

Staff members sign confidentiality agreements and receive training and supervision to ensure they understand their responsibility. They must maintain the confidentiality of your information even if they no longer provide care to you.

BCPRA's Executive Director, with guidance from the Data Stewardship Committee, makes decisions about how to use and protect your information, including:

- how to apply privacy law, other law, and ethical and privacy principles;
- creating management structures that support a “privacy sensitive” culture;
- management, policies and procedures for security; and
- audits to ensure privacy and security policies are upheld.

### **In what cases is my personal health information disclosed?**

PROMIS data is disclosed on a need-to-know basis. Disclosures are based on the law, best practices and professional codes of ethics. Staff may release personal information for your care or where permitted by law. As mentioned earlier, disclosure for research is subject to specific law and policy. Your data is also sent to the Canadian Institute for Health Information, which gathers statistics from across Canada for the Canadian Organ Replacement Registry. Your personal information may only be sent outside Canada under very limited conditions.

### **How long is my information kept?**

As part of BC Ministry of Health Services policy, all health care information created as part of your care is never destroyed.

### **How do I access my personal health information?**

You have the right to know what information we hold about you, to see it and to correct it. Your health care team will provide you with key pieces of your health information on a regular basis, and encourage you to follow along with your progress. You can request additional information at any time. Comments or complaints can be sent to BCPRA, the privacy officer in your local health authority or the BC Information and Privacy Commissioner.



# Your Personal Health Information and Privacy



## Questions and Answers for BC Kidney Patients

**BC Provincial Renal Agency**  
700–1380 Burrard Street  
Vancouver, BC V6Z 2H3  
604.875.7340  
bcpra@bcpra.ca  
www.bcrenalagency.ca

**Office of the Information and Privacy Commissioner for British Columbia**  
Mailing Address  
PO Box 9038, Stn Prov Govt  
Victoria, BC V8W 9A4  
(250) 387-5629 or 800-663-7867  
info@oipc.bc.ca  
www.oipc.bc.ca



## Your Personal Health Information and Privacy

### Questions and Answers for BC Kidney Patients

Kidney care services are delivered through dialysis units and chronic care clinics across the six BC health authorities. The BC Provincial Renal Agency (BCPRA), an agency of the Provincial Health Services Authority, has overall responsibility for planning and coordinating these services. Our goal is to ensure equitable access to high quality care no matter where patients live.

The BCPRA must manage personal health information under the *BC Freedom of Information and Protection of Privacy Act* (FIPPA). This Act makes the Agency and its staff accountable for how it collects, uses and discloses your personal information. What follows are answers to questions patients often ask about this topic.

#### How is my information collected?

Most often, information is collected by staff members at the centre where you receive care (e.g. the hospital or community dialysis unit). We also receive your information from other health facilities and laboratories that participate in your care. This information is transferred electronically to BCPRA's database system, called PROMIS, and stored in a secure central location.



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Personal information is gathered by these professionals under the *Health Authorities Act* and the *Hospitals Act*, and is collected by BCPRA under the province's *Freedom of Information and Protection of Privacy Act* (Section 26[c]).

Responsibility for your information is shared by BCPRA and the local health authorities and hospitals.

For more information about the collecting or sharing of information by BCPRA, contact our Director of Health Informatics at 604-875-7340 or the privacy officer in your local health authority.

#### What is PROMIS?

With input from the health authority renal programs, BCPRA developed an information system called PROMIS (Patient Record/Registration and Outcome Management Information System). It provides the information link between hospital outpatient clinics and dialysis units, community dialysis units and doctors' offices.

PROMIS supports direct patient care, program management and research related to chronic kidney disease in BC. The system holds personally identifiable health information about the services and treatments you receive.

Information is securely stored at BCPRA's central site, and its use is strictly controlled.

#### Who has access to my information and how is it used?

PROMIS data is primarily used to provide patients with renal care wherever that occurs — in their home, at a community unit or in a hospital. This includes scheduling, providing supplies and medication.

Those participating in your care are allowed to see your personal information — others are not. Strict controls are maintained to ensure only those who are actively treating you have access, and to only what they need. For example, your community

pharmacist can only see your prescription information.

De-identified data — i.e. data that cannot be directly linked to a specific patient — is used for administration of renal programs, improving renal services, education and research.

Data may only be used for research if it meets strict legal requirements. All research requests must be reviewed by both the BCPRA Data Stewardship Committee and a research ethics board before any research studies can take place. Even so, the BCPRA does not release identifiable data to researchers, unless you have provided consent.

It is important to note that the data used in research and education projects supports positive changes to patient care and better health outcomes.

#### What steps are taken to protect my privacy?

All personal information is protected under the *BC Freedom of Information and Protection of Privacy Act*. All BCPRA staff, and anyone who uses PROMIS data, must protect your information (electronic or paper) from inappropriate or unauthorized use and disclosure. Measures include the use of frequently changed passwords, security for electronic transmission of data and physical security.