

Plain Language Summary: Design and Implementation of Neonatal Family Research Advisory Council (NFRAC)

This study aims to address the gaps in the ways that pediatric participants and families experience research. This study is specifically looking at the way of working with individuals with lived experience directly.

Research involving infants in the NICU setting can be challenging because of critical illness, the range of the families' experience, and the time-sensitive nature of interventions. To expand and improve our approach to neonatal research, this study focused on creating a Neonatal Family Research Advisory Council (NFRAC). The goal of this council is to involve families with lived experiences in research projects being conducted at their healthcare facilities.

Since December 2023, sixteen family members expressed interest in joining the NFRAC. Six of the families agreed to an optional demographic survey. Across these six families, they have had eleven children combined in the NICU and experienced over 700 days of NICU care and have participated in a total of ten research studies.

In the first year of development, the council members focused on best practices in approaching families for consent. These best practices are now being used for recruitment and consent processes at UnityPoint Health Meriter NICU and Newborn Nursery. The formation of the NFRAC has created a group of family, medical, and research team members who hope to better the research process. The best practices may be a starting point for consent and recruitment consideration for other neonatal and pediatrics research groups to create a comfortable, accessible, and smooth consent process in critical and time-sensitive settings.

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