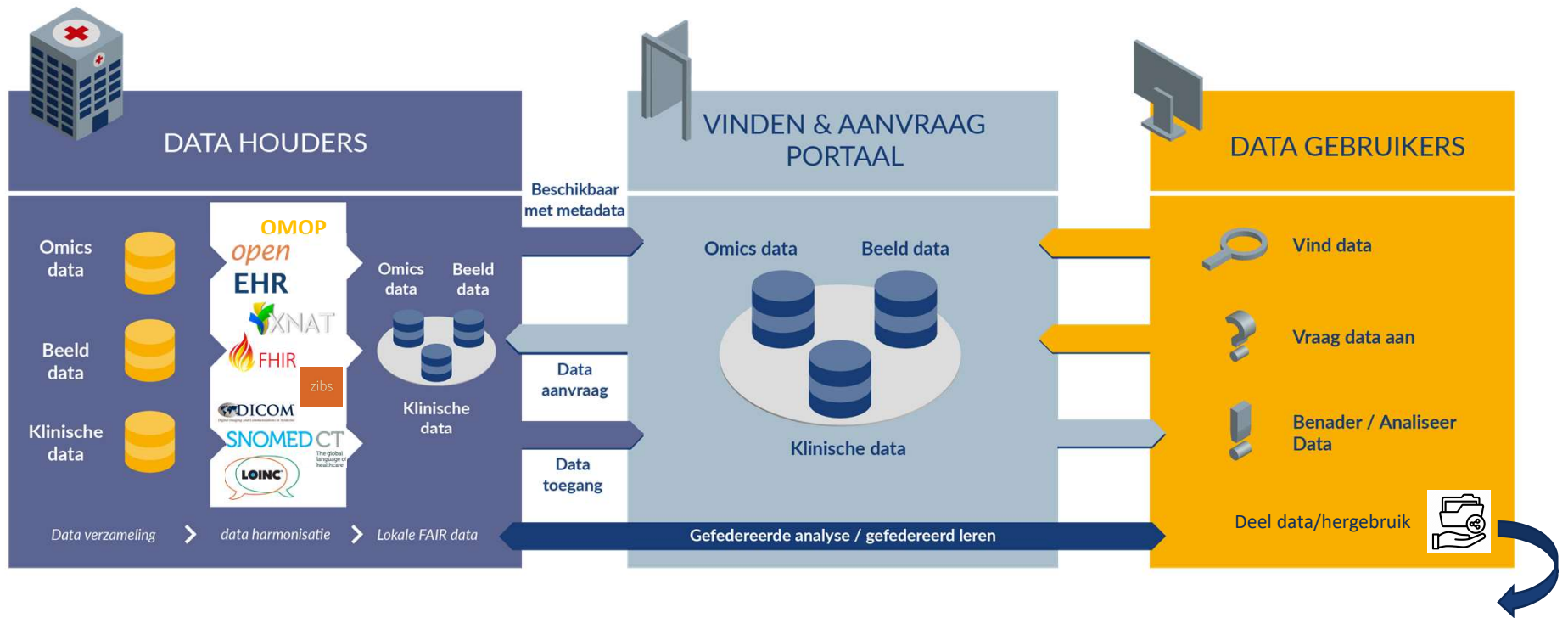




# Health-RI COVID19 project Experiences and bottlenecks re: SSH data

BY-COVID Spring 23 Use Cases Workshop:  
Integration of socioeconomic data in observational  
studies on vaccine effectiveness  
Jeroen Belien, VUmc (Amsterdam UMC), Health-RI

Towards a National observational COVID (→ Health) data portal  
(see also <https://www.health-ri.nl/covid-19-data-portal>)



## Think big – start small – act now



**Think big:** *national health data infrastructure*

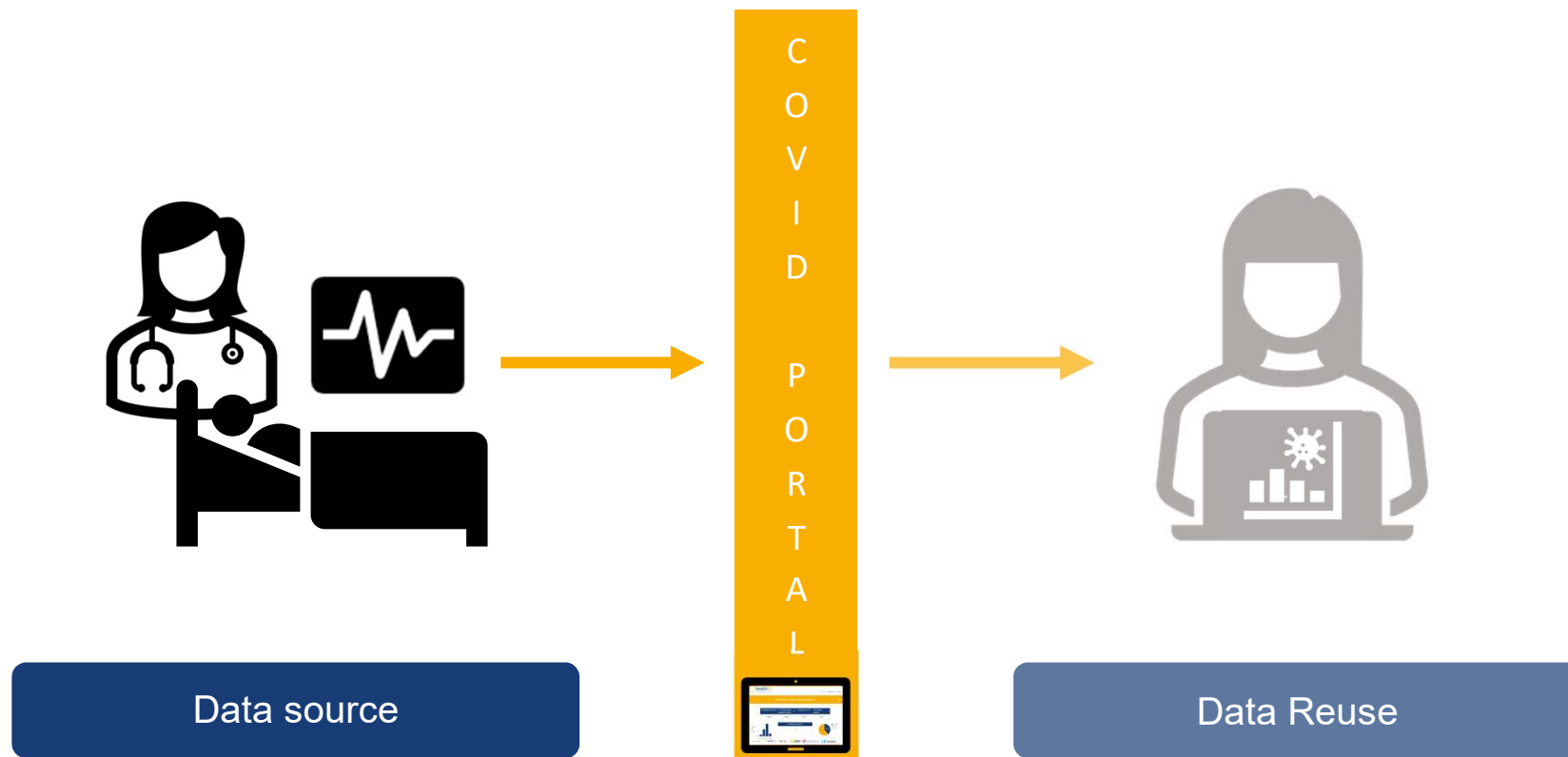
**1** Connecting communities

**2** Expertise, tools & services

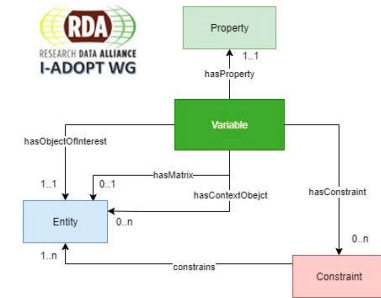
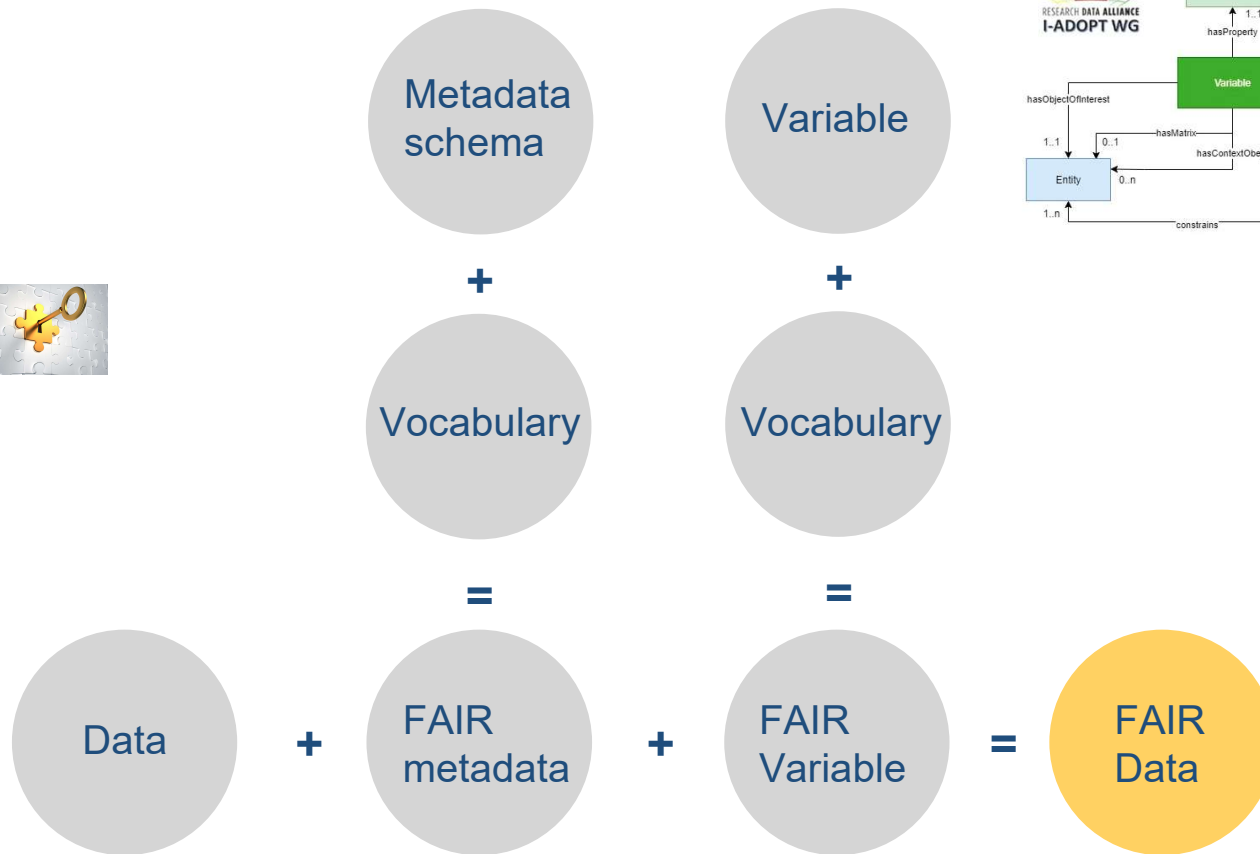
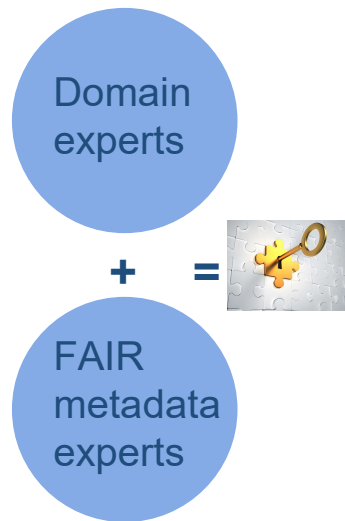
**3** Best practices



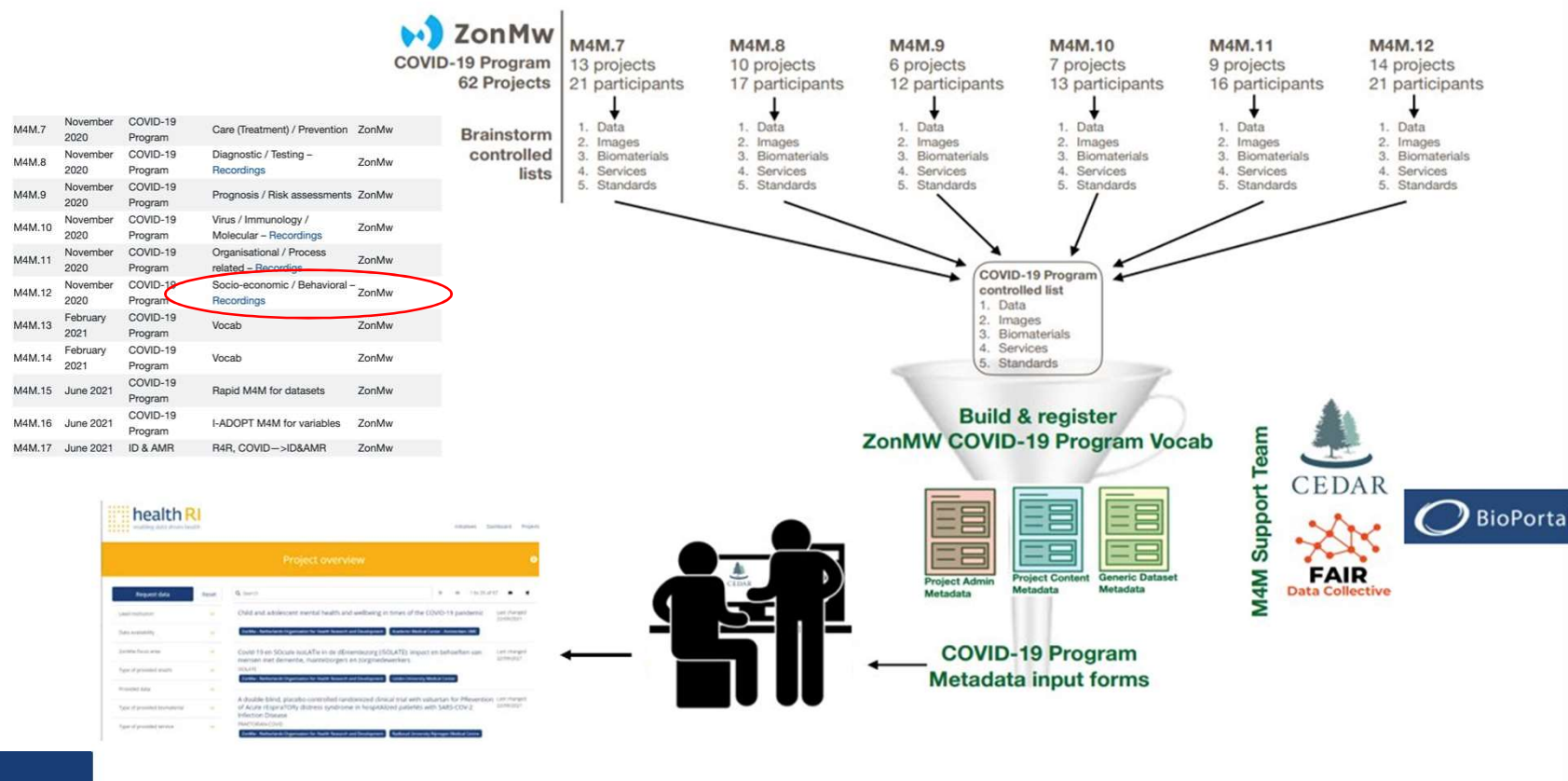
**Start small:** [national COVID-19 portal](#)



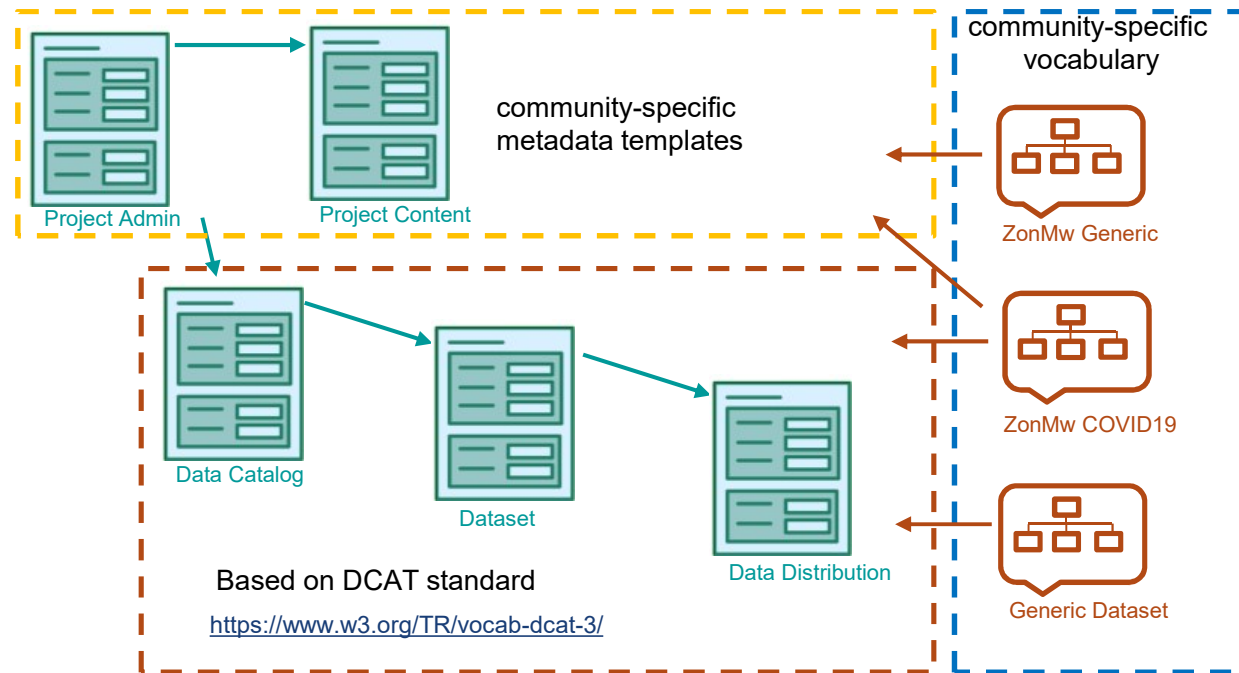
## Road (so far) to machine actionable (meta)data



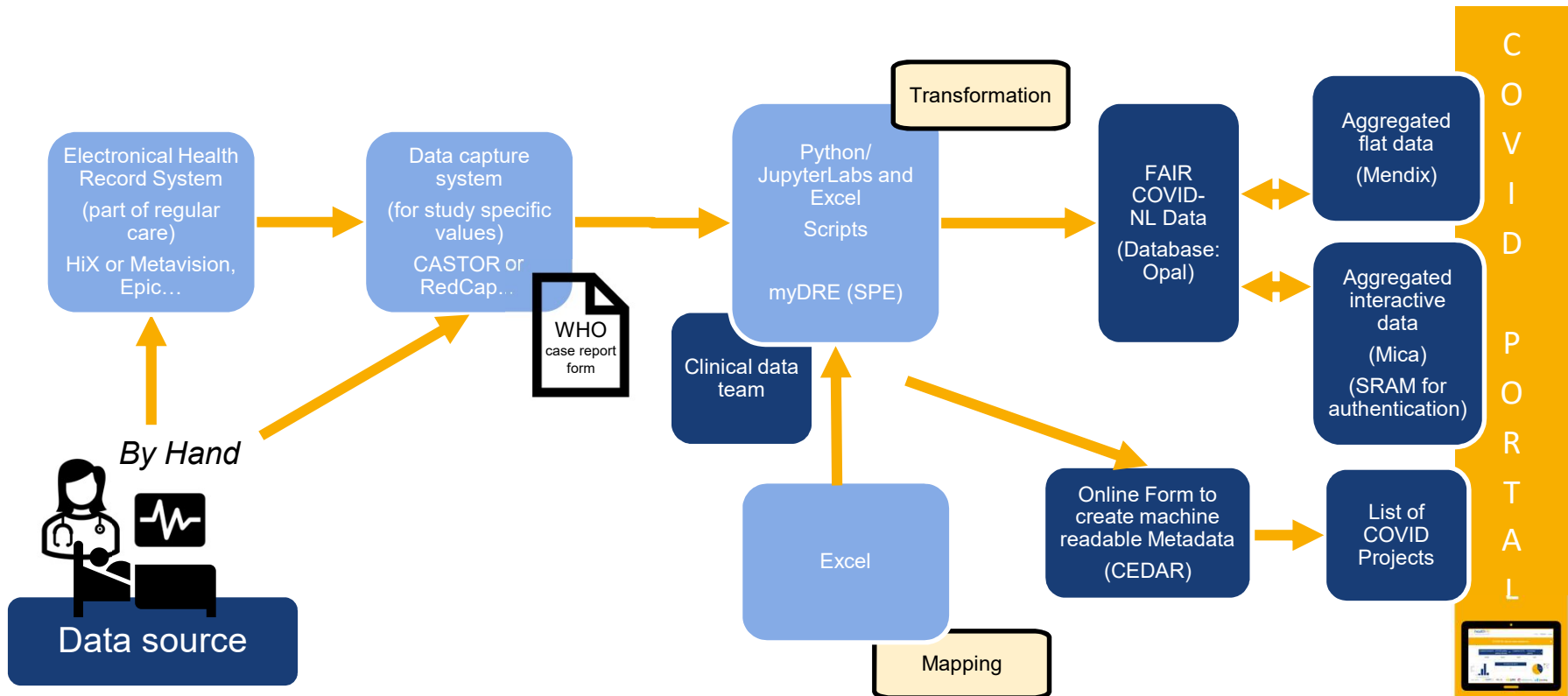
# From Community to Data Portal



## Metadata templates and vocabulary for projects and datasets



Data ETL workflow from an institute/collaboration to a portal





Metadata portal: <https://covid19initiatives.health-ri.nl/p/ProjectOverview>  
(machine readable metadata / human readable portal )

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Projects Dashboard Initiatives

Project overview

Request data Reset

Search 1 to 25 of 130

Lead institution	SamenSlimOpen - Datagedreven Simulatie Games voor de Evaluatie en Preventie van SARS-CoV-2 Transmissie in Binnenruimtes en de Impact van Veranderende Naleving van Maatregelen	Last changed 06/04/2023
Data availability	SamenSlimOpen	
ZonMw focus area	ZonMw - Netherlands Organisation for Health Research and Development Wageningen University & Research	
Type of provided assets	The impact of COVID-19 on illiterate people and people with a mild intellectual disabilities: preventative measures, (mental) health and support needs.	Last changed 31/03/2023
Provided data	COVID-19: LVB en laaggeletterden	
Type of provided biomaterial	ZonMw - Netherlands Organisation for Health Research and Development Radboud University Nijmegen Medical Centre	
Type of provided service	Ethiek van e-Health tijdens de coronacrisis en daarna: lessen uit de pandemie	Last changed 28/03/2023
Subjects	ZonMw - Netherlands Organisation for Health Research and Development Erasmus MC	
Variables	COVID-19 impact welzijn ziekenhuispersoneel. Wat zijn de korte- en langetermijneffecten van COVID-19 op het psychosociale en emotionele welzijn van ziekenhuispersoneel en hoe gaan we daarmee om?	Last changed 21/03/2023
	ZonMw - Netherlands Organisation for Health Research and Development University of Groningen	
	MOCOLODO: Mobility during and after corona lock-down: sustainability, safety, inclusion	Last changed

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DTL

GO FAIR

NFDU  
NEDERLANDSE FEDERATIE VAN  
UNIVERSITAIR MEDISCHE CENTRA

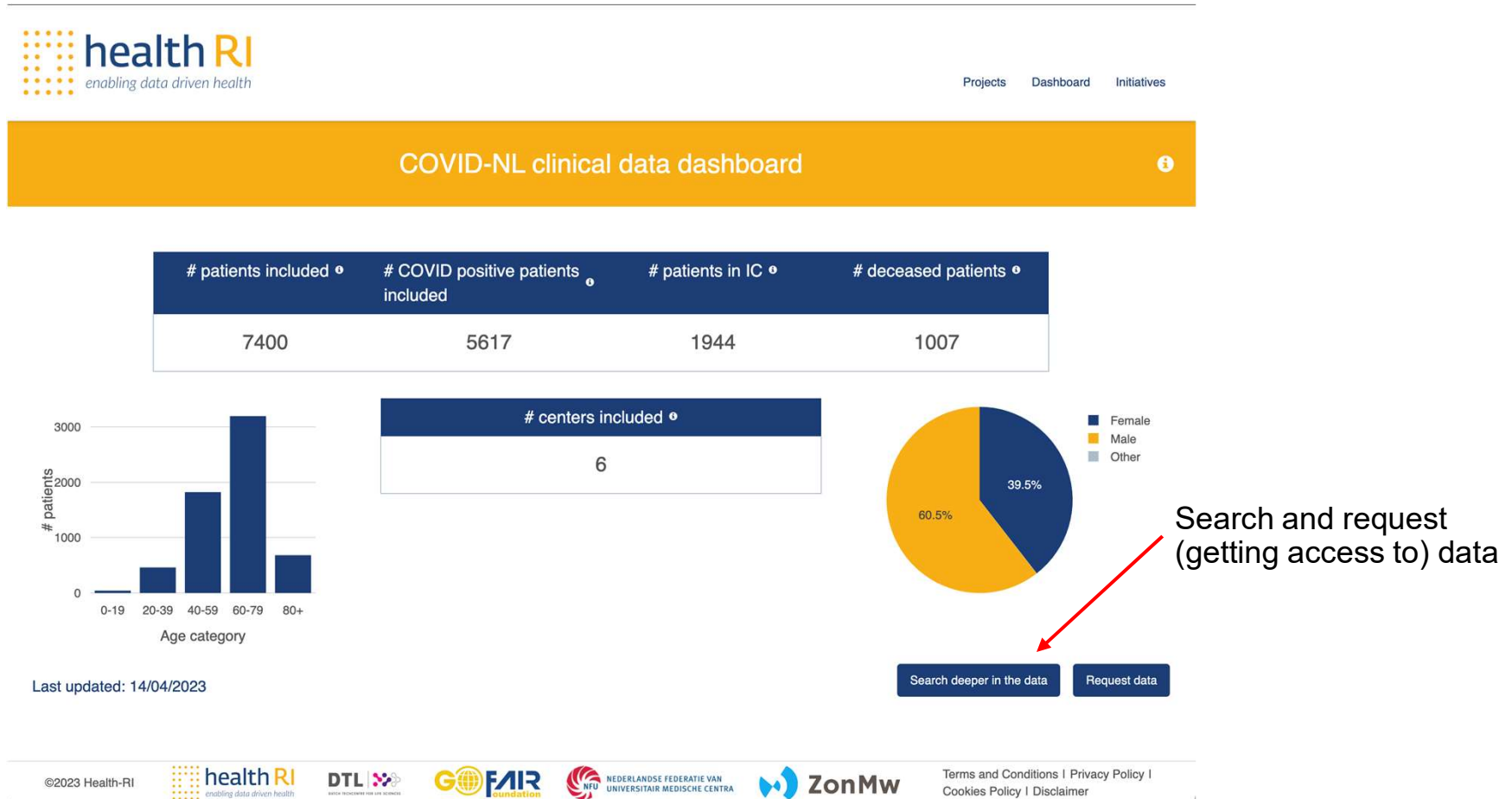
ZonMw

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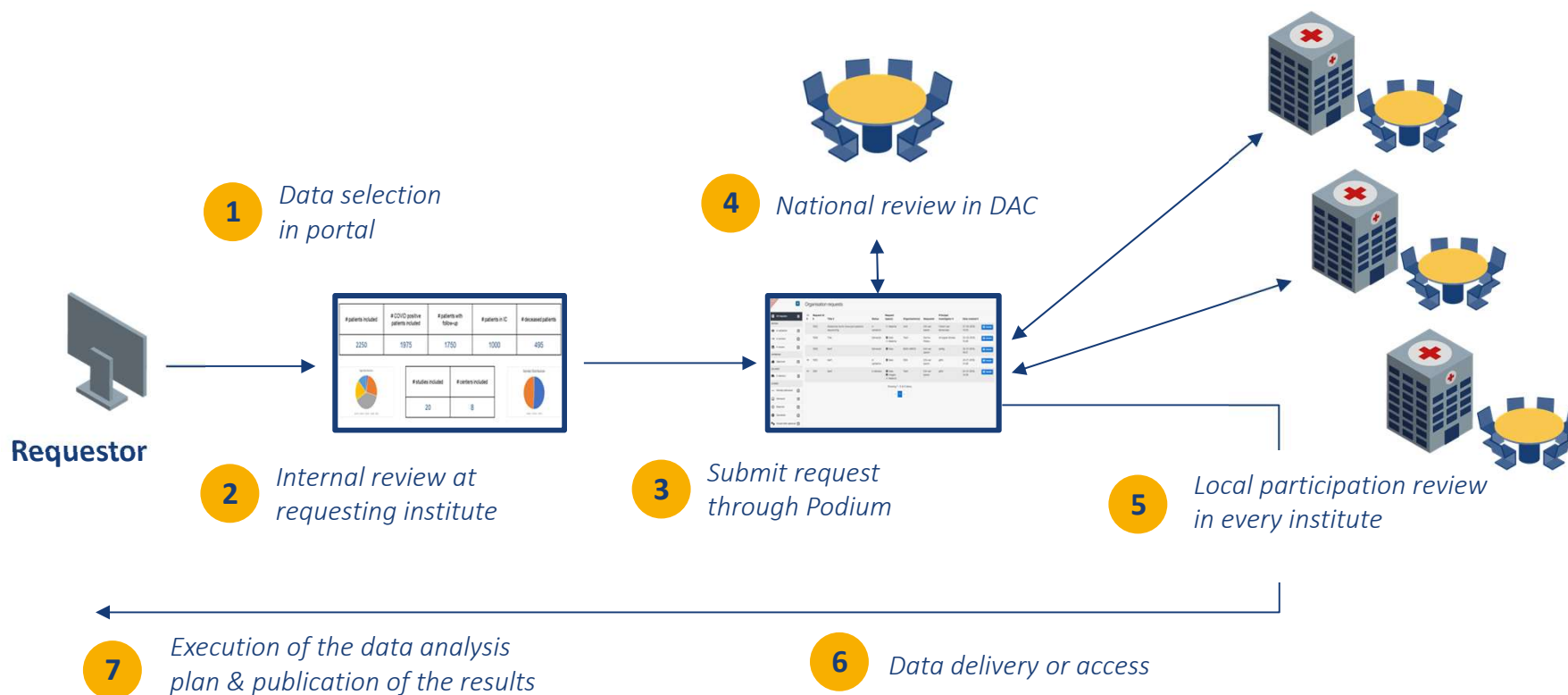
NFU COVID-NL metadata portal: <https://covid19initiatives.health-ri.nl/p/Dashboard>  
(also built on machine readable metadata from CEDAR)

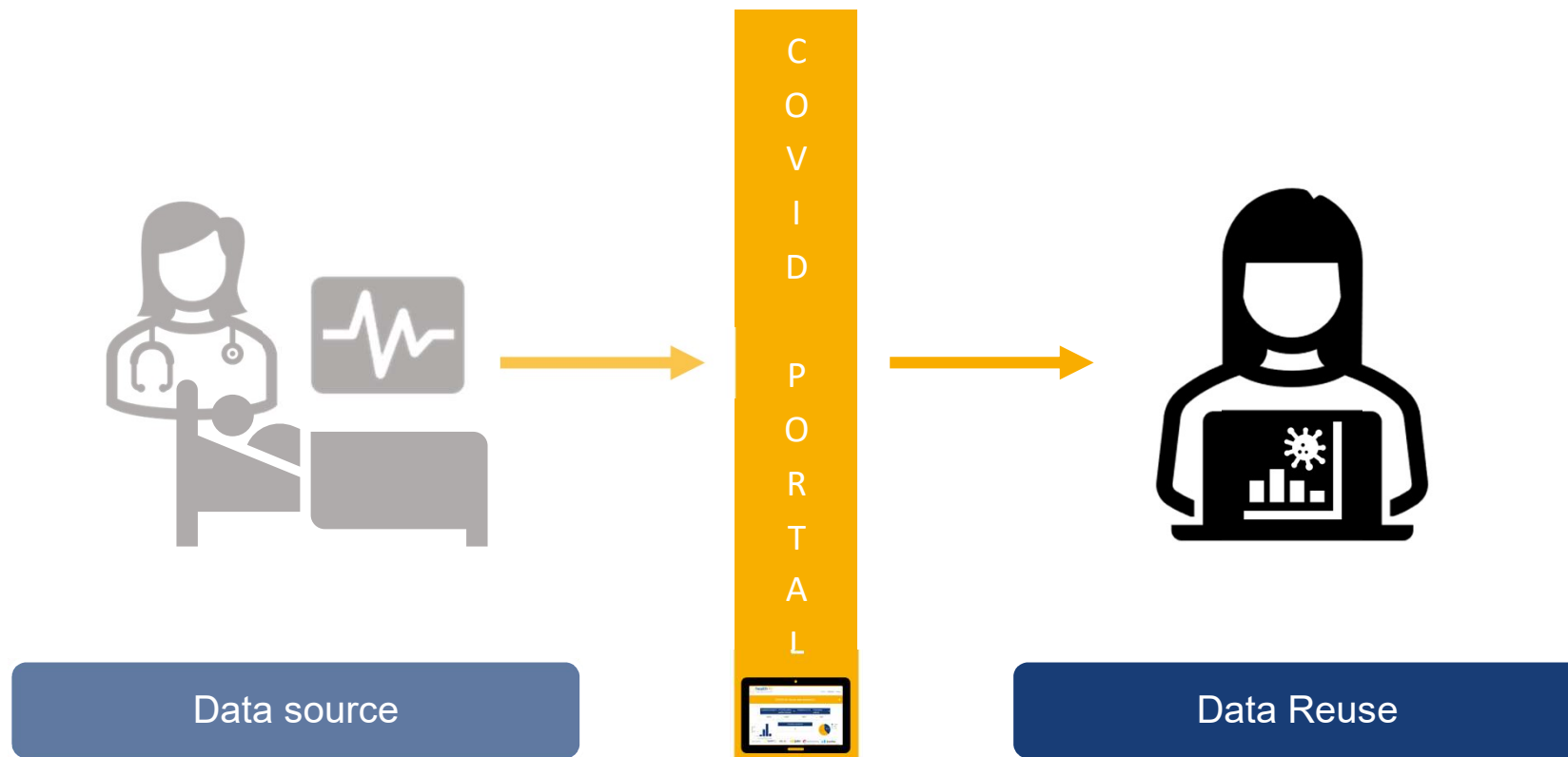


## COVID-NL data governance – the challenges

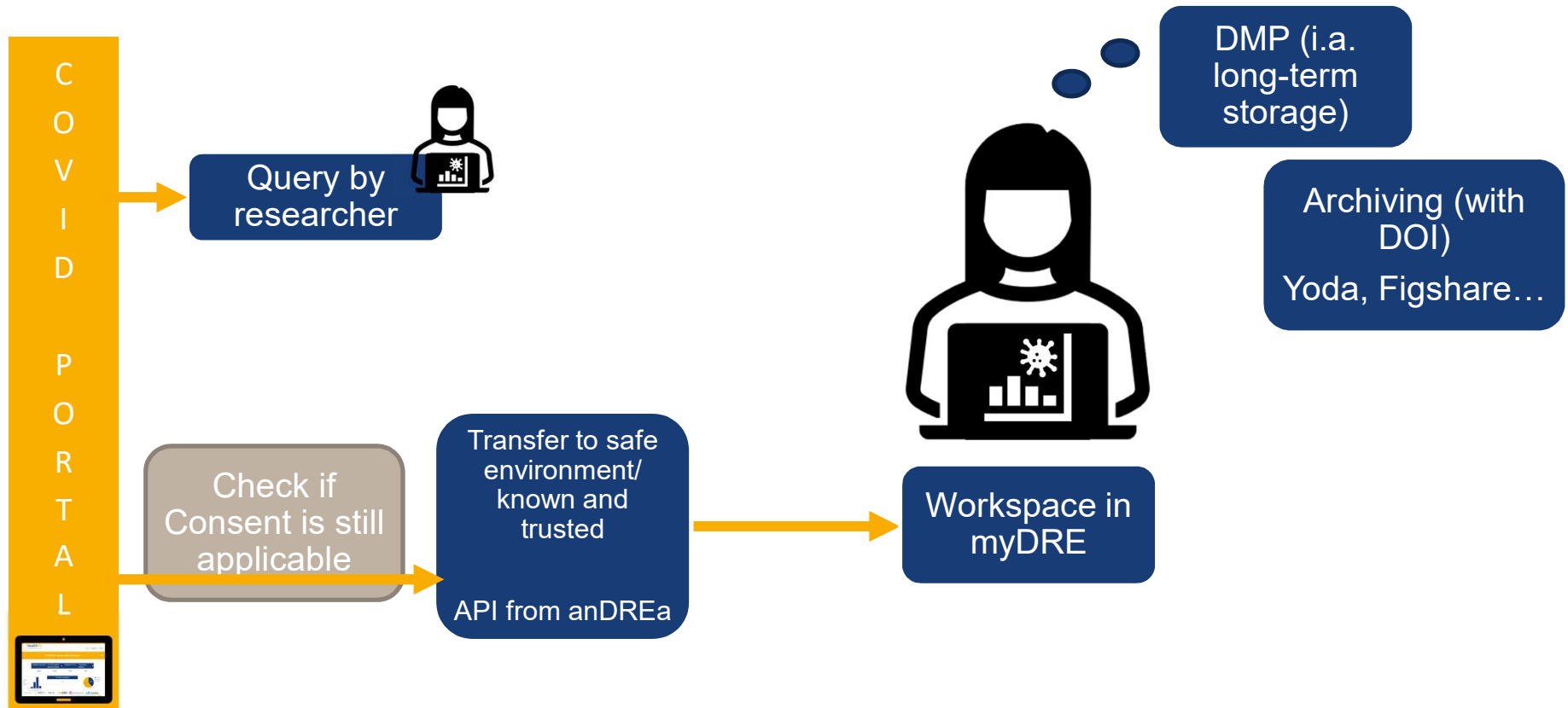
- COVID-NL is not only technology: data governance & regulatory aspects
- Already some procedures in place in most institutes
- Often based on a somewhat different interpretation of the legislation
  - In particular for the GDPR legal basis
- Responsibilities for secondary use of data are not always clearly defined
- Key stakeholders (legal support (often outsourced), DPOs, data managers, security officers, etc.) had to be identified while working on the procedures

# Data governance workflow – the result



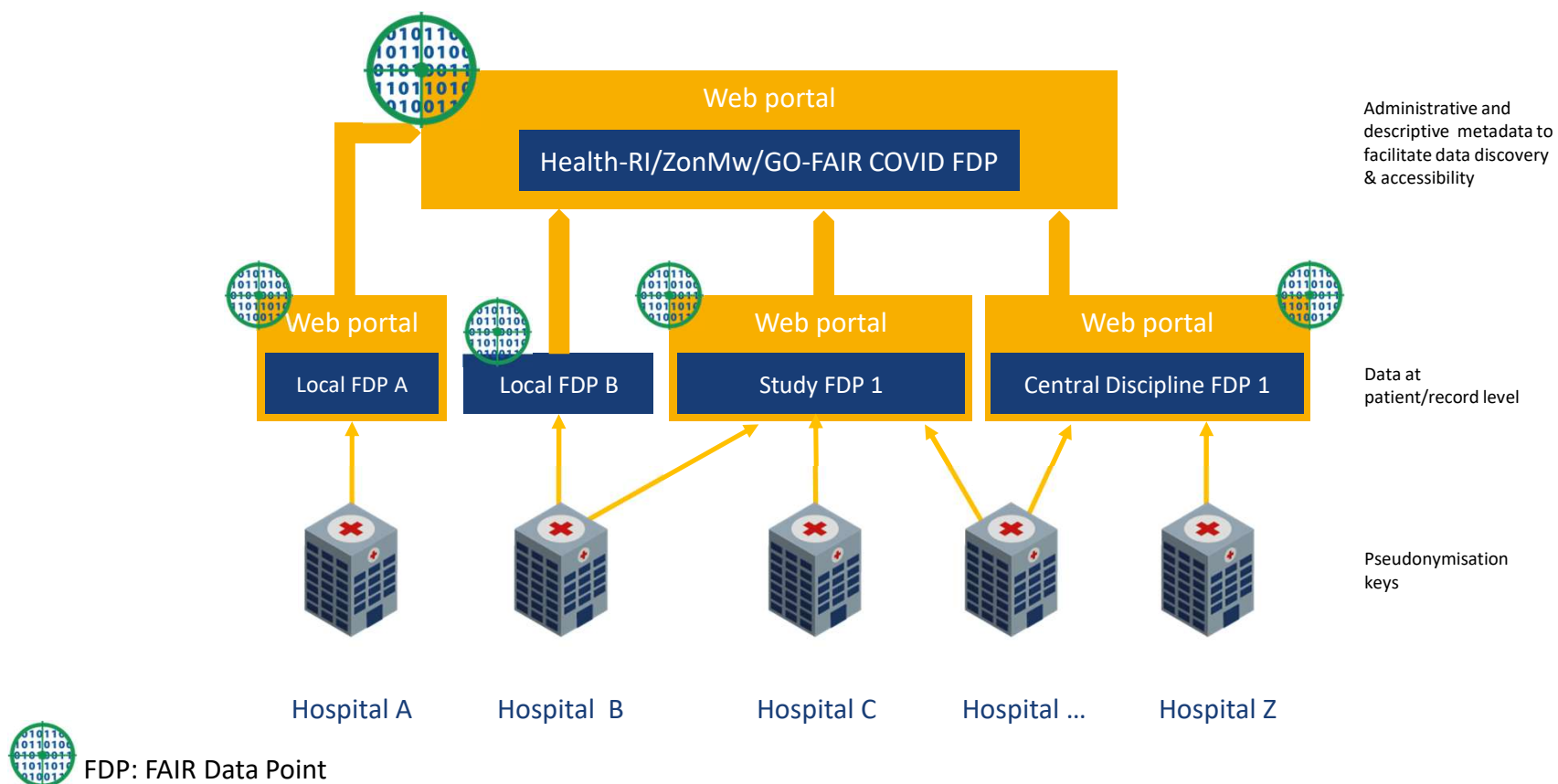


## Secondary Data Use



myDRE (anDREa product) == Secure Processing Environment

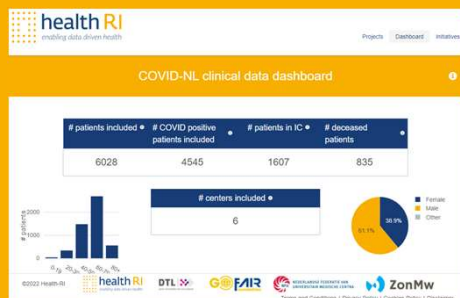
## Towards a national COVID-19 observational data portal using FDPs



## Lessons learned:

- machine readable metadata → easier → human readable portal
- study metadata already **findable** from *the start* of projects while new data still is being generated
- metadata is **interoperable**
  - at the same portal
  - metadata no longer is restricted to “that one portal”
    - based on standards, like DCAT, that facilitates interoperability between data catalogues/repositories published on the Web
    - E.g. DCAT of NFU COVID data -> <https://www.covid19dataportal.org/>
- **discoverability** of metadata increased
- linkage of datasets from different domains possible, though
  - Interpretation of regulations/law can be an obstacle
  - Linking different datasets at subject level not easy





## Questions?/Discussion

During workshop:

Still Questions /

Something to Discuss



Robin Navest

**Thank you!**