
Appendix 12.3

Suggested List of Data Variables to Collect for Prenatally Diagnosed Defects

(Note: Items in italics can be collected based on a program's needs.)

12.3.1 Prenatal Information

Date of last menstrual period

Estimated date of delivery

Date and gestational age of first ultrasound for dating purposes, regardless of whether a defect was diagnosed or suspected (record the earliest ultrasound available if there is no information about the very first ultrasound done)

Date and result of prenatal diagnostic tests (amniocentesis, CVS, ultrasound, fetal echo, etc.)

Date of prenatal diagnoses – final confirmation if multiple tests or procedures

Gestational age at confirmation of prenatal diagnoses

Fetal sex

Plurality (single, multiple gestation; if multiple, number of fetuses)

Date of first prenatal visit

Date of initial screening

Gestational age at screening

Prenatal screening provider

Screening tests administered

Screening test findings

Prenatal diagnosis provider(s)

12.3.2 Outcome Information

Pregnancy outcome (if known from prenatal record)

Live birth, stillbirth, spontaneous abortion, elective termination, unknown

Date of pregnancy outcome

Place of pregnancy outcome

Gestational age at outcome

Date and result of any post-delivery evaluation of defects

Cytogenetic analyses performed (normal and abnormal)

Pathologic or autopsy examination of the fetus or infant (if a live birth)

Postnatal diagnostic tests and procedures performed (if a live birth)

Final diagnoses

Infant's name if a live birth

Location of outcome

Delivery and post-delivery care providers

12.3.3 Demographic Information

Mother's data:

Age

Race

Ethnicity

Residence at time of prenatal diagnosis or at delivery: street address, city, county, state, zip code, census tract (*exactly which items are collected will depend on the program's needs*)

Name

Date of birth

Education

Father's data:

Age

Race

Ethnicity

Name

Date of birth

Education