



Prepared for Department of Health, Disability and Ageing
20 August 2025

NCSR – Enduring Data Linkage Projects

Summary Privacy Impact Assessment

Department of Health, Disability and Ageing – PIA

NCSR – Enduring Data Linkage Projects

Executive Summary

1. The Department of Health, Disability and Ageing (**Department**) commissioned a Privacy Impact Assessment (**PIA**) to consider the privacy impacts of two enduring data linkage projects (**Projects**) which involve linking data held in the National Cancer Screening Register (**Register, NCSR data**) with:
 - 1.1. information in the Australian Bureau of Statistics' (**ABS**) Personal Level Integrated Data Asset¹ (**PLIDA Project**)
 - 1.2. information in the Australian Institute of Health and Welfare' (**AIHW**) National Health Data Hub² (**NHDH**) (among other things) (**NHDH Project**).
2. The Projects will create enduring data linkages to facilitate the provision of data and information across the cancer continuum and enable comprehensive person-level research and analysis in relation to lung, cervical and bowel cancer and screening. Once established, access to the de-identified integrated data will be available to both the Department and external researchers through data governance arrangements.

Scope of this PIA

3. The PIA considered a range of practical and operational issues, such as:
 - 3.1. compliance with the secrecy provisions in the *National Cancer Screening Register Act 2016* (**NCSR Act**) and the National Health and Medical Research Council Guidelines (**NHMRC Guidelines**) under s 95 of the *Privacy Act 1988* (**Privacy Act**).
 - 3.2. opportunities for minimisation of data sharing
 - 3.3. the adequacy of privacy notices and other communications
 - 3.4. opportunities to minimise re-identification risks as well as other security protections and safeguards.
4. We did not examine Australian Privacy Principles (**APP**) 2, 3, 4, 7, 8, 9, 12 or 13 which are unlikely to raise significant privacy issues in the context of the Projects.

Summary of findings

5. Each Project will involve new ways of handling personal information. AGS have assessed these activities for compliance with the Privacy Act, in particular the APPs.³
6. While the Project has the potential to impact on the privacy of individuals, it also represents an opportunity to improve and enable comprehensive research and analysis in relation to lung, cervical and bowel cancer and screening.
7. If the Department implements the 19 recommendations within this PIA, the privacy impacts of the Project will be reasonable, necessary and proportionate.

¹ Formerly known as the Multi-Agency Data Integration Project (**MADIP**).

² Formerly known as the National Integrated Health Services Information (**NIHSI**).

³ The Appendix contains a list of the APPs which this PIA does not examine in details.

Content of this summary report

8. Our report contains 4 parts:
 - 8.1. [Part 1](#): Background to the Projects
 - 8.2. [Part 2.1](#) and [Part 2.2](#): an overview of the information flows for the Projects
 - 8.3. [Part 3](#): a summary of the key issues
 - 8.4. [Part 4](#): Our recommendations.

Part 1 – Background

9. The Department will work with the ABS and the AIHW to link data from the Register with the PLIDA and NHDH respectively.
10. Each agency is an APP entity for the purposes of the Privacy Act and their information handling arrangements must comply with the APPs and relevant secrecy regimes.

The Register

11. The Register is a digital platform established under s 9 of the NCSR Act which currently supports the Australian Government's Screening Programs. Under the [Administrative Arrangement Order](#) made on 13 May 2025, the Department administers the Register on behalf of the Minister for Health, Disability and Ageing.
12. The Screening Programs are designed to encourage age-eligible individuals to screen regularly to facilitate the early detection and treatment of relevant cancers. The Register contains a record for each eligible person and provides a national electronic infrastructure for the collection, storage, analysis and reporting of screening program data.

PLIDA

13. PLIDA is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time to support government decision making and academic research.
14. The ABS is the Accredited Integrating Authority for PLIDA, collecting and combining datasets and providing access to authorised researchers. PLIDA includes administrative data shared with the ABS and ABS survey data.
15. Data Custodians can include data in PLIDA on an enduring or one-off basis (i.e. for a specific project using point in time data). Where Data Custodians include data on an enduring basis, the dataset is retained within PLIDA and updated with new data provided by the Data Custodian over time.

NHDH

16. The AIHW is a national agency established under the *Australian Institute of Health and Welfare Act 1987 (AIHW Act)* as an independent statutory body to collect and produce information and statistics on Australia's health and welfare. The AIHW produces authoritative and accessible information and statistics to inform and support better policy and service delivery decisions, leading to better health and wellbeing for all Australians.

17. The NHDH is a major national linked health data asset for health research and analysis. It comprises data on admitted patient care services (in public and private hospitals), emergency department services and outpatient services in public hospitals for all participating states and territories. The NHDH also includes Medicare Benefits Schedule (**MBS**) data; Pharmaceutical Benefits Scheme (**PBS**) data and Repatriation Pharmaceutical Benefits Scheme (**RPBS**) data; Residential Aged Care services data; National Death Index (**NDI**) data and Australian Immunisation Register (**AIR**) data.

Critical privacy issues

18. The Department obtained early advice from AGS about the critical privacy issues associated with the PLIDA and NHDH Projects. The advices were finalised on 11 February 2025 and made a total of 13 recommendations to address identified privacy issues.
19. The PIA built on those advices by proposing additional solutions to minimise or eradicate privacy impacts.

Part 2.1 – Information flows (PLIDA)

20. The Department will handle personal information as part of the following activities to link Register data with the ABS's PLIDA.

Activity	Description
Activity 1	NCSR service provider extracts relevant NCSR data
Activity 2	The Department upload NCSR data extract
Activity 3	ABS download NCSR data
Activity 4	ABS provide the Department with access to integrated 'de-identified' PLIDA products
Activity 5	ABS provide access to de-identified NCSR data to external researchers
Activity 6	Regular disclosure of NCSR data for enduring linkage

Table 1: Information flows (PLIDA Project)

Part 2.2 – Information flows (NHDH)

21. The Department will handle personal information as part of the following activities to link NCSR data with relevant data sets held by the AIHW.

Activity	Description
Activity 1	NCSR service provider send monthly raw data extract (RDE) to AIHW
Activity 2	AIHW extract subset of NCSR data from RDE
Activity 3	AIHW link NCSR data with relevant data sets
Activity 4	AIHW provide the Department with access to linked de-identified NCSR data
Activity 5	AIHW provide external researchers access to linked de-identified NCSR data
Activity 6	Ongoing use of RDE data for enduring linkage
Activity 7	Future linkage with ABS's PLIDA

Table 2: Information flows (NHDH Project)

Part 3 – Summary of Privacy Impacts

22. Following is a high-level summary of the privacy impacts of the Projects.

Public benefit vs privacy impact

23. The integration of NCSR data with data from other PLIDA datasets will enable the Department's Cancer Data Section to undertake analysis activities to understand engagement with the NCSR with the goal of improving screening participation.
24. Similarly, the NHDH Project will progressively link in scope NCSR data with proposed NHDH datasets with a view to creating an enduring data linkage that will support the provision of data and information across the cancer continuum and enable comprehensive person-level research and analysis in relation to lung, cervical and bowel cancer and screening.
25. Balanced against this, the Projects give rise to privacy impacts associated with the regular transfer of large amounts of personal information to the ABS and AIHW⁴, the handling of personal information for secondary purposes and reliance on de-identification to permit data linkage.
26. Having regard to the robust systems and policies implemented by the ABS and AIHW to manage re-identification risks and secure personal information, and the Department's commitment to implement the recommendations made in our earlier critical issues advices, the Department can minimise the privacy impacts associated with the Projects, and any impacts will be proportionate to the benefits to the Australian community.
27. As the Projects remain in the early stages of development and implementation, [Recommendation J1](#) suggests the Department:
- 27.1. seek legal advice or a supplementary PIA for future iterations of each Project involving new or changed ways of handling personal information
- 27.2. inform individuals about changes or updates to each Project which alter the handling of their personal information, including through the publication of this PIA or a summary version or edited copy ([Recommendation J2](#)).

APP 1 - Open and transparent handling of personal information

28. In our critical issues advices, we reviewed the NCSR Privacy Policy against both Projects and in both cases recommended that the Department update the NCSR Privacy Policy to better reflect the proposed information sharing arrangements, ensure compliance with APP 1.4(c), and improve overall transparency: see [Recommendation P4](#), [Recommendation N3](#).

APP 5 – Notice of collection

29. Our critical issues advices identified that each Project will involve a regular disclosure of NCSR data to the ABS (PLIDA) and AIHW (NHDH) for a new purpose. The Department will need to take reasonable steps to provide notice of this usual disclosure: APP 5.2(f).

⁴ For the NHDH Project, we note that this transfer already occurs via the pre-existing RDE arrangements.

30. We suggested that this can occur through progressive updates to public facing online and electronic materials, and printed privacy notices: see [Recommendation P5](#) and [Recommendation N4](#).

APP 6 – Use and disclosure of personal information

31. Each Project will involve the use and disclosure for a secondary purpose of NCSR data which is protected information and key information under the NCSR Act. Section 18 prohibits any activity which makes a record of, uses or discloses this information unless an exception in s 17 applies.
32. In our view, the Department's proposed disclosure of NCSR data for each Project is authorised under s 17(3)(a)(i) on the basis that it is for the purposes of the NCSR Act, specifically, research relating to healthcare, screening or a designated cancer: s 12(1)(n). In turn, this enlivens the authorisation in s 17(3)(f), enabling the ABS or AIHW to handle NCSR data for the purpose for which the Department disclosed the data under s 17(3)(a)(i).
33. To the extent the proposed activities occur consistently with ss 17(3)(a)(i) and 17(3)(f), this will engage the exception in APP 6.2(b), as the use and disclosure of personal information for a secondary purpose is authorised by an Australia law.
34. For the respective Projects, the Department should take steps to ensure it:
- 34.1. complies with the Guidelines made under s 95 of the Privacy Act, where necessary: [Recommendation P1](#) and [Recommendation N1](#)
 - 34.2. shares relevant and necessary data items only: [Recommendation P2](#) and [Recommendation N2](#)
 - 34.3. establishes a clear use case before sharing sensitive 'screening outcome' data: [Recommendation P3](#)
 - 34.4. remains alive to possible re-identification risks associated with external access requests and seek legal advice as needed: [Recommendation J3](#).

APP 10 – Data quality

35. Data transferred to the ABS (PLIDA) and the AIHW (NHDH) will be subject to the same data quality risks that exist within the Register. However, these data quality risks are minimised in two ways:
- 35.1. by data being relevantly categorised as 'point in time'
 - 35.2. by appropriately de-identifying the data so that it no longer comprises personal information for the purposes of the Privacy Act or protected information or key information for the purposes of the NCSR Act.
36. At present, we consider the proposed approach to transfer full data sets rather than new or updated information (deltas) will have the lowest privacy impact. However, we recommend the Department explore a delta approach in future: [Recommendation P7](#).

APP 11 – Security of personal information

37. To the extent the Projects will involve new information handling processes, including:
- 37.1. preparation of the NCSR extract for PLIDA

- 37.2. access to and use of the dashboard (once implemented)
- the Department should ensure staff receive appropriate training with respect to handling personal and protected information: [Recommendation J4](#).
38. In relation to access to linked data, both the ABS and AIHW apply mature access security mechanisms to protect personal information, including to manage re-identification risks when providing access to external researchers.
39. To manage the risk of re-identification by Department staff of integrated PLIDA and NHDH data, we suggest the Department:
- 39.1. enquire with the ABS if it can develop PLIDA projects for the Department containing aggregate level data only: [Recommendation P8](#)
- 39.2. limit access to unit-level data in the NHDH: [Recommendation N5](#)
- 39.3. obtain staff agreement to not re-identify data: [Recommendation J5](#).
40. Additionally, we suggest the Department consult with the ABS and AIHW to devise a clear procedure for responding to actual or suspected data breaches involving NCSR data: [Recommendation J6](#).
41. Lastly, the Department should take steps to delete the NCSR data extract once securely transferred to the ABS: [Recommendation P6](#).

Conclusion

42. If the Department implements the 19 recommendations within this PIA, the privacy impacts of the Project will be reasonable, necessary and proportionate.

Part 4 - Recommendations

This section summarises the recommendations from our Critical Issues Advices and the further recommendations made in this PIA, indicating the nature of the risk using the flags below. Recommendations from our PLIDA critical issues advice are labelled **P#** and shaded in **green**. Recommendations from our NHDH critical issues advice are labelled **N#** and shaded in **blue**. Recommendations from the joint PIA are labelled **J#** and shaded in **purple**.

	Compliance risk: implementation of this recommendation is required to comply with the requirements of the <i>Privacy Act 1988</i> (Privacy Act)		Privacy protection: implementation of this recommendation will minimise privacy risk and improve privacy protections
#	AGS Recommendation	Department Response	
P1	 Seek legal advice about application of s 95 Guidelines before sharing ‘screening outcome’ information The Department should seek further legal advice about the application of the s 95 Guidelines before including ‘screening outcome’ data in a future phase of the Project.	Agreed.	
P2	 Only share data that is necessary and relevant The Department should undertake further review of the data fields it proposes to disclose to the ABS to ensure these are relevant and necessary for the purpose of the Project.	Noted.	
P3	 Establish clear use case before sharing ‘screening outcome’ information The Department should not use or disclose sensitive ‘screening outcome’ data without first establishing a clear use case to ensure privacy impacts are fair, reasonable and proportionate.	Agreed.	
P4	 Update NCSR Privacy Policy The Department should make the following updates to the NCSR Privacy Policy: • update the ‘disclosure’ table to include a reference to the ABS for the purposes of the Project • update the ‘opt out’ information to reflect the proposed disclosure to the ABS for the purposes of the Project.	Agreed.	

#		AGS Recommendation	Department Response
P5		Notify individuals about 'usual disclosure' of data to ABS To ensure APP 5 compliance, the Department should: • update public facing online and electronic materials (eg, information about PLIDA on the NCSR website, electronic correspondence and online portal) • gradually update privacy notices contained in Screening Program materials (eg, letters and bowel cancer screening kits) to reflect the new information sharing arrangements.	Agreed.
P6		Take steps to delete, de-identify or appropriately archive NCSR extract data To minimise data quality and data security risks, we recommend the Department take steps to delete the NCSR data extract from Informatica once securely transferred to the ABS.	Agreed.
P7		Explore opportunity for partial data transfer to ABS Before completing the second transfer of NCSR data to the ABS, the Department should determine if it is possible to transfer new or amended data only (deltas), and if this will have a lower privacy impact balancing security and data quality concerns.	Noted.
P8		Implement measures to minimise risk of re-identification To reduce re-identification risks, the Department should: • enquire with the ABS if it can develop PLIDA products for the Department containing aggregate level data only • restrict access to unit level data through the dashboard for staff accessing PLIDA products through the DataLab.	Noted.
N1		Ensure compliance with s 95 Guidelines / HREC approval As the Project involves research of a kind to which the s 95 Guidelines apply, the Department and the AIHW must ensure the activities comply with the NHMRC Guidelines in order to satisfy s 17(5).	Agreed.
N2		Only share data that is necessary and relevant The Department and AIHW should continue to review the data items the Department propose to share for a Project purpose (i.e. data linking and analysis activities) to ensure these are relevant and necessary for that purpose.	Noted.

#		AGS Recommendation	Department Response
N3		Update NCSR Privacy Policy The Department should make the following updates to the NCSR Privacy Policy: • update the 'disclosure' table to include a reference to the linkage project as a relevant purpose for disclosure to the AIHW and/or ABS • update the 'opt out' information to reflect the proposed disclosure to the AIHW for the purpose of enduring data linkage and research.	Agreed.
N4		Notify individuals about 'usual disclosures' of data to AIHW To ensure APP 5 compliance, the Department should: • update public facing online and electronic materials (eg, information about the NHDH on the NCSR website, electronic correspondence and online portal) • gradually update privacy notices contained in Screening Program materials (eg, letters and bowel cancer screening kits) to reflect the new information sharing arrangements.	Agreed.
N5		Implement measures to minimise risk of re-identification To reduce re-identification risks, the Department should: • limit access to unit-level data in the NHDH to the extent possible • restrict access to unit level data through the dashboard for staff accessing NHDH products via the AIHW RON.	Noted.
J1		Regularly review privacy impacts The Department should: (a) Seek legal advice or a supplementary PIA for future iterations of each Project involving new or changed ways of handling personal information (b) Inform individuals about changes or updates to each Project which alter the handling of their personal information	Noted.
J2		Consider publishing PIA The Department should: (a) Publish this PIA, or a summary version or edited copy, on its website or otherwise make it available on request (b) List this PIA on the register of PIAs	Noted.

#		AGS Recommendation	Department Response
J3		Remain alive to re-identification risks in external requests	
		As the data custodian for NCSR data, the Department should remain alive to possible re-identification risks associated with external access requests and seek legal advice as needed.	Noted.
J4		Staff receive appropriate training for new processes	
		The Department should ensure staff receive appropriate privacy training with respect to new information handling processes, including: • preparation of the NCSR extract for PLIDA • access to and use of the Dashboard (once implemented).	Noted.
J5		Obtain staff agreement not to re-identify data	
		As a further reasonable step, Departmental staff should be subject to a strict agreement not to attempt to reidentify NCSR data contained in either the dashboard or integrated PLIDA or NHDH Products.	Agreed.
J6		Develop a shared approach to data breach response	
		The Department should consult with the ABS and AIHW to devise a clear procedure for responding to actual or suspected data breaches.	Noted.

Table 3: PIA recommendation