Health Information Workforce Census
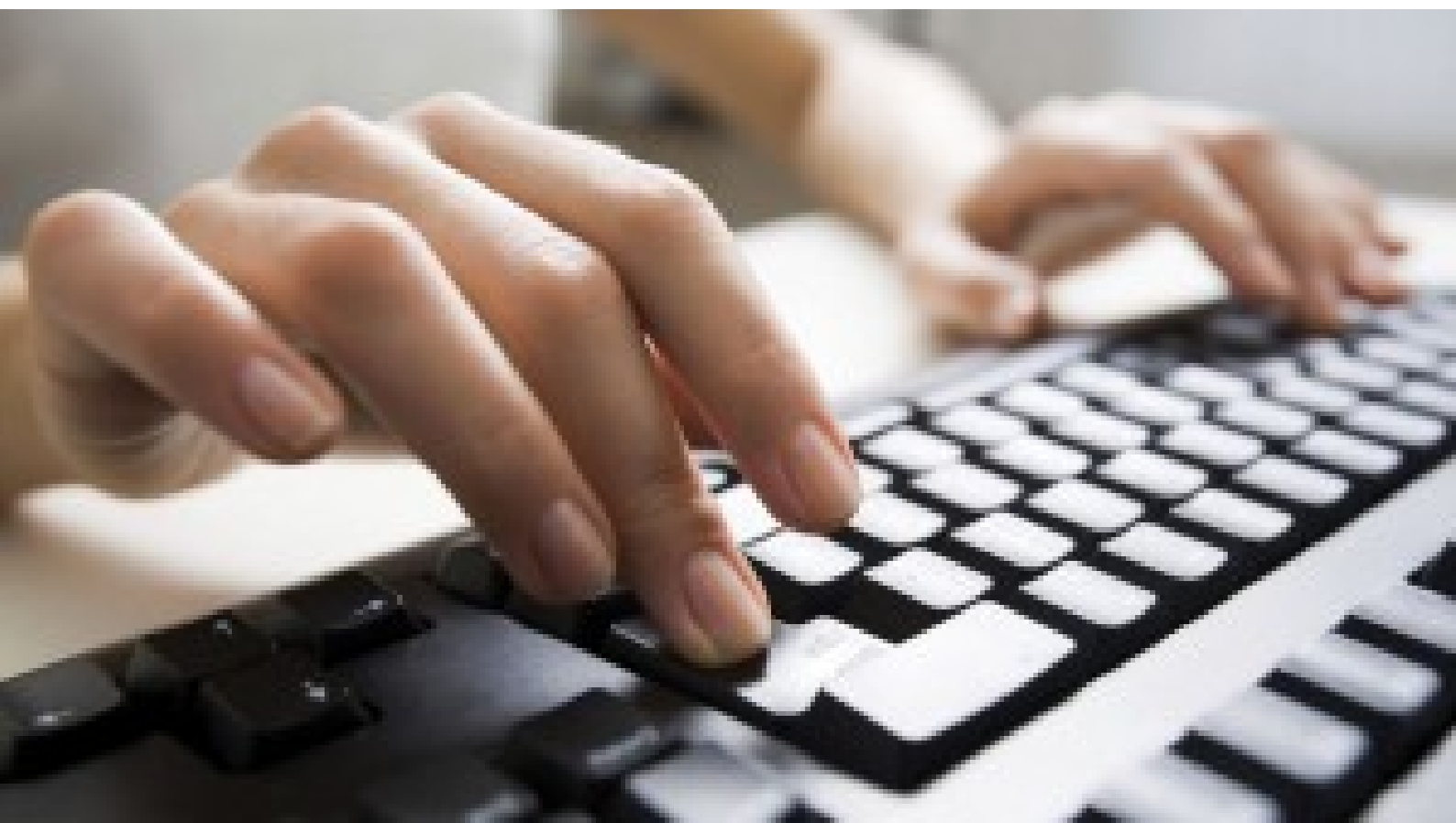
Data Management and Access Policy

Document Information

Version	Date	Author	Reason	Sections
1.0	4 April 2018	Kerryn Butler-Henderson and Kathleen Gray	Initial release for Australia census	All
2.0	16 November 2018	Karen Day	Adjusted for New Zealand from Australian study	All

Contact

Should you have any questions about the Data Management and Access Policy for the Health Information Workforce Census, New Zealand/Aotearoa, please contact:

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Contents

Introduction

The Data Management and Access Policy outlines how the data collected through the Health Information Workforce Census (HIWC) project is maintained, shared, and destroyed. The HIWC 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.

This policy was developed by the Australian study and adjusted for the New Zealand study (HIWC-NZ). 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 HIWC-NZ states:

The collection of data and all associated data access projects must comply with the Privacy Act 1993 and Health Information Privacy Code of 1994. All data must be treated with confidentiality.

The HIWC data must be stored in a safe and secure location that can only be accessed by authorised personnel. Only the HIWC investigators listed under the section 'Contacts' and research staff employed specifically for the HIWC project can access the HIWC 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 HIWC.

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

Data collection and storage

The primary HIWC-NZ data will be collected and stored in the software application Qualtrics. It will then be downloaded into a password protected MS Excel spreadsheet and stored on the University of Auckland secure network server. The data will then be uploaded into the password protected HIWC database for data cleaning and maintenance.

Data access

The HIWC project has an open data access strategy. We 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 Model[3] 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, and safe outputs.
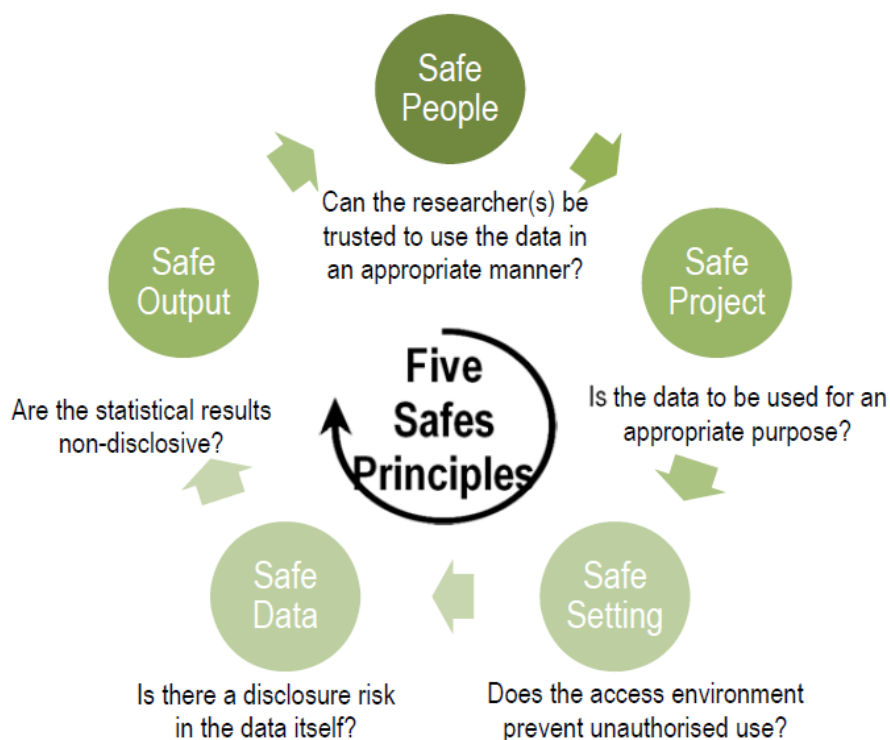

Figure 1: Five safes model

Safe projects

The HIWC 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. Where linked data is requested, only the re-identified data files can be accessed.

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 birth date, country of birth, ethnic identity) may be removed or aggregated. Such data will only be available if relevant to the specific research proposal and with appropriate ethics approval.

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 it is essential that you specify in your proposal

1. The variable names.
2. Any limits on responses to that variable (e.g. only "Females").
3. Which census year/s for that variable.

Aggregated data

If you are requesting access to aggregated data it is essential that you specify in your proposal

1. Which aggregates you require by variable names
2. Any limits on responses to that variable (e.g. only "Females")
3. Which census year/s for that variable.

Longitudinal linked data

If you are requesting access to longitudinal linked data, please ensure this is clearly documented in your proposal and application. The longitudinal linked data is a sub-set of the census data.

Data access application

An application must be submitted to request access to the HIWC data. The application must be completed online and a link to the application can be found on the HIWC 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 research proposal outlining

- Why you want to access the data.
- What data variables 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

1. The information provided in this application, including its attachments, is true and accurate.
2. I agree that I will maintain the confidentiality and security of the data that I receive and will destroy the data as per New Zealand data retention requirements outlined in the attached proposal.
3. I will only use the data received for purposes outlined in the attached proposal. If in future I wish to use the data for another project, I will complete a new application form.
4. I understand that if the project has changed significantly from what is submitted here, I will need to submit a new application.
5. 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.
6. I agree that I will provide a copy of any publication resulting from this project to the Health Information Workforce Census Management Group.
7. I agree to the listing on the Census website of any publication related to this project (or provide details where in confidence exists).
8. I agree to report any breach to the above or to the proposal attached will be reported immediately to the Health Information Workforce Census Management Group.
9. I understand that any breach of these conditions may result in the reporting of my misconduct to my HREC or to the New Zealand Ministry of Health.

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 Principal Investigator of the HIWC project. Where the Applicant is applying to access without ethical approval, the application will need to be reviewed by the Management Group. Please contact the HIWC team for the date of the next meeting. The outcome of their application will be provided within one week of the meeting. 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 HIWC 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 Management Group. 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 publically shared), the Applicant must make an application to the Management Group 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 Health and Disability Ethics Committees website (https://ethics.health.govt.nz/) website for further information.

Governance

The HIWC project is governed by the HIWC Management Group. The purpose of the Management Group is to

1. Provide expert advice regarding the
   a. Development of a minimum dataset for a national health information workforce census, informed by scientific method
   b. Resources required to develop and maintain the national health information workforce census.
   c. Development of an online portal to deploy a national census, and
   d. Future directions for the deployment and ongoing maintenance of a national census
2. Provide governance to the HIW census project
3. Respond to matters referred to the Health Information Workforce Census Management Group
4. Provide timely reports to external organisations about the status of the project.

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.