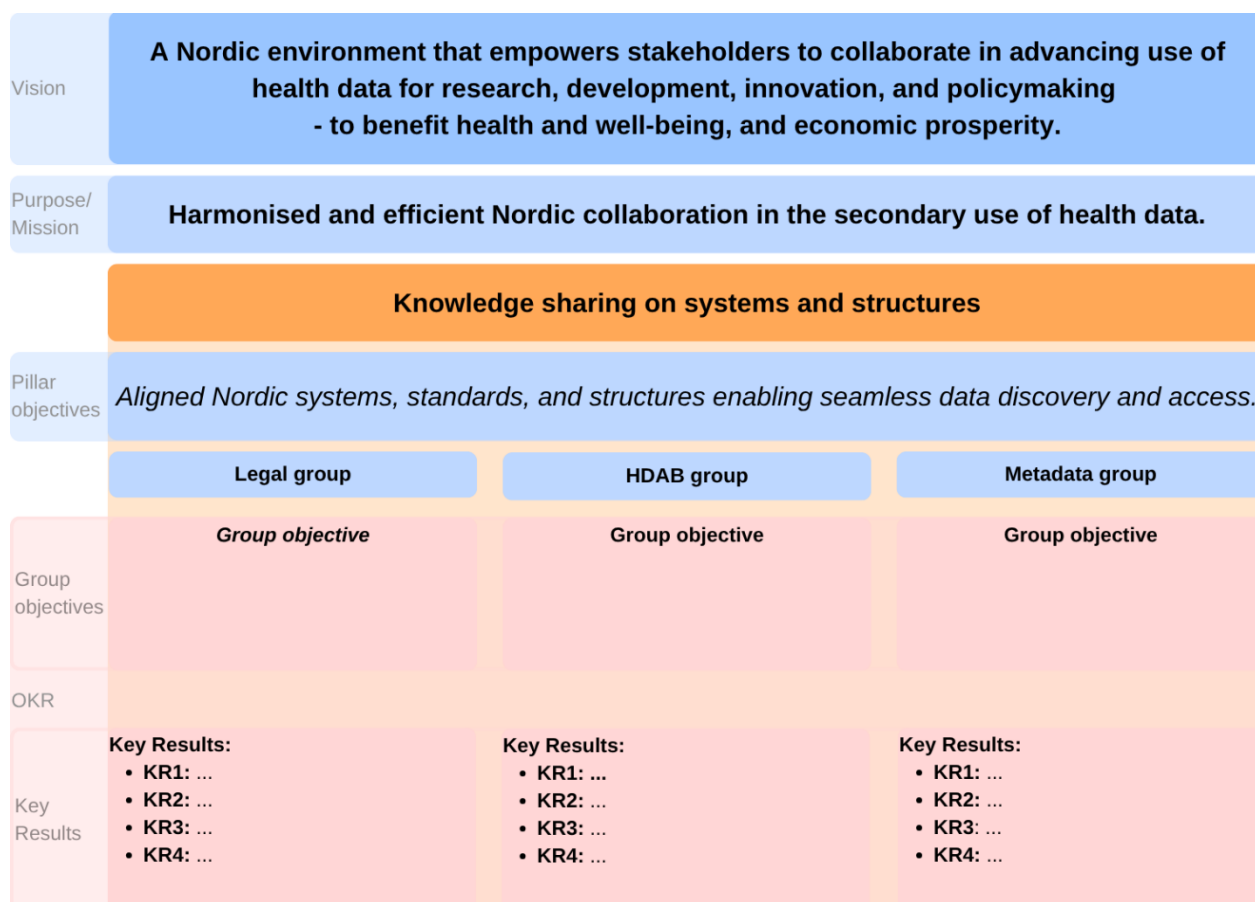


Figure 4. A template of Objectives and Key Results presented at the 6th Nordic EHDS2 Competence Forum.

6 VALO Unconference, January 2026

Unlike a traditional conference where speakers present to an audience, an unconference is a participant-driven format in which those attending set the agenda themselves. Anyone can propose a topic, and the discussions that follow are open, exploratory, and shaped by whoever is in the room. It is a format that works particularly well when the questions are genuinely open, when the organisers do not have all the answers and want to find them together with others.

That was the spirit that guided VALO in bringing an unconference to the Radical Health Festival in Helsinki in January 2026. The aim was to take the Nordic model beyond the usual circle of project partners and invite a wider audience to engage with it openly, to raise the more difficult questions about what Nordic collaboration should look like, who it serves, and how it can be made sustainable. This took place in an inclusive setting where no perspective was assumed to be less valid than another. Three groups (approx. 5 persons in each) formed around proposed topics and carried out their discussions in parallel. The following section summarises the main themes that emerged from the citizen and patient group, the federated analysis group, and the group on regulation and innovation at the Radical Health Festival.

The *citizen and patient group's* discussion highlighted a theme that had previously been identified but remained underdeveloped in the model, i.e. the importance of public trust and its fragility. Participants noted that, while confidence in Nordic institutions is generally high, citizens often struggle to understand what secondary use of health data actually entails. In addition, the opt-out provisions in the EHDS regulation were seen as a source of new uncertainty. The group argued that citizens need to understand the direct personal benefit, namely that the use of health data for research and development leads to better care. Transparency and feedback loops were described as essential, meaning that people should be actively informed about how their data is used and what research findings emerge from that use. NGOs were identified as well-placed to carry these messages to hard-to-reach groups, given the trust they hold within their communities.

The *federated analysis group* clarified technical terminology, distinguishing federated analysis as a one-way, non-iterative approach from federated learning as an iterative process, and identified Nordic coordination on OMOP standardisation as a significant opportunity. The group noted a lack of national-level coordination on OMOP in some countries and proposed a shared Nordic open-source mapping project to address this gap. Data access speed was again raised as a competitive differentiator, with OMOP mapping identified as one way to reduce time-to-access. The group also proposed expanding collaboration beyond the Nordic countries to include the Baltics and potentially Benelux as a way to strengthen the region's collective position.

The group on *regulation and innovation* used the Finnish Secondary Use Act as a central case study. A striking finding was that very few data applications in Finland indicate innovation as their stated purpose. This reflects regulatory incentives rather than lack of interest, as R&D data requests allow only access to aggregated data, whereas a scientific research data permit enables access to pseudonymised data. Users are therefore labelling work as research even when it also serves innovation purposes. The group contrasted this with Luxembourg's approach, where the Data Governance Act, adopted in December 2025, interprets scientific research in the broadest possible terms. The central conclusion of the group's discussion was that the real barrier may not be legislation itself but rather the implementation culture. In Finland, constraints appear to stem not from the law but from the perceived consequences for officials in case mistakes occur, fostering risk aversion that

manifests in slower processes and increased bureaucracy. The group also challenged the common assumption that regulation is the primary obstacle, noting that Europe was not demonstrating strong innovation in health data even prior to GDPR. The group suggested that, in some cases, regulation may serve as a convenient scapegoat for what is, in part, resistance to change. The practical implication is that a broad interpretation of existing legislation, along Luxembourg lines, could unlock substantially more innovation without requiring any change in the law.

VALO unconference – Radical Health Festival, Helsinki, January 2026

- Trust in Nordic institutions is present but fragile — citizens need to understand the direct personal benefits of health data use.
- NGOs are well-placed organisations for public communication about EHDS, given their existing relationships with communities and hard-to-reach groups.
- Implementation culture, not legislation, may be the real barrier to innovation – risk aversion among officials can lead to delays beyond what the law requires.
- Federated analysis and OMOP standardisation are growing in importance under EHDS; Nordic coordination on OMOP mapping was identified as an opportunity.
- Data access speed is a competitive differentiator requiring structural improvement.
- Expanding collaboration beyond the Nordics – to the Baltics and potentially Benelux – was proposed as a way to strengthen the region's competitive position, both as a destination for international health data research and as a more influential voice within European governance structures.

The VALO unconference was important for the model's development in two key respects. First, it reinforced the need to treat citizens and patients not as a background condition, but as active stakeholders in the governance structure. Second, the discussions, within the group on regulation and innovation and on implementation culture added an important nuance to what had previously been framed primarily as a legislative issue. Together, these insights became valuable to the subsequent work on the Nordic model. These themes reflect the perspectives of three smaller discussion groups rather than a broad or representative sample of stakeholders.

The turnout at the unconference was lower than at previous VALO events. This was the first time VALO tried this format. Rather than conducting separate promotion, the unconference relied on being part of the Radical Health Festival's own agenda to draw participants. A lesson for future editions is that dedicated outreach activities is needed to attract a larger and more diverse audience, even if the event is organised as part of a larger event. Nonetheless, the unconference format proved to be a valuable way of creating space for open, exploratory dialogue. For a more detailed summary of the discussions at the VALO Unconference please review Annex 1.

7 Dialogue with the secretariat of the Nordic Council of Ministers, February 2026

In February 2026, the proposed Nordic model for collaboration on health data was presented to the secretariat of NCM for Health and Social Affairs (MR-S) in a meeting designed as an open conversation rather than a formal presentation. The team presented the full architecture of the proposed model, including its value proposition, design principles, and governance structure, and sought guidance on whether the direction aligned with NCM's strategic priorities and how the proposed structures could be operationalised.

The initial proposal presented an existing NCM body as a potential institutional home for the Driver, based on its established mandate, Nordic relationships, and practical experience. It also outlined a two-stage funding model, moving from initial NCM investment toward a more sustainable coordination or membership-based arrangement over time.

The feedback was cautiously encouraging but realistic about institutional constraints. The proposal was seen as worth pursuing, although funding emerged as the most significant challenge, with coordination functions considered relatively easier to fund than pilot initiatives or operational activities. The proposed institutional home was considered a less obvious fit for a health data role, and alternatives, including NCM eHealth Group, were suggested. A key condition for progress was also identified, namely that the initiative must be made compelling to the cooperation ministers across all member countries, rather than relying solely on support from the presidency country.

Furthermore, two directions that had been under consideration but not yet actively pursued, were reinforced in the meeting, i.e. strengthening engagement with the NCM eHealth Group, and more explicitly addressing the boundary between primary and secondary use of health data. While both themes had been implicit in the model's development, the discussion with the secretariat of the NCM gave them more prominence. In addition, the meeting brought renewed attention to the need for a longer-term transition phase to bridge from project-based development to a more permanent structure. These threads have continued to evolve since the meeting and remained open questions.

A follow-up meeting took place in April 2026 with a representative from the NCM secretariat for Health and Social Affairs (EK-S), which confirmed that the proposed institutional home was not the right fit for the Driver role. A significant development had taken place in parallel: the Nordic eHealth Group was independently reviewing its own scope and structure in a way that matched the direction of the VALO project. This created an opportunity to integrate WS1's results into a broader EHDS framework. This directly addresses the boundary question between primary and secondary use that had been raised throughout the VALO project.

The agreed next steps involved an active dialogue between VALO and the eHealth Group that was preparing a concept paper for presentation at a meeting of the Nordic Committee of Senior Officials for Social and Health Policy (EK-S) in August 2026. No final decision is expected at that meeting, but it is hoped that the discussion will enable WS1 to present a provisional statement from the NCM at the VALO final event in late September 2026.

8 The model evolves: Workshop in May 2026

The workshop at Vitalis in Gothenburg in May 2026 was the most intensive governance design session of the project so far. Prior to the workshop, the model had been updated to incorporate insights from citizen and patient engagement at the VALO unconference in Helsinki. As a result, Citizens, Patients and Health Systems were integrated as a distinct and core component of the model, rather than treated as a contextual background. In parallel, a dedicated Governance layer was introduced to make the accountability structure more explicit (Figure 5).

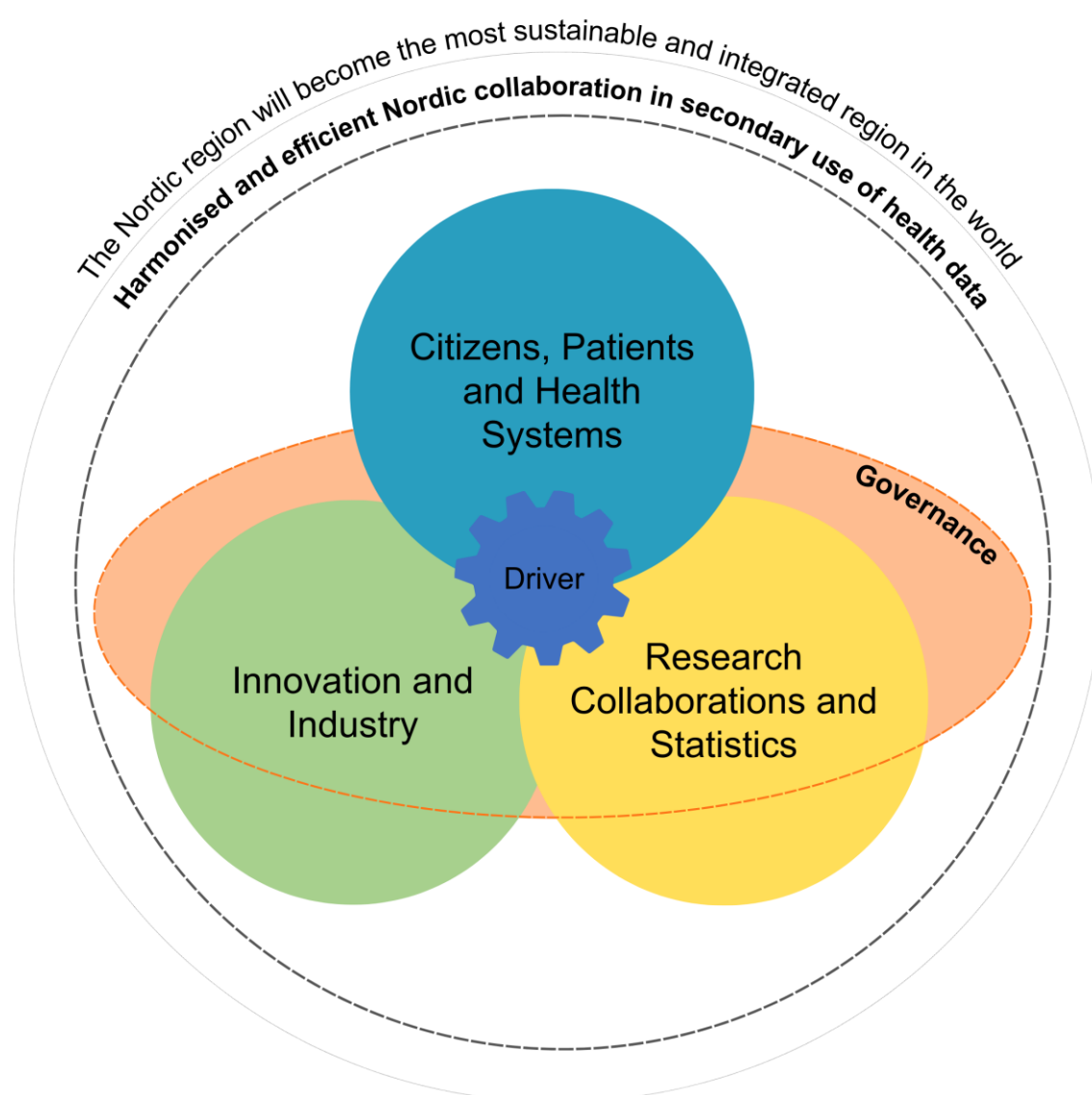


Figure 5. The Nordic model as presented at the Vitalis workshop, May 2026, with Citizens, Patients and Health Systems as a full component.

The workshop at Vitalis was a closed session for members of the VALO2 project and was organised into four groups (Figure 6). Each group worked through the proposed governance structure in detail: the chair committee, the secretariat, the task forces, and the broader ecosystem design.

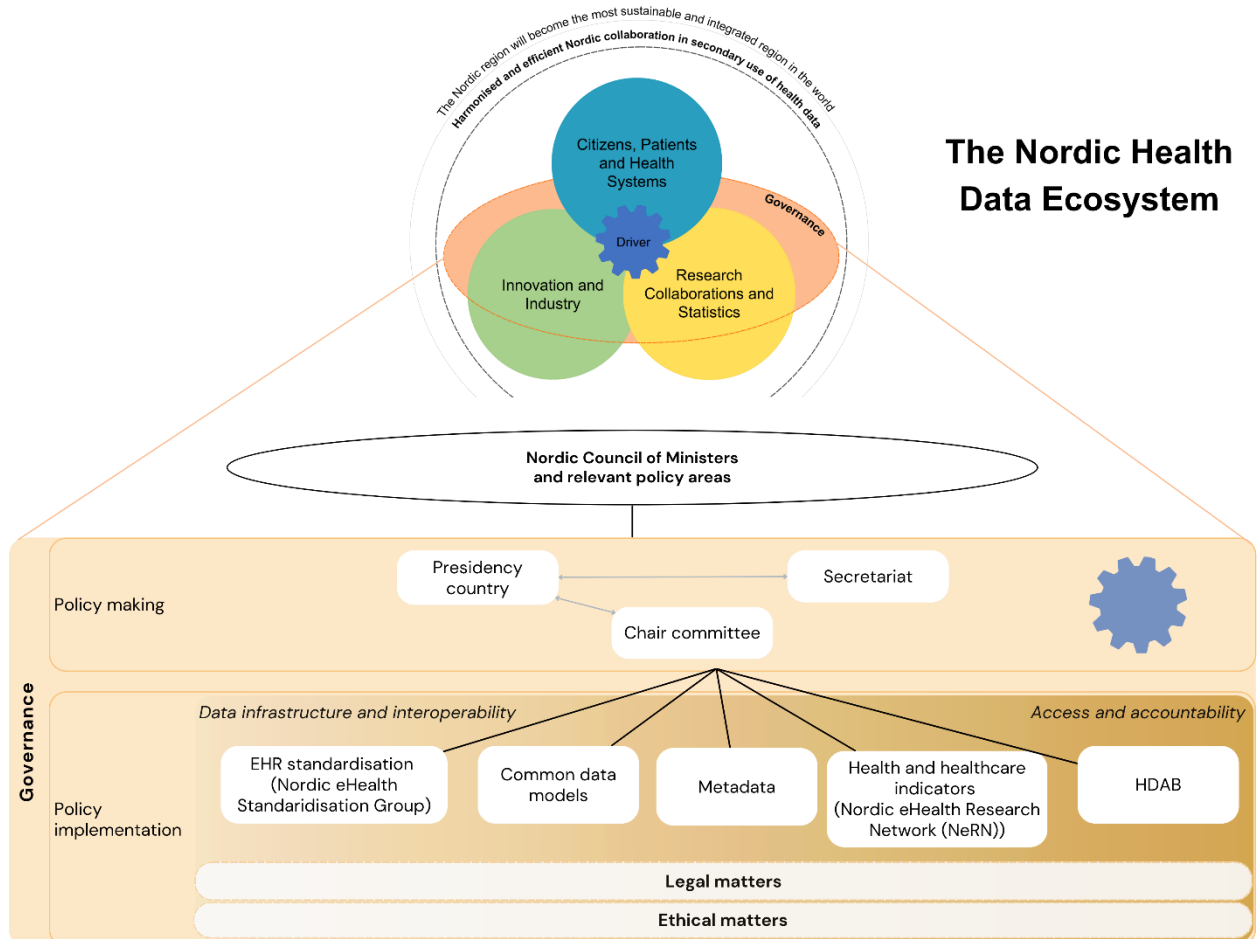


Figure 6. The proposed governance structure.

The secretariat emerged as the most discussed element at the workshop. All groups agreed that it was essential, and there was strong consensus that it should be positioned closer to the operational level than to ministry level, with clear lines of communication to the governance structure. Groups 2 and 3 cautioned against placing it too close to political structures while Group 4 reinforced the view of the secretariat as a practical enabler of cooperation rather than a political body. Group 4 also emphasised that part of the secretariat should take responsibility for a customer facing interface, actively attracting international pharmaceutical companies and research projects to work with Nordic health data, with a clear message: *come to the Nordics, it is the world's best place to conduct research with health data*.

Group 4 also raised a broader challenge that has been identified across multiple Nordic health data initiatives. Pilots frequently lose momentum and institutional knowledge when project funding ends, leaving subsequent initiatives to start from scratch rather than building on what came before. The Nordic model was proposed as a potential platform for providing

a permanent home where pilot results and lessons learned could be preserved and made accessible, enabling continuity across successive projects.

The governance layer was broadly supported. The Chair Committee comprising two members per country and meeting twice a year in alignment with the NCM cycle, was endorsed by groups 1 and 2. Group 3 raised an important caution, noting that the structure risks becoming overly complex at an early stage and that a lighter approach, developed gradually from the bottom up, may be more sustainable and realistic. The appropriate level of governance at the outset, and who should determine it, remained unresolved. A point raised in at least one group was the need for an explicit connection between the policy-making layer and the EHDS Board. As the Nordic model operates within the EHDS framework, it will be important that the Chair Committee has a defined relationship with the EHDS Board, enabling Nordic positions to be coordinated and fed into European-level governance. This linkage was seen as essential for ensuring that the Nordic voice is coherent and influential within EHDS structures. This connection does not imply that the same individuals should sit on both the Chair Committee and the EHDS Board – ministerial representatives at that level are unlikely to have the capacity for the intensive work the Nordic model requires. Rather, as experience from the long-standing eHealth Network has shown, effective governance relies on structured communication between political representatives and the expert groups working below them. The Nordic model's value lies in creating a regional expert layer that can feed coherent Nordic positions upward into EHDS governance structures, rather than duplicating those structures.

Coordination of the Health Data Access Bodies (HDABs) was discussed extensively. Participants emphasised the complexity of coordinating HDABs both within and across countries and proposed an establishment of a dedicated Nordic HDAB coordination forum. Legal interoperability was identified across all groups as a significant challenge requiring focused attention in the final report.

The HDAB discussions also brought into sharper focus a question that the NCM dialogue in February had already flagged: the relationship between primary and secondary use of health data. As the model has grown in scope, incorporating Citizens, Patients and Healthcare Providers as a core component and increasingly touching on infrastructure questions that straddle both uses, the boundary between the two has become harder to treat as a given. The existing Nordic eHealth group provides an active forum for primary use, and the VALO work has been deliberately focused on secondary use within the EHDS framework. Several workshop discussions, however, particularly around HDAB coordination and the governance of patient-facing interfaces, pointed toward areas where the two cannot be cleanly separated. How the Nordic model should position itself in relation to primary use, whether by maintaining a clear boundary, by explicitly bridging the two, or by acknowledging the overlap without attempting to govern it, is a question the final report will need to address.

Workshop outcomes on Nordic model – Vitalis, Gothenburg, May 2026

- Strong consensus on a secretariat sitting close to the operational layer, not ministry level, with strong upward communication to governance
- The secretariat should carry responsibility for a customer-facing interface, positioning the Nordics as the world's best place to work with health data
- Chair Committee: two members per country, meeting twice a year aligned with NCM rhythms; rotating presidency
- Task forces should be lean and action-oriented, with rotating leadership and close connections to people doing actual work in each country
- An annual summit, rotating between countries, co-developed and led by the presidency country with secretariat support
- HDAB coordination is complex; a dedicated coordination forum was proposed
- Secretariat contracts should run longer than one year to allow institutional memory to accumulate
- The Nordic model could serve as a permanent home for findings from Nordic pilots and lessons learned, enabling future initiatives to build on previous work rather than starting from scratch

The workshop also raised a question that had been in the background for some time: does the name "Nordic model" still fit? With Baltic countries joining as observers and the scope of the work continuing to expand, the current name felt to some participants like it was underselling both the ambition and the reach of the work. Participants were invited to propose alternative names and then vote on them, with similar suggestions grouped together. The results are shown in Figure 7. The clear frontrunner was Nordic Health Data Space, drawing 40.7% of votes. No decision was taken at the workshop, and the naming question remains open, to be addressed later in the project. For a more detailed summary of the discussions from the VALO2 workshop at Vitalis please review Annex 2.

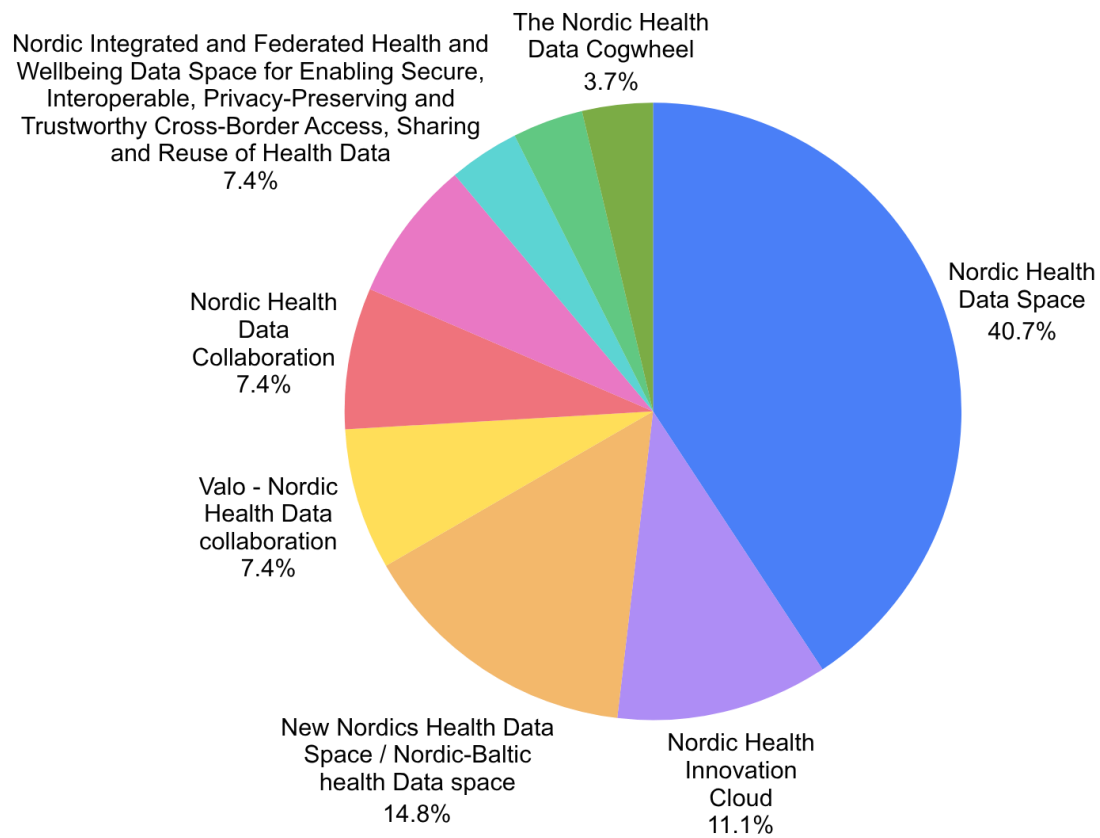


Figure 7. Ideas of new names of the Nordic model.

9 Where the model stands now

The most recent working version of the Nordic model integrates the developments described above and departs from earlier iterations by no longer presenting the components as a single unified structure. Instead, it is organised as a Quadruple Model in which distinct components are made explicitly visible, while still allowing for significant overlap between specific elements. In this configuration, Innovation, RDI, and Research Collaborations and Statistics form partially overlapping domains, while Citizens and Patients and Healthcare Providers are positioned as equally central components of the ecosystem. The Driver remains at the centre as a coordinating mechanism, and Governance is represented as an encompassing layer that frames the system and clarifies accountability (Figure 8). The governance layer is represented here as a single encompassing structure, however its internal organisation including the distinction between a policy-making layer and a policy implementation layer are described in the previous chapter and illustrated in Figure 6.

Each part of the model reflects a distinct role in the health data lifecycle, from data generation through to the benefits that flow from its use. Health data is generated through interactions between citizens, patients, and healthcare providers, but also through wellness applications and self-reported surveys. Those who use the generated data – researchers and innovators – are represented by the Research Collaborations and Statistics and Innovation components, which overlap in the RDI space where the boundary between scientific inquiry and commercial application is often unclear. Healthcare providers occupy a dual role in this lifecycle, generating data through clinical interactions while also using it to improve treatments and delivery of care. Their inclusion as a distinct component rests on this lifecycle logic and on the triple helix model underpinning the Nordic model, rather than on direct stakeholder engagement through VALO. Unfortunately, the VALO partners have had limited interaction with healthcare providers as a group, beyond the university hospital contributing to the pilots. Structured engagement with this stakeholder group remains a gap. The benefits of secondary use flow back to everyone: patients who receive more accurate diagnoses, citizens who live in a healthier society, and an innovation ecosystem that attracts investment and develops new health technologies.

Underpinning the entire lifecycle is Governance – the enabling layer that makes lawful, trustworthy data access possible through regulatory harmonisation, policy alignment, and coordination between national authorities and HDABs across the region. Beyond supporting current and future initiatives, the Model has also been proposed as a permanent home for the outputs of past Nordic pilots, so that results and lessons learned are not lost when project funding ends but can be carried forward by the next initiative facing the same challenge.

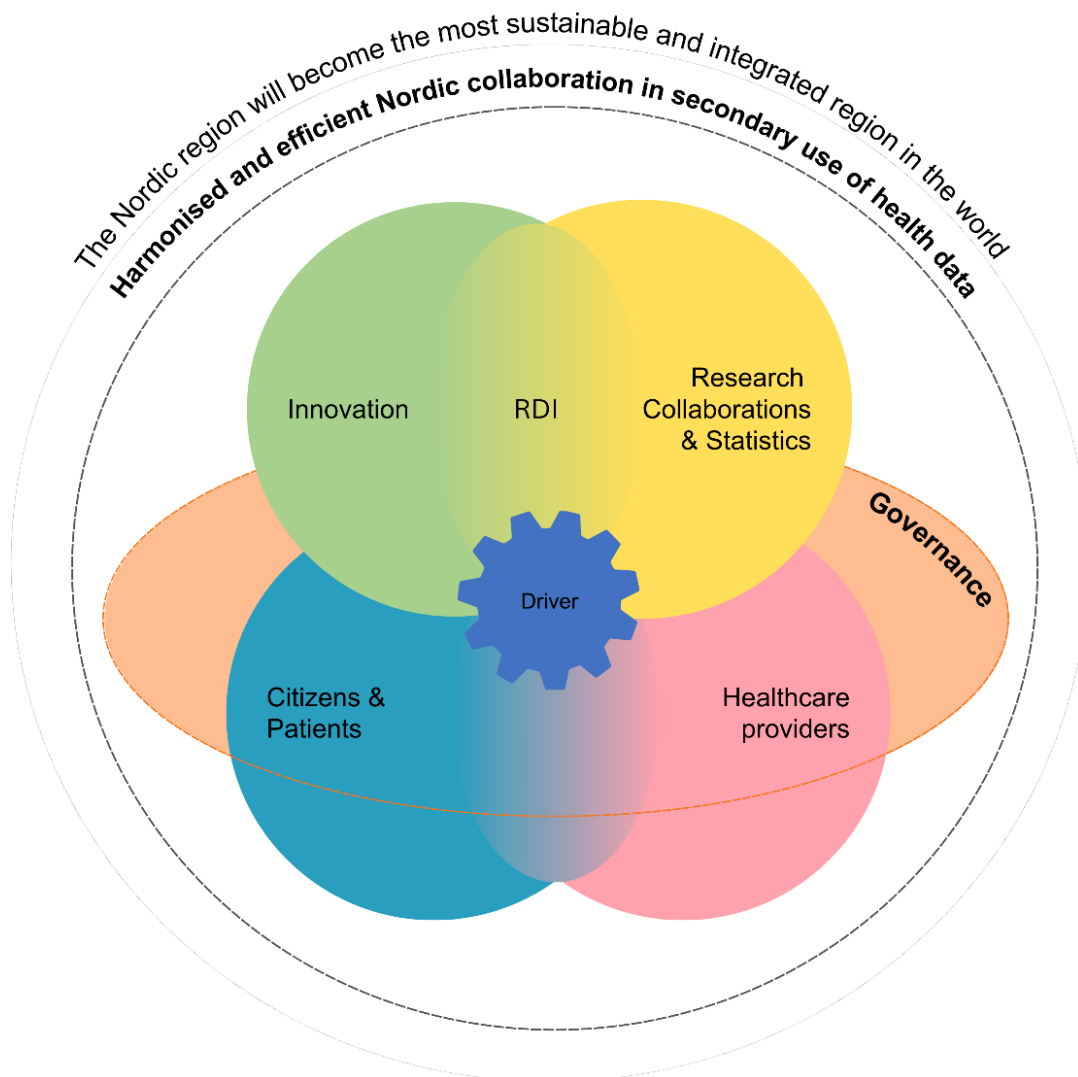


Figure 8. Working version of the Nordic model in June 2026.

This version is not yet finalised. The workshop organised in May 2026 left several important questions unresolved, which the final report will need to address. These include the appropriate level of governance at the outset; whether innovation and research should be more closely integrated rather than treated as separate components of the ecosystem; the design of the funding model; and how the relationship between the Nordic model and the EHDS governance structures at the European level should be defined.

What is clear, however, is that the Model has been genuinely responsive to the process that produced it. Each iteration reflects new insights gained from stakeholder interviews and stakeholder panel, the VALO unconference, political engagement, and the governance workshop. This responsiveness, in itself, provides evidence that the process is functioning as intended.

10 Conclusion and next steps

This report has documented the journey of Work Stream 1 through its major milestones: from the foundational situational analysis and stakeholder interviews, through the first public presentation of the Nordic model, through its refinement at successive Competence Forums and events, to the intensive governance design session at Vitalis in May 2026.

The journey has been one of progressive concretisation. The Model has moved from a high-level framework to an increasingly detailed governance proposal. The stakeholder base has broadened from researchers and industry to citizens, patients, policymakers, and NCM. The questions have sharpened from “what should a Nordic model look like” to “How heavy should the governance structure be at the start?” and “how should the Nordic model relate to the EHDS governance architecture at European level?”

The remaining work is defined. The final report – *Nordic Model for Collaboration on the Secondary Use of Health Data: Steps Toward Implementation* (working title), due in September 2026 – aims to address the open governance questions, incorporate lessons from the second Nordic EHDS pilot being The Vitalis workshop clarified the key questions and highlighted the governance structure to refine.

The broader ambition – to position the Nordic region as the world’s most attractive destination for health data research and innovation – remains as relevant as when the project began. What has changed is that a proposal on how to build the necessary institutional foundation for that ambition is now well underway.



References

1. Secondary use of health data in Nordic co-operation. Available from: <https://www.sitra.fi/en/publications/secondary-use-of-health-data-in-nordic-co-operation/>
2. 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>
3. Nordic model for collaboration on the secondary use of health data - a proposal [Internet]. 2025 Nov [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. Norwegian Centre for E-health Research [Internet]. 2025 [cited 2026 July 2]. NHDS - Nordic Health Data Spaces. Available from: <https://ehealthresearch.no/en/projects/nordic-health-data-spaces>
5. Nordic Health Data Summit - A VALO and FinHITS Forum [Internet]. 2025. Available from: <https://www.sitra.fi/en/events/valo-stakeholder-forum-nordic-health-data-summit/>
6. Etzkowitz H, Leydesdorff L. THE TRIPLE HELIX---UNIVERSITY-INDUSTRY-GOVERNMENT RELATIONS: A LABORATORY FOR KNOWLEDGE BASED ECONOMIC DEVELOPMENT. 1995 Jan;14(1):14–9.

11 Annex 1: VALO unconference – Radical Health Festival, Helsinki, January 2026

The VALO unconference was held as an open session at the Radical Health Festival in Helsinki in January 2026. Unlike the Competence Forums and the Vitalis workshop, this event was open to all festival participants, deliberately designed to bring in perspectives from beyond the VALO membership. This was the first time VALO used this format, and rather than conducting separate promotion, it relied on the festival's own audience to draw participants. Three small groups (approximately five participants each) worked in parallel on distinct themes; the summaries below should be read as discussion points from these groups rather than as representative or consensus findings.

Group 1: Patient and citizen engagement with EHDS

Trust emerged as the central concern – not its absence, but its fragility and conditionality. Participants noted that while confidence in Nordic institutions is generally high, citizens struggle to understand what secondary use of health data actually means. The opt-out provisions in EHDS were seen as creating new uncertainty about how existing trust will be maintained. Nationalism was identified as a complicating factor: people may trust their own country's systems but feel differently about their data crossing borders.

Participants argued that citizens need to understand the direct personal benefit – that using health data leads to better care for them. Transparency and feedback loops were seen as essential: actively telling people how their data was used and what the research found. The group identified NGOs as well-placed trusted intermediaries who can carry messages to hard-to-reach groups, and proposed a range of communication tools including patient portal notifications, webinars with umbrella organisations, and a communication toolkit for EHDS patient education.

Group 2: Federated analysis and OMOP standardisation

The group clarified terminology: federated analysis refers to one-way, non-iterative analysis; federated learning involves iterative processes. Both will grow in importance under EHDS, particularly for large datasets and data that cannot be centrally shared. OMOP was identified as a significant opportunity for Nordic coordination, with the caveat that purpose must be defined clearly upfront – how data will be used and what quality level is required.

Data access speed was again identified as a competitive differentiator. The group proposed that OMOP mapping could potentially help reduce time-to-access. A notable gap was the absence of national-level OMOP coordination in some countries, pointing to an opportunity for a shared Nordic open-source mapping project. Expanding collaboration beyond the Nordic countries – to the Baltics and potentially Benelux – was proposed as a way to strengthen the region's position.

Group 3: How regulation enables or blocks health data innovation

The group examined the Finnish Secondary Use Act as a case study. Very few data applications have indicated innovation as their stated purpose, because R&D purposes only allow access to aggregated data. Users instead indicate research as their purpose – even when the work is also for innovation – in order to access pseudonymised data. The group contrasted this with Luxembourg, which adopted its Data Governance Act in December 2025 and interprets scientific research in the broadest possible terms.



The key finding was that the real barrier may not be legislation itself but implementation culture - the practical consequences of getting it wrong, which produces risk-averse implementation, matter more than the law itself. Slowness and bureaucracy are the practical result. The group proposed that how legislation is interpreted and applied matters as much as what it says, and that broad interpretation along Luxembourg lines could unlock more innovation without requiring legislative change.

12 Annex 2: Workshop on Nordic model – Vitalis, Gothenburg, May 2026

The workshop at Vitalis in Gothenburg in May 2026 was a closed session for VALO members. Four groups worked through the proposed governance structure of the Nordic model in detail. The following is a compiled summary of their discussions.

Governance layer: Chair Committee and presidency

All groups engaged with the governance structure and broadly supported its core elements. The Chair Committee was seen as the appropriate policy-making body, with two members per country meeting twice a year aligned with NCM rhythms. Groups 1 and 2 affirmed this structure. Group 3 raised an important caution: the structure risks becoming too heavy from the outset, and a lighter starting point built from the bottom up may be more sustainable and realistic. Group 4 proposed that subgroups and task forces could sit under steering committees, and suggested a dedicated horizontal subgroup to coordinate on cross-cutting topics such as data quality and the link between primary and secondary use. At least one group also raised the need for an explicit connection between the policy-making layer and the EHDS Board, so that the Chair Committee can coordinate Nordic positions and engage coherently with European-level governance.

All groups supported rotation of the presidency, consistent with the NCM model. The presidency country should take leadership of the annual summit. Group 2 stressed the importance of identifying formal bodies and ministry contacts in each country at an early stage, with a clearly defined mandate from the outset.

Secretariat

There was strong consensus across all groups on the importance of the secretariat. The secretariat should collect and track information on EHDS implementation across member states, produce materials for the Chair Committee, maintain a central website for information exchange, and serve as the primary resource for Nordic health data. Groups 2 and 3 cautioned against placing the secretariat too close to ministry level – it should sit closer to the operational layer, with strong upward communication to governance.

Group 4 added two important dimensions: the secretariat should involve all countries in its work; and contracts should run for longer than one year to allow institutional memory to accumulate. Group 4 also proposed that part of the secretariat should take explicit responsibility for a customer-facing interface – actively attracting international pharmaceutical companies and research projects to work with Nordic health data.

Group 4 also raised the recurring challenge of pilots losing momentum and institutional knowledge when project funding ends. The Nordic model was proposed as a potential platform for preserving pilot results and lessons learned, enabling future initiatives to continue from where previous ones left off rather than starting from scratch. This problem was noted as having been identified across multiple Nordic health data initiatives and forums.

Task forces and working groups

Groups 2, 3, and 4 emphasised that task forces should be kept lean and action-oriented, with rotating leadership and communication that goes beyond formal meetings. Task forces should be closely connected to the people doing actual work in each country. Group 3 noted



that the Nordic eHealth standardisation group already exists and should not be duplicated. HDAB coordination was discussed at length; a coordination forum for HDABs was proposed, and legal interoperability was flagged as a significant challenge across all groups.

Key open questions

The workshop left a number of important questions unresolved, to be addressed in the final report:

- How heavy should the governance structure be at the start, and who decides?
- Should innovation and research sit closer together rather than in separate ecosystem components?
- What does the funding model look like, and how does it transition from grant-based to sustainable membership or service fees?
- How should the Nordic model relate to EHDS governance structures at the European level?
- What is the role of Health Data Access Bodies in a Nordic coordination context?