

Nearly 4800 Patients Respond to Second National Survey of US Hemophilia Treatment Centers



In the spring and summer of 2018, nearly 4800 Hemophilia Treatment Center (HTC) patients or caregivers answered the Second National HTC Patient Satisfaction Survey. The number of people taking the survey was similar to the first survey a few years ago.

Ninety-two percent of the HTCs in the US sent surveys to patients.

What questions were asked? The survey asked how satisfied patients were with care received in 2017 from HTC team members, services, and how care was delivered. It also asked how often insurance and language were problems to getting HTC services. Patients could comment about their care at the end of the survey.

Who answered the survey? The 4767 patients answering were males and females with hemophilia A or B, von Willebrand Disease, and other rare inherited bleeding disorders. People who completed the survey were from all racial and ethnic backgrounds and all ages. Surveys were available in Spanish and English. All surveys were anonymous.

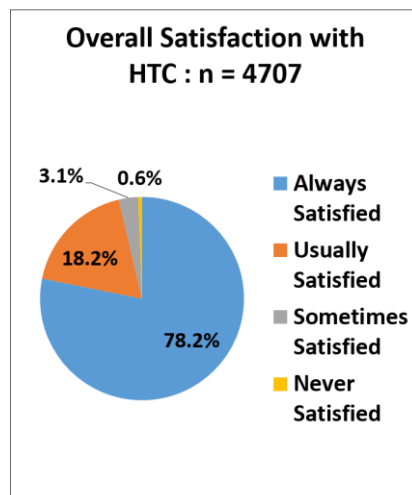
What was new in this survey? In this survey, two questions were added: satisfaction with the HTC 340B factor/pharmacy program, and whether hemophilia patients had an active inhibitor.

Results: Satisfaction is high nationally!

Overall HTC Care:

In 2017, 96% reported being “always” or “usually” satisfied with their overall HTC, just like in 2014.

HTC Team: Over 85% reported that they were ‘always’



or ‘usually’ satisfied with the HTC hematologist, nurse or nurse practitioner, social worker, or physical therapist.

HTC Services and Care: Between 93% - 98% were ‘always’ or ‘usually’ satisfied with HTC services and how HTCs provided care. In addition, 96% indicated they were ‘always’ or ‘usually’ satisfied with their HTC 340B factor/pharmacy program.

Teen Transition: Over 92% of 12-17 year olds reported they were ‘always’ or ‘usually satisfied’ with how HTCs talked about how to care for and become independent in managing bleeding disorders as they grew up.

Insurance: Overall, about 13% reported that insurance was ‘always’ or ‘usually’ a problem to getting needed HTC services.

Language problems: Just under 8% reported that language was ‘always’ or ‘usually’ a problem to getting needed HTC services

How can this data be useful? What’s next?

This national data tells us that patients around the country in 2017 were generally very satisfied with HTCs, just like in 2014. That’s important because being satisfied with medical care means patients are more likely to get the care they need to stay healthy. The responses that were not as positive are helpful feedback as well. All results allow centers to focus on what services need to improve at the local, regional, and national levels.

These 2017 results were sent to each HTC and will be compared to the 2014 responses to see changes over time. Highlights of these new national results were presented at the National Hemophilia Foundation Annual Conference and the ATHN Data Summit. More will be shared in 2019.

Articles addressing various trends that we found in the data will be shared at our website over the coming year. The next survey is tentatively scheduled to be sent out in 2021.

Regional HTC leadership thank all patients and caregivers who participated and the HTCs for their collaboration.

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