Maddocks

Australian Bureau of Statistics

Expanded Health Data Linkage to the Personal Level Integrated Data Asset

Consultation Report

17 April 2024

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Part A Overview

1. Introduction

1.1 The Australian Bureau of Statistics (**ABS**) engaged Maddocks to conduct an independent privacy impact assessment (**PIA**) in relation to proposals to integrate additional datasets containing particular types of health data (**Health Data**, described in more detail in **Attachment 1**), into the Personal Level Integrated Data Asset (**PLIDA**).

1.2 PLIDA is a secure research data asset used by authorised researchers for approved projects in a secure, virtual access environment, which presents benefits for Australian agencies, other researchers, and ultimately the Australian public. The expanded linkage of health datasets to PLIDA would provide a more complete picture of the programs and services used by Australians accessing healthcare services across the country. This information would be used for research and policy development initiatives and evaluation of health programs with an aim to help improve the lives and health outcomes of all Australians.

1.3 PLIDA already includes a range of datasets about the health of Australians, including datasets which are retained on an enduring basis so that they are available for analysis by authorised researchers in accordance with the PLIDA governance arrangements. This PIA will explore the sharing, integration and use of some new types of Health Data into PLIDA on an enduring basis, against the Australian Privacy Principles set out in the *Privacy Act 1988* (Cth). Where appropriate, the PIA will identify any privacy risks and provide best practice recommendations that seek to minimise any potential privacy impacts.

1.4 To assist with considering the privacy impacts of the proposed linkages, the PIA will draw upon case studies from the following organisations for the potential integration of Health Data into PLIDA:

1.4.1 Cancer Institute New South Wales;

1.4.2 Cancer Alliance Queensland; and

1.4.3 Cancer Council Victoria.

1.5 The PIA is not limited to these case studies, but will be a broader privacy assessment of all new types of Health Data included in PLIDA.

1.6 Throughout October and November 2023, the ABS conducted an extensive consultation process with stakeholders and members of the community.

1.7 This Consultation Report provides a summary of the feedback and concerns raised in the consultation sessions held with stakeholders. The consultations will inform the privacy risk analysis and recommendations for the PIA being conducted by Maddocks.

2. Approach to stakeholder consultations

2.1 The objectives of the consultation processes were to:

2.1.1 invite stakeholder feedback and insights in relation to current processes for integrating Health Data;

2.1.2 inform stakeholders about PLIDA, including its current privacy practices and protections; and

2.1.3 listen to issues and concerns stakeholders may have about the expanded Health Data linkage to PLIDA and the privacy arrangements for the future use of Health Data in PLIDA.

2.2 The stakeholders consulted included university academics, government officials, the Office of the Australian Information Commissioner and its State and Territory regulator counterparts, data custodians from States and Territories, health representative organisations, and members of the medical community. **Attachment 2** at the end of this report sets out the full list of stakeholder organisations that participated in the consultations.

2.3 Stakeholders were invited to participate in consultation sessions based on their:

2.3.1 health or health data expertise;

2.3.2 involvement in current, or prior Australian Government data integration activities and projects;

2.3.3 special interest or expertise, such as advocating for medical research and advancements, or about privacy and data; and

2.3.4 representation of a key sector of Australian society that is likely to be impacted by PLIDA and its outputs; such as Aboriginal and/or Torres Strait Islander Australians.

2.4 Whilst stakeholders had the opportunity to raise any concerns they had during the consultation sessions, the sessions particularly sought to identify and discuss stakeholder views on the following topics:

2.4.1 the governance, oversight, transparency and security protections that will apply to Health Data integration and the administration of PLIDA;

2.4.2 the authority under which data custodians (including government entities) would provide Health Data to PLIDA, and the on-sharing of de-identified data under data-sharing agreements;

2.4.3 the protections in place, or proposed to address the risk of re-identification of individuals considering the often highly sensitive nature of health information;

2.4.4 the data retention and destruction policies for information collected in PLIDA;

2.4.5 the permissible uses of Health Data in PLIDA, and the controlled access to that data; and

2.4.6 the outputs and outcomes that may be derived from the expanded Health Data linkage into PLIDA.

2.5 The consultation sessions were conducted virtually in 5 sessions of up to two hours each with different stakeholder groups. Participants were provided with information about the Health Data, and how it would be handled in connection with PLIDA, at least one week in advance of each session. The sessions were run by the ABS and supported by Maddocks.

2.6 Consultation sessions were split into four parts, covering an overview of PLIDA and the underlying infrastructure, how data is kept safe, ethics and specific privacy considerations. At the conclusion of each part, stakeholders were invited to ask questions and provide feedback on what had been discussed. Questions were also encouraged throughout each session. Participants were also invited to provide any further written feedback about the project in the 2 week period following the session. All such feedback received was provided to Maddocks by the ABS.

2.7 In addition, this consultation report reflects feedback received by ABS from the AIHW's Advisory Council for the National Integrated Health Services Information (**NIHSI**) which is being rebranded in 2024 as the National Health Data Hub (**NHDH**)[1].

[1] This Consultation Report refers to NIHSI, as it was known at the time of the relevant consultation sessions.

Part B Summary of stakeholder feedback

3. Introduction

3.1 This Part sets out a thematic summary of the views, opinions and key discussion points expressed by stakeholders throughout the consultation process.

3.2 Maddocks has prepared this summary without attributing any particular opinion to any individual or stakeholder. However, some comments have been attributed to the type of stakeholder who provided the view (e.g. a Government entity), to provide context.

3.3 Responses that the ABS provided during the consultations are also included below as "ABS comment at consultation session". However, where the ABS simply noted the relevant concern but did not provide any further information, explanation, or indication of future approach, we did not include any "ABS comment at consultation session".

3.4 The aim of the consultations was to understand stakeholder views on the purpose and potential benefits of expanded Health Data linkage to PLIDA, as well as to highlight any areas of concern amongst the stakeholders. These concerns could then be considered and addressed in the PIA report.

3.5 The summary of stakeholder feedback below details key issues that were raised during the consultation sessions.

4. Expanded Health Data Linkage

4.1 During the consultation sessions the stakeholders were told what types of data is currently being considered to be "in" and "out" of scope for the PIA (see **Attachment 1**). The ABS explained that any future proposals to integrate a dataset containing data which was "out of scope" would require further privacy consideration.

Topic 1: In Scope Health Data

4.2 Most stakeholders were cautiously supportive of including Health Data within PLIDA, and indicated that they could see the potential value that could be derived from research that could be undertaken using Health Data linked with a wider range of demographic, economic, education and program data.

4.3 Stakeholders also generally understood the intended scope of the types of Health Data that would be covered by the PIA. They did not raise any significant privacy concerns about any of the intended scope, but there was some discussion about categorisation and clarification about what some categories of Health Data entailed. In particular, some stakeholders queried whether "hospital data" included information about children and young adults who were legally still minors.

4.4 ***ABS comment at Consultation Session:*** *The ABS explained that health information that has already been collected by governments (also known as administrative data) would be in scope for inclusion in PLIDA. The ABS also confirmed that the data in scope would include information about children and minors which is consistent with existing data in PLIDA, which contains information about these population groups.*

4.5 Separately, some stakeholders suggested that data from radiotherapy centres should be able to be integrated into PLIDA. This is because radiation and oncology data is often collected and held separately to other data. There was discussion between stakeholders in relation to whether radiotherapy would fit into the "hospitals" or "patient health" category. Some stakeholders believed that categorisation into the hospital category would be inappropriate considering 90-95% of radiotherapy is delivered in a non-admitted setting and, by private providers, including in standalone facilities that are not linked to hospitals.

4.6 ***ABS comment at Consultation Session:*** *The ABS noted that the types of Health Data in scope of the PIA are not mutually exclusive, and some data may span multiple categories. The ABS confirmed that radiotherapy data will be included in the scope of the PIA as part of the 'patient health and disease' category provided to the ABS from government bodies (state, territory and commonwealth) and/or not-for profit organisations.*

4.7 Stakeholders questioned whether data collected by Aboriginal Community Controlled Health Organisations (ACCHOs) was in scope.

4.8 ***ABS comment at Consultation Session:*** *The ABS noted that the scope of the PIA only includes Health Data provided to PLIDA by government bodies (State, Territory and Commonwealth) and not-for-profit data custodians. The ABS noted that further privacy analysis would need to take place to consider datasets not in scope of the PIA.*

Topic 2: Datasets not in scope

4.9 Stakeholders queried whether the in scope and out of scope categorisation of "primary care", as well as "patient health and disease", in **Attachment 1** was sufficiently clear. Stakeholders also questioned the consent arrangements for primary care data especially in the case where de-identified data is collected from a provider, company or private health insurer's software or servers.

4.10 Stakeholders expressed particular concern in relation to the disclosure of data collected by General Practitioners, especially if a patient is not informed about how their data will be used. Stakeholders flagged incoming independent research and community consultation on this point.

4.11 ***ABS comment at Consultation Session:*** *The ABS noted the difference between administrative data about health which is already collected and held by governments (which is in scope) compared to data held by treating practitioners as part of the provision of health care (which is not in scope). The ABS acknowledged the potential for some scenarios whereby Health Data may be collected by a health service provider and then provided to a government body as part of an administrative data collection. The data collected by the government body would be in scope as Health Data that could be provided to the ABS for PLIDA. The ABS also acknowledged that the PIA will not consider any data provided directly to the ABS from health service providers.*

The ABS also acknowledged the concern around linking data to PLIDA initially collected by General Practitioners, including about the origins of particular data sets (for example, free form data obtained from doctors' records). The ABS clarified that data from General Practitioners is not in scope other than where:

4.11.1 *it is already collected and held by a government entity for an administrative purpose, or a not-for-profit organisation (such as a cancer registry) – that is, the PIA will not consider inclusion of any datasets received directly from General Practitioners or other treating practitioners; and*

4.11.2 *the data custodian has confirmed that the data can be included in PLIDA under relevant Commonwealth, State or Territory laws.*

4.12 Stakeholders expressed interest in the process for determining whether particular data will be deemed to be in or out of scope. This interest was related to concerns about the use of information collected during health emergencies, particularly the covid-19 pandemic. Stakeholders sought clarification around how consent is provided for datasets included in PLIDA.

4.13 ***ABS comment at Consultation Session:*** *The ABS provided details on its legislative authority to collect data and also emphasised that it is the responsibility of the data custodian to ensure that all data provided to the ABS for linkage to PLIDA has an appropriate basis (such as legislative authority or consent) for that data to be included in PLIDA (either by consent or another legislative basis).*

4.14 Stakeholders also questioned whether data that includes genetic information, which has acquired consent to be linked to PLIDA, would be considered in scope.

4.15 ***ABS comment at Consultation Session:*** *The ABS clarified that any genetic information including full genome mapping is not within the scope of this PIA and would require further privacy consideration for any proposal to link this type of data to PLIDA. The PIA does consider patient health and disease data, which may include outcomes of medical tests, biomedical markers and genetic testing for diagnosis of diseases or conditions.*

Topic 3: Relationship with other Government Databases

4.16 Stakeholders were interested in understanding the various existing integrated data sets, their data collection processes, and their compatibility with PLIDA, including whether they would operate in parallel. Some of the concerns raised were in relation to the:

4.16.1 National Disability Data Asset (NDDA);

4.16.2 NIHSI;

4.16.3 Admitted Patient Database;

4.16.4 National Hospital Morbidity Database; and

4.16.5 National Non-Admitted Patient Emergency Department Care Database.

4.17 Stakeholders were particularly interested in how data from these assets is currently shared with the ABS.

4.18 ***ABS comment at Consultation Session:*** *The ABS acknowledged that mechanisms to receive Health Data from AIHW have not been confirmed. The ABS is currently working in collaboration with AIHW to consider options for integrating Health Data into PLIDA through the NIHSI data asset. Under this arrangement, AIHW is likely to manage some of the governance arrangements under the potential pathway for Health Data in the NIHSI into PLIDA. The ABS recognised that governance arrangements will need to maximise data use, whilst managing privacy considerations.*

4.19 The ABS also noted the work being undertaken in relation to the NDDA and confirmed that the PIA will not consider use of the NDDA data in PLIDA.

4.20 Stakeholders expressed concern in relation to the ABS managing Health Data, compared to the AIHW's management under the obligations in the *Australian Institute of Health and Welfare Act 1987* (Cth).

4.21 ***ABS comment at Consultation Session:*** *The ABS explained that data would be collected by the ABS under the Census and Statistics Act 1905 (Cth), which also contains strong protections for the handling of data. The ABS also noted that once Health Data is linked to PLIDA, it is de-identified so that no individual can be identified from the information and cannot be released in a manner that may identify an individual. A governance arrangement will be needed to facilitate any arrangements with AIHW about the provision of Health Data it holds for linking into PLIDA. Data custodians will retain control over the approvals to use integrated health data.*

4.22 Stakeholders questioned whether Health Data received from other entities would be raw data or data that has been cleaned (and therefore manipulated) by the data custodian. Stakeholders expressed concern that this may impact the future use and assumptions made in relation to the data.

4.23 Stemming from this broader discussion, stakeholders noted the challenge of explaining data transferal and consent processes to members of the community who the data is about, particularly where a project requires authorisation from the data custodian or States and Territories.

4.24 ***ABS comment at Consultation Session:*** *The ABS recognised that decision-making processes concerning data integration and how data will be use must be explained to members of the public. The ABS recognised the need to develop materials that clearly explain when and how decisions are made in relation to an individual's data.*

4.25 Stakeholders expressed a desire to avoid multiple data transferal processes or the sharing of identifiers with the ABS, and where possible to have spine to spine connections using existing linkages (like AIHW). Stakeholders suggested that this could ensure consistency across databases and minimise the administrative burden on smaller registries.

4.26 ***ABS comment at Consultation Session:*** *The ABS expressed a desire to use the most recent data and efficient process to link data, including utilising existing linkages and spines where possible.*

4.27 Stakeholders also commented on the need to consider issues that may arise with interactions between PLIDA and other government data assets, such as, NIHSI. For example, there is the potential increased burden in terms of ethics and governance approvals. Some stakeholders expressed the view for the potential need to consider the alignment between approval processes across government data sets.

Topic 4: Data Duplication

4.28 Stakeholders highlighted the value of storing data centrally to avoid producing copies of the data. There were concerns that Health Data transferred to multiple locations may compromise the quality and security of the data. Similarly, State and Territory stakeholders highlighted the value (and reduced privacy risk) of distributed networks and coordinated national models that avoid data custodians sharing data sets more times than they have to.

4.29 ***ABS comment at Consultation Session:*** *The ABS stated the intention to use existing ABS and AIHW data sharing processes in place whilst minimising the burden on data providers and ensuring that there is minimal duplication during the data collection process. The ABS acknowledged the need to have conversations with data custodians about how information is stored, and expressed an intention to use integrated data networks where they already exist.*

5. Transparency and consent

Topic 5: Obtaining Consent

5.1 Some stakeholders expressed concern about the unspoken "social licence" in PLIDA's data governance arrangements. Some stakeholders questioned whether adding data to PLIDA is moving too far away from the data custodian's original purpose for data collection and whether the necessary consents have been obtained for PLIDA's secondary use of the data.

5.2 Considering PLIDA's purpose, some stakeholders expressed a need for ongoing and dynamic consent to account for secondary uses of the data. Other stakeholders recognised that while consent of individuals were not needed for all datasets to be linked to PLIDA, it was important individuals be notified about how data will be used. Some stakeholders also suggested ensuring that there is a feedback loop to capture the concerns of individuals and data custodians. They added that individuals must also be able to understand the benefit of their information being included in PLIDA.

5.3 Some stakeholders noted that the sensitive nature of Health Data, as well as perceived privacy risks associated with PLIDA, may prevent data sharing, particularly in areas of great research value and interest.

5.4 Similar concerns were expressed in relation to the ability to clearly communicate PLIDA's function, the intended uses of the data, and the associated privacy risks to members of the public when seeking consent (if required).

5.5 ***ABS comment at Consultation Session:*** *ABS acknowledged the above and reiterated that there needs to be an appropriate basis (such as consent, consent waiver or other legislative authority) before data can be provided to the ABS for inclusion in PLIDA.*

The ABS also acknowledged the importance of being able to explain and assure the public that it has considered privacy protections through PLIDA's governance arrangements.

Topic 6: State and Territory Involvement

5.6 State and Territory stakeholders expressed an interest having a role in the data linkage process. Specifically, some State and Territories generally sought a high level of involvement in the approval of projects and the ability to ensure the original purpose for collection of the data is maintained.

5.7 ***ABS comment at Consultation Session:*** *ABS recognised that data custodians (including States and Territory entities) play an important role in the approval of projects. The ABS explained that all project proposals are provided to data custodian for approval as part of the ABS data integration process.*

5.8 Similarly, stakeholders suggested that consultation sessions should be expanded to include Population Based Cancer Registries (PBCR) from every jurisdiction, as well as the Manager of the Australian Cancer Database. Stakeholders suggested that the PIA should explore PBCR's more generally including their ownership expectations, legislative ability to share data and any associated conditions.

Topic 7: PLIDA Purpose

5.9 Some stakeholders suggested that it would be helpful to include an overview of the advantages of linking Health Data into PLIDA in the draft Project Description which was provided to stakeholders (or other publicly available materials about PLIDA).

5.10 Stakeholders expressed a desire for the ABS to provide further information about the types of data sets that will be linked to PLIDA and how these linkages differentiate from what is already available in other integrated data assets such as NIHSI and NDDA (once operational).

6. Use and disclosure of linked data

Topic 8: Disclosure

6.1 Stakeholders expressed concern in relation to research access to Health Data, once it has been linked to PLIDA. Some stakeholders felt that data custodians would be relinquishing control of the data through the disclosure process.

6.2 ***ABS comment at Consultation Session:*** *The ABS explained that all project proposals are provided to data custodians for approval as part of the PLIDA processes. The ABS also described the* operation *of the data minimisation principle, under which the ABS only provides researchers with access to PLIDA data modules, which are required for the particular approved project (this is considered on a case-by-case basis at the project approval stage).*

6.3 In addition, stakeholders questioned the mechanisms in place for checking data before it is publicly released. Stakeholders expressed concerns in relation to the potential misinterpretation or inappropriate statistical approach to the data by researchers after ethics approval has been granted.

6.4 As a solution some stakeholders suggested that data custodians should have a "veto power" that can stop misguided research from being published. However, many stakeholders also recognised that these issues could be addressed on a case-by-case basis through agreement with researchers, before the projects are commenced.

6.5 ***ABS comment at Consultation Session:*** *The ABS acknowledged these challenges, and noted that data custodians carefully review the proposed use of PLIDA data at the project proposal stage, including consideration of what is trying to be achieved, the various datasets proposed to be used and dataset quality. Data custodians typically request researchers provide them with advance copies of their research for review two weeks prior to publication so custodians can raise issues of concern for consideration.*

6.6 Stakeholders questioned the possibility of being able to directly upload data onto the DataLab for approved projects.

6.7 ***ABS comment at Consultation Session:*** *The ABS explained that it manages disclosure risk by applying the Five Safes framework to support safe and effective access to microdata for authorised researcher use. For this reason, data custodians cannot upload data directly into the DataLab.*

6.8 Stakeholders sought further information about the accessibility of Health Data (within PLIDA) by community health research organisations. Currently, community organisations are required to partner with universities or academics to access data held in PLIDA.

Topic 9: 'Enduring' or 'one-off' data linkages

6.9 Stakeholders expressed interest in the consideration behind whether Health Data would be linked on an enduring basis, or only stored and linked for a particular approved project (also known as a 'one-off' linkage). Stakeholders questioned whether data received by the ABS for a particular approved project could then be used in another project undertaken by the same researcher.

6.10 Further, stakeholders sought confirmation and clarification that data custodians could agree to have their Health Data within PLIDA on a strictly defined and limited basis and that only people approved by that custodian could access the data.

6.11 Stakeholders also suggested that the PIA should clarify that the purpose for the linkage of expanded Health Data is to create enduring linkages rather to facilitate one-off linkage for specific projects.

6.12 ***ABS comment at Consultation Session:*** *The ABS clarified that data can be included in PLIDA on an enduring basis (where the dataset is retained within PLIDA and updated with new data provided by the data custodian over time), or data that can be included in PLIDA on a 'one-off' basis (usually for a specific project, where the data is not updated over time).*

The ABS confirmed that the PIA will consider Health Data being provided on an enduring basis.

For both enduring and one-off data sets in PLIDA:

6.12.1 *researchers are only able to access data if a particular project has been approved by the relevant data custodian(s) (each project requires separate approval); and*

6.12.2 *when providing data to the ABS for PLIDA, and when considering particular research projects, data custodians can impose restrictions on how that data can be used or governance measures that must be followed. For example, only one-off linkages would be undertaken if a data custodian indicated that this is the limit of what is permitted (for example, because of legislative restrictions governing the use and disclosure of the Health Data). The ABS is required to comply with data custodian requirements under its data sharing agreement with the data custodian(s).*

6.13 Stakeholders expressed a desire to avoid a situation where the ABS gives approval for a research project involving Health Data before the data custodian has given approval.

ABS comment at Consultation Session: *The ABS confirmed that Health Data in PLIDA would only be made available where it has been approved or otherwise allowed by the data custodian.*

Topic 10: Outcomes from Data Use

6.14 Although stakeholders generally indicated that they could see the potential value of research that could be facilitated by integration of Health Data with other PLIDA data, some stakeholders expressed concerns about potential research outcomes.

6.15 For example, some stakeholders noted that Health Data may include data about persons with a disability, and that care needed to be taken in categorising and referring to such data in the disability context. They noted the negative connotations surrounding disabilities that can be propagated through research using Health Data.

6.16 One stakeholder noted the difference between feeling safe that data will be kept secure, and feeling safe that the story being told by researchers about that data will be done responsibly.

6.17 This discourse is reflective of wider conversations about upholding the central purpose of the initial data collection, and the view of some stakeholders that there is a need to ensure that Health Data is used for the benefit of the people that it is about (see also Topic 5 above and Topics 14 and 15 below).

6.18 ***ABS comment at Consultation Session:*** *The ABS described the processes in place to ensure that research projects using PLIDA data are considered by data custodians. These include application of the Five Safes principles, one of which is 'Safe Outcomes'. This means that issues such as those raised can be considered by data custodians at the research project proposal stage.*

Topic 11: Re-identification risk

6.19 Stakeholders acknowledged the increased amount of information currently in the public domain and the difficulty associated with controlling the risk of re-identification from Health Data, particularly in smaller jurisdictions and/or relation to vulnerable communities. Stakeholders encouraged the PIA to consider how the risk of re-identification can be appropriately mitigated to ensure that there is no reasonable likelihood of re-identification. Further, it was suggested that the PIA should also consider the gravity of harm that could arise from re-identification due to the sensitive nature of Health Data.

6.20 However, stakeholders suggested that without integration using PLIDA, further privacy issues could arise in relation to data sharing of Health Data. Notably, the current lack of a centralised and integrated system means Health Data is already being shared for particular research projects without adequate consideration of privacy risks. The systematic linkage and distribution of Health Data through PLIDA was viewed by these stakeholders as an opportunity to better manage these privacy risks.

6.21 Stakeholders also noted the increased privacy risks associated with times and dates typically included within Health Data. There was consensus amongst stakeholders that the NIHSI arrangements in relation to the use of dates are adequate and could be replicated with amendments to PLIDA.

6.22 ***ABS comment at Consultation Session:*** *The ABS informed stakeholders that PLIDA data is collected under the Census and Statistics Act 1905 (Cth) and that it cannot release information of a personal nature in a manner that is likely to enable the identification of that person. The ABS noted that researchers are also required to sign undertakings before using data in PLIDA. In addition, ABS manages disclosure risk through implementation of the Five Safes Framework, which is used to support safe and effective access to the microdata for authorised users, in the ABS DataLab, The risk of re-identification is mitigated by ABS' control over the DataLab, particularly through the process of checking research outputs before they can be released from the DataLab. As part of the Five Safes assessment, the ABS Disclosure Review Committee also considers the risk of re-identification and recommends steps to minimise disclosure risk.*

7. Governance and oversight arrangements

Topic 12: Data Ownership

7.1 Stakeholders sought general clarification in relation to the ownership arrangements of the data once it is integrated into PLIDA.

7.2 Stakeholders (particularly State and Territory data custodians) were aware of the legislative arrangements that govern the use and sharing of data.

7.3 ***ABS comment at Consultation Session:*** *The ABS noted that the data custodian will be responsible for sharing the information, including considering that any necessary privacy notices are in place and identifying the basis upon which they are permitted to provide the Health Data to the ABS for inclusion in PLIDA. The ABS emphasised the distinction between the responsibilities of the ABS and the data custodian. The ABS is responsible for the integration of the data and processing requests for use of that data in accordance with the PLIDA governance, but the data custodian maintains responsibility for whether, and if so how, the data can be used for those research projects.*

Topic 13: Composition of the PLIDA Board

7.4 Stakeholders observed that currently the PLIDA Board comprises only of Commonwealth agency nominees and suggested that the ABS establish another mechanism for engagement with data custodians.

7.5 ***ABS comment at Consultation Session:*** *The ABS confirmed this was correct but noted that the governance arrangements do mean that other stakeholders are involved in consideration of research projects (including data custodians and an ABS Centre of Aboriginal and Torres Strait Islander Statistics (**CoATSIS**) team), so that advice is obtained and any necessary restrictions or limitations can be implemented before use of PLIDA data.*

The ABS confirmed that it engages directly with all data custodians and has data sharing agreements with custodians covering all data shared for use in PLIDA.

8. Ethics

Topic 14: Mandatory Ethics Approval

8.1 There was a significant amount of stakeholder feedback in relation to the potential need for researchers to obtain ethics approval before accessing Health Data.

8.2 Stakeholders emphasised the importance of ethics approval as another means to reduce risk in relation to research projects. Some stakeholders were concerned that, currently, not all data projects require an ethics assessment and some, particularly non-academic projects, may be able to bypass any form of ethics approval.

8.3 Many stakeholders noted that it was their default standard to require an ethics approval for research projects, particularly in relation to use of data about Aboriginal and Torres Strait Islander peoples or vulnerable populations. However, exceptions included the use of aggregate data for policy development.

8.4 Stakeholders suggested that in addition to the ABS seeking and recording data custodian approval, it would be useful for the ABS to seek and retain a copy of the research protocols and methodologies that have been approved by ethics committees, because data custodians will need these to make appropriate decisions when deciding whether to grant approval.

8.5 ***ABS comment at Consultation Session:*** *The ABS agreed with the importance of obtaining (and retaining copies of) appropriate ethics approvals, particularly in relation to the use of hospital data. The ABS noted the possibility of requiring all projects involving Health Data to obtain ethics approval, not just projects involving handling of data about Aboriginal and Torres Strait Islander people (as is currently required). Alternatively, it may be appropriate for exemptions from ethics approval requirements for projects looking at systemic government program improvements or policy-based work. Currently data custodians are responsible for imposing any requirements for ethics approvals to be obtained and researchers are responsible for obtaining those ethics approvals.*

8.6 Stakeholders questioned whether ethics approval should and could be granted at the PLIDA system level as well as at the individual approved project level.

8.7 Simultaneously, stakeholders acknowledged the practicalities and administrative burden associated with obtaining ethics approval and suggested that this may have an adverse impact on smaller researchers and community organisations trying to access expanded Health Data within PLIDA. Other stakeholders noted that this burden could be mitigated by support and expedited processes for community groups wanting to undertake smaller pieces of research.

Topic 15: Data management and cultural competency

8.8 A dedicated consultation session was held to discuss the expanded use of Health Data with Aboriginal and Torres Strait Islander peoples.

8.9 Stakeholders at this session were particularly interested in PLIDA's research output-vetting process and questioned its interplay with management of data about Aboriginal and Torres Strait Islander people. In particular, they highlighted the need for input from Aboriginal and Torres Strait Islander people into any proposed approach.

8.10 ***ABS comment at Consultation Session:*** *The ABS noted that there are additional review processes in place for projects that seek to access sensitive information in PLIDA. When a researcher requests access to sensitive health information in PLIDA, the project proposal documents why this data is needed and how it will be used.*

The ABS CoATSIS team also undertake cultural safety assessments for proposals seeking access to Aboriginal and Torres Strait Islander data and recommend whether approval from a Human Research Ethics Committee (HREC) is required. The ABS CoATSIS team consider the proposed use of the data, whether there has been engagement with the community, and the risk of deficit narrative or harm to communities.

In addition, data custodians consider project proposals and determine whether ethics approval is required on a project-by-project basis.

Attachment 1 Health Data Types and Descriptions

Set out below is the description which was provided to stakeholders about data which is "in scope" for this PIA, and what is "out of scope" for this PIA.

Broad types of Health Data	Description and data items

1. Administrative Health Data	Includes information that is routinely collected by governments and non-government organisations as part of administering the delivery of health related services.
	
	Data items may include:
	• patient demographic information
	• medicare records (e.g., Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data)
	• vaccination status and coverage
	• health workforce data
	• prescriptions and medications
	• notifiable disease treatment records
	• public health management variables (e.g., health event such as COVID, infectious period, quarantine measures)
	
	Examples:
	• Australian Immunisation Register. Data items include vaccination coverage, immunisation provider and location, episode reason, vaccine product code, vaccination status. *[linked to PLIDA]*
	  ○ Data custodian: Department of Health and Aged Care
	• Medicare Benefits Schedule: Data items include medicare claims information, benefit paid, broad type of service, number of services claimed, referring provider ID, patient demographic information, and bulk billing information. *[linked to PLIDA]*
	  ○ Data custodian: Department of Health and Aged Care
	
	Primary care, community, and other health data provided to the ABS via government and not-for-profit organisations is in scope of the PIA, and would be considered administrative health data.

2. Patient health and disease data	Includes information in clinical information systems, registers and databases that record data for chronic conditions, illnesses, and diseases. This includes cancer registry data and infectious and communicable disease data. This also includes outcomes of medical tests, biomedical markers and genetic testing for diagnosis of diseases or conditions. Data items may include: • cancer incidence • type of cancer • diagnostic information • disease type • mortality and survival • notification to heath authority • patient demographic information

Broad types of Health Data	Description and data items

	Examples:
	• Victoria Cancer Registry. Data items include patient information, cancer type and incidence, diagnosis information including notifying hospital and mortality. *[dataset being considered as one of the case studies]*
	  ○ Data custodian: Victorian Department of Health
	
	• National Notifiable Diseases Surveillance System (NNDSS), supplied by state and territory health authorities to Department of Health and Aged Care. Data items include disease code, date of onset, date of notification to health authority and patient information *[not linked to PLIDA, provided as example]*
	  ○ Data custodian: Department of Health and Aged Care

3. Health survey data	Includes information collected by clinical questionnaires, surveys, and studies of population health undertaken by government and/or not-for-profit organisations.
	
	Data items may include:
	• Health status
	• Medications and prescriptions
	• Injuries
	• Long term health conditions
	• Income and private health insurance
	
	Examples:
	• National Health Survey. Data items include chronic conditions, mental and behavioural conditions, general health status and health risk factors*. [linked to PLIDA]*
	  ○ Data custodian: Australian Bureau of Statistics
	
	• South Australian Population Health Survey. Data items include information on participants overall health status, health service utilisation, chronic conditions, disability and carers, risk factors, food security, mental health, wellbeing and disadvantage and inequity. *[not linked to PLIDA, provided as example]*
	  ○ Data custodian: SA Health
	
	• Victorian Population Health Survey. Data items include mental health and wellbeing status, chronic diseases, dental health, lifestyle risk factors and social determinants of health. *[not linked to PLIDA, provided as example]*
	  ○ Data custodian: Victorian Agency for Health Information (VAHI)

Broad types of Health Data	Description and data items
4. Ambulance and patient transport data	Includes information collected as part of responding to and treating out-of-hospital medical emergencies, patient transport services to assist patients and their families to attend appointments and transfers between heath facilities. Data items may include: • patient demographics • emergency medical care and interventions • pain management • facility transferred to (e.g., travel time, response locations and treatment time) • event type Example: • NSW Ambulance Patient Health Care Record. Data items include clinical information, patient care episodes, facility transfers, arrival time and location. *[linked to PLIDA]* ○ Data custodian: NSW Ministry of Health
5. Emergency department and outpatient data	Includes information about patients registered for care in emergency departments and responding to and treating out-of-hospital medical emergencies. Data items may include: • clinical records for non-admitted and emergency patients • screening or monitoring information • crisis and general counselling information • intervention type • medications and prescription information • Laboratory and diagnostic test and procedures (including pathology, x-ray or other medical imaging examinations) • reason for attendance • pain management Example: • QLD Emergency Department Data Collection. Data items include patient waiting times, urgency of care, presentation date, and complexity of presentations, patients who go on to be admitted to hospital or who are discharged and demand for ED services. *[linked to PLIDA]* ○ Data custodian: Queensland Department of Health
6. Hospital data	Includes information about care provided to admitted and non-admitted patients, including acute and non-acute care and mental health services. Data items may include: • patient demographics and physical characteristics • hospital episodes (e.g., length of stay, waiting times for care, admission date) • clinical information (e.g., patient diagnosis, interventions, and procedures) • hospital charges and health insurance information

Broad types of Health Data	Description and data items
	• admission, waiting times and length of stay. • perinatal care (mothers and babies) • obstetric records related to artificial insemination and in-vitro fertilisation (excluding donor records) Example: • Adult Patient Database. Data items include patient episodes, hospital type, ICU outcome, illness severity, diagnosis, and patient information. *[linked to PLIDA]* ○ Data custodian: Australia and New Zealand Intensive Care Society
7. Primary care, community, and other health data	Includes information collected from general practitioners, pharmaceutical services, dentistry, allied health services, maternal and child health, alcohol and drug treatment and other health related services. Data items may include: • Treatment illness and injury and service type • Attendance at general practitioners and specialist services • Diagnostic imaging information (including blood test and x ray results) • Mental health records • Dental records • Drug, gambling, smoking and alcohol data • Medication and prescriptions Example: • Public Dental Waiting times database. Data items include dental treatment, clinical assessment, number of appointments, area and waiting times for dental assessment. [*not linked to PLIDA, provided as example]* ○ Data custodian: Australian Institute of Health and Welfare (AIHW)
8. Out of scope	Specific Health Data out of scope: • My Health Record data • Private health insurance data • Clinical trial data • Genetic data (except outcomes of medical tests, biomedical markers and genetic testing for diseases of diseases or conditions) • Primary care, community and other health data collected directly from the health services provider

Attachment 2 Stakeholders consulted for the 2023/24 Expanded Health Data Linkage to the Personal Level Integrated Data Asset PIA

The list below sets out the organisations and other bodies that attended the consultation sessions for the Expanded Health Data Linkage PIA:[2]

1. Australian Bureau of Statistics (ABS)
2. Australian Capital Territory Department of Health
3. Australian Institute of Health and Welfare (AIHW)
4. Barang Regional Alliance - Empowered Communities (EC)
5. Cancer Alliance Queensland
6. Cancer Council Victoria
7. Cancer Institute New South Wales (CINSW)
8. Centre for Big Data Research in Health University of NSW
9. Consumers Health Forum of Australia
10. Data Linkage Queensland
11. Department of Employment & Workplace Relations (DEWR)
12. Department of Health & Aged Care (DOHAC)
13. Department of Home Affairs (DoHA)
14. Department of Social Services (DSS)
15. Disability Advocacy Network Australia (DANA)
16. Empowered Communities (Independent) – Independent Social Alchemist
17. Families Australia
18. Grattan Institute
19. Inclusion Australia
20. Indigenous Data Network
21. Kimberley Aboriginal Medical Services (KAMS)
22. Mental Health Australia
23. Monash University
24. Northern Territory Cancer Registry
25. Northern Territory Department of Health
26. Northern Territory Office of the Information Commissioner
27. Office of the Australian Information Commissioner (OAIC)
28. Population Health Research Network (University of Western Australia)
29. QLD Health in Thursday Islands and QLD Peninsular communities
30. Safer Care Victoria
31. South Australian Department of Health
32. Tasmanian Data Linkage Unit
33. Tasmanian Department of Health
34. The Peter Doherty Institute for Infection and Immunity
35. University of Sydney
36. Victorian Agency for Health Information
37. Victorian Cancer Registry
38. Victorian Department of Health
39. Western Australian Department of Health

Several other organisations were invited to participate in the consultation sessions but were not able to attend.

[2] One or more individuals from the listed entities attended the consultation sessions, but views provided by those individuals may not necessarily have been representative of the views of their entity. Several other organisations and other bodies were also invited to participate in the consultation sessions but were not able to attend.