



RACGP

Royal Australian College of General Practitioners

Submission to the Office of the National Data
Commissioner:

Data sharing and release legislative reform

October 2019

Healthy Profession.
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1. Key recommendations

With respect to health-related data collected by Commonwealth Government entities, the Royal Australian College of General Practitioners (RACGP) supports, in principle, the proposed Data sharing and release legislative reforms.

However, the RACGP recommends:

- the Data Sharing Principles, which form part of the legislations risk management framework, be expanded to strengthen the governance structures and risk management for the sharing of public data
- the development of a concise checklist style document containing summary information to support the *Best Practice Guide to Applying Data Sharing Principles*
- strengthening the protections for possible re-identification of de-identified data shared under this legislation
- the ministerial power to amend legislative rules be transferred to a body independent of government such as the National Data Advisory Council
- that organisations, as well as individuals should be held accountable for inappropriate activities under this legislation
- that the legislation defines at which point private data forms part of public sector data, when that data is shared with an entity covered under this legislation
- clear articulation regarding the context of data sharing and continued communication with relevant parties in order to build public trust
- adequate resourcing to drive behaviour changes and support best practice when sharing data
- Aboriginal and Torres Strait Islanders peoples are engaged in the development of legislation through an ongoing Indigenous Advisory Committee to the National Data Commissioner.

2. Executive summary

The RACGP welcomes the opportunity to provide written comment to the Office of the National Data Commissioner on the Data sharing and release legislative reforms. We recognise the value of data sharing to better inform policy, population health and research. We support, in principle, de-identified data sharing and release to deliver benefit to Australians as part of the many datasets overseen by the National Data Sharing Commissioner.

The RACGP's mission is to improve the health and wellbeing of all people in Australia by supporting general practitioners (GPs), general practice registrars and medical students. The RACGP is Australia's largest professional general practice organisation, representing more than 40,000 members who treat almost 22 million patients across Australia every year.

For the benefits of data sharing to be realised, the challenges of data collection, data quality, information security and data governance must be addressed. Those providing data need to see the benefits of sharing data and feel confident that patient privacy will be preserved.

3. Consultation response

3.1 Consultation questions

3.1.1 Do you think the distinction between data sharing and data release is clear? How could this distinction be clearer?

The RACGP believes the distinction between data sharing and data release is clear.

3.1.2 What are the challenges for open release of public sector data?

The RACGP believes the key challenge for open release of public sector data will be the management of these data once released. Whilst the release of public data can be prescribed through the legislation, once data are released it is difficult to control its subsequent use and retrieval.

3.1.3 Do you think the Data Sharing and Release legislative framework will achieve more streamlined and safer data sharing?

The RACGP believes the proposed legislative framework has the potential to achieve more streamlined and safer data sharing. However, in order for the maximum potential of the data to be realised, data quality must be addressed across various systems, including the use of core common health data sets and consistent clinical terminology. To this end the RACGP supports work by the CSIRO, commissioned by the Department of Health, to co-develop foundation products to support improving data quality in primary health care.

3.1.4 What do you think about the name, Data Sharing and Release Act?

The RACGP is supportive of this title.

3.1.5 Do the purposes for sharing data meet your expectations? What about precluded purposes?

The RACGP acknowledges most general practice data are out of scope for this legislation. However, under the Practice Incentive Program Quality Improvement, where data is provided to the Primary Health Networks (PHNs) and the Australian Institute of Health and Welfare (AIHW), private general practice does fall under the Data sharing and release legislation. Where these circumstances occur, the RACGP is supportive of the proposed legislation.

3.1.6 What are your expectations for commercial uses? Do we need to preclude a purpose, or do the Data Sharing Principles and existing legislative protections work?

The RACGP strongly believes public sector data, including healthcare data, should not to be sold by government organisations. The RACGP supports the sharing and release of data for commercial purposes where a public benefit is proven. In a health context, a health equity lens should be applied to offers of commercialisation, which would help determine public good – i.e. public data may be used to develop an app to allow a particular community to access health services serving their specific needs.

Whilst commercial entities may use the data for commercial reasons, the on-selling of data must be prohibited.

3.1.7 Do you think the Data Sharing Principles acknowledge and treat risks appropriately? When could they fall short?

The RACGP believes the Data Sharing Principles should be expanded to strengthen the governance structures and risk management for the sharing of public data. This will ensure those sharing data have confidence in doing so, knowing patient's health information is well protected. Governance needs to be

strong enough to protect the public interest and to ensure the sharing and use of data does not cause any unintended harms

3.1.8 Is the Best Practice Guide to Applying Data Sharing Principles helpful? Are there areas where the guidance could be improved?

The RACGP believes the *Best Practice Guide to Applying Data Sharing Principles* is a comprehensive and helpful reference. To further improve the guide, the RACGP recommends the development of a concise checklist style document containing summary information, whilst maintaining the full guide as a reference tool. The Office of the National Data Commissioner needs to be adequately resourced to drive the necessary behaviour changes required to facilitate the sharing of data and support best practice in line with the legislation and data sharing principles.

3.1.9 Do the safeguards address key privacy risks?

The RACGP recommends strengthening the protections for the possible re-identification of de-identified data within the legislation. The 2016 reidentification of patient information from published MBS and PBS data (which had been de-identified) is an example of why robust structures need to be in place to protect personal information and build public trust.

3.1.10 Are the core principles guiding the development of accreditation criteria comprehensive? How else could we improve and make them fit for the future?

The RACGP recommends the ministerial power to amend legislative rules should be transferred to a body independent of government such as the National Data Advisory Council.

3.1.11 Are there adequate transparency and accountability mechanisms built into the framework, including Data Sharing Agreements, public registers and National Data Commissioner review and reporting requirements?

The RACGP is supportive of the transparency and accountability mechanisms outlined.

3.1.12 Have we achieved the right balance between complaints, redress options and review rights?

Due to the principles based nature of the proposed legislation, the RACGP is supportive of a remedial process for individuals/organisations for non-malicious breaches. Serious penalties should be reserved for malicious breaches.

3.1.13 Have we got our approach to enforcement and penalties right for when things go wrong? Will it deter non-compliance while encouraging greater data sharing?

The RACGP is concerned only individuals, rather than both individuals and organisations, are held accountable and disciplined under the proposed legislation. The RACGP recommends the legislation recognises individuals may be acting in the interest of an organisation, and that organisations therefore need to be accountable. Penalties for an individual or organisation should be determined on a case-by-case basis.

3.1.14 What types of guidance and ongoing support from the National Data Commissioner will provide assurance and enable safe sharing of data?

The RACGP advocates for the delivery of robust education and support for accrediting data service providers and users, and supports the view that accreditation will engender trust and increase transparency in the system.

3.2 Indigenous data, data sovereignty, sharing and release

In relation to Indigenous data, data sovereignty, sharing and release, the RACGP:

- welcomes the work being done to acknowledge the unique considerations required in the sharing and release of Indigenous data
- believes data sovereignty, and how this is enacted in the legislation and in practicality, is significant to this work and requires guidance from Aboriginal and Torres Strait Islander Communities. This includes the development of legislation through an ongoing Indigenous Advisory Committee to the National Data Commissioner
- believes the categorisation of Indigenous data requires careful consideration and consultation. Whilst some government data sets may not be considered Indigenous data, those data sets with a disproportionately greater representation of Aboriginal and Torres Strait Islander peoples may be considered such. Care must be taken in Indigenous identification within data sets, as identification methods differ i.e. in a healthcare context self-identification at a general practice, or self-identification to My Health Record, or identification through the Voluntary Indigenous Identifier. Consideration should be given to the removal of Indigenous identifiers prior to data sharing unless specifically required
- encourages the use of data by Aboriginal and Torres Strait islander communities. However communities need to be empowered as data governors, building capacity to use this data, both in personnel, training and IT/infrastructure, in order for these benefits to be realised. Similarly, agencies seeking access and use of Indigenous data should be required to have an Indigenous advisory group or governance structure in place as part of their accreditation/access.

3.3 Additional comments

The RACGP is largely supportive of the proposed framework, and believes it is reasonable and balanced. We are acutely aware of the sensitive nature of health information and the paramount importance of respecting and preserving patient privacy.

The sharing of public sector data is complex. Whilst general practice data is considered private data, and thus outside the scope of the proposed legislation, there may be a subsequent impacts for general practice through the sharing of data with other entities such as Primary Health Networks (PHNs). The legislation must define at which point private data forms part of public sector data through such data sharing mechanisms. Whilst the RACGP is not necessarily opposed to the inclusion of such data under the legislation, appropriate governance must be in place.

Whilst the RACGP supports the secondary use of anonymised health data to improve health outcomes, we would not support the use of data sharing for purposes such as managing performance of healthcare providers, professional revalidation and unnecessary compliance and are pleased to see this addressed in the legislation. The RACGP recognises other legislation is in place addressing data sharing for compliance purposes i.e. using data analytics to target compliance activities under the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS).

The recent context of government use of data, rightly or wrongly, demonstrates how easily public trust can be undermined by concerns over privacy and inappropriate use of data. Examples include the Medicare 'robo-debt' scheme, the dissemination of letters to persons prescribed particular medications as identified through PBS data, and the implementation of My Health Record – which required legislative changes to build public confidence. Building public trust for this legislation will be critical and the context of data sharing and release needs to be clearly articulated and communicated.

The RACGP recommends that where data is held by contracted agencies such as PHNs, or where data is held by state agencies, the use of that data be subject to contracts/legislation that is consistent with the proposed National legislation.

4. Final comments

The RACGP is a key stakeholder with the necessary expertise and knowledge to consult on the implementation of data sharing and release legislation, to deliver health benefit to Australians.

The RACGP is pleased that a number of the concerns outlined in the 2018 RACGP response to the *Issues Paper: New Australian Government Data Sharing and Release Legislation* consultation, have been addressed and the RACGP looks forward to continued engagement throughout the consultation process and the development and implementation of the legislation.