



NHPCC Patient Experience of Care Survey

HTC How to Get Started

Overview

The US HTC Network (USHTCN) is required to report upon five Healthy People 2020 (HP2020) measures. HP2020 is a national health platform. The Patient Experience of Care Survey (also known informally as the “transition” survey) is a mechanism for capturing required data for Health Resources and Services Administration (HRSA) reporting upon Healthy People (HP2020) measure (Disability and Health) DH-5, to “Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.”

To provide historical context, it is important to note that the NHPCC National Patient Needs Assessment of 2013 asked the following questions for DH-5 as a baseline:

- 1) Have HTC staff talked about how to care for the bleeding disorder as this person becomes an adult?
Respondent Choices: Yes, No, Not sure, Not applicable (not a teen or young adult)
- 2) Have HTC staff encouraged this person to become more independent in managing the bleeding disorder (such as using medication, recognizing bleeds, following medical advice, making healthy lifestyle choices)?
Respondent Choices: Yes, No, Not sure, Not applicable (not a teen or young adult)

The Patient Experience of Care Survey (PEC) was developed to capture progress on the DH-5 measure, building upon the baseline data captured in the National Patient Needs Assessment. Annual reporting on DH-5 will be required through 2022 (i.e., end of current HRSA project period). A database is in place with all previous data from the inception of the project through October 2018, at which time HTC staff were requested to pause in the survey administration while the project was internalized to ATHN. Survey will be administered annually to patient/caregiver. Where multiple patients reside in one household, a survey will be completed for each patient.

IRB Determination

A Project Overview is available for local IRB submission. Also available and on file is the determination letter for research exempt status by ATHN’s central IRB, Advarra.

Online Survey Process

HTC staff will be able to send patients the link via email. Patient instructions will include detail on how to scan the QR code.

URL: <https://www.surveymonkey.com/r/PatientExperienceCare>

URL: https://www.surveymonkey.com/r/PatientExperienceofCare_Spanish



A QR code, for smartphone use, is available



Paper Survey Process

Previously collected paper forms should be sent to the following address:

ATHN
ATTN: Angela Riedel
67 Red Rock Circle
Rochester, NY 14626

Paper survey forms and patient instructions, in both English and Spanish, will be available for the remainder of the project (i.e., through 2022). Downloadable versions of the paper forms will be available on athn.org. **Please ensure the center's three-digit HTC ID number is populated on the paper forms prior to dissemination and/or photo copying.** HTC staff will collect paper forms in a sealed envelope, once completed by the patient or caregiver, and send in batches to an ATHN-designated address per above. Paper forms collected from the relaunch point will be manually added to the existing database via ATHN staff.

See accompanying attachments which include a project overview, the HTC Instructions for administering the survey, the survey document in English/Spanish, and the caregiver instructions in English/Spanish.

Thank you for your assistance in meeting HRSA reporting requirements. Your time and attention to this ongoing initiative is greatly appreciated!