

NATIONAL HEALTH (PRIVACY) RULES 2018 REVIEW

ABS response to OAIC consultation paper June 2021







INTRODUCTION

The Australian Bureau of Statistics (ABS) welcomes the opportunity to contribute to the review of the *National Health (Privacy) Rules 2018* (the Rules) by the Office of the Australian Information Commissioner (OAIC). This submission provides some general comments about the Rules and addresses some specific questions raised in the consultation paper.

About the ABS

The ABS is the central statistical authority for the Australian Government and, by legal arrangements, the provider of statistical services to State and Territory Governments. The ABS's purpose is to inform Australia's important decisions by delivering relevant, trusted and objective data, statistics and insights.

The ABS takes privacy and data security very seriously and maintains a strong data protection culture and extensive experience in keeping data secure. The ABS was the first Government agency to become an accredited Integrating Authority which recognises that the ABS has the appropriate settings, experience and capability, and arrangements to manage high risk data integration projects that involve Commonwealth data for statistical and research purposes. For data integration projects, the ABS is responsible for linking relevant data, providing access to authorised users via highly secure ABS systems, and safeguarding privacy—ensuring that no individual person is likely to be identified.

As a key user of Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data in data integration projects, the ABS is keen to provide input to revision of the Rules to support statistical and research purposes, including statistical data integration.

GENERAL COMMENTS

The ABS seeks to maximise the value of public data for statistical and research purposes, while keeping data safe and maintaining public trust in government use of data. The ABS sees significant value and public benefit in using MBS and PBS data for statistical and research purposes, particularly through statistical data integration initiatives. Such use of MBS and PBS data should be supported by robust privacy protections that ensure public trust is maintained in the use of data by the ABS as well as in the national data system more broadly.

The current Rules are very complex and open to different interpretation. The ABS supports a revision of the Rules to provide greater clarity on permitted uses of MBS and PBS data, including for statistical and research purposes.







Maximising the value of public data

The ABS is a strong advocate of sharing public data, where it is safe to do so.¹

The ABS is keenly aware of the potential for public sector data to generate new insights and improve data quality, while reducing data collection burden on the general public. For many years, the ABS has used a range of public sector data to create official statistics.

The MBS and PBS datasets are high-value public sector data assets. They provide detailed information about how patients interact with the Australian health system, thus providing an evidence base to support policy development and program evaluation.

The ABS integrates public sector data as part of the <u>Multi-Agency Data Integration Project</u> (MADIP). MADIP is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time. MADIP provides whole-of-life insights about various population groups in Australia, such as the interactions between their characteristics, use of government services, and outcomes related to aspects such as health and employment. MBS and PBS data are important sources of health information in MADIP that have been accessed by researchers for a range of analytical projects within the strict requirements of the multi-dimensional data protection framework in operation.

Maintaining privacy and public trust

The ABS recognises the sensitivity around personal health information. MADIP includes a number of sources of data that, if accessible with personal identifiers, would be considered "sensitive information" under the Privacy Act 1988. The ABS has robust privacy protections for information in MADIP, including use of the 'separation principle' to ensure data are not accessible with personal identifiers. The ABS also uses the 'Five Safes' data access framework to minimise disclosure risk.² Such protections are important in maintaining public trust, which is a key enabler of a more open and dynamic public data environment.

RESPONSES TO SELECTED DISCUSSION QUESTIONS

Form and function of the Rules – Prescriptive versus principles-based

Question 5

In general, the ABS supports principles-based primary and subordinate legislation. While we expect that principles for protection of the privacy of personal health information are unlikely to change significantly in the short to medium term, a principles-based approach allows for operations to be

² See "<u>Privacy Impact Assessment (PIA) Update for the Multi-Agency Data Integration Project (MADIP)</u>" November 2019.



¹ See "<u>ABS Submission to the Productivity Commission Inquiry on Data Availability and Use</u>" July 2016 and "<u>New Australian Government Data Sharing and Release: Australian Bureau of Statistics Response to Issues</u> <u>Paper</u>" August 2018.





adjusted to take into account current context, information technology developments and modern day best practice.

Technological specificity versus technological neutrality - Storing claims information in separate databases

Question 6 & 7

The ABS notes that the requirements in the Rules for the storage of MBS and PBS data in separate databases flow from provisions in the *National Health Act 1953*. The ABS acknowledges the view of the OAIC that the requirements will remain part of the Rules until the primary legislation is amended.

However, the ABS is of the view that this requirement is no longer meaningful in the current digital environment, and there is significant confusion among data users about how to interpret this requirement. The ABS supports the introduction of a principles-based approach to provide Government agencies with greater clarity about this issue.

The Rules in practice – Modernisation and trends in government information policy

Questions 10 & 11

The ABS considers it important for the Rules to be clear and transparent around how MBS and PBS data can be handled and used for statistical and research purposes. Subsection 7(1) of Part 2 of the Rules requires Australian Government agencies to store MBS claims information in a separate database to PBS claims information.

The ABS suggests further clarity could be provided on how this requirement can be satisfied for statistical and research purposes, including data integration initiatives, involving access to deidentified data only.

The ABS suggests reference could be made to the principle of using a modern, multi-dimensional data protection framework to ensure safe access to MBS and PBS data. The ABS uses the "Five Safes" framework to manage safe access to ABS data. The framework is internationally recognised and provides a structure for assessing and managing disclosure risk that is appropriate to the intended data use. The framework has been adopted by the ABS, as well as several other Australian Government agencies and National Statistical Organisations internationally. The Five Safes framework is also the basis for the 'Data Sharing Principles'³ recently published by the Department of the Prime Minister and Cabinet.

³ Best Practice Guide to Data Sharing Principles, Department of the Prime Minister and Cabinet, March 2019







Medicare PINs

Questions 16 & 17

Medicare PINs enable the linkage of MBS and PBS information with other data, such as the Medicare Consumer Directory (MCD) and the Australian Immunisation Register (AIR). Medicare PINs also enable streamlined data linkage of different data assets through interoperability, which reduces the cost and privacy risk associated with statistical data integration.⁴

The ABS supports less restrictive requirements around the use of Medicare PINs (in an appropriate format) for the purposes of statistical data integration. The ABS also supports existing requirements that Medicare PINs should not directly reveal personal or health information.

⁴ See N von Sanden, "Improving Inter-Agency Data Sharing Through Linkage Spine Interoperability", *International Journal of Population Data Science*, 5(5), 2020.

