

# Health Data Space Event

4 APRIL 2022

#5 Data standards, the key to enable a European Health Data Space

Chapter 2a: Breakout Session



# Chapter 2a: Breakout Use cases



- **#5 Data standards, the key to enable a European Health Data Space**

# Welcome and Opening



- **Enrique Bernal-Delgado MD PhD**, Senior Health Services and Policy Researcher, Data Science for Health Services and Policy Research Group, Institute for Health Sciences. IACS
- **Carlos Telleria**, Carlos Tellería, Biocomputing Unit, Aragon Health Science Institute

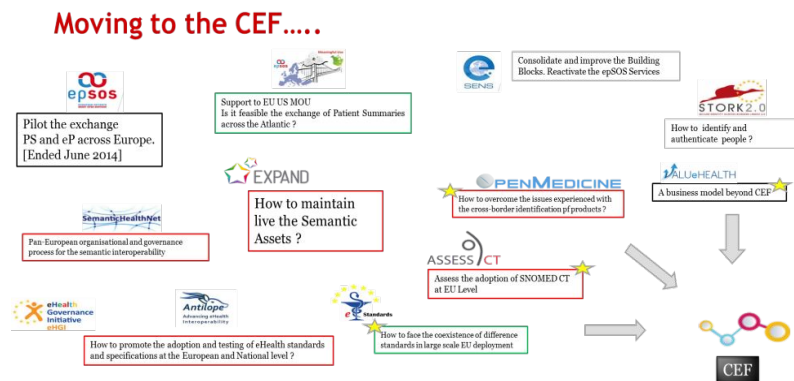
# The International Patient Summary Data Model, 2<sup>nd</sup> edition



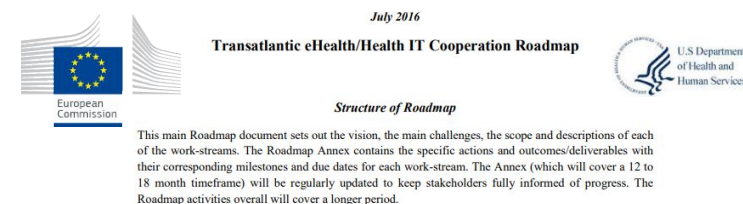
- **Stephen Kay**, IPS Project leader, CEN & ISO Health Informatics



## The more recent part of a long history ..







































The **epSOS projects**, cross-border pilot for PS and eP Exchange, 2009-2014... and several others ..to the **eHDSI**



**2010 EU US EU/US MoU:** ONC Standards and Interoperability Framework (ONC S&I) EU/US eHealth Cooperation Initiative; EU Trillium Project; 2013 The INTERPAS Project, HL7

**2015 Transatlantic eHealth/health IT Cooperation Roadmap:** enforcement of the IPS concept.



                 		                 	
<h1 style="text-align: center;">JOINT ACTION</h1> <p style="text-align: center;">to support the eHealth Network</p>		<h1 style="text-align: center;">JOINT ACTION</h1> <p style="text-align: center;">to support the eHealth Network</p>	
<h2 style="text-align: center;">GUIDELINE</h2>		<h2 style="text-align: center;">GUIDELINE</h2>	
<p style="text-align: center;">on</p>		<p style="text-align: center;">on</p>	
<p style="text-align: center;">the electronic exchange of health data under Cross-Border Directive 2011/24/EU</p>		<p style="text-align: center;">the electronic exchange of health data under Cross-Border Directive 2011/24/EU</p>	
<p style="text-align: center;">Release 2</p>		<p style="text-align: center;">Release 2</p>	
<p style="text-align: center;">Patient Summary for unscheduled care</p>		<p style="text-align: center;">Patient Summary for unscheduled care</p>	
<p>Document Information</p>			
Document status	Adopted by the eHealth Network at their 10th meeting on 25th November 2013	Document Version	1.0.0
Approved by JSA/EN/EC	Yes	Document Number	EN-51
Document Version	1.0.0	Joint Action to support the eHealth Network	
Document Number	EN-51	<ul style="list-style-type: none"> <li>• <a href="#">WP1 - Interoperability and Interconnection</a></li> <li>• <a href="#">Task 1.3 - Update to version 1.0 of the eHealth Guidelines</a></li> </ul>	
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# eHealth Network Guidelines 2013-2016, 2021

# Expectations: No Standard PS

Variants of a PS  
are implemented  
in all provider  
systems ...

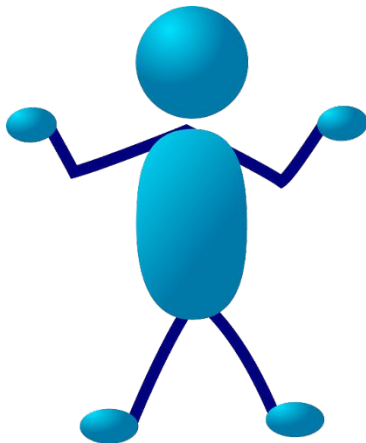


'Local perfection'  
is the enemy of  
the good!



## Expectations: Stakeholders

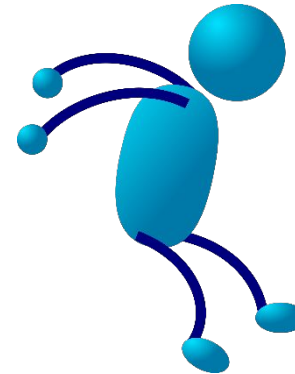
The PS is  
perhaps more  
complex than  
first impressions  
would suggest



**“A sum can be put right:  
but only by going back  
till you find the error and  
working it afresh from  
that point, never by  
simply going on.”**

**-- C. S. Lewis,  
The Great Divorce**

***“A **summary** can be put  
right: ...”***





# ***The International Patient Summary Standards Project\****

*\*Funded by the European Commission*



## Expectations: The 'new' IPS

**“the separate elements already existed and floated through history, but they were never before assembled in this manner. Joining, assembling, the new will always consist of that.”**

*-- A. Kleppe,  
Software Language  
Engineering*

## The IPS: An International Standard – ISO 27269: 2021

- Stand out from the crowd, ‘international’ was a goal but an aspiration too - now a reality.
- SDO collaboration on the shared vision of a single IPS from the start
- A ‘new’ abstract reference specification that comprises a dataset for IPS, with associated rules and reusable, scalable data blocks.

For local, regional and global use,  
for planned and unplanned care



# Everyday Summarization

“We all summarize, very often, when reporting about the movie we saw yesterday or the negotiations during a meeting, recoding an accident, or writing a resume’ of a stage play at school. *Everyday summarizing skills belong to everybody’s communication competence.*”



Endres-Niggemeyer B. Summarizing Information. Springer-Verlag, Berlin Heidelberg, 1998.

# The IPS Properties (1)



Provide an **healthcare summary** for a citizen at the point of care



It is **minimal and non-exhaustive**



It is **specialty-agnostic** and **condition-independent.....**but still **clinically relevant**

## The IPS Properties (2)



Designed to be **simple**



Usable **any time**, in **any place**; by **any one**



**Multi-beneficiaries:** Individuals, Healthcare Providers, Society



# EN 17269: 2019


## The IPS Use Case, and 4 Scenarios

- Original use case was to exchange a Patient Summary cross-border for unscheduled care at the point of care.
- The Scope was extended:
  - **IPS Scenario 1: Cross-Border, Unscheduled care**
  - **IPS Scenario 2: Local, Unscheduled care**
  - **IPS Scenario 3: Cross-border, Scheduled care**
  - **IPS Scenario 4: Local, Scheduled care**

Fast-tracked to ISO and superseded by **EN ISO 27269: 2021, first edition**



# Change requests to Datablocks

Patient attributes	Allergies & intolerances	Problems (incl. diagnosis)	Medication summary	Immunization (incl. Vaccinations)	Results	Vital signs
Cross-border (conditional)	History of procedures	History of past illness/problems	History of pregnancy	Medical devices (incl. implants)	Functional status	Social history (incl. life style factors)
Provenance	Advance directives	Care plan	Address-book	Healthcare provider		

Non-Exhaustive dataset

## New Macro IPS Datablocks

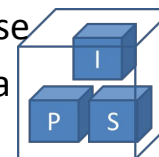
— Because

- New use cases
- New scenarios
- New Requirements
- ...

## Refinement of existing IPS Datablocks

• Because

- More precision & examples required
- New features for reuse
- Conformance criteria
- ...



EN ISO 27269: 2021, 1<sup>st</sup> edition  
Is the IPS Data Model

# IPS DataBlocks for Rare Disease case?

## An example for testing inclusion ...

Patient attributes	Allergies & intolerances	Problems (incl. diagnosis)	Medication summary	Immunization (incl. Vaccinations)	Results	Vital signs
Cross-border (conditional)	History of procedures	History of past illness/problems	History of pregnancy	Medical devices (incl. implants)	Functional status	Social history (incl. life style factors)
Provenance	Advance directives	Care plan	Address-book	Healthcare provider	Child-health	Family history (incl. Genetics)
Alerts (incl. Risks)	Patient story (incl. Author)	Recent encounters	Computable guidelines (incl. Orthacodes)	...		

Estimated 6-8000 Rare Diseases...

- Surely not 6-8000 datablocks required ... but will six candidate IPS Datablocks suffice?
- Evidence for these six as opposed to others?
- Are the blocks of generic use?
- Assessment of relevance?
- Transparency via Inclusion Rules?

## The IPS and the EHR

- The EHR is one source, perhaps other sources to for producing a summary. A summary is essentially a derivative.
- Although the **IPS** extends by design, the extensions are not intended to create a full EHR.
- The **IPS** fulfils a fundamentally different purpose to an EHR.





# Summarization and the IPS

- The reduction of information to its most essential points; it retains the relevant and discards the irrelevant for the purpose of effective, efficient communication.
- Determining what is important and assessing what is relevant is non-trivial.
- Both the producer and user of the summary actively engage in **relevance assessment**, which goes largely unnoticed.

# The IPS ... Critical and Challenging

“Patient summaries can be considered as clinical tools, providing unique support for clinical decision making.”

- Sittig D F., et al. (2008) *Grand Challenges in clinical decision support*

The ‘unscheduled care’ scenario is stressful; the summary user is “expected to pick up the content, to restructure it with respect to their own prior knowledge, to integrate it into their own knowledge structure and finally to use it”.

- Endres-Niggemeyer B. (1998) *Summarizing Information*. Springer-Verlag, Berlin Heidelberg

“The farther back you can look,  
the farther forward you are likely to see.”

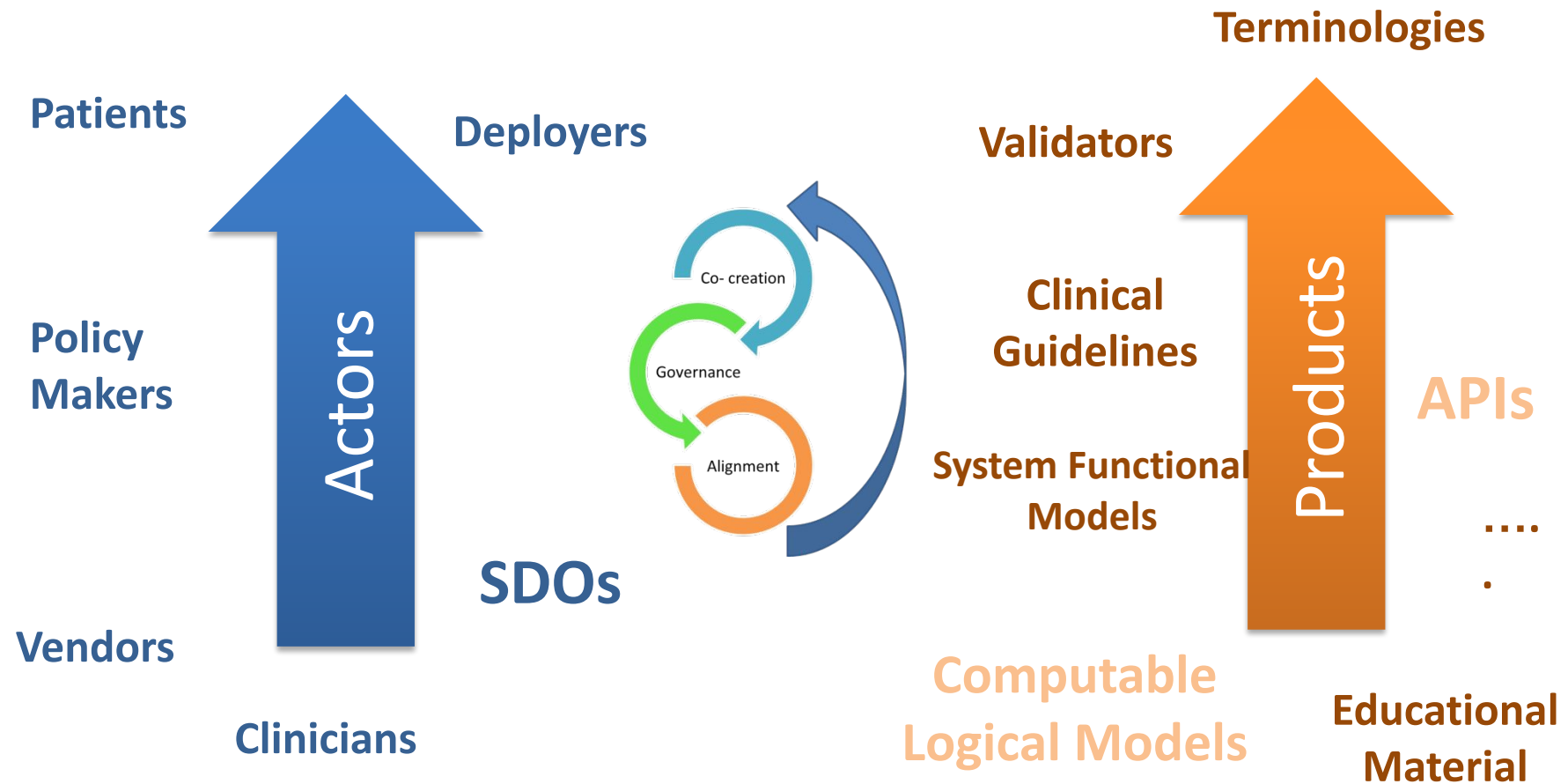
Winston Churchill

# The IPS and G7

- The value of data is found in its use; “data by itself has no value. It’s the ever-changing ecosystem surrounding data that gives it meaning”.
  - Borgman C, L. (2015) [Big Data, Little Data, No Data](#).
- There does seem to be momentum with respect to the [IPS](#). In June 2021, the G7 health ministers made the following commitments in relation to digital health:

“38. We commit to work towards adopting a standardized minimum health dataset for patients’ health information, including through [the International Patient Summary \(IPS\) standard](#), with the shared objectives of facilitating health interoperability within and between countries, ... To achieve this goal, we will work with the Global Digital Health Partnership (GDHP) as they are already advancing [IPS](#) efforts.”

# Towards an «IPS ecosystem»





# Up to Date News:



Kick-off meeting

2<sup>nd</sup> edition of ISO 27269

co-leads: Stephen Kay and Rob Hausam

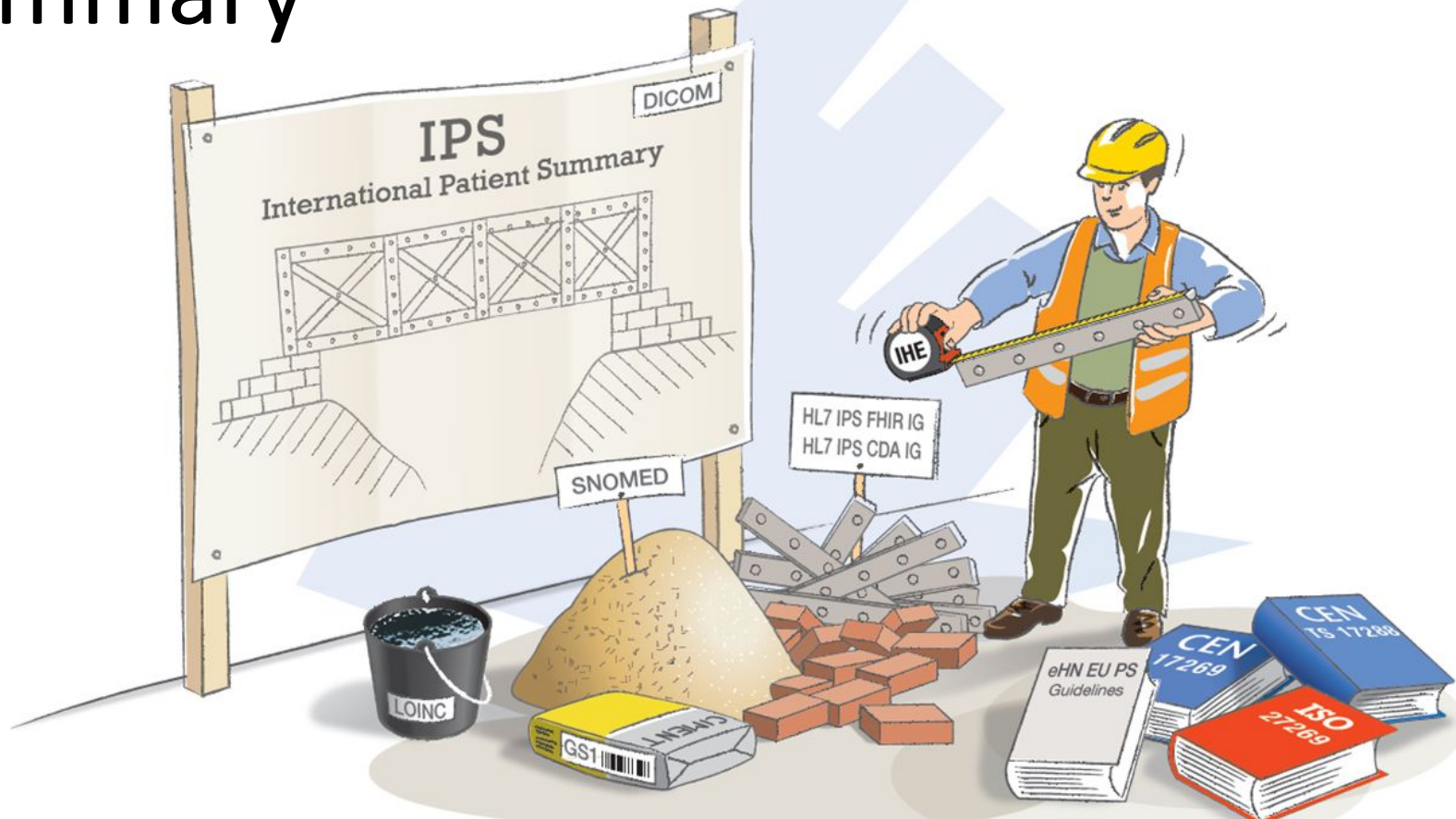
30/03/2022

[International-Patient-Summary.net](http://International-Patient-Summary.net)

1

WEB-SITE:  
[International-Patient-Summary.net](http://International-Patient-Summary.net)

# Acknowledgements ... ... a summary



# EHDEN - OMOP and common data models



- **Sebastiaan van Sandijk**, Clinical Informatician, Odysseus Data Services



## 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 standardized to a common data model





# EUROPE: AN OCEAN OF DATA, A DESERT FOR ANALYSIS





# PILLARS OF THE EHDEN APPROACH

## Infrastructure



Creation of an **EU-wide** federated network architecture

**Privacy** by design

**Data harmonisation** to the OMOP common data model

Training & certification of **SMEs**

## Research & Outcomes



**Use cases** to evaluate the EHDEN federated network

Collaboration on consistent **methodologies**

Collaboration with the global **OHDSI** research network

Incorporation of the **ICHOM** health outcome standards

## Education & Community



Establishment of an **EHDEN Academy**

Expansion of the **OHDSI** network in Europe

Collaboration on **collective memory** for research use cases

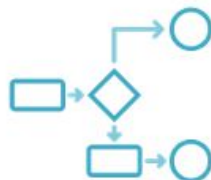
# ENABLERS FOR REAL-WORLD EVIDENCE (RWE)



Data interoperability



Data network



Standardised analytics



Technical Infrastructure



Strong community



**Clinical characterisation:**

What happened to them?

description



**Patient-level prediction:**

What will happen to me?

prediction



**Population-level effect estimation:**

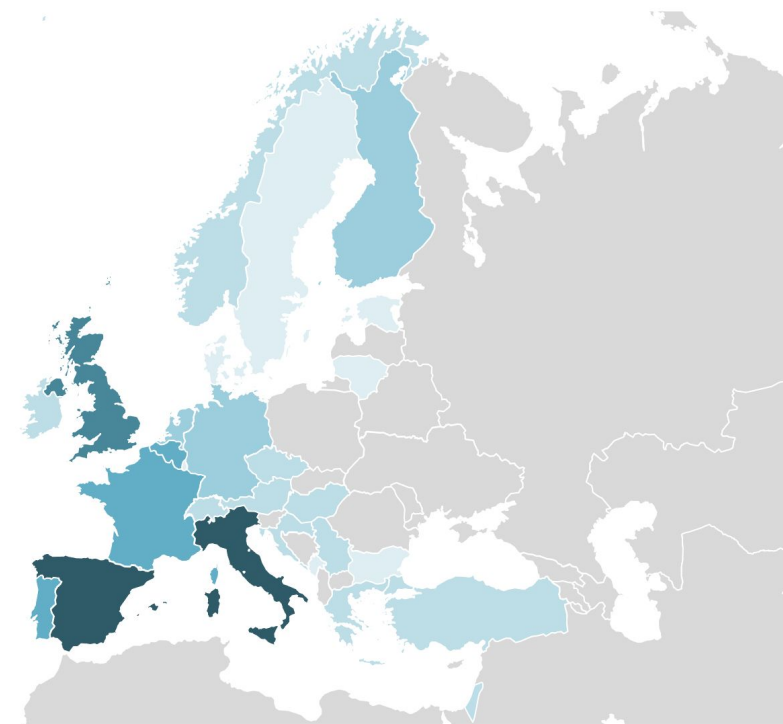
What are the causal effects?

causality

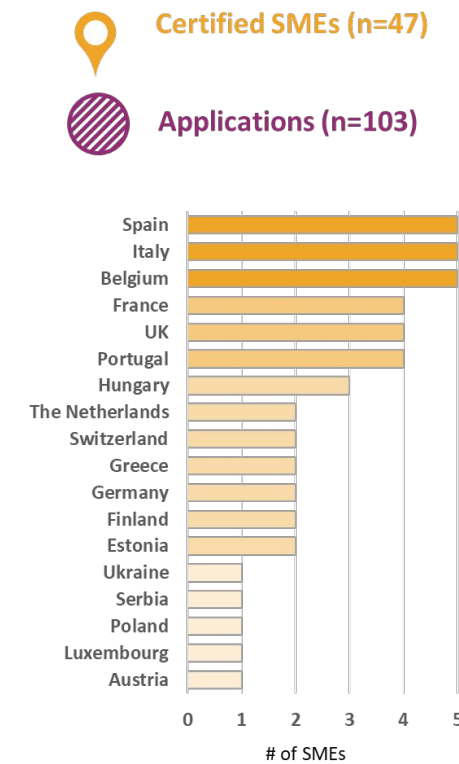
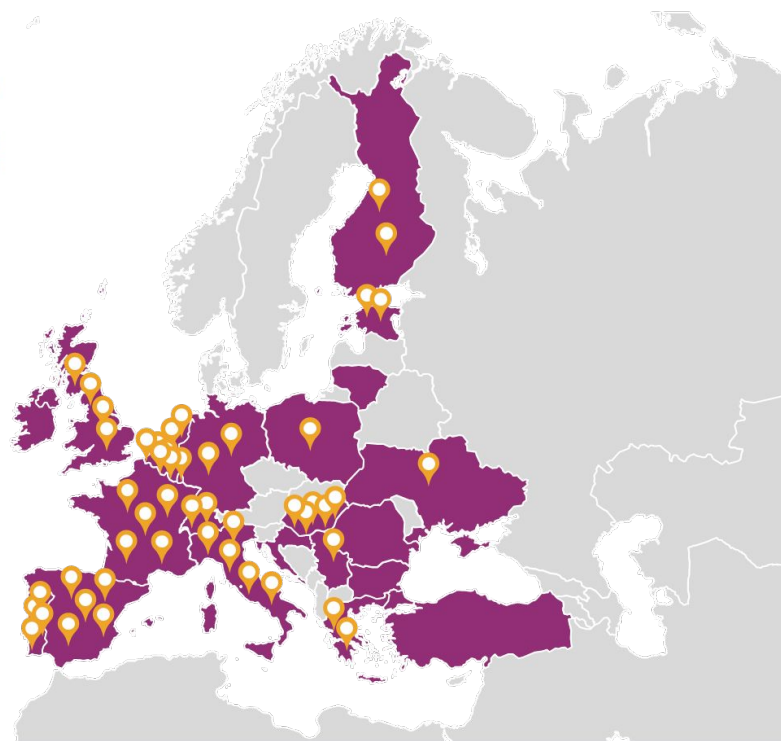
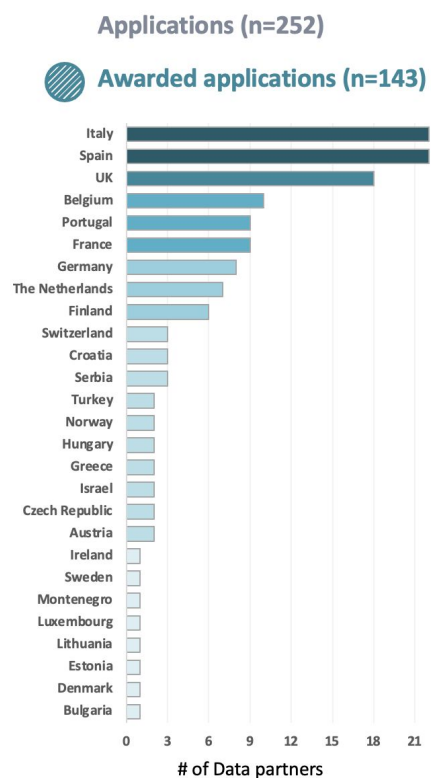




# EHDEN DATA NETWORK AND SUPPORT NETWORK



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





# GLOBAL ADOPTION OF OMOP-CDM



Big Data for  
Better Outcomes



PIONEER



miracum



H<sub>2</sub>O

HEALTH OUTCOMES  
OBSERVATORY



NICE National Institute for  
Health and Care Excellence



SOPHIA  
Stratification of Obese Phenotypes to Optimize  
Future Obesity Therapy



OECD

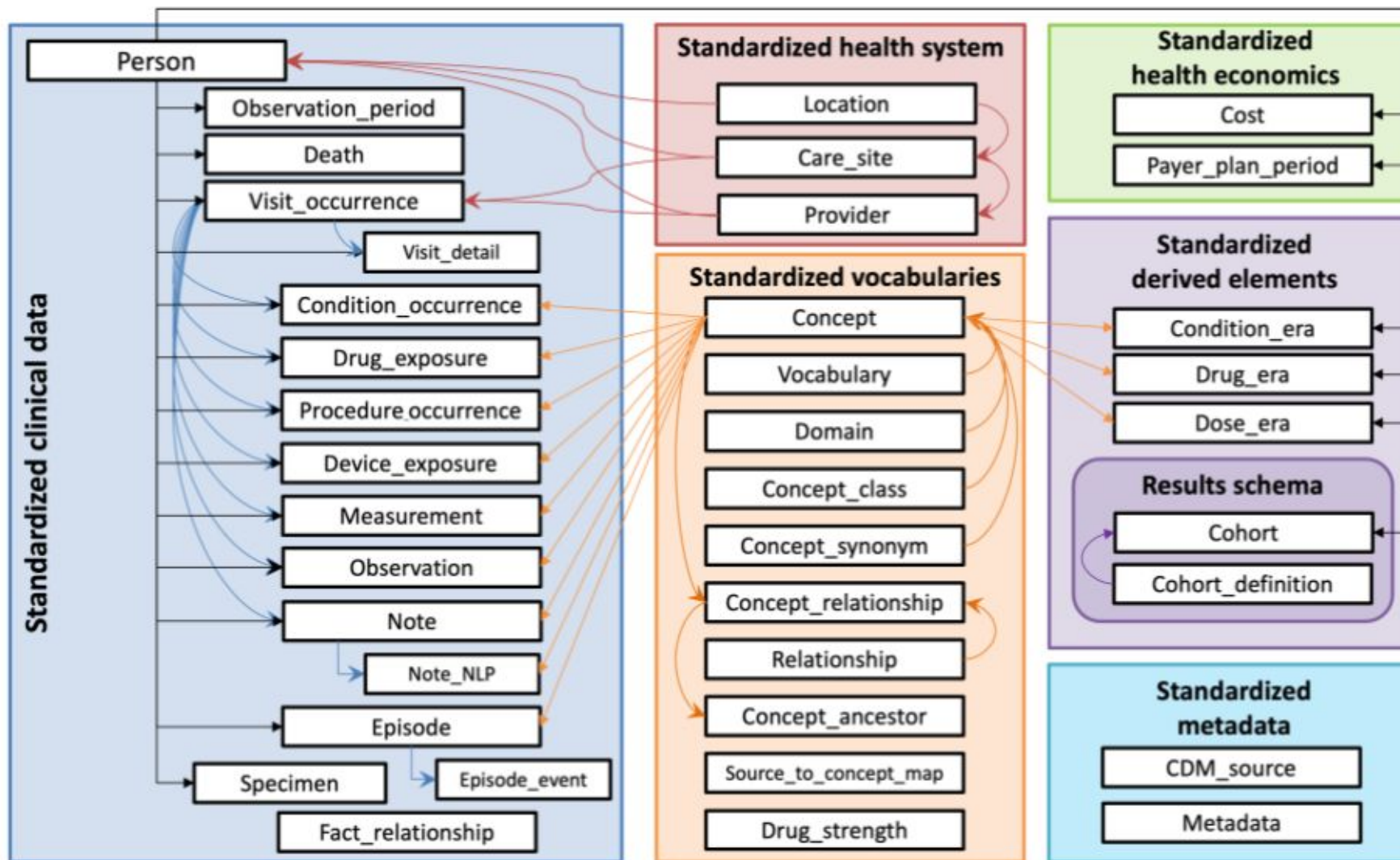


Health Data Research UK



**EHDEN**

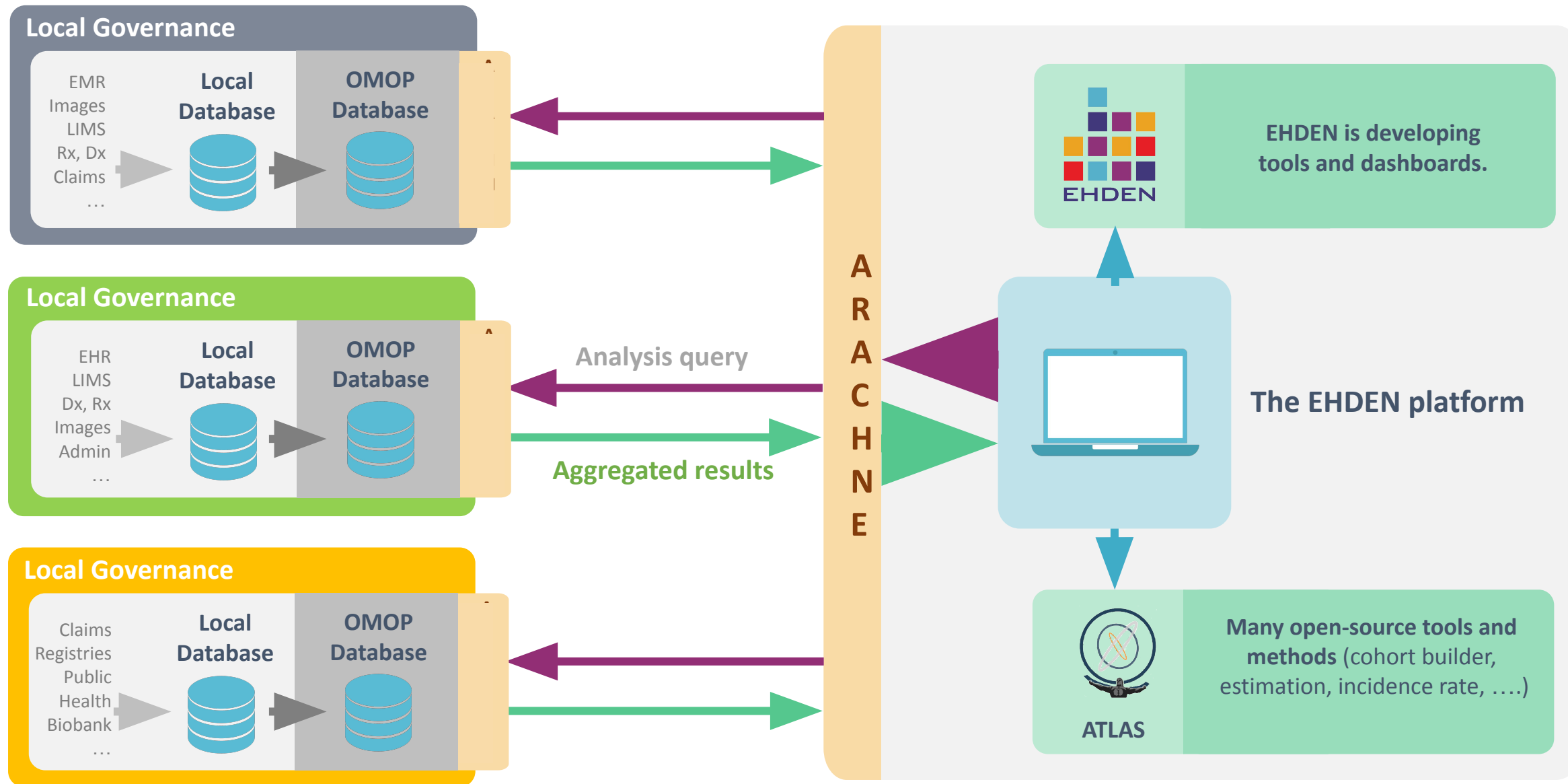
EUROPEAN HEALTH DATA & EVIDENCE NETWORK



Patient-centric  
Tabular  
**Extendable**  
Relational design  
**Standardised  
analytics**



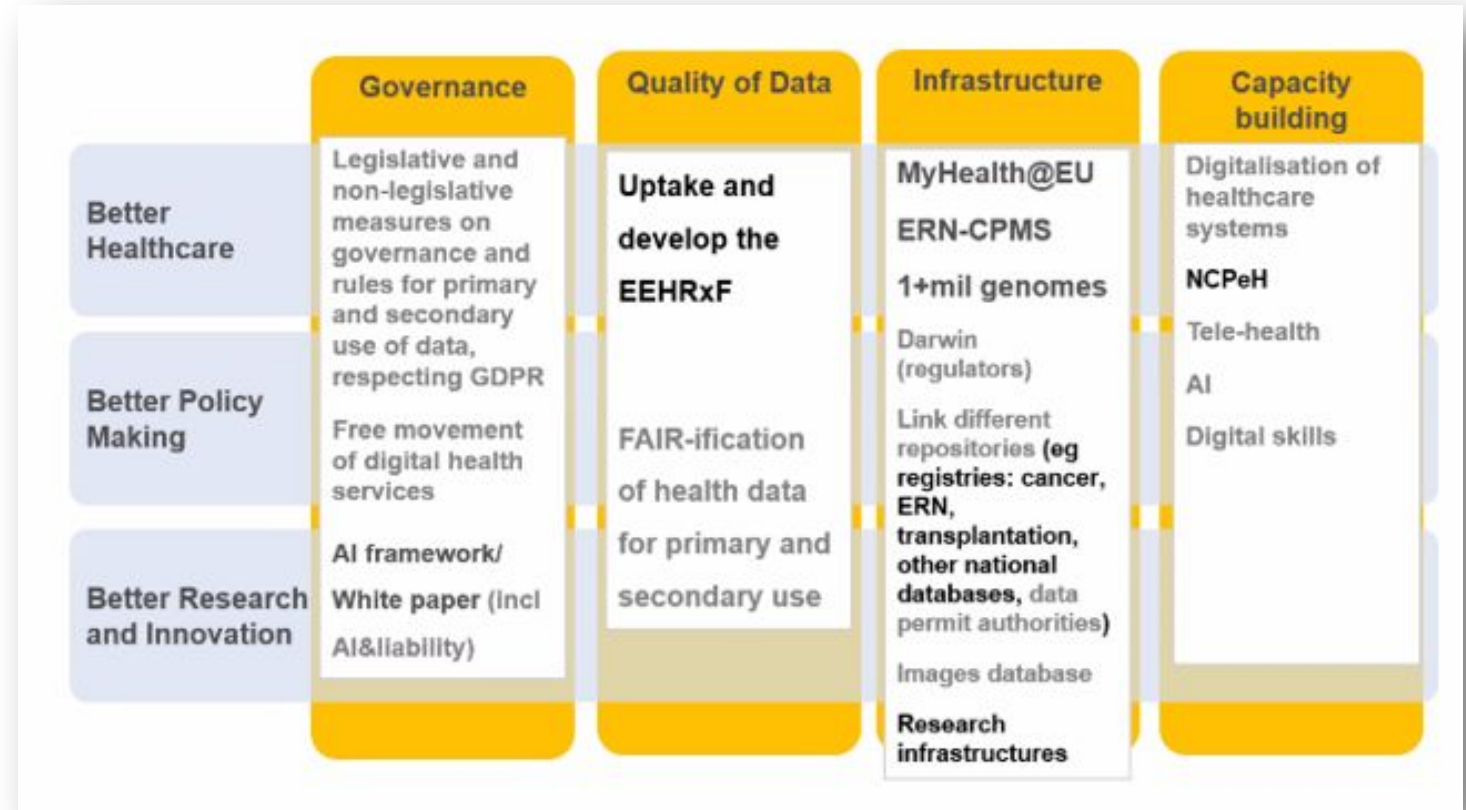
# EHDEN FEDERATED STUDY NETWORK: CROSS-BORDER, MULTI-SITE







- EHDEN is and will be aligned with EHDS, GAIA-X, ...
- Network of federated networks, shared approach(es)
- Multiple nodes within a resilient international framework
- Interoperability via standards, systems and governance for cross-border networking
- Attitudinal change on the role of data for research





# EHDEN IMPACT TODAY AND TOMORROW

- Project in fourth year. Ends in 2024, but to continue as new legal entity
- Building one of the largest international collaborative research networks on the planet
- EHDEN has contributed to understanding and response of COVID-19
- We are informing, educating and working with a remarkable network
- Numerous projects benefitting from our expertise, knowledge, skills
- We keep extending and enhancing capabilities for federated research / analysis
- Aligned with evolving data spaces and networks



[www.ehden.eu](http://www.ehden.eu)



[@IMI\\_EHDEN](https://twitter.com/IMI_EHDEN)



[IMI\\_EHDEN](https://www.linkedin.com/company/IMI_EHDEN)



[github.com/EHDEN](https://github.com/EHDEN)



This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 806968. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.

# Data Standardisation



- **Rubén Villoria**, Head of Business Solutions for Health Evidence, Harmony Alliance





HARMONY



ALLIANCE

# Data Standardisation

Gaia-X Health Data Space Event 4 April 2022

Rubén Villoria. Head of Business Solutions for Health Evidence



UNE-EN ISO 9001 UNE-ISO/IEC 27001 UNE 166302 ISO 27701  
ERO 023/2003 SI 0003/2004 IDI-0003/2013 PI-0001/2020



**CMMIDEV / 3**<sup>SM</sup>  
Exp. 2019-04-22 / Appraisal #26155

GMV SOLUCIONES GLOBALES INTERNET S.A.U.

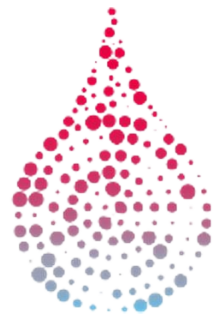
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# HARMONY



## ALLIANCE

Public-Private Partnership for Big Data in Hematology  
Accelerating better treatment of blood cancer patients



Community of  
approx.

**400** professionals



Big Data Platform with  
**>70.000**

**patientized**  
records  
identified



Ove  
**100**  
organizatio  
ns



Research and  
Multi- stakeholder  
projects

from  
**18**  
countrie  
s



key targeted  
blood  
cancers



Big Data  
analytic  
services

Funded by



Innovative  
Medicines Initiative

Support  
from



European Union's  
Horizon 2020 Research  
and Innovation  
Programme



European Federation of  
Pharmaceutical  
Industries and  
Associations

Part of



Big Data for  
Better Outcomes

IMI Big Data for  
Better Outcomes  
(BD4BO)

# Core elements of the HARMONY Architecture

## FOCUS BLOOD CANCERS

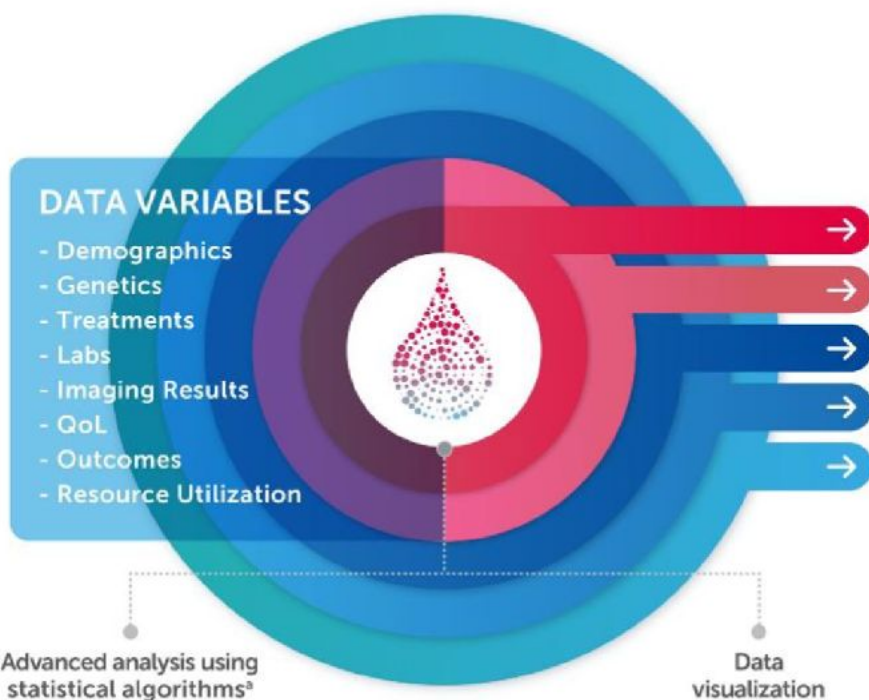


## DATA PROVIDERS Partners and Associated members

- DATA SOURCES
- Hospitals
  - Interventional and non-interventional trials
  - Biobanks
  - Pharma

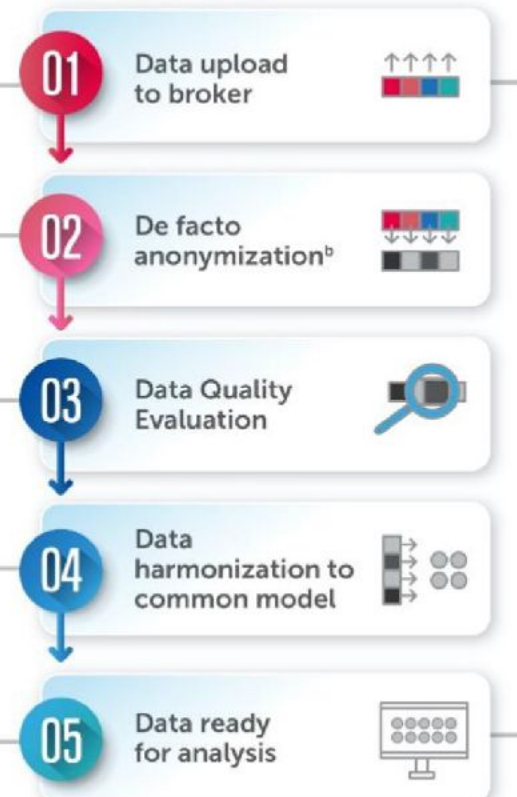
FULL PROJECT RESEARCH

## HARMONY BIG DATA PLATFORM DATA PROCESSING



<sup>a</sup> Only data essential to the analysis are accessible (to a limited group of users during a specific time span)  
<sup>b</sup> Data anonymization process is ISO 27001 certified

## BIG DATA PLATFORM ANALYTICS



## CURRENT AND UPCOMING PROJECTS

- Project Research publications
- New Research Projects
- Harmonization of Outcomes
- Guidelines
- Speed up drug development
- Increase application of omics data in clinical practice
- Additional safety signals
- Patient journey and disease knowledge

# Data Standardisation in HARMONY



# Data Standardisation in HARMONY

## Challenges and Requirements



01

### Multiple Data Providers

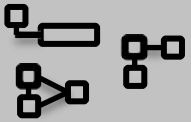
Hospitals, BioBanks, Cooperative Groups,  
Pharma Industry



04

### Need to measure data quality

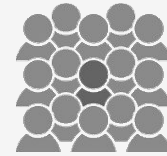
The data in the platform should be  
HIGH Quality data



02

### Lots of different Structures

EHR, CRF, EMR, Cooperative Groups  
registries



05

### Working with rare diseases

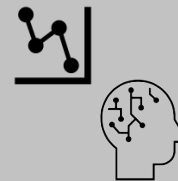
Most of haematological Malignancies  
are rare diseases with specific types  
of OMICS Data



03

### Data Collected for different purposes

Primary Care, Secondary Care, Clinical  
Trials, investigation



06

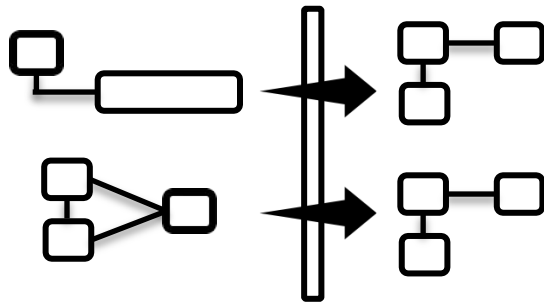
### Support for different analysis

The data should be used in different  
and diverse research proposals

# Data Standardisation/Harmonisation in HARMONY

We need to put together different structures different content meaning, with very specific variables, to allows to measure the quality of the data and to allow to use the date for different research Objectives

We need, we must, we have to harmonise data



# HARMONY Standard selection

## Needs

Vocabulary and structure extension, support different categories of data, quality, efficiency...

## Standards

FHIR, i2b2, OMOP CDM, ...



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Vocabulary and structure extension, support different categories of data, quality, efficiency...

## Standards

FHIR, i2b2, OMOP CDM, ...

## Look around

Look at other projects: EMIF, EHR4CR, BigData@Heart, Pioneer, EHDEN...

## Tools

Tools available to standardization, analysis, etc...



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Vocabulary and structure extension, support different categories of data, quality, efficiency ...

## Standards

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Look at other projects: EMIF, EHR4CR, BigData@Heart, Pioneer, EHDEN...

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## OMOP CDM

Worldwide multi stakeholder open community,

Supports standard a non standar vocabularies

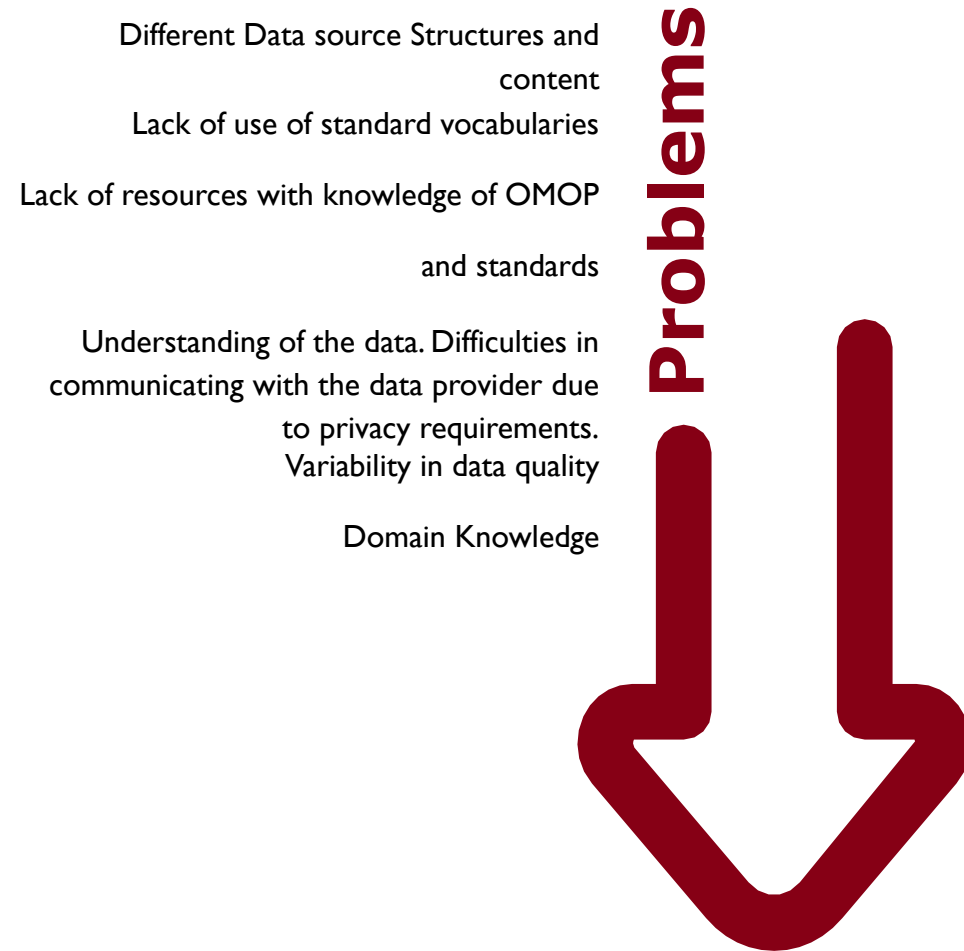
Specific working groups: OMIC data, Oncology working group

Robust analytical tools for research and quality improvement





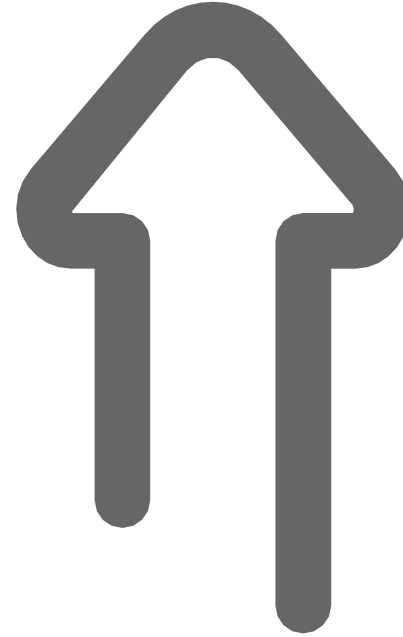
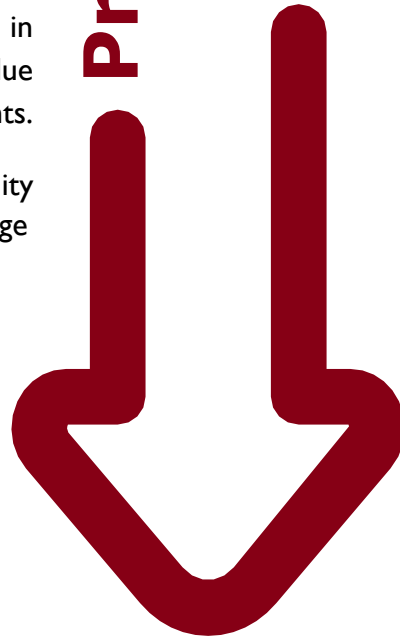
# HARMONY Standardisation problems/solutions



# HARMONY Standardisation problems/solutions

Different Data source Structures and content  
Lack of use of standard vocabularies  
Lack of resources with knowledge of OMOP and standards  
Understanding of the data. Difficulties in communicating with the data provider due to privacy requirements.  
Variability in data quality  
Domain Knowledge

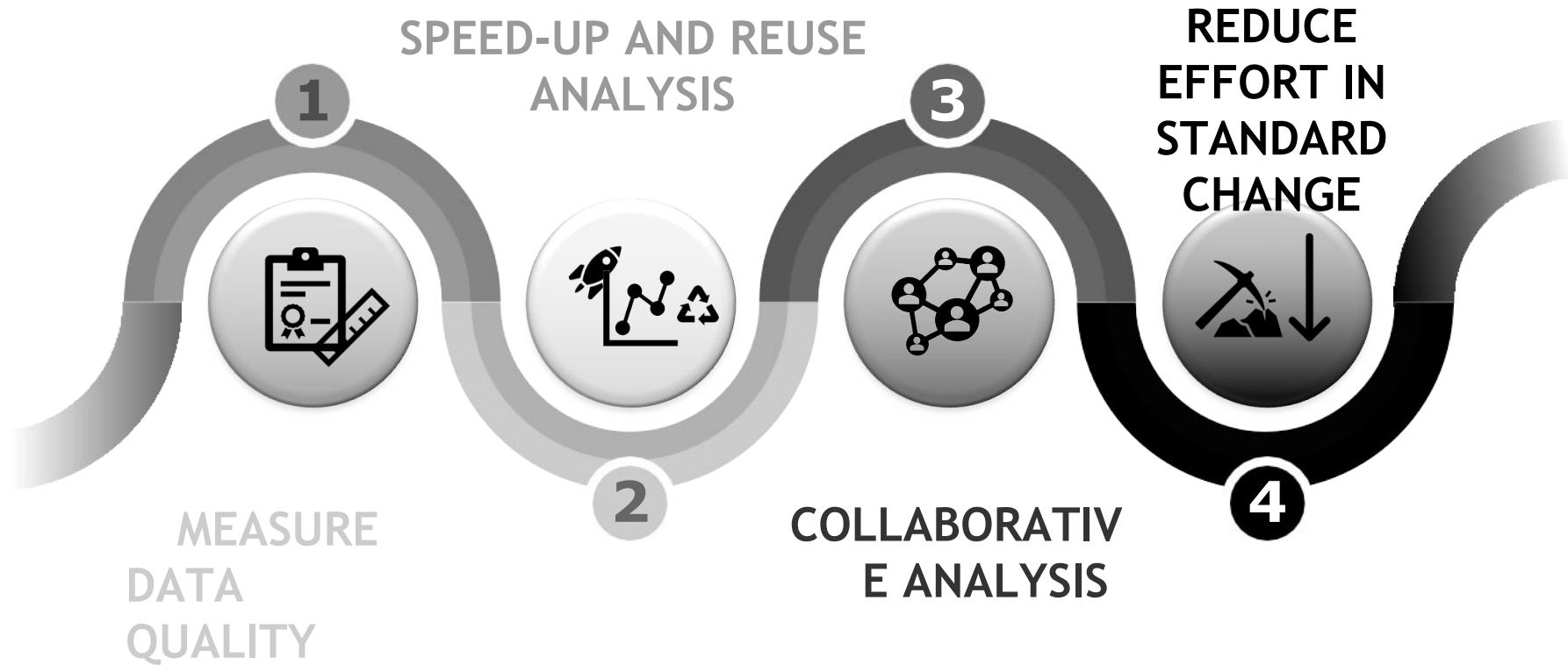
## Problems



## Solutions

Establishing new processes and communication channels.  
Prioritising the harmonisation based on type and quality of data.  
Creation of tools and processes  
Include clinical experts at some points in the process (Key Opinion Leaders)  
Collaboration with OHDSI community

# Why do we have to use STANDARDS?



# Challenges we need to address in the short term

## STANDARD

Each standard has a purpose and its structure responds to a specific use, but all standards have to be adaptable and create bridges between them.

## TEAM

Build teams with high specialisation and knowledge of data and structures as well as standards. BIO-TEC capabilities

## INDUSTRIALISATION

Tools that enable the industrialisation of the harmonisation process and easy adaptation between standards.

# Health-RI & clinical data standards



- **Jan-Willem Boiten**, Program Manager, health RI



**health RI**

*enabling data driven health*

## Health-RI & clinical data standards

Jan-Willem Boiten; April 6<sup>th</sup> 2022

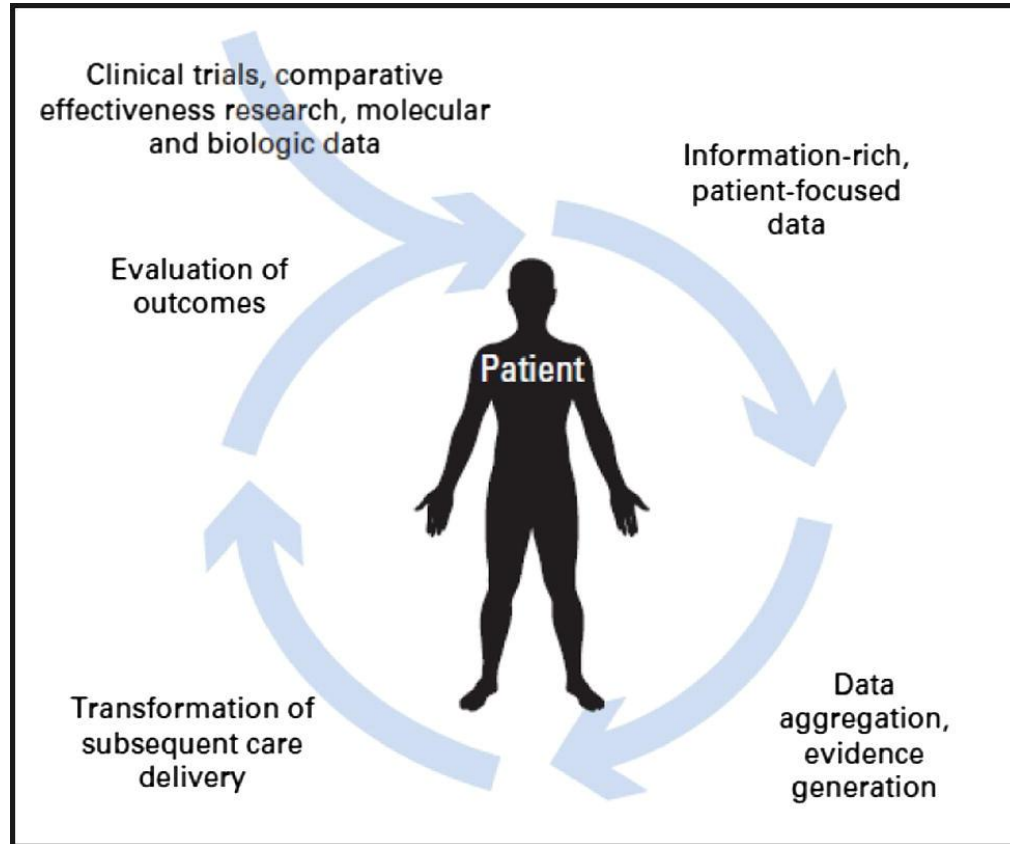


janwillem.boiten@health-ri.nl



# Goal - Learning health system

## Real time evidence from real world data



*Copied from Radiotherapy and Oncology 109, 159-164, 2013*

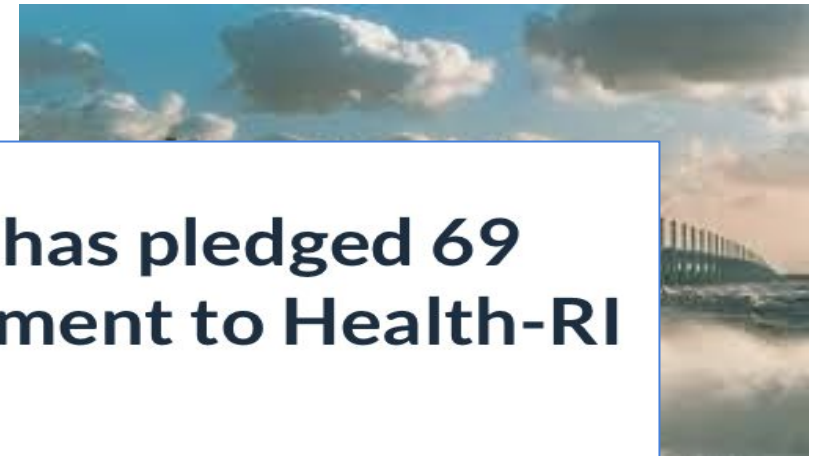




# Why do we need Health-RI?

- Optimally profit from Big Data, AI & Deep learning for Personalized Health asks for **focus and pooling of expertise**
- Maximize utilization of **real world data**
- Momentum for unlocking healthcare vs. research data asks for a **collective voice**
- Many initiatives and infrastructures, often with overlapping scope and people **defragmentation** is desirable
- **Collaboration and convergence** requires a national partner

Point solution



← News

**Dutch Government has pledged 69 million euros investment to Health-RI**

News | 9 April 2021

Collective infrastructure

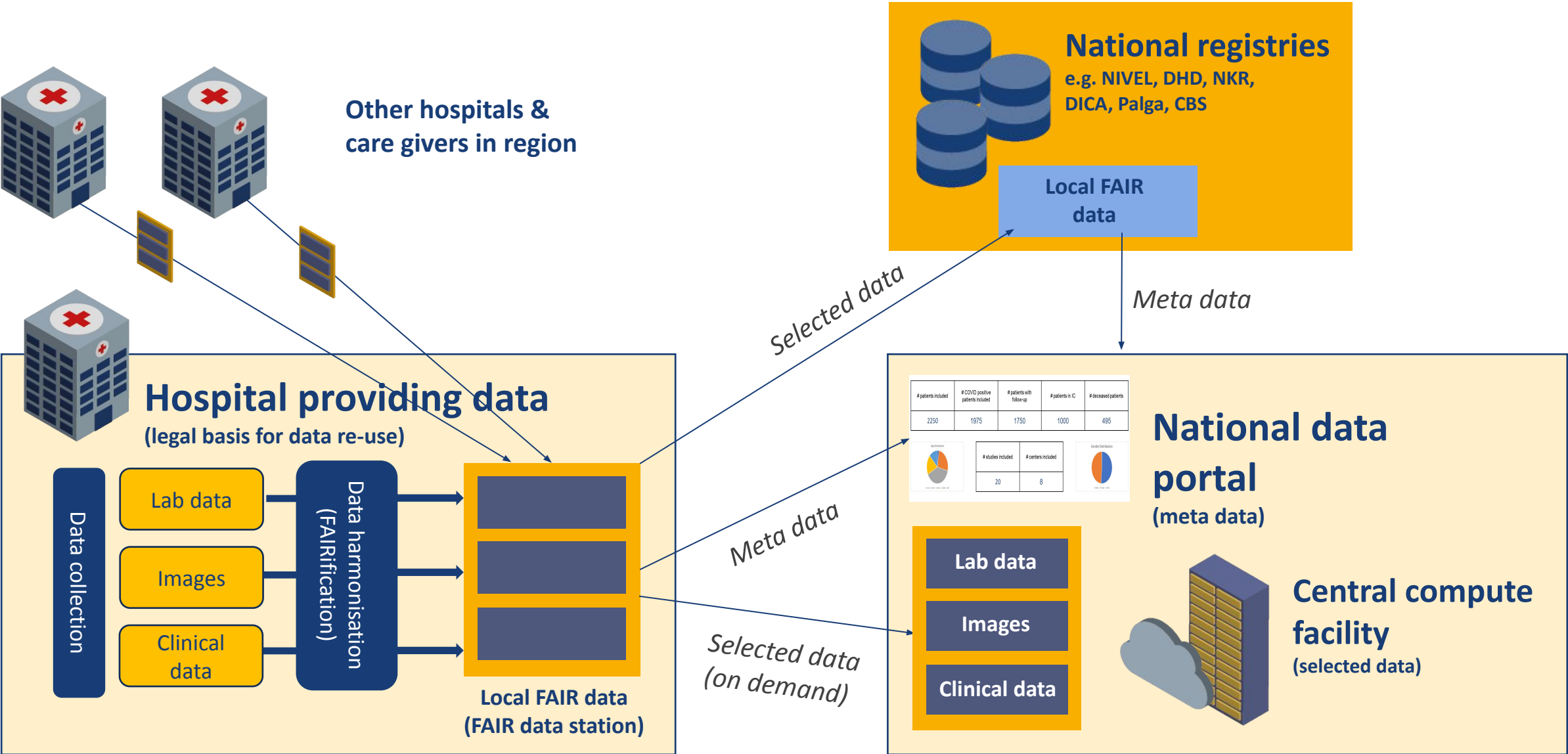


# HOW - Hub and nodes model

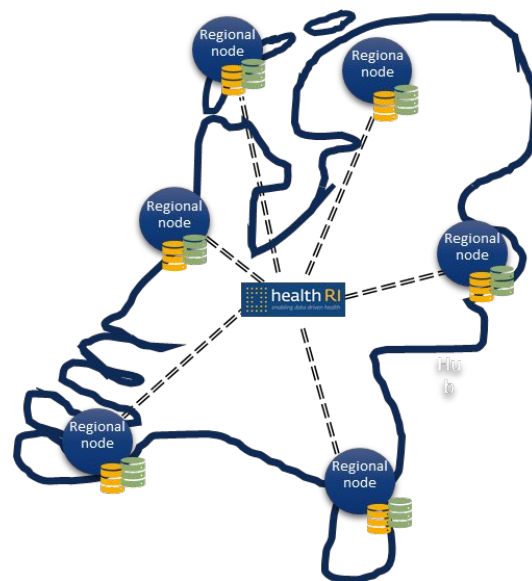
- Network of regional nodes
- Leave data at the source whenever possible
- Resource for AI and machine learning
- Four focus areas building a network nationally & regionally in every node
  1. ELSI ☐ Compliance by design
  2. FAIR Data Implementation ☐ FAIR at the source
  3. Architecture & implementation
  4. Biobanking & registries
- Use cases should provide demonstrators for any solution from these networks



# Architectural landscape – making data available



# Think big – start small – act now: COVID-NL portal



**Think big:** national health data infrastructure

1

Connecting communities

2

Expertise, tools & services

3

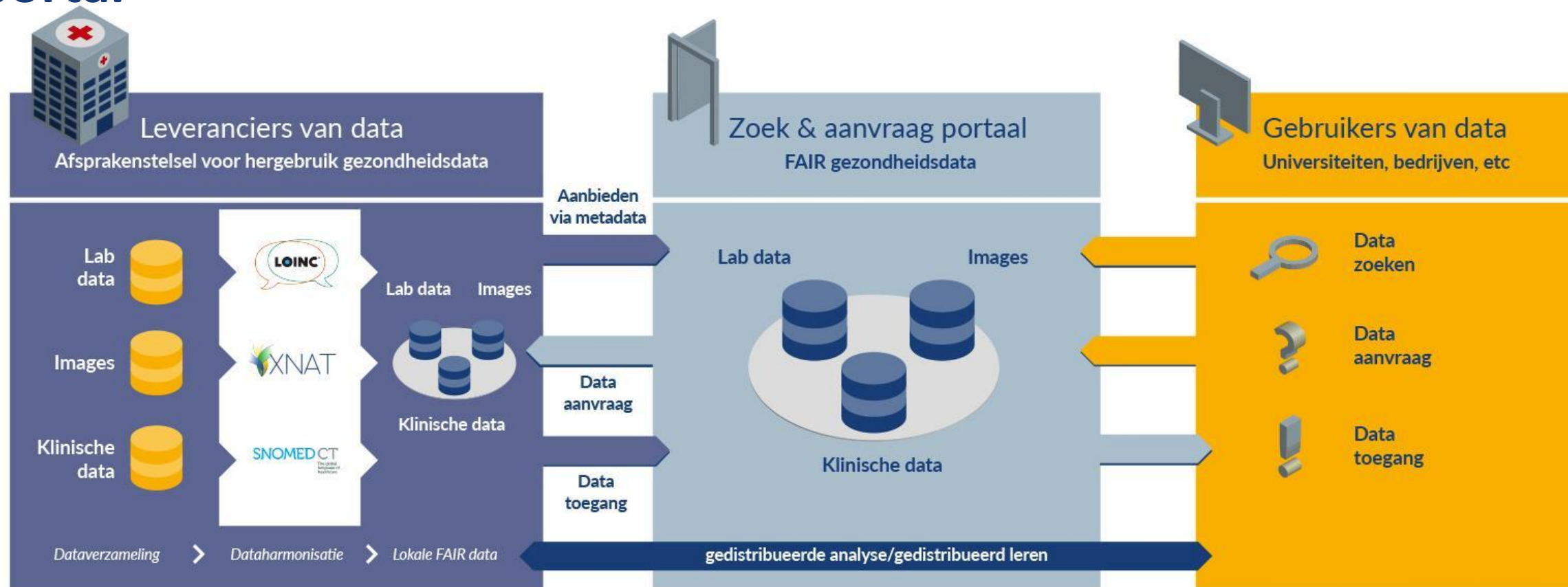
Best practices



Creativity is the key

**Start small:** national COVID-19 portal

# A Health-RI demonstrator - a national COVID-19 observational data portal



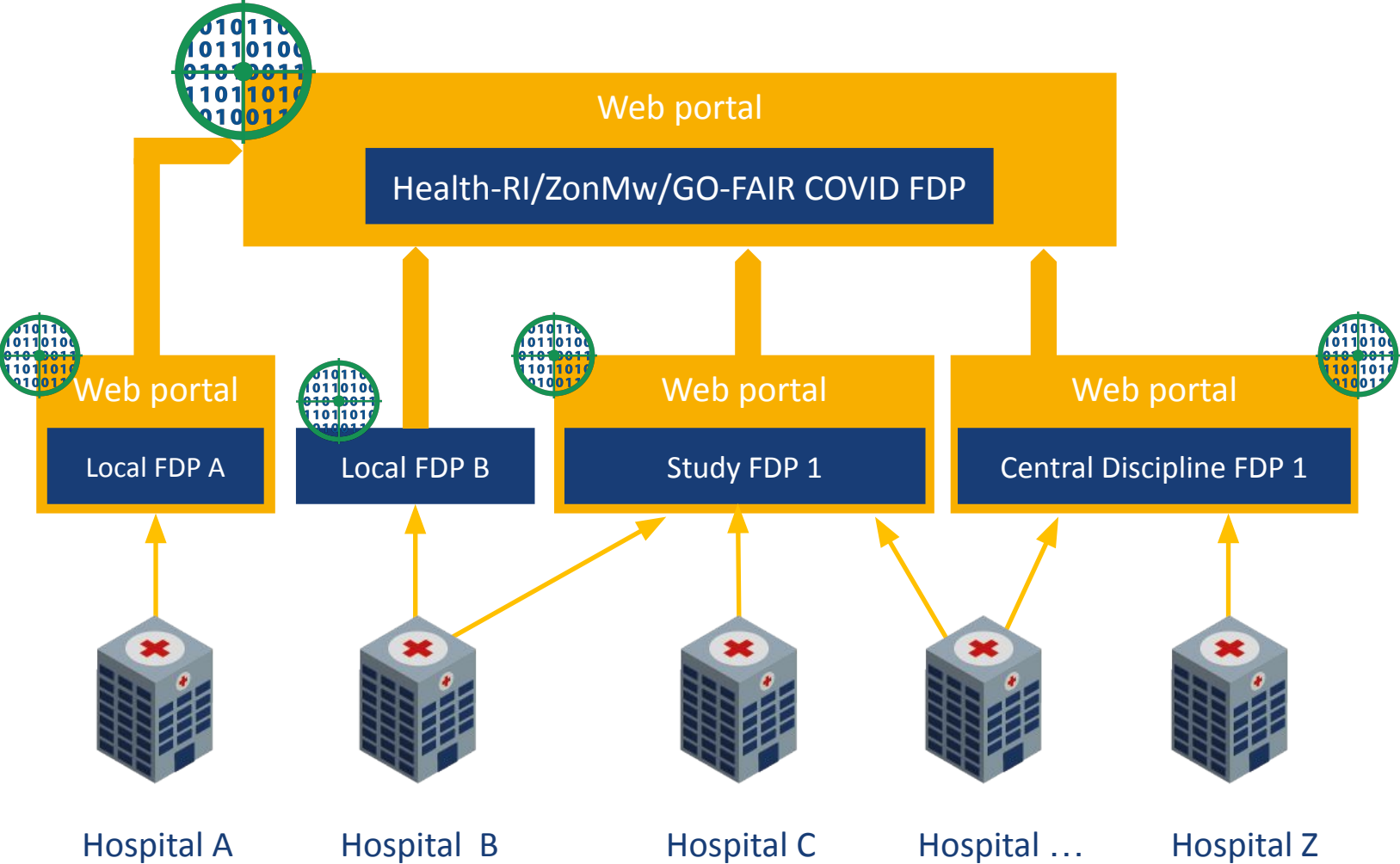
*The hospitals - data contributors:  
Legal basis, data harmonization*

*The national portal - data discovery  
& accessibility*

*Users – controlled access &  
data reuse*

# Integrating local data portals into one national portal

*Different portals requiring specific meta data standards (“sunflower” principle\*)*



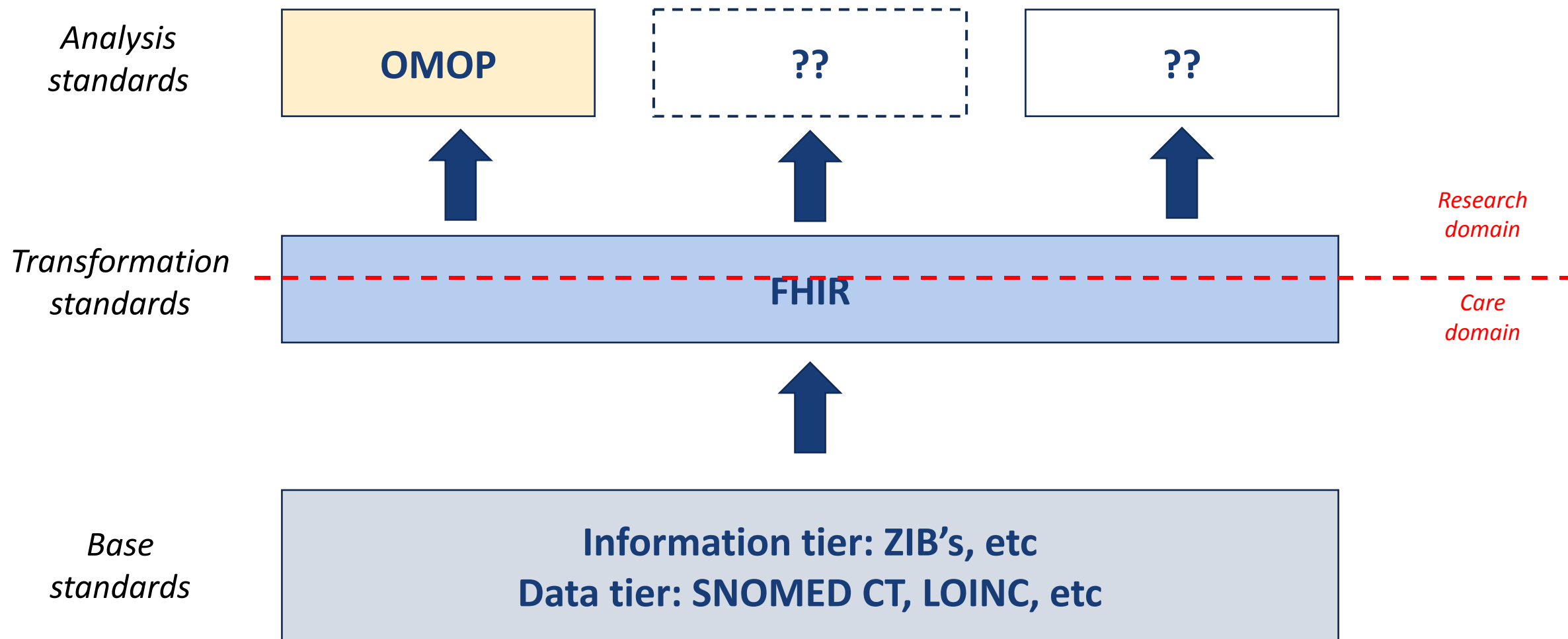
*Administrative and descriptive metadata to facilitate data discovery & accessibility*

*Data at patient/record level*

*Pseudonymisation keys*

*\*) Metaphor copied from Vincent van Pelt (NICTIZ)*

# Clinical data standards – results from first workshop





# COVID-NL - Challenge of scaling towards a national health data hub



DATA



# Rare Disease Data in Health Data Spaces



- **Tala Haddad**, Scientific Project Manager,  
Orphanet Inserm US-14



# The specific challenges of rare disease data

## *Rarity!*

*International is the right scale*

## *Domain evolutivity*

*New RD are frequently described*

## *Heterogeneity*

*Need for cross-domain harmonisation*

## *Portability*

*For a consistent healthcare pathway*

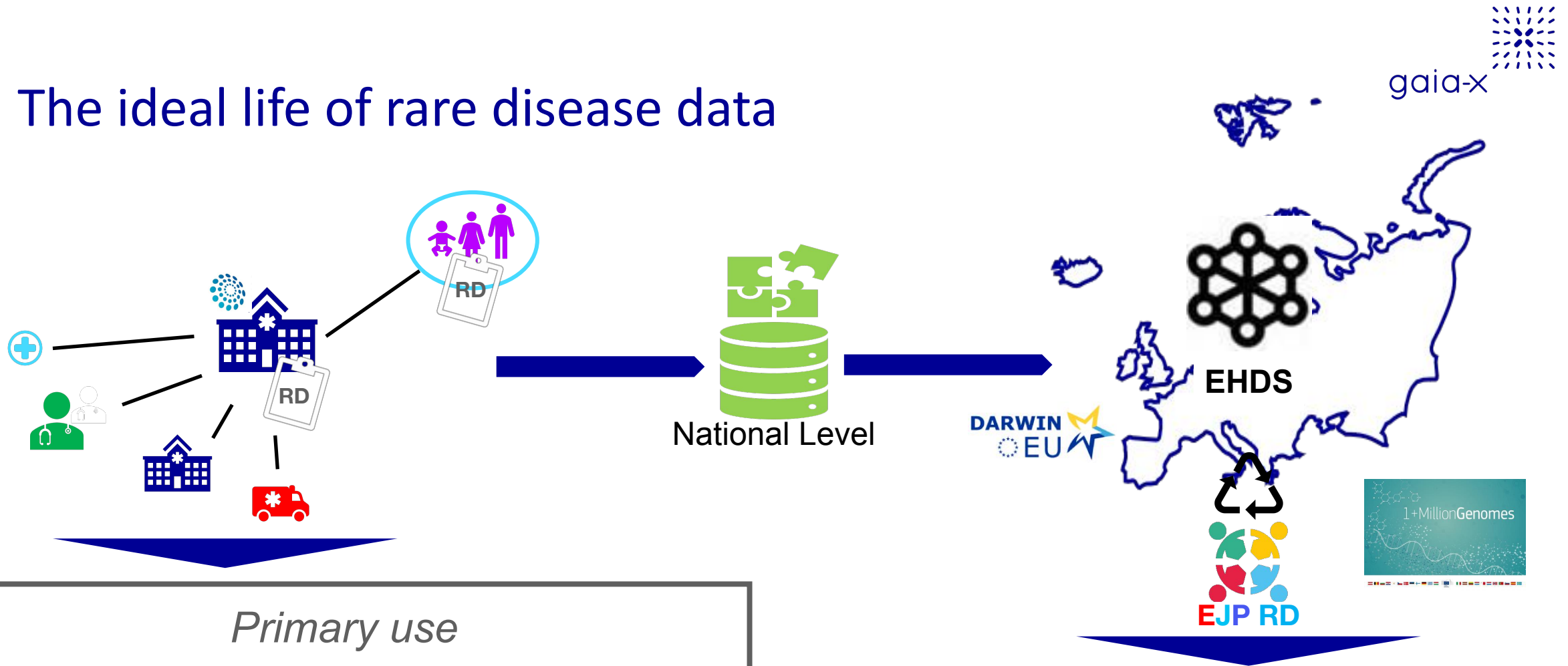
## *Reusability*

*For knowledge generation based on data*

## *Invisibility*

*RD are ill-represented in health terminologies: need for codification*

# The ideal life of rare disease data



## Primary use

- *Better knowledge, best practices*
- *Continuity of care*
- *Better disability evaluation and compensation*
- *Adequate cross-border and primary care*

## Secondary use

- *Research*
- *Evidence-base decision-making*

# ORPHANET NOMENCLATURE IN DETAIL



[ A MEDICAL TERMINOLOGY **SPECIFIC TO RARE DISEASES** (<1 in 2000 cases) ]  
Improved rare disease codification is a European priority since the Council Recommendation on the field of rare diseases in 2009.



**Fanconi-Bickel syndrome** **PREFERRED TERM** [Suggest an update](#)

**Disease definition** **DEFINITION**

A rare glycogen storage disease due to a deficiency in solute carrier family 2, facilitated glucose transporter member 2 and characterized by hepatorenal glycogen accumulation leading to severe renal tubular dysfunction and impaired glucose and galactose metabolism.

**ORPHA:2088** **ORPHAcode**

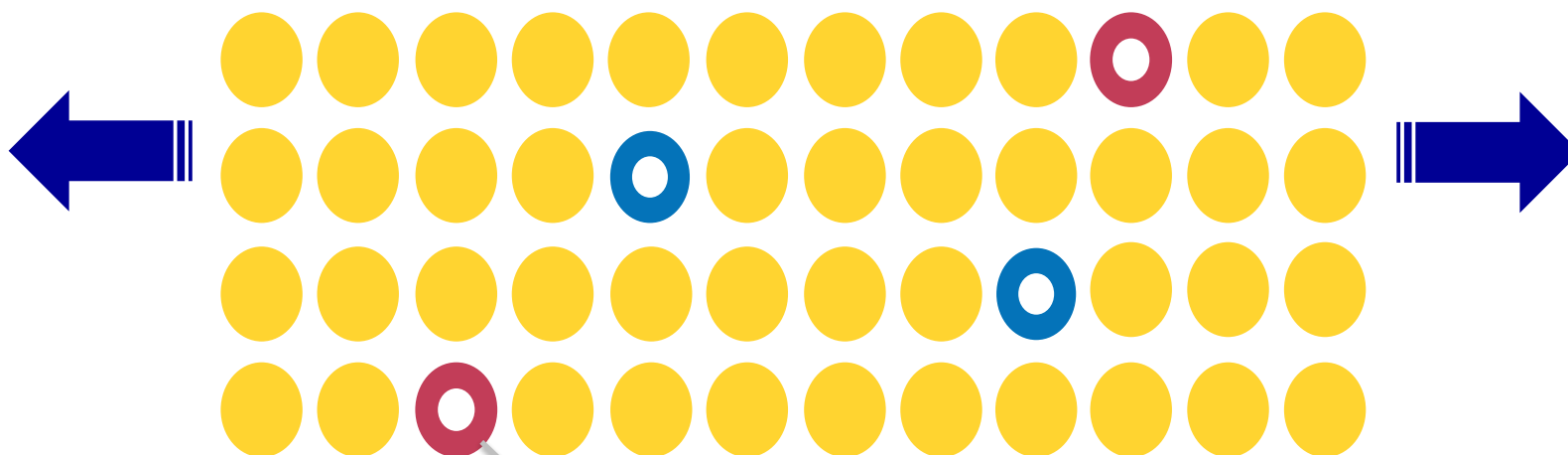
<u>Classification level: Disorder</u>	Glycogen storage disease type XI	ICD-10: E74.0
Synonym(s):	Glycogenosis due to GLUT2 deficiency	OMIM: <a href="#">227810</a>
GSD due to GLUT2 deficiency		UMLS: C3495427
GSD type 11	Prevalence: Unknown	MeSH: -
GSD type XI	Inheritance: Autosomal recessive	GARD: <a href="#">2268</a>
Glycogen storage disease due to GLUT2 deficiency	Age of onset: Infancy, Neonatal	MedDRA: -
Glycogen storage disease type 11		

**SYNONYMS**

# RD General interoperability



International  
Classification of Diseases  
(ICD)



SNOMED CT

GSD due to  
GLUT2  
deficiency

Choroba spichrzania  
glikogenu z  
powodu niedoboru  
GLUT2

ORPHA:2088

Fanconi-Bickel  
syndrome

Syndroom van  
Fanconi-Bickel

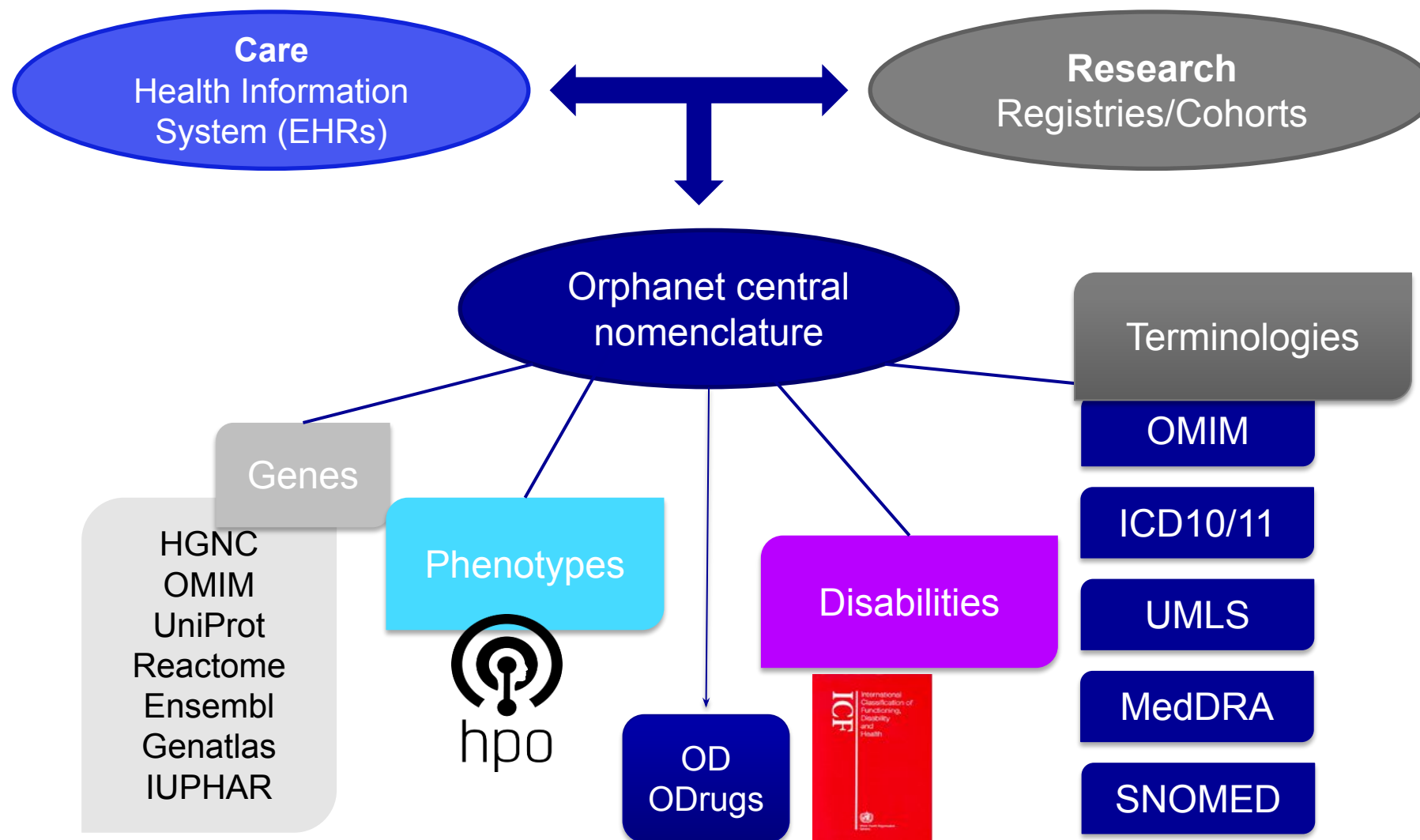


Research

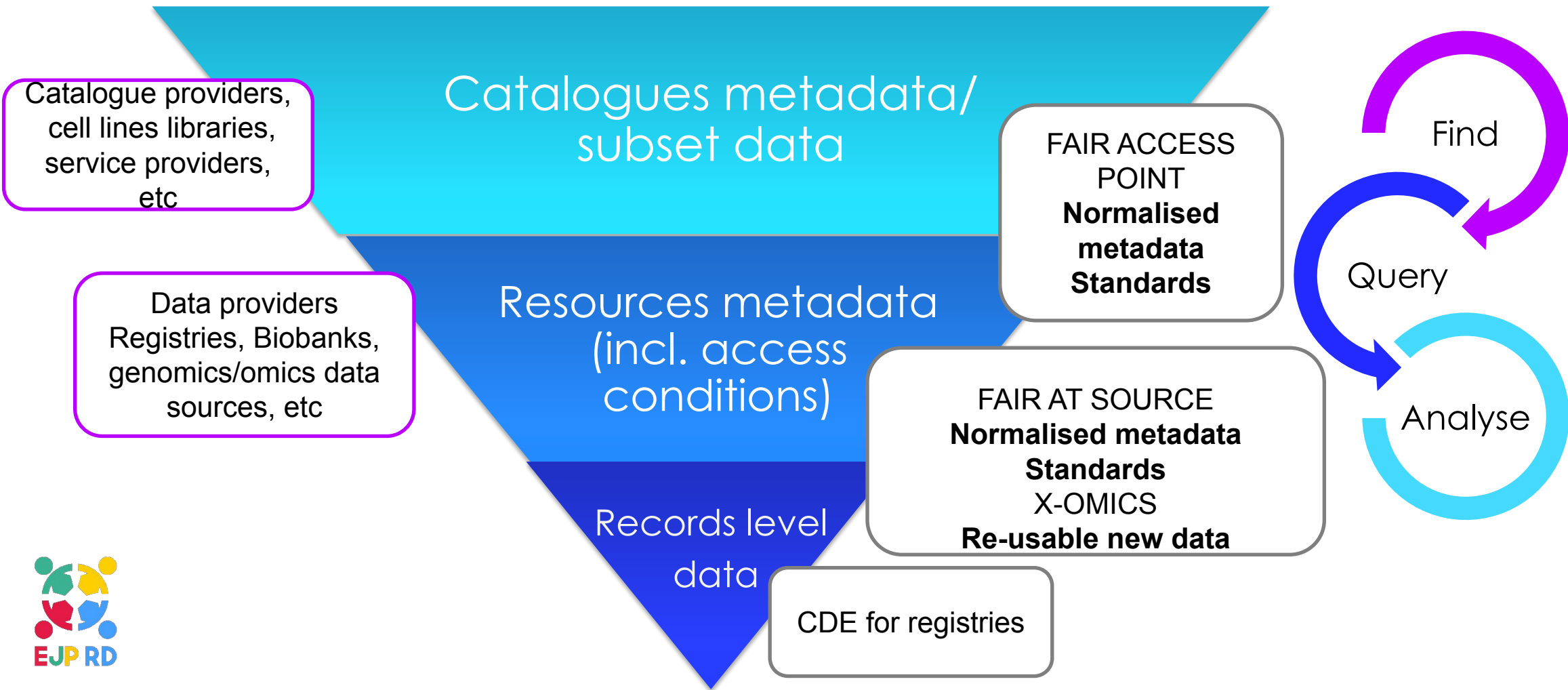
- Registries, - Cohorts, - Biobanks

Care  
Health Information Systems

# RD General interoperability



# European Joint Programme on Rare Diseases. “Virtual” Platform discoverability layers





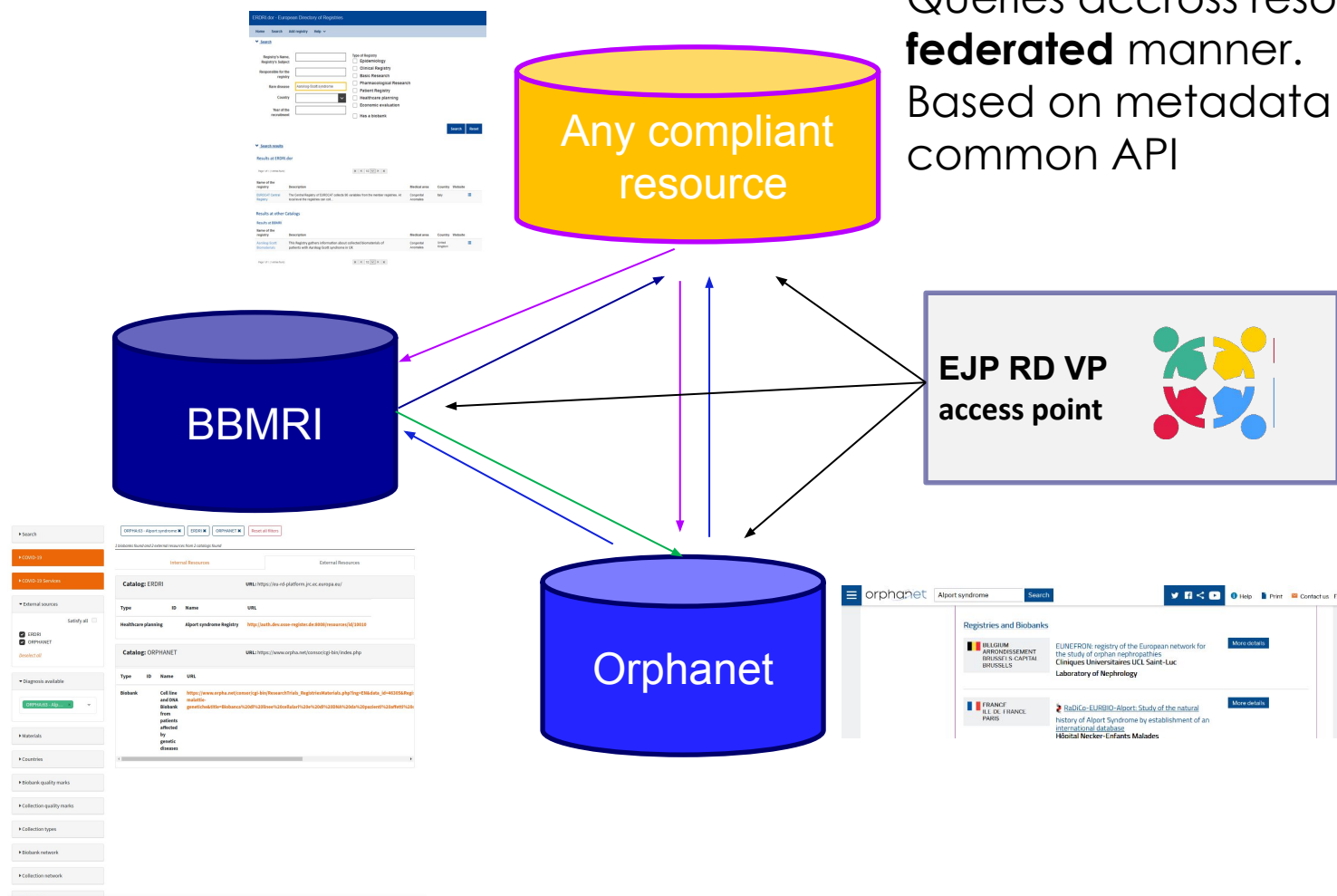
# European Joint Programme on Rare Diseases

Queries accross resources in a **federated** manner.

Based on metadata alignements and common API



EJP-RD Query Builder - Federated Resource Discovery



# European Joint Programme on Rare Diseases

- **Catalogs and resource metadata description based on DCAT 2.0**
- **Rare Diseases registries specific “CDE” (common data elements)**
- **Ontologies & controlled vocabularies**  
Provides a consistent way to describe dataset **ORDO**, **HPO**, LOINC, ICD...
- **Mappings services**
  - Semantic (ORDO ⇔ ICD, Snomed...)
  - Models (HL7, OMOP, FHIR...)

Building an ecosystem for RD data exchanges.  
Not reinventing the



## List of Ontologies in the model

brunasv edited this page on 21 Dec 2021 · 3 revisions

Edit New Page

This table has a list of all the ontologies used in the CDE semantic model. The first column has links to either download the ontology or to browse it. The prefix links are not all resolvable. Some comments on the usage of ontologies or the prefixes of the ontologies as used in the model are also given.

Disclaimer: This table is outdated (version from 2020) and it will be updated in 2022.

Ontology name	Prefix link	Prefix	Comments
<a href="#">Ontology for Biomedical Investigations (OBI)</a>	<a href="http://purl.obolibrary.org/obo/">http://purl.obolibrary.org/obo/</a>	obo	
<a href="#">RDConnect Ontology</a>	<a href="http://rdf.biosemantics.org/ontologies/rd-connect/">http://rdf.biosemantics.org/ontologies/rd-connect/</a>	rdc-meta, rdc	In the images the prefix is <i>rdc-meta</i> but in the ShEx and Turtle files the prefix is <i>rdc</i> .
<a href="#">NCBI Taxon</a>	<a href="http://purl.obolibrary.org/obo/">http://purl.obolibrary.org/obo/</a>	ncbi, obo	In the images the prefix is <i>ncbi</i> but in the ShEx and Turtle files the prefix is <i>obo</i> .
<a href="#">National Cancer Institute Thesaurus (NCIT)</a>	<a href="http://purl.obolibrary.org/obo/">http://purl.obolibrary.org/obo/</a>	ncit, obo	In the images the prefix is <i>ncit</i> but in the ShEx and Turtle files the prefix is <i>obo</i> .
<a href="#">SNOMED CT</a>	<a href="http://purl.bioontology.org/ontology/SNOMEDCT/">http://purl.bioontology.org/ontology/SNOMEDCT/</a>	snomedct	
<a href="#">HL7</a>	<a href="http://purl.bioontology.org/ontology/HL7/">http://purl.bioontology.org/ontology/HL7/</a>	hl7	
<a href="#">The Phenotype and Trait Ontology (PATO)</a>	<a href="http://purl.obolibrary.org/obo/">http://purl.obolibrary.org/obo/</a>	pato, obo	In the images the prefix is <i>pato</i> but in the ShEx and Turtle files the prefix is <i>obo</i> .
<a href="#">Orphanet Rare Disease Ontology (ORDO)</a>	<a href="http://www.orpha.net/ORDO/">http://www.orpha.net/ORDO/</a>	orpha	ORDO is only used in the image and not in the ShEx and Turtle files.
<a href="#">Logical Observation Identifier Names and codes (LOINC)</a>	<a href="http://purl.bioontology.org/ontology/LNC/">http://purl.bioontology.org/ontology/LNC/</a>	loinc	

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  - [Personal information](#)
  - [Patient status](#)
  - [Care pathway](#)
  - [Disease history and diagnosis](#)
  - [Genetic diagnosis](#)
  - [Undiagnosed](#)
  - [Consent](#)
  - [Biobanks](#)
  - [Disability](#)
- [Modules \(v0.2.0\)](#)
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  - [Pseudonym](#)
  - [Personal information](#)
  - [Patient status](#)
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  - [Undiagnosed](#)
  - [Consent](#)
  - [Biobanks](#)
  - [Disability](#)

Clone this wiki locally

<https://github.com/ejp-rd-vp/CDE>

# HL7 Interoperability lessons learned



- **Lloyd McKenzie**, Management Consulting Principal Director - Healthcare Standards

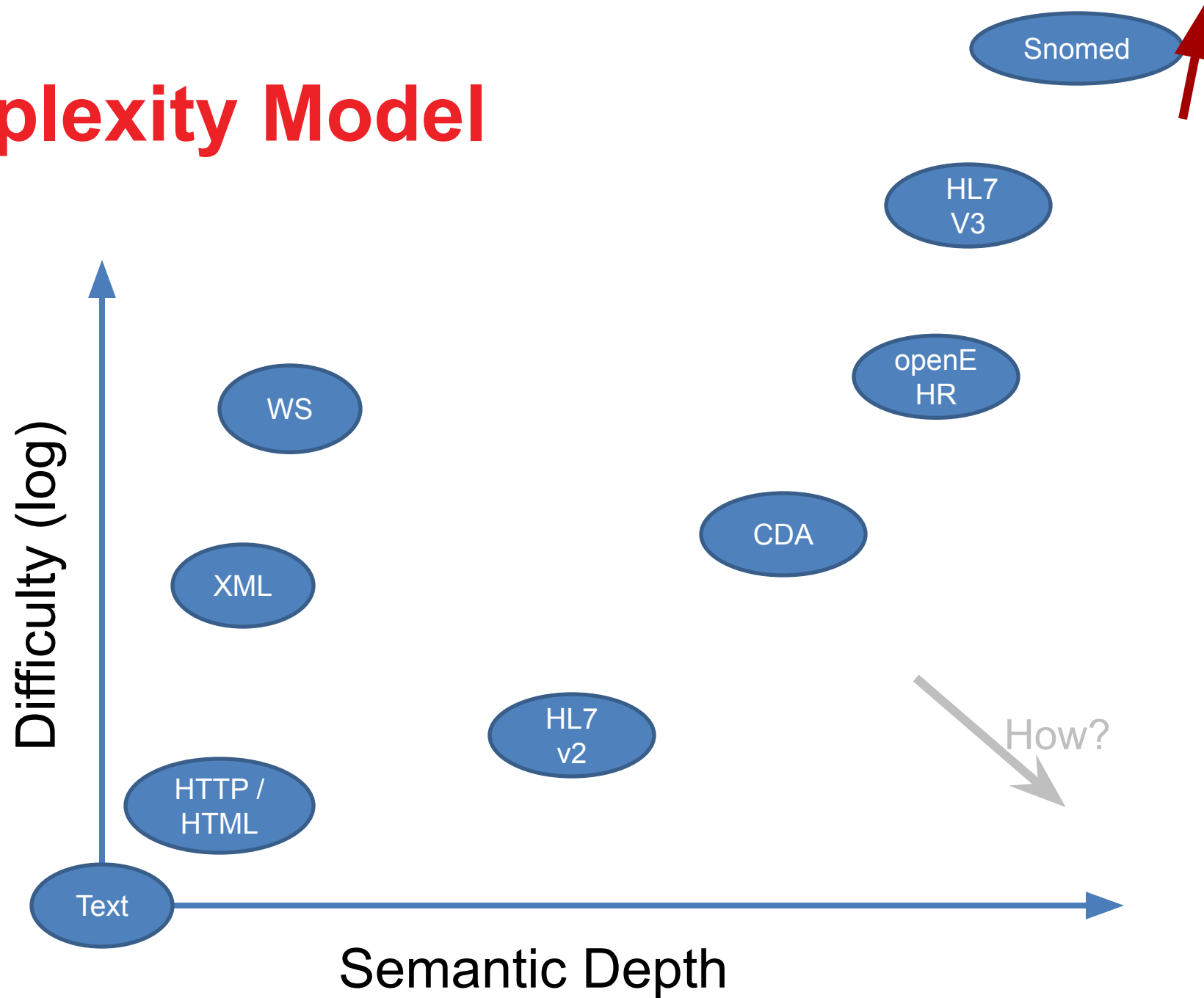
# HL7 Interoperability lessons learned

Gaia-X – Enable the future of  
Health

Lloyd McKenzie  
Apr. 4, 2022



# Complexity Model



# FHIR – Key differences

- Focus on **Implementers**
- Target support for **common scenarios**
- Leverage cross-industry **web technologies**
- Require **human readability** as base level of interoperability
- Make content **freely available**
- Support multiple **paradigms** & architectures
- Demonstrate best practice **governance**



# Other keys to modern interoperability

- Extensibility
- Discoverability
- Provenance
- Data tagging
- Computable profiling
- Shared registries
- Flexibility in sharing approaches

# Contact me

- [lloyd.mckenzie@accenture.com](mailto:lloyd.mckenzie@accenture.com)
- Or, better yet, <http://chat.fhir.org>



# Q&A



# Session Summary

