Value from Nordic Health Data (VALO): A Hands-On Case Study of a pan-European Cancer Research Project Using OMOP

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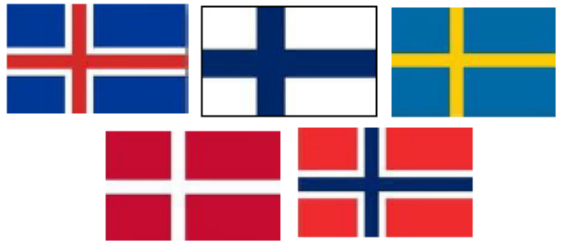
VALO Pilot - Metastatic non-small cell lung cancer (NSCLC) study

Funded by the Nordic Council of Ministers

The VALO-project - Value from Nordic Health Data

OBJECTIVES OF OVERALL NORDIC PROJECT

1. **Strengthen Nordic cooperation** and the secondary use of health data in research, development and innovation
2. **Jointly prepare for the EHDS legislation** (European Health Data Space) by starting to implement changes and reforms and sharing best practices
3. **Test** in practice and demonstrate the effectiveness of **cross-border Nordic cooperation in the use of health data**
4. to achieve and maintain **Nordic leadership in the secondary use of health data**



the VALO-pilot

Link to more information: https://www.sitra.fi/en/projects/value-from-nordic-health-data-valo/#what-is-it-about

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VALO Pilot project: Benchmarking care quality for patients with metastatic NSCLC in the Nordic countries

The purpose

This study aims to explore the **treatment patterns** and **patient characteristics** of patients diagnosed with **mNSCLC,** with a focus **on efficacy in different age-groups.**

A separate aim of this study is to pilot the **use of OMOP CDM across the 5 Nordic countries** and to pool data to increase the Nordic RW study impact.

VALO Pilot Study

Aim:

To explore opportunities to increase the Nordic Health Data Collaboration

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

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

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

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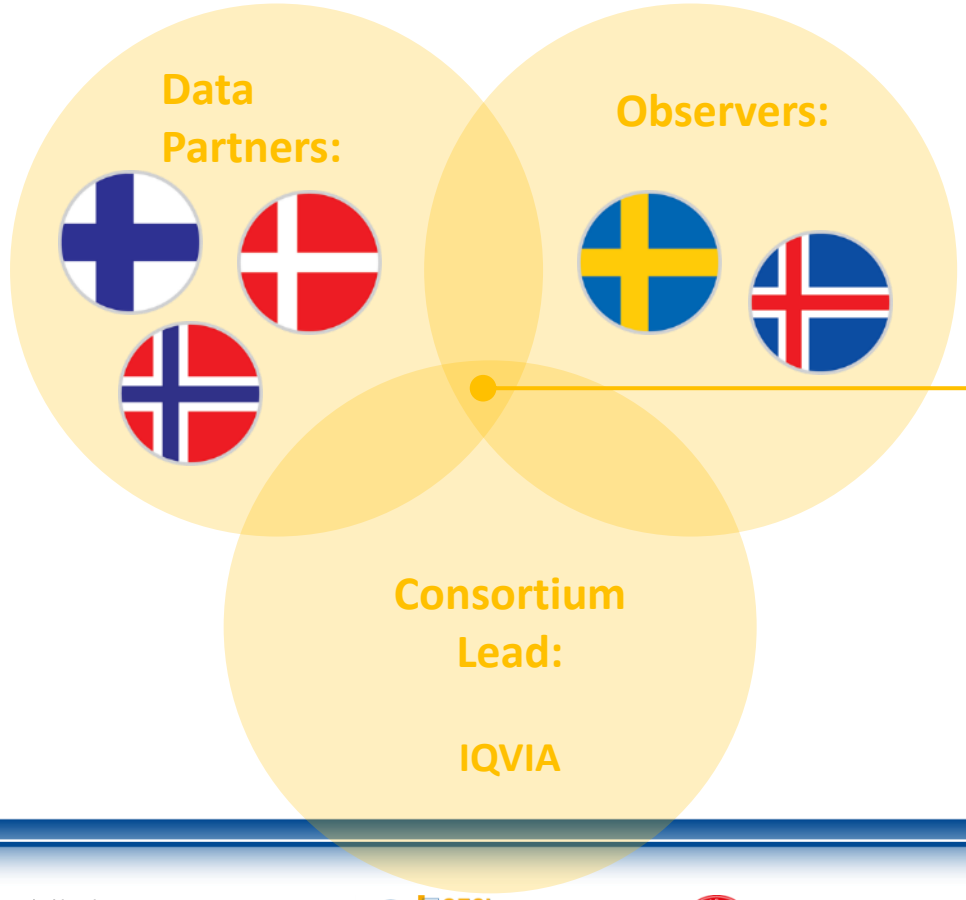
VALO Pilot Study – Consortium Members



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Study Objectives

Main Objectives

- Describe baseline demographic and clinical characteristics of metastatic NSCLC patients receiving first-line immune checkpoint inhibitor (ICI) therapy across Denmark, Finland, and Norway.
- Analyze longitudinal treatment patterns including sequence, duration, and intensity of therapies (ICI, chemotherapy, radiotherapy, surgery).
- Evaluate overall survival outcomes stratified by age and country.
- Assess healthcare resource utilization and costs (not completed due to data limitations).

Exploratory Objectives

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

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

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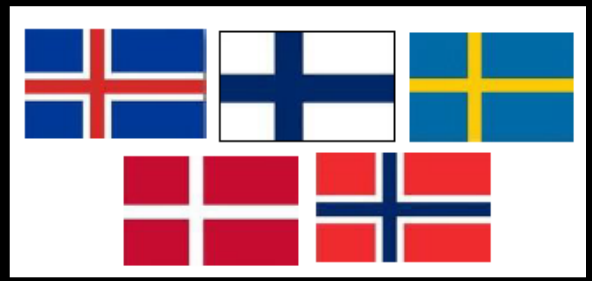
Multi-National Federated Analysis

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

All Nordic countries

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



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Baseline Characteristics Results

Demographics Overview

Key Findings:

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

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

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Baseline Characteristics Results

Comorbidity Assessment

Key Findings:

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

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

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Treatment Patterns

First-Line ICI Patterns and Progression

Key Findings:

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

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

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Treatment Patterns

Treatment Duration by Line of Therapy

Key Findings:

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

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

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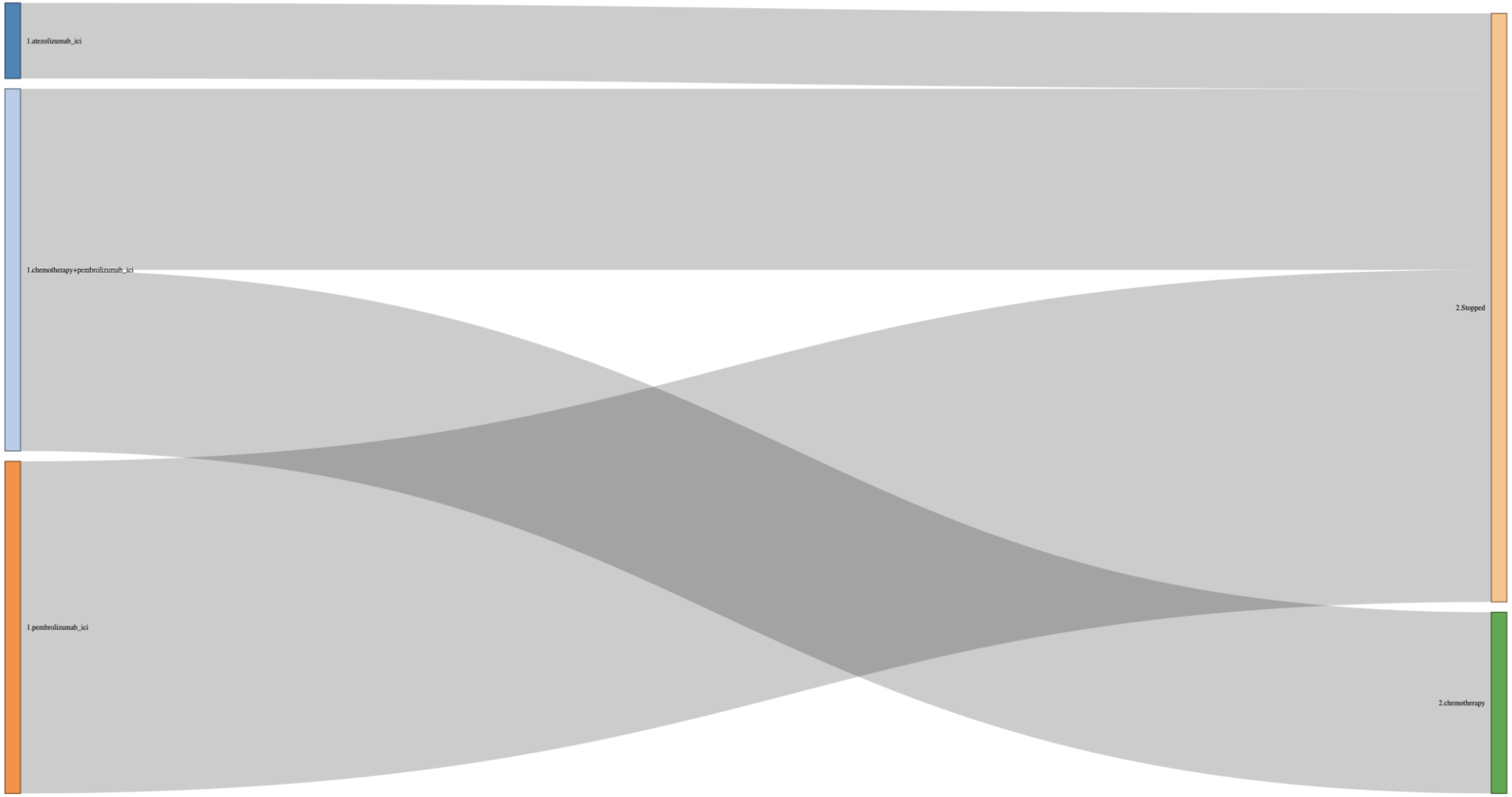
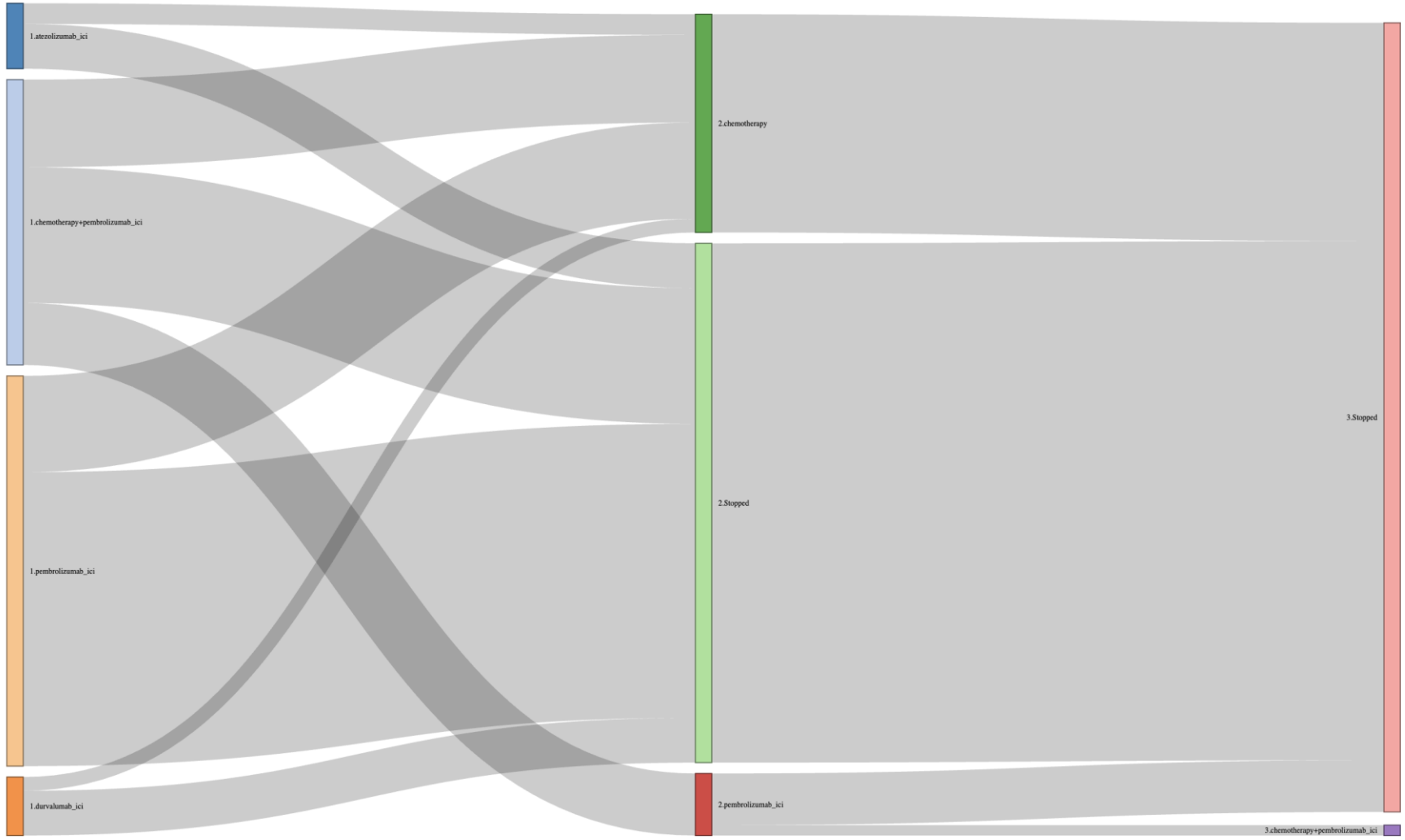
Treatment Patterns

Treatment Sequence - Norway



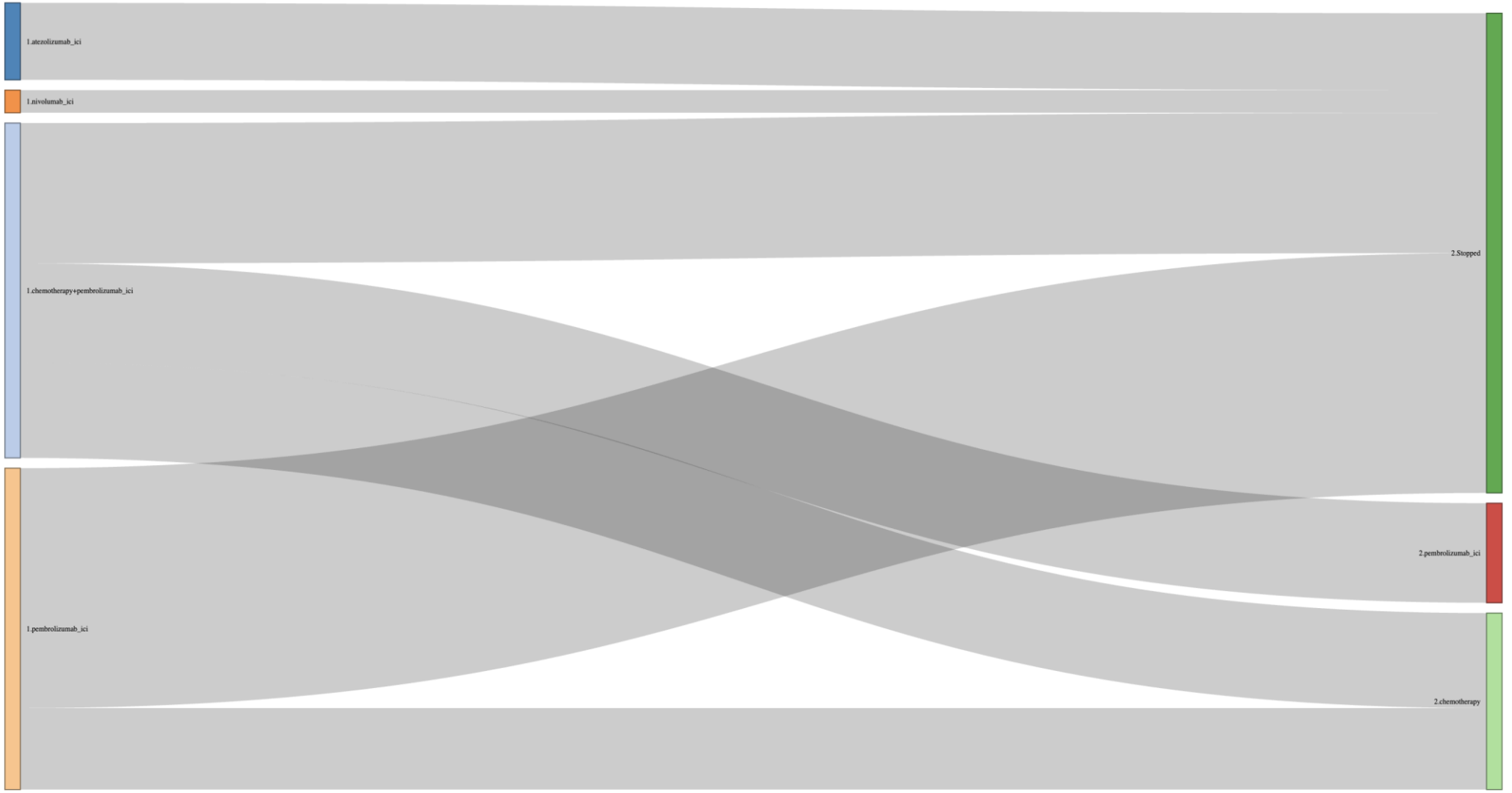
Treatment Patterns

Treatment Sequence - Denmark



Treatment Patterns

Treatment Sequence - Finland



Strategic Takeaways for Federated OMOP Network Development

1

Capability maturity & organisational readiness

Implementation Follows a Three-Year Capability Maturation Curve

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

2

Data governance & regulatory frameworks

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

3

Data life cycle & availability

Three-Tier Data Availability Framework Defines Study Feasibility Boundaries

Variable Surveys Must Precede Analytical Package Development

4

Data processing & technical infrastructures

Vocabulary Governance Requires Consortium-Level Coordination

ETL Solutions Are Reusable Assets Requiring Systematic Documentation

Analytical Environment Standardization Enables Reliable Package Execution

5

Study execution & quality assurance

Iterative Clinical Review Is Essential for Data Quality Validation

6

Methodological advancement & scientific rigor

Progression from Descriptive to Inferential Analytics Defines Scientific Maturity

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

- Data permit timelines: 1-4 weeks

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

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

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

- Data feasibility to be completed prior to protocol finalization.

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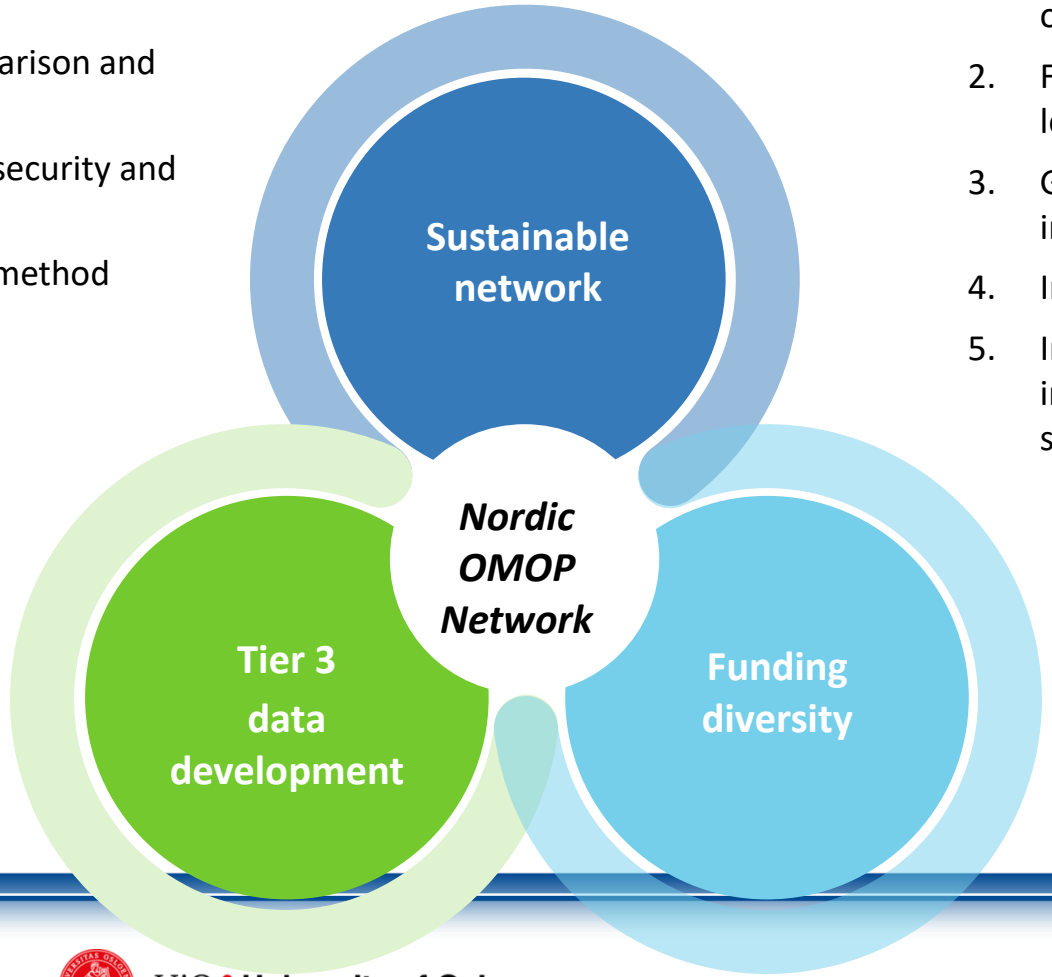
Long-term Investment Recommendations: Nordic OMOP Network

Advanced Analytics Platform

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

Clinical Documentation Enhancement Program

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



Sustainable Network Funding Model

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

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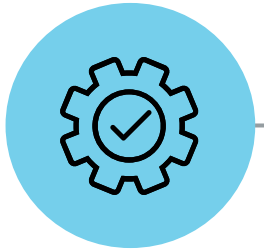
Key points



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

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

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

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Thank you for your attention