

OBTAINING DATA FROM THE BIRTH DEFECTS EPIDEMIOLOGY AND SURVEILLANCE BRANCH (TEXAS DEPARTMENT OF STATE HEALTH SERVICES):

POLICY AND REQUEST PROCEDURES

ONLINE RESOURCES

The interactive web site called “Texas Health Data” will provide many tabulations of data from the Texas Birth Defects Registry at <http://soupfin.tdh.state.tx.us/>. If that does not meet your needs, feel free to request data from the Texas Birth Defects Epidemiology and Surveillance Branch through this document, which can also be obtained online at http://www.dshs.state.tx.us/birthdefects/BD_data.shtm.

BRIEF DESCRIPTION OF THE REGISTRY

Data Collection

The Texas Birth Defects Registry is a population-based registry which collects statewide data on pregnancies affected by birth defects. It is run by the Birth Defects Epidemiology and Surveillance Branch (BDES).

The Registry is based upon active surveillance. This means it does not require reporting by hospitals or medical professionals. Instead, trained program staff members regularly access medical facilities where they have the authority to review log books, hospital discharge lists, and other records. From this review, a list of potential cases is created. Program staff then review medical charts for each potential case identified. If the infant or fetus meets the registry’s case definition, detailed demographic and diagnostic information is abstracted. That information is entered into the computer and submitted for processing into the registry. Quality control procedures for finding cases, abstracting information, and coding defects help ensure completeness and accuracy.

Records based on abstracted medical information are matched to vital records (such as birth certificates and fetal death certificates) filed with the Texas Vital Statistics Unit. Sometimes information on the same field is found in both medical records and vital records. For those fields, data can usually be requested from (a) the medical record, (b) the vital record, or (c) these two combined. For most pieces of demographic data, the information from vital records is used (i.e. takes priority) but if that is missing, then the information from medical records is used. The combination rule for each field is presented in Form E. Note that all diagnostic information is abstracted only from medical records.

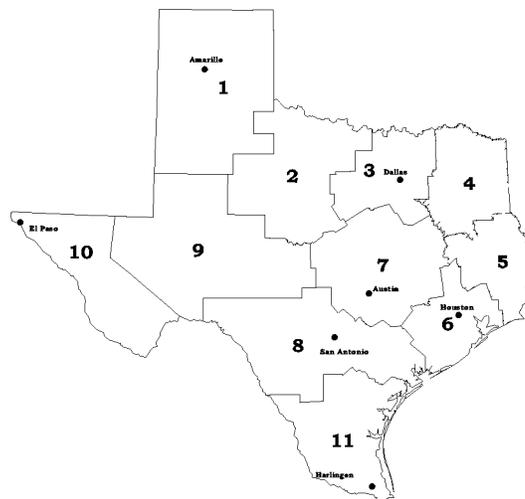
Case Definition

A case is an infant or fetus with a birth defect. To be included as a case in the Texas Birth Defects Registry, all of the following criteria must be met:

- The mother’s residence at the time of delivery must be in an area covered by the registry (see below).
- The infant or fetus must have a structural or chromosomal birth defect monitored by the registry.
- The defect must be diagnosed prenatally or within one year after delivery. This is extended to six years of age for special cases, currently only for fetal alcohol spectrum disorders.

The current case definition includes all pregnancy outcomes (live births, spontaneous fetal deaths, and induced pregnancy terminations) at all lengths of gestation. Prior to April 5, 2001, when the current case definition was adopted, the registry did not collect information on birth defects among fetal deaths before 20 weeks gestation.

Registry Coverage and Changes



The Texas Birth Defects Registry ascertained cases from the above Health Service Regions for the shaded time periods shown below:

Region	Year in which case was delivered			
	1996	1997	1998	1999 and later
01				
02				
03				
04				
05				
06				
07				
08				
09				
10				
11				

The BDES tries to continually improve Registry operations, for example by changing the case definition, birth defect codes, and data collection procedures as needed. When possible, changes have been applied to previous, relevant cases in the Registry (e.g. updating codes for all cases with that birth defect).

The new data collection software was implemented on 2/1/2002. If a case was abstracted before that time (affecting most cases delivered before 2001), several fields are likely to have null values, and other fields have values but were collected under different rules and definitions; all those fields should be analyzed with care. Both kinds of fields are indicated in Form E.

GAINING ACCESS TO DATA IN THE TEXAS BIRTH DEFECTS REGISTRY

The Registry includes some data items that could potentially identify a case, parents of a case, or an institution. These data items are:

- Name
- Newborn screening number
- Medical record number
- Vital records number
- Facilities of delivery, diagnosis, or treatment
- Address information including geocoded location and possibly zipcode
- Telephone numbers

It is critical that confidentiality be protected when researchers and others make use of the data, so additional review is required when any of those items are requested (described in #4 below).

Data from the Birth Defects Registry can be obtained in the following four ways. In filling out all listed forms, feel free to electronically complete the downloaded form.

1. Published Tabulated Data

This includes numbers of cases and rates of 48 birth defects broken down by:

- Maternal age
- Maternal race/ethnic group
- Infant/fetus sex
- Health service region
- County of mother's residence at delivery
- Mother's residence at delivery is or is not in a county bordering Mexico

These reports are available at <http://www.dshs.state.tx.us/birthdefects/Data/reports.shtm>. These data tabulations can also be obtained at the Texas Health Data interactive web site, <http://soupfin.tdh.state.tx.us/>.

2. Unpublished Data without Identifying Information (in tabular or aggregated format)

Step 1: Complete the following forms.

- Form A. Request for Unpublished Birth Defects Registry Data (pgs. 8-11)
- Form B. Request for Statistics, Tabulations, or Aggregated Data (pg. 12)

Please Note: Form E, Request for Variables / Data Fields, may be used as a reference.

Step 2: Send the completed forms by mail or email to:

Lisa Marengo
Birth Defects Epidemiology and Surveillance Branch, Mail Code 1964
Texas Department of State Health Services
PO Box 149347, Austin, TX 78714-9347
Email: lisa.marengo@dshs.state.tx.us, Phone: 512-776-6657

Please Note: In some situations, the number of cases may be so few that identification of individuals is considered possible. In that case, the BDES reserves the right to suppress data in certain cells or to require a data requestor to follow the process outlined in # 4 below.

3. Unpublished Data without Identifying Information (in individual record format)

Step 1: Complete the following forms.

- Form A. Request for Unpublished Birth Defects Registry Data (pgs. 8-11)
- Form C. Agreement for Use of Non-identifying Birth Defects Registry Data in Individual Record Format (pg. 13)
- Form E. Request for Variables / Data Fields (pgs. 15-19)
- Form F. Request for Vital Records Data (only if you need this information) (pg. 20)

Step 2: Send the completed forms by mail or email to:

Lisa Marengo
Birth Defects Epidemiology and Surveillance Branch, Mail Code 1964
Texas Department of State Health Services
PO Box 149347, Austin, TX 78714-9347
Email: lisa.marengo@dshs.state.tx.us, Phone: 512-776-6657

Please Note: In some situations, the number of cases may be so few that identification of individuals is considered possible. In that case, the BDES reserves the right to suppress data in certain cells or to require a data requestor to follow the process outlined in # 4 below.

4. Unpublished Data with Identifying Information (in individual record format)

Please note that individuals with indication of adoption or relinquishment will be excluded from Birth Defects Registry data sets that contain identifying information.

Step 1: Complete the following forms.

- Form A. Request for Unpublished Birth Defects Registry Data (pgs. 8-11)
- Form D. Agreement for Use of Identifying Birth Defects Registry Data (pg. 14)
- Form E. Request for Variables / Data Fields (pg. 15-19)
- Form F. Request for Vital Records Data (only if you need this information) (pg. 20)

Step 2: Complete an application for the Texas Department of State Health Services Institutional Review Board #1 (DSHS IRB #1). The form can be found from the DSHS IRB website at <http://www.dshs.state.tx.us/irb/default.shtm>.

Also complete the IRB “Initial Submission Detail Form”. In the appropriate sections of the form or in additional sections, include the following information which is legally required for BDES review:

- Brief literature review and justification for the study
- Study objectives and study design
- Population (time period of delivery and geographic area)
- Birth defects and other health outcomes of interest
- Exposures (independent variables) of interest, and methods for assessing exposure
- Methods for any further data collection or linkage if applicable (be specific).
- Will contact be made with any individual or institution identified from the requested data? If yes, describe.
- Methods for data analysis. Include power or sample size calculations, as well as methods to address confounding.
- Estimated completion date for the study
- Describe specific steps you will take to keep the data confidential
- Level and sources of funding to complete study
- Potential benefits and disadvantages of involving human subjects

Note that you can also fill out a request for exemption from review or for expedited review; if your research meets the criteria in those request forms, it may speed up the review process.

Step 3: Send the completed forms from Step 1 and 2 by mail or email to:

Lisa Marengo
Birth Defects Epidemiology and Surveillance Branch, Mail Code 1964
Texas Department of State Health Services
PO Box 149347, Austin, TX 78714-9347

Please note: The deadline for receipt of these materials by BDES is the 15th of the month to allow adequate time for review and revisions, prior to forwarding to the DSHS IRB.

These materials will be reviewed in the following order:

1. By the Birth Defects Epidemiology and Surveillance Branch (mainly to check for scientific merit);
2. Then by the DSHS IRB (mainly to check for ethics and protection of human subjects).
3. Then by the Executive Steering Committee (mainly to check for legal and policy review);
4. Finally, possibly by the Commissioner of Health.

Once all required approval has been obtained, a researcher is considered to have established a “valid scientific interest” as required in the law establishing the Texas Birth Defects Registry.

Fees

The Birth Defects Epidemiology and Surveillance Branch is committed to providing accurate, complete, and timely birth defects data for use in the research and prevention of birth defects. Whenever possible, data and reports will be supplied at no cost to the public. However, in certain circumstances such as very time-consuming requests, the BDES will charge a fee for data or reports according to DSHS operating policy AA-5007.

Violations of the Terms of the Agreements

If any terms of the agreements in this policy are violated, the Branch Manager of the BDES may request immediate termination of the study in progress, may deny future access to Texas Birth Defects Registry data, and may confiscate any Birth Defects Registry data in possession of the requestor. The remedies specified in this provision are in addition to any other remedies provided by law for the benefit of the Texas Department of State Health Services or other persons.

EXPECTATIONS FOR USE OF T.B.D.R. DATA

Due to the many unique features involved in using and analyzing TBDR data, the Texas Birth Defects Epidemiology and Surveillance Branch recommends that data requestors include a BDES staff member when analyzing and conducting research using Registry data. Over many years of collecting, maintaining, and analyzing birth defects data, BDES staff are knowledgeable and well equipped to provide relevant, useful contributions to research and data analyses.

If research carried out by a data requestor is intended to be used for presentations and/or publications, submission for review by the BDES Branch is requested at key points along the process. If working towards a deadline, please allow no less than 5 business days for BDES to review each submission.

Cooperation with these expectations is greatly appreciated.

SUGGESTIONS ON IMPROVING THIS DOCUMENT

Suggestions are welcome from data users on how to improve any aspect of this document (description of the Registry, policy, forms, etc.). Please send suggestions by e-mail to Peter Langlois at peter.langlois@dshs.state.tx.us.

**Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

REQUEST FOR UNPUBLISHED BIRTH DEFECTS REGISTRY DATA

I. IDENTIFICATION

Today's date:

Name and university degrees:

Title:

Daytime phone number:

Fax number:

Email address:

Agency name, institution, or firm:

Mailing address:

Physical address (if different from the mailing address above):

Specific purpose for which the requested data will be used:

If you are a student, also complete the following identification regarding your primary academic advisor or teacher.

Name and university degrees:

Title:

Agency, institution, or firm:

Daytime phone number:

Fax number:

E-mail address:

II. TYPE OF DATA YOU ARE REQUESTING (Check one)

- Data **without** identifying information, in aggregated/tabular format
- Data **without** identifying information, in individual record format
- Data **with** identifying information, in individual record format

III. SELECTION CRITERIA

Please indicate the criteria you would like used in selecting the data.

Dates of Delivery

The earliest date of delivery available is January 1, 1996. The earliest date for statewide data is Jan 1, 1999. For more information, see page 2 of the policy. You can request data up to and including data released in the most recent Texas Birth Defects Registry data report found at <http://www.dshs.state.tx.us/birthdefects/Data/reports.shtm>.

(Check one and specify if needed.)

- All data available
- Data within the following start and finish delivery dates *(specify)*:

Geographic Area (based on mother's residence at delivery)

The Texas Birth Defects Registry began with deliveries to residents of the Houston/Galveston area (Health Service Region 6) and South Texas (Health Service Region 11). It gradually expanded so that beginning with deliveries on January 1, 1999, the entire State was covered. For more information, see page 2 of the policy.

(Check one and specify if needed.)

- All data available
- Data from the following geographic area(s) *(specify)*:

Birth Defect Diagnoses To Use In Selecting Cases

- a. Identify which birth defects you would like to select. Note: The 6-digit code list can be found at <http://www.dshs.state.tx.us/birthdefects/Data/reports.shtm>, and clicking on “6-Digit Codes for Reportable Birth Defects”.

(Indicate both description and codes. Attach separate page if necessary.)

Verbal label or description of birth defect(s)	ICD-9 or 6-Digit Birth Defect Code(s)

- b. Routine data reports and analyses from the Texas Birth Defects Registry only include definite diagnoses. However, a small percentage of our cases have possible/probable diagnoses, which are available upon request. Indicate whether you want us to select these birth defects using (*check one*):

- Only definite diagnoses (default value)
- Both definite and possible/probable diagnoses (Note: there is a variable that identifies which diagnoses are considered possible/probable.)

Other Selection Criteria

These may include pregnancy outcome, plurality, birth weight, etc. Form E may be used as a reference for the variables we can use in selection.

(*Check one and specify if needed.*)

- No further selection criteria desired.
- Please further select records that meet the following criteria (*specify*):

IV. FURTHER DETAILS ON DIAGNOSIS DATA

Cases With Multiple Birth Defect Diagnoses

ONLY FOR REQUESTS FOR DATA IN INDIVIDUAL RECORD FORMAT: We will select all cases with one or more of the birth defects you listed in the table above (Birth Defect Diagnoses To Use In Selecting Cases), and that meet your other selection criteria. However, some cases will also have other birth defects not included in that list. Do you want those?

(*Check one.*)

- Yes; send all defect diagnoses for the selected cases. (Default value)
 - Only definite diagnoses. (Default value)
 - Both definite and possible/probable diagnoses. (Note: there is a variable that identifies which diagnoses are considered possible/probable.)
- No; send only the defects listed in the table "Birth Defect Diagnoses To Use In Selecting Cases" above.

V. INFORMATION FORMAT CHARACTERISTICS

Physical Format

Please check the desired format for receiving the information from us. If you can accept multiple formats, please indicated with a '1' your most preferred format, with a '2' your next most desired format, etc. This will help us quickly identify other options in case your highest preference will not work.

Check, or indicate preference number	Options
	Paper tables or lists, sent by US mail
	Compact disk
	Electronic file sent as an e-mail attachment (available only if you are requesting data without identifying information in aggregated/tabular format)
	Secure file transfer through your institution (specify):

File Type

Please check the desired format for receiving the information from us. If you can accept multiple formats, please indicated with a '1' your most preferred format, with a '2' your next most desired format, etc. This will help us quickly identify other options in case your highest preference will not work.

Check, or indicate preference number	Options	Most Recent Version You Can Read
	Microsoft Access database	
	Microsoft Excel spreadsheet- NOTE: If you are requesting individual record format data, be aware that old versions of Excel truncates text beyond 255 characters. This can impact the data fields containing results and interpretation of prenatal and postnatal tests and procedures. For full information from large text fields, request data in a Microsoft Access database.	
	SAS data file- NOTE: If you are requesting individual record format data, be aware that SAS truncates text beyond 1024 characters. This can impact the data fields containing results and interpretation of prenatal and postnatal tests and procedures. For full information from large text fields, request data in a Microsoft Access database.	
	ASCII (text) file	No version needed
	.PDF (Portable Document Format)	
	Not applicable (requesting paper output)	No version needed

**Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

REQUEST FOR STATISTICS, TABULATIONS, OR AGGREGATED DATA

Statistics

Check one or more of the following; these will be reported for each level of the breakdown you request or each cell of the cross tabulation.

- Number of cases
- Birth prevalence (number of cases per 10,000 live births)
- 95% confidence intervals for birth prevalence
- Denominators for birth prevalence (number of live births)

Breakdowns or Cross Tabulations

Tables may be broken down in a variety of ways. Please note that the more ways you request, the more time it may take us to fulfill your request. The most common variables used to break down a table or cross tabulate are:

- Birth defect (recommended)
- Time period of delivery (e.g. year)
- Geographic area of maternal residence at delivery (e.g. health service region, county)
- Demographic characteristics (e.g. maternal age, maternal race/ethnic group)

Notes:

- One-way breakdowns produce a tabulation using one variable (e.g. by birth defect). Cross tabulations or multi-way breakdowns use two or more variables (e.g. birth defect by year).
- A single cross tabulation of many variables can quickly produce a huge amount of statistical data. Example: routinely reported birth defect (49 values) by year (1996-1999 = 4 values) by maternal age group (6 values) would produce $49 \times 4 \times 6 = 1,176$ cells.
- If you use 95% confidence intervals for your estimates or alpha values of 0.05 for hypothesis testing, then 5% of your comparisons will show differences that are statistically significant just by chance. That can make breakdowns with many cells problematic; e.g. 5% of 1,176 cells = 59 results that will be significant by chance.
- If you have questions or want to discuss possible approaches, contact Lisa Marengo at the Texas Birth Defects Epidemiology and Surveillance Branch 512-776-6657.

Specify the breakdown(s) or cross tabulation(s) you would like:

**Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

**AGREEMENT FOR USE OF NON-IDENTIFYING BIRTH DEFECTS REGISTRY DATA IN
INDIVIDUAL RECORD FORMAT**

Instructions: Data requestors—please copy and distribute this statement to all people who will have access to the data you request, then collect and return the signed statements.

Maintaining the confidentiality of information in the Texas Birth Defects Registry is mandated by law and is the highest priority of Registry operations.

In order for the Birth Defects Epidemiology and Surveillance Branch (BDES) to provide data to you, it is necessary that you agree to the following provisions.

1. You will not use nor permit others to use the data in any way other than for the project with the title below.
2. You will not make the data available nor permit others to make the data available to any person or organization except with the written approval of the BDES, and controls shall be maintained to prevent unauthorized access.
3. You will not present/publish data in which an individual or institution can be identified.
4. You will not attempt to link nor permit others to link the data with individually identified records in another database.
5. You will not attempt to learn the identity of any person whose data are contained in the supplied file(s).
6. If the identity of any person is discovered inadvertently, the following will be done:
 - a. You will not make use of this knowledge;
 - b. You will notify the BDES of the incident;
 - c. You will not inform anyone else of the discovered identity.
7. You will credit the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, as the source of the data.
8. You will send a copy of the finished product (e.g. report, thesis, dissertation, or paper) to the BDES.

My signature indicates that I agree to comply with the above stated provisions.

Title of Project

Signature

Date

Name (printed or typed)

Title

Organizational Affiliation

**Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

AGREEMENT FOR USE OF IDENTIFYING BIRTH DEFECTS REGISTRY DATA

Instructions: Data requestors: please copy and distribute this statement to all people who will have access to the data you request, then collect and return the signed statements.

Maintaining the confidentiality of information in the Texas Birth Defects Registry is mandated by law and is the highest priority of Registry operations.

In order for the Birth Defects Epidemiology and Surveillance Branch (BDES) to provide data with identifying information for this study, it is necessary that you agree to the following provisions.

1. You will not use nor permit others to use the data for any purpose other than that specifically set forth in your submitted request with the title below.*
2. You will not make the data available nor permit others to make the data available to any person or organization except with the written approval of the BDES, and controls shall be maintained to prevent unauthorized access.*
3. You will not present/publish data in which an individual or institution can be identified.
4. You will treat all Registry data as strictly confidential.*
5. Any confidential information which is copied or otherwise transferred, electronically or through other means, shall be destroyed at the completion of the research unless otherwise stated in the research protocol.
6. You will credit the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, as the source of the data.
7. You will send a copy of the finished product (e.g. report, thesis, dissertation, or paper) to the BDES.

* Federal agencies which are subject to the federal Freedom of Information Act and the Federal Privacy Act shall not release confidential identifying data except as is required by those Acts.

My signature indicates that I agree to comply with the above stated provisions.

Title of Project

Signature

Date

Name (printed or typed)

Title

Organizational Affiliation

**Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

REQUEST FOR VARIABLES / DATA FIELDS

You may use this list to develop your own list, or you can check below and return this form with the other required information. Terms in square brackets illustrate some possible responses, for clarification. More detail on what each variable means and valid responses can be obtained through Lisa Marengo, BDES (phone 512-776-6657).

Variables in italics are considered to be identifying data. If you request any of those variables, you must go through the process for requesting identifying data, described in approach (4); the variables must correspond to the Initial Detail Submission Form you submit.

Table 1. Items Collected From Medical Records or Vital Records

Under "Comments": D = derived from other variables in this table
 2004/05 & earlier: Available from vital records only for 2004 and earlier birth certificates and 2005 and earlier fetal death certificates
 2005/06 & forward: Available from vital records only for 2005 and forward birth certificates and 2006 and forward fetal death certificates
 2005 & forward: Available for 2005 and forward birth certificates.
 2006+: No longer available on fetal death certificates from 2006 forward.

Under "Combination": M = medical records
 V = vital records
 If the cell is filled in, data are not available from that source

Variable/Field Name	Comments	Combination: Priority Source	Source You Want Data From:		
			Medical	Vital	Combined
Identification Information					
<i>Infant's most current first name</i>		V			
<i>Infant's most current middle name</i>					
<i>Infant's most current last name</i>		V			
Infant's sex	see *	see *			
Infant's birth weight		M			
Date of delivery		V			
Year of infant's date of delivery	D	V			
Pregnancy outcome [live birth, spontaneous fetal death, induced termination]		M			
Plurality [singleton, twins, etc.]		V			
Birth sequence (for plural births)					
<i>Facility where delivery occurred</i>		M			
Delivery facility city					
Mother's Demographic Information					
<i>Birth mother's first name</i>	2005/06 & forward	V			
<i>Birth mother's middle name</i>	2005/06 & forward	V			
<i>Birth mother's last name</i>	2005/06 & forward	V			
<i>Birth mother's maiden first name</i>					
<i>Birth mother's maiden middle name</i>					
<i>Birth mother's maiden last name</i>					

Variable/Field Name	Comments	Combination: Priority Source	Source You Want Data From:		
			Medical	Vital	Combined
Birth mother's date of birth		V			
Birth mother's age (years)	D	V			
Birth mother's age group (6 5-yr groups)	D	V			
Birth mother's race		V			
Birth mother Hispanic [yes/no]		V			
Birth mother's Hispanic origin [e.g. Mexican, Central/South American, Cuban]					
Birth mother's race/ethnicity-CDC Categories	D	V			
Birth mother's birthplace					
<i>Birth mother's residence at delivery: Street / P.O Box</i>		V			
Birth mother's residence at delivery: City		V			
Birth mother's residence at delivery: County - DSHS codes		V			
Birth mother's residence at delivery: County - FIPS codes		V			
Birth mother's residence at delivery: County on border with Mexico	D	V			
Birth mother's residence at delivery: Health service region	D	V			
<i>Birth mother's residence at delivery: Zip code</i>		V			
<i>Birth mother's residence at delivery: Latitude</i>					
<i>Birth mother's residence at delivery: Longitude</i>					
<i>Birth mother's residence at delivery: Census tract – 2000</i>					
Birth mother's residence at delivery: Geocoding accuracy (simplified)					
Birth mother's residence at delivery: Geocoding date					
Birth mother's education in years	2004/05 & earlier				
Birth mother's education collected in 8 groups	2005/06 & forward				
Birth mother's education group [less than high school, high school, greater than high school]	D				
Father's Demographic Information					
<i>Father's first name</i>		V			
<i>Father's last name</i>		V			
Father's date of birth					
Father's age (years)	D				
Father's age group (6 5-yr groups)	D				
Father's birthplace					
Father's race	2006+				
Father Hispanic [yes/no]	2006+				
Father's Hispanic origin [e.g. Mexican, Central/South American, Cuban]	2006+				
Father's race/ethnicity-CDC Categories	D, 2006+				
Father's education in years	2004/05 & earlier				
Father's education collected in 8 groups	2005 & forward				
Father's education group [less than high school, high school, greater than high school]	D, 2006+				
Mother's Diabetes Information					
Mother had diabetes at any time	D				
Mother had diabetes diagnosed in this pregnancy (gestational diabetes)	2005/06 & forward				

Variable/Field Name	Comments	Combination: Priority Source	Source You Want Data From:		
			Medical	Vital	Combined
Mother had diabetes diagnosed prior to this pregnancy	2005/06 & forward				
Mother's Height, Weight, and Body Mass Index					
Mother's height	2005/06 & forward				
Mother's prepregnancy weight	2005/06 & forward				
Mother's prepregnancy Body Mass Index (BMI)	D, 2005/06 & forward				
Mother's prepregnancy BMI group (standard 4 groups)	D, 2005/06 & forward				
Prenatal Care					
Gestational month that prenatal care began	2004/05 & earlier				
Date of first prenatal visit	2005/06 & forward				
Source of Payment for Delivery					
Principal source of payment for this delivery	2005 & forward				
Pregnancy History					
Number of total previous pregnancies					
Number of previous live births		V			
Number of previous pregnancies that did not end in a live birth					
Gestational Age and Estimated Date of Conception					
Date of last menstrual period (LMP)		M			
Gestational age at delivery by clinical exam		M			
BDES-calculated estimated date of conception (derived from LMP or from gestational age at delivery by clinical exam; LMP takes precedence)	D	M			
BDES-calculated estimated gestational age at delivery (derived from LMP, or equal to gestational age at delivery by clinical exam; LMP takes precedence)	D	M			
Source of BDES-calculated estimated date of conception and gestational age at delivery [LMP or clinical exam]		M			
Infant's Isolated Defect Status and Severity					
Infant's isolated defect status [4 categories]					
Severity of infant's birth defects [5 categories]					
Death Information					
Liveborn infant reported to have died at any age	see **	see **			
Liveborn infant reported to have died < 1 year of age	see **	see **			
Date of death		V			
Vital Records Certificate Numbers					
Birth certificate file number					
Fetal death certificate file number					
Death certificate file number					

* Infant sex: If medical records indicate infant sex is ambiguous, the combined sex variable is set to "ambiguous". Otherwise, the sex indicated in vital records takes priority for the combined variable.

** If a liveborn infant was reported to have died according to medical or vital records, the combined field is set to "true".

Please see next page for Table 2.

Table 2. Items Collected Only From Medical Records

Under "Comments": N = old cases (most delivered before 2001) are have null (missing) data for this field
 O = old cases have data for this field available, but follow old definitions

Variable/Field Name	Comments	Check If Desired
Identification Information		
Case number		
<i>Infant's most current last name suffix</i>	N	
<i>Infant's most current middle name</i>		
<i>Infant's other last name</i>	N	
<i>Infant's other last name suffix</i>	N	
<i>Infant's other first name</i>	N	
<i>Infant's other middle name</i>	N	
<i>Infant's newborn screening number</i>		
Data Sources and Facility Information		
<i>Facility (code and name)</i>		
Medical record location [department or clinic within a facility]		
<i>Medical record number</i>		
<i>Medical record of [infant, mother, both]</i>		
Final results (of chart review or abstraction)	N	
Demography and Contacts		
<i>Birth mother's most recent mailing address: Street / P.O. Box</i>	N	
Birth mother's most recent mailing address: City	N	
Birth mother's most recent mailing address: State	N	
<i>Birth mother's most recent mailing address: Zip code</i>	N	
Birth mother's most recent mailing address: Nation	N	
<i>Birth mother's home phone number</i>		
<i>Birth mother's other phone number</i>		
<i>Father's home phone number</i>	N	
<i>Father's other phone number</i>	N	
Child living with: Relationship to child code	O	
<i>Child living with: Last name</i>	O	
<i>Child living with: First name</i>	O	
<i>Child living with most recent mailing address: Street / P.O. Box</i>	O	
Child living with most recent mailing address: City	O	
Child living with most recent mailing address: State	O	
<i>Child living with most recent mailing address: Zip code</i>	O	
Child living with most recent mailing address: Nation	O	
<i>Child living with: phone number</i>	O	
<i>Other contact's last name</i>	O	
<i>Other contact's first name</i>	O	
<i>Other contact's phone number</i>	O	
Pregnancy History		
Total pregnancies		
Live births		
Spontaneous fetal deaths		
Induced terminations of pregnancy		
Unspecified fetal deaths / pregnancy terminations		
Indication of multiple gestation pregnancies	N	
Infant deaths		
Maternal Illnesses, Conditions, or Complications		
Maternal illness, condition, or complication	O	
Present before this pregnancy	O	
Present during this pregnancy	O	
Family History of Birth Defects		
Relationship to child	O	
Family member's birth defect	O	

Variable/Field Name	Comments	Check If Desired
Maternal Exposures		
Maternal exposures	O	
Quantity, frequency, and timing of alcohol use	N	
Prenatal Care		
Mother received prenatal care	N	
Prenatal Procedures and Tests		
Prenatal procedure		
Prenatal lab test		
Date prenatal procedure performed		
<i>Facility (where prenatal procedure/test results are found)</i>		
Prenatal procedure/test results not found	N	
Prenatal procedure/test results and interpretation		
Gestational Age		
Estimated date of delivery by last menstrual period (LMP)		
Gestational age at delivery by LMP	N	
Date of ultrasound		
Gestational age at time of ultrasound		
Estimated date of delivery by ultrasound	N	
Gestational age at delivery based on ultrasound	N	
Estimated date of delivery by unknown source	N	
Gestational age at delivery by unknown source	N	
Delivery Information		
Apgar (1 minute)		
Apgar (5 minute)		
Head circumference		
Length		
Infant/Fetal Complications		
Infant/fetal complication [chosen from specified list]	O	
Other infant/fetal complications [open text]	O	
Postnatal Procedures		
Postnatal procedure		
Postnatal procedure (specify other)		
Postnatal procedure: specialty of person making the diagnosis		
Date postnatal procedure performed		
<i>Facility where postnatal procedure results are found</i>		
Postnatal procedure results not found	N	
Postnatal procedure results and interpretation		
Birth Defect Information		
Birth defect description		
6-digit birth defect code		
Laterality		
Possible/probable		

**Texas Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services**

REQUEST FOR VITAL RECORDS DATA

This form is typically used by requestors who want to use vital records data in their analysis of birth defects. Maintaining the confidentiality of health information is mandated by law and is the highest priority of Registry operations. Thus all provisions to protect confidentiality that you agreed to in forms C or D also cover these data.

VITAL RECORDS DATA REQUESTED

Please check one of the options below:

- Live birth data for denominators for birth prevalence calculations (live births only, includes children with birth defects in the TBDR).
- Data for live born controls for case-control studies (live births only, excludes children with birth defects in the TBDR).
- Birth certificate numbers of children with birth defects in the TBDR, so that you can exclude them from birth certificate data you already have or will obtain directly from the Center for Health Statistics.
- Death certificate data.
- Other (specify):

NOTE: Any request for identifying/sensitive information or birth certificate number must be approved by the DSHS IRB.

FOR REQUESTS FOR INDIVIDUAL LEVEL DATA

If you are requesting individual level data (as opposed to tabulated data) please complete the following:

My signature indicates that I agree to comply with the provisions in Form C or D as they pertain to the vital records data I am requesting.

Title of Project

Signature

Date

Name (printed or typed)

Title

Organizational Affiliation