
Plan Overview

A Data Management Plan created using DMPonline

Title: Use of existing GWAS data from the Manchester Cognitive Ageing Cohort

Creator: Antony Payton

Principal Investigator: Antony Payton

Data Manager: Antony Payton

Affiliation: University of Manchester

Template: University of Manchester Generic Template

Project abstract:

GWAS data is available from the Manchester Cognitive Ageing cohort from >1500 volunteers. This data is accompanied by longitudinal health and cognitive data collected for up to 37 years. The cohort has generated over 100 publications, including in Nature and Nature Genetics. There are still many more phenotypes to analyse. The GWAS and phenotype data will continue to support student projects (under/postgrad) and collaborative research.

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Use of existing GWAS data from the Manchester Cognitive Ageing Cohort

Manchester Data Management Outline

1. Will this project be reviewed by any of the following bodies (please select all that apply)?

- Ethics

2. Is The University of Manchester collaborating with other institutions on this project?

- Yes - Part of a collaboration and owning or handling data

3. What data will you use in this project (please select all that apply)?

- Re-use existing data (please list below)

The GWAS data was generated in 2009. The phenotype data was collected between 1983 and 2019. Consent from volunteers and ethics approval was obtained. Ethics for the use of the GWAS data expired in 2019 and we're looking to renew this.

4. Where will the data be stored and backed-up during the project lifetime?

- University of Manchester Research Data Storage Service (Isilon)

5. If you will be using Research Data Storage, how much storage will you require?

- 1 - 8 TB

The data is stored on the RDS and is <2GB in size.

6. Are you going to be working with a 3rd party data provider?

- No

7. How long do you intend to keep your data for after the end of your project (in years)?

- 21+ years

Questions about personal information

Personal information, also known as personal data, relates to identifiable living individuals. Special category personal data is more sensitive information such as medical records, ethnic background, religious beliefs, political opinions, sexual orientation and criminal convictions or offences information. If you are not using personal data then you can skip the rest of this section.

Please note that in line with [data protection law](#) (the General Data Protection Regulation and Data Protection Act 2018), personal information should only be stored in an identifiable form for as long as is necessary for the project; it should be pseudonymised (partially de-identified) and/or anonymised (completely de-identified) as soon as practically possible. You must obtain the appropriate [ethical approval](#) in order to use identifiable personal data.

8. What type of personal information will you be processing (please select all that apply)?

- Anonymised personal data

All volunteers are anonymised using a 5 digit ID.

9. How do you plan to store, protect and ensure confidentiality of the participants' information (please select all that apply)?

- Store data on servers or computers that are approved by The University of Manchester and securely backed up
- Anonymise data
- Impose suitable data sharing and collaboration agreements
- Impose suitable non-disclosure agreements (e.g. for managers or users of personal data)
- Where needed, follow The University of Manchester guidelines for disposing of personal data

10. If you are storing personal information (including contact details) will you need to keep it beyond the end of the project?

- Not applicable

11. Will the participants' information (personal and/or sensitive) be shared with or

accessed by anyone outside of the University of Manchester?

- Yes - Public institutions with contractual arrangements (e.g. NHS research sites)

12. If you will be sharing personal information outside of the University of Manchester will the individual or organisation you are sharing with be outside the EEA?

- Yes

Anonymised genetic/phenotype data will be shared with institutions in America. Previous research has included collaborations with Harvard university and we are planning a collaboration with Stanford.

13. Are you planning to use the personal information for future purposes such as research?

- Yes

14. Who will act as the data custodian for this study, and so be responsible for the information involved?

Dr Tony Payton

15. Please provide the date on which this plan was last reviewed (dd/mm/yyyy).

2014-03-31

Project details

What is the purpose of your research project?

To investigate genetic (GWAS) and environmental risk factors for cognitive ability and its decline over time in an older (aged 50+) population.

What policies and guidelines on data management, data sharing, and data security are relevant to your research project?

University of Manchester Information Security Policy
- <http://documents.manchester.ac.uk/display.aspx?DocID=6525>

Responsibilities and Resources

Who will be responsible for data management?

Dr Tony Payton

What resources will you require to deliver your plan?

The data is already stored on the RDS and no further funding is required.

Data Collection

What data will you collect or create?

This is secondary data use and no further data will be collected or generated. Data dictionaries and quality control have already been created/applied.

How will the data be collected or created?

NA

Documentation and Metadata

What documentation and metadata will accompany the data?

A data dictionary has been created. The cohort has extensive phenotypes (>400) and genetic data, thereby requiring metadata to be generated on a project specific basis.

Ethics and Legal Compliance

How will you manage any ethical issues?

All data is anonymised. UoM ethics for use of secondary data is being applied for.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

The data is owned by UoM. All collaborative projects are assessed by Dr Payton and data transfer/IP agreements are overseen by the UoM legal team where required.

Storage and backup

How will the data be stored and backed up?

<http://ri.itservices.manchester.ac.uk/rds>.

How will you manage access and security?

Data is stored on the RDS. For collaborative projects metadata is provided where possible. Where this is not possible, anonymised data is transferred via a secure server. DTA's are adhered to.

Selection and Preservation

Which data should be retained, shared, and/or preserved?

All data will be preserved for future research. Technologies such as Next Generation Sequencing, synchrotron and epigenetic research will extend the uses of the phenotype data, in addition to future collaborative studies. The existing data can also be used to support student projects and provides a non-lab alternative during Covid-19.

What is the long-term preservation plan for the dataset?

As mentioned above a comprehensive data dictionary is available for future researchers.

Data Sharing

How will you share the data?

Dr Payton currently assesses proposals from internal and external research groups and checks that they align with consent/ethics and are from bona fide researchers. Anonymised or meta data is transferred between secured servers.

Authorship and acknowledgements are agreed in advance of data sharing. Our cohort is advertised on

the UoM website and we are exploring promoting it on other medical research sites such as <https://g2aging.org/>

We are also part of the CHARGE consortium: <http://www.chargeconsortium.com/>

Are any restrictions on data sharing required?

The consent from volunteers restricts the data for the use in cognitive research.