



Data Use and Re-Use at the Centre for Mental Health Research

Kaarin J. Anstey

Associate Professor & Director, Ageing Research Unit, Centre for Mental Health Research, NHMRC Senior Research Fellow

- Funded by grants from NHRMC, ARC, Alzheimer's Australia, NRMA ACT Road Safety Trust, Lifeline, DoHA, FaCSIA, others
- 7 academic staff B+, 3 postdocs, 18 PhD students, 20-30 research staff, 2 administrative staff

Research streams

- ageing, e-Health,
- methodology,
- family and community mental health,
- consumer





Personality and Total Health Through Through Life (PATH)

ORIGINAL AIMS – Prof Tony Jorm, 1999

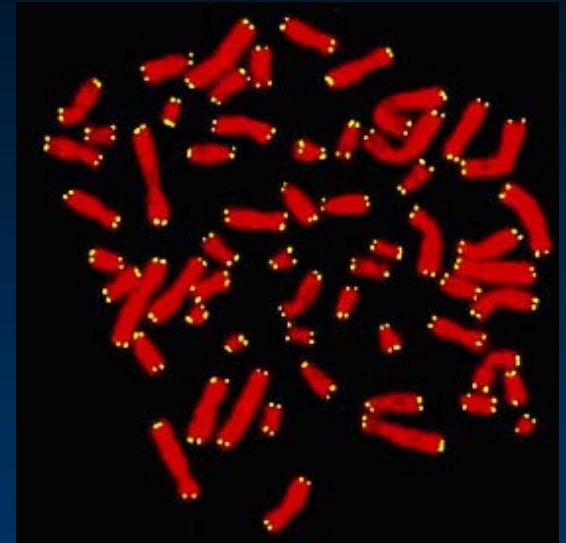
- a) to delineate the course of depression, anxiety, substance use and cognitive ability with increasing age across the adult life span;
- b) to identify environmental and genetic risk factors
- c) to investigate interrelationships over time between the three domains

- Narrow cohort study
- 3 cohorts with 4 year age-bands, c. 2500 per cohort
- 4 year follow-up
- 20 year schedule
- Separation of ageing from cohort effects

Substudies:

1. Normative MRI study
2. Health and Memory study
3. Genetics – cheek swab taken at Wave 1

- Demographics – partner,
- children, education
- Mental Health
- Trauma history, work stress
- Social Support
- Childhood adversity
- Activities – RAISIC scales
- Life Events
- Physical health
- Physical activity
- Genetic markers



*Photo of human chromosomes (coloured red).
The telomeres which are found at the tips of
chromosomes are highlighted in yellow.
Courtesy of Axel Neumann, Children's
Medical Research Institute, Sydney*

- Blood pressure
- Lung function (FEV)
- Handgrip
- Vision
- List of Illnesses
- Antihypertensive use
- Short form SF-12
- History of head injury

- Smoking
- Marijuana use
- Religiosity
- Financial strain
- Alcohol

- Goldberg depression and anxiety inventory
- Suicidality
- Eysenck Personality Questionnaire (EPQ)
- BISBAS
 - Behavioural inhibition
 - Behavioural activation
 - Reward
 - Activation
 - Fun

Selected as indicators of broad abilities

- Simple reaction time
- Choice reaction time
- California verbal learning test
 - immediate, short delay
- Digits backwards
- Symbol digit
- Spot-the-Word

Added to Wave 2

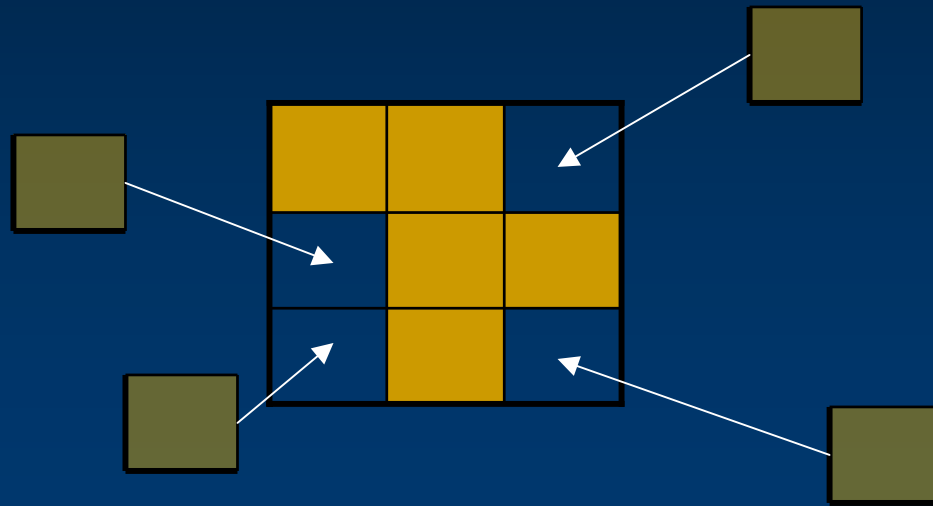
- Trails B
- Face Recognition

Data pooling

- Increasing trend to pool epidemiological studies
- Enables more data on rare events
- Facilitates collaboration
- Builds on investment in data
- Infrastructure required
- Documentation, data management critical to success
- Compounds the challenges involved in managing individual studies

DYNOPTA – Dynamic analyses to optimize ageing well

- Project draws together nine existing Australian Longitudinal Studies of Ageing
- Key strengths are the longitudinal dimension, breadth of data, multidisciplinary approach



Studies included

Study	Sample size and age	Duration (years)
The Australian Diabetes, Obesity and Lifestyle Study	7296 (45+)	5-
Australian Longitudinal Study of Ageing	2087 (65+)	14-
Australian Longitudinal Study of Women's Health	12762 (45-50) 14011 (70-75)	9-

Studies included (cont.)

Study	Sample size and age	Duration (years)
Blue Mountains Eye Study	4860 (49+)	5-
Canberra Longitudinal Study of Ageing	1000 (70+)	12
Household, Income & Labour Dynamics in Australia	4742 (45+)	4-

Studies included (cont.)

Study	Sample size and age	Duration (years)
Melbourne Longitudinal Studies on Healthy Ageing	1000 (65+)	9-
Personality and Total Health Through Life Project	2528 (40-44) 2551 (60-64)	4-
Sydney Older Persons Study	647 (75+)	10

Seven Points for Successful Science and Social Science Data!

- **Ethics** - consent for uses of data
- **Storage and management**
- **Analysis** – skills to extract knowledge
- **Sharing** – collaboration or donation?
- **Intellectual property** – ‘owner’ vs ‘steward’
- **Careers** - Balancing research careers with the opportunity cost of developing and managing data
- **Planning for the future** – archiving Australia’s science data

- Informed consent
 - Understand intended and potential use of data
 - Separate consent for sub-studies
 - Separate consent for data linkage
- Confidentiality
- Clinical responsibility

Storage

- Infrastructure required for storage of large datasets
- Cataloguing, documenting data essential, meta-data

Management

- Setting up the data files, cleaning, quality control
- Updating of errors, recodes, computed variables
- Dealing with data requests
- Merging files
- Managing confidentiality and privacy

3. Data analysis

- High level of skill required for longitudinal data analysis
- Expertise across domains
- Investment in training in longitudinal methods, analysis of clustered data, is required
- Complexity compounded with pooling

4. Sharing : Data requests by other scientists

- Issue of protecting research 'territory'
- Do we want to collaborate?
- Should we collaborate?
- To what extent should data be publicly available?
- Collaborative Research Agreements

5. Intellectual property

- Who 'owns' the study?
- Relationship between IP and the study data
- Are we just custodians?
- Institutional vs individual IP
- Commercialization
- New ideas need protecting

6. Research Careers

- Individuals need to develop research areas and teams based on defined themes
- Project funding based on individual productivity
- Studies can't occur without leaders who can attract funding

Expectations of researchers need to be compatible with the demands of funding schemes, academic systems and infrastructure

7. Future Models for Managing Science Data

- Different models required for different purposes
- Stored data only useful if it is documented
- Not all data is worth storing
- Cost of data archiving, documentation and management needs to be acknowledged
- Mechanisms required to fund archiving, train managers
- Careers for expert data study managers