

What is the ADPKD registry?

BC has developed a first of its kind registry that aims to include all British Columbians living with autosomal dominant polycystic disease (ADPKD), regardless of disease or treatment status. This registry is a way of using provincial information technology to collect existing data and analyze it to better understand ADPKD in BC. The registry is housed within PROMIS, a powerful information system managed by the BC Renal Agency that serves as a database for care delivered to British Columbians living with kidney disease.

Why build an ADPKD registry?

Standardized collection of data across the province is necessary to better describe the burden of disease, care and outcomes of polycystic disease in BC. This information will be used by clinicians across the province to improve the quality of care offered to people living with polycystic disease and to better understand its treatment and outcomes. The information may also be used in research settings to help improve our understanding and ultimately benefit all people living with ADPKD.

How does the ADPKD registry work?

The registry is a centralized database for polycystic disease in BC. No new information is collected from people enrolled in the registry. The registry uses information technology to compile and analyze existing data that is already collected in clinical care. This data will be stored in PROMIS and is similar to that captured for other renal patients in BC.

What steps will be taken to protect my personal information?

The BC Renal Agency is the caretaker of the ADPKD registry and has a long history of using best practices to ensure patient privacy for data that is collected on people across the spectrum of kidney diseases. When the data from the ADPKD registry is analyzed for quality improvement or research purposes, it will be done in an aggregate and anonymous fashion so that no individuals can be identified. If formal research is conducted on any people included in the registry, they may be approached for formal consent where applicable.

As a public body, the BC Renal Agency must comply with the *Freedom of Information and Protection of Privacy Act* in terms of collection, use, retention, disclosure and security of personal information. The BC Renal Agency takes all reasonable measures to ensure that personal patient information is treated in a confidential manner, is only available to authorized staff for the purpose for which it is collected, and is stored securely.

For more information on the steps the BC Renal Agency takes to protect personal information please visit the BCPRA website (<http://www.bcrenalagency.ca/>).

Although ADPKD is an inherited disease, no information from the registry will be shared with or linked to other family members. This would be a breach of confidentiality, so including one person from a family in the registry will have no impact on others, regardless of whether or not the other family members have been tested for the disease, have the disease or are included in the registry themselves.