

PRIVACY IMPACT ASSESSMENT

National Study of Mental Health and Wellbeing Data Integration Project

November 2020



TABLE OF CONTENTS

A. GLOSSARY AND ACRONYMS	4
B. EXECUTIVE SUMMARY	6
1. BACKGROUND	6
2. UNDERTAKING THE PIA	7
2.1 Approach for the PIA	
2.2 Scope	
2.3 Personal information used in this Project 2.4 Methodology	
3. APP COMPLIANCE SUMMARY	
TABLE 1 – SUMMARY OF COMPLIANCE AGAINST THE APPs	
4. ABS RESPONSE TO RECOMMENDATIONS AND NEXT STEPS	13
C. INTRODUCTION	14
5. NATIONAL STUDY OF MENTAL HEALTH AND WELLBEING	14
5.1 Aims	
5.2 Field work	
5.3 Collecting mental health information	
6. DATA INTEGRATION	
6.1 Data integration overview	
6.2 Data integration at the ABS	
6.4 Five Safes Framework	
6.5 The Multi-Agency Data Integration Project (MADIP)	
7. KEY PRIVACY CONSIDERATIONS	18
7.1 Strengths of the approach for this Project	18
7.2 Suggestions to enhance proposed process	19
D. INFORMATION FLOWS	20
1. Integration of data from the Study with MADIP	
2. Supplementing Study data with information from MADIP	21
E. COMPLIANCE AGAINST THE AUSTRALIAN PRIVACY PRINCIPLES	23
APP 1-OPEN AND TRANSPARENT MANAGEMENT OF PERSONAL INFORMATION	23
APP 2-ANONYMITY AND PSEUDONYMITY	25
APP 3-COLLECTION OF SOLICITED PERSONAL INFORMATION	26
APP 4-DEALING WITH UNSOLICITED PERSONAL INFORMATION	28
APP 5-NOTIFICATION OF THE COLLECTION OF PERSONAL INFORMATION	30
APP 6-USE OR DISCLOSURE OF PERSONAL INFORMATION	32

	APP 7-DIRECT MARKETING	36
	APP 8–CROSS-BORDER DISCLOSURE OF PERSONAL INFORMATION	37
	APP 9-ADOPTION, USE OR DISCLOSURE OF GOVERNMENT RELATED IDENTIFIERS	38
	APP 10-QUALITY OF PERSONAL INFORMATION	39
	APP 11–SECURITY OF PERSONAL INFORMATION	40
	APP 12–ACCESS TO PERSONAL INFORMATION	43
	APP 13-CORRECTION OF PERSONAL INFORMATION	44
F. I	NEXT STEPS	45
	8. IMPLEMENTATION OF THE PIA	45
	8.1 Changes outside the scope of this PIA	45
	9. MORE INFORMATION	45
G.	APPENDICES	46
	APPENDIX A: KEY DOCUMENTS CONSULTED FOR THIS PIA	46
	APPENDIX B: STAKEHOLDERS CONSULTED FOR THE PIA	47

A. GLOSSARY AND ACRONYMS

Acronyms

ABS Australian Bureau of Statistics
ASD Australian Signals Directorate

MADIP Multi-Agency Data Integration Project

MBS Medicare Benefit Schedule

OAIC Office of the Australian Information Commissioner

ONDC Office of the National Data Commissioner

PIA Privacy Impact Assessment
PBS Pharmaceutical Benefit Scheme

Glossary

Term Accredited Integrating Authority	Definition An agency authorised to undertake high risk data integration projects involving Commonwealth data for statistical and research purposes.
Australian Privacy Principles (APPs)	Principles contained in the <u>Privacy Act 1988 (Cth)</u> that regulate the way personal information is collected, used, and disclosed, and affect the way personal information is stored and accessed.
Collection by 'creation'	The OAIC provides the following explanation for this concept in its Guide to Data Analytics and the Australian Privacy Principles: "The concept of 'collects' applies broadly, and includes gathering, acquiring or obtaining personal information from any source and by any means. This includes collection by 'creation' which may occur when information is created with reference to, or generated from, other information the entity holds."
Data custodian	The agency that collects or generates data for any purpose, and is accountable and responsible for the governance of that data. Another term for data custodian is data steward.
DataLab	A secure statistical analysis environment at the ABS for undertaking real time complex analysis of microdata by approved users for approved projects. See About the DataLab .
Data minimisation	The principle of only authorising the sharing and use of data that is reasonably necessary for a permitted purpose.
De-identified data	De-identification involves removing or altering information that identifies an individual or is reasonably likely to do so. De-identification involves the removal of direct identifiers (such as name and address) and additional safeguards to prevent re-identification.

Microdata Data in a unit record file that provides detailed information about

people, households, businesses or other types of records.

Personal information As defined in section 6(1) of the *Privacy Act 1988* (Cth), this is:

'Information or an opinion about an identified individual, or an

individual who is reasonably identifiable:

• whether the information or opinion is true or not; and

whether the information or opinion is recorded in a material

form or not.'

Person linkage spine Provides the central index around which person-centred linkage is

managed in the MADIP infrastructure.

Public Interest Certificate A certificate, authorised under the relevant data custodian's (or data

steward's) legislation, for the disclosure of relevant information. Specifies the data to be released, the recipient, and the purposes for

which the data will be released and used.

Sensitive information As defined in section 6(1) of the *Privacy Act 1988* (Cth). The definition of

'sensitive information' in s 6(1) includes health information.

Separation Principle Personal identifiers (like name and address) are stored separately from

other information (like use of health services) at all times. The ABS applies the Separation Principle when undertaking data integration. Staff are allocated different roles so that no one has the ability to access the identifying details of an individual at the same time as accessing other information about that individual. See Separation

Principle.

The Study National Study of Mental Health and Wellbeing.

The Study processing team The team responsible for converting responses from the Study

participants into de-identified statistical information.

TableBuilder An online tool for creating your own tables, graphs and maps using ABS

microdata. See About TableBuilder.

> required for statistical purposes (including integration), so there could be steps needed to turn it into a characteristic of a person, business or other entity, often through strategies such as categorising or creating

ranges. This can help de-identify the information.

B. EXECUTIVE SUMMARY

1. BACKGROUND

The Australian Bureau of Statistics (ABS) is undertaking the Intergenerational Health and Mental Health Study (the Intergenerational Study) from 2020 to 2023, to provide updated evidence about Australia's mental health, general health, nutrition and physical activity.

As part of the Intergenerational Study, the ABS will conduct the National Study of Mental Health and Wellbeing (the Study) to produce updated evidence of the prevalence and impact of mental health conditions in Australia, whether people are using services, and their outcomes over time. The Study will be known during field work as the National Survey of Health and Wellbeing.

A shorter follow up study is proposed for 12 months after the main study, aimed at understanding outcomes over time for people with mental health conditions and the impact of service use. In the model for a follow up, study participants will have the option of volunteering to take part.

A significant opportunity exists to deliver additional insights from the Study, particularly for government policy and health service evaluation, and to reduce the time taken for each survey interview through data integration. Data integration means bringing information together, and it is an efficient and effective way of creating new insights by reusing existing data to address important questions about Australian society.

The ABS and other Australian Government partners have invested in making better use of existing public data through data integration. The <u>Multi-Agency Data Integration Project</u> (MADIP) is a secure data asset combining information on health, education, government payments, income, taxation, employment, and population demographics (including the Census) over time.

Given the sensitive nature of the information collected in the Study, the ABS is undertaking a Privacy Impact Assessment (PIA) to formally examine the potential impacts of conducting data integration with Study information ('the Project') on the privacy of individuals in relation to:

- i. the collection and use of data for the purposes of the Project;
- ii. data integration of Study data to other data assets, in particular the Multi-Agency Data Integration Project ('MADIP'), and
- iii. supplementing Study data with information from existing sources in MADIP through integration (instead of through survey questions).

A PIA identifies how a project can have an impact on individuals' privacy, and makes recommendations for managing, minimising or eliminating privacy impacts.

This PIA covers privacy considerations specific to the potential integration activities that make use of data collected in the Study, rather than for the Study as a whole. As with all of the ABS's household surveys, the Study is conducted under the authority of the *Census and Statistics Act 1905* (Cth). The ABS's household survey program is an established and important part of the ABS's functions, and is compliant with the *Privacy Act 1988* (Cth).

2. UNDERTAKING THE PIA

2.1 Approach for the PIA

This PIA was conducted and assured in accordance with the Office of the Australian Information Commissioner's (OAIC) <u>Guide to undertaking privacy impact assessments</u>, including assessing compliance against the Australian Privacy Principles (APPs) outlined in the <u>Privacy Act 1988 (Cth)</u>.

The ABS is also subject to the following legislation:

- Census and Statistics Act 1905 (Cth);
- Australian Bureau of Statistics Act 1975 (Cth).

All Commonwealth Government Agency data custodians (also known as data stewards), including the ABS, are further subject to the <u>Australian Government Agencies Privacy Code</u> (relevant to APP 1).

Feedback on the ABS's existing governance, privacy and security protections for data integration projects, and the approach planned for the Study's data integration, was received through stakeholder consultation with a range of mental health service providers, advocacy groups, consumer and carer representatives, researchers and other Government stakeholders.

This PIA follows a different process from that followed by <u>Human Research Ethics Committees</u> (HRECs) implementing the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research*. However, while the processes vary, both this PIA and HRECs consider the protection of privacy for individuals in health research "by considering whether the research proposal conforms to relevant legislation, principles and guidelines. This includes Commonwealth and/or state/territory legislation as well as the s95 and s95A guidelines [in the *Privacy Act 1988*]¹."

2.2 Scope

Proposed data integration activities

Integrated datasets offer richer opportunities for research and analysis of complex issues. In order to maximise the usefulness of the Study, the ABS is proposing the following data integration activities:

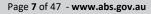
1. Integration of data from the Study with MADIP

The ABS has successfully and safely integrated other survey datasets such as the 2014-15 National Health Survey (NHS 2014-15) and the 2018 Survey of Disability, Ageing and Carers (SDAC 2018) with the MADIP asset to facilitate ongoing use of these datasets for research and analysis. This use is contingent on approval of analytical projects within the MADIP governance and approvals framework.

The ABS proposes to link data from the Study to data assets in the MADIP environment, using existing privacy protocols and data security infrastructure, so the de-identified data are available for future approved research projects to deliver new insights for Australia.

The ability to analyse data from other MADIP sources like Social Security and Related Information (SSRI) or the Census in the context of Study responses could facilitate research on social or risk factors for

¹ National Health and Medical Research Council. 2019. 'Health Privacy' in *Human Research Ethics Committees*. Accessed on 13 November 2020 https://www.nhmrc.gov.au/research-policy/ethics/human-research-ethics-committees.



mental health conditions. Linkage of follow up survey data to MADIP would provide an opportunity for longitudinal research, such as the impacts of services on mental health outcomes.

The proposed linkage to MADIP is intended to be enduring, that is, creating a permanent de-identified resource for approved researchers for approved projects, rather than a one-off integration project.

2. Supplementing Study data with information from MADIP

No survey can capture all the relevant information on a topic, and the ABS aims to reduce participant burden in surveys where possible. This proposal to supplement Study data with information from MADIP provides an opportunity for the ABS to reduce the questions it asks survey participants by re-using information that's already available from other sources.

The ABS proposes to add important data items derived from existing data in the MADIP asset in lieu of asking additional questions in the Study interview. Contingent on approval from data custodians, this approach would allow for additional information to be permanently included in the Study files and released via Study data outputs such as aggregate data tables or confidentialised microdata products like TableBuilder.

One proposed example is to use administrative data from the Pharmaceutical Benefit Scheme (PBS) to replace questions about what government subsidised prescription medications are taken. The data included in the Study would not look the same as PBS data, but would be transformed into person-related data to create aggregate level outputs such as Number of Prescribed Medications Taken or Type of Medication Taken (eg: anxiolytics) for different cohorts of people.

The Project is currently scheduled to commence in 2023, contingent on the completion of fieldwork and approval from data custodians.

The proposed linkages are covered in <u>section D Information Flows</u>.

2.3 Personal information used in this Project

As defined in section 6(1) of the <u>Privacy Act 1988 (Cth)</u>, personal information is 'information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- whether the information or opinion is true or not; and
- whether the information or opinion is recorded in a material form or not.'

Personal information can range from sensitive and confidential information to information that is publicly available.

For this Project, the ABS will use personal information which is collected in the Study, and will also use personal information provided to the ABS by other agencies. The <u>types of information</u> about individuals collected by the ABS or disclosed to it by other agencies for use in data integration projects include:

- Personal identifiers which could directly identify a person (e.g. name, address, date of birth). This is only used to enable datasets to be linked; it is not used for analytical purposes.
- Analytical information (e.g. occupation, income, health services use). Information such as health data are considered 'sensitive information' under the *Privacy Act 1988* (Cth).

Personal identifiers are used in the ABS's Secure Data Integration Environment to link datasets such as the Study to MADIP. Identifiers are stored separately from other information in MADIP in accordance with the

<u>Separation Principle</u>. This other information may, in some circumstances, be considered personal information even when it is separated from direct identifiers as it may enable the re-identification of an individual (e.g. through the combination of data items). Access to personal information in MADIP is strictly controlled and limited to a small team of ABS staff.

The MADIP data that the ABS makes available for authorised researchers in the secure ABS DataLab does not include personal information. It is provided in a manner that is not likely to enable the identification of an individual and therefore meets the requirements to be "de-identified" under the <u>Privacy Act 1988 (Cth)</u>. The ABS uses the <u>Five Safes Framework</u> to manage disclosure risks associated with providing access to de-identified MADIP data.

2.4 Methodology

This Privacy Impact Assessment evaluates the Project against legislative requirements and community expectations, and considers potential risk events and mitigations required. Compliance against the Australian Privacy Principles (APPs) and feedback from stakeholders was central to this analysis. Key documents consulted for this PIA are listed in Appendix A. Privacy strengths and areas for development are highlighted in section 7.

Legislative compliance

This PIA assessed compliance of the Project against privacy and ABS legislation, ABS policies and the Australian Privacy Principles outlined in the *Privacy Act 1988* (Cth).

A number of privacy issues raised by the Study have been previously addressed in other related PIAs completed or commissioned by the ABS, including the <u>2019 Multi-Agency Data Integration Project (MADIP)</u> <u>PIA Update</u>, the <u>2021 Census PIA</u> and the <u>2014-15 National Health Survey (NHS) Linkage Project PIA</u>.

Consultation

Community and stakeholder expectations were elicited through targeted stakeholder consultation, in particular with peak bodies for mental health, advocates and consumer representatives. See <u>Appendix B</u> for a list of stakeholders who participated in consultation sessions.

The consultation sessions aimed to identify and discuss stakeholder views on the following topics:

- Linking Study data with other datasets, using the ABS's existing MADIP privacy protocols and data security infrastructure.
- Linking information from other datasets into the Study files as supplementary information, with the aim of publication on the ABS website and potential inclusion in microdata products such as TableBuilder and the DataLab. The specific example proposed was using transformed administrative data from the Pharmaceutical Benefit Scheme (PBS) to replace information on medications taken for mental health that would otherwise be asked of participants.
- Feedback on the ABS's existing governance, privacy and security protections for data integration projects, and this Project in particular.

Stakeholders were invited to participate based on:

Consumer and carer expertise and lived experience perspectives;

- Involvement in preparations for the Study;
- Involvement in and/or knowledge of Commonwealth data integration activities and projects;
- Special interest or expertise (including lived experience and advocacy);
- Representation of a key sector of Australian society;
- Involvement in the strategic review of available mental health data.

Some stakeholders who attended had been involved in previous consultations on government data integration.

Several two-hour sessions were held with mixed groups of stakeholders via teleconference during July 2020. Each of the sessions provided valuable feedback about the proposed Project.

Governance considerations were discussed with representative data custodians through the targeted stakeholder consultation. Representatives from the Commonwealth Office of the Australian Information Commissioner (OAIC) and the Office of the National Data Commissioner (ONDC) were included in consultations.

Independent assurance

External privacy advisor, Maddocks, was engaged by the ABS to provide independent advice and review of the PIA process and report, to ensure considered and appropriate outcomes from the process.

3. APP COMPLIANCE SUMMARY

The following table provides summary information on actions required for compliance against each Australian Privacy Principle (APP) or recommendations to reflect best practice and enhance privacy protections. Feedback from stakeholders and the privacy advisor, Maddocks, informed the best practice recommendations.

The ABS conducted this PIA and consultation with stakeholders to ensure that critical privacy considerations were addressed.

TABLE 1 – SUMMARY OF COMPLIANCE AGAINST THE APPS

APPs	Findings: Integration of data from the Study with MADIP	Findings: Supplementing Study data with information from MADIP	Compliance recommendations	Best practice recommendations
APP 1—Open and transparent management of personal information	Fully complies	Fully complies	None.	R1. The ABS should continue to update online content for the public on MADIP and integration projects, particularly outlining privacy, security and legislative protections in a straightforward and accessible manner.
APP 2—Anonymity and pseudonymity	Fully complies	Fully complies	None.	None.
APP 3—Collection of solicited personal information	Fully complies	Fully complies	None.	None.
APP 4—Dealing with unsolicited personal information	Fully complies	Fully complies	None.	None.
APP 5—Notification of the collection of personal information	Fully complies	Fully complies	None.	None.
APP 6—Use or disclosure of personal information	Fully complies	Fully complies	None.	R2. Clarify the details of governance arrangements with data custodians of the relevant data, in relation to use of data to supplement the Study, in accordance with ABS data integration processes.

APP 7—Direct marketing	Fully complies	Fully complies	Not applicable.	None
APP 8—Cross-border disclosure of personal information	Fully complies	Fully complies	None.	None.
APP 9—Adoption, use or disclosure of government related identifiers	Fully complies	Fully complies	Not applicable.	None
APP 10—Quality of personal information	Fully complies	Fully complies	None.	None.
APP 11—Security of personal information	Fully complies	Fully complies	None.	See R1.
APP 12—Access to personal information	Fully complies	Fully complies	None.	None.
APP 13—Correction of personal information	Fully complies	Fully complies	None.	None.

4. ABS RESPONSE TO RECOMMENDATIONS AND NEXT STEPS

The ABS aims to undertake field work for the Study from December 2020, contingent on the trajectory of the COVID-19 pandemic.

The ABS has reviewed the proposed recommendations from this report and will implement or continue to progress the recommendations provided.

This PIA has been published prior to the commencement of field work for the Study, to ensure that recommendations can be implemented ahead of field work as needed, and for transparency.

Data integration work is scheduled to begin after all fieldwork is completed in 2023. To prepare for the data integration of the Study, the ABS will undertake the required governance activities with MADIP data custodians to ensure the Project meets all requirements.

Changes in the Project's scope or changes in the measures used to assess compliance against the APPs in this PIA could require a PIA update to consider new privacy risks or community concerns. See section 8 for further details.

C. INTRODUCTION

5. NATIONAL STUDY OF MENTAL HEALTH AND WELLBEING

The National Study of Mental Health and Wellbeing (the Study) will be the third national mental health survey conducted by the ABS. The Study will be known during field work as the National Survey of Health and Wellbeing.

The last National Survey of Mental Health and Wellbeing was run in 2007. The Study is designed for comparability with the 2007 survey, and has been updated to reflect contemporary mental health priorities. The proposed follow up study is a new element since 2007, and is intended to deliver a better understanding of mental health outcomes and mental health service use over time.

The Study will be conducted by the ABS with funding support from the Australian Government Department of Health. The ABS will be the data custodian for the Study information.

5.1 Aims

The aims of the Study are to produce evidence in five key areas:

- 1. How many Australians have mental disorders?
- 2. What is the impact of these disorders?
- 3. How many people have used services and what are the key factors affecting this?
- 4. Are services making a difference to the lives of people experiencing a mental illness?
- 5. How many Australians have a lived experience of suicide and what services have they used?

5.2 Field work

The Study is aiming for a total participant sample of 17,000 people across Australia. Only people living in private dwellings (i.e. excluding people in a hospital or other institution, and those without a fixed address) will be in scope for the sample. People in very remote areas of Australia will not be in scope.

Data collection for the Study will be in person via Computer Assisted Personal Interviews (CAPI) with trained ABS Interviewers. More information on how CAPI are administered can be found on the ABS website: Data Collection Methods.

As is customary for household surveys run by the ABS, information on the Study, its purpose, uses of the data, and the process for participation will be provided to participants (see the commentary for <u>APP 5</u> for more details).

The ABS has protocols in place to manage potential distress among participants and Interviewers, including specific training around collecting sensitive mental health information for Interviewers.

5.3 Collecting mental health information

The Study will use an internationally accepted diagnostic instrument that was designed to be comparable to a clinical diagnosis by a medical professional. Similar to the 2007 mental health survey, the Study will use the World Health Organization's Composite International Diagnostic Interview (CIDI 3.0) which assesses the lifetime and 12-month prevalence of selected mental disorders through the measurement of symptoms and

their impact on day-to-day activities, adapted where necessary for the Australian cultural context.

The CIDI 3.0 does not deliver diagnoses on the spot; rather it captures information on participants' symptoms through a series of standard questions. Assessment of mental health conditions occurs during processing using a series of algorithms based on the definitions and criteria of two classification systems: the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV); and the WHO International Classification of Diseases, Tenth Revision (ICD-10). Each classification system lists sets of criteria that are necessary for diagnosis of a condition.

The CIDI interviews are designed to be conducted face-to-face by a trained interviewer.

6. DATA INTEGRATION

6.1 Data integration overview

Data integration is a way to maximise the value of data for public benefit by combining data from two or more sources to produce new insights, while maintaining the privacy and security of the people or businesses to whom it relates. It is particularly useful when no single dataset can answer policy or research questions about our society. For example, understanding barriers to access or patterns of unmet need for mental health services across the population can have significant public value, particularly given the ongoing investments in accessible Medicare services, such as the telehealth options brought in during COVID-19.

Opportunities for increased public benefit in the mental health sector

The Productivity Commission's (PC) 2017 <u>Inquiry into Data Availability and Use</u> of public sector information highlighted Australia's lost opportunities, including greater opportunities with health sector data.

In 2020, the PC's report on their <u>Inquiry into the Economic Cost of Mental Health</u> identified further opportunities to tackle complex issues through better utilisation of mental health data, including data integration projects, and made a recommendation for a strategy to improve data usability (action 24.1).

The PC highlighted the potential for important analytical outcomes through integration, such as:

- consumer and carer outcomes that may be realised over a long period of time
- the relationship over time between use of services in one sector (such as psychosocial supports) and outcomes in another sector (such as health)
- the social determinants or risk factors for mental illness.

Similarly, the recent Report from the Consumer Panel for the 2019 MBS Review also recommended that "Use of MBS data is maximised for public benefit, and with appropriate governance to ensure that public benefit does not cause harm to the individual."

This view was strongly echoed in the PIA consultation, with stakeholders emphasising the importance of access to data to inform service planning, evaluate policy and programs, and better understand risks and opportunities that impact mental health outcomes in the community.

6.2 Data integration at the ABS

Over the last two decades, the ABS has developed a strong framework for undertaking data integration to deliver insights from existing data sources, while ensuring that personal and sensitive statistical information

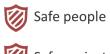
is managed safely and securely, and in a manner that protects privacy.

6.3 Accreditation as an integrating authority

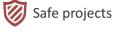
As an <u>accredited Integrating Authority</u>, the ABS has the necessary skills, tools and resources to undertake data integration projects involving Commonwealth data. Any data integration project must meet key guidelines set out in the Commonwealth endorsed <u>High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes</u> (High Level Principles for Data Integration), including demonstrable public benefit of the integration, and preservation of privacy and confidentiality of information to the maximum extent possible.

6.4 Five Safes Framework

When considering the right balance between unlocking the benefits of public sector data while maintaining privacy and security of information, the ABS must consider a range of factors, some of which vary from project to project. The ABS uses a principles-based, internationally recognised framework called the Five Safes to holistically assess integration projects.



Is the researcher authorised to access and use the data appropriately?



Is the data to be used for an appropriate purpose?



Does the access environment prevent unauthorised use?



Has appropriate and sufficient protection been applied to the data?



Are the statistical results non-disclosive?



The elements are assessed independently, but also considered as a whole. They can be thought of as a series of adjustable levers or controls to effectively manage risk and maximise the usefulness of a data release.

For example, tables released as part of standard ABS publications are released to the general public via the website or ABS.Stat. As these are in easily accessible products (the Settings), without project approvals required, open to most members of the public and with minimal vetting of outputs by the ABS, the ABS would ensure that the data were highly aggregated and confidentialised to ensure that no individuals, families or households could be identified (Safe Data).

By comparison, to undertake complex research and modelling using extracts from integrated datasets in the ABS's DataLab, approved researchers must sign Conditions of Use agreements that includes penalties for breaching confidentiality (Safe People), undertake training in using the ABS's locked-down data integration environment (Safe Settings), submit their projects for approval by all relevant data custodians (Safe Projects) and analytic outputs (about groups, not individuals) are vetted by the ABS before the ABS will release them into an external environment (Safe Outputs). In this scenario, the ABS is therefore able to provide more analytic detail than for general publications (Safe Data).

This is consistent with the ONDC's **Data Sharing Principles**.

6.5 The Multi-Agency Data Integration Project (MADIP)

MADIP is a secure data asset combining information on healthcare, education, government payments, income, taxation, employment, and population demographics (including the Census) over time. Data custodians, or entities authorised by data custodians, share data with the ABS for MADIP. As the accredited Integrating Authority for MADIP, the ABS is responsible for securely receiving, storing, and linking data, as well as assembling extracts of integrated data for analysis and providing access to these extracts to authorised researchers. The information in MADIP is also protected under the <u>Census and Statistics Act 1905</u> (Cth).

MADIP combines existing public data to:

- Inform policy development and better targeting of services, such as health and early childhood services, to people and communities who need them; and
- Provide insight into the effectiveness of government programs to ensure they are delivering value to the Australian public.

MADIP is enabled through a partnership among the:

- Australian Bureau of Statistics;
- Australian Taxation Office;
- Department of Education, Skills and Employment;
- Department of Health;
- Department of Social Services; and
- Services Australia.

Security and privacy protections

The end-to-end data integration process at the ABS uses a privacy-by-design approach to ensure the confidentiality and security of integrated information. Security and privacy protections are in place for all datasets, including:

- The cyber security controls for ABS IT systems comply with the Australian Signals Directorate's (ASD) Information Security Manual;
- An independent ASD certified security assessor has certified ABS IT platforms at a very high (protected classification) level;
- The Australian Signals Directorate (ASD) Information Security Registered Assessors Program (IRAP) is conducted every two years;
- Strict control of access to all ABS premises in line with the Commonwealth Protective Security Manual;
- Personnel security arrangements, including security checks for all ABS staff and a requirement to sign a lifelong Undertaking of Fidelity and Secrecy under the <u>Census and Statistics Act 1905 (Cth)</u> the penalty for breach includes fines of up to \$25,200 or imprisonment for two years, or both;
- Regular protective security risk reviews;
- An ongoing program of security audits;
- Strict control of access to information, limited to only the information that is required to perform a specific role within a project;

- Logging and monitoring of access and use of information; and
- Information is only combined in a secure environment within the ABS, by a dedicated team.

As per the High Level Principles for Data Integration, the ABS's data integration assets cannot be used for reporting or compliance purposes. The assets can only be used for producing statistics and research. Any request to bring data together must be supported by strong justification and undergo a rigorous assessment and approval process by data custodians to ensure the project both provides a significant public benefit and safeguards privacy.

Only data that is absolutely required is included in any integrated set of data.

7. KEY PRIVACY CONSIDERATIONS

The ABS considered privacy risks and community expectations in light of the Project. Strengths of the approach and areas for improvement are set out below, and discussed in more detail in the relevant APP section.

7.1 Strengths of the approach for this Project

- Stakeholders recognised the public benefits of the Project and the need for greater research and analysis to underpin evolving mental health policy and funding. Data integration was seen as an important opportunity to undertake such work for the public benefit.
- Overall, given the robust governance legislative framework, existing privacy protections and the
 potential risks to data utility, mental health stakeholders agreed that it was not critical for
 participants' consent to be sought for the use of the Study data for integration. However, there was
 consensus that the ABS must be transparent with participants about the proposed uses of data, and
 the privacy and security protections in place for integration activities.
- The Project will use existing data sources to deliver new insights. Data integration can enhance the
 use of the Study and other government data assets, while still adhering to the ABS' strict privacy and
 security protocols.
- Data integration at the ABS uses a privacy by design approach, and uses the <u>Five Safes Framework</u> to
 deliver enhanced public benefits from data assets while ensuring the ongoing security and privacy of
 information.
- The Project will also be compliant with both the <u>High Level Principles for Data Integration</u> as well as the <u>Data Sharing Principles</u>.
- The ABS uses the <u>Separation Principle</u> to ensure that personal and analytical information are never stored together, and that no person in or outside the organisation can access both types of information to re-identify people. Personal information is not available as part of data integration analysis files.
- The ABS has strong IT systems and security protocols, which are discussed in more detail in APP 11. This includes implementing Australian Signals Directorates strategies, the use of an isolated secure environment for key integration activities, and regular security audits.
- In addition to the <u>Privacy Act 1988 (Cth)</u>, all data in the Project will be protected under the ABS's <u>Census and Statistics Act 1905 (Cth)</u>, which has strong penalties for staff who breach their legal obligations, including prison and/or monetary fines.
- Additional data items derived from supplementary sources will undergo the same rigorous levels of confidentialisation as the Study collections to ensure the privacy of information.

• No concerns were raised in consultation about using data from other sources to supplement the Study.

7.2 Suggestions to enhance proposed process

- While data custodians supported the aims of the Project, some suggested additional approval processes
 might be required in terms of the proposal to supplement Study data with information from existing
 sources through data integration. This is reflected in the recommendations for <u>APP 6</u>. Noting the Project
 is intended to commence in 2023, the ABS will work with data custodians to ensure appropriate
 processes and approvals are in place ahead of integration work.
- Stakeholders suggested the information available online about privacy and security protections for data integration should be updated for further clarity and ease of understanding among the general public.

D. INFORMATION FLOWS

This Project involves the following uses of personal information (including sensitive information):

- use of personal information collected by the ABS in conducting the Study authorised by the <u>Census</u> and <u>Statistics Act 1905 (Cth)</u>;
- b. use of personal information collected by the ABS from other entities for the purposes of data integration authorised by the *Census and Statistics Act 1905* (Cth); and
- c. potential collection by creation by ABS in undertaking data integration.

This Project will have two data integration information flows:

- Integration of data from the Study with MADIP
- 2. Supplementing Study data with information from MADIP

As mentioned earlier, the Project will use MADIP governance and infrastructure to ensure the secure integration of the Study data with other data assets. The ABS is the <u>accredited Integrating Authority</u> for MADIP and this Project.

Detailed diagrams and descriptions of how information flows through MADIP (including the separate flows for linkage variables and analytical variables) can be found in section 3.5 and Appendix 6 of the 2019 MADIP PIA Update. That update outlines inputs to the Person Linkage Spine, the Secure Data Integration Environment (SDIE) and functionally separate roles, and assembly of customised extracts and outputs. The MADIP information flow is outside the scope of this PIA, but is referenced as contextual information.

The following information flows are targeted to this Project only, using the MADIP infrastructure and the ABS's analytical environment.

1. Integration of data from the Study with MADIP

The first flow is the addition of the Study data into MADIP, which follows a standard process developed by the ABS for secure linkage. Throughout this process, personal identifiers and analytical information are never stored, accessed or used together. The ABS treats all MADIP data in the ABS environment, including administrative data, with standards appropriate for personal information regardless of whether the data contains personal information or not.

The ABS will link the Study data to a central linkage infrastructure or MADIP 'Person Linkage Spine' in the Secure Data Integration Environment (SDIE). The Person Linkage Spine is the central linking of identifiers for data held in MADIP. Linkage variables are encrypted and are sourced from Medicare, social security and tax information. The Person Linkage Spine facilitates access to additional MADIP data.

The MADIP includes personal information such as name, address, and date of birth. This information is used to build the central linkage infrastructure and to link separate datasets to this infrastructure. Personal identifiers are stored separately from other analytical information in MADIP. This analytical information may, in some circumstances, be considered personal information even when it is separated from direct identifiers as it may enable the re-identification of an individual (e.g. through the combination of data items). Access to identifiers in MADIP is strictly controlled and limited to a small team of ABS staff.

The data integrated with MADIP sit separately from each other until required for specific research projects. Then only the data required for the approved research project is put together and provided to researchers. More information about MADIP is available on the ABS Website.

Contingent on project approval by data custodians, the ABS can assemble analytical extracts of integrated datasets for specific purposes and provide secure access in the ABS DataLab to these extracts for authorised researchers undertaking approved projects. This makes the data accessible for important research by authorised researchers in future approved research projects to look at patterns and trends in the Australian population. Research provides new insights into the development and evaluation of government policies, programs, and services (such as healthcare) to ensure they are delivering value to the people and communities who need them. This data integration model is shown in **Diagram 1** below.

The MADIP data that the ABS makes available for authorised researchers in the secure ABS DataLab does not include personal information as it is provided in a manner that is not likely to enable the identification of an individual (and therefore meets the requirements to be "de-identified" under the <u>Privacy Act 1988 (Cth)</u>). The ABS uses the <u>Five Safes Framework</u> to manage disclosure risks associated with providing access to de-identified MADIP data.

The ABS does not share MADIP microdata (that is individual record data that provides detailed information about people, households, businesses or other types of entities) outside of the ABS environment.

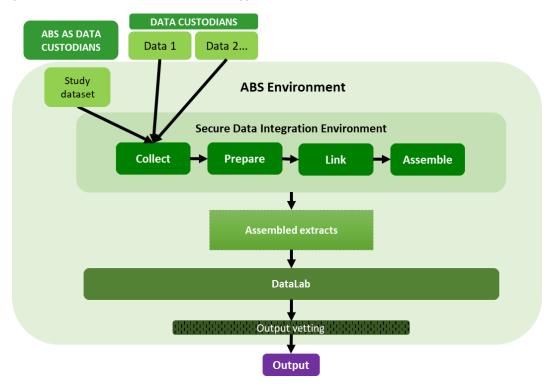


Diagram 1. Integration of data from the Study with MADIP

2. Supplementing Study data with information from MADIP

Contingent on data custodian and project approval, the second proposed data integration information flow will leverage the initial linkage of Study data to the MADIP 'spine' as described above.

De-identified supplementary data will be extracted from MADIP and will be delivered to a secure processing drive in the ABS environment. Access to this drive is restricted to the Study processing team who are responsible for creating output products that include the supplementary data.

Some MADIP data sets, like the Medicare Benefits Schedule (MBS) or the Pharmaceutical Benefits Scheme (PBS), are administrative data while others might be ABS survey or Census information. Administrative data

are not necessarily captured or stored in the format required for the Study's data outputs, so there could be steps required to transform it into a characteristic of a person, business or other entity, often through strategies such as categorising or creating ranges. This in turn contributes to the de-identification of the information.

The Study processing team will transform data as required into characteristics of respondents in the Study and join these to the main Study dataset.

The Study processing team will then create output products (for example, a publication or a TableBuilder product) from the main Study dataset, potentially including further confidentialisation or transformation steps. These output products will be accessible to a wider range of people than for the MADIP asset, and correspondingly, the data would go through extra confidentiality processes and checks. Once the processing is completed, the extract of the de-identified supplementary data originally taken from MADIP will be destroyed. Transformed variables derived from the extract will be retained permanently on the Study file. This data integration model is shown in **Diagram 2** below.

The data included in analytic Study files and output products does not include information that can reasonably re-identify an individual, and therefore is considered "de-identified" under the <u>Privacy Act 1988</u> (Cth).

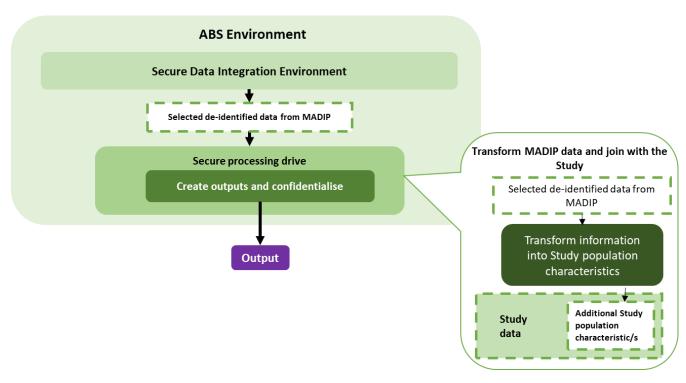


Diagram 2. Supplementing Study data with information from MADIP

E. COMPLIANCE AGAINST THE AUSTRALIAN PRIVACY PRINCIPLES

APP 1-OPEN AND TRANSPARENT MANAGEMENT OF PERSONAL INFORMATION

An APP entity must manage personal information in an open and transparent way. This includes having a clearly expressed and up to date privacy policy.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-1-app-1-open-and-transparent-management-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	R1. The ABS should continue to
assets		update online content for the
☑ Fully complies		public on MADIP and integration
☐ Partially complies		projects, particularly outlining
☐ Does not comply		privacy, security and legislative
		protections in a straightforward
2. Supplementing Study data		and accessible manner.
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

ABS privacy policies publicly available on the ABS website include:

- ABS Privacy Policy for Statistical Information how the ABS handles personal information for producing statistics; and
- <u>ABS Privacy Policy for Managing and Operating our Business</u> how the ABS handles personal information for use in business operations.

The ABS Privacy Policy for Statistical information covers all ABS statistical projects, including data integration projects and comprises:

- the kinds of personal information collected and held by the ABS;
- how that information is collected and held; and
- the purposes for which the information is collected, held, used and disclosed.

It also explains how privacy complaints and enquiries can be raised and managed. The ABS Privacy Policy for Statistical Information contains links to the ABS's authorising legislation and the document <u>Your personal information - statistical purposes</u>, which provides more detail on the personal information collected for different purposes.

The ABS Privacy Policy for Statistical Information is compliant with APP 1, and has been assessed as such in previous Privacy Impact Assessments (PIAs), including for the 2019 Multi-Agency Data Integration Project (MADIP) PIA Update and the 2014-15 National Health Survey Linkage Project (NHS). The ABS Privacy Policies have been updated since then to meet best practice recommendations. The 2019 MADIP PIA Update outlines the privacy protections and management strategies in place for integrating data into MADIP, while the NHS PIA outlines the way in which privacy is managed in the circumstances where ABS survey data are integrated with MADIP.

In compliance with the <u>Australian Government Agencies Privacy Code</u>, the ABS has appointed a Privacy Officer and Privacy Champion to ensure an ongoing strong privacy culture.

The ABS has made a range of information about its data integration framework and activities publicly available on the ABS website:

- The MADIP Privacy Policy, published in June 2018, outlines data management, privacy and security information for MADIP integration projects. The policy was assessed as compliant against APP 1.4 in the recent MADIP PIA Update, which means that it contains all the information which is mandatory to include in a privacy policy under the Australian Privacy Principles.
- The MADIP data and legislation page on the ABS website provides information about the data in MADIP and data that may be included in the future, the types of information shared for MADIP, and the legislation under which data are shared for MADIP.
- As an Accredited Integrating Authority, the ABS complies with the <u>High Level Principles for Data</u> <u>Integration Involving Commonwealth Data for Statistical and Research Purposes.</u>
- The <u>Five Safes Framework</u> (cat. no. 1160.0) is used to manage the risk of disclosure as required by the ABS's legislation and the *High Level Principles*. These are consistent with the Office of the National Data Commissioner's <u>Data Sharing Principles</u>.
- MADIP overview pages, covering what MADIP is, who can gain access, what projects are already being undertaken using MADIP, ABS as an Integrating Authority, and other useful information.

Information about integration projects undertaken by the ABS is also available online, both for MADIP-related and other data integration projects:

- MADIP Research Projects presents up-to-date information about approved research projects that use MADIP data; and
- <u>Data Integration Project Register</u> provides a summary description of current and historic ABS data integration projects.

The ABS aims to be transparent regarding privacy considerations for specific projects by publishing Privacy Impact Assessments or summaries of Privacy Impact Assessments for sensitive data integration projects on the ABS website. They can be found on the ABS Privacy Impact Assessments webpage.

The work that has been done since the MADIP PIA Update and the information that is now available online about data integration projects demonstrates ABS's commitment to transparency. As with current practices, information about data integration projects using Study data will be made available on ABS's website. Continuing with these practices will ensure ABS will continue to meet its APP 1 obligations in the context of data integration projects.

During consultation, stakeholders emphasised the need for transparency and straightforward communication with respondents regarding the Project via online and written materials. In the course of preparing this PIA, the ABS considered how to increase transparency about the Study for Study participants, and have since revised the Study materials to be made available to participants in response. See <u>APP 5</u> for more information about the work that has been done to increase transparency for Study participants.

The ABS recognises the need to continue to update online content for the public on MADIP and integration projects, particularly outlining privacy, security and legislative protections in a straightforward and accessible manner (R1), and is continuing to publish plain language information pages on the ABS website to meet stakeholder expectations.

APP 2-ANONYMITY AND PSEUDONYMITY

An APP entity must give an individual the option of not identifying themselves or of using a pseudonym.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-2-app-2-anonymity-and-pseudonymity/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

For ABS household surveys such as the Study, the participant does not have to give their name or date of birth, but is encouraged to do so in order to enable more accurate data integration to government administrative data. If participants do not wish to provide their names, they can use a pseudonym as outlined in the Household Survey Participant Information FAQs. As part of the data integration process, names are anonymised and new random record linkage IDs are assigned for each individual.

Otherwise, data in MADIP is covered by exceptions to the anonymity and pseudonymity requirements provided by APP2.2(b). The entities who collect other sources of information (e.g. administrative data) may enable people to identify anonymously or use pseudonyms as practical for their operations.

APP 3-COLLECTION OF SOLICITED PERSONAL INFORMATION

Any personal information collected from individuals must be reasonably necessary for one or more of the collecting APP entity's functions or activities. Higher standards apply to the collection of sensitive information, which require that the individual to whom the sensitive information relates must consent to the collection, unless an exception applies.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-3-app-3-collection-of-solicited-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

This Project involves the following collections of personal information (including sensitive information):

- a. collection of personal information by the ABS in conducting the Study which is authorised by the
 <u>Census and Statistics Act 1905 (Cth)</u> (so that APP 3.4(a) and APP 3.6(a)(ii) applies) [out of scope of this
 PIA];
- collection of personal information by the ABS from other entities under the <u>Census and Statistics Act</u>
 <u>1905 (Cth)</u> for the purposes of data integration (so that APP 3.4(a) and APP 3.6(a)(ii) applies) [out of scope of this PIA]; and
- potential collection by creation by ABS in undertaking data integration (and APP 3.4(a) and APP 3.6(b) applies) [in scope of this PIA].

ABS is authorised by the <u>Census and Statistics Act 1905 (Cth)</u> to collect personal and sensitive information in order to compile and release statistics which includes integrating data for statistical or research purposes. The ABS only collects information that is relevant to its functions, and ensures that only the minimum amount of personal information required for statistical and integration purposes is collected.

Mental health information is considered to be sensitive and, under the principle of data minimisation, should only be used when necessary for the purposes of the Project. This principle is standard MADIP practice and will also apply for future approved research projects in the MADIP environment.

Each agency involved in MADIP is authorised by law to collect personal information as part of its core functions, to share that information with the ABS for MADIP, and to use it for policy analysis, research, and statistical purposes. See MADIP data and legislation for more information.

Data integration uses existing data holdings at the ABS and other agencies. However, such integration may lead to the creation of, and consequently, the collection of additional personal information (referred to as 'collection by creation').

As the OAIC notes, the Information Accountability Foundation has described the generation of new personal information in three categories. The two below are particularly relevant for this PIA:

- 'Derived data' is generated from an original dataset in a simple way, for example calculating a score from responses to a set of questions about wellbeing.
- 'Inferred data' is produced by using a more complex method of analytics to find correlations between datasets and using these to categorise or profile people, for example by predicting future health outcomes.

Data integration in this Project may involve the 'collection by creation' of personal information as through the use of statistical processes information may be derived or inferred about an individual based on the above definitions. APP 3 is satisfied as ABS has the function and legislative authority to conduct data integration projects, and it is reasonably necessary for it to collect any information by creation to fulfil this function. Any sensitive information created by collection in this Project will be weighed in relation to ABS fulfilling its functions (for the purposes of APP 3.4(a)) in balance with a consideration of whether the collection by creation is reasonably necessary. If information for this Project is 'collected by creation', it will not be from individuals directly, however it is unreasonable and impracticable for the ABS to ask participants to provide all the desired information during the interview, particularly where it can be obtained, derived or inferred from existing data. APP 3.6(b) therefore applies to this Project.

The ABS commits to undertaking this Project by lawful and fair means as required by APP 3.5.

APP 4-DEALING WITH UNSOLICITED PERSONAL INFORMATION

Where an APP entity receives unsolicited personal information, it must determine whether it would have been permitted to collect the information under APP 3. If the information could not have been collected under APP 3, and the information is not contained in a Commonwealth record, the APP entity must destroy or de-identify that information as soon as practicable, but only if it is lawful and reasonable to do so.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-4-app-4-dealing-with-unsolicited-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data assets	Nil.	Nil.
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data through		
integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

The ABS has policies and procedures in place to securely manage data in accordance with APP 4 and also undertake appropriate communication with stakeholders.

Staff in the Librarian and Assembler roles within the Data Integration areas are responsible for receiving, storing, and processing data shared to the ABS for integration with the MADIP asset. Staff in these roles undertake routine checks, including looking out for unsolicited personal information, on all data received. Additionally, staff accessing data in Librarian, Linker and Assembler roles must be Australian citizens, not be contractors, hold and maintain a BASELINE security clearance, and have signed the:

- Undertaking of Fidelity and Secrecy under the Census and Statistics Act 1905 (Cth); and
- Official Secrecy and Legal Obligations Acknowledgement.

Where unsolicited personal information is discovered on a dataset that has been shared with the ABS, data items are moved to a separate folder and the ABS Privacy Officer is notified. The data provider is informed of the incident. The ABS and the data provider collaboratively determine whether the data are destroyed and resupplied, or whether the ABS clean the data set, removing and destroying the unsolicited data.

The ABS and other data custodians are required to operate under the <u>Notifiable Data Breaches Scheme</u>, under Part IIIC of the Privacy Act. The ABS assesses the severity of any incidents and works with data custodians to minimise the risks that the provision of unsolicited information to the ABS is or becomes a Notifiable Data Breach. No Notifiable Data Breaches have occurred for MADIP.

Additionally, supply of unsolicited personal information to the ABS is unlikely to result in serious harm to the individuals to whom the data relates. This is due to the checks outlined above, the protections of the <u>Census</u> <u>and Statistics Act 1905 (Cth)</u>, and also because the ABS is guided by the Five Safes framework, which includes the "Safe People" element and the <u>Separation Principle</u>. This means that ABS officers have undergone

training to apply the Separation Principle and handle data safely and cannot access personal identifiers and analytical information at the same time.

Because of this, the supply of unsolicited personal information to ABS is unlikely to result in a notifiable data breach as it would not meet the harm threshold. However, this will be assessed at the time of any provision of unsolicited personal information.

APP 5-NOTIFICATION OF THE COLLECTION OF PERSONAL INFORMATION

An APP entity that collects personal information about an individual must take reasonable steps either to notify the individual of certain matters or to ensure the individual is aware of those matters.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-5-app-5-notification-of-the-collection-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
□ Fully complies		
☐ Partially complies		
☐ Does not comply		

The ABS aims to undertake field work for the Study from December 2020, and will provide households with the information required for a full notification of the collection of personal information (privacy notice).

As for other household surveys, prior to being visited by the ABS Interviewer, selected households will be sent a guide, cover letter and invitation letter (materials). The materials will be written in plain language, and will include information about the Study, the public benefit from participating, how to access and correct personal information held by the ABS, how to make a privacy complaint, and how the data will be collected and used. Information on, and a link to, the ABS's Privacy Policy is also included in materials.

Since 2018, the ABS has included a statement in materials to survey respondents advising of the use of data for integration purposes. The materials for the Study will include a statement regarding the use of data for both proposed integration activities, similar to the following:

"To create insights about Australia, and to keep the survey as short as possible, we will link your information with data from other sources. For more information, please visit our Survey Information Page at www.abs.gov.au/surveyinfo"

Given the limited space available in the materials supplied to households, links are provided in the materials pointing to more detailed information on the ABS website, including for APP 5 matters. As the use of existing data to supplement an ABS survey is a new process, this is not commonly part of the standard information the ABS provides to households. The ABS will add information on supplementing Study data through integration to information provided on the website for the Study to ensure full compliance with APP 5, such as:

"Will the information I provide be combined with other data?

The information you provide will be combined with the information from other respondents to produce vital statistics about Australian households.

We often combine data from two or more sources because combining data helps fill the gaps — and saves you time. The information you provide for the National Survey of Health and Wellbeing will be combined with information from other government sources. Combining data from these sources will provide a clearer picture of the health and wellbeing of people in Australia than can be achieved by any one of these sources. By reusing existing data, we also reduce the need for Australian households and businesses to provide more information.

Governments, researchers and community groups will use this vital data to better understand the health and lifestyles of Australians and the health services Australians use and need. This will help design policies and services to improve the lives of Australians. For an example of how combining data from multiple sources has been used to inform health policies and services, click here."

Additional information for participants can be found in online FAQs for the Study to ensure that all the required elements for a privacy notice compliant to APP 5 are in a single place for ease of access and comprehension, including information on overseas disclosure. A link will be provided in the materials which will guide potential participants to the Study FAQs. The information provided will be similar to examples from the 2020 National Health Survey FAQ and the ABS Privacy Policy for Statistical Information webpages.

Further to the materials and FAQs, the ABS Interviewer will show their identification and authority to collect information for the ABS. They will have a card providing information about whether the Study is compulsory and the consequences for not participating which they will show if queried. If queried about confidentiality they will provide a response along these lines:

- "It is an offence for any ABS staff, past or present, to divulge, directly or indirectly, any information collected under the *Census and Statistics Act 1905*. Breaching this requirement can result in heavy penalties, including fines and imprisonment" or
- "The answers you provide will be treated confidentially. The ABS is required by the *Census and Statistics Act 1905* to maintain the secrecy of all information provided to it. No information will be released in a way that would enable an individual or household to be identified."

ABS Interviewers may also use the pre-approach material to point the participant to further information that can be found on the ABS website. As part of continuous improvement, the ABS is developing an information card on data integration for Interviewers to provide to participants on request. This is not yet finalised, but if ready in time for field work, may also be carried by Interviewers.

Finally, the ABS website includes information on the ABS Privacy Policies, information about the MADIP and information about data integration:

- ABS Privacy Policy for Statistical Information;
- ABS Privacy Policy for Managing and Operating our Business;
- Multi-Agency Data Integration Project (MADIP);
- MADIP data and legislation; and
- Integrated data.

APP 6-USE OR DISCLOSURE OF PERSONAL INFORMATION

An APP entity can only use or disclose personal information for the particular purpose for which it was collected (primary purpose) or for a secondary purpose if an exception applies, such as where the individual has consented to the use or disclosure of the information, or would reasonably expect it, or where it is required or authorised by law.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-6-app-6-use-or-disclosure-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data assets ☑ Fully complies ☐ Partially complies	Nil.	R2. Clarify the details of governance arrangements with data custodians of the relevant data, in relation to use of data to
☐ Does not comply 2. Supplementing Study data		supplement the Study, in accordance with ABS data integration processes.
through integration ⊠ Fully complies		
☐ Partially complies☐ Does not comply		

The following privacy risks were considered as part of assessing compliance against APP 6:

- Whether it is necessary for the ABS to seek informed consent for the Project, given its authorising legislation;
- Whether stakeholders and the broader community would expect the ABS to seek informed consent for data integration;
- Whether participants in the Study (and the community generally) would reasonably expect their data to be used for data integration;
- Community concerns about adverse consequences for participants if their mental health information can be accessed by third parties for commercial purposes (such as insurance companies); and
- Whether mental health information or particular types of data items were considered too sensitive for inclusion in integrated datasets by people with lived experience of mental illness.

Authority to conduct integration with Study data

Under the <u>Australian Bureau of Statistics Act 1975 (Cth)</u>, the ABS's function is "to collect, compile, analyse and disseminate statistics and related information," which includes the integration of statistics and the maximum possible utilisation of data for statistical purposes (Part II, 6(1)(b)-6(2)). It carries out these functions in line with legislative privacy and security requirements in the <u>Census and Statistics Act 1905 (Cth)</u>, the <u>Privacy Act 1988 (Cth)</u> and the <u>Privacy (Australian Government Agencies – Governance) APP Code 2017</u>.

Approach to seeking consent

The ABS recognises that seeking consent from individuals is an important mechanism for protecting privacy. However, the ABS also works within a particular legislative framework and needs to also consider the utility of data in performing its functions.

There is some evidence from Australia and overseas that there are differences in "health behaviours and health status between responders and non-responders²" when seeking consent for data integration, and that consent rates could range anywhere from less than 50% to 95% or higher³. Lower rates of consent for data integration would seriously limit the utility of the information, and run the risk of leading to flawed mental health policy and research.

The ONDC noted in their 2019 <u>Discussion Paper</u>, following a series of public consultations on data sharing, that "the research sector presented particularly robust arguments against taking a one-size-fits-all approach to consent during consultations. (p.33)"

With the risk of low consent rates, the value of data required to inform complex policy, service planning and funding decisions for mental health could be significantly diminished, with potential biases resulting in skewed data which risks poorly designed mental health planning. These are important considerations for the ABS. The ABS is responsible for ensuring Study data is as comprehensive and robust as possible.

In order to maximise the usefulness of the data as well as manage respondent burden and the length of the interview, the ABS intends to undertake integration for the full sample without seeking consent from individual respondents, noting as discussed above that the ABS's legislative framework enables the ABS to undertake integration activities without consent. However, as outlined in APP 5, the ABS is transparent in the materials provided to the respondent that the information can be used for data integration purposes.

Stakeholder support of the Project

The ABS sought feedback on its approach to the proposed integration from a range of stakeholders, including mental health sector experts, service providers, people with lived experience of mental illness, carers, advocates, and other Government agencies. Data custodians, federal privacy and data sharing governance bodies, including the OAIC and the ONDC, participated in consultation.

During consultation, information on the current privacy and security protocols was presented, as well as the intention to integrate without seeking participant consent. Overall, given the potential public benefits, the ABS's legislative framework and existing protections, and the potential risks to data utility, stakeholders agreed that it was not critical for participants' consent to be sought for the use of the Study data for integration, but emphasised the importance of clear and transparent communication about data integration with Study data. The representatives were supportive of the integration with appropriate data security protections in place. For more information, see section 7 - Key Privacy Considerations.

² Stanley F. Privacy or public good? Why not obtaining consent may be best practice. Significance 2010 May 18;7(2):72-75.

³ Graves, A., McLaughlin, D., Leung, J. et al. Consent to data linkage in a large online epidemiological survey of 18–23 year old Australian women in 2012–13. BMC Med Res Methodology 19, 235 (2019).

APP 6 compliance – Integration of data from the Study with MADIP

(i) Use of the data

The inclusion of Study data into MADIP is consistent with the primary purpose of the Study as notified to participants, that is, research and statistical purposes, and therefore is compliant with APP 6.1 (see APP 5 for further information on notification of the collection of personal information, including for data integration purposes). No secondary uses of personal information are foreseen as the data is only used (including after linkage to MADIP) for statistical and research purposes.

For context, we note that each agency involved in MADIP or data integration with the ABS is authorised by law to collect personal information as part of its core functions; to share that information with the ABS for MADIP; and for the information to be used for policy analysis, research, and statistical purposes in keeping with required governance and approval processes. There are standard governance practices for data sharing agreements with the ABS, which can include the approval of a Public Interest Certificate by data custodians for the release of the data into MADIP.

During consultation, stakeholders emphasised the need for new data and new insights into mental health, showing support for future integration projects that could demonstrate public benefits, particularly for service jurisdictions. Respondents could also reasonably expect data integration with MADIP to occur as they are notified that Study data is used for integration in printed and online material for the Study (see APP 5).

No mental health topics or data items were identified as too great a risk to include in MADIP by stakeholders, given the legislative framework and privacy and security arrangements in place.

(ii) Disclosure of data

There will be no disclosure of personal information outside the ABS environment for this Project.

Any potential subsequent disclosure of de-identified Study data that has been linked to MADIP will require approval in line with standard MADIP processes. The ABS's data integration assets can only be used for statistical and research purposes, and not for regulatory or compliance purposes. Projects seeking access to MADIP integrated data that do not demonstrate statistical and research benefits will not be approved.

The ABS has instituted a range of measures to ensure transparency and clarity around uses of the Study data (as outlined in <u>APP 5</u> and <u>APP 1</u>) and the numerous security protections in place (as outlined in <u>APP 11</u>) to ensure the privacy and protection of information.

APP 6 compliance – Supplementing Study data with information from MADIP

(i) Use of the data

Including data from MADIP to enhance the Study may be considered a new secondary use of the data by some data custodians, particularly where data custodians are required to comply with specific legislation governing the data.

From the ABS's perspective, the proposed inclusion of data from MADIP into Study files would be conducted under the <u>Census and Statistics Act 1905 (Cth)</u> (s12(1)) (an APP 6.2 (b) exception to APP 6). Additionally, participants are notified of the potential use of supplementary information in combination with their Study

responses in printed and online material for the Study (see APP 5).

However, custodians of administrative or non-ABS data sets held in MADIP may consider the use of this data to supplement the ABS's collections may not be consistent with existing data sharing agreements with the ABS or Public Interest Certificates (PICs) and accordingly the use of that data is for a purpose other than that for which it was collected by the ABS from the data custodian (i.e. for a secondary purpose).

As per standard MADIP governance for new uses of the data, the ABS would undertake a review of the permitted uses of the data in data sharing agreements with the relevant data custodian before undertaking any data integration activities to supplement the Study data. In these circumstances, additional approval processes may be required by the relevant data custodian. Where applicable, use of the data to supplement the Study will be certified as in the public interest (where this mechanism is available under legislation administered by a relevant data custodian for the specific data), so that the secondary use will be authorised by law and accordingly the data can be used to supplement Study data as a secondary purpose under APP 6.2(b).

In considering the proposed use of PBS data to supplement the Study, the ABS will work with the Australian Government Department of Health to ensure that legislative, policy and data custodian requirements are met, and that approval is granted by the Department for this work. A PIC may be used to certify that the work is in the public interest. This will ensure that the secondary use will be authorised by law and accordingly the data can be used to supplement Study data as a secondary purpose under APP 6.2(b).

Data custodians for other Commonwealth datasets involved in consultation supported the potential for supplementing the Study from MADIP sources, contingent on approval from the relevant data custodian(s).

(ii) Disclosure of the data

Any outputs produced from the Study, including from supplementary sources, are subject to and protected under the <u>Census and Statistics Act 1905</u> (Cth), which states that the ABS cannot release information in a manner likely to identify a person.

The ABS's statistical products from the Study therefore will only release data that meets the requirements of being 'de-identified' under the <u>Privacy Act 1988 (Cth)</u>. A range of statistical techniques are used to de-identify or 'confidentialise' ABS products, which are described in the <u>ABS Confidentiality Series</u>, <u>August 2017</u>, including:

- information on the Five Safes Framework,
- managing the risk of disclosure for aggregate data, and
- managing the risk of disclosure for microdata.

APP 7-DIRECT MARKETING

APP 7 requires that an organisation must not use or disclose personal information it holds for the purpose of direct marketing unless an exception applies.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-7-app-7-direct-marketing/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Not applicable.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

APP 7 is not relevant to the ABS (or to the Project). In addition, the ABS's legislation prohibits the release of data in a way that could identify an individual, and ABS will not use either integrated datasets or enhanced Study information for direct marketing.

APP 8-CROSS-BORDER DISCLOSURE OF PERSONAL INFORMATION

Outlines the steps an APP entity must take to protect personal information before it is disclosed overseas.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-8-app-8-cross-border-disclosure-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

Cross border data transfers are not currently relevant to integrated datasets in MADIP. Data are not transferred or accessed outside of Australia for MADIP. The ABS and its secure ICT environment used for MADIP is fully located in Australia and data custodians (and authorised entities) that disclose personal information to the ABS for MADIP are also located in Australia.

APP 9-ADOPTION, USE OR DISCLOSURE OF GOVERNMENT RELATED IDENTIFIERS

An APP entity must not adopt, use or disclose a government related identifier of an individual as its own identifier of the individual unless an exception applies. APP 9 is not relevant to the ABS (or to the Project).

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-9-app-9-adoption-use-or-disclosure-of-government-related-identifiers/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Not applicable.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

APP 9 does not apply to the ABS and accordingly is not considered.

APP 10-QUALITY OF PERSONAL INFORMATION

An APP entity must take reasonable steps to ensure the personal information it collects is accurate, up to date and complete. An APP entity must also take reasonable steps to ensure the personal information it uses or discloses is accurate, up to date, complete and relevant, having regard to the purpose of the use or disclosure.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-10-app-10-quality-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

Data collection for the Study is conducted over a specified period of time called the 'reference period', and personal information and analytical information is relevant and accurate for that period. For example, the reference period for the previous iteration of the Study is 2007 as data was collected over several months in that year.

As the purpose of collection is to reflect data for the reference period, subsequent updates are not required. Statistical information undergoes rigorous quality assurance ahead of dissemination or data integration. Information relating to bias or error is publicly released in the Technical Manuals or User Guides for surveys. Similarly, upon integration with MADIP or other data assets, an evaluation will be carried out to establish the quality of the integration and the resulting customised data extracts.

Integrated data in the ABS is only used for statistical and research purposes, and not for compliance or regulatory purposes. Assessments are made about fitness for purpose of integrated data for each project.

Given these circumstances, the Project has been assessed as compliant against APP 10.

APP 11–SECURITY OF PERSONAL INFORMATION

An APP entity must take reasonable steps to protect personal information it holds from misuse, interference and loss, and from unauthorised access, modification or disclosure. An APP entity has obligations to destroy or de-identify personal information in certain circumstances unless an exception applies.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-11-app-11-security-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	See R1.
assets		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☐ Partially complies		
☐ Does not comply		

In evaluating the security of the personal and statistical information for the Project, particular consideration was given to the following:

- Concerns that the increased detail and volume of information held about individuals and households could increase the risk of re-identification;
- Concerns that incorporating additional data in survey files through integration with other sources could include more information about an individual than they were aware of;
- The value of data to third parties is high, and data sharing with commercial institutions might result in negative outcomes for individuals; and
- The data could be the target of external attacks (e.g. hacking).

All personal data collected as part of the Study is subject to the ABS's Retention of Personal Identifiers Policy, which requires that personal data should not be kept beyond the processing period without strong rationales and/or approval from the appropriate delegate.

In exceptional circumstances, a defined (non-speculative) use for personal identifiers may be recognised after the information has been collected but prior to the deletion of the identifiers. Under such circumstances, the retention of personal identifiers is permitted if:

a. a Privacy Impact Assessment has been undertaken to identify and assess privacy implications; and b. the Australian Statistician has approved the retention for that defined use.

The ABS has a long tradition of ensuring the security and privacy of statistical and personal information collected, and is continuously evolving to ensure its protections and security are commensurate with the changing external and digital environment. It was recommended in the 2019 MADIP PIA Update that ABS should finalise and implement the MADIP Data Retention and Destruction policy. The policy for security, retention and destruction of information in MADIP is covered in the broad MADIP Privacy Policy. The one element outstanding to meet the MADIP PIA Update recommendation is for ABS to work with the MADIP

Board to agree on a standard practice for data custodians to request information be destroyed. Options will be presented to the MADIP Board in early 2021.

The ABS uses privacy by design to ensure that integration projects comply with the robust framework of legislative, Information and Communication Technology (ICT), and data governance controls for protecting privacy and ensuring data security in its data integration environment.

The end-to-end integration process is therefore compliant with legislation and best practice standards, including for staff and ICT used.

Privacy is incorporated into **Risks** every stage of a project Data **Project Project** Data Data Data Data access and initiation approval acquisition linking assembly storage analysis Ways of managing risks

Privacy by design in the ABS's Data Integration Environment

Protocols such as applying the <u>Separation Principle</u>, storing data sets separately in the MADIP environment, the robust governance and approvals process for proposing an integration project (including justifications for using certain data sets or data items), and the use of the internationally-recognised <u>Five Safes Framework</u> to govern access address many concerns around the security of personal and sensitive information.

In particular, the Five Safes Framework is designed to manage disclosure risk with integrated data assets such as the MADIP, and acts as a series of levers to strike the right balance between enabling further research and analysis while maintaining the privacy and security of participants' information.

Upon appointment, all ABS staff undergo security checks. Additionally, a minimum BASELINE security clearance is required for staff involved in integrating MADIP data. The ABS undertakes Regular Protective Security risk reviews to ensure that security arrangements continue to be effective.

ICT security measures for the MADIP environment include:

- Conforming with information technology security arrangements set out in the Australian Government Information Security Manual (ISM);
- Ensuring that data collection, data integration, and data assembly activities for MADIP information is only conducted by a dedicated team in an isolated secure environment the Secure Data Integration Environment (SDIE). This environment has no external connectivity (i.e. no email, internet, etc.) to mitigate risks of data exfiltration;

- Access to data via a secured internet gateway which is reviewed annually by the Australian Signals
 Directorate (ASD); and
- An ongoing program of security audits and system accreditations, including an independent assessment by the ASD.

Every two years, the ABS will undertake independent assessment of the MADIP Secure Data Integration Environment under the Information Security Registered Assessors Program (IRAP), as recommended in the 2019 MADIP PIA Update, most recently undertaken in July 2020.

When data custodians share their data with the ABS, personal and analytical information are provided in separate files. This enables the ongoing privacy of information through functionally separating personal identifiers like names from other characteristics of a person. When received by ABS, these files remain separate, being secured, stored and used in separate locations that require different roles and authorisation to access them. No-one will have the necessary roles and authorisation to access both at the same time. Personal information is not included in de-identified analytical data files made available to researchers, and is never supplied to researchers. Personal information is only retained for as long as required for statistical and linkage purposes. More information can be found in the MADIP Privacy Policy.

The ABS and partner agencies on the MADIP Board remain committed to ensuring the security of personal information in MADIP. The ABS's capacity for delivering enhanced data services while maintaining privacy and security is a core feature of current and potential future data sharing models for data integration. The ABS will continue to explore the capabilities that future IT environment and infrastructure developments may provide for data security.

Accessibility of data in MADIP is managed under the "safe people" aspect of the Five Safes Framework used in the ABS and MADIP access arrangements. Currently MADIP is accessed primarily by government agencies, public policy research institutions and university researchers, but as the ABS and other agencies are continually seeking to improve access while maintaining privacy, this might change in the future.

The current security measures used in the MADIP operating environment were widely supported by stakeholders involved in the PIA consultation, with some recommending that the ABS increase public awareness about security measures with clear, easy to follow information on the website. A similar best practice recommendation was made in the 2019 MADIP PIA Update.

APP 12-ACCESS TO PERSONAL INFORMATION

An APP entity that holds personal information about an individual must give the individual access to that information unless a specific exception applies.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-12-app-12-access-to-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

The ABS's <u>Privacy Policy for Statistical Information</u> outlines how a request for access to personal information is handled, specifically:

We will take all reasonable steps to address your request. In some cases, we won't be able to provide your personal information as we have:

- destroyed the physical forms, and
- deleted personal identifiers (such as name and address) from the statistical data, which we do as soon as possible.

Information that is collected under the authority of the <u>Census and Statistics Act 1905 (Cth)</u> is exempt from Freedom of Information requests (<u>Freedom of Information Act 1982 (Cth)</u> Schedule 2, Part II, Division 2). This means that a specific exception to APP 12 exists for statistical information, data, survey forms and any other similar information requested under the <u>Freedom of Information Act 1982 (Cth)</u>.

The ABS is not exempt from requests under the <u>Freedom of Information Act 1982 (Cth)</u> that relate to managing and operating ABS business.

For personal information originally collected by other data custodians and shared with the ABS for data integration, each individual data custodian (and authorised entity) remains responsible for managing access requests relating to their own data holdings.

Accessing and correcting personal information specific to MADIP is addressed in the MADIP Privacy Policy.

The Project has been assessed as compliant with APP 12.

APP 13-CORRECTION OF PERSONAL INFORMATION

An APP entity that holds personal information about an individual must take reasonable steps to correct personal information to ensure that, having regard to the purpose for which it is held, it is accurate, up-to-date, complete, relevant and not misleading.

Further information can be found on the OAIC website here: https://www.oaic.gov.au/privacy/australian-privacy-principles-guidelines/chapter-13-app-13-correction-of-personal-information/

Compliance	Compliance recommendations	Best practice suggestions
1. Integration with other data	Nil.	Nil.
assets		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		
2. Supplementing Study data		
through integration		
☑ Fully complies		
☐ Partially complies		
☐ Does not comply		

The ABS's <u>Privacy Policy for Statistical Information</u> outlines how requested corrections to personal information are handled, specifically:

We will take all reasonable steps to address your request. In some cases, we won't be able to provide your personal information as we have:

- destroyed the physical forms, and
- deleted personal identifiers (such as name and address) from the statistical data, which we do as soon as possible.

As noted in APP 10, for the Study, the ABS will collect information for a specified reference period, and take steps to quality assure and understand potential biases in the data collected. A quality review will also be carried out after linkage to the MADIP asset. As data is required to be accurate for the reference period of the Study, subsequent updates are not required.

Data custodians that have shared data with the ABS are also required to provide mechanisms for dealing with corrections and complaints, usually detailed in their respective privacy policies.

Accessing and correcting personal information specific to MADIP is addressed in the MADIP Privacy Policy.

The Project has been assessed as compliant with APP 13.

F. NEXT STEPS

8. IMPLEMENTATION OF THE PIA

The assessment undertaken in this PIA indicates that measures to be undertaken are appropriate, and that the ABS is compliant with privacy requirements. The ABS has reviewed the proposed recommendations from this report and will implement or continue to progress the recommendations provided. If comparable, the outcomes of this PIA may be considered for other elements of the Intergenerational Health and Mental Health Study.

Further discussions will be undertaken with the MADIP Board and relevant data custodians on what additional governance processes might be required for the Project prior to integration commencing.

As noted in <u>APP 6</u> commentary, the ABS and the Australian Government Department of Health will through current governance processes confirm that PBS data within the MADIP data asset can be used as supplementary information for the Study.

Supplementary data items from other data assets linked to MADIP could also become necessary to add to the Study to fulfil its aims or deliver greater insights on post-pandemic impacts.

8.1 Changes outside the scope of this PIA

Future situations that may necessitate an update to the PIA include but are not limited to:

1. Updates to the ABS's, the MADIP Partner Agencies' or the broader data legislative environment

The ABS and data custodians do not operate only within the MADIP framework, but are subject to the broader data and privacy environment.

For example, the proposed *Data Availability and Transparency Bill* could have implications for the ABS's data sharing framework and environment; the ABS and MADIP partners may wish to closely align MADIP processes and practices with the new data sharing legislation and guidelines.

2. Changes in Project scope

An example of a scope change would be the inclusion of mental health data in a standard ABS data integration product, which has not been assessed in this PIA.

3. Further updates to how MADIP information is stored or accessed

MADIP is an evolving product, and the ABS anticipates that it will evolve to keep pace with technology and community progress. Nevertheless, in the event that there are changes to data handling arrangements, including changes to the outlined privacy and/or security safeguards, a new PIA process might be required.

9. MORE INFORMATION

For more information on the Project, please contact the ABS at mental.health.statistics@abs.gov.au.

G. APPENDICES

APPENDIX A: KEY DOCUMENTS CONSULTED FOR THIS PIA

Australian Bureau of Statistics. ABS Privacy Policy for Statistical Information. https://www.abs.gov.au/websitedbs/ D3310114.nsf/Home/Privacy+Policy Last accessed 09 October 2020.

Australian Bureau of Statistics. 2019. Retention of Personal Identifiers for Statistical Purposes. Internal policy. Last accessed 09 October 2020.

Australian Bureau of Statistics. 2018. Independent Privacy Impact Assessment (PIA) on the National Health Survey (NHS) Linkage Project. https://www.abs.gov.au/websitedbs/d3310114.nsf/0/9099c77cb979d558ca258198001b27a0/\$FILE/Linkage%20of%20National%20Health%20Survey%20with%20MADIP.pdf Last accessed 09 October 2020.

Australian Bureau of Statistics. 2019. Privacy Impact Assessment (PIA) Update for the Multi-Agency Data Integration Project (MADIP). https://www.abs.gov.au/websitedbs/d3310114.nsf/0/9099c77cb979d558ca258198001b27a0/5FILE/2019%20MADIP%20PIA%20Update%20-%20PIA%20Report.pdf Last accessed 09 October 2020.

Australian Bureau of Statistics. 2020. Privacy Impact Assessment – Summary Jobs Related Data Integration Project. https://www.abs.gov.au/websitedbs/d3310114.nsf/0/9099c77cb979d558ca258198001b27a0/\$FILE/Jobs%20re-lated%20data%20integration%20project%20-%20PIA%20Summary.pdf Last accessed 09 October 2020.

Biddle, Nick et al. 2019. Public attitudes towards data governance in Australia. https://csrm.cass.anu.edu.au/research/public-attitudes-towards-data-governance-australia-0 Last accessed 09 October 2020.

Department of the Prime Minister and Cabinet. 2019. Data Sharing and Release Legislative Reforms discussion paper. https://www.datacommissioner.gov.au/resources/discussion-paper Last accessed 09 October 2020.

Frazer, Ian. 2019. Better access to public sector data critical to health and medical science. https://www.datacommissioner.gov.au/media-hub/better-access-public-sector-data-critical

Galexia and Department of the Prime Minister and Cabinet. 2019. Galexia Privacy Impact Assessment on the Proposed Data Sharing and Release (DS&R) Bill and Related Regulatory Framework. https://www.datacommissioner.gov.au/sites/default/files/2019-09/PIA Proposed%20DS%26R%20Framework 2019June.pdf Last accessed October 2020.

National Health and Medical Research Council. National Statement on Ethical Conduct in Human Research (2007) - Updated 2015. https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research#toc 1 Last accessed 09 October 2020.

Productivity Commission. 2019. The Social and Economic Benefits of Improving Mental Health. https://www.pc.gov.au/inquiries/completed/mental-health/issues Last accessed 09 October 2020.

Stanley F. Privacy or public good? Why not obtaining consent may be best practice. *Significance* 2010 May 18;7(2):72-75. https://www.pc.gov.au/ data/assets/pdf file/0014/200903/sub005-data-access-attachment1.pdf. Last accessed 09 October 2020.

APPENDIX B: STAKEHOLDERS CONSULTED FOR THE PIA

- Aboriginal and Torres Strait Islander Lived Experience Centre, Black Dog Institute
- Consumers Health Forum of Australia
- Department of Health
- Department of Social Services
- Federation of Ethnic Communities' Councils of Australia
- Lived Experience Australia
- Mental Health Australia
- National LGBTI Health Alliance
- National Mental Health Commission
- National Mental Health Consumer and Carer Forum
- National Study of Mental Health and Wellbeing Reference Group [comprised of experts in mental and related health statistics, consumer and carer representation, and advisory bodies relating to mental health, wellbeing and suicide prevention]
- Office of the Australian Information Commissioner
- Office of the National Data Commissioner
- Productivity Commission
- Roses in the Ocean
- Services Australia