

GDPR and European Law

Barend Mons

Network meeting 16-19 February 2020



An Internet of FAIR Data and Services & Privacy network for (regional) FAIR data

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GO FAIR International Support and Coordination Office
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Senior IT adviseur, Informatie manager research
Leiden University Medical Center
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Network meeting 16-19 February 2020





TNO



02:51



Personal Health Train - English

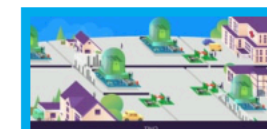
4 years ago



DTL

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Personal Health T...

DTL

<https://vimeo.com/143245835>

February
2019

Happy birthday, Internet

- 50 years old this year!
- First 20 years of R&d supported generously by DARPA produced first NCP then TCP/IP for the ARPAnet (a few hundred nodes)
- Then 10 years of r&D supported generously by NSF produced the NSFnet (thousands of nodes)
- Then the private sector "took over" just as the Internet rocket took off (first millions now billions of nodes)

THE WESTIN
ALEXANDRIA

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A Framework for Distributed Digital Object Services

Robert Kahn

Corporation for National Research Initiatives

Robert Wilensky

University of California at Berkeley

May 13, 1995 

cnri.dlib/tn95-01

1. Introduction

This document describes fundamental aspects of an infrastructure that is open in its architecture and which supports a large and extensible class of distributed digital information services. Digital libraries are one example of such services; numerous other examples of such services may be found in emerging electronic commerce applications. Here we define basic entities to be found in such a system, in which information in the form of **digital objects** is stored, accessed, disseminated and managed. We provide naming conventions for identifying and locating digital objects, describe a service for using object names to locate and disseminate objects, and provide elements of an access protocol.

We use the term **digital object** here in a technical sense, to be defined precisely below. Files, databases and so forth that one may ordinarily think of as objects with a digital existence are not digital objects in the sense used here, at least not until they are made into an appropriate data structure, etc., as we will describe shortly.

Only the most basic elements of the infrastructure are described herein. These elements are intended to constitute a minimal set of requirements and services that must be in place to effect the infrastructure of a universal, open, wide-area digital information infrastructure system ("the System"). We anticipate that many other services and elaborations will come into existence as the System is further developed, either building upon or otherwise added to these elements.


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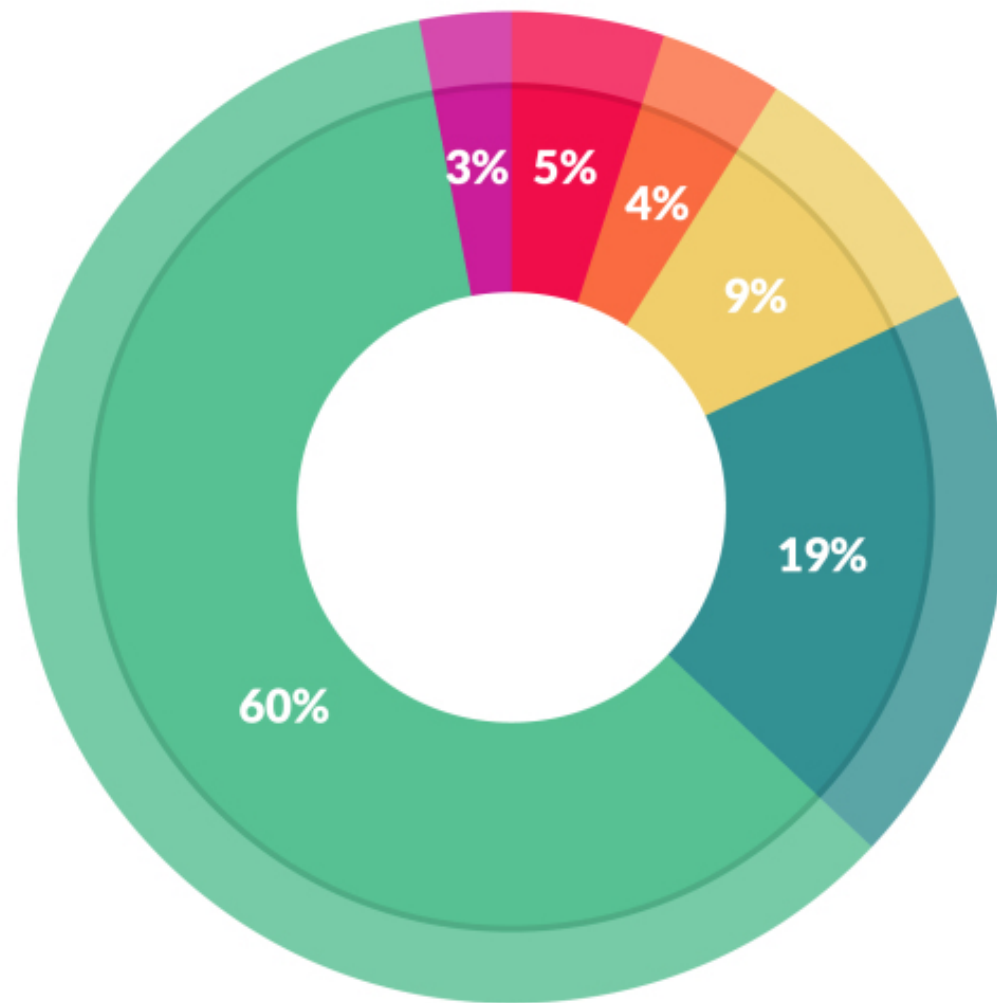
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2016 Costs of Data Inefficiencies



What data scientists spend the most time doing

- Building training sets: 3%
- Cleaning and organizing data: 60%
- Collecting data sets; 19%
- Mining data for patterns: 9%
- Refining algorithms: 4%
- Other: 5%

79% of data scientists time spent doing data preparation.

- **4 days per week is for data preparation.**
- **1 day per week is for science.**

2014

Lorentz
center

Jointly Designing a Data FAIRPORT

Workshop: 13 - 16 January 2014, Leiden, the Netherlands

Scientific Organizers

- Scott Lusher, NLeSC Amsterdam
- Barend Mons, Leiden UMC

Topics

- Towards a Modular Blueprint
'Floor-plan' of a Safe and Fair Data
Stewardship, Trading and Routing
Environment
- A Public Private Partnership to
Ensure Long Term Solutions for
Data in the eScience Era.

The Lorentz Center is an international center in the sciences. Its aim is to organize workshops for scientists in an atmosphere that fosters collaborative work, discussions and interactions. For registration see: www.lorentzcenter.nl

Image: Structure Plan Schiphol Airport by
KCAP Architects/Planners.
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2016

nature > scientific data > comment > article



SCIENTIFIC DATA

Comment | **OPEN** | Published: 15 March 2016

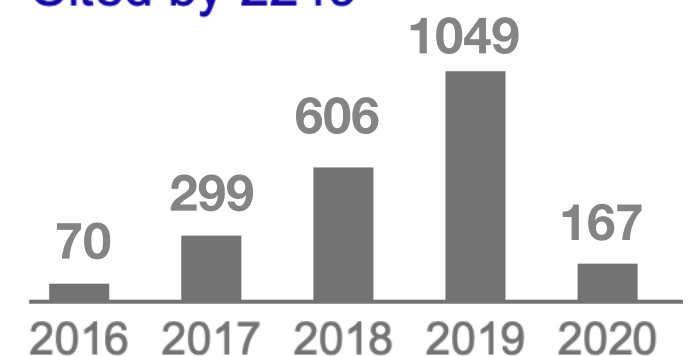
The FAIR Guiding Principles for scientific data management and stewardship

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Data and services that are **findable**, **accessible**, **interoperable**, **re-usable** both for **machines** and for people.

2016

nature > scientific data > comment > article



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To be Interoperable:

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To be Reusable:

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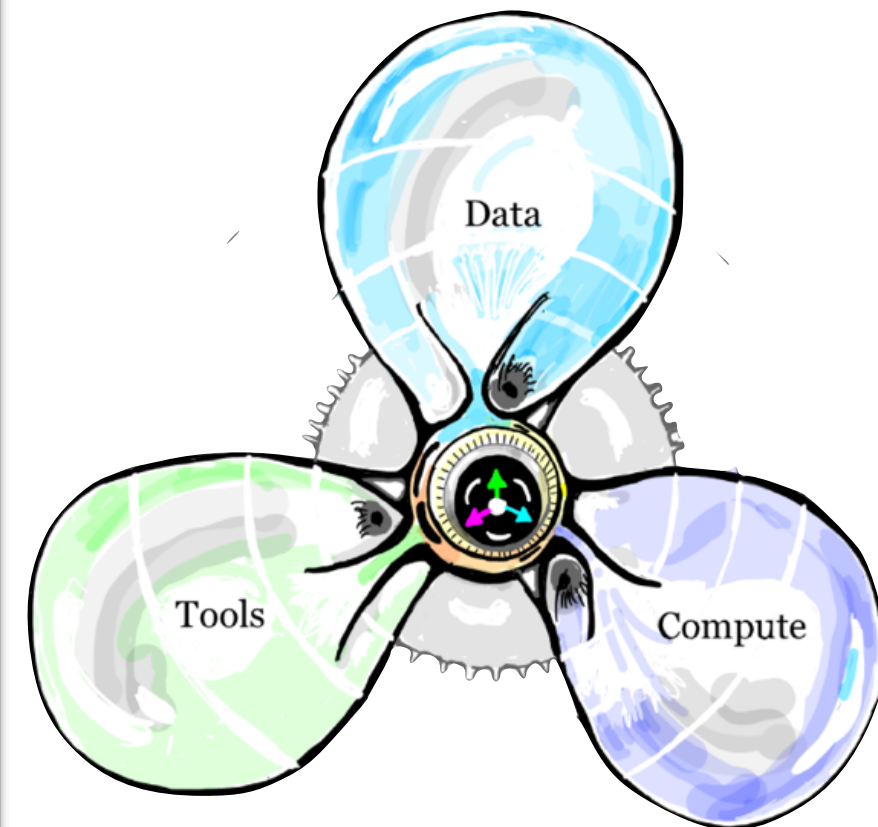
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Internet of FAIR Data & Services

2016

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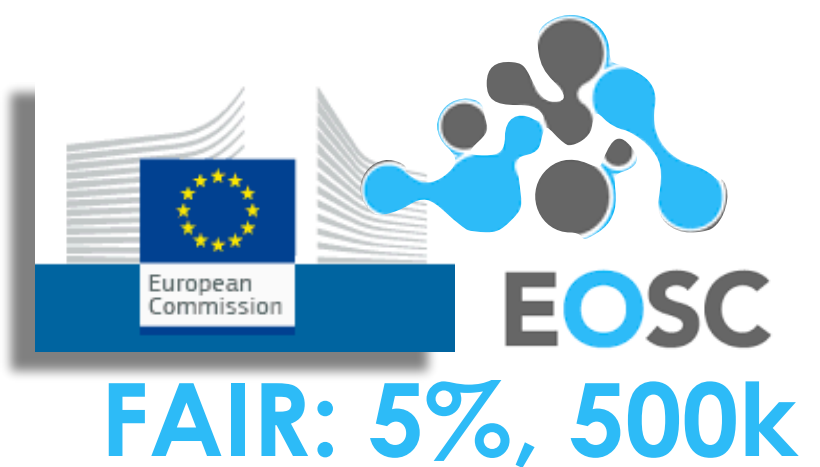
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Automating F, A, I, and R

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M4M #2: Preclinical Trials + M4M #3: Funders

Jan 14 2019



Making it easy for humans to make metadata for machines

Following the [Inaugural M4M Workshop](#) (October 15-16 2018, Leiden), members from GO FAIR and RDA are supporting back-2-back M4M Workshops to create machine-actionable metadata for the Preclinical Trials Research Community (#2) and for Scientific Funders (#3). Participants include: members from the Preclinical Trails and Funders communities and metadata experts from the Centre for Extended Data and Annotation and Retrieval.


At 12.00 there will be a social lunch hosted by GFISCO

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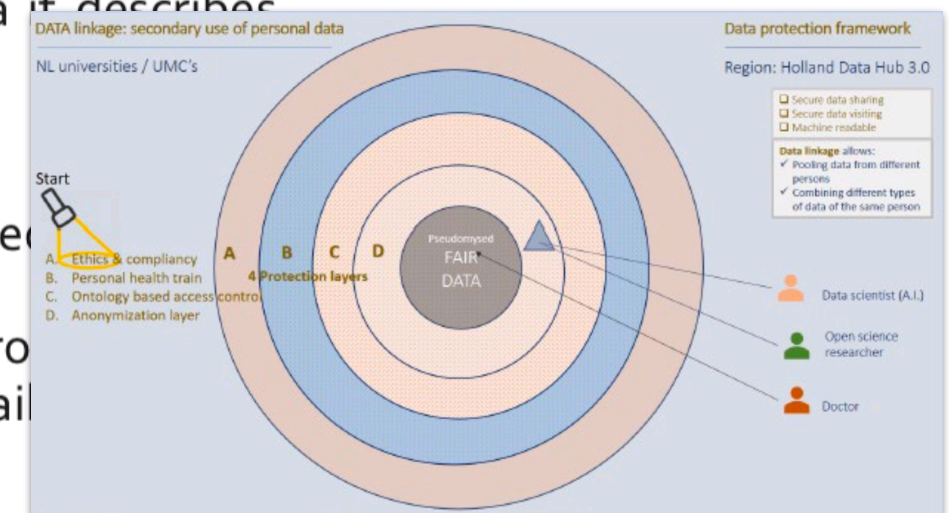
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2017 What FAIR is not...

FAIR is **not** a standard

FAIR is **not** only semantic web / LOD

FAIR is **not** equal to 'Open' or 'Free'

*Data are often Open (Access) but **not** FAIR*

*Some data can **never** be Open, yet be perfectly FAIR*

By design, FAIR is **not explicit about data quality, trustworthiness, responsibility, ethics, etc.**



Technical infrastructure (generic operations)

Data (domain-specific content)

Box 2 | The FAIR Guiding Principles

To be Findable:

- F1. (meta)data are assigned a globally unique and persistent identifier
- F2. data are described with rich metadata (defined by R1 below)
- F3. metadata clearly and explicitly include the identifier of the data it describes
- F4. (meta)data are registered or indexed in a searchable resource

To be Accessible:

- A1. (meta)data are retrievable by their identifier using a standardized communications protocol
 - A1.1 the protocol is open, free, and universally implementable
 - A1.2 the protocol allows for an authentication and authorization procedure, where necessary
- A2. metadata are accessible, even when the data are no longer available

To be Interoperable:

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.
- I2. (meta)data use vocabularies that follow FAIR principles
- I3. (meta)data include qualified references to other (meta)data

To be Reusable:

- R1. meta(data) are richly described with a plurality of accurate and relevant attributes
 - R1.1. (meta)data are released with a clear and accessible data usage license
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Technical infrastructure (generic operations) Data (domain-specific content)

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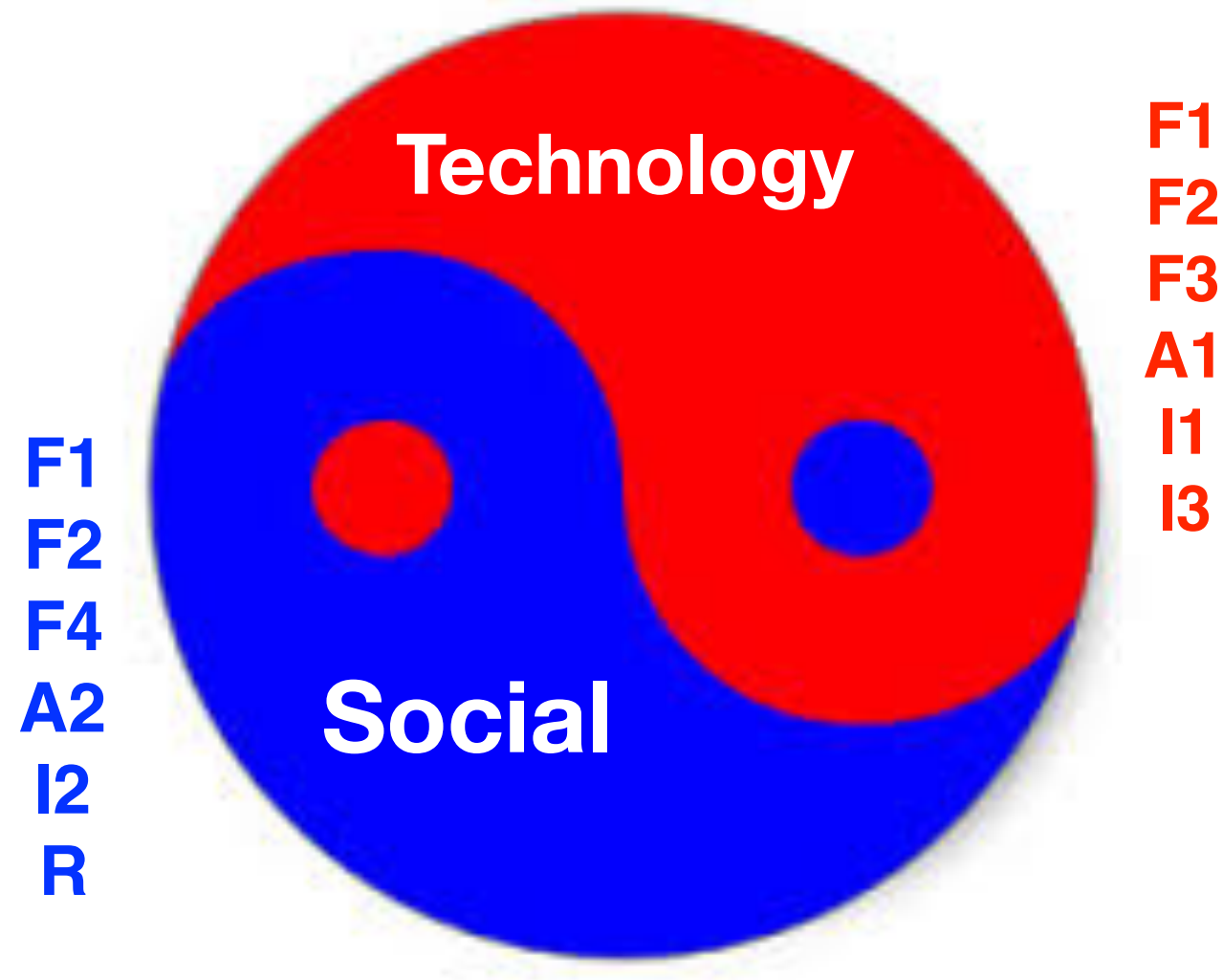
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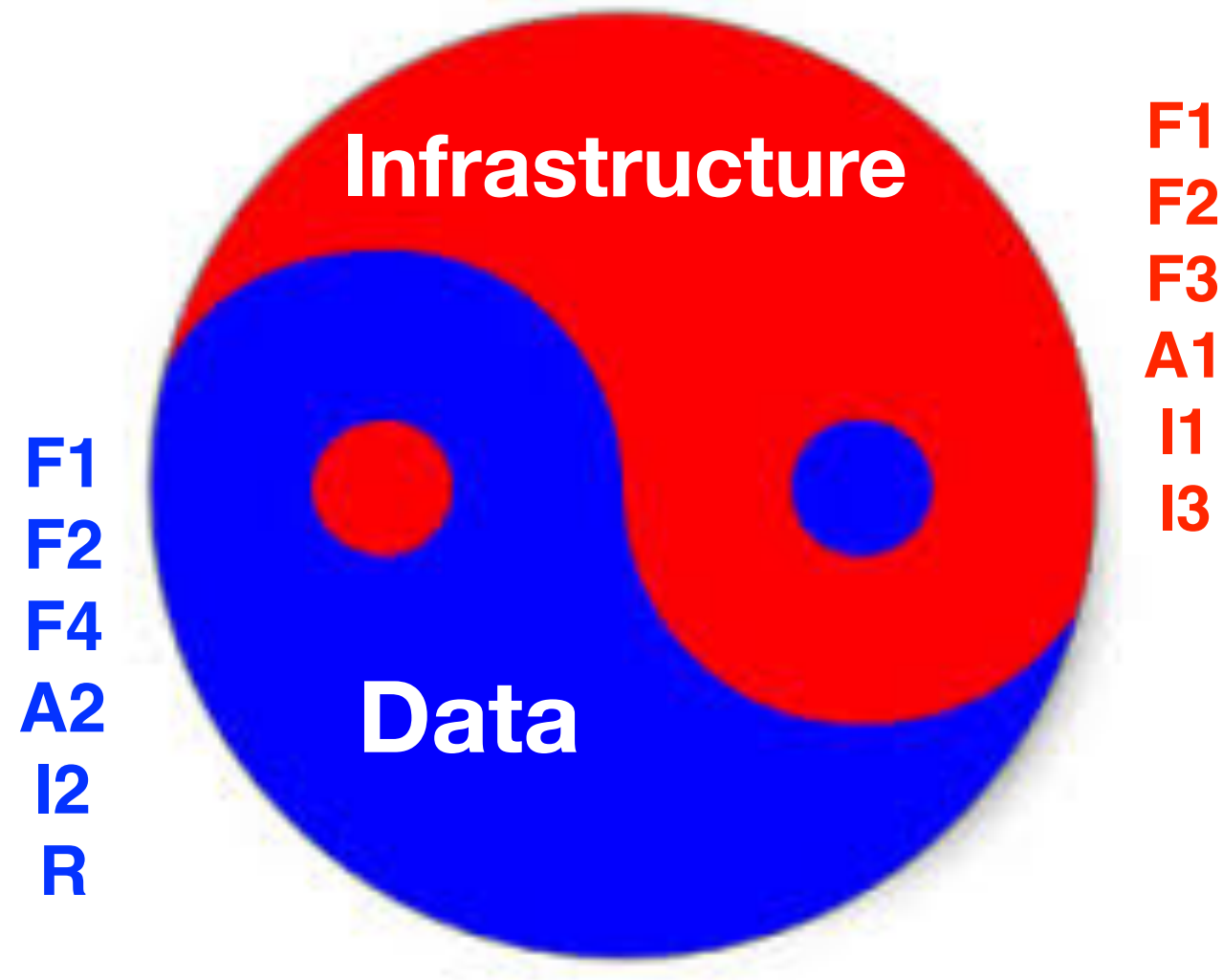
There are no fundamental technology barriers to FAIR



The hard problems are social

- **Community Agreements**
- **Choices**

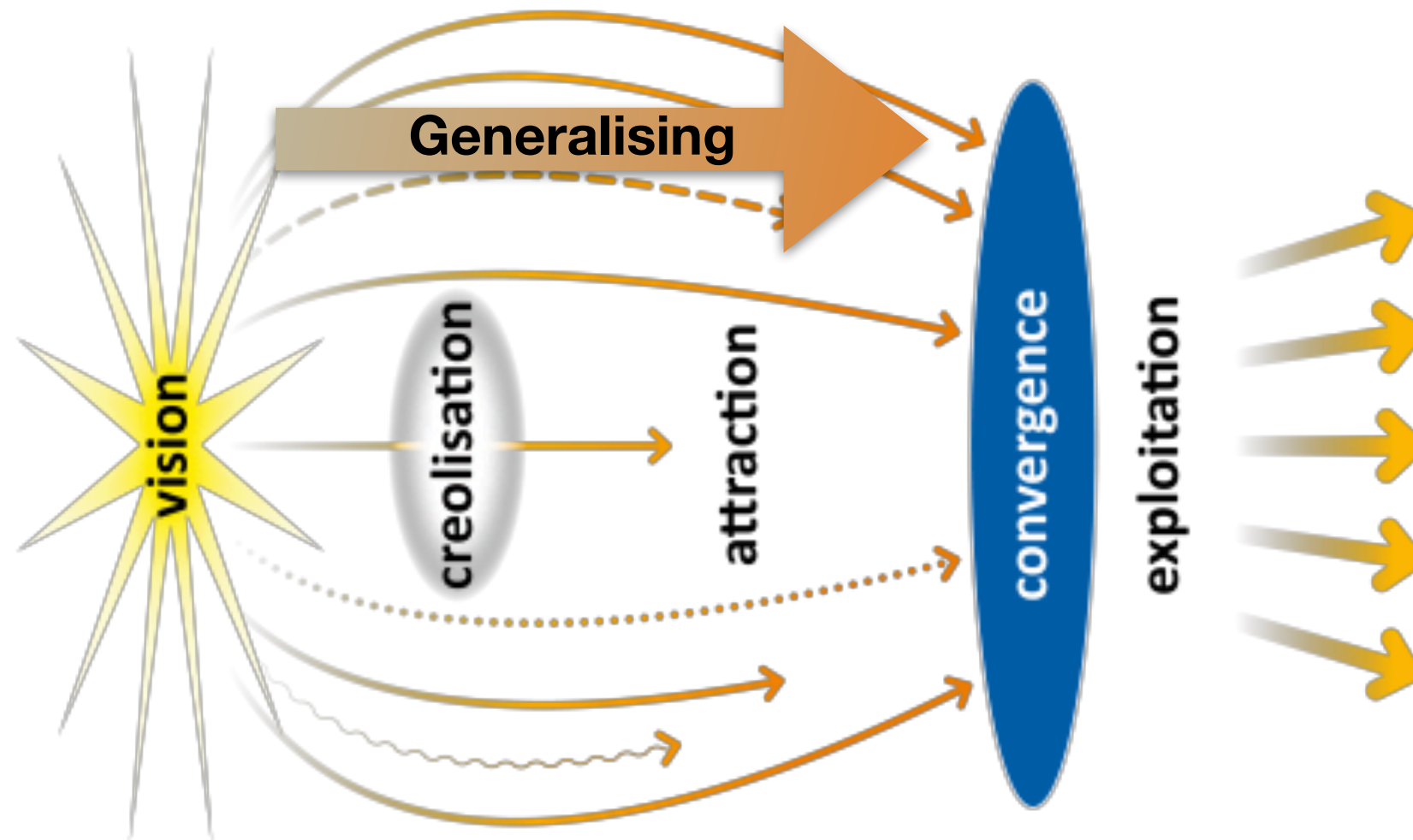
There are no fundamental technology barriers to FAIR



The hard problems are social

- **Community Agreements**
- **Choices**

Convergence



Common Patterns in Revolutionary Infrastructures and Data

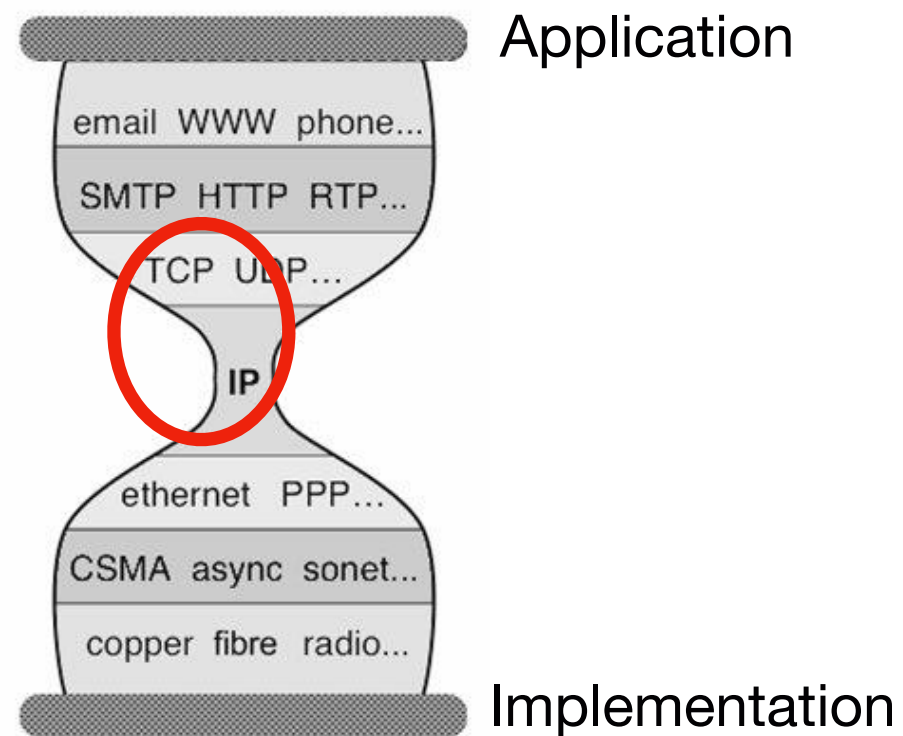
Peter Wittenburg, Max Planck Computing and Data Facility

George Strawn, US National Academy of Sciences

February 2018

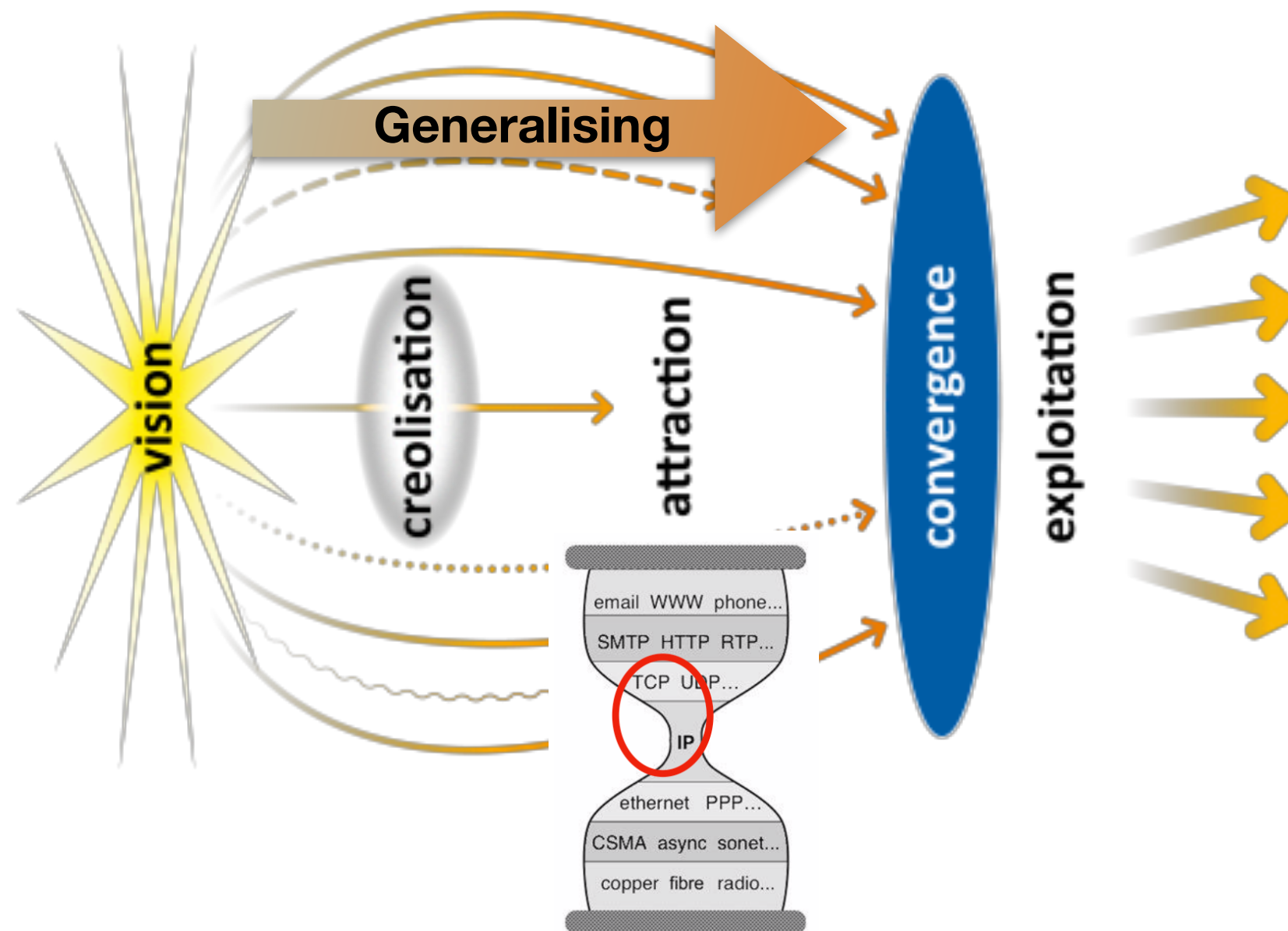
https://www.rd-alliance.org/sites/default/files/Common_Patterns_in_Revolutionising_Infrastructures-final.pdf

Convergence: Internet

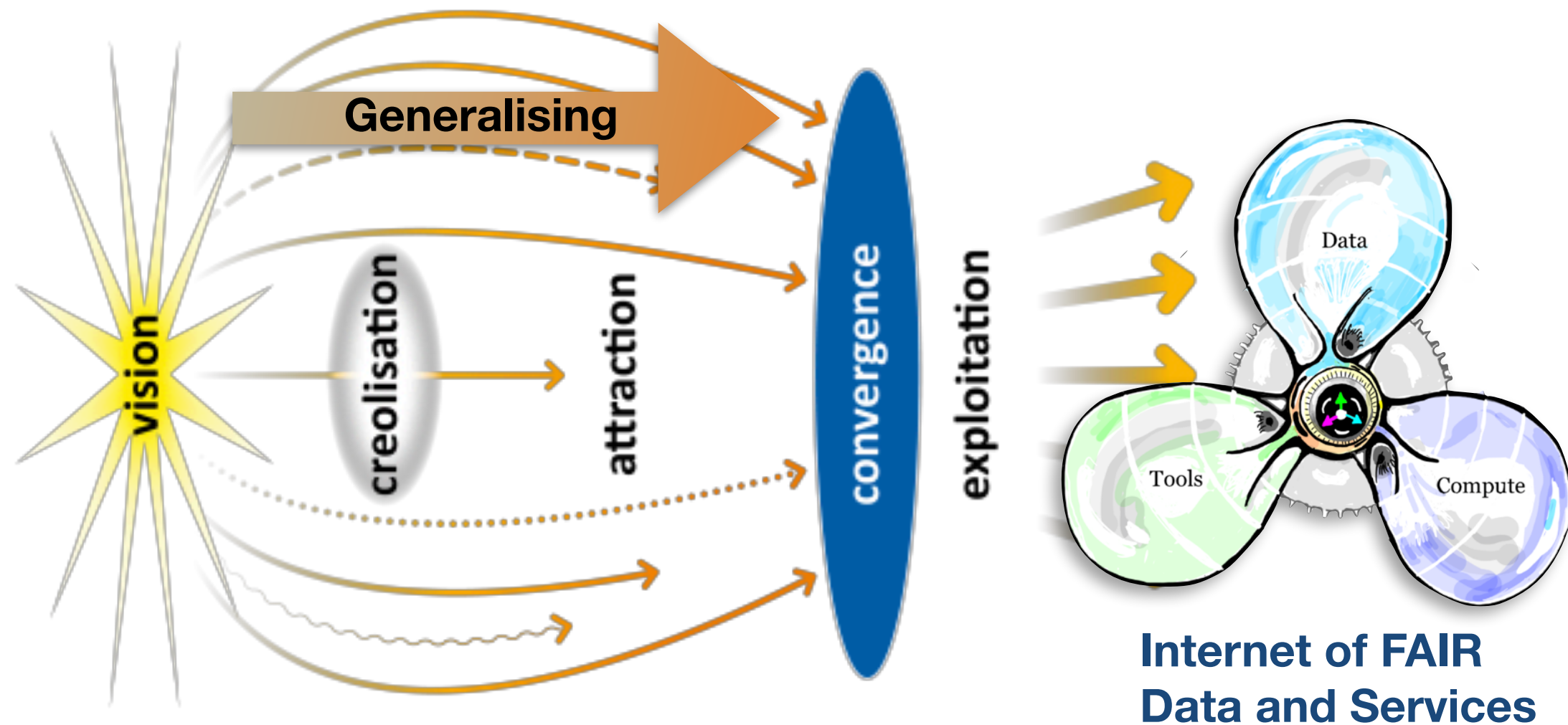


- Rough consensus, running code
- Minimal standard + Freedom to operate
- Voluntary participation
- Critical mass of users

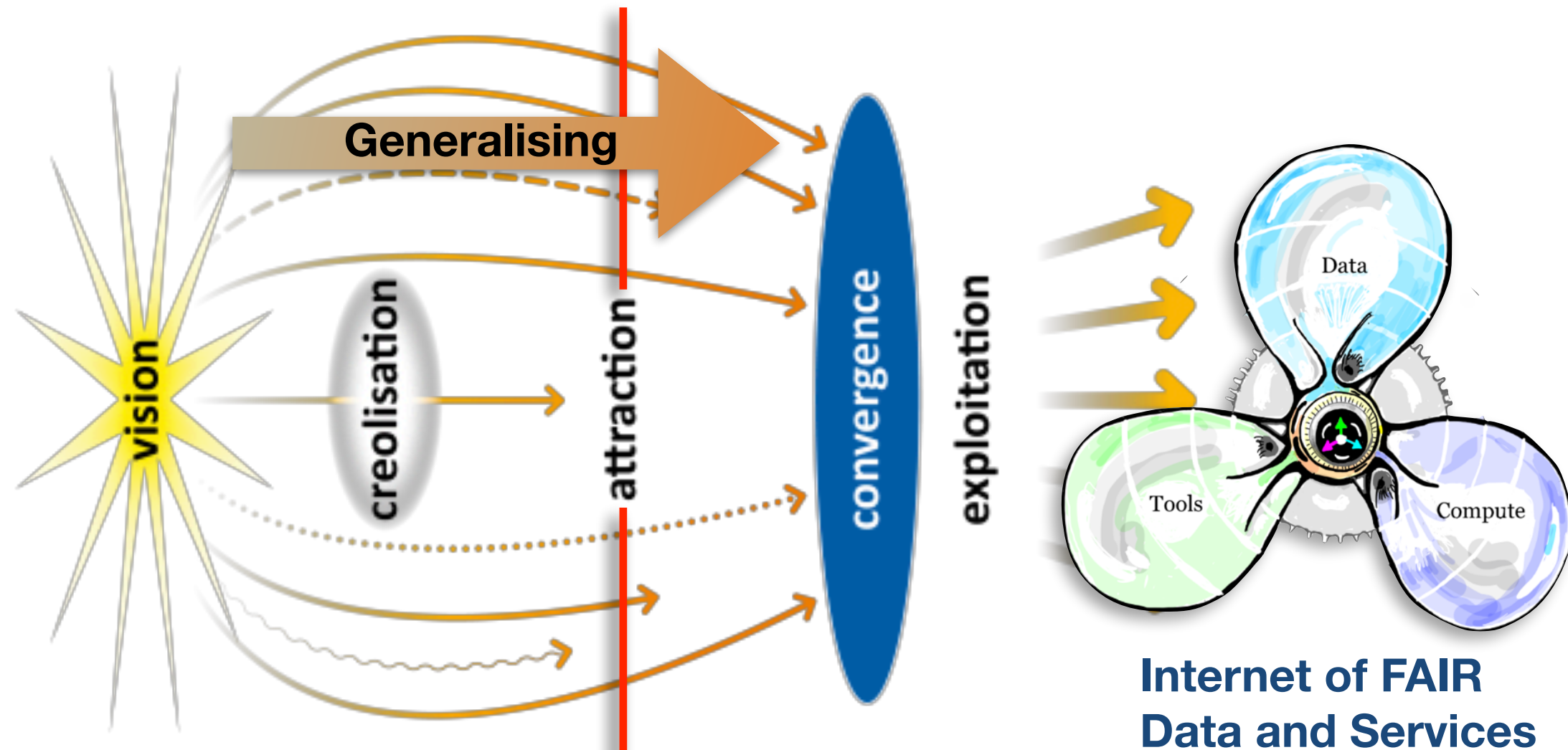
Convergence: Internet



Convergence: Dataneet



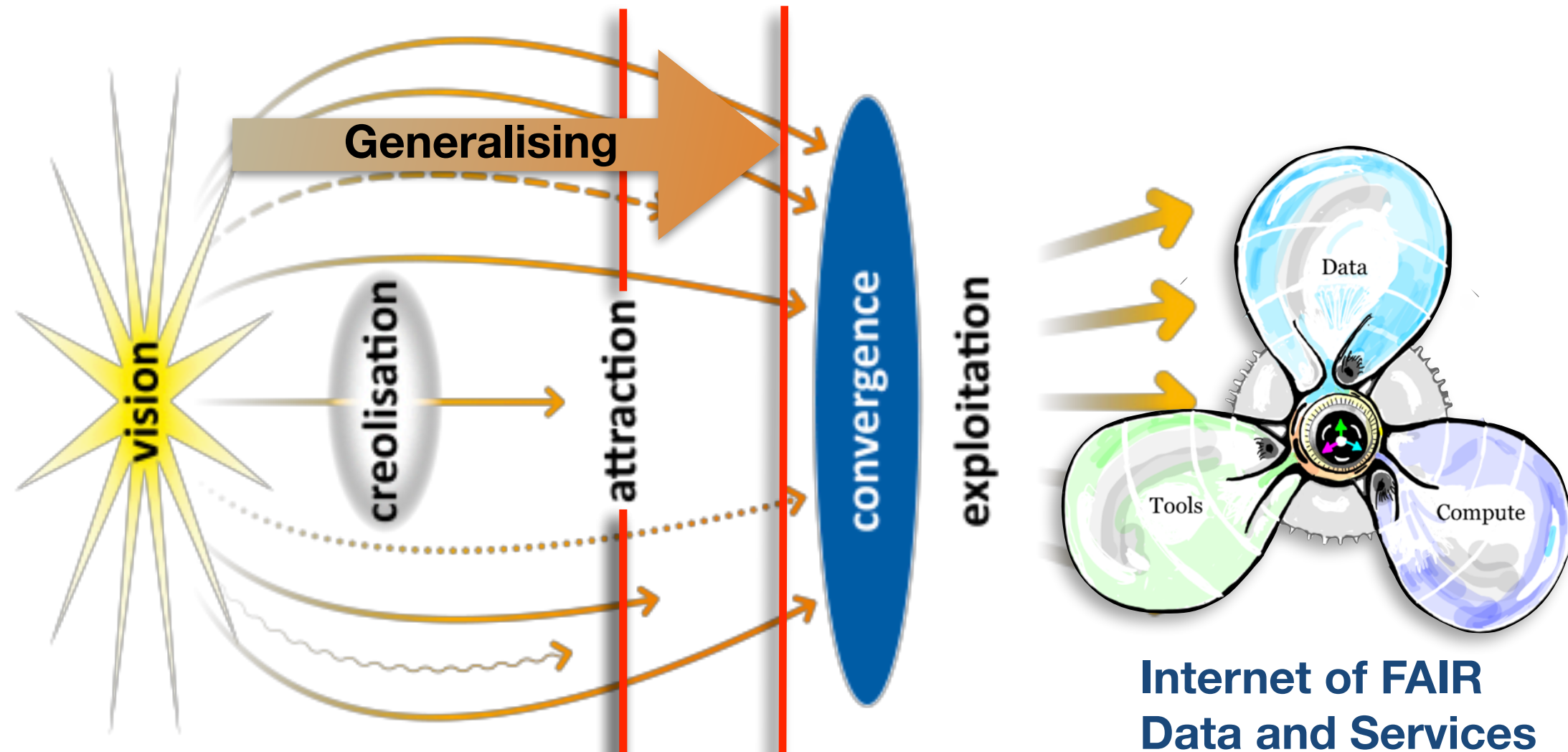
Convergence: Dataneet



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2014

Convergence: Dataneet

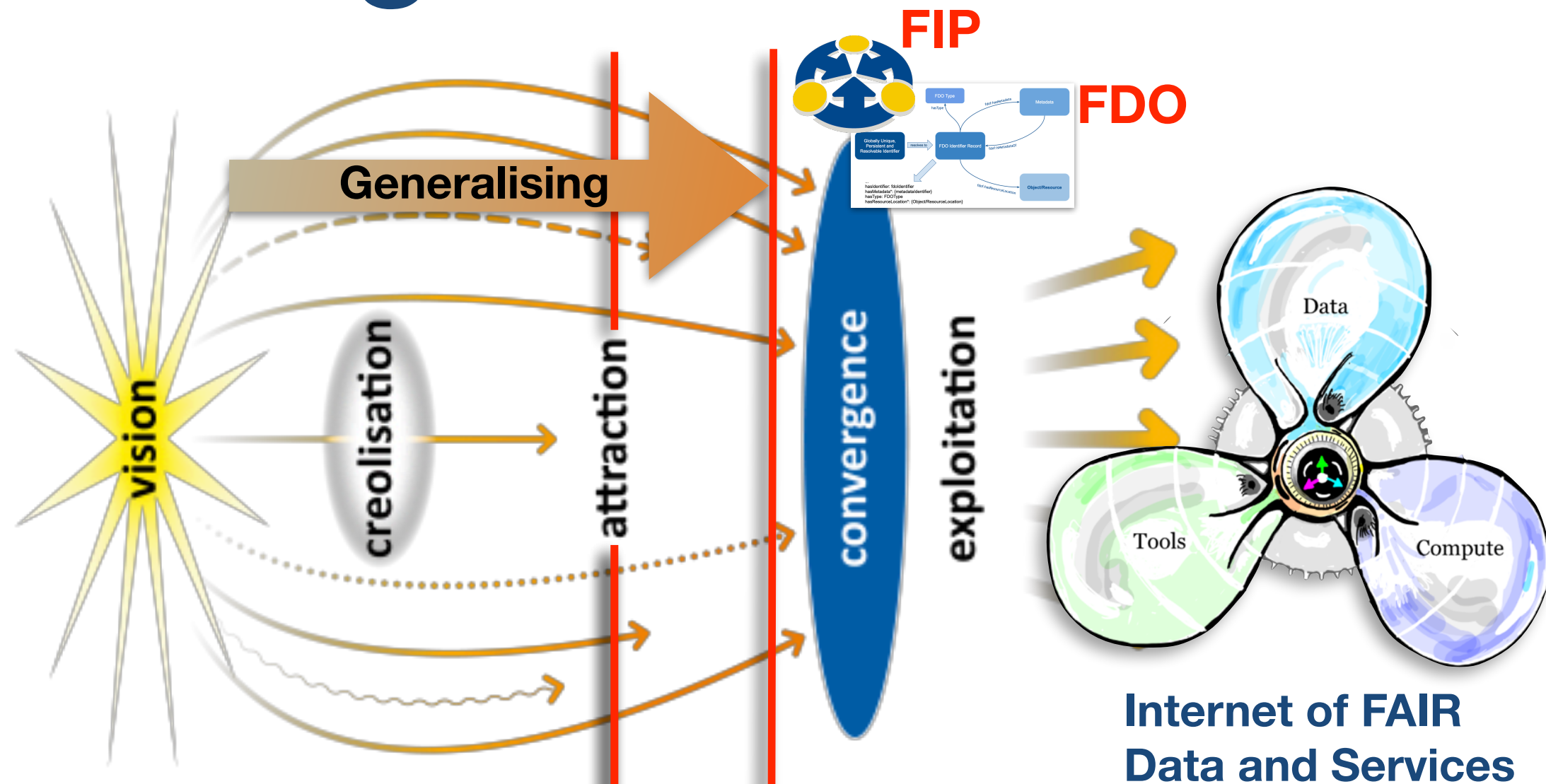


Box 2 The FAIR Guiding Principles	
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2014 2018

Convergence: Dataneet



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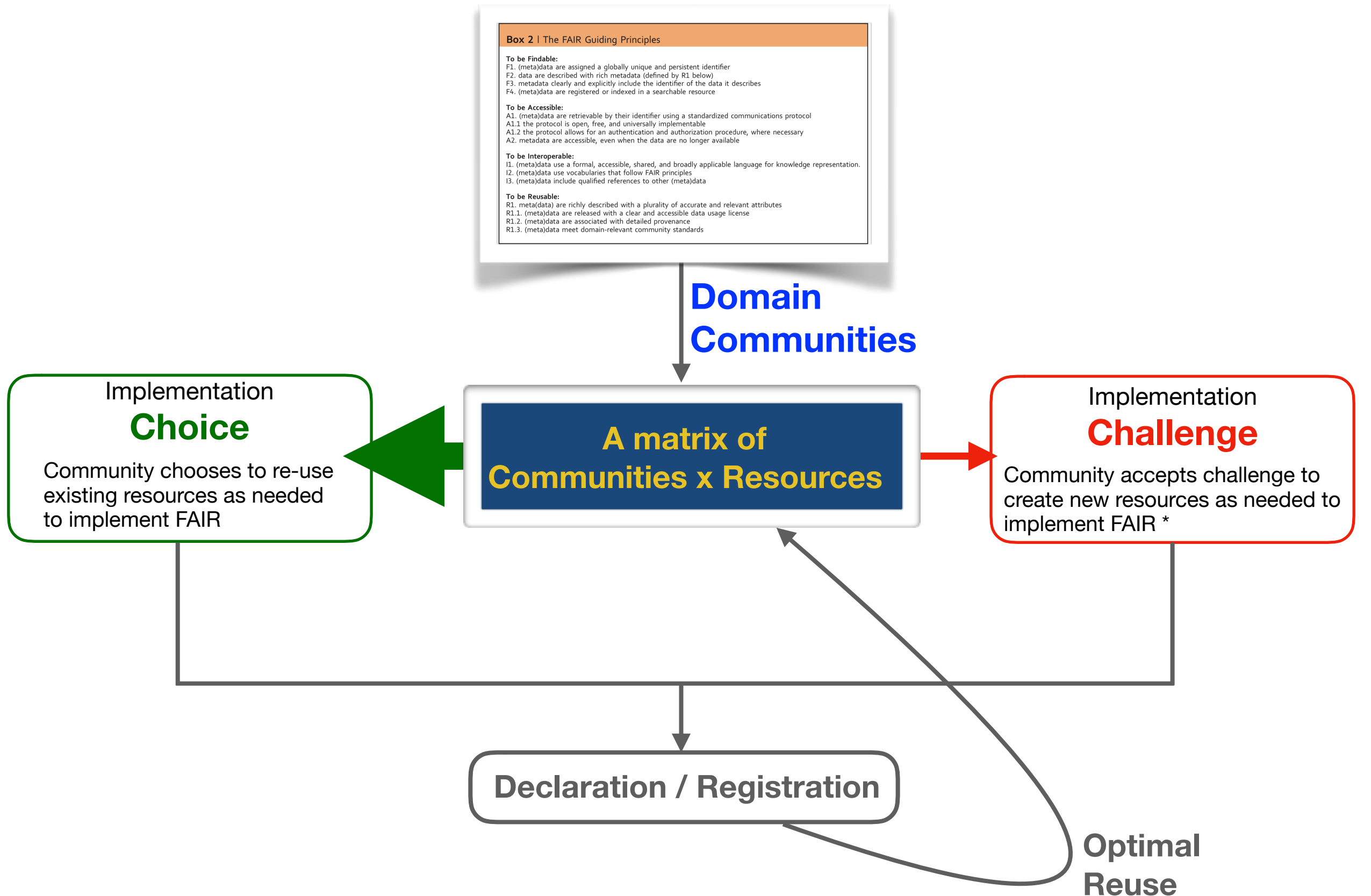


2014 2018

FAIR Convergence Matrix & FIP

<https://www.go-fair.org/today/FAIR-matrix/>

Coordinating decisions to optimize FAIR Implementation



** every “choice” was once a “challenge”*

SUBJECT	PREDICATE	OBJECT
name of IN (UPRI)	has-coordinator	ORCID
name of IN (UPRI)	has-participant	ORCID
name of IN (UPRI)	has-member-organisation	VIVO / CrossRef
name of IN (UPRI)	uses-repository	CTS?
name of IN (UPRI)	uses-registry-service	PW ?
name of IN (UPRI)	provides-registry-service	
name of IN (UPRI)	uses-data-format	format-PID
name of IN (UPRI)	provides-data-format	format-PID
name of IN (UPRI)	provides-access-protocol	format-PID
name of IN (UPRI)	uses-access-protocol	protocol-PID
name of IN (UPRI)	has-persistence-policy	policy
name of IN (UPRI)	is found by	Search engine
name of IN (UPRI)	uses-term-system	Term System-PID
name of IN (UPRI)	provides-term-system	Term System-PID
name of IN (UPRI)	uses-license	MR-license ID
name of IN (UPRI)	uses-metadata-format	format-PID
name of IN (UPRI)	provides-meta-data-format	Format-PID
name of IN (UPRI)	provides-training-material	Resource-ID
name of IN (UPRI)	uses-uses-training-material	Resource-ID
name of IN (UPRI)	provides-DS-tools	Resource-ID
name of IN (UPRI)	uses-DS-tools	Resource-ID
name of IN (UPRI)	uses-workspace-tool	Resource-ID
name of IN (UPRI)	Provides-workspace-tool	Resource-ID

F1
F1
F2
F2
A1
A1
F1 / A2
F4
I
I
R1.1
R1.2
R1.2

InChIKey
canonical SMILES
InChI
PubChem CID
ChemSpider ID
isomeric SMILES
ChEBI ID
CAS Registry Number
UNII
ChEMBL ID
DSSTOX substance identifier
EC ID
Beilstein Registry Number
KEGG ID
ECHA InfoCard ID
Drugbank ID
Guide to Pharmacology Ligand ID
HMDB ID

Survey https://docs.google.com/forms/d/1Oug6GowuG1jNZNsJkIXOeEvPbUrhyuS_F-d185SOy6A/edit

Matrix <https://docs.google.com/spreadsheets/d/1MUZn7uh4x5YLPjqxi-V8XubsSEEnQWvx2jBlcyyNdU/edit#gid=0>



IN Profile Matrix



File Edit View Insert Format Data Tools Add-ons Help All changes saved in Drive



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fx

FAIR Implementation Matrix

On the OSF <https://osf.io/n7uwp/>

Red indicates waist of hourglass

Blue is an Implementation Choice

Orange is Implementation Challenge

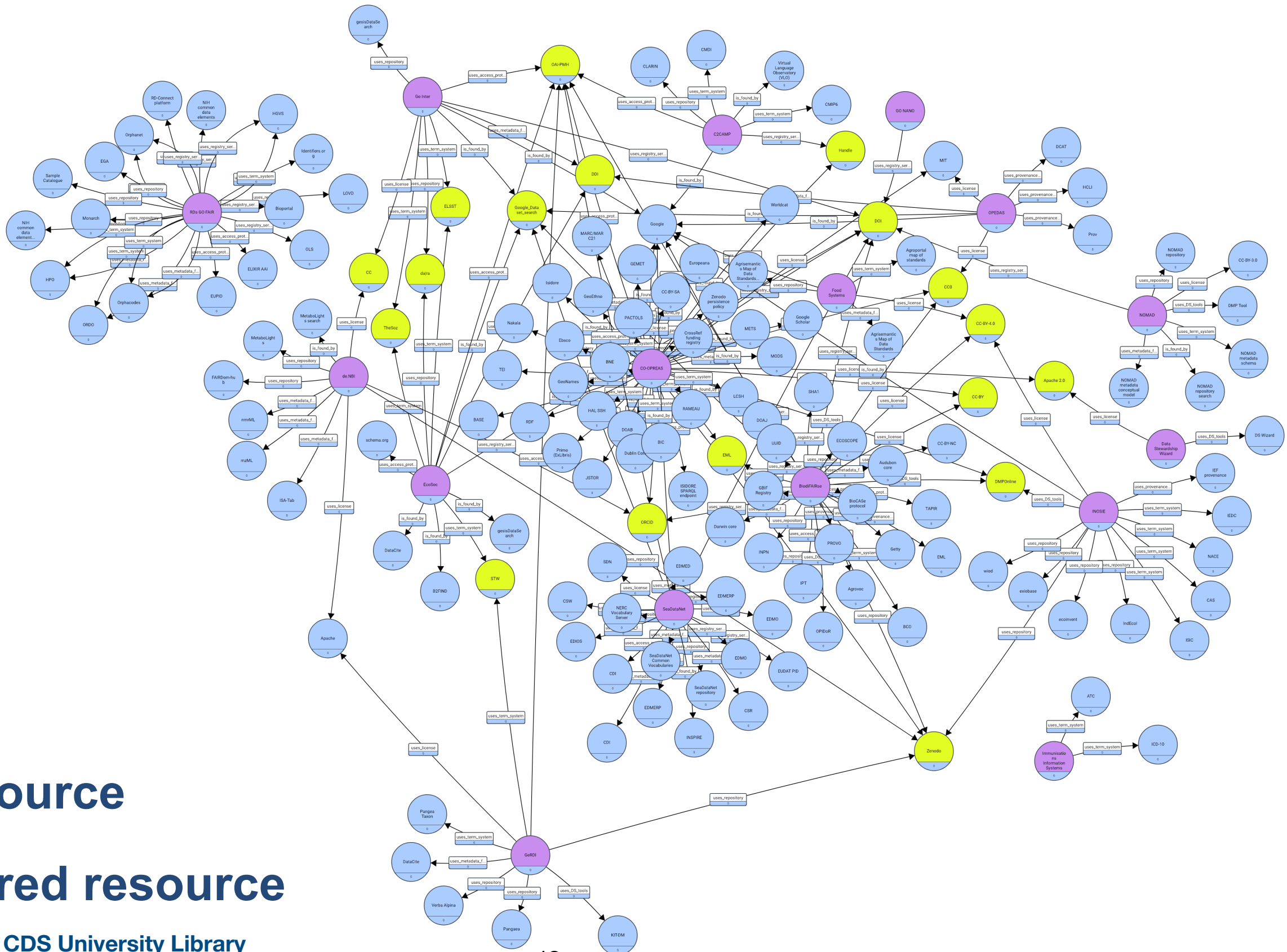
Green highlight indicates a service provided by the IN or spin-off

Blank cell is not relevant for IN

FAIR Principle	Services	Component	Most used	C2CAMP	OPEDAS	PHT	Rare-Diseases	GERI
	central to all	DOIP	DOIP	DOIP	DOIP	DOIP	DOIP	
	central to all	Metadata format	RDF		RDF	RDF	RDF	
	central to all	Metadata access protocol			LDP/FDP	LDP/FDP	LDP/FDP	
	central to all	Metadata core elements	TBD on M4M		TBD on M4M	TBD on M4M	TBD on M4M	
	Technology	Data Format			RDF for interop.	RDF for interop.	RDF for interop.	
	Technology	Data Access Protocols (MR/A)			LDP/FDP	PHT-standard	PHT-standard	
	Technology	Computer-actionable license description language			RDF	RDF	RDF	
	Tooling	Repository (Data/Metadata)		DONA	IFDS Data Station	IFDS Data Station	ERN?	GERI
	Tooling(Repository)	https://www.dataone.org						
	Tooling	Registry Service		DONA	IFDS Station Registry	IFDS Station Registry	ERN?	
	tooling	Metadata forms/creators			CEDAR/CASTOR			
	Tooling	Search capability		DOIP	IFDS Station Registry	IFDS Station Registry	IFDS Station Registry	
	Policy	Persistence Policy			TBD	TBD	TBD	
	Technology	Computer-actionable policy description language			RDF	RDF	RDF	
	Tooling	License protocols			TBD	TBD	TBD	
	Tooling	Training Materials			Training-IN	Training-IN	EJP	

Community FAIR Implementation Choices & Challenges

<https://osf.io/4v9pm/>



INs

Resource



Shared resource

Kristina Hettne, CDS University Library

Matrix Development

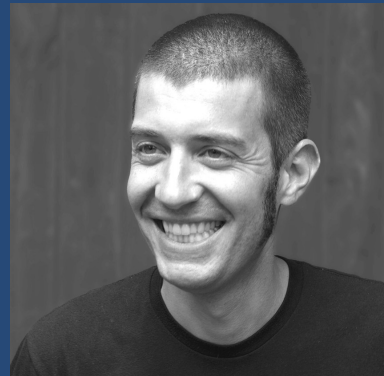
June 13 2019



Kristina Hettne



Peter Wittenburg



Tobias Kuhn



Robert Pergl



Pete McQuilton



Universiteit
Leiden



RESEARCH DATA ALLIANCE



MAX-PLANCK-GESELLSCHAFT



nanopublication

assertion

provenance

publication info



CZECH
TECHNICAL
UNIVERSITY
IN
PRAGUE



UNIVERSITY OF
OXFORD



DATA STEWARDSHIP WIZARD

FAIRsharing.org
standards, databases, policies



Barbara Magagna

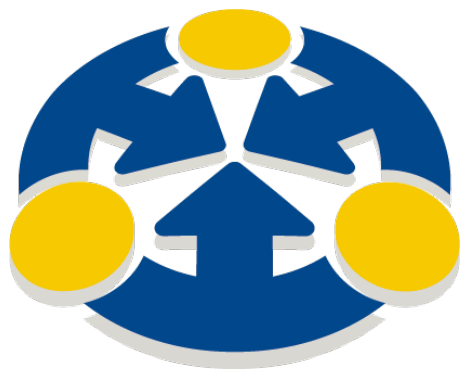
ENVRI-FAIR KICK OFF MEETING

Hotel International Prague, Czech republic

January 14-16, 2019

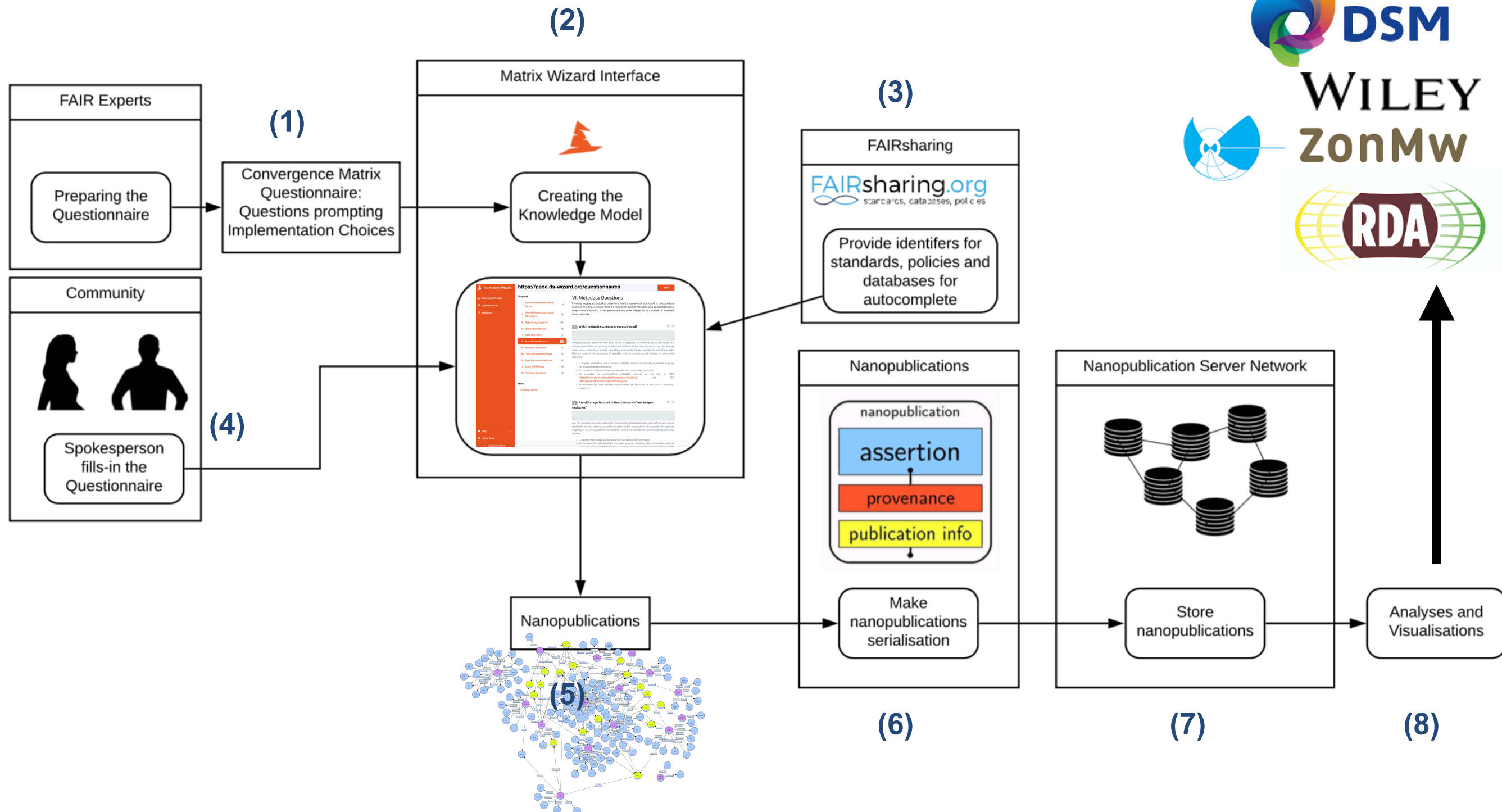
Register at www.envri.eu

umweltbundesamt
ENVIRONMENT AGENCY AUSTRIA



FAIR Convergence Matrix

Trusted 3rd party endorsement
of FAIR best practices

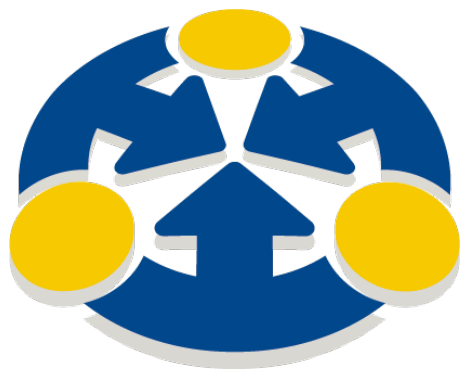




FAIR Convergence Matrix

FAIR Implementation Profiles

		Communities									
		A	B	C	D	E	F	G	H	I	J
Resources	F	Resource 1	0	1	0	0	0	0	0	0	0
		Resource 2	1	1	1	0	1	1	1	1	0
	A	Resource 3	1	1	0	0	0	0	0	1	0
		Resource 4	0	0	1	1	1	1	1	1	1
	I	Resource 5	1	0	0	0	0	0	0	1	0
		Resource 6	0	1	1	0	1	1	1	1	0
	R	Resource 7	1	0	0	0	0	0	0	0	0
		Resource 8	1	0	1	0	1	1	1	1	0



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		A	B	C	D	E	F	G	H	I	J
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	A	Resource 3	1	1	0	0	0	0	0	1	0
		Resource 4	0	0	1	1	1	1	1	1	1
	I	Resource 5	1	0	0	0	0	0	0	1	0
		Resource 6	0	1	1	0	1	1	1	1	0
	R	Resource 7	1	0	0	0	0	0	0	0	0
		Resource 8	1	0	1	0	1	1	1	1	0



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Resources	F Resource 1	0	1	0	0	0	0	0	0	0	0
	Resource 2	1	1	1	0	1	1	1	1	1	0
	A Resource 3	1	1	0	0	0	0	0	0	1	0
	Resource 4	0	0	1	1	1	1	1	1	1	1
	Resource 5	1	0	0	0	0	0	0	0	1	0
	I Resource 6	0	1	1	0	1	1	1	1	1	0
	R Resource 7	1	0	0	0	0	0	0	0	0	0
	Resource 8	1	0	1	0	1	1	1	1	1	0

FAIR Implementation Profile for Community C = {0,1,0,1,0,1,0,1}



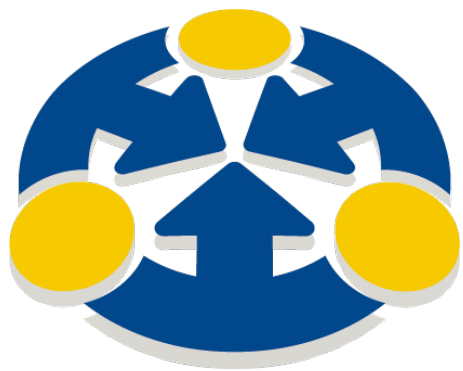
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	Resource 2	1	1	1	0	1	1	1	1	1	0
	A Resource 3	1	1	0	0	0	0	0	0	1	0
	Resource 4	0	0	1	1	1	1	1	1	1	1
	I Resource 5	1	0	0	0	0	0	0	0	1	0
	Resource 6	0	1	1	0	1	1	1	1	1	0
	R Resource 7	1	0	0	0	0	0	0	0	0	0
	Resource 8	1	0	1	0	1	1	1	1	1	0

FAIR Implementation Profile for Community C = {0,1,0,1,0,1,0,1}

Community E, F, G, H, and I have reused the FIP of Community C



FAIR Convergence Matrix

FAIR Implementation Profiles

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FAIR Implementation Profile for Community C = {0,1,0,1,0,1,0,1}

Community E, F, G, H, and I have reused the FIP of Community C

Community I has made two modifications of Community C



FAIR Convergence Matrix

FAIR Implementation Profiles

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		A	B	C	D	E	F	G	H	I	J
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	Resource 4	0	0	1	1	1	1	1	1	1	1
	I Resource 5	1	0	0	0	0	0	0	0	1	0
	Resource 6	0	1	1	0	1	1	1	1	1	0
	R Resource 7	1	0	0	0	0	0	0	0	0	0
	Resource 8	1	0	1	0	1	1	1	1	1	0

FAIR Implementation Profile for Community C = {0,1,0,1,0,1,0,1}

Community E, F, G, H, and I have reused the FIP of Community C

Community I has made two modifications of Community C

Community J reused the FIP of Community D

What are the relevant domain standards for *your community*?

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What are the relevant domain standards for *your community*? Especially for metadata?

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FAIR Convergence Matrix: Optimizing the Reuse of Existing FAIR-Related Resources



Hana Pergl Sustkova , Kristina Maria Hettne, Peter Wittenburg, Annika Jacobsen, Tobias Kuhn, Robert Pergl, Jan Slifka, Peter McQuilton, Barbara Magagna, Susanna-Assunta Sansone, Markus Stocker, Melanie Imming, Larry Lannom, Mark Musen, Erik Schultes hidden

DOI: [10.1162/dint_a_00038](https://doi.org/10.1162/dint_a_00038)

439 | 43 | 0

Abstract & Keywords

Abstract: The FAIR Principles and Reusable by machines consider actual implementation preferences approach remains a global challenge the GO FAIR community has any community of practice, Matrix is itself a FAIR resource practice (not only the GO Convergence Matrix support technologies in the emerging

Keywords: FAIR Implementation

Acknowledgments

References

Reusable FAIR Implementation Profiles as Accelerators of FAIR Convergence

Erik Schultes

GO FAIR International Support and Coordination Office, Leiden, The Netherlands

[ORCID 0000-0001-8888-635X](https://orcid.org/0000-0001-8888-635X)

Version 2.0 DRAFT: DO NOT CIRCULATE

December 11, 2019

On OSF: <https://osf.io/8sv5f/>

Abstract

There are now powerful incentives driving the adoption of FAIR practices among a broad cross section of public and private sector organizations¹. This adoption process requires considerations on both domain-specific and infrastructural resources. Together, these considerations compose a potentially very large number of decisions on the use and reuse of standards and technologies. Many of the relevant factors in these considerations are likely to exceed the knowledge and experience of individual domain specialists and data stewards. For communities adopting FAIR practices, the collection of their implementation choices compose their *FAIR Implementation Profile* (FIP). The FIPs of numerous communities can be systematically acquired from the FAIR Convergence Matrix² and used as the basis to optimize the reuse of existing resources and interoperation within and between domains. Ready-made and well-tested FIPs created by trusted community authorized representatives could find widespread reuse and thus vastly accelerate well informed

FAIR Digital Objects

<https://www.go-fair.org/today/fair-digital-framework>

FAIR Digital Objects

- August - GO FAIR - Leiden
- September - NAS - Washington DC
- September - CODATA - Beijing
- October - RDA GEDE - Helsinki



Moving Forward on Data Infrastructure Technology Convergence

Expert Meeting: 28/29.10.2019.
at the Observatoire of Paris



Goal of the Meeting

The goal of the meeting is to decide on a **Joint Agreement on FAIR Digital Objects** stating the requirements for FAIR Digital Objects and to agree on a governance structure to advance FAIR DO development. The contributions and discussion aim for a constructive approach towards these goals. We welcome by the way all participants to come up with a better label for the declaration, since it should be remembered.

Label Suggestions:

Joint Agreement on FAIR Digital Object Specifications" - people will use "The Paris Agreement"
Paris Agreement on Research Infrastructure Standards Declaration, Giving P.A.R.I.S Declaration

Tentative Agenda

Join the **Paris Declaration** to formulate a common FDO specification:

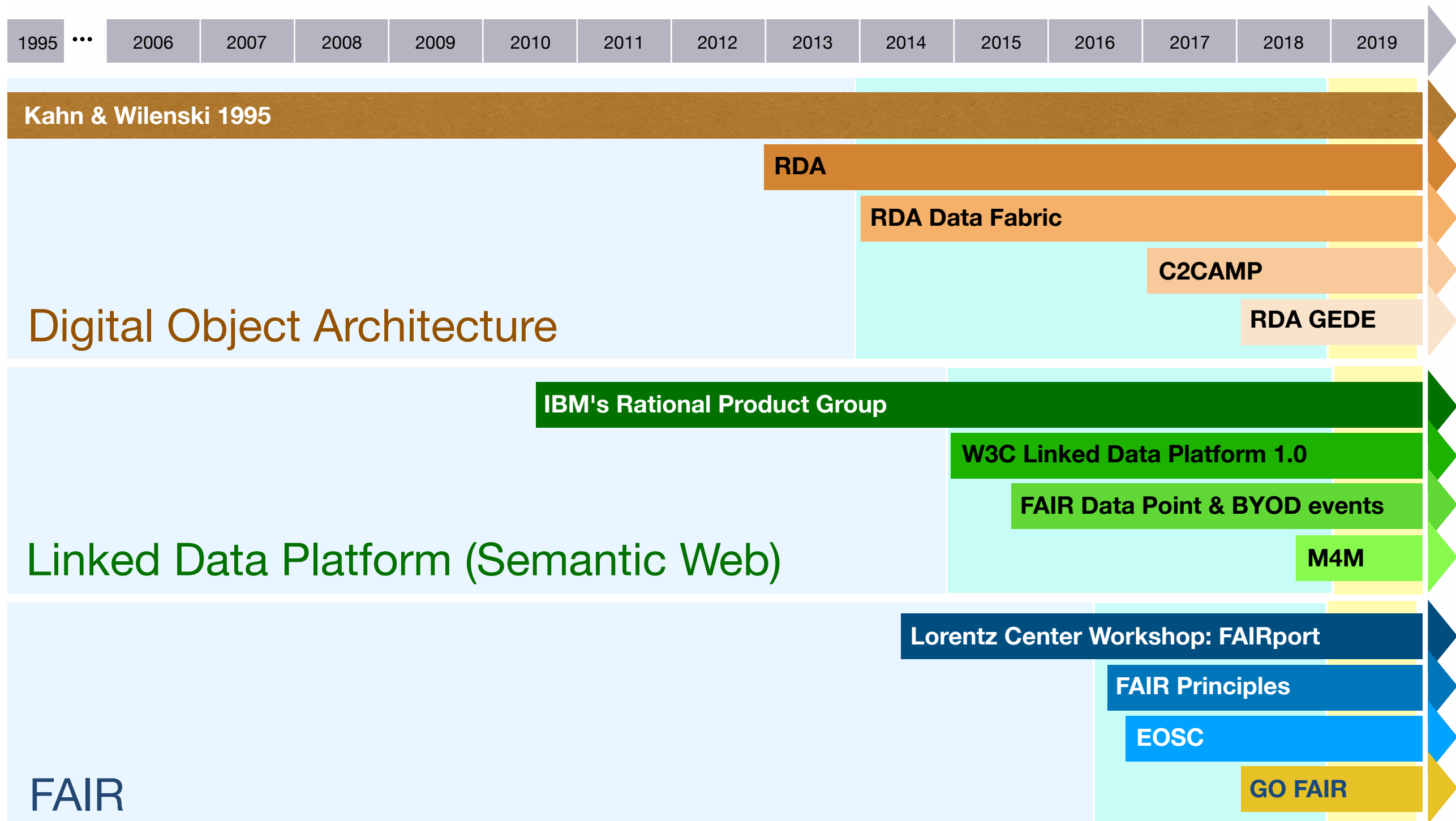
- Have impact on the spec
- Speak with one voice

<https://docs.google.com/document/d/11FmDxgncy-LynQqTlvxFProW-i5II7JBFtp7ELyztlg/edit>

<https://github.com/GEDE-RDA-Europe/GEDE/tree/master/FAIR%20Digital%20Objects>

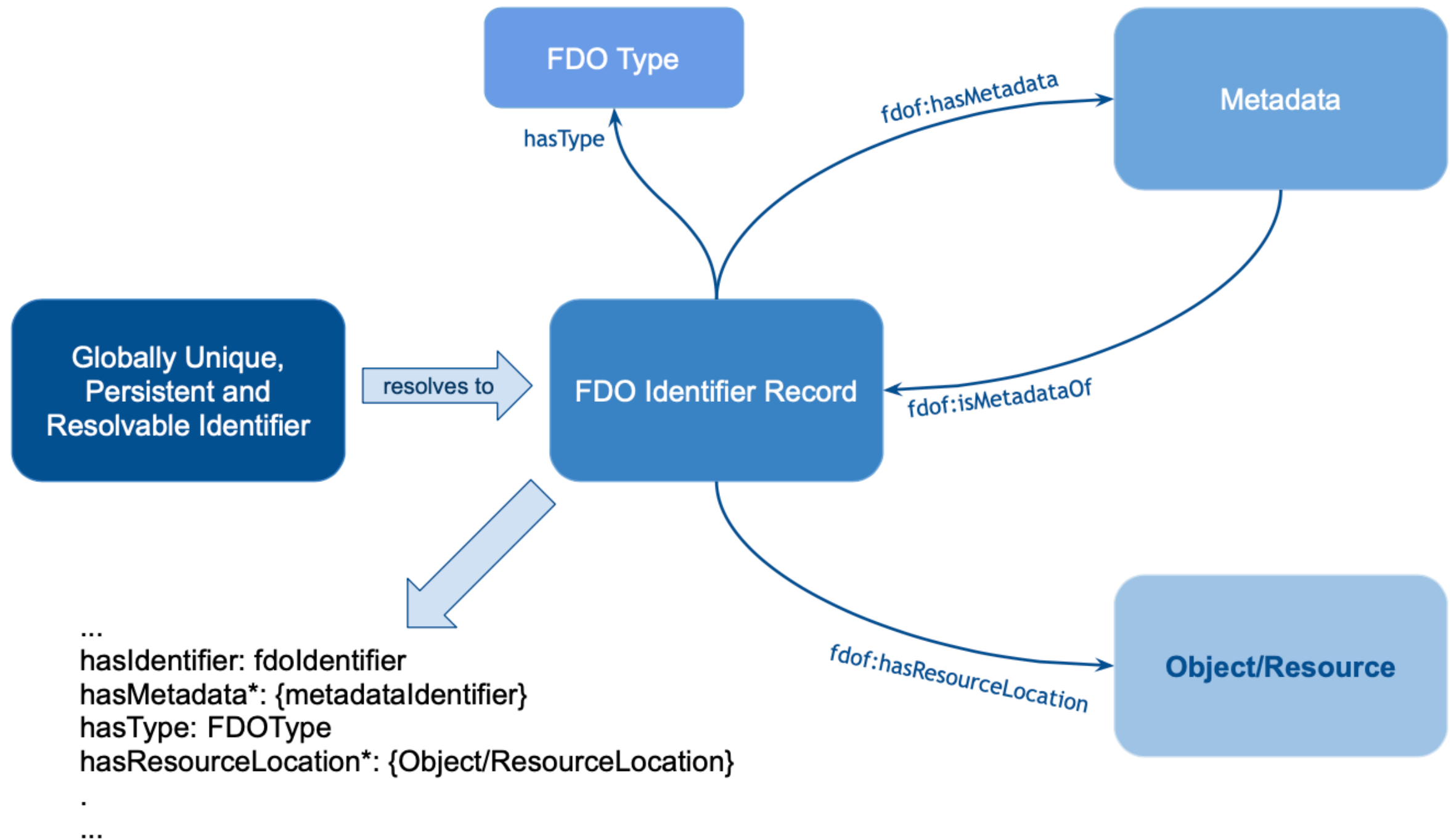
<https://github.com/GEDE-RDA-Europe/GEDE/tree/master/FAIR%20Digital%20Objects/Paris-FDO-workshop>

FAIR Digital Objects

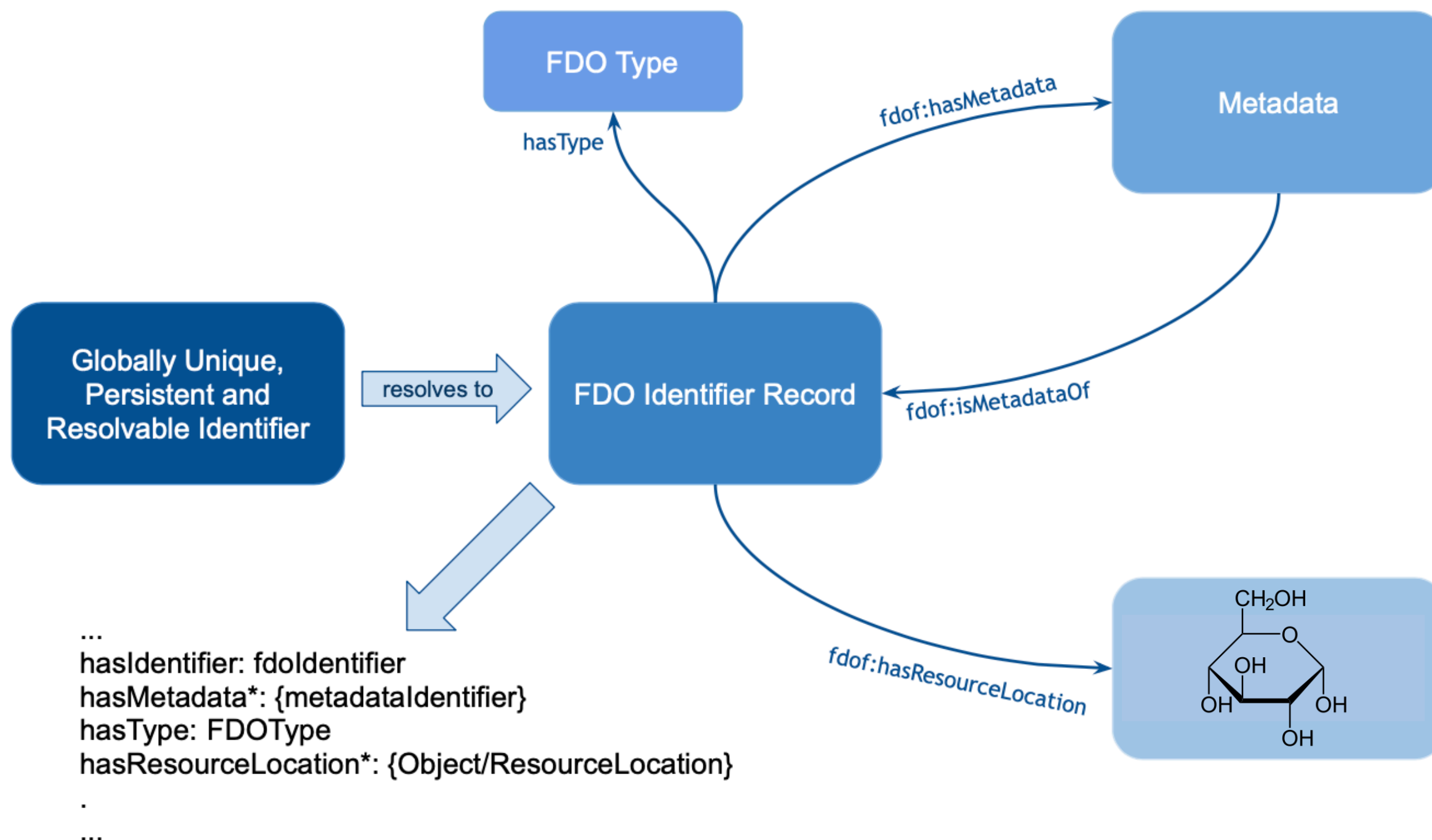


Timeline of developments in the convergence of various approaches to data infrastructures: conceptualization (blue background), design (green background), and implementation (yellow background)

FAIR Digital Objects



FAIR Molecule Hackathon



Hamburg, January 21-22, 2020

<https://osf.io/ft6wn/>

End users are domain scientists

LE/EOSC

E's, services, interfaces

VMNs, Workflows Algorithms

Repositories & Registries

Data (formats)

Long tail metadata

Domain metadata

Core



Metadata

Identifier systems

AAI (access)

Network (routing of FDO's)

File, Cloud, DB, HPC Systems

e-INFRA

FIP

FDO

Driving applications

- ESFRIs
- Cluster projects
- Many others



GÉANT