

Who do I contact with questions regarding the collection of the information?

Provincial Director,  
Provincial Blood Coordinating Office  
Address: 3rd Floor – 1867 West Broadway, Vancouver, BC, V6J 4W1  
Telephone: 604-714-2888  
Email: pbcoinfo@pbco.ca

Who is the BC Provincial Blood Coordinating Office?

The BC Provincial Blood Coordinating Office (PBCO), a program of the BC Clinical and Support Services Society (BCCSS) promotes initiatives that advance safe, appropriate and sustainable use of blood and blood products across the province. The program helps to establish and maintain national standards of care and to ensure patients have access to proper resources. The PBCO plans, coordinates, monitors, funds and evaluates the Inherited Bleeding and Red Cell Disorders services provided at the program sites.



What is the Inherited Bleeding and Red Cell Disorders (IBRCD) Services?

The BC Inherited Bleeding and Red Cell Disorders (IBRCD) Services supports patients and families with genetic blood disorders, including hemophilia and hemoglobinopathy patients from across the province. There are two specialist program sites in British Columbia. BC Children's Hospital supports the pediatric program while St. Paul's Hospital supports the adult program.



*Inherited Coagulopathy  
and Hemoglobinopathy  
Information Portal*

#### **BC Children's Hospital**

Hemophilia and Hemoglobinopathy Programs  
Room 1A13 - 4480 Oak Street  
Vancouver BC V6H 3V4  
Tel: 604-875-2345 ext. 5335 (Hemophilia)  
604-875-2345 ext. 7103 (Hemoglobinopathy)  
Toll free line in BC only: 1-888-300-3088 ext. 5335  
Fax: 604-875-2533

#### **St. Paul's Hospital**

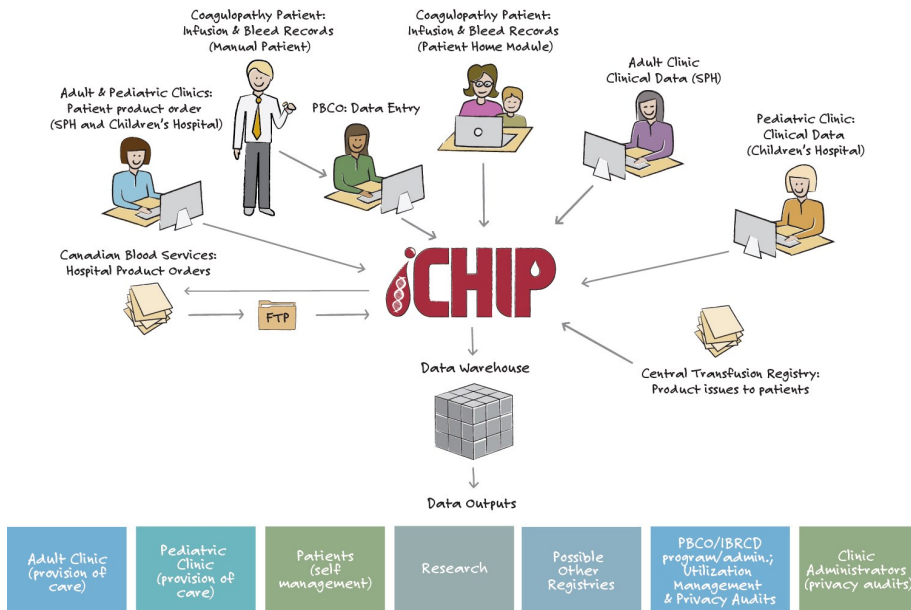
Hemophilia and Hemoglobinopathy Programs  
Burrard Building, Room 493 - 1081 Burrard Street  
Vancouver, BC V6Z 1Y6  
Tel: 604-806-8855  
Toll-Free: 1-877-806-8855  
Fax: 604-806-8784

## What is iCHIP?

The Inherited Coagulopathy and Hemoglobinopathy Information Portal (iCHIP) is a secure web-based registry that is used to collect and store health information including treatment protocols, tests, product orders, and contact information for coagulopathy and hemoglobinopathy patients in BC. iCHIP has two modules - a Patient Home Module and a Clinic Module. Hemophilia patients are encouraged to use the Patient Home Module to enter their home infusion and bleed information. The hospital program healthcare team uses iCHIP to improve patient outcomes through the management of patient care and the effective use of blood products.

## How does iCHIP work?

The data stored in iCHIP comes from patients, clinicians, hospitals and Canadian Blood Services. Patients, clinicians and the BC Provincial Blood Coordinating Office (PBCO) access information and reports to support clinical care and help patients manage their own care. The PBCO manages the iCHIP program and accesses information for provincial program planning with clinicians.



## Your Personal Health Information and Privacy

The BC Provincial Blood Coordinating Office (PBCO) is committed to maintaining and protecting the confidentiality and privacy of your information. The PBCO collects your personal information as authorized under section 26 (c) of BC's *Freedom of Information and Protection of Privacy Act* (FIPPA). The PBCO established the BC Inherited Bleeding and Red Cell Disorders (IBRCD) Services which encompasses clinical program sites located at BC Children's Hospital and St. Paul's Hospital.

## How is my information used?

The PBCO collects, uses and shares your information for the following purposes:

- To identify you and keep in contact with you about your health care
- To provide ongoing care, treatment and services from the clinics
- To help plan, monitor, maintain and improve patient care and services
- For clinical education and training
- To conduct research with consent or as permitted by law
- To support agencies such as the BC Ministry of Health, Canadian Blood Services and the Public Health Agency of Canada for strategic planning, quality improvement, performance measurement and funding allocation
- To analyze, manage and monitor the overall patient population health
- As required by law (i.e. court order, reportable conditions) and as authorized by FIPPA

## 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 PBCO and clinical staff and anyone who uses iCHIP data must protect your information from inappropriate or unauthorized use and disclosure. Measures include the use of frequently changed passwords, security for electronic transmission of data and physical security.