

Respecting your privacy

How the Registry of Kidney Diseases uses your personal information

The Registry of Kidney Diseases (ROKD) is committed to the protection of personal privacy of its patients, staff and other customers. The following policy is based on the Health Privacy Principles (HPPs) as detailed in the Health Records Act 2001 (Vic) and the National Privacy Principles (NPPs) as detailed in The Privacy (Private Sector Amendment) Act 2000 (Cth).

The ROKD collects information from hospitals, clinical registries, and medical or health-related databases from Australia and New Zealand about patients for chronic kidney disease (CKD) across a spectrum of renal specific diseases (RSDs). This information will help us to identify patients at earlier stages of CKD, monitor the course of their disease progression, and assess the quality of care provided to these patients in their medical management. Where reasonably necessary, we may also collect information from our supporters, and other interested parties, to conduct our functions or activities.

What information may we collect about you?

The types of personal information we may collect about you, and the purposes for collecting that information, include:

- Research activities: for ROKD participants, we collect information that may include your name, date of birth, gender, as well as some of your health information.
- Communication: you may give us your name and/or other personal information to receive newsletters and other communications (both print and electronic) from time to time. We may also collect this information to assist you with your queries regarding the ROKD.
- Conducting events: we may collect contact details, and other personal information, including photographs and videos, about our supporters and/or other stakeholders who participate in our events.

The ROKD will only collect health and personal information that is necessary to perform our services.

How do we use this information?

We use your personal information to enable us to conduct or promote research into specific renal diseases. Results of our research activities may be reported back to the medical research community but are always presented as non-identifiable, summary data to protect the identity of research participants.

All human research undertaken by the ROKD is approved by relevant Human Research Ethics Committees. Personal information is only accessible by authorised ROKD personnel or authorised service providers who use the information to administer the business of the ROKD.

How is your information protected?

We are committed to ensuring the privacy and confidentiality of your personal information. We take all reasonable steps to protect the personal information we hold and protect it from

misuse, interference and loss, and from unauthorised access, modification or disclosure. We keep our paper and electronic data stores securely protected.

Upon cessation of the ROKD, data will be managed in accordance with the Australian Code for the Responsible Conduct of Research.

With whom might we share your information?

The ROKD will not transfer personal or health information about an individual unless the individual has consented or the transfer is authorised or required by any other law as described in HPP 9.1 and NPP 9.

We may disclose your personal information to the parties listed below (subject to approval from relevant governance and ethics committees):

- Other national and international researchers or research organisations or institutions
- Government departments, agencies or bodies.

We may also sometimes share non-personal, non-sensitive and non-identifiable information with other research organisations.

Identifiers

The ROKD will not adopt as its own identifier an identifier that has been assigned by a government agency.

The ROKD will not use or disclose an identifier assigned to an individual by a government agency except in those situation described in HPP 7.3 and 7.4.

How can you access your information?

The ROKD will, on request, provide you with information we hold about you unless there is an exception which applies under relevant privacy laws. Unless there is an exception, we will provide you with a printout of information. We request that you identify, as clearly as possible, the type(s) of information requested and we will provide a print-out of your personal information within 30 days. We may charge you for reasonable costs incurred in supplying you with access to this information.

Keeping your personal information up to date

We take reasonable steps to ensure that your personal information is accurate, complete, and up-to-date.

Our Website

When you access our website (www.rokd.org.au), we may use embedded software (such as Javascript) that places small data files (or cookies) on your device to collect information about you browsing activities.

A cookie does not identify people, but it does identify computers. You can set your browser to notify you when you receive a cookie and you can either accept or reject it.

We may create links to third party websites. The ROKD is not responsible for the content or privacy practices employed by linked websites.

How do I get more information?

If you have a query on how your personal information is collected or used, or any other query relating to this Privacy Policy, please contact:

ROKD Project Officer
Transfusion Research Unit
Department of Epidemiology and Preventive Medicine
Monash University
Alfred Hospital
Commercial Road
Melbourne VIC 3004
Phone: 1800 811 326
Email: sphpm-rokd@monash.edu