

Patient Satisfaction with U.S. Hemophilia Treatment Centers: Voices of Adolescents



The teen years are a time of change, moving from childhood to adulthood. Teens who have a medically complex bleeding disorder—like hemophilia or von Willebrand Disease—have added challenges growing up. These challenges include understanding and managing the disorder, how to minimize bleeds, how to infuse factor or take other medications, how and when to call the clinic, and how to make appointments. Building these skills takes a lot of help: from parents, other caregivers, and from the Hemophilia Treatment Center (HTC).

Improving the health, safety, and well-being of adolescents and young adults is a national priority¹. Making sure teens with health issues like a bleeding disorder gain the confidence to manage their medical needs as they mature has become a focus in HTCs nationwide. One priority is increasing communication between HTC providers and teens about planning for adult health care.

What did we ask youth with bleeding disorders about their care?

“Encouraging independence.”

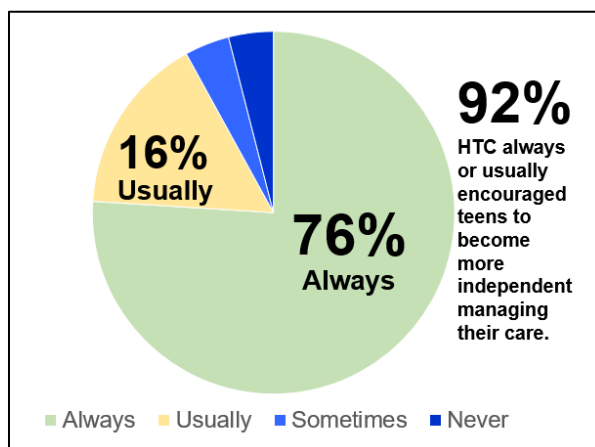
15 year old male with severe hemophilia from Texas

Over 800 HTC patients ages 12-17, or their caregivers, completed the First National Patient Satisfaction Survey (PSS). The survey asked this age group two specific questions about how HTCs encouraged teens to take charge of their own care. The questions asked if they were satisfied with the way the HTC talked about how to care for their bleeding disorder as they become adults, and whether the HTC encouraged the teens to become more independent in managing their disorder. The feedback was sent back to each HTC so they could find ways to better help teens take charge of their own care.

So, how are HTCs doing? What did we find out?

Overall, 90% of the teens and caregivers reported that they were ‘always or usually’ satisfied with how the HTC

talked about how to care for the bleeding disorder as they become adults.



We also learned that 92% of the teens or caregivers were ‘always or usually’ satisfied with how the HTC encouraged the 12-17 year old to become more independent in managing their bleeding disorder. However, about 8-10% of teens were only ‘sometimes’ or ‘never’ satisfied with HTC adolescent transition discussions with their HTCs.

What’s next?

HTCs are paying extra attention to the ‘teen transition’ to adult care and finding ways to improve their services. Many HTCs are offering skill building workshops: teaching teens how to schedule appointments; how to order and manage medications; and how to work with caregivers to help them take on these responsibilities as they mature.

The second national Patient Satisfaction Survey is now open and available until **June 30, 2018**. We are again asking teens how the HTC is meeting their needs as they adjust to adult care. By comparing answers from both surveys HTCs can see if they made progress and what work remains.

Details on the 2014 survey and a link to take the current survey are available at www.htcsurvey.com.

For any questions regarding the PSS, please contact us at HTCSurvey@ucdenver.edu.

“Now that my child is a teenager, the staff can talk to him more than they talk to me—he usually won’t talk, so they need to engage him better.”

Parent of 13 year old male with von Willebrand Disease from Ohio

¹Healthy People 2020: Adolescent Health <https://www.healthypeople.gov/2020/topics-objectives/topic/Adolescent-Health>