

Research data management when working with children and youth



DAY 1

Workshop
Ljubljana, Slovenia
27 – 28 March 2023



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101008589





GUIDE pilot survey: Example of the data management plan and content of child and parental consent

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The first European-wide
longitudinal study of children

Growing Up In Digital Europe (GUIDE)



<https://www.coordinate-network.eu/>



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Growing Up in Digital Europe

High quality comparative data on child wellbeing

- Harmonised instruments
- Longitudinal coverage

Europe's only longitudinal cohort survey of child wellbeing

- 19 partner countries
- National Nodes
- Central Hub

Accelerated cohort design

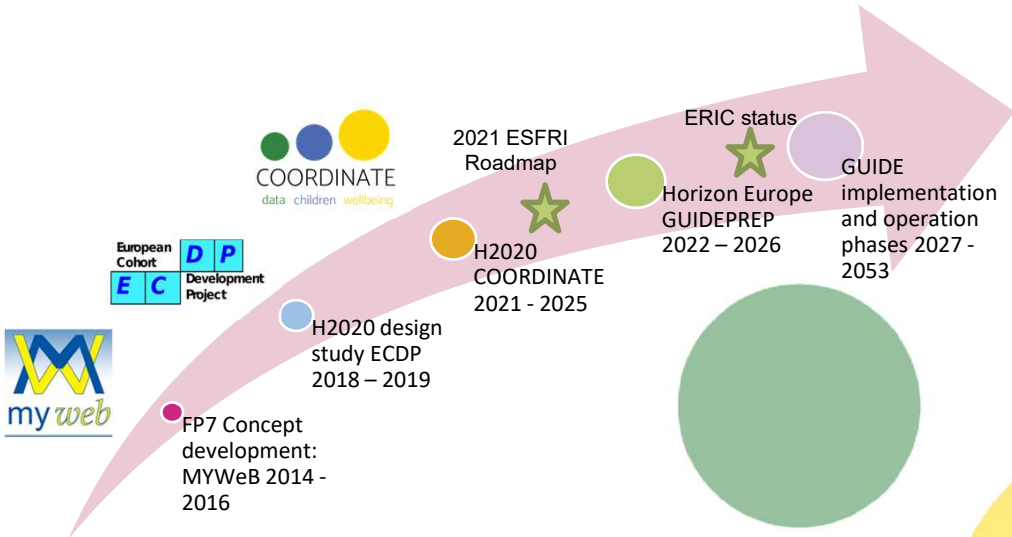
- Child cohort age 8 in 2027
- Infant cohort age 9 months in 2029

<https://www.coordinate-network.eu/>

Why We Need GUIDE



GUIDE – On the Road to ERIC Status



ESFRI - European Strategy Forum on Research Infrastructures
ERIC - European Research Infrastructure Consortium

Sample Design

Probability sample

- For each cohort, a sample of children resident in the country within the relevant **one-year age** range

Sample design

- Varies between countries and cohorts, to recognise **national availability**, adhering to common principles and parameters

Common prescribed level of statistical precision

- For each national sample design (which will depend on sample size, stratification, selection probabilities and clustering)

Clustered sampling allowed

- (within schools or localities) this will necessitate a larger sample size to compensate for relative homogeneity (design effects)

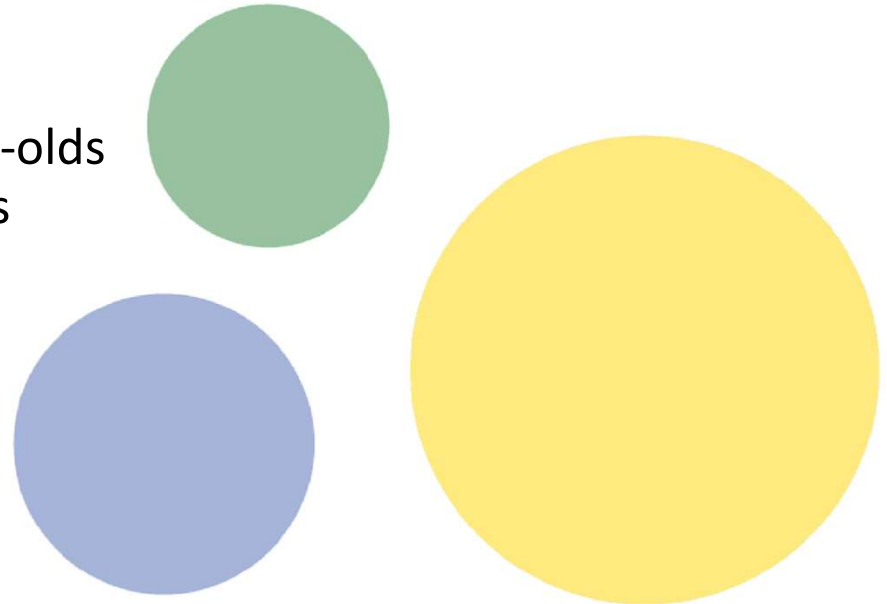
Sample Size

Attrition rates will differ over a 25-year period for both cohorts and between countries. In setting the **initial target sample sizes** for each cohort it is necessary to anticipate likely levels of attrition in such a way as to ensure that the **later data collection waves retain sufficient respondents for inferential statistical analysis**

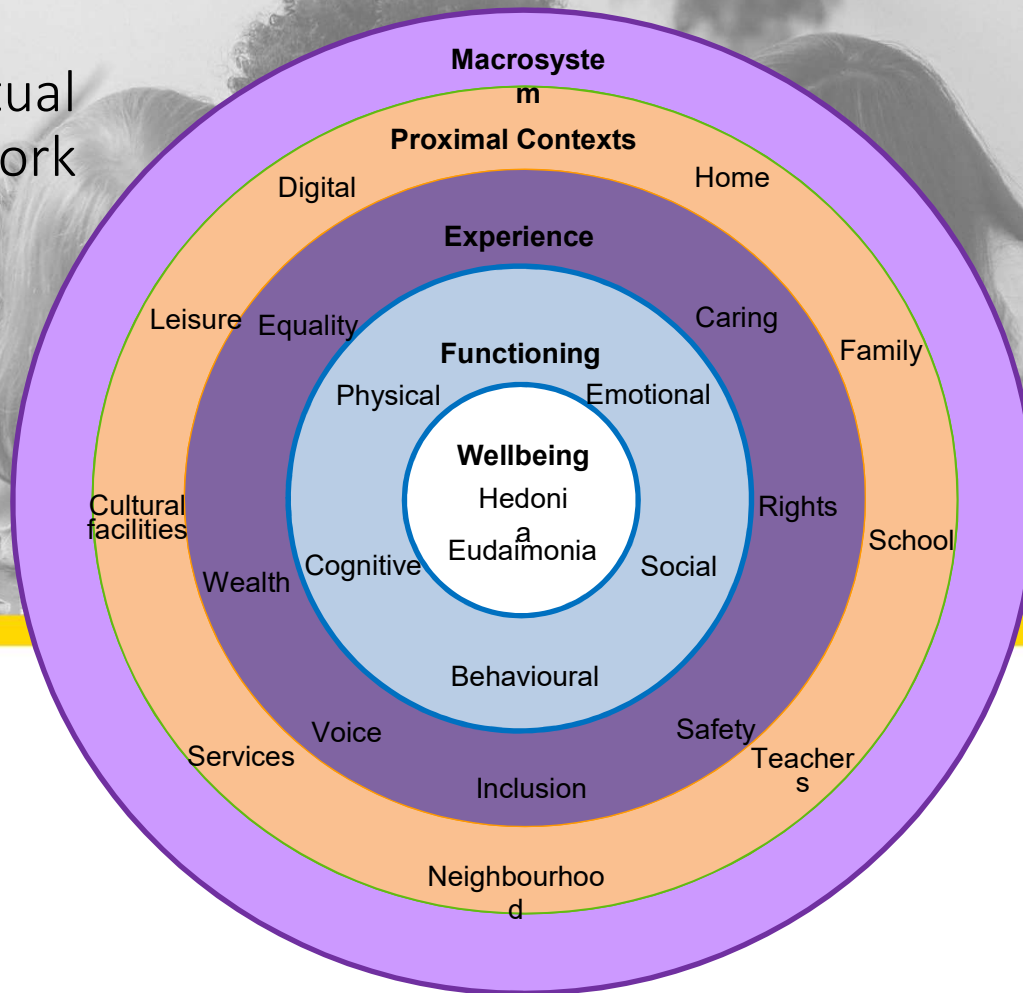
Maximum sample sizes in large countries are **10,000** for the birth cohort (C2) and **8,000** for the childhood cohort (C1). Sample sizes will be smaller in smaller countries although the minimum sample size should allow for robust statistical analyses after attrition.

Questionnaire Pilot Sample

- Large and diverse enough to test psychometric validity of the scales (e.g., wellbeing scale)
- Large and diverse enough to evaluate performance of categorical items (e.g., housing, marriage, gender)
 - 250 8-year olds
 - 250 parents of 8-year-olds
 - 250 parents of infants



GUIDE Conceptual Framework



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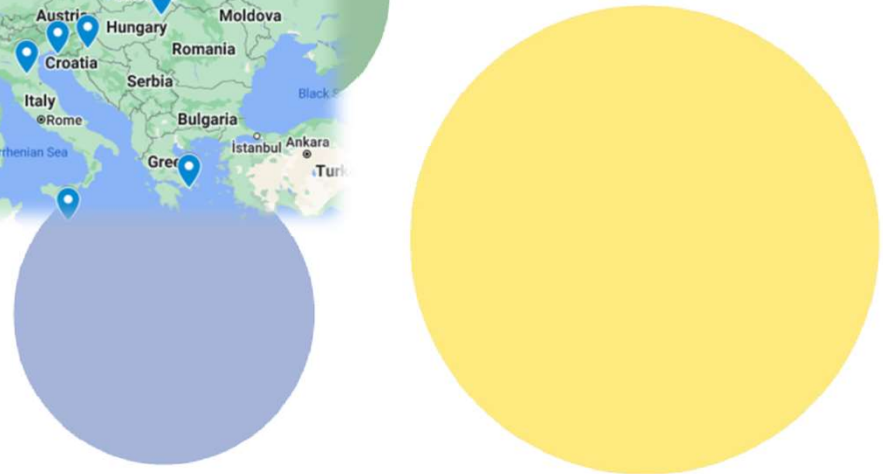
COORDINATE
COhort cOMmunity Research and Development
Infrastructure Network for Access Throughout Europe

GUIDE Consortium

23 Partners



19 Countries



Questionnaire pilot countries

Croatia: Ivo Pilar Institute

- Toni Babarovic

France: INED

- Ognjen Obucina
- Sandra Florian
- Aurélie Santos
- Zoé Perron

Finland: University of Helsinki

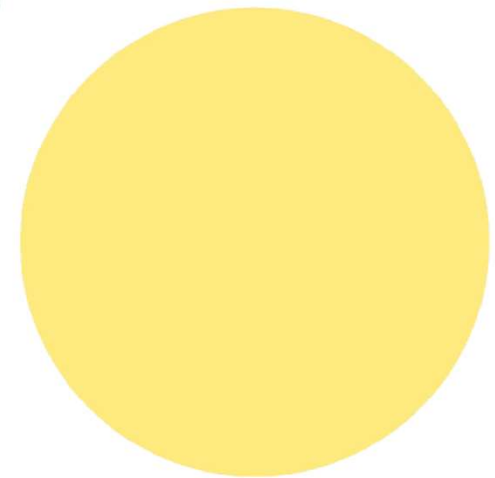
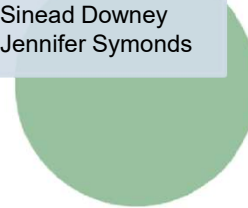
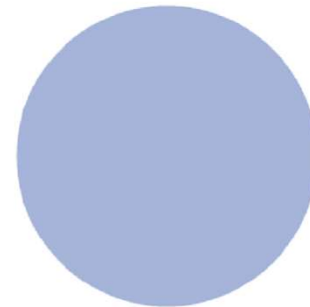
- Katariina Salmela-Aro
- Katja Upadyaya

Ireland: University College Dublin

- Laura Taylor
- Andrea Maynard
- Jessica Surdey
- Sinead Downey
- Jennifer Symonds

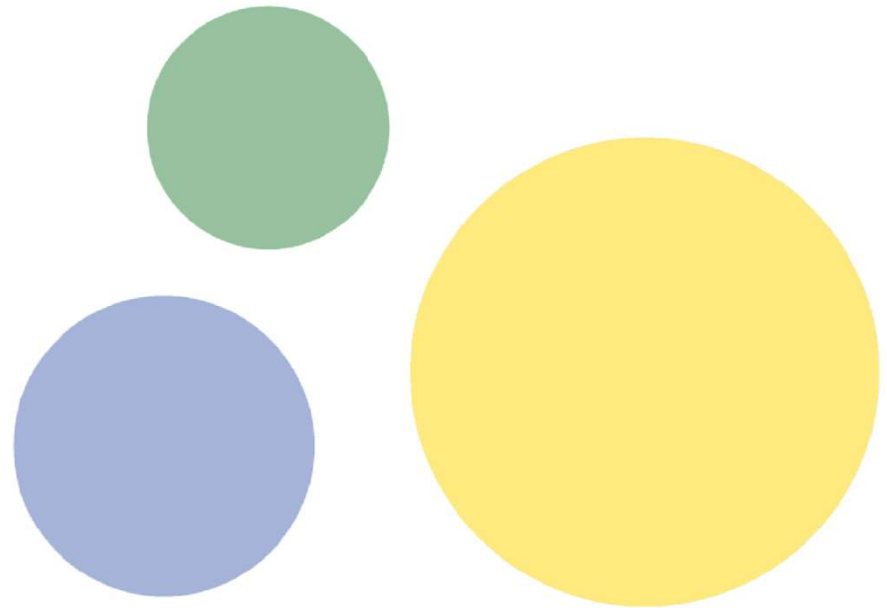
Slovenia

- Mateja Sedmak



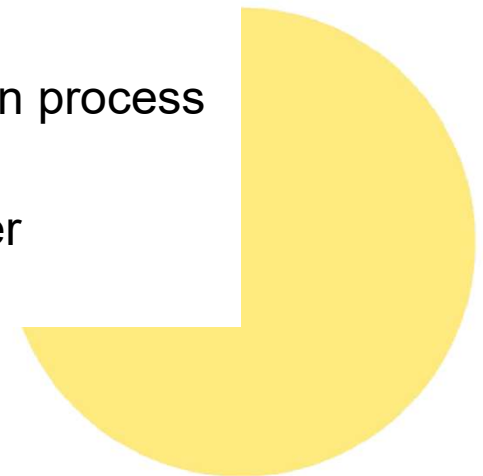


DANA MANAGEMENT PLAN



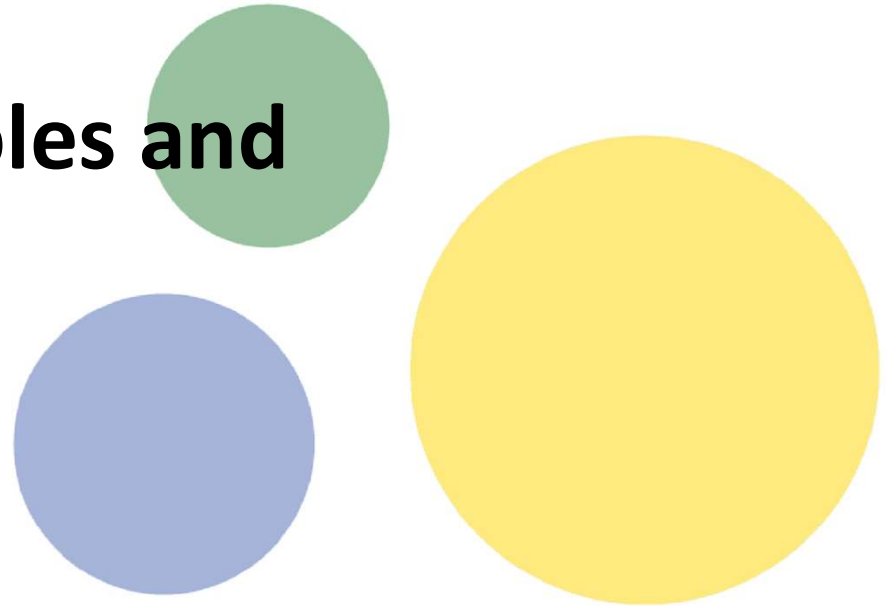
DATA MANAGEMENT PLAN

- The purpose of data management plan (agreement) is to join all participating organisations in shared data processing practices
- DMP defines the procedures related to data collection, data protection and data flow
- DMP defines roles and responsibilities of each project partner in processing and archiving data
- DMP specifies types of databases with regard to the respondents' data protection levels
- DMP should be developed before data collection process
- DMP should be signed off by all partners
- Each partner should have Data protection officer



Elements of DMP

1.1. Partners' roles and responsibilities

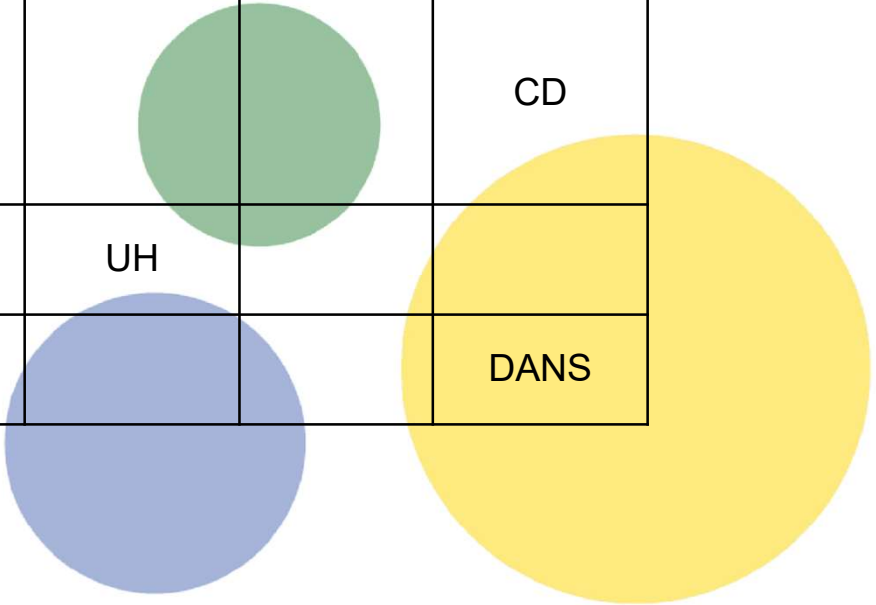


Partners

Partner	Acronym
Institut National d'Etudes Démographiques (INED)	INED
Ivo Pilar Institute (IPI)	IPI
University College Dublin (UCD)	UCD
University of Helsinki (UH)	UH
Znanstveno-raziskovalno središče Koper	ZRS
Kantar France	Kantar-F
Ipsos Croatia	Ipsos-C
Ipsos Ireland	Ipsos-I
Kantar TNS	Kantar-TNS
IPSOS Slovenia	Ipsos-S
Centerdata	CD
Data Archiving and Networked Services (DANS)	DANS

Partner Responsibilities

	France	Croatia	Ireland	Finland	Slovenia	Netherlands
Survey agency	KANTAR-F	IPSOS-C	IPSOS-I	KANTAR-TNS	IPSOS-S	
National partner	INED	IPI	UCD	UH	ZRS	
Software programmer & data collection host						CD
Intermediate archiving	INED	IPI	UCD	UH		
Historical archiving						DANS



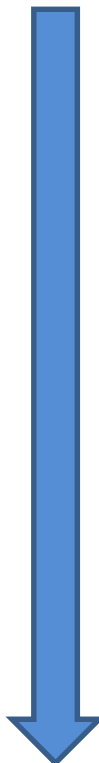
Partner Roles

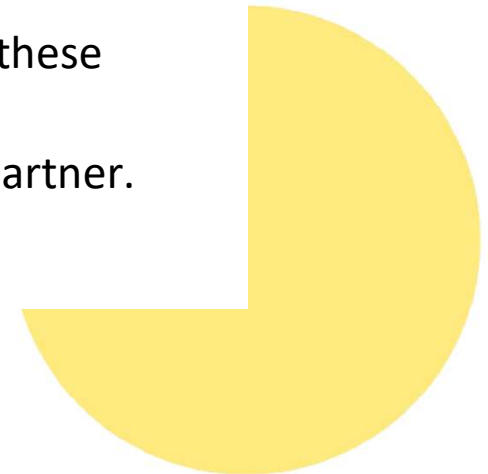
Partner	Role
UCD	Joint data controller for all non-sample data (France, Croatia, Finland) and data controller for all Irish data.
INED	Joint data controller for France; data processor for Ireland, Croatia, Finland (pseudo-anonymization).
IPI	Joint data controller for Croatia; data processor for Ireland, France, Finland (psychometric evaluation).
UH	Joint data controller for Finland.
ZRS	Joint data controller for Slovenia.
Survey agencies	Data processors.
Centerdata	Data processor.
DANS	Data processor.

1.2. Produced databases

Title	Description
SAMPLE	National sample data which will be collected by national survey agency.
SAMPLE-P	Pseudonymised sample data.
CONTACT	Contact attempts, refusals, etc.
QUEST-N	National datasets for the child and caregiver questionnaires.
QUEST-I	International datasets for the child and caregiver questionnaires.
PSEUDO-N	Pseudonymised national datasets for the child and caregiver questionnaire.
PSEUDO-I	Pseudonymised international datasets for the child and caregiver questionnaire.

1.3. Data flow

- 
1. Survey agencies collect SAMPLE data, CONTACT, and QUEST-N data.
 2. Survey agencies transfer QUEST-N, SAMPLE-P and CONTACT to CD.
 3. Survey agencies transfer SAMPLE and CONTACT data to national partners.
 4. CD transfers QUEST-N and CONTACT data to INED and UCD for merging into QUEST-I.
 5. INED and UCD de-identify QUEST-N and QUEST-I (these become PSEUDO-N and PSEUDO-I).
 6. INED transfers PSEUDO-N and PSEUDO-I to each partner.
 7. INED transfers PSEUDO-I to DANS for archiving.



1.4. Data storage and transfer

Dataset	File storage requirement	File transfer requirement
SAMPLE	Encrypted, password	Encrypted files, Secure file sender
SAMPLE-P	password protected	Encrypted files, Secure file sender
CONTACT	password protected	Encrypted files, Secure file sender
QUEST-N	password protected	Encrypted files, Secure file sender
QUEST-I	password protected	Encrypted files, Secure file sender
PSEUDO-N	No password protection required	Encrypted files, Secure file sender
PSEUDO-I	No password protection required	Encrypted files, Secure file sender

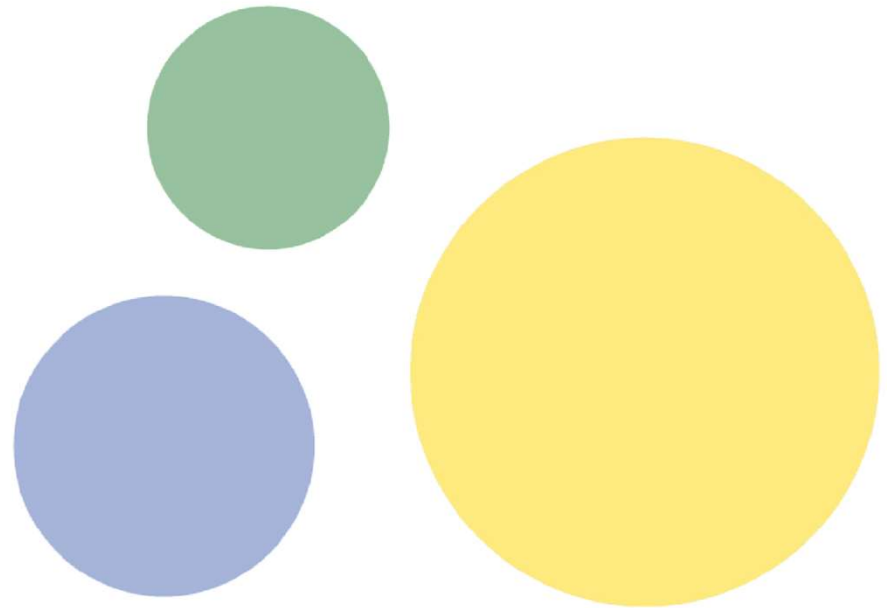
1.5. Data breaches

If any of the named datasets are stolen or lost, all data controllers and processors will follow all steps in the protocol below:

- Survey agencies report all breaches to the national partner
- National partner reports all breaches to the national data protection officer and to UCD and INED
- UCD reports all breaches to Manchester Metropolitan University who are the COORDINATE project leads.
- Each data breach case is reviewed by a team comprising each partner involved, the national DPO(s), and any person who is responsible for the breach.
- A written plan for how to recover or destroy the breached data should be compiled.
- If lost data are not retrieved within one week, and in all cases of stolen data, national.
- partners should report the data breach to participants via email, or by post or telephone.



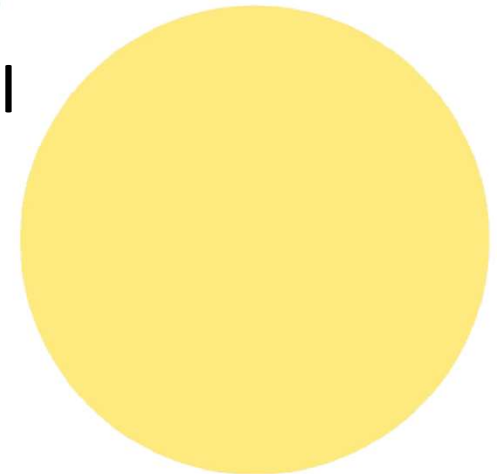
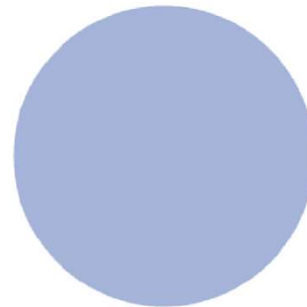
CONSENT FORMS



Consent forms

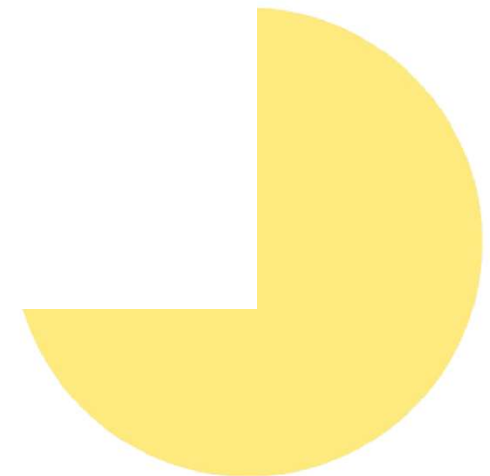
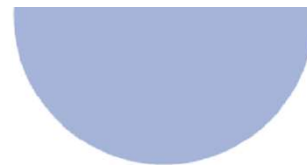
- CF for parents of 8-year-olds
- CF for parents of infants
- CF for 8-year olds

- Information & consent part
- Filled in and signed within CAPI



Information part

1. Introduction to project and survey
2. Invitation to participate in research
3. Respondent tasks and survey length
4. Confidentiality and data protection and storage
5. Rights to redraw from survey or data redraw
6. Complaining process
7. Contacts and more info links



Consent part for parents

I confirm that I have read and understood the information on this form

Yes No

I agree to participate in this interview

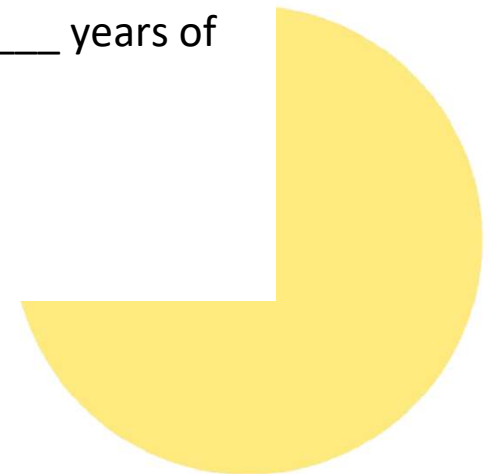
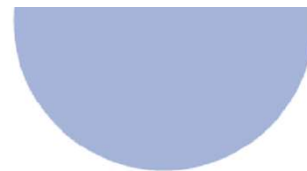
Yes No

I agree to the processing of data on my health or that of my child

Yes No

I, the parent or guardian of _____, a minor _____ years of age, consent to his/her participation in the study.

Signature



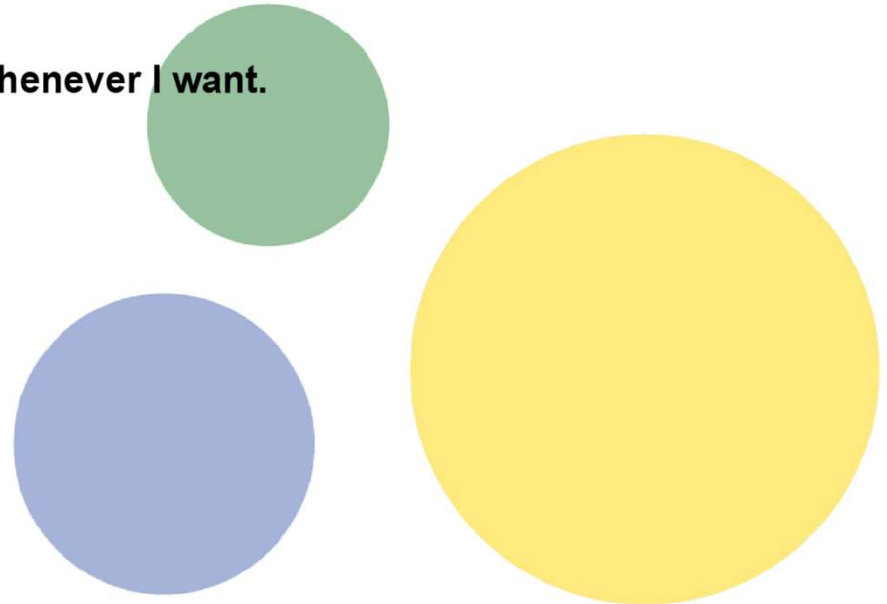
Consent part for children

1. I want to participate.

- 
- 

2. I understand that I can stop whenever I want.

- 
- 



Questions?

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