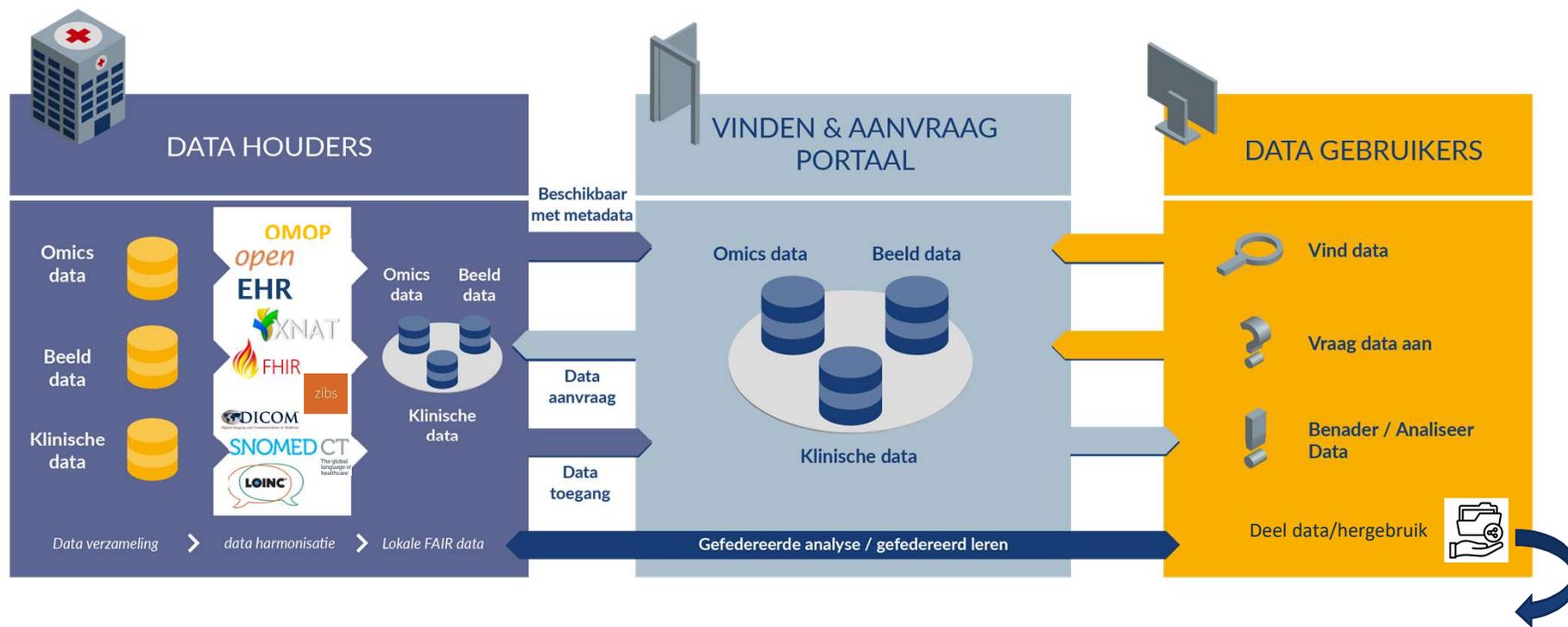


An illustration of a diverse group of people in a meeting or workshop setting. The background is a dark blue with abstract, wavy shapes. The people are shown in various poses, some talking, some looking at devices, and some in professional attire like lab coats. The overall style is modern and professional.

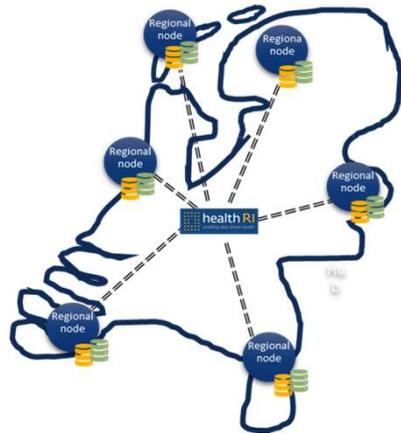
Health-RI COVID19 project Experiences and bottlenecks re: SSH data

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

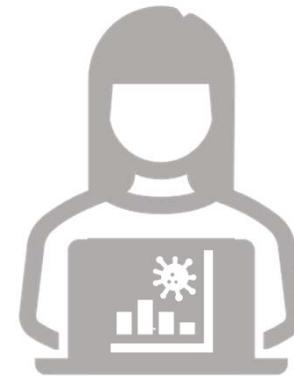
3 Best practices



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

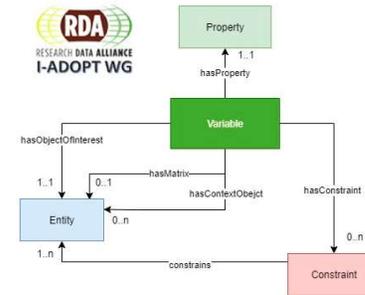
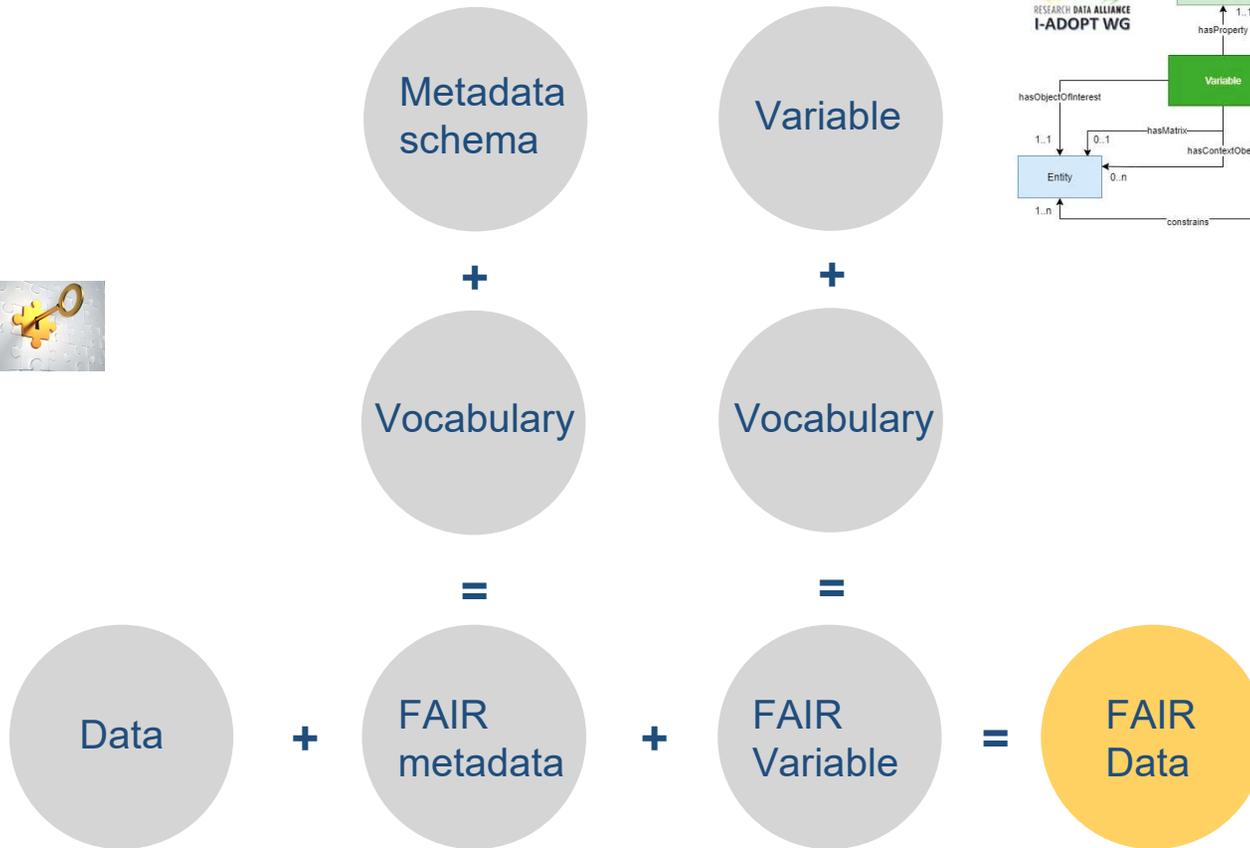
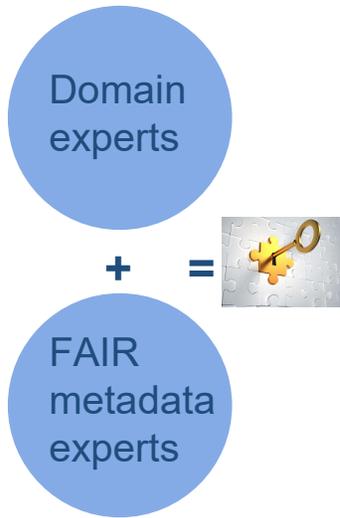


Data source

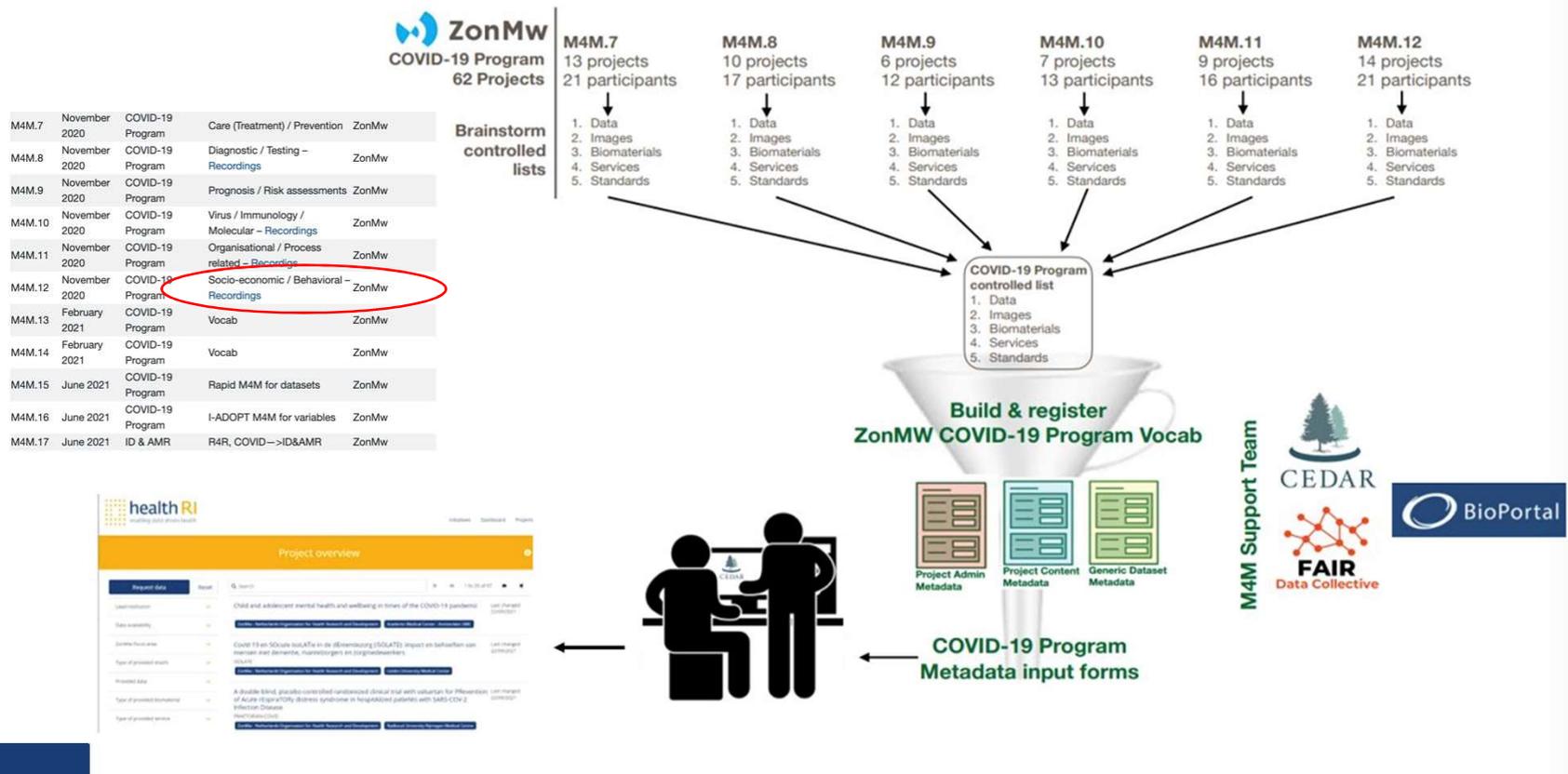


Data Reuse

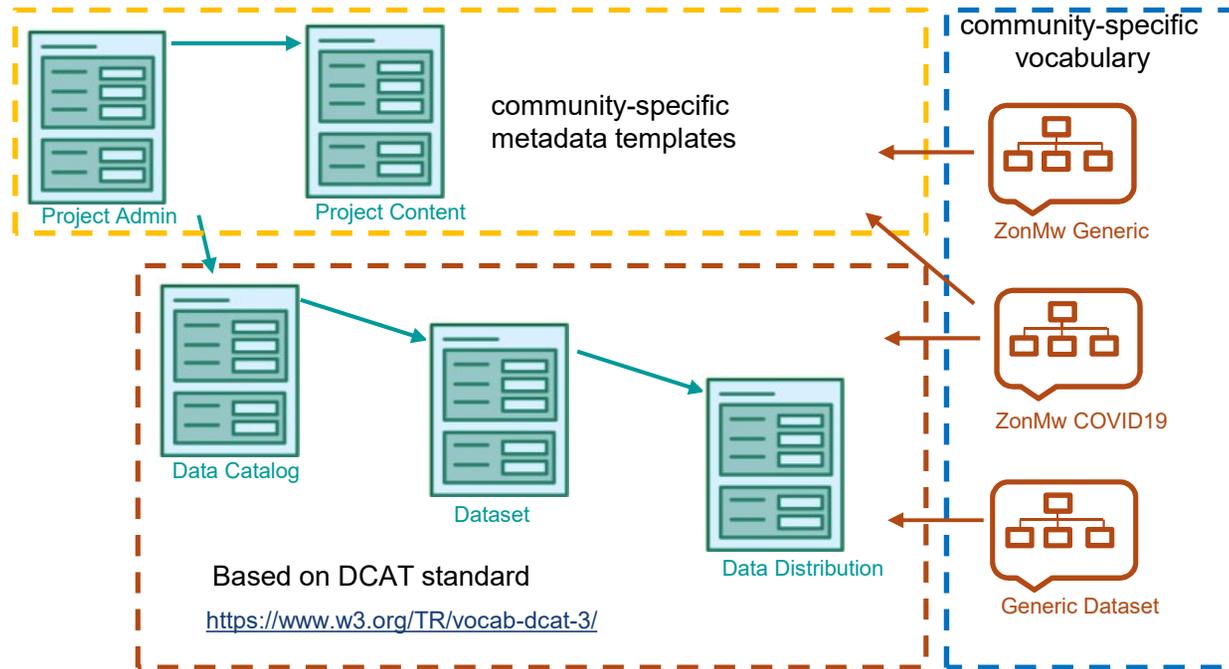
Road (so far) to machine actionable (meta)data



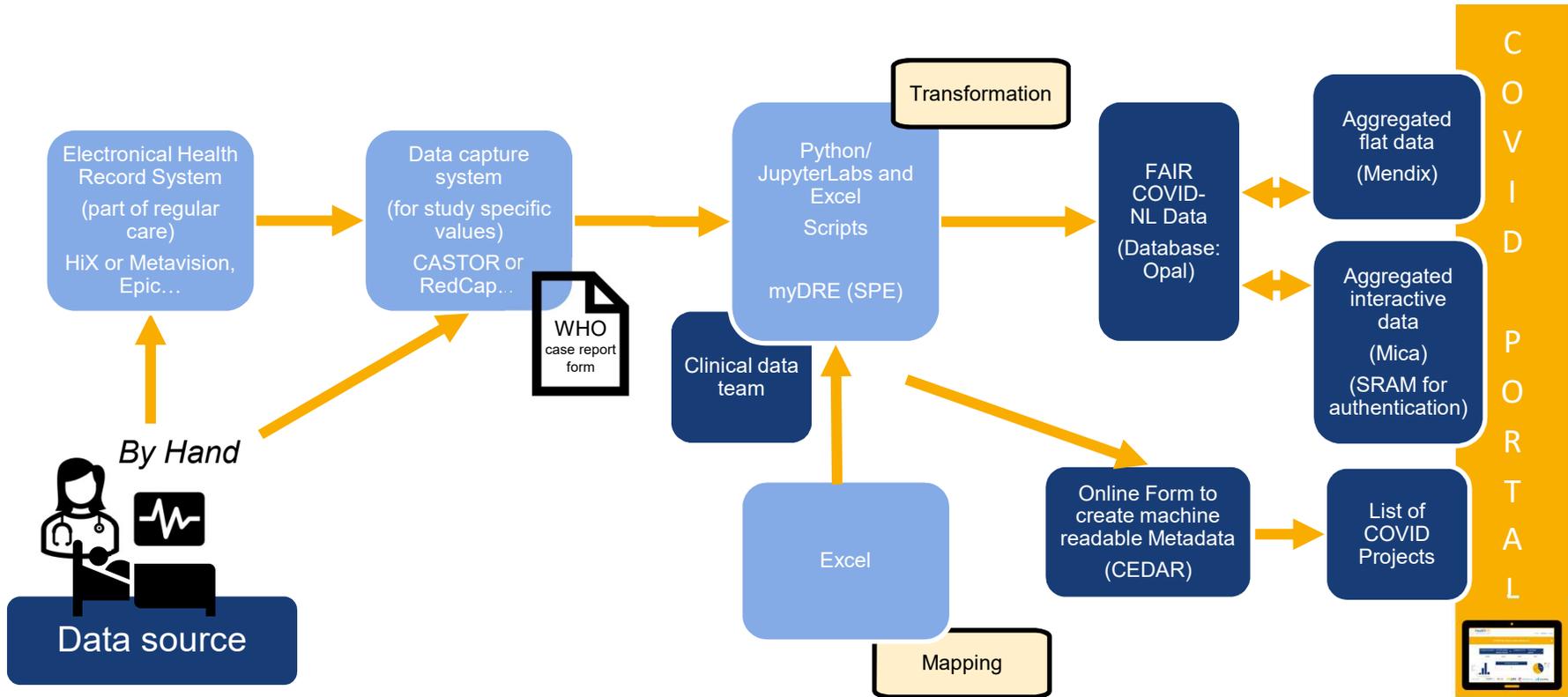
From Community to Data Portal



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)

Project overview

Request data

Reset

Search

1 to 25 of 130

Lead institution

Data availability

ZonMw focus area

Type of provided assets

Provided data

Type of provided biomaterial

Type of provided service

Subjects

Variables

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

SamenSlimOpen

ZonMw - Netherlands Organisation for Health Research and Development Wageningen University & Research

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

COVID-19: LVB en laaggeletterden

ZonMw - Netherlands Organisation for Health Research and Development Radboud University Nijmegen Medical Centre

Ethiek van e-Health tijdens de coronacrisis en daarna: lessen uit de pandemie

Last changed
28/03/2023

ZonMw - Netherlands Organisation for Health Research and Development Erasmus MC

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

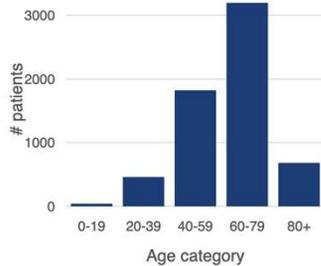
semantic faceted
search using the
provided
metadata

and contact data
custodian and
request
(getting access
to) data

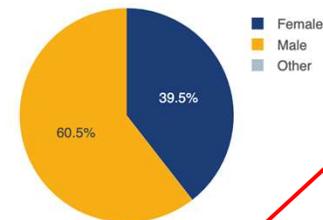
NFU COVID-NL metadata portal: <https://covid19initiatives.health-ri.nl/p/Dashboard>
(also built on machine readable metadata from CEDAR)

COVID-NL clinical data dashboard

# patients included	# COVID positive patients included	# patients in IC	# deceased patients
7400	5617	1944	1007



centers included
6



Search and request
(getting access to) data

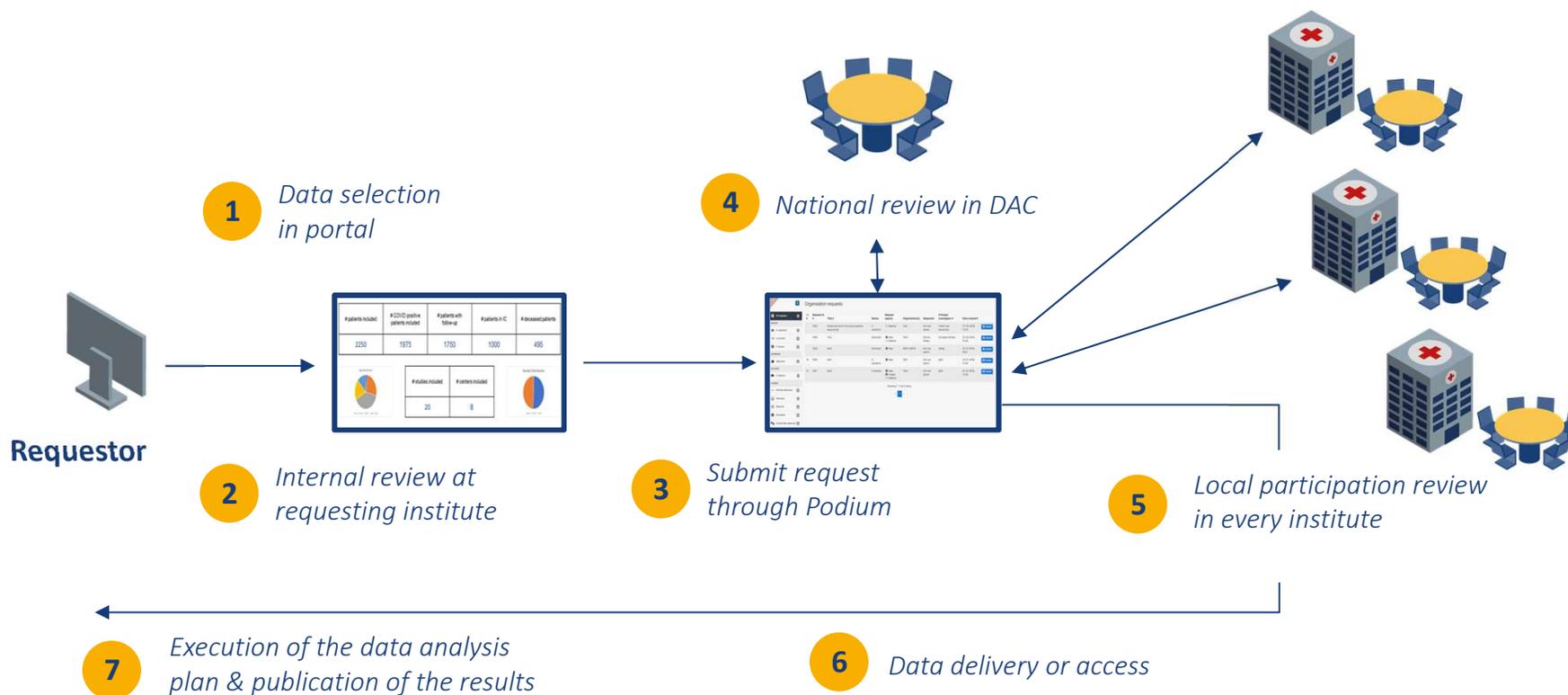
Last updated: 14/04/2023

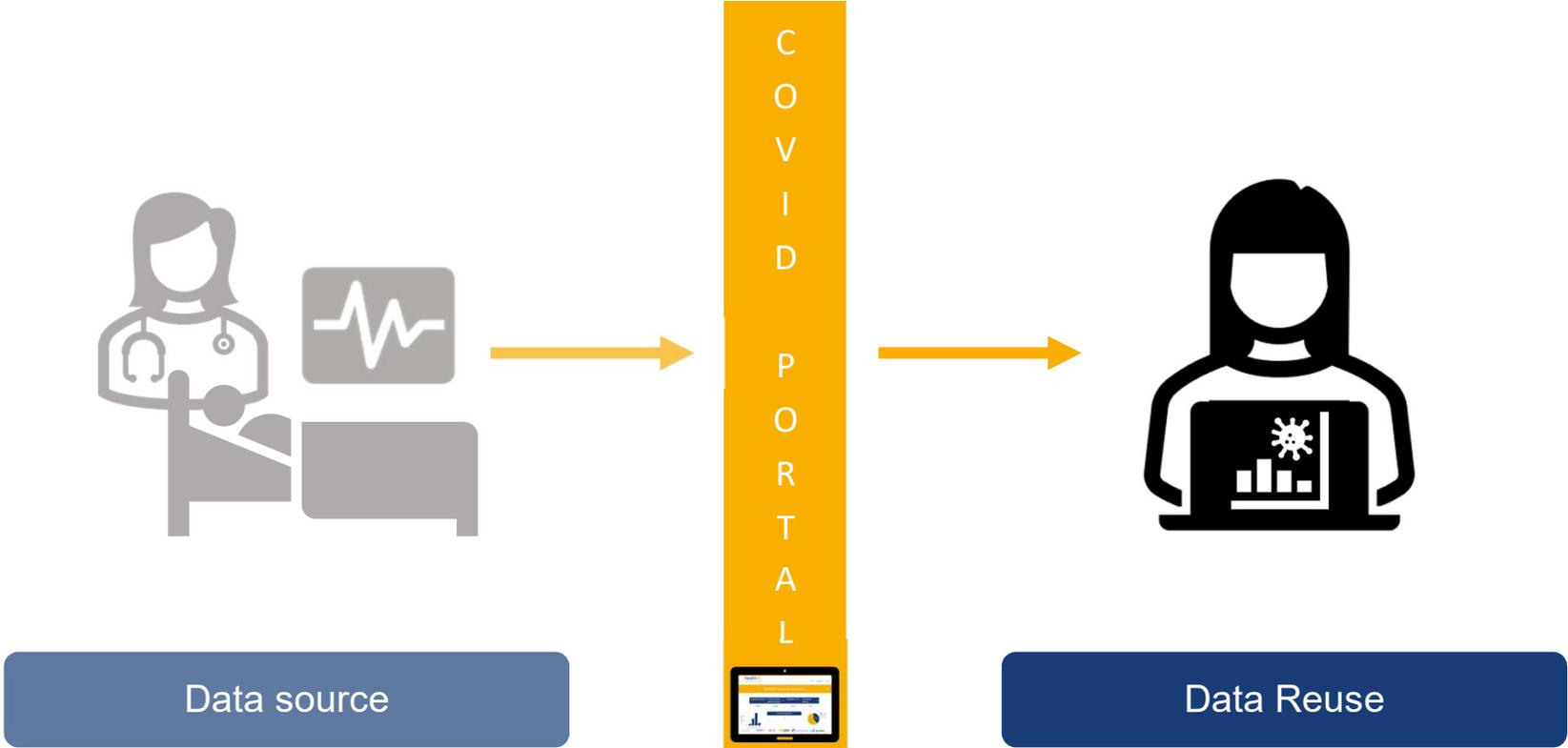
[Search deeper in the data](#) [Request data](#)

COVID-NL data governance – the challenges

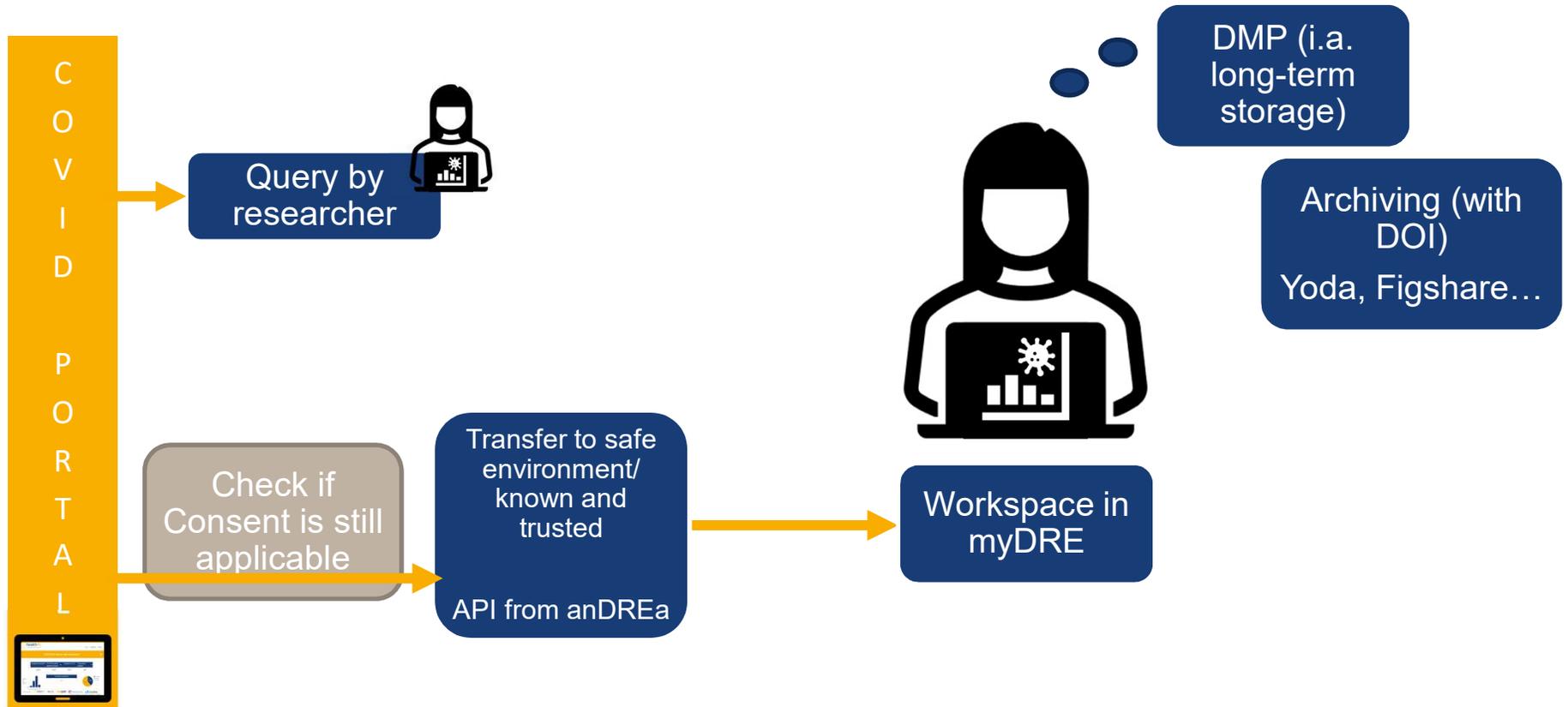
- COVID-NL is not only technology: data governance & regulatory aspects
- Already some procedures in place in most institutes
- Often based on a somewhat different interpretation of the legislation
 - In particular for the GDPR legal basis
- Responsibilities for secondary use of data are not always clearly 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



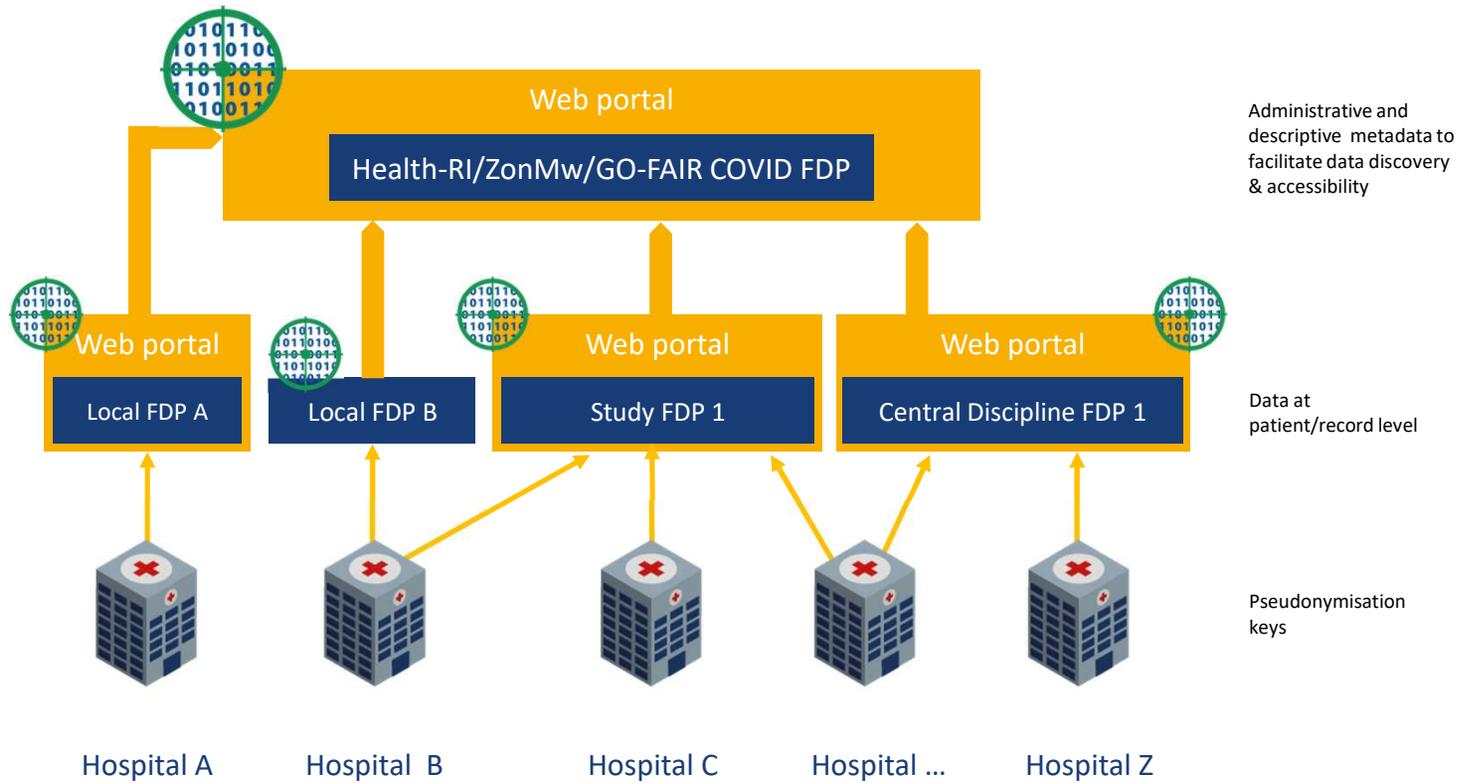


Secondary Data Use



myDRE (anDREa product) == Secure Processing Environment

Towards a national COVID-19 observational data portal using FDPs



 FDP: FAIR Data Point

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!