In Africa they do it already: FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa

Mirjam van Reisen, Mouhamad Mpezamihigo, Francisca Oladipo, Putu Hadi Purnama Jati, Ruduan Plug, Samson Yohannes, Getu Tadelle, ZOnMw 22 June 2022

The problem

Poor Data quality and Data stewardship in Africa:

- At large scale data taken away from the African continent (example: the digital ebola data from Liberia are no longer in Liberia)
- Data removed from places where it is produced (example: health facilities do not have, use, visualise and analyse their own data)
- Health data from Africa is not representative (example: COVID-19 data reflect mostly people that can afford health care in capitals)
- Vertical digital health data solutions are not integrated and interoperable for patients, doctors or health facilities

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The Economist

Regulating the internet giants May 6th 2017 edition

The world's most valuable resource is no longer oil, but data

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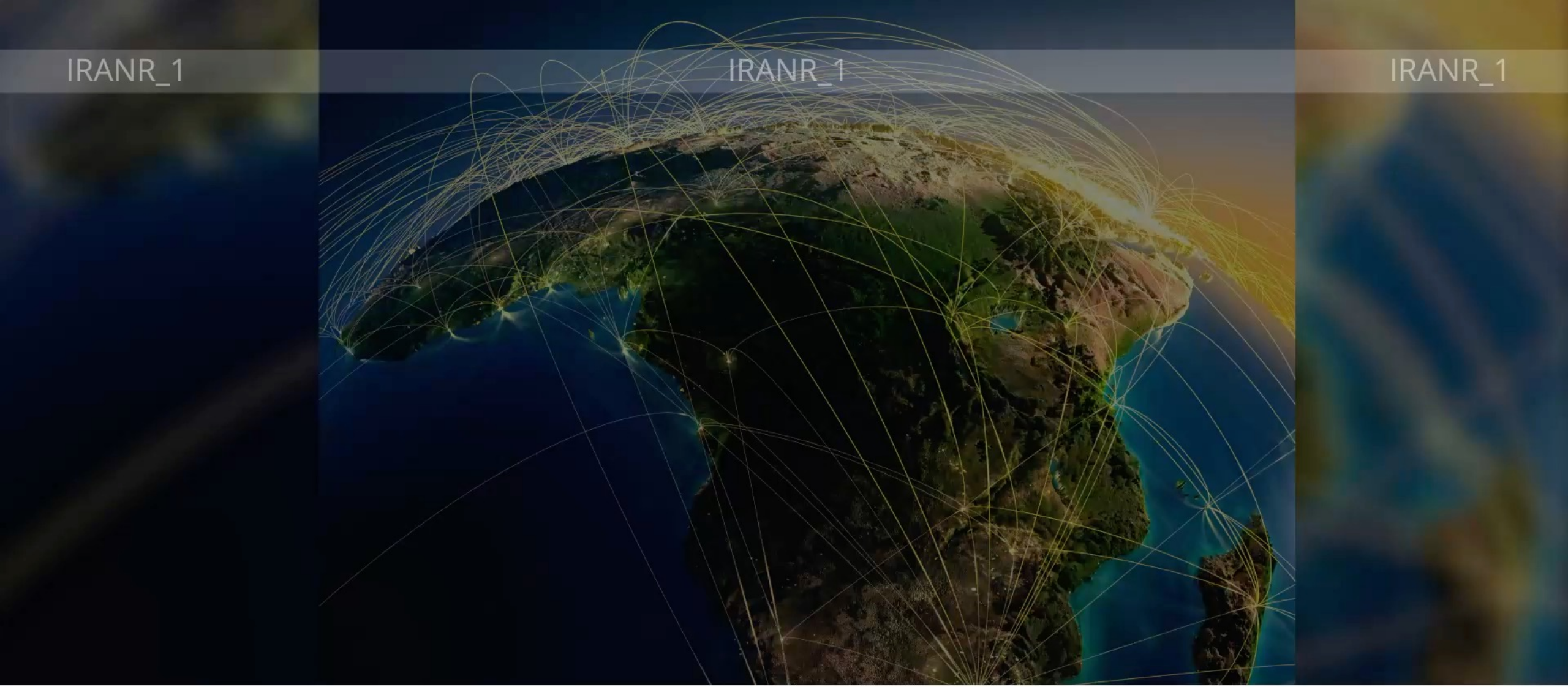

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WILEY

Design of a FAIR Digital Data Health Infrastructure in Africa for COVID-19 Reporting and Research

DOI: 10.1002/GGN2.10050

Localising and FAIRification of CEDAR as an ethical pipeline of data in residence

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Prof. Dr Mark Musen, Professor of Biomedical Informatics at Stanford University, Director of the Stanford Centre for Biomedical Informatics Research - *CEDAR: Centre for Expanded Data Annotation and Retrieval*

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Establisment of a Regional Interdisciplinary VODAN-Africa Leadership Team

Name	Role
Mouhamad Mpezamihigo	Chairman of the VODAN-Africa Board
Prof. Francisca Oladipo	VODAN-Africa Executive Coordinator
Prof. Mirjam van Reisen	VODAN-Africa Global Coordinator Chair of Steering Committee
Dr. Reginald Nalugala	VODAN-Africa Coordinator of Country Coordinator
Putu Hadi Purnama Jati	VODAN-Africa Privacy Officer
Dr Ibrahim Abdulahi	VODAN-Africa Security Officer
Aliya Aktau	VODAN-Africa IT Architecture and Documentation
Mariam Basajja	VODAN-Africa Data Interoperability and Queries
Oluwole Olumuyiwa Afolabi	VODAN-Africa IT architect
Araya Medhanyie	VODAN-Africa Deployment preparation and coordination
Ruduan Plug	VODAN-Africa Machine Learning Engineer
Samson Yohannes	VODAN-Africa Quality Control and System Integration
Ezra Mwesigwa	VODAN-Africa Visualization and Dashboard
Abdullahi Abubakar Kawu	VODAN-Africa Data Quality Monitoring
Dr. Jamal Kasimi	VODAN-Africa Data Access Permission
Dr. Sakinat Folorunso	VODAN-Africa Data Stewardship Competence
Dr. Wondimu Ayele	VODAN-Africa Capacity Building

FAIR enables autonomy

Individual instances that can interact with one-another based on a common understanding, in accordance with their own ethics and regulatory framework.

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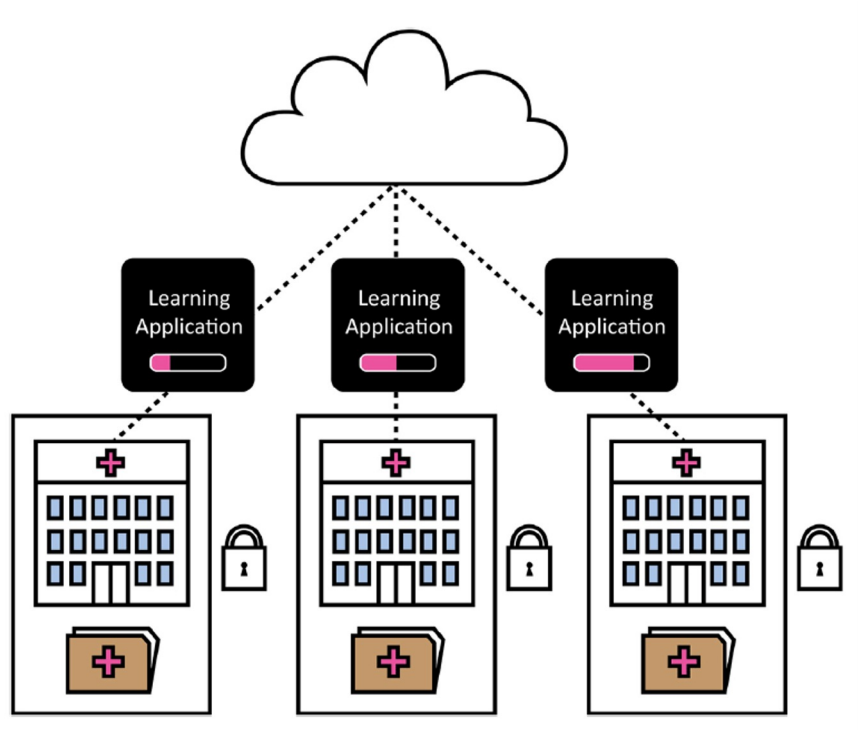
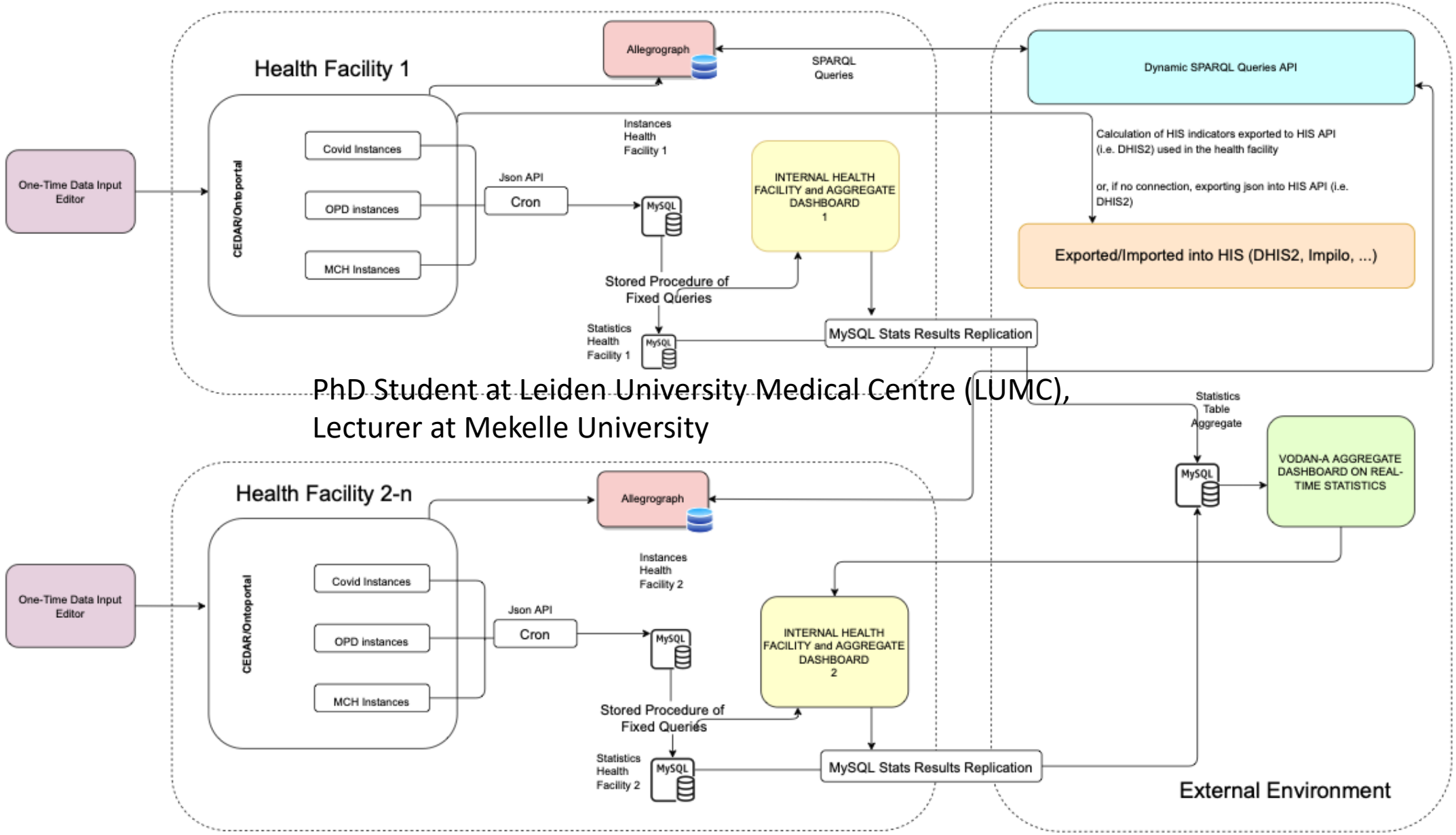
#4 DATA VISITING RISK

"In the data visiting concept, the questions or analysis algorithms travel to the data. Instead of the data to the analysis. The data visiting solutions speeds up the progress towards earlier diagnosis and new treatments of rare diseases. It avoids double data entry and ambiguity. It standardizes and harmonizes the dataset only once at the source"

(Peter-Bram 't Hoen - Interoperability and FAIRification Work Package Lead)



VODAN-AFRICA INTERNAL & AGGREGATE DASHBOARD & HIS INTEGRATION



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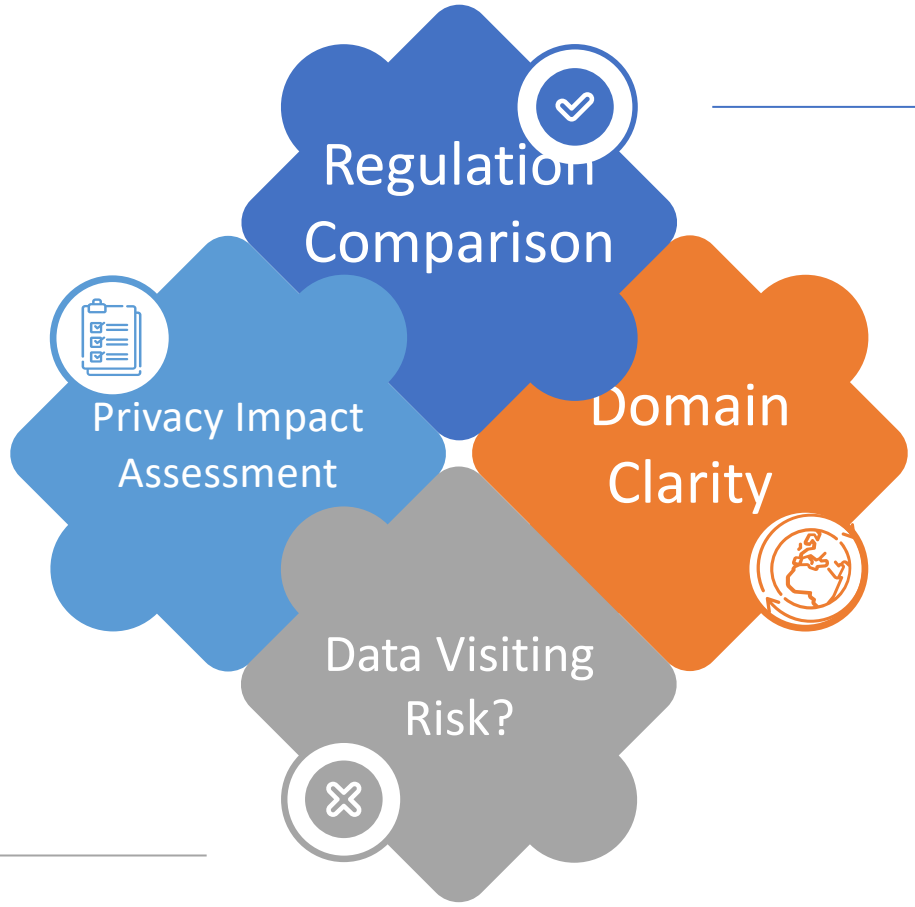
VODAN-A Data Privacy Concern

#2 Privacy Impact Assessment

To check the privacy risk from the project that already deployed



#1 Regulation Comparison

To check the data protection regulation in the cuntry related

#4 Data Visiting Risk

To identify data visiting risk for the future development of the project

#3 Domain Clarity

GDPR x Uganda Law x Country Law?

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VODAN-A has achieved:

- Deployment of interoperable machine-actionable FAIR Data production instances in 88 health facilities across 8 countries;
- Creation of a data sovereign quality ethical and FAIR data pipeline that is GDPR compliant and respects national regulatory frameworks;
- Capacity for Data Stewardship from machine-actionable data generation to federated analytics.

How to join us?

- Please contact us for FAIR Data Deployment
- This is the website – join the newsletter:

https://www.vodan-totafrica.info/

- Publications:

https://onlinelibrary.wiley.com/doi/full/10.1002/ggn2.10050

Upcoming soon: Special Issue of Data Intelligence