

What is Community Counts?

The purpose of this project is to gather and share information about common health issues, medical complications, and causes of death that affect people with bleeding disorders who receive care at U.S. Hemophilia Treatment Centers (HTCs).

Community Counts is a project funded by the Centers for Disease Control and Prevention (CDC) through a cooperative agreement awarded to the American Thrombosis and Hemostasis Network (ATHN) in partnership with the U.S. Hemophilia Treatment Center Network.

Community Counts consists of three components:

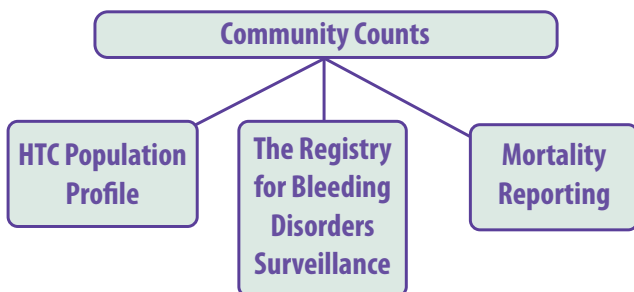
The **HTC Population Profile** (HTC PP) gathers basic information on all HTC patients with bleeding disorders or blood clots. The goal of the HTC PP is to learn more about the patients at HTCs, such as how many receive care at the centers.

The **Mortality Reporting** project tracks the characteristics, diagnoses, and causes of death of HTC patients with bleeding disorders who have died.

At many HTCs, people who receive care and have eligible diagnoses are automatically included in the HTC PP and Mortality Reporting. This information is collected and used in accordance with Health Insurance Portability and Accountability Act (HIPAA) regulations.

The **Registry for Bleeding Disorders Surveillance** gathers detailed information on HTC patients with bleeding disorders. People who volunteer to participate will have routine medical information collected once a year during their comprehensive HTC visit. Only HTC patients with bleeding disorders can participate in the Registry. Participation in the Registry is voluntary and patients who choose to participate must give their written permission.

Community Counts Program Structure



When you sign up to participate in the Registry for Bleeding Disorders Surveillance, you are agreeing to

- Allow information about your health to be included in the Registry for Bleeding Disorders Surveillance. Your patient information is kept confidential.
- Give one or more blood samples for inhibitor and virus (HIV, hepatitis C) testing, if requested.
- Answer a few questions about health-related matters during your routine clinic visits, if requested.

You enrolled in the Community Counts Registry for Bleeding Disorders Surveillance at

(HTC name)

on _____

(Date)

For more information, visit

<http://www.cdc.gov/communitycounts/>

Community Counts is supported by cooperative agreement # DD001155.

How you can benefit from participating in Community Counts Registry for Bleeding Disorders Surveillance

PATIENT BROCHURE



www.cdc.gov/communitycounts/



Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



**YOUR PARTICIPATION IN THE REGISTRY
FOR BLEEDING DISORDERS SURVEILLANCE
WILL BENEFIT YOU AND THE BLEEDING
DISORDERS COMMUNITY AT LARGE.**

Why should I participate?

Community Counts aims to improve the medical care and health outcomes of people with hemophilia and other bleeding disorders. By participating in the Registry for Bleeding Disorders Surveillance, you will

Help improve treatment for people with bleeding disorders. Information collected by the project will be used to inform, improve, and guide physicians' treatment of patients with bleeding disorders. Participants are helping to shape the future of medical care for people with bleeding disorders.

Help CDC monitor trends in bleeding disorders over time and contribute to knowledge benefitting the bleeding disorders community. CDC is working to gather information about the bleeding disorders population over time, such as the size of the population, medical complications, life span, and more.

Studies using information collected from past projects have found that

- Males with hemophilia who are overweight or obese are more likely to have less mobility in their joints than those who are normal weight.

- Regularly scheduled treatment using clotting factor to prevent bleeding prevents joint damage and appears to decrease the risk for bleeding inside the head (also known as intracranial hemorrhage).
- People with inhibitors, which are antibodies made by the immune system that make it more difficult to treat bleeding episodes, are at higher risk for joint disease and other medical complications from bleeding, which reduce their quality of life.

Receive free laboratory testing: Participants can be tested for inhibitors for free. Patients will also receive free testing for exposure to hepatitis C and HIV viruses.

***Finding an inhibitor early
and receiving treatment can lower
your risk for developing
serious health problems.***

Frequently Asked Questions

Who is eligible to participate?

If you have hemophilia A, hemophilia B, von Willebrand disease, or a rare bleeding or platelet disorder, you may choose to participate in the Registry for Bleeding Disorders Surveillance. For more information about eligible diagnoses, please visit the Community Counts website: <http://www.cdc.gov/communitycounts/>

What information is collected from me?

The Registry for Bleeding Disorders Surveillance collects information in three main areas:

- General issues, such as health insurance, educational, and employment status;
- Bleeding disorders complications, such as the number of bleeding episodes, joint disease, and pain; and
- Treatment practices, including clotting factor usage and hospitalizations.

Community Counts does not collect your name. A randomly generated identification (ID) number is used to label the information from each participant.

What should I expect if I choose to participate in the Registry for Bleeding Disorders Surveillance?

If you choose to participate in the Registry for Bleeding Disorders Surveillance, health information will be collected at your annual comprehensive clinic visit, including treatment product use, presence of other medical conditions, past bleeding events. Depending on your bleeding disorder diagnosis and the type of treatment product that you have received, a blood sample may also be requested. The blood sample will be tested by the laboratory at the CDC for viruses, such as hepatitis, an inhibitor (antibody) to treatment product, or both. Also, with your permission, a portion of your blood sample will be stored for possible use in future investigations of treatment product safety.

