

Measurement-level Data Sharing Workflow

CHeBA Research Bank as a Use Case of
Dementias Platform Australia (DPAU)

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Acknowledgements

I begin today by acknowledging the Traditional Custodians of the land on which we meet today, and pay my respects to their Elders past and present.

I extend that respect to Aboriginal and Torres Strait Islander peoples here today.

About me

- Manager of Dementias Platform Australia (DPAU)
- Statistical background

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Today's Talk

Introduction

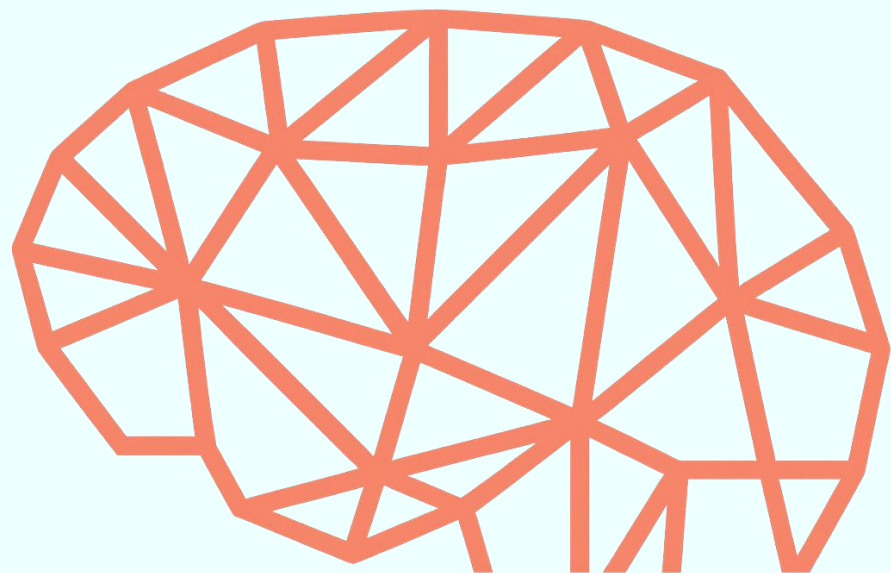
- Dementias Platform Australia (DPAU)
- Centre for Healthy Brain Ageing (CHeBA)
- CHeBA Research Bank

Workflow walkthrough

Questions



Dementias Platform Australia (DPAU)



Dementias Platform ^{AU}



macquarie
CLOUD SERVICES

We ride the waves of **data**,
FIVE SAFES in our tune,
Dementia's story shared,
bright as a June moon,
FAIR horizons guide the crew.

FAIR data, open doors,
for ageing minds we soar,
Together we can heal,
with every data store,
DPAU leads, forevermore.

Dementias Platform Australia (DPAU)



FAIR

Findable

Accessible

Interoperable

Reusable

Dementias Platform Australia (DPAU)

Infrastructure



UNSW
SYDNEY



MONASH
University



Funding



National Institute
on Aging



Australian Research Data Commons

Partner

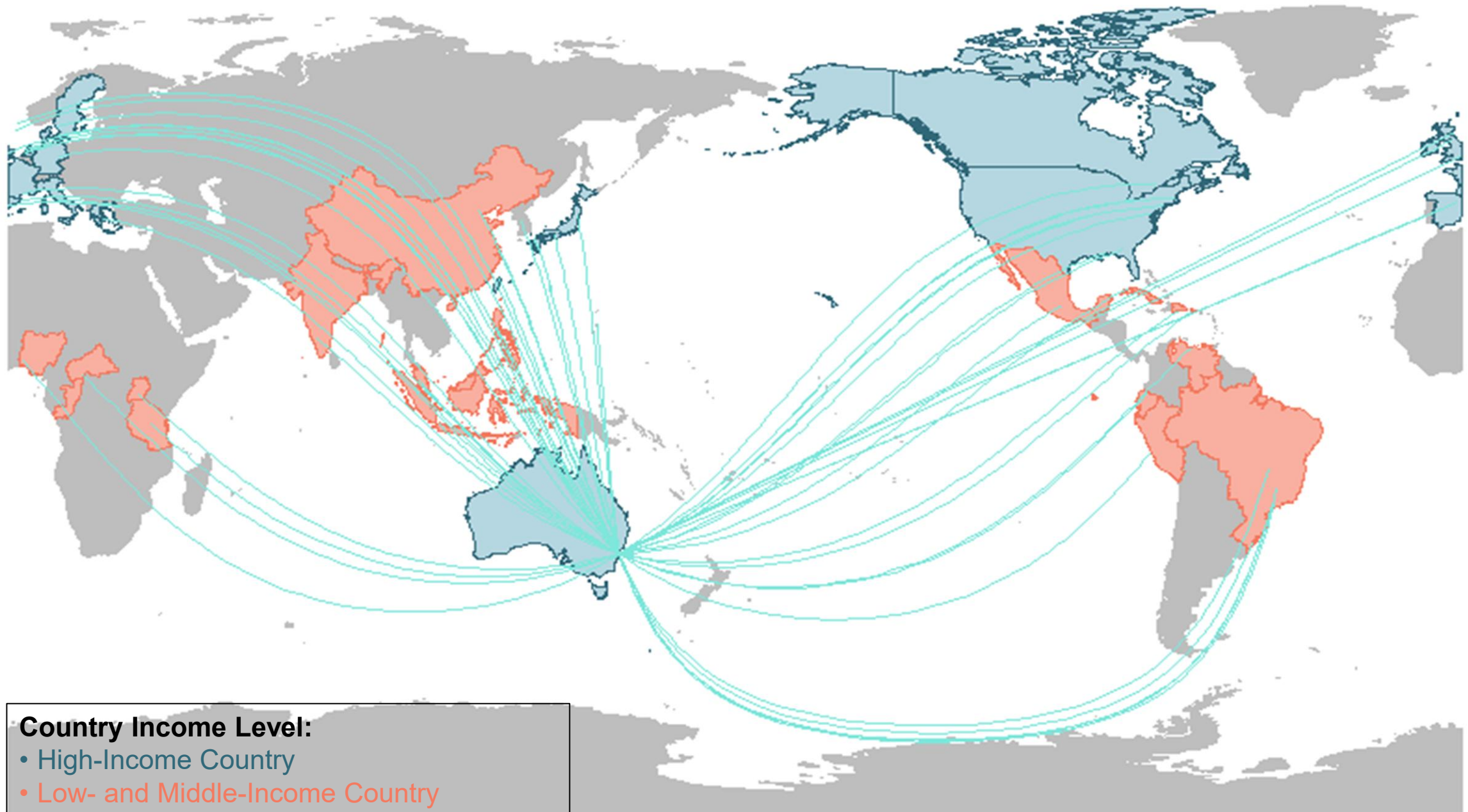


Dementias
Platform^{UK}



ADDI
Alzheimer's Disease
Data Initiative

Fig 1. Global Reach of Dementias Platform Australia (DPAU)



Country Income Level:

- High-Income Country
- Low- and Middle-Income Country

Dementias Platform Australia (DPAU)

Empower Research Community

- ✓ Foster Collaborations
- ✓ Generate insights from already collected data
- ✓ Reduce Research Costs
- ✓ Share experience

Contributing Research Studies (CRS)

- ✓ FAIR & FIVE SAFES
- ✓ Compliance
- ✓ Increases the long-term impact and legacy of study data
- ✓ Reduces administrative burden
- ✓ Accommodate various level of engagement and control

Researchers

- ✓ Systematically find relevant datasets
- ✓ Efficiently access multiple datasets
- ✓ Offers secure, global TRE access
- ✓ Supports cross-cohort and international collaborations

Overall Impact

- ✓ Accelerates progress in dementia research
- ✓ Transforms understanding of ageing and dementia
- ✓ Maximizes the value and reach of every Contributing Research Studies (CRS)

Centre for Healthy Brain Ageing (CHeBA)



EPIDEMIOLOGY



NEUROIMAGING



NEUROPSYCHOLOGY



GENOMICS &
EPIGENOMICS



NEUROPSYCHIATRY



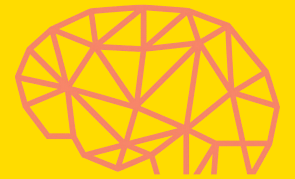
MOLECULAR
BIOMARKERS



PERMINDER
SACHDEV



HENRY
BRODATY

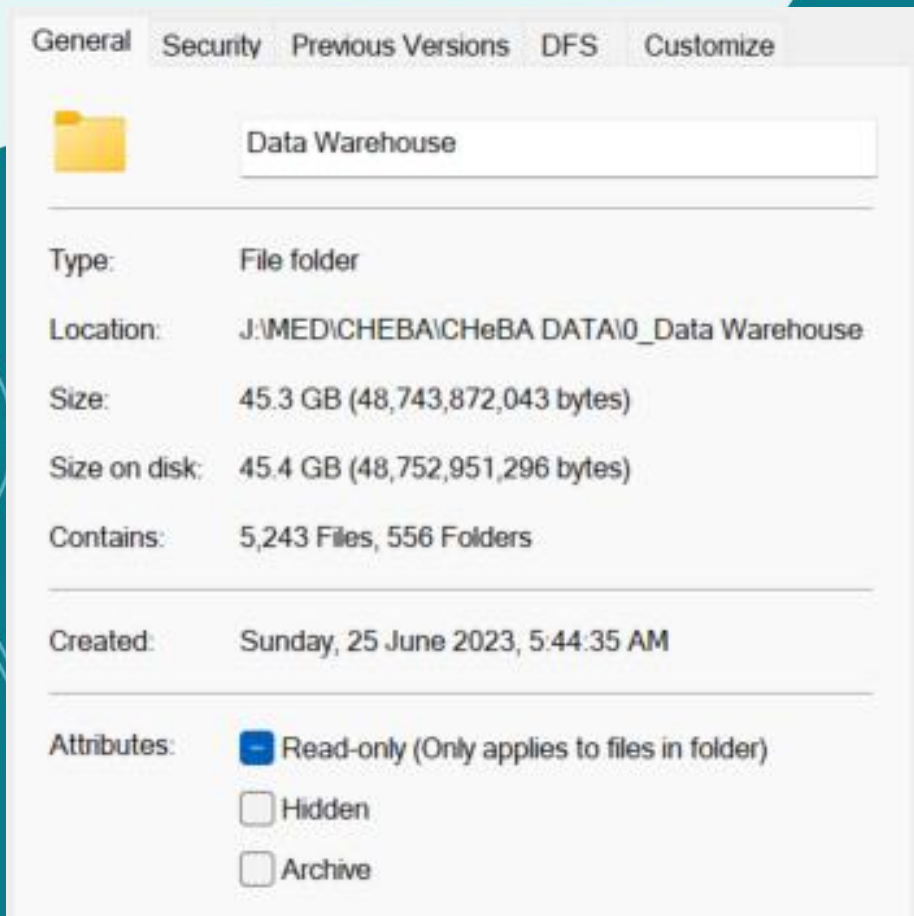


Dementias
Platform AU



UNSW
SYDNEY

CHeBA Research Bank



Sydney Memory & Ageing Study (MAS)

- 7 waves & 6 interim waves
- 2005 - 2020



Sydney Centenarian Study (SCS)

- 4 Waves + Re-launch (6 Waves)
- 2013 - 2020



Older Australian Twins Study (OATS)

- 4 waves & imaging sub-study
- 2006 - 2017

Memory & Ageing Study Data Request CHeBA Research Bank

REQUESTED DATA/BIOSPECIMENS DETAILS:

Please indicate ALL data being requested by placing an X in the appropriate box(es). Add additional comments as appropriate.

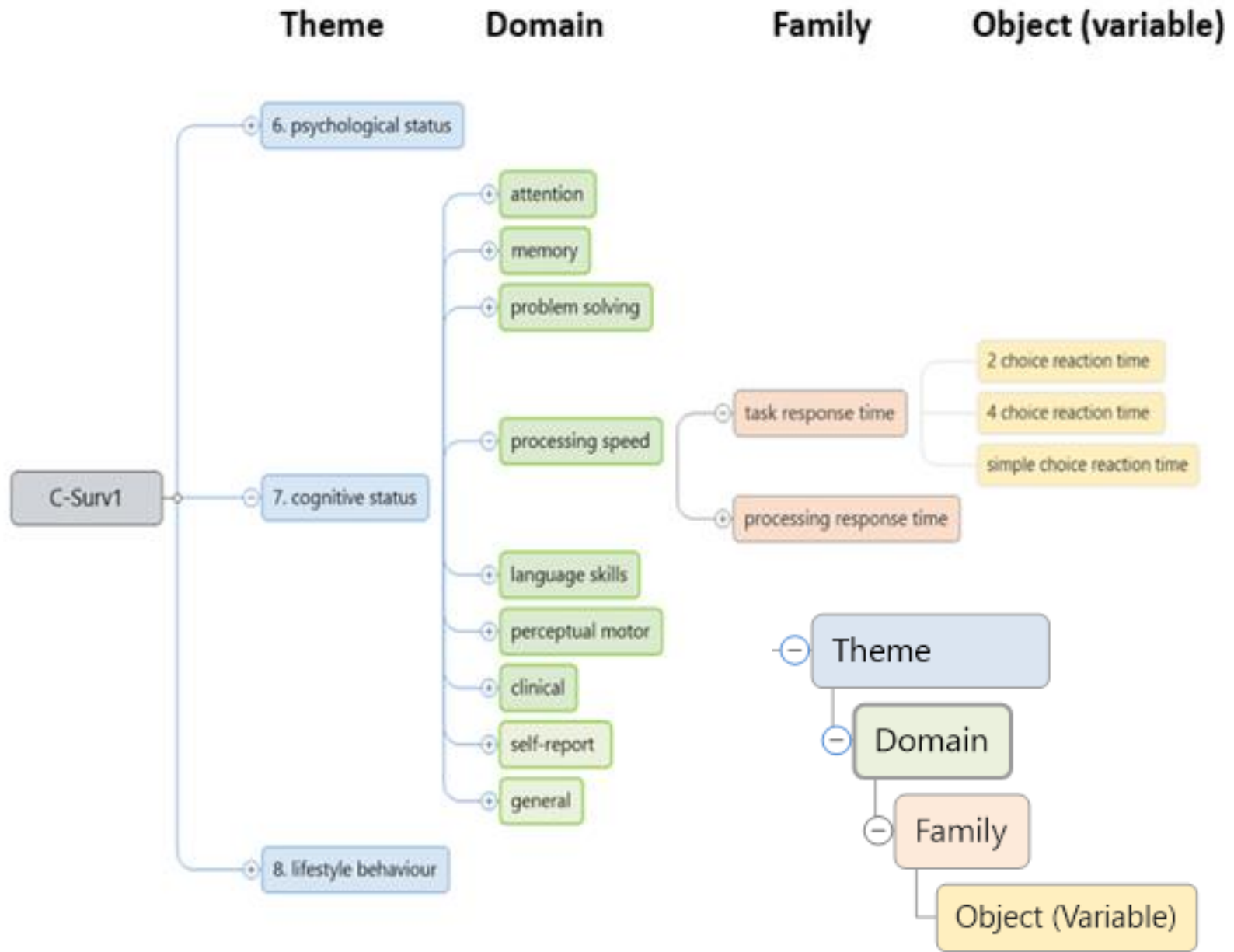
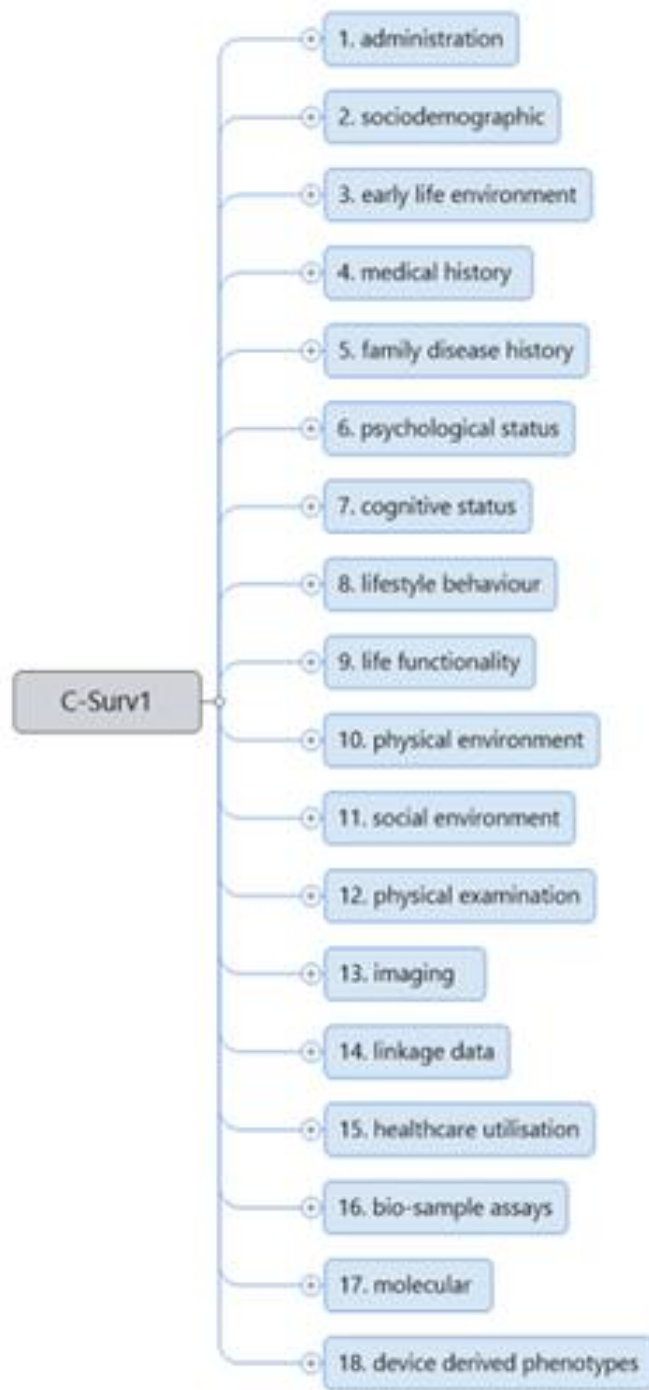
ASSESSMENT DATA*	Wave							Comments
	1	2	3	4	5	6	7	
Assessment metadata (age, birth date, sex, NESB, education, death, and assessment status information)								
Demographics								
Clinical Status								
Clinical diagnosis (MCI/Dementia)								
CDR								
Cognitive Complaints								
Subjective cognitive complaints								
MAC-Q								
IQCODE								
GPCOG								
CICAQ								
Cognitive Status								
ACE-3/ACE-R								
MMSE								
NeuroPsych/cognitive domain scores								
TICS-M								
Prospective memory								
Psychological Status								
GAS								
GDS								
PANAS								
K10								
NEO-FFI								
MINI								
NPI								

Last Updated: 30/9/2021

PHQ-9								
Physical Health								
Medical exam								
Medical history								
Family health history								
Current medications (pls specify requirements)								
Cardiovascular disease risk (Framingham index)								
Vascular Risk Factor Presence (diabetes, hypertension, smoking, alcohol) status (ever/never)								
Metabolic syndrome status								
Hypertension status								
Balance & falls risk								
FFQ								
Sleep questionnaire								
Health service utilisation								
Medicare history → PBS data								
→ MBS data								
Biomarkers								
Blood chemistry → Routine analysis								
→ Special chemistry								
→ Inflammatory markers								
→ MIC-1								
→ Full blood count								
→ Vitamin D								
→ Afamin								
→ Other blood data or samples								Please provide further details overleaf
Arterial stiffness								
Retinal scan data								
MRI → Grey matter volumes								
→ White matter hyperintensities								
→ Microbleeds								
→ Functional MRI								
→ Other MRI data (pls specify)								
Genetics → APOE status								

It is not sustainable!
Is there a better way?

C-Surv Ontology



File Naming Structures

Each file name has five elements comprising **study**, **theme**, **measurement**, **study waves** and the **date** file created/updated.

Example: **MAS06_GAS_1_v20220519.sav**

- The Contributing Research Study (**CRS**) is identified using a **three-digit alphabetic character**, **MAS** for Sydney Memory and Ageing Study.
- The '**Theme**' is identified using a two-digit numeric (01 - 18) based on the 18 data themes of C-Surv data model developed by DPUK. **06** for **psychological status**.
- The **measurement** is described by an alphabetic abbreviation, **GAS** for **Goldberg Anxiety Scales (GAS)**.
- The **study wave** is indicated by an integer, **1** for **baseline**, 2 for first follow-up, etc.
- Finally, a **date** suffix for version control in the format of **_vYYYYMMDD**.

Curated File Name

	filename
290	MAS16_bloodroutine_4_v20220608.sav
291	MAS16_bloodspecchem_1_v20220518.sav
292	MAS16_bloodspecchem_2_v20220518.sav
293	MAS16_bloodvitd_1_v20220518.sav
294	MAS17_apoe_1_v20220518.sav

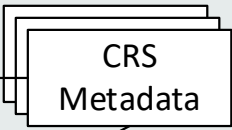
Sydney Memory & Ageing Study
DATA/BIOSPECIMENS DETAILS:

ASSESSMENT DATA*	Wave							Comments
	1	2	3	4	5	6	7	
01_Administration								
Descriptives: assessment metadata (age, birth date, sex, NESB, education, death, and assessment status information).								
Informant contact & confidence	■				■	■	■	
02_Sociodemographic	1	2	3	4	5	6	7	
Demographics								
03_Early Life Environment	1	2	3	4	5	6	7	
Early Life Events	■	■	■			■	■	
Childhood Trauma Questionnaire	■	■	■			■	■	
	1	2	3	4	5	6	7	
Cardiovascular disease risk (Framingham index)					■	■	■	
Balance & falls risk					■	■	■	
Frailty Index Searle								
Frailty Phenotype Fried								
Medical history, incl Vascular Risk Factor Presence (diabetes, hypertension, smoking, alcohol) status (ever/never)								
Medication Groups						■	■	
Current medications (pls specify requirements)						■	■	
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		■	■	■	■	■	■	

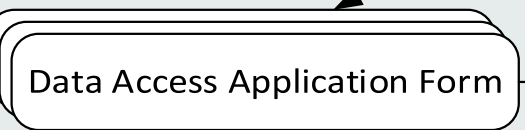
06_Psychological Status	1	2	3	4	5	6	7
Attitudes towards Ageing Scale (AAS)		■	■	■	■	■	
Apathy Evaluation Scale (AES)						■	
Assessment of Quality of Life (AQOL – by informant)							■
Assessment of Quality of Life (AQOL) – by participant					■	■	
DeJong Loneliness Scale (DJLS)		■	■	■	■	■	
Goldberg Anxiety Scale (GAS)				■	■		
Geriatric Depression Scale (GDS)					■	■	
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)			■	■	■	■	
The Positive and Negative Affect Schedule (PANAS), Positive only							
Patient Health Questionnaire (PHQ-9) depression module – by informant		■	■	■	■	■	■
Patient Health Questionnaire (PHQ-9) depression module – by participant			■	■	■	■	
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)				■	■		
Clinical Dementia Rating (CDR)					■	■	■
Change in Cognition with Age Questionnaire (CICAQ)				■	■		
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)					■		

I still don't want use
word + excel

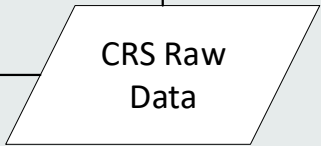
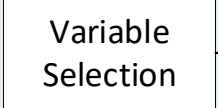
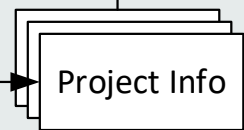
DPAU Structure



Portal



Update





GLADSE



- Statement
- Study List
- CSURV Matrix
- Study Directory
- Filters
- Measurements
- Other Repositories

GLobal Ageing and Dementia Study Explorer (GLADSE)

This R-shiny app was developed to improve the findability, accessibility, interoperability and reusability (FAIR) of dementia research data. The app enables researchers to explore and visualise data from participants that match certain criteria or interests. The app was primarily developed to support data sharing of Cohort Studies of Memory in an International Consortium (COSMIC) [1] and Dementias Platform Australia (DPAU) [2]. The development of a generalised version of this app is described in Chen et al. [3]. The

Not word + excel

Maybe -



Create REDCap Data Dictionary From Curated File Name

	filename	vname	CRS	themeid	measurement	wave
290	MAS16_bloodroutine_4_v20220608.sav	mas16_bloodroutine_4	MAS	16	bloodroutine	4
291	MAS16_bloodspecchem_1_v20220518.sav	mas16_bloodspecchem_1	MAS	16	bloodspecchem	1
292	MAS16_bloodspecchem_2_v20220518.sav	mas16_bloodspecchem_2	MAS	16	bloodspecchem	2
293	MAS16_bloodvitd_1_v20220518.sav	mas16_bloodvitd_1	MAS	16	bloodvitd	1
294	MAS17_apoe_1_v20220518.sav	mas17_apoe_1	MAS	17	apoe	1

Create REDCap Data Dictionary From Curated File Name

A	B	C	D	E	F	R	S
Variable / Field Name	Form Name	Section He	Field Type	Field Label	Choices, C	Field Annotation	
mas16_bloodspecchem_6	crs_101_mas_measurement		checkbox	Blood - Special chemistry	1, *	@READONLY	
mas16_bloodspecchem_7	crs_101_mas_measurement		checkbox	Blood - Special chemistry	1, *	@READONLY	
mas16_bloodspecchem_x	crs_101_mas_measurement		checkbox	Blood - Special chemistry	1, *	@READONLY	
mas16_bloodvitd_1	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *		
mas16_bloodvitd_2	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_3	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_4	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_5	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_6	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_7	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas16_bloodvitd_x	crs_101_mas_measurement		checkbox	Blood - Vitamin D	1, *	@READONLY	
mas17_apoe_1	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *		
mas17_apoe_2	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_3	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_4	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_5	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_6	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_7	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	
mas17_apoe_x	crs_101_mas_measurement		checkbox	Genetics - APOE status	1, *	@READONLY	

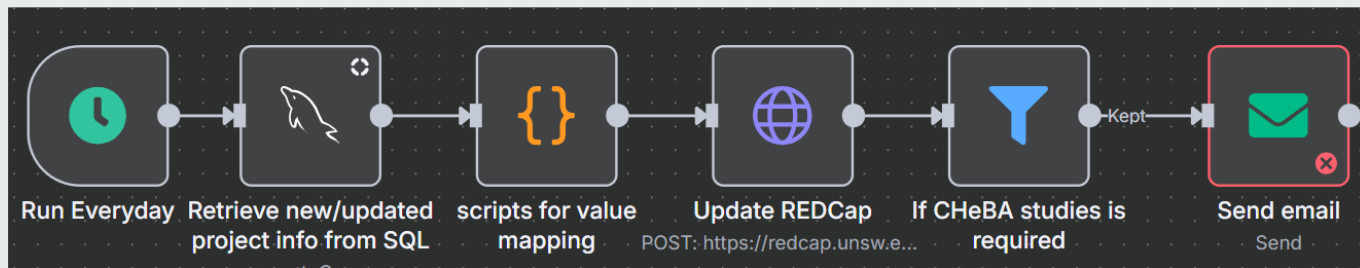


python™

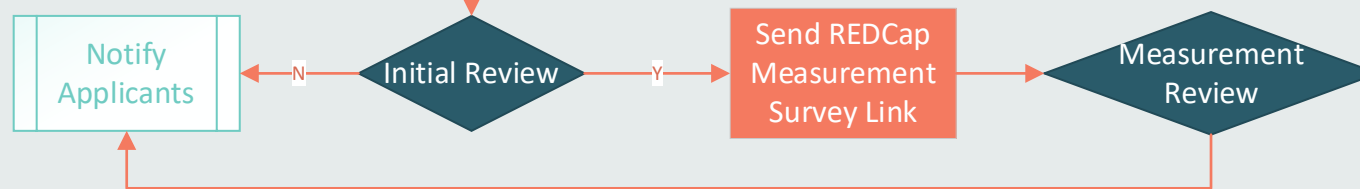


What else?

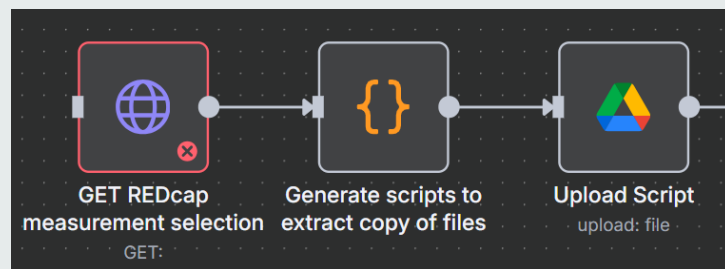
Automation



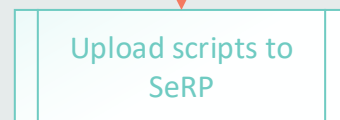
CHeBA - REDCap



Automation



SeRP



Experimental solution



Find us:

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www.linkedin.com/in/rorychenxy/

<https://portal.dementiasplatform.com.au/>

Thank you & Questions