



Action Guide for 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.

Clinical
Microsystems

A PATH TO HEALTHCARE EXCELLENCE

The place where
patients, families,
and care teams meet



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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.

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 data, 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 and clotting 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.

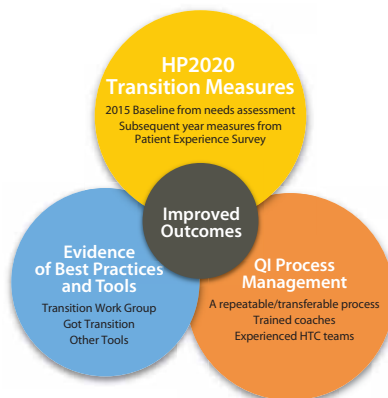
THE NATIONAL HEMOPHILIA COORDINATING CENTER

The National Hemophilia Program Coordinating Center (NHPCC) was funded through ATHN by the federal Health Resources and Services Administration (HRSA) in 2012 to create value on 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 going one step further. It is coordinating and supporting a national quality improvement (QI) effort to ensure that the science of quality improvement further improves care and outcomes for individuals with bleeding disorders. The national strategy for QI has three interdependent components:

- ◆ *Collecting national metrics focused on national priority areas*
- ◆ *Identifying evidence of best practices and assembling tools for support, and*
- ◆ *Managing QI at the HTC level with trained coaches and a repeatable, transferable improvement process.*

Key to the NHPCC strategy is the leveraging of ATHN Clinical Manager and the ATHN dataset to inform improvement activities that result in improved care and outcomes for patients.



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 to address this priority, 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. The national measure will be the Health People 2020 DH5 indicator: "Increase the proportion of youth with special healthcare needs whose provider has discussed transition of care planning from pediatric to adult healthcare."

This measure was first collected 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 improvements over the coming years.

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 (Batalden & Davidoff, 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 that 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. QA has a "punitive" approach and identifies outliers through a required inspection process. In contrast, CQI is a preventive, proactive process to continuously improve and learn how current **processes** and systems are performing. Everyone in the delivery of care and services including patients and families can work together to apply improvement sciences in the daily work of providing care, constantly learning to achieve improved patient outcomes, system performance and professional development.

Making the best care even better - striving for exemplary care and achieving the goal of supporting quality care, research, advocacy and clinical outcomes - will take a concerted commitment and a multi-faceted approach. NHPCC and ATHN are committed to supporting the improvement of care for patients with bleeding and clotting disorders. This Action Guide is one of the resources to enable achieving the goals.

References

Batalden, P.B. & Davidoff F. 2007. "What is "quality improvement" and how can it transform healthcare?" Qual Saf Healthcare. February; 16(1): 2-3

Parand A, et al. 2014. BMJ Open 2014;4:e005055. doi:10.1136/bmjopen-2014-005055

* Words that appear in **bold and italic** are defined in the glossary, page 49.

Hemophilia Treatment Center Clinical Microsystems

Strategies for improving “*The place where patients, families and care teams meet.*”

Assessing, Diagnosing and Treating Your HTC an Overview

People with bleeding disorders have many interdisciplinary 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 contributing unit and the “hand-offs” between **contributing units**. Microsystems also include patients, families, staff, **processes**, technology and recurring **patterns** of information, behavior and results. The microsystem is where

- ◆ Care is made
- ◆ Quality, safety, reliability, efficiency and innovation are made
- ◆ Staff morale and patient satisfaction are made

Clinical microsystems are the frontline units that provide 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.”

Clinical microsystems (the places where care is delivered within home care, an **HTC** or an inpatient unit) are the building blocks that form the **HTC** system of care.

For quality of care to be improved and to be sustained, work must continually be done within and across the respective microsystems. Therefore, all healthcare **professionals**—this is inclusive of everyone working within the microsystem—have two jobs. Job 1 is to provide high-quality, safe, patient-and family-centered care. Job 2 is to continually work with patients and families to improve care.

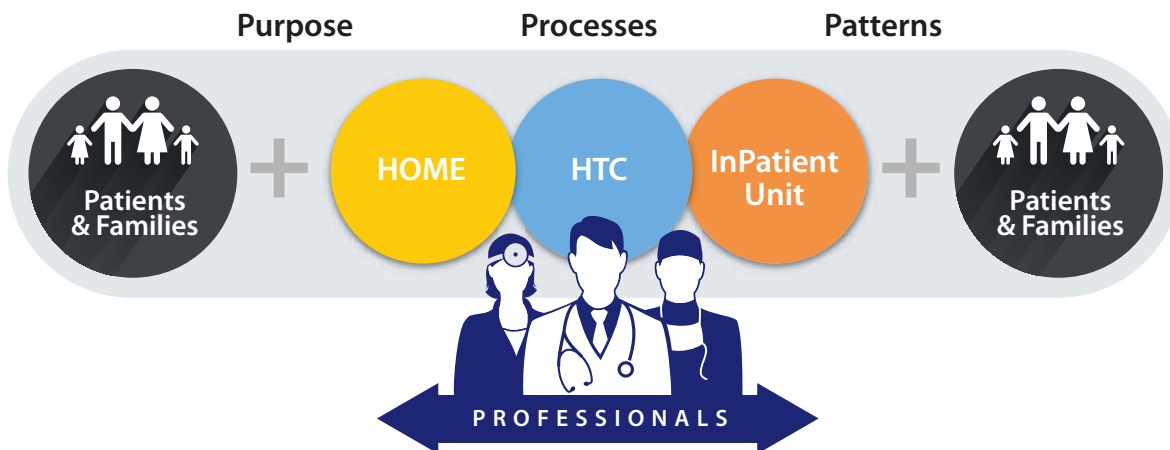
To effectively accomplish these two jobs, improvement efforts must be blended into the everyday activities of everyone. Absent this dedicated effort to continually improve how both work is done and care is provided, optimal quality will not be achieved and the unit, as a microsystem, will not perform at its highest level.

This action guide provides the tools, methods and discipline that will help staff, patients and families achieve the improvement goals in the HTC **clinical microsystem**. The tools in this action guide present a tested approach to provide effective collaboration of people with bleeding disorders and their families, healthcare teams and senior leaders, in conjunction with an effective use of technology and performance data within the **clinical microsystem**.

To learn more about Microsystems, refer to QuIRK #2: Clinical Microsystem and Mesosystem Fundamentals.

IMPORTANT REMINDER: These tools are intended to provide an organizing structure that can be adapted to local settings.

HTC SYSTEM OF CARE



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 worklife 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. 38 to get a better sense of how a microsystem was able to improve.

💧 STEP 1: ORGANIZE A “Lead Improvement Team”

Successful sustainable change requires the commitment and active engagement of all

INSTITUTE OF MEDICINE'S SIX AIMS

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 waits 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.

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, hematologists, nurse coordinators, dietitians, physical therapists, social workers and clerical 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.

- ▶ Use effective meeting skills and timed **agendas** to ensure productive meetings.
- ▶ Hold “**huddles**” before your **HTC** starts to review recent activities, plan for the day and subsequent days in a proactive manner (see pg. 33).
- ▶ Hold weekly Lead Improvement Team meetings to maintain focus, make plans and oversee improvement work.
- ▶ Hold monthly “town hall” meetings to engage and inform patients and families as well as all members of the center.
- ▶ Explore creative ways for the Lead Improvement Team to communicate and keep all staff engaged in the improvement work. Develop strategies for communicating with patient and family advisors. Use e-mail, newsletters, listservs, paper, visual displays, communication boards and conversation.
- ▶ Actively engage people with bleeding disorders and families with the lead improvement team. See pg. 44-46 and **ATHN** (www.athn.org) to learn more about engaging people with bleeding disorders and families.

🔥 STEP 2: DO THE ASSESSMENT

Review the action guide contents and create a timeline for the assessment process using the worksheet on pg. 10. 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, **Professionals**, **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. 29. 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

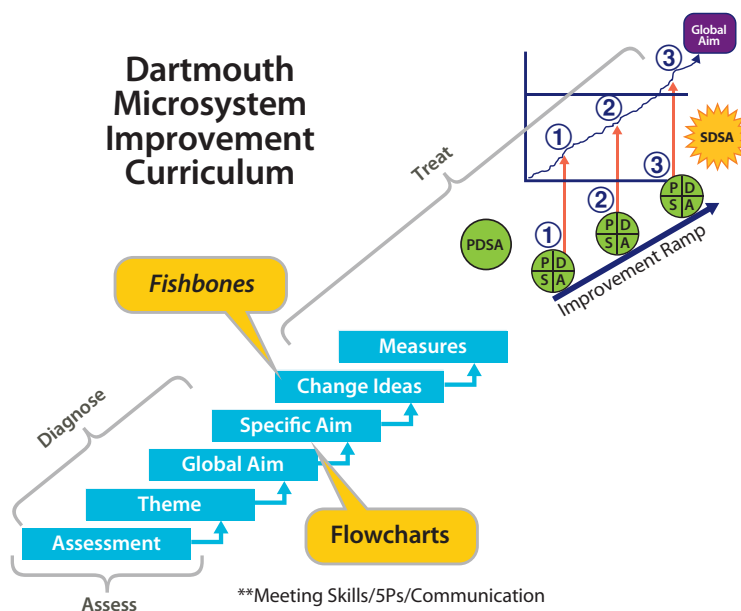
The Lead Improvement Team must analyze the 5Ps assessments, Registry data from www.athn.org and www.clinicalmicrosystem.org, and **Metrics That Matter** worksheets and identify a “theme” for improvement. A theme may be selected using the Institute of Medicine’s Six Aims (see page 6). Opportunities for improvement may come from within your own microsystem, your organization’s strategic goals or may come from outside your microsystem, such as NHPCC. 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** statement 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. 35 and **SDSA (standardize-do-study-act)** pg. 36 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.



STEP 1

Form Your Lead Improvement Team

Which Senior Leaders will “sponsor” HTC improvement?

	Pediatric Program	Adult Program
Hospital Administrator		
Division Chief		
Department Chair		
Site Contact		

◆ 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?

	Pediatric Program	Adult Program
MD		
HTC Coordinator		
RN Coordinator		
Social Worker		
RN		
Physical Therapist		
Dietitian		
Medical Assistant/Technician		
Administrative Staff		
Pharmacist		
NP/Advanced Practice Registered Nurse/PA		
Patient/Family (1-2 Advisors)		
Genetic Counselor		
Dental Hygienist		
Clinical Research Coordinator		

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

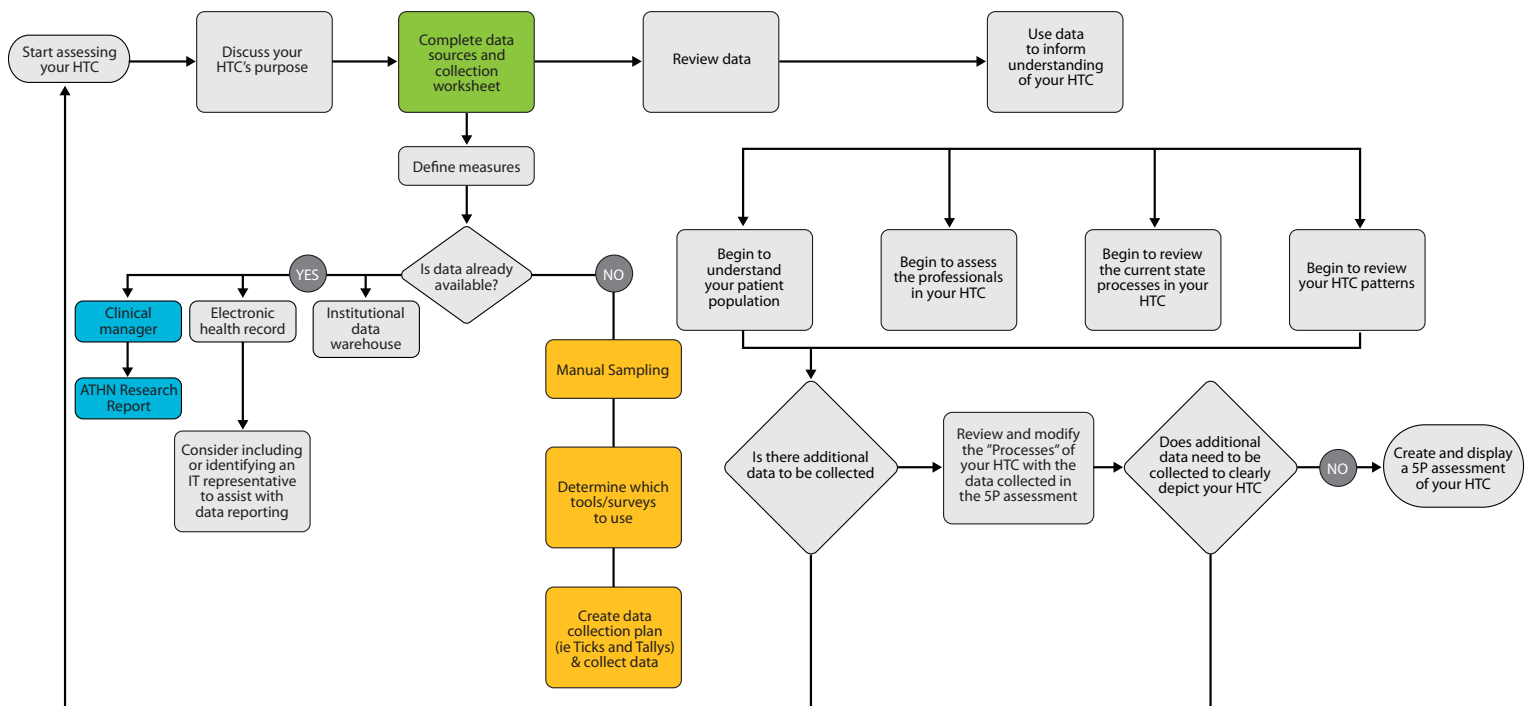
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List communication strategies to share information with all staff of the involved units and patients and families. Identify who will oversee the various communications, for example, newsletters, bulletin boards, e-mails and all staff meetings.

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 5P framework. The 5P 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 5P flowchart maps the path forward to explore the 5Ps in an organized fashion.



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- ◆ 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 5P Flowchart on pg. 9 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.

HTC MICROSYSTEM ASSESSMENT OF DATA SOURCES AND DATA COLLECTION

Type of Data/Pages	Data Source/Data Collection Action	Date/Owner
Know Your Patients (see pages 11-15)		
Estimated Age Distribution of Patients	ATHN Clinical Manager Report	
Patient Demographics	ATHN Clinical Manager Report	
Health Outcomes		
Top 5 Diagnoses	ATHN Clinical Manager Report	
Top 5 Services Used - referrals		
Percent of patients seen annually in comp HTC	ATHN Clinical Manager Report	
ER Visit Rate		
Patient Satisfaction Scores - Access		
Patient Population Census - Overall	ATHN Clinical Manager Report	
Through the Eyes of the Patient		
Know Your Professionals (see pages 16-21)		
Current Staff		
On-Call Staff		
Supporting Departments		
Staff Satisfaction		
Personal Skills Assessment		
Activity Survey		
Know Your Processes (see pages 22-26)		
Create Flow Charts of Routine Processes		
Patient Cycle Time Tool		
Core and Supporting Processes		
The "Hand-Offs"		
Know Your Patterns (see pages 27-28)		
Telephone Tracking Log		
Unplanned Activity Tracking		
Most Significant Patterns		
Successful Change		
Most Proud of		
Financial Status / 340B Reporting		
Know Your Outcomes/Measures/Metrics that Matter (see page 29-30)		
Inhibitor Rate	HTC-Level Quality Metrics from ATHN	
Continuous Prophylaxis	HTC-Level Quality Metrics from ATHN	
Comp. HTC Attendance	HTC-Level Quality Metrics from ATHN	
BMI	HTC-Level Quality Metrics from ATHN	
Bleed-related days lost from work/school	HTC-Level Quality Metrics from ATHN	

Reference Measures:

STEP 2

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.

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.

HTC PROFILE

Patient Demographics	Percent (%)
0 - 2 years	
3 - 12 years	
13 - 18 years	
19 - 29 years	
30 - 49 years	
50 - 74 years	
75+ years	
% Males	
% Females	
% of those with severe hemophilia on continuous prophylaxis	

List Your Top 5 Diagnoses	
1.	
2.	
3.	
4.	
5.	

Access/Patient Satisfaction Scores	% Excellent
Experience via phone	
Length of time to get appointment	
Saw who I wanted to see	
Personal manner	
Time spent with person you saw	

List Your Top 5 Other Services Used		
	Services	What other services are used?
1.		
2.		
3.		
4.		
5.		

Patient Population Census	#	Y/N
Do these numbers change by the season? (Y/N)		
# Pts seen in a day		
# Pts seen in the past week		
Acute visit		
Follow-up visit		
Comprehensive care clinic visit		
# New Pts in the past month		
# Encounters per provider per year		
# Comprehensive care clinic visits		
# Telephone consults		
per day		
per week		
per month		
per year		

Health Outcomes
Annual bleed rate
BMI
Joint Score
% Pts with inhibitor
School/work days missed due to bleeding disorder
Comprehensive care clinic visits
% of those with severe hemophilia on prophylaxis

Out-of-HTC Visits	
Emergency Room Visit Rate	
Direct Hospital Admissions	

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?

Patients

The HRSA cooperative agreement grant requires that the regional grantees and NHPCC report on five HP2020 measures annually. One of these HP2020 measures is to “Increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning.” The baseline measure was reported in the Patient Needs Assessment conducted by the NHPCC in 2013. Annual follow-up of the HP2020 transition measure is collected through the Patient Experience Survey. All **HTCs** are expected to administer this survey annually until 2020 at comprehensive care visits. The survey is completed if by the parent if the child is under 17 years and by the patient if the young adult is 18-22 years. **HTC** level data from this survey is available through the regional core centers or the NHPCC. The survey can be downloaded from the **ATHN** website www.athn.org and www.clinicalmicrosystem.org.

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 12-22 years old.

Please complete the questions below:

Date

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 ☐ Platelet disorder
☐ 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

The following questions are about your child's experience in this bleeding disorders clinic:

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 your child's healthcare needs as they relate to their bleeding disorder have been helpful?

- ☐ 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

HTC 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.

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

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?

☐ Would choose this HTC

☐ Might prefer someplace else

☐ Not sure

13. "I am delighted with everything about this HTC because my expectations for service and quality of care are exceeded."

☐ Agree

☐ Disagree

☐ Not sure

14. In the past 12 months, how many times have you or the patient gone to the emergency room for care?

☐ None

☐ One time

☐ Two times

☐ Three or more times

15. In the past 12 months, was it always easy to get a referral to other specialists when needed?

☐ Yes

☐ No

☐ Does not apply to me

16. 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?

☐ Never

☐ Sometimes

☐ Frequently

17. Are you or the patient able to get to appointments when you choose?

☐ Never

☐ Sometimes

☐ Frequently

18. Is there anything our HTC can do to improve the care and services?

☐ No, everything is satisfactory

☐ Yes, some things can be improved (please specify): _____

☐ Yes, lots of things can be improved (please specify): _____

19. Did you or the patient have any good or bad surprises while receiving care?

☐ Good ☐ Bad ☐ No Surprises

Please describe: _____

20. In general, how would you rate your overall health or the health of the patient?

☐ Excellent

☐ Very Good

☐ Good

☐ Fair

☐ Poor

21. What is your age or the age of the patient?

☐ Under 18 years

☐ 18 - 25 years

☐ 26 - 35 years

☐ Over 35 years

22. What is your gender or the gender of the patient?

☐ Male

☐ 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?

☐ Yes

☐ No

☐ Maybe

Name _____

Phone _____

E-mail _____

Best time to reach you? ☐ Morning ☐ Afternoon ☐ Evening ☐ Other _____

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.

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**?

Current Staff (Enter names below totals)	FTE	HTC Days and Times					
		MON	TUES	WED	THURS	FRI	SAT
MDs – Total							
NP/Advanced Practice Registered Nurses/PAs – Total							
RN Coordinator							
RNs – Total							
Social Worker – Total							
PTs – Total							
LPN/NA/MAs – Total							
Pharmacist – Total							
Clerical Staff (e.g., receptionist, front desk staff)							
Administrative Staff – Total							
Others – Total							

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

- ◆ Your organization may conduct staff surveys that you can use instead of this survey, but be sure it is **CURRENT** data, not months old, and that you are able to capture the data from all **professionals** specific to your **HTC**.
- ◆ Creating a joyful work environment starts with a basic understanding of staff perceptions of the **HTC**. If you do not currently have a staff satisfaction survey specific to your **HTC**, you can distribute this survey to all staff. You will find a tally sheet at www.athn.org and www.clinicalmicrosystem.org to summarize your results.
- ◆ Ask all **HTC** staff to complete the staff survey. Often you can distribute this survey to any professional who spends time in your **HTC**. Set a deadline of one week and designate a place for the survey to be dropped off.

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 than 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?

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 _____		HTC _____		
Role _____		Date _____		
Clinical Competencies: Please create your list of clinical competencies and evaluate.	Want to Learn	Never Use	Occasionally	Frequently
Prophylaxis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immune Tolerance Induction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home INR Monitoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prescribed Treatment Plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Range-of-Motion Measurements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New Treatment Products	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telemedicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Healthy Lifestyles	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Risk-Reducing Behaviors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Developmental Needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Activities of Daily Living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-Advocacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-Infusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laboratory Self-Testing or Monitoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preventive Self-Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intended Effects and Potential Adverse Effects of Proposed Therapies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Information Systems (CIS): What features and functions do you use?	Want to Learn	Never Use	Occasionally	Frequently
ATHN Clinical Manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATHN Advoy/Electronic Bleeding Logs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATHNready	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Provider/On-Call Schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient Demographics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lab Results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient and Family Goals and Action Plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Review Reports/Notes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Note Templates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication Lists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insurance Status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiology	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Electronic Bleeding Records	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phone Coordination/Documentation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.	Want to Learn	Never Use	Occasionally	Frequently
Electronic Health Record Systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-mail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smart Phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dictation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Word Processing (e.g., Word)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spreadsheet (e.g., Excel)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Presentation (e.g., Power Point)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet/Intranet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Printer Access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fax	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Copier	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone System	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voice Mail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pagers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATHN Clinical Manager	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATHN Advoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ATHN Ready	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meeting and Interpersonal Skills: What skills do you currently use?	Want to Learn	Never Use	Occasionally	Frequently
Effective Meeting Skills (brainstorm/multi-vote)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Timed Agendas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Role Assignments During Meetings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Delegation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problem Solving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-mail	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smart Phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dictation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient Advocacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Improvement Skills and Knowledge: What improvement tools do you currently use?	Want to Learn	Never Use	Occasionally	Frequently
Flowcharts/Process Mapping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trend Charts (Run Charts)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Control Charts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plan-Do-Study-Act (PDSA) Improvement Model	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Standardize-Do-Study-Act (SDSA) Improvement Model	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aim Statements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fishbones	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measurement and Monitoring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surveys – Patient and Staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
STAR Relationship Mapping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient-centered and Family-centered Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Professionals

- What do you spend YOUR time doing? What is your best estimation of how much time you spend doing it? The goal is to have the right person doing the right thing at the right time. The group can discuss which activities are or are not appropriate for the individual's level of education, training and licensure.
- You can start with one group of **professionals** such as MDs, APRNs, RNs or clerical staff, assessing their activities using the Activity Survey. This estimate of who does what is intended to reveal, at a high level, where there might

be mismatches between education, training, licensure and actual activities. It is good to eventually have all roles and functions complete this survey for review and consideration. Be sure to create the same categories for each functional role. Some groups may hesitate to make time estimates; if this happens, just ask them to list their activities for the first review.

- Electronic versions, blank sheets and examples can be found at www.athn.org and www.clinicalmicrosystem.org.

ACTIVITY SURVEY SHEET

Position: MD	% of Time
Activity: See Patients in the HTC Specific Items Involved: • Review chart history • Assess/diagnose patient • Determine treatment plan	30%
Activity: Minor Procedures	9%
Activity: OR Procedures	10%
Activity: See Patients in Hospital	2%
Activity: Write Prescriptions	5%
Activity: Dictate/Document Patient Encounter Specific Items Involved: • Dictate encounter • Review transcriptions and sign off	20%
Activity: Complete Forms Specific Items Involved: • Referrals • Prior Authorizations	5%
Activity: Follow-up Phone Calls/Emails Specific Items Involved	5%
Activity: Manage Charts	5%
Activity: Evaluate Test Results Specific Items Involved: • Review results and determine next actions	5%
Activity: See Patients in Outreach Clinics	2%
Activity: Miscellaneous Specific Items Involved: • CME; attend seminars; attend meetings	2%
Total	100%

Position: RN	% of Time
Activity: Triage Patient Issues/Concerns Specific Items Involved: • Phone • Face to face	15%
Activity: Patient/Family Education Specific Items Involved:	3%
Activity: Direct Patient Care Specific Items Involved: • See patients in the HTC • Assist Provider with patients • Infusions	30%
Activity: Follow-up Phone Calls/Emails Specific Items Involved:	22%
Activity: Review and Notify Patients of Lab Results Specific Items Involved: • Normal with follow-up • Drug adjustments	5%
Activity: Complete Forms Specific Items Involved: • Referrals • Prior Authorizations	18%
Activity: Call in Prescriptions Specific Items Involved:	5%
Activity: Miscellaneous Specific Items Involved: • CME; attend seminars; attend meetings	2%
Total	100%

DIAGNOSE YOUR HTC

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.

Role: RN	Date: July 1	Day of Week: Monday	
Visit Activities	AM	PM	Total
Triage Patient Concerns			14
Family/Patient Education			7
Direct Patient Care			42
Non-Visit Activities	AM	PM	
Follow-up Phone Calls/E-mails			26
Complete Forms			17
Call in Prescriptions			16
Miscellaneous			15
Total	68	75	143

ACTIVITY SURVEY SHEET

Position: MD	% of Time
Activity: Specific Items Involved: • • •	
Activity:	
Activity:	
Activity:	
Activity:	
Activity: Specific Items Involved: • •	
Activity: Complete Forms Specific Items Involved: • •	
Activity: Specific Items Involved • •	
Activity:	
Activity: Specific Items Involved: •	
Activity:	
Activity: Specific Items Involved: •	
Activity: Specific Items Involved: •	
Activity: Specific Items Involved: •	
Activity:	
Total	100%

Position: RN	% of Time
Activity: Specific Items Involved: • •	
Activity: Specific Items Involved:	
Activity: Specific Items Involved: • • •	
Activity: Specific Items Involved:	
Activity: Specific Items Involved: • • •	
Activity: Specific Items Involved: • • •	
Activity: Specific Items Involved: • • •	
Activity: Specific Items Involved: •	
Activity: Specific Items Involved: •	
Activity: Specific Items Involved: •	
Activity:	
Total	100%

DIAGNOSE YOUR HTC

ACTIVITY OCCURRENCE (this is the printable)

What's the next step?

Insert the activities from the Activity Survey here. 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.

Role: RN	Date: July 1	Day of Week: Monday	
Visit Activities	AM	PM	Total
Non-Visit Activities	AM	PM	
Total			

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?

Do you use any of the following?

Check all that apply

- | | |
|--|---|
| <input type="checkbox"/> Phone follow-up | <input type="checkbox"/> E-mail |
| <input type="checkbox"/> Phone care management | <input type="checkbox"/> Website |
| <input type="checkbox"/> ATHN reports | <input type="checkbox"/> RN clinics |
| <input type="checkbox"/> Protocols/guidelines | <input type="checkbox"/> Conference calls with patients |
| <input type="checkbox"/> Group visits | <input type="checkbox"/> Coordination |

Appointment Types	Duration	Cycle Time	# of Exam Rooms	Comments

IDENTIFY SUPPORTING MICROSYSTEMS

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

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

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



UNKNOWN STEP OF PROCESS



PROCESS BEGINNING OR END



DECISION POINT



PROCESS FLOW DIRECTION



ACTIVITY STEP

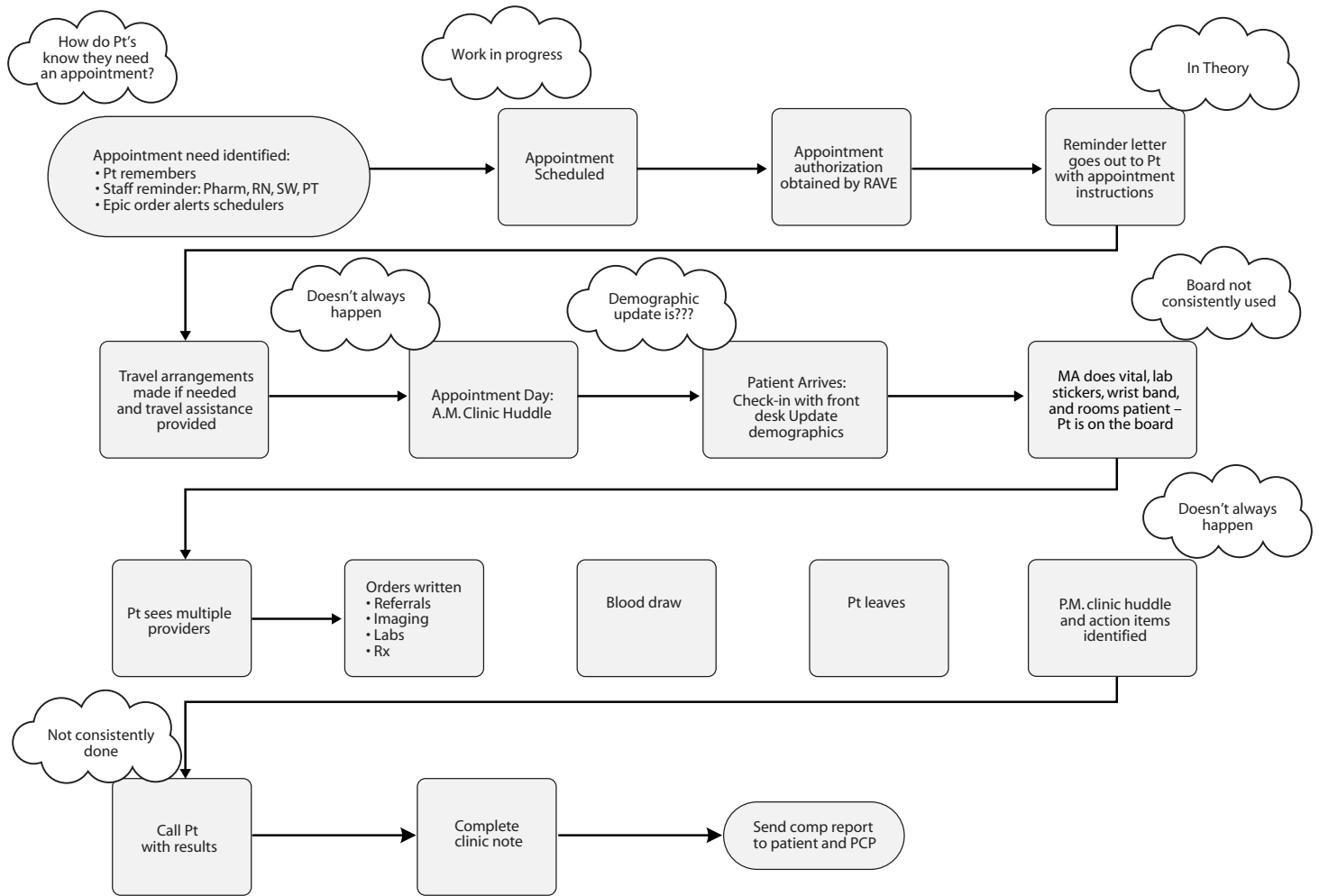


WAIT OR DELAY

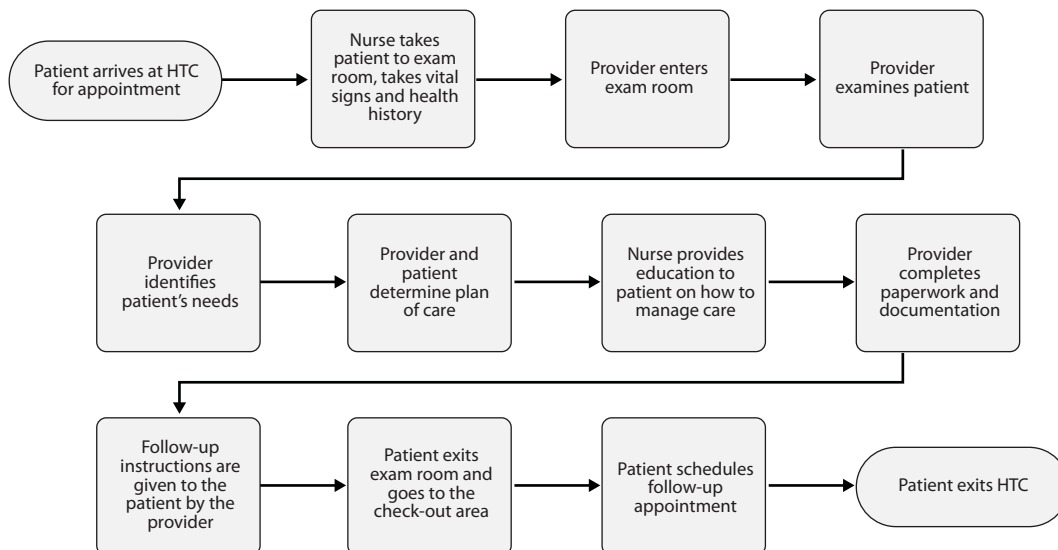


CONNECTOR (E.G. OFF PAGE)

Comprehensive Care Clinic Process Flowchart



HTC Visit Process



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 _____

TIME	
	1. Time you arrived at the HTC.
	2. Time you checked in.
	3. Time you were shown to the exam room.
	4. Time the nurse finished measurements (e.g. weight, height, b/p, temp).
	5. Time you were ready to see the first HTC team member.
	6. Note below the times the clinicians entered and left the room.

	Nurse	Social Worker	PT	Physician	Other	Other
Time In:						
Time Out:						
	Other	Other	Other	Other	Other	Other
Time In:						
Time Out:						

TIME	
	7. Time you were ready to leave the HTC.

COMMENTS:

Processes

Beginning to have all staff understand the **processes** of care and services in the practice is a key to developing a common understanding and focus for improvement. Start with the process of a patient entering your practice by using the Patient Cycle Time tool. You can assign someone to track all visits for a week to get a sample, or the **cycle time tool** can be initiated for all visits in a period with many people contributing to the collection and completion of this worksheet.

Typically, other **processes** will be uncovered to measure and you can create time tracking worksheets like this template to measure other cycle times.

HTC Patient Appointment Cycle Time	
Day: _____ Date: _____	
Scheduled Appointment Time _____ Provider(s) you are Seeing Today _____	
Time	
<input type="text"/>	1. Time you checked in.
<input type="text"/>	2. Time you sat in the waiting room.
<input type="text"/>	3. Time staff came to get you.
<input type="text"/>	4. Time staff member left you in exam room.
<input type="text"/>	5. Time first provider came in room. <input type="text" value="Provider 1"/>
<input type="text"/>	6. Time first provider left the room.
<input type="text"/>	7. Time second provider came in room. <input type="text" value="Provider 2"/>
<input type="text"/>	8. Time second provider left the room.
<input type="text"/>	9. Time third provider came in room. <input type="text" value="Provider 3"/>
<input type="text"/>	10. Time third provider left the room.
<input type="text"/>	11. Time fourth provider came in room. <input type="text" value="Provider 4"/>
<input type="text"/>	12. Time fourth provider left the room.
<input type="text"/>	13. Time you left the exam room.
<input type="text"/>	14. Time you arrived at check out.
<input type="text"/>	15. Time you left HTC.
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

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

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 people 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?

- ◆ **Patterns** are present in our daily work and we may or may not be aware of them. **Patterns** can offer hints and clues to our work that inform us of possible improvement ideas. The Unplanned Activity Tracking Card is a tool you can ask staff to carry to track **patterns** of interruptions, waits and delays in the process of providing smooth and uninterrupted patient care. Start with any group in the staff. Give each staff member a card to carry during an **HTC** day or shift to mark each time an interruption occurs when direct patient care is delayed or

- ◆ Are people with bleeding disorders and families involved? (Use www.familycenteredcare.org or www.athn.org and www.clinicalmicrosystem.org).
- ◆ What is the most significant pattern of variation?
- ◆ What have you successfully changed?
- ◆ What 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?





interrupted. The tracking cards should then be tallied by each person and within each group to review possible process and system **redesign** opportunities. Noticing **patterns** of unplanned activities can alert staff to possible improvements.

- ◆ This collection tool can be adapted for any role in the **HTC** to discover interruptions in work flow. Circles in the example indicate **processes** to further evaluate for possible improvements.

UNPLANNED ACTIVITY TRACKING CARD

Unplanned Activity Tracking	
Name:	
Date:	Time:
Place a tally mark for each occurrence of an unplanned activity	Total
Interruptions	
◆ Phone	
◆ Secretary	
◆ RN	
◆ Provider	
Hospital Admissions	
Patient Phone Calls	
Pages	
Missing Equipment	
Missing Supplies	
Missing Chart: Same-Day Patient	
Missing Chart: Patient	
Missing Test Results	
Emergent Cases	
Unexpected insurance issues	
Pharmacy Phone Calls	
Refill Requests	
Contact re: Industry studies/surveys	
Phone calls/visits from pharmaceutical companies	
Coordinating services with outside providers	
Coordinating outside procedures (planned and unplanned)	
Providing assistance to Hemostasis/Oncology department due to high pt. volumes or unplanned staffing conflicts	

EXAMPLE

Unplanned Activity Tracking	
Name:	
Date:	Time:
Place a tally mark for each occurrence of an unplanned activity	Total
Interruptions	
◆ Phone 	15
◆ Secretary	
◆ RN 	⑩
◆ Provider	
Hospital Admissions 	⑫
Patient Phone Calls	
Pages 	20
Missing Equipment	
Missing Supplies 	5
Missing Chart: Same-Day Patient	
Missing Chart: Patient 	⑩
Missing Test Results	
Emergent Cases	
Unexpected insurance issues	
Pharmacy Phone Calls	
Refill Requests	
Contact re: Industry studies/surveys	
Phone calls/visits from pharmaceutical companies	
Coordinating services with outside providers	
Coordinating outside procedures (planned and unplanned)	
Providing assistance to Hemostasis/Oncology department due to high pt. volumes or unplanned staffing conflicts	

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 clerical staff to track the telephone calls over the course of a week to find the **patterns** of each 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.

◆ 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.

HTC TELEPHONE TRACKING LOG

Week of <input type="text"/>	Day of Week <input type="text"/>		Day of Week <input type="text"/>		Week Total
	AM	PM	AM	PM	
Appointment for Today					
Total					
Appointment for Tomorrow					
Total					
Appointment for Future					
Total					
Follow-up Visit					
Total					
Comprehensive Visit					
Total					
Acute Visit					
Total					
Test Results					
Total					
Nurse Care					
Total					
Prescription Refill					
Total					
Referral Information					
Total					
Need Information					
Total					
Message for Provider					
Total					
Talk with Provider					
Total					
Telephone Consult					
Total					
Prior Authorizations for Factor					
Total					
Insurance Calls					
Total					
Day Total					

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 their 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 time patient enters exam room in minutes)

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)

◆ 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.

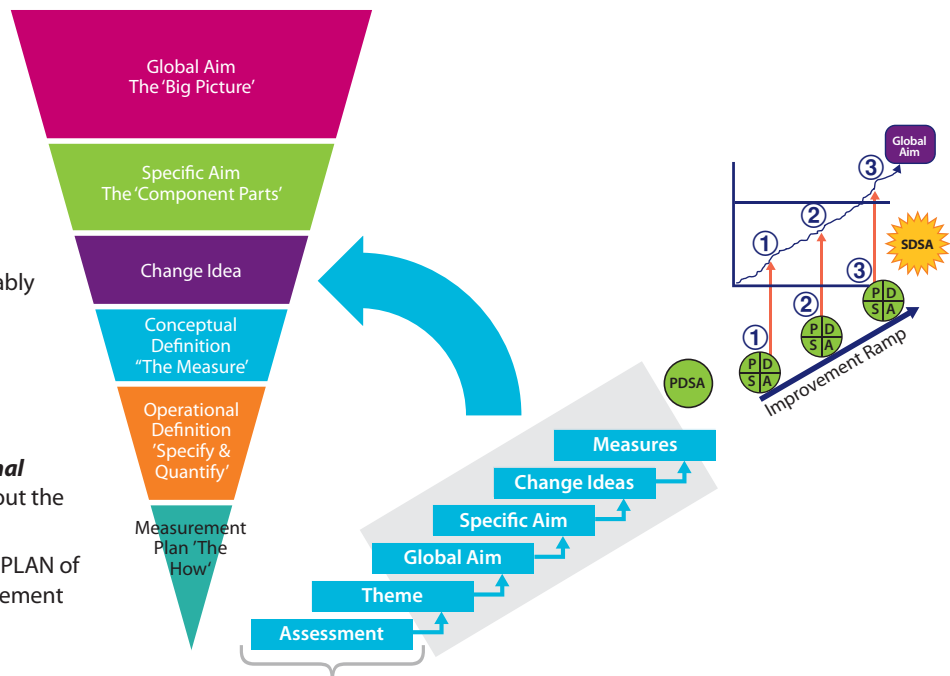
Strongly consider using the metrics reported in the **ATHN** center-specific registry reports, The Joint Commission metrics whenever they are relevant to your microsystem, vital metrics based on your own experience and strategic initiatives and other "gold standard" sets such as measures from the National Quality Foundation.

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 ramp.

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 PDSA cycles. Together, these models create an improvement process that is grounded in improvement sciences.



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.

Name of Measure	Goal	Current and Target Values	Definition and Data Owner	Action Plan and Process Owner
HTC Patient Registry Outcome Measures				
◆ Rate of joint bleeds per patient per year				
◆ Surgical readmissions for bleeding				
◆ Emergency Room Visits				
◆ Lost time from school or work				
◆ Care Experience Metrics				
◆ Staff Engagement Metrics				
Process Measures				
◆ Use of Prophylaxis				
◆ Comprehensive Visit Rate				
◆ Inhibitor Testing				
◆ Use of ITI				
◆ HCV Testing and Treatment Offer				
◆ Discuss Transition				
◆ Access				
◆ Waiting Room Time				
◆ Return Phone Call Time				
Costs				
◆ Factor Units per Patient per Year				
Other				
◆				

STEP 3

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, MASAC, 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.

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

Diagnose Your HTC

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)

In _____

(Clinical location in which process is embedded)

The process begins with _____

(Name where the process begins)

The process ends with _____

(Name where the process ends)

By working on the process, we expect _____

(List benefits)

It is important to work on this now because _____

(List imperatives)

STEP 4

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've 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 we 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.ihl.org (Institute for Healthcare Improvement) or www.clinicalmicrosystem.org.

Specific Aim Statement

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

Use numerical goals, specific dates, and specific measures.

SPECIFIC AIM

MEASURES

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

HTC CHANGE IDEAS TO CONSIDER

Change Ideas to Improve Access to Care
(www.clinicalmicrosystem.org/access.htm)

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
(www.clinicalmicrosystem.org)
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" (ICIC)
(www.improvingchroniccare.org)

Change Ideas to Improve Vitality

9. Engage all staff in continuous improvement and research
10. Develop strategies to actively develop individual staff
11. Create a favorable financial status which supports investments in the practice
12. 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)

*visit www.ihl.org and www.clinicalmicrosystem.org for the latest ideas

Consider the **Change Concepts** on page 295 of *The Improvement Guide* by Langley, Nolan, Nolan, Norman and Provost (1996). The main change categories are listed below.

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

Langley G, Nolan K, Nolan T, Norman T, Provost L. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. 1st ed. The Jossey-Bass Business & Management Series. San Francisco, CA: Jossey-Bass Publishers; 1986; xxix, 370.

- | Huddle Sheet | |
|--|------------------|
| HTC: | |
| Date: | |
| Aim: Enable the HTC to proactively anticipate and plan actions based on patient need and available resources, and contingency planning. | |
| FOLLOW-UPS | |
| “HEADS UP” FOR TODAY: (include special patient needs, sick calls, staff flexibility, contingency plans) | |
| Patient Needs: | Meetings: |
| Clinic/Staff Needs: | |
| REVIEW OF NEXT CLINIC DAY AND PROACTIVE PLANNING | |
| | Meetings: |

Driver Diagram

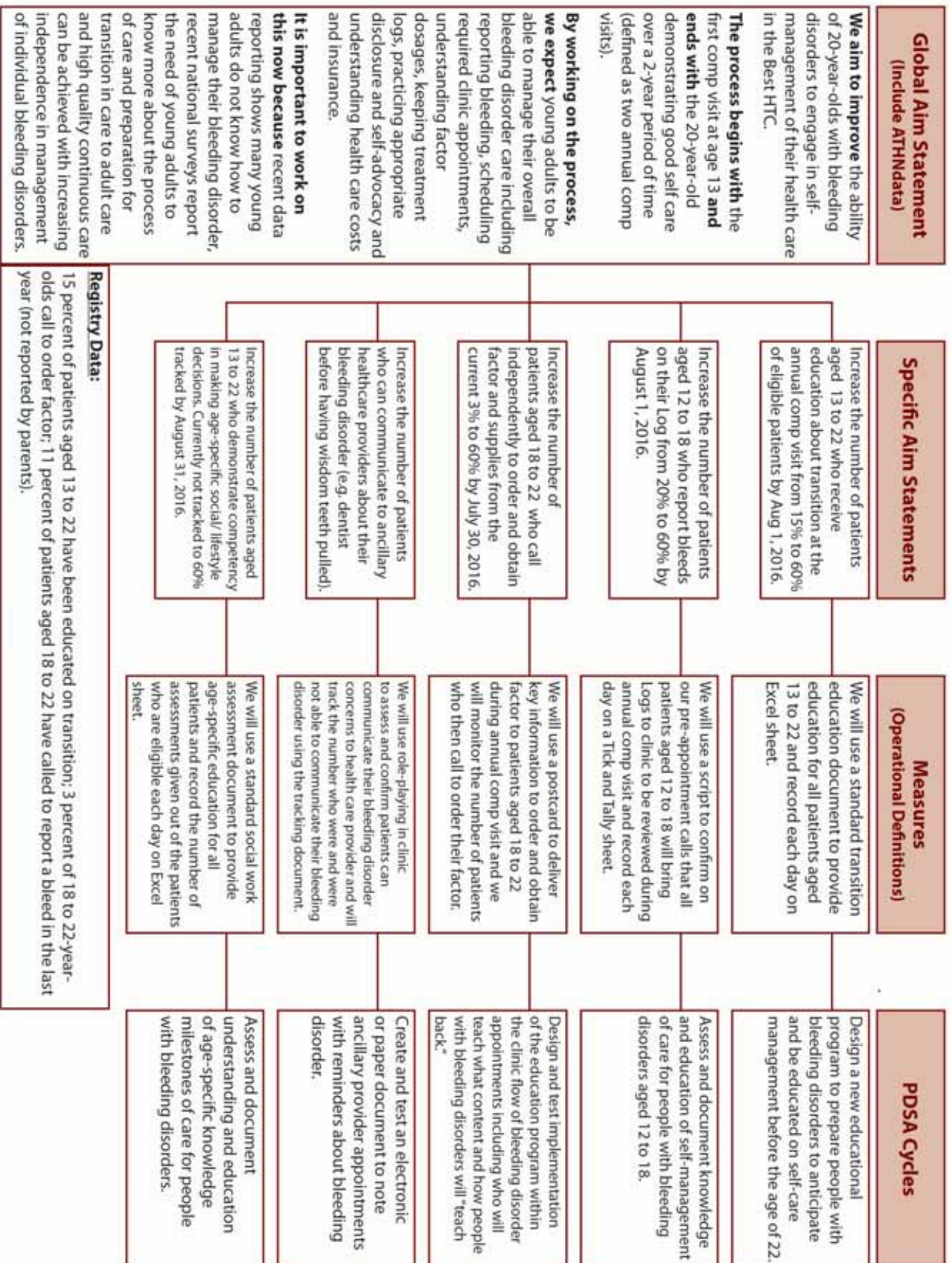
The **driver diagram** (shown on pg.34) is a tool to organize and track multiple improvements to achieve the “Global Aim” of the “Theme” of improvement.

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 conduct to reach the goals of improvement.

2. The **PDSA cycles** can be conducted one-by-one (especially when you are learning improvement skills).
3. 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.



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. 40.

PLAN



How shall we PLAN the **pilot test**? Who? What is the task? When? With what tools? What baseline data will be collected, over what period of time, to determine if the AIM is being achieved?

Tasks to be completed to run test of change	Who	When	Tools Needed	Measures

DO



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

STUDY



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

ACT



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.

Reference: QuIRK#10: PDSA and SDSA Cycles

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**).

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.

STANDARDIZE

How shall we STANDARDIZE the process and embed it into daily practice? Who? What's the task? When? With what tools? What needs to be "unlearned" to allow this new habit? What data will inform us if this is being standardized daily?

Tasks to be completed to "embed" standardization and monitor process	Who	When	Tools Needed	Measures

*Playbook – Create standard process maps to be inserted in your Playbook.

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?

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?

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.35).

STEP 5

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.



What	When	Who	Where
HTC Huddles			
Weekly Meetings – Lead Improvement Team			
Monthly Meetings <ul style="list-style-type: none"> ◆ All Staff ◆ Patient & Family Advisors 			
Quarterly Reports of Outcomes and Progress to Senior Leaders			
Annual Retreat for Review and Reflection			
Annual ATHN Meeting			
Data Wall			
Storyboards			

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 AND AIMS

The **HTC** embarked on the journey of continuous improvement through the **ATHN** and NHPCC 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** dataset, Community Counts and HP2020 indicator on transition measure. The large number of pediatric patients who had passed their 22nd birthday and still were being care 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**.

DIAGNOSE 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

(Name the process)

In Best HTC

(Clinical location in which process is embedded)

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

(Name where the process begins)

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

(Name where the process ends)

By working on the process, we expect young adults to be able to manage their overall bleeding disorder care including understanding the

(List benefits)

details of their bleeding disorder including complications such as bleeding, scheduling required clinic appointments, understanding factor dosage, keeping treatment 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 shows many young adults do not know how to manage their bleeding

(List imperatives)

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 and high-quality continuous care can be achieved with increasing independence in management of individual bleeding disorders.

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

Specific Aim Statement
Create a specific aim statement that will help keep your focus clear and your work productive.
Use numerical goals, specific dates and specific measures.
SPECIFIC AIM
We will increase the number of patients aged 17-22 that order and obtain their own factor from 31% to 65% by September 1, 2016.
MEASURES

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 chairs, 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)

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 dataset 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 FTEs 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 changing our **processes** and **patterns** based on the recommendations. We created a fishbone diagram to identify causes of the effect of not transitioning by the age of 22 years from pediatric to adult care teams.

We developed a flowchart of our current appointment and visit process. Looking at the data from the transition survey given to patients, the staff skills assessment and www.GotTransition.org, we developed a high-level overview of **change ideas** that we believed would support an improvement in the number of patients between the ages of 13 and 22 years who transition from the pediatric to adult care teams. These **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.

TESTS OF CHANGE

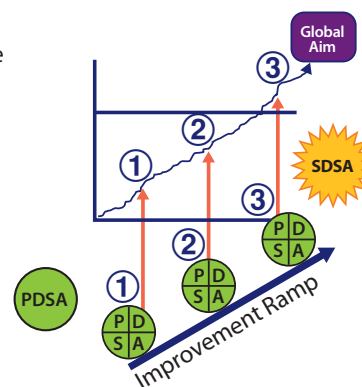
We conducted the following **tests of change** or cycles of **Plan-Do-Study-Act (PDSA)**.

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



Driver Diagram

Tests of Change and PDSA Cycles

PDSA Cycle 4 — Provide educational materials and role-play transition related scenarios based on age.

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 before the age of 18.

PDSA Cycle 3

- ◆ Design and test implementation of the education program within the clinic flow of bleeding disorder appointments 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 maintain a supply of factor in a dorm room or apartment)

Measurement

As our process changed we instituted a system to measure the impact of the changes. We agreed to measure the following metrics, analyze our practice **patterns** and post results on our **data wall** for all staff to review.

- ◆ Number of patients of the age 13 to 22 years and the hematologist who is responsible for their care
- ◆ Number of patients who have not received education about transition

- ◆ The percent of patients per clinic who receive education about transition
- ◆ The percent of patients per clinic who demonstrate understanding of the information presented on transition
- ◆ The percent of patients who transition by the age of 22 years (reported monthly)

Standardization and Follow-Up

Concluding our **tests of change** and standardizing our process (**SDSA – Standardize-Do-Study-Act**) of transitions of patients from the pediatric to adult care team, we created a **playbook** of our work. This book is a compilation of our current transition process outlining who does what, when and recommended measures and monitors to ensure the process is consistent and standardized. This **playbook** is utilized to orient new staff, conduct performance appraisals and reinforce actions to standardize the process. Now that we have successfully changed the process related to the transition of patients, we are going to use the same process and focus on ways we can improve the joint score of patients at Best **HTC**, Happy Medical Center.

EXAMPLE OF DESIGNING THE PDSA CYCLE STARTING WITH THE PLAN

PLAN

How shall we **PLAN** the **pilot test**? Who? What is the task? When? With what tools? What baseline data will be collected, over what period of time, to determine if the AIM is being achieved?

Tasks to be completed to run test of change	Who	When	Tools Needed	Measures
Educate the staff on new education plan	Lead RN and Lead MD	Tuesday morning meeting	Measurement Plan	Number of staff present at meeting / Total number of staff
Follow up with staff not able to attend meeting via email	Lead RN	Tuesday afternoon	Measurement Plan	Number of staff who received email/ Number of staff not present at meeting
Create checklist of topics for pharmacist to discuss with patient	Lead Pharmacist	Wednesday afternoon	TBD	Completed checklist, reviewed by team
Checklist to be shared and reviewed by lead improvement team	Team	Thursday morning	Checklist (draft)	Agreement on checklist
Implement new education plan	Team	Monday morning	Checklist (draft)	N/A
Audit new education plan	Lead MD, pharmacist	Tuesday afternoon	Tick and Tally sheet for prior two weeks	Number of patients receiving education from pharmacist/ Total number of transition age patients seen in clinic each day

DO

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

STUDY

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

ACT

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.

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	Kathy Jones, RN
Elizabeth Watson, APRN	Tim Brown, MD
Andrea Clark, RN	George Smith, Pharm.D
Rick Schmidt, 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

- ◆ Design 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

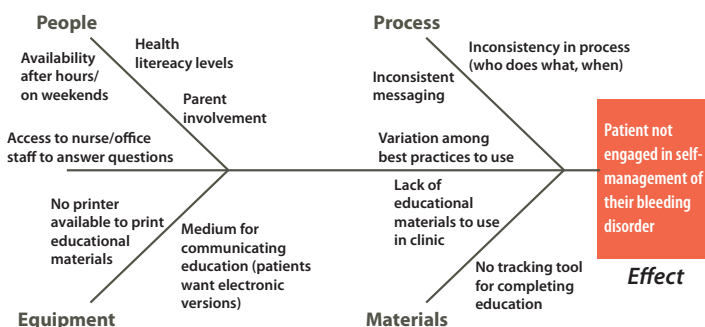
- ◆ Assess and document knowledge and education of self-management of care for people with bleeding disorders starting at age 13

PDSA Cycle 3

- ◆ Design and test implementation of the education program within the clinic flow of bleeding disorder appointment 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 ATHNdataset

January 2016

- ◆ Established regular team meetings (day, time and place)
- ◆ Began identifying and collecting the 5Ps

February 2016

- ◆ Attended on-site Dartmouth Improvement Program learning session
- ◆ Finalized a draft of the 5Ps
- ◆ 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 numbers 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"
- ◆ Identified educational gaps and created a plan to review, modify, update and create educational materials to be provided to people with bleeding disorders

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 maintain a supply of factor in a dorm room or apartment)

July 2016

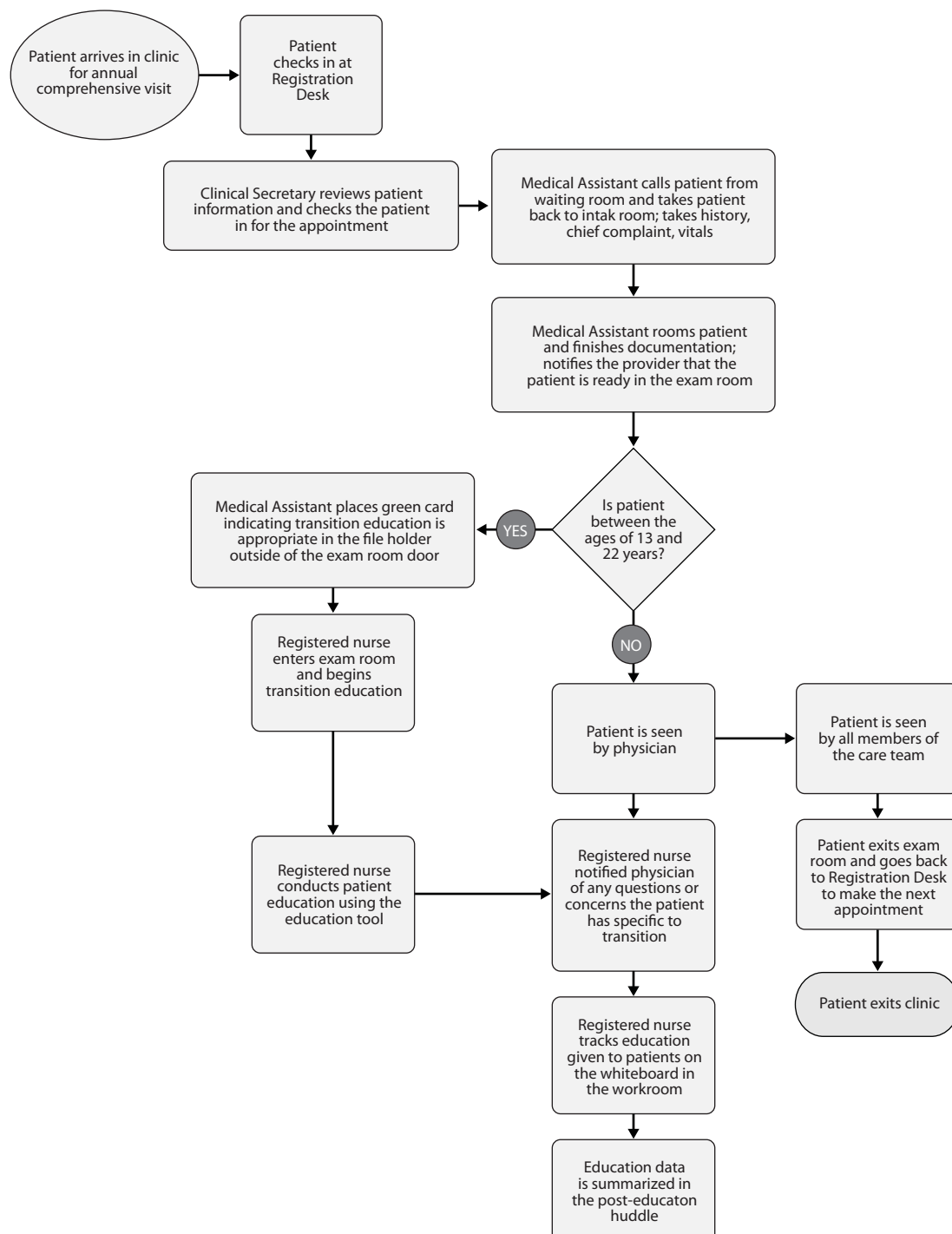
- ◆ Specific Aim: Assess and increase ability to fill factor orders
- ◆ Developed a detailed flowchart of the pharmacy process for filling factor orders
- ◆ Created a specific aim around increasing the number of people with bleeding disorders who obtain and order their own factor

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: 15%
- ▶ 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



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 to ensure 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 age 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/4153?category=1&by=Total&fips=-1>)

The National Hemophilia Program Coordinating Center has conducted a national survey to learn ways 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) engaging receiving care; 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. Vaks, 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.hjdsi.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 capability at the front line of care in HTCs. Central to the HTC transition of care improvement is the “Got 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).

GotTransition identifies three top transition-of-care needs:

- ◆ *Improving care coordination*
- ◆ *Improving communication*
- ◆ *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 means for integrating young adults into adult care. These transition resources are consistent with the AAP AAFP/ACP 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 support shared learning among the ATHN community and will support sustainable improvement efforts across the United States.
3. Developing improvement capability 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.

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.



Patient/Family Roles ^{1, Δ}	Patient/Family Responsibilities	Staff/Healthcare Provider Responsibilities Preparation/Compensation
Patients or Families as Participants <ul style="list-style-type: none"> Respond to surveys and questionnaires Members of focus group 	<ul style="list-style-type: none"> Family perceptions of care and quality are elicited and used in shaping improvement initiatives. Data/information from families is used in measuring improvement. Responsibilities end when their input is received unless they are asked to provide feedback on the interpretation of the data. Review and give feedback related to materials developed specifically for patients or families, e.g., educational materials. Provide suggestions for improvement in writing as appropriate. Respond to surveys/questions openly and honestly. 	PREPARATION: <ul style="list-style-type: none"> All efforts should be made to ensure that patients' and families' real experience is accurately measured and interpreted. Attention is focused more on the instruments, methods and analysis than on significant patient or family participation, training or preparation of them as participants (beyond what is necessary for them to make an informed choice to participate and to complete the activity). In keeping with a patient- and family-centered approach, efforts to ensure that all (or an adequate sample that reflects the diversity of populations served) are included. COMPENSATION: <ul style="list-style-type: none"> Acknowledgement of appreciation for their participation is necessary. Supplying patients/families with a summary of the data and information about how the data is/will be used to improve area of focus (e.g., quality care, education, etc.). This can occur in a patient/family meeting, education day, written summary, etc., and may be additional compensation.

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

^Δ Notes are on page 50.

Patient/Family Roles ¹	Patient/Family Responsibilities	Staff/Healthcare Provider Responsibilities Preparation/Compensation
<p>Patients or Families as Advisory Board Members²</p> <ul style="list-style-type: none"> ◆ Members of committee ◆ Members of task force ◆ Patients or families serve on advisory boards for the quality improvement team 	<ul style="list-style-type: none"> ◆ Responsibilities will depend on level of involvement of the advisory board. <ul style="list-style-type: none"> ▶ If the advisory board is used to review policies, programs and evaluation methods after staff has written them, there are few opportunities for teamwork. ▶ 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. 	<p>PREPARATION:</p> <ul style="list-style-type: none"> ◆ The most effective patient/family advisory boards have established means for recruitment, selection, membership requirements and setting bylaws, as well as ongoing strategic planning that identifies goals, activities and evaluation. Support for these boards can be space for meetings, or administrative support (e.g., mailings, secretarial support, printing costs, etc.). ◆ Staff members are identified to serve as liaisons to the advisory boards (and their time is covered by the unit/hospital) in order to build communication, coordination and partnership. <p>COMPENSATION:</p> <ul style="list-style-type: none"> ◆ Care centers can show their commitment by providing the advisory board regular opportunities for the board to report to senior leadership and/or to participate within a shared governance model. ◆ The more involved the patients and families are in the planning, implementation and evaluation, the more there is a building of a partnership rather than just giving the “rubber-stamp” approval of an activity. ◆ Other preparation issues to consider include childcare, meetings that include meals, parking and other transportation costs and stipends for participation.

Patient/Family Roles ¹	Patient/Family Responsibilities	Staff/Healthcare Provider Responsibilities Preparation/Compensation
<p>Patients or Families as Active Advisors/Consultants³</p> <ul style="list-style-type: none"> ◆ Active task force/committee members ◆ Faculty for staff education ◆ Participants at collaborative meetings/conferences ◆ Mentors for others in work (patients, families or staff) ◆ Trainers for other patients or families involved ◆ Orientation of staff ◆ Work closely with the quality improvement team 	<ul style="list-style-type: none"> ◆ At this level, patients/families have a continuous and more active involvement with the care center, e.g., improvement lead improvement team, educational materials. ◆ Service time is usually clearly limited, e.g., 2-3 years or whatever is agreed upon by the care center, patient and/or family member. ◆ They would be active participants as members of the teams who are planning, implementing and evaluating either individual projects and/or the work of the collaborative team as a whole. ◆ Help in the quality improvement effort, all components of the Plan-Do-Study-Act (PDSA) cycle. 	<p>PREPARATION:</p> <ul style="list-style-type: none"> ◆ In order for patients and families to participate at this level, training, preparation and support would be comparable to what the staff receives. They require training specifically in the area of responsibility, e.g., quality improvement model and processes. Consider joint training sessions with patients, families and staff. ◆ Expectations for involvement would be defined and regularly reviewed. In addition, this level would also require that teams receive training in working collaboratively with patients and families.⁴ ◆ Experienced staff, patients and/or families can serve as experienced trainers and mentors for others. <p>COMPENSATION:</p> <ul style="list-style-type: none"> ◆ 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. ◆ Commitment by the care center and value of the patient/family input is demonstrated through the continuing funding of patient and/or family participation.

Patient/Family Roles ¹	Patient/Family Responsibilities	Staff/Healthcare Provider Responsibilities Preparation/Compensation
Patients or Families as Co-Leaders <ul style="list-style-type: none"> ◆ Facilitator ◆ Content expert ◆ Evaluator⁵ ◆ Author ◆ Hospital/HTC employee 	<ul style="list-style-type: none"> ◆ A high level of involvement by patient and/or 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. 	<p>PREPARATION:</p> <ul style="list-style-type: none"> ◆ This level 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 employing 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. <p>COMPENSATION:</p> <ul style="list-style-type: none"> ◆ 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.

These patient and family role ideas are based on work from the Vermont-Oxford Network. Mutual trust and respect must be built no matter what level people are serving in or whether they are staff, a patient or family member. This takes time. As patients and families are offered more opportunities to participate, the time spent in building an understanding of individual areas of expertise and common goals will help strengthen a team's capacity to collaborate and further

partnership in improving blood-disorder care. This will require integration of team building activities while building the partnership between patients, families and care centers. **ATHN** believes that increasing patient/family involvement in the work at the care center supports our mission to find a cure and improve the quality of life for people with blood disorders.

Notes:

¹ The framework for the roles was adapted from an article on participatory action research by Turnbull, Friesen, Ramirez, 1998 (see references).

² For a comprehensive resource on family advisory boards, refer to Webster, Johnson, 2000 (see references).

³ Refer to Dillon, 2003 (see references) for guidance on parent participation on quality improvement teams.

⁴ Refer to Jeppson, Thomas, 1995, 1997 and Turnbull, et al., (see references).

⁵ For an annotated bibliography of families serving on evaluation teams refer to Jivanjee, et al., 2004 (see references).

Selected References

American Hospital Association, Institute for Family-Centered Care. Strategies for Leadership: Patient and Family-Centered Care. Chicago, IL: American Hospital Association; 2004.

Batalden PB, Nelson EC, Edwards WH, Godfrey MM, Mohr JJ: Microsystems in Healthcare: Part 9. Developing Small Clinical Units to Attain Peak Performance. *Jt C J Qual Saf.* 2003;29(11):575-585.

Blaylock B, Ahmann E, Johnson BH. Creating Patient and Family Faculty Programs. Bethesda, MD: Institute for Family-Centered Care; 2002.

Boote J, Telford R, Cooper C. Consumer involvement in health research: A review and research agenda. *Health Policy.* 2002;61:213-236.

Connor JM, Nelson EC. Neonatal intensive care: Satisfaction measured from a parent's perspective. *Pediatrics.* 1999;103(1):336-349.

Dillon AD. Parents Partners: Creative Forces on Medical Home Improvement Teams. Greenfield, NH: Center for Medical Home Improvement; 2003.

Giachello AL, Arrom JO, Davis M, et al. Reducing diabetes health disparities through community-based participatory action research: The Chicago Southeast Diabetes Community Action Coalition. *Public Health Rep.* 2003;118:309-323.

Hanson JL, Randall VF. Evaluating and improving the practice of family-centered care. *Pediatr Nurs.* 1999;25(4):445-449.

Jeppson ES, Thomas J. Families as Advisors: A Training Guide for Collaboration. Bethesda, MD: Institute for Family-Centered Care; 1997.

Jeppson ES, Thomas J. Essential Allies: Families as Advisors. Bethesda, MD: Institute for Family-Centered Care; 1995.

Jivanjee P, Schutte K, Robinson A. Families as Evaluators: Annotated Bibliography of Resources in Print. Portland, OR: Portland State University Research and Training Center on Family Support and Children's Mental Health; 2004.

Turnbull AP, Friesen BJ, Ramirez C. Participatory action research as a model for conducting family research. *JASH.* 1998;23(3):178-188.

Vander Stoep A, Williams M, Jones R, Green L, Trupin E. Families as full research partners: What's in it for us? *J Behav Health Serv Res.* 1999;26(3):329-344.

Webster PD, Johnson BH. Developing and Sustaining a Patient and Family Advisory Council. Bethesda, MD: Institute for Family-Centered Care; 2000.

White G, Suchowierska M, Campbell M. Developing and systematically implementing participatory action research. *Arch Phys Med Rehabil.* 2004;85(2):S3-S12.

Patient and 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 time-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 their **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 issues and problems identified; i.e., start with the satisfaction survey in "Assess Your HTC" (pg. 11).
- ◆ 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 inservice programs. Topics 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 families 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.



- ◆ Create regular opportunities (e.g., monthly meetings, coffee hours) for patients and families to talk with department heads or the senior management team.
- ◆ Ask patients and families to join the healthcare providers when they meet with local, state or federal government representatives, funders or other community groups.
- ◆ Conduct follow-up phone calls with patients and families after hospital discharge or, as consented, have a patient or family member call the person who was discharged (or their family) as a mentor post-hospitalization.
- ◆ Set up "exit interviews" with administrators when patients and families are leaving the hospital or transferring to another HTC.
- ◆ Organize support groups or e-mail pen-pals for patients.

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.

*Adapted from Jeppson, E. & Thomas, J. (1994). Essential Allies: Families as Advisors. Institute for Family-Centered Care. 1994, Bethesda, MD. Revised 2005. American Thrombosis and Hemostasis Network (ATHN) has resources available through ATHN (www.athn.org) or the Institute for Family-Centered Care (www.familycenteredcare.org). Webster, P. D., & Johnson, B. H. (2000). Developing and Sustaining a Patient and Family Advisory Council. Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). Creating Patient and Family Faculty Programs.

Assessing Your Practice Discoveries and Actions

Common High Yield Wastes	Recommended Method to Reduce Waste	Traps to Avoid
1. Exam rooms not stocked or standardized – missing supplies or equipment	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • Don't assume rooms are being stocked regularly – track and measure. • Providers will only use "their own" rooms • Providers cannot agree on standard supplies; suggest "testing"
2. Too many appointment types which create chaos in scheduling	<ul style="list-style-type: none"> • Reduce appointment types to 2-4 • Utilize standard building block to create flexibility in schedule. 	<ul style="list-style-type: none"> • Frozen schedules of certain types • Use one time (e.g. 10-15 minute "building blocks")
3. Poor communication amongst the providers and support staff about clinical sessions and patient needs	<ul style="list-style-type: none"> • Conduct daily morning "huddles" to provide a forum to review the schedule, anticipate needs of patients, plan supplies/ information needed for a highly productive interaction between patient and provider. 	<ul style="list-style-type: none"> • 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 • Don't sit down
4. Missing information or chart for patient visit	<ul style="list-style-type: none"> • Review patient charts BEFORE the patient arrives – recommended the day before to ensure information and test results are available to support the patient. 	<ul style="list-style-type: none"> • Avoid doing chart review when patient is present • If you have computerized test results, don't print the results
5. Confusing messaging system	<ul style="list-style-type: none"> • Standardize messaging processes for all providers • Educate/ train messaging content • Utilize a process with prioritizing methods such as a "bin" system in each provider office. 	<ul style="list-style-type: none"> • 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 – test something
6. High prescription renewal request via phone	<ul style="list-style-type: none"> • Anticipate patient needs • Create "reminder" systems in office, e.g. posters, screensavers • Standardize the information support staff obtain from patients before the provider visit – include prescription information and needs. 	<ul style="list-style-type: none"> • Doesn't need to be the RN – Medical assistants can obtain this information
7. Staff frustrated in roles and unable to see new ways to function	<ul style="list-style-type: none"> • Review current roles and functions using activity survey sheets • Match talent, education, training, licensure to function • Optimize every role • Eliminate functions 	<ul style="list-style-type: none"> • Be sure to focus on talent, training and scope of practice not individual people.
8. Appointment schedules have limited same day appointment slots	<ul style="list-style-type: none"> • 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.icsi.org • Consider phone care 	<ul style="list-style-type: none"> • Don't set a certain number of same day appointments without matching variations throughout the year.
9. Missed disease-specific/ preventive interventions and tracking	<ul style="list-style-type: none"> • Utilize the flow sheets to track preventative activities and disease-specific interventions. • Utilize "stickers" on charts to alert staff to preventative/ disease specific needs • Review charts before patient visits • Create registries to track subpopulation needs. 	<ul style="list-style-type: none"> • Be alert to creating a system for multiple diseases and not have many stickers and many registries.
10. Poor communication and interactions between members	<ul style="list-style-type: none"> • Hold weekly staff meetings to review practice outcomes, staff concerns, improvement opportunities. • Education and Development 	<ul style="list-style-type: none"> • Hold weekly meetings on a regular day, time and place • Do not cancel – make the meeting a new habit
11. High no-show rate	<ul style="list-style-type: none"> • Consider improving same day access • Reminder systems 	<ul style="list-style-type: none"> • Automated reminder telephone calls are not always well received by patients
12. Patient expectations of visit not met, resulting in phone calls and repeat visits	<ul style="list-style-type: none"> • CARE vital sign sheet – www.howsyourhealth.org • Evaluating patient at time of visit if their needs were met 	<ul style="list-style-type: none"> • Use reminders to question patient about needs being met • New habits not easily made.

Glossary

5P Framework: The 5P framework can be thought of as a structured and organized method of inquiring into the anatomy of an HTC

Action plan: Detailed “next steps” and “to do” with clearly identified and accountable 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 measures

ATHN: 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. A systematic process of continuously 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 list 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 measured (e.g. patient waiting for HTC clinic visit)

Continuous Quality Improvement: Continuous quality improvement is a preventive, proactive 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: Graphic 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 intermittently provide care and services to support the process of care

Cycle Time Tool: Study to measure time intervals during a visit to identify waits, delays and waste

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

Data Wall: Designated space to display measures and improvement progress over time. Utilizes daily and weekly to review current values and target values to assess progress toward aims. Based 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

Facilitator: Person with training, skill and expertise in both clinical improvement and group process

Flow Chart: Graphic representation of a process using symbols and arrows

Gantt Chart: A Gantt Chart is 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

Hold the Gains: System improvement over time and assurance that new habits are embedded in daily practice

HRSA: Health Resources and Services Administration

HTC: Hemophilia Treatment Center

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

ITI: Immune Tolerance Induction

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

NHPCC: 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 time patients enters exam room in minutes)

Owner: Person with the responsibility and authority to lead the improvement of a process. Also, the person with responsibility for a given process

Patterns: Repeating predictable cycles and behaviors which can be observed and articulated, e.g. meeting frequency, social activities, financial performance

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 accountable for

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 end resulting in products or outcomes

Professionals: Members of the frontline team including administrative staff, lead MDs, nurses, therapists, social workers, 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, systems and creating a new process

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

SDSA (Standardize-Do-Study-Act Cycle): Steps taken when one or more PDSA Cycles have been successfully done to determine that original aim is reached. Purpose is to hold the gains that were made using PDSA cycles and standardize process in daily work

Storyboards: Visual display used to document and communicate a team's improvement journey. Includes aims, PDSAs, 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

Tests of Change: See PDSA

Time Trend Charts: Chronological data over time, also known as a run chart

Notes

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Notes

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www.athn.org



www.clinicalmicrosystem.org