



Benefits of a national patient registry

A national patient registry is a valuable tool for:

- effectively managing resources,
- improving patient well-being and saving lives ,
- saving money by improving purchasing processes, and
- efficiently delivering quality patient care.

What is a patient registry?

A patient registry for bleeding disorders is a database or a collection of records of people identified with hemophilia, von Willebrand disease, and/or other inherited bleeding disorders. It includes:

- personal information (such as name, age, sex, etc.);
- clinical information (type of bleeding disorder, severity, type and amount of treatment received); and/or
- information on complications (such as inhibitors, liver disease, joint disease, etc).

Generally, this data is kept in a computer database. A national registry centralizes this data for an entire country to avoid duplication of names.

Benefits of a national registry

- **Monitoring trends in health.** Data from a national registry can provide health outcome data to monitor patient needs and identify health problems that need prompt attention. Examples of health outcome data include the number of infections with blood-borne viruses (HIV, hepatitis C virus, etc.), the number of patients with severe joint disease, the number of patients that have inhibitors, liver disease, are hospitalized, or die.
- **Allocating resources – priority setting.** Data from a centralized national registry is invaluable in identifying resource needs and the highest priorities for successful outcomes.
- **Improving the purchasing process.** Reliable data from a national registry can be used when purchasing treatment products nationally to help determine the quantity of treatment products needed. It can also be used as part of an audit of the whole purchasing process.
- **Serving as a distribution mechanism.** A registry helps organize and monitor the national distribution and use of treatment products. Patterns of product usage can be evaluated and excessive use of treatment products can be identified, evaluated, and addressed. If a particular product is recalled or identified as having some safety or quality issue, registry data can be used to identify the patients who received it so they can be contacted.
- **Helping establish a communication network.** By identifying where patients live, a registry is an essential part of the communication network that includes treatment centres and the patient organization. Access to the registry allows the national hemophilia association to distribute educational materials and other information important to the health and well-being of patients with bleeding disorders.
- **Ensuring better global data.** Data collected nationally and globally by the WFH has been extremely useful for advocating for improving care for the people with bleeding disorders worldwide. The data show the effectiveness of starting national programs and providing even small amounts of safe clotting factor concentrates on health outcomes for patients with hemophilia.