

# CD<sup>2</sup>

## Connecting Data in Child Development

Otto Lange & Dorien Huijser

*On behalf of the entire CD<sup>2</sup> team*

ODISSEI conference

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Utrecht  
University



Platform Digitale Infrastructuur  
Social Sciences & Humanities



Consortium on  
Individual  
Development

# Why & How *FAIR metadata in CKAN*

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Consortium on  
Individual  
Development

# Project CD<sup>2</sup>

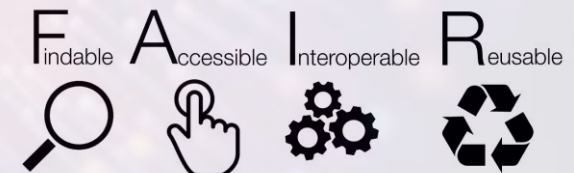
## Connecting Data in Child Development



- Joint effort of six Dutch cohort studies from *Consortium on Individual Development* (NWO Gravity Program 2013-2023)
- Funded from PDI-SSH
- Objectives:
  - Increase findability of (rich!) child development data
  - Establish community portal
  - Harmonize the field of CID
  - Apply FAIR principles in this domain



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## CHALLENGES

- Sensitive data that cannot be openly shared
- Cross-disciplinary data: SSH (e.g. surveys) and biomedical (e.g. tissues, fMRI)
- Data heterogeneity across cohorts
- Heterogeneity in RDM practices (maturity, legacy data, resources, policies)
- No common metadata standard available for this specific field
  - Profile based on DDI LifeCycle natural candidate, but needs additional vocabularies and does not cover well the biomedical aspects

# CD<sup>2</sup>

## “IF YOU UNDERSTAND THE MEASUREMENT YOU WILL UNDERSTAND THE DATA”

Harmonization at intermediate level: **measurements**

*A measurement defines what will be measured with the child under which conditions and which scientific assumptions*

New (mitigated) challenge:

- Identify common measurements across partners
- Identify baseline of common metadata for measurement description
- Inspect available vocabularies and invent new ones where needed
- Collect metadata for common and specific measurements

# CD<sup>2</sup>

## METADATA

Some ingredients of baseline metadata for description of **measurements**

- Phenomenon that is measured (vocabulary, construct / keywords)
- Assign waves (ages) where measurement takes place (cohort-dependent)
- Reference papers: scientific assumptions (e.g. described by, related)
- Wave information (e.g. demographic)
- Usual suspects like abstract, contact point, collaborators, *PIDs*, etc.
- Resembles CESSDA DDI Profile – mappable onto DataCite 4.x



# CD<sup>2</sup> – PUBLISHING IN (EXTENDED) CKAN

metadata model

Study

Cohort

Wave

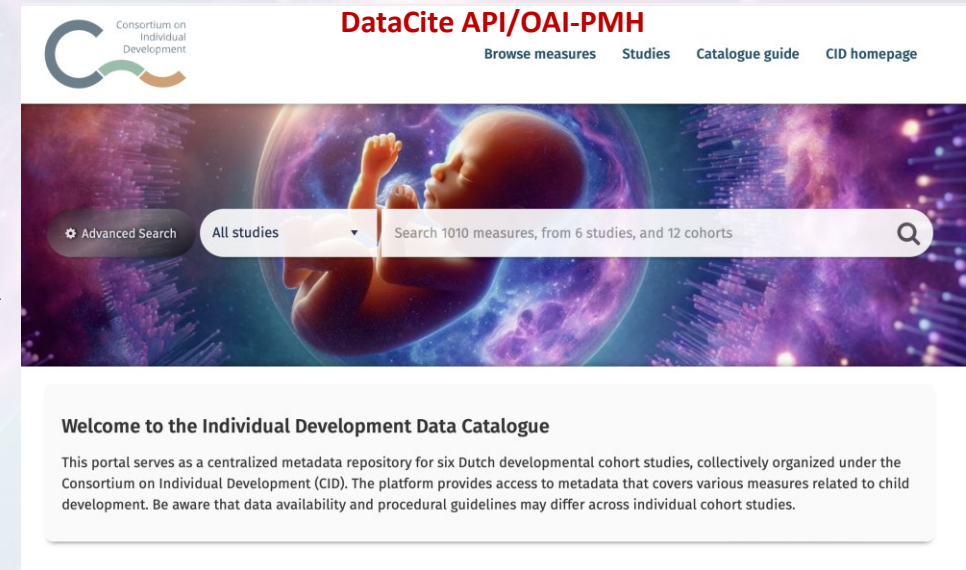
Measure

DataCite DOI



DCAT-AP?

Create  
CKAN Package



Not really data publications: measures are published with DOI!

# Who

## *A community effort*

Dorien Huijser, Utrecht University Library ([d.c.huijser@uu.nl](mailto:d.c.huijser@uu.nl))





# Project organisation

## Team

- Project coordinator
- Metadata specialist
- Developers
- Project data manager
- Cohort representatives
- Cohort data managers

## Timeline

- Initial planning: 2020-2023
- Extension into 2024
- Status: final phase



[illegible]

### Child Gap Prosaccade

Please separate your keywords with a comma.

\_\_\_\_\_

Term	Definition	Source_uncontrolled	Source_URI	Related_terms
Parenting	All actions related to the raising of children	<a href="https://dictionary.apa.org/parenting">https://dictionary.apa.org/parenting</a>		Narrower: Parent
Physiology	Science of the functions of organs and tissues	<a href="https://dictionary.apa.org/physiology">https://dictionary.apa.org/physiology</a>		Broader: Human
Physical health	Condition of one's body, taking into account physical fitness and the absence of disease	<a href="https://toolbox.eupati.eu/glossary/physical-health">https://toolbox.eupati.eu/glossary/physical-health</a>		Narrower: Physic
Mental health	Emotional, psychological, and social well-being of an individual	<a href="https://id.nlm.nih.gov/mental-health">https://id.nlm.nih.gov/mental-health</a>		Narrower: Psych
Demographics	Population-based characteristics of individuals or groups. Demographic variables include age, sex, race, and education			Related: Demogr
Personality	Enduring configuration of characteristics that distinguish one individual from another	<a href="https://dictionary.apa.org/personality">https://dictionary.apa.org/personality</a>		
Cognition	All forms of knowing and awareness	<a href="https://dictionary.apa.org/cognition">https://dictionary.apa.org/cognition</a>		Related: Cognitiv
Lifestyle	Typical way of life or manner of living	<a href="https://dictionary.apa.org/lifestyle">https://dictionary.apa.org/lifestyle</a>		Related: Lifestyle
Life history	History of major events or significant experiences	<a href="https://doi.org/10.1007/978-94-007-0100-0">https://doi.org/10.1007/978-94-007-0100-0</a>		Related: Life histo
Sociocognitive and emotional development	Changes across life stages that are related to the way individuals understand and interact with the world			Narrower: Emotio
Relationships	Continuing and often committed association between two or more individuals	<a href="https://dictionary.apa.org/relationship">https://dictionary.apa.org/relationship</a>		Broader: Relation
Work and school	An individual's occupational and educational activities, including performance			Narrower: Emplo
MRI	Technique that uses a magnetic field to create a computerized image of internal structures	<a href="https://concepts.nlm.nih.gov/mri">https://concepts.nlm.nih.gov/mri</a>		Broader: Technica
EEG	Recording of electric currents generated in the brain by electrodes	<a href="https://id.nlm.nih.gov/eeg">https://id.nlm.nih.gov/eeg</a>		Broader: Technica
Eyetracking	Technique that can measure an individual's gaze direction and what is being looked at			Broader: Technica
Behavioral/cognitive	Measurement, experiment, procedure, or paradigm to obtain an objective measure of behavior			Narrower: Neuro
Biological sample/material	Biological material obtained from a living organism, or tissue	<a href="https://ddialia.nlm.nih.gov/biological-sample">https://ddialia.nlm.nih.gov/biological-sample</a>		Narrower: Biolog
Anthropometrics/Bio	Technique that deals with the measurement of the size and shape of the human body	<a href="https://id.nlm.nih.gov/mesh/MC">https://id.nlm.nih.gov/mesh/MC</a>		
Echo	Visualization of deep structures of the body by recording reflected sound waves	<a href="https://id.nlm.nih.gov/echo">https://id.nlm.nih.gov/echo</a>		Broader: Technica
X-ray	Technique that uses electromagnetic radiation to create an image of internal structures	<a href="https://dictionary.apa.org/x-ray">https://dictionary.apa.org/x-ray</a>		Broader: Technica
EMG	Recording of the changes in electric muscle activity by electrodes	<a href="https://id.nlm.nih.gov/emg">https://id.nlm.nih.gov/emg</a>		Broader: Technica
ECG	Recording of the changes in electric activity of the heart by means of electrodes			Broader: Technica

- Sub ModeOfCollection::MeasurementsAndTests
- Category



# Harmonisation



## Identifying overlapping measures

Same questionnaire / task  
→ same references, main description, category, keywords

cd2_name	cd2_id	NTR	L-CID	Gen R	Youth	RADAR	RADAR G3	TRA
Rey's Verbal Learning Test	0001_CD2	Rey's Verbal Learning Test						Rey'
Berkeley Puppet Interview (BPI)	0002_CD2				Berkeley Puppet Interview (BPI)			
Adult Behavior Checklist (ABCL)	0003_CD2					Adult Behaviour Checklist (Adu		
Adult Self Report (ASR)	0004_CD2	Adult Self Report (ASR)			Adult Self Re	Adult Self Report (ASR)		Adu
Adult Temperament Questionnaire (ATQ)	0005_CD2		Adult Temperament Questionnaire			Adult Temperament Quest Adu		
Ages and Stages Questionnaire - Social-Emotional (0006_CD2						Ages and Stages Questionn Ages and Stages C		
Alabama Parenting Questionnaire (APQ)	0007_CD2		Alabama Parenting (Alabama Pars		Alabama Parenting Questionnaire (APQ)			
Amsterdam Neuropsychological Tasks (AN1)	0008_CD2		Amsterdam Neuropsychological tasks (AN1)					Amc
Diffusion Tensor Imaging (DTI)	0009_CD2		Diffusion Tensor Imaging (DTI)					
Child Behavior Checklist (CBCL) 1½-5	0010_CD2	Child Behavior Checklist (CBCL) 1	Child Behavior Checklist (C	Child Behavior Checklist (C	Child Behavior Ch			
Iowa and Bangor Gambling Tasks	0011_CD2	Iowa and Bangor Gambling Tasks				Iowa Gambling Task		Ban
Behavioral Inhibition and Activation Scale (BIS/BAS	0012_CD2		Behavioral Inhibition and			Behavioral Inhibition Scale, BIS/		
Big Five Inventory (BFI)	0014_CD2				Short big five Quick Big Five	Big Five (BF)		
Blood sample	0015_CD2	Blood sample			Blood sample	Blood sample		Bloc
Cord blood sample	0016_CD2				Cord blood sample	Cord blood		
Blood pressure	0017_CD2	Blood Pressure			Blood pressure			Bloc
3D ultrasound	0018_CD2				Brain structural Echo/3D Ultrasound			
Brief Problem Monitor (BPM) 6-18	0019_CD2	Brief Problem Monitor (BPM)			Brief problem monitor-youth form (BMP-p)			
Brief Symptom Inventory (BSI)	0020_CD2	Brief Symptom Invent	Brief Symptom Inventory (BSI)			Brief symptom inventory (BSI)		
Buccal swab	0021_CD2	Buccal swab	Buccal swab			Buccal		Buo
Teacher Report Form (C-TRF)	0023_CD2				Teacher Report Form (TRF)			
Confusion, Hubbub, and Order Scale (CHAOS)	0024_CD2		Confusion, Hubbub and Order Scale			CHAOS Quest	CHAOS Questionr	
Children's Behavior Questionnaire (CBQ)	0026_CD2	Children's Behavior	Children's Behavior (Child Behavior		The Children's Behavior Q	Childhood Behavi		
Childhood Trauma Questionnaire (CTQ)	0027_CD2				Childhood tra	Childhood Tra	Childhood Trauma Questionnai	
Children's Report of Parental Behavior Inventory (C	0028_CD2					Child's report	Children's Report of Parental Be	
CITO score	0029_CD2	CITO score	CITO scores of the ci		CITO score			
MacArthur Communicative Development Inventory (M	0030_CD2				MacArthur Co	Communicative Development Inventories (N-		
Delay of gratification task	0032_CD2	Delay of gra	Delay Discounting - I		Gift delay tas	Delay of gratification - gift		
Early Adolescent Temperament Questionnaire (EAT	0033_CD2				Early Adolescent tem	Early Adolescent	Early adolescent temperament question	Earl
Early Childhood Behavior Questionnaire (ECBQ)	0034_CD2					The Early Childhood Behavi	Early Childhood B	
Family Interaction Task (FIT)	0035_CD2		Family Interaction Task (FIT)				Conflict task, Discussion task	
Edinburgh Postnatal Depression Scale (EPDS)	0036_CD2				Edinburgh po	Edinburgh postnatal depression scale (EPDS)		
Egna Minnen Beträffande Uppfostran (EMBU)	0038_CD2					Perceived parental rearing (Genit about the mother's p	Egm	
Index of Empathy for Children and Adolescents (IE	0039_CD2					Empathy for children and a	Index of Empathy for Children a	
Family Assessment Device (FAD)	0040_CD2	Family Asses	Family Assessment (F		Family Assessment Device (FAD), general functioning s Fam			

## Similar datasets

### Generation R: Main Cohort

13-14 years

### TRAILS: Population cohort T1

T3 T4 T5

### TRAILS: Clinical cohort T1 T3

T4 T5

### LCID: Middle Childhood Cohort

T4 T6

### LCID: Early Childhood Cohort

T6 - Covid

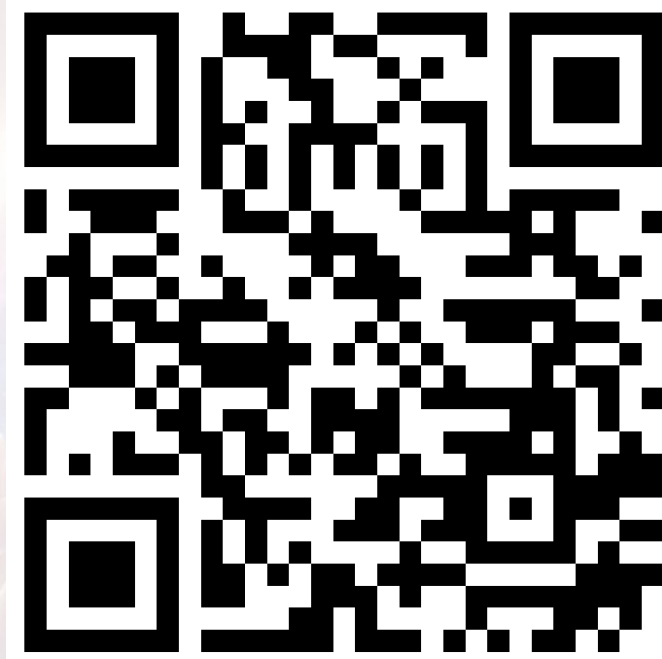
### LCID: Middle Childhood Cohort

T3 T4 T5 T5 - Covid T6

View all



# Demo



<https://data.individualdevelopment.nl/>

Special thanks: Pascal Pas, Utrecht University

# Or: via ODISSEI!

<https://portal.odissei.nl/dataverse/cid>







# The CD2 team

## Cohort experts

- *YOUth*: Gijs Holleman, Ron Scholten
- *L-CID*: Simone Mulder, Lara Wierenga, Sharon Buitenweg
- *TRAILS*: Melissa Vos, Tineke Oldehinkel, Catharina Hartman
- *Generation R*: Pauline Jansen, Yuchan Mou, Nathalie Tamayo Martinez
- *NTR*: Fiona Hagenbeek, Lannie Ligthart, Yola Sol
- *RADAR*: Andrik Becht, Dzhanseel Karakash, Thao Kieu, Susanne Schulz, Stefanos Mastrotheodoros, Susan Branje

## Project coordination

- Otto Lange
- Tess Beking

## Developers

- Pascal Pas
- Harm de Raaff
- Jelmer Zondergeld

## Project data manager

- Dorien Huijser

## Policy

- Coosje Veldkamp



# Thank you!

<https://data.individualdevelopment.nl/>

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Dorien Huijser, [d.c.huijser@uu.nl](mailto:d.c.huijser@uu.nl)

On behalf of all CD2 project members