Health2B Open

Sammen skaper vi fremtidens helsetjenester

Velkommen til Health2B Open

From Nordic health data to safe analysis and clinical value

22. september 2026 kl 13-16

Oslo universitetssykehus

IQVIA

Health2B - partnerskap og arena for åpen innovasjon

Etablere kultur og metodikk for offentlig-privatsamhandling

Øke gjensidig forståelse av behov, infrastruktur og kompetanse

Bidra til raskere og mer målrettet utvikling og bruk av teknologi og tjenester

www.health2b.no
LinkedIn: Health2B Norway

H2Bs verdikompass - slik samhandler vi

Tillit 

Vi bygger **tillit** gjennom å:

- operere **åpent og inkluderende**.
- ta utgangspunkt i pasienter og/eller brukere av helsetjenesters reelle utfordringer.
- fokusere på løsninger som gir **verdi** for pasient og/eller samfunn.
- sikre at bransjespesifikke etiske retningslinjer, regler og lovverk etterleves slik at verken uavhengighet, integritet eller medisinske vurderinger kan trekkes i tvil.
- ikke dele informasjon av konfidensiell/ sensitiv art.
- sørge for at samarbeid i H2B som kvalifiserer til bla. eierskap, IPR eller kjøp og salg av tjenester mellom aktørene, reguleres i egne avtaler.

Likeverdighet 

Vi sikrer **likeverdighet** gjennom å:

- fremme en kultur for **åpen dialog** hvor mangfoldet av ideer, perspektiver og kompetanse verdsettes**.**
- være nysgjerrige, **anerkjenne hverandres kompetanse** og spille hverandre gode.
- være åpen om og proaktivt dele **egne interesser**.
- ha **respekt** for hverandres interesser og ståsted.
- umiddelbart og tydelig flagge og håndtere potensielle **interessekonflikter.**
- involvere personer på ulike nivåer og med ulike roller, ansvar og erfaring slik at **vi sikrer bred involvering**.

Samskaping 

Vi **samskaper** gjennom å**:**

- sette av tid til å bli kjent og jobbe sammen på tvers.
- ha et **helhetlig blikk** på utfordringer og muligheter.
- sikre **aktiv deltakelse,** bruk av egen ekspertise og kompetanse og deling av relevant informasjon for å bidra til økt felles innsikt i behov, ønsker og utfordringer.
- **sammen definere** hvilke utfordringer vi skal fokusere på og hva vi ønsker å oppnå**.**
- bli enige om hvordan vi skal organisere arbeidet og **dele ansvar** for innhold og videreutvikling av partnerskapet og arenaen.
- forplikte oss til å **dedikere ressurser** for å sikre avtalt fremdrift og samarbeid.

Kreativitet 

Vi ivaretar **kreativitet** ved å:

- være åpne for nye idéer og eksperimentering, sammen utforske **nye løsninger**, **samarbeidsmodeller, teknologier** og **konsepter.**
- skape **entusiasme og engasjement** for nye måter å jobbe på.
- **gi hverandre handlingsrom** og mulighet til å jobbe på en utforskende måte.
- sikre smidighet og dynamisk utvikling av partnerskapet ved å dokumentere det vi **lærer**, regelmessig **evaluere** samarbeidet og gjøre nødvendige justeringer.

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22ND SEPTEMBER 2026

Privacy-preserving analytics and lessons learned from NHS England's Federated Data Platform

Jonathan Green, Director
Privacy Analytics, Europe

IQVIA's Privacy Analytics

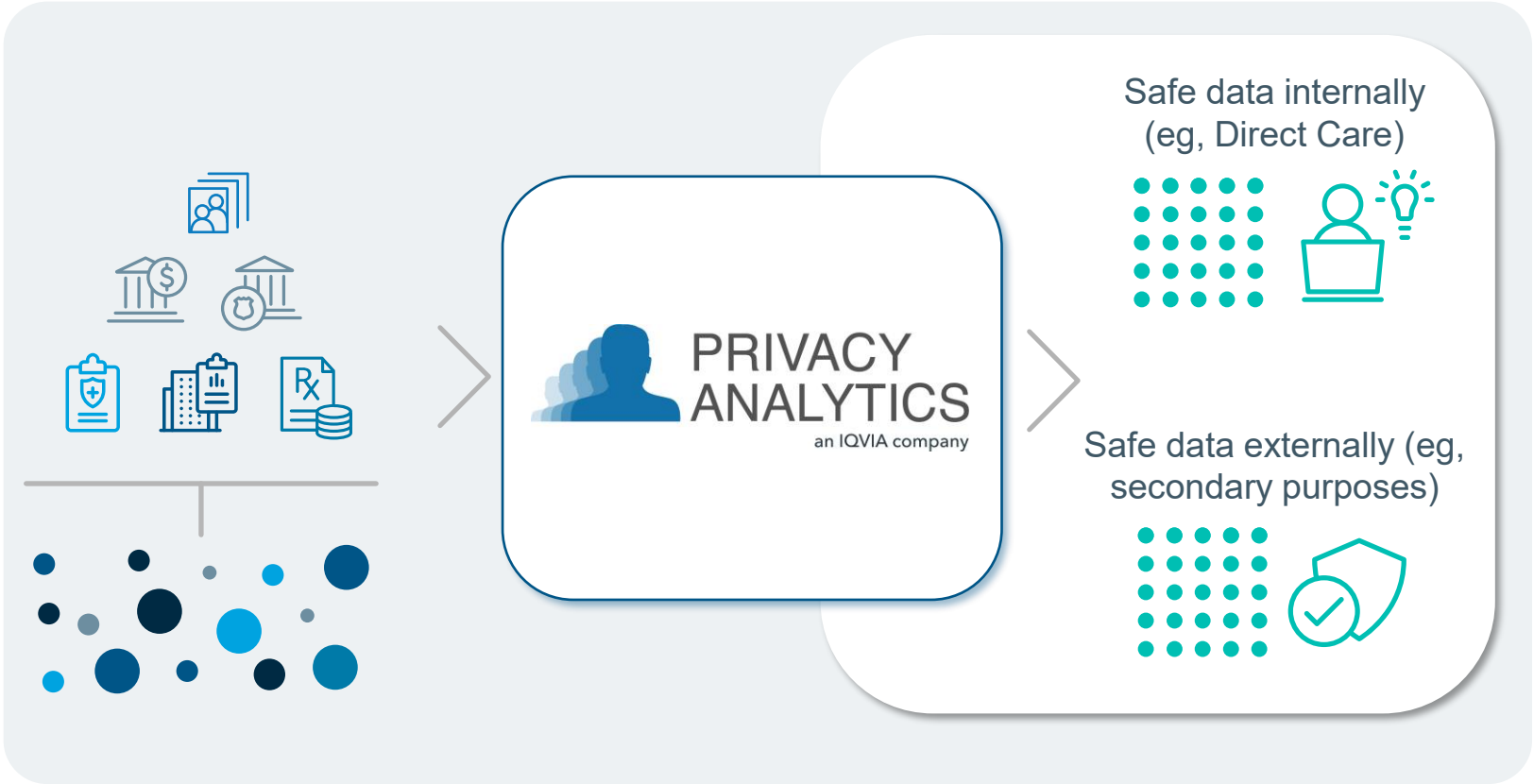
Over 20 years in practice
Protected 10,000s of sensitive data assets in healthcare and life sciences

1B+ patient lives protected
Using our software, helping clients earn trust to drive innovation

Informed 25+ guidelines
Represented in regulatory guidance and standards worldwide (eg, ISO DeID)

Over 100 technical experts
Hands-on experience advising and enabling clients in safe data & AI

Enabling protected data to be used safely at scale



The need to earn trust to thrive in a privacy compliant world

Health systems facing lawsuits for data breaches

BECKER'S HOSPITAL REVIEW

NHS England faces lawsuit over patient privacy fears linked to new data platform

The Guardian

Lawmakers stress data privacy in health AI oversight

HEALTHCAREDIVE

FORBES > INNOVATION > AI

Advancing Healthcare With Data: The Critical Juncture Between Privacy And Progress

GOV.UK

Home > Health and social care > Techn

Policy paper

Data saves lives: reshaping health and social care with data

This final version of the strategy sets out ambitious plans to harness the potential of data in health and care in England, while maintaining the highest standards of privacy and ethics.

Harvard Business Review

How Data Collaboration Platforms Can Help Companies Build Better AI

European Parliament

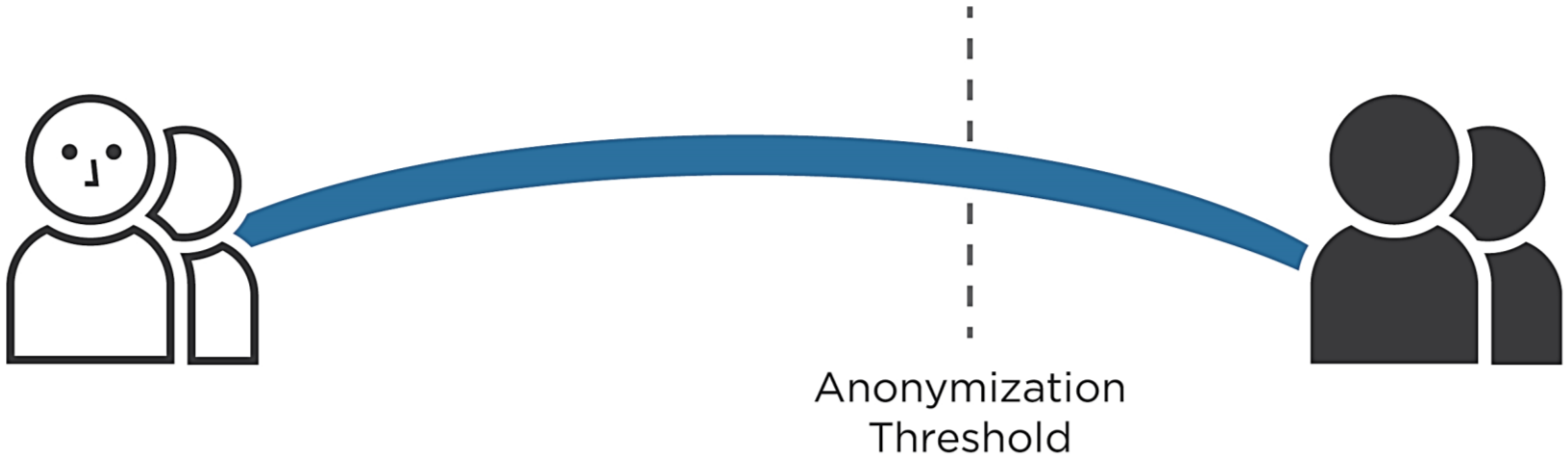
Nearly €11 billion

Expected savings in the EU in the next ten years as a result of better access, exchange and use of health data.

The challenge for Data Holders – the ‘Identifiability Spectrum’

Identifiability can be viewed on a spectrum:

- At the left end there is data containing personal information, where individuals are fully identified.
- As we move to the right, we get pseudonymous data that has less identifiability.
- At the right end of the spectrum, we hit a point where data is not identifiable to individuals.



Hintze, M. & El Emam, K. (2018). Comparing the benefits of pseudonymization and anonymization under the GDPR, Journal of Data Protection & Privacy, 2(2), 145-158.

Our Privacy Solution’s credentials

Privacy by design & well-architected

ASSURED

IQVIA-managed platform security, independently reviewed architecture by NHS and AWS Well-Architected principles.

CSOC MONITORED

Dedicated cyber security operations centre providing continuous oversight.

PEN TESTED

Independent penetration testing validates the platform on a regular cycle.

ISO ACCREDITED PROCESSES

Operated under independently certified management systems.

MULTI-AWARD WINNING

Independent industry recognition for privacy-enhancing technology.

PRIVACY BY DESIGN

No data is retained by the service.

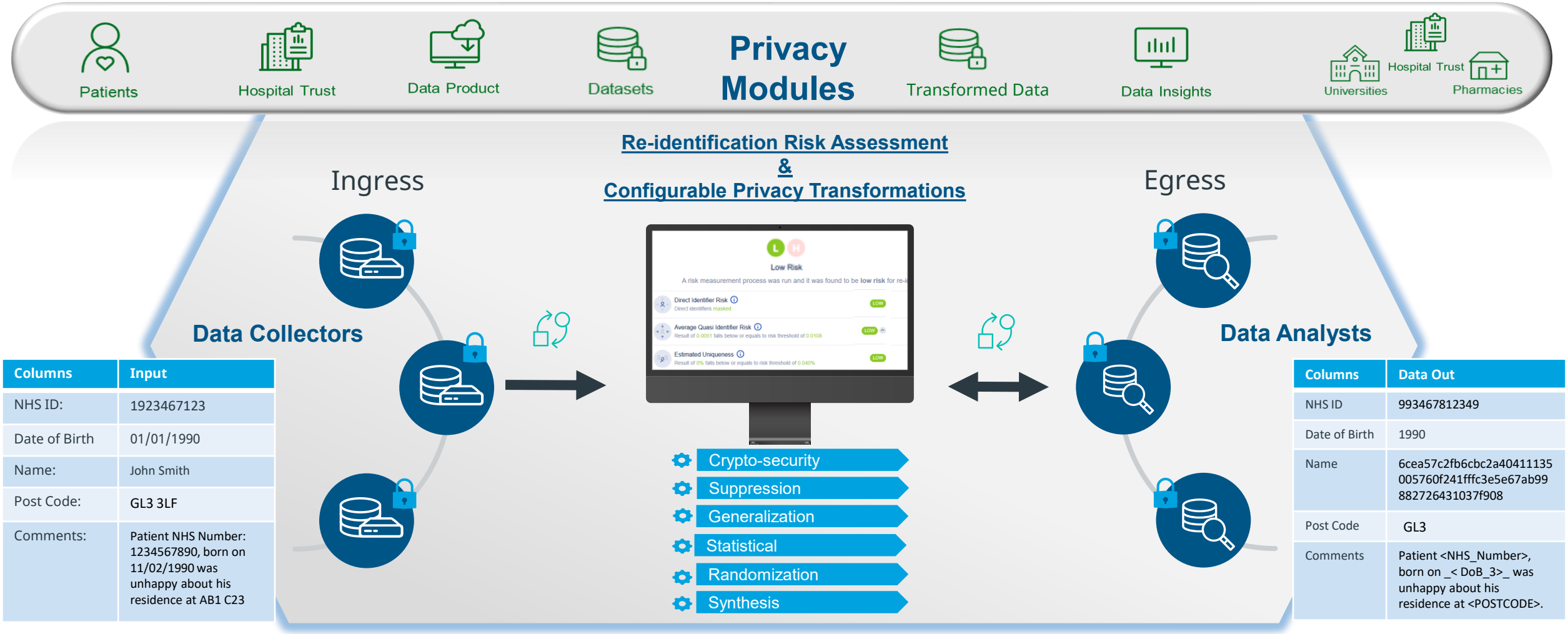
ISO ACCREDITATIONS HELD

ISO/IEC 27001	ISO/IEC 27017	ISO 9001
Information security management	Cloud security controls	Quality management

Flexible deployment options: On Premise | Private Cloud | Public Cloud

IQVIA's Privacy Enhancing Technology

Risk Assessment & Privacy Transformations at Enterprise scale enabling safe sharing of data



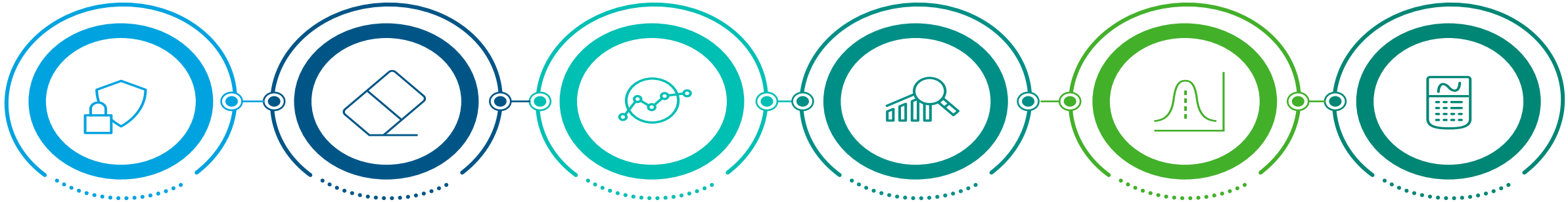
Columns	Input
NHS ID:	1923467123
Date of Birth	01/01/1990
Name:	John Smith
Post Code:	GL3 3LF
Comments:	Patient NHS Number: 1234567890, born on 11/02/1990 was unhappy about his residence at AB1 C23

Columns	Data Out
NHS ID	993467812349
Date of Birth	1990
Name	6cea57c2fb6cbc2a40411135005760f241fffc3e5e67ab99882726431037f908
Post Code	GL3
Comments	Patient <NHS_Number>, born on _< DoB_3>_ was unhappy about his residence at <POSTCODE>.

PET acts as a secure transformation layer within your pipeline.

Data Privacy Transformation ‘Menu’

Data privacy transformation can be made available based on the client’s requirements



Cryptographic

Masking elements, computing on masked data

- Format Preserving Encryption (FPE)
- Hashing (SHA-256)
- Re-Identification

Suppression

Removing information; values, fields, records

- Sensitive Field Suppression
- Free text De-ID
- Imaging De-ID

Generalization

Reducing precision through rounding, grouping

- Find & Replace
- Lookup Derivation (Postcode Lookup)
- Date Generalization
- Age Calculation
- Find & Protect

Statistical

Transformations based on statistical measures of identifiability

- Adding Noise
- Aggregate Data

Randomization

Reordering data elements

- Date Shifting
- Data Shuffling

Synthesis

Creating artificial data

- Mask to new value
- Synthetic Data Generation

Examples of our impact: NHS England PET case study

Situation

- The National Health Service (NHS) in England established a Federated Data Platform (FDP) in 2022 to bring together 55M+ patients' data across different care settings and data types.
- The FDP requires a high level of privacy controls, which require a technology solution which can safely transform data at scale.

Solution

- IQVIA's NHS-PET allows the NHS to appropriately manage, anonymise and audit all data flows into the platform, using the technology and expertise of IQVIA's Privacy Analytics team.
- Now being rolled out across wider NHS – for NHS Secure Data Environments.

Results

>70,000

Datasets onboarded in 18 months

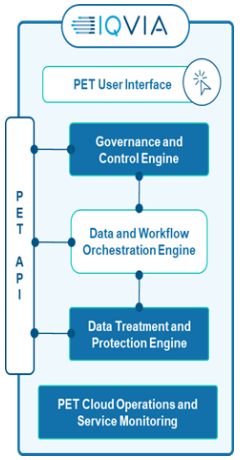
>3.25 trillion

Fields of data transformed in 12 months

500% improvement

Performance improvement on legacy privacy transformations

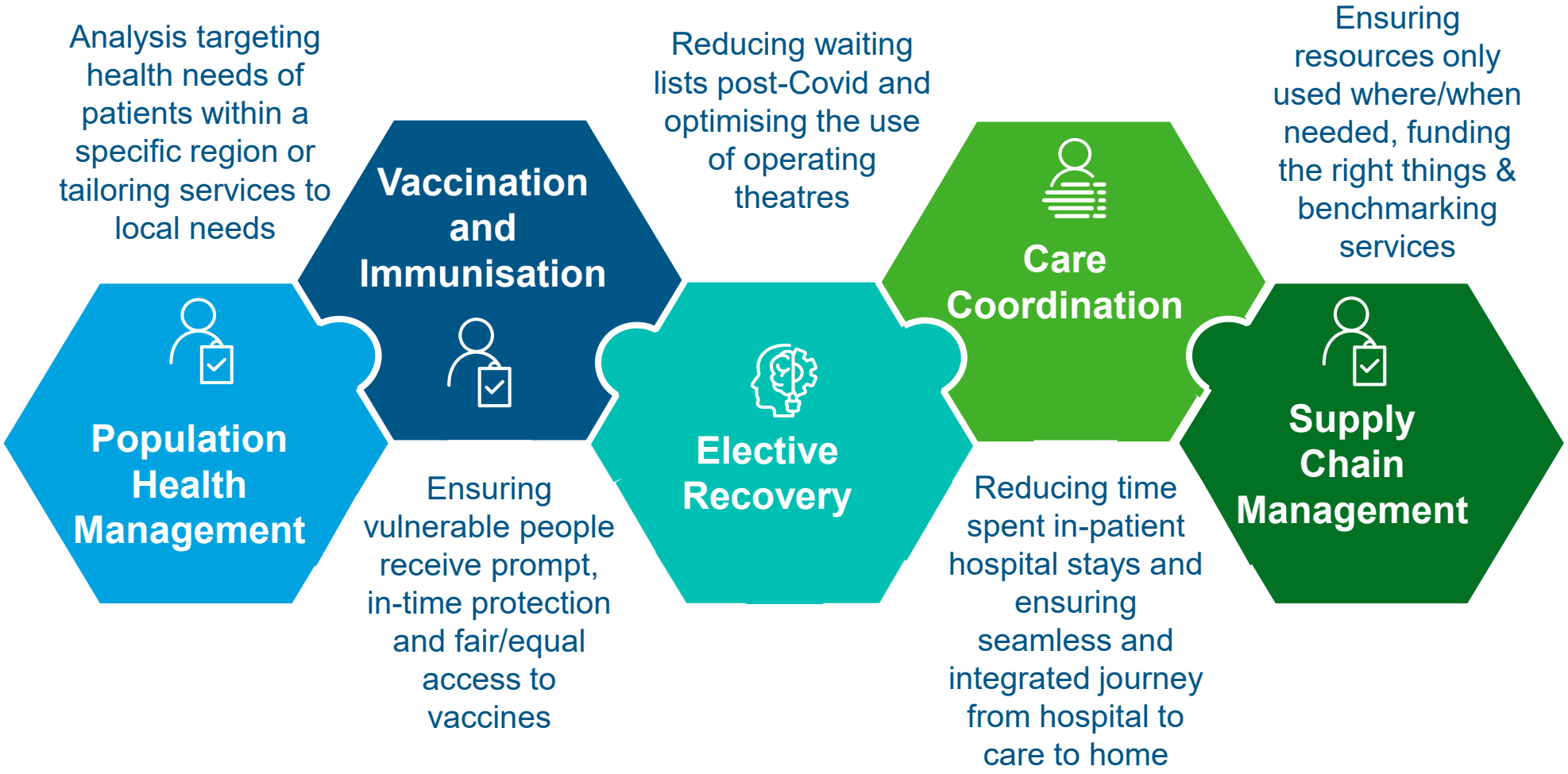
- Demonstrates IQVIA's ability to implement integrated privacy modules for use by national healthcare system in the UK, ensuring safe data sharing at scale.



IQVIA

Examples of how protected data is being put to work in UK NHS

Five Real World Use Cases for NHS Federated Data Platform impact.



Case Study

NHS

NHS-PET: Performance 2025/26

Headline usage figures as of 31st August 2026

187

Local Trusts Onboarded

187 Local Hospital Trusts have been successfully onboarded to NHS PET Catalogue Service.

54k

National datasets onboarded

Non PII datasets from a range of national Products used by the onboarded Hospital Trusts are set up in the NHS PET Catalogue.

208 million

Registrations processed

Over 208 million registrations have been processed across 54k (non PII) datasets flowing from 187 local NHS trusts.

10

Treatment Types

The Treatment Engine offers 10 types of data transformation, enabling advanced treatment techniques to optimize patient privacy and data insights throughout the journey.

3.2 Trillion

Treated Fields

NHS PET has transformed over 3.2 trillion fields to make datasets compliant and safe for sharing across NHS organisations.

>633

Treated Datasets

NHS PET is successfully transforming PII data for 633 datasets across NHS.

IQVIA

Case Study NHS

NHS-PET: Trusted Use of Data

Summary of some of the benefits delivered to NHS and patients in England

4.7 mil
Shorter Wait Times

Validated 4.69 million patient pathways, helping ensure patients receive the right care at the right time.

111k
More Patients Treated

Enabled 111,589 additional patients to receive treatment through better operational planning.

300,000+
Earlier Discharges

Supported 300,000+ patients to leave hospital sooner through improved discharge coordination.

94,000
Better Cancer Care

Helped 93,600+ patients progress through cancer pathways faster and more effectively.

15+%
Smarter Resourcing

Reduced long-stay discharge delays by 15% through better use of NHS resources.

55 mil
Trusted Use of Data

Enabled privacy-safe use of health data across a population of more than 55 million patients.

IQVIA

Our guidance papers and relevant articles

Privacy Frontline Report: https://privacy-analytics.com/get-the-data-privacy-frontline-report/#subscribe

Future of Privacy Forum (FPF): A new standard for anonymization
A new standard for anonymization | IAPP

ISO/IEC 27559:2022 Information security, cybersecurity and privacy protection
Privacy enhancing data de-identification framework
https://www.iso.org/standard/71677.html

UK ICO Anonymisation: managing data protection risk code of practice
https://ico.org.uk/media/1061/anonymisation-code.pdf

UK ICO Privacy-enhancing technologies (PETs)
privacy-enhancing-technologies-1-0.pdf

Using Synthetic Data in Financial Services (UK Synthetic Data Expert Group)
https://www.fca.org.uk/publication/corporate/report-using-synthetic-data-in-financial-services.pdf

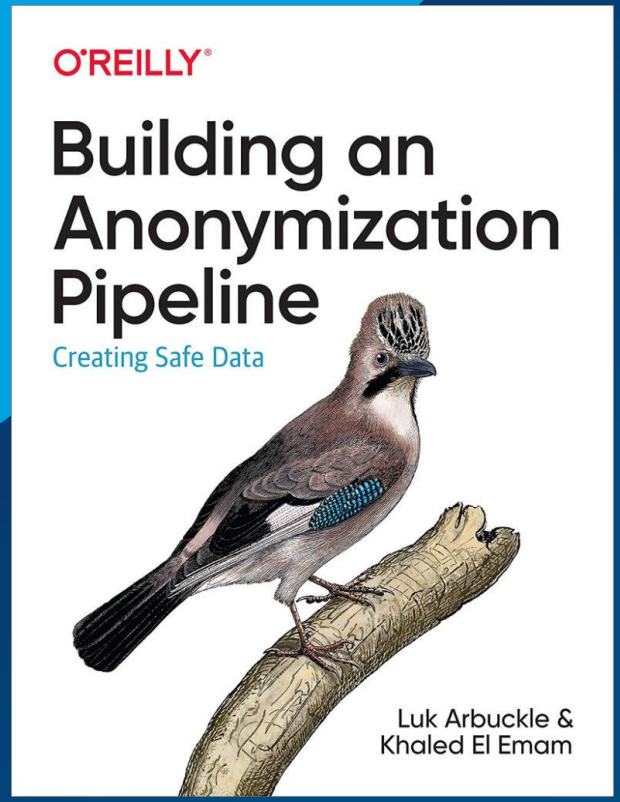
Engineering Risk-Based Anonymisation Solutions for Complex Data Environments
https://www.ingentaconnect.com/contentone/hsp/jdpp/2020/00000003/00000003/art00011

The Five Safes of Risk-Based Anonymization
https://ieeexplore.ieee.org/document/8821469

Pragmatic Application of Healthcare AI Governance (white paper)
Pragmatic Application of Healthcare AI Governance - IQVIA

Privacy Strategy: Accelerating the Journey to Big Data Outcomes (Insight Brief)
Privacy Strategy: Accelerating the Journey to Big Data Outcomes – IQVIA

Collection of articles, case studies, webinars, white papers and more available on PA website
https://privacy-analytics.com/resources/



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PAUSE Health2B

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Beyond VALO – How do we leverage EHDS and move forward to a more connected Nordic health data ecosystem

The 22nd of September 2026

Agenda & speakers

1. **VALO Pilot Study 1**
   - Introduction
   - VALO Pilot Study Consortium Lessons Learned Survey Results
2. **VALO Pilot Study 2**
   - Study introduction
3. **Nordic Hospital Network**

Susanna Flaherty
Healthcare Director, Finland
Finland Country Manager

susanna.flaherty@iqvia.com

Carl Jarling
Healthcare Director, Sweden

carl.jarnling@iqvia.com

How do we move forward to a more connected Nordic health data ecosystem?

Pilot projects

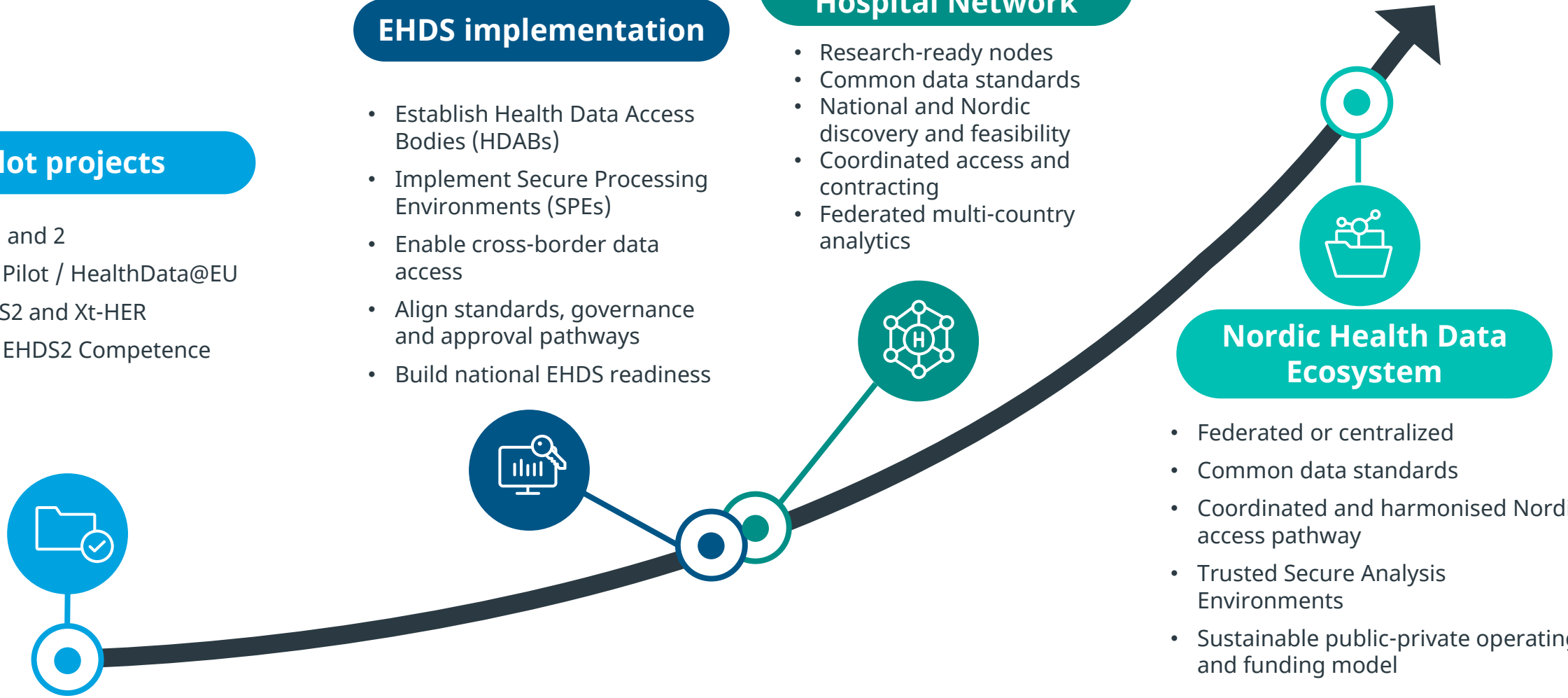
- VALO 1 and 2
- EHDS2 Pilot / HealthData@EU
- TEHDAS2 and Xt-HER
- Nordic EHDS2 Competence Forum

EHDS implementation

- Establish Health Data Access Bodies (HDABs)
- Implement Secure Processing Environments (SPEs)
- Enable cross-border data access
- Align standards, governance and approval pathways
- Build national EHDS readiness

Nordic University Hospital Network

- Research-ready nodes
- Common data standards
- National and Nordic discovery and feasibility
- Coordinated access and contracting
- Federated multi-country analytics



Nordic Health Data Ecosystem

- Federated or centralized
- Common data standards
- Coordinated and harmonised Nordic access pathway
- Trusted Secure Analysis Environments
- Sustainable public-private operating and funding model

VALO Pilot Study 1

VALO Pilot Study

Aim:

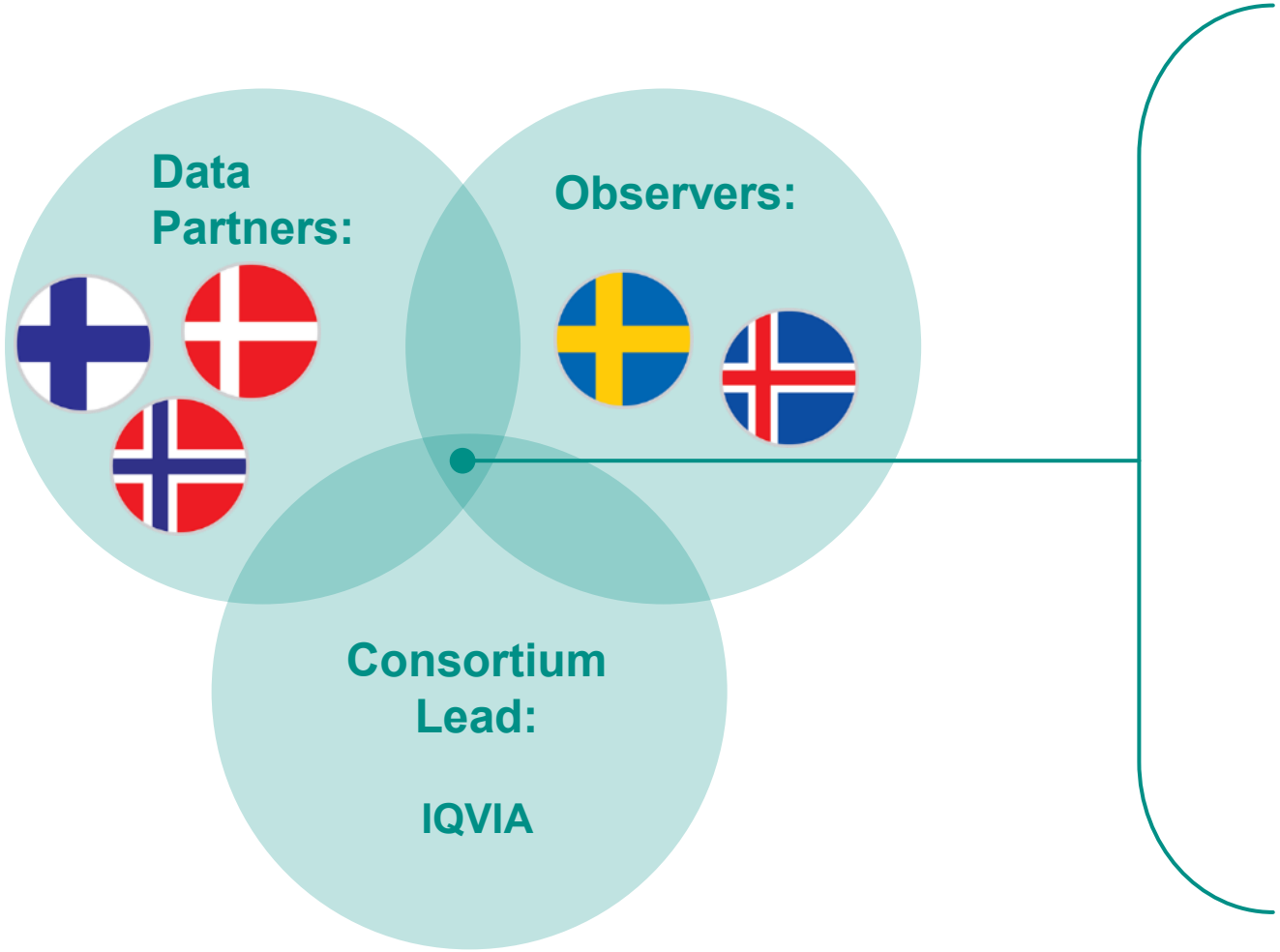
To explore opportunities to increase the Nordic Health Data Collaboration

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

VALO Pilot Study – Consortium Members



IQVIA

OSLO UNIVERSITY HOSPITAL

HUS Helsinki University Hospital

REGION H Rigshospitalet

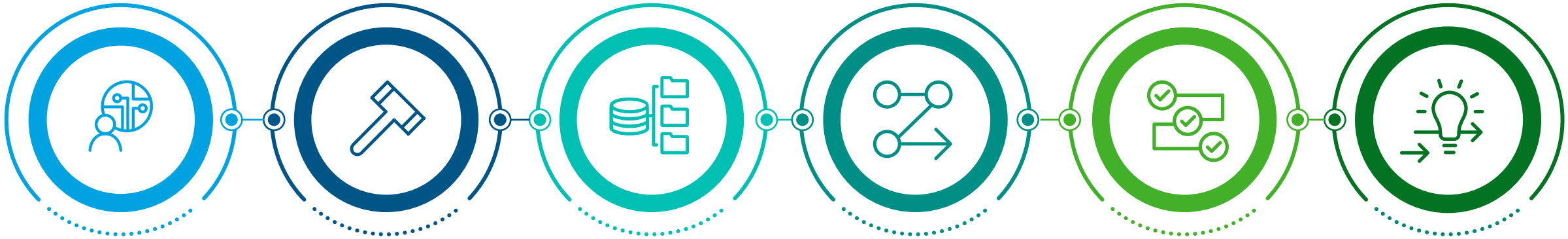
KAROLINSKA UNIVERSITY HOSPITAL

Karolinska Institutet

LANDSPÍTALI

VALO1 Pilot Study Consortium Lessons Learned Survey Results

NSCLC Pilot Study - Survey categories



Background and maturity

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 & availabity

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

Data Processing

1. Data infrastructure
2. Variables captured
3. Script execution success
4. Implementation challenges

VALO Study execution

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 Findings - Federated OMOP Network Development

Maturity & readiness

- Sites vary widely in OMOP and federated research maturity despite similar healthcare systems.
- Experience is concentrated in small teams rather than institutionalized capability.
- Observer sites gained insight into requirements.

Data governance

- Knowledge of ethics approvals and data-permit requirements was often fragmented.
- Governance responsibilities varied by role rather than being institutionally defined.
- OMOP-specific governance frameworks were inconsistently established across sites.

Data life cycle & availability

- Core clinical data is broadly available
- Data linkage capabilities existed but varied in maturity and implementation.
- Advanced oncology data elements showed systematic availability gaps.

Data processing

- Tech infrastructure compatibility was a larger challenge than OMOP conceptual understanding.
- ETL specification design required the greatest effort among processing steps.
- QA/QC processes became largely routine once environments were established.

VALO Study Execution

- Final analytical cohorts represented a small fraction of initial population estimates.
- Multi-site coordination added material time beyond technical execution.
- Execution efficiency improved with structured communication and coordination.

Future investments

- Infrastructure and environment limits OMOP execution and needs to be addressed.
- OMOP maturity takes years, not months, to establish.
- Respondents called for better coordination across sites, not only local improvements.

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IQVIA SITRA

IQVIA SITRA

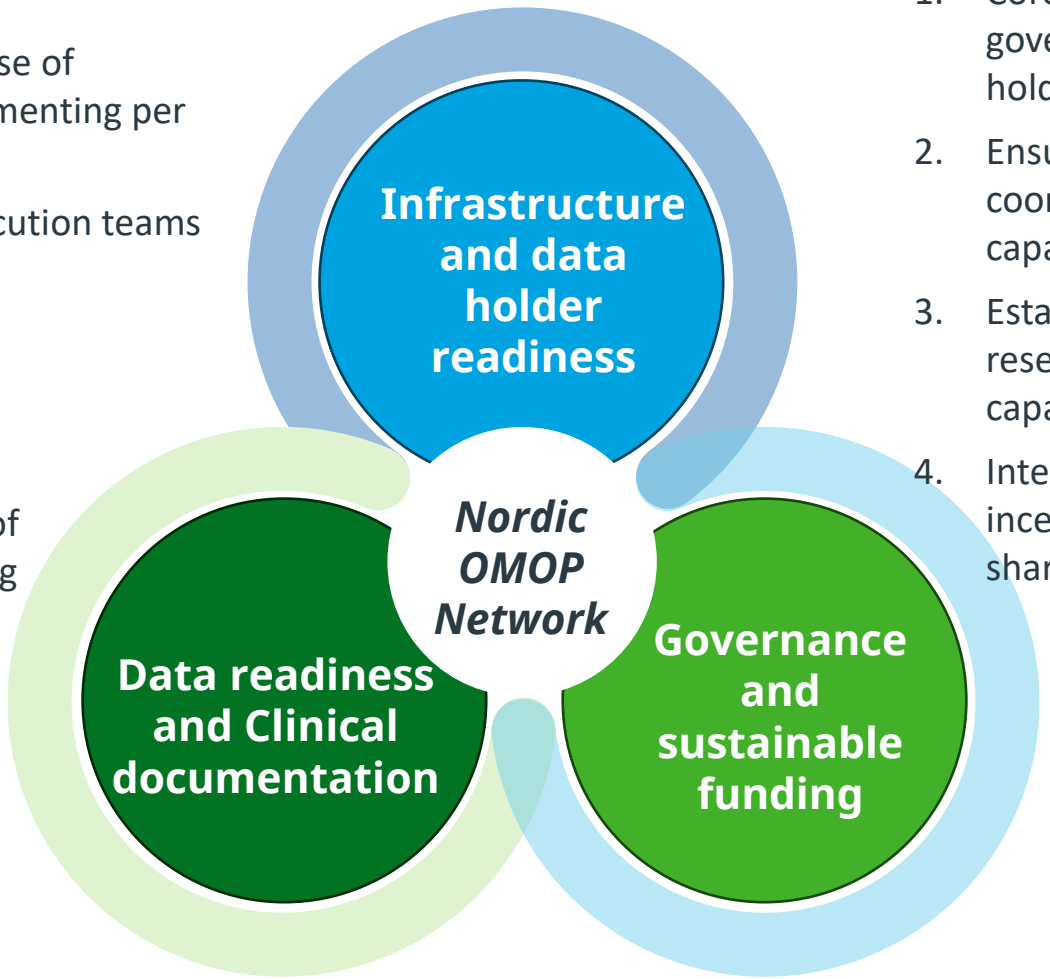
Suggestion: Establish a Nordic University hospital health data Network

Infrastructure and data holder readiness

1. Ensure baseline infrastructure and analytical environment readiness.
2. Fund collaborative ETL design and reuse of technical assets, rather than re-implementing per project.
3. Support small, stable local OMOP execution teams at each university hospital.

Data readiness and clinical documentation enhancement

1. Mandate or incentivize structured capture of key prognostic variables (e.g. ECOG, smoking status, biomarkers).
2. Align EHR documentation practices with research-grade data needs
3. Adopt a data-tier approach to set realistic expectations for which research questions are feasible across sites.



Governance and sustainable funding

1. Core infrastructure support from government or foundation sources to data holders
2. Ensure long-term, predictable funding for coordination, maintenance, and shared capabilities (OHDSI node)
3. Establish business model for commercial research studies leveraging network capabilities
4. Intellectual property frameworks that incentivize contribution while enabling sharing

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IQVIA SITRA

Key takeaways

OMOP-based federated analytics is a long-term capability and investment
Successful adoption requires multi-year investment. Building reusable ETL assets, stable infrastructure, and skills over time enables scalable Nordic collaboration and investment under EHDS.

What data is routinely captured determines what research is possible
Improving structured capture of biomarkers, performance status, and outcomes aligned among Nordic countries is key to advancing precision and policy-relevant research.

Governance, coordination and operational readiness are decisive for cross-border scientific validity
Aligned governance, shared vocabularies, and clear coordination will enable faster, compliant, and trustworthy federated analyses.

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VALO Pilot Study 2

Nordic Health Data Summit 2026

Wednesday 23.09.2026 at 08.30-18.00 in Oslo, Norway
On-site and online

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.

The event is organised by Sitra on behalf of the VALO2 project, in cooperation with the Norwegian Institute of Public Health. Participation is possible onsite in Oslo, with parts of the programme streamed online.

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

This session presents key outcomes, lessons learned, and recommendations from the VALO2 pilot on real-world use of cancer immunotherapies in Denmark, Finland, and Norway.

Serving as a hands-on rehearsal for the upcoming European Health Data Space (EHDS), the pilot demonstrates how researchers can securely access and analyse sensitive health data across borders via remote access in secure processing environments without data leaving its home country. The session highlights feasibility, practical challenges, and what is needed to scale this approach.

SPEAKERS

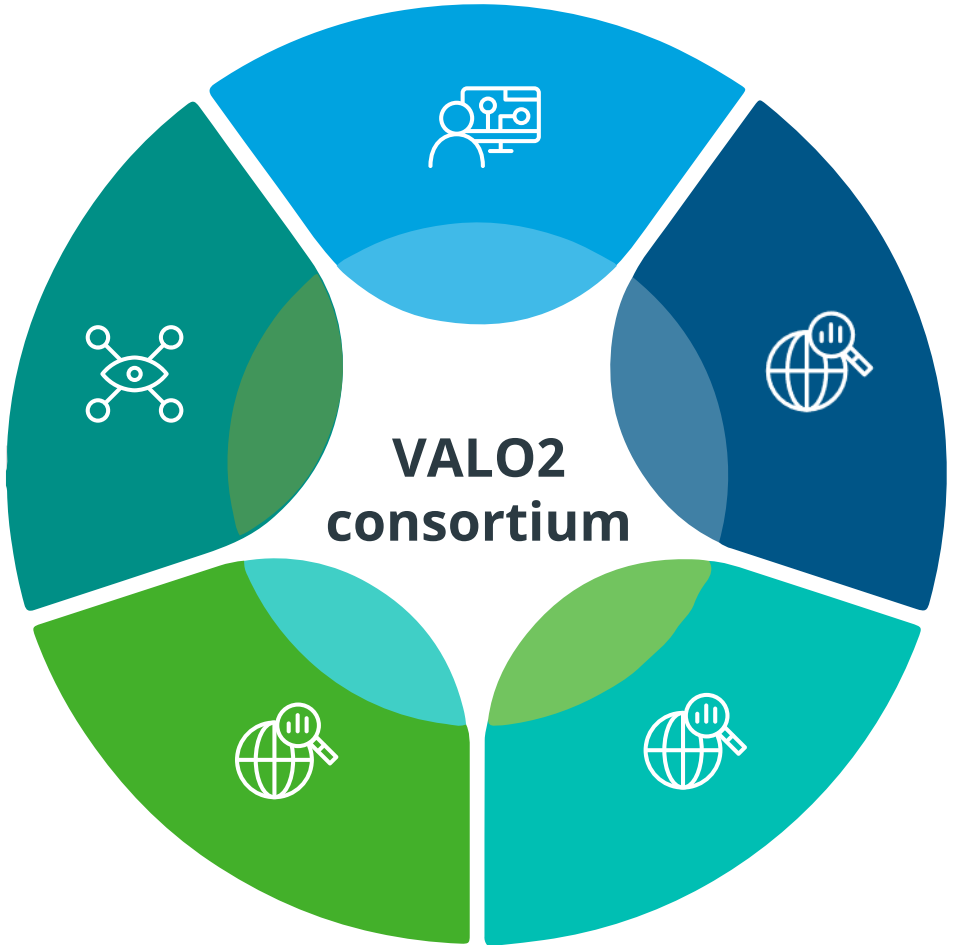
Mads Albrecht Andersen
MD, PhD student, Department of Oncology at Rigshospitalet, Capital Region of Denmark

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

VALO2 pilot study Consortium members



IQVIA Consortium Leadership
- PM leads Consortium and coordinates VALO 2 activities

Rigshospitalet, DK
- PI Andreas Bjerrum accesses SPE in NO, FI (and DK)
- SPE: DataBricks platform TRE

Helsinki University Hospital, FI
- PI Sami Pakarinen
- SPE: HUS Academic

Oslo University Hospital, NO
- PI Åslaug Helland
- SPE: TSD

Observer: Sweden
- Karolinska University Hospital and Karolinska Institutet
- No participation in VALO 2 data –related activities

**Iceland is not part of VALO 2*

VALO1 NSCLC study scope extension to VALO2

NSCLC VALO1 study protocol amendment

- To compare overall survival (OS) and time to treatment discontinuation (TTD) in patients with metastatic NSCLC
- To assess the feasibility of accessing Nordic health data sources via SPE

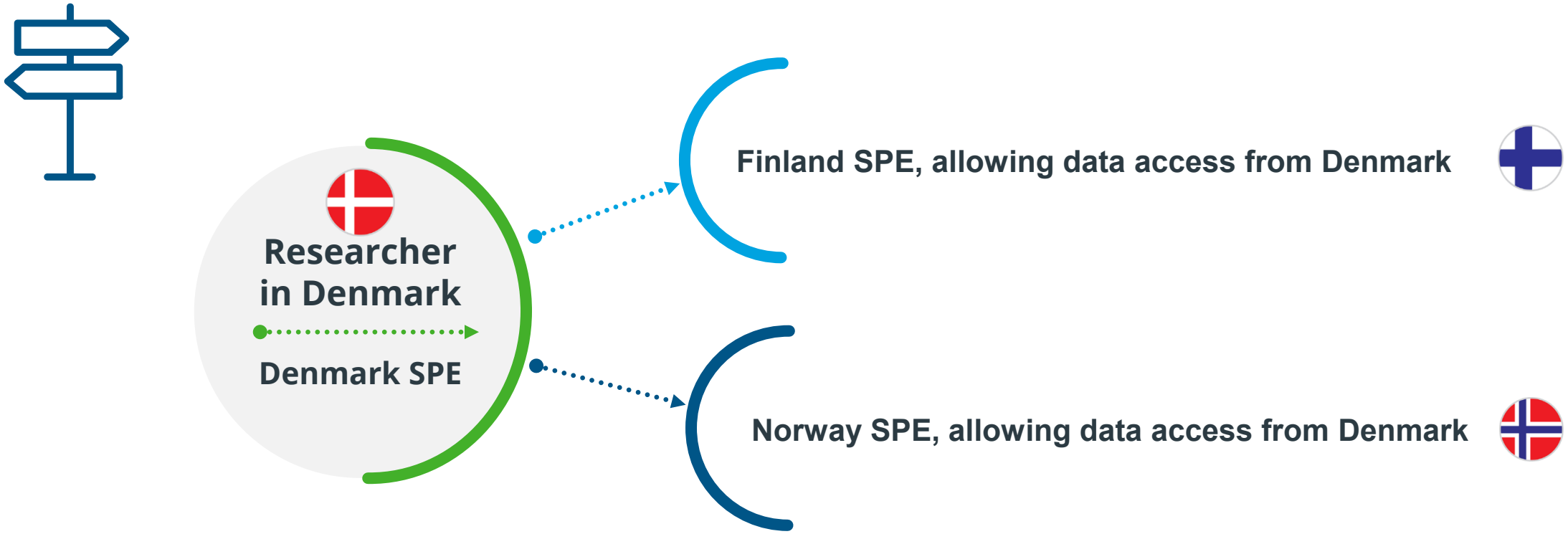
Data availability

- Data permit extensions for Finland, Norway and Denmark
- Established datasets for NSCLC available from VALO1 at the sites

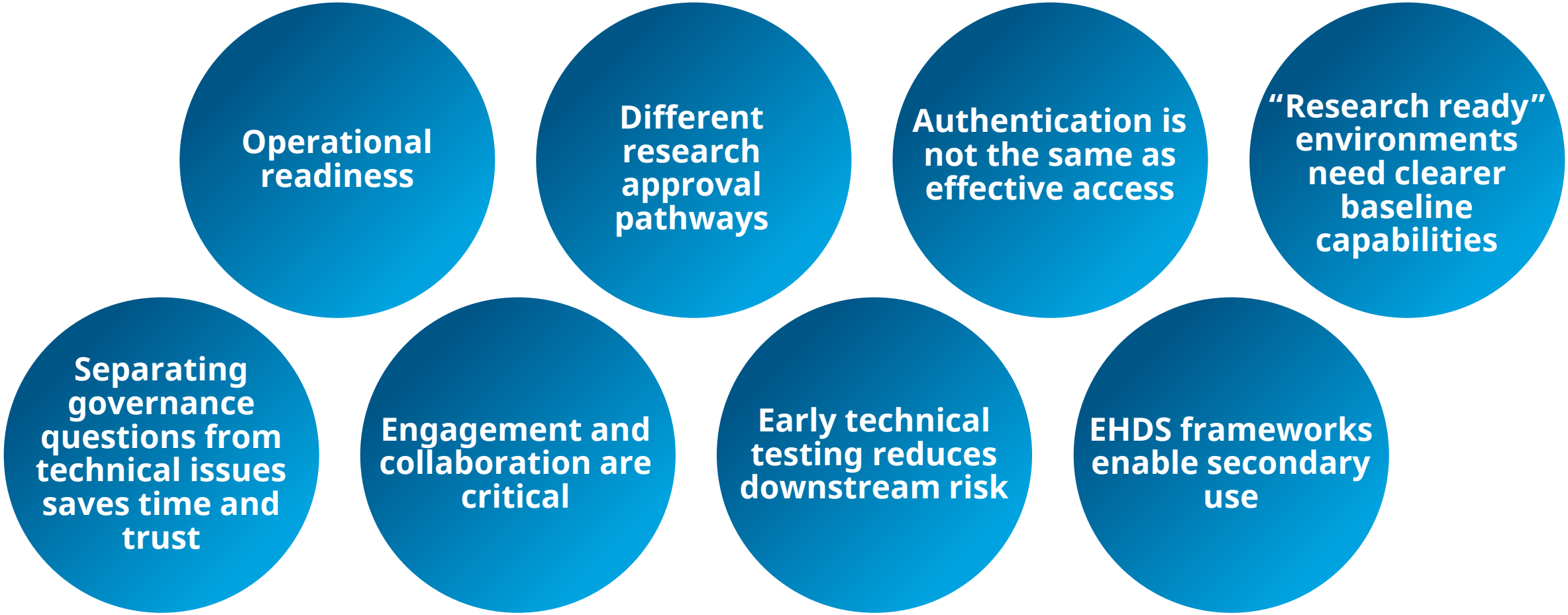
National SPE/TRE inclusion

- Finland: HUS Academic SPE
- Norway: TSD = Services for Sensitive Data
- Denmark: DataBricks platform TRE

VALO 2 data access model: A Nordic cross-border research environment using controlled data access infrastructures



VALO2 pilot – Insights / *EHDS readiness is as much about operational maturity, collaboration, and clarity of research approval pathways as it is about legislation and policy.*



A Nordic University Hospital RWE Network built on VALO

Pharma and Medtech message : ”Access and speed to data”

Strategy
Expand to all Nordic countries (NUHA)
Add other University hospitals

Goals
Start with NSCLC
Expand to other cancers and diseases

Feasibility
Rapid patient counts and statistics

Standardised Analytics
Cohort and patient characteristics
Treatment patterns
Drug Utilization
Clinical Outcomes

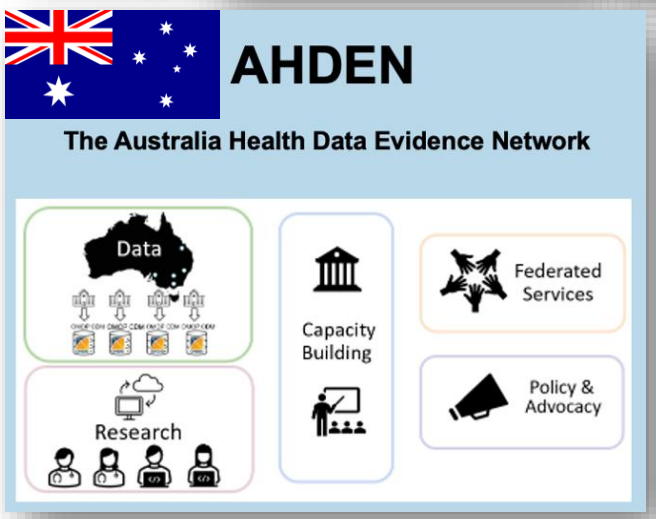
Analytics
Complex studies in Nordics and wider OHDSI Network

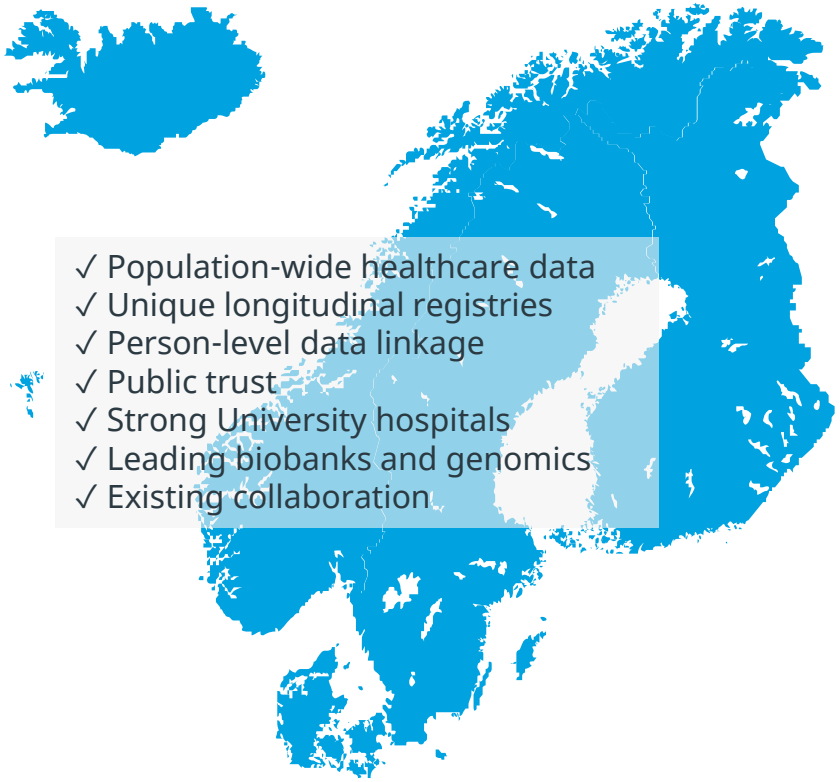
Industry as connector
Build on regional and global industry demand and collaboration

Nordic Collaboration

- Position Nordics as leader in RWE generation
- Attract more research collaboration and funding
- Infrastructure for rapid responses to data request in EHDS
- Framework agreements - established contracts and processes for rapid study execution

Countries are investing heavily in health data research infrastructure





✓ Population-wide healthcare data
✓ Unique longitudinal registries
✓ Person-level data linkage
✓ Public trust
✓ Strong University hospitals
✓ Leading biobanks and genomics
✓ Existing collaboration

How can the Nordic compete?

UK HDRS	Canada Vital	Australia AHDEN	DARWIN EU
£600M+	$210M	A$9.5M	250M patients
National gateway	160 hospitals	OMOP harmonisation	Regulatory RWE network

How do we move forward to a more connected Nordic health data ecosystem?

Pilot projects

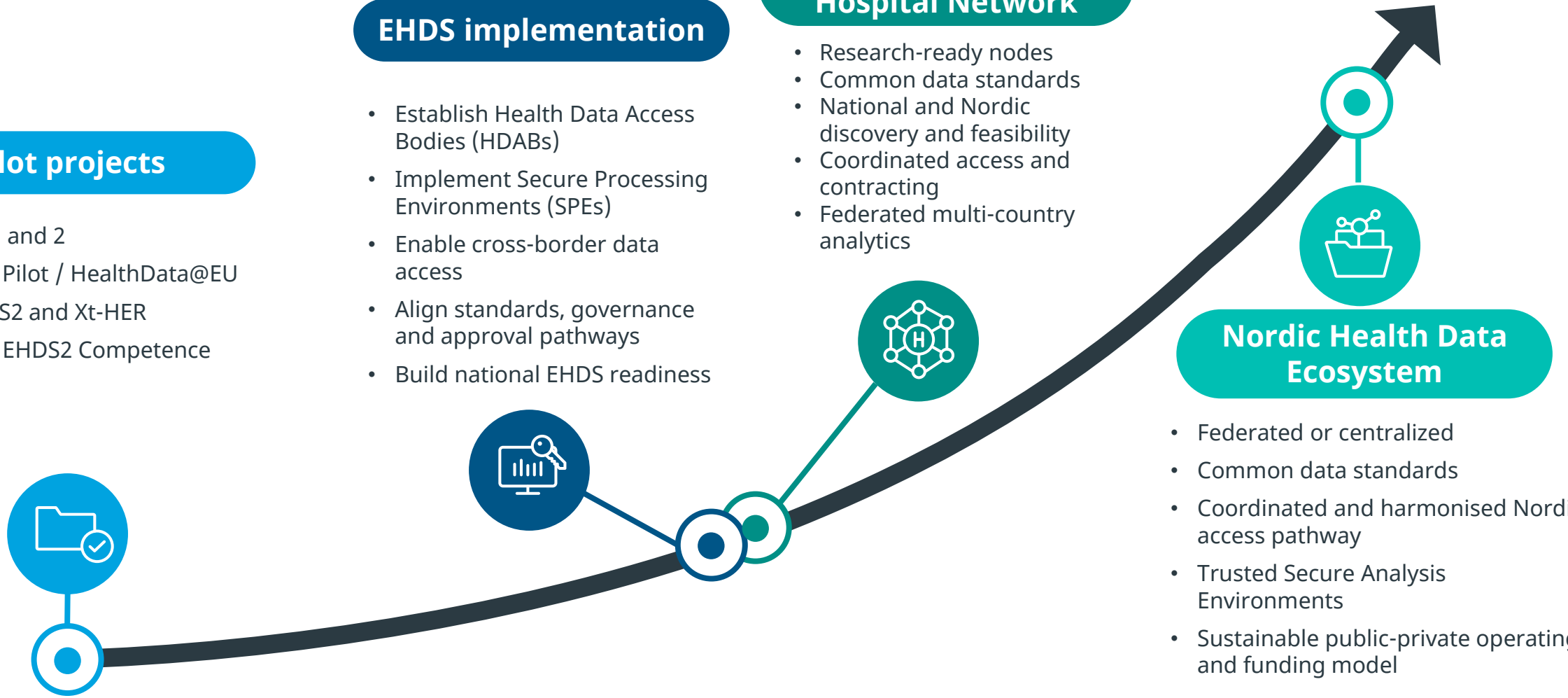
- VALO 1 and 2
- EHDS2 Pilot / HealthData@EU
- TEHDAS2 and Xt-HER
- Nordic EHDS2 Competence Forum

EHDS implementation

- Establish Health Data Access Bodies (HDABs)
- Implement Secure Processing Environments (SPEs)
- Enable cross-border data access
- Align standards, governance and approval pathways
- Build national EHDS readiness

Nordic University Hospital Network

- Research-ready nodes
- Common data standards
- National and Nordic discovery and feasibility
- Coordinated access and contracting
- Federated multi-country analytics



Nordic Health Data Ecosystem

- Federated or centralized
- Common data standards
- Coordinated and harmonised Nordic access pathway
- Trusted Secure Analysis Environments
- Sustainable public-private operating and funding model

Thank you!

Time	Title	Speaker
13:00-13:10	Welcome and introduction to today's program	Elen Høeg, Head of Health2B Mia Kråkstad, Healthcare Director IQVIA Norway
13:10-13:30	Safe Data, National Impact: Privacy Analytics in NHS England's Federated Data Platform	Jonathan Green, Director, Privacy Analytics, Europe, IQVIA
13.30–13.55	Beyond VALO - How do we leverage EHDS and move forward to a more connected Nordic health data ecosystem	Susanna Flaherty, Healthcare Director Finland, Carl Jarnling Healthcare Director Sweden, IQVIA
13.55–14.10	Pause and networking	
14:10-14:35	OMOP as an Enabler for Scalable Cancer Research	Åsa Öjlert, Post doc, MD, PhD, Oslo University Hospital
14:35-14:55	Down in the mine: perspectives from a clinical neuroscience registry	Cathrine Tverdal, Special Adviser in the Neuroscience Registry and Biobank, Oslo University Hospital
14:55-15:20	Dialogue, discussion	
15:30	End of meeting	

OMOP as an enabler for scalable cancer research

Åsa Öjlert

Oncologist / postdoc Oslo University Hospital

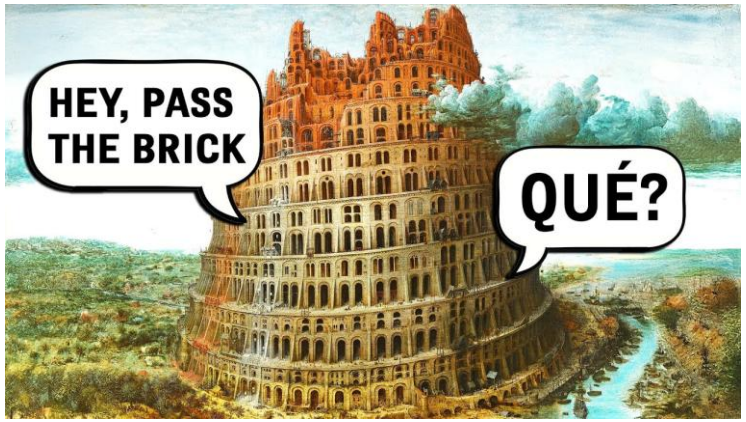
22 September 2026

The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)

- Background: why and when?
- Practical aspects: how it works
- Examples / OMOP projects at OUH
- Future perspectives

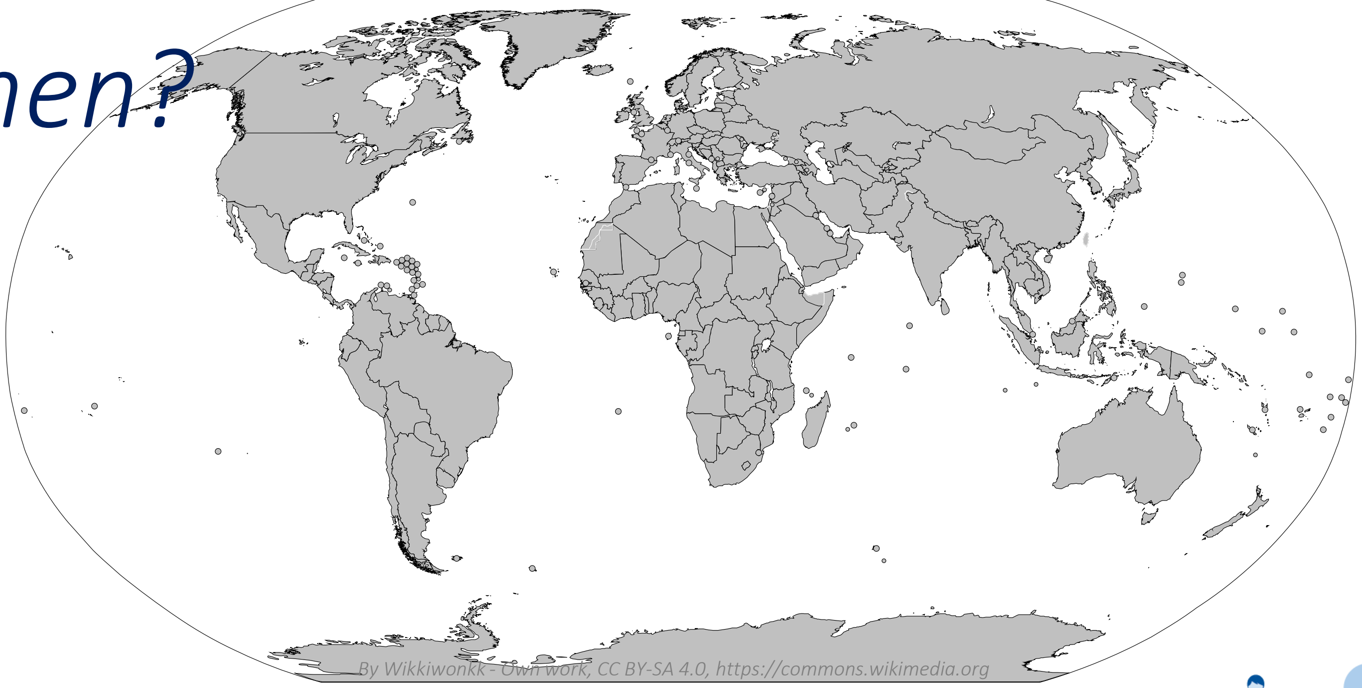
Why and when?

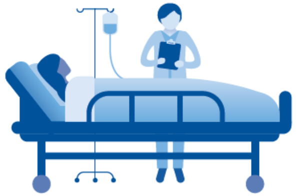

muralsyourway.com

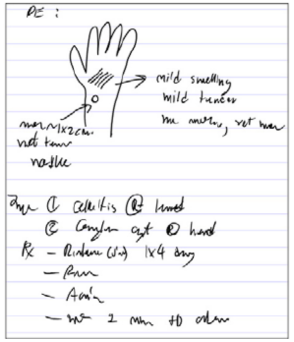

HEY, PASS THE BRICK
QUÉ?


Mi parolas esperante!

Why and when?



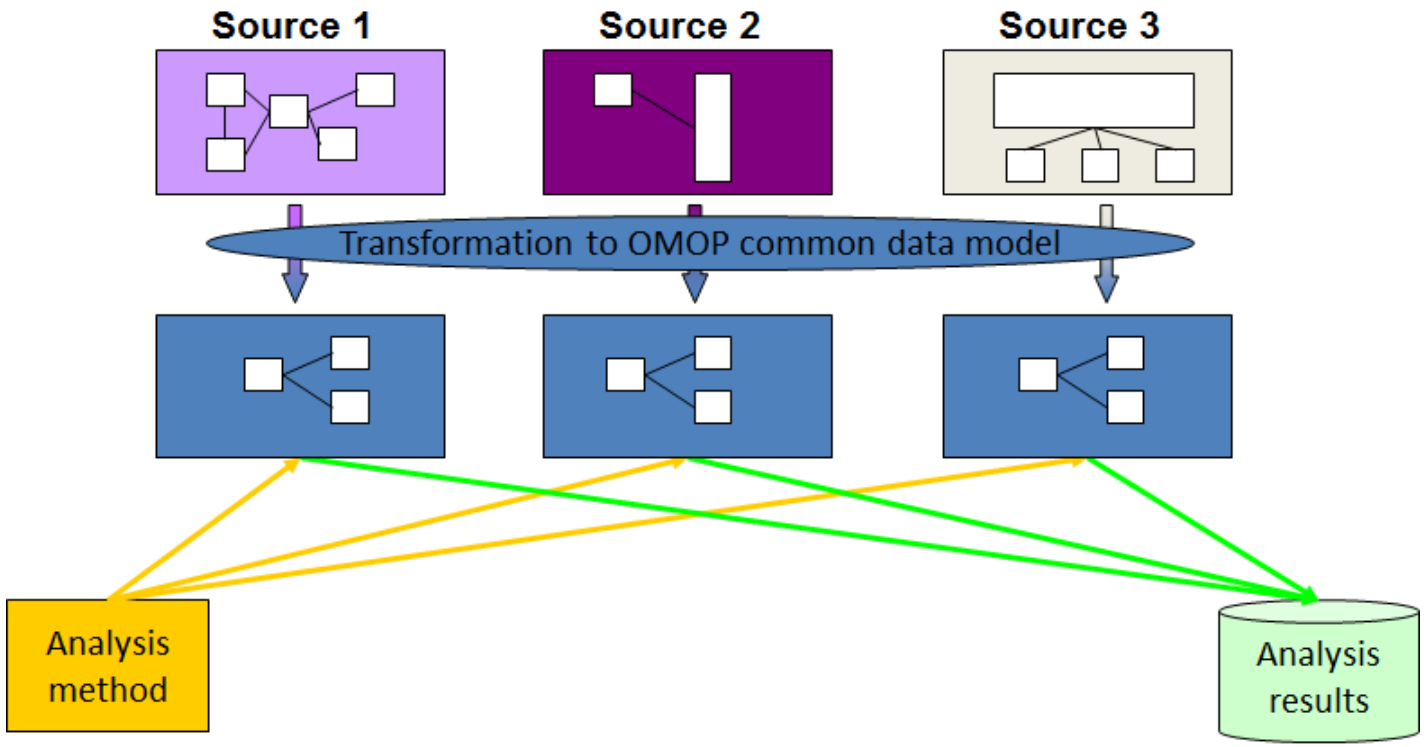




Why and when?

The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)

- 5-year FDA grant to study the risks / benefit of medical products (2008)
- Public-private partnership (pharma, academia, government)
- Standardized data structure
- Standardized vocabulary
- Standardized analyses methods
- Open-source, maintained and further developed by the Observational Health Data Sciences and Informatics (OHDSI) community



Clinical study

ECOG
Comorbidities
Polypharmacy
Age

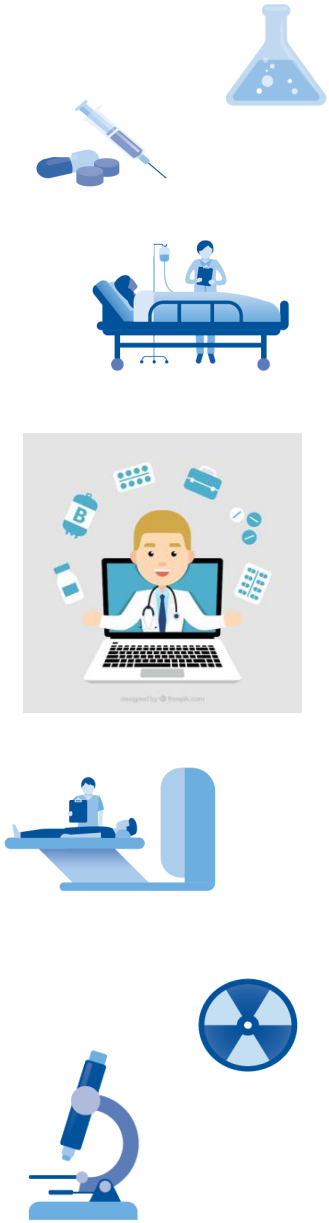
Real world

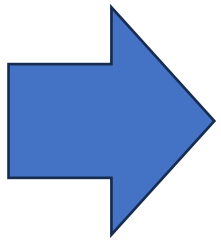
Risks / benefits of drugs, procedures

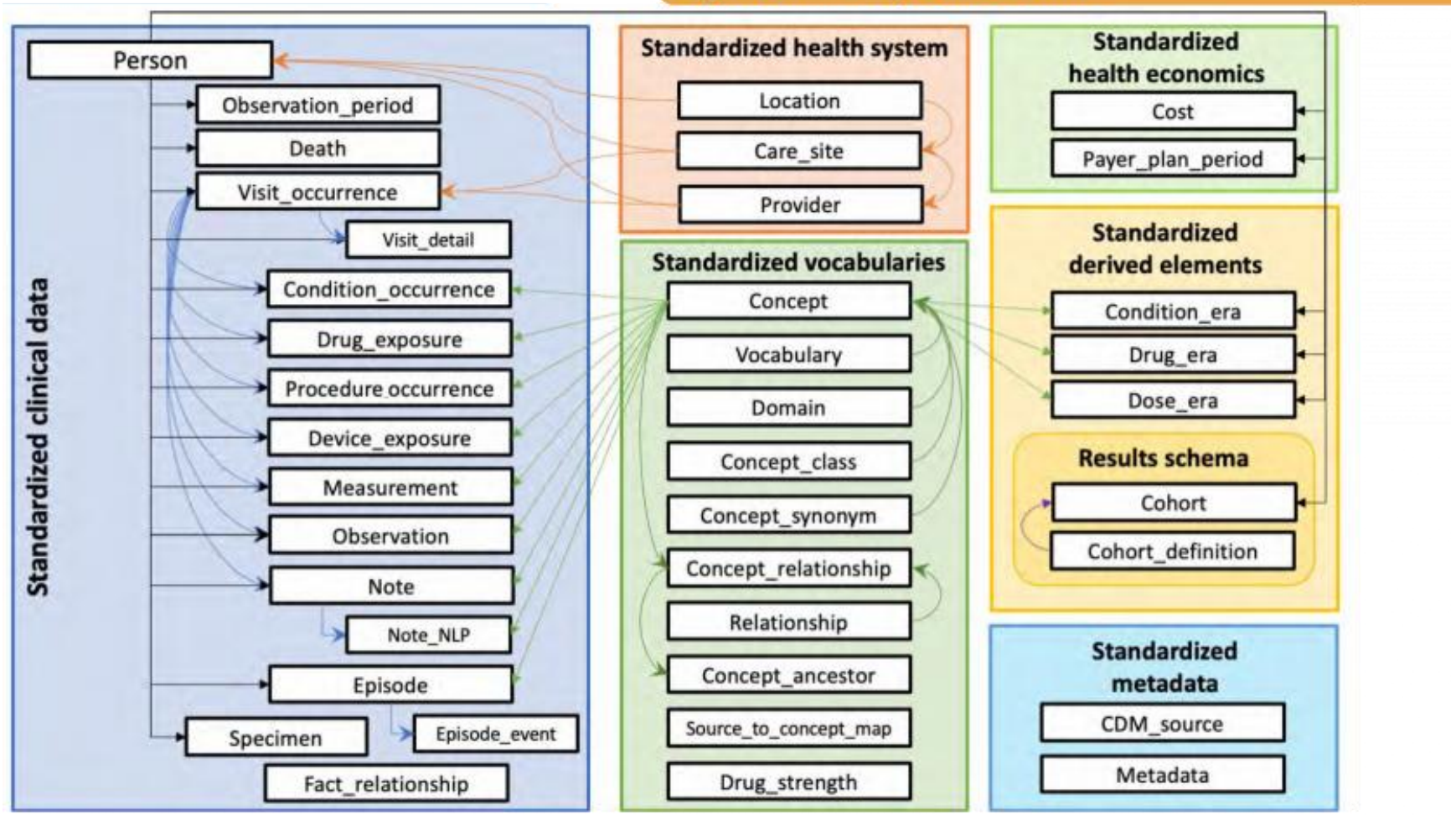
The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) is an ***open community data standard****, designed to* ***standardize the structure and content of observational data*** *and to enable efficient analyses that can produce* ***reliable evidence****.*

Resources / health economy / political decisions

How it works






OMOP CDM By The Numbers
37 tables
• 17 to standardize clinical data
• 10 to standardize vocabularies
394 fields
• 193 with _id to standardize identification
• 101 with _concept_id to standardize content
• 43 with _source_value to preserve original data
1 Open Community Data Standard
Standardized clinical data
Person
Observation_period
Death
Visit_occurrence
Visit_detail
Condition_occurrence
Drug_exposure
Procedure_occurrence
Device_exposure
Measurement
Observation
Note
Note_NLP
Episode
Specimen
Episode_event
Fact_relationship
Standardized health system
Location
Care_site
Provider
Standardized vocabularies
Concept
Vocabulary
Domain
Concept_class
Concept_synonym
Concept_relationship
Relationship
Concept_ancestor
Source_to_concept_map
Drug_strength
Standardized health economics
Cost
Payer_plan_period
Standardized derived elements
Condition_era
Drug_era
Dose_era
Results schema
Cohort
Cohort_definition
Standardized metadata
CDM_source
Metadata

How it works: OHDSI tools

- WHITERABBIT and RABBIT-IN-A-HAT
- ATHENA
- USAGI
- DATA QUALITY DASHBOARD
- ACHILLES
- ATLAS
- HADES

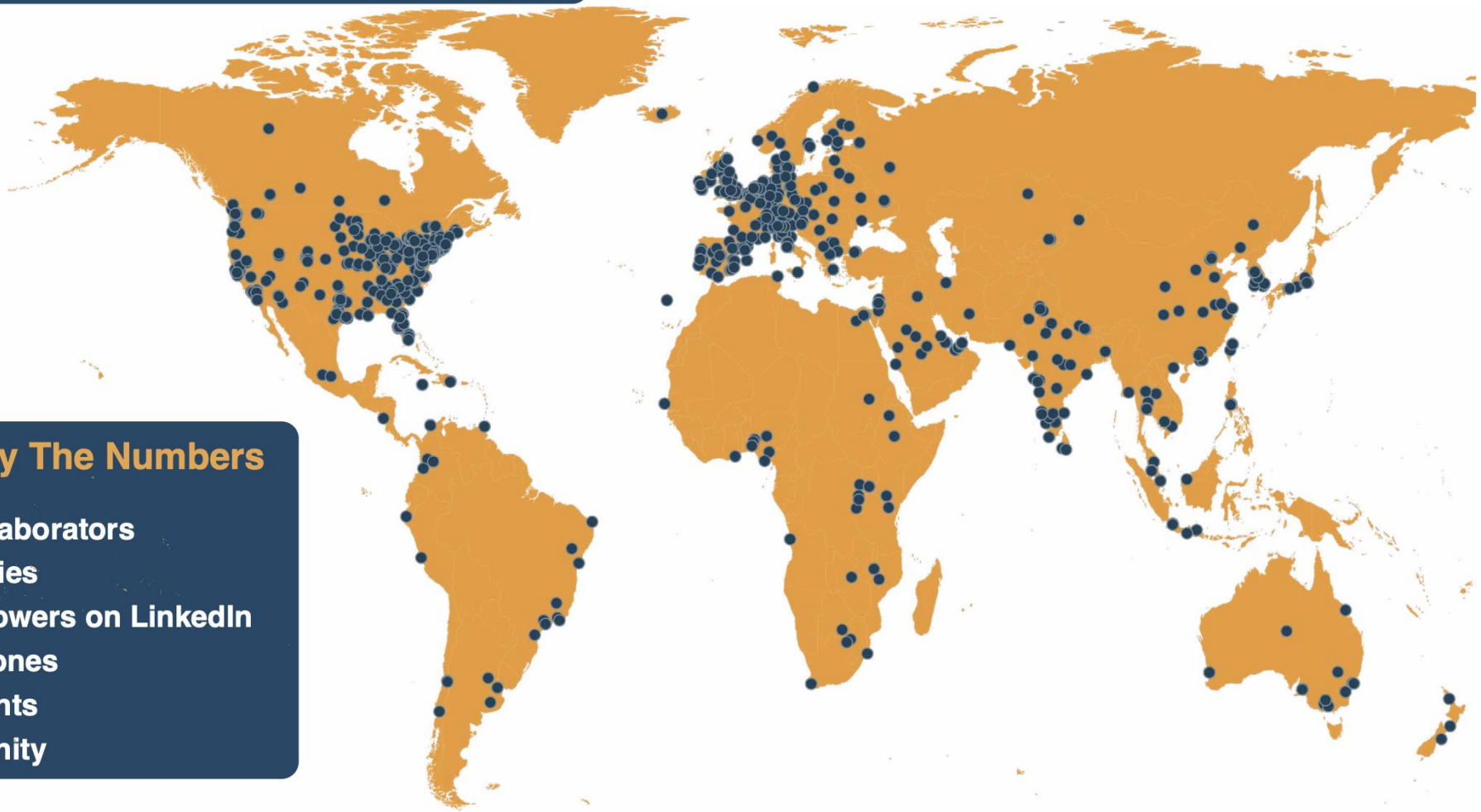
- Prepare the transition to OMOP-CDM
- Vocabulary
- Data quality
- Define cohorts
- Perform analyses
- Visualization

OHDSI COLLABORATORS

Map of Collaborators

The OHDSI community brings together volunteers from around the world to establish open community data standards, develop open-source software, conduct methodological research, and apply scientific best practices to answer public health questions by generating reliable clinical evidence.

Our community is ALWAYS seeking new collaborators. Do you want to focus on data standards or methodological research? Are you passionate about open-source development or clinical applications? Do you have data that you want to be part of global network studies? Do you want to join a global community that truly values the benefits of open science? Add a dot to the map below and JOIN THE JOURNEY!

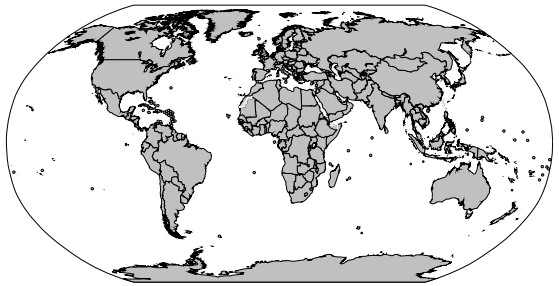


OHDSI By The Numbers

- 4,751 collaborators
- 88 countries
- 9,004 followers on LinkedIn
- 21 time zones
- 6 continents
- 1 community

Examples at OUH

Cancer data dashboard: quality of care, monitoring etc



Federated Alliance for Large-Scale Cancer Observational Network (**FALCON**)

- 45 partners across 19 countries (academic hospitals, public registries, public–private institutions)
- Studies on metastatic lung cancer and bladder cancer

DIGital Institute for Cancer Outcomes Research (**DIGICORE**)

- A non-profit European Economic Interest Grouping*
- Members and associate members in 16 European countries:
  - 36 European cancer centers (including OUS)
  - 2 industrial members (IQVIA, Illumina)
  - 2 national cancer networks (UNICANCER in France and Alleanza contro il cancro in Italy)

** A type of legal entity of the European corporate law, designed to make it easier to cooperate within the EU.*

Examples: DIGICORE / DigiOne

€ 3M funding for OMOP / federation pilots (IQVIA)

Frankfurt University Hospital

Leeds Teaching Hospital

Maastricht University Medical Center

Oslo University Hospital

Cliniques Universitaires Saint-Luc (Brussels)

San Raffaele University Hospital (Milan)

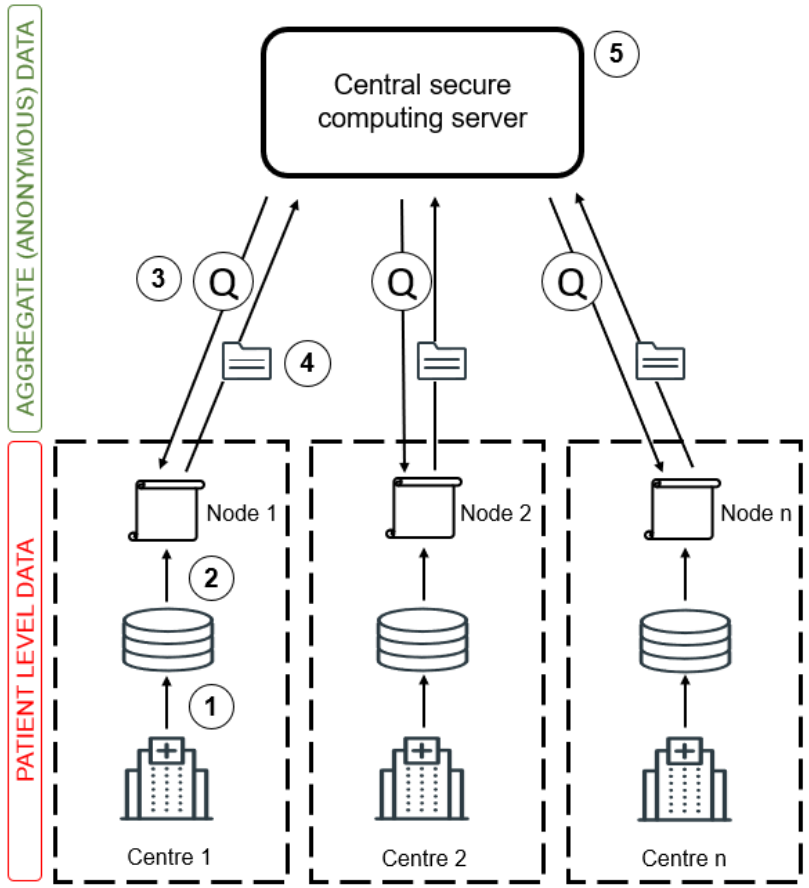
DigiOne: results

Minimal Essential Description of Cancer (MEDOC)

- 36 variables to describe the patient, cancer disease, treatments and outcomes

	MEDOC ID	MEDOC Data Concept
Demographics	1.1	Date of birth
	1.2	Sex
	1.3	Weight
	1.4	Height
	1.5	Healthcare ID
	1.6	Legal basis for data processing
Clinical phenotype	2.1	ICD-10 for primary diagnosis
	2.2	Charlson comorbidity index
	2.3	Date of primary diagnosis
	2.4	Method of primary diagnosis
	2.5	Performance status
	2.6	Disease Stage with timestamp
	2.7	Histological Cell type
Bio-markers	3.1	Biomarker name with timestamp
	3.2	Biomarker measure with timestamp
	3.3	Biological sample ID with timestamp
Treatments & Procedures	4.1	Line of therapy
	4.2	Anti-cancer treatment name
	4.3	Molecule generic name
	4.4	Start date for drug treatment
	4.5	Treatment dose
	4.6	End date for drug treatment
	4.7	Radiotherapy type (e.g. procedure code)
	4.8	Radiotherapy Start date
	4.9	Radiotherapy dose
	4.10	Radiotherapy end date
	4.11	Surgery type (e.g. procedure code)
	4.12	Surgery date
	4.13	Participation in clinical trial
	4.14	Date of trial consent
Outcomes	5.1	Date of death (any location)
	5.2	Time to next treatment (derived)
	5.3	Metastasis presence / absence
	5.4	Metastasis location
	5.5	Date of last visit/follow-up
	5.6	Vital status (derived)

Federated analysis (vantage6)



DigiOne studies

DigiONE 01: the number of new primary cancers diagnosed during the covid-19 pandemic, and 12 months survival

DigiONE 02: **di**sease **na**tural hi**st**ory and care qualit**y** assessment (DINASTY) in metastatic non-small cell lung cancer

DigiONE 03: DINASTY in HR+/HER2− metastatic breast cancer

DigiONE 04: Real-World Insights on Cancer Burden and Treatment Delays – A Comprehensive Observation Study Based on DigiONE Treatment Centres (DigiACT)

DINASTY in NSCLC

- A DISEASE NATURAL HISTORY AND OUTCOMES STUDY WITH CARE QUALITY ASSESSMENT IN METASTATIC NON-SMALL-CELL LUNG CANCER (DINASTY IN NSCLC)

Primary objective:

1. To describe the patient and tumor characteristics at diagnosis of metastatic NSCLC

Secondary objectives:

2. Describe the 1st and 2nd line of treatment
3. Outcomes: OS and time to next treatment
4. 1st line immunotherapy: duration of treatment, dose intensity according to age, gender, BMI.
5. Care quality, according to ESMO guidelines

Objective 1-3: all patients + subgroups based on site(s) of metastases

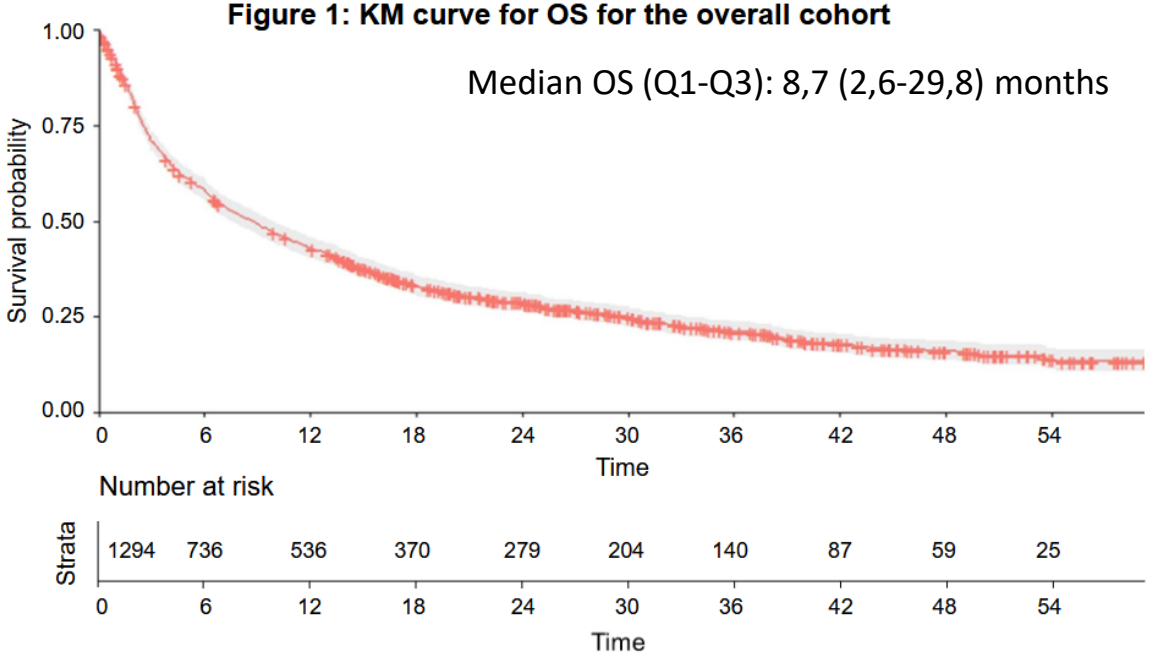
DINASTY in NSCLC

OS: mNSCLC diagnosed 1 Nov 2018-30 Sept 2022 (Leeds, Maastricht, Oslo)

Patient characteristics		Overall cohort N = 1294	Leeds N = 600	Maastricht N = 363	Oslo N = 331
Age	Median	70	70	69	70
Sex	Male	683 (53%)	309 (52%)	195 (54%)	179 (54%)
	Female	611 (47%)	291 (49%)	168 (46%)	152 (46%)
Metastatic disease presentation	De novo	949 (73%)	441 (74%)	301 (83%)	207 (63%)
	Recurrence / refractory	345 (27%)	159 (27%)	62 (17%)	124 (37%)

Figure 1: KM curve for OS for the overall cohort

Median OS (Q1-Q3): 8,7 (2,6-29,8) months



Data privacy:

- *Federated analysis*
- *Counts <5 not presented*
- *Gaussian-noised survival times*

https://digicore-cancer.eu/Posters/2024-esmo-poster.pdf

DINASTY in NSCLC

OS: mNSCLC diagnosed 1 Nov 2018-30 Sept 2022 (Leeds, Maastricht, Oslo)

Figure 2: KM curve for OS for patient subgroups by metastasis location

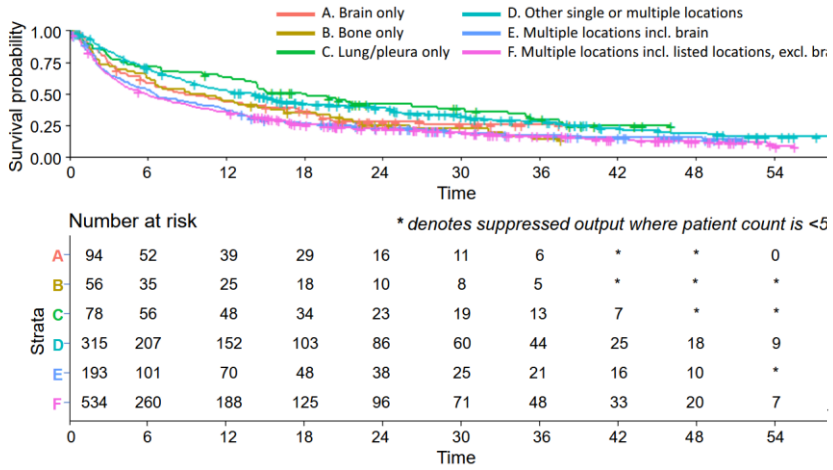


Table 4: Pairwise logrank test by metastasis location

Pairwise logrank test (p-value)	A. Brain only	B. Bone only	C. Lung / pleura only	D. Other single / multiple locations	E. Multiple locations incl. brain
B. Bone only	0.61	NA	NA	NA	NA
C. Lung/pleura only	0.194	0.11	NA	NA	NA
D. Other single/ multiple locations	0.244	0.194	0.515	NA	NA
E. Multiple locations incl. brain	0.194	0.538	**0.005**	**0.001**	NA
F. Multiple listed locations excl. brain	0.11	0.334	**0.001**	**0.001**	0.61

***P-value in bold** denotes statistically significant comparison*

Table 3: Median OS (mOS) and survival probability (95% CI) of patients at 6 – 24 months timepoints of patient subgroups by metastasis location

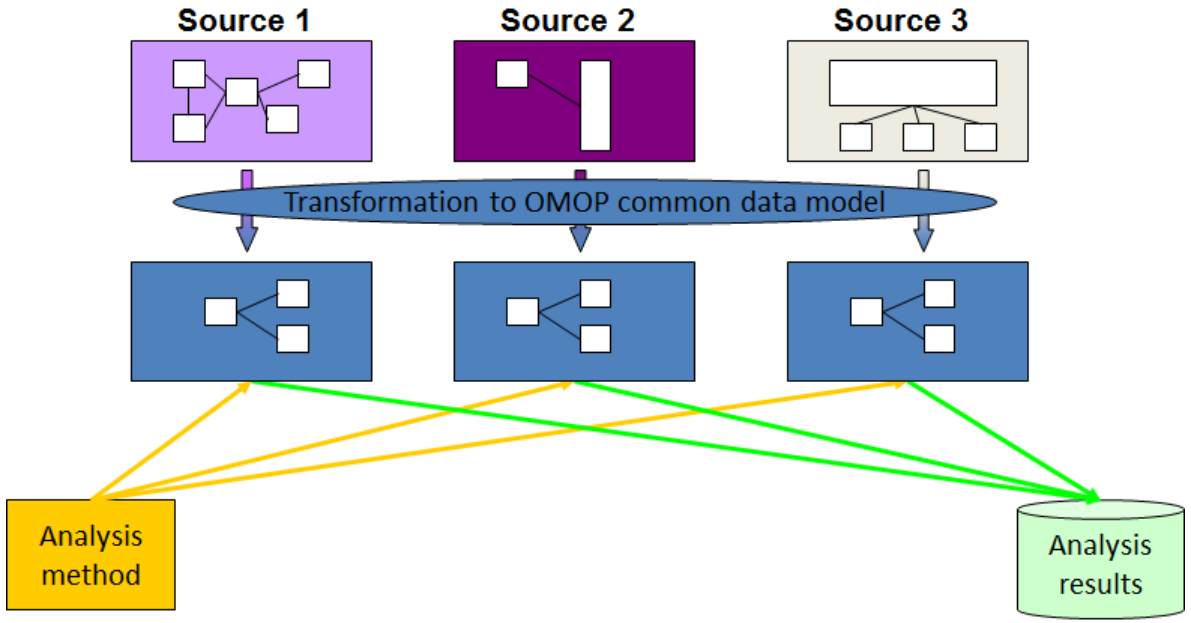
Patient subgroups	A. Brain only N = 94 (7.3%)	B. Bone only N = 56 (4.3%)	C. Lung / pleura only N = 78 (6.0%)	D. Other single / multiple locations N = 315 (24.3%)	E. Multiple locations incl. brain N = 193 (14.9%)	F. Multiple listed locations excl. brain N = 534 (41.3%)
mOS (Q1 – Q3)	8.84 (3.12 – NA)	9.82 (2.27 - 26.05)	17.81 (3.91 - 37.85)	14.16 (4.6 - 39.75)	6.6 (2.07 - 20.34)	5.88 (2.07 - 19.42)
Timepoint	Number of patients Survival probability (95% CI)					
6 Months	52 58.5 (47.7, 67.8)	35 62.5 (48.5, 73.7)	56 71.8 (60.4, 80.4)	207 70.5 (65.0, 75.4)	101 53.2 (45.9, 60.0)	260 49.1 (44.8, 53.2)
12 Months	39 43.9 (33.5, 53.8)	25 44.6 (31.4, 57.0)	48 62.8 (51.0, 72.4)	152 52.6 (46.8, 58.2)	70 36.9 (30.1, 43.7)	188 35.5 (31.4, 39.6)
18 Months	29 35.8 (26.0, 45.7)	18 35.5 (23.2, 47.9)	34 49.5 (38.0, 60.1)	103 41.9 (36.2, 47.6)	48 26.6 (20.5, 33.1)	125 26.2 (22.5, 30.1)
24 Months	16 28.0 (18.9, 37.8)	10 25.2 (14.5, 37.4)	23 42.0 (30.7, 52.9)	86 39.0 (33.2, 44.7)	38 23.1 (17.4, 29.4)	96 22.5 (19.0, 26.2)

Longest OS: lung/pleural metastases only
Shortest OS: multiple metastases

https://digicore-cancer.eu/Posters/2024-esmo-poster.pdf

The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)

- Standardized data structure, vocabulary, analyses methods
- Facilitates use of health data within a health institution, and when collaborating nationally and internationally
- Several ongoing projects and constant improvements of the methods / data model



Future perspectives

- Transfer from a local solution (the clinical data warehouse) to a regional solution (RDAP)
- Federated methods: host / organize this at OUH, alternatives to vantage6
- Ethical approval: research vs quality control, implement a general informed consent for the use of health data
- Add new data modalities (imaging)


Thank you for your attention!

Time	Title	Speaker
13:00-13:10	Welcome and introduction to today's program	Elen Høeg, Head of Health2B Mia Kråkstad, Healthcare Director IQVIA Norway
13:10-13:30	Safe Data, National Impact: Privacy Analytics in NHS England's Federated Data Platform	Jonathan Green, Director, Privacy Analytics, Europe, IQVIA
13.30–13.55	Beyond VALO - How do we leverage EHDS and move forward to a more connected Nordic health data ecosystem	Susanna Flaherty, Healthcare Director Finland, Carl Jarnling Healthcare Director Sweden, IQVIA
13.55–14.10	Pause and networking	
14:10-14:35	OMOP as an Enabler for Scalable Cancer Research	Åsa Öjlert, Post doc, MD, PhD, Oslo University Hospital
14:35-14:55	Down in the mine: perspectives from a clinical neuroscience registry	Cathrine Tverdal, Special Adviser in the Neuroscience Registry and Biobank, Oslo University Hospital
14:55-15:20	Dialogue, discussion	
15:30	End of meeting	

22 Sep 2026 · Health2B

Down in the mine

Perspectives from a clinical neuroscience registry — NevroVit

Cathrine Tverdal, BsN MPhil PhD

Special advisor

Division of Clinical Neuroscience

Cathrine Tverdal

Special advisor · Division of Clinical Neuroscience

Oslo University Hospital

CURRENT ROLE

Set strategy and drive implementation across health data registries, interdisciplinary research, education, and competence development.

PROFESSIONAL BACKGROUND

Health data registries

Research

Nursing

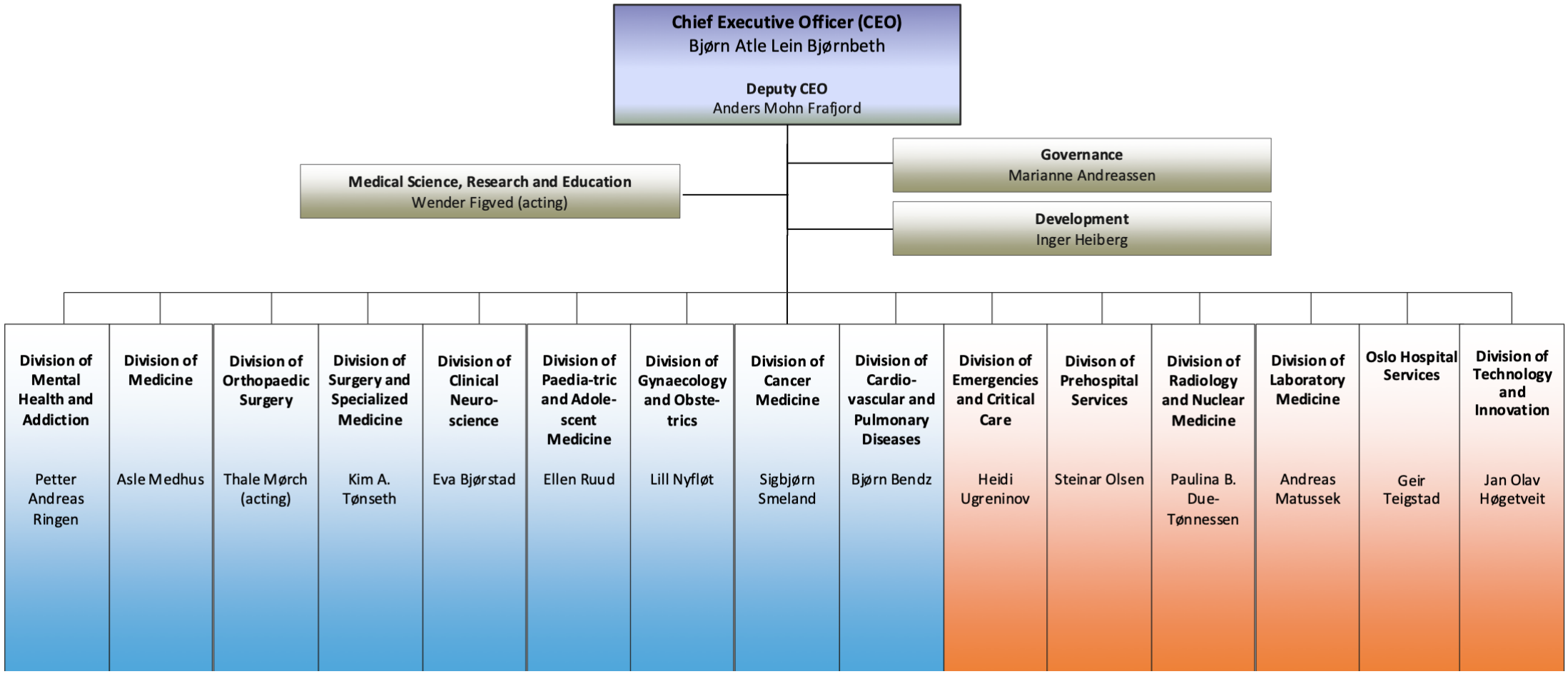
More than ten years working with data collection and registry data.

EDUCATION

PhD in Medicine and Health Sciences · MPhil in Health Sciences · Neuroscience Nursing · Bachelor's in Nursing


Framework Conditions
• Regulations
• Funding Mechanisms
Research and Innovation
• Clinical Research
• Collaborative Structures and Partnerships
Data and Infrastructure
• Health Data
• Registries
• Research Infrastructure

Oslo University Hospital



Where we work

Oslo University Hospital

4 hospital locations

1800 beds

24 000 employees

14 Clinical Divisions

Division of Clinical Neuroscience

DEPARTMENTS

Epilepsy (SSE)
Gender dysphoria
Neurohabilitation
Neurology x 2
Neurosurgery x 2
Physical Medicine and Rehabilitation
Research and Innovation

NevroVit - Neuroscience Registry and Research Biobank

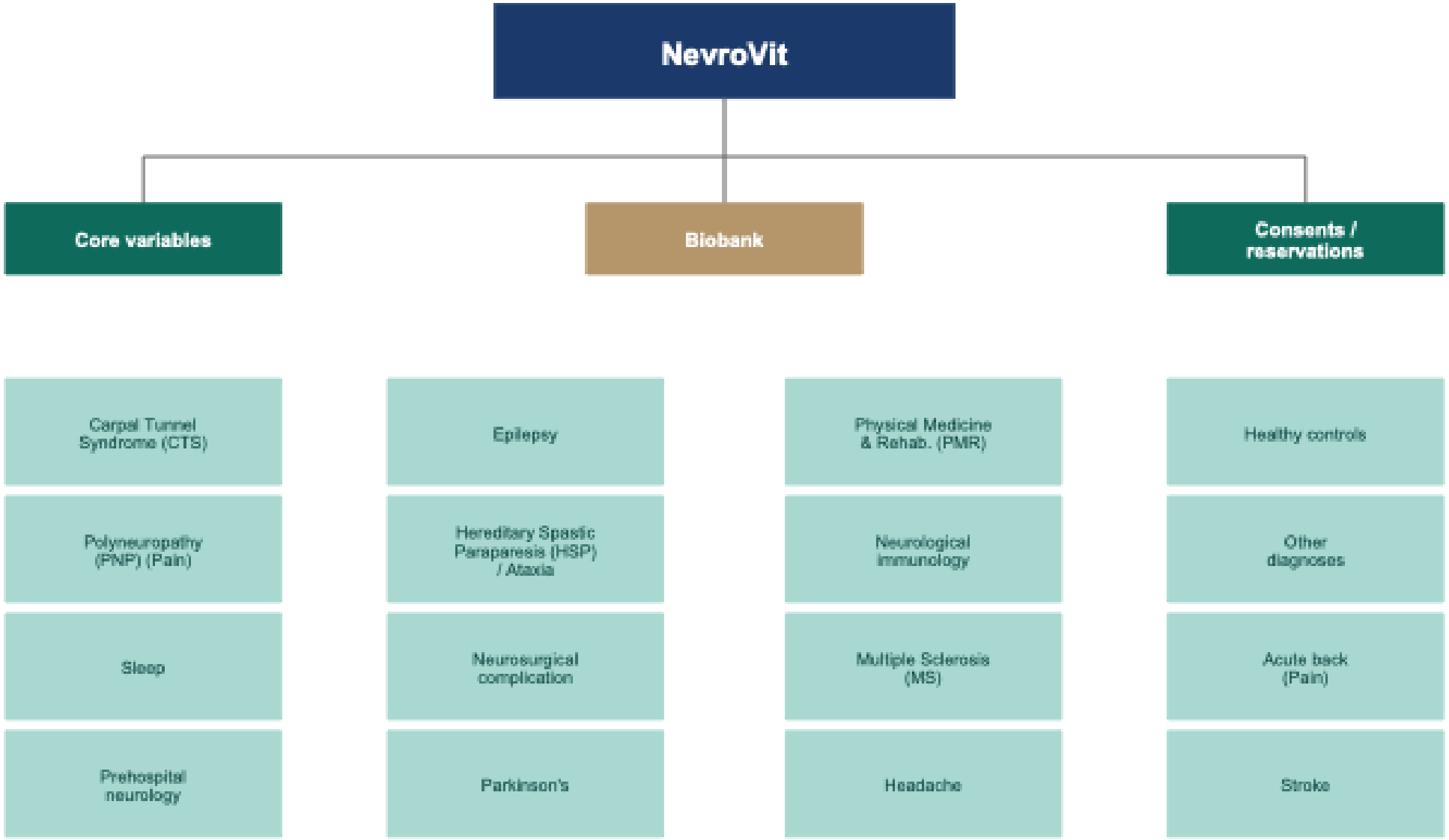
Division of Clinical Neuroscience is leading and future oriented in use of quality registries to develop and improve patient treatment and care

STRATEGIC DIRECTION

"The Division of Clinical Neuroscience shall have quality registries with high coverage and quality that can be used for continuous quality assurance, professional development, better treatment and follow-up of patients at all levels of the organization

> **NevroVit will utilize new technology to facilitate quality registries of high data quality that enable good quality assurance and medical research"**

https://www.oslo-universitetssykehus.no/avdelinger/nevroklinikken/forskning-og-utvikling-nevroklinikken/nevrovitenskapelig-register-og-forskningsbiobank/


NevroVit
Core variables
Biobank
Consents / reservations
Carpal Tunnel Syndrome (CTS)
Polyneuropathy (PNP) (Pain)
Sleep
Prehospital neurology
Epilepsy
Hereditary Spastic Paraparesis (HSP) / Ataxia
Neurosurgical complication
Parkinson's
Physical Medicine & Rehab. (PMR)
Neurological immunology
Multiple Sclerosis (MS)
Headache
Healthy controls
Other diagnoses
Acute back (Pain)
Stroke

Daily challenges we face – and handle

The route is rarely straight—even when the destination is clear.

WHY THE PATH IS COMPLEX

01 **Overview** — hospitals, registries and use

02 **Registry scope** — national, research and hospital registries

03 **Measurement** — what is measured and which quality indicators

04 **Data quality** — no feedback loops, weak system integration and unclear ownership

05 **Data analysis** — requires statistical expertise

06 **Interoperability** — software systems do not communicate

07 **Regulation** — complicated requirements

08 **Vulnerability** — processes depend heavily on individuals

The “registry gold” is not one uniform resource

When we say “registries,” what exactly do we mean?

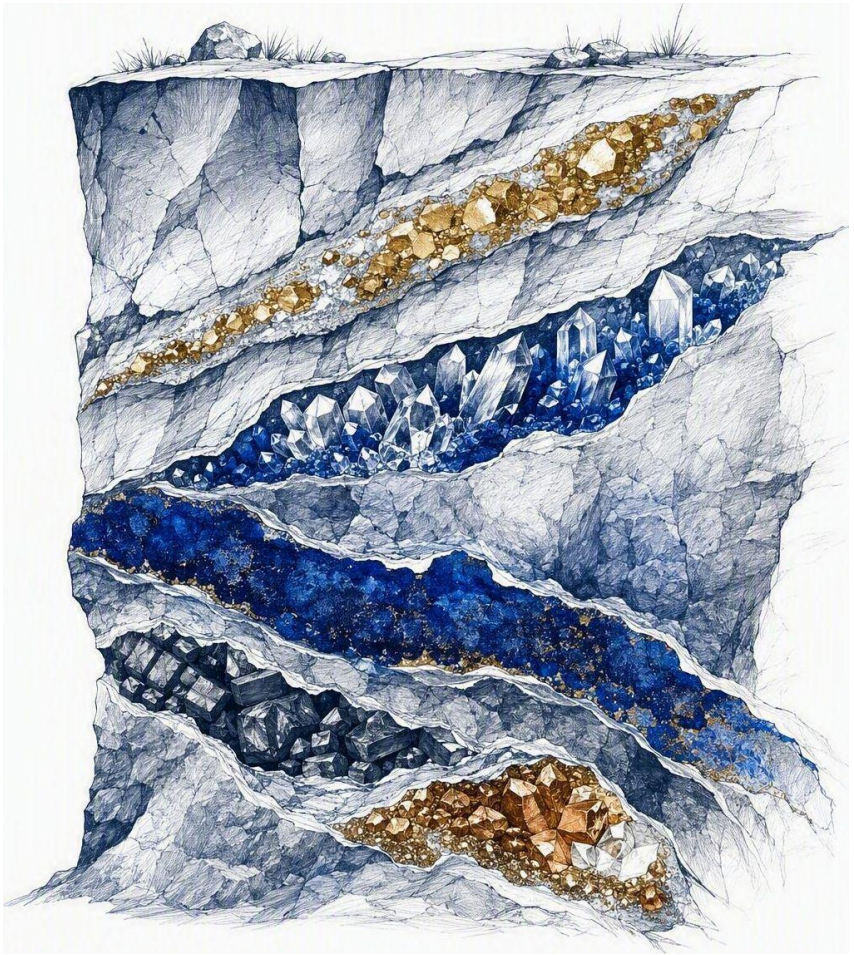
REGISTRY IS AN UMBRELLA TERM

National, research and hospital registries capture different data and support different purposes.

VALUE AND LIMITATIONS VARY

A registry can be highly valuable for one use—and unsuitable for another.

> **Define the registry type before ambitions about comparing, linking or sharing data.**



The health-data stack is only as strong as its source

Registry types differ—but every layer still depends on the quality of the underlying clinical data.

Political / strategic

Orchestration & consulting

Data models & methodology

Secure environments

Registries & research platforms

DATA FROM CLINICAL SYSTEMS
Where health data originates

WHERE CONFERENCES FOCUS

Strategies, governance, platforms and access—the visible upper layers.

WHERE WE MUST START

Clinical systems: structure, completeness, quality and ownership.

Weak source data propagate upward.

Health data the new oil??

The oil era was built on long-term thinking, infrastructure and expertise—with public stewardship.

FOR THOSE CLOSEST TO THE DATA SOURCE

01 **Long-term approach** — Build capacity beyond individual projects and funding cycles.

02 **Digital infrastructure** — Strengthen clinical systems, standards and feedback loops.

03 **Expertise** — Keep clinical, technical and statistical knowledge close to the data.

04 **Ownership** — Define responsibility and safeguard public stewardship.

> **Value is created where health data originate.**

Collaboration works only when the hard questions are explicit

THE ELEPHANT IN THE ROOM

Who pays for the work?

Collaboration requires people. People require protected time and sustainable funding.

WORK + PEOPLE + FUNDING

Without a funding model, collaboration remains an ambition.

THREE MORE CONDITIONS

01 **Transparency and trust**

Each partner must see a clear benefit: what is in it for us—and for you?

02 **Vendor participation**

Integration depends on technology suppliers collaborating as well. No vendor lock-in

03 **Shared direction**

EHDS can provide a common direction across borders.

Thank you

Cross-border value depends on trustworthy data
where it originates.

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SPØRSMÅL OG DIALOG MED SALEN

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Takk for idag!

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