



## PERSON LEVEL **INTEGRATED DATA** ASSET

# RESPONSE TO 2024 EXPANDED HEALTH DATA LINKAGE PRIVACY IMPACT ASSESSMENT

## Background

The Person-Level Integrated Data Asset (PLIDA), is a secure, person-based, research data asset that combines broad sets of information about Australian citizens, to facilitate the use and re-use of public data for research purposes.

The PLIDA Board<sup>1</sup> is responsible for the strategic direction and oversight of PLIDA and its members represent the cross-portfolio government partnership of seven Commonwealth agencies enabling PLIDA. The Australian Bureau of Statistics (ABS) is the Accredited Integrating Authority for PLIDA responsible for collecting and combining data, providing access to authorised researchers, protecting privacy, and keeping information secure.

The ABS engaged independent privacy consultant Maddocks to conduct a Privacy Impact Assessment (PIA) to assess the privacy impacts of linking Expanded Health Data<sup>2</sup> to PLIDA. PLIDA includes several enduring datasets about the health of Australians, such as the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme, from Commonwealth government agencies. The PIA covers expanded linkage of Health Data, including those maintained by Commonwealth, State, and Territory governments, and not-for-profit organisations (NFP), to PLIDA. The PIA was informed by three case study projects from the Cancer Alliance Queensland, Cancer Council Victoria, and the Cancer Institute New South Wales to broadly consider proposed uses of Health Data (including cancer registry and hospital data) with PLIDA.

The ABS with support from Maddocks consulted with a broad range of stakeholders to inform this PIA between October and November 2023. Maddocks produced the PIA report with recommendations informed by the outcomes from the consultation sessions. Maddocks made one recommendation to improve compliance with the [Australian Privacy Principles \(APPs\)](#) and three recommendations to ensure best privacy practice in PLIDA.

The PIA report, Consultation Report and this response can be accessed on the ABS website: [Privacy Impact Assessments | Australian Bureau of Statistics \(abs.gov.au\)](#)

The PLIDA Board welcomes the findings of the PIA which recognises the Board and the ABS' commitment to upholding the privacy, confidentiality, and security of information in PLIDA and the robust protections currently in place. The PLIDA Board agrees with the recommendations in the PIA and this document outlines the PLIDA Board's response to the recommendations.

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<sup>1</sup> The PLIDA Board member agencies are the Australian Bureau of Statistics, Australian Taxation Office, Department of Education, Department of Health and Aged Care, Department of Home Affairs, Department of Social Services and Services Australia.

<sup>2</sup> Health data includes the following types: administrative health data, patient health and disease data, health survey data, ambulance and patient transport data, emergency department and outpatient data and hospital data.



## PERSON LEVEL **INTEGRATED DATA ASSET**

### **Response to Recommendation**

#### **Recommendation 1: Addressing Re-identification Risk**

##### **Recommendation 1**

That the ABS build into its PLIDA arrangements a standard process for the ABS Disclosure Review Committee (or another body) to review the strategies used to address re-identification risks for PLIDA from a holistic perspective.

##### **Response**

Agreed.

The PLIDA Board notes that there are a range of existing processes in place to manage the risk of re-identification including through the implementation of the Five Safes Framework, which is used to support safe and effective access to microdata for authorised users in the ABS DataLab.

The PLIDA Board and the ABS are committed to ensuring the risks of re-identification of PLIDA data remain low. The ABS agreed to implement an internal review process to assess the existing strategies used to address re-identification risks for PLIDA. The ABS will complete this re-identification review process within the next 12 months and subsequent reviews will be triggered where any new or significant health data assets are identified for integration. The ABS will seek input from data custodians as needed throughout the process. This process will ensure the ABS continues to follow best practice management of re-identification risks.

Timing – 12 months (end April 2025)

### **Response to Best Practice Recommendations**

#### **Recommendation 2: Justifying inclusion of Health Data into PLIDA**

##### **Recommendation 2**

While the overarching criteria for including datasets into PLIDA is being developed by the ABS and PLIDA Board, the ABS should for Expanded Health Data Linkage (potentially using the data to be received from Cancer Registries as a test case):

- document the process for considering the Minimum Criteria for each dataset that contains Health Data to be included in PLIDA;
- record the basis for reaching the conclusion that the public benefit factors for including a dataset outweighs the risks of including a dataset; and
- continue to ensure that any data sharing agreement (DSA) between the ABS and relevant Data Custodian for inclusion of a dataset containing Health Data should record the public benefit factors (see also Recommendation 4)

##### **Response**

Agreed.



## PERSON LEVEL **INTEGRATED DATA ASSET**

The PLIDA Board is responsible for the strategic direction and oversight of PLIDA, and regularly considers priorities for expansion of the PLIDA asset and how it can be accessed and used.

The PLIDA Board endorsed the ‘Principles for Considering New Datasets and Data Types in PLIDA’ (the Principles) in April 2024. The ABS developed the Principles in response to Recommendation 2 from the 2022 MADIP PIA Update. The final Principles will be published on the ABS website and embedded in the ABS data integration process to help assess inclusion of new Health Data with PLIDA.

The ABS remains committed to ensuring the broad uses of data, and any restrictions on use, are documented in DSAs between data custodians and the ABS. The ABS will continue to work with data custodians to ensure public benefit factors are documented in DSAs for linking Health Data with PLIDA.

Timing – 3 months (end July 2024)

### **Recommendation 3: Ethics Approval Requirements**

#### **Recommendation 3**

The ABS consider further strengthening the ethics approval arrangements for PLIDA by developing a PLIDA Ethics Framework to provide a systematic process for considering the ethical use of PLIDA datasets containing Health Data, to assist researchers and stakeholders understand the potential ethical issues.

#### **Response**

Agreed.

The PLIDA Board and ABS agree that a PLIDA Ethics Framework will help to standardise decisions about data use and transparency and will build upon existing governance requirements for PLIDA data.

The ABS agrees to develop the framework for the use of PLIDA datasets, including those containing Health Data. The PLIDA Ethics Framework will be published on the ABS website to ensure transparency and build trust with the community.

Timing – 12 months (end April 2025)

### **Recommendation 4: Assurance processes in relation to the linkage of Health Data to PLIDA**

#### **Recommendation 4A**

That any DSA, or governance arrangement, in respect of any pre-integrated data to be linked to PLIDA clearly specifies which entity (or entities) will be the Data Custodian of the relevant data under the PLIDA governance framework, and therefore responsible for assuring that the data is able to be linked to PLIDA and for approving research projects using that data. The agreed Data Custodian could be the original entity or entities who provided the data to the integrating body (such as the AIHW, which will then supply the data to the ABS for PLIDA), or the integrating body itself because of the arrangements between that body and originally supplying entity.

#### **Response**

Agreed.



## PERSON LEVEL **INTEGRATED DATA** ASSET

The PLIDA Board notes that existing ABS DSAs outline the legislative authority under which data custodians are permitted to share data with the ABS for data integration projects. The ABS agrees to continue to work with data custodians to confirm legislative requirements and governance arrangements for on-supply of pre-integrated data to the ABS. The ABS will ensure that any future DSAs will specify the data custodian of pre-integrated data to be linked with PLIDA.

Timing – 3 months (end July 2024)

### **Recommendation 4B**

That any DSA covering pre-integrated data set out how any data breaches will be managed, including the role of Data Custodians in the data breach management process (for example, clearing communications).

### **Response**

Agreed.

The PLIDA Board notes that existing data sharing agreements outline the ABS' approach for handling data. This includes detail about the ABS' approach to mitigate the risk of a notifiable data breach. The ABS agrees to continue to ensure future DSAs include additional information about the role of data custodians in the data breach management process for pre-integrated data.

Timing – 3 months (end July 2024)

### **Recommendation 4C**

That any DSA with a data custodian about the integration of a dataset containing Health Data into PLIDA includes written assurances from the Head of the Agency, or other senior personnel of the Data Custodian, such as the Chief Data Officer, that:

- the data custodian is legally able to disclose the Health Data to the ABS for inclusion in PLIDA (e.g., because the individual consented to that disclosure at the time of collection; or because of specified legislative provisions which authorise the disclosure);
- use by the ABS of the Health Data in accordance with the DSA (if ABS complies with any restrictions set out in the DSA) will not breach any applicable legislation in the Data Custodian's jurisdiction.

The basis on which these assurances are made should also be documented in the DSA (for example, that the Health Data is collected/disclosed under XYZ Act 2024 (NSW)).

### **Response**

Agreed.

The PLIDA Board notes that existing ABS DSAs outline the legislative authority under which data custodians are permitted to share data with the ABS for data integration projects. The ABS agrees to continue to work with data custodians to update the data sharing agreements to include information about the ABS' use of Health Data in relation to jurisdictional legislation.

Timing – 3 months (end July 2024)