

Over 5000 Respond to National Survey of US Hemophilia Treatment Centers



What do people with bleeding disorders really think about their Hemophilia Treatment Center (HTC)? How satisfied are they with their care? Are there groups of patients that have specific problems with getting the HTC services they need? These are some of the

questions that over 5,000 people with bleeding disorders answered in the first national survey of HTC patient satisfaction.

What is the National HTC Patient Satisfaction Survey?

In early 2015, HTCs in the United States sent out a survey to their patients, called the Patient Satisfaction Survey (PSS). The two-page PSS was designed using questions similar to other national surveys using input from the ten HTC Regional Coordinators. The intent was to measure the level of satisfaction with care that people received at their local HTC. Each center mailed paper copies to their patients or provided an online option. The survey was voluntary and anonymous. Patients returned completed surveys to the HTC at the University of Colorado, which compiled and shared the results with each region and center.

Why was the Survey Conducted?

While many centers have conducted their own satisfaction surveys in the past, this was the first survey of how HTCs nationwide are doing. The surveys were sent from 133 centers to over 28,000 patients or their caregivers, representing over 95% of all HTCs in the US. The feedback is valuable to centers and delivers a snapshot of national, regional and local views of success and areas for improvement. Patients responding included males and females with bleeding disorders such as hemophilia A, hemophilia B, and von

"The only thing I can think of would be to have the hemophilia clinics closer to my home."

54 year old male with severe hemophilia from West Virginia

Willebrand Disease. The survey was in both Spanish and English, asked about severity, age, race and ethnicity, and allowed people to rank the level of satisfaction with care received. Questions included the option to write in comments on what their center was doing well or how it could improve. While all surveys were anonymous, the form indicated the name of the center where the patient received care.

"The care and caring there is far beyond anything I have experienced elsewhere!"

37 year old female with von Willebrand Disease from Illinois

What will be done with the results?

The PSS responses describe satisfaction with HTC care throughout the country. While most surveys showed a high level of satisfaction, some responses were not as positive. The results showed that patients have different challenges with their care around the country, including insurance access, language barriers and communication with staff. Patients described what worked well and what did not at their center, providing details to the HTC that may not have been received as openly from patients in person. This vital patient feedback helps all centers focus on what services need to improve at the local, regional, and national levels.

"Communication needs to improve."

Parent of 3 year old male with severe hemophilia from California

The results of the 2015 Patient Satisfaction Survey led national leaders to agree that surveys should be sent out every three years to see if positive change is occurring at centers over time and to help identify trends in patient satisfaction. The hope is that an increased number of patients will participate, growing the feedback regarding satisfaction, which is an important measure of quality of care. The next survey is tentatively scheduled to be sent out in 2018. Regional HTC leadership thank all patients and caregivers who participated and the HTCs for their collaboration.

For more information go to: www.htcsurvey.com.