NEW SOLUTIONS
IN DIGITAL HEALTH

28.-29.06.2022

dbb forum berlin
www.smith.care

DATA-DRIVEN HEALTHCARE
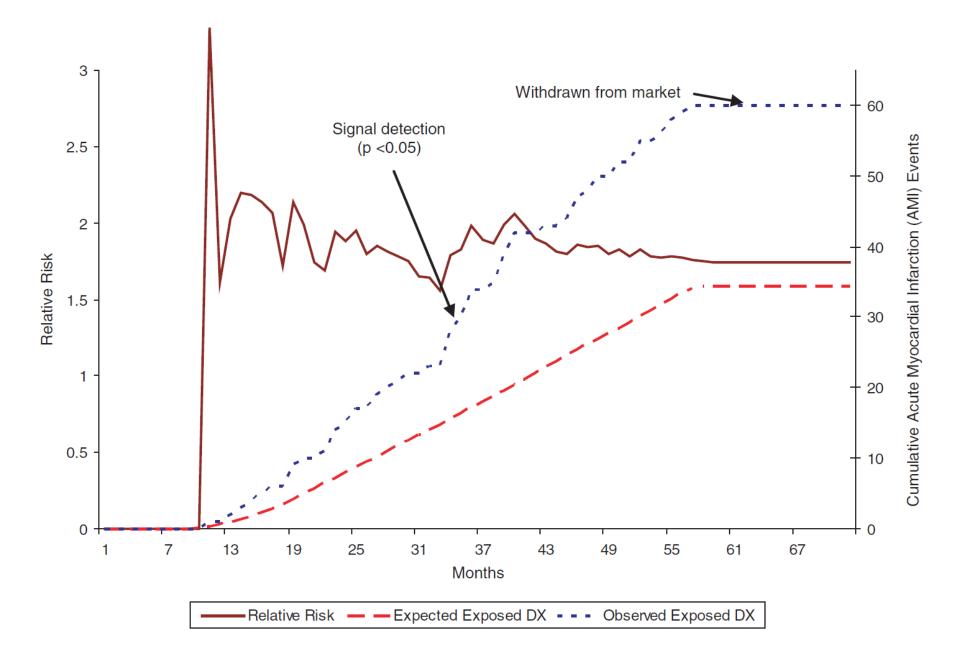# TODAY'S RESEARCH FOR TOMORROW'S HEALTHCARE

Ronald Cornet | June 28th 2022

NEW SOLUTIONS
IN DIGITAL HEALTH

28.-29.06.2022

dbb forum berlin
www.smith.care
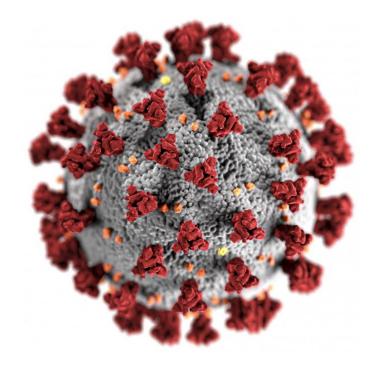
- Drivers
- Challenges
- Approaches
- Experiences

Drivers

Source: Challenges for the FDA: The Future of Drug Safety, Workshop Summary

Other examples

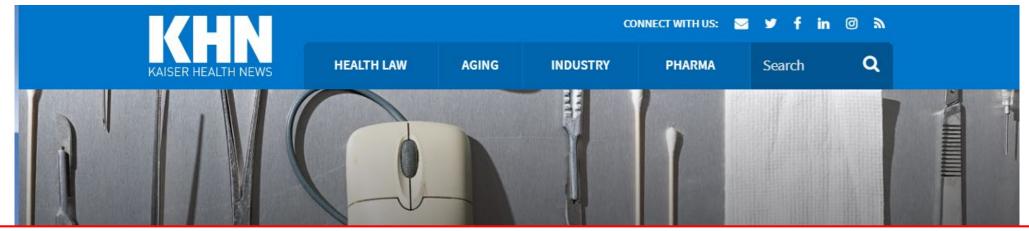Source: https://mobile.twitter.com/DataSavesLives_/photo

Challenges

Human   Machine   Data exchange   Data use

Interaction

#data saves lives

Source: New Yorker June 26th, 1995, drawing by J.P. Rini

The ideal — creating a useful, interoperable, nationwide records system — was "utterly infeasible to get to in a short time frame."
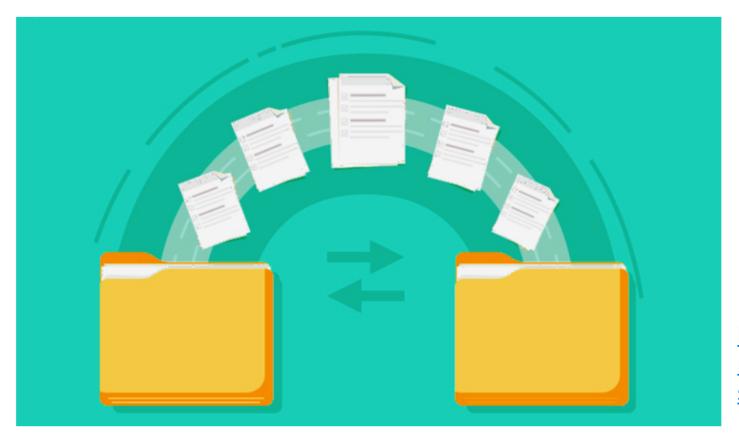
BOTCHED OPERATION

Death By 1,000 Clicks: Where Electronic Health Records Went Wrong

The U.S. government claimed that turning American medical charts into electronic records would make health care better, safer and cheaper. Ten years and $36 billion later, the system is an unholy mess. Inside a digital revolution that took a bad turn.

https://khn.org/news/death-by-a-thousand-clicks/

One-Third of Health Systems Still Struggle with Interoperability

A new survey shows that health systems are still struggling to share data both within their own organizations and with other entities.

Shared Semantics

Standards

Information models & Vocabularies

Economic Policy

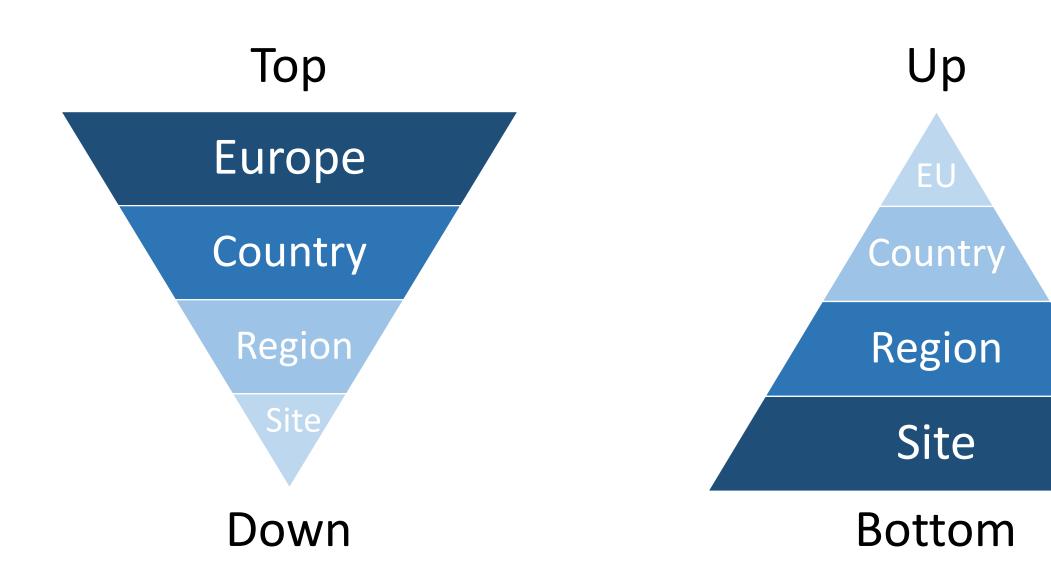# The solutions to all our problems may be buried in PDFs that nobody reads
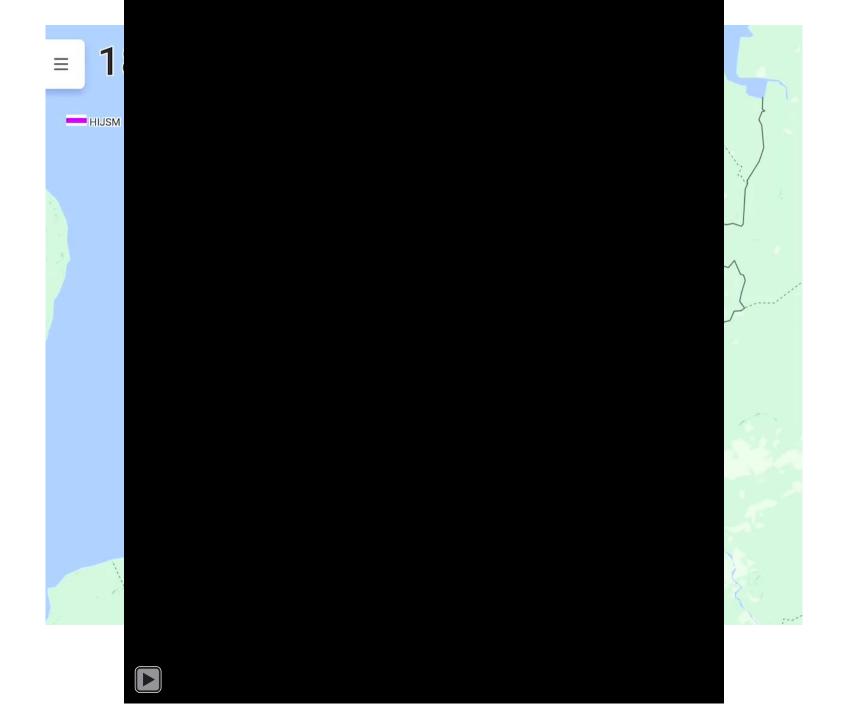
By **Christopher Ingraham**

May 8, 2014

What if someone had already figured out the answers to the world's most pressing policy problems, but those solutions were buried deep in a PDF, somewhere nobody will ever read them?

Approaches

HIJSM

Refined eHealth European Interoperability Framework

Legal and regulatory	Legal and regulatory constraints
Policy	Collaboration agreements
Care Process	Alignment of care processes
Information	Defining and coding of information
Applications	Integration in healthcare systems
IT Infrastructure	Communication protocols

Source: European Commission, 2017

European Health Data Space Regulation

Empower individuals to control their health data

Foster a single market for digital health services and products

Ensure interoperability and security of health data and a level playing field for manufacturers

Unleash the power of the health data economy

Ensure a consistent and efficient framework for the reuse of health data for research, innovation, policy-making and regulatory activities

Source: A European Health Data Space: harnessing the power of health data for people, patients and innovation

European approaches

- EHDS: a "health-specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework".

- GAIA-X project; **a federated system** linking cloud service providers and users in a transparent environment that will drive the European data economy

International health data standardization

- HL7 (FHIR – Fast Healthcare Interoperability Resources)
  - facilitating exchange of healthcare data
    - Based on OpenAPI specification
- OHDSI (Observational Health Data Sciences and Informatics)
  - facilitating analysis of federated observational data for Real-World Evidence
- CDISC (Clinical Data Interchange Standards Consortium)
  - to enable interoperability to improve medical research

- … and many more, including OpenEHR and ISO-standards, and terminologies

Applications in the Netherlands

- National Switchboard – based on HL7 CDA

- MedMij – standard for secure exchange of health data between care users and care providers (person health environments)

- VIPP – Providing patients' access to their health data

NEW SOLUTIONS
IN DIGITAL HEALTH

28.-29.06.2022

dbb forum berlin
www.smith.care

Experiences

Data standardization

- Data Curation Tool, for conversion into HL7 FHIR Repository

- Data Privacy Tool, HL7 FHIR API-based

- FAIR4Health platform, to support the execution of algorithms

See for all details:

https://www.fair4health.eu/en/news/fair4health-key-outputs-for-the-scientific-community
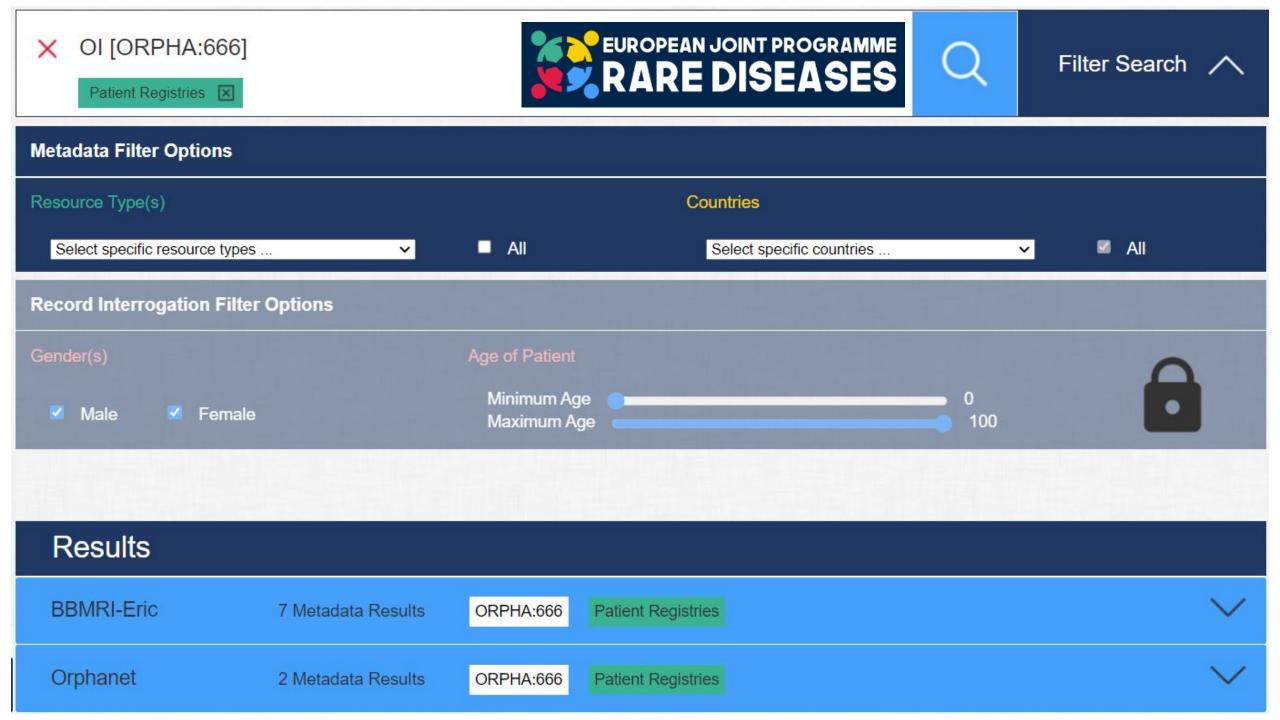
Data standardization

- Application of the **OHDSI** model and tools
    - CAPABLE – quality of life after cancer treatment
    - Mental health of children and young adults
    - NICE – Dutch ICU registry
    - CovidPredict – ICU data of COVID-19 patients
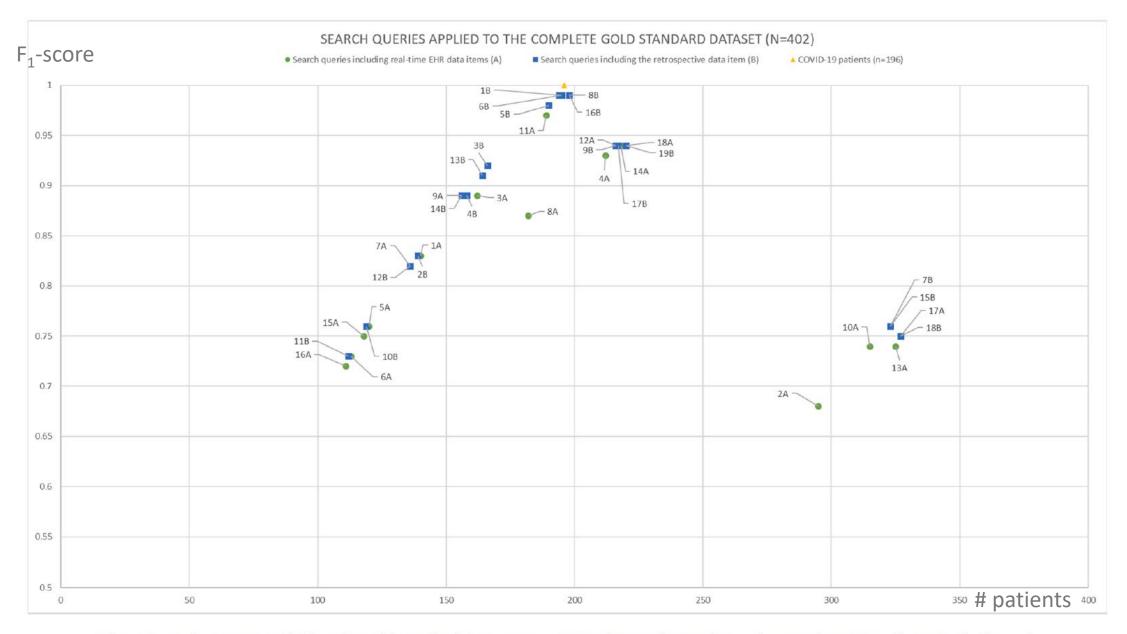   - Common data elements of rare disease registries

Fig. 3. Search queries applied to the gold standard dataset (n = 402). The numbers indicate the search queries, shown in the legend.

Pre-condition – "FAIR" from the start

1. Post-hoc FAIRification, after data collection in an EDC system

EDC system → Data collection → Non-FAIR dataset → Pre-FAIRification → FAIRification → FAIR dataset / FAIR metadata → Host FAIR Data → Using FAIR Data

2. De-novo FAIRification via an EDC system

Pre-FAIRification → Facilitating FAIRification → Data collection → Generating FAIR data → FAIR dataset / FAIR metadata → Host FAIR data → Using FAIR data

EDC system

Kersloot et al., De-novo FAIRification via an Electronic Data Capture system by automated transformation of filled electronic Case Report Forms into machine-readable data
J Biomed Info 2021; https://doi.org/10.1016/j.jbi.2021.103897

Graphical abstract

> J Biomed Inform. 2022 May;129:104071. doi: 10.1016/j.jbi.2022.104071. Epub 2022 Apr 13.

Diagnosis clarification by generalization to patient-friendly terms and definitions: Validation study
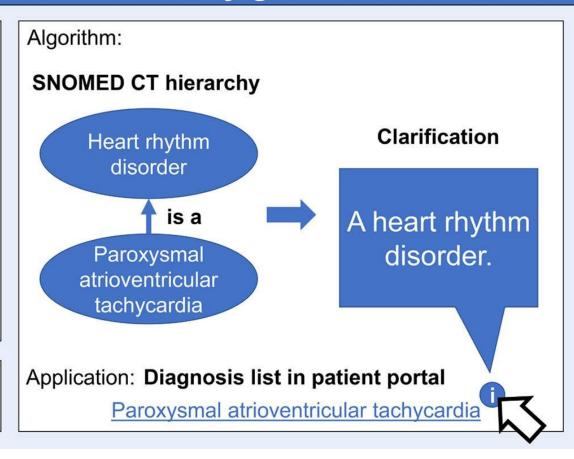
Hugo J T van Mens [1], Savine S M Martens [2], Elisabeth H M Paiman [3], Alexander C Mertens [4], Remko Nienhuis [5], Nicolette F de Keizer [6], Ronald Cornet [7]

Experiences – summary

- Sociotechnical effort

- Knowledge intensive, many gaps
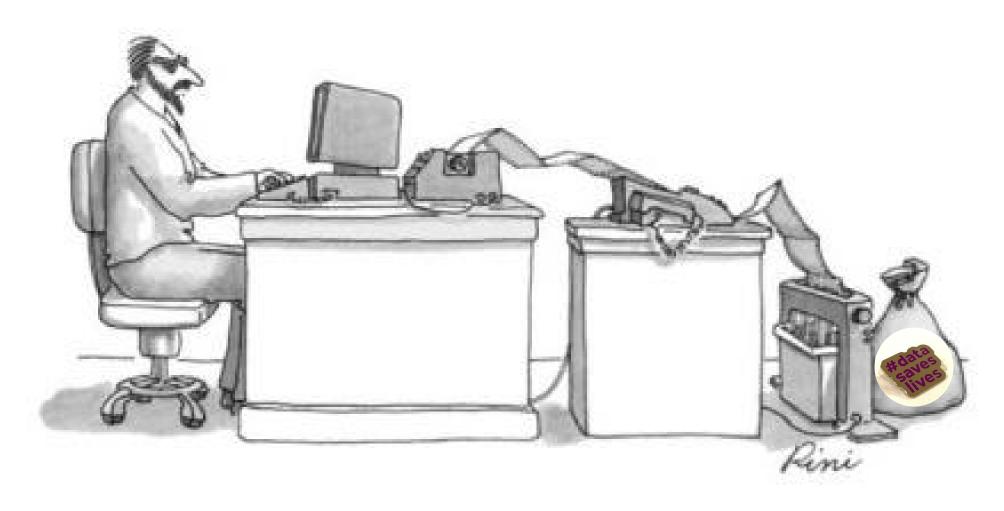
- (medical) informatics needs to further mature

NEW SOLUTIONS
IN DIGITAL HEALTH

28.-29.06.2022

dbb forum berlin
www.smith.care

Agenda

Source: Challenges for the FDA: The Future of Drug Safety, Workshop Summary

Source: New Yorker June 26th, 1995, drawing by J.P. Rini

Source: New Yorker June 26th, 1995, drawing by J.P. Rini

Re-use of health(care) data: integral approach of the obstacles to tackle

Common interest

Rules

Technology put in practice

General principles / Rating support / Communication
Patients/citizens are **not well informed** about the importance of re-use of health(care) data
Lack of clarity about who has **control** over the health(care) data
Fear of lack of **recognition** by organisations generating health(care) data
Access to health(care) data by/from companies can be particularly challenging

Framework: Legal / Ethical / Societal / Privacy / Knowledge Security
(Perceived) Legal / ethical / societal **barriers** of re-use of health(care) data
Health(care) data **cannot be linked** to other data **securely and precisely**
Safeguarding **privacy**
Safeguarding **knowledge security**
Multiple and varying **review procedures** for re-use of health(care) data
Difficult to share health(care) data **internationally**

Technical / Logistics / Organisation / Services
Health(care) data are **difficult to obtain and fragmented**
Health(care) data are **changed and/or deleted** (due to administrative burden)
Health(care) (meta)data are **not structured** according to standards
Technical / logistic / organisational **(compliance-by-design) barriers**

Continuous interaction

Source: https://www.health-ri.nl/data-reuse-obstacles-removal-traject

health RI
enabling data driven health

Priorities – data

- Focus on high-quality, standardized, structured data at the source – where possible
- Involve clinicians

- Get clear descriptions of data and datasets
- Minimize copy-pasting of data

- Use the data
- Involve patients

Priorities – field

- Establish infrastructures

- Establish communities

- Provide training in medical informatics

Ronald Cornet, PhD | Associate professor ; Principal Investigator
Medical Informatics
Amsterdam Public Health Research Institute
Location AMC | J1b-115 | Meibergdreef 15, 1105 AZ Amsterdam
T: +31 20-566 51 88 | E: r.cornet@amsterdamumc.nl | kik.amc.nl/home/rcornet
www.amsterdamumc.nl | www.amc.nl