CRITICAL PATH INSTITUTE

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



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

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# 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 International Neonatal Consortium (INC) is a multi-stakeholder global collaboration formed to forge a predictable regulatory path for evaluating the safety and effectiveness of therapies for neonates.

#### Deliverable

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 in NICU, Current Communication Flow in NICU, Education and Training of Personnel on Role of Neonatal Research, Research Consent Process, Research Results Disclosure
- >>> Survey format utilized: Likert scales, multiple choice & binary questions, 2 free-text questions Definitions were provided within the survey
- >>> Chi-square tests evaluated differences in responses of stakeholder groups.
- >> IRB: University of Utah # 00143250 Exempt

## **Survey Population**

#### PHYSICIANS (52)



- United States (38.5%)
- Canada (1.9%)
- EU/EAA (38.5%)
- Switzerland (1.9%)Japan (9.6%)
- Argentina, Mexico, Ecuador, Australia (9.6%)

#### **NURSES (188)**



- United States (78.7%)
- Canada (3.2%)
- EU/EAA (9.6%)
- Japan (3.2%)
- New Zealand, Middle East,
- Australia, Africa, Southeast Asia, Thailand (5.3%)

#### PARENTS (83)

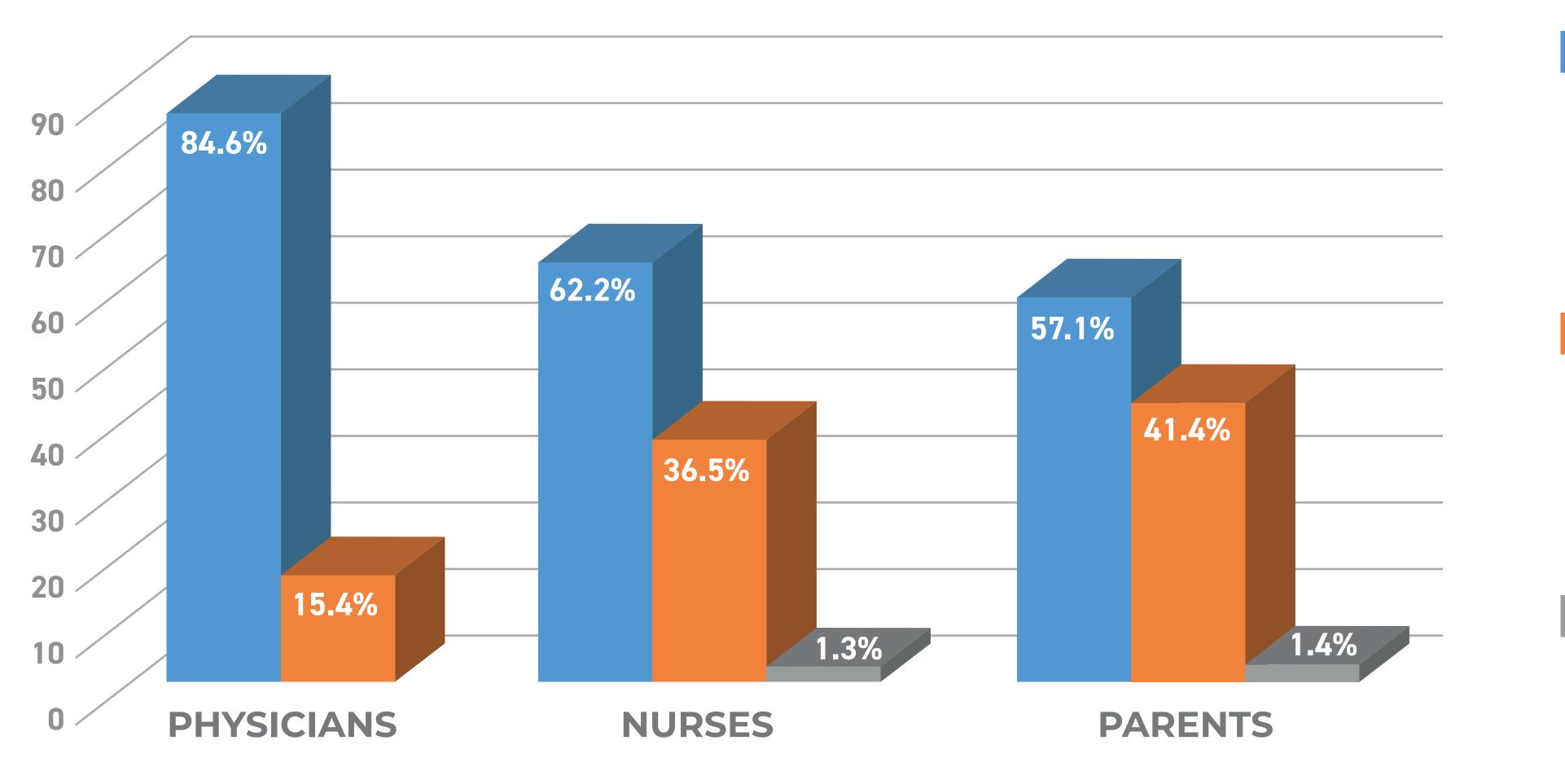


- United States (66.3%)
- Canada (2.4%)
- EU/EAA (21.7%)
- Brazil (4.8%)
- Japan (1.2%)
- Argentina, Taiwan, Australia (3.61%)
- >>> Most responding nurses and parents held a bachelor's degree or higher.
- >>> Majority of medical professionals defined their NICU's level of care as 3 or 4.
- >>> Majority (69%) 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.

# Results

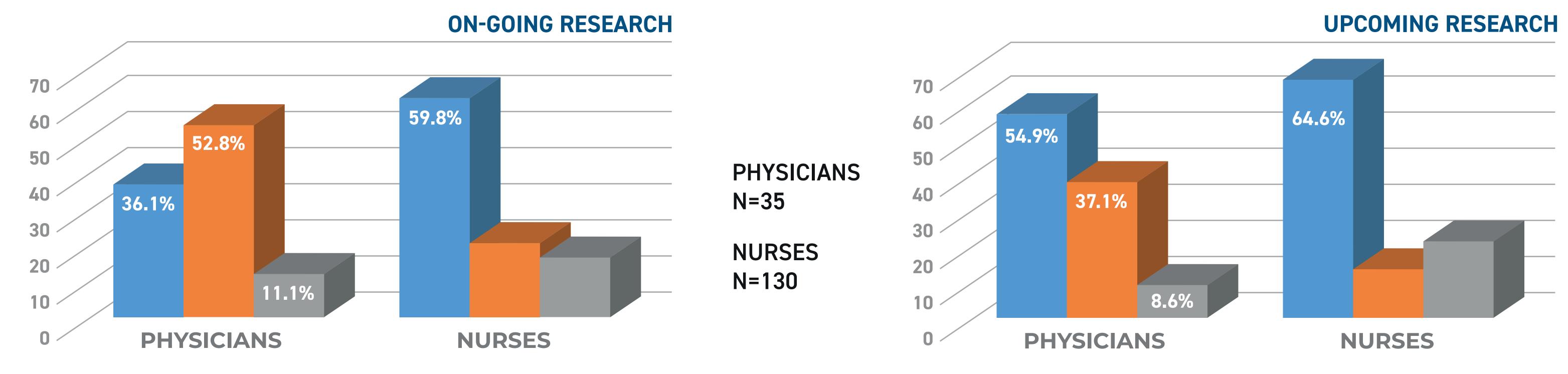
Significant differences were noted between stakeholder groups with respect to the need for research in sick neonates (chi-square p = 0.01)

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 demontrated 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?



- >> Specific research meetings were rated most effective by physicians and nurses for both ongoing (63% and 67%, respectively) and upcoming (85% and 55.5%, respectively) research.
- Only a small proportion of nurses surveyed (15% [17/114]) reported that they were asked to provide input on a study at their institution.
- >> Additional survey results are available via the QR code.

## 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
- >>> Involve nurses and
  parents as key
  stakeholders in all aspects
  research

### Full Survey Results



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