



DPAU DATA ACCESS APPLICATION GUIDANCE

The application form is used by DPAU and relevant Contributing Research Studies (CRS) to assess whether proposed studies are worthwhile, in the public interest, likely to be feasible with available data and conform to each CRS's access policies.

In order to help ensure your application is successful, below is guidance on how to fill out the DPAU Data Access Application Form:

General

- Please ensure you provide all the details requested - incomplete applications will be returned for revision.
- Please do adhere to word limits. Applications that do not conform to the word limits will be returned for revision.
- Please ask a colleague to read your application and provide constructive comments on its completeness and ease of reading before submission.

Main Applicant Details

- In this section, please ensure your email address is an academic or industry address. Unfortunately, we cannot accept applications that do not comply to this requirement (Gmail, Yahoo, Hotmail etc).
- The Main Applicant can select multiple roles in the Project.

Co-ApPLICANT(s)

- At a minimum, you are required to list all applicants that may require access to the CRS data for your project on the application.
- Student applicants are required to include their supervisors on the application.
- Please ensure the email address of all co-apPLICANT(s) is an academic or industry address. Unfortunately, we cannot accept applications that do not comply to this requirement (Gmail, Yahoo, Hotmail etc).

Project Details

- In this section, please describe clearly how the project is being undertaken in the public interest. Direct benefits, such as expected outcomes and outputs associated with the aim of project should be outlined in this section.

Scientific Context

- As a guideline, up to 200 words for each of 'Project Overview', 'Scientific Rationale', 'Methods/Study Design', 'Analysis Plan', of the scientific context section should be adequate.
- The aims and objectives of your project should be outlined in the 'Project Overview' section.
- The reasons why your project is valuable or novel should be explained in the 'Scientific Rationale' section.
- Please detail any new variables that may be generated during your project, e.g. a summary score such as a frailty index.



- Please provide details of your ethics approval. If researchers cannot provide details of ethical approval, they need to justify the exemption from ethical approval on the application form.
- Multiple “Expected Outputs” can be selected.

Other Information

- If you acknowledge any overlaps/conflicts with other research, you must make a declaration [here](#).
- Please also read the Terms and Conditions as outlined in the [DPAU Data Access Agreement \(DAA\)](#) and the [Monash SeRP End User Terms](#) to confirm you will abide by these.

Technical Specification

If you wish to also include your own data in your study, you must make a declaration [here](#).

- In order to ensure users’ requirements for software, packages and computing power, and that any bespoke arrangements can be accommodated, we ask that you outline the specification of the Analysis Environment necessary for your project at the application stage. Further information on available applications can be found [here](#); details of SPSS extensions [here](#); and details of packages for Stata, Python and R [here](#).
- On receipt of your application, if any upscaled or bespoke requirements are selected, a member of the DPAU team will contact you to discuss implementation and any potential costs.

Study Selection

- This section is where you indicate which CRS are of interest to you and, dependent on the CRS, you may select which waves and categories of data from that CRS you wish to analyse. You may apply for only one or for multiple categories of data, but you will need to justify your selection based on your design. CRS are likely to reject proposals where the applicant has requested data without providing a suitable justification.

Key guidance on which data categories/waves/CRS to request

- Please be aware that, in order to have the greatest possible chance of having your access request approved by the relevant CRS, you should ensure that you justify your selection of data categories/waves in the Scientific Rationale and Analysis Plan sections of the Application Form. If you select all, or the vast majority of data categories/waves for a CRS, a justification of the relevance of your selection must be provided on the form. Similarly, when selecting your CRS, we advise only choosing CRS that hold data that are clearly relevant to your study and match the information provided by you on the Application Form. Information to assist you is provided by the [CRS Directory of DPAU’s CRS Metadata Explorer](#), as well as on the CRS’s own websites and in their published literature.

Data Access Application Form

Purpose of the form

This form is to be completed when requesting access to data from the Dementias Platform Australia (DPAU). By submitting this application, you are agreeing to the terms and conditions specified by the DPAU and the Contributing Research Studies (CRS).

Summary of the application form processing

Your application will first undergo an initial review by the DPAU to ascertain whether the form you've submitted is completed correctly and evaluate the project's rationale. Incomplete applications will be returned for revision and unqualified applicants will be advised.

Ready for review applications will be circulated to the data custodians of the CRS that you request access to, based on their individual governance requirements and scientific objectives. The data custodians may ask you to clarify any parts of your application. The data custodians for each CRS will then approve or decline your request for data access. It is possible you will need to have a collaboration discussion and/or sign additional Data Access Agreements with an individual CRS, depending on their requirements. Decisions are expected within 28 days but may vary depending on the access procedures of each CRS.

Once an application is approved by DPAU and the relevant CRS, DPAU will require all project team members that seek to access data on DPAU to sign the DAA. If data for a project is provisioned outside of the SeRP environment, the requesting authorised officer of the main researcher's institution (which is usually the lead institution for the collaboration) of the project is required to sign a separate Data Access Agreement. Policies surrounding use of DPAU can be found [here](#).

Contact information

If you require further information about the DPAU Access Application Form, the application process, or your application then please contact dpau@unsw.edu.au with subject "DPAU Data Access Application Enquiry"



1. Main Applicant Details

Main Applicant's Title	Associate Professor Dr Miss Mr Mrs Professor Other: _____
Main Applicant's First Name	
Main Applicant's Other Name(s)	
Main Applicant's Last Name	
Main Applicant's Email (work/institutional)	
Mobile Country Code	
Mobile Number	
ORCID identifier	
Main Applicant's Role in the Project <i>You can specify more than one role; student researchers must provide their supervisor's details in the co-applicant section.</i>	Student Researcher Student's Supervisor Principal Investigator Co-investigator/Other Researcher Administrator Other: _____
What is the applicant's highest qualification and relevant experience	
Main Applicant's Institution	
Main Applicant's Position in the Institution	
Main Applicant Department/Division/School	
Institution Country	
Institution Address	
Type of Institution	Academic Government Non-profit Commercial Other: _____
Safe Data Handling Training History: Can you describe any safe data handling training, or equivalent experience you've had in the last 5 years?	
Will this co-applicant have a role in the data analysis or for other reasons need access to the data?	Yes/No
Do you have a co-applicant/s for the project? Please note that all researchers accessing the data and all supervisors of student researchers need to be added as co-applicants.	Yes/No



2. Co-applicant(s) Details

Co-applicant's Title	Associate Professor Dr Miss Mr Mrs Professor Other: _____
Co-applicant's First Name	
Co-applicant's Other Name(s)	
Co-applicant's Last Name	
Co-applicant's Email (work/institutional)	
Co-applicant's Mobile Country Code	
Co-applicant's Mobile Number	
Co-applicant's ORCID identifier	
Co-applicant's Role in the Project <i>You can specify more than one role; student researchers must provide their supervisor's details in the co-applicant section.</i>	Student Researcher Student Supervisor Principal Investigator Other Researcher Administrator Other: _____
What is the co-applicant's highest qualification and relevant experience	
Co-applicant's Institution	
Co-applicant's Position in the Institution	
Co-applicant Department/Division/School	
Institution Country	
Institution Address	
Type of Institution	Academic Government Non-profit Commercial Other: _____
Will this co-applicant have a role in the data analysis or for other reasons need access to the data?	Yes/No
Safe Data Handling Training History: Can you describe any safe data handling training, or equivalent experience you've had in the last 5 years?	

3. Project Details

Project title	
Is this project part of a consortia	Yes/No
If yes - consortia name	
Is there funding support for the project?	Yes/No
If yes, source?	
If yes, is the funder a commercial agency?	Yes/No



If commercial funding, please provide more details on the commercial funding, including source, background and purpose.	
How is the project being undertaken in the public interest? <i>e.g. What are the benefits of your research to the community? What are the potential clinical or public health implications?</i>	
Project Intended Start Date	
Project Intended Completion Date	

4. Scientific Context

Search terms/keywords <i>Separate with comma.</i>	
Project Overview (background, aims and any specific hypotheses)	
Scientific Rationale	
Methods/Study Design	
Analysis Plan	
Outcome of interest (measurement) <i>Please provide details as this will help us understand your project, including potential overlaps and/or conflicts with other projects.</i>	
New Variables to be Generated	
Ethical Approval Status	Yes – approved Yes – in progress No
Ethics - if approved, ethics approval number	
Ethics - if approved/in progress, name of ethics committee	
Ethics - if approved/in progress, comments regarding ethics approval, if any	
Ethics, if in progress, expected approval date	
Ethics, if no, please justify	
Expected Output: What kind of output do you expect your project to produce and when? <i>Can select multiple</i>	Journal Article Books & Book Chapters PhD thesis and dissertations Conference Poster Conference Presentation Report Other: _____
Please provide further details of your selected output/s including a general description of all likely IP arising from your proposed project.	
Is this project indented to produce an IP for commercial purposes?	Yes/No



If yes to IP for commercial purposes, please provide details	
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5. Technical Specification

Type of Project <i>Can select multiple</i>	Statistical Analysis Multi-modal Analysis Genomics Imaging Machine Learning Other: _____
DPAU has a dedicated research environment for secure analysis (SeRP). The platform caters for analysis of tabular data, but not for analysis of raw imaging nor genomics data. Will you be able to use this platform for your project? Please note that you can also bring in data not included in this application into the platform.	Yes/No/Unsure
If not able to use SeRP, please justify.	
If unsure about ability to use SeRP, please provide more details.	
Do you intend to include your own data in your analysis? Please describe them here.	
If able to use SeRP, Type of Desktop Requested	Standard (8GB RAM, 4CPUs) Medium (16GB RAM, 4CPUs) – AUD\$3.72/Day Large (32GB RAM, 8CPUs) – AUD\$5.22/Day XL (64GB RAM, 16CPUs) – AUD\$8.22/Day Turbo (128GB RAM, 32CPUs) – AUD\$14.22/Day
If (possibly) able to use SeRP: Bespoke requirements (Software) – Please outline software needed for your analysis, if not already available as standard . Common Packages for STATA , R and Python and for SPSS have already been installed. If applicable, please also outline specific packages needed for your analysis.	

6. Other Information

Please describe any known or potential overlaps/conflicts with other research using these data.	
If you have any further comments regarding the application, please provide them here.	
Kindly review the Data Access Agreement for DPAU and Monash SeRP to ensure the terms are amenable to the applicant and co-applicants. Please do not sign the agreement at this point.	



How did you learn that data from this study are accessible for secondary analysis?	Study website UNSW Works Literature Health Data Australia (HDA) Colleague/Researcher Other: _____
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7. Study Selection

Is this a COSMIC project? <i>DPAU is funded by a NIH grant to the Cohort Studies of Memory in an International Consortium (COSMIC). The data application process for COSMIC is mediated via DPAU.</i>	Yes/No
If a COSMIC project: Do you want to request data from all available COSMIC member studies?	Yes/No
If a COSMIC project but not requesting data from all member studies: COSMIC projects are encouraged to consider the participation of all member studies when they are able to contribute. If you are limiting your request to specific studies, please provide justification here.	
If a COSMIC project, you will be asked to download and complete a specific COSMIC data application (see example overleaf, page 9-11).	
Do you require data from other studies (Not COSMIC)? <i>These include CHeBA cohort studies and other studies of cognition and ageing.</i>	Yes/No
Request for data from CHeBA cohort studies require you to select which measurements and waves of assessment you are interested in. Current details of available data are shown in the tables overleaf (MAS page 12-17; OATS page 18-21; SCS page 22-24).	

EXAMPLE COSMIC DATA REQUEST

Data Request for COSMIC Project: Life's Essential 8 Cardiovascular Health and Prospective Risk of Dementia across Diverse Populations

We are requesting the following types of data:

1. Demographics
2. Assessment wave
3. LE8 metrics at baseline (predicting variables)
4. Dementia and MCI status at baseline and follow-up waves (outcome variables) and Cognitive test scores at baseline and follow-up waves (outcome variables)
5. Other risk factors at baseline (covariates)
6. Vital status
7. Number of APOE ε4 alleles

Note:

- **Please label the variables clearly and provide the units (or formats) of the continuous variables, and explanations of the categorical variables.**
- **Please convert all missing values to system missing or clearly identify missing value codes.**
- **The preferred format is Excel (.csv; .xls; .xlsx). Stata (.dta) or SPSS (.sav) files are happily received too.**

1. Demographics

- a. Age and/or Birth date
- b. Sex
- c. Race and/or Ethnicity
- d. Educational attainment

2. Assessment wave

- a. Date of assessment for each wave

3. Life's Essential 8 (LE8) metrics at baseline (and follow-up if available):

NOTE:

- ※ For this project, the minimum amount of required LE8 metrics is 6 out of 8 at baseline.
- ※ If the preferred measurement below is not available, it would also be helpful if you could provide as much detailed raw data as possible on related variables.
- ※ Continuous values are strongly preferred for all LE8 metrics. Where only categorical or self-reported data are available, those are also welcomed.
- ※ If possible, please also provide the item-level scores.

a. Diet

- i. Daily intake of a healthy eating pattern. (e.g. Mediterranean Eating Pattern for Americans (MEPA) score, Healthy Eating Index (HEI), DASH score, Mediterranean Diet Score (MedDietScore, aMED), fruit/vegetable intakes or other cohort-specific questionnaire)



- b. Physical activity
 - i. Minutes per week of moderate-to-vigorous physical activity (e.g. IPAQ, GPAQ, NHANES PAQ, EPIC, or cohort-specific questionnaire)
- c. Nicotine exposure
 - i. Current smoking status (current / former / never)
 - ii. Pack-years or cigarettes per day for current/former smokers; years since quitting for former smokers.
- d. Sleep health
 - i. Average hours of sleep per night – Even this single item is sufficient.
- e. Body Mass Index (BMI)
 - i. Measured values preferred over self-reported, but both are acceptable.
- f. Blood lipids
 - i. Plasma/serum Total cholesterol and HDL-cholesterol (with units)
 - ii. Use of lipid-lowering medication
 - iii. Self-reported or physician-diagnosed dyslipidemia or hypercholesterolemia
- g. Blood glucose
 - i. Fasting blood glucose or HbA1c (with units)
 - ii. Use of glucose-lowering medication
 - iii. Self-reported or physician-diagnosed diabetes
- h. Blood pressure
 - i. Systolic and diastolic BP (mmHg)
 - ii. Use of antihypertensive medication
 - iii. Self-reported or physician-diagnosed hypertension

4. Dementia and MCI status and cognitive test scores at baseline and all follow-up waves:

- a. Dementia: Date of diagnosis and criteria used
 - i. Type of dementia - if available
- b. MCI: Date of diagnosis and criteria used
 - i. Type of MCI (amnesic single, amnesic multiple, non-amnesic single, or non-amnesic multiple) – if available
 - ii. If MCI diagnoses are not made, the measures of activities of daily living (e.g., disability assessment for dementia [DAD]) and subjective memory or cognitive complaints (e.g., Camdex Memory Complaint Questionnaire) are happily received too.
- c. Global or screening test (e.g., MMSE, CDR, Sum of boxes of CDR, or CERAD-total score I & II)
- d. All other neuropsychological or cognitive tests in the form of raw scores and Z-scores (For Z scores, we prefer those based on external norms, though Z scores based on the control group within the study sample are also acceptable in case external norms are not available).

5. Other risk factors at baseline only:

- a. Current status of severe hearing loss or vision loss
 - i. ‘Severe’ means that hearing or reading would be impossible even with the use of hearing and visual aids.



- b. Depression (Preferably in the scores of rating scales, but other measures [e.g. depression diagnosed by clinical interview] can also be received)
- c. Cohabitation status (e.g. married/partnered, living alone, etc)

6. Vital status

- a. Date of death or date of last known contact (for censoring in survival analyses)
 - i. This information is needed to properly account for death as a competing risk in our survival models

7. Number of APOE $\epsilon 4$ alleles, if available



Sydney Memory & Ageing Study DATA/BIOSPECIMENS DETAILS:

ASSESSMENT DATA*	Wave							Comments
	1	2	3	4	5	6	7	
01_Administration								
Descriptives: assessment metadata (<i>age, birth date, sex, NESB, education, death, and assessment status information</i>).								
Informant contact & confidence								
02_Sociodemographic	1	2	3	4	5	6	7	
Demographics								
03_Early Life Environment	1	2	3	4	5	6	7	
Childhood Trauma Questionnaire								
Early Life Events								
Life Experience Questionnaire								
04_Medical History	1	2	3	4	5	6	7	
Balance & falls risk								
Cardiovascular disease risk (Framingham index)								
Frailty Phenotype Fried								
Frailty Index Searle								
Medical history, incl Vascular Risk Factor Presence (diabetes, hypertension, smoking, alcohol) status (ever/never)								
Current medications (pls specify requirements)								
Medication Groups								
Metabolic syndrome status								
World Health Organisation Disability Assessment Schedule 2.0 (WHODAS-II) – by informant								
World Health Organisation Disability Assessment Schedule 2.0 (WHODAS-II) – by participant								
05_Family (Disease) History	1	2	3	4	5	6	7	
Family health history								



06_Psychological Status	1	2	3	4	5	6	7	
Apathy Evaluation Scale (AES)								
Assessment of Quality of Life (AQOL – by informant)								
Assessment of Quality of Life (AQOL) – by participant								
Attitudes towards Ageing Scale (AAS)								
DeJong Loneliness Scale (DJLS)								
Geriatric Depression Scale (GDS)								
Goldberg Anxiety Scale (GAS)								
Interpersonal Reactivity Index (IRI)								
Kessler Psychological Distress Scale (K10) – by Informant								
Kessler Psychological Distress Scale (K10) – by participant								
Mini International Neuropsychiatric Interview (MINI)								
Neuroticism-Extraversion-Openness Five-Factor-Inventory (NEO-FFI)								
Patient Health Questionnaire (PHQ-9) depression module – by informant								
Patient Health Questionnaire (PHQ-9) depression module – by participant								
Positive and Negative Affect Schedule (PANAS), Positive only								
Purpose in Life Scale								
Satisfaction With Life Scale (SWLS)								
07_Cognitive Status	1	2	3	4	5	6	7	
Addenbrooke's Cognitive Examination (ACE-R/ACE-3)								
Change in Cognition with Age Questionnaire (CICAQ)								
Clinical Dementia Rating (CDR)								
Diagnosis (MCI/Dementia)								
Emotion Recognition Task (ERT)								
General Practitioner assessment of Cognition (GP-COG)								



Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – by Informant								
Memory Assessment Clinic Q (MAC-Q)								
Mini Mental State Examination (MMSE)								
Neuropsychiatric Inventory (NPI)								
Neuropsych/cognitive domain scores								
Prospective memory task								
Reading the Mind in the Eyes Test (RMET)								
Subjective cognitive complaints – by Informant								
Subjective cognitive complaints – by participant								
Telephone Interview for Cognitive Screening - Modified (TICS-M)								
Voice recordings (Cookie Theft)								*Voice data only available to those on MAS ethics
Voice recordings (NART)								
Walk & Talk test								
Wechsler Adult Intelligence Scale (WAIS)								
08_Lifestyle behaviour	1	2	3	4	5	6	7	
Care burden – by informant about self								
Cognitive (mental) activity								
Food Frequency Questionnaire (FFQ)								
Food Frequency Questionnaire (FFQ) – food intakes								
Physical activity								
Retrospective cognitive (mental) activity								
Zarit Burden – by informant								
Sleep questionnaire – by informant								
Sleep questionnaire - by participant								
09_Life functionality	1	2	3	4	5	6	7	
Bayer Activities of Daily Living (B-ADL) – by Informant								
Bayer Activities of Daily Living (B-ADL) – by Participant								



Modified Lawton-Brody Instrumental Activities of Daily Living (MLB-IADL) - by Informant								
Physical Self-Maintenance Scale (ADL) – by Informant								
Physical Self-Maintenance Scale (ADL) – by Participant								
Sydney Test of Activities of Daily Living in Memory Disorders (STAM) - by Participant								
10_Physical environment	1	2	3	4	5	6	7	
Geospatial data								W1 ~ 2006, W4 ~ 2011, W6 ~2016
11_Social environment	1	2	3	4	5	6	7	
Lubben Social Network Scale (LSNS)								
Social activity								
12_Physical examination	1	2	3	4	5	6	7	
Audiology								
Hypertension status								
Medical exam								
13_Imaging	1	2	3	4	5	6	7	
Arterial stiffness								
DEXA X-ray Scans								
MRI IDP: DWI- Difference in Distribution Function (DDF)								
MRI IDP: Peak width of Skeletonized Mean Diffusivity (PSMD)								
MRI IDP: WMH- TOPMAL JHU								
MRI IDP: White Matter Hyperintensities (WMH)- UBO PV								
MRI IDP: cortical thickness								
MRI IDP: cortical volume								
MRI IDP: subcortical volume								
Micro bleeding								
Other Imaging Data - plz specify								* In consultation with CHeBA imaging team
MRI - Raw MRI data (pls specify)								*In consultation with CHeBA imaging team
Retinal scan derived data								



Retinal scan raw data								
14_Linkage	1	2	3	4	5	6	7	
Pharmaceutical Benefits Scheme (PBS) data*								*PBS/MBS data only available to those on MAS ethics
Medicare Benefits Schedule (MBS) data*								
15_Healthcare utilisation	1	2	3	4	5	6	7	
Health service utilisation								
16_Bio-sample assays	1	2	3	4	5	6	7	
Blood - AD Biomarkers								
Blood - Afamin								
Blood - Apolipoprotein								
Blood - Full blood count								
Blood - Inflammatory markers								
Blood - Routine chemistry								
Blood - Special chemistry								
Blood - Vitamin D								
Blood - macrophage inhibitory cytokine 1 (MIC-1)								
Blood - Fatty acids								
Other blood data or biosamples								Please provide further details
17_Molecular	1	2	3	4	5	6	7	
APOE genotype								
Gene expression data								
Genetics - Genome-wide genotyping data								
Genetics & Other genetic data or samples								Please provide further details
Interim Assessments	1	2	3	4	5	6	7	
04_Medical History								
Interim history (demographics, med history etc)								
05_Psychological Status	1	2	3	4	5	6	7	
Patient Health Questionnaire (PHQ-9) depression module – by participant								
07_Cognitive Status	1	2	3	4	5	6	7	



Subjective cognitive complaints – by Participant									
Subjective cognitive complaints – by Informant									
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – by Informant									
Cognitive status (TICS-M)									
09_Life functionality	1	2	3	4	5	6	7		
Bayer Instrumental Activities of Daily Living (B-ADL) – by Informant									
Physical Self-Maintenance Scale (ADL) – by Informant									
Physical Self-Maintenance Scale (ADL) – by Participant									
Modified Lawton-Brody Instrumental Activities of Daily Living (MLB-IADLs), - by Participant									

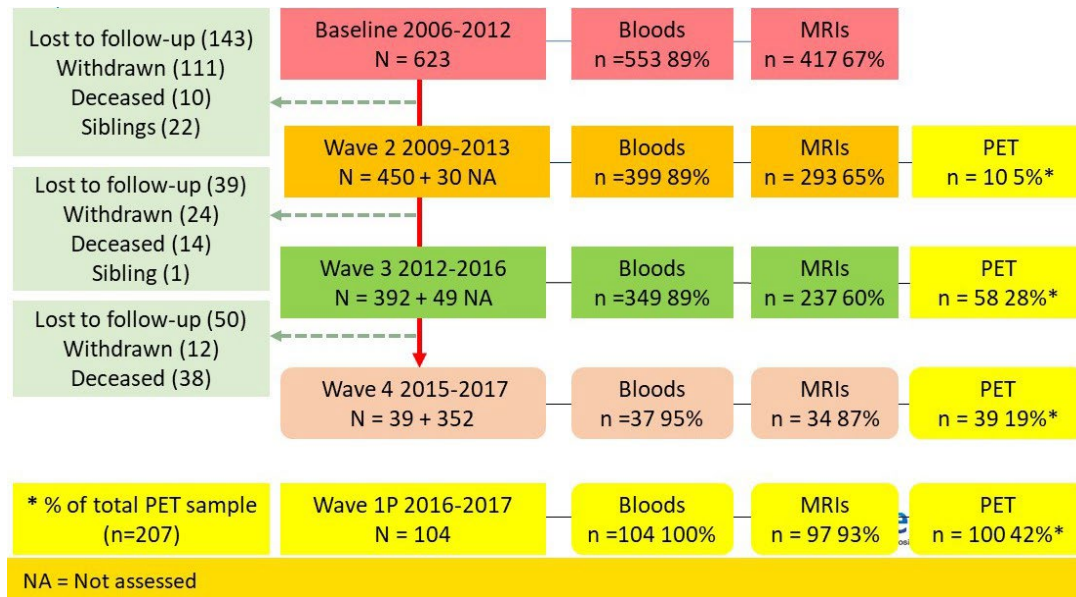
Key:

	Data available for analysis
	Data not yet available for analysis
	Data not collected at this wave



Older Australian Twins Study

DATA/BIOSPECIMENS DETAILS:



- For 'CRS_90X_OTP' – the sample size is 104. Additional 103 participants that have PET scans, separate data requests are needed.
- For total sample with PET scans, separate data request to 'CRS_90X_OAT' is required.

ASSESSMENT DATA	1	2	3	4P	1P	Comments
01_Administration	1	2	3	4P	1P	
Assessment metadata (<i>age, sex, twin number, zygoty, NESB, education, death, and assessment status information</i>).						
02_Sociodemographic	1	2	3	4P	1P	
Demographics						
03_Early Life Environment	1	2	3	4P	1P	
Being Twins Questionnaire						Late life Being Twins Qs (W2-W4) are in Social Network dataset
Life Experience Questionnaire (LEQ)						
04_Medical History	1	2	3	4P	1P	
Cardiovascular disease risk (Framingham index)						
Cardiovascular History						
Falls History						
Medical history						
Medications (self-report)						



World Health Organisation Disability Assessment Schedule 2.0 (WHODAS-II)						
05_Family (Disease) History	1	2	3	4P	1P	
Family health history						
06_Psychological Status	1	2	3	4P	1P	
Apathy Evaluation Scale (AES) – by informant						
Assessment of Quality of Life (AQOL) – by participant						
Goldberg Anxiety Scale (GAS)						
Geriatric Depression Scale (GDS)						
International Personality Disorder Examination (IPDE - ICD10)						
Kessler Psychological Distress Scale (K10) – by participant						
Neuroticism-Extraversion-Openness Five-Factor-Inventory (NEO-FFI)						
The Positive and Negative Affect Schedule (PANAS), Positive only						
Satisfaction With Life Scale (SWLS)						
Successful Ageing Questionnaire						
Structured Clinical Interview for DSM (SCID)						
07_Cognitive Status	1	2	3	4P	1P	
Clinical Dementia Rating (CDR) – by informant						
Change in Cognition with Age Questionnaire (CICAQ) – by informant						
Diagnosis (MCI/Dementia)						
General Practitioner assessment of Cognition (GP-COG)						
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – by Informant						
Memory Assessment Clinic Q (MAC-Q)						
Mini Mental State Examination (MMSE)						
Neuropsychiatric Inventory (NPI) – by informant						
Neuropsych/cognitive domain scores						



Subjective cognitive complaints						
08_Lifestyle behaviour	1	2	3	4P	1P	
Carer burden – by informant about self						
Food Frequency Questionnaire (FFQ)						
Sleep questionnaire						

09_Life functionality	1	2	3	4P	1P	
Physical Self-Maintenance Scale (ADL) – by Informant						
Bayer Activities of Daily Living (B-ADL) – by Informant						
10_Physical environment	1	2	3	4P	1P	
Geospatial data						W1 ~ 2006; W3 ~ 2012; W4 ~ 2018
11_Social Environment	1	2	3	4P	1P	
Significant Life Events						
Social Networks						
12_Physical examination	1	2	3	4P	1P	
Cardiovascular Assessment						
Hypertension status						
Medical exam						
13_Imaging	1	2	3	4P	1P	
MRI - Grey matter volumes						
MRI - Microbleeds						
MRI - Functional MRI						
MRI - White matter hyperintensities						
MRI - Other MRI data						Please provide further details
PET – Beta amyloid						
14_Linkage	1	2	3	4P	1P	
Medicare Benefits Schedule (MBS) data*						*PBS/MBS data only available to those on OATS ethics
Pharmaceutical Benefits Scheme (PBS) data*						
15_Healthcare utilisation	1	2	3	4P	1P	
Health service utilisation						



16_Bio-sample assays	1	2	3	4P	1P	
Blood - Full blood count			*		*	
Blood - Inflammatory markers						
Blood - Insulin						
Blood – Lipidome						
Blood - Routine chemistry						
Blood - Special chemistry						
Other blood data or samples						Please provide further details
17_Molecular	1	2	3	4P	1P	
Genetics - APOE status						
Genetics - Genome-wide genotyping data						
Gene expression data						
Genetics - Other genetic data or samples						Please provide further details
Interim Assessments	1	2	3	4		Comments
04_Medical History	1	2	3	4P	1P	
Interim history (demographics, med history etc)						
07_Cognitive Status	1	2	3	4P	1P	
Subjective cognitive complaints (SCC)						
Cognitive status (TICS-M)						

Key:

	Data available for analysis
	Data not <u>yet</u> available for analysis
	Data not collected at this wave



Sydney Centenarian Study

DATA/BIOSPECIMENS DETAILS:

ASSESSMENT DATA	Original cohort 2007-2015				Out of Area	Comments	Relaunch cohort 2016-2020					
	1	2	3	4			1	2	3	4	5	6
01_Administration												
Assessment metadata (<i>age, sex, NESB, education, mortality, and assessment status information</i>).												
02_Sociodemographic	1	2	3	4	OoA		1	2	3	4	5	6
Demographics												
04_Medical History	1	2	3	4	OoA		1	2	3	4	5	6
Medical history												
Informant Medical History												
Current medications (pls specify requirements)												
SARCF												
Falls questionnaire												
Secrets to longevity												
05_Family (Disease) History	1	2	3	4	OoA		1	2	3	4	5	6
Family health history												
06_Psychological Status	1	2	3	4	OoA		1	2	3	4	5	6
Geriatric Depression Scale (GDS)												
Kessler Psychological Distress Scale (K10)												
Interpersonal Reactivity Index (IRI)												
Satisfaction With Life Scale (SWLS)												
The 12-Item Short Form Health Survey (SF-12)												
Apathy Evaluation Scale (AES)												
Attitudes to End-Of-Life Issues (AEOLI)												
Trauma												



07_Cognitive Status	1	2	3	4	OoA		1	2	3	4	5	6
Clinical diagnosis (MCI/Dementia)												
Clinical Dementia Rating (CDR) by informant												
Subjective cognitive complaints – by pt and inf												
Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – by Informant												
General Practitioner assessment of Cognition (GP-COG)												
Mini Mental State Examination (MMSE) & Addenbrooke's Cognitive Examination (ACE-R/ACE-3)												
Neuropsych scores												
Everyday Problem Solving for Cognitively Challenged Elderly (EPCCE)												
Autobiographical Memory Interview (AMI)												
Reading the Mind in the Eyes Test (RMET)												
Neuropsychiatric Inventory (NPI)												
08_Lifestyle behaviour	1	2	3	4	OoA		1	2	3	4	5	6
Physical Activity												
Cognitive (mental) activity												
Dietary questionnaire												
09_Life functionality	1	2	3	4	OoA		1	2	3	4	5	6
Bayer Activities of Daily Living (B-ADL) – by Informant												
Physical Self-Maintenance Scale (ADL) – by Informant												
11_Social Environment	1	2	3	4	OoA		1	2	3	4	5	6
Social Integration												
12_Physical examination	1	2	3	4	OoA		1	2	3	4	5	6
Medical exam												



13_Imaging	1	2	3	4	OoA		1	2	3	4	5	6
MRI - Grey matter volumes												
MRI - White matter hyperintensities												
MRI - Microbleeds												
MRI - Functional MRI												
Other MRI data						Please provide further details						
14_Linkage	1	2	3	4	OoA		1	2	3	4	5	6
Pharmaceutical Benefits Scheme (PBS) data*						*PBS/MBS data only available to those on SCS ethics						
Medicare Benefits Schedule (MBS) data*												
15_healthcare_utilisation												
Resource Utilization in Dementia - Lite Version (RUD-Lite)												
16_Bio-sample assays	1	2	3	4	OoA		1	2	3	4	5	6
Blood - Routine chemistry												
Blood - Full blood count												
Blood – AD Biomarkers												
Other blood data or samples						Please provide further details						
17_Molecular	1	2	3	4	OoA		1	2	3	4	5	6
APOE genotype												
Genome-wide genotyping data												
Other genetic data or samples						Please provide further details						

Key:

	Data available for analysis
	Data not yet available for analysis
	Data not collected at this wave