## **Vermont Oxford Network**

2024

Extremely Low Birth Weight Infant Follow-up Database for Infants at 18 to 26 Months' Corrected Age
Data Definitions & Infant Data Sheets

Release 27.0

Published November 2025



# Extremely Low Birth Weight Infant (ELBW) Follow-up Database for Infants at 18 to 26 Months' Corrected Age Eligibility

- Any infant whose birth weight was less than or equal to 1000 grams OR whose gestational age was less than or equal to 27 weeks, 6 days and was born from January 1, 2024 to December 31, 2024 and who was:
  - o born at your center and survived until ultimate hospital disposition; or,
  - born at another center, transferred to your center on or before day 28, and survived until ultimate hospital disposition from your center; or,
  - born at your center, transferred on or before day 28 from your center,
     readmitted to your center after transfer, and survived until ultimate hospital
     disposition from your center.
- Ultimate hospital disposition is the infant's final discharge from the birth
  hospitalization to home or chronic care. The ultimate hospital disposition may or
  may not be from your center. <u>Do not</u> collect data for infants who were never
  admitted to your center.

**Examples** 

Date of Birth	Birth Weight	Gestational Age (Weeks/Days)	Meets Eligibility for Birth Year 2024 Cohort?
December 31, 2023	500	25	No
January 1, 2024	400	21/6	Yes
January 1, 2024	400	22/0	Yes
January 1, 2024	401	22/0	Yes
January 1, 2024	380	22/0	Yes
January 1, 2024	1000	28/0	Yes
January 1, 2024	1001	28/0	No
January 1, 2024	1001	27/6	Yes
January 1, 2024	1100	27/6	Yes

## **Revisions for Birth Year 2024**

## Eligibility

• 18 to 26 months corrected age (see p. 1)

#### Health Status Form

#### **New Data Items**

• P-202: Cardiac catheterization and/or intervention

#### **Developmental Status Form**

#### New Data Items

• Autism Screen Completed: If yes, were concerns noted

#### Revised Data Items

#### **Discontinued Data Items**

- Autism Screen Completed: If yes, choose one
- Autism Screen Completed: Results M-CHAT-R/F

## Contents

Revisions for Birth Year 2024	i
Overview	. 1
Database Administration and Center Responsibilities	. 2
Data Definitions	. 4
Data Forms	19

#### Overview

## **Purpose**

 To describe the health and neurodevelopmental outcomes of infants at 18 to 26 months corrected age

#### Goals

- To link neonatal intensive care units and their follow-up clinics
- To evaluate the impact of perinatal events and neonatal interventions on 18 to 26 months corrected age outcome status
- To provide "gold standard" data collection sets for future testing of simplified followup tools
- To describe, for ELBW infants, health and developmental status of surviving infants at 18 to 26 months corrected age at participating Vermont Oxford Network member centers

## **Center Eligibility**

- The Center has contributed to a VON database (VLBW, Expanded, or Global Health) from January 1, 2024.
- The Center is affiliated with a follow-up clinic that assesses all surviving ELBW infants cared for at the center. Infant follow-up assessment should routinely use the Bayley Scales of Infant Development.
- The Center designates one specific coordinator to manage data submission.
- The Center discusses the possible need for Institutional Review Board review and patient consent with its local Institutional Review Board (IRB).

## **Infant Eligibility**

- The infant's date of birth was between January 1, 2024 and December 31, 2024; and
- The infant's birth weight was less than or equal to 1000 grams OR the infant's gestational age was less than or equal to 27 weeks, 6 days; and
- The infant survived until ultimate hospital discharge; and
- The infant completes a follow-up visit between 18 months, 0 days corrected age and 26 months, 30 days corrected age.

#### **Outcome Measures**

- Health Status: survival status, support after discharge, medical re-hospitalizations, and surgical procedures for the infant
- Developmental Status: growth parameters, visual and auditory impairments, cerebral palsy, achievement of gross motor milestones, results of the Ages & Stages Questionnaire, results of the Bayley Scales of Infant Development, and the clinical assessment of the infant's neurodevelopmental status
- Health-related social needs

## <u>Database Administration and Center Responsibilities</u>

The ELBW Infant Follow-up Databases are managed by Vermont Oxford Network (VON). VON is responsible for tools for data collection, data management, data analysis, and annual reporting.

#### **Institutional Review Board**

VON <u>does not</u> require Institutional Review Board approval or patient consent from each hospital. Instead, each participating center determines with its local Institutional Review Board whether the local Institutional Review Board needs to review participation in the database, and whether patient consent for data submission needs to be obtained.

#### **Center Database Materials**

VON will grant the Center's ELBW Data User and Report Viewer access to the ELBW Follow-Up section of the Member Portal to access the Infant Follow-up Database Report Log for all eligible infants, error reporting, the data entry tool, and annual reports.

## **Center Responsibilities**

Each participating center will designate a Center Follow-up Database Contact and a Center Follow-up Data Coordinator who will coordinate data collection at the local Center. The Center's Follow-up Database Contact is responsible for reviewing the need for IRB approval and patient consent. The Center Follow-up Database Contact oversees accurate data collection, assures any training that may be necessary is completed, and manages data submission. The ELBW Follow-up Data Coordinator identifies infants eligible for follow up, ensures completeness and accuracy of data collection and submission in the VON data entry tool, and works with VON to reconcile any data errors or omissions.

#### **Data Collection**

Data may be collected using paper-based Birth Year 2024 Cohort Infant Follow-up Data Forms and then typed into the data entry tool or entered directly into the data entry tool. Please ensure that the correct VON ID number is used when collecting and submitting data. It is the responsibility of the individual center to verify the accuracy of the information submitted. It is expected that all data submissions will be completed by **August 31, 2027.** 

In accordance with the Federal Health Insurance Portability and Accountability Act (HIPAA), all data collected for the Infant Follow-up Database is de-identified.

Dates for follow-up are between 18 months, 0 days to 26 months, 30 days corrected age date for each infant. You will use the infant's date of birth and gestational age in weeks and days to determine the 18 months corrected age date and the 26 months corrected age date. An online corrected age calculator supported by the NICHD Neonatal Research Network can be found at: https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main.

The Infant Follow-up Report Log identifies infants from your Center who qualify for the Infant Follow-up Database. VON will send you instructions for online access to the Infant Follow-up

Report Log for your Center. Enter the date of the infant's scheduled health follow-up visit and the developmental follow-up visit in the appropriate columns in the Infant Follow-up Project Report Log. When the Health Status Report and the Developmental Status Report are complete, enter the date on which the data were submitted using the data entry tool. Some infants from your Center may not have data from a Health Status Report or a Developmental Status Report completed.

Keep your Infant Follow-up Report Log. This log is the <u>only way</u> to identify infants in the ELBW Infant Follow-up Database. You may need to use this log to find specific charts for review. You may wish to make copies of this log in case the originals are lost. Keep your log in a safe and secure place.

#### **Data Use**

Research using the Vermont Oxford Network Databases supports quality improvement by describing relevant clinical outcomes, trends over time, and improvements in the quality, safety, and value of neonatal care. Vermont Oxford Network also undertakes research to address specific questions that seek to improve the quality of neonatal care.

For more information about how Vermont Oxford Network data may be used please reference the Policy on Data Use and the Policy and Guidelines for Collaborative Research Using the Vermont Oxford Network Databases. Both policies can be found on the Vermont Oxford Network public website.

## **Getting Help**

An account manager is available to assist you with any questions you may have about collecting, recording, or submitting data, as well as questions about the data definitions in this manual. You may contact the ELBW Follow-Up Account Manager by email (abriody@vtoxford.org) or telephone (802) 865-4814 between the hours of 9:00am – 5:00pm Eastern Standard Time.

Technical support is available from 9:00 A.M. to 5:00 P.M., Monday through Friday, UTC - 05:00 at (802) 865-4814 or support@vtoxford.org

#### **Data Definitions**

Please be sure to use release 27.0 of the manual of operations and the forms when collecting data for the Birth Year 2024 Cohort Follow-up.

#### Health Status Form

#### Status at 18 to 26 months corrected age

Indicate the infant's status at the time of the follow-up visit between the 18 to 26 months corrected age dates.

Answer "Alive" if the infant is known to be alive at the 18 to 26 months corrected age health follow-up visit date.

Answer "Expired" if the infant died between the ultimate hospital discharge date and the 18 to 26 months corrected age health follow-up visit date.

Answer "Unknown" if the status of the infant is unknown at the 18 to 26 months corrected age health follow-up visit date, because the infant was lost to follow-up.

IF "Expired" or "Unknown" is answered, you may stop here: the record is complete.

Visit completed by this follow-up clinic between 18 to 26 months corrected age

An eligible follow-up visit will occur between 18 to 26 months corrected age at the reporting center's designated follow-up clinic. If two follow-up visits occur between 18 to 26 months corrected age, only submit date from the most recent visit. For example, if a visit occurs at 18 months and 23 months corrected age, only submit data from the 23 months corrected age visit.

Answer "Yes" if a follow-up visit occurred between 18 to 26 months corrected age at the reporting center's designated follow-up clinic.

Answer "No" if a follow-up visit did not occur between 18 to 26 months corrected age.

Answer "No" if a follow-up visit did not occur at the reporting center's designated follow-up clinic.

IF "No" is answered, you may stop here: the record is complete.

#### Form Completed

Indicate how the information to complete this form was captured. The information could have been captured from more than one source.

#### In person Visit

Answer "Yes" if the information used to complete this form was <u>first</u> captured during an in-person clinic visit.

Answer "No" if the information used to complete this form was not first captured from an in-person clinic visit.

#### Virtual/Video Visit

Answer "Yes" if the information used to complete this form was <u>first</u> captured from a virtual or video visit.

Answer "No" if the information used to complete this form was not first captured from a virtual or video visit.

#### Health Record

Answer "Yes" if the information used to complete this form was <u>first</u> captured from a health record such as an electronic health or medical record (EHR or EMR).

Answer "No" if the information used to complete this form was not captured from a health record such as an electronic health or medical record (EHR or EMR).

#### Note:

- If an infant had an in-person clinic visit that was documented in an electronic health or medical record and used to complete these forms, the answer to In Person Visit is "Yes" and the answer to Health Record is "Yes."
- If an infant had a virtual/video that was documented in an electronic health record and used to complete these forms, the answer to Virtual/Video Visit is "yes" and the answer to Health Record is "Yes."

#### Section A: Health Status

#### ITEM 1: Corrected age at the follow-up visit (months/days)

Enter the months and days of the corrected age at the follow-up visit. You will use the infant's date of birth and gestational age in weeks and days and the follow-up visit date to determine the infant's corrected age. An online corrected age calculator supported by the NICHD Neonatal Research Network can be found at:

https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main.

#### **Section B: Living Situation**

#### ITEM 2: Caregiver(s) Primary Language (U.S. centers only)

Indicate the primary language of the caregiver used in the home.

Answer "English" if English is the primary language.

Answer "Spanish" if Spanish is the primary language.

Answer "Other" if a language other than English or Spanish is used. The "other" language does not need to be specified.

#### ITEM 3: Health related social needs screen

Indicate whether a health-related social needs screen was performed at this visit.

Answer "Yes" if a health-related social needs screen was completed.

Answer "No" if a health-related social needs screen was not completed.

Answer "Unknown" if it is unknown whether a standard health related social needs screen was completed.

If yes, was a need identified for the following: If a health-related social needs screen was performed at this visit, indicate whether a need was identified for each domain (food insecurity, housing instability, transportation needs, utility needs, financial strain, interpersonal safety, employment/unemployment, other).

Answer "Yes" if a need was identified.

Answer "No" if a need was not identified.

Answer "Not assessed" if the domain was not assessed.

Answer "Unknown" if it is unknown whether a need was identified or whether the domain was assessed.

#### **Section C: Support After Discharge**

#### ITEM 4: Any outpatient support after discharge

Indicate whether the infant had any of the listed supports or interventions at any time between the ultimate birth hospital discharge and the follow-up visit. The support or intervention may have been initiated prior to ultimate birth hospital discharge (and continued after discharge) or may have been initiated between the ultimate birth hospital discharge and the follow-up visit. The support may have been discontinued before the follow-up visit or be in place at the time of the follow-up visit. These supports or interventions are specific to the outpatient setting. Do not answer a support or intervention that was started AND stopped during a medical or surgical readmission. However, if a support was started during a readmission and continued upon discharge from the readmission, then the support qualifies as applied.

Answer "Yes" if the infant received any of the listed supports or interventions after the ultimate birth hospital discharge.

Answer "No" if the infant did not receive any of the listed supports or interventions after the ultimate birth hospital discharge.

Answer "Unknown" if it is unknown whether the infant received any of the listed supports or interventions listed after the ultimate birth hospital discharge.

#### If yes, complete the following:

If "Yes" is answered, assess each category of support.

For support at any time after discharge, answer "Yes," "No," or "Unknown."

If "Yes" is answered for support at any time after discharge, answer "Yes," "No," or "Unknown" for support at present clinical visit.

<u>Tracheostomy</u>: Indicate whether the infant had a functional tracheostomy.

<u>Ventilator</u>: Indicate whether the infant received ventilator support. Ventilator support includes intermittent mandatory ventilation or continuous positive airway pressure.

Oxygen: Indicate whether the infant received supplemental oxygen. Supplemental oxygen includes oxygen given with a ventilator, as well as free flow oxygen through a nasal cannula or hood.

<u>Gastrostomy</u>: Indicate whether the infant had a functional gastrostomy.

<u>Apnea or CP monitor</u>: Indicate whether the infant was on an apnea monitor or a cardiopulmonary (CP) monitor. Continuous or spot monitoring is permissible.

<u>Pulse oximetry</u>: Indicate whether the infant was on a pulse oximeter monitor. Continuous or spot monitoring is permissible.

Respiratory medication: Indicate whether the infant was receiving respiratory medication. Respiratory medications may include diuretic therapy, inhaled or nebulized bronchodilators or steroid medications. Medications may be given on any interval (e.g., daily) or used PRN. For this category of support, palivizumab (Synagis<sup>®</sup>) or other antiviral prophylactic agents are <u>not</u> considered respiratory medications.

<u>Nasogastric or post-pyloric feeds</u>: Indicate whether the infant received nasogastric or post-pyloric (e.g. naso-duodenal or naso-jejunal) feeds.

<u>SLP/OT (feeding)</u>: Indicate whether the infant is receiving any support to directly promote, establish, or maintain oral feeding.

<u>SLP/OT (speech)</u>: Indicate whether the infant is receiving any support to promote or establish speech.

<u>OT/PT (motor)</u>: Indicate whether the infant is receiving any support to promote, establish, or maintain gross or fine motor activities.

<u>Developmental specialist</u>: Indicate whether the infant is receiving any developmental support from a developmental specialist.

<u>Dietician</u>: Indicate whether the infant is receiving any nutritional support from a dietician.

#### Section D: Emergency Department Visits and Medical Readmissions After Discharge

#### ITEM 5: Any emergency department visit

Answer "Yes" if the infant had an emergency department between the ultimate birth hospital discharge and the follow-up visit.

Answer "No" if the infant did not have an emergency department between the ultimate disposition from the birth hospitalization and the follow-up visit.

Answer "Unknown" if it is unknown whether the infant had an emergency department between the ultimate disposition from the birth hospitalization and the follow-up visit.

#### ITEM 6: Any medical readmissions

Indicate whether the infant was readmitted at any time between the ultimate birth hospital discharge and the follow-up visit. Medical readmissions require an overnight hospital stay. Medical readmissions <u>exclude</u> visits to a hospital-based primary care medical or developmental follow-up clinic, other hospital-based specialty clinic, or the emergency department.

Answer "Yes" if the infant was readmitted.

Answer "No" if the infant was not readmitted.

Answer "Unknown" if it is unknown whether the infant was readmitted.

#### If yes, complete the following:

Indicate whether the infant was hospitalized for each of the specific medical readmission categories listed. A hospital admission should be assigned to only one readmission category.

Answer "Yes," "No," or "Unknown" for each of the readmission categories.

Respiratory illness: This category includes medical readmissions for the sequelae of respiratory distress syndrome, chronic lung disease, and other conditions. These conditions may require oxygen therapy, mechanical ventilation, or tracheostomy. These conditions include pulmonary disease (due to congenital or inherited anomalies of the airway), pulmonary aspiration (due to neurological or neuromuscular disorders), disorders of the chest wall diaphragm or abdominal wall resulting in hypoventilation, or sequelae arising from surgical problems in the neck or chest. These conditions include readmissions related to pulmonary infections (e.g., RSV- bronchiolitis), Acute Life-Threatening Event, near SIDS, or Brief Resolved Unexplained Event.

<u>Nutrition/failure to thrive</u>: This category includes medical readmissions for nutritional issues or failure to gain weight. This category excludes medical readmissions related to gastrointestinal infections.

<u>Seizure disorder</u>: This category includes medical readmissions for partial, generalized or unclassified seizures and convulsive disorders which may or may not have EEG correlates. Non epileptic paroxysmal physiologic events which mimic seizures (e.g. migraines) or pseudoseizures should be included in this category. This category excludes medical readmissions as related to CNS infections: if the seizure is sequelae of a specific acute infection of the cerebrum or meninges, the readmission should be coded under "Infection".

<u>Infections (not respiratory or shunt infections)</u>: This category includes medical readmissions for any type of infection including, but not limited to: bacterial or aseptic meningitis; those related to either the upper or lower urinary tracts such as acute pyelonephritis, chronic pyelonephritis, cystitis, and urethritis; infectious diarrhea illnesses such as endemic diarrhea, food-borne or water borne diarrhea, anti-microbial associated diarrhea and diarrhea in immunocompromised hosts; and infections not meeting the inclusion requirements of one of the above. The diagnosis of meningitis requires a single positive CSF culture. Infections related to or associated with cerebrospinal fluid shunts are excluded from this category. The diagnosis of a urinary tract infection requires a positive quantitative urine culture. The diagnosis of a gastrointestinal infection does not require a positive culture.

<u>Shunt complication</u>: This category includes medical readmissions for complications related to or associated with cerebrospinal fluid shunts and readmissions related to shunt infections. Fever, irritability, vomiting, and abdominal symptoms typically indicate shunt infection. The diagnosis of a shunt infection does not require blood or CSF culture to be positive. Shunt malfunction may occur.

<u>Other medical readmissions</u>: This category includes medical readmissions that do not meet the inclusion requirements of one of the above categories. This category excludes readmissions for surgeries or for monitoring after surgery.

#### **Section E: Surgeries**

#### ITEM 7: Surgical procedures

Indicate whether the infant had a surgical procedure performed at any time between the ultimate hospital discharge date and the follow-up visit. Surgical procedures may occur as outpatient, same-day surgeries, or may require readmission.

Answer "Yes" if the infant required a surgical procedure.

Answer "No" if the infant did not require a surgical procedure.

Answer "Unknown" if it is unknown whether the infant required a surgical procedure.

If "Yes", select the three digit "P-Code" from the list of surgical procedures on the back of the Health Status Report or below. If the infant had a surgical procedure not listed, enter "P- 900" (Other Surgical Procedure).

Please note that the surgical procedure codes for the ELBW Infant Follow-up Database are NOT the same as codes used to record surgeries in the VON VLBW Database. ELBW Infant Follow-up Procedure codes (P-codes) are listed on the back of the Health Status Form and below.

Surgica	l Procedure Codes (P-Codes)		
P-		P-	
Code	Procedure	Code	Procedure
	Central Nervous System Surgery		Otolaryngology Surgery
P-101	Shunt or shunt revision for hydrocephalus	P-501	Tracheostomy
P-102	Other neurosurgical procedure	P-502	Tympanostomy tubes
	Congenital Heart Defect Surgery	P-503	Other ENT surgical procedure
P-201	Cardiac surgery		Ophthalmologic Surgery
P-202	Cardiac catheterization and/or intervention	P-603	Strabismus surgery
	Gastrointestinal Surgery	P-604	Other ophthalmologic surgical procedure
P-301	Gastrostomy tube placement	P-605	Vitrectomy
P-302	Inguinal hernia repair		Orthopedic Procedure
P-303	Other gastrointestinal surgical procedure	P-701	Tendon release
	Genitourinary Surgery	P-702	Casting
P-401	Circumcision	P-703	Other orthopedic surgical procedure
P-402	Other genitourinary surgical procedure	P-900	Other surgical procedure

#### Developmental Status Report

#### Form Completed

Indicate how the information to complete this form was captured. The information could have been captured from more than one source.

#### In person Visit

Answer "Yes" if the information used to complete this form was <u>first</u> captured during an in-person clinic visit.

Answer "No" if the information used to complete this form was not first captured from an in-person clinic visit.

#### Virtual/Video Visit

Answer "Yes" if the information used to complete this form was <u>first</u> captured from a virtual or video visit.

Answer "No" if the information used to complete this form was not first captured from a virtual or video visit.

#### Health Record

Answer "Yes" if the information used to complete this form was <u>first</u> captured from a health record such as an electronic health or medical record (EHR or EMR).

Answer "No" if the information used to complete this form was not captured from a health record such as an electronic health or medical record (EHR or EMR).

#### Note:

- If an infant had an in-person clinic visit that was documented in an electronic health or medical record and used to complete these forms, the answer to In Person Visit is "Yes" and the answer to Health Record is "Yes."
- If an infant had a virtual/video that was documented in an electronic health record and used to complete these forms, the answer to Virtual/Video Visit is "yes" and the answer to Health Record is "Yes."

#### Section A: Growth

#### ITEM 1: Weight (kg)

Enter the weight recorded at the developmental follow-up visit. Enter the weight in kilograms (kg), to the tenths place. If the weight is unknown because it was not measured at the developmental follow-up visit, enter "999.9". If the data entry system gives an error that the weight is out of range, enter "999.9". Do not enter a weight measured at another visit.

#### ITEM 2: Head circumference (cm)

Enter the head circumference recorded at the developmental follow-up visit. Enter the head circumference in centimeters (cm), to the tenths place. If the head circumference is unknown because it was not measured at the developmental follow-up visit, enter "999.9". If the data entry system gives an error that the head circumference is out of range, enter "999.9". Do not enter a head circumference measured at another visit.

#### ITEM 3: Length (cm)

Enter the length recorded at the developmental follow-up visit. Enter the length in centimeters (cm), to the tenths place. If the length is unknown because it was not measured at the developmental follow-up visit, enter "999.9". If the data entry system gives an error that the length is out of range, enter "999.9". Do not enter a length measured at another visit.

#### ITEM 4: Corrected age growth measurements obtained (months/days)

Enter the months and days of the corrected age at the follow-up visit. You will use the infant's date of birth and gestational age in weeks and days and the follow-up visit date at which the growth parameters were obtained to determine the infant's corrected age. An on-line corrected age calculator supported by the NICHD Neonatal Research Network can be found at: <a href="https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main">https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main</a>.

#### ITEM 5: Infant is up to date on all recommended vaccines based on national guidelines

Answer "Yes" if the infant is up to date on all recommended vaccines.

Answer "No" if the infant is not up to date on all recommended vaccines.

Answer "Unknown" if it is not known whether the infant is up to date on all recommended vaccines.

#### Section B: Vision & Hearing

#### ITEM 6: Post discharge eye treatment

Indicate whether the infant received post discharge eye treatment for retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

#### ITEM 6a. Laser

Answer "Yes" if the infant received laser surgery for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

Answer "No" if the infant did not receive laser surgery for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

Answer "Unknown" if it is unknown whether the infant received laser surgery for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

#### ITEM 6b. Anti-VEGF

Answer "Yes" if the infant received bevacizumab (Avastin®) or other anti-vascular endothelial growth factor (anti-VEGF) drugs for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

Answer "No" if the infant did not receive bevacizumab (Avastin®) or other anti-vascular endothelial growth factor (anti-VEGF) drugs for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

Answer "Unknown" if it is unknown whether the infant received bevacizumab (Avastin®) or other anti-vascular endothelial growth factor (anti-VEGF) drugs for the treatment of retinopathy of prematurity at any time from the ultimate hospital discharge to the follow-up visit.

#### ITEM 7: Blindness

Answer "One eye" if the infant has a loss of vision in one eye only (including uncorrectable profound impairment or near blindness), regardless of whether the defect causing the visual loss is in the eye, optic nerve or the brain.

Answer "Both eyes" if the infant has a loss of vision in both eyes (including uncorrectable profound impairment or near blindness), regardless of whether the defect causing the visual loss is in the eye, optic nerve or the brain.

Answer "Neither" if the infant does not have loss of vision. Infants "not blind" may have other types of visual impairment such as: glaucoma (cloudy or asymmetrically enlarged cornea), hypermetropia (farsightedness), myopia (nearsightedness), strabismus (squint as elicited by the corneal light reflex or unilateral cover test), or other visual impairment not classified as blindness.

Answer "Unknown" if the infant's visual status is unknown.

#### ITEM 8: Prescription glasses

Answer "Yes" if prescription glasses are used some or all of the time.

Answer "No" if prescription glasses are never used.

Answer "Unknown" if it is unknown whether the infant currently uses prescription glasses.

#### ITEM 9: Hearing impairment

Answer "One ear" if the infant has any hearing impairment in one ear only.

Answer "Both ears" if the infant has any hearing impairment in both ears.

Answer "Neither" if the infant does not have any hearing impairment.

Answer "Unknown" if the infant's hearing status is unknown.

#### ITEM 10: Amplification

Answer "Yes" if a corrective aid(s) is/are used for amplification in one or both ears.

Answer "No" if corrective aids are never used.

Answer "Unknown" if it is unknown whether the infant currently uses corrective hearing aids.

#### Section C: Cerebral Palsy

#### ITEM 11: Cerebral palsy

Indicate whether the infant has cerebral palsy at the developmental follow-up visit. Cerebral palsy is a disability of the central nervous system and is characterized by abnormal control of movement or posture or both. The abnormalities of cerebral palsy are not due to mental retardation, meningomyelocele or other spinal cord lesions, or isolated hypotonia and are not transient, or the result of a progressive disease.

Answer "Yes" if the infant has cerebral palsy.

Answer "No" if the infant does not have cerebral palsy.

Answer "Unknown" if it is unknown whether the infant has cerebral palsy.

If Yes, impairment

Answer "Diplegia" if the infant is affected in both lower extremities.

Answer "Hemiplegia" if the infant is affected in the upper and lower extremity on only one half of the body.

Answer "Quadriplegia" if the infant is affected in all extremities.

Answer "Unknown" if it is unknown how the infant is affected.

If No, muscle tone

Answer "Hypotonia" if the infant had a decrease in muscle tone or resistance to passive movement, including dystonia not associated with or suspect for cerebral palsy.

Answer "Hypertonia" if the infant had an increase in muscle tone or resistance to passive movement including dystonia not associated with or suspect for cerebral palsy.

Answer "Both (hypotonia and hypertonia)" if the infant had a decrease and increase in muscle tone or resistance to passive movement including dystonia not associated with or suspect for cerebral palsy.

Answer "Normal" if the infant did not have any abnormalities in muscle tone.

Answer "Unknown" if the infant's muscle tone is unknown.

#### **Section D: Gross Motor Milestones**

#### ITEM 12: Sits independently

Indicate whether the infant can sit independently. Independently is defined as sitting without holding on to anyone or anything.

Answer "Yes" if the infant can sit independently.

Answer "No" if the infant cannot sit independently.

Answer "Unknown" if it is unknown whether the infant can sit independently.

If No, sits with support

Answer "Yes" if the infant can sit with support.

Answer "No" if the infant cannot sit with support.

Answer "Unknown" if it is unknown whether the infant can sit without support.

#### ITEM 13: Walks ten (10) steps independently

Indicate whether the infant can walk ten (10) steps independently. Independently is defined as walking without holding on to anyone or anything. Gait can be symmetric or asymmetric when walking independently.

Answer "Yes" if the infant can walk ten (10) steps independently.

Answer "No" if the infant cannot walk ten (10) steps independently.

Answer "Unknown" if it is unknown whether the infant can walk ten (10) steps independently.

If No. walks ten (10) steps with support

Answer "Yes" if the infant can walk ten (10) steps with support.

Answer "No" if the infant cannot walk ten (10) steps with support.

Answer "Unknown" if it is unknown whether the infant can walk ten (10) steps with support.

#### Section E: Clinical Appraisal

The clinical appraisal is a summary of the impressions of the health care team upon seeing the infant at the developmental follow-up visit. The clinical appraisal is based on observation and examination of the infant during a face to face or virtual visit or both. The clinical appraisal may be informed by results of a development screen completed by a caregiver or a developmental assessment performed by an experienced clinician or both.

#### ITEMS 14-16: Clinical appraisal

For each domain (cognitive function, language function, motor function):

Answer "Normal" if the infant's functioning is appropriate for 18 to 26 months age.

Answer "Suspect" if it is unclear whether the infant's functioning is normal or delayed for 18 to 26 months age.

Answer "Impaired" if the infant's functioning is abnormal for 18 to 26 months age.

Answer "Unknown" if the infant's cognitive functioning at 18 to 26 months is unknown.

Appraisal by:

For each domain (cognitive function, language function, motor function):

Answer "Clinical assessment" if a clinical evaluation was used to inform the clinical appraisal.

Answer "Caregiver questionnaire" if a caregiver completed questionnaire was used to inform the clinical appraisal.

Answer "Both" if both a clinical evaluation and a caregiver completed questionnaire were used to inform the clinical appraisal.

Answer "Neither" if neither a clinical evaluation nor a caregiver completed questionnaire were used to inform the clinical appraisal.

#### **Section F: Developmental Testing**

#### ITEM 17: Developmental screen completed by caregiver

Indicate whether the infant's caregiver completed a developmental screening questionnaire for the 18 to 26 months corrected age developmental follow-up visit.

Answer "Yes" if a developmental screening questionnaire was completed.

Answer "No" if a developmental screening questionnaire was not completed.

Answer "Not applicable" if the follow-up clinic does not ask caregivers to complete a developmental screening questionnaire.

Answer "Unknown" if it is unknown whether a caregiver completed a developmental screening questionnaire.

ITEM 17a: If yes, screen

If the answer to Item 17: Developmental screen completed by caregiver is "Yes":

Answer "Ages and Stages Questionnaire" if this questionnaire was completed by the caregiver.

Answer "Other Screen" if a developmental questionnaire other than the Ages and Stages Questionnaire was completed by the parent.

Answer "Unknown" if which developmental questionnaire was completed by the caregiver is unknown.

#### ITEM 18. Ages & Stages Questionnaire

If the answer to Item 17a: If yes, screen is "Ages and Stages Questionnaire":

Answer which form of the Ages and Stages screening questionnaire the caregiver completed for the follow-up visit. Choose only one form. If the caregiver completed more than one form, choose the most recent version.

#### ITEM 19. Results (ASQ): Answer one for each category

If the answer to Item 17a: If yes, screen is "Ages and Stages Questionnaire":

Indicate the results of the Ages and Stages questionnaire completed by the caregiver. For each of the five domains (communication, gross motor, fine motor, problem solving, personal-social), answer only one result for each domain. If an Ages and Stages Questionnaire was completed at two different ages within the 18 to 26 month follow-up interval, enter the most recent questionnaire results.

Answer "Concerns" if there was a concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "Possible concerns" if there was a possible concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "No concerns" if there was not a concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "Unknown" if it is unknown whether a concern or possible concern was indicated by the results of the developmental questionnaire for the specific domain.

#### ITEM 20: If Other screen, were concerns noted

If the answer to Item 17a: If yes, screen is "Other screen":

Answer "Yes" if there was a concern indicated by the results of the developmental questionnaire.

Answer "No" if there was not a concern indicated by the results of the developmental questionnaire.

Answer "Unknown" if it is unknown whether there was a concern indicated by the results of the developmental questionnaire.

#### ITEM 21. If concerns were noted, in which domain(s)

If the answer to Item 20: If Other screen, were concerns noted is "Yes":

Indicate the results of the other questionnaire completed by the caregiver. For each of the five domains (communication, gross motor, fine motor, problem solving, personal-social), answer only one result for each domain. If a questionnaire was completed at two different ages within the 18 to 26 month follow-up interval, enter the most recent questionnaire results.

Answer "Concerns" if there was a concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "Possible concerns" if there was a possible concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "No concerns" if there was not a concern indicated by the results of the developmental questionnaire for the specific domain.

Answer "Unknown" if it is unknown whether a concern or possible concern was indicated by the results of the developmental questionnaire for the specific domain.

#### ITEM 22: Evaluation completed by provider

Answer "Yes" if the infant's development was evaluated by a health care provider using any developmental assessment tool.

Answer "No" if the infant's development was not evaluated with any developmental assessment tool.

#### ITEM 22a: If no, why?

Indicate why a developmental evaluation was not done. Answer "Yes", "No", or "Unknown" to each.

Neurosensory impairment: The child was blind or deaf or both and could not complete the test.

Too severely delayed: The child was too severely delayed to administer testing. Do not answer this reason if the test was not administered because the child had a neurosensory impairment (was blind or deaf).

Uncooperative: The child was unable to sufficiently cooperate for the test to be performed.

Other: There was another reason the test was not administered.

#### ITEM 22b: If yes, choose one:

If a developmental evaluation was completed, indicate which evaluation assessment was used.

Answer "Bayley – 4<sup>th</sup> Edition" if the Bayley Scales of Infant and Toddler Development (BSID-4) was used in the developmental evaluation.

Answer "Other" if another assessment tool was used in the developmental evaluation.

#### ITEM 23: If Bayley – 4<sup>th</sup> Edition, Corrected age used In scoring Bayley

If the answer to Item 22b is "Bayley – 4<sup>th</sup> Edition," enter the corrected age used in scoring the BSID-4 as the age in months and days. You will use the infant's date of birth and gestational age in weeks and days and the follow-up visit date at which the developmental assessment was administered to determine the infant's corrected age. An online corrected age calculator supported by the NICHD Neonatal Research Network can be found at: <a href="https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main">https://neonatal.rti.org/index.cfm?fuseaction=AdjustedAgeCalculator.main</a>.

#### ITEM 24: Evaluation Results

Enter the results for the BSID-4. There are three scales: the cognitive scale, the language scale and the motor scale.

For each of these, answer "Done" if the scale was performed; answer "Not Done" if the scale was not performed. If "Done," enter the corresponding standard score.

If "Done" is answered for BSID Language performed, enter the Expressive Communicated Scaled Score and Receptive Communication Scaled Score.

If "Done" is answered for BSID Motor performed, enter the Gross Motor Scaled Score and Fine Motor Scaled Score.

#### ITEM 25: Autism screen completed

Answer "Yes" if an autism screening was completed at the 18 to 26 months corrected age follow-up visit.

Answer "No" if autism screening was not completed at the 18 to 26 months corrected age follow-up visit.

Answer "Unknown" if it is unknown whether an autism screening was completed at the 18 to 26 months corrected age follow-up visit.

#### ITEM 25a: If yes, were concerns noted:

Answer "Yes" if an autism screening was completed at the 18 to 26 months corrected age follow-up visit and concerns for autism were noted.

Answer "No" if an autism screening was completed at the 18 to 26 months corrected age follow-up visit and concerns for autism were not noted.

Answer "Unknown" if it is unknown whether concerns were noted during an autism screening completed at the 18 to 26 months corrected age follow-up visit.

VERMONT OXFORD NETWOR		ANT FOLL alth Statu		at 18 to 26 MO	NTHS CO	RRECTE	D AGE	
Patient's Name								
Patient's Name: MRN: Center Number: Center Name:								
VON ID: Year of Birth (YYYY):								
(Please do not transmit information in this box)								
Status at 18 to 26 months corrected age:	☐ Ali			☐ Expired		□U	nknown	
Visit completed by this follow-up clinic between 18 and 26 months corrected age: ☐ Yes ☐ No								
	☐ In F	Person Vis	it	☐ Video Visit			ealth Record	
Section A: Health Status	th / . l	١.	ما د د دد	مردمام				
1. Corrected age at the follow-up visit (m	ionths/days	):	_ montr	is days				
Section B: Living Situation			<b>5</b> !! !				Other	
2. Caregiver(s) primary language:	.c		English		panish		Other	
3. Health related social needs screen per <i>If yes,</i> was a need identified for the following		nis visit:	□ Y€	es 🗆 N	No.	□ U	nknown	
	∏g. ] Yes	□No		☐ Not assess	ed	□ I In	known	
,	] Yes	□ No		□ Not assess	_		known	
,	∃ Yes	□ No		☐ Not assess	ed	□Un	known	
d. Utility needs:	☐ Yes	□ No		☐ Not assess	ed	□Un	known	
e. Financial strain:	☐ Yes	□ No		☐ Not assess	ed	□Un	known	
f. Interpersonal safety:	] Yes	□ No		☐ Not assess	ed	□Un	known	
	] Yes	□ No		☐ Not assess			known	
	] Yes	□ No		☐ Not assess	ed	□ Un	known	
Section C: Support After Discharge				1				
4. Any outpatient support: ☐ Yes	□ No			known	<b>A + 10 110 0</b>	نمائد خمد	in init	
If yes, complete the following:  a. Tracheotomy:		-	-	<u>discharge</u> □ Unknown	At pres  ☐ Yes	ent <i>clini</i>	<u>c visit</u> □ Unknown	
b. Ventilator:				☐ Unknown				
c. Oxygen:		□ Yes	_	☐ Unknown	□ Yes		☐ Unknown	
d. Gastrostomy:		□ Yes		□ Unknown	□ Yes		□ Unknown	
e. Apnea or CP monitor:		□ Yes		□ Unknown	□ Yes		□ Unknown	
f. Pulse oximeter:		□ Yes		□ Unknown	□ Yes	□ No	□ Unknown	
g. Respiratory medications:		□ Yes		□ Unknown	☐ Yes		☐ Unknown	
h. Nasogastric or post-pyloric feeds:		☐ Yes		☐ Unknown	☐ Yes		□ Unknown	
i. SLP/OT (feeding):		☐ Yes		☐ Unknown	☐ Yes		□ Unknown	
j. SLP/OT (speech): ☐ Yes ☐ No ☐ Unknown ☐ Yes ☐ No ☐ Unknown							☐ Unknown	
k. OT/PT (motor):		☐ Yes	□ No	☐ Unknown	☐ Yes		☐ Unknown	
I. Developmental specialist:		☐ Yes	□ No	☐ Unknown	☐ Yes	□ No	☐ Unknown	
m. Dietician:		☐ Yes	□ No	☐ Unknown	☐ Yes	□ No	☐ Unknown	

Complete form on reverse side

Section D: Emergency Department Visits and Hospital Readmissions After Discharge							
5. Any emergency department visit:	☐ Yes	□ No	□ Unknown				
6. Any medical readmissions:	☐ Yes	□ No	☐ Unknown				
If yes, complete the following:							
a. Respiratory illness:	☐ Yes	□ No	□ Unknown				
b. Nutrition:	☐ Yes	□ No	☐ Unknown				
c. Seizure disorder:	☐ Yes	□ No	☐ Unknown				
d. Infections (not respiratory or shunt infections):	☐ Yes	□ No	□ Unknown				
e. Shunt complication (including infections):	☐ Yes	□ No	□ Unknown				
f. Other medical readmissions:							
Section E: Surgeries After Discharge							
7. Any surgical procedures:	☐ Yes	□ No	☐ Unknown				
If yes, enter all that apply:							
a. (P-Code)							
b. ( <i>P-Code</i> )							
c. (P-Code)							
d. (P-Code)							
e. ( <i>P-Code</i> )							

Surgical	Procedure Codes (P-Codes)		
P-Code	Procedure	P-Code	Procedure
	Central Nervous System Surgery		Otolaryngology Surgery
P-101	Shunt or shunt revision for hydrocephalus	P-501	Tracheostomy
P-102	Other neurosurgical procedure	P-502	Tympanostomy tubes
	Congenital Heart Defect Surgery	P-503	Other ENT surgical procedure
P-201	Cardiac surgery		Ophthalmologic Surgery
P-202	Cardiac catheterization and/or intervention	P-603	Strabismus surgery
	Gastrointestinal Surgery	P-604	Other ophthalmologic surgical procedure
P-301	Gastrostomy tube placement	P-605	Vitrectomy
P-302	Inguinal hernia repair		Orthopedic Procedure
P-303	Other gastrointestinal surgical procedure	P-701	Tendon release
	Genitourinary Surgery	P-702	Casting
P-401	Circumcision	P-703	Other orthopedic surgical procedure
P-402	Other genitourinary surgical procedure	P-900	Other surgical procedure

VERMONT OXFORD NETWORK ELBW INFANT FOLLOW UP at 18 to 26 MONTHS CORRECTED AGE  Developmental Status Form								
Patient's Name: MRN:								
Center Number: Center Name:								
VON ID:         Year of Birth (YYYY):								
(Please do not transmit information in this box)								
								_
Form completed (check			on	□ Vide	eo visit		Health record	_
Section A: Growth and F								
1. Weight: k	•				_	n:	<u>.                                    </u>	
4. Corrected age growth								
5. Infant is up to date on		cines based	on nation	al guideline	s: [	□ Yes □	No 🗆 Unknown	_
Section B: Vision and He	_							
6. Post discharge eye tre	atment: a. Laser: 🗆 Y	'es □ No □ I	Unknown	b. Anti	i-VEGF: ☐ `	Yes 🗆 No 🏻	□ Unknown	
7. Blindness:		☐ One eye	☐ Both	eyes	☐ Neithe	r 🗆 Unk	known	
8. Prescription glasses:								
9. Hearing impairment:	☐ One ear	ne ear		☐ Neither ☐ Unknown				
10. Amplification: ☐ Yes ☐ No ☐ Unknown								
Section C: Cerebral Palsy	1							
11. Cerebral palsy:	☐ Yes	□ No		☐ Unkno	own			
If yes, impairment:	☐ Diplegia	☐ Her	miplegia	☐ Quadr	iplegia [	□ Unknow	'n	
If no, muscle tone:	☐ Hypoton	іа 🗆 Нур	pertonia	☐ Both	[	□ Normal	□ Unknown	
Section D: Gross Motor	Milestones							
12. Sits independently:		☐ Yes		□ No		☐ Unknov	vn	
If no, sits with suppo	rt:	☐ Yes	☐ Yes			☐ Unknown		
13. Walks ten (10) steps	independently:	☐ Yes	☐ Yes ☐ No		☐ Unknown		vn	
If no, walks ten (10) s	steps with support:	☐ Yes	☐ Yes ☐ No		☐ Unknown		vn	
Section E: Clinical Appra	isal							
14. Cognitive function:	☐ Concerns	☐ Poss	sible conce	erns	☐ No co	ncerns	☐ Unknown	
Appraisal by:	☐ Clinical assessmen	nt 🗆 Care	egiver que	stionnaire	$\square$ Both		☐ Neither	
15. Language function:	☐ Concerns	☐ Poss	sible conce	erns	□ No co	ncerns	☐ Unknown	
Appraisal by:	☐ Clinical assessmer	nt 🗆 Care	egiver que	stionnaire	☐ Both		☐ Neither	
16. Motor function:	☐ Concerns	☐ Poss	sible conce	erns	□ No co	ncerns	□ Unknown	
Appraisal by:	☐ Clinical assessmer	nt 🗆 Care	egiver que	stionnaire	☐ Both		□ Neither	

Complete form on reverse side

Section F: Development							
17. Developmental screen of	ompleted by car	egiver:	☐ Yes	□ N	o [	Not applicable	☐ Unknown
a. <i>If yes,</i> screen: ☐ Ages	& Stages Questi	onnaire (A	sq) 🗆	Other scree	n 🗆 U	nknown	
18. If ASQ, form (Reference	: ASQ Calculator	- Ages and	d Stages):				
☐ 16-month	☐ 18-month		□ 2	0-month		☐ 22-month	
☐ 24-month	☐ 27-month		□ 3	0-month			
19. If ASQ, results:							
a. Communication:	☐ Concerns	☐ Possib	ole concerr	าร	☐ No co	ncerns	□ Unknown
b. Gross motor:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
c. Fine motor:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
d. Problem solving:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
e. Personal – Social:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
20. If Other screen, were co	ncerns noted:		☐ Yes		□ No		☐ Unknown
21. If concerns were noted,	in which domair	ı(s):					
a. Communication:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
b. Gross motor:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
c. Fine motor:	☐ Concerns	☐ Possible concerns			□ No co	ncerns	☐ Unknown
d. Problem solving:	☐ Concerns	☐ Possib	le concerr	าร	☐ No concerns		☐ Unknown
e. Personal – Social:	☐ Concerns	☐ Possib	le concerr	าร	□ No co	ncerns	☐ Unknown
22. Evaluation completed b	y provider:		☐ Yes		□ No		
a. <i>If no,</i> why:							
Neurosensory impa	irment $\square$	Yes [	□No	☐ Unknow	n		
Too severely delaye				☐ Unknow			
Uncooperative				☐ Unknow			
Not available	_			Unknow			
Other	Ц			☐ Unknow			
b. <i>If yes,</i> choose one:			/ – 4th Edi		Other		
23. If Bayley – 4 <sup>th</sup> Edition, <u>Co</u>				mon	ths	_days	
Reference: NICHD Neon			<u>ı.org)</u>		'tandard	Caara	
24. If Bayley – 4 <sup>th</sup> Edition, Ba	gyley (BSID) resu		☐ Not Do	_	Standard	<u>score</u>	
a. BSID cognitive:							
b. BSID language:	□ Do		☐ Not Do		-	<u> </u>	
c. BSID motor:	□ Do		□ Not Do	iie		<del></del>	□ Unknows
25. Autism screen complete			☐ Yes		□ No		Unknown
a. <i>If yes,</i> concerns noted	d:		☐ Yes		□ No		☐ Unknown

## 2024

The Vermont Oxford Network Extremely Low Birth Weight Followup Database for Infants at 18 to 26 Months Corrected Age is owned and maintained by Vermont Oxford Network, Inc., in Burlington, Vermont. The manual of operations, data forms, and data submitted to Vermont Oxford Network, Inc. are the property of Vermont Oxford Network, Inc.

Institutions and individuals participating in the Vermont Oxford Network Extremely Low Birth Weight Follow-up Database for Infants at 18 to 26 Months Corrected Age may be identified by name in reports or descriptions of the database. Data and summaries of data from the Vermont Oxford Network Extremely Low Birth Weight Follow-up Database for Infants at 18 to 26 Months Corrected Age may be published and distributed at the discretion of Vermont Oxford Network, Inc. Data specific to an individual center will not be publicly released without the center's permission.

## **How to Contact Us**

#### **Address**

Vermont Oxford Network 33 Kilburn Street Burlington, Vermont 05401 USA

#### Phone

+1 802.865.4814

#### Fax

+1 802.865.9613

#### **General Email**

mail@vtoxford.org

## **Finance Department**

finance@vtoxford.org

## **Technical Support**

support@vtoxford.org

#### Web site

www.vtoxford.org