NORDIC HEALTH DATA SUMMIT

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MINISTRY OF TRANSPORT AND COMMUNICATIONS FINLAND

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AGENDA

9:15-9:35	**Session 1: The Nordics and Baltics taking the lead on EHDS implementation**
9:35-10:35	**Session 2: Unlocking the potential of federated analysis and OMOP — insights, challenges, and future directions**
10:35-11:00	**Coffee break**
11:00-11:50	**Session 3: Advancing Nordic collaboration in health data**
11:50-12:25	**Session 4: Strengthening Finland's health data infrastructure**
12:25	**Conclusion of morning sessions**
12:35	***Live stream ends***

Read more

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AGENDA

12:35-13:40	**Lunch break**
13:40-14:40	**Session 5: Case studies on the secondary use of Finnish social and health data**
14:40-14:50	**Break**
14:50-15:45	**Session 6: Learning from cross-border data collaboration and AI use in the transport sector**
15:45-16:00	**Closing remarks**
15:00-17:00	**Findata pop-up – A glimpse into the future of data**
16:00-17:00	**Networking reception**

Read more

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SESSION 1

The Nordics and Baltics taking the lead on EHDS implementation

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The Nordics and Baltics taking the lead on EHDS implementation

Markus Kalliola, Programme Director,
The Finnish Innovation Fund Sitra

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EHDS has entered into force March 26 2025

1. Chapter 1: General provisions (Art. 1 -2)
2. Chapter 2: Primary use of electronic health data (Art. 3 - 24)
3. Chapter 3: EHR systems and wellness applications (Art. 25 - 32)
4. Chapter 4: Secondary use of electronic health data (Art. 50 - 81)
5. Chapter 5: Additional actions (Art. 82 - 91)
6. Chapter 6: European governance and coordination (Art. 92 - 96)

7-9 Chapter 7-9: Delegation, Miscellaneous, Deferred application (Art. 97 - 105)

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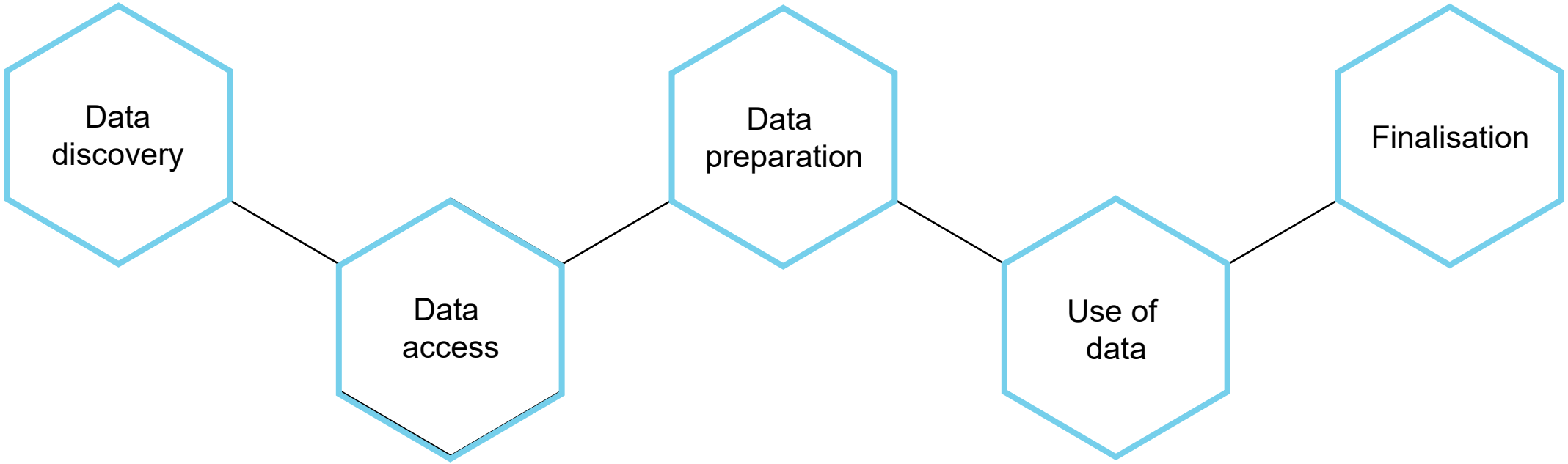
EHDS User journey for secondary use



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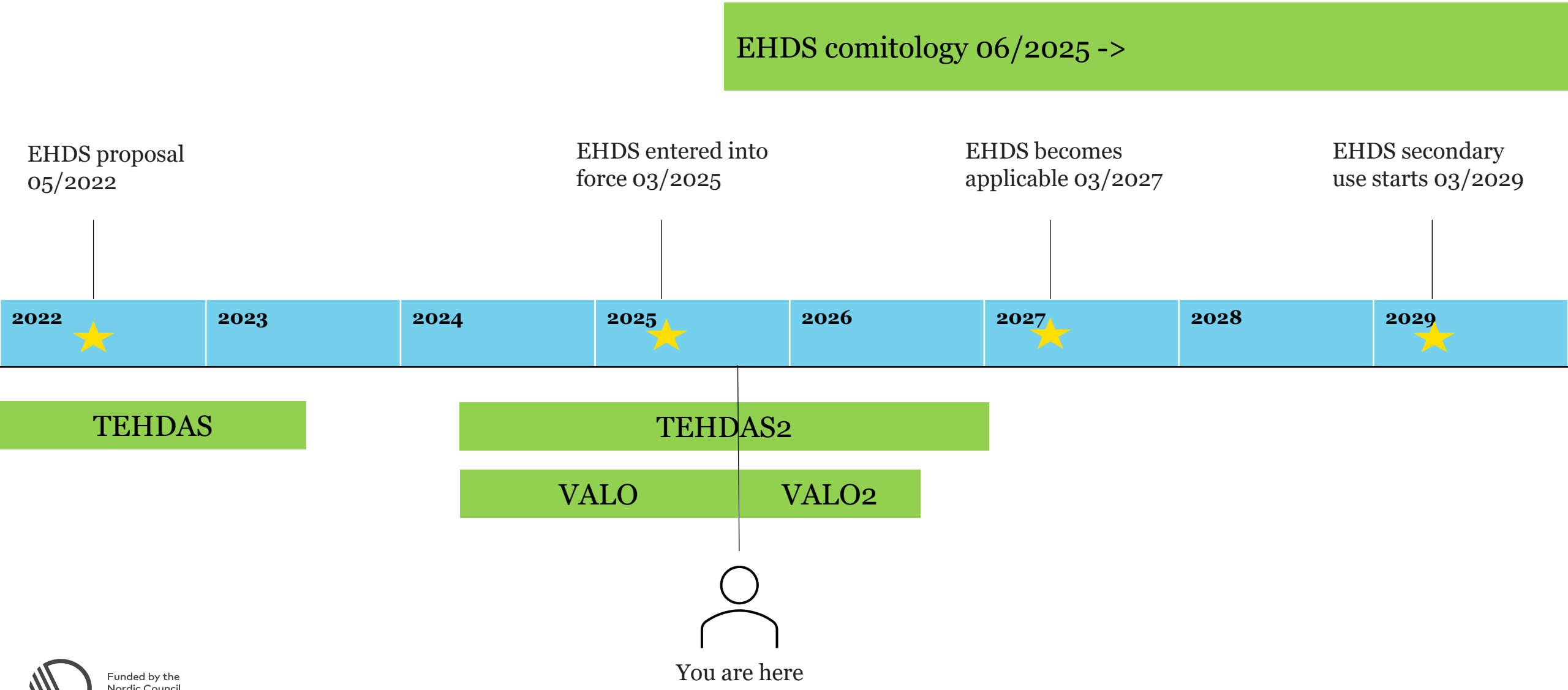
EHDS timeline and VALO



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TEHDAS 2
EXPECTED RESULTS

Guidelines and technical specifications

for

data users, data holders and health data access bodies

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TEHDAS2
EXPECTED IMPACTS

Better preparedness for implemeting EHDS

and

better coordination on policies and less fragmentation on practices for secondary use of health data

Public consultations open!

Deadline 30 November at
www.tehdas.eu/public-consultation/

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Value from Nordic health data – VALO

- **Strengthens Nordic co-operation** in the secondary use of health data
- **Prepares for the European Health Data Space legislation** in the Nordic countries
- **Showcases results** by piloting a Nordic federated analysis use case
- **Targets to reach and maintain a leading position** for the Nordic countries in the secondary use of health data

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Work structure

PHASE 0: PROJECT PLAN AND FEASIBILITY STUDY (Feb - Apr 2024)

WS1 Nordic model for secondary use of health data	WS2 Harmonised preparation & implementation of EHDS2	WS3 Nordic federated analysis pilot and Nordic EHDS pilot

PHASE 1 (May 2024 – Apr 2025)

– Defining objectives and opportunities in the long run – Defining **common value proposition**	– Preparing jointly for the EHDS legislation in the Nordics – **EHDS2 Competence Forums**	– Procurement: Piloting a **Nordic federated analysis study** using the OMOP Common Data Model

Stakeholder event in Gothenburg – interim results

PHASE 2 (May – Oct 2025)

– **Nordic model for collaboration** in the secondary use of health data	– Coordinating implementation efforts in the Nordics – **EHDS2 Competence Forums** continue	– Procurement preparation: Piloting EHDS use case e.g. cross-border use of Secure Processing Environments

Final event in Helsinki – final results

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Harmonised preparation for EHDS2

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A platform for knowledge sharing on EHDS implementation

Invited experts from ministries, governmental authorities and agencies across all Nordic countries and Baltics share experiences and coordinate national preparatory actions for the upcoming EHDS legislation.

Country representatives present updates on their EHDS preparations, sharing insights on implementation and challenges. These presentations are followed by joint discussions that promote cross-border collaboration.

The EHDS2 Competence Forums

26/9/2024 in Helsinki
25/2/2025 in Copenhagen
19/5/2025 in Gothenburg
1–2/9/2025 in Reykjavik
29/10/2025 in Helsinki

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Key points from Competence Forums

- National progress reports
  - Strategy & Legislation
  - Organisational readiness
  - Cost & Impact assessment
  - Technical readiness
  - Communication & Engagement
  - International collaboration
- Break out sessions
  - HDAB
  - Metadata
  - Legal

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Nordic federated analysis pilot

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Nordic federated analysis Pilot procurement

- Public call for tender during fall 2024. The amount of the procurement 500 000 including VAT.
- Showcasing Nordic collaboration by piloting a federated analysis study using the OMOP Common Data Model in at least three Nordic countries
- Four proposals received. IQVIA won the tender
  - Three data partners: HUS, Oslo university hospital, Rikshospital Copenhagen
  - Karolinska (SE) and Landhospital (IS) observing
- Study subject: NSCLC (Non small cell lung cancer)
- Mid-term results in May 2025
- Final results Today

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VALO2 starts next week

During 11/2025 – 10/2026

- Updates the Nordic model in the fall 2026
- Continues the Nordic Competence Forums for another year
- Conducts a second pilot

-> FI, SE, IS, NO and DK as partners, EE and LT as observers

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Second Nordic pilot focus in health research using SPEs

- Showcasing Nordic collaboration by piloting a cross-border health research using health data and **Secure Processing Environments in at least three Nordic countries**
- Public call for tender during August – September
- The amount of the procurement 250 000 euros including VAT
- Project timeline 11/2025 – 09/2026

- And the winner is…

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Thank you!

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SESSION 2

Unlocking the potential of federated analysis and OMOP — insights, challenges, and future directions

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Unlocking the potential of federated analysis and OMOP — insights, challenges, and future directions

Åslaug Helland, MD, PhD, Research Director, Institute for Cancer Research, Oslo University Hospital

James Brash, PhD, Senior Healthcare Data Scientist, IQVIA

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VALO Pilot - Metastatic non-small cell lung cancer (NSCLC) study

Final results

The 30th of Oct, 2025

Åslaug Helland, Professor, University of Oslo

James Brash, Associate AI Scientist Director, IQVIA

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Agenda

1. Aim and objectives of the pilot study
2. Nordic pilot study consortium
3. Protocol overview
4. Final NSCLC pilot study results
5. Nordic pilot study consortium survey results & recommendations

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VALO Pilot Study - Aim & Objectives

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VALO Pilot Study

Aim:

To explore opportunities to increase the Nordic Health Data Collaboration

Nordic region
Experiment in practice with cross-border Nordic co-operation in health data reuse

Pilot Study with OMOP CDM
Piloting a Nordic federated data analysis example

Learnings
Increase knowledge on how to work technically and semantically with distributed health data in the Nordics

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VALO Pilot Study - Nordic Consortium

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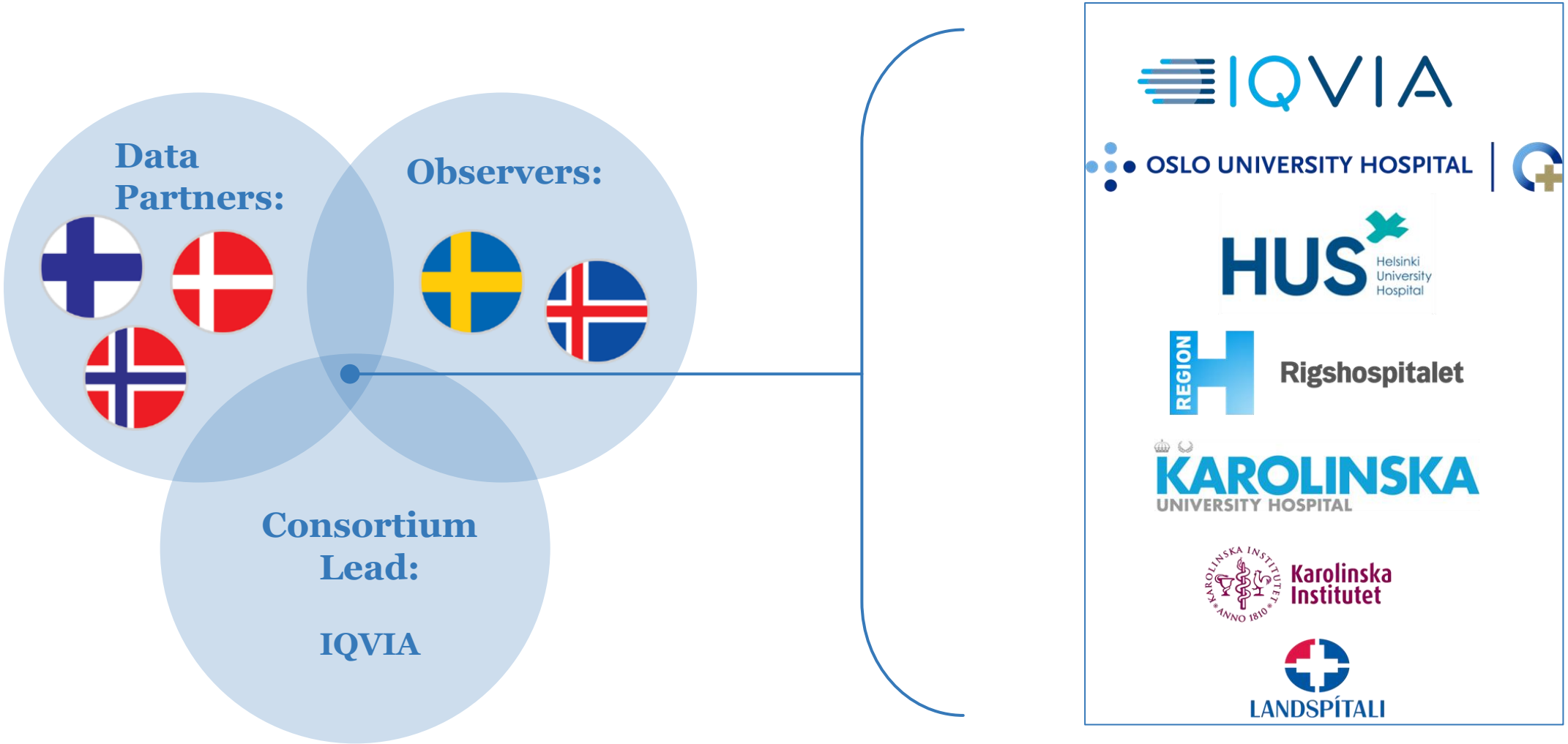
VALO Pilot Study – Consortium Members



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Protocol overview

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Study Objectives

Main Objectives

- Describe baseline demographic and clinical characteristics of metastatic NSCLC patients receiving first-line immune checkpoint inhibitor (ICI) therapy across Denmark, Finland, and Norway.

- Analyze longitudinal treatment patterns including sequence, duration, and intensity of therapies (ICI, chemotherapy, radiotherapy, surgery).

- Evaluate overall survival outcomes stratified by age and country.

- Assess healthcare resource utilization and costs (not completed due to data limitations).

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Objectives continued

Exploratory Objectives

- Contextualize ICI and chemotherapy treatment patterns according to clinical guideline-defined lines of therapy.

- Conduct subgroup analyses for patients aged ≥75 years and <75 years at ICI initiation.

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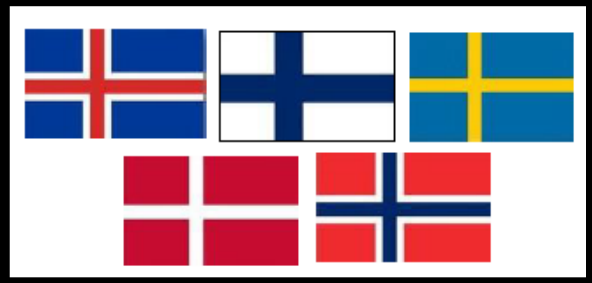
Multi-National Federated Analysis

- **Design:** Retrospective observational cohort study
- **Period:** January 1, 2018 - December 31, 2023
- **Patient identification:** Through June 30, 2023 (ensuring ≥6 months follow-up)
- **Framework:** OMOP Common Data Model

All Nordic countries

Denmark, Finland and Norway with data, Sweden and Iceland as observers



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NSCLC Pilot Study - Final Results

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Demographics Overview

- **Key Findings:**

- Median age uniformly 68 years (range 36-90) across all cohorts
- Elderly representation ranged from 20.9% to 23.1% of populations
- Sex distribution varied: male proportion 45.0% (Denmark), 56.3% (Finland), 68.7% (Norway)
- Sample sizes reflect catchment populations and study period recruitments

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Baseline Characteristics Results

Demographics Overview

Key Findings:

- Median age uniformly 68 years (range 36-90) across all cohorts
- Elderly representation ranged from 20.9% to 23.1% of populations
- Sex distribution varied: male proportion 45.0% (Denmark), 56.3% (Finland), 68.7% (Norway)
- Sample sizes reflect catchment populations and study period recruitments

Characteristic	Denmark (n=489)	Finland (n=199)	Norway (n=67)
Age, median (IQR)	68 (61-74)	68 (60-74)	68 (59-74)
Age groups, n (%)			
<75 years	378 (77.3%)	153 (76.9%)	53 (79.1%)
≥75 years	111 (22.7%)	46 (23.1%)	14 (20.9%)
Sex, n (%)			
Male	220 (45.0%)	112 (56.3%)	46 (68.7%)
Female	269 (55.0%)	87 (43.7%)	21 (31.3%)

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Baseline Characteristics Results

Comorbidity Assessment

Key Findings:

- Dual ascertainment (diagnosis codes + medications) reveals differential capture patterns
- Cardiovascular medication prevalence (83.6%-99.5%) exceeds diagnosis-based prevalence 4-fold
- COPD demonstrates complete concordance between diagnostic and medication criteria
- Modified Charlson Comorbidity Index components show diabetes prevalence 5.5%-23.6%

Comorbidity	Assessment	Denmark	Finland	Norway
Diabetes	Diagnosis-based	27 (5.5%)	13 (6.5%)	<5
	Medication-based	54 (11.0%)	47 (23.6%)	7 (10.4%)
Cardiovascular	Diagnosis-based	117 (23.9%)	65 (32.7%)	14 (20.9%)
	Medication-based	478 (97.8%)	198 (99.5%)	56 (83.6%)
COPD	Diagnosis-based	58 (11.9%)	37 (18.6%)	9 (13.4%)
	Medication-based	58 (11.9%)	37 (18.6%)	9 (13.4%)

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Treatment Patterns

First-Line ICI Patterns and Progression

Key Findings:

- Pembrolizumab-based regimens constitute 51.5%-76.1% of first-line therapy, with monotherapy (26.6%-35.0%) exceeding combination approaches (15.6%-17.9%)
- Second-line progression rates (34.3%-41.7%) indicate majority of patients receive single-line therapy, reflecting disease aggressiveness or clinical deterioration
- Age-related disparity in second-line access evident: 37.7%-45.1% of younger patients versus 28.8%-30.4% of elderly patients progress to subsequent therapy
- Limited third-line penetration (≤5.0%) confirms rapid attrition after first-line failure

Outcome	Denmark (N=489)	Finland (N=199)	Norway (N=67)
Pembrolizumab mono only	171 (35.0%)	53 (26.6%)	22 (32.8%)
Chemo + Pembrolizumab only	79 (16.2%)	31 (15.6%)	12 (17.9%)
Total pembrolizumab-based	252 (51.5%)	106 (53.3%)	51 (76.1%)
Progressed to Line 2	186 (38.0%)	83 (41.7%)	23 (34.3%)
- Age <75	153/378 (40.5%)	69/153 (45.1%)	20/53 (37.7%)
- Age ≥75	32/111 (28.8%)	14/46 (30.4%)	<5/14
Progressed to Line 3	23 (4.7%)	10 (5.0%)	<5

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Treatment Patterns

Treatment Duration by Line of Therapy

Key Findings:

- First-line duration demonstrates 2-fold variation (median 52-100 days), with Finland's abbreviated duration potentially reflecting early switching philosophy or aggressive disease biology
- Age-stratified patterns reveal site-specific heterogeneity: elderly patients show shorter duration in Denmark/Finland but paradoxically longer duration in Norway (127 vs 84 days)
- Second-line duration convergence (63-85 days) despite first-line variability suggests consistent limitations in salvage therapy efficacy
- Wide interquartile ranges (e.g., 42-215 days) indicate substantial within-population heterogeneity in treatment response and discontinuation timing

Treatment Line	Denmark (n=489)	Finland (n=194)	Norway (n=67)
Line 1 median (IQR)	86 (42-215)	52 (22-111)	100 (42-182)
- Age <75	116 (43-245)	55 (22-106)	84 (28-169)
- Age ≥75	72 (43-212)	44 (16-124)	127 (63-186)
Line 2 median (IQR)	79 (41-156)	85 (49-147)	63 (43-117)
- Age <75	74 (33-150)	88 (49-146)	68 (43-116)
- Age ≥75	108 (71-184)	72 (46-167)	NA

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NSCLC Pilot Study - Lessons Learned Survey Results

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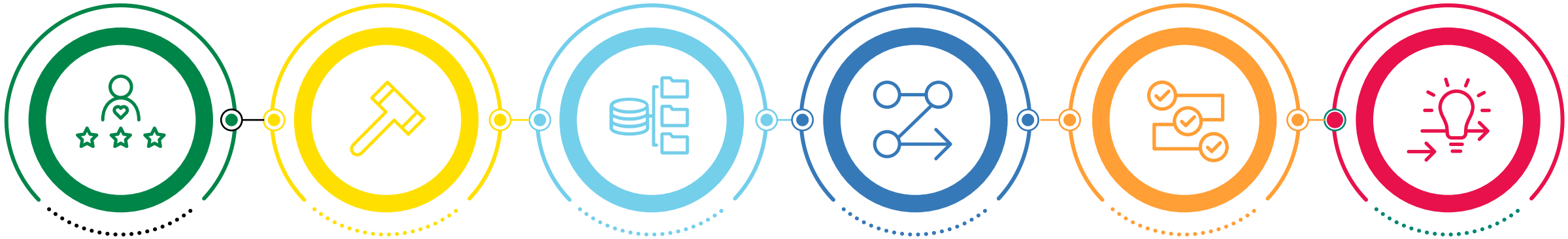
NSCLC Pilot Study - Survey categories



Background

1. Respondent identification
2. Country and role
3. OMOP/RWE experience
4. Previous network participation

Data Governance

1. Contracting processes
2. Ethical committee requirements
3. Data permits
4. OMOP governance frameworks

Data Life Cycle

1. Data source types
2. Linkage capabilities
3. Coding systems
4. Data availability status

Data Processing

1. Variables captured
2. Script execution success
3. Implementation challenges

VALO Study Process Steps

1. ETL specification feedback
2. QA/QC processes
3. Package execution

Future Investments

1. Infrastructure needs
2. Capability assessments
3. Recommendations

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Strategic Takeaways for Federated OMOP Network Development

1

Capability maturity & organisational readiness

Implementation Follows a Three-Year Capability Maturation Curve

Technical Expertise Must Be Integrated into Governance Structures: Centra-lised Coordination and PMing at hospitals

2

Data governance & regulatory frameworks

Pre-Study feasibility Assessment Requires Data Availability Validation, Not Assumption

3

Data life cycle & availability

Three-Tier Data Availability Framework Defines Study Feasibility Boundaries

Variable Surveys Must Precede Analytical Package Development

4

Data processing & technical infrastructures

Vocabulary Governance Requires Consortium-Level Coordination

ETL Solutions Are Reusable Assets Requiring Systematic Documentation

Analytical Environment Standardization Enables Reliable Package Execution

5

Study execution & quality assurance

Iterative Clinical Review Is Essential for Data Quality Validation

6

Methodological advancement & scientific rigor

Progression from Descriptive to Inferential Analytics Defines Scientific Maturity

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VALO NSCLC Pilot: Project Management & Execution – Key Lessons Learned

- Data permit timelines: 1-4 weeks (process currently at hospital level)

- Federated data sharing model permit process to be established and recommended to align within Nordics

- Federated studies require coordination overhead: Governance structure and clear role mapping (data scientist, ETL expert, clinical expert, PM) not yet established

- Technical Execution Challenges: Database system variability and measurement mapping required site-specific code adaptations and flexible protocol design

- Data feasibility to be completed prior to protocol finalization

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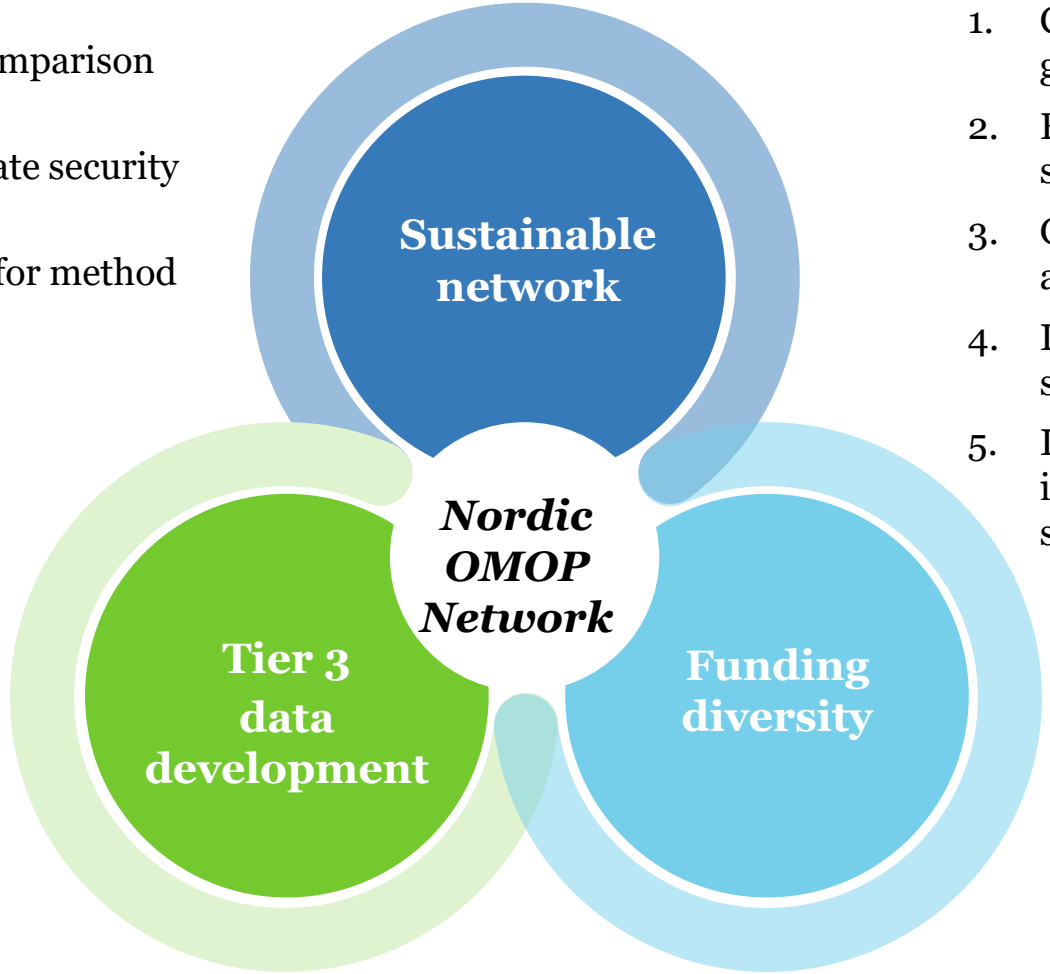
Long-term Investment Recommendations: Nordic OMOP Network

Advanced Analytics Platform

1. Development environment for federated methods with secure testing capabilities
2. Validation datasets enabling method comparison and benchmarking
3. Production environment with appropriate security and privacy controls
4. Documentation and training resources for method implementation

Clinical Documentation Enhancement Program

1. Stakeholder engagement to build clinical buy-in for documentation improvements
2. EHR template modifications to capture structured data at point of care
3. Training programs for clinical staff on documentation importance
4. Quality monitoring and feedback loops to ensure sustained improvement



Sustainable Network Funding Model

1. Core infrastructure support from government or foundation sources
2. Fee-for-service model for commercial studies leveraging network capabilities
3. Grant funding for methods development and innovation
4. In-kind contributions from participating sites
5. Intellectual property frameworks that incentivize contribution while enabling sharing

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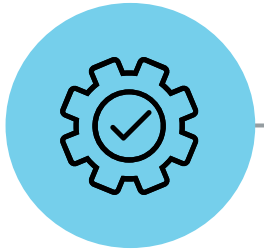
Key points



Making OMOP "part of regular operations" further emphasises that infrastructure alignment, determines implementation success.

The establishment of cross-functional teams that bridge project management, technical, clinical, and regulatory domains emerges as a fundamental requirement for successful implementation.

The evolution from descriptive to inferential analytical capabilities, represents the next frontier for federated networks.

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Unlocking the potential of federated analysis and OMOP — insights, challenges, and future directions

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PhD, Assistant professor of Medical Informatics, Erasmus MC

Christian Högberg

Health Data Entrepreneur & Change Agent, edenceHealth NV & Passion 2 Improve AB

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SESSION 3

Advancing Nordic collaboration in health data

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Nordic model for collaboration on secondary use of health data

Rebekka Björg Gudmundsdottir, Project manager, Directorate of Health Iceland

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Advancing Nordic collaboration in health data

Nordic model for collaboration on secondary use of health data

October
30th, 2025

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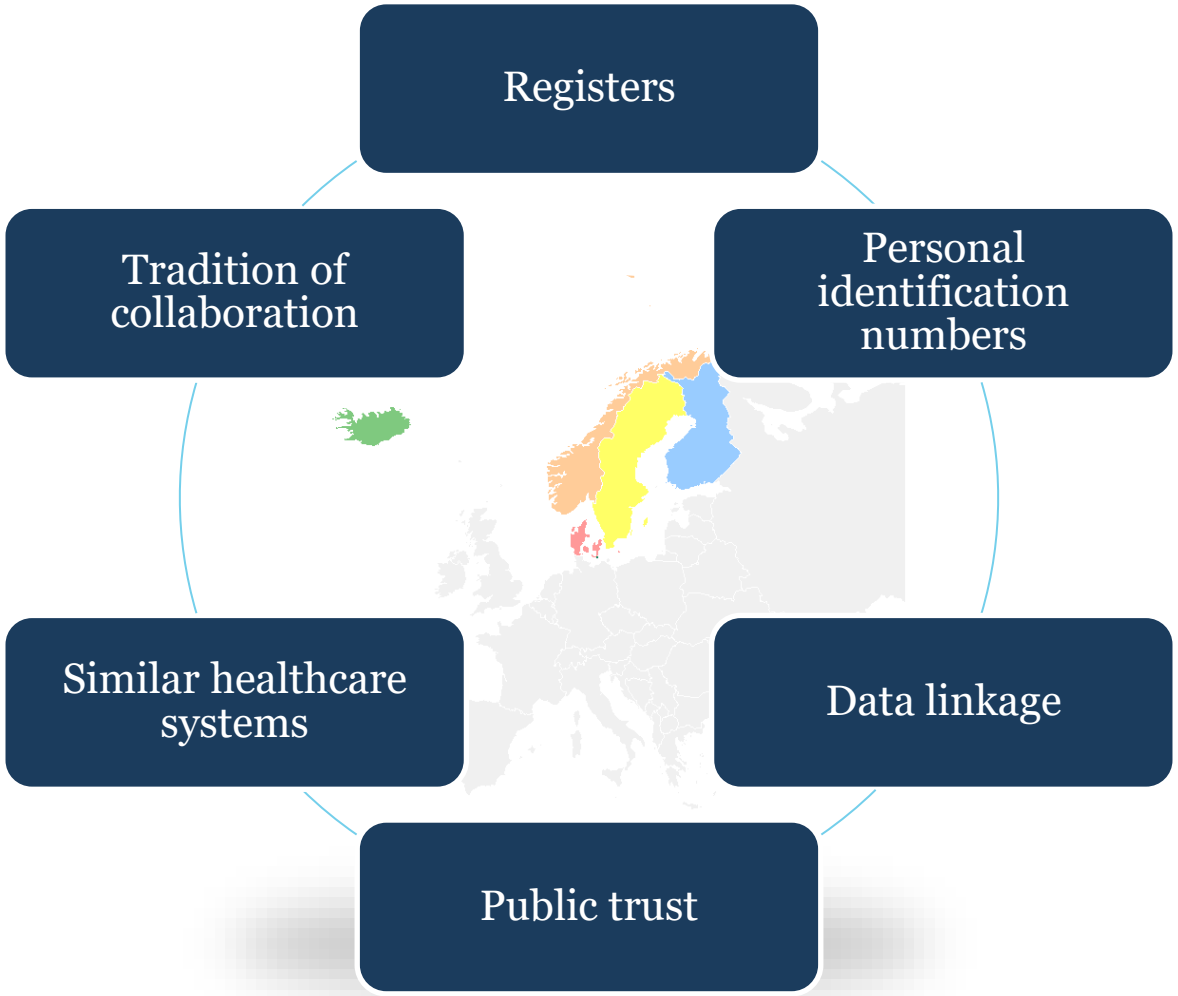
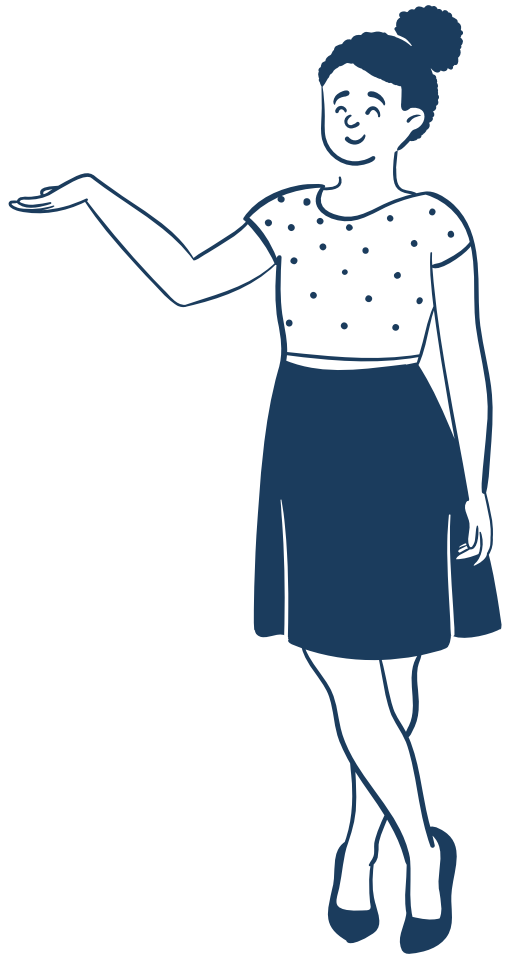
Nordic Advantage





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Challenges

Data access timelines

- "*Frustratingly long and unpredictable timelines*" from application to data delivery
- Access time is our "*single biggest challenge*" affecting competitive positioning
- "*Data access delays force us to choose between Nordic data quality and operational efficiency*"

Cross-border complexities

- "*It's very rare that we collect data in all Nordic countries and merge them together because it's too complicated*"

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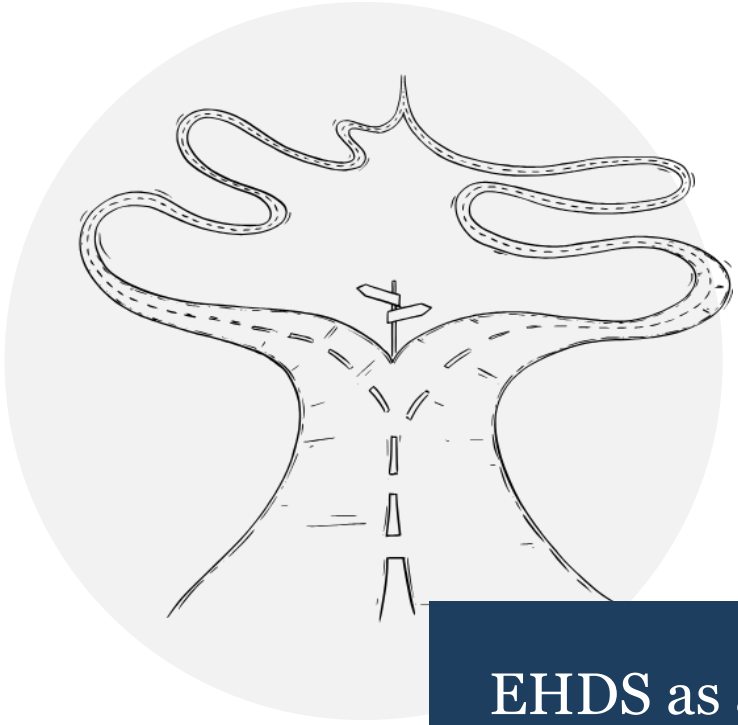
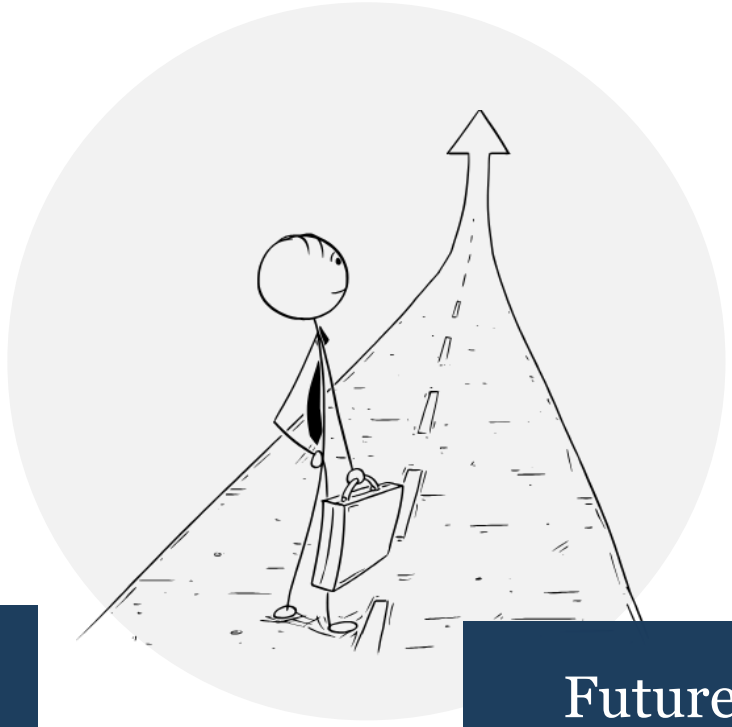
Why implement EHDS together?

GDPR



EHDS as an opportunity



Future

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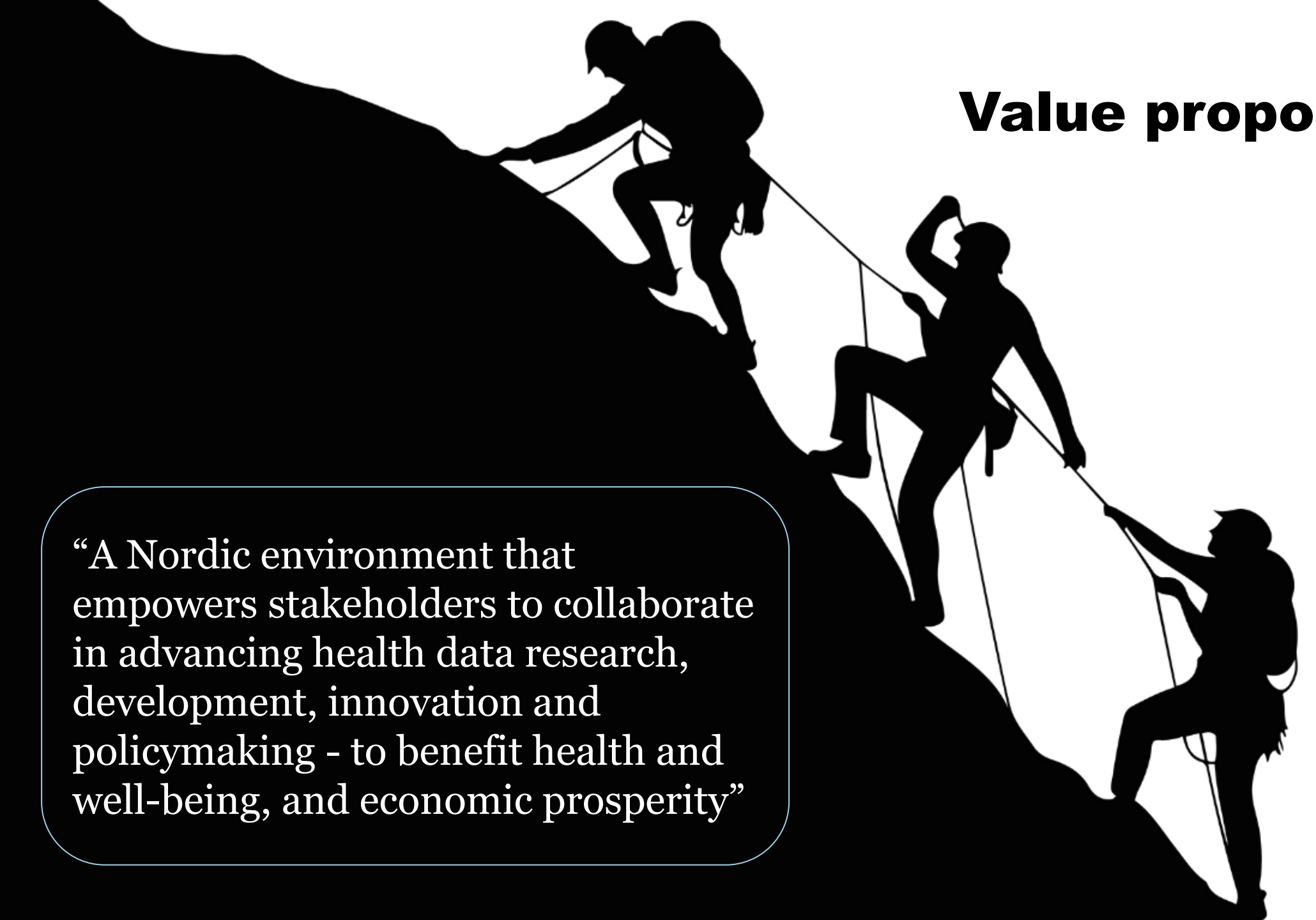
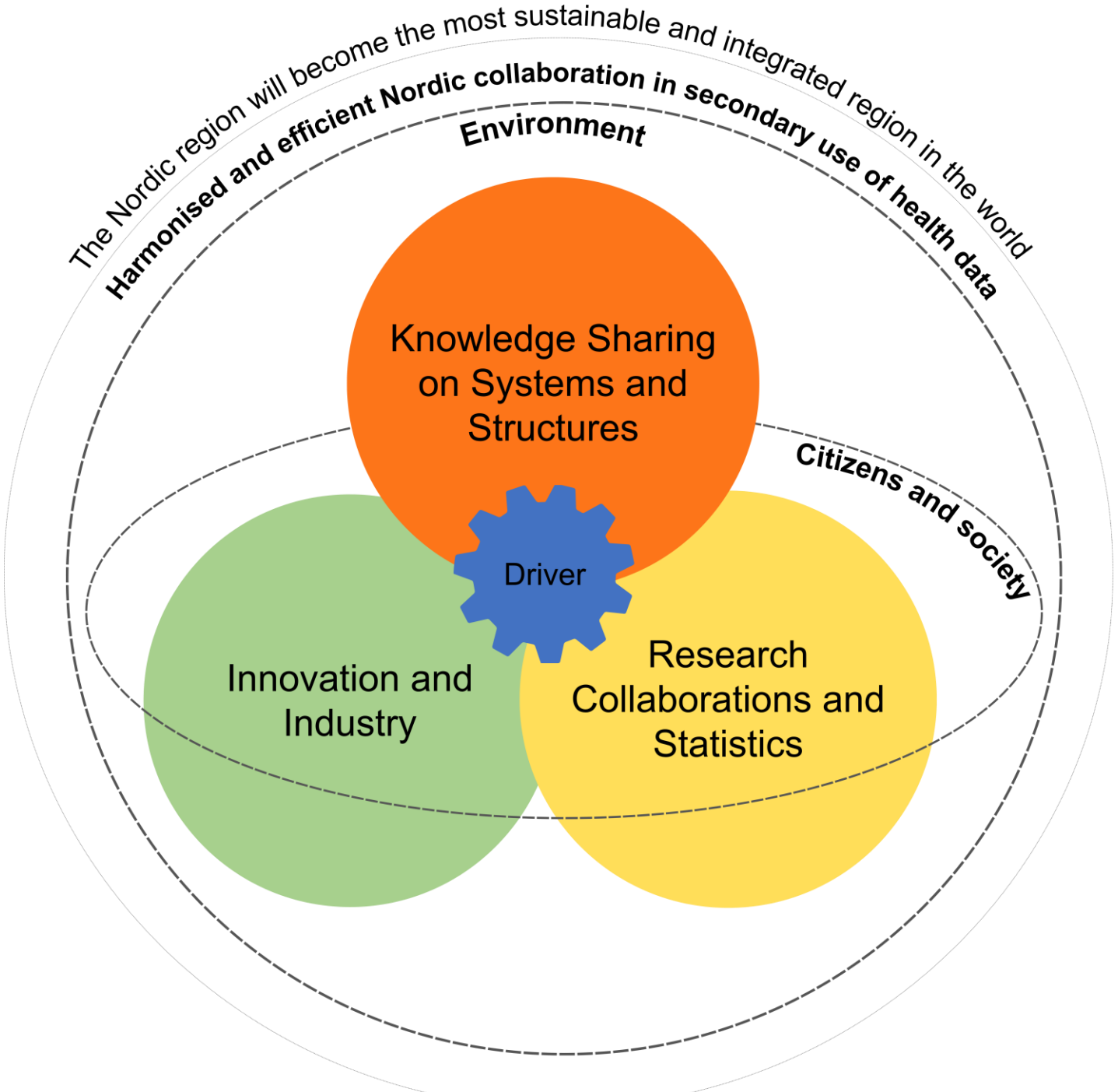
Value proposition



"A Nordic environment that empowers stakeholders to collaborate in advancing health data research, development, innovation and policymaking - to benefit health and well-being, and economic prosperity"

Nordic model for collaboration on secondary use of health data

- Proposal



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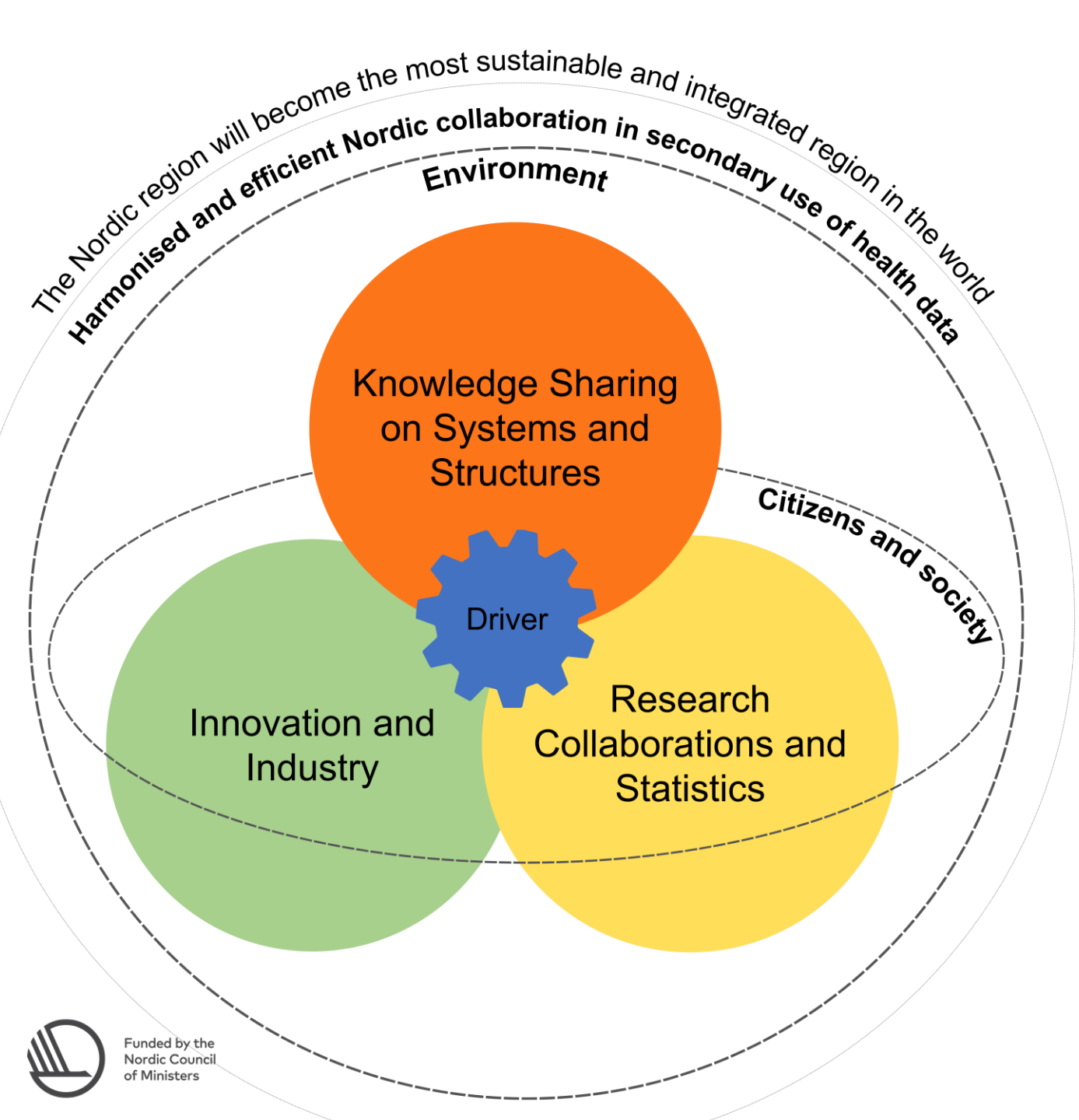

Design principles

- Coordinate existing services
- Respect existing mandates
- Leverage rather than conflict with EHDS

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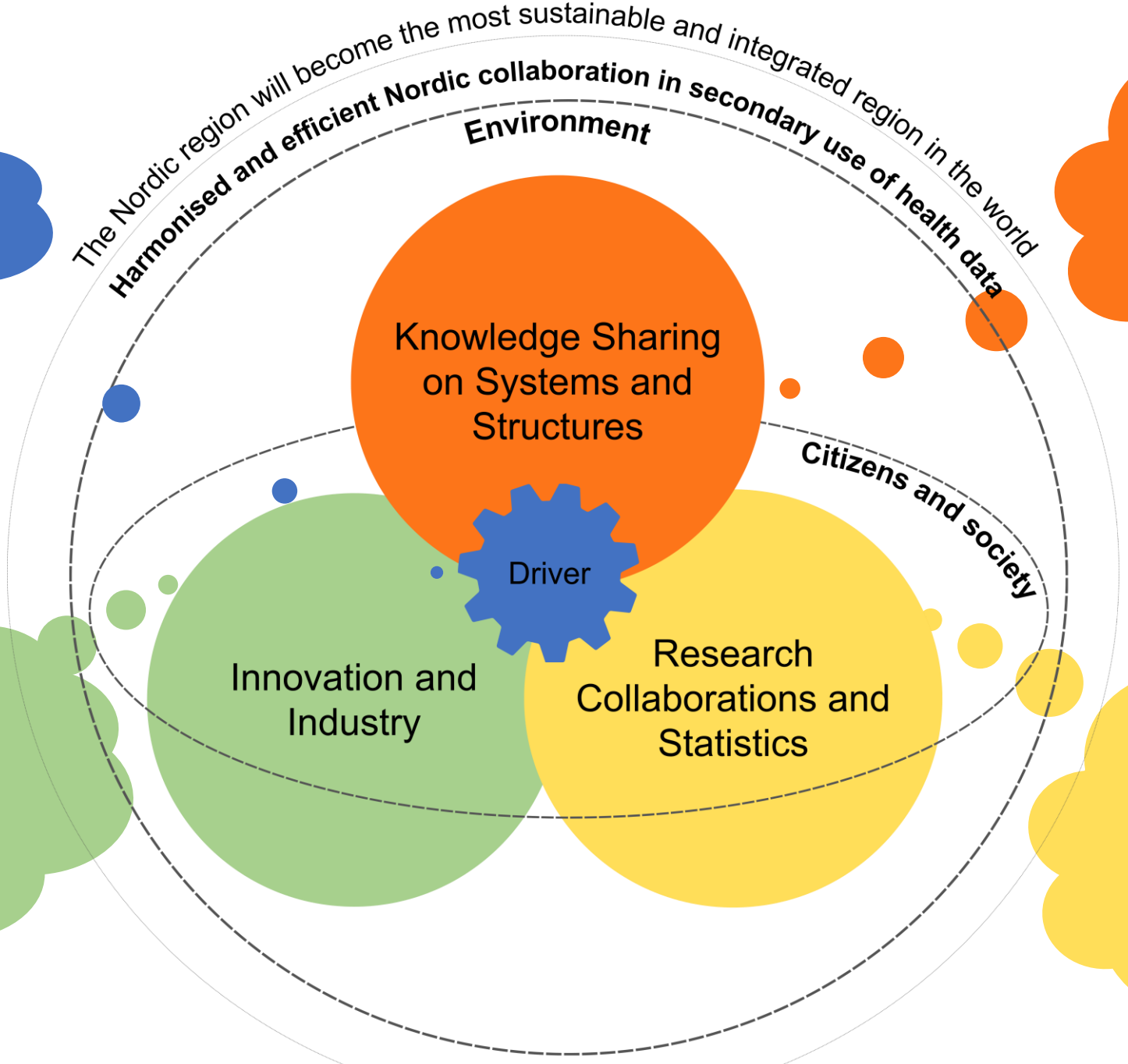
From components to ecosystem

Aligning policy and governance functions across the region



Facilitating economic development and technology advancement

Advancing scientific excellence and evidence generation through joint initiatives

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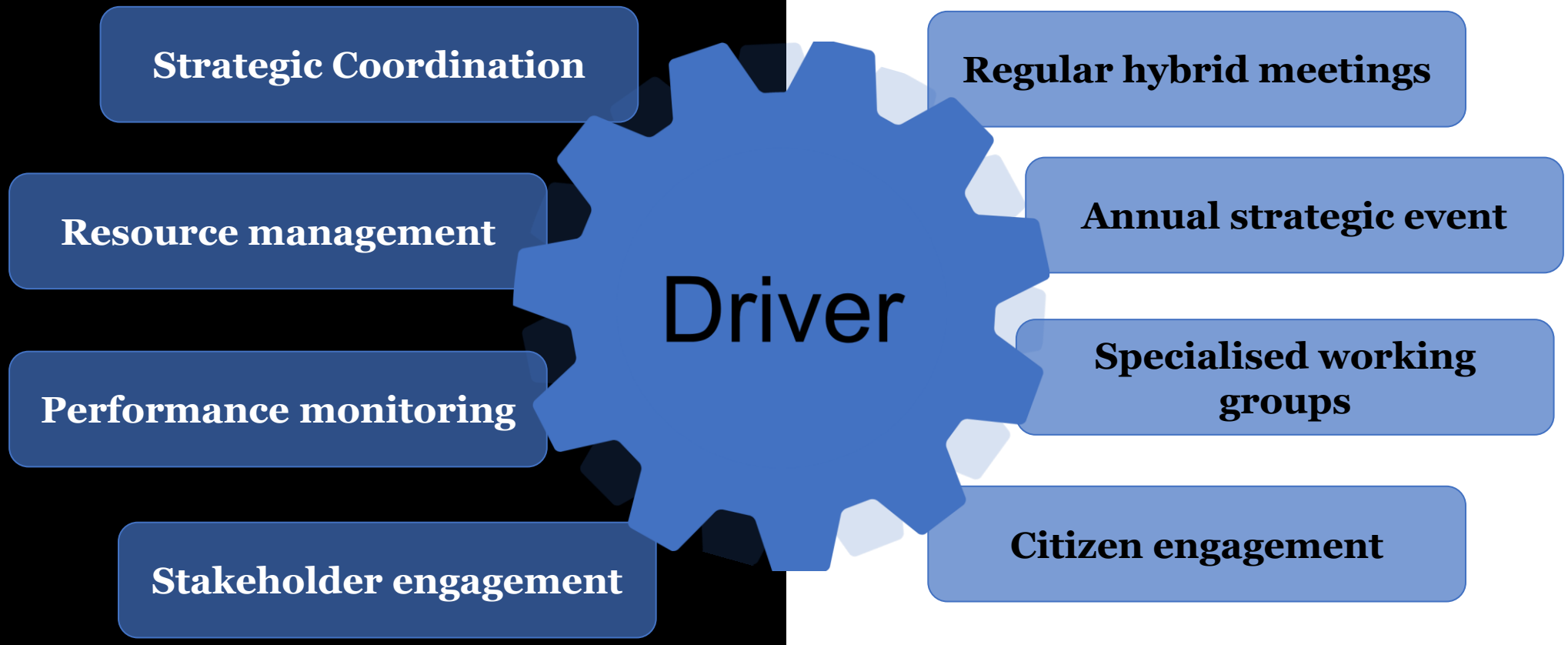
What the Driver should do

How the Driver could operate



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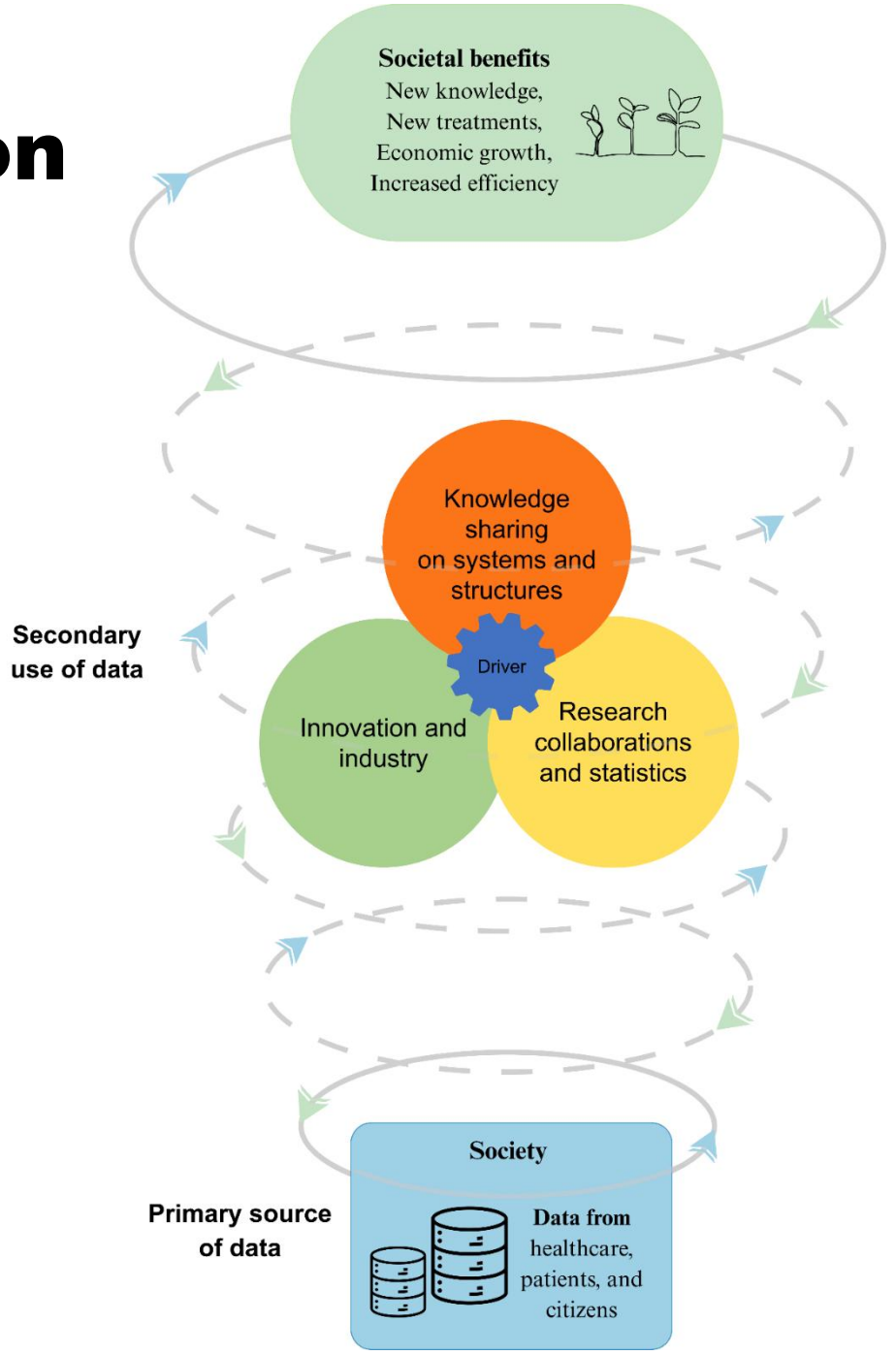
Value creation

Government
Coordinated policymaking and enhanced regional evidence

Industry
Simplified market access and partnership opportunities

Research
Easier access to larger datasets and streamlined processes



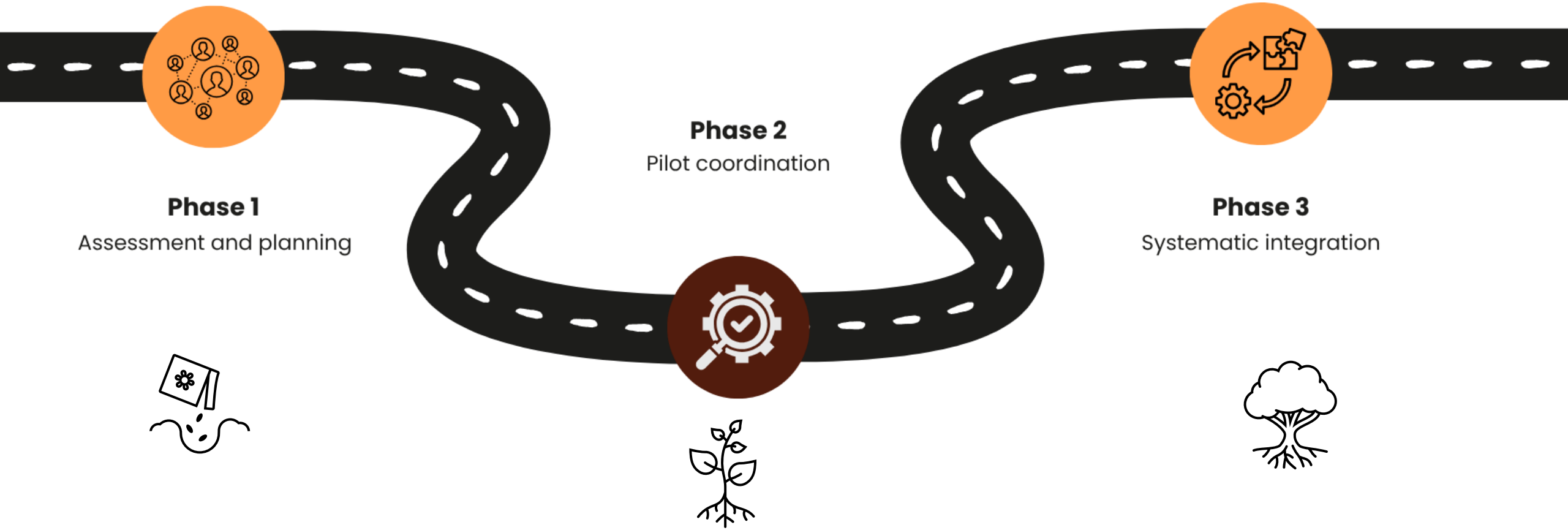
Healthcare systems
Evidence-based improvements validated across multiple contexts

Citizens
Improved health outcomes, transparent governance, and meaningful participation in decisions

Funded by the Nordic Council of Ministers

First steps toward operationalising the Nordic model

- Finding a suitable driver



Funded by the Nordic Council of Ministers

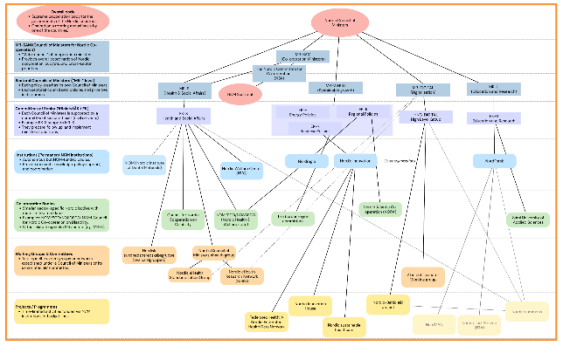
First steps toward operationalising the Nordic model

- Finding a suitable driver

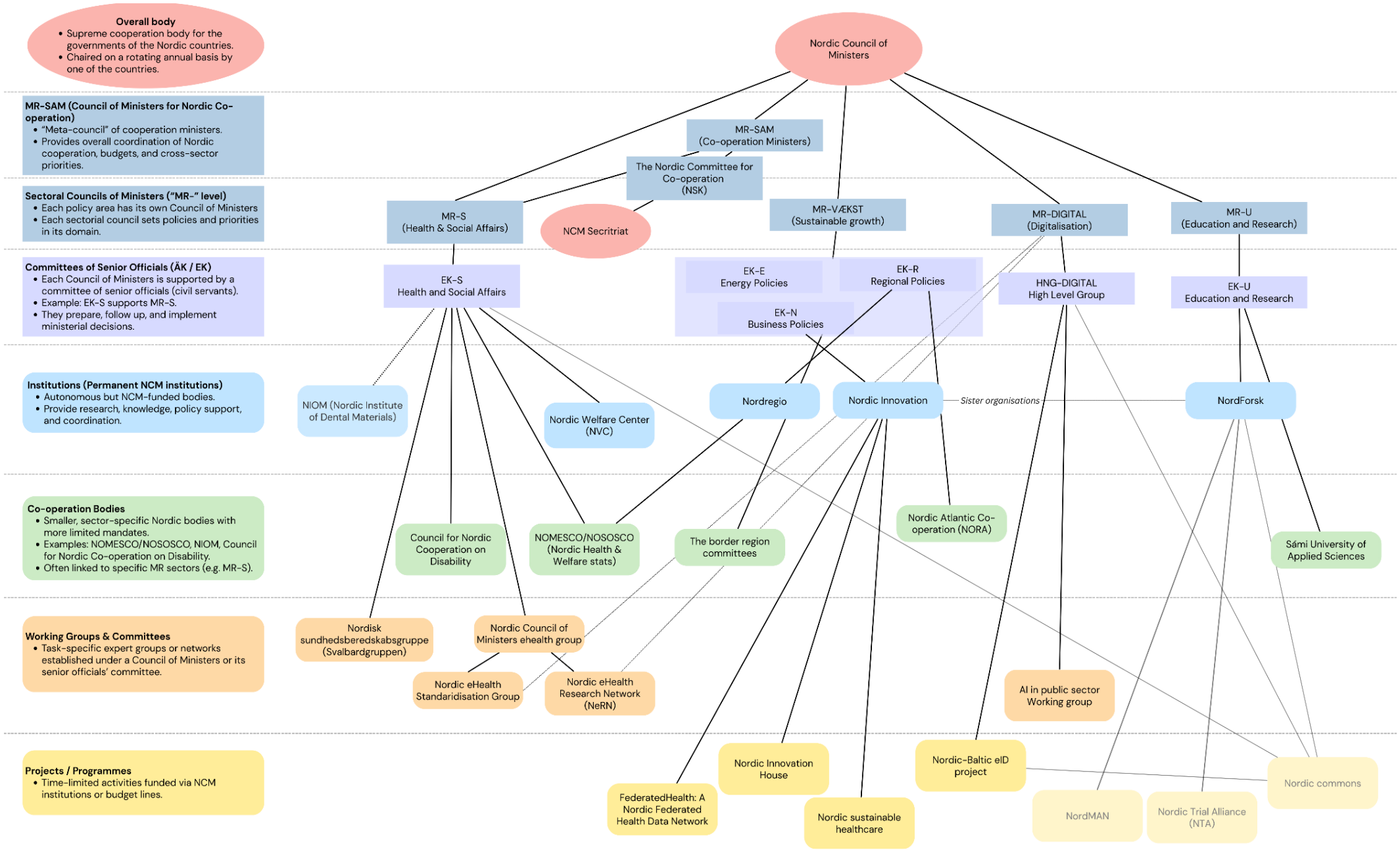
Phase 1
Assessment and planning

Phase 2
Pilot coordination

Phase 3
Systematic integration



Funded by the Nordic Council of Ministers



Funded by the Nordic Council of Ministers

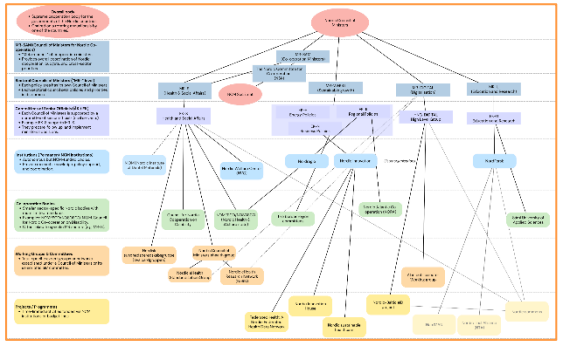
First steps toward operationalising the Nordic model

- Finding a suitable driver

Phase 1
Assessment and planning

Phase 2
Pilot coordination

Phase 3
Systematic integration



Funded by the Nordic Council of Ministers

Next steps

- Feedback from stakeholders on Nordic model
- Continued coordinated EHDS implementation, e.g. through Competence Forums
- Clear success metrics
- Ensuring sustainability of the Nordic model

Funded by the Nordic Council of Ministers

Advancing Nordic collaboration in health data

Julius Joudakis

Head of the Health Data Team, State Data Agency

Marketta Liljeström

Coordinator for Patient and Public Involvement and Communications, iCAN – Digital Precision Cancer Medicine

Nicolas E. Vaugelade-Baust

M.D, Nordic Evidence Generation Director, Novartis

Sigríður Haraldsdóttir Elínardóttir

Head of division health information, Directorate of Health Iceland

Funded by the Nordic Council of Ministers

Co-funded by the European Union

MINISTRY OF TRANSPORT AND COMMUNICATIONS

FINDATA

SITRA

SESSION 4

Strengthening Finland’s health data infrastructure

Funded by the Nordic Council of Ministers
Co-funded by the European Union
MINISTRY OF TRANSPORT AND COMMUNICATIONS
FINDATA
SITRA

Strengthening Finland's health data infrastructure

Maari Parkkinen, Development manager, Findata

Funded by the Nordic Council of Ministers

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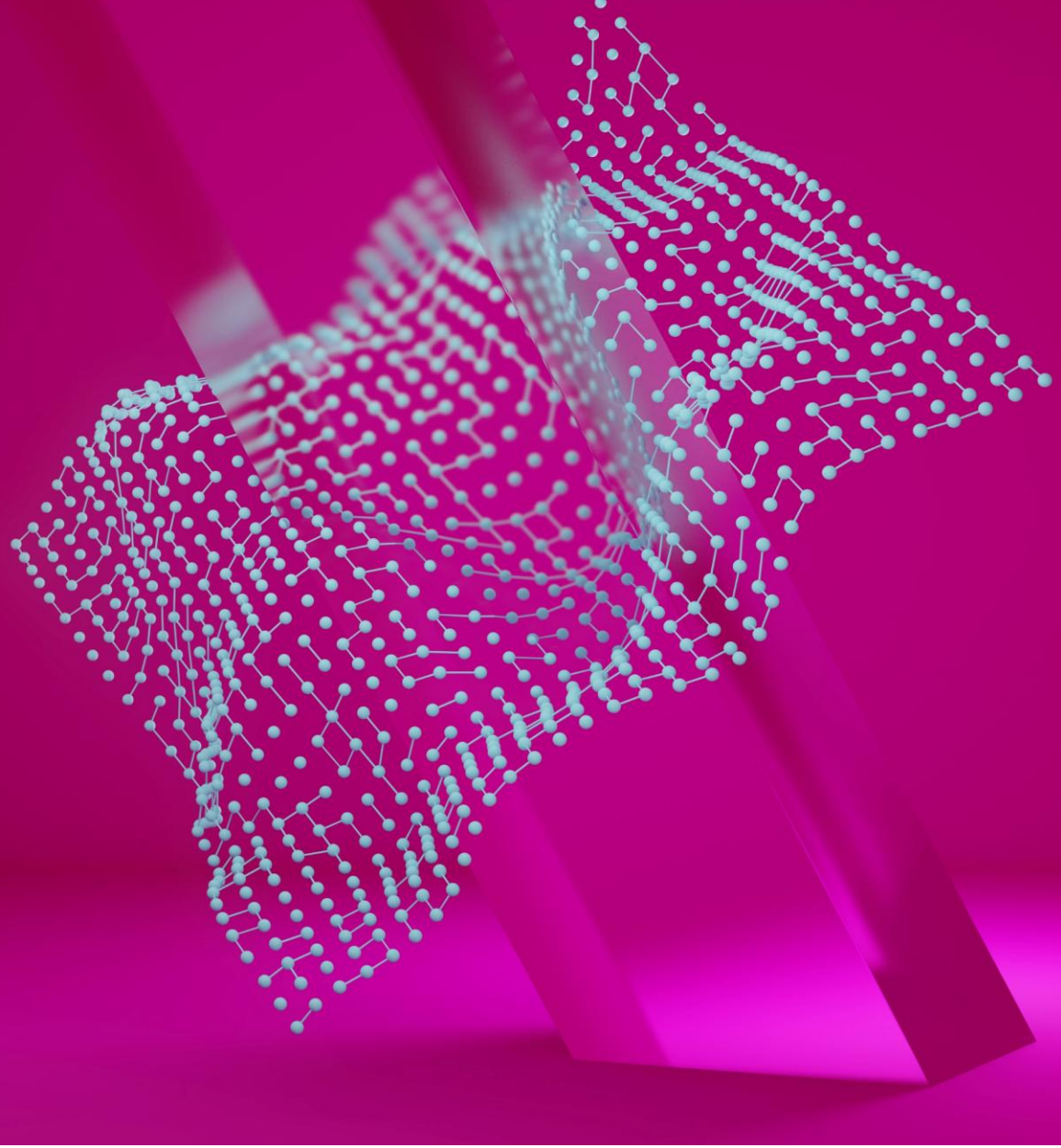
SITRA

FinHITS – Towards the Future of Secondary Use of Health Data

Maari Parkkinen, Development Manager
Finnish Social and Health Data Permit Authority Findata



FINDATA

Co-funded by the European Union

Introducing Findata – Finnish social and health data permit authority

A centralized data permit authority for secondary use of national social and health data. **Founded in 2019**, operation based on the national Act.

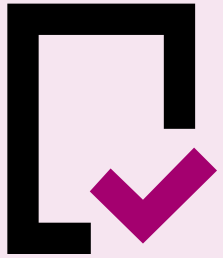
MISSION: Improve access to rich nation-wide datasets and **enhance** data security and the data protection of individuals.

Data from national registers, public and private social and health care service providers and Kanta services.

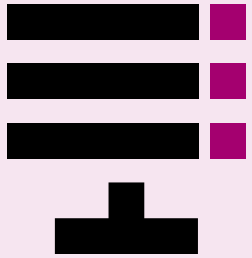
Positioned in Finnish Institute for Health and Welfare, steered by the Ministry of Social Affairs and Health.

Findata’s core services

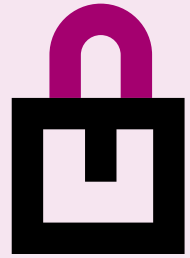
Help Desk & Metadata Catalogue



Grants access to data, provides aggregated data



Collects and pre-processes data



Provides Kapseli SPE and transfer services

Use purposes stated in the Act

Individual level data

- Scientific research
- Statistics
- Planning and reporting duties by authorities
- Teaching
- *Knowledge management*
  (organisations own data without a permit)

Aggregated data

- **All the above**
- Development and innovation activities
- Knowledge management
  (reference data from other data controllers)

FinHITS – Strengthening Finnish Health Data IT for Secondary use

- **Funding:** EU4Health / Direct grants to Member States: for setting up services by Health Data Access Bodies - Secondary use of health data.
- **Budget:** Approx. 2.5 million € (funding 60 %)
- **Duration:** 1.11.2023–31.10.2027
- **Objectives:**
  - Strengthen the Finnish infrastructure to ensure efficient and secure secondary use of health data
  - Enable Finland to integrate seamlessly into the EHDS
- **More information:** findata.fi/finhits

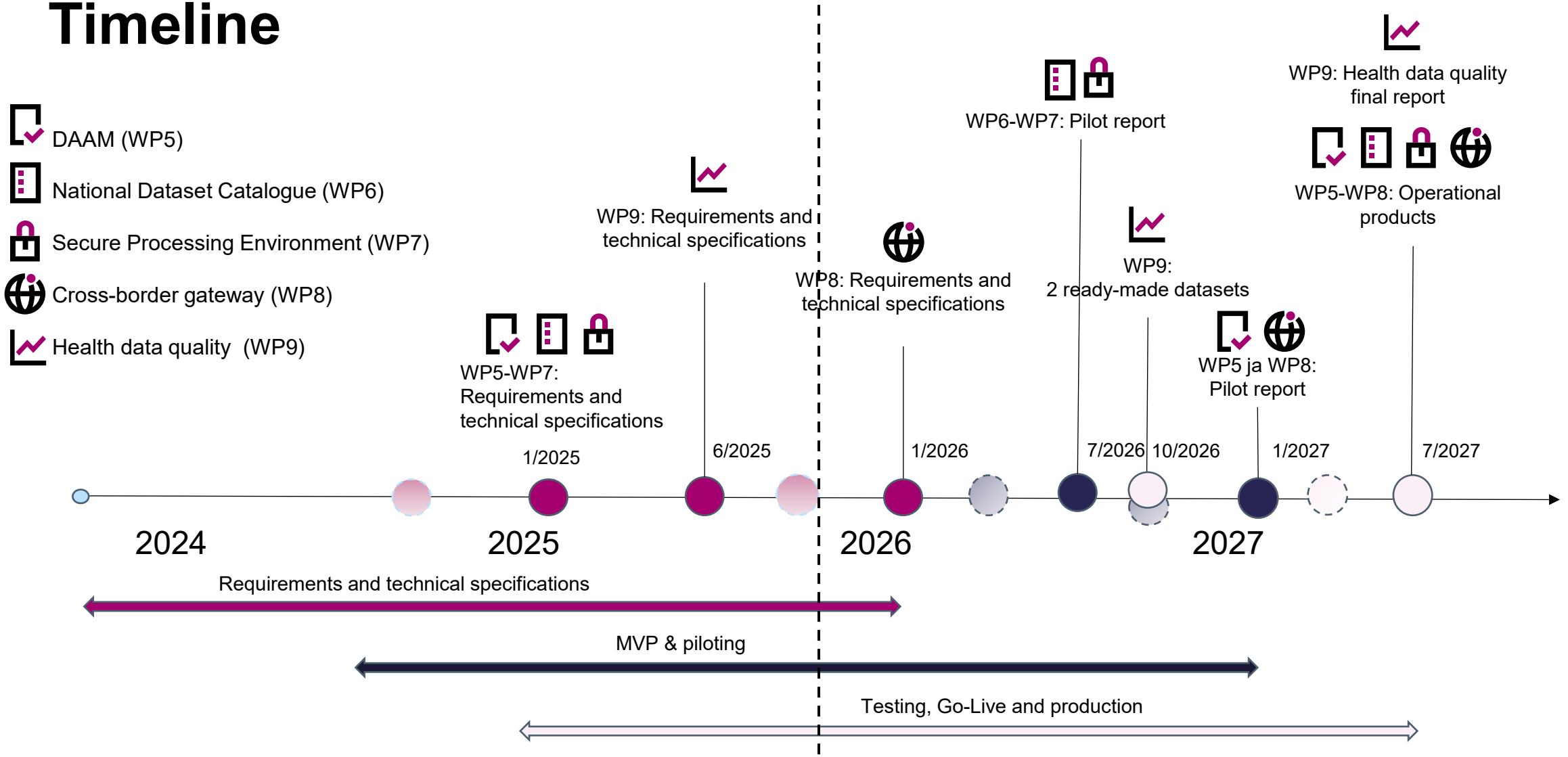
Key areas of development

1. Expand **help desk services**
2. Improve Findata's **data access application management system**
3. Further develop **the national data catalogue**
4. Improve the **secure processing environment**
5. Connect to the **HealthData@EU infrastructure**
6. Promote the **quality of health data**

Principles for developing services

- **Service development is based on:**
  - The content and objectives of the European Health Data Space (EHDS) regulation
  - Practical experiences, feedback, and ideas from national stakeholder groups
  - Insights from EU projects and collaborations, such as HealthData@EU Pilot, Tehdas2, Quantum, and the Community of Practice
- **Main challenges:**
  - The project schedule and uncertainties related to the content of the EHDS implementing acts and their national-level implementation
  - Possible reforms in the national legislation and resources needed to their implementation

Timeline


DAAM (WP5)
National Dataset Catalogue (WP6)
Secure Processing Environment (WP7)
Cross-border gateway (WP8)
Health data quality (WP9)
WP5-WP7: Requirements and technical specifications
WP9: Requirements and technical specifications
WP8: Requirements and technical specifications
WP6-WP7: Pilot report
WP9: 2 ready-made datasets
WP5 ja WP8: Pilot report
WP5-WP8: Operational products
WP9: Health data quality final report
1/2025
6/2025
1/2026
7/2026
10/2026
1/2027
7/2027
2024
2025
2026
2027
Requirements and technical specifications
MVP & piloting
Testing, Go-Live and production

Stakeholder participation in development work

Definition 2023–2025

Advisory Group

Satisfaction survey 1 (Q1/2024)

Kick-off workshops (April 2024)

Meetings and presentations (working groups, steering group)

Stakeholder webinar (November 2024)

Development 2024–2027

Advisory Group

Satisfaction survey (Q4/2025)

FinHITS Forums 2025–2026 and testing groups

Meetings and presentations (working groups, steering group)

Other project events (Nordic Health Data Summit, federated analysis workshops, trainings)

Deployment 2024–2027

Advisory Group

Satisfaction survey (Q1-2/2027)

Final seminar (2027)

Deployment trainings and info sessions

Expected results

Help desk services and training
Better support for international applicants to find relevant data and submit complete applications.

Data access application management system
Improvements in collaboration for defining needed data and information flow to support more efficient processes, fewer errors and better anticipation.

National dataset catalogue
Improve user-friendliness to enhanced discoverability and prepare for standards coming from EHDS.

Expected results

Secure processing environment
Support for more advanced methods and large datasets, efficiency in verifying anonymity of results.

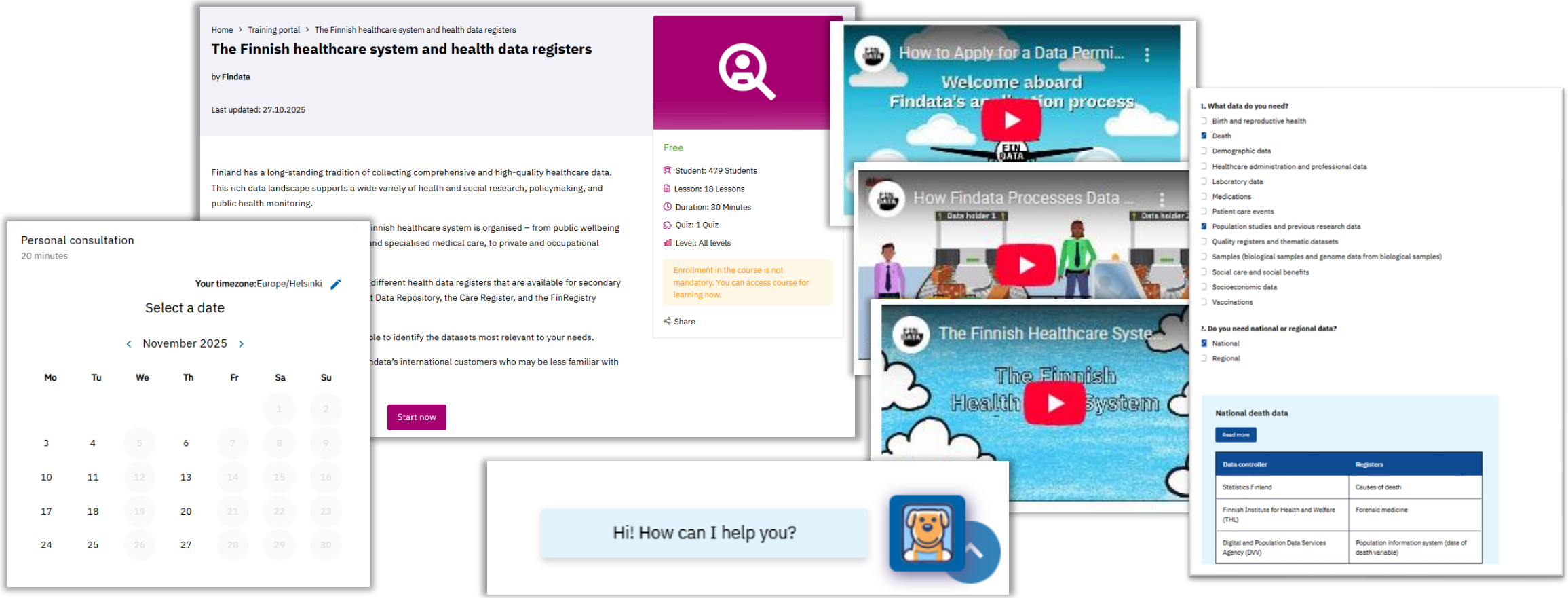
Cross-border gateway
Joining in the HealthData@EU infrastructure.

Data quality
Support for data quality, data quality and utility label & two ready-made datasets.

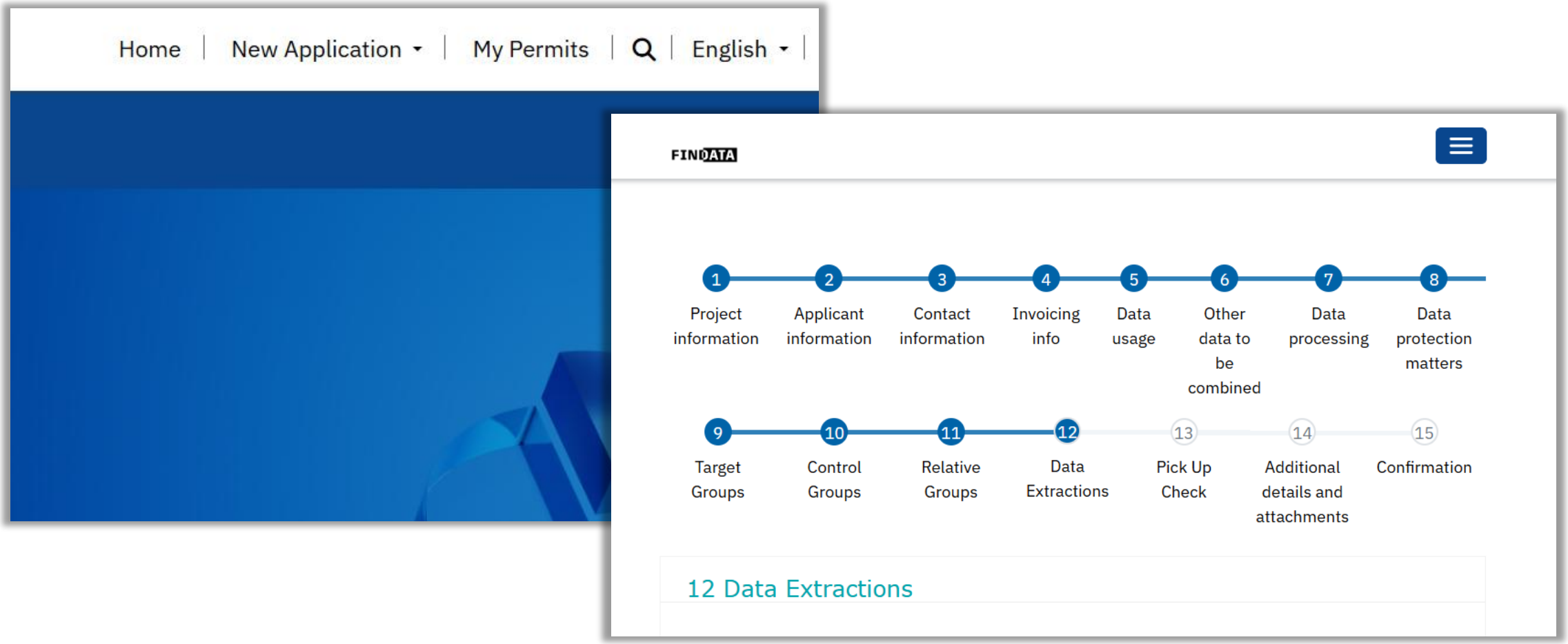
Key achievements this far

- Expanded help desk services and traning portal to support national and international applicants
- Faster data transfer services to streamline data collection
- Faster anonymisation verification with new tools
- New ready-made dataset from FinRegistry study
- 2 events, 4 FinHITS Forums for collaboration, 1 survey, 6 workshops

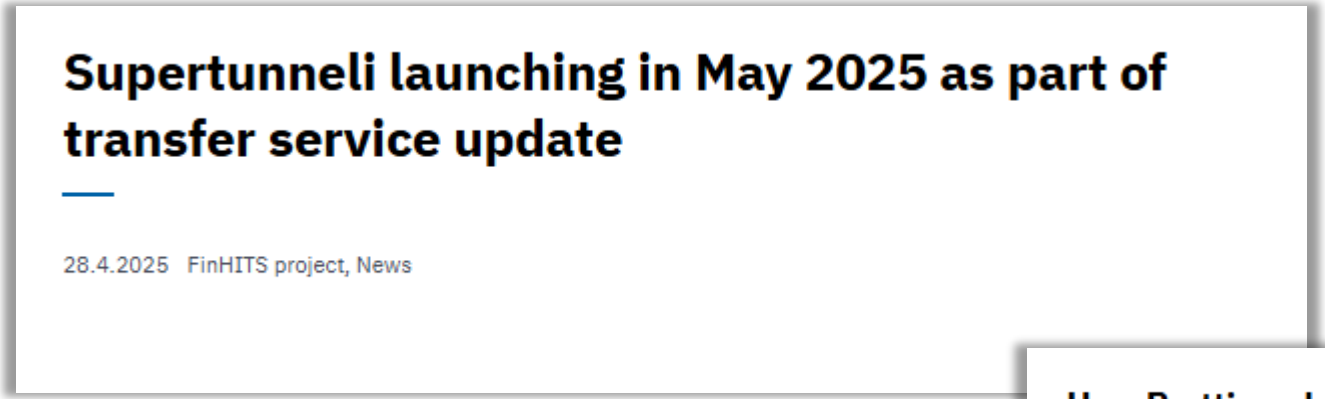
WP2: Expanded help desk services and traning portal to support national and international applicants (2024–2025)



WP5: First version of the improved E-Service tested by Findata and stakeholders (6-9/2025)

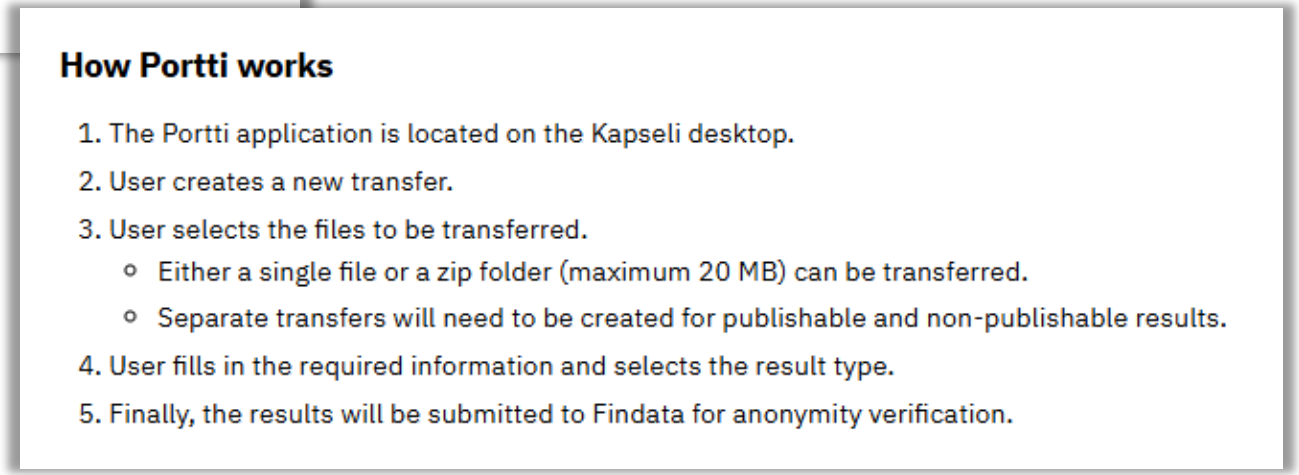


Improvements in the secure processing environment (2025)



Supertunneli launching in May 2025 as part of transfer service update

28.4.2025 FinHITS project, News



How Portti works

1. The Portti application is located on the Kapseli desktop.
2. User creates a new transfer.
3. User selects the files to be transferred.
   - Either a single file or a zip folder (maximum 20 MB) can be transferred.
   - Separate transfers will need to be created for publishable and non-publishable results.
4. User fills in the required information and selects the result type.
5. Finally, the results will be submitted to Findata for anonymity verification.

2 connections ready/testing

6 contracts signed for connection

3 contracts in progress

What’s next?

Help desk and training

- New courses in the training portal in (Q1/2026)
- Campaigns for citizen awareness and trust (2026)

Data access application management

- Piloting new data access application management system (Q1/2026)

National dataset catalogue

- FinHITS Forum on the improvements in the National dataset Catalogoue on (Q1/2026)
- Plan on implementing HealthD-CAT mapping in the national catalogue (2026)

Secure processing environment

- Working paper on federated computing
- Dynamic GPU and licence management

Connection to the HealthData@EU

- Development work starts in Q4/2025

Data quality

- Data quality work to start in 2026
- One ready-made dataset

More information in Findata’s pop up! (2nd floor)

Join us in developing secondary use services!

Stakeholder collaboration

- **2025–2026**
  FinHITS Forums on ongoing development work
- **2025–2027**
  Two satisfaction surveys on digital services

Events

- **2025**
  Nordic Health Data Summit, Helsinki
- **2027**
  Final seminar and service presentation

Trainings

11 Nov 2025
Application clinic

12 Dec 2025
Aineistoeditori training for data holders

Follow FinHITS!

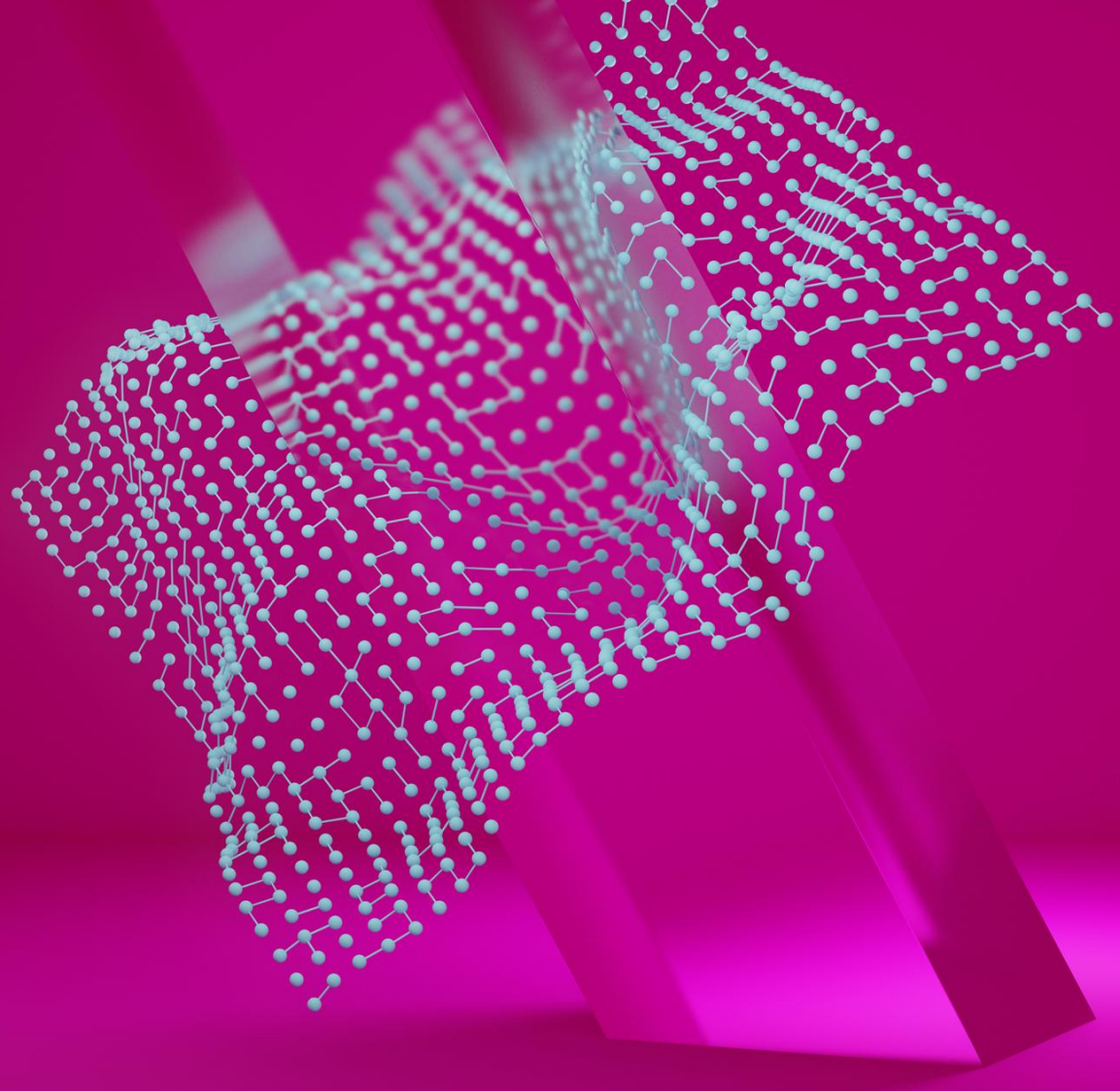
- Newsletter and LinkedIn
- Events and training sessions
- Findata.fi/finhits

Key takeaways

- **Collaboration:** Efficient processes require close collaboration with ecosystem stakeholders and customers, developing digital capabilities to serve everyone involved.
- **Trust:** Transparent communication and guidance for all stakeholders is a must and builds trust and efficiency.
- **Agile operations:** Learning by doing and learning fast, focus on solving problems one by one.

Thank you!

findata.fi/finhits
info@findata.fi | @FindataFi



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the European Union

SESSION 5

Case studies on the secondary use of Finnish social and health data

Funded by the Nordic Council of Ministers
Co-funded by the European Union
MINISTRY OF TRANSPORT AND COMMUNICATIONS
FINDATA
SITRA

Case 1: Comparative strengths of Nordic RWE

Emilie Toresson Grip, Director, Head of RWE and Data Analytics, Quantify Research

Funded by the Nordic Council of Ministers

Co-funded by the European Union

MINISTRY OF TRANSPORT AND COMMUNICATIONS

FINDATA

SITRA

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Session 5: Case studies on the secondary use of Finnish social and health data

Comparative strengths of Nordic RWE

Emilie Toresson Grip
Head of RWE & Analytics, Quantify Research

Disclosures

- Affiliated to Karolinska Institute
- Head of RWE and Analytics; board member of Quantify Research

- **Quantify Research** was founded in 2011, with staff across 5 countries.
  - Provides consultancy services in health economics, outcomes research, real-world evidence and market access.
  - Since 2025, part of the Athagoras Group, combining global reach with local expertise across Europe.

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A PARTNER YOU CAN TRUST
athagoras

Introduction

- Global RWE trends and implications for Nordic RWE
- Selected case examples of Nordic RWE studies
- Comparative learnings and practical insights
- Take aways and calls to action

- *“”A critical aspect when assessing the suitability of RWD for a regulatory purpose is data quality, including data reliability and relevance…and the extent to which the data reflects routine clinical practice.”*

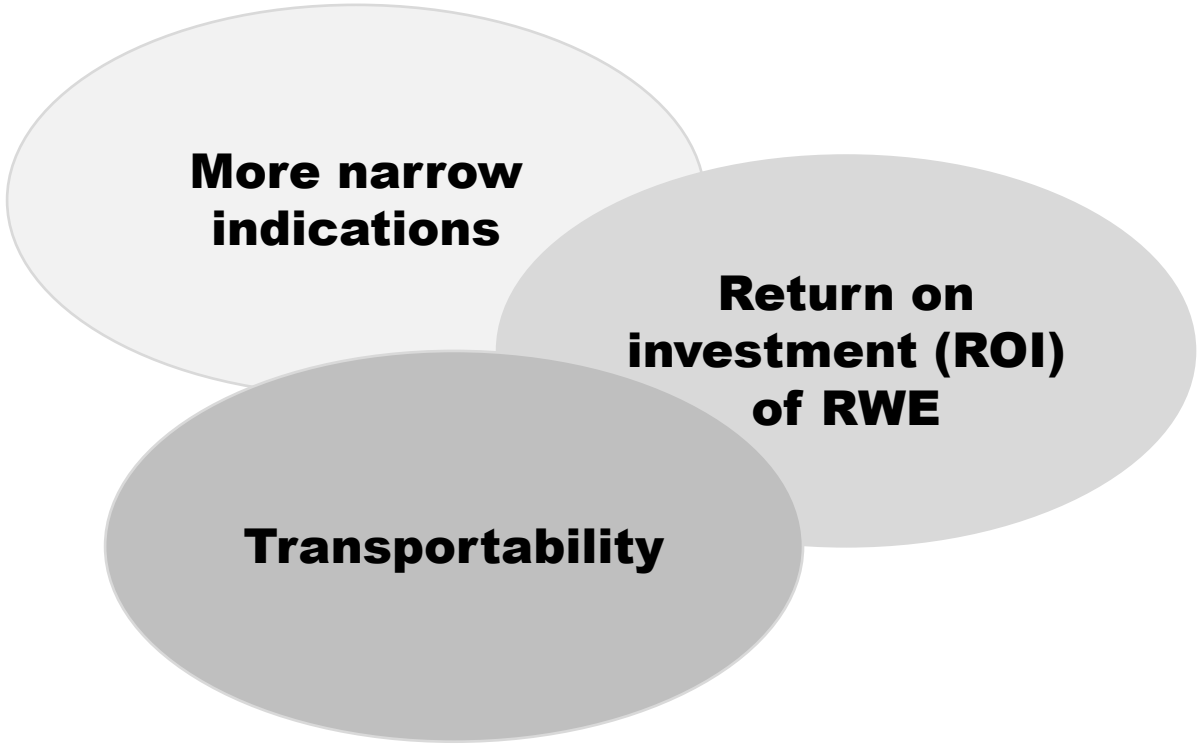
*EMA. **Reflection paper on use of real-world data in noninterventional studies to generate real-world evidence for regulatory purposes**. 2025. EMA/99865/2025. https://www.ema.europa.eu/en/documents/other/reflection-paper-use-real-world-data-non-interventional-studies-generate-real-world-evidence-regulatory-purposes_en.pdf*

EMA’s NIS RWE for regulatory use reflection paper (2025) focuses on methodological principles for the conduct of NIS using RWD for regulatory decision-making throughout a medicine's lifecycle.

Outlines consideration for:

- **Bias** (selection, information, time, confounding, effect modification)
- **Governance** (including ethics, GDPR)
- **Transparency** (registration, reporting)
- **Data quality** (reliability, relevance, multi-database studies, linkage, frameworks)
- **Statistical analyses** (specification, estimation & precision, time-dependency, stratification, sensitivity, missingness, heterogeneity)

Other global RWE trends with implications for the Nordics

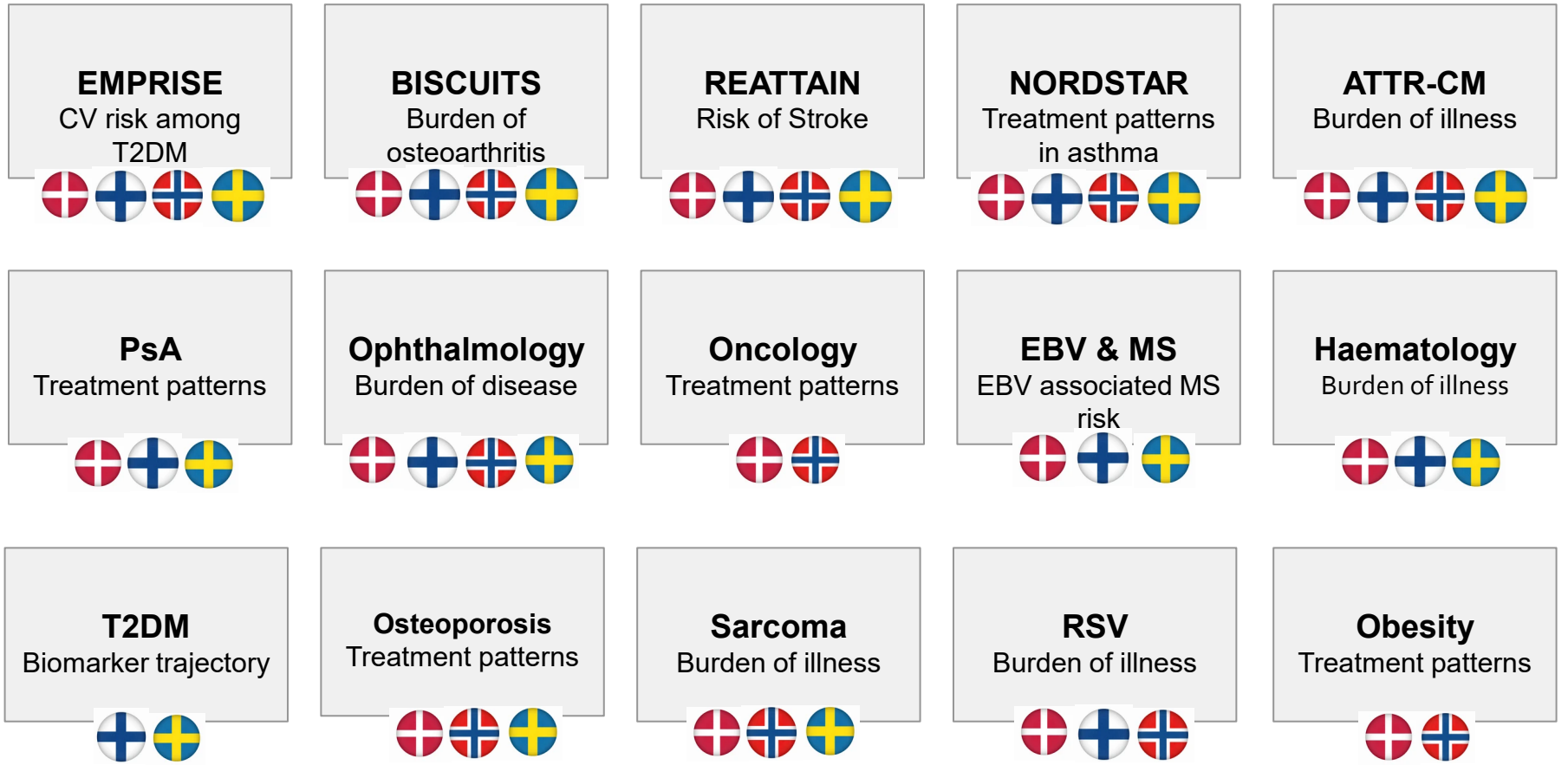


Understanding Nordic key comparative strengths – more relevant than ever

QUANTIFY

A selection of Quantify's Nordic multi-country RWE studies

Study name or main disease area in focus as the title of the studies



Studies conducted between 2018–2025 (ongoing and completed)

QUANTIFY

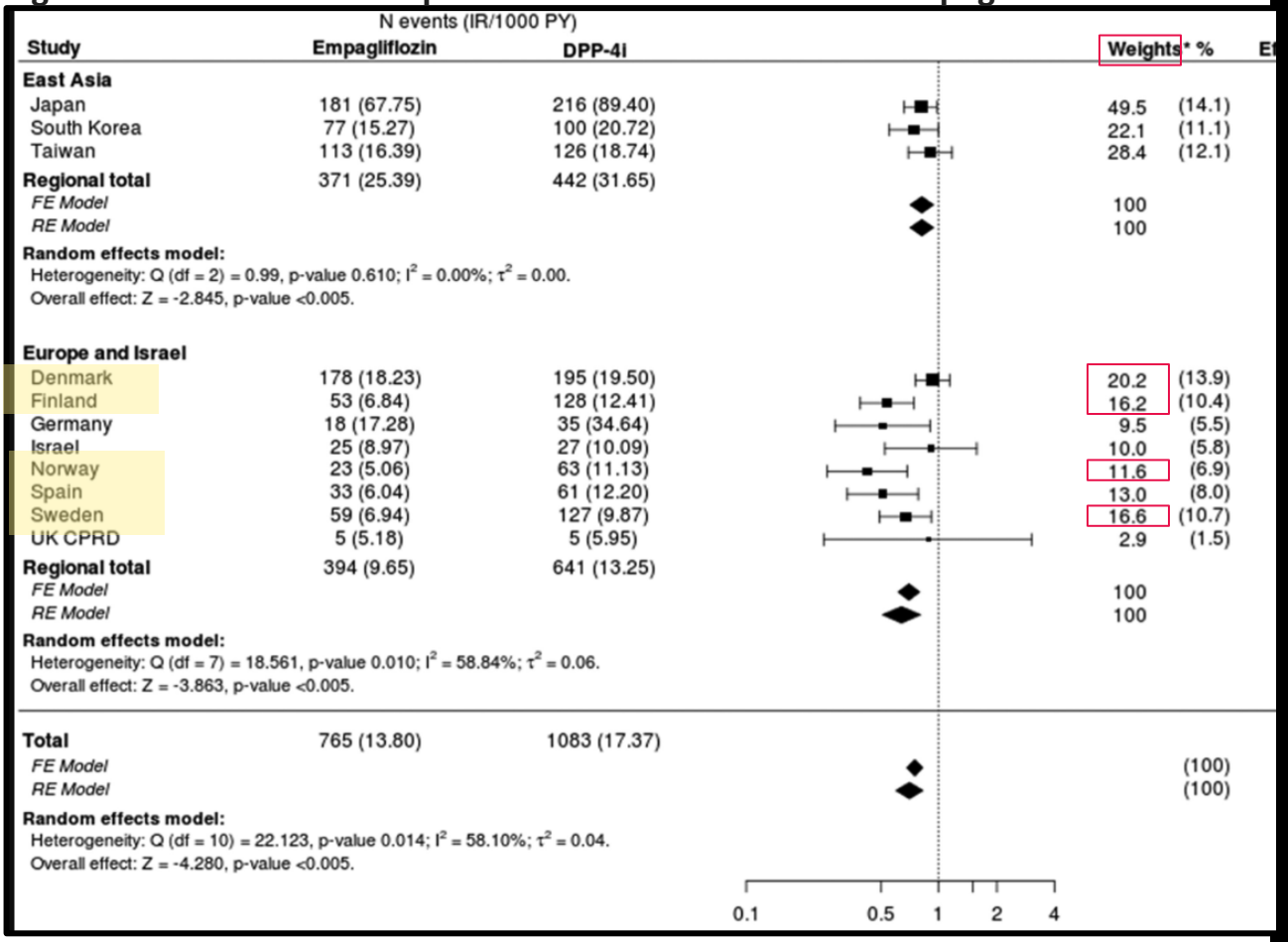
Commonly used Nordic RWD for high-quality RWE

QUANTIFY

Type				
Specialist care	Danish National Patient Register, Health Data Authority (HDA)	Care register for health care (HILMO), THL	Patient Register, Norwegian Institute of Public Health	Swedish National Patient Register, NBHW
Prescription medicines	The Danish National Prescription Registry, (HDA)	The Reimbursement Register, Kela	Prescription Register, Norwegian Institute of Public Health	Swedish Prescribed Drug Registry, NBHW
Primary care	The National Health Insurance Service Registry (SSR)	Register of Primary Health Care Visits (AvoHILMO), THL	KPR-KUHR, Norwegian Institute of Public Health	Regional (county) databases1
Mortality	Danish Causes of Death Registry, (HDA) and The Population Register (BEF/CPR), Statistics Denmark (SD)	Finnish Causes of Death register, Statistics Finland	Causes of Death register, Norwegian Institute of Public Health	Swedish Causes of Death Registry, NBHW
Work absence	Sickness absence compensation and maternity pay register (SGDD, SOCP, DREAM), (SD)	The sickness insurance Register, Kela; Finnish Centre for Pensions (ETK)	FD-Trygd, Statistics Norway	MIDAS, The Swedish Social Insurance Agency; LISA, Statistics Sweden
Population registers	The central population register, HDA and SD	The Population Register (DVV), Statistics Finland	The Population Register, Statistics Norway	The National Population Register, Statistics Sweden
Socioeconomics	Education (UDDA), income (IND), family income (FAIK), various registers for labour force statistics and transfer payments, SD	Longitudinal database of personal data (FOLK), Statistics Finland	Income and Education registers, Statistics Norway	LISA, Statistics Sweden
Disease specific	Various quality of care registers	A few specific quality of care registers	Various quality of care registers	Various quality of care registers
Lab data/ other clinical	The National Laboratory Database (HAD), Quality registers (SUNDK), Pathology registers	Various WSC databases/data lakes; Kanta, Kela	Various population surveys	Quality registers, Regional databases

Protective effects on heart failure of empagliflozin compared to DPP-4i

Fig. 2. Hazard ratios for hospitalization for heart failure in empagliflozin vs. DPP-4i



QUANTIFY

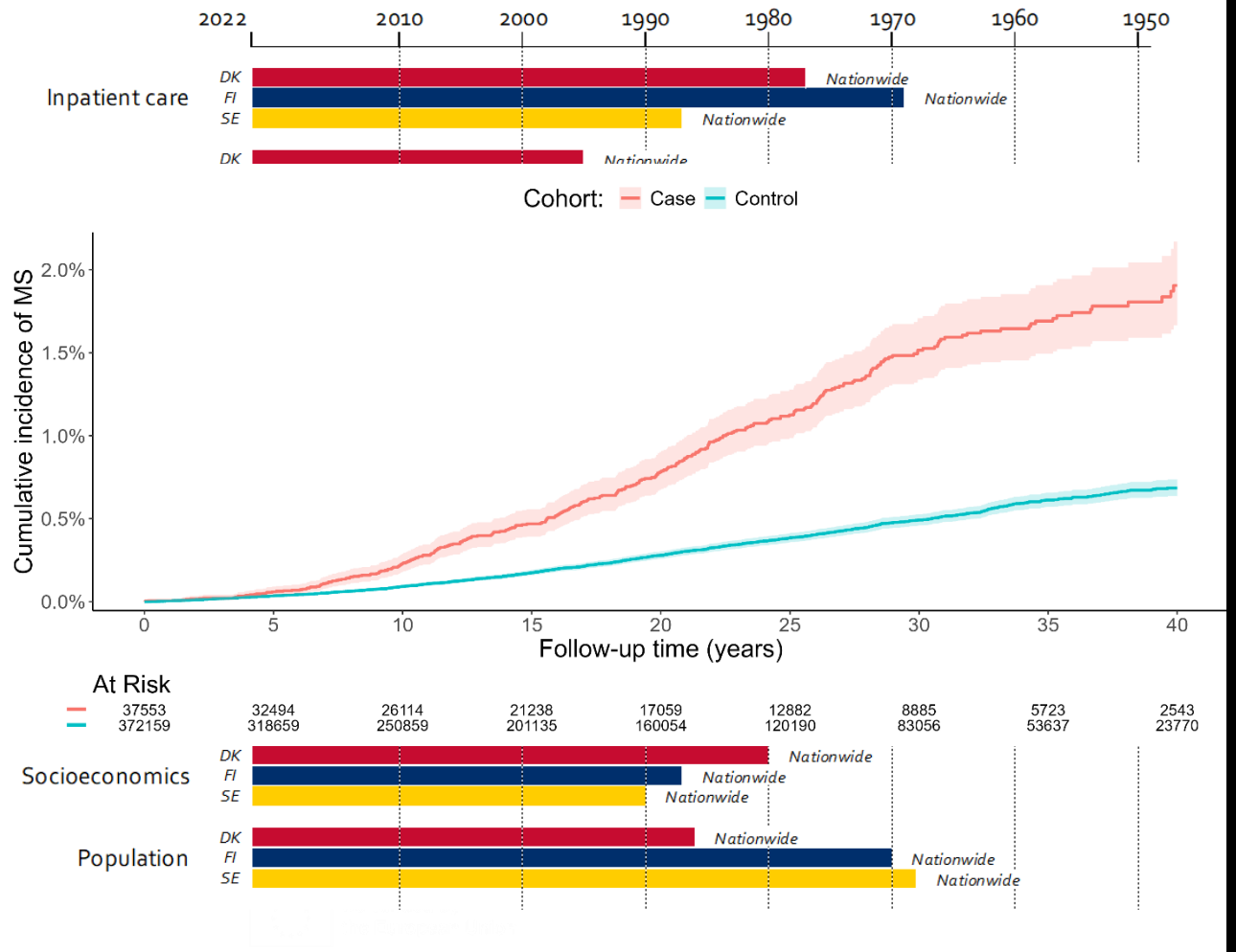
EMPRISE

- The Nordics provided the largest power to the multi-country meta analysis

- Finland, Denmark, and Sweden allowed for unique lab based adjustments of confounders

Karasik et al. *Empagliflozin cardiovascular and renal effectiveness and safety compared to dipeptidyl peptidase-4 inhibitors across 11 countries in Europe and Asia: Results from the EMPagliflozin compaRative effectIveness and SafEty (EMPRISE) study*

EBV-associated infectious mononucleosis linked to nearly three times higher multiple sclerosis incidence



EBV- associated MS risk

- 40+ year of follow up in the Nordics

- Enabled analyses of risk exposure in adolescence and outcomes in adulthood

Key comparative strengths

Denmark	Finland	Norway	Sweden
• Nationwide data on hospital drugs and pathology • Infrastructure for survey linked register-based data	• Advanced infrastructure for regional data access to clinical data • Centralised access to various biobank data	• Centralised access to quality of care data • Indication based prescription data	• Vast amount of disease specific registers

Funded by the Nordic Council of Ministers

Areas for development

Denmark	Finland	Norway	Sweden
• Limited clinical info from primary care • Limited access to quality of care registers	• Detailed clinical data largely regional • Remote platform for data access incurs large costs for advanced data mgmt.	• Continuous change in access process from outside Norway • Limited infrastructure in local/regional clinical data	• Detailed clinical data largely regional + limited infrastructure for access • Fragmented access to quality of care registers

Common limitations:

Changing legislations, guidelines, prices and timelines → prevents competitive RWE with high ROI

Key take aways and call to actions

- The Nordic population-based registers are well-suited to meeting regulators' data quality requirements
- The longitudinal coverage and granular data linkage often more important than nationwide coverage
- Understanding the comparative advantages is key to increase use and acceptability

  → Suitability of the Nordic countries' specific RWD differs across studies

Call to actions

- Streamline Nordic data access to ensure high ROI
- Strengthen data sharing and pooling of Nordic data
- **Investments in infrastructure for collection of detailed clinical data from routine care is key to retain relevance of Nordic RWD on a global stage**

Thank you

Contact

Emilie Toresson Grip, Head of RWE & Analytics

emilie.toresson-grip@quantifyresearch.com

Case 2: JASMINE

Mika Torhola, Director, New Business, Atostek

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Co-funded by the European Union
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JASMINE
”Joyful ApparitionS of Medical INtelligencE”

Research project: 2020 – ~~2021~~ 2024

Focusing on Secondary use of health data in Kanta for research.

ATOSTEK

Main goal for the research

The main goal was to demonstrate the feasibility of developing AI components using machine learning methods by leveraging the national data repository (Kanta).

Kanta

KANSALLINEN TERVEYSARKISTO

Timeline

Secondary Use Act — 2019

Project starts, BF approves application — 2020

Data permit application — 03/2021

Data permit decision — 05/2022

Data received in ”Kapseli” environment. Atostek’s researchers are given access. — 04/2023

Atostek performs research

Research papers submitted for peer review — 2024

Sosiaali- ja terveysministeriö

ATOSTEK ⇅ BUSINESS FINLAND

ATOSTEK ↓ FINDATA Social and Health Data Permit Authority

ATOSTEK ↑ FINDATA Social and Health Data Permit Authority

ATOSTEK ↑ FINDATA Social and Health Data Permit Authority

ATOSTEK

JMIR Publications

FinJeHeW

Suomen Telelääketieteen ja e-Health seura
Finnish Society of Telemedicine and eHealth

Explosion of AI on Timeline

Secondary Use Act

Project starts, BF approves application

Data permit application

Data permit decision

Data received in ”Kapseli” environment. Atostek’s researchers are given access.

Atostek performs research

Research papers submitted for peer review

2019

2020

03/2021

05/2022

04/2023

2024

Sosiaali- ja terveysministeriö

ATOSTEK

BUSINESS FINLAND

FINDATA

Social and Health Data Permit Authority

JMIR Publications

FinJeHeW

Suomen Telelääketieteen ja e-Health seura

Finnish Society of Telemedicine and eHealth

GPT-3
Summer 2020
175E9 parameters

ChatGPT (GPT 3.5)
November 2022
1 million users in 5 days

GPT-4 (GPT 3.5)
3/2023
1E12 parameters

Competition matures: Anthropic, DeepMind, Mistral, Meta, DeepSeek,...

What kind of data was used for research?

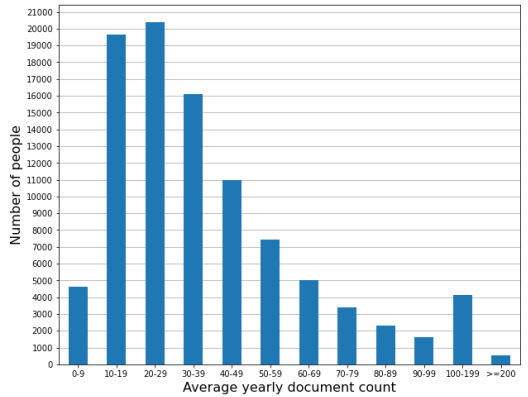
- Medical history of 200,000 individuals from the Kanta Patient Data Repository.
  The data were requested in authentic **CDA R2 XML** format.
  By default, **Findata** provides the data in **CSV** format.
- **Data extraction criteria:**
  - Random sample from the entire population of Finland
  - Only individuals who had reached the age of 18
  - Information notices, prohibitions, and consents were excluded
  - E-prescriptions were excluded (by Findata's request)
- Extractions were performed in **06/2022** → All individuals have documents recorded between **2012 and 06/2022**

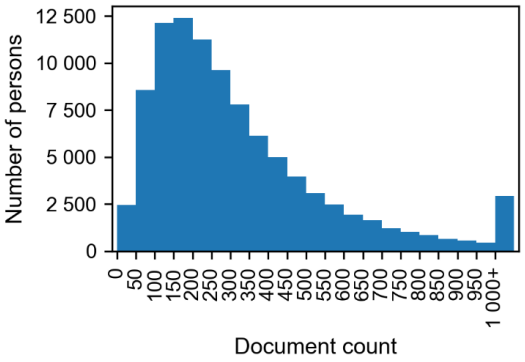
Medical information content in the dataset

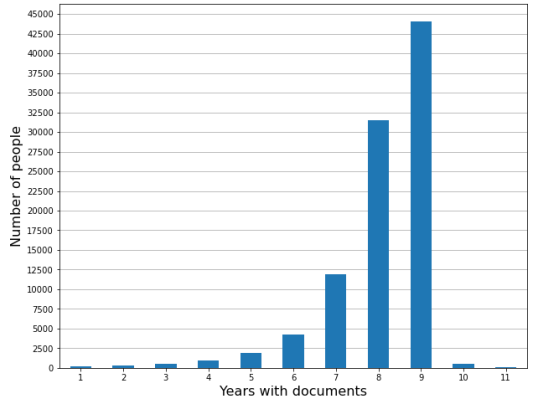
- Encounter notes: visit/clinical notes, nursing notes, progress notes
- Referrals and responses: referral, consultation, feedback reports
- Discharge summaries and episode/care summaries (incl. Patient Summary)
- Care/treatment plans (incl. nursing/rehabilitation plans)
- Diagnoses and problem list
- Allergies and adverse reactions
- Procedures and operation/anesthesia notes
- Vaccinations
- Laboratory orders and results (incl. microbiology, pathology)
- Imaging orders and radiology reports (reports only; images remain in PACS)
- Measurements and observations (vital signs, anthropometrics, scores)
- Certificates and medical statements (e.g., sickness/work capacity)
- Oral/dental care documents
- Maternity/child health clinic records
- Implants/devices and risk/alert information
- ~~Advance directives and organ donation declarations (where applicable)~~
- Medication summaries/medication statements (excluding ePrescriptions, which are in the Prescription Centre, not eArkisto)

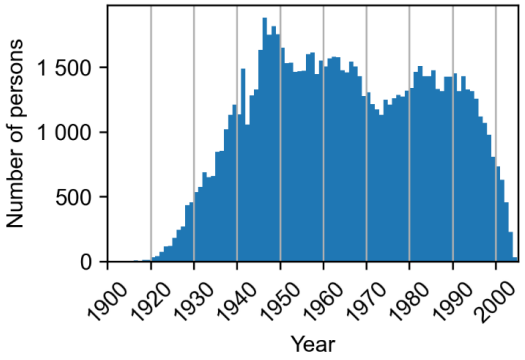
Statistics on the received data

- A total of **6.3 million CDA R2 documents**.
- When compressed into **.zip files**, the total size is **306 GB**.
- The data extracted into an **SQLite database** occupy **6.7 GB** for **96,200 individuals**.
- The **average length of the medical history** obtained is **8–9 years**.
- On average, individuals accumulate **10–40 documents per year** in the **Kanta repository**
  - Excluding consents, prohibitions, and information notices.









What was (and is) the data flow?

Healthcare organisations

Public

Private

3rd sector

Legally mandatory Push of EMR data to Kanta.

Kela

National Health Record

Kanta

KANSALLINEN TERVEYSARKISTO

Data extraction By KELA

FINDATA

Social and Health Data Permit Authority

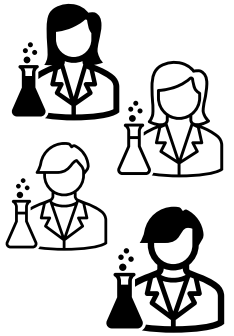
Secure processing environment

Kapseli®

Data pseudonymization by Findata

ATOSTEK

Researchers



...are granted Access to pseudonymized data in Kapseli Environment.

Findata approves certain research outputs from Kapseli environment, as long as it doesn't contain PHI (protected health information).

Scientific Results: Research Publications + 1 D.Sc. (Tech.)

- **Overview** of Finnish National Patient Data Repository for Research on Medical Risk Assessment – *Finnish Journal of eHealth and eWelfare*
- **Compatibility** of Medical Risk Calculators with Data from Finnish National Health Record System – *Finnish Society of Telemedicine and eHealth*
- Finnish National Patient Data Repository as Data Source for **FINRISK** Risk Calculator – *Finnish Journal of eHealth and eWelfare*
- A Large-Scale Risk Assessment and Classification Model for **Pneumococcus** Using Finnish National Health Data – *Healthcare Analytics*
- Large-Scale Evaluation and **Liver Disease** Risk Prediction in Finland's National Electronic Health Record System: Feasibility Study Using Real-World Data – *JMIR Medical Informatics*

All publications available here:

https://atostek.com/en/services/secondary-use-of-health-data/

Research and Publications

Large-Scale Evaluation and Liver Disease Risk Prediction in Finland's National Electronic Health Record System: Feasibility Study Using Real-World Data – JMIR Medical Informatics

Authors: Viljami Männikkö, Janne Tonnesla, Eeemi Tikkanen, Olli-Pekka Kähönen and Fredrik Åberg

Globally, the incidence and mortality of chronic liver disease are escalating. Early detection of liver disease remains a challenge, often occurring at symptomatic stages when preventative measures are less effective. The Chronic Liver Disease score (CLivD) is a predictive risk model developed using Finnish health care data, aiming to forecast an individual's risk of developing chronic liver disease in subsequent years.

The Kanta Service is a national electronic health record system in Finland that stores comprehensive health care data including patient medical histories, prescriptions, and laboratory results, to facilitate health care delivery and research...

Read more

A Large-Scale Risk Assessment and Classification Model for Pneumococcus Using Finnish National Health Data – Healthcare Analytics

Authors: Viljami Männikkö, Juha Tonnesla, Heidi Ahonen and Esa Hanja

Streptococcus pneumoniae, or pneumococcus, poses a significant health risk, particularly to infants, the elderly, and individuals with underlying medical conditions. In Finland, pneumococcal vaccination is part of the national immunization program, with vaccination provided to young children and only selected at-risk adult populations included.

This study aims to leverage the Finnish national electronic health record system, Kanta, to analyze treatment histories and identify individuals at increased risk for disease to improve vaccination strategies...

Read more

Finnish National Patient Data Repository as Data Source for FINRISK Risk Calculator – Finnish Journal of eHealth and eWelfare

Authors: Viljami Männikkö, Hanna Kujanen, Jaana Munukka and Klaus Förger

The FINRISK risk calculator is a tool for the evaluation of the 10-year risk of cardiovascular diseases (CVDs). It is based on a Finnish population survey and is frequently used in Finnish healthcare. Currently, risks are calculated manually by inputting the required values.

An alternative source of input values could be the Finnish Kanta Patient Data Repository (PDR). Risk calculation based on the Kanta PDR could enable monitoring of predicted CVD risks at the level of the Finnish population and targeting of preventive healthcare to high-risk individuals...

Read more

Overview of Finnish National Patient Data Repository for Research on Medical Risk Assessment – Finnish Journal of eHealth and eWelfare

Authors: Viljami Männikkö, Klaus Förger, Hanna Virkanen, Jani Tikkanen, Simo Antikainen and Jaana Munukka

The Kanta Patient Data Repository contains healthcare data from the population of Finland for more than a decade. The repository is a continuously expanding real world dataset produced by many information systems and healthcare service providers.

Kanta data has been accessible for secondary uses such as scientific research since 2019. The data can be requested from the Finnish authority Findata. However, before a request has been accepted, it is difficult to assess if the accumulated data allows answering a specific research question...

Read more

Compatibility of Medical Risk Calculators with Data from Finnish National Health Record System – Finnish Society of Telemedicine and eHealth

Authors: Viljami Männikkö, Klaus Förger and Hanna Virkanen

Medical risk calculators are effective tools in preventative healthcare. Kanta Services is a Finnish national healthcare data registry that contains data from almost the whole Finnish population. This work presents an estimate if the input variables of medical risk calculators can be found from Kanta.

With medical risk calculators, the development of an individual's health can be monitored by individuals themselves, by healthcare professionals, or as a result of selective mass analysis. This helps to detect high-risk potential for certain diseases at an early stage...

Read more

Challenges in research

- **Timeline of the application process**
  - Our application was first of its kind, probably faster now.
- **Timeline of data extraction and pseudonymization process**
  - Our dataset was first of its kind, probably a bit faster now.
- **Current secure environments inadequate for applying LLMs to the data.**
  - Still no secure environment, that would contain a state of the art LLM (e.g. GPT 4 or 5 or similar) as part of the secure environment, that would allow Kanta-PHI data to be subjected to the LLM.
  - LUMI can run sufficient LLMs, but is not a secure environment.
  - Prove me wrong in this one, please!

Current secure environments as registered in Astori

Results (10)

Operating environment	Environment service provider
Aurian Atoll	Southwest Finland Welfare Region
FIMM Sandbox	University of Helsinki
FinnGen Sandbox	University of Helsinki
HUS Academic	HUS Group
Capsule	Social and health sector data licensing authority Findata
SD Desktop	CSC-Science Information Technology Center Ltd.
SECDATA	Aalto University Foundation sr
SPECIOR	ESiOR Ltd.
T3 Researcher's workspace	Istekki Ltd.
Statistics Finland's Fiona user environment	Statistics Finland

Future possibilities – fusing more Finnish RWD sources

FINDATA Social and Health Data Permit Authority

FINGENIOUS® Your Gateway to Finnish Biobanks and Biomedical Research

Kanta PHR ?

Kanta KANSALLINEN TERVEYSARKISTO

FINBB

TALTION

	Healthcare data (Kanta)	**Genome data** (9 Biobanks)	**Citizen generated data** (PHR)
Primary use	OK	No access	Technical interfaces exist, but legislation doesn't support straightforward use
Secondary use (Data-driven management in healthcare)	• Too much delay in the process • One-shot, not live-updated data • Problems can be circumvented to some extent	• Too much delay in the process • One-shot, not live-updated data	Could be done cumbersomely via well-being apps?
Secondary use (research)	OK'ish. Delays in the processes. Not easy to combine w/ genome data.	OK'ish. Delays in the processes. Not easy to combine w/ Kanta-data.	Could be done cumbersomely via well-being apps?
Personal use by citizens	OK	No access.	OK

Better population health management

Better research

Future possibilities – What do we need to truly enable AI based research & development?

- A secure computing environment where:
  - State-of-the-art LLMs can be run inside EU / Finland
  - Kanta data can be imported and processed
  - Data from other aforementioned RWD sources can also be imported
    - As well as data from biobanks and citizen-generated information
- LUMI is not such an environment — **could Roihu be?**
  - **Maybe the "AI regulatory sandbox" as described in AI Act article 3, could be implemented in Finland by utilizing Roihu and certifying it as a secure computing environment?**

Thank you!

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Case 3: FinnGen

Aarno Palotie, Research Director, Institute for Molecular Medicine Finland

Funded by the Nordic Council of Ministers

Co-funded by the European Union

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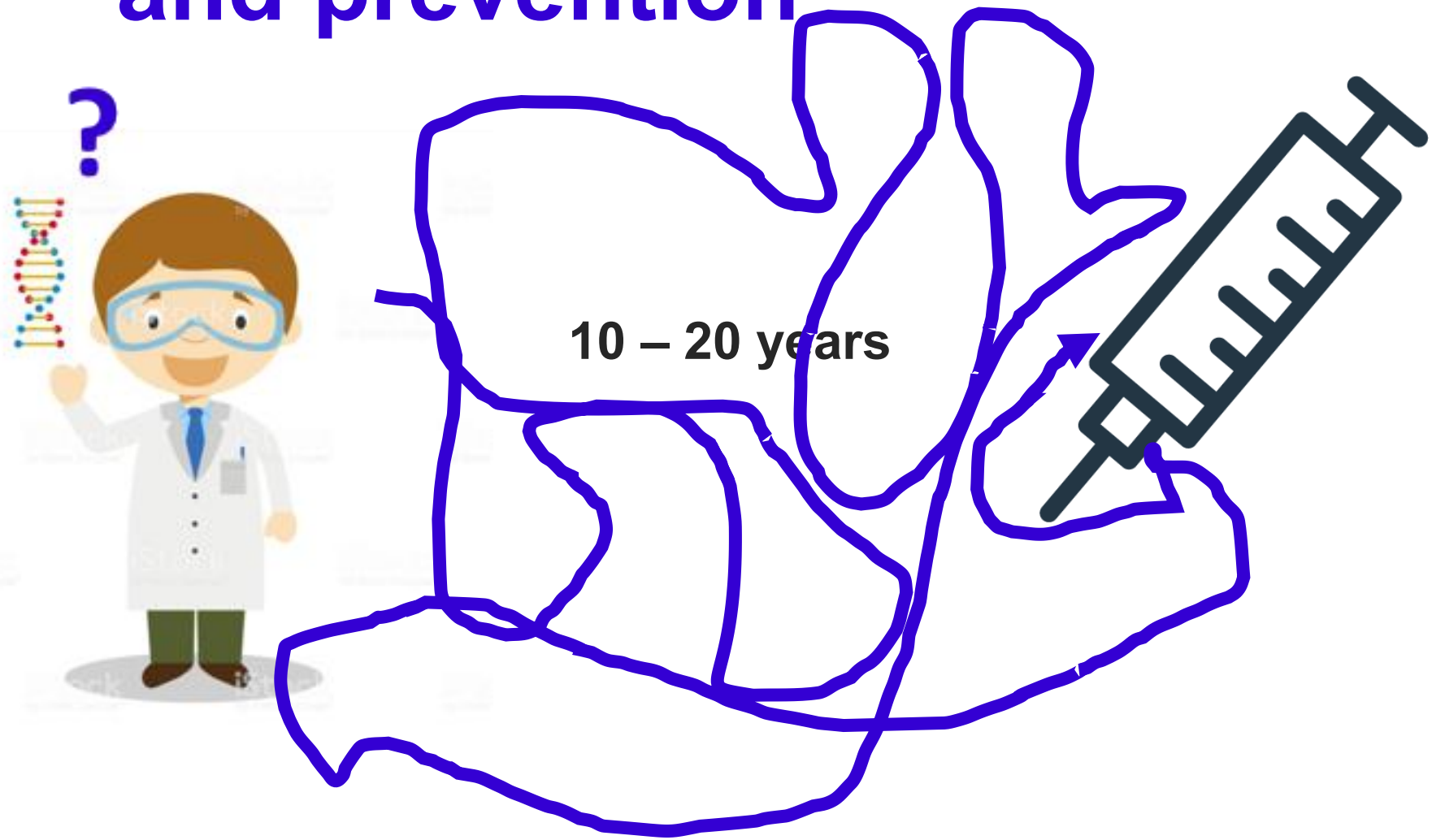
FINNGEN
Aarno Palotie, M.D., Ph.D.
MGH
1811
BROAD
INSTITUTE
STANLEY CENTER
FOR PSYCHIATRIC RESEARCH
HiLIFE
FIMM
Institute for Molecular Medicine
Nordic EMBL Partnership for Molecular

From Discovery to treatment and prevention

10 – 20 years

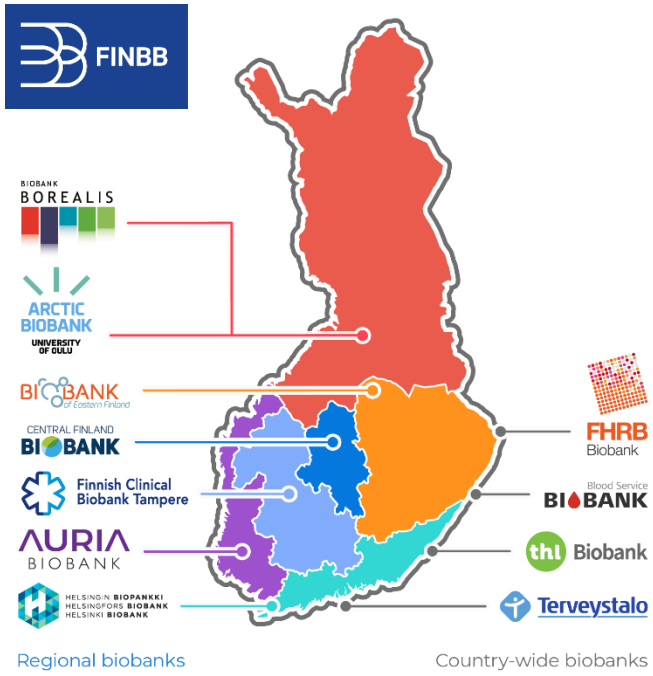
From Discovery to treatment and prevention



Could genetics help?

Public-private research project

FINNGEN



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Academic institutions and public health care

Pharmaceutical industry

BAYER
Boehringer Ingelheim
abbvie
AstraZeneca
Biogen
Bristol-Myers Squibb
Genentech
A Member of the Roche Group
gsk
janssen
PHARMACEUTICAL COMPANIES OF Johnson&Johnson
MSD
NOVARTIS
Pfizer
SANOFI

thl
UNIVERSITY OF HELSINKI
HUS

BUSINESS FINLAND

Pharma €140M

BF €20M

15 Finnish partners & 15 international pharma partner

Lifetime health and genetic data from 520 000 participants

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Nationwide health registries

10% of the population

Hospital outpatient, primary care visits
Procedure codes
Drug perscription and purchase
Cancer register
Cause of death
Laboratory tests
Screening data etc

Data curation
Data harmonisation
QC
OMOP mapping

>4000 disease endpoints
>400 health events/person
>210 Million lab tests

Hospital data

- drug, ECG,
- spirometry, OCT (in progress)

Axiom GWA array

Different phases need different skills and different decisions

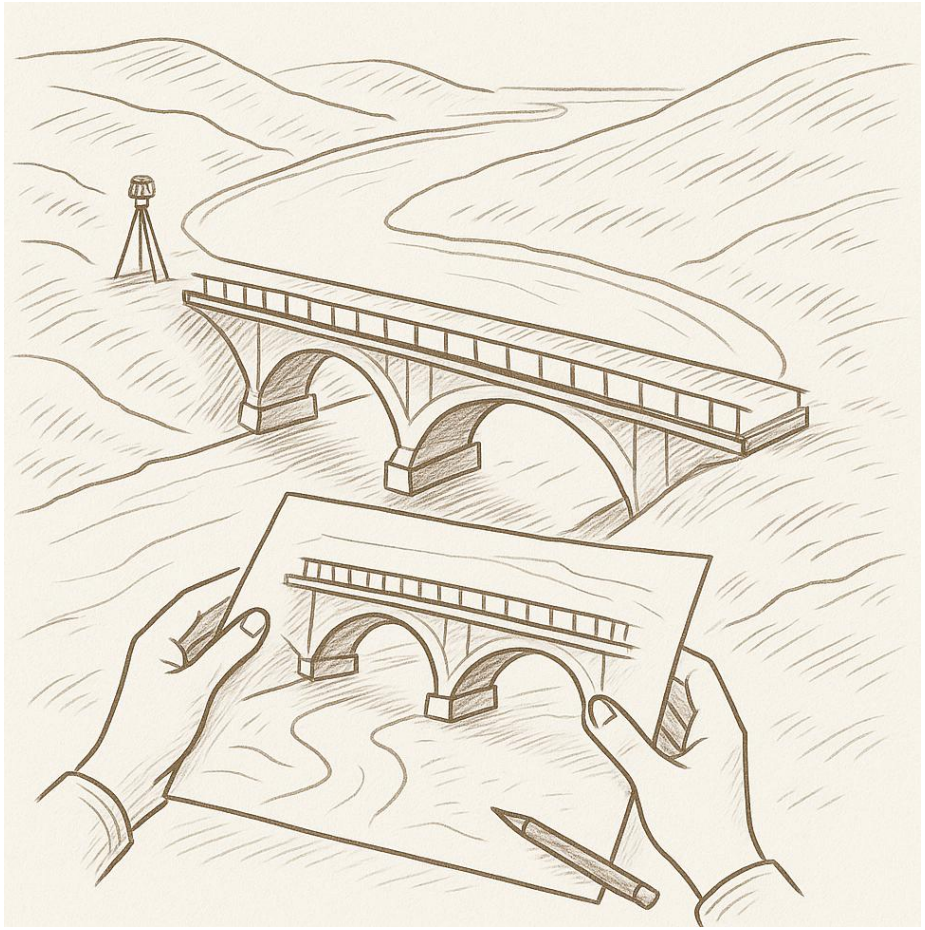
FINNGEN

Constructing FinnGen 2017-2023

Using and maintaining FinnGen 2023-2027

Further developing FinnGen 2026 ->

Planning phase, how could the vision be constructed



- Vision was rather obvious:
  - Nordic health registers + population isolate + legislation
- All EU and national funding failed
- Pharma companies established genetics groups
- Could there be a public-private alliance

How would the study look like?

Mark Daly

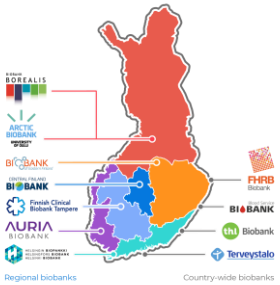
Robert Plenge

Sally John

FinnGen construction phase

FINNGEN

Constructing FinnGen 2017-2023

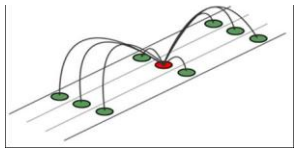


Samples:
550 000 individuals

126

+

Imputation



Genotypes:
520 210 individuals
21M markers

+

Health data:
>4000 disease endpoints

TRE computing infrastructure

FinnGen construction phase

Constructing FinnGen 2017-2023

- Very operational
- Focus and vision easy to understand
- Building resources for infrastructure
- Easy to build deliverables and milestones

“Construction groups” remained happy

Using data to achieve research goals

FINNGEN

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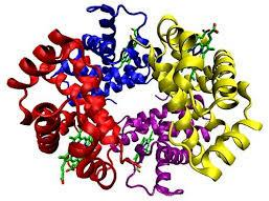
Aim1:
Understanding disease trajectories

Aim2:
From variant to function

Using and maintaining FinnGen 2023-2027

>2600 publications
606 analysis proposals



→ Omics analyses from a subset of samples

Kanta → 211 million clinical lab tests

OHDSI OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS → Data harmonization

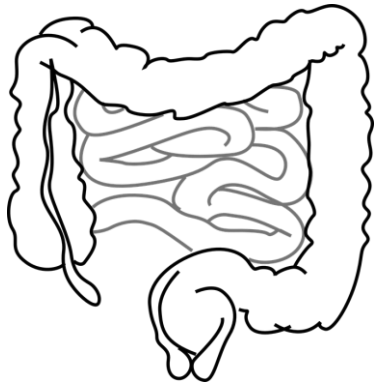
→ Improving analysis tools

• Novel findings

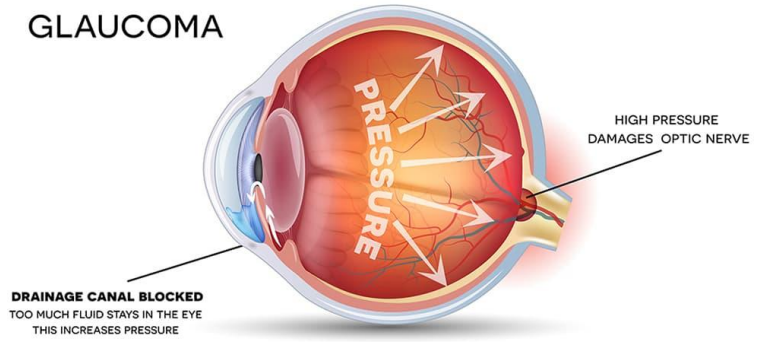
Over 2 200 diseases analyzed
Over 10 000 associated variants identified
For over 1000 diseases at least one associated variant

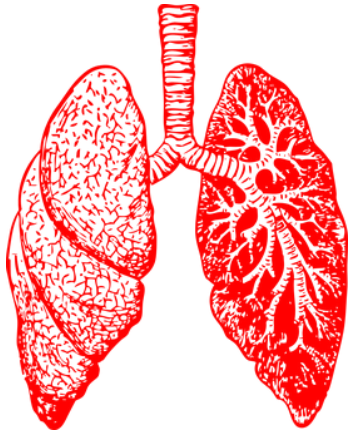
FINNGEN

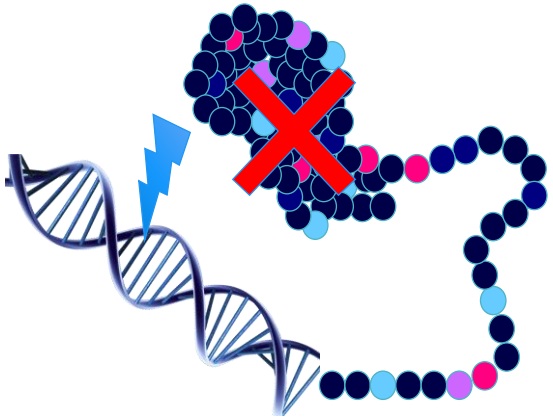
TNRC18 increases the risk of IBD



ANGPTL7 protects from glaucoma







SPDL1 increases the risk of pulmonary fibrosis but protects from cancers

MFGE8 protects from heart disease

Using data to achieve research goals

FINNGEN

Using and maintaining FinnGen 2023-2027

>2600 publications
606 analysis proposals

Positive:

- Dynamic phase of the project
- Active research
- Lots of new health register data
- Initiation of other omics data

Challenges:

- A dynamic project but a stiff partnership model
- How to maintain the biobank infrastructure when collection completed
- Retrieving data from hospitals more challenging
- How to meet the different expectations between research, clinics and infrastructure support

Towards the next phase of FinnGen

FINNGEN

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- **Understanding disease trajectories**
- **Functional studies to understand biological consequences of variants**

Further developing FinnGen 2026, 2027 ->

+

- Meta-analyses across multiple international studies
- Additional phenotyping
- New analytical tools (AI)
- Expanding omics analyses?
- Expanding cohort?

Some take home messages

FINNGEN

- You can never plan a perfect study/infrastructure
- We did plan but nothing will be ready in one shot,
- => just go and do it, and finetune while moving
- Don’t underestimate the amount of data cleaning and harmonization
- => even more essential when data analyzed across projects (e.g.OMOP mapping)
- Don’t expect that biobanks are profitable units
- Steep learning curve for the wider medical research community
- This base work is essential to enable next steps for translation


Thank you!

SESSION 6

Learning from cross-border data collaboration and AI use in the transport sector

Funded by the Nordic Council of Ministers
Co-funded by the European Union
MINISTRY OF TRANSPORT AND COMMUNICATIONS
FINDATA
SITRA

Learning from cross-border data collaboration and AI use in the transport sector

Janne Lautanala, Chief Ecosystem and Technology Officer, Fintraffic

Olli Soininen, Head of Programs, Fintraffic

Funded by the Nordic Council of Ministers

Co-funded by the European Union

MINISTRY OF TRANSPORT AND COMMUNICATIONS

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SITRA

From Roads, Rails, Skies and Seas to Health: Lessons from Finland’s Traffic Data Ecosystem

Context: Finland's Traffic Data Ecosystem

- **Fintraffic** is government owned company responsible of traffic management and control in all modes of traffic.
  - Fintraffic is also responsible of aggregating, managing and publishing traffic related data in Finland.
- **Traffic Data Ecosystem** is A national collaboration forum enabling open and interoperable traffic data.
  - Who's involved: public agencies, private companies, startups, academia – more than 230 organizations.
  - Key purpose: safer, smoother, more efficient and more sustainable mobility and logistics through shared data.

From Traffic Data to Real-World Value — and What kind of analogies exist for Health?

🚦 **Predictive Traffic Management → Predictive Health Operations**

- Combining weather, vehicle, and sensor data to prevent congestion.
- *Parallel in health:* anticipate hospital bottlenecks or ICU surges using shared data.

🚌 **Multimodal Journey Planning → Integrated Care Pathways**

- Data from all transport modes fused for seamless trip planning.
- *Parallel:* integrate primary care, specialist, and telehealth data for patient "journey planning."

🚑 **Real-Time Disruption Alerts → Real-Time Patient Monitoring**

- Live incident feeds help emergency services reroute ambulances.
- *Parallel:* real-time patient data streams enable faster interventions.

🌍 **Environmental Impact & Emission Tracking → Health Impact Analytics**

- CO_2 and traffic flow analytics inform urban policy.
- *Parallel:* link air-quality and mobility data to public health outcomes.

💡 **Innovation Sandbox → Safe Data Sharing Sandbox**

- Companies test new mobility services with controlled access to data.
- *Parallel:* regulated testbeds for AI/ML health solutions using anonymized patient data.

Why do ecosystems matter?

- **The challenge**: multiple actors, fragmented data, limited interoperability, i.e. **system level problems**
- **The solution**: ecosystem thinking — aligning incentives and trust across sectors.
- **Result**: faster, cheaper and better innovation, new business models, better user outcomes.
- **Analogy**: “From traffic jams to data jams — and how to clear them.”

“Not all smart people work for you. “
- Bill Joy, Sun Microsystems

There are plenty of challenges…

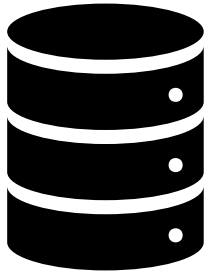
€ Data sharing incentives (carrots & sticks)

€ Risks related to data sharing

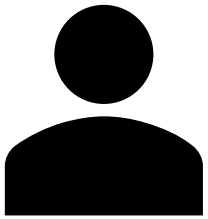
€ Risks related to data consumption

€ Data usage incentives (carrots & sticks)

Data Perceived value <> objective value

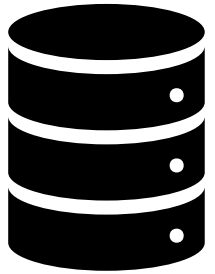


Data Perceived value <> data objective value

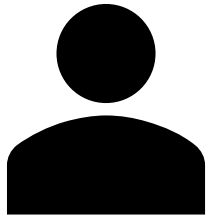


€ Cost of making data available

€ Cost of consuming data



Product – market fit challenges



Data provider
Skills, capabilities,
Incentives, governance

Data consumer
Skills, capabilities,
Incentives,
governance

Core principles for Traffic Data Ecosystem

- **Open, standard data**: transparency builds innovation.
- **Open interfaces**: interoperability by design.
- **Open innovation**: co-creation across silos.
- **Clear governance**: rulebook, roles, and responsibilities.
- **Shared value creation:** value needs to be both created and captured / shared.

- **Lesson: openness accelerates trust and efficiency.**

Governance, trust and business logic

- How we built trust:
  - Clear governance model, Fintraffic as neutral orchestrator.
    - Shared rulebook for data sharing.
    - Level playing field for all parties – Nordic equality
  - Value creation for all parties — “no one wins alone.”

  - **Parallels to healthcare**: patient data governance, secondary use of data, data spaces.
  - **Key learning**: *Impact grows when data sharing is predictable, secure, and easy.*

Challenges and how we overcome them?

- Data quality and standardization
- Legal uncertainty and fear of misuse
- Unequal capabilities among participants
- Value capture / sharing between parties
- Overcame through: analysis, education, pilots with seed investments, transparency, and feedback loops.

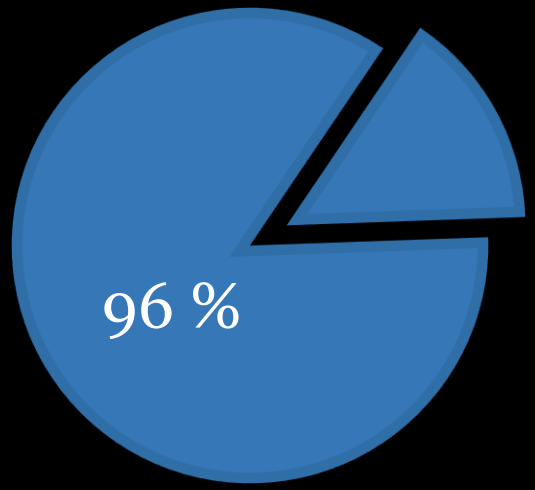
- **Lesson:** *ecosystem maturity takes patience and iteration*.

What Healthcare Could potentially Learn from Traffic?

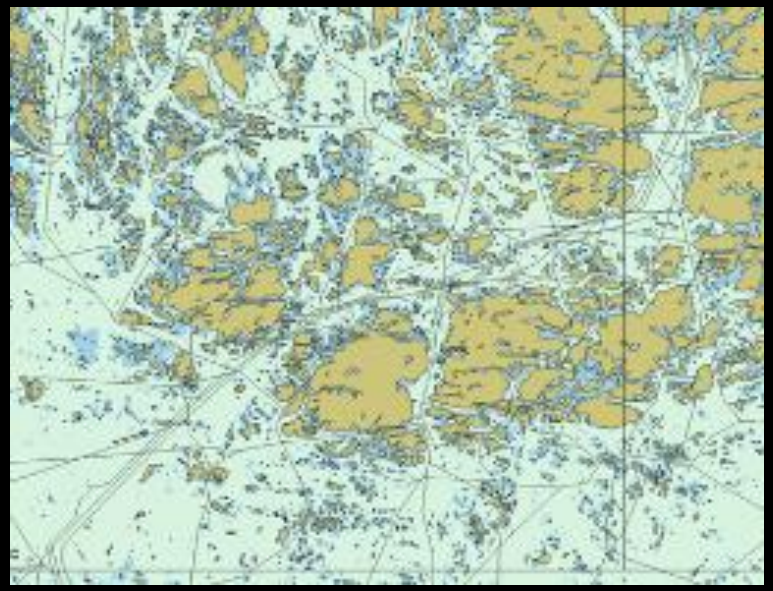
- Build the trust!
- Invest in neutral orchestration roles (not just platforms).
- Combine open standards + strong privacy.
- Enable safe experimentation with real-world data and relevant use cases.
- Apply ecosystem rulebook concept for health data spaces.
- Shift from “data ownership” to “shared value creation.”

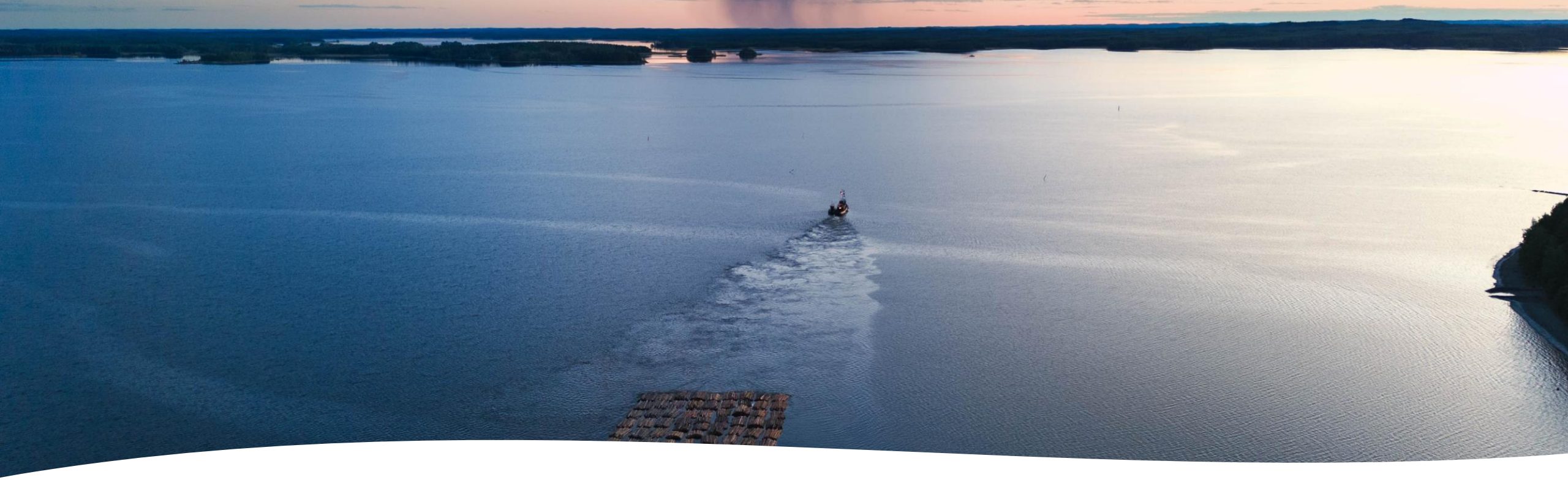
Case 1:
Maritime & Port collaboration

Olli Soininen, Fintraffic



96% OF FINLAND'S FOREIGN TRADE IS CARRIED BY SEA

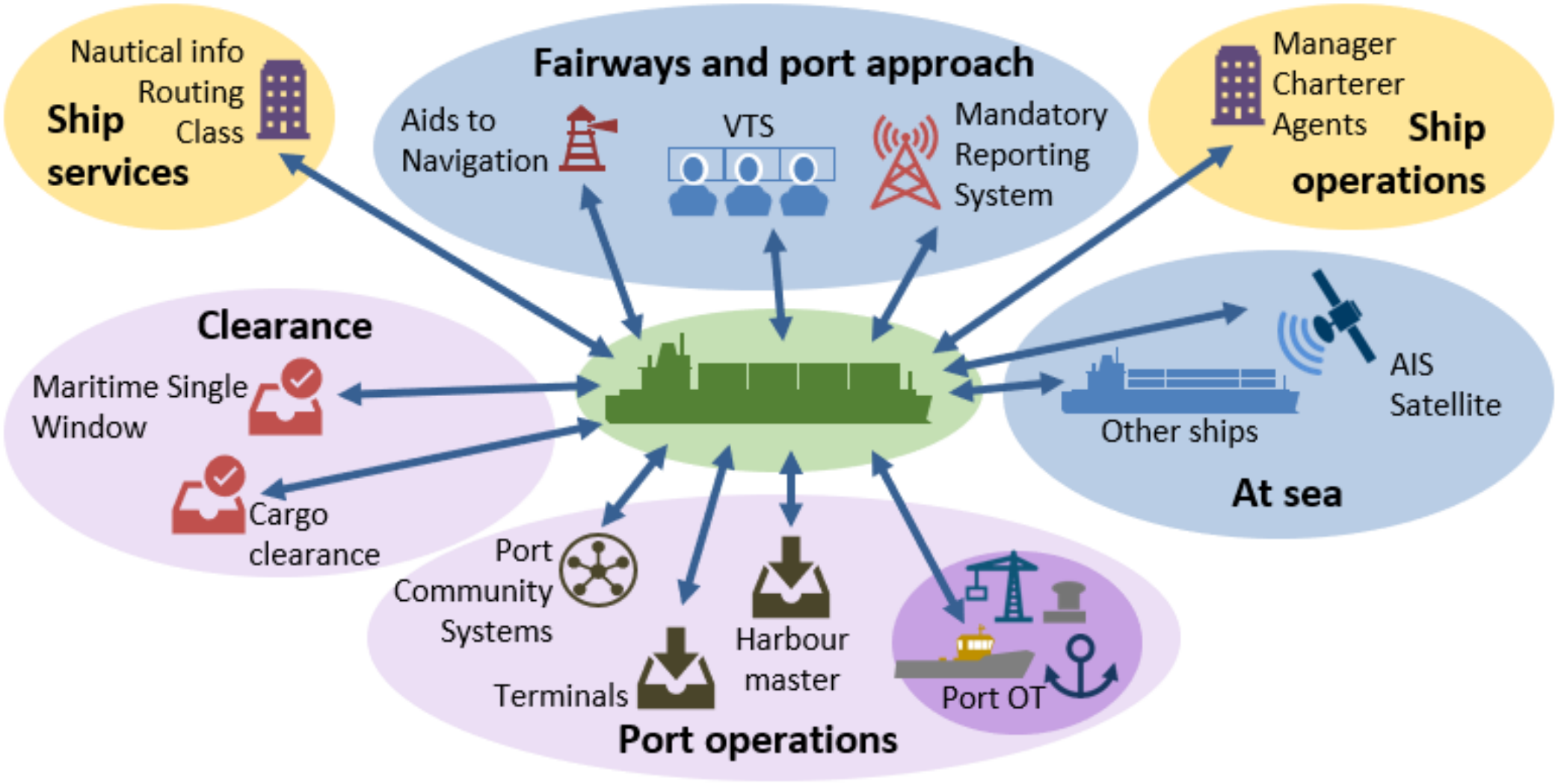




“Slower at sea and faster in port”

- About 96 % of Finland's trade (EU 80%) relies on maritime transport,
- Global shipping is undergoing rapid transformation at an unprecedented pace.
- Regulatory and market demands for low-emission shipping are increasing.
- The transition to alternative fuels is essential but hindered by high costs and limited availability.
- Bunker fuel accounts for 50–80% of a ship’s operating costs in global shipping.
- Enhanced situational awareness, connectivity, and operational optimization are critical for success.
- Lower logistics costs directly reduce domestic product prices and strengthen global export competitiveness.

Digital Maritime environment

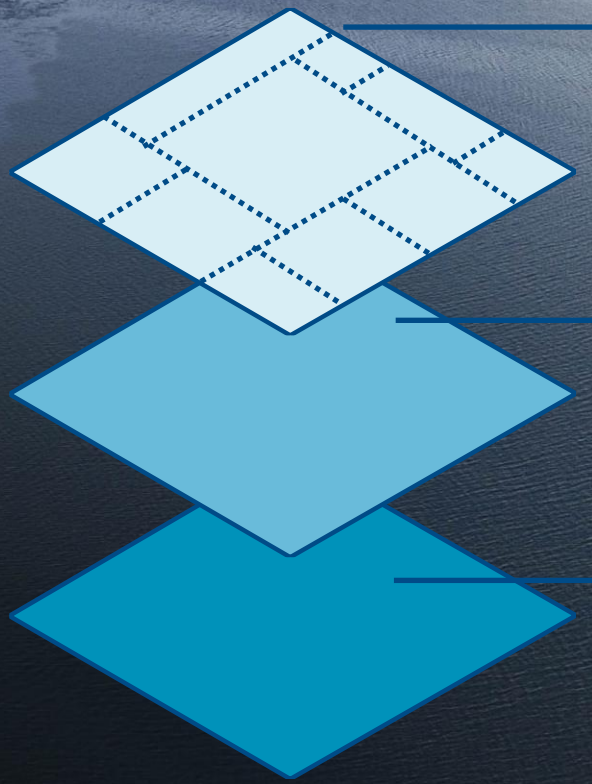


GRAVITY ECOSYSTEM & PROJECT

GRAVITY- Main goals of the ecosystem

Developing and implementing Just In Time (JIT) and Virtual Port Arrival (VPA) as a common platform:

1. Reduces the environmental impact of shipping and promotes sustainable shipping
2. Supports digital development aimed at emission reductions for various operators
3. Harmonizes operational processes, relevant documentation and agreement
4. Supports data sharing and trust between maritime stakeholders.
5. Produces financial and competitive advantages
6. Aligns with regulatory needs and changes



JIT / VPA implementations
- Scaled to the actors' needs and environment

JIT platform
- Data platform
- Situational awareness data
- Real time

JIT framework
- Standards
- Rules & procedures
- Contracts
- Technical services

The change through GRAVITY ecosystem activities

Current Situation at the Baltic Sea
(Pre-Gravity Project)

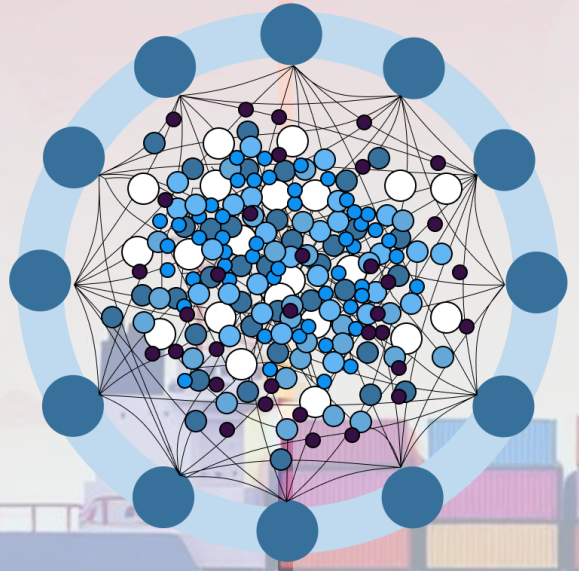
Inefficient Communication

Isolated Data

Lack of Coordination

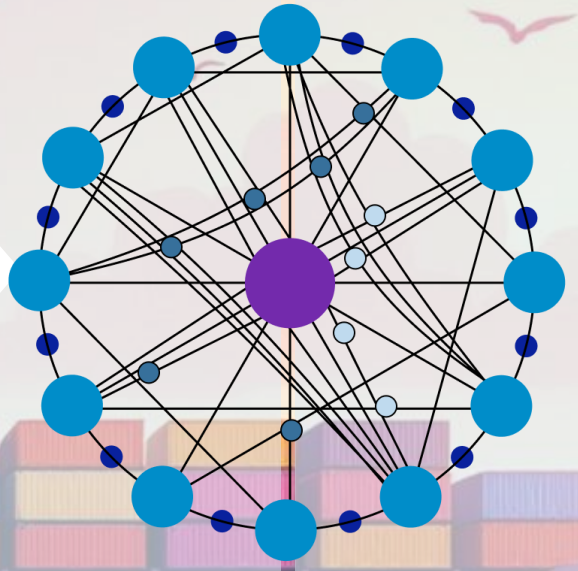
Impact on Operations

Local Projects



Unified Process and Data Platform

Common Standards



Future Situation After the Gravity Project
(Post-Implementation)

Collaborative Ecosystem

Data Integration

Efficiency Gains

Enhanced Situational Awareness

Maritime Dataspace value mapping heatmap

How value is created?

Understanding the value drivers that drive shareholder value creation.

What can you do?

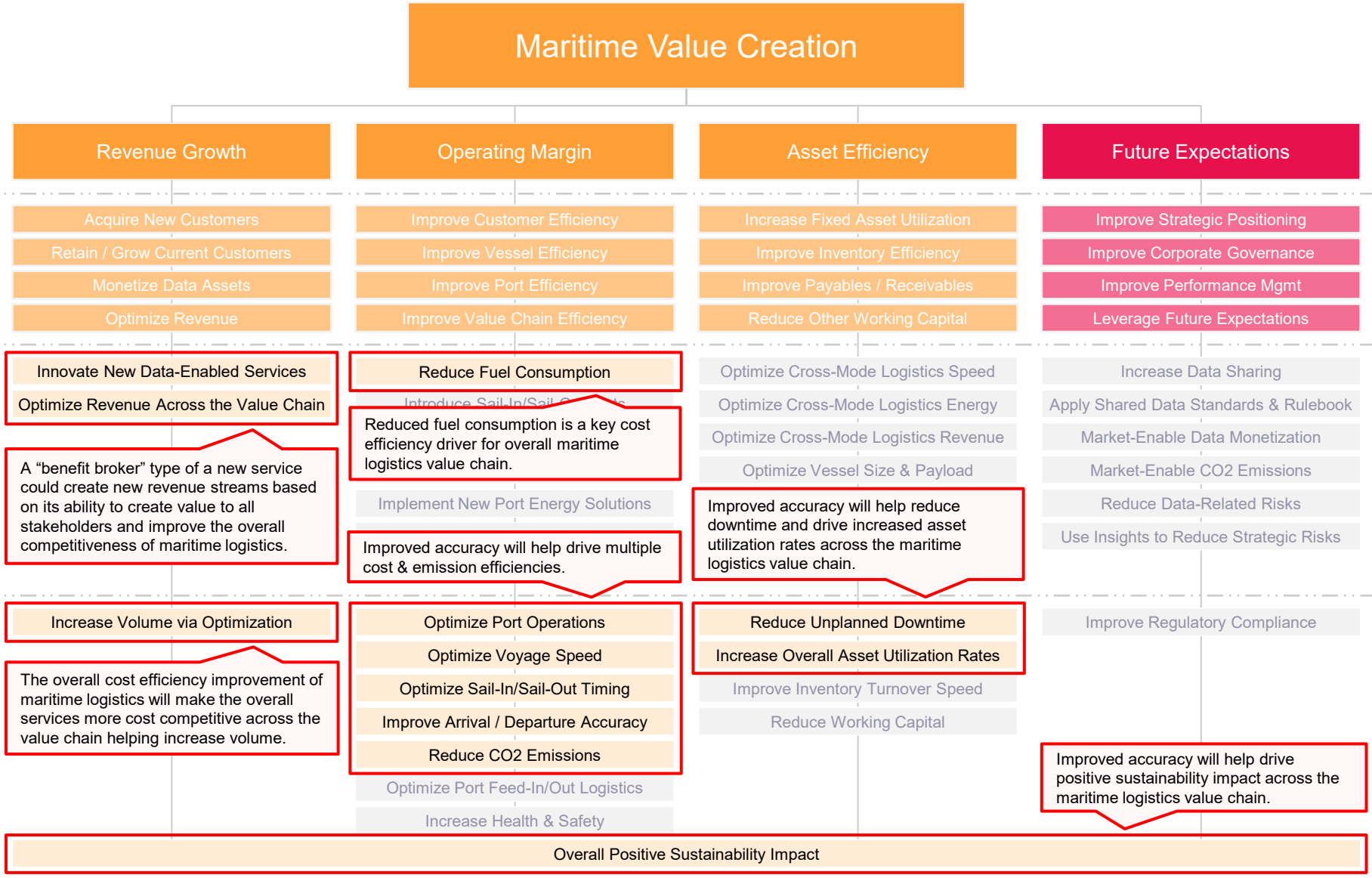
What are the levers that are available to you to positively impact the value drivers?

Change what you do!

Use the available Data enablers to change what you do?

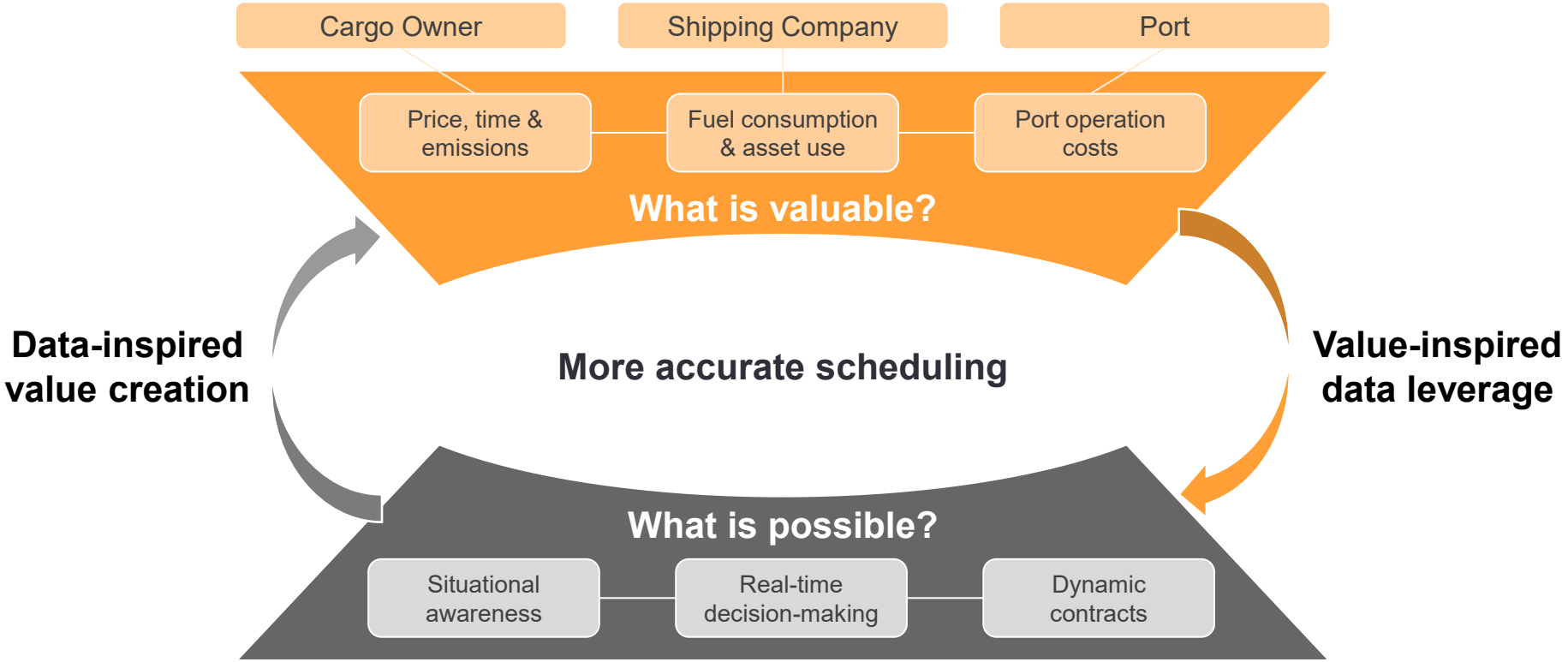
Do what you do, but better!

Use the available Data enablers to do what you already do, but better.



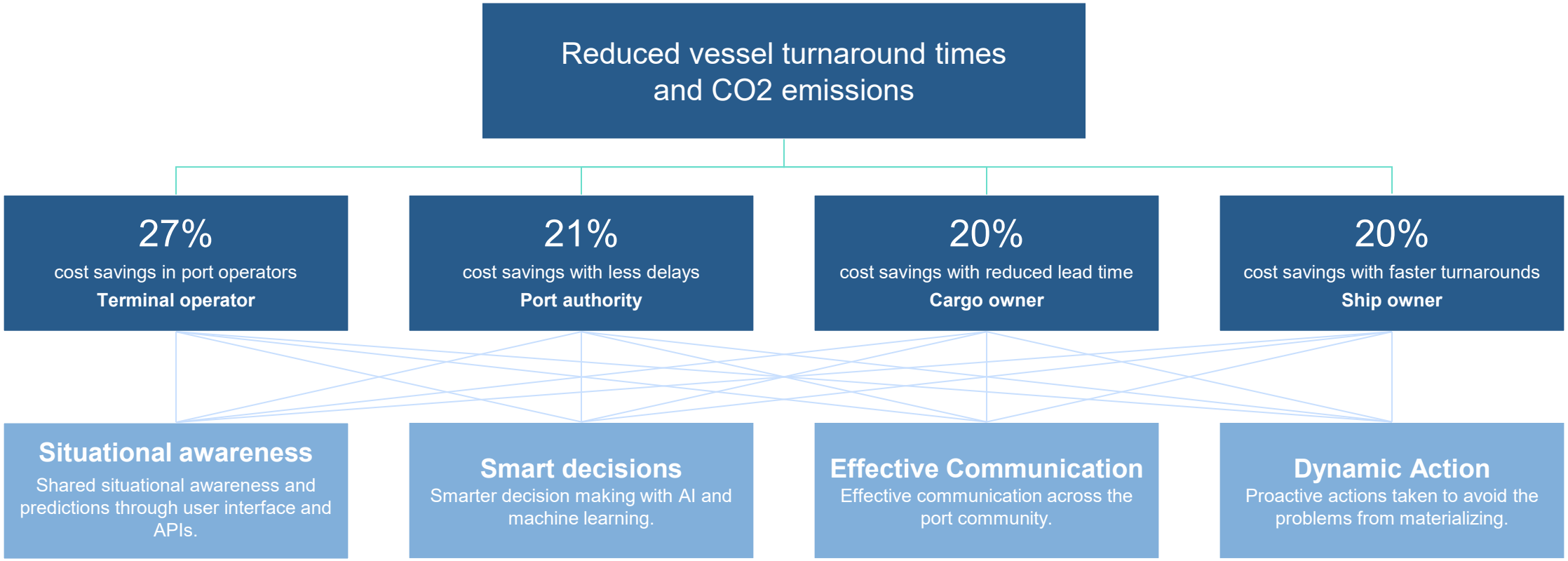
Value potential

- Maritime Logistics value chain currently compensates individual parties for inefficiencies resulting in costs and CO2 emissions that could be avoided with more accurate value chain wide scheduling capabilities. Maritime Data Space could act as an overall “benefit broker” using its data capabilities to optimize overall costs and emissions across the different stakeholders.

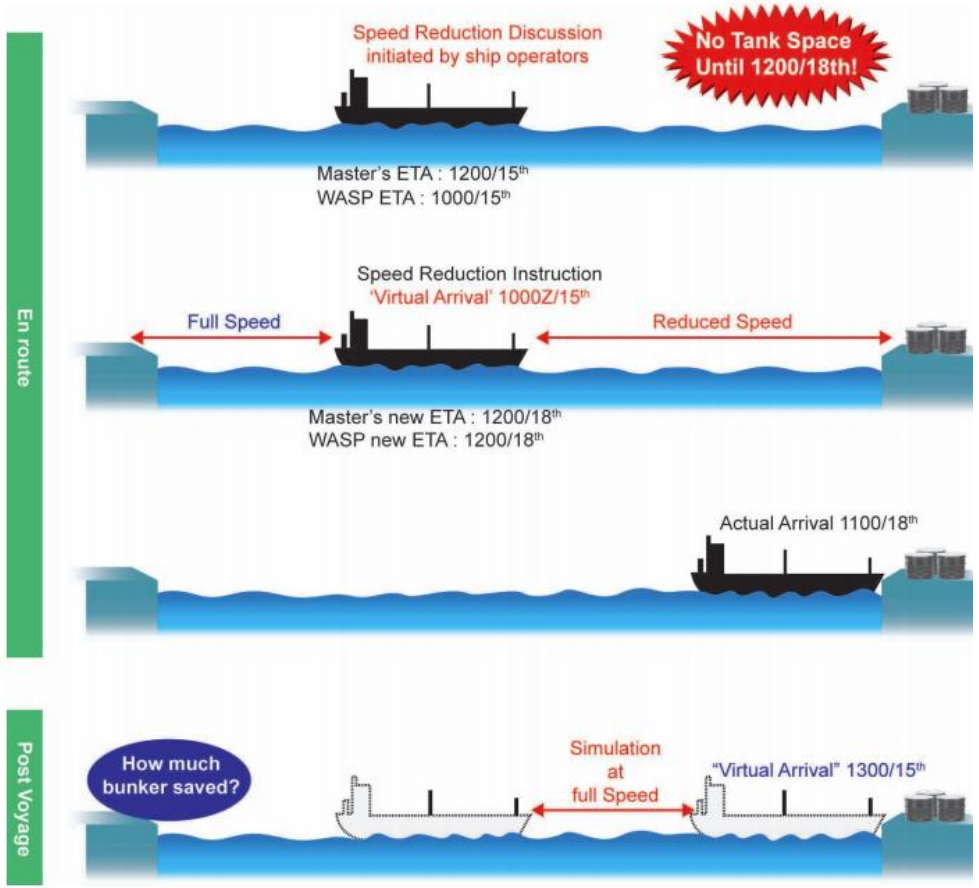


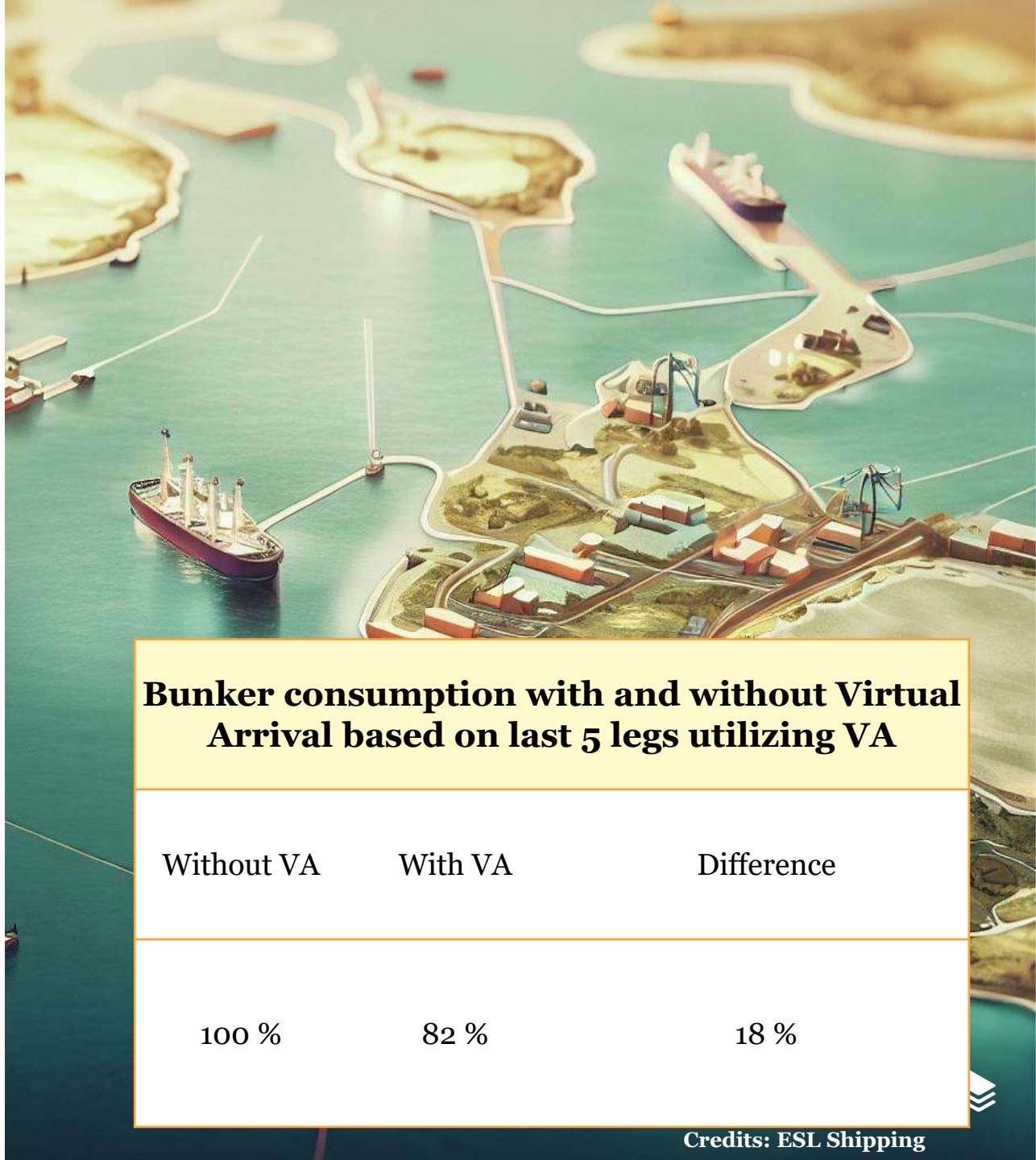
JIT Case: Identified value potential

JIT (Just-in-Time) operations in maritime transport refer to the precise timing of vessel arrivals and departures at ports, minimizing waiting times and optimizing the use of resources. This improves logistics efficiency, reduces fuel consumption and emissions, and enhances the operational performance of both ports and vessels..



Virtual Arrival





Bunker consumption with and without Virtual Arrival based on last 5 legs utilizing VA

Without VA	With VA	Difference
100 %	82 %	18 %

Credits: ESL Shipping

Digitalization of maritime safety and logistics

How data and AI can be used for better situational awareness in operations

Case: ETD/ETA estimation service

- **Problem**: Actors in the maritime supply chain do not have up to date shared knowledge of current and future vessel schedules. *This leads to unnecessary manual work and makes operational planning less efficient*.

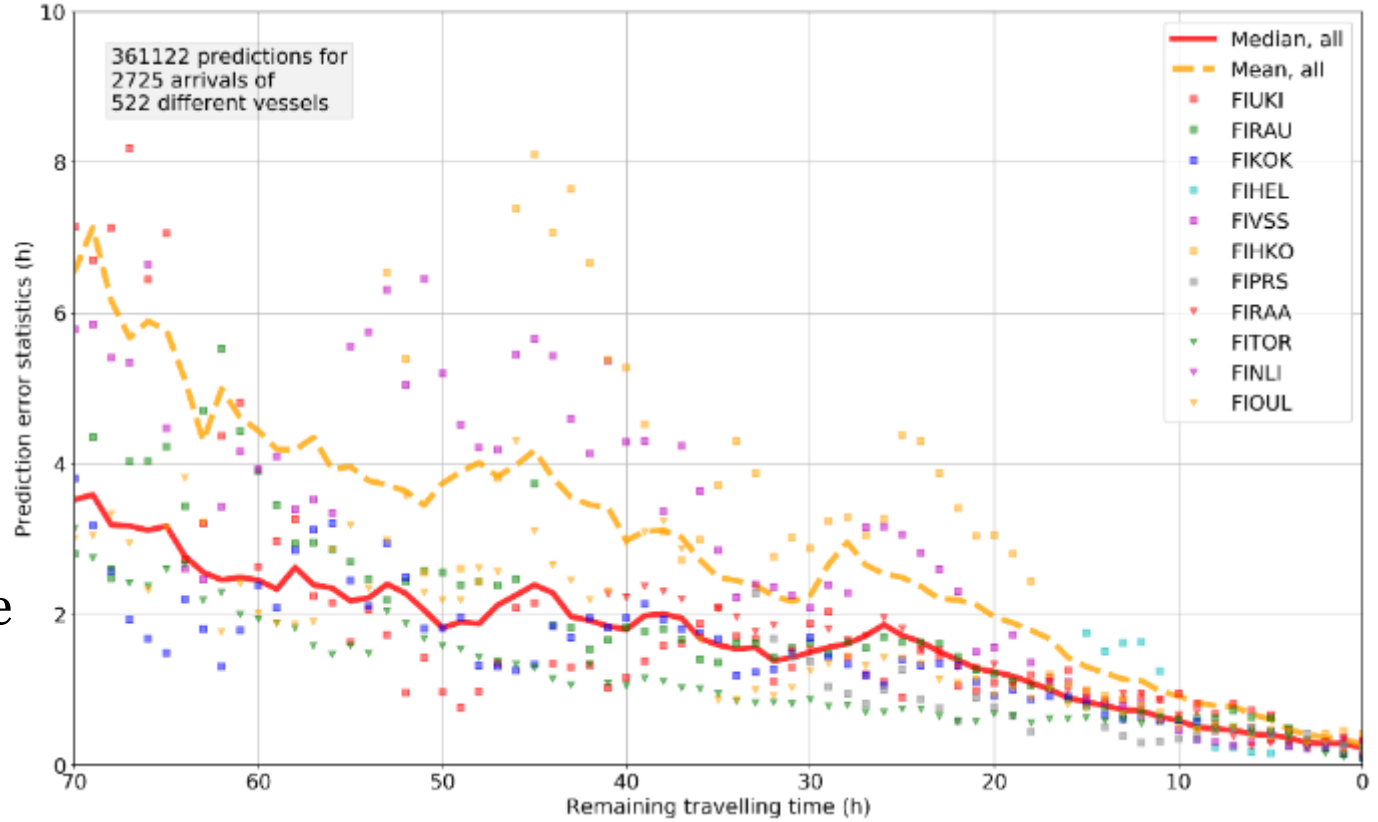
- **Solution**: A machine learning based system which monitors incoming traffic for all ports in the Baltic region, providing schedule predictions and up to date traffic events. *Integrates global vessel data with regional port call plans, weather information, etc.*

- **Beneficiaries**: Port operations planners and coordinators (e.g. terminal operators, agents, port authorities), port service providers (e.g. towage, pilotage), cargo owners, land transport operators

Nation wide maritime data solution in Finland: Port call estimation and time stamp service

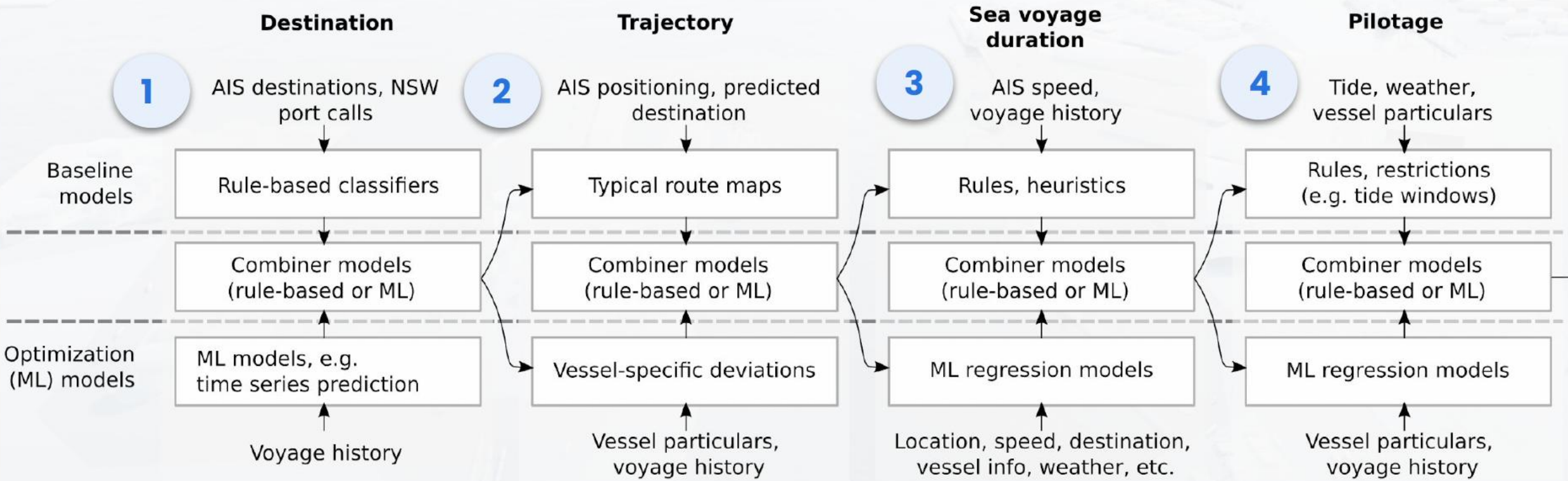
Time data forecasting service – at deployment phase

- Time data forecasting service calculates ETA forecasts for commercial transport vessels entering Finnish ports (ETB berth)
- In the future, ETA forecasts of the arrival of vessels at pilot sites will also be included in the service
- Time forecasts are calculated for vessels that are constantly on the move in focus (continuous distance)
- New forecast data is calculated on every 5-30 minutes, depending on the availability of AIS data



ETA prediction architecture outline

- Modularity allows combining and customizing features as needed
- Ensemble approach allows combining benefits from rule-based baseline and machine learning (ML) optimization models:
  - Baseline models provide explainability, verifiability, and scalability
  - ML models allow optimization for outliers and customer-specific variations

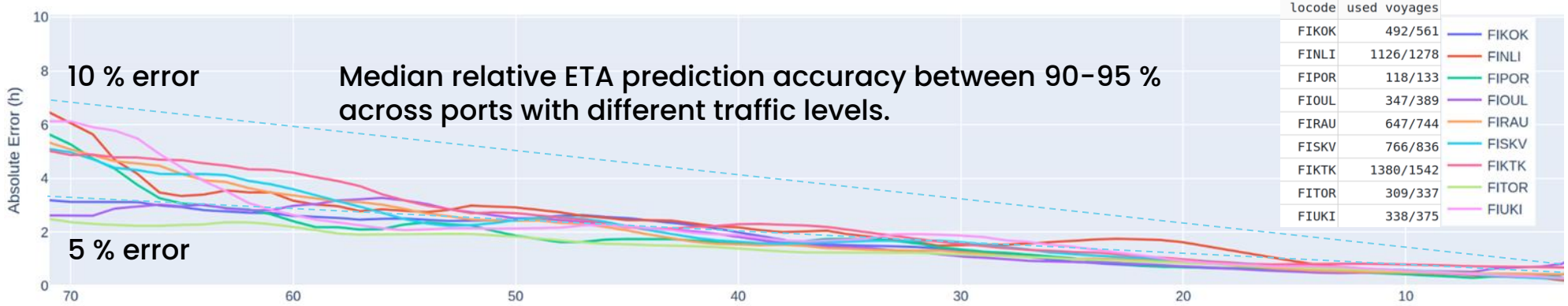


ETA predictions, March 2024 - February 2025

2024-03-01 → 2025-02-09

Filter trajectory outliers

Apply filters | Download data



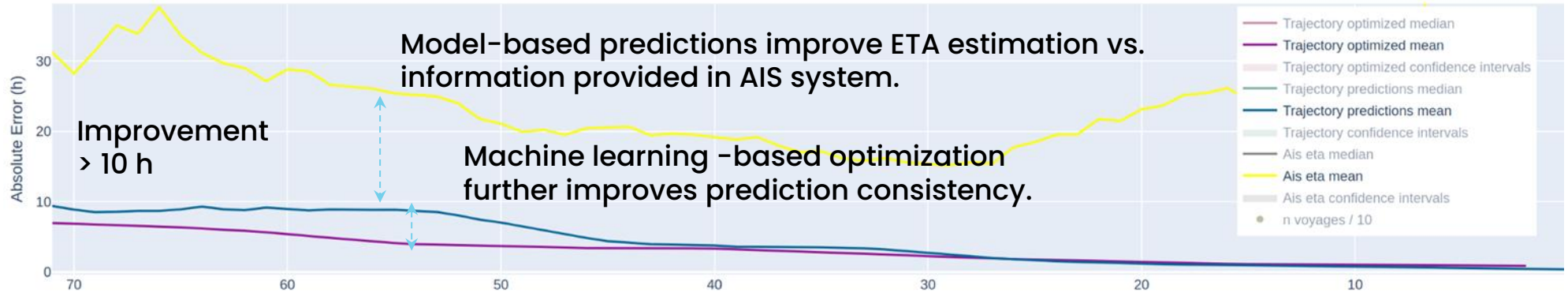
Locode and time selection:

2024-03-01 → 2025-02-09

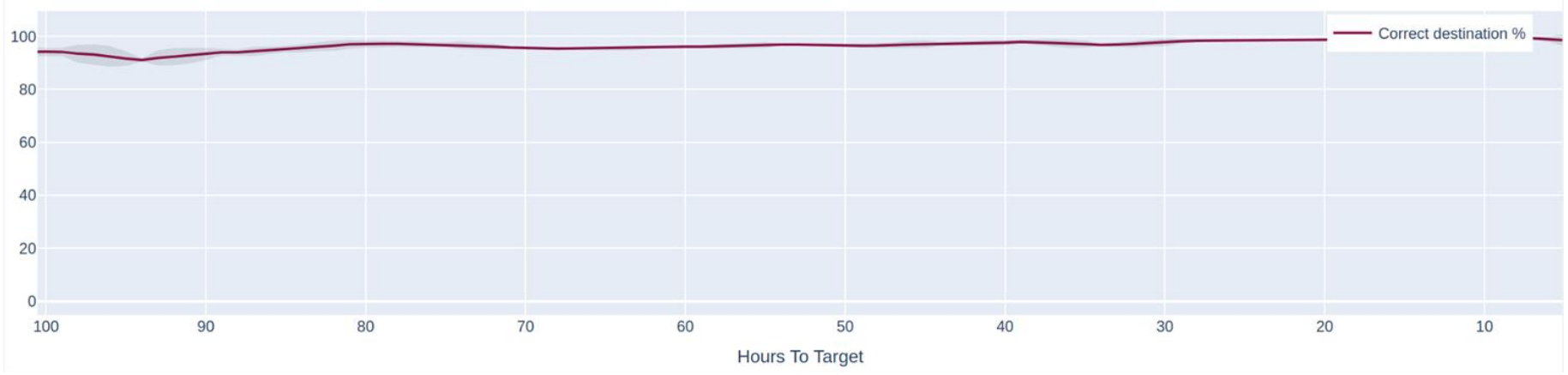
Filter trajectory outliers

Filter ais outliers

Apply filters | Download data

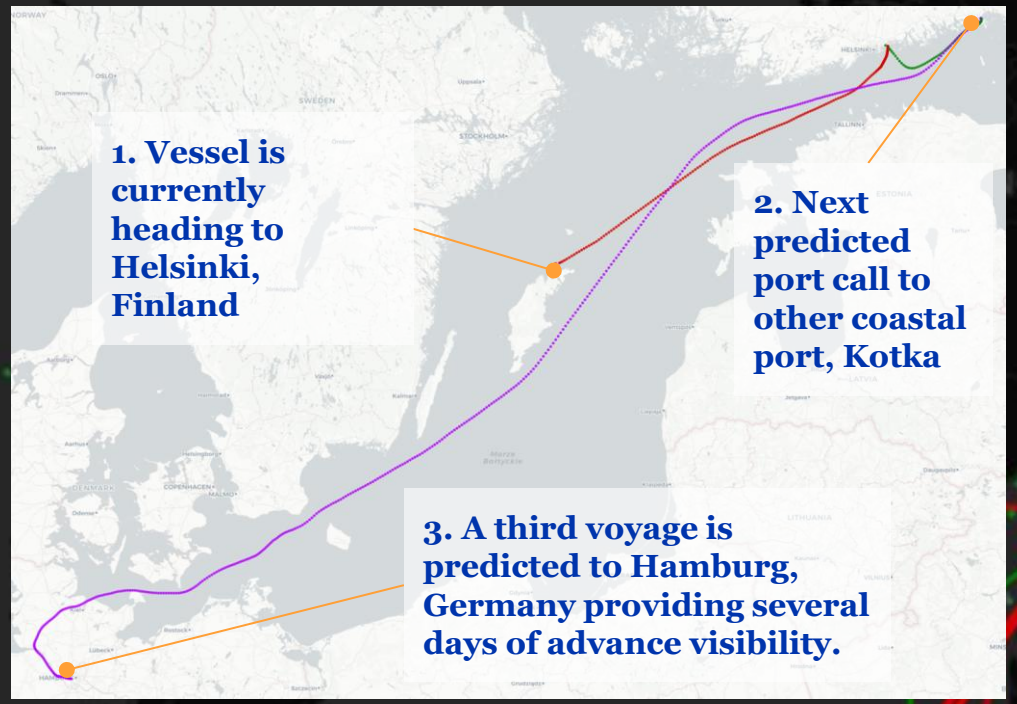


Vessels under way to a selected port can be detected automatically, early, and with high reliability.



Multihop voyage predictions for short sea shipping

By aggregating port call plans from all ports in the region and combining these with vessel-specific voyage predictions, advance visibility of short sea arrivals is extended significantly.



0
1
2
3
4
5

This figure shows a snapshot of cascading voyage predictions for vessels inbound to Finnish ports, multiple port calls ('hops') to the future.

From Ports to Patients – Shared Value Through Trusted Data

The same principles driving digital transformation in maritime logistics — interoperability, governance, and trust

- Both sectors face fragmented data, complex regulation, and cross-border collaboration needs.
- Both build federated, secure ecosystems where data can flow responsibly and create value.
- In maritime, shared data means reduced emissions, improved efficiency, and safer operations.
- In health, shared data means better outcomes, innovation, and sustainability.

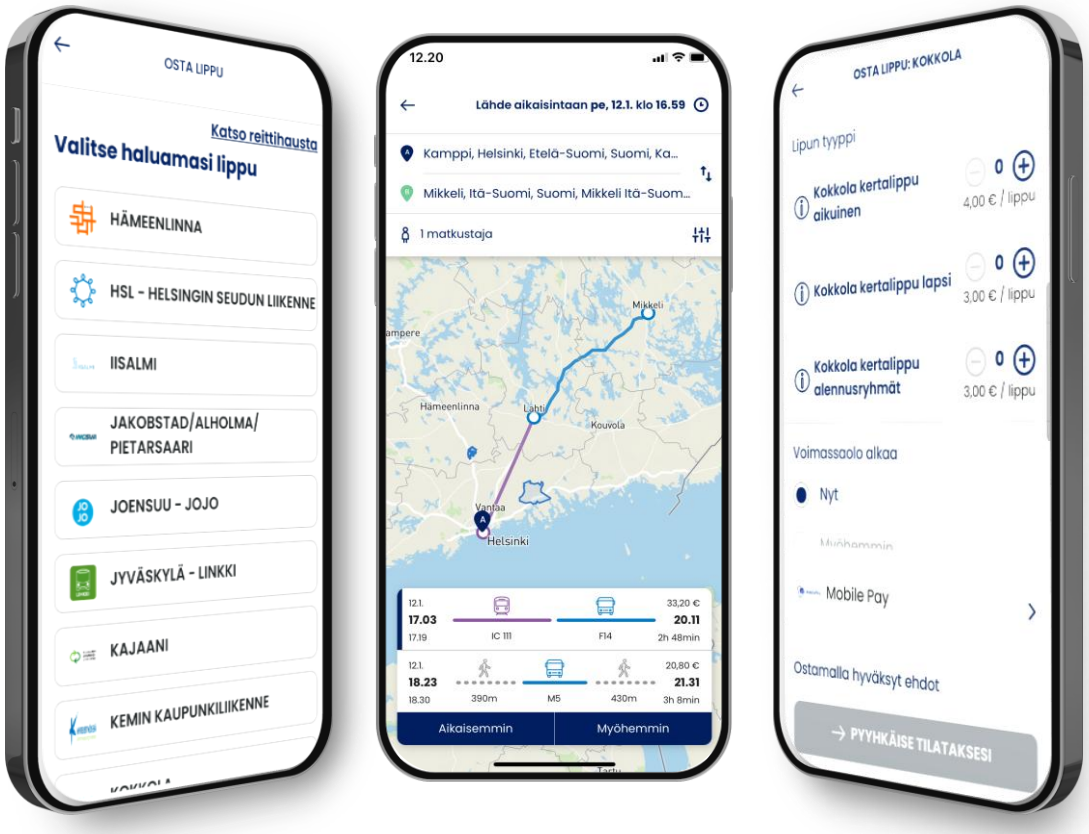
When data moves safely and meaningfully, societies move forward — by sea and by health.


Thank you

Case 2:
Multimodal, cross-border mobility

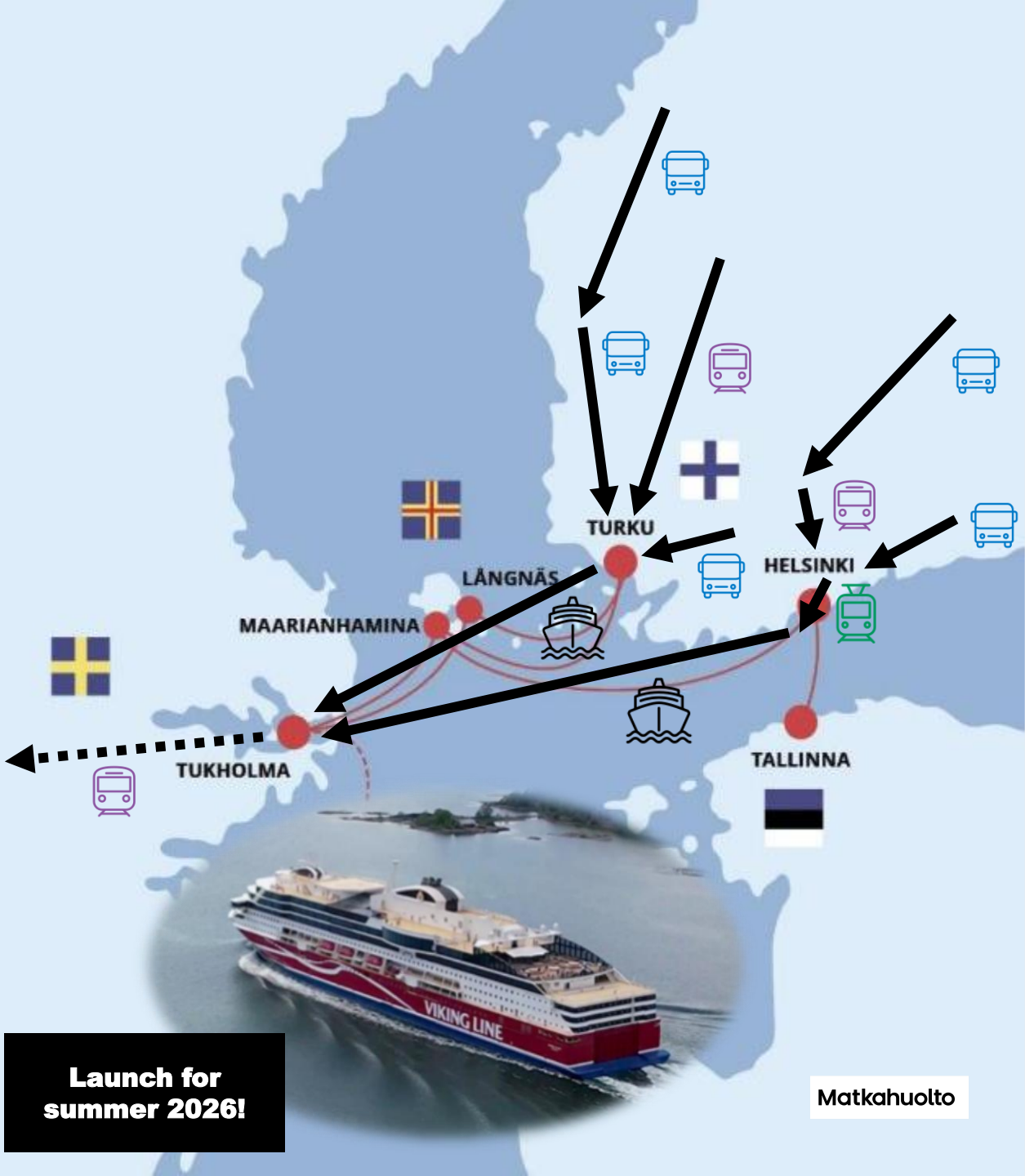
Trips and Tickets app – all public transport in Finland

- Over 500 000 users – 80 000 active monthly
- Routing from address to address using OTP
- Single tickets to nearly all public transport in Finland
- Integrated single ticket systems:
  - Matkahuolto, Onnibus, VR, Helsinki HSL, Tampere Nysse, Waltti (15 city regions), Vinka DRT platform
- Matkahuolto's ticket system:
  - Single, season and serial tickets for regional services
  - Single tickets for long distance bus services
  - Subsidised tickets for students and pupils
  - Nationwide serial tickects for buses
- Several payment methods (incl. employee benefit)
- Billing service for organisations

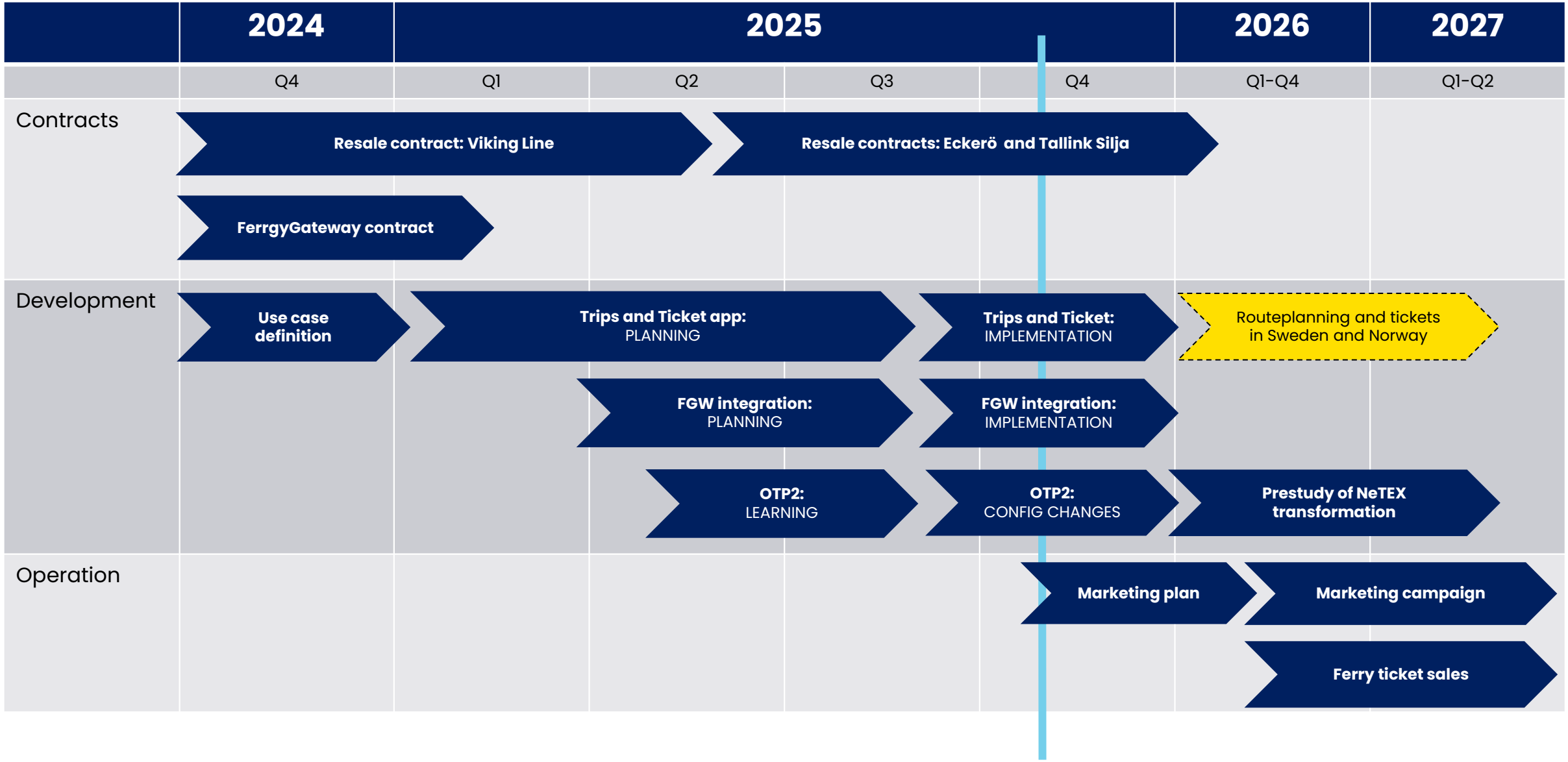


In the NEMU project Matkahuolto adds ferry services to Trips and Tickets app

- For people living in Finland travelling to Sweden, Åland, Tallinn and back.
- Contracts:
  - FerryGateway, the API provider (signed)
  - Viking Line (signed)
  - Eckerö and Tallink (in negotiation!)
- During the NEMU project Matkahuolto tries to find out whether facilitating Nordic cross border ground based travel chains can be a business.
  - Who is willing to pay for the travel chaining?
  - Enough to get return on investment?



Matkahuolto NEMU schedule



Closing

- “Health and traffic share the same DNA — both are about saving lives.”
- Collaboration beats control.

Contact US!

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Thank you!

Funded by the Nordic Council of Ministers

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