

The Universal Data Collection (UDC) System

Lessons Learned and Future Directions

Hemophilia and other bleeding disorders can cause lifelong problems and complications. The Centers for Disease Control and Prevention (CDC) established the Universal Data Collection (UDC) system to gather information about complications that occur among patients receiving care in hemophilia treatment centers (HTCs) throughout the United States. Researchers are using this information to learn more about why some people with bleeding disorders develop complications while others do not.

What have we learned from UDC?

The UDC system was designed to monitor trends and changes over time, so some of the analyses are just beginning. However, many articles have been published describing the findings to date. Following are a few of the areas in which some of these findings are detailed:

Joint Health

Joint infections are a rare complication of hemophilia and occur mostly in target joints or in joints that have undergone joint surgery.

Males with hemophilia who are overweight are more likely to have less mobility in their joints than those who are not overweight.

Inhibitors

The rate of new inhibitors among previously treated patients with hemophilia is very low, but more study is needed to determine why they occur.

People with inhibitors are at higher risk for joint disease and other complications from bleeding, resulting in reduced quality of life.

Treatment Practice

Treatment practices (such as prophylaxis, which is regularly scheduled treatment using clotting factor to prevent bleeding) differ among HTCs. Further study is needed to understand why these differences exist.

Prophylaxis appears to decrease bleeding inside the head (which is known as intracranial hemorrhage)

among patients with severe hemophilia who do not have an inhibitor or human immunodeficiency virus (HIV).

Babies

The most common sites of bleeding among babies are the circumcision site and the head (either inside or outside the skull). Bleeding inside the head (intracranial hemorrhage) is a serious complication and results in serious brain injury among 20% of patients.

More than 70% of the 580 babies with hemophilia enrolled in UDC from 2003 to 2007 reported having a bleeding episode before 2 years of age, and one in five of these bleeds involved the head.

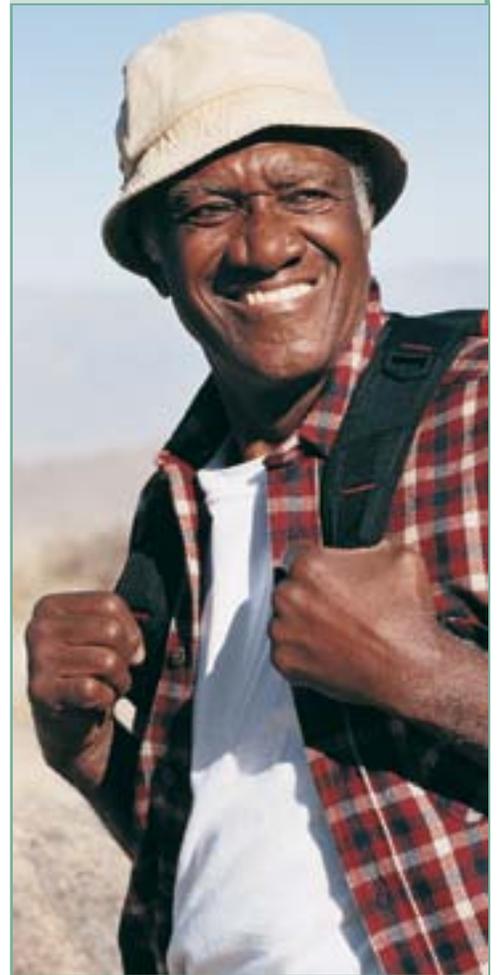
In the United States, most people with hemophilia are diagnosed at a very young age. Half of those people with mild hemophilia are diagnosed by 3 years of age, half of those with moderate hemophilia by 8 months of age, and half of those with severe hemophilia by 1 month of age.

Academic Achievement

Men with hemophilia A graduate from high school at a similar or higher rate than the national population of men.

The UDC system monitors major complications of bleeding disorders, such as:

- Developing or worsening joint disease, or both
- Developing inhibitors (a substance in the body that inhibits—that is, stops—bleeding disorder treatments from working)
- Acquiring diseases such as hepatitis and acquired immune deficiency syndrome (AIDS) through blood products





Overweight and Obesity

Youth with hemophilia are just as likely to be overweight as youth among the general population; however, the extra weight puts them at increased risk for long-term damage to their joints.

Males with hemophilia who are overweight are more likely to have less joint mobility than those who are not overweight.

Blood Safety

Since 1998, no new infections of hepatitis A, hepatitis B, hepatitis C, or HIV have been linked to using blood products to treat bleeding disorders.

Samples of stored blood from UDC system participants from the early days of the West Nile virus epidemic (2002–2003; before the virus

spread across the country) showed no evidence of spread of the virus through clotting factor products.

In 2004, a study of stored blood showed that very young children who used plasma-derived clotting factor products were more likely to have been exposed to parvovirus B19 infection. This led to increased testing as part of the manufacture of these products.

Changes in Causes of Mortality

Among deaths of people with bleeding disorders reported to CDC during the period 1997–2007, the most common causes were related to HIV (19%) and liver disease (22%). Hemophilia-related (bleeding) causes were less common (12%).

What studies currently are being conducted using UDC system data?

HTC investigators are busy looking at the UDC system data to find out more about:

- Inhibitors and ways to find and measure them.
- Links (if any) between the type of genes a person has and if the person will develop an inhibitor.
- Joint disease among people with severe von Willebrand disease.
- Hereditary bleeding disorders among women.
- Causes and consequences of bleeding in or around the brain.
- Use of routine preventive treatment.
- Use of devices that allow health care providers access to a patient's vein to provide treatment or draw blood.
- Joint disease and how it progresses among people who already have damaged joints.
- Parvovirus B19 and whether the testing the manufacturing companies are doing has decreased the risk of this infection from clotting factor.
- The extent of vaccination among the community with bleeding disorders and the effectiveness of prevention messages.

What future studies are planned?

Researchers plan to study:

- Reasons why some children with hemophilia have more loss of joint mobility than others, even though they do not bleed more often.
- Bleeding symptoms and other signs of severe von Willebrand disease.
- Complications among children with hemophilia who are younger than 2 years of age.

