

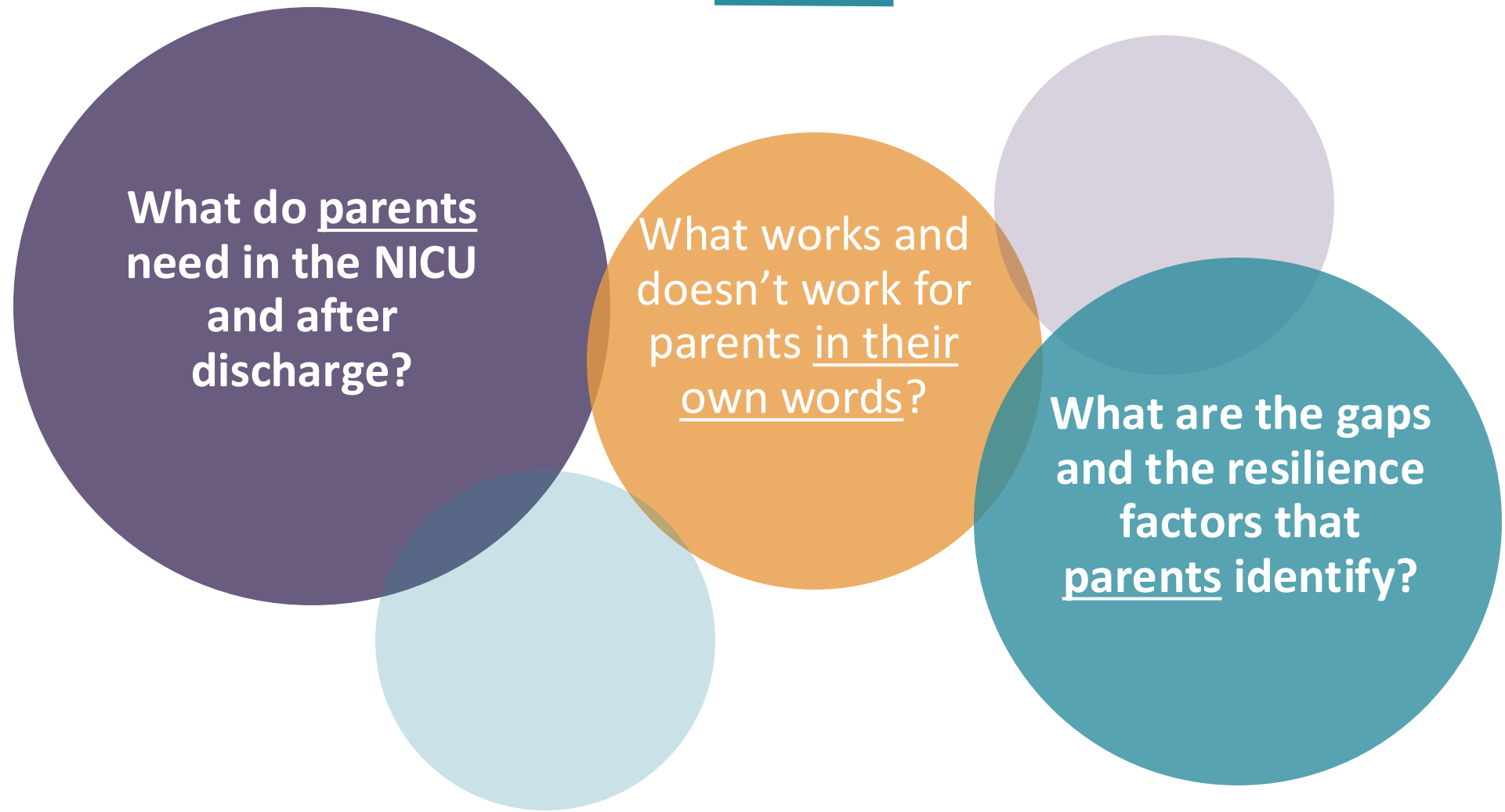


**PARENT**  
**VOICES**

**Your Experience Matters. Help Improve NICU and Follow-Up Care**

# Listening to Parent Voices

What works and what doesn't for parents and families *during their journey*?



What do parents need in the NICU and after discharge?

What works and doesn't work for parents in their own words?

What are the gaps and the resilience factors that parents identify?

- Very preterm infants (<32 weeks GA) and their families face:
  - Prolonged NICU stays
  - Ongoing medical and social support needs
  - Challenges and barriers in day-to-day for parents – for their children and for them.
- Historical approach: clinician-focused, child-only
  - **Gap:** little integration of *parent perspectives* on real-life challenges and resilience factors across the NICU to HRIF continuum.

## METHODS

### Eligibility

Parents of infants <32 weeks GA, at discharge or HRIF follow-up

### Recruitment

QR-code linked REDCap survey  
(English/Spanish/Mandarin/Vietnamese)

### Confidentiality

No identifiers, optional demographic questions,  
emails only for gift cards (removed afterward)

### Analysis

Thematic coding of parent responses;  
results shared with NICUs/HRIF teams

## Mixed Method Survey / Interview Project

Goal: at least 10-15 NICUs + HRIF sites - Diverse Representation

Part 1: **Survey** (short, open-ended queries)

- Around NICU discharge, or
- At any HRIF Follow Up visit
  - 4 - 6 months
  - ~ 1-2 years

Goal ~ 150 predischARGE  
and ~ 150 outpatient

Part 2: **Qualitative Parent Interviews**

Goal ~ 20-30 interviews

## HOW CAN YOUR SITE PARTICIPATE?

Project developed to MINIMIZE time and effort by sites!

1. Socialize/discuss Parent Voices project with NICU and HRIF teams.
2. Share handout (flyer) with parents/families:
  - Print/Post flyer in NICU and HRIF Clinic patient areas

**\*\* Stanford IRB approved**





## PART 1: SURVEY



*Your Experience Matters - Help Improve NICU and Follow up Care*

Please select your preferred language:

Por favor seleccione su idioma preferido:

请选择您的首选语言:

Vui lòng chọn ngôn ngữ bạn muốn:

\* must provide value

- ☐ English
- ☐ Español
- ☐ 中国人
- ☐ Tiếng Việt

reset

Submit

Parents / primary caregivers like you are the most important people in the lives of their babies in the Neonatal Intensive Care Unit (NICU) and after discharge. Although there is a lot of information about medical issues that a very premature baby may experience, **we want to learn more about what parents / primary caregivers like you need at different times in your journey to feel more supported. We invite you to share your experiences:**

- In the NICU or
- After NICU discharge

We will use combined parent responses to share with clinics and community services to help them understand how parents / primary caregivers can be better supported.

**These surveys are for parents of babies who were born early and received care in a NICU.** If you have more than one child who qualifies, you are welcome to complete both surveys.

Select the survey you would like to complete:

\* must provide value

**SURVEY I: The child is currently in the NICU and is expected to be discharged.**

**SURVEY II: The child was discharged from the NICU and is younger than 3 years old.**

reset

Submit





### SURVEY I: Child is currently in the NICU and expected to be discharged

We invite you to share with us what things helped you and what made it harder for you as a parent in the NICU by filling out this survey. Your response will be kept anonymous (information not shared individually, and never attached to your name) and confidential. The survey will take about 5 - 10 minutes to complete.

To thank you for your time and sharing your experience, a \$10 Amazon gift card can be sent to you in about a week if your responses to non-optional questions are completed. If you wish to receive a gift card, please enter your email address at the end of this survey. Email addresses will be removed after gift card is sent.

#### SURVEY QUESTIONS

The gestational age of my baby at birth (the weeks into pregnancy at delivery) was:

\* must provide value

- ☐ Less than 24 weeks  
☐ 24 through 26 weeks  
☐ 27 through 29 weeks  
☐ 30 or 31 weeks

reset

Please tell us two of the most important things that HELPED you as a parent during your time in the NICU and how they HELPED you.

Expand

Please tell us two of the things that were most DIFFICULT for you as a parent during your time in the NICU and how they made it DIFFICULT for you.

Expand

Expand

I feel that I was treated differently in the NICU than other parents.

☐ No ☒ Yes

reset

If you feel comfortable doing so, please share more about this experience.

Expand

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**SURVEY II. Child was discharged from the NICU and is under the age of 3 years old.**

**We invite you to share with us what things helped you and what made it hard for you as a parent after going home from the NICU by filling out this survey.** Your response will be kept anonymous (information not shared individually, and never attached to your name) and confidential. The survey will take about 5 - 10 minutes to complete.

To thank you for your time and sharing your experience, a \$10 Amazon gift card can be sent to you in about a week if your responses to non-optional questions are completed. If you wish to receive a gift card, please enter your email address at the end of this survey. Email addresses will be removed after gift card is sent.

**SURVEY QUESTIONS**

**The gestational age of my baby at birth (the weeks into pregnancy at delivery) was:**

\* must provide value

- ☐ Less than 24 weeks
- ☐ 24 through 26 weeks
- ☐ 27 through 29 weeks
- ☐ 30 or 31 weeks

reset

**The current age of my child is** (from your baby's birthday, not "adjusted" for prematurity):

\* must provide value

- ☐ Less than 6 months
- ☐ 6 through 11 months
- ☐ 12 through 17 months
- ☐ 18 through 23 months
- ☐ More than 2 years old

reset

Please tell us two of the most important things that HELPED you as a parent since your baby went home from the NICU, and explain how they HELPED you.

Expand

Expand

Please tell us two of the things that were most DIFFICULT for you as a parent since your baby went home from the NICU, and how they made it DIFFICULT for you.

Expand

Expand

**I feel that I was treated differently in clinics and other appointments since my baby went home from the NICU than other parents.**

- ☐ No
- ☐ Yes

reset

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OPTIONAL - IF YOU FEEL COMFORTABLE DOING SO, PLEASE SHARE

I am a:

☐ Mother   ☐ Father   ☐ Other

reset

I identify myself with the following ethnicity and races (choose all that apply):

- ☐ Asian
- ☐ Black or African-American
- ☐ Hispanic / Latino
- ☐ Middle Eastern or North African
- ☐ Native American or Alaskan Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ White
- ☐ Other
- ☐ Prefer not to say

THANK YOU GIFT CARD

If you would like to receive a \$10 Amazon gift card to thank you for your time and sharing your experience, please provide your email address below. You should receive the gift card by email in about a week, if your responses are found to be complete. Email addresses will be removed after gift card is sent.

Email:

WILLING TO PARTICIPATE IN A CONFIDENTIAL INTERVIEW?

We have so much to learn from parents like you about what needs to be improved to support you in the NICU and after discharge. We can learn some things from a survey like this, but we need to learn much more.

**We invite you to participate in a conversation about your experience as a parent in the NICU and what it was like for you after taking your baby home.**

If you would be interested in learning more about doing an interview with someone from our team - which will also be anonymous and confidential - please provide your name let us know the best way to reach you. It is possible that not all parents who express interest will be contacted. If you are interviewed, you will receive a \$50 gift card to thank you for your time and experience.

**NOTE: Your participation and contact information will not be shared with the Hospital/NICU or your child's medical care providers.**

Your Name (first and last):

Please let us know the best way to contact you (enter one or all below):

Home Phone Number:

Mobile Number:

Email Address:



### LONG-TERM GOALS:

In this project, we hope to center and learn from parent voices to:

- 1) Educate NICUs and HRIF programs about *what works* and *does not work* for parents in their journey → leading to improvement;
- 2) Ultimately - develop family-centered NICU to home and community tools, supporting the life-course journey for children and families.

*\*Partnering with California state agencies  
including CDPH/ MCAH, DHCS\**