



NATIONAL HEMOPHILIA PROGRAM
COORDINATING CENTER

QUALITY IMPROVEMENT CASE STUDY

Transition of Care: Mountain States

Improving Transition of Care for People with Bleeding Disorders Through Quality Improvement

Introduction

The Health Resources and Services Administration (HRSA) regional hemophilia network (RHN) was established to promote and improve the comprehensive care of individuals with bleeding or clotting disorders. Among the regional program requirements is collaboration with the National Hemophilia Program Coordinating Center (NHPCC), an HRSA-funded program that coordinates and provides collaborative national infrastructure to the eight regions. The NHPCC partners with the RHN to promote implementation and participation in national quality improvement (QI) projects. HRSA has identified the transition from pediatric to adult care as one of three main QI focus areas.

The Mountain States Hemophilia Network (MSHN) spans a large geographic area that includes Alaska, Arizona, Colorado, Idaho, Montana, New Mexico, Oregon, Utah, Washington, and Wyoming. The hemophilia treatment centers (HTCs) in the MSHN implemented region-wide QI initiatives surrounding transition from pediatric to adult care. These case studies feature QI efforts from three states in the region—Idaho, New Mexico, and Washington. Read on to learn about how these HTC teams followed the QI framework to develop aims, implement change ideas, and measure success.

NATIONAL HEMOPHILIA PROGRAM
COORDINATING CENTER

QUALITY IMPROVEMENT CASE STUDY



Background

The Mountain States' transition QI efforts kicked off at a regional meeting brainstorming session designed to identify common areas for improvement among all HTC in the region. It was decided that each center would implement a QI initiative for the transition from pediatric to adult care within one year and utilize the framework recommended in the NHPCC's *Action Guide for Improving Care for People with Bleeding Disorders*. This framework consists of a **Global Aim** and at least one **Specific Aim** to ensure clear goals, parameters, and measures. Each HTC identified a QI leader, and held monthly region-wide calls, chaired by three regional QI experts and the regional coordinator. On the monthly calls, HTC leads received general QI education and reported on their QI progress. Collaboration and trouble-shooting support was provided by the regional experts. It was recognized that within the broader regional goal, each center required flexibility to work within their own space and parameters for the initiative to succeed. On average, there was 75% HTC participation on each call. Centers unable to attend a call were contacted to see if they needed assistance or support and to assess for progress.

Idaho: St. Luke's Hemophilia Center

Idaho's St. Luke's Hemophilia Center (SLHC) embarked on two QI initiatives: 1) transition and 2) communication.

The **Global Aim** of Idaho's transition initiative was to improve patient readiness and confidence in the process of transitioning from being a pediatric patient to an adult bleeding disorder patient, which typically begins at age 12 and ends with successful transition (as defined by the center) by age 30. The center began the process by addressing the need to educate patients and their families about transition-related issues. In working through this process, efforts focused

18 Steps to 18

This successful program was developed by the Indiana Hemophilia & thrombosis Center (IHTC) and provides 18 self-management steps for transitioning to adult care by the age of 18. Topics range from self-care to emergency planning to understanding their diagnosis and treatment protocol, procedures, prevention, insurance, and more.

on helping patients and families feel supported, providing ongoing education pre- and post-transition, and reducing the number of young adults lost to follow-up.

A baseline of 34% of patients (i.e., 22/64 patients) completed the "18 Steps to 18" process developed by the Indiana Hemophilia & Thrombosis Center (IHTC). As a **Specific Aim**, the SLHC sought to increase to 68% the number of patients who had completed the 18 Steps to 18 form following a discussion regarding transition.

New Mexico: Ted R. Montoya Hemophilia Program and Treatment Center, University of New Mexico

The University of New Mexico's Hemophilia Program and Treatment Center (UNM) followed a modified version of IHTC's "18 Steps to 18" to identify areas where patients needed additional education and to assess their readiness for transition. UNM learned that many adolescent patients did not know standard rest, ice, compression, and elevation (RICE) protocol in the event of a bleed, and that they did not have their HTC's phone number readily available, or know how to order their own factor. Resulting **Aims** therefore focused on enhancing teen comfort in speaking to healthcare providers, ordering their own factor, and taking ownership of their healthcare.

To address areas of need, UNM implemented a number of **Change Ideas**, including the creation of personalized wallet cards with essential information including how to order factor; HTC, physician, insurance, and pharmacy information; and other pertinent health information. Success was measured through **process measures** by surveying teen patients whether or not they carry their card and how well it works for them. **Outcome measures** were based on improved scores on readiness assessments.

QUALITY IMPROVEMENT CASE STUDY

Washington: Washington Center for Bleeding Disorders

Three pediatric centers—Providence Sacred Heart Children's Hospital in Spokane, Mary Bridge Hematology Clinic in Tacoma, and Seattle Children's Hospital in Seattle—work in collaboration with and refer adult patients to the Washington Center for Bleeding Disorders (WCBD) at Bloodworks Northwest in Seattle. With a focus on adolescent and young adult patients age 17 to 25, the Washington-wide QI initiative relied on efforts between all four centers to work toward the **Global Aim** to ensure that patients learn to take ownership of their care by attending their annual comprehensive clinic visit. **Specific Aims** for the QI project included: 1) to increase the percentage of patients receiving on-time comprehensive care (not overdue visits), and 2) to increase the number of patients completing the American Society of Hematology (ASH) Readiness Assessment during their comprehensive visits starting at age 12.

To meet the **Specific Aim** of increasing the percentage of patients receiving their care on time, a number of **Change Ideas** were introduced to reduce no-show rates. These included the initiation of various methods of contacting patients by phone, text message, and postal mail. To address the **Specific Aim** related to transition readiness, all Washington centers utilized the ASH Readiness Assessment at the annual comprehensive visit for continuity and consistency. At the first visit to WCBD at Bloodworks NW, the following information was discussed: diagnosis information, name of doctors, location of nearest emergency room, and how to contact the after-hours on-call bleeding disorder nurse.

The three pediatric centers contributed to a single comprehensive database of all patients 17-25 years of age. The database included demographic and medical information, whether they are up to date on comprehensive care visits or overdue, as well as dates of the last four comprehensive clinic visits and the date of transition to adult care at WCBD. Success of the transition QI initiative was measured by tracking the number of days between comprehensive clinic visits, as well as the communication from WCBD to the three centers to confirm that a patient had successfully attended their first adult transition clinic appointment.

Conclusion

HTCs in the Mountain States Hemophilia Network achieved their common regional goal by successfully implementing QI programs to address transition from pediatric to adult care within the one-year time frame. The QI projects varied as determined by the individual HTC and patient needs. Helpful region-wide implementation strategies included: 1) engaging the existing regional QI expertise, 2) providing ongoing and available support, 3) conducting biannual in-person QI lead meetings, and 4) sharing QI efforts at other centers with opportunities to ask questions that helped provide valuable perspective and contributed to QI initiative success.

NATIONAL HEMOPHILIA PROGRAM
COORDINATING CENTER



This publication was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$800,000 with 0 percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

www.athn.org

Securing Data. Advancing Knowledge. Transforming Care.