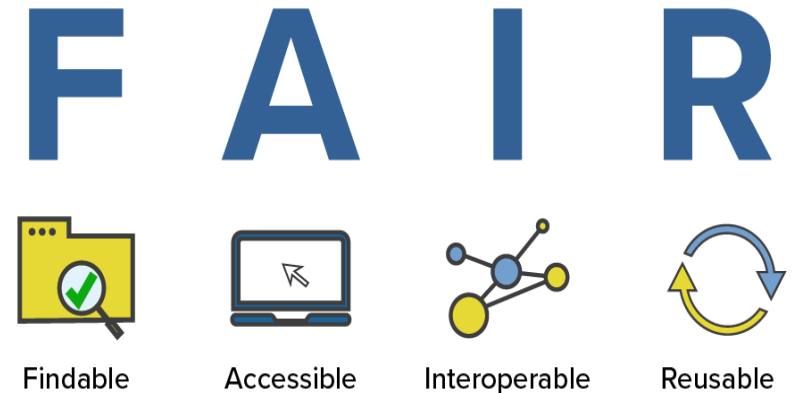


# *FAIR Data Project*

*Neha Moopen | Research Data Manager*

# Dynamics of Youth - Voordelen FAIR data

- Meer zichtbaarheid
- Breder scala aan vragen beantwoorden
- Uitwisselen datasets
- Nieuwe samenwerkingen



# FAIR data project

## Meetings met onderzoekers - Ophalen belemmeringen en behoeften

- Geen tijd om data FAIR te maken
- Gevoel van overweldiging
- Onbekendheid met FAIR principles
- Onvoldoende beloning en erkenning
- Twijfels over AVG
- Onbekendheid met bestaande infrastructuur

# FAIR data project

## FAIR data handbook

→ Handvat bij FAIRification: tips en tools

## Ondersteunen onderzoekers bij projecten

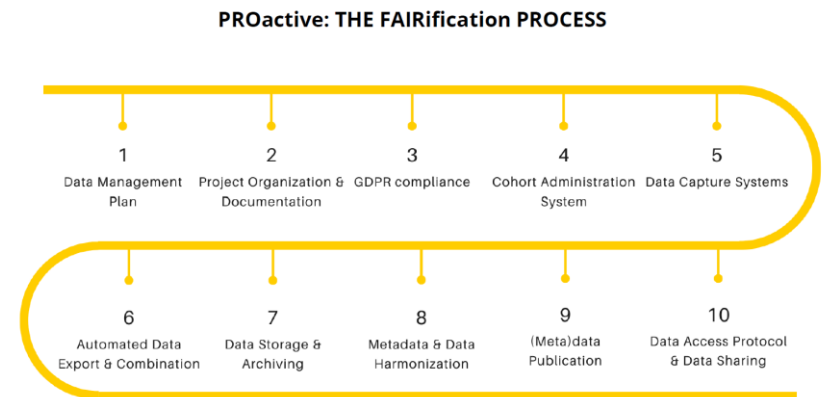
→ Ontwikkelen FAIR workflow

## FAIR data meetings

→ Uitwisselen kennis en ervaringen

## DoY catalog

→ Data zoeken o.b.v. kernwoorden



# FAIR data project

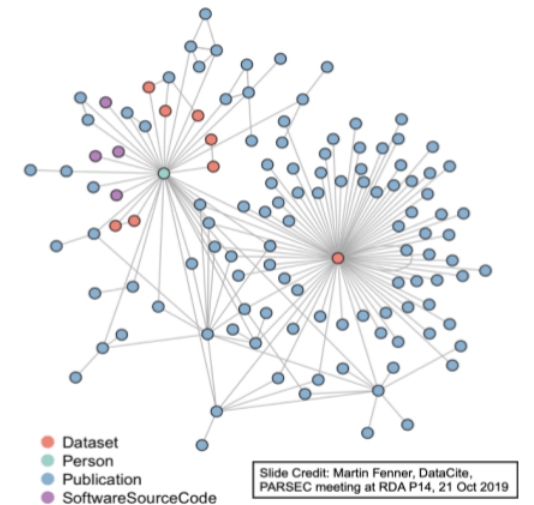
Waar lopen we tot nu toe tegenaan?

- FAIR data heeft geen prioriteit voor onderzoekers
- Onderzoekers weten ons niet te vinden
- Duurzaamheid
- Samenwerking UU en UMCU

# FAIR data project

## Vervolgstappen

- 'FAIRification of people'
- DoY incentives voor FAIR maken van data en hergebruik van data
- Cohorten
  - Visie
  - Obstakels



## A LITTLE MORE IN DETAIL... 😊

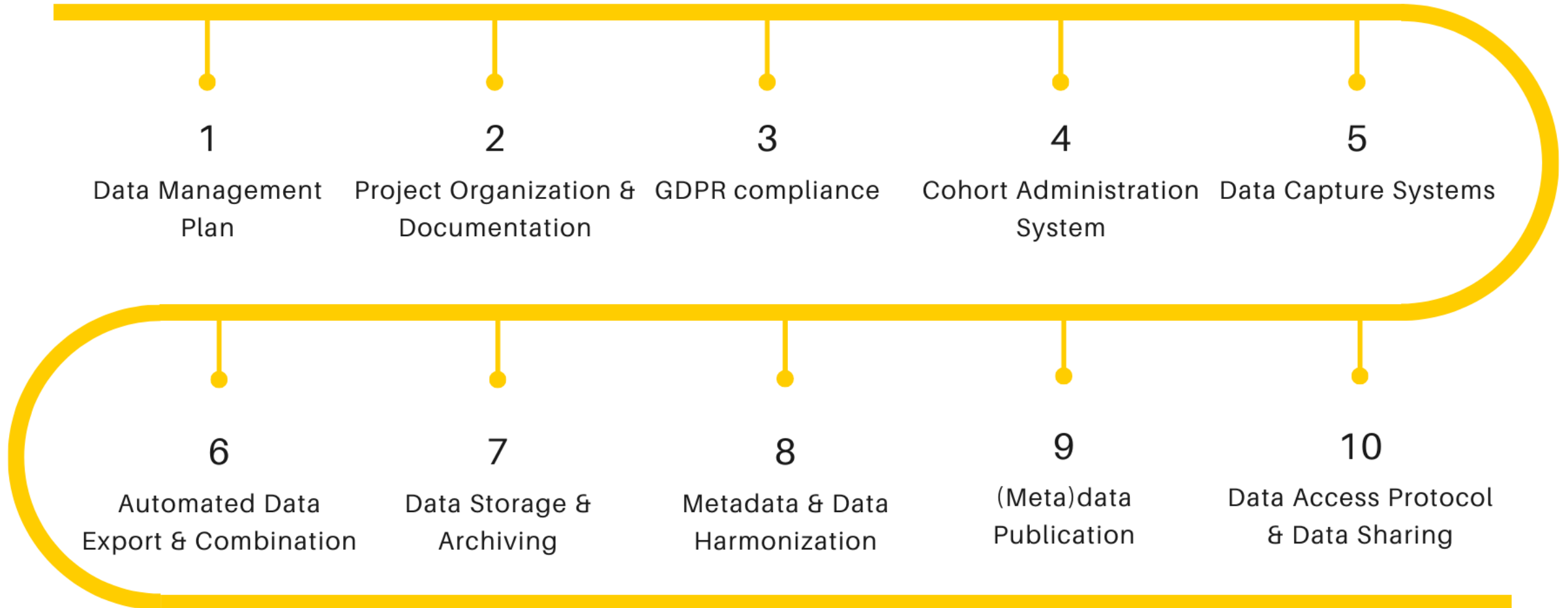
- FAIRification of:
  - PROactive Cohort Study (UMCU/WKZ)
  - Belonging project (FSW)
- DoY Data Catalog
- DoY Data Handbook

# PROactive Cohort Study: NEEDS & REQUIREMENTS

- More efficiency in data management / data workflow.
- Automation wherever possible.
- Solutions for collaboration & data sharing: should be efficient, structured, and secure.
- Findability and visibility.
- Homogenization with other cohorts.
- Upgrade data management and storage systems.
- The patient remains central, that can't be compromised.



# 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](#)

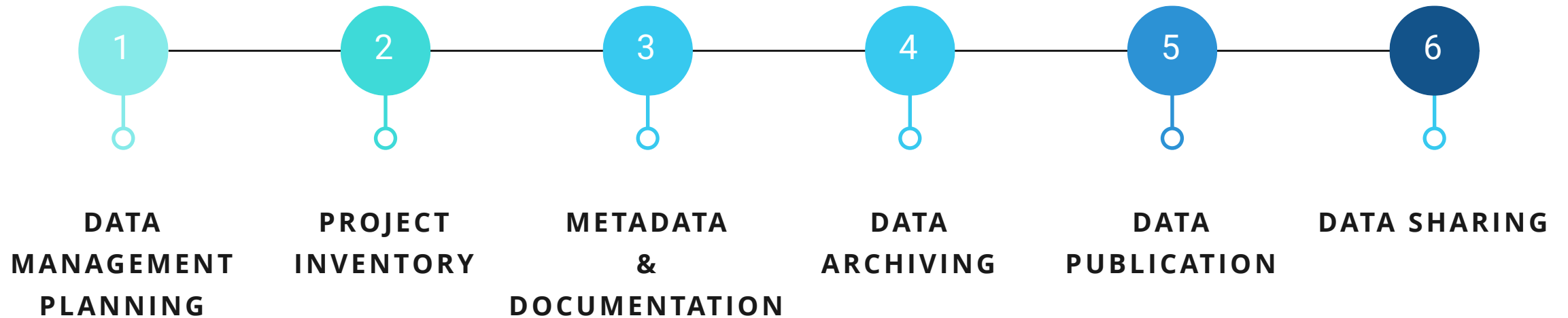
 This article has been [updated](#)

### 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

# Belonging Project: The FAIRification Process











# Belonging Project: so far...

## Current Challenges (for Belonging & Beyond):

- How to achieve **As Open as Possible, as Closed as Necessary** within Yoda? The infrastucture does not allow for selective publication/restriction of (sub)folders. Can this be implemented or is there a workaround?
- **Data Governance & Sustainability:** The project has effectively come to an end. The researchers are happy to have their data reused, but they only have the time to review and approve/reject data request forms, not necessarily prepare the requested data package and hand it over to the requesting researcher.

## research-belonging

- | <input type="checkbox"/> | Name  |
|--------------------------|---|
| <input type="checkbox"/> |  01-study-documentation    |
| <input type="checkbox"/> |  02-data-documentation     |
| <input type="checkbox"/> |  03-materials              |
| <input type="checkbox"/> |  04-raw-data              |
| <input type="checkbox"/> |  05-processed-data       |
| <input type="checkbox"/> |  06-data-access-protocol |
| <input type="checkbox"/> |  07-archive              |
| <input type="checkbox"/> |  00-README.txt           |

# DoY Data Catalog

We wish to develop a data catalog for Dynamics of Youth, using CKAN.

Similar data catalogs have been/are being implanted at UU: [EPOS](#) & Institutions for Open Societies.

We are attempting to align with the CD2 Catalog project within the [Consortium of Individual Development](#).

Still ongoing, it is currently an exercise in making the CKAN development scripts reproducible for those outside the CD2 project.

The screenshot shows the DoY Data Catalog website. At the top left is the logo for the Consortium on Individual Development (CID), which consists of a stylized 'C' made of three colored segments (blue, green, orange) and the text 'Consortium on Individual Development'. To the right of the logo are navigation links: 'Browse datasets', 'Catalogue guide', 'News', and 'About CID'. Below the navigation links is a large banner image showing a close-up of a rock surface with a dark, branching pattern. Overlaid on the banner is a search bar with the text 'Search 465 datasets, from 4 studies, and 7 cohorts' and a magnifying glass icon. To the left of the search bar is a dropdown menu labeled 'All studies' and a button labeled 'Advanced Search'. Below the banner, there are two sections: 'Most used labels' and 'Most used constructs'. The 'Most used labels' section lists: mental health, parenting, questionnaire, demographics, cognition, personality, diagnosis, parent-child relationship, anxiety, and more... The 'Most used constructs' section lists: Mental health, Physiology, Cognition, Personality, Parenting, Physical health, Sociocognitive and emotional development, Sociocognitive-and-emotional development, Lifestyle, and more... At the bottom, there is a section titled 'Recently updated' which contains three items: 'Early Adolescent Temperament', 'Family Assessment Device (FAD)', and 'Pandemic Questionnaire'. Each item has a right-pointing arrow icon next to it.

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 health parenting questionnaire demographics cognition personality diagnosis parent-child relationship anxiety more...

**Most used constructs**

Mental health Physiology Cognition Personality Parenting Physical health Sociocognitive and emotional development Sociocognitive-and-emotional development Lifestyle 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 at [nehamoopen.github.io/doy-data-guide/](https://nehamoopen.github.io/doy-data-guide/). The page has a teal header with the title "FAIR Handbook" and a search bar. A left sidebar lists navigation options: "Welcome!", "Rdm in practice" (with sub-items: Data Archiving, Data Collection, Data Management Planning, Data Pipelining, Data Publication, Data Sharing, Data Storage, GDPR Compliance, Metadata & Documentation, Project Organization), and "The fair principles" (with sub-items: Accessibility, FAIR Assessment Checklists, Findability, Interoperability, Reusability). The main content area features a "Welcome!" message and a large, colorful illustration of the FAIR Principles. The illustration depicts a large puzzle forming the words "FAIR PRINCIPLES". Surrounding the puzzle are five circular icons: "FINDABLE" (with a lightbulb and "PERSISTENT"), "ACCESSIBLE" (with a padlock and "MEANINGFUL INTERACTION"), "REUSABLE" (with a puzzle piece and "FULL DISCLOSURE"), "INTEROPERABLE" (with two puzzle pieces), and "FAIR" (with a person). The signature "Scriberia" is at the bottom right of the illustration. Below the illustration, a caption reads: "The Turing Way project illustration by Scriberia. Used under a CC-BY 4.0 licence. DOI: [10.5281/zenodo.3332807](https://doi.org/10.5281/zenodo.3332807)." The footer of the page includes the Universiteit Utrecht logo and the text "Next Data Archiving →".



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*shaping tomorrow*