

November 2020

In 2020, the ABS undertook a Privacy Impact Assessment (PIA) for a project to link three Cancer Institute of NSW (the Institute) datasets to the Multi-Agency Data Integration Project (MADIP). The PIA examines the privacy considerations of the project and outlines strategies to mitigate any residual privacy risks, in relation to the [Australian Privacy Principles](#), [NSW Health Privacy Principles \(HPPs\)](#) and community expectations. The PIA was undertaken by the ABS, with independent advice and review provided by Privcore, which specialises in provision of privacy services.

The three Institute datasets are the NSW Cancer Registry, BreastScreen NSW and the NSW Pap Test Registry. These sources provide crucial data about cancer screening programs and people who have had cancer.

Linking the Institute datasets to MADIP provides a significant opportunity to provide a greater understanding of the importance of sociodemographic factors (e.g. age, education level, income) on all stages of the cancer journey, from prevention through to survivorship or end-of-life. MADIP datasets such as the Census of Population and Housing will be extremely useful in providing this context. The results will be used to inform the development of cancer prevention and management programs, with the overall aim of increasing cancer screening participation, reducing cancer incidence, and improving the quality of care and outcomes for people with cancer in NSW.

The PIA acknowledges there are strong measures in place to protect the privacy of individuals in the linkage process and associated analytical outputs including legislative safeguards, application of the [separation principle](#) and the [Five Safes Framework](#). Further approvals by data custodians and ethic committees for additional use of the linked data also aids in protecting the data and ensures the data is being used for research projects that are in the public interest.

The Institute has provided detailed information to demonstrate compliance with the APPs and HPPs, which has greatly aided the ABS in completing this PIA.

The ABS is committed to upholding the privacy, secrecy and security of personal information, and to being transparent and open about the uses of the data resulting from the linkage.

The PIA makes two recommendations to increase transparency and align with best practice.

RECOMMENDATIONS

- 1. The ABS will advocate with entities responsible for collection notices to enhance transparency about their disclosure of personal information to the ABS for MADIP by taking reasonable steps to update notices or otherwise make individuals aware of data disclosure and use.**

The ABS will make recommendations to data custodians, including the Institute, around best practice with regards to collection notices. The incorporation of data integration as an activity for data disclosure and use would help address community expectations in relation to how their data may be used.

This recommendation was also made in the [2019 MADIP PIA Update](#), which can be found on the [ABS Privacy Impact Assessments](#) page. Implementation is still in progress, and has been delayed due to the ABS response to COVID-19.

- 2. The ABS will continue to increase transparency about the collection and use of data, including personal information, for MADIP in online materials.**

The ABS is updating its online materials, and new information will be published in late 2020 and early 2021. Interim updates have been made to key pages like the [MADIP data and legislation](#) page, the [MADIP research project register](#), and the [Data Integration Project register](#). The ABS will continue to look for opportunities to engage with its partners about improving transparency for MADIP.