



# Parent Participation in Research in the NICU

## Understanding parental choices in determining their child's participation in NICU research

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### Background

- Newborn & infant time period is critical for growth & development – to mitigate this negative health outcomes, there is a important need for clinical research at the NICU<sup>3</sup>
- Reasons parents decline their child's enrollment in research includes feeling they lack time/space to make the decision<sup>1</sup>

### Objective

The purpose of this study is to

1. understand parents' experience of being approached for research participation in the NICU
2. understand when parents' are able to engage in research conversations
3. how to best support them in that decision.

### Methods

- Parents with current or previous lived experience of having newborn(s)/infant(s) in the NICU within the past 15 years were eligible to participate
- Parents with previous lived experience were recruited via social media and parents with current experience were contacted in person or via letter with contact information
- Semi-structured interviews completed between Sept 2018 – Sept 2019
- Thematic analysis was completed as described by Nowell, et al. (2017)<sup>2</sup>

### Conclusion

The data has illuminated that readiness is not associated with one specific point in time. **Parents who have adapted to the NICU environment, have developed their caregiver role, and who's infant's health was improving, are able to listen and make informed decisions to participate in NICU research.**

### Future Directions

Results from this study will be used to develop a parent-centred approach to research in the NICU.

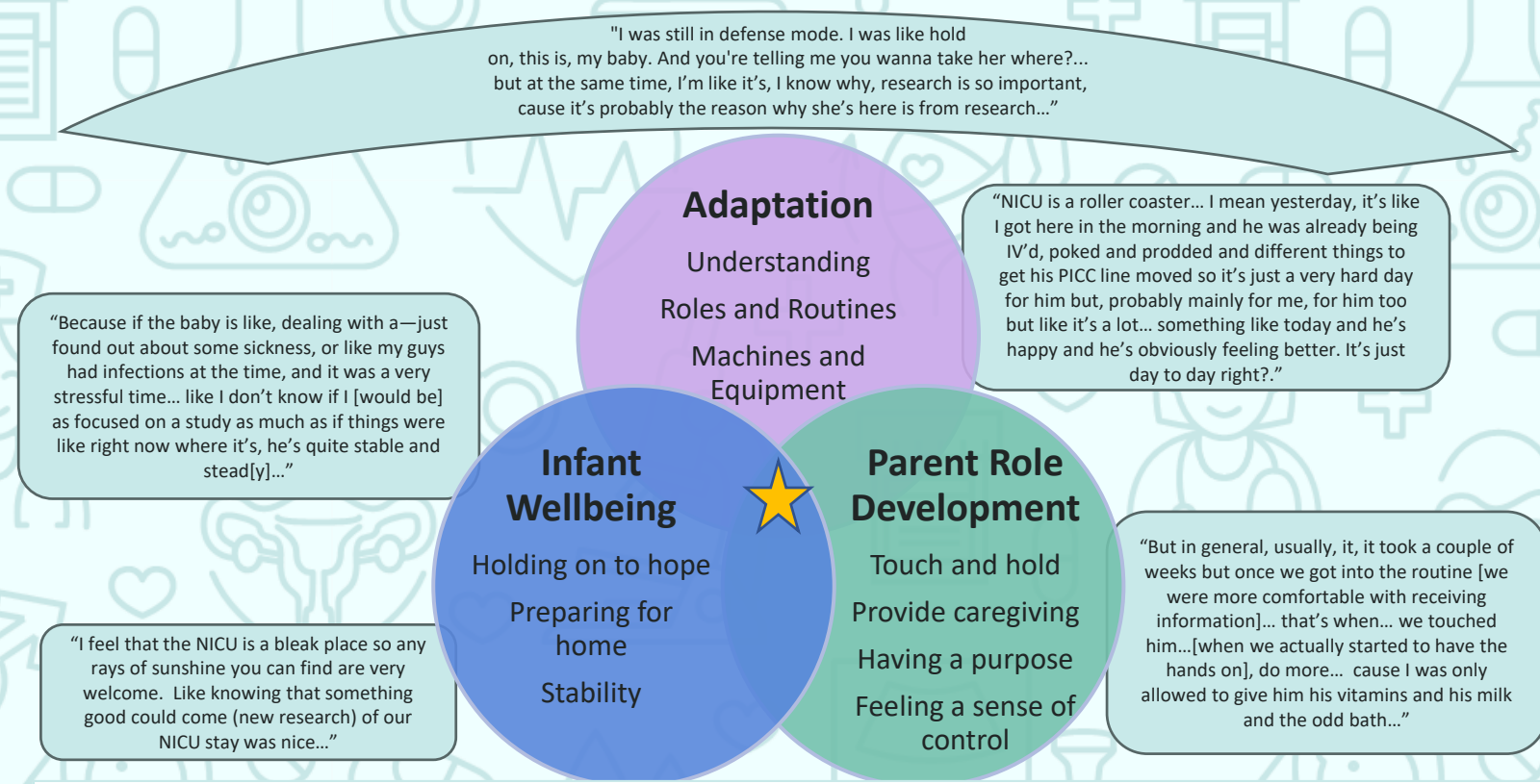
### Demographics

- 31 participants (23 mothers; 8 fathers)
- 11 parents had no experience with research

### Results

Thematic analysis revealed 3 themes: 1) Adaptation to the NICU Environment 2) Confidence in Infant Wellbeing 3) Parental Role Development

- Overarching each of these themes, parents expressed emotions that moved between an internal, natural need to protect their baby and wanting to help future families by participating in research
- Parents expressed how they felt and what they needed during different times in the NICU and what helped them feel prepared to participate in research
- Research also helped give parents a purpose and a way to give back to the community



### References:

1. Currie, V & Jull, A. (2012). Clinical trials in new zealand--An update. *New Zealand Medical Journal*, 125, 22-29
2. Nowell, et al. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1). <https://doi.org/10.1177/1609406917733847>
3. Vanhelst J, Hardy L, Bert D, et al. Effect of child health status on parents' allowing children to participate in pediatric research. *BMC Med Ethics*. 2013;14(1). doi:10.1186/1472-6939-14-7