



# The role of SOLID in the future of our healthcare

We Are Days 2025

“Zorgen voor mensen, gedragen door data”

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Better Health, Brighter Future

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# Data in healthcare: missed opportunities



Data sitting in silos



Difficult access to patient data



Only looking at one aspect of the patient, but not holistically



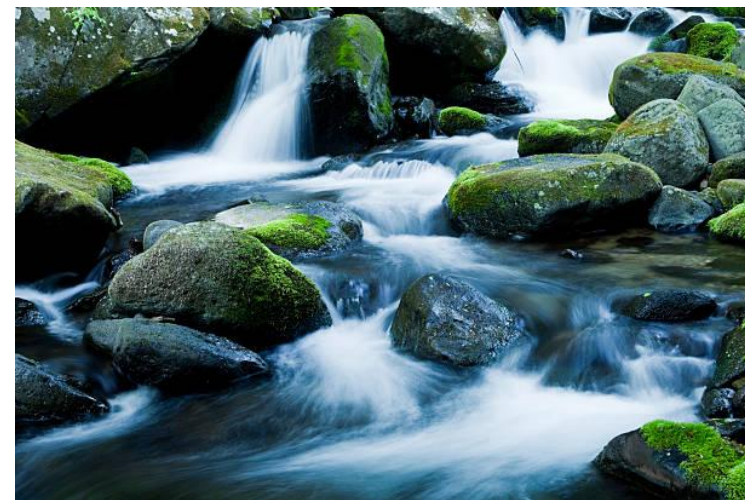
No continuity in data: only in the hospital and not when the patient is at home



Involve the patient as an active partner when it comes to data



Re-use of data: primary collected for clinical management, secondary used for data-based insights



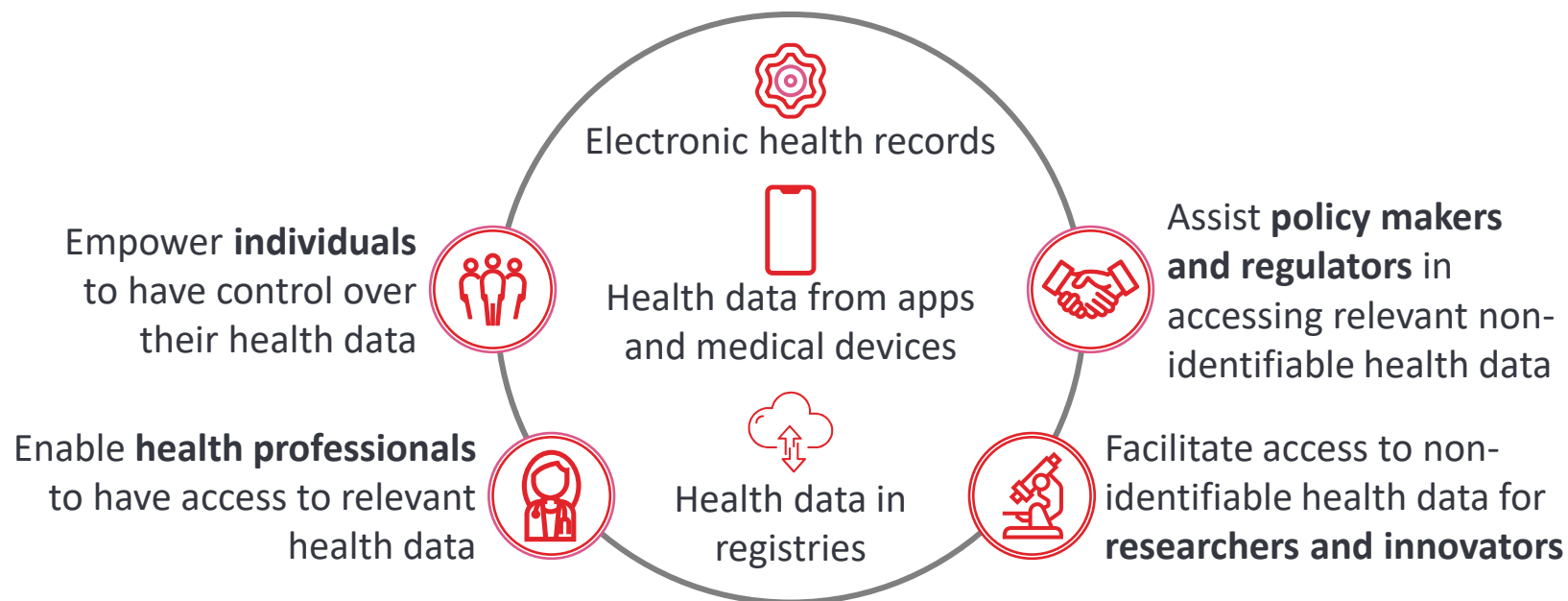
# What does the regulator say?



## European health data space

#EUDigitalHealth

Better diagnosis  
and treatment,  
improved patient  
safety, continuity  
of care and  
improved  
healthcare  
efficiency



Better health  
policy, greater  
opportunities for  
research and  
innovation

Health specific ecosystem of rules, common standards and practices, infrastructures and a governance framework for:

1. **Citizen ownership** of their health data
2. **Integration** of health data from different sources
3. **Secondary use** of health data

# Secondary use of which data? Look at patient data holistically



- Disease registry data

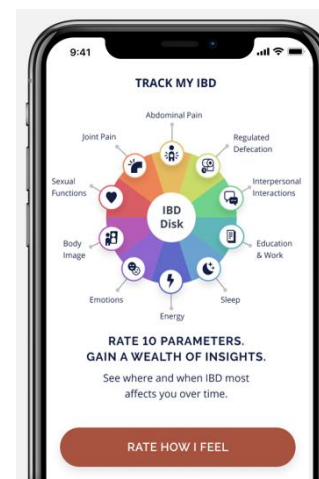
- Wellness app data

- Clinical trial data

- Electronic Health Record data
- Pathogen genomic data
- Human genetic, genomic, proteomic data



- Research cohort data
- Survey data



- Digital health apps (PROMS/PREMS)
- Medical device data, telemonitoring



- Biobank data



- Claims data
- Reimbursement data

# Why



## EVIDENCE GENERATION WITH SECONDARY DATA USE

The pharmaceutical industry perspective

1

**ASSURE MARKET ACCESS OF  
INNOVATIVE MEDICINE**

2

**IMPROVE PATIENT  
OUTCOMES AND PATIENT  
CARE**

3

**EMPOWER DATA-DRIVEN  
HEALTHCARE  
DECISION MAKING**



# What

F<sub>indable</sub> A<sub>ccessible</sub> I<sub>nteroperable</sub> R<sub>eusable</sub>

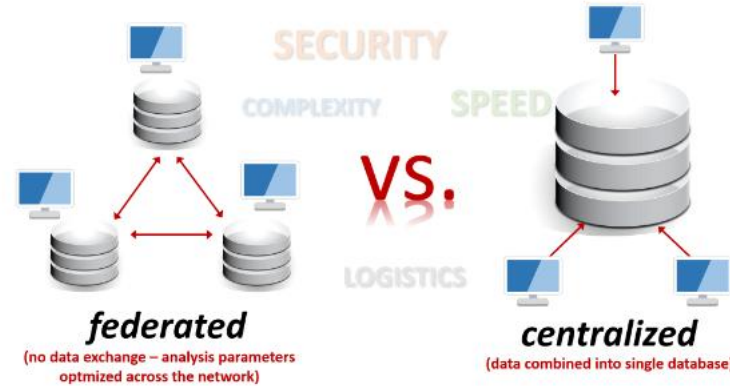


Technology

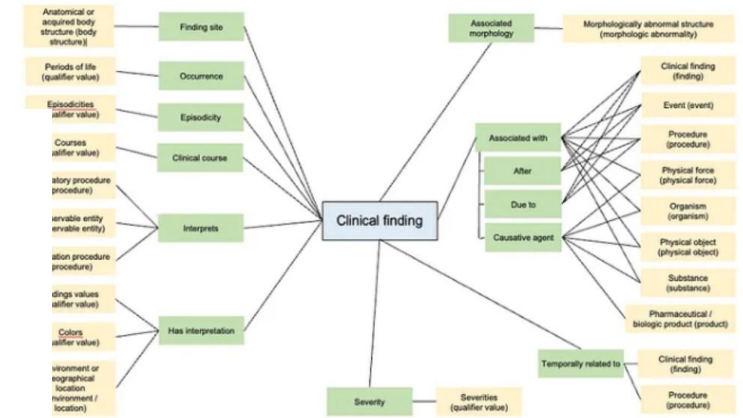


Personalized data pods

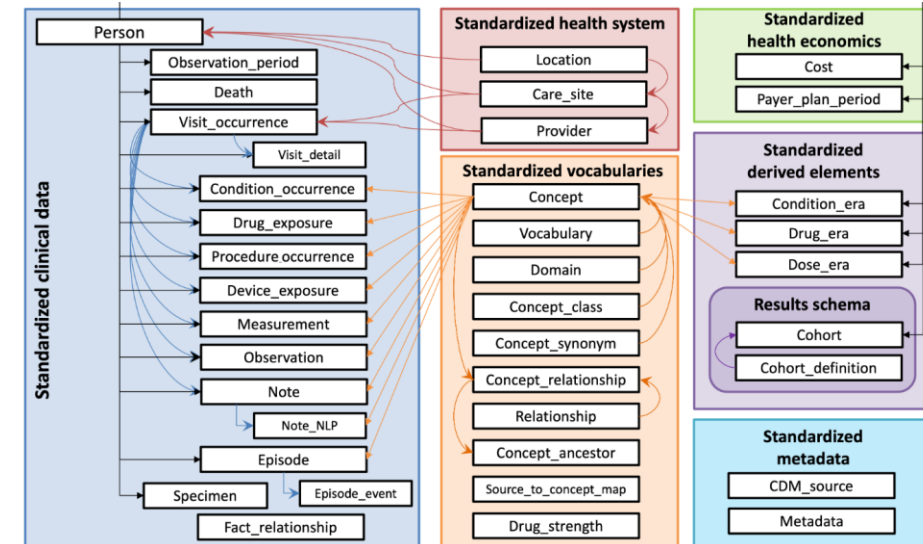
Structured Data vs Unstructured Data



Federated analytics



Excerpt of the SNOMED CT Clinical Finding Concept Model



OMOP-CDM

# How



Collaboration



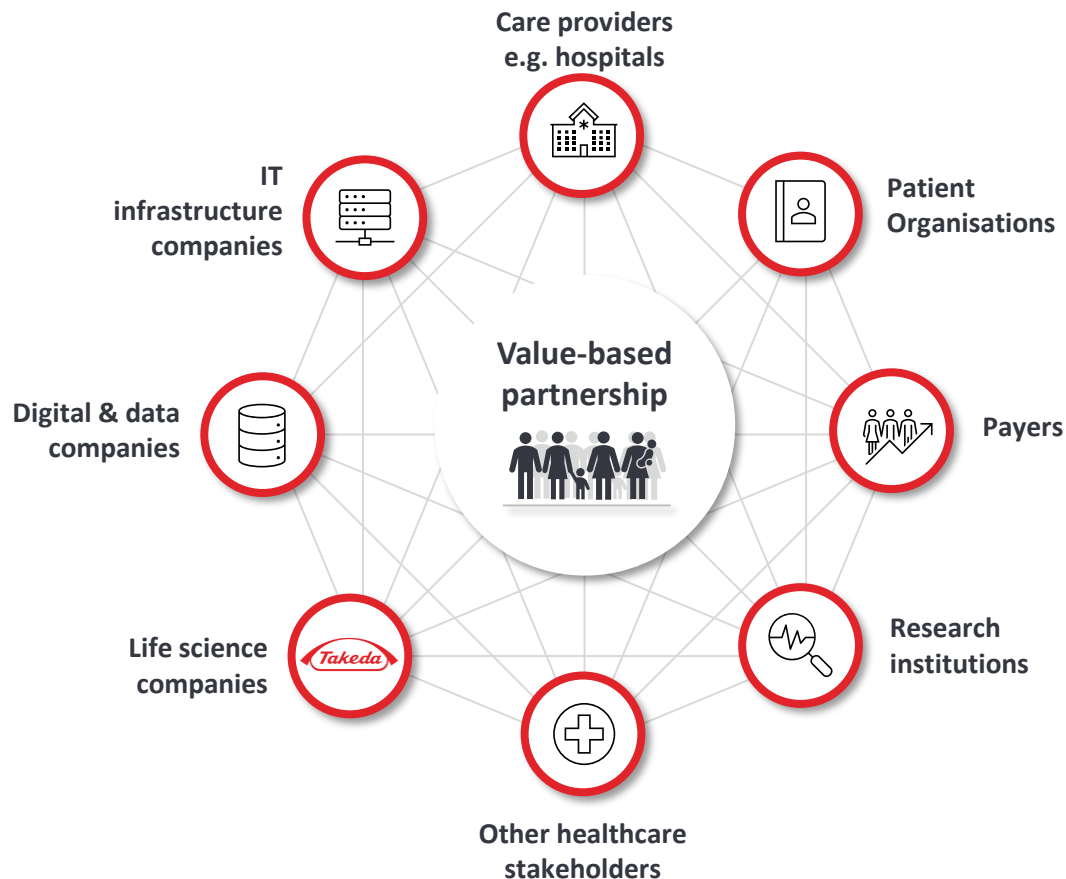
Creating value

## VALUE-BASED<sup>1</sup> PARTNERSHIPS:

Working together brings you further



A new paradigm for healthcare globally and for healthcare suppliers



$$\text{Value} = \frac{\text{Outcomes that matter to patients}}{\text{Cost of delivering the outcomes}}$$

- Is a new way of working
- Based on co-creation
- Involves sharing of risk between partners
- Requires trust among partners
- Needs openness and honesty about objectives
- Results in better value for all partners, and not at least the patient

# Patient survey on Burden of Illness of TTP using solid data pods

- **Need?**
  - Data of burden of illness and healthcare use in a rare blood disease (thrombotic thrombocytopenic purpura)
- **Who?**
  - **TTP Community**, TTP patient association
  - **VITO**, **We are platform** and **SAVE DATA** project
  - **UZLeuven** and **Cliniques Universitaires St-Luc**
  - **Sanofi**
- **What?**
  - **Collaborative, value-based partnership** in which hematologists, the TTP patient association and the We are platform work together
  - To launch a **patient survey** in an **innovative, privacy-preserving approach** using personalized data pods (Solid platform, method)
    - Patients explicitly give consent for data analysis
    - Data pods will be filled with relevant patient data (survey results)
    - Data will be aggregated and anonymized before analysis
  - **Insights** from the survey **will be shared with participating patients** on their individual data pods, closing the information loop





# Future?



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Citizen

Personalized data pods



GP

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Collaboration



Technology



Creating value



“If I had asked people what they wanted, they would have said faster horses. “

Henry Ford

## **Because informed decisions lead to better outcomes.**

“Inspraak zonder inzicht resulteert in uitspraak zonder uitzicht.” Liesbet Peeters

“Health is our greatest asset; we are obliged to take this seriously.”

Passion provides purpose, but data drives decisions. Andy Dunn

*The key to success is not the size of the investment, but the quality of the collaboration.*



**Better Health, Brighter Future**