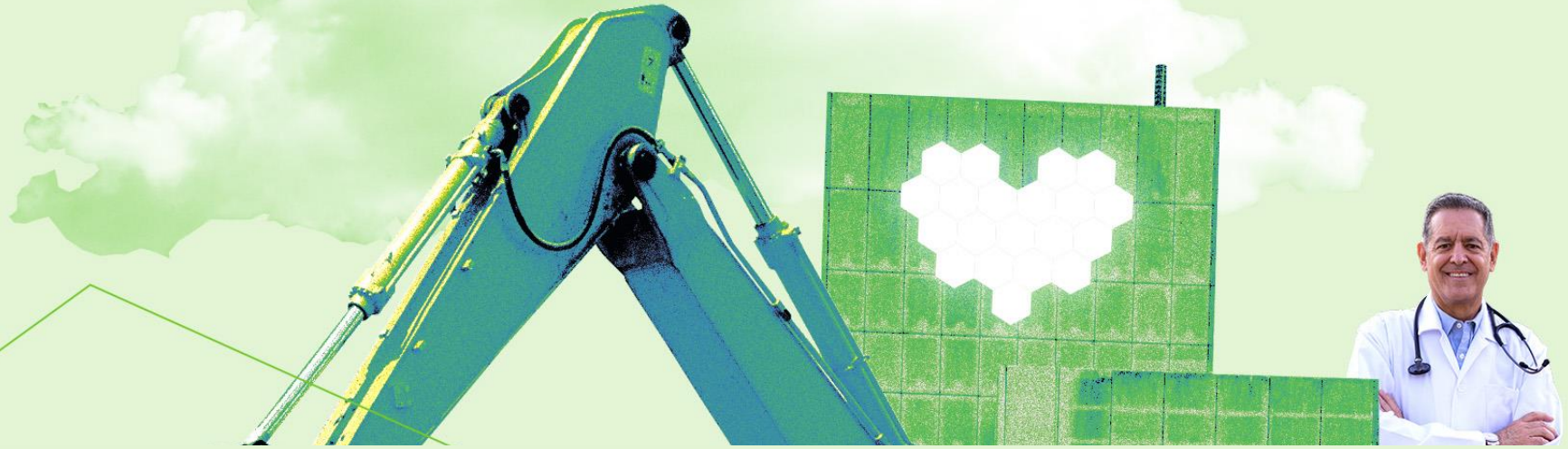
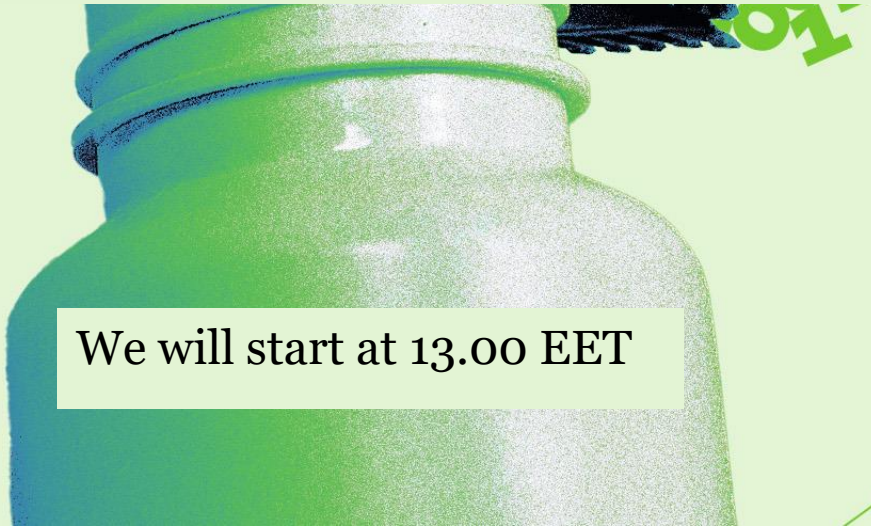


# Tietomallien mahdollisuudet sote-sektorilla

Unlocking the potential of data models in the health sector



We will start at 13.00 EET

11.3.2024

The presentations will be recorded and added to the event's website.

# Programme / Ohjelma

13.00 **Welcome and opening words**
**Kristo Lehtonen**, Director, Fair Data Economy, Sitra

Moderator: Saara Malkamäki, Specialist, Sitra

13.05 **OpenEHR-based software procurement in Stockholm and Gotland region**
**Erik Sundvall**, Information Architect, Karolinska University Hospital

13.25 **Questions and comments**

13.35 **European health data network: using the OMOP CDM for collaborative studies**
**Maxim Moinat**, Scientific Researcher, Erasmus MC

13.55 **Questions and comments**

14.05 **Break**

SITRA TYÖPAPERI 8.5.2023

DATASTA VOIMAA SOTE-JÄRJESTELMÄÄN

Sote-dataa hyödyntämällä parempaa hoitoa ja kustannussäästöjä

**Antti Larsio**
Knowledge Broker Oy

Sote-data sisältää sosiaali- ja terveydenhuollossa syntyvää tietoa, kuten lääkitystiedot ja hoitotoimenpiteet. Data liikkuu muun muassa sote-palveluita tuottavissa organisaatiossa ja kansallisissa tietojärjestelmäpalveluissa. Suomella on merkittäviä vahvuuksia ja kehitystä on tehty paljon, mutta jäljellä olevat liikkuvuuden pullonkaulat ja järjestelmien käytettävyysongelmat estävät sote-datan parhaan mahdollisen hyödyntämisen.

Sote-datan liikkuvuutta ja saatavuutta parantamalla voidaan sujuvoittaa hoitoammattilaisten työtä, kehittää palveluita, vapauttaa työvoimaa tuottavampiin töihin sekä saavuttaa merkittäviä kustannussäästöjä. Eurooppalainen lainsäädäntö on luomassa EU:n laajuista terveystietoaluetta, joka edellyttää terveystietojen siirtymistä sujuvasti yli maarajojen ja potilastietojärjestelmien välillä. Suomen on tärkeää valmistautua tähän kehitykseen.

Esitetyt suositukset auttavat uudistamaan sote-sektoria data edellä. Lisäksi ne vahvistavat myös terveysteknologioiden vientimahdollisuuksia.

# Powering the social and healthcare system with data and AI

To improve quality and effectiveness of care

Improve productivity of work

Moving towards more personalised and preventive healthcare

- **Implementing individual-centric, international data models** one out of seven recommendations

SITRA

# Programme / Ohjelma

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SITRA

# Buying openEHR systems & services
# Why & how

**openEHR-based software procurement in region Stockholm and Gotland, coordinated by Karolinska University Hospital**

**(+ Swedish RFI by seven regions).**

Presented remotely 11th March 2024 at the Sitra webinar
”Unlocking the potential of data models in the health sector”, Finland

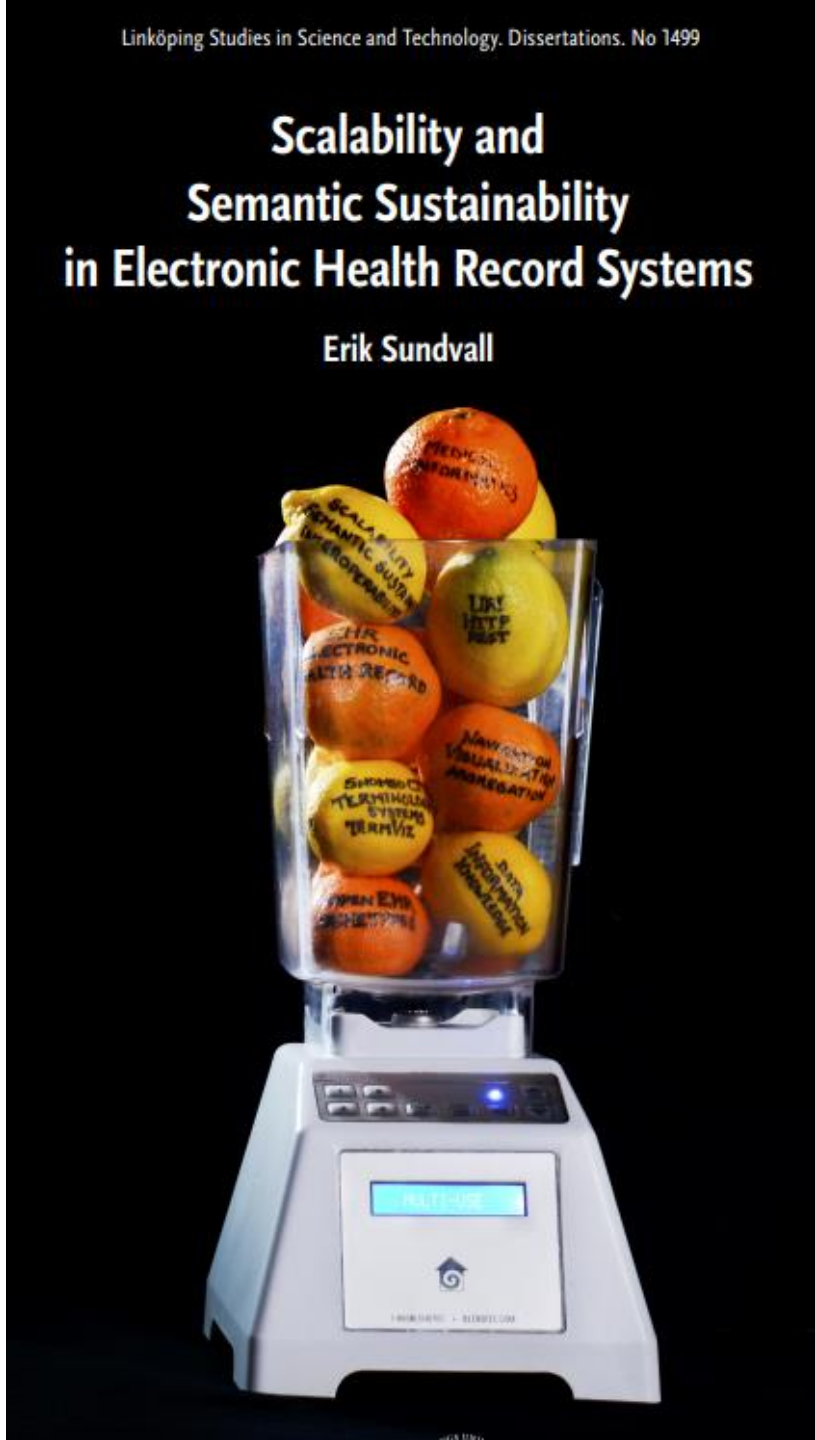
by Erik Sundvall, PhD, MSc
Information Architect @Karolinska University Hospital.
Associated researcher @ Karolinska Insitutet.
Senior adjunct lecturer @ Linköping University.

# Scaling things. Sustainability?

What limits adoption/use?

My researcher journey

- Patient overviews
  (need standardisation of data structure and terminology use - to be possible at all & to be adopted at scale)
- Scaling storage solutions
  (avoid DBA manual indexing/reinterpretation as a limiting factor)
- Scaling learning/knowledge
- Scaling local ecosystem beyond one vendor
  – openEHR RESTful vendor neutral app ecosystem needs APIs (2010, before FHIR)
- Why not used more? Seldom bought!
  Research --> Used in practice at healthcare providers?
  - Spread/share knowledge
  - Scaling procurement. Stop buying yesterday's sytems!
    How can we push the market/ecosystem in sustainable direction?






https://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-87702

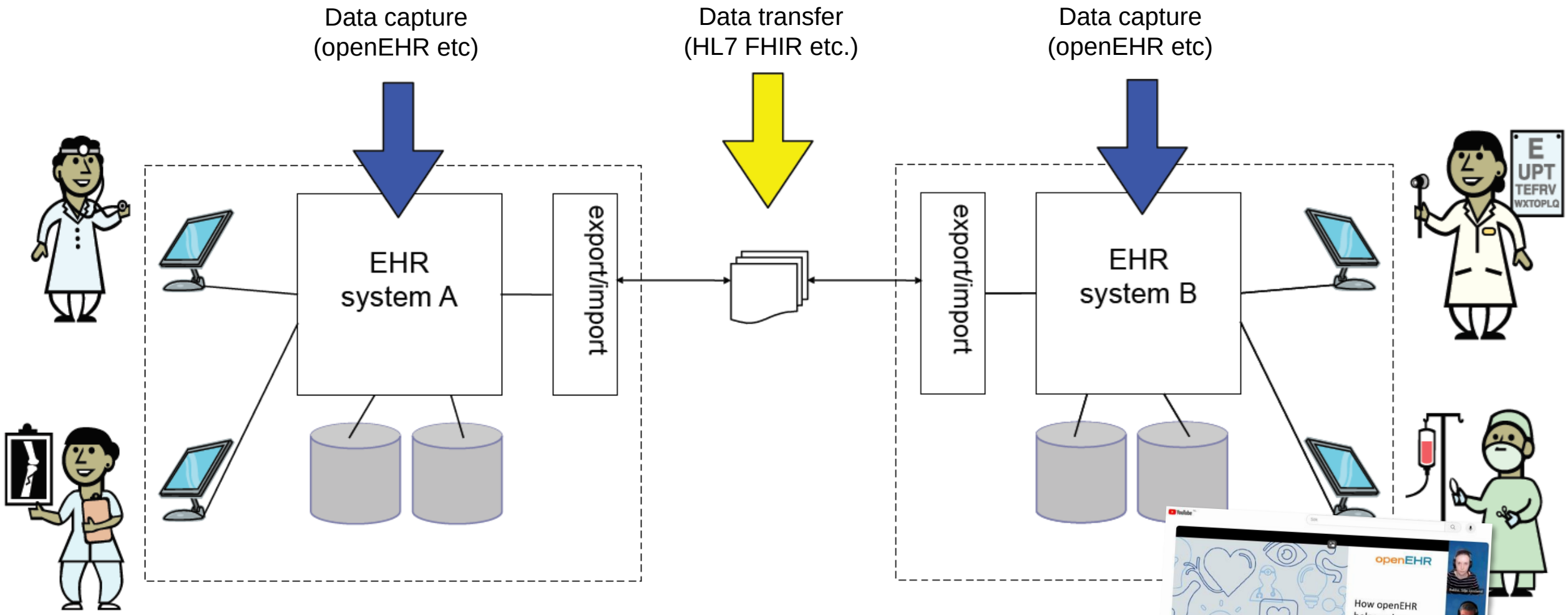
## Different…

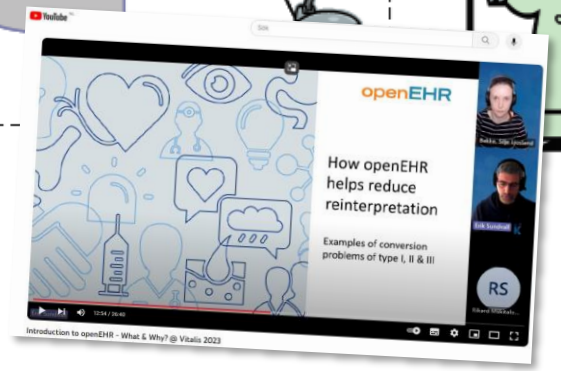
# INTEGRATION STRATEGIES

## …enable  different procurement strategies

- Core system strategy
- Mapping/conversion-based strategy
- Shared, model-driven strategy ♥

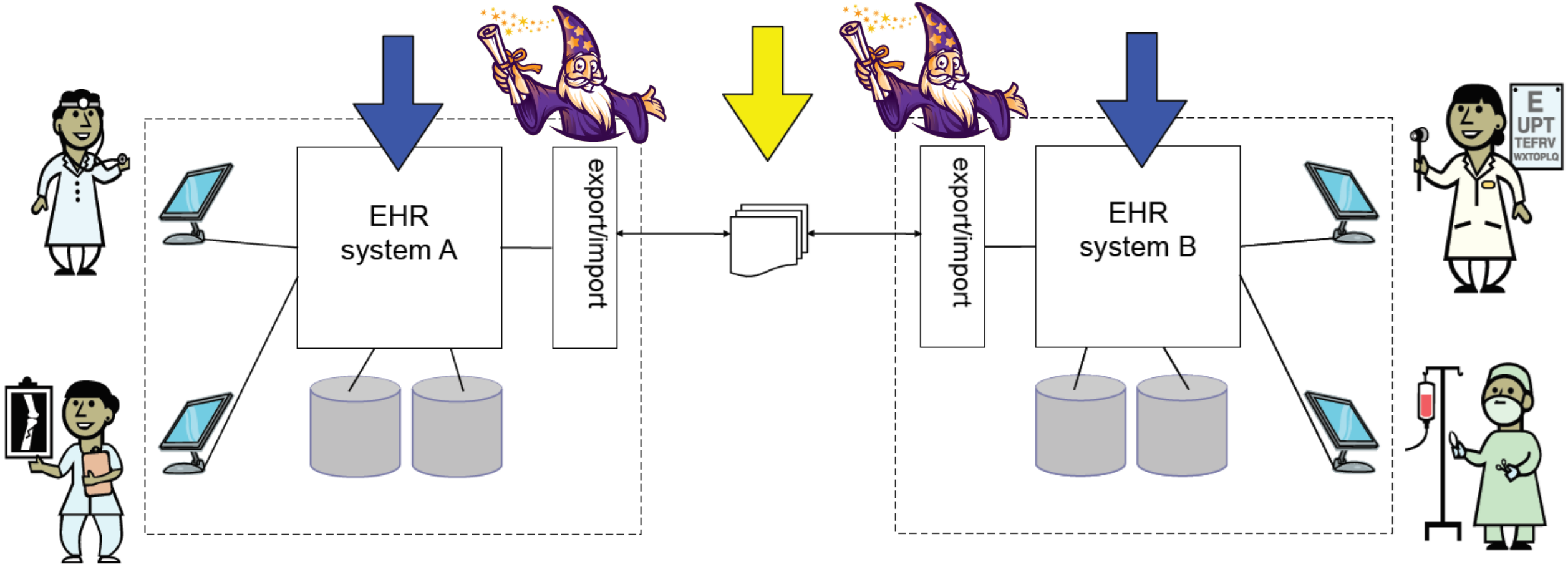
# Agree where?




See presentation **Introduction to openEHR, part 1: What & Why**" by Silje & Erik at Vitalis/MIE2023 https://youtu.be/KgXVsIsr_Ts?feature=shared&t=774

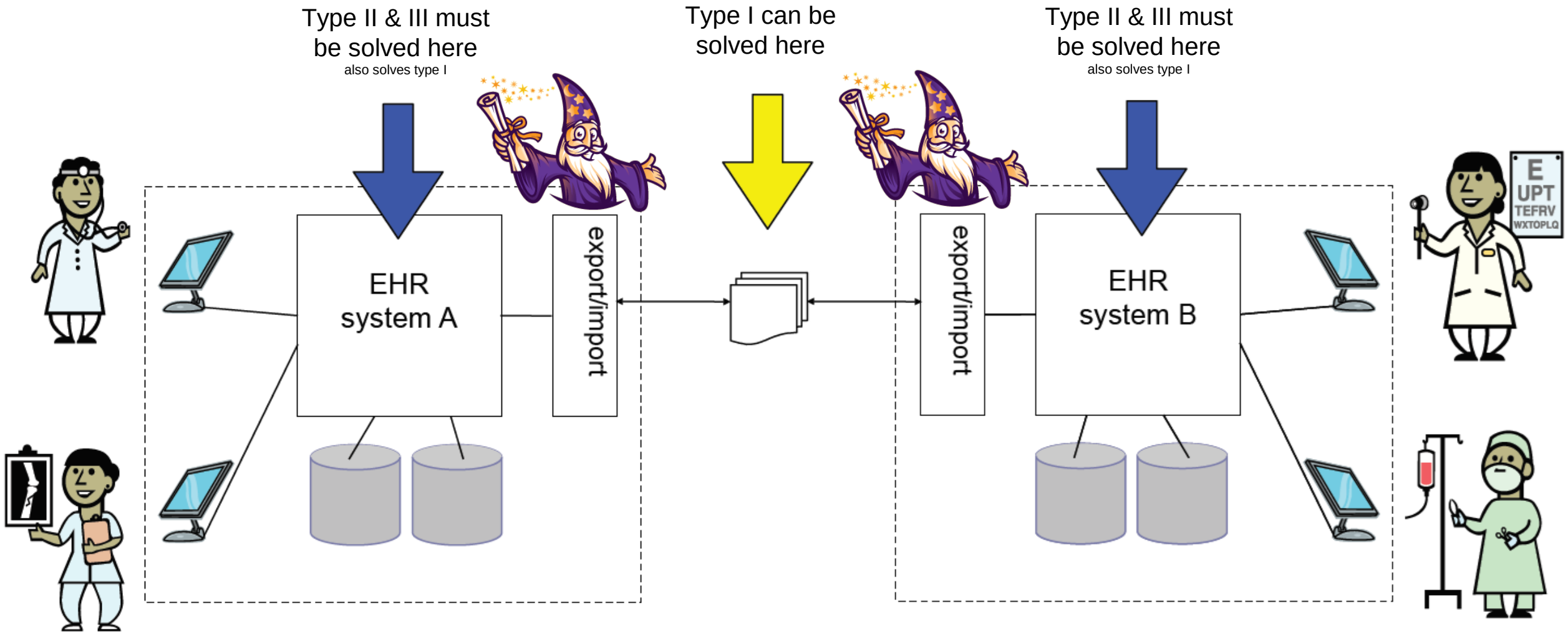
# What can conversion/reinterpretaion solve?



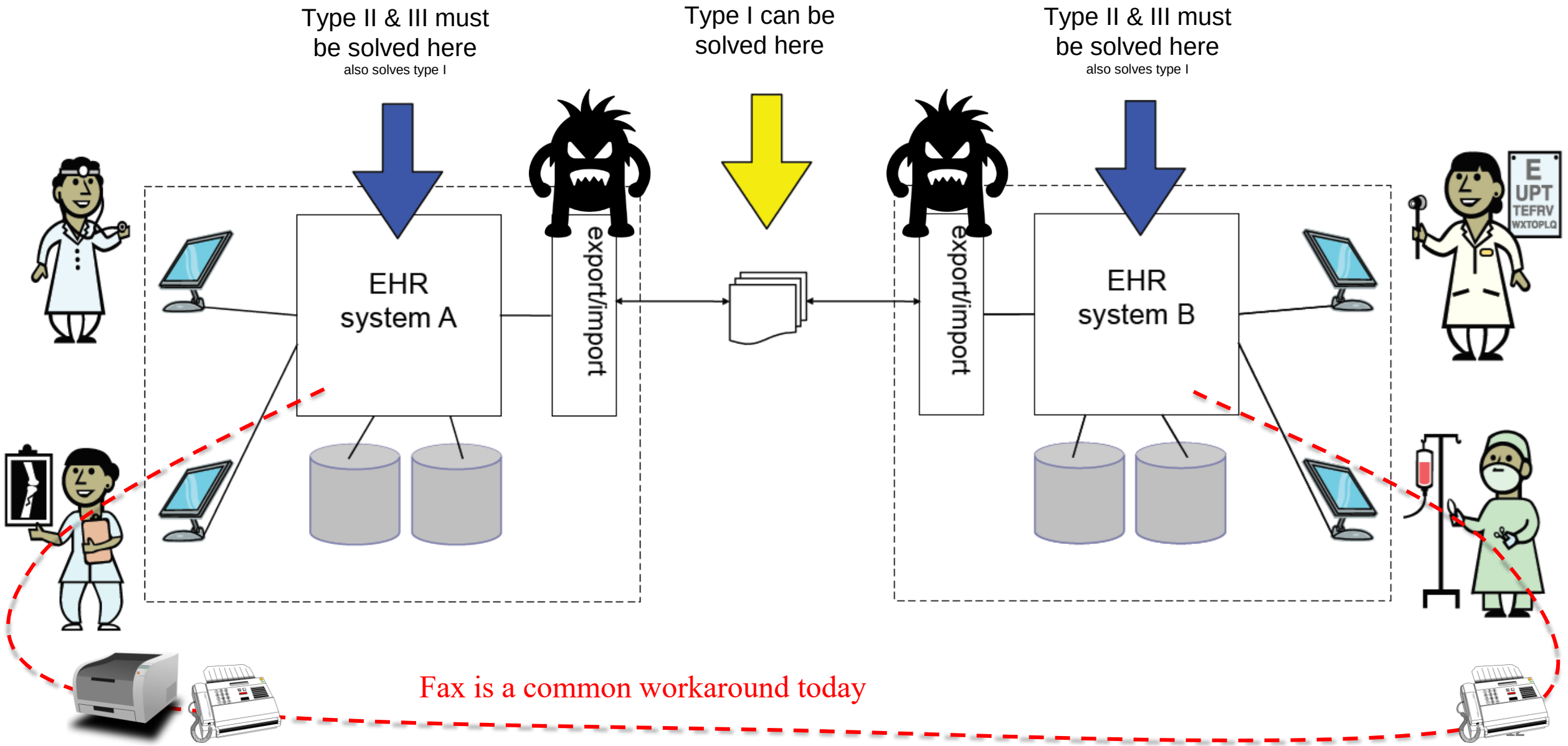
# Reinterpretation problems, Type I, II & III

| Example | System A | System B |
|---|---|---|
| Type I<br>A <-- --> B<br>Can be done with algoritm/program | **Birth weight**: 3300g<br>**Date**: 1954-03-13 | **Body weight**: 3,3 kg<br>**TImepoint**: 13 Mar 1954 |
| Type II<br><br>A --> B<br>Semantic loss and distortion due to reinterpretations.<br><br>Hard, dangerous or impossible with algorithm/program…<br><br>*…but often done manually by medically skilled staff over and over for each transfer…*<br><br>B --> A<br>Missing information impossible with algorithm/program | **Needs surgery at latest**: 2018-01-30<br>**Surgery scheduled**: 2018-01-20 15:30<br>**Main diagnose***:<br>323291000119108 \| Osteoarthritis of left hip joint\|<br>**Other Diagnosis***:<br>25343008 \| Secondary localized osteoarthrosis of pelvic region\|<br>299308007 \| Hip joint painful on movement \|<br>**Procedure***:<br>19954002 \| Reconstruction of hip with use of methyl methacrylate\|<br>**Surgery type****: Lubinus SP II<br>**Preferred anesthesia***: 18946005 \| Epidural anesthesia \|<br>**NEWS2-score at admission**: 1<br>**Anesthesia assessment**:<br>- Fitness: can handle light physical exercise<br>- Cardiovascular: OK<br>- Lungs: OK<br>- Throat: OK<br>- Gastrointestinal*: 16331000 \| Heartburn | **Surgery date**: 2018-01-20<br>**Diagnosis code**: M16.7 \| Other secondary coxarthrosis<br>**Surgery code*****: NFB49 \| Primär total höftledsplastik med cement (Primary total hip arthroplasty with cement)<br>**Anesthesia code*****: ZXH50 \| Epiduralanestesi (epidural anestesia)<br>**ASA-classification**: ASA I = normal healthy patient<br><br>**) Codes from Snomed CT*<br>***) special kind of hip replacement with cement*<br>****) Codes from the Swedish "KVÅ" terminology* |
| Type III<br>Reinterpretaion impossible (even for skilled humans) due to aggregations etc. | **Number of cigarettes smoked per week**: 6-10<br>…specified in a system with the options:<br>0, 1-5, 6-10, 11-15, 16-30, 31-50, 51-100, 101+ | **Number of cigarettes per week**: ?<br>…specified in a system with the options:<br>0, 1-3, 4-7, 8-14, 15-28, 29-69, 70+ |

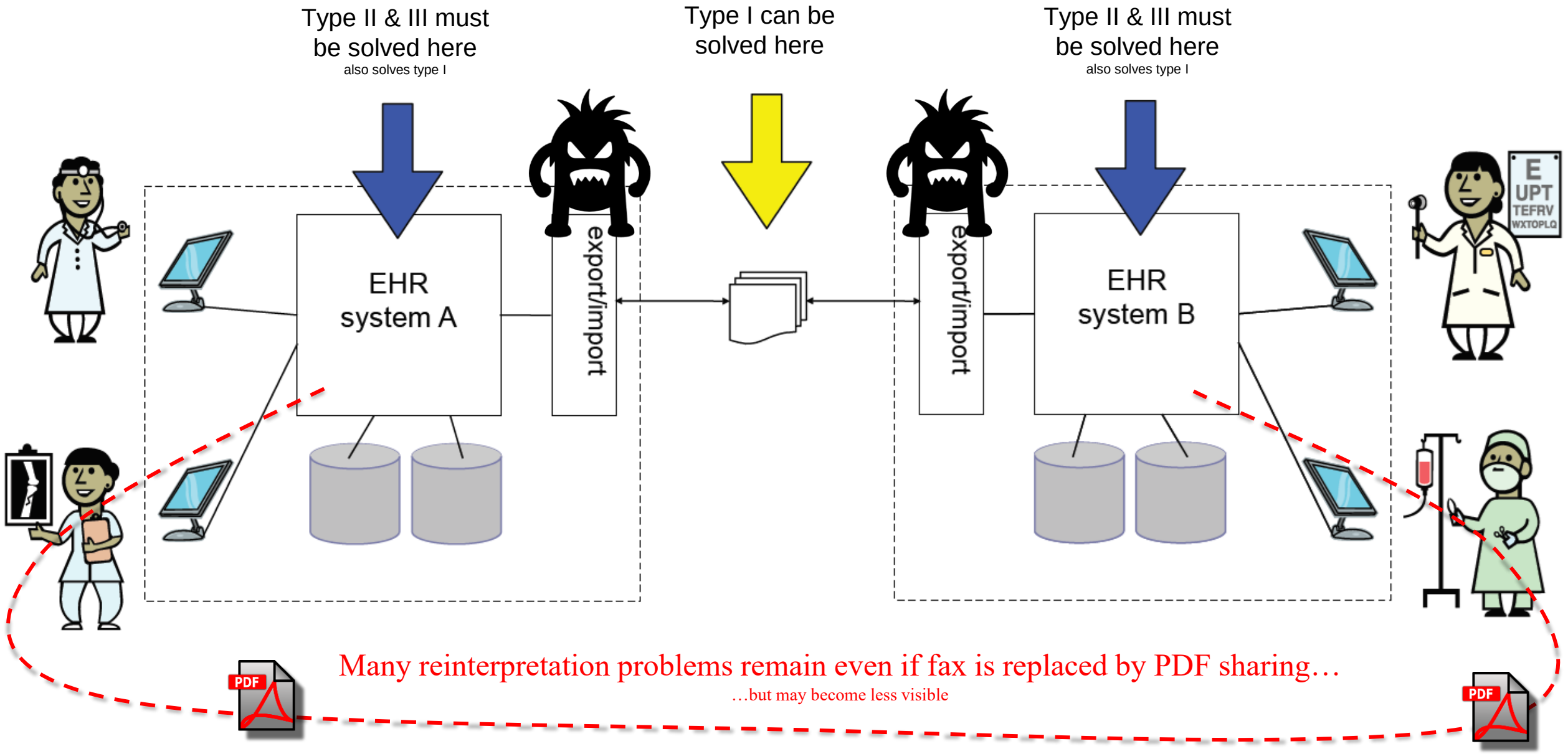
# Agree on what, where? How wide is the focus of the procurement?



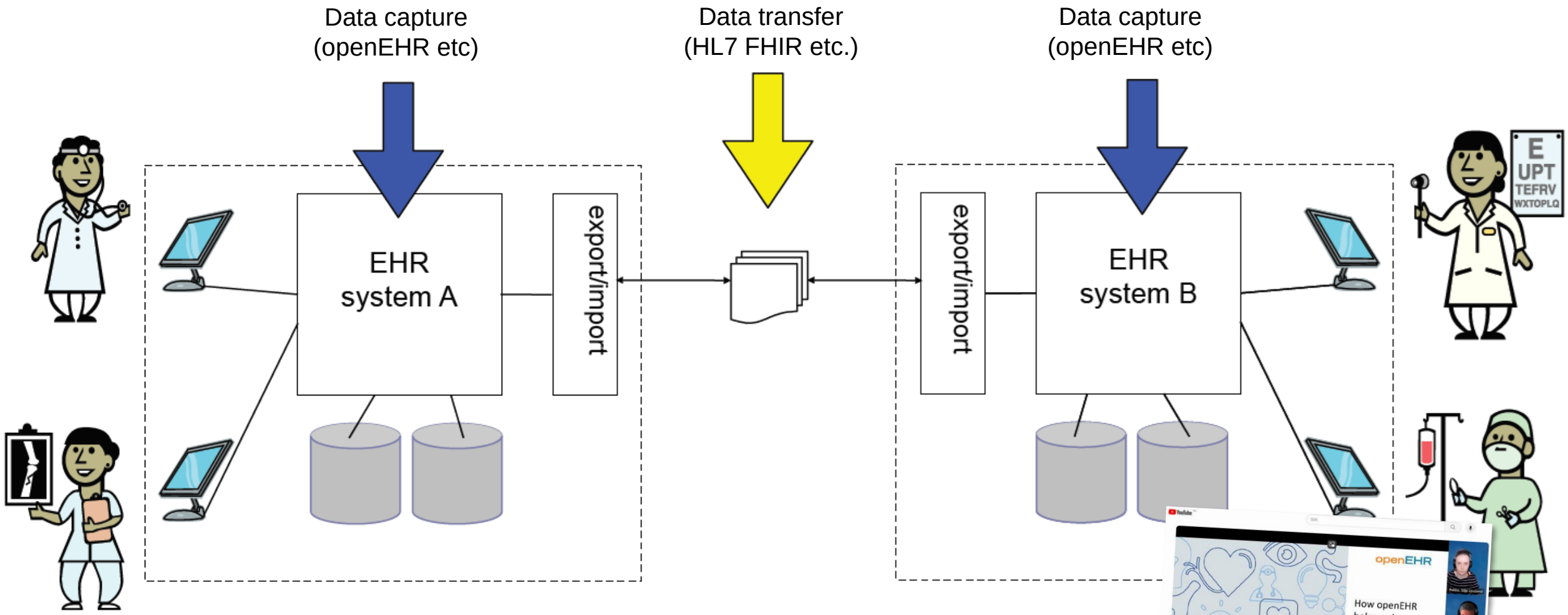
# Agree on what, where?



# Agree on what, where?



# Agree where?

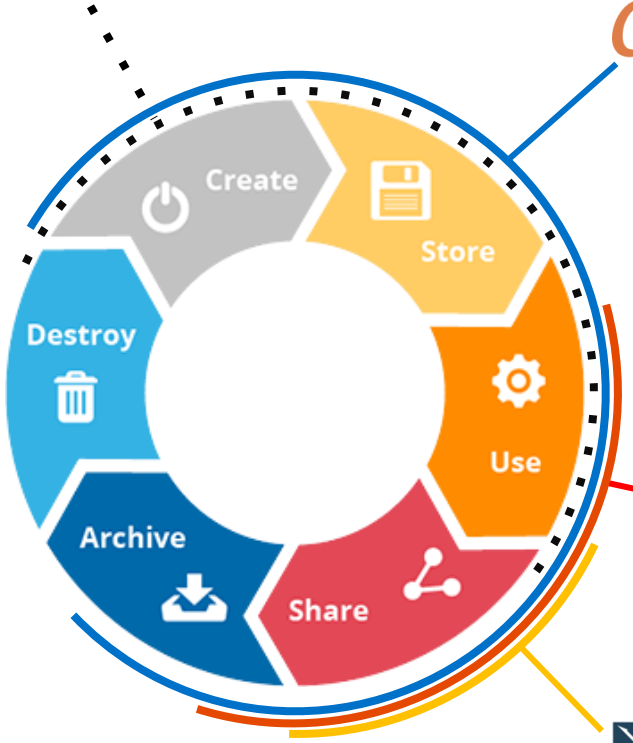



See presentation **Introduction to openEHR, part 1: What & Why**" by Silje & Erik at Vitalis/MIE2023 https://youtu.be/KgXVsIsr_Ts?feature=shared&t=774

# Data – how Karolinska views standards in the data life cycle.

**Any may be useful for a given purpose, depending on the need and relevant constraints.**

Most of the proprietary EHR internal models




openEHR

HL7 FHIR

OHDSI OMOP etc.

*"Gartner believes that truly effective and sustainable open architectures will need a capability for vendor-neutral data persistence, such as utilizing a common schema or set of openEHR archetypes and rules for managing structured and unstructured data (for example, a VNA, openEHR or IHE XDS repository in combination with services for trust/consent, ecosystem governance and oversight, and reuse of data and processes for secondary purposes, such as research and population health).*

*Providing open messaging standards (for example, FHIR, HL7) for data exchange in specific use cases will only go so far in meeting the architectural challenges of digital citizen-centric care delivery"*

**Healthcare Provider CIOs Need to Rally Their Enterprise Architects Around Citizen-Centric Care Delivery, Gartner 2017**

All these standards can be combined with SNOMED CT

The global language of healthcare



Extended from a slide by Patrik Georgii-Hemming, CMIO at Karolinska University Hospital

## Different…

# INTEGRATION STRATEGIES

## …enable  different procurement strategies

- Core system strategy
- Mapping/conversion-based strategy
- Shared, model-driven strategy ☺

# 1. Core system strategy

Buy the **same system, install the same way** at all organizations that will share or exchange information. Pretend “there is no system B”

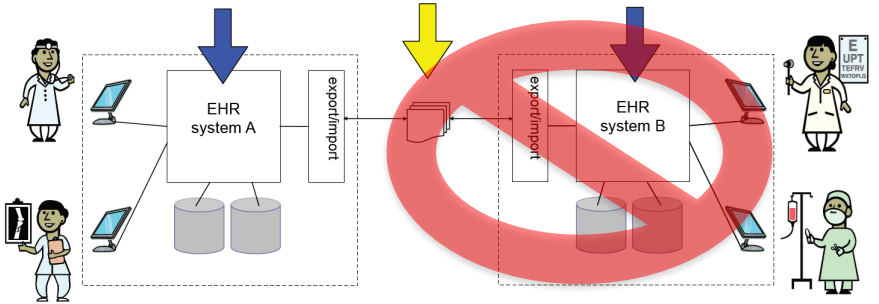
**Consequence**: Causes vendor dependency and anti-competitive effects at the level where the strategy is applied. A single system rarely does everything well.

**It is a common strategy locally/regionally**: Large systems exist, but they are not comprehensive and thus need to be combined with other strategies

… and then the interoperability problems usually reappear!

**Example**: A region procures large EHR system + encourages municipalities and others within the geographic area to use the same system for the information to be shared.

Stockholm started but cancelled a core system procurement, but now in practice started a ”smaller” core system procurement again.... VGR (Gothenburg etc) and Skåne (Malmö etc) have bought and are now installing Cerner Millenium as a core system.



# 2. Mapping/conversion based strategy

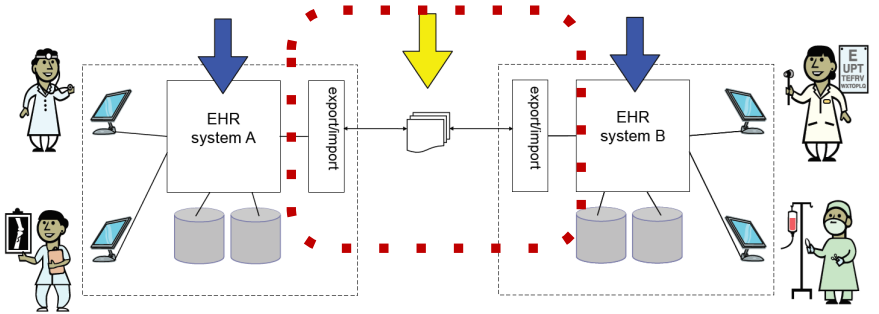
**Translate, where possible** (only works for ”type 1” differences), from system specific semantics and structures to a standardized exchange format (message format, API, etc.).

**Consequences**:

- Reinterpretations increase **risk of loss or distortion of information**,
  Data that is too different may need to be omitted (Sometimes no data may be better than incorrect data…)
- Can sometimes require health-IT systems to be **rebuilt** internally to be able to capture and export required shared data in some agreed form (This can be expensive, time/**resource consuming**, and dependent on vendors’ priorities).

**It is a common strategy today in national cross-regional information exchanges**.

**Examples**: HL7 v2, HL7 v3 CDA, HL7 FHIR, certain applications of ISO 13606, Swedish national "service contracts" in the service platform coordinated by SKR/Inera.



# 3. Shared model-driven strategy

Handle data (semantics and information structure) **the same way within systems** using open standardization of the content.

**Consequences**:

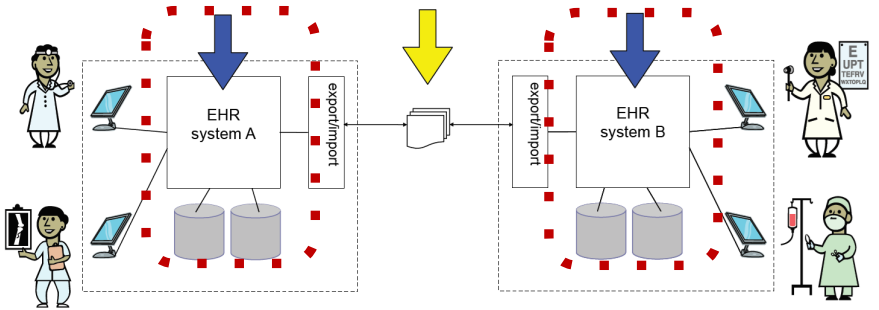
- facilitates vendor independence
- limits selection to products that can internally use the open standardized models, or that can be configured flexibly enough to broadly match the standardized

**Used today in the Nordic region in components of several EHR systems** (but is rarely a requirement in procurements). Further development is underway at several suppliers, including open-source alternatives

**Examples**: openEHR, HL7 CIMI and some applications of ISO 13606

Region Stockholm might choose this, Karolinska University Hospital has procured and are setting up an openEHR based system.

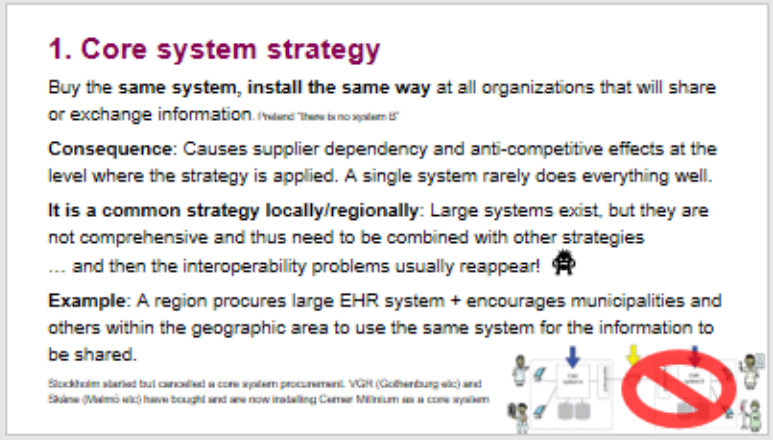
Most Swedish regions use or will use Cambio Cosmic that is piece by piece converting modul (Norwegian DIPS started such a transition several years ago.)

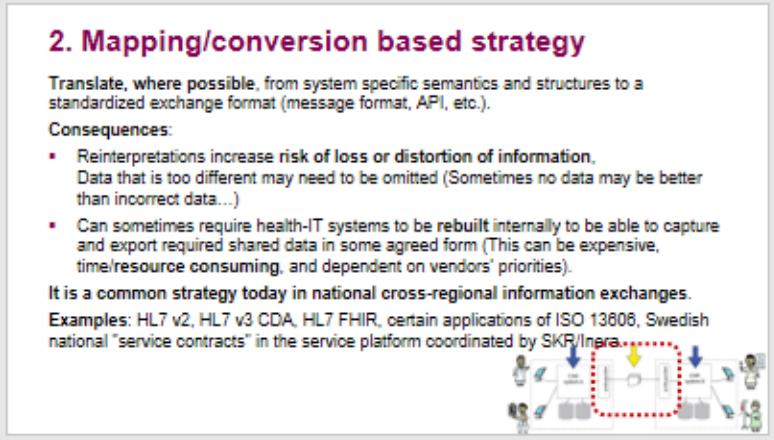


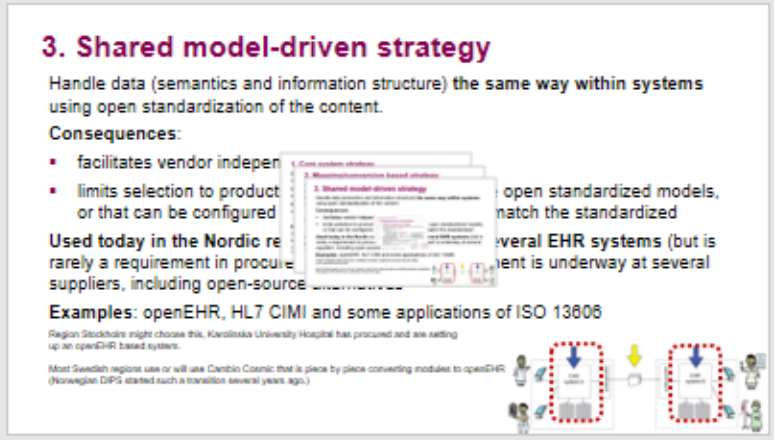
# The three integration strategies combined

Not mutually exclusive and can be combined depending on e.g.

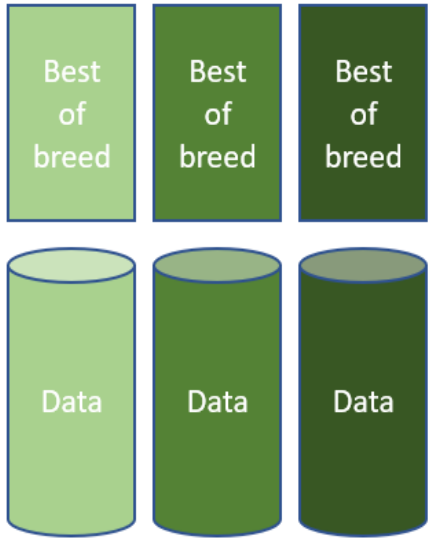
- Geographical granularity
  (international, national, regional and local)
- Timeframe – gradual changes
  (1 year, 5 years, 20 years)



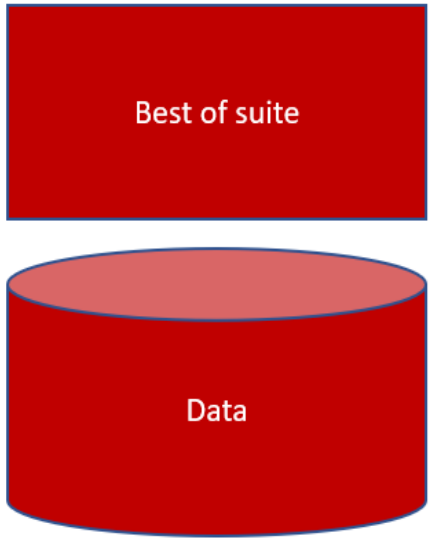



**Best of Breed**
(Closed Ecosystems)



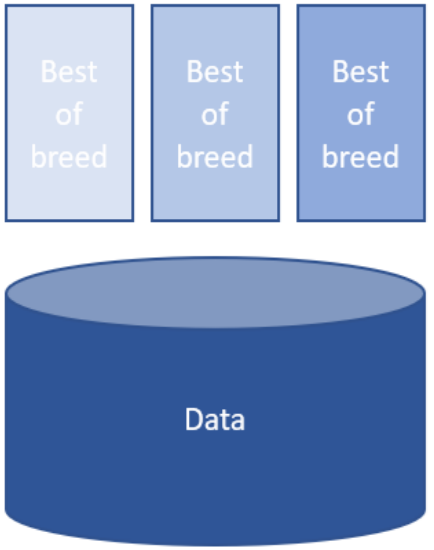

No agreed persistence information models

**Best of Suite**




Persistence models designed for single vendor

**Best of Breed 2.0**
(Open Ecosystems)




Agreed persistence information models (single or distributed storage)

Source: Martin Grundberg, Cambio, https://www.cambio.se/

Best of Breed 2.0 already partially done for medical images (PACS) etc

# Let’s compare!

# The way it used to be…

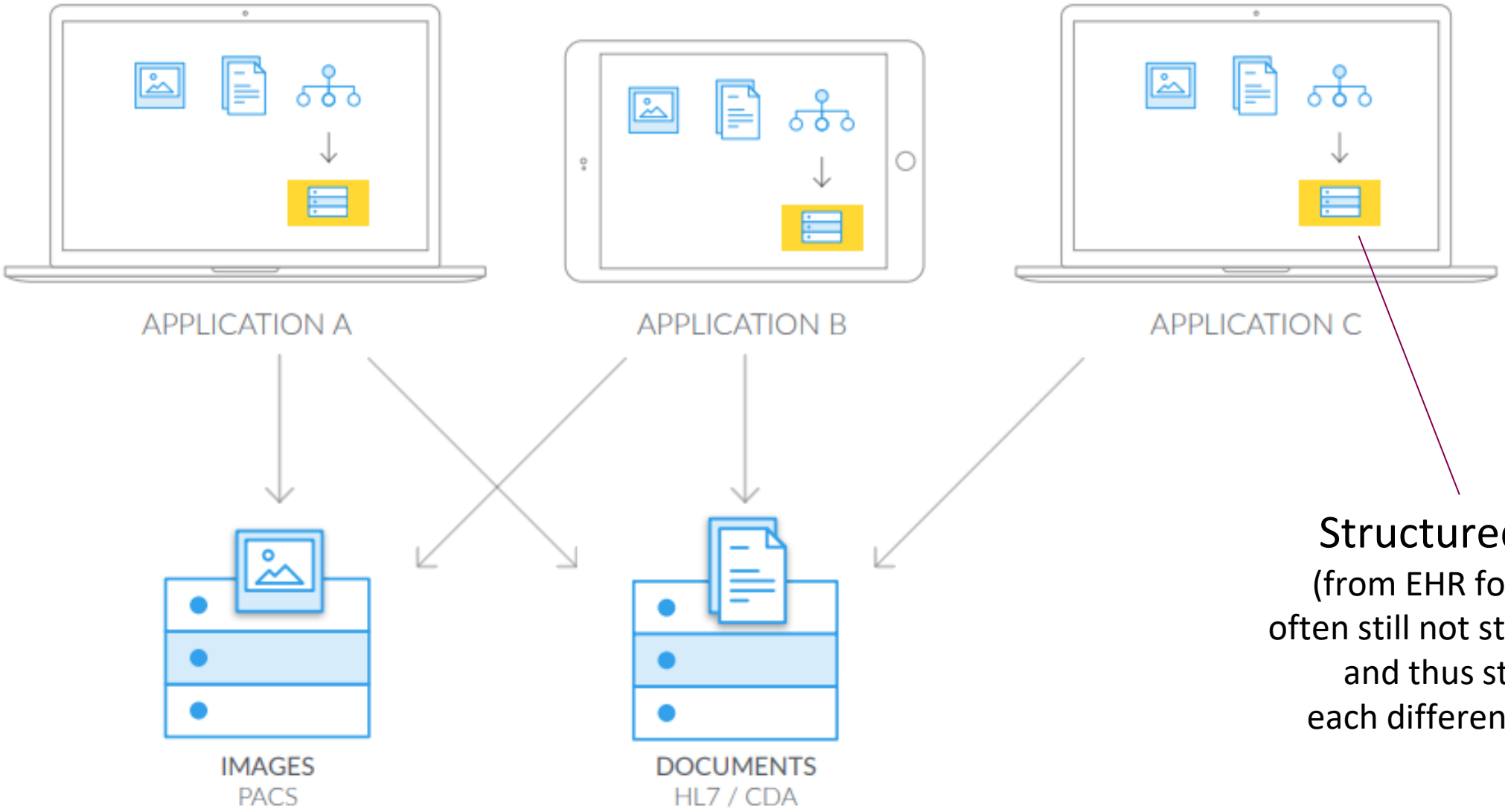
Image data
(X-ray, ultrasonic imaging, MR, potos etc.)

Structured data
(from EHR forms etc)

Documents
(Scanned, fax, PDF etc)

Illustrations based on images from Better, https://www.better.care/

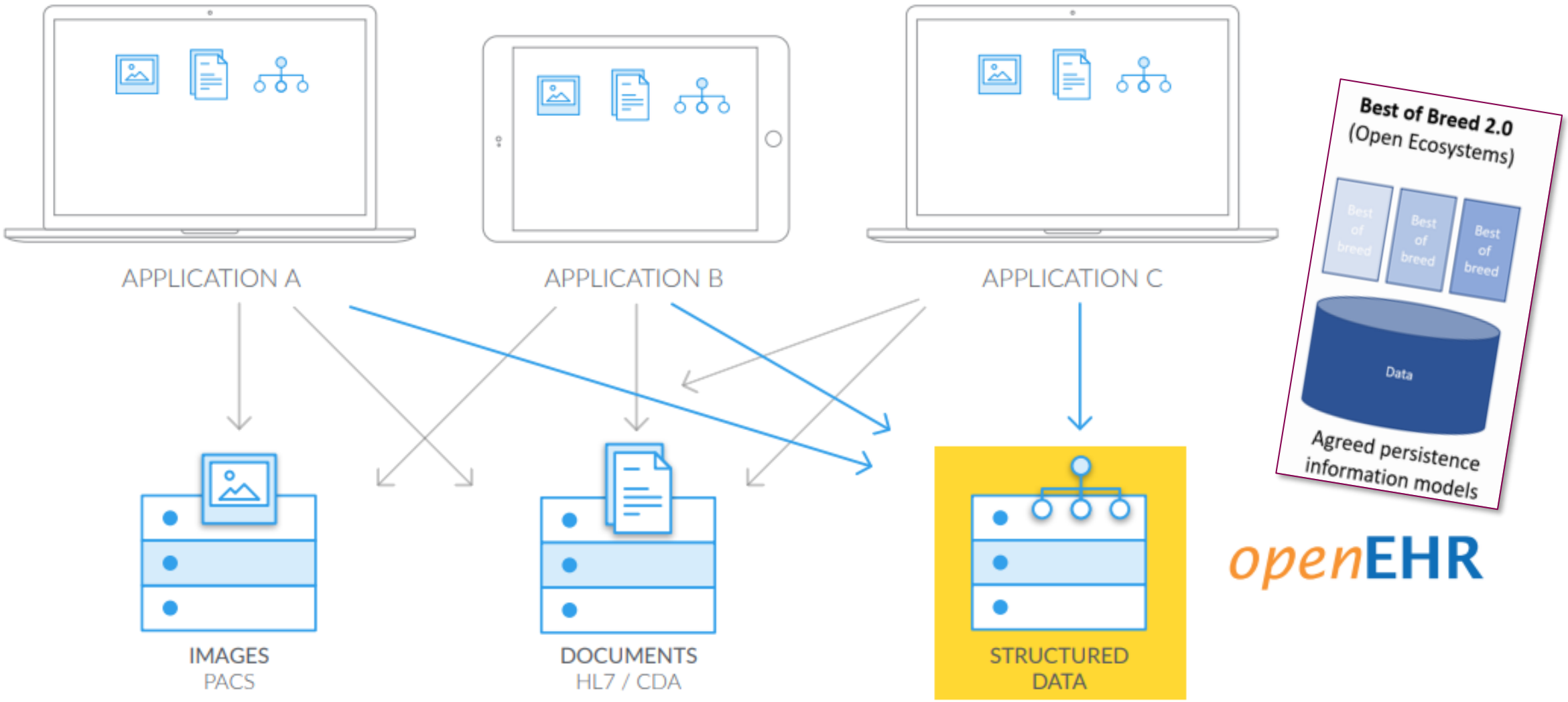
# Then we shared image and document storage…




Structured data
(from EHR forms etc)
often still not standardised
and thus stuck in
each different system

Illustrations based on images from Better, https://www.better.care/

# A goal




Illustrations based on images from Better, https://www.better.care/

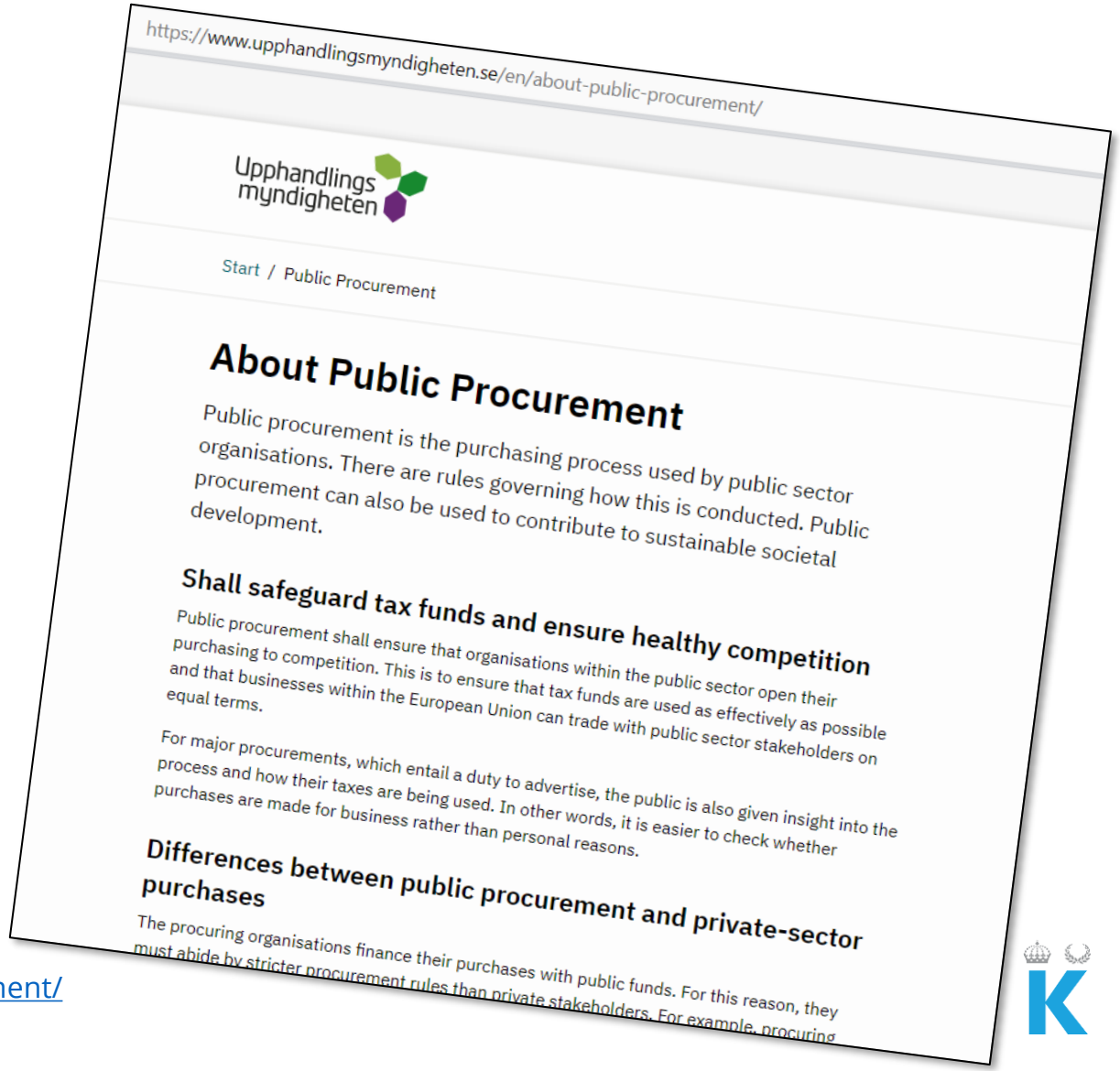
# Public Procurement – avoids corruption?

## Not simpler (not always cheaper)

The basic procurement principles are:

- non-discrimination
- equal treatment
- proportionality
- transparency
- mutual recognition

They mean that procuring organisations must always remain objective and neutral to the stakeholders that wish to become suppliers, and the entire procurement process must be characterised by transparency and proportionality.


https://www.upphandlingsmyndigheten.se/en/about-public-procurement/

Upphandlings myndigheten

Start / Public Procurement

**About Public Procurement**

Public procurement is the purchasing process used by public sector organisations. There are rules governing how this is conducted. Public procurement can also be used to contribute to sustainable societal development.

**Shall safeguard tax funds and ensure healthy competition**

Public procurement shall ensure that organisations within the public sector open their purchasing to competition. This is to ensure that tax funds are used as effectively as possible and that businesses within the European Union can trade with public sector stakeholders on equal terms.

For major procurements, which entail a duty to advertise, the public is also given insight into the process and how their taxes are being used. In other words, it is easier to check whether purchases are made for business rather than personal reasons.

**Differences between public procurement and private-sector purchases**

The procuring organisations finance their purchases with public funds. For this reason, they must abide by stricter procurement rules than private stakeholders. For example, procuring



https://www.upphandlingsmyndigheten.se/en/about-public-procurement/

# Public Procurement – avoids corruption?

## Not simpler (not always cheaper)

Too common today:

- What did others pick (without getting fired)?
- The procurement (ir)responsible just want to finish the procurement project and go on to new positions/projects…
  …but the harder implementation, integration and maintainance work is dumped on others [Stockholm 3rd/4th attempt now…]
- Pick your favourite and bend the procurement requrements to fit it? [High corruption risk!]

More sustainable:

- Maintaining long term healthty competition – we want many experienced suppliers to pick from

Dilemmas - risks to handle/mitigate:

- Encourage new suppliers

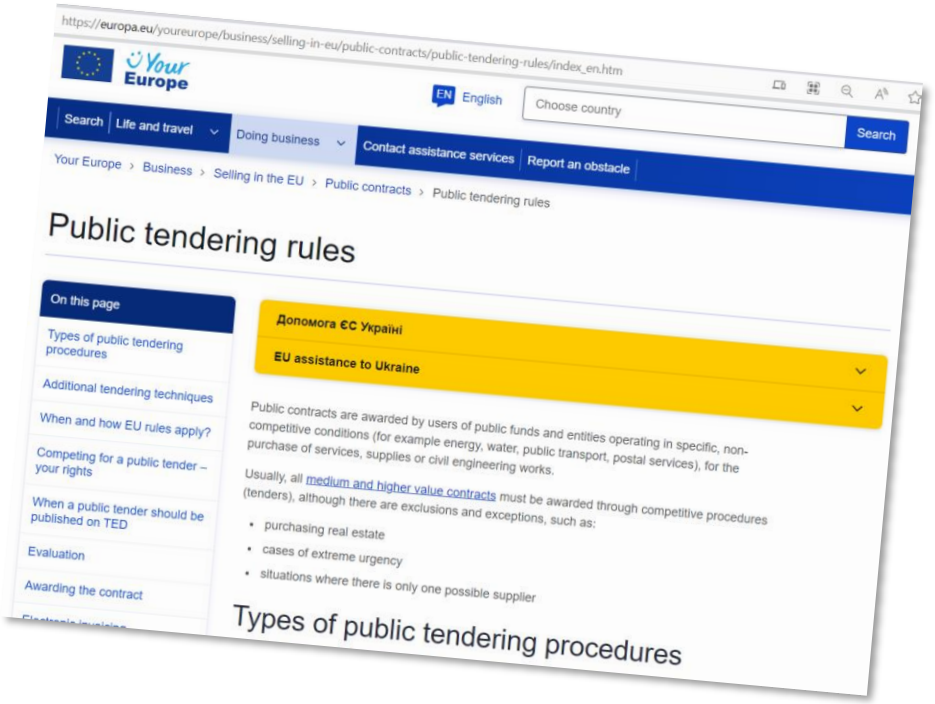
  vs

  Not become alpha testers of immature products

# Variants of EU procurement

- **Open procedure**
  Anyone may submit a full tender. This procedure is **used most frequently.**
- **Restricted procedure**
  anyone may ask to participate … but only those who are pre-selected may submit tenders.
- **Competitive negotiated procedure**
  …anyone may ask to participate, but only those who are pre-selected will be invited to submit **initial** tenders and to **negotiate**. (used when negotiations are necessary due to the specific or complicated nature of the purchase)
- **Competitive dialogue**
  This procedure can be used by a contracting authority with the aim of proposing a method of addressing a need defined by the contracting authority.
- **Innovation partnership**
  This procedure may be used when there is a need to purchase a good or service that is still unavailable on the market. A number of companies may participate throughout the process.
- **Design contest**

  This procedure is used to obtain an idea for a design**.**




- Additional tendering techniques … a contracting authority may:
  - sign a **framework agreement** with one or **a number of companies** for tenders requiring recurring purchases
  - when using the restricted procedure - authorise the use of the **electronic dynamic purchasing system for making recurring purchases**
  - decide that to get the best offer, the final choice of the winner will be made through an **electronic auction**



https://europa.eu/youreurope/business/selling-in-eu/public-contracts/public-tendering-rules/index_en.htm

# Legal variants of EU procurement

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Region Östergötland 2020 referral

K/Region Stockholm openEHR platform procurement 2023-2024

Region Stockholm ”traditional” EHR

Good for national cooperation?



https://europa.eu/youreurope/business/selling-in-eu/public-contracts/public-tendering-rules/index_en.htm

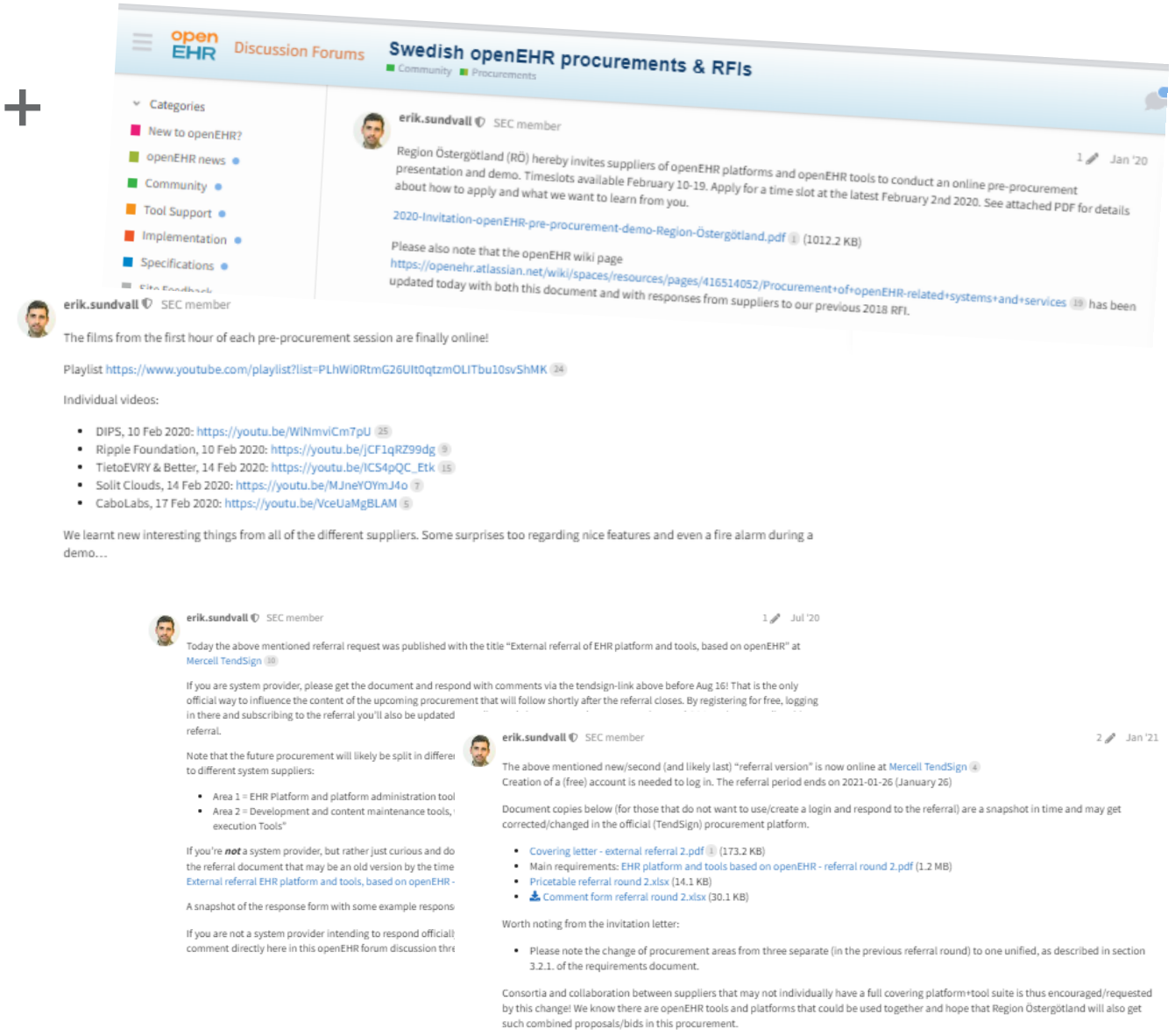
# Region Östergötland 2020+

- Pre-procurement presentations
- Requirement referral – round 1
- Requirement referral – round 2
- Internal reorganisation + covid cancelled the procurement ☹

All available via

https://discourse.openehr.org/t/swedish-openehr-procurements-rfis/247

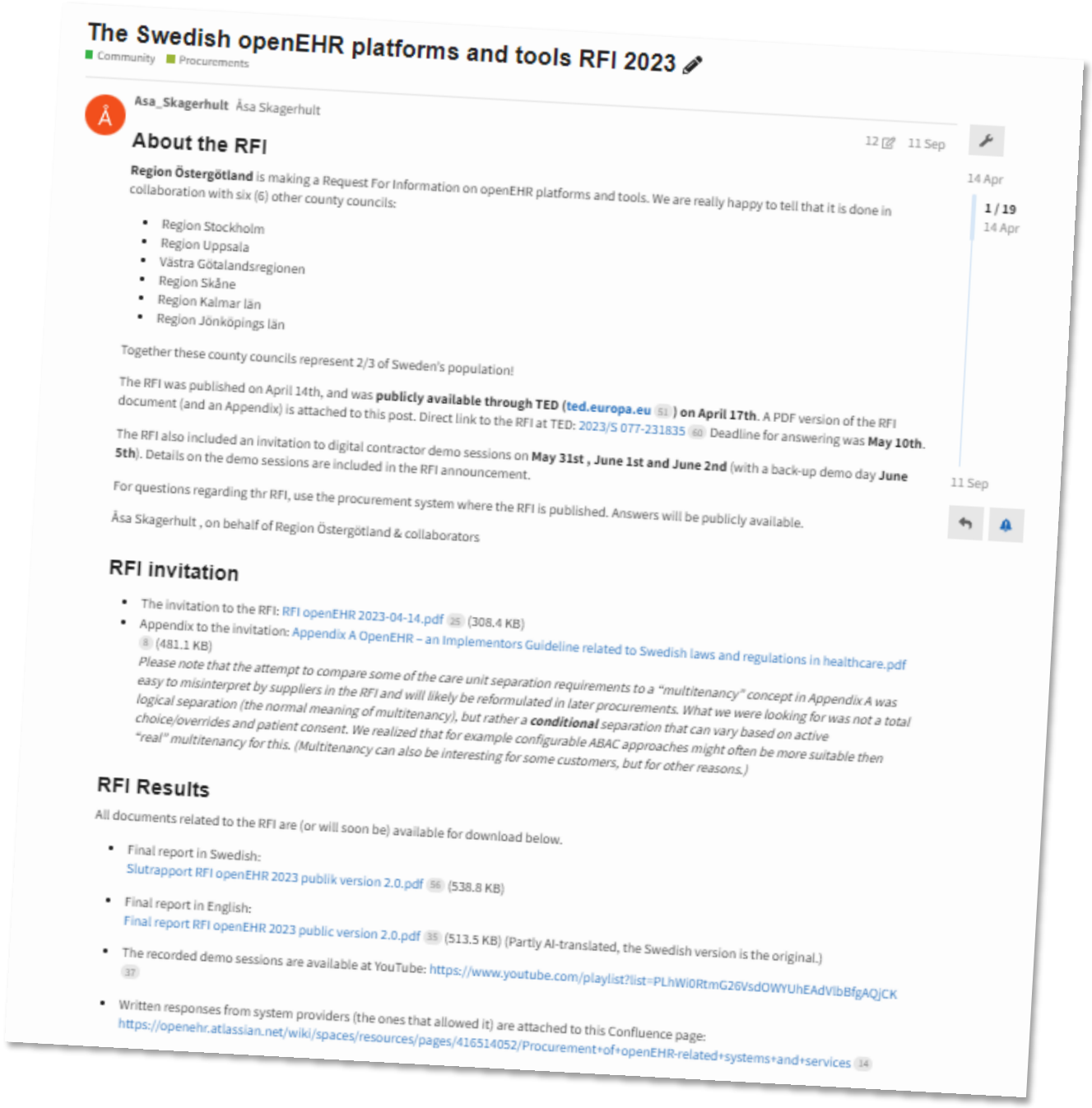
including presentations on YouTube



# 2023, seven regions, RFI – Request for information

- Very low legal risks for all parties…
- …but still consumes time/resources from all parties
- Collaborate to save time/resources that could be used for important things!

- Questions, responses, youtube-videos and report/summary available  https://discourse.openehr.org/t/the-swedish-openehr-platforms-and-tools-rfi-2023/3840



The Swedish openEHR platforms and tools RFI 2023

Community · Procurements

Asa_Skagerhult Åsa Skagerhult

## About the RFI

12 · 11 Sep

**Region Östergötland** is making a Request For Information on openEHR platforms and tools. We are really happy to tell that it is done in collaboration with six (6) other county councils:

- Region Stockholm
- Region Uppsala
- Västra Götalandsregionen
- Region Skåne
- Region Kalmar län
- Region Jönköpings län

Together these county councils represent 2/3 of Sweden's population!

The RFI was published on April 14th, and was **publicly available through TED** (**ted.europa.eu** 51 ) **on April 17th**. A PDF version of the RFI document (and an Appendix) is attached to this post. Direct link to the RFI at TED: 2023/S 077-231835 60 Deadline for answering was **May 10th**.

The RFI also included an invitation to digital contractor demo sessions on **May 31st , June 1st and June 2nd** (with a back-up demo day **June 5th**). Details on the demo sessions are included in the RFI announcement.

For questions regarding thr RFI, use the procurement system where the RFI is published. Answers will be publicly available.

Åsa Skagerhult , on behalf of Region Östergötland & collaborators

14 Apr

1 / 19

14 Apr

11 Sep

## RFI invitation

- The invitation to the RFI: RFI openEHR 2023-04-14.pdf 25 (308.4 KB)
- Appendix to the invitation: Appendix A OpenEHR – an Implementors Guideline related to Swedish laws and regulations in healthcare.pdf 8 (481.1 KB)

*Please note that the attempt to compare some of the care unit separation requirements to a "multitenancy" concept in Appendix A was easy to misinterpret by suppliers in the RFI and will likely be reformulated in later procurements. What we were looking for was not a total logical separation (the normal meaning of multitenancy), but rather a **conditional** separation that can vary based on active choice/overrides and patient consent. We realized that for example configurable ABAC approaches might often be more suitable then "real" multitenancy for this. (Multitenancy can also be interesting for some customers, but for other reasons.)*

## RFI Results

All documents related to the RFI are (or will soon be) available for download below.

- Final report in Swedish:
  Slutrapport RFI openEHR 2023 publik version 2.0.pdf 56 (538.8 KB)
- Final report in English:
  Final report RFI openEHR 2023 public version 2.0.pdf 35 (513.5 KB) (Partly AI-translated, the Swedish version is the original.)
- The recorded demo sessions are available at YouTube: https://www.youtube.com/playlist?list=PLhWi0RtmG26VsdOWYUhEAdVlbBfgAQjCK 37
- Written responses from system providers (the ones that allowed it) are attached to this Confluence page:
  https://openehr.atlassian.net/wiki/spaces/resources/pages/416514052/Procurement+of+openEHR-related+systems+and+services 14

# Current Stockholm/Gotland procurement, 3-phases + 3 areas

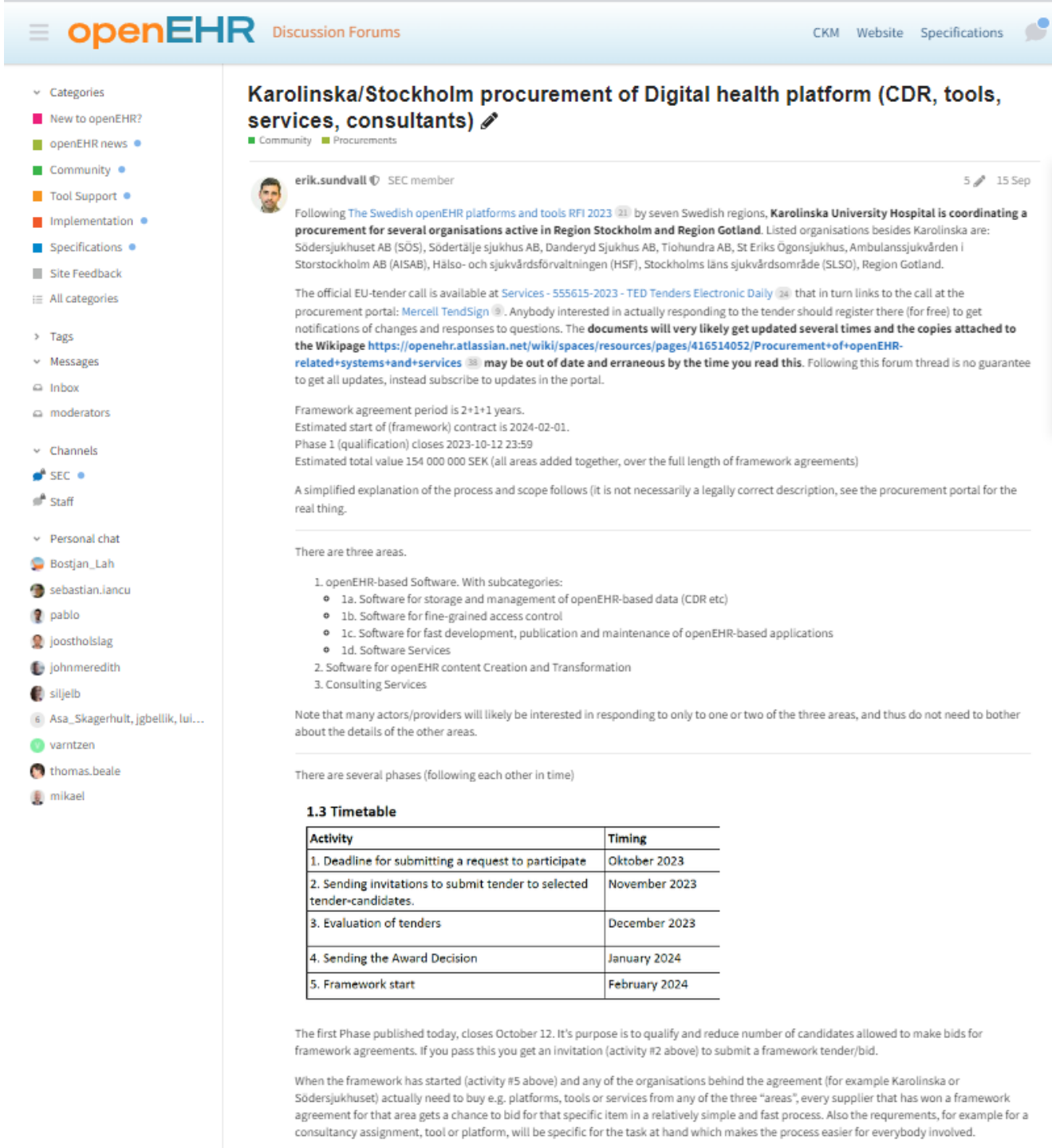
1. openEHR-based Software. With subcategories:
    - 1a. Software for storage and management of openEHR-based data (CDR etc)
    - 1b. Software for fine-grained access control
    - 1c. Software for fast development, publication and maintenance of openEHR-based applications
    - 1d. Software Services

1. Software for openEHR content Creation and Transformation

1. Consulting Services

https://discourse.openehr.org/t/karolinska-stockholm-procurement-of-digital-health-platform-cdr-tools-services-consultants/4457

Collaboration! Cross-regional question-bank based on previous work in Sweden, Germany, Great Britain. Will be openly published.



# Managing lock-in effects - A telephone analaogy

1. **Telecom operator** (Vodaphone, KPN, ...)
   - Number portability (keep your old phone number when switching) crucial!
   - Minor capability differences (but sometimes important, like rural coverage)
2. **Operating system** (iOS, Android, ...)
   - Not as standardised as GSM/3G/4G/5G
3. **Important applications**
   - Things with very standardised content, like mail clients, can be switched
   - App versions for each operating system can be made
     - By others, e.g. for commercial apps like Spotify, LinkedIn, ...
     - By yourself for ”homegrown” apps
     - By you and others in collaboration (e.g. open source apps)

1. **openEHR CDR** (used via standard APIs) ...and having control of your own template- and archetype usage
2. **Form/Low-code tools, integration tools, portals** etc*
   - Very limited openEHR standardisation for this now, but SMART on openEHR (draft) and some simplified integration formats are available
3. **Important applications**
   - App versions or components for each vendor specific portal/framework can be made
     - By others
     - By yourself for ”homegrown” apps
     - By you and others in collaboration (e.g. open source apps)

*) Freestanding apps using the CDR via APIs can skip using tools and some parts of portals/frameworks (#2 above)

# The healthcare professionals and units are now asking for well structured information! (No longer asking just for ”some useful IT-system”)

# Questions? Discussion!

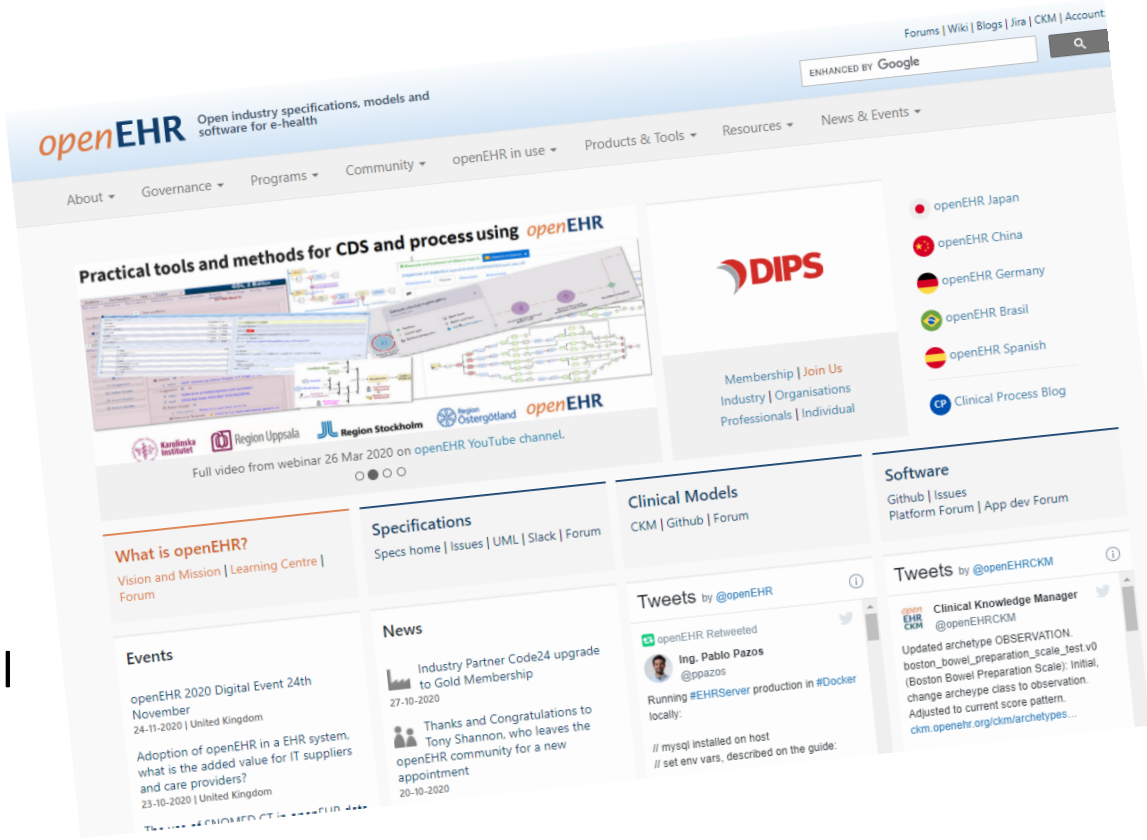
More openEHR details follow
(bonus material, if time allows)

# What is openEHR? Formally...

A technology for e-health
– **open specifications + clinical models** (archetypes and templates)
– **software** (tools etc.)

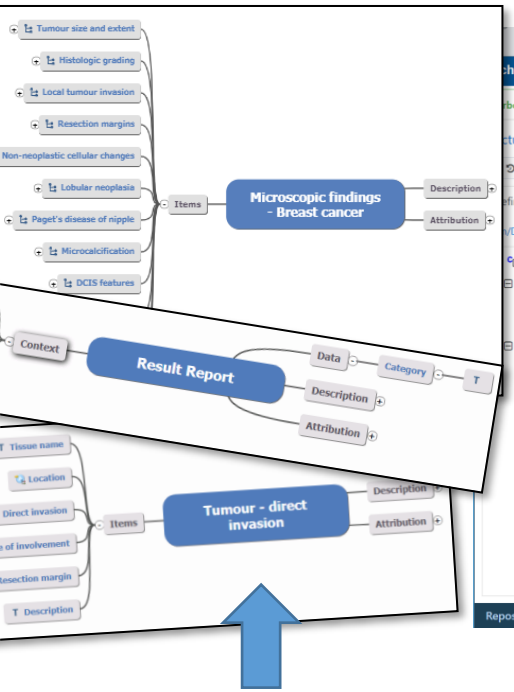
...to build **information and interoperability solutions for healthcare**.

Artefacts of openEHR are produced by the openEHR **community** and managed by **openEHR International**, a **non-profit organisation** established in 2003



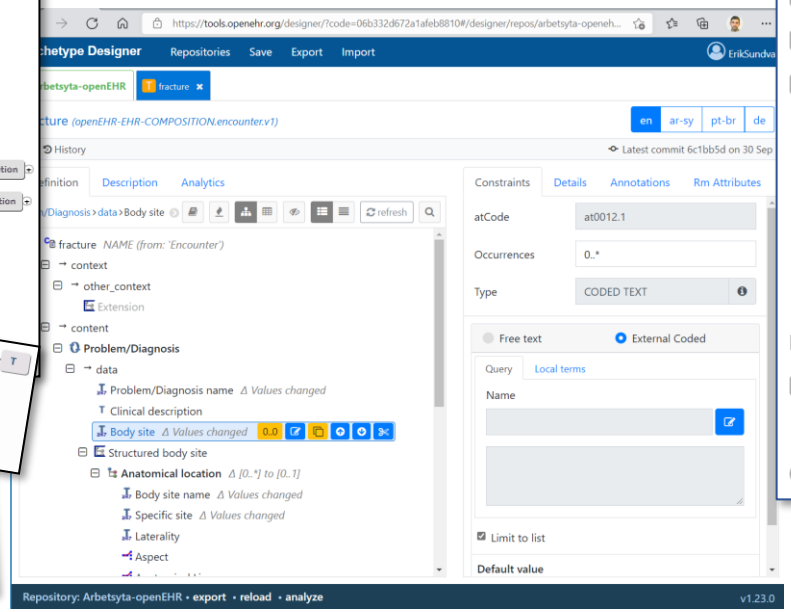

https://openehr.org/about/what_is_openehr
EHR = Electronic Health Record = Elektronisk Patientjournal

# openEHR modeling toolchain



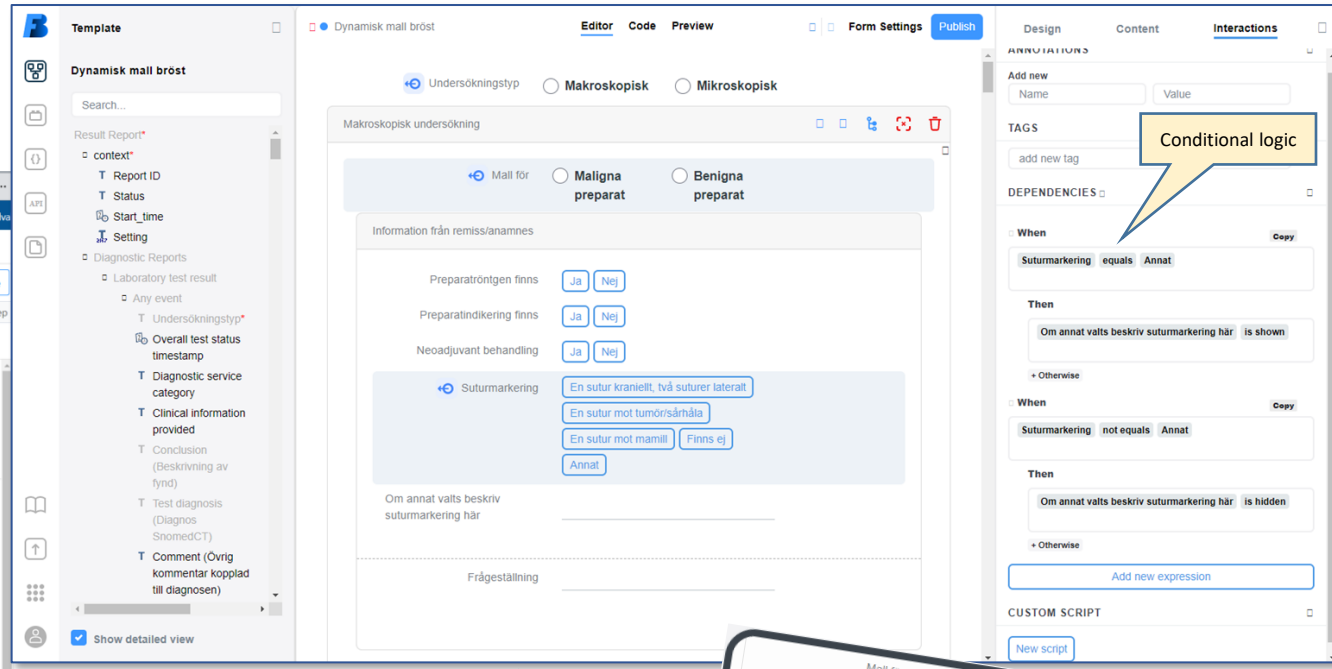

**openEHR ”archetypes”**
Clinical data models.
Found in internatioinal repository
https://ckm.openehr.org/ckm/

Maximi-datasets, intended for many use cases. Multilingual



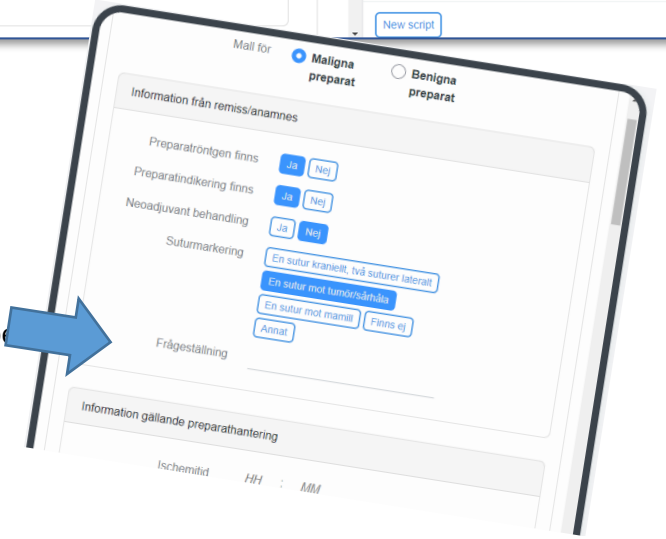

**openEHR ”template”**
For specific use case, e.g. local, regional or national.

Free archetype and editing tool at https://tools.openehr.org/designer/




**Form builder**

**”Form renderer”**
Web-component that can be included in any webapp. It displays forms and submits validated data to openEHR backends via standardized API.



# Template (mall)

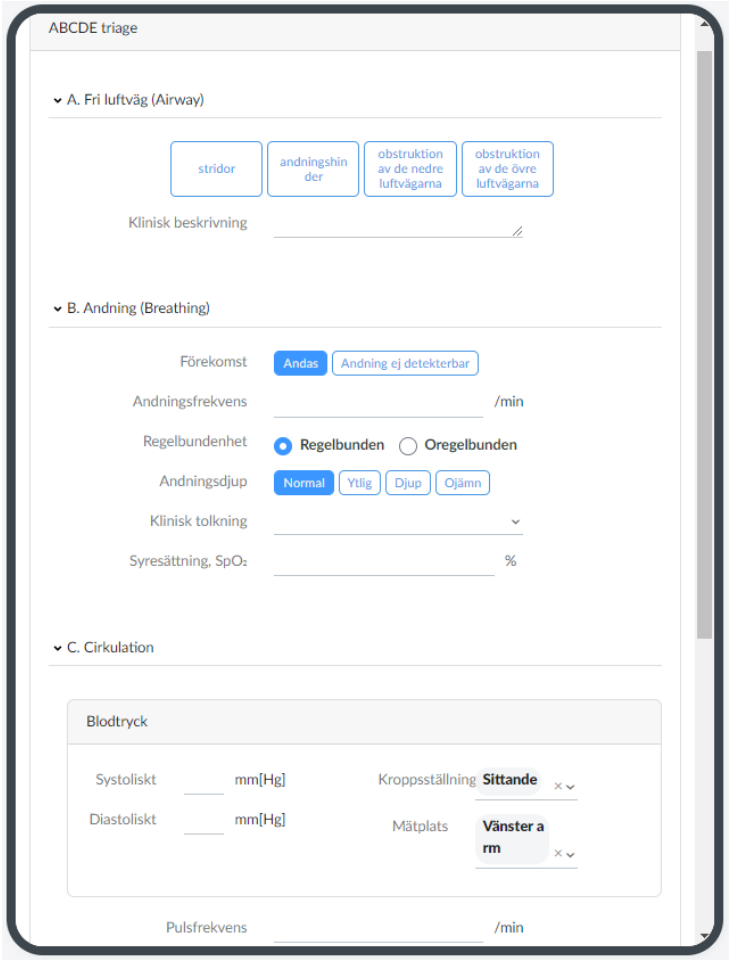
**Specifik för ett användningsfall.**
**Kombinerar och konfigurerar flera arketyper.**

# Archetypes (arketyper)

**Återanvändbara dokumentationsmönster**

# Form (formulär/gränssnitt)

**Automatiskt genererat från template, sedan manuellt justerat**




akutmall_demoexempel_3b *(openEHR-EHR-COMPOSITION.encounter.v1)*

Definition | Description | Analytics

refresh

_3b > content > ABCDE triage > items > C. Cirkulation > items > Blodtryck > data > Ospecificerad händelse > state > Ställning

- akutmall_demoexempel_3b *NAME (from: 'Vårdtillfälle')*
  - context
  - content
    - Skada *NAME (from: 'Rubrik')*
      - items
        - Problem/Diagnos *Δ [0..1] to [0..*]*
    - ABCDE triage *NAME (from: 'Rubrik')*
      - items
        - A. Fri luftväg (Airway) *NAME (from: 'Rubrik')*
          - items
            - Luftväg *Δ [0..1] to [0..*] NAME (from: 'Problem/Diagnos')*
        - B. Andning (Breathing) *NAME (from: 'Rubrik')*
          - items
            - Andning
            - Pulsoximetri
        - C. Cirkulation *NAME (from: 'Rubrik')*
          - items
            - Blodtryck
              - data
                - Ospecificerad händelse
                  - data
                    - Systoliskt
                    - Diastoliskt
                  - state
                    - Ställning 0..0
              - protocol
                - Mätplats
            - Puls/Hjärtfrekvens

Constraints | Details | An

atCode: at0008.

Occurrences: 0..1

Type: CODED

Internal coded

| | Code | Text |
|---|---|---|
| ☑ | at1000 | Stående |
| ☐ | at1001 | Sittande |
| ☑ | at1002 | Halvliggande |
| ☑ | at1003 | Liggande |
| ☑ | at1014 | Liggande med |

Assumed value: Not set

Default value

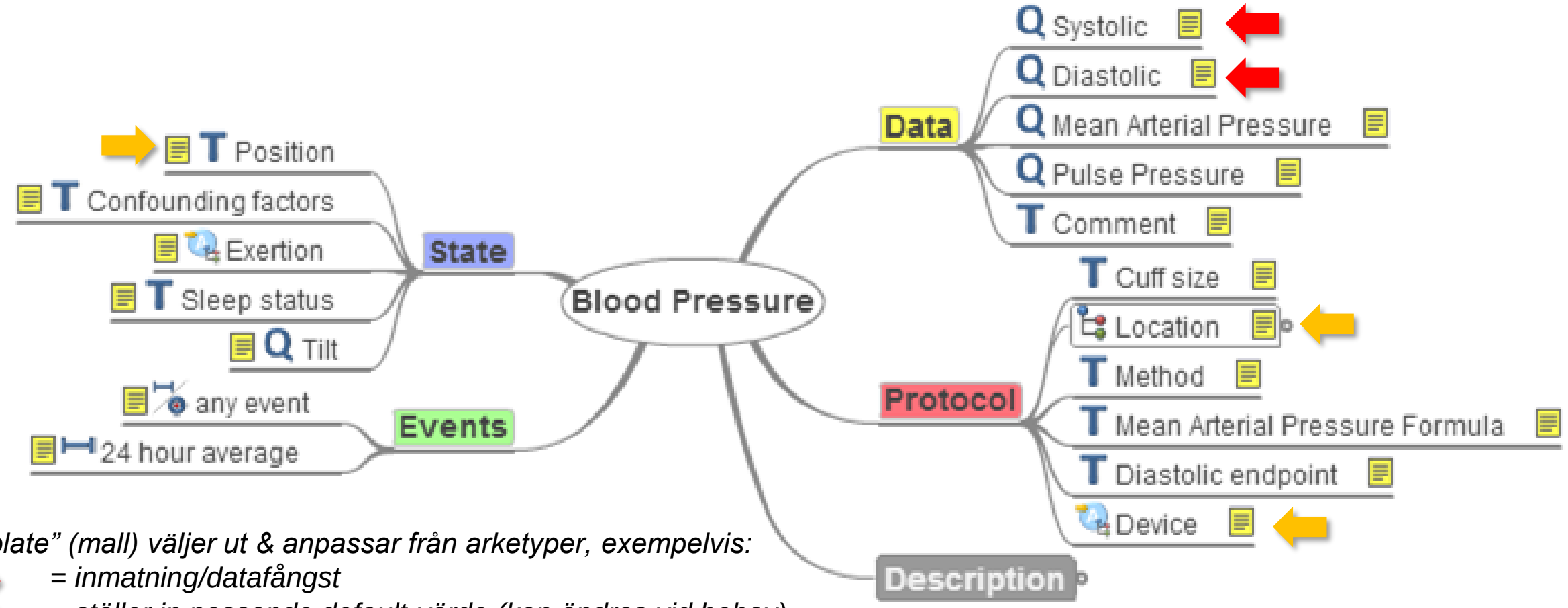
Value: Sittande

https://tools.openehr.org/

# Exempel på en ”arketyp” från openEHR

Kliniskt intressanta saker angående blodtrycksmätning?
”Maximi-tänk” istället för minsta gemensamma nämnare.

Det finns metod/formalism/verktyg att fånga och krav i, och forum att diskutera i.




*”Template” (mall) väljer ut & anpassar från arketyper, exempelvis:*

= *inmatning/datafångst*

= *ställer in passande default-värde (kan ändras vid behov)*

utan pil = *fält som inte behövs i just detta exempel/användningsfall, syns då ej i formulär*

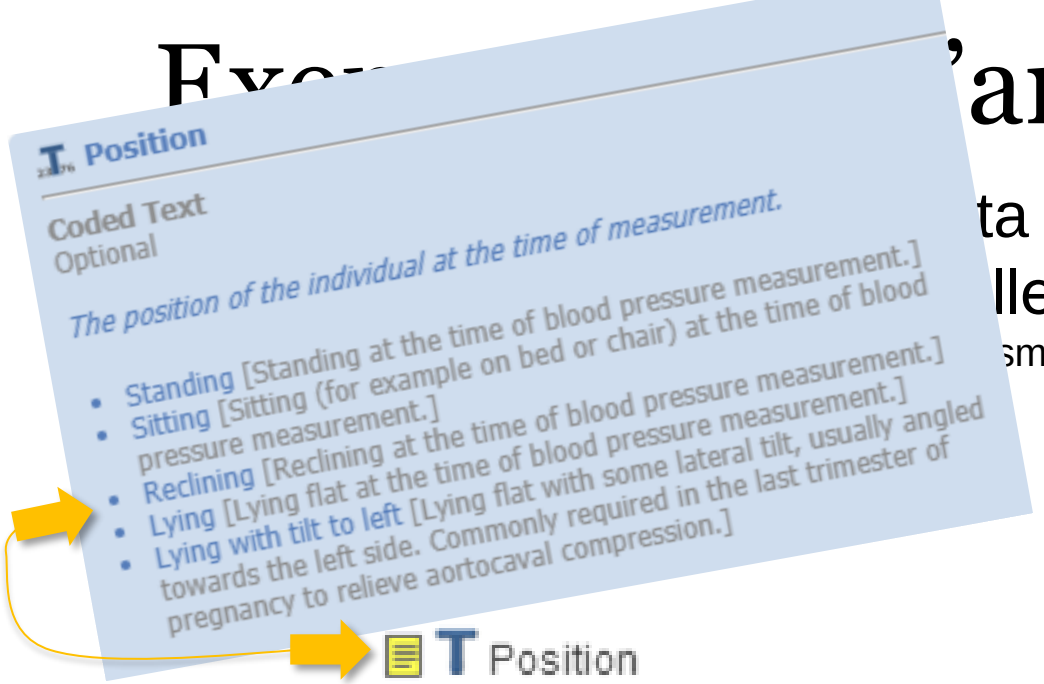
**Se norsk video: https://youtu.be/JW8pBJvdsHQ**

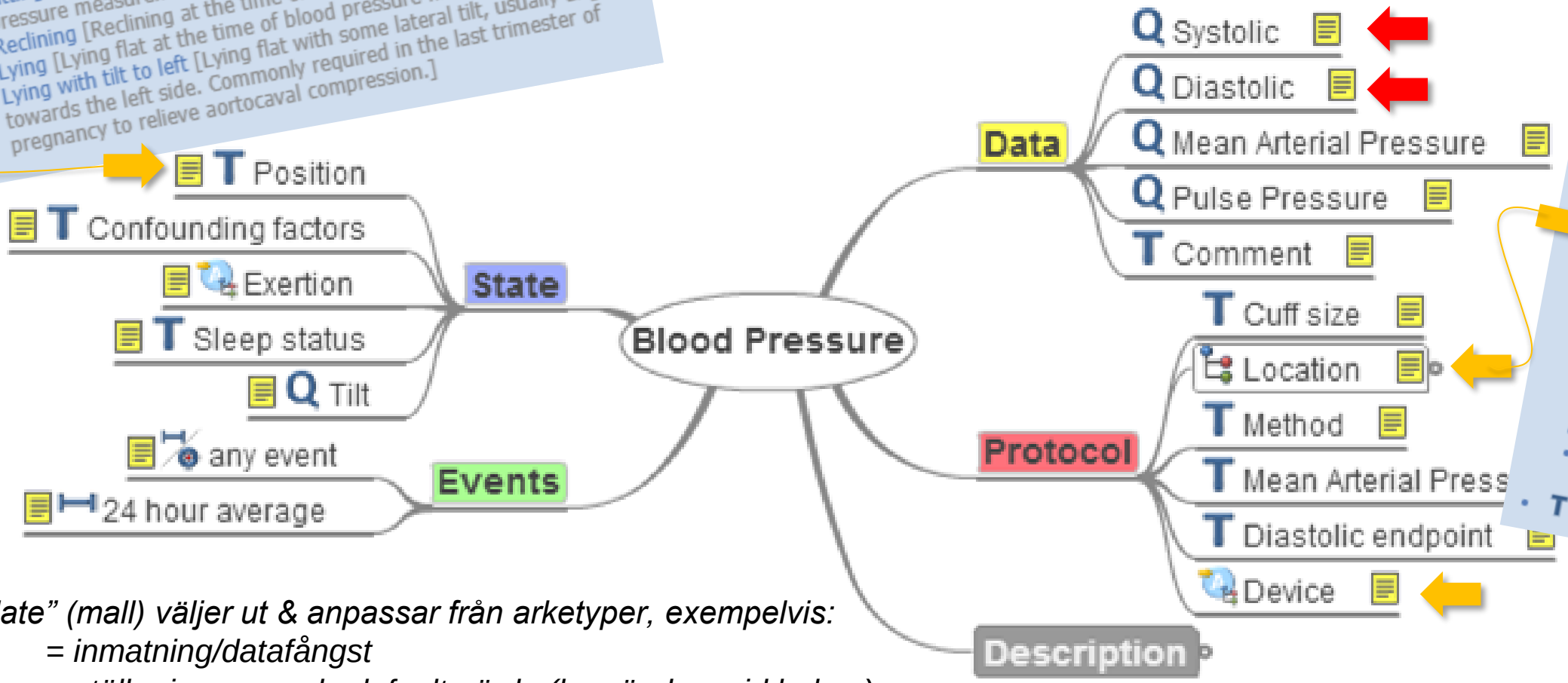
# Exe…'arketyp" från openEHR

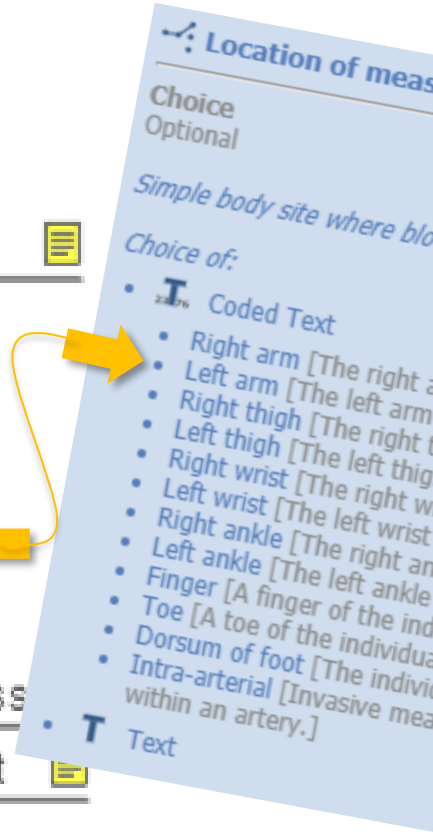
…ta saker angående blodtrycksmätning?

…llet för minsta gemensamma nämnare.

…sm/verktyg att fånga och krav i, och forum att diskutera i.

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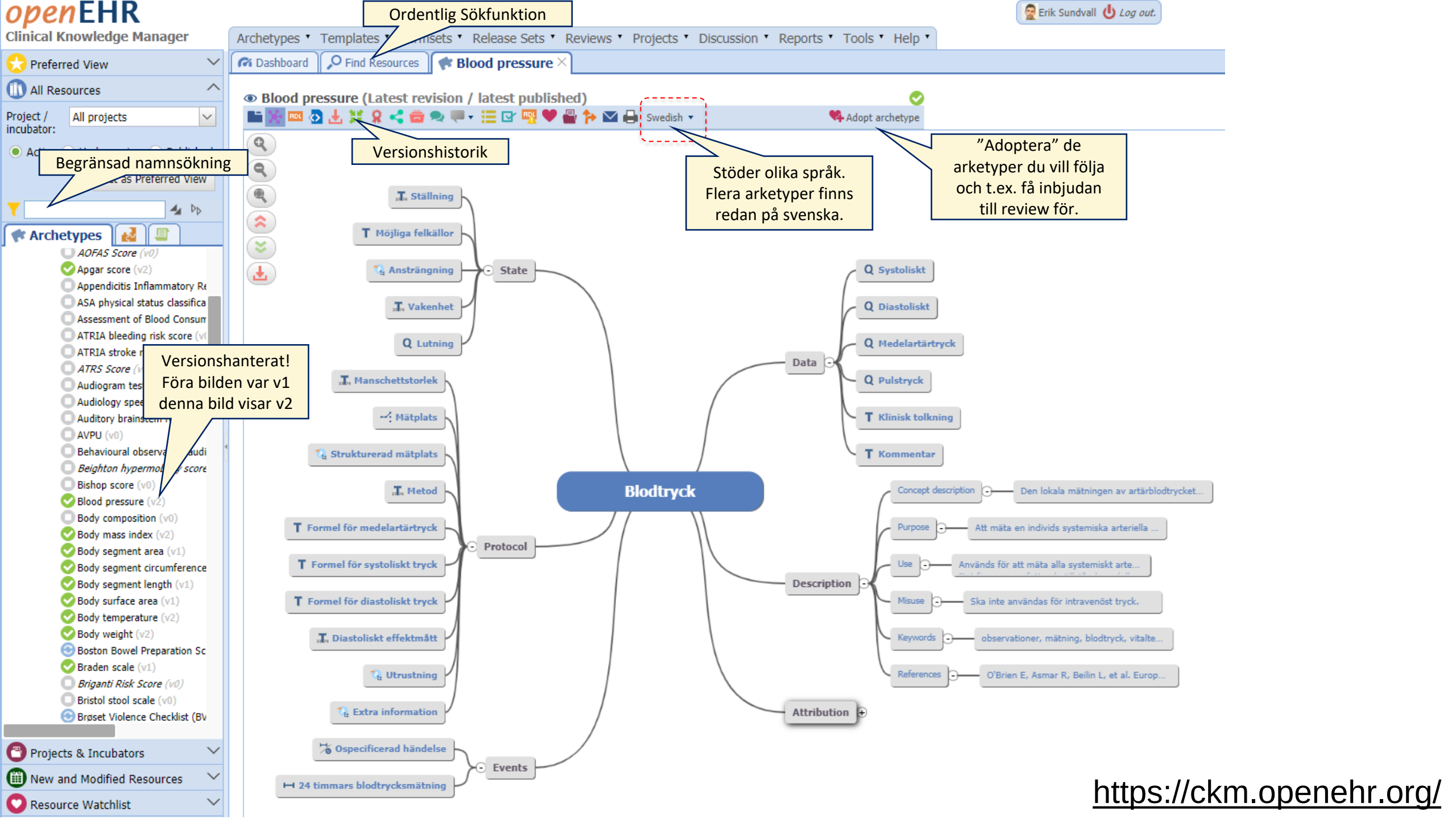
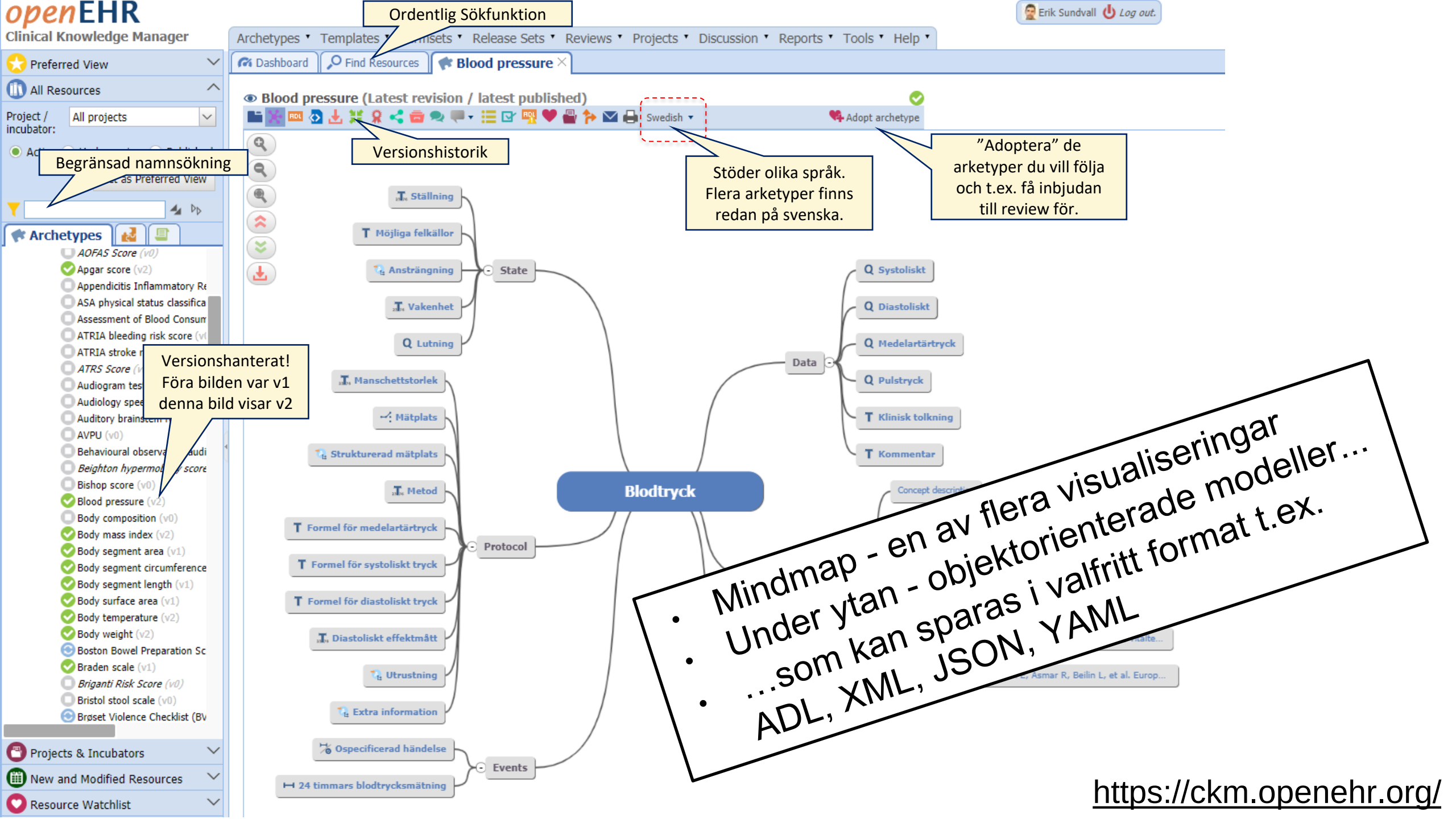
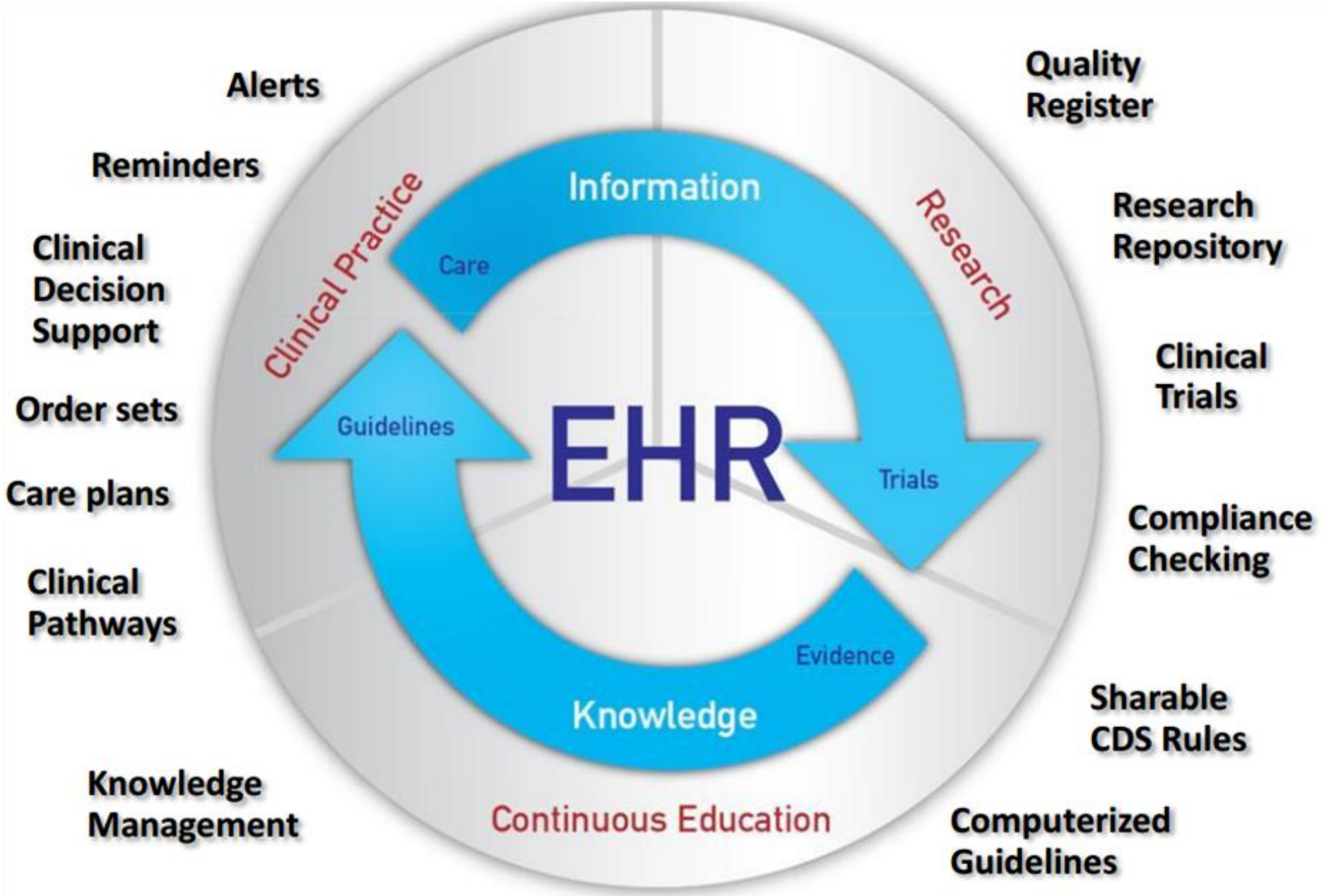



https://ckm.openehr.org/


openEHR
Clinical Knowledge Manager
Erik Sundvall Log out.
Archetypes Templates Release Sets Reviews Projects Discussion Reports Tools Help
Dashboard Find Resources Blood pressure
Ordentlig Sökfunktion
Preferred View
All Resources
Project / incubator:
All projects
Begränsad namnsökning
Archetypes
Blood pressure (Latest revision / latest published)
Swedish
Adopt archetype
Versionshistorik
Stöder olika språk. Flera arketyper finns redan på svenska.
”Adoptera” de arketyper du vill följa och t.ex. få inbjudan till review för.
Versionshanterat! Föra bilden var v1 denna bild visar v2
Blood pressure (v2)
Blodtryck
State
Ställning
Möjliga felkällor
Ansträngning
Vakenhet
Lutning
Protocol
Manschettstorlek
Mätplats
Strukturerad mätplats
Metod
Formel för medelartärtryck
Formel för systoliskt tryck
Formel för diastoliskt tryck
Diastoliskt effektmått
Utrustning
Extra information
Events
Ospecificerad händelse
24 timmars blodtrycksmätning
Data
Systoliskt
Diastoliskt
Medelartärtryck
Pulstryck
Klinisk tolkning
Kommentar
Mindmap - en av flera visualiseringar
Under ytan - objektorienterade modeller…
…som kan sparas i valfritt format t.ex.
ADL, XML, JSON, YAML
https://ckm.openehr.org/

# AGILITY AND EFFICIENCY?




Towards interoperable and knowledge-based electronic health records using archetype methodology
Rong Chen (PhD thesis), http://urn.kb.se/resolve?urn=urn%3Anbn%3Ase%3Aliu%3Adiva-54822

# Bimodal IT http://blogs.gartner.com/it-glossary/files/2015/01/bimodaltable.png

| | Mode 1 | Mode 2 |
|---|---|---|
| **Goal** | Reliability | Agility |
| **Value** | Price for performance | Revenue, brand, customer experience |
| **Approach** | Waterfall, V-model, "high-ceremony IID"* | Agile, Kanban, "low-ceremony IID"* |
| **Governance** | Plan-driven, approval-based | Empirical, continuous, process-based |
| **Sourcing** | Enterprise suppliers, long-term deals | Small, new vendors; short-term deals |
| **Talent** | Good for conventional processes and projects | Good for new and uncertain projects |
| **Culture** | IT-centric, removed from customer | Business-centric, close to customer |
| **Cycle times** | Long (months) years | Short (days, weeks) months |

**Think marathon runner**

**Think sprinter**

Health IT organizations & vendors are often slower than Gartners average system examples (perhaps due to complexity, regulations etc?)

http://www.gartner.com/it-glossary/bimodal/

# Reliability+Agility? Quality+Speed/Innovation? Bimodal IT (1+2)

Finding suitable abstraction layers and suitable management (people+process)…

Mr Smith's time report for June (an instance)

*X instances*

Y instances

Software manipulating/using X instances

Rules & data flows

GUIs generating/reading/querying instances

Spreadsheet template, e.g. time report for company X

*XML Schema Y using V+W*

XML Schema X using U+V

Template Y using V+W

Template X using U+V

Archetype U

XML Schema U

XML Schema V (national?)

XML Schema W (international?)

Archetype V (national?)

Archetype W (international?)

Tools, editors…

*Rule engines*

General XML database systems

EHR storage system RM+AQL+…

General XML Tools (editors, processors etc)

Spreadsheet Software (e.g. Excel)

Specifications, e.g.: XML, XML Schema (the "language"), XPath & XQuery

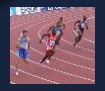
Specifications, e.g.:
-Reference Model (RM),
-Archetype Model (AM),
-AQL (query language)
-GDL (decision support lang.)…

Tell the truth!
Listen to science!
Solutions are possible!

- Actors betting on long term sustainable, scalable solutions
- Educated protestors, willing to contribute to solutions!
- Educated leaders daring to choose and support sustainable solutions?

Mode 1
*"Marathonl"*

Mode 2
*"Sprint"*



Mode 2
*"Sprinter", delar konfigurerbara av verksamhet*

Support
Sys. admin
Customer group

Custromer repr.
Investigation
Prioritisation
Pre-study

Delivery
Release mgmnt.
Programming

GUI/client-design
API-design
Database design
Objekt-modelling

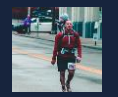
Test
Configuration
Roll-out (during planned service ”windows”)

Adjusting related systems (integrations
Statistical reports etc)

Upload to system
(”live” in an active system)
Test and quality control
Sometimes: Extra programming & optimisations

Find/create archetypes
Create template
Create form/GUI and ”task planning”
incl. dynamic w/ ”low code”
Sometimes: Modify or create CDS rules

Tech sys. administration and improvement of CDR and tools



Mode 1
*"Maratonlöpare"*
*Stabil informatik och teknisk grundplattform*

"...still many organizations choosing ... traditional route and we know that this will be the last cohort adopting this... already a legacy technology... not going to be what we use in the future"

https://youtu.be/RYTmMQJFpAc?t=718

- Actors betting on long term sustainable, scalable solutions
- Educated protestors…?, willing to contribute to solutions…?
- Educated leaders daring to choose and support sustainiable solutions…?

# Programme / Ohjelma

13.00 **Welcome and opening words**
**Kristo Lehtonen**, Director, Fair Data Economy, Sitra

Moderator: Saara Malkamäki, Specialist, Sitra

13.05 **OpenEHR-based software procurement in Stockholm and Gotland region**
**Erik Sundvall**, Information Architect, Karolinska University Hospital

13.25 **Questions and comments**

13.35 **European health data network: using the OMOP CDM for collaborative studies**
**Maxim Moinat**, Scientific Researcher, Erasmus MC

13.55 **Questions and comments**

14.05 **Break**

SITRA

# Programme / Ohjelma

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13.55 **Questions and comments**

14.05 **Break**

EHDEN

EUROPEAN HEALTH DATA & EVIDENCE NETWORK

# A EUROPEAN HEALTH DATA NETWORK: USING THE OMOP CDM FOR COLLABORATIVE STUDIES

**Maxim Moinat**

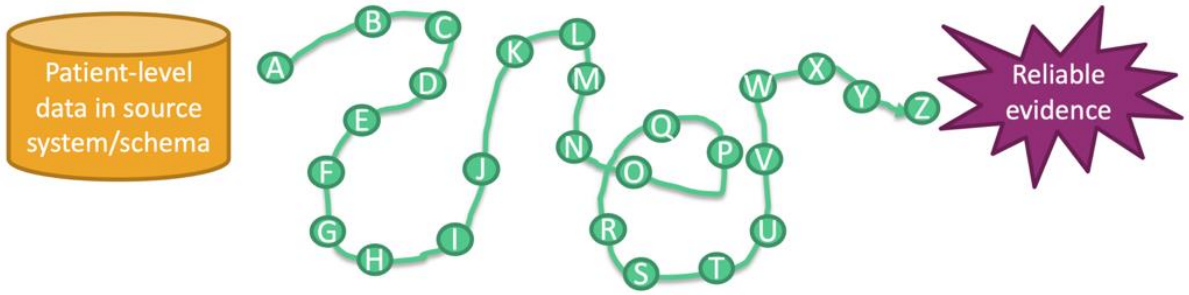
2024-03-11, Sitra

Department of Medical Informatics
Health Data Science
Erasmus MC Rotterdam

Health Data Science

Erasmus MC
Universitair Medisch Centrum Rotterdam

# Generating Reliable Evidence at Scale

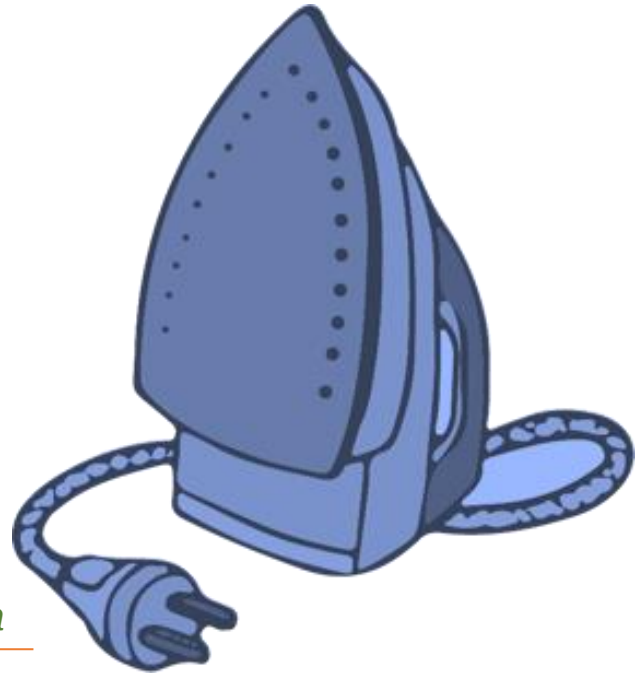



*How can we generate reliable evidence at a large scale, i.e. on many data sources in Europe for many research questions?*

Erasmus MC

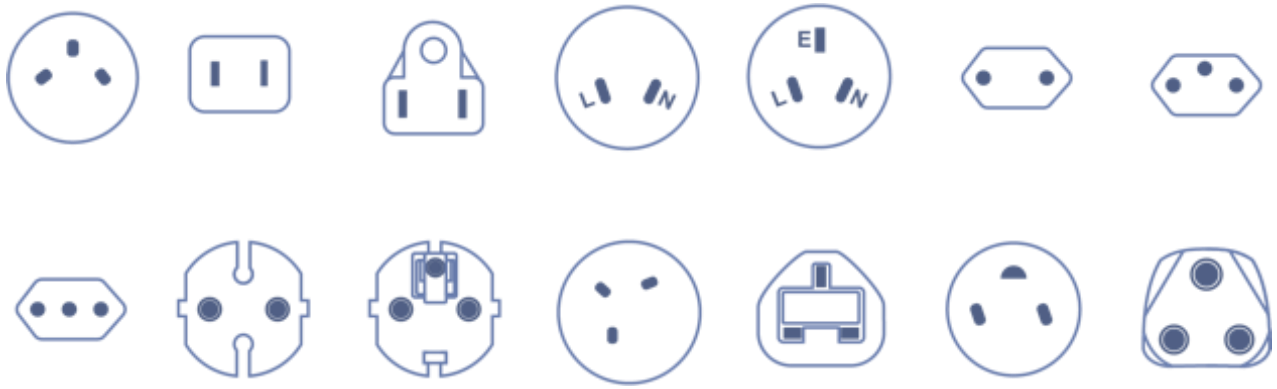
# Improving Interoperability

## *Analytical method*



*Link to data*

## *The structure…*




## *The language…*

*110V, 120V, 127V, 220V, 230V, 204V, …*

Erasmus MC

# Standardization to a common data model

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

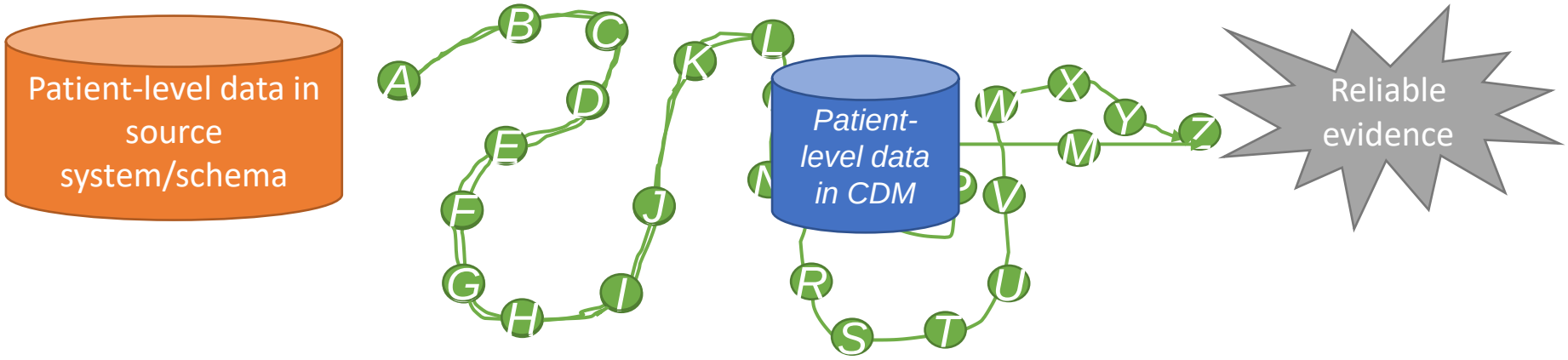
www.ohdsi.org

EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

www.ehden.eu

DARWIN EU

www.darwin-eu.org



# The OMOP CDM

## Standardized clinical data

- Person
- Observation_period
- Visit_occurrence
- Visit_detail
- Condition_occurrence
- Drug_exposure
- Procedure_occurrence
- Device_exposure
- Measurement
- Note
- Note_NLP
- Survey_conduct
- Observation
- Specimen
- Fact_relationship

## Standardized health system data

- Location
- Location_history
- Care_site
- Provider

## Standardized derived elements

- Condition_era
- Drug_era
- Dose_era

***Results Schema***

- Cohort
- Cohort_definition

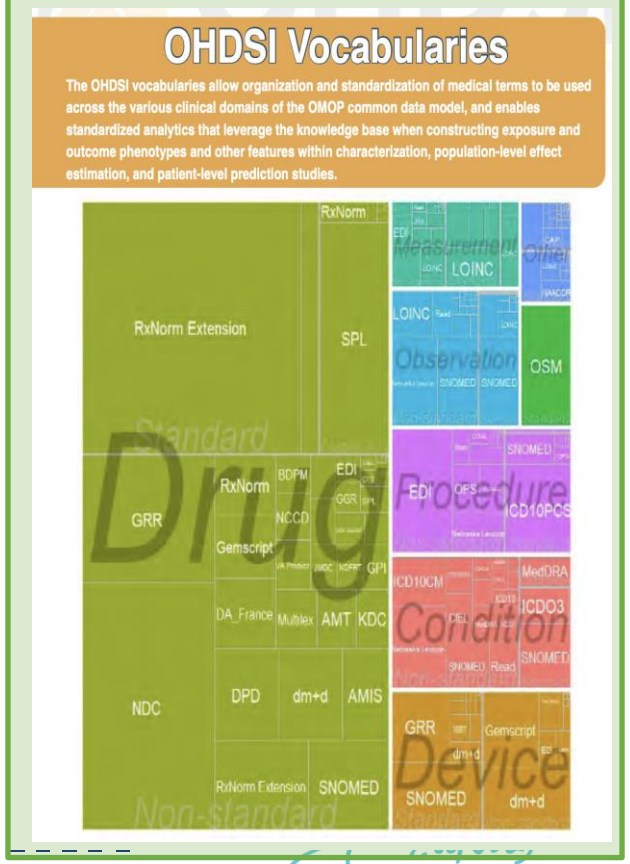
## Standardized health economics

- Cost
- Payer_plan_period

## Standardized metadata

- CDM_source
- Metadata

## Standardized vocabularies




https://ohdsi.github.io/CommonDataModel/

# Questions asked across the patient journey

## Clinical characterization

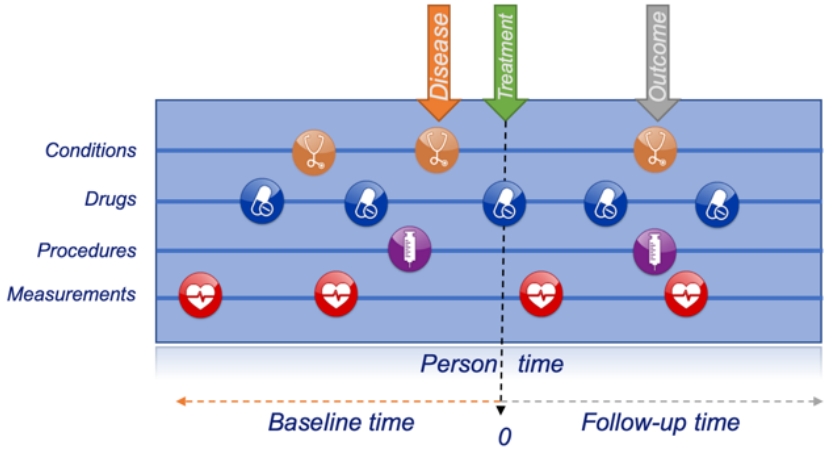
- Natural history: How many have diabetes, what proportion takes metformin?
- Quality improvement: What proportion of patients with diabetes experience complications?

## Population-level effect estimation

- Safety surveillance: Does metformin cause lactic acidosis?
- Comparative effectiveness: Does metformin cause lactic acidosis more than glyburide?

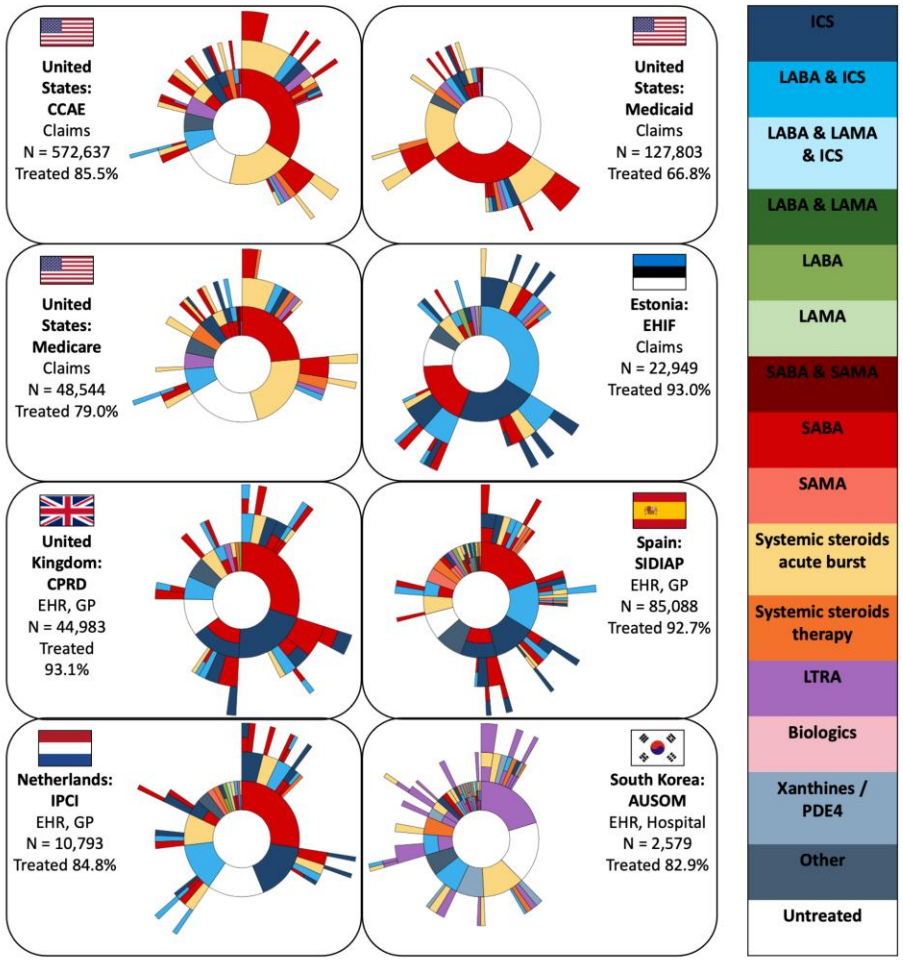
## Patient-level prediction

- Precision medicine: Given everything you know about me, now I started using metformin, what is the chance I will get lactic acidosis?
- Disease interception: Given everything you know about me, what is the chance I will develop diabetes?

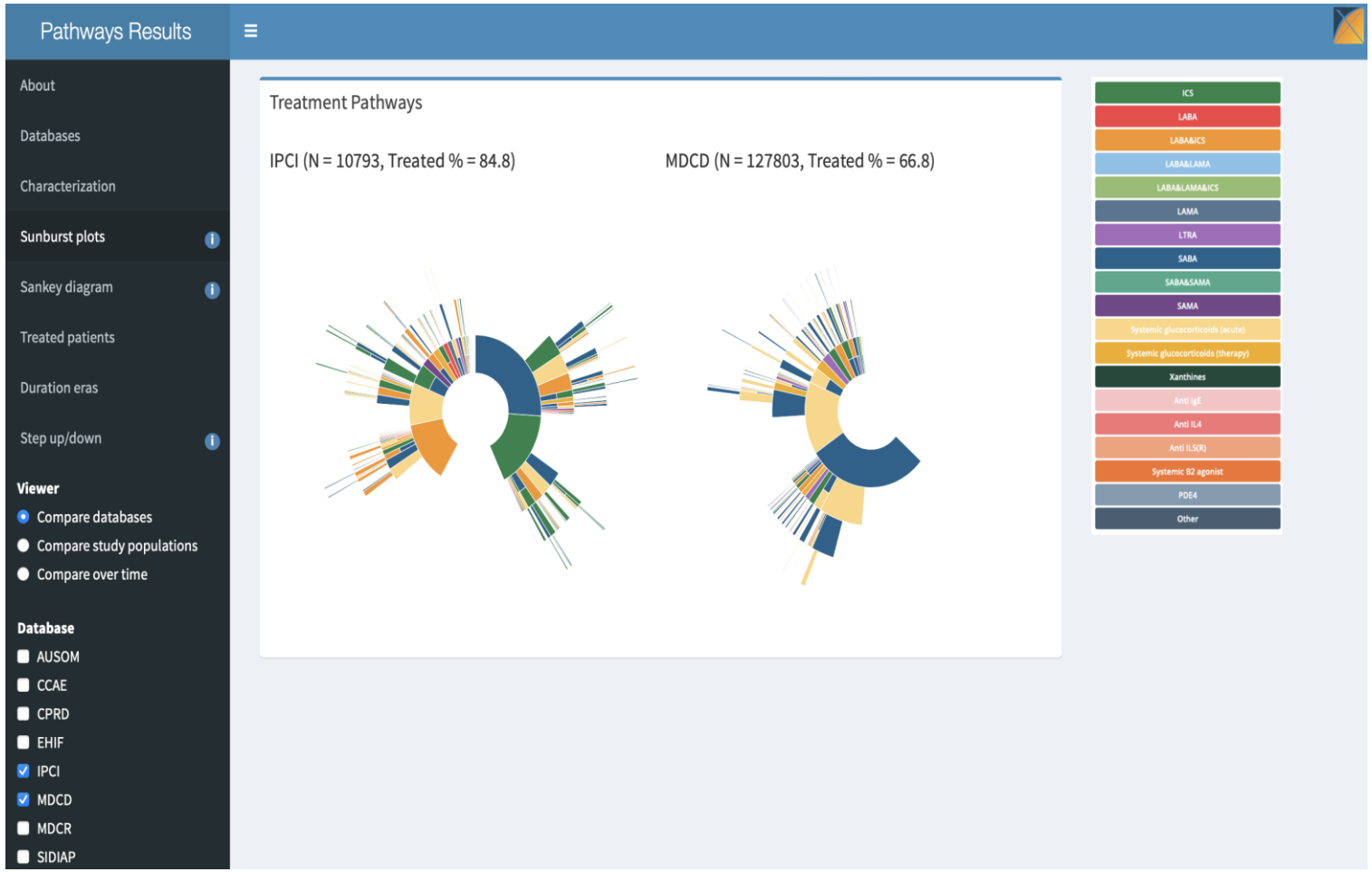



Erasmus MC

# Characterisation: Treatment Patterns




*Treatment Patterns across countries*




*Interactive web-application*

**Markus, A. F.**, Verhamme, K. M., Kors, J. A., Rijnbeek, P. R. (2022). TreatmentPatterns: An R package to facilitate the standardized development and analysis of treatment patterns across disease domains. *Computer Methods and Programs in Biomedicine.*

# Observational Health Data Sciences and Informatics (OHDSI)

*Mission:*

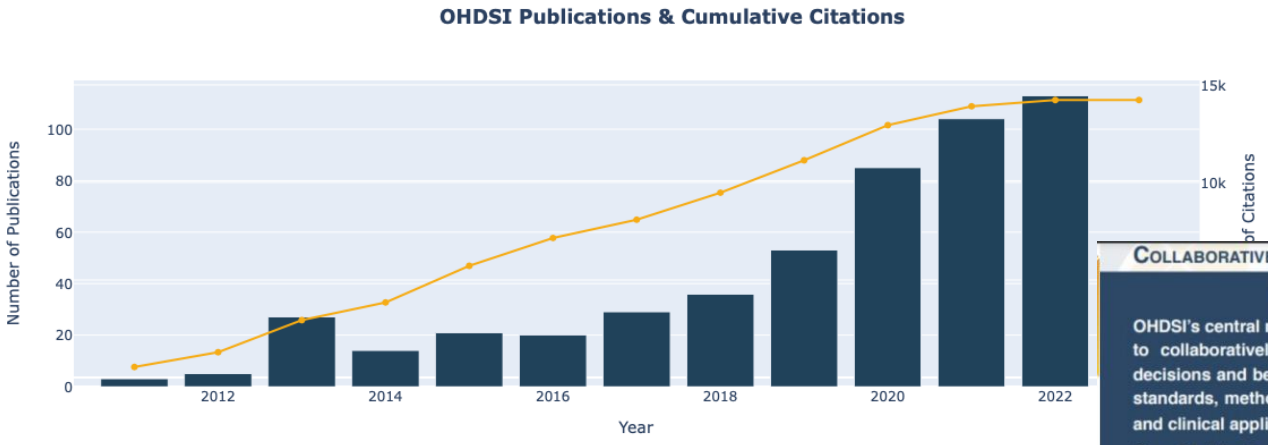
*To improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care*

[www.ohdsi.org](http://www.ohdsi.org)

OHDSI.org

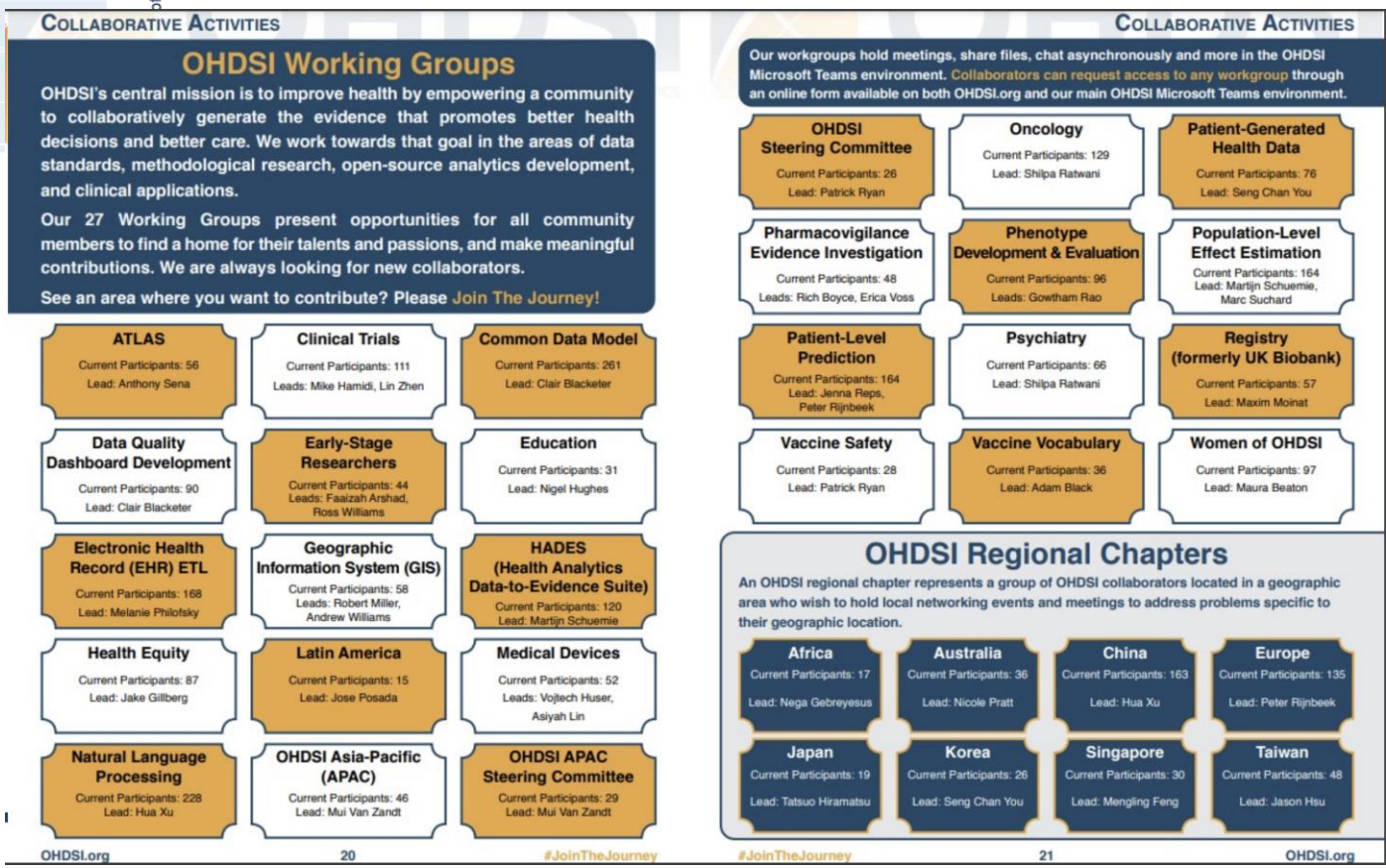
*'Our Journey' https://www.ohdsi.org/wp-content/uploads/2023/11/OHDSI-Book2023.pdf*

Erasmus MC




OHDSI Community scaled up fast in number of publications (516) and distinct co-authors (2000+)

Active collaboration in 33 working groups and 8 regional chapters




https://www.ohdsi.org/wp-content/uploads/2022/01/Welcome-to-OHDSI-2022.pdf

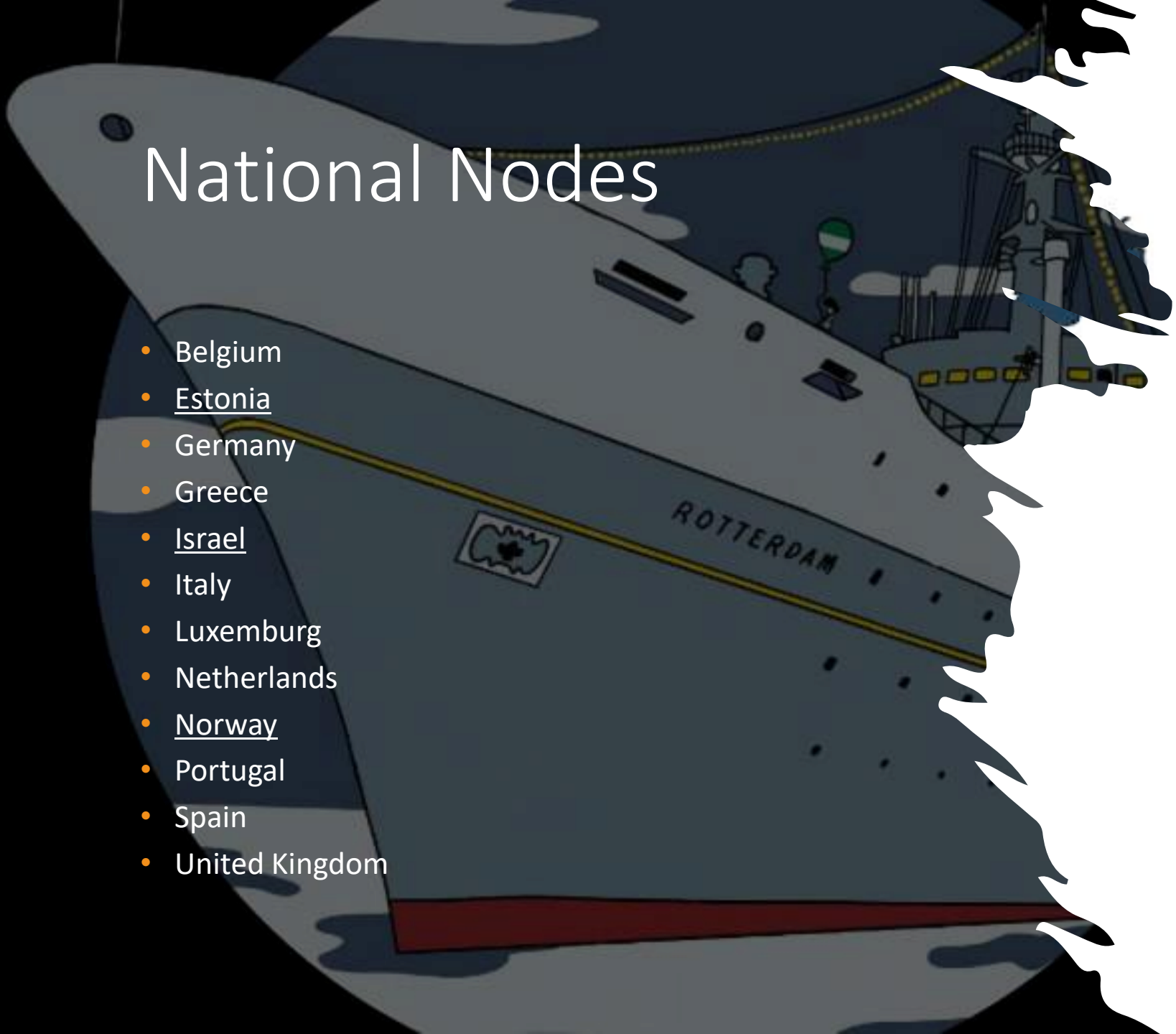
# The numbers

- 3 days
- 350 attendees
- 5 plenary sessions
- 10 rapid fire presentations
- 89 posters
- 7 national nodes
- 5 software demo's
- 2 blues brothers

Thank you for your support!

# National Nodes

- Belgium
- Estonia
- Germany
- Greece
- Israel
- Italy
- Luxemburg
- Netherlands
- Norway
- Portugal
- Spain
- United Kingdom



# EHDEN: Vision and Mission

EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

## Vision

*The European Health Data & Evidence Network (EHDEN) aspires to be the trusted observational research ecosystem to enable better health decisions, outcomes and care*

## Mission

*Our mission is to provide a new paradigm for the discovery and analysis of health data in Europe, by building a large-scale, federated network of data sources standardised to a common data model*

# EHDEN IMI CONSORTIUM

***Start date**: 1 Nov 2018*
***End date**: ~~30 Apr 2024~~*
*October 2024*
***Duration**: 66 months*

***23 partners***

***Almost €29 million***

*Universities, public bodies and research organisations*

Erasmus MC Universitair Medisch Centrum Rotterdam — ***Academic coordinator***

Uppsala Monitoring Centre

universidade de aveiro

NICE National Institute for Health and Care Excellence

Tartu Ülikool 1632 Universitas Tartuensis

University of Oxford

*SME & Mid-sized companies*

SYNAPSE Research Management Partners

The Hyve

Odysseus Data Services Inc

*Non-profit organisations*

EPF European Patients Forum

ICHOM

*EFPIA & Associated partners*

***EFPIA Lead***

Janssen Pharmaceutical Companies of Johnson & Johnson

Bayer

Celgene

Pfizer

Lilly

abbvie

Boehringer Ingelheim

AstraZeneca

Sanofi

UCB

Novartis

Servier

Erasmus MC

# EHDEN IS ABOUT …

## FEDERATION

Creation of an EU-wide architecture for federated analyses of real world data

## HARMONISATION

Harmonise more than 100 million anonymised health records to the OMOP common data model

## COMMUNITY

Establish a self-sustaining open science collaboration in Europe, supporting academia, industry, regulators, payers, government, NGOs and others

## OUTCOMES

Enabling outcomes driven healthcare at a European level

## EDUCATION

The establishment of an EHDEN Academy, webinars and face-to-face training sessions to train all stakeholders

# A SUSTAINABLE ECOSYSTEM: CALL PROCESS OVERVIEW

**Harmonisation fund**

| Data sources | Open calls | Grant awarding |
|---|---|---|
| | Tailored for project objectives and sustainability | Evaluated via a pre-defined set of criteria by the Data source prioritisation committee |
| **Supporting SMEs** | **Open calls** | **Training & Certification** |
| | Focusing on SMEs able to support mapping and sustainability | SME certification committee prioritizes SMEs for training and certification |

Data sources can choose the SME from the pool of EHDEN certified SMEs

SMEs are paid via grants from the harmonisation fund

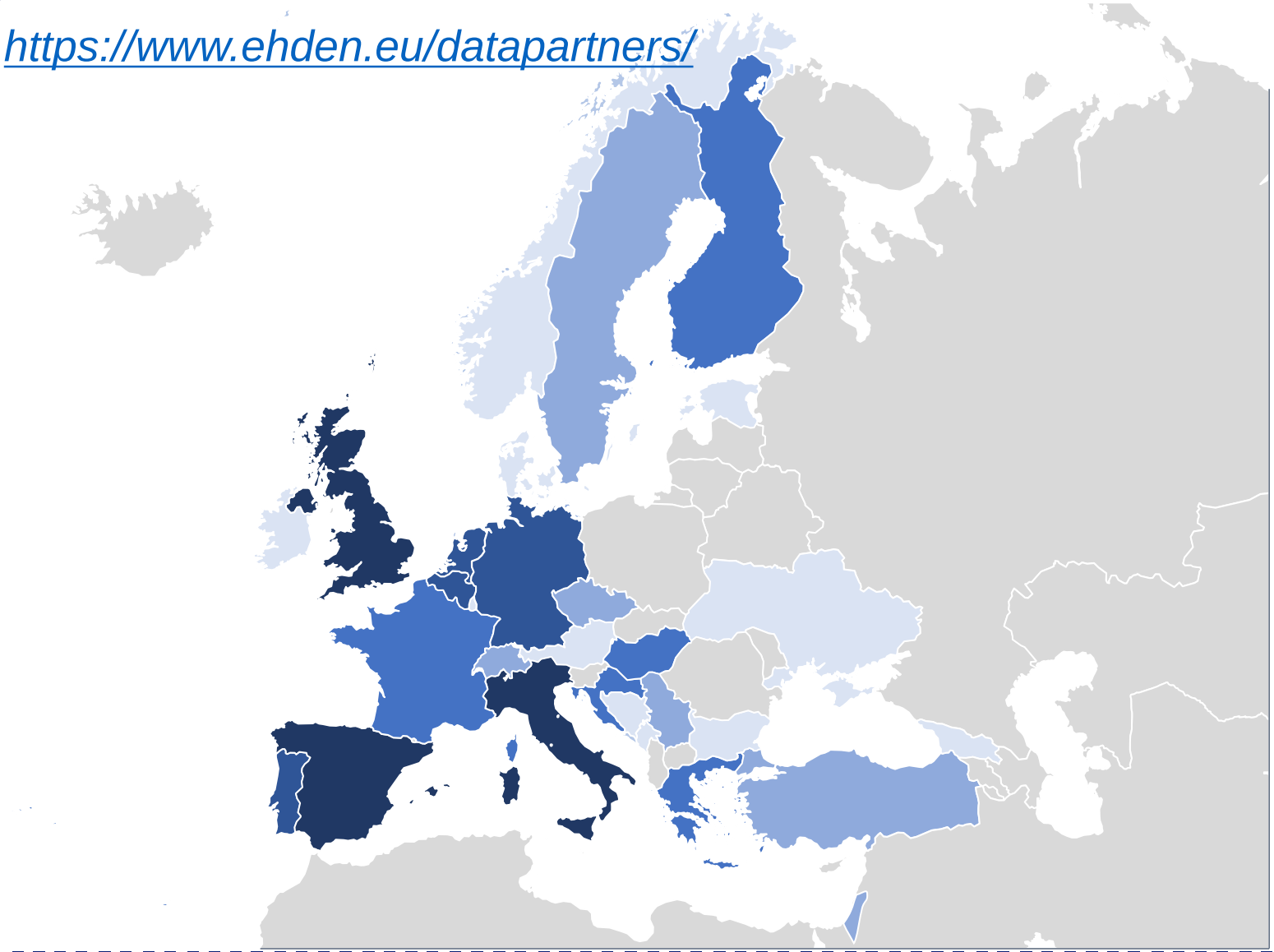
Payments are milestone based

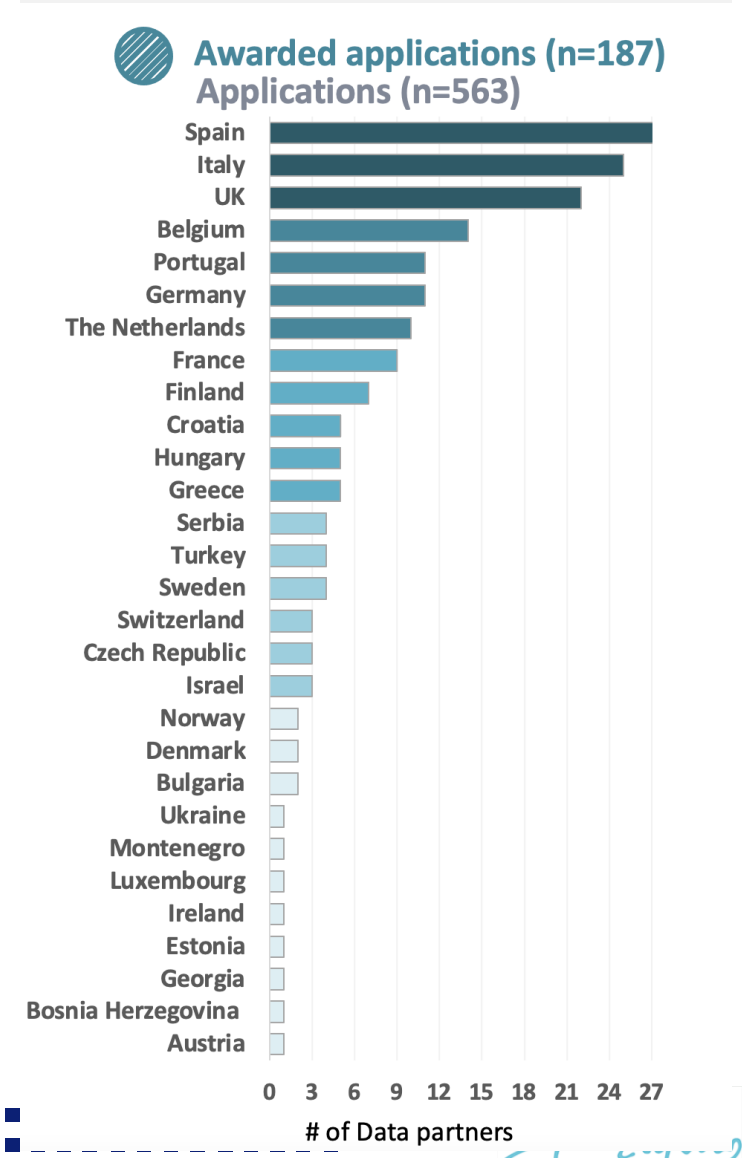
Mapped data sources are encouraged to be active members of the **EHDEN community**, participating in **research studies.**


66

# CURRENT EHDEN DATA PARTNERS

https://www.ehden.eu/datapartners/



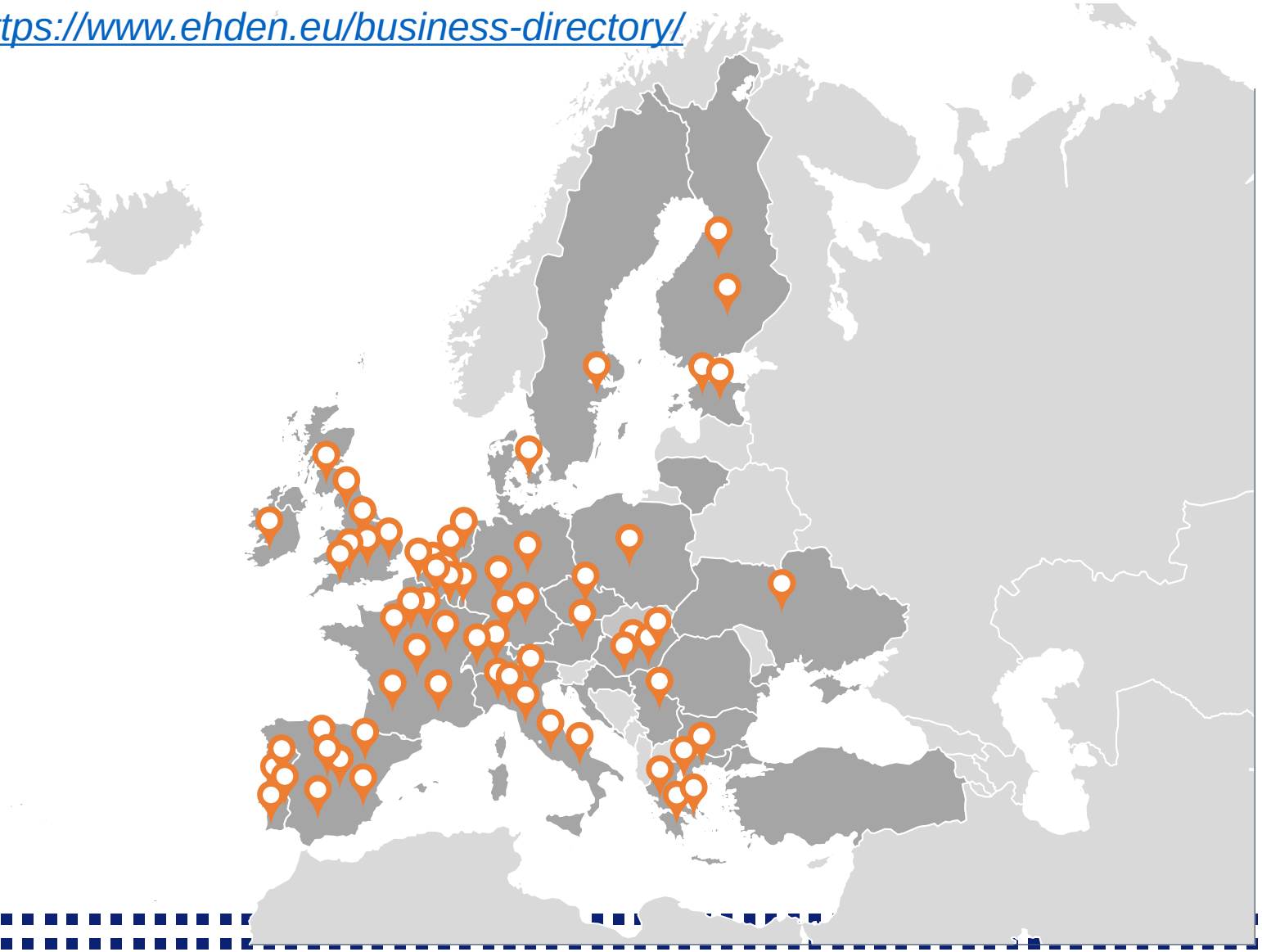


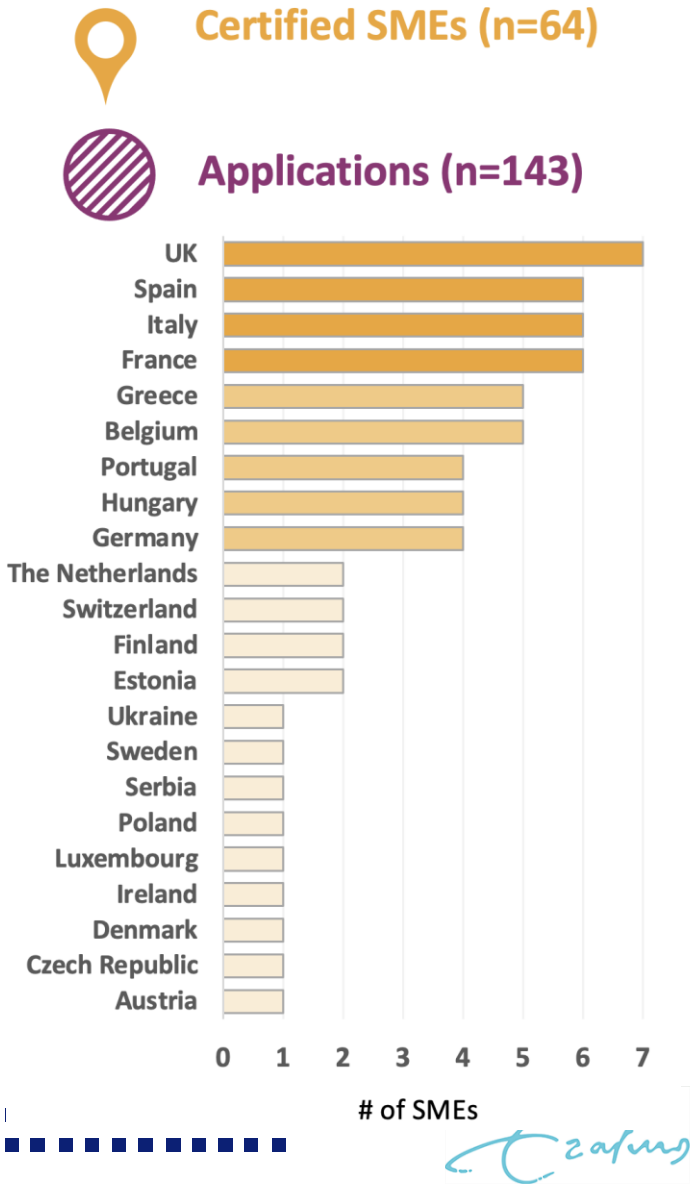

*Geographic spread of data partners. The shade of blue indicates the # of data partners in that country (darker = more)*

OHDSI

# CERTIFIED SMALL TO MEDIUM-SIZED ENTERPRISES

https://www.ehden.eu/business-directory/





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# EVIDENCE GENERATION

In addition to the originally planned studies, the study planning and execution (evidence generation) work has increased this year after the approval of the new task (T1.8). An Evidence Generation Task Force was created to evaluate internal proposals for new studies.

**29 requests** were received and a methodology created to prioritise the **4 studies for execution**. WP1 is co-leading or supporting the planning and execution of these 4 additional studies with the use of the Evidence Generation Fund

### Characterisation of Heavy Menstrual Bleeding

This is a study led by Bayer, WP1 co-lead, aiming to describe the presentation of heavy menstrual bleeding. Bayer has led the design of the study and the selection of suitable Data Partners within the EHDEN network. UOXF is helping with the liaison with the selected data partners, and with the planning of analyses and dissemination activities.

1

### Expansion of the CDM with a pregnancy extension table

Led by one of the EHDEN Data Partners (SIDIAP), this study has resulted in the creation of an extension table to enable future studies on pregnancy and neonatal epidemiology. Currently, SIDIAP, UOXF and an additional EHDEN DP (University of Oslo) are testing the resulting table in some of the existing datasets. This study should be completed during the first half of 2023.

2

### Extrapolation of survival data for Health Technology Assessments

Led by NICE and UOXF and in close collaboration with WP2, tools have been developed for the extrapolation of survival data for several cancers. More detail is provided as part of WP2 activities.

3

### Long COVID

Led by UOXF, this study is describing the different presentations of persistent COVID amongst patients diagnosed in the community and in hospital settings. Phenotypes have been developed for all 25 key symptoms identified in the WHO definition of long COVID, and for key sequelae/complications including thromboembolic events. The study is currently being conducted at three EHDEN Data Partners, and will be rolled out by invitation to many others during Q1 and will conclude in the form of a Study-A-Thon in Q2 2023.

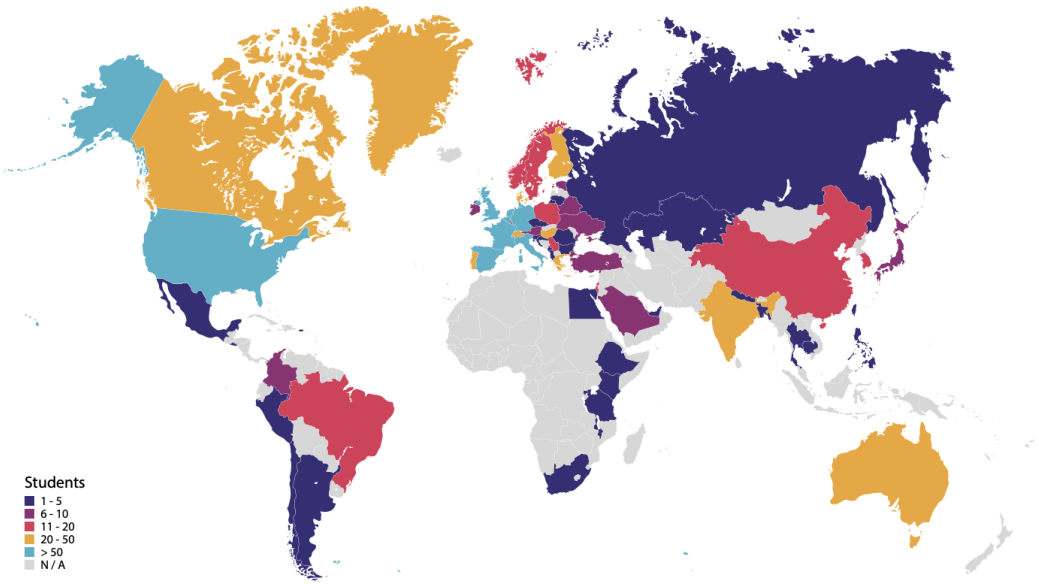
4

# EHDEN ACADEMY

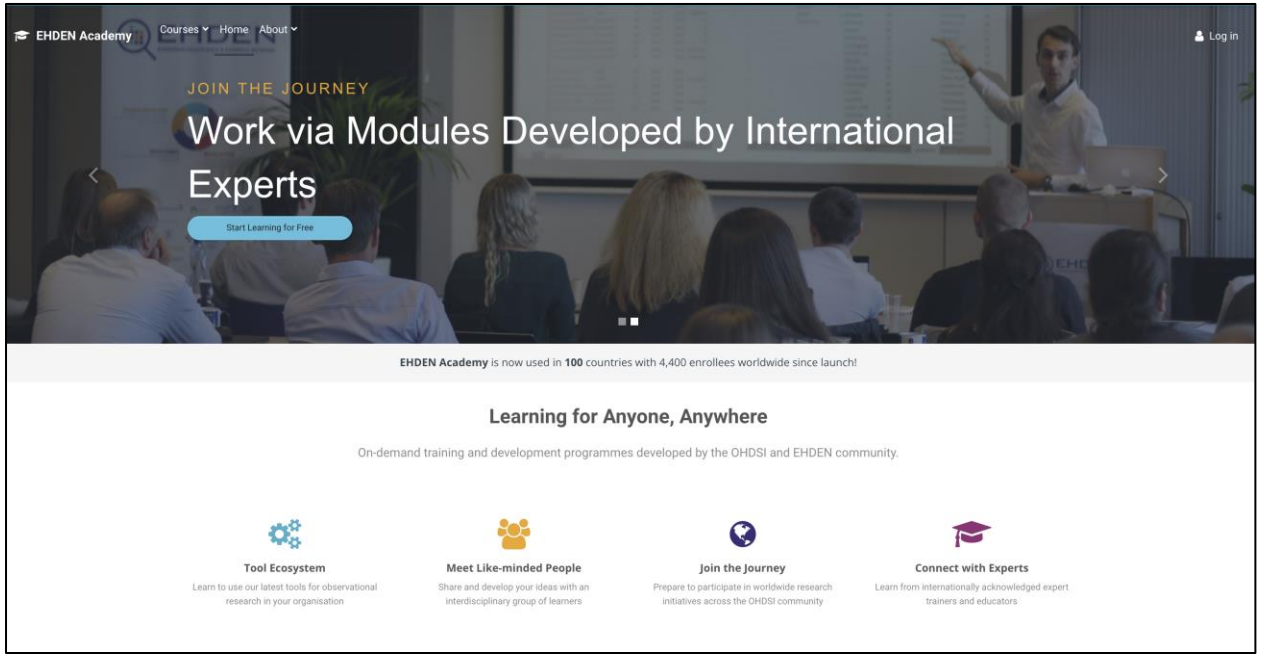
The **EHDEN Academy** has grown to be a significant educational and collaborative resource for EHDEN, OHDSI and the global community with regard to training and upskilling.

At the end of the fourth year, **over 3,500 users** from **70 countries** have started their learning journey in the Academy.

With **17 courses** currently available, the Academy continues to update its curriculum and number of expert trainers, with specific focus on more HTA and regulatory science trainings planned for launch in year five.




academy.ehden.eu



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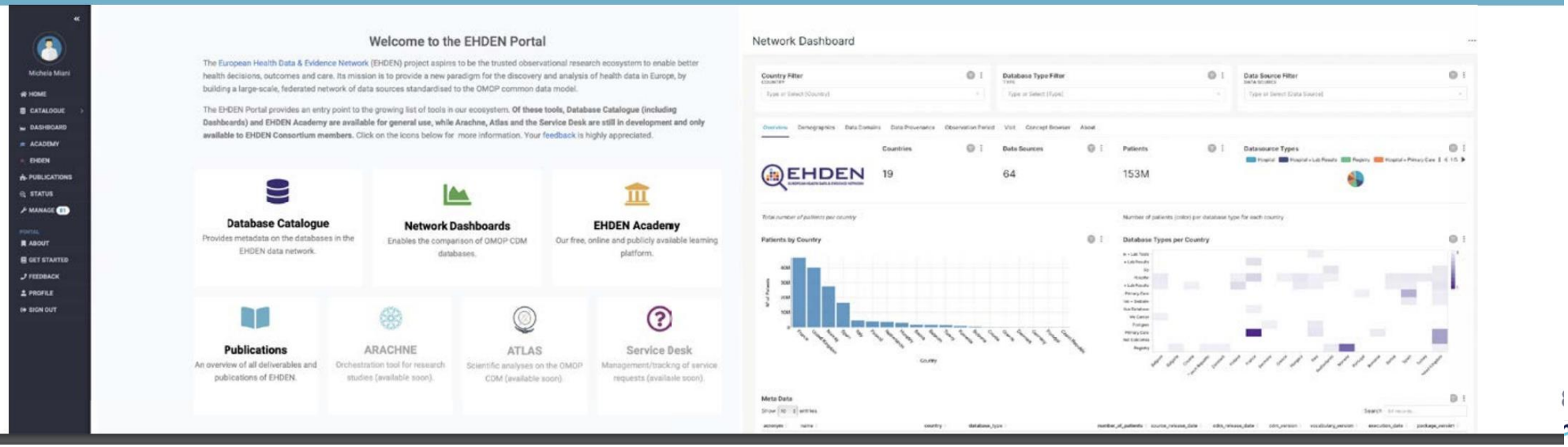
# EHDEN PORTAL

## EHDEN PORTAL

The EHDEN technical framework comprises the entire set of technical constructs, i.e. applications and their interoperability, including security setup within the context of the IMI EHDEN Project.

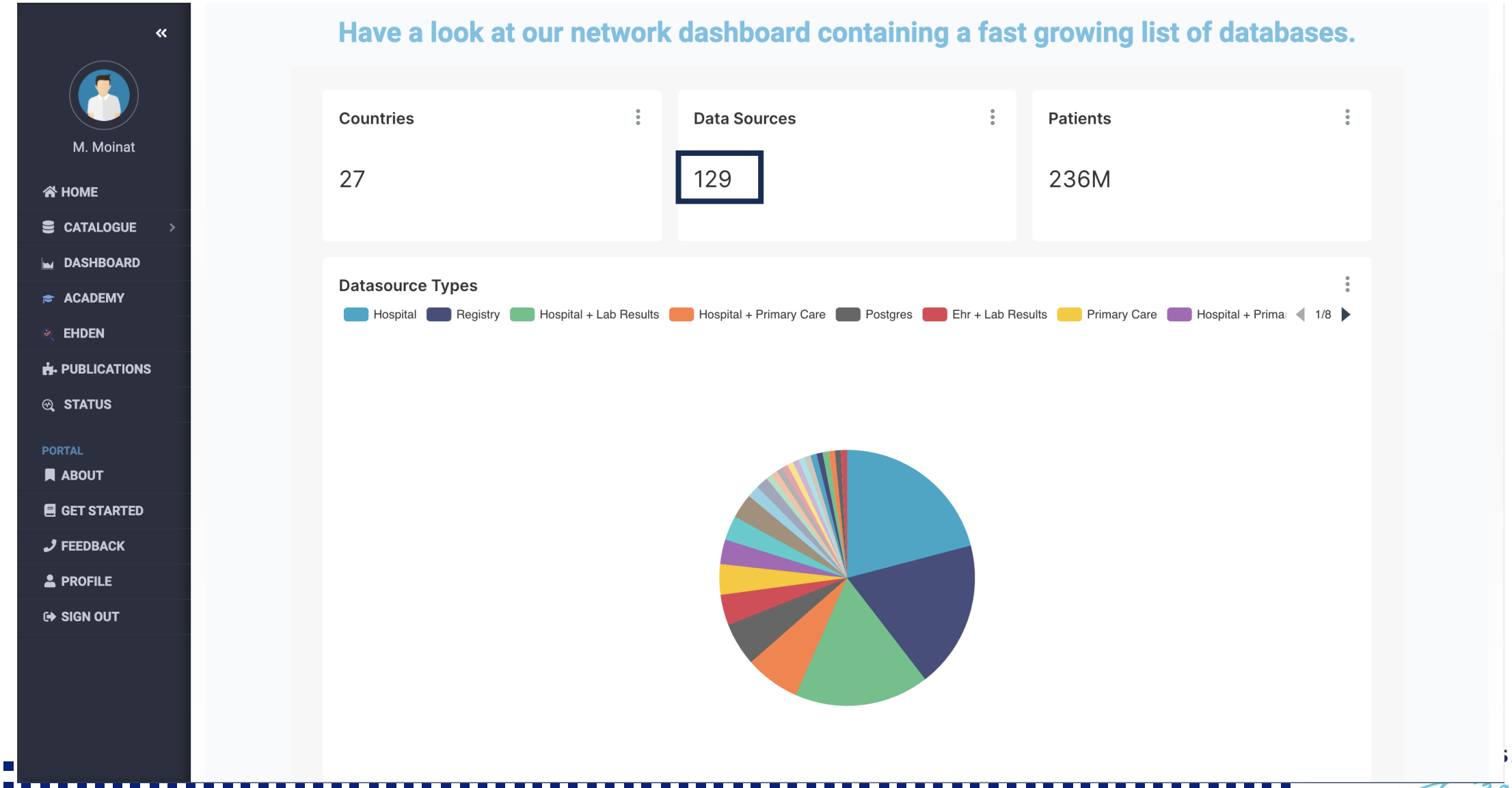
The **EHDEN Portal** has been publicly released on June 24th 2022, making it available to the wider community. Currently, it provides metadata of 80 healthcare databases in the database catalogue and data exports based on full conversion into the OMOP CDM from **64** Data Partners that are available in the network dashboard.

Since its launch, more than **500 active users** have been registered and more than **9,000 new users** have visited the Portal.




EHDEN Year 4 report: https://www.ehden.eu/wp-content/uploads/2023/05/Year-4-partner-report_final.pdf

# EHDEN Portal – Catalogue of Metadata




https://portal.ehden.eu/

# AND WE ARE NOT DONE YET!

## HARMONIS

Harmonise more than
anonymised health records to
common

Enabling outcomes d

ehden.eu

ABOUT | EHDEN Foundation | WORK PACKAGES | NETWORK | EVIDENCE GENERATION | COMMUNICATION/EDUCATION | NEWS | CONTACT

### EHDEN Foundation

EUROPEAN HEALTH DATA & EVIDENCE NETWORK
EHDEN Foundation

**EHDEN Data Partners & SMEs share their aspirations for the EHDEN Foundation**

EHDEN's five-year IMI 2 phase will end in 2024. We are proud of the progress of the project to date, achieving beyond our original aims in the build of the Data Partner network, infrastructure development, evidence generation, and education by our midpoint. EHDEN has created a growing network currently consisting 187 Data Partners in 29 countries across the European region, with greater than 850 million anonymous health records being harmonised to the OMOP common data model. In parallel, 64 small-to-medium-sized enterprises (SMEs) have been trained across 22 countries, certified and are working with Data Partners on a consistent data harmonisation process of their source data.

Our evidence-generation work is accelerating and we have contributed to over 70 publications to date, with increasing scientific exposure through international meetings and via OHDSI. The EHDEN Academy has supported over 4,000 participants with its now 19 courses since its launch, and we continue to expand our educational activities, also via the OHDSI Education Working Group.

For the remainder of the project, we want to leverage these achievements and focus even more on evidence generation. Our vision remains the same: *a Europe where harmonised real-world data is used by the healthcare community to more rapidly generate high quality insights that improve outcomes for patients, revolutionising how treatment and care are implemented and evaluated.*

Building on EHDEN's successes, a new legal entity, the EHDEN Foundation, was created in The Netherlands. It will serve to transition the project into a long-term, sustainable operation in 2024 — and will facilitate the developing ecosystem, operationalising the research operating model post project, working in parallel on the transition and cross-fade between the project and the EHDEN Foundation.

As a sustainable entity, the EHDEN Foundation will continue to promote and foster a strong and growing open science community with Data Partners, SMEs, researchers, public & private, and NGOs. It will also continue to provide research, training certification, and service research in the EHDEN network and wider research community, supporting studies, study-a-thons, methodological and technical developments, and research programmes.

Watch this space for further updates as we develop the EHDEN Foundation and ensure a smooth sustainability path beyond the original EHDEN project — and we look forward to collaborating with many of you in doing so!

Erasmus MC
Universitair Medisch Centrum Rotterdam

# Programme / Ohjelma

13.00 **Welcome and opening words**
**Kristo Lehtonen**, Director, Fair Data Economy, Sitra

Moderator: Saara Malkamäki, Specialist, Sitra

13.05 **OpenEHR-based software procurement in Stockholm and Gotland region**
**Erik Sundvall**, Information Architect, Karolinska University Hospital

13.25 **Questions and comments**

13.35 **European health data network: using the OMOP CDM for collaborative studies**
**Maxim Moinat**, Scientific Researcher, Erasmus MC

13.55 **Questions and comments**

14.05 **Break**

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**Maxim Moinat**, Scientific Researcher, Erasmus MC

13.55 **Questions and comments**

14.05 **Break** (we will start at 14.15)

SITRA

# PROGRAMME CONTINUED IN FINNISH

@sitrafund

# HYVÄÄ HUOMISTA, SUOMI!