

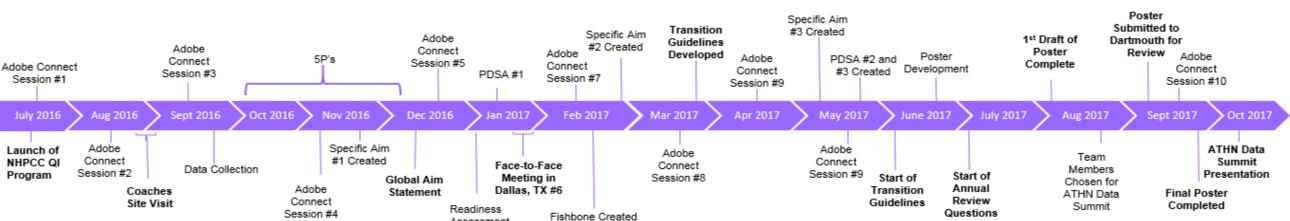
Transition to Independence: A Collaborative Team Approach to Improve Care and Self Advocacy





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Background

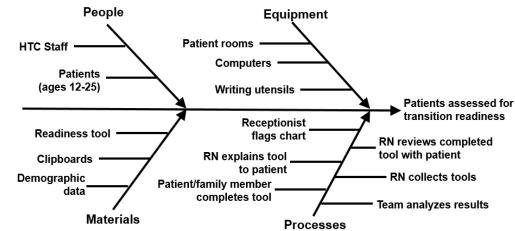
The Hemophilia Center of Western New York is an independent lifespan center located in an urban setting in Buffalo, NY. Our HTC encompasses 8 counties of Western New York. Our treatment center manages approximately 500 patients with bleeding disorders and thrombosis.

Problem Description

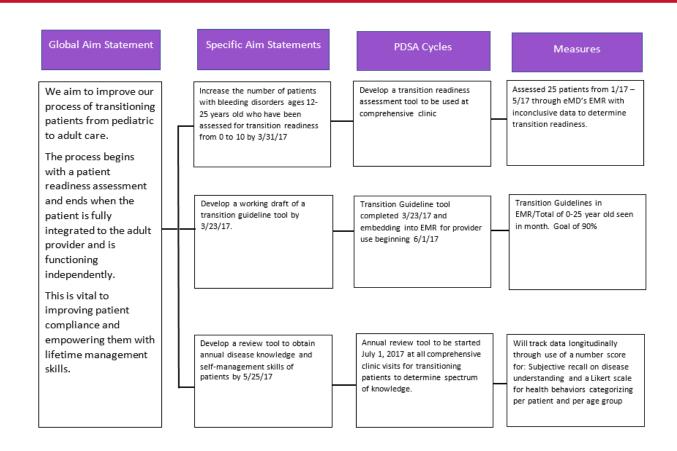
Our Center lacks a current process to transition patients from pediatric to adult care, as well as an ability to assess and measure patients knowledge of disease, self-management skills and readiness to transition.

Transition Readiness Fishbone Diagram

We will increase the number of patients ages 12-25 years old that are assessed for transition readiness from 0 to 10 by 3/31/2017

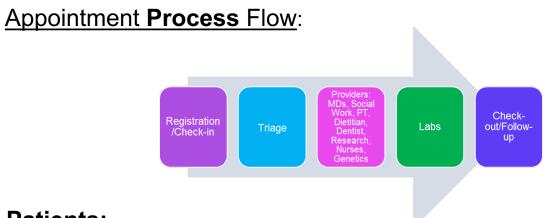


Aim Statements/PDSA Cycles

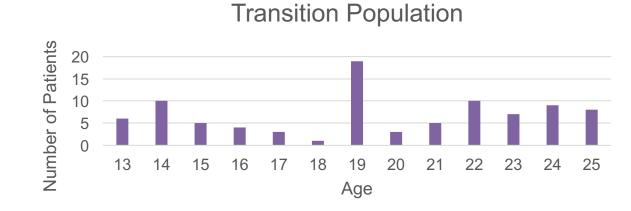


5 P's

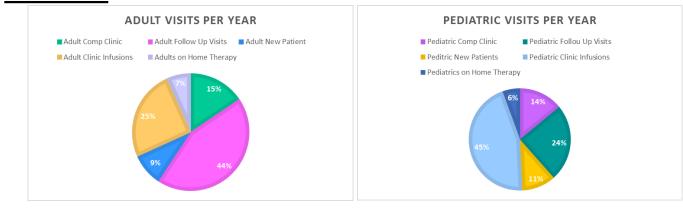
Purpose Statement: To improve the patient experience and center operations.



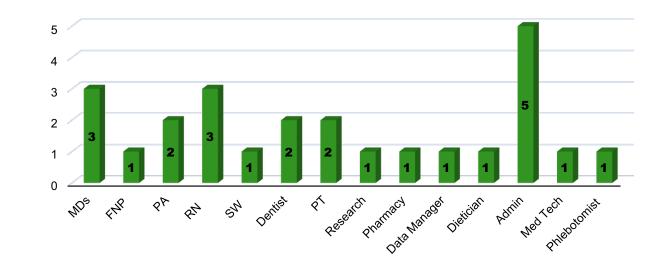
Patients:



Patterns:



Professionals:



Transition Documents

My diagnosis is		My factor leve My target join asma-derived C	t is		n	Transition Guidelines Transition Guidelines Dentist				
Type of infusion or medicine for bleeding: Name: E What is the dose and schedule of your medicine? Who infuses?	□ P	sma-derived C	Recombinan		n	Social Work Dentist				
Name: E What is the dose and schedule of your medicine? Who infuses?					n					
Name: E What is the dose and schedule of your medicine? Who infuses?					n				$\overline{}$	
What is the dose and schedule of your medicine? Who infuses?	DVIII D IX	□Other	□Not kn	own □DDAVP		Social Support Birth 1 2 3 4				_
What is the dose and schedule of your neclicine? Who infuses?	DVIII D IX	□Other	□Not kn	own DDDAVP		Meet another HTC family in clinic Monitor of coping difficult relative to new diseases's and provide emotional susport or referral Independent Health Care Behaviorr Birth			$\overline{}$	_
nedicine? Who infuses?					□ None					-
redicine? (ho infuses?						Encourage involvement in local blamodrifts Chapter	_		—	╄
redicine? (ho infuses?						Encourage monovement monovement and a compare	1			1
ho infuses?						Encourage interaction with other hids who have a bleeding disorder zee dentirt every six munity, soft briefle touthbrush.	1			1
						Encourage participation in non-bleeding disorders community events/social organisations	1			1
						Provide information internet resources, online support groups, contacts for various hemophilia	1			
ossible side effects						organizations (NEF, ME, NEA, etc.)	_		+	₩
						Discuss benefits of contact with other parents? support groups Discuss benefits of contact with other parents? support groups			-	_
						Educational/Yocational/Financial Planning Dir curz raft tayz and utonzilz, enforce a fety ruler to prevent mouth b				
						Discuss Pre-school Program/Day-Care Discuss Pre-school Program/Day-Care Discuss a polyting pressure to treat mouth blooding, contact dentist			$\overline{}$	г
in this past year, how aften does the			Very		I'm not sure	Provide assistance with resources and guestions to ask child care provider	1			1
following occur? Never	er Rare	y Sometime	often	Always	or not		_		-	-
			orten		applicable	Self Advocacy & Self Esteem				-
ear my seatbelt in the car 1	2	3	4	5		Describe what the parent can expect from the HTC (comprehensive care, annual clinic visit, etc.). Discuss conditional hardinationum einhalt and injusen HTP AND assess from desiral information.				
year a medical alert device (bracelet,						Discuss conliderhalty/disclosure rights and issues (HPAA), access to medical information, consents, decision making process.				
cklace) 1	2	3	4	5		Consents, processing managements. Discuss importance of papern educating child rediagnosis, pain, and adult notification for Independent Health Care Behaviors.	5	6	7	
(Kilduc)		-	-	12701		Independent Health Care Dehaviors To provent dental carior, diretury diet and gral hygiene with parenty, see dentirt	_		_	$\overline{}$
year protective equipment during							1			1
sports/biking 1	2	3	4	5			1			1
			_	_	_	Arthess senaration ansietr (narent antifor rekits) diet, normalation ansietr (narent antifor rekits)				_
an tell when I am having a joint or	2	2	4	5		Address any psychological behavioral concerns Director wing non-arpirin pain reliever for earing exfoliation/or uption pain				
uscle bleed 1	-	,				Enforce sefety rules of preventing mouth blooding				
ake it easy or rest when I have a	. 20			a 5000	252	Direur applying pregrupe to treat mouth bleeding and contact dentirt and	_		-	-
bleed	2	3	4	5		Age: 5-8 gears old	1			1
500	_	_		-			_		+	₩
rave used an app/website to learn	1 2		4			Continue to discuss benefits of community supports/provide contact information (NHFIHFA) Discurse eliminating and habits and arthadantic consultation				┸
out my bleeding problem	_ Z	3	4			Involve child in social activities with other kids who have a bleeding disorder				
ise condoms/birth control to prevent						Encourage social networking with kids who do not have a bleeding disorder (scours, clubs, youthinelgious				
Ds and pregnancy 1	2	3	4	5		Discuss importance of Hemophila CampHTC group activities Discuss temporal recommendation of the CompHTC group activities Discuss temporal recommendation of the CompHTC group activities Age: 9-12 years = 14				
		_		_		Unicous reeings in preparing to ratio as oning goes to screece or camp Education/Processions/Financial Planning Independent Health Care Behavierz		40	- 11	_
ur family has participated in events							7	10	_ 11_	_
rough the HTC, like camp 1	2	3	4	5		Liscous and economic encountered Diricusz diot and anal hygiono with parents, see dentire every Collaborate with school to require plan is induse to address any in school bleeding complications, schedule	1			1
ur family has had problems			_	_		Discuss importance of set times for homework/school projects, child's responsibilities at homelichores is: zix monthu, rooft briefle toothbrush, toothparke, flour, mouthwash decrease	1			1
	2	3	4	5		and the concept of allowance rugar in diet, no rugar liquidr during napar feed time, no retentive anacks, check			1	1
constituting factor at home		,		,		Vork with school as needed to establishedeline 504 plans/IEP 's, attend CSE migs, as necessary Flueride Government Government Flueride Government Gov	1			1
ur family has run out of factor at		200		933			_		+-	+
me 1	2	3	4	5		Discuss biling/insurance concerns Discuss biling/insurance concerns Discuss biling/insurance concerns Discuss biling/insurance concerns	_			╨
	_	_	_	_	_	Self Advocacy & Self Esteem Enforce and use of sports mouthquards to prevent mouth			1	1
ur family has thrown out an unused	1 2	2	4			Ensure child knows the name of disorder bleeding	1	l	1	1
of factor		,	-	,		Child begins to interact independently with medical team Discuss applying pressure to treat mouth bleeding and contact dentist and			$\overline{}$	\Box
ir family has forgotten to infuse						Encourage school in-services by HTC staff	1	l	1	1
fore 1	2	3	4	5		Discuss whenhive to take place, any problems with peers and awkward skuations that may arise (i.e.	+	_	+-	+

Results/Key Findings

- To date there are 74 Transition patients who have the Transition Guidelines in place in their electronic medical records.
- All 74 Transition patients have documentation by providers on their Transition Guidelines Documents, for a 100% completion rate YTD.
- From July-September 2017: 20 Annual Review Questionnaires have been administered to patients (4 ages 9-12y, 6 ages 13-15y, and 10 ages 16y +) and 13 have been administered to parents (4 ages 9-12y, 6 ages 13-15y, and 3 ages 16y +).
- Annual Review Questionnaires are being used to prioritize educational goals, with ongoing PDSAs to refine questionnaires and identify optimum patient population. These processes are ongoing.

Lessons Learned

- Transition is ongoing and not easily measured.
- Quality improvement training has revolutionized how our practice approaches patient care, communication and center operations.
- PDSAs are valuable tools for continual process review, and illustrate whether interventions are meeting our Center's needs.

Next steps

- Establish a center-wide quality improvement committee to include representation from patients and board members
- · Act as a QI resource for other HTCs in our region
- Continue to re-evaluate our transition guidelines and impact on patients

