



RACGP

*Secondary use of  
general practice data*



## Secondary use of general practice data

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*We recognise the traditional custodians of the land and sea on which we work and live.*

# Contents

<i>1. About this document</i>	<i>1</i>
<i>2. Introduction</i>	<i>1</i>
<i>3. Secondary use of general practice data</i>	<i>1</i>
3.1 Is my practice required to provide healthcare data to external organisations that request it?	1
3.2 What do my patients need to know?	2
3.3 What sort of healthcare data does general practice collect?	2
3.4 How can general practice data make a difference?	2
3.5 Can my practice use its own data for secondary purposes?	2
<i>4. Requests for secondary use of general practice data</i>	<i>3</i>
4.1 Secondary use of data principles	3
<i>Decision-making support tool</i>	<i>4</i>
<i>Further reading</i>	<i>6</i>
<i>Definition of terms</i>	<i>6</i>

# 1. About this document

The Royal Australian College of General Practitioners' (RACGP's) *Secondary use of general practice data* provides decision-making support to assist you and your practice staff to decide whether it is appropriate to release de-identified healthcare data at the request of an external organisation.

A definition of terms used throughout this guide is available at the end of this document.

## 2. Introduction

Health information collected as part of delivering clinical care can be used for secondary purposes. When data is used outside of the general practice setting, for purposes other than which it was originally collected, it is referred to as 'secondary use' of data. It includes such activities as research, quality and safety measurement, provider certification or accreditation and marketing.

The introduction of electronic health records has enabled data to be collected as part of routine clinical care. Patient healthcare data is stored in multiple places, such as general practice management systems and clinical information systems, hospital patient management systems, pathology and diagnostic imaging systems, clinician notes, medical correspondence, insurance claims and billing information.

Data has become a highly valued commodity and practices need to think carefully about the worth of their data and the intended purpose of the secondary use.

## 3. Secondary use of general practice data

Potential public health gains from secondary use of de-identified patient data include clinical research outcomes, better informed epidemiological research, and improved service planning and quality assurance. However, as healthcare information is considered one of the most sensitive types of personal information, the use of healthcare data is controlled through legislation to ensure patient privacy is maintained.

### 3.1 Is my practice required to provide healthcare data to external organisations that request it?

Your practice is ordinarily not obliged to provide healthcare data for secondary use outside your practice, unless it has been mandated to do so by government, for example, for use in cancer screening programs. However, practices are encouraged to participate in initiatives that contribute to quality improvement and better health outcomes.

Therefore, your practice needs to be able to determine whether the request for secondary use of your patients' healthcare data is appropriate. For example, PHNs often seek population health data to improve the provision of primary care support. Data provided needs to be de-identified with respect to the confidential nature of patient, provider and practice information.

## 3.2 What do my patients need to know?

Your practice needs to ensure that your patients' rights and privacy are protected. Your patients need to be assured that data collection, disclosure and the way the data is held is conducted in accordance with the *Privacy Act 1988*. It is a requirement to advise your patients that their healthcare information may be de-identified and used for secondary purposes.

Your practice must display information publicly, for example, in the waiting room or on your practice website. The information should provide patients with assurances and advice on their rights, and how their data is protected, and must clearly state your practice's approach to collection of healthcare information for primary and secondary purposes.

## 3.3 What sort of healthcare data does general practice collect?

General practice collects basic medical and clinical patient records and other data linked to them, including:

- family history
- pathology reports
- diagnostic imaging
- prescribing history
- consultation notes
- therapy recommendations
- measurements
- images
- biographical information.

Healthcare information may be held in multiple clinical and administrative systems, databases and reporting systems, both structured and unstructured.

## 3.4 How can general practice data make a difference?

The healthcare system in Australia is facing a number of challenges, including the management of chronic disease and caring for an ageing population. The collection of high-quality health data at a general practice level has the potential to:

- facilitate increased efficiencies in care delivery
- create more proactive preventive interventions
- identify at-risk populations
- inform health strategy and planning
- support quality improvement initiatives in Australian general practice.

The collation and aggregation of patient healthcare data creates new analytical possibilities for healthcare researchers, providers and policymakers.

## 3.5 Can my practice use its own data for secondary purposes?

Appropriate use of healthcare information to improve a patient's health outcomes within the general practice is not considered secondary use of data. Practice data can be used within the practice for quality improvement, undertaking clinical audits of the practice population, and benchmarking where the appropriate permissions exist.

Any decisions on changes to practice systems and clinical care as a result of quality improvement initiatives should be based on practice data and can include:

- implementing preventive programs for patients
- demonstrating a population's level of need
- providing better community facilities and services to promote preventive measures, for example, promoting physical activity where obesity could be a population health problem, clinical audits and quality improvement activities.

## *4. Requests for secondary use of general practice data*

Requests for secondary use of data can come in many forms, such as research projects conducted by universities, and government initiatives such as cancer screening and immunisation programs.

Data is a highly valued commodity and practices need to think carefully about the worth of their data and the intended purpose of the secondary use.

When considering a request for releasing healthcare data for secondary purposes, your practice needs to ensure that relevant standards and ethical principles are used to protect the needs and interests of patients and general practitioners (GPs).

General practices need to consider when de-identification may be appropriate, how to choose appropriate de-identification techniques and how to assess the risk of re-identification. The Office of the Australian Information Commissioner (OAIC) resource [De-identification of data and information](#) provides further information to assist businesses to protect privacy when using or sharing information.

### **4.1 Secondary use of data principles**

The use of all information for secondary purposes should be transparent and appropriate. Consider incorporating the following principles when developing a practice policy for the management of requests for the secondary use of data:

- Nominate an authorised person within your practice who will provide permission to external organisations for your practice data to be used for secondary purposes.
- Data should only be provided for secondary use where your patients have provided informed consent. To be able to give informed consent, your patients should be provided with specific information about how the data will be used.
- Any data that is provided by your practice for secondary use must be de-identified with respect to any patient, provider and practice details.
- Where the data makes it possible to identify a particular patient, provider or practice, that data should not be provided for secondary use.
- Ensure that data is provided in such a way to ensure that it cannot be used for any other purposes.
- Ensure any data that has the appropriate consents to remain identifiable cannot be forwarded or 'on-sold' to other organisations.

## Decision-making support tool

If your practice receives a request to provide data for secondary use, the following considerations can assist you to make an informed decision about whether to comply with the request. It is important for you and your practice staff to understand what the data will be used for and to ensure that it will be kept safe and secure.

Working through the questions of the decision-making support tool can help form part of your risk mitigation strategy when providing data for secondary use. This tool provides guidance only and certain questions may not apply to de-identified data.

The questions in the decision-making tool will help you determine how comprehensive processes and procedures are to ensure information is collected ethically, legally, securely and confidentially.

Each section of the decision-making tool has explanatory notes to guide you on what information should be included to address each question. Once all of the questions have been completed you will need to analyse the information to make an informed decision on whether to provide your practice data for secondary use.

Management of secondary use of data	
<b>Does your practice have a policy regarding data management?</b>	Your practice should develop a policy for everyone to understand and follow.
<b>Do you have patient consent to release data outside of your practice?</b>	All entities need to comply with the Privacy Act and The Australian Privacy Principles, ideally setting out their obligations in an open and transparent manner.
<b>Does the external entity requesting your practice's data have a secondary use of data policy?</b>	The entity requesting your practice's data should have a secondary use of data policy in place explaining how the data will be protected.
<b>To provide your practice with appropriate assurances, can the entity requesting the data outline their responsibility as custodian of the data? How do they monitor this?</b>	Your practice will need to carefully consider if the data you are providing will be adequately protected.
<b>Is ethics approval required for this research? If so, has this been approved?</b>	Research involving human participants will usually require ethics approval.
<b>What, specifically, will the data collected be used for?</b>	The organisation requesting the data should clearly state what the data will be used for.
<b>Will the data be forwarded on to other parties in the future?</b>	The entity requesting the data should have security and assurances put in place to ensure its protection and your patients' continued protection.

### Practice processes for providing data for secondary use

<b>Does your practice have a process to manage consent?</b>	Patients must be informed that their data is being used for secondary purposes outside of your practice. Your practice policy should be published publicly (eg on your website or in the waiting room).
<b>What process is being used to extract the data from your practice?</b>	List any data extraction software that your practice uses and how the data will be represented. Consider if the extraction process will impact on the functioning of the practice's clinical information system.
<b>How is the data to be transferred? Is this transfer secure?</b>	List if the data will be transferred electronically, via USB or other means. Describe the security arrangements to protect the data (eg data will be encrypted).
<b>Is the data de-identified, anonymised or pseudonymised?</b>	Explain how the data is presented with regards to any potentially identifying features.
<b>Is your practice or healthcare provider identifiable from the de-identified patient data provided?</b>	De-identified patient data may still retain the prescribing healthcare provider and therefore there is a higher risk of the data being re-identified.

### Risk assessment of providing data for secondary use

<b>For how long will the entity requesting the data keep it?</b>	Ensure the date of request and the end date are recorded as part of any risk assessment template or analysis.
<b>What secure means will be used to destroy the data?</b>	Ensure that you obtain this information from the entity collecting the data.
<b>Where will the data be kept?</b>	Data must be kept within Australian borders, as per legislation.
<b>How will the data be protected?</b>	The entity requesting the data should provide information regarding how the data will be stored, any details regarding encryption and any physical security requirements for storage of devices that hold the data.
<b>How will access to the data be controlled?</b>	The entity requesting the data should provide information regarding who will have access to the information, how this access will be granted and if access to the data can be audited.

### Value of the request for your practice's data

<b>What are the benefits for your practice, patients, GPs, and for public health? Can the value of the outcomes be measured?</b>	Consider whether the request for use of your practice's data will result in any population health improvements and whether this value can be measured.
<b>What feedback and benefit will be provided to your practice? Can the societal benefits be explained in the use of this data? How will your practice be given the opportunity to review the results and comment on the outcomes, prior to publication?</b>	Ask the entity requesting your data to explain how they will provide feedback, results or outcomes of the research to your practice.

## Further reading

General practice staff required to make decisions about secondary use of data will need to be familiar with the Privacy Act. GPs in Victoria, New South Wales and the Australian Capital Territory should also be familiar with their state's health records acts. In Victoria, responsibilities are further clarified in the Health Complaints Commissioner's guidelines on the collection and use of health information for medical research. Visit [www.health.vic.gov.au/hsc](http://www.health.vic.gov.au/hsc) for further information.

## Definition of terms

**Anonymised data:** Information that has had any data identifiable to an individual removed.

**Confidentiality:** The assurance that patient data is not made available or disclosed to unauthorised individuals. This protects the privacy of information being exchanged between communicating parties.

**Data:** Information that has been translated into a form that is more convenient to move or process. It can represent real world facts, concepts or instructions in a formalised manner suitable for communication, interpretation or processing.

**De-identified data:** Data has had sufficient personally identifiable information removed using a method to guarantee that an individual cannot be re-identified.

**Identified data:** If a data item includes an identifier that is sufficient, within a specific context, to allow decoding to accurately produce the name of a specific individual then this data should be referred to as 'identified data'. Examples of identifiers may include the individual's name, Medicare number or driver's licence number. The accuracy of these identifiers is enhanced by the availability of other details such as date of birth or address. In relatively small data sets, even non-specific information such as date of birth or postcode may be sufficient to act as an identifier on its own.

**Informed consent:** Permission granted by an individual in full knowledge of the possible consequences, such as risks, benefits and the alternatives.

**Pseudonymised data:** Information that has had unique identifying data about an individual replaced with artificial identifiers, or pseudonyms.

**Secondary use of health data:** When personal health information is used outside of direct care delivery. It includes such activities as analysis, research, quality and safety measurement, public health, payment, provider certification or accreditation, marketing, and other business applications.





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