Action Guide to Improving Care for People with Bleeding Disorders

Making the Best Care Even Better

We believe that the quality of life for people with bleeding disorders can be improved through the consistent implementation of evidence-based clinical care and practice improvement.
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All forms, examples, and electronic improvement learning modules are available electronically at www.athn.org and www.clinicalmicrosystem.org.

Special acknowledgement to the American Thrombosis and Hemostasis Network (ATHN)* and the many colleagues who have made critical substantive contributions to the development of these materials.

NOTE: We have developed this action guide with tools to give ideas to those interested in improving healthcare for people with bleeding disorders. The Dartmouth Institute Microsystem Academy and the ATHN developers of this action guide are pleased to grant use of these materials without charge, providing that recognition is given for their development, and that the uses are limited to an individual’s own use and not for resale.

*Project funded through HRSA Cooperative Agreement UC8MC24079
Making the Best Care Even Better for People with Bleeding Disorders

THE AMERICAN THROMBOSIS AND HEMOSTASIS NETWORK

The American Thrombosis and Hemostasis Network (ATHN) is a nonprofit organization dedicated to improving the lives of people affected by bleeding and clotting disorders. ATHN is using technology to secure and advance knowledge and transform care as stewards of a secure national database and electronic infrastructure powered by ATHN Clinical Manager. By utilizing the national infrastructure for gathering patient health information, ATHN affiliated Hemophilia Treatment Centers (HTCs) are helping the community gain a better understanding of bleeding and clotting disorders, and then using that knowledge to inform healthcare improvement.

Indeed, significant progress has been made over the past 35 years in the treatment, diagnosis and comprehensive care of patients with bleeding disorders. Interdisciplinary teams at HTCs across the United States have succeeded in extending life span and minimizing disabilities and complications. We believe that the community is prepared to work together to make the best care even better.

THE NATIONAL HEMOPHILIA PROGRAM COORDINATING CENTER

The National Hemophilia Program Coordinating Center (NHPCC) was funded through ATHN by the federal Health Resources and Services Administration (HRSA) in 2012 to create a national scale. Toward that end, the NHPCC serves as a bridge between the regional hemophilia treatment center (HTC) networks and collaborates with regional leadership to support HTCs nationwide to identify gaps in services, barriers to care and national priorities to improve care.

In response to the 2014 HRSA Cooperative Agreement, the NHPCC is bringing in step further to coordinate and support a national quality improvement (QI) effort to ensure that the science of quality improvement (QI) is used.

TRANSITION FROM PEDIATRIC TO ADULT CARE

The first priority for national quality improvement is transition from pediatric to adult care. To develop QI capacity across the network, the NHPCC is teaming with The Dartmouth Institute Microsystem Academy to train coaches, support improvement capability development among HTC teams and test changes specifically related to transition from pediatric to adult care at the hemophilia treatment centers. This national measure will be the Health People 2020 DSH indicator “Increase the proportion of youth with special healthcare needs whose provider has discussed transition of care planning from pediatric to adult healthcare.”

This was measured first in the 2012 NHPCC national needs assessment with subsequent data collected in the annual Patient Experience Survey administered through the HTCs. Best practices and tools including those developed for Got Transition (www.gottransition.org) and a growing list of peer-reviewed works found at www.athn.org will be incorporated into the quality improvement activities.

The methods, skills, and improvement discipline developed are expected to be applicable to other priority areas.

WHY DO IT?

Continuous quality improvement in healthcare is the combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, payers, planners and educators to make changes that will lead to better patient outcomes, better system performance and better professional development (Bakken & Davioff, 2007). Healthcare professionals have a legal and moral obligation to ensure a high quality of patient care and to strive to improve care in daily delivery of care and services (Parand et al., 2014). Physician specialty organizations require evidence of quality improvement initiatives, such as those led by the NHPCC, for Maintenance of Certification.

Quality improvement can be empowering. The difference between quality assurance (QA) and continuous quality improvement (CQI) is significant. QA is an inspection process to ensure compliance with standards. CQI has a "process" approach and is systematic and continuous.

Quality, safety, reliability, efficiency and innovation are made possible outcomes. Each person’s quality of care depends on what systems are performing. Everyone in the delivery of care and services (Parand et al., 2014). Physician specialty organizations require evidence of quality improvement initiatives, such as those led by the NHPCC, for Maintenance of Certification.

Technical, clinical microsystems can be defined as the smallest replicable units in the healthcare system and are defined as:

A small group of people who work together on a regular basis to provide care to discrete subpopulations of patients. It has clinical and business aims, linked processes and a shared information environment and it produces performance outcomes.

Hemophilia Treatment Center Clinical Microsystems

Assessing, Diagnosing and Treating Your HTC an Overview

People with bleeding disorders have many interdependent health professionals coming together with them and their family to provide care and services. We call this place where patients, families and care teams come together "the HTC Clinical Microsystem."

The HTC clinical microsystem is one unit in the system of care for people with bleeding disorders as shown in the diagram. Collectively, these contributing units come together to provide care for bleeding disorders patients. The HTC clinical microsystem has essential functions that must be carefully assessed and improved to result in the best possible outcomes. Each person’s quality of care depends on what happens within each HTC microsystem and the “hand-offs” between contributing units. Microsystems also include patients, families, staff, processes, technology and resuming patterns of information, behavior and results. The microsystem is where:

- Care is made
- Safety, quality, reliability, efficiency and innovation are made
- Staff morale and patient satisfaction are made

Clinical microsystems are the core components of the day-to-day healthcare. It can most easily be thought of as “the places where patients, families, and healthcare professionals meet.”

Technically, clinical microsystems can be seen as the smallest replicable units in the healthcare system and are defined as:

A small group of people who work together on a regular basis to provide care to discrete subpopulations of patients. It has clinical and business aims, linked processes and a shared information environment and it produces performance outcomes.
A Path Forward

This action guide supports you and those who work with you to attain a higher level of performance. Just as you can assess, diagnose and treat patients, you can assess, diagnose and treat your clinical microsystem, in this case, the HTC.

The steps in this action guide can help you evaluate how your HTC functions and how it can be improved. The tools and forms have been tested and adapted in HTCs.

Although this is not the only way in which improvement can be achieved, it is a method that has been demonstrated to be effective in achieving higher quality care, enhanced workforce morale, satisfaction and partnerships with patients and their families in healthcare systems across the United States and around the world.

Colleagues around the USA have implemented this methodology. Seek them out to gain support and advice through the ATHN website resource section at www.athn.org and www.clinicalmicrosystem.org.

All action guide forms and additional information, forms, tools, and examples are available at the ATHN website, www.athn.org, and The Dartmouth Institute Clinical Microsystem website, www.clinicalmicrosystem.org.

For a clinical microsystem to achieve optimal performance, the steps for enabling improvement are ones that are never ending. Once one cycle of improvement is completed, another cycle can begin and then many more cycles will follow. Opportunities for improvement are never ending as patient care and the workforce experience can always be improved.

**STEPS IN THE PATH**

The following steps walk you through the process of evaluating and improving your HTC. After reviewing the steps, you can read the case study on pg. 37 to get a better sense of how a microsystem was able to improve.

### STEP 1: ORGANIZE A “Lead Improvement Team”

Successful change requires the commitment and active engagement of all members of the HTC clinical microsystem with identified senior leader sponsors. To keep your HTC improvement on track and focused, a “lead improvement team” of representatives of all roles from the HTC microsystem should be formed.

The person with bleeding disorders travels across several clinical units; therefore, representatives from all contributing units in the HTC system of care can be included in the Lead Improvement Team. For example, the HTC lead improvement team should include people with bleeding disorders and family members, hemotologists, nurse coordinators, dietitians, physical therapists, social workers and clinical staff (and front office staff), RNs, support staff from the inpatient adult or pediatric unit and key contacts from the specialties such as pharmacy, orthopedics, hepatology, infectious disease, gynecology and dentistry.

**Team Tips:** The following tips can be found at www.athn.org and www.clinicalmicrosystem.org along with helpful tools and forms.

- **Effective:** providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.

- **Patient-centered:** providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.

- **Timely:** reducing wait times and sometimes harmful delays for both those who receive and those who give care.

- **Efficient:** avoiding waste, in particular waste of equipment supplies, ideas and energy.

- **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location and socioeconomic status.

**INSTITUTE OF MEDICINE’S SIX AIDS**

In 2001, the Institute of Medicine (IOM) described a “quality chasm” that exists within today’s healthcare system. The IOM called for fundamental reform of healthcare for all Americans. In its report, Crossing the Quality Chasm: A New Health System for the 21st Century, the IOM articulated six quality aims for improving care, stating that care should be:

1. Safe – avoiding injuries to patients from care that is intended to help them.

2. Effective – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.

3. Patient-centered – providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.

4. Timely – reducing wait times and sometimes harmful delays for both those who receive and those who give care.

5. Efficient – avoiding waste, in particular waste of equipment supplies, ideas and energy.

6. Equitable – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location and socioeconomic status.

**STEP 2: DO THE ASSESSMENT**

Review the action guide content and create a timeline for the assessment process using the worksheet on pg. 11. Designate individuals who will have principal responsibility for each major section. The whole action guide can be completed at the pace that suits your setting. Some microsystems have the capacity and resources to move quickly through the action guide in a short period of time. Many microsystems need to pace themselves through the action guide and complete the worksheets and assessment over a longer timeline such as two months. Some microsystems may need to start an important improvement immediately while starting the assessment process. In this case, the ongoing assessment will give you valuable information and will help you make better improvements.

Complete an assessment of your HTC based on Purpose, Patients, Professional, Processes, Patterns (the 5Ps) and review the ATHN research report or your clinical manager data at www.athn.org and www.clinicalmicrosystem.org and Metrics That Matter, on pg. 28. The worksheets in this action guide will lead you. The aim is to create the big picture of your HTC system to see beyond one person at a time. Assessing the 5Ps, using data from www.athn.org and www.clinicalmicrosystem.org and then reflecting on their connections and interdependence usually reveals new improvement and redesign opportunities.

This assessment process is best achieved when completed by the lead improvement team. Building common knowledge and insight into the microsystem by all members of the HTC will create a sense of equal value, ability to contribute to improvement activities and ownership. Remember, however you choose to progress through the action guide, it should be done within the context of your lead improvement team.

**STEP 3: MAKE A DIAGNOSIS**

The Lead Improvement Team must analyze the 5Ps assessments, Registry data from www.athn.org and www.clinicalmicrosystem.org, and Metrics That Matter worksheets and identify a “theme” for improvement. A theme may be selected using the Institute of Medicine’s Six Aims (see page 6). Opportunities for improvement may come from within your own microsystem, your organization’s strategic goals or may come from outside your microsystem, such as NHPCP.

Focus on improving only one theme at a time and working with all the “players” in your system to make a big improvement in the area selected.

**STEP 4: TREAT YOUR MICROSYSTEM**

Based on your selected theme, global aim and flow chart, create a specific aim statement and identify measures that will keep everyone focused and productive. Use proven quality improvement techniques such as PDSA (plan-do-study-act) pg. 34 and SDSA (standardize-do-study-act) pg. 35 to test changes and then ensure the improvements are adapted into the workflow.

**STEP 5: FOLLOW UP**

Improvement in healthcare is a continuous journey. Monitor the new patterns of results and move to new themes. Embed new habits into daily work with the use of “huddles” to review and remind staff, weekly lead improvement team meetings, monthly “town hall” meetings, data walls and storyboards. These reminders keep everyone focused on improvements and sustaining results.
Form Your Lead Improvement Team

Which Senior Leaders will "sponsor" HTC improvement?

<table>
<thead>
<tr>
<th>Pediatric Program</th>
<th>Adult Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Administrator</td>
<td></td>
</tr>
<tr>
<td>Division Chief</td>
<td></td>
</tr>
<tr>
<td>Department Chair</td>
<td></td>
</tr>
<tr>
<td>Site Contact</td>
<td></td>
</tr>
</tbody>
</table>

- Are you a LifeSpan HTC?  □ Yes  □ No
- Check your type of HTC  □ Academic  □ County  □ Freestanding  □ Hospital

Who will be on the Lead Improvement Team and attend regular meetings?

<table>
<thead>
<tr>
<th>Pediatric Program</th>
<th>Adult Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>MD</td>
<td></td>
</tr>
<tr>
<td>HTC Coordinator</td>
<td></td>
</tr>
<tr>
<td>RN Coordinator</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
</tr>
<tr>
<td>RN</td>
<td></td>
</tr>
<tr>
<td>Physical Therapy</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td>Medical Assistant/Technician</td>
<td></td>
</tr>
<tr>
<td>Administrative Staff</td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td></td>
</tr>
<tr>
<td>NP/Advanced Practice Registered Nurse/PA</td>
<td></td>
</tr>
<tr>
<td>Patient/Family (1-2 Advisors)</td>
<td></td>
</tr>
<tr>
<td>Genetic Counselor</td>
<td></td>
</tr>
<tr>
<td>Dental Hygienist</td>
<td></td>
</tr>
<tr>
<td>Clinical Research Coordinator</td>
<td></td>
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</tbody>
</table>

Who are the "as needed" members to be included?
Identify key contacts for each supporting unit such as pharmacy, orthopedics, hepatology, infectious disease, gynecology and dentistry. These members will be included based on the process being considered or improvement.

Regular Meeting Time  Date  Location

List communication strategies to share information with all staff of the involved units and patients and families. Identify who will oversee the various communications, for example, newsletters, bulletin boards, e-mails and all staff meetings.

Assessing the 5Ps of Your HTC

To begin to increase self-awareness and to assess or diagnose the unique features of any microsystem, use the SP framework. The SP framework can be thought of as a structured and organized method of inquiring into the anatomy of an HTC. Every complex adaptive system has structure, process, patterns and outcomes. This SP flowchart maps the path forward to explore the 5Ps in an organized fashion.
With your Lead Improvement Team, review this action guide. Use this form to determine which measures you can obtain from your organization and therefore don’t need to use the worksheets. Be sure the data is current and not months old.

Review the SP Flowchart on pg. 8 to guide data collection.

Data that needs to be manually collected requires determining which worksheets will be used. Plan who, when and how the worksheets will be completed.

 Decide who oversees the completion of each worksheet or alternative data source.

Create your timeline.

Assess Your Hemophilia Treatment Center

**Purpose**

**WHY DOES YOUR HTC EXIST?**

Raise this question to EVERYONE, including patients and families in your HTC to create the best statement of *purpose* that everyone can relate to. This engages everyone in meaningful conversation that isn’t achieved by just taking out a mission statement. Use your *purpose* to guide decision making and to focus all improvements. Please do not use your mission statement. The key point of the PURPOSE statement is the discussion among the team members.

**Patients**

KNOW YOUR PATIENTS

Take a close look at your center; create a “high level” picture of the PATIENT POPULATION that you serve. Who are they? What resources do they use? How do the patients view the care they receive?

Use the Profile to know your patients. Determine if there is information you need to collect or if you can obtain this data from existing sources.

**HTC PROFILE**

**Patient Demographics**

<table>
<thead>
<tr>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 - 2 years</td>
</tr>
<tr>
<td>3 - 12 years</td>
</tr>
<tr>
<td>13 - 18 years</td>
</tr>
<tr>
<td>19 - 29 years</td>
</tr>
<tr>
<td>30 - 49 years</td>
</tr>
<tr>
<td>50 - 74 years</td>
</tr>
<tr>
<td>75+ years</td>
</tr>
</tbody>
</table>

**Percent of those with severe hemophilia on continuous prophylaxis**

**Out-of-HTC Visits**

**Emergency Room Visit Rate**

**Direct Hospital Admissions**

**Health Outcomes**

**Annual bleed rate**

**BMI**

**Joint Score**

**% Pts with inhibitor**

**# School/work days missed due to bleeding disorder**

**List Your Top 5 Other Services Used**

**List Your Top 5 Diagnoses**

**Access/Patient Satisfaction Scores**

<table>
<thead>
<tr>
<th>% Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience via phone</td>
</tr>
<tr>
<td>Length of time to get appointment</td>
</tr>
<tr>
<td>Saw who I wanted to see</td>
</tr>
<tr>
<td>Personal manner</td>
</tr>
<tr>
<td>Time spent with person you saw</td>
</tr>
</tbody>
</table>

**Reference Measures:**

**HTC MICROSYSTEM ASSESSMENT OF DATA SOURCES AND DATA COLLECTION**

**Type of Data/Pages**

**Data Source/Data Collection Action**

**Date/Owner**

| Estimated Age Distribution of Patients | ATHN Clinical Manager Report |
| --- |
| Patient Demographics | ATHN Clinical Manager Report |
| Health Outcomes | ATHN Clinical Manager Report |
| Top 5 Diagnoses | ATHN Clinical Manager Report |
| Top 5 Services Used - referrals | ATHN Clinical Manager Report |
| Percent of patients seen annually in comp. HTC | ATHN Clinical Manager Report |
| ER Visit Rate | ATHN Clinical Manager Report |
| Patient Satisfaction Scores - Access | ATHN Clinical Manager Report |
| Patient Population Census - Overall | ATHN Clinical Manager Report |

**Know Your Professionals (see pages 15-20)**

Current Staff

On-Call Staff

Supporting Departments

Staff Satisfaction

Personal Skills Assessment

Activity Survey

**Know Your Processes (see pages 21-25)**

Create Flow Charts of Routine Processes

Patient Cycle Time Tool

Care and Supporting Processes

The “Hand-Off”

**Know Your Patterns (see pages 26-27)**

Telephone Tracking Log

Unplanned Activity Tracking

Most Significant Patterns

Successful Change

Most Proud of

Financial Status / JMOB Reporting

**Know Your Outcomes/Measures/Metrics that Matter (see page 28-29)**

Inhibitor Rate

Continuous Prophylaxis

Comp. HTC Attendance

BMI

Bleed-related days lost from work/school

**List Your Top 5 Other Services Used**

Services What other services are used?

1.

2.

3.

4.

5.

**List Your Top 5 Diagnoses**

1.

2.

3.

4.

5.

Remember, the goal is to collect and review data and information about patients and families that might lead to new designs in processes and services.
Patients

- Patients and families have valuable insight into the quality and process of care we provide. Three surveys are included here that measure overall satisfaction: the HTC Patient Viewpoint Survey, Patient Experience of Care Survey and Patient Access Survey.

- You can choose to measure patient feedback specific to “access to care”—how patients and families experience getting an appointment—using the Patient Access Survey. Feedback can pave the way for rapid responses and quick tests of change. This “Point of Service” Survey can be completed at the time of service to give measurement of satisfaction.

- You can also choose to measure the overall visit experience using the HTC Patient Viewpoint Survey.

- Conduct the patient/family satisfaction surveys for 2 weeks if you currently DO NOT have a survey method. If you have a method, be sure the data are up to date and reflect the current state of your HTC.

- Currently the HTC network is collecting patient satisfaction with the HTCs through the National Patient Satisfaction Survey conducted by the Regional Core Centers through the HTCs every two years. The first survey was conducted in 2015 and is available at www.htcsurvey.com. Data can be obtained from their regional core center.

### PATIENT ACCESS SURVEY

Think about this HTC visit. Date _______________

1. How would you rate your satisfaction or the patient’s satisfaction with getting through to the HTC by phone?

- Excellent
- Very Good
- Good
- Fair
- Poor

2. How would you rate your satisfaction or the patient’s satisfaction with the length of time to get today’s appointment?

- Excellent
- Very Good
- Good
- Fair
- Poor

3. Did you or the patient see the preferred clinician or staff member today?

- Yes
- No
- Didn’t matter who I saw today

4. How would you rate your satisfaction or the patient’s satisfaction with the personal manner of the person seen today (courtesy, respect, sensitivity, friendliness)?

- Excellent
- Very Good
- Good
- Fair
- Poor

5. How would you rate your satisfaction or the patient’s satisfaction with the time spent with the person seen today?

- Excellent
- Very Good
- Good
- Fair
- Poor

6. What would make this HTC better for you or the patient?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you rate your satisfaction or the patient’s satisfaction with getting through to the HTC by phone?</td>
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<td></td>
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<tr>
<td>How would you rate your satisfaction or the patient’s satisfaction with the length of time to get today’s appointment?</td>
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</table>

**PATIENT EXPERIENCE OF CARE SURVEY**

Thank you for completing this form. Your answers will help us improve care to our patients. Please complete this for only one child. If you have multiple children being seen today, please complete one for each child. If you are 18-22 please complete this survey yourself. For this survey, child refers to anyone with a bleeding disorder who is 12-22 years old.

Please complete the questions below:

1. How old is your child? ________ years old (if your child is younger than 12 years old or older than 22 years old, please do not answer this survey)

2. What is your gender of your child or you if you are over 18?  □ Male □ Female

3. What is your child’s diagnosis or your diagnosis if you are over 18?

- □ Hemophilia A or B (factor 8 or 9 deficiency)
- □ Von Willebrand disease
- □ Other bleeding disorder
- □ I do not know my/my child’s disorder

4. What is the ethnicity of your child or your ethnicity if you are over 18?

- □ Hispanic or Latino □ Not Hispanic or Latino

5. What is the race of your child? (please check all that apply)

- □ American Indian or Alaska Native
- □ Asian
- □ Black or African American
- □ Native Hawaiian or other Pacific Islander
- □ White or Caucasian
- □ Other

6. During the past 12 months, how many times was your child seen at this clinic?

- □ 1 time
- □ 2 times
- □ 3-6 times
- □ 6 or more times

7. Have the healthcare providers at this clinic talked to you or your child about your child’s bleeding disorder healthcare needs as s/he becomes an adult?

- □ Yes
- □ No
- □ I’m not sure

If no: Would a discussion about health insurance have been helpful to you or your child?

- □ Yes
- □ No
- □ I’m not sure

8. Have the healthcare providers at this clinic encouraged your child to take responsibility for managing the bleeding disorder (such as using medication, understanding his/her diagnosis, recognizing bleeds, following medical advice, making healthy lifestyle choices)?

- □ Yes
- □ No
- □ I’m not sure

If yes: How often do the healthcare providers at this clinic encourage your child to take responsibility for managing his/her bleeding disorder?

- □ Always (every visit)
- □ Usually (most visits)
- □ Sometimes (some visits)
- □ Never (no visits)

9. Have the healthcare providers at this clinic talked to you or your child about how your child can obtain or keep health insurance coverage as s/he becomes an adult?

- □ Yes
- □ No
- □ I’m not sure

If no: Would a discussion about health insurance have been helpful to you or your child?

- □ Yes
- □ No
- □ I’m not sure

10. During the past 12 months did the clinic staff talk with you or your child about your child eventually seeing doctors who treat adults with bleeding disorders?

- □ Yes
- □ No
- □ I’m not sure

If no: Would you or your child like to talk to the clinic staff about doctors that treat adults with bleeding disorders?

- □ Yes
- □ No
- □ I’m not sure
HCT PATIENT VIEWPOINT SURVEY

Today's HTC Visit. Date

Here are some general questions about the visit you or the patient just made to this HTC. We would like to know how you would rate each of the following.

- 1. Length of time to wait to get an appointment
- 2. Convenience of the location of the HTC
- 3. Getting through to the office by phone
- 4. Length of time waiting at the office
- 5. Time spent with the person in the HTC
- 6. Explanation of what was done at the HTC
- 7. The technical skills (thoroughness, carefulness, competence) of the person seen
- 8. The personal manner (courtesy, respect, sensitivity, friendliness) of the person seen
- 9. The clinician's sensitivity to special needs or concerns
- 10. The satisfaction with getting the help and information that you or the patient needed
- 11. The quality of the visit overall

General Questions

Here are some general questions about your satisfaction or the patient's satisfaction with the HTC.

- 12. If you or the patient could go anywhere to get care for your bleeding disorder, would you choose this HTC or would you prefer to go someplace else?
- 13. Would choose this HTC
- 14. Might prefer someplace else
- 15. Not sure

- 16. I am delighted with everything about this HTC because my expectations for service and quality of care are exceeded:
- 17. Agree
- 18. Disagree
- 19. Not sure

- 20. In the past 12 months, how many times have you or the patient gone to the emergency room for care?
- 21. None
- 22. One time
- 23. Two times
- 24. Three or more times

- 25. In the past 12 months, was it always easy to get a referral to other specialists when needed?
- 26. Yes
- 27. No
- 28. Does not apply to me

- 29. In the past 12 months, how often did you or the patient have to see someone else when you wanted to see a personal doctor or nurse?
- 30. Never
- 31. Sometimes
- 32. Frequently

- 33. You or the patient able to get to appointments when you choose?
- 34. Never
- 35. Sometimes
- 36. Frequently

- 37. Is there anything else you or the patient could do to improve the care and services?
- 38. No, everything is satisfactory
- 39. Yes, some things can be improved (please specify):
- 40. Yes, lots of things can be improved (please specify):

- 41. 18. Did you or the patient have any good or bad surprises while receiving care?
- 42. Good
- 43. Bad
- 44. No Surprises

- 45. Please describe:

- 46. In general, how would you rate your overall health or the health of the patient?
- 47. Excellent
- 48. Very Good
- 49. Good
- 50. Fair
- 51. Poor

- 52. What is your age or the age of the patient?
- 53. Under 18 years
- 54. 18 - 25 years
- 55. 26 - 35 years
- 56. Over 35 years

- 57. What is your gender or the gender of the patient?
- 58. Male
- 59. Female

OPTIONAL: As we continue to strive to improve bleeding disorders care, would you be interested in serving as an advisor to the care center?

- 60. Yes
- 61. No
- 62. Maybe

Name

Phone

E-mail

Best time to reach you? Morning Afternoon Evening Other

Date: Role Play/Walk Through Begins When: Ends When:

Staff Members:

- Positives
- Negatives
- Surprises
- Frustrating/Confusing
- Gratifying

THROUGH THE EYES OF YOUR PATIENTS AND FAMILIES

Tips for making the experience most productive

1. Determine with your staff where the starting and ending points should be, taking into consideration the usual journey of patients across several contributing units.

2. Two members of the staff should role-play with each playing a role: patient and partner/family member.

3. Set aside a reasonable amount of time to experience the patient journey. Consider doing multiple experiences along the patient journey at different times to piece together the whole journey.

4. Make it real. Include time with registration, lab tests, new patient appointment, follow-up, minor procedures, prescriptions, and referrals. Sit where the patient sits. Wear what the patient wears.

5. Experience the diagnostic and treatment process. Make a realistic paper trail including chart and lab reports.

6. During the experience note both positive and negative experiences, as well as any surprises. What was frustrating? What was gratifying? What was confusing? Was there variation by day of the week? Again, an audio- or videotape can be helpful.

7. Debrief your staff on what you did and what you learned.
Professionals

KNOW YOUR PROFESSIONALS

Use the following template to create a comprehensive summary picture of your HTC. Who does what and when? Is the right person doing the right activity? List all roles, total FTEs and overtime by role.

<table>
<thead>
<tr>
<th>Current Staff (Enter names below totals)</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>HTC Days and Times</td>
<td></td>
</tr>
<tr>
<td>MON</td>
<td>TUES</td>
</tr>
<tr>
<td>MDs – Total</td>
<td></td>
</tr>
<tr>
<td>NP/Advanced Practice Registered Nurses/PAs – Total</td>
<td></td>
</tr>
<tr>
<td>RN Coordinator</td>
<td></td>
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<tr>
<td>RNs – Total</td>
<td></td>
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<tr>
<td>Social Worker – Total</td>
<td></td>
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<tr>
<td>PTs – Total</td>
<td></td>
</tr>
<tr>
<td>LPNs/NA/MAs – Total</td>
<td></td>
</tr>
<tr>
<td>Clinical Staff (e.g., receptionist, front desk staff)</td>
<td></td>
</tr>
<tr>
<td>Administrative Staff – Total</td>
<td></td>
</tr>
<tr>
<td>Others – Total</td>
<td></td>
</tr>
</tbody>
</table>

Are the roles being optimized? Are all roles that contribute to the patient experience listed? What days and hours is the HTC open? How satisfied are staff in the HTC?

STAFF SATISFACTION SURVEY

1. I am treated with respect every day by everyone that works in the HTC.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

2. I am given everything I need—tools, equipment, and encouragement—to make my work meaningful to my life.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

3. When I do good work, someone in this HTC notices that I did it.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

4. How stressful would you say it is to work in this HTC?
   - Very Stressful
   - Somewhat Stressful
   - A Little Stressful
   - Not Stressful

5. How easy is it to ask anyone a question about the care we provide?
   - Very Easy
   - Easy
   - Difficult
   - Very Difficult

6. How would you rate other people’s morale and their attitudes about working here?
   - Excellent
   - Very Good
   - Good
   - Fair
   - Poor

7. This HTC is a better place to work that it was 12 months ago.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

8. I would strongly recommend this HTC as a great place to work.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

9. What would make this HTC better for patients and their families?

10. What would make this HTC better for those who work here?

Do you use on-call staff? □ Yes □ No
Do you conduct outreach clinics? □ Yes □ No

STAFF SATISFACTION SCORES

How stressful is this HTC? (% Very Stressful)

Would you recommend it as a great place to work? (% Strongly Agree)

SUPPORTING MICROSYSTEMS

such as pharmacy, orthopedics, hepatology, infectious disease, gynecology and dentistry.
Professionals

- Development of each HTC member is a key to success for staff and the microsystem. The Personal Skills Assessment tool helps determine the education and training needs of staff. All staff members complete this survey and then discuss a personal/professional development plan.
- A plan can be developed to help members achieve goals so they can become the best they can be.
- This tool provides guidance for individual development plans along with assessing the "group" needs to plan larger learning and training sessions.

HTC — PERSONAL SKILLS ASSESSMENT

**Name**

**Role**

**Date**

**Clinical Competencies:**

<table>
<thead>
<tr>
<th>Want to Learn</th>
<th>Never Use</th>
<th>Occasionally</th>
<th>Frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prophylaxis</td>
<td></td>
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<tr>
<td>Immune-Tolerance Induction</td>
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<tr>
<td>Home INR Monitoring</td>
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<tr>
<td>Prescribed Treatment Plan</td>
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<tr>
<td>Range-of-Motion Measurements</td>
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<tr>
<td>New Treatment Products</td>
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<tr>
<td>Telemedicine</td>
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<tr>
<td>Healthy Lifestyles</td>
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<tr>
<td>Risk-Reducing Behaviors</td>
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<tr>
<td>Developmental Needs</td>
<td></td>
<td></td>
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<tr>
<td>Activities of Daily Living</td>
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<tr>
<td>Self-Advocacy</td>
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<tr>
<td>Self-Infusion</td>
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<tr>
<td>Laboratory Self-Testing or Monitoring</td>
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<tr>
<td>Preventive Self-Care</td>
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<tr>
<td>Intended Effects and Potential Adverse Effects of Proposed Therapies</td>
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</tbody>
</table>

**Clinical Information Systems (CIS):**

<table>
<thead>
<tr>
<th>Want to Learn</th>
<th>Never Use</th>
<th>Occasionally</th>
<th>Frequently</th>
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</thead>
<tbody>
<tr>
<td>ATHN Clinical Manager</td>
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<tr>
<td>ATHN Advoy/Electronic Bleeding Logs</td>
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<tr>
<td>ATHN Ready</td>
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<td></td>
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<tr>
<td>Provider/On-Call Schedule</td>
<td></td>
<td></td>
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<tr>
<td>Patient Demographics</td>
<td></td>
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<tr>
<td>Lab Results</td>
<td></td>
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<tr>
<td>Patient and Family Goals and Action Plan</td>
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<td></td>
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<tr>
<td>Review Reports/Notes</td>
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<tr>
<td>Note Templates</td>
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<tr>
<td>Medication Lists</td>
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<tr>
<td>Insurance Status</td>
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<tr>
<td>Radiology</td>
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<tr>
<td>Electronic Bleeding Records</td>
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<td></td>
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<tr>
<td>Phone Coordination/Documentation</td>
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</tbody>
</table>

**Meeting and Interpersonal Skills:**

What skills do you currently use?

<table>
<thead>
<tr>
<th>Want to Learn</th>
<th>Never Use</th>
<th>Occasionally</th>
<th>Frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective Meeting Skills (brainstorm/multi-vote)</td>
<td></td>
<td></td>
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<tr>
<td>Timed Agendas</td>
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<tr>
<td>Role Assignments During Meetings</td>
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<td>Delegation</td>
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<td>Patient Advocacy</td>
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</tbody>
</table>

**Improvement Skills and Knowledge:**

What improvement tools do you currently use?

<table>
<thead>
<tr>
<th>Want to Learn</th>
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<tbody>
<tr>
<td>Flowcharts/Process Mapping</td>
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<tr>
<td>Trend Charts (Run Charts)</td>
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<tr>
<td>Control Charts</td>
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<tr>
<td>Plan-Do-Study-Act (PDSA) Improvement Model</td>
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<tr>
<td>Standardize-Do-Study-Act (SDSA) Improvement Model</td>
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<tr>
<td>Aim Statements</td>
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<tr>
<td>Fishbones</td>
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<tr>
<td>Measurement and Monitoring</td>
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<tr>
<td>Surveys – Patient and Staff</td>
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<tr>
<td>STAR Relationship Mapping</td>
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<tr>
<td>Patient-centered and Family-centered Care</td>
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</table>

NOTE: CIS refers to hospital or HTC based information systems used for such functions as checking patients in, electronic medical records and accessing lab and x-ray information. Customize your list of CIS features to determine skills needed by various staff members to optimize their roles.

**HTC — PERSONAL SKILLS ASSESSMENT, CONTINUED**

Name

**HTC**

**Technical Skills:** Please rate the following on how often you use them.

<table>
<thead>
<tr>
<th>Electronic Health Record Systems</th>
<th>Want to Learn</th>
<th>Never Use</th>
<th>Occasionally</th>
<th>Frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-mail</td>
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<td>Smart Phone</td>
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<tr>
<td>Dictation</td>
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<tr>
<td>Word Processing (e.g., Word)</td>
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<tr>
<td>Spreadsheet (e.g., Excel)</td>
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<tr>
<td>Presentation (e.g., Power Point)</td>
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<tr>
<td>Internet/Intranet</td>
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<tr>
<td>Printer Access</td>
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<td>Fax</td>
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<td>Copier</td>
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<td>Telephone System</td>
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<td>Voice Mail</td>
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**Meeting and Interpersonal Skills:**

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<td>Problem Solving</td>
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**Improvement Skills and Knowledge:**

What improvement tools do you currently use?

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<tr>
<td>Patient-centered and Family-centered Care</td>
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</tbody>
</table>
## ACTIVITY SURVEY SHEET

### Activity: See Patients in the HTC
- Specific Items Involved:
  - Review chart history
  - Assess/diagnose patient
  - Determine treatment plan
- % of Time: 30%

### Activity: Miscellaneous
- % of Time: 15%

### Activity: Patient/Family Education
- Specific Items Involved:
  - See patients in the HTC
  - Assist Provider with patients
  - Educators
- % of Time: 30%

### Activity: Follow-up Phone Calls/Emails
- Specific Items Involved:
  - Normal with follow-up
  - Drug adjustments
- % of Time: 22%

### Activity: Complete Forms
- Specific Items Involved:
  - Referrals
  - Prior Authorizations
- % of Time: 18%

### Activity: Calls in Prescriptions
- Specific Items Involved:
  - Manage charts
- % of Time: 5%

### Activity: Miscellaneous
- Specific Items Involved:
  - CME, attend seminars, attend meetings
- % of Time: 2%

### Activity: Total
- % of Time: 100%

---

### ACTIVITY OCCURRENCE EXAMPLE

#### What's the next step?
Activities are combined by role from the data collected above. This creates a master list of activities by role. Fill in the NUMBER OF TIMES PER SESSION (AM and PM) THAT YOU PERFORM THE ACTIVITY. Make a mark by the activity each time it happens, per session. Use one sheet for each day of the week. Once the frequency of activities is collected, the HTC should review the volumes and variations by session, day of week and month of year. This evaluation increases knowledge of predictable variation and supports improved matching of resources based on demand.

### ACTIVITY SURVEY SHEET

<table>
<thead>
<tr>
<th>Role: MD</th>
<th>% of Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity: Triage Patient Issues/Concerns</td>
<td>15%</td>
</tr>
<tr>
<td>Activity: Direct Patient Care</td>
<td>3%</td>
</tr>
<tr>
<td>Activity: Review and Notify Patients of Lab Results</td>
<td>5%</td>
</tr>
<tr>
<td>Activity: Complete Forms</td>
<td>18%</td>
</tr>
<tr>
<td>Activity: Calls in Prescriptions</td>
<td>5%</td>
</tr>
<tr>
<td>Activity: Miscellaneous</td>
<td>2%</td>
</tr>
<tr>
<td>Activity: Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

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### ACTIVITY OCCURRENCE EXAMPLE

#### What's the next step?
Activities are combined by role from the data collected above. This creates a master list of activities by role. Fill in the NUMBER OF TIMES PER SESSION (AM and PM) THAT YOU PERFORM THE ACTIVITY. Make a mark by the activity each time it happens, per session. Use one sheet for each day of the week. Once the frequency of activities is collected, the HTC should review the volumes and variations by session, day of week and month of year. This evaluation increases knowledge of predictable variation and supports improved matching of resources based on demand.
Processes

KNOW YOUR PROCESSES

How do things get done in the microsystem? Who does what? What are the step-by-step processes? How long does the care process take? Where are the delays?

<table>
<thead>
<tr>
<th>Appointment Types</th>
<th>Duration</th>
<th>Cycle Time</th>
<th># of Exam Rooms</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
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</table>

IDENTIFY SUPPORTING MICROSYSTEMS

For example, pharmacy, orthopedics, hepatology, infectious disease, gynecology, and dentistry.

CREATE FLOWCHARTS OF ROUTINE PROCESSES

- Deming has said, “If you can’t draw a picture of your process you can’t improve anything.” He is referring to the improvement tool of process mapping. With your lead improvement team, create a high-level flowchart of the appointment process or the entire treatment experience. Start with just ONE flowchart. Eventually you will wish to create flowcharts for many different processes in your HTC and processes with other microsystems. Keep the symbols simple!

- Review the flowchart to identify unnecessary rework, delays and opportunities to streamline and improve.
- See www.athn.org and www.clinicalmicrosystem.org for flowcharts examples.

Suggested Processes to Flowchart

1. Overall appointment process
2. Overall treatment process
3. Transition from pediatric to adult care

 Symbol Key

<table>
<thead>
<tr>
<th>Symbol</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="Unknown Step of Process" /></td>
<td>Unknown Step of Process</td>
</tr>
<tr>
<td><img src="image" alt="Process Beginning or End" /></td>
<td>Process Beginning or End</td>
</tr>
<tr>
<td><img src="image" alt="Decision Point" /></td>
<td>Decision Point</td>
</tr>
<tr>
<td><img src="image" alt="Process Flow Direction" /></td>
<td>Process Flow Direction</td>
</tr>
<tr>
<td><img src="image" alt="Activity Step" /></td>
<td>Activity Step</td>
</tr>
<tr>
<td><img src="image" alt="Connector (E.G. Off Page)" /></td>
<td>Connector (E.G. Off Page)</td>
</tr>
</tbody>
</table>

Reference: QuIRK#6: Process Maps/Flowcharts

© 2001, Trustees of Dartmouth College
Adapted American Thrombosis and Hemostasis Network (ATHN), June 2016
### Processes

**CYCLE TIME TOOL**

One key measure of clinical microsystem efficiency is the patient cycle time. It is important to understand that cycle time is a result of systems, processes and individual style. This is defined as the time from when a patient enters the HTC until they leave. The Patient Cycle Time Tool can be administered in several ways: a) Patients and families can carry the clipboard through their visit and note the times, b) Staff can write the times as the patient travels through the clinic or c) Patients can be "shadowed" by a person to document the times. There is space to write comments along the way.

**INSTRUCTIONS:** Please fill in the time for each step of the HTC visit.

Scheduled appointment time ______________ Date ______________

<table>
<thead>
<tr>
<th>TIME</th>
<th>1. Time you arrived at the HTC.</th>
<th>2. Time you checked in.</th>
<th>3. Time you were shown to the exam room.</th>
<th>4. Time the nurse finished measurements (e.g. weight, height, b/p, temp).</th>
<th>5. Time you were ready to see the first HTC team member.</th>
<th>6. Note below the times the clinicians entered and left the room.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse</td>
<td>Social Worker</td>
<td>PT</td>
<td>Physician</td>
<td>Other</td>
<td>Other</td>
<td>Other</td>
</tr>
<tr>
<td>Time In:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Out:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TIME</th>
<th>7. Time you were ready to leave the HTC.</th>
</tr>
</thead>
</table>

**HTC Patient Appointment Cycle Time**

<table>
<thead>
<tr>
<th>Time</th>
<th>1. Time you checked in.</th>
<th>2. Time you sat in the waiting room.</th>
<th>3. Time staff came to get you.</th>
<th>4. Time staff member left you in exam room.</th>
<th>5. Time first provider came in room.</th>
<th>6. Time first provider left the room.</th>
<th>7. Time second provider came in room.</th>
<th>8. Time second provider left the room.</th>
<th>9. Time third provider came in room.</th>
<th>10. Time third provider left the room.</th>
<th>11. Time fourth provider came in room.</th>
<th>12. Time fourth provider left the room.</th>
<th>13. Time you left the exam room.</th>
<th>14. Time you arrived at check out.</th>
<th>15. Time you left HTC.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Provider 2</td>
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<tr>
<td>Provider 3</td>
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<tr>
<td>Provider 4</td>
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<td></td>
</tr>
</tbody>
</table>

**COMMENTS:**
**Processes**

- Review, adapt and distribute the Core and Supporting Processes Assessment form to ALL HTC staff. Be sure the list is accurate for your center and then ask staff to evaluate the CURRENT state of these processes. Rate each process by putting a tally mark under the heading that most closely matches your understanding of the process. Also mark if the process is a source of patient complaints. Tally the results to give the lead improvement team an idea as to where to begin to focus improvement from the staff perspective.

- Some HTCs create and hang a wall-sized version of the Core and Supporting Process Assessment chart and ask all staff to select choices with using different colored dots for each role. This creates a visual display showing all the ratings and priorities for all staff to see.

- Steps for improvement: Explore improvements for each process based on the outcomes of this assessment tool. Each of the processes below should be flowcharted in its current state. Based on the flowcharts of the current state of your processes and determinations of your Change ideas (see pg. 32), you will use the PDSA (plan-do-study-act) cycle worksheet (pg. 35) to run tests of change and to measure your change ideas.

---

**HTC CORE AND SUPPORTING PROCESSES ASSESSMENT**

<table>
<thead>
<tr>
<th>Processes</th>
<th>Works Well</th>
<th>Small Problem</th>
<th>Real Problem</th>
<th>Totally Broken</th>
<th>Cannot Rate</th>
<th>We’re Working on it</th>
<th>Source of Patient/ Family Complaint</th>
</tr>
</thead>
<tbody>
<tr>
<td>Answer phones</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contact patients due for an appointment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Phone advice</td>
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</tr>
<tr>
<td>Messaging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scheduling appointments or procedures</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making referrals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retrieving needed diagnostic test results</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription renewals</td>
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</tr>
<tr>
<td>Pre-authorization for services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Billing/Coding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtaining medical records</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Check-in process</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Orientation of patients to your HTC</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>New patient work-ups</td>
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</tr>
<tr>
<td>Comprehensive HTC flow</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Patient and family education</td>
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</tr>
<tr>
<td>Chronic disease treatment and management</td>
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<tr>
<td>Infectious disease collaboration</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Goal-setting and plan for patients/families</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Prevention assessment/activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td>Research enrollment</td>
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<tr>
<td>Data entry</td>
<td></td>
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</tr>
<tr>
<td>Data collection</td>
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<td>Transition from pediatric to adult care</td>
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<td>Check-out process</td>
<td></td>
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</tr>
<tr>
<td>Outreach clinics</td>
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</tr>
<tr>
<td>Factor dispensation</td>
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<td></td>
</tr>
<tr>
<td>Community outreach</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

---

**Patterns**

**KNOW YOUR PATTERNS**

- What patterns are present but not acknowledged in your microsystem? What is the leadership and social pattern? How often does the microsystem meet to discuss patient care? Are you with bleeding disorders and families involved? What are your results and outcomes?

- Does every member of the HTC meet regularly as a team?

- How often does your HTC microsystem meet to discuss bleeding disorders care?

- How do leaders across your HTC microsystem relate to one another?

- Do the members of the HTC regularly review and discuss quality, safety and reliability issues?


- What is the most significant pattern of variation?

- Have you successfully changed?

- Are you most proud of?

- What is the financial trend for your HTC?

- What are your bleeding disorders results and outcomes?

- How do leaders relate to staff?

---

**UNPLANNED ACTIVITY TRACKING CARD**

**Unplanned Activity Tracking**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
<th>Time:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place a tally mark for each occurrence of an unplanned activity</td>
<td>Interruptions</td>
<td></td>
</tr>
<tr>
<td>Phone</td>
<td>Secretary</td>
<td>RN</td>
</tr>
<tr>
<td>Physician</td>
<td>Provider</td>
<td>Past/Current Patient</td>
</tr>
<tr>
<td>Hospital Admissions</td>
<td>Patient Phone Calls</td>
<td>Pagers</td>
</tr>
<tr>
<td>Nursing Equipment</td>
<td>Medication Supplies</td>
<td>Missing Chart: Same-Day Patient</td>
</tr>
<tr>
<td>Missing Chart: Same-Day Patient</td>
<td>Missing Chart: Patient</td>
<td>Missing Test Results</td>
</tr>
<tr>
<td>Emergency Cases</td>
<td>Unexpected Insurances Issues</td>
<td>Pharmacy Phone Calls</td>
</tr>
<tr>
<td>Refill Requests</td>
<td>Contact or Industry Studies/Surveys</td>
<td>Phone calls from pharmaceutical companies</td>
</tr>
<tr>
<td>Coordinating services with outside providers</td>
<td>Coordinating outside procedures (planned and unplanned)</td>
<td>Providing assistance to Hemostasis/Oncology department due to high pt. volumes or unplanned staffing conflicts</td>
</tr>
</tbody>
</table>

---

**EXAMPLE**

**Unplanned Activity Tracking**

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date:</th>
<th>Time:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place a tally mark for each occurrence of an unplanned activity</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td>Interruptions</td>
<td>Phone</td>
<td>Secretary</td>
</tr>
<tr>
<td>Provider</td>
<td>Hospital Admissions</td>
<td>Patient Phone Calls</td>
</tr>
<tr>
<td>Nursing Equipment</td>
<td>Medication Supplies</td>
<td>Missing Chart: Same-Day Patient</td>
</tr>
<tr>
<td>Missing Chart: Patient</td>
<td>Missing Test Results</td>
<td>Emergency Cases</td>
</tr>
<tr>
<td>Unexpected Insurances Issues</td>
<td>Pharmacy Phone Calls</td>
<td>Refill Requests</td>
</tr>
<tr>
<td>Contact or Industry Studies/Surveys</td>
<td>Phone calls from pharmaceutical companies</td>
<td>Coordinating services with outside providers</td>
</tr>
<tr>
<td>Coordinating outside procedures (planned and unplanned)</td>
<td>Providing assistance to Hemostasis/Oncology department due to high pt. volumes or unplanned staffing conflicts</td>
<td></td>
</tr>
</tbody>
</table>

---

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Adapted American Thrombosis and Hemostasis Network (ATHN), June 2016
Patterns

- Patterns can be found through tracking the volumes and types of telephone calls. Review the categories on the telephone tracking list to ensure they reflect the general categories of calls your HTC receives. Ask clinical staff to track the telephone calls over the course of a week to find the patterns of type of call and the volume peaks and valleys. New processes, such as using a Web site to reorder prescriptions or make appointments, may eliminate some calls. Be alert for new design possibilities.

**HTC TELEPHONE TRACKING LOG**

<table>
<thead>
<tr>
<th>Week of</th>
<th>Day of Week</th>
<th>Day of Week</th>
<th>Week Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AM</td>
<td>PM</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appointment for Today</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appointment for Tomorrow</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appointment for Future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up Visit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Comprehensive Visit</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Acute Visit</td>
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<td></td>
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<tr>
<td>Total</td>
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<td></td>
<td></td>
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<tr>
<td>Test Results</td>
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<tr>
<td>Total</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Nurse Care</td>
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</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription Refill</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Referral Information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Need Information</td>
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<td></td>
</tr>
<tr>
<td>Total</td>
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<td></td>
</tr>
<tr>
<td>Message for Provider</td>
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<tr>
<td>Total</td>
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<tr>
<td>Talk with Provider</td>
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<td>Telephone Consult</td>
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</tr>
<tr>
<td>Prior Authorizations for Factor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insurance Calls</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Total</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Put a tally mark each time one of the phone calls is for one of the listed categories. Total the calls for each day and then total the calls in each category for the week. Note the changes in volume by the day of the week and am/pm.

**Metrics That Matter**

- Measures are essential if a microsystem is to make and sustain improvements toward high performance. Query your data, Clinical Manager, and ATHN Research Report and Clinical Manager Data to identify opportunities for improvement. All clinical microsystems are awash with data but relatively few have rich information environments that feature daily, weekly and monthly use of Metrics That Matter (MTM). The key to doing this is to get started in a practical, doable way, and to build out your Metrics That Matter and then vital use over time.
- Some guidelines for your consideration are listed below. Remember these are just guidelines and your microsystem should do what makes sense in the way of collecting, displaying and using measures or Metrics That Matter.

**HTC METRICS THAT MATTER**

1. **What?** Every microsystem has vital performance characteristics, things that must happen for successful operations. Metrics That Matter (MTM) should reflect your microsystem’s vital performance characteristics.
2. **Why?** The reason to identify, measure and track MTM is to ensure that you are not “flying blind” safe, high-quality and efficient performance will give you specific, balanced and timely metrics that show:
   a. When improvements are needed
   b. If improvements are successful
   c. If improvements are sustained over time
   d. The amount of variation in results over time
3. **How?** Here are steps you can make to take advantage of MTMs.

**LEAD IMPROVEMENT TEAM**

Work with your lead improvement team to establish the need for metrics and their routine use. Quality begins with the intention to achieve measured excellence.

**BALANCED METRICS**

Create a balanced set of metrics to provide insight into what’s working and what’s not working. Some categories to consider are: Healthy People 2020 metrics, NHPCC national quality metrics, clinical outcomes, key steps in core and supporting processes, safety practices, patient and family experiences of care and financial measures. (The measurement triangle is found on pg. 30.)

Every metric should have an operational definition, data owner, current and target value and an action plan.

**Conceptual Definition:** tells what will be measured (e.g. patient waiting for HTC clinic visit)

**Operational Definition:** tells how it will be measured (e.g. time elapsed from patient appointment time until patient enters exam room in minutes)

**DATA WALL DISPLAYS**

A data wall is a designated space to display your Metrics That Matter over time. Build a data wall and use it daily, weekly, monthly and annually. Gather data for each metric and display it on the “data wall” reporting:

- Current Value
- Target Value
- Action Plan to improve or sustain level

Display metrics as soon as possible—daily, weekly and monthly metrics are most useful—using visual displays such as time trend charts and bar charts.

**DATA OWNER**

Start small and identify a data wall owner(s) who is guided by the lead improvement team. Identify a data owner(s) for each metric. The owner will be responsible for getting this measure and reporting it to the lead improvement team. Seek sources of data from organization-wide systems.

If the needed data are not available, use manual methods to sample and provide a snapshot of the data. Strive to build data collection into the flow of daily work.

**REVIEW AND USE**

Review your set of metrics on a regular basis—daily, weekly, monthly, quarterly and annually.

Use metrics to make needed improvements whenever possible.

Make metrics fun, useful and a lively part of your microsystem development process. Discuss Metrics That Matter frequently and take action on them as needed.

**KEY METRICS SPECIFIC TO HEMOPHILIA**

1. Joint Bleeds (per patient per year)
2. Factor Units Consumed / Factor Units Prescribed
3. Prophylaxis Prescribed for Severe Hemophilia
4. Comprehensive Care Visits
5. Emergency Room Visits
6. Inhibitors
7. ITI Initiated for New Inhibitor
8. Days Lost from Work/School (per patient per year)
The Dartmouth Microsystem Improvement Ramp with Measurement

Improvement activities and measurement are inextricably connected. To assist you to "see" this relationship, the Dartmouth Microsystem Improvement Ramp and the Measurement Triangle illustrate how improvement measurement can be woven into each step of the improvement process.

Careful consideration of the conceptual and operational definitions will ensure reliable measurement throughout the improvement process.

The development of data collection plans support the PLAN of improvement process.

**HTC METRICS THAT MATTER**

- Review the currently determined "best metrics" that HTCs should be monitoring.
- List current performance on these metrics and what targets are.

### HTC Patient Registry Outcome Measures

<table>
<thead>
<tr>
<th>Name of Measure</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate of joint bleeds per patient per year</td>
<td></td>
</tr>
<tr>
<td>Surgical readmissions for bleeding</td>
<td></td>
</tr>
<tr>
<td>Emergency Room Visits</td>
<td></td>
</tr>
<tr>
<td>Lost time from school or work</td>
<td></td>
</tr>
<tr>
<td>Care Experience Metrics</td>
<td></td>
</tr>
<tr>
<td>Staff Engagement Metrics</td>
<td></td>
</tr>
</tbody>
</table>

### Process Measures

<table>
<thead>
<tr>
<th>Name of Measure</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of Prophylaxis</td>
<td></td>
</tr>
<tr>
<td>Comprehensive Visit Rate</td>
<td></td>
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<td>Inhibitor Testing</td>
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<td>Use of ITI</td>
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<td>HCV Testing and Treatment Offer</td>
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<tr>
<td>Discuss Transition</td>
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<td>Access</td>
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<tr>
<td>Waiting Room Time</td>
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<tr>
<td>Return Phone Call Time</td>
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<td>Costs</td>
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</table>

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<thead>
<tr>
<th>Name of Measure</th>
<th>Goal</th>
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<tbody>
<tr>
<td>Factor Units per Patient per Year</td>
<td></td>
</tr>
<tr>
<td>Other</td>
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</table>

### Diagnose

With the improvement lead improvement team review the 5Ps assessment and Metrics That Matter, and with consideration of your organizational strategic plan, select a first "theme" (e.g., transition of patients from pediatric to adult care) for improvement.

**The purpose of assessing is to make an informed and correct overall diagnosis of your microsystem.**

- First, identify and celebrate the strengths of your system.
- Second, identify and consider opportunities to improve your system.
- The opportunities to improve may come from your own microsystem—based on assessment, staff suggestions and/or patient and family needs, perceptions, priorities and concerns.
- The opportunities to improve may come from outside your microsystem—based on a strategic project or external performance/quality measures, e.g. NHPCC, HRSA, MASSAC, CDC, etc.
- Not only look at the detail of each of the assessment tools, but also synthesize all of the assessments and Metrics That Matter to "get the big picture" of the microsystem. Identify linkages within the data and information. Consider:
  - Waste and delays in the process steps. Look for processes that might be redesigned to result in better functions for roles and better outcomes for patients.
  - Patterns of variation in the microsystem. Be mindful of smoothing the variations or matching resources with the variation in demand.
  - Patterns of outcomes you wish to improve.
  - It is usually smart to pick or focus on one important theme to improve at a time and to work with all the "players" in your system to make a big improvement in the area selected.
  - Suggestions on how to make your diagnosis and select a theme follow next.

**STEP 3**

**Diagnose**

**Write your Theme for Improvement**

"GLOBAL" AIM STATEMENT FOR THEME

Create an aim statement that will help keep your focus clear and your work productive.

**We aim to improve**

(Name the process)

(Clinical location in which process is embedded)

(Name where the process begins)

(Name where the process ends)

(List benefits)

(List imperatives)
**Treat Your HTC**

Draft a clear **specific aim statement** and way to measure the aim using improvement models—PDSA (Plan-Do-Study-Act, pg. 35) and SDSA (Standardize-Do-Study-Act, pg. 36). For additional information about improvement tools and methods, please refer to the electronic improvement modules at www.athn.org and www.clinicalmicrosystem.org.

- Now that you have made your diagnosis and selected a theme worthy of improving, you are ready to begin using powerful **change ideas**, improvement tools and the scientific method to change your microsystem.
- This begins with making a **specific aim** and using Plan-Do-Study-Act (PDSA), which is known as the “model for improvement.” The improvement model raises three important questions to answer before starting to make changes.
  1. What are you trying to accomplish?
  2. How will we know that a change is an improvement?
  3. What changes can we make that will result in an improvement?
- After you have run your tests of change and have reached your measured aim, the challenge is to maintain the gains that you have made. This can be done using Standardize-Do-Study-Act (SDSA), which is the other half of making improvement that has “staying power.”
- You will be smart to avoid totally reinventing the wheel by taking into consideration best known practices, **Change Ideas** that other clinical teams and patients and families have found to really work. A list of some of the best “Change Ideas” that might be adapted and tested in your clinic follows the aim statement worksheet.
- The **Change Ideas** will continue to develop as more field testing is done and more colleagues design improvements. These ideas are derived from the collaborative innovation work of ATHN for more information visit www.athn.org, www.ihi.org (Institute for Healthcare Improvement) or www.clinicalmicrosystem.org.
- Reference: QuIRK#7: Specific Aim Statement

---

**Huddle Sheet**

- **Date:**

  **Aim:** Enable the HTC to proactively anticipate and plan actions based on patient need and available resources, and contingency planning.

  **Follow-ups**

  **MEASURES**

  **Patient Needs:**

  **Clinic/Staff Needs:**

  **REVIEW OF NEXT CLINIC DAY AND PROACTIVE PLANNING**

  **Huddle Sheet**

  **Date:**

  **Aim:** Enable the HTC to proactively anticipate and plan actions based on patient need and available resources, and contingency planning.

  **Follow-ups**

  **MEASURES**

  **Patient Needs:**

  **Clinic/Staff Needs:**

  **REVIEW OF NEXT CLINIC DAY AND PROACTIVE PLANNING**

**HTC Change Ideas to Consider**

**Change Ideas to Improve Access to Care**

1. Shape demand
2. Match supply and demand
3. Redesign the system

**Change Ideas to Improve Interaction**

4. Design group visits or shared medical appointments
5. Utilize email care
6. Create a practice website
7. Optimize professional roles to subpopulation care management

**Change Ideas to Improve Reliability**

8. Adapt the Chronic Care Model: “Improving Chronic Illness Care” (CIC)
   (www.improvingchroniccare.org)
9. Change Ideas to Improve Vitality
   1. Engage all staff in continuous improvement and research
   2. Develop strategies to actively develop individual staff
   3. Create a favorable financial status which supports investments in the practice
   4. Utilize “daily huddle” process with MDs, RNs and clerical staff to review yesterday, plan for today, tomorrow and the coming week (see Huddle Sheet page 33)

*An example of this worksheet is found on pg. 38.

**Driver Diagram**

The **driver diagram** (shown on pg.34) is a tool to organize and track multiple improvements to achieve the “Global Aim” of the “Theme” of improvement.

The driver diagram also shows the relationships between the theme, global aim, specific aims, measures and PDSA cycles in a quick visual way. Creating a “gantt chart” to add pace to the improvement is often helpful.

The driver diagram can be used in two ways for improvement teams.

1. It can be used at the beginning of improvement to list and organize the evidence-based, best known practices and other improvement PDSA cycles to reach the goal of improvements.

   - The PDSA cycles can be conducted one-by-one (especially when you are learning improvement skills).

   - It can be used as a road map when multiple staff know the discipline of improvement and multiple PDSA cycles can be conducted simultaneously to move in a more timely fashion toward the desired goals.

**Change Concepts**


  A. Eliminate Waste
  B. Improve WorkFlow
  C. Optimize Inventory
  D. Change the Work Environment
  E. Enhance the Producer/Consumer Relationship
  F. Manage Time
  G. Manage Variation
  H. Design Systems to Avoid Mistakes
  I. Focus on the Product or Service


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Plan-Do-Study-Act (PDSA)

Complete the Plan-Do-Study-Act worksheet to execute the Change idea in a disciplined, measured manner, to reach the specific aim. See www.athn.org and www.clinicalmicrosystem.org for examples.

*An example of this worksheet is found on pg. 43.

**How shall we PLAN the pilot test?**

Who is the task? What tools? What baseline data will be collected, over what period of time, to determine if the AIM is being achieved?

<table>
<thead>
<tr>
<th>Tasks to be completed to run test of change</th>
<th>Who</th>
<th>When</th>
<th>Tools Needed</th>
<th>Measures</th>
</tr>
</thead>
</table>

**DO**

What are we learning as we DO the pilot? What happened when we ran the test? Any problems encountered? Any surprises?

As we STUDY what happened, what have we learned? What do the measures show?

As we ACT to hold the gains or abandon our pilot efforts, what needs to be done? Will we modify the change? Make a PLAN for the next cycle of change.

The lead improvement team should continue to meet weekly to review progress in the design of the PDSA and then during the execution of the test of change in a pilot format to observe and learn about the Change idea implementation. Remember to always test Change Ideas in small pilots to learn what adaptations and adjustments need to be made before implementing on a larger scale. Data collection and review during the testing is important to answer the question: How will we know if the Change Idea is an improvement? Once the PDSA cycle is completed and the lead improvement team reviews the data and qualitative findings, the plan should be revised or expanded to run another cycle of testing until the aim is achieved.

When the Change Idea has been tested and adapted to the context of the clinical microsystem and the data demonstrate that the Change Idea makes an improvement, the lead improvement team should design the Standardize-Do-Study-Act (SDSA, pg. 36) process to ensure the process is performed as designed. During this process it is important to continually learn and improve by monitoring the steps and data to identify new opportunities for further improvement. You will move from PDSA to SDSA and back to PDSA in your continuous improvement environment. New methods, tools, technology or best practice will often signal the need to return to PDSA to achieve the next level of high performance. You want to be able to go from PDSA to SDSA and back to PDSA as needed. The scientific method is a two-way street that uses both experimentation (i.e., PDSA) as well as standardization (i.e., SDSA).
Follow-Up

IMPROVEMENT IN HEALTHCARE IS A CONTINUOUS JOURNEY

The new patterns need to be monitored to ensure the improvements are sustained. Embedding new habits into daily work with the use of “huddles” to review and remind staff, as well as weekly lead improvement team meetings keeps everyone focused on improvements and results that can lead to sustained and continuous improvements.

Data walls, storyboards and monthly all-staff and patient/family advisor meetings are methods to embed new habits and thinking for improvement.

The lead improvement team should repeat the process for newly recognized themes and improvements that are identified in the assessment and outcomes/performance metrics.

---

**STEP 5**

**Standardize-Do-Study-Act (SDSA)**

**STANDARDIZE CURRENT BEST PROCESS AND HOLD THE GAINS**

**STANDARDIZE** the process (specify which roles do what activities in what sequence with what information flow). A good way to track and standardize process is through the creation of a **Playbook**. The **Playbook** is the collection of **process maps** to provide care and services that all staff are aware of and accountable for. The **Playbook** can be used to orient new staff and patient/family advisors, document current **processes** and contribute to performance appraisals.

**DO** the work to integrate the standard process into daily work routines to ensure reliability and repeatability.

**STUDY** at regular intervals. Consider if the process is being adhered to and what adjustments are being made. Review the process when new innovation, technology or roles are being considered. Review what the measures of process are showing.

**ACT** based on the above, maintain or tweak the standard process and continue doing this until the next wave of improvements/innovations takes place with a new series of **PDSA** cycles.

---

<table>
<thead>
<tr>
<th>Task to be completed to “embed” standardization and monitor process</th>
<th>Who</th>
<th>When</th>
<th>Tools Needed</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Playbook – Create standard process maps to be inserted in your Playbook.</em></td>
<td></td>
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</tbody>
</table>

**DO**

What are we learning as we DO the standardization? Any problems encountered? Any surprises? Any new insights to lead to another PDSA cycle? Any surprises?

As we STUDY the standardization, what have we learned? What do the measures show? Are there identified needs for change or new information or “tested” best practice to adapt?

As we ACT to **hold the gains** or modify the standardization efforts, what needs to be done? Will we modify the standardization? What is the Change Idea? Who will oversee the new PDSA? Design a new PDSA cycle. Make a **PLAN** for the next cycle of change. Go to PDSA worksheet (pg.34).

---

**STUDY**

As we STUDY the standardization, what have we learned? What do the measures show? Are there identified needs for change or new information or “tested” best practice to adapt?

As we ACT to **hold the gains** or modify the standardization efforts, what needs to be done? Will we modify the standardization? What is the Change Idea? Who will oversee the new PDSA? Design a new PDSA cycle. Make a **PLAN** for the next cycle of change. Go to PDSA worksheet (pg.34).

---

**ACT**

As we ACT to **hold the gains** or modify the standardization efforts, what needs to be done? Will we modify the standardization? What is the Change Idea? Who will oversee the new PDSA? Design a new PDSA cycle. Make a **PLAN** for the next cycle of change. Go to PDSA worksheet (pg.34).
Case Study: HTC

BEST HEMOPHILIA TREATMENT CENTER, HAPPY MEDICAL CENTER

CONTEXT

The Best HTC cares for approximately 120 patients. Our pediatric clinic is located in the pediatric multispecialty outpatient department of the Happy Medical Center and our adult program is approximately 3 miles away in the hematology outpatient department. We operate as two separate teams. The pediatric team consists of 2 hematologists, 1 advanced practice nurse, 2 registered nurses, a social worker and a physical therapist. A genetic counselor is shared between the pediatric and adult teams. Pediatric outpatient clinic is held three times a week as a full day clinic, with one day dedicated to annual comprehensive visits only. The adult clinic is a full day clinic once a week with one additional full clinic day held at a rural community 75 miles from Happy Medical Center for outreach. Patients with specific issues such as HIV, joint pain and women’s health issues see specialists through separate appointments in the appropriate departments. Each team convenes a pre- and post-clinic meeting to address patient issues on the full clinic day, with an additional meeting on Tuesday to review the upcoming week of patients. The pediatric and adult HTC teams meet once a month to review transition-age patients.

THEME, PURPOSE ANDAIMS

The HTC embarked on the journey of continuous improvement through the ATHN and NHPCF improvement program. The lead improvement team consisted of staff from the pediatric and adult HTC teams.

The purpose of the HTC was determined by the team to “improve the lives of patients and families living with bleeding disorders in the region by providing a multidisciplinary approach to patient care throughout their lifespan.” These efforts include patient and family education, quality improvement, research, and supporting a broader system of physicians and care providers within and outside the region.”

The lead improvement team reviewed the Clinical Manager, ATHN/Dastast, Community Counts and HP2020 indicator on transition measure. The large number of pediatric patients who had passed their 22nd birthday and still were being cared for by the pediatric hematologist was identified.

The lead improvement team determined the care for people with bleeding disorders could be improved by designing and implementing a transition program to prepare people with bleeding disorders to transfer to the adult program.

The first improvement theme was transition of care. To pursue this theme, the lead improvement team started by identifying transition-age patients, focusing on children ages 13 to 22 years as the global aim.

Our specific aim in the short term was to improve the number of patients who could independently order and obtain factor and supplies.

CONFIGURE YOUR HTC

Write your Theme for Improvement: transition of pediatric patients to adult for hemophilia care

“GLOBAL” AIM STATEMENT FOR THEME

Create an aim statement that will help keep your focus clear and your work productive.

We aim to improve the ability of a 20-year-old to engage in self-management of their healthcare

In Best HTC

The process begins with the first annual comprehensive visit at age 13

The process ends with the 20-year-old demonstrating self-care management over a 2-year period of time (defined as two comprehensive annual visits)

By working on the process, we expect young adults to be able to manage their own bleeding disorder care including understanding the details of their bleeding disorder including complications such as bleeding, scheduling required clinic appointments, understanding factor dosage, keeping pertinent logs, practicing appropriate disclosure and self-advocacy and understanding healthcare costs and insurance.

It is important to work on this now because recent data reporting those young adults do not know how to manage their bleeding disorder recent national surveys report the need of young adults to know more about the process of care and preparation for transition in care to adult care.

High-quality care should continue with increasing independence in management of individual bleeding disorders.

With our aims in place, we felt it was important to adopt a communication plan to get everyone involved. Upon the lead improvement team’s return from the on-site meeting, we had an all staff HTC care team meeting, including administrative staff, key pediatric and adult providers and specialists. The lead improvement team assumed a different role in the meeting to review what was taught at the on-site meeting, share the HTC’s data and the global and specific aims. We also met with senior leaders, e.g. department chair, section chiefs, vice presidents, to share our work and aim.

Another key set of stakeholders we engaged early in the effort were our patients and families. We agreed to be transparent and share our HTC’s specific patient registry data. We asked for their help to improve the transition of patients from the pediatric to adult care teams. Our goal was to engage them as active partners in the quality improvement work of the center. The use of a driver diagram may be beneficial at this step in the improvement process to organize and catalogue multiple specific aims (see page 31)

PDSA Cycle 1 — Design a new educational program to prepare people with bleeding disorders to anticipate and be educated on self-care management before the age of 18

PDSA Cycle 2 — Assess and document knowledge and education of self-management of care for people with bleeding disorders starting at age 13

PDSA Cycle 3 — Design and test implementation of the education program within the clinic flow of bleeding disorder appointment.

PDSA Cycle 2 — Assess and document knowledge and education of self-management of care for people with bleeding disorders starting at age 13

PDSA Cycle 1 — Design a new educational program to prepare people with bleeding disorders to anticipate and be educated on self-care management before the age of 18.

TESTS OF CHANGE

We conducted the following tests of change or cycles of Plan-Do-Study-Act (PDSA)

PDSA Cycle 1

• Design a new educational program to prepare people with bleeding disorders to anticipate and be educated on self-care management before the age of 18

PDSA Cycle 2

• Assess and document knowledge and education of self-management of care for people with bleeding disorders starting at age 13

PDSA Cycle 3

• Design and test implementation of the education program within the clinic flow of bleeding disorder appointment.


PDSA Cycle 1 — Design a new educational program to prepare people with bleeding disorders to anticipate and be educated on self-care management before the age of 18.

ASSESSMENT – CURRENT STATE

In trying to understand how we currently deliver care and how we currently support our patients in the transition from pediatric to adult providers we realized we needed to collect data on our patients, professionals, processes and patterns. We started to understand our patient population in several ways. We reviewed our HTC registry data and ATHN/Dastast and categorized patients by the percent of males and females and the age distribution of our patients, e.g. birth-2 years, 2-5 years, 6-12 years, etc. We asked patients to complete a patient satisfaction survey and an additional survey about transition if between the ages of 13 and 22 years. We also initiated a patient and family advisory group to help us and invited interested patients and families to our center meetings.

As we were getting a sense of our practice through the eyes of the patients, we also started to collect data about our professionals. We tallied data on the number of HTC’s in our clinics, provided an anonymous staff satisfaction survey and asked clinicians to complete a skills assessment. This information was invaluable and helped us have a few crucial conversations as a team.

At the heart of our assessment was our look at the evidence-based recommendations around transition from ATHN, MASAC and other organizations in the bleeding disorders community. With these resources, we began working toward HTC’s change ideas included educating patients, verifying patient’s understanding of key information needed to self-manage their health, who and how this understanding would be demonstrated and competency tracked and how many members on the care team would provide the education.
Transition and Transfer of Patients from Pediatric to Adult Care

Why focus on transition?

Life expectancy has increased dramatically for a wide range of childhood-onset medical conditions enabling many affected children to survive into adulthood. The transition from pediatric to adult care presents many challenges for care providers and healthcare systems, including the continuity of care. Health Resources and Services Administration (HRSA) has worked to identify national priority areas that are supported both by research and national data metrics. For people with bleeding disorders, HRSA has identified transition from pediatric to adult as a priority focus.

According to the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the Health Resources and Services Administration, Maternal and Child Health Bureau, and Centers for Disease Control and Prevention, National Center for Health Statistics (HRSA/MCHB and CDC/NCHS), only 40% of youth aged 12 to 17 years old with special health needs received pediatric-to-adult health care transition planning in 2009-2010. Healthy People 2020 has set a goal to increase that percentage to 45.3% by 2020. (https://www.healthypeople.gov/2020/data/Chart/415315/category=1&dps=1)

The National Hemophilia Program Coordinating Center has conducted a national survey to learn how to improve care and services through Hemophilia Treatment Centers (HTCs). In addition, the network of HTCs has recommended adoption of a systematic approach to support youth, families and young adults in their transition from pediatric to adult health care.

What does the literature say about transition of pediatric patients with serious chronic illnesses?

Literature suggests that when health care systems do not have a process in place to support the transition planning of pediatric patients with serious chronic illnesses, the patient will often experience increased health services utilization and costs associated with emergency room visits and unnecessary hospitalizations due to gaps in care. In 2015, there were three areas of focus identified to create “a safer and lower cost transition to adult care: (1) building and supporting self-management during the critical transition, (2) engaged care coordinator, and (3) providing checklist-driven services during the transition.” Additional needs identified to help support the transition of pediatric to adult care include improved communication, improved care coordination, empowering the pediatric patient while engaging the patient and family and addressing insurance changes. Y. Yakas, et al., Better Health, less spending: Redesigning the transition from pediatric to adult health care for youth with chronic illness, Healthcare (2015), http://dx.doi.org/10.1016/j.hc.2015.09.001

What have we seen in the hemophilia community around transition?

ATHN and The Dartmouth Institute Microsystem Academy co-developed a quality improvement program that introduced a model to cultivate improvement capacity at the front line of care in HTCs. Central to the HTC transition of care improvement is the “Transition” website that has implementation guidelines, sample forms, measurement tools, resources and recommendations all of which have been validated and tested in clinical settings. (www.gottransition.org)

GottTransition identifies three top transition-of-care needs:

1. Improving care coordination
2. Improving communication
3. Identifying appropriate providers

The Six Core Elements of Health Care Transition 2.0 define the basic components of health care transition support and the corresponding sample tools provide tested methods for integrating young adults into adult care systems. These transition resources are consistent with the AAP/AACAP Clinical Report on Transition.

Pediatric Setting

1. Transition Policy
2. Transition Youth Registry
3. Transition Preparation
4. Planning
5. Transfer of Care
6. Transfer Completion

Adult Setting

1. Young Adult Privacy and Consent Policy
2. Young Adult Registry
3. Transition Preparation
4. Transition Planning
5. Transition and Transfer of Care
6. Transition Completion

HTC teams, with support from the coaches, identified self-management of care as a priority in preparing their patients for transition. As the teams began developing the plan for PDSA cycles, several themes came out of their work including: (1) enhancing communication with the patient, (2) educating the patient on the importance of self-management, (3) identifying proactively changes or gaps in insurance coverage and (4) developing age-specific goals or milestones of the patient to gauge readiness for transition.

How can we adapt the recommendations and what have we learned in the early stages to help us prepare for the future and to make the care of people with bleeding disorders even better? “Got Transition” recommends using a quality improvement approach to adapt the six core elements. This Action Guide tools and processes help achieve this recommendation. Their recommendations suggest creating a collaborative pediatric and adult team that could include physicians, nurse practitioners, physician assistants, nurses, social workers, care coordinators, medical assistants, administrative staff, IT staff and young adult/young adults and families to implement the six core elements. Leadership support from the practice, plan or academic department is critical as well.

Some key learning points include:

1. This Action Guide offers a foundational understanding of the individual microsystem (HTC) through assessment of current practice, processes, structures and outcomes, to inform improvement within that HTC.
2. Identifying transition themes among the HTCs supports shared learning among the ATHN community and will support sustainable improvement efforts across the United States.
3. Developing improvement capacities and sharing the “best practices” created by the HTCs will have a larger impact on the national metrics through dissemination of these best practices.

The HTC community will continue to learn and share valuable lessons, tools and resources to reach the Healthy People 2020 goal of pediatric-to-adult health care transition planning to 45.3% by 2020.
Best HTC, Happy Medical Center... making the best care even better

Aim: Improve the ability of 20-year-olds to engage in self-management of their healthcare

Specific Aim: Increase the number of patients aged 13-22 that receive education on self-management of their bleeding disorder from 15% to 65% by September 1, 2016.

Team Members:
- Sue White, MD
- Elizabeth Watson, APRN
- Andrea Clark, RN
- Rick Smith, IT
- Evelyn Williams, MA

Measurement:
- Number of patients with hemophilia aged 13 to 22 years seen at the Best HTC: 82
- Number of staff trained with the education tool: 12
- Number of patients seen since education tool implemented: 36
- Number of patients eligible to educate since tool implemented: 14
- Number of patients seen and educated since tool implemented: 10

Improvement/Changes:

PDSA Cycle 1
- Display a new educational program to prepare people with bleeding disorders to anticipate and be educated on self-care before the age of 18.

PDSA Cycle 2

PDSA Cycle 3
- Design and test implementation of the education program within the clinic flow of bleeding disorder appointment including who will teach what content and how people with bleeding disorders will “teach back”.

PDSA Cycle 4
- Provide educational materials and role-play transition related scenarios based on age (e.g. talking to a friend about not being able to play contact sports at recess, ordering and obtaining factor, discussions with roommates about storing and maintaining a supply of factor in a dorm room or apartment).

TIMELINE

December 2015
- Began the Dartmouth Improvement Program
- Reviewed HTC data and ATHN dataset

January 2016
- Established regular team meetings (day, time, and place)
- Began identifying and collecting the SPI

February 2016
- Attended on-site Dartmouth Improvement Program learning session
- Finalized a draft of the SPI
- Met with larger HTC team to review drafts of theme, global aim and flowchart of current transition processes

March 2016
- Created specific aim and cause-and-effect diagram (fishbone) of opportunities to make improvements
- Specific Aim: Assess and educate self-management
- Decided to focus on change idea of a new educational program to prepare people with bleeding disorders to anticipate and be educated and engage in self-management of care before the age of 18.

April 2016
- Created a plan to assess and document knowledge and education of self-management of care for people with bleeding disorders starting at age 13.
- Developed the documentation tool for knowledge and education assessment.
- Collected data about number of people with bleeding disorders who had knowledge and education and those who did not.

May 2016
- Designed and tested new education program during the clinic flow of bleeding disorder appointments. Included who will teach what content and how people with bleeding disorders will “teach back”.

June 2016
- Provide educational materials and role-play transition related scenarios based on age (e.g. talking to a friend about not being able to play contact sports at recess, ordering and obtaining factor, discussions with roommates about storing and maintaining a supply of factor in a dorm room or apartment).

Measures:
- Number of patients of the age 13 to 22 years who follow up with a pediatric hematologist: 62
- Number of patients who have not received education about transition: 51
- The percent of patients per clinic who receive education about transition: 75%
- The percent of patients per clinic who demonstrate understanding of the information presented on transition: 0%
- The percent of patients who transition by the age of 22 years (reported monthly): 2%

NEXT STEPS:
1. Analyze data related to education delivered in clinic during annual comprehensive visits.
2. Re-evaluate and modify the education tool.
3. Follow evidence-based education milestones for other patient education programs, such as learning how to self-infuse factor.
4. Develop a plan to have the leadership group at camp present on the changes made in clinic and how they feel about transition readiness.

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Adapted American Thrombosis and Hemostasis Network (ATHN), June 2016

ACTION GUIDE FOR IMPROVING CARE FOR PEOPLE WITH BLEEDING DISORDERS

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Adapted American Thrombosis and Hemostasis Network (ATHN), June 2016
Framework Patient and Family Involvement in an HTC*

The following represents a framework for ways to think about including patients and families in HTC work. Overall, the table is divided into different levels of patient and family involvement. The suggestions build on each other, i.e., the ways in which patients, families and/or staff might prepare within one level assumes the preparation included at all previous levels as well as that particular level. Examples of specific patient or family responsibilities are listed at each level. These lists are not comprehensive, but examples of what patients or family members responsibilities might be.

<table>
<thead>
<tr>
<th>Patient/Family Roles</th>
<th>Patient/Family Responsibilities</th>
<th>Staff/Healthcare Provider Responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients or Families as Participants</strong></td>
<td><strong>Patient/Family Responsibilities</strong></td>
<td><strong>Preparation/Compensation</strong></td>
</tr>
<tr>
<td>Family perceptions of care and quality are elicited and used in shaping improvement initiatives.</td>
<td>Responsibilities will depend on level of involvement of the advisory board.</td>
<td></td>
</tr>
<tr>
<td>Data/information from families is used in measuring improvement.</td>
<td>Members of task force</td>
<td></td>
</tr>
<tr>
<td>Responsibilities end when their input is received unless they are asked to provide feedback on the interpretation of the data.</td>
<td>Members of committee</td>
<td></td>
</tr>
<tr>
<td>Review and give feedback related to materials developed specifically for patients or families, e.g., educational materials.</td>
<td>Patients or families serve on advisory boards for the quality improvement team.</td>
<td></td>
</tr>
<tr>
<td>Provide suggestions for improvement in writing as appropriate.</td>
<td>Responsibilities will depend on level of involvement of the advisory board.</td>
<td></td>
</tr>
<tr>
<td>Respond to surveys/questionnaires</td>
<td>If the advisory board is used to review policies, programs and evaluation methods after staff has written them, there are few opportunities for teamwork.</td>
<td></td>
</tr>
<tr>
<td><strong>Patients or Families as Advisory Board Members</strong></td>
<td><strong>Patient/Family Responsibilities</strong></td>
<td><strong>Preparation/Compensation</strong></td>
</tr>
<tr>
<td>Active task force committee members</td>
<td>Responsibilities will depend on level of involvement of the advisory board.</td>
<td></td>
</tr>
<tr>
<td>Faculty for staff education</td>
<td>Members of the committee.</td>
<td></td>
</tr>
<tr>
<td>Participants at collaborative meetings/conferences</td>
<td>Patients or families serve on advisory boards for the quality improvement team.</td>
<td></td>
</tr>
<tr>
<td>Mentors for others in work (patients, families or staff)</td>
<td>Responsibilities will depend on level of involvement of the advisory board.</td>
<td></td>
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<tr>
<td>Trainers for other patients or families involved</td>
<td>If the advisory board assists in the planning, implementation and evaluation of improvement projects, education materials, etc., then its responsibilities will be much greater and they will be viewed as more of a partner than advisor/reviewer.</td>
<td></td>
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<tr>
<td>Orientation of staff</td>
<td><strong>Preparation:</strong></td>
<td></td>
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<tr>
<td>Work closely with the quality improvement team</td>
<td>The most effective patient/family advisory boards have established means for recruitment, selection, membership requirements and setting bylaws, as well as ongoing strategic planning and activities.</td>
<td></td>
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</tbody>
</table>

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*For more information on patient and family involvement and creating an advisory council, visit www.ethn.org or the Institute for Family Centered Care website at www.familycenteredcare.org

*Notes are on page 50.
### Patient/Family Roles

- Facilitator
- Content expert
- Author
- Hospital/HTC employee

### Patient/Family Responsibilities

- A high level of involvement by patient and family
- Adequate skills and knowledge are required.
- Previous work/education in focused content (e.g., QI, healthcare) is very valuable.
- Consider community leadership experiences when choosing members to bring a different perspective and an awareness of other community needs.
- Experiences serving in any of the previously outlined roles may provide the necessary knowledge without professional or educational experience.

### Staff/Healthcare Provider Responsibilities

- Preparation/Compensation

**PREPARATION:**

- The task role requires all of the preparation included in all previous levels of involvement as well as additional preparation related to how to effectively collaborate with HTC/hospital leaders/administration.
- Supervision and evaluation of those involved should be formalized.
- Consider appointing patients and/or families as HTC/hospital staff because of the requirements, commitment and role expectations of the co-leaders.
- Intensive training and support for patients, families, and staff who participate at this level should be developed. Consider participation in retreats, on-site coaching, even off-site training and evaluation.

**COMPENSATION:**

- Determine how staff, patients and families will be compensated and provided the means to participate at meetings. Consider reimbursement for time and travel. Don’t forget to plan for other issues such as childcare, transportation costs, parking and meals.

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### Patient/Family Involvement Beyond the HTC*

There are countless ways that patients and families can participate in care. They can serve as advisors help with orientation of staff, education, quality improvement and in making connections with others. Some are formal and ongoing, others are limited and informal. At other times, it may be important to seek patients’ and families’ input on one specific issue. All are necessary to ensure that healthcare is truly responsive to the needs, priorities, goals and values of people with bleeding disorders and their families. Below is a list of some of the ways that patients and families can be involved in your HTC care. You can find more ideas and tools at www.athn.org and www.clinicalmicrosystem.org.

#### Education

- Have patients and families involved in planning, developing and/or revising educational materials.
- Involve patients and families in the development of center’s Web site.
- Ask patients and families to assist in translating patient information materials, e.g., into another language or making information understandable to others.
- Have families and patients involved in planning, developing and presenting at center’s Family Education Day.

#### Quality Improvement

- Include patient and family in benchmarking visits to other programs.
- Get their idea of what can be improved at your care center.
- Develop, with patients and families, a consumer satisfaction survey and involve them in developing the responses to problems and identify issues, i.e., start with the satisfaction survey in “Assess Your HTC” (pg. 12).
- Keep suggestion forms in waiting rooms, so patients and families can record their ideas. Allow opportunity for suggestions to be submitted anonymously either in the HTC or by mail if desired.

#### Orientation

- Invite patients or families to present at staff orientation and in-service programs.
- Topic such as:
  - Care needs of the patient/family
  - Infection control
  - Discuss snacks and nutritional needs inpatient and outpatient

- Ask patients or families to host a dinner for a professional-in-training.
- New residents, fellows, medical students
- New nurses, therapists, social workers – both inpatient and outpatient

- Have patient or family orient new families to care center —e.g., moved to the center or transitioned from pediatric to adult or newly diagnosed.

#### Making Connections

- Develop a newsletter about care center happenings — written and produced by patients/families.
- Hold a monthly/regular family/staff coffee hour.
- Create peer mentor or family liaison positions, e.g., for newly diagnosed, first hospitalization.

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### Selected References

- Blaylock B, Ahmann E, Johnson BH. Creating Patient and Family Faculty Programs. Bethesda, MD: Institute for Family-Centered Care; 2002.
- Dillon AD, Parents Partners: Creative Focus on Medical Home Improvement Teams. Greenfield, NTL: Center for Medical Home Improvement; 2010.

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### Advisory Council

- Create an advisory council with patients and families to provide input and direction to HTC work, e.g., QI activities, educational materials, support network.
- Have a patient/family task force that reviews suggestions or is a contact for others for suggestions/issues/comments. This task force works closely with the professional care providers to make change happen.
- Appoint patients and families to task forces and work groups related to HTC flow, quality improvement, infection control processes, renovations when occurring, admitting procedures, discharge planning, patient safety, pain management and other continuous quality improvement endeavors.
- Convene focus groups of patients and families as specific issues arise. Have the task group members serve for a specific amount of time.

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Adapted American Thrombosis and Hemostasis Network (ATHN), June 2016

National Hemophilia Program Coordinating Center Action Guide for Improving Care for People with Bleeding Disorders

Common High Yield Wastes:
- Exams not stocked or standardized—missing supplies or equipment
- Too many appointment types which create chaos in scheduling
- Poor communication amongst the providers and support staff about clinic operations and patient needs
- Missing information or chart for patient visit
- Confusing messaging system
- High prescription renewal request via phone
- Staff frustrated in roles and unable to see new ways to function
- Appointment schedule has limited or non-existent follow-up calls, no day appointment slots
- Missed disease-specific/preventive interventions and tracking
- Poor communication and interactions between members
- Patient expectation of visit not met, resulting in phone calls and repeat visits

Assessing Your Practice Discoveries and Actions

Recommended Method to Reduce Waste

- Create Standard Inventory supplies for all exam rooms.
- Design process for regular stocking of exam rooms with accountable person.
- Standardize and utilize all exam rooms.
- Reduce appointment types to 2-4.
- Utilize standard building block to create flexibility in schedule.
- Conduct daily morning “huddles” to provide a forum to review the schedule, anticipate needs of patients, plan supplies/information needed for a productive interaction between patient and provider.
- Review patient’s chart before the patient arrives—review the day before to ensure information and test results are available to support the patient.
- Review current roles and functions using activity survey sheets.
- Match talent, education, training, licensure to function.
- Evaluate the use of protocols and guidelines to provide advice for homecare.
- Anticipate patient needs.
- Create “reminder” systems in office, e.g. postits, screen savers.
- Standardize the information support staff obtains from patients before the provider visit—include prescription information and needs.
- Evaluate follow-up appointments and return visit necessity. Extend intervals of standard follow-up visits. Consider RN visits.
- Evaluate the use of protocols and guidelines to provide advice for homecare—www.icd.org.
- Utilize the flow sheets to track preventative activities and disease-specific interventions.
- Utilize “stickers” on charts to alert staff to preventative/disease-specific needs.
- Hold weekly staff meetings to review practice outcomes, staff concerns, improvement opportunities.
- Hold weekly meetings on a regular, day time and place.
- Evaluate patient at time of visit if their needs were met.
- Automated reminder telephone calls are not always well received by patients.

Traps to Avoid

- Don’t assume rooms are stocked regularly—track and measure.
- Providers will only use “their” own rooms.
- Providers cannot agree on standard supplies; suggest “testing.”
- Don’t set schedules of certain types.
- Use one time (e.g. 10-15 minute “building blocks”)
- People not showing up for scheduled huddles. Gain support of providers who are interested, test ideas and measure results.
- Huddles last longer than 15 minutes, use a work sheet to guide huddle.
- Avoid doing chart review when patient is present.
- If you have computerized test results, don’t print the results.
- Providers want their “own” way—adding to confusion to support staff and decreases ability for cross coverage.
- Content of message can’t be agreed upon—use test something.
- Doesn’t need to be the RN—Medical assistants can obtain this information.
- Be sure to focus on talent, training and scope of practice not individual people.
- Don’t set a certain number of same day appointments without matching variations throughout the year.
- Be alert to creating a system for multiple diseases and not have many stickers and many registries.
- Hold weekly meetings on a regular, day time and place. Do not cancel—make the meeting a new habit.
- Hold annual meetings a day appointment, day time and place.
- Consider improving same day access.
- Use reminders to question patient about needs being met.

Glossary

SP Framework: The SP framework is thought of as a structured and organized method of inquiring into the anatomy of an HCT Action plans: refers to “next steps” and “to do” with clearly identified accountable and measurable people and time line.

Agenda: Plan for meeting with roles, timed segments and clear objectives.

Aim (Global): Goal of improvement with clear boundaries, reasons to improve and projected results.

Aim (Specific): Detailed measurable goal with specific dates and specific time line.

ATN: American Thrombosis and Hemostasis Network

Balanced Set of Metrics: Set of measures that include data from a variety of perspectives.

Benchmarking: Search for best practices that consistently produce best-in-the-world results.

Continuous Quality Improvement (CQI): Process of continually measuring an organization’s critical business processes and results against leaders anywhere in the world to gain information that will help the organization take action to improve its performance. Steps include planning the study, collecting information, analyzing results and implementing improvements.

Change Concepts: Family of change ideas.

Change ideas: Specific action ideas to kit in a process that result in a change.

Clinical Microsystem: The place where patients, families and care teams meet. A small group of people who work together on a regular basis to provide care to discrete subpopulations of patients. Frontline clinical units including patients, families, professionals, data and information with common purpose with shared business and clinical aims. It produces performance outcomes.

Conceptual Definition: The conceptual definition tells what metrics will be included in the follow-up, who will collect the data.

Continuous Quality Improvement: Continuous quality improvement is a preventative process to continuously improve and learn how current processes and systems are performing.

Contributing Units: Multiple clinical units a patient travels through for an episode of care.

Control Chart: Graphical format for displaying information that show data points in the order in which they occurred with statistically calculated upper and lower natural process limits.

Core and Supporting Processes: Core processes are the routine activities that are essential to functioning within a system of care. Supporting processes intermitently provide care and services that are essential to functioning within a system of care. Supporting processes.

Data Owner: Accountable person to oversee specific data collection and display.

Data Wall: Designated space to display measures and improvement process over time. Utilizes daily and weekly to review current values and target values to assist progress toward an aim defined on the structure or anatomy of a clinical microsystem. Purpose, Patients, Professional, Processes and Patterns.

Driver Diagram: The driver diagram is a tool to organize and track multiple improvements to achieve the “Global Aim” of the “Theme” of improvement. It also shows the relationships between the theme, global aim, specific aims, measures and PDSA cycles in a quick visual way.

Family of change ideas.

FMEA: Failure Mode and Effects Analysis.

Gantt Chart: A chart in which a series of horizontal lines shows the amount of work done or production completed in certain periods of time in relation to the amount planned for those periods.

HCV: Hepatitis C virus.

HCT: Hemophilia Treatment Center

Huddle: Short meeting, no longer than 10 minutes, of a clinical team to review care, anticipate and needs and review any improvement progress.

ITI: Immune Tolerance Initiatives

MASAC: Medical and Scientific Advisory Council

Metrics That Matter: Key measures specific to diagnostic group or system of care. Can include organizational goals, professional standards and national benchmarks, e.g. hemophilia outcome measures such as joint bleeds, days lost from work/school.

NPCC: National Hemophilia Program Coordinating Center

Operational Definition: The operational definition tells how metrics will be measured (e.g. time elapsed from patient appointment time until patient enters exam room in minutes).

PDSA: Plan-Do-Study-Act Cycle: Schema for continuous quality improvement originally developed by Walter Andrew Shewhart and made popular by W. Edwards Deming, who ascribed inherent variation in processes to chance and intermittent variation to assignable causes. The PDSA cycle is a four-part method for discovering and correcting assignable causes to improve the quality of processes.

Pilot Test: Small scale test of a proposed solution.

Playbook: Collection of process maps to standardize care and processes that all staff are aware of and follow.

Point of Service: Exact real time of interacting with patients to deliver care or services.

Process Maps: Chronological graphical displays of steps in a process. Different types of process maps include flowcharts, deployment charts and value stream mapping.

Processes: Any activity that is a series of steps with a beginning and ending in products or outcomes.

Professionals: Members of the frontline team including administrative staff, nurses, therapists, dietitians, etc.

Purpose: Common aim and reason to come together to strive and be accountable for achieving.

Quality Assurance: Quality assurance is an inspection process to ensure compliance with standards. QA has a “punitive” approach and identifies outliers through a required inspection process.

Redesign: Methodical process of opening insight into current states, exploring best knowledge practices, and creating a new process.

Rework: Work to redo or correct what was not done right the first time.

SDA: Standardize Do-Study-Act Cycles: Steps taken when one or more PDSA cycles have been successfully tested to determine that original aim is reached.

Tests of Change: Short meetings, no longer than 10 minutes, of a clinical team to review care, anticipate and needs and review any improvement progress.

Touchpoints: Digital display used to document and communicate a team’s improvement journey. Includes aims, PDSA’s, team members, measured outcomes and next steps.

Supplier: Person, business or other entity (such as another department, individual or unit) responsible for an input to a process.