



# Health-RI FAIR Data stewards basics course 19 & 20 June + 3 July 2023

Fieke Schoots & Mijke Jetten

# Welcome

## Mijke Jetten

FAIR Data Lead



## Fieke Schoots

Training Coördinator FAIR Data



Contact us via

[Fairservicedesk@health-ri.nl](mailto:Fairservicedesk@health-ri.nl)

<https://www.health-ri.nl/nl/over-health-ri/health-ri-team>

## About the course

- **Introductory course**, that touches upon many topics of data stewardship in the health domain (follow-up of previous Helix Academy courses)
- Participants come from **different backgrounds and have different levels of expertise**. We try to cater for all, but inevitably some topics may be too specific, others too general for individual participants.
- We try to make the course as interactive as possible. We invite you **participate actively**, and relate the information to your daily practice.
- You are the first cohort, of the course in this form. Please **tell us your experiences** so that we can improve. During the course and in the final evaluation.
- We try to be flexible: **the training is a success if you feel that it is time well spent!**

# Programme

- Day 1: Data stewardship, policy and planning
- Day 2: Tools and workflows for FAIR (meta)data
- Day 3: Sharing and reuse for research

The full programme is in the Teams folder and [here](#)





# Data stewardship, Policy and Planning

Day 1 | 19 June 2023

# DAY 1 | Programme

Day 1	Topic	Trainers	Type
10.00 - 11.00	Welcome & Programme Research data life cycle & FAIR principles	Course organisers	Informal; Presentation
11.00 – 11.30	Demonstrator project: <a href="#">Duchenne Data Platform</a>	Nawel Lalout, Project Manager Duchenne FAIR Data	Presentation
11.30 – 11.45	Coffee break		
11.45 – 12.30	Data stewardship: introduction to profiles and competencies & learning goals	Course organisers	Group activity
12.30 – 13.15	Lunch break		
13.15 – 14.00	Perspectives on FAIR data stewardship - Funder - Health institutions	- Ellen Carbo, ZonMW	Presentation
14.00 – 14.15	Tea break		
14.15 – 15.30	Data Management Planning - Reviewing Data Management Plans activity	Petra Overveld & Martiene Moester, LUMC	Presentation; Hands-on
15.30 – 16.30	Ethical, Legal and Societal Implications (ELSI) of FAIR data - Informed consent - Frequently Asked Questions (and answers)	- Elize Vlainic, AUMC, - Miriam Beusink, ELSI Team Health-RI	Presentation; Hands-on
16.30 – 16.45	Wrap-up	Course organisers	

# DAY 1 | Data stewardship, Policy and Planning

**10.00 - 11.00**

## **Introduction(s)**

**Fieke Schoots, Mijke Jetten**  
**FAIR data implementation team, Health-RI**

### **Learning outcomes**

- Identify the focus, goals and program of the course
- Understand the ambitions of Health-RI
- Explain the different phases in the research data life cycle
- Explain what the FAIR principles stand for

# Agenda

- Introduction round
- Introduction Health-RI & FAIR implementation team in H-RI
- Research data life cycle
- FAIR Principles

# Let's get to know each other

- As an icebreaker, in 1 minute, tell us:
  - What is your role?
  - A fun fact about yourself



# From the registration form

## 5. How long have you been working in your current role?

Meer details

● Less than 3 months	9
● Between 3 and 6 months	2
● Between 6 and 12 months	6
● Longer than 1 year	5

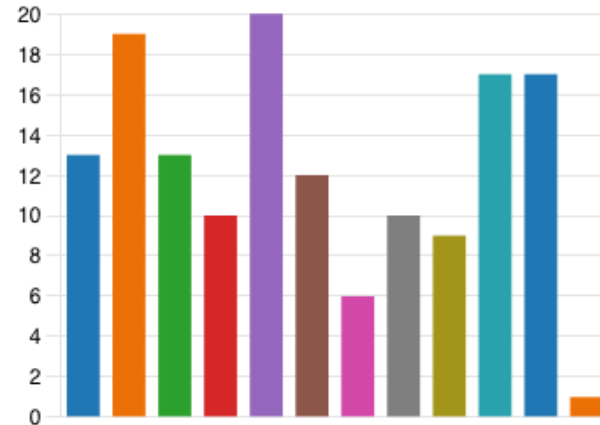


# From the registration form

## 6. In which topics are you particularly interested?

### Meer details

● Data stewards task areas and co...	13
● FAIR principles	19
● Reviewing data management pl...	13
● Ethical, Legal, Social Implications	10
● Metadata & ontologies	20
● RDM infrastructure and tools	12
● Software sustainability	6
● Data discovery and capture	10
● Data processing	9
● Data publishing and archiving	17
● Awareness raising & delivering t...	17
● Andere	1



# Landscape

- Many initiatives and communities on a local, domain, national and global level
- In this presentation, we provide a quick overview of the most important ones
- Click the links for further info + how to join
- In case of questions (later), contact Mijke or Fieke and we are happy to further explain / help you



# Domain community (LSH)

## Harmonise good data access & stewardship

Develop the TDCC as data stewardship hub for the LSH domain, supporting data access across LSH stakeholders (and beyond)

## Enhance Interoperability of digital solutions & resources

Develop the TDCC as "LSH interoperability-network", supporting the need to combine data, software and models across teams and organisations

## Strengthen capacity & expertise base in digital research

Develop the TDCC as LSH community platform to strengthen the training & support network in digital LSH research, aligned with the international field



## Supporting the future of data driven health & life sciences

### Training & community building



<https://tdcc.nl/lsh>



UMCG Digital Competence Center (DCC)

We help researchers to make the research data FAIR and compliant with applicable laws and regulations.

# Domain community (LSH)

## Health-RI Data Stewardship Community

The Health-RI Data Stewardship Community (DSC) is a community hub for health and life sciences data stewards that facilitates sharing experiences and collaboration.

The Health-RI Data Stewardship Community aims to:

- Accelerate the implementation of data stewardship in health care and life sciences institutes
- Share experiences between data stewards across the health care and life sciences domain
- Join forces to tackle cross-domain and cross-institutional problems together



### Get involved

The next meeting will be scheduled soon.

Are you a data steward working in the health or life sciences domain? [Sign up](#) to become a member of the Health-RI DSC and receive updates on meetings and other activities.

### Previous meetings:

- 2023-04-20 [Shared notes](#)

- 2023-03-13 [Shared notes](#)

The Health-RI DSC is facilitated by Fieke Schoots and Mijke Jetten (Health-RI). Feel free to [contact](#) us to learn more about the Health-RI DSC or if you want to collaborate.

[Website](#)

[Mailinglist](#)

# National community (cross domain)

## Data Stewards Interest Group (DSIG)

- Informal, inclusive community for data stewards and like-minded, fostering the (Dutch) national implementation of data stewardship
- Gradually changed into a cross-domain community: it currently welcomes data stewards related to all three Dutch Thematic Digital Competence Centres (LSH, SSH and NES)) and international colleagues
- Open to everyone interested in data stewardship: not limited to a specific academic discipline, nor to the Netherlands, but it is Netherlands based
- Facilitates direct peer-learning and knowledge sharing in a very fruitful way
- Via the DSIG website and TDCC website all materials are available for others who want to set up a similar community within their own country, region or discipline
- The DSIG facilitates a mailing list and a Slack community, to promote events, ask each other questions or feedback, and share experiences

# National community (cross domain)



Home ▾ Results ▾ RDM NL ▾ (L)DCC About ▾ Contact



<https://www.lcrdm.nl/en>

## THE DATA SUPPORT COLLECTIVE

The National Coordination Point Research Data Management (LCRDM) is a national **network** of experts in the field of research data management (RDM). The LCRDM forms the link between **policy and solution**. Within the LCRDM, experts work together to put RDM topics on the agenda that require a joint national approach.

Results ▾ RDM NL ▾

- Data Stewardship
- Engagement of researchers
- Financial aspects of FAIR
- Governance & policy
- Legal aspects & privacy
- Metadata & vocabularies
- Sustainable software

Tools & I RDM NL ▴ (L)DCC

- Glossary
- Online tools
- Repositories
- Research infrastructures
- Training
- Working groups

# National community (cross domain)

## Regieorgaan Open Science officieel van start onder de naam Open Science NL

23 maart 2023

Vertegenwoordigers van vijftien kennisinstellingen en het ministerie van OCW hebben het convenant voor Open Science NL ondertekend. Hierin staan nadere afspraken over het nieuw op te zetten regieorgaan Open Science bij NWO, dat Open Science NL heet. De feestelijke ondertekening vond plaats tijdens een bijeenkomst aan de TU in Delft, die geheel in het teken stond van open science.



[Persbericht](#)  
[Nationaal Programma Open Science](#)

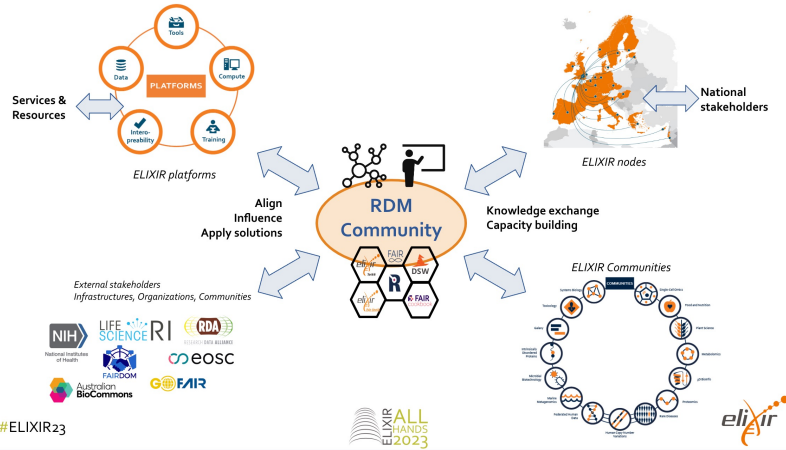
Met de ondertekening van het convenant is het nieuw op te richten regieorgaan een feit. Het doel van Open Science NL is om de transitie naar open science in Nederland verder te versnellen. Open Science NL zal organisatorisch onderdeel zijn van NWO, maar heeft een breed gedragen governance, waarin alle belangrijke partijen uit het veld die op dit onderwerp samenwerken hun perspectief geven.



“Met de ondertekening breekt de volgende fase aan, waarin we vernieuwende financieringsprogramma's gaan ontwikkelen om de hoge ambities die we in Nederland hebben te ondersteunen en versnellen.”

Hans de Jonge, kwartiermaker/directeur Regieorgaan Open Science NL

# European community (LSH)



## Mailinglist

## The recipes

Guiding you through the key steps of a FAIRification journey. Recipes provide you with the levels and indicators of FAIRness, the maturity model, the technologies, the tools and the standards available, as well as the skills required, and the challenges, to achieve and improve FAIRness. Each recipe tells you the audience type, reading time, level of difficulty, and the level of FAIR maturity it allows you to reach. Recipes are citable via their unique Identifier, and their authors are credited.

### Use the wizard to search all recipes

Search Wizard

### Or browse the various sections

<https://rdmkit.elixir-europe.org>  
<https://faircookbook.elixir-europe.org>  
<https://ds-wizard.org>





# Global community (cross domain)

**O&A Members** 63 **MEMBERSHIP** Members: 10956

Active Organisational & Affiliate members

Becoming a member of RDA is simple and open to both individuals and organizations

[Register now](#)

ABOUT RDA GET INVOLVED GROUPS RECOMMENDATIONS & OUTPUTS RDA FOR DISCIPLINES PLENARIES & EVI

Home » Working and Interest Groups » Interest Group » Professionalising Data Stewardship IG

## Professionalising Data Stewardship IG

Taxonomy:

- Posts
- Create Wiki index
- Events
- Repository
- Outputs
- Charter
- Plenaries
- Members

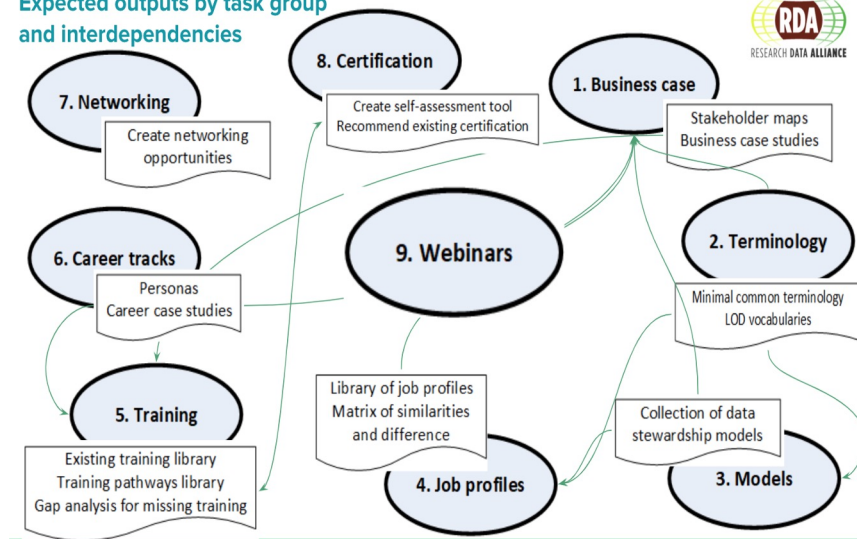
Group Status: + Not yet endorsed

**Status:** In Group Revisions  
**Chair (s):** Mijke Jetten, Marta Teperek, Peter Neish

This is the webpage of the RDA Interest Group (in formation) on professionalising data stewardship. The idea to create a session during the 14th Plenary (Helsinki), and a first informal group of interested people was established. At the 15th Plenary was organised.

We are currently in the process of submitting the charter (proposal charter available for community feedback via the 'discussions' tab) and the endorsement of a formal Interest Group.

## Expected outputs by task group and interdependencies



[Website + join option](#)  
[Slack community](#)

# European community (cross-domain)



## The European Open Science Cloud

The ambition of the European Open Science Cloud, known as EOSC, is to develop a **'Web of FAIR Data and Services' for science in Europe**. EOSC will be a multi-disciplinary environment where researchers can publish, find and re-use data, tools and services, enabling them to better conduct their work.

EOSC builds on existing infrastructure and services supported by the European Commission, Member States and research communities. It brings these together in a federated 'system of systems' approach, adding value by aggregating content and enabling services to be used together.

## Data stewardship, curricula and career paths

The Task Force **Data stewardship, curriculum and career paths** will focus on the Data Stewards role and their core activities. To help researchers to make FAIR data it is necessary to have professional staff. To keep professional staff, we need to have a common curriculum for their skills and possibilities for career paths.

[Website](#)

## Metadata and data quality

To ensure research objects can be discovered, understood and reused, as well as content can be relied on.

- ✓ FAIR Metrics and Data Quality Task Force
- ✓ Semantic Interoperability Task Force
- ✓ PID Policy and Implementation Task Force (PID TF)

## Research careers and curricula

The most important stakeholders for EOSC are the researchers.

- ✓ Data Stewardship, Curricula and Career Paths Task Force
- ✓ Research Careers, Recognition and Credit Task Force
- ✓ Upskilling Countries to Engage in EOSC Task Force
- ✓ Researcher Engagement & Adoption Task Force (REA TF)

## Technical challenges

on implementing the technical architecture and interoperability in EOSC a

Authentication and Authorization Infrastructure Architecture (AAI) Task Force


- ✓ Infrastructures for Quality Research Software Task Force
- ✓ Technical Interoperability of Data and Services Task Force
- ✓ Long-Term Data Preservation Task Force



# European Commission regulation (cross-domain)



## European Health Data Space

[Website](#)

In order to unleash the full potential of health data, the European Commission is presenting a [regulation to set up the European Health Data Space](#) . This proposal

- supports individuals to take control of their own health data
- supports the use of health data for better healthcare delivery, better research, innovation and policy making and
- enables the EU to make full use of the potential offered by a safe and secure exchange, use and reuse of health data

The European Health Data Space is a health specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework that aims at

- empowering individuals through increased digital access to and control of their electronic personal health data, at national level and EU-wide, and support to their free movement, as well as fostering a genuine single market for electronic health record systems, relevant medical devices and high risk AI systems ([primary use of data](#) )
- providing a consistent, trustworthy and efficient set-up for the use of health data for research, innovation, policy-making and regulatory activities ([secondary use of data](#) )

# Health-RI & FAIR data

- Quick overview of Health-RI as an organisation, including current activities
- Focus on the FAIR team efforts, as that is where this course, trainers and many of your UMCs RDM/FAIR colleagues are positioned
- In case of questions (later), contact Mijke or Fieke and we are happy to further explain / help you

## Our mission

Better health(care)  
for citizens and  
patients

*by*

reusing health data

*with*

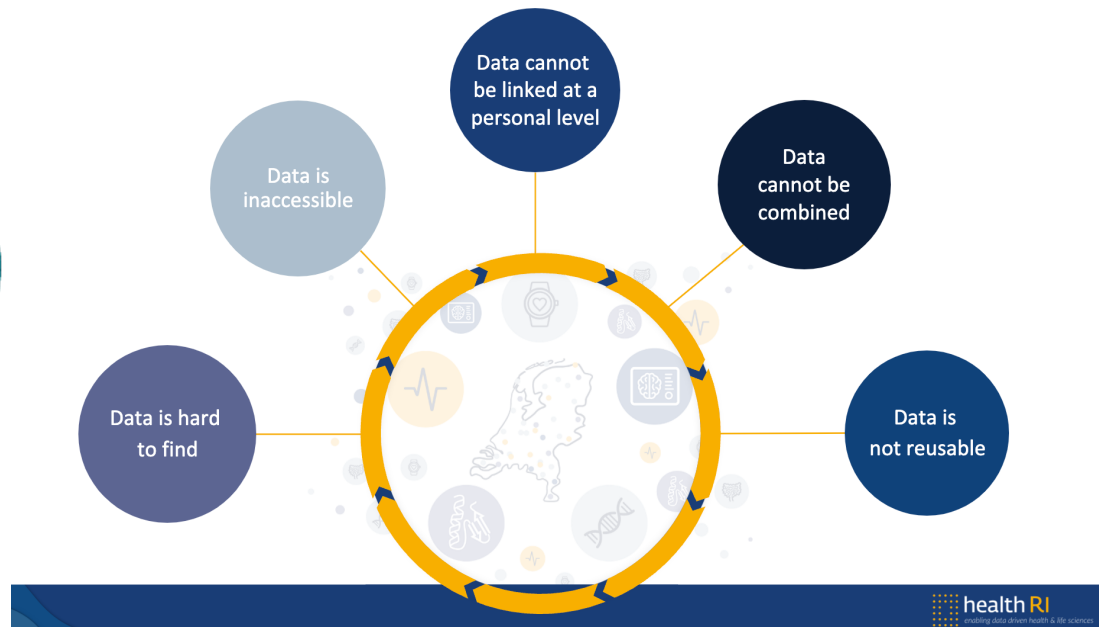
an integrated health  
data infrastructure

*for*

research and  
innovation



## The problem





# The challenge: fragmentation

Not a technical problem, but an organizational, social and cultural problem

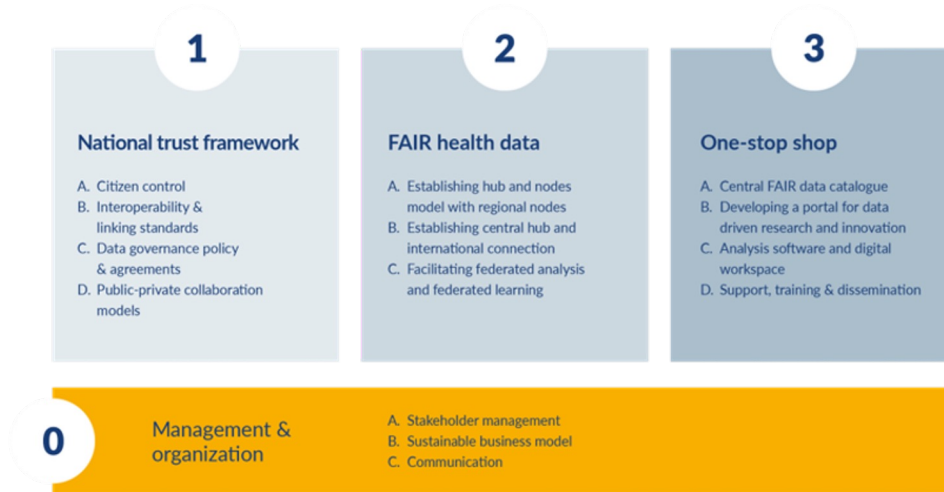
## Momentum

← News

**Dutch Government has pledged 69 million euros investment to Health-RI**

News | 9 April 2021

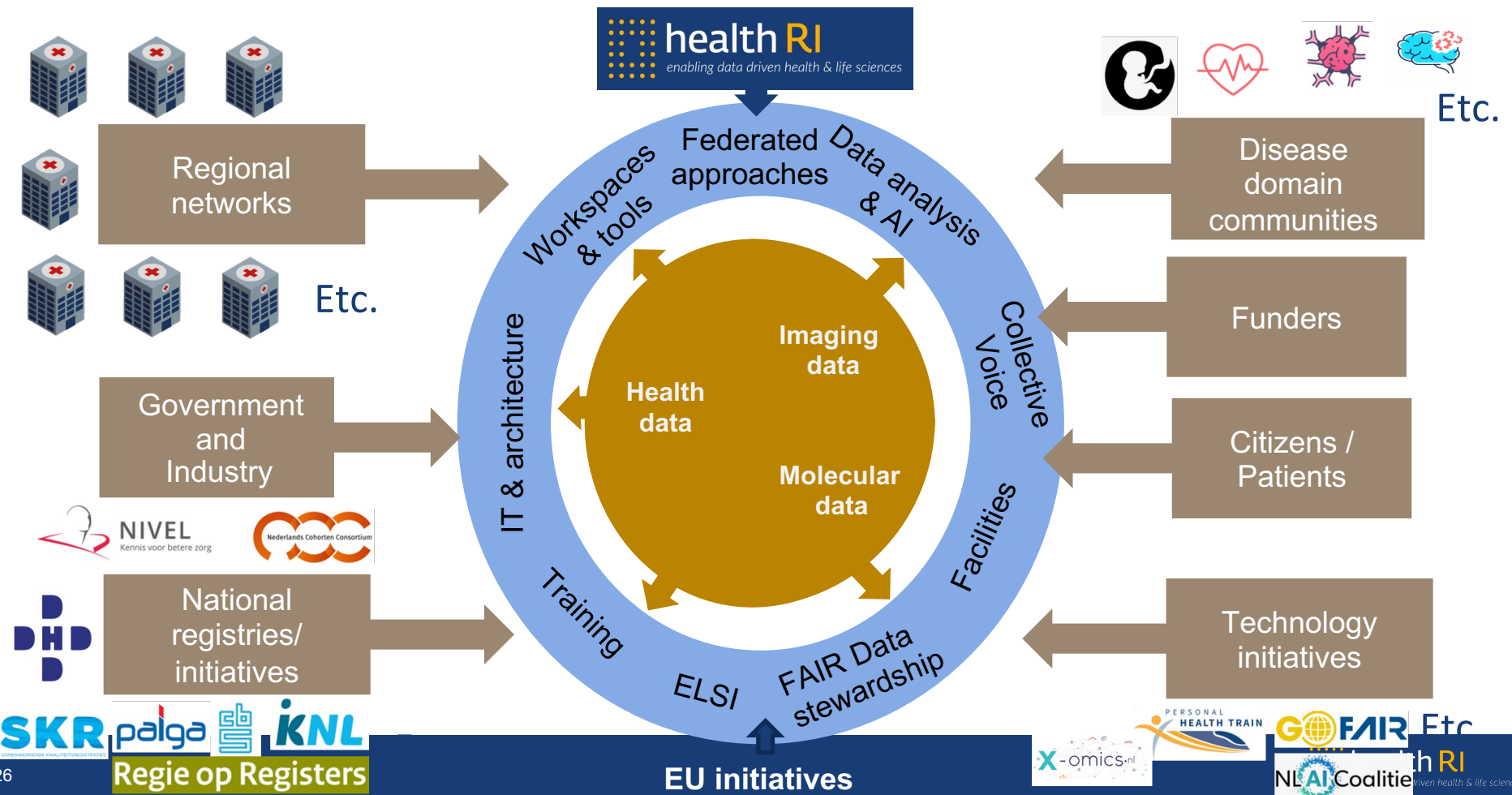
# How does Health-RI work?



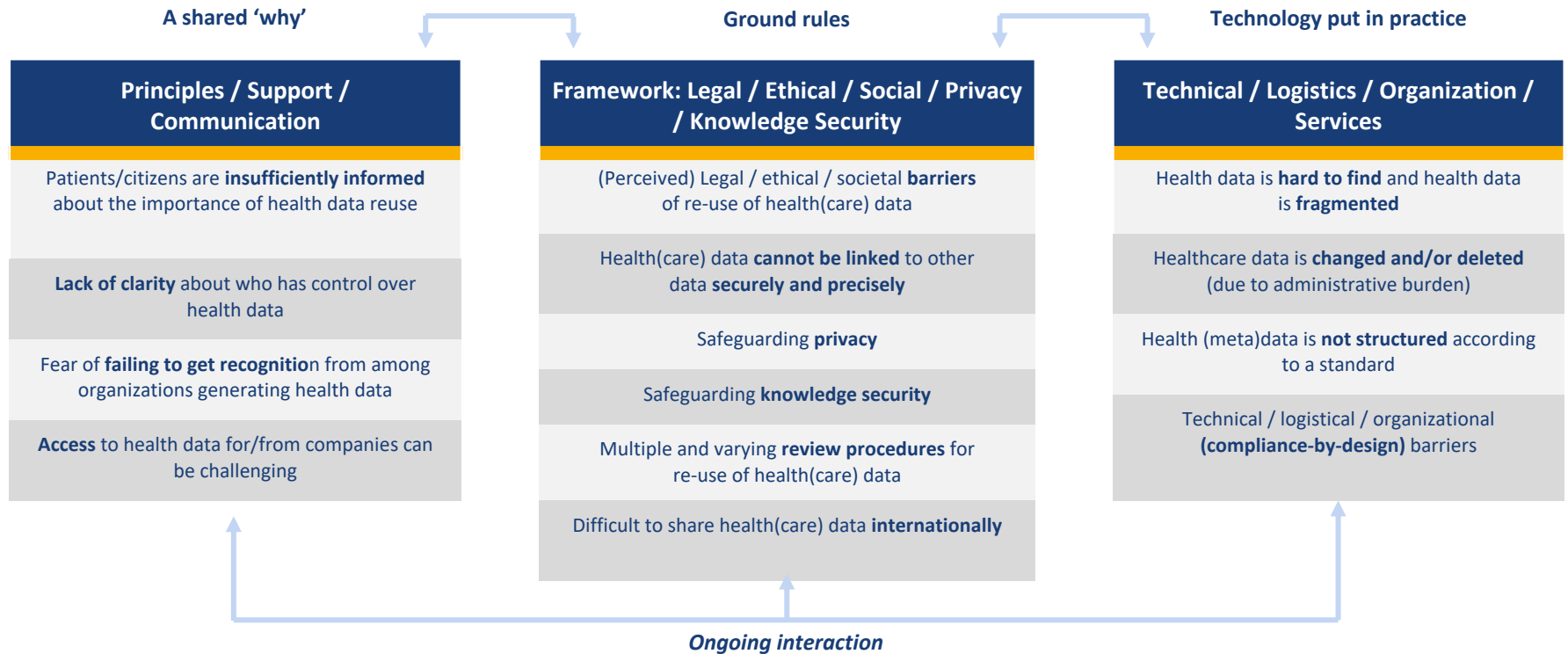
## TEAMS

ELSI, FAIR, ARCHITECTURE, BIOBANK&COLLECTIONS, SERVICES

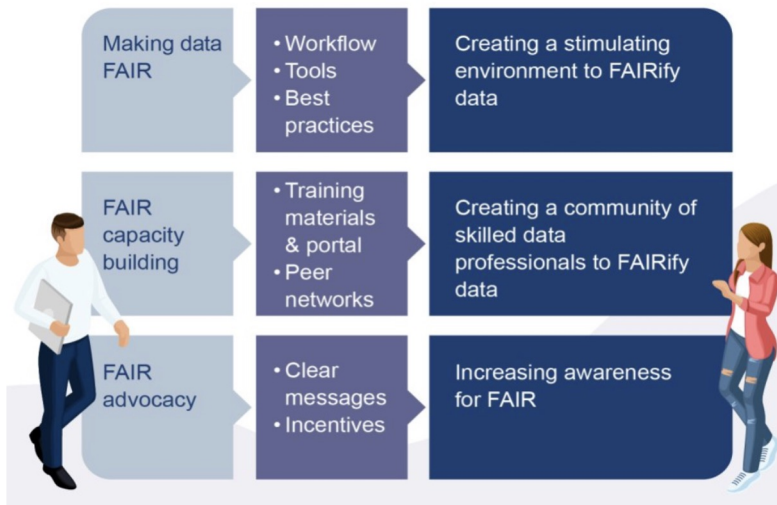
# Health-RI: integrated health data infrastructure for research and innovation



# Data reuse obstacle-removal-traject (OVT)



# FAIR activities



Together with the FAIR Data Implementation team, a group of experts within the Health-RI regional nodes is taking the next steps for these three core activities. Details can be found in our [2022-23 workplan](#).








## Links to blogs

- [Health-RI demonstrator projects and data champions: the FAIR principles put into practice](#)
- [Looking back at 2022 within the Health-RI FAIR Data Implementation team](#)

## Newsletters

- [#19 08-MAY-2023](#)
- [#18 28-MAR-2023](#)
- [#17 27-FEB-2023](#)
- [#16 17-JAN-2023](#)
- [#15 23-DEC-2022](#)

[Website](#)

 <p><b>Mijke Jetten</b> <i>FAIR Data Lead</i></p> <p>in ✉ →</p>	 <p><b>Pauline L'Hénaff</b> <i>Program Manager FAIR Data</i></p> <p>in ✉ →</p>	 <p><b>Bruna dos Santos Vieira</b> <i>Working with FAIR since 2019; Radboudumc; Health-RI</i></p> <p>in ⚙ →</p>	 <p><b>Jolanda Strubel</b> <i>Working with FAIR since 2019; Health-RI</i></p> <p>in ⚙ →</p>
 <p><b>Sander de Ridder</b></p>	 <p><b>Fieke Schoots</b> <i>Training Coordinator FAIR Data</i></p> <p>in ✉ →</p>	 <p><b>Ruben Kok</b> <i>Chief Strategic Alliances, Board member</i></p> <p>in ✉ →</p>	





## Health-RI FAIR coordinators at regional nodes

Morris Swertz & Efi Gkoumasi (node Groningen), Rudy Scholte (node Amsterdam), Viola Woeckel (node Rotterdam), Klaske Siegersma (node Utrecht), Olav Palmen (node Maastricht), Marco Roos, Marian Beekman (node Leiden), Mirjam Brullemans-Spansier (node Nijmegen), Toine Kuiper (node Eindhoven).



# Demonstrator & Data Champions portfolio

- Currently **5** Demonstrator projects and **10** Data Champions published
- Register your projects and champions (see overview pages)
- Contact: Jolanda Strubel

 <p><b>Duchenne Data Platform (DDP)</b> Key facts:</p> <ul style="list-style-type: none"> <li>- Rare Diseases Domain</li> <li>- Patient Clinical Data</li> <li>- Patient Reported Outcomes</li> <li>- Data Access Restricted</li> <li>- First sustainable patient-empowered FAIR registry</li> <li>- Custom-designed Extract, Transform and Load pipeline</li> <li>- Open source 'FAIR-in-a-Box' solution</li> </ul> <p style="text-align: right;">→</p>	 <p><b>Vascular Anomalies Registry (VASCA)</b> Key facts:</p> <ul style="list-style-type: none"> <li>- De novo FAIRification</li> <li>- Real Time FAIRification upon data collection</li> <li>- FAIRification at the source installed in electronic data capture system</li> <li>- Data collected and controlled locally</li> <li>- Local data from all centers can be queried in real time</li> </ul> <p style="text-align: right;">→</p>	 <p><b>CovidPredict</b> Key facts:</p> <ul style="list-style-type: none"> <li>- largest high granular covid database of admitted patients in the Netherlands</li> <li>- ongoing inclusions and scientific projects</li> <li>- ongoing scientific output</li> <li>- societal Impact in many national newspapers</li> </ul> <p style="text-align: right;">→</p>	 <p><b>X-omics</b> Key facts:</p> <ul style="list-style-type: none"> <li>- A National Roadmap Large-Scale Research Infrastructure</li> <li>- Multi-omics data analysis integration &amp; stewardship</li> </ul> <p style="text-align: right;">→</p>
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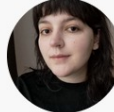




**The YOUTH Cohort Study**  
Key facts:

- YOUTH has been awarded the Dutch Data Prize at the FAIR Data Day 2022
- More than 4000 children from the general population and their parents participate in YOUTH
- Data are of high quality: rigorous measurements protocols and data quality control

→

Your project here

 <p><b>Bruna dos Santos Vieira</b> FAIR specialist at Radboudumc and Health-RI</p> <p style="text-align: right;">→</p>	 <p><b>Nawel Latout</b> Working with FAIR since 2020; Radboudumc and World Duchenne Organization</p> <p style="text-align: right;">→</p>	 <p><b>Jolanda Strubel</b> Program Manager FAIR data at Health-RI</p> <p style="text-align: right;">→</p>	 <p><b>Joeri van der Velde</b> Working with FAIR since 2019; University Medical Center Groningen</p> <p style="text-align: right;">→</p>
 <p><b>Sjerd Manger</b> Working with FAIR since 2020; Amsterdam UMC</p> <p style="text-align: right;">→</p>	 <p><b>XiaoFeng Liao</b> Working with FAIR since 2019; Radboudumc</p> <p style="text-align: right;">→</p>	 <p><b>Shuxin Zhang</b> Working with FAIR since 2020; Amsterdam UMC</p> <p style="text-align: right;">→</p>	 <p><b>Inês Henriques</b> Working with FAIR since 2022; Radboudumc</p> <p style="text-align: right;">→</p>
 <p><b>Meriem Manai</b> Working with FAIR since 2021; Amsterdam UMC</p> <p style="text-align: right;">→</p>	 <p><b>Coojje Veldkamp</b> Working with FAIR since 2012; Universiteit Utrecht</p> <p style="text-align: right;">→</p>	<p style="border: 2px solid red; padding: 10px; color: red; font-weight: bold;">Your champion here</p>	

# Research Data Life Cycle

- Quick overview of the different stages
- Activities related to the different stages
- Course topics according to the research data life cycle

# Research data life cycle



Data life cycle

## Planning

- What is data management planning?
- Why is data management planning important?
- What should be considered for data management planning?
- Related pages
- More information

[https://rdmkit.elixir-europe.org/data\\_life\\_cycle](https://rdmkit.elixir-europe.org/data_life_cycle)

## Planning data

Design research; plan data management; plan consent for sharing; plan data collection, processing protocols and templates; explore existing data resources

## Collecting data

Collect data; capture data with metadata; acquire existing third party data

## Processing and analysing data

Enter, digitize, transcribe and translate data; check, validate, clean, anonymize; derive data; describe; manage and store data; analyse and interpret data; produce research output; cite data sources

## Publishing and sharing data

Establish copyright; create user documentation; create discovery metadata; select appropriate access to data; publish/share data; promote data

## Preserving data

Migrate data to best format/media; store and backup data; create preservation documentation; preserve and curate data

## Re-using data

Conduct secondary analyses; undertake follow-up research; conduct research reviews; scrutinize fundings; use data for teaching and learning

# The Research Data Life Cycle in this course

Best practices

FAIRification workflows

Health-RI (meta) data portal

FAIR data point

Software sustainability

Data archiving



Policy DMP's

ELSI

iCRF

Metadata

Data organisation in spreadsheets

RDMkit

# FAIR

Findable, Accessible, Interoperable, Reusable

Wilkinson, M., Dumontier, M., Aalbersberg, I. *et al.* The FAIR Guiding Principles for scientific data management and stewardship. *Sci Data* **3**, 160018 (2016).  
<https://doi.org/10.1038/sdata.2016.18>

# The **FAIR** data principles



## **F**indable

To identify data for both humans and computers by computerising metadata that facilitate searching for specific datasets.



## **A**ccessible

Data is stored properly -for long term- so that it can easily be accessed and/or downloaded with well-defined access conditions. These could be access to the metadata (only) or getting access to the actual data.



## **I**nteroperable

The ability to combine different datasets either by humans or by computers. Therefore multiple agreements have to be made with respect to the terminology used to prevent ambiguities of the meanings of these terms.



## **R**eusable

Data should be ready to be used for future research and to be further processed using computational methods. This requires adequate information about how the data were obtained and processed (provenance), and an appropriate license.

<https://www.dtls.nl/fair-data/data-stewardship/>

Refer to data (or any digital object), metadata (information about that digital object), and infrastructure

## Findable

- The data must be findable. It should be possible to find a suitable data set for a research project based on what it contains
- The first step in (re)using data is to find them. Metadata and data should be easy to find for both humans and computers
- Machine-readable metadata are essential for automatic discovery of datasets and services
- F1. (Meta)data are assigned a globally unique and persistent identifier  
F2. Data are described with rich metadata (defined by R1)  
F3. Metadata clearly and explicitly include the identifier of the data they describe  
F4. (Meta)data are registered or indexed in a searchable resource



# Accessible

- The data must be accessible. A description should exist of how the data can be obtained. And there should be guarantees that this will still work after years.
- Once the user finds the required data, she/he needs to know how they can be accessed, possibly including authentication and authorisation
- A1. (Meta)data are retrievable by their identifier using a standardised communications protocol
  - A1.1 The protocol is open, free, and universally implementable
  - A1.2 The protocol allows for an authentication and authorisation procedure, where necessary
- A2. Metadata are accessible, even when the data are no longer available

# Interoperable

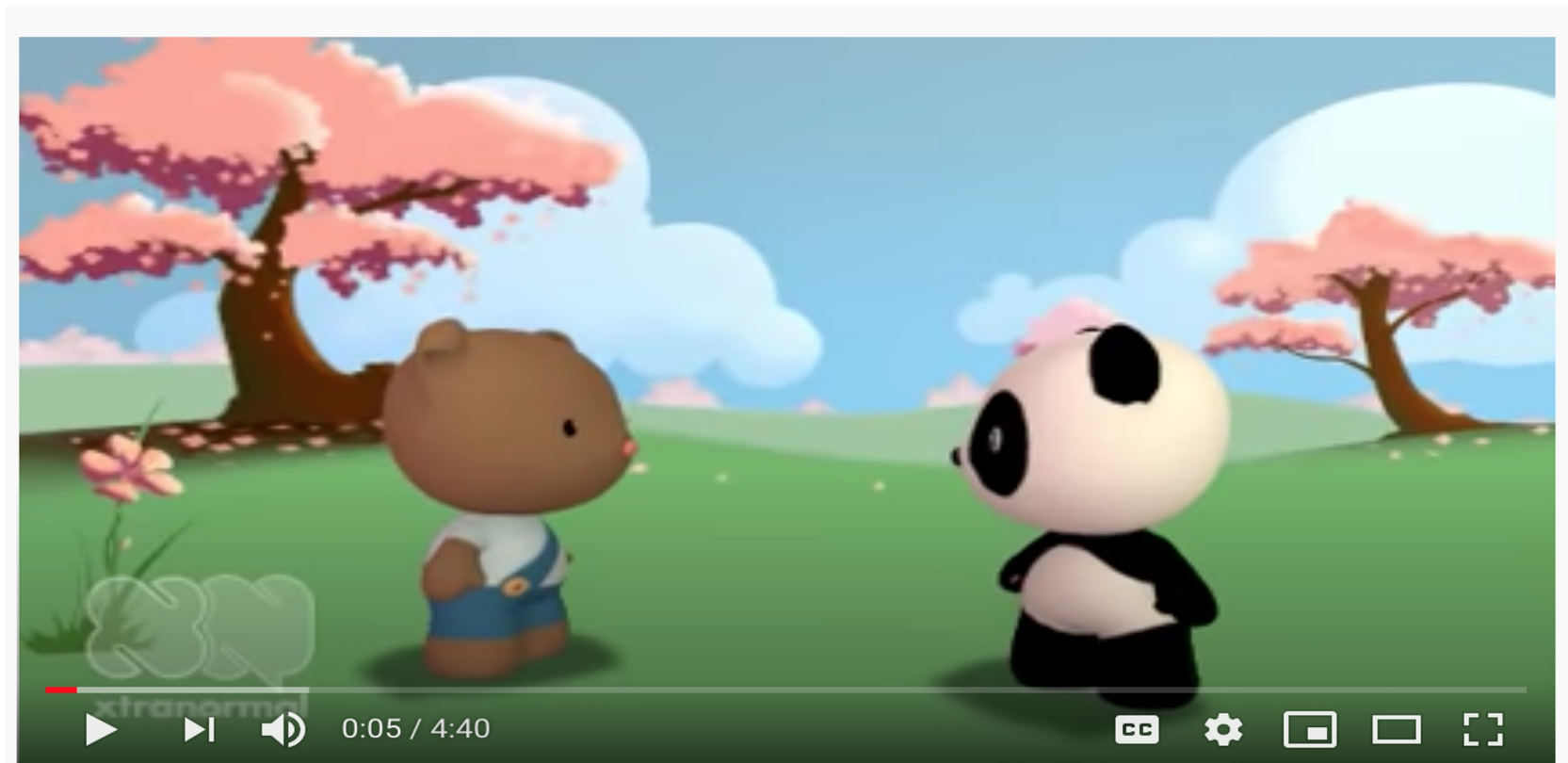
- The data should be interoperable. It should be structured in a way that is well described, maybe even self-described. References to values and methods (SOPs) should be unambiguous
- The data usually need to be integrated with other data. In addition, the data needs to interoperate with applications or workflows for analysis, storage, and processing
- 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

# Reusable

- Obviously, we want to ultimately make the data reusable. This requires that the data is well enough described so that it is clear how it was obtained. Also, it requires that the licensing actually permits the reuse
- The ultimate goal of FAIR is to optimise 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
- 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
  - R1.2. (Meta)data are associated with detailed provenance
  - R1.3. (Meta)data meet domain-relevant community standards

FAIR for human beings, for machines and taking into account legal requirements (such as privacy)

## The data problem



# Resources on FAIR principles in health

- Webinars:
  - FAIR principles in practice for health data: Personalized Health Informatics group, SIB Swiss Institute of Bioinformatics: <https://youtu.be/fXCR8lkxcw8>
  - [FAIR training from the World Duchenne Organization](#) (March 2023)
    - Programme: [https://www.worldduchenne.org/wp-content/uploads/fds\\_fair\\_training\\_programme\\_2023\\_final-.pdf](https://www.worldduchenne.org/wp-content/uploads/fds_fair_training_programme_2023_final-.pdf)
    - Slides: <https://drive.google.com/drive/folders/142ayXVAU8DpXesaMdXTwxEqJgPD6kYlw>
    - Videos: <https://www.youtube.com/playlist?list=PLi4jXxW5UG9hozZlkeodQGxQGkNH9JYio>
- FAIR cookbook: <https://faircookbook.elixir-europe.org/content/home.html>
- Tess training portal on FAIR data: [https://tess.elixir-europe.org/materials?scientific\\_topics=FAIR+data](https://tess.elixir-europe.org/materials?scientific_topics=FAIR+data)

# DAY 1 | Data stewardship, Policy and Planning

**11.00 - 11.30**

## **Demonstrator project: Duchenne Data Platform**

**Nawel Lalout**

**Project manager Duchenne FAIR data**

### **Learning outcomes**

- Recognize steps in FAIR implementation in an example project (patient registry)

# DAY 1 | Data stewardship, Policy and Planning

**11.45 - 12.30**

## **Data stewardship: introduction to profiles and competencies**

**Fieke & Mijke**

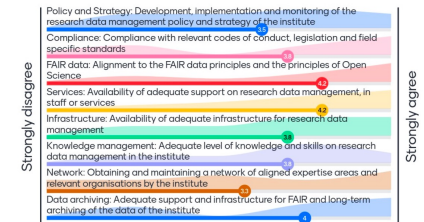
### **Learning outcomes**

- Recognise the data steward competency framework in the learning outcomes of the course
- Apply data stewards profiles and competency framework to own tasks and role
- Define learning goal

# Agenda

- Introduction into the competence and task areas of a data steward
- Discuss in groups which are most important / prioritise
- Sketch individual profile
- Identify gaps in knowledge / skills / abilities and define individual learning goal(s)

These competence areas are very important in my role as a data steward





# FAIR Data stewardship and the need for skills and capacity building

**Data Stewardship** is the responsible planning and executing of all actions on digital data before, during and after a research project, with the aim of optimizing the usability, reusability and reproducibility of the resulting data

Data stewardship and data management skills are **essential in research**

Role	Task	FTEs needed per 1000 researchers
Data Steward	Assisting researchers with effective management of research data	26
Trainer on data stewardship	Training researchers on data management skills	4

<https://doi.org/10.5281/zenodo.4769514>

WORLD VIEW · 25 FEBRUARY 2020

## Invest 5% of research funds in ensuring data are reusable

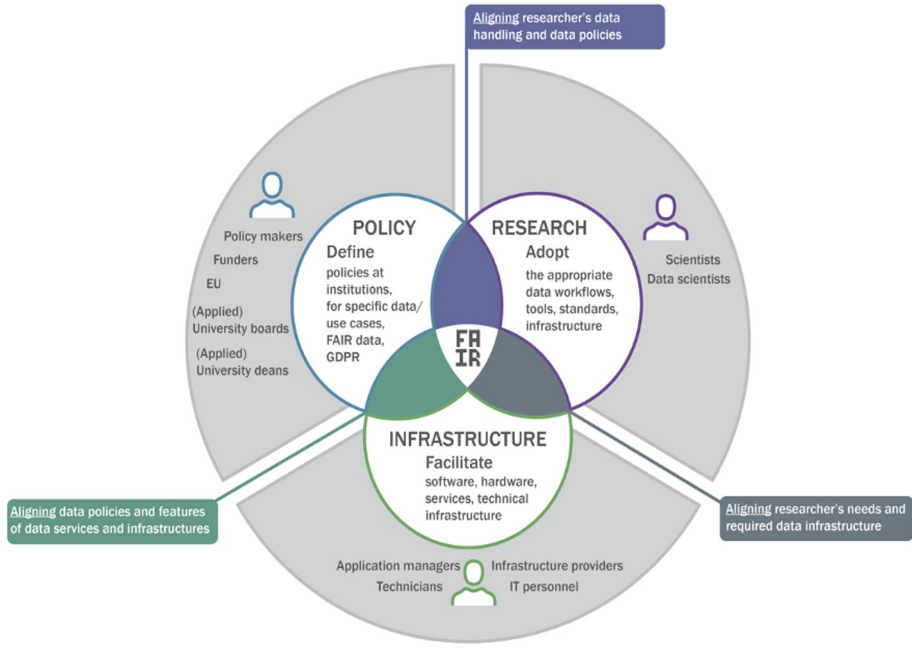


It is irresponsible to support research but not data stewardship, says Barend Mons.

Barend Mons

<https://doi.org/10.1038/d41586-020-00505-7>

# FAIR Data stewardship task areas



ZonMw/ELIXIR data stewardship roles in the data stewardship landscape (2018 /2019)

<http://doi.org/10.5281/zenodo.3474789>

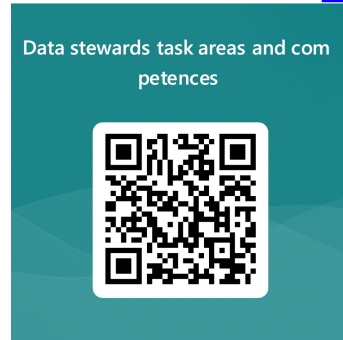
<https://doi.org/10.5281/zenodo.3243909>



Professionalising data stewardship in the Netherlands. Competences, training and education. Dutch roadmap towards national implementation of FAIR data stewardship <https://doi.org/10.5281/zenodo.4320504>

# How about you?

- Browse the eight competence areas in the Competence Hub for data steward: <https://competency.ebi.ac.uk/framework/datasteward/1.0>
- Answer the questions in the form: <https://forms.office.com/e/EEpkZjWUKc>



- Write down your learning goal for this course in the shared notes: [Shared notes & links - Day 1 - Health-RI FAIR data stewards basics course.docx](#)

# DAY 1 | Data stewardship, Policy and Planning

**13.15 - 14.00**

## **Perspective on FAIR data stewardship from funder**

**Ellen Carbo**

**Project lead FAIR data & Open Access, ZonMW**

### **Learning outcomes**

- Understanding the role of the funder
- Realizing the benefits of FAIR data
- Understanding the role of machine actionable metadata for a funder

# DAY 1 | Data stewardship, Policy and Planning

14.15 - 15.30

## Data Management Planning

Petra Overveld, LUMC

### Learning outcomes

- After this hour, you can:
- Describe what a data management plan is
- Describe the relevance and benefits of writing a data management plan
- Explain why writing a data management plan is part of FAIR
- Develop questions for a data management plan
- Provide researchers with advice and feedback on a data management plan
-

# DAY 1 | Data stewardship, Policy and Planning

15.30 - 16.30

**Ethical, Legal and Societal Implications of FAIR data**

**Elize Vlainic AUMC**

**Miriam Beusink, Health-RI**

**Learning outcomes**

By participating in this part of the course, you will:

- Gain understanding how legislation such as the AVG/GDPR affect requirements within the Informed Consent Form
- Understand how the ICF (and IC-withdrawal) may impact future use and related procedures defined in your DMP
- Increase knowledge on how to find and contribute to new policies
- Be up to date on current (national) developments regarding digital consent
- Apply ELSI questions to real life examples

# DAY 1 | Data stewardship, Policy and Planning

**16.30 - 16.45**

**Wrap-up**

**Please take 5 minutes to write down today's tips and tops in the shared document!**