



### **Facts:**

- Glomerulonephritis are comprised of more than 20 different specific types of rare diseases, with a global primary incidence of 0.2 -2.5 per 100,000 people/year.
- Patients with kidney disease are often excluded from clinical trials due to perceived risk, and few randomised clinical trials are conducted in patients with glomerulonephritis, which could generate evidence to improve therapy within nephrology.

### **Project cycle:**

2018 – Ongoing

### **Partners:**

The George Institute for Global Health

### **Supporters:**

The George Institute for Global Health

### **Background:**

- Glomerulonephritis or glomerular disease are a group of rare diseases characterised by an injury to the basic filtration unit of the kidney - the glomerulus - which can lead to serious morbidity and high mortality.
- There are no glomerular disease registries in Australia and therefore no methods to comprehensively and systematically collect demographic and outcome data on patients with glomerulonephritis. There are also currently no methods to easily link patients with clinical trials and novel treatments.

### **Aims:**

- The overall aim of this project is to create an accurate registry of patients with glomerular disease, and a biobank of patient samples.
- The project will enable better understanding of clinical outcomes for glomerular disease and easier patient recruitment for future trials.

### **Methods:**

- Patients will provide consent to be entered into the registry and/or biobank, as well as participate in clinical trials. Research staff will then retrieve data from glomerular disease patients' hospital records, including medical history, demographics and the details of their disease diagnosis.
- Patients will be followed up every 12 months through medical record and physician reviews, as well as evaluation of each patient's particular disease condition. This will also allow records to be updated for trial eligibility assessment.

### **Impact:**

- The project will develop the first registry dataset in Australia that will accurately ascertain the disease burden and improve long-term treatment and outcomes for patients with glomerular disease.
- The project will strengthen the capacity of future clinical research trials to discover new therapeutic agents for glomerular disease.

### **Contact:**

To find out more about this study, its principal investigator Dr Sradha Kotwal or The George Institute for Global Health, please contact Tina Wall +61 410 411 983 or [twall@georgeinstitute.org.au](mailto:twall@georgeinstitute.org.au)

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