Adolescent Transition Quality Improvement Collaborative: The Yale HTC Experience

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Background/Problem Statement

Our Hemophilia Treatment Center at Yale is centrally based in the Department of Pediatrics, where all patients with hemophilia or carriers of hemophilia are cared for throughout their lifetime, regardless of age.

During the 2014 Patient Needs Assessment Survey, the lack of a clear transition process for patients was brought out as an area for improvement in our practice. Given that our hemophilia patients and families continue to receive their care from childhood through adulthood with the same providers, there is no physical transition of care that often accompanies the emotional and intellectual transition to accessing healthcare as an adult.

A change in our practice to include a more formalized transition process for these patients would make the concept of transition more apparent and allow for more open communication regarding the importance of taking responsibility for one's own health and healthcare needs.

Objectives

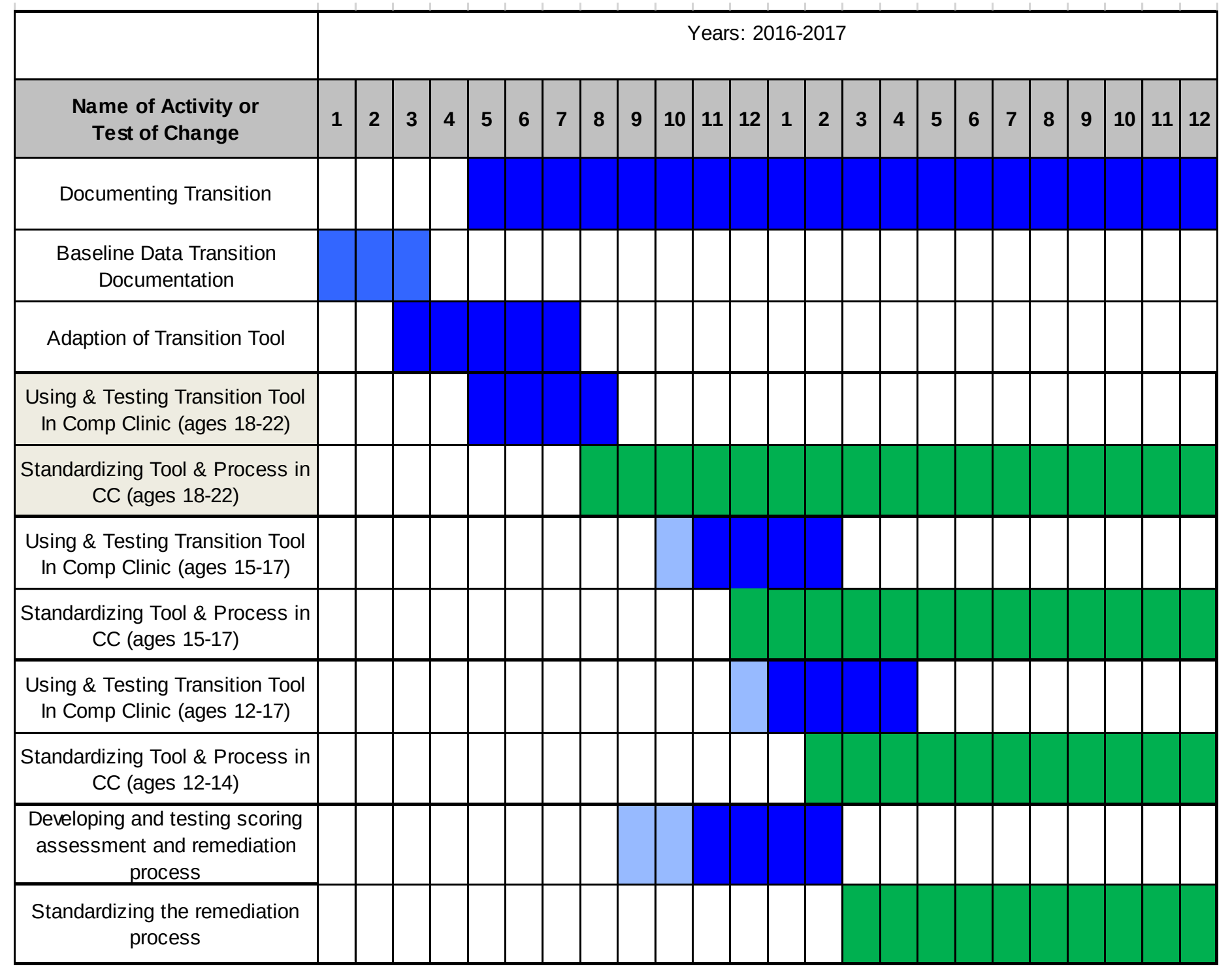
Global Aim

We aim to improve adolescent transition in the Yale HTC.

Specific Aim

Increase the number of patients ages 18-22 years seen in comprehensive clinic that have discussed and documented age appropriate hemophilia transition and milestones. Will expand to patients aged 12-18 years in the next cycle of testing, once process is standardized.

Timeline



	Years: 2016-2017																							
Name of Activity or Test of Change	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
Documenting Transition					🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦
Baseline Data Transition Documentation	🟦	🟦	🟦																					
Adaption of Transition Tool			🟦	🟦	🟦	🟦	🟦																	
Using & Testing Transition Tool In Comp Clinic (ages 18-22)					🟦	🟦	🟦	🟦																
Standardizing Tool & Process in CC (ages 18-22)								🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Using & Testing Transition Tool In Comp Clinic (ages 15-17)										▨	🟦	🟦	🟦	🟦										
Standardizing Tool & Process in CC (ages 15-17)												🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Using & Testing Transition Tool In Comp Clinic (ages 12-17)												▨	🟦	🟦	🟦	🟦								
Standardizing Tool & Process in CC (ages 12-14)														🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Developing and testing scoring assessment and remediation process									▨	▨	🟦	🟦	🟦	🟦										
Standardizing the remediation process															🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩

5-P's: Purpose

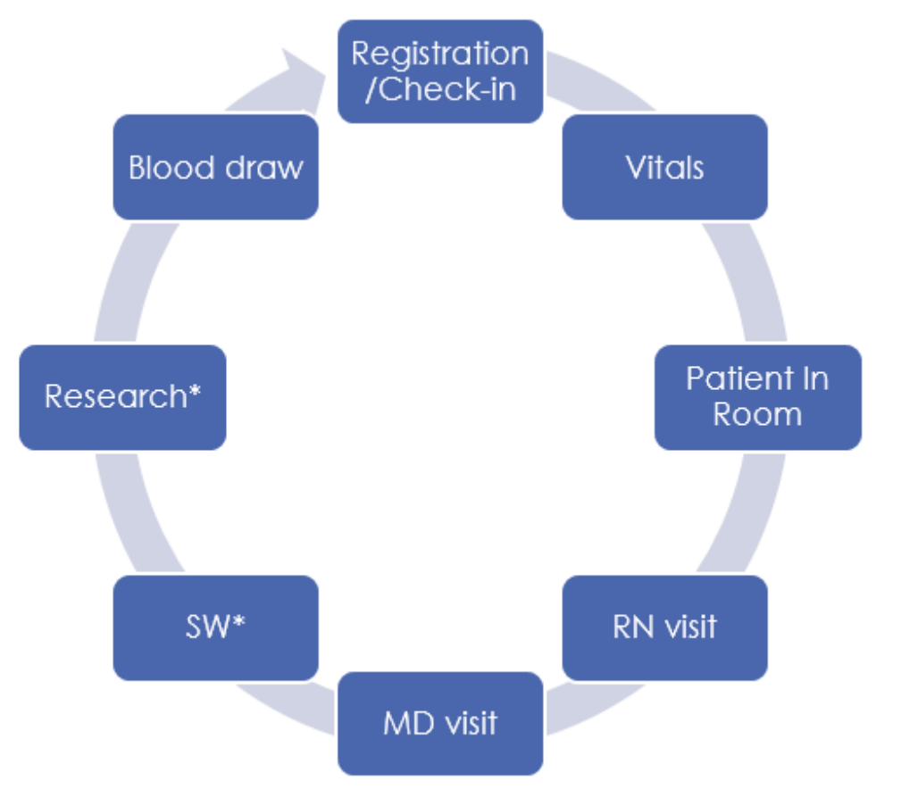
The Yale Hemostasis and Hemophilia Treatment Center partners with patients and families to provide comprehensive medical care through our coordinated efforts which will work to improve clinical outcomes, increase adherence to recommended treatments and enhance quality of life in all patients with bleeding and thrombotic disorders.

5-P's: Patients

			<1	12-24m	25m - 4y	5y-9y	10y-14y	15y-19y	20y-24y	25y+
Bleeding Disorders										
	Hem A	mild	0	0	2	0	2	7	3	6
		moderate	0	0	1	0	0	1	2	6
		severe	0	0	2	9	8	4	3	7
	Hem B	mild	0	0	0	0	0	0	0	2
		moderate	0	0	0	1	1	0	1	0
		severe	0	0	0	1	2	2	1	2
	vWD		0	4	13	36	40	46	18	4
	Other		0	1	3	7	10	7	2	1
	Totals		0	5	21	54	63	67	30	26
Thrombotic Disorders										
	Thrombosis, on anticoagulation		1	1	4	8	11	22	4	n/a
	Thrombophilia		2	4	8	16	18	48	7	n/a
	Totals		3	5	12	24	29	60	11	n/a

5-P's: Processes

Hemostasis Clinic Flow



Additional Post- Clinic Visit Flow Elements:
Clinical Data entry Clinical Manager
Research forms (paper only)
Sample processing for studies, shipping etc
RN/APRN follow up of lab results, review with MD
Modify treatment plan as needed
Update prescriptions and obtain prior auth for medications
Update emergency care letters
Generate comp clinic summary to be sent to pt and PCP
Phone follow up with patient/family

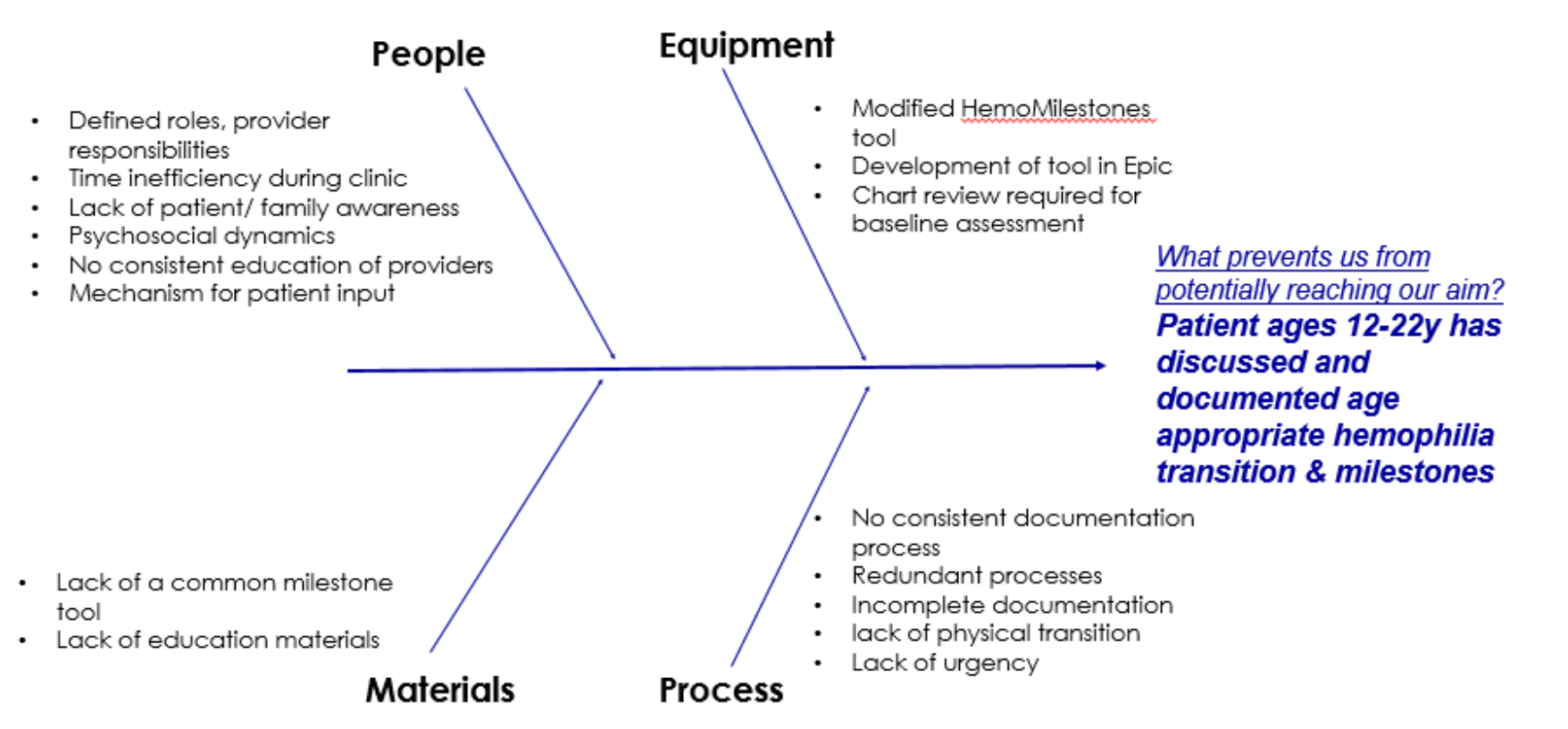
5-P's: Professionals & Patterns

- MDs (2)
- APRN(s) (2)
- RN (1)
- SW (0.5)
- Data manager (1)
- Administrator (1)
- PT (0.2)

- Prior Formal QI Work
  - Surgery Planning Template
- Team Meetings
  - Weekly Meeting with Core Hemostasis Team
  - Agenda items include
    - Weekly clinic list review
    - Updates on Scheduling Comp clinics
    - Updates on Study enrollment
    - Study issues
    - Update on Staffing structure/issues
    - Psychosocial Update on patients
    - Medication/Factor/Insurance/340B Issues

Yale HTC QI Team

Fishbone for Transition Aim



People:
- Defined roles, provider responsibilities
- Time inefficiency during clinic
- Lack of patient/ family awareness
- Psychosocial dynamics
- No consistent education of providers
- Mechanism for patient input

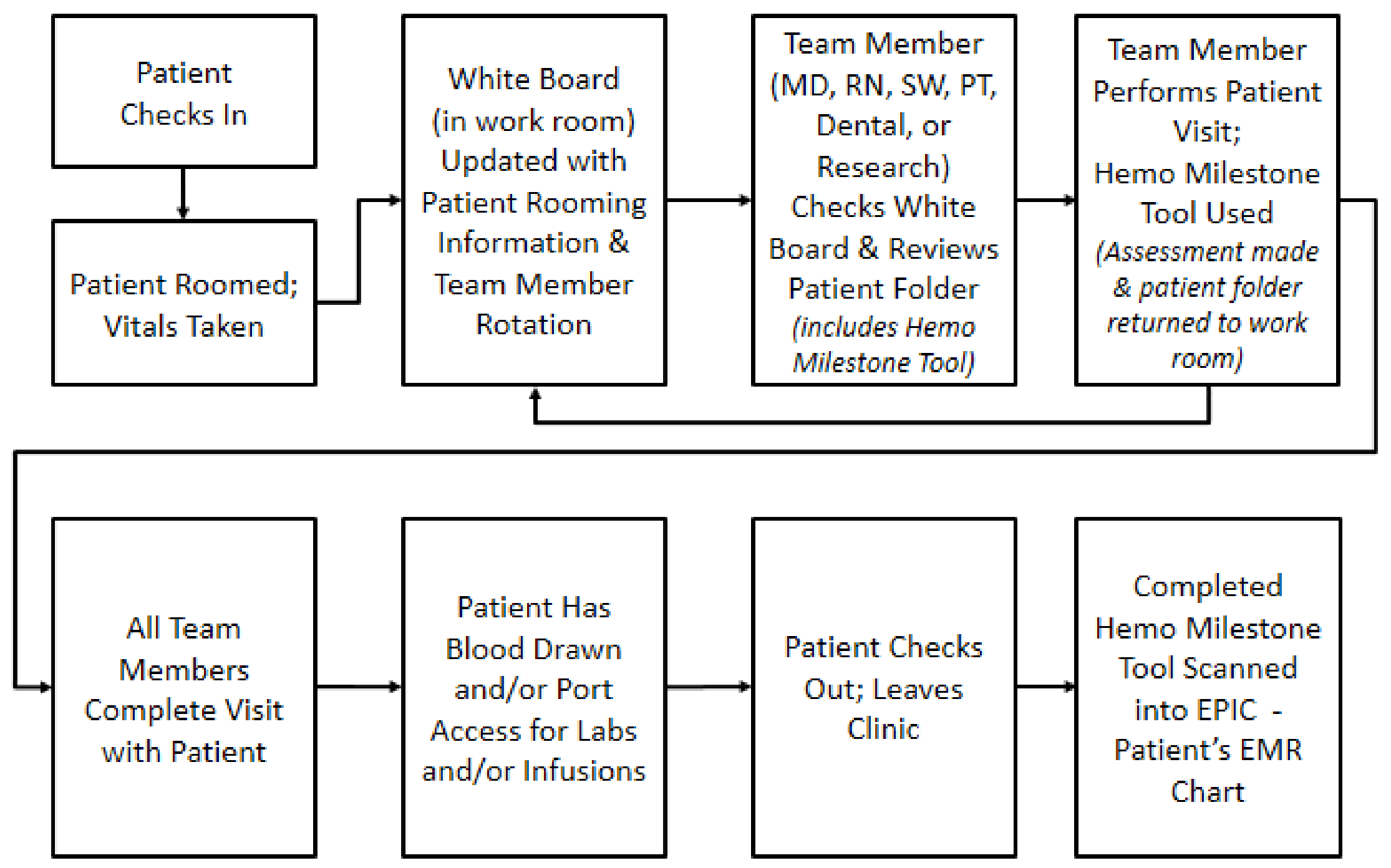
Equipment:
- Modified HemoMilestones tool
- Development of tool in Epic
- Chart review required for baseline assessment

Materials:
- Lack of a common milestone tool
- Lack of education materials

Process:
- No consistent documentation process
- Redundant processes
- Incomplete documentation
- lack of physical transition
- Lack of urgency

What prevents us from potentially reaching our aim?
Patient ages 12-22y has discussed and documented age appropriate hemophilia transition & milestones

Yale HTC – Comprehensive Clinic Visit Process Flow



PDSA # 1

Plan: Review and establish age-specific transition milestones; create milestone tool, adapting Boston *HEMO-Milestones* tool for specific age groups.

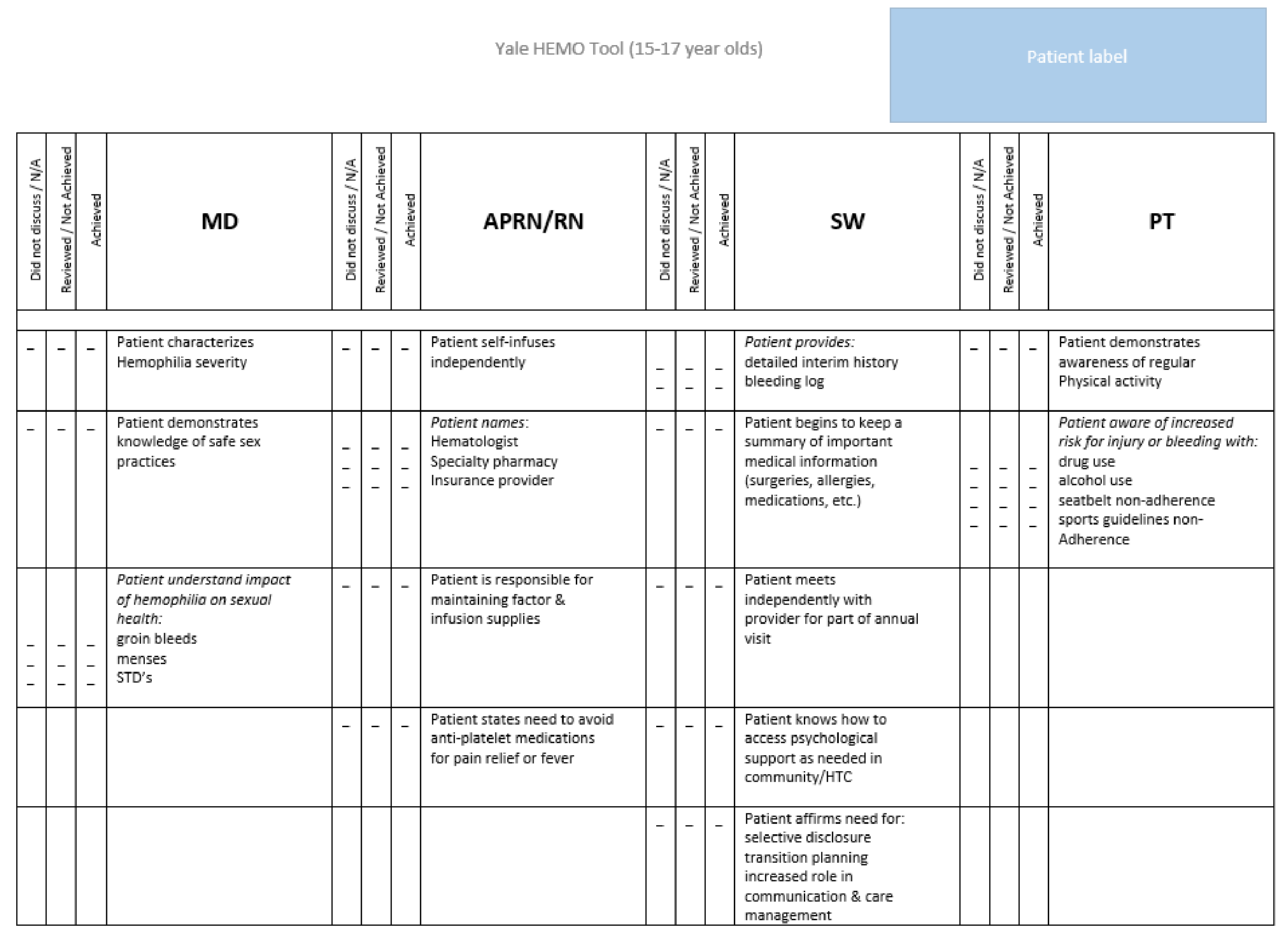
Do: Implement in comprehensive clinic using it on three patients, then repeating with three patients and then all eligible patients in comprehensive clinic.

Study: Tool takes time to use; patient feedback positive – very engaged and eager for more information. Number of patients actually used.

Act: Changes made to make responsibilities more clear and milestones already achieved marked ahead of time. Additional plans to provide patient with copy of completed tool and personalized action plan.

***Adaptation of the Tool*:**

1. Use of an existing tool (*HEMO-Milestones*, ref. 1)
2. Team members made recommendations regarding wording and addition or removal of items (18-22yo age group)
3. Team meetings to review, discuss and vote on changes to the milestone items in the tool
4. Placement of items refined, providing clearer outline by provider role (MD, APRN/RN, SW and PT)
5. Addition of "Did not discuss/NA", "Reviewed/Not Achieved" & "Achieved" to allow for patient advancement through time
6. Addition of space for patient label
7. Formulation of plan to upload into EPIC (Yale's EMR)
8. PDSA cycle #1: Hemophilia Comprehensive Clinic use and Patient feedback
9. Team members reviewed *HEMO-Milestones* for ages 12-18yo.
10. Decision made to break 12-18yo into two groups, tool refined and finalized for ages 12-14yo, 15-17yo



Yale HEMO Tool (15-17 year olds)

Patient label

Did not discuss / N/A	Reviewed / Not Achieved	Achieved	MD	Did not discuss / N/A	Reviewed / Not Achieved	Achieved	APRN/RN	Did not discuss / N/A	Reviewed / Not Achieved	Achieved	SW	Did not discuss / N/A	Reviewed / Not Achieved	Achieved	PT
_	_	_	Patient characterizes Hemophilia severity	_	_	_	Patient self-infuses independently	_ _	_ _	_ _	*Patient provides:* detailed interim history bleeding log	_	_	_	Patient demonstrates awareness of regular Physical activity
_	_	_	Patient demonstrates knowledge of safe sex practices	_ _ _	_ _ _	_ _ _	*Patient names*: Hematologist Specialty pharmacy Insurance provider	_	_	_	Patient begins to keep a summary of important medical information (surgeries, allergies, medications, etc.)	_ _ _ _	_ _ _ _	_ _ _ _	*Patient aware of increased risk for injury or bleeding with:* drug use alcohol use seatbelt non-adherence sports guidelines non-Adherence
_ _ _	_ _ _	_ _ _	*Patient understand impact of hemophilia on sexual health:* groin bleeds menses STD's	_	_	_	Patient is responsible for maintaining factor & infusion supplies	_	_	_	Patient meets independently with provider for part of annual visit				
				_	_	_	Patient states need to avoid anti-platelet medications for pain relief or fever	_	_	_	Patient knows how to access psychological support as needed in community/HTC				
								_	_	_	Patient affirms need for: selective disclosure transition planning increased role in communication & care management				

Measures

- Use in eligible patients in Comprehensive Clinic
- Future analysis of patient achievement

Results

Patient Feedback:

It is great that you are doing this, I feel like I already know all of this stuff, but I guess there are other people my age who don't.

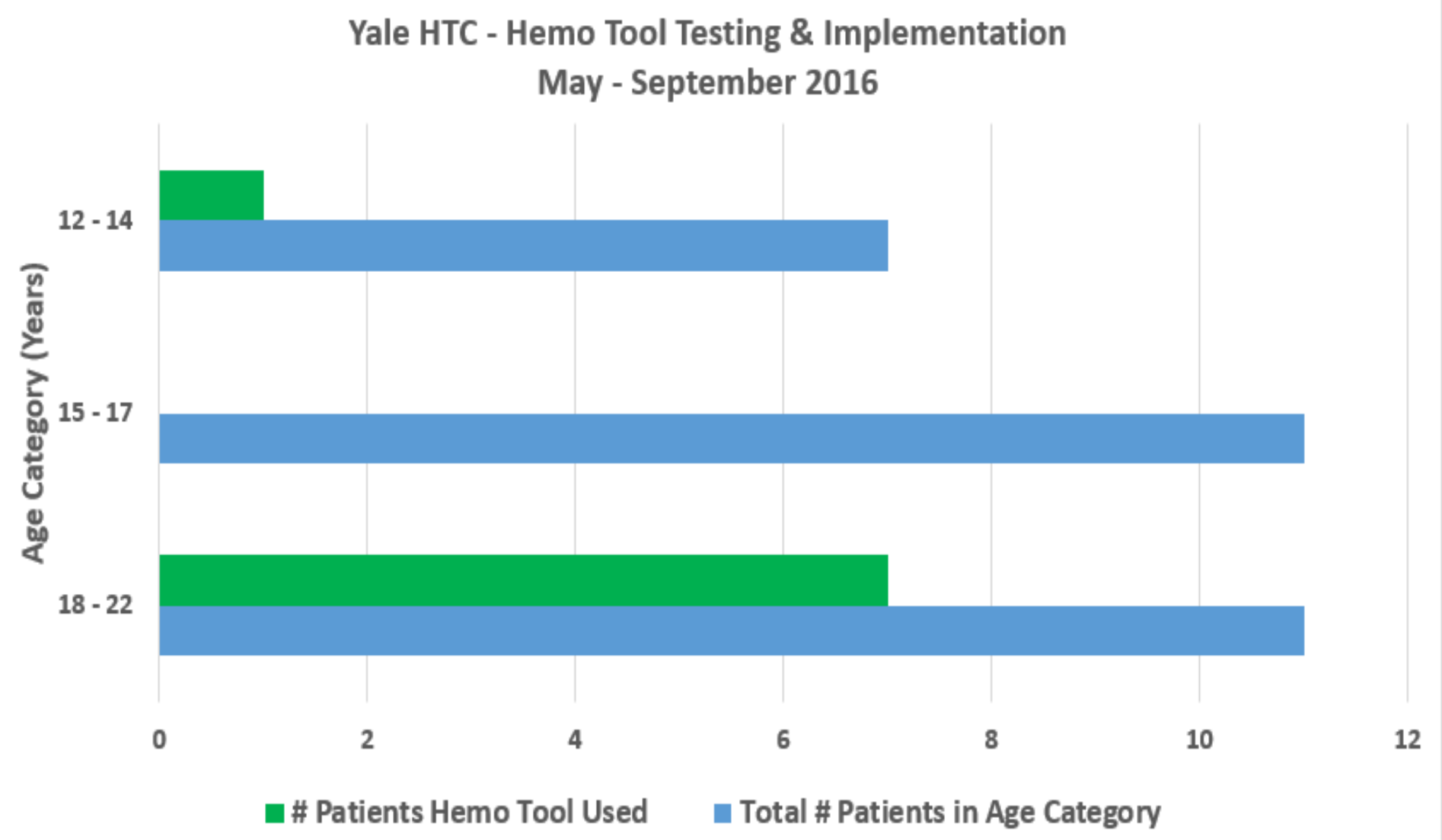
– 18yo M with severe Hemophilia A

I think people are going to respond well to the assessment, but what if they need help with something. Do you have handouts or pamphlets or something?

– 19yo F with moderate Hemophilia A

This is great! Can I get a copy?

– 21yo M with severe Hemophilia A



Summary

The Yale HTC providers have developed an improved quality improvement capability through the Quality Improvement Learning Collaborative partnering with ATHN and The Dartmouth Institute Microsystems Academy (TDIMA).

Through careful reflection and self-assessment in the 5 P's evaluation, the development of global and specific aims allowed the team to clarify our comprehensive clinic flow, choose and modify a patient assessment tool and develop our first PDSA cycle.

Successful implementation of the milestone tool within our clinics will allow us to better understand patient needs and provide optimal care to our patients and families.

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References

Croteau, S. E., Padula, M., Quint, K., D'Angelo, L. and Neufeld, E. J. (2016), Center-Based Quality Initiative Targets Youth Preparedness for Medical Independence: *HEMO-Milestones Tool* in a Comprehensive Hemophilia Clinic Setting. Pediatr Blood Cancer, 63: 499–503.