



RESEARCH QUESTION

Can we build a collaborative national platform to understand the natural history of GN across Canada and create resources to better understand both the biology of GN and the patient experience with these diseases?



PROJECT GOAL

The overarching goal of establishing this resource is to build a national effort to develop precise, personalized, patient-centred treatment strategies for patients with GN and to bolster GN-focused collaborative research capacity in Canada. This will be accomplished by creating a rigorous protocol to follow patients with GN across Canada using a new web-based clinical registry and federated biobank.



POPULATION

Eligible male and female subjects with biopsy-proven diagnoses of GN, aged 18-80 years inclusive, will be followed during the course of the study.



DEFINITIONS, RESULTS, OTHER

Our team of nephrologists, researchers, clinical and data managers, and patient representatives spans 10 sites across Canada. Together we develop protocols for collection of clinical and lab data and a catalogue of blood and urine samples to facilitate research into the biology of GN. In parallel this network allows better patient access to information about GN and ultimately opportunities to access novel treatments for GN.

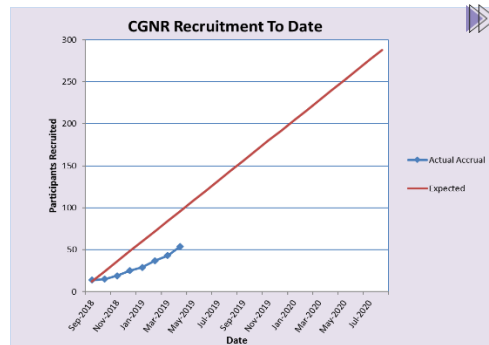
BACKGROUND

Glomerulonephritis (GN) is a group of rare diseases (<5 per 250,000 population) yet is a leading cause of kidney failure. There are few treatments for these conditions and no cures. Patients with GN need better access to new therapies to improve wellbeing and prevent kidney failure.



KNOWLEDGE NUGGETS

- ▶ Built web-based tools for follow-up of patients with GN from across Canada
- ▶ Enrolled patients from west to east coast Canada, engaged centres not previously involved in GN research networks
- ▶ Through patient engagement we have refined our research priorities and protocols and placed more value on studying the patient experience
- ▶ Next steps: boost enrollment, improve access to knowledge about GN and clinical trials across Canada



CURRENT STATE

Currently, 54 participants have been recruited from all 9 active Canadian sites. Another site addition is imminent.

TRANSFORMATION PROCESS

Each site has an invested and dedicated team working actively to pre-screen and contact patients for recruitment and enrollment. Weekly updates within the study teams as well as monthly data checks ensure accountability and data quality.

FUTURE STATE

350 patients will be followed. Data and samples will be available for state-of-the-art biology research.

PROJECT TIMELINE

