

# Third National Survey of US Hemophilia Treatment Centers – Over 5300 Patients Report on Care Obtained in 2020



From March through August 2021, over 5300 of patients or caregivers from 92% of U.S. Hemophilia Treatment Centers (HTCs) joined the third HTC Patient Satisfaction Survey. This is the largest number of people to ever take the survey.

## What questions were asked?

The survey asked how satisfied patients were with HTC team members, care, and services received in 2020. Other questions asked how often insurance, language, and COVID-19 were a problem with getting HTC services. The survey asked for patient age, diagnosis and severity, gender, race, ethnicity. Patients or their caregivers could add comments about their HTC care.

## Who answered the survey?

The 5308 patients who answered the survey had hemophilia A or B, von Willebrand disease, other factor deficiencies, or other rare inherited bleeding disorders. Patients were from many racial and ethnic backgrounds, ages, and areas of the country. The survey was anonymous and in both Spanish and English.

## What questions were new in the Third Survey?

New questions asked about telehealth (video visits) and COVID-19.

## Results: Patients were very satisfied with HTCs!

**Overall HTC Care:** 97% were ‘always’ or ‘usually’ satisfied with their overall HTC care. This is like the high satisfaction levels reported for 2014 and 2017.

**HTC Team:** Over 97% were ‘always’ or ‘usually’ satisfied with the HTC doctor, nurse, nurse practitioner, social worker, or physical therapist.

**HTC Clinical Services and Care:** Between 93% - 98% were ‘always’ or ‘usually’ satisfied with HTC services and how HTCs provided care.

**HTC Pharmacy Services:** Over 97% were ‘always’ or ‘usually’ satisfied with HTC pharmacy services.

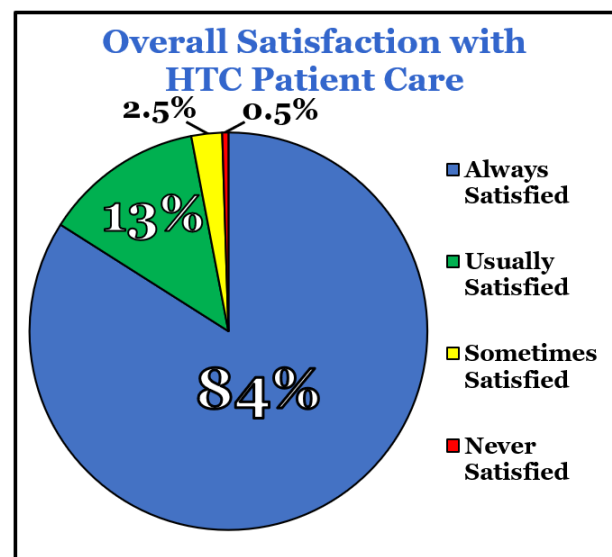
**Getting Ready for Adulthood:** Over 90% of 12–17-year-olds were ‘always’ or ‘usually’ satisfied with how their HTC talked about how to care for and become independent in managing bleeding disorders as they became an adult.

**Telehealth:** Over 35%, or 1875 patients, reported that they had at least one HTC telehealth visit in 2020. Over 96% of those who had a telehealth visit were ‘always’ or ‘usually’ satisfied with their overall care.

**Insurance Problems:** Just over 16%, or 779 patients, reported that insurance was ‘always,’ or ‘usually,’ or ‘sometimes’ a problem to getting needed HTC services. 93% of those reporting insurance problems were still ‘always’ or ‘usually’ satisfied with HTC care.

**Language problems:** Only 1%, or 66 patients, reported that language was ‘always,’ or ‘usually,’ or ‘sometimes’ a problem to getting needed HTC services.

**COVID-19:** 701 (13%) persons reported COVID-19 was a barrier to care. For those 701 persons, 90% were ‘always,’ or ‘usually,’ or ‘sometimes’ satisfied with overall HTC care, 80% were satisfied with HTC staff, and 72% were satisfied with HTC services.



## How can these data be useful? What's next?

These results show that patients nationwide were generally very satisfied with HTCs in 2020, even though the COVID-19 pandemic required many HTCs to provide services using telehealth. That's important because being satisfied with medical care means people are more likely to get the care that they need. Knowing when and why patients are not satisfied helps HTCs to focus on what services need to improve at the local, regional, and national levels.

Results were sent to each HTC. They will be compared to the 2014 and 2017 surveys to see changes over time. Highlights of national results are presented at many national bleeding disorders conferences.

Articles about what we learn from the US HTC Patient Satisfaction Survey are added on our website. The next survey is planned for 2024. We thank all patients and caregivers who joined the survey, and all the HTCs for their work. For more information: [www.htcsurvey.com](http://www.htcsurvey.com)