Perceptions of Parents, Nurses, and Physicians Regarding Research Communication in the NICU: Results of an International Survey

Jennifer Degl 1, Mary Short 2, Robert Ward 3, Communications Workgroup of International Neonatal Consortium (INC) 4

The authors do not receive financial interests. 1. Speaking for Moms & Babies, Inc.; 2. Retired Industry Member of INC; 3. The University of Utah; 4. Critical Path Institute

Background

Drug and device development for neonates has been quite limited in the NICU over the past 20 years. A multidisciplinary effort to improve research and communication in the NICU is essential and must engage parents, nurses and physicians to optimize efforts. Launched in 2015, C-Path’s Critical Path Institute (CPI) is a multi-stakeholder global collaboration formed to forge a predictable regulatory path for evaluating the safety and effectiveness of therapies for neonates.

Deliverables

Development of parallel multi-stakeholder survey to identify communication practices in NICUs regarding neonatal research and research practice

Objectives

Evaluate current communication practices in NICUs across the globe

Identify communication challenges in NICUs that impede successful implementation of clinical research

Provide physicians, nurses, and research professionals with a range of recommended methods to improve communication between all stakeholders involved in neonatal clinical research

Methods

3 Parallel surveys launched August 2018, closed November 2018 using Survey Monkey®:

- to parents, nurses, and physicians, a convenience sample of INC members, who then disseminated invitation to relevant organization and interested individuals.
- Participation was voluntary and without compensation.
- Data were collected across 6 domains: Demography & Characteristics, Role of Research, Research Consent Process, Research Results Disclosure, Communication in the NICU, Current Communication Flow in NICU, Education and Training of Personnel on research in the NICU?
- Participation was voluntary and without compensation.
- Data were collected across 6 domains: Demography & Characteristics, Role of Research, Research Consent Process, Research Results Disclosure, Communication in the NICU, Current Communication Flow in NICU, Education and Training of Personnel on research in the NICU?
- Wide variability among parents between the time their child was cared for in the NICU and their participation in the survey.
- Most responding nurses and parents held a bachelor’s degree or higher.
- Majority of medical professionals defined their NICU’s level of care as 3 or 4.
- Majority by (49%) of neonatologists indicated that they engage in both patient care and research at their institution as compared to 17% of nurses.
- Wide variability among parents between the time their child was cared for in the NICU and their participation in the survey.

Survey Population

PHYSICIANS (32)

- United States (36.5%)
- Canada (1.6%)
- EU/EAA (38.5%)
- Switzerland (1.6%)
- Japan (9.6%)
- Australia, Mexico, Ecuador, Australia (9.8%)

NURSES (168)

- United States (78.7%)
- Canada (3.2%)
- EU/EAA (19.4%)
- Japan (3.2%)
- New Zealand, Middle East, Australia, Africa, Southeast Asia, Thailand (3.3%)

PARENTS (32)

- United States (64.3%)
- Canada (2.4%)
- EU/EAA (21.7%)
- Brazil (1.4%)
- Japan (1.2%)
- Argentina, Taiwan, Australia (3.1%)

Survey Question: Which of the following statements best represents your beliefs about the necessity of drug studies in sick newborns?*

- A study is necessary to determine if a drug is safe and effective in sick newborns even after the drug’s efficacy and safety have been demonstrated in adults
- An additional smaller study is necessary to determine dosing and to evaluate the safety of a drug in sick newborns after the drug’s safety and efficacy have been demonstrated in adults
- No drug studies are necessary in sick newborns once the drug’s efficacy and safety have been demonstrated in adults

Results

Significant differences were noted between stakeholder groups with respect to the need for research in sick neonates (chi-square p = 0.001)

Survey Question: Which of the following statements best represents your beliefs about the necessity of drug studies in sick newborns?*

- A study is necessary to determine if a drug is safe and effective in sick newborns even after the drug’s efficacy and safety have been demonstrated in adults
- An additional smaller study is necessary to determine dosing and to evaluate the safety of a drug in sick newborns after the drug’s safety and efficacy have been demonstrated in adults
- No drug studies are necessary in sick newborns once the drug’s efficacy and safety have been demonstrated in adults

Inconsistent response between study cohorts in perception of their institution’s current methods of communication regarding neonatal research that is ongoing (chi-square p=0.0001) or upcoming (chi-square p= 0.02).

Survey Question: Does your NICU have a system in place to provide updates to families on on-going/upcoming research in the NICU?

- Participation was voluntary and without compensation.
- Data were collected across 6 domains: Demography & Characteristics, Role of Research, Research Consent Process, Research Results Disclosure, Communication in the NICU, Current Communication Flow in NICU, Education and Training of Personnel on research in the NICU?
- Wide variability among parents between the time their child was cared for in the NICU and their participation in the survey.
- Most responding nurses and parents held a bachelor’s degree or higher.
- Majority of medical professionals defined their NICU’s level of care as 3 or 4.
- Majority by (49%) of neonatologists indicated that they engage in both patient care and research at their institution as compared to 17% of nurses.
- Wide variability among parents between the time their child was cared for in the NICU and their participation in the survey.

Conclusions

The survey suggest neonatologists have the opportunity to:

- Educate nurses and parents on the need for the study of drugs in neonates to determine efficacy and safety
- Improve research communication practices in the NICU
- Define, standardize and implement appropriate communication strategies
- Involves nurses and parents as key stakeholders in all aspects research

Full Survey Results

Acknowledgments: Critical Path Institute is supported by the Food and Drug Administration (FDA) of the U.S. Department of Health and Human Services (HHS) and is 54.2% funded by the FDA/HHS, totaling $13,239,950, and 45.8% funded by non-government source(s), totaling $11,196,634. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, FDA/HHS or the U.S. Government. Authors acknowledge INC Communications WG and INC Leadership Team