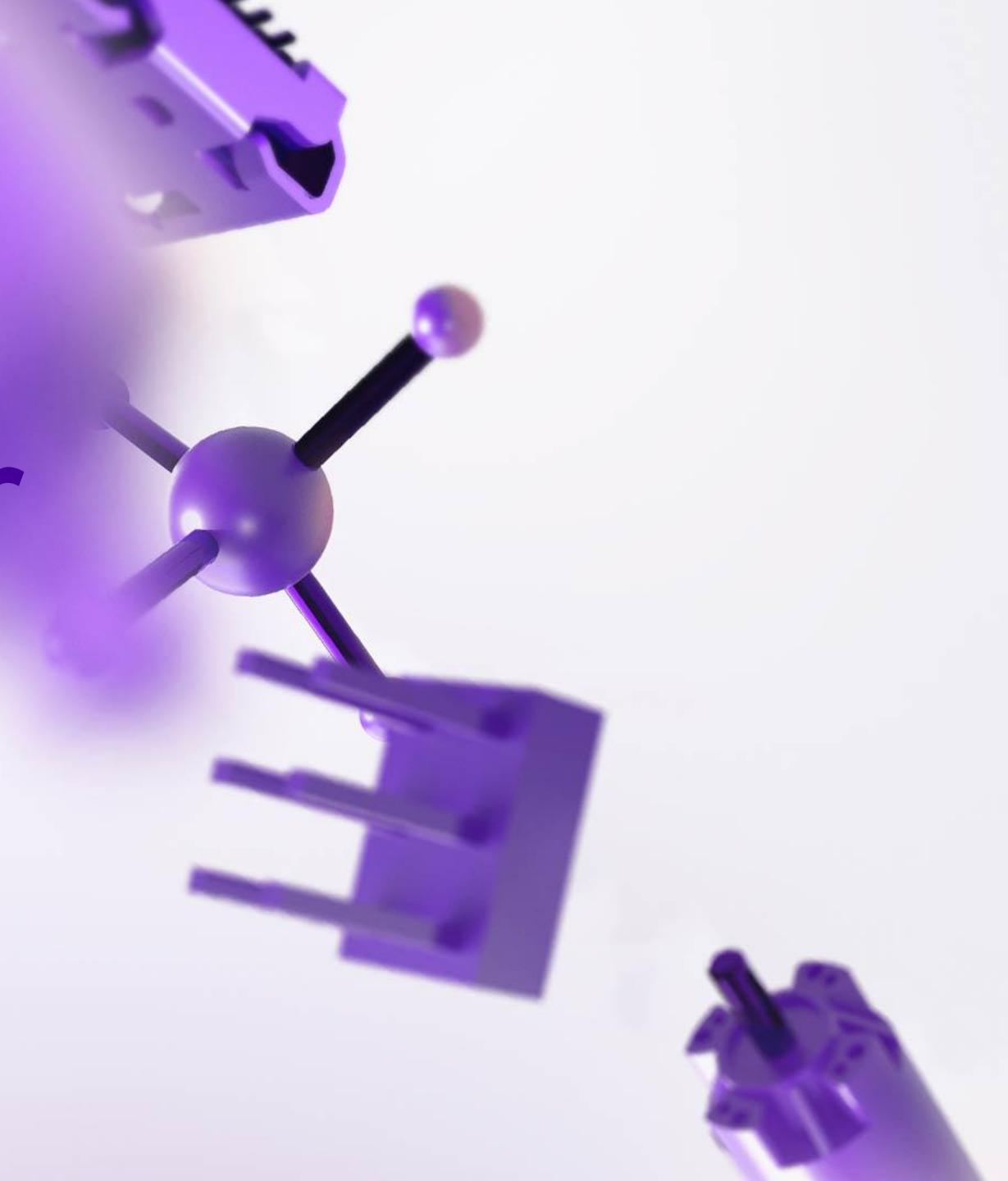




The case for OMOP in Sweden

Jordan Kane

Co-lead: OMOP4Sweden



OMOP is not '*just another standard*' – it's a resilient global research system

OMOP's Standard Concept Layer insulates terminology changes and makes study logic portable, reproducible, and shareable across the entire network.



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Stabilization:

- OMOP 're-codes' leading clinical terminologies
 - SNOMED CT, RxNorm, LOINC, UCUM, CVX +
 - Domained in CDM, versioned, relationships maintained
- Prevents disruption from **upstream terminology changes**
 - Keeping cohorts and queries stable over time and sites

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Acceleration:

- Reuse *everything*
 - local terminology mappings
 - cohort definitions & phenotypes
 - queries, analytics
 - common tooling (maintenance, analysis)
 - network-wide quality assessment
 - versioned studies reproducibly

OMOP's Standard Concept Layer insulates terminology changes and makes study logic portable, reproducible, and shareable across the entire network.



This creates powerful benefits

Scalable – very large global cohorts, comparable network

Fast – map once, *re-use everything*

Broad – cross therapeutic areas and disciplines

Private – aggregation cuts privacy risk, opening-up access

Open-Source – no vendor lock-ins, global development community



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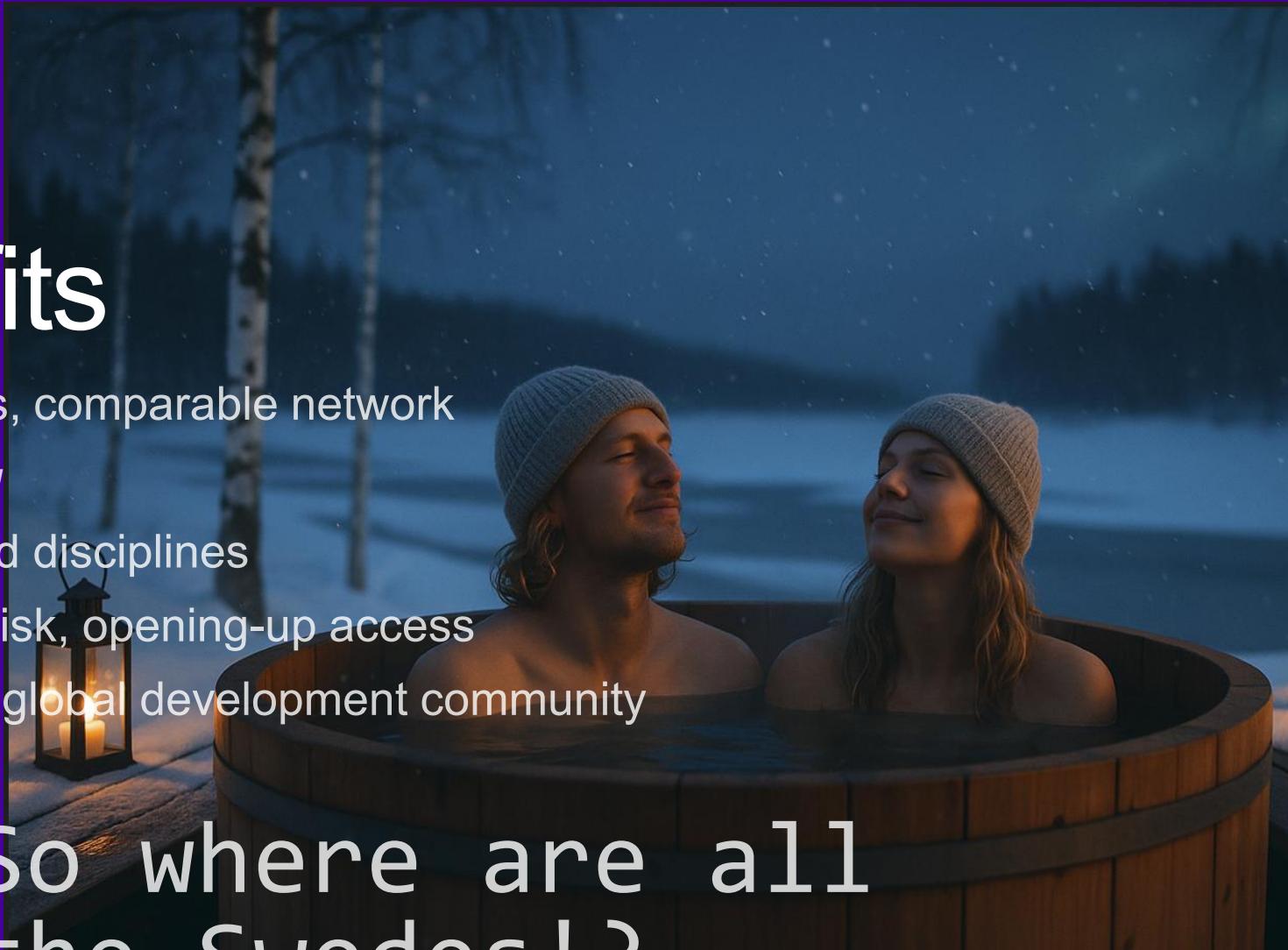
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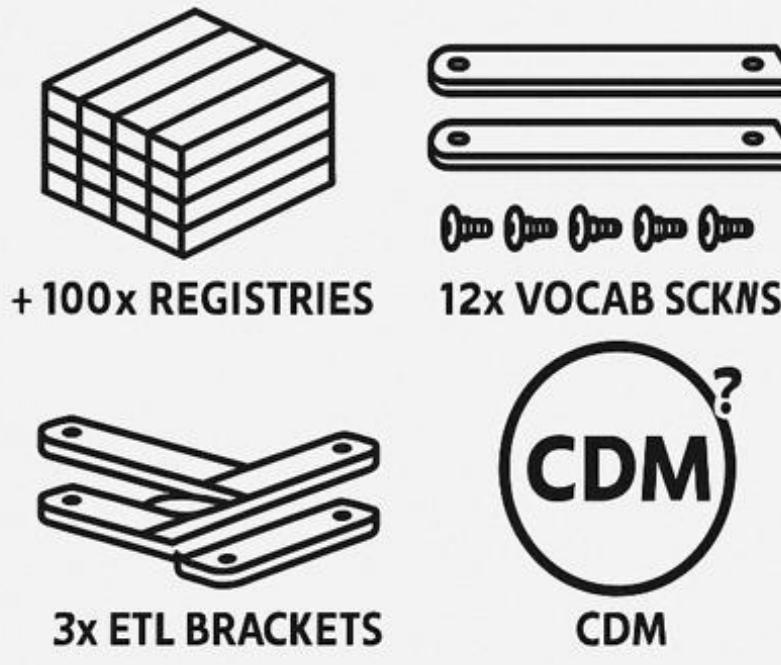
Open-Source – no vendor lock-ins, global development community



So where are all
the Swedes!?



OMÖP



Some assembly required.
Allen key included.

Does OMOP *feel* Swedish
to you?

Strong standards focus

Mature disclosure control
framework for aggregated
statistics

Distributed informatics
capability across regions

Strong observational
research culture

Belief in evidence and
prevention

BUT where should OMOP
live '*in the system*'?

Can Sweden's Registries Benefit from OMOP?

Yes – for growing research.

- Global research participation → research quality, collaboration
- Perform global studies → impact, smaller sub-groups
- Efficient analysis → re-use everything, research output
- Auditable / reproducible analysis → integrity



Can Sweden's Registries Benefit from OMOP?

What about infrastructure?

100+ registries, many >50 years data!

Different: data models / pipelines / locations

= **scaled duplication of data / cost / privacy risk**



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Is this scale of duplication justifiable?

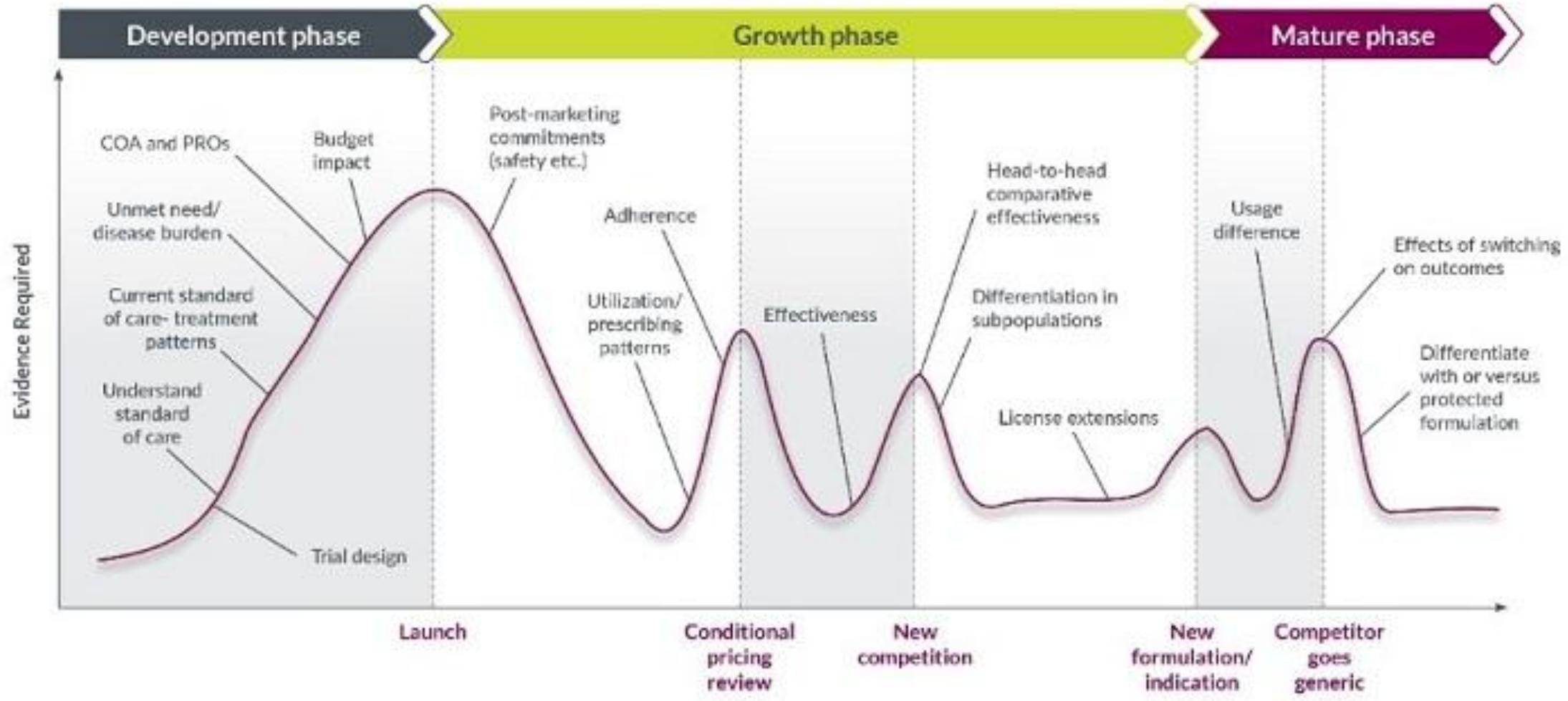
- *In principle, yes,* if the data models deliver the use cases that justify funding for each.

KEY QUESTION:

- How much can the data models be harmonised while preserving core use-cases?



RWE drives value across the full medicine development lifecycle



What role could industry play in sustainable data infrastructure?

How could OMOP change industry engagement in Sweden?

OMOP equalises access to insights

- Faster insights possible
- Minimized data sharing

Shifting lifescience competitive advantage towards data-driven capabilities

Data-driven capabilities:

- Identifying commercial insights
- Effective promotion
- Generating insight

External Deals:
Exclusive data access



How can the lifescience industry strengthen insight capabilities

while

Advancing common
Public/Private strategic
needs:

- Policy alignment
- Shared research capacity
- Collective risk management



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Investment Approach

1. Data Utilisation Centres of Excellence

- “Health Data Learning Labs” with hospitals and universities
- National training curricula on OMOP analytics

2. Federated Evidence Acceleration Hubs

- RWE sub-networks (geographic, TA, method etc)
- Develop open analytics tools in partnership with academia

3. Embedded Data-Science Fellowships in Hospitals

- Clinician–data scientist joint roles
- Rotations between pharma and hospital analytics projects

4. Public–Private RWE Governance Forums

- RWE Governance Roundtable
- Guidelines on data governance, synthetic data, FAIR use, etc.

5. Joint Clinical–Commercial Evidence Sprints

- 6-week OMOP-based “evidence hackathons” with clinical partners
- Co-branded RWE prototypes (e.g., outcomes dashboards)

6. Open Data Literacy & Fellowship Programs

- OMOP courses, scholarships, MOOCs, micro-credentialling
- Partner with universities for postgraduate training in RWE

7. Real-Time Evidence-to-Action Pilots

- Co-develop live dashboards tracking key HTA assumptions
- Jointly test/explore tiered access models under EHDS frameworks

8. Health-System Co-Innovation Platforms

- Multi-sector OMOP innovation consortia (Digital health solutions)
- Open challenges around unmet needs

9. Data Ethics & Transparency Index

- Annual transparency reporting by pharma on RWE use
- Voluntary data-ethics charter for OMOP use cases

10. OHDSI Ecosystem Participation

- OHDSI Working Groups operations
- OHDSI nodes administrative and event support

Industry investment goals can align with OMOP sustainability needs

Investment approach → OMOP needs ↓	CoE (methods & training)	Federated hubs / node hosting	Embedded fellowships	Governance forums	Evidence sprints (methods)	Data-literacy programs	Real-time pilots	Co-innovation platform	Ethics & transparency index	OHDSI Ecosystem Participation
Map OMOP data sets	○	●	○	○	●	○	○	○	—	○
Maintain OMOP data sets	○	●	○	○	—	—	○	○	—	○
Quality control activities	○	○	○	—	●	○	●	○	○	●
Hosting	—	●	—	—	—	—	○	○	—	○
Governance & compliance capacity	○	—	○	●	—	—	—	○	●	○
Training & literacy	●	—	●	—	—	—	○	○	—	○
Federated participation costs	—	●	—	—	—	—	○	○	—	○
Metadata & catalogue work	○	○	○	○	○	—	—	●	○	○
Benchmark data / Portals	○	○	○	—	●	—	●	○	—	○

Chart works both ways

Fill public gaps

OR

Action industry priorities

Legend:

● strong fit

○ partial fit

— minimal fit

AstraZeneca invests 1.3 billion euros in its R&D center in Barcelona, doubling its job creation forecast to 2,000

15 MAR 2024

AstraZeneca Global Hub in Barcelona was inaugurated in 2023 and is expected to be one of **Europe's largest centers of excellence and clinical innovation.**

 The *shift* is real

So, where should Sweden consider implementing OMOP?

Tourist to farmer:
“Can you tell me how to get from Malmö to Dalarna?”



So, where should Sweden consider implementing OMOP?

It would be vastly simpler if it was legal to build a national research data base of all health care data....

Tourist:

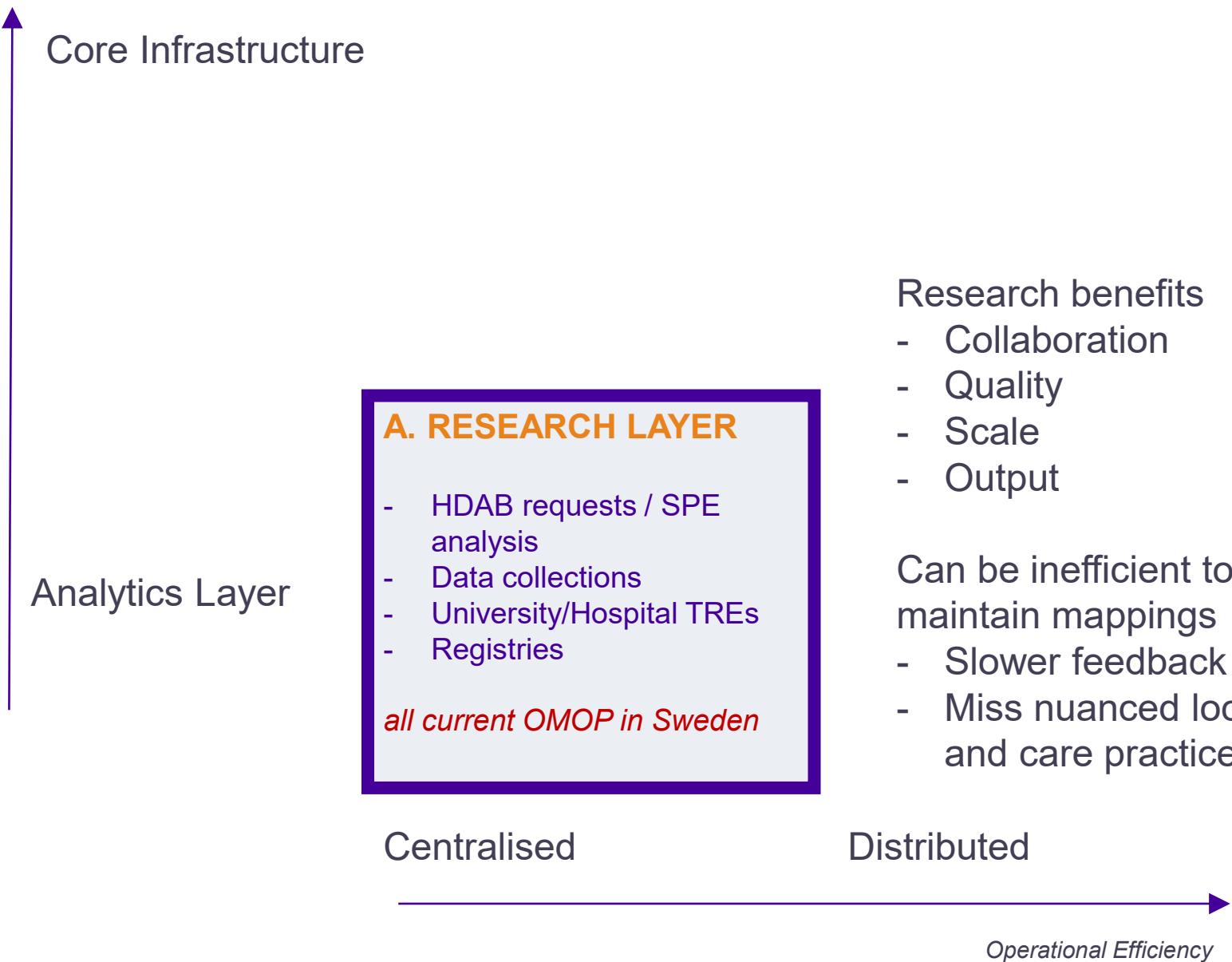
“Can you tell me how to get from Malmö to Dalarna?”

Farmer:

“Well, if you wanted to get to Dalarna, I wouldn’t start in Malmö”



OMOP Implementation Approaches



OMOP Implementation Approaches

Technical Leverage

Core Infrastructure

Analytics Layer

Centralised

Distributed

Operational Efficiency

C. DATA PLATFORM

- OMOP is sole data model
- May need to use extensions

EBMT registry

- National scope
- Uncommon choice for registries
- Potential sustainability pathway for registries
- Can be inefficient to centrally maintain mappings

A. RESEARCH LAYER

- HDAB requests / SPE analysis
- Data collections
- University/Hospital TREs
- Registries

all current OMOP in Sweden

B. REGIONAL HUBS

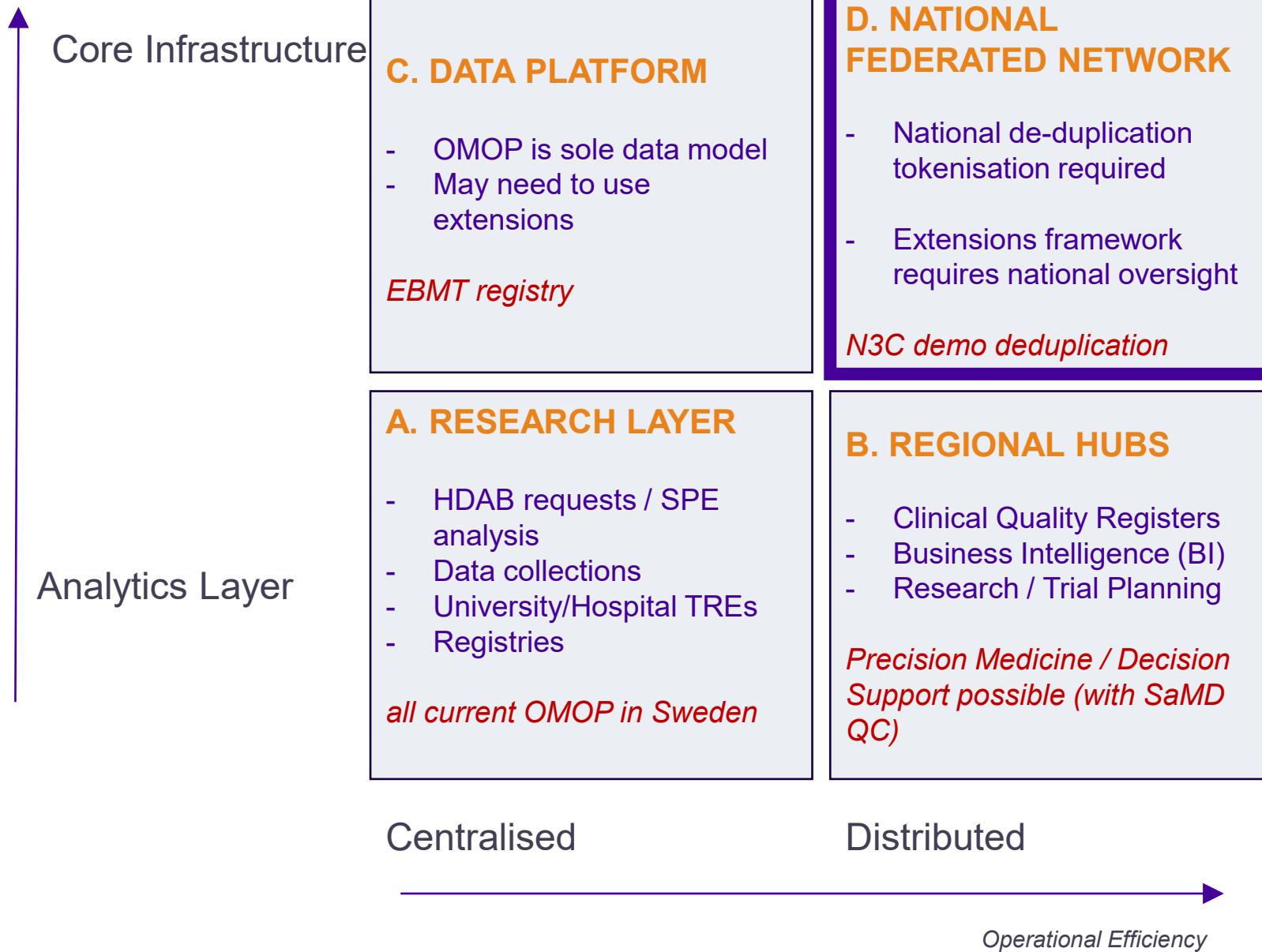
- Clinical Quality Registers
- Business Intelligence (BI)
- Research / Trial Planning

Precision Medicine / Decision Support possible (with SaMD QC)

- The original and intended use-case for OMOP
- Close to care expertise: strengthens mapping quality
- Richest variables possible
- Lacks national scope

OMOP Implementation Approaches

Technical Leverage



- Retains key benefits of all others
 - Research
 - Richness
 - Efficiency (proximity)
 - National scope
- Depends upon emerging solutions
 - Deduplication
 - Extension framework

How should we design OMOP pilots to best align with Sweden's needs?

