



Published in final edited form as:

Pediatr Res. 2023 February ; 93(3): 453–456. doi:10.1038/s41390-022-02048-1.

The Family Network Collaborative: Engaging Families in Pediatric Critical Care Research

Robert Tamburro¹, Ann Pawluszka², Deborah Amey³, Elyse Tomanio⁴, Whit Coleman⁵, Markita Suttle⁶, Anne McKenzie⁷, Sue R. Beers⁸, Kevin A. Van⁹, Ruth Grosskreuz¹⁰, Tessie W. October⁴, Mary Ann Diliberto¹¹, Randi Willey⁵, Stephanie Bisping⁵, Ericka L. Fink¹², CPCCRN and CPCCRN Family Network Collaborative

¹*Eunice Kennedy Shriver National Institute of Child Health and Human Development, Bethesda, MD*

²*Children's Hospital of Michigan, Wayne State University School of Medicine, Detroit, MI*

³*Great Falls, Virginia*

⁴*Children's National Hospital, Washington, DC*

⁵*Primary Children's Hospital, University of Utah School of Medicine, Salt Lake City, UT*

⁶*Nationwide Children's Hospital, Columbus, OH*

⁷*UCSF Benioff Children's Hospital, San Francisco, CA*

⁸*UPMC Western Psychiatric Hospital, University of Pittsburgh School of Medicine, Pittsburgh, PA*

⁹*Children's Hospital Colorado, Aurora, CO*

¹⁰*Medpace, a Contract Research Organization, Children's Hospital Colorado, Aurora, CO*

¹¹*Children's Hospital of Philadelphia, Philadelphia, PA*

¹²*UPMC Children's Hospital of Pittsburgh, University of Pittsburgh School of Medicine, Pittsburgh, PA*

The need for family and patient input into clinical care has become well established in pediatrics. More recently, the value of such input into pediatric research has also become more accepted with many funding opportunities now requiring such engagement. Although

Users may view, print, copy, and download text and data-mine the content in such documents, for the purposes of academic research, subject always to the full Conditions of use:http://www.nature.com/authors/editorial_policies/license.html#terms

Corresponding Author: Robert F. Tamburro, MD., MS., *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*, 6710B Rockledge Drive, Room 2331-C, Bethesda, Maryland, 20817, Phone: 301-480-2619, robert.tamburro@nih.gov.

Author contributions

RT, ELF, AP, ET, DA: Substantial contributions to manuscript conception/design, acquisition, analysis, and interpretation of data, and manuscript preparation. ET and DA contributed to manuscript preparation. SB and RW provided management for this work. All authors contributed to manuscript revision. All authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved and approved the final version for submission.

The remaining authors report no conflicts.

Patient consent: Not applicable or required

Category of Study: Correspondence

lacking in a universally accepted definition, Patient and Public Involvement and Engagement can be generally defined as the inclusion of patients and families in research endeavors. Involvement can be passive – as in a lecture provided by the investigator to the family, or deliberative – with families engaged in all aspects of the research program. Examples of family engagement include setting research priorities, contributing to study design elements, reviewing patient and family facing materials, and assisting in dissemination of research implications^{1,2}. Given the unique aspects of pediatric research³, family input may be of particular value. However, identifying the optimal method of soliciting such input in a meaningful manner that is respectful of the family participant time and effort remains a challenge. This may be particularly true in the setting of critical care research with a paucity of published data to guide such efforts. To better understand how to secure and utilize family input into pediatric critical care research, we recently reviewed our experience with the Collaborative Pediatric Critical Care Research Network (CPCCRN) and surveyed key stakeholders.

The CPCCRN, supported by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), has conducted multicenter pediatric critical care research since 2005⁴. As the Network evolved, it became increasingly important to ensure that the research questions and outcome variables prioritized by investigators aligned with those valued by patients and families. This recognition occurred alongside the growing value attributed to family participation in pediatric intensive care unit (PICU) processes including daily rounds, invasive procedures and cardiopulmonary resuscitation^{5,6}. Further, data suggest that family input can improve research processes such as consent language and adherence to protocols⁷. Thus, a growing interest in engaging families in PICU research planted the seed for what has become the CPCCRN Family Network Collaborative (FNC).

Family input was solicited since the inception of the CPCCRN, however, it was conducted in a non-structured manner over the first two cycles (10 years) of the Network. This manuscript focuses on its third cycle, in which renewed interest in formalizing family engagement was spawned. The term the “Family Network Collaborative” was coined to embody a philosophy in which parents and investigators worked collaboratively to conduct research for critically ill children in a manner that is most respectful and inclusive of families’ needs and values.

To operationalize this vision, the FNC is composed of the following members: (1) the NICHD project scientist; (2) a site liaison (research coordinator, investigator, or other delegated clinician from each Network site); and (3) up to two parent participants from each of the seven Network sites and the Data Coordinating Center. The parent participants were identified and recruited by the site liaison. The parent participants, who were asked to serve for the full Network cycle, each had a child with a prior admission to the PICU. The FNC leadership included each site’s liaison, a family representative (DA), and the NICHD Project Scientist.

Employing this structure, the FNC leadership developed a “job description” for FNC participants in response to previous Network cycle concerns regarding the role of the family participants and how best to utilize and incorporate their unique insight. The job description delineated three primary responsibilities for family/parent participants:

- To provide input on outcomes of interest to families of critically ill and injured children that should be considered priorities in research studies;
- To review and to provide feedback on the consent process for CPCCRN studies;
- To share insight regarding overall research priorities for the Network.

In terms of commitment and workflow, family participants were provided a one-hour introductory webinar overview of the CPCCRN and its FNC at the start of the Network cycle. Subsequently, FNC members participated in monthly meetings during which their input was solicited and shared as proposed in the job description, and updates regarding Network research were provided. In addition to monthly meetings, parent participants were solicited periodically for feedback and/or to receive education regarding CPCCRN research topics via webinar or email. CPCCRN investigators who sought FNC input submitted their request to the FNC leadership often providing a brief presentation for discussion with FNC parent participants. FNC responses were compiled by the Network administrator and sent to the investigator for review.

During this past cycle, FNC parent participant feedback proved to be invaluable in several instances. For example, FNC participants provided important insights on the sharing of genetic testing results with parents obtained during Network research⁸. Their collective response was instrumental in formulating an approach to sharing these data in the most effective and sensitive manner possible. Additionally, FNC parent participants provided input on the use of pre-morbid assessment tools as part of an interventional clinical trial enrolling children following cardiac arrest. Based on their input, the investigators omitted a lengthy measure to assess baseline functioning and instead added a more succinct validated measure⁹. This reduced the burden placed on the child's caregiver during an emotionally most difficult time while also facilitating robust data collection. Moreover, FNC parent participants contributed to a Network project aimed at developing a Core Outcomes Set that should be considered in any clinical and research program involving critically ill children¹⁰. Parent participants helped assure survey comprehension in addition to providing the needed family stakeholder input via the Delphi survey. Finally, FNC input regarding the development of a new clinical trial protocol guided the Principal Investigators to add long-term child and family centered outcomes to the project.

A survey was conducted at the end of the Network cycle to solicit parent member (Table 1) and investigator (Table 2) perspectives to inform and improve subsequent FNC integration into the Network. Fourteen of sixteen parents and all eight site primary investigators responded to a web-based survey that was created and managed by the Network. Respondent answers were anonymous and survey participation was not required. A descriptive analysis of responses affirmed many of the purported FNC benefits, but also identified opportunities for improved utilization. There was much overlap in the feedback from the two groups including in the identification of these opportunities for improvement and in offering responses to the challenges described below.

Despite the successes and great motivation by parent members to give back and contribute to research, the FNC is faced with many challenges; the optimal engagement of parent/family participants being the greatest. Participating FNC parents offered that many of them who

volunteer (or who will volunteer) to be part of the FNC have children with ongoing health issues thereby limiting their structured availability as much of their time is committed to caring for their child. These parents provided meaningful insight in sharing that they prefer task-oriented work and the ability to work on their own time in contrast to monthly webinars. Additionally, a deliberate approach is needed to assure that FNC membership is diverse and representative of all PICU families. Moreover, limited funding dollars prevent adequate participant compensation for their time and effort. Budgeting for such input and participation in the original grant application was offered as one method to overcome this challenge (Table 2). Another approach to enhance inclusivity and diversity in engagement is to include adolescents and adults who survived pediatric critical illness; who may offer a unique perspective for the FNC and for the Network. Further, assuring that FNC participants are well informed of their roles and successfully focusing the group on the needed input is another challenge. The introductory webinar and the developed job description appear to help overcome these hurdles. Finally, parents bring unique skills and interests (e.g. public speaking and advocacy experience); recognizing and utilizing these talents was suggested as an approach to promote the value of the FNC and participant satisfaction.

With regard to Network investigators, many had not previously participated in multiple stakeholder research. Thus, education and creation of established processes to best utilize the FNC as a resource is a key need. To help address this need, a form was created to facilitate an ‘ask’ and a timeline for FNC participants’ response. FNC updates are also provided at Network Steering Committee Meetings to keep all members of the Network informed. Parents are invited to attend these Meetings, but few do so. Further, investigators may benefit from an evidence-based summary of the positive impact and value an FNC may impart on research programs to improve engagement.

In conclusion, while it is clear that the FNC has contributed enormously to the NICHD and Network’s objective “... *to enhance the lives of children and adolescents, and optimize abilities for all*”, there remains much to be learned regarding optimal utilization of this essential and much needed resource. As family and community input appropriately becomes a standard part of clinical trials and network research, identifying and sharing best practices is critical. Although examples exist of successful community participation in pediatric research ¹¹, further research into structuring and incorporating such input in a pragmatic manner respectful to all is needed.

Acknowledgements

We would like to acknowledge all of the CPCCRN FNC parent and site liaison participants over the first three cycles of the Network for their dedication to incorporating families into research to improve the lives of critically ill children. We thank Tammara L. Jenkins, MSN, RN, PCNS-BC, FCCM for her support and encouragement in FNC development as a Program Officer, Pediatric Trauma and Critical Illness Branch of the NICHD.

Statement of Financial Support

Funding for this project was provided by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN). It was approved by the CPCCRN Steering Committee and funded by grant numbers U01-HD049934, UG1-HD083171, UG1-HD050096, UG1-HD063108, UG1-HD049983, UG1-HD049981, UG1-HD083170, and UG1-HD083166. EF reports funding from NIH (NINDS) R01 NS096714.

Disclosure Statement

Ms. Pawluszka, Ms. Tomanio, Ms. McKenzie, Mr. Van, Ms. Diliberto, Ms. Willey, Ms. Bisping, and Dr. Fink have grant support from the National Institutes of Health. At the time of submission, Drs. October and Tamburro are employed by the National Institutes of Health.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

References

1. Manafò E, Petermann L, Vandall-Walker V, Mason-Lai P. Patient and public engagement in priority setting: A systematic rapid review of the literature. *PLoS One*. 2018;13(3):e0193579. [PubMed: 29499043]
2. Ball S, Harshfield A, Carpenter A, Bertscher A, Marjanovic S. Patient and public involvement in research: Enabling meaningful contributions. Santa Monica, CA: RAND Corporation; 2019.
3. Slora EJ, Harris DL, Bocian AB, Wasserman RC. Pediatric clinical research networks: current status, common challenges, and potential solutions. *Pediatrics*. 2010;126(4):740–745. [PubMed: 20837583]
4. Willson DF, et al. Collaborative Pediatric Critical Care Research Network (CPCCRN). *Pediatr Crit Care Med*. 2006;7(4):301–307. [PubMed: 16738501]
5. Phipps LM, et al. Assessment of parental presence during bedside pediatric intensive care unit rounds: effect on duration, teaching, and privacy. *Pediatr Crit Care Med*. 2007;8(3):220–224. [PubMed: 17417129]
6. Henderson DP, Knapp JF. Report of the National Consensus Conference on Family Presence During Pediatric Cardiopulmonary Resuscitation and Procedures. *Pediatr Emerg Care*. 2005;21(11):787–791. [PubMed: 16280958]
7. Zheng K, et al. Impressions of Early Mobilization of Critically Ill Children-Clinician, Patient, and Family Perspectives. *Pediatr Crit Care Med*. 2018;19(7):e350–e357. [PubMed: 29649021]
8. Botkin JR. Ethical issues in pediatric genetic testing and screening. *Curr Opin Pediatr*. 2016;28(6):700–704. [PubMed: 27606958]
9. Pollack MM, et al. Functional Status Scale: new pediatric outcome measure. *Pediatrics*. 2009;124(1):e18–28. [PubMed: 19564265]
10. Fink EL, et al. Development of a Core outcome set for Pediatric critical care outcomes research. *Contemp Clin Trials*. 2020:105968.
11. Fiks AG, Cutler M, Massey J, Bell LM. Partnering With Parents to Create a Research Advisory Board in a Pediatric Research Network. *Pediatrics*. 2018;142(5).

Table 1.

Themes identified from family/parent participant responses to the end of the Network cycle survey regarding the Family Network Collaborative (FNC).

I. What motivates you to participate in this group?

- Gratitude and an opportunity to give back
- Improve outcomes for future critically ill and/or injured children and their families
- Facilitate and promote family-centered research

II. What would you like to see accomplished by the FNC to support the Network researchers?

- Advancement of the goals of the Network
- Incorporation of family perspectives into research design, protocols, wording/content of family facing documents, and research topics
- Improvement in retention of patients in studies
- Promotion of pediatric intensive care unit (PICU) research through advocacy

III. List the benefits you perceive to the Network researchers from your participation as a FNC member since you've joined.

- Assurance that family perspectives are considered valued aspects of PICU research
- Improved communication between family members and investigators of research needs
- Provision of a community resource for families and for the research Network

IV. Describe the current challenges you see in collaborating with our Network researchers most effectively.

- Adequate meeting time with investigators to assure robust communication
 - Timely and effective communication outside of meetings
 - Consensus commitment to the FNC from all Network investigators
 - Assurance that all family participants find value in their contribution to the Network
 - Utilization of family participant special skills to benefit the Network (e.g. advocacy, public speaking, grant writing)
-

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2.

Themes identified from principal investigator responses to the end of the Network cycle survey regarding the Family Network Collaborative (FNC).

I. What were the benefits of FNC family member involvement this cycle?

- Integration and optimization of family perspectives and priorities into Network research activities
- Guidance in interacting with families during follow-up data collection and in the dissemination of research results
- Assistance in communicating pediatric intensive care unit (PICU) science to families and the general public

II. Describe the current challenges you see in collaborating with our FNC members most effectively.

- Utilizing family participant time and effort most efficiently and effectively
 - FNC family member input may not be representative of all PICU families
 - Identifying the optimal way to facilitate FNC participation for both the investigators and the family participants particularly when family participant feedback is needed in a timely manner
 - Securing financial resources to support the FNC and its members for their time and effort and to attend in
 - Understanding the special skill sets of FNC family members
-