

What is Chronic Kidney Disease?

Chronic Kidney Disease (CKD) is common in Australia. Approximately one in ten Australian adults have some degree of CKD. As the Australian population ages, the frequency of CKD in Australia continues to rise.

CKD includes all conditions of the kidney where a person has had evidence of kidney damage and/or reduced kidney function for at least 3 months.

Although CKD is common, there is a lot we still do NOT know about this disease. There is also a lot of variation in treatment and care provided to people with CKD in Australia and we are yet to understand how best to treat this disease.



What is the Registry of Kidney Diseases?

The Registry of Kidney Diseases (ROKD) is a clinical quality registry which collects data from patients with Chronic Kidney Disease (CKD) across a spectrum of renal specific diseases (RSDs). The primary objective of the ROKD is 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.

How Do Clinical Registries Work?

Clinical quality registries are a particular subset of registries which focus on improving the safety and quality of healthcare by providing high quality and clinically relevant data (outcomes) back to clinicians to drive quality improvement.

They may also be used to identify a group of patients with a particular condition who may be eligible to participate in future research.



Which conditions are being studied?

There are currently seven causes of CKD on which the registry collects information. These include:

Focal segmental glomerulosclerosis

Membranous glomerulonephritis

Autosomal dominant polycystic kidney disease

IgA nephropathy

Alport syndrome

Fibromuscular dysplasia

Tuberous sclerosis complex

Will I be included in the registry?

If you have been diagnosed with one of the above conditions, your doctor may put you forward for inclusion in the registry. You will then receive an information package by post, including instructions on how to opt out of the registry. If you would like to volunteer to be included in the registry, your doctor can arrange this.

What information is collected?

Registry researchers will collect the following information directly from your medical record:

- Your name, age, and details of your treating doctor so we can identify the progress of your treatment over time;
- Your physical characteristics such as height, weight and gender;
- Symptoms and circumstances leading up to the diagnosis of chronic kidney disease;
- Your diagnostic test results such as blood and urine test results;

Safeguarding your Privacy

Protecting your privacy is paramount. The registry has been designed in accordance with the strictest privacy principles, including State and Commonwealth privacy laws and has been reviewed by an independent ethics committee. ROKD has the potential to link with other nationally established registries which focus on more advanced kidney disease. The information collected will remain confidential and will not be released to researchers in any form which could identify you. The data will be stored indefinitely in a secure fashion, with restricted access to approved registry officers, each of whom is committed to maintaining confidentiality. The data may be used for unspecified future research subject to approval by a Human Research Ethics Committee.

Questions & Concerns

If you would like more information on the Registry of Kidney Diseases, please visit our website: www.rokd.org.au

If you have any concerns regarding the privacy of your personal information, or if you would like to withdraw from the registry, please contact our project manager via the details below:

Telephone— (03) 9076 8845

Email— sphpm-rokd@monash.edu

