https://privacy.org.au
Secretary@privacy.org.au
https://privacy.org.au/about/contacts/

Submission to the Draft National Health (Privacy) Rules, 2025

Australian Privacy Foundation, 1 May 2024.

About the Australian Privacy Foundation and this submission

The Australian Privacy Foundation (APF) is the country's leading privacy advocacy organisation. Information about the APF appears at the end of this submission.

The APF welcomes this invitation to respond to the Office of the Australian Information Commissioner's (OAIC's) *Draft National Health (Privacy) Rules, 2025*[1] (the Rules). The APF has made previous submissions in response to the *National Health (Privacy) Rules, 2018*, review[2], the Senate Standing Committee on Legal and Constitutional Affairs re *the Privacy Legislation Amendment (Enforcement and other Legislation) Bill 2022*[3], the OAIC's National *Health Privacy ACCC*[4] and the government in response to the Attorney-General's *Review of the Privacy Act 1988 (Cth) –Issues Paper*[5]. These responses inform this submission. The responses are also consistent with a range of detailed official and civil society analyses over the past few years, as discussed in those submissions.

Over more than a decade, previous submissions from the APF about health security and privacy controls have focused on the 'what', the content, of various Reviews, Bills and Rules. The resulting legislative instruments have demonstrated a significant lack of engagement from federal health authorities. Recommendations from the IIS, Information Integrity Solutions, consultation of public views was reviewed by the OAIC for inclusion into the 2025 Rules[6]. So, **our submission focusses on the 'why' of things, rather than the 'what', in the hopes of more engaged**

responses from the OAIC. That is, the APF feedback is limited to the 'why' of the *OAIC Response to the IIS Final Report*[6].

APF Feedback

With respect, **the documents supporting this review are too vague to be a meaningful discussion of the Rules**, which remain a complex legislative instrument under section 135AA of *the National Health Act 1953*[7]. The Act and Rules, accompanied by supporting amendments, annexes and notes, comprise more than 100 A4 pages of complex reading, not to mention frequent and significant cross-referencing: a body of dense documentation and legislation demonstrating both that the Rules continue to require simplification and that the review timeline is insufficient. Both problems need to be addressed before or alongside our submission. Nonetheless, we offer initial feedback here.

Response Overview

None of the responses made by the OAIC about IIS recommendations is transparent. The Overview broadly outlines the aim of the Office in seeking to implement as many of the recommendations as practically possible, but does not clearly explain why so many were not accepted or were only partially accepted- why were some of them impractical? Neither does the Response clarify how OAIC decisions about why recommendations were made.

Rather **the Response appears to consider ways**, in the context of new and emerging technologies, **government, researcher and health industry information handling processes, can be refreshed to remove legislative obstacles** to collecting and using every Australian's health information, while paying scant attention to community concerns. Indeed, we note that **most of the IIS recommendations that can empower individual community members are either partly accepted or not accepted in the OAIC final report**.

The 'key features' section of the Response has addressed some principles that seem to reflect community concerns about national health privacy rules, such as the introduction of express provisions to authorise the use of health claims information, the introduction of data minimisation applying to authorised users of health information and requirements for formal agreements between agencies sharing or disclosing information[6]. **All the agreed recommendations revise the Rules in ways that efficiently and directly benefit government, researcher and health industry information gathering efforts, while reducing budgetary costs. The community is not openly or transparently considered at all in the Report**. The OAIC Response does not seem to have reflected on the real-life costs to the community about simplifying legislatively sanctioned, traceable access to all Australian's health information by third parties seeking to collect, disclose and share it for secondary purposes[1,6].

OAIC responses to IIS recommendations

IIS 1, 3, 5, 10 &16	The APF analysis of the OAIC responses suggests **each instance of accepting an IIS recommendation for inclusion in the *Rules* enables identifiable information sharing between the Department of Health and Ageing and Services Australia, both primary agencies and, at times, secondary agencies**. **The OAIC did not accept recommendations about clearly and legally delineating when these agencies are acting as primary or secondary** (IIS 2,10 & 16). Secondary agencies can collocate MBS and PBS claims numbers in apparently de-identified health databases and sell them, as has previously occurred with Primary Health Networks[8], primary agencies cannot. **The same lack of transparency is true regarding recommendations to clarify arrangements for the sharing of identifiable information under the *Data Availability and Transparency Bill* (DATB)**[9] (IIS 3 & 5).
IIS 16	**The OAIC only partly accepts recommendations about extending primary agency rules about name linkages and claims information controls for secondary agencies** (IIS16). The APF requests the reasoning behind this decision given community attitudes and expectations regarding the handling of their personal information by primary and secondary agencies. We already experience outlandish privacy invasions when secondary agencies are not governed by the same rules as primary agencies, such as collocated MBS and PBS details stored in larger health information databases, like the Personal Health Network databases for private sale to researchers[8].
IIS 14	The APF was glad to note that the OAIC did accept recommendations asking that identifiable claims from primary agencies be limited to medical researchers (**IIS 14**). But this **is a minor advance for protecting an individual's private health information because an indeterminate number of people can already access everyone's data**. This includes anyone providing you with healthcare or related help – appointment booking systems, clinicians, their support staff and employers, practice managers and IT staff, research bodies and agencies, services can read, share, use and disclose this identified (or open) information[10].

IIS 6 & 12	**Unit level claims information can be released as open data (IIS 6) and the OAIC did partly agree to link personal IDs to old health information for primary agencies** (IIS12).
IIS 2, 8 & 15	The OAIC accepted other recommendations about requirements to account for varied data retention requirements (IIS15) and keeping technology neutral to the extent possible (IIS 2). But **a recommendation about clarifying data separation arrangements was not adopted** (IIS 8). The OAIC responses to these recommendations are only useful for auditors, not the community, because in many instances, **despite the capacity of health agencies to track information, individuals can't ask to see the data held about them**.
IIS 11	**The OAIC did not agree to primary agencies publishing linkage reports (IIS 11) either. The Office's decision makes the job of people trying to locate where their health information is stored impossible**. The APF asks for further open discussion as to why the OAIC has made this choice for the community.
IIS 4 & 10	Also, **the OAIC did not prohibit secondary uses resulting in 'individuated intervention', while not even defining the meaning of the term** (IIS 4). Disclosure requirements for primary agencies were simplified and a recommendation to permit disclosure to secondary services received partial agreement (IIS 10). Also, **the Office did not agree to remove overlap under DATB sharing agreement requirements.** The APF calls for a meaning to the term 'individuated intervention' to help us understand how secondary uses, such as DATB sharing, will intersect with 'individuated attention'. We also request a fuller discussion of disclosure requirements to ensure a transparent process for community members.
IIS 7 & 13	The OAIC did not adopt recommendations about formally imposing governance and security requirements that align with the *National Privacy Act (1988)***,** Australian Privacy Principles (APP) 1 and 11 (IIS 7)[11]. The APF agrees that alignment with the APPs at this point would not be useful because the government has been slow to implement the findings of their response to the *Privacy Act Review Report*[12], due to be tabled in 2024. Alignment with the current APPs may create conflict, confusion and problems for the community after the Privacy Act Review Report is implemented.

	Further **the OAIC did not even accept recommendations about the desirability of the rules aligning more closely with the format of s 16B(3) (IIS13) in the Privacy Act**[13]**, an action that would have helped to clarify overlapping Australian health privacy rules for now**. The APF requests clarification of the decision-making process here.
Timing	At the same time, **the APF is concerned about the timing of implementing the Health Privacy Rules, 2025, at all before the national *Privacy Act (1988)* has been amended. This action is 'putting the cart before the horse', ensuring confusion continues to reign in interactions between national privacy laws and national health privacy laws**. This outcome needs to be reconsidered considering community expectations about the scheduling of the tabling of the draft Report. We do **generally support IIS' recommendations that these Rules all be consistent with the Privacy Act, especially the long-overdue revised version** expected soon.
Private right of action	Finally, **while the proposed reforms look like useful improvements for bureaucrats and researchers in most cases, we flag the urgent need for a citizen-centric private right of action**[14]**, with strong enforcement options for the individual concerned**.
Error?	A couple of typographical errors in the Response document have interfered with our understanding of it- namely the response to IIS 10, where we interpret 'PICs' as 'PINs' and the response to IIS 16, where we interpret clauses '13 and 14' as clauses '12 and 13'.

Conclusion

The APF is of the view that **provisions in the draft Rules, 2025, do not work well for the Australian community, and require explanation or replacemen**t. The opaque and complex matrix of responsibilities outlined in the Rules, especially between primary and secondary agencies and complex interrelationships between government agencies, on the one hand, accompanied by the lack of consequences for misuse or misinterpretation by end-users (with limited or ineffective transparency and remedies for those affected by these flaws) on the other hand, is a persistent discomfort.

The APF think both:

a. the specific issues described here need to be explicitly addressed, and also

b. that the **broader overall failure of the Rules** to deliver a clear, comprehensible and patient-centric health privacy governance regime **needs further fundamental work if Australian patients are not going to have good reason to lose confidence that it is safe to trust clinicians with their most sensitive personal information, and in the trustworthiness of regulators, government, researchers and health care professionals.**

The APF believes this ongoing lack of transparency about which agencies and why their health information is being shared erodes peoples' trust in government information sharing processes, signaling to many that refreshing *the National Health Information (Privacy) Rules* in 2025 is only useful to bureaucrats, politicians and health researchers.

Contact: Dr. Juanita Fernando, Vice-Chair, Australian Privacy Foundation.
Phone: 0408` 131 535

References

1. Office of the Australian Information Commissioner. Draft National Health (Privacy) Rules 2025. 3 April 2024; available https://www.oaic.gov.au/__data/assets/pdf_file/0018/178200/DRAFT-National-Health-Privacy-Rules-2025-for-public-consultation.pdf
2. Australian Privacy Foundation. Submission in response to the National Health (Privacy) Rules 2018 review, 4 June 2021. Available https://privacy.org.au/wp-content/uploads/2021/06/OAIC-NatHlthPRules-210604.pdf
3. Australian Privacy Foundation. The Privacy Legislation Amendment (Enforcement and Other Measures) Bill 2022, 8 November 2022. https://privacy.org.au/wp-content/uploads/2022/11/SLCAL-PrivEnfBill-221108.pdf
4. Australian Privacy Foundation. Australia's failed privacy laws Australian Privacy Foundation submission to the Australian Government on implementation of the ACCC's Digital Platforms Inquiry—Final Report' 10 September 2019. Available https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3341044
5. Australian Privacy Foundation. Bringing Australia's Privacy Act up to international standards (Submission in response to the Privacy Act Review - Issues Paper), 17 December 2020. Available https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3752152
6. Office of the Australian Information Commissioner. National Health Privacy Rules OAIC Response to Final IIS Report, 2024. Available https://www.oaic.gov.au/__data/assets/pdf_file/0019/178201/National-Health-Privacy-Rules-OAIC-response-to-IIS-Final-Report.pdf
7. Australian Government National Health Act 1953, Federal Legislation. 22 July 2020. https://www.legislation.gov.au/Details/C2017C00250
8. Australian Privacy Foundation. Media Release: Every 3 minutes Australian health services collect 400 data points of up to 25m patients' medical records, April 25, 2021. Available https://privacy.org.au/2021/04/25/media-release-every-3-minutes-australian-health-services-collect-400-data-points-of-up-to-25m-patients-medical-records/

9. Towards a post-privacy world: proposed bill would encourage agencies to widely share your data. Arnold, B, Available https://privacy.org.au/2020/09/17/towards-a-post-privacy-world-proposed-bill-would-encourage-agencies-to-widely-share-your-data/
10. Kemp, K. Popular fertility apps are engaging in widespread misuse of data, including on sex, periods and pregnancy, Commentary, 222 March 2023. Available https://privacy.org.au/home/updates/
11. Office of the Australian Information Commissioner. The Australian Privacy Principles, 12 March 2014. Available https://www.oaic.gov.au/privacy/australian-privacy-principles
12. Attorney-General's Department, Australian Government. Government response to the Privacy Act Review Report, 28 September 2023. Available https://www.ag.gov.au/rights-and-protections/publications/government-response-privacy-act-review-report/
13. Australian Government; Federal Register of Legislation- Privacy Act 1988, 18 October 2023. The Conversation. Available https://www.legislation.gov.au/C2004A03712/latest/text
14. Attorney-General's Department, Australian Government. Government response to the Privacy Act Review Report, 28 September 2023. Available https://www.ag.gov.au/rights-and-protections/publications/government-response-privacy-act-review-report/

About the Australian Privacy Foundation

The Australian Privacy Foundation (APF) is the nation's foremost independent civil society body concerned with community data protection, privacy and information security expectations. The APF is supported and advised by a panel of notable Australians, and worldwide luminaries including former judges and former Ministers of the Crown.

The Foundation leads the fight to defend the right of people to control their personal information and to be free of needless intrusions. The APF continues to draw government attention to human privacy rights issues in frequent submissions to parliamentary committees and government agencies.

The following pages provide access to further information about the APF:

Policies	https://privacy.org.au/publications/by-date/
Media Releases	https://privacy.org.au/home/updates/
Current Board Members	https://privacy.org.au/about/contacts/
Patrons and Advisory Panel	https://privacy.org.au/about/contacts/advisorypanel/