



# Treatment Adherence Predictors: Indicators from the US Hemophilia Treatment Center Patient Satisfaction Survey 2015

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## INTRODUCTION

Shared decision-making and a positive patient/healthcare provider relationship foster patient satisfaction (PS)<sup>1</sup> which, in turn, associated with improved treatment adherence.<sup>2</sup> PS is a core patient reported outcomes measure, critical to clinical care, quality performance management, and clinical research.<sup>3</sup> Adherence to new treatment regimens and care delivery innovations merit nationally consistent metrics to assess PS.

Many US Hemophilia Treatment Centers (HTC) assess PS. Yet the lack of uniform data across the US HTC Network limits a national understanding of PS. Without a nationally uniform PSS survey instrument, HTCs cannot compare national and regional PS trends over time, and cannot identify national and regional predictors that could help inform quality improvement initiatives to strengthen treatment adherence.

## OBJECTIVE

To remedy the knowledge gap in patient satisfaction with HTC services, the US HTC Network implemented a national, uniform patient satisfaction survey in 2015.

## METHODS

A Regional HTC Coordinator workgroup reviewed existing survey instruments, harmonized, piloted, and finalized a two-page survey for self-administration online, at clinic or at home, and mailed to households. Surveys were available in English and Spanish. Respondents were asked to assess satisfaction with HTC care obtained in 2014.

Survey content and format were based on three national health questionnaires to enhance comparability and scientific robustness, informed by legacy regional HTC surveys: National Survey of Children's Health,<sup>4</sup> National Survey of Children with Special Health Care Needs,<sup>5</sup> and the CAHPS Clinician and Group Surveys.<sup>6</sup> Survey questions were chosen to assess key federal health priorities.

Questions assessed patient demographics; overall satisfaction with services, satisfaction with nine distinct team members, and satisfaction with eight unique care processes including shared decision making, ease of getting needed and timely care and understandable information, respect and care coordination. Two questions assessed satisfaction with adolescent transition planning among patients age 12-17 years, aligned with Healthy People 2020 objective DH-5.<sup>7</sup> Shared decision making was assessed with one question, "How often did HTC clinic staff involve you (or your child) in decisions about care?" Three open ended questions captured qualitative data on what the HTC is doing well, areas to improve, and any other information respondent wished to share.

Eligibility: Persons with genetic bleeding disorders who had HTC contact in 2014. Respondents were anonymous but each survey contained a three digit HTC identifier. A single survey was available to each eligible household, regardless of the number of eligible individuals per household. Participation was voluntary. Respondents were anonymous but identified their respective HTCs.

During February 2015, 133 (96%) of the 138 US HTCs from all regions administered surveys to 28,289 households. Parents were asked to complete surveys for children under age 15. No reminders were sent. Data were collected from February – May 2015.

Data were entered and analyzed at the central data coordinating center at the University of Colorado, Denver, and were aggregated at national, regional and HTC levels.

## RESULTS

Demographics: 5006 patients returned surveys from all 133 participating HTCs (Fig. 1). The response rate was 17.7% (regional range 14% - 23%), with one in five respondents residing in a single region (Fig. 1). 29% were female (range 22% - 38%). Regions differed markedly in respondent race, age, diagnosis and severity (Figs. 2-4.) Over 500 (11%) were Hispanic (range 2% - 33%). Of the 94% who identified their race, 754 (16%) identified as a race other than Caucasian (range 10% - 39%) (Fig. 2). Over 59% were > 18 years of age (range 52% to 70%) (Fig. 3).

Overall Satisfaction: 91% were either 'always' or 'usually' satisfied with HTC care. Satisfaction with HTC Core team members: Over 95% were either 'always' or 'usually' satisfied with the HTC Hematologist, Nurse, Social Worker and Physical Therapist (Fig. 5).

Satisfaction with Shared Decision Making and Care Processes Related to Patient/ Healthcare Provider Interactions (Fig. 6): 97% were either 'always' or 'usually' satisfied with shared decision making, 95% with obtaining care in a timely manner, 94% with getting needed information, 97% with adequacy of time spent with HTC clinicians, 95% respectful treatment. Over 77% of the respondents were satisfied with how HTCs talked about how to care for and become independent in managing the bleeding disorder as they become an adult (Fig. 7).

Respondents provided >3000 comments regarding satisfaction with HTC services.

## CONCLUSIONS

The vast majority of the 5006 individuals who obtained care within the US Hemophilia Treatment Center Network in 2014 report very high levels of satisfaction in their relationships with HTC clinicians, in shared decision making, and care processes that impact adherence.

Future analyses will explore variations in satisfaction-related adherence predictors by diagnosis, severity, demographics, and region to identify priorities for interventions. Qualitative data analyses may further inform strategic directions to strengthen adherence.

Regional analyses are vital to a deeper understanding of patient satisfaction with HTCs, and to guide future action given the skewed response rate and variation in respondent diagnosis, severity, demographics and region.

## ACKNOWLEDGEMENTS

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Figure 1: Survey Responses by Region

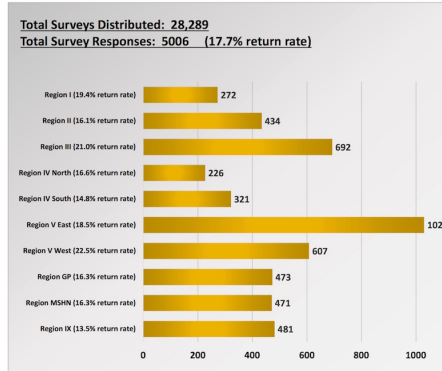


Figure 2: Survey Responses by Region and Respondent Race

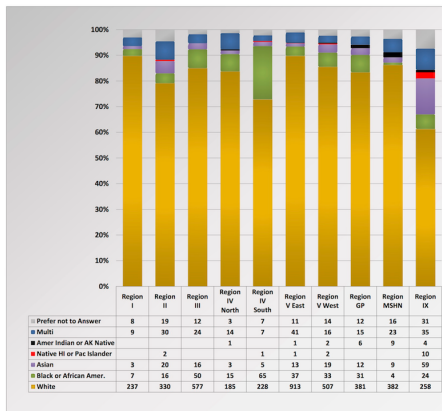


Figure 3: Survey Responses by Region and Respondent Age

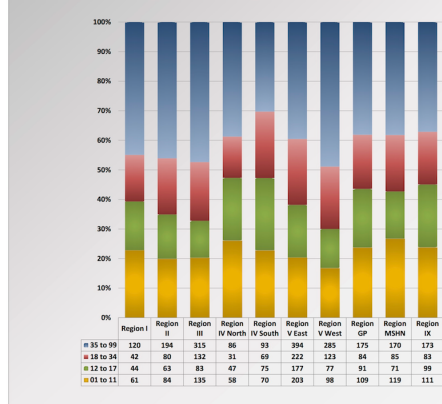


Figure 4: Responses by Region and Diagnosis

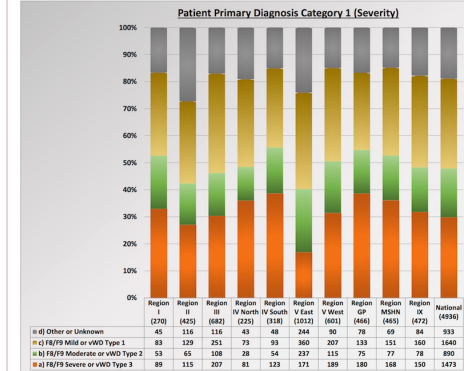


Figure 5: Satisfaction with HTC Hematologist, Nurse, Social Worker and Physical Therapist

| Professional       | Satisfaction Rate |
|--------------------|-------------------|
| Hematologist       | 97%               |
| Nurse              | 97%               |
| Social Worker      | 95%               |
| Physical Therapist | 97%               |

Figure 6: Satisfaction with Shared Decision Making and Care Processes Related to Patient/Healthcare Provider Interactions

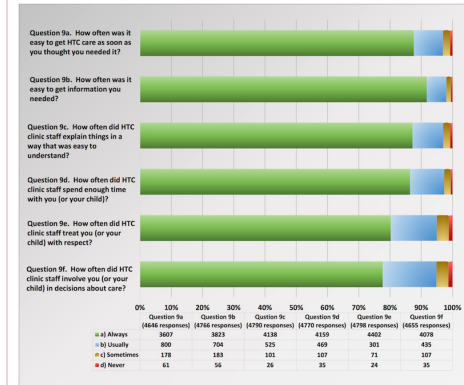
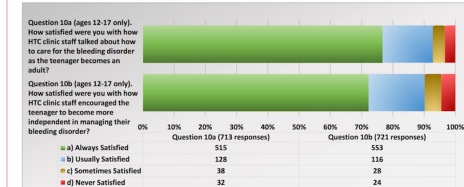


Figure 7: Satisfaction with Adolescent Transition Planning Related to Patient/Healthcare Provider Interactions per Healthy People 2020 Objective DH-5



References: <sup>1</sup>Vernerey et al J Clin Pharm Ther 2011; <sup>2</sup>Glickman et al Clin Diabetes Care 2010 and <sup>3</sup>Joosten et al Psychopharmacology and Psychosomatics 2008; <sup>4</sup>Institute of Medicine, Crossing the Quality Chasm 2001; <sup>5</sup>http://nhs.uk/healthcarequality/; <sup>6</sup>https://www.healthcarequality.org/; <sup>7</sup>https://www.healthypeople.gov/2020/data/details

Regions: Region I = Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont; Region II = New Jersey, New York, Puerto Rico; Region III = Delaware, Maryland, Pennsylvania, Virginia, West Virginia; Region IV = Kentucky, North Carolina, South Carolina, Tennessee; Region V = Alabama, Florida, Georgia, Mississippi; Region V East = Indiana, Michigan, Ohio; Region V West = Illinois, Minnesota, North Dakota, South Dakota, Wisconsin; Region GP = Arizona, Iowa, Kansas, Louisiana, Missouri, Nebraska, Texas; Region MSNH = Arkansas, Colorado, Montana, New Mexico, Utah, Wyoming; Region IX = California, Guam, Hawaii, Nevada; Region X = Alaska, Idaho, Oregon, Washington.