

FAIR Federated Data Space - A proposed Landscape

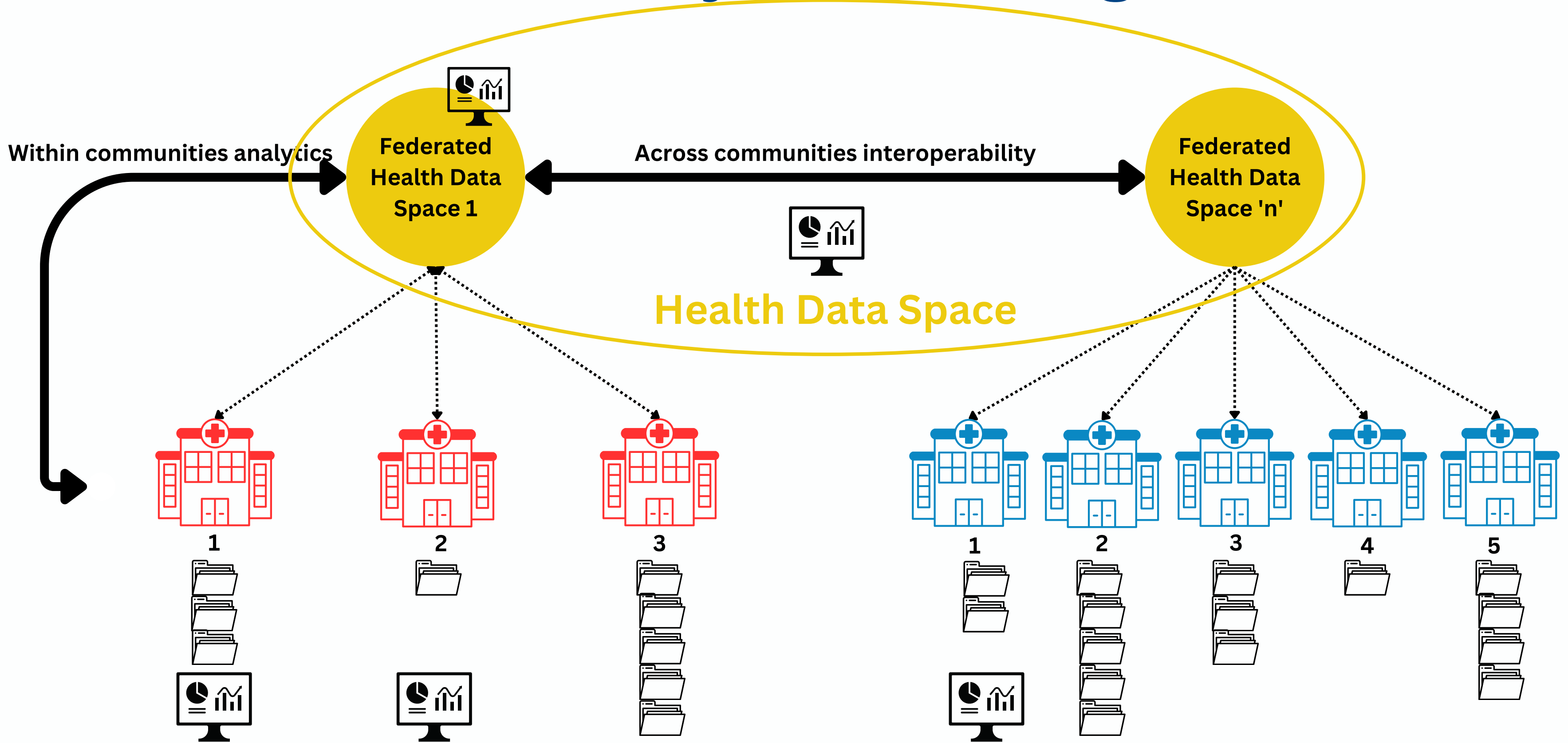
**Presentation for the Conference
“Connected Data - Connected Everything”
Wageningen University, 20 October 2023**

Mirjam van Reisen

Slide authors: Mirjam van Reisen, Samson Yohannes Amare, Getu Tadele, Tesfit Gebremeskel, Ruduan Plug, Putu Hadi Purnama Jati, Joëlle Stocker for
VODAN

20 October 2023

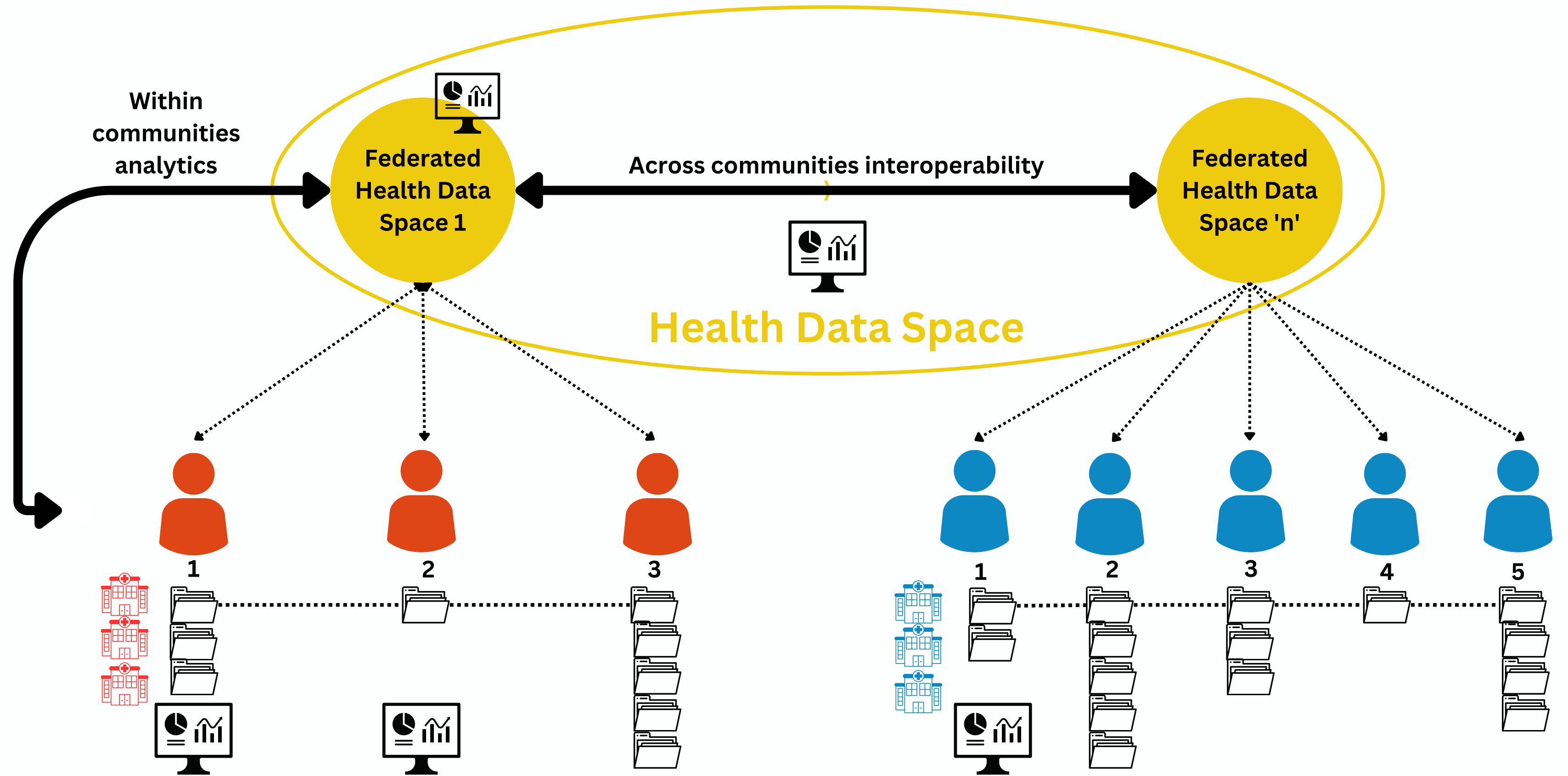
FAIR-OLR Federated analysis & learning



Within Community Machine-Actionable Semantic Data

Within Community Machine-Actionable Semantic Data

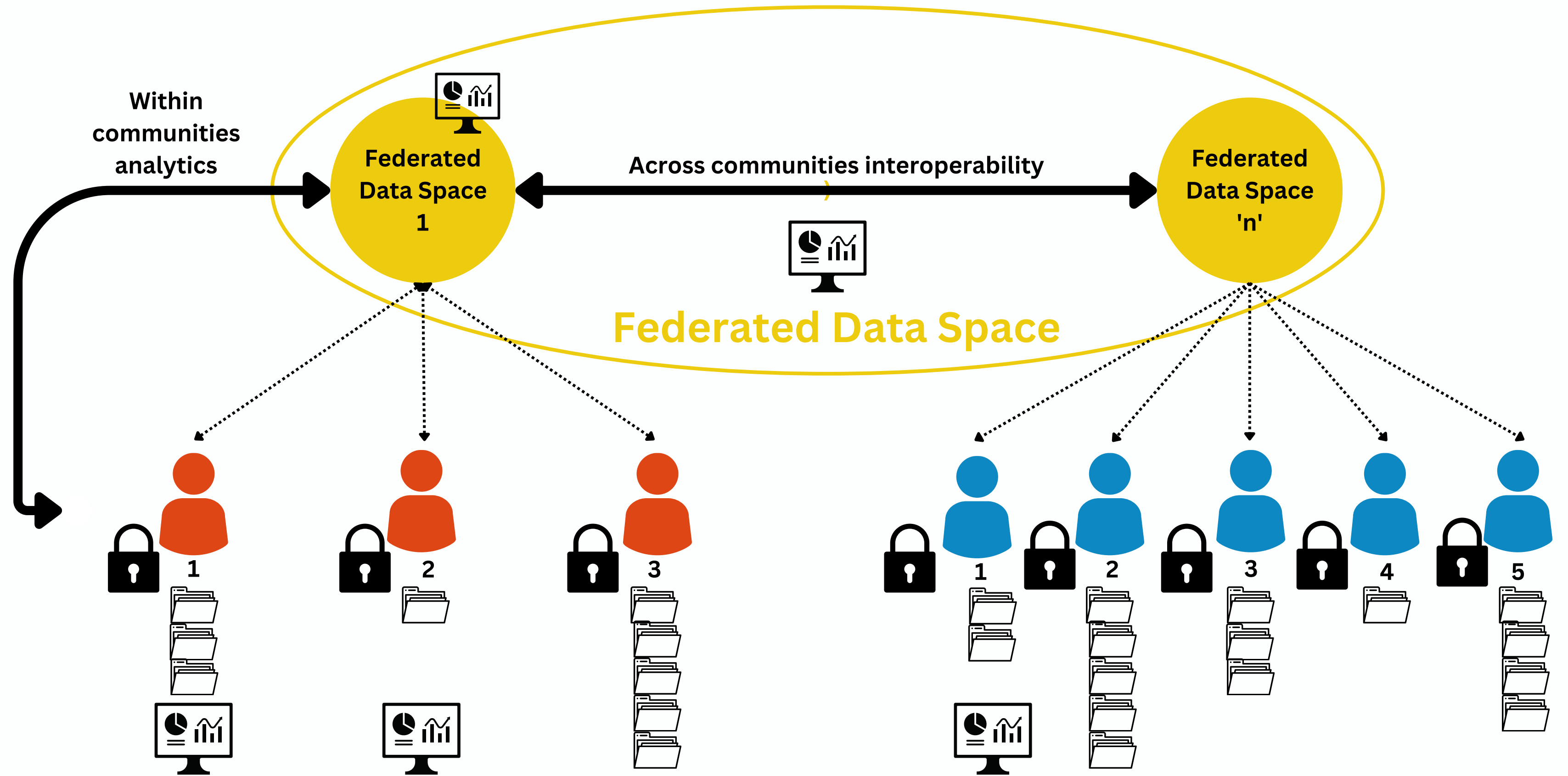
FAIR-OLR Federated Personal Pods



Within Community Machine-Actionable Semantic Data

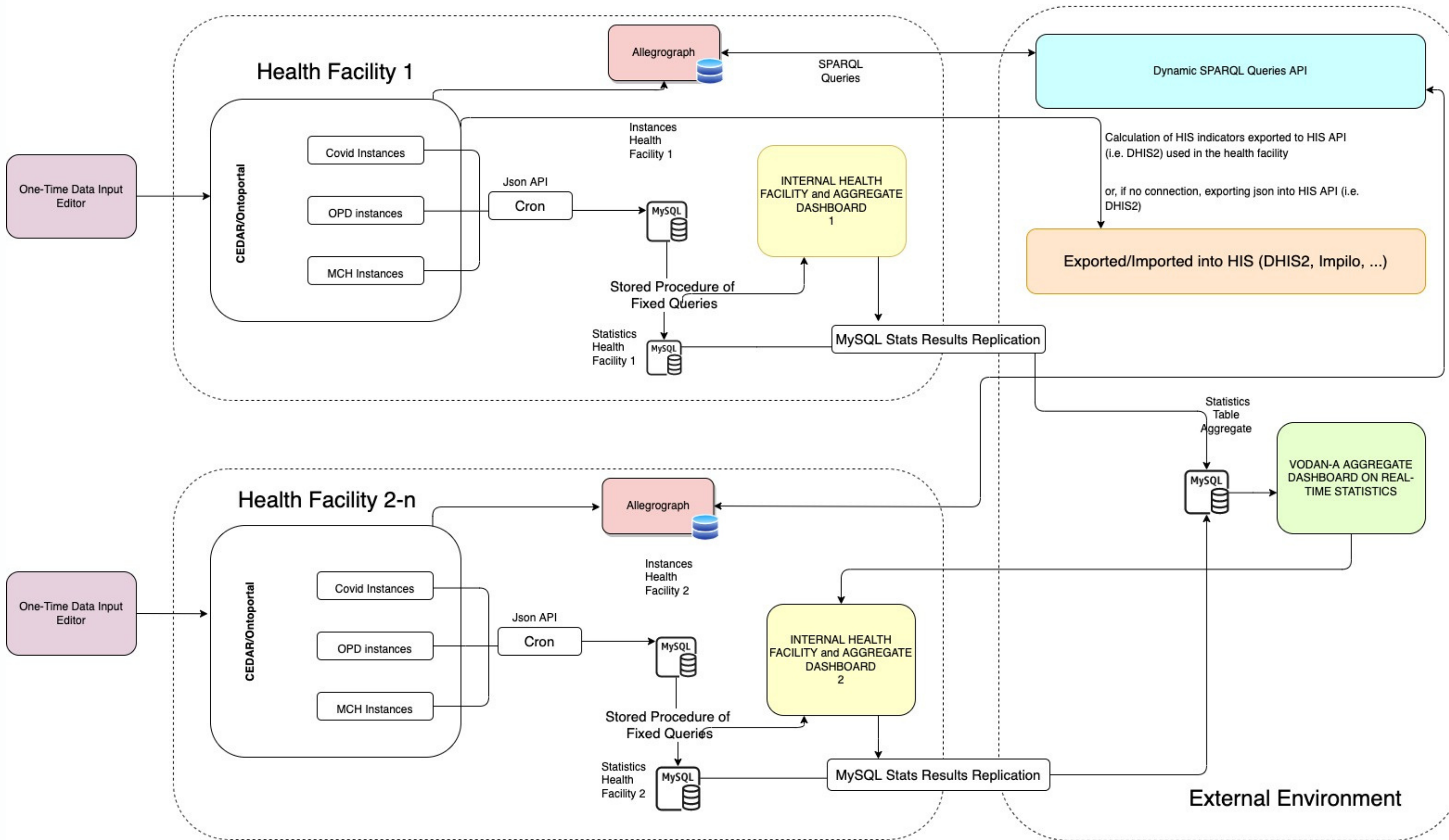
Within Community Machine-Actionable Semantic Data

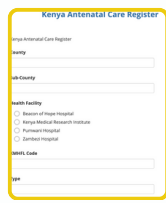
FAIR-OLR Federated Personal Pods



Within Community Machine-Actionable Semantic Data

Within Community Machine-Actionable Semantic Data





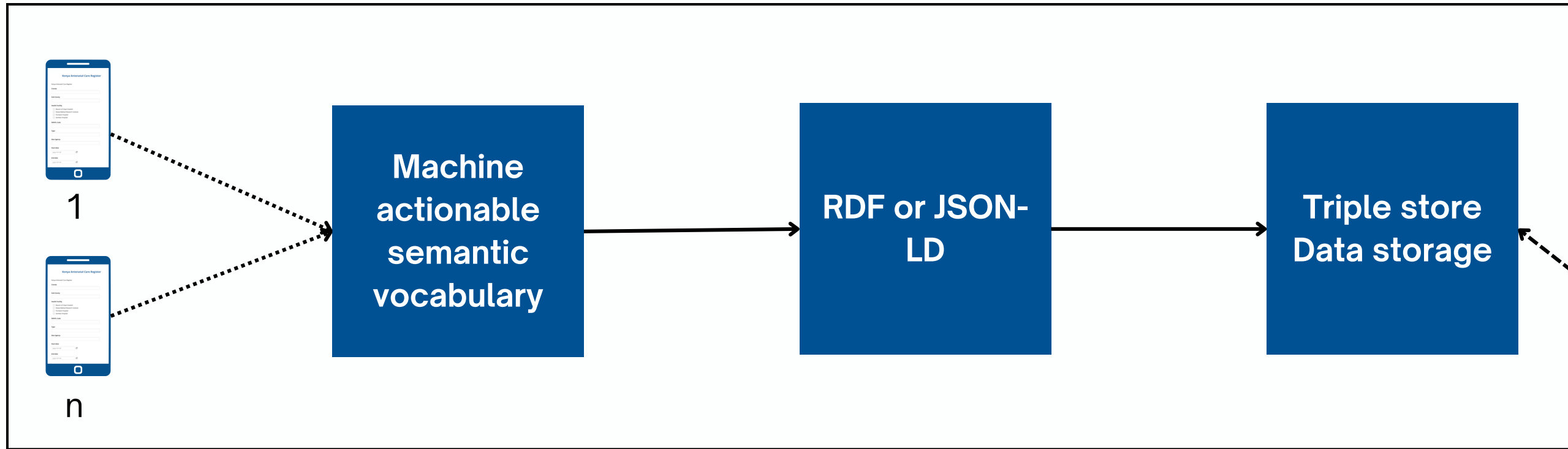
ConceptScheme URI	A	B	C	D
PREFIX	euvoct	http://data.sparna.fr/vocabularies/euvoct#	http://publications.europa.eu/ontology/euvoct#	
PREFIX	days	http://data.sparna.fr/vocabularies/days#		
PREFIX	concept-status	http://publications.europa.eu/resource/authority/concept-status/		
dc:title		Weekdays		
dc:description		The days of the week		

This example illustrates the use of prefix declarations. Here, 3 prefixes are defined above :
The prefix "euvoct" is used as the prefix of a column
The prefix "days" is used as the prefix of the concept URIs
The prefix "concept-status" is used as the prefix a column value

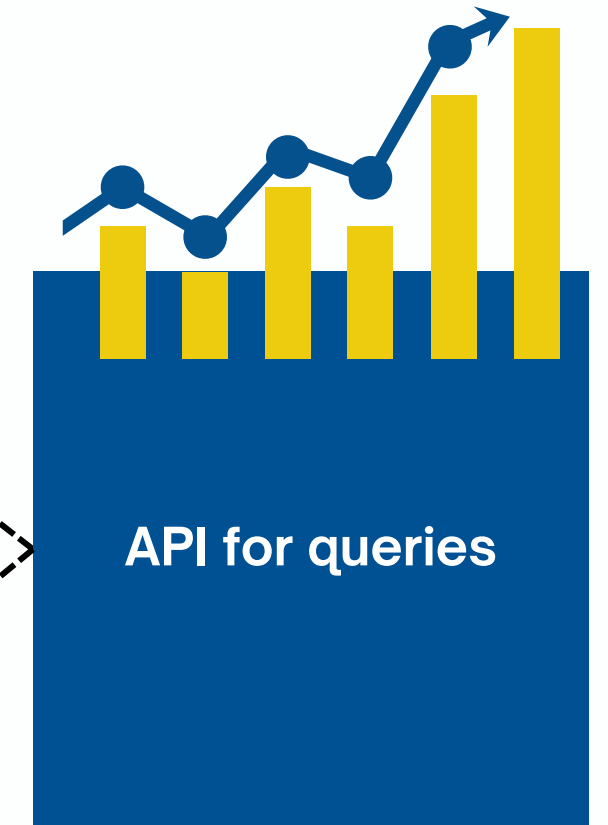
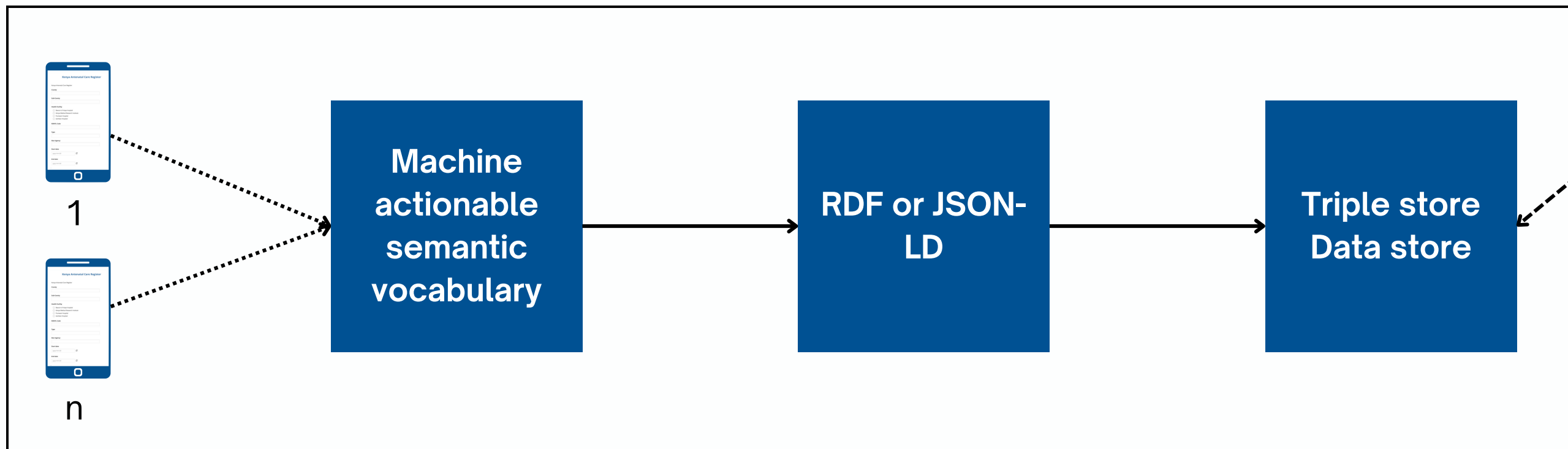
```
{  
  "@context": "https://json-ld.org/contexts/person.jsonld",  
  "@id": "http://dbpedia.org/resource/John_Lennon",  
  "name": "John Lennon",  
  "born": "1940-10-09",  
  "spouse": "http://dbpedia.org/resource/Cynthia_Lennon"  
}
```



1



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FAIR Data production and processing

Data creation process

Kenya Antenatal Care Register

Kenya Antenatal Care Register

County

Sub-County

Health Facility

Beacon of Hope Hospital

Kenya Medical Research Institute

Pumwani Hospital

Zambazi Hospital

KMHFL Code

Type

Man Agency

Start date

End date

*Date of visit

Vocabulary does not exist

Vocabulary exists

	A	B	C	D	E
1	ConceptScheme URI	http://data.sparna.fr/vocabularies/days			
2	PREFIX	euvoc	http://publications.europa.eu/ontology/euvoc#		
3	PREFIX	days	http://data.sparna.fr/vocabularies/days#		
4	PREFIX	concept-status	http://publications.europa.eu/resource/authority/concept-status/		
5	dct:title	Weekdays			
6	dct:description	The days of the week			
7					
8	This exemple illustrates the use of prefix declarations. Here, 3 prefixes are defined above :				
9	The prefix "euvoc" is used as the prefix of a colum				
10	The prefix "days" is used as the prefix of the concept URIs				
11	The preix "concept-status" is used as the prefix a colum value				

Triple store

Storage and data analytics

CEDAR template

PART 4: TREATMENT AUTHENTICATION

Enter Preferred Label

Enter Element Help Text

To be filled by the Hospital Representative

Patients' Date of Attendance

Check In Time

Check Out Time

Primary Diagnosis

Secondary Diagnoses

ICD 10 CODE

Procedure Code

Bioportal

Ontology repository

Link: <https://bioportal.bioontology.org/>

OWL

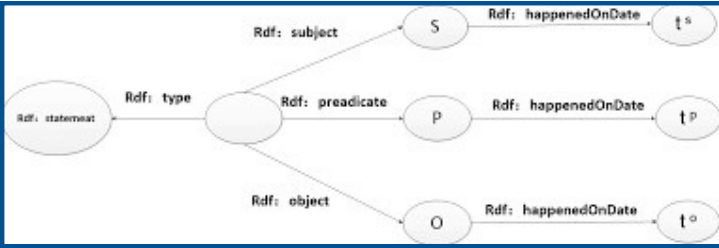
Open Web Language

RDF or JSON LD

SKOS

SKOS PLAY:

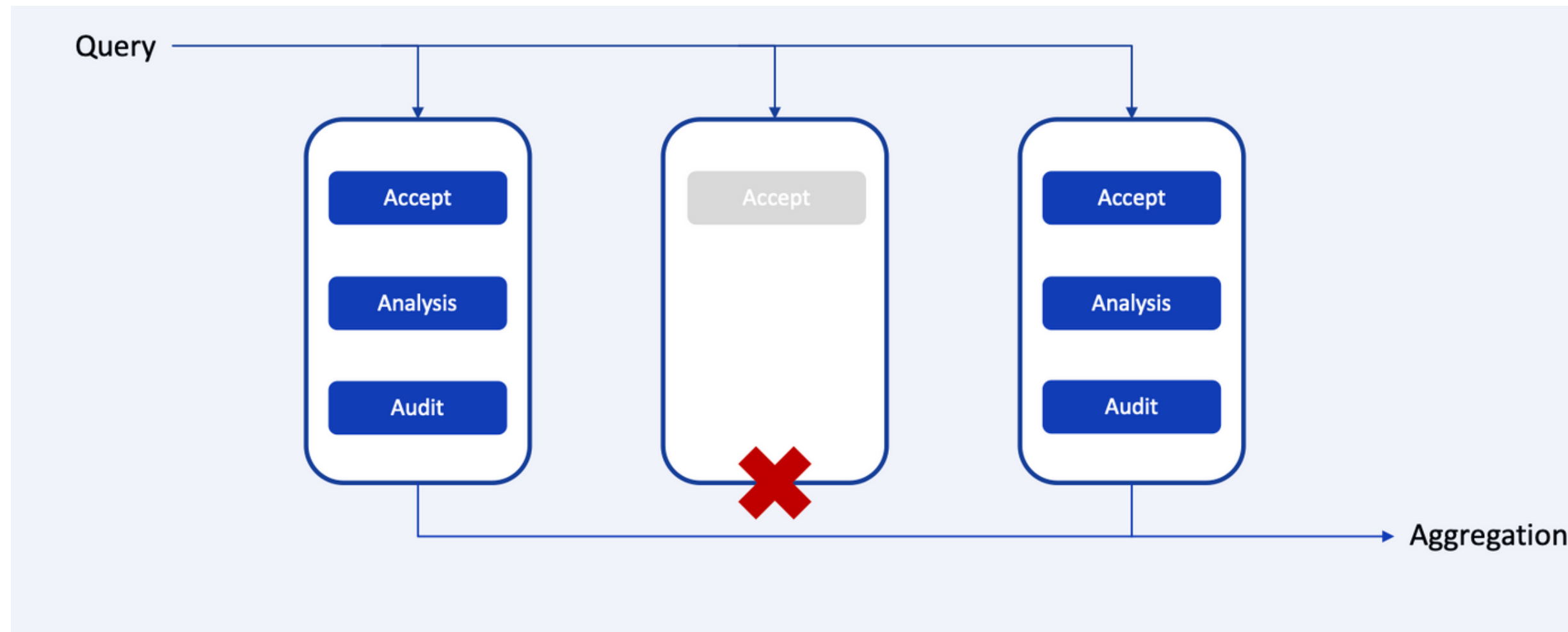
to test and verify a vocabulary during the conception phase to exchange and communicate the vocabulary when validating it with domain experts to publish it when it is shared on the web.

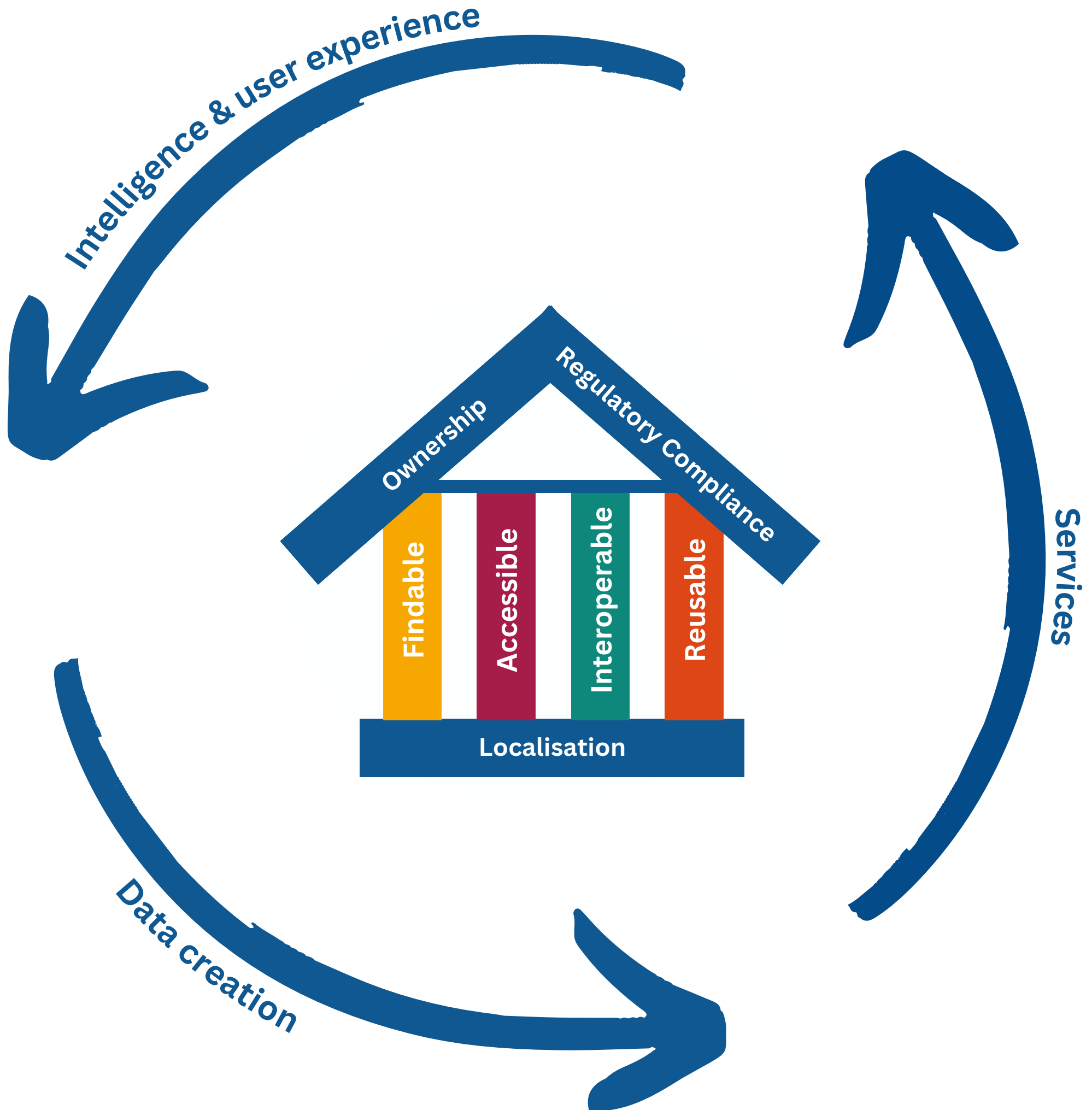


Source: Haixia Li and Li Yan. 2021. A Temporal RDF Model for Multi-grained Time Information Modeling. In 2021 4th International Conference on Data Science and Information Technology (DSIT 2021), July 23-25, 2021, Shanghai, China. ACM, New York, NY, USA, 9 Pages. <https://doi-org.tilburguniversity.idm.oclc.org/10.1145/3478905.3478908>

Link: <https://more.metadatascenter.org/tools-training/cedar-template-tools>

FAIR Federated Analysis





Federated Health Data Space – a proposed landscape

Generic connective capabilities - users

Ecosystem APIs

Intelligence



User Experience



Infrastructure services

Data storage and hosting

Hosting & operations

Hybrid in location & local cloud

Generic Data Capabilities - services

Federated data management

Regulatory Compliance,
Privacy & Protection

Data Visiting &
interoperability

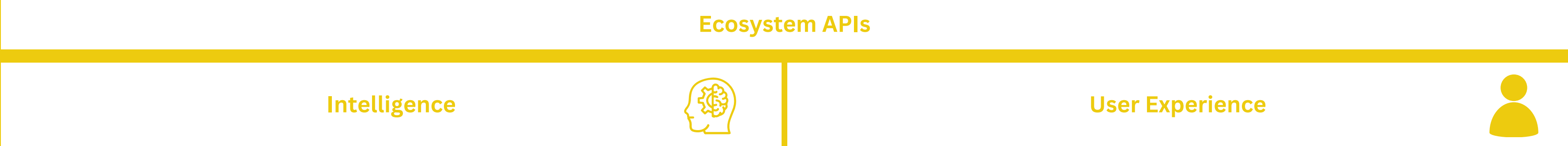
Digital IT & Customer
service

Data layer-single copy, machine actionable data creation

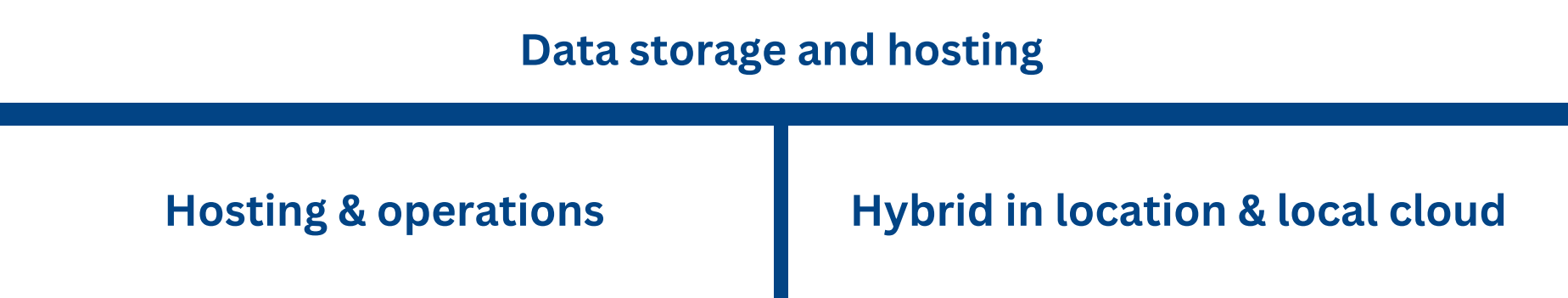
Machine-actionable and semantically linked clinical, operational & research data at point of creation
(produced for instance : in point of care, point of service, or at research data collection)

Federated Data Space – a proposed landscape

Generic connective capabilities - users



Infrastructure services



Generic Data Capabilities - services



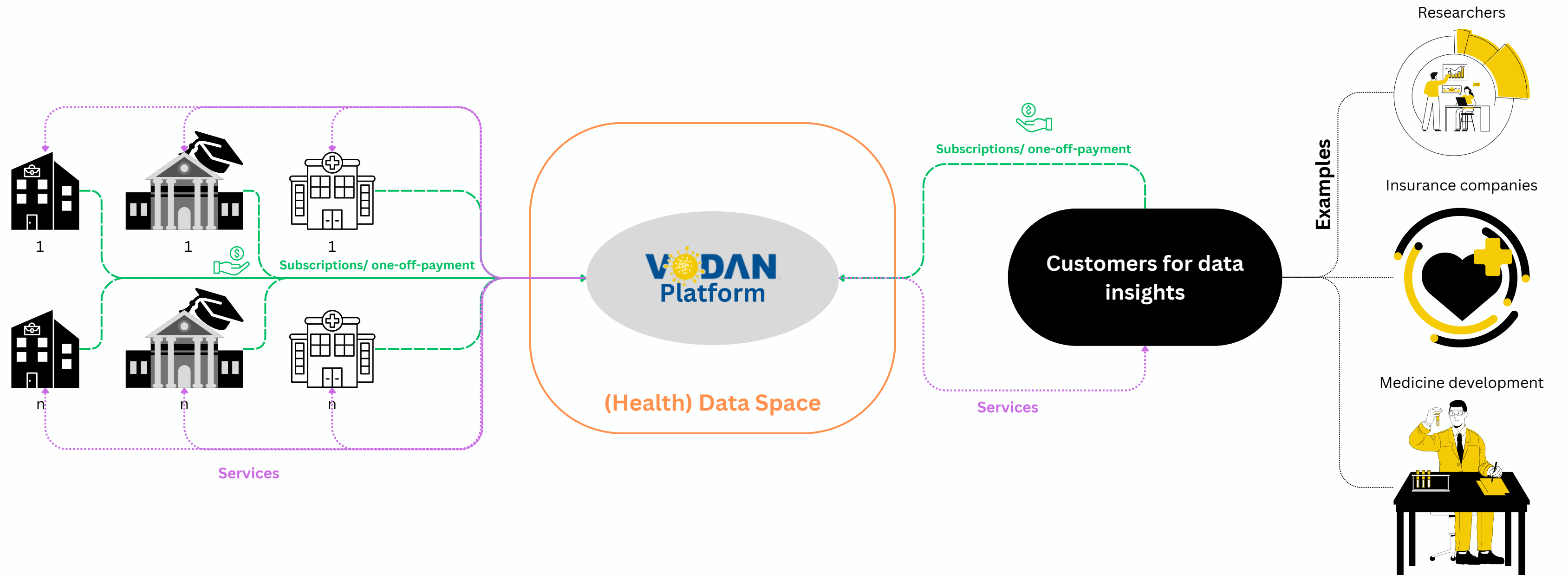
Data layer-single copy, machine actionable data creation



Customers data stewardship

Services

Customers third party data re-use



Activities Google Chrome 2 Nov 15:04

AllegroGraph WebView x AllegroGraph WebView x Gruff x You are screen sharing Stop Share x Gruff x VODAN | Africa x Update

localhost:10035/gruff/34815/

Gruff 8.1.2 on AllegroGraph 7.3.0 Covid_Stats read / write 14 triples server 127.0.0.1:10035

File View Text Search Display Link Remove Layout Select Edit Global Options Visual Graph Options Help

Daily visits
Facility name
Located in
Monthly visits
Reported by
Status
Total visits
Type
Multiple Predicates

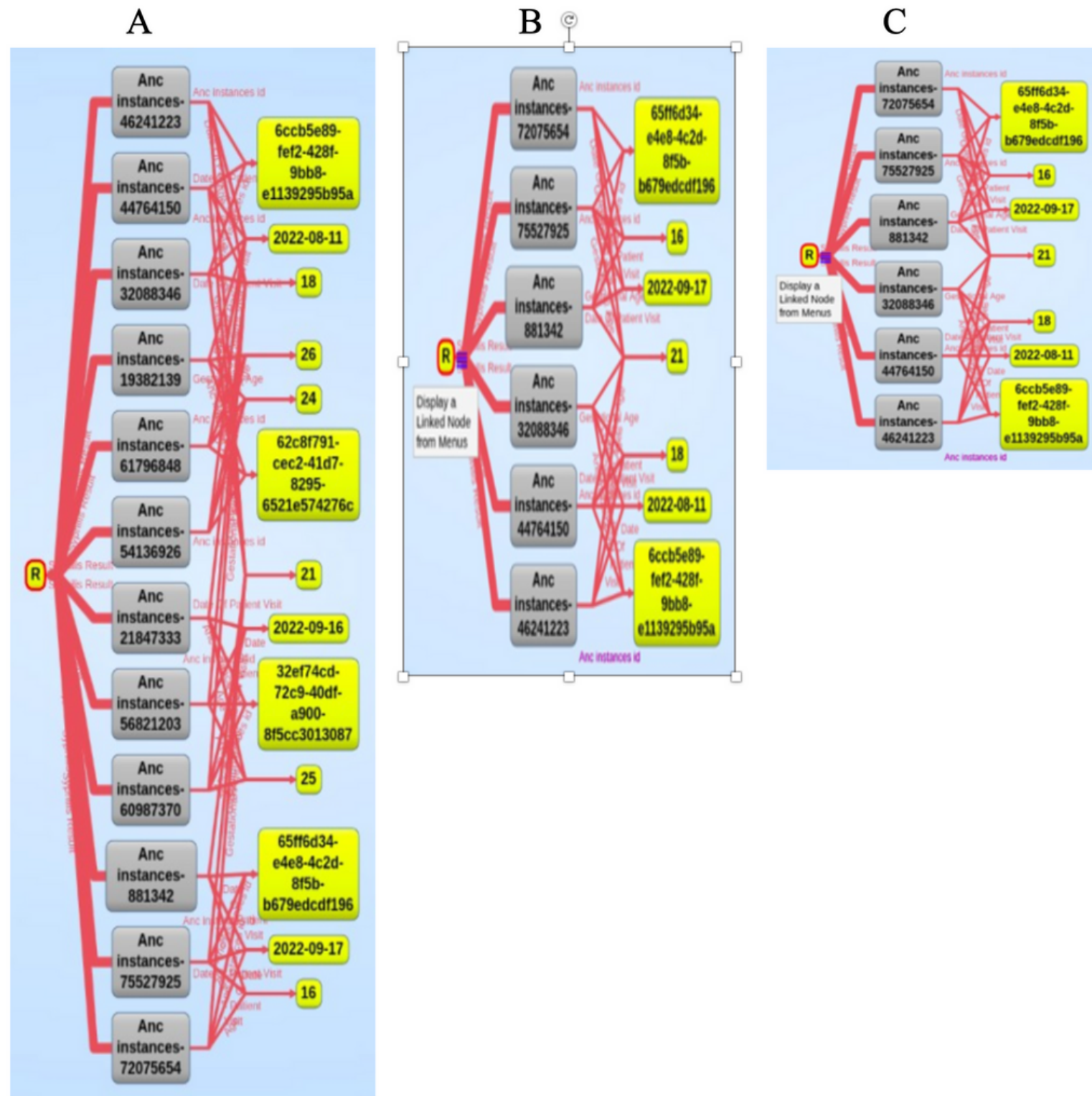
Country
Facility
Literal
No Type

Talking: Samson Y

The graph visualization displays the following relationships:

- Ayder Referral Hospital** (purple node) is connected to **Government** (yellow node) via a blue arrow.
- Ayder Referral Hospital** is connected to **Ethiopia** (green node) via a grey arrow.
- Ayder Referral Hospital** is connected to **Facility** (grey node) via a blue arrow.
- Ayder Referral Hospital** is connected to **Covid statistics** (grey node) via a purple arrow.
- Covid statistics** is connected to **Government** (yellow node) via a yellow arrow with the value **91**.
- Covid statistics** is connected to **Ethiopia** (green node) via a green arrow with the value **70**.
- Covid statistics** is connected to **Uganda** (green node) via a purple arrow with the value **21**.
- Ethiopia** is connected to **Country** (grey node) via an orange arrow.
- Uganda** is connected to **Country** (grey node) via an orange arrow.
- Facility** is connected to **KIU Teaching Hospital** (grey node) via a green arrow.
- KIU Teaching Hospital** is connected to **Private** (yellow node) via a blue arrow.

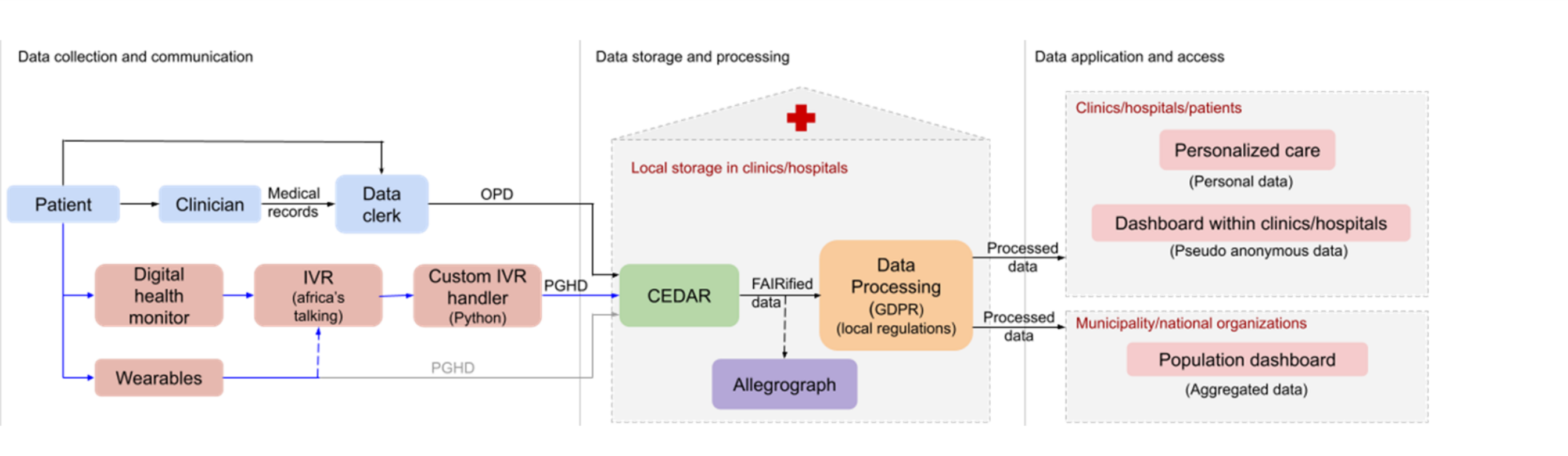
(A) All Syphilis Reactive Cases; (B) Syphilis Reactive Adolescent Cases; (C) Congenital Syphilis (CS) at Risk Cases



Sample of a Knowledge Graph Created in Allegrograph from the FAIRified Data on Labour and Delivery Data from Saving Little Lives Project in Tigray Region



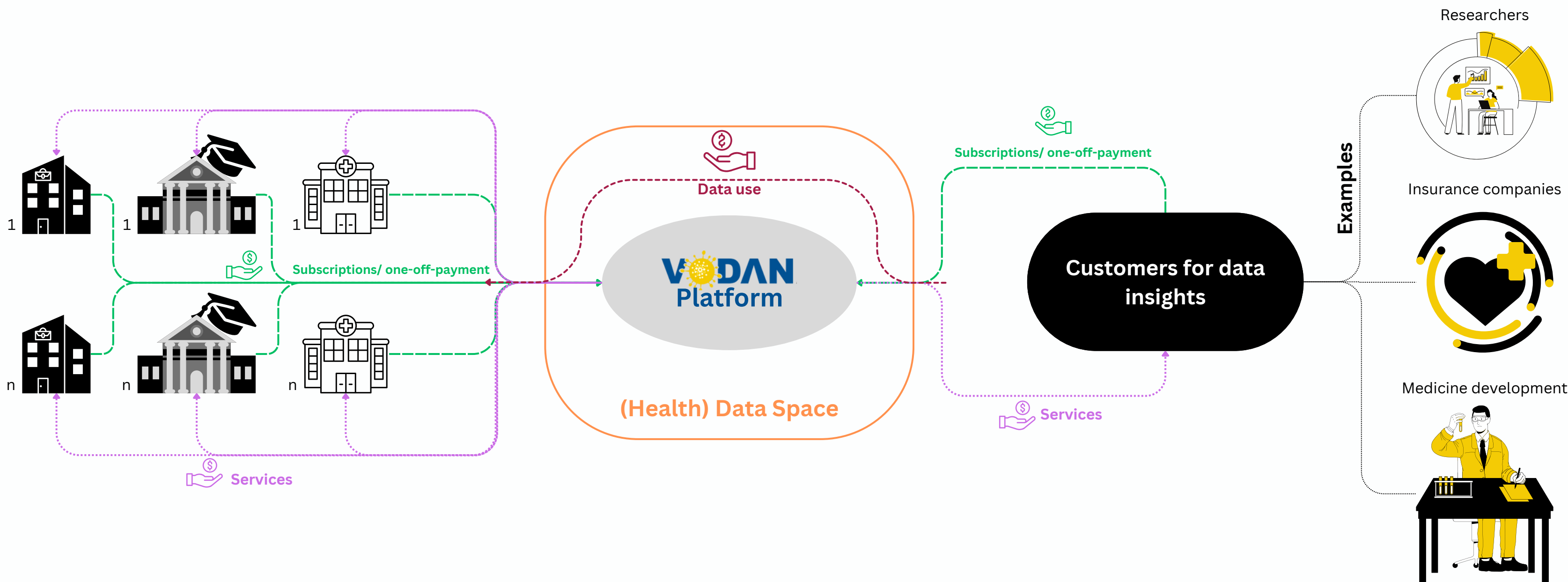
Proposed Architecture of Federated Patient Generated Health Data (PGHD) Interoperability with Patient Data Curated at Health Facility



Customers data stewardship

Services

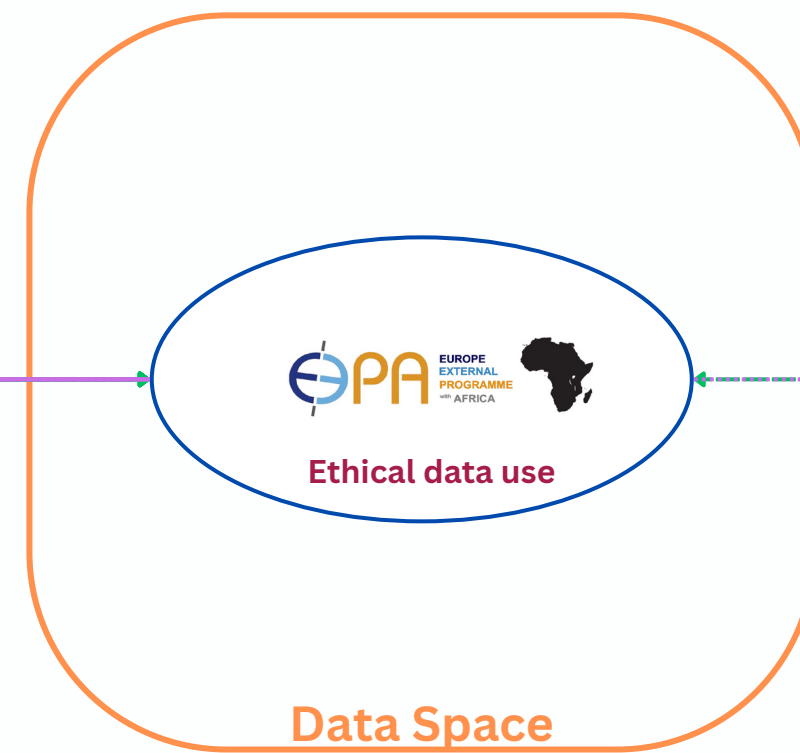
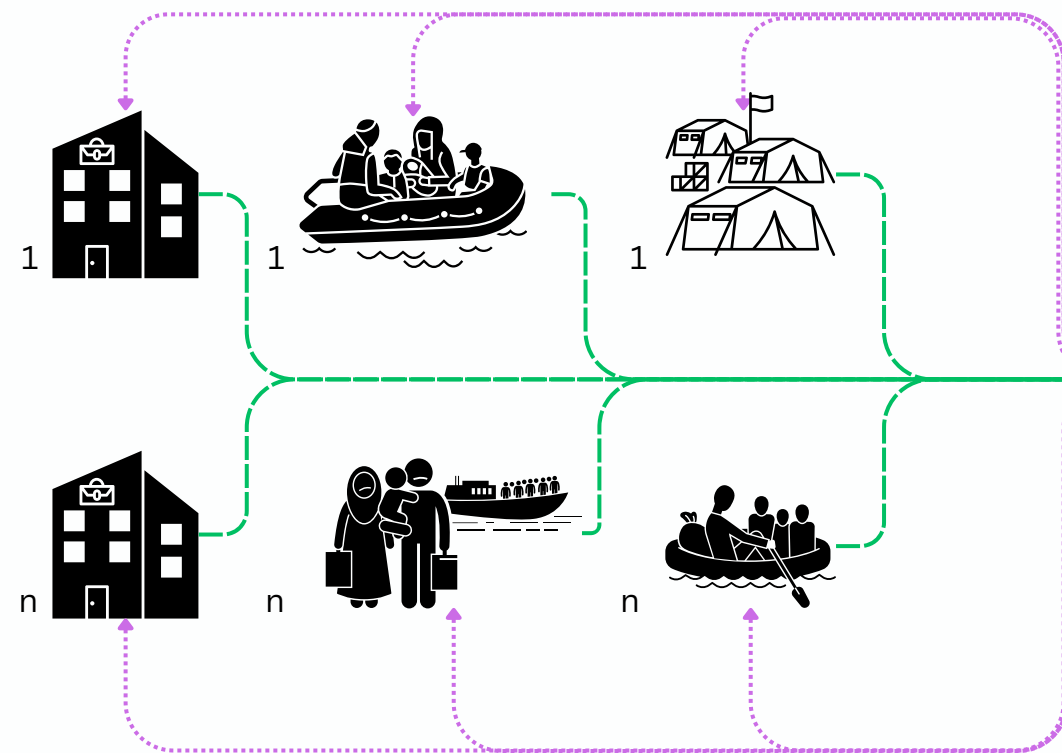
Customers third party data re-use



Data stewardship

Technical services

Advocacy for Ethical Digital Data Ownership & Re-use



Researchers

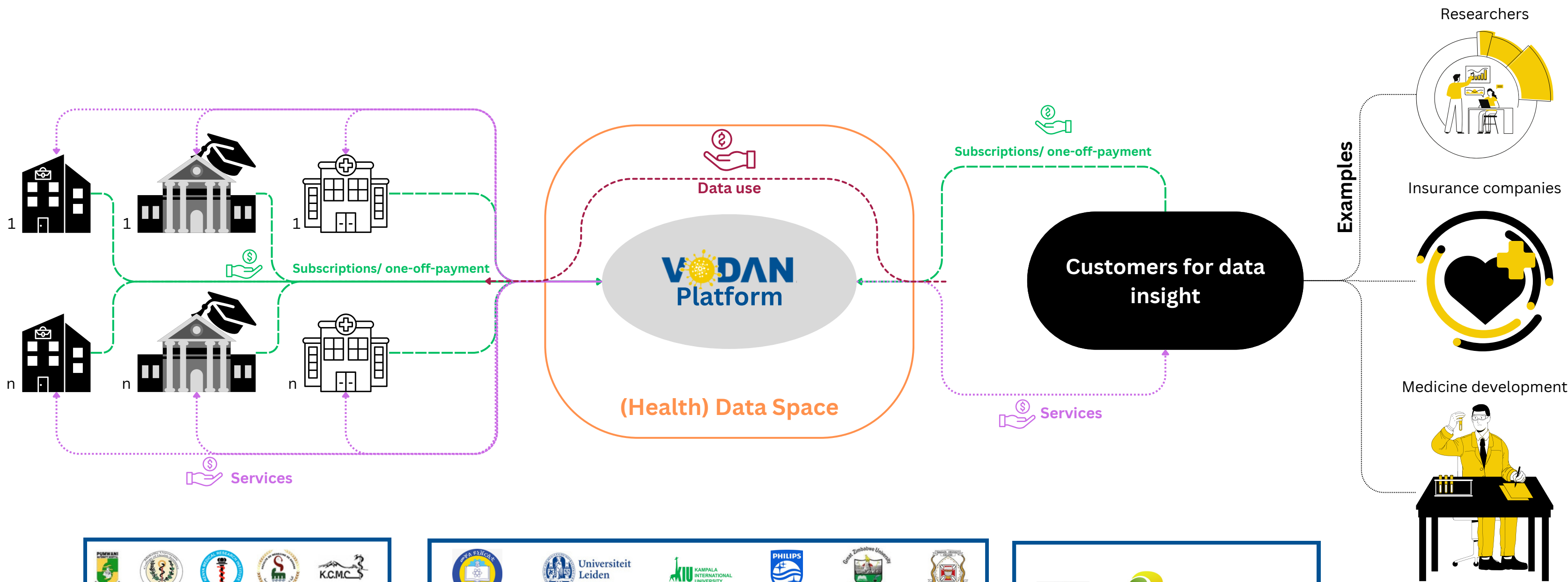


Advocating an ethical Federated FAIR Data Space for All

Customers data stewardship

Services

Customers third party data re-use



2020 2021 2022 2023 2024 2025 2026 2027 2028 2029 2030

<i>Proof of Concept</i>	<i>Minimal Viable Product and adoption assessment</i>	<i>Africa Health Data Space - Africa data Space with selected partners</i>	<i>Professional Service Organisation linked to the Africa University Network on FAIR Open Science to root capacities</i>	<i>Integration of domains in the Global Data Space with private sector customers</i>
LUMC-KIC	8 countries in Africa, 88 health facilities, research data	Partnership of 10 countries in Africa, 2 countries in Asia, 3 countries in the EU and US	Africa-based HQ	Leader for service development with new content domains
Go-FAIR tooling	CEDAR-based tooling, business proposition	VODAN software, test of business model, strengthen permission control, security and protection	Administrative independent business operation	VODAN software, test of business model
Philips Foundation	Philips, Philips Foundation and Invest International	Philips, IMS, Microsoft, Achmea, Accenture, ..	Soft loan and investment partnerships and strengthening of market position	Solid products and strengthening of market position
Article advanced genetics	Special Issue & Datastewardship manual	Book FAIR Data Science in Africa, research group established in GAIC Research Network	6 dissertations published by PhDs	20 dissertations published by PhDs
2 Datastewards	30 Datastewards and technical data science team	40 Datastewards, software engineering team, data quality assessment team, data analytics capacity, permission and security capacity	Leadership available in all business domains, and specialised data-stewardship service	Integration of interoperable services in data production and data analytics and services provision

Researchers

Abdullahi Kawu	FAIR-data based Interoperable Digital Generated Data
Aliya Aktau	Vocabulary creation for interoperable FAIR-data
Charles Kahiro	Models for ethical value creation on federated FAIR Data production
Getu Tadele Taye	Modeling a regional surveillance health system of FAIR-data
Ibrahim Bwaga	Identifying communities of differentiated risk profiles
Joëlle Stocker	FAIRification of soundscape data for resilience modeling
Kai Smits	Human Trafficking analytics in Libya
Kudakwashe Kindoza	Deployment factors of federated FAIR-Data for interoperable solutions
Liya Manu	Integration of harmonised federated FAIR Data information for off-line use
Mariam Basajja	Creation of a FAIR-data based digital information system in Uganda
Mildred Akandinda	Identifying communities of differentiated profiles in Uganda
Morgane Wirtz	Migrants health analytics in Tunisia
Natascha Buchs	Business disruption through the FAIR-data based Federated Data Space
Putu Hadi Purnama Jati	GDPR-based access and control permission architecture
Rens Kievit	Automated permission controls for a GDPR compliant secure dynamic architecture
Ruduan Plug	Statistical models for federated FAIR Data models of privacy data produced
Samson Yohanes Amare	Federated software services for FAIR-data
Tesfit Gebremeskel	Modeling of vocabularies of federated FAIR-data

KIU Senate (Uganda)



Presidency of the VODAN-Africa Foundation

Mohamed Mpezamihigo; Francisca Oladipo; Han Baartmans, James Wilderspin



VODAN Executive Board

Country coordinators	Technical Team	Medical & Outreach Team	Research Team
Reginald Nalugala Mariam Basajja Araya Medhanyie Ephrem Biruk Ibrahim Abdullahi Sakinat Folorunsa Bernard Chazovacchii Jeremy Pyuza Jamal Mohamed Warsawe Julia Duncan-Cassell Meriam Ghardalou	Samson Yohannes Rudian Plug	Frank Kaharuza Lieve Fransen	Munyaradzi Mawere Mirjam van Reisen Simcha Jong Joshua Pos