

## Health-RI course: FAIR data stewardship basics

Did you recently start a job as a data steward at one of the Health-RI nodes or their regional partners? Or have you been performing data stewardship tasks in the medical field for some time already but need to get a refresher on the FAIR principles and how to apply them in practice? Join this introductory course to FAIR data stewardship in the health domain!

#### **Dates**

The course exists of the following three days, that together form a full course:

- Day 1, 19 June 2023, 10.00 17.00
- Day 2, 20 June 2023, 10.00 17.00
- Day 3, 3 July 2023, 10.00 17.00

#### Location

JIM, 6th floor, Beatrix building, Jaarbeursplein 6, Utrecht (next to Central Station)

#### Language

Will be adjusted to the participants (English and/or Dutch)

## **Target audience**

This introductory course is for data stewards and other data professionals interested in the topic of FAIR data stewardship in the health domain.

#### **Course description**

This course will introduce you to the basics of FAIR data stewardship in the health domain. It will touch upon several topics in research data management and technologies which ease the process of creating and maintaining FAIR research data. The different tasks areas of data stewards will be discussed and there will be presentations of successful implementation of data stewardship in projects dealing with health data. Knowledge can be put into practice in hands-on sessions. You will define your own learning goals and draft a plan for awareness raising in your institution.

#### **Course topics**

We will pass the stages of the data life cycle and the FAIR principles in more detail. The following topics will be discussed at an introductory level:

- Data stewardship task areas and competency framework
- FAIR data stewardship landscape
- FAIR principles
- (Reviewing) data management plans
- ELSI topics (Ethical, Legal, Social Implications)
- Data security and privacy
- Data discovery and capturing data
- Metadata & ontologies
- Infrastructure for storing and sharing data
- Tools for processing and analysing data
- Organising, versioning and documenting data
- Data and software carpentry
- Publishing and archiving data
- Raising awareness on FAIR



The detailed course program can be found below.

#### **Required skills**

There are no formal prerequisites for the workshop, but participants are expected to be familiar with research methods in the health domain. Also, it is recommended to study the online materials of the RDNL <u>Essentials 4 Data Support</u> course beforehand if you're new to data stewardship.

#### **Learning objectives**

Participants will be able to:

- describe their data stewardship profile and competencies needed in their daily practice
- reflect on their learning goals
- explain the different phases in the research data life cycle
- explain the importance of the FAIR principles during a research project's life cycle
- understand the importance of metadata standardization
- understand the importance of software sustainability
- evaluate data management practices described in a Data Management Plan
- recognize ethical, legal or societal implications of data sharing
- advise researchers on services and tools during the research data life cycle
- understand the concept of the carpentries and data cleaning
- organise awareness raising activities for their target groups

## **Registration & Certification**

There is a maximum of 20 participants.

There is no registration fee, but participants from Health-RI partners have priority access. You can register via the <u>registration form</u>.

Participants register for the full programme and attend all three course days. Only those who attended the full course receive a certificate of attendance.

### Partners for this course

The training is organised by Health-RI and its regional partners (Amsterdam UMC, Erasmus MC, LUMC, MUMC+, Radboudumc, UMCG, UMCU and e/MTIC)

## Trainers / organisers

Fieke Schoots & Mijke Jetten, FAIR Data Implementation team Health-RI Trainers & speakers from Health-RI Regional Nodes and partners

Contact: fairservicedesk@health-ri.nl



# Course program

Day 1	Topic	Trainers	Туре
9.45 –	Coffee/tea		
10.00			
10.00	Welcome	Course organisers	Informal;
11.00	- Getting to know each other		Presentation
	- Programme		
	- Introduction into Health-RI and FAIR		
	data stewardship landscape; - Introduction into research data life		
	cycle and FAIR principles		
	https://doi.org/10.5281/zenodo.8116590		
11.00 -	Demonstrator project: <u>Duchenne Data</u>	Nawel Lalout, Project	Presentation
11.30	Platform	Manager Duchenne	
		FAIR Data	
11.30 -	Coffee break		
11.45			
11.45 –	Data stewardship: introduction to profiles	Course organisers	Group activity
12.30	and competencies		
	- What kind of data steward are you?		
12.20	- What are your learning goals?		
12.30 – 13.15	Lunch break		
13.15 –	Perspective on FAIR data stewardship from	Ellen Carbo, ZonMW	Presentation
14.00	funder	Elleli Carbo, Zollivivi	Fresentation
14.00 -	Tea break		
14.15	red break		
14.15 -	Data Management Planning	Petra Overveld,	Presentation;
15.30	- Reviewing Data Management Plans	LUMC	Hands-on
	activity		
15.30 –	Ethical, Legal and Societal Implications	- Elize Vlainic,	Presentation;
16.30	(ELSI) of FAIR data	AUMC,	Hands-on
	- Informed consent	- Miriam Beusink,	
	- Frequently Asked Questions (and	ELSI Team	
	answers)	Health-RI	
16.30 -	Wrap-up	Course organisers	
16.45			



Day 2	Topic	Trainers	Туре
9.45 –	Coffee/tea		
10.00			
10.00 -	Welcome & Recap & Program	Course organisers	Informal
10.15	https://doi.org/10.5281/zenodo.8116590		
10.15 –	Capturing data (iCRF)	Sander de Ridder &	Presentation;
11.15		Jeroen Beliën,	Hands-on
		Health-RI	
11.15 -	Coffee break		
11.30		5 .	
11.30 -	- European Joint Programme on Rare	- Nirupama Benis,	Presentation
12.30	Diseases (EJP-RD) example & FAIRopoly - FAIRification Workflow	AUMC, EJP-RD - Jolanda Strubel	
	- FAIRification Workflow	- Jolanda Strubel & Sander de	
		Ridder, Health-RI	
12.30 -	Lunch break	Ridder, Health-Ki	
13.00	Lunch break		
13.00 -	- Metadata: introduction	- Bruna Vieira dos	Presentation
14.00	- FAIR Data Point Populator	Santos, Health-RI	T Teseritation
		- Daphne	
		Wijnbergen,	
		LUMC	
14.00 -	FAIR data point populator		Hands-on
15.00			
15.00 -	Tea break		
15.15			
15.15 –	Health-RI metadata portal	Marianne Knoop	Presentation
15.45		Pathuis-Baarda,	
		Health-RI	
15.45 –	- Metadata activity (continued)	Health-RI FAIR team	Hands-on
16:15		_	
16.15 -	Wrap-up	Course organisers	
16.30			



Day 3	Topic	Trainers	Туре
9.45 –	Coffee/tea		
10.00			
10.00 -	Welcome & Recap Program:	Course organisers	Informal
10.15	https://doi.org/10.5281/zenodo.8116590		
10.15 -	Software sustainability	Carlos Martinez Ortiz	Presentation
10.45		(eScience center)	
10.45 –	Coffee break		
11.00			
11.00 -	Publishing and archiving data:	Cees Hof & Kim	Presentation +
12.00	https://doi.org/10.5281/zenodo.8101838	Ferguson, DANS	hands-on
12:00-	Sharing images	Esther Bron, Health-	Presentation
12:00	Sharing images	RI architecture team	riesentation
12.13		/ Erasmus UMC	
12.15 –	Lunch break		
12.45			
12.45 –	Carpentry lesson: Data Organization in	Kristina Hettne,	Hands-on
14.15	Spreadsheets (for Social Scientists)	Centre for Digital	
		Scholarship, Leiden	
		University & Carpentry instructor	
14.15 –	Tea break	carpenary matractor	
14.30			
14.30 -	Awareness raising & community building	Course organisers	Group activity
15.30	- Group activity: how to raise awareness		
	on FAIR in your institution		
15.30 –	Evaluation of initial learning goals and	Course organisers	
16.15	wrap-up		
16.15 –	Drinks		
17.00			