

**THE EXTREMELY-LOW-BIRTH-WEIGHT
INFANT FOLLOW-UP PROJECT
YEAR 2008 COHORT**

**For infants born between
January 1, 2008 and December 31, 2008**

MANUAL OF OPERATIONS

THE VERMONT OXFORD NETWORK

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Version 11

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EXTREMELY LOW BIRTH WEIGHT INFANT FOLLOW-UP PROJECT - YEAR 2008 COHORT

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TABLE OF CONTENTS

I.	INTRODUCTION.....	6
II.	PROJECT OVERVIEW.....	7
	A. Purpose.....	7
	B. Goals.....	7
	C. Center Eligibility.....	7
	D. Infant Eligibility.....	7
	E. Outcome Measures.....	8
	F. Version 11.0 Updates: Health Status Report.....	8
	G. Version 11.0 Updates: Developmental Status Report.....	8
	H. Parental Interview and Reporting Questionnaire.....	8
III.	STUDY ADMINISTRATION.....	9
	A. Overview.....	9
	B. VON Clinical Trials & Follow-Up Data Coordinating Center.....	9
	C. Steering Committee.....	9
IV.	CENTER PARTICIPATION.....	10
	A. Center Responsibilities.....	10
	B. Center Project Materials.....	10
	C. Center Project Timeline.....	10
V.	DATA COLLECTION.....	10
	A. Data Legibility.....	10
	B. Which Infants Need Forms Completed.....	11
	C. Patient and Center Identification Data.....	11
	D. HIPAA Compliance.....	12
VI.	ELBW INFANT FOLLOW-UP PROJECT REPORT LOG.....	12
	A. Introduction.....	12
	B. Using the ELBW Infant Follow-up Project Report Log.....	13

1. Establishing An Infant's Eligible Follow-Up Dates.....	13
2. Tracking The Progress of The Infant's Follow-Up.....	13
VII. THE ELBW INFANT FOLLOW-UP PROJECT DATA FORMS	14
A. THE HEALTH STATUS REPORT (Version 11)	14
1. Infant Status at the 18 to 24 Months Corrected Age Visit.....	14
2. Report Completion	15
Section A: Health Status.....	15
Section B: Living Situation	16
Section C: Support After Discharge	18
Section D: Medical Re hospitalizations & Surgeries.....	19
B. THE DEVELOPMENTAL STATUS REPORT (Version 11)	22
Patient and Center Identification Data.....	23
Section A: Growth Parameters	23
Section B: Vision & Hearing	24
Section C: Cerebral Palsy.....	26
Section D: Gross Motor Milestones	27
Section E: Developmental Testing.....	28
Section F: Overall Clinical Appraisal.....	30
VIII. HOW TO TRANSMIT DATA.....	31
IX. PUBLICATIONS	32
X. REFERENCES	34
XI. APPENDICES.....	38
Appendix A: ELBW Infant Follow-up Project - 2007 Cohort Center List.....	38
Appendix B: Instructions for Using the Corrected Age Calculator	39
Appendix C : Script for Question 8 (Health Status Report)	42
Appendix D: Surgical Procedure Codes (P-Codes).....	43
Appendix E: Sample Report Log and Data Forms.....	44

VERSION 11

INFANT ELIGIBILITY for the ELBW Follow Up Year 2008 Cohort

For 2005 and subsequent cohort years, eligibility criteria for the ELBW Follow Up Infant Study will include infants whose birth weights are between 401 and 1000 grams (inclusive) OR whose gestational ages are between 22 weeks, 0 days and 27 weeks, 6 days (inclusive). This change reflects a 2005 revision to the VON VLBW Database Eligibility criteria. This change will allow the ELBW Follow Up Study to include the entire population of infants between 22 and 27 weeks gestation.

Examples

Date of Birth	Birth Weight	Gestational Age (Weeks/Days)	Eligibility Year 2008 Cohort
December 30, 2007	500	25	No
January 5, 2008	400	21/6	No
January 5, 2008	400	22/0	Yes
January 5, 2008	401	22/0	Yes
January 5, 2008	380	22/0	Yes
January 5, 2008	1000	28/0	Yes
January 5, 2008	1001	28/0	No
January 5, 2008	1001	27/6	Yes
January 5, 2008	1100	27/6	Yes

I. INTRODUCTION

New approaches for both the obstetrical management of preterm birth and the neonatal care of the premature infant have resulted in the decreased mortality of infants at lower birth weights and gestational ages (2,5,8,9,10,22,26,27,28). This decrease in mortality occurred primarily in the early 1990s with no significant improvement in survival after 1995 (17). The more widespread use of antenatal glucocorticoid treatment for women at risk for preterm delivery (23,31,32), and surfactant therapy for the prevention and treatment of neonatal respiratory distress syndrome (18,19,25) were two practice approaches significantly contributing to improved survival of the premature infant.

Conversely a practice approach that did not contribute to increased survival and may have contributed to increased morbidity of the premature infant was the use of postnatal corticosteroids (dexamethasone) for the prevention and treatment of chronic lung disease. At the peak of their use in the late 1990s, postnatal corticosteroids were administered to as many as 28.5% of very low birth weight (VLBW) infants enrolled in the Vermont Oxford Network (17) and 25% of VLBW infants enrolled in the Canadian Neonatal Network (21). However, at a similar time, reports of early follow-up of extremely low birth weight infants exposed to corticosteroid therapy began to associate postnatal steroid use with developmental motor delays and cerebral palsy (1,3,20,24,33). These reports increased the awareness of the importance of follow-up outcomes assessment in randomized controlled trials and suggested standardized provision of follow-up services for high risk infants were needed.

As a group, extremely low birth weight (ELBW) infants are known to be at high risk for subnormal growth, medical illnesses, and neuro-developmentally based disabilities. The spectrum of developmentally based disabilities include a range of issues in cognition and neuromotor functioning from learning and attention disabilities to the more severe issues of mental retardation and cerebral palsy. Hack and coworkers, reporting on the outcome of surviving infants with birth weights less than 750 grams (11,13) note that thirty percent of survivors born at 23 weeks gestation are severely disabled. At 24 weeks gestation the rate of severe neurodevelopmental disability ranged from 17% to 45%, and at 25 weeks gestation 12% to 35% are similarly affected. At school age, these children are at high risk for neurobehavioral dysfunction and poor school performance (11). Longer term follow-up studies indicate that the adverse consequences of low birth weight were still apparent in adolescence.

II. PROJECT OVERVIEW

A. Purpose

The purpose of the ELBW Infant Follow-Up Project is to determine the health and neurodevelopmental outcomes of infants with birth weights between 401 and 1000 grams (inclusive) OR with gestational ages between 22 weeks, 0 days and 27 weeks, 6 days (inclusive) enrolled in the Vermont Oxford Network database through a standardized and systematic collection of data indicators.

B. Goals

To link Neonatal Intensive Care Units and their Follow-Up Clinics.

To describe the 2-year corrected age health and developmental status of surviving infants with birth weights between 401 and 1000 grams (inclusive) OR with gestational ages between 22 weeks, 0 days and 27 weeks, 6 days (inclusive) at participating Vermont Oxford Network Centers. Status indicators will include survival, growth, medical re-hospitalizations, surgical procedures, and neurologic and developmental status.

To evaluate the impact of perinatal events and neonatal interventions on short-term outcome status.

To provide “gold standard” data collection sets for future testing of simplified follow-up tools.

C. Center Eligibility

- The Center has contributed to the VON VLBW database from January 1, 2008.
- The Center is affiliated with a Follow-Up Clinic which assesses all surviving ELBW infants cared for at the Center. Infant follow up assessment must be at least through two years corrected age and routine use the Bayley Scales of Infant Development.
- The Center designates one specific Project Coordinator to manage data submission.
- The Center obtains local Institutional Review Board (IRB) approval for the project.

D. Infant Eligibility

The infant was born between January 1, 2008 and December 31, 2008;

The infant had a birth weight of between 401 to 1000 grams (inclusive); OR

The infant had a gestational age of between 22 weeks, 0 days and 27 weeks, 6 days (inclusive);
The infant survived until ultimate hospital discharge; and
Parental consent for participation, as determined by local IRB approval, is obtained.

E. Outcome Measures

- Home Living Situation: the type of living situation, and educational level of the primary care giver.
- Health Status: survival status, support after discharge, medical re hospitalizations, and surgical procedures for the infant.
- Developmental Status: growth parameters, visual and auditory impairments, the presence of cerebral palsy, achievement of gross motor milestones, and results of the Bayley Scales of Infant Development for the infant.

F. Version 11 Updates: Health Status Report

The overall format of the ELBW FUP Health Status Report Version 11 is unchanged from Version 10. Income levels reflecting the 2008 poverty guideline were amended (35).

G. Version 11 Updates: Developmental Status Report

Version 11 of the ELBW FUP Developmental Status Report is unchanged from Version 10.

H. Parental Interview and Reporting Questionnaire

Infants enrolled in the ELBW Infant Follow-Up Project who are **alive and evaluated** are also eligible to have the Parental Interview and Reporting Questionnaire (Version 2.0) completed at the time of the two year corrected age follow-up visit. The Parental Interview and Reporting Questionnaire is completed independently of the follow-up visit evaluation. Data collected for the Parental Interview and Reporting Questionnaire supplements data collected for the ELBW Infant Follow-up Project Health Status Report and the Developmental Status Report. The Parental Interview and Reporting Questionnaire **does not** replace the Health Status Report or the Developmental Status Report.

Before the Parental Interview and Reporting Questionnaire is used to collect data, each participating Network Center must obtain local Institutional Review Board (IRB) approval. Most commonly, approval will be obtained by submitting **an addendum** to the IRB approval received

for participating in the ELBW Infant Follow-Up Project. Each participating Network Center should submit a copy of the addendum to their current IRB approval for the ELBW Infant Follow-Up Project. The VON Clinical Trials & Follow-Up Data Coordinating Center must have a copy of this addendum before any data may be collected.

III. STUDY ADMINISTRATION

A. Overview

The ELBW FUP Year 2008 Cohort is a project conducted by the Vermont Oxford Network (VON), Division of Clinical Trials & Follow-Up. The VON Clinical Trials & Follow-Up Data Coordinating Center will administer data collection, data management, and data analysis. Each participating Network Center will designate a Center Principal Investigator, who will be the contact person at that institution, and a Center Study Coordinator, who will coordinate data collection at the local Center. Each participating Network Center will obtain approval for the study from their Institutional Review Board and submit a copy of the approval to the VON Clinical Trials & Follow-Up Data Coordinating Center.

B. VON Clinical Trials & Follow-Up Data Coordinating Center

The VON Clinical Trials & Follow-Up Data Coordinating Center will be responsible for all aspects of biostatistical design, data analysis, and data management for the study. The VON Clinical Trials & Follow-Up Data Coordinating Center will submit periodic progress reports to the ELBW Infant Follow-Up Project Steering Committee. The staff at the VON Clinical Trials & Follow-Up Data Coordinating Center can be reached between 9:00 am - 17:00 pm, Eastern Standard Time. You may contact Karla Ferrelli at the Clinical Trials & Follow-Up Data Coordinating Center by email karla@vtoxford.org, telephone (802) 865-4814 ext 212, or fax (802) 865-9613 or (802) 865-0359 with any questions.

C. Steering Committee

The ELBW Infant Follow-Up Project Steering Committee is comprised of members of Vermont Oxford Network and individuals with expertise in neonatal follow-up and neurodevelopment. The Steering Committee is responsible for approving the study proposal and materials, and monitoring study implementation and enrollment. The Steering Committee will participate in drafting the report of the study results for publication.

IV. CENTER PARTICIPATION

A. Center Responsibilities

The Center's Principle Investigator is responsible for obtaining local Institutional Review Board (IRB) approval for the project. If required, the Center Investigator completes periodic IRB reviews, and submits necessary amendments or renewals or both. The Center Investigator is also responsible for sending a copy of current IRB approval to the VON Clinical Trials & Follow-Up Data Coordinating Center. Finally, the Center Investigator oversees accurate data collection, and assures any training that may be necessary.

The Center's Project Coordinator is responsible for managing data submission. The Project Coordinator maintains logs to identify infants eligible for follow up, ensures completeness and accuracy of data collection, submits data forms to VON, and works with VON to reconcile any data errors or omissions or both. The Project Coordinator may also assist in obtaining IRB approval for project participation.

B. Center Project Materials

Upon receiving a copy of the Network Center's Institutional Review Board (IRB) approval, the VON Clinical Trials & Follow-Up Data Coordinating Center will send the Center's Principal Investigator a set of *The Extremely Low Birth Weight Infant Follow-Up Project 2008* data collection log and forms. All participating Centers must obtain IRB approval at their respective center before initiating data collection. Documentation of IRB approval must be received by the VON Clinical Trials & Follow-Up Data Coordinating Center before data will be accepted.

C. Center Project Timeline

Data forms are to be completed during the time of the infant's follow-up visit between 18 and 24 months' corrected age. Although exact dates of follow-up visits will depend on the infants' gestational ages and dates of birth, the visits are expected to occur between October 2009 and April 2010.

V. DATA COLLECTION

A. Data Legibility

Please answer every item on the *ELBW Infant Follow-Up Data Forms*. Please complete all items carefully and clearly. All textual data should be clearly printed; numbers should be legible and

easy to distinguish. Coded data should be completed according to the detailed instructions for each *ELBW Infant Follow-Up Project Data Form*. Please erase mistakes thoroughly for entries in pencil. For mistakes in entries completed in ink, the mistake should be erased with correction fluid and rewritten. Please proofread each Data Form for completeness, clarity, and legibility before mailing it to the Clinical Trials & Follow-Up Data Coordinating Center.

It is extremely important that you use caution in filling out the data forms. Please ensure that the correct VON ID number is used. As a result of de-identification of patient data, we are no longer able to verify the accuracy of the patient information you submit.

B. Which Infants Need Forms Completed

All infants with birth weight between 401 and 1000 grams (inclusive) **OR** gestational age between 22 weeks, 0 days and 27 weeks, 6 days (inclusive) born at your Center who survive until ultimate hospital disposition are eligible for the ELBW Infant Follow-Up Project. Ultimate hospital discharge is the infant's final discharge from the hospital to home or chronic care facility. The ultimate hospital discharge may or may not be from your Center.

In summary, infants in the ELBW Infant Follow-up Project include:

- All infants who were transferred at initial disposition from your Center. The infant may or may not have been re-admitted to your Center after transfer.
- All infants with birth weight between 401 and 1000 grams (inclusive) **OR** gestational age between 22 weeks, 0 days and 27 weeks, 6 days (inclusive) born at another hospital and admitted to your Center on or before day 28 and surviving until ultimate hospital disposition.

Do not complete logs and reports for infants who were never admitted to your Center, but who are patients in your Follow-Up Clinic.

C. Patient and Center Identification Data

At the top of each *ELBW Infant Follow-Up Project Data Form* are two enclosed areas for patient and center identification. These sections should be completed on all *ELBW Infant Follow-Up Project Data Forms*.

- Patient Identification: In the topmost section, the Infant's Name and Medical Record Number (MRN) is recorded. This information in this section is for individual center use in completing the ELBW Infant Follow-Up Project Data Form and facilitating any additional reviews or edits.

In order to preserve confidentiality of patient data, this section must be masked when the form is copied for mailing to the Data Coordinating Center. Do not send patient name and medical record number for any infant. These should remain confidential.

- **Center Identification:** In the second and lower section, the Center Name, Center Number, Infant Network ID Number, and Infant Year of Birth are recorded. The Center Name is the name of your medical center and the Center Number is the number assigned to your center for the VON Database. These fields will be the same for all infants enrolled in the ELBW Infant Follow-Up Project at your center. The Infant Network ID Number is the number assigned to the infant for the VON Database according to the VON Database Manual of Operations, Release 11.0 (see page 34). The Infant Year of Birth is recorded using four digits. For example, an infant born in 2008 will have the Infant Year of Birth recorded as "2008".

D. HIPAA Compliance

In accordance with the Federal Health Insurance Portability and Accountability Act (HIPAA), which establishes standards for privacy of individually identifiable health information, all data for the Extremely Low Birth Weight Follow-Up Project was de-identified as of January 1, 2002. This important and significant change to the Follow-Up Project is consistent with procedures at the Vermont Oxford Network for data collection and submission of de-identified data.

Please note:

- As of January 1, 2002, no data forms were accepted with patient identifiers (date of birth, date of health status follow-up visit, date of developmental follow-up visit).
- All 2008 Cohort follow-up data must be submitted on de-identified data forms: ELBW Infant Follow-Up Project Data Forms, Version 11.

VI. ELBW INFANT FOLLOW-UP PROJECT REPORT LOG

A. Introduction

The *ELBW Infant Follow-Up Report Log* identifies infants from your Center who qualify for the ELBW Infant Follow-Up Project. The VON Clinical Trials & Follow-Up Data Coordinating Center will send you the *ELBW Infant Follow-Up Report Log* for your Center. To complete this Log, you will need your Vermont Oxford Network Database Patient Log, your 28-Day Forms, and the corrected age calculator (refer to Appendix B, Instructions for Using the Corrected Age Calculator).

B. Using the ELBW Infant Follow-up Project Report Log

The *ELBW Infant Follow-Up Project Report Log* serves as a tool for establishing eligible follow-up dates, noting the follow-up report progress of infants from your Center who are eligible for the ELBW FUP, and coordinating follow-up visits for infants from your Center who are eligible to participate in the ELBW Infant Follow-Up Project but who may not receive their 18 to 24 Months Corrected Age Follow-Up Visit at your follow-up clinic. The Clinical Trials & Follow-Up Data Coordinating Center will send you the *ELBW Infant Follow-Up Project Report Log* for all eligible infants from your Center.

1. Establishing An Infant's Eligible Follow-Up Dates

Follow-up dates are between the 18 Months Corrected Age date and the 24 Months Corrected Age date for each infant. You will determine the 18 Months Corrected Age date and the 24 Months Corrected Age date using the corrected age calculator and adjusting for the number of weeks the infant was premature (Refer to Appendix B, Instructions for Using the Corrected Age Calculator). The VON Clinical Trials & Follow-Up Data Coordinating Center will send you a list of the gestational ages for each eligible infant. You will need to enter the infant's date of birth and the infant's gestational age in weeks and days into the corrected age calculator to determine the 18 Months Corrected Age date and the 24 Months Corrected Age date.

2. Tracking The Progress of The Infant's Follow-Up

Enter the date of the infant's scheduled Health Follow-Up visit and the Developmental Follow-Up visit in the appropriate columns in the *ELBW Infant Follow-Up Project Report Log*. When the *Health Status Report* and the *Developmental Status Report* have been completed (Refer to Sections VIII: Health Status Report, and IX: Developmental Status Report), enter the date on which the reports were mailed or faxed to the Clinical Trials & Follow-Up Data Coordinating Center in the appropriate columns.

Some infants may not have a *Health Status Report* or a *Developmental Status Report* completed (Refer to Section VIII: A: Infant Status at the 18 to 24 Months Corrected Age Visit). Other infants from your Center may not receive their 18 to 24 Months Corrected Age Follow-Up Visit at your follow-up clinic.

For example, if an infant was **inborn**, and **transferred at initial hospital disposition**, you may need to coordinate data collection for the 18 to 24 Months Corrected Age Follow-Up Visit with another Follow-Up clinic. Parental consent for participation in the study will still need to be obtained even if an infant is seen at another Follow-Up clinic.

As another example, if an infant was **outborn**, you may also need to coordinate data collection for the 18 to 24 Months Corrected Age Follow-Up Visit with another Follow-Up clinic. Parental consent for participation in the study will still need to be obtained even if an infant is seen at another Follow-Up clinic.

Remember, data should be mailed or faxed within one month of the 24 Months Corrected Age date listed on the ELBW Infant Follow-Up Project Report Log (Refer to Section X: How To Transmit Data).

Keep your *ELBW Infant Follow-Up Report Log*. This Log is the only way to identify infants in the ELBW Infant Follow-Up Project. 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.

VII. THE ELBW INFANT FOLLOW-UP PROJECT DATA FORMS

There are two *ELBW Infant Follow-Up Project Data Forms*. The purpose of the *ELBW Infant Follow-Up Project Data Forms* is to document the health and developmental status of the infant from the time of ultimate hospital discharge to the Follow-Up visit. The *ELBW Infant Follow-Up Project Data Forms* include the *Health Status Report* and the *Developmental Status Report*. Please be sure to use the current version (11) of these forms for the 2008 Cohort.

A. THE HEALTH STATUS REPORT (Version 11)

The *Health Status Report* documents the health status of the infant at the follow-up visit. The *Health Status Report* should be completed at a Health Follow-Up visit between the 18 Months Corrected Age date and the 24 Months Corrected Age date. To complete the *Health Status Report*, you may need to review patient specific hospital charts or outpatient clinical records to answer some of the data items.

1. Infant Status at the 18 to 24 Months Corrected Age Visit

The status of the infant at 18 to 24 Months Corrected Age will determine which sections of the Health Status Report should be completed.

- If the infant expired prior to the time of the 18 to 24 Months Corrected Age Health Follow-Up visit, complete only Section A: Health Status, Item #1 of the *Health Status Report*.

- If the infant was alive but was not seen at the time of the 18 to 24 Months Corrected Age Health Follow-Up visit, complete only Section A: Health Status, Item #1 of the *Health Status Report*.
- If the infant was alive and was seen at your Center at the time of the 18 to 24 Months Corrected Age Health Follow-Up visit, but the infant's parent(s) or legal guardian(s) did not give consent to participate in the ELBW Infant Follow-Up Project, complete only Section A: Health Status, Items #1 and 2 of the *Health Status Report*. If the infant's parent(s) or legal guardian(s) gave consent to participate, complete all sections of the Health Status Report.
- If the infant was alive and was seen at another follow-up clinic, and the infant's parent(s) or legal guardian(s) gave consent to participate, coordinate data collection with the Follow-Up clinic at the time of the 18 to 24 Months Corrected Age Health Follow-Up visit, and complete all sections of the *Health Status Report*.

2. Report Completion

Patient and Center Identification Data

In the topmost section of the first page of the *Health Status Report*, enter the Patient Name and Medical Record Number. In the second and lower section, enter the Center Name, Center Number, Network ID Number, and Infant Year of Birth (YYYY).

Section A: Health Status

ITEM 1: Status at 18 – 24 Months Corrected Age

Indicate the infant's status at the time of the Health Follow-Up visit between the 18 - 24 Months Corrected Age dates.

Check "Alive" if the infant is known to be alive at the 18 - 24 Months Corrected Age Follow-Up visit dates.

Check "Expired" if the infant died between the ultimate hospital discharge date and the 18 - 24 Months Corrected Age Follow-Up visit dates.

Check "Unknown" if the status of the infant is unknown at the 18 - 24 Months Corrected Age Follow-Up visit dates, because the infant was lost to follow-up.

ITEM 2: Consent Obtained at the Follow-Up Visit

Indicate whether informed consent was obtained from the infant's parent(s) or legal guardian(s) to collect health and developmental follow-up data. Consent may be obtained at the time of, or any time prior to the 18 - 24 Months Corrected Age Follow-Up visit.

Check "Yes" if the infant's parent(s) or legal guardian(s) gave consent to participate.

Check "No" if the infant's parent(s) or legal guardian(s) did not give consent to participate.

ITEM 3: Corrected Gestational Age at the Follow-Up Visit

You must determine the infant's corrected gestational age in months and days using the corrected age calculator (refer to Appendix B, Instructions for Using the Corrected Age Calculator). Enter the infant's date of birth, gestational age at birth in weeks and days, and the date of the follow-up visit. The corrected age calculator will display the infant's corrected gestational age on the date of the Health Follow-Up visit.

Section B: Living Situation

ITEM 4: Maternal Age at Infant Birth

Indicate the age of the mother at the time of the infant's birth. Enter the age in years.

Check "Unknown", if the age of the mother at the infant's birth is not known.

ITEM 5: Home Child Resides

Indicate the infant's home living situation between the ultimate hospital discharge and the Health Follow-Up visit. If the infant's home living situation changed between the ultimate hospital discharge and the Health Follow-Up visit, check the category that best describes where the infant lived during the majority of time. Check only one category.

Check "Parent/Family member" if the infant lives with the biological mother or father or other family members, or in the case of adoption, the legal guardian(s) who is/are the primary care giver(s).

Check "Foster Care" if the infant lives with an adult(s) who is/are the primary care giver(s) but who are not the infant's legal guardians.

Check "Chronic Care Facility" if the infant lives and is cared for in an institution or chronic care facility.

ITEM 6: Caregiver(s)

Indicate the type of social support in the infant's home living situation between the ultimate hospital discharge and the Health Follow-Up visit. If the infant's caregiver(s) changed between the ultimate hospital discharge and the Health Follow-Up visit, check the category that best describes the infant's caregiver(s) during the majority of time. Check only one category.

Check "Single parent" if the infant lives with a single parent as the primary care giver without other adults in the home.

Check "Single parent extended family" if the infant lives with a single parent as the primary care giver and with other related adults who are not the primary caregiver's partner in the home.

Check "Two parent" if the infant lives with two parents as the primary care givers without other adults in the home.

Check "Two parent extended family" if the infant lives with two parents as the primary care givers and with other related adults in the home.

Check "Institutional" if the infant lives in a chronic care facility or remains hospitalized.

ITEM 7: Primary Caregiver Education

Indicate the highest level of education of the primary care giver in the home between the ultimate hospital discharge and the Health Follow-Up visit. If the caregiver's level of education changed between the ultimate hospital discharge and the Health Follow-Up visit, check the category that best describes the level of education during the majority of time. Check only one category.

Check "Some high school or less" if the primary caregiver has attained grade school education and some high school education, but has not graduated from high school.

Check "High school graduate/GED" if the primary caregiver has graduated from high school or attained the equivalent (GED).

Check "Some college/university" if the primary caregiver has graduated from high school and has attended some college courses, but has not graduated from college.

Check "College/university graduate" if the primary caregiver has graduated from a college or university.

Check "Unknown" if the highest level of education of the primary caregiver is not known or is unclear.

Check "Not applicable" only if the infant lives in a chronic care facility or institution.

FOR PARTICIPATING USA CENTERS ONLY

ITEM 8: Income Below 2008 HHS Poverty Guideline

Indicate whether the household income for 2008 was below the 2008 HHS Poverty Guideline (35) level for the given number of people currently residing in the infant's home.

Many caregivers feel uncomfortable asking parents or caregivers a question about their household income. To help ask this question we have provided a script and an income reference table (Appendix C). Please note the question does not ask for a specific income level or range. Rather, the question is phrased so as to be answered in a "Yes" or "No" format. Interviewers may give the parents or caregivers the income reference table as a tool to facilitate their answer to the question as "Yes", "No", or "I don't know" ("Unknown").

To use the table, instruct the parent or caregiver to look at the column on the left and find the number of adults and children who lived in the home for part or all of 2008. Next have the parent or caregiver look at the column on the right and answer "Yes" or "No" to the question "Was your household income for the year 2008 below the number in the column?"

Check "Yes" if the 2008 household income for the number of people (adults plus children) residing in the home is less than the dollar amount listed in the corresponding column.

Check "No" if the 2008 household income for the number of people (adults plus children) residing in the home is equal to or more than the dollar amount listed in the corresponding column.

Check "Unknown" if the parent or the caregiver is unsure of the 2008 household income.

ITEM 9: Caregiver(s) Primary Language

Indicate the primary language of the caregiver used in the home in which the child resides. Check "Other" if a language other than English or Spanish is used. The "other" language does not need to be specified.

Section C: Support After Discharge

ITEM 10: Support after ultimate hospital discharge

Indicate whether the infant had any of the listed specific supports or interventions at any time between the ultimate hospital discharge and the Health Follow-Up visit. The specific support or interventions may have been in place prior to ultimate hospital discharge or may have been placed between the ultimate hospital discharge and the follow-up visit.

Check "Yes" if the infant received any of the listed supports or interventions after discharge.

Check "No" if the infant did not receive any of the listed supports or interventions after discharge.

Check "Unsure" if you are not sure if the infant received any of the listed supports or interventions listed after discharge.

ITEM 10a: If Yes

If Item #7 "Support After Discharge" is marked "Yes", check all that apply.

Tracheostomy: Indicate whether the infant had a functional tracheostomy.

Ventilator: 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.

Gastrostomy: Indicate whether the infant had a functional gastrostomy.

Nasogastric feeds: Indicate whether the infant received nasogastric or nasojejunal feeds.

Apnea or Cardio-Respiratory Monitor: Indicate whether the infant was on an Apnea Monitor or a Cardio-Respiratory Monitor.

Section D: Medical Re hospitalizations & Surgeries

ITEM 11: Medical Re hospitalizations

Indicate whether the infant was re hospitalized at any time between the ultimate hospital discharge and the Health Follow-Up visit. Medical re hospitalizations require an overnight hospital stay. Medical re hospitalizations exclude visits to a Hospital-based Primary Care Medical or Developmental Follow-Up Clinic, or other hospital-based specialty clinic or the Emergency Room.

Check "Yes" if the infant was re hospitalized.

Check "No" if the infant was not re hospitalized.

Check "Unsure" if you are not sure if the infant was re hospitalized.

ITEM 11a: If Yes, Category

If Item #8 "Medical Re hospitalizations" is checked "Yes", indicate whether the infant was hospitalized for a specific medical re hospitalization category as defined below, and check all that apply. Enter the "Number of Admissions" as the number of hospital admissions for each specific medical re hospitalization category. If you are unsure of the number of admissions for a medical re hospitalization category, enter "99".

A hospital admission should be assigned to only one re hospitalization category.

ITEM 11a1: Respiratory Illness

Includes medical re hospitalizations 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 re hospitalizations as related to pulmonary infections (e.g. "RSV-bronchiolitis"), "Acute Life Threatening Event", or "Near SIDS".

ITEM 11a2: Nutrition/Failure to Thrive

Includes medical rehospitalizations for nutritional issues or failure to gain weight. Excludes medical rehospitalizations as related to gastrointestinal infections.

ITEM 11a3: Seizure Disorder

Includes medical re hospitalizations for partial, generalized or unclassified seizures and convulsive disorders. 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. Excludes medical re hospitalizations as related to CNS infections: if the seizure is sequelae of a specific acute infection of the cerebrum or meninges, the re hospitalization should be coded under the appropriate category of "Infection".

ITEM 11a4: Shunt Complication

Includes medical re hospitalizations for complications related to or associated with cerebrospinal fluid shunts and re hospitalizations as 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.

ITEM 11a5: Infections (not respiratory or shunt infections)

ITEM 11a5a: Meningitis

Includes medical re hospitalizations for bacterial or aseptic meningitis. The diagnosis of meningitis requires a single CSF culture to be positive. Excludes infections related to or associated with cerebrospinal fluid shunts.

ITEM 11a5b: Urinary tract infection

Includes medical re hospitalizations for infections related to either the upper or lower urinary tracts such as acute pyelonephritis, chronic pyelonephritis, cystitis, and urethritis. Primary or secondary vesicoureteral reflux may or may not be involved. The diagnosis of a urinary tract infection requires a positive quantitative urine culture.

ITEM 11a5c: Gastrointestinal infection

Includes medical re hospitalizations for infectious diarrhea illnesses such as endemic diarrhea, food-borne or water borne diarrhea, anti-microbial associated diarrhea and diarrhea in immunocompromised hosts. This category also includes re hospitalizations for excessive fluid and electrolyte losses and subsequent replacement therapies. The diagnosis of a gastrointestinal infection does not require a positive culture.

ITEM 11a5d: Other infection (specify)

Includes medical re hospitalizations for infections not meeting the inclusion requirements of one of the above categories. Enter a specific infection.

ITEM 11a6: Other Medical Re hospitalization Category (specify):

Includes medical re hospitalizations for a category that does not meet the inclusion requirements of one of the above categories. Describe the specific reason for re hospitalization in the space provided for the description.

ITEM 12: Surgical Procedures After Discharge

Indicate whether the infant required a surgical procedure after discharge. Includes one or more surgical procedures performed at any time between the ultimate hospital discharge date and the time of the Health Follow-Up visit. Surgical procedures may be with or without re hospitalizations (i.e. they may occur as outpatient or day surgeries).

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

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

Check "Unsure" if you are not sure if the infant required a surgical procedure.

Please note that the surgical procedure codes EBLW Infant Follow up Study are NOT the same as codes used to record surgeries in the VON VLBW Database. ELBW Infant Follow up Procedure codes (P-codes) can be found on the reverse side of the Health Status Report Form or in Appendix C.

Enter the three digit "P- Code" from the list of surgical procedures on the back of the Health Status Report; or refer to Appendix C: Surgical Procedure Codes. If the infant had Other neurosurgical procedure (code "P-102"), Other gastrointestinal surgical procedure (code "P-303"), Other genitourinary surgical procedure (code "P-402"), Other ENT surgical procedure (code "P-503"), or Other ophthalmologic surgical procedure (code "P-604"), enter the code number and describe the specific surgery in the space provided for description. If the infant had a surgical procedure not listed on the back of Health Status Report or in Appendix C, enter "P-900" (Other Surgical Procedure). Describe the specific surgical procedure in the space provided for description.

Enter the "Number of Procedures" as the number of surgical procedures performed for each surgical category.

B. THE DEVELOPMENTAL STATUS REPORT (Version 11)

The *Developmental Status Report* documents the neurodevelopmental status of the infant at the follow-up visit. The *Developmental Status Report* should be completed at a Developmental Follow-Up visit between the 18 Months Corrected Age date and the 24 Months Corrected Age date. You recorded these dates on the ELBW Infant Follow-Up Report Log (Refer to Section VI: C: The ELBW Infant Follow-Up Project Report Log and Appendix B: Instructions for Using the Corrected Age Calculator). To complete the Developmental Status Report, you may need to

review patient specific hospital charts or outpatient clinical records to answer some of the data items.

1. INFANT STATUS AT THE 18 TO 24 MONTHS CORRECTED AGE VISIT

The status of the infant at 18 to 24 Months Corrected Age will determine which sections of the *Developmental Status Report* should be completed.

- If the infant expired prior to the 18 to 24 Months Corrected Age Developmental Follow-Up visit, do not complete the Developmental Status Report.
- If the infant was alive but was not seen at your Center at the 18 to 24 Months Corrected Age Developmental Follow-Up visit, do not complete the Developmental Status Report.
- If the infant was alive and was seen at your Center at the time of the 18 to 24 Months Corrected Age Developmental Follow-Up visit, but the infant's parent(s) or legal guardian(s) did not give consent to participate in the ELBW Infant Follow-Up Project, do not complete the Developmental Status Report. If the infant's parent(s) or legal guardian(s) gave consent to participate, complete all sections of the Developmental Status Report.
- If the infant was alive and was seen at another follow-up clinic, and the infant's parent(s) or legal guardian(s) gave consent to participate, coordinate data collection with the Follow-Up clinic at the time of the 18 to 24 Months Corrected Age Developmental Follow-Up visit, and complete all sections of the Developmental Status Report.

2. REPORT COMPLETION

Patient and Center Identification Data

In the topmost section of the first page of the Developmental Status Report, enter the Patient Name and Medical Record Number. In the second and lower section, enter the Center Name, Center Number, Network ID Number, and Infant Year of Birth (YYYY).

Section A: Growth Parameters

ITEM 1: Corrected Gestational Age when Growth Parameters Obtained

You must determine the infant's corrected gestational age in months and days using the corrected age calculator (refer to Appendix B, Instructions for Using the Corrected Age Calculator). Enter the infant's date of birth, the gestational age at birth in weeks and days, and the date when growth parameters were obtained. The corrected age calculator will display the

infant's corrected gestational age on the date of the Developmental Follow-Up Visit when the growth parameters were obtained.

ITEM 2: Weight

Enter the weight recorded at the Developmental Follow-Up visit. Enter the weight in kilograms (kg), to the hundredths place. If the weight was not obtained at the Developmental Follow-Up visit, enter "99.9". Do not enter a weight obtained at another visit.

ITEM 3: Head Circumference

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 was not obtained at the Developmental Follow-Up visit, enter "99.9". Do not enter a head circumference obtained at another visit.

Section B: Vision & Hearing

ITEM 4: Formal Ophthalmologic Exam

Indicate whether the infant received a formal ophthalmologic exam at any time from hospital discharge to the 18-24 Months Corrected Age Developmental Follow-Up visit. A formal ophthalmologic exam is an examination by an ophthalmologist.

Check "Yes" if the infant had a formal ophthalmologic exam.

Check "No" if the infant did not have a formal ophthalmologic exam, or if you are unsure if the infant had a formal ophthalmologic exam.

ITEM 5: Blindness

Indicate whether the infant has any loss of vision.

Check "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.

Check "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.

Check "Not blind" 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.

Check "Unsure" if you are unsure of the infant's visual status.

ITEM 6: Prescription glasses

Indicate whether the infant currently uses prescription glasses.

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

Check "No" if prescription glasses are never used.

ITEM 7: Formal Hearing Test

Indicate whether the infant had formal testing at any time from hospital discharge until the day of the 18-24 Months Corrected Age Developmental Follow-Up visit. The formal testing may be for confirmation of a suspected hearing loss based on a failed hearing screen, observation of problems with the infant's behavioral response to sound, or a caregiver's report of emerging communication and auditory behavior difficulties. Formal testing must include otoacoustic emissions (OAEs) and/or auditory brainstem response (ABR).

Check "Yes" if the infant had formal testing.

Check "No" if the infant did not receive formal testing, or if you are unsure if the infant had formal testing.

ITEM 8: Hearing Impairment

Indicate whether the infant has evidence of any hearing impairment.

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

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

Check "Not impaired" if the infant does not have any hearing impairment.

Check "Unsure" if you are unsure of the infant's hearing status.

ITEM 9: Amplification

Indicate whether corrective hearing aid(s) are currently used for amplification.

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

Check "No" if corrective aids are never used.

Section C: Cerebral Palsy

ITEM 10: 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.

Check "Yes" if the infant has cerebral palsy.

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

ITEM 10a: If Yes, Impairment

If Item # 10 "Cerebral Palsy" is "Yes" the infant has cerebral palsy, then indicate the type of impairment. Check only one type.

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

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

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

ITEM 10b: If No, Muscle Tone

If Item #10 "Cerebral Palsy" is "No" the infant does not have cerebral palsy, indicate whether the infant has an abnormality in muscle tone. Check only one type.

Check "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.

Check "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.

Check "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.

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

Section D: Gross Motor Milestones

ITEM 11: Sits independently

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

Check "Yes" if the infant can sit independently.

Check "No" if the infant cannot sit independently.

ITEM 11a: If No, sits with support

If the answer to Item #11 is "Yes", do not answer Item #11a. If the answer to Item #11 is "No", indicate whether the infant can sit with support in his/her current usual performance.

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

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

ITEM 12: 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.

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

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

ITEM 12a: If No, walks ten (10) steps with support

If the answer to Item #12 is "Yes", do not answer Item #12a.

If the answer to Item #12 is "No", indicate whether the infant can walk ten (10) steps with support in his/her current usual performance.

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

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

Section E: Developmental Testing

ITEM 13: Bayley Scales of Infant Development

Indicate whether the infant's development was evaluated at the Developmental Follow-Up visit using the Bayley Scales of Infant Development (BSID). Either the BSID-II (2nd Edition) or the BSID-III (3rd Edition) may have been used in the assessment.

Check "Completed" if the infant's development was evaluated with the Mental Developmental Index (MDI) and Psychomotor Developmental Index (PDI) of the BSID-II or with the Cognitive Language and Motor subtests of the BSID-III .

If "Completed" is checked, Items 13a and 13b must be answered.

Check "Partially completed" if the infant's development was evaluated with either the Mental Developmental Index (MDI) or Psychomotor Developmental Index (PDI) of the BSID-II or with any one or two of the Cognitive Language or Motor subtests of the BSID-III .

If "Partially completed is checked, Items 13a, 13b and 13c must be answered.

Check "Not performed" if the infant's development was not evaluated with any of the subtests of the BSID-II or BSID-III.

If "Not performed" is checked, Item 13c must be answered.

ITEM 13a: Corrected age used in scoring

If the answer to Item #13 is "Completed" or "Partially completed", enter the corrected age used in scoring the BSID as the age in months and days. You can determine the infant's corrected age in months and days using the corrected age calculator (refer to Appendix B, Instructions for Using the Corrected Age Calculator). Enter the infant's date of birth, gestational age at birth in weeks and days, and the date on which developmental testing was performed. The corrected age calculator will display the infant's corrected age on the date of the developmental testing.

ITEM 13b: Results (Check all sections that apply)

If the answer to Item #13 is "Completed" or "Partially completed", enter the results for the BSID test administered. For each subtest completed enter the corresponding score.

If the Bayley II was performed, one or both of the following two questions need to be answered.

1. BSID-II MDI

If the MDI subtest of the BSID II was completed, check the box. Enter the Raw Score and the Index Score for Corrected Age. The Index Score for Corrected Age is the raw score corrected for the infant's degree of prematurity (Refer to Appendix B: Instructions for Using the Corrected Age Calculator).

2. BSID-II PDI

If the PDI subtest of the BSID II was completed, check the box. Enter the Raw Score and the Index Score for Corrected Age. The Index Score for Corrected Age is the raw score corrected for the infant's degree of prematurity (Refer to Appendix B: Calculating Corrected Age Dates).

If the Bayley III was performed, some or all of the following three questions need to be answered:

1. BSID-III Cognitive

If the Cognitive subtest of the BSID III was completed, check the box. Enter the Scaled Score and the Composite Score for the Cognitive Subtest.

2. BSID-III Language

If the Language subtest of the BSID III was completed, check the box. Enter the Sum Scaled Score and the Composite Score for the Language subtest. The Sum Scaled Score is the sum of the Receptive Communication (RC) and the Expressive Communication (EC) scaled scores.

3. BSID-III Motor

If the Motor subtest of the BSID III was completed, check the box. Enter the Sum Scaled Score and the Composite Score for the Motor subtest. The Sum Scaled Score is the sum of the Fine Motor (FM) and the Gross Motor (GM) scaled scores.

ITEM 13c: Check why

If the answer to Item #13 is "Partially completed" or "Not performed", indicate the reason why.

Check "Neurosensory impairment (blind or deaf)" if the child had one or both of these impairments and could not complete the test.

Check "Too severely delayed" if the child was too severely delayed to administer testing. Do not check this reason if the BSID was not administered because the child had a neurosensory impairment (was blind or deaf).

Check "Uncooperative" if the child was unable to sufficiently cooperate for the exam to be performed.

Check "Other" if there was another reason the BSID was not administered.

ITEM 14: Other Developmental or Cognitive Test Performed

Indicate whether another developmental or cognitive test was performed (i.e. Peabody). Complete this item even if the infant was evaluated with the Bayley Scales of Infant Development.

Check "Yes" if another developmental or cognitive test was performed.

Check "No" if another developmental or cognitive test was not performed.

ITEM 14a: If "Yes", Abnormal results

If another developmental or cognitive test was performed, indicate whether the results of the test were abnormal.

Check "Yes" if the infant was assessed as abnormal from the other developmental test.

Check "No" if the infant was not assessed as abnormal from the other developmental test.

Section F: Overall Clinical Appraisal

Item 15: Clinical Appraisal

Cognitive Function

Indicate the clinical appraisal of the infant's cognitive functioning. 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 the visit.

Check "Normal" if the infant's cognitive functioning is appropriate for 18-24 months age corrected for prematurity.

Check "Suspect" if it is unclear whether the infant's cognitive functioning is delayed for 18-24 months age corrected for prematurity.

Check "Impaired" if the infant's cognitive functioning is abnormal for 18-24 months age corrected for prematurity.

Language

Indicate the clinical appraisal of the infant's language. The clinical appraisal is a summary of the impressions of the health care team upon seeing and listening to the infant at the Developmental Follow-Up visit. The clinical appraisal is based on observation and examination of the infant during the visit.

Check "Normal" if the infant's language is appropriate for 18-24 months age corrected for prematurity.

Check "Suspect" if it is unclear whether the infant's language is delayed for 18-24 months age corrected for prematurity.

Check "Impaired" if the infant's language is abnormal for 18-24 months age corrected for prematurity.

Motor Function

Indicate the clinical appraisal of the infant's motor functioning. 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 the visit.

Check "Normal" if the infant's motor functioning is appropriate for 18-24 months age corrected for prematurity.

Check "Suspect" if it is unclear whether the infant's motor functioning is delayed for 18-24 months age corrected for prematurity.

Check "Impaired" if the infant's motor functioning is abnormal for 18-24 months age corrected for prematurity.

VIII. HOW TO TRANSMIT DATA

Mail or Fax All Data to:

ELBW Infant Follow-Up Project
Vermont Oxford Network
33 Kilburn St.
Burlington, VT 05401
Fax: 802-865-9613
Fax: 802-865-0359

1. Do not photocopy the infant's name or medical record number on the top of the ELBW Infant Follow-Up Project Data Forms. This information should remain confidential.
2. Keep your original ELBW Infant Follow-Up Project Data Forms on file. Send copies only.
3. Complete all data on the data forms. Confirm accuracy of all data before submission. Check that all forms have the correct Center number, VON ID number, and Infant Year of Birth. Do not submit incomplete forms.
4. Care should be taken anytime a form is changed or updated, since the most recent data received will be entered into the database without further verification. All changes/updates made on ELBW Infant Follow-Up Project Data Forms previously submitted should be highlighted or noted as being "corrected" when the forms are mailed to VON.
5. Keep your ELBW Infant Follow-Up Project Report Log secure. The ELBW Infant Follow-Up Project Report Log is the only way to identify infants and to track their status in the follow-up project. You may need to use the logs to find specific charts for review. We recommend making copies of the ELBW Infant Follow-Up Project Report Log as each page of the Log is completed in case the original is lost.
6. Keep your ELBW Infant Follow-Up Project Report Log up to date. Enter data on the Log as data forms are submitted.

IX. PUBLICATIONS

Vermont Oxford Network will author all publications, which are based on data collected at all centers during the conduct of this follow-up project. An appendix listing each participating center, up to two investigators from each of the centers, and the study coordinator from each center will be included. The centers will be listed in alphabetical order. The appendix will also list the members of ELBW Infant Follow-Up Project Steering Committee and the VON Clinical Trials & Follow-Up Data Coordinating Center. The appendix will list Charles E. Mercier, MD (Principal Investigator); Roger F. Soll, MD (co-Principal Investigator, Vermont Oxford Network Trials & Follow-Up Director); and Karla Ferrelli, Study Coordinator. All investigators listed in the appendix will be considered co-authors of the manuscript and entitled to include the publication in their curricula vitae.

Publications based on follow-up data collected at individual centers or a subgroup of centers which address ancillary research questions may be authored by the individual investigators responsible, but will not be submitted for publication until after the primary follow-up manuscript has been submitted. All ancillary studies must have prior approval of the Steering Committee to ensure that these studies will not interfere with the main study.

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

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VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

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VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
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VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
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VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

XI. APPENDICES

Appendix A: ELBW Infant Follow-up Project – 2007 Cohort Center List

Aultman Hospital/ OH	New Hanover Regional Medical Center/ NC
Akron Children's Hospital / OH	Ospedale Maggiore Policlinico/ Italy
Cape Fear Valley Medical Center/ NC	Presbyterian/St. Luke's Medical Center/ CO
Baptist Memorial Hospital for Women/ TN	Providence St. Vincent Medical Center/ OR
Children's Hospital of Iowa	Rainbow Babies and Children's Hospital/ OH
Children's Hospital of SW Florida	Sacred Heart Medical Center/ WA
Children's Hospital of Wisconsin	St. Barnabas Medical Center/ NJ
Children's Hospitals & Clinics/MN	CHOI at OSF St. Francis Medical Center/IL
Children's of Orange County/CA	St. John Hospital & Medical Center/MI
Deaconess Medical Center/ WA	St. Joseph's Hospital/WI
DeVos Children's/Spectrum Health/ MI	Sunnybrook Health Science Centre/ Canada
Encino Tarzana Regional Medical/ CA	Thomas Jefferson University Hospital/ PA
Henry Ford Hospital/ MI	UCSF Medical Center/CA
K.K. Women's & Children's Hospital/ Singapore	U. Mass Memorial Health Care/ MA
Legacy Emanuel Children's Hospital/ OR	University Kebangsaan/ Malaysia
Mercy San Juan Hospital/CA	Wake Medical Center/ NC
Mississippi Baptist Health Systems/ MS	Wheaton Franciscan Healthcare/ WI
Morristown Memorial Hospital/ NJ	Women's Hospital of Greensboro/ NC
	Women's Hospital / IN

Continued participation of Centers in the Year 2008 Cohort is anticipated for the Year 2007 Cohort. New Centers, having completed Center eligibility requirements are welcome.

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

Appendix B: Instructions for Using the Corrected Age Calculator

The Corrected Age calculator is intended to easily and accurately provide you with the infant's corrected gestational age at the time of the follow-up visit, as well as the 18-24 month corrected age test date range. The calculator is available on the Vermont Oxford Network website (www.vtoxford.org) under "Follow-Up Project."

To calculate the infant's corrected gestational age:

- Click on the tab labeled "Corrected Age" at the top of the calculator on the screen.
- Enter the infant's date of birth. Confirm with your records that this is the correct date of birth.
- Enter the developmental test date. Confirm that this is the correct developmental test date.
- Enter the infant's gestational age in weeks. Confirm that this is the correct age in weeks.
- Enter the infant's gestational age in days. Confirm that this is the correct age in days.
- Hit the "Calculate" tab at the bottom of the calculator. The infant's corrected gestational age will appear in the box labeled " Corrected Age". This is the corrected age that you will use on the Health and Developmental Status Reports. Do not round these numbers.

To calculate the follow-up test date range for the infant:

- Click on the tab labeled "Test Date Range" at the top of the calculator on the screen.
- Enter the infant's date of birth. Confirm that the date of birth is correct.
- Enter the infant's gestational age in weeks. Confirm that this is the correct age in weeks.
- Enter the infant's gestational age in days. Confirm that this is the correct age in days.
- Hit the "Calculate" tab at the bottom of the calculator. The test date range will appear in the boxes labeled "18 month Corrected Age Date" and "24 month Corrected Age Date".

Helpful hint: In order to accurately calculate the infant's corrected gestational age and the follow-up test date range, you must use the gestational age in weeks and days listed on the infant's VON 28 Day form. (If you do not have direct access to these forms, please contact your center's VON data

VERMONT OXFORD NETWORK
 THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
 Release 11

coordinator for this information.) Do not round the gestational age in weeks and days before entering them into the calculator.

In calculating the Corrected Age:

The Corrected Age of the child is calculated based upon the Bayley Scales of Infant Development formula.

1. Calculate the child's chronological age by subtracting the date of birth from the date of testing. As per the BSID, all months are assumed to have 30 days.
2. Compute the months and days the child was premature by subtracting the number of days gestational age from the number of days in a 40-week gestation. Divide the number of days premature by 30 to get the months, and its remainder is the number of days.
3. Subtract the time the child was premature from the chronological age to compute the corrected age in months and days.

Example: An infant born on 1/1/2003 with a gestational age of 26 weeks and 2 days and tested on 11/15/2004 will have an corrected age of 19 months and 8 days.

1.

Year	Month	Day
2004	11	15
2003	1	1
1	10	14

2. $(40 \times 7) - ((26 \times 7) + 2) = 96$

3. $96 \div 30 = 3$ months with remainder of 6 days

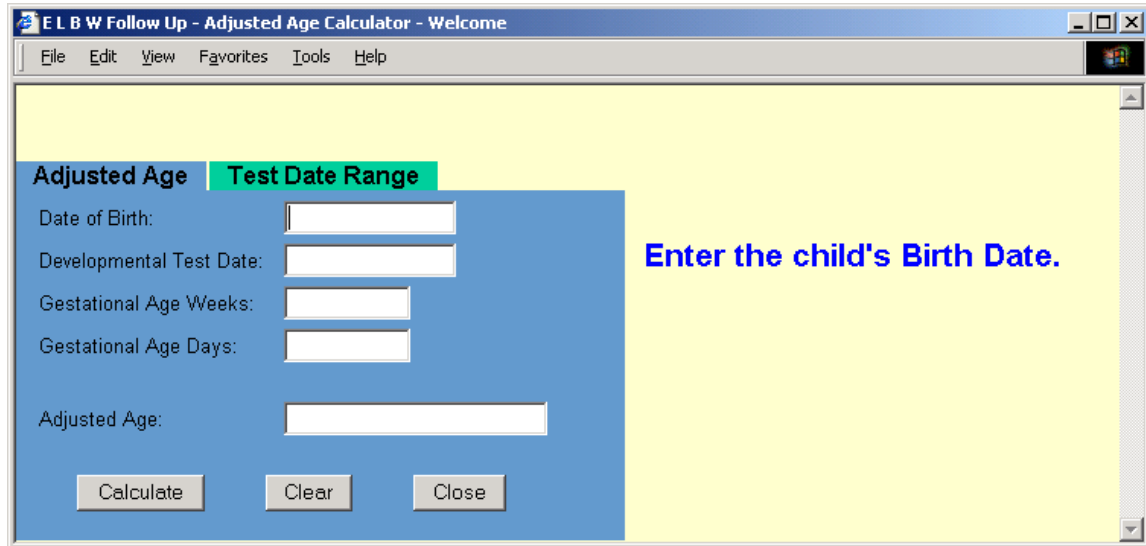
4.

Year	Month	Day
1	10	14
	3	6
1	7	8

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

5. Convert the 1 year to 12 months. $12 + 7 = 19$ months

1. Corrected Age = 19 months 8 days



Adjusted Age | **Test Date Range**

Date of Birth:

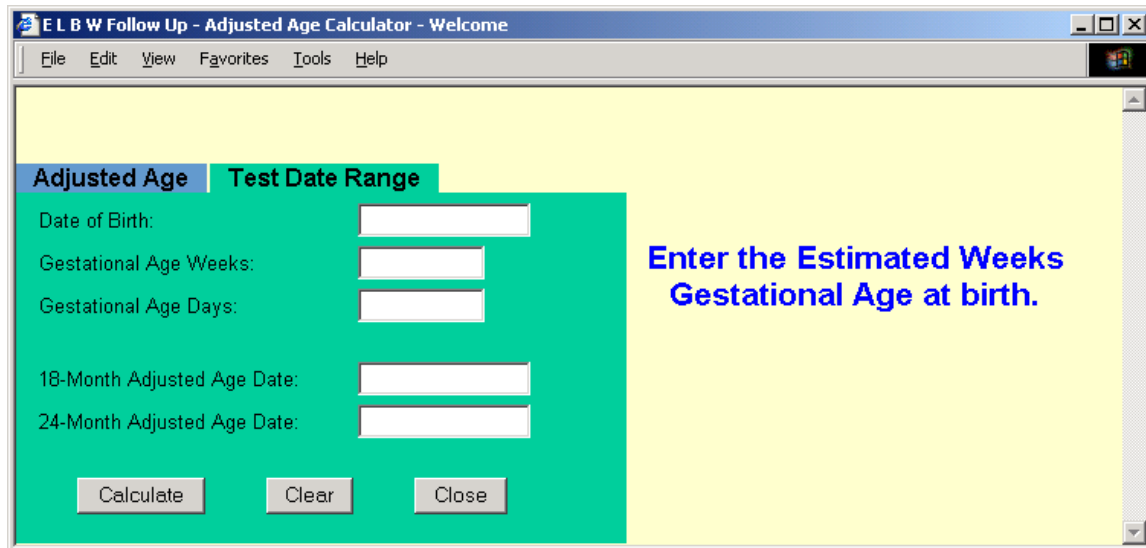
Developmental Test Date:

Gestational Age Weeks:

Gestational Age Days:

Adjusted Age:

Enter the child's Birth Date.



Adjusted Age | **Test Date Range**

Date of Birth:

Gestational Age Weeks:

Gestational Age Days:

18-Month Adjusted Age Date:

24-Month Adjusted Age Date:

Enter the Estimated Weeks Gestational Age at birth.

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
Release 11

Appendix C : Script for Question 8 (Health Status Report)

We would like to ask you a question about your household income in calendar year. Your household income is the amount of money earned by adults living in your house.

After thinking about this for a minute, please take a look at the following table and tell us whether your household income in for the year 2008 was below the number listed in the table.

To use this table look at the column on the left and find the number of adults and children who lived in your home for part or all of 2008. Next look at the column on the right and answer "Yes" or "No" to the question "Was your household income for the year 2008 below the number in the column?"

Interviewer hands table to parent; parent answers question and returns table to interviewer.

HOUSEHOLD INCOME Tool

Persons in Household	Household Income in 2008
2	\$ 14,000
3	\$ 17,600
4	\$ 21,200
5	\$ 24,800
6	\$ 28,400
7	\$ 32,000
8	\$ 35,600
Each additional person	\$ 3,600

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
 Release 11

Appendix D: Surgical Procedure Codes (P-Codes)

P-CODE	CATEGORY
	<u>Central Nervous System Surgery</u>
P-101	Shunt or shunt revision for hydrocephalus
P-102	Other neurosurgical procedure
	<u>Congenital Heart Defect Surgery</u>
P-201	Cardiac surgery
	<u>Gastrointestinal Surgery</u>
P-301	Gastrostomy tube placement
P-302	Inguinal hernia repair
P-303	Other gastrointestinal surgical procedure
	<u>Genitourinary Surgery</u>
P-401	Circumcision
P-402	Other genitourinary surgical procedure
	<u>Otolaryngology Surgery</u>
P-501	Tracheostomy
P-502	Tympanostomy tubes
P-503	Other ENT surgical procedure
	<u>Ophthalmologic Surgery</u>
P-601	Retinal cryosurgery or laser surgery: single eye
P-602	Retinal cryosurgery or laser surgery: both eyes
P-603	Strabismus surgery
P-604	Other ophthalmologic surgical procedure
P-900	<u>Other Surgical Procedure</u>

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
 Release 11

Appendix E: Sample Report Log and Data Forms

1. Extremely Low Birth Weight Infant Follow-up Report Log

Extremely-Low-Birth-Weight Infant Follow-Up Project REPORT LOG										
CENTER: XX		CENTER NAME: Your Center Name					Birth Year: 2008			
Network ID Number	Date of Birth	Patient's Name	GA Weeks	GA Days	18 Months Adjusted Age Date	24 Months Adjusted Age Date	Health and Developmental Status Follow-up Date	Health and Developmental Status Follow-Up Report Mailed	PIRQ Date	PIRQ Mailed
3638			27	0						
3753			27	0						
3756			27	0						
3765			27	0						
3841			27	0						
3915			26	0						
3988			23	4						
4005			27	2						
4006			23	5						
4007			25	0						
4008			25	0						
4012			30	4						
4013			25	2						
4014			25	5						
4016			24	0						
4018			25	6						
4020			27	0						
4034			29	1						
4036			25	6						
elbwfup@vtoxford.org					© Vermont Oxford Network, Inc.					

VERMONT OXFORD NETWORK
THE EXTREMELY-LOW-BIRTH-WEIGHT INFANT FOLLOW-UP PROJECT: 2008 COHORT
MANUAL OF OPERATIONS
 Release 11

3. Sample: Developmental Status Report (Version 11)

Patient's Name: _____	Medical Record: _____ <small>(Please do not transmit information in this box.)</small>
VERMONT OXFORD NETWORK Extremely-Low-Birth-Weight Infant Follow-Up Project Year 2008 Cohort DEVELOPMENTAL STATUS REPORT	
Center Number: _____	Center Name: _____
Network ID Number: _____	Year of Birth (YYYY): _____
SECTION A: GROWTH PARAMETERS	
1. Corrected Age Growth Parameters Were Obtained (months/days): _____ months _____ days	
2. Weight: _____ kg	3. Head Circumference: _____ cm
SECTION B: VISION & HEARING	
4. Formal Ophthalmologic Exam: <input type="checkbox"/> Yes <input type="checkbox"/> No	
5. Blindness: <input type="checkbox"/> One eye <input type="checkbox"/> Both eyes <input type="checkbox"/> Not blind <input type="checkbox"/> Unsure	
6. Prescription Glasses: <input type="checkbox"/> Yes <input type="checkbox"/> No	
7. Formal Hearing Test: <input type="checkbox"/> Yes <input type="checkbox"/> No	
8. Hearing Impairment: <input type="checkbox"/> One ear <input type="checkbox"/> Both ears <input type="checkbox"/> Not impaired <input type="checkbox"/> Unsure	
9. Amplification: <input type="checkbox"/> Yes <input type="checkbox"/> No	
Section C: Cerebral Palsy	
10. Cerebral Palsy: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<i>IF Yes, a. Impairment:</i> <input type="checkbox"/> Diplegia <input type="checkbox"/> Hemiplegia <input type="checkbox"/> Quadriplegia	
<i>IF No, b. Muscle tone:</i> <input type="checkbox"/> Hypotonia <input type="checkbox"/> Hypertonia <input type="checkbox"/> Both (hypo- & hypertonia) <input type="checkbox"/> Normal	
SECTION D: GROSS MOTOR MILESTONES	
11. Sits independently: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<i>IF No, a. Sits with support:</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	
12. Walks ten (10) steps independently: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<i>IF No, a. Walks ten (10) steps with support:</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	
SECTION E: DEVELOPMENTAL TESTING	
13. Bayley Scales of Infant Development: <input type="checkbox"/> Completed <input type="checkbox"/> Partly completed <input type="checkbox"/> Not performed	
<i>IF completed or partially completed,</i>	
a. Corrected age used in scoring: _____ months _____ days	
b. Results: Check (✓) all sections that apply.	
<input type="checkbox"/> BSID-II MDI: Raw Score: _____	Index Score for Corrected Age: _____
<input type="checkbox"/> BSID-II PDI: Raw Score: _____	Index Score for Corrected Age: _____
<input type="checkbox"/> BSID-III Cognitive: Scaled Score: _____	Composite Score: _____
<input type="checkbox"/> BSID-III Language: Sum Scaled Score: _____	Composite Score: _____
<input type="checkbox"/> BSID-III Motor: Sum Scaled Score: _____	Composite Score: _____
<i>IF partially completed or not performed,</i>	
c. Check (✓) why: <input type="checkbox"/> Neurosensory impairment (blind or deaf) <input type="checkbox"/> Too severely delayed	
<input type="checkbox"/> Uncooperative <input type="checkbox"/> Other reason	
14. Other Developmental Test Performed: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<i>IF Yes, a. Abnormal results:</i> <input type="checkbox"/> Yes <input type="checkbox"/> No	
SECTION F: OVERALL CLINICAL APPRAISAL	
15. Clinical Appraisal: Cognitive Function: <input type="checkbox"/> Normal <input type="checkbox"/> Suspect <input type="checkbox"/> Impaired	
Language: <input type="checkbox"/> Normal <input type="checkbox"/> Suspect <input type="checkbox"/> Impaired	
Motor Function: <input type="checkbox"/> Normal <input type="checkbox"/> Suspect <input type="checkbox"/> Impaired	
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