

# Survey for Neurodevelopmental Clinics

This survey will address the following questions:

- Survey respondent demographics
- Patient population, referral, and scheduling processes for developmental follow-up
- Structure for developmental follow-up at the clinic
- Staffing and clinic operations
- Barriers, needs, and priorities for the clinic
- Partnership with local hospitals

The survey should take between 15-20 min to complete. Thank you for your time and consideration of these questions.

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Please note that for this survey, standardized screening for developmental delay post-NICU discharge includes assessments such as Bayley Scales of Infant Development (BSID), hearing screens, or other validated tools to assess developmental delay.

## Survey Respondent Demographics (for documentation purposes)

Name (Last, First)

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Organization/Hospital/Clinic Name

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Are you considered part of the ESIT program?

- Yes  
 No

Which ESIT program are you a part of?

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Title (your role in the organization; for example, Director, etc.)

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Email Address (optional)

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**Patient Population, Referral and Appointment Scheduling Process**

About how many children do you see in your neurodevelopmental clinic per month that are neonates referred for standardized screening for potential neurodevelopmental delays or impairments after NICU hospitalization?

- Less than 10 children per month
- 10-20 children per month
- 21-30 children per month
- 31-40 children per month
- More than 40 children per month

About how many children do you see in total per month (e.g., NICU graduates and other children that may have been referred from Pediatricians or other community providers/organizations) that receive standardized screening assessments to evaluate for potential neurodevelopmental delays or impairments?

- Less than 10 children per month
- 10-20 children per month
- 21-30 children per month
- 31-40 children per month
- More than 40 children per month

How are appointments for infants discharged from the NICU typically scheduled for your follow-up clinic?

- Parent calls the clinic to schedule the appointment
- NICU discharge coordinator calls the clinic to schedule the appointment
- A NICU social worker calls the clinic to schedule the appointment
- A scheduler from your clinic calls the patient's family to schedule the appointment
- Other \_\_\_\_\_

Does your clinic have a way to track no-show appointments?

- Yes
- No

What is the average percentage of no-shows for the first scheduled appointments to the neurodevelopmental follow-up clinic?

- 0 to 25% no-show rate
- 26-50% no-show rate
- 51-75% no-show rate
- 76-100% no-show rate
- unknown

What is the average percentage of no-shows for the 12-month corrected gestational age visit to the neurodevelopmental follow-up clinic?

- 0 to 25% no-show rate
- 26-50% no-show rate
- 51-75% no-show rate
- 76-100% no-show rate
- unknown

What are the common barriers that result in no-shows or prevent attendance at the neurodevelopmental follow-up clinic?

What aspects of your neurodevelopmental follow-up clinic have families expressed that make it easier or motivate them to return to your clinic?

**Details of NICU Neurodevelopmental Follow-Up**

Is preauthorization required before scheduling the FIRST follow-up appointment for NICU babies?

- Yes  
 No  
 Unsure

Is preauthorization required before scheduling SUBSEQUENT follow-up appointments for NICU babies? (e.g., after the first visit)

- Yes  
 No  
 Sometimes  
 Unsure

At what corrected gestational age (CGA) in months is the first neurodevelopmental follow-up appointment scheduled? Please write "00" if you are unsure.

\_\_\_\_\_ (months CGA)

What is the standard/routine cadence, in the absence of additional concerns, for follow up for a NICU graduate? Please consider the corrected gestational age (CGA) of the patient.

For example: follow up at 4 months CGA, 9 months CGA, 12 months CGA, 18 months CGA, 24 months CGA. Please write "Unsure" if you do not have access to this information.

Are patients able to attend neurodevelopmental follow up appointments via telehealth?

- Yes  
 No

Does your clinic follow up with ESIT (Early Intervention) programs about the patients you see?

- Yes  
 No

Please describe how your clinic follows up with ESIT providers about patients you see in clinic.

Please describe what barriers exist to following up with ESIT providers about patients you see in the clinic.

**Details of the Services or Assessments Offered**

What types of assessments are provided in the Neurodevelopmental Follow-Up Clinic? Select all that apply.

- Medical assessments (e.g., MD, ARNP, PA)
- Motor assessments
- Cognitive assessments
- Speech and language assessments
- Clinical feeding/swallowing evaluations
- Occupational Therapy Assessments
- Physical therapy assessments
- Hearing assessment (e.g., Otoacoustic Emission (OAE) or Brainstem Auditory Evoked Response (BAER) testing)
- Vision assessment
- Nutritional assessment
- Assessment for community resources (e.g., ESIT, WIC, parent to parent)
- Parent Mental Health Screens (e.g., Edinburgh Postnatal Depression Scale (EDPS))
- Social Determinants of Health (SDOH) screening
- Other \_\_\_\_\_

Which, if any, of these standardized assessments are performed for NICU graduates at your clinic? Select all that apply.

- Bayley Scales of Infant Development (BSID)
- General Movements Assessment (GMA)
- Test of Infant Motor Performance (TIMP)
- Hammersmith Infant Neurological Exam (HINE)
- Movement Assessment of Infants (MAI)
- Alberta Infant Motor Scales (AIMS)
- Developmental Assessment for Young Children (DAYC)
- Ages and Stages Questionnaire (ASQ)
- Early Feeding Skills Assessment (EFS) Tool
- Neonatal Eating Assessment (NeoEAT)
- Pediatric Eating Assessment Tool (PediEAT)
- Other \_\_\_\_\_
- none of these

Who administers these assessments for NICU graduates in the Neurodevelopmental Follow-Up Clinic? Select all that apply.

- Nurse Practitioners
- Registered Nurses
- Physician Assistants
- Medical Assistants
- Physicians
- Psychologists
- Therapists (e.g., physical, occupational, or speech/language therapists)
- Feeding specialists
- Researchers
- Social Workers
- Other \_\_\_\_\_

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How is information regarding the results of neurodevelopmental screening tests conveyed to the family? Select all that apply.

- Results are shared directly with the family by the clinic's physical, speech, and/or occupational therapist
- Results are shared directly with the family by a provider (ARNP, MD, DO, etc.) at the neurodevelopmental follow up clinic
- Results are shared with the patient's Primary Care Physician (PCP) to share with the family
- Results are shared back to the referring provider (e.g. NICU, another provider) to share with the family
- A referral is recommended for other evaluations (e.g. Neurodevelopment, Neurology, etc.), and results are shared with the family during that referral visit
- Results of the neurodevelopmental screening tests are not shared with the family
- Results are not shared with other providers
- Other \_\_\_\_\_
- I am not sure

**Neurodevelopmental Follow-Up Clinic Staffing and Operations**

Please share which of the following team members are represented in your clinic (select all that apply)

- Neonatologists
- Developmental-Behavioral Pediatricians
- General Pediatricians
- Pediatric Neurologists
- Pediatric Psychologists
- Nurse Practitioners
- Occupational Therapists
- Physical Therapists
- Speech and Language Therapists
- Feeding therapists
- Audiologists
- Registered Dieticians
- Social Workers
- Medical Assistants
- Patient Care Technicians
- Clinic Managers
- Clinic Schedulers
- Other providers \_\_\_\_\_

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What are the neurodevelopmental clinic office hours? (i.e. daily versus only specific days/hours of the week)

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Are the clinic days/hours consistent from week to week?

- Yes
- No

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When considering your neurodevelopmental follow-up clinic, which of the following funding sources are included in supporting clinic operations? Select all that apply.

- Local Institutional Support
- National Grants Funding
- Endowments
- Donations/fundraising
- State/Department of Health (DOH) Funding
- Insurance Coverage
- Other \_\_\_\_\_
- I am not sure

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Are there any grants to which your clinic consistently applies for funding of the clinic operations? If yes, please explain.

- Yes \_\_\_\_\_
- No

**Current Barriers, Needs, Priorities, and Goals for Neurodevelopmental Care at Your Center**

What are the current barriers or obstacles that prevent your clinic from operating at its full capacity?

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What are the current unmet needs for your clinic?

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What are the goals and priorities for your clinic?

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What are your future aspirations for your clinic?

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What are you most proud of about your clinic?

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**Partnership or Collaboration with Local Hospitals**

Do you currently have a partnership or collaborative agreement in which hospitals caring for neonates send at-risk newborns to your clinic for neurodevelopmental standardized screening assessments to evaluate for potential neurodevelopmental delay?

- Yes  
 No

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What are the names of the hospital(s) you partner or collaborate with?

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Is there a direct connection between the electronic medical record (EMR) for the collaborating NICU(s) and your neurodevelopmental follow-up clinic? (This includes Epic Care Everywhere)

- Yes  
 No  
 Unsure

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Please describe how your clinic routinely shares results of neurodevelopmental testing with the NICU that placed the original referral to your clinic?

- Epic Care Everywhere  
 Other Electronic Medical Record (EMR)  
 Clinic to Clinic messaging  
 Email  
 Phone  
 Other \_\_\_\_\_  
 We do not routinely share the results of testing with the NICU placing the clinic referral

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What barriers or obstacles prevent you from collaborating or partnering with hospitals caring for newborns that may want to refer their at-risk babies for screening neurodevelopmental assessments to evaluate for potential neurodevelopmental delay?

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What makes it easier for your clinic to collaborate or partner with hospitals caring for newborns that may want to refer their at-risk babies for screening neurodevelopmental assessments to evaluate for potential neurodevelopmental delay?

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Please provide any additional details about your Neurodevelopmental Follow-Up Clinic that may be relevant.

For example: "We provide evaluations for Individualized Family Service Plans (IFSP) but do not consider ourselves a Neurodevelopmental Clinic"