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**DEPARTMENT OF HEALTH SUBMISSION TO THE NATIONAL HEALTH (PRIVACY) RULES 2018 REVIEW**

The Department of Health (the Department) welcomes the opportunity to contribute to the remake of the *National Health (Privacy Rules) 2018* (the Rules).

**Introduction**

The Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS) are key components of Australia’s health system aimed at providing Australians with affordable accessible and high-quality health care. The Department uses MBS and PBS data, together with other health system data, to understand how patients interact with the health system, and to support evidence-based policy, well targeted programs, evaluation and best practice regulation. The Department also uses MBS and PBS data for provider compliance purposes (incorrect claiming, inappropriate practice and fraud in relation to Medicare programs).

Data held by the Australian Government is a strategic national resource, and it is critical that the MBS and PBS datasets are utilised for public benefit. In doing so, the Department recognises the sensitivity of health data, and the importance of having appropriate safeguards in place to maintain the privacy and security of this information.

The *National Health Reform Agreement Addendum 2020-2025* refers to ‘enhanced health data’ as a critical enabler for long term health reform, and the Commonwealth and State/Territory Governments have committed to working together to harness data and analytics to drive meaningful improvements in the health system. The Governments have committed to achieving comprehensive health data access, usage and sharing, while at the same time maintaining data security and preserving individuals’ privacy. The Governments have also committed to progress mechanisms and interoperable systems for secure and comprehensive integration of data across patient journeys.

Linked data assets hold a broad range of data that allow complex questions to be analysed, with new insights that aren’t available from a single data source[[1]](#footnote-1). The ability to link key health datasets is critical to understanding patient pathways through the health system, and implications for patient health outcomes. The Department’s submission to the Senate Select Committee on Health’s inquiry into big data and data linkage noted the potential for significant benefits in the health system as a result of analysing linked data[[2]](#footnote-2).

The Department supports revision of the Rules so as to facilitate the effective use of linked MBS and PBS data to achieve best practice policy, evaluation and service planning, while maintaining strict privacy and security of this data. For example, a mechanism to allow analysis of a linked MBS and PBS dataset to inform the Government’s response to the COVID-19 pandemic and to evaluate the policy and program interventions being put in place, would be extremely beneficial. This activity was precluded due to the current form of the Rules.

The Department has supported the inclusion of MBS, PBS and other departmental data in the ABS Multi Agency Data Integration Project and the AIHW National Integrated Health Services Information Analysis Asset to enable access by government and non-government researchers to de-identified data consistent with the governance arrangements in place for these enduring linked datasets. These data assets can support analyses to strengthen evidence based policy making and advances in health care delivery, which in turn can improve patient outcomes and health system effectiveness.

In addition, the Department uses MBS and PBS data for compliance purposes to identify incorrect claiming, in appropriate practice and fraud in relation to Medicare programs. The *National Health Act 1953* (National Health Act) was amended in late 2019 to enable the Department to undertake data-matching, including MBS and PBS data matching, for permitted purposes relating to Medicare compliance. This ability to match data is in the public interest as it will improve the Department’s ability to identify fraud and incorrect or inappropriate claiming, and protect the integrity of the health programs by ensuring only eligible services are paid for. Further information regarding these data matching arrangements can be found in [Data matching for Medicare compliance purposes](https://www1.health.gov.au/internet/main/publishing.nsf/Content/data-matching-for-medicare-compliance-purposes).

**Response to questions**

1. *What provisions in the Rules work well and should remain as they are or with minimal changes?*
2. *What provisions in the Rules are no longer fit for purpose? Why?*
3. *Do the Rules get the balance right between protection of privacy on the one hand and use of claims information on the other? Why or why not?*
4. *Which provisions in the Rules are too prescriptive / not prescriptive enough?*
5. *Would any parts of the Rules benefit from being made more principles-based? Why?*

The Rules provide legal authority for Services Australia to disclose MBS and PBS claims information to the Department, and for the Department to use and disclose this information in specified circumstances. It is critical that the Rules retain provisions to enable the Department to continue to collect (such as r 8(9)), use (such as r13(1)), and disclose (such as r 13(6)) MBS and PBS data as appropriate, for policy development,

service planning delivery, research, regulatory and compliance purposes.

As a general comment, the Department considers that the Rules are in need of an update to take account of changes in community expectations with respect to use of public sector data, changes in the Privacy Act including the commencement of the *Australian Privacy Principles*, changes in technology and the need to better leverage public sector data to address complex issues. In addition, there are aspects of the Rules that are complex, and provisions which appear repetitive, and these can result in differing interpretations, or delays in using the data because of the need to seek advice to clarify what is permitted within the Rules. And there are some provisions that impose specific requirements that are not clearly associated with the privacy risk that is being mitigated. As a result, the Department supports the Rules being more principles-based.

The Department also favours revisions to Section 13 of the Rules (or Sections 9 and 11 as appropriate) as they relate to use and linkage of MBS and PBS by the Department for purposes other than compliance. In particular, where a linked dataset is authorised by the Secretary, Section 13(3) effectively requires the creation of bespoke linked datasets which must then be destroyed within one month of their creation. The Department has a range of requirements for regular or ongoing longitudinal analyses of linked MBS and PBS data, and to be able to refresh and update the linked dataset as needed. The purposes for linkage include policy development, service planning and delivery, modelling and costings, evaluations, and analyses for committees such as Medical Services Advisory Committee and the Pharmaceutical Benefits Advisory Committee. It is inefficient to destroy a linked dataset and then re-create given this ongoing use, and we are keen to explore options for the Rules to authorise the retention of a linked dataset with appropriate safeguards, where there is a requirement for ongoing use.

The Department notes that the Rules only apply to use of MBS and PBS claims information by the Commonwealth. Consistent with provisions for disclosure in the primary legislation, MBS and PBS data has been authorised for release to organisations outside of the Commonwealth (States and Territories, universities, research institutes, etc.) where appropriate safeguards are in place, and they are capable of storing the data together and undertaking direct linkage for as long as they need the data to be linked. The Rules do not apply to other health datasets that the department holds which are equally sensitive.

1. *How could the Rules be updated to better accommodate current information technologies and modern data practices in a way that continues to protect privacy?*
2. *Which parts of the Rules are no longer fit for purpose due to technological change or need adjustment?*

The Department agrees that some of the provisions in the Rules do not take account of modern technology and data practices. The references to paper copies and databases are clearly outdated. Within the limits set out in the National Health Act (s 135AA(5)(a) with respect to the creation of paper copies, and s 135AA(5)(d) and (e) with respect to databases), there would be benefit in moving to a more principles-based approach, being that changes in technology (e.g. new storage) and process steps (e.g. linkage or de-identification) could be adapted to the Rules and could result in improved privacy and security. For example, the Department notes that the De-identification Decision–Making Framework released by the OAIC and CSIRO Data 61 provides guidance to assist organisations to de-identify their data effectively.

In addition, the references to the Department of Health and the Department of Human Services (now Services Australia) were nominally updated to reflect the 2015 Machinery of Government changes, but are now out of date. It would be helpful to have a framework for updating references to agencies when machinery of government changes occur (perhaps drawing on s 19B of the *Acts Interpretation Act 1901*)*.*

1. *What additional requirements should apply to MBS and PBS information over and above the APPs? Why?*
2. *Which provisions in the Rules (if any) should be removed or adjusted in light of the APPs*?

The Department considers that the APPs provide a high level of privacy protection. In addition, the Department complies with whole of government arrangements in relation to privacy and security requirements, and our internal data governance arrangements provide additional protection. Given the strength of these protections, a case for additional requirements in the Rules for MBS and PBS data has not been made. It is also worth noting the Department is subject to the secrecy provisions in primary legislation that apply to claims information.

The Department is interested to hear the views of stakeholders on this issue.

1. *How can the Rules be modernised or made more effective, while remaining within the parameters of the primary legislation?*
2. *How might the Rules better align with current government policies pertaining to information use, re-use and sharing while still protecting privacy?*

As discussed above, there are benefits in the Rules moving to a more principles-based approach, to improve their effectiveness and alignment with current government policies pertaining to information use, re-use and sharing while protecting privacy.

1. *Should these requirements (about separation of claims information from enrolments and entitlements and exclusion of personal identification components) stay the same or be changed? Why?*

In general the Department notes that the separation principle is a privacy preserving measure and considers that it should continue to apply where practicable.

The Department requires personal identification components to support linkage (particularly with datasets that do not have the Medicare PIN), but does not require personal identification components to be included in the resulting linked dataset.

1. *Is having dedicated detailed technical standards for MBS and PBS claims databases necessary given the range of other information security requirements applying to Services Australia?*
2. *Should the technical standards cover any other matters?*
3. *Should any other agencies be required to have technical standards of this sort? Which agencies and why?*

Specific detailed technical standards and the requirement to report any changes to the standards to the OAIC may be able to be dispensed with given that Commonwealth agencies are subject to the APPs, the Australian Government Protective Security Policy Framework, the Australian Government Information Security Manual and other Commonwealth requirements that may exist and vary from time to time. The need for other Commonwealth agencies who hold MBS and PBS claims information and personal identification components to adhere to technical standards could be required only where necessary based on the identified privacy risk.

1. *Are the provisions regulating the creation, use and disclosure of Medicare PINs fit for purpose?*
2. *Should there be more permissive or more restrictive use of Medicare PINs? Why?*

The Department notes that the Medicare PIN is not part of a MBS or PBS claim and is a computer system applied artefact of having to store MBS and PBS entitlement and claims data in separate databases. The main function of the Medicare PIN is to maintain linkage between the separate databases as required by the Rules, so there seems to be no reason for the PIN to be a controlled item. There are also issues with respect to the quality of the PIN in maintaining linkage across the databases.

Consistent with the requirement that the Medicare PIN not reveal personal or health information about the individual, an alternate approach could be to develop more general principles regarding a common identifier that brings together MBS and PBS claims information. The Department recommends that such principles be developed in consultation with organisations involved in statistical linkage.

If the Department continues not to receive personal identification components, then the Medicare PIN should be retained.

1. *Do disclosure provisions get the balance right between data sharing and protection of privacy? Why or why not?*
2. *Is APP 6 adequate for regulating disclosure of claims information? What additional requirements, if any, need to be spelt out in the Rules?*

The Department is currently precluded from forming its own patient centred view of health (and aged care) using the data it has available or could readily acquire, which constrains effectiveness in discharging duties under primary legislation. This inhibits evidence-based analyses that can support improvements in the health system and patient outcomes.

The Rules authorise Services Australia to disclose claims information to the Department. An amendment to the Rules to include a specific authorisation for the Department to collect this information would be useful.

In addition, the Department is interested to explore options that would allow Services Australia to disclose personal identification components for Health to use as a variable to support linkage of MBS and PBS claims information with other health and aged care datasets. Once the linkage is undertaken, the personal identification components would be destroyed or de-identified, and no personal identification components would be present in the final analytical dataset.

1. *Should linkage of MBS and PBS claims information be allowed in other circumstances? What circumstances and why? How could this be done in a way that continues to protect privacy?*
2. *Are the data retention requirements appropriate? Should linked claims information be able to be retained for longer?*
3. *Are reporting arrangements appropriate? Should reporting categories be changed in any way?*
4. *Should the Department of Health be able to link claims information in a wider range of circumstances? What circumstances?*
5. *Are provisions enabling disclosure of claims information by the Department of Health appropriate?*

The Department is seeking to create an enduring and regularly refreshed linked MBS and PBS dataset with the resulting analytical content (excluding personal identification components) being available to support internal use including policy development, service planning/delivery, evaluation and regulation. Departmental use of the dataset would be subject to the APPs, and whole of government arrangements in relation to privacy and security requirements, and our internal data governance arrangements.

The Department believes that linked claims information should be maintained indefinitely provided the information does not contain personal identification components, and its persistence does not attract significant privacy risks.

With respect to reporting arrangements, the Department notes that there are no reporting arrangements for MBS and PBS claims information linkages conducted by other organisations.

1. *Are the provisions applying to old information appropriate?*
2. *In what circumstances (if any) should old information be able to be re-linked with personal identification components? How could this be done in a way that continues to protect privacy?*

We favour consistent requirements for all data in the context of longitudinal analyses to understand causation, consequences of problems, and to examine change over time. Because longitudinal data tracks individual pathways, it can show how different people respond to opportunities and setbacks, and how their responses and outcomes change in the short and long term.[[3]](#footnote-3) For evaluations, it is often important to analyse the data pre and post the intervention.

There are instances where linking old information with personal identification components is necessary to resolve data quality issues, and to ensure that data linkages are accurate.

1. *Is this provision necessary given it already applies under the Privacy Act? If yes, does it need to be modified in any way? Should claims information be able to be used for other forms of research? If yes, should there be any limitation on this use?*

The Department considers that the current provisions relating to disclosure of claims information for medical research are duplicative given requirements under the Privacy Act.

However MBS and PBS data is regularly sought to support other types of research including socio-economic analyses, evaluations of policies and programs, policy development, service planning and delivery, health effectiveness and expenditure analyses etc. Clarification in the Rules that the data can be disclosed for these purposes would be useful, including any requirements that should be in place.

1. *Are name linkage provisions appropriate? Should name linkage be allowed in any other circumstances?*
2. *Are provisions relating to paper copies of claims information appropriate? Why or why not?*

As discussed above, the Department wishes to explore accessing personal identification components for the purpose of linkage with other datasets. Once the linkage is undertaken, the personal identification components would be removed from the analytical dataset.

The requirements relating to paper copies are outdated. The Department does not have any requirements for paper copies to MBS and PBS information.

**Further feedback**

The Department would be happy to provide further specific feedback with respect to this submission.

Yours sincerely

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1. https://www.abs.gov.au/about/data-services/data-integration/use-and-benefits [↑](#footnote-ref-1)
2. https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Health/Health/Submissions

   Department of Health – supplementary to submission 155: [↑](#footnote-ref-2)
3. https://www.dss.gov.au/sites/default/files/documents/01\_2017/ncld\_longitudinal\_data\_fact\_sheet\_final\_12\_january\_2017.pdf [↑](#footnote-ref-3)