



Unlocking the potential of data models in the health sector



100
100
100

We will start at 13.00 EET



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

11.3.2024

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**

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 organisaatioissa 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 maaraajojen 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

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A photograph of the Karolinska University Hospital building at dusk. The building is a modern, multi-story structure with a glass facade and several balconies. The sky is a deep blue, and the building's lights are on, creating a warm glow. The text is overlaid on the image.

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 systems!

How can we push the market/ecosystem in sustainable direction?

Scalability and Semantic Sustainability in Electronic Health Record Systems

Erik Sundvall



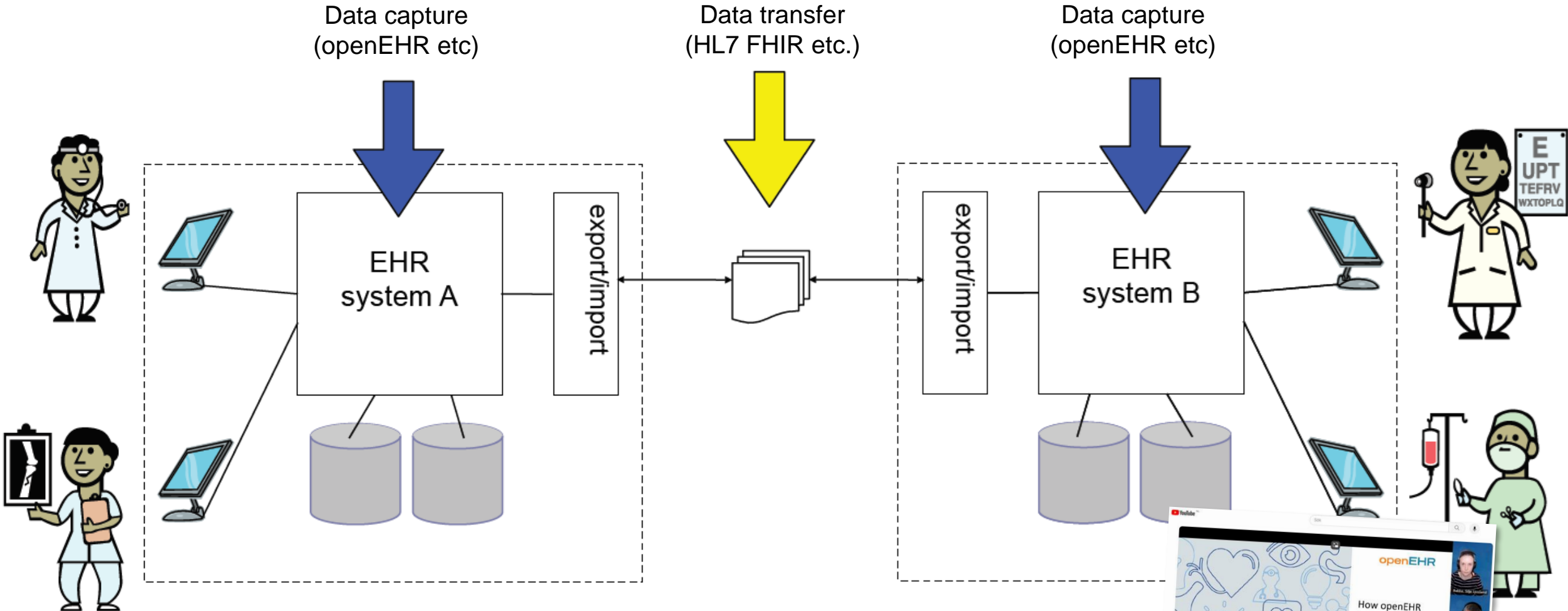
Different...

INTEGRATION STRATEGIES

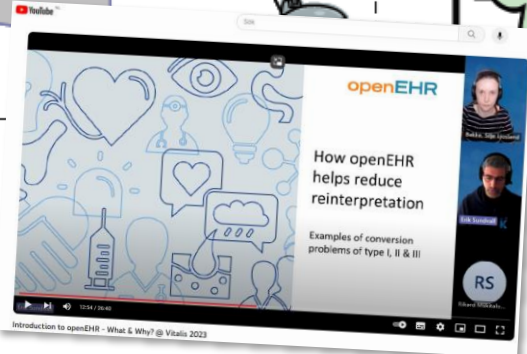
...enable different procurement strategies

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

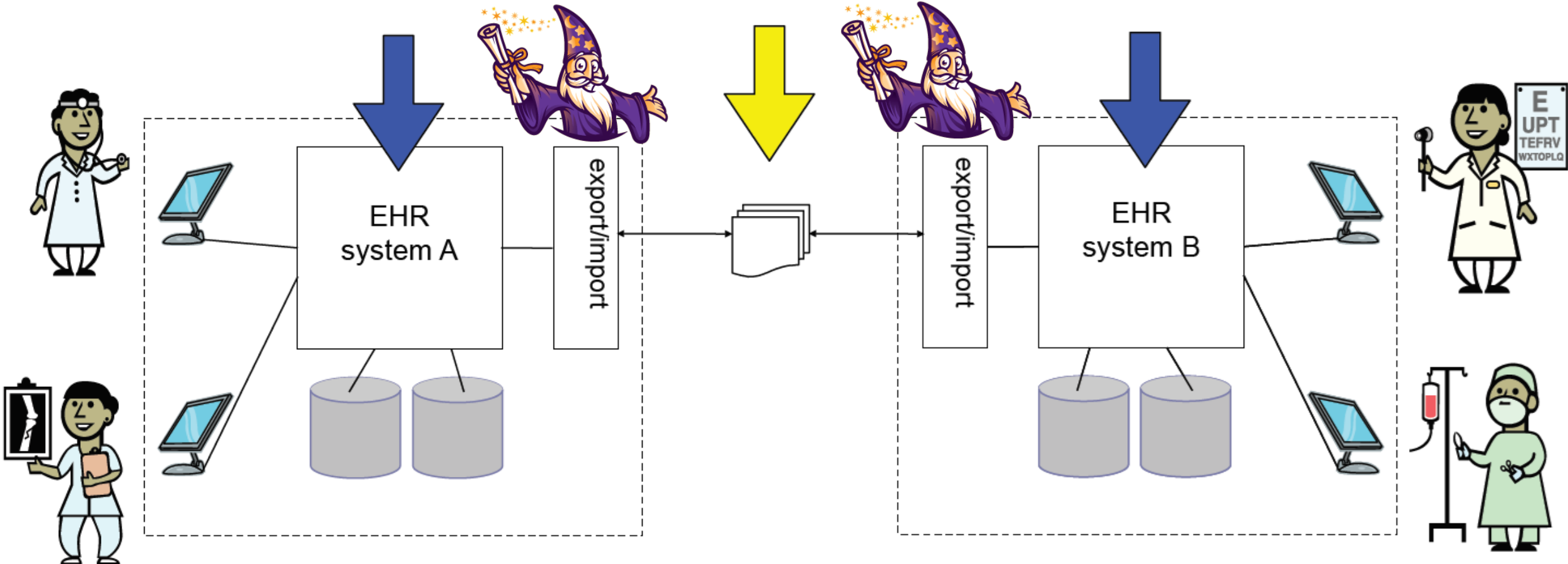
Agree where?



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



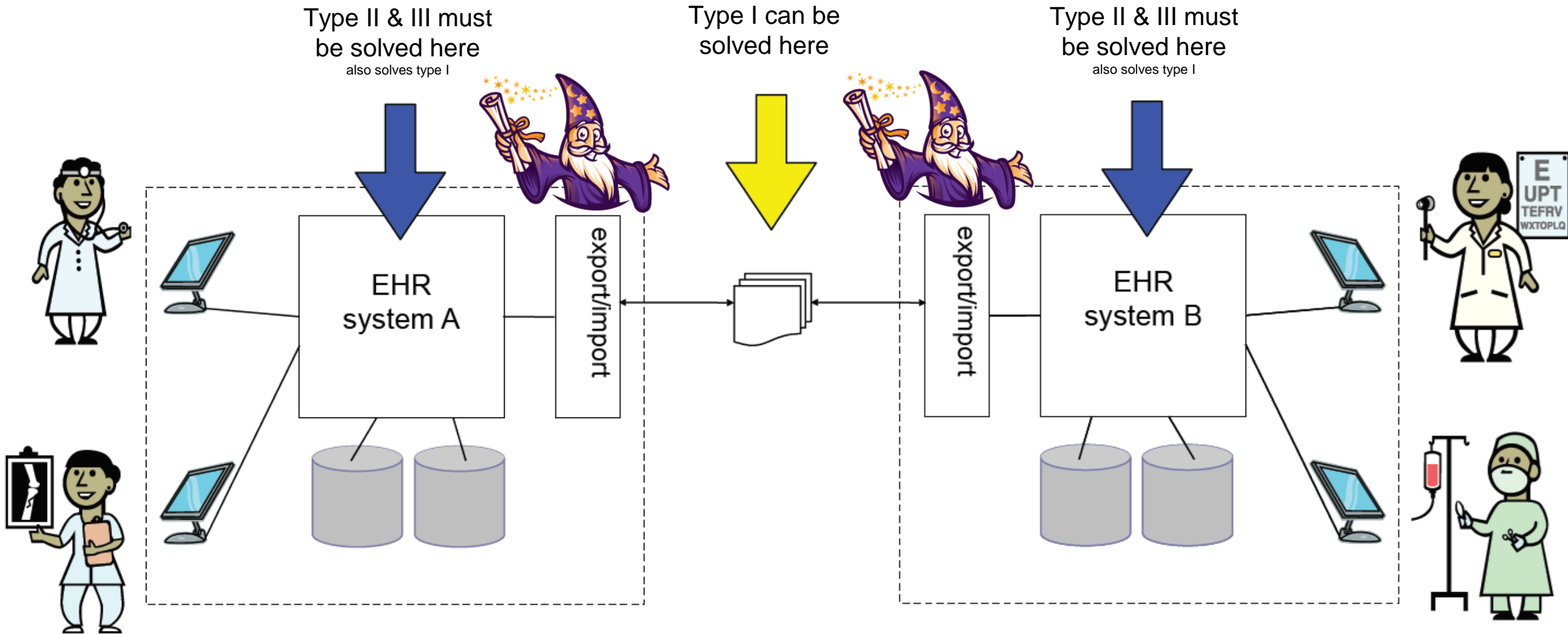
What can conversion/reinterpretation solve?



Reinterpretation problems, Type I, II & III

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

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

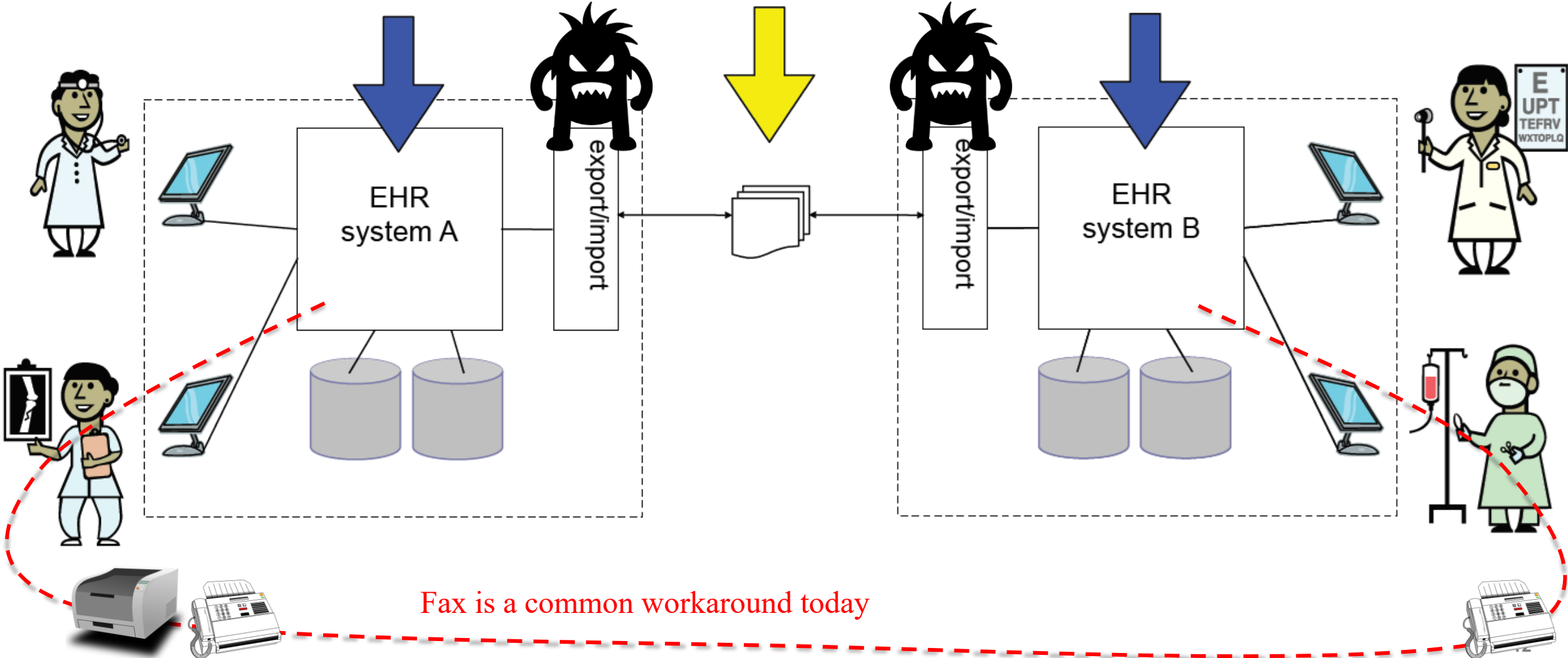


Agree on what, where?

Type II & III must be solved here
also solves type I

Type I can be solved here

Type II & III must be solved here
also solves type I

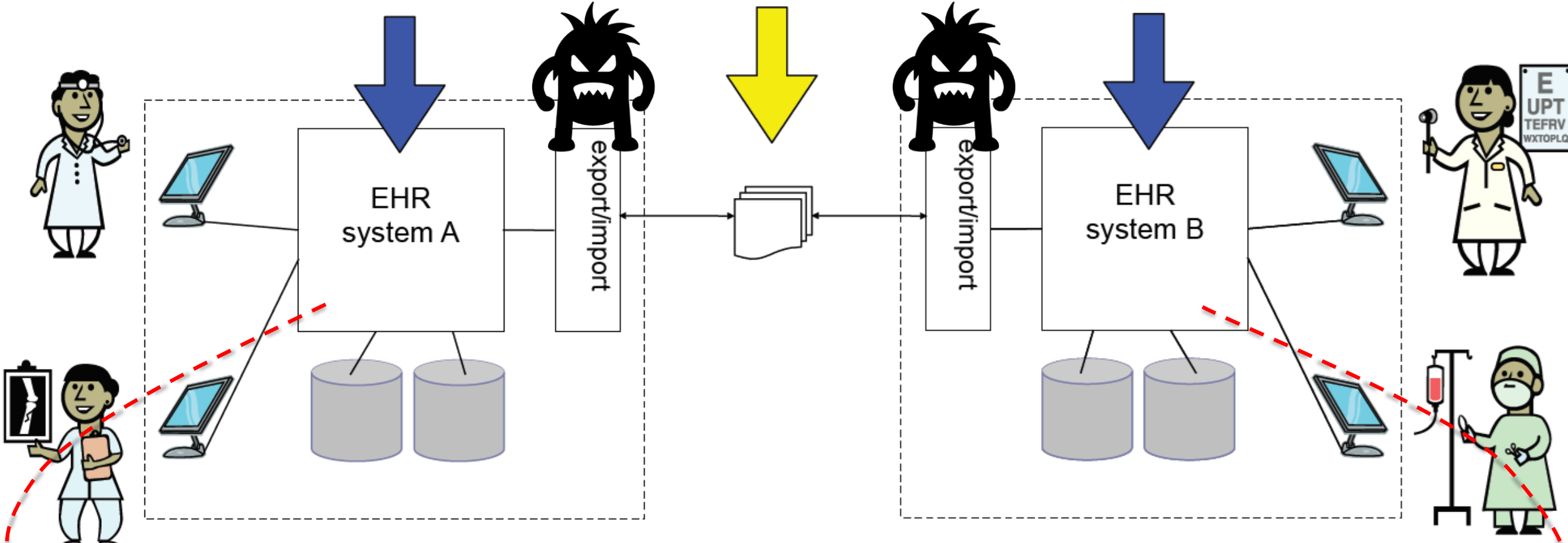


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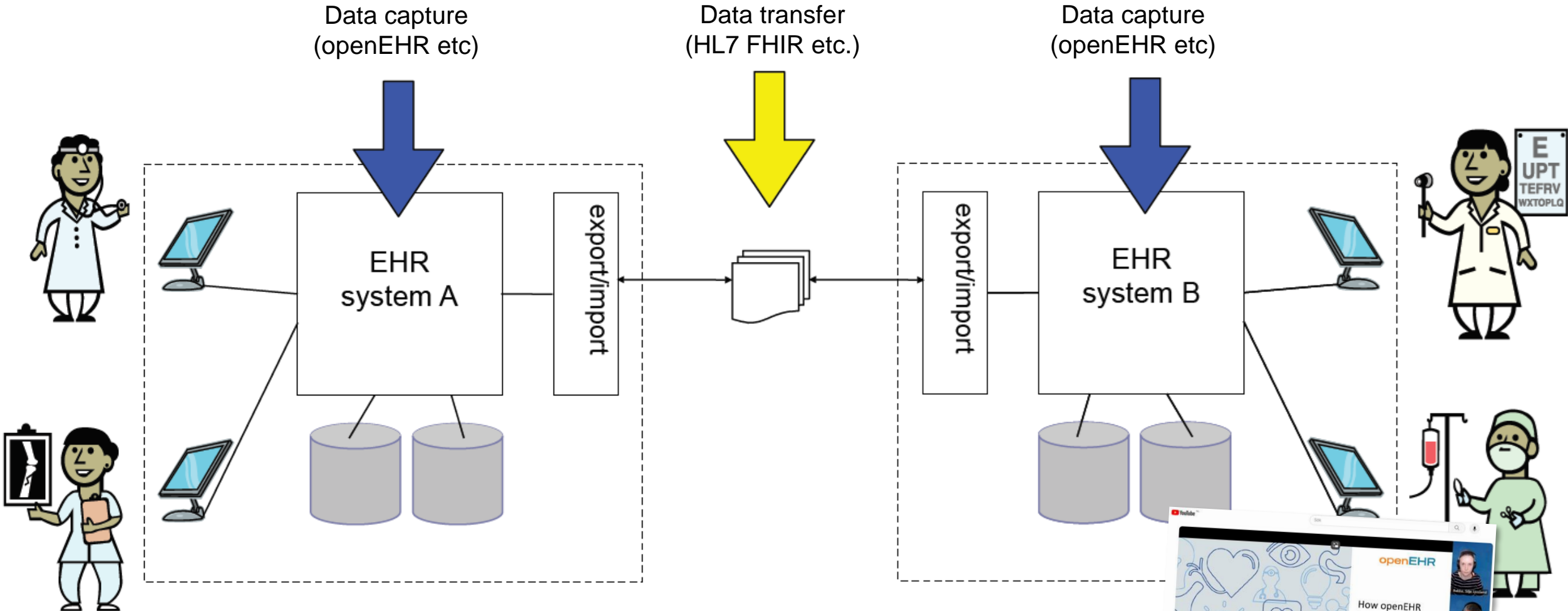


Many reinterpretation problems remain even if fax is replaced by PDF sharing...

...but may become less visible



Agree where?



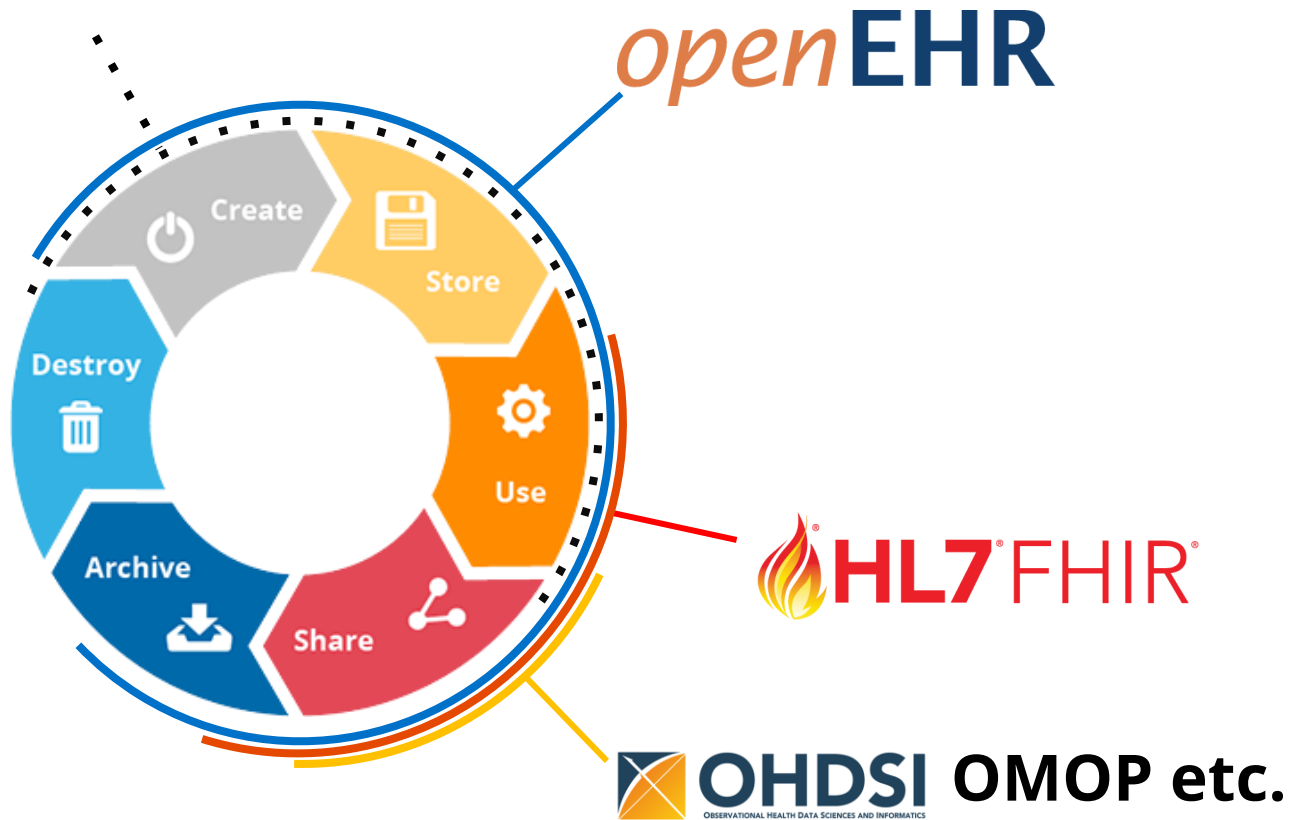
See presentation **Introduction to openEHR, part 1: What & Why** by Silje & Erik at Vitalis/MIE2023 https://youtu.be/KgXVslsr_Ts?feature=shared&t=774



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



*“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

Different...

INTEGRATION STRATEGIES

...enable different procurement strategies

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

1. Core system strategy

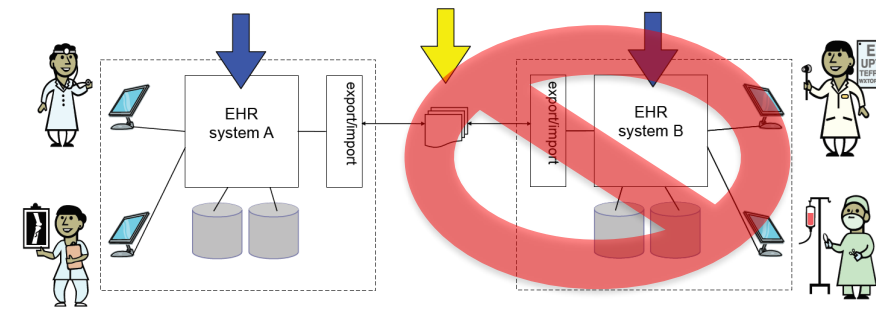
Buy the **same system, install the same way** at all organizations that will share or exchange information. Pretend “there is no system B”

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 Millennium as a core system.



2. Mapping/conversion based strategy

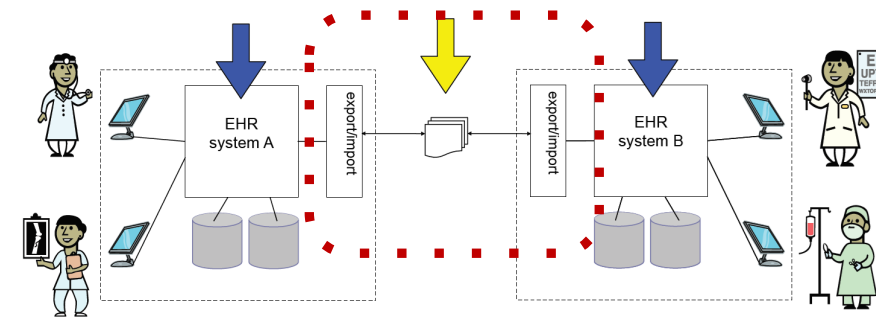
Translate, where possible (only works for "type 1" differences), from system specific semantics and structures to a standardized exchange format (message format, API, etc.).

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:

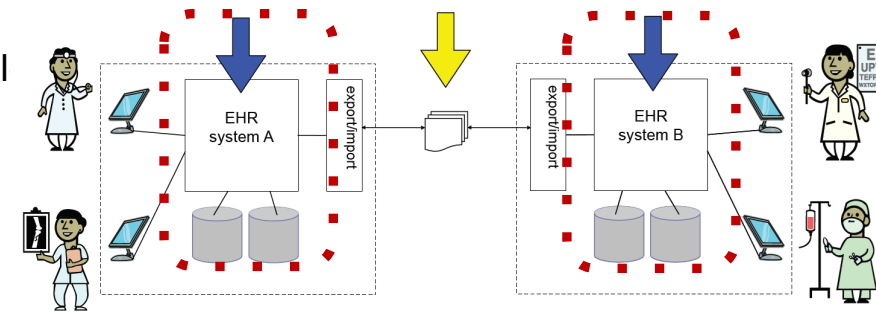
- facilitates vendor independence
- limits selection to products that can internally use the open standardized models, or that can be configured flexibly enough to broadly match the standardized

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)

1. Core system strategy

Buy the **same system, install the same way** at all organizations that will share or exchange information. 1. Prudent: "There is no system B!"

Consequence: Causes supplier 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! 

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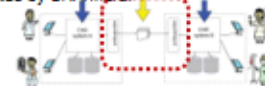
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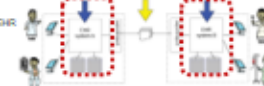
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- limits selection to products or that can be configured

Used today in the Nordic region: open standardized models, match the standardized several EHR systems (but is rarely a requirement in procurements) is underway at several suppliers, including open-source

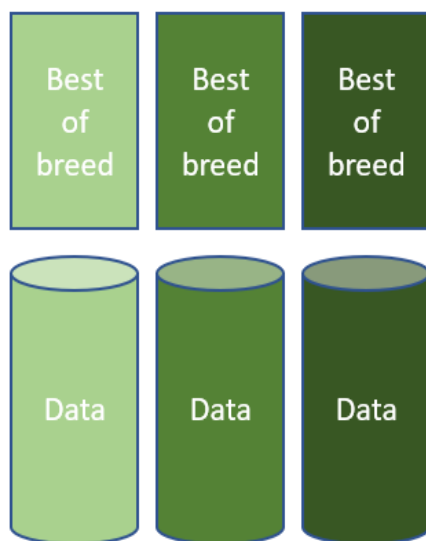
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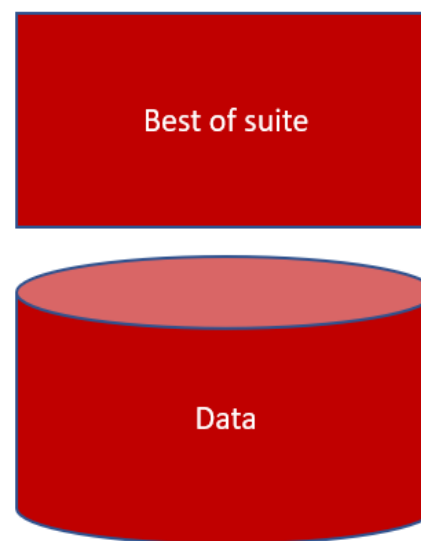


Best of Breed (Closed Ecosystems)



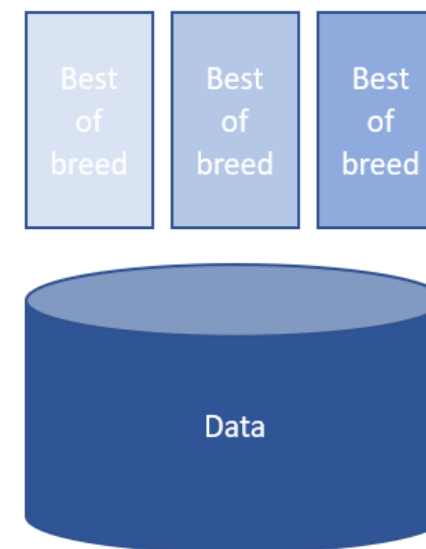
No agreed
persistence
information models

Best of Suite



Persistence models
designed for single
vendor

Best of Breed 2.0 (Open Ecosystems)



Agreed persistence
information models
(single or
distributed storage)

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.)

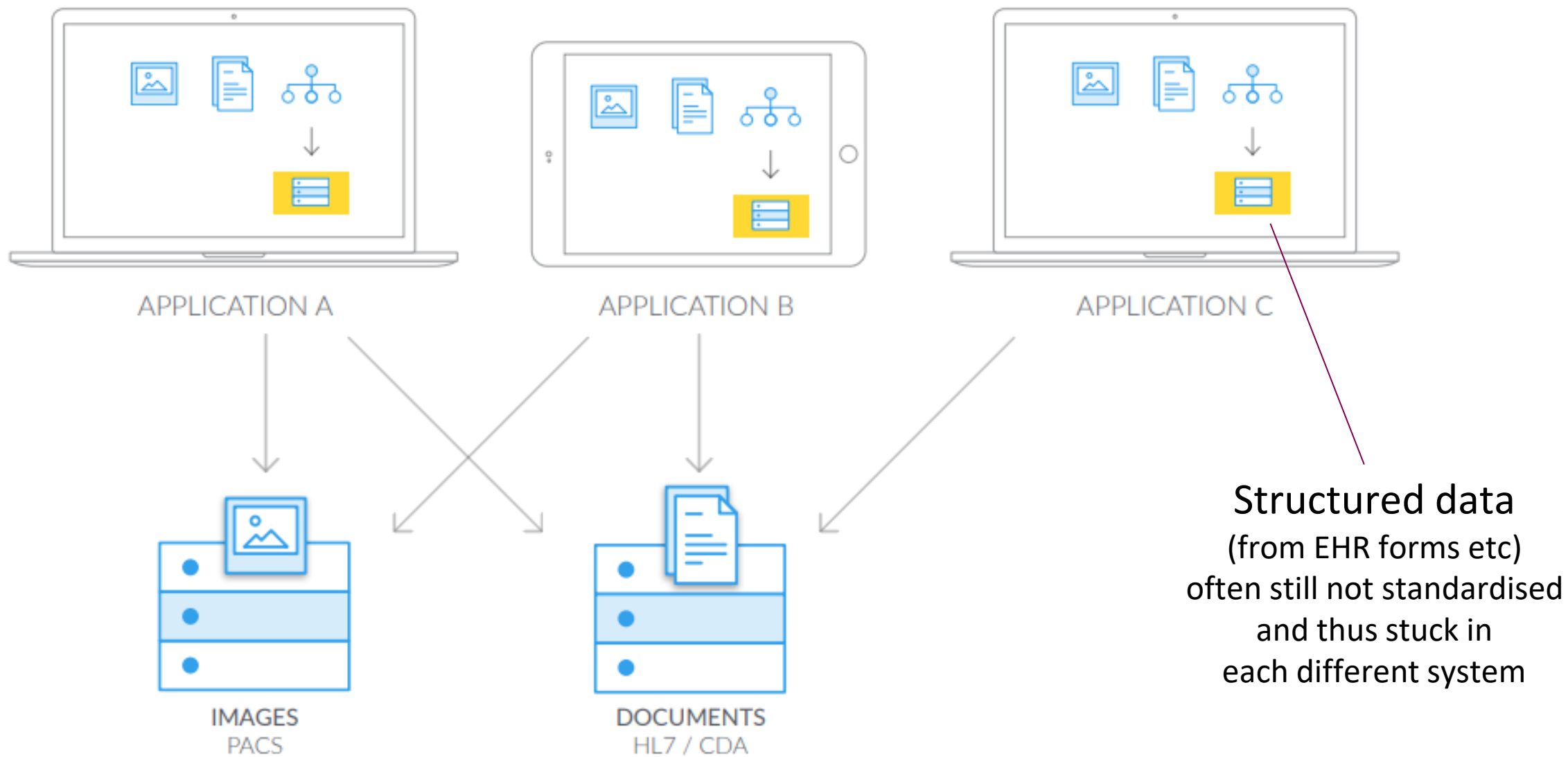
Structured data

(from EHR forms etc)

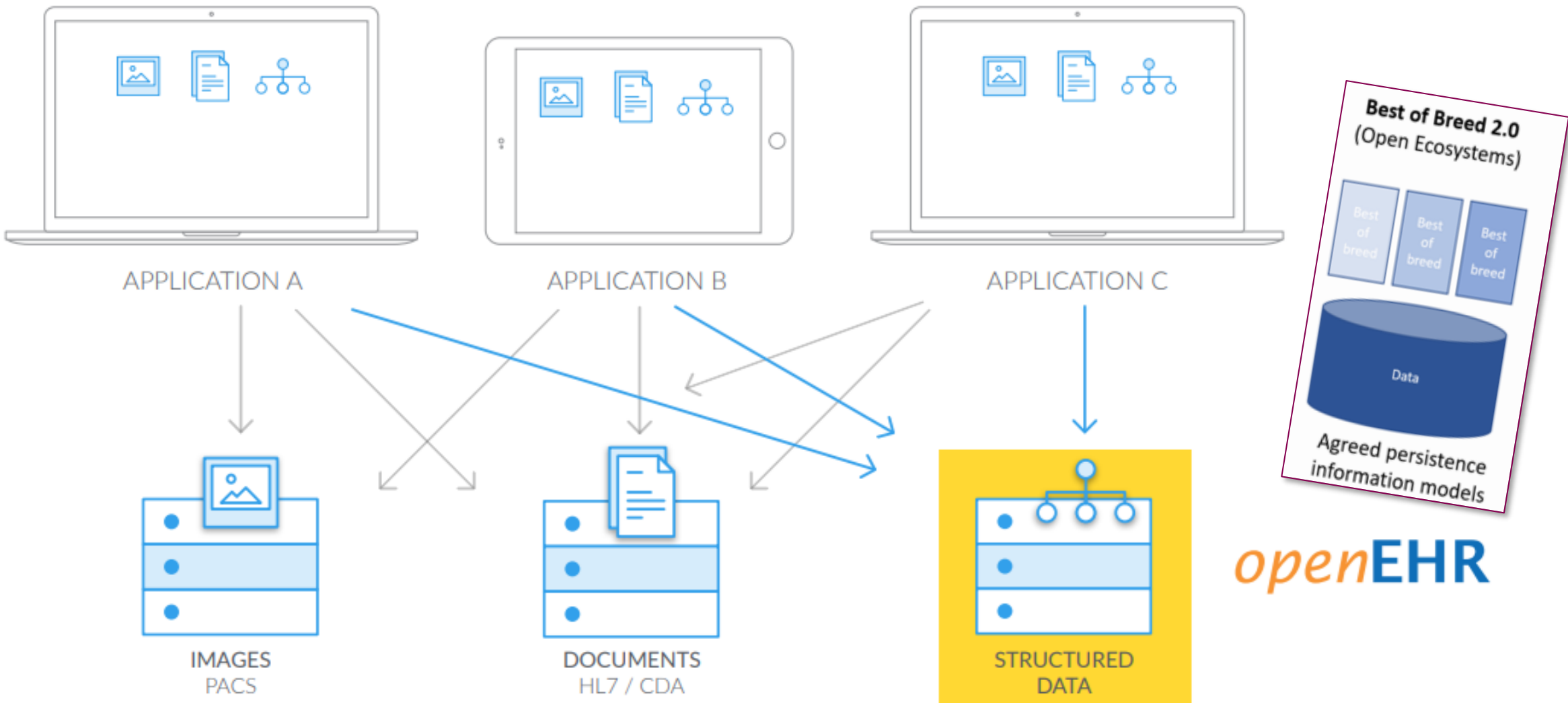
Documents

(Scanned, fax, PDF etc)

Then we shared image and document storage...



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.



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 requirements to fit it?
[High corruption risk!]

More sustainable:

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

Dilemmas - risks to handle/mitigate:

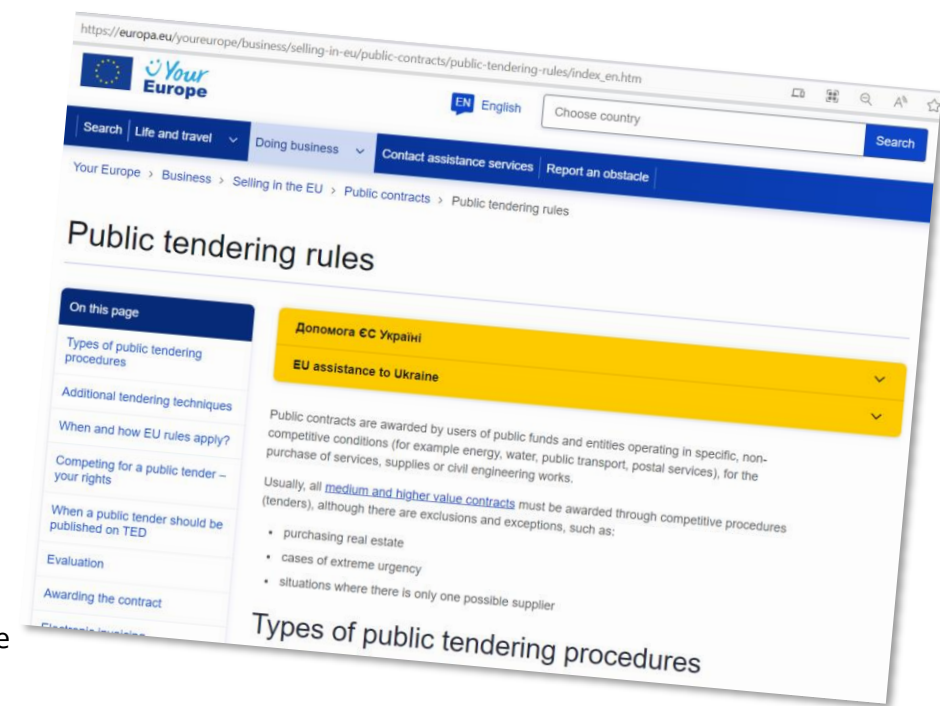
- Encourage new suppliers

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**



Legal variants of EU procurement

- **Open procedure**

Anyone may submit a full tender. This procedure is **used most frequently**.

Region Östergötland
2020 referral

- **Restricted procedure**

anyone may ask to participate ... but only those who are pre-selected may submit tenders.

K/Region Stockholm openEHR
platform procurement 2023-2024

- **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)

Region Stockholm
"traditional" EHR

- **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.

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Good for national
cooperation?

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

openEHR Discussion Forums Swedish openEHR procurements & RFIs

Community Procurements

Categories

- New to openEHR?
- openEHR news
- Community
- Tool Support
- Implementation
- Specifications

erik.sundvall SEC member

Region Östergötland (RÖ) hereby invites suppliers of openEHR platforms and openEHR tools to conduct an online pre-procurement presentation and demo. Timeslots available February 10-19. Apply for a time slot at the latest February 2nd 2020. See attached PDF for details

[2020-Invitation-openEHR-pre-procurement-demo-Region-Östergötland.pdf](#) (1012.2 KB)

Please also note that the openEHR wiki page <https://openehr.atlassian.net/wiki/spaces/resources/pages/416514052/Procurement+of+openEHR-related+systems+and+services> has been updated today with both this document and with responses from suppliers to our previous 2018 RFI.

erik.sundvall SEC member

The films from the first hour of each pre-procurement session are finally online!

Playlist <https://www.youtube.com/playlist?list=PLHwI0RtmG26Uit0qtzmOLITbu10svShMK>

Individual videos:

- DIPS, 10 Feb 2020: <https://youtu.be/WINmviCm7pU>
- Ripple Foundation, 10 Feb 2020: <https://youtu.be/CF1qRZ99dg>
- TietoEVERY & Better, 14 Feb 2020: https://youtu.be/ICS4pQC_Etk
- Solt Clouds, 14 Feb 2020: <https://youtu.be/MJneYDymJ4o>
- CaboLabs, 17 Feb 2020: <https://youtu.be/VceUaMgBLAM>

We learnt new interesting things from all of the different suppliers. Some surprises too regarding nice features and even a fire alarm during a demo...

erik.sundvall SEC member

Today the above mentioned referral request was published with the title "External referral of EHR platform and tools, based on openEHR" at Merrell TendSign

If you are system provider, please get the document and respond with comments via the tendsign-link above before Aug 16! That is the only official way to influence the content of the upcoming procurement that will follow shortly after the referral closes. By registering for free, logging in there and subscribing to the referral you'll also be updated referral.

Note that the future procurement will likely be split in differer to different system suppliers:

- Area 1 = EHR Platform and platform administration tool
- Area 2 = Development and content maintenance tools, 'execution Tools'

If you're **not** a system provider, but rather just curious and do the referral document that may be an old version by the time External referral EHR platform and tools, based on openEHR -

A snapshot of the response form with some example respons

If you are not a system provider intending to respond official comment directly here in this openEHR forum discussion thr

erik.sundvall SEC member

The above mentioned new/second (and likely last) "referral version" is now online at Merrell TendSign

Creation of a (free) account is needed to log in. The referral period ends on 2021-01-26 (January 26)

Document copies below (for those that do not want to use/create a login and respond to the referral) are a snapshot in time and may get corrected/changed in the official (TendSign) procurement platform.

- Covering letter - external referral 2.pdf (173.2 KB)
- Main requirements: EHR platform and tools based on openEHR - referral round 2.pdf (1.2 MB)
- Pricetable referral round 2.xlsx (14.1 KB)
- Comment form referral round 2.xlsx (30.1 KB)

Worth noting from the invitation letter:

- Please note the change of procurement areas from three separate (in the previous referral round) to one unified, as described in section 3.2.1. of the requirements document.

Consortia and collaboration between suppliers that may not individually have a full covering platform+tool suite is thus encouraged/requested by this change! We know there are openEHR tools and platforms that could be used together and hope that Region Östergötland will also get such combined proposals/bids in this procurement.

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

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)** 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](https://ted.europa.eu/udl?uri=TED:2023/S/077-231835) 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 the RFI, use the procurement system where the RFI is published. Answers will be publicly available.

Åsa Skagerhult, on behalf of Region Östergötland & collaborators

RFI invitation

- The invitation to the RFI: [RFI openEHR 2023-04-14.pdf](#) (308.4 KB)
- Appendix to the invitation: [Appendix A OpenEHR – an Implementors Guideline related to Swedish laws and regulations in healthcare.pdf](#) (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 than “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](#) (538.8 KB)
- Final report in English: [Final report RFI openEHR 2023 public version 2.0.pdf](#) (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=PLhWl0RtMg26VsdOWYUhEAdVibBfgAQJCK>
- 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>

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.

- Categories
 - New to openEHR?
 - openEHR news
 - Community
 - Tool Support
 - Implementation
 - Specifications
 - Site Feedback
- All categories
- Tags
- Messages
- Inbox
- moderators
- Channels
 - SEC
 - Staff
- Personal chat
 - Bostjan_Lah
 - sebastian.iancu
 - pablo
 - jostholslag
 - johnmeredith
 - siljelb
 - Asa_Skagerhult, jgbellik, lul...
 - varntzen
 - thomas.beale
 - mikael

Karolinska/Stockholm procurement of Digital health platform (CDR, tools, services, consultants)

erik.sundvall SEC member 5 15 Sep

Following [The Swedish openEHR platforms and tools RFI 2023](#) by seven Swedish regions, **Karolinska University Hospital is coordinating a procurement for several organisations active in Region Stockholm and Region Gotland.** Listed organisations besides Karolinska are: Södersjukhuset AB (SOS), Södertälje sjukhus AB, Danderyd Sjukhus AB, Tiohundra AB, St Eriks Ögonsjukhus, Ambulanssjukvården i Storstockholm AB (AISAB), Hälso- och sjukvårdsförvaltningen (HSF), Stockholms läns sjukvårdsområde (SLSO), Region Gotland.

The official EU-tender call is available at [Services - 555615-2023 - TED Tenders Electronic Daily](#) that in turn links to the call at the procurement portal: [Merzell TendSign](#). Anybody interested in actually responding to the tender should register there (for free) to get notifications of changes and responses to questions. **The documents will very likely get updated several times and the copies attached to the Wikipage <https://openehr.atlassian.net/wiki/spaces/resources/pages/416514052/Procurement+of+openEHR-related+systems+and+services> may be out of date and erroneous by the time you read this.** Following this forum thread is no guarantee to get all updates, instead subscribe to updates in the portal.

Framework agreement period is 2+1+1 years.
 Estimated start of (framework) contract is 2024-02-01.
 Phase 1 (qualification) closes 2023-10-12 23:59
 Estimated total value 154 000 000 SEK (all areas added together, over the full length of framework agreements)

A simplified explanation of the process and scope follows (it is not necessarily a legally correct description, see the procurement portal for the real thing.

- There are three 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
 2. Software for openEHR content Creation and Transformation
 3. Consulting Services

Note that many actors/providers will likely be interested in responding to only to one or two of the three areas, and thus do not need to bother about the details of the other areas.

There are several phases (following each other in time)

Activity	Timing
1. Deadline for submitting a request to participate	Oktober 2023
2. Sending invitations to submit tender to selected tender-candidates.	November 2023
3. Evaluation of tenders	December 2023
4. Sending the Award Decision	January 2024
5. Framework start	February 2024

The first Phase published today, closes October 12. It's purpose is to qualify and reduce number of candidates allowed to make bids for framework agreements. If you pass this you get an invitation (activity #2 above) to submit a framework tender/bid.

When the framework has started (activity #5 above) and any of the organisations behind the agreement (for example Karolinska or Södersjukhuset) actually need to buy e.g. platforms, tools or services from any of the three "areas", every supplier that has won a framework agreement for that area gets a chance to bid for that specific item in a relatively simple and fast process. Also the requirements, for example for a consultancy assignment, tool or platform, will be specific for the task at hand which makes the process easier for everybody involved.

Managing lock-in effects - A telephone analogy

- 1. Telecom operator** (Vodafone, 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)

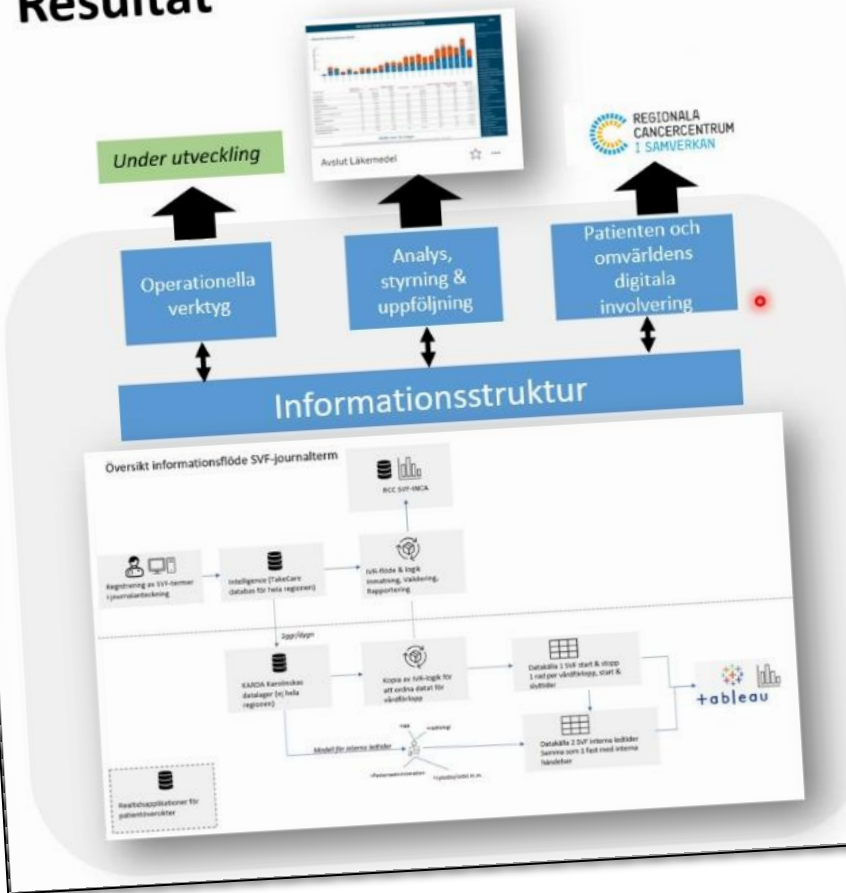
- 1. openEHR CDR** (used via standard APIs) ...and having control of your own template- and archetype usage
- 2. Form/Low-code tools, integration tools, portals** etc*
 - Very limited openEHR standardisation for this now, but SMART on openEHR (draft) and some simplified integration formats are available
- 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")

Arbetsmaterial

Resultat



Analys, styrning & uppföljning

- RIS
- Orbit
- TC
- Cyt
- Lab

Patientförlopp ID 2103818 Äggstockscancer2023-01-04
Klicka på ett individuellt SVF-förlopp i någon av ovan grafer för att se detaljerad information

Händelsenamn	Händelstyp
Start av första behandl. SVF-förlopp: Äggstockscancer	Start av första behandling, kirurgi
DT thorax	DT, remiss skickad
	DT, utförd
	DT, preliminär signatur
	DT, slutsignatur
Granskning med konferens avancerad	Rond/Konferens, remiss skickad
	Rond/Konferens, utförd
	Rond/Konferens, slutsignatur
DT buk	DT, remiss skickad
9 Distanskontakt, enskild X5008 Konferens om pati. Bilateral salivglandulärcykeli	Öppenvårdstillfälle
	MDK
0 Nybesök enskilt	Op-anmälan
1 Återbesök enskilt	Operation utförd
1 Återbesök enskilt	Nybesök
9 Distanskontakt, enskild C762 Malign tumör i buken	Öppenvårdstillfälle
	Öppenvårdstillfälle
	Slutenvårdstillfälle

Datadriven verksamhetsutveckling 2030

- Informationsstruktur**
 - Infrastrukturella knutar är upplösta**
 - Vi har beräkningskapacitet för hantering av större datamängder & algoritmer.
 - Datadelning mellan FoU och vård och mellan regioner sker smidigt, säkerheten kring data är klanderfri.
 - Nytt journalsystem**
 - Vi har ett smidigt och systemoberoende huvudjournalsystem som möter de behov som ställs längs hela cancerpatientens vårdförlopp för både prevention, utredning, behandling, rehabilitering och uppföljning.
 - Vi är en viktig aktör vid kravställning av övriga journalsystem för exempelvis läkemedelshandtering och patologi.
 - Ny arbetsmodell (och styrmodell?)**
 - Verksamhetsuppföljningsprojekt kommer ha en större fokus på hela processer så som patientresor/vårdprocesser/patientflöden snarare än produktionsstyrning.
 - Bashygien:**
 - Informationsbärande data är strukturerad.
 - Masterdatastruktur och informationsflöden för olika områden, exv. läkemedelsdata, är genomlysta och effektiviserade.
 - Bättre kravställare:**
 - Vi kan kontinuerligt kravställa utvecklingen av vårddataagrets innehåll utifrån cancerpatientens perspektiv.
 - Vi har och kan nyttja data för alla typer av behov inom analys, applikationsutveckling, AI-modeller samt för kravställning och utveckling av indatasegment.
 - Vi ser synergieffekter mellan IT-utvecklingsprojekt och arbetar med vidareutveckling snarare än innovationer.

Patientens digitala involvering

- Patientens digitala plattform**
 - Patienten har en plattform för att kunna delta i, påverka och engagera sig i sin vård. Den plattformen är nära integrerad i vår verksamhet och har oändliga möjligheter till lokal utveckling och anpassning.
 - Patienten ska kunna följa sin process och hälsostatus. Kunna kontinuerligt lämna återkoppling på sitt mående och bemötande.

Operationella digitala verktyg

- Produktutveckling**
 - Vi har stöd att kunna utveckla verktyg utifrån vår egna data.
 - Prediktiva modeller ska kunna utvecklas och applikationer lär och finner korrelation i befintlig data för att förbättra sitt mål.
 - Process för att applicera dessa applikationer som beslutsstöd finns.

Analys, styrning och uppföljning

- Förbättrad analyskapacitet**
 - Analyskapaciteten är stärkt, med hjälp av vårddataagret kan analyser bli heltäckande och sträcka sig över hela patientens vårdförlopp.
 - Vi har metoder och verktyg för avancerade statistiska analyser av data så som att finna urval för hypotesprövning m.m.
- Rapid prototyping**
 - Koncept av produkter för operationella verktyg ska gå att utveckla snabbt.

Frida Bulukin Wilén

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)

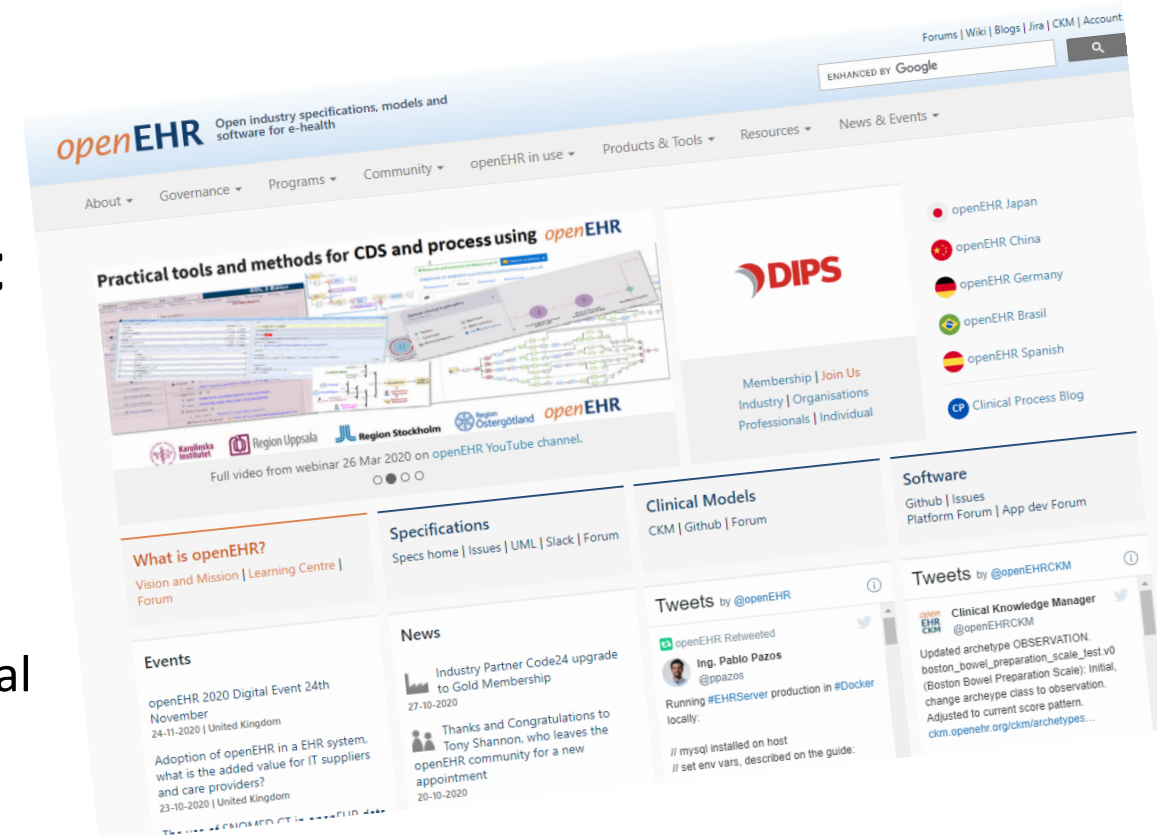
– **software** (tools etc.)

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

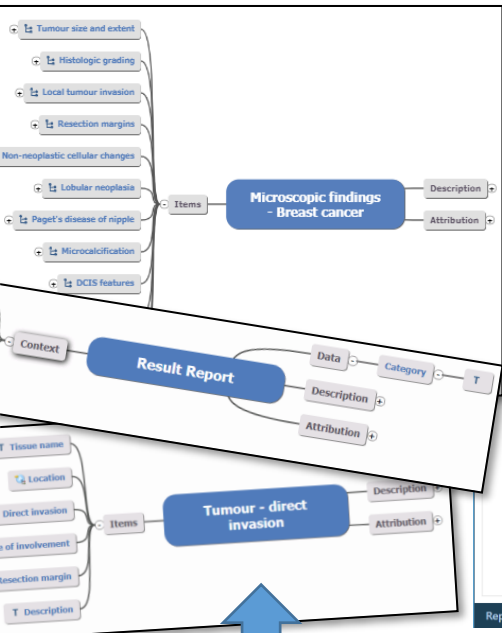
Artefacts of openEHR are produced by the openEHR **community** and managed by **openEHR International**, a **non-profit organisation** established in 2003

[https://openehr.org/about/what is openehr](https://openehr.org/about/what_is_openehr)

EHR = Electronic Health Record = Elektronisk Patientjournal



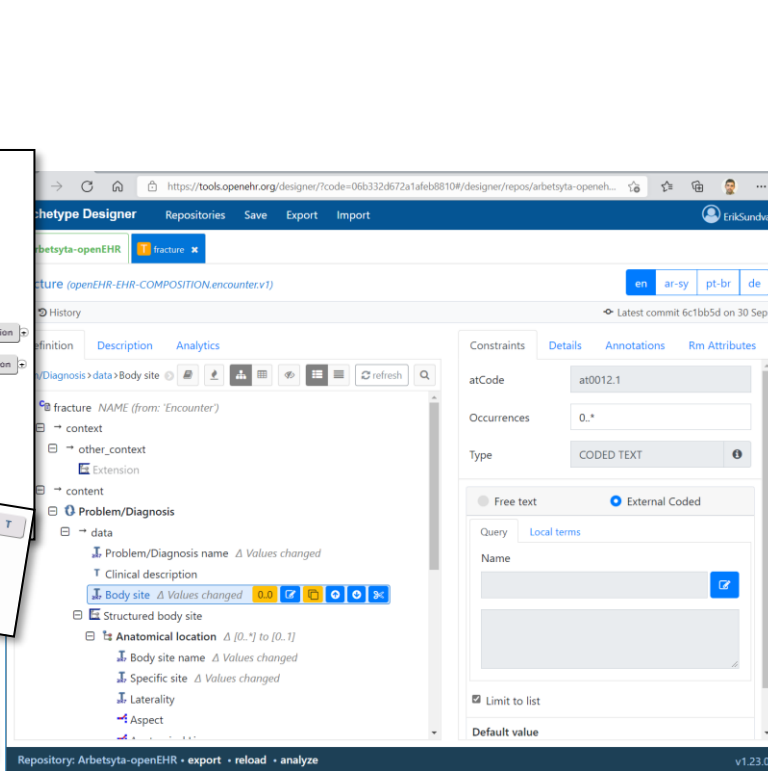
openEHR modeling toolchain



openEHR "archetypes"

Clinical data models.
Found in international repository
<https://ckm.openehr.org/ckm/>

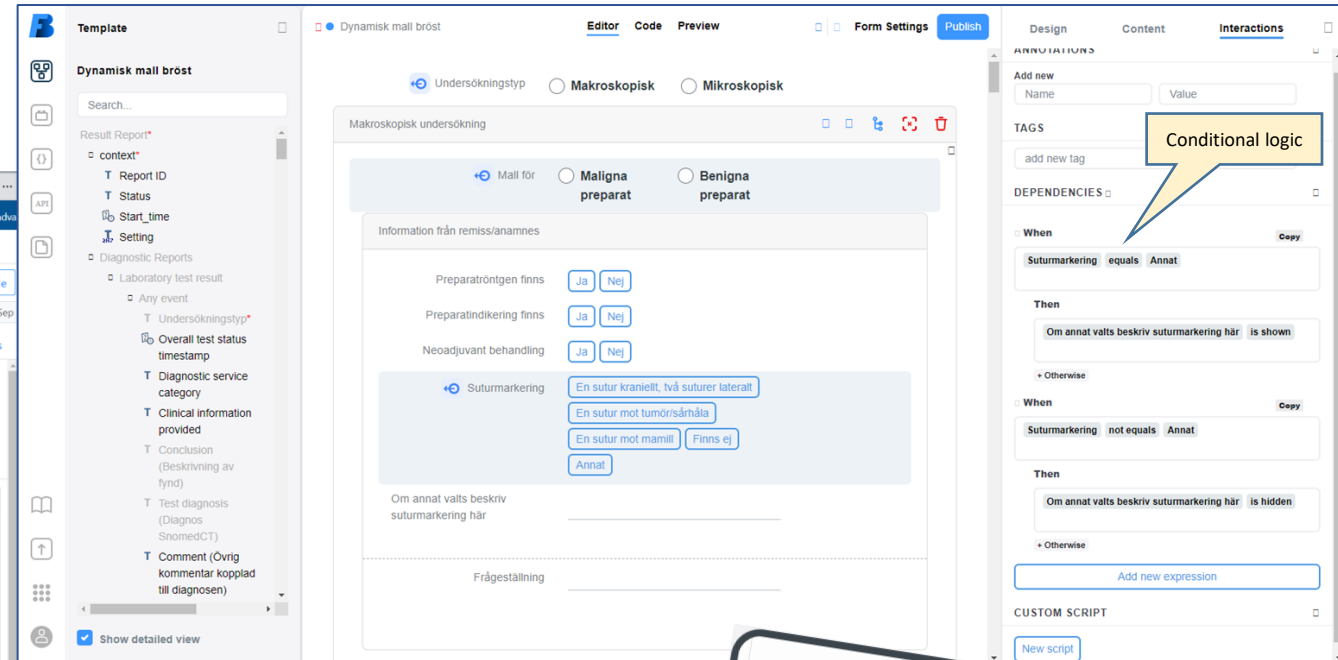
Maximi-datasets, intended for many use cases. Multilingual



openEHR "template"

For specific use case, e.g. local, regional or national.

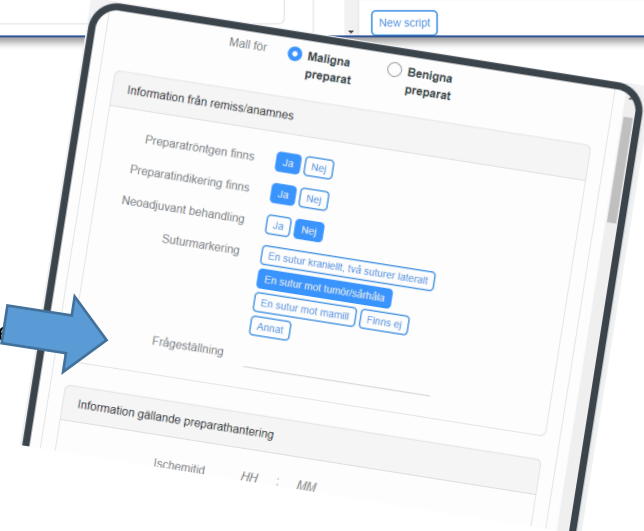
Free archetype and editing tool at
<https://tools.openehr.org/designer/>



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

ABCDE triage

▼ A. Fri luftväg (Airway)

stridor andningshinder obstruktion av de nedre luftvägarna obstruktion av de övre luftvägarna

Klinisk beskrivning _____

▼ B. Andning (Breathing)

Förekomst Andas Andning ej detekterbar

Andningsfrekvens _____ /min

Regelbundenhet Regelbunden Oregelbunden

Andningsdjup Normal Ytlig Djup Ojämn

Klinisk tolkning _____

Syresättning, SpO₂: _____ %

▼ C. Cirkulation

Blodtryck

Systoliskt _____ mm[Hg] Kroppsställning Sittande

Diastoliskt _____ mm[Hg] Mätplats Vänster arm

Pulsfrekvens _____ /min

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

Definition Description Analytics

↻ 🔍 refresh 🔍

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

<input checked="" type="checkbox"/>	Code	Text
<input checked="" type="checkbox"/>	at1000	Stående
<input type="checkbox"/>	at1001	Sittande
<input checked="" type="checkbox"/>	at1002	Halvliggande
<input checked="" type="checkbox"/>	at1003	Liggande
<input checked="" type="checkbox"/>	at1014	Liggande med

Assumed value

Not set

Default value

Value

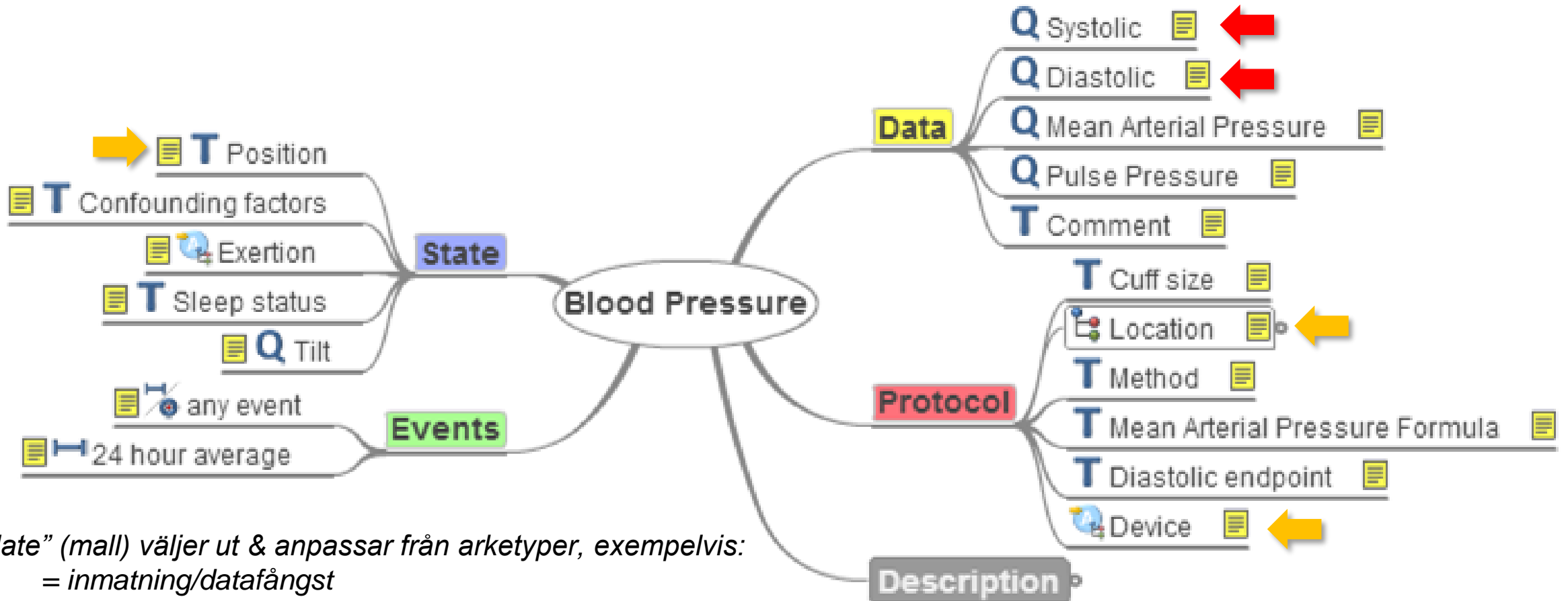
Sittande

<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

Exempel på "arketyper" från openEHR

ta saker angående blodtrycksmätning?
 llet för minsta gemensamma nämnare.
 sm/verktyg att fånga och krav i, och forum att diskutera i.

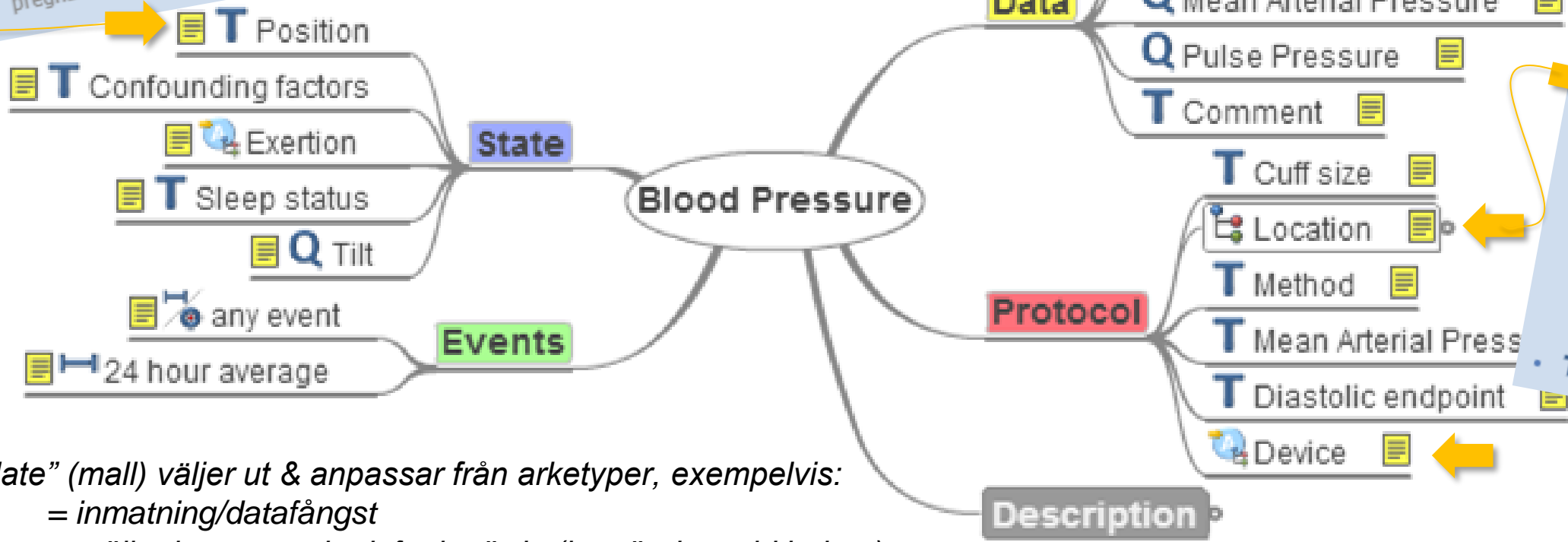
T Position
 Coded Text
 Optional
The position of the individual at the time of measurement.

- Standing [Standing at the time of blood pressure measurement.]
- Sitting [Sitting (for example on bed or chair) at the time of blood pressure measurement.]
- Reclining [Reclining at the time of blood pressure measurement.]
- Lying [Lying flat at the time of blood pressure measurement.]
- Lying with tilt to left [Lying flat with some lateral tilt, usually angled towards the left side. Commonly required in the last trimester of pregnancy to relieve aortocaval compression.]

Location of meas
 Choice
 Optional
Simple body site where blo

Choice of:

- **T** Coded Text
- Right arm [The right a
- Left arm [The left arm
- Right thigh [The right t
- Left thigh [The left thig
- Right wrist [The right wr
- Left wrist [The left wr
- Right ankle [The right an
- Left ankle [The left ankle
- Finger [A finger of the ind
- Toe [A toe of the individua
- Dorsum of foot [The indivi
- Intra-arterial [Invasive mea within an artery.]
- **T** Text



"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

Begränsad namnsökning

Ordentlig Sökfunktion

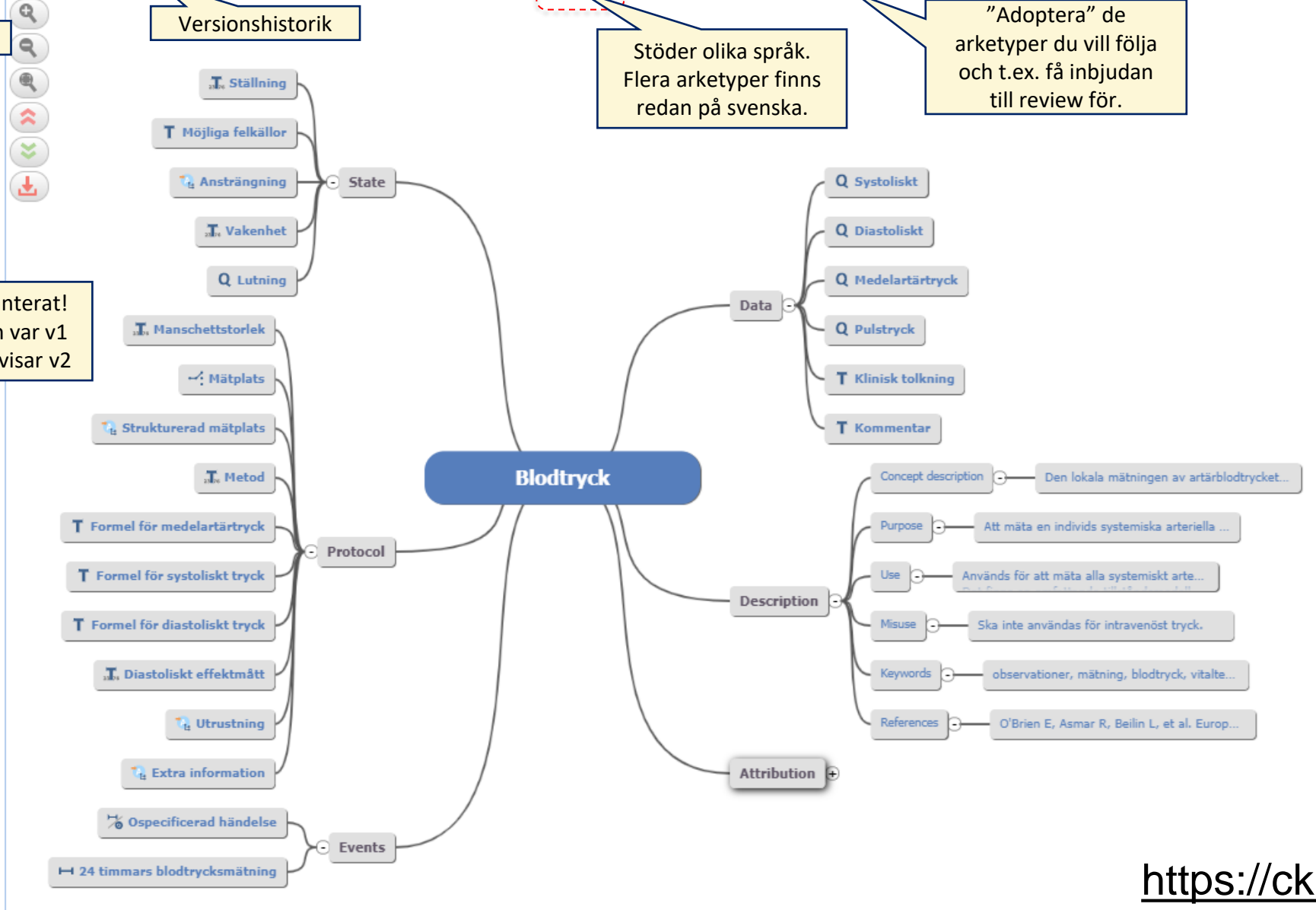
Versionshistorik

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

- Archetypes
- AOFA Score (v0)
- ✓ Appgar score (v2)
- Appendicitis Inflammatory R...
- ASA physical status classifica
- Assessment of Blood Consum...
- ATRIA bleeding risk score (v1)
- ATRIA stroke r...
- ATRS Score (v1)
- Audiogram tes...
- Audiology spee...
- Auditory brainstem...
- AVPU (v0)
- Behavioural observa...
- Beighton hypermo...
- Bishop score (v0)
- ✓ Blood pressure (v2)
- Body composition (v0)
- ✓ Body mass index (v2)
- ✓ Body segment area (v1)
- ✓ Body segment circumference
- ✓ Body segment length (v1)
- ✓ Body surface area (v1)
- ✓ Body temperature (v2)
- ✓ Body weight (v2)
- Boston Bowel Preparation Sc...
- ✓ Braden scale (v1)
- Briganti Risk Score (v0)
- Bristol stool scale (v0)
- Brisset Violence Checklist (BV...



Begränsad namnsökning

Ordentlig Sökfunktion

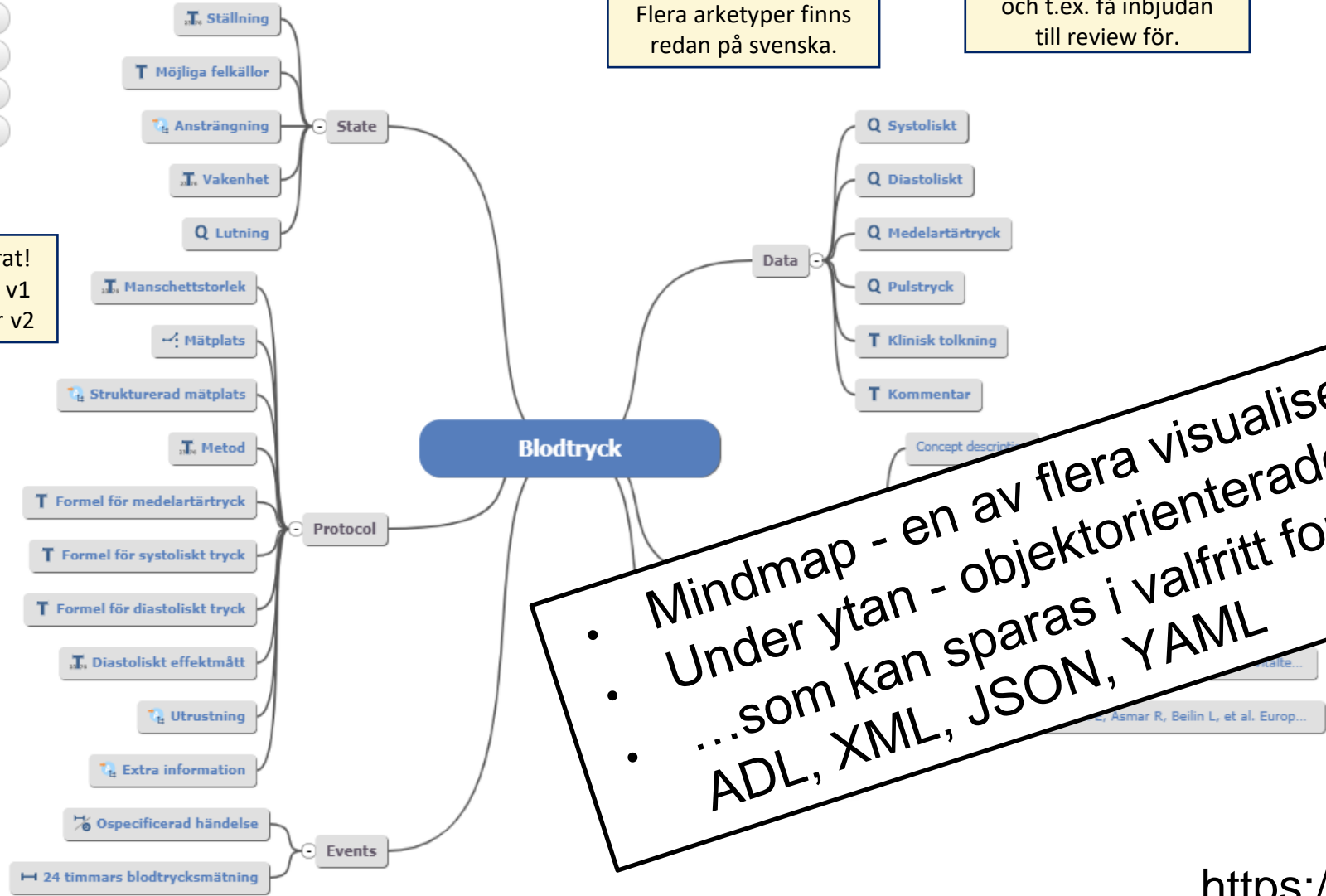
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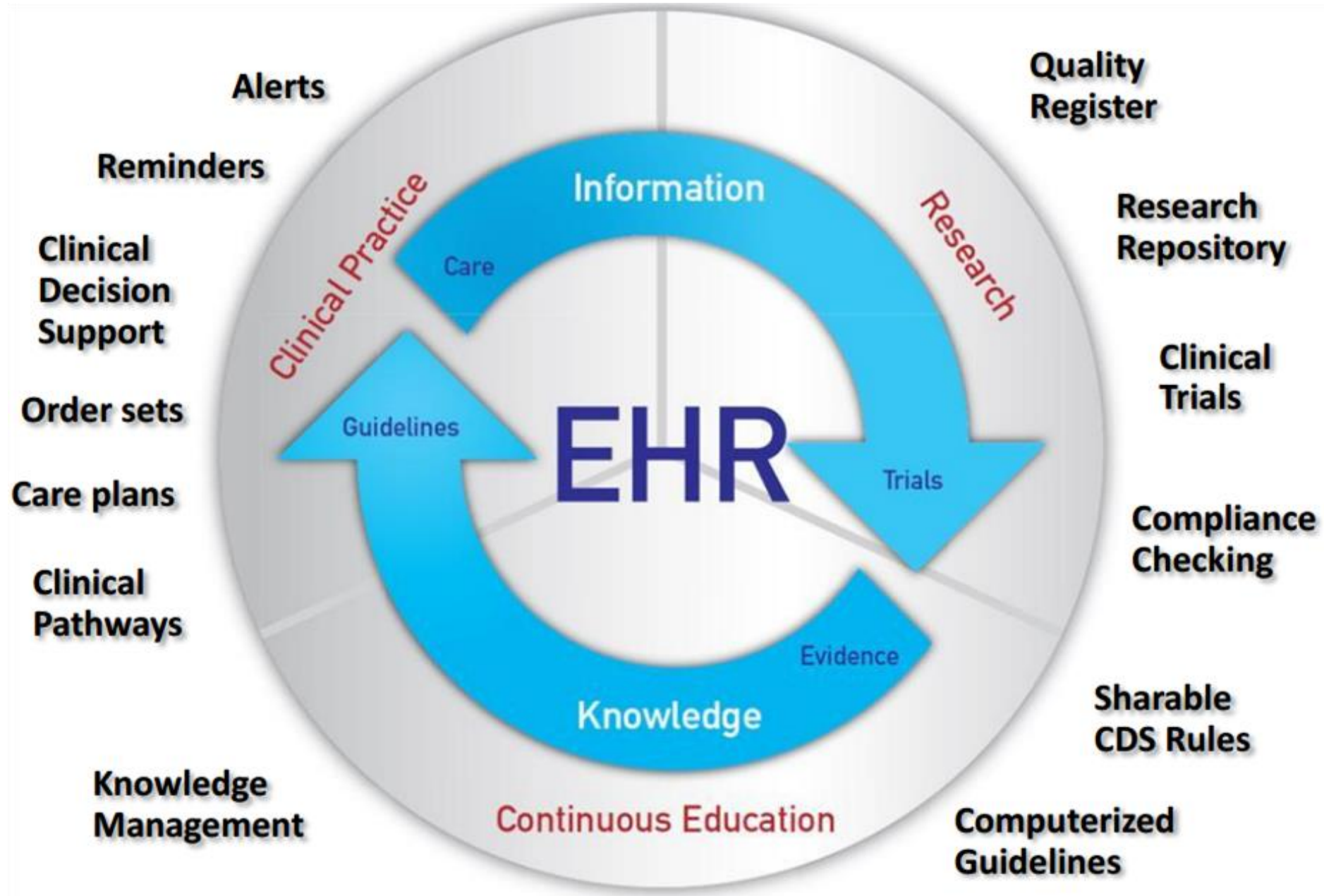
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- Braden scale (v1)
- Briganti Risk Score (v0)
- Bristol stool scale (v0)
- Brøset Violence Checklist (BV...



Mindmap - en av flera visualiseringar
 Under ytan - objektorienterade modeller...
 ...som kan sparas i valfritt format t.ex. ADL, XML, JSON, YAML

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 Gartner's average system examples (perhaps due to complexity, regulations etc?)

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

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

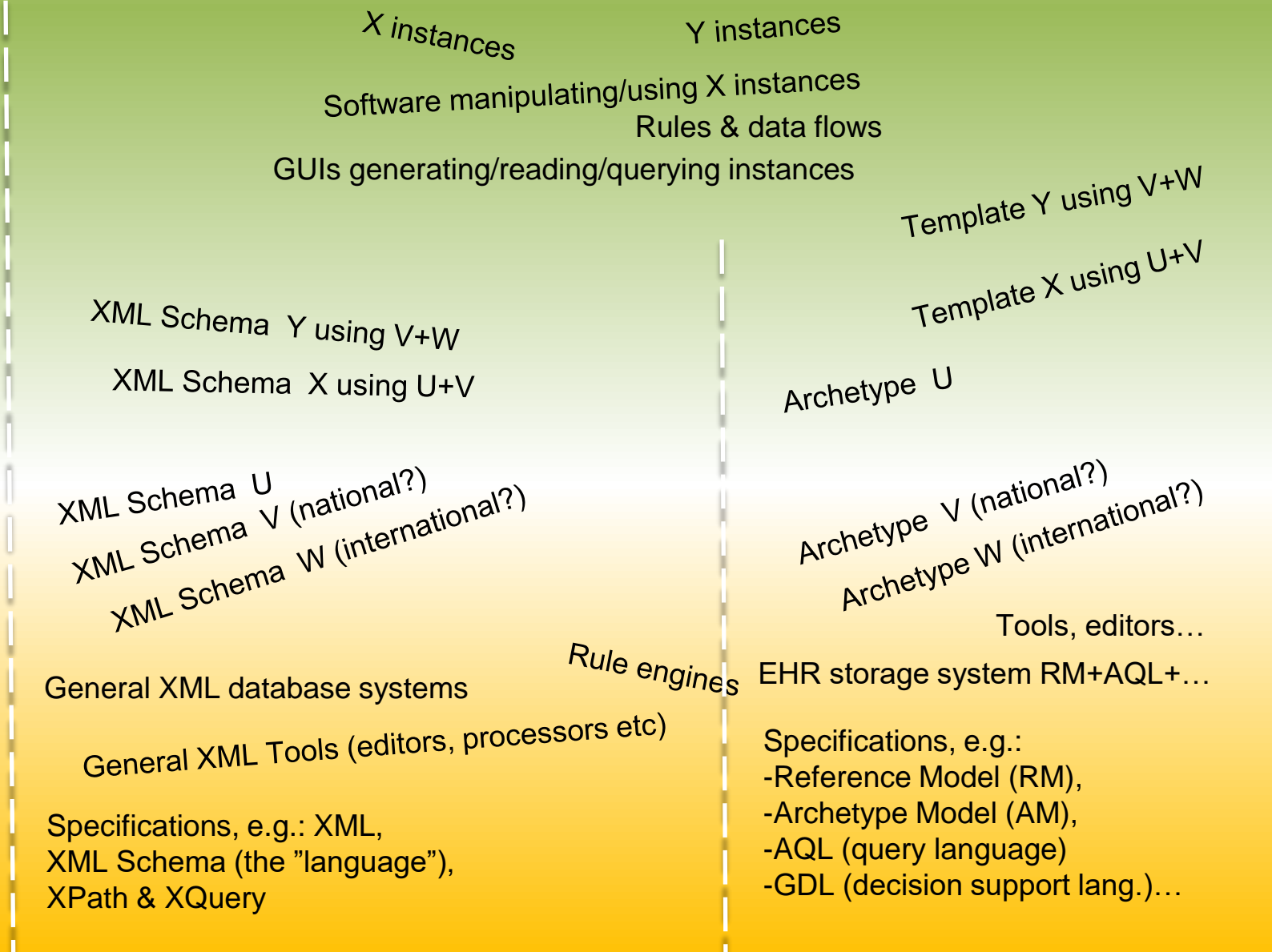


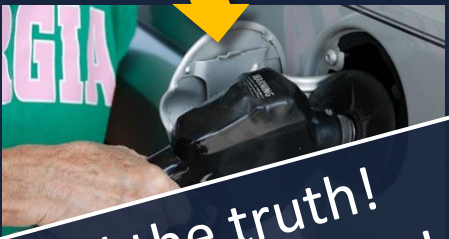
Mr Smith's time report for June (an instance)

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



Spreadsheet Software (e.g. Excel)





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
"Marathon!"

Mode 2
"Sprinter", delar
konfigurerbara
av verksamhet

Mode 2
"Sprint"

Support
Sys. admin
Customer group

Delivery
Release mgmnt.
Programming

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

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

Customer repr.
Investigation
Prioritisation
Pre-study

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

Adjusting related
systems (integrations
Statistical reports etc)

Tech sys. administration
and improvement
of CDR and tools

Mode 1
"Maratonlöpare"
Stabil informatik och
teknisk grundplattform



Emily Mailes, EY - KEYNOTE: The journey from legacy to postmodern EHR

What are the immediate steps?

- ▶ Right leadership team
- ▶ Shrink the core: create an adaptable health IT system that supports frictionless, permissioned data sharing
- ▶ Separate data from the applications that collect, edit and display it
- ▶ Adopt a bi-modal operating model
- ▶ Stop being at the mercy of big vendors
- ▶ Collaborate with peers to encourage and seed the marketplace



skills matter

skillsmatter.com @skillsmatter #codenode

"...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 sustainable solutions...?

Mode 2
"Sprinter"

Leta/skapa arketyper
Skapa template
Skapa formulär/GUI och "task planning" inkl. dynamik m. "low code"

Teknisk förvaltning av grundplattform och verktygsstöd
Mode 1
teknisk grundplattform

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**



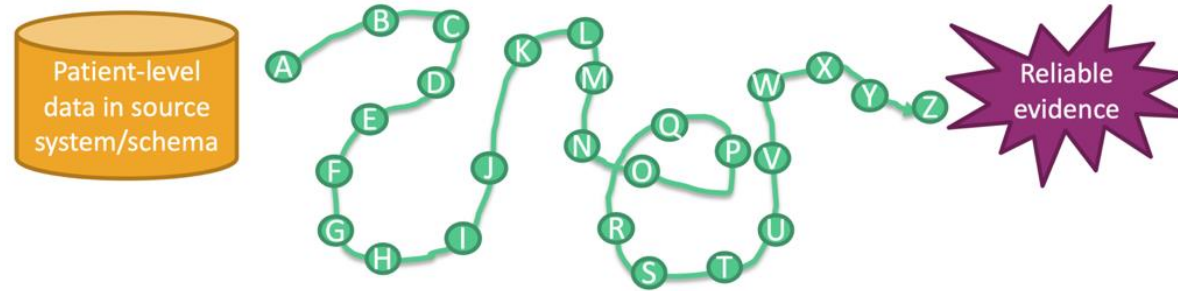
A EUROPEAN HEALTH DATA NETWORK: USING THE OMOP CDM FOR COLLABORATIVE STUDIES

Maxim Moinat
2024-03-11, Sitra

Department of Medical Informatics
Health Data Science
Erasmus MC Rotterdam



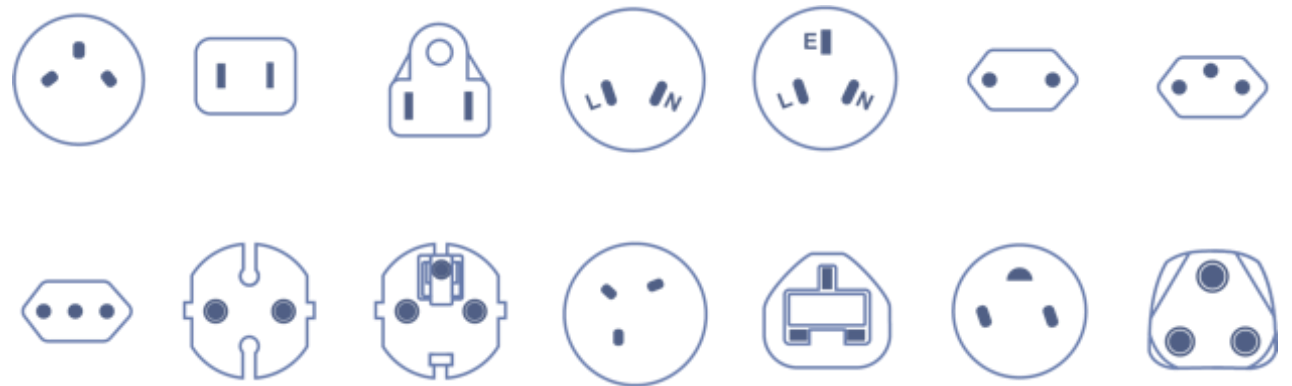
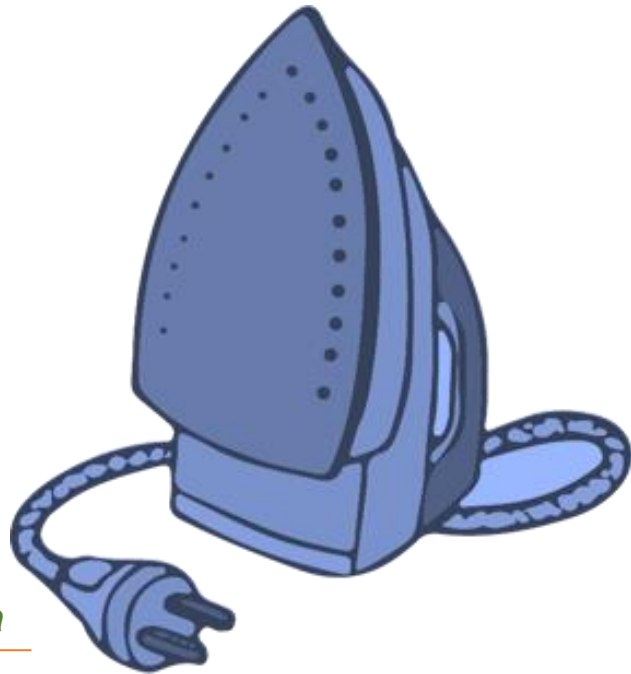
Generating Reliable Evidence at Scale



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

Improving Interoperability

Analytical method The structure ...



[Link to data](#)

The language ...

110V, 120V, 127V, 220V, 230V, 204V, ...

Standardization to a common data model



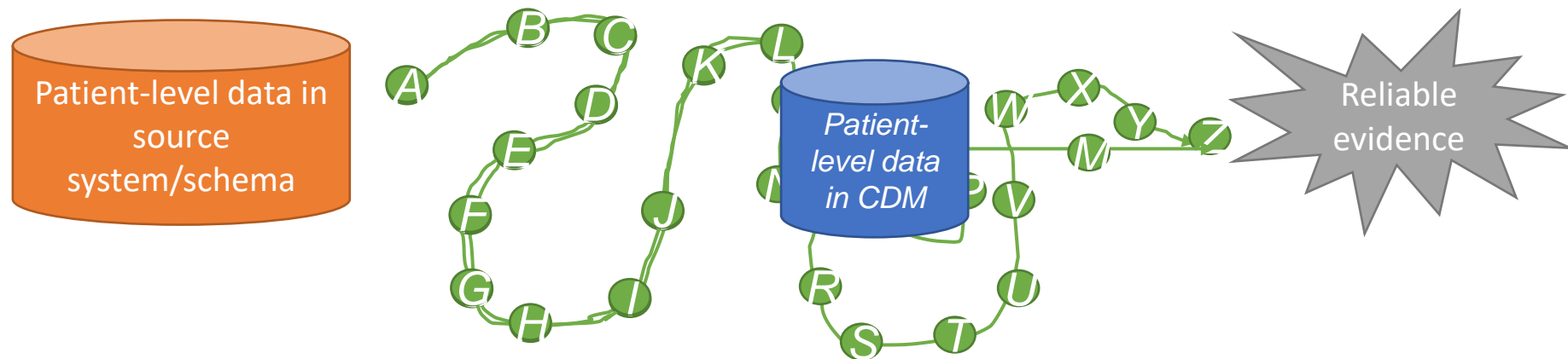
www.ohdsi.org



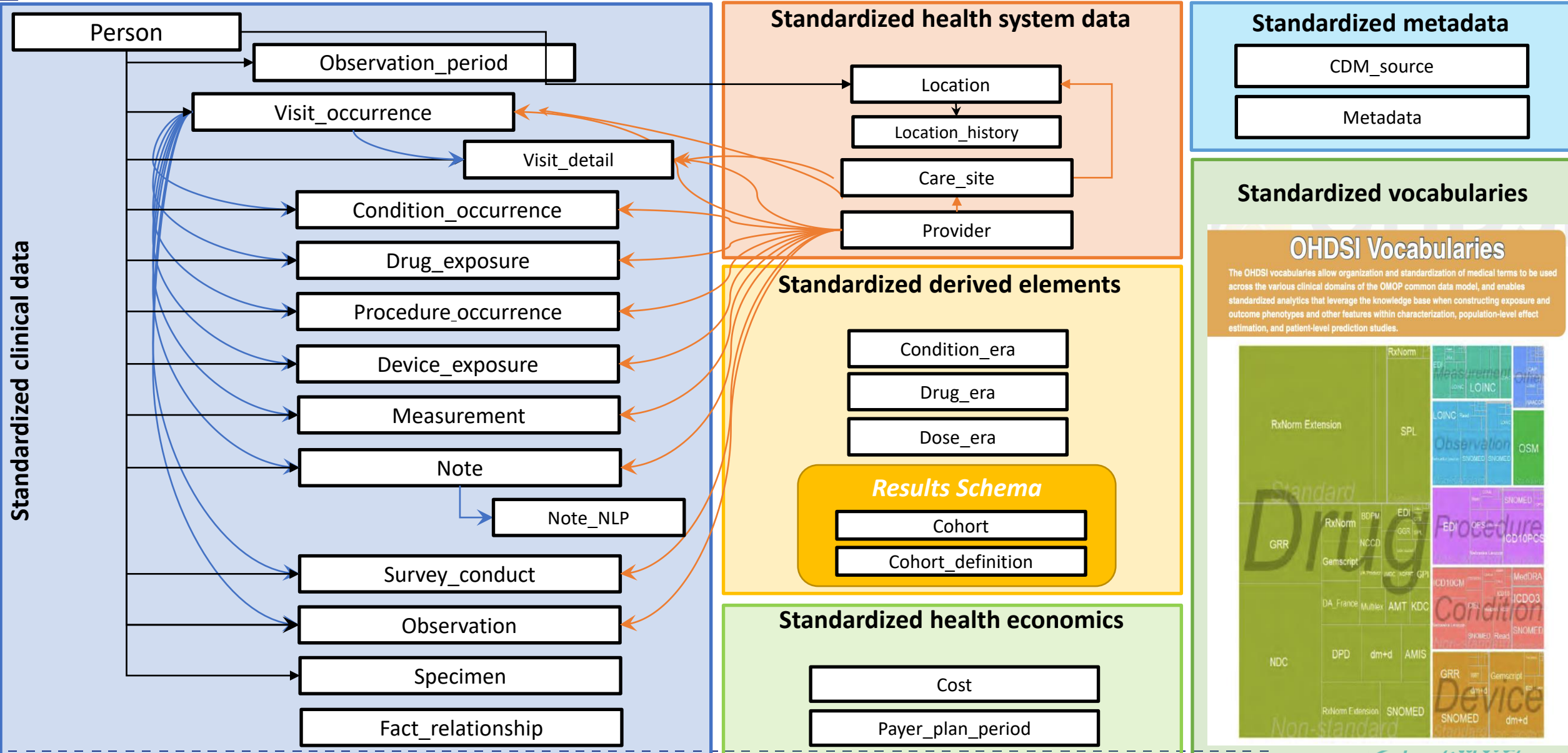
www.ehden.eu



www.darwin-eu.org



The OMOP CDM



Questions asked across the patient journey

Clinical characterization

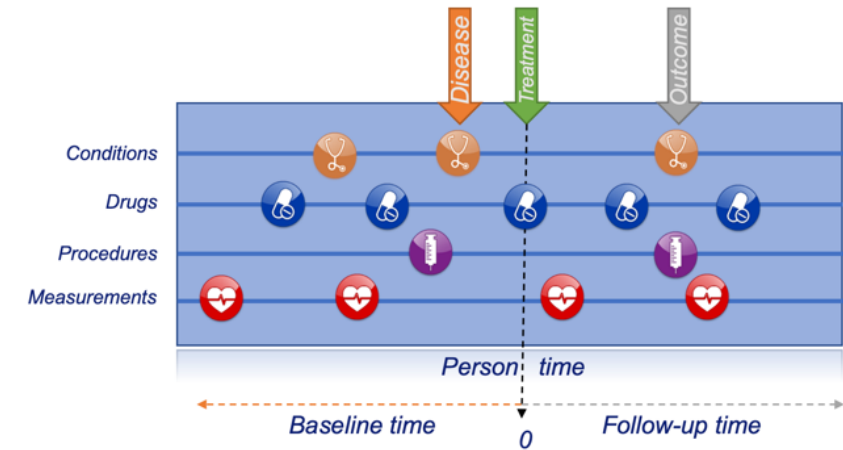
- Natural history: How many have diabetes, what proportion takes metformin?
- Quality improvement: What proportion of patients with diabetes experience complications?

Population-level effect estimation

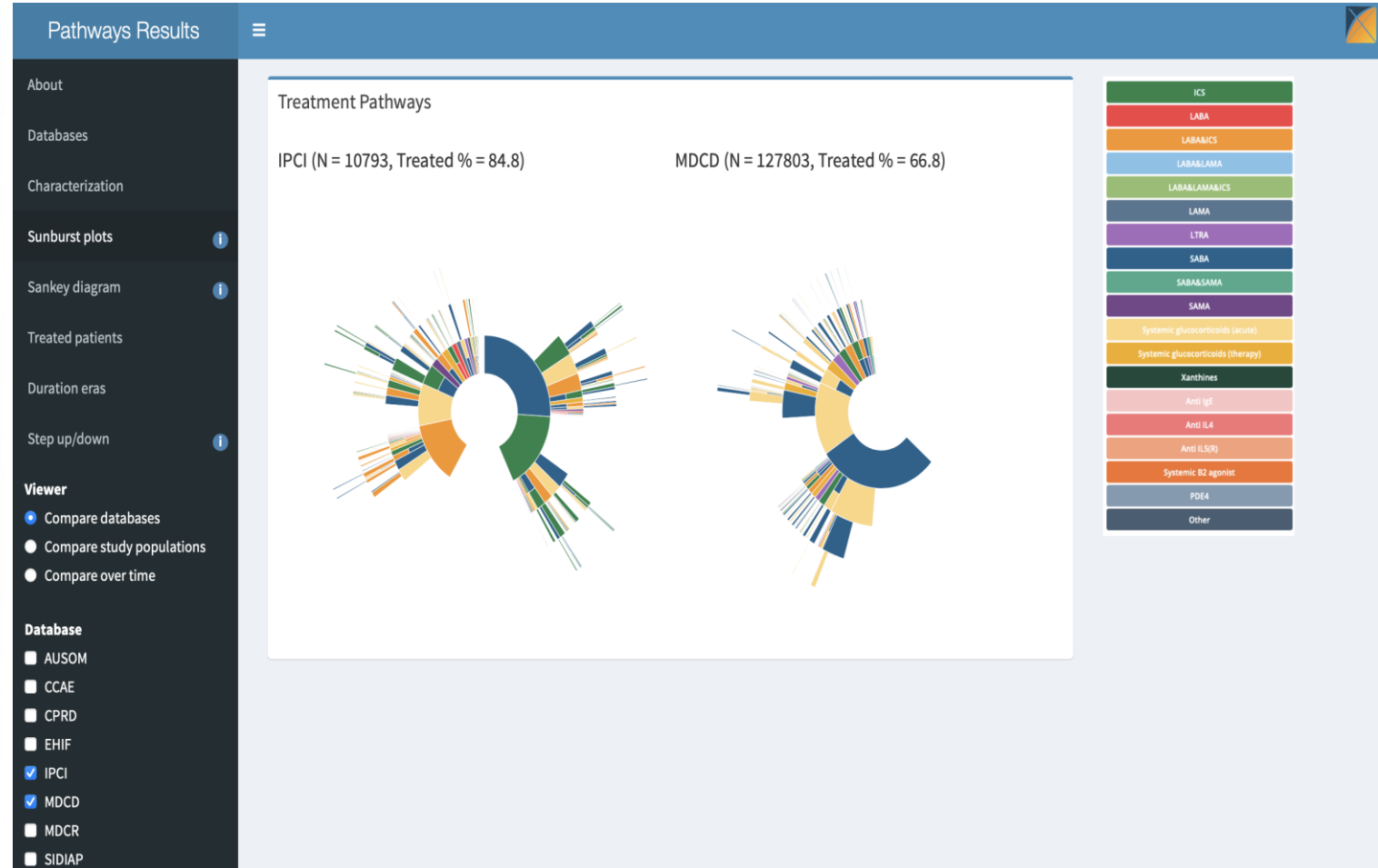
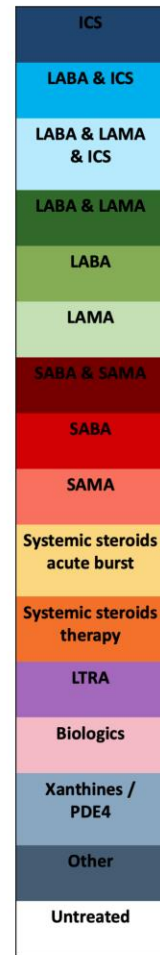
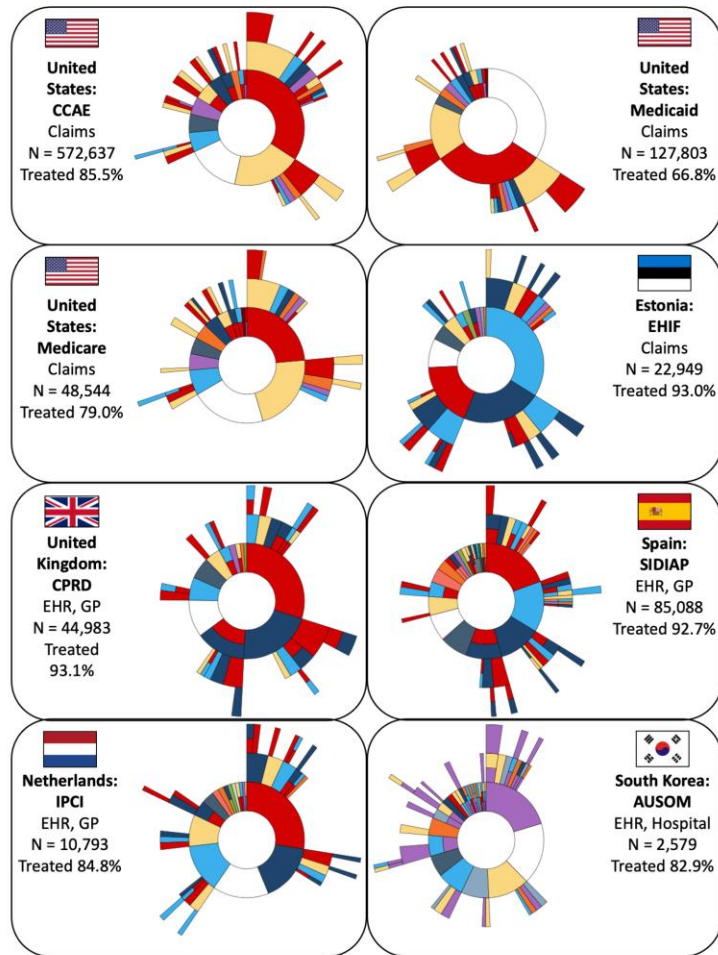
- Safety surveillance: Does metformin cause lactic acidosis?
- Comparative effectiveness: Does metformin cause lactic acidosis more than glyburide?

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?



Characterisation: Treatment Patterns



Treatment Patterns across countries

Interactive web-application

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

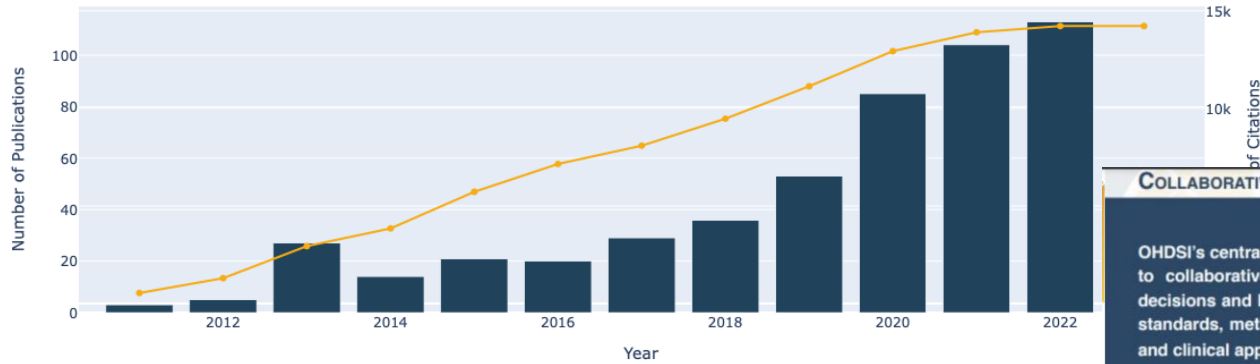


OHDSI By The Numbers

- 3,758 collaborators
- 83 countries
- 21 time zones
- 6 continents
- 1 community

Erasmus MC

OHDSI Publications & Cumulative Citations



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

COLLABORATIVE ACTIVITIES

OHDSI Working Groups

OHDSI's central mission is to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care. We work towards that goal in the areas of data standards, methodological research, open-source analytics development, and clinical applications.

Our 27 Working Groups present opportunities for all community members to find a home for their talents and passions, and make meaningful contributions. We are always looking for new collaborators.

See an area where you want to contribute? Please [Join The Journey!](#)

ATLAS Current Participants: 56 Lead: Anthony Sena	Clinical Trials Current Participants: 111 Leads: Mike Hamidi, Lin Zhen	Common Data Model Current Participants: 261 Lead: Clair Blacketer
Data Quality Dashboard Development Current Participants: 90 Lead: Clair Blacketer	Early-Stage Researchers Current Participants: 44 Leads: Faalzah Arshad, Ross Williams	Education Current Participants: 31 Lead: Nigel Hughes
Electronic Health Record (EHR) ETL Current Participants: 168 Lead: Melanie Philotsky	Geographic Information System (GIS) Current Participants: 58 Leads: Robert Miller, Andrew Williams	HADES (Health Analytics Data-to-Evidence Suite) Current Participants: 120 Lead: Martijn Schuemie
Health Equity Current Participants: 87 Lead: Jake Gillberg	Latin America Current Participants: 15 Lead: Jose Posada	Medical Devices Current Participants: 52 Leads: Vojtech Huser, Asiyah Lin
Natural Language Processing Current Participants: 228 Lead: Hua Xu	OHDSI Asia-Pacific (APAC) Current Participants: 46 Lead: Mui Van Zandt	OHDSI APAC Steering Committee Current Participants: 29 Lead: Mui Van Zandt

COLLABORATIVE ACTIVITIES

Our workgroups hold meetings, share files, chat asynchronously and more in the OHDSI Microsoft Teams environment. Collaborators can request access to any workgroup through an online form available on both OHDSI.org and our main OHDSI Microsoft Teams environment.

OHDSI Steering Committee Current Participants: 26 Lead: Patrick Ryan	Oncology Current Participants: 129 Lead: Shilpa Ratwani	Patient-Generated Health Data Current Participants: 76 Lead: Seng Chan You
Pharmacovigilance Evidence Investigation Current Participants: 48 Leads: Rich Boyce, Erica Voss	Phenotype Development & Evaluation Current Participants: 96 Leads: Gowtham Rao	Population-Level Effect Estimation Current Participants: 164 Lead: Martijn Schuemie, Marc Suchard
Patient-Level Prediction Current Participants: 164 Lead: Jenna Reys, Peter Rijnbeek	Psychiatry Current Participants: 66 Lead: Shilpa Ratwani	Registry (formerly UK Biobank) Current Participants: 57 Lead: Maxim Moinat
Vaccine Safety Current Participants: 28 Lead: Patrick Ryan	Vaccine Vocabulary Current Participants: 36 Lead: Adam Black	Women of OHDSI Current Participants: 97 Lead: Maura Beaton

OHDSI Regional Chapters

An OHDSI regional chapter represents a group of OHDSI collaborators located in a geographic area who wish to hold local networking events and meetings to address problems specific to their geographic location.

Africa Current Participants: 17 Lead: Nega Gebreyesus	Australia Current Participants: 36 Lead: Nicole Pratt	China Current Participants: 163 Lead: Hua Xu	Europe Current Participants: 135 Lead: Peter Rijnbeek
Japan Current Participants: 19 Lead: Tatsuo Hiramatsu	Korea Current Participants: 26 Lead: Seng Chan You	Singapore Current Participants: 30 Lead: Mengling Fang	Taiwan Current Participants: 48 Lead: Jason Hsu

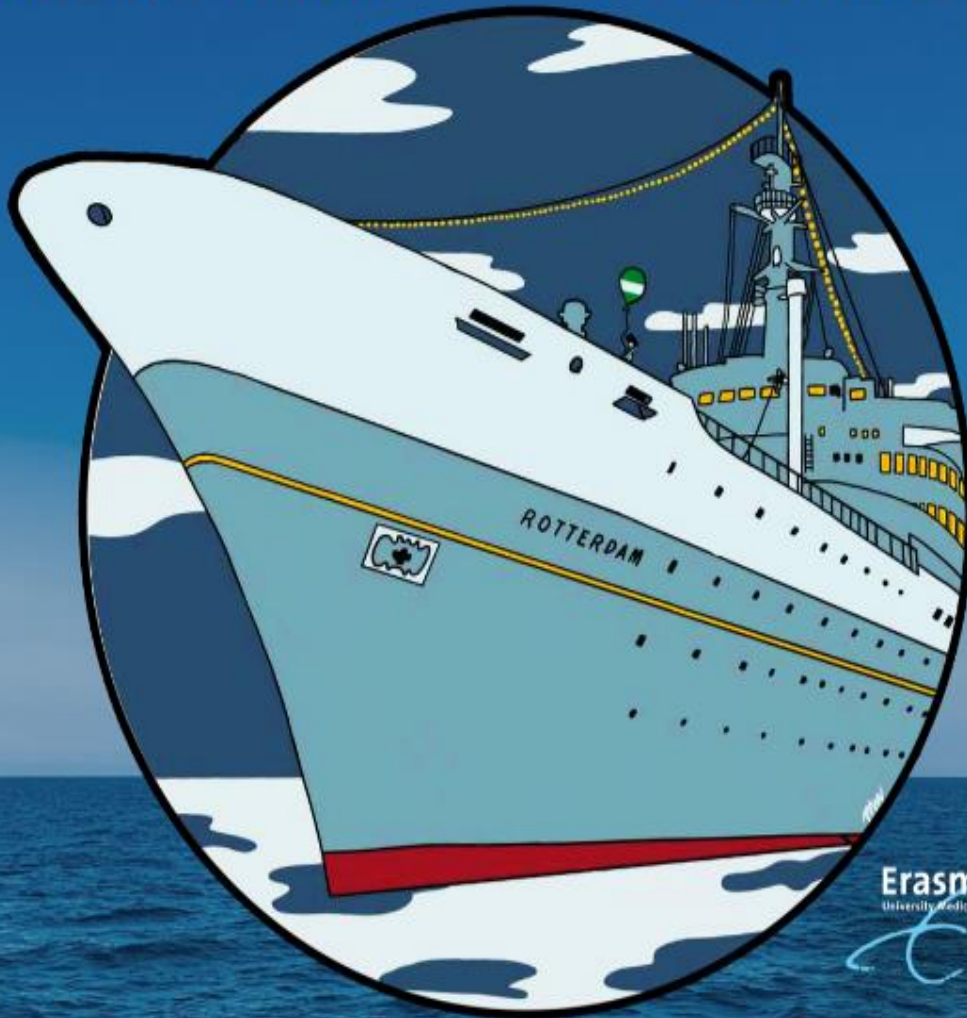


EUROPEAN OHDSI SYMPOSIUM

July 3rd 2023 Rotterdam

Tutorials: July 1st and 2nd

“Full Steam Ahead!!”

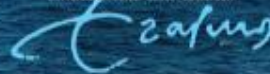


The numbers

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

Organised by:

Erasmus MC
University Medical Center Rotterdam



Health
Data
Science



Thank you for your support!



Erasmus MC
University Medical Center Rotterdam



The Hyve



ODYSSEUS
DATA SERVICES INC.



BIOMERIS

PROMPTLY



IOMED



LYNXCARE

IMS Health & Quintiles are now



IQVIA



MTG
DATA SCIENCE
PREDICTIVE LEARNING
REAL-WORLD EVIDENCE
Robust Data to Real-World Healthcare Data Services



edence Health



OHDSI
Observational Health Data Science and Informatics



EHDEN
European Health Data Ecosystem

National Nodes

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





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



Academic coordinator



SME & Mid-sized companies



Non-profit organisations



EFPIA & Associated partners



EFPIA Lead





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

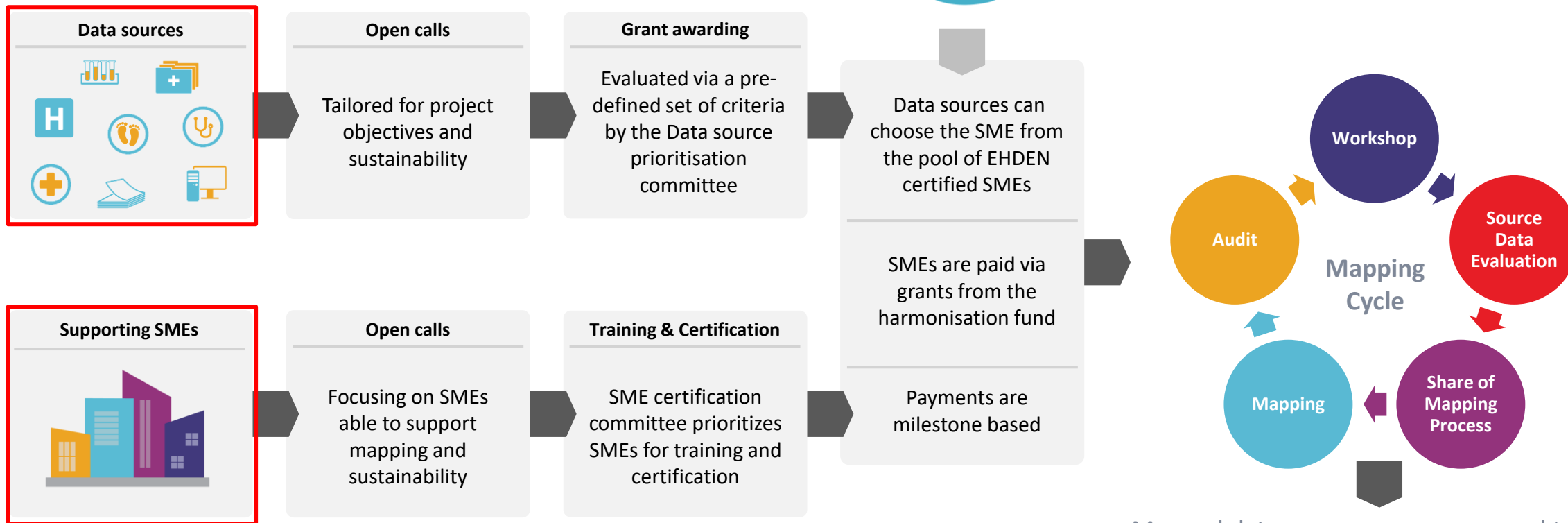




A SUSTAINABLE ECOSYSTEM: CALL PROCESS OVERVIEW



Harmonisation fund



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

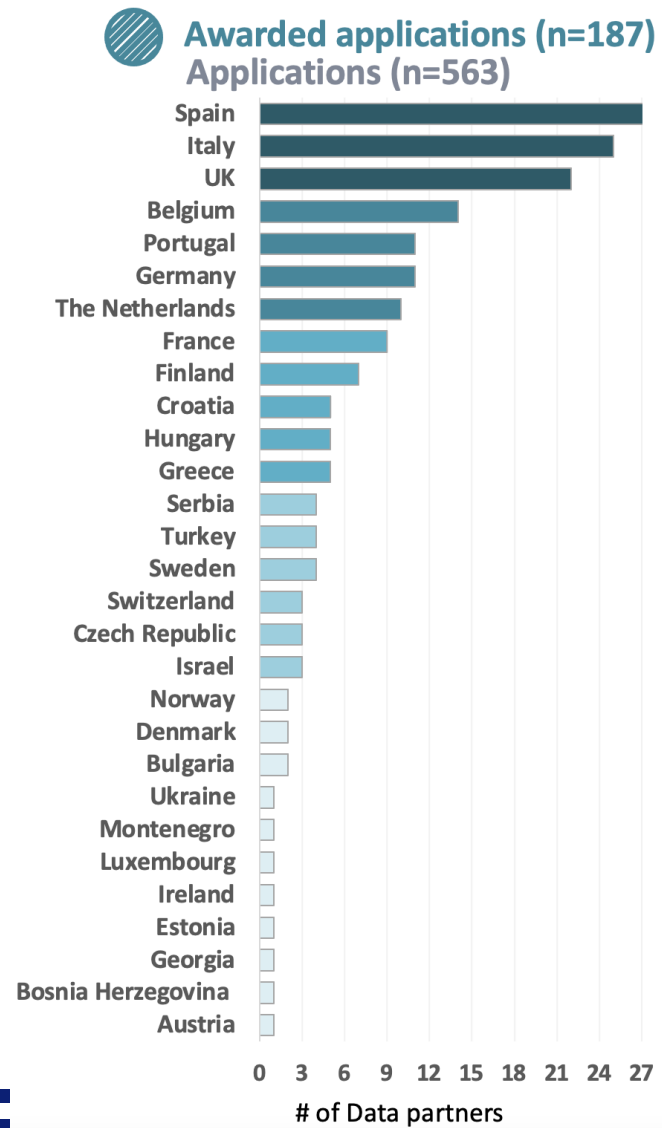
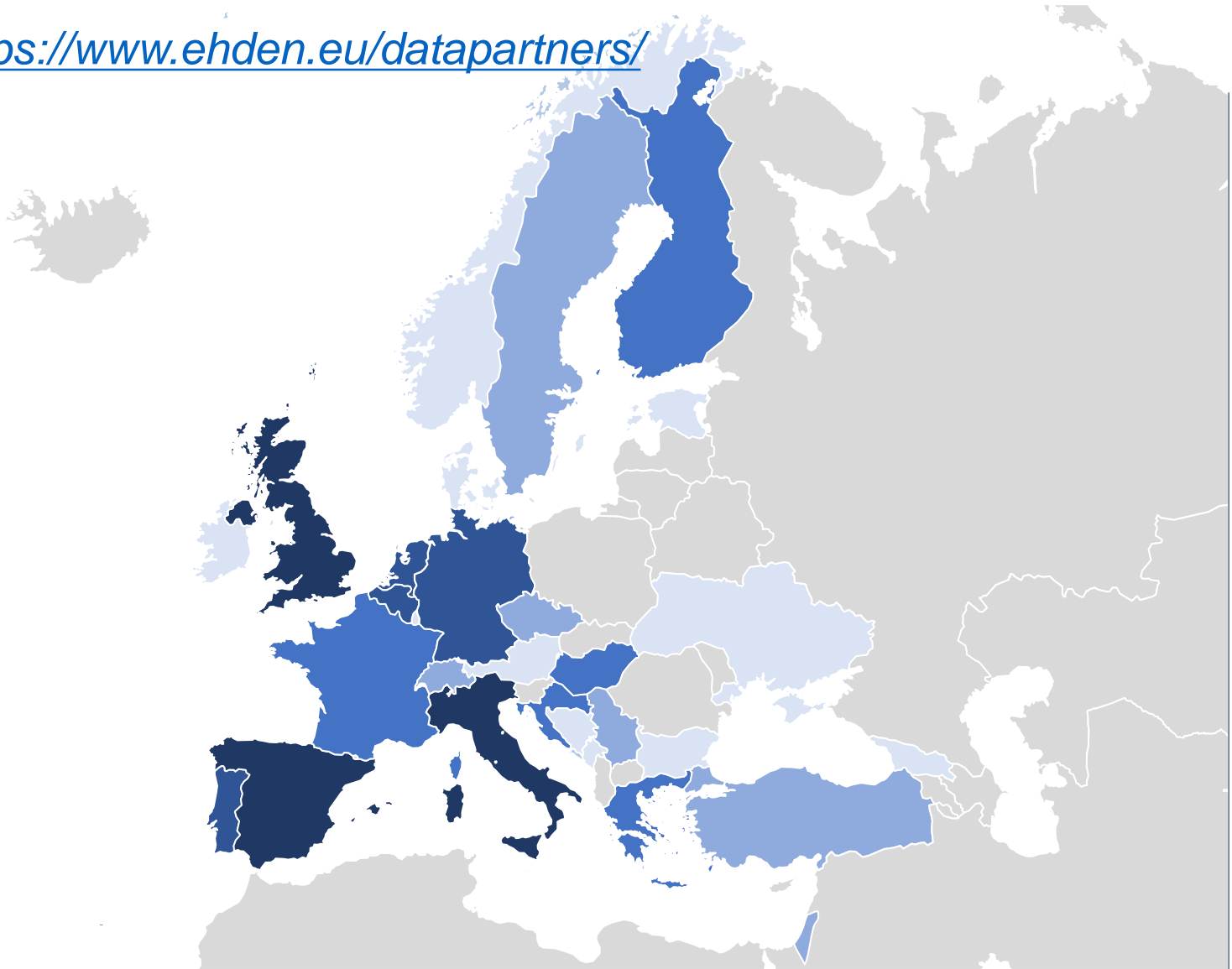
Erasmus MC





CURRENT EHDEN DATA PARTNERS

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

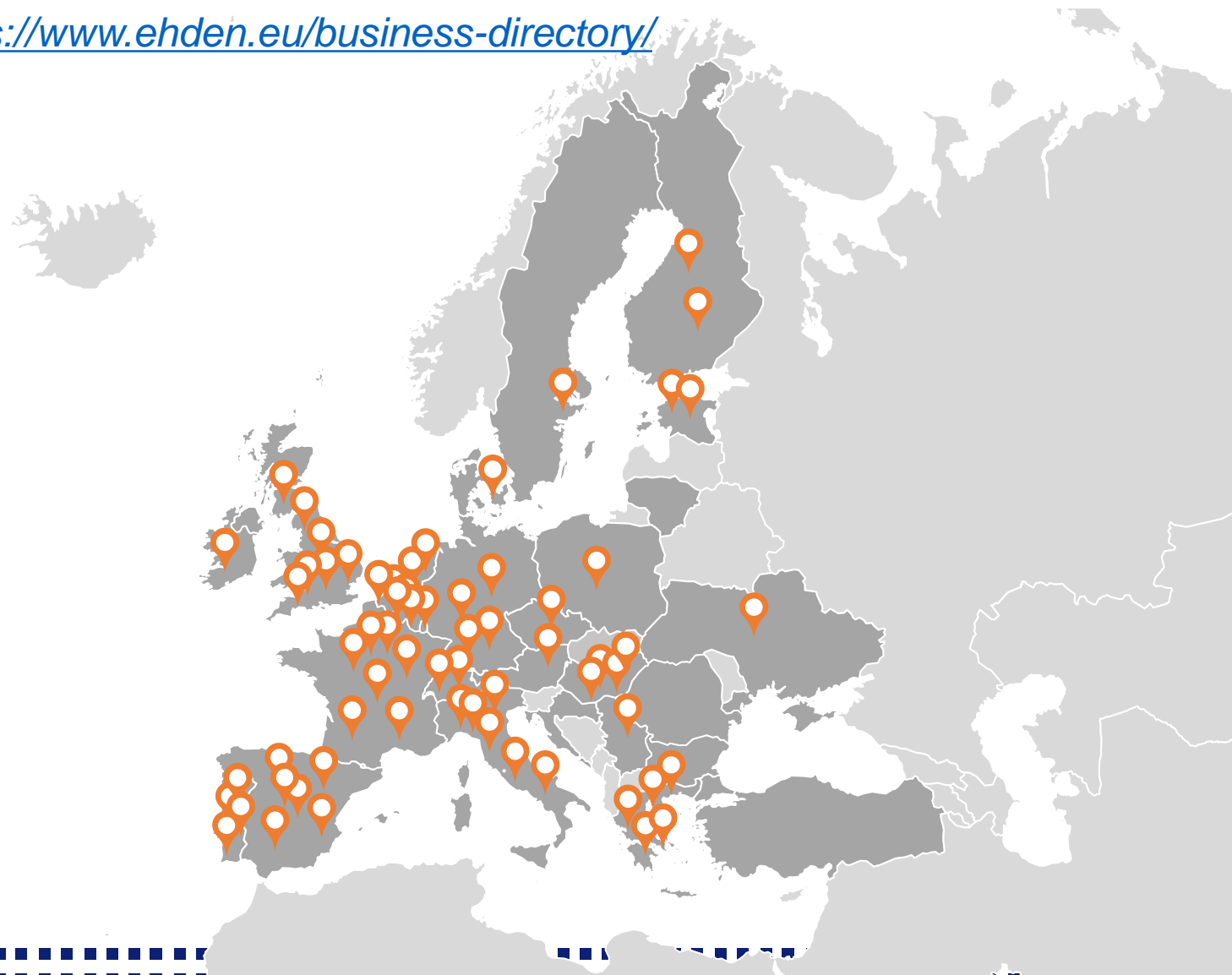


Geographic spread of data partners. The shade of blue indicates the # of data partners in that country (darker = more)



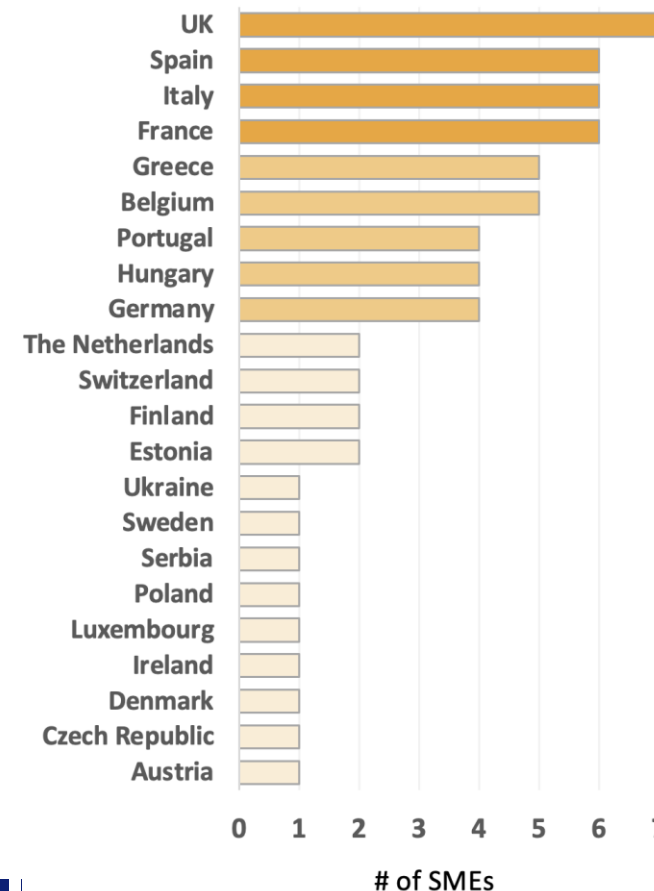
CERTIFIED SMALL TO MEDIUM-SIZED ENTERPRISES

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



 Certified SMEs (n=64)

 Applications (n=143)





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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



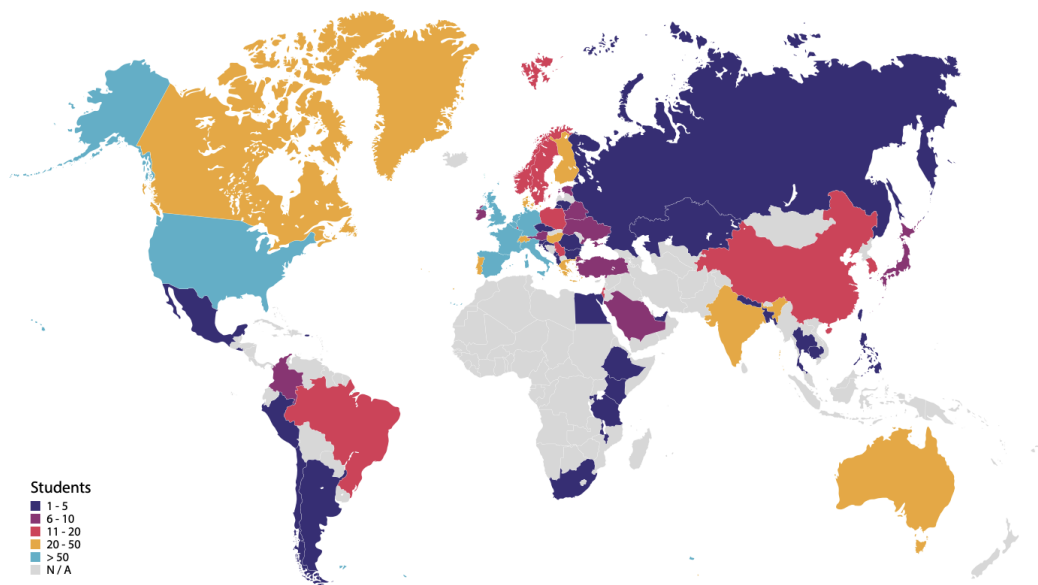


EHDEN ACADEMY

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

EHDEN Academy Courses Home About Log in

JOIN THE JOURNEY

Work via Modules Developed by International Experts

Start Learning for Free

EHDEN Academy is now used in 100 countries with 4,400 enrollees worldwide since launch!

Learning for Anyone, Anywhere

On-demand training and development programmes developed by the OHDSI and EHDEN community.

- Tool Ecosystem**
Learn to use our latest tools for observational research in your organisation
- Meet Like-minded People**
Share and develop your ideas with an interdisciplinary group of learners
- Join the Journey**
Prepare to participate in worldwide research initiatives across the OHDSI community
- Connect with Experts**
Learn from internationally acknowledged expert trainers and educators



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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.

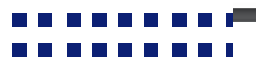
Since its launch, more than **500 active users** have been registered and more than **9,000 new users** have visited the Portal.

The screenshot displays the EHDEN Portal interface. On the left is a dark sidebar with navigation options: HOME, CATALOGUE, DASHBOARD, ACADEMY, EHDEN, PUBLICATIONS, STATUS, MANAGE, and a user profile for 'Michela Miani'. The main content area is divided into two sections:

- Welcome to the EHDEN Portal:** A central text block explaining the project's mission. Below it are six icons representing: Database Catalogue, Network Dashboards, EHDEN Academy, Publications, ARACHNE, ATLAS, and Service Desk.
- Network Dashboard:** A data visualization area with filters for Country, Database Type, and Data Source. It features a summary table:

Country	Data Sources	Patients
19	64	153M


 Below the table are two charts: 'Patients by Country' (a bar chart) and 'Database Types per Country' (a heatmap).





EHDEN PORTAL – CATALOGUE OF METADATA

«


M. Moinat

- HOME
- CATALOGUE >
- DASHBOARD
- ACADEMY
- EHDEN
- PUBLICATIONS
- STATUS
- PORTAL
- ABOUT
- GET STARTED
- FEEDBACK
- PROFILE
- SIGN OUT

Have a look at our network dashboard containing a fast growing list of databases.

Countries

27

Data Sources

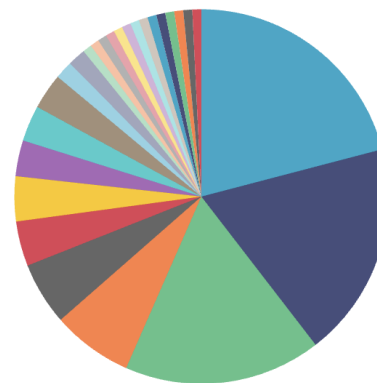
129

Patients

236M

Datasource Types

Hospital Registry Hospital + Lab Results Hospital + Primary Care Postgres Ehr + Lab Results Primary Care Hospital + Prima 1/8



SMC

Erasmus

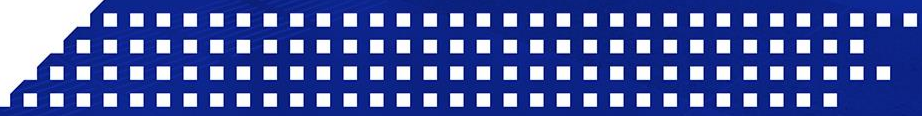


AND WE ARE NOT DONE YET!

HARMONIS
Harmonise more than
anonymised health records to
common

Enabling outcomes d

The screenshot shows the EHDEN Foundation website. At the top, there is a navigation menu with links: ABOUT, EHDEN Foundation, WORK PACKAGES, NETWORK, EVIDENCE GENERATION, COMMUNICATION/EDUCATION, NEWS, and CONTACT. Below the navigation is the EHDEN Foundation logo, which includes the text 'EUROPEAN HEALTH DATA & EVIDENCE NETWORK' and 'EHDEN Foundation'. The main content area features a section titled 'EHDEN Data Partners & SMEs share their aspirations for the EHDEN Foundation'. This section contains a grid of seven video thumbnails, each with a red play button icon and a title 'Hopes for EHDEN's future'. Below the grid, there are three paragraphs of text. The first paragraph discusses the project's progress, mentioning 187 Data Partners and 64 SMEs. The second paragraph talks about evidence-generation work and the EHDEN Academy. The third paragraph describes the transition to the EHDEN Foundation as a sustainable entity. The website also features a search bar in the top right corner.



Erasmus MC
Universitair Medisch Centrum Rotterdam



Programme / Ohjelma

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Maxim Moinat, Scientific Researcher, Erasmus MC
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- 14.05 **Break** (we will start at 14.15)



PROGRAMME CONTINUED IN FINNISH

**HYVÄÄ
HUOMISTA,
SUOMI!**

