



## FIRST TECH TALK

Data for the common good,  
but what about "me"?

**Dr. Isabelle De Zegger**

**Founder @ b!loba**

# Data for the “common good”, but what about “me”?

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Isabelle de Zegher, MD, MSc

Founder, b!loba

Women in Data Sciences,  
Maastricht 7th March 2023



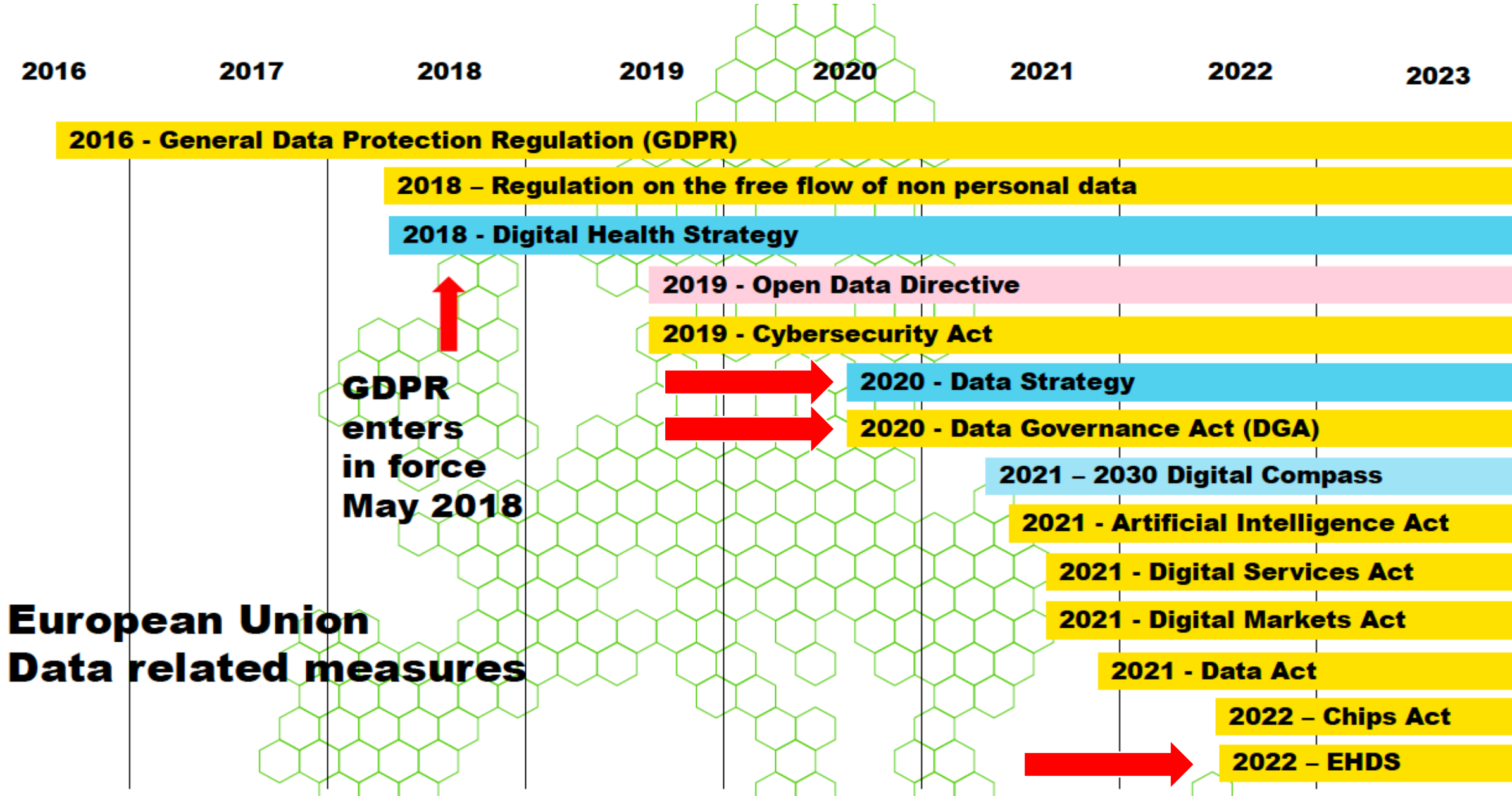
**WOMEN IN DATA SCIENCE**  
MAASTRICHT

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# Background



# Deploying the strategy through 4 Pillars



**DGA**

## A cross-sectoral governance framework for data access and use

including a legislative framework for the governance of European data spaces and other cross-sectoral measures for data access and use



## Enablers

Total investments of € 4-6 billion in a High Impact Project on European data spaces and federated cloud infrastructures



## Competences

Empowering individuals, investing in digital skills & data literacy and in dedicated capacity building for SMEs.



**EHDS**

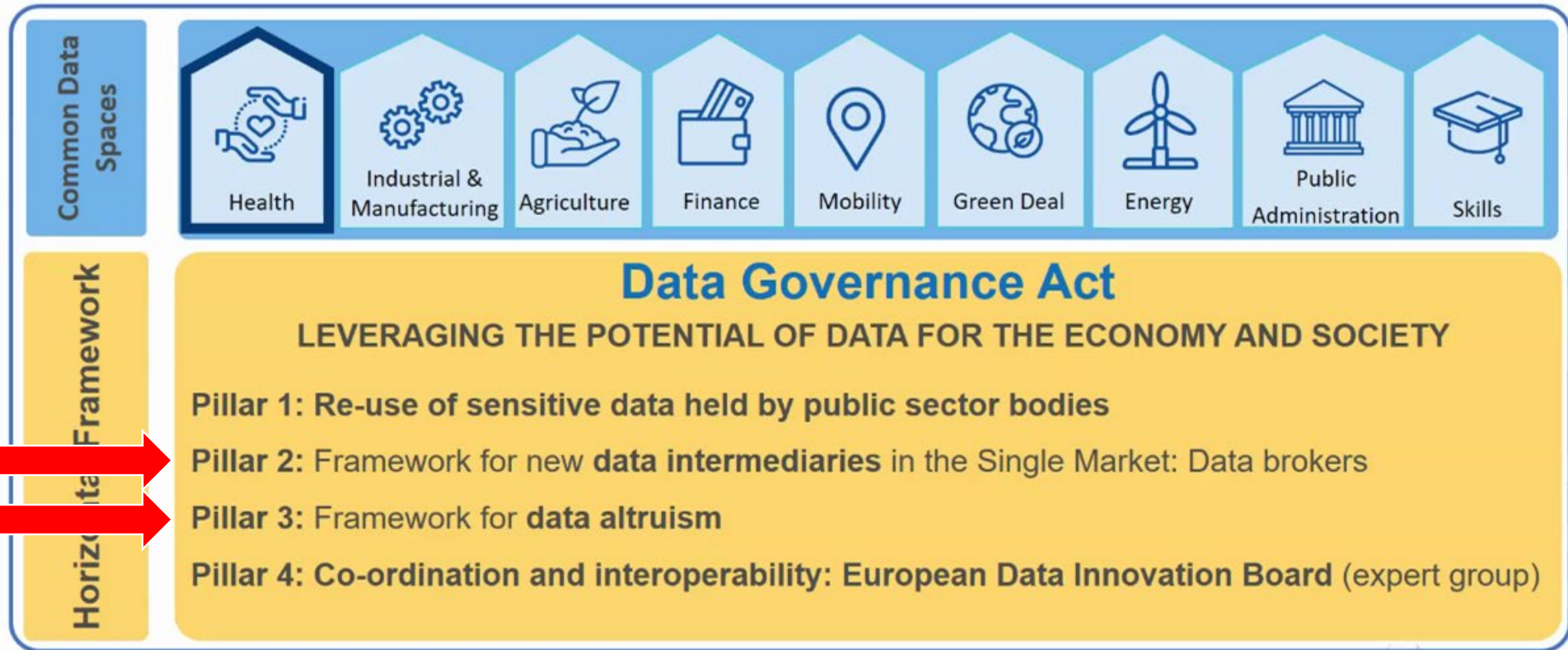
## Rollout of common European data spaces

in crucial economic sectors and domains of public interest, looking at data governance and practical arrangements.

International Aspects

# Data Governance Act (DGA) - approved December 2021

## Overview



# Data Governance Act (DGA) - approved December 2021

## *Data Sharing (through intermediaries) and Data Altruism*

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### Pillar 2. Data Intermediaries

- Data sharing for specific purpose
- Dynamic consent, per request (Digital Wallet)
- Linkage across data sources, consent  
=> complete view of individual
- Citizen keeps control
- Value for citizens and “data users”

Basis for Health Data Intermediaries

### Pillar 3. Data Altruism

- Data donation
- Consent once for data donation
- Lawful linkage permitted across sources  
=> partial view of individual
- Citizen loses control
- Value for “data users”

Proposed for secondary data use in EHDS

**“Common Good”:  
Data Sharing  
Or  
Data Donation ?**



# European Health Data Space (EHDS) - draft May 2022

## Overview

### MyHealth@EU Clinical Care/Primary use

- National Contact Points for Digital Health with national coordination
  - Certified in each Member State
  - Centralize all patient data
  - Accessible by patient & care providers
- Catalogue of Data Sources
- Cross border request of Patient Data

### HealthData@EU Research/Secondary use

- Health Data Access Bodies (HDAB) with national coordination
  - Support request by data users
  - "Permit" to process patient data
  - Patient can check public website
- Catalogue of Data Sets
- Cross border request of Data Sets

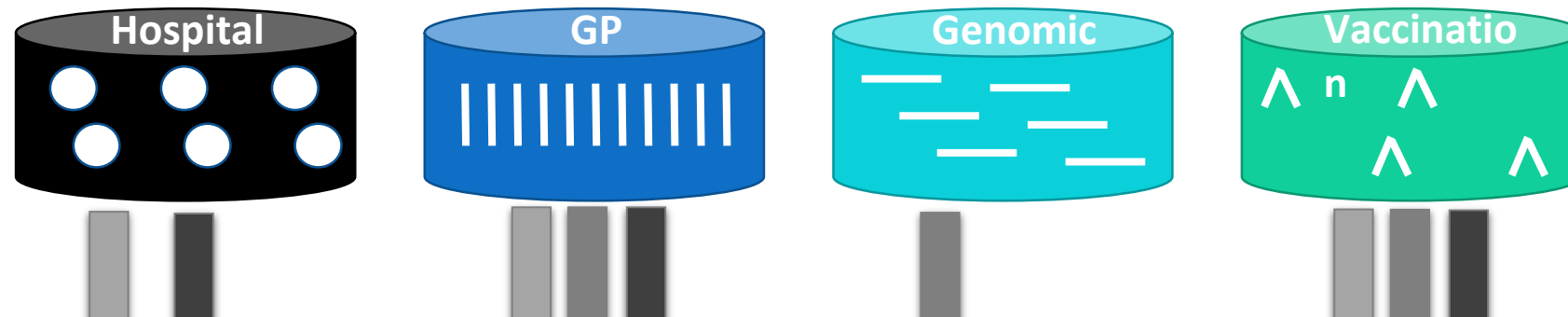
**"Common Good":  
In EHDS =  
Data Donation**

Focus on clinical care data : no mention SDH, Clinical trials, Genomics  
Secondary data use based on Data Altruism with PERMIT, not on CONSENT

# Approaches to Data curation

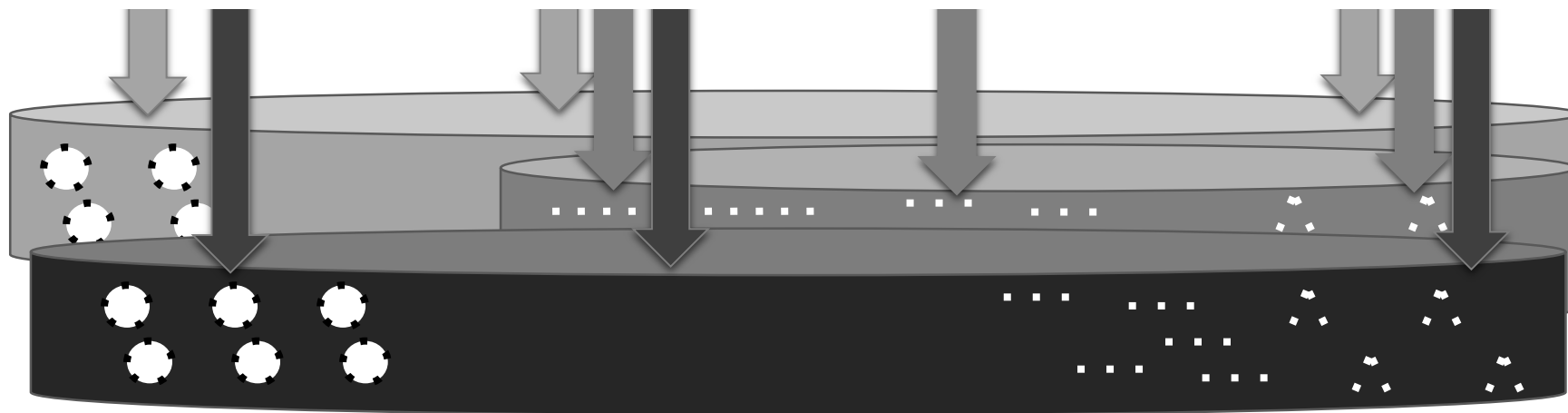
# Approaches to Data Curation

## *Vertical curation*



Raw data  
Spread across systems  
Heterogenous  
Identifiable  
Partial view of “me”

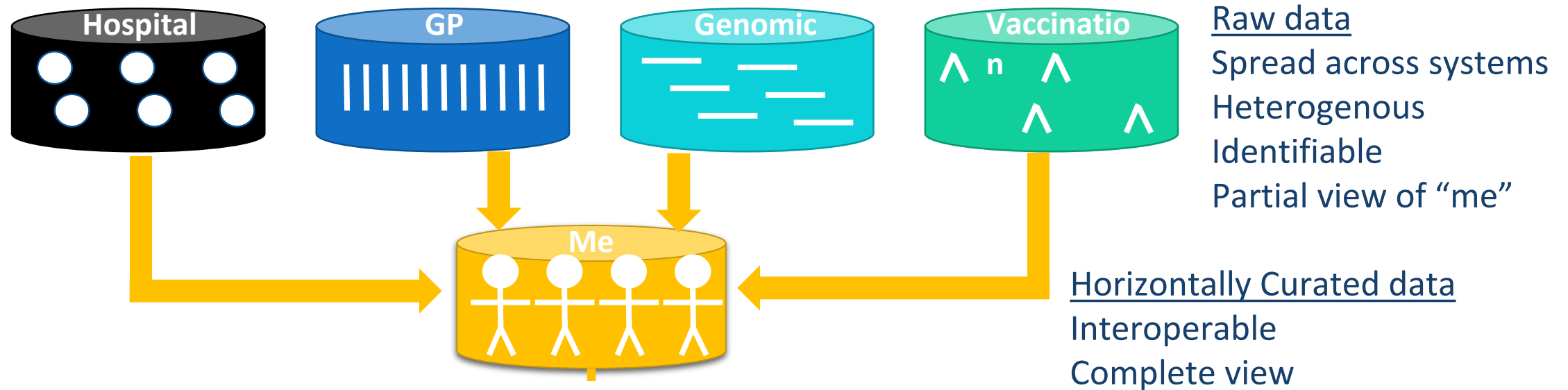
***“curate many times, use once  
(and then dump them when analytics is done)”***



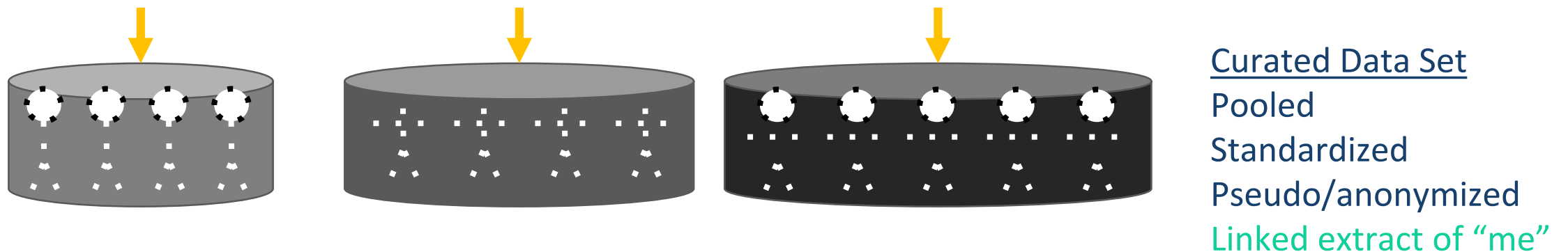
Curated Data Set  
Pooled  
Standardized  
Pseudo/anonymized  
**No linked view of “me”**

# Approaches to Data Curation

## Horizontal curation



***"curate once, use many times"***



# Approaches to Data Curation

## *Horizontal curation: myth or reality ?*

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- Asking patients to fully curate their data, as if they were data scientists, is not a realistic option but they can & want to contribute !
- Europe ambition: Digital Compass - 2030
  - All EU citizens will have access to their health records
  - There will be 20 millions skilled ICT specialists (to support patients)

 We can develop tools to maximize automation in data curation and simplify the task for patients (or their delegates)

Practically: “**me**” – with the support of  
AI Based DAta curation Virtual Assistant (AIDAVA)

# AIDAVA - Horizon Europe project (2022 to 2026)

## Problem & proposed approach

### Heterogenous data sources

	Summary in GP's file (paper)	Lab result (electronic file)	EHR (electronic file)	Imaging (electronic file)
Same doctor?	From: Dr John Smith Patient: Adele X	Requestor: J. Smith Patient: Adele X	Treating Dr: J Ed Smith Patient: Adele X	Physician: J Smith Patient: A. X
Same time/visit?	Visit: 07/09/21	Request date: 09/07/2021	September, 1 <sup>st</sup> , 2021	Date: 09/07/2021
Different units	The patient was diagnosed with diabetes 2 in 2011. She complained about regular tiredness and nausea... And is overweighted.	Chemistry value range Blood Glucose 6 mmol/l 4-7	Blood glucose= 120 mg/dl	
No unit?	Physical exams showed BP of 6/10 Lab test done today: ... Scan displayed... Diagnosis: Depression due to ... Treatment: keep metformin same dosage, follow if symptoms persist			

### Integrated data (one example)

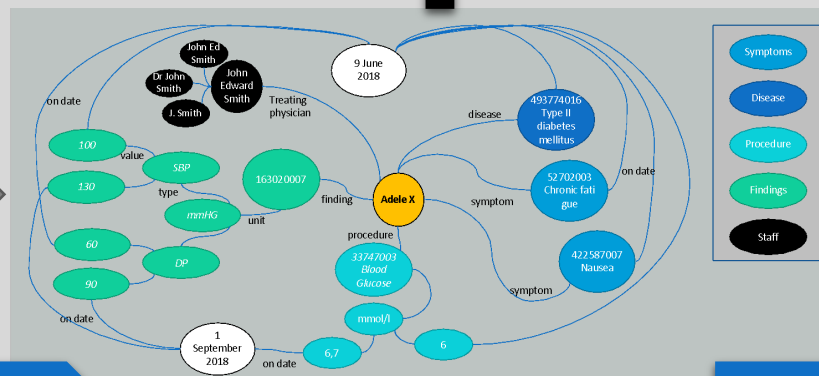
Patient: Adele X  
Treating Physician: Doctor John Edward Smith

	DD/ MONTH/ YYYY		09 JUN 2018	01 SEP 2018	XXX
	CODE	LABEL	UNIT	VALUE	VALUE
Medical History	493774016	Type II diabetes mellitus		YES	
Complaints	52702003	Chronic fatigue (76%)		YES	
				130	XXX
				90	XXX
				6,7	XXX

**The key challenge is how much we can automate this process by orchestrating multiple (AI) tools**

AI based tools for

- Integration across data sources
- Harmonization of format, into Knowledge Graph
- Quality enhancement



- Transformation of Personal Health Knowledge Graph into consumer ready format
- Imputation of missing data

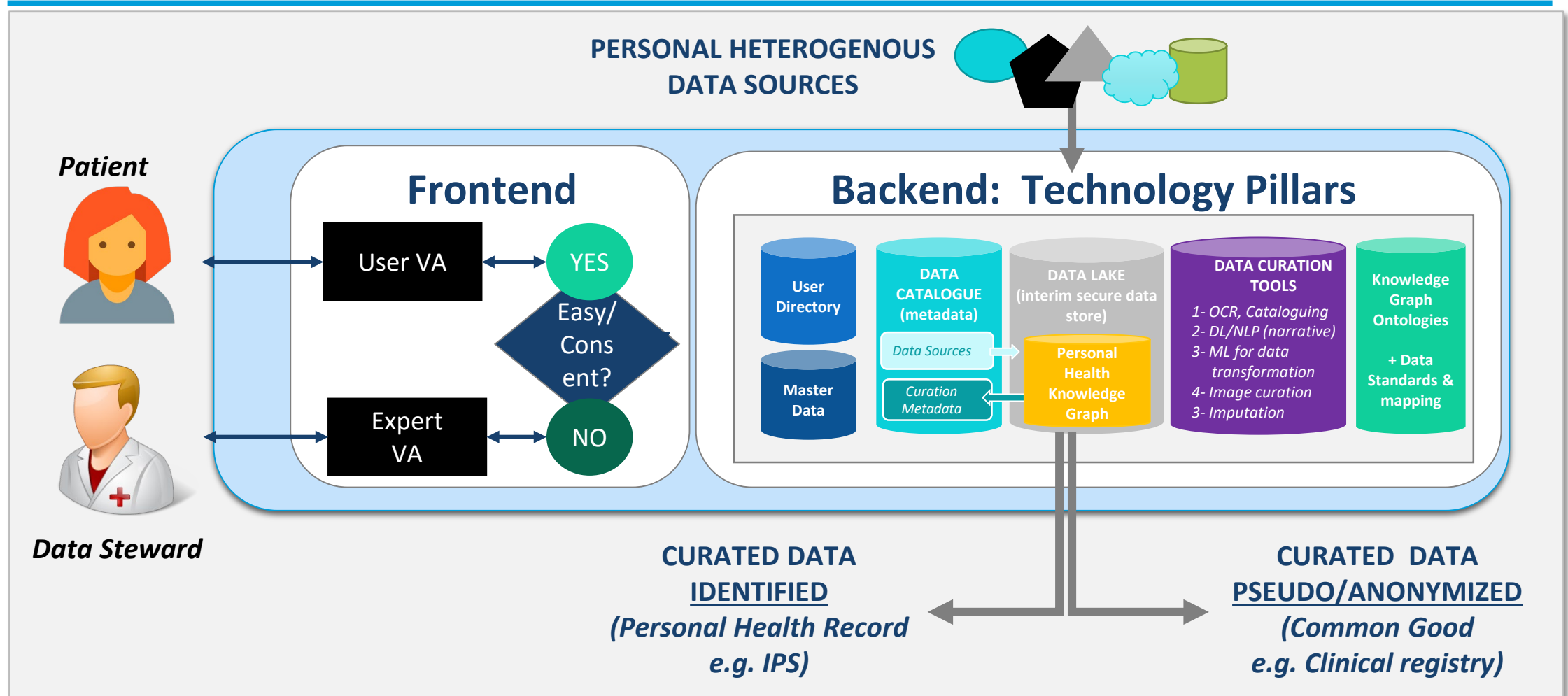
**Data Curation: Harmonization, Integration  
Consent Management**

**Personal Health  
Knowledge Graph (me)**

**Data Publishing: Transformation, Imputation  
Consent Management**

# AIDAVA

## Overview of proposed solution



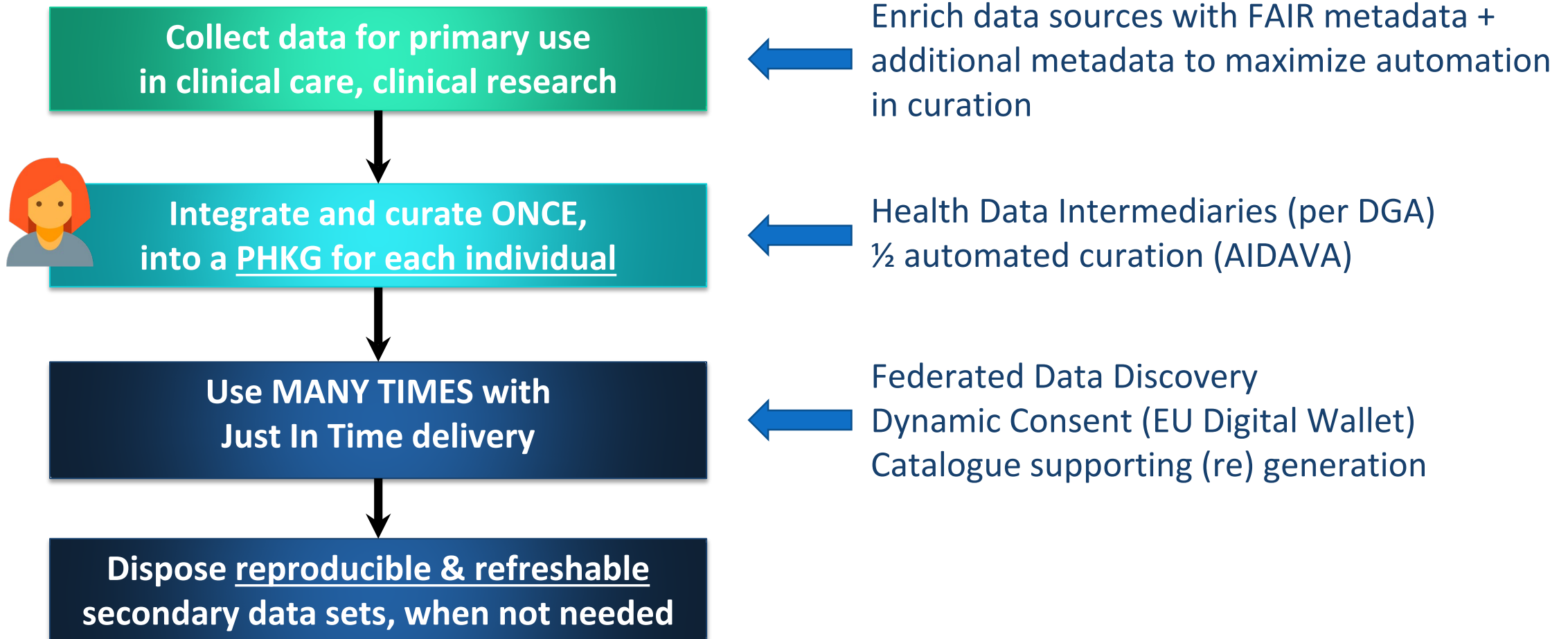


What is next:

Just-in-time data for the **common good**

# What is the next *Vision & needs*

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***The best way I, as an EU citizen, can support  
the common good in health care  
is to start by my personal data,  
by maximizing their quality and  
agreeing to share them in trust***

# THANK YOU

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For questions, please contact

[isabelle@dezegher.com](mailto:isabelle@dezegher.com)

+32 478 48 28 54