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

steps towards implementation

Extended executive summary
Value from Nordic health data – VALO2 project

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Document info

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List of terms and definitions

Term	Definition
Nordic Health Data Governance Network	The proposed permanent policy-alignment structure for Nordic cooperation on primary and secondary use of health data, led by a Nordic Health Data Governance 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 experiences 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 Committee, Secretariat, 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, healthcare providers and health workforce, public authorities, industry, patient organisations, and citizens.

Extended 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. Combined with the wider Nordic-Baltic region, this represents a population and research base at a scale no single country can achieve alone. Yet 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, and industry actors describe avoiding cross-border data projects altogether due to the complexity and time involved.

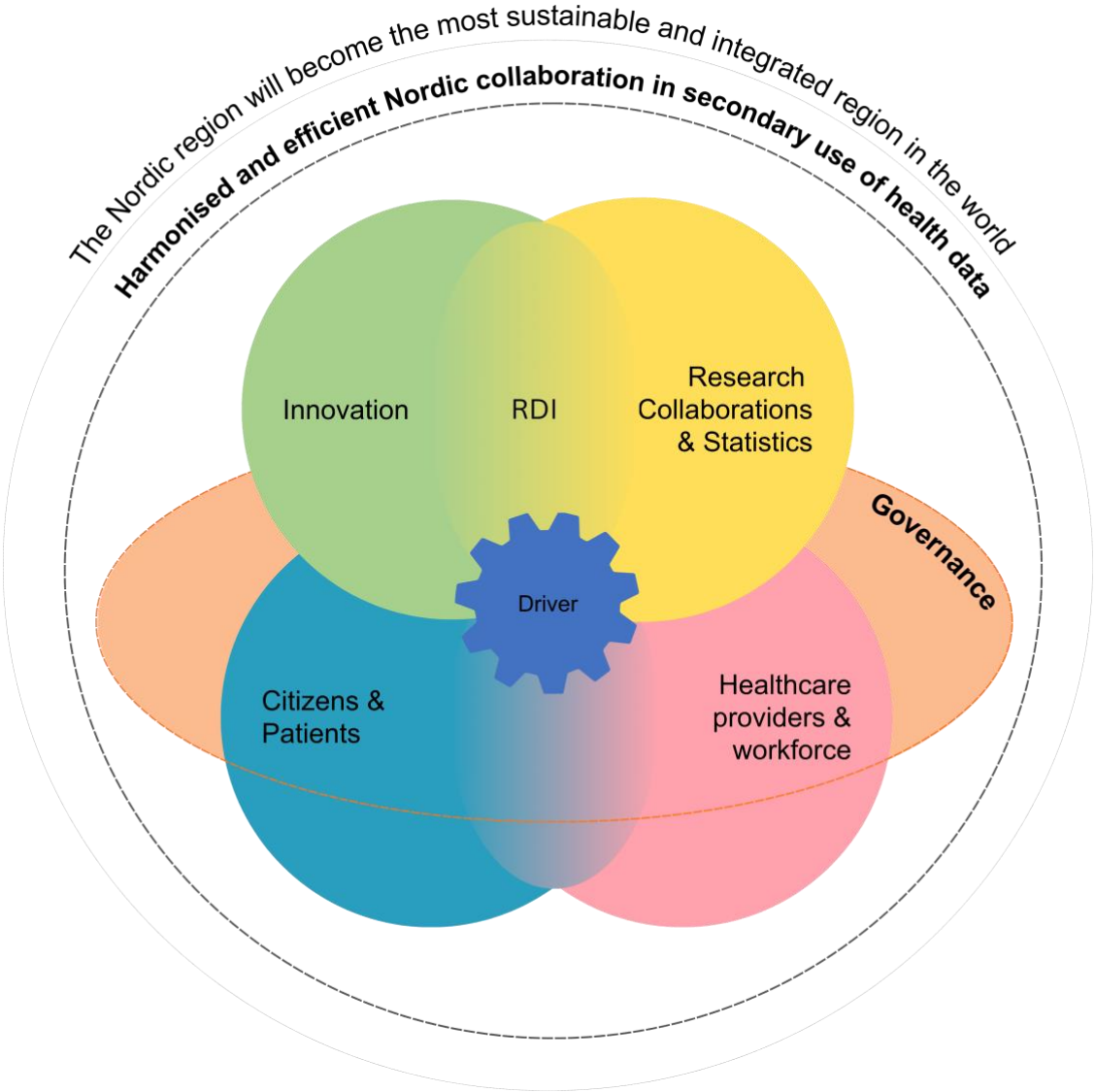

Figure 1. Nordic model for collaboration on secondary use of health data.

The Value from Nordic Health Data (VALO) project was launched in 2024 to strengthen Nordic cooperation 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 (Figure 1).

The report focuses on the governance arrangements, since other elements of the model depend on them being established. The focus of the VALO projects has been on the secondary use ecosystem and the recommendations in this report reflect that focus. Nonetheless, as our work developed, the close connection between the primary and secondary use of health data became increasingly clear. The Nordic model presents four recommendations, designed to work together

rather than as separate initiatives, in order to set out the initial steps required to move from project-based cooperation to a permanent and sustainable structure (see Figure 2 for how the Nordic Health Data Governance Committee, Secretariat and thematic expert working groups fit together):

Recommendation 1: Establish a Nordic Health Data Governance Committee, building on the existing NCM eHealth Group, with a rotating presidency aligned to the NCM cycle.

Recognising the synergies and dependencies between primary and secondary use of health data, we propose expanding the mandate of the NCM eHealth Group to cover both domains. The Nordic Health Data Governance Committee and the Presidency country would hold primary responsibility for setting common priorities and implementing them. Thematic working groups would be tasked with developing recommendations on specific issues, and the Committee would be responsible for acting on the results they deliver, ensuring accountability.

Recommendation 2: Establish a permanent Secretariat, to provide institutional continuity and knowledge maintenance across presidency rotations.

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

Recommendation 3: Endorse and resource a permanent Nordic Health Data Competence Forum, adopting the proven operational structure built through VALO, meeting on a regular basis to support national authorities through EHDS implementation and beyond.

The Forum should bring together authorities' representatives, 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 practice examples, and address common challenges. Much of the Forum's work would be carried out through thematic working groups, focused on specific areas of common priorities.

Recommendation 4: Support an annual Nordic Health Data Summit, a public forum convening the whole ecosystem, building on events already run under VALO.

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 should remain open to those who want to contribute and should consistently create value for citizens, researchers, and institutions it is intended to serve.

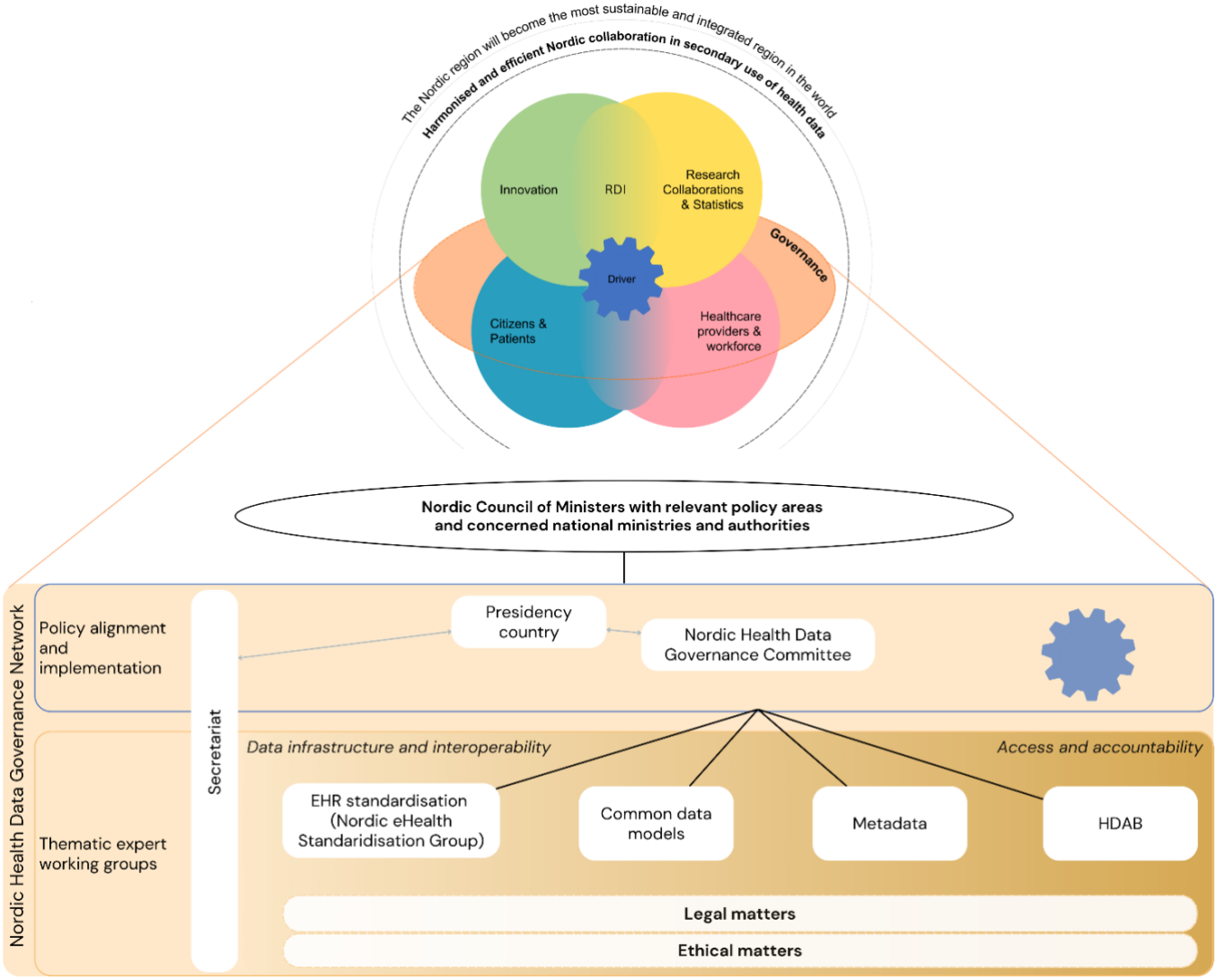

Figure 2. Governance layer of the Nordic model.

The Nordic region is 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 advance collaboration and utilise the region's established strengths in health data, research, innovation and public administration.

The model developed through the VALO project provides a practical framework for organising Nordic collaboration, relying on tested guiding principles: building on what exists, respecting existing responsibilities, and leveraging synergies, rather than duplicating efforts.

None of the proposed recommendations requires creation of new structures from scratch. Each recommendation builds on the arrangements and partnerships developed and tested through VALO and earlier Nordic initiatives in the area of health data. Together, they are designed to work as a single, coherent structure rather than as separate, project-based initiatives. The key requirement now is a commitment from the Nordic Council of Ministers and national authorities to

formalise and sustain these structures, so that decades of national investment in health data can be translated into durable, shared Nordic – and increasingly Nordic-Baltic – advantage.