

Supplemental File 1: Table 1 - Crosswalk of Federal Agency Initiatives and Measurement Domains to Questions in 1st 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 Experience and CMS – Medicare ACO Quality Measures	Getting timely care, appointments, and information	9a-b
	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/consumer-reporting/measure/index.html>.

CAHPS – Consumer Assessment of Health Providers and Systems. CAHPS Surveys and Guidance. Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/cahps/index.html> 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*. <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/Downloads/MSSP-QM-Benchmarks.pdf> 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*. <https://www.healthypeople.gov/2020/topics-objectives/objective/dh-5>. Also see: Healthy People 2020. Objective Adolescent Health (AH-1), *Increase the proportion of persons with health insurance*. <https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services/objectives> accessed March 28, 2020.

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: <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs>

USHTCN – US Hemophilia Treatment Center Network

9. In 2014, how often:

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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Was it easy to get information you (or your child) needed?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Did HTC clinic staff explain things in a way that was easy to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Did HTC clinic staff spend enough time with you (or your child)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Did HTC clinic staff treat you (or your child) with respect?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Did HTC clinic staff involve you (or your child) in decisions about care?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Did HTC clinic staff coordinate care with your (or your child's) primary doctor?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Did HTC clinic staff coordinate care with other specialists or providers?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Was insurance a problem in getting HTC services you (or your child) needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Was language a problem in getting HTC services you (or your child) needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 NA=Not Applicable					
	4	3	2	1	NA
a. Talked about how to care for the bleeding disorder as they become an adult?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Encouraged the 12-17 year old to become more independent in managing their bleeding disorder?.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. How satisfied is the patient (you or your child) with the overall HTC care?

- Always Satisfied
 Usually Satisfied
 Sometimes Satisfied
 Never Satisfied
 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.