

Implementing FAIR in Real World Evidence

Opportunities and challenges for OHDSI and EHDEN

Tess Korthout, Business Developer

tess@thehyve.nl

PHUSE EU Connect 2020

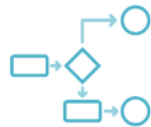
The challenge of real world data



What will it require?



Data interoperability



Standardised analytics



Data network

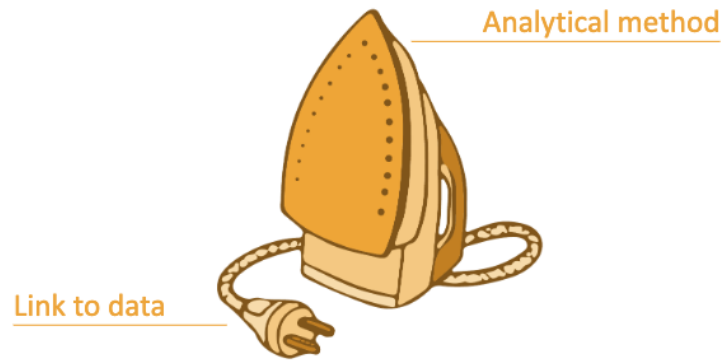


Strong community



The challenge of real world data

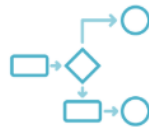
- Not scalable
- Not transparent
- Expensive
- Slow
- Prohibitive to non-expert routine use



What will it require?



Data interoperability



Standardised analytics



Data network

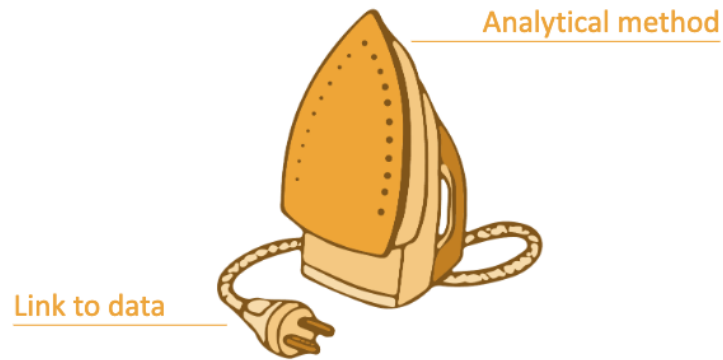


Strong community



The challenge of real world data

- Not scalable
- Not transparent
- Expensive
- Slow
- Prohibitive to non-expert routine use



The data...



Observational databases differ in both **purpose** and **design**:

- Logical organizations
- Physical formats
- Terminologies used

What will it require?



Data interoperability



Standardised analytics



Data network



Strong community



Multi-stakeholder,
interdisciplinary collaborative to
bring out the **value of health
data** through large-scale
analytics



OHDSI: a global community



OHDSI Collaborators:

- 2,770 users
- 25 workgroups
- 18,700 posts on 3,250 topics

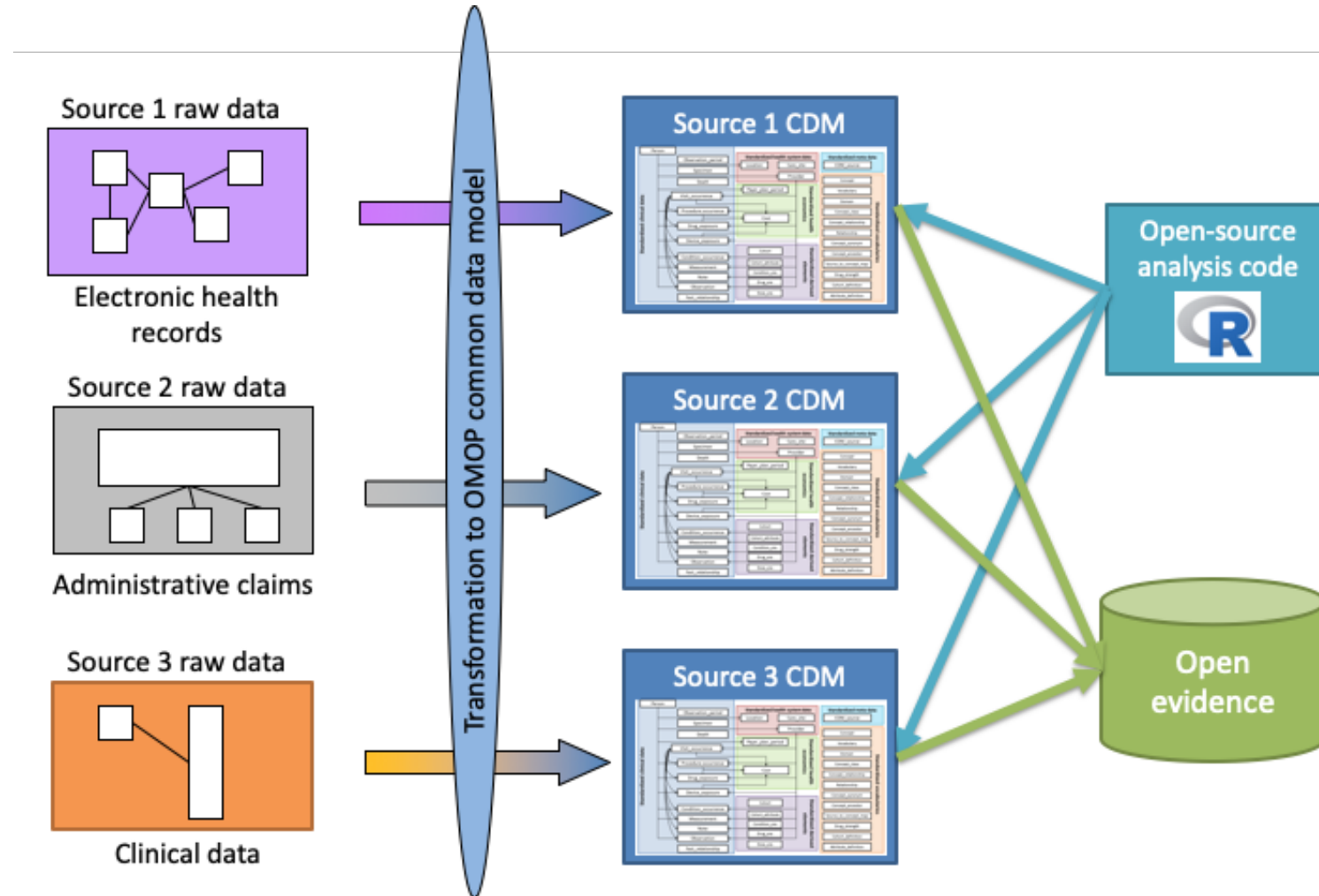
OHDSI Network:

- 152 databases
- 18 countries
- approx. 600M patient records

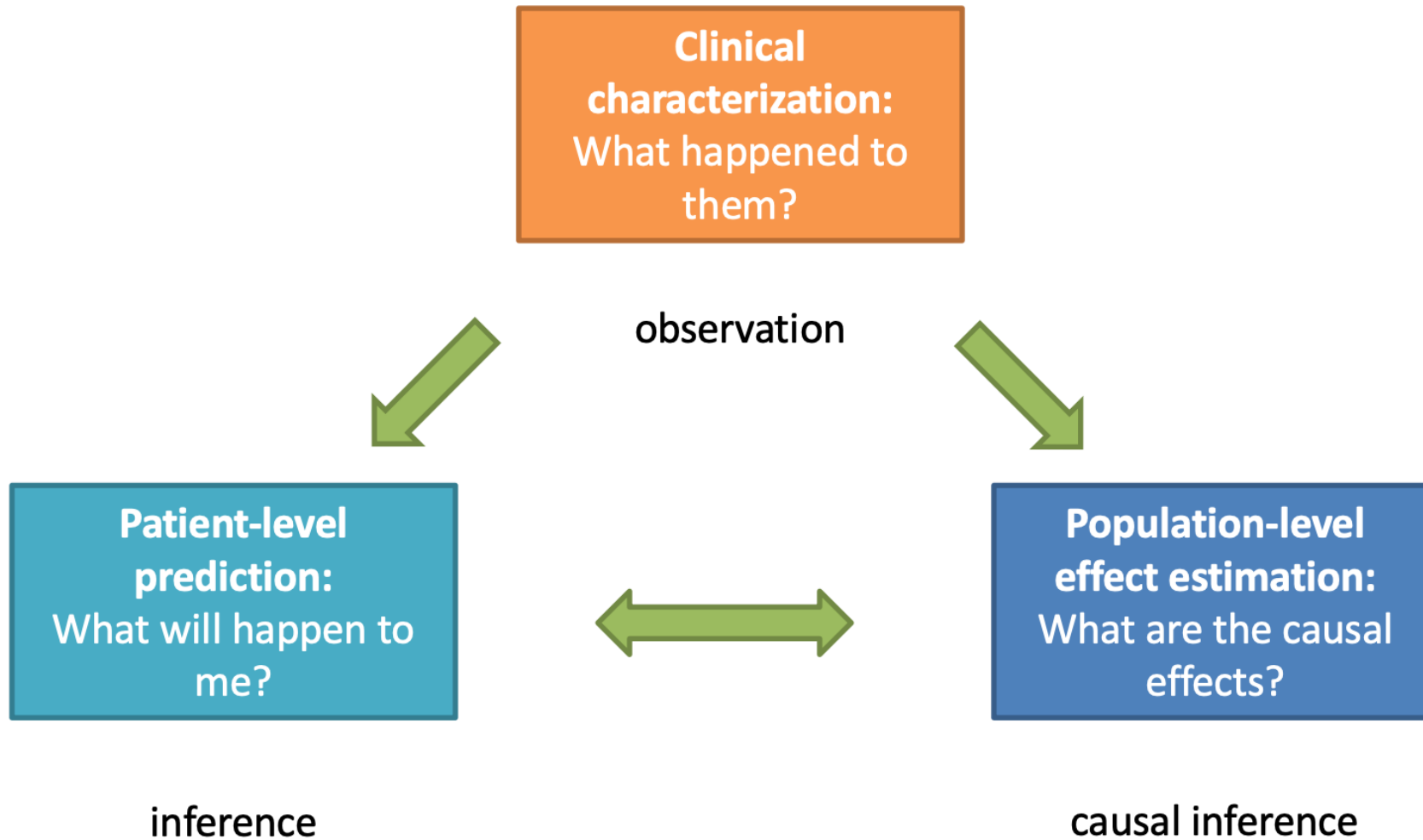
- Open source community leveraging the **OMOP CDM** for observational research
- Provides complete **suite of tools** for ETL design, data standards and data analysis
- **Federated network**: disseminate query around the world



Interoperable data network



Generate evidence from observational data



Case study:

Covid-19 study-a-thon

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

COVID-19 Study-A-Thon
ohdsi.org/covid-19-updates

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Three focus areas, Twelve Questions

Analytic use case	Study
Characterization	
	COVID-19 positive patients
	COVID-19 +ve subgroup analyses
	Influenza, symptoms, and complications
	Invasive treatments for respiratory distress
	other questions?
Prediction	
	1) Who presenting with flu, symptoms, or complications will be admitted to hospital?
	2) Who sent home with symptoms will progress to require hospitalization?
	3) Who admitted to hospital will require intensive care services or die?
	other questions?
Estimation	
	Effects of hydroxychloroquine
	Effects of IL6 and JAK inhibitors
	Effects of HIV protease inhibitors
	Effects of HepC protease inhibitors
	Effects of ACE inhibitors

THE LANCET Rheumatology

Log in

ARTICLES | [ONLINE FIRST](#)

Risk of hydroxychloroquine alone and in combination with azithromycin in the treatment of rheumatoid arthritis: a multinational, retrospective study

Jennifer C E Lane, MRCS [†] • James Weaver, MSc [†] • Kristin Kostka, MPH • Talita Duarte-Salles, PhD • Maria Tereza F Abrahao, PhD • Heba Alghoul, MD • et al. [Show all authors](#) • [Show footnotes](#)

[Open Access](#) • Published: August 21, 2020 • DOI: [https://doi.org/10.1016/S2665-9913\(20\)30276-9](https://doi.org/10.1016/S2665-9913(20)30276-9)

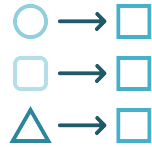
 Check for updates



Creating a European
network of OMOP
datasets with **EHDEN**



Objectives of the EHDEN project



Harmonisation

Harmonise in excess of **100 million** anonymised **health records** to the OMOP common data model, supported by an ecosystem of certified SMEs, and technical architecture for a federated network



Evidence

Impact our understanding of, and improvement of, clinical **outcomes for patients** within diverse healthcare systems in the EU

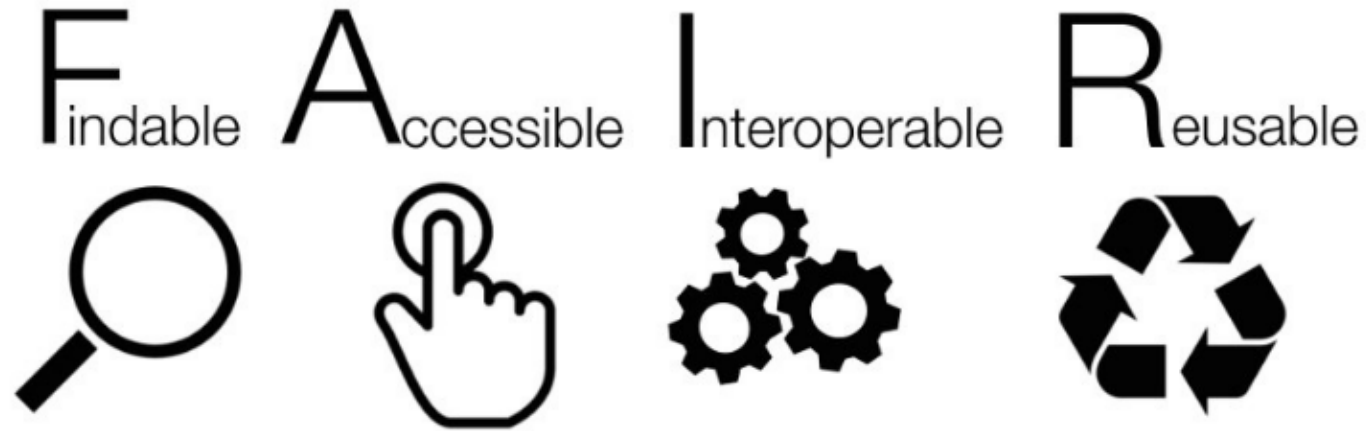


Community

Establish a self-sustaining **open science collaboration** in Europe, supporting academia, industry, regulators, payers, government, NGOs and others



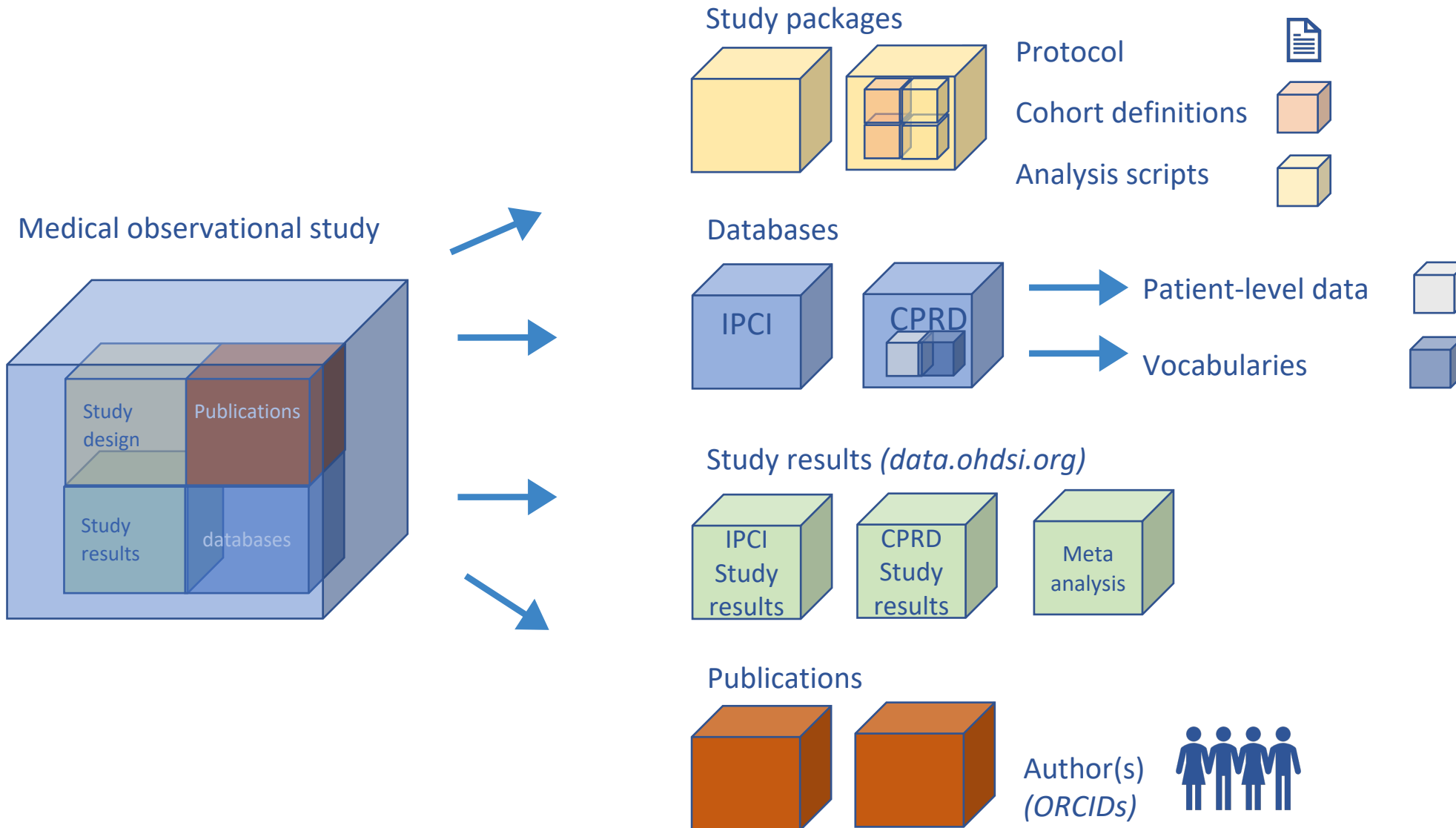
One objective of the EHDEN project



Assessment and improvement of **FAIRness** for a number of **digital objects** in the OHDSI ecosystem and EHDEN

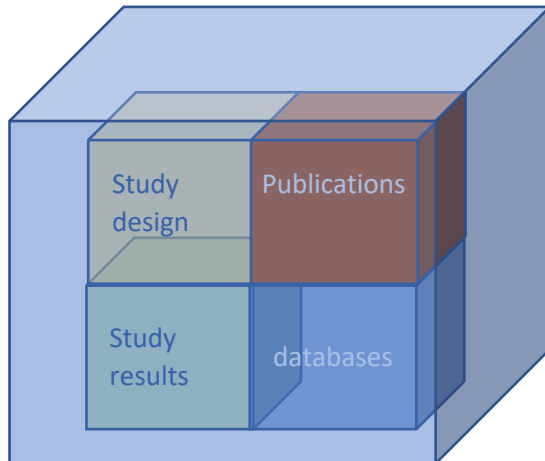


Digital objects in OHDSI



Selecting digital objects to FAIRify

Medical observational study



Study packages

Databases (database metadata including type, domains included, number of patient years and followup, inclusion/exclusion triggers etc., database snapshot versions, database reports for example Achilles, DQ)) 62%



Studies (e.g. study protocols, study results, study publications, study authors etc.) 62%



Data model (CDM versions and definition including domains, fields, constraints, and the vocabularies and vocabulary versions) 50%



Software (analysis packages, visualization tools, ETL tools, ATLAS etc.) 25%



Discourse (protocol discussions, CDM choices, forum posts, WG materials from wiki, papers etc.) 0%

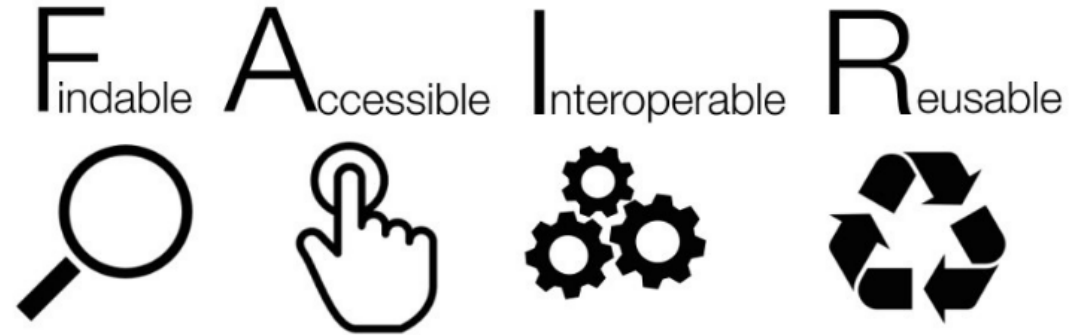
8
voters

16
total
votes

(ORCIDS)



FAIR assessment of studies and databases



- Controlled, standardized vocabularies are part of the OMOP CDM
- Databases and studies are not very findable
- No persistent identifiers used for studies
- Studies lack rich metadata (especially provenance metadata)
- Metadata is described in free text, instead of using metadata concepts from ontologies (PROV-O or DCAT)



<https://covid19.ohdsi.app/>

Provide visibility of the ongoing collaborative research to the rest of the world:
both to **humans** and **machines**

Create an **overview** and **future reference** for study-a-thon participants on the
various digital assets created in the study process



<https://covid19.ohdsi.app/>

Details Software Databases JSON-LD

Drugs:

- Hydroxychloroquine
- Amoxicillin
- Sulfasalazine
- Azithromycin

Health Conditions:

- Disease caused by severe acute respiratory syndrome coronavirus 2
- Rheumatoid arthritis

Event: COVID-19 virtual study-a-thon (2020-03-26 to 2020-03-29) at ,
Organizer: Observational Health Data Sciences and Informatics

Results:

- Risk of hydroxychloroquine, alone and in combination with azithromycin: a multi-national study
- Risk of hydroxychloroquine, alone and in combination with azithromycin: a multi-national study

Details Software Databases JSON-LD

 Copy to clipboard

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      },
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    }
  ]
}
```



Risk of hydroxychloroquine, alone and in combination with azithromycin: a multi-national study

Daniel Prieto-Alhambra

Last updated on Sep 20, 2020

Start date: 2020-04-02

Identifier: EUPAS34497

Study Type: Methods Research

Use Case(s): Population-Level Estimation

Status: Results Available

[URL](#)

[Forum Discussion](#)

Retrospective, real-world, observational study to estimate the population-level effects of hydroxychloroquine among patients with rheumatoid arthritis.

Designed and executed during the OHDSI community COVID-19 virtual study-a-thon (March 26-29) to inform healthcare decision-making in response to the current global pandemic.



Conclusion

- OHDSI and EHDEN aim to make healthcare data FAIR for the benefit of medical practice
- FAIR assessment of OHDSI digital objects: room for improvement
- We created structured metadata for covid-19 study-a-thon studies

Future perspective:

- Create identifier scheme for OHDSI digital objects
- Easy-to-use framework to quickly instantiate website



Questions

Check out the result:

<https://covid19.ohdsi.app/>

For questions, comments, feedback:

tess@thehyve.nl

@tesskorthout





the hyve

We enable open science by developing and implementing
open source solutions and FAIRifying data in life sciences