

# Patient Satisfaction with U.S. Hemophilia Treatment Centers: Where is Insurance a Barrier to HTC Care?



The first National Patient Satisfaction Survey (PSS) of care received at Hemophilia Treatment Centers (HTC) in the United States was conducted in early 2015. Patients were asked for feedback on their satisfaction of the HTC care they received in calendar year 2014.

HTCs are specialty clinics. The doctors, nurses and staff are specifically trained to work with

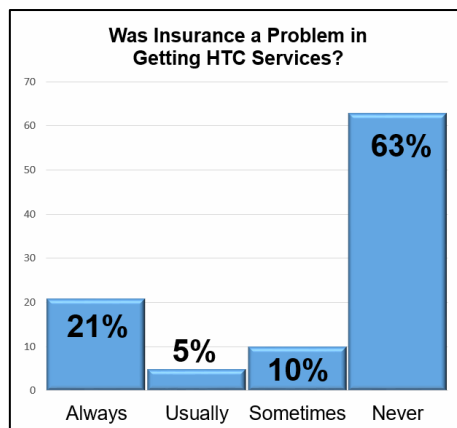
bleeding disorders. They can identify problems and find solutions a general doctor or pediatrician may not be aware of. This specialty care requires a unique understanding of how blood and clotting works. In fact, studies show that care at HTCs is linked with 40% fewer deaths<sup>1</sup> and hospitalizations<sup>2</sup> than bleeding disorder care provided outside HTCs.

However, patients often face the problem of how their care will be covered by insurance, if at all. Many patients struggle to find insurance coverage they can afford. The medication for bleeding disorders is expensive and not always available at a regular pharmacy. It may be hard to find insurance that covers these medications. This can lead to frustrating hoops that patients must jump through to get care to treat their condition.

In the PSS, we asked HTC patients and caregivers how often insurance was a problem getting HTC services. Over 5000 patients or caregivers from over 130 HTC around the country responded.

## What did we find out?

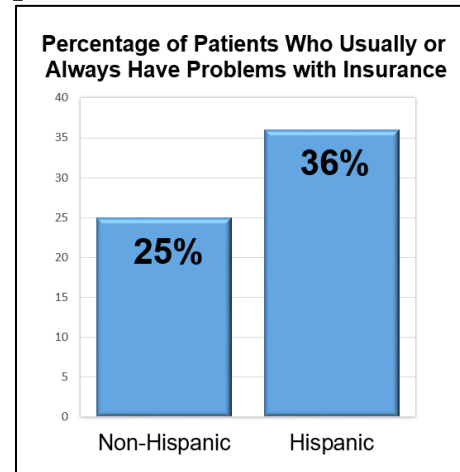
Overall, one in every four persons (26%) reported that insurance was always or usually a problem getting HTC services. Ten percent more stated that insurance was 'sometimes' a problem getting HTC services.



**"They always handle all issues concerning insurance."**

34 year old man with severe hemophilia from New York

## Which patients reported more insurance problems?



Hispanics indicated insurance was a problem more than ten percentage points higher than non-Hispanics. More than one in three Hispanics (36%) reported that insurance was 'always' or 'usually' a

problem getting HTC services, compared to an average of 25% of non-Hispanics. When analyzed, no other group had as high a percentage that struggled to get HTC services with their insurance.

There were also differences by race.

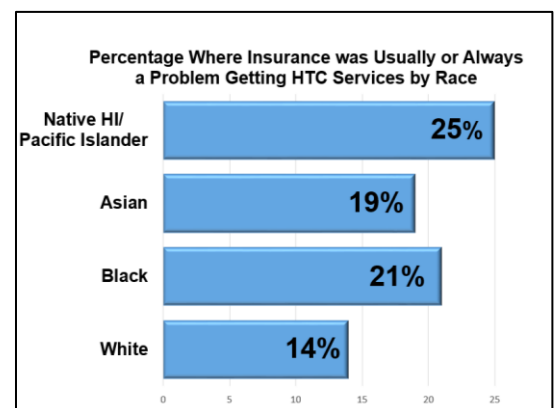
Insurance was usually or always a problem getting HTC services the least for Whites (14%), higher for Asians (19%) and Blacks (21%) and the most for Native Hawaiians/Pacific Islanders (25%).

**"Need better communication between HTC and Billing."**

31 year old man with severe hemophilia from California

## What's next?

Because some HTC patients need more help with their insurance plans, many HTCs are focusing on ways to reduce insurance obstacles.



The second national Patient Satisfaction Survey will be available in early 2018. We will monitor insurance problems in the new survey.

For more details on the PSS please go to [htcsurvey.com](http://htcsurvey.com) and direct any questions to [HTCSurvey@ucdenver.edu](mailto:HTCSurvey@ucdenver.edu).

<sup>1</sup>Soucie et al. *Blood* 2000    <sup>2</sup>Soucie et al. *Haemophilia* 2001