



Using QI Methodology to Engage Parents & Caregivers in Guideline Development

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Objective & Conflict of Interest Disclosure

To describe Texas Children's implementation of Parent/Family Engagement using Quality Improvement Methodology

We have no conflict of interests to disclose

Texas Children's Hospital

Evidence Based Outcomes Center

- Evidence Based Outcomes Center (EBOC) started in 2010 to oversee evidence-based guideline development and clinical decision support implementation
- Created over 100 evidence-based clinical guidelines
 - Updated every 5 years by Multidisciplinary Content Expert Teams
- Current structure of department
 - Manager
 - EBP Specialists
 - Advanced Quality Specialists
 - Project Analyst



History of Parent Engagement at Texas Children's

Parent Involvement - 2015

- Goal: To standardize process to incorporate parent feedback in guideline development
- Parents were selected by the TCH Family Centered Care Specialist based upon their child's experience
- Parent Involvement with EBOC
 - Involved in the development of PICO questions and identification of critical/important outcomes
 - Helped review recommendations and final documents
- Sustainability Issue
 - Competing priorities in Volunteer Services that led to a delay in parent assignments
 - Uncertainty in the value of parent feedback

Evidence-based Practice

- “Using the best evidence available, combined with the practitioner's clinical expertise and the **patient's preferences**, to inform the care of patients.”



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Our AIM

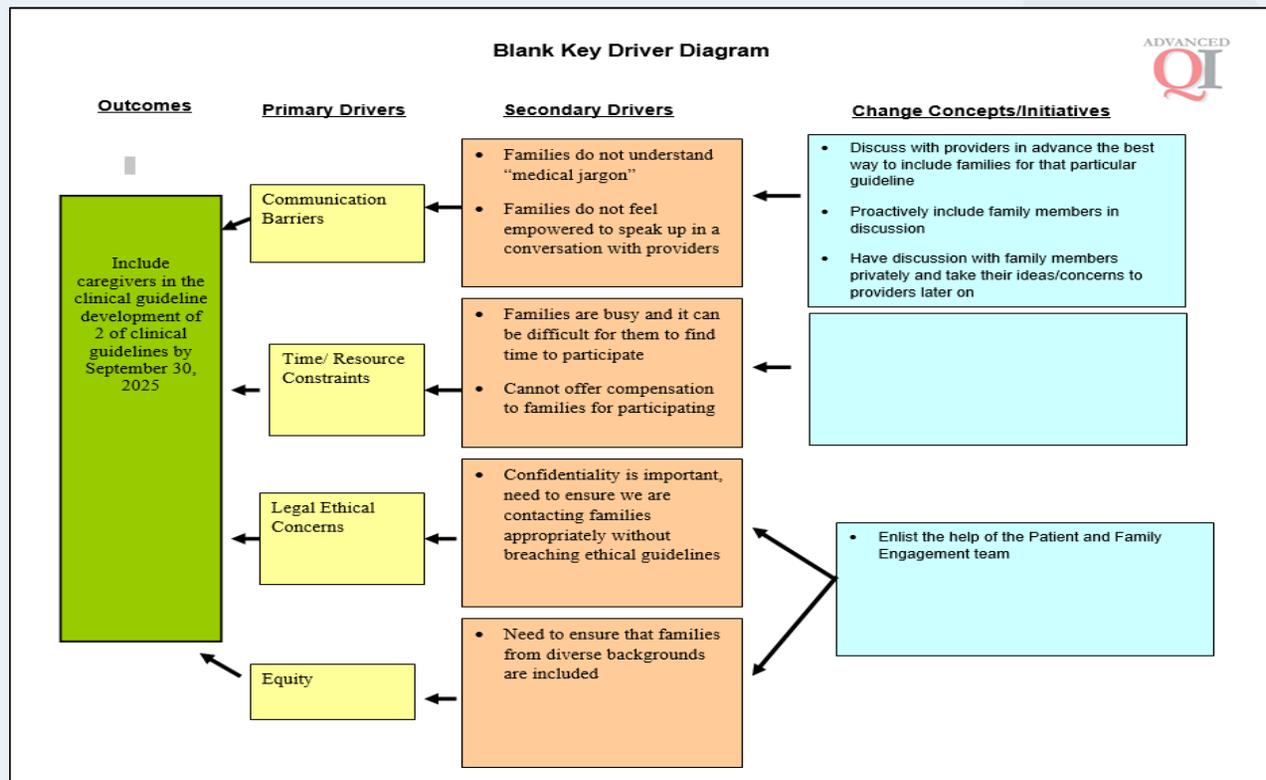
Problem Statement: Patient and family engagement in guideline development is important and currently not part of our standard practice. Their perspective, values, and preferences are necessary in managing care. They should be incorporated as part of the healthcare team.

AIM: Include caregivers in the clinical guideline development of 2 of clinical guidelines by September 30, 2025.



Parent & Caregiver Engagement

QI Key Driver Diagram



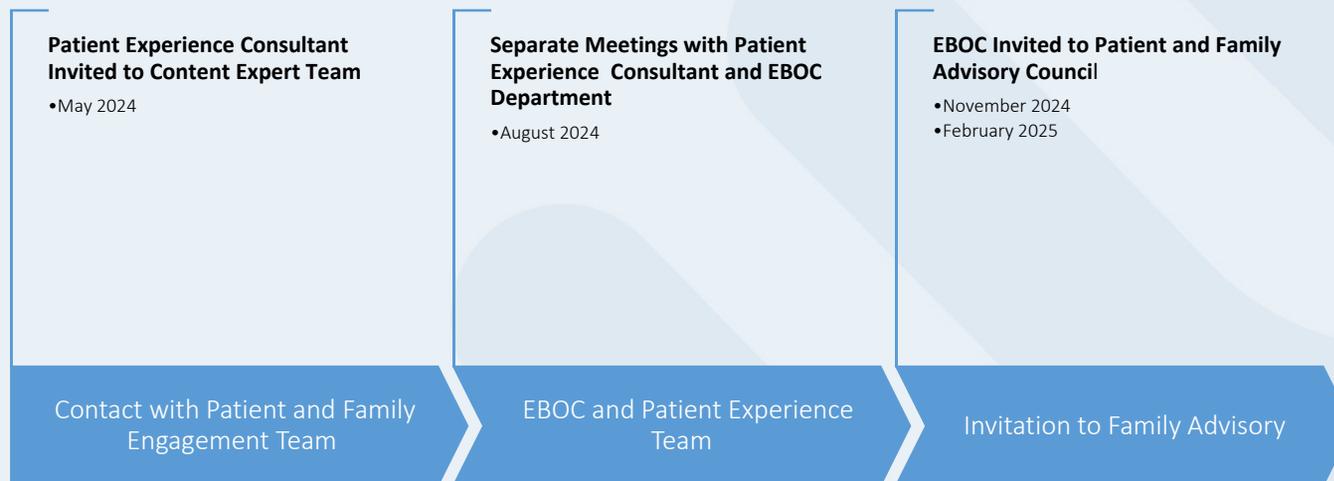
PDSA 1- Brief Resolved Unexplained Event Guideline

- Brief Unexplained Event (BRUE) Guideline updated in 2024
 - Infant < 1 year of age appears to stop breathing, they may turn pale or blue, their muscles may tense up or relax completely, or they may be hard to wake up or seem to pass out
 - With a BRUE diagnosis, no further workup (labs, imaging, etc.) is needed (Tieder, 2016)
- Texas Children's Current After Visit Summaries for a BRUE were inconsistent
 - SIDS/Safe Sleep
 - Brief information regarding BRUE
- Lack of education through Krames/KidsHealth®
- Caregivers struggle with the uncertainty of this diagnosis (Khan, 2019; Nama, 2024)



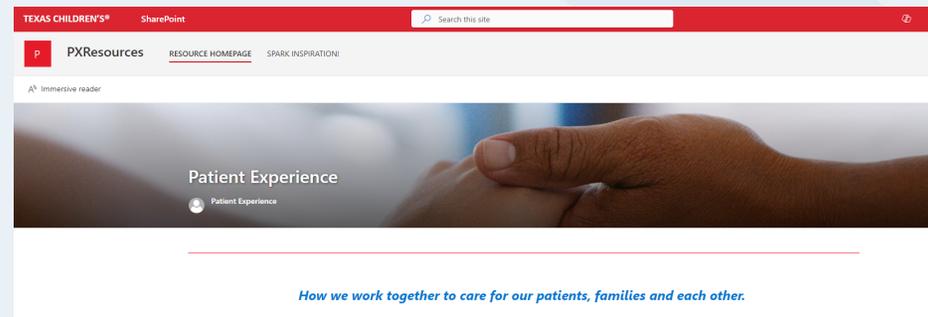
PDSA 1- Brief Resolved Unexplained Event Guideline

- During BRUE Guideline Update, discussion among the Content Expert Team members regarding parent education
- EBOC Department contacted Patient and Family Engagement Team



Patient and Family Advisory Council

- Attended Patient & Family Advisory Council in November 2024
 - Discussed BRUE, lack of testing, and parental anxiety
 - Preliminarily discussed education handout & timing
 - Best way for parents/caregivers to understand evidence of decreased testing
 - Linking Education to Guideline Metrics – EKG testing & Head Imaging



Brief Resolved Unexplained Event (BRUE) Parent Information Handout

What is a BRUE?

Brief Resolved Unexplained Events (BRUE for short) happen quickly and can be scary for parents and caregivers. When a BRUE happens, you may notice

- Your baby may seem to stop breathing
- Their skin color may turn pale or blue
- Their muscles may tense up or relax
- They may be hard to wake up or seem to pass out

After a brief period of time, they recover (with or without medical help) and begin to return to normal.

The diagnosis of a BRUE is made after your baby's doctor or a healthcare professional has examined your baby and there was no known concerning cause for the event. If there is an obvious reason for the event, including choking/gagging related to feeding or congestion, it is not considered a BRUE.

References

Texas Children's (2024, October). Brief resolved unexplained event.

American Academy of Pediatrics 2016 clinical practice guideline Brief Resolved Unexplained Events (Formerly Apparent Lifethreatening Events) and Evaluation of Lower-risk Infants

Frequently Asked Questions After a BRUE

Q: Why did my baby have this event?

A: After examining your baby, the healthcare team was unable to identify a cause and cannot say why this event happened. If another event occurs, call your baby's doctor or healthcare professional.

Q: Should my baby be monitored in the hospital?

A: Babies who are considered lower risk by the healthcare team do not need to stay in the hospital to be monitored. No imaging, blood tests, or monitoring of their heart or lungs are needed. It is safe for your baby to be cared for at home.

Q: Does having a BRUE make my baby higher risk for Sudden Infant Death Syndrome (SIDS)?

A: NO- although the causes of SIDS is unknown, BRUE events do not increase your baby's risk of SIDS. There's no guaranteed way to prevent SIDS. However, research tells us that a safe sleep environment can help reduce your baby's risk of SIDS.

For all babies, it is important to create a safe home and sleep environment. Your baby should not be exposed to smoky environments and they should always be put to sleep on their back in a crib or bassinet without any pillows, loose blankets, padding or stuffed animals. To learn more about creating a safe sleep environment for your baby, visit www.HealthyChildren.org/safesleep

Q: What should I do if it happens again?

A: Call 911 or your local emergency number

Q: Does my baby need extra care after having a BRUE? Is my baby more delicate or weak?

A: No, no special care is needed. Continue to love and care for your baby as you normally do.

Important Reminders for Parents and Caregivers

- Remember to take your baby to their regular well-child visits to keep them healthy and safe.
- Though your baby is not more likely to need it, it is a good idea for everyone who cares for infants and small children to know how to perform CPR. You may also use it one day to help someone else in need. To find a class near you, ask your child's healthcare provider, or visit the American Red Cross, the American Heart Association, or a national or local organization that offers training.

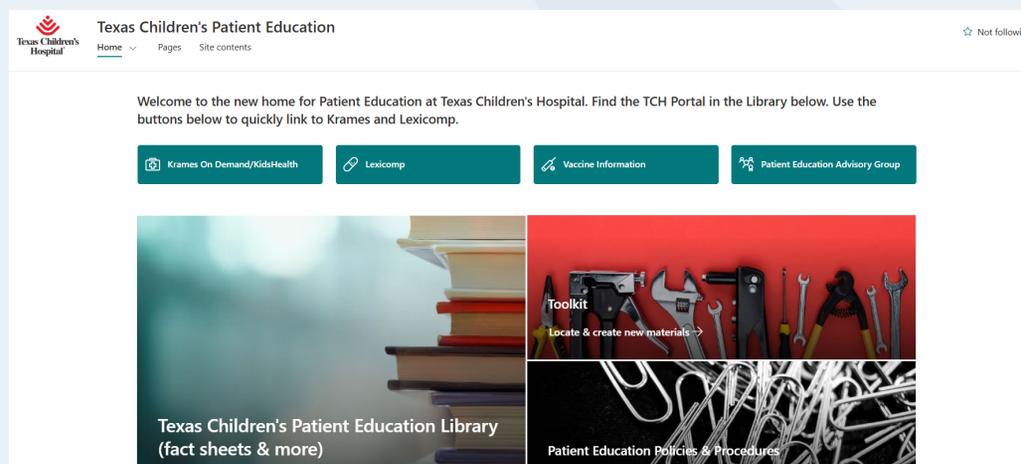
Texas Children's Parent Advice Line (832)824-2535 is monitored by Registered Nurses 24/7- Leave a message and they will call you back ASAP



PDSA 1- Brief Resolved Unexplained Event Guideline

- Next Steps

- Continue discussion with Parent & Family Advisory Council
- Potential focus group with parents that have had infants that experienced BRUE
- Engage Emergency Center personnel & BRUE Content Expert Team Leader
- Turn project over to Patient Education Department



References

Khan, A., Wallace, S. S., Sampayo, E. M., & Falco, C. (2019). Caregivers' perceptions and hospital experience after a brief resolved unexplained event: a qualitative study. *Hospital pediatrics*, 9(7), 508-515.

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