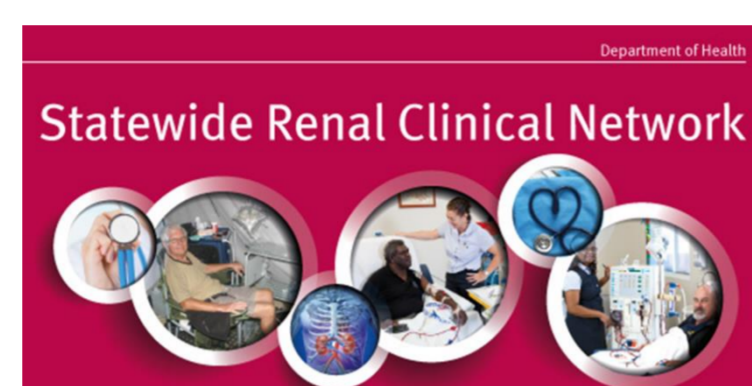


Queensland Glomerulonephritis Registry

D Ranganathan^{1,6,9}, D Jegatheesan^{2,3,6,9}, L Francis^{4,9}, GT John^{1,6,9},
A Mallett^{1,3,6,9}, A Revell^{5,9}, P Trnka^{3,7,9},
SK Venuthurupalli^{3,6,8,9}, Z Thet⁹, A Cameron^{1,3,6,9}, WE Hoy^{3,6}

Affiliations: ¹ Kidney Health Services (RBWH), Metro North Hospital and Health Service, Brisbane, QLD, Australia; ² Nambour Hospital, QLD, Australia; ³ The University of Queensland, Australia; ⁴ Pathology Queensland, QLD, Australia; ⁵ Kidney Health Australia; ⁶ NHMRC CKD.CRE & CKD.QLD, The University of Queensland, Australia; ⁷ Lady Cilento Children's Hospital, Brisbane, QLD, Australia; ⁸ Renal Services, Toowoomba Hospital, QLD, Australia; ⁹ QLD.GN Registry Working Group, Statewide Renal Clinical Network



Background

Care of patients with glomerulonephritis [GN] is a significant burden on the healthcare system. As reported by ANZDATA¹, GN is the leading cause of end stage renal disease [ESRD] for those patients that survive to go onto renal replacement therapy [figure 1]. CKD.QLD², a registry of patients with precursor stages of kidney disease, reports a prevalence of 12% for those patients referred to the public state renal services [figure 2].

Internationally, GN registries have been established to further the understanding, and ultimately improve, patient clinical outcomes^{3,4}.

There is a paucity of data pertaining to the spectrum of GN in Australia, supporting the formation of a registry.

Aims

- To establish a registry for biopsy-proven glomerulonephritis [GN], commencing in Queensland, Australia.
- To provide a dataset that will enable prospective research into the epidemiology, clinical course, prognostic indicators and treatment of GN in the Australian setting.
- Ultimately, the objective is to collaborate nationally and internationally to form a broader renal biopsy registry program, supporting research endeavors.

Methods

- Demographic, clinico-pathological and therapeutic information is planned to be collected from patients with biopsy-proven GN, commencing with collaborative public renal services within Queensland Health.
- Data will be collected at time of renal biopsy and at intervals thereafter, with endpoints of dialysis-dependence, transplantation, death or withdrawal from registry.

GN Registry establishment – a phased approach

- Phase 1
 - ✓ formation of the Statewide Renal Clinical Network GN Working Group (Sept 2016)
 - ✓ development of eDatabase, facilitated by Queensland Health
 - ✓ first cohort identified for inclusion: patients consented to the CKD.QLD registry within the Kidney Health Service of Metro North HHS.
- Phase 2
 - ✓ Multi-centre ethics/Public Health Act application for inclusion of incident and prevalent patients.
- *Key outcomes will be evidenced patient survival, change in renal function and progression to ESRD across different GN sub-types, influence of geographic locations and of socio-economic status.*

Conclusion

The QLD.GN registry, the first of its kind in Australia, will provide a robust, transparent and real-time dataset capable of improving patient care, supporting observational research in GN. Furthermore, the dataset may facilitate identification of key patient populations for recruitment into clinical trials. The registry will be a nucleus from which affiliations will grow.

Enquiries: Dr Dwarakanathan: Dwarakanathan.Ranganathan@health.qld.gov.au

Figure 1
ANZDATA 2014
Primary renal disease in Australian RRT population.
n=22,234

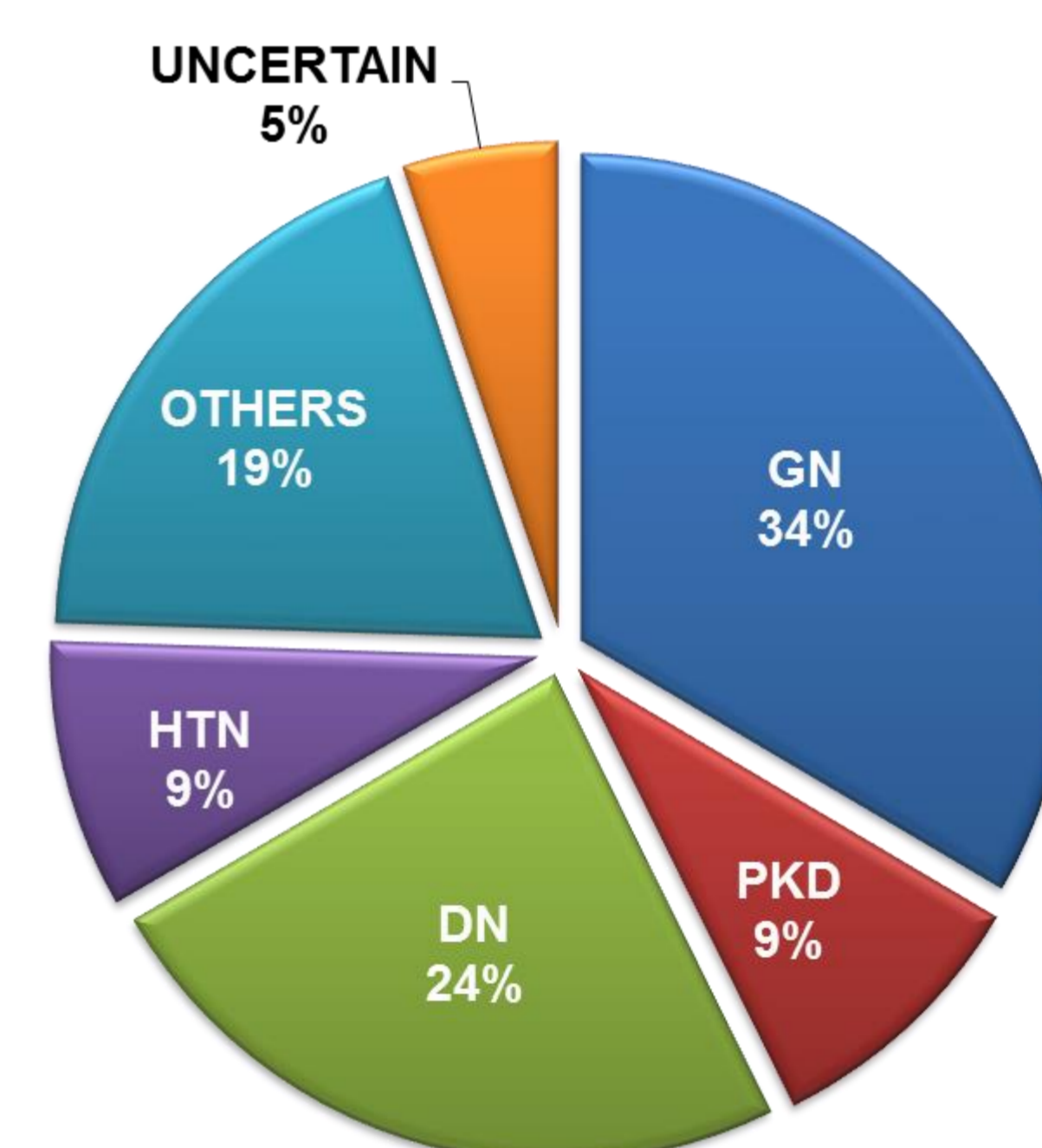
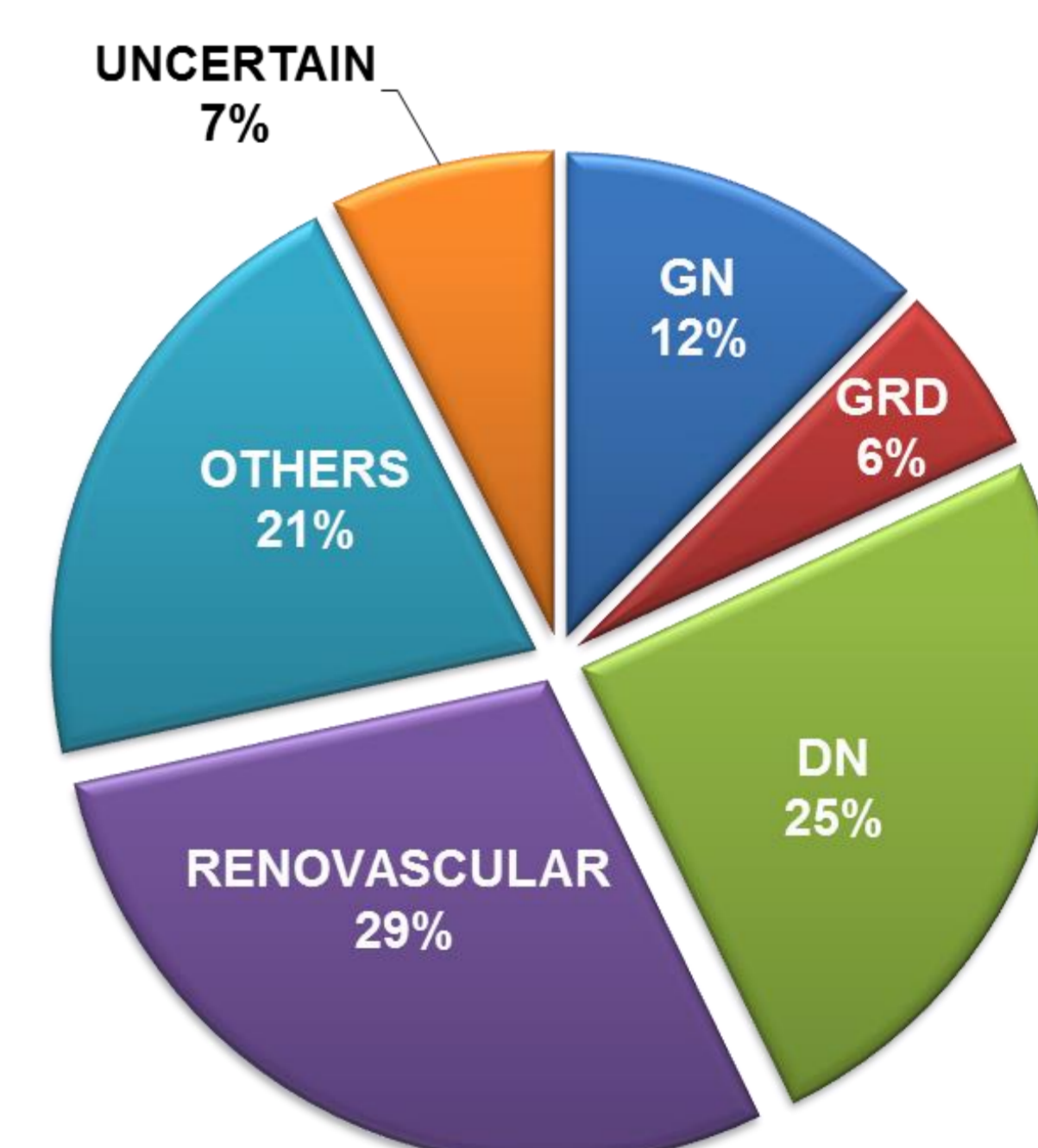


Figure 2
CKD.QLD 2016
Primary renal disease in CKD population
n=5,773



References

- 1 ANZDATA Registry. 38th Report, Chapter 2: "Prevalence of End Stage Kidney Disease. Australia and New Zealand Dialysis and Transplant Registry". Adelaide, Australia. 2016. Available at: <http://www.anzdata.org.au>
- 2 Venuthurupalli SK, Hoy WE, Healy HG, et al. "CKD.QLD: Growth of Chronic Kidney Disease Surveillance in Queensland, Australia." Invited Review for: "Taming the Chronic Kidney Disease Epidemic: A Global View of Surveillance Efforts". KI 2014.
- 3 Barbour S et al. "An overview of the British Columbia Glomerulonephritis network and registry: integrating knowledge generation and translation within a single framework." *BMC Nephrol* 2013; 14: 236
- 4 Juan M et al. "Spanish Registry of Glomerulonephritis." *Clin J Am Soc Nephrol* 2008; 3: 674-681