



*As Open As Possible,
As Closed As Necessary.*

Neha Moopen

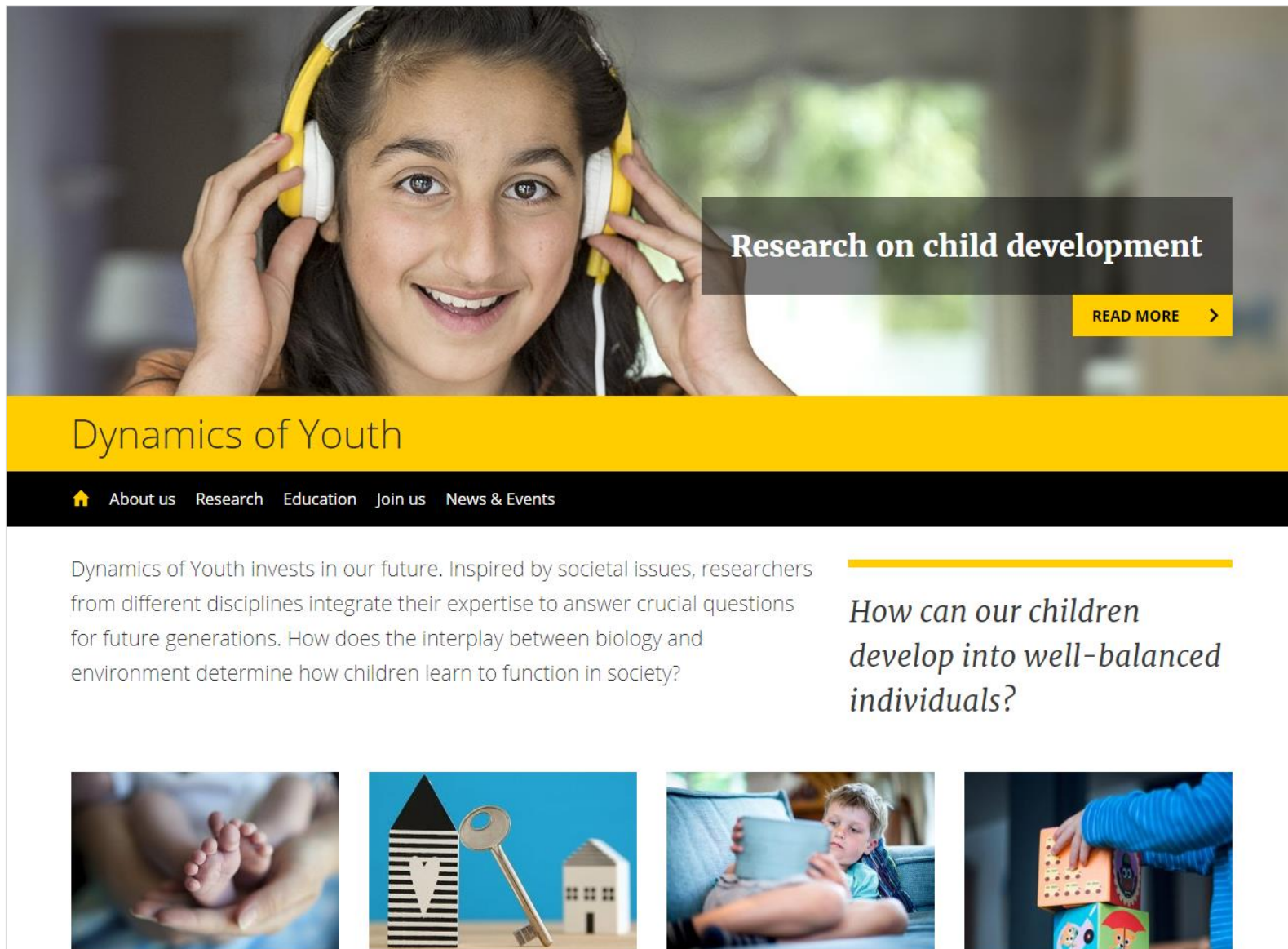
Research Data Manager

INTRODUCTION 🙌

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



image: <https://www.archilovers.com/projects/130396/utrecht-university-library.html>



INTRODUCTION 🙌

I support the strategic theme *Dynamics of Youth* with activities related to RDM & FAIR for 3x days per week.



Background

“I like open science...but I cannot just make my data open because it’s sensitive data from children and parents”

Definitions

in context

RESEARCH DATA MANAGEMENT

RDM = an activity / practice

FAIR DATA

FAIR = principles that guide RDM activities / practices

OPEN DATA

data does not have to be 'open' to be FAIR!

YOUR DATA DOESN'T HAVE TO BE OPEN TO BE FAIR...



What does “as open as possible, as closed as necessary” mean?

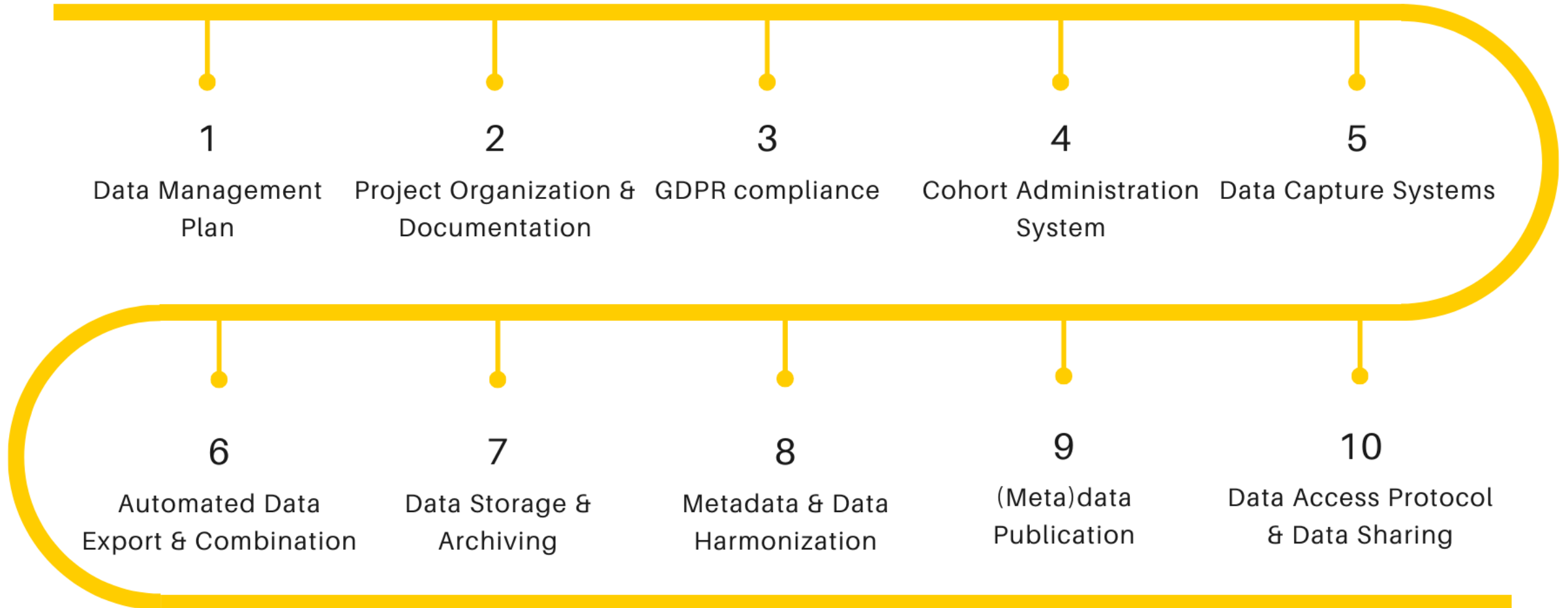
Results and data may be kept closed if making them public in open access is against the researcher’s legitimate interests. Examples include to commercially exploit their research results, or if it is against any obligations mentioned in the Grant Agreement (e.g. personal data protection).

Source: https://rea.ec.europa.eu/open-science_en



Use Case

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)

At

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 the PROactive Cohort Study. The repository is owned by 'proactive-cohort-study' and has 4 repositories, 3 projects, 3 packages, 3 teams, and 3 people. The repository name is 'PROactive Cohort Study' and it has 1 follower and is located in the Netherlands. The repository contains a README.md file. The README file has a title 'PROactive Cohort Study' and a description: '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.' The README file also includes links to the Cohort Design Publication, DataverseNL, and OSF.

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.

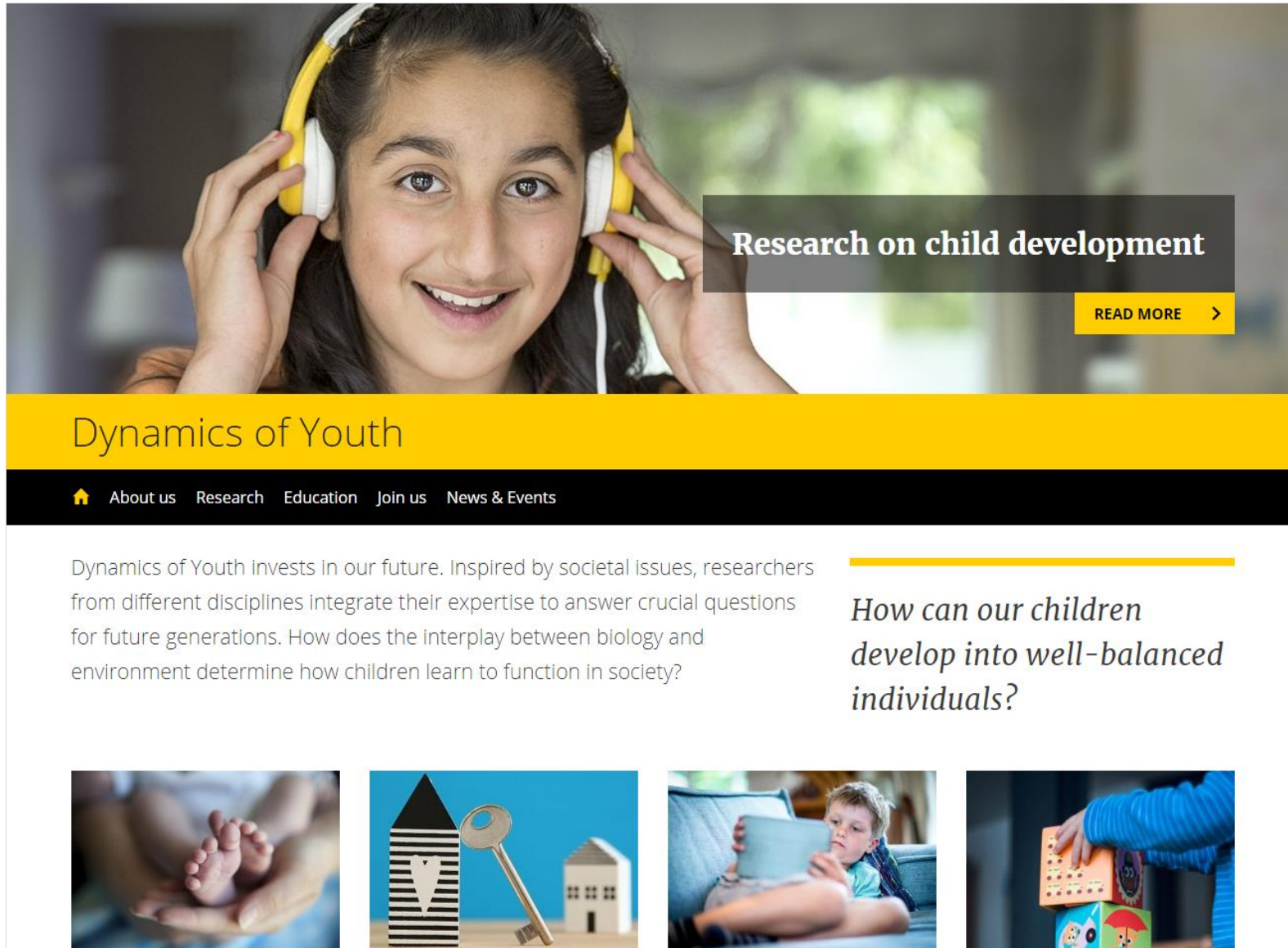


Team Science

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.

ACTIVITIES



Hands-On Support
& Consultancy



Data Catalog



FAIR Data Handbook

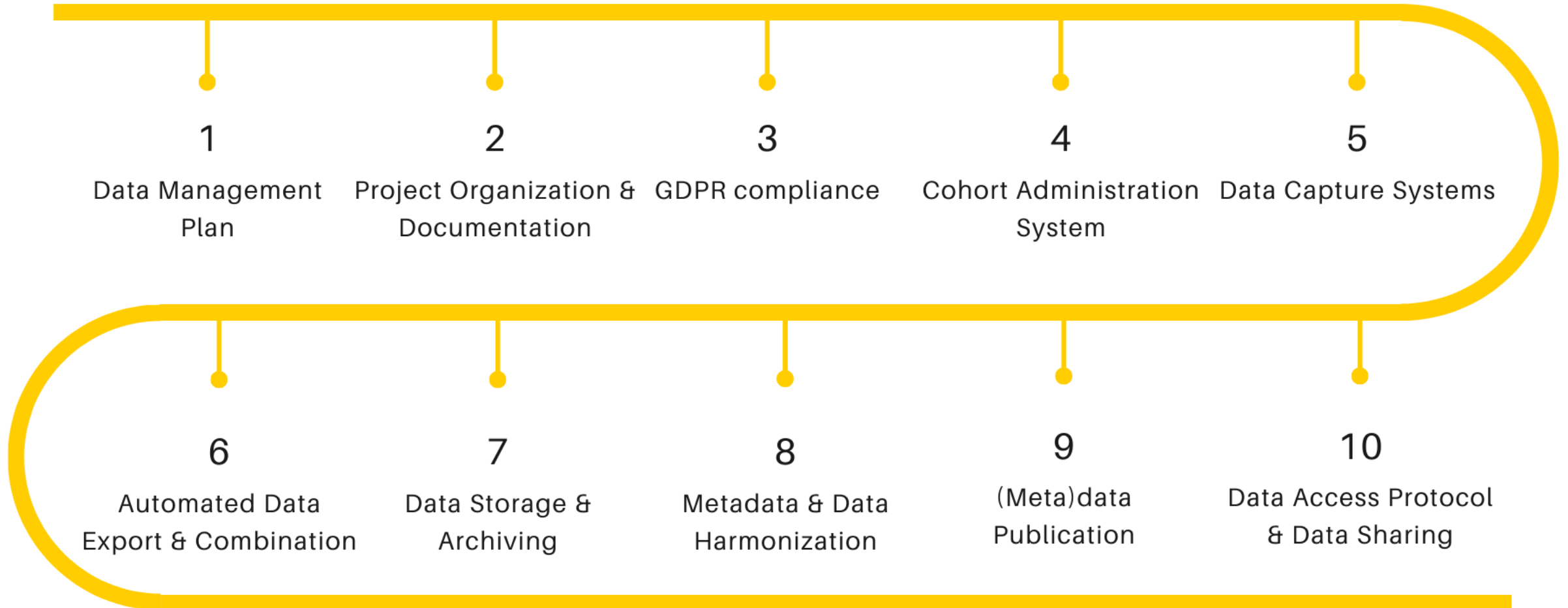


Community Building



Workshops & Training

PROactive Cohort Study: THE FAIRification PROCESS





Take-Home Message

Your data doesn't have to open to be FAIR

*You don't have to do everything yourself.
Open Science is Team Science!*



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.