Patient and Family Engagement in Pediatric Clinical Pathways

Jarrod Dusin PhD, RD, CPHQ

Director, Evidence Based Practice
Children’s Mercy Kansas City

Objectives

Define Patient and Family Engagement (PFE) and Clarify Misconceptions

Provide an overview of Children's Mercy Kansas City's
PFE Program

Highlight Improvements Due to PFE

Present Pathways4Kids Survey and Focus Group Results

Connection to Patient and Family Engagement and Clinical Pathways

Evidence-based practice is fundamental to clinical pathway development

Patient value and preferences is foundational to evidence-based practice

Patient and Family Engagement Myths

- Clinical Pathways are for Clinicians and should only involve Clinicians
- This work is too complicated for parents
- Clinical Pathways are based on evidence only
- You should pay families to participate

Patient and Family Engagement Keys to Success

- Be open and flexible
  - Not all engagement is the same
- Groundwork and expectations
  - Prepare families AND the rest of the committee
  - Meeting with family and committee chair
- It's not going to be great every time

Patient and Family Engagement at Children's Mercy Kansas City

- Primary Contact: **Patient and Family Engagement Team**
  - Liaisons to Family Advisory Board and all Patient Family Advisory Councils
- Goal of 50% representation for eligible Pathways
- How do we prepare family members for success

Children's Mercy
KANSAS CITY

Does PFE lead to improvement?

End of Life

PF rep guided inclusion of patient and family throughout the process with a focus on shared decision making between the care team and the family – included in new huddle documentation note

Sexually Transmitted Infections

The teen advisory board provided input and direction for screening tools and how to approach patients (screening tools and confidentiality tips)

Congenital Diaphragmatic Hernia

Incorporated parent perspective when developing the post-operative care aspect pertaining to involving occupational therapy and meaningful conversations surrounding discharge expectations, follow-up outpatient care, and long-term considerations.

Does PFE lead to improvement?

First, Non-Febrile Seizure

Parent perspective when modifying the discharge instructions handout; instrumental in helping us create a provider education video on how to speak with families about first, non-febrile seizures.

Anaphylaxis Clinical Pathway

Universal Epi Auto-Injector Handout

Patient and Family Quotes

“There was a family compote that was overlooked, and it was hugely beneficial having a family member on the committee.”

“It allowed me to direct all that pain into something that will be useful in helping children and families in the future. I cannot fully describe what that feels like, but this experience offered some additional closure, unburdened feelings of guilt, while providing a sense of accomplishment that I am truly grateful for.”

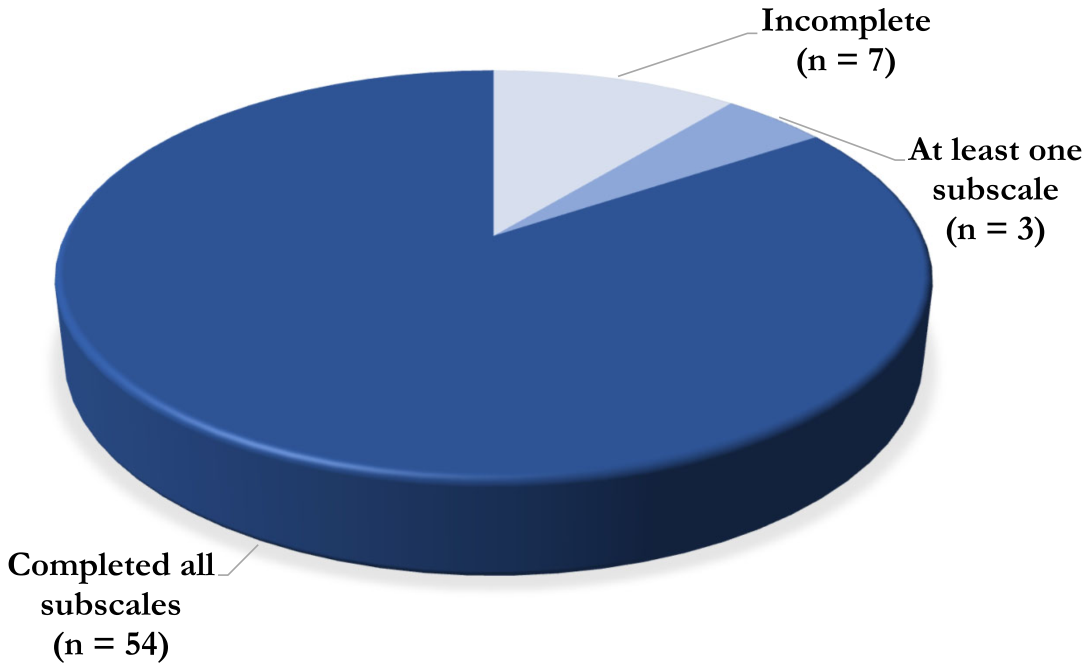
“When I found out that a standard pathway was being created for concussions, I was thrilled!!! Also, to be asked to review the documents and provide feedback, I was even more thrilled!!! There was such a need for this, and now families will have a lot more guidance and help with the aftercare.”

Patient and Family Quotes

'Participating in the development of the End-of-Life (EOL) clinical pathway was both invaluable and challenging for me. As a parent who experienced the sudden loss of a child due to cardiac arrest in a PICU, I can distinctly recall the supportive actions of the care team, as well as areas that could have been improved. Contributing to this group allowed me to honor my daughter and her life, hoping to enhance EOL experiences for other children and their families."

Pathways4kids Mixed Methods Study

Scale Participants

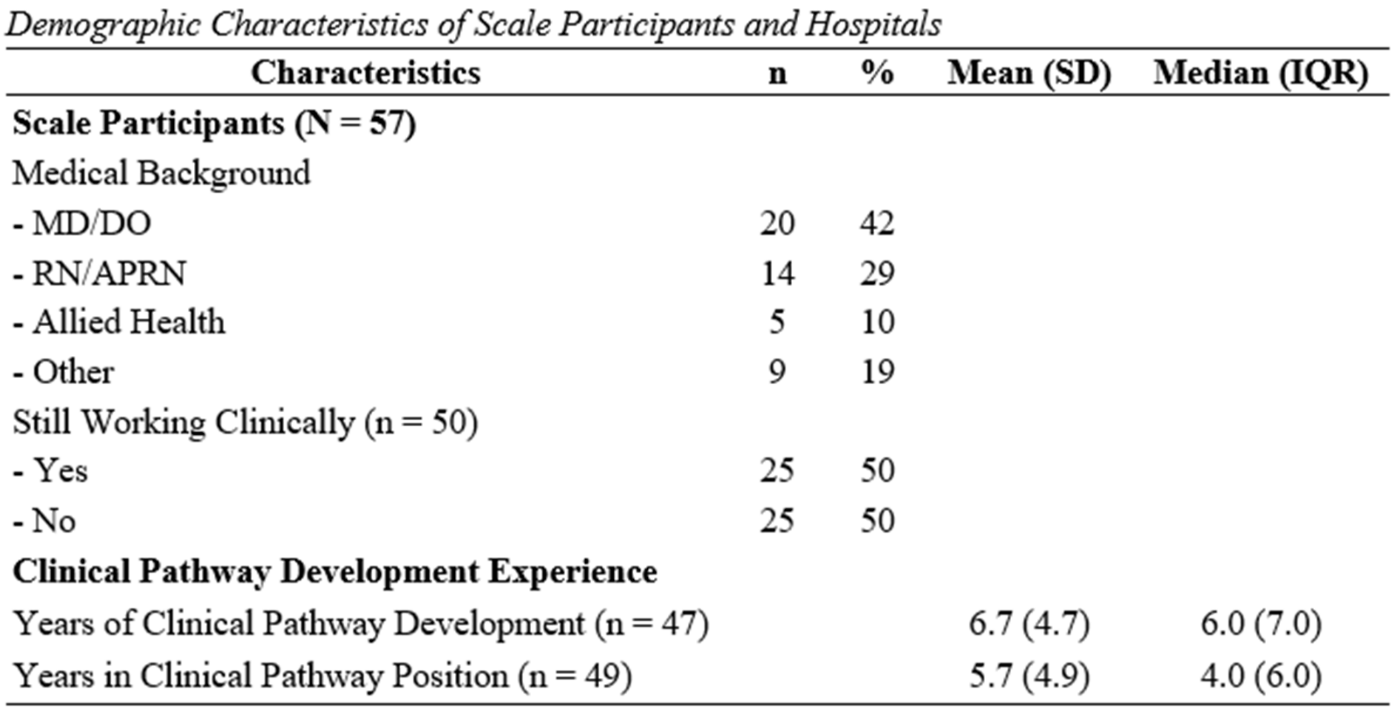


46% Response rate

43% Completed all subscales

Response rate from 71% of participating hospitals (25 of 35 hospitals)

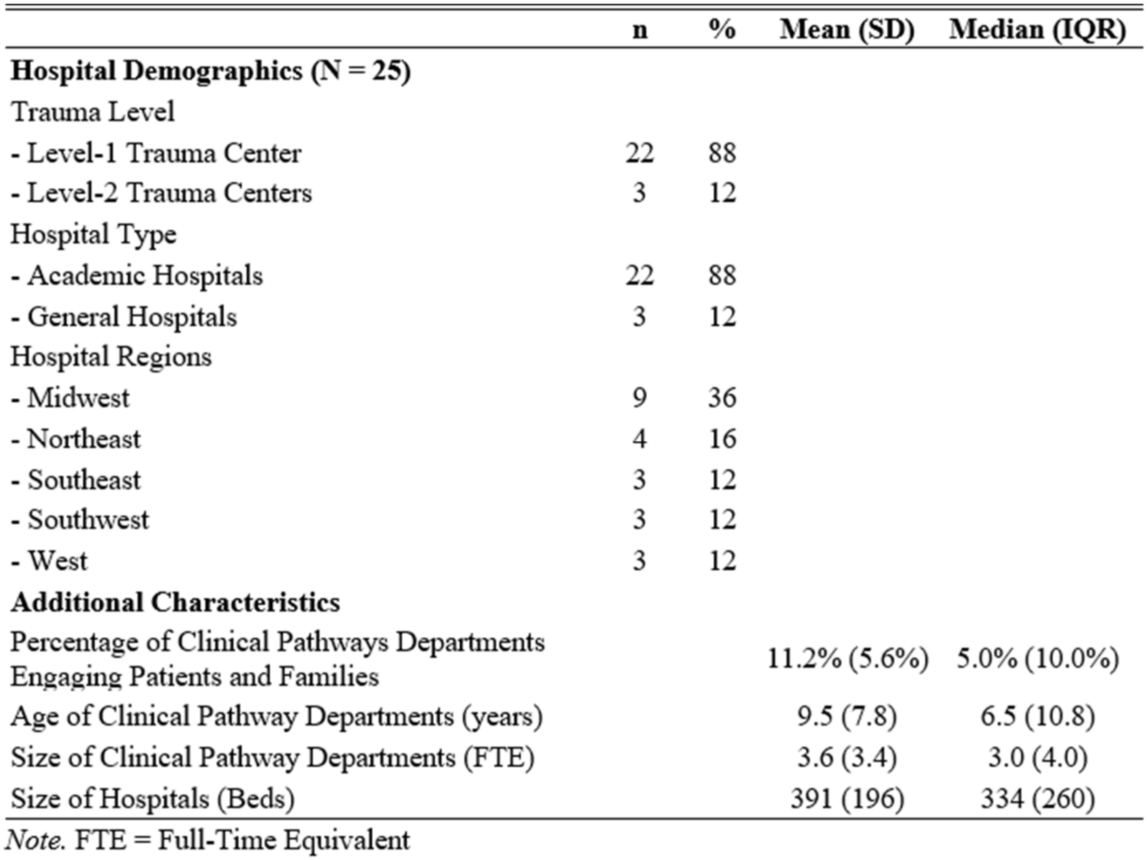
Demographics



Demographic Characteristics of Scale Participants and Hospitals

Characteristics	n	%	Mean (SD)	Median (IQR)
Scale Participants (N = 57)				
Medical Background				
- MD/DO	20	42		
- RN/APRN	14	29		
- Allied Health	5	10		
- Other	9	19		
Still Working Clinically (n = 50)				
- Yes	25	50		
- No	25	50		
Clinical Pathway Development Experience				
Years of Clinical Pathway Development (n = 47)			6.7 (4.7)	6.0 (7.0)
Years in Clinical Pathway Position (n = 49)			5.7 (4.9)	4.0 (6.0)

Demographics



	n	%	Mean (SD)	Median (IQR)
Hospital Demographics (N = 25)				
Trauma Level				
- Level-1 Trauma Center	22	88		
- Level-2 Trauma Centers	3	12		
Hospital Type				
- Academic Hospitals	22	88		
- General Hospitals	3	12		
Hospital Regions				
- Midwest	9	36		
- Northeast	4	16		
- Southeast	3	12		
- Southwest	3	12		
- West	3	12		
Additional Characteristics				
Percentage of Clinical Pathways Departments Engaging Patients and Families			11.2% (5.6%)	5.0% (10.0%)
Age of Clinical Pathway Departments (years)			9.5 (7.8)	6.5 (10.8)
Size of Clinical Pathway Departments (FTE)			3.6 (3.4)	3.0 (4.0)
Size of Hospitals (Beds)			391 (196)	334 (260)

Note. FTE = Full-Time Equivalent

Scale Scores of Patient and Family Engagement in Clinical Pathway Development

	Number of Items	Mean	SD	α
Attitudes	8	4.76	1.36	0.85
Skill	11	2.59	1.51	0.92
Knowledge	11	4.09	1.51	0.92

Note. Response options ranged from 1 (Strongly Disagree) to 6 (Strongly Agree). α = Cronbach's alpha.

Focus Group Participants

Four focus groups with 14 participants from 11 hospitals.

Focus group participants
- Nurses (RN/ARPN, n = 5, 35%),
- Other Healthcare Roles (n = 4, 28%)
- Physicians (MD/DO, n = 2, 14%)
- Allied health professional (n = 1, 7%).

Of the focus group participants, four still worked clinically (29%).

Participants had an average 5.8 years (SD = 3.4) of experience in clinical pathway development

Focus Group Themes

- Why patient and family engagement is important
- Recognizing patient and family engagement is a continuum
- Perceived barriers to engaging patients and families
- Setting up patient and family engagement for success

Qualitative Focus Group Themes

"The term evidence-based care, includes patient experience, clinician's expertise, and the role of evidence. The three components interact. How much weight each of those components have depends. It is very contextual, depending on the patient itself depending on the condition.”

Qualitative Focus Group Themes

“I don't think people [pathway committee] are disagreeing about the evidence most of the time. I think people are disagreeing about the process or system in place that you're trying to … put in around the pathway itself. And I think a lot of times, patients and families can be very helpful in that work”

References

Bolin, G., Kalmus, V., & Figueiras, R. (2023). Conducting Online Focus Group Interviews With Two Generations: Methodological Experiences and Reflections From the Pandemic Context. *International Journal of Qualitative Methods, 22*, 16094069231182029.

Brownson, R. C., Fielding, J. E., & Maylahn, C. M. (2009). Evidence-based public health: a fundamental concept for public health practice. *Annual review of public health, 30*, 175-201.

Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs, 32*(2), 223-231.

Cho, Y. I., Johnson, T. P., & Vangeest, J. B. (2013, Sep). Enhancing surveys of health care professionals: a meta-analysis of techniques to improve response. *Eval Health Prof, 36*(3), 382-407. https://doi.org/10.1177/0163278713496425

Creswell, J. W., Clark, V. L. P., Gutmann, M. L., & Hanson, W. E. (2003). ADVANCED MIXED. *Handbook of mixed methods in social & behavioral research*, 209.

Cullen, L., Hanrahan, K., Farrington, M., Tucker, S., & Edmonds, S. (2022). *Evidence-based Practice in Action: Comprehensive Strategies, Tools, and Tips from University of Iowa Hospitals & Clinics*. Sigma Theta Tau.

Dang, D., Dearholt, S. L., Bissett, K., Ascenzi, J., & Whalen, M. (2021). *Johns Hopkins evidence-based practice for nurses and healthcare professionals: Model and guidelines*. Sigma Theta Tau.

Dusin, J., Melanson, A., & Mische-Lawson, L. (2023a). Evidence-based practice models and frameworks in the healthcare setting: a scoping review. *BMJ open, 13*(5), e071188.

Dusin, J., Peltzer, J., (2023b) Patient and engagement in evidence based practice models and frameworks. Manuscript in preparation.

References

Engle, R. L., Mohr, D. C., Holmes, S. K., Seibert, M. N., Afable, M., Leyson, J., & Meterko, M. (2021). Evidence-based practice and patient-centered care: Doing both well. *Health care management review, 46*(3), 174.

Guyatt, G. (1991). Evidence-based medicine. *ACP J Club*, A-16.

Hennink, M. M., Kaiser, B. N., & Weber, M. B. (2019). What influences saturation? Estimating sample sizes in focus group research. *Qualitative health research*, *29*(10), 1483-1496.

McCarron, T. L., Moffat, K., Wilkinson, G., Zelinsky, S., Boyd, J. M., White, D., Hassay, D., Lorenzetti, D. L., Marlett, N. J., & Noseworthy, T. (2019). Understanding patient engagement in health system decision-making: a co-designed scoping review. *Systematic reviews, 8*(1), 1-10.

McDonald, N., Schoenebeck, S., & Forte, A. (2019). Reliability and inter-rater reliability in qualitative research: Norms and guidelines for CSCW and HCI practice. *Proceedings of the ACM on human-computer interaction, 3*(CSCW), 1-23.

Melnyk, B. M. (2012). Achieving a high-reliability organization through implementation of the ARCC model for systemwide sustainability of evidence-based practice. *Nursing administration quarterly, 36*(2), 127-135.

Melnyk, B. M., & Fineout-Overholt, E. (2022). *Evidence-based practice in nursing & healthcare: A guide to best practice.* Lippincott Williams & Wilkins.

Organization, W. H. (2016). Patient engagement. *Pathways4kids.org.* PATHWAYS4KIDS.ORG -. (n.d.). https://pathways4kids.org/

Rotter, T., de Jong, R. B., Lacko, S. E., Ronellenfitsch, U., & Kinsman, L. (2019). Clinical pathways as a quality strategy. *Improving healthcare quality in Europe*, 309.

Rotter, T., Kinsman, L., James, E. L., Machotta, A., Gothe, H., Willis, J., Snow, P., & Kugler, J. (2010). Clinical pathways: effects on professional practice, patient outcomes, length of stay and hospital costs. *Cochrane database of systematic reviews*(3).

References

Sackett, D. L. (1997). Evidence-based medicine. Seminars in perinatology,

Sheridan, S., Schrandt, S., Forsythe, L., Hilliard, T. S., & Paez, K. A. (2017). The PCORI engagement rubric: promising practices for partnering in research. *The Annals of Family Medicine, 15*(2), 165-170.

Sweet, C. (2001). Designing and conducting virtual focus groups. *Qualitative Market Research: An International Journal, 4*(3), 130-135.

Tashakkori, A., & Teddlie, C. (2021). *Sage handbook of mixed methods in social & behavioral research*. SAGE publications.

Teede, H., Jones, A., Enticott, J., & Johnson, A. A Learning Health System: Learning together for better health-User guide.

Wind, A., van der Linden, C., Hartman, E., Siesling, S., & van Harten, W. (2022). Patient involvement in clinical pathway development, implementation and evaluation–A scoping review of international literature. *Patient education and counseling, 105*(6), 1441-1448.

Vanhaecht, K., Panella, M., Van Zelm, R., & Sermeus, W. (2010). An overview on the history and concept of care pathways as complex interventions. *International Journal of Care Pathways*, *14*(3), 117-123.

Zimerman, A. L. (2013). Evidence-based medicine: a short history of a modern medical movement. *AMA Journal of Ethics, 15*(1), 71-76.