

Artificial
Intelligence is
transformational
for health &
requires quality
data, globally

Presentation
about DATA

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- Secured access to personal data is needed first for the patients themselves and for their health providers (**primary use**), but also to quickening research and development of tools and treatments (**secondary use**- anonymous data).
- Transformation through AI to advance health and health care, needs **quality data** and a health data space.
- **A health data space** is a health specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework.
- **Data fragmentation** across the healthcare continuum is driving a need for tools and solutions (Including AI) that can accelerate the unification of various processes and practices.

DATA critical GLOBALLY

Global health
care AI market:
Euro 26 Billion in
2025

- If AI models aren't trained on **data from people in under-resourced places**, those populations and the world in general will be poorly served by the algorithms.
- The last thing that we want to see happen as part of this leap forward with technology is the amplification of **inequities** and biases against some people and countries around the world.
- Potential for industrial capture and crowding out of academia and regulators would be detrimental .
- The WHO guidelines are already a good start and recommend that independent third parties perform and publish mandatory post-release audits of Large Language Models like chat gpt.
- Audits should assess how well a tool **protects both data and human rights**.

FAIR DATA
Principles
defined in March
2016
&

adopted at the
G20 Hangzhou
summit.

A game changer
for Global Health.

FAIR data are to meet the principles of

- **Findability:** data and metadata should be easy to find by humans and machines. Machine readable data are essential.
- **Accessibility:** Once the user finds the required data, they need to know how they can be accessed, possibly including authentication and authorization using a standardized communication protocol.
- **Interoperability:** The data usually need to be integrated with other data. In addition, the data need to interoperate with applications or workflows for analysis, storage and processing.
- **Reusability :** The ultimate goal of FAIR is to optimize the reuse of data. To achieve this, metadata and data should be well-described so that they can be replicated and/or combined in different settings.

The lack of information and practical experiences on how to implement the guidelines have led to inconsistent interpretations of them.

European Health Data
Space or EHDS
will benefit people,
patients, research,
pharma , insurance
companies and
healthcare
institutions as well as
bring health
innovation to the
next level.

Interinstitutional negotiations under the Belgian presidency to remove **obstacles** to curate health data as FAIR:

- Interoperability has remained difficult due to the different systems for health data in each country, which are operating under different jurisdictions .
- The reusability of clinical data has been poorly addressed .
- The vague definitions of ‘electronic health data’ and ‘data holder’ need to be clarified.
- The proposed IP framework possibly conflicts with existing legal safeguards aimed at protecting the scientific and technological potential and interests of researchers and innovators.
- The introduction of excessive and unclear data localization and international health data transfer requirements, on top of the GDPR, may block essential data flows and lead to inconsistent implementation of rules across the EU.

Some countries in Europe such as Finland made very good progress and techniques become available to solve some of the obstacles.

Some platforms in Africa made an impressive progress in implementation.

- **Making progress to solve the problems globally is critical .**

A leap forward in AFRICA.

Towards an
African health
data space with
VODAN

=

value driven
ownership of data
and accessibility
network

- Vodan is an African lead network of partners created in 2019. Ten African countries already involved.
- VODAN data implementation is certified as **Findable, Accessible, Interoperable and Reusable (FAIR)** with **Ownership, Localization, and Regulatory Compliance (OLR)**.
- The OLR-features reveal data curation as an **ethical process**, recognizing the value of the **federated data** and of keeping these data **in residence**.
- *A federated database system is a meta-database management system, which maps multiple autonomous database into a single system .The constituent data bases are interconnected via a computer network and can be geographically decentralized.*
- The essence of the architecture is a **one-time data entry** which generates multiple parallel use trajectories of the data.

The African lead VODAN network aims to facilitate the creation of an **African Health Data Space** & partner with the European Health Data Space.

- *to* recommend **regulations** that protect patients' data privacy and information integrity while not stifling the utilization and mobility of health data for R&D.
- To establish a **common norm**, centred around FAIR Data and data ownership.
- To organize **interoperability** in the health data layer.
- The VODAN system has been tested to do disease monitoring, medical and pharma research or post market surveillance of medication.
 - Some of the value of the data can also become a **source of income** to make the systems **sustainable** and the development of business models for value creation ongoing.

Five recommendations

From major fragmentation of data collection platforms towards integration.

- From under-representation of data from Africa to **access to comprehensive health data** that provide insights and AI based systems and tools.
- The EU, the AU and WHO to provide support through **setting standards** and develop a **regulatory framework** for data interoperability and re-use.
- Donors, EDCPT, Gates Foundation and the WHO to recommend all initiatives to work with **FAIR data, allowing data-interoperability** to work.
- Make further investments to provide equitable access of **high- performance computational infrastructure** to process massive datasets from all sources.
- **Respectful, equal partnerships** for Health data spaces and AI would go a long way to rebuild trust through learning from and with each other.