Descriptions of NBDPN Data Elements

for Population-based Birth Defects Surveillance

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Summary List of Data Elements

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Unique Case ID	1	A code or number that uniquely identifies each case or record	• Every infant/fetus with a birth defect in the database must have a unique ID. • Only one ID per case.
Date of Delivery (for a live birth)	1	Date of delivery for a live birth	• Every live birth must have a date of birth. • The date should include valid month, day, and year. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. • The date of delivery for a live birth should be after the date of last menstrual period (LMP) and date of conception.
Gender (Sex)	1	Gender (sex) of the infant or fetus	• Values should be: 'Male', 'Female', 'Ambiguous', 'Unknown'
Name	1	A word or set of words by which an infant/fetus/ potential case is known, addressed, or referred to (e.g.: first, middle, last name(s), suffix)	• Every record must have at least one name and should have two names, generally first and last. • Multiple names are possible. • If the infant's last name is hyphenated, both names should be in the last name field.
Source of Report	1	A place, person, or thing from which the data were obtained	• This field should not be missing. • Standard codes (hospitals, clinics, laboratories, autopsy, etc.) unique to each program/organization. Multiple sources are possible for a given case. • Helpful to develop expected number of reports or cases by source of report to identify potential source reporting concerns.
Medical Record Number(s) (Infant/Child)	1	Text and/or numbers used by the source from which the information was obtained to identify an individual who received health care from that organization	• The case must have at least one medical record number only if the infant was delivered alive. • Multiple medical record numbers are possible. Medical record numbers should be different for different sources. All case medical record numbers must be different from all mother's medical record numbers. The mother's medical record number may be used by the source to identify a fetal death, but would not be allowable in this field.
Birth Certificate ID	1	Unique number/text assigned to a birth certificate and maintained by Vital Records and birth defects programs	• This ID must not be missing if any birth certificate data for the infant are available to the birth defects program. • This ID should not be the same as any Medical Record Number for the newborn or the mother.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Death Certificate ID	1	Unique number/text assigned to a death certificate and maintained in Vital Records and birth defects programs	• This ID must not be missing if any death certificate data for the infant are available to the birth defects program. • This ID should not be the same as any Medical Record Number for the newborn or the mother.
Place of Pregnancy Outcome	1	Location where the delivery or pregnancy outcome occurred	• This field should always be filled out and must be a valid code. • The name of the facility or other place where the delivery occurred; the city, town or location of birth; the county of birth; if a birthing facility, the facility's National Provider Identification (NPI) or state hospital code; and the type of place where the birth occurred.
Pregnancy Outcome	1	Outcome of the index pregnancy	• This field should always be filled out, except in cases of prenatal diagnosis where the pregnancy has not yet ended. • Live birth, fetal death, termination, unspecified non-live birth, Unknown
Birth Weight	1	Weight (in terms of grams or pounds and ounces) of the infant or fetus at delivery	• Missing values are possible. Attention is needed to ensure the value used for missing, such as 999, is considered when converting between metrics. • If the weight is less than or equal to 227 grams or greater than or equal to 5,000 grams, the weight should be checked.
Plurality	1	Number of fetuses delivered live or dead at any time in the pregnancy	• This field should always be filled out. • An integer greater than 0. Check on any integer greater than 5.
Birth Order	1	Order in which infants of a multiple gestation pregnancy are delivered	• Blank for unknown. • An integer greater than 0. Check on any integer greater than 5. • Must be less than or equal to plurality.
Gestational Age	1	Completed weeks of gestation at the time of delivery, as-derived from prenatal ultrasound, last menstrual period, postnatal exam, etc.	• Gestational age should not be missing if the method of determining gestational age is known. • Any value less than 9 or greater than 44 should be checked. • If Pregnancy Outcome is live birth, gestational age less than 20 weeks should be checked. Program may want to check for consistency with Birth Weight.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Method of Determining Gestational Age	1	Method of calculating completed weeks of gestation	• Should not be missing if gestational age is 20 weeks or more. • Allowable methods can include: prenatal ultrasound with a reported gestational age of less than 14 weeks, date of the last menstrual period, prenatal ultrasound with a reported gestational age of 14 weeks or greater, or clinical examination after delivery.
Diagnosis Code	1	A standard set of letters, numbers or other symbols used to categorize a text description of a diagnosis	• Every case should have at least one birth defect diagnosis code or use standardized missing value codes such as those Vital Records uses for verified missing data. • Each case may have multiple codes; all should have the standard diagnostic code format used by the birth defects program. • Every diagnosis description should have a corresponding code.
Date of Death for a live born infant	1	Date of demise after a live birth. Generally consists of a month, day and year	• This field should only be filled out if the pregnancy outcome is "live birth" and the child is known to have died. If any of the three parts is missing, all known date elements should be recorded, in separate fields if necessary. • The date should include month, day, and year. . • The date of death should be on or after the date of delivery and on or after any date of prenatal diagnostic procedure or prenatal ultrasound.
Underlying Cause of Death	1	A standard set of letters, numbers or other symbols used to categorize a text description of the underlying cause of death.	• The underlying cause of death should not be missing if the Death Certificate ID is non-missing. • Each case may have only one underlying cause code; all codes should meet the cause of death coding standards and format used by the Vital Records program.
Was the infant transferred within 24 hours of delivery?	1	Indication if the live-born infant was transferred from the birthing facility to another facility	• Should not be missing for a live-born infant. • Codes for 'Yes', 'No', and 'Unknown' • Must be 'Yes' if Name of Facility transferred to has a facility name (other than 'Unknown') or code.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Name of transferred facility	1	Name of the facility to which the newborn was transferred (if live born infant was transferred from the birthing facility to another facility within 24 hours of delivery)	• Should not be missing for a transferred infant. • Any valid facility code or name; "Unknown" text or code. Standard facility codes should be used and should include codes for hospitals in bordering States. • Must be a facility name or code (other than 'Unknown') if 'Infant Transferred' is 'Yes'; if 'Infant Transferred' is 'Unknown', must be 'Unknown'. If the infant was not transferred, there should not be a facility name or code.
Infant living at time of report	1	Whether the newborn was living at the time of filing a birth certificate	• Should not be missing for a live-born infant. • Allowable value: 'Yes', 'No', or 'Unknown' • For a live-born infant, this status does not depend on any other data element. If 'No', the program should look for death information.
Mother's Date of Birth	1	Birth mother's date of birth	• If any of the three parts is missing, all known date elements should be recorded, in separate fields if necessary. • The date should include month, day, and year. • Maternal age calculated outside of the range of 12 to 49 years suggests the need for verification. If the mother's date of birth is the same as the father's date of birth, the birth defects program should double check to make certain that this is true.
Mother's Race	1	The race(s) that best describes what the mother considers herself to be.	• Every record should have mother's race recorded except when the mother's identity is unknown (such as when the baby was left at a safe haven or abandoned.) • Racial categories should be compatible with the federal standards in current use for race. More than one racial category may be selected.
Mother's Ethnicity	1	A category of social group that has a common national or cultural tradition; ethnicity is a designation separate from race	• Every record should have the mother's ethnicity recorded except when the mother's identify is unknown (such as when the baby was left at a safe haven or abandoned.) • Ethnic categories should be compatible with NCHS standards in current use for ethnicity. More than one ethnicity category may be selected.
Mother's Name	1	A word or set of words by which the birth mother of an infant/fetus/potential case is known, addressed, or referred to: [e.g.: first, middle, last name(s), suffix]	• Every record must have at least one name for the mother and should have first and last names. To establish the existence of missing names, there should be separate fields. • A woman may have multiple names. • If the mother's last name is hyphenated, both names should be in the last name field.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Mother's Residence at Time of Pregnancy Outcome	1	Geographical location where the mother was living at the time of the outcome of the index pregnancy: street address, city, county, state, and zip code; or equivalent.	• Maternal residence should be the physical address and not a P.O. Box unless there is no physical address in any record for the mother. • If a physical address, there should be separate fields for street address, apartment number, city, county, state, and zip code. • It may be advisable to process data through geocoding software to correct self-reported residency attributes, e.g., zip, county, etc.
Fetal Death Certificate ID	2	Unique number/text assigned to a fetal death certificate and maintained in Vital Records and birth defects programs	• This ID must not be missing if any fetal death data for the non-live born infant are available from Vital Records to the birth defects program. • Allowable value criterion: This ID should not be the same as any Medical Record Number for the mother.
Date of Delivery (for a fetal death)	2	Date of delivery of a fetal death.	• The date should include month, day, and year. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. • The date of fetal death should be after the date of last menstrual period and date of conception.
Diagnostic Tests and Procedures Performed	2	Method(s) used to reach diagnosis	• Each case should have at least one diagnostic test or procedure. • There should be multiple fields for multiple methods used. • If the case has multiple defects, each procedure/description should be associated with the correct diagnosis code and text.
Newborn's Apgar Scores	2	A systematic measure for evaluating the physical condition of the infant at specific intervals following the birth	• The score should be present if the case is a live birth and the infant lived for at least one minute. Depending on the source of the data, there may be one minute, five minute, and ten minute scores. There should be separate field for each Apgar score. • Values range from 0 through 10; there may be a code for unknown/not applicable.
Autopsy Performed	2	Indicates whether an autopsy was conducted	• Should not be missing if the child died. If "Not Applicable" code is used when child is living, should not be missing for any case. • Allowable value: Yes, No, Unknown, Not Applicable [Optional]
Physicians of Record	2	Physician(s) identified as being involved in the medical care of the case	• Missing value is allowed. • Multiple physicians are possible.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
NICU Admission	2	Admission into a neonatal intensive care unit or facility staffed and equipped to provide the most advanced level of care to high-risk newborns	• This data element should be present for all live-born infants. • Allowable value: 'Yes', 'No', 'Unknown'
Name of Responsible Party	2	A word or set of words by which the person taking custody of the child is known (e.g., first, middle, last name(s), suffix)	• This field could be unknown. • This data element should contain at least the first and last name of the responsible party. • If the baby is discharged home with the mother, this data element should match the mother's names. Otherwise, it should be different from the mother's names.
Address of Responsible Party	2	The most recent mailing address of the responsible party: street address, apartment number, city, county state and zip code; or equivalent	• This field could be unknown. • Should be completed if the name of the responsible party is completed.
Telephone Number of Responsible Party	2	Most recent telephone number of the responsible party	• This field could be unknown. • This field should contain a valid phone number, including area code. If applicable, include extension.
Mother's Education	2	The number of years of school completed or the highest degree attained	• Should check if high school graduate or education > 12 years and maternal age < 16 years. Should also check if the number of years exceeds 25.
Prior Live Births Now Living	2	Number of previous live births now living (does not include index child) NOTE: Parity can be calculated by summing: 1) prior live births (LB) now living, 2) prior LB now dead, and 3) prior other pregnancy outcomes.	• When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome of live birth or fetal death. • The value should be a whole integer.
Prior Live Births Now Dead	2	Number of previous live births now dead (does not include index child) NOTE: See parity note within the "prior live births now living" data element.	• When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome of live birth or fetal death. • The value should be a whole integer.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Prior Other Pregnancy Outcomes	2	Number of other pregnancy outcomes (spontaneous or induced losses or ectopic pregnancies) NOTE: Does not include the index pregnancy. See parity note within the "prior LB now living" data element.	• When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome of live birth or fetal death. • The value should be a whole integer.
Month Prenatal Care Began	2	The number of the month in this pregnancy (second, third, fourth, etc.) when the mother first received prenatal care from a physician or other health professional	• Every record should have the month prenatal care began recorded except when the mother's identity is unknown. • Allowable value: 1-9, 0 or code for no prenatal care, unknown
Date of First Prenatal Care Visit	2	Month/day/year when the mother first received prenatal care from a physician or other health professional or attended a prenatal clinic	• The date should include month, day, and year. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. • This date must occur on or before the baby's delivery date, and not more than 10 months or 300 days before the baby's delivery date. It should occur after the conception date and after LMP date.
Date of Last Prenatal Care Visit	2	Month/day/year when the mother last received care from a physician or other health professional or attended a prenatal clinic prior to birth outcome.	• Date; unknown; no prenatal care. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. • This date must occur on or before the baby's delivery date and on or after the date of the first prenatal care visit. This date should not be more than 300 days prior to the delivery date.
Number of Prenatal Visits	2	The number of prenatal care visits by a physician or other health care provider	• The range is 0-70; Missing or Unknown. The number should be checked if it exceeds 42 (one visit per week for about 9 months). • This number should only be 0 if mother had no prenatal care; it should only be 1 if the date of first prenatal care = date of last prenatal care.
Maternal Pre-pregnancy Body Mass Index (BMI)	2	Pre-pregnancy Body Mass Index (BMI) is a number calculated from a person's pre-pregnancy weight and height	• Missing values allowed. • BMI should be checked if it does not range between15 and 45.Weight should be checked if not between 75 pounds (34 kg) and 300 pounds (136 kg); height should be checked if less than 3 feet (0.9 meters) or more than 7 feet (4.2m). BMI at delivery should be greater than pre-pregnancy BMI.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Maternal Body Mass Index (BMI) at Delivery	2	Body Mass Index (BMI) at delivery is a number calculated from a person's weight at delivery and height	• Missing values allowed. • BMI should be checked if it does not range between15 and 45.Weight should be checked if not between 75 pounds (34 kg) and 350 pounds (159 kg); height should be checked if less than 3 feet (0.9 meter) or more than 7 feet (4.2 meters). BMI at delivery should be greater than pre-pregnancy BMI. • This number should be checked if it is less than the pre-pregnancy BMI.
Diabetes, Prepregnancy	2	Diabetes mellitus – glucose intolerance, requiring treatment – before this pregnancy began.	• Allowable value: 'Yes', 'No', 'Unknown' • If Gestational Diabetes is 'Yes', this should be 'No'.
Diabetes, Gestational	2	Diabetes mellitus – glucose intolerance, requiring treatment – during this pregnancy.	• Allowable value: 'Yes', 'No', 'Unknown' • If pre-pregnancy diabetes is 'Yes', this should be 'No'.
Pregnancy Resulting from Infertility Treatment	2	Any assisted reproductive treatment used to initiate this pregnancy, including drugs, artificial insemination, or technical procedures such as in-vitro fertilization.	• Allowable value: 'Yes', 'No', 'Unknown'
Prepregnancy Hypertension (Chronic)	2	Chronic elevation of blood pressure above normal for age and physiological condition that was present prior to pregnancy.	• Allowable value: 'Yes', 'No', 'Unknown' • If Gestational Hypertension/Preeclampsia is 'Yes', this should be 'No'.
Gestational Hypertension (PIH, Preeclampsia)	2	Pregnancy-induced hypertension or hypertension diagnosed in this pregnancy, not before.	• Allowable value: 'Yes', 'No', 'Unknown' • If pre-pregnancy hypertension is 'Yes', this should be 'No'.
Eclampsia	2	Hypertension with proteinuria with generalized seizures or coma; may include pathologic edema.	• Allowable value: 'Yes', 'No', 'Unknown' • If eclampsia is 'Yes', then pre-pregnancy hypertension or gestational hypertension (preeclampsia) – but only one of these —must also be 'Yes'.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Previous Preterm Birth	2	History of pregnancy(ies) resulting in a live birth of less than 37 completed weeks of gestation	• Allowable value: 'Yes', 'No', 'Unknown' • Should be 'No' if previous live births = 0.
Other Previous Poor Pregnancy Outcome	2	A previous poor pregnancy outcome other than preterm birth, including a pregnancy that ended in a perinatal death or gestational age/intrauterine growth abnormalities.	• Allowable value: 'Yes', 'No', 'Unknown' • Should be 'No' if previous live births = 0.
Father's Date of Birth	2	Date father was born.	• Missing values allowed. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. • The date should include month, day, and year. • Paternal age calculated outside of the range of 12 to 60 years suggests the need for verification. If the father's and mother's dates of birth are the same, the birth defects program should verify both dates.
Father's Name	2	A word or set of words by which the birth father of an infant/fetus/potential case is known (e.g., first, middle, last name(s), suffix).	• Missing values allowed. If the birth father's identity is known, there should be two names, generally first and last. To establish the existence of missing names, there should be separate fields. • A man may have multiple names. • If the father's last name is hyphenated, both names should be in the last name field.
Father's Education	2	The number of years of school completed or the highest degree attained	• The program should verify if high school graduate or education > 12 years and paternal age < 16 years. Should also check if total number of years exceeds 25.
Father's Race	2	The race(s) that best describes what the father considers himself to be.	• Missing values allowed. • Racial categories should be compatible with the National Center for Health Statistics (NCHS) standards in current use for race. More than one racial category may be selected.
Father's Ethnicity	2	A category of social group that has a common national or cultural tradition; ethnicity is a designation separate from paternal race.	• Missing values allowed. • Ethnic categories should be compatible with the National Center for Health Statistics (NCHS) standards in current use for ethnicity. More than one ethnicity category may be selected.

Name of Data Element	Required for Standard Level	Definition	Quality Assurance Checks
Description of Prenatal Screening or Diagnostic Procedure	3	Description of prenatal diagnostic procedure to identify signs and symptoms; organ system(s) included in the procedure; the possible birth defect or condition; whether the test was screening, preliminary, or diagnostic.	• Multiple procedure codes are permitted. Codes should conform to the range and format of the coding system used. Codes for screening, examination, or diagnostic procedure should follow an established standard. • There should be at least one procedure code and corresponding text for each procedure. Text should contain key words associated with the codes used.
Date of Prenatal Screening or Diagnostic Procedure	3	Date of prenatal procedure	• Missing value allowed. If any of the three parts of the date is unknown, all known date elements should be recorded, in separate fields if necessary. • The date should include month, day, and year. • The procedure date should be on or before the pregnancy outcome date.
Results of Prenatal Screening or Diagnostic Procedure	3	All available results/findings from tests or procedures to screen, rule out, or diagnose a birth defect.	• There should be at least one procedure code and corresponding text for each procedure. Text should contain key words associated with the codes used.

Detailed Descriptions of Data Elements

General Information on Data Element Descriptions

This section presents information that applies to all or many data element descriptions. Two types of general notes are presented here:

- Format used for all data element descriptions; and
- Definitions of terms used consistently across descriptions.

Format for Descriptions

Name	Name of data collection element
Standard Level	NBDPN Standard Level 1, 2 or 3
Definition	Definition of data collection element
Justification	Reason the birth defects program may want to include element in its database
Data Source	Possible source(s) of the data element, whether it is collected, derived, or created from data sources, and location within data sources where data element is most likely to be consistently found
Type	How the data element should be stored or converted for shared use: text, number, date, alpha numeric, code, checkbox
Quality Assurance Checks	The minimum limits, ranges, or other criteria the element should meet. Criteria used include: *missing value*, *allowable value* and *consistency*.
Comments	Other notes or comments about the element.

Standard Level 1

Infant

Name	***Unique Case ID***
Standard Level	1
Definition	Identification code or number; a code or number that uniquely identifies each case or record.
Justification	With a unique ID code, the birth defects program can refer to a particular case more easily than having to refer to a set of other elements. For example, it is easier to refer to an abstract with ID 1234567 than to an abstract of John Doe, date of birth 04/27/1999, born to mother Jane Doe. The ID permits easy linkage between multiple case reports and/or data sets as long as each report or data set contains the ID as one of its fields. This is essential for data transfer and processing, so that data for a particular case do not get mixed up with data from other cases.
Data Source	Created by the registry as cases are added
Type	Alpha numeric
Quality Assurance Checks	*Missing value criterion:* Every infant/fetus with a birth defect in the database must have a *unique* ID. *Allowable value criterion:* Only one ID per case.

Name ***Date of Delivery (for a live birth)***

Standard Level 1

Definition Date of delivery for a live birth

Justification In conjunction with other fields, such as mother's last name, this field helps to identify a case uniquely.

Data Source May be abstracted from:
- Maternal medical record
- Infant's medical record
- Birth certificate

Type Date

Quality Assurance Checks *Missing value criterion:* Every live birth should have a date of birth.

Allowable value criterion: The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary.

Consistency criterion: The date of delivery for a live birth should be after the date of last menstrual period (LMP) and date of conception.

Comments The birth defects program may require that, for live births, a diagnosis be made within a certain time period after the date of delivery (e.g., within one year) or by a particular age (e.g., prior to age 6). The date of delivery is necessary in order to determine whether the diagnosis was made within the time limit.
Dates should not be missing if any information is available on the birth.

Name	***Gender (Sex)***
Standard Level	1
Definition	Gender (sex) of the infant or fetus
Justification	The birth defects program can use the sex of the infant or fetus in order to evaluate differences in birth defect rates by sex.
Data Source	May be abstracted/derived from: • Maternal medical record • Infant medical record • Vital record
Type	Code
Quality Assurance Checks	*Missing value criterion:* Every record should have sex recorded unless it was not possible to determine upon delivery, e.g. early fetal deaths. *Allowable value criterion:* 'Male', 'Female', 'Ambiguous', 'Unknown'
Comments	If a karyotype was performed, the sex should match the karyotype, except in rare cases of such discordances as XY females and XX males.

Name	***Name***
Standard Level	1
Definition	A word or set of words by which an infant/fetus/potential case is known, addressed, or referred to (e.g.: first, middle, last name(s), suffix).
Justification	The birth defects program should record all of the names for easier record finding, matching, linkage, and de-duplication. The infant's name is helpful when referring the family to care or services.
Data Source	May be abstracted from: • Infant medical record • Vital records
Type	Text
Quality Assurance Checks	*Missing value criterion:* Every case must have at least one name and should have two names, generally first and last. To establish the existence of missing names, there should be separate fields. *Allowable value criteria*: A case may have one or more aliases ("'also known as" or AKA). Multiple names are possible. *Consistency criteria:* If the infant's last name is hyphenated (e.g., the legal name includes the father's last name and the mother's maiden name), both names should be in the last name field.
Comments	Individual field lengths of at least 50 characters are recommended to avoid truncated names. If the name of the infant/case/fetus is the same as the father's or mother's name, or a combination of the two, mismatches in the spelling should be checked. The birth defects program should consider recording all aliases, with a standardized method of identifying the order of their occurrence, to remain current with name use or name changes.

Name	***Source of Report***
Standard Level	1
Definition	A place, person, or thing from which the data were obtained.
Justification	The source of report allows the birth defects program to identify where information in a case abstract comes from. This is important for resolving data edit issues, confirming the data, and conducting audits of facility reporting. The data source fields permit the birth defects program to evaluate the usefulness of specific data sources.
Data Source	Abstracted
Type	Code
Quality Assurance Checks	*Missing value criterion:* This field should not be missing. *Allowable value criterion:* Standard codes (hospitals, clinics, laboratories, autopsy, etc.) unique to each program/organization. Multiple sources are possible for a given case. *Consistency criterion:* Helpful to develop expected number of reports or cases by source of report to identify potential source reporting concerns.
Comments	It is useful to record all data sources for a given case. For example, an infant may be identified with a birth defect at the delivery hospital, tertiary care hospital, cytogenetic laboratory, etc. (see also Chapter 6 on Case Ascertainment Methods). It is useful to maintain a list of potential data sources and standard codes (hospitals, clinics, laboratories, autopsy, etc.), which may be unique to each program.

Name	***Infant's Medical Record Number(s)***
Standard Level	1
Definition	Text and/or numbers used by the source from which the information was obtained to identify an individual who received health care from that organization.
Justification	A medical record number allows facilities to retrieve an individual's records easily. Although it may be possible to locate medical records using the patient's name and date of birth, the birth defects program may have a name different than that recorded at the data source.
Data Source	May be abstracted from: • Infant medical record • Birth certificate
Type	Alpha numeric
Quality Assurance Checks	*Missing value criterion:* The case must have at least one medical record number only if the infant was delivered alive. *Allowable value criteria:* (1) Multiple medical record numbers are possible. Medical record numbers should be different for different sources unless the sources are within a single organization, such as a healthcare consortium. (2) All case medical record numbers must be different from all mother's medical record numbers. The mother's medical record number may be used by the source to identify a fetal death, but would not be allowable in this field.
Comments	Medical record numbers are not the same as visit, service, or encounter numbers. Medical record numbers may be very long. The birth defects program should allow for entry of the entire medical record number. Multiple numbers are likely if the infant received care from more than one organization. Although not standard practice, multiple 'real' medical record numbers may be assigned to the same person, so it is important to identify each number for a given data source and to check for data entry errors such as transpositions.

Name	***Birth Certificate ID***
Standard Level	1
Definition	Unique number/text assigned to a birth certificate and maintained by Vital Records and birth defects programs
Justification	Maintaining this ID in both Vital Records and the birth defects program assures ongoing ability to link to birth records, important because the birth data may be corrected by Vital Records after the first linkage. The birth certificate is the legal, validated, consolidated source for details of the event occurrence.
Data Source	May be abstracted or assigned from: • Vital records • Birth defects program
Type	Alpha numeric
Quality Assurance Checks	*Missing value criterion:* This ID must not be missing if any birth certificate data are available to the birth defects program. *Allowable value criterion:* This ID should not be the same as any Medical Record Number for the newborn or the mother.
Comments	This ID need not be the "Birth Number" or "State File Number," by which the birth is registered in the State where it happened. The birth certificate is a source of data on medical history and health information about the infant and mother that may not be available from other sources because vital records are checked and queried at the local, State, and national levels and corrected or amended by Vital Records as needed.

Name	***Death Certificate ID***
Standard Level	1
Definition	Unique number/text assigned to a death certificate and maintained in Vital Records and birth defects programs
Justification	Maintaining this ID in both Vital Records and the birth defects program assures ongoing ability to link to death records, which is important because certified data may be corrected or amended. For example, Vital Records may change cause of death based on a delayed autopsy. The death certificate is the legal, validated, consolidated source for the occurrence and causes of death including autopsy information, infant's name at time of death, and demographic information about the decedent and family.
Data Source	May be abstracted or assigned from: Vital records Birth defects program
Type	Alpha numeric
Quality Assurance Checks	*Missing value criterion:* This ID must not be missing if any death certificate data are available to the birth defects program. *Allowable value criterion:* This ID should not be the same as any Medical Record Number for the newborn or the mother.
Comments	This ID need not be the "Death Certificate Number" or "State File Number," by which the death is registered in the State where it happened. The death certificate is a validated source of data that may not be available from other sources because death records are checked and queried at the local, State, and national levels and corrected or amended by Vital Records as needed.

Name	***Place of Pregnancy Outcome***
Standard Level	1
Definition	Location where the delivery or pregnancy outcome occurred.
Justification	Mother and infant records at the delivery facility often provide important information not found in tertiary care facility records (unless the delivery records are copied into the tertiary care records). The birth defects program can use the delivery location (hospital, midwifery, residence, etc.) to identify where delivery records need to be reviewed and abstracted. The birth defects program may employ the delivery location in addition to other fields to link to other data sets, such as vital records. This includes those situations where delivery occurs outside of health care facilities as well as inside health care facilities. The location where the delivery occurred allows the birth defects program to provide facility-specific statistics.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Vital record • Attendant (non-facility births only)
Type	Code
Quality Assurance Checks	*Missing value criterion:* This field should always be filled out and must be a valid code. *Allowable value criterion:* The name of the facility where the delivery took place; the city, town or location of birth; the county of birth; the facility's National Provider Identification (NPI) or if no NPI, the state hospital code; and the type of place where the birth occurred. If en-route births, code to the destination facility. If the event occurred in international air space or waters, enter "plane" or "boat."

Name	***Pregnancy Outcome***
Standard Level	1
Definition	Outcome of the index pregnancy, which can include live births, stillbirths, and/or other pregnancy loss, e.g. induced terminations.
Justification	The pregnancy outcome, in conjunction with gestational age fields, may determine whether a record should be included in the birth defects program. Best practices would include birth defect programs distinguishing the outcomes of live birth, fetal death, and induced termination. Part of the mission of the birth defects program may be to refer families to social services. Since only live births would be referred to many of the services, it is important to know whether a given case is a live birth. Knowing which cases are elective terminations aids in evaluating trends in prenatal diagnosis, as well as evaluating the impact of prevention strategies such as folic acid supplementation and fortification.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Code
Quality Assurance Checks	*Missing value criterion:* This field should always be filled out, except in cases of prenatal diagnosis where the pregnancy has not yet ended. *Allowable value criterion:* Live birth, Fetal death, Miscarriages, Termination, Unspecified non-live birth, Unknown
Comments	See Chapter 3 on Case Definition for definitions of pregnancy outcomes.

Name	***Birth Weight***
Standard Level	1
Definition	Weight (in terms of grams or pounds and ounces) of the infant or fetus at delivery.
Justification	The birth weight may be needed for case definition if inclusion/exclusion criteria for selected birth defects, such as for undescended testes and patent ductus arteriosus, are based on birth weight. In conjunction with gestational age, length, and head circumference, birth weight can be used to assess prenatal growth retardation, a characteristic of fetal alcohol syndrome.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* Missing values are possible. Attention is needed to ensure the value used for missing, such as 999, is considered when converting between metrics. *Allowable value criterion:* If the weight is less than or equal to 227 grams or greater than or equal to 5,000 grams, the weight should be checked.
Comments	The data source may report birth weight in grams or kilograms, pounds and ounces, or pounds with decimals. The birth defects program may decide to record the weight in the units reported or in a uniform fashion, such as always as grams and kilograms. In this latter case, the birth defects program must be able to convert from one type of unit to another while collecting the data. Data fields can have computerized calculation functions.

Name	***Plurality***
Standard Level	1
Definition	The number of fetuses delivered live or dead at any time in the pregnancy regardless of gestational age or if the fetuses were delivered at different dates in the pregnancy. ("Reabsorbed" fetuses, those which are not "delivered" (expulsed or extracted from the mother) should not be counted.)
Justification	The plurality, in association with other fields such as county of residence and mother's social security number, can be used to avoid duplication of records in the birth defects program.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* This field should always be filled out. *Allowable value criterion:* This should either be a whole number of 1 or more.
Comments	Because some twin pregnancies are anomalous, such as conjoined twins, there may not be the expected two vital records for a pregnancy that is identified as a twin pregnancy.

Name	***Birth Order***
Standard Level	1
Definition	The order in which infants of a multiple gestation pregnancy are delivered. If not single birth, specify born 1st, 2nd, etc. For multiple deliveries, the order this infant was delivered in the set. Include all live births and fetal losses.
Justification	The birth order, recorded on Birth and Fetal Death certificates, can be useful for linkage with the correct vital record in cases of multiple gestation pregnancies, especially if delivery records do not refer to the infants or fetuses by name.
Data Source	May be abstracted from: • Infant medical record • Birth certificate worksheet • Birth Certificate
Type	Number
Quality Assurance Checks	*Missing value criterion:* Blank for unknown. *Allowable value criterion:* An integer greater than 0. Check on any integer greater than 5. *Consistency criteria:* Must be less than or equal to plurality.

Name	***Gestational Age***
Standard Level	1
Definition	Completed weeks of gestation at the time of delivery, as-derived from prenatal ultrasound, last menstrual period, postnatal exam, etc.
Justification	Gestational age can be used to determine whether a pregnancy outcome meets the case definition for the birth defects program. Certain diagnoses may be considered birth defects only when the infant is of a particular gestational age. For example, patent ductus arteriosus is common among premature infants and is often subject to exclusion criteria before being counted as a birth defect.
Data Source	May be abstracted/derived from: • Maternal medical record • Infant medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* Gestational Age should not be missing if the Method of Determining Gestational Age is known. *Allowable value criterion:* Any value less than 9 or greater than 44 should be checked. *Consistency criteria:* If Pregnancy Outcome is live birth, gestational age less than 20 weeks should be checked. Program may want to check for consistency with Birth Weight.
Comments	The gestational age can be derived via several methods, and conflicting gestational age information may be reported in the medical record (Alexander et al., 1990; Hall, 1990). As a result, the birth defects program will want to have a method for prioritizing gestational age estimates from different sources. See Chapter 3 on Case Definition for further information.

Name	***Method of Determining Gestational Age***
Standard Level	1
Definition	Method of calculating completed weeks of gestation.
Justification	Given the importance of gestational age to ascertainment of some birth defect cases, it is also important to know how precise the age determination might be, which varies by the method of calculation.
Data Source	May be abstracted/derived from: • Maternal medical record • Infant medical record • Vital records
Type	Code or Check-box
Quality Assurance Checks	*Missing value criterion*: Should not be missing if gestational age is 20 weeks or more. *Allowable value criterion:* Allowable methods can include: prenatal ultrasound with a reported gestational age of less than 14 weeks, date of the last menstrual period (LMP), prenatal ultrasound with a reported gestational age of 14 weeks or greater, or clinical examination after delivery.
Comments	The birth defects program may want to establish an order of preference for method of calculation. If calculation occurs during pregnancy, ultrasound measurement at less than 14 weeks may be the preferred method. If applicable, date of in vitro fertilization or artificial insemination may be the preferred method. Other methods are reported date of last menstrual period, ultrasound at 14 weeks or greater, and clinical examination. See also NBDPN Surveillance Guidelines Manual, Chapter 3.

Name	***Diagnosis Code***
Standard Level	1
Definition	A standard set of letters, numbers or other symbols used to categorize a text description of a diagnosis.
Justification	Coding birth defects eliminates the need to sort through slightly differing descriptions of the same defect and differentiates defects within the same organ system. Thus, coding allows for timely and efficient analyses of data and identification of cases for research and referral.
Data Source	May be collected/derived from: • Infant medical record • Provider or laboratory reports • Administrative data sets, e.g., Vital records, hospital discharge
Type	Code
Quality Assurance Checks	*Missing value criterion:* Every case should have at least one birth defect diagnosis code or use standardized missing value codes such as those Vital Records uses for verified missing data. *Allowable value criterion:* Each case may have multiple codes; all should have the standard diagnostic code format used by the birth defects program. *Consistency criterion:* Every diagnosis description should have a corresponding code.
Comments	The registry should accommodate a minimum of 20 unique diagnostic codes per case. Standardized coding systems include the International Classification of Disease (ICD) and the CDC's 6-digit code. See Chapter 5 on Classification and Coding for further information.

Name	***Date of Death for a Live Born Infant***
Standard Level	1
Definition	Date of demise after a live birth. Generally consists of a month, day and year
Justification	The date of death permits the birth defects program to know that most postnatal procedures will not occur after this date, the exceptions being such procedures as autopsies, cytogenetic analyses, and other laboratory analyses. The delivery date for a live birth along with the date of death can be used to determine length of survival and appropriate follow-up contact.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Vital records
Type	Date
Quality Assurance Checks	*Missing value criterion:* This field should only be filled out if the pregnancy outcome is "live birth" and the live born child is known to have died. If any of the three parts is missing, all known date elements should be recorded, in separate fields if necessary. *Allowable value criterion:* The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). *Consistency criterion:* The date of death should be on or after the date of delivery and on or after any date of prenatal diagnostic procedure or prenatal ultrasound.
Comment	When applicable, this field can be used to for date of death beyond infancy.

Name	***Underlying Cause of Death***
Standard Level	1
Definition	A standard set of letters, numbers or other symbols used to categorize a text description of the underlying cause of death.
Justification	Understanding categories of mortality among persons with birth defects contributes to epidemiologic goals of understanding trends, risk factors, and co-morbidities associated with birth defects.
Data Source	May be abstracted from: • Death certificate data
Type	Code
Quality Assurance Checks	*Missing value criterion:* The underlying cause of death should not be missing if the Death Certificate ID is non-missing. *Allowable value criterion:* Each case may have only one underlying cause code; all codes should meet the cause of death coding standards and format used by the Vital Records program.
Comments	When applicable, this field can be used for cause of death beyond infancy. Standardized coding systems should be based on the International Classification of Disease (ICD) codes used in the health care delivery system and by Vital Records and should be convertible to the ICD edition that NCHS uses.

Name	***Was infant transferred within 24 hours of delivery?***
Standard Level	1
Definition	The transfer status of the infant is "Yes" if the live-born infant was transferred from the birthing facility to another facility (generally a hospital with a higher level of newborn care) within 24 hours of delivery.
Justification	This status flags a high-risk condition and may lead to identification of another hospital that has data on the newborn.
Data Source	May be abstracted from: • Birth certificate • Infant medical record • Transfer record
Type	Code
Quality Assurance Checks	*Missing value criterion:* Should not be missing for a live-born infant. *Allowable value criterion:* Codes for 'Yes', 'No', and 'Unknown' *Consistency criteria:* Must be 'Yes' if Name of Facility transferred to has a facility name (other than 'Unknown') or code.
Comments	If abstracted from the birth certificate record, this will be "unknown" if the facility to which the newborn was transferred is unknown.

Name	***Name of transferred facility***
Standard Level	1
Definition	If live born infant was transferred from the birthing facility to another facility within 24 hours of delivery, the name of the facility to which the newborn was transferred. If the live-born infant was transferred more than once, the name of the first facility to which the infant was transferred.
Justification	This status flags a high-risk condition and may lead to identification of another hospital that has data on the newborn.
Data Source	May be abstracted from: • Birth certificate • Infant medical record • Transfer record
Type	Code or Text
Quality Assurance Checks	*Missing value criterion:* Should not be missing for a transferred infant. *Allowable value criterion:* Any valid facility code or name; "Unknown" text or code. Standard facility codes should be used and should include codes for hospitals in bordering States. *Consistency criteria:* Must be a facility name or code (other than 'Unknown') if 'Infant Transferred' is 'Yes'; if 'Infant Transferred' is 'Unknown', must be 'Unknown'. If the infant was not transferred, there should not be a facility name or code.

Name	***Infant living at time of report***
Standard Level	1
Definition	Indicates whether the newborn was living at the time of filing a birth certificate
Justification	The program should check the vital status of an infant. If infant is not living at time of report, the program should check for a death record. Knowing that an infant has died helps inform referral activities.
Data Source	May be abstracted from: • Vital records
Type	Code
Quality Assurance Checks	*Missing value criterion:* Should not be missing for a live-born infant. *Allowable value criterion:* 'Yes', 'No', or 'Unknown' *Consistency criteria:* For a live-born infant, this status does not depend on any other data element. If 'No', the program should look for death information.
Comments	Note that this information is not intended to agree with any subsequent report of the death that Vital Records maintains on the electronic birth certificate and does not include any registered (legal) cause of death information.

Mother

Name	***Mother's Date of Birth***
Standard Level	1
Definition	Birth mother's date of birth
Justification	Mother's date of birth can be used to facilitate matching with other data sources. The birth defects program can use the mother's date of birth and infant's date of delivery to calculate the mother's age at delivery, which can be used in clinical review, demographic reporting, and research on the relationship between age of mother and birth defects.
Source	May be abstracted from: • Maternal medical record • Infant medical record • Birth certificate worksheet • Birth certificate
Type	Date
Quality Assurance Checks	*Missing value criterion:* If any of the three parts is missing, all known date elements should be recorded, in separate fields if necessary. *Allowable value criterion:* The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). *Consistency criteria:* (1) Maternal age calculated outside of the range of 12 to 49 years suggests the need for verification. (2) Medical records may sometimes confuse maternal and paternal information. If the mother's date of birth is the same as the father's date of birth, the birth defects program should double check to make certain that this is true.
Comments	See also Chapter 6 on Case Ascertainment Methods, the section on Data Sources.

Name	***Mother's Race***
Standard Level	1
Definition	The race(s) that best describes what the mother considers herself to be.
Justification	The birth defects program can use the mother's race in order to present data on birth defect rates by maternal race in descriptive epidemiology.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Vital certificate
Type	Code
Quality Assurance Checks	*Missing value criterion:* Every record should have mother's race recorded except when the mother's identity is unknown (such as when the baby was left at a safe haven or abandoned.) *Allowable value criterion:* Racial categories should be compatible with the National Center on Health Statistics (NCHS) standards in current use for race. More than one racial category may be selected.

Name	***Mother's Ethnicity***
Standard Level	1
Definition	A category of social group that has a common national or cultural tradition
Justification	Ethnicity is a designation separate from maternal race. The birth defects program can use the Maternal ethnicity in order to evaluate differences in birth defect rates by mother's ethnicity.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Birth certificate
Type	Code
Quality Assurance Checks	*Missing value criterion:* Every record should have the mother's ethnicity recorded except when the mother's identify is unknown (such as when the baby was left at a safe haven or abandoned.) *Allowable value criterion:* Ethnic categories should be compatible with the the National Center on Health Statistics (NCHS) standards in current use for ethnicity. More than one ethnicity category may be selected.
Comments	Ethnicity data need not be limited to NCHS standard categories. The registry should be able to monitor the health of ethnic populations of special interest to the health of the public in its catchment area, as long as data can be aggregated into standard categories.

Name	***Mother's Name***
Standard Level	1
Definition	A word or set of words by which the birth mother of an infant/fetus/potential case is known, addressed, or referred to: [e.g.: first, middle, last name(s), suffix].
Justification	The birth defects program should record all of the names – with separate fields for first, middle, last, maiden, and suffix (if used) – for easier record finding, matching, linkage, and de-duplication.
Data Source	May be abstracted from: • Maternal medical record • Infant medical record • Vital records
Type	Text
Quality Assurance Checks	*Missing value criterion:* Every record must have at least one name for the mother and should have first and last names except when the mother's identity is unknown (such as when the baby was left at a safe haven or abandoned). To establish the existence of missing names, there should be separate fields for different names. *Allowable value criterion:* A woman may have one or more aliases ("also known as" or AKA). Multiple names are possible. *Consistency criterion:* If the mother's last name is hyphenated (e.g., her legal name includes her married and maiden names), both names should be in the last name field.
Comments	Individual field length of 50 characters is recommended to avoid truncated names. The program should be aware of the handling of parents' names in cases of adoption.

Name	***Mother's Residence at Time of Pregnancy Outcome***
Standard Level	1
Definition	The geographical location where the mother was living at the time of the outcome of the index pregnancy: street address, city, county, state, and zip code; or equivalent.
Justification	Geographical location is needed to determine if a case falls within the program's catchment area and for descriptive epidemiology.
Source	May be abstracted from: • Maternal medical record • Infant medical record • Birth certificate
Type	Code or text
Quality Assurance Checks	*Missing value criterion:* Maternal residence should be the physical address, not the mailing address if they are different and not a P.O. Box unless there is no physical address in any record for the mother. *Allowable value criteria:* If a physical address, there should be separate fields for street address, apartment number, city, county, state, and zip code. *Consistency criterion:* It may be advisable to process data through geocoding software to correct self-reported residency attributes, e.g., zip, county, etc.

Standard Level 2

Infant

Name	***Fetal Death Certificate/Report ID Number***
Standard Level	2
Definition	Identification code or number that uniquely identifies a fetal death. Unique number/text assigned to a fetal death certificate/report and maintained by Vital Records and birth defects programs
Justification	Maintaining this ID in both Vital Records and the birth defects program assures ongoing ability to link to fetal death records, important because the fetal death data may be corrected (e.g., autopsy report) by Vital Records after the first linkage.
Data Source	May be abstracted or assigned from: • Vital records • Birth defects program
Type	Alpha numeric
Quality Assurance Checks	*Missing value criterion:* This ID must not be missing if any fetal death data for the non-live born infant are available from Vital Records to the birth defects program. *Allowable value criterion:* This ID should not be the same as any Medical Record Number for the mother.
Comments	This ID need not be the "State File Number" by which the fetal death is registered in the State where it happened.

Name	***Date of Delivery (for a fetal death)***
Standard Level	2
Definition	Date of delivery of a fetal death ‘‘Fetal death’’ means death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy and which is not an induced termination of pregnancy.
Justification	In conjunction with other fields, such as mother’s last name, this field helps to identify a case uniquely.
Data Source	May be abstracted from: • Maternal medical record • Fetal death certificate
Type	Date
Quality Assurance Checks	*Allowable value criterion:* The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. *Consistency criterion:* The date of fetal death should be after the date of last menstrual period and date of conception.
Comments	Birth defects programs should use the current revision of the Model State Vital Statistics Act and Regulation: ‘‘Each fetal death of 350 grams or more, or if weight is unknown, of 20 completed weeks gestation or more…”

Name	***Diagnostic tests and procedures performed***
Standard Level	2
Definition	Method(s) used to reach diagnosis
Justification	To determine the certainty of a diagnosis
Source	May be abstracted from: • Infant medical record • Maternal medical record
Type	Code or text
Quality Assurance Checks	*Missing value criterion:* Each case should have at least one diagnostic test or procedure. *Allowable value criterion:* There should be multiple fields for multiple methods used. *Consistency criteria:* If the case has multiple defects, each procedure/description should be associated with the correct diagnosis code and text.
Comments	All methods should be recorded when possible. Examples include: echocardiogram, genetic tests, physician's notes, ultrasound, and autopsy. Among the multiple methods recorded, the most certain method should be indicated using a specific hierarchy based on diagnostic accuracy.

Name	***Newborn's Apgar Scores***
Standard Level	2
Definition	A systematic measure for evaluating the physical condition of the infant at specific intervals following the birth.
Justification	Apgar scores are a gross measure of early neonatal health or health risks.
Source	May be abstracted from: • Infant medical record • Birth certificate work sheet • Birth certificate
Type	Code
Quality Assurance Checks	*Missing value criteria:* The score should be present if the case is a live birth and the infant lived for at least one minute. Depending on the source of the data, there may be one minute, five minute, and ten minute scores. There should be separate field for each Apgar score. *Allowable value criteria*: Values range from 0 through 10; there may be a code for unknown/not applicable.
Comments	If the last score recorded is lower than 4, the birth defect program may want to check that the infant is still living before contacting the family/responsible party.

Name	***Autopsy Performed***
Standard Level	2
Definition	Indicates whether an autopsy was conducted.
Justification	Knowing whether an autopsy was performed will identify an additional data source.
Data Source	May be abstracted from: • Infant medical record • Death certificate, fetal death report
Type	Code
Quality Assurance Checks	*Missing value criterion:* Should not be missing if the child died. If "Not Applicable" code is used when child is living, should not be missing for any case. *Allowable value criterion:* Yes, No, Unknown, Not Applicable [Optional]

Name	***Physicians of Record***
Standard Level	2
Definition	Physician(s) identified as being involved in the medical care of the case
Justification	Information on the physicians of record may be used to obtain additional information or for outreach.
Data Source	May be abstracted from: • Infant medical record • Newborn metabolic screening data • Vital records
Type	Text
Quality Assurance Checks	*Missing value criterion:* Missing value is allowed. *Allowable value criterion:* Multiple physicians are possible.
Comments	If possible, include the physician's name, contact information, specialty and standardized information, such as NPI. Individual field length of 50 characters is recommended to avoid truncated names.

Name	***NICU Admission***
Standard Level	2
Definition	Admission into a neonatal intensive care unit or facility staffed and equipped to provide the most advanced level of care to high-risk newborns.
Justification	NICU admission is an indicator of a high-risk newborn and there may be additional information separate from the delivery record.
Data Source	May be abstracted from: • Infant's records • Birth certificate
Type	Code
Quality Assurance Checks	*Missing value criterion:* This data element should be present for all live-born infants. *Allowable value criterion:* 'Yes', 'No', 'Unknown'
Comment	NICU admission could include transfers.

Name	***Name of Responsible Party***
Standard Level	2
Definition	A word or set of words by which the person taking custody of the child is known (e.g., first, middle, last name(s), suffix)
Justification	Useful for programs to know who has custody of the child, such as programs that refer a family to services
Data Source	May be abstracted from: • Infant medical record • Vital records • Other administrative database, e.g., immunization registry, metabolic screening database
Type	Text
Data Assurance Checks	*Missing value criterion:* This field could be unknown. *Allowable value criterion:* This data element should contain at least the first and last name of the responsible party. *Consistency Criterion:* If the baby is discharged home with the mother, this data element should match the mother's names. Otherwise, it should be different from the mother's names.
Comments	The birth defects program should record all of the names – with separate fields for first, middle, last, and suffix or degree (if used) – for easier record finding, matching, or linkage. Multiple names are possible where a couple takes custody of a child. Individual field lengths of at least 50 characters are recommended to avoid truncated names.

Name	***Address of Responsible Party***
Standard Level	2
Definition	The most recent mailing address of the responsible party: street address, apartment number, city, county, state and zip code; or equivalent.
Justification	Useful for contacting the responsible party
Data Source	May be abstracted from: • Infant medical record • Vital records • Other administrative database, e.g., immunization registry, metabolic screening database
Type	Text
Quality Assurance Checks	*Missing value criterion:* This field could be unknown. *Consistency Criterion:* Should be completed if the name of the responsible party is completed.
Comments	There should be separate fields for the street address, apartment number, city, state, and zip code of sufficient length that no street or city name is truncated.

Name	***Telephone Number of Responsible Party***
Standard Level	2
Definition	Most recent telephone number of the responsible party
Justification	Useful for contacting the responsible party
Data Source	May be abstracted from: • Infant medical record • Vital records • Other administrative database, e.g., immunization registry, metabolic screening database
Type	Numeric or text
Quality Assurance Checks	*Missing value criterion:* This field could be unknown. *Consistency Criterion:* Should be completed if the name of the responsible party is completed. *Allowable value criterion:* This field should contain a valid phone number, including area code. If applicable, include extension.

Mother

Name	***Mother's Education***
Standard Level	2
Definition	The number of years of school completed or the highest degree attained
Justification	Education can be used as an indicator of socioeconomic status (SES). Collecting maternal education would allow the birth defects program to evaluate its relationship to birth defect risk.
Data Source	May be abstracted from: • Birth certificate worksheet • Birth certificate, fetal death report/certificate
Type	Code or text
Quality Assurance Checks	*Consistency criterion*: Should check if high school graduate or education > 12 years and maternal age < 16 years. Should also check if the number of years exceeds 25.

Name	***Prior Live Births Now Living*** (Previously collected as one data element "prior pregnancy history")
Standard Level	2
Definition	Number of prior live births now living to the birth mother. Does not include the index pregnancy.
Justification	Information can be used to identify women for whom the index pregnancy is not the first pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome. *Allowable value criteria:* The value should be a whole integer.
Comment	For prior pregnancy history, this is now captured in multiple fields: 1) Prior live births now living 2) Prior live births now dead (prior history of fetal loss, if any, is not counted in this data element) 3) Prior other pregnancy outcomes (prior history of infant or child death before this case pregnancy) The parity can be calculated by adding these three fields together.

Name	***Prior Live Births Now Dead*** (Previously collected as one data element "prior pregnancy history")
Standard Level	2
Definition	Number of prior live births now dead to the birth mother. Does not include the index pregnancy.
Justification	Information can be used to identify women with a history of live born infants who died, women for whom the index pregnancy is not the first pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome. *Allowable value criteria:* The value should be a whole integer.
Comments	For prior pregnancy history, this is now captured in multiple fields: 4) Prior live births now living 5) Prior live births now dead (prior history of fetal loss, if any, is not counted in this data element) 6) Prior other pregnancy outcomes (prior history of infant or child death before this case pregnancy) The parity can be calculated by adding these three fields together.

Name	***Prior Other Pregnancy Outcomes*** (Previously collected as one data element "prior pregnancy history")
Standard Level	2
Definition	Number of other pregnancy outcomes (spontaneous or induced losses or ectopic pregnancies) prior to the index pregnancy.
Justification	Information can be used to identify women with a history of fetal loss, and women for whom the index pregnancy is not the first pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* When the mother's identity is known, pregnancy history should be known for every case with a pregnancy outcome of live birth or fetal death. *Allowable value criteria:* The value should be a whole integer.
Comments	For prior pregnancy history, this is is now captured in multiple fields: 1) Prior live births now living 2) Prior live births now dead (prior history of fetal loss, if any, is not counted in this data element) 3) Prior other pregnancy outcomes (prior history of infant or child death before this case pregnancy) The parity can be calculated by adding these three fields together.

Name	***Month Prenatal Care Began***
Standard Level	2
Definition	The number of the month in this pregnancy (second, third, fourth, etc.) when the mother first received prenatal care from a physician or other health professional
Justification	Identify level of prenatal care women received during pregnancy
Data Source	Sources: • Maternal medical record • Vital records
Type	Code or number
Quality Assurance Checks	*Missing value criterion:* Every record should have the month prenatal care began recorded except when the mother's identity is unknown. *Allowable value criterion:* 1-9, 0 or code for no prenatal care, unknown
Comment	Sometimes this is calculated based on date of delivery and date of first prenatal visit. If calculated value, program should use a standard method. A program can collect either the 'month prenatal care began' or 'date of first prenatal care visit'.

Name	***Date of First Prenatal Care Visit***
Standard Level	2
Definition	Month/day/year when the mother first received prenatal care from a physician or other health professional or attended a prenatal clinic
Justification	To determine the level of prenatal care women received during pregnancy
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Date
Quality Assurance Checks	*Allowable value criterion:* Date; unknown; no prenatal care. The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. *Consistency Criteria:* (1) This date must occur on or before the baby's delivery date, and not more than 10 months or 300 days before the baby's delivery date. (2) It should occur after the conception date and after LMP date.
Comment	A program can collect either the 'month prenatal care began' or 'date of first prenatal care visit'.

Name	***Date of Last Prenatal Care Visit***
Standard Level	2
Definition	Month/day/year when the mother last received care from a physician or other health professional or attended a prenatal clinic prior to birth outcome.
Justification	Information can contribute to measures of the appropriateness of prenatal care women received during pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Date
Quality Assurance Checks	*Allowable value criterion:* Date; unknown; no prenatal care. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). If day is unknown, month and year should be recorded, in separate fields if necessary. *Consistency Criterion:* (1) This date must occur on or before the baby's delivery date and on or after the date of the first prenatal care visit. (2) This date should not be more than 300 days prior to the delivery date.

Name	***Number of Prenatal Visits***
Standard Level	2
Definition	The number of prenatal care visits to a physician or other health care provider
Justification	Information can contribute to measures of the appropriateness of prenatal care women received during pregnancy
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Number
Quality Assurance Checks	*Allowable value criterion:* The range is 0-70; Missing or Unknown. The number should be checked if it exceeds 42 (one visit per week for about 9 months). *Consistency Criterion:* This number should only be 0 if mother had no prenatal care; it should only be 1 if the date of first prenatal care visit = date of last prenatal care visit.

Name	***Maternal Pre-pregnancy Body Mass Index (BMI)***
Standard Level	2
Definition	Pre-pregnancy Body Mass Index (BMI) is a number calculated from a person's pre-pregnancy weight and height.
Justification	BMI provides a reliable indicator of body fatness for most people and is used to screen for and study the effects of health problems related to weight.
Data Source	Abstracted or calculated based on height and pre-pregnancy weight from: • Maternal medical record • Vital Records
Type	Number
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. *Allowable value criterion:* BMI should be checked if it does not range between15 and 45.Weight should be checked if not between 75 pounds (34 kg) and 300 pounds (136 kg); height should be checked if less than 3 feet (0.9 meters) or more than 7 feet (4.2m). BMI at delivery should be greater than pre-pregnancy BMI.
Comments	Should record pre-pregnancy weight even if height unknown. BMI can be calculated as: 1) Maternal pre-pregnancy weight in kilograms/height in meters squared; or 2) [weight in pounds/height in inches squared] x 703.

Name	***Maternal Body Mass Index (BMI) at Delivery***
Standard Level	2
Definition	Body Mass Index (BMI) at delivery is a number calculated from a person's weight at delivery and height.
Justification	BMI provides a reliable indicator of body fatness for most people and is used to screen for and study the effects of health problems related to weight.
Data Source	Abstracted or calculated based on height and mother's weight at delivery from: • Maternal medical record • Birth certificate worksheet • Vital records
Type	Number
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. *Allowable value criterion:* BMI should be checked if it does not range between15 and 45.Weight should be checked if not between 75 pounds (34 kg) and 350 pounds (159 kg); height should be checked if less than 3 feet (0.9 meter) or more than 7 feet (4.2 meters). BMI at delivery should be greater than pre-pregnancy BMI. *Consistency Criterion:* This number should be checked if it is less than the pre-pregnancy BMI.
Comments	Should record delivery weight even if height unknown. BMI can be calculated as: 1) mother's delivery weight in kilograms/height in meters squared; or 2) [weight in pounds/height in inches squared] x 703.

Name	***Diabetes, Prepregnancy***
Standard Level	2
Definition	Diabetes mellitus – glucose intolerance, requiring treatment – before this pregnancy began.
Justification	This condition can affect the mother's health during the pregnancy and may have an effect on the pregnancy outcome.
Data Source	May be abstracted from: • Maternal medical record • Birth certificate worksheet • Vital Records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* If Gestational Diabetes is 'Yes', this should be 'No'.

Name	***Diabetes, Gestational***
Standard Level	2
Definition	Diabetes mellitus – glucose intolerance, requiring treatment – during this pregnancy.
Justification	This condition can affect the mother's health during the pregnancy and may have an effect on the pregnancy outcome.
Data Source	May be abstracted from: • Maternal medical record • Birth certificate worksheet • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* If pre-pregnancy diabetes is 'Yes', this should be 'No'.

Name	***Pregnancy Resulting from Infertility Treatment***
Standard Level	2
Definition	Any assisted reproductive treatment used to initiate this pregnancy, including drugs, artificial insemination, or technical procedures such as in-vitro fertilization.
Justification	Information can contribute to measures of the mother's health at time of pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Vital records • Specialty reports, e.g., fertility specialist
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown'
Comments	If possible, specify infertility treatment, e.g. artificial insemination or intra-uterine insemination, assisted reproductive technology with or without intracytoplasmic sperm injection, fertility drug and name, etc.

Name	***Pre-pregnancy Hypertension (Chronic)***
Standard Level	2
Definition	Chronic elevation of blood pressure above normal for age and physiological condition that was present prior to pregnancy.
Justification	Measure of mother's health that may affect pregnancy outcome.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* If Gestational Hypertension/Preeclampsia is 'Yes', this should be 'No'.

Name	***Gestational Hypertension (PIH, Preeclampsia)***
Standard Level	2
Definition	Pregnancy-induced hypertension or hypertension diagnosed in this pregnancy, not before.
Justification	Measure of mother's health that may affect pregnancy outcome.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* If pre-pregnancy hypertension is 'Yes', this should be 'No'.

Name	***Eclampsia***
Standard Level	2
Definition	Hypertension with proteinuria with generalized seizures or coma; may include pathologic edema.
Justification	Information can contribute to measures of the mother's health at time of pregnancy.
Data Source	May be abstracted from: • Maternal medical record • Birth certificate worksheet • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* If eclampsia is 'Yes', then pre-pregnancy hypertension or gestational hypertension (preeclampsia) – but only one of these —must also be 'Yes'.

Name	***Previous Preterm Birth***
Standard Level	2
Definition	History of pregnancy(ies) resulting in a live birth of less than 37 completed weeks of gestation
Justification	Information can be used to identify women with a history of previous preterm birth.
Data Source	May be abstracted from: • Maternal medical record • Birth certificate worksheet • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* Should be 'No' if previous live births = 0.

Name	***Other Previous Poor Pregnancy Outcome***
Standard Level	2
Definition	A previous poor pregnancy outcome other than preterm birth, including a pregnancy that ended in a perinatal death or gestational age/intrauterine growth abnormalities.
Justification	Information can be used to identify women with a history of poor birth outcomes.
Data Source	May be abstracted from: • Maternal medical record • Vital records
Type	Code or text
Quality Assurance Checks	*Allowable value criterion:* 'Yes', 'No', 'Unknown' *Consistency Criterion:* Should be 'No' if previous live births = 0.

Father

Name	***Father's Date of Birth***
Standard Level	2
Definition	Date father was born.
Justification	Demographics
Data Source	May be abstracted from: • Medical record • Birth certificate worksheet • Birth or fetal death records
Type	Date
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. If any of the three parts is unknown, all known date elements should be recorded, in separate fields if necessary. *Allowable value criterion:* The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). *Consistency criteria:* (1) Paternal age calculated outside of the range of 12 to 60 years suggests the need for verification. (2) If the father's and mother's dates of birth are the same, the birth defects program should verify both dates.

Name	***Father's Name***
Standard Level	2
Definition	A word or set of words by which the birth father of an infant/fetus/potential case is known (e.g., first, middle, last name(s), suffix).
Justification	Linkage and deduplication
Data Source	May be abstracted from: • Vital records • Maternal medical record • Birth certificate worksheet • Infant medical record
Type	Text
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. If the birth father's identity is known, there should be two names, generally first and last. To establish the existence of missing names, there should be separate fields. *Allowable value criterion:* A man may have one or more aliases ("also known as" or AKA). Multiple names are possible. *Consistency criterion:* If the father's last name is hyphenated (e.g., his legal name includes two parental family names), both names should be in the last name field.
Comments	Individual field lengths of 50 characters are recommended to avoid truncated names.

Name	***Father's Education***
Standard Level	2
Definition	The number of years of school completed or the highest degree attained
Justification	Demographic
Data Source	May be abstracted from: • Vital records • Birth certificate worksheet
Type	Code or text
Data Assurance Checks	*Consistency criteria:* The program should verify if high school graduate or education > 12 years and paternal age < 16 years. Should also check if total number of years exceeds 25.

Name	***Father's Race***
Standard Level	2
Definition	The race(s) that best describes what the father considers himself to be.
Justification	The birth defects program can use the birth father's race in descriptive epidemiology.
Data Sources	May be abstracted from: • Vital records • Infant medical record • Maternal medical record
Type	Code
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. *Allowable value criterion:* Racial categories should be compatible with the National Center for Health Statistics (NCHS) standards in current use for race. More than one racial category may be selected.

Name	***Father's Ethnicity***
Standard Level	2
Definition	A category of social group that has a common national or cultural tradition; ethnicity is a designation separate from paternal race.
Justification	The birth defects program can use the father's ethnicity in descriptive epidemiology and research.
Data Source	May be abstracted from: Vital records Infant medical record Maternal medical record
Type	Code
Quality Assurance Checks	*Missing value criterion:* Missing values allowed. *Allowable value criterion:* Ethnic categories should be compatible with the National Center for Health Statistics (NCHS) standards in current use for ethnicity. More than one ethnicity category may be selected.
Comments	Ethnicity data need not be limited to National Center on Health Statistics (NCHS) categories. The birth defects program should be able to monitor the health of ethnic populations of special interest to the health of the public in its catchment area, as long as data can be aggregated into standard categories.

Standard Level 3

Name	***Description of Prenatal Screening or Diagnostic Procedure***
Standard Level	3
Definition	Description of prenatal diagnostic procedure to identify signs and symptoms; organ system(s) included in the procedure; the possible birth defect or condition; whether the test was screening, preliminary, or diagnostic.
Justification	This information is useful for case-finding and to alert the program of potential cases.
Data Source	May be abstracted from: • Outpatient or hospital medical records • Specialty or sub-specialty records, e.g. such as genetics clinics, perinatologists, maternal-fetal medicine or high-risk obstetric specialists • Records from prenatal diagnostic facilities • Laboratory reports, e.g. cytogenetic labs
Type	Code or text
Quality Assurance Checks	*Allowable value criteria:* Multiple procedure codes are permitted. Codes should conform to the range and format of the coding system used. Codes for screening, examination, or diagnostic procedure should follow an established standard. *Consistency criteria:* There should be at least one procedure code and corresponding text for each procedure. Text should contain key words associated with the codes used.
Comments	The locations where defects are diagnosed prenatally can vary widely across states and within a state, region, or other surveillance area. These may or may not be the same sites where pregnancies are electively terminated after a prenatal diagnosis is made. Refer to Chapter 12 (Inclusion of Prenatal Diagnoses in Birth Defects Surveillance) of the *NBDPN Guidelines for Conducting Birth Defects Surveillance* for additional details.

Name	***Date of Prenatal Screening or Diagnostic Procedure***
Standard Level	3
Definition	Date of prenatal procedure
Justification	This information is useful for case-finding and to alert the program of potential cases.
Data Source	May be abstracted from: • Outpatient or hospital medical records • Specialty or sub-specialty records, e.g. such as genetics clinics, perinatologists, maternal-fetal medicine or high-risk obstetric specialists • Records from prenatal diagnostic facilities • Laboratory reports, e.g. cytogenetic labs
Type	Date
Quality Assurance Checks	*Missing value criterion:* Missing value allowed. If any of the three parts of the date is unknown, all known date elements should be recorded, in separate fields if necessary. *Allowable value criterion:* The date should include month, day, and year. The range for month should be 1 to 12; range for day is 1 to 31; and the year should be captured as four digits (YYYY). *Consistency criterion:* The procedure date should be on or before the pregnancy outcome date.

Name	***Results of Prenatal Screening or Diagnostic Procedure***
Standard Level	3
Definition	All available results/findings from tests or procedures to screen, rule out, or diagnose a birth defect, e.g., results of diagnostic examinations, procedures, and tests such as amniocentesis to detect or exclude chromosomal abnormalities, CVS, ultrasound to identify or exclude structural malformations, fetal echo, etc.
Justification	This information is useful for case-finding and to alert the program of potential cases.
Data Source	May be abstracted from: • Outpatient or hospital medical records • Specialty or sub-specialty records, e.g. such as genetics clinics, perinatologists, maternal-fetal medicine or high-risk obstetric specialists • Records from prenatal diagnostic facilities • Laboratory reports, e.g. cytogenetic labs
Type	Code or text
Quality Assurance Checks	*Consistency criteria:* There should be at least one procedure code and corresponding text for each procedure. Text should contain key words associated with the codes used.
Comments	Refer to Chapter 12 (Inclusion of Prenatal Diagnoses in Birth Defects Surveillance) of the *NBDPN Guidelines for Conducting Birth Defects Surveillance* for additional details.