Development of a Transition Program from Pediatric to Adult Care

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Objective

- Discuss Implementation of Pathways to Allow for Successful Transition of Chronic Disease Patient Population to Adult Care

What is Transition?

Health care transition is the process of changing from a pediatric to an adult model of health care

Castillo, C., & Kitsos, E. (2017)

More on Transition . . .

~ 18 million adolescents, ages 18-21, require transition from pediatric to adult healthcare.

Without transition support, data shows impact on health, quality of care and health care costs

Many patients and families are not well prepared for this change

Surveys of health care providers show lack a systematic way to support youth, families, and young adults in transition from pediatric to adult health care

White, P. Got Transition
Prior et. al. Pediatrics

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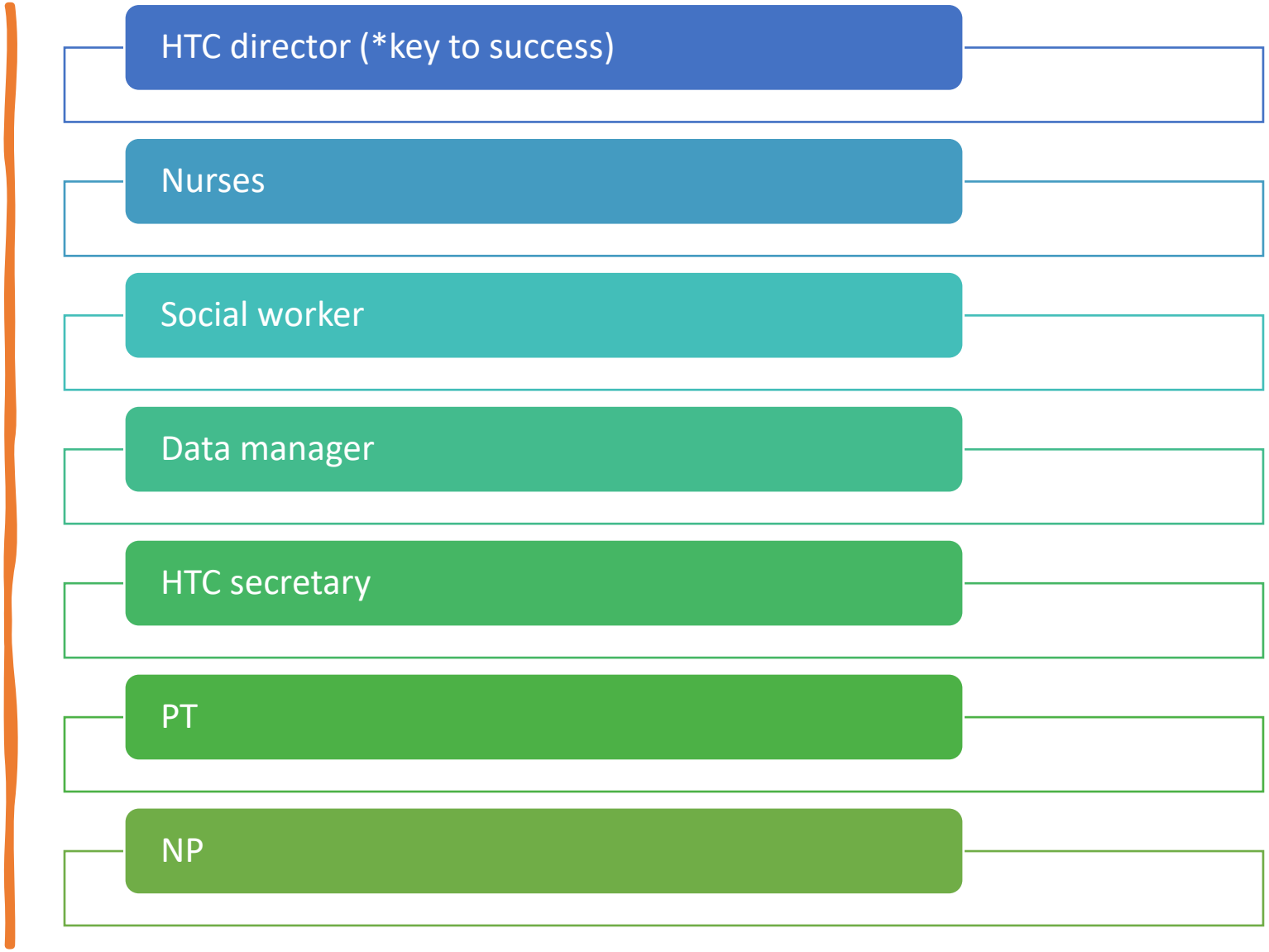
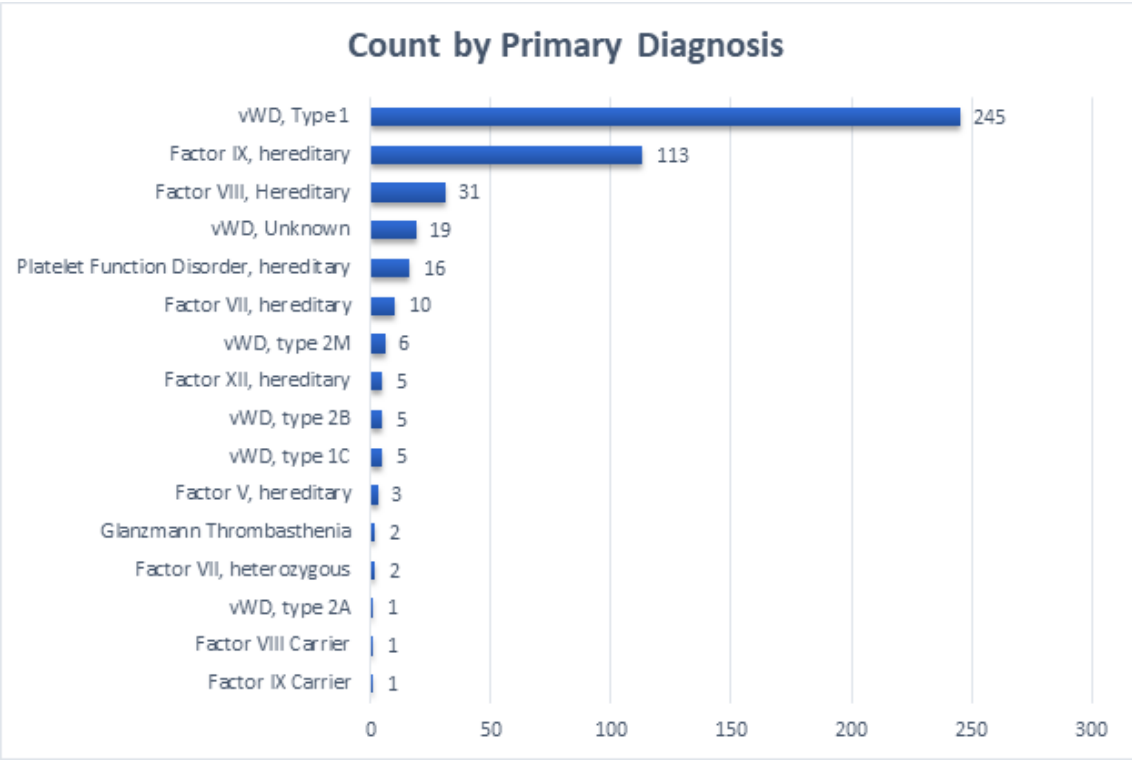
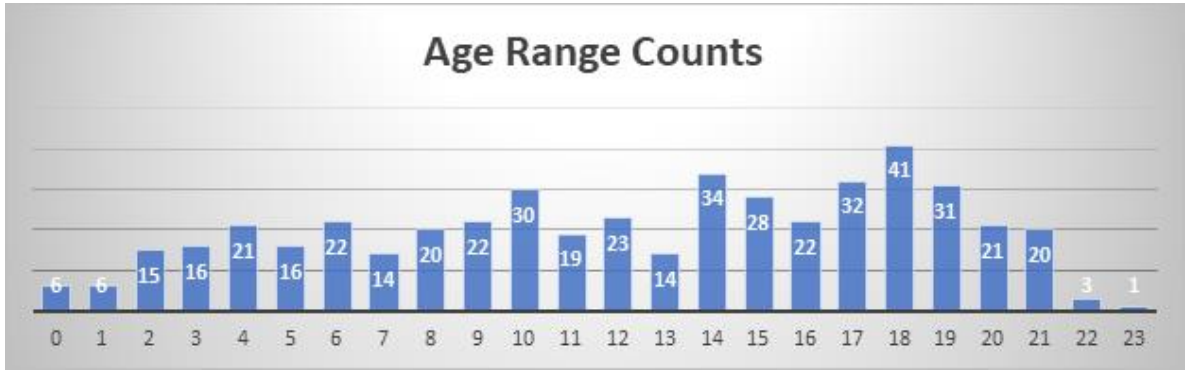
Create Lead Team

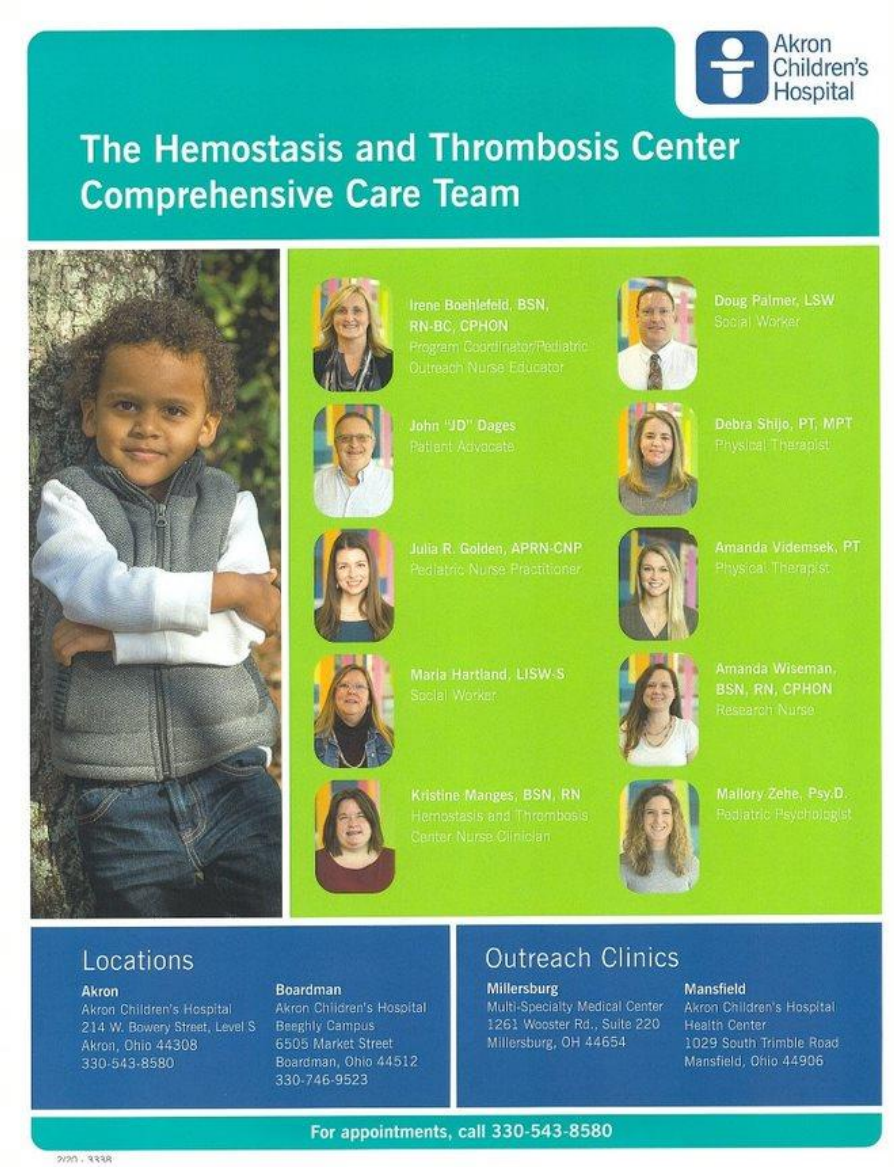


Identify Patient Population

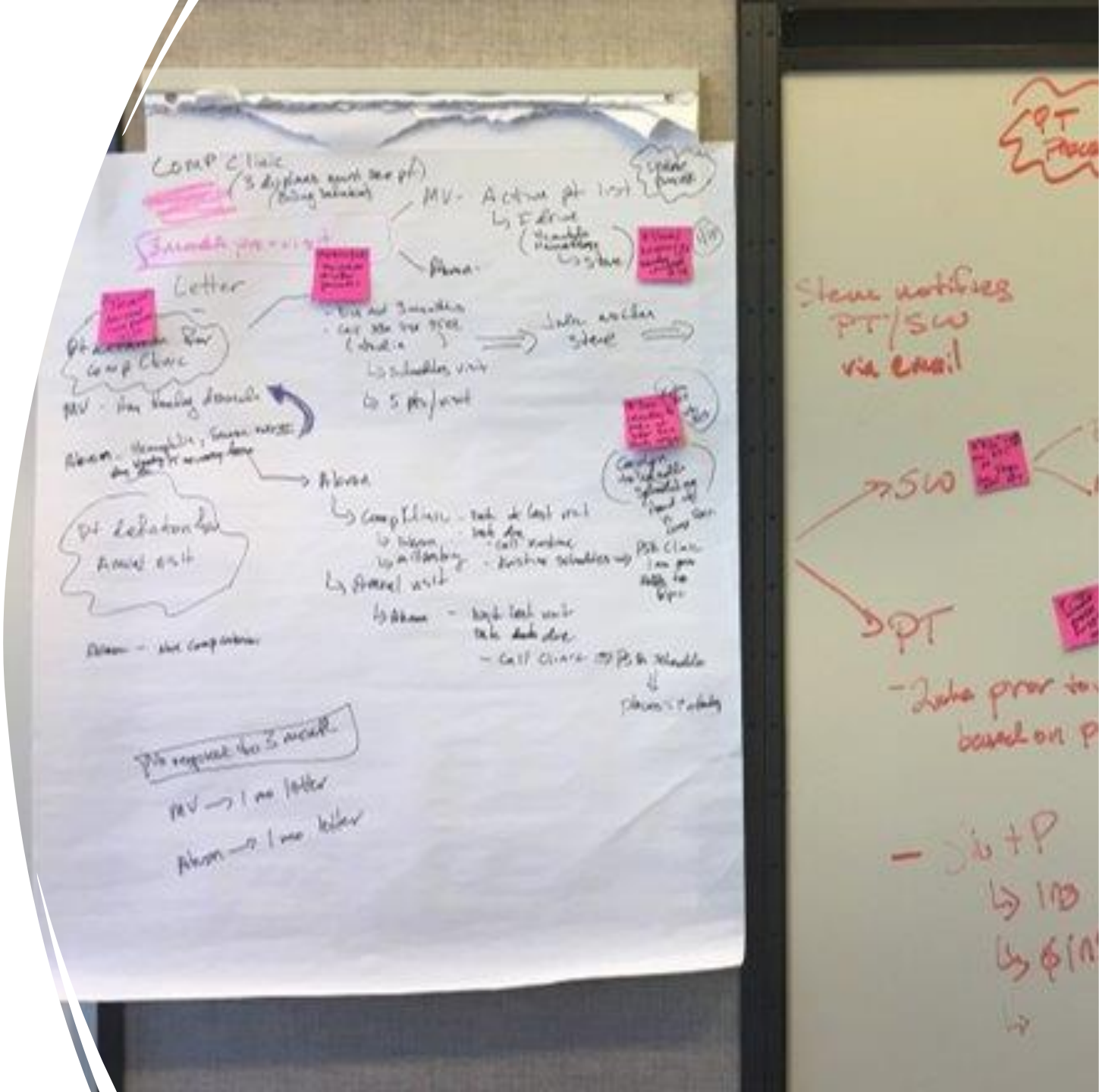




Develop Staff Roles



Process



Develop Transition Policy

Hemostasis & Thrombosis Center

Akron Children's Hospital

Transition Policy

Akron Children's Hospital Hemostasis and Thrombosis Center is committed to helping our patients make a smooth transition from pediatric to adult health care by addressing common issues and concerns. This process involves working with youth, beginning at age 11 years, and their families to prepare for the change from a "pediatric" model of dependent care to an "adult" model of independent care where youth take full responsibility for their health care.
This means we will spend time during the visit with the adolescent/young adult, without the parent/guardian present, in order to assist them to set health priorities and support them to become more independent with their own health care.

At age 18 years, patients legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult's consent will we be able to discuss any personal health information with family members. If the patient has a condition that prevents him/her from making health care decisions, we will encourage parents/caregivers to consider options for supported decision making.

- We will work with our patients to transition to adult hematology care by age 21, ideally in the setting of a Hemostasis & Thrombosis Center.
- We will facilitate transferring to an adult provider during a patient's annual visit within 1 year prior to their 21st birthday.
- We will assist with this transfer process, including helping to identify an adult provider, sending medical records and communicating with the adult provider about the unique needs of our patients.
- We will provide services to our patients during the year following their last visit with the understanding that during this time patients will establish care with an adult provider.

As always, if you have any questions or concerns, please feel free to contact your HTC Team.

Assessing Patient Readiness for Transition

Literature review

- *National Hemophilia Foundation (NHF) Transition Guidelines*
- *Got Transition*
- *American Society of Hematology (ASH)*
- *OnTrac (Canada)*
- *Transition Health Care -Transition Guide (Maternal Child Health)*

Developed HTC related content

- *Independent Health Care Behaviors*
- *Social Support*
- *Health and Lifestyle Educational/Vocational/Financial Planning Self-Advocacy and Self Esteem*
- *Sexual Health*

Readiness Assessment Tool (RAT)

atient Name DOB Today's Date

Please circle the answer that applies to you right now.

Independent Health Care Behaviors

A. **I know the different names for the disorder that affects me.**

I know this I need to learn this

B. **I can explain my medical condition to others.**

I know this I know but I have questions I need to learn this

C. **I know my Hemostasis and Thrombosis Center (HTC) and my hematologist's name and how to contact them.**

I know this I know but I have questions I need to learn this.

D. **I know what an HTC hematologist is and why I go to an HTC.**

I know this I know but I have questions I need to learn this.

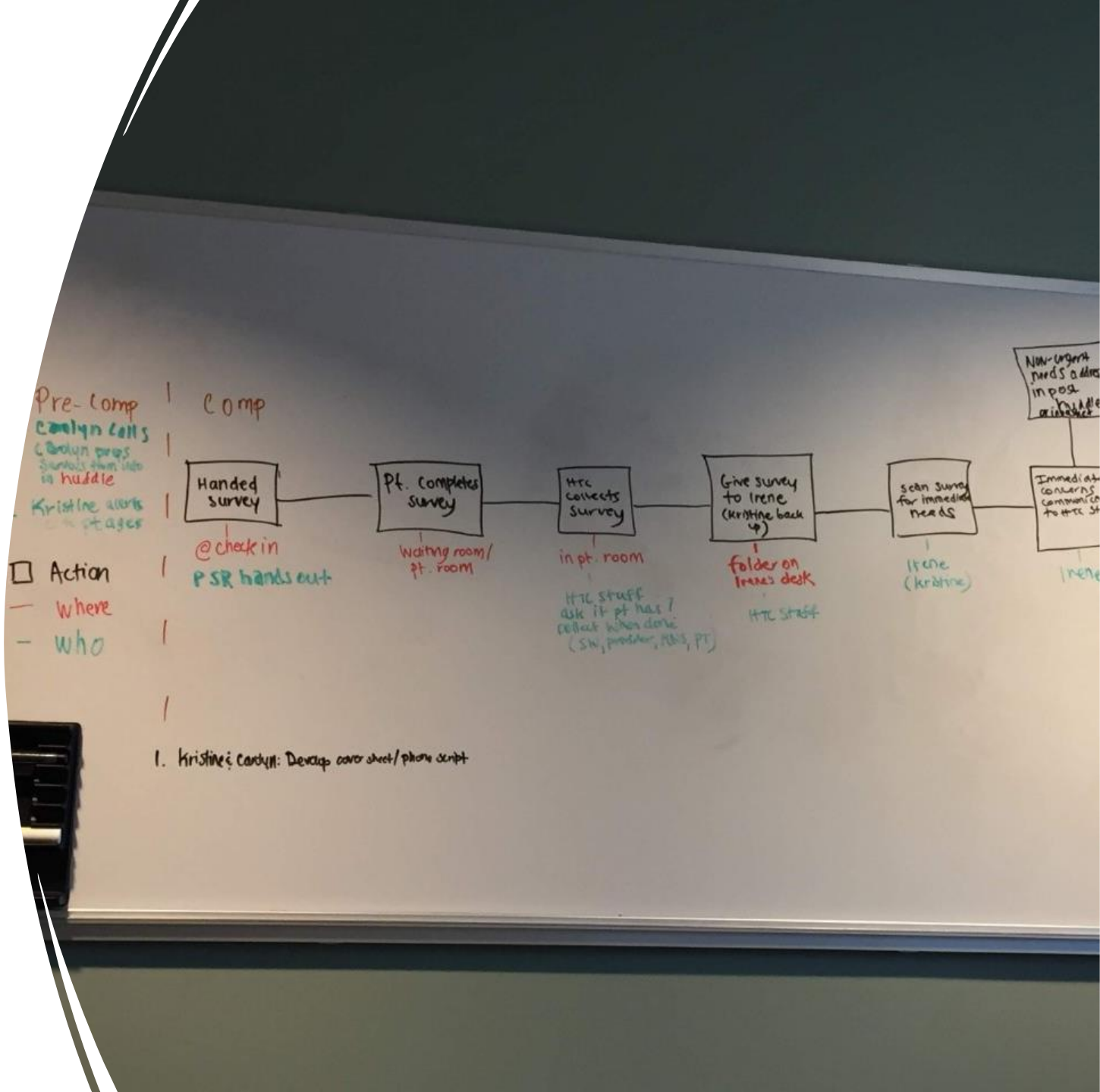
I know when to call my HTC.

I know this I know but I have questions I need to learn this.

Steps to a good survey

- Goal of survey is clear
- Avoid social desirability bias
- Eliminate double-barreled questions
- Specific to medical condition
- Ideally 20 questions or less
- Sections with clear, understandable headings
- Ensure each question useful
- Know what answers mean
- Use answers in a meaningful way

Process for Pilot Survey



Cognitive Interview Process

- Sample size
- Explain process & goal
- Determine team member
- Allow dialogue and feedback

Role of Cognitive Interviewing

- Patient and parent feedback
- Identified words patients did not understand
- Identified healthcare terms that required clarification
- Cultural considerations

2. I can explain my medical condition to others.

I know this I know but I have questions I need to learn this

didn't understand words

3. I know my Hemostasis and Thrombosis Center (HTC) and my hematologist's name and how to contact them.

I know this I know but I have questions I need to learn this.

I know what + is work

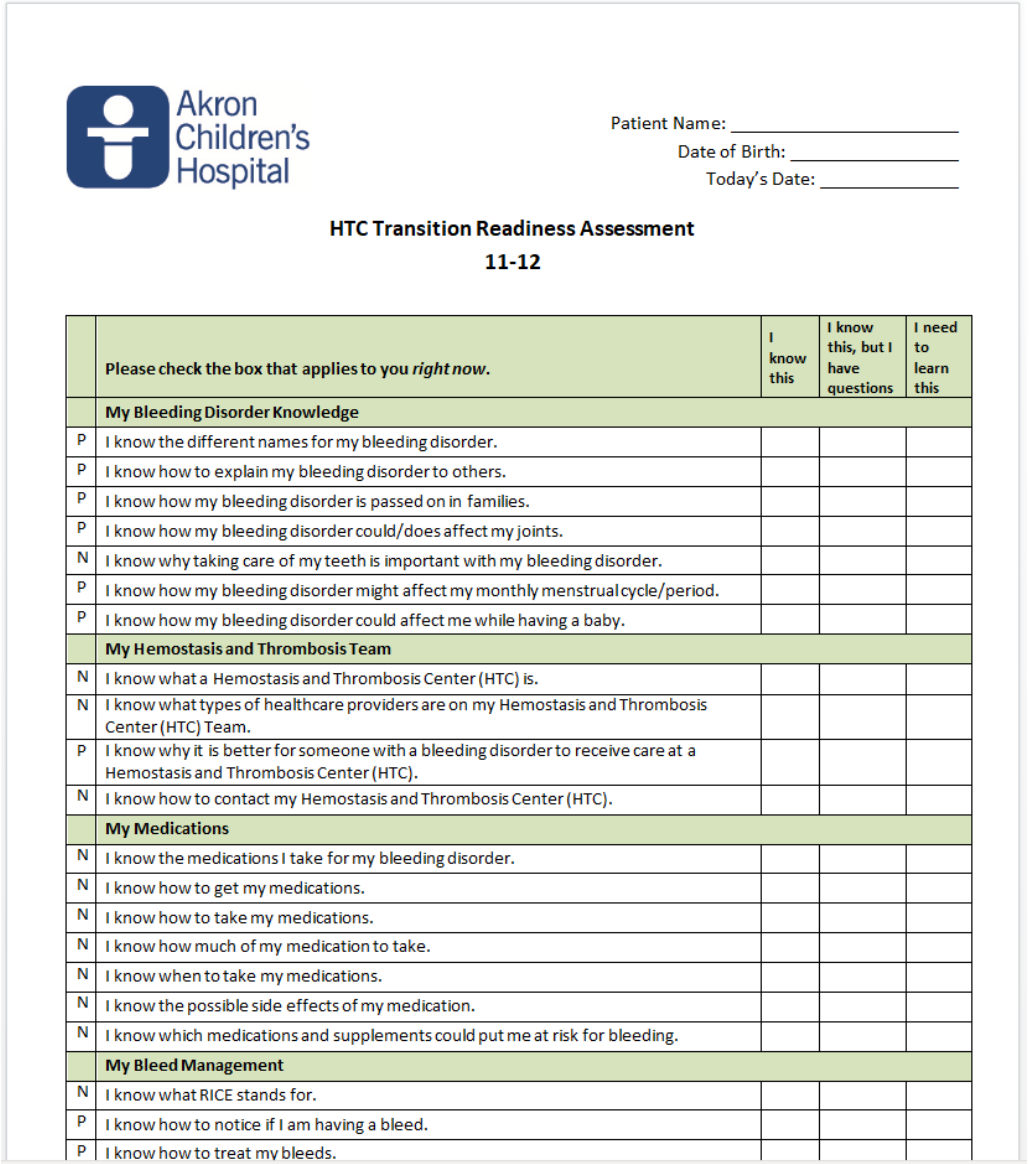
4. I know what an HTC hematologist is and why I go to an HTC.

I know this I know but I have questions I need to learn this.

5. I know when to call my HTC.

Difficult Words/Phrases
"Confidentiality"
"School Assistance Plans"
"Genetics"
"Patient Rights"
"Hematologist"
"Long-term Health Complications"
"Nutritional"
"Feelings"

Final RAT



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Patient Name: _____
Date of Birth: _____
Today's Date: _____

HTC Transition Readiness Assessment
11-12

	Please check the box that applies to you *right now*.	I know this	I know this, but I have questions	I need to learn this
	My Bleeding Disorder Knowledge			
P	I know the different names for my bleeding disorder.			
P	I know how to explain my bleeding disorder to others.			
P	I know how my bleeding disorder is passed on in families.			
P	I know how my bleeding disorder could/does affect my joints.			
N	I know why taking care of my teeth is important with my bleeding disorder.			
P	I know how my bleeding disorder might affect my monthly menstrual cycle/period.			
P	I know how my bleeding disorder could affect me while having a baby.			
	My Hemostasis and Thrombosis Team			
N	I know what a Hemostasis and Thrombosis Center (HTC) is.			
N	I know what types of healthcare providers are on my Hemostasis and Thrombosis Center (HTC) Team.			
P	I know why it is better for someone with a bleeding disorder to receive care at a Hemostasis and Thrombosis Center (HTC).			
N	I know how to contact my Hemostasis and Thrombosis Center (HTC).			
	My Medications			
N	I know the medications I take for my bleeding disorder.			
N	I know how to get my medications.			
N	I know how to take my medications.			
N	I know how much of my medication to take.			
N	I know when to take my medications.			
N	I know the possible side effects of my medication.			
N	I know which medications and supplements could put me at risk for bleeding.			
	My Bleed Management			
N	I know what RICE stands for.			
P	I know how to notice if I am having a bleed.			
P	I know how to treat my bleeds.			

Hemo-milestones

HemoMilestones ACH Adaptation

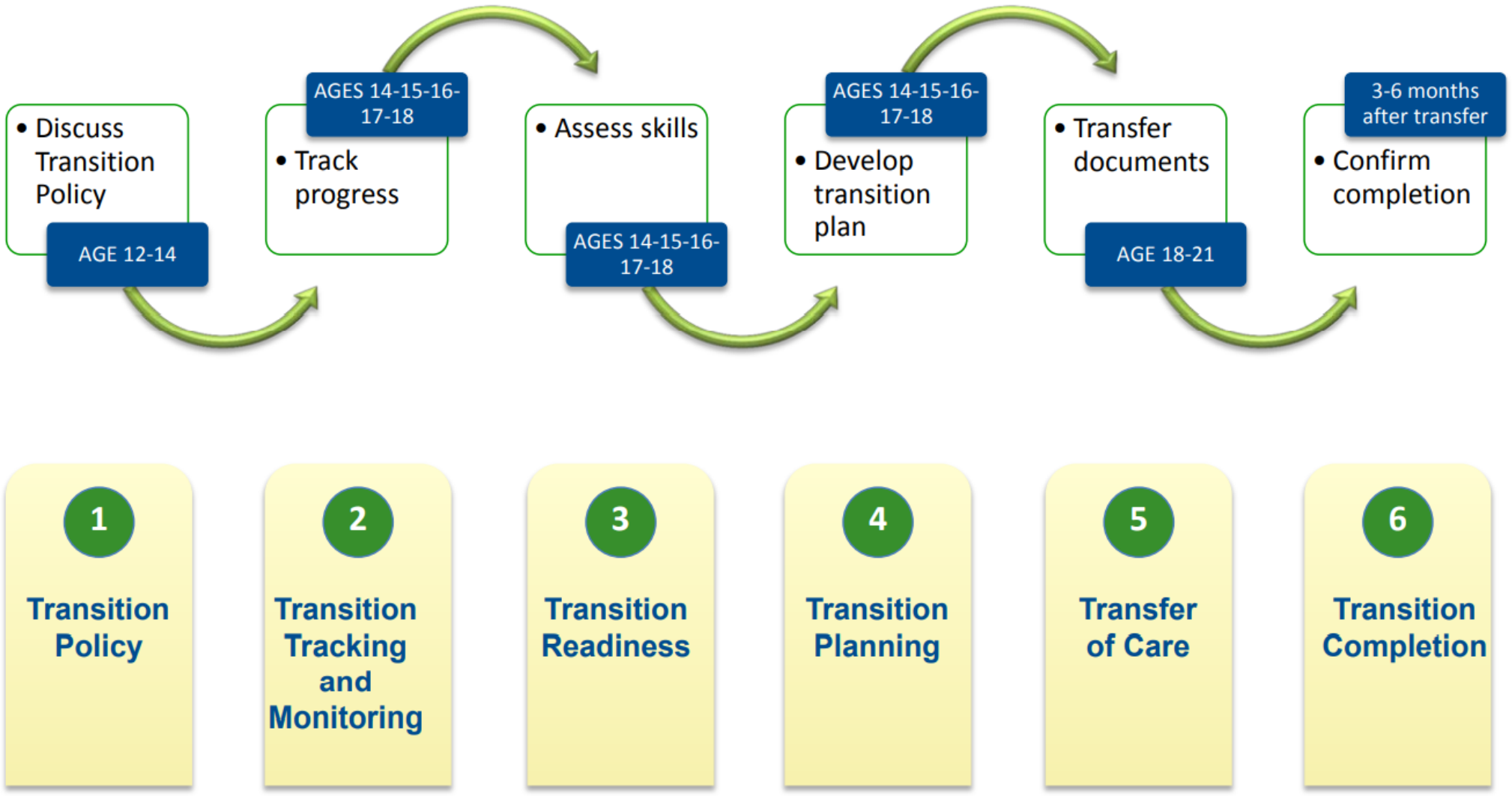
Age	Nurse	Provider	Social Work	Physical Therapy
14-18 years old	___Patient lists healthcare providers on HTC team and roles ___Patient sometimes self-administers medication ___Patient identifies name of pharmacy where they get specialty medication ___Patient is responsible for maintaining medication and supplies ___Patient states the need to avoid anti-platelet medications for pain relief or fever Patient provides: ___detailed interim history ___treatment log ___Patient begins to keep a summary of important medical information (surgeries, allergies, medications, etc.) ___Patient understands availability of assistance with school IEP or 504 ___Patient aware of increased risk for injury or bleeding with: ___seatbelt non-adherence ___tattoos/piercings	Patient characterizes bleeding disorder Hemophilia as: ___mild ___moderate ___severe VWD ___type 1 ___type 2 ___type 3 ___Other ___Patient aware of importance of regular physical activity Patient understands impact of bleeding disorder on sexual health: ___groin bleeds ___menses ___fertility (if appropriate) ___Patient meets independently with provider for part of the annual visit ___Patient can explain bleeding disorder to others Patient affirms need for: ___increased role in communication and self-care management ___transition planning Patient aware of increased risk for injury or bleeding with: ___dental procedures ___surgery ___careers that require physical work	___Patient demonstrates knowledge of safe sex practices ___Patient knows how to access psychological support as needed in community or HTC Patient understands availability of: ___insurance options ___patient assistance programs ___State Health financial counselors (if available) ___community programs (ex. NOHF, NHF, HTC services, bleeding disorders, camp) ___Patient has rapport with HTC team to address concerns/issues ___Patient names insurance provider Patient aware of increased risk for injury or bleeding with: ___drug use ___alcohol use	___Patient states how to prevent/recover from injuries with: ___assistive devices ___proper shoes ___warm up before exercise ___alter activities to make safer ___Patient aware of increased risk for injury or bleeding with non-adherence to sports guidelines

Where to Transition?

Locate	Locate adult practices interested in collaborating
Build	Build ongoing collaborative relationship with adult providers
List	Have a list of adult specialty providers willing to care for patient population

Transfer of Care

- Handoff
- Develop consistent process
- Reach out and offer consultation with next provider as needed
- Ensure transfer of care completion



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Lessons learned

- Patience makes a process
- Interdisciplinary team collaboration and buy-in
- Using resources (sooner rather than later!)
- Don't reinvent the wheel

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References

- Castillo, C., & Kitsos, E. (2017). Transitions From Pediatric to Adult Care. *Global pediatric health*, *4*, 2333794X17744946. https://doi.org/10.1177/2333794X17744946
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