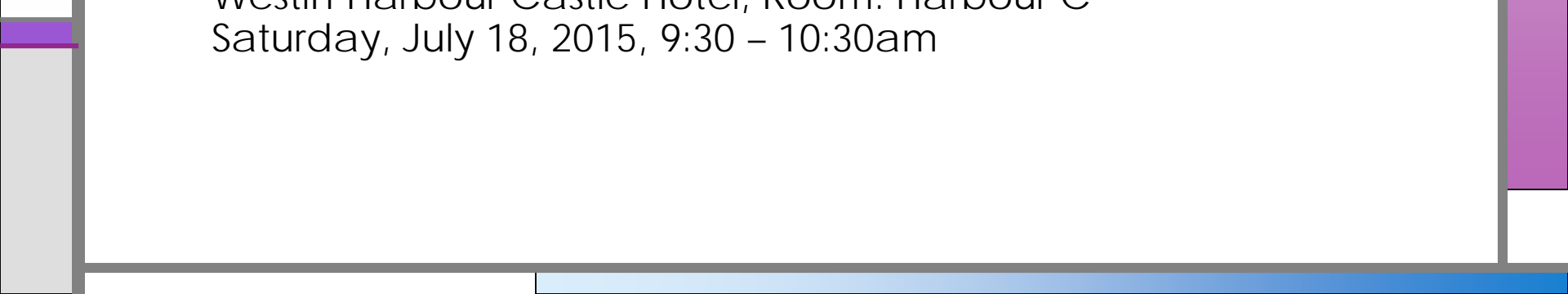




2016 Symposia: Design and Data Analytics (DaDA)

Westin Harbour Castle Hotel, Room: Harbour C
Saturday, July 18, 2015, 9:30 – 10:30am



Schedule

- Opening Remarks and Overview of DaDA PIA and IALSA/Maelstrom Metadata Catalogue and Harmonization Platform, **Scott Hofer**, University of Victoria, British Columbia, Canada, Oregon Health & Science University, Portland, Ore., United States
- Harmonizing Measurements Across Studies of Dementia and Cognitive Aging, **Richard Jones**, Brown University, Providence, R.I., United States
- The EPAD Approach: Using Longitudinal Data for Selection into Dementia Trials, **Graciela Muniz**, University of Edinburgh, Edinburgh, United Kingdom
- Estimation of Causal Effects with Outcomes Truncated by Death in a Longitudinal Study, **Andrew Zhou**, University of Washington, Seattle, Wash., United States
- Longitudinal And Survival Models In Dementia Research, **Sharon Xie**, University of Pennsylvania, Philadelphia, Pa., United States
- The Dementias Platform UK: Tools for Population Science, **John Gallacher**, University of Oxford, United Kingdom
- Discussant, **Jonathan King**, National Institute on Aging, Bethesda, Md., United States

Overview of DaDA PIA

DaDA Objectives:

- To support and coordinate joint research activities involving a variety of study designs and facilitate access to metadata from existing studies.
- To stimulate innovative research on optimal design, measurement, and harmonization of exposures and outcomes, and research synthesis of multiple sources of data.
- To promote, facilitate, and organize training in advanced statistical methods and develop and disseminate best practices in the field.



Integrative Analysis of Longitudinal Studies on Aging

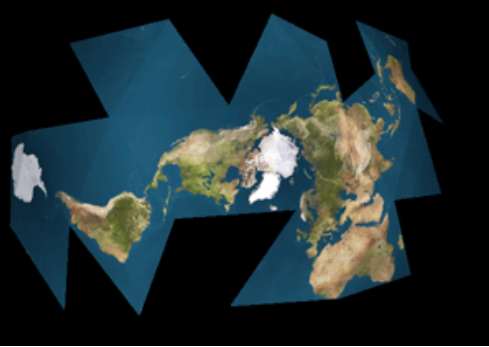
Integrative Analysis of Longitudinal Studies of Aging and Dementia (IALSA):

IALSA/Maelstrom Metadata Catalogue and Harmonization Platform

Scott M. Hofer, Isabel Fortier,

Graciela Muniz, Andrea Piccinin, & Jeffrey Kaye

The Integrative Analysis of Longitudinal Studies of Aging (IALSA; www.ialsa.org) research network is supported by a grant from the National Institutes of Health/NIA: 1P01AG043362; and previously by NIH/NIA 1R01AG026453 and the Canadian Institutes of Health Research: 200910MPA Canada-UK Aging Initiative.



Integrative Analysis of Longitudinal Studies of Aging

www.ialsa.org

- The IALSA network (NIH/NIA 1P01AG043362) is comprised of over 100 longitudinal studies on aging, health and dementia.
 - Mix of samples aged from birth to 100 years, with birth cohorts ranging from 1880 to 1980.
 - Assessed from 1921 to the present.
 - Time between assessments ranges from 6 months to 17 years (the majority 1-5 years), with up to 32 (typically 3-5) measurement occasions spanning 4 to 48 years of monitoring within each individual.
- Reproducibility of results (i.e., direction and pattern of effects) across populations, historical periods, measurements, designs, and statistical models.

Integrative Data Analysis:

Systematic Study of Testable Hypotheses

- Cross-Method
 - Sensitivity of results to design (e.g., different confounds) and analysis (e.g., different models of change)
- Cross-Cohort (Between-Group)
 - Changing outcomes and influences, critical periods
- Cross-Country (Between-Group)
 - Natural experiments: diffs in secular trends and policies
- Long-term longitudinal (Within-Person)
 - Cognitive reserve (childhood IQ; educ), impact of early and middle life predictors, detection of indiv. change-points
- Prediction
 - Extrapolation to prospective studies / recent birth cohorts

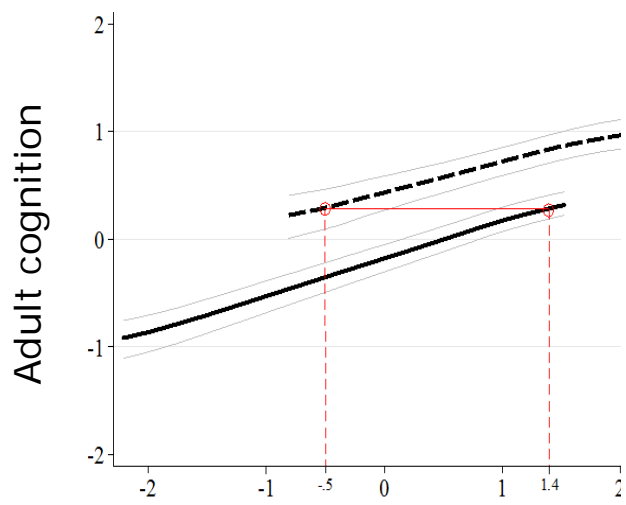
Benefits of Educational Attainment: Midlife fluid cognition associated with childhood cognition and level of educational qualifications (Clouston et al., 2013, IJE)

Wisconsin 1939 birth cohort

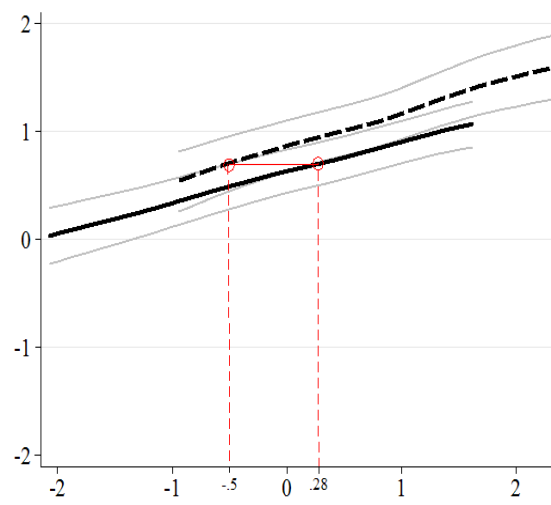
NSHD 1946 birth cohort

NCDS 1958 birth cohort

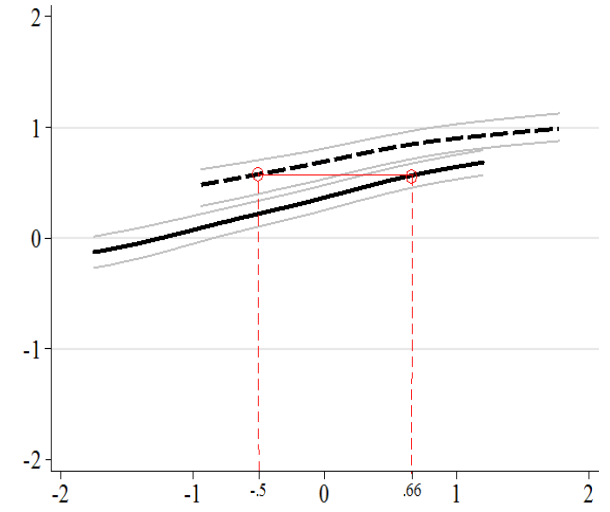
- ■ ■ ■ University degree
- Secondary qualifications
- Cognitive offset



Childhood cognition



Childhood cognition



Childhood cognition

Standardised scores.
Adjusted for gender & father's social class

Clouston et al IJE 2013
IALSA/HALCyon collaboration

<https://www.maelstrom-research.org/>

The screenshot shows a web browser window displaying the homepage of maelstrom-research.org. The browser's address bar shows the URL. The main banner features a background image of a plant stem with five circular cutouts in different colors (yellow, orange, green, red). The text 'Maelstrom Research' is centered, with a sub-headline: 'We develop tools to leverage and achieve rigorous data documentation, harmonization, integration and analysis'. A 'Learn More' button is positioned below the text.

Below the banner are three circular icons representing different services:

- What we offer:** Represented by a wrench and screwdriver icon. The text below reads: 'Maelstrom offers a suite of methods and software as well as expertise to partners to facilitate data documentation, harmonization and integration'.
- Maelstrom Repository:** Represented by an icon of three books. The text below reads: 'The Maelstrom Repository catalogues standardized information about research networks, studies and collected data'.
- Partnerships:** Represented by an icon of two hands shaking. The text below reads: 'Learn about our key partnerships with international networks and consortia to harmonize, integrate and analyse study data'.

There are two main content sections below:

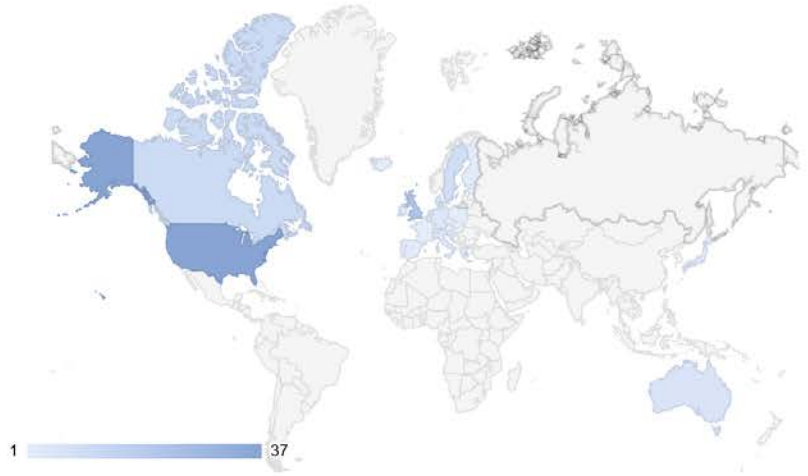
- Projects:** Features a world map graphic with blue arrows pointing outwards. Below the map is a dark box with the text: 'Integrative Analysis of Longitudinal Studies of Aging project'.
- News:** A list of recent updates, each with a small icon:
 - Studies and variables available in the repository:** 135 studies and over 307 000 Variables from 52 studies are now available. (2016-05-05)
 - Research Networks part of the repository:** 10 Networks now available, 4 added recently (ATHLOS, BoACh, MR_Cancer_network and MINDMAP) (2016-05-05)
 - Maelstrom Harmonization Workshop:** The last Maelstrom Research Harmonization Workshop was held in Groningen from 20-22 April 2016.
 - Software:** A new search tool is now available. Its features help to search studies and variables of interest in a dynamic and efficient way.
 - New grant received:** We received an operating grant from Canadian Institutes for Health Research (CIHR) to support the creation of a cohort registry leveraging research on Developmental Origins of Health and Disease.

IALSA - Integrative Analysis of Longitudinal Studies of Aging and Dementia

Summary Statistics

Geographical Distribution | Study Design | Number of Participants | Collected Biological Samples

Distribution of Studies by Country of Residence (N=100)



Country	Studies
Luxembourg	1
Netherlands	3
Poland	1
Portugal	1
Slovenia	1
Spain	2
Sweden	9
Switzerland	2
Taiwan	1
United Kingdom	21
United States of America	37

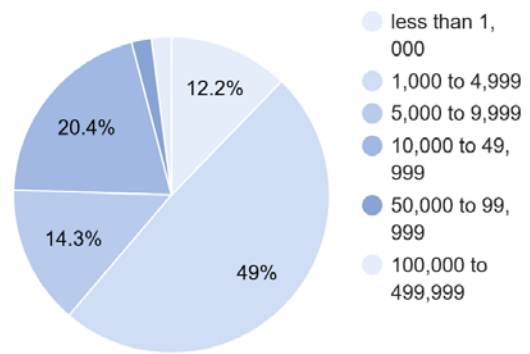


IALSA - Integrative Analysis of Longitudinal Studies of Aging and Dementia

Summary Statistics

Geographical Distribution Study Design **Number of Participants** Collected Biological Samples

Distribution of Studies by Number of Participants (N=100)



Number of Participants	Studies
less than 1,000	12
1,000 to 4,999	48
5,000 to 9,999	14
10,000 to 49,999	20
50,000 to 99,999	2
100,000 to 499,999	2

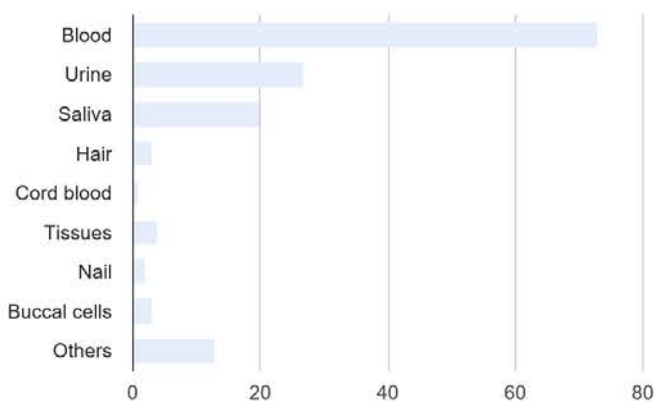


IALSA - Integrative Analysis of Longitudinal Studies of Aging and Dementia

Summary Statistics

- Geographical Distribution
- Study Design
- Number of Participants
- Collected Biological Samples**

Distribution of Studies by Type of Biological Samples Collected (N=100)

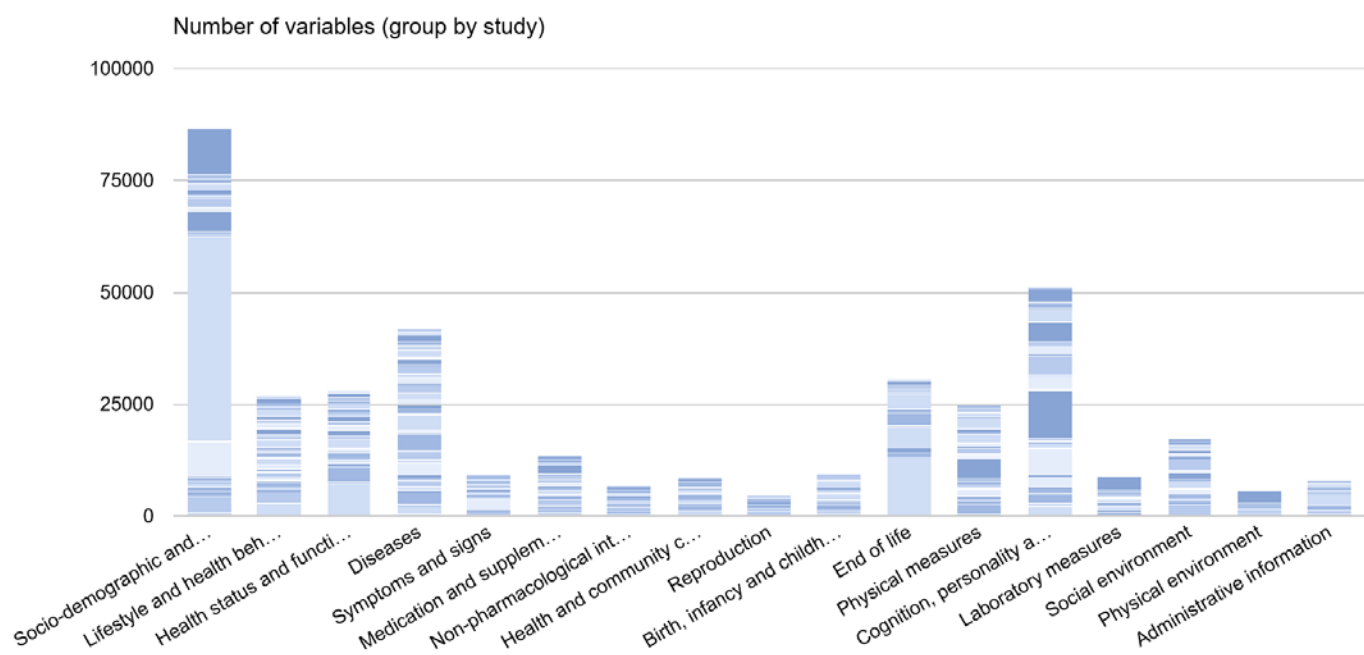


Collected Biological Samples	Studies
Blood	73
Urine	27
Saliva	20
Hair	3
Cord blood	1
Tissues	4
Nail	2
Buccal cells	3
Others	13



IALSA - Integrative Analysis of Longitudinal Studies of Aging and Dementia

Information classification developed by Maelstrom Research






The Maelstrom Research Repository search page allows researchers to browse our epidemiological study and variable catalogue and helps identify studies collecting variables of interest to support your collaborative research projects. Perform queries such as:

- Compare information collected on cancer, food, alcohol, tobacco or illicit drug intake across studies
- Find Canadian studies collecting biological samples

All ▾ e.g. study name, anxiety, alcohol, cancer, cohort

Filter by: Variables ▾ Scales/Measures ▾ Studies Browse All

Clear  IALSA ▾

List Comparison Table Summary Statistics

Networks (1) Studies (100) Variables (344,395) 10 ▾ « < 1 2 3 ... > » 1 - 10 of 344395



Search

Acronym	Name	Study Design	Data Sources Available				Participants	Variables	
								Study	DataSchema
CHS	Cardiovascular Health Study	Cohort	✓	✓	✓	-	5,888	-	-
CLS	Canberra Longitudinal Study	Cohort	✓	✓	-	-	1,045	8,182	-
CLSA	Canadian Longitudinal Study on Aging	Cohort	✓	✓	✓	-	50,000	5,234	-
CSHA	Canadian Study of Health and Aging	Cohort	✓	✓	✓	-	11,949	13,233	-
CaG	CARTaGENE	Cohort	✓	✓	✓	✓	40,000	3,522	709
CaPS	Caerphilly Cohort Study of Older Men	Cohort	✓	✓	✓	-	2,959	5,246	-
CogUSA	Cognition and Aging in the USA	Cohort	✓	✓	-	✓	1,514	382	-
DCS-1905	Danish 1905 Cohort Study	Cohort	✓	✓	✓	✓	2,262	1,707	-
DCS-1915	Danish 1915 Cohort Study	Cohort	✓	✓	✓	✓	1,584	-	-
DEAS	German Ageing Survey	Cohort	✓	✓	-	✓	14,713	18,942	-



Areas of Information

- Non-pharmacological interventions
- Health and community care utilization
- Reproduction
- Birth, infancy and childhood
- End of life
- Physical measures
- Cognition, personality and other psychological measures**
- Laboratory measures
- Social environment
- Physical environment
- Administrative information

Cognition, personality and other psychological measures

Add to query

Refers to information about an individual's cognition, personality and psychological functioning. See Sect. 17 "Administrative information" for measure related information (e.g. date of test).

Cognitive functioning

Psychological distress and emotions

Personality

Cognitive functioning

Add to query

Test-based measurement (in contrast to R40-46) of a person's ability to remember, solve problems, work/respond quickly or their level of knowledge and verbal abilities. Also see Sect. 5 "Symptoms and signs", under 'Cognition, perception, emotional state and behaviour (R40-R46)', for questions about memory problems not involving measurement (symptoms).

Clear

IALSA

Physical activity

OR

Education | Age/birthdate | Se...

OR

Cognitive functioning

Basic

 Search

<input type="checkbox"/>	CC75C	1	2	22	46	787
<input type="checkbox"/>	CFAS	103	33	31	72	2,121
<input type="checkbox"/>	CLS	60	22	10	26	2,906
<input type="checkbox"/>	CLSA	25	29	12	312	12
<input type="checkbox"/>	CSHA	32	16	24	48	2,552
<input type="checkbox"/>	DCS-1905	10	4	12	16	144
<input type="checkbox"/>	DEAS	716	738	207	315	33
<input type="checkbox"/>	ELSA	686	355	491	295	548
<input type="checkbox"/>	HAS	47	12	9	31	41
<input type="checkbox"/>	HCS	10	9	2	171	0
<input type="checkbox"/>	HELIAD	9	1	6	30	151
<input type="checkbox"/>	HS	32	32	9	9	0
<input type="checkbox"/>	HSAD	7	0	21	9	21

Age/birthdate

IALSA Approach

- Coordinated/Parallel analysis
 - Aim: To maximize the data value from each study while making results as comparable as possible
 - Expect similar *conclusions* regardless of the exact variables used.
 - Construct-level comparison
 - Common statistical models
 - Emphasis on cross-culture, cross-study comparisons
 - Evaluation of sensitivity to statistical model
 - Meta-Analysis / Meta-Regression
 - Evaluation of subgroup interactions (e.g., age) across studies

Measurement Harmonization

- What to do when measurements differ?
 - Select congruent items (lowest common denominator)
 - Select studies with identical measures
 - Algorithms/transformations (expert review)
 - Compare standardized effects (c-scores)
 - Compare at construct level (coordinated analysis)
 - Calibration/statistical models
 - IRT/Factor models
 - Incomplete data methods
- How generalizable are harmonization rules?
 - Can we obtain definitive harmonization rules or will we always need to evaluate/apply new rules within each multi-study analysis?

Strengths: Item Library

- Retrospective Harmonization: Linkage across studies
 - Permits comparison of past, current, and future studies (i.e., cohort / social change)
 - Difficult to achieve measurement “standardization” in either national or international context
 - Evaluation of measurement equivalence and commonality/uniqueness of particular indicators
 - Retains breadth and innovation in study-specific measurement by permitting item/scale mapping to common constructs across studies
 - Provides basis for selection of “optimal” items/scales for current and future studies



The Studies section of our Repository is an inventory of epidemiological studies participating in diverse partner networks. This section can help users identify studies making use of relevant designs and collecting data of interest to answer specific research questions.

146 Studies

Name [v] Asc. [v] [Q] []

Search Studies

1970 British Cohort Study

In 1970, the aims of the BCS70 study were to look at the social and biological characteristics of the mother in relation to neonatal morbidity, and to compare the results with those of the 1958 National Child Development Study. With each successive sweep, the scope of the enquiry has broadened from ... [Read more](#)

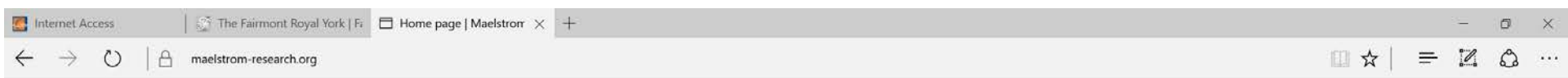
Study design: cohort study ; Target number of participants: 17,198

3D Study - Design, Develop, Discover

The main objective of the 3D study is to create a large pregnancy and birth cohort, allowing for the assessment of the effects of combined prenatal



<https://www.maelstrom-research.org/>



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- WHAT WE OFFER ▾
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We develop tools to leverage and achieve rigorous data documentation, harmonization, integration and analysis

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