

Support & community building for researchers and data stewards

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Outline

- FAIR, what's in it for me?
- Supporting researchers
- Building a community of FAIR experts



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

“Invest 5% of research funds in ensuring data are reusable. It is irresponsible to support research but not data stewardship (...). Many top universities are starting to see that the costs of not sharing data are significant and greater than the associated risks. Data stewardship offers excellent returns on investment.”

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

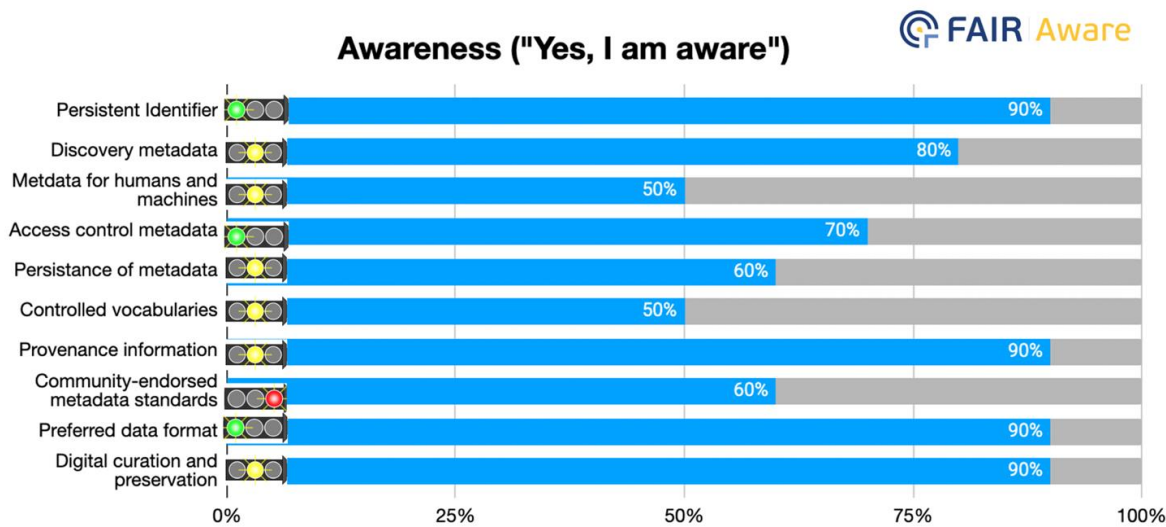
Better health for citizens and patients
by
reusing health data
with
an integrated health data infrastructure for research and innovation

FAIR, what's in it for me?

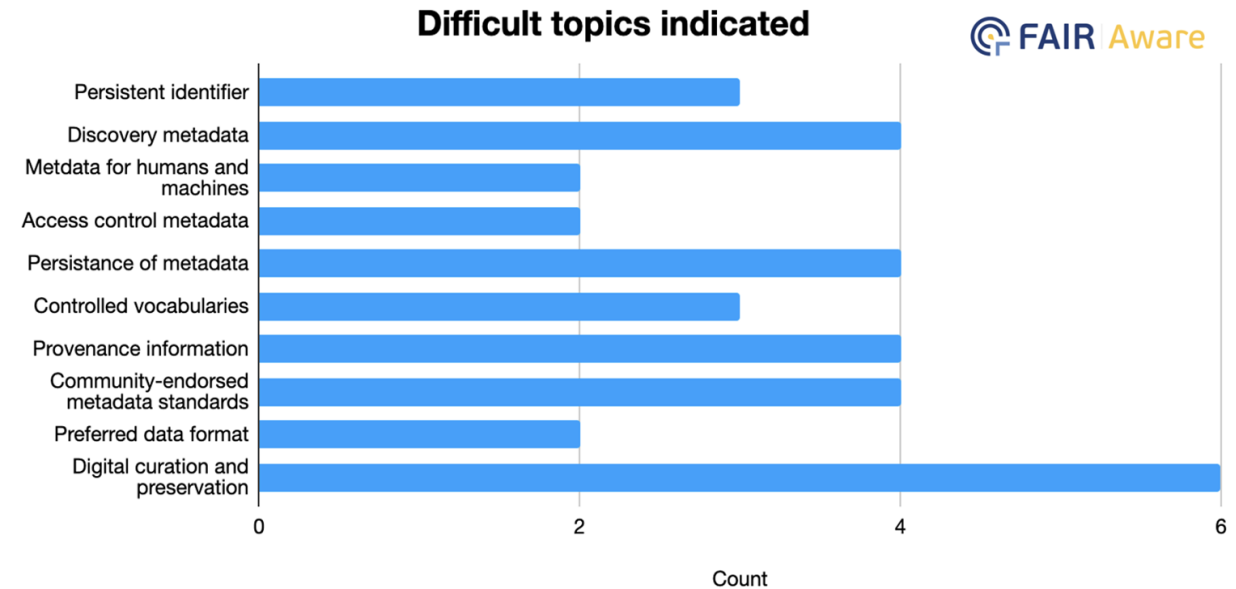
FAIR for researchers

FAIR awareness

FAIR starts right at the beginning of your research, in the planning phase. Use the [FAIR Aware tool](#) to reflect on your (future) FAIR practices. Keep your project's (future) dataset in mind. [What are already good practices/what is feasible and what are the challenges or bottlenecks?](#)



FAIR difficulties



FAIR for hospitals

Highest scored questions

- Are the FAIR principles explicitly mentioned in the **data policy** of your organization?
- Is the general research data policy supported by dedicated **service units**?
- Which means are used to **communicate** the research data policy **to the researchers**?
- Which services does your organization provide to comply with the **F principles**?
- Does your organization offer or take part in **collaborations that work on new tools**, services, expertise and other components of the FAIR data ecosystem?

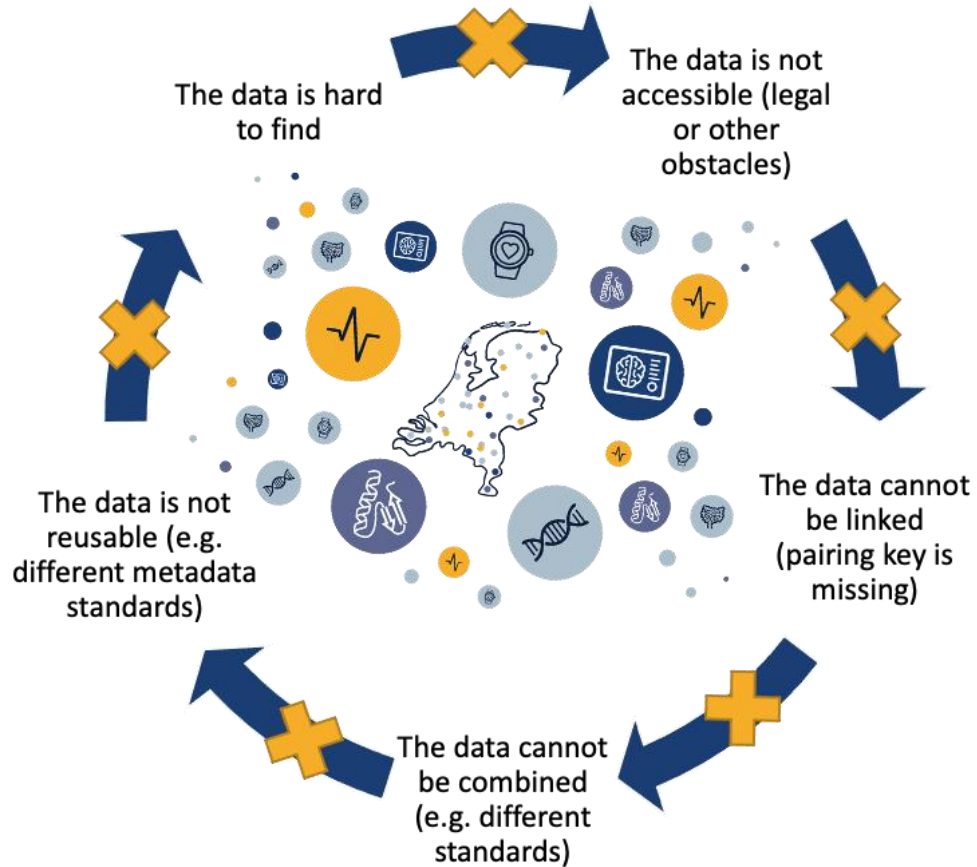
Lowest scored questions:

- Which services does your organization provide to comply with the R principles? **Develop services/tools in this area**
- Does your organization have a job description for the different roles in data stewardship? **Set of tasks / responsibilities defined together**
- Is FAIR data recognized and rewarded by your organization? **Improve the reward system**
- Does your organization include FAIR data as a criterion in the evaluation process? **Could be added in the workflow / tools**
- Does your DCC know the amount of data, the number of datasets produced within your organization? **Need to monitor this closely**

What are your organization's most important barriers in becoming FAIR enabling?

- Cultural change / time consuming / (lack of) resources and finances - **Even though scores are high in the policy category, there seem to be a need to explain again that FAIR can be simple & not resource heavy**
- No clear data management policy / insufficient coordination - **Further explore together**
- Fear of sharing data with respect to GDPR - **Flag to the ELSI Theme**
- Lack of incentives for researchers / insufficient reward for working FAIR - **Already set as an activity to explore**
- Lack of skills (trainings + personnel) - **Training is one of the 3 pillars, Health-RI will play a big role in centralising information on training available and providing training too**
- Lack of good examples - **Demonstrator portfolio will be useful to provide good examples / reassure people on how they could make steps / what the benefits are of FAIR**

Obstacles



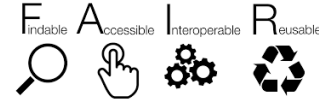
← Home

Data reuse obstacles removal traject

Collaborative commitment to remove obstacles that block the (re)use of health data for research and innovation

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

... and how to tackle them

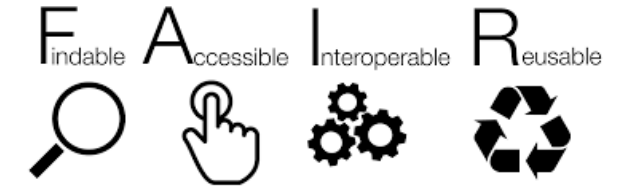


Our work is guided by the [FAIR principles](#), according to which data (in our case, health research data) must be:

- **Findable** – Making data findable for people and computers enables people to know **if the data they want exists already or whether they need to collect it**
- **Accessible** – Making data accessible allows people to know whether **they can get hold of data** to use for the things they want to
- **Interoperable** – Making data interoperable makes it easy for people to **bring data together** with other data to gain insights
- **Reusable** – Making data reusable will help people know what they **can and cannot do with data** through rich metadata, a clear license and/or terms of use

Also, FAIR data does not always mean open data (e.g., sensitive data). Nor is open data by itself FAIR.

Great, but what's in it for me?



Some benefits of implementing the FAIR principles:

- Save time and avoid duplication of effort / Gain maximum potential from data assets
- More easily reuse data for new purposes
- Enable new research questions to be answered
- Use new innovative research approaches and tools
- Achieve maximum impact from research
- Enable others to verify your work, increasing public trust in research
- Improve reproducibility and reliability

Some consequences of not implementing the FAIR principles:

- Data loss
- Loss of overview of research
- Delay of research
- Lack of reproducibility
- Reputation damage
- Losing or having to refund a research grant

In turn enable a learning healthcare system and accelerate sustainable and affordable personalized medicine and health for patients.

Supporting researchers

Implementing these principles at Health-RI

- Hub & node model
 - Central team at the hub
 - Co-creation process with regional nodes (UMCs, TU/e, STZs etc.)
- Different action lines
 - ELSI, IT/Architecture, Biobanks & Collections, Services, Companies, FAIR



Example: FAIR Theme (Mijke Jetten) action plan



Data management

- Data life cycle
- Your role
- Your domain
- Your tasks
- Tool assembly
- National resources
- All tools and resources
- All training resources

Are you working with data in the Life Sciences? Do you feel overwhelmed when you think about Research Data Management?

The ELIXIR Research Data Management Kit (RDMkit) is an online guide containing good data management practices applicable to research projects from the beginning to the end. Developed and managed by people who work every day with life science data, the RDMkit has guidelines, information, and pointers to help you with problems throughout the data's life cycle. RDMkit supports FAIR data — Findable, Accessible, Interoperable and Reusable — by design, from the first steps of data management planning to the final steps of depositing data in public archives.

The RDMkit organises information into the six sections displayed below, which are interconnected but can be independently.

Data life cycle

Start here to get an overview of research data management. Click on a section of the diagram below to get an overview of that stage of the data management life cycle.



Your role

Identify your role in research data management, find data management resources relevant for you, and information to help you progress in your career path.

Show pages

Your domain

Learn about the data management problem your domain or research community, and adopted to address them.

Show pages

Your tasks

Find guidelines and solutions for tackling common data management problems.

Show pages

Tool assembly

Find concrete combinations of tools and re-assembled into a workflow for research data management.

Tool assembly page

National resources

All tools and resources



Partners About Contact

Search

All audiences All themes All data life cycle ph...

<p>Academic integrity</p> <p>Integrity implies responsible research data management by LERU (Europe)</p> <p>ethics policy development</p>	<p>Assessment of FAIR</p> <p>Checklist for assessment of FAIRness of your data by LCRDM (NL)</p> <p>FAIR</p>	<p>Budget for RDM</p> <p>NPOS report – Project A: Transitiekosten Open Science</p> <p>policy development</p>	<p>Budget for RDM</p> <p>Invest 5% of total research expenditure on properly managing and stewarding data on nature</p> <p>policy development</p>
<p>Career paths</p> <p>Global goals and career paths with employment conditions from the association of universities in the Netherlands (VNU)</p> <p>policy development</p>	<p>Career paths</p> <p>Data Stewardship on the map by LCRDM (NL)</p> <p>policy development</p>	<p>Career paths</p> <p>Towards FAIR data steward as profession for the life sciences by ZONMw (NL)</p> <p>policy development</p>	<p>Code of conduct</p> <p>The Netherlands Code of Conduct for Research Integrity</p> <p>ethics</p>
<p>Coding and data science skills</p> <p>Training on foundational coding and data science skills for researchers by Software Carpentry</p> <p>training</p>	<p>Coding and data science skills</p> <p>Programming skills by Code Refinery</p> <p>training</p>	<p>Coding and data science skills</p> <p>Foundational coding and data science skills by Code Refinery (EU)</p> <p>training</p>	<p>Coding and data science skills</p> <p>Foundational coding and data science skills training by Data Carpentry</p> <p>training</p>
<p>Community of RDM experts</p> <p>Mailing list for Data Support Experts by JISC (UK)</p> <p>community of practice</p>	<p>Community of RDM experts</p> <p>Mailing list for Data Support Experts by LCRDM (NL)</p> <p>community of practice</p>	<p>Community of RDM experts</p> <p>Community for Data Support Experts by DTI (NL)</p> <p>community of practice</p>	<p>Community of RDM experts</p> <p>Community for Data Support Experts by the Research Data Alliance</p> <p>community of practice</p>
<p>Community of RDM experts</p> <p>Support community for Data Support Experts by the UKR (NL)</p> <p>community of practice</p>	<p>Community of RDM Experts</p> <p>Community of research data management experts National Coordination Point RDM (NL)</p> <p>community of practice</p>	<p>Community of RDM Experts</p> <p>FAIRsharing community network of policy makers adopted by RDA</p> <p>community of practice</p>	<p>Community of Research Software Engineers</p> <p>A community of researchers in Amsterdam Science Park (NL)</p> <p>community of practice</p>

Community of Research Community of Research Community of Research Community of Research

FAIR cookbook

FAIR Cookbook

Created by researchers and data managers professionals, the FAIR Cookbook is an online resource for the Life Sciences with recipes that help you to make and keep data Findable, Accessible, Interoperable and Reusable (FAIR).

Turning FAIR into practice

The FAIR Principles put specific emphasis on enhancing the ability of machines to automatically find and use the data, in addition to supporting its reuse by individuals. However, the FAIR Principles are aspirational and generic. The FAIR Cookbook guides **researchers** and **data stewards** of the Life Science domain in their FAIRification journey; and also provides **polymakers** and **trainers** with practical examples to recommend in their guidance and use in their educational material.

<https://faircookbook.elixir-europe.org/>



<https://rdmkit.elixir-europe.org/>



<https://23things.sites.uu.nl/>

Building a community of FAIR experts

What does a data steward/FAIR expert do?

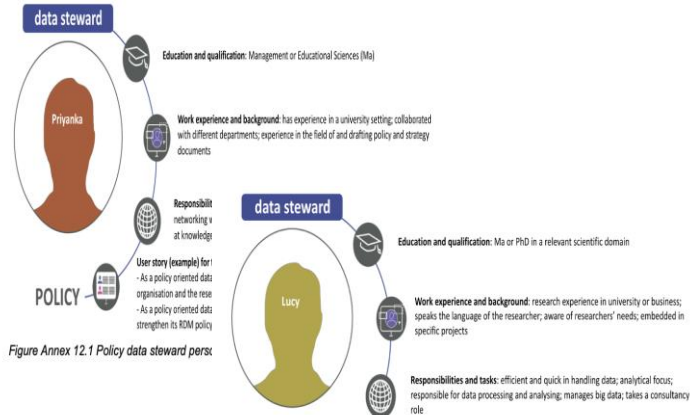


Figure Annex 12.1 Policy data steward perso

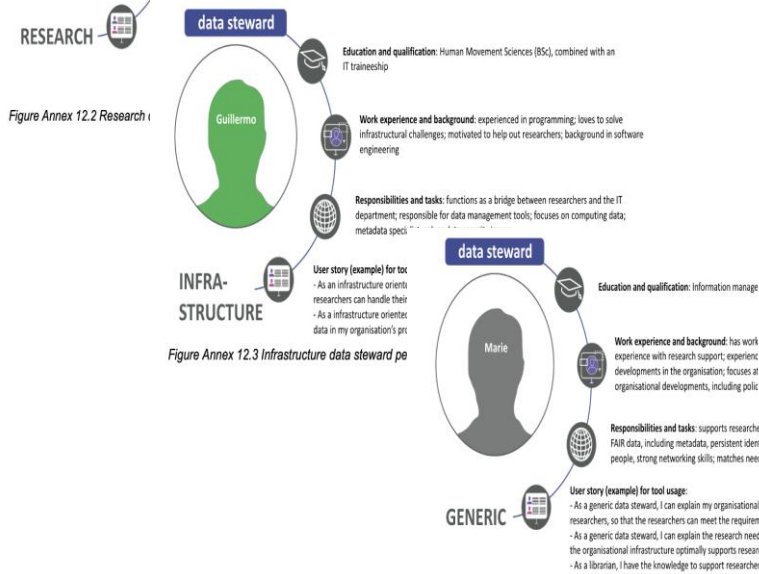


Figure Annex 12.2 Research

Figure Annex 12.3 Infrastructure data steward pe

Figure Annex 12.4 Generic data steward persona (organisational perspective)

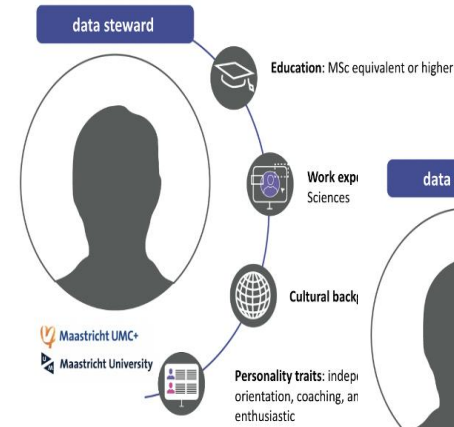


Figure Annex 2.9 Maastricht UMC data steward

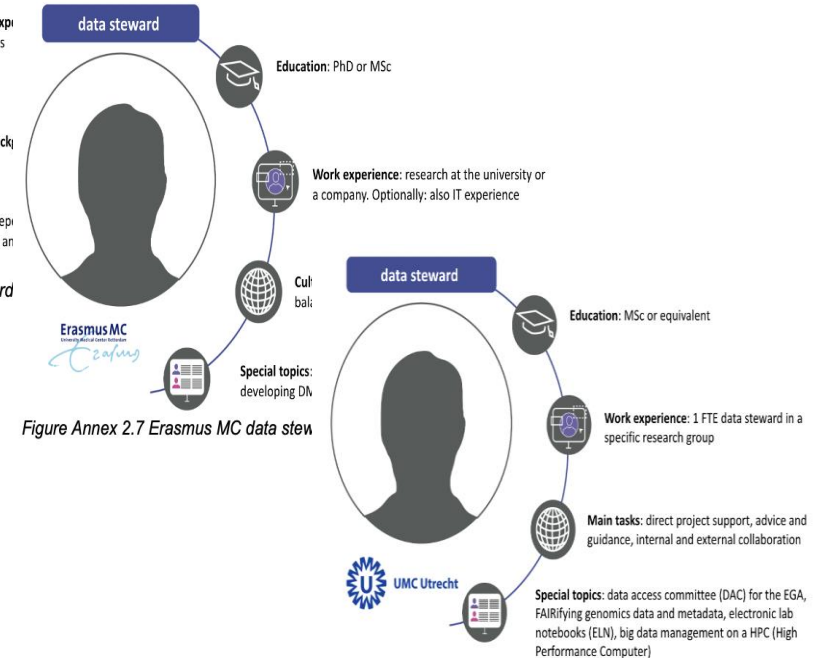


Figure Annex 2.7 Erasmus MC data stew

Figure Annex 2.5 UMC Utrecht data steward

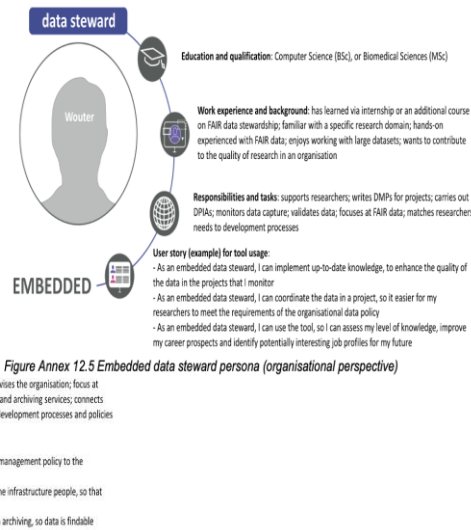
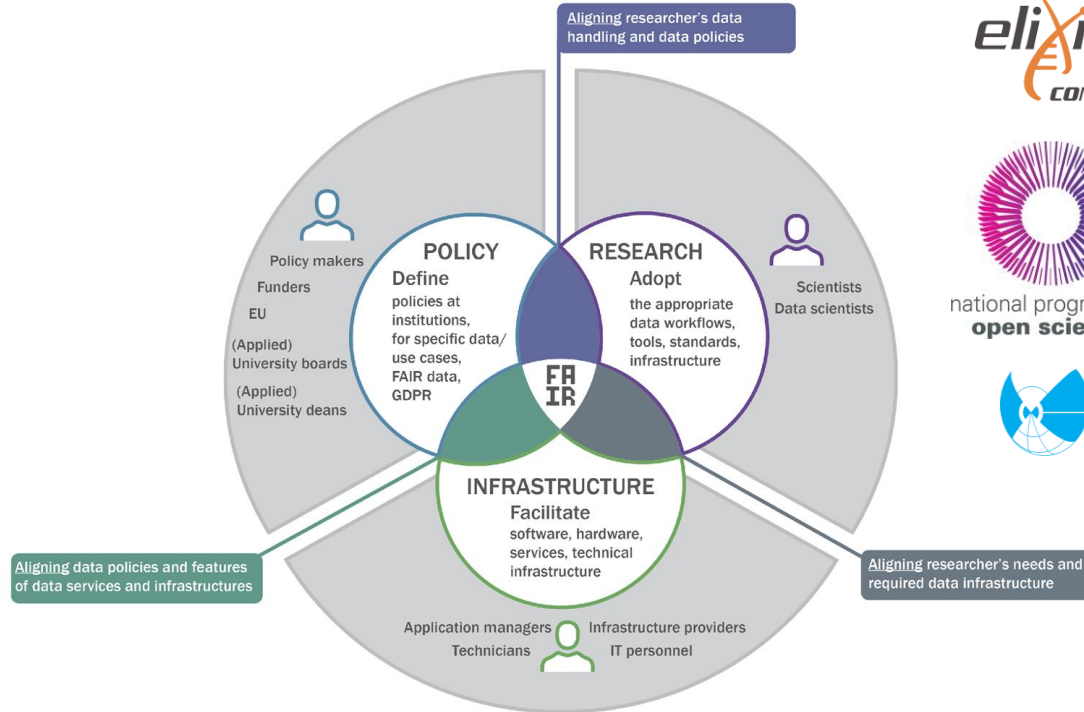


Figure Annex 12.5 Embedded data steward persona (organisational perspective)

What does a data steward/FAIR expert do?



Ask yourself:

- Where are you and your colleagues in the diagram?
- Research-oriented data stewards = data-oriented researchers

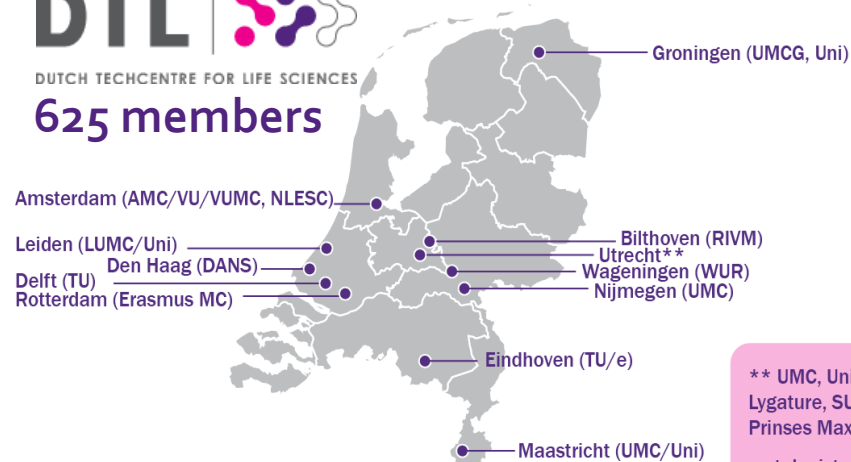
Read full report at <https://doi.org/10.5281/zenodo.4320504>

Data Stewardship Interest Group

A professional community for Data Stewards and alike in "Life Sciences"



625 members



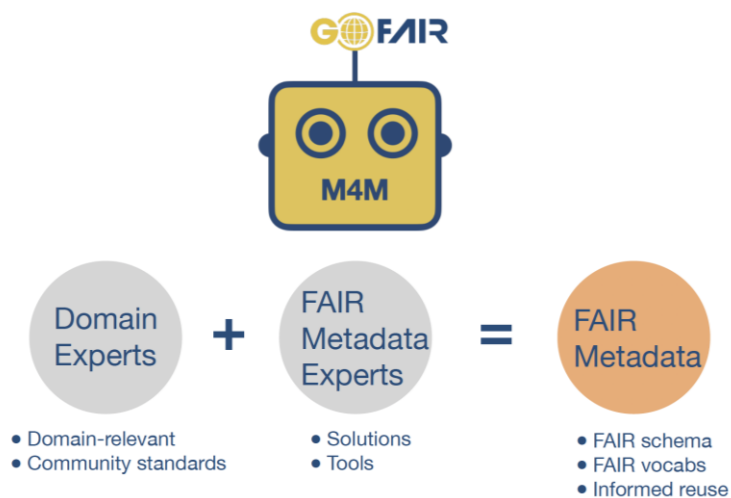
** UMC, University Utrecht, Lygature, SURF, The Hyve, Prinses Maxima Centrum
not depicted:
Ontoforce (Ghent, Belgium)

- Facilitating communities is essential, to exchange experiences and good practices and jointly tackle data challenges
- For many years, DTL facilitates the [Data Stewards Interest Group](#) (DSIG), with regular meetings and a vibrant ([slack channel](#)) community for data stewards and like-minded in the Netherlands and beyond to share experiences and foster the (Dutch) national implementation of data stewardship
- In Health-RI, the [Data Stewardship Community](#) (DSC) unites healthcare data stewards in national collaborations, so each institute does not have to reinvent the wheel locally

ZonMw COVID and AMR/ABR FAIR projects

- Importance of capacity building & the community for data stewards, as a main item of the ZonMw research grant requirements and recommendations
- Embedded in the DSIG community, to prevent to creation of another community
- The data stewards (all disciplines) as catalysts for FAIR data in all future research projects
- [Webinars](#) and [workshops](#) for support and community building to raise awareness and create and share good practices for FAIR data stewardship
- FAIR improvements plans with the AMR/ABR community

Metadata for Machines Workshops



← Dutch COVID-19 Data Support Programme

Workshops on delivering FAIR metadata for COVID-19 data portal

The Dutch research community and health care system are generating much COVID-19 related data. Health-RI and the GO FAIR foundation are developing a portal together with ZonMw that will help researchers find and reuse this data. Access to COVID-19 related data is essential in developing optimal ways of preventing the disease, treating patients and managing the impact of the pandemic for society.

Collaborating on COVID-19 Data Portal

ZonMw funded projects are required to collaborate with Health-RI and Go-FAIR by delivering FAIR (meta)data towards the national platform. Health-RI is organising a series of workshops with ZonMw and the GO-FAIR Foundation to guide researchers and data stewards in developing the COVID FAIR data services and portal.

Community Q&A sessions	▼
M4M Vocabulary Champions Workshop	▼
Project M4M workshops and Portal requirement gathering	▼
Data Stewards Metadata For Machines (M4M) workshop preparation	▼
Information sessions	▼

For more information on the workshops, please contact the [COVID-19 health data portal project leads](#)

[More information on the COVID-19 Health Data Portal](#)



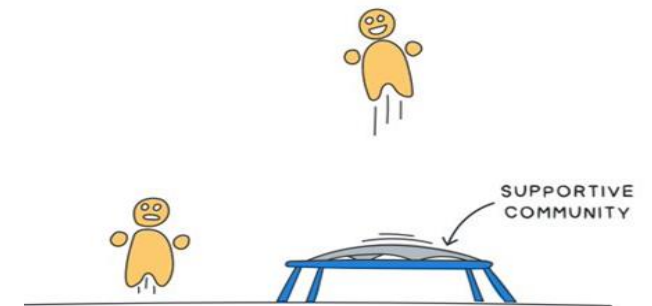
Take aways

With this presentation, I hoped to convince you

- of the **relevance of FAIR data** from a researcher perspective
- how **various initiatives** help to support you as a researcher
- how **communities inspire** to be an even better researcher and/or data steward

Data stewardship is a new profession and things are not set in stone yet

- Research-oriented data stewards = data-oriented researchers
- There is a lot going on in NL (and beyond) where you can build on, for yourself and for your institute
- Discuss current and future roles, responsibilities and tasks in your local team and institute
- Become part of the data stewards community



@OzolinsJanis

Does this resonate with your work? Do you see the benefits of our activities?
Any suggestions how to link to your interests?

Thank your for your time

Contact me if you want to be involved!
(mijke.jetten@health-ri.nl, mijke.jetten@dtls.nl)