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ORIGINAL ARTICLE

Patient satisfaction with US Hemophilia Treatment Center Care, Teams and Services: The First National Survey

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Abstract

Introduction: Patient satisfaction with health care is a key quality metric, associated with adherence and better outcomes. However, satisfaction with US Hemophilia Treatment Centers (HTC) is unknown.

Aim: To assess patient satisfaction with US Hemophilia Treatment Centers.

Methods: A nationally uniform survey was conducted using the US HTC Network's regional infrastructure. Satisfaction with multidisciplinary team members, services and care processes was assessed. The anonymous survey, in English and Spanish, was disseminated to 28 289 households. Data were aggregated using 4 standard US Census regions.

Results: 5006 individuals (17.7%) who obtained care from 133 (96.4%) of 138 HTCs in 2014 responded. Satisfaction with overall HTC care at 'always' or 'usually' (A/U) levels ranged 94.2%-97.9% regardless of patient gender, age, race, ethnicity, language, diagnosis, severity, region or frequency of HTC contact. A/U satisfaction with HTC haematologist, nurse, social worker or physical therapist, individually, ranged 95.1%-97.3% nationally. A/U satisfaction with three HTC services was 89.5%-96.9% and 94.9%-98.0% for five HTC care processes nationally. Regional satisfaction at A/U levels was at least 87.0%. Nationally, 26.4% and 21.2% rated insurance and language, respectively, as A/U problems in getting needed HTC services.

Conclusion: Patient satisfaction with US Hemophilia Treatment Center care, multidisciplinary teams, services and processes was consistently high, documenting the value patients place on HTCs. The successful survey administration demonstrates the capability of the Network's regional infrastructure. Access to the US HTC Network is particularly critical to ongoing health in this new era of novel and gene therapies.

KEYWORDS

adolescent transition, haemophilia, Hemophilia Treatment Centers, multidisciplinary care team, patient satisfaction, sustainability

1 | BACKGROUND

Patient satisfaction with healthcare delivery is a key quality metric, associated with treatment adherence[1] and better health outcomes.[2,3] In the United States, this metric can prompt enhanced reimbursement,[4,5] important in the US healthcare system for continued financial support of Hemophilia Treatment Centers (HTCs). The multidisciplinary healthcare team (MDT), a chief element of the patient-centered medical home model for primary care, is increasingly the focus of patient satisfaction.[6] The MDT has its roots in the model of care for children with complex, chronic and rare conditions,[7] many of whom have now grown to adulthood.[8]

However, measuring patient satisfaction with the MDT, team services and processes is challenging for rare disorder (RD) populations.[9] RD populations are inherently small, scattered geographically and obtain care from disparate clinical facilities that are not typically organized to collect uniform data. As a result, RD patient satisfaction assessments are often confined to single specialty programmes[10] or limited geographic areas.[11,12] This narrow reach limits broad understanding of where to improve systems of RD health care.

Hemophilia Treatment Centers in the United States are organized using a regional infrastructure that today includes a national clinical network of 150 HTCs with extensive geographic reach and requirements to provide MDT care to people with bleeding or clotting disorders.[13] HTC MDTs consist of a haematologist, nurse or nurse practitioner, social worker and physical therapist[14] who provide expert diagnostic, treatment, prevention, education, counselling, rehabilitation and care coordination services.[13] HTCs conduct surveillance and implement national registries.[15,16] Regional directors and regional coordinators provide leadership, oversight and technical assistance; build capacity; and foster best practice dissemination.[13] At the federal government level, the US Health Resources and Services Administration (HRSA) provides limited funding support to the eight designated regions which encompass the entire country.

Registries and surveillance projects in the US bleeding disorders population typically focus on patient demographics, clinical status and mortality; none examine patient satisfaction with individual MDT members, services or care processes. Some individual HTCs,[10] and most HTC regions, periodically monitor patient satisfaction; four regions harmonized their survey instruments in the mid-2000s. New HRSA requirements in 2012 to document HTC service impact, strengthen patient input and foster adolescent transition to adult care prompted the US HTC Network to conduct the first nationally uniform patient satisfaction survey (PSS). This report describes the development, implementation, results and implications of the US HTC Network's first PSS.

2 | METHODS

A Steering Committee composed of three regional coordinators initiated and managed the PSS. The domains in the PSS reflected HRSA's performance standards for its National Hemophilia Program: families as partners in decision-making, access to a medical home, easy-to-use services, adequate insurance and facilitating transition to adulthood. Question content aligned with legacy regional surveys. Question formats were harmonized with nationally validated surveys to facilitate comparisons to other populations,[17] and to enhance scientific robustness (File S1).

The PSS assessed patient demographics (diagnosis and severity, age, gender, race and ethnicity, and HTC name) and used a four-point Likert scale to rate satisfaction with MDT core and affiliated clinicians, services and care processes. Frequency in which language and insurance posed barriers to care was also asked. The survey concluded with open-ended questions that asked what the HTC is doing well and what improvements could be made, and solicited additional comments. Core MDT clinicians rated were the hematologist , nurse, nurse practitioner, social worker and physical therapist. Three HTC services were assessed: shared decision-making, care coordination with primary doctor and care coordination with other specialists/providers. Five HTC processes were examined: timeliness of care, ease of getting needed information, communication, time spent with patient and being treated with respect (File S1). The survey and a cover letter template were translated into Spanish by a certified translator. Patients at the University of Colorado Denver HTC reviewed a draft version of the survey and had the opportunity to make recommendations to improve the content and administration process.

All 138 HTCs operating in 2014 throughout all eight regions were invited to participate. Regional coordinators promoted survey implementation throughout their regions to foster participation. They disseminated the instructions, cover letter and surveys to their HTCs, and provided technical assistance to facilitate nationally consistent administration. During February and March 2015, HTC clinicians and/or administrative staff disseminated the survey to an estimated 28 289 households of patients with which the HTC had a significant clinical interaction in 2014. The data collection period was open through June 2015. HTCs primarily mailed surveys to their patients' households (one/household) or provided the paper survey in clinic. A web address was included on the survey for those who preferred to respond electronically. The 'home' HTC name and 3-digit identifier were on each survey to attribute responses to the correct HTC during analysis. HTCs generally bore the costs of printing, envelopes, postage and staff time to inform patients about the survey, prepare mailings and/or distribute in clinic. Some HTCs provided a stamped envelope for patients to return the survey via mail, and at other HTCs, patients bore the cost of the envelope and stamp.

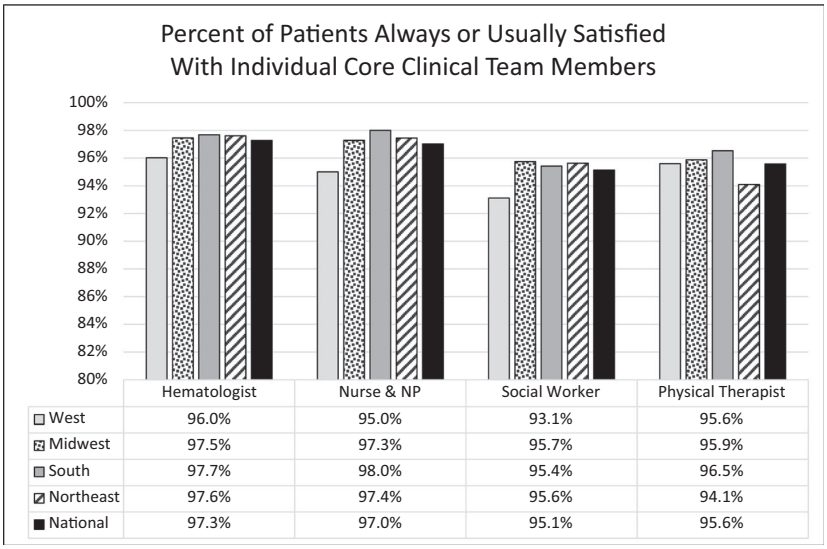
This project was deemed quality improvement, not patient research, during a September 2015 review by the University of Colorado Anschutz Medical Campus Institutional Review Board (IRB). Some centers submitted the survey to their institution's IRB per local requirements.

The University of Colorado served as the central Data Coordinating Center, received all completed surveys and aggregated data at the national, regional and HTC levels. Each regional coordinator received the national data set and their region's results, including reports which compared each HTC in their region to regional and national responses. Similarly, each individual HTC received a report with only their center and region identified, comparing their HTC to regional and national responses. To enable comparative analyses of PSS results to other populations, the PSS SC collapsed the eight HTC regions into the four standard US Census regions: West, Midwest, South and Northeast (File S2). In conducting the analyses, non-responses and non-applicable were excluded from the denominator for each item.

The Steering Committee convened a PSS Dissemination Work Group (DWG) quarterly, comprised of thought leaders from national hemophilia agencies. The DWG's charge was to advise on potential

DEMOGRAPHICS, SATISFACTION WITH OVERALL HTC CARE

	# of responses	% of responses	% of group always or usually satisfied with overall HTC care
Race			
White	3998	79.9	96.3
Black or African American	282	5.6	96.5
Asian	159	3.2	97.4
HI/Pac Islander, AK or Amer. Indian	39	0.8	94.9
Multi	214	4.3	97.0
Unidentified	314	6.3	95.4
Ethnicity			
Hispanic or Latino	515	10.3	96.2
Not Hispanic or Latino	4288	85.7	96.4
Unidentified	203	4.1	96.6
Gender			
Male	3502	70.0	96.4
Female	1462	29.2	97.0
Unidentified	42	0.8	100.0
Age group			
1-11	1048	20.9	96.3
12-17	827	16.5	96.3
18-34	951	19.0	95.2
35-60	1169	23.4	97.4
61-99	836	16.7	97.3
Unidentified	175	3.5	91.3
Geographic region			
West (AK, AZ, CA, CO GU, HI, ID, NM, NV, OR, UT, WA)	952	19.0	94.2
Midwest (IA, IL, IN, MI, MN, MO, ND, OH, SD, WI)	2109	42.1	96.7
Southeast (AL, DC, FL, GA, KY, LA, MD, MS, NC, OK, TN, TX, VA, WV)	547	10.9	97.4
Northeast (CT, MA, ME, NH, NJ, NY, PA, PR, RI, VT)	1398	27.9	96.8
Bleeding disorder type			
Haemophilia	3106	62.0	96.3
VWD	1299	25.9	97.0
Other, unknown or unidentified	601	12.0	95.5
Bleeding disorder severity			
Severe haemophilia or VWD type 3	1473	29.4	95.9
Moderate haemophilia or VWD type 2	890	17.8	96.8
Mild haemophilia or VWD type 1	1640	32.8	97.9
Other, unknown or unidentified	1003	20.0	95.5
Survey language			
English	4875	97.4	96.4
Spanish	131	2.6	94.4
Number of encounters w/HTC during year			
Less than 2 times	1194	23.9	96.1
2-4 times	1832	36.6	96.8
5-10 times	1186	23.7	96.0
More than 10 times	708	14.1	96.3
Not reported	88	1.7	94.0



Demographic Group	Demographic Group Size (N)	% Always or Usually Satisfied or N/A* for all Core Team Clinicians Combined
Race: White	3998	91.4%
Race: Non-White	710	91.8%
Ethnicity: Hispanic	515	89.9%
Ethnicity: Non-Hispanic	4288	91.3%
Gender: Male	3502	90.8%
Gender: Female	1462	91.9%
Age 1-17	1875	91.1%
Age 18+	2956	91.5%
Geographic West	952	87.9%
Geographic Midwest	1897	92.4%
Geographic South	1000	91.2%
Geographic Northeast	1157	91.9%
Geographic National	5006	91.2%
Disease: Hemophilia	3106	90.4%
Disease: vWD	1299	93.1%
Disease Severity: Severe	1473	87.0%
Disease Severity: Moderate	890	91.6%
Disease Severity: Mild	1640	94.1%
<5 HTC Encounters	3026	92.5%
5+ HTC Encounters	1894	89.5%
*N/A in this case includes both Not Applicable and Not Answered responses.		

GRAPH 1 Satisfaction with Core Clinical Team

dissemination activities to maximize the impact of PSS findings among key stakeholders and provide input regarding the tone and content of PSS communiques. Target audiences were, in order, patients; agencies engaged in bleeding disorders healthcare delivery advocacy or funding; healthcare professionals; and the public. Key dissemination strategies included creating one-page articles on PSS findings written for the patient audience, accessible to all stakeholders; presenting results via a Centers for Disease Control and Prevention webinar; exhibiting results at national bleeding disorder conferences; and uploading the articles to a newly created PSS website (www.htcsurvey.com).

3 | RESULTS

3.1 | Respondent demographics and HTC encounters

Participation rate of HTCs across the country was 96.4% (133/138 centers) (Table 1). Overall, 5006 individuals who obtained care from these centers in the US HTC Network in 2014 completed a survey, for a 17.7% national response rate. Females represented nearly a third (29.2%). Participants were predominantly White, non-Hispanic; 2.6% of respondents completed the Spanish language version. Patients (or parent/caregivers of children) representing all age categories participated at relatively similar levels. Participation differed by geographic region, with 42.1% (2109) from the Midwest, 27.9% (1398) from the Northeast, 19.0% (952) from the West and 10.9% (547) from the Southeast. Of all respondents, 3106 (62.0%) had haemophilia, 1299 (25.9%) had von Willebrand disease (VWD), and 601 (12.0%) reported diagnosis as other, unknown or did not specify. Among all respondents, those with severe haemophilia and VWD type 3 accounted for 29.4% (1473), those with moderate disease (moderate haemophilia or VWD type 2) accounted for 17.8% (890) and those with mild disease (mild haemophilia and VWD type 1) numbered 1640 (32.8%). Bleeding disorder severity was other, unknown or unidentified in 1003 (20.0%) participants. Annually, 60.5% had 4 or fewer encounters with the HTC, 23.7% reported 5-10 encounters, and 14.1% (708) reported over 10 encounters, and for 1.7%, the number of encounters was not reported.

3.2 | Satisfaction with overall HTC care by patient demographics

Nationally, 94.2%-97.9% reported being 'always' or 'usually' (A/U) satisfied with overall HTC care. This A/U satisfaction-level range encompassed respondents regardless of gender, age, race, ethnicity, survey language, diagnosis, severity, geographic region and number of annual HTC encounters.

3.3 | Satisfaction with HTC core team members

Graph 1 demonstrates high patient satisfaction with care obtained from the four-core HTC MDT clinicians individually and as a combined team. The bar chart displays satisfaction with each of the individual MDT members regionally and nationally. Nationally, 4645 respondents rated satisfaction with their HTC haematologists, 4684 rated HTC nurses, 3828 rated nurse practitioners, 3509 rated social workers, and 2735 rated HTC physical therapists. Examining patient satisfaction with these clinicians individually, 97.3% of respondents were A/U satisfied with the HTC haematologist, 97.0% with the HTC nurse and nurse practitioner (combined), 95.1% with the social worker and 95.6% with the physical therapist, nationally.

Graph 1's table displays A/U satisfaction ratings for all MDT members combined, by patient demographics. A/U satisfaction, when scores for all four-core MDT members were aggregated, ranged from 87.0% among respondents with severe disease to 94.1% among patients with mild disease. These A/U satisfaction levels differed only

slightly regardless of patient race, ethnicity, gender, age, geographic region, diagnoses and number of annual HTC encounters.

3.4 | Satisfaction with HTC services

Nationally, 96.9% of respondents were A/U satisfied with how HTC staff engaged them in decision-making about their care (Table 2). Patients were A/U satisfied with how HTCs coordinated care with their primary care provider (89.5%) and with their specialists (92.8%). Regionally, A/U satisfaction for each of these three services was at least 87.0%.

3.5 | Satisfaction with HTC Care processes

Nationally, over 95% of respondents were A/U satisfied with each of the five care processes (Table 2). Specifically, these were as follows: timeliness of care (94.9%); ease of getting needed information (95.0%); ease of understanding how the HTC clinic staff explained things (97.3%); time spent with clinic staff (97.0%); and being treated with respect (98.0%). Regionally, A/U satisfaction for each of the five care processes was at least 91.2%.

3.6 | Satisfaction with adolescent transition preparation

Nationally, among respondents aged 12-17 years, 90.2% reported being A/U satisfied with how their HTC talked about how to care for their bleeding disorder as they became adults (Table 2). Similarly, 92.8% of adolescents were A/U satisfied with how their HTC encouraged them to become more independent in managing their bleeding disorder. Regionally, A/U satisfaction with these transition preparation approaches was at least 88.3%.

3.7 | Insurance and language problems

Table 3 shows that nationally, 26.4% of respondents and 31.3% in the West rated insurance as A/U problem in getting needed HTC services. Language was identified as an A/U problem in 21.2% of

TABLE 2 Satisfaction with HTC services and processes

	% of responses always or usually satisfied				
	West	Midwest	South	Northeast	National
HTC services					
Did HTC clinic staff involve you in decisions about care?	94.6	97.2	97.8	97.7	96.9
Did HTC clinic staff coordinate care with your primary doctor?	87.0	90.5	89.2	90.4	89.5
Did HTC clinic staff coordinate care with other specialists or providers?	90.1	93.4	92.6	94.2	92.8
HTC processes					
Was it easy to get HTC care as soon as you thought you needed it?	91.2	95.7	95.2	96.2	94.9
Was it easy to get information you needed?	92.8	95.6	95.8	95.0	95.0
Did HTC clinic staff explain things in a way that was easy to understand?	95.9	97.5	97.7	98.0	97.3
Did HTC clinic staff spend enough time with you?	95.2	97.3	97.3	97.8	97.0
Did HTC clinic staff treat you with respect?	96.6	98.4	98.4	98.2	98.0
Adolescent transition					
For patients aged 12-17, how satisfied were you with how HTC clinic staff talked about how to care for the bleeding disorder, as they become an adult?	88.3	89.1	91.7	92.4	90.2
For patients aged 12-17, how satisfied were you with how HTC clinic staff encouraged the teenager to become more independent in managing their bleeding disorder?	92.4	91.1	94.0	94.8	92.8

TABLE 3 Problems with insurance and language

	% of responses always or usually experiencing problems[a]				
	West	Midwest	South	Northeast	National
In 2014, how often was *insurance* a problem in getting HTC services you needed?	31.3	25.8	26.1	23.7	26.4
In 2014, how often was *language* a problem in getting HTC services you needed?	25.9	20.0	21.2	19.2	21.2

[a]Excludes respondents who indicated these problems were not applicable or did not respond.

respondents nationally, with the highest reported rate in the West (25.9%). These figures excluded respondents who indicated that these problems were not applicable or who did not respond.

4 | DISCUSSION

These analyses document consistently high satisfaction with Hemophilia Treatment Center clinicians, services and care processes that 5006 persons with haemophilia, von Willebrand disease and other bleeding disorders reported receiving during 2014 from 133 federally recognized HTCs across the United States. The high satisfaction levels provide strong evidence of the value of HTCs to the patient populations served. This initiative's success provides proof of concept for the importance of a regional infrastructure in conducting a national assessment of care for persons with genetic bleeding disorders given such a high HTC participation rate. Furthermore, to our knowledge this is the largest such nationally uniform survey of patient satisfaction in any rare disorder population. No European bleeding disorder registry assesses patient satisfaction with care delivery.[18]

The vast majority of US HTC patients were 'always' or 'usually' satisfied with HTC care overall, with the core multidisciplinary HTC team members, HTC services and care processes. Data elicited from this survey documented remarkably high levels of patient satisfaction (over 90%) with the core multidisciplinary HTC clinical team:, hematologist nurse or nurse practitioner, social worker and physical therapist. The 2016 National Hemophilia Foundation (NHF)-McMaster Guideline on Care Models for Haemophilia Management[14] highlighted knowledge gaps about the HTC patient perspective regarding HTC core team members and HTC services. These data begin to fill those identified gaps. That NHF-McMaster guideline recommended an integrated care model as optimal for people with haemophilia over non-integrated care models. The guideline also recommended that the team consist of the disciplines noted above. This care team composition is required by HRSA and recommended in the NHF Standards and Criteria for the care of people with inherited bleeding disorders.[19]

This HTC PSS initiative provides new national data, reducing evidence gaps in quantifying the extent to which patients value the different healthcare professionals on the integrated HTC team, HTC services, processes and overall care. These high levels of patient satisfaction were articulated regardless of patient diagnoses, severity of disease, gender, race or ethnicity, or geographic location, and pose several implications. First, these data indicate that patients highly value the HTC multidisciplinary team approach. Next, these data confirm that the HTC services which patients rate as highly satisfactory are the nationally recognized measures of quality of care: timeliness, communication, respect, coordination with specialists and primary care practitioners. Those high ratings should convince US insurance plans to welcome HTCs in their networks, so people with rare genetic bleeding disorders have access to needed HTC teams of experts and their services.

Patient satisfaction (A/U) with how HTC staff assist adolescents transition to adult care was consistently over 90% compared to 17% among children with special healthcare needs nationally who receive transition planning support.[20] Overall, the HTC PSS feedback indicates high levels of achievement in addressing not only HRSA's goals for adolescent transition, but also HRSA's broader goals throughout the US HTC Network, from the patient perspective. These PSS data provide valuable patient input at the HTCs and regional levels to inform quality improvement.

That insurance and language problems in getting needed services were identified as highest in the West was not unexpected. It corresponds to higher levels of non–English-speaking, non–US-born populations in that area of the United States.[21] Furthermore, non–English speakers in the West are primarily Hispanic, whose challenges with obtaining insurance are well-documented.[22]

Limitations: One region—the Midwest—had 2109 respondents, two thirds of whom were patients at 16 HTCs. In comparison, the other three regions had considerably fewer respondents by region: 547 (Southeast), 952 (West) and 1398 (Northeast). Moreover, the Midwest's respondents primarily reported mild disease. These differences could skew national-level results as one area of the country was over-represented. However, this potential bias was mitigated by conducting regional-level analyses. While the response rate was 17.7%, this was a voluntary survey using no follow-up.

5 | CONCLUSION

This first national survey of patient satisfaction from 133 (96.4%) centers in the US Hemophilia Treatment Center Network used the network's regional structure for implementation and accrued 5006 individual responses. The overwhelming majority of respondents

were always or usually satisfied with overall HTC care, with core HTC clinical team members, services and processes. This demonstrates proof of principle in several important areas. First, for using a regional approach to successfully conduct a rare disorder survey nationwide. Nationally uniform surveys to document patient satisfaction of healthcare delivery for rare disorder populations are needed so a sufficient volume of participants can be solicited to substantively characterize care, to make comparisons among demographic and diagnostic subgroups, and to reduce threats to generalizability. Second, this initiative documents the high value that patients place on the care they receive at the HTCs, by individual HTC core clinicians and by those clinicians working together as a team.

High patient satisfaction with healthcare providers and HTC services is increasingly understood as a proxy for high-quality care.[23] Satisfaction in the hospital setting is more typically examined and is linked with enhanced reimbursement.[24,25] The high level of patient satisfaction documented in this inaugural national survey of the US HTC Network's ambulatory services has several important policy implications. Specifically, in the United States, access to HTC care must be guaranteed. All payers must include HTCs in their networks to maintain high-quality patient care. This may not be an issue in countries with nationalized healthcare services. In the United States, such policies should ensure that HTCs, and not local health plans, retain the authority to determine medical necessity as it relates to blood disorders. Such policies should prohibit health plans from delaying, denying or modifying HTC diagnostic and treatment recommendations. Such policies will foster health equity. All persons with suspected or diagnosed rare genetic blood disorders, regardless of payer method, must have uninterrupted access to the expert US HTC Network clinical care that reduces patient mortality,[26] morbidity and costs.[27]

Across the world, healthcare reimbursement policies must promote HTC sustainability. HTC patients are medically vulnerable. Their chronic lifelong conditions are complex. They affect multiple organ systems and result in not only physical but also social, emotional and economic burdens.[28] The specialized HTC care team often need extensive time—well beyond the typical 10- to 15-minute visit (in the United States) to assess and educate patients, and co-devise, and monitor treatment plans. Payers and payment sources must reimburse HTCs adequately for the services that core team members provide. These services are typically conducted in ambulatory care clinics and include care coordination with hospitals, emergency departments and community-based clinicians, primary care and other specialists. Adequate reimbursement is particularly critical today; so the US HTC Network, and other rare disorder population centers, can facilitate safe patient access to new novel therapies, including gene therapy, that promise enhanced wellness.

Lastly, the US HTC Network's regional leadership, and leaders from each of the core team disciplines, as well as patients and patient advocates, must be involved in shaping policies and advocacy strategies to promote HTC sustainability. Globally, comparable high-level leadership is needed where HTC sustainability is at risk.

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DISCLOSURES

None of the authors have any competing interest to declare.

AUTHOR CONTRIBUTIONS

Brenda Riske and Judith Baker developed the concept of the Patient Satisfaction Survey and coordinated all regional centers who, in turn, coordinated the HTC participation. Rick Shearer developed the database, data collection system, cleaning data and distribution of all the HTC regional- and national-level data reports. Each of the authors participated in data analysis, writing and editing of the manuscript. Judith Baker developed the dissemination plan with the assistance of Brenda Riske.

FOOTNOTES

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[1]The Centers for Disease Control and Prevention, *Hemophilia Treatment Center Directory* https://www2a.cdc.gov/ncbddd/htcweb/Dir_Report/Dir_Search.asp. Assessed on 2 June 2020.

[2]The US Hemophilia Treatment Center Network's Regions IV-South, VI, VIII and IX aligned their regional patient satisfaction surveys in the mid-2000s, the authors JRB and BKR, personal communication with John Drake and Karen Droze.

[3]https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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