

Event begins at 09:00 (CEST)

**NORDIC
HEALTH
DATA
SUMMIT**



Funded by the
Nordic Council
of Ministers



Norwegian Institute of Public Health

SITRA



NORDIC HEALTH DATA *SUMMIT*



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Welcome!



Mikael Rinnetmäki
Specialist, The Finnish
Innovation Fund Sitra



Håvard Kolle Riis
Project Owner EHDS, Norwegian
Institute of Public Health



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AGENDA

09:00	Opening session	13:45
09:25	Session 1: Advancing EHDS – lessons from VALO	
10:25	Session 2: Building a stronger Nordic health data region – from vision to implementation	15:45
11:25	Coffee break	16:05
11:45	Session 3: Unlocking cross-border use of health data – lessons from a Nordic SPE pilot	17:05
12:15	Q&A and discussion	17:15
12:45	Lunch	18:15

Live stream ends

Session 4: NOR-OMOP and Nordic-Baltic OMOP – building blocks in the Nordic health data landscape

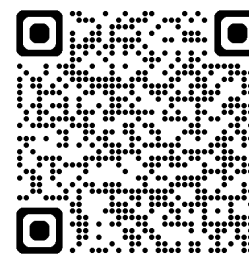
Coffee break

Session 5: Status and possibilities for Norwegian health data

Closing session

Networking reception

Event ends



View the agenda



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OPENING SESSION



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Opening address

Ellen Rønning-Arnesen

State Secretary

Ministry of Health and Care Services (NO)



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Greeting from the Nordic Council of Ministers

Karen Ellemann

Secretary General

Nordic Council of Ministers



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Thank you!



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Question wall

- Submit questions during sessions 1–3.
- Indicate clearly which speaker your question is directed to.
- You can submit multiple questions.
- Vote for up to 4 questions you want answered.
- We'll address the top-voted questions live during the Q&A session at 12:15 CEST.

Join via **menti.com**, code: **4320 6979**
or by scanning the QR code



SESSION 1:

Advancing EHDS – lessons from VALO



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EU health policy landscape

Markus Kalliola

Programme Director

The Finnish Innovation Fund Sitra



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The three drivers in EU health policy

1 ACCELERATE

Innovation & scale

Biotech Act
AI and health data

2 SIMPLIFY

Rules & pathways

Digital Omnibus
MDR / IVDR reform

3 SECURE

Resilience & autonomy

Cybersecurity
Supply chains & geopolitics

From what to regulate to how to make regulation work

EUROPEAN BIOTECH ACT

Scale health biotechnology

- Connect R&D, manufacturing and finance
- Facilitate AI, data and digital solutions
- Shorten time-to-market
- Keep biosecurity and trust in the frame

“Over the last six years, 66 out of 67 EU biotechnology companies that went public chose to list on non-EU stock exchanges”

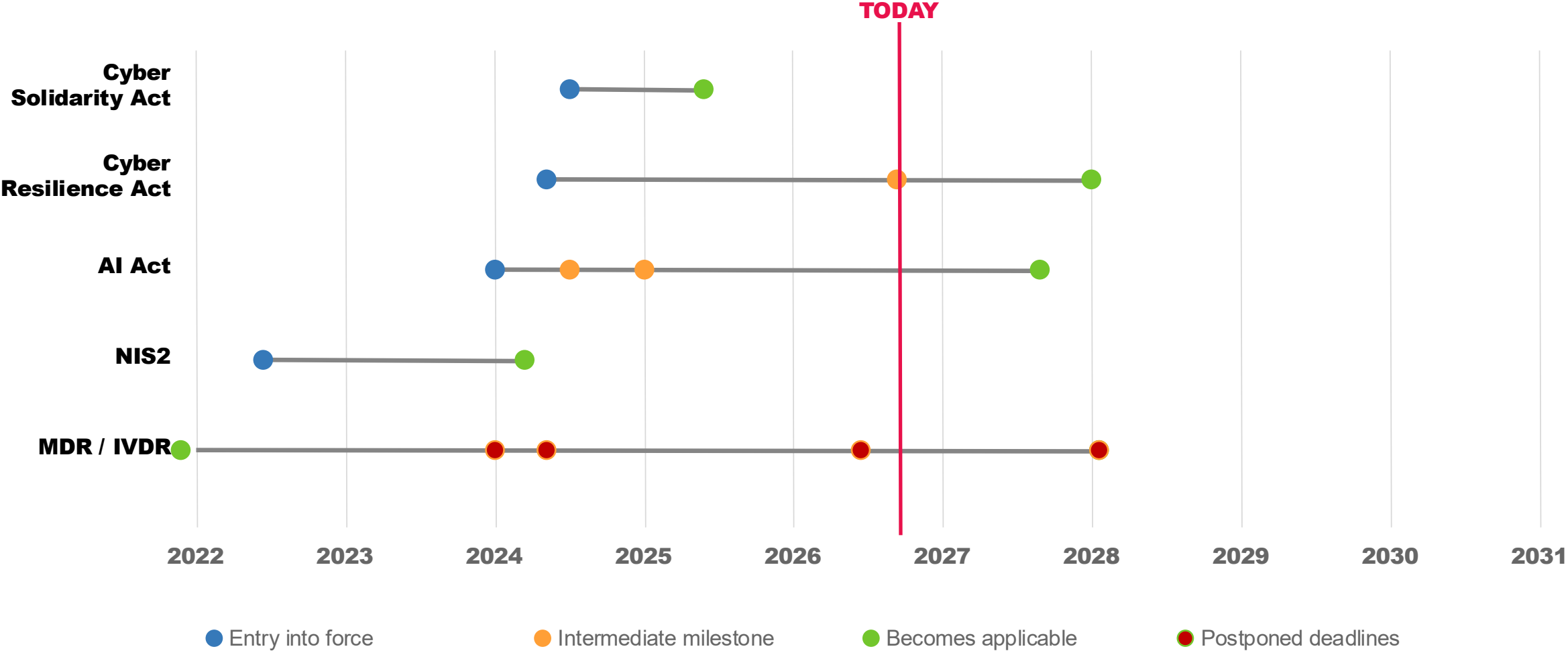
DIGITAL OMNIBUS + MDR/IVDR

Reduce friction, avoid duplication

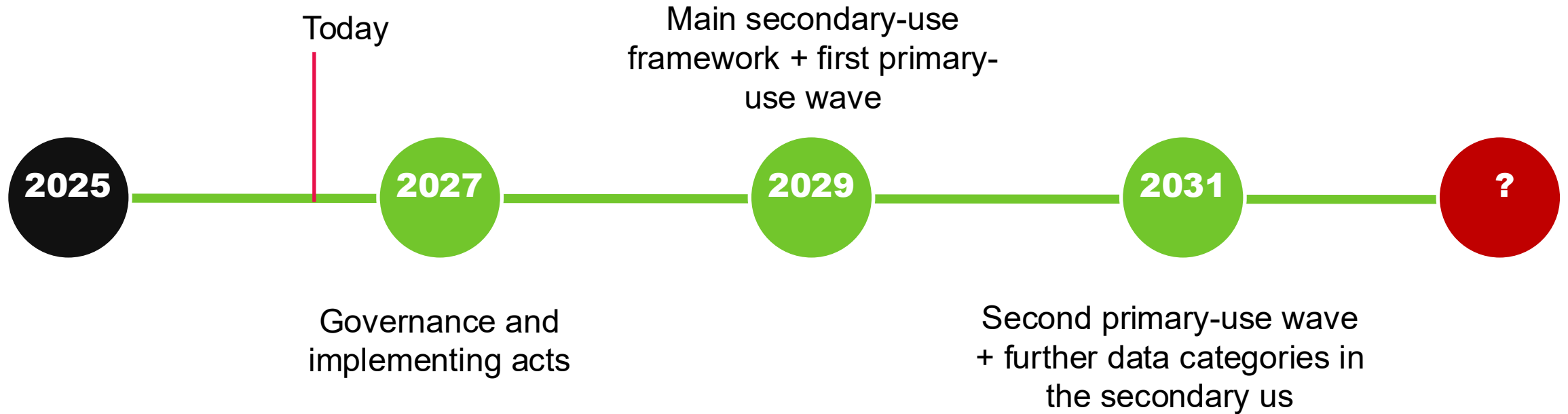
- Align horizontal AI/data rules with sector law
- Address bottlenecks and administrative burden
- Protect device availability

Risk: Simplification sets a precedent that shapes expectations around future regulation among others EHDS. The expectation of future changes weakens implementation efforts today, making delays more likely tomorrow.

Towards safer healthcare



EHDS: the implementation has started



VALO1&2: created a trusted peer exchange and piloting to support EHDS, but did we stop before the fun starts?

Policy risk is now a delivery risk

EU4Health deadlock

2026 work programme has yet secured the required Member State majority

Funding delays and uncertainty for health projects

US “Most Favoured Nation” pricing

External price referencing can transmit pressure across markets

Launch sequencing, access and pricing spillovers

Geopolitical risks

Trade, sanctions and also crises that risk critical supply chains

Medicines, devices, components and data services exposed

Regulatory simplification

Parallel reforms can reduce burden but create transition ambiguity

Implementation capacity becomes strategic

Can we build resilience in the Nordics together?



VALO showed what Nordic co-operation can do

For two and a half years, you have turned regulation into shared learning, practical implementation and mutual support.



**THANK
YOU**

This model should be repeated:

in health policy and beyond.

Congratulations to everyone who made VALO and VALO2 possible.



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The Value from Nordic Health Data (VALO) project

Mikael Rinnetmäki

Specialist

The Finnish Innovation Fund Sitra



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*The Nordic Region will become
the most sustainable and
integrated region in the world
by 2030*

- Nordic Prime Ministers (Reykjavik declaration 2019)



Goals of the Nordic Council of Ministers for Digitalisation for 2025–2030

- Goal 1: The Nordic-Baltic region is a front runner in realising the digital and green transition.
- Goal 2: The Nordic-Baltic region is secure, connected, and integrated.
- Goal 3: The Nordic-Baltic region is secure, inclusive, and promotes a human-centric digital transformation to ensure resilient societies.

VALO pursues the same goals in secondary use of health data



VALO Objectives

1 Strengthen Nordic co-operation in the secondary use of health data

2 Prepare for the European Health Data Space legislation in the Nordic countries

3 Showcase results by piloting a Nordic federated analysis use case



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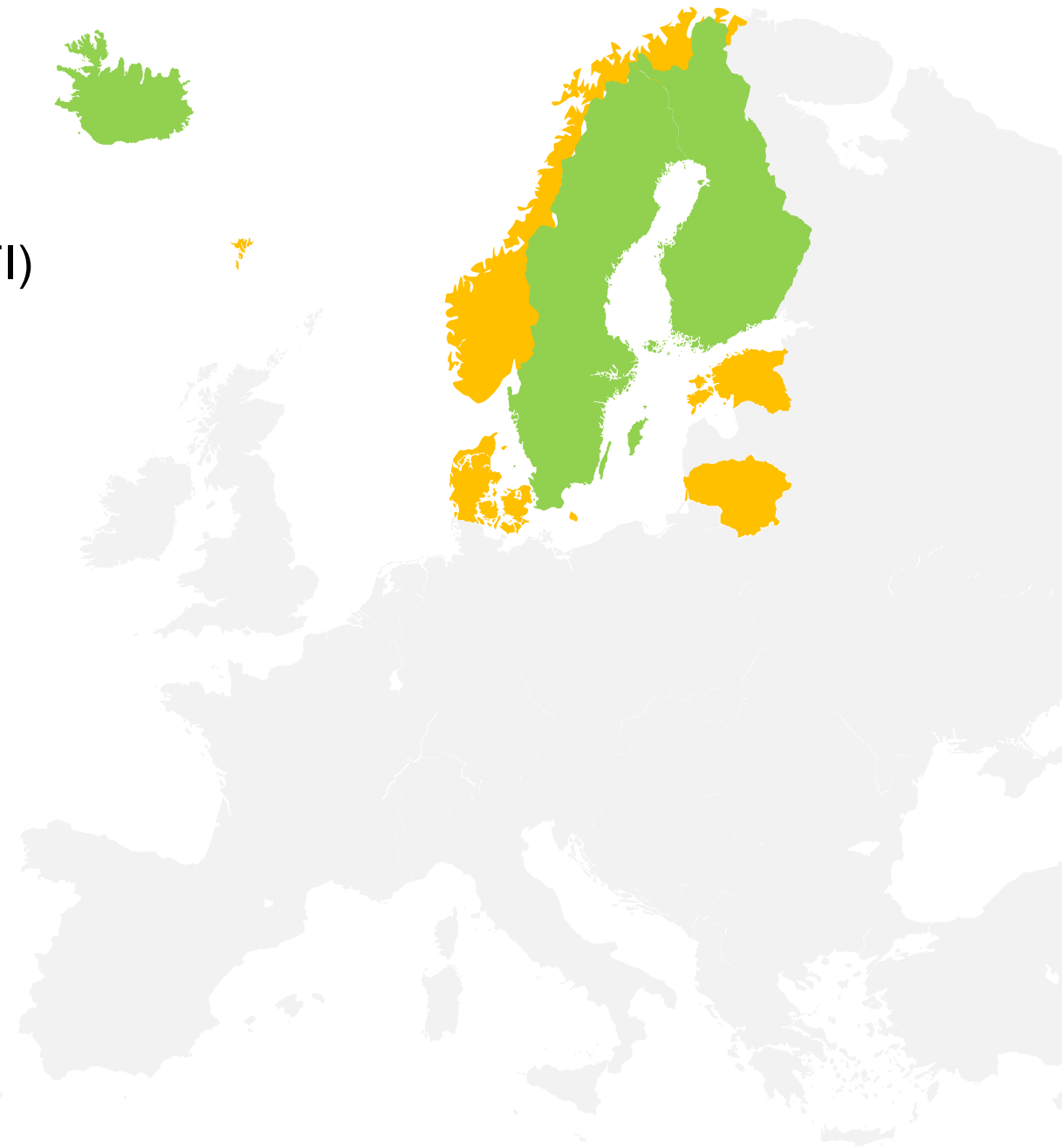
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PARTNERS

- Ministry of Social Affairs and Health (FI)
- THL - Finnish Institute for Health and Welfare (FI)
- Sitra, The Finnish Innovation Fund (FI)
- Ministry of Health (IS)
- Directorate of Health (IS)
- University of Iceland (IS)
- Ministry of Health and Social Affairs (SE)
- The National Board of Health and Welfare (SE)
- Swedish eHealth Agency (SE)

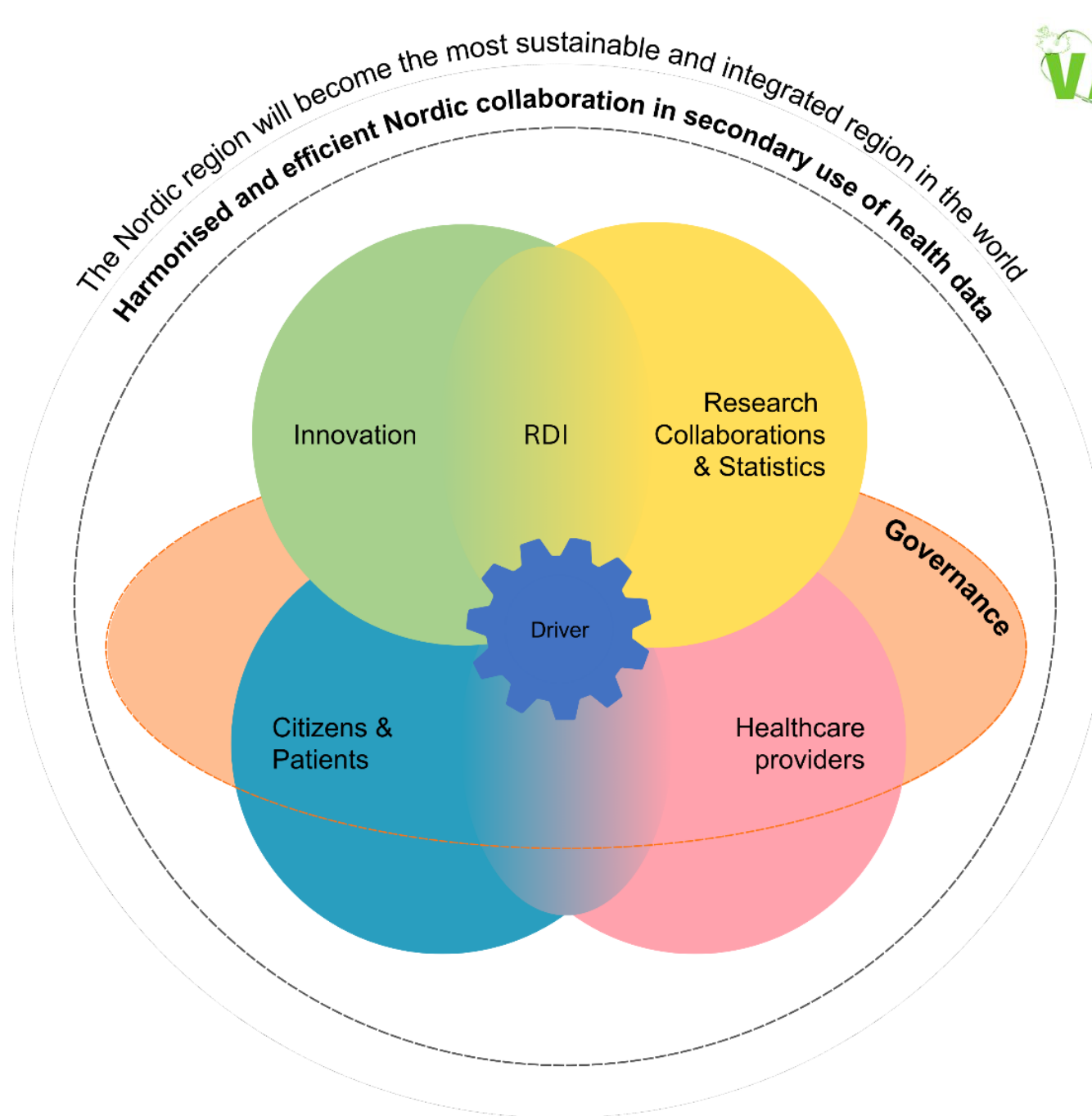
OBSERVERS

- Denmark
- Estonia
- Norway
- Lithuania



Nordic model for collaboration on secondary use of health data

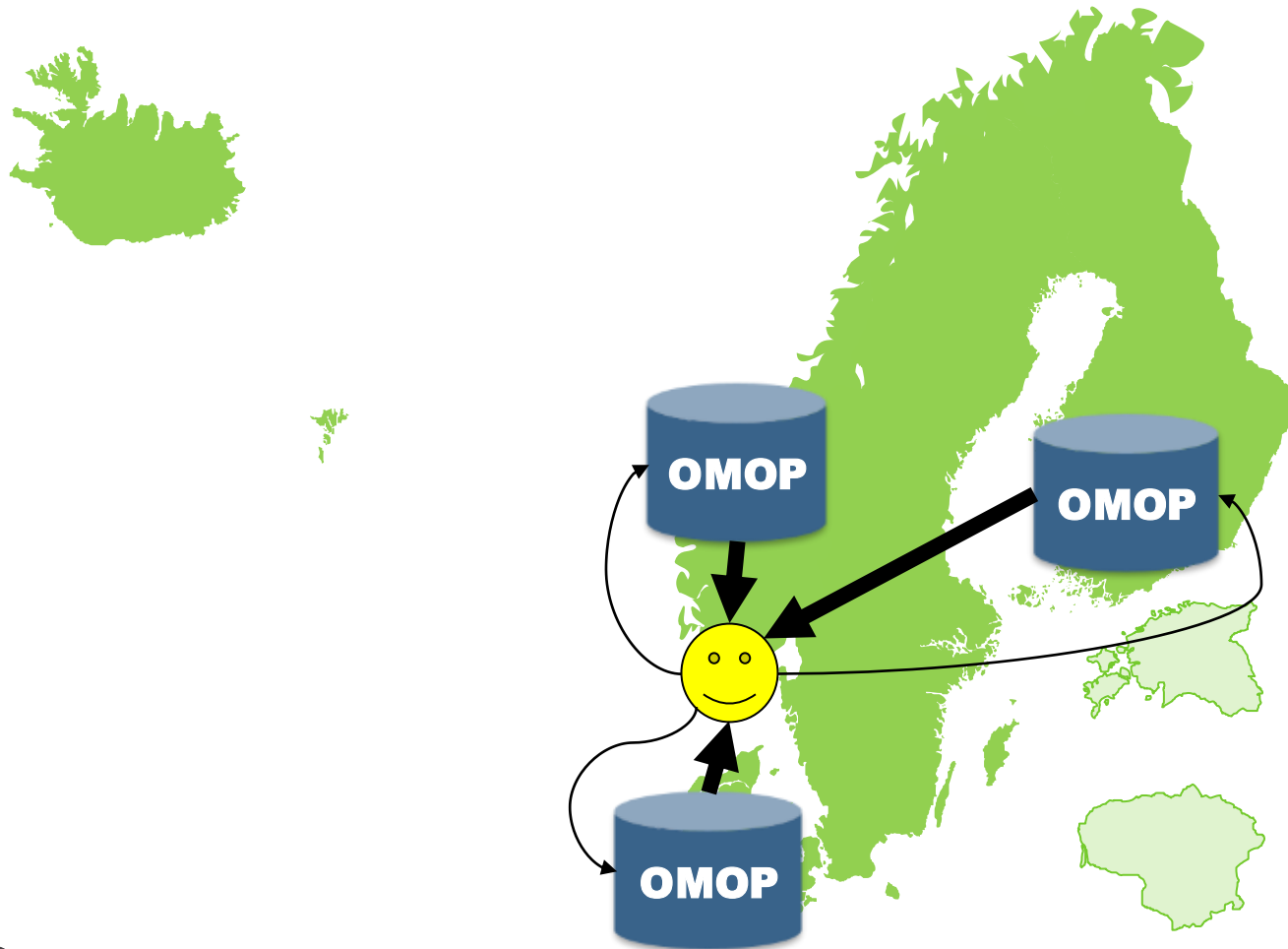
- *Proposal*



EHDS2 Competence Forums



VALO Pilot Study: Federated Data Analysis





Pohjoismaiden
ministerineuvoston
rahoittama

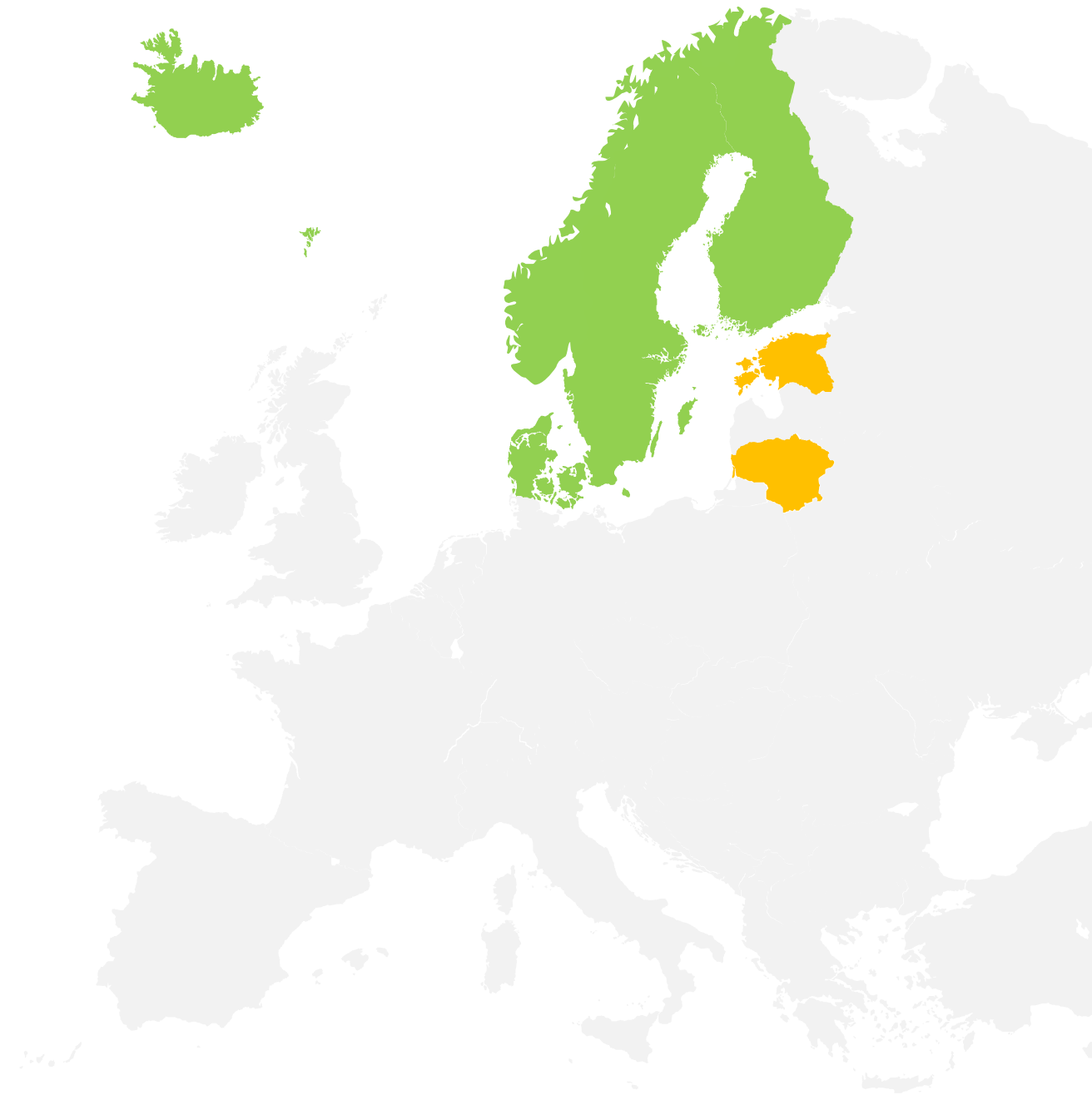
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PARTNERS

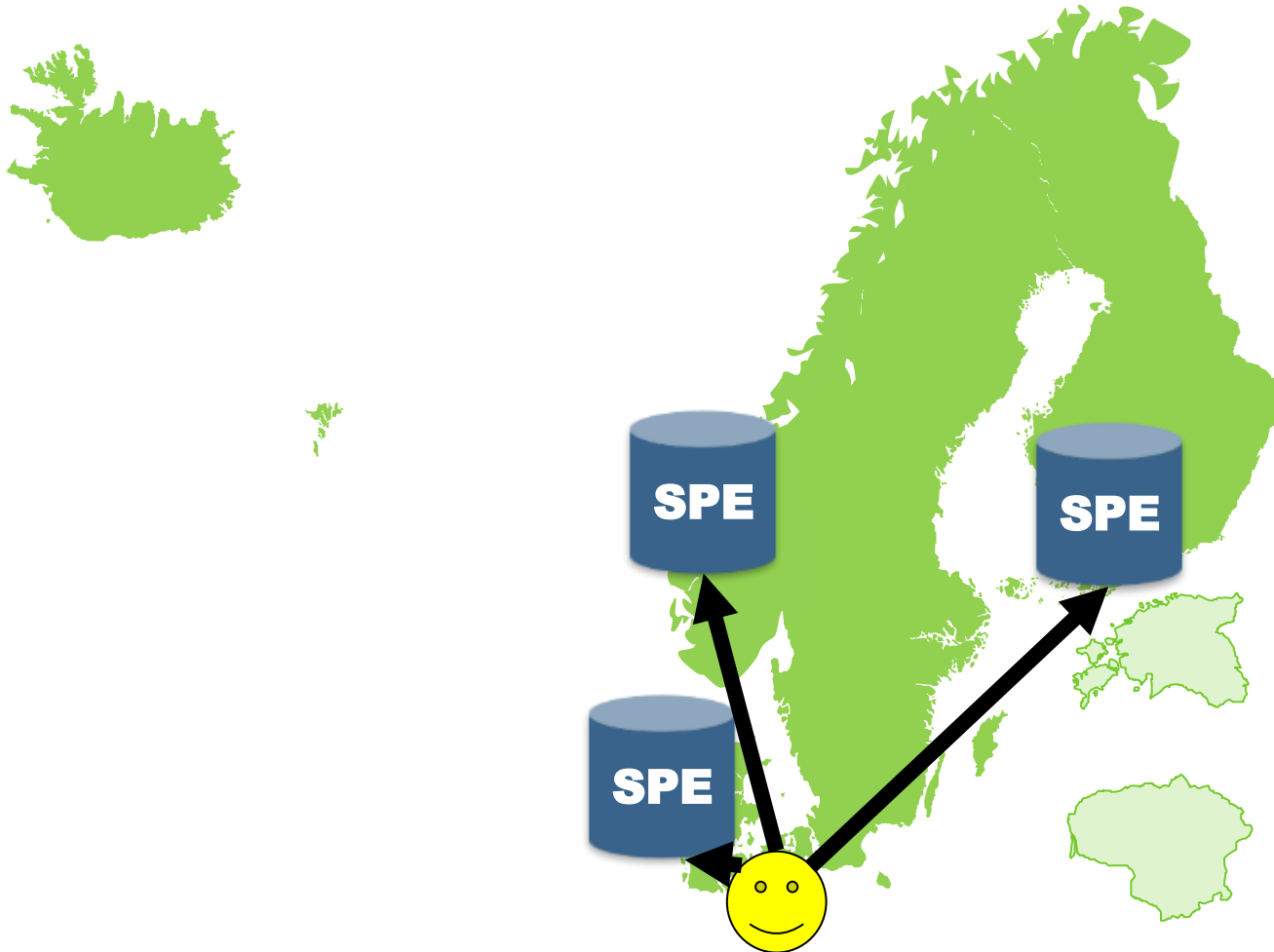
- Denmark
- Finland
- Iceland
- Norway
- Sweden

OBSERVERS

- Estonia
- Lithuania



VALO2 Pilot Study: Remote Access to Secure Processing Environments



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Find out more!

sitra.fi/valo



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@SitraFund



@Sitra **in**



Nordic preparations for the EHDS



Michel Silvestri

Senior Adviser,
Swedish eHealth Agency



Mari Mäkinen

Senior Specialist, Finnish
Institute for Health and
Welfare



Jenina Soimala

Lawyer, Finnish Institute
for Health and Welfare

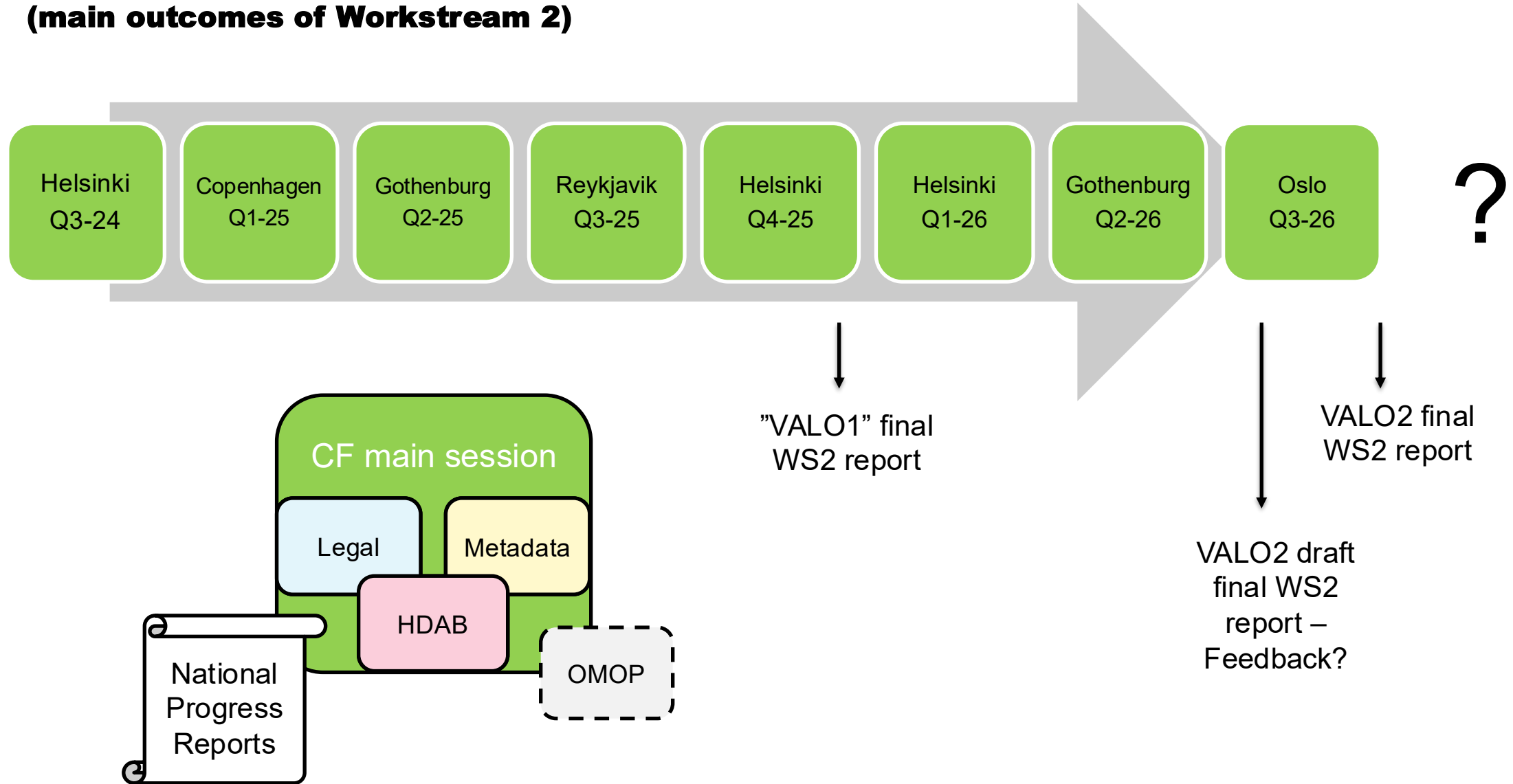


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The Competence Forum concept

(main outcomes of Workstream 2)





Conference

CONFERENCE RECEPTION
CORNER
GOTHIA TOWERS RECEPTION
HEAVEN 23
TWENTYFOURSEVEN
UPPER HOUSE / BAR / SPA
WEST COAST
P → TOWER 1

The Competence Forum concept

(main outcomes of Workstream 2)

- Limited target group (government ministries and agencies)
- **Trusting environment**
- Information & experiences – avoid "inventing the wheel..."
- "EHDS2/HDAB networking" – and benchmarking
- Harmonisation (direct/indirect)
- User Journey – bottlenecks – and recommendations how to avoid them!
- Breakout sessions and work groups:
 - HDAB (policy/organisation)
 - Legal (and Ethical)
 - Metadata



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Metadata work in VALO

1

Continuation of previous Nordic co-operation.

2

Increased importance of metadata with EHDS, including common metadata specification HealthDCAT-AP and data quality and utility label.

3

Competence Forums and monthly open network meetings.

4

Main aim: Increase understanding of HealthDCAT-AP to support its national implementation.

5

Also increase understanding of EHDS health data landscape in Nordics and other requirements for metadata, like leveraging AI solutions.



Findings & achievements

- 1) HealthDCAT-AP not easy to understand.
 - Gathered questions and needs related to HealthDCAT-AP mandatory properties.
- 2) Nordic health data landscape not yet well known.
 - Started building understanding of EHDS data categories by collecting examples.
- 3) Metadata quality seems to be critical enabler of trustworthy AI use.
 - Started scratching the surface of metadata and AI connections.
- 4) Co-operation is crucial.
 - Shared national progress, learned together and from one another, shared experiences and knowledge.



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Recommendations

- 1) Continue co-operation.
- 2) Take findings in EU discussions in a consolidated manner: need for practical guidance & examples.
- 3) Make rationale visible, include different stakeholders.
- 4) Strengthen understanding of Nordic health data landscape, develop tools for health data holder self-assessment.
- 5) Continue aiming for harmonized implementation when possible.
- 6) Invest in metadata and metadata support to data holders.

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Legal and ethical work in VALO2

- 1 Expert opinions (varying country participation)
- 2 Continued from VALO with updates **v.** onboarding on March 2026
- 3 Competence Forums and monthly online meetings
- 4 Topics/why: relevance and knowledge at the time of working – national leeway **v.** ethical review based on Art. 54(e) EHDS (ethical provisions)
- 5 A trusting and safe testing ground for alternative interpretations and learning



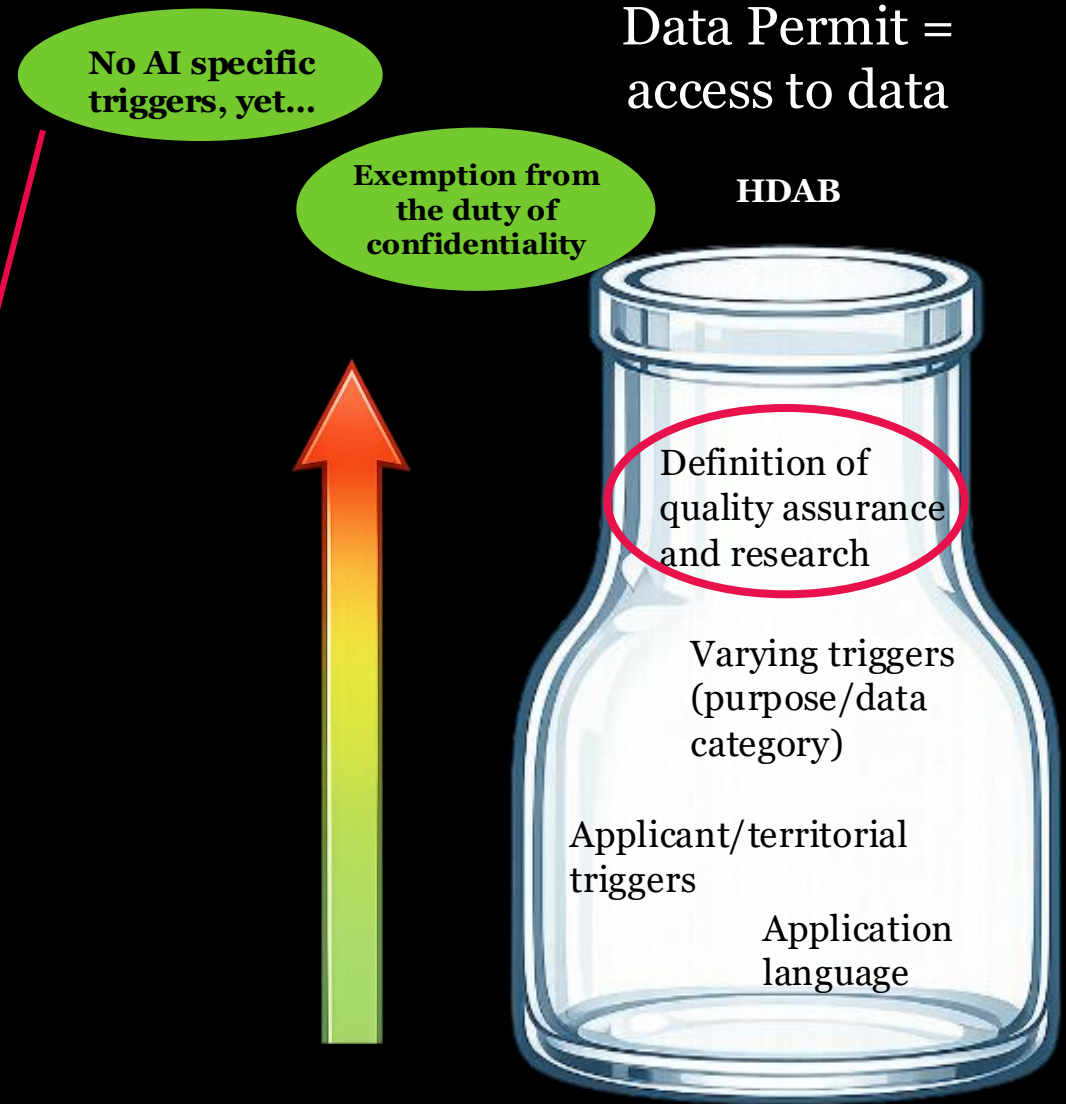
Legal conclusions

- 1 - Consent
- 2 - Opt-out & IPR and trade secrets
- 3 - Definition of a health data holder
- 4 - Health data intermediation entities
- 5 - Significant findings
- 6 - Fees
- 7 - Consideration of ethical aspects under Art. 68(1)(b)



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Ethical conclusions



Quotes from evaluations

What did you appreciate the most?

Breakout
sessions

The breakout
session

Open and
trusted
atmosphere

Candid and
trustful
ambiance

Breakout
session
discussions

Open
atmosphere...

Constructive
climate

Open climate

Did the Competence Forum and its breakout sessions have any impact on your national preparations for EHDS?

Survey answers from
national representatives

Inside and interesting
perspectives

...different perspectives on
EHDS implementation, role and
organization of HDAB...

...a lot of comparative knowledge –
helped to look at the implementation
choices

...valuable arena for exchanging experiences...
...particularly useful - how colleagues in other
Nordic countries have interpreted different
provisions of the Regulation

...helped us establish more international contacts.
...share experiences and learned that countries
interpret certain provisions of the regulation
differently.
...help assess most effective implementation options
for our own country.



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Draft Final report published for feedback

[Nordic Health Data Summit 2026 - Sitra](#)

[VALO2 WS2 Consolidated Final Report v0.9b.pdf](#)

VALO2 Work Stream 2 consolidated final report 2026: *towards a Nordic guide to efficient and secure access to health data for secondary use under the EHDS*

WORKING DRAFT v0.9| September 2026
Pending final title



Events

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FRONT PAGE > EVENT > NORDIC HEALTH DATA SUMMIT 2026

EVENT

Nordic Health Data Summit 2026

On 23 September, the Nordic Health Data Summit 2026 brings together policymakers, experts, researchers, innovators and stakeholders from across the Nordic region and Europe to explore how health data can be used more effectively for research, innovation and better health outcomes.

LOCATION

Oslo Congress Center, Youngs gate 21, 0181, Oslo, Norway
and online

SCHEDULE

Wednesday 23.09.2026 at 08.30-18.00
CEST / UTC+2





What next?

- The needs remain (EHDS2)
- New Nordics / Extended Nordics
- Nordics - Europe win-win
- Consistency and continuity –
A Nordic Model?



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Thank you!

Join the live question wall

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SESSION 2:

Building a stronger Nordic health data region – from vision to implementation



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The Nordic model for collaboration

Rebekka Björg Guðmundsdóttir

Project Manager

Directorate of Health Iceland

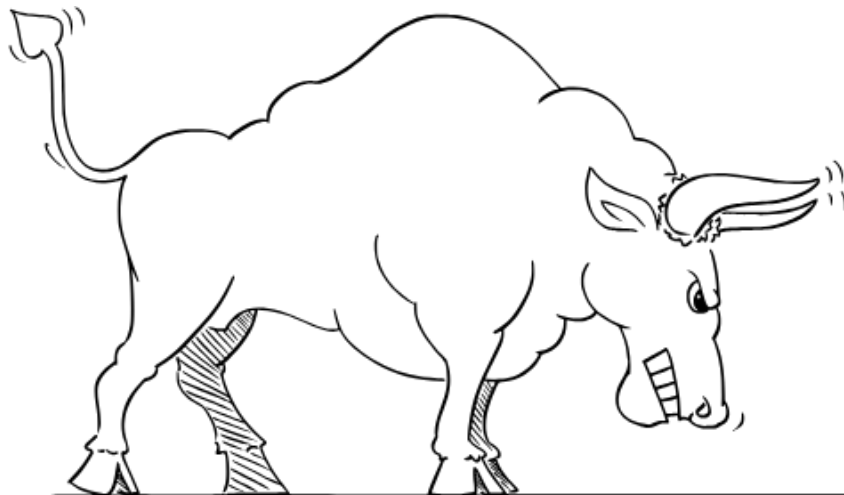


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Nordic Advantage

- Registers
- Personal identification numbers
- Data linkage
- Public trust
- Similar healthcare systems
- Tradition of collaboration



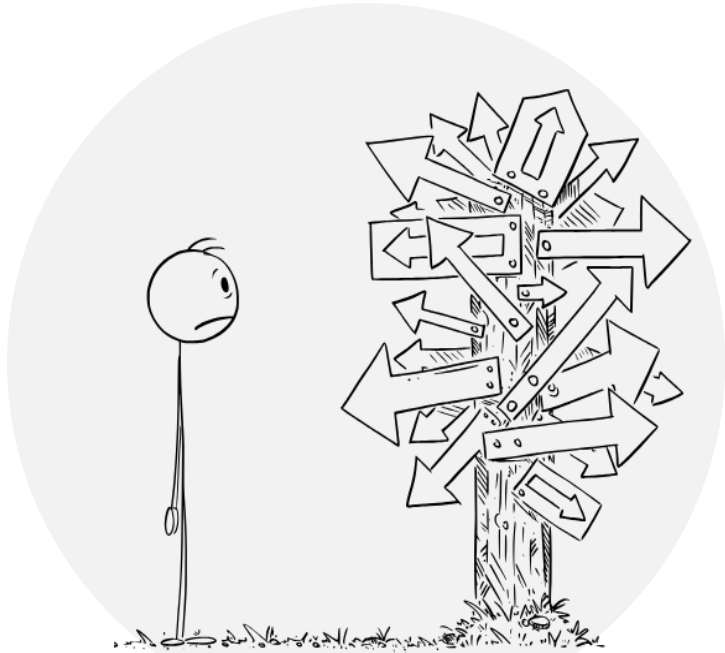
Challenges

- “long and unpredictable timelines”
- “Access time is our single biggest challenge”
- “It’s very rare that we merge data across all Nordic countries – it’s too complicated”

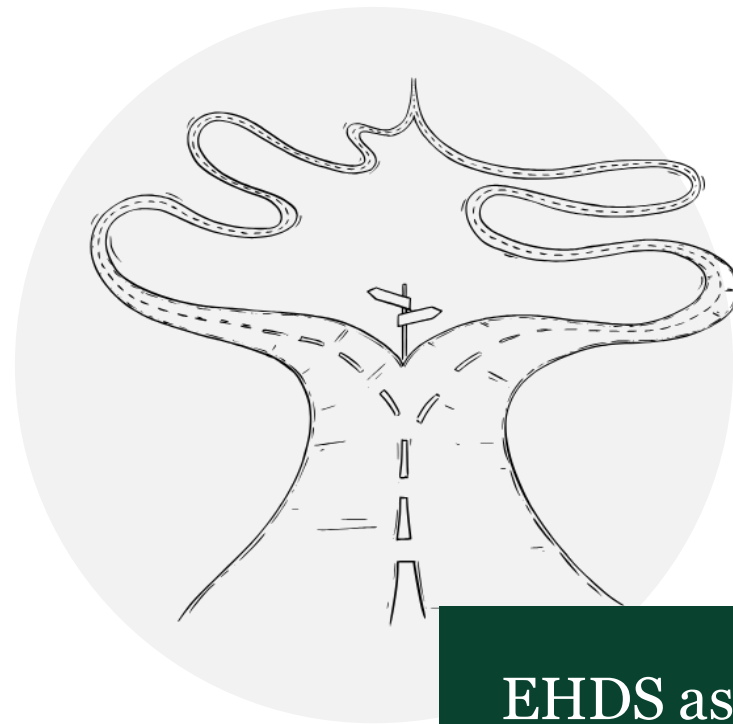


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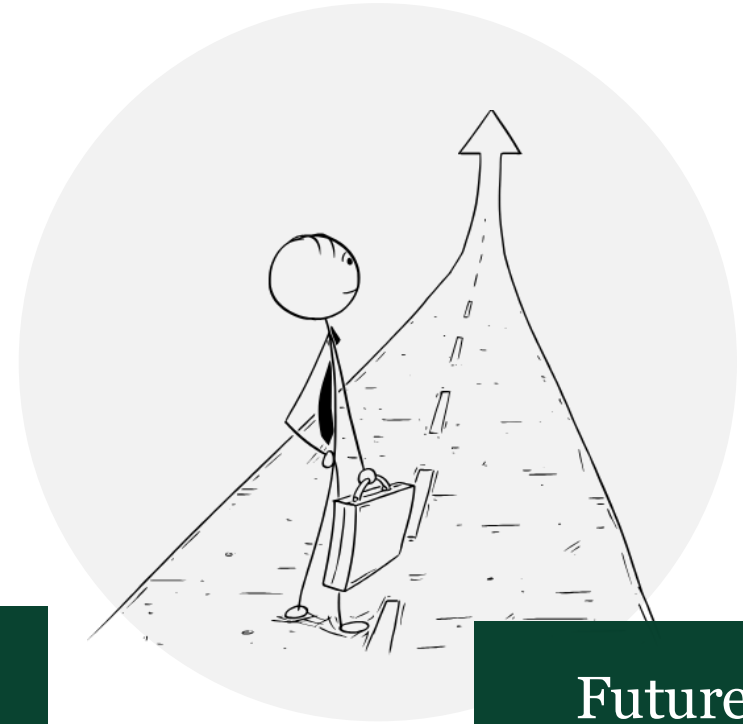
Why harmonise the implementation of the EHDS regulation?



GDPR



EHDS as an
opportunity



Future



A Nordic environment that
**empowers stakeholders to
collaborate** in advancing use of
health data for research,
development, innovation and
policymaking – **to benefit
health and wellbeing, and
economic prosperity.**

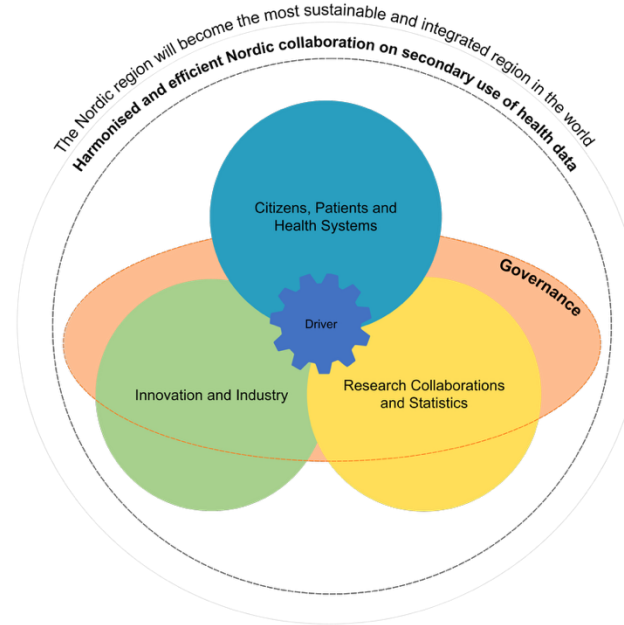


The development of the Nordic model



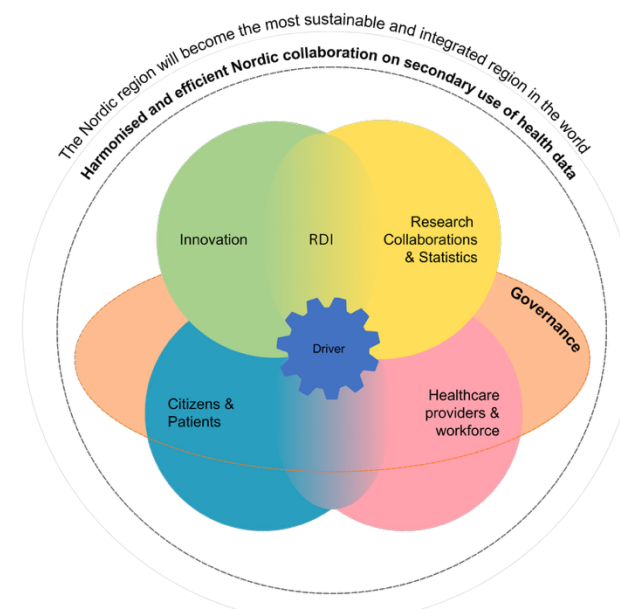
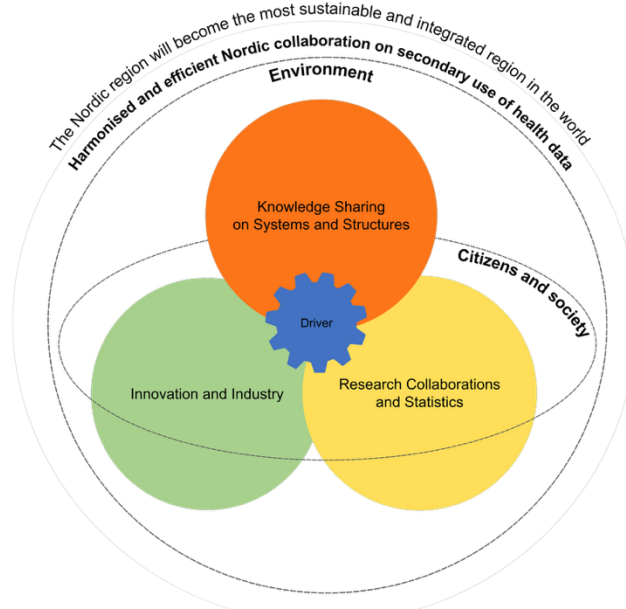
February 2025

December 2025



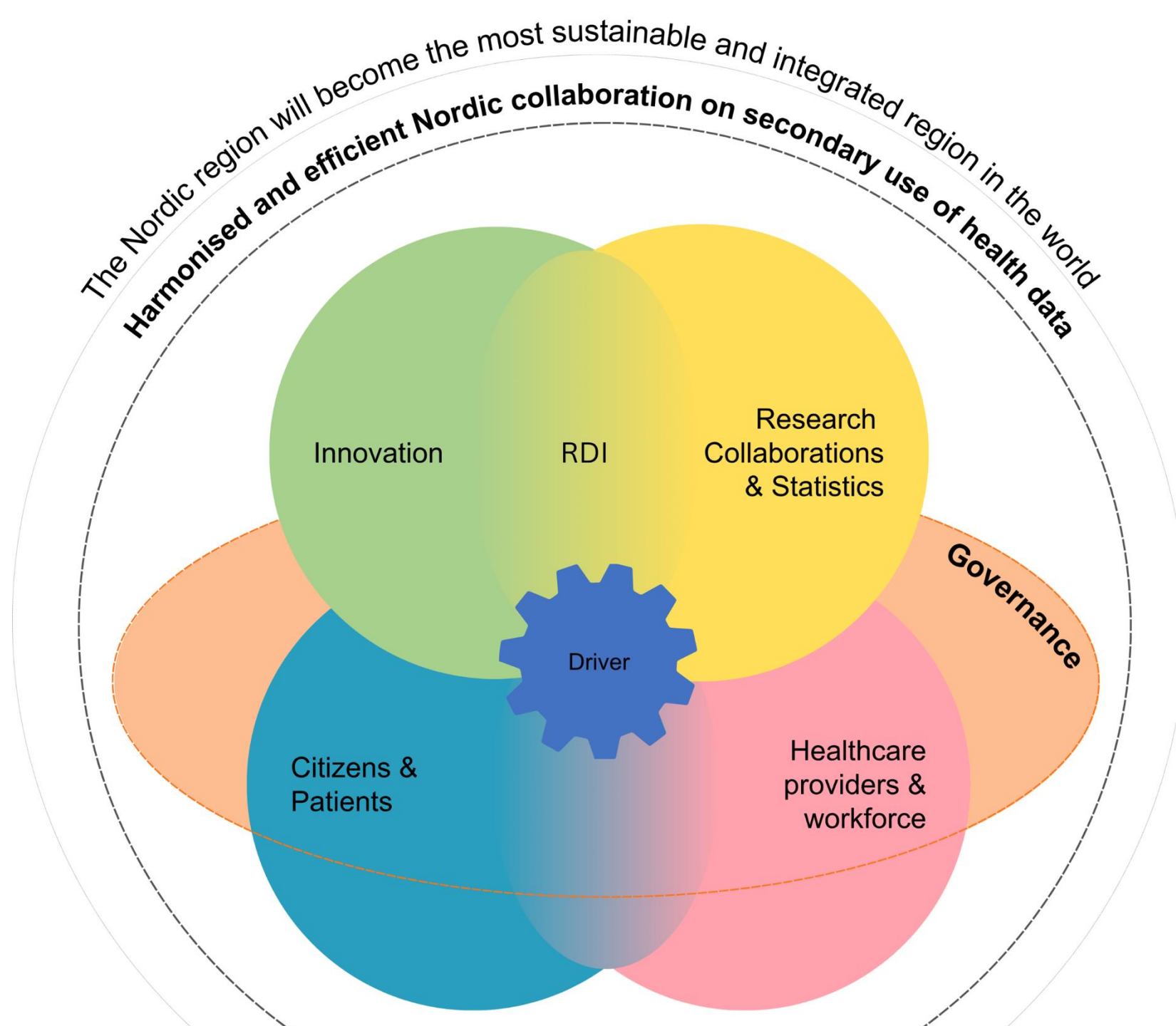
May 2026

June 2026



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The Nordic model



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Policy alignment and implementation

Thematic expert working groups

Nordic Council of Ministers with relevant policy areas and concerned national ministries and authorities

Presidency country

Nordic Health Data Governance Committee



Data infrastructure and interoperability

Access and accountability

EHR standardisation
(Nordic eHealth
Standardisation Group)

Common data
models

Metadata

HDAB

Legal matters

Ethical matters

Recommendations

Recommendation 1

Establish a
Nordic Health
Data Governance
Committee

Recommendation 2

Establish a
permanent
Secretariat

Recommendation 3

Endorse and
resource a
permanent
Nordic Health
Data Competence
Forum

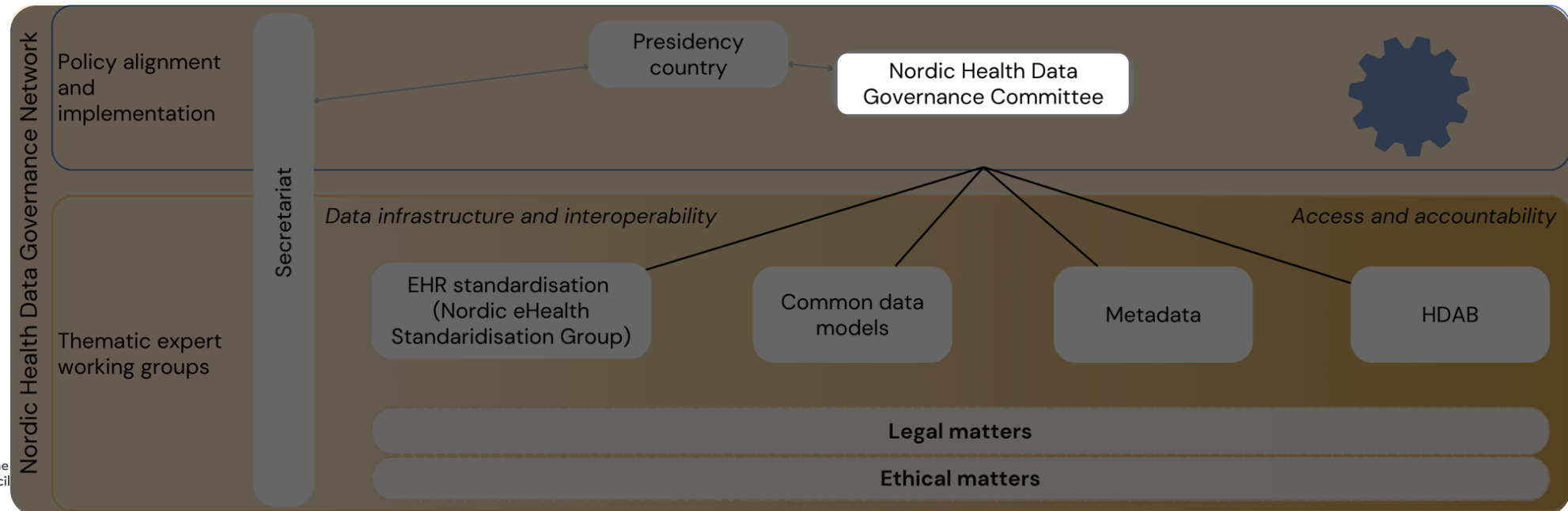
Recommendation 4

Support an
annual Nordic
Health Data
Summit

Recommendation 1

Establish a Nordic Health Data Governance Committee

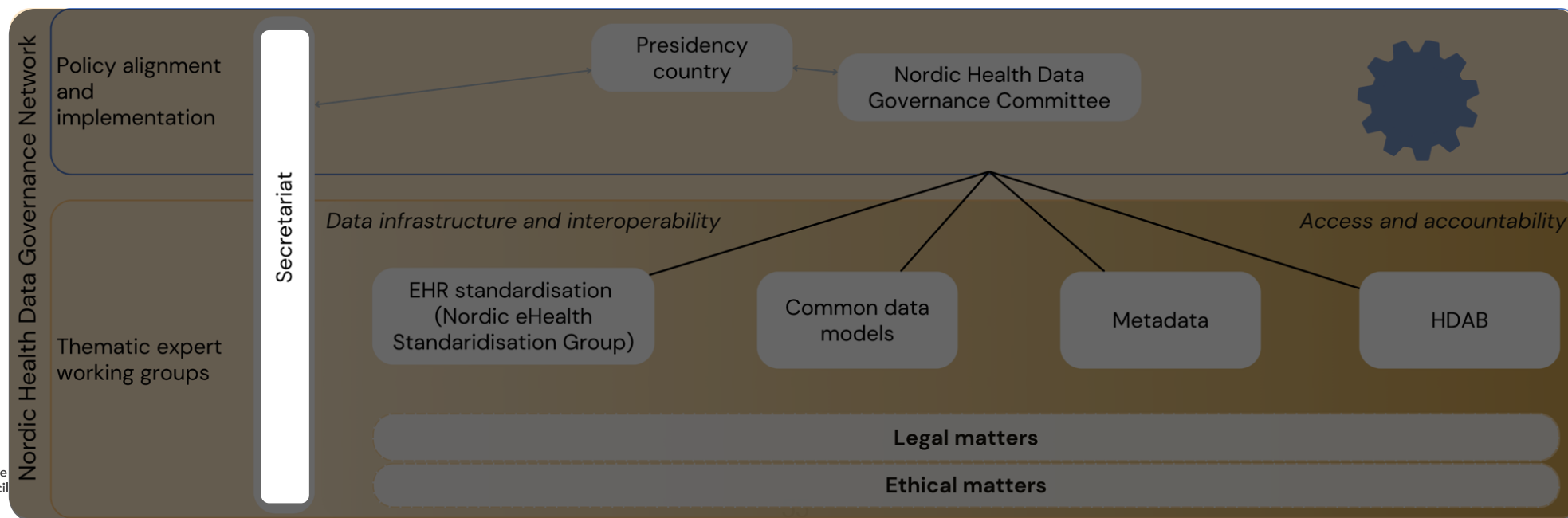
- Builds on the existing NCM eHealth Group
- Sets annual work programme and a shared multiannual roadmap
- Tasks working groups with developing recommendations
- ~10–15 members, meets at least 2x/year, rotating Presidency on the NCM cycle



Recommendation 2

Establish a permanent Secretariat

- Provides institutional memory across rotating Presidencies
- Provides the continuity a rotating Precedency can not sustain on its own
- Prepares Committee agendas and coordinates thematic expert working groups

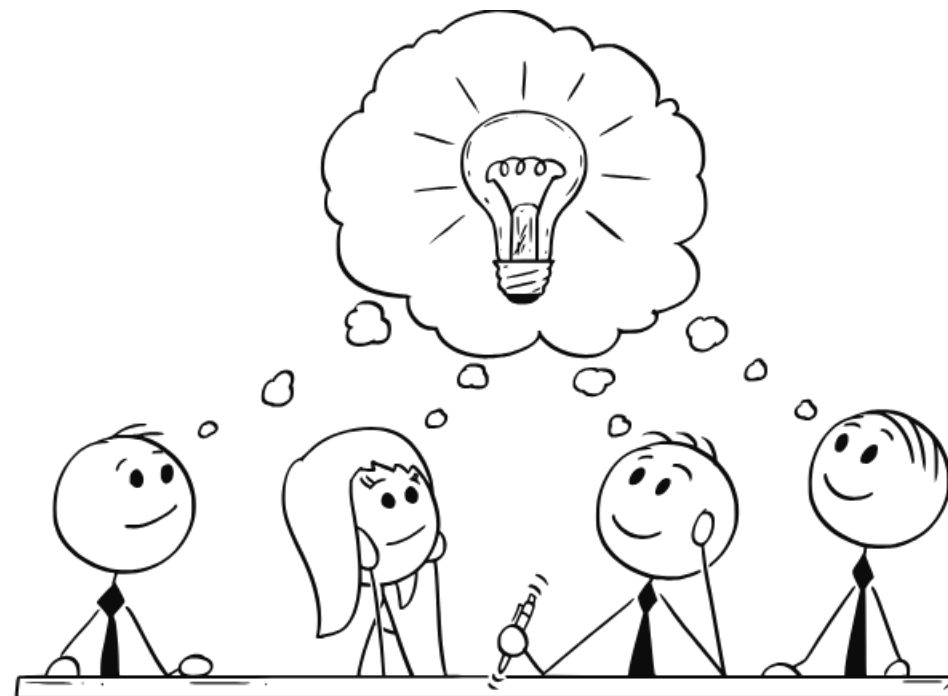


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Recommendation 3

Endorse and resource a permanent Nordic Health Data Competence Forum

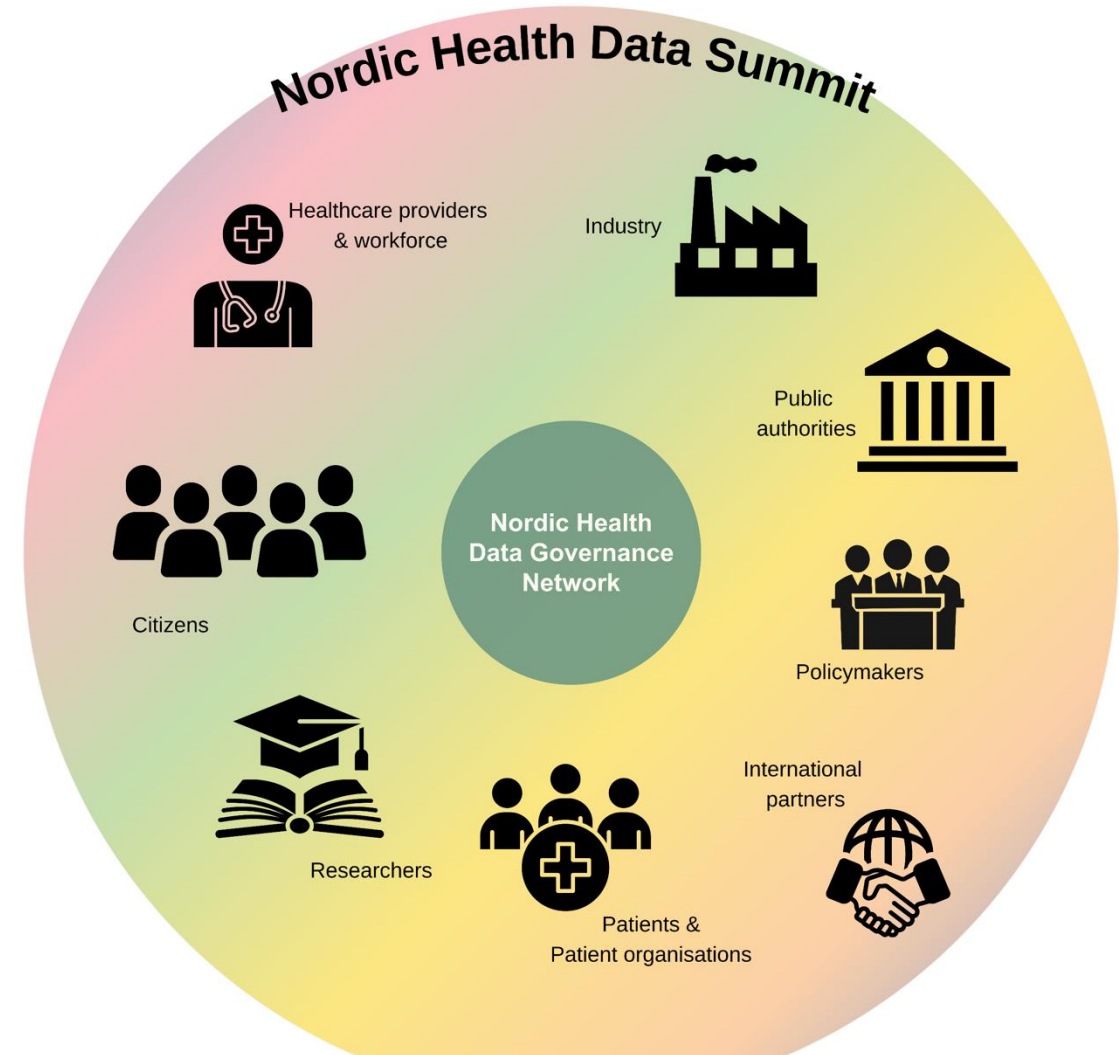
- Already running since 2024 through the VALO project
- Organised as a place where the Nordic Health Data Governance Network and working groups can meet face-to-face and discuss in a trusting environment about relevant topics
- Direct link between Nordic Health Data Governance Committee decisions and on-the-ground implementation



Recommendation 4

Support an annual Nordic Health Data Summit

- Hosted by the Presidency country, co-located with an existing national conference
- Brings the whole ecosystem together once a year
- Feedback gathered at the Summit can inform the Committee's priorities for the following year



Recommendations

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Committee

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Secretariat

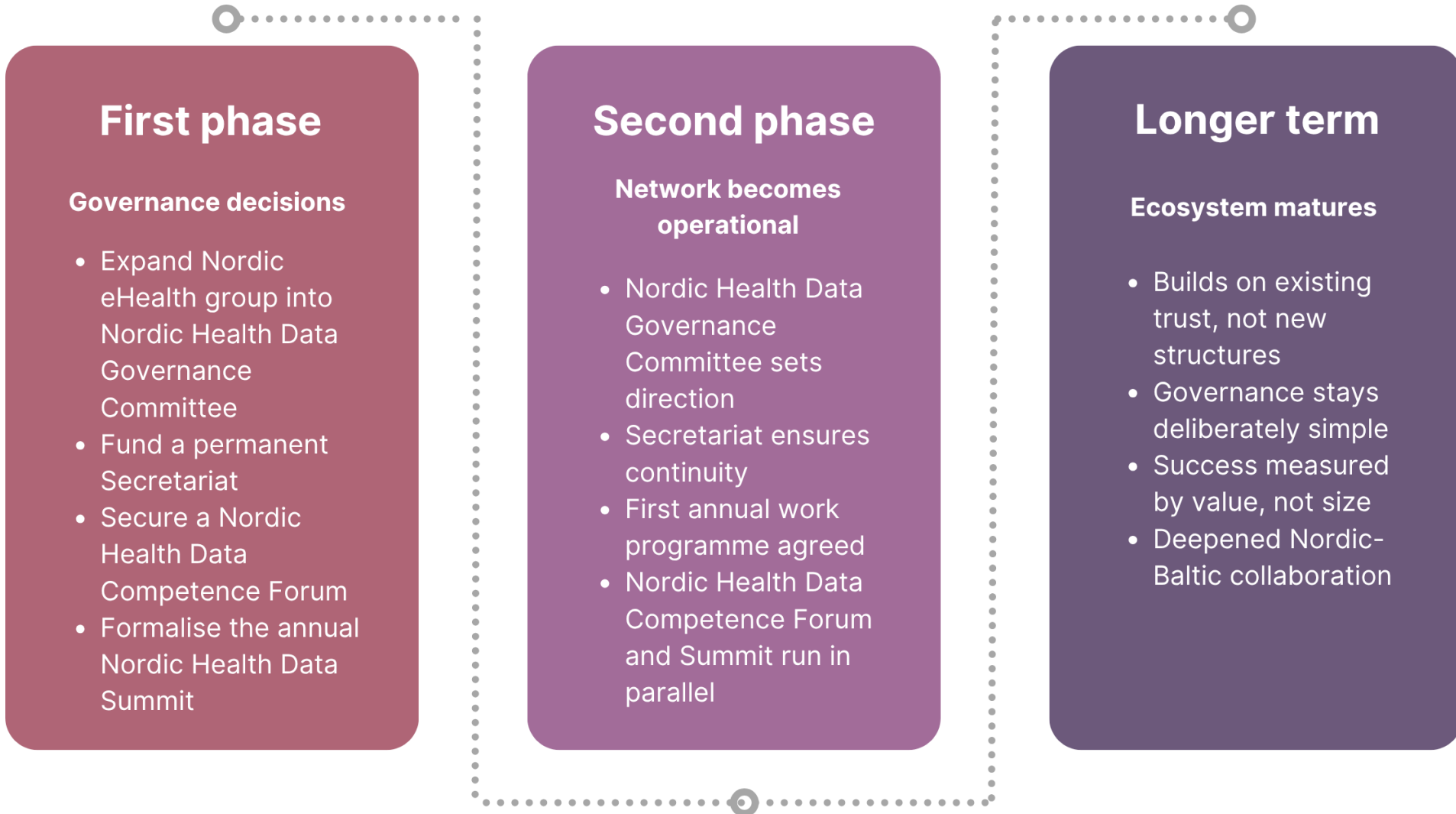
Recommendation 3

Endorse and
resource a
permanent
Nordic Health
Data Competence
Forum

Recommendation 4

Support an
annual Nordic
Health Data
Summit

Phased path forward



Thank you!

Recommendation 1

Establish a
Nordic Health
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Committee

Recommendation 2

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permanent
Secretariat

Recommendation 3

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resource a
permanent
Nordic Health
Data Competence
Forum

Recommendation 4

Support an
annual Nordic
Health Data
Summit



Building a stronger Nordic health data region – from vision to implementation



**Sigríður Haraldsdóttir
Elínardóttir**
Head of Division, Health
Information, Directorate of
Health Iceland



Jennifer Bartell
PhD, Senior Scientific
Manager, Health
Innovation, Novo Nordisk
Foundation



Kirsi Talonen
Senior legal counsel,
CIPP/E, University of
Helsinki



Annemieke Ålenius
Deputy Director General,
Swedish eHealth Agency,
President of the Nordic
Council of Ministers
eHealth Group



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Thank you!

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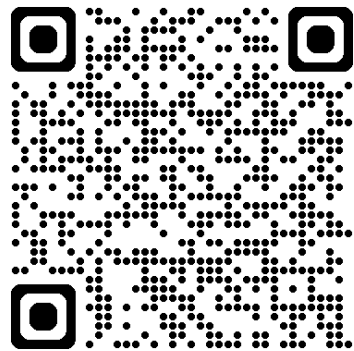
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Coffee break

The event continues at 11:45 (CEST)!

View the agenda here



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SESSION 3:

Unlocking cross-border use of health data – lessons from a Nordic SPE pilot



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Session 3: Unlocking cross-border use of health data – lessons from a Nordic SPE pilot



Susanna Flaherty

Healthcare Director
Finland, Payers, Providers
and Governance Nordics,
IQVIA



Donna Franklin

Program Manager, Privacy
Analytics, Europe, IQVIA



Jonathan Green

Director, Privacy
Analytics, Europe,
IQVIA



**Mads Albrecht
Andersen**

MD, PhD student,
Department of Oncology at
Rigshospitalet, Capital Region
of Denmark



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Unlocking cross-border use of health data – lessons from a Nordic SPE pilot

- Mads Albrecht Andersen, Study Investigator
- Donna Franklin, Data Governance Workstream Lead
- Dr Jonathan Green, Data Governance Expert

Moderator: Susanna Flaherty, VALO2 Pilot Project Oversight



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23.09.2026

The case for VALO2 pilot

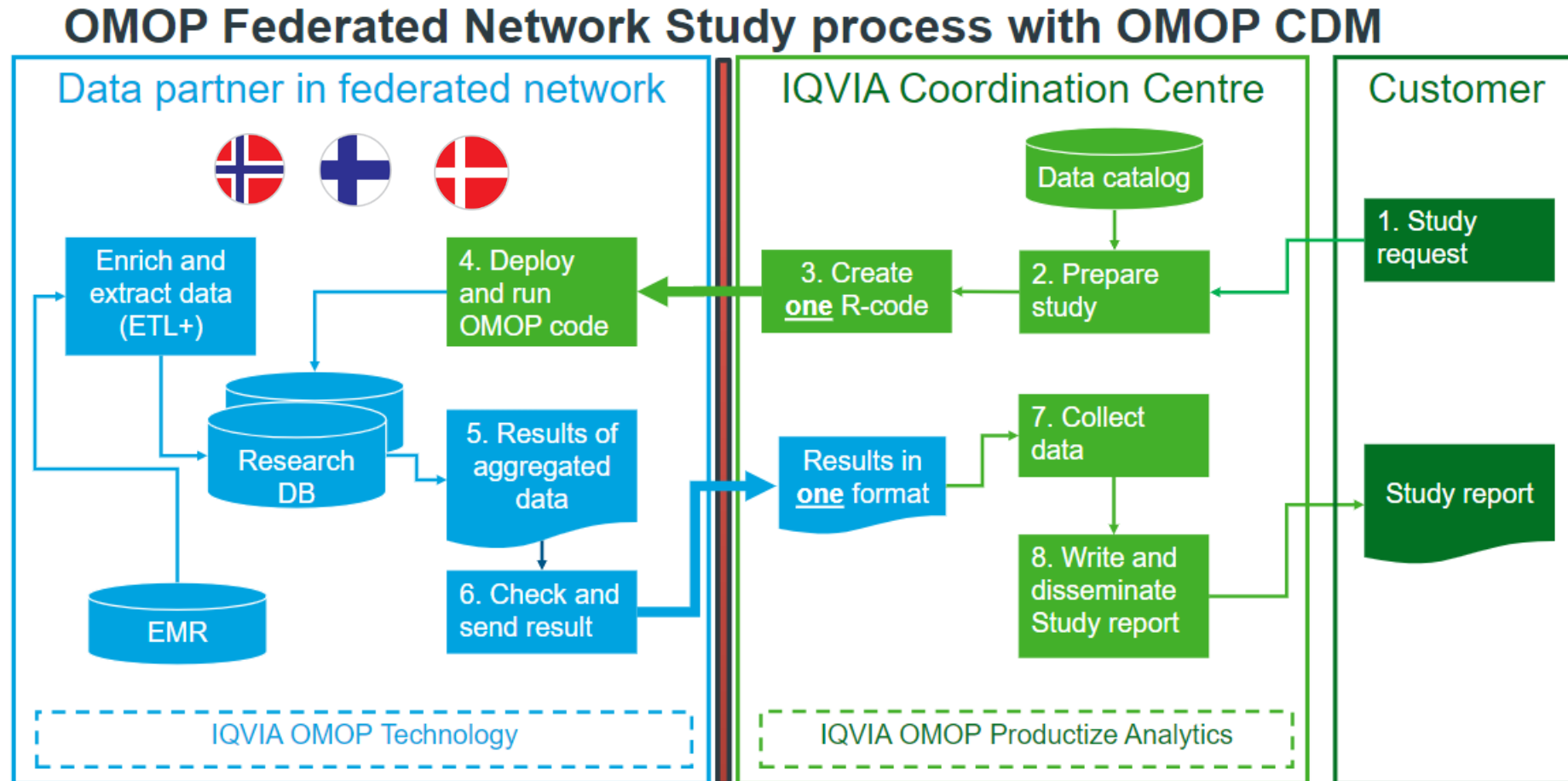
Why was this a Nordic study?

- Relevant patient populations are distributed across countries
- High quality EMR data across participating countries
- Access to multiple data sources broadens evidence generation
- The study provided an ideal opportunity to test cross-border research through SPEs building on VALO1 pilot study



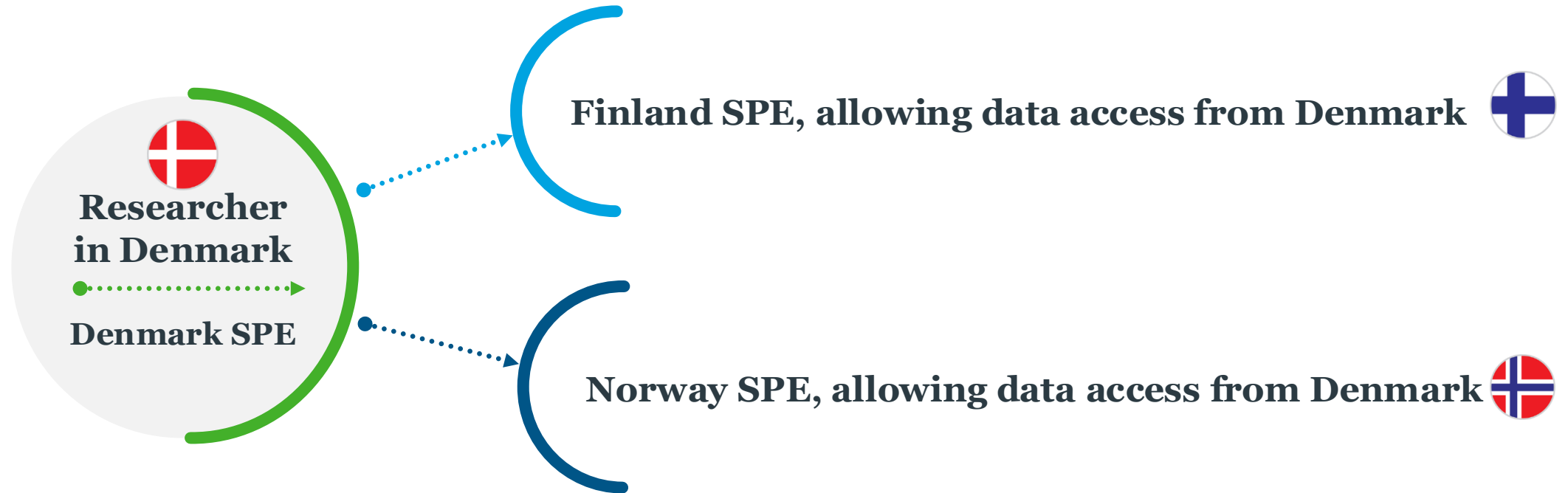
From VALO1 pilot to VALO2 pilot

VALO1 pilot study operating model



From VALO1 pilot to VALO2 pilot

VALO2 pilot study operating model

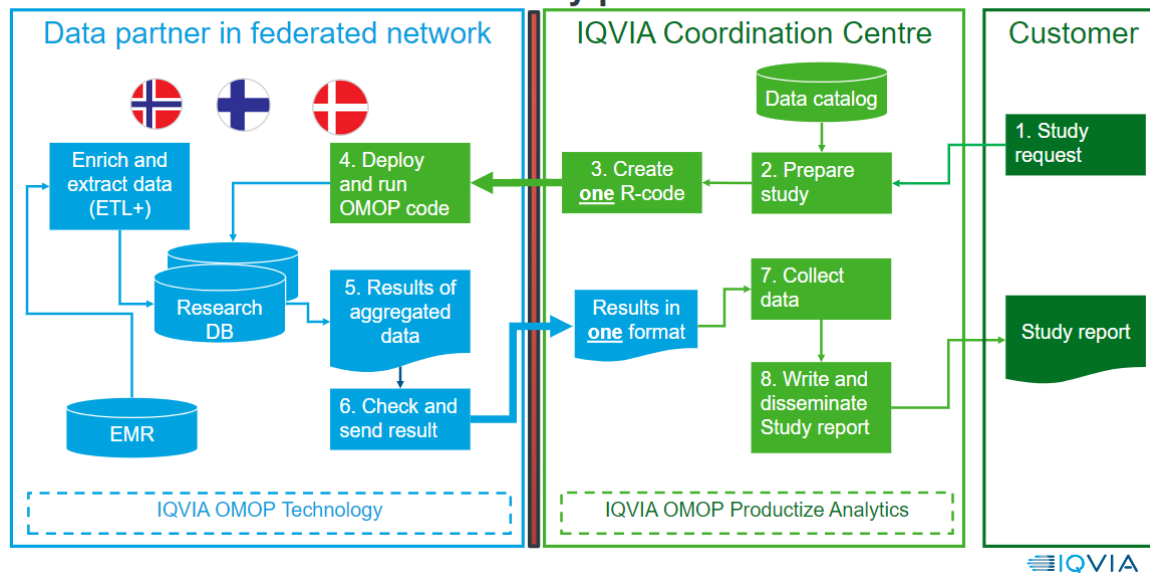


From VALO1 pilot to VALO2 pilot

Different operating models

VALO1 Pilot Study

OMOP Federated Network Study process with OMOP CDM



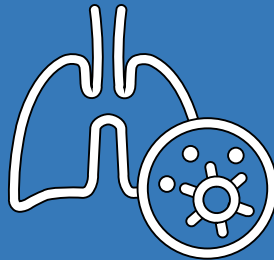
VALO2 Pilot Study



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The science and benefits of VALO2 pilot study

Nordic Multicentre Retrospective Cohort Study in Metastatic Non- Small Cell Lung Cancer



Primary objective

Compare treatment outcomes in patients with advanced lung cancer receiving first-line immunotherapy with pembrolizumab, atezolizumab or cemiplimab



Secondary objective

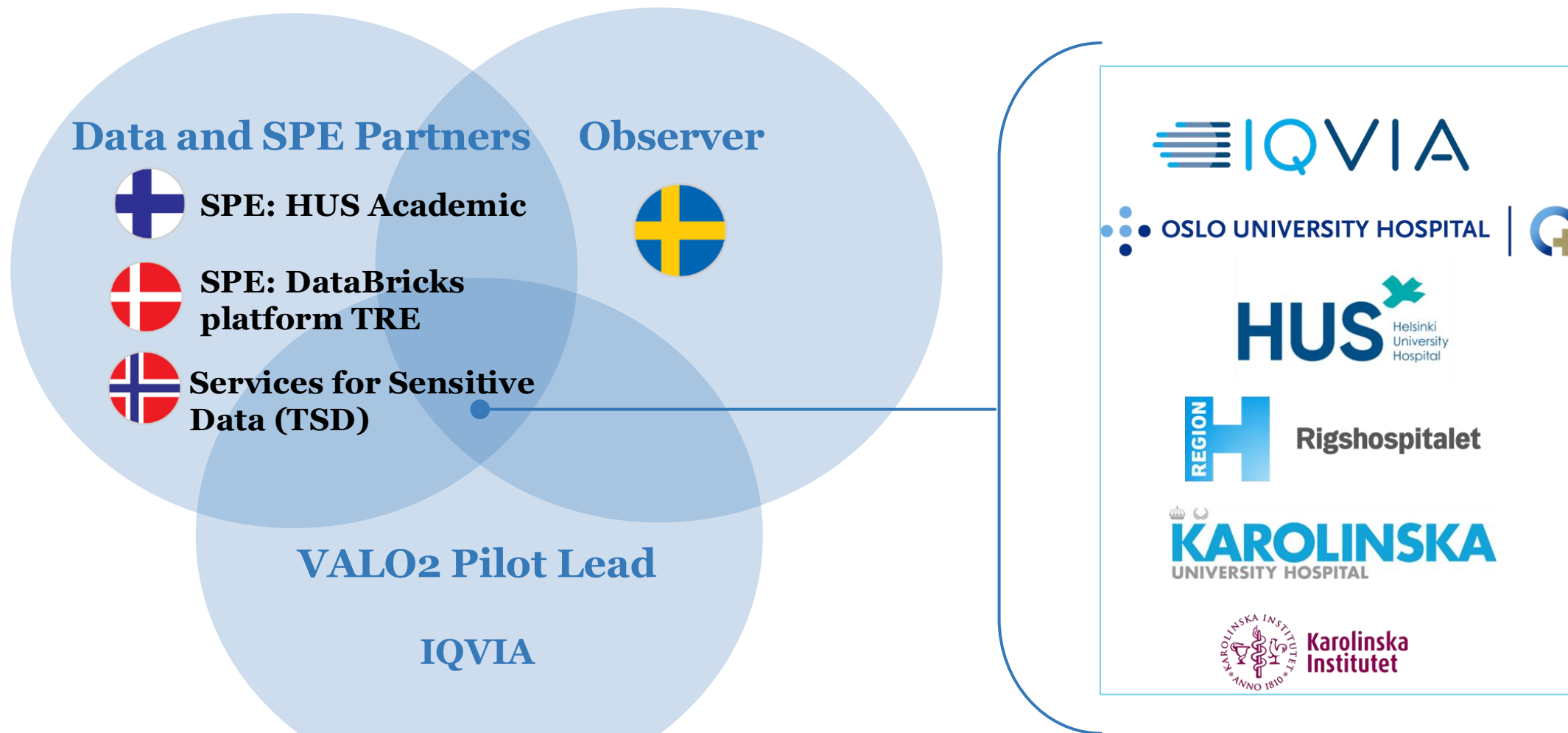
Describe patient characteristics and treatment outcomes, including differences by performance status and comorbidity burden



Exploratory objective

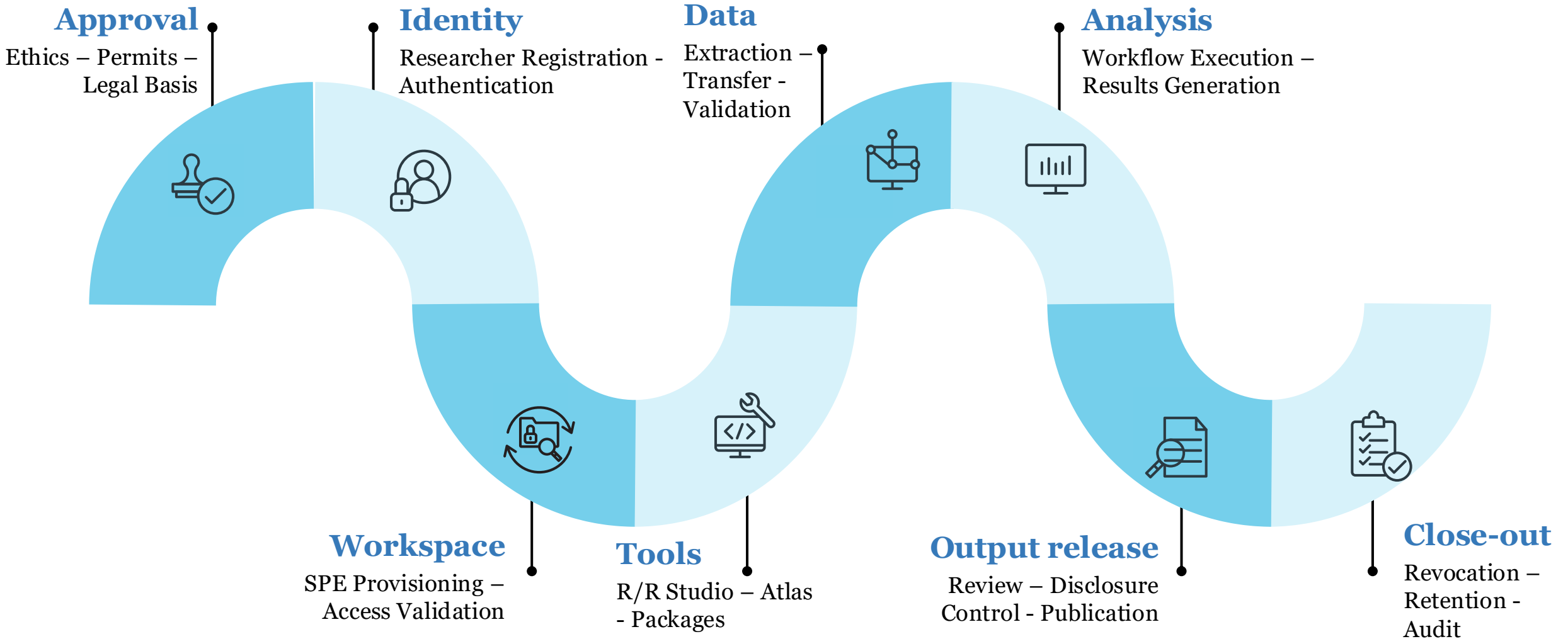
Investigate prognostic scores (LIPI, LIPS-3), and whether they can improve risk adjustment between treatment groups

VALO2 pilot partners



Funded by the
Nordic Council
of Ministers

The researcher journey through an SPE

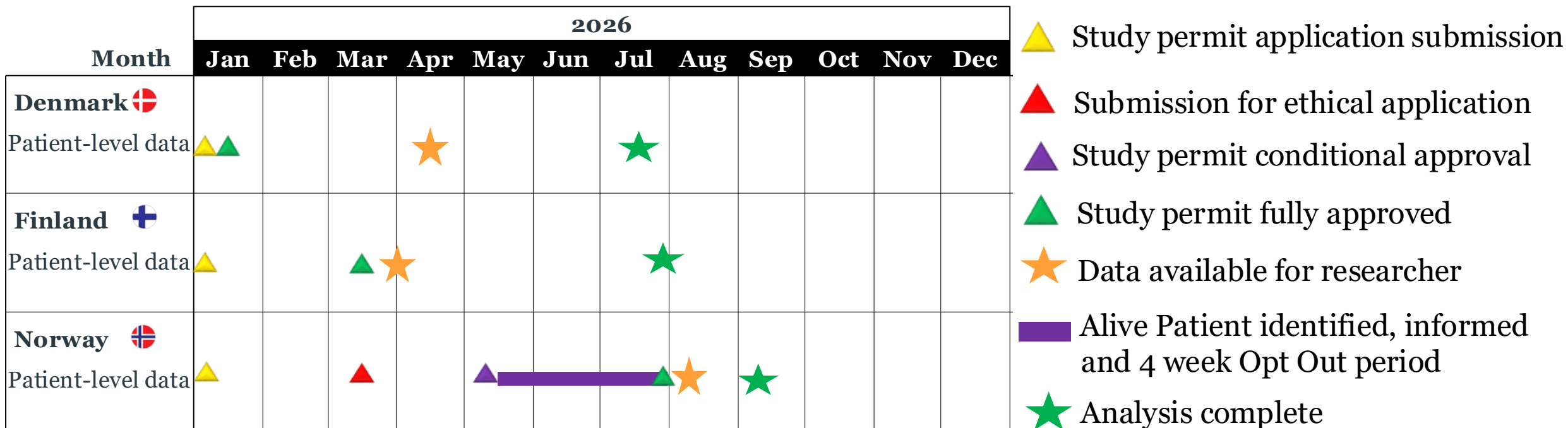


Support and escalation operate across the full researcher journey rather than representing a single sequential stage.



Funded by the
Nordic Council
of Ministers

VALO2 Pilot Timeline



Funded by the
Nordic Council
of Ministers

What the cross-border SPE approach enabled and challenged



Enabled



Patient-level data remained
within local environments



Cross-border analysis
without moving patient-level data



Shared analytical approach
across countries



Local control
over governance and output release



Direct researcher access
to Nordic datasets



First-hand understanding
of future EHDS-style SPE



Challenged



Different onboarding processes
across sites



Access involved more
than obtaining login credentials



Workspace, tools and permissions
needed to align before analysis could begin



Output review and release processes
varied between sites

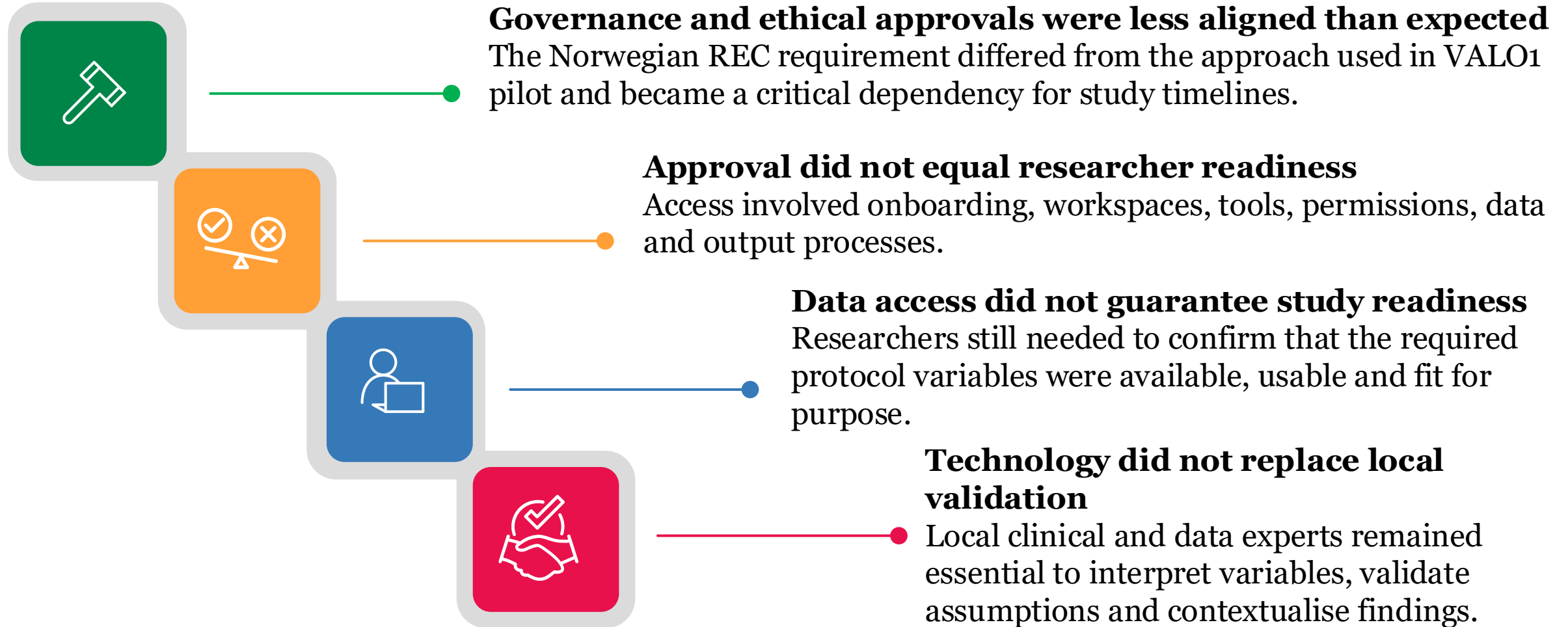


Researcher onboarding
differed between environments

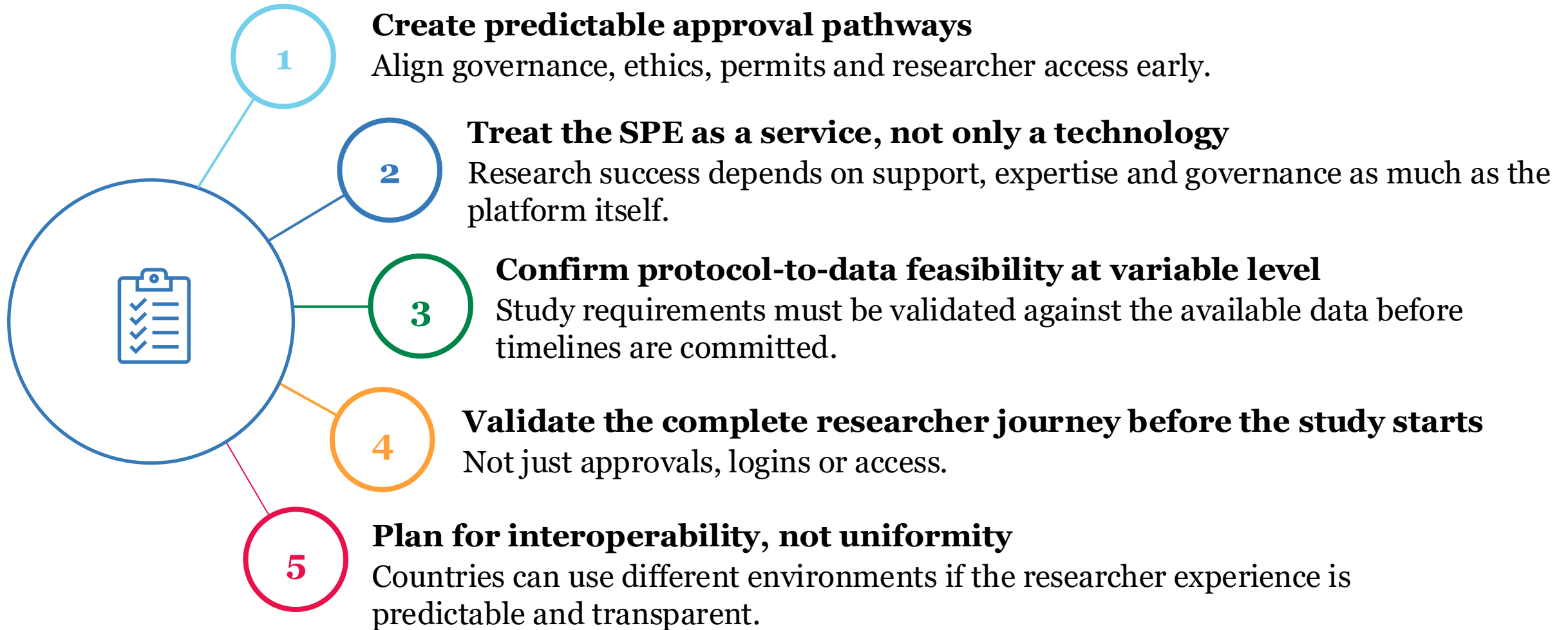


Local expertise remained essential
for interpreting data and resolving issues

Challenges and learnings



Recommendations to the next research project

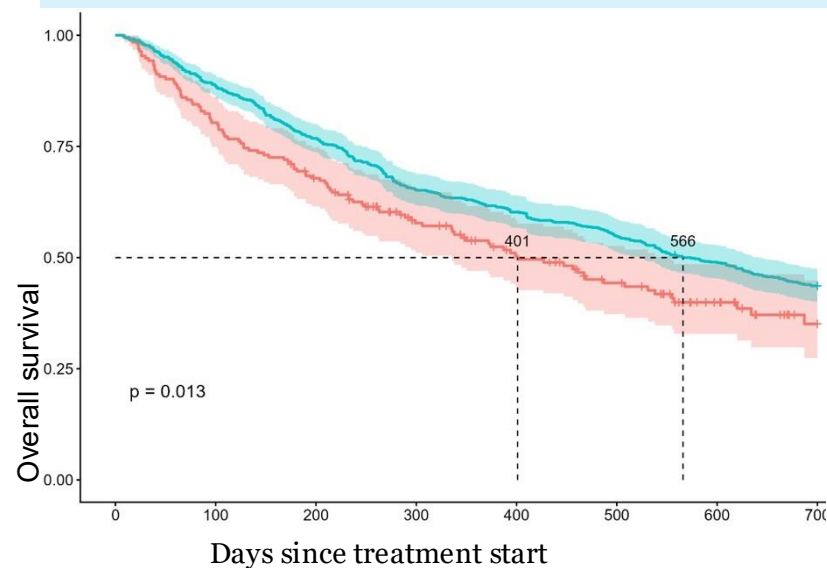


What the study found - results



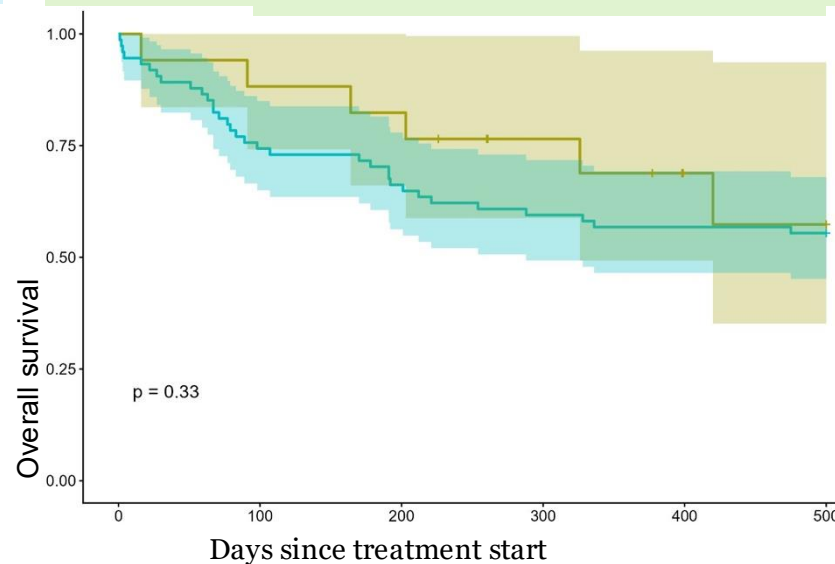
2 of 3 countries

showed a significant difference between the treatments



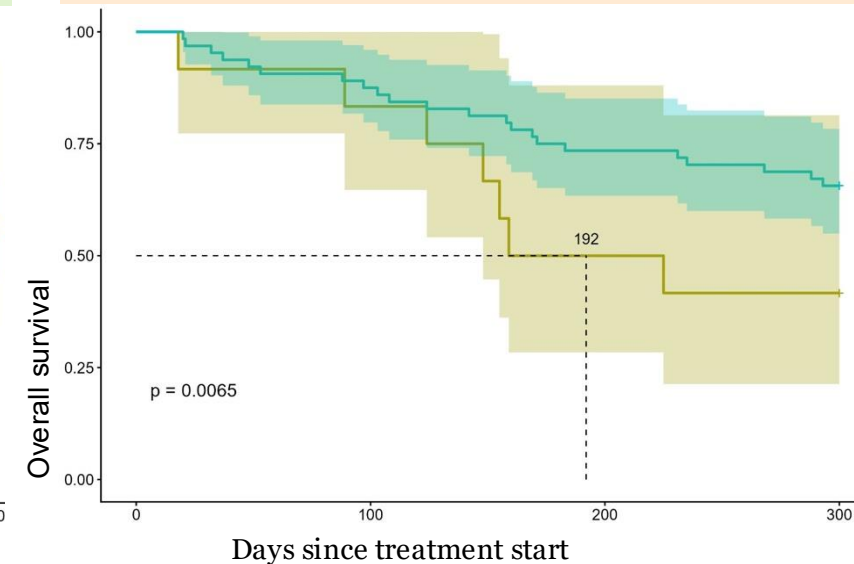
Data availability varied

between countries, challenging inclusion of patients



Patient characteristics

were largely similar between countries and treatment groups



— Pembrolizumab — Atezolizumab — Cemiplimab



Funded by the
Nordic Council
of Ministers

What VALO2 pilot revealed about running an SPE study in the Nordics today?

Technical interoperability

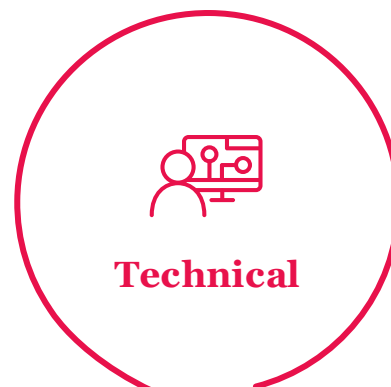
What proved feasible

- ✓ Researchers accessed multiple SPEs
- ✓ Analysis could be conducted without moving patient-level data
- ✓ Common analytical approaches could be applied

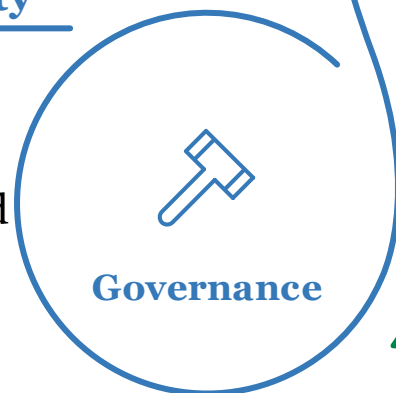
Governance interoperability

Still requires standardisation

- ! Approval pathways differed
- ! Research access processes varied
- ! Timelines were not always predictable



**Critical
to
Success**



Service interoperability

Largest scaling challenge

- ! Researcher experience varied
- ! Support models differed
- ! Analysis readiness was not consistently achieved after access was granted



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of Ministers

Question to the panel and audience



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What is currently the greatest obstacle to routine cross-border health-data research?

Governance

Technology

**Data
readiness**

**Researcher
service**



Funded by the
Nordic Council
of Ministers

Key takeaway



Funded by the
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of Ministers

What did the VALO2 pilot reveal about running an SPE study in the Nordics today?

**Researchers crossed borders,
Patient-level data did not.**

**Scaling it requires interoperable
researcher services, governance and
data readiness.**





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Nordic Council
of Ministers



Thank you!

Join the live question wall

menti.com, code: **4320 6979**
or by scanning the QR code



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of Ministers

Q&A: Open discussion on sessions 1–3



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of Ministers

SITRA



Join the live question wall and vote for questions

menti.com, code: **4320 6979**
or by scanning the QR code



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Nordic Council
of Ministers



Thank you for joining us online!

The live stream has now ended.



Funded by the
Nordic Council
of Ministers

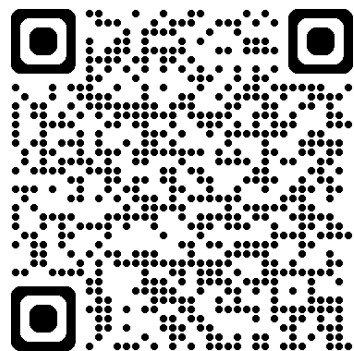
SITRA



Lunch break!

The event continues at 13:45 (CEST)!

View the agenda here



Funded by the
Nordic Council
of Ministers

SITRA

SESSION 4: NOR-OMOP and Nordic- Baltic OMOP – building blocks in the Nordic health data landscape



Funded by the
Nordic Council
of Ministers

SITRA



Espen Enerly

Researcher, Cancer Registry of
Norway, Norwegian Institute of
Public Health



Kristin Oterholt Knudsen

Senior Adviser, Cancer Registry of
Norway, Norwegian Institute of
Public Health



OMOP in practice across data partners and research networks

The community and collaboration behind effective reuse

23.09.2026 – Nordic Health Data Summit 2026

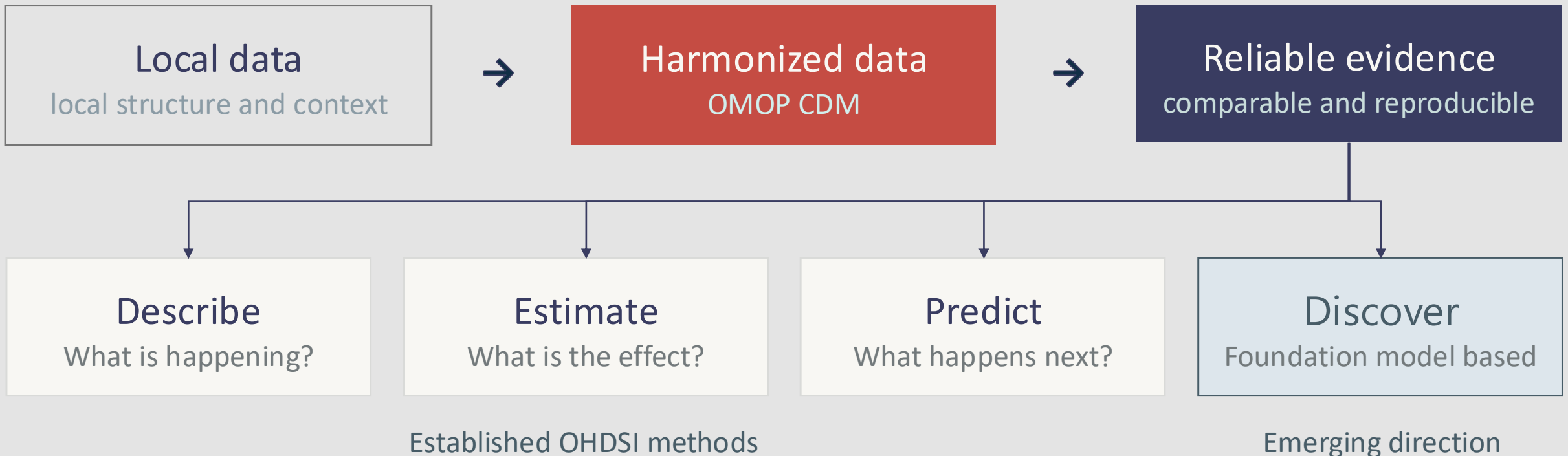
Kristin Oterholt Knudsen and Espen Enerly

Cancer Registry of Norway, Norwegian Institute of Public Health

Community enables reliable evidence

OHDSI MULTI-STAKEHOLDER COMMUNITY

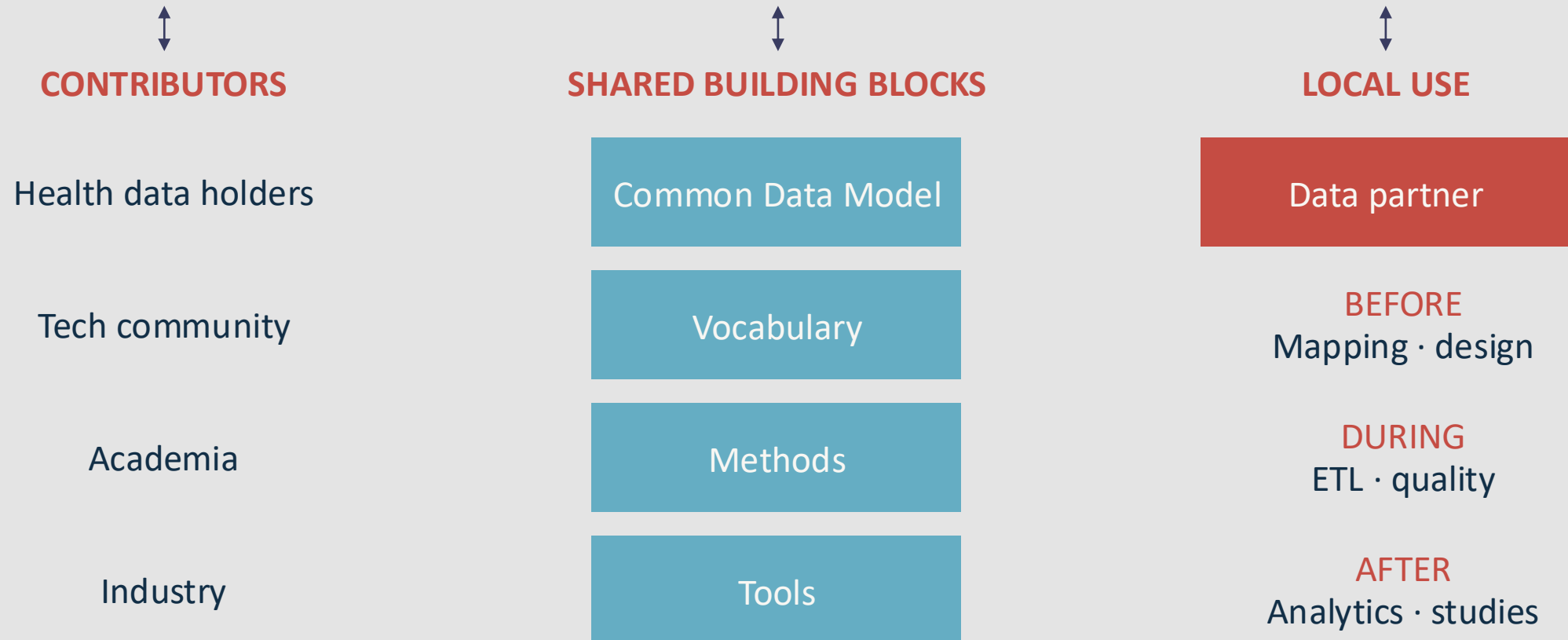
common model · vocabulary · methods · tools



Shared building blocks enable local reuse

OHDSI MULTI-STAKEHOLDER COMMUNITY

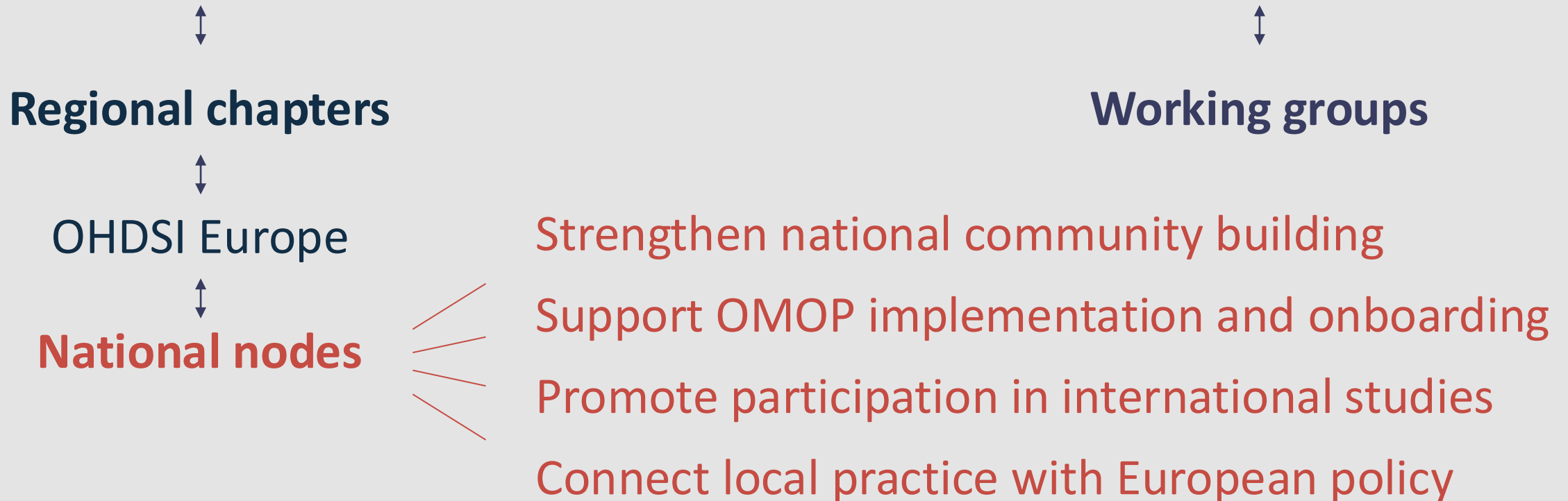
common model · vocabulary · methods · tools



Collaboration supports local practice

OHDSI MULTI-STAKEHOLDER COMMUNITY

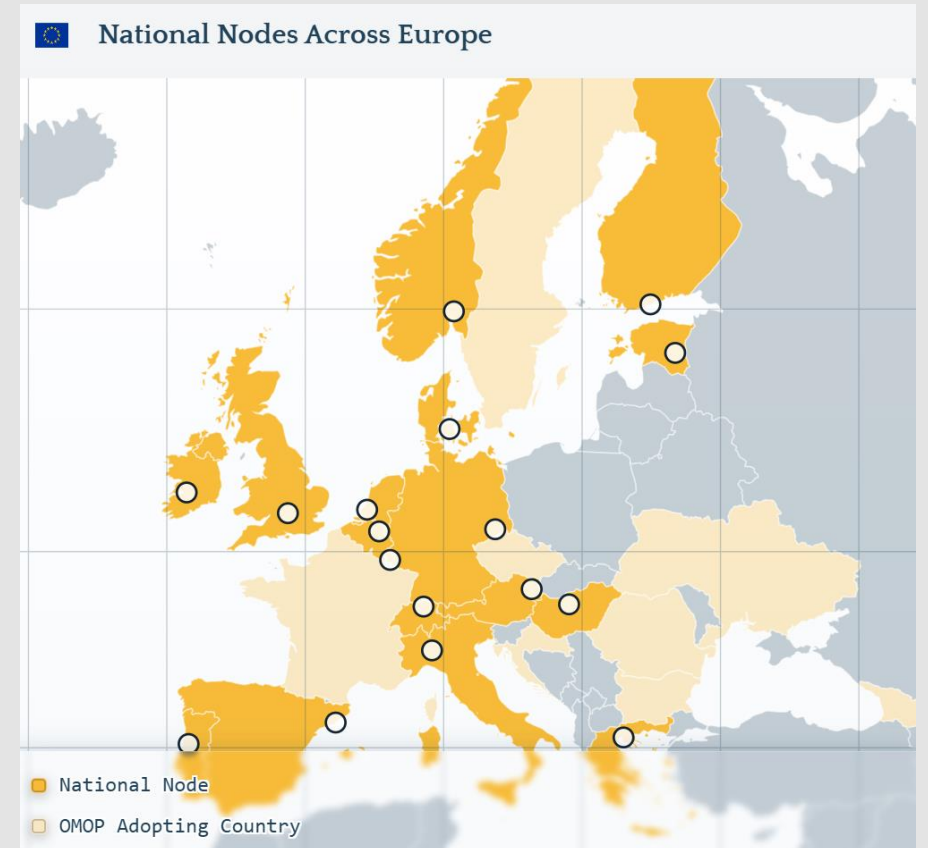
common model · vocabulary · methods · tools



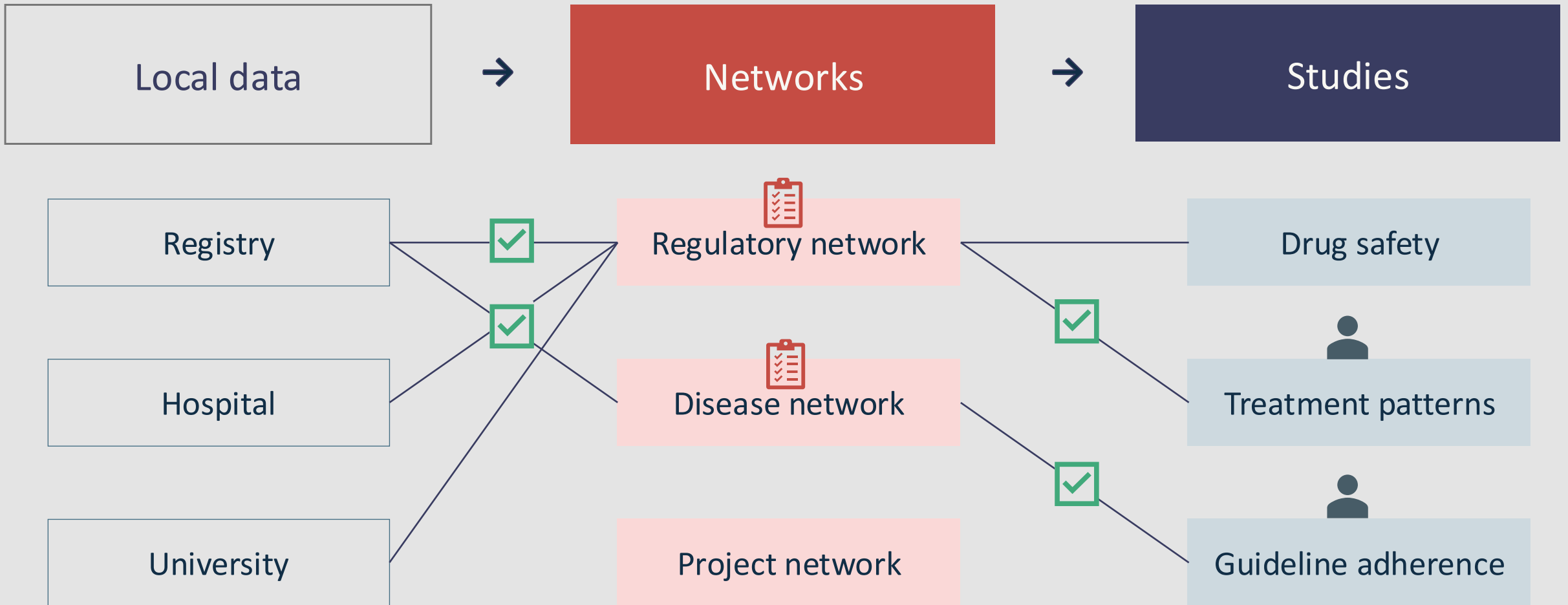
OHDSI Europe national nodes

- OHDSI Denmark
- OHDSI Finland
- OHDSI Norway
- Sweden – an OMOP-adopting country

Nordic-Baltic Network Forum

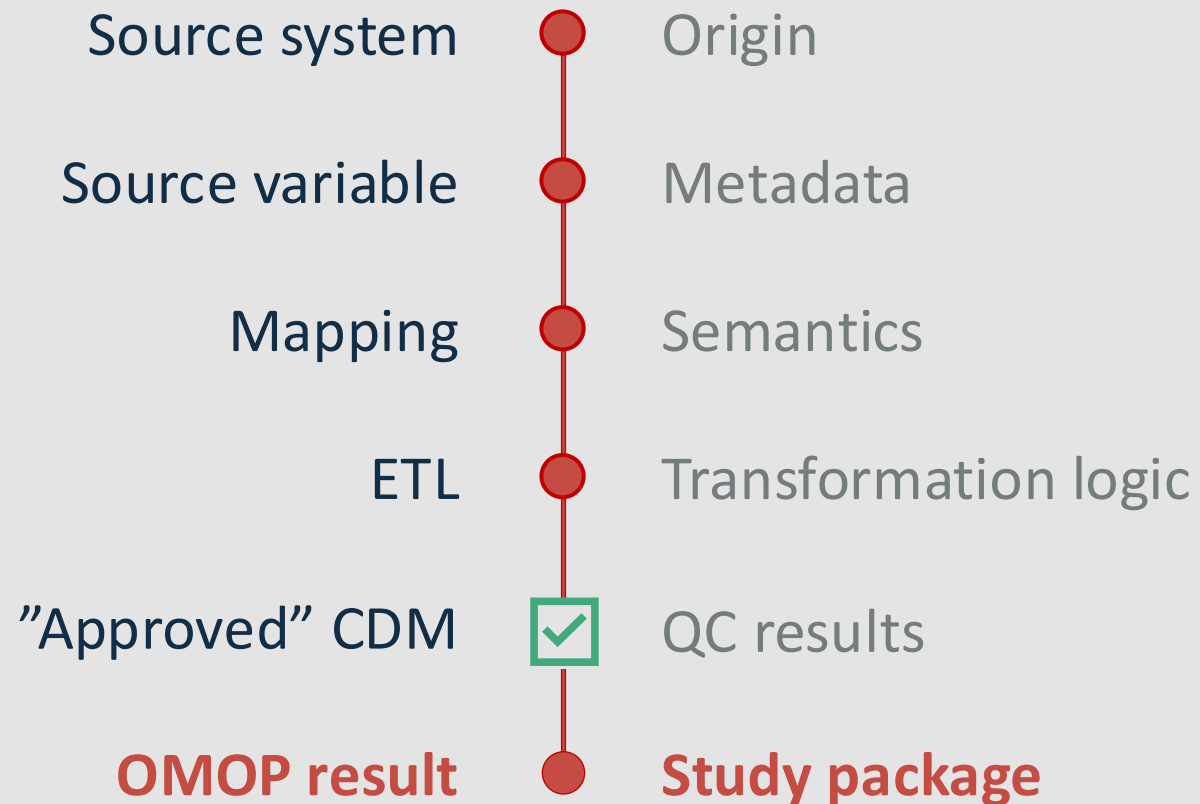


Matching questions to data



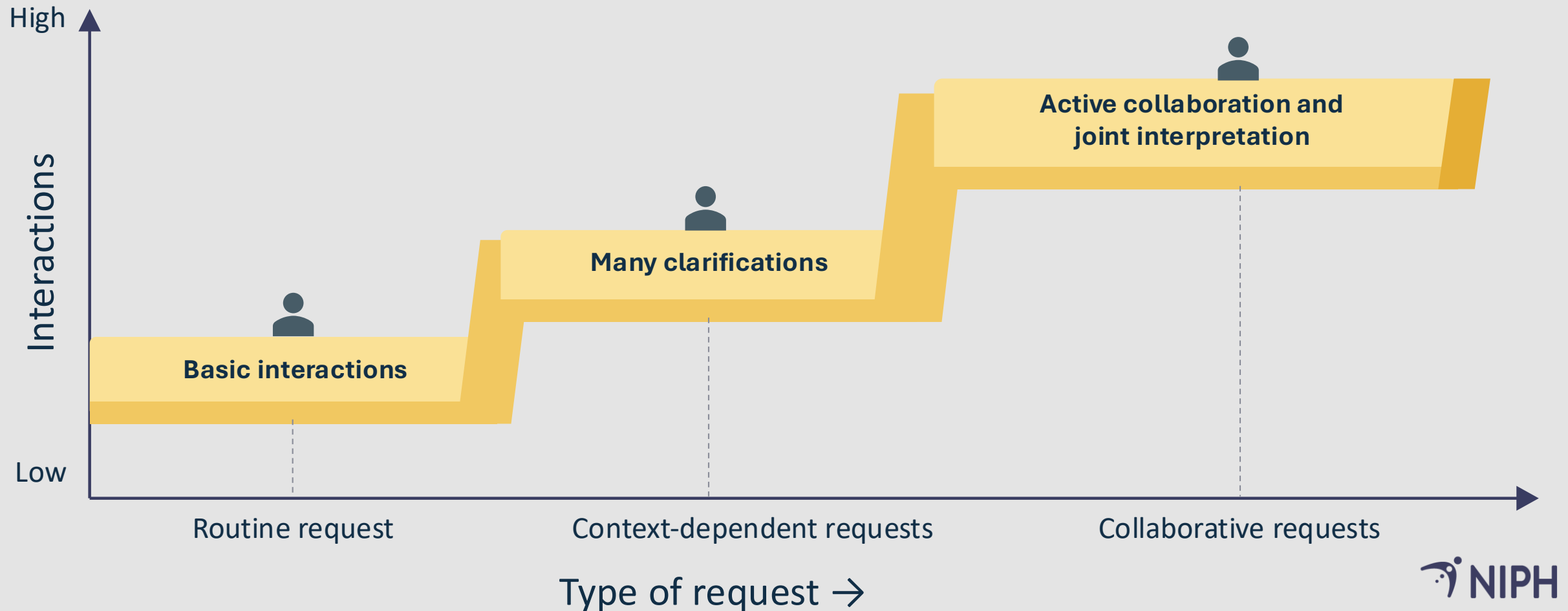
Building trust in the OMOP CDM

Documentation and metadata



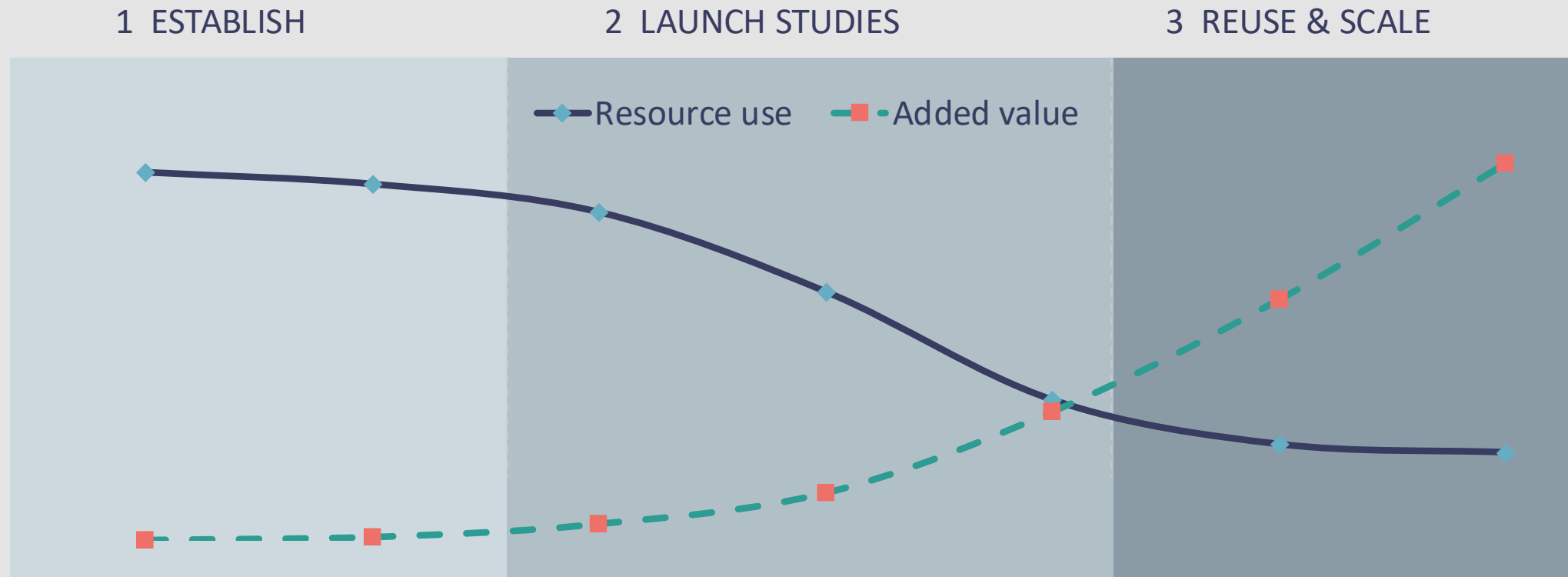
From clarification to interpretation

Interactions with source experts



Upfront investment – growing returns

Value grow over time



Invest. Reuse. Maintain

Sources and further reading

- OHDSI
 - <https://www.ohdsi.org/>
 - <https://www.ohdsi-europe.org/>
 - <https://www.ohdsi-europe.org/index.php/national-nodes>
- Darwin EU[®] network
 - <https://www.darwin-eu.org/>
 - <https://www.darwin-eu.org/index.php/studies>
- FALCON network
 - <https://www.falcon-network.org/>



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University Hospital



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Postdoctoral Researcher,
Oslo University Hospital



Petrică-Ioan Olteanu
Petrică Ioan Olteanu, PhD
Research Fellow, Pharmacy
Department, University of
Oslo





Paediatric Health Data Management and Sharing

Tasmeia Yousaf

Senior Advisor, Data and Analysis – OUS

Nordic Health Data Summit 2026

23 September 2026



PHEMS

Paediatric Health Data Management and Sharing



ECHO

European Children's
Hospitals Organisation

PHDS

Paediatric Health Data Space

EHDS

European Health Data Space



OSLO UNIVERSITY HOSPITAL



Why is Paediatric Health Data Management and Sharing needed?

Small number of complex paediatric and rare diseases patients per country

Limited real-world data to evaluate new expensive therapies

Need for more engagement with Medtech Industry & Innovation ecosystems

Many countries only have few specialized children's hospitals



PHEMS (Paediatric Health Data Management and Sharing)

Federated infrastructure to enable secure and GDPR-compliant access to paediatric health data.

Establish common governance, legal and ethical frameworks for responsible data use



Hospitals and Universities



Technical and Business



Promote interoperability and standardization among hospitals

Build a sustainable business and exploitation model ensuring long-term continuity of the PHDS

Create data services supporting research, clinical benchmarking, and public health innovation.

How do we do it?

Collaboration | Technology | Use Cases

14+
partners

Including hospitals,
universities, technology,
and biotech companies

7 M€

Funded through
Horizon Europe and
UK Research & Innovation

3-years

October 2023 -
September 2026



www.ECHOhospitals.org

Hospitals and Universities



Technical and Business



How do we do it?

Collaboration | Technology | Use Cases

Clinical Use Cases to Demonstrate Value

1

Cardiology operations benchmarking

- ▶ Limited Supporting creation of benchmarking standard and promote a culture of benchmarking across pediatric cardiac institutions, **enabling the adoption of 'best-practice' across institutions.**

2

Pediatric Intensive Care Unit Sepsis

- ▶ Limited Investigating the benefits of the federated network to **develop, train and test algorithms to predict sepsis** on a large scale between pediatric intensive care units in four large European children's hospitals.

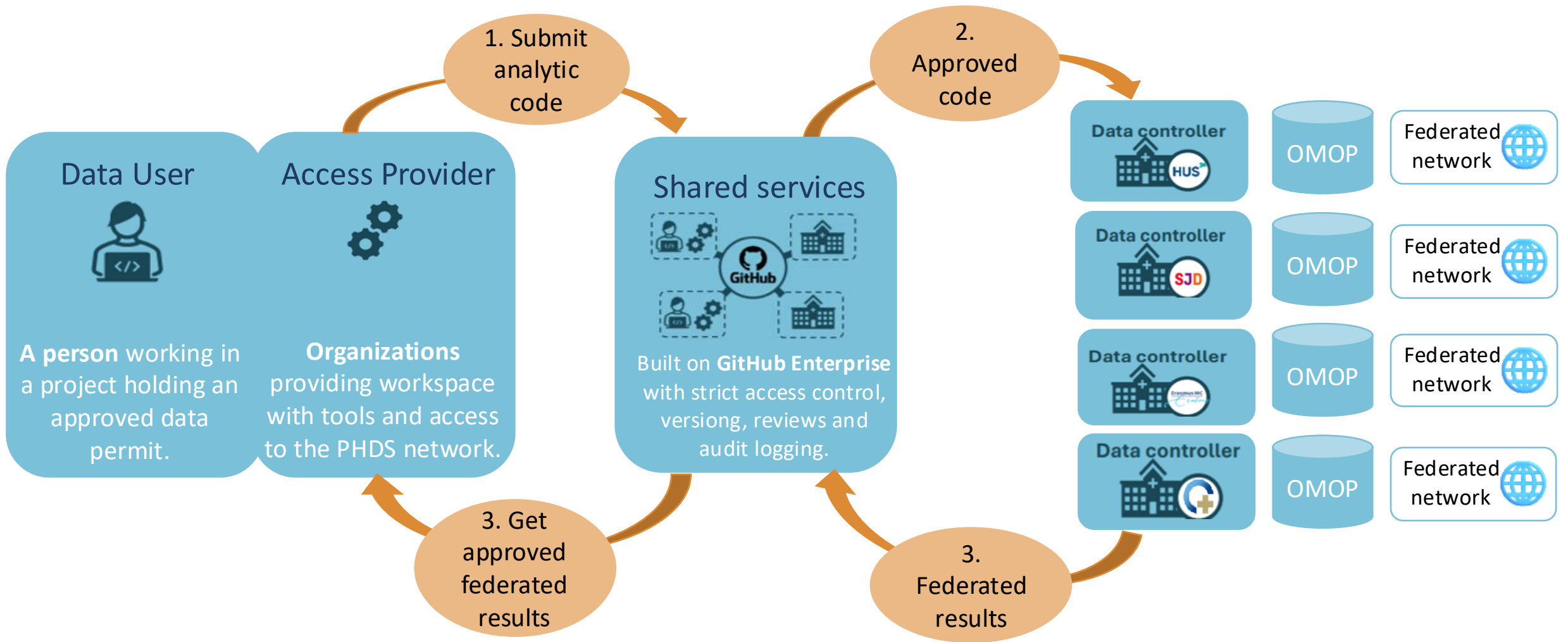
3

Hematology - hemophilia

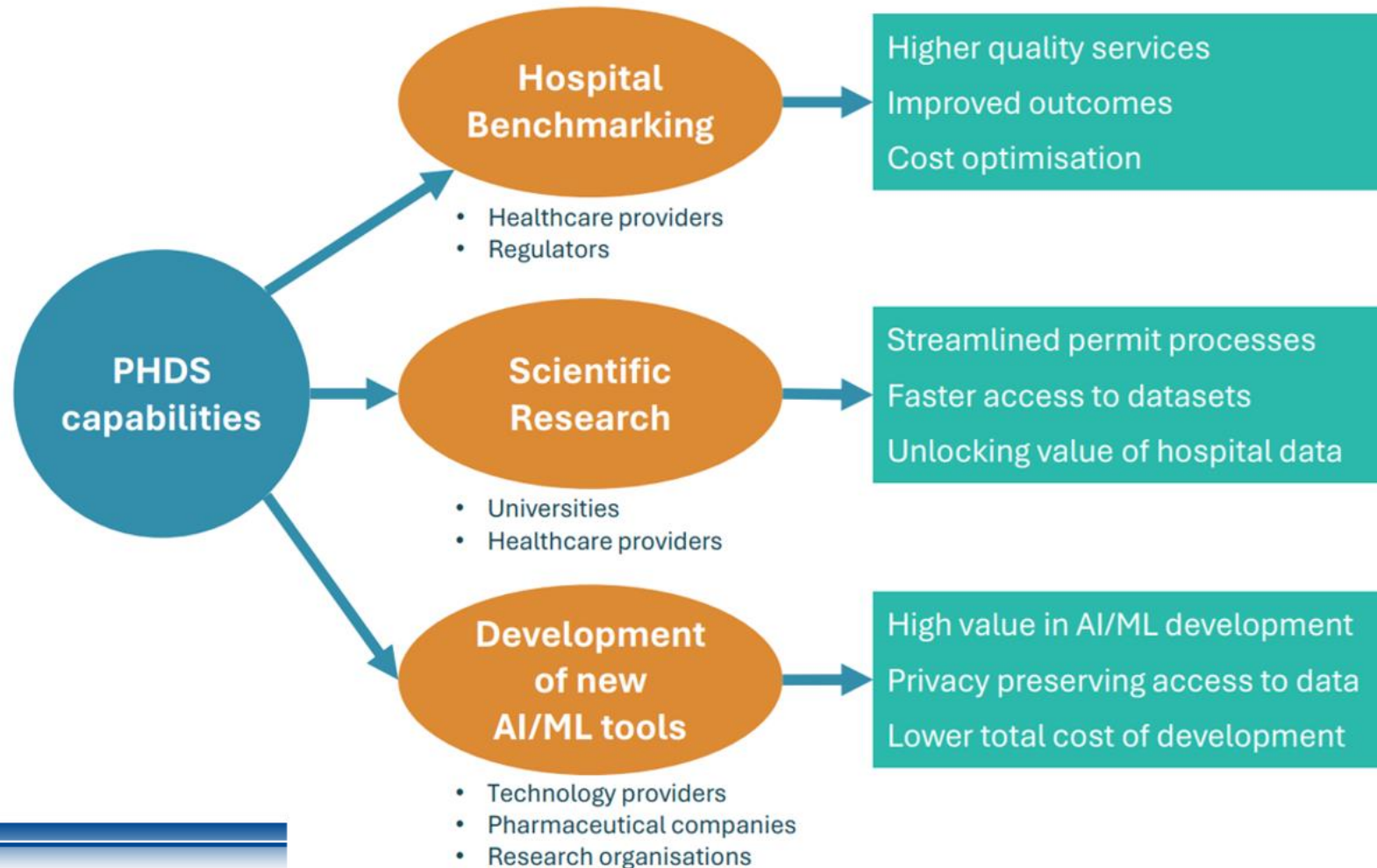
- ▶ Limited **Personalize treatment** for pediatric patients with hemophilia A through **new machine learning models** that provide more accurate exposure predictions of coagulation factor concentrates.

How do we do it?

Collaboration | Technology | Use Cases



From PHEMS project to Paediatric Health Data Space (PHDS)



Benefits across multiple domains

Fostering collaboration
between hospitals, sharing best practices

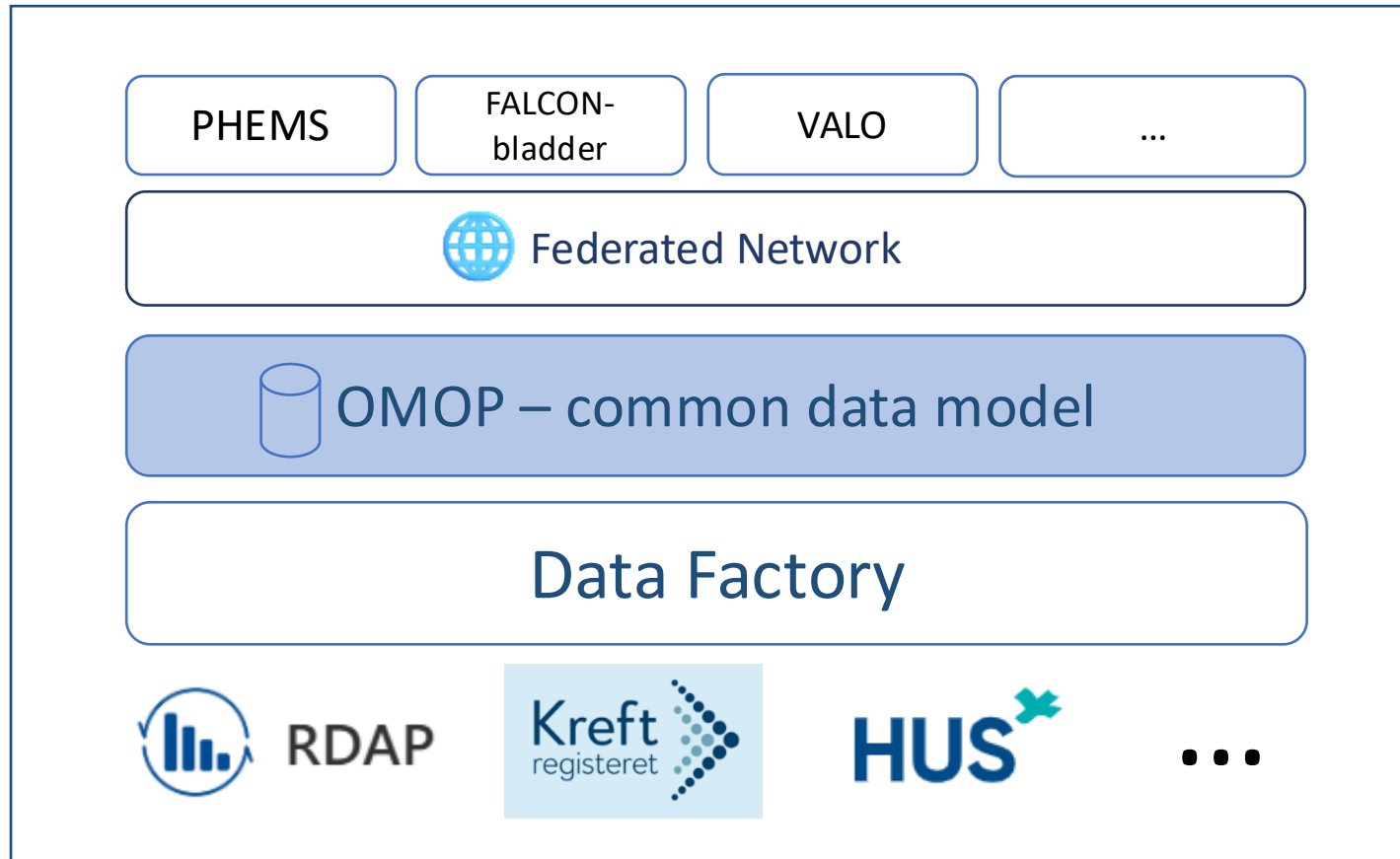
Social benefit
through improved outcomes and cost optimisation

Unlocking value of data
by making it accessible and harmonized for use

Income
from collaborative research and AI/ML development

Beyond traditional benchmarking, the PHDS will unlock new avenues for strategic partnerships and research, catalysing advancements in healthcare.

Oslo University Hospital – OMOP Setup



OMOP – A Universal Adapter for Health Data



The Road Ahead

***Data is the lifeblood of Healthcare AI research
and there is a shortage of available high quality data***

Joseph J. Frassica. Executive Director, MIT – Hood Pediatric Innovation Hub (Paediatric Innovation Day – Sep. Helsinki 2026)

One common data model
Analysis travel, data stays

Harmonize → Federate → Scale

Every hour invested in PHDS data harmonization accelerates the realization of the EHDS.

Thank You

Questions & Discussion

PRIME-ROSE

«Crossing borders» in data standardisation: application of OMOP CDM
in an international clinical trial network in precision cancer medicine

Maria Martin Agudo & Gabriel Bratseth Stav

Institute for Cancer Research, Oslo University Hospital, Oslo (Norway)



Funded by
the European Union

Oslo, 23rd September 2026

Introduction

PRIME-ROSE (Precision Cancer Medicine Repurposing System Using Pragmatic Clinical Trials)



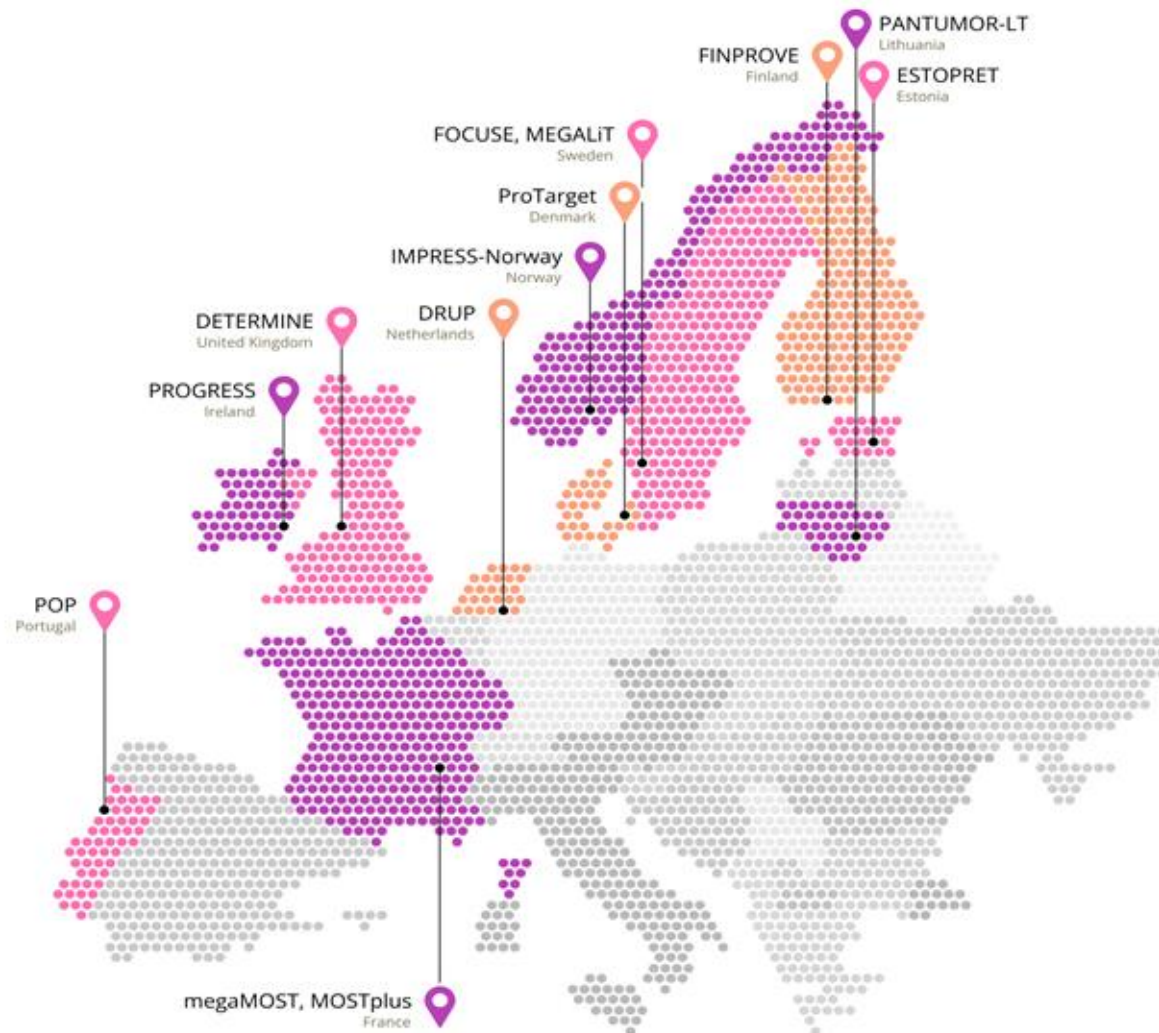
PRIME-ROSE

Precision Cancer Medicine Repurposing System Using Pragmatic Clinical Trials



PRIME-ROSE

Precision Cancer Medicine Repurposing System Using Pragmatic Clinical Trials

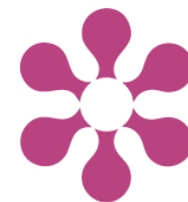


*Taskén K, F. Haj Mohammad S, Fagereng GL, Sørum Falk R, Helland Å, Barjesteh van Waalwijk van Doom-Khosrovani S, et al. PCM4EU and PRIME-ROSE: Collaboration for implementation of precision cancer medicine in Europe. Acta oncologica. 2024;63(1):385–91.

Introduction

DLCTs DRUP-Like Clinical Trials

Network of pragmatic clinical trials in precision medicine inspired by the design of the original DRUP protocol



Benefits

Data from individual trials are shared and aggregated for patients with the same **tumor type**, **biomarker**, and **drug** combination

- ✓ Cohort are filled quicker
- ✓ Accelerates evidence generation
- ✓ Improves patient care

Introduction

The Team (WP1)

Gabriel Bratseth Stav
(OUH, Norway)

Tina Kringelbach
(Capital Region,
Denmark)

Maria Martin Agudo
(OUH, Norway)

Eivind Hovig
(OUH, Norway)

Henk van der Pol
(LUMC, Netherlands)

WP leader

Hans Gelderblom
(LUMC, Netherlands)

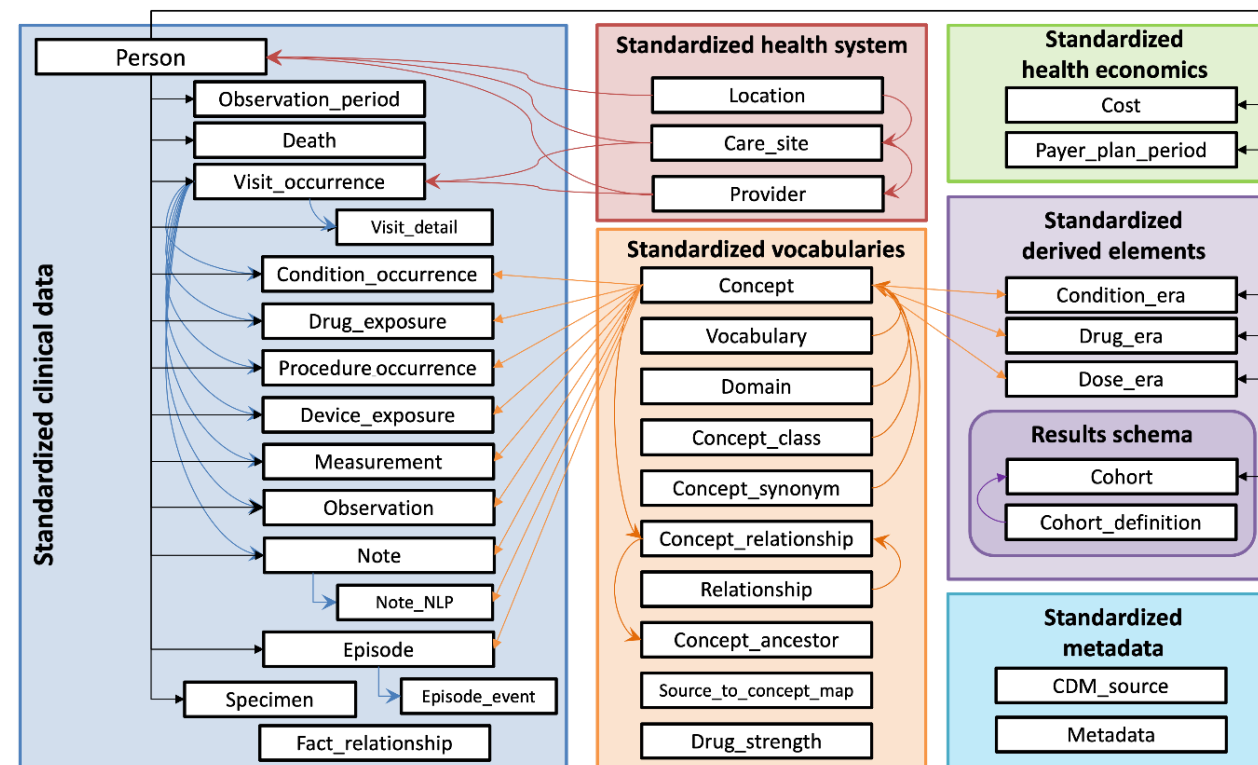
Project manager

Gro Live Fagereng
(OUH, Norway)



“Create the data platform, collect and aggregate data from each participating institution to generate evidence”

OMOP Common Data Model (CDM)



OMOP CDM in PRIME-ROSE

Goals

Standardise data to the
OMOP* Common Data Model (CDM)

Example
Tumor type

CRC

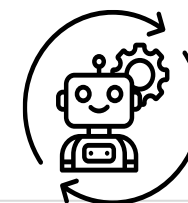
Colorectal
cancer

colorectal



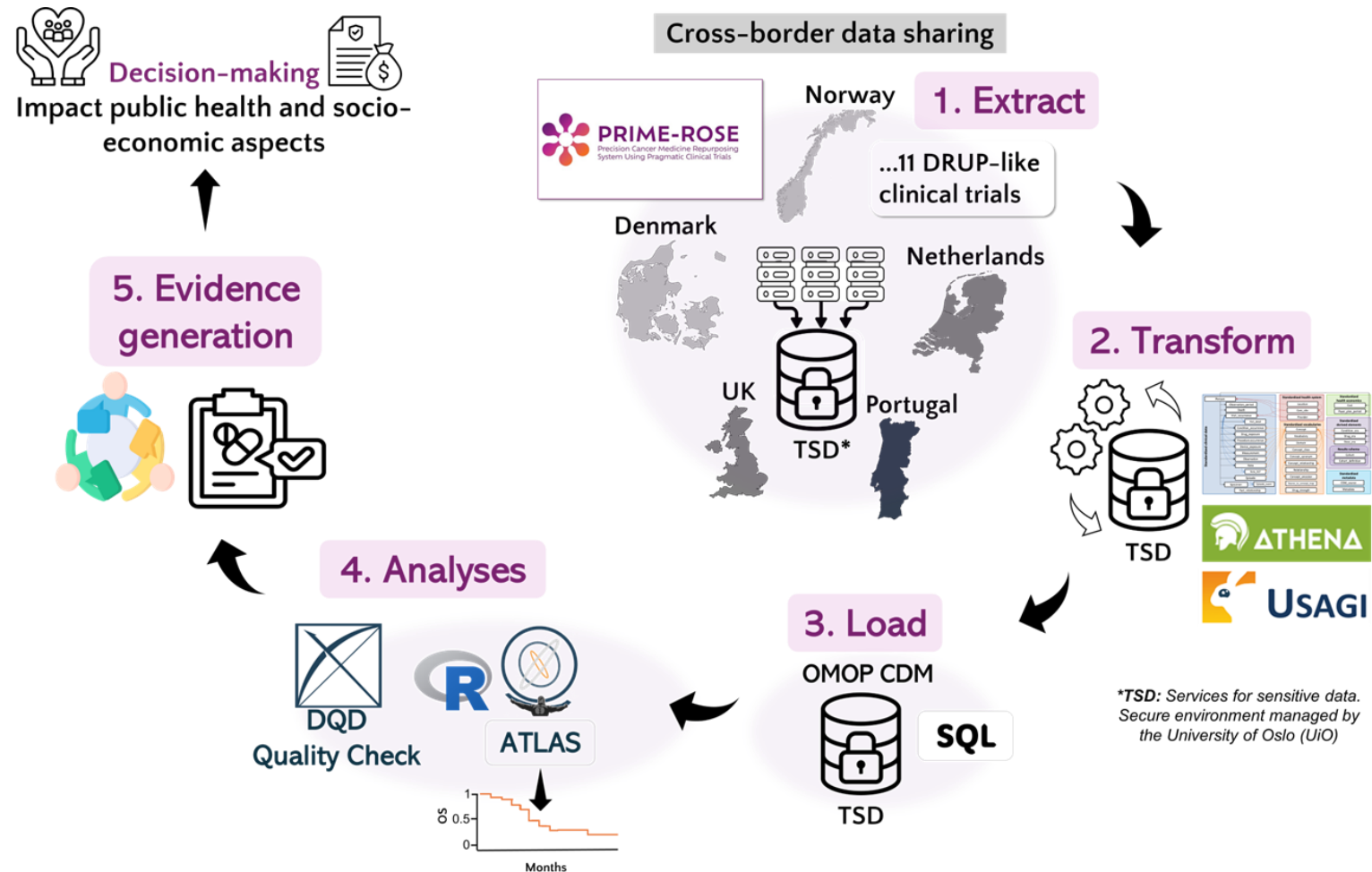
**SNOMED
Condition**

Malignant
colorectal
neoplasm



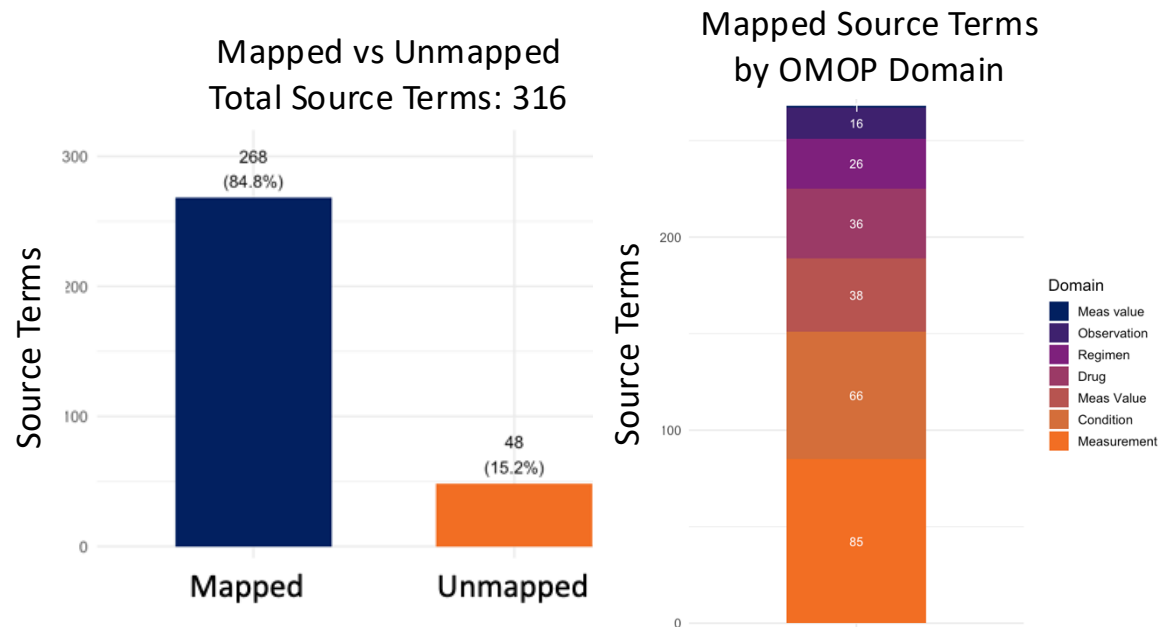
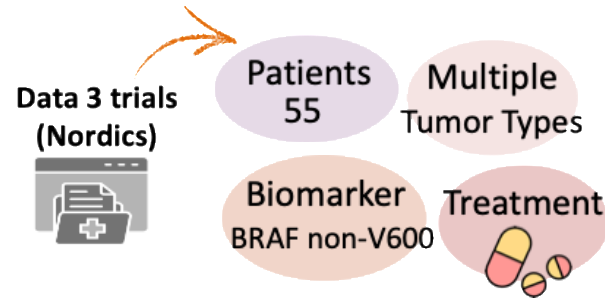
Automate the standardisation using an
Extract, Transform and Load pipeline (ETL)

«Crossing borders» in data standardisation

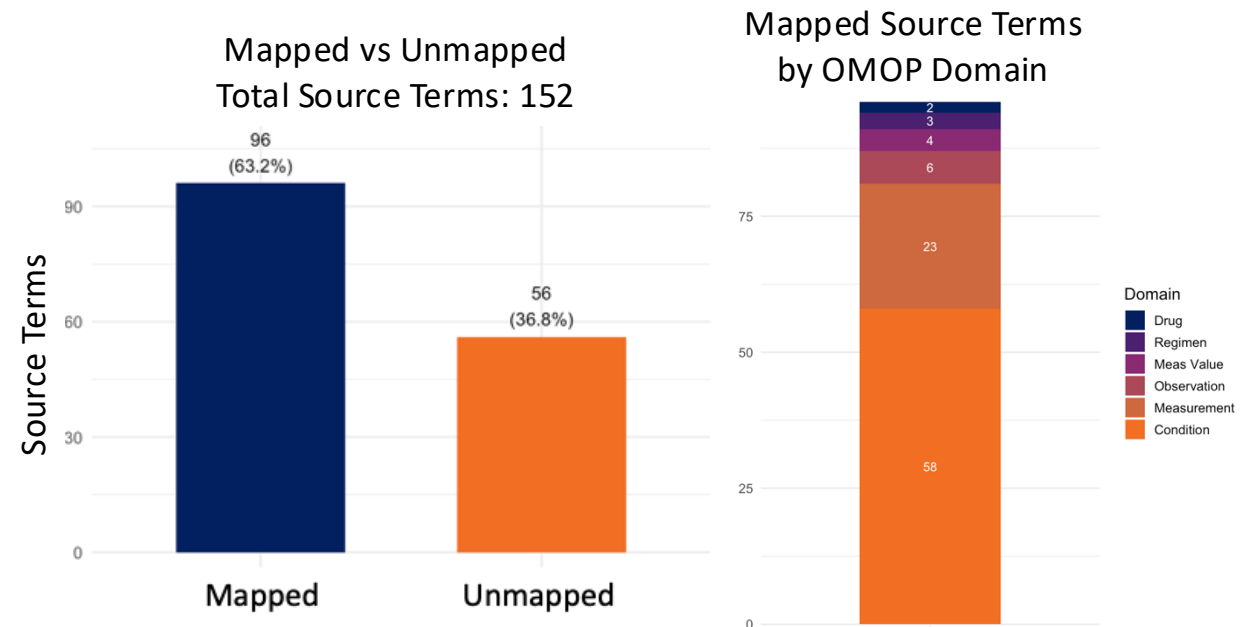
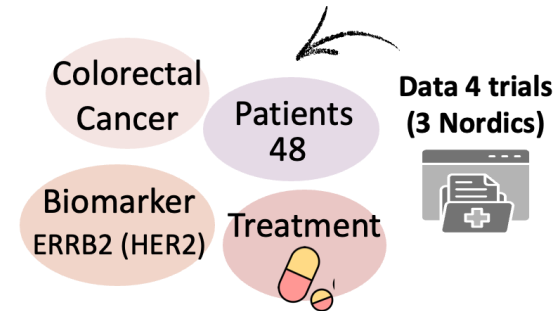


Mapping Progress

Cohort BRAF non-V600

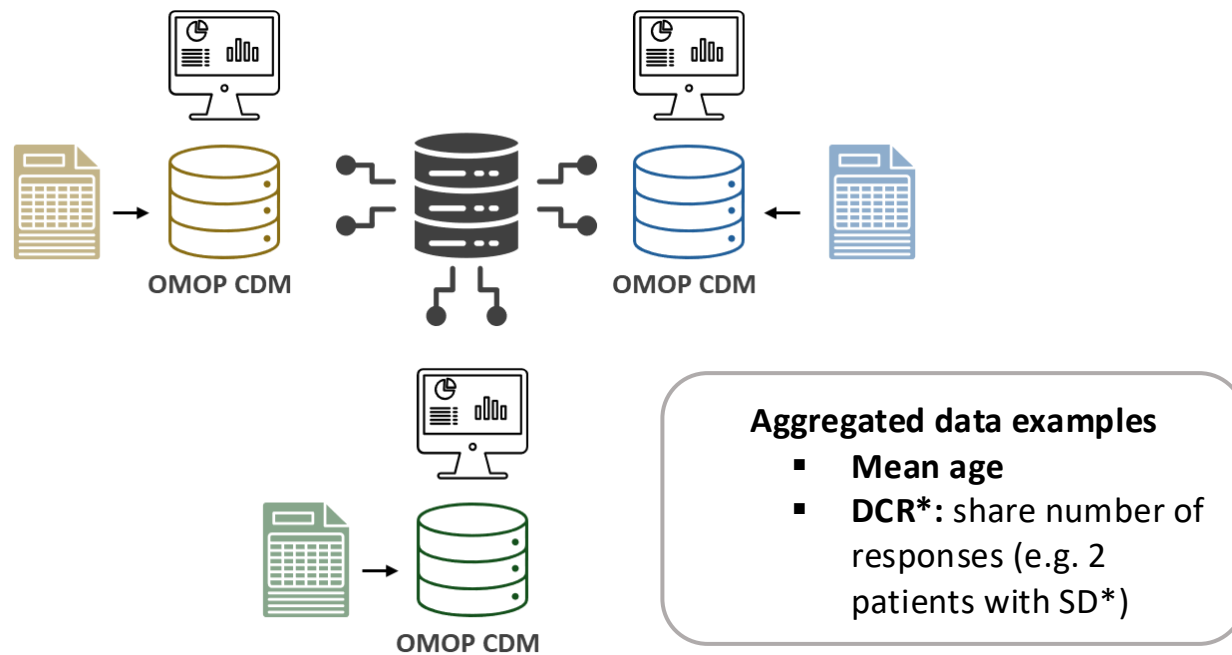


Cohort HER2 crc



Federated Analyses

Collaborations outside PRIME-ROSE



Source data is kept locally

Avoids sharing sensitive data

Each site shares **outcome statistics** of a complete cohort

Thank you!

Acknowledgements

Kjetil Taskén - PRIME-ROSE Project Coordinator (Oslo University Hospital)

All members of the PRIME-ROSE consortium

NOR-OMOP (OHDSI Norwegian node) - Siri Larønningen & Espen Enerly



Funded by
the European Union

PRIME-ROSE: HORIZON-MISS-2022-CANCER-01-03 Grant 101104269



Maria Martin Agudo

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Gabriel Bratseth Stav

g.b.stav@ous-reasearch.no



Mapping Nordic Drug Product Identifiers to OMOP Standard Vocabularies

Petrica Olteanu

PhD cand.

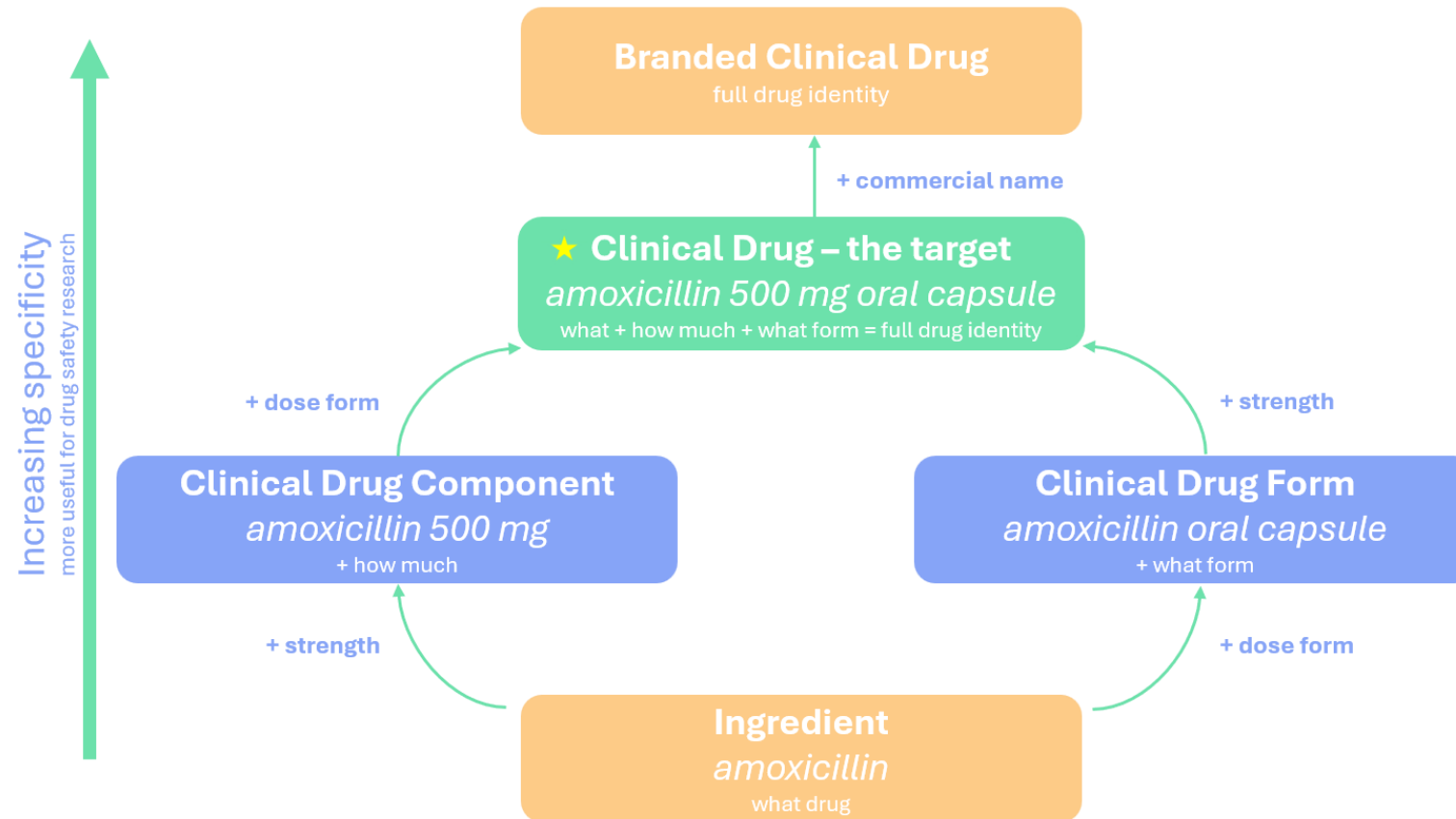
Pharmacoepidemiology and Drug Safety Research Group

23.09.2026



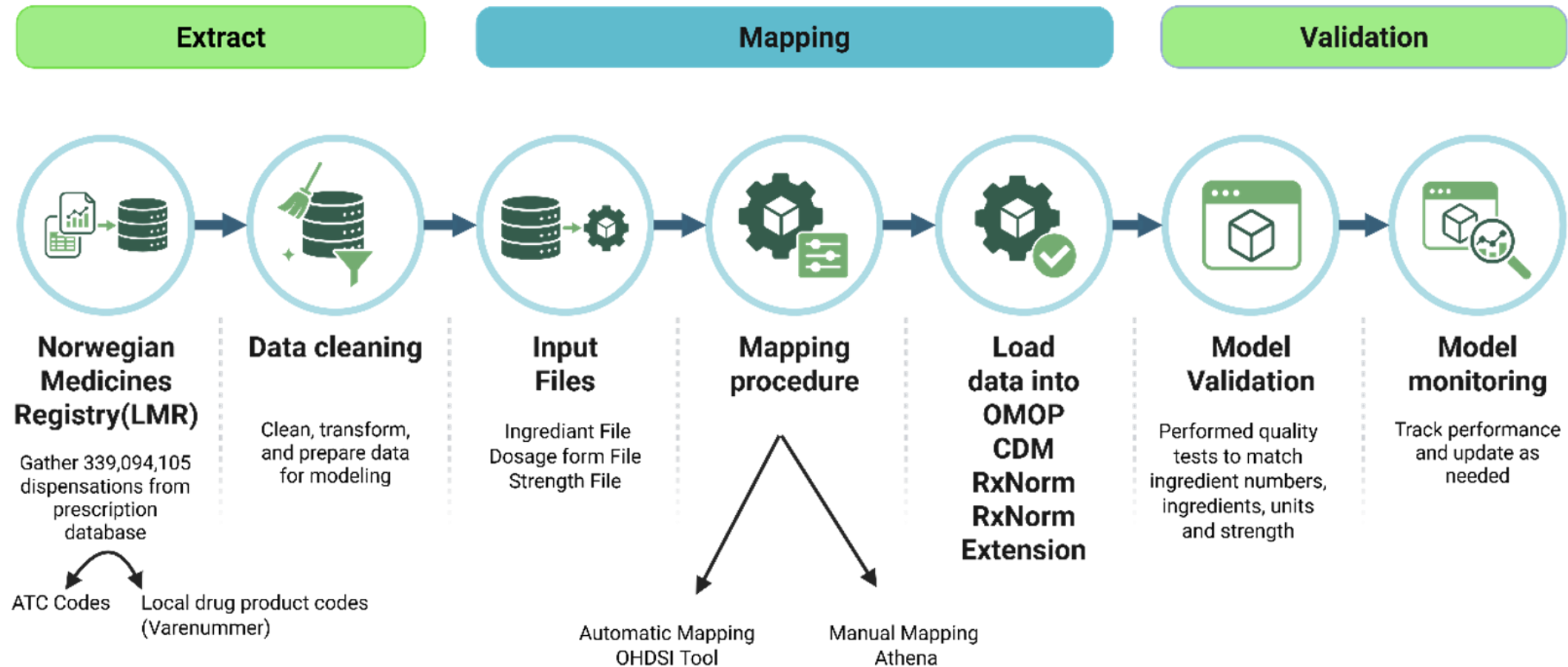
The shared problem

- Every Nordic country codes drugs with Varenummer
- Standard mappings usually stop at the *ingredient* — you know *what*, not *how much* or *what form*



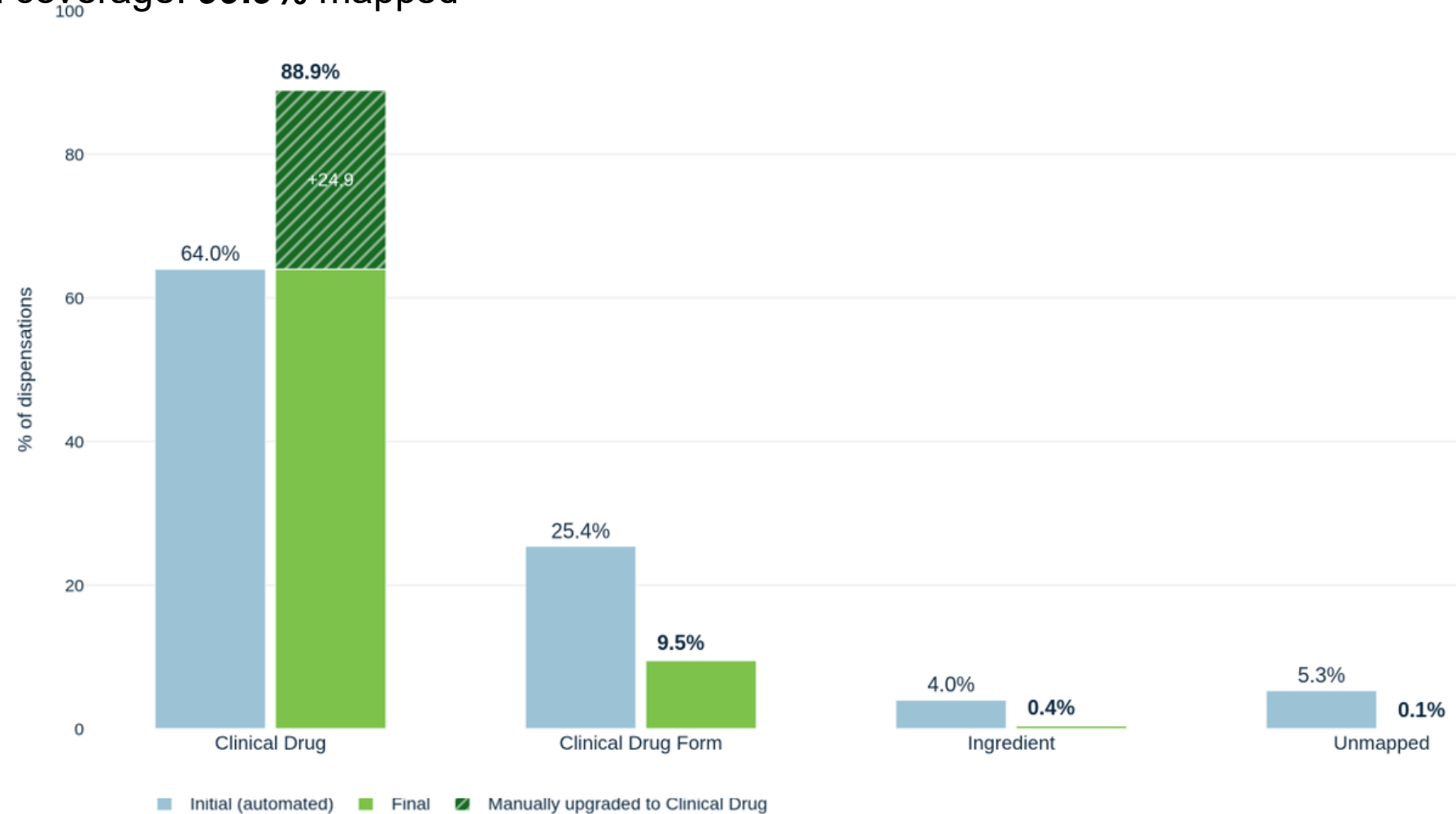
What we did

- 339M dispensations · 11,341 Varenummer · 2018–2023
- Two stages: **automated mapping** → **targeted manual curation**



It works

- Full drug identity: **64%** → **89%** of dispensations
- Overall coverage: **99.9%** mapped



The lesson

Automated mapping provides a strong foundation,
with **manual mapping** solving combination and multipack products

Implement **quality checks** to verify both the automated and the manual mapping

Source data quality matters

Yearly reiterations are needed

Mapping and validating the mapping is a project in itself

Thank you!

Read more about our research at [PharmaSafe@UiO](https://pharmasafe.uio.no/)





OMOP – interactive session

Nordic Health Data Summit 2026

Siri Larønningen, NOR-OMOP, Cancer Registry of Norway, Norwegian Institute of Public Health

23.09.2026



Results from the interactive OMOP-session

Nordic Health Data Summit 2026

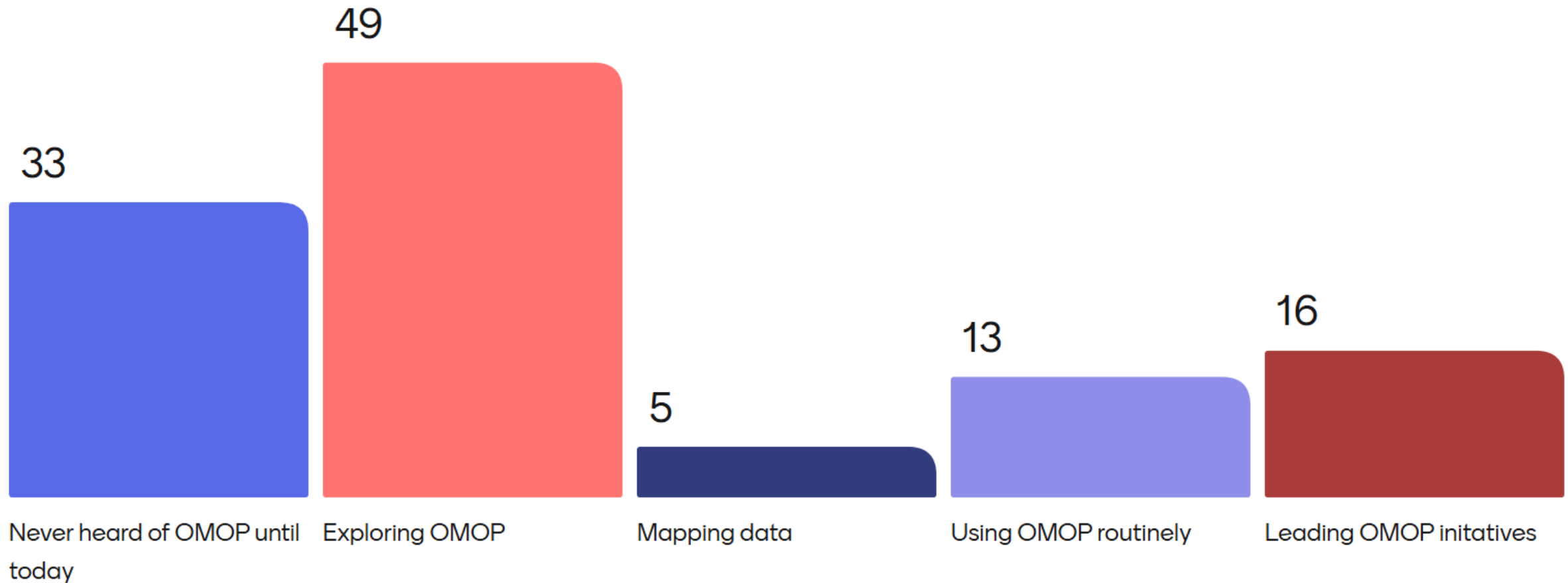
23.09.2026

Key insights (generated by Menti)

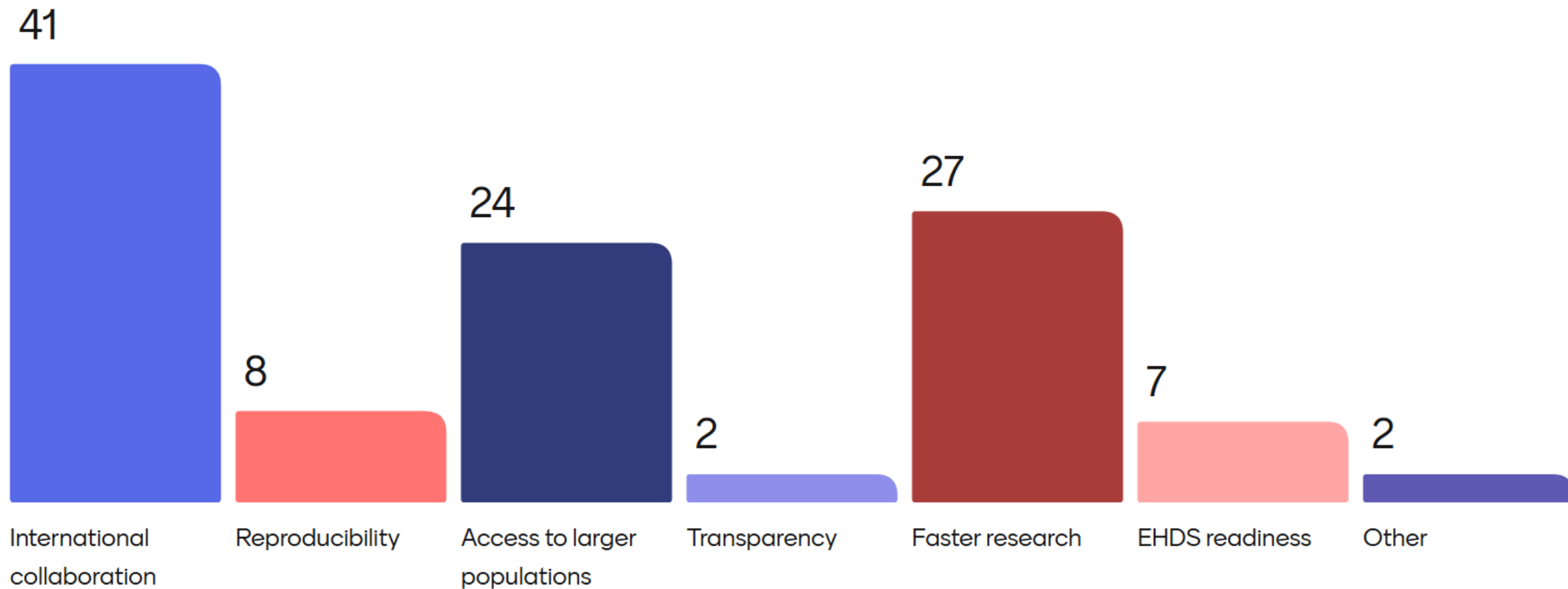
Participants see legal and governance barriers as the main constraint on Nordic health-data collaboration.

- OMOP interest is broad but maturity is uneven, suggesting the audience needs both entry-level clarity and advanced use cases.
- Rare diseases stand out as the clearest collaboration focus, suggesting strong demand for cross-border scale in smaller populations.
- Faster data access and better timeliness outrank AI tools, suggesting practical data usability matters more than advanced technology.

Where are you in your OMOP journey?



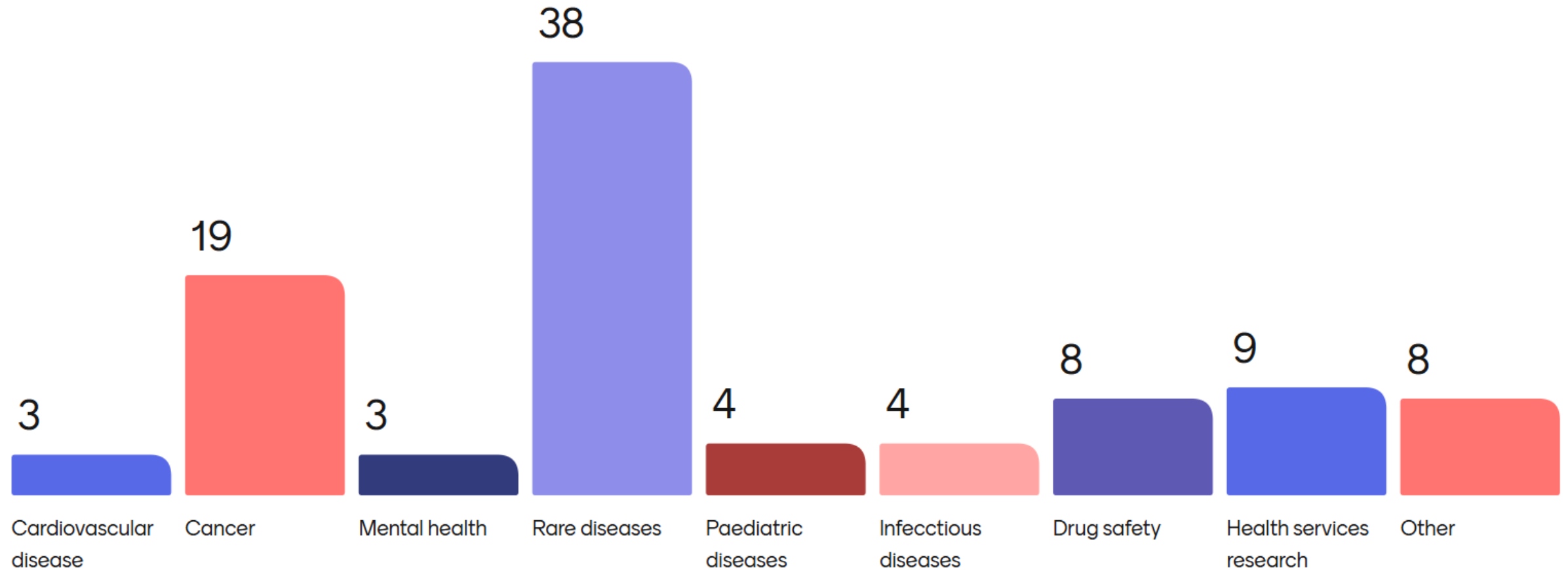
In your opinion - what is the biggest value of OMOP?



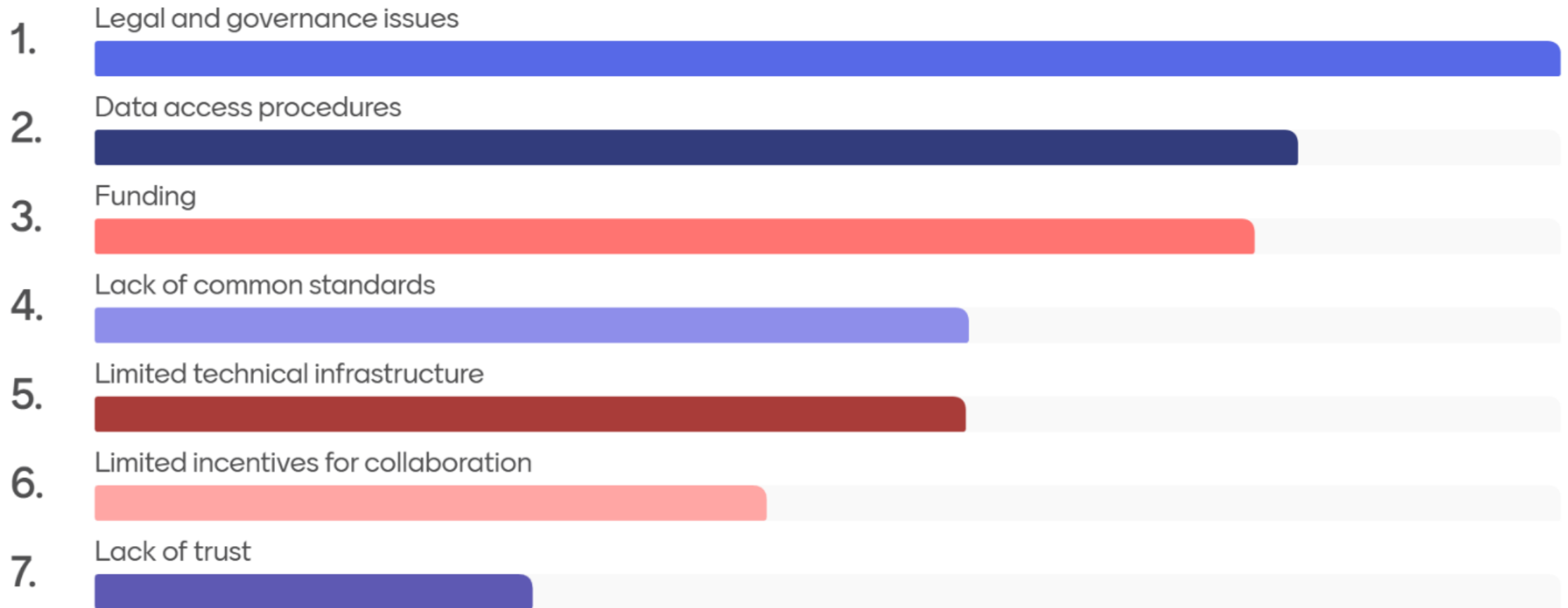
What is the biggest issue with OMOP?



Which area would benefit most from Nordic-Baltic OMOP collaboration?



Rank the biggest barriers to Nordic health data collaboration today





Rate the following statements

The Nordic countries are well prepared for EHDS

3.3

OMOP should become a core standard for secondary use of health data in the Nordics

3.3

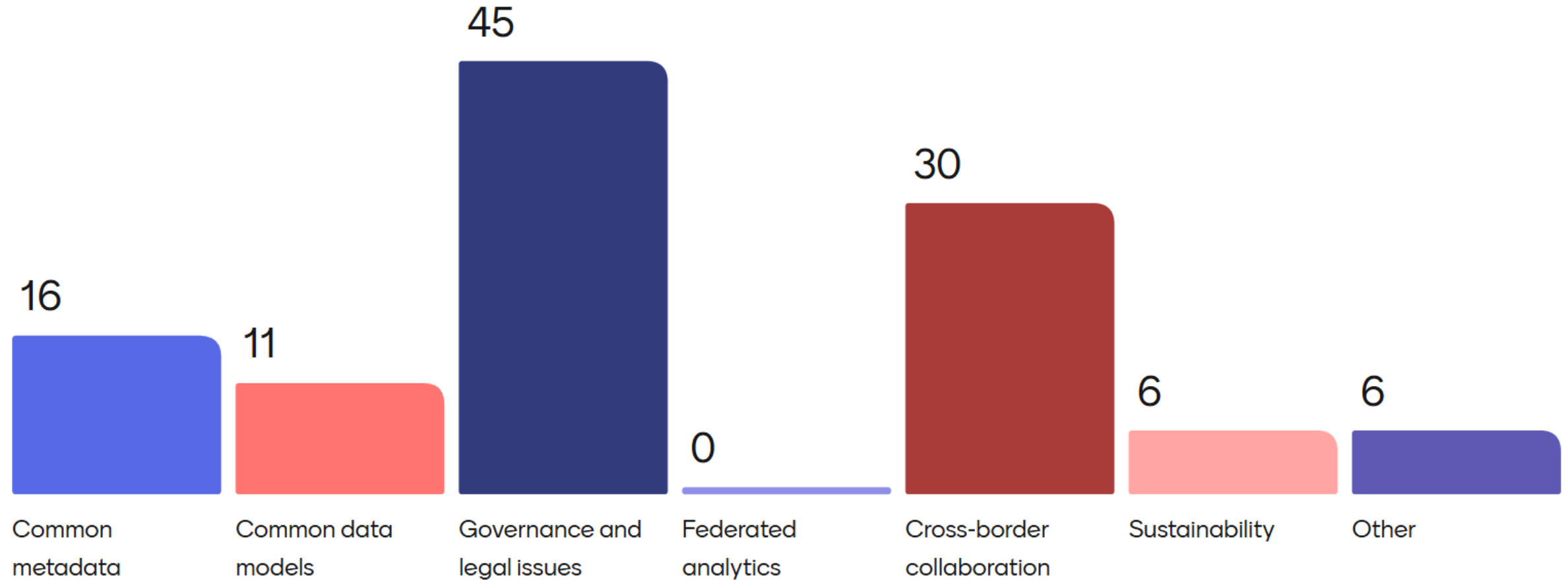
The biggest barriers to EHDS implementation are legal issues, governance and policy, not technology

4.0

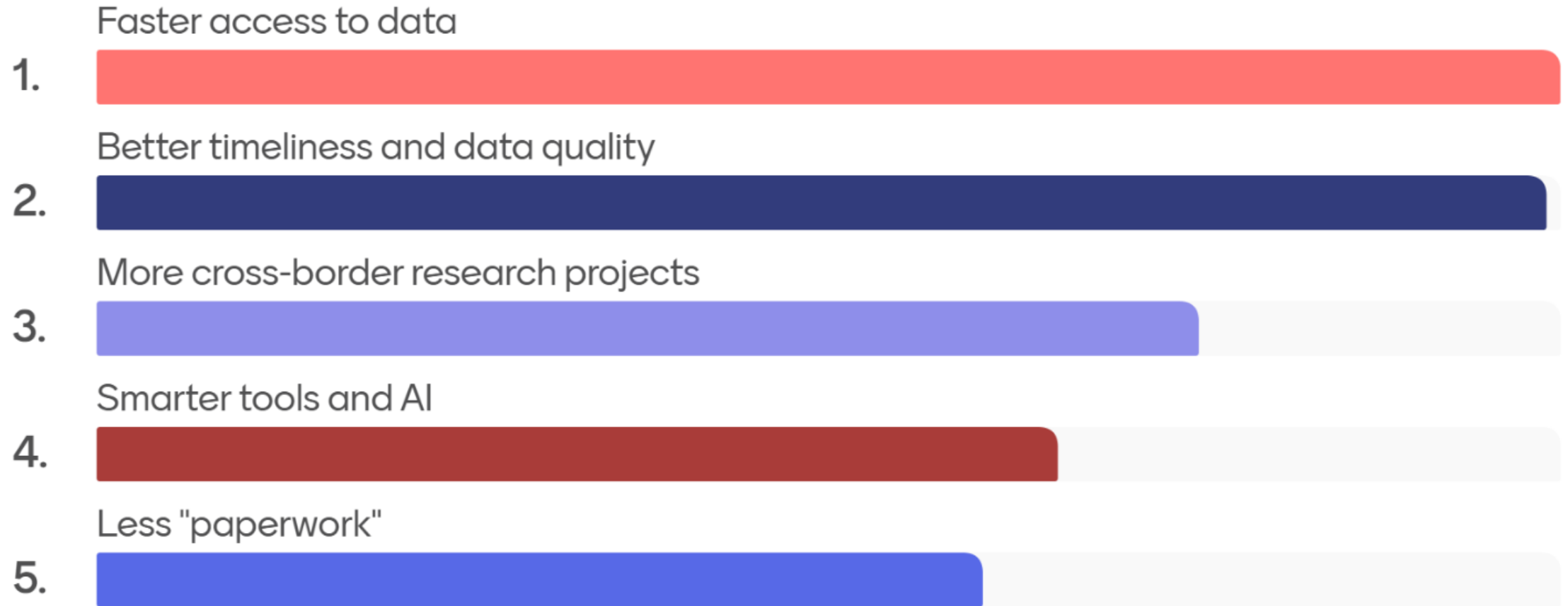
Strongly disagree

Strongly agree

What should be our top priority during the next 3 years?



If you had €5 million to improve health data research in the Nordics, what would you prioritize?



What is your advice for the Nordic OMOP-nodes for the next 2 years?

70 / 125

80



All groups

Expansion

Showcasing Impact

Data Mapping

Examples and Use Cases

Industry Engagement

Collaboration

Support for Countries

Communication

Inclusivity

Organizational Structure

Expansion

13 responses

Functional

Evaluate and change

Spread the word

Spread the word

Breath

More omop

Keep up

Keep up

Go fast

Keep going

VALO1B

Keep going!

Preach omop even more

Showcasing Impact

12 responses

Showcase citizen benefit

Show the results

Experience Sharing

More visibility

Promote awareness

Show value

Bring information out about possibilities

Publish more

Mobilize leadership and desition makers to understand what this is all about

Let's raise our ambition to next level and be bold nordics. From academic talk to concrete and commercialed outcomes.

Keep positive

Continue the good work

Data Mapping

11 responses

Share mappings	Share mappings
Mapping of free-text	Pocedure code mapping
Procedure code mapping	Describe your datasets and variables well and support each other in publishing in your metadata catalogues in harmonised manner
Make it ready for federated AI Analysis	Set a target to get OMOP known.
Optimize ATLAS	Look outside registry data
Optimizing freetext	

Examples and Use Cases

11 responses

More use-cases

More examples

More examples

Examples of cases that actually work

Communicate better what omop really is with examples

Write criteria where it works

Criteria for when OMOP actually works

Publish a set of synthetic data for use in teaching, student projects and analysis pipeline development

Involve a wide range of different research fields. Use of register data differs a lot between disciplines. Not one size fits all!!!

Think about automation and quantitative measures of quality

It's not needed

Industry Engagement

7 responses

Involve industry

Involve industry

Involve industry

Involve industry

Involve pharma/industry

Explore health dataholders in other sectors, both public and private

Talk to the register owners.

Collaboration

7 responses

Collaborate

Collaborate

Collaborate

Private - Public collaboration

Collaborate on quality of vocabulary mappings

More hype, information and collaboration across the borders.

Partnership among major EU players

Support for Countries

6 responses

Expand with more partners in each country

Motivate registry holders in all countries

Support Sweden, they are lagging behind. :)

Support Finland, they want to succeed

Support those those exploring OMOP

Embrace the Baltics

Communication

6 responses

Communicate success	Transparency
Beer	Beer
Take care	Dont hive lo

Inclusivity

4 responses

Inform and include

Include all dataholders

Be more inclusive! Invite more people to your regulator meeting. What about using Viva engage for this purpose? Or opus calendar?

Involve patients and their families from the early stages of planning, development, execution and implementation of Research projects, initiatives and their results in lay man terms

Organizational Structure

3 responses

organizational structure

Organise well

Lets have lower level meetings as well



A look ahead

EHDS, Nordic collaboration and the future
of Nordic and Norwegian health data

Nordic Health Data Summit 2026

Siri Larønningen, NOR-OMOP, Cancer Registry of Norway, Norwegian Institute of Public Health

23.09.2026

Nordic health data

... are the best in the world...

- Unique personal identifiers
- Strong governments
- Long history of health registries
- Universal health care
- High-quality public data
- Trusted public institutions
- High levels of societal trust
- Culture of collaboration
-



Data sharing methods



Public, anonymous statistics

Web-based, online statistics

Adjusted public statistics on demand (via application)



Tailor-made statistics



Self-service systems



Distributed analysis



Federated computing



Data processing in Secure Processing Environments (SPE)/Trusted Research Environments (TRE)

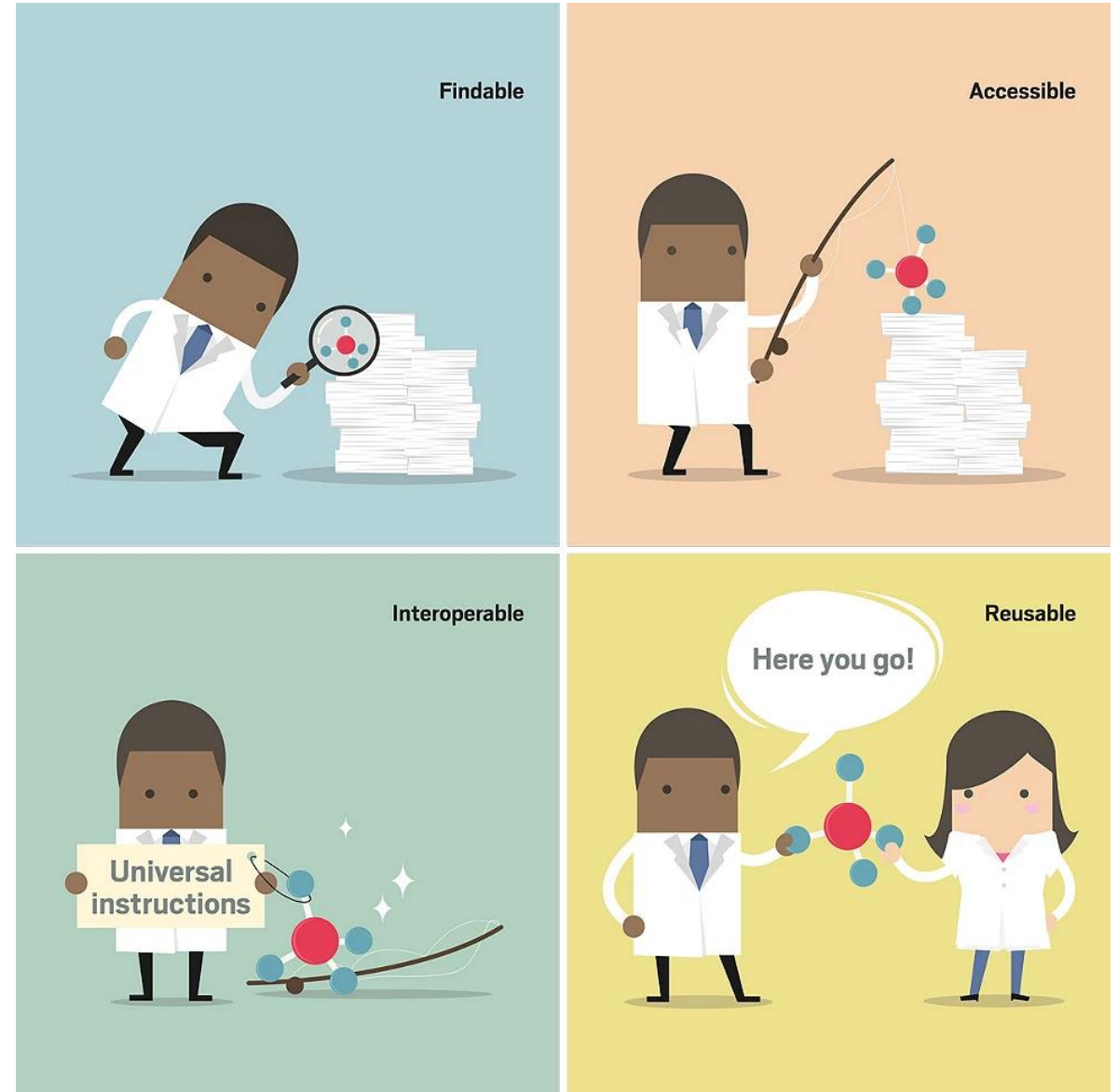


«Old school» sharing of datasets (copying data for local use)

FAIR data

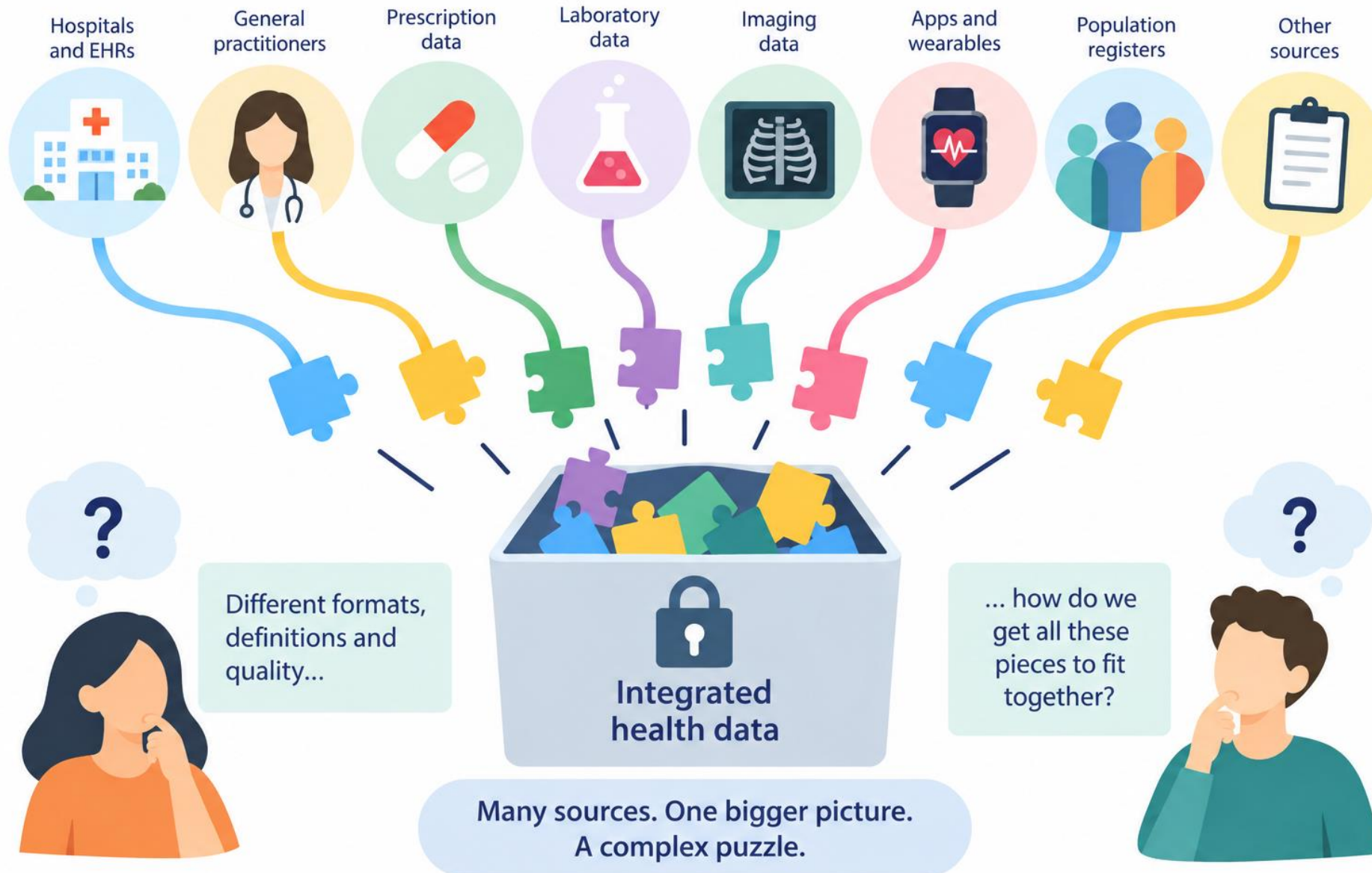
- Findable
 - Through metadata catalogues
- Accessible
 - As open as possible, as closed as necessary
 - “One way in”
- Interoperable
 - Common data models
- Reusable
 - Metadata
 - Common data models

→ EHDS



Credit: Yang H. Ku/C&EN/Shutterstock

Puzzling it all together



Common Data Models

Driven by local/thematic needs

- «Call for data»

Efforts to bridge different sources

Examples...

- FHIR (Fast Healthcare Interoperability Resources)
- EEHRxF (European Electronic Health Record exchange Format)
- OMOP (Observational Medical Outcomes Partnership)

Data protocol for ECIS

Table 1. Variable name, description, format, missing/unknown values and coding schema

Variables should be separated by a semi-colon

Patient variables

Variable name	Variable description	Format	Maximum length	Missing/unknown	Coding
PAT ¹	Patient identification code	A	50	Not allowed	According to registry coding
MoB	Month of birth	F	2	99	Range of allowed values: 1 - 12
YoB	Year of birth	F	4	9999	Range of allowed values: > 1842 and ≤ the current year
Sex	Sex at birth	F	1	9	1 → Male 2 → Female 3 → Other

Tumour variables

Geo_code	Code for the geographical area of residence at Diagnosis	A	10	XX99	NUTS2 when available or the highest level of administrative sub-division that can be provided. Blank → not applicable
Geo_label	Name of the geographical area of residence at Diagnosis	A	50	9	Blank → not applicable
TUM	Tumour identification	A	50	Not allowed	According to registry coding
Age	Age at diagnosis (incidence date) in years	F	3	999	Range of allowed values: ≥ 0 and < 121
Moi	Month of incidence	F	2	99	Range of allowed values: 1 - 12
Yoi	Year of incidence	F	4	Not allowed	Range of allowed values: From 1941 to present

**We have shown that it is
actually possible!**

However...

- OMOP is not perfect
 - Loss of granularity
 - Unmappable concepts
 - Same concept doesn't necessarily mean same meaning
 - Quality measures and descriptions are important
- Also
 - OMOP requires investment (money, people, work)
 - OMOP requires interdisciplinary collaboration
 - OMOP requires sustainability!!!



Goals of the Nordic-Baltic OMOP Network

- Connect people
- Learn together
- Support each other
- Share what works
- Reuse, don't reinvent
- Solve real problems



→ Making every OMOP project easier than the previous one

Closing remarks on session 4



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of Ministers

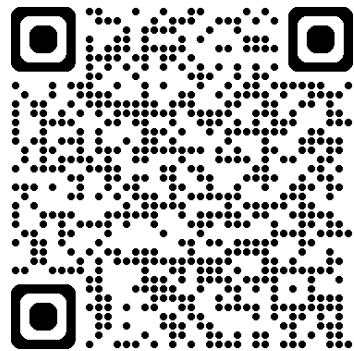
SITRA



Coffee break

The event continues at 16:05 (CEST)!

View the agenda here



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SITRA

SESSION 5:

Status and possibilities for Norwegian health data



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SITRA

Session 5: Status and possibilities for Norwegian health data

Time	Title	Speaker
16:05 – 16:07	Introduction to the session	
16:07 – 16:20	Norwegian Health data Strategy 2025 - 2027	Trine Orten Groven
16:20 – 16:33	The national landscape of Norwegian health data	Håvard Kolle Riis
16:33 – 16:48	Why we need Cohort studies – lessons from the Mother, father and child cohort study (MoBa)	Siri Eldevik Håberg
16:48 – 17:03	Opportunities and pitfalls in Norwegian survey and register data for ageing research - lessons from The HUNT Study	Håvard Kjesbu Skjellegrind
17:03 – 17:05	Closing remarks	

Status and possibilities for Norwegian health data



Trine Orten Groven

Department director,
Norwegian Institute of
Public Health



Håvard Kolle Riis

Project Owner EHDS,
Norwegian Institute of
Public Health



Siri Eldevik Håberg

Research director, Norwegian
Institute of Public Health and
Director, Centre for Fertility
and Health, Norwegian
Institute of Public Health



**Håvard Kjesbu
Skjellegrind**

Associate Professor, Hunt
Research Centre,
Norwegian University of
Science and Technology



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of Ministers



Nordic Health Data Summit 2026

Session 5: Status and possibilities for Norwegian health data

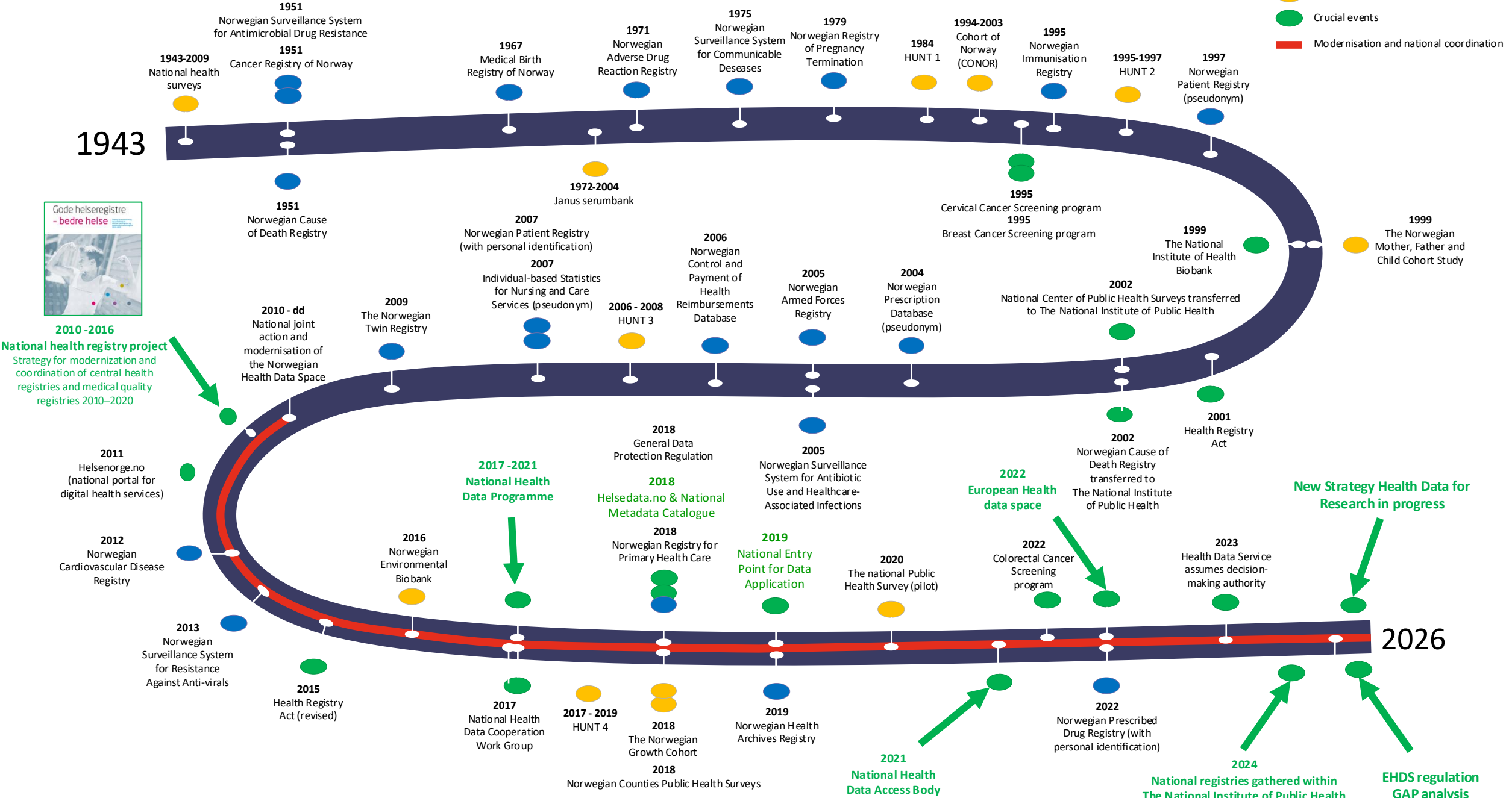
23.09.2026



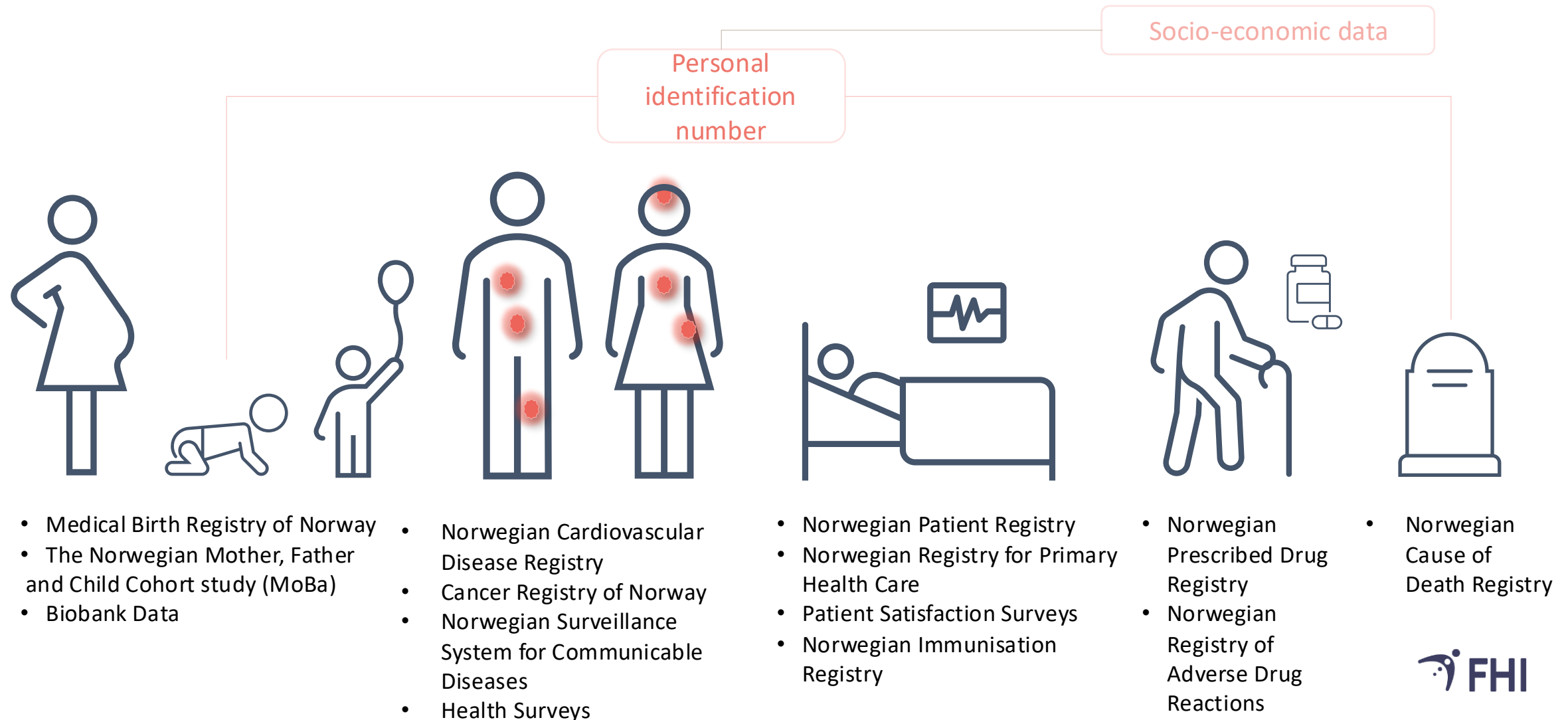
Norwegian Health Data Strategy 2025 - 2027

Eight Decades of Norwegian Health Data

- Establishment of health registry
- Establishment of health survey
- Crucial events
- Modernisation and national coordination



New Opportunities Through a Unified Health Data Environment at the Norwegian Institute of Public Health

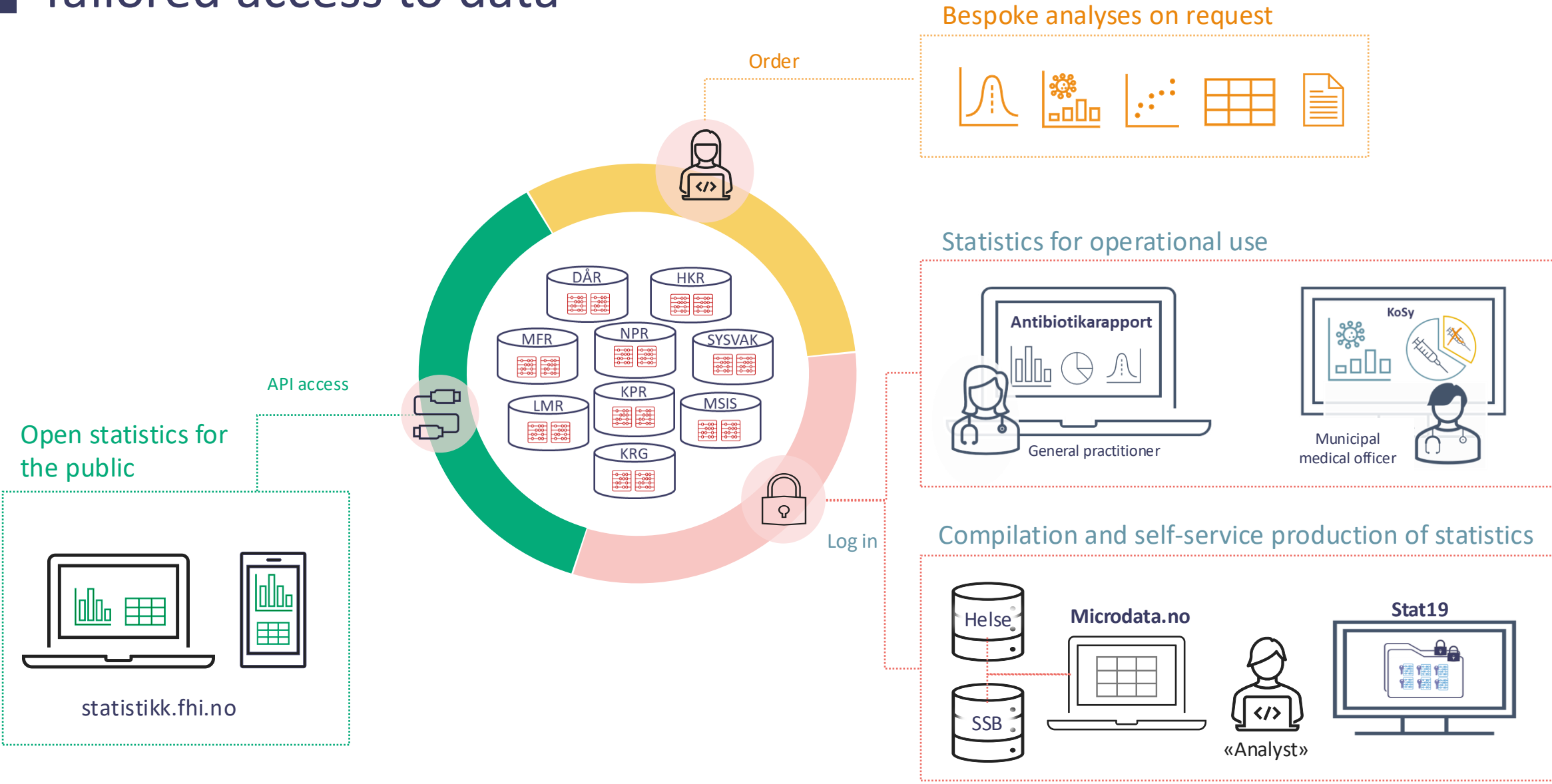


Norwegian Health Data Strategy 2025 - 2027

		Sub-goal 2025-2027:	Strong foundations Effective value chains across our organisation 
1	 Deliver data and statistics rapidly	• Fast-track applications • Tailored access • Expanded self-service	
2	 Enrich data, focusing on the municipal services and population	• Full municipal service coverage • Continuous data flows • Insight into fast-evolving services	
3	 Reduce the reporting burden on healthcare personnel	• Relevant and current • Simple by design • Automated wherever possible	
4	 Strengthen crisis resilience and knowledge development through national and international collaboration	• United in crisis • World-class data • European alignment	
5	 Safeguard public trust through responsible handling of health data	• Transparent data processing • Protected participant rights • Precaution first	



Tailored access to data

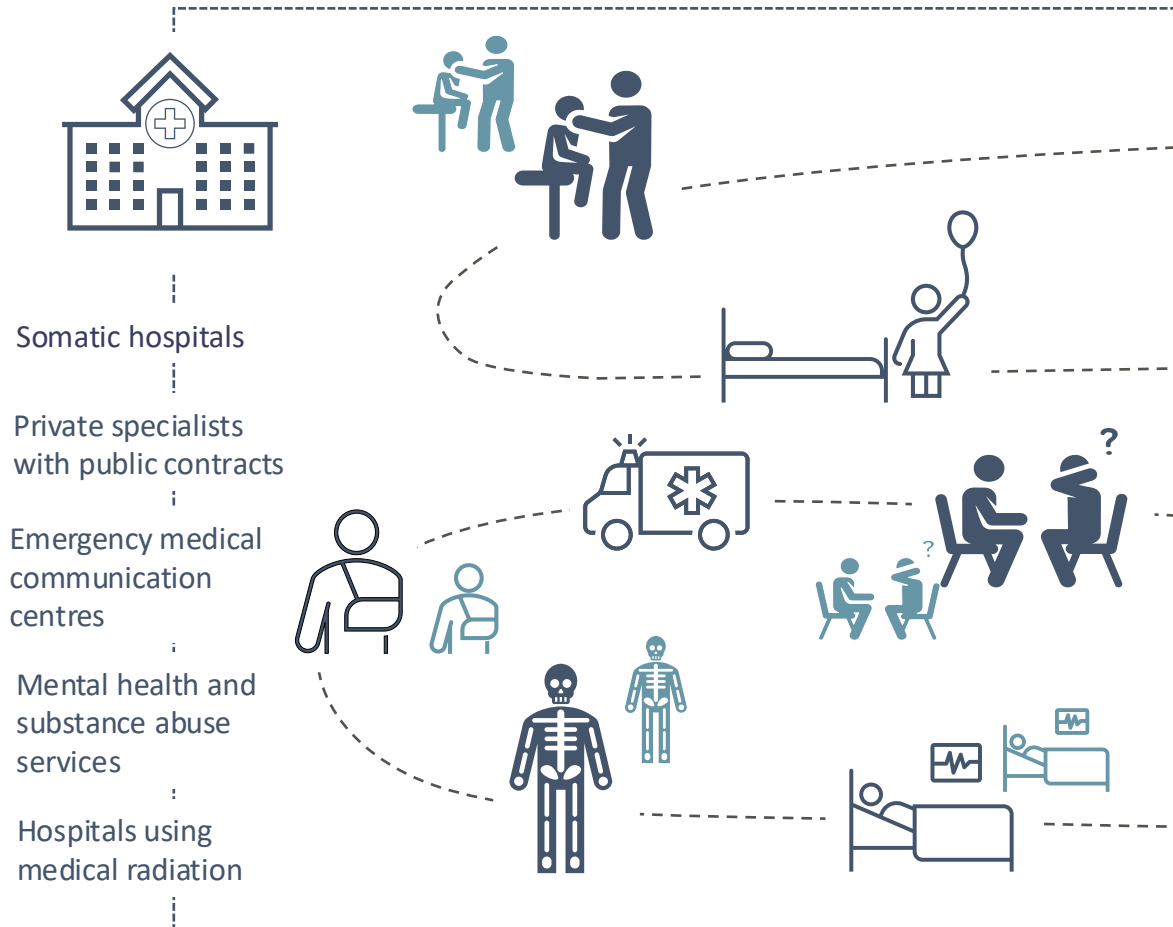




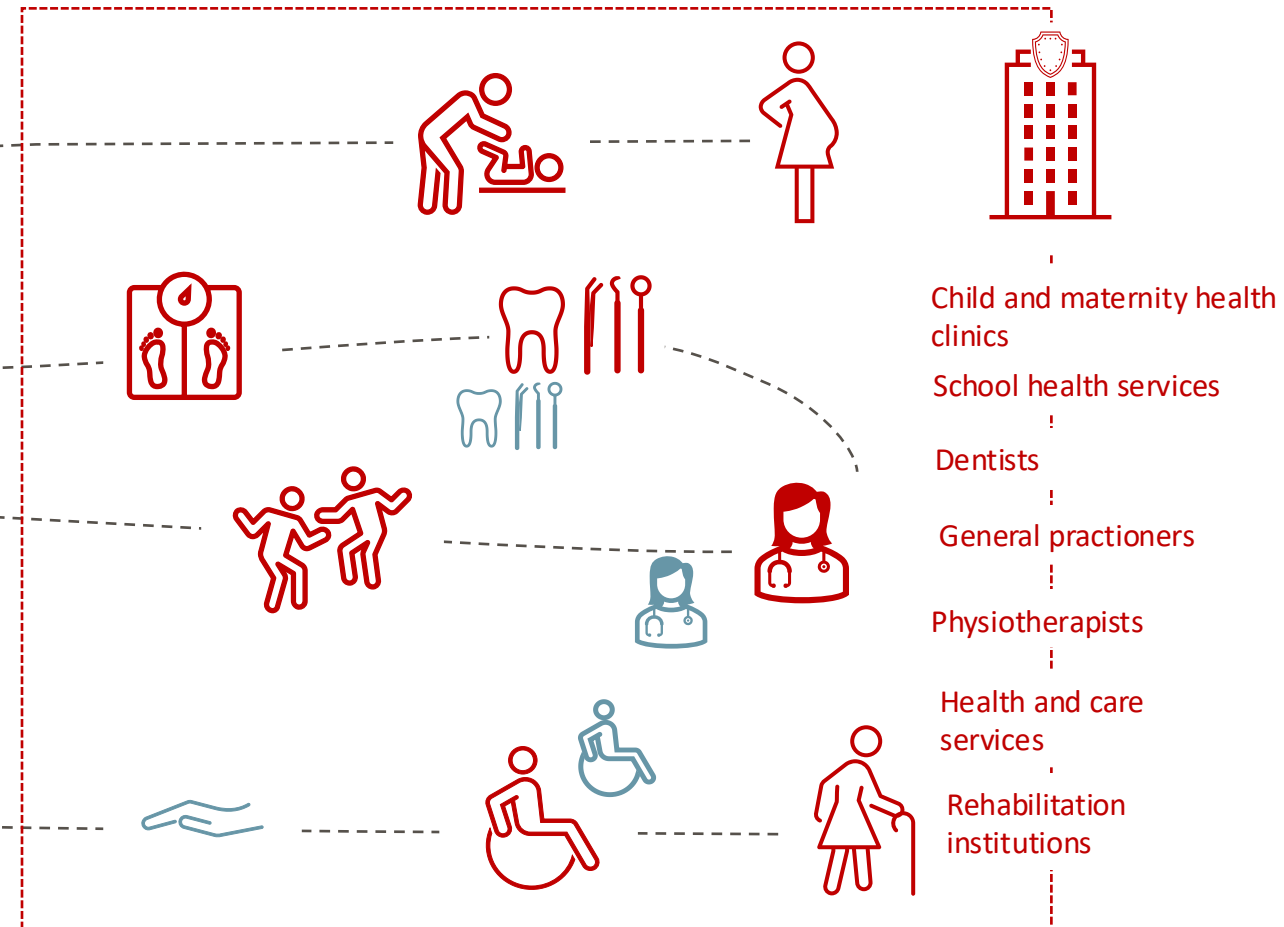
Enriching data on municipal health services

Our registries do not yet cover the whole health service

Specialist health services



Municipal health and care services



Goal: full coverage, continuous data flows, and insight into rapidly evolving services

Norwegian Health Data Strategy 2025 - 2027

		Sub-goal 2025-2027:	Strong foundations Effective value chains across our organisation 
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5	 Safeguard public trust through responsible handling of health data	• Transparent data processing • Protected participant rights • Precaution first	



Strong Foundations: Effective value chains across our organisation

Joint management of national health data creates the opportunity to build coherent, high-quality value chains by aligning systems, organisation and processes across data sources.

We will harmonise data, processes and infrastructure, reuse existing solutions where appropriate, and explore how AI can advance the health data field.

Our enablers for implementation:

People	 Resource allocation	 Competence	 Motivation	 Organisation and processes	 Recruitment
Legal and regulatory framework	 Interpretation and practice	 New rules and legislation			
Technology	 Sourcing and vendor management	 Information security	 Architecture governance	 Technology development	 Technology research
Data governance	 Standardisation	 Data sharing principles	 Data management principles	 Metadata	 Information models
Funding	 Financial management	 Core funding	 External funding	 Service fees	
External collaboration	 Governance dialogue	 Alliances and partnerships			
Communication	 External communication	 Information sharing	 User engagement		





The national landscape of Norwegian health data

Norwegian Health Data ready for secondary use: adding EHDS categories to existing structured registries (1950–2031)

Growth of National health registries, Medical quality registries, Health surveys, and effect of additional EHDS categories

- Key Insights
- Quality registries: 1 → 70
 - EHDS require adding categories: → by 2031
 - Registries provide the foundation

Foundation

National health registries: 6, incl.

- Birth
- Adverse drug reactions
- Communicable diseases

Health surveys: 2, incl.

- X-ray screening TBC

Acceleration

National health registries: 10, incl.

- Prescription database
- Specialised care services
- Cardiovascular diseases

Medical quality registries: 35, incl.

- Breast cancer
- Melanoma
- MI

Health surveys: 22, incl.

- Regional health surveys
- (Oslo) Immigrant Health Study

EHDS ERA

National health registries: 15+?

Medical quality registries: 70+?

Health surveys: 15+?

- Additional categories and data holders
- Omics and images causing exponential growth
- Clinical studies

2029 -2031

Early beginning

National health registries: 2

- Deaths
- Cancer

Expansion Begins

National health registries: 7, incl.

- Immunisation

Medical quality registries: 6, incl.

- Paediatric cancer
- Cardiac surgery

Health surveys: 5, incl.

- MoBa
- HUNT
- The age-40 programme

Today's ecosystem

National health registries: 14, incl.

- Primary care services
- Anti-virus resistance

Medical quality registries: 64, incl.

- Pulmonary cancer
- Gyn. Cancer
- Pancreatic cancer

Health surveys: 15, incl.

- National health survey
- Youth studies

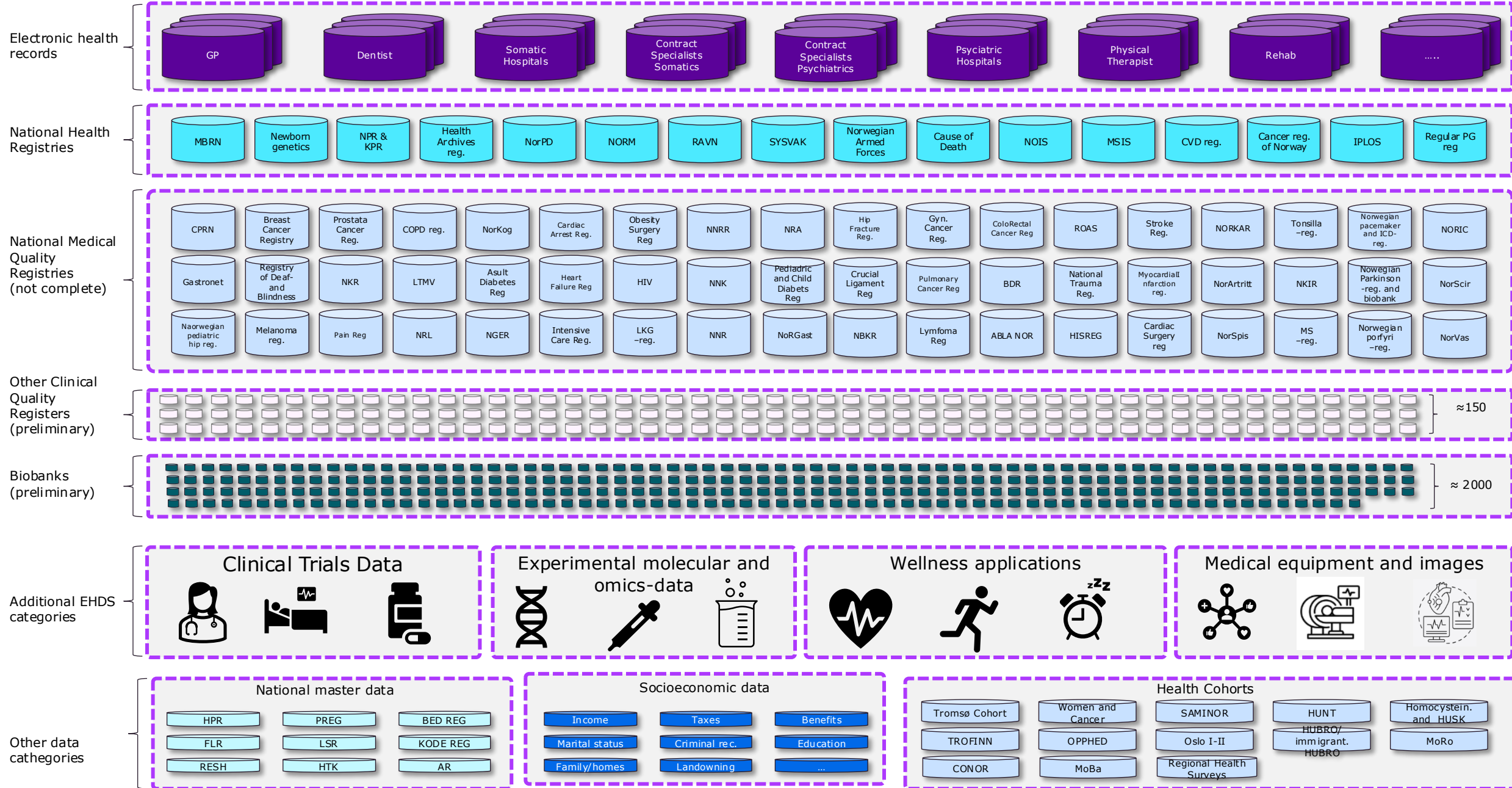
(Electronic patient records)e

Alternatives TBD:

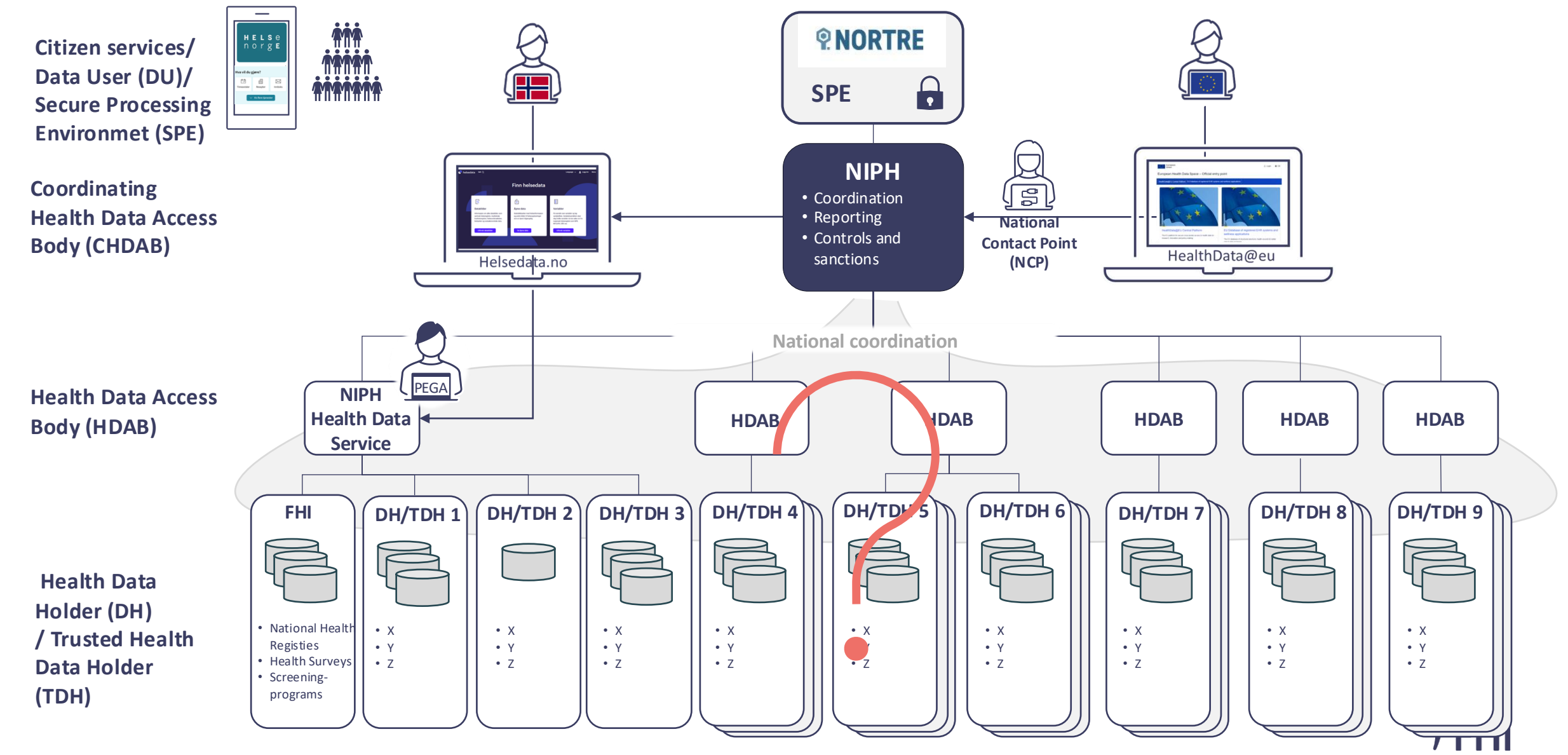
- a) include EHDS categories in registries?
- b) distributed or centralized storage of omics and images?
- c) add ~2000 required data holders 1 by 1?
- d) combination of a) + c), depending on b)

Norwegian health data structured largely as registries parallel to EHR systems. **How** and **where** to structure additional required categories for secondary use under EHDS to be decided.

Data Sources / Data Holders on Individual Level Health Data

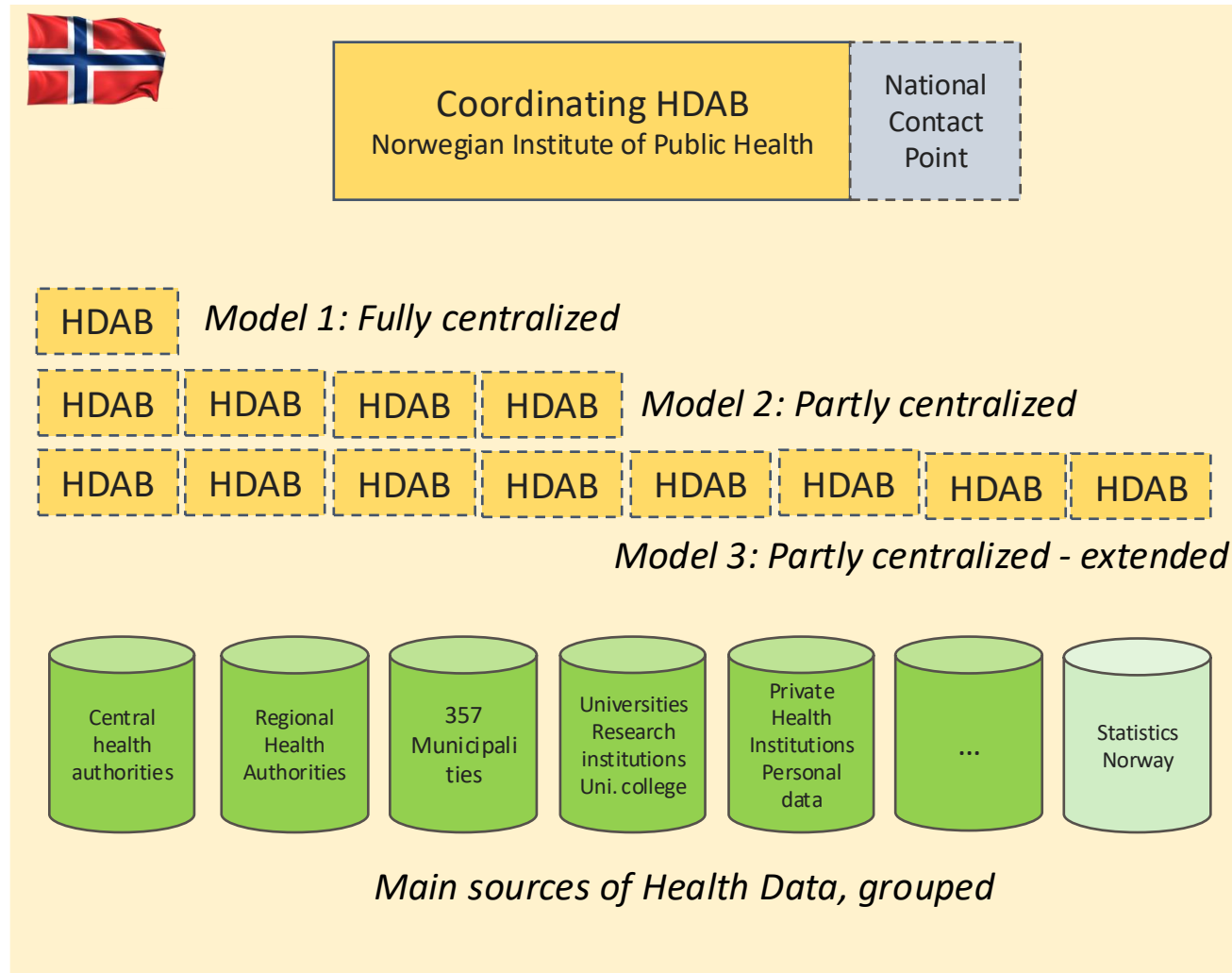
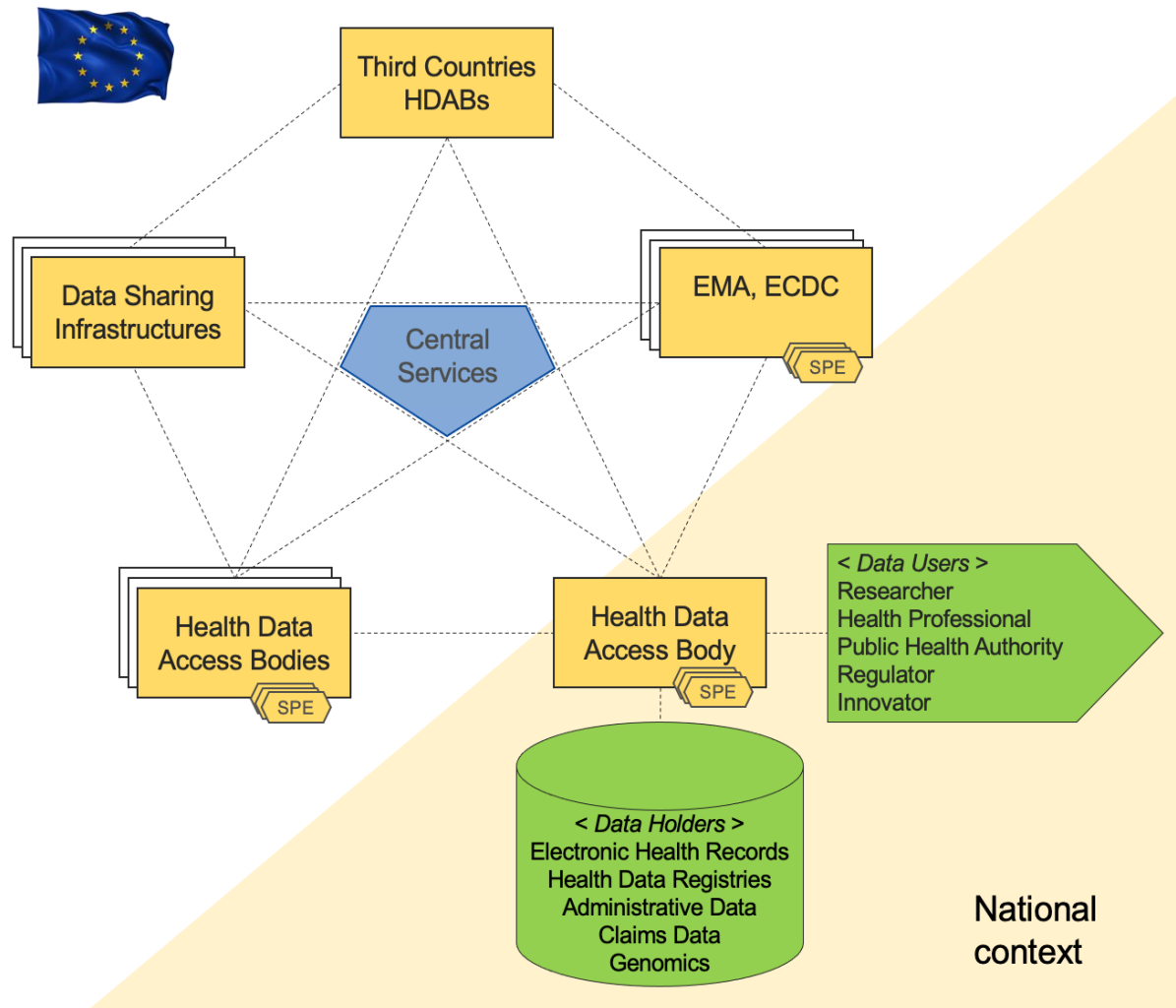


EHDS: We have to establish a national network for health data access within 2029

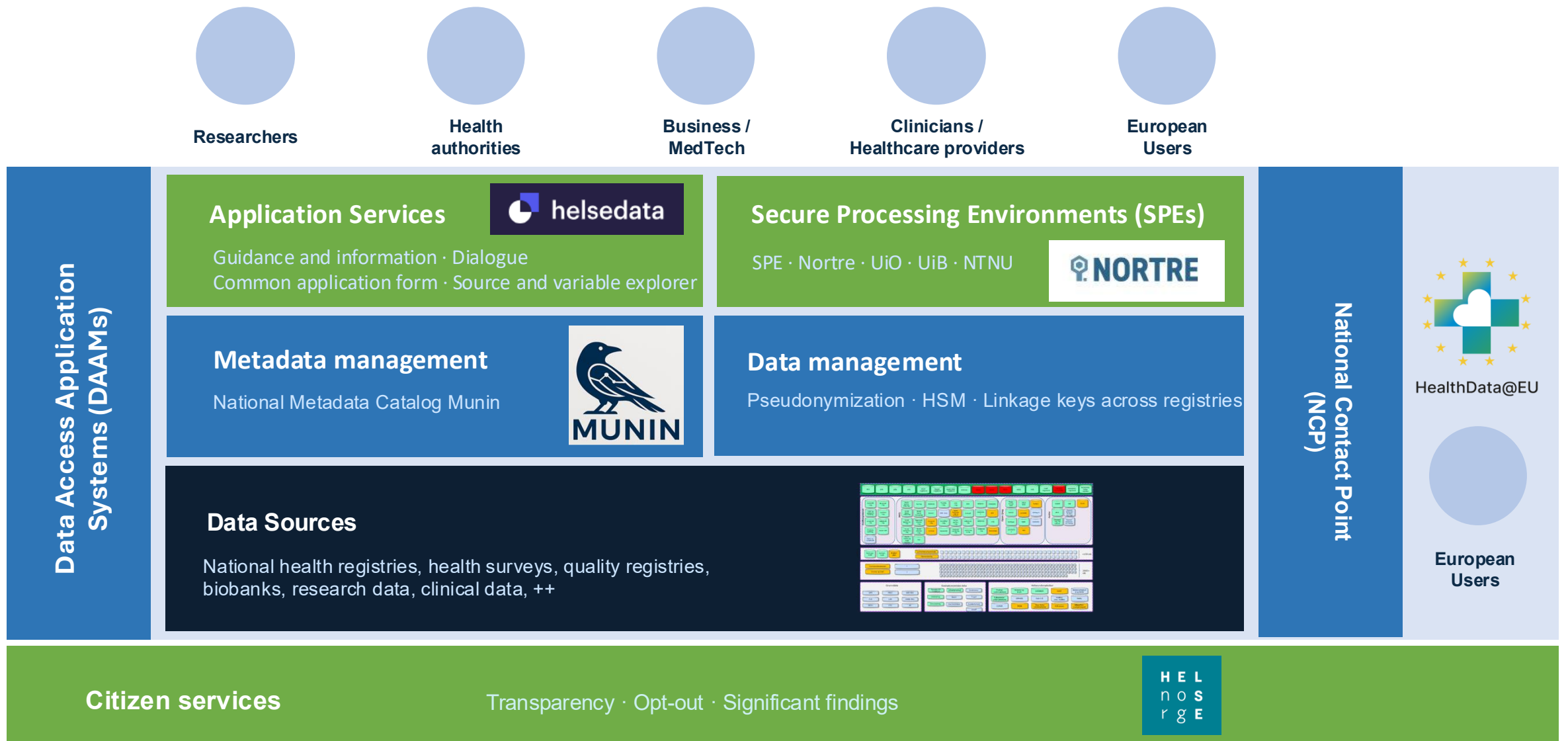


Deciding on HDAB structure in Norway:

Alternative models are being evaluated by cost-benefit analysis



EHDS – National Target Architecture for Digital Capabilities



- Norwegian Patient Registry
- Norwegian Registry for Primary Health Care
- Norwegian Cause of Death Registry
- Medical Birth Registry of Norway
- Norwegian Surveillance System for Communicable Diseases
- Norwegian Immunisation Registry
- Norwegian Cardiovascular Disease Registry
- Norwegian Adverse Drug Reaction Registry
- Norwegian Prescribed Drug Registry
- Norwegian Health Archives Registry
- Cancer Registry of Norway

Health Data Access Body



National access point
for health data
for secondary use



www.helsedata.no

Guidance & Information



The portal helsedata.no



100 sources

Case Management System



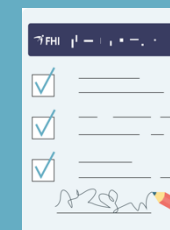
PEGA

Variable and source explorer



47 sources

National Application Form



50 sources

National Data Permit Authority



11 kilder

www.helsedata.no



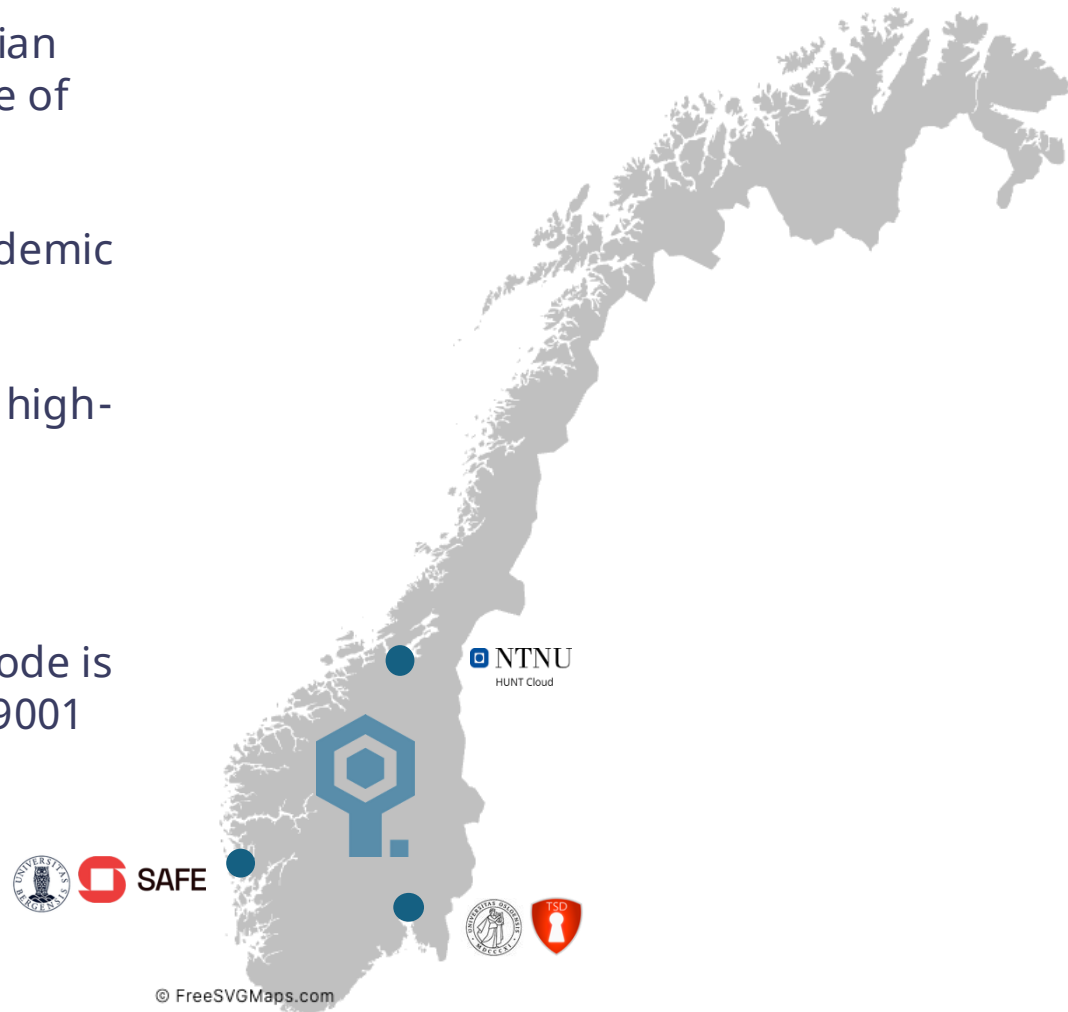
Helsedataservice

service@helsedata.no



Norwegian Institute of Public Health

- Established through an active collaboration between the Norwegian Ministries for health and education to enable more and better use of secondary health data.
- We have connected and strengthened three well-established academic infrastructures for sensitive data to meet EHDS requirements.
- We got access to a broad portfolio of research services, including high-capacity computation and advanced AI capabilities.
- Current user base is >10,000 researchers and >2,000 projects.
- The security foundation is built on international standards: one node is compliant with ISO 27001 (security), ISO 27701 (privacy) and ISO 9001 (quality). Two nodes are certifying for ISO 27001.
- We support further development towards a distributed SPE:
 - One point of contact for the government
 - Common governance and harmonized EHDS implementation
 - One secure data-entry point from HDABs
 - Continuous service adaptation as scientific fields evolve





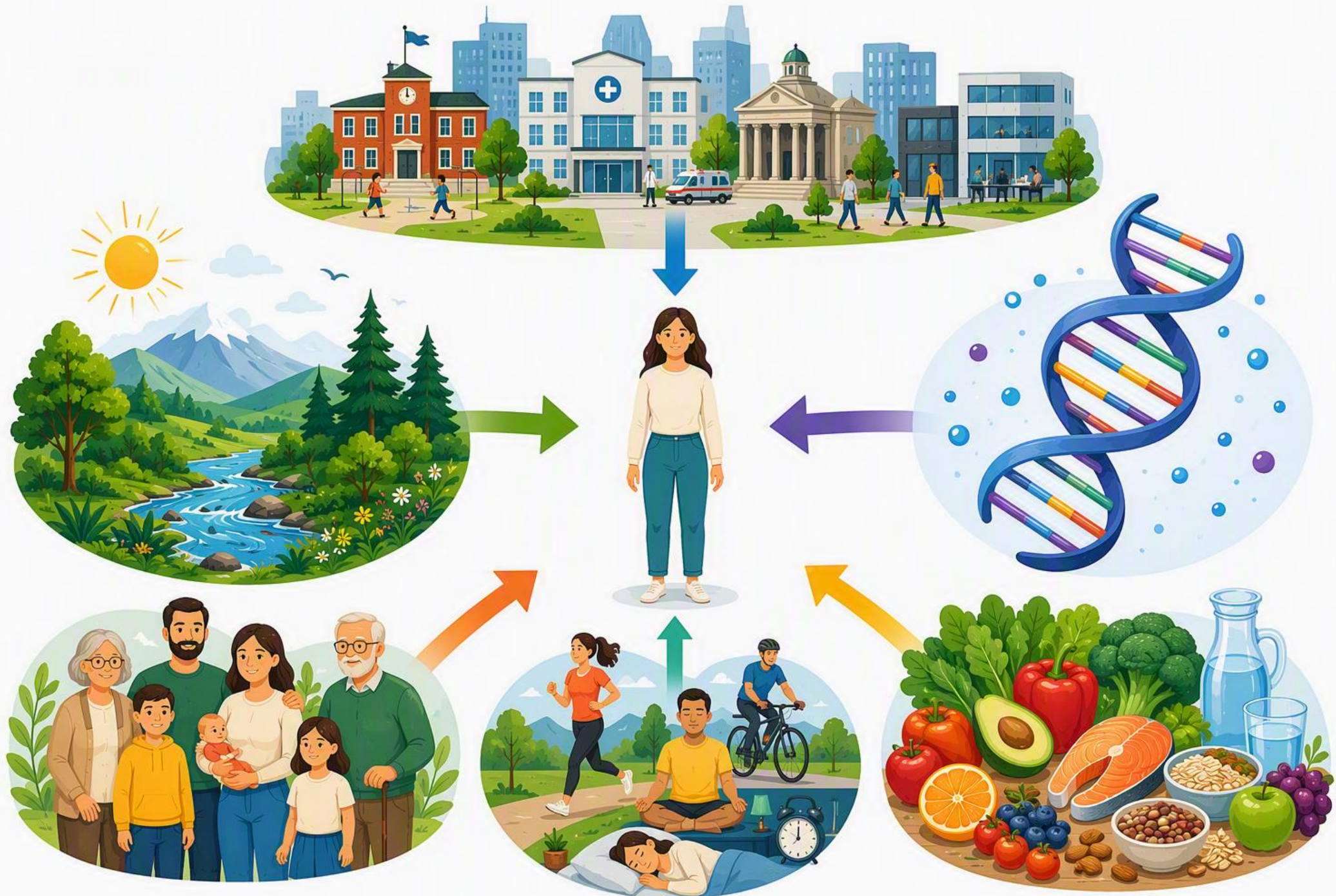
Why we need Cohort studies – lessons from the Mother, father and child cohort study (MoBa)

Siri Eldevik Håberg, MD, PhD

Research Director NIPH

Improving population health

- Understand trends in health and diseases
- Find effective prevention and interventions
- Develop effective treatments







The Norwegian **Mother, Father and Child** Cohort Study 

Lifecourse

Generations & Families

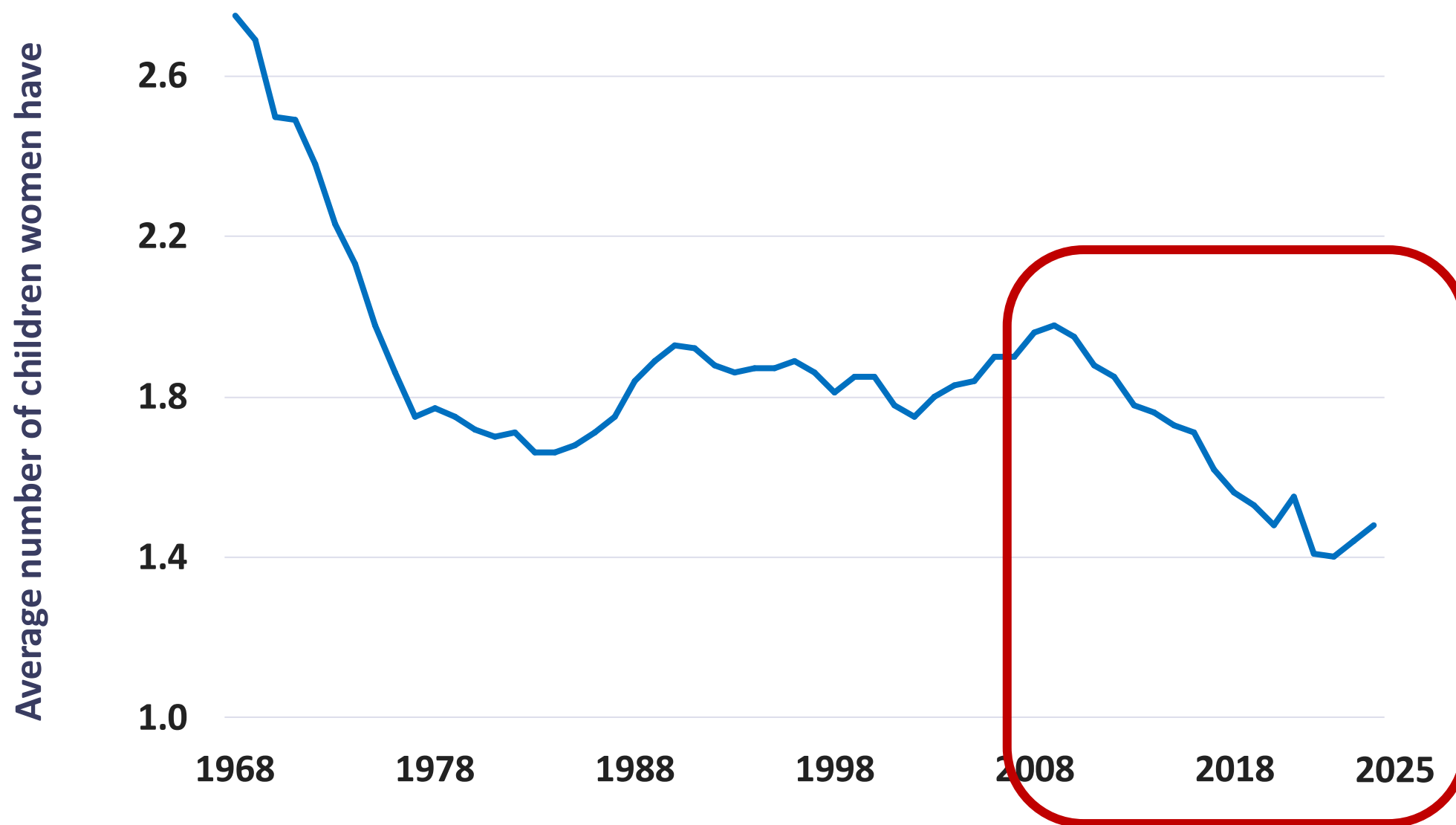
25 years of follow-up of
114 000 children,
mothers and fathers



AIM: Find **causes of health and disease**

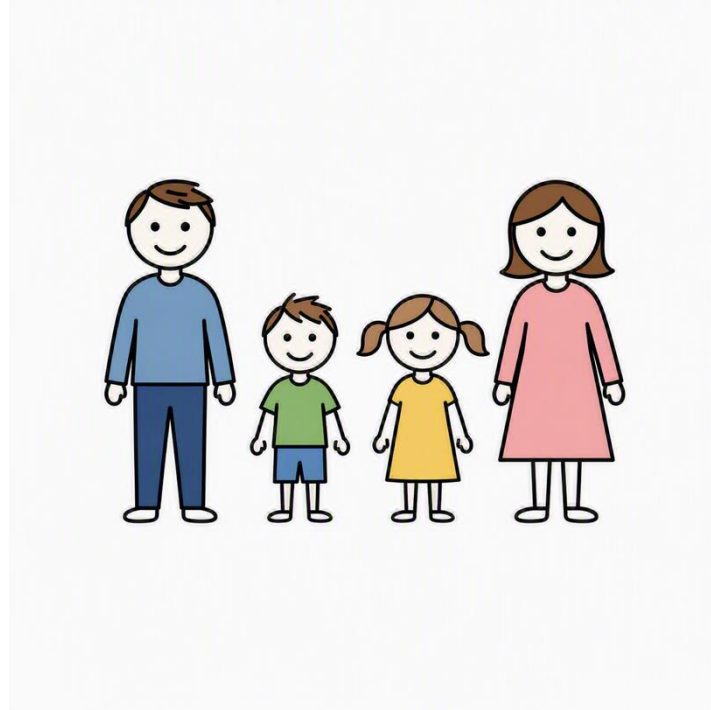


Total Fertility Rate for women in Norway 1967 - 2025



Fertility and health

Health
and
diseases



- Pregnancy health
- Infections
- Breast cancer
- Mortality
- Mental health

....

Psychological
factors

Social factors



Fertility
intentions



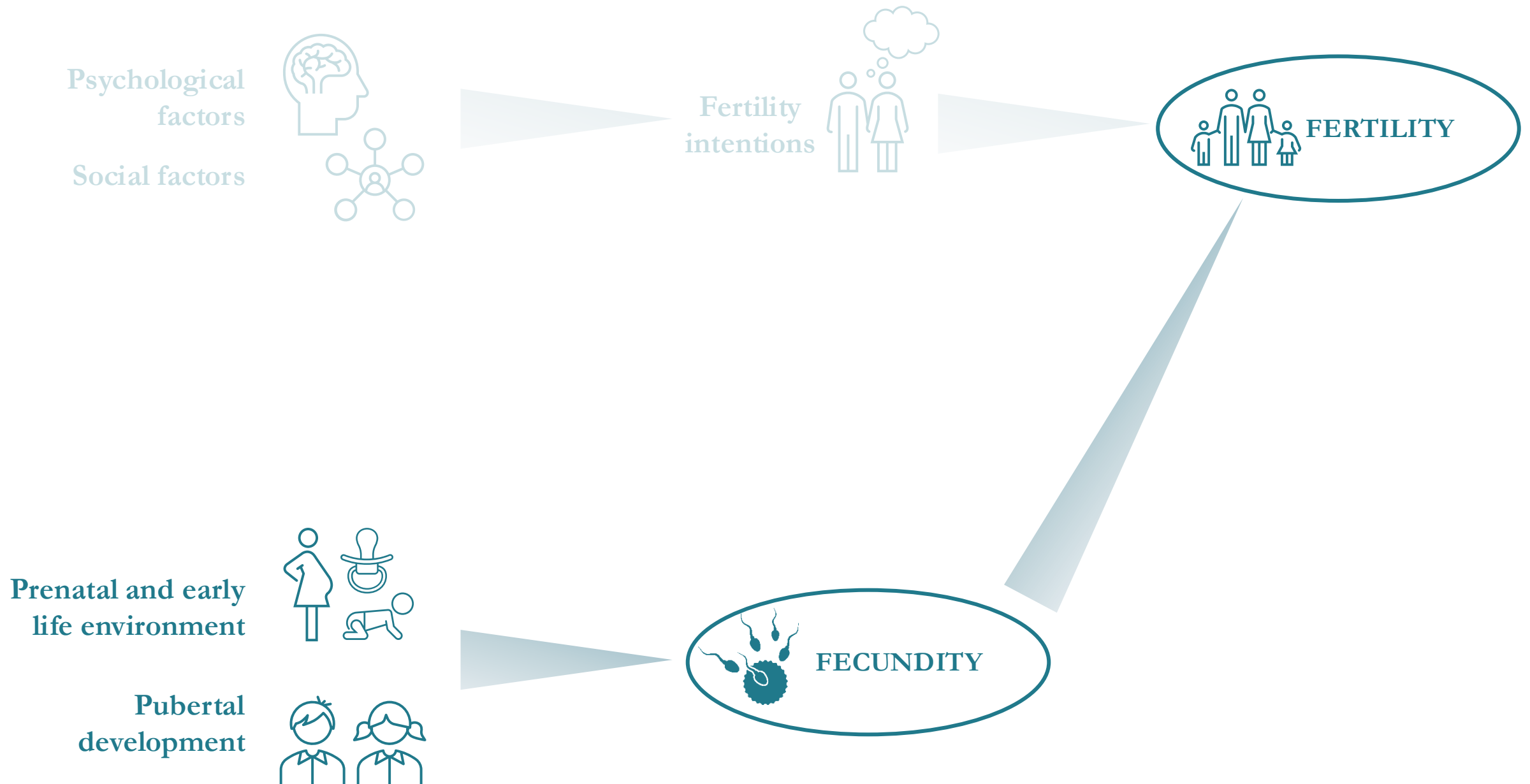
Psychological
factors

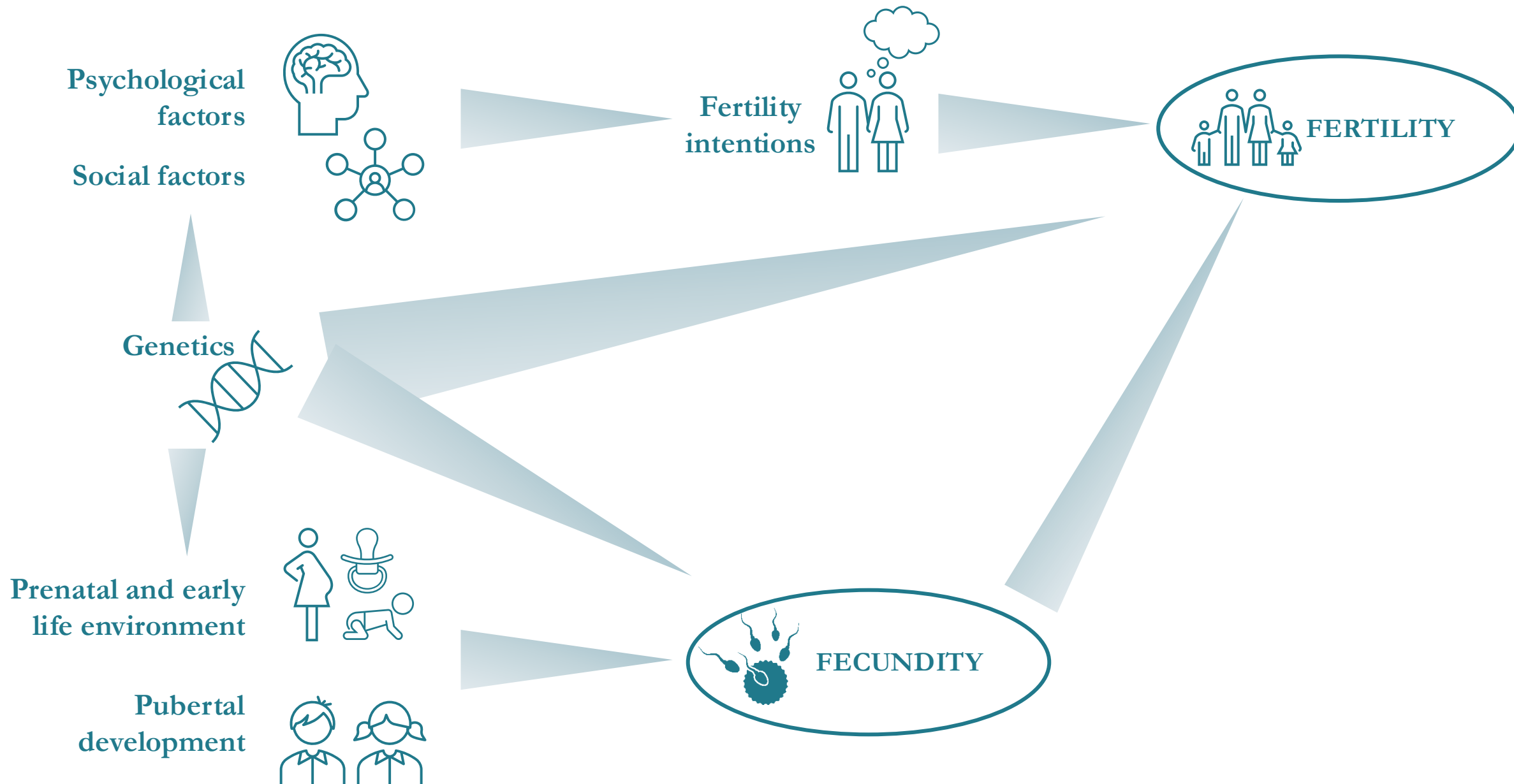
Social factors



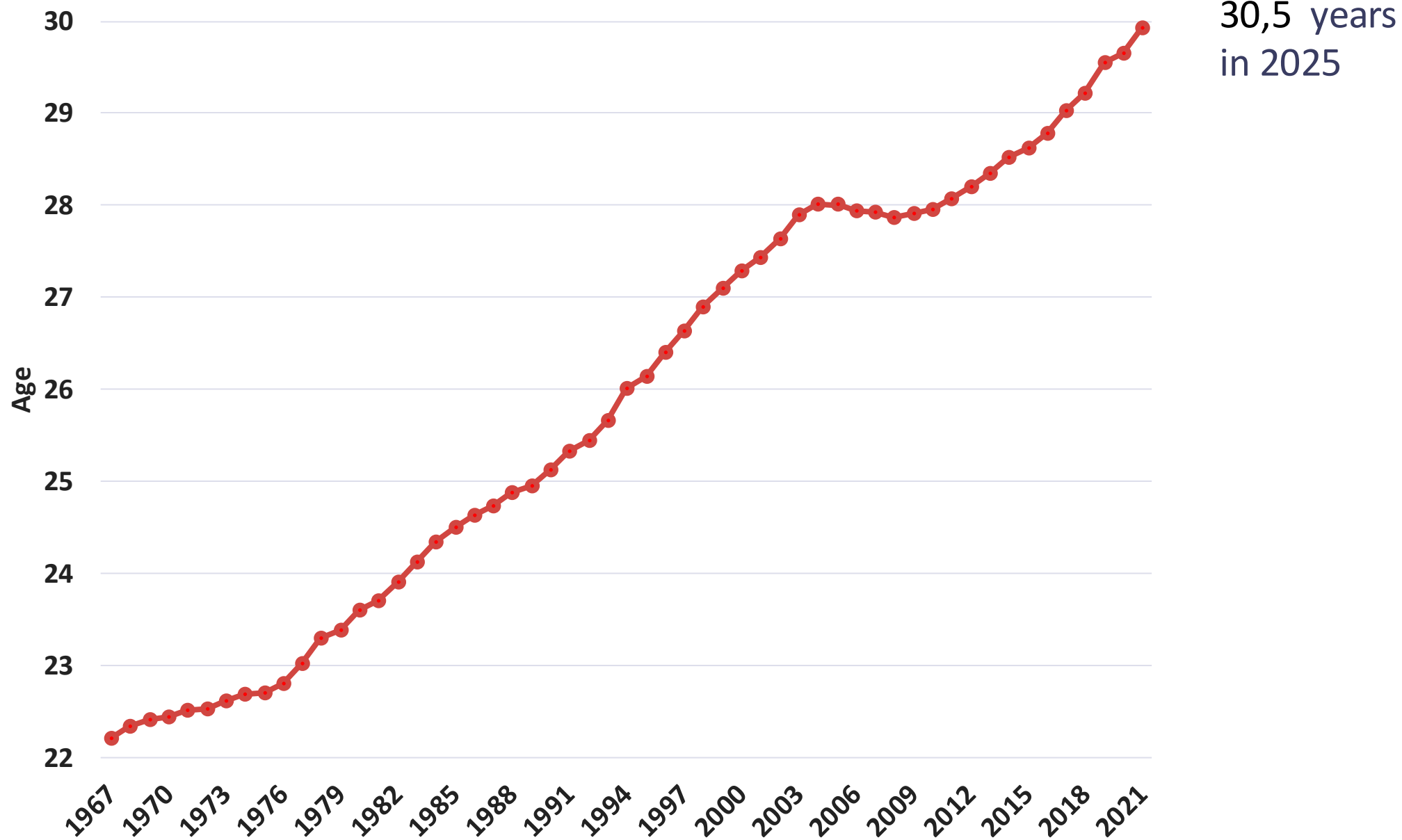
Fertility
intentions







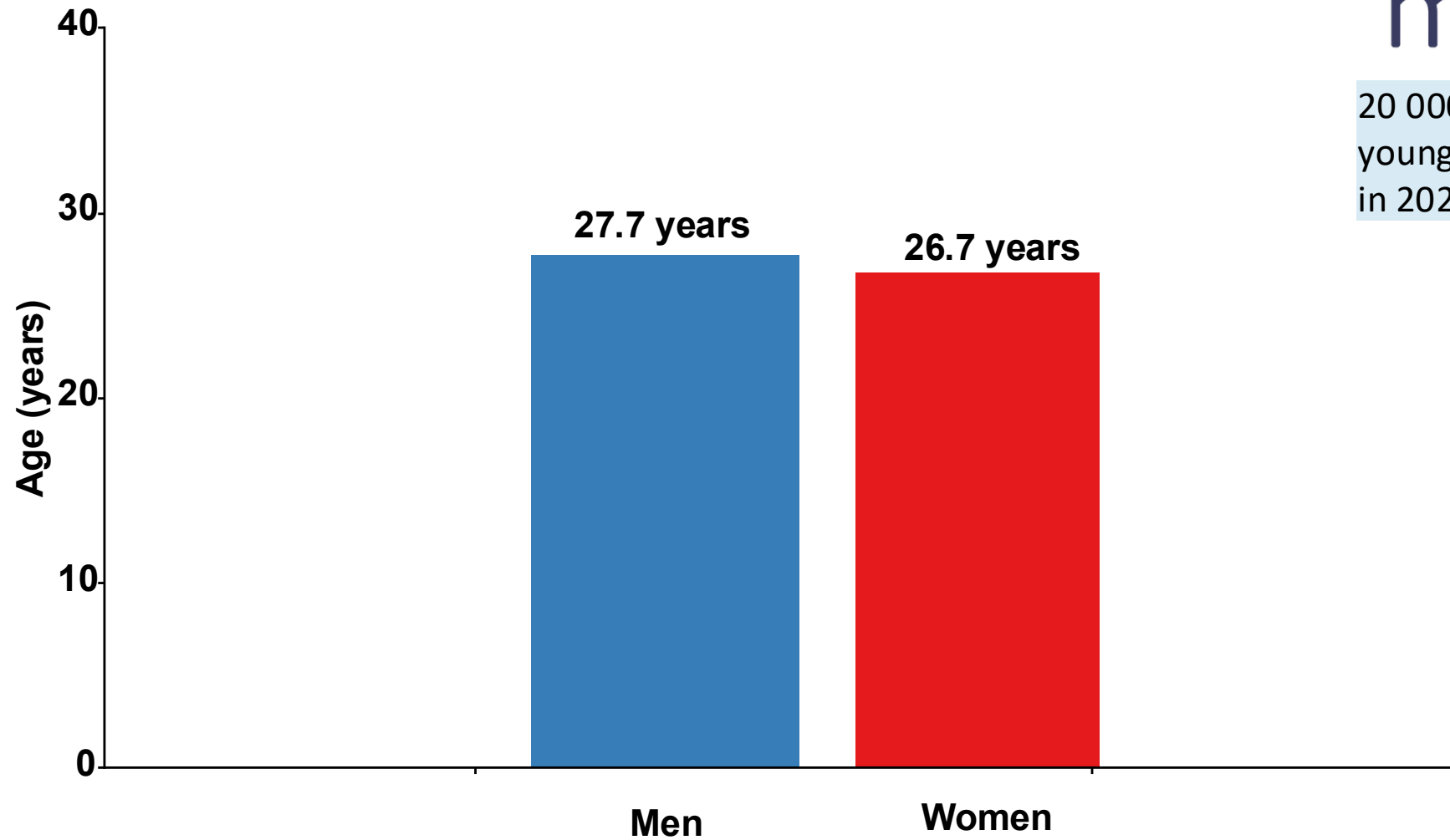
Women's age at first birth



At what age do you want to have your first child?



20 000 second generation
young adults ages 18-25
in 2025



TWO OF THE WORLD'S LARGEST PREGNANCY COHORTS

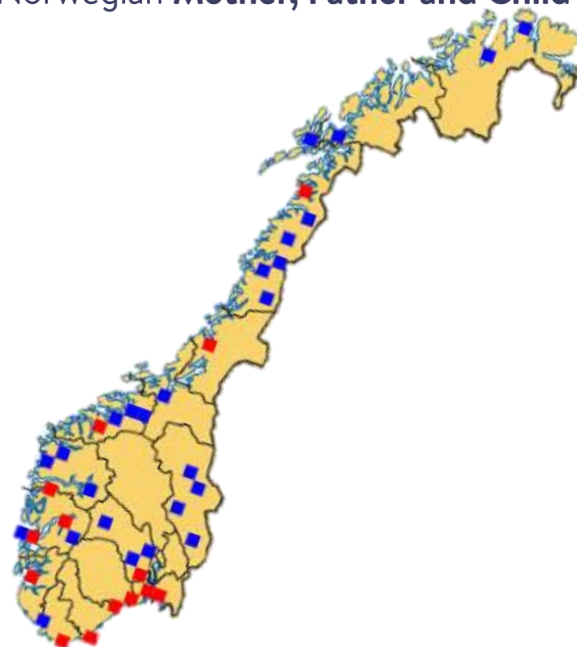
200,000 CHILDREN FOLLOWED TO YOUNG ADULTHOOD



Danish National
Birth Cohort



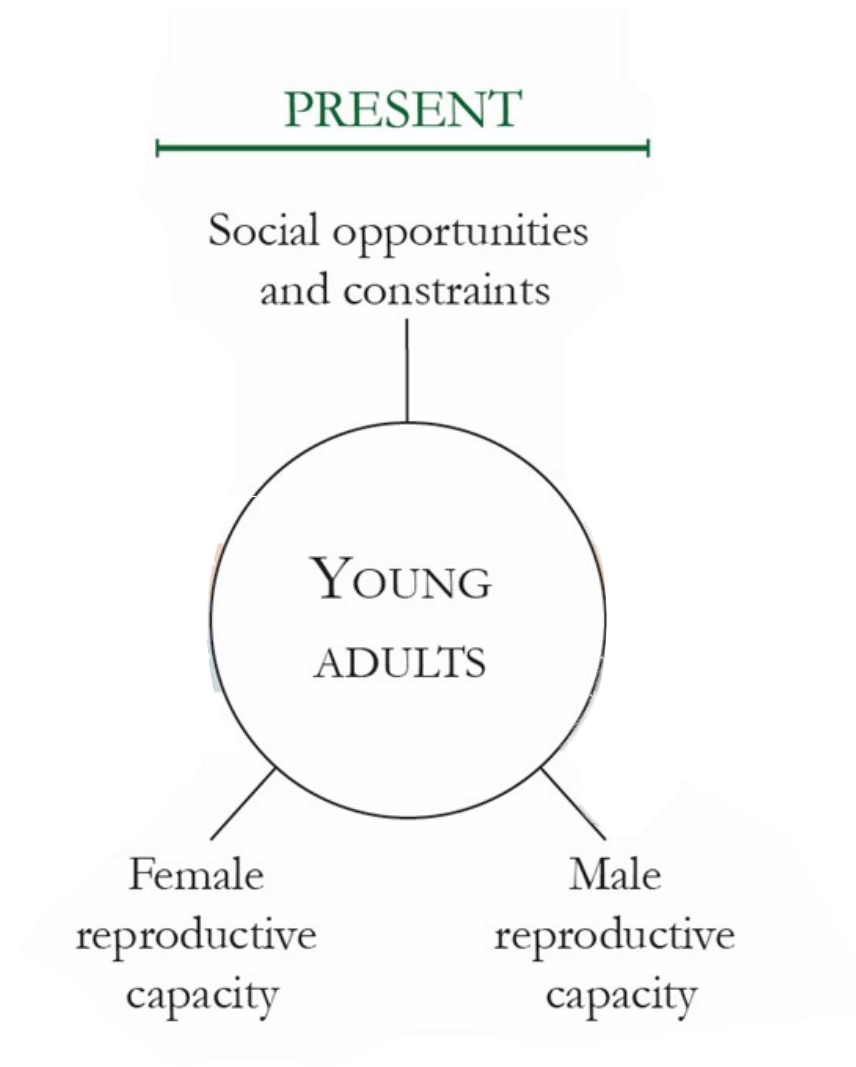
The Norwegian **Mother, Father and Child** Cohort Study

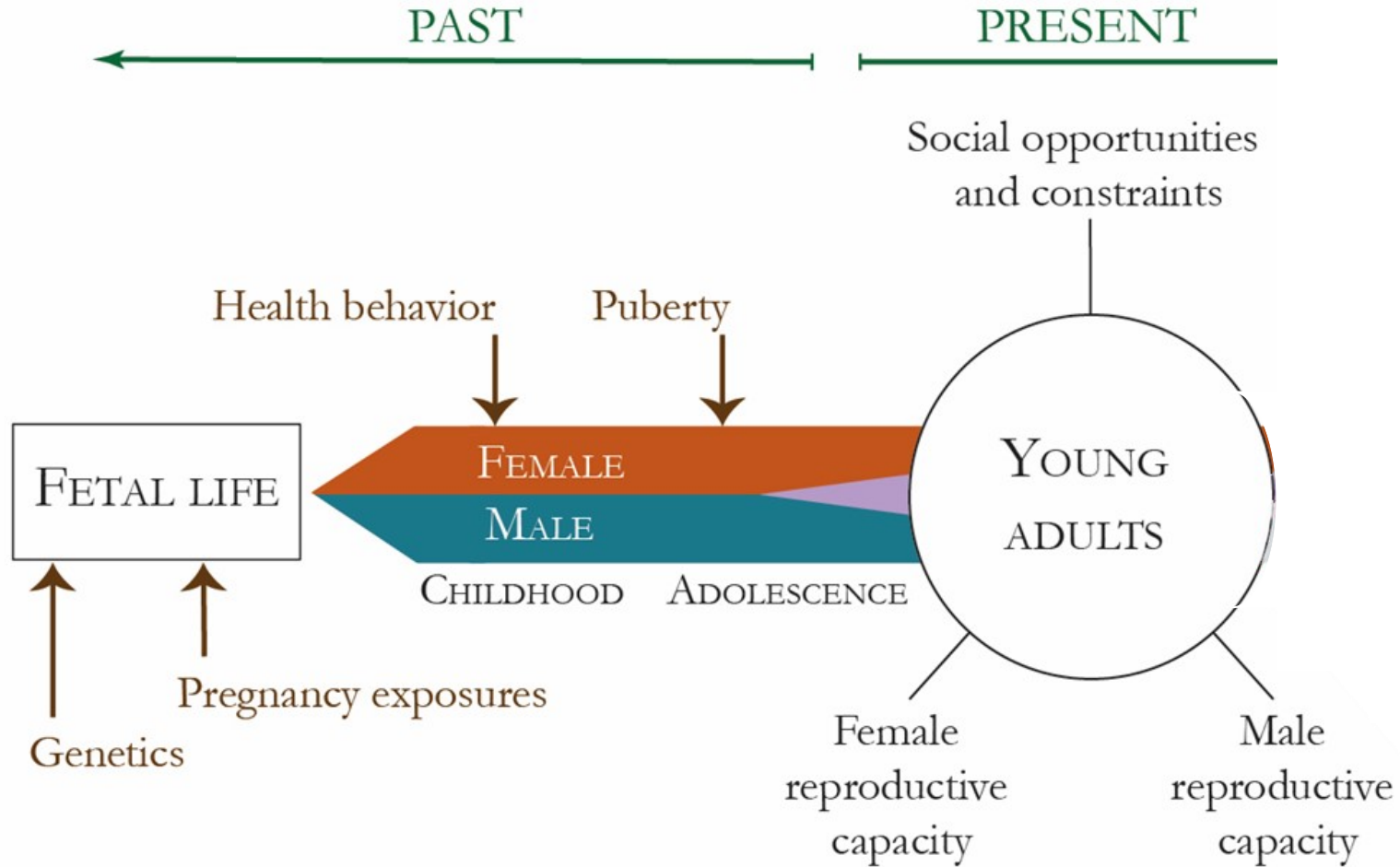


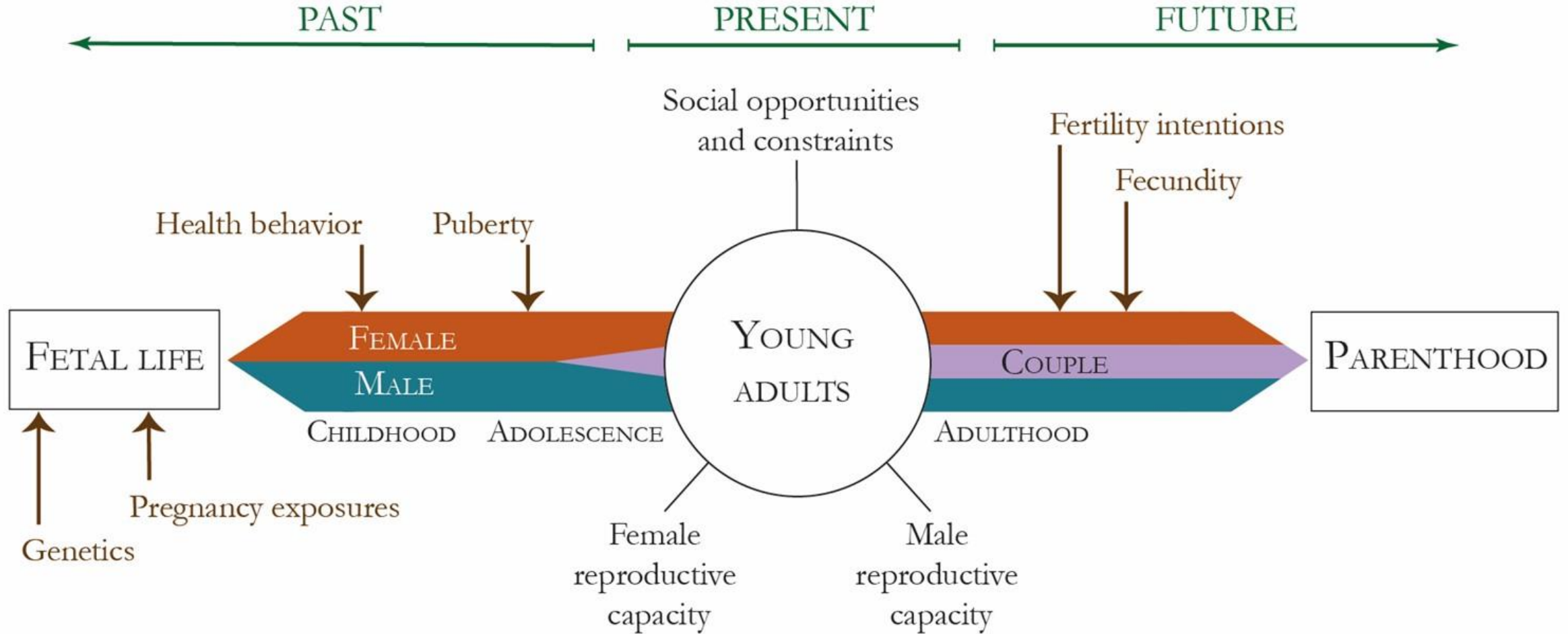
Funded by
the European Union



European Research Council
Established by the European Commission



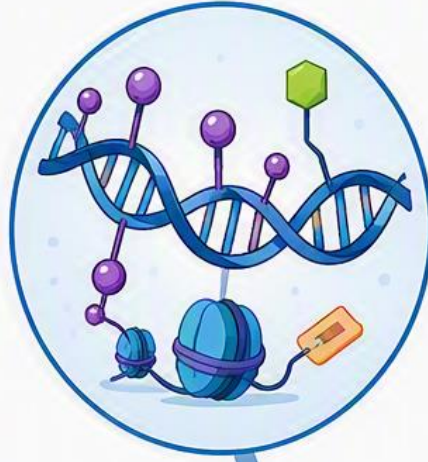




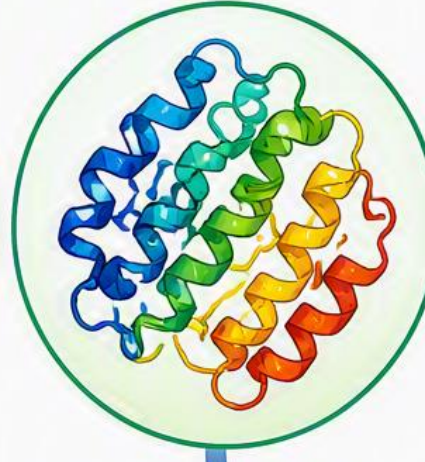
Genetics



Epigenetics



Proteomics

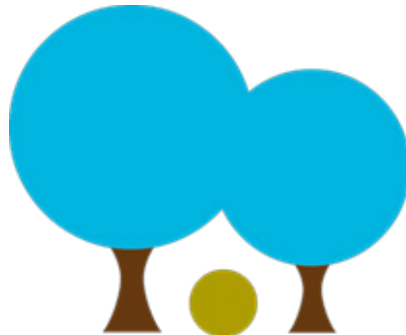


Society and environment



Cohorts + Biobanks + Registries

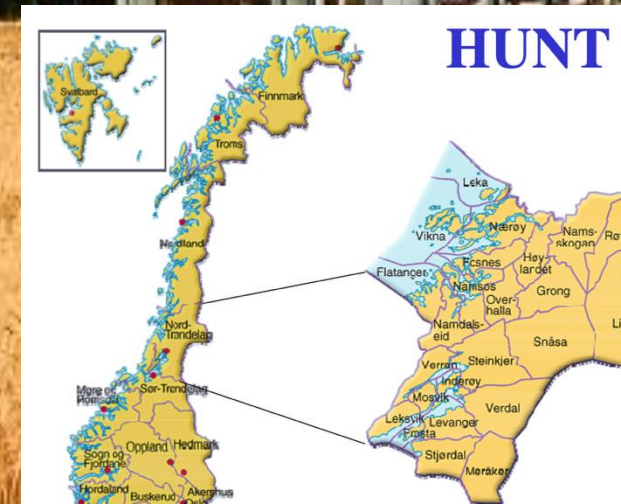
- Find CAUSES of trends in health and diseases
- Effective = TARGETED prevention and interventions
- Effective = PERSONALIZED treatments



Opportunities and pitfalls in Norwegian survey and register data for ageing research - lessons from The HUNT Study

Håvard Skjellegrind, MD PhD
Associate Professor of Family Medicine
HUNT Research Centre, NTNU, Levanger
havard.skjellegrind@ntnu.no

Nordic Health Data Summit 2026



HUNT

The Trøndelag
Health Study

1984 - 1986

HUNT1

77 000 participants

Questionnaire data
Clinical measurements

1995 - 1997

HUNT2

65 000 participants

Questionnaire data
Clinical measurements
Genomics
Biological samples

2006 - 2008

HUNT3

51 000 participants

Questionnaire data
Clinical measurements
Metabolomics | Genomics | Proteomics
Biological samples

2017 - 2019

HUNT4

56 000 participants

+ 106 000 participants from the southern
part of the county (only questionnaire)

Questionnaire data
Clinical measurements
Genomics
Biological samples

2021 - 2023

HUNT COVID

30 000 participants

+ 40 000 participants from the southern part
of the county (only questionnaire)

2028 - 2030

HUNT5

Participation in
HUNT1 and HUNT2:
47 000

Participation in
HUNT2 and HUNT3:
37 000

Participation in
HUNT3 and HUNT4:
34 000

Participation in
HUNT1, 2, 3 and 4:
19 000

1995-1997
Young-HUNT1

1999-2000
Young-HUNT2

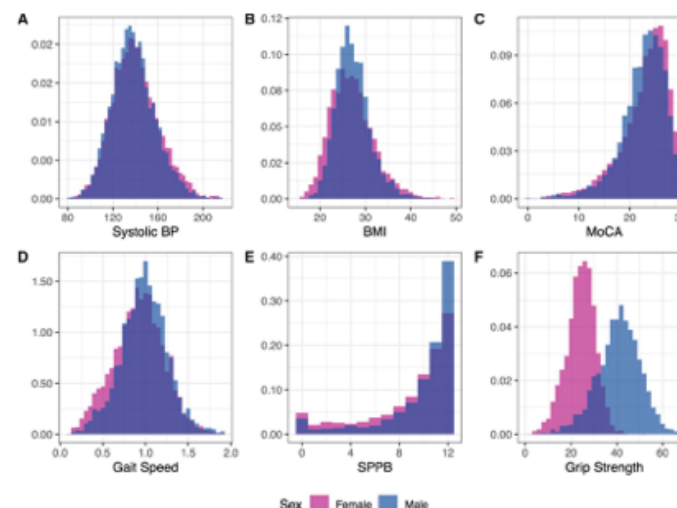
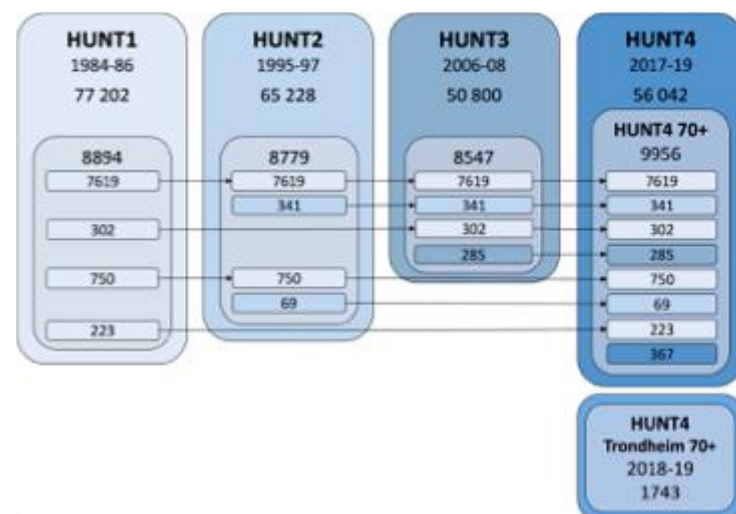
2006-2008
Young-HUNT3

2017-2019
Young-HUNT4

2021-2023
Young-HUNT
COVID

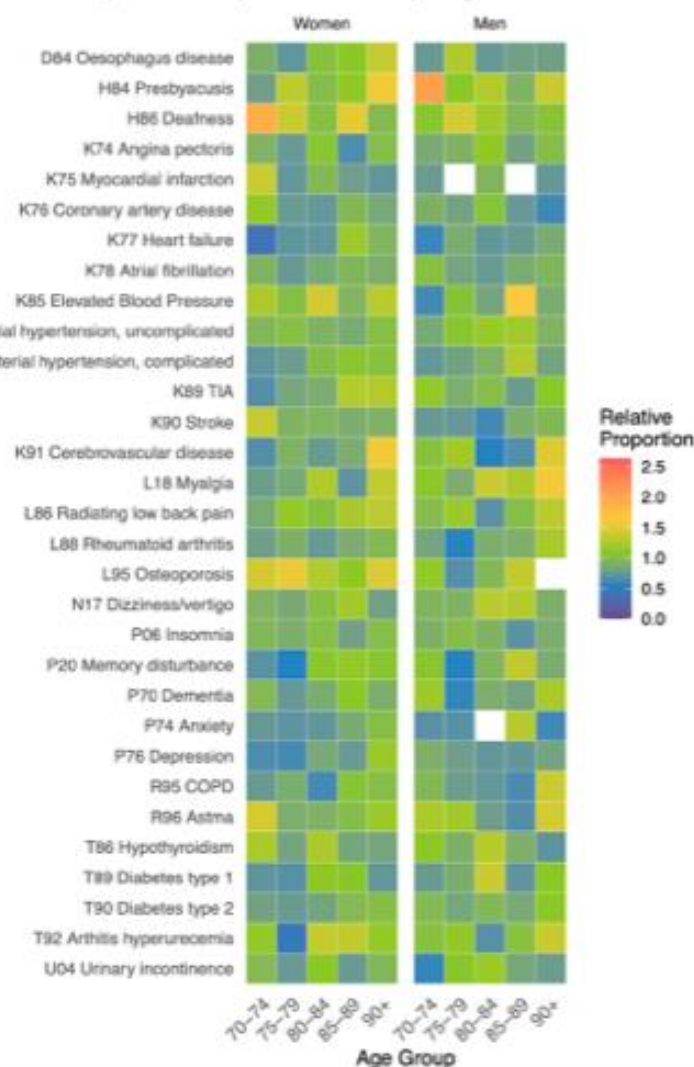
Cohort Profile Update: HUNT4 70+

Håvard K. Skjellegrind^{1,2,*}, Pernille Thingstad^{3,4}, Linda Gjøsæter^{5,6}, Marit Kolberg⁷, Grete Kjelvik⁶,
 Linda Ernsten^{8,9}, Tone N. Fagerhaug⁸, Arnulf Langhammer^{1,2}, Steinar Krokstad^{1,2},
 Bjørn Olav Åsvold^{1,10,11}, Marit Næss^{1,2}, Geir Selbæk^{6,12,13}



ICPC-2 Diagnoses from Primary Care

Representativity of the cohort by diagnosis

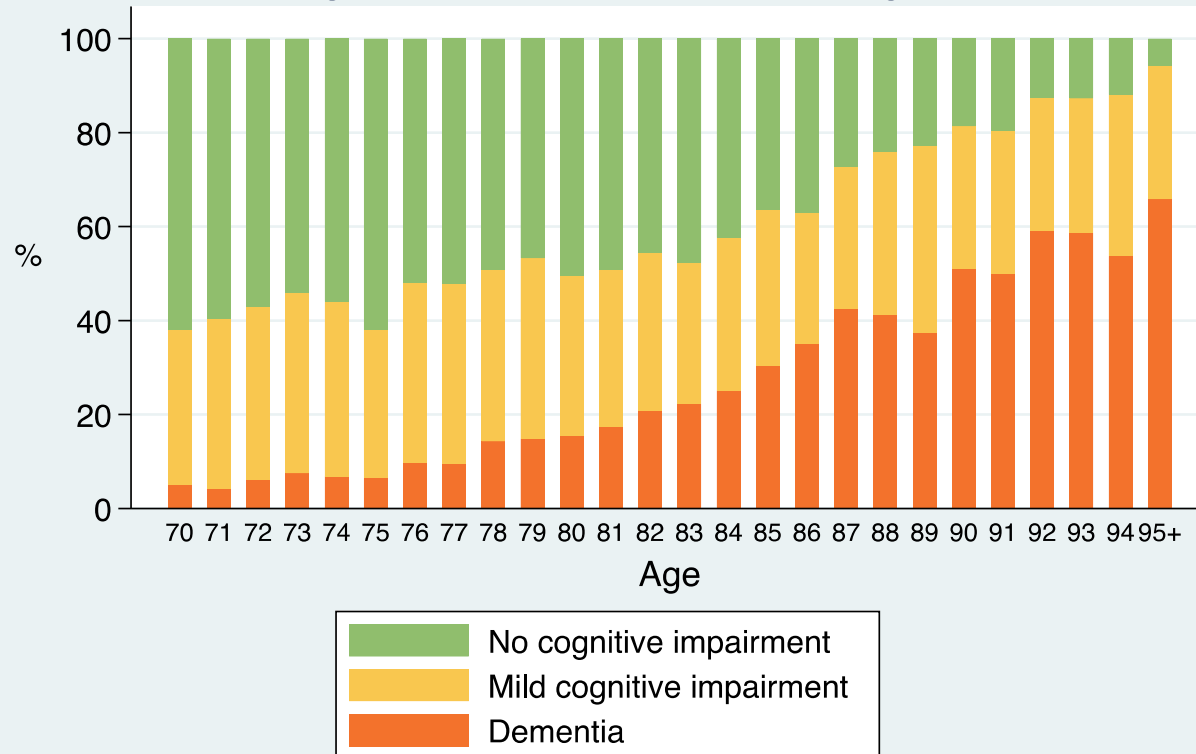


Dementia data in HUNT4 70+

HUNT4
70+

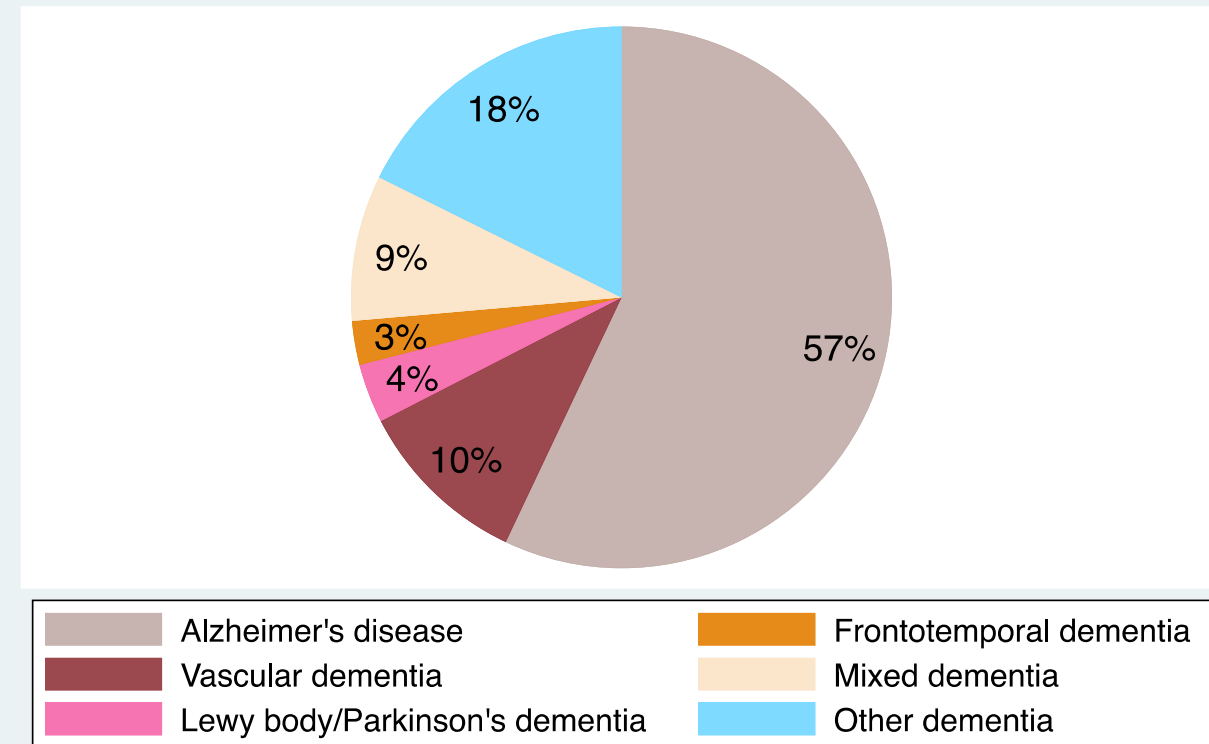


Cognitive function at different ages



n=9746

Distribution of dementia diagnoses



n=1527

Article

Prevalence of Alzheimer's disease pathology in the community

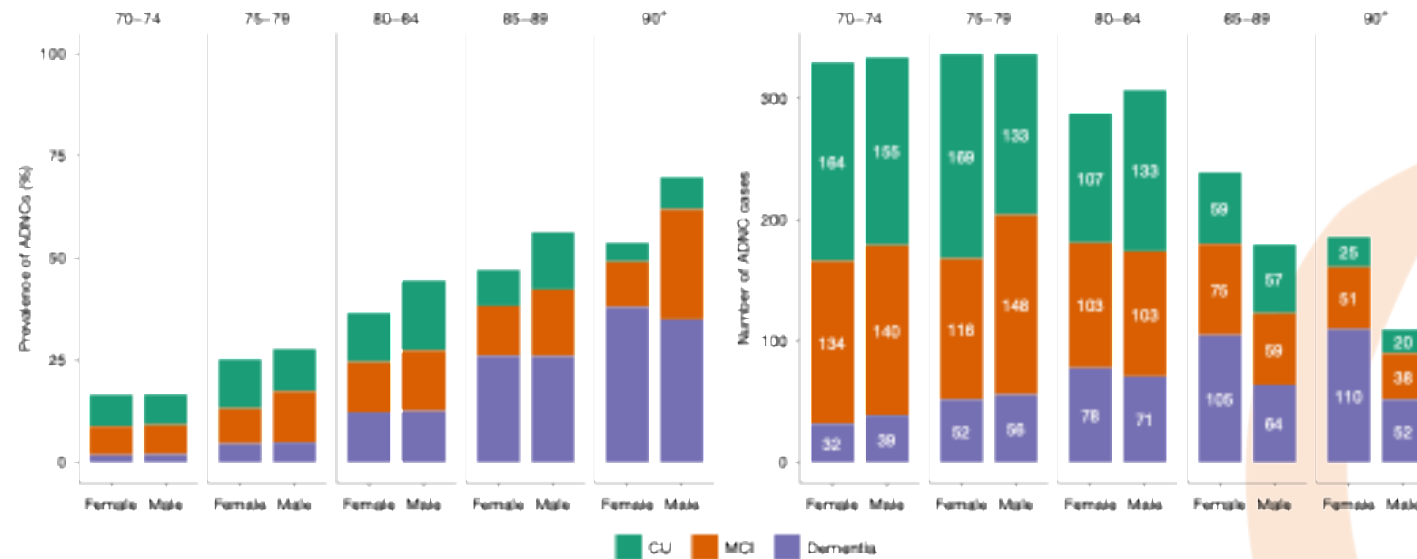


<https://doi.org/10.1038/s41586-025-09841-y>

Received: 4 March 2025

Accepted: 31 October 2025

Dag Aarsland^{1,2,3,4}, Anita Lenora Sunde^{1,3,5,6}, Diego A. Tovar-Rios^{1,4,5,6}, Antoine Leuzy⁷, Tormod Fladby⁷, Henrik Zetterberg^{8,9,10,11,12,13}, Kaj Blennow^{8,13,14,15}, Kübra Tan⁶, Giovanni De Santis⁶, Yara Yakoub¹⁶, Burak Arslan⁶, Hanna Huber^{6,17}, Ilaria Pola⁶, Lana Grötschel⁶, Guglielmo Di Molfetta⁶, Håvard K. Skjellegrind^{18,19}, Geir Selbaek^{20,21,22} & Nicholas J. Ashton^{8,23,24}

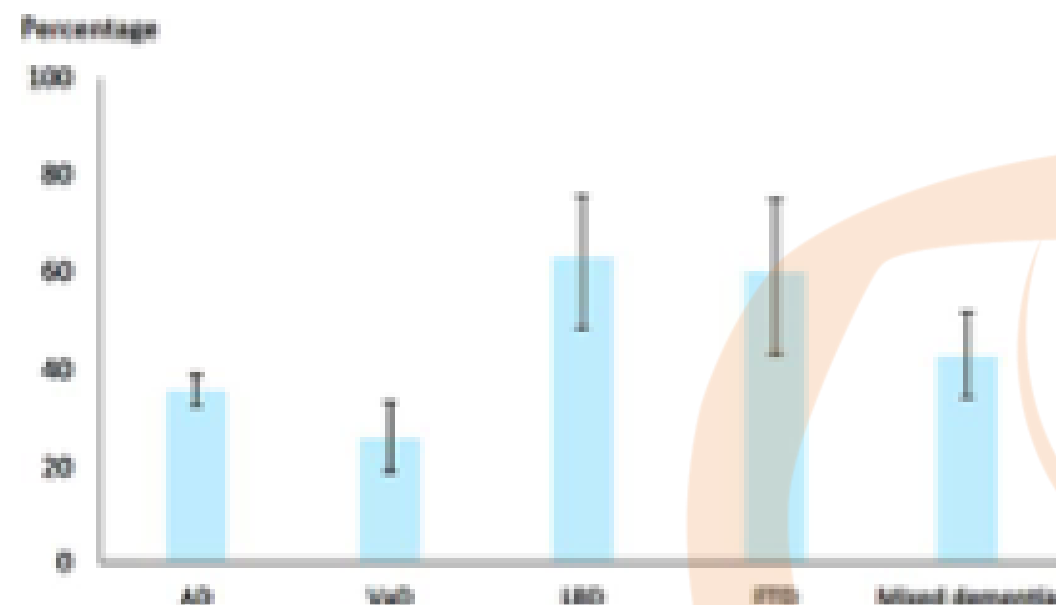


	% diagnosed
	35.6
Sex	
male	29.9
female	39.6
Age	
70–74 y	16.9
75–79 y	35.3
80–84 y	41.7
85–89 y	40.8
90+ y	37.7
Home-dwellers	19.8
HD living with others	16.1
Place of participation	
field station	12.8
home visit	31.2
nursing home	66.0
Education	
elementary	36.6
secondary	33.0
tertiary	42.1
Dementia in the family	41.5
MoCA mean (SD)	
HD HADS-D	
score 1–7	15.5
score 8–10	19.7
score 11–14	33.3
score 15–21	28.6
HD I-ADL	
needs little help	9.3
needs some help	29.1
needs a lot of help	31.3
NH CDR	
score 1	48.2
score 2	68.4
score 3	83.2



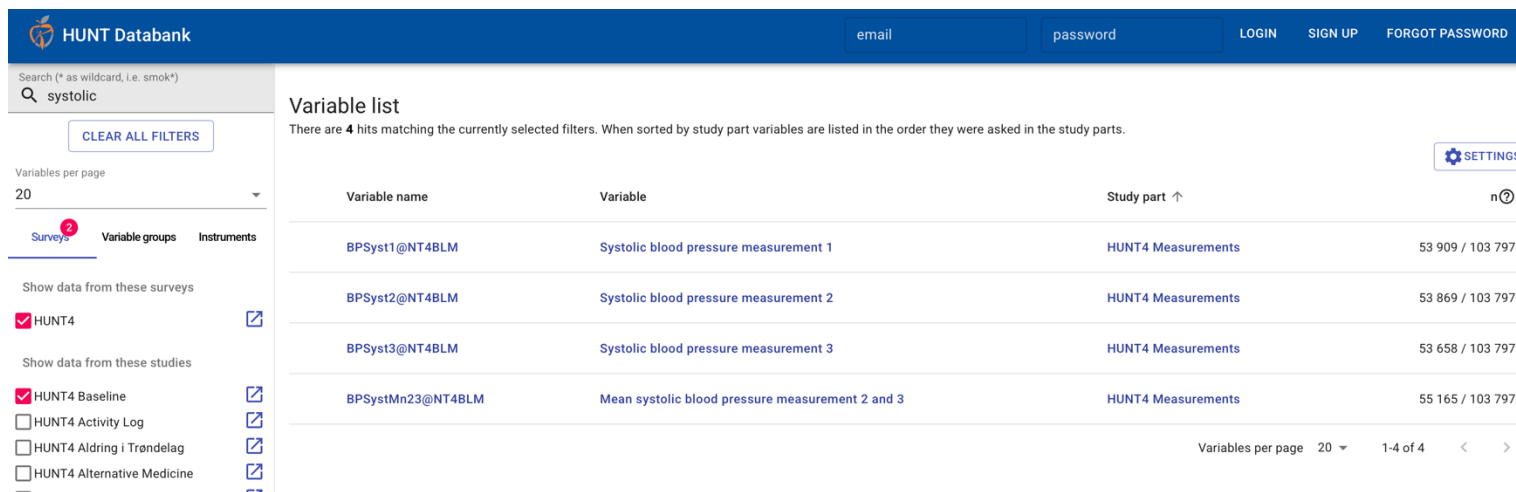
Prevalence and Determinants of Diagnosed Dementia: A Registry Linkage Study Linking Diagnosis of Dementia in the Population-Based HUNT Study to Registry Diagnosis of Dementia in Primary Care and Hospitals in Norway

Linda GjØra^{a,c,d,*}, BjØrn Heine Strand^{a,b,e}, Sverre Bergh^{a,f}, Ingunn Bosnes^g, Aud Johannessen^a, Gill Livingston^{h,i}, Håvard Kjesbu Skjellegrind^{j,k} and Geir Selbæk^{a,b,l}



Application process

- REC approval + DPIA
- Application (project protocol) + variable order (web-store solution)
- Data access committee meetings every 2 weeks
3-4 weeks from application to data delivery
- In-house made database software
 - independency on overseas resources



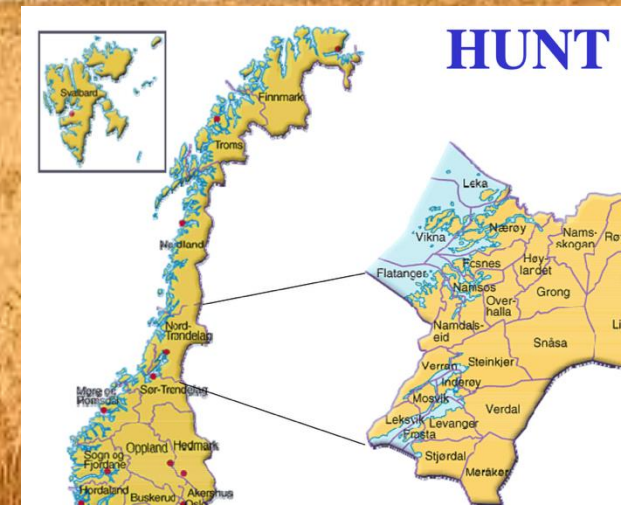
The screenshot displays the HUNT Databank web application. The top navigation bar includes the HUNT Databank logo, a search bar with the text 'systolic', and links for 'email', 'password', 'LOGIN', 'SIGN UP', and 'FORGOT PASSWORD'. Below the search bar, there are filters for 'Variables per page' (set to 20) and 'CLEAR ALL FILTERS'. The left sidebar shows a list of surveys and studies, with 'HUNT4' and 'HUNT4 Baseline' selected. The main content area is titled 'Variable list' and shows 4 hits matching the filters. The table lists variables such as 'BPSyst1@NT4BLM' (Systolic blood pressure measurement 1) and 'BPSystMn23@NT4BLM' (Mean systolic blood pressure measurement 2 and 3), all associated with 'HUNT4 Measurements' and showing counts like '53 909 / 103 797'. A 'SETTINGS' button is visible in the top right of the table area.

Variable name	Variable	Study part	n
BPSyst1@NT4BLM	Systolic blood pressure measurement 1	HUNT4 Measurements	53 909 / 103 797
BPSyst2@NT4BLM	Systolic blood pressure measurement 2	HUNT4 Measurements	53 869 / 103 797
BPSyst3@NT4BLM	Systolic blood pressure measurement 3	HUNT4 Measurements	53 658 / 103 797
BPSystMn23@NT4BLM	Mean systolic blood pressure measurement 2 and 3	HUNT4 Measurements	55 165 / 103 797

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Nordic Health Data Summit 2026



Closing remarks on session 5



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