



RDM & FAIR for Dynamics of Youth

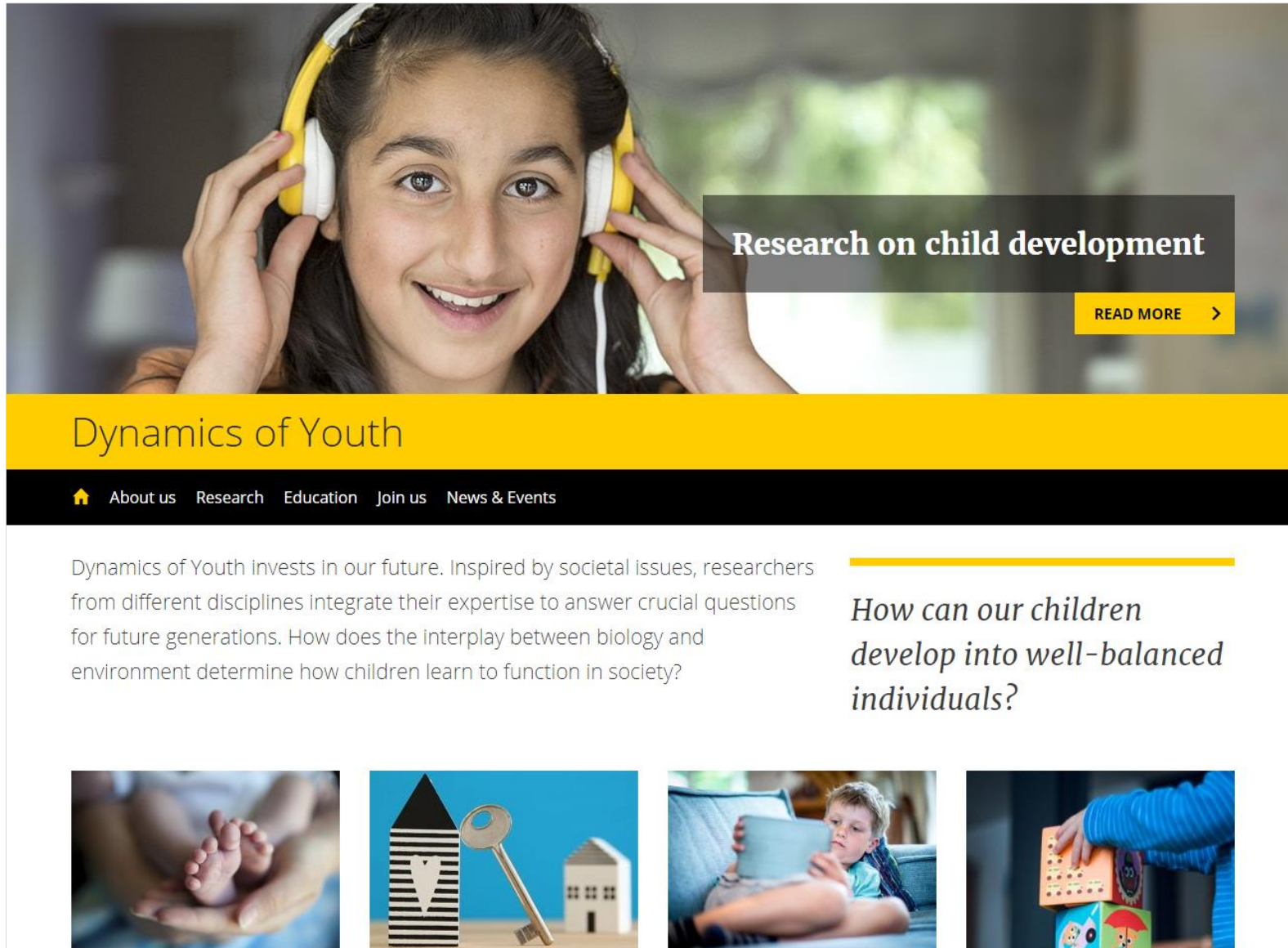
Neha Moopen

Research Data Manager

SO YOU WANT TO MAKE YOUR DATA FAIR

BUT

- ...you don't have the time 🕒
- ...you don't have the money 💰
- ...you don't have any incentive 😊
- ...you just don't know where to start 🤔



INTRODUCTION 🙌

- DoY has the aim to improve the FAIRness of data within the strategic theme.
- They have arranged for a Research Data Manager to be embedded in DoY for 3x days per week.
- 🕒 💰 🧑 is taken care of.

INTRODUCTION 🙌

- [Research Data Manager](#) @ University Library
- We support researchers with everything RDM, in line with open science & FAIR principles.
- More information: [RDM Support website](#)



ACTIVITIES



Hands-On Support
& Consultancy



Data Catalog



FAIR Data Handbook

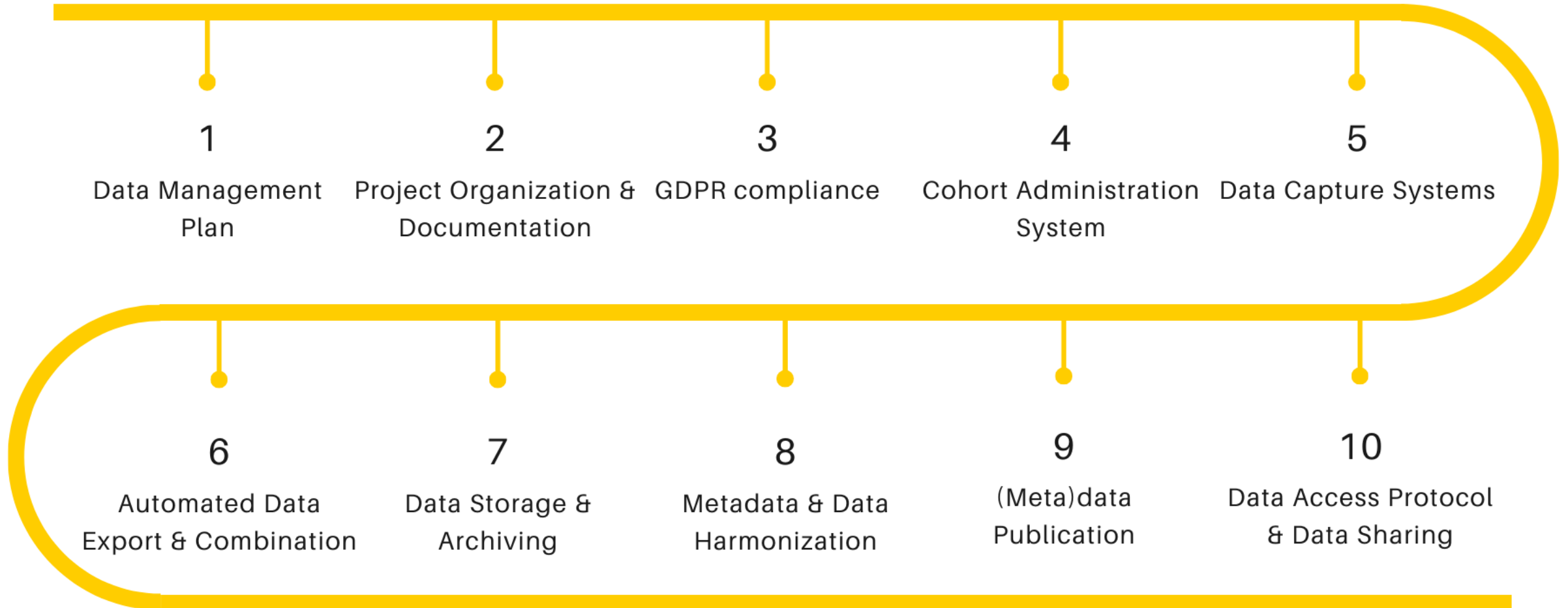


Community Building



Workshops & Training

PROactive Cohort Study: THE FAIRification PROCESS




PROactive Cohort Study: OUTCOMES

Nijhof, Sanne; Putte, Elise van de; Hoefnagels, Johanna Wilhelmina, 2021, "PROactive Cohort Study", <https://doi.org/10.34894/FXUGHW>, DataverseNL, V7

As Open as Possible, as Closed as Necessary:

The data itself is not published, but there is a DOI for findability and citeability. There is extensive metadata and documentation (including Data Access Guidelines) that outline the Accessibility and ensures Reusability.






Pediatrics
(UMCU)

DataverseNL > University Medical Center Utrecht > Pediatrics >

PROactive Cohort Study

Version 7.0



Nijhof, Sanne; Putte, Elise van de; Hoefnagels, Johanna Wilhelmina, 2021, "PROactive Cohort Study", <https://doi.org/10.34894/FXUGHW>, DataverseNL, V7

[Cite Dataset](#) [Learn about Data Citation Standards.](#)

Description ⓘ

Children with a chronic disease face more obstacles than their healthy peers, which may impact their physical, social-emotional, and cognitive development. In the long run, children with a chronic disease reach developmental milestones later than their healthy peers and many children will remain dependent on medication and/ or will be limited in their daily life activities.

The PROactive Cohort Study aims to assess fatigue, participation, and psychosocial well-being across children with various chronic diseases over the course of their lifespan since their increased vulnerability is a fact. These factors have the potential to influence their identity and how they grow into autonomous adults that take part in our society. Also the PROactive Cohort Study is aimed at supporting people with chronic and/or life-threatening conditions to increase their ability to adapt, and

[Read full Description \[+\]](#)

Subject ⓘ

Medicine, Health and Life Sciences; Social Sciences

Keyword ⓘ

Child Health, Chronic Disease, Lifecycle Paediatrics, Biopsychosocial Model, PROactive

Related Publication ⓘ

der Vlist, M.M.Nv., Hoefnagels, J.W., Dalmeijer, G.W. et al. The PROactive cohort study: rationale, design, and study procedures. Eur J Epidemiol (2022). <https://doi.org/10.1007/s10654-022-00889-y>
doi: <https://doi.org/10.1007/s10654-022-00889-y>

License/Data Use Agreement


[Custom Dataset Terms](#)

PROactive Cohort Study: OUTCOMES

Nap- van der Vlist, M., Hoefnagels, J.W., Dalmeijer, G.W. *et al.* The PROactive cohort study: rationale, design, and study procedures. *Eur J Epidemiol* **37**, 993–1002 (2022). <https://doi.org/10.1007/s10654-022-00889-y>

COHORT PROFILE | [Open Access](#) | [Published: 18 August 2022](#)

The PROactive cohort study: rationale, design, and study procedures

[Merel M. Nap- van der Vlist](#), [Johanna W. Hoefnagels](#) , [Geertje W. Dalmeijer](#), [Neha Moopen](#), [Cornelis K. van der Ent](#), [Joost F. Swart](#), [Elise M. van de Putte](#) & [Sanne L. Nijhof](#)

European Journal of Epidemiology **37**, 993–1002 (2022) | [Cite this article](#)

1344 Accesses | [Metrics](#)



This article has been [updated](#)

Abstract

Children with a chronic condition face more obstacles than their healthy peers, which may impact their physical, social-emotional, and cognitive development. The PROactive cohort study identifies children with a chronic disease at high risk of debilitating fatigue, decreased daily life participation and psychosocial problems, as well as children who are resilient and thrive despite the challenges of growing up with a chronic condition. Both groups will teach us how we can best support children, adolescents and parents to adapt to and manage a disease, as well as tailor interventions to their specific needs.

This cohort follows a continuous longitudinal design. It is based at the Wilhelmina Children's

PROactive Cohort Study: OUTCOMES

GitHub: <https://github.com/proactive-cohort-study>

DOI: Nijhof, S., Hoefnagels, J. W., der Vlist, M. N., & Moopen, N. (2023, August 16). PROactive Cohort Study: Scripts.
<https://doi.org/10.17605/OSF.IO/3U4QZ>



The screenshot shows the GitHub repository page for 'proactive-cohort-study'. The repository has 4 repositories, 3 people, and 1 follower. The README file is displayed, featuring the title 'PROactive Cohort Study' in large blue text. Below the title, there are three links with their respective DOIs: 'Cohort Design Publication' (https://doi.org/10.1007/s10654-022-00889-y), 'DataverseNL' (https://doi.org/10.34894/FXUGHW), and 'OSF' (https://doi.org/10.17605/OSF.IO/3U4QZ). The README text describes the study as identifying children with a chronic disease at high risk of debilitating fatigue, decreased daily life participation, and psychosocial problems, as well as children who are resilient and thrive despite the challenges of growing up with a chronic condition. The study is based at the Wilhelmina Children's Hospital (WKZ) in the Netherlands and has been running since December 2016.

proactive-cohort-study

Overview Repositories 4 Projects Packages Teams People 3 Settings

PROactive Cohort Study

1 follower Netherlands

README .md

PROactive Cohort Study

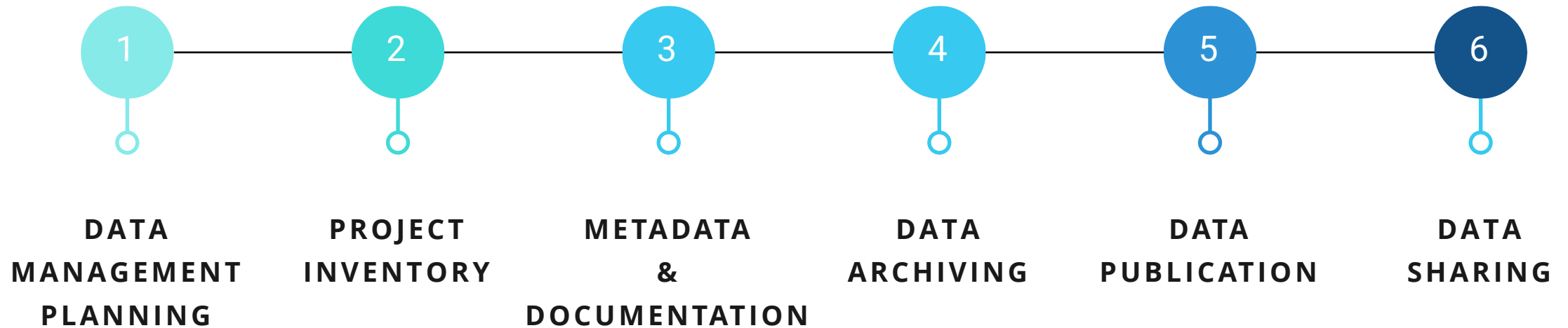
Cohort Design Publication <https://doi.org/10.1007/s10654-022-00889-y>

DataverseNL <https://doi.org/10.34894/FXUGHW>

OSF <https://doi.org/10.17605/OSF.IO/3U4QZ>

The PROactive cohort study identifies children with a chronic disease at high risk of debilitating fatigue, decreased daily life participation and psychosocial problems, as well as children who are resilient and thrive despite the challenges of growing up with a chronic condition. Both groups will teach us how we can best support children, adolescents and parents to adapt to and manage a disease, as well as tailor interventions to their specific needs. This cohort follows a continuous longitudinal design. It is based at the Wilhelmina Children's Hospital (WKZ) in the Netherlands and has been running since December 2016.

Belonging Project: The FAIRification Process



DoY Data Catalog

As we make DoY data more FAIR, we want to list all the datasets in a data catalog to maximize findability. This activity consists of two components:

DoY Data Roadmap (Survey)

As a short-term goal, we want to build a lightweight overview of data available within DoY. The DoY Data Roadmap can encompass studies that are not FAIRified as well.


This overview begins with a brief Qualtrics survey where researchers can fill out information about their project. The studies will be presented in a standardized way in the overview, so it will be easier to explore.

DoY Data Catalog (CKAN)

As a long-term goal, we wish to build a data cataog based on CKAN which can list all of the FAIRified data based on their DOIs or repositories where they have been deposited.



QR code for DoY Data Roadmap



Consortium on Individual Development

[Browse datasets](#)[Catalogue guide](#)[News](#)[About CID](#)

Advanced Search

All studies

Search 465 datasets, from 4 studies, and 7 cohorts

Most used labels

mental healthparentingquestionnairedemographics

cognitionpersonalitydiagnosis

parent-child relationshipanxiety more...

Most used constructs

Mental healthPhysiologyCognitionPersonality

ParentingPhysical health

Sociocognitive and emotional development

Sociocognitive-and-emotional developmentLifestyle

more...

Recently updated

Early Adolescent Temperament

Family Assessment Device (FAD)

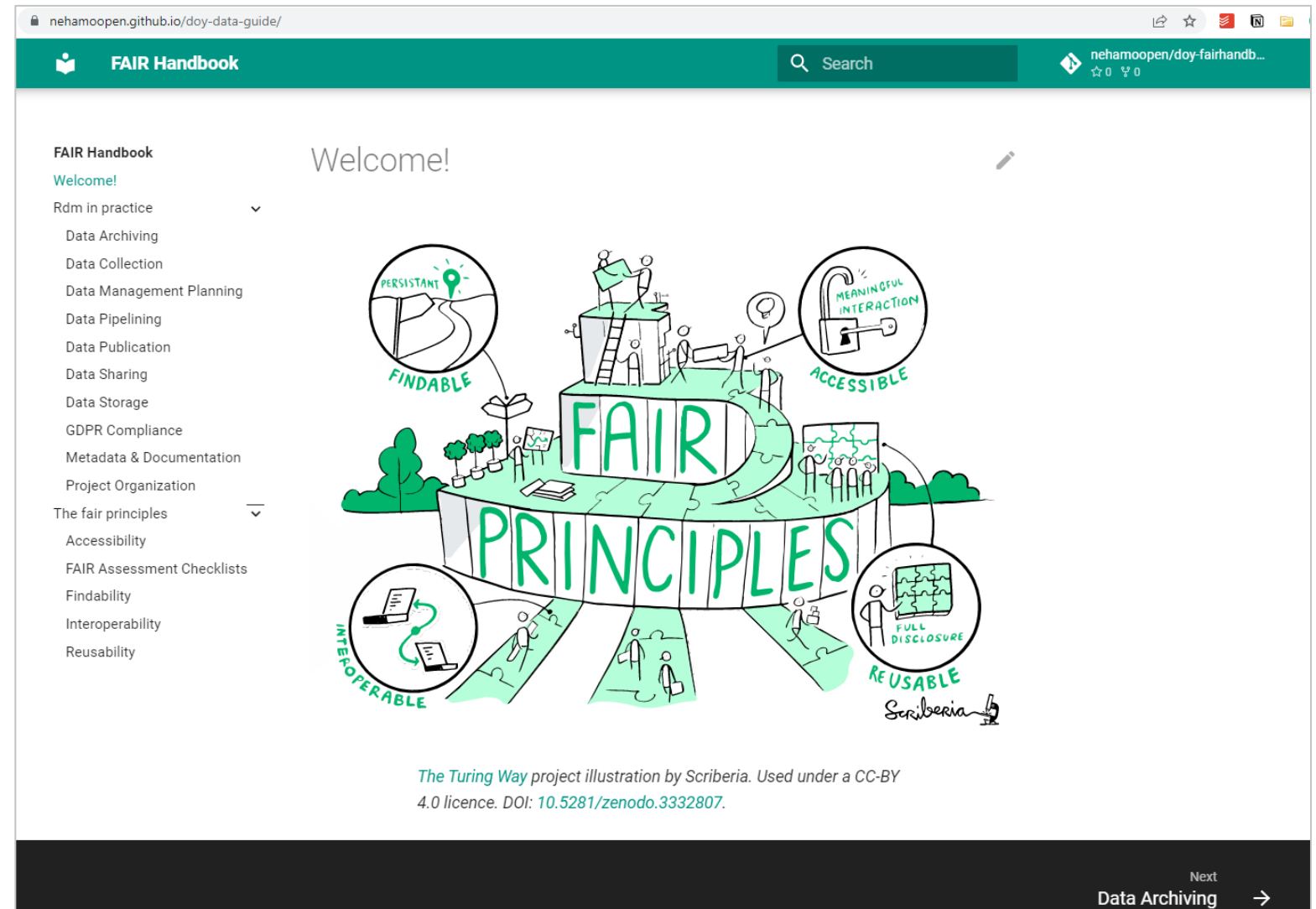
Pandemic Questionnaire

DoY Data Handbook

A [DoY Data Handbook](#) is in the works.

It is not meant to reinvent the wheel (of existing information) but curate what is available in a brief manner + incorporate resources already circulating within the DoY community.

It is also something we hope to building a community/conversation around.



The screenshot shows the FAIR Handbook website. The header includes the title "FAIR Handbook" and a search bar. The main content area features a large illustration of the FAIR Principles, which are represented as puzzle pieces forming a circular structure. The principles are: FINDABLE (with a lightbulb icon), ACCESSIBLE (with a padlock icon), REUSABLE (with a puzzle piece icon), and INTEROPERABLE (with a puzzle piece icon). The central text "FAIR PRINCIPLES" is prominently displayed. Below the illustration, there is a caption: "The Turing Way project illustration by Scriberia. Used under a CC-BY 4.0 licence. DOI: 10.5281/zenodo.3332807." The left sidebar lists various topics under the heading "FAIR Handbook", including "Welcome!", "Rdm in practice", "Data Archiving", "Data Collection", "Data Management Planning", "Data Pipelining", "Data Publication", "Data Sharing", "Data Storage", "GDPR Compliance", "Metadata & Documentation", "Project Organization", "The fair principles", "Accessibility", "FAIR Assessment Checklists", "Findability", "Interoperability", and "Reusability".

nehamoopen.github.io/doy-data-guide/

FAIR Handbook

Welcome!

Rdm in practice

- Data Archiving
- Data Collection
- Data Management Planning
- Data Pipelining
- Data Publication
- Data Sharing
- Data Storage
- GDPR Compliance
- Metadata & Documentation
- Project Organization

The fair principles

- Accessibility
- FAIR Assessment Checklists
- Findability
- Interoperability
- Reusability

FAIR PRINCIPLES

FINDABLE

ACCESSIBLE

REUSABLE

INTEROPERABLE

Full Disclosure

Scriberia

The Turing Way project illustration by Scriberia. Used under a CC-BY 4.0 licence. DOI: 10.5281/zenodo.3332807.

Next
Data Archiving →

WHAT BROUGHT YOU HERE?

- How can UMCU science managers learn to trust UU staff?
- I'm new at the faculty so it would be great to meet other colleagues and learn about opportunities to collaborate, including data sharing. |
- I would like to learn what people need to share data and to apply FAIR data principles.
- Meeting people
- With respect to transcripts, is meta-data sufficiently FAIR? I feel that others would then only be able to use our data the same way we have (we only measure certain variables from the transcripts that are useful for us), and not use the data for other purposes.
- Tips and tricks for turning existing datasets into FAIR datasets
Tips and tricks for when you start a new data collection (how can you design your datamanagement in such a way that it helps with making your data FAIR)

That's the short version!

READING TIP

[FAIR, safe and high-quality data: The data infrastructure and accessibility of the YOUth cohort study](#)

QUESTIONS?

You can get in touch anytime!

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Utrecht University



UMC Utrecht

DISCLAIMER

The information in this presentation has been compiled with the utmost care,
but no rights can be derived from its contents.