



NHPCC Patient Experience of Care (PEC) Survey Project Overview

This document serves as a project overview for the Patient Experience of Care (PEC) Survey. The PEC survey serves as a proxy measure to capture and report on the required Healthy People 2020 measure annually, as detailed below. This document may be submitted to local IRBs when seeking a determination on research exemption for the project. A copy of ATHN's IRB (Advarra) determination is on file and may be requested.

Purpose: Monitor HTC care of adolescents as they transition to adult care. The Health Resources and Services Administration (HRSA) requires monitoring of Healthy People 2020 (HP2020) objective Disability and Health (DH)-5: "Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care." The NHPCC has captured these survey data since 2015, utilizing calendar year 2014 patient experiences of care in the area of transition as a baseline, and will continue collecting this information through 2022.

Target Population/Eligibility: 1) children 12-17 years who come in for a comprehensive care clinic (NOTE: children are to complete the questionnaire, with assistance of the parent/guardian/caregiver, as needed) 2) Persons with bleeding disorders ages 18-22 years.

Frequency: Annual survey administration for every unique patient seen at the HTC for a comprehensive care visit.

Survey Format: The survey contains 11 questions: 1 date of completion; 5 demographic; 5 regarding transitions (healthcare needs related to frequency of treatment, transition process, self-management, insurance, transition to adult providers).

The survey has two formats for completion in both English and Spanish:

Electronic Questionnaire: The electronic versions are available through Survey Monkey at these link: <https://www.surveymonkey.com/r/PatientExperienceCare> OR https://www.surveymonkey.com/r/PatientExperienceofCare_Spanish

Paper Questionnaire: A written version of the survey can also be provided to the parent/guardian/caregiver along with a self-addressed, stamped envelope. The link and electronic versions of the paper form can be found here



Address for paper submission:

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

Completing the Questionnaire: Children ages 12-17 years are to complete the questionnaire with the assistance of parents/guardians/caregivers, as needed. Persons with bleeding disorders between the ages of 18-22 years are asked to complete the survey on their own. For patients that don't have access to the internet, options include 1) Completing the survey online after the clinical visit, but prior to leaving the office and 2) Providing a paper version to the patient along with a self-addressed stamped envelope made out to the collection site. Paper survey responses are collected for data aggregation.

Paper surveys previously collected should be bundled and sent to above physical address.

Analysis: The completed surveys are collected by ATHN for aggregation and analysis. An answer of Yes to any question 8-11 will be considered to have discussed transition planning. Questions 8 and 9 will be used for comparison to prior national needs assessment data (from 2014) and for the reporting of progress on HP2020 measure DH-5.

Results: The number of questionnaires received from each HTC is sent to the regional coordinator quarterly. Data collected from June 2019 moving forward are aggregated by HTC, region and the nation. These data are sent to the regional coordinators in February of each year. Data may be available by contacting your regional coordinator.

IRB: This is a QI effort and was deemed as exempt from IRB oversight according to 45 CFR 46.104(d) category 5 by ATHN's Central IRB, Advarra, in June 2019. Each regional core center will address center-specific IRB issues. Determination letter is on file for use with host institutions, as needed.