

ELSI workshop gegevensbescherming

19 feb 2021

Special Interest Group Veilige Datakoppeling

De Special Interest Group Veilige Datakoppeling richt zich op een veilige uitwisseling en koppeling van persoonsgebonden data t.b.v. onderzoek.

Veilige data koppeling

De Special Interest Group (SIG) werkgroep "Veilige data koppeling" richt zich op een veilige uitwisseling en koppeling van persoonsgebonden data t.b.v. onderzoek, met onderwerpen als standaardisatie met oog op internationaal en nationaal beleid, en innovatieve big data technologie ontwikkelingen. De beoogde doelstellingen zijn beleid en strategie te vormen m.b.t. deze thema's.



NETHERLANDS FEDERATION OF UMCS
DATA4LIFESCIENCES

WP6 GRP



NFU-
SIG-IB

SURF SARA



Data delen en koppelen

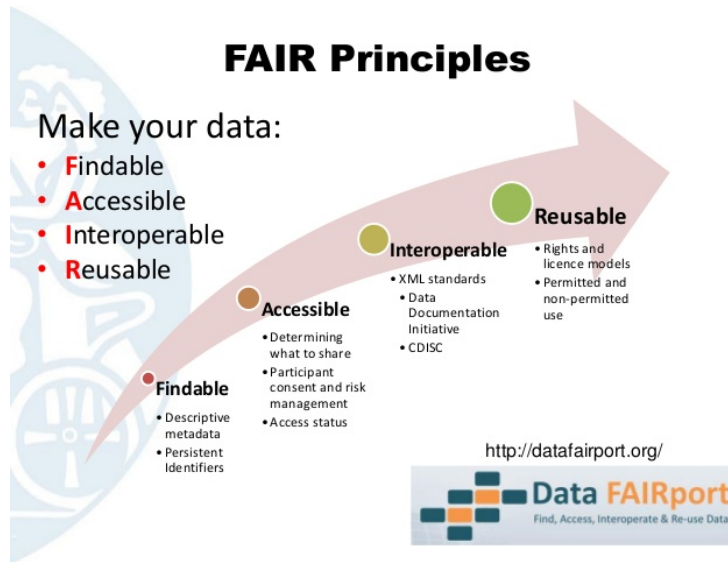
[ELSI Servicedesk](#)

in relatie tot mens gebonden onderzoek
(bijv. zorg, biomedisch, sociaal onderzoek)

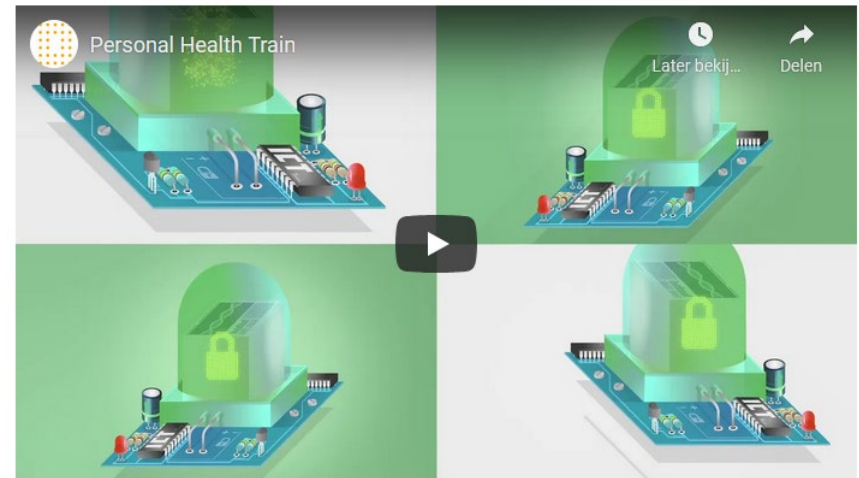


Toolkit overdracht

FAIR en de afsprakenstelsels over de data en data koppelingen



<https://www.go-fair.org/fair-principles/>



Personal Health Train video

<https://www.health-ri.nl/initiatives/personal-health-train>



Current Implementation Networks

<https://www.go-fair.org/implementation-networks/overview/>

Focus vandaag : Covid-19 data wereldwijd koppelen volgens de FAIR principes



LEIDEN UNIVERSITY MEDICAL CENTER

FAIR Data Point architecture

Data stations

Implementation Network

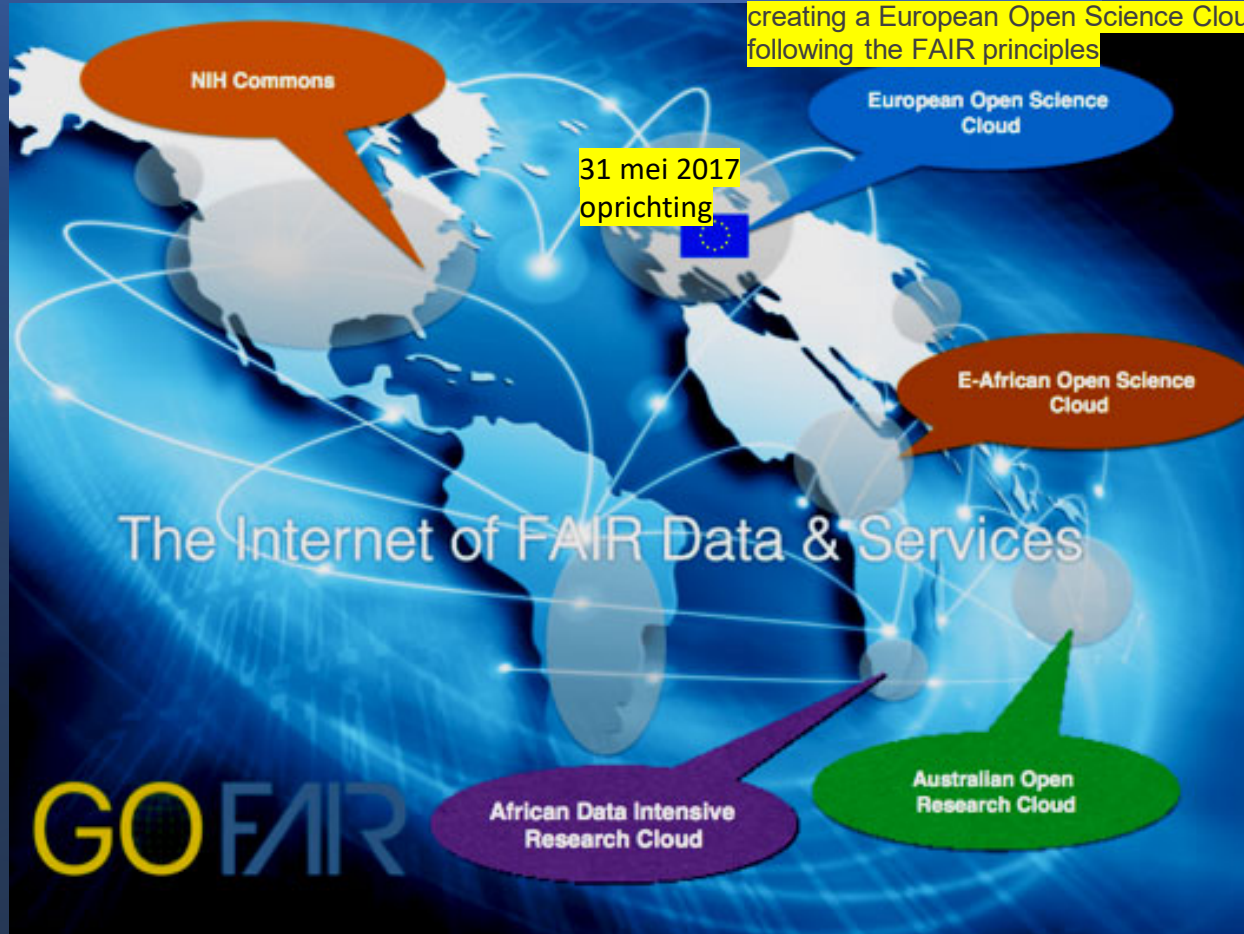


e.flikkenschild@lumc.nl (Erik)

Wereldwijde samenwerking: Open Science

In May 2015, the Commission proposed creating a European Open Science Cloud following the FAIR principles

31 mei 2017 oprichting



2020
1^e Realisatie
FAIR principes
intercontinentaal



Digital Health and Care



TRANSFORMATION OF HEALTH AND CARE IN THE DIGITAL SINGLE MARKET - Harnessing the potential of data to empower citizens and build a healthier society

European health challenges

- ⊗ Ageing population and chronic diseases putting pressure on health budgets
- ⊗ Unequal quality and access to healthcare services
- ⊗ Shortage of health professionals

Potential of digital applications and data to improve health

- ✍ Efficient and integrated healthcare systems
- ✍ Personalised health research, diagnosis and treatment
- ✍ Prevention and citizen-centred health services

What EU citizens expect...

90% agree

To access their own health data
(requiring interoperable and quality health data)

80% agree

To share their health data
(if privacy and security are ensured)

80% agree

To provide feedback on quality of treatments

Support European Commission:

1

Secure access and exchange of health data

Ambition:

Citizens securely access their health data and health providers (doctors, pharmacies...) can exchange them across the EU.

Actions:

- eHealth Digital Service Infrastructure will deliver initial cross-border services (patient summaries and ePrescriptions) and cooperation between participating countries will be strengthened.
- Proposals to extend scope of eHealth cross-border services to additional cases, e.g. full electronic health records.
- Recommended exchange format for interoperability of existing electronic health records in Europe.



Updated 24/04/2018

2

Health data pooled for research and personalised medicine

Ambition:

Shared health resources (data, infrastructure, expertise...) allowing targeted and faster research, diagnosis and treatment.

Actions:

- Voluntary collaboration mechanisms for health research and clinical practice (starting with "one million genomes by 2022" target).
- Specifications for secure access and exchange of health data.
- Pilot actions on rare diseases, infectious diseases and impact data.



3

Digital tools and data for citizen empowerment and person-centred healthcare

Ambition:

Citizens can monitor their health, adapt their lifestyle and interact with their doctors and carers (receiving and providing feedback).

Actions:

- Facilitate supply of innovative digital-based solutions for health, also by SMEs, with common principles and certification.
- Support demand uptake of innovative digital-based solutions for health, notably by healthcare authorities and providers, with exchange of practices and technical assistance.
- Mobilise more efficiently public funding for innovative digital-based solutions for health, including EU funding.

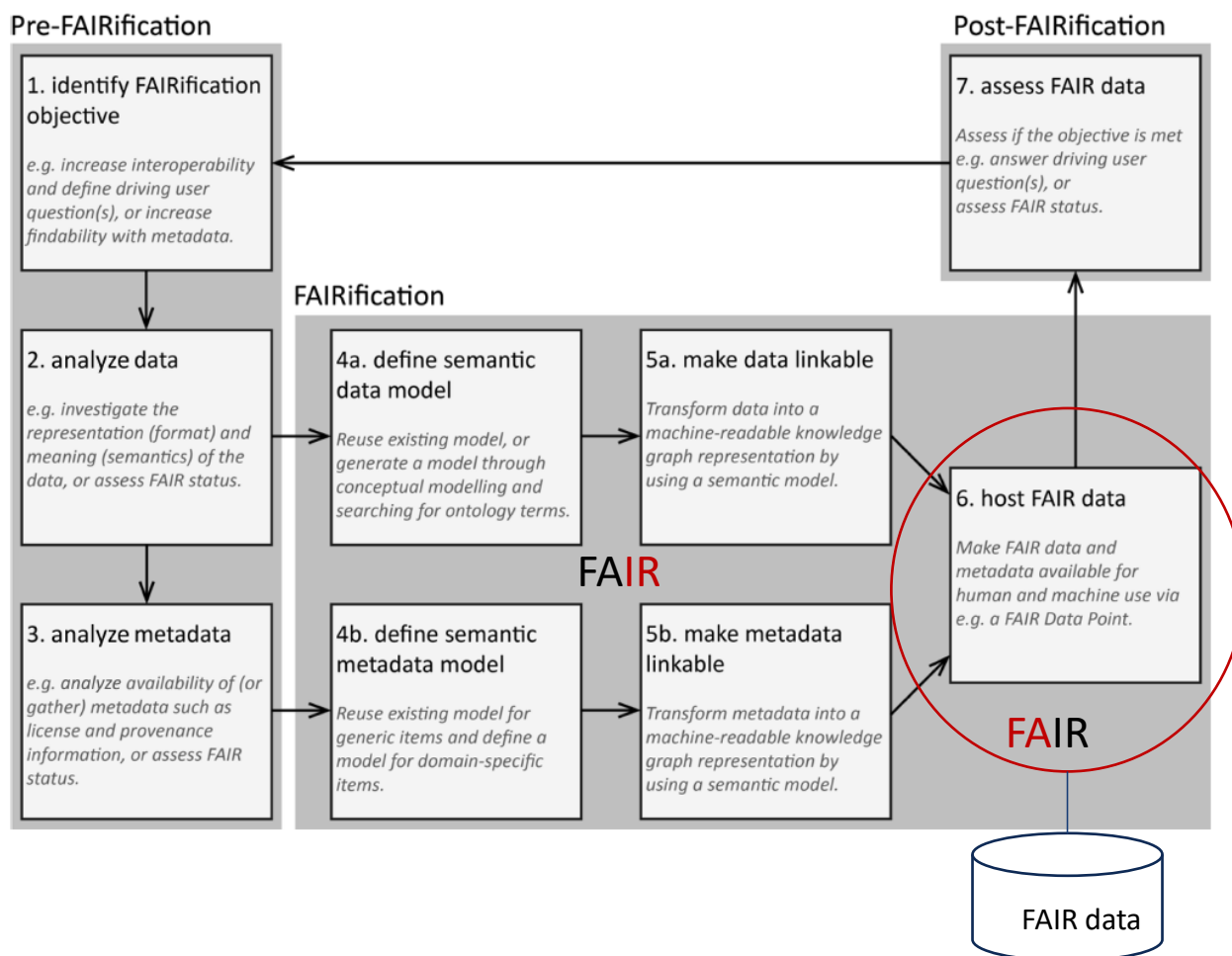


A Generic Workflow for the Data FAIRification Process

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Barend Mons^{1,2}, Erik Schultes², Marco Roos¹ & Mark Thompson¹

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²GO FAIR International Support & Coordination Office (GFISCO), Leiden, The Netherlands



Breng de vraag naar de data (data visiting)
(Go-FAIR VODAN implementation Network)

[AllegroGraph WebView \(lumc.nl\)](https://lumc.nl) (demo)

Data koppelingen 2.0
FAIR Data Point



- Data: test patiënten
- Type koppeling: alle
- Method: data visiting
- Doel: data pooling & linking

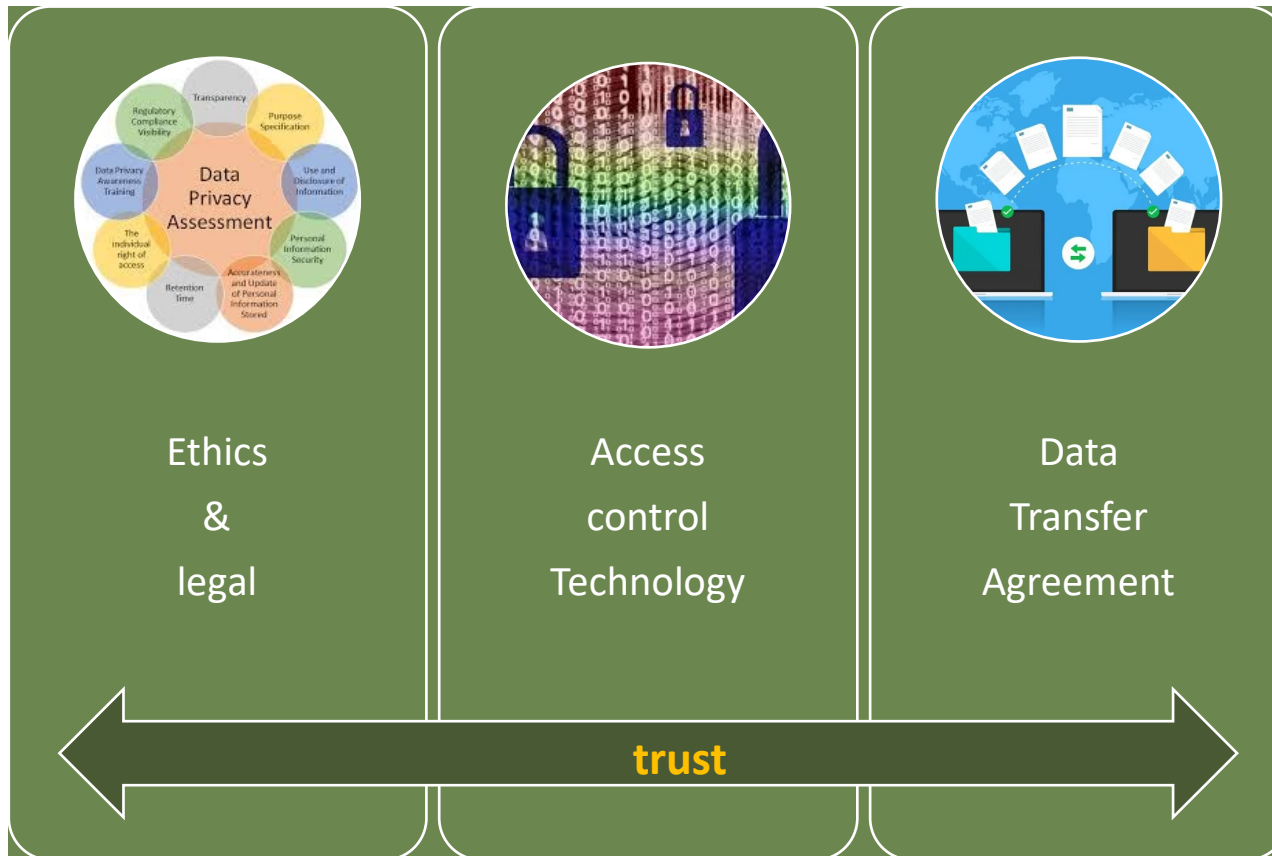
Prof. Dr. Mirjam van Reisen – Global Coordinator VODAN Africa.

Prof. Francisca Oladipo – Executive Secretary, VODAN Africa

[Historic First Data Visiting of Patient Data Stored in Residence Across Continents - VODAN-Africa & Asia \(vodan-totafrica.info\)](https://vodan-totafrica.info)

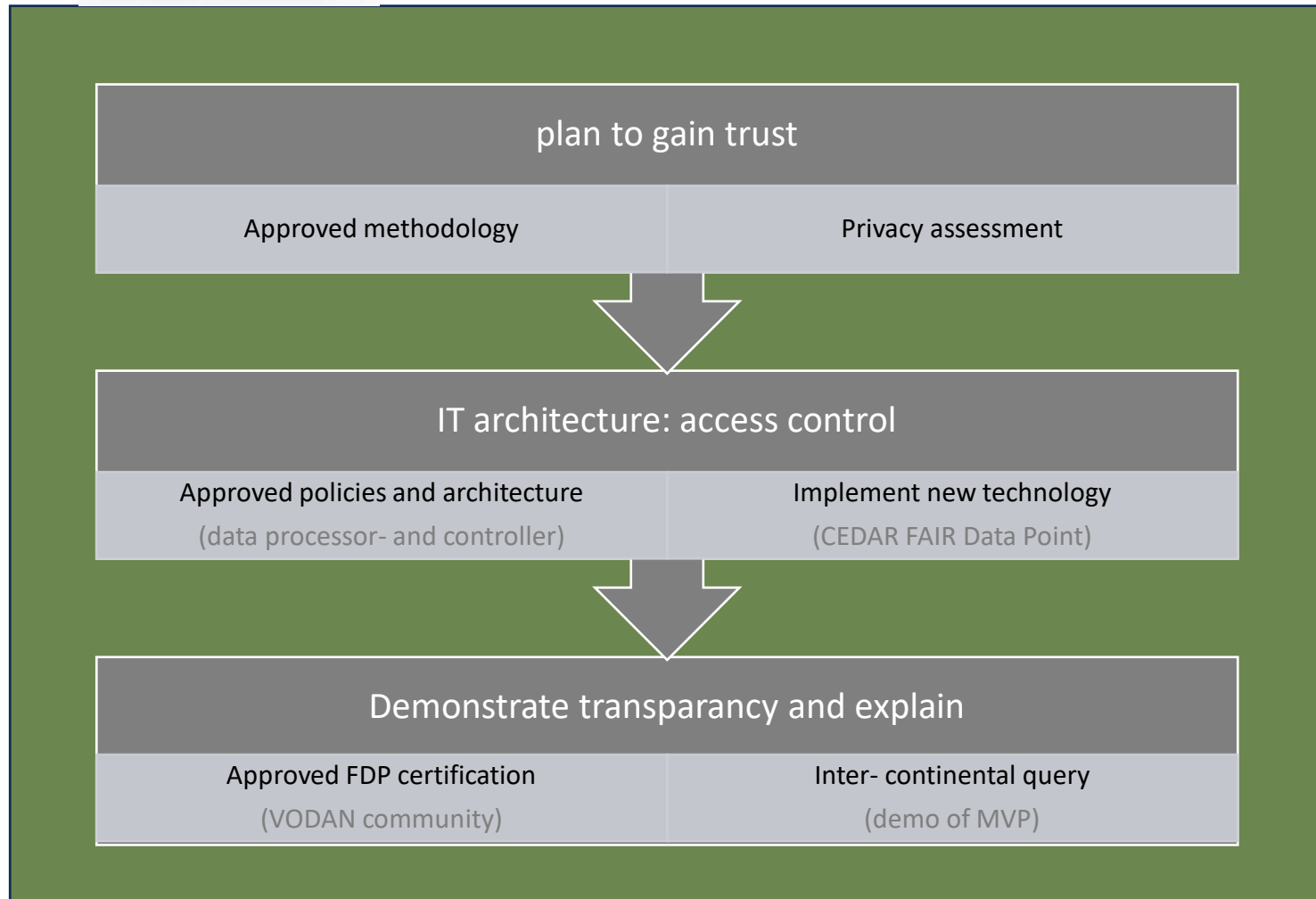


VODAN-Africa / LUMC approach



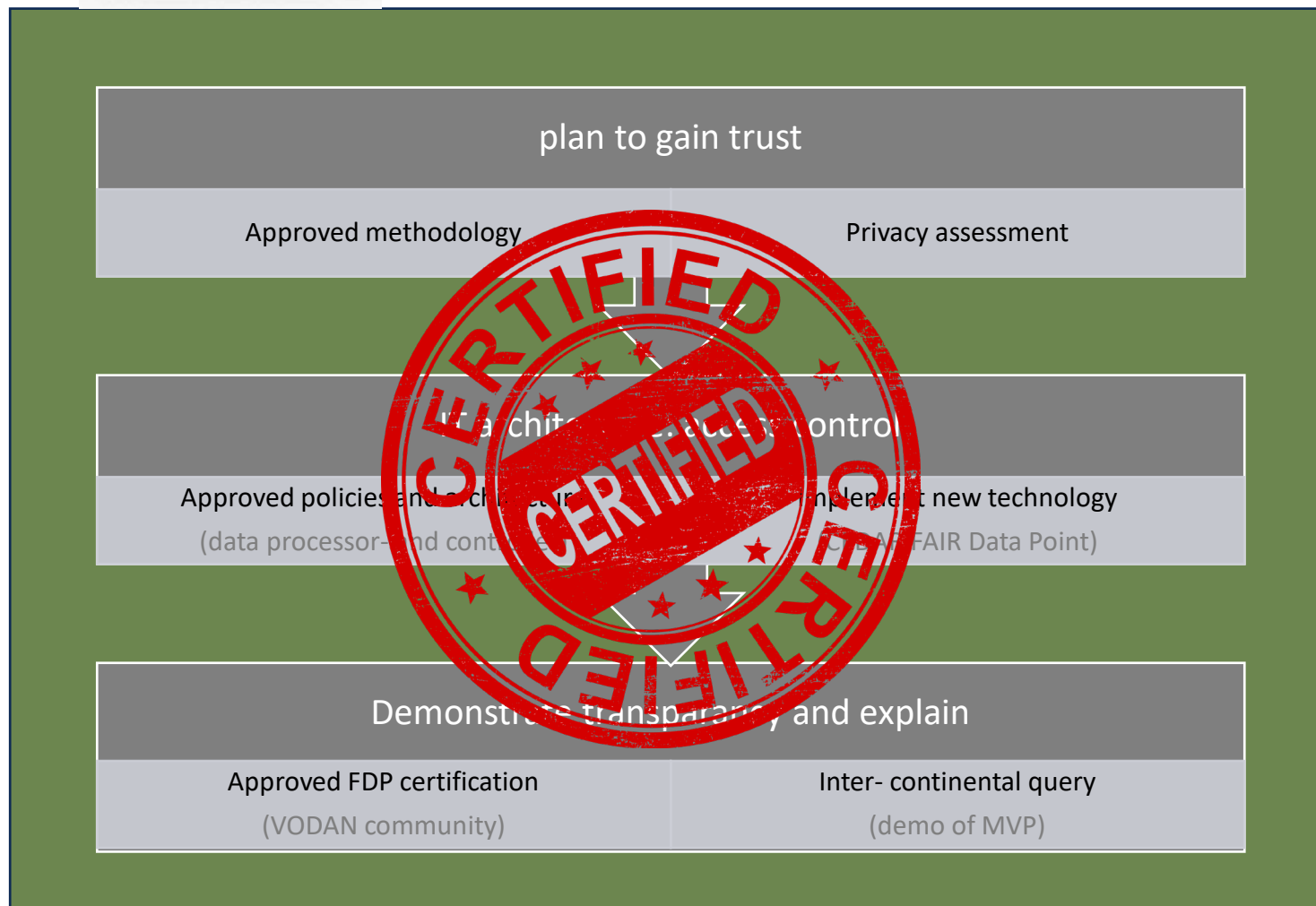


VODAN trust roadmap

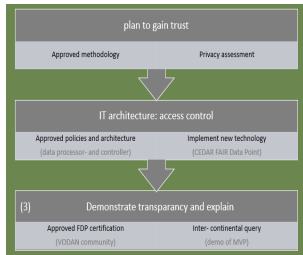




VODAN trust roadmap



Step 1: Plan to gain trust



Secure data linkage for the secondary use of personal data

Privacy Framework for (regional) FAIR data

Towards a richer dataset: supporting a learning health system

Perspectives like Open Science, Artificial intelligence and Personal Medicine can become data trusted if:

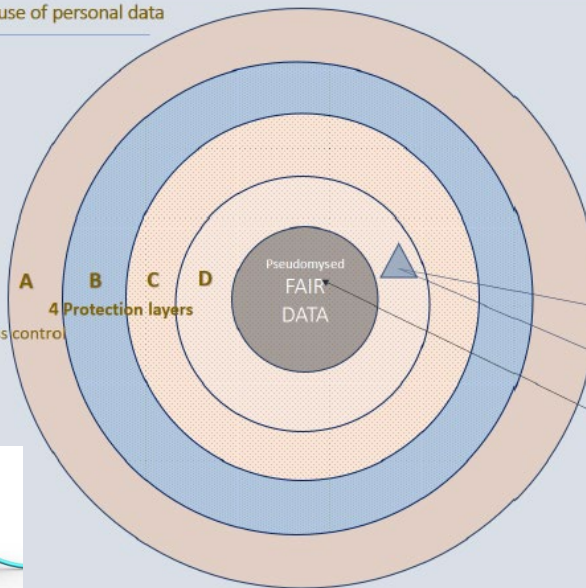
The GDPR / AVG is combined with an ethical view suitable for designing an institutional and regional IT design
Pseudomised and anonymised personal data will be protected with state of the art technology (MPC, DF)
An appointment system is in place (Personal Health Train concept)

DATA linkage: secondary use of personal data

NL universities / UMC's

Start

- A. Ethics & compliancy
- B. Personal health train
- C. Ontology based access control
- D. Anonymization layer



Data protection framework

Region: Holland Data Hub 3.0

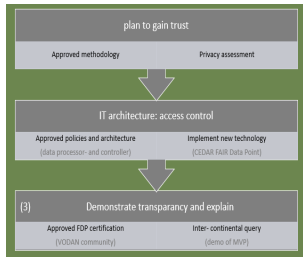
- ☐ Secure data sharing
- ☐ Secure data visiting
- ☐ Machine readable

Data linkage allows:

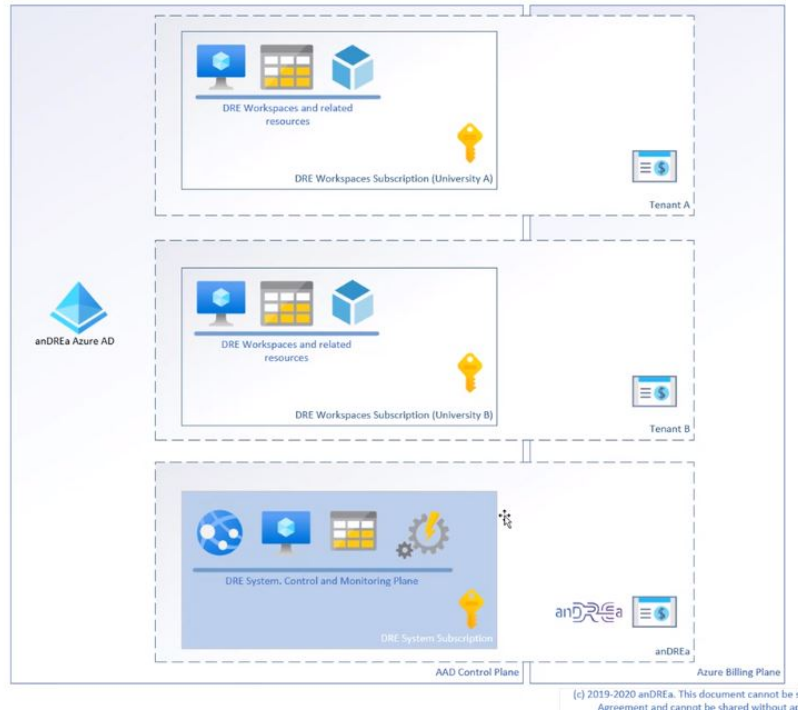
- ✓ Pooling data from different persons
- ✓ Combining different types of data of the same person

- Data scientist (A.I.)
- Open science researcher
- Doctor

Poster Health-RI conference 2020, Erik Flikkenschild (LUMC); Marlon Domingus (EUR)
More info: e.flikkenschild@lumc.nl; marlon.Domingus@eur.nl



Stap 1: Plan to gain trust



anDREa Policies & Procedures

Home

Security Manifesto

✓ CIA / BIV

ISO 27001

NEN 7510

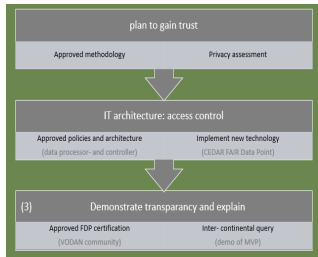
GDPR Compliance
Assessment

DPIA

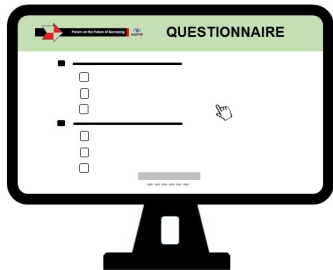
Privacy Shield

Goede basis met een VRE workspace

Generic FDP data access control truth table (no, consult, yes)



 Informed Consent	 Data license	 NWO consortium	 Institutional ethical
 PI approval	 Legal National AVG	 Legal EU GDPR	 Biobank community
 USA Patriot Act	 Afrika ethical		
			



Privacy Assessment,

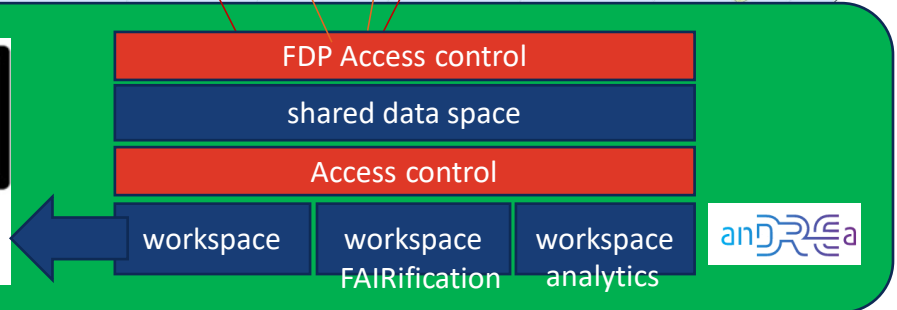
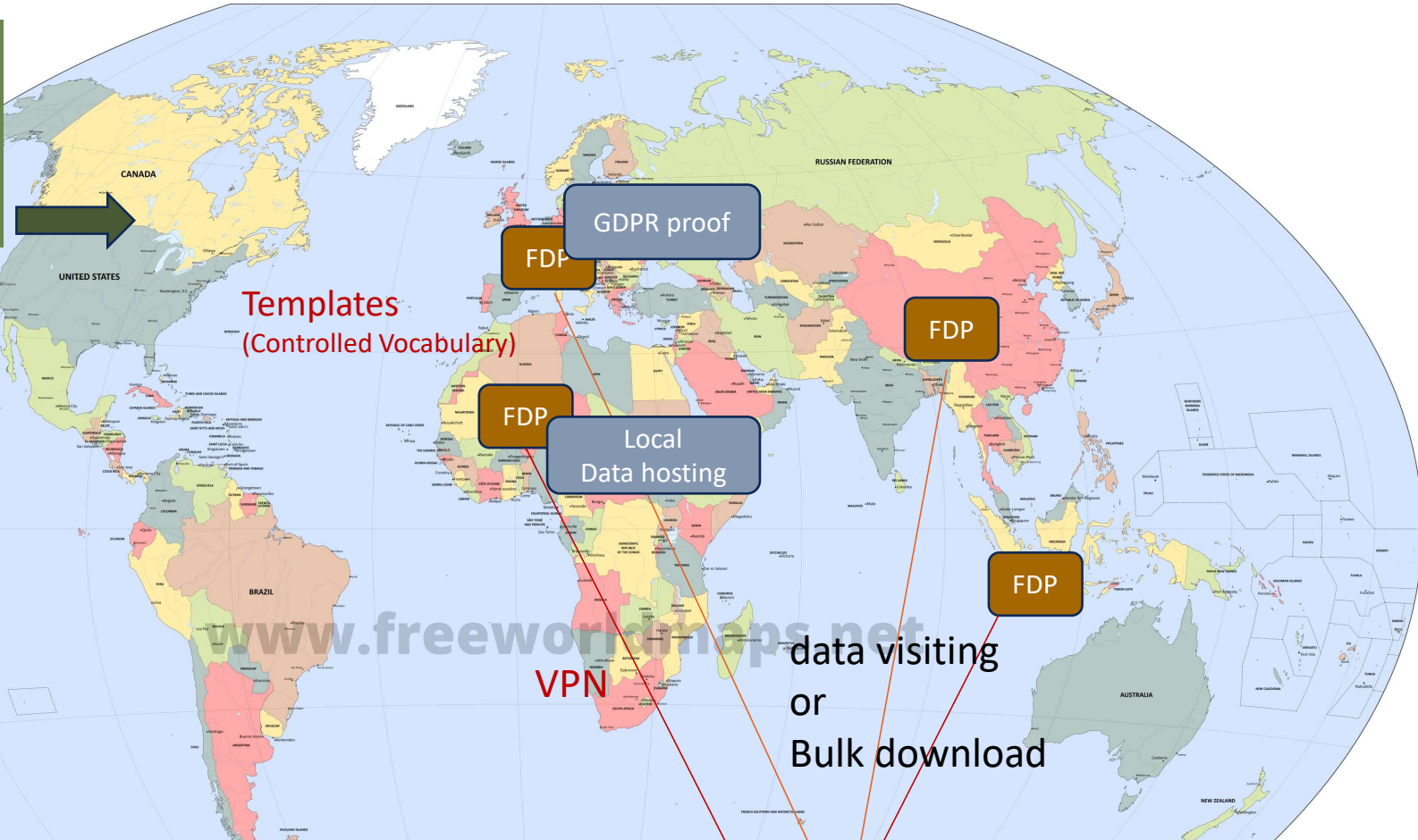
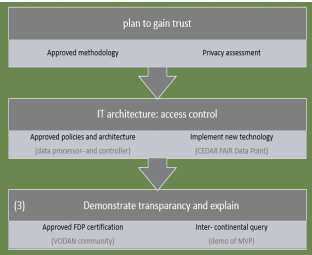
- Legal, ethical
- data ownership



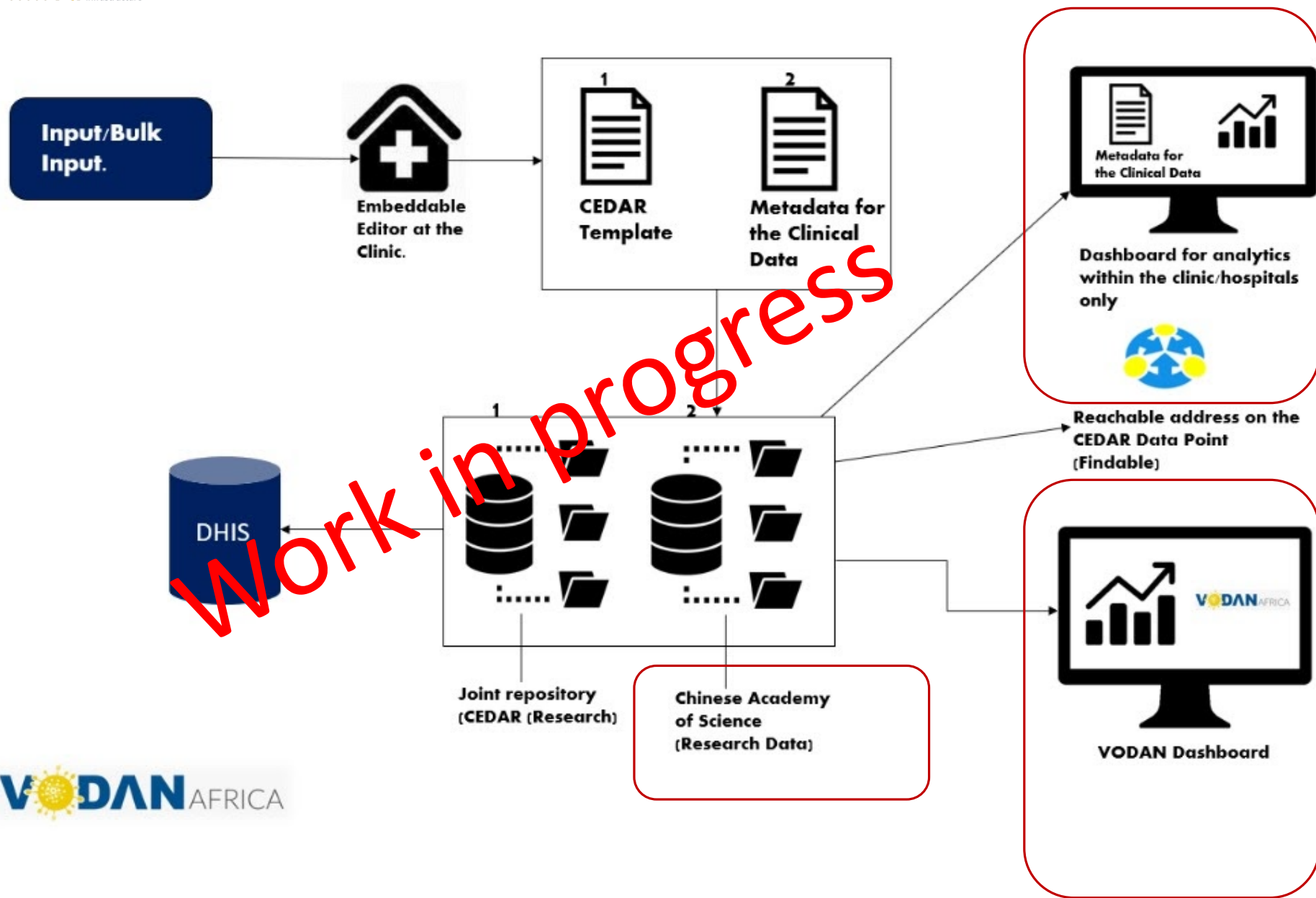
Afsprakenstelsel (PHT)

All lights must Be **green**!

Community decides on access control policy requirements



VODAN access control architecture



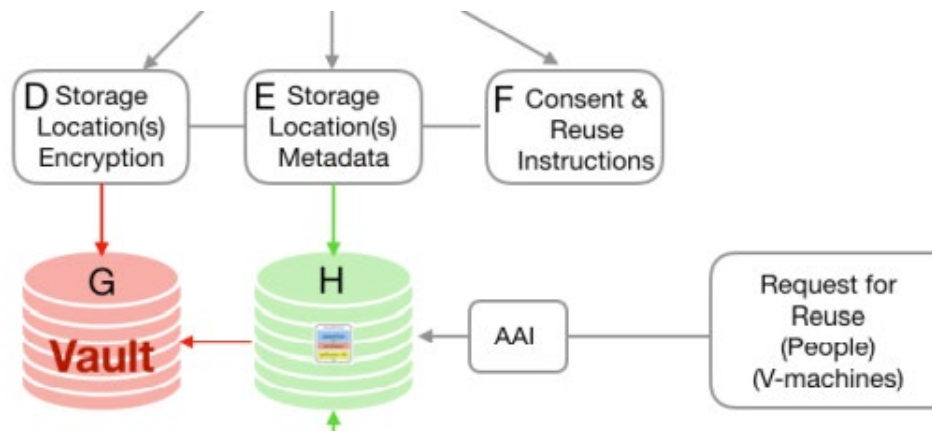
C4yourself public private consortium

Citizen Centred and Controlled COVID-19 data for reuse

A joint proposal for a high-throughput, safe, trusted and citizen-centric test and vaccination logistics, including a certified personal data ecosystem based on co-creation around open standards and protocols

Basic Principles

- The **citizen is in control** of personal data (includes privacy by design)
- This 'control issue' is all **clearly explained to the citizen**.
- The ecosystem that supports this principle is built on **open standards and protocols**
- The ecosystem is built of **scalable and interoperable components**
- No **single vendor**, no **monopolies**
- All data **FAIR where possible, metadata always FAIR**
- Metadata **separated from actual data** (no re-identification possibilities on metadata)
- Metadata **contain clear consent level** and **re-use instructions** (i.e. FAIR licences)
- Re-use is **requested at metadata level** (AAI both for people and VMs)
- As **open** as possible as **closed** as necessary
- As **distributed** as possible, as **centralised** as necessary
- All components certified (in steps during the project where needed)





Special issue data intelligence journal (April 2021)

Launching an international FAIR data network for COVID data

This Special Issue provides an analysis of how the opportunity emerged to launch the FAIR data network during this pandemic.

FAIR Equivalency, Regulatory Frameworks and Adoption potential of FAIR data in health

Article: Privacy protection on VODAN Africa Architecture

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<http://www.data-intelligence-journal.org>

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