FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa

VODANAFRICA

InvestInternational
Welcome by the Chair of VODAN-Africa

Prof. Dr Muhamad Mpezamihigo, VC of Kampala International University
Thank you to sponsors

Prof. Dr Francisca Oladipo, Prof. Computer Science at the University of Lokoja, Nigeria and Executive Coordinator of VODAN-Africa
Opening Address

By President Fortune Charumbira, President of the Pan-African Parliament
Moderators

• Christine Kirkpatrick, San Diego Supercomputer Centre (SDSC)

• Prof. Dr Mirjam van Reisen, Chair Fair Data Science, Leiden University Medical Centre (LUMC), Chair of International Relations Innovations and Care, Tilburg University, Coordinator of the Research Network Globalisation, Accessibility, Innovation and Care (GAIC)
Introduction of the Ethical FAIR Data Pipeline

• Dr Katy Wolstencroft, Leiden Institute for Advanced Computer Science (LIACS)
• Ruduan Plug, Leiden Institute for Advanced Computer Science (LIACS)
Introduction to the Ethical FAIR Data Pipeline

Ruduan Plug, Dr. Katy Wolstencroft | LIACS
Global Data Creation is About to Explode
Actual and forecast amount of data created worldwide 2010-2035 (in zettabytes)

1 zettabyte is equal to 1 billion terabytes.

Source: Statista Digital Economy Compass 2019

Discover the world at Leiden University
Structured and Unstructured Data

80.000 PB

2013

300.000 PB

+56% /year

2015

88% unstructured data

12% structured data

Discover the world at Leiden University
Biomedical Data Landscape
Ethics in Biomedical Data Landscape

- Security
- Privacy
- Equity
- Sovereignty
Personal data stolen from Dutch coronavirus track-and-trace programme

AMSTERDAM (Reuters) - Personal information of a large number of people who participated in the Netherlands’ coronavirus track-and-trace programme has been leaked, the Dutch health authorities (GGD) said on Friday.

Dutch government quits over 'colossal stain' of tax subsidy scandal

THE HAGUE (Reuters) - Prime Minister Mark Rutte’s government resigned on Friday, accepting responsibility for wrongful accusations of fraud by the tax authorities that drove thousands of families to financial ruin, often on the basis of ethnicity.
Digital Colonialism: The 21st Century Scramble for Africa through the Extraction and Control of User Data and the Limitations of Data Protection Laws

September 11, 2019

nature

NEWS | 18 June 2019

Africa’s science academy leads push for ethical data use

The goal is to create the continent’s first cross-disciplinary guidelines for collecting, storing and sharing data and specimens.
Discover the world at Leiden University

- Lorentz Centre workshop
- Data specialists
  - Academia
  - Publishing
  - Industry
- Develop a lightweight common solution
- Build on existing initiatives
FAIR Biomedical Data Landscape

FAIR Sequence Data is foundation for all FAIR life science data

FAIR pipeline involves fully *exploiting* and reusing research and clinical data
Discover the world at Leiden University

Accessible is not Open
Discover the world at Leiden University

FAIR Benefits

• Accessible to those with authorization and permission
• Accessible only in prescribed ways
  - Data remains in location
  - Data visited by algorithms

Individual instances interact with one-another based on a common understanding, in accordance with their own ethics and regulatory framework.
Video demonstration of VODAN-Africa

- Mariam Basajja, PhD Student, Leiden Institute for Advanced Computer Science (LIACS)
- Aliya Aktau, PhD Student, Leiden University Medical Centre (LUMC)
- Putu Hadi Purnama Jati, PhD Student, Leiden University Medical Centre (LUMC)
- Getu Tadelle, PhD Student, Faculty of Humanities and Digital Sciences, Tilburg University and Lecturer, Mekelle University
- Oluwole Olumuyiwa Afolabi, Kampala International University
- Ezra Mwesigwa, Lecturer at Makerere University, Uganda
Localising and FAIRification of CEDAR as an ethical data pipeline

• Samson Yohannes, PhD Student at Leiden University Medical Centre (LUMC), Lecturer at Mekelle University
• 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
Health Data Interoperability in Science

• Margreet Bloemers, ZonMw
• Erik Schultes, GO FAIR Foundation
• Aliya Aktau, PhD Student, Leiden University Medical Centre (LUMC)
YOU ARE INVITED!

FAIR ETHICAL PATIENT DATA RECORDS DEPLOYMENT IN HEALTH FACILITIES IN AFRICA

20TH APRIL 2022

10 AM US EST
3 PM WAT
4 PM CAT/CET
5 PM EAT
10 PM BEIJING

Physical Address: RM 109 Gorlaeus Building, Einsteinweg 55, 2333 CC Leiden, Netherlands

REGISTRATION LINK
bit.ly/FAIREthical

Margreet Bloemers, ZonMw
Erik Schultes, GO FAIR Foundation
Aliya Aktau, LUMC
Strategy: **FAIR Data Visiting**

- **Automated F, A, I and R**
- **Machine-actionable**
  - Wilkinson et al. (2016) [https://www.nature.com/articles/sdata201618](https://www.nature.com/articles/sdata201618)

- Data are “visited” by algorithms, not copied and “shared”
- Data are made reusable, but remain localized
- Access is permitted under well-defined conditions
  - Personal Health Train [https://www.youtube.com/watch?v=mktAtHmy-FM](https://www.youtube.com/watch?v=mktAtHmy-FM)
  - Farm Data Train [https://www.youtube.com/watch?v=JWzScb3pC8](https://www.youtube.com/watch?v=JWzScb3pC8)
  - SPHN Data Ecosystem for FAIR Data [https://www.youtube.com/watch?v=pqYQap4oaIM](https://www.youtube.com/watch?v=pqYQap4oaIM)

**Beginning April 2020**

- Virus Outbreak Data Network (VODAN) ◆ GO FAIR / Phillips
- LUMC FAIR Data Point (Vaccine Research Project) ◆ ZonMw
- ZonMw National COVID-19 Program ◆ GO FAIR / Health-RI / ZonMw
Architecture

**Bulk Upload**
Uploading bulk datasets from different sources.
- COVID-19

**HMIS**
Push aggregated data from CEDAR to HMIS.
- DHIS2

**Internal Dashboard**
Aggregated data visualisation at each facility

**FDP**
Enables data visiting by exposing metadata globally in a machine readable format.
- Triple Store (Allegrograph)

**External Dashboard**
Aggregated data visualisation at VODAN Africa
LUMC FAIR Data Point

CEDAR

anDRRea workspace

FAIRification goal driving user question

Selection of variables to be FAIRified

CEDAR
Deployed locally in anDRRea

Developing CEDAR Templates

BioPortal
Vocabularies

Populating data in JSON-LD and RDF format, which can be queried by machines

Excel spreadsheets converted into SKOS, published -> BioPortal

Data kept in anDRRea, access levels to data can be controlled in this environment

Adjusted CSV files ready for bulk uploaded into CEDAR

Metadata Instances

Populating CEDAR

LUMC FDP

LUMC FDP

Raw data
FAIRification
Data that are FAIR-ready
FAIR Digital Objects (FDO)

FAIR orchestration
Data Analytics
National COVID-19 Program

ZonMw
COVID-19 Program
62 Projects

Brainstorm controlled lists

M4M.7
13 projects
21 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

M4M.8
10 projects
17 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

M4M.9
6 projects
12 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

M4M.10
7 projects
13 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

M4M.11
9 projects
16 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

M4M.12
14 projects
21 participants
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

COVID-19 Program controlled list
1. Data
2. Images
3. Biomaterials
4. Services
5. Standards

Feb 9: Consolidation of lists and terms describing the project assets
Feb 17: Building the COVID-19 Program Vocabulary

COVID-19 Program metadata input forms

Data Stewards support researchers to routinely create metadata instances

https://www.gofairfoundation.org/m4m/
FAIR Hourglass for Implementing FAIR Data Visiting
The Interoperability Challenge

https://osf.io/7xuyz/
The Interoperability Challenge

For early movers in FAIR data visiting…

… can you demonstrate interoperability?

https://osf.io/7uy2z/
The Interoperability Challenge

For early movers in FAIR data visiting…

… can you demonstrate interoperability?

https://osf.io/7xuyz/

- https://www.fdo2022.org
FAIR well…
Security, Reliability and Trust of Digital Heath Patient Data

Prof. Dr Tegawendé Bissyandé, Interdisciplinary Centre for Security, Reliability and Trust (TruX), University of Luxembourg and Burkina Faso
Interdisciplinary collaboration of Innovative Science and Business

Prof. Dr Simcha Jong Kon Chin, Paris Polytech, Institute of Interdisciplinarity and Innovation, LIACS
Interdisciplinary collaboration of innovative science and business

Simcha Jong

Professor Science Based Business, Leiden University
Visiting Professor, Dept Innovation, Management, and Entrepreneurship, École Polytechnique

FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa workshop

LUMC, 20 April 2022
Outline

FAIR/VODAN Africa pilot opening way to learning health systems

Building vibrant FAIR innovation ecosystem together with:

• Internal stakeholders – How to provide incentives to buy into ecosystem?

• External stakeholders – How does the FAIRification of healthcare innovation ecosystems shift value creation dynamics?
Current medical knowledge production

• While learning from large, complex data is becoming routine in digital firms, medicine has been slow to catch on.

• Medical practice still anchored in producing knowledge through narrow studies that avoid real-world complexities

• Clinical trials – often detached from local contexts – tend to exclude “complicated” cases with multiple ailments, complex treatments

• Trials are moreover expensive, take years to complete
The promise of learning health systems

- Data generated every day for different practical purposes could serve as valuable source of knowledge to fuel learning health system
- Currently, these data are largely “wasted” and locked in data silos
- Advances in medical research methods pertinent to big data has confined to more basic biomedical sciences such as bioinformatics

FAIR health information systems opening way to learning health systems
Ecosystems key to success FAIR platforms

• Concept finds origins in ecology – describes community of organisms, which together with environment interact as system.

• Shift in innovation research promoting idea that organizations’ strategic position not seen as primarily shaped by position in single industry, but in ecosystem

• Particularly apt in context of firms organized around platforms blurring industry boundaries

• Rise ecosystems also linked to the process of modularization
Ecosystem development around FAIR platforms

Internal user groups

External user groups
Ecosystem development around FAIR platforms

External user groups
Expanding the FAIR ecosystem
Expanding the FAIR ecosystem

External user groups
Expanding the FAIR ecosystem

External user groups

VODAN AFRICA & ASIA
Four stages of digital operating model transformation

Source: Lakhami and Iansiti, 2020
Challenges of digital transformation

• Value of data platforms increases as more user groups interact with these platforms

• Persistence of data silos within healthcare organizations – within/across electronic health record systems, disease registries, claims data, etc. key barrier to digital transformations in healthcare

• FAIR offers major advantages. Yet, FAIR implementation remains project of profound organizational change

Firms, other external stakeholders key to value co-creation efforts to support FAIR implementation
However, FAIR significantly alters value creation dynamics
Shifts in value creation dynamics

Quality, styling, comfort, ride quality, cost, brand.

Availability of drivers, wait time, trust in company’s policies on driver certification, customer ratings of drivers, ease of use, cost
Shifts in value creation dynamics

Digitization

Quality, maintenance, features, cost, brand, training support

Customization, (remote) performance monitoring, patient involvement
Strategic trade-offs in platform development

1. Restrictions on participation in development, commercialization, or use.
2. To what extent are restrictions reasonable and applied without discrimination – i.e. applied uniformly
Strategic trade-offs in platform development

- Demand-side platform users
- Supply-side platform users
- Platform providers
- Platform sponsors

OPEN

CLOSED
Comparison of openness by role in platform-mediated networks

<table>
<thead>
<tr>
<th>Role</th>
<th>Linux</th>
<th>Windows</th>
<th>Macintosh</th>
<th>iPhone</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demand-Side User</strong></td>
<td>Open</td>
<td>Open</td>
<td>Open</td>
<td>Open</td>
</tr>
<tr>
<td>(End User)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Supply-Side User</strong></td>
<td>Open</td>
<td>Open</td>
<td>Open</td>
<td>Closed</td>
</tr>
<tr>
<td>(Application Developer)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Platform Provider</strong></td>
<td>Open</td>
<td>Open</td>
<td>Closed</td>
<td>Closed</td>
</tr>
<tr>
<td>(Hardware/OS Bundle)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Platform Sponsor</strong></td>
<td>Open</td>
<td>Closed</td>
<td>Closed</td>
<td>Closed</td>
</tr>
<tr>
<td>(Design &amp; IP Rights Owner)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Digital platform design choices affect value creation dynamics...
Shifts in value creation dynamics

Digititalization

| Quality, maintenance, features, cost, brand, training support | Customization, (remote) performance monitoring, patient involvement |

Medtronic

PHILIPS Healthcare

Cepheid®

A better way.
FAIR impact on value creation dynamics in biomedical innovation system

Digitization

“FAIRification”

| Quality, maintenance, features, cost, brand, training support | Customization, (remote) performance monitoring, patient involvement | System-level decision support, real-time clinical / cost optimization, | ? |
Concluding remarks

- FAIR infrastructures key to realising learning health systems

- FAIRification as a process of organisational transformation

- FAIRification represents disruptive challenge for business, while opening up many new opportunities for value co-creation
Overcoming Challenges with FAIR Ethical Health Data

• Dr Hagos, Director Bureau of Health, Tigray, Ethiopia
• Dr Amanuel, Chief Medical Officer Ayder Hospital, Tigray, Ethiopia
Documentation and Publication

Fenghong Liu, Data Intelligence Journal and Chinese Academy of Sciences
The next generation of African-led GO FAIR

Prof. Dr Munyadzi Mawere, Co-Chair of the GO Fair Implementation Network Africa, Professor Extraordinarius of Interdisciplinary Research at Unisa, Great Zimbabwe University (GZU), Zimbabwe
The Next Generation of African-led GO FAIR: A Window of Opportunity for Stewarding Africa’s Own Heritage in Contemporary Systems?

Munyaradzi Mawere (PhD), Professor Extraordinarius of Interdisciplinary Research; Professor of African Studies & Research Chair, Great Zimbabwe University (20 April 2022, 16:00 – 18:00: 17:50-17:55pm)
Ladies and Gentlemen, Distinguished Guests, Colleagues and Compatriots, I’m overjoyed to have been honoured to speak to you today at this important occasion where we have gathered under the Theme “FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa”.

**INTENTION:** discuss the duty & mandate of “The next generation of African-led GO FAIR” as one of the most important opportunities for Africa not only to showcase its innovations and solutions from within the continent, but to steward its own heritage. This TALK is therefore meant to:

i). Interrogate FAIR CULTURE practice in Africa. This is critical because, in a world marked by historic asymmetrical relationships as ours, there is a sense (or at least a feeling by some) that FC in Africa is being approached from an outsider’s frame of reference, based on assumptions that may not apply at all in an African context, or are at least in need of incisive interrogation.

ii). Suggest novel strategies for FAIR CULTURE acceptance & adaptation by The next generation of African-led GO FAIR that will help build more trust on FAIR & contribute towards real heritage stewardship for Africa.
GLOBAL POSITIONING OF FAIR CULTURE (FC)

FC stands as one of the possible local-global opportunities for all – globally and particularly in Africa – to contribute towards self heritage stewardship & showcasing of home-based solutions. More so, there is an interest in FC within & btwn nations, as well as the possibility that such interest, if well attended to, can help navigate African challenges. However, interest in FC within Africa and the international community is treated by some with scepticism, bcz of perceived downsides of FC & Africa’s historical past. This scepticism shld be dealt with now & not later to allow the next generation of African-led GO FAIR to have a smooth take-off. In fact, while ideally FC in view of international cooperation has been lodged by its proponents as a –tve venture, many of our African nations still remain sceptical & unsure if this will remain the case at least in the future. The FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa we are LAUNCHING here 2day shld prove wrong all the skeptics now – and the sooner the better. But how to prove the skeptics wrong is the BIG QUESTION?
Proving the FAIR Skeptics Wrong

While FAIR CULTURE in Africa is no doubt a window of opportunity for stewarding its own heritage, this is only possible if FAIR Ethical Patient Data Records Deployment in Health Facilities in Africa will:

- Surely enhance quality of care in a manner that promotes the African Phy of Ubuntu, particularly the virtues of love, respect (for human life), solidarity and care for each other’s well-being.

- Help increase efficiency in Research & health care (among other sectors) by avoiding unnecessary diagnostic or therapeutic interventions, which in turn, lower healthcare provision cost.

- Prove helpful in creating a connected and operational referral and diagnostic system in the context of the enlarged mobility of patients (Government of Kenya, 2014: 44), including cross-border mvnts. etc.
● Make sure that health data gathered remains in Africa and is indeed INDEPENDENTLY governed by Africa;

● Ensure that digital applications for FAIR architecture are designed with the active involvement of local expertise to take into account system diversity and to embrace specific or rather African contextual realities.

● Make sure that political measures that allow equitable access of Digital Tech for all (the rich and the poor, the rural and the urban populations, the male and the females, as well as the young and the old people) are seriously considered so as not to create digital divide and black holes that will in turn deepen & widen the gap between the have-nots (or the poor) and the haves (or the rich).
Concln: Globally, FC has proven to be a window of opportunity, esp for Africa to steward its own heritage & to liberate its destiny for a better future. Yet, and I reiterate, there is a belief by some that FC in Africa often assumes neo-positivistic paradigms (that exclude different worldviews other than Western) and is indeed approached from an outsiders’ frame of reference, based on assumptions that may not apply in an African context, or are at least in need of duteous interrogation. To counter this scepticism, the current FAIR initiative has made sure that the next generation of GO FAIR implementation is African-led. Yet, being African-led alone is not enough UNLESS FAIR symmetrical relationships are genuinely established & architectural applications are designed with local expertise that takes into cognisance proportional intellectual division of labour, heritage stewardship & systems diversity as well as specific local realities and circumstances. Otherwise, without all this taken into account, the next generation of African-led GO FAIR will be nothing OTHER THAN an amplified CAMPAIGN for recession of African humanity in the name of technology.

With this, I hope to have challenged and inspired many of us to understand the duty & mandate of the next generation of African-led GO FAIR.

Ndatenda! I Thank You!!
Moving forward - building a GO FAIR Architecture for Health

• Prof. Dr Barend Mons, Chair GO FAIR Foundation
• Prof. Dr Francisca Oladipo, Prof. Computer Science at the University of Lokoja, Nigeria and Executive Coordinator of VODAN-Africa
Closure

• Christine Kirkpatrick, San Diego Supercomputer Centre (SDSC)

• Prof. Dr Mirjam van Reisen, Chair Fair Data Science, Leiden University Medical Centre (LUMC), Chair of International Relations Innovations and Care, Tilburg University, Coordinator of the Research Network Globalisation, Accessibility, Innovation and Care (GAIC)
How to join us?

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

• Join the newsletter via the VODAN website

n2.10050