

## ***Appendix 4.1***

### ***Descriptions of Minimum (Core) Data Variables***

## Appendix 4.1 Descriptions of Minimum (Core) Data Variables

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## Appendix 4.1 Descriptions of Minimum (Core) Variables

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### Format for Variable Descriptions

<b>Variable Name</b>	Name of data collection variable
<b>Definition</b>	Definition of data collection variable
<b>Justification</b>	Reason the birth defects program may want to include variable in its database
<b>Source</b>	Where variable comes from – abstracted, derived, created
<b>Location</b>	Data sources and location within data sources where variable is most likely to be consistently found
<b>Type</b>	How variable should be stored – text, number, date, code (letters and/or numbers), checkbox
<b>Checks</b>	Any limits, ranges, or other criteria the variable should meet
<b>Comments</b>	Other notes or comments about the variable
<b>Options</b>	Recommended options for the variable

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Unique ID</i></b>
<b>Definition</b>	Identification code or number; a code or number that uniquely identifies each case or record
<b>Justification</b>	<p>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 variables. 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.</p> <p>The ID permits easy linkage between multiple data sets as long as each table 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. This field permits linking multiple case reports for individual children.</p>
<b>Source</b>	Created by the registry as cases are added.
<b>Location</b>	N/A
<b>Type</b>	Code
<b>Checks</b>	Every individual in the database should have a <i>unique</i> ID.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Date of pregnancy outcome</i></b>
<b>Definition</b>	Date of delivery or end of the index pregnancy
<b>Justification</b>	<p>In conjunction with other fields, such as mother’s last name, this field helps to identify a case uniquely. It is useful to researchers and social workers in verifying that they are referring to the pregnancy of interest when contacting mothers who may have had other pregnancies.</p> <p>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.</p> <p>Secular trends have been reported for certain birth defects (Nielsen et al., 2000; O’Leary et al., 1996; Centers for Disease Control and Prevention, 1992). The birth defects program can use the date of delivery in order to produce statistics and reports by delivery year and to examine secular trends in birth defects.</p> <p>Cluster investigations are based on a defined diagnosis, geographical area, and time period. Knowing the delivery date allows investigators to determine which cases qualify to be included in a particular investigation.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (labor and delivery record)</li> <li>• Infant’s medical record (face sheet, labor and delivery record, birth certificate worksheet)</li> <li>• Vital record</li> </ul>
<b>Type</b>	Date
<b>Checks</b>	Every record must have a pregnancy outcome date, except in cases of prenatal diagnosis where the pregnancy has not ended yet. The pregnancy outcome date should be after the mother’s and father’s date of birth, date of last menstrual period, and date of conception; on or after any prenatal diagnostic procedure date or prenatal ultrasound date; and on or before a postnatal procedure date.
<b>Comments</b>	Date of pregnancy outcome can be: date of birth, date of fetal demise, or date pregnancy ends.

## Infant Variables – Core

<b>Variable Name</b>	<b>Sex</b>
<b>Definition</b>	Sex of the infant or fetus
<b>Justification</b>	Birth defect risk may be associated with sex (Whiteman et al., 2000). The birth defects program can use the sex of the infant or fetus in order to evaluate differences in birth defect rates by sex.
<b>Source</b>	Abstracted Derived (from the karyotype)
<b>Location</b>	<ul style="list-style-type: none"><li>• Mother’s delivery medical record (labor and delivery record)</li><li>• Infant’s medical record (face sheet, labor and delivery record, birth certificate worksheet)</li><li>• Vital record</li></ul>
<b>Type</b>	Code
<b>Checks</b>	Every record should have sex recorded.
<b>Comments</b>	If a karyotype was performed, the sex should match the karyotype, except in rare cases of such discordances as XY females and XX males.
<b>Options</b>	<ul style="list-style-type: none"><li>• Male</li><li>• Female</li><li>• Ambiguous</li><li>• Unknown</li></ul>

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Infant’s name</i></b>
<b>Definition</b>	Name of infant or fetus
<b>Justification</b>	<p>Field staff can use the infant’s name and date of birth or pregnancy outcome date to locate medical records.</p> <p>The birth defects program will use the name to unduplicate the reported cases and may employ the infant’s name in addition to other fields to link to other data sets, such as vital records.</p> <p>The infant’s name is helpful when referring the family to social work, treatment, and prevention agencies.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Infant’s medical record (face sheet, birth certificate worksheet)</li> <li>• Vital record</li> </ul>
<b>Type</b>	Text
<b>Checks</b>	If the infant’s last name is the same as the father’s or mother’s last name, or a combination of the two, the spelling should usually match.
<b>Comments</b>	<p>This variable may be collected as a single field or multiple fields. Separate fields for first, middle, last name, and suffix are recommended to improve unduplication and record linkage success. Individual fields of up to 25 digits each should be considered to avoid truncated names. This variable should include at least the infant’s first and last name and may include the infant’s middle name and any suffixes. An infant may be given more than one name or alias, sometimes referred to as “also known as” or AKA. The birth defects program may want to record all of the names, for easier linkage with other databases, to prevent duplication of cases in the database and to remain current with name use.</p> <p>Fetuses resulting from fetal deaths and elective terminations often do not have names. The birth defects program should consider using the surname of the mother and inserting a standard first name (e.g., fetus) so that name data fields are complete in the database.</p>

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Source of report</i></b>
<b>Definition</b>	Any data source where information was obtained or where a case report originated.
<b>Justification</b>	<p>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, for confirming the data, and for conducting audits of facility reporting.</p> <p>The data source fields permit the birth defects program to evaluate the usefulness of utilizing specific facilities as data sources.</p>
<b>Source</b>	Abstracted
<b>Location</b>	Any data source pertinent to program objectives
<b>Type</b>	Code, with allowance for multiple sources
<b>Checks</b>	This field should always be filled out and should be a valid code.
<b>Comments</b>	There can be multiple data sources for a given case. For example, an infant may be identified with a birth defect at the delivery hospital, tertiary care hospital, cytogenetics laboratory, etc. (see also Chapter 6 on Case Ascertainment Methods).
<b>Options</b>	It is useful to maintain a list of potential data sources and standard codes (hospitals, clinics, laboratories, autopsy, etc.) unique to each program.
<b>Variable Name</b>	<b><i>Medical record number(s)</i></b>
<b>Definition</b>	Medical record number(s) used by the source from which the information was obtained.
<b>Justification</b>	A medical record number allows facilities to retrieve 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.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Infant’s medical record (face sheet)</li> </ul>
<b>Type</b>	Code
<b>Comments</b>	Medical record numbers are not the same as visit, service, or encounter numbers. 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. Medical record numbers may also be very long. The birth defects program should make certain the computer program and registry database allow for entry of the entire medical record number.



## Infant Variables – Core

<b>Variable Name</b>	<i>Vital record certificate number</i>
<b>Definition</b>	Unique number assigned to a certificate by Vital Records.
<b>Justification</b>	<p>Vital record certificate numbers can be linked to other vital records certificates. Often, vital records will reference or link the death certificate to the birth certificate for infant deaths.</p> <p>Programs can use an algorithm of data variables to find a potential match to a vital record. This process assists in identifying unique cases, establishing residency, and securing all of the data variables on the vital record.</p> <p>Birth certificate and fetal death certificate numbers can be the unique ID numbers for a program. Other ‘program’ numbers can be created using a similar format for cases that do not match to a birth certificate or fetal death certificate.</p>
<b>Source</b>	Abstracted
<b>Location</b>	On the certificate of birth, death, or fetal death and in the vital records database
<b>Type</b>	Number
<b>Comments</b>	Separate fields for the live birth or fetal death and for the death record number are recommended.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Place of pregnancy outcome</i></b>
<b>Definition</b>	Location where the delivery or pregnancy outcome occurred
<b>Justification</b>	<p>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.</p> <p>The birth defects program may employ the delivery location in addition to other fields to link to other data sets, such as vital records.</p> <p>The location where the delivery occurred allows the birth defects program to provide facility-specific statistics.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet)</li> <li>• Infant’s delivery medical record (face sheet)</li> <li>• Vital record</li> </ul>
<b>Type</b>	Code
<b>Checks</b>	This field should always be filled out and must be a valid code.
<b>Comments</b>	This includes those situations where delivery occurs outside of health care facilities as well as inside health care facilities.
<b>Options</b>	<p>It is useful to maintain a list of potential data sources (hospitals, etc.) unique to each program.</p> <ul style="list-style-type: none"> <li>• Home/residence</li> <li>• Other</li> <li>• Unknown</li> </ul>

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Pregnancy outcome</i></b>
<b>Definition</b>	Outcome of the index pregnancy
<b>Justification</b>	<p>The pregnancy outcome, in conjunction with gestational age fields, may determine whether a record should be included in the birth defects program.</p> <p>At a minimum birth defect programs should distinguish the outcomes of live birth, fetal death, and induced termination.</p> <p>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.</p> <p>Pregnancy outcome can be used to evaluate rates of birth defect by pregnancy outcome.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother's delivery medical record (face sheet, discharge summary, labor and delivery record)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Code
<b>Checks</b>	This field should always be filled out, except in cases of prenatal diagnosis where the pregnancy has not yet ended.
<b>Comments</b>	See Chapter 3 on Case Definition for definitions of pregnancy outcomes.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Birth weight</i></b>
<b>Definition</b>	Weight of the infant or fetus at delivery
<b>Justification</b>	<p>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.</p> <p>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.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"><li>• Mother’s delivery medical record (labor and delivery record)</li><li>• Infant’s medical record (admission summary, labor and delivery record, birth certificate worksheet)</li><li>• Vital records</li></ul>
<b>Type</b>	Number
<b>Checks</b>	The birth weight must range between 0 and 10,000 grams or 0 and 50 pounds.
<b>Comments</b>	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.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Plurality</i></b>
<b>Definition</b>	Number of fetuses or infants.
<b>Justification</b>	<p>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.</p> <p>Knowing that the infant is from a multiple birth alerts the birth defects program that more effort may be needed to link to a particular vital record (Forrester and Canfield, 2000).</p> <p>The birth defects program can use this data item to evaluate differences in birth defect rates for singletons and multiple births.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet, admission summary, discharge summary, prenatal care record, labor and delivery record)</li> <li>• Infant’s medical record (face sheet, admission summary, discharge summary, prenatal care record, labor and delivery record, birth certificate worksheet).</li> <li>• Vital records</li> </ul>
<b>Type</b>	Number
<b>Checks</b>	This field should always be filled out.
<b>Comments</b>	Because some twin pregnancies are anomalous (for example, conjoined twins or fetus papyraceus), there may not be the expected two vital records for a pregnancy that is identified as a twin pregnancy.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Gestational age</i></b>
<b>Definition</b>	Gestational age at pregnancy outcome
<b>Justification</b>	Gestational age can be used to determine whether a pregnancy outcome meets the case definition for the birth defects program.  Certain diagnoses are 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.
<b>Source</b>	Abstracted Derived (see comments)
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (labor and delivery record)</li> <li>• Infant’s delivery medical record (admission summary, discharge summary, gestational age score record, labor and delivery record, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Number
<b>Checks</b>	The gestational age should range between 0 and 52 weeks.
<b>Comments</b>	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.
<b>Options</b>	See Chapter 3 on Case Definition for further information.

## Infant Variables – Core

<b>Variable Name</b>	<b><i>Diagnosis code</i></b>
<b>Definition</b>	Code used for the diagnosis
<b>Justification</b>	Coding birth defects eliminates the problem of having to sort through a variety of differing descriptions. It allows for timely and efficient analyses of data and identification of cases for research and referral. Coding of birth defects enables birth defects researchers to know that they are talking about the same birth defect, and allows for comparability between different birth defects registries using the same or comparable coding systems (Rasmussen et al., 2001).
<b>Source</b>	Derived
<b>Location</b>	N/A
<b>Type</b>	Code
<b>Checks</b>	Every case should have at least one diagnosis code (except if the birth defects program includes non-malformed controls, in which case the program may create specific ‘disease codes’ for use as the data variable in the diagnosis code field).
<b>Comments</b>	<p>A case may have more than one diagnosis code. Every diagnosis description should have a corresponding code and vice versa.</p> <p>The International Classification of Disease (ICD) coding system is the standard used in the health care delivery system. NBDPN currently requires that programs report cases using ICD-9-CM codes. The registry should accommodate a minimum of 15 unique diagnostic codes per case.</p>
<b>Options</b>	The recommended coding system is the CDC 6-digit code, which is easily converted to ICD-9-CM. See the Chapter 5 on Classification and Coding for further information.

## Contact Information – Core

<b>Variable Name</b>	<b><i>Name of responsible party</i></b>
<b>Definition</b>	Name of parent, custodial parent, or guardian
<b>Justification</b>	Useful in programs that refer a family to services when contact with a parent may be inappropriate.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Face sheet, signed authorization, social worker’s notes, birth certificate worksheet</li> <li>• Immunization registry, metabolic screening database</li> <li>• Vital record</li> </ul>
<b>Type</b>	Text
<b>Comments</b>	The name may be collected as a single field or multiple fields for first, middle, and last name. Allowing for up to 25 characters for each portion of the name should be considered.
<b>Variable Name</b>	<b><i>Address of responsible party</i></b>
<b>Definition</b>	Address of parent, custodial parent, or guardian
<b>Justification</b>	Useful in programs that refer a family to services when contact with a parent may be inappropriate.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Face sheet, signed authorization, social worker’s notes, birth certificate worksheet</li> <li>• Immunization registry, metabolic screening database</li> <li>• Vital record</li> </ul>
<b>Type</b>	Text
<b>Comments</b>	Include fields for the street address, city, state, and zip code. Allow at least 25 digits for street address and 20 digits for city name. If the residence address and the mailing address of the responsible party are different, collect the mailing address for this item.
<b>Variable Name</b>	<b><i>Telephone number of responsible party</i></b>
<b>Definition</b>	Telephone number of child’s parent, custodial parent, or guardian
<b>Justification</b>	Useful in programs that refer a family to services when contact with a parent may be inappropriate and when telephone contact may be indicated.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Face sheet, signed authorization, social worker’s notes, birth certificate worksheet</li> <li>• Immunization registry, metabolic screening database</li> <li>• Vital record</li> </ul>
<b>Type</b>	Number
<b>Comments</b>	Include area code with number.



## Maternal Variables – Core

<b>Variable Name</b>	<i>Mother's date of birth</i>
<b>Definition</b>	Birth mother's date of birth
<b>Justification</b>	<p>In conjunction with other fields, such as mother's name, the birth defects program field staff can use the mother's date of birth to locate medical records when the mother's medical record number is not known. The birth defects program can use the mother's date of birth and other fields to determine whether a case has been abstracted or added to the registry under a different ID.</p> <p>The birth defects program can employ the mother's date of birth in addition to other fields to link to other data sets, such as vital records or Medicaid.</p> <p>The birth defects program can use the mother's date of birth and infant's date of delivery in order to calculate the mother's age at delivery. The mother's age at delivery can then be used in clinical review.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"><li>• Mother's delivery medical record (face sheet, prenatal care record)</li><li>• Infant's medical record (face sheet, prenatal care record, birth certificate worksheet)</li><li>• Vital records</li></ul>
<b>Type</b>	Date
<b>Checks</b>	This date must be earlier than all other dates except possibly the father's date of birth. 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.
<b>Comments</b>	See also Chapter 6 on Case Ascertainment Methods, the section on Data Sources.

## Maternal Variables – Core

<b>Variable Name</b>	<i>Mother's race</i>
<b>Definition</b>	Birth mother's race
<b>Justification</b>	The birth defects program can use the mother's race in order to present data on birth defect rates by maternal race, one of the most important person variables in descriptive epidemiology.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother's delivery medical record (face sheet, prenatal care record)</li> <li>• Infant's medical record (admission summary, prenatal care record, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Code
<b>Comments</b>	Racial categories and codes used by birth defects surveillance programs should be compatible with the federal standards in current use for race.
<b>Variable Name</b>	<i>Mother's ethnicity</i>
<b>Definition</b>	Birth mother's ethnicity
<b>Justification</b>	Ethnicity is a designation separate from maternal race. The birth defects program can use the mother's ethnicity in order to evaluate differences in birth defect rates by maternal ethnicity.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother's delivery medical record (face sheet, prenatal care record)</li> <li>• Infant's medical record (admission summary, prenatal care record, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Code
<b>Comments</b>	It is important to collect ethnicity data that meets the needs of the registry to monitor the health of the ethnic populations within the state. Generally, each state Department of Public Health will have identified the populations of special interest to that state. Ethnicity categories and codes should be compatible with the federal standards in current use for ethnicity.

## Maternal Variables – Core

<b>Variable Name</b>	<i>Mother's name</i>
<b>Definition</b>	Full name of birth mother
<b>Justification</b>	<p>In conjunction with other fields, such as mother's date of birth, the birth defects program field staff can use the mother's name to locate medical records when the mother's medical record number is not known. The birth defects program can employ the mother's name in addition to other fields to unduplicate case reports and to link to other data sets, such as vital records or Medicaid.</p> <p>The mother's name is needed so that she can be contacted by researchers conducting approved studies and by social workers or others for outreach efforts.</p>
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"><li>• Mother's delivery medical record (face sheet)</li><li>• Infant's medical record (face sheet, birth certificate worksheet)</li><li>• Vital records</li></ul>
<b>Type</b>	Text
<b>Comments</b>	<p>This variable may be collected as a single field or multiple fields. This variable should include at least the mother's first and last name and may include the mother's middle name and maiden name (name before marriage). A woman may have more than one name or alias (also known as or AKA). Separate fields for first, middle, and last name and for maiden name are recommended. Field lengths of 25 characters or larger for each portion of the name should be considered. The birth defects program should record all of the names, for easier linkage with other databases and to prevent entering duplicate cases in the database.</p>

## Maternal Variables – Core

<b>Variable Name</b>	<b><i>Mother’s street address of residence at pregnancy outcome</i></b>
<b>Definition</b>	Street address of birth mother’s residence at the time of the outcome of the index pregnancy
<b>Justification</b>	Street address is necessary for geocoding location of residence and linking with other data systems through geographical information systems (GIS). The street address field may be needed when assigning the county of residence, particularly when a city includes part of more than one adjacent county.
<b>Source</b>	Abstracted
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet)</li> <li>• Infant’s delivery medical record (face sheet, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Text
<b>Comments</b>	<p>Include apartment numbers, etc. A field length of up to 40 characters should be considered.</p> <p>If there is a difference between residence address and mailing address, choose residence address. Only use P.O. Box if there is no physical address for the mother.</p>

<b>Variable Name</b>	<b><i>Mother’s city of residence at pregnancy outcome</i></b>
<b>Definition</b>	City of address of birth mother’s residence at the time of the outcome of the index pregnancy
<b>Justification</b>	The city at delivery field is often needed when assigning the county of residence.
<b>Source</b>	Abstracted Derived (from zip code or census tract number)
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet)</li> <li>• Infant’s delivery medical record (face sheet, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Text
<b>Comments</b>	If there is a difference between residence address and mailing address, choose residence address. Allow for up to 25 characters for city name text fields. A separate city code field may be used to correspond with the city name to facilitate statistical analysis. City coding structures should be compatible with Federal Information Processing Standards (FIPS).

## Maternal Variables – Core

<b>Variable Name</b>	<b><i>Mother’s county of residence at pregnancy outcome</i></b>
<b>Definition</b>	County code of birth mother’s county of residence at the time of the outcome of the index pregnancy
<b>Justification</b>	The county of residence, in association with other fields such as plurality and mother’s social security number, can be used to avoid duplication of records in the registry.
<b>Source</b>	Abstracted Derived (from street address and city, zip code, or census tract number)
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet)</li> <li>• Infant’s delivery medical record (face sheet, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Code
<b>Comments</b>	If there is a difference between residence address and mailing address, choose residence address. County coding schemes should be compatible with standard federal FIPS codes.

<b>Variable Name</b>	<b><i>Mother’s state of residence at pregnancy outcome</i></b>
<b>Definition</b>	State in which birth mother resided at the time of the outcome of the index pregnancy
<b>Justification</b>	The state in which the mother resided is needed if the birth defects program’s inclusion criteria include only residents of a certain state. The state of residence, along with other address components, is needed so that researchers and social workers can contact the family, provided a more recent address is not known.
<b>Source</b>	Abstracted Derived (from other residence information such as city, zip code, and census tract number)
<b>Location</b>	<ul style="list-style-type: none"> <li>• Mother’s delivery medical record (face sheet)</li> <li>• Infant’s delivery medical record (face sheet, birth certificate worksheet)</li> <li>• Vital records</li> </ul>
<b>Type</b>	Standard 2-letter state codes used by US Postal Service
<b>Comments</b>	If there is a difference between residence address and mailing address, choose residence address. Procedures for reporting information for places outside the US need to be contemplated.

## Maternal Variables – Core

<b>Variable Name</b>	<i>Mother's zip code of residence at time of pregnancy outcome</i>
<b>Definition</b>	Zip code of birth mother's residence at the time of the outcome of the index pregnancy
<b>Justification</b>	<p>Cluster investigations are based on a defined diagnosis, geographical area, and time period. Knowing the zip code of residence may allow investigators to determine which cases qualify to be included in cluster investigations.</p> <p>The zip code, along with other address components, is needed so that researchers, social workers, and others can contact the family, provided a more recent address is not known.</p>
<b>Source</b>	<p>Abstracted</p> <p>Derived (from other residence information such as street address and city or census tract number)</p>
<b>Location</b>	<ul style="list-style-type: none"><li>• Mother's delivery medical record (face sheet)</li><li>• Infant's delivery medical record (face sheet, birth certificate worksheet)</li><li>• Vital records</li></ul>
<b>Type</b>	Number
<b>Comments</b>	If there is a difference between residence address and mailing address, choose residence address. This code only applies to United States zip codes and may be the 5-digit or the 9-digit code.