

FIRST IN CANADA: A COMPREHENSIVE PROVINCIAL AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE (ADPKD) PATIENT REGISTRY IN BRITISH COLUMBIA (BC)

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Introduction

Early identification, assessment of renal progression and implementation of appropriate treatments are key components of modern ADPKD care¹.

Existing BC Renal administrative data focused on patients in later disease stages when they access chronic kidney disease clinics, renal replacement modalities, or renal formulary drugs, but data capture of early stage ADPKD patients who are most likely to benefit from specialized nephrology care was limited.

Objective

The overarching goal of the ADPKD registry is **to enhance identification, understanding and management of ADPKD in BC through creation of a comprehensive ADPKD patient registry.**

Functions of the ADPKD Registry include:

- Maximizing identification of all British Columbians with ADPKD, regardless of the current stage of their disease
- Supporting data capture and therefore application of prognostic tools to identify ADPKD patients who are most likely to have progressive disease
- Comprehensive clinical data and outcome monitoring of all patients with ADPKD, regardless of disease or treatment status, facilitated by a proven and comprehensive information system (PROMIS)
- Integration of information with other relevant databases

Methods

The ADPKD registry was created within the Patient Records and Outcome Management Information System (PROMIS), the dedicated BC Renal database.

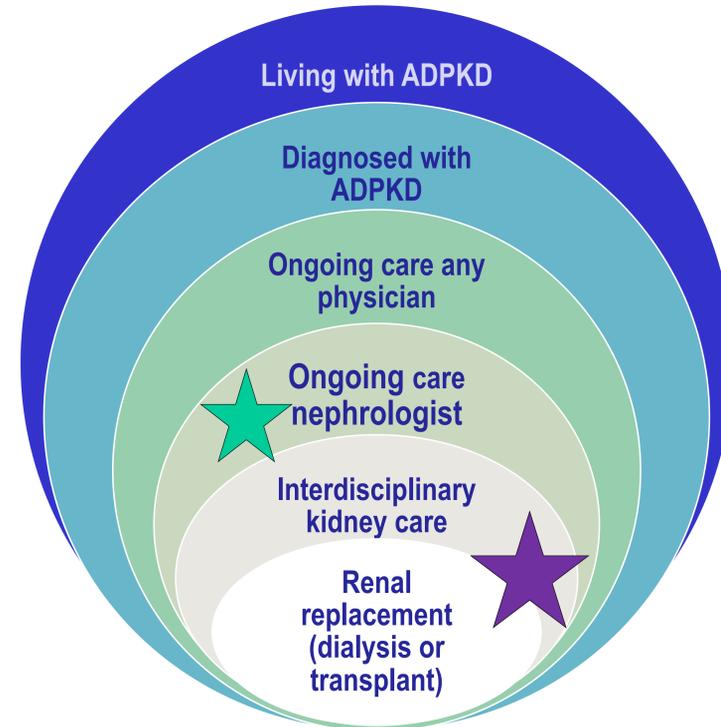
- Additional registration capabilities were added for ADPKD patients not cared for in any other existing renal care program
- Minimum registry data set includes: basic patient name; date of birth; provincial healthcare number and; diagnosis
- Laboratory and outcome data are captured via existing PROMIS infrastructure.

A specific focus was registration of ADPKD patients seen in nephrologists' private offices not accessing other BC Renal services. The process included:

- Identification of all nephrology offices in BC, development of a streamlined registration process with stakeholder feedback
- Training to Medical Office Assistants to search electronic medical records for ADPKD patients and register in PROMIS
- Time-limited reimbursement to nephrologists' office to support the new workflow and change management of identifying and registering patients

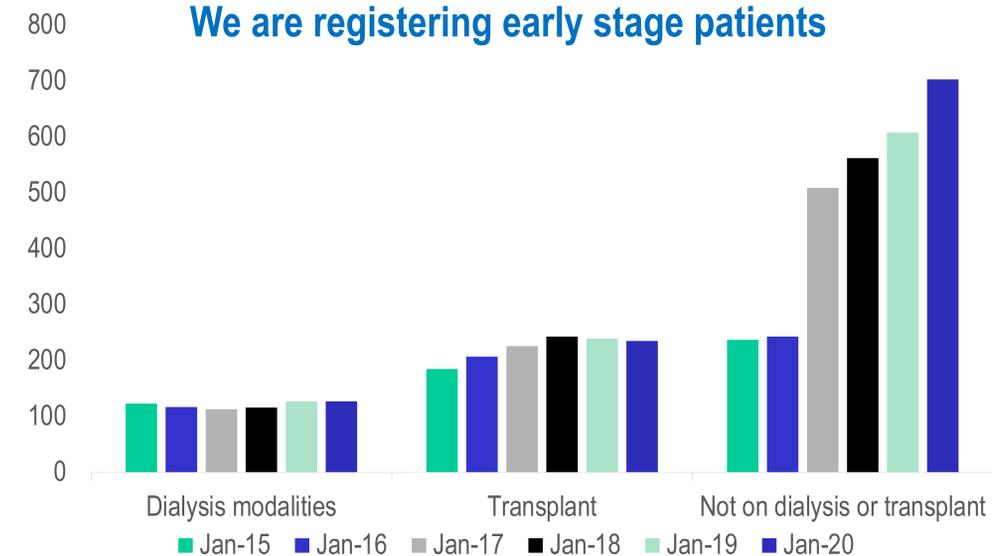
Methods

The two innermost patient groups (purple star) were already well known to BC Renal database; the goal of the ADPKD registry is to continue expanding outward with the immediate objective being those already known to neurologists (green star).



Results

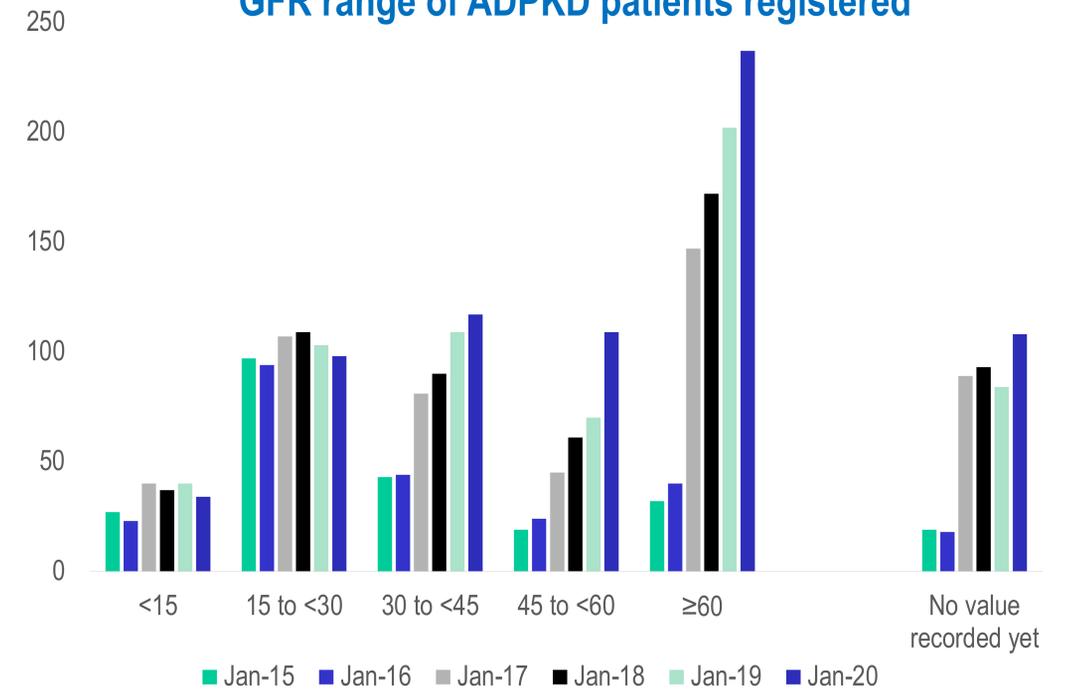
We are registering early stage patients



Results

With the ADPKD registry, the number of ADPKD patients registered in PROMIS has increased from 545 to 1065 as of January 2020. The increase in patient registration has been most prominent in the early stage patients not on dialysis or transplant (increased from 237 to 703).

GFR range of ADPKD patients registered



Conclusions

Through creation of a comprehensive ADPKD registry, greater numbers of ADPKD patients have been identified in BC, particularly patients earlier in their disease course.

The registry will continue to build on this with next steps including enhancements to clinical data, patterns of treatment use, quality metrics for care delivery, and clinical outcomes.

References

1. Chebib FT, Torres VE. Recent Advances in the Management of Autosomal Dominant Polycystic Kidney Disease. Clinical Journal of the American Society of Nephrology. 2018 Jul 26;CJN.03960318.