



health **RI**

*enabling data driven health*

Once data are FAIR,  
machines and people can find and use them

Projectleidersbijeenkomst Infectieziekten bestrijding & Antimicrobiële resistentie, ZonMw “Over het FAIRificeren van data in de IZB & AMR-projecten van ZonMw”

June 22, 2022 Jeroen Belien



# FAIR Hourglass

Raw Data  
[freedom to operate]

FAIRification

FAIR Layer 1: Creation of data & capture of data-reuse consent choices made by appropriate stakeholders

FAIR Layer 2: ETL and 'harmonization' processes for data & consent targeting domain-relevant machine-readable vocabularies & schema

Data that are FAIR-Ready  
[a minimal standard that is FAIR, open, and technology-independent]

FAIR Center: Storage of data, metadata, and consent as machine-actionable units of information (distributed)

FAIR Digital Object Framework

FAIR Orchestration

FAIR Layer 3: Exposure of FAIR metadata & gateways for ontology-based access control

FAIR Layer 4: Automated FAIR services for indexing, search, semantic resolution, data integration, object routing & workflow execution

Data Integration  
Data Sharing/Visiting  
Data Analytics  
[freedom to operate]

FAIR Layer 5: High-level data use applications such as data landscape surveys, data exchange, distributed learning and data analytics

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

Domain experts

+ =



FAIR metadata experts

Data

+

FAIR metadata

+

FAIR Variable

=

FAIR Data

Metadata schema

+

Vocabulary

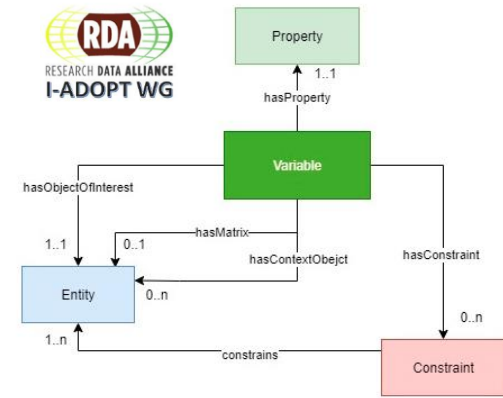
=

Variable

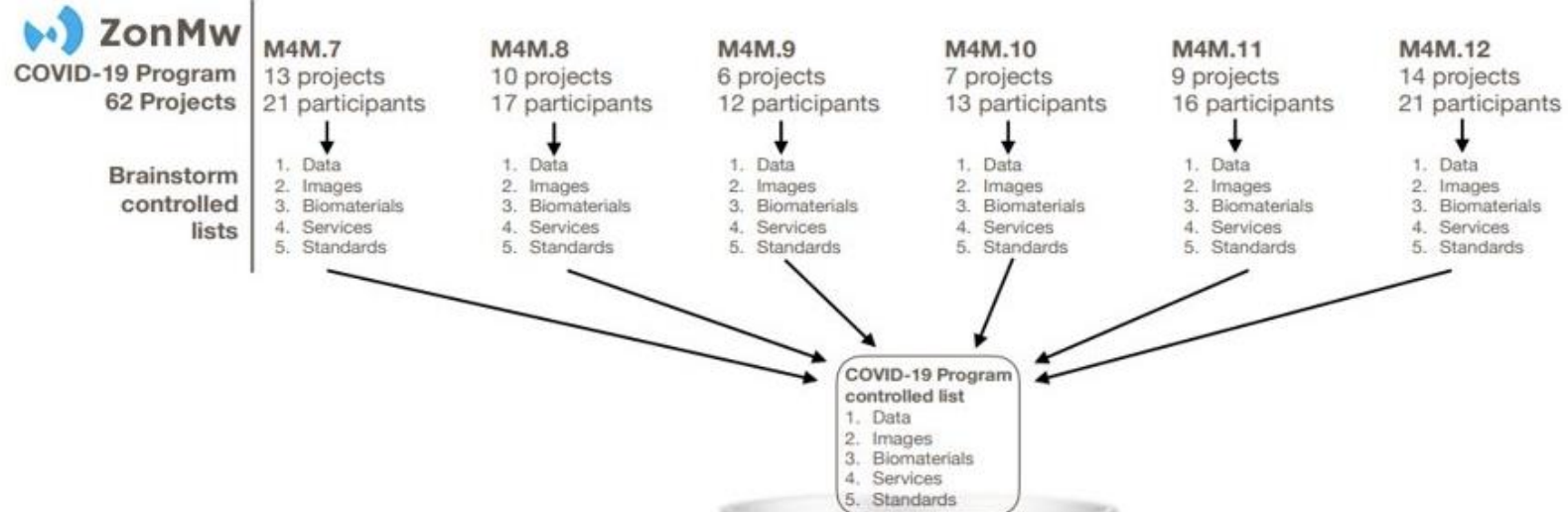
+

Vocabulary

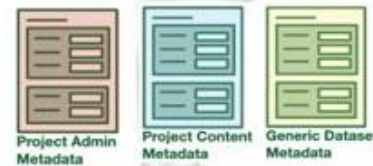
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# From Community to Data Portal



**Build & register  
ZonMw COVID-19 Program Vocab**



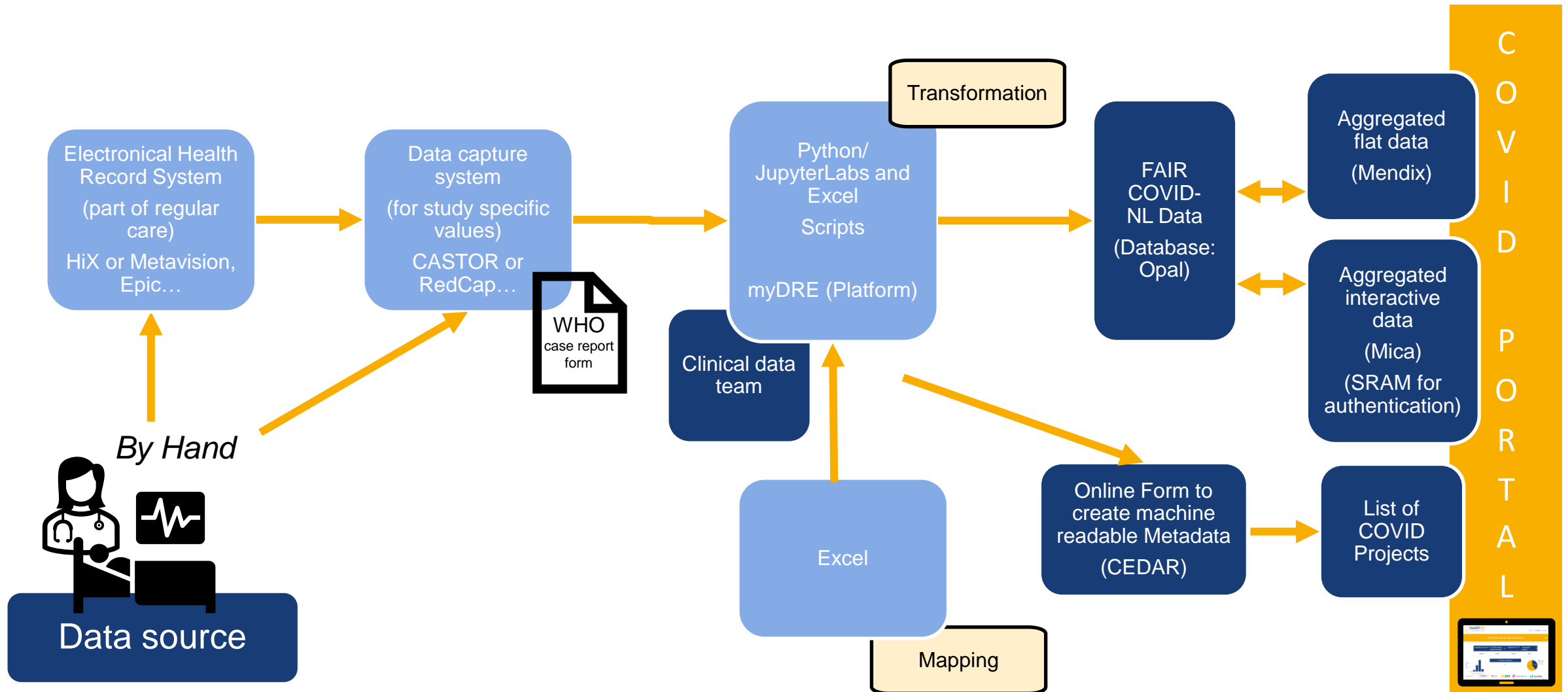
**COVID-19 Program  
Metadata input forms**

**M4M Support Team**





# Data ETL workflow from an institute/collaboration to a portal



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

The screenshot shows the 'Project overview' page of the ZonMw metadata portal. The page features a search bar at the top with the text 'Zoeken' and a 'Request data' button. Below the search bar, there are several filter categories on the left, each with a dropdown arrow: 'Lead institution', 'Data availability', 'ZonMw focus area', 'Type of provided assets', 'Provided data', 'Type of provided biomaterial', 'Type of provided service', 'Subjects', and 'Variables'. The main content area displays a list of projects, each with a title, a description, and a 'Last changed' date. The projects listed are:

- The impact of COVID-19 on illiterate people and people with a mild intellectual disabilities: preventative measures, (mental) health and support needs.** Last changed 01/06/2022. Metadata tags: ZonMw - Netherlands Organisation for Health Research and Development, Radboud University Nijmegen Medical Centre.
- Homeless and COVID-19 lessons for the future** Last changed 31/05/2022. Metadata tags: ZonMw - Netherlands Organisation for Health Research and Development, Radboud University Nijmegen Medical Centre.
- De impact van de coronacrisis op de rechtspraak en de positie van kwetsbare rechtszoekenden** Last changed 19/05/2022. Metadata tags: ZonMw - Netherlands Organisation for Health Research and Development, Radboud University Nijmegen.
- Inzicht in aanhoudende klachten na Covid-19 besmetting: een mixed methods benadering** Last changed 05/04/2022. Metadata tags: ZonMw - Netherlands Organisation for Health Research and Development, NIVEL - Netherlands Institute for Health Services Research.
- Changes in the use and organization of care in general practices and out-of-hours services: lessons learned from the COVID-19 pandemic** Last changed 05/04/2022. Metadata tags: ZonMw - Netherlands Organisation for Health Research and Development, NIVEL - Netherlands Institute for Health Services Research.
- Aanhoudende klachten na COVID-19 infectie: epidemiologie, pathofysiologie, predictie, en communicatie, de CORona Follow Up (CORFU) studie** Last changed 14/03/2022.

At the bottom of the page, there are logos for Health-RI, DTL, FAIR, NFDU, and ZonMw, along with links for Terms and Conditions, Privacy Policy, Cookies Policy, and Disclaimer.

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)



Search and request (getting access to) data

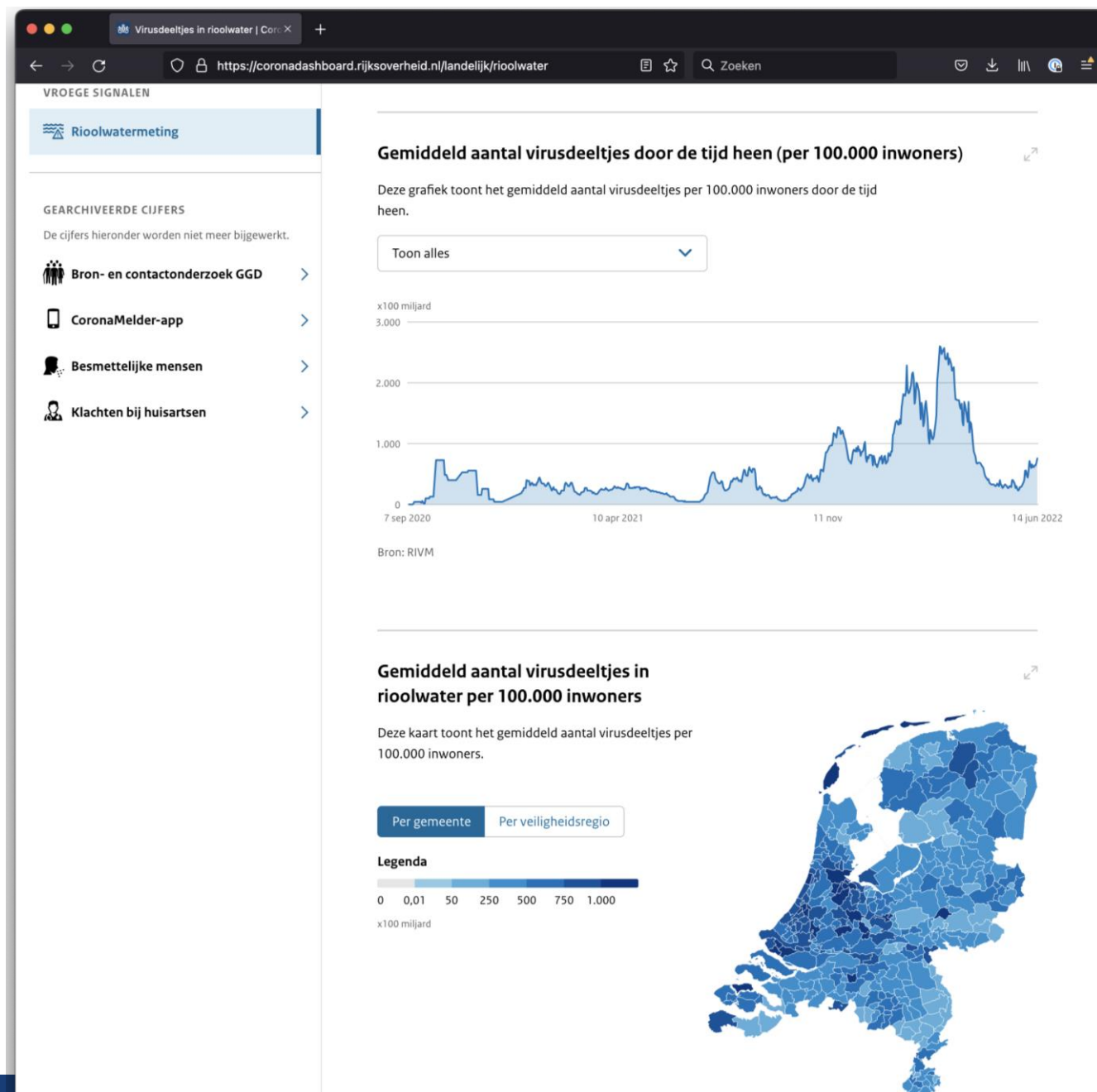
# So why do we need machine readable data?

- Lessons learned so far:
  - 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. NFU COVID data -> <https://www.covid19dataportal.org/>
  - **discoverability** of metadata increased

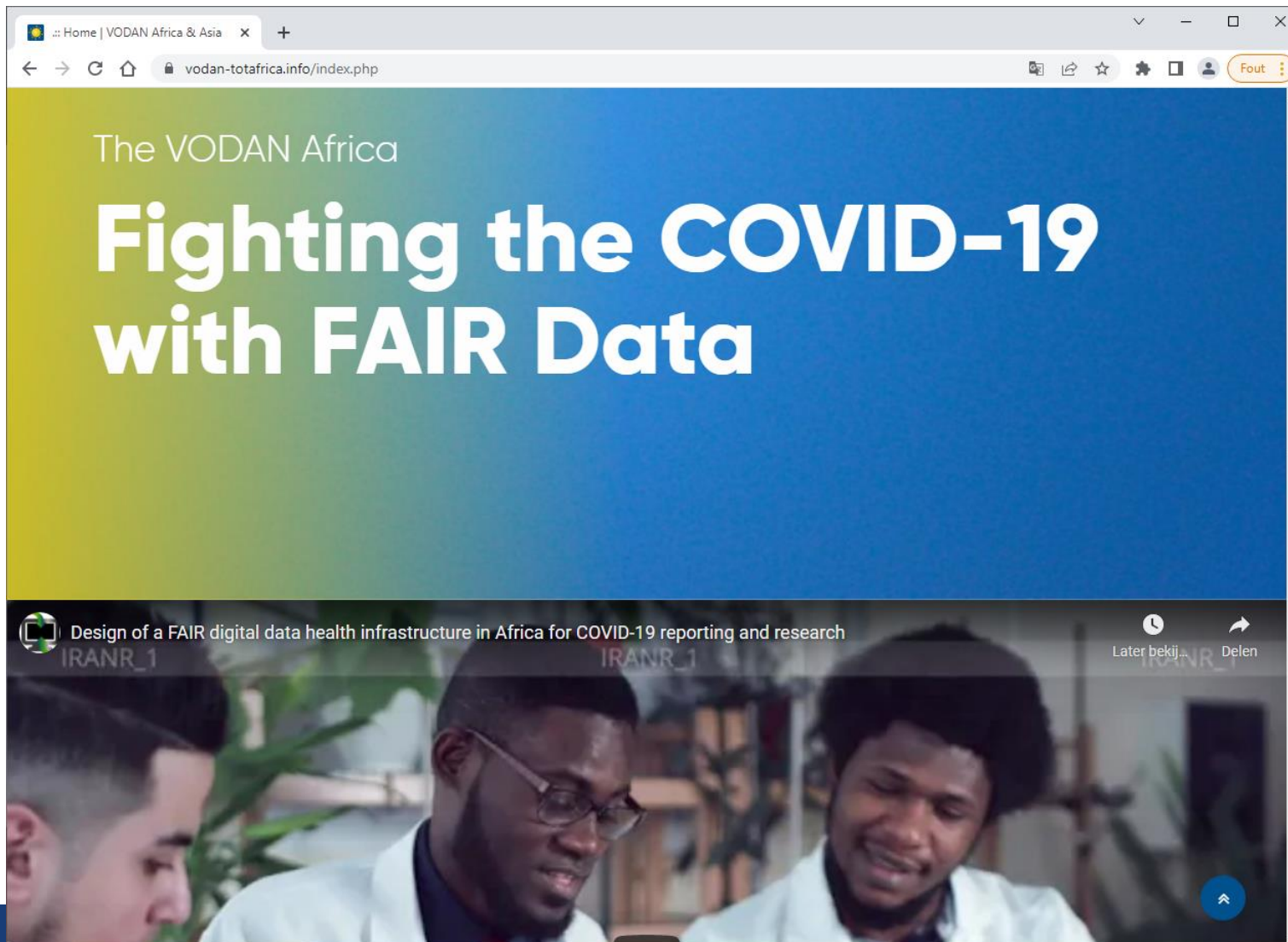


# Other examples

- Open data: corona dashboard
- Rioolwater



# FAIR orchestration: FAIR Data Points etc. by Mirjam van Reisen see what's FAIRly possible now in Africa thanks to VODAN Africa



The screenshot shows a web browser window with the URL `vodan-totafrika.info/index.php`. The page header reads "The VODAN Africa". The main heading is "Fighting the COVID-19 with FAIR Data". Below the heading is a video player with the title "Design of a FAIR digital data health infrastructure in Africa for COVID-19 reporting and research" and the identifier "IRANR\_1". The video shows three men in white lab coats looking at a device. The browser interface includes a "Fout" button in the top right corner.