Assessment of Transition Needs for Hemophilia Patients Age 12-18: A Quality Improvement Initiative for Transition from Pediatric to Adult Care

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Background

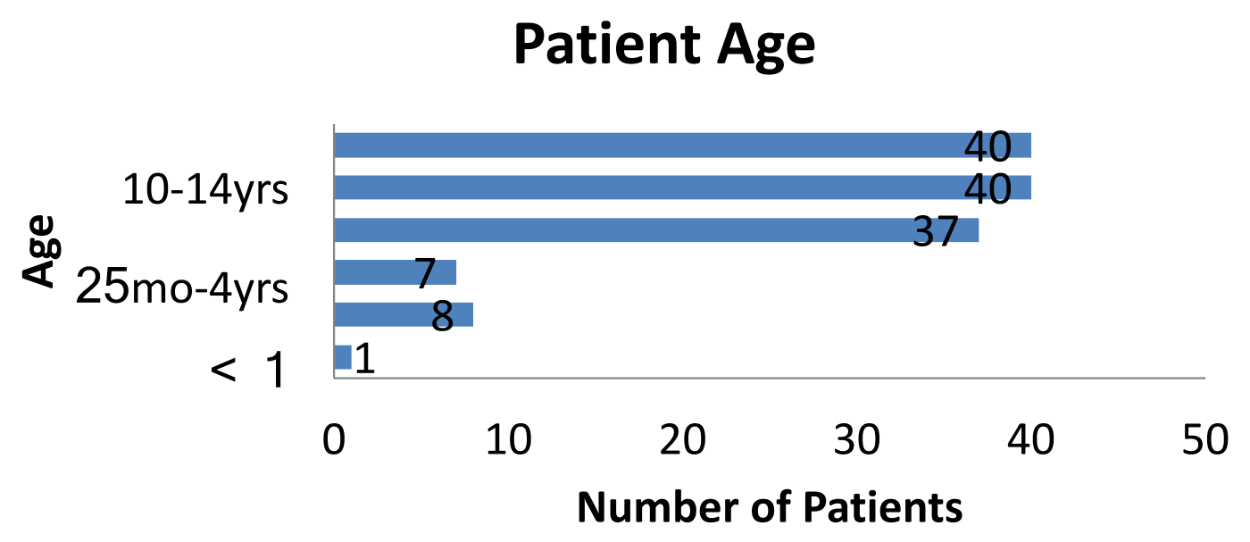
The Hemophilia Treatment Center (HTC) at UCSF Benioff Children's Hospital, Oakland (BCHO) provides comprehensive, patient and family centered care to children and adolescents with hemophilia and other bleeding disorders, in urban Oakland, CA and surrounding areas. Our HTC is one of 14 federally funded HTC's in the Western States Regional Hemophilia Network. Our **purpose** is to providing high quality, multidisciplinary, compassionate care to improve the quality of life of patients with bleeding disorders by providing medical, emotional, and practical support and serving as a link between the HTC and the community. We strive to facilitate communication that is consistent, reliable, and culturally sensitive.

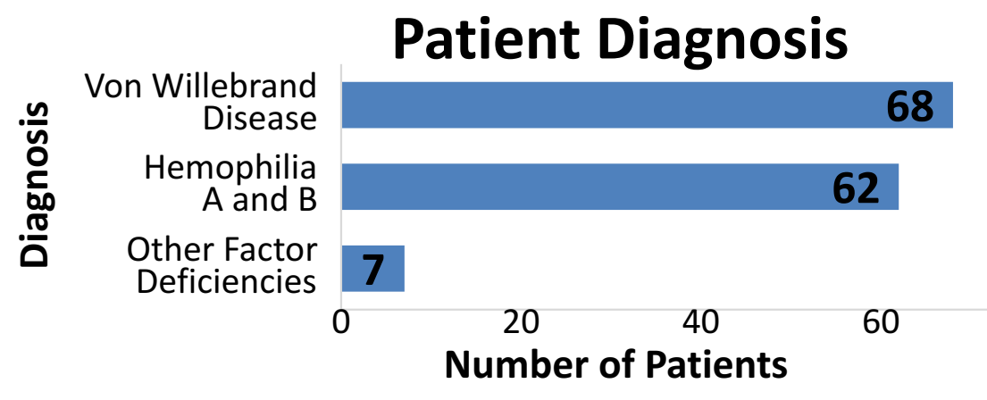
Problem Description

Effective transition of pediatric patients to an adult treatment center is a necessary to pediatric hemophilia care and ideally should start with care onset. However, given the multiple care demands on the patient, family and providers, this process may not begin until late in adolescence at BCHO. A review of the 5Ps (purpose, patients, professionals, processes and patterns showed that we were not effectively identifying the transition needs of our patients, particularly those with Hemophilia A and B ages 12-18.

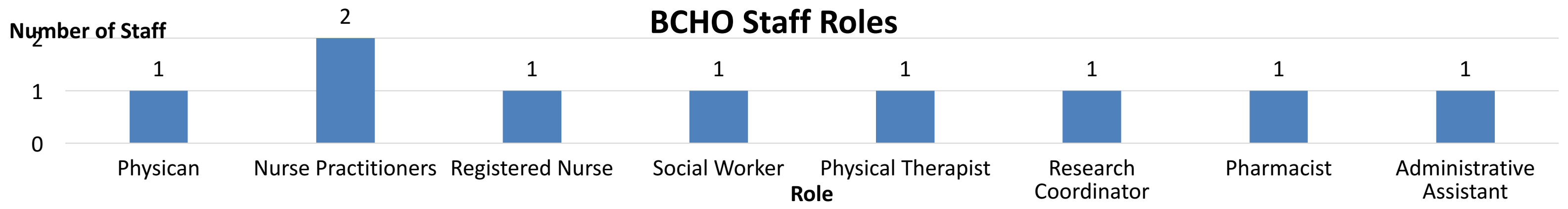
Patients

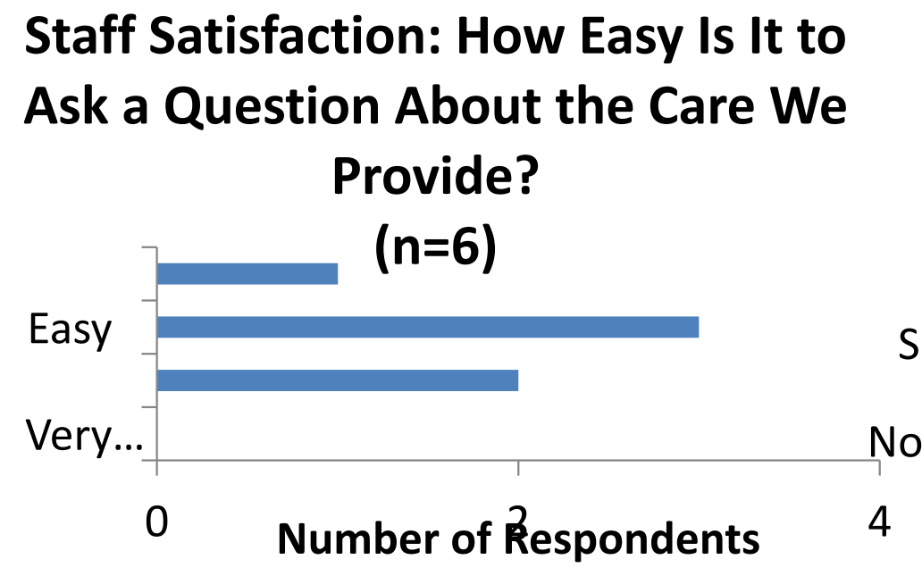
A total of 137 patients were treated at our HTC from January-December 2016. Comprehensive clinic attendance was most prevalent in the spring and summer months, with more "no-shows" occurring during the fall and winter. The Patient Access Survey (n=13) revealed that our patients were overall satisfied with personal manner of our HTC staff, the time HTC staff spent with patients in clinic, and access to clinicians over the phone.

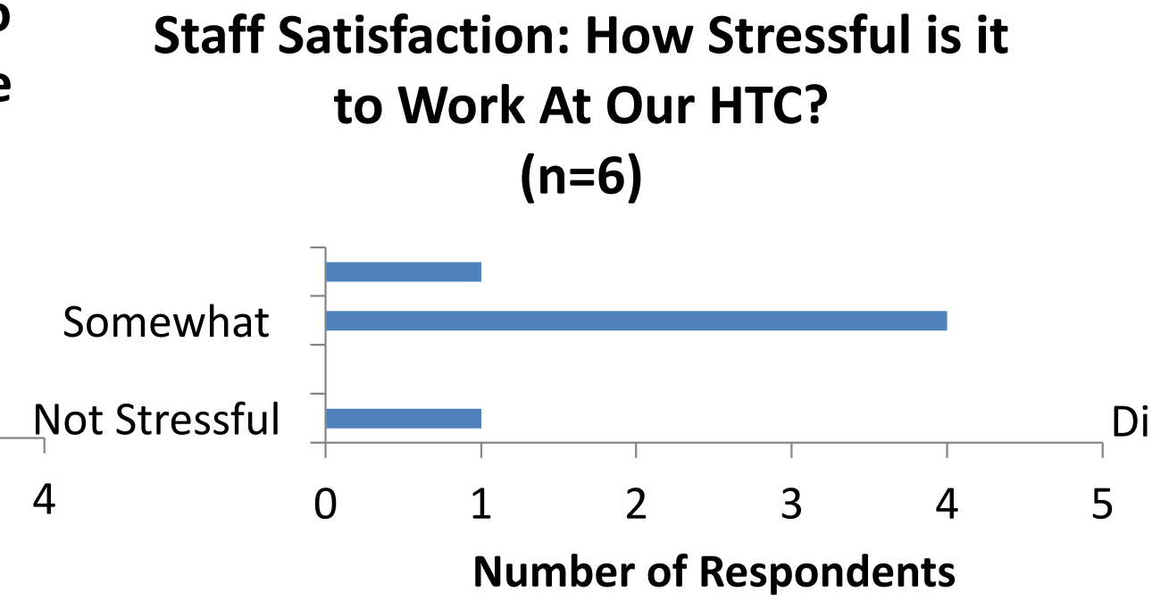


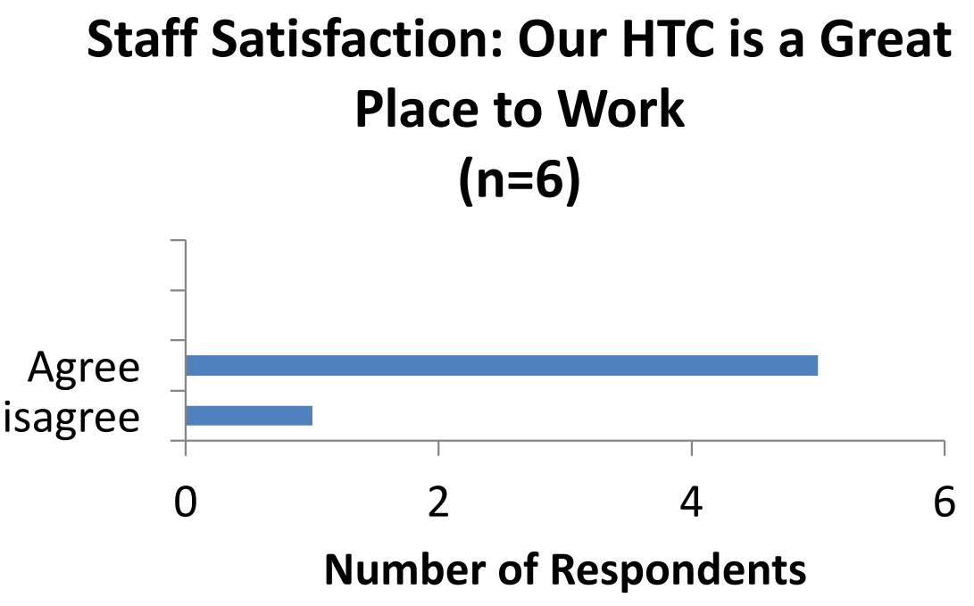


Professionals

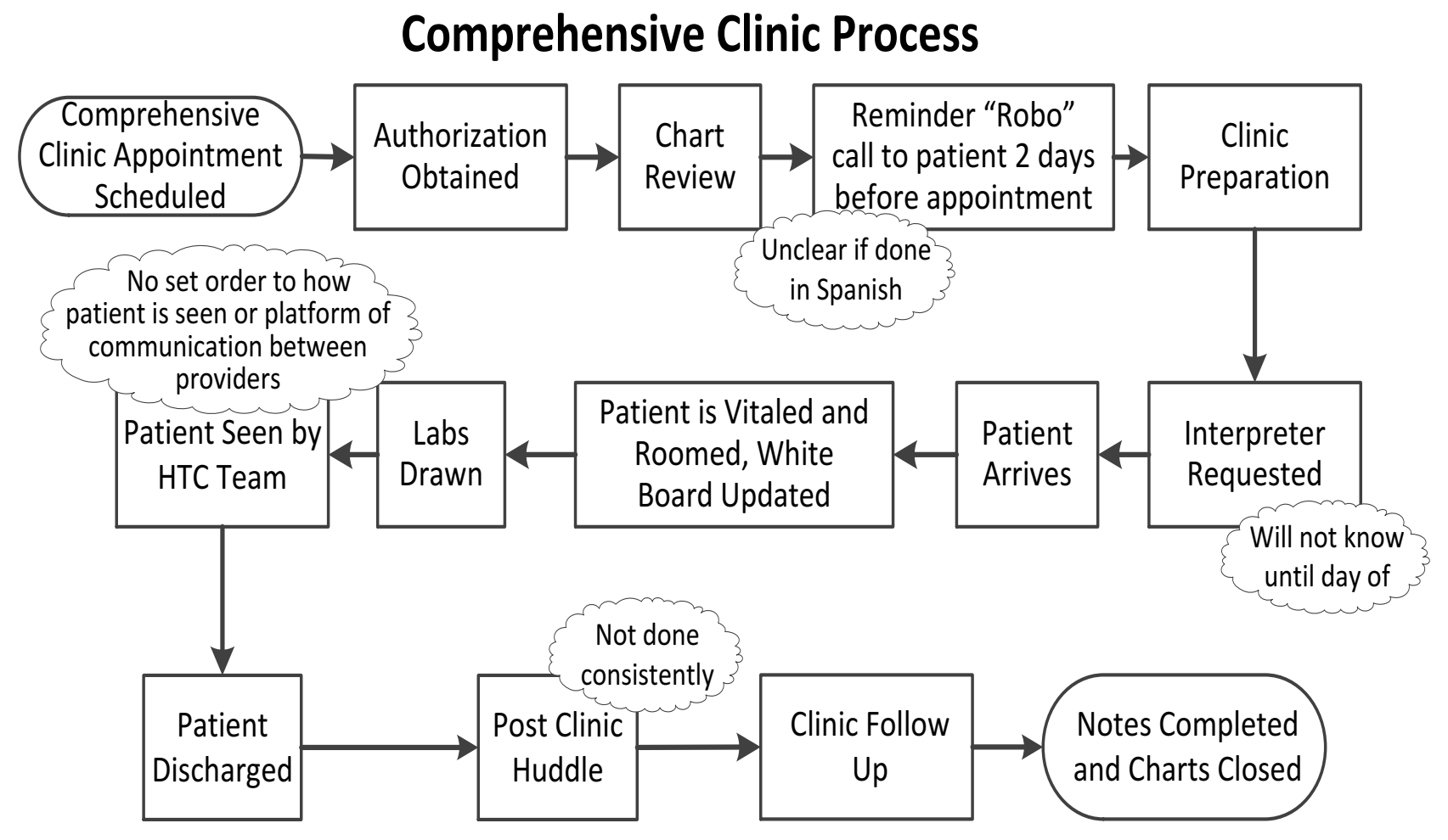








Processes



Comprehensive Clinic Process

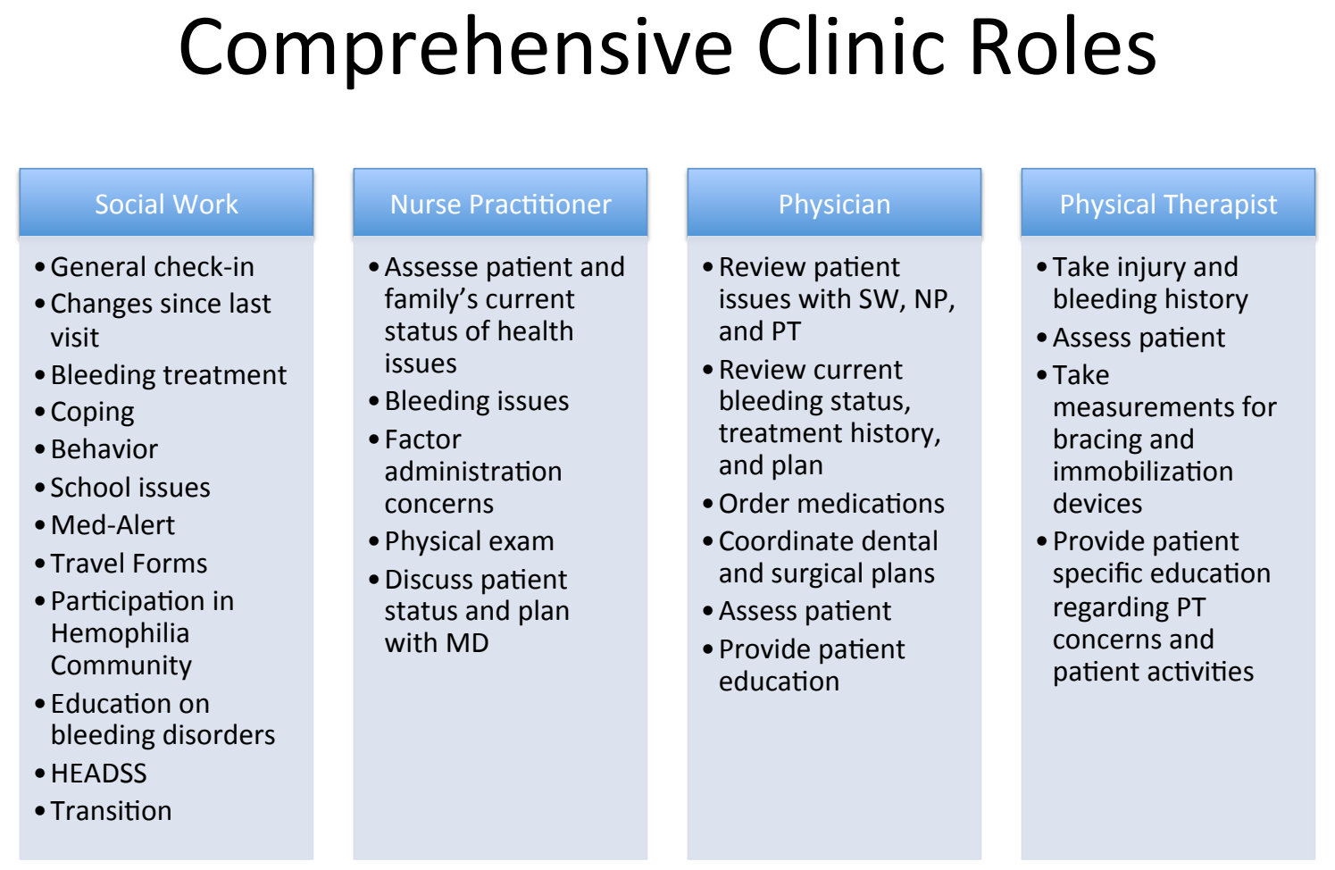
Comprehensive Clinic Appointment Scheduled → Authorization Obtained → Chart Review → Reminder "Robo" call to patient 2 days before appointment → Clinic Preparation → Interpreter Requested → Patient Arrives → Patient is Vitaled and Roomed, White Board Updated → Labs Drawn → Patient Seen by HTC Team → Patient Discharged → Post Clinic Huddle → Clinic Follow Up → Notes Completed and Charts Closed

Unclear if done in Spanish

Will not know until day of

No set order to how patient is seen or platform of communication between providers

Not done consistently



Comprehensive Clinic Roles

Social Work
- General check-in
- Changes since last visit
- Bleeding treatment
- Coping
- Behavior
- School issues
- Med-Alert
- Travel Forms
- Participation in Hemophilia Community
- Education on bleeding disorders
- HEADSS
- Transition

Nurse Practitioner
- Assesse patient and family's current status of health issues
- Bleeding issues
- Factor administration concerns
- Physical exam
- Discuss patient status and plan with MD

Physician
- Review patient issues with SW, NP, and PT
- Review current bleeding status, treatment history, and plan
- Order medications
- Coordinate dental and surgical plans
- Assess patient
- Provide patient education

Physical Therapist
- Take injury and bleeding history
- Assess patient
- Take measurements for bracing and immobilization devices
- Provide patient specific education regarding PT concerns and patient activities

Patterns

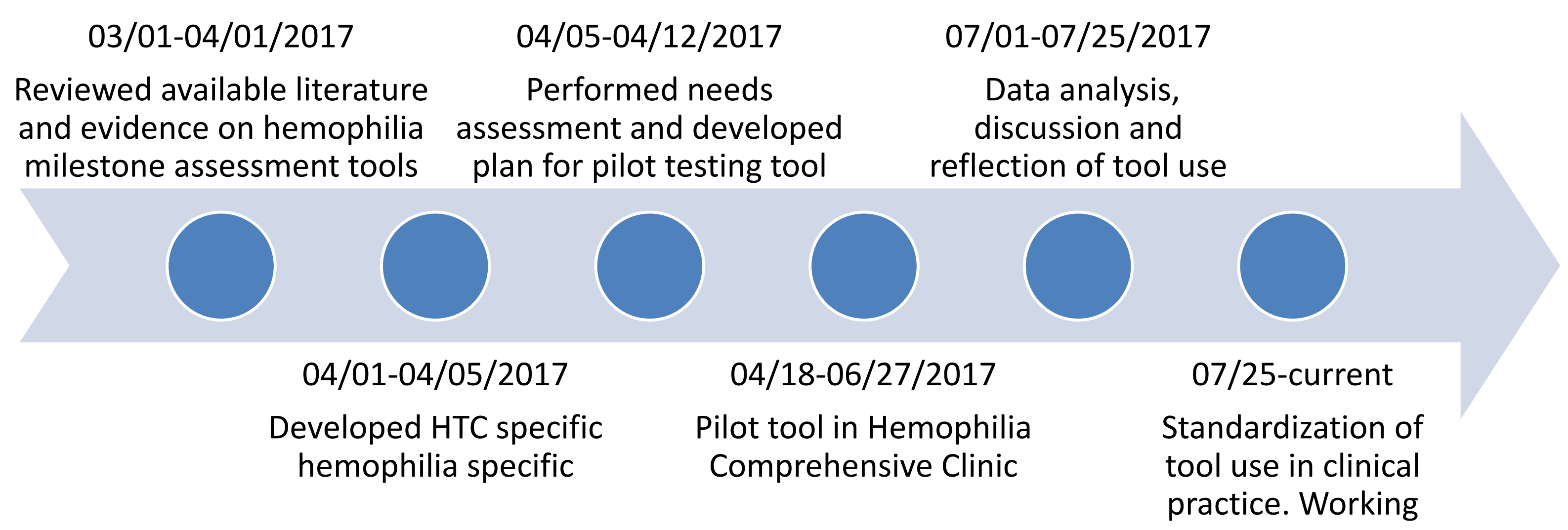
Team meetings: Our HTC team meets every Friday to review the upcoming patients for our Tuesday Hemophilia/Hemostasis clinic, patient concerns, and research and project updates.

Ad Hoc Meetings: These meetings are held as needed, and are usually multidisciplinary and project specific (e.g. dental, teen clinic, 340B).

Communication: GroupWise email is the preferred method of communication with HTC team members outside of team meetings

QI: Weekly conference call with QI team members and ATHN coaches.

Timeline of Activities



03/01-04/01/2017
Reviewed available literature and evidence on hemophilia milestone assessment tools

04/01-04/05/2017
Developed HTC specific hemophilia specific

04/05-04/12/2017
Performed needs assessment and developed plan for pilot testing tool

04/18-06/27/2017
Pilot tool in Hemophilia Comprehensive Clinic

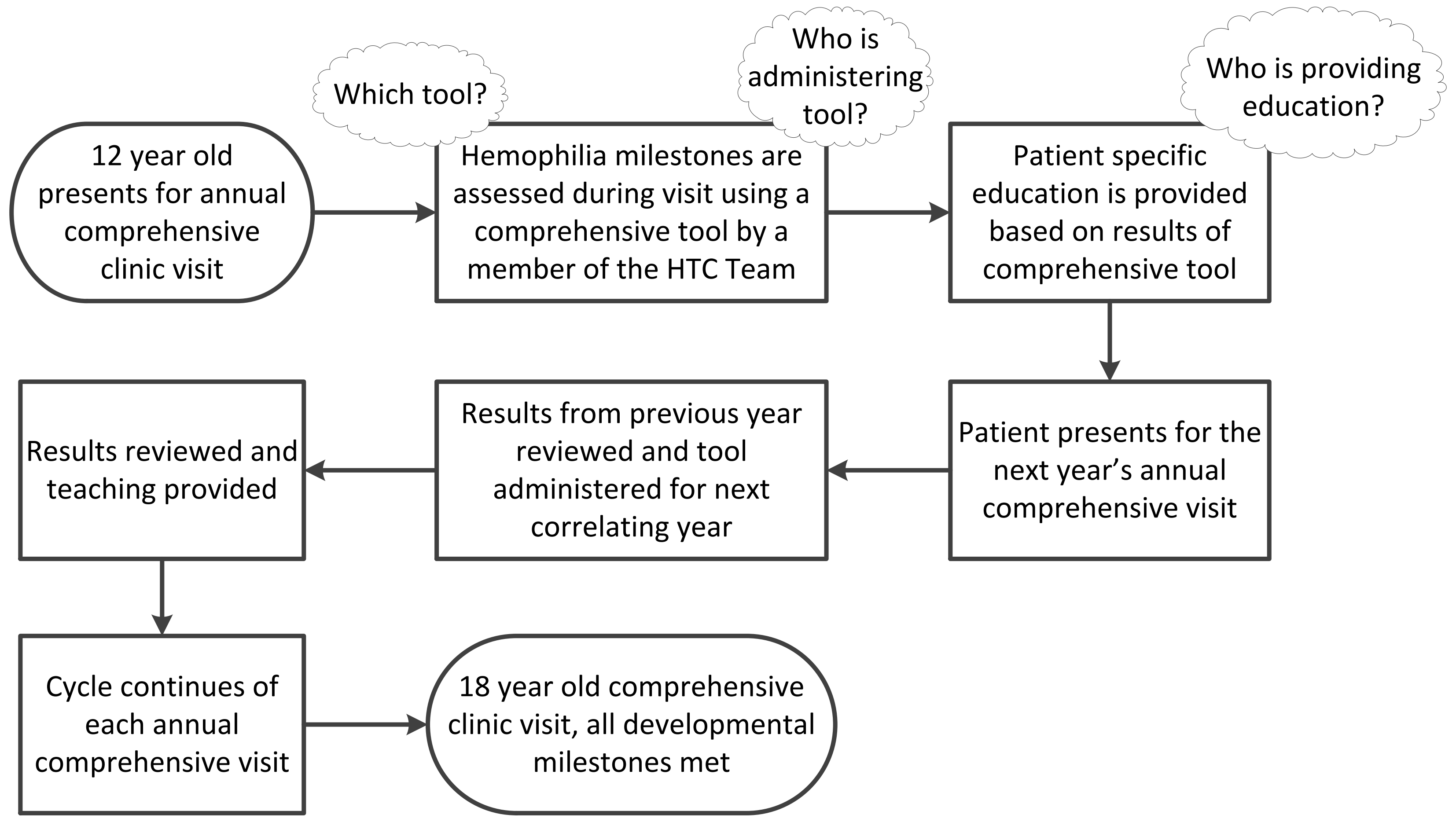
07/01-07/25/2017
Data analysis, discussion and reflection of tool use

07/25-current
Standardization of tool use in clinical practice. Working

Global Aim Statement

To improve the assessment of health knowledge for patients with Hemophilia A and B between the ages of 12-18 in the HTC of UCSF Benioff Children's Hospital Oakland. The process begins at the first annual comprehensive clinic visit at age 12. The process ends at the comprehensive clinic visit at age 18 when the patient has successful met all milestones By working on this process we expect to identify patient knowledge deficits. It is important to do this now so that we can prepare patients 12-18 to be knowledgeable about Hemophilia and be better prepared to transition to an adult care facility.

Flowchart



12 year old presents for annual comprehensive clinic visit → Hemophilia milestones are assessed during visit using a comprehensive tool by a member of the HTC Team → Patient specific education is provided based on results of comprehensive tool → Patient presents for the next year's annual comprehensive visit → Results from previous year reviewed and tool administered for next correlating year → Results reviewed and teaching provided → Cycle continues of each annual comprehensive visit → 18 year old comprehensive clinic visit, all developmental milestones met

Which tool?

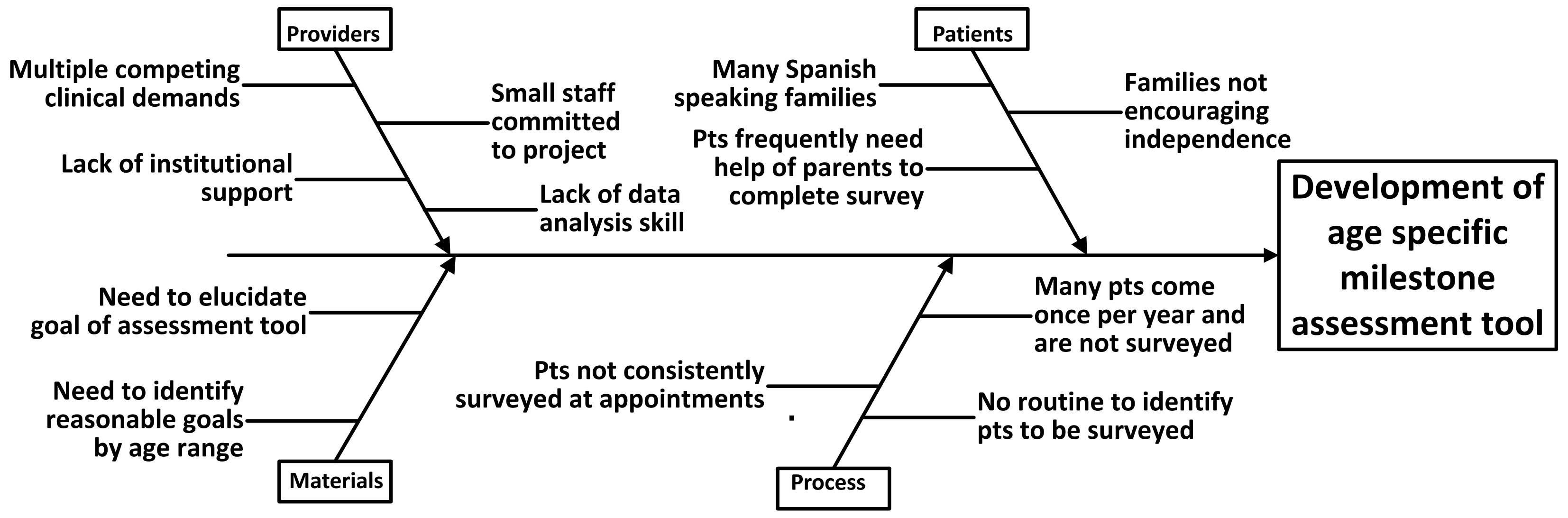
Who is administering tool?

Who is providing education?

Specific Aim Statement(s)

We will increase the percentage of patients between 12-18 pts with Hemophilia A and B who have age specific milestones assessed from 25% to 75% by 6/27/17, by identifying a milestone assessment tool and implementing a milestone tool in comprehensive clinic visits starting 4/18/17

Fishbone



PDSA

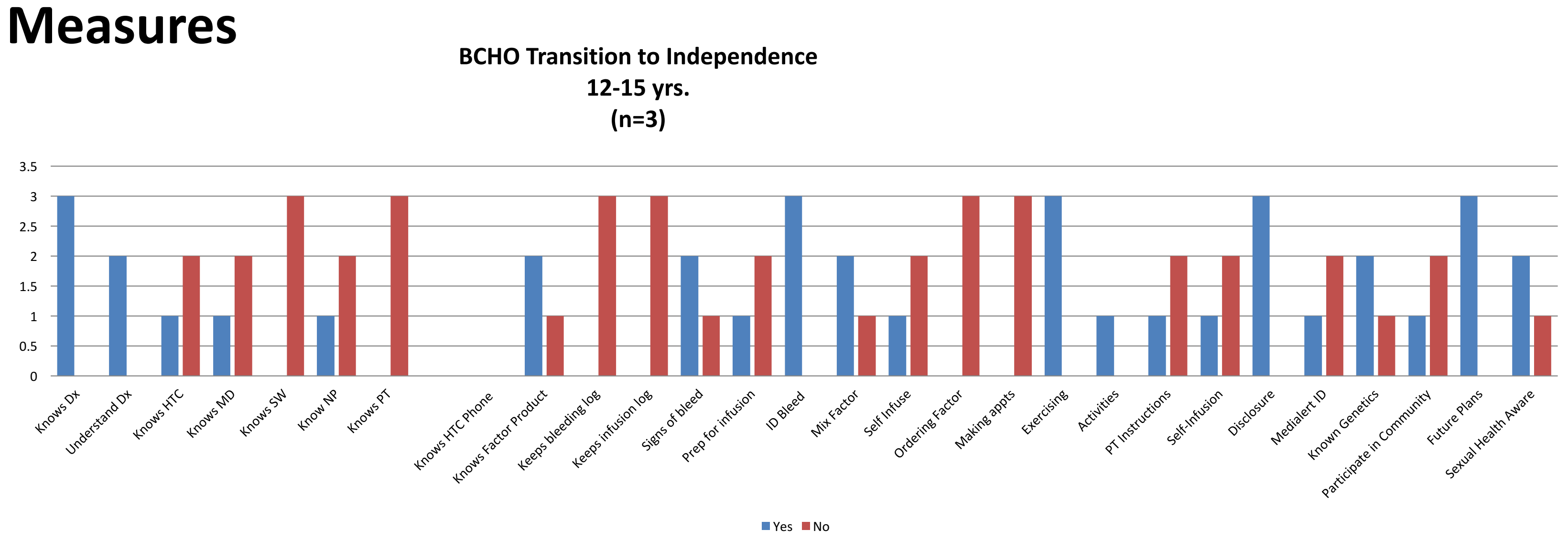
Plan: HTC specific evidenced based adolescent milestone tools for patients 12-15 and 16-18 were developed, and presented to the team during a weekly team meeting. A plan for identifying eligible patients, tool administration, data collection and data entry was developed.

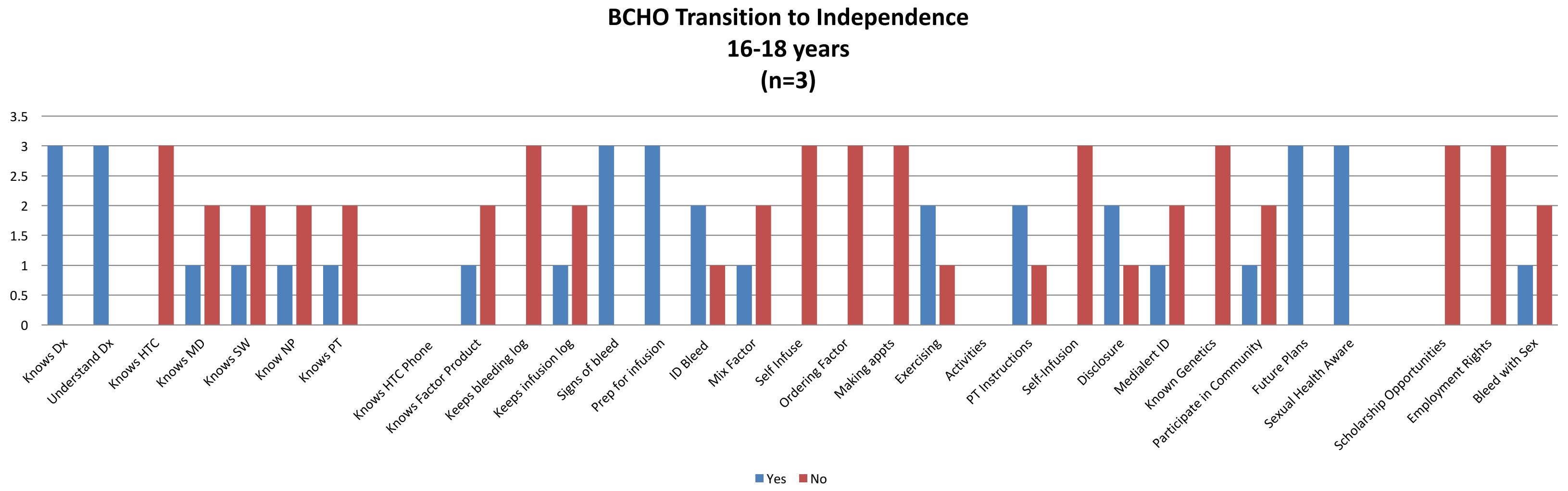
Do: Tool was piloted from April 18 to June 27, 2017;capturing 20% of our patient population with Hemophilia.

Study: Tools were successfully administered to all eligible patients during the pilot. Patient learning needs identified.

Act: Tools integrated in as a standard for annual comprehensive visits. New PDSA identified to improve patient education and achievement.

Measures





Results/Key Findings

Strengths: All of our patients age **12-15**, all could verbalize their diagnosis, have disclosed their diagnosis to close friends and family, could mix factor independently, exercise regularly, have had sex education, and have future plans (work college etc.)

For patients **16-18 ,** 100% could verbalize and have demonstrated understanding of their diagnosis.

Weaknesses: For patients **12-15**, deficits were noted in identifying the name of our physical therapist , identifying the phone number of our HTC, keeping bleeding or infusions logs, making appointments independently, and ordering their own factor.

For patient **16-18** deficits were noted in knowing the names of providers (MD, NP, SW, PT), keeping bleeding logs, and ordering their own factor. Additionally, our patients age 16-18 struggle with understanding the genetics of hemophilia transmission, as well as hemophilia scholarships and employment rights.

Summary/Lessons Learned and Next Steps

As a result of the milestone assessments it was identified that patients 12-18 with Hemophilia A and B had difficulty accurately identifying team members by name or by role. Based on this information a new two pronged PDSA cycle was started. An automated phrase was developed containing the names, roles and contact information for each HTC team member. This phrase is now added in the patient information section of the after visit summary that each family receives at the end of their visit. The team administrative assistant has been requested to highlight this information when she exits the patient.

In addition, a brochure is being developed highlighting our 340B program. The brochure will include pictures of each team member and their roles.

We will be able to study the effectiveness of these interventions when we conduct milestone assessments next year and determine whether patients have improved in their ability to identify team members and their roles.

NHPCC Dartmouth Quality Improvement Program July 2016 – October 2017