

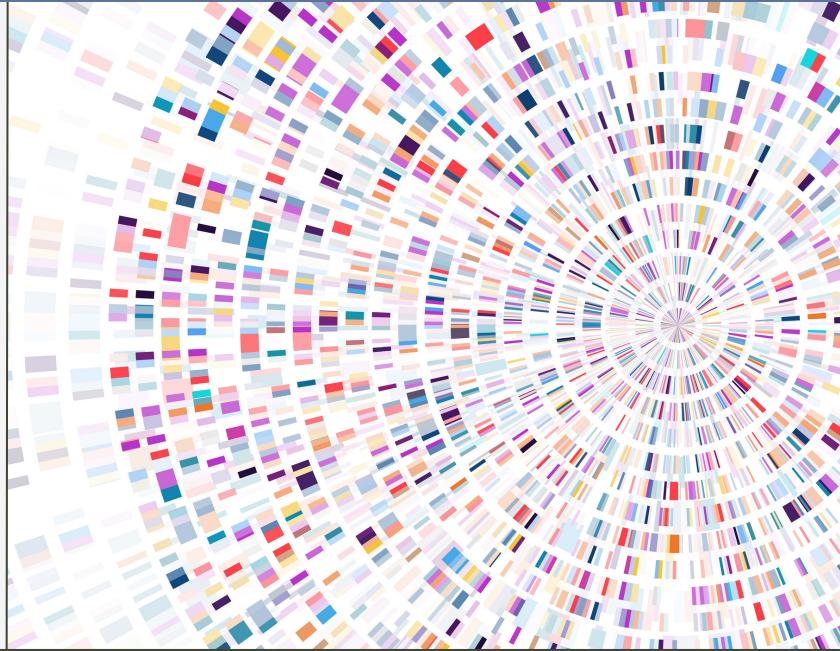
Hemophilia HubKit

" Because hemophilia is a rare disease, new therapies are made only because most patients are willing to participate in research and volunteer for trials. The future for patients with hemophilia has never looked brighter thanks to cutting-edge research and the patients who are willing to be part of that research." - Dr. Cindy Leissinger

Diagnostic Inequities

- The median age at diagnosis in the U.S. is 36 months for people with mild hemophilia, 8 months for those with moderate hemophilia, and 1 month for those with severe hemophilia.
- About 70% of people with hemophilia in the U.S. receive multidisciplinary, comprehensive care in a network of federally funded hemophilia treatment centers.
- Latinx patients with severe hemophilia are about twice as likely to develop an inhibitor than non-Latinx white patients.
- The World Federation of Hemophilia estimates that over 75% of expected people living with hemophilia worldwide have not yet been identified and diagnosed.

[Source: [Source](#)]



Tests and Diagnostic Tools

- **Complete Blood Count (CBC):** measures the amount of hemoglobin (the red pigment inside red blood cells that carries oxygen), the size and number of red blood cells, and numbers of different types of white blood cells and platelets found in blood.
 - For people with hemophilia, the hemoglobin and red blood cell count can be low.
- **Activated partial thromboplastin time (APTT) test:** measures how long it takes for blood to clot. It measures the clotting ability of factors VIII (8), IX (9), XI (11), and XII (12). If any of the clotting factors are too low, it takes longer than normal for blood to clot.
 - Results of the test will show a longer clotting time among people with hemophilia A (lack of factor VIII) or B (lack of factor IX).
- **Prothrombin time test (PTT):** measures the time it takes for blood to clot. It measures primarily the clotting ability of factors I (1), II (2), V (5), VII (7), and X (10). If any of the clotting factors are too low, it takes longer than normal for blood to clot.
 - Results of this test will be normal among most people with hemophilia A or B.
- **Fibrinogen test:** fibrinogen is another name for clotting factor I (1); This test assesses a person's ability to form a blood clot. Typically ordered along with other blood clotting tests and/or when a person has an abnormal PT or APTT test results.
- **Clotting factor tests:** also called factor assays. Shows type of hemophilia and severity (mild/moderate/severe) in order to create the best treatment plan.

[Source: [Source](#)]

Access Barriers

- Socioeconomic barriers
- Physical access to services in rural vs. urban settings
- Diagnostic delays
- Access to care for patients with rare or undiagnosed bleeding disorders
- Lack of patient awareness around 'normal' versus 'abnormal' bleeding
- Lack of specialist availability
- Difficulties accessing a hematologist for benign diseases due to long waiting list

[Source]

Call to Action

Read up. Keep reading to increase your awareness and understanding of diagnostic testing.

Learn. If you have a disease or health problem, learn about the specific tests and how they may impact your health and treatment outcomes.

Understand. Know what's normal and abnormal for you.