

SUBMISSION

National Health (Privacy) Rules 2018 Review

Office of the Australian Information Commissioner (OAIC)

Date 4 June 2021



INTRODUCTION

The Pharmacy Guild of Australia (the **Guild**) is the national peak organisation representing community pharmacy. The Guild supports community pharmacy in its role of delivering quality health outcomes for all Australians. It strives to promote, maintain, and support community pharmacies as the appropriate providers of primary healthcare to the community through optimum therapeutic use of medicines, medicines management and related services.

Community pharmacies are the most frequently accessed and most accessible health destination, with over 462 million individual patient visits annually.

Community pharmacy is consistently viewed by the Australian public as a highly trusted and valued part of our nation's healthcare system and an essential primary healthcare destination providing services that extend well beyond the dispensing and provision of medicines. Community pharmacies operate in well-distributed and accessible locations, and often operate over extended hours, seven days a week in urban, rural and remote areas.

The network of over 5,800 equitably distributed community pharmacies play a pivotal role in the delivery of the National Medicines Policy, by ensuring timely access to safe, effective, and affordable medicines under the Pharmaceutical Benefits Scheme (**PBS**) for all Australians.

Community pharmacies are small businesses recognised under the *Privacy Act 1988* and therefore are required to comply with the Australian Privacy Principles (**APP**). Community pharmacies operate in a highly regulated environment and are central to the effective operation of the PBS; having privileged access to personal and confidential health information that inform patient care.

Community pharmacies rely on the PBS to be an efficient and effective system and one that uses and shares data for quality and system improvement. The Guild submits that the *National Health (Privacy) Rules 2018* (**Rules**) and their application should fundamentally support PBS quality and system improvement without compromising the intent of both the *Privacy Act 1988* (Cth) and the *National Health Act 1957* (Cth).

We set out below our submissions following the format of the questions set out in the Consultation Paper: National Health (Privacy) Rules 2018 review dated 5 May 2021.

KEY ISSUES AND GENERAL QUESTIONS

The Rules and their provisions

1. What provisions in the Rules work well and should remain as they are or with minimal changes?

Overall, the Guild believes the Rules are appropriate and are supportive of their current scope.

Current key provisions	Guild position
Separate storage	Supported with no recommended change
Storage without identifiers	Supported with no recommended change
Disclosure to the Department of Health	Supported with no recommended change
Linkage of claims information	Supported with no recommended change
Retention of linked claims information	Supported with no recommended change
Old information	Supported with no recommended change
Disclosure of claims information for medical research	Supported with no recommended change
Use of claims information by the Department of Health	Supported with no recommended change
Name linkage	Supported with no recommended change

2. What provisions in the Rules are no longer fit for purpose? Why?

The Guild has no comment.

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?

The Guild believes the balance is right, however, it wishes to emphasise the continued need for vigilance in ensuring the Rules are applied and adhered to across the relevant government agencies and that any mechanisms that are used to support this adherence is communicated to key stakeholders.

Form and function of the Rules - prescriptive versus principles-based

4. Which provisions in the Rules are too prescriptive / not prescriptive enough?

The Guild believes the Rules need to be as prescriptive as possible so as to minimise any ambiguity in their application by government agencies.

5. Would any parts of the Rules benefit from being made more principles-based? Why? Refer to previous comment.

Technological specificity versus technological neutrality

6. How could the Rules be updated to better accommodate current information technologies and modern data practices in a way that continues to protect privacy?

The Guild recommends that both PBS and MBS de-identified datasets be available more broadly than just government agencies to better support health sector-wide policy development and innovation. And this is supported by the statement made by Deputy Chief Medical Officer Professor Michael Kidd at the recent 2021 National Medicines Symposium (NMS) where Professor Kidd stated:

"Medicines data needs to be connected across systems and settings, and we need to better use appropriately designed digital platforms to support good decisions about quality use of medicines".

Additionally, the Guild cites the Data Availability and Transparency Bill 2020 (the Bill) introduced to the Australian Parliament on 9 December 2020. If enacted, the Bill would create a national scheme for organisations to request access to Australian Government data in a controlled manner for prescribed purposes, namely: (i) improving government service delivery, (ii) informing government policy and programs, and (iii) research and development.

7. Which parts of the Rules are no longer fit for purpose due to technological change or need adjustment?

It is the Guild's understanding that identifiers are already in use when processing PBS prescriptions for the National Residential Medication Chart and supports the continued use of these identifiers and additionally, the Royal Commission into Aged Care Quality and Safety recommendation that:

- The Australian Government should implement an aged care identifier by no later than 1 July 2022 in the MBS and PBS datasets for regular public reporting purposes, and
- All governments should implement a legislative framework by no later than 1 July 2023 for health and aged care data to be directly linked, shared and analysed to understand the burden of disease of current and prospective people receiving aged care and their current and future health needs.

Interaction with the APPs

8. What additional requirements should apply to MBS and PBS information over and above the APPs? Why?

The Guild does not believe additional requirements need to be implemented above and beyond the APPs. However, the Guild recommends that in addition to 'government agencies collecting and use (of MBS/PBS data) to enable payment of benefits for medical care and medicines', the Rules should unambiguously include the use of MBS/PBS for medical and policy research purposes. This potential additional use of the data by government agencies should be unambiguous and clearly articulated in the Rules.

9. Which provisions in the Rules (if any) should be removed or adjusted in light of the APPs?

The Guild recommends that consideration be given to a stronger alignment and/or linkage between the Rules and the APPs so as to better support compliance by government agencies. This would also support a better understanding of the practical application of the APPs by government agencies.

Modernisation and trends in government information policy

10. How can the Rules be modernised or made more effective, while remaining within the parameters of the primary legislation?

No comment.

11. How might the Rules better align with current government policies pertaining to information use, re-use and sharing while still protecting privacy?

The Guild believes that the approach should not be so much as 'alignment' but more to embedding the Rules in government agency practices. This could be achieved by ensuring the impact and application of the Rules are assessed against the program objectives, for example, in a program's privacy impact assessment (PIA), and also ensure a program's impact assessment on key stakeholders such as healthcare practitioners and consumers/patients is also conducted.

The Guild also suggests the Rules need to be better known across the healthcare stakeholder community so as support clear expectations around what government agencies can and cannot do in the use of MBS an PBS data.

It is also the Guild's view that de-identified PBS claims data should also be available for the Department of Health to use to prepare and publish aggregate data as part of its public reporting arrangements, including the annual PBS Expenditure and Prescriptions Report.¹

It would also be reasonable for similar arrangements to be in place for reporting on MBS expenditure.

Storing claims information in separate databases

12. 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?

It is the Guild's view that this requirement should remain.

Requirement for Services Australia to maintain technical standards

13. 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?

The Guild believes that the technical standards applied by Services Australia should provide for confidence and surety across its user groups, stakeholders, and the Australian public.

14. Should the technical standards cover any other matters?

The Guild has no comment.

15. Should any other agencies be required to have technical standards of this sort? Which agencies and why?

It is the Guild's view that any government agency responsible for using private data to conduct its programs should be required to adhere to uniform technical standards. For example, the Department of Veterans' Affairs uses Services Australia data as part of the MBS and the Repatriation Pharmaceutical Benefits Scheme (RPBS) and the Australian Institute of Health and Welfare uses MBS and PBS data as part of its analytical work. It is critical that these government agencies continue to have access to the necessary data for their work, but it is also reasonable to expect the adherence to uniform technical standards that underpin this work. Moreover, PBS and MBS de-identified datasets should be available to stakeholders beyond government agencies for the purposes of research and advocacy.

¹ Pharmaceutical Benefits Scheme (PBS) | PBS Expenditure and Prescriptions

The Guild has <u>no further comments</u> in relation to the following remaining topics included in the review:

- 16. Medicare PINs
 17. Disclosure to the Department of Health
 18. Linkage of claims information
 19. Retention and reporting of linked claims information
- 20. Old information
- 21. Disclosure of claims information for medical research
- 22. Use of claims information
- 23. Name linkage
- 24. Other matters including management of paper copies