



CIBD's Transition Journey: (Don't Stop Believin') In Ordering Factor

Center for Inherited Blood Disorders

Spencer Dunn MSW, Khanh Pham RN, Tanya Melendrez CPhT, Matthew Cianciulli MS

About CIBD

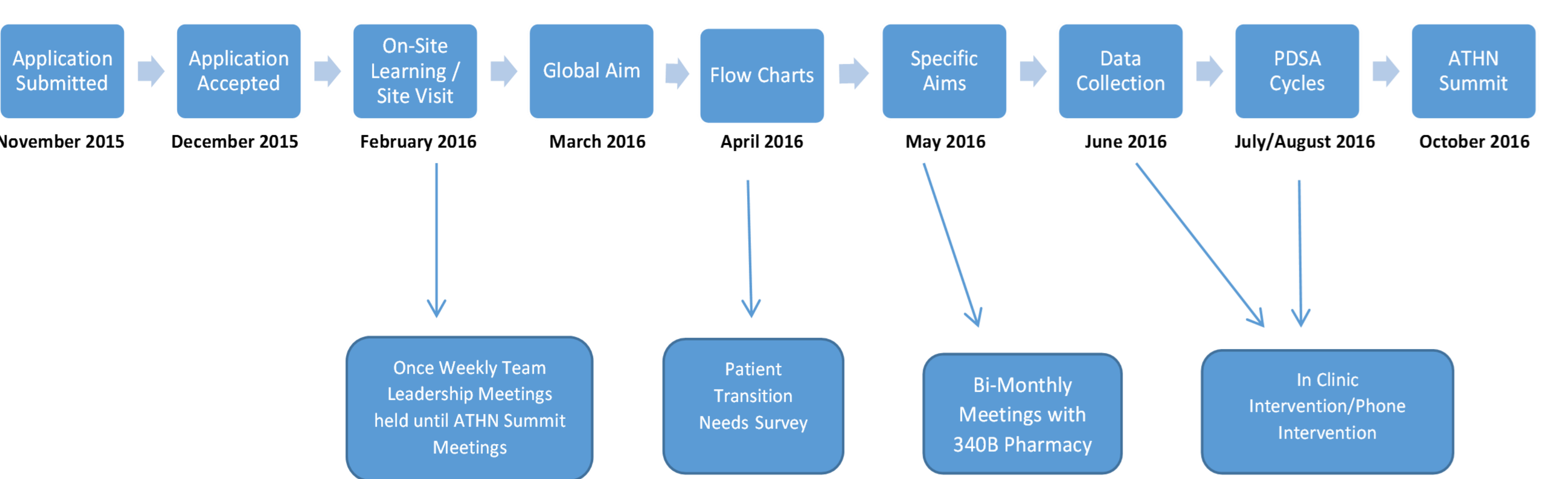
MISSION STATEMENT: At CIBD, we believe that a family-centered, multidisciplinary team approach is essential to helping our patients live normal and productive lives. Care should begin at birth, and last a lifetime.

INTERDISCIPLINARY TEAM APPROACH: We are a multidisciplinary team that treats patients of all ages. Our mission is to improve the quality of life for people with bleeding disorders, and their families. As a 501(c)(3) (nonprofit) community health center, we accomplish this by providing education, support, and services. By connecting patients with the sources that they need, we treat the whole person, and family. Our team of physicians include adult providers from UC Irvine and pediatricians from CHOC Children's.

OUR HEALTHCARE PROFESSIONALS:

- Hematologists: Diane Nugent MD, Amit Soni MD, Nina Hwang MD, Arash Mahajerin MD, Susan Claster MD, David Buchbinder MD, Loan Hsieh MD, Geetha Puthenveetil MD
- Nurses: Jeri Tucker RN, Marianne McDaniel RN, Nicole Crook RN, Khanh Pham RN
- Physical Therapists: Grace Hernandez PT
- Psychologist: Sharonne Herbert PhD
- Social Worker: Spencer Dunn MSW
- Clinical Pharmacist: Jason Zamora Pharm D
- 340B Patient Pharmacy Patient Representative: Tanya Melendrez CPhT
- Director of Clinical Operations and Quality Services: Matt Cianciulli MS

Project Activity Timeline



Transition Problems

- Prior to starting this project CIBD had no formal process of tracking the transition barriers and milestones of patients.
- Originally we were under the impression that the lapse in insurance for state insured patients was an issue. While reviewing this patient population we determined that our center had a very low rate of insurance lapse.
- Through record review we determined we had center wide transition issues and needed to better understand actual patient issues.
- To understand the transition needs of our patients we decided to send out a patient survey to 59 patients ages 13 to 21.

Patient Survey

Your CIBD providers are conducting an anonymous survey to better understand the knowledge our teenage and young adult patients have on their hemophilia care. **We kindly ask that patients (not parents) would fill this survey out and return it to CIBD by March 31st, 2016.**

Please leave blank any answers you do not know, *it's ok*, we need to know how to do a better job teaching you and others about this important information.

1. What is your age? _____
2. What is the name of your Hemophilia Treatment Center? _____
3. What is the phone number of your Hemophilia Treatment Center? _____
4. What brand of factor do you use? _____
5. What is your current factor dosage (units)? _____
6. How often do you infuse factor? _____
7. How many bleeds have you had in the past 12 months? _____
8. What is the name of your insurance? (if applicable) _____
9. How often do you visit your Hemophilia Treatment Center? _____

Please circle your answers below

10. What type of Hemophilia do you have?

Hemophilia A	Hemophilia B	Not Sure
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11. What are signs of an active bleed? (All that apply)

Bruising	Warm to Touch	Redness	Pain
Cold to Touch	Swelling	Flexible	Not Sure

12. Who orders your factor?

Parents	Guardian	Relative	Myself
Someone Else	Not Sure		

13. Who infuses your factor?

Parents	Guardian	Relative	Myself
Infusion Center	Significant Other	Not Sure	

!!!!!!! **THANK YOU** !!!!!

Patient Survey Results

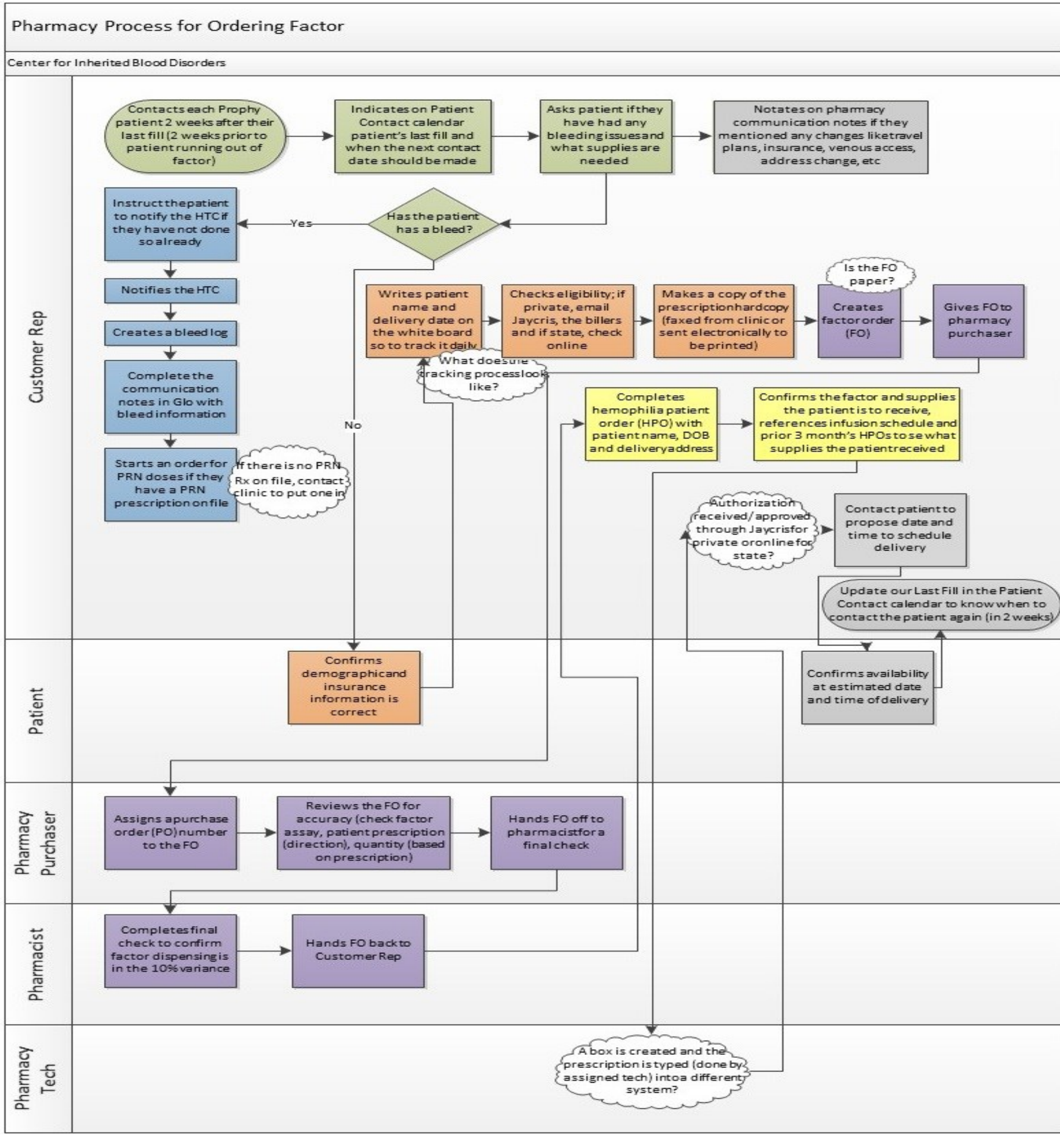
Survey Responses	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9	Patient 10	Patient 11	Patient 12	Patient 13	Patient 14	Patient 15	Patient 16	General Observations	Transition Specific Observations
Age	13	20	20	18	19	19	14	18	15	19	16	20	16				61.5% (8 of 13) correctly identified the name of their HTC	75% (10 of 13) correctly identified the name of their HTC
Name of HTC	St Josephs Hospital	CIBD	CIBD	CIBD	CIBD Orange, CA	Center for Inherited Blood Disorders	CIBD	CIBD	CIBD			Kaiser Fontana						
Phone Number of HTC	Not sure					714.221-1200						(909)427-2000						
Brand of Factor	Advate Factor 8	Baycr	Elctate	Advate	Aproline and Humate P	Helixate	Helixate	Advate	Advate			Factor 9	Advate	Recombinate			70% (9 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Current Factor Dosage	1800	2000	3500				2500	4500				1204					85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Infusion frequency	3x/week	3x/week	2x/week	3x/week	as needed	3x/week	3x/week	3x/week	+ 1	Only when needed	Thursday and Sunday	As needed	2-3x/week				85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Bleeds in last 12 months	1	0	2	1,3	3	0	10	4,6	0	0	0	0	0	0	0	0	0	0
Name of Insurance	Not sure	BlueShield	Arthem Blue Cross	Arthem Blue Cross	CCS	Arthem Blue Cross	Caloptima	Blue Cross	Aetna			Kaiser	Blue Cross				85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Frequency of Visits to HTC	1x/year	1x/year	1x/year	1x/year	as needed and checkups	1x/year	1x/year	1x/year	1x/year	1x/year	1x/year	Every November	as needed				85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Type of Hemophilia	Hemophilia B	Hemophilia A	Hemophilia A	Hemophilia A	Hemophilia B	Hemophilia A	Hemophilia A	Hemophilia A	Hemophilia A	Hemophilia A	Hemophilia B	Hemophilia A	Hemophilia A	Hemophilia A	Hemophilia A		85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Signs of Active Bleed	Warm to touch, pain, swelling	Bruising, pain	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Warm to touch, pain, swelling, flexible	Not sure	Warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible	Bruising, warm to touch, pain, swelling, flexible		85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Who orders factor	Someone else	Parents	Mostly myself, occasional y parents	Parents, someone else, not sure (doctor)	Parents	Myself	Parents	Parents	Parents	Parents	Parents	Parents	Parents	Parents	Parents		85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor
Who infuses your factor	Relative, training myself	Myself	Parents, myself	Myself	Parents, someone else, not sure (doctor or SED if needed)	Parents, myself	Myself	Parents	Myself	Parents	Parents	Parents	Parents	Parents	Parents		85% (11 of 13) correctly identified the name of their factor	85% (11 of 13) correctly identified the name of their factor

Global Aim

- CIBD aims to improve the transition care for patients between the ages of 15 and 21. This process will begin with the annual visit at the age of 15 and end with the annual visit at age 21.
- By working on the process, we expect: patients to be educated on their disease, make social and lifestyle decisions on their disease, and independently manage their own bleeding disorder care.
- It is important to work on this now because: we do not have a formal transition process and we believe it will lead to longer, healthier and more productive lives for our patients.

Understanding Workflow

- From the patient survey results we found that patients were not ordering their own factor.
- We met with the 340B Pharmacy to understand the workflow process and to come up with a way to track if patients were ordering their own factor.
- We determined the 340B Patient Representative (PR) was already tracking who was ordering the patient's factor.
- We decided that the Social Worker (SW) would have a discussion with the patient during their annual visit on the importance of ordering their own factor.
- The SW would track the patients who receive education in clinic and compare it to the PR's tracking sheet.



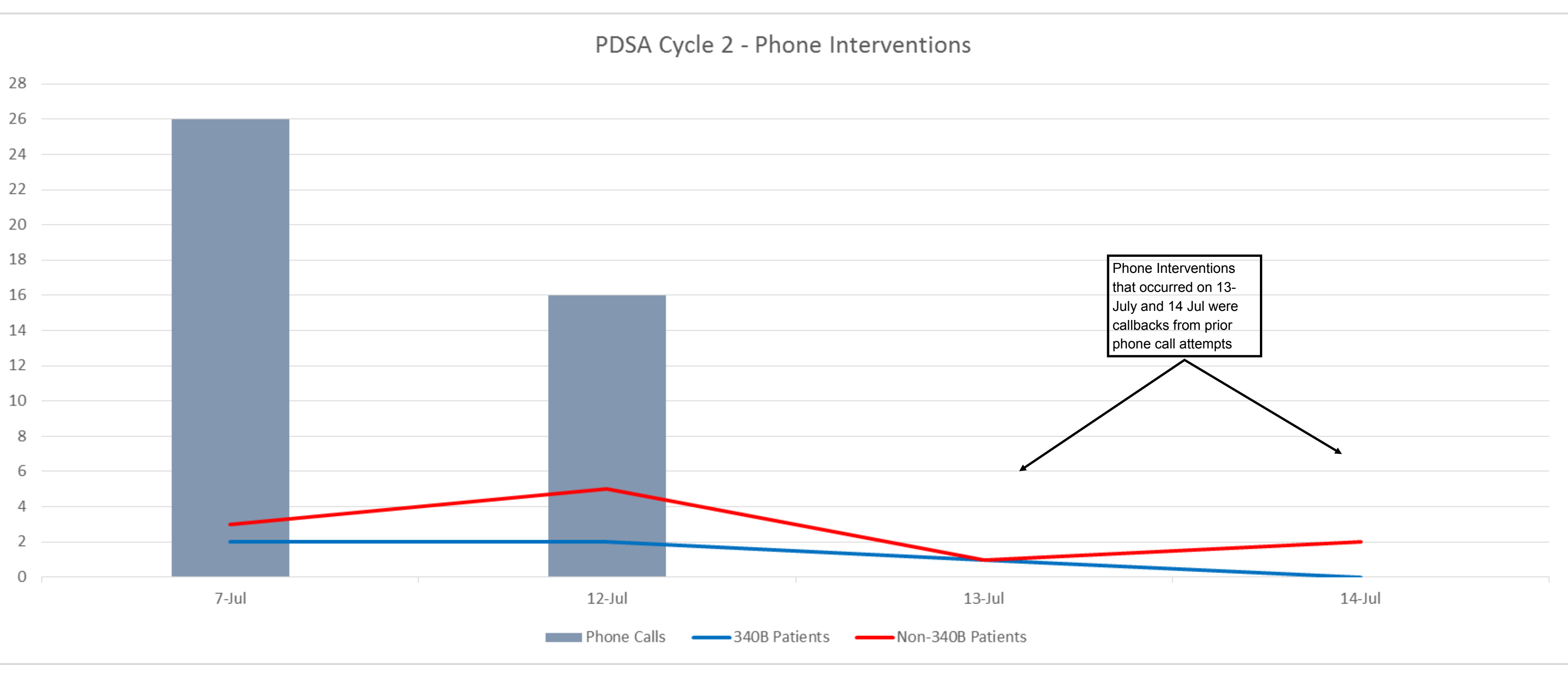
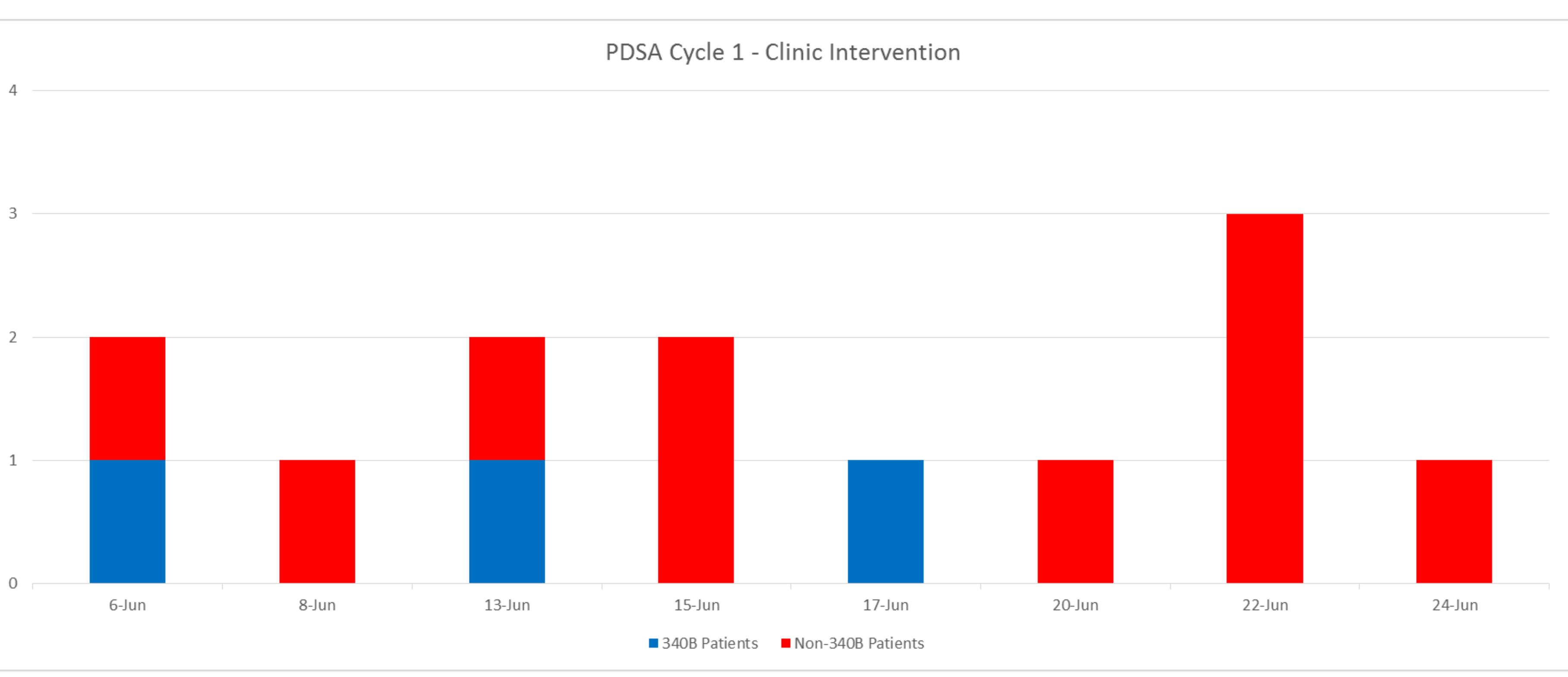
Specific Aim

•CIBD will increase the number of 340B pharmacy patients that order their own factor by the age of 21 to 70% by January 1st, 2017

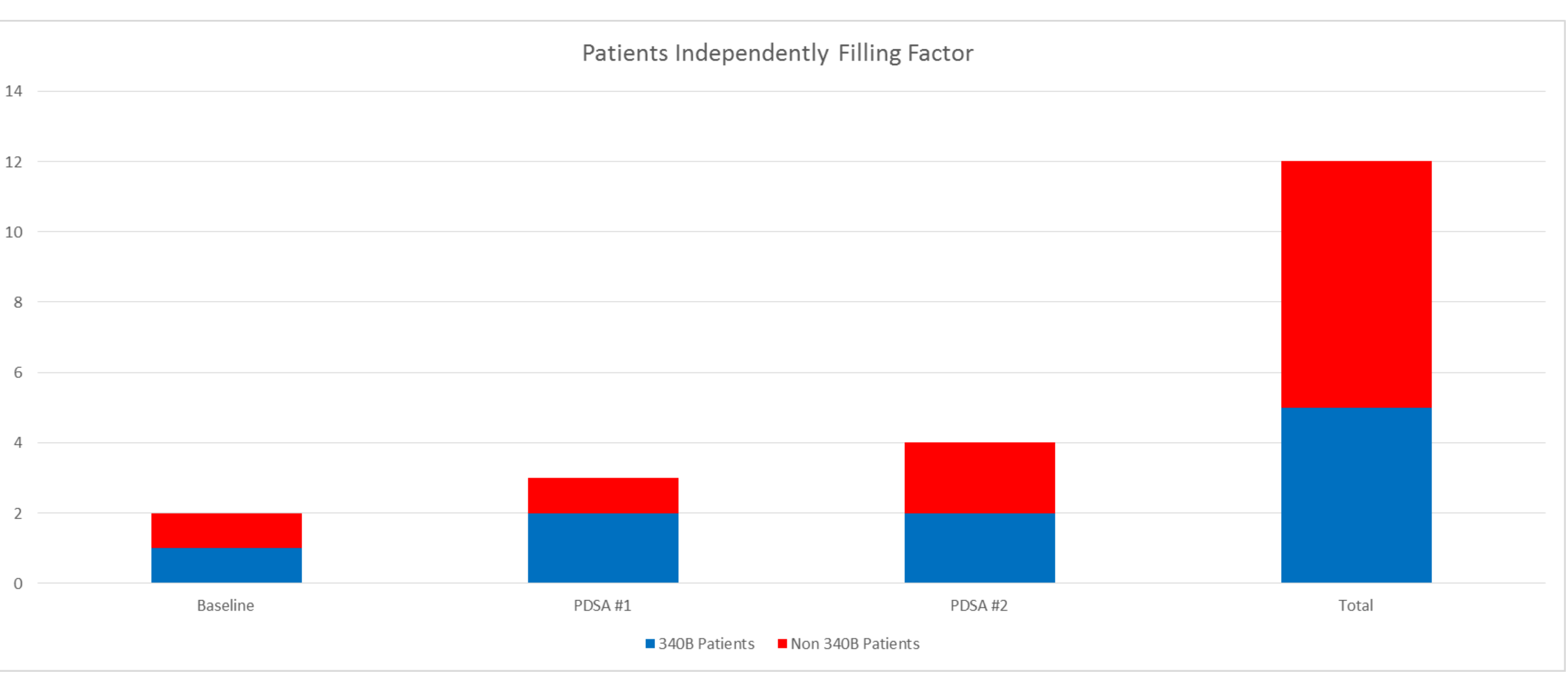
PDSA and SDSA

- We determined that the intervention for encouraging patients to order their own factor would be best performed by the Social Worker (SW) during the patient's annual visit.
- We started PDSA Cycle 1 in June with the SW talking with the patients and caregiver on the importance of ordering their own factor.
- Our 340B pharmacy Patient Representative (PR) tracked factor orders, refills and who contacted them.
- We realized that the in-clinic intervention would not reach enough patients in a timely manner.
- We decided to contact the patient and caregivers via phone intervention.
- In July, the SW began calling all patients that were not seen in clinic during the PDSA cycle 1. The PR tracked factor orders, refills and who contacted them.
- Non 340B pharmacy patients were tracked by self-reported interactions with their pharmacy.

PDSA Results



PDSA Outcomes



Key Findings

- We were able to increase the number of both 340B and non 340B patients who order their own factor.
- We found a way to track transition age patients ordering their own factor and we will continue to track and educate patients when they are in clinic.
- We found a way to partner our Hemophilia Treatment Center and 340B Pharmacy to produce and track patients outcomes.
- We identified patient educational transition needs and will test the outcomes using PDSA cycles.

Lesson Learned

- This project allowed a more formalized tracking system of transition issues.
- We learned how to track patients self ordering factor. We will continue to expand other areas of transition needs with more PDSA cycles.
- We see the need for a national HTC network to standardize transition education and protocols.

Funding Source

•HRSA grant number UC8C24079