Supplemental File 1: Table 1 - Crosswalk of Federal Agency Initiatives and Measurement Domains to Questions in 1<sup>st</sup> Patient Satisfaction Survey of US Hemophilia Treatment Centers, conducted 2015.

Agency / Initiative	Measurement Domain	USHTCN Patient Satisfaction Survey Question
HRSA / Healthy People 2020	Transition to Adult Care	10
	Insurance Adequacy	9i and 9j
CDC / National Survey of Children with Special Healthcare Needs	Shared Decision Making	9f
	Medical Home (Comprehensive and Coordinated)	8, 9i, 9j
	Satisfaction (services integrated	8, 9-12
AHRQ / CAHPS Measures of Patient	Getting timely care, appointments, and	9a-b
Experience and CMS – Medicare	information	
ACO Quality Measures		
	How well Doctors Communicate	8, 9b-c
	Patients' Rating of Doctors	8
	Specialist Access	7,8,9,10,11
	Health Promotion and Education	8,9,10
	Shared Decision Making	9f (9,10)
	Health Status / Functioning Status	8,9,10

### ACO – Accountable Care Organization

AHRQ – Agency for Healthcare Research and Quality: CAHPS Measures of Patient Experience. Content last reviewed May 2017. Agency for Healthcare Research and Quality, Rockville, MD.

https://www.ahrq.gov/cahps/consuerer-reporting/measures/index.html.

CAHPS — Consumer Assessment of Health Providers and Systems CAHPS Surv

CAHPS – Consumer Assessment of Health Providers and Systems. CAHPS Surveys and Guidance. Agency for Healthcare Research and Quality, Rockville, MD. <a href="https://www.ahrq.gov/cahps/index.html">https://www.ahrq.gov/cahps/index.html</a> Accessed March 28, 2020. CDC – Centers for Disease Control and Prevention

CMS – Centers for Medicare and Medicaid – *Medicare Shared Savings Program Quality Measure Benchmarks for the 2014 Reporting Year.* <a href="https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/Downloads/MSSP-QM-Benchmarks.pdf">https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/Downloads/MSSP-QM-Benchmarks.pdf</a> Accessed March 28, 2020.

HP 2020 – Healthy People 2020. Objective DS 5: Disability and Health, Barriers to Health Care - *Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care*. <a href="https://www.healthypeople.gov/2020/topics-objectives/objective/dh-5">https://www.healthypeople.gov/2020/topics-objectives/objective/dh-5</a>. Also see: Healthy People 2020. Objective Adolescent Health (AH-1), *Increase the proportion of persons with health insurance*. <a href="https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/objectives/access-to-Health-Services/access-to-Health-Ser

HRSA – Health Resources and Services Administration: HRSA indicates that adequate Insurance is a component of an effective system of care for Children with Specialty Healthcare Needs: <a href="https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs">https://mchb.hrsa.gov/maternal-child-health-needs</a>

USHTCN – US Hemophilia Treatment Center Network

#### Hemophilia Treatment Center (HTC) - National Patient Satisfaction Survey 2014

### **University of Colorado HTC**

Your Hemophilia Treatment Center (HTC) - along with other HTCs in the US - is asking patients to complete this form to help us provide the best care to people with bleeding disorders. Please answer the questions about the care from the HTC clinic in 2014. Please complete the on-line version of the survey at www.HtcSurvey.com **or** complete this form and mail it to us using the attached envelope. Your answers will be kept private. The answers you provide will not affect your care. Thank you! Please complete both pages of the survey.

1. **Patient's Age:** (in years) > > > > > > > > > > > > > > >

2. I am a: (select one - parent should complete form if the patient is under 18 years old)

0	Patient O Patient's Parent/Caregive	er en
3. <b>Pa</b>	tient's Gender: (select one)	
0	Male O Female O Other	
4. <b>Pa</b>	tient's Race: (select all that apply)	
	White	☐ Black or African American ☐ Asian
	Native Hawaiian or Pacific Islander	American Indian or Alaska Native Prefer not to answer
5. <b>Is</b>	the patient Hispanic or Latino? (select	one)
0	Yes O No	
6. <b>Pa</b>	tient's Primary Diagnosis: (select one,	note: Factor VIII or IX is also known as Hemophilia A or B)
0	Factor VIII or IX deficiency - SEVERE	O Von Willebrand Disease - TYPE 1
0	Factor VIII or IX deficiency - MODERATE	O Von Willebrand Disease - TYPE 2
0	Factor VIII or IX deficiency - MILD	O Von Willebrand Disease - TYPE 3
0	Factor VIII or IX deficiency - do not know s	everity On Willebrand Disease - do not know type
0	Other Factor Deficiency	Other Bleeding Disorder
0	Do not know	
7. <b>In</b>	2014, how many times did the patient (	you or your child) talk to the HTC staff (in person, by phone, or electronic)?
0	Less than 2 times O 2 to 4 times	O 5 to 10 times O More than 10 times
o II		
	ow would you rate the patient's (you or dicate N/A (not applicable) for HTC st	your child's) level of satisfaction with the HTC staff seen in 2014?  aff that were not seen during 2014.
Resp	onse Definition: 4=Always Satisfied 3=Us	ually Satisfied 2=Sometimes Satisfied 1=Never Satisfied NA=Not Applicable
		4 3 2 1 NA
	•	0000
	·	nt
	d. Social Worker	0000
	e. Physical Therapist	
	f. Orthopedist	
		0000
	g. Psychologist	
		0000
	h. Nutritionist	
	h. Nutritionist i. Genetic Counselor	00000
	h. Nutritionist  i. Genetic Counselor  j. Other	00000

# Hemophilia Treatment Center (HTC) - National Patient Satisfaction Survey 2014

# **University of Colorado HTC**

9.	In	201	4,	how	often	:
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Response Definition: 4=Always 3=Usually 2=Sometimes 1=Never NA=Not Applicable					
	4 3 2 1 NA				
a. Was it easy to get HTC care as soon as you thought you (or your child) needed it?					
b. Was it easy to get information you (or your child) needed?	0 0 0 0 0				
c. Did HTC clinic staff explain things in a way that was easy to understand?	0000				
d. Did HTC clinic staff spend enough time with you (or your child)?					
e. Did HTC clinic staff treat you (or your child) with respect?					
f. Did HTC clinic staff involve you (or your child) in decisions about care?	00000				
g. Did HTC clinic staff coordinate care with your (or your child's) primary doctor?	00000				
h. Did HTC clinic staff coordinate care with other specialists or providers?					
i. Was insurance a problem in getting HTC services you (or your child) needed?	00000				
j. Was language a problem in getting HTC services you (or your child) needed?					
J. Was language a problem in getting TITE services you (or your child) needed:					
ANSWER QUESTION #10 ONLY IF THE PATIENT'S AGE IS BETWEEN 12 and 17:					
10. For patients age 12 to 17, how satisfied were you (or your child) with how HTC clinic staff:					
Response Definition: 4=Always Satisfied 3=Usually Satisfied 2=Sometimes Satisfied 1=Never Satisfied	A 3 2 1 NA				
a. Talked about how to care for the bleeding disorder as they become an adult?					
b. Encouraged the 12-17 year old to become more independent in managing their bleeding disorder?					
b. Encouraged the 12-17 year old to become more independent in managing their bleeding disorder					
11. How satisfied is the patient (you or your child) with the overall HTC care?	_				
O Always Satisfied O Usually Satisfied O Sometimes Satisfied O Never Satisfied	O Not Applicable				
12. What is the HTC doing well?					
13. How can the HTC improve services?					
14. Is there anything else you would like to share?					

End of Survey. Thank you for your time.

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