



Roadmap College

Webinar #5

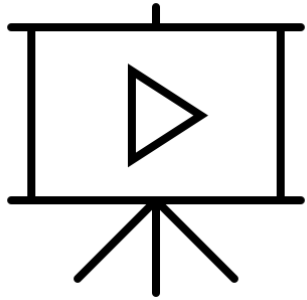
Build assessment and surveillance into your clinic workflow, part 1

Thursday, September 8th

3pm - 4pm ET

Welcome & Current State

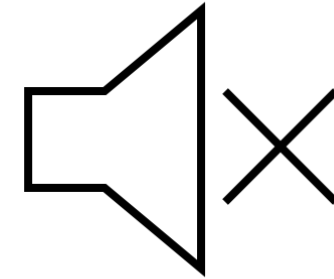
Abby Zier Alyesh



Webinar is
being recorded



Recording &
slides will be
posted



Mute mic

Housekeeping





Our goal,
simply put

*“Ask how the child
and family are doing.
Every visit. Every
time.”*



SETUP

STEP 1

Self-assess your readiness using the Readiness Checklist

STEP 2

Collect simple baseline data:

Was there documentation that patient and family emotional health was assessed during this visit?

STEP 3

Set an aim



TRY CHANGES, MEASURE IMPROVEMENT

STEP 4

Conduct PDSA cycles. Begin with Key Driver 1 and progress through Key Drivers 2, 3, and 4, focusing your tests of change on improvements related to your readiness self-assessment. Use the “potential change strategies” in the driver diagram to gather ideas to try. Start small; for example, one patient, one clinic day, one inpatient rounds. Revise as you learn and improve.

Key Driver #1: Develop Awareness

Use the potential change strategies to increase your awareness of the challenges and stresses of living with/parenting a child with a chronic condition.



Key Driver #2: Identify resources; make them available

Use the *Developing a Resource List* tool to create or update a list of resources specific to your practice's location and patient population. Ensure you have a crisis plan for mental health emergencies for patients and for families.



Key Driver #3: Develop knowledge, know-how and confidence

Review Roadmap videos and conversation guides to develop or hone your approach to initiating conversations about emotional health.



Key Driver #4: Build assessment and surveillance into your clinic flow

Begin assessing emotional health at the time of diagnosis and continue through each clinical encounter.

STEP 5

Continue to test and measure ways to embed discussions about emotional health into your daily care. Collect additional measure data and repeat the Roadmap Readiness Checklist. Expand your successful PDSA cycles, and **implement successful changes**. Ensure that your measure data support the effectiveness of the changes as you move to implementation.

Objectives

Understand

Understand how to embed assessing and addressing emotional health needs into routine clinic visits

Assess

Assess progress on readiness for assessing emotional health needs

Agenda

5 min	Welcome & Current State	Abby Zier Alyesh
10 min	Midpoint Reflections	Abby Zier Alyesh
5 min	Recap of Developing Knowledge, Know-how, and Confidence, Part 2	Carole Lannon
35 min	A “holistic model of care”: Hard wiring changes for the long run	Becky Lois Mary Pat Gallagher
5 min	Next Steps	

Midpoint Reflections

Patient and Family Involvement

Poll 1:

- How has your team engaged parents/patients while working on Roadmap?

Poll 2:

- Does your center connect patients with peer-to-peer groups locally or nationally?



Readiness Checklist

CHECKLIST COMPONENT Baseline

- a. I am aware of the stresses of living with / parenting a child with a chronic condition and the importance of addressing emotional health, in addition to physical health, for patients/families with chronic pediatric conditions
- b. My practice setting has an up-to-date list of resources to support the emotional health of children with chronic conditions and their families that includes:
- mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available
 - local or national peer-to-peer support resources for patients
 - local or national peer-to-peer support resources for families (e.g., parents and/or siblings)
- c. My practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for patients (Check N/A if your patient population is too young to experience a mental health emergency, such as infants)
- d. My practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for family members (e.g., parents)
- e. I feel confident and competent initiating discussions about emotional health topics with children, adolescents, and family members of children and adolescents with chronic medical conditions

Staff Awareness

A. I, and my clinical colleagues and staff with patient or family contact, are aware of and can state

- the **stresses of living with / parenting a child with a chronic condition**, and
- the **importance of addressing emotional health**, in addition to physical health, for patients/families with chronic pediatric conditions

Mental Health in Pediatric Heart Disease



2 in every 3 or 65% of pediatric patients with single ventricle heart disease experience a mental health condition in their lifetime.



1 in every 2 or 50% of adults with congenital heart disease have a mental health diagnosis, such as depression or anxiety.



Half of parents/families of children with CHD report needing psychosocial care for themselves.

Cousino et al., 2021; Demaso et al., 2017; McCormick et al., 2022; Rea et al., 2021

Resource List

B. Our practice setting has an up-to-date list of resources available to support the emotional health of children with chronic conditions and their families that includes:

- mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available
- local or national peer-to-peer support resources for patients
- local or national peer-to-peer support resources for families (e.g., parents and/or siblings)



Developing a Resource List For Providers and Clinical Teams

Following are several resource documents that have been developed in collaboration with patients, parents, and clinicians as part of The Roadmap Project, which aims to improve the emotional health of children and adolescents *with chronic conditions* and their families. These resources and the template may also be helpful for children, adolescents, and families without the experience of chronic conditions.

1. **Overview: Developing a resource list:** An introductory page that outlines what questions a clinical team will want to consider when developing a resource list and what to share with patients.
2. **Example resources for clinical centers to consider:** Clinicians and clinical teams highlighted the need to develop a resource list for their practice setting for those families who wanted referrals for resources outside of the health system.
3. **Resource list template:** A template that can be adapted by local centers to give to patients and families about "how to find a therapist". This template can be adapted as appropriate by the center, perhaps including identified local or state resources.



THE AMERICAN BOARD OF PEDIATRICS
FOUNDATION

Funded by the American Board of Pediatrics Foundation, the Roadmap Project aims to improve the emotional health of children and adolescents with chronic conditions and their families. Direct questions to the [Roadmap Project Team](#).

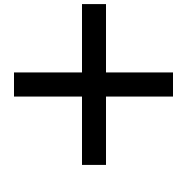
Provider Confidence

E. Providers in our practice setting feel **confident and competent initiating discussions about emotional health topics** with children, adolescents, and family members of children and adolescents with chronic medical conditions

NORMALIZE + ASK + PAUSE + CONNECT



Crisis Plan



Routine Assessment

C. Our practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for patients

(Check N/A if your patient population is too young to experience a mental health emergency, such as infants)

F. Providers in our practice build assessment of emotional health into a routine clinic visit

Recap of Developing Knowledge, Know-how, and Confidence, Part 2

Carole Lannon

Conclusions:

Patients usually don't expect their doctors & nurses to be their therapists.

At the same time, **asking, listening, and caring** can go a long way.

A “holistic model of care”: Hard wiring changes for the long run

Integrated, holistic care at NYU Pediatric Diabetes Clinic

- Moved from **testing** (changes) to **implementation** (the way we do things)
 - Work began with testing a screening tool
 - Recognized Roadmap strategies were needed to wrap around screening
 - Now reach all providers in one practice and spreading across settings

From Idea to Implementation: Roadmap in Action

Mary Pat Gallagher, MD
Becky Lois, PhD
Hassenfeld Children's Hospital



Mary Pat Gallagher, MD

- Director, Robert I. Grossman, MD and Elisabeth J. Cohen, MD Pediatric Diabetes Center at Hassenfeld Children's Hospital at NYU Langone
- Team Leader, Roadmap Pilot Collaborative



Becky Lois, PhD

- Director, Ambulatory Integrated Behavioral Health
- Co-Director, KiDS of NYU Integrated Behavioral Health
- Sala Institute for Child and Family Centered Care
Hassenfeld Children's Hospital at NYU Langone
- Team member, Roadmap Pilot Collaborative

Integrated, holistic care vs. “co-located” care

- **Medical provider-driven discussion** with youth AND parent/caregiver re: their emotional health and well-being
- Systems in place to refer as needed to social work, child life, psychology, psychiatry; these are *complementary to, not in place of*, provider discussion

Screening & surveillance: a starting point and lessons learned

- At the start of Roadmap pilot, there was no designated tool in place to screen for anxiety or depression even though our patients are at higher risk (providers chose based on their clinical judgement)
- Screening goal: implementation of PHQ-4
- Aim: increase depression and anxiety screening within 3 months by 50%

Implementation of change

Scoring:

Total distress scores: mild = 3-5,
moderate 6-8, severe 9-12

Anxiety subscale: items 1+2 (score 0-6)

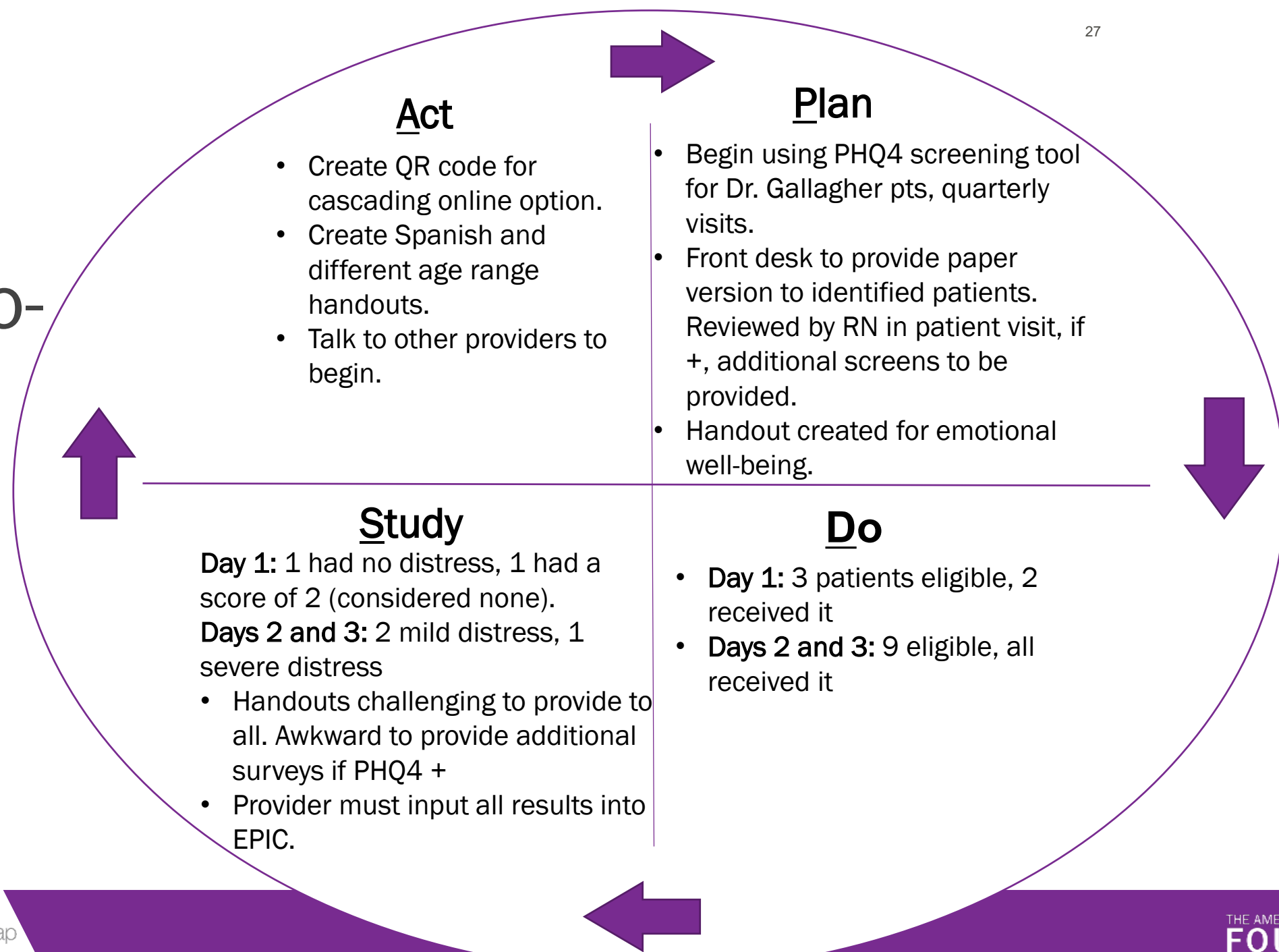
Depression subscale: items 3+4 (score 0-6)

A score of 3 or higher on either subscale is
considered positive (and the GAD7 or PhQ9
will cascade open)

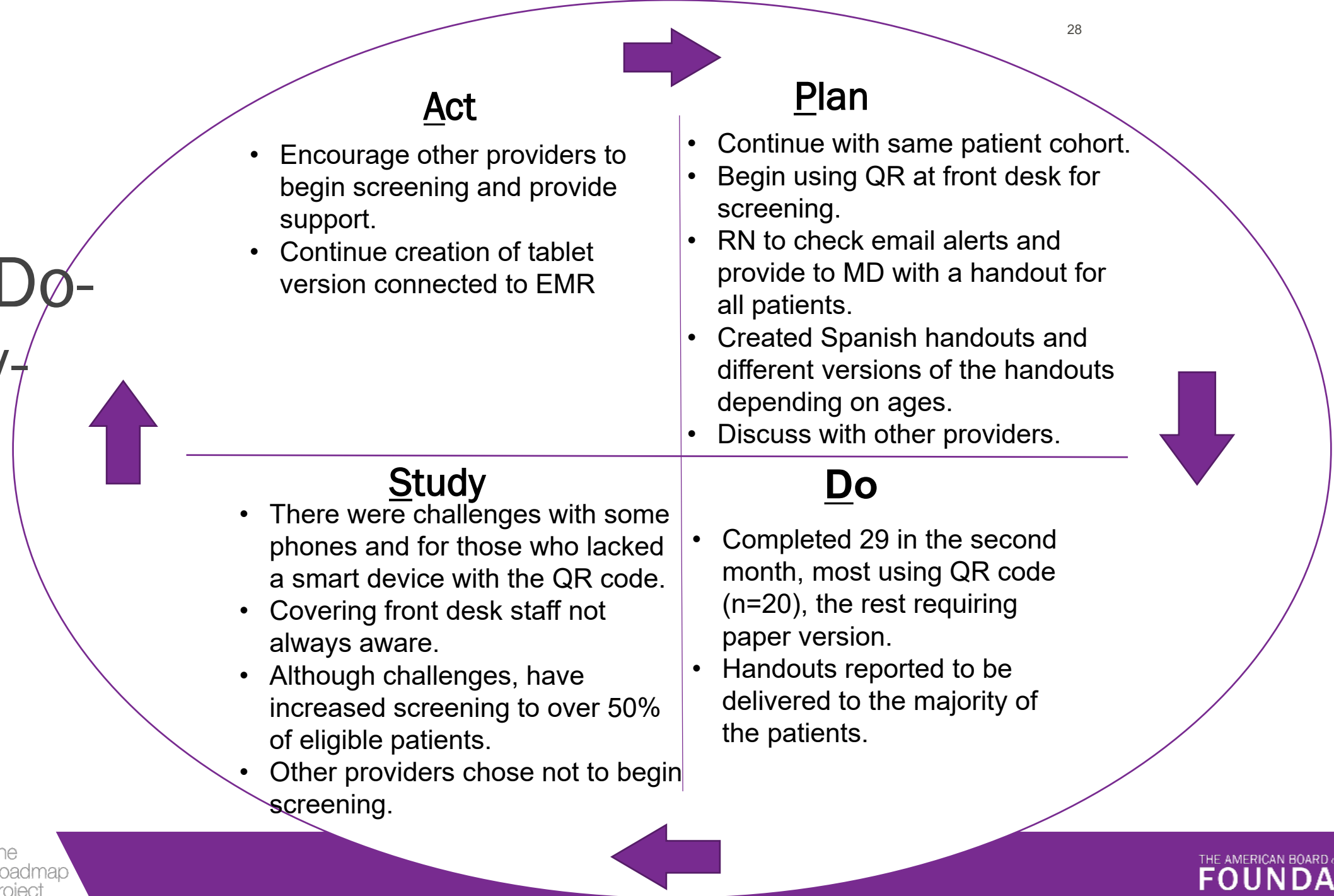
PHQ-4

Over the <u>last 2 weeks</u> , how often have you been bothered by the following problems? <i>(Use "✓" to indicate your answer)</i>	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Little interest or pleasure in doing things	0	1	2	3
4. Feeling down, depressed, or hopeless	0	1	2	3

Plan-Do- Study- Act



Plan-Do- Study- Act





Handouts

- Available in Spanish and English
- Different versions for Kids and Parents in ages 12 and under, 13-17 and >18



Information for Kids: Diabetes and My Feelings

Kids with Diabetes Sometimes Feel...

- **WORRIED** or **SCARED** about things like injections or their blood sugar going too low or high.
- **SAD** or **UPSET** about feeling different from their siblings or friends, having to change the way they eat, or having to think about things that other kids don't have to. Often they think "Why me?" or "This isn't fair!"
- **ALONE** because other kids don't need to think about their blood sugar.
- **ANGRY** about having diabetes or **JEALOUS** of a sibling or friend who doesn't have diabetes.
- **EMBARRASSED** about having diabetes or **AFRAID** to tell others about their diabetes.
- **GUILTY** and wondering if they did something to cause their diabetes.



When Kids Feel this Way, Sometimes They...

- **AVOID** thinking or talking about their diabetes to parents, siblings, or friends.
- **ISOLATE** from other people and stay in their rooms.
- **YELL** or get **ANGRY** at their parents or siblings.
- **CRY** because they feel sad or different.
- **EAT** as a way to deal with feelings or "get back" at their diabetes

What Can You Do About These Feelings? Check off the ones you'd like to try!

- TALK** to a trusted friend or adult about how you feel. You might even try talking with another person who has diabetes and who can understand how you feel.
- ASK QUESTIONS** about things you are wondering about.
- WRITE** down your feelings in a journal.
- DRAW** a picture of how you are feeling.
- Designate a "**WORRY TIME**". Work with your parent(s) to set up 10-minute time every day where you can tell them your worries. Try not to talk about your worries outside of worry time.
- LISTEN** to your favorite music or **READ** a favorite book.
- MOVE YOUR BODY**. You could play a sport, go for a walk outside, or have a dance party.
- Practice taking **DEEP BREATHS**. Breathe in through your nose for 3 seconds and out through your mouth for 3 seconds. Do this 5 times.
- Spend time playing with your favorite **PET**.
- WATCH** a funny movie or TV show.
- MAKE A LIST** of all the things that you like to do and some new fun things that you have never done before. When you feel sad or overwhelmed, pick something from the list and try it.
- Notice **EMOTIONAL HUNGER**, which is when you eat past fullness or feel guilty afterwards. Try to do a fun activity to distract you from your emotional hunger.
- Close your eyes and **IMAGINE A HAPPY OR CALM PLACE** (like the beach). Imagine hearing the waves crashing or feeling the sand in your toes.
- CREATE A CHART WITH YOUR DAILY ROUTINE**. Check off the things that you do during the day to keep yourself on track.



Information for Parents: Diabetes and My Feelings

Your child's diabetes is one part of your life, but sometimes parents feel like it takes up their whole life. Many parents of children/teens with diabetes struggle with overwhelming emotions, such as stress, guilt, anxiety, or sadness. These emotions are normal and there are many things that you can do to lessen the intensity of these emotions.

- **ACKNOWLEDGE YOUR FEELINGS.** Allow yourself to recognize that managing diabetes is hard.
- **GET SUPPORT.** Talk to a partner or friend about how you're feeling. You might even want to be connected to another parent of a child/teen with diabetes.
- Take a **WALK** outside.
- **REFRAME YOUR THOUGHTS.** Instead of, "I'm frustrated" try saying "I'm having the feeling that I'm frustrated". Instead of "This is hard" try saying "I'm having the thought that this is hard." Reframing your thoughts like this can create distance and make the emotion more tolerable.
- Remind yourself of **POSITIVE THINGS** or of how you've gotten through challenges in the past.
- **TAKE TIME FOR YOURSELF.** If you can, try taking a few minutes of kid free "me time."
- **SLEEP.** Try to sleep 7-8 hours per night.
- Learn to **RECOGNIZE PATTERNS.** Does your child's sports practice typically result in a drop in their blood sugar? Take notice and see if there are ways that you can prevent this from happening.
- If possible, **ENLIST** friends, family, and school staff to help. It's important to enlist the help of allies, because while you can (and will) do a lot for your child, you can't do it all on your own.
- If your emotions start to impact your family, social, or work life, it might be helpful for you to speak with a **MENTAL HEALTH PROVIDER.** Ask your child's diabetes provider to connect you with a member of the psychosocial team.

Children with diabetes may feel strong emotions too. Here are some ways that you can help your child cope with their emotions:

- **ACKNOWLEDGE YOUR CHILD'S FEELINGS.** Check in with your child and listen to what they say.
- Foster **INDEPENDENCE.** Try to resist the urge to lower your expectations or overprotect your child with diabetes. Instead, encourage the same independence that you'd expect from other kids.
- Use **SUPPORTIVE LANGUAGE.** As your child gains more independence, it can be tempting to say things like, "Your BG is too high. You need to take better care of yourself." Instead, acknowledge the challenge and offer help. Say, "I know that managing your BG is hard work. Is there anything I can do to help?" When talking about blood sugar levels, use "high" BG not "bad" BG.
- **POSITIVE REINFORCEMENT.** Children and teens don't typically respond well to punishment/fear because they have a hard time visualizing future consequences. Instead, try rewarding positive behavior with short-term rewards, which will help make the good behavior more likely to occur again in the future. Try making a reward chart and allowing your child to earn a prize for engaging in 1 responsible behavior each day, or multiple times a week.
- **CATCH YOUR CHILD BEING GOOD.** If you notice your child is checking their BG or giving insulin on their own, let them know you see. Say, "Thank you for doing that without me needing to ask you."
- Help your child **FIND THEIR STRENGTHS.** Is your child a writer, a soccer player, or an art lover? Remember, diabetes does not define your child's life – it's only a small part of who your child is.
- Encourage **SOCIAL SUPPORT.** Encourage your child to tell trusted friends or adults about their diabetes and how they feel. It may also be helpful for your child to talk with someone else who has diabetes. Ask your provider about how your child can get connected with a similarly aged peer.
- **CORRECT MISCONCEPTIONS.** Talk to your child about the fact that people do nothing to deserve diabetes – it just happens. Offer reassurance that there's no reason to feel guilty.
- **GET YOUR CHILD HELP WHEN THEY NEED IT.** If your child's distress begins to impact their school or social life, it might be helpful for your child to speak with a mental health provider. Ask your child's diabetes provider to connect you with a member of the psychosocial team.

Materials adapted from Nemours and the JDRF

Providing space for discussion

- Monthly didactic & debriefing sessions
- Re-assessment of team members' comfort level
- Ongoing education and discussion
- Input from Family Advisors and Youth Advisors



Maintenance of change

Beyond training: changing practice

After PHQ-4: what do you do?

- We need to be **authentically** non-judgmental
- Our language will reflect our attitudes and beliefs
- Work on being comfortable being uncomfortable
- Recognize you don't need to "fix" everything

Lessons learned

Screening tools without staff education/awareness 😞

Screening tools without family education/awareness 😞

Useful for risk identification but not sufficient for broad-based education

Limitations of screening tools

- Under-reporting
- Only a conversation starter
- Negative screens still warrant discussion

Toolbox

- Weekly meetings with behavioral health team members
- Dedicated time for behavioral health in meetings
- Welcome honest feedback about hesitancy and worries
- Ask behavioral health team to listen, validate, educate
- Role play
- Plan small tests of change
- Communicate and *celebrate* progress

Integrated, holistic care vs. “co-located” care

- **Medical provider-driven discussion** with youth AND parent/caregiver re: their emotional health and well-being
- Systems in place to refer as needed to social work, child life, psychology, psychiatry; these are *complementary to, not in place of*, provider discussion
- 90% of the time, the medical provider listening and validating *has been the intervention*

In summary



Find a physician champion



Recruit behavioral health team support- **critical**



Share youth and family stories- can be transformative



Engage people from every discipline



Encourage self-reflection before launching



Recognize that listening might **be** the intervention

Thank you!

Next Steps



Evaluation





Webinar #6

What do you want to hear?



Roadmap's Next Phase

- What support would you need to put this into practice?



Before Webinar #6

Takeaway tests:

- Consider ways to share your learning across your clinical setting

Tasks:

- Visit the Roadmap College participant page to see pre-reading
- Report Month 5 data on REDCap by September 30