



DATA MANAGEMENT AND ACCESS POLICY

Version 3.0

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CONTACT

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INTRODUCTION

The Data Management and Access Policy outlines how the data collected through the Specialist Digital Health Workforce (SDHW) Census project is maintained, shared, and destroyed. The SDHW Census project has a strong privacy statement, which underpins this policy. The project also has an open access data strategy for non-commercial use of the data, supported by this policy.

The development of this policy has been informed by the University of Tasmania GradTrack Data Access Framework,¹ the University of Melbourne MABEL User Manual,² and the University of the West of England Five Safes Model.³

PRIVACY STATEMENT

The Privacy Statement for the SDHW Census states:

The collection of data and all associated data access projects must comply with the Privacy Act 1988 and state privacy legislation. All data must be treated with confidentiality.

The Specialist Digital Health Workforce Census data must be stored in a safe and secure location that can only be accessed by identified personnel. Only the Census investigators listed under the section 'Contacts' and research staff employed specifically for the Census project can access the Census database.

All data must be stored in a de-identified manner. Data collected for the longitudinal study must be stored separate from the linkage log.

An individual should not be identifiable in the publication or presentation of data from the Census.

Access to data by external organisations must comply with this privacy statement.

DATA COLLECTION AND STORAGE

The primary Census data will be collected and stored in the Census survey tool (2018-2021 – REDCap; 2023 onwards Qualtrics). It will then be downloaded into a password protected MS Excel spreadsheet and stored on the Charles Sturt University secure network server. The data will then be uploaded into the password protected Census database for data cleaning and maintenance.

DATA ACCESS

The Census project has an open data access strategy. The Steering Committee wish for the data to be analysed and reported, particularly for research purposes. Applications for access to the census data to be used for non-commercial purposes is encouraged. As such, this project shall adopt the Five Safes Model to inform the data access application process.

FIVE SAFES MODEL

The University of the West of England Five Safes Model³ has been developed for data providers, data users, and regulators for designing, describing and evaluating access systems for data. The model incorporates a set of five risk (or access) dimensions: safe projects, safe people, safe data, safe settings, safe outputs.

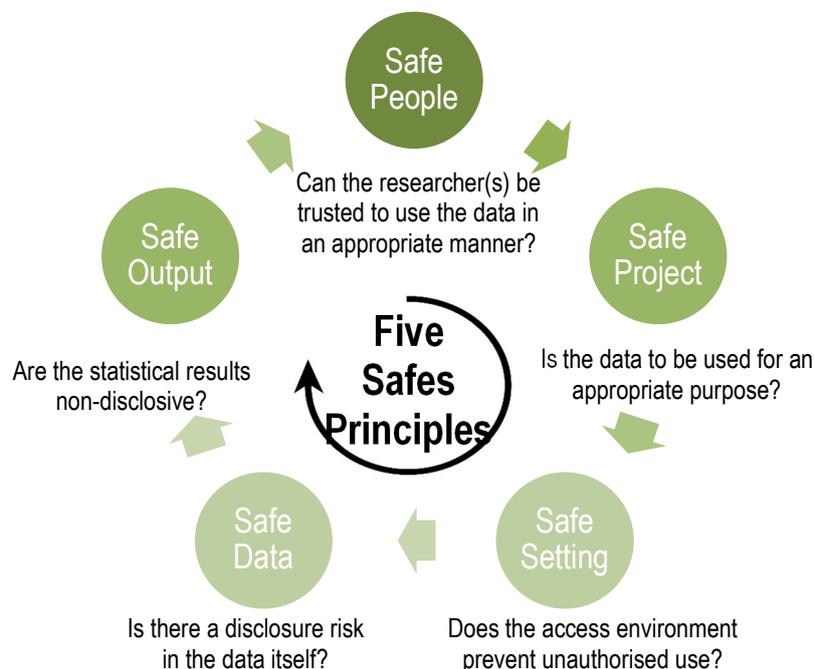


Figure 1: The Five Safes Model.¹

Safe projects

The Census project requires applicants to submit a research protocol so it can be established that the data will be used for appropriate, non-commercial purposes. Where the data will be published or presented, ethical approval is required as part of the access application process.

Safe people

The access application requires the Applicant to list all personnel who will have access to the data. The Applicant is also required to provide information about their position and the organisation of each person. This is to ensure the persons requesting access to the data are appropriate people and to ensure the data will not be used for commercial purposes.

Safe data

Only de-identified data can be accessed. Only data where there are >5 responses will be provided to maintain anomaly of the data.

Safe settings

The organisation/s requesting access to the data should be legitimate organisations and demonstrate they are requesting access for non-commercial purposes. The protocol should also elaborate on the data management plan within the organisation to demonstrate adherence with the Privacy Statement.

Safe outputs

The Applicant must upload a protocol outlining how they will maintain data confidentiality when reporting the project findings.

DATA AVAILABLE FOR ACCESS

Data are compiled in such a way as to ensure confidentiality and anonymity, thus some survey items (such as year of birth, country of birth, Indigenous identity) may be removed or aggregated. Such data will only be available if relevant to the specific research proposal and with appropriate ethics approval. Where there is less than five (5) respondents for a particular data item or a combination of items (e.g. year of birth and postcode), that item will not be provided (i.e. we may instead provide age group and state or province if this provides a greater number of responses).

Data supplied is true and correct at the time of provision, but subject to change should new information become available and the data cleaned after provision.

Raw data

If you are requesting access to raw data, in your protocol, it is essential that you specify:

1. The data section.
2. Any limits on responses to that section (e.g. only “Females”).
3. The census year/s requested.

Aggregated data

If you are requesting access to aggregated data, in your protocol, it is essential that you specify:

1. Which aggregates you require by data section.
2. Any limits on responses to that section (e.g. only “Females”).
3. The census year/s requested.

Longitudinal linked data

Longitudinal data is no longer available for request.

DATA ACCESS APPLICATION

An application must be submitted to request access to the Census data. The application must be completed online and a link to the application can be found on the Census website. All mandatory questions must be completed in the application.

Before commencing the application, please ensure you have read this document thoroughly and obtained the necessary approvals.

You are required to upload a protocol outlining:

- Why you want to access the data?
- What data sections you want to access (see above)?
- How will the data be used/analysed?
- How will the data be stored?
- Who will have access to the data?
- How will the findings be reported?
- How will the data be destroyed and when?

The Declaration at the end of the application states:

- The information provided in this application, include its attachments, are true and accurate.
- I agree that I will maintain the confidentiality and security of the data that I receive and will destroy the data as per jurisdictional data retention requirements outlined in the attached protocol.
- I will only use the data received for purposes outlined in the attached protocol. If in future I wish to use the data for another project, I will complete a new application form.
- I understand that if the project has changed significantly from what is submitted here, I will need to submit a new application.
- I agree that I will cite the publication listed in the Data Management and Access Policy in any publication or presentation related to this project.
- I agree that I will provide a copy of any publication resulting from this project to the Specialist Digital Health Workforce Census Steering Committee.
- I agree to the listing on the Census website any publication related to this project (or provide details where in confidence exists).
- I agree to report any breach to the above or to the protocol attached will be reported immediately to the Steering Committee.
- I understand that any breach of these conditions may result in the reporting of my misconduct to my HREC or to the Australian Research Council.

DATA ACCESS APPLICATION PROCESS

You will receive an acknowledgement of your application immediately upon submission. The time to process your application will depend on the type of application.

Where an Applicant provides Human Research Ethics Approval (HREC), they will be informed of the outcome of their application within four weeks of submission. The application will be reviewed by the Research Officer of the Census project.

Where the Applicant is applying to access without ethical approval, the application will need to be reviewed by the Census leadership. The outcome of their application will be provided within two weeks of the application. Where an application is approved for data access, typically data will be provided within four weeks of approval. This time may be longer depending on the data requested or how recently the previous census was held.

PUBLICATION OR PRESENTATION CITATION

Where data access results in either a publication or presentation of findings, the Applicant agrees to cite the Census project as the source of that data. The citation that should be used is:

Butler-Henderson K, Gray K, Greenfield D, Low S, Gilbert C, Ritchie A, Trujillo M, Bennett V, Brophy J, & Schaper LK 2017, The development of a national census of the health information workforce: expert panel recommendations, *Stud Health Technol Inform*, 239: 8-13, doi:10.3233/978-1-61499-783-2-8.

In signing the Declaration, the Applicant agrees to provide a copy of any publication resulting from the data access to the Steering Committee. This is to close the loop on the Five Safes approach, by ensuring the data was used appropriately and findings shared with the health information community.

The Applicant also agrees to the listing of this publication, or a link to the publication, on the Census. This is again to close the loop on the Five Safes approach and for transparency in sharing this information with the community.

Where in confidence exists (i.e. the publication cannot be publicly shared), the Applicant must make an application to the Steering Committee to withhold the public sharing of any publication.

ETHICAL REQUIREMENTS

Any use of the data for research purposes or where the findings of the data analysis will be published or presented, the project will require HREC approval. Where the organisation of an Applicant does not have a registered HREC, the applicant can apply for HREC approval at another organisation. Please see the National Health and Medical Research Council (NHMRC) website for further information.

All research studies must adhere to the NHMRC's *National Statement on Ethical Conduct in Human Research* and the *Australian Code for the Responsible Conduct of Research*.

GOVERNANCE

The Census project is governed by the Census Steering Committee.

REFERENCES

1. University of Tasmania. (2017) GradTrack Data Access Framework, version 1.2, The University of Tasmania, Burnie, Tasmania.
2. La N, Taylor T, Scott A, Leahy A. (2017) 'MABEL User Manual: Wave 9 Release', Melbourne Institute of Applied Economic and Social Research, The University of Melbourne, Melbourne, Victoria.
3. Desai T, Ritchie F, Welpton R. (2016) Five Safes: designing data access for research, University of the West of England, Bristol.

SPECIALIST DIGITAL HEALTH WORKFORCE CENSUS
DATA ITEMS

Broad description of data items.

SECTION	Topic
1 Demographic	Country, state and postcode of residence
	Country of birth and citizenship status
	Year of birth
	Gender
	Indigenous or ethnic group
2 Professional Membership and Health Practitioner Registration	Disability
	What digital health memberships they hold
	If they are a registered health professional and field
3 Formal education	Hours worked in clinical role
	Specialist digital health formal education at vocational or higher education level
	Clinical qualifications
4 Credentials	Other relevant qualifications
	Relevant credentials
5 Occupation And Paid Employment Information	Discipline group
	Time worked in the specialist DH workforce
	Seeking work
	Current DH role/s – for up to 2 roles, including: country, state, postcode, role title, time in role, role intentions next 12 months, top 5 functions, permanency, organisations type (both public/private and service type (e.g. hospital/educational/department/NFP etc) and remuneration
	How many different DH roles they have
Unpaid & Voluntary work	Voluntary roles and other unpaid related work
Professional development	What PD they have done in the last 12 months
	PD needs and plans for next 3 years
Workforce intentions	How much longer they plan to stay in the workforce
	Why they will leave
	If they will continue to volunteer or do unpaid specialist digital health work
Women and DH	Questions from the Women and Digital Health survey