

Community Counts: Fact Sheet for HTC Clinicians and Staff

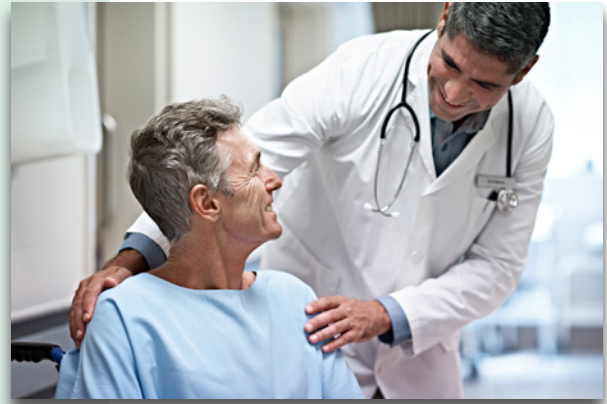
Community Counts is a program funded by the Centers for Disease Control and Prevention (CDC) that gathers information about the people who visit Hemophilia Treatment Centers in order to improve the care and health outcomes for people with bleeding disorders.

What is Community Counts?

Community Counts is a public health monitoring program funded by the CDC. The purpose of this program 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 over 130 Hemophilia Treatment Centers (HTCs) in the United States. Community Counts advances the work of the Universal Data Collection (UDC) system, which ended in 2011.

The Three Parts of Community Counts

- **HTC Population Profile:** Collects demographic data annually on all HTC patients with bleeding disorders or blood clots.
- **Registry for Bleeding Disorders Surveillance (“The Registry”):** Collects detailed medical information on patients with bleeding disorders who receive treatment within the US Hemophilia Treatment Center Network (USHTCN); this includes laboratory data, inhibitors, and other medical conditions.
- **Mortality Reporting:** Collects demographic information, diagnoses, and causes of death of individuals with bleeding disorders who have died.



Who are the key partners in Community Counts?

CDC provides resources, scientific and programmatic guidance, laboratory testing, and technical assistance to **The American Thrombosis and Hemostasis Network (ATHN)** and **HTCs**. CDC also maintains project data, performs analyses, and develops reports.

ATHN serves as the coordinating center for HTCs on all Community Counts activities and provides the data platform to electronically record and send data to CDC. ATHN also provides training and technical assistance to HTC staff on using the data platform.

HTCs in the USHTCN identify and enroll patients with eligible diagnoses at their centers and collect patient information and appropriate blood specimens. HTCs also participate in analyses and provide vital feedback on Community Counts.

What information is collected for each of the three parts of Community Counts?

Community Counts collects information about demographics, health status, bleeding disorders complications, and treatment practices. A randomly generated ID number is used to label the information from each participant.

Information collected for each of the three parts of Community Counts

	HTC Population Profile	The Registry	Mortality Reporting
Demographic Information	Birth year, sex, ethnicity, and race	Date of birth, sex, ethnicity, race, weight, height, education level, and employment status	Age at death, sex, ethnicity, and race
Zip Code	3-digit	5-digit	N/A
Insurance Status	Insured, uninsured, unknown	Type(s) of insurance, uninsured, unknown	N/A
Patient Diagnoses	Primary diagnosis	All bleeding disorder diagnoses	Primary diagnosis
Bleeding Events	N/A	Date of first bleed, joint bleeds, intracranial hemorrhages, and others	N/A
Inhibitors	N/A	Most recent inhibitor laboratory test values, history of an inhibitor, inhibitor treatment, and follow-up data collection on new inhibitor cases	N/A
Treatment	N/A	Treatment regimen and products used	N/A
Infectious Disease Status	HCV, HIV infection	HBV, HCV, HIV infection, Hepatitis A & B vaccinations, and follow-up data collection on new infections	HBV, HCV, HIV infection
Other Medical Conditions	N/A	Heart, liver, and kidney disease; thrombosis, cancer(s), and others	N/A
Cause of Death	N/A	N/A	Primary and contributing causes
Specimen Collection*	N/A	Serum tested for HIV and HCV infection, and emerging issues; plasma tested for inhibitors (factor VIII, factor IX, and type 3 von Willebrand disease only)	N/A
Other Medical Procedures	N/A	Hysterectomy, circumcision, kidney or liver transplant, surgery within past 12 months	N/A

*Specimen collection is based on the potential risk to participants of exposure to blood-borne agents or development of inhibitors due to their diagnosis and use of certain types of treatment products. For more information, please refer to the Blood Specimen Procedure Manual. HBV: hepatitis B virus; HCV: hepatitis C virus; HIV: human immunodeficiency virus; N/A: not applicable; DOB: date of birth; ICH: intracranial hemorrhages.

How does Community Counts benefit the medical community?

- **Inhibitor testing is offered free of charge** – CDC provides centralized inhibitor testing for Community Counts participants, either for screening or for confirmatory testing of locally identified new onset inhibitors, at no cost to the patient. Centralized testing will help CDC to
 1. Establish national estimates of new and existing inhibitor cases;
 2. Identify inhibitor trends over time;
 3. Identify potential inhibitor “outbreaks”; and
 4. Determine factors that might influence how inhibitors develop.

- **Data help change and improve public health practice** – Community Counts provides critical information on the occurrence and distribution of bleeding disorders and their complications. This information can help to identify opportunities to prevent complications and improve the health of people affected by bleeding disorders.
- **Data help to direct decision-making** – The data collected in Community Counts can help inform program planning and policy efforts at the local, regional, and national levels. Healthy People 2020 (HP2020) is the national agenda for improving health and preventing disease in the United States. Community Counts serves as the national data source for the HP2020 bleeding disorder-specific measures. CDC and the Health Resources and Services Administration use HP2020 measures and other Community Counts data to bring visibility to bleeding disorders at the federal level.
- **Data offer HTC providers the opportunity to conduct research** – HTC providers may submit proposals to analyze Community Counts data. They may also participate on work groups that explore specific topics or serve on committees that review analysis proposals, manuscripts, and other research products.



For more information please visit our webpage at <http://www.cdc.gov/ncbddd/hemophilia/communitycounts/about.html>

Who can participate in Community Counts?

People with the following disorders who receive care at an HTC can take part in Community Counts:

Clotting Factor Deficiency

VIII (8)	X (10)
IX (9)	XI (11)
I (afibrinogenemia) (1)	XIII (13)
I (dysfibrinogenemia) (1)	V-VIII (combination 5 and 8)
I (hypofibrinogenemia) (1)	VII (7)
I (factor 1, hereditary, unspecified)	PAI-1 deficiency (plasminogen activator inhibitor-1 deficiency)

Von Willebrand Disease

VWD type 1	VWD type 2N
VWD type 1C	VWD type 2, type unknown
VWD type 2A	VWD type 3
VWD type 2B	VWD type unknown
VWD type 2M	VWD type other
II (prothrombin) (2)	α 2-AP deficiency (α 2-antiplasmin deficiency)
V(5)	

Inherited or Functional Platelet Disorder

Bernard-Soulier syndrome
Glanzmann thrombasthenia
Grey platelet syndrome
Hermansky-Pudlak syndrome
Inherited thrombocytopenia
Release defect
Storage pool defect
Hereditary platelet function disorder

Bleeding Disorder, no laboratory diagnosis

Blood coagulation disorder with prolonged coagulation time
Blood coagulation disorder with prolonged bleeding time
Blood coagulation disorder with impaired clot retraction time

Ehlers-Danlos syndrome and venous thromboembolism (HTC Population Profile only)