

## Overview

The Australian Bureau of Statistics (ABS) is committed to transparency and openness about data included in the Multi-Agency Data Integration Project (MADIP).

The ABS is considering a proposal to integrate national intensive care data collected by a private organisation (the Australia and New Zealand Intensive Care Society (ANZICS)) to MADIP, as part of a once-off linkage for the COVID-19 Vaccine Strategy project. This project is led by the Department of Health and Aged Care, in collaboration with other Commonwealth and State agencies and other partner groups. If this project proceeds, it will be the first private sector data linked to MADIP.

In October 2022, the ABS consulted with a small group of targeted stakeholders to consider privacy issues with linking this new type of data. The ABS also sought views on whether the current protections and safeguards in place for MADIP data are sufficient.

The targeted stakeholders were selected based on their involvement in the project, understanding of research uses of health data, and privacy expertise. Stakeholders consulted included the data custodian (ANZICS), project owner (Department of Health and Aged Care), consumer advocates (Consumer Health Forum) and privacy regulator (Office of the Australian Information Commissioner).

This summary report presents the feedback and concerns raised at sessions that the ABS held with stakeholders to inform the proposed integration of ANZICS to MADIP.

Feedback received as part of the consultation process were considered by the ABS to help inform the decision of whether to include this new type of data in MADIP. The decision on linking intensive care data to MADIP and reasons for that decision will be published on the ABS Data and Legislation webpage in November 2022.

The MADIP Board were consulted about the proposal. No additional governance requirements or restrictions were identified.

A summary of the consultation feedback is provided in Table 1.



Table 1: Targeted stakeholders consultations

Questions	Consolidated feedback
<p>1. Do you have concerns about the new type of private sector health data proposed to be linked to the MADIP?</p>	<p>Stakeholders did not raise significant concerns about this new type of data being linked to MADIP.</p> <p>All stakeholders recognised the potential benefit for integrating this type of data to MADIP and how it could be used to inform the COVID-19 Vaccine Strategy project. They also saw potential benefit in the integrated data being used for other projects in the future. One stakeholder noted ABS' strong commitment to privacy safeguards and privacy by design at all stages of data integration projects.</p> <p>One stakeholder sought clarification around ABS' existing security protections for data integration projects as cyber-attacks are a key risk.</p> <p><b>ABS comments at the session:</b></p> <p>ABS noted that it would continue to apply existing MADIP infrastructure and governance arrangements for this new type of data, including application of the Five Safes framework to provide effective data protections and control for risks. ABS clarified that there are no other specific proposals to link private sector data to MADIP at this time.</p> <p>The ABS is committed to keeping the personal information it holds safe and secure. The secure data integration environment used for MADIP has been certified by the Australian Signals Directorate under the Information Security Registered Assessors Program (IRAP). Further information on the range of security controls in place are detailed extensively in the 2020 Cloud DataLab PIA and the MADIP PIAs.</p>



Table 1: Targeted stakeholders consultations

Questions	Consolidated feedback
<p>2. In addition to the standard MADIP arrangements, are there any additional governance measures or protections that should be considered in linking ANZICS data to MADIP?</p>	<p>Stakeholders agreed that the standard MADIP arrangements are appropriate for linking ANZICS data to MADIP. A couple of stakeholders sought clarification about the mechanism for consent for this type of data.</p> <p>One stakeholder suggested that any new data should be provided with a data dictionary to explain the data items and help ensure data is interpreted correctly. They also suggested that the data custodian could assist with interpreting data outputs.</p> <p><b>ABS comments at the session:</b></p> <p>ABS noted that data custodians provide information about the legislative basis for sharing data with ABS for integration in MADIP, which is documented in data sharing agreements. Most data is shared without the requirement for consent.</p> <p>The ABS has a range of options available to data custodians to review outputs prior to data being released in the public domain.</p>
<p>3. Should there be any restrictions imposed on linking ANZICS data to MADIP?</p>	<p>Stakeholders generally agreed that the current MADIP infrastructure and arrangements are appropriate for this type of data.</p> <p>One stakeholder questioned whether the private sector data custodian would be able to access MADIP data.</p> <p><b>ABS comments at the session:</b></p> <p>ABS noted that access to MADIP data is limited to approved researchers, including from government agencies, researchers, academic organisations and public policy institutes. ABS stated that opening up access to private sector organisations is not currently under consideration.</p>



Table 1: Targeted stakeholders consultations

Questions	Consolidated feedback
<p>4. What can be done to improve transparency and/or assessing public benefit for this type of data?</p>	<p>Most stakeholders did not propose additional transparency measures.</p> <p>One stakeholder noted that the ABS could publish the results from research using this data on the ABS webpage.</p> <p><b>ABS comment at the session:</b></p> <p>The ABS is transparent about its data integration. We publish Privacy Impact Assessments (or summaries of assessments) as well as information about the datasets involved, the research projects granted access to the integrated data, and how we keep data safe. Stakeholder consultation is often conducted as part of the PIA process and is another mechanism for increasing transparency of work underway and gauging stakeholder concerns or support.</p>
<p>5. Would you be comfortable with this data being used for other projects</p>	<p>All stakeholders agreed that they were comfortable with the data being used for other projects. Stakeholders noted that standard MADIP governance arrangement are appropriate to use to approve researcher access to the integrated data.</p> <p>One stakeholder suggested that arrangements for this type of data be reviewed on an annual basis. One stakeholder noted the importance for ABS to continue to assess the re-identification risks for this data once linked with MADIP or any other future projects.</p> <p><b>ABS comments at the session:</b></p> <p>The ABS continues to manage re-identification risks through its legislative framework and by applying the principles of the Five Safes framework to support safe and effective access to microdata (i.e. unit record/person level data) for authorised researcher use.</p>



Table 1: Targeted stakeholders consultations

Questions	Consolidated feedback
	<p>ABS noted that there must be a clear business need and public benefit to bring data into MADIP. Future requests to link this data on an enduring basis could be considered.</p> <p>Standard MADIP governance arrangements will be used to approve researcher access to the integrated data. This includes ABS and data custodian approvals being required for each project seeking to access and publish the ANZICS data.</p>