



SUBMISSION

NATIONAL HEALTH (PRIVACY) RULES 2021 REVIEW

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OVERVIEW

The *National Health (Privacy) Rules 2021*, a legislative instrument made under section 135AA of the *National Health Act 1953*, are due to repeal on 1 April 2025. The Rules set out how Australian Government agencies may use, store, disclose and link Medicare Benefits Scheme (**MBS**) and Pharmaceutical Benefits Schedule (**PBS**) claims information.

The Office of the Australian Information Commissioner (**OAIC**) has issued a draft version of [National Health \(Privacy\) Rules 2025](#) (the **Rules**), and is seeking submissions from interested stakeholders on all elements and aspects of the draft Rules, including, but not limited to, their effect on individuals, the operation of MBS and PBS processes, public sector operations and policy development, and open data and associated research initiatives.

This document is Calabash Solutions' submission to the revised Rules.

Calabash Solutions welcomes the opportunity to contribute to the review of the Rules, and makes ourselves available for further discussion, questions and comments.

Calabash Solutions consents to the publication of all or part of our submission to public fora.

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CONSULTATION QUESTIONS

1. Within the scope of section 135AA of the National Health Act, do the revised Rules appropriately reflect community attitudes and expectations regarding the handling of their personal information; in particular, certain health information?

As noted in the most recent Australian Community Attitudes to Privacy Survey 2023¹ (**ACAPS 2023**), Australians rated health service providers, followed by federal government agencies, as the most trusted industry sectors across most aspects of personal information handling (74% and 67% respectively as ‘very trustworthy’ or ‘somewhat trustworthy’) (base: Australians 18+ years n=1,642).

While ACAPS 2023 did not specifically examine community attitudes to the handling of their health information, the ACAPS 2023 trend mirrors findings from a 2022 study undertaken by The American Medical Association², which surveyed 1,000 patients across the USA on their perspectives toward the privacy of their medical information (**AMA Survey 2022**). The AMA Survey 2022 indicated patients are most comfortable with physicians and hospitals having access to personal health data (75.2% ‘My doctor’s office’ and 64.2% ‘Hospital or health system’, n=1,000).

It is Calabash Solutions’ view that the revised Rules go a long way to reflect community attitudes and expectations regarding the handling of their personal information, and health information. The revised Rules specify the ways in which claims information may be stored, permitted uses, circumstances in which agencies may disclose claims information, storage requirements, and prohibitions of certain linkages of claims information. We believe that the revised Rules provide the necessary guiderails to protect both claims information and old information, and thereby contribute to the currently held view that federal government agencies can be trusted with the handling of personal information.

¹ Office of the Australian Information Commissioner, Australian Community Attitudes to Privacy Survey 2023 (https://www.oaic.gov.au/data/assets/pdf_file/0025/74482/OAIC-Australian-Community-Attitudes-to-Privacy-Survey-2023.pdf), 2023.

² American Medical Association, Patient perspectives around data privacy 2022 (<https://www.ama-assn.org/system/files/ama-patient-data-privacy-survey-results.pdf>), 2022.

2. Within the scope of section 135AA of the National Health Act, do the revised Rules appropriately reflect public policy approaches favouring data use and re-use in research, evidence-based decision-making, and the provision of government services generally?

Findings from ACAPS 2023³ indicate that 44% of Australians were very or somewhat comfortable with the government using their personal information for research and service and policy development (base: Australians 18+ years n=1,642). While this result reflects a rise in community attitudes to governments' use of data (up from 38% in 2017 and 40% in 2020), Calabash Solutions continues to hold the view⁴ that, where it is reasonably possible to identify an individual from the information, the obligation to seek informed consent from individuals to the use of the information for medical research is extended to all circumstances where reasonably identifiable information is used for medical research purposes.

The current draft of the revised Rules only require informed consent for disclosures by a primary agency to a person who is not an agency for medical research, where it is reasonably possible to identify an individual from the information that is proposed to be disclosed, and where the research is not conducted in accordance with guidelines issued by the National Health and Medical Research Council under section 95 of the *Privacy Act 1988* (s11(6) National Health (Privacy) Rules 2025).

It is our view that consent provisions be extended to all uses of reasonably identifiable information for medical research purposes, including circumstances where a primary agency uses claims information for medical research purposes (s10 National Health (Privacy) Rules 2025), and where a primary agency shares information with an agency for medical research purposes.

Our position is supported by responses from the previous Australian Community Attitudes to Privacy Survey 2020⁵ (**ACAPS 2020**), which showed that Australians are far less likely to be comfortable with Government agencies sharing their personal information with businesses in Australia (53% 'very

³ Office of the Australian Information Commissioner, Australian Community Attitudes to Privacy Survey 2023 (https://www.oaic.gov.au/data/assets/pdf_file/0025/74482/OAIC-Australian-Community-Attitudes-to-Privacy-Survey-2023.pdf), 2023.

⁴ Refer Calabash Solutions National Health (Privacy) Rules 2018 review submission (https://www.oaic.gov.au/data/assets/pdf_file/0026/9629/8-calabash-solutions-national-health-privacy-rules-2018-review.pdf), 2021.

⁵ Office of the Australian Information Commissioner, Australian Community Attitudes to Privacy Survey 2020 (https://www.oaic.gov.au/data/assets/pdf_file/0015/2373/australian-community-attitudes-to-privacy-survey-2020.pdf), 2020.

uncomfortable' or 'somewhat uncomfortable') (base: Australians 18+ n=1,004). These ACAPS 2020 results mirror the AMA survey 2022⁶ findings, which indicate that almost 80% of patients want to be able to opt-out of sharing some or all their health data with companies, more than 75% of patients want to opt-in before a company uses any of their health data, and more than 75% of patients want to receive requests prior to a company using their health data for a new purpose (n = 1,000).

We note further that in the ACAPS 2023⁷, 84% of Australians want more control over the collection and use of their personal information, a proportion that is consistent across all demographic segments. It is our view that individuals must be presented with choice when information that reasonably identifies them is shared for medical research purposes. Individuals may have strongly held views regarding the nature of the research being undertaken or may wish to be excluded for fear of harm if their information is compromised in some way by researchers.

3. Within the scope of section 135AA of the National Health Act, do the revised Rules appropriately reflect privacy protective measures to ensure MBS and PBS data are appropriately safeguarded?

s7(1) of the revised Rules outlines the technical specifications required to store claims information in a database. On this, Calabash Solutions continues to hold the view⁸ that s7(1)(b), which imposes the obligation for the primacy agency to notify the Information Commissioner of the technical specification and any non-minor variations, is a redundant, and burdensome, obligation that (1) adds nothing to the intent of the requirement and (2) does not talk to what actions, if any, the Information Commissioner will take in response to receipt of such information. We continue to support amendments to s(7)(1), to place the burden of accountability and ensuring technical specifications are current, up to date and adhere with industry best practice, on primary agencies. The Rules could be updated to include provisions on the cadence of technical specification reviews; for example, at a minimum, an annual review, or a review in

⁶ American Medical Association, Patient perspectives around data privacy 2022 (<https://www.ama-assn.org/system/files/ama-patient-data-privacy-survey-results.pdf>), 2022.

⁷ Office of the Australian Information Commissioner, Australian Community Attitudes to Privacy Survey 2023 (https://www.oaic.gov.au/data/assets/pdf_file/0025/74482/OAIC-Australian-Community-Attitudes-to-Privacy-Survey-2023.pdf), 2023.

⁸ Refer Calabash Solutions National Health (Privacy) Rules 2018 review submission (https://www.oaic.gov.au/data/assets/pdf_file/0026/9629/8-calabash-solutions-national-health-privacy-rules-2018-review.pdf), 2021.

response to a proposed or planned change (technological or information handling practice change) or in response to a privacy impact assessment finding, a data breach or an improvement initiative.

We know too from the ACAPS 2023⁹ that there is a common view that government agencies should do more to protect Australians' personal information (89% 'agree' or 'strongly agree') (base: Australians 18+ years, n=1,916). To this end, it is our view that s9 of the revised Rules, which outlines the circumstances in which prohibits the creation of copies of claims information in paper or similar form, be amended to strengthen privacy protective measures. Specifically, we suggest amending s9 to either clarify what is meant by a '*similar form*' or reference '*copies of claims information in any form*' (and thereby exclude '*claims information in paper or similar form*').

Calabash Solutions supports Schedule 1 of the revised Rules, which specifies the requirements for data sharing agreements. However, we suggest an amendment to s2 of Schedule 1 which outlines data sharing agreement provisions where the intended recipient of the disclosed claims information is an agency. Specifically, we suggest that s2 provisions be updated to include the same or similar storage and security requirements and retention and destruction requirements as currently outlined in s3 of Schedule 1 of the revised Rules (where the intended recipient of the disclosed claims information is not an agency).

4. Additional commentary on the revised Rules

Calabash Solutions notes the following additional commentary on the revised Rules:

- (1) The term '*on-disclose*' is used in s2(5) and in s3(4) of Schedule 1—Data sharing agreements. It is our view that '*on-disclose*' is neither a grammatically correct nor widely used, well-known, term. While its meaning may be inferred from the context, we suggest amending the term '*on-disclose*' to better reflect the intended meaning of '*onward disclosure*' or '*further disclosure*'.
- (2) Several obligations in the revised Rules refer to reporting obligations:
 - Refer s16(3) for obligations for a primary agency to provide annual reporting to the Information Commissioner on linkages of records; and

⁹ Office of the Australian Information Commissioner, Australian Community Attitudes to Privacy Survey 2023 (https://www.oaic.gov.au/data/assets/pdf_file/0025/74482/OAIC-Australian-Community-Attitudes-to-Privacy-Survey-2023.pdf), 2023.

- Refer s21 for obligations for a primary agency to provide annual reporting to the Information Commissioner on re-linkages of old information.

It is our view that these reporting obligations are arbitrary, and place unnecessary burden on the Information Commissioner. The Rules do not include provisions for what actions, if any, the Information Commissioner will take in response to receipt of annual reports, other than to decide whether to make them publicly available.

If the intent of the reporting obligations is to monitor and provide oversight on the handling of linked claims information and re-linked old information by primary agencies, then the purpose may be better served by requiring primary agencies to publish and make public such reports. It is our view that such an amendment would increase transparency and improve accountability.



OUR VISION

Healthy. Safe. Respected. Free.

We believe in a world where all people are healthy, safe, free, and respected.

OUR MISSION

Helping Others.

The best versions of ourselves emerge when we help others to be the best versions of themselves.

OUR APPROACH

Listen. Support. Analyse. Discover

- We value patient privacy, and work with health service providers to assure and implement compliant privacy programs.
- We listen to patients and carers as they talk about their journeys through all systems of care.
- We develop and deliver Continuous Professional Development (CPD) for clinicians, support staff, and practice managers.
- We work with small and medium datasets to understand what inhibits or enables treatment compliance within unique patient cohorts.
- We embrace solutions that work, from technology to the creative arts, to cultivate health systems that deliver patient-centred care.

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OUR PRIVACY SERVICE OFFERINGS

Online Privacy Training

Designed specifically for private sector health care workers. Offers a commonsense, practical view of the Australian Privacy Principles. Demonstrates how to apply the Australian Privacy Principles in Australian private health care sector.

Face-to-Face Training

Register for face-to-face training delivered at your practice, for your team.

Face-to-face training lets you and your team discuss your practice-specific privacy questions, concerns.

Privacy Compliance Assessment

Does your practice comply with the Australian Privacy Act?

We assess your practice's compliance with the privacy principles using our privacy compliance assessment tools.

Onsite visit and review of your privacy systems, processes, and practices against the thirteen Australian Privacy Principles contained in the Privacy Act.

Privacy Compliance Heat Map

After the privacy compliance assessment, we produce your unique privacy compliance heat map showing areas of strong and weak compliance against the thirteen Australian Privacy Principles.

Templated Privacy Processes

Use our privacy compliance heat map to uncover your areas of weak compliance. We work with you to strengthen the gaps and create privacy processes for your practice

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