

# IMPLEMENTATION OF PEDIATRIC TO ADULT EPILEPSY TRANSITION CLINIC

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Second Reviewer: Bethany Coyne, PhD, CPNP-PC, RN

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**UVA**

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# INTRODUCTION

**Epilepsy is a complex and unpredictable medical condition that requires comprehensive care across the lifespan**

Approximately 1 in 150 children are diagnosed with epilepsy during the first 10 years of life, with the highest incidence rate observed during infancy (Aaberg et al., 2017).

Over half of children diagnosed with epilepsy require ongoing care into adulthood (Zulfiqar et al., 2024).



# ADOLESCENCE

The World Health Organization (WHO) defines adolescence as the transitional phase of growth and development between childhood and adulthood, generally ages 10-19.

It is a unique stage of human development and an important time for laying the foundations of good health.

## Self-identity and autonomy

- Brain still developing, which impacts impulse control
- Change from parental to peer influence
- Increase in risky behavior

# HEALTH CARE TRANSITION (HCT)

## Definition:

The process of moving from a child/family-centered model of healthcare to an adult/patient-centered model of healthcare (GOT Transition, 2025)

## Goals of a Transition Service:

Improve ability of adolescent to manage their own healthcare and effectively use health services

Ensure organized process in healthcare practices to facilitate transition preparation, transfer of care and integration into an adult setting

# SIGNIFICANCE

**National Survey of Children's Health shows 80% of youth (12-17yoa) do not meet national HCT performance measures:**

- Self management skills
- Self advocacy & communication
- Transition readiness
- Patient/provider satisfaction (NSCH, 2019)

**Lack of structured HCT associated with adverse effects:**

- Non-adherence to treatment/medication plan
- Discontinuity of care
- Patient dissatisfaction
- Higher emergency department & hospital use
- Higher cost of care (McManus et al., 2023)

# SIGNIFICANCE IN EPILEPSY

Comorbid mental health and neurodevelopmental conditions can complicate the transition in adolescence.

Adolescents with epilepsy have a non-adherence rate range from 35%-79% (Carbone et al, 2013)

## Resource utilization:

- Frequent use of ED/Healthcare services
- Urgent Neurology Follow-Up:
  - Avg. wait time- 44 days for epilepsy (American Academy of Neurology, 2025)
- Missed Education/Occupation

# EBPQI: THE IOWA MODEL REVISED & PDSA

Identifying Triggering Issues/Opportunities

State the Question or Purpose

- Is this topic a priority?

Assemble, Appraise, Synthesize Body of Evidence

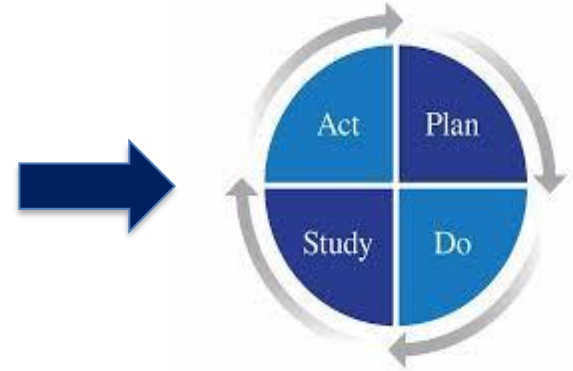
- Is there sufficient evidence?

Design and Pilot the Practice Change

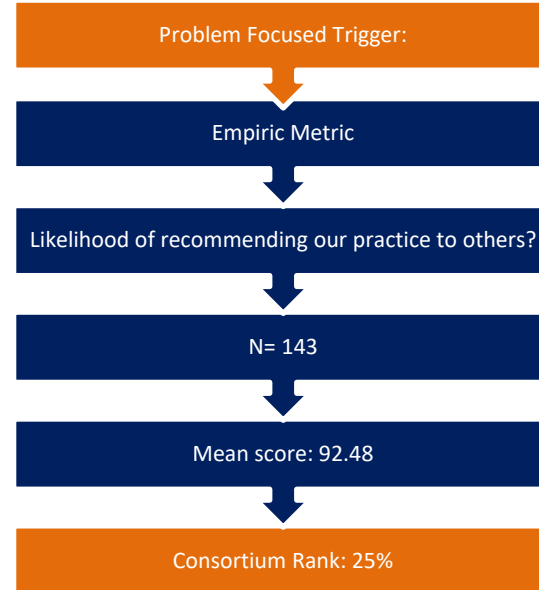
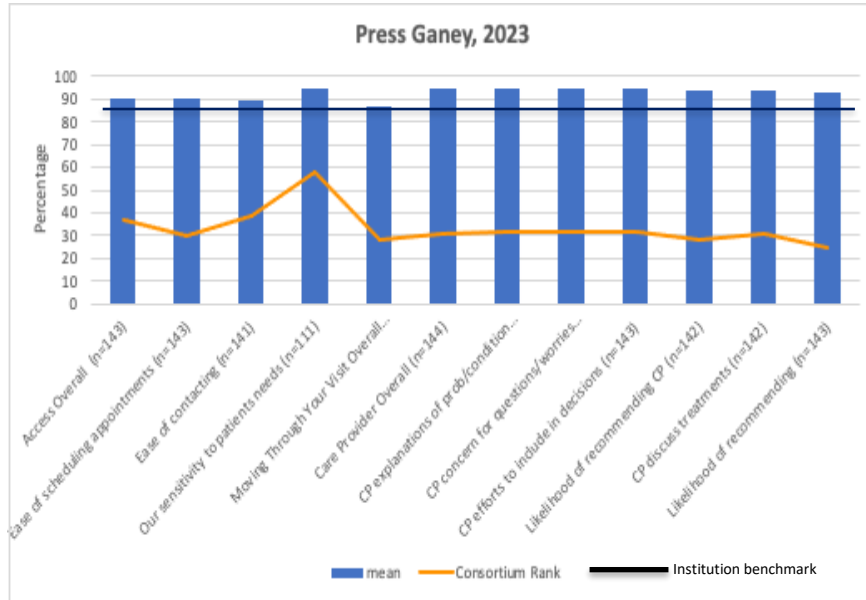
- Is the change appropriate for adoption in practice?

Integrate and Sustain the Practice Change

Disseminate Results



# IDENTIFIED TRIGGER



**Institution Benchmark for Empiric Metric: 95.3%**

# STATE THE QUESTION

Is patient experience improved with the implementation of a pediatric to adult epilepsy transition clinic?

# IS THIS A PRIORITY?

Healthcare is a consumer market that is greatly impacted by patient experience.

The institution's strategic plan prioritizes improving access and experience of care through superior quality, patient safety, and improved patient outcomes

Required Transition elements for accreditation of a comprehensive epilepsy center

# FORM A TEAM

**Advisor: Terri L. Yost, PhD, FNP-BC**

**Second reviewer: Bethany Coyne, PhD, CPNP-PC, RN**

**Practice Mentor: Edward Bertram, MD**

**Pediatric Collaborator: Alana Harrison, PNP**

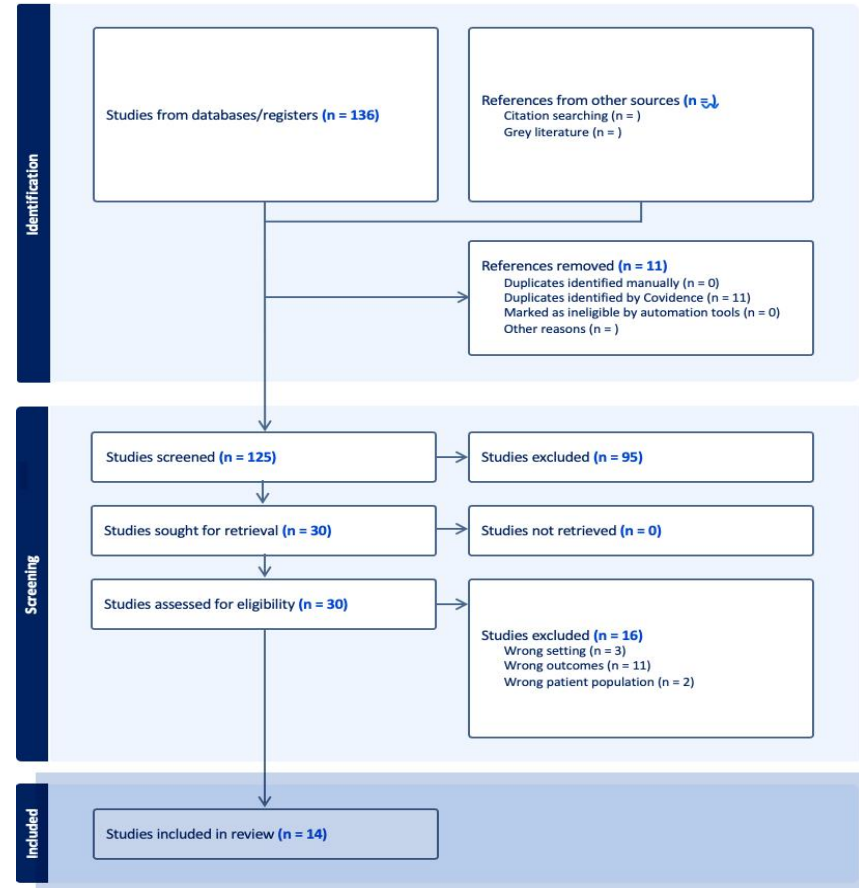
**Clinic Team: Manager, Registered Nurse Care Coordinator, Scheduling,  
Epilepsy Foundation of Virginia (EFVA) Volunteer**

# ASSEMBLE BODY OF EVIDENCE

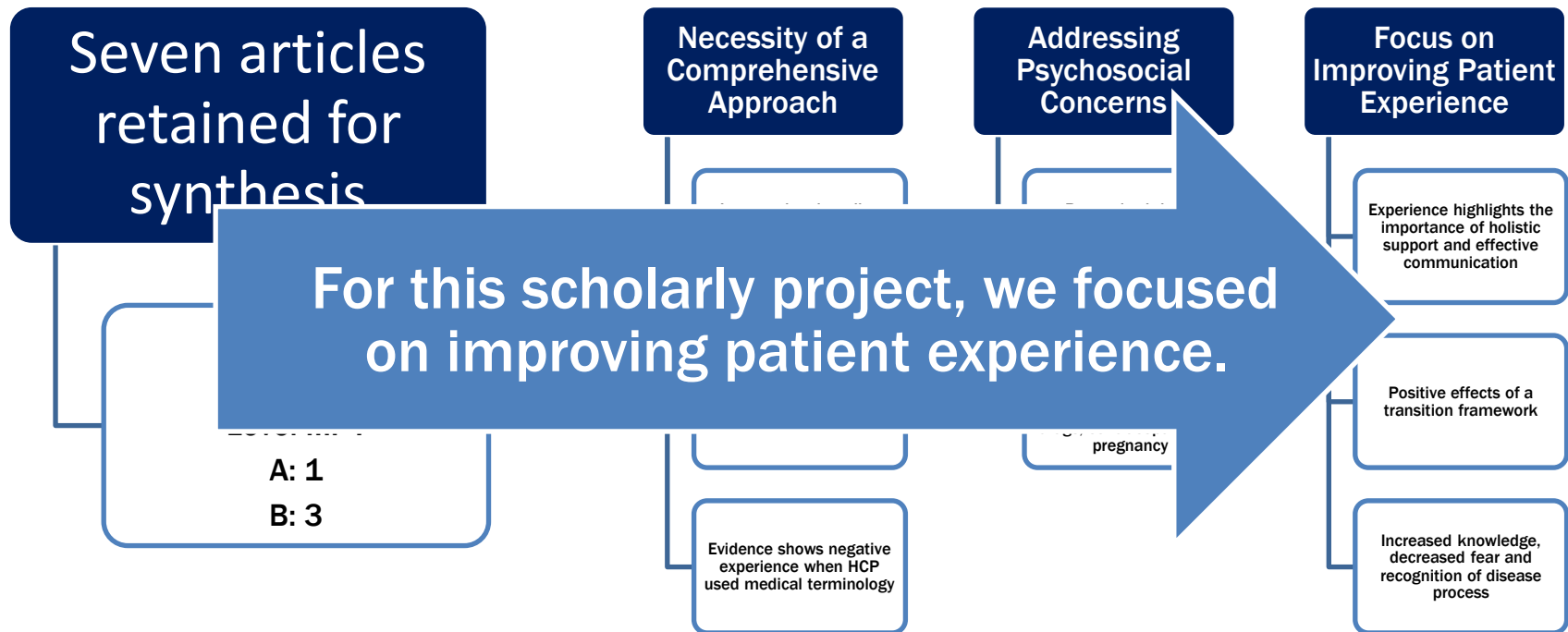
4 databases: PubMed, Embase, Scopus, and PsycINFO

Keywords: Epilepsy, Transition, Outcome, Adolescent, Patient Experience, Quality of life.

Limits: 2014-2024 and English Language



# APPRAISE AND SYNTHESIZE

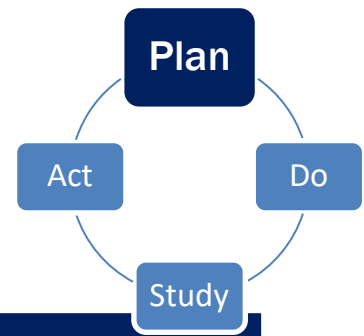


# PATIENT EXPERIENCE



(AHRQ, 2024)

# PILOT THE PRACTICE CHANGE



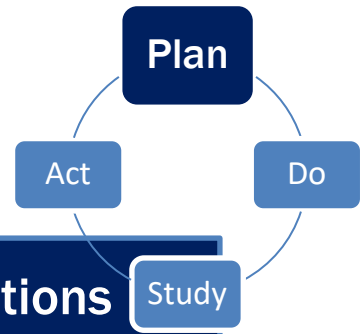
## Purpose:

- Create a comprehensive pediatric-to-adult epilepsy HCT clinic to improve patient experience

## Patients:

- Adolescents with Epilepsy (AWE) in current pediatric neurology clinic
  - Inclusion: all AWE with and without intellectual or developmental disability

# PLANNING CONSIDERATIONS



## DEI Considerations

**Inclusivity:** Inclusion of those with severe intellectual disability and limited capacity

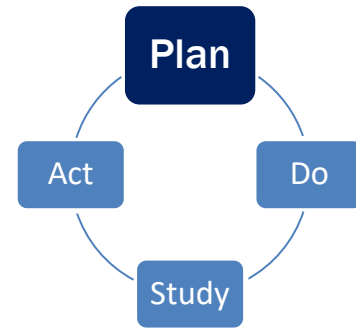
**Equity:** providing services through telemedicine

## Ethical Considerations

**Autonomy:** Evolving capacity

**Confidentiality:** Seeing patients with or without a guardian present as sensitive information exchanged

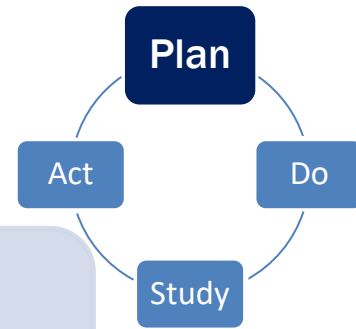
# PILOT THE PRACTICE CHANGE



## SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



# PILOT THE PRACTICE CHANGE



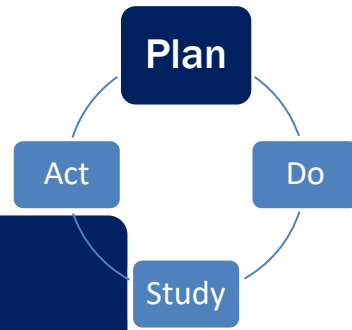
## Comprehensive Approach

- Policy: expectations/goals
- Tracking/Monitor: completeness
- Transition Readiness Assessment: identify opportunities
- HCT Plan: individualized
- Transfer of Care: coordination
- Transition Completion: elicit consumer feedback

## Nurse Practitioner (NP) Led

- Peds NP: 30 minutes for evaluation and management
- Adult NP: 30 minutes for education and counseling

# PILOT THE PRACTICE CHANGE



## Setting:

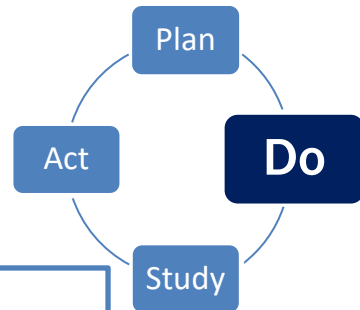
Level 4 Comprehensive  
Epilepsy Center at an  
academic institution in  
Virginia

## Time Frame:

10/01/2024-12/05/2024

1st Thursday/Month  
3 months  
4 patient per clinic  
n=12

# PILOT THE PRACTICE CHANGE



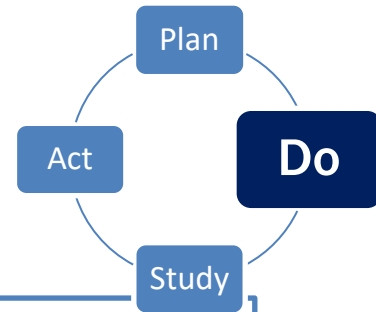
## Primary Outcome:

- Patient Experience, “Likelihood of recommending to others”

## Secondary Outcomes:

- ED visit/Admission
- Access to HCP
- Seizure Action plan offered & completed
- Attendance
- No-Show Rate

# PILOT THE PRACTICE CHANGE



## Data Collection: Primary Outcome

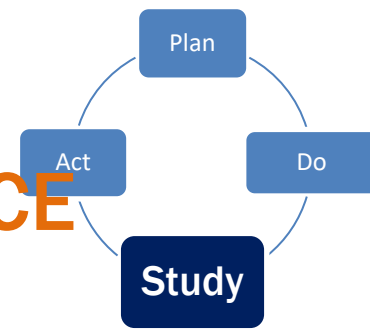
- For patients seen in the pediatric and adult clinic with ICD G40 (Epilepsy)
- Baseline: Press Ganey Patient Experience Survey FY 2023 and FY'23 Q2
- After practice change: Press Ganey Patient Experience Survey FY 2024 and FY'24 Q2

## Data Collection: Secondary Outcomes

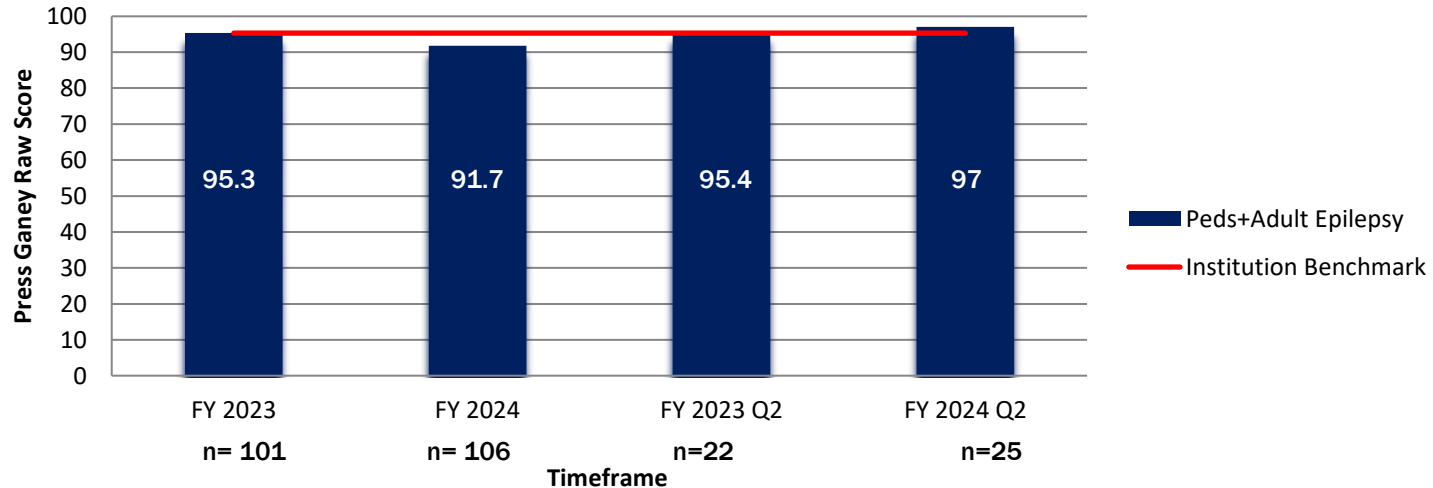
- Secured Spreadsheet
- Electronic Medical Record (EMR)

# PRIMARY OUTCOME

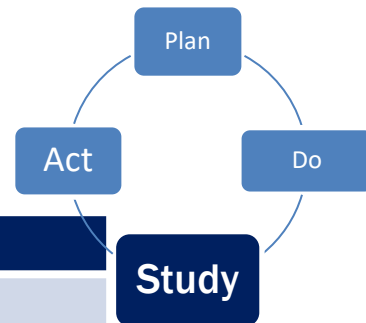
## PRESS GANEY PATIENT EXPERIENCE



### LIKELIHOOD OF RECOMMENDING



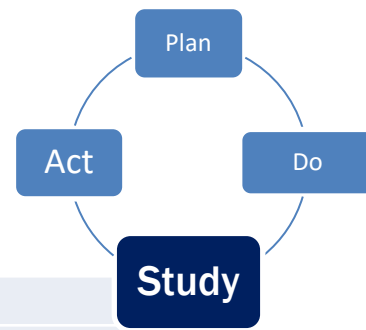
# SECONDARY OUTCOMES



Scheduled	12	Percentage
No Show	5/12	42%
Attended	7/12	58%
Seizure Action Plan Offered	7/7	100%
Seizure Action Plan Completed	3/7	42%
Access to HCP/My Chart	5/7	71%
Emergency Department/Admission	0/12	0%

# FINANCIAL CONSIDERATIONS

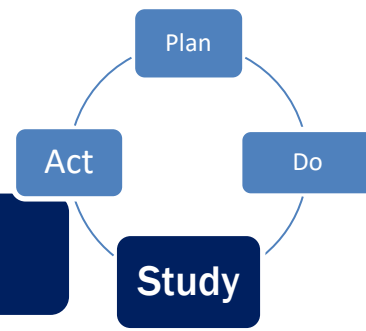
## Epilepsy HCT Clinic



### Pediatric NP- Follow Up/Medication Management

Moderate Complexity	CPT 99214	\$335
High Complexity	CPT 99215	\$473
Outpatient complex E&M	CPT G2211	\$40
<b>Adult NP- Education/Counseling</b>		
CPT	99402	\$184
Per visit (avg between 99214 and 99215)		\$628
For 7 patients during data collection		\$4,396

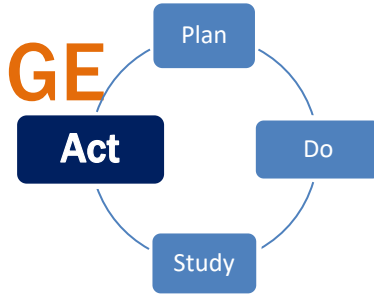
# FINANCIAL CONSIDERATIONS



## Emergency Department (ED) visit for ICD G40 (Epilepsy, Recurrent Seizures)

Emergency Department- Neurology Services (only)		
Moderate Complexity:	CPT 99284	\$339
High Complexity:	CPT 99285	\$590
Imaging: CT of Head		
Professional Fee		\$148
Medical Center Fee		\$2,210
Per visit (avg between 99284 & 99285)		\$2,822.50

# INTEGRATE & SUSTAIN THE CHANGE



## Barriers

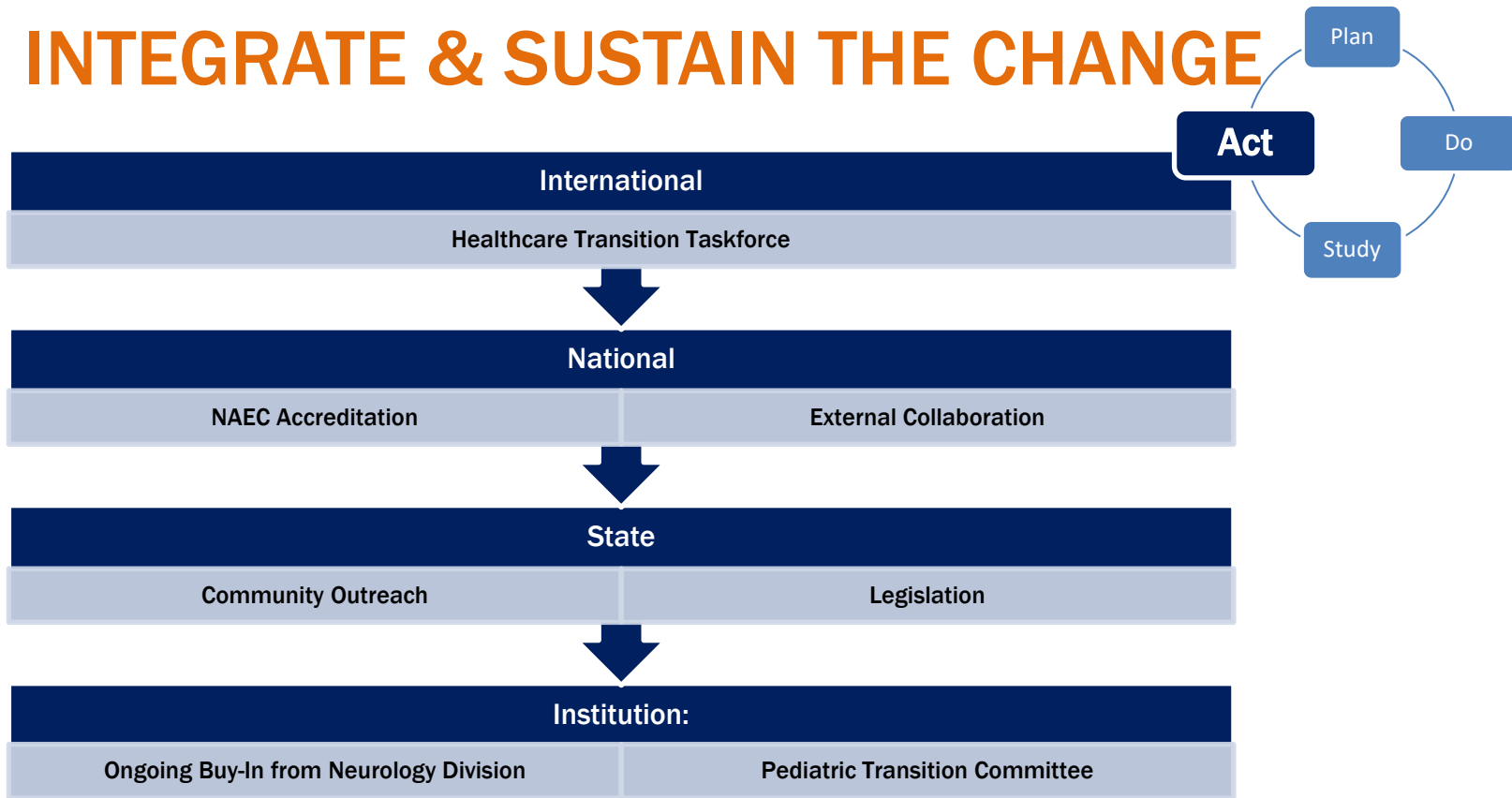
Expected setbacks with integration into EMR

Low Collection Rate

Changes in clinic operations

Completion of Press Ganey survey

# INTEGRATE & SUSTAIN THE CHANGE



# SUSTAINABILITY AND INTEGRATION

## Ongoing Buy in from Epilepsy & Neurology Division

- Increased interested from Peds Neurology
- Our template is filled for 6+ months
- Request for expansion for other chronic neurologic conditions (MD, CP)
- Documentation as required for NAEC Accreditation

## Positive Patient/Family responses

- “Appreciate being seen”
- “Think this service is helpful for teens to take part in their health”
- “Got to meet people with epilepsy”
- “Think its nice to talk without parents around about college”

**Press Ganey surveyed one of our adolescent's who scored the practice as 5/5**

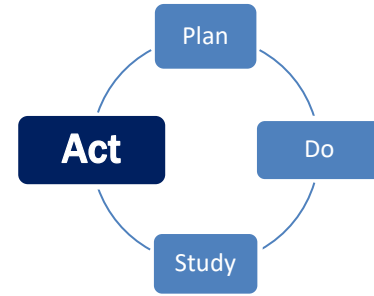
# DISSEMINATION

Executive summary to  
be given to neurology  
faculty

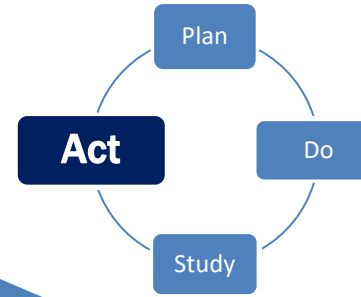
Present to Pediatric  
Transition Committee

Submit abstract and  
poster presentation at  
American Epilepsy  
Society's 2025  
Conference

Manuscript to be sent  
to Epilepsy & Behavior  
Reports



# RECOMMENDATIONS



Long-term  
process that  
will require  
ongoing  
PDSA Cycles

Consider  
alternative  
surveys

Collect  
specific  
patient data  
from AWE

Reevaluate  
literature  
specific to  
psychosocial  
concerns.

# SPECIAL THANKS TO

## Advisory:

Mark Quigg, MD, FAES,  
FAAN

Clareen Wiencek, PhD,  
APRN, ACNP, FAAN

## Collaborator:

Alana Harrison, PNP

## Statistics:

Dave Martin, PhD

Patient Experience Office

IT Analytics Team



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QUESTIONS?



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