

Hemophilia Treatment Center Needs for Technical Assistance

In 2012, the American Thrombosis and Hemostasis Network (ATHN) contracted with the South Carolina Rural Health Research Center to conduct an evaluation of the National Hemophilia Program Coordinating Center (NHPCC). In 2013, an electronic survey of hemophilia treatment centers (HTC) was conducted to identify future needs for technical assistance that may be offered by the NHPCC.

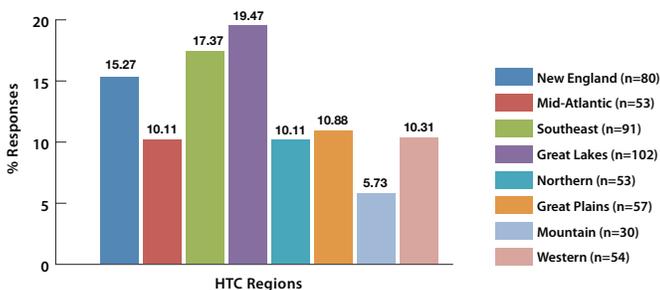
Survey respondents were asked to list current sources of and needs for technical assistance (TA) on matters related to staff development or improving patient care as well as future TA needs. TA was defined as the provision of knowledge, tools, models and other resources that improve quality of care, access to care and availability of services to persons with bleeding disorders.

HTC staff from 140 treatment centers (97.90% HTC response rate) completed a total of 524 surveys. Individual-level analyses were conducted to describe current needs and sources of TA and identify regional differences in future TA needs.

Key Findings

→ Survey respondents were represented in each of the eight HRSA regions (Figure 1).

SURVEY RESPONDENTS BY HTC REGION (N=524)



Sources of Technical Assistance

- Regional Core Center was cited as a source of technical assistance by 75.38% of respondents. Other sources were other HTCs (71.76%) and their own HTC or institution (71.18%).
- Of those responding with other sources (n=87), ATHN was the most frequently cited source of TA (17.24%).

Technical Assistance Needs: Past vs. Future

- Respondents were to reflect on their TA support experiences in the previous year. The most frequently cited TA support received in the past year was WebTracker (now ATHN Clinical Manager) and data management (n=353; 67.37%). Other critical TA topics identified were staff development (n=246), 340B pharmacy (n=244) and lifespan transition (n=208).
- Compared to the previous year, fewer HTC staff prioritized WebTracker and staff development as a future TA need. However, there was a marked increase in those identifying geographic access as a future TA need. The top five future TA needs identified by the respondents were WebTracker and data management (n=315), staff development (n=314), 340B pharmacy (n=307), lifespan transition (n=261) and geographic access and 340B pharmacy (n=255).
- WebTracker/data management was identified as a future need for the New England and Western regional respondents. Staff from the Mid-Atlantic, Southeast, Great Lakes and Mountain regions identified staff development as the top future TA need. Information technology was identified as the top future need for Northern and Great Plains staff.

About the NHPCC

In June 2012, the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration (HRSA) funded the American Thrombosis and Hemostasis Network (ATHN) to establish the first National Hemophilia Program Coordinating Center. The NHPCC serves as a bridge between the regional hemophilia treatment center networks, helping to create value on a national scale. The NHPCC is partnering with regional leadership, over 130 ATHN Affiliate HTCs, NHF, HFA and other patient advocacy groups, government partners, 340B pharmacy programs, the genetics and newborn screening collaborative, payers and thought leaders to guarantee a community-wide perspective.



To learn more about the NHPCC, visit www.athn.org.