



Data Abstraction Guide

U.S. Zika Pregnancy Registry and Zika Birth Defects Surveillance

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About the Data Abstraction Guide

The Data Abstraction Guide has been developed to provide guidance for reviewing and abstracting medical records of pregnancies with laboratory evidence of Zika virus infection (for the U.S. Zika Pregnancy Registry), or infants with birth defects potentially related to Zika virus. It provides basic variable descriptions, definitions of terms, and tips on where to find information in the medical records.

Users can contact CDC U.S. Zika Pregnancy Registry and Zika Birth Defects Surveillance staff if they have additional questions that are not addressed by the Abstraction Guide. CDC staff are available for consultation on the U.S. Zika Pregnancy Registry and Zika Birth Defects Surveillance, as well as for clinical consultation regarding pregnant women or infants. CDC staff can be reached by calling the CDC Emergency Operations Center Watch Desk at 770-488-7100 and requesting the Zika Pregnancy Hotline or by emailing ZIKApregnancy@cdc.gov for the US Zika Pregnancy Registry or eocevent273@cdc.gov for the Zika Birth Defects Surveillance.

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Maternal Health History Form

Mother's Zika Virus Infection

Question	Acceptable Responses	Abstraction Instructions
MHH.1. State/territory ID	Free text field	Enter the mother's jurisdiction ID. This is a state specific identifier chosen by the Health Department.
MHH.2. Maternal age at diagnosis	Free text field	Enter maternal age in years.
MHH.3. State/territory reporting	Free text field (Drop down in PDF- fillable forms)	Select the abbreviation for reporting jurisdiction.*
MHH.4. County of reporting	Free text field	If possible, enter the reporting county.
MHH.5. Ethnicity	Hispanic or Latino, or Not Hispanic or Latino	Choose one, if reported. This information might be found in the History & Physical (H&P) or Patient Registration Form. Hispanic may also be recorded as Latina and Non-Hispanic recorded as Anglo. Possible abbreviations include Hisp or Non-H.
MHH.6. Race (check all that apply)	American Indian or Alaskan Native, Asian, Black or African-American, Native Hawaiian or other Pacific Islander, White, Unknown/Not Specified, Other, specify Free text field	Choose all that apply, if reported. This information might be found in the H&P or Patient Registration Form. Possible abbreviations include American Indian (AI), Alaska Native (AN), Asian (As), Black (BL) or African- American (AA), Native Hawaiian (NH or Haw) or other Pacific Islander (PI), White (W) or (Wh). If other, please specify.
MHH.7. Indication for maternal Zika virus testing	Exposure history only, no known fetal abnormalities; Exposure history and fetal abnormalities; OR No known exposure	Choose one. Determine whether maternal Zika virus testing was performed based on exposure only, or if it was performed due to discovery of potential fetal abnormalities (i.e., abnormal ultrasound findings, birth defects at delivery) before maternal testing. This information might be found in the maternal H&P, prenatal visit notes, or ultrasound report. If there is no known exposure, check box 'No known exposure' and skip to MHH.38. This will help determine if there is a bias toward the identification of infants with

Question	Acceptable Responses	Abstraction Instructions
		birth defects and may allow separate analysis to evaluate selection bias.
MHH.8. Date of Zika virus symptom onset	mm/dd/yyyy	Please list the first date of onset of any symptoms. This information might be found in the maternal History & Physical (H&P), prenatal visit notes, or laboratory report. If mother had no symptoms during pregnancy, then check asymptomatic in MHH.9.
MHH.9. Asymptomatic	Check box	Check 'asymptomatic' if mother did not report any symptoms of Zika infection. This information might be found in the maternal H&P, laboratory report, or prenatal visit notes. If mother had symptoms, leave blank.
MHH.10. If symptomatic, gestational age at onset (weeks, days)	Whole number	Enter weeks and days of gestational age at the onset of Zika symptoms. This can be determined using the estimated date of delivery (EDD) and date of symptom onset using an online pregnancy calculator (e.g., http://www.medcalc.com/pregnancy.html , http://www.calculator.net/pregnancy-calculator.html) OR pregnancy wheel (e.g., www.prokerala.com).
MHH.11. If gestational age not known, trimester of symptom onset	1 st , 2 nd , 3 rd	If gestational weeks and days of symptom onset is not known, write in the trimester (1 st , 2 nd , or 3 rd) of onset of Zika symptoms. This might be found in the maternal H&P, prenatal visit notes or calculated based on the date of symptom onset, using an online pregnancy calculator, for instance.
MHH.12. Symptoms of mother's Zika virus disease: (check all that apply)	Fever (Temperature Min: 34.0°C, Max: 42.0°C), Arthralgia, Conjunctivitis, Rash Other clinical presentation Free text field	Check all that apply (fever, arthralgia, conjunctivitis, rash). If fever was present, enter maximum temperature documented for Zika virus infection as either Fahrenheit or Celsius. If additional symptoms were reported or recorded, check box for 'other clinical presentation' and enter description in free text field. This information might be found in nursing notes, vital signs records, prenatal visit notes, and maternal H&P. Note that symptoms may be abbreviated in these source documents.

Question	Acceptable Responses	Abstraction Instructions
MHH.13. If rash, check all that apply	Maculopapular, Petechial, Purpuric, Pruritic (Itchy) Describe rash distribution Free text field	If rash was present, check all that apply related to the type of rash. This information might be found in the maternal H&P or prenatal visit notes. Note that symptoms may be abbreviated in these source documents. Please describe rash distribution to indicate if rash was on trunk (body), face, limbs, or other areas. This may be represented by a figure rather than text.
MHH.14. Hospitalized for Zika virus disease	No, Yes, Unknown	Choose one. This information might be found in the prenatal visit notes or maternal H&P, inpatient progress notes, or discharge summary for an inpatient hospital stay. This specifically refers to hospitalization that resulted from complications of Zika virus infection or disease.
MHH.15. Maternal death	No, Yes, Unknown	Choose one. This information might be found in the maternal progress notes, death note, discharge summary, or death certificate. This information might not be in the medical record and could require telephone consultation/confirmation with the provider's office if death is suspected.
MHH.16 If yes, cause of death	Free text field	If the mother died, describe the cause of death. This information might be found in the maternal progress notes, death note, discharge summary, or death certificate. It will be very important to note if the maternal death was associated with Zika virus infection or disease.
MHH.17. If yes, date of death	mm/dd/yyyy	This information might be found in the maternal progress notes, death note, discharge summary, or death certificate.

Question	Acceptable Responses	Abstraction Instructions
<p>MHH.18. What was the suspected mode of Zika virus transmission?</p>	<p>Human-mosquito-human (vector), Sexual, Other, please specify____, Unknown</p> <p>Free text field</p>	<p>Choose one. If suspected route of exposure was from a mosquito bite, choose ‘human-mosquito-human.’ If exposure was sex with a partner with symptoms, relevant travel history or confirmed Zika virus infection was documented, chose ‘sexual.’ This information might be found in the maternal H&P or prenatal visit notes.</p> <p>For other routes of possible exposure (blood transfusion, laboratory exposure) choose ‘other’ and please specify. In general, ‘sexual’ or ‘other’ routes of transmission should only be selected if human- mosquito-human transmission is implausible for the woman. For an updated list of areas with active Zika virus transmission, visit the CDC’s Areas with Zika webpage (http://www.cdc.gov/zika/geo/index.html).</p> <p>This information is very important to try to obtain as it is important to help us better understand if sexual transmission has different risks than other modes.</p>
<p>MHH.19. Did the woman spend time in any areas outside the U.S. states or U.S. territories where there was active Zika virus transmission during the periconceptual period or during pregnancy?</p>	<p>No, Yes, Unknown</p>	<p>Choose one.</p> <p>If no travel occurred to an area outside the 50 states and DC and the US territories, choose ‘no’. If no, skip to MHH.27.</p> <p>If the pregnant woman traveled to an area with active Zika virus transmission outside the 50 states and DC or US territories during the relevant timeframe, choose ‘yes.’</p> <p>The periconceptual period is defined as 6 weeks before the first day of the last menstrual period (LMP) to 2 weeks after the LMP (when conception is estimated to occur).</p> <p>For an updated list of areas with active Zika virus transmission, visit the CDC’s Areas with Zika webpage (http://www.cdc.gov/zika/geo/index.html).</p> <p>Travel information might be found in the maternal H&P or prenatal visit notes. This will help us understand patterns of spread.</p>

Question	Acceptable Responses	Abstraction Instructions
MHH.20. If yes, please characterize the type of travel	Incoming travel (one way travel to U.S. states or U.S. territories <u>from</u> an area with active Zika virus transmission) OR Outgoing and incoming travel (roundtrip <u>from</u> U.S. states or U.S. territories <u>to</u> an area with active Zika virus transmission)	If yes, choose either 'incoming (one way)' or 'outgoing and incoming (roundtrip)' and select either U.S. states or territories based on final destination. U.S. territories include: American Samoa, Guam, Northern Mariana Islands, Puerto Rico, U.S. Virgin Islands. If incoming or outgoing travel, please list location and dates of travel.
MHH.21, 23, 25. Country(ies) of Exposure	Free text field	List country(ies) of travel. This might be found in the maternal H&P or prenatal visit notes. If there are multiple countries listed for single dates of travel, separate each country with a semi-colon and a space. Do not include any additional notes in this field.
MHH.22, 24, 26. Start Date	mm/dd/yyyy	Indicate beginning date of travel in country of exposure. This might be found in the maternal H&P or prenatal visit notes.
MHH.22, 24, 26. End Date	mm/dd/yyyy	Indicate end date of travel or residence in country of exposure. This might be found in the maternal H&P or prenatal visit notes. For one-way travel/immigration from outside the U.S. to inside the U.S., this date is generally the U.S. arrival date unless the patient transits through another country between the country of exposure and the U.S.

Question	Acceptable Responses	Abstraction Instructions
MHH.27. Was there Zika virus exposure within the 50 states, DC, or U.S. territories?	No, Yes, Unknown	Choose one. If the pregnant woman was not exposed to an area with known local mosquito-borne transmission in the 50 U.S. states, DC or U.S. territories, check 'no.' If the pregnant woman was exposed to an area with known local mosquito-borne transmission in the 50 U.S. states, DC, or U.S. territories, check yes. U.S. territories include: American Samoa, Guam, Northern Mariana Islands, Puerto Rico, U.S. Virgin Islands. For an updated list of areas with active Zika virus transmission, visit the CDC's Areas with Zika webpage (http://www.cdc.gov/zika/geo/index.html). This information might be found in the maternal H&P or prenatal visit notes. This will help us better understand the risks of local transmission.
MHH.28, 30, 32. If exposure occurred within the 50 and D.C., list states/territories where exposure occurred	Free text field	Enter the state/territory. This might be found in the maternal H&P or prenatal visit notes.
MHH.29, 31, 33. Start Date and End Date	mm/dd/yyyy	Enter the start and end dates of travel. This might be found in the H&P or visit notes. If the pregnant woman is still located in the state or territory of exposure at the time of form completion, check box for 'Still at location.'
MHH.34. If suspected mode of transmission is sexual, was the pregnant woman's sexual partner(s) (please check all that apply)	Male, Female	Check all that apply. If suspected route of exposure was from a sexual partner, indicate if the mother's sexual partner(s) are male, female, or both. This might be found in the maternal H&P or prenatal visit notes, or may be obtained on patient interview. It is very important to collect this information as accurately as possible to better understand if sexual exposure manifests with different pregnancy outcomes.
MHH.35. Did any sexual partner(s) have an illness that included fever, rash, joint pain, or pink eye during or within 2 weeks of <u>spending any time in</u> an area with active Zika virus transmission?	No, Yes, Unknown	Choose one. This questions asks about symptoms of Zika virus disease in any male or female sexual partner(s). This information might be found in the maternal H&P or prenatal visit notes, or other clinical notes (e.g., ER visit). Please indicate 'yes' if partner(s) had <u>any</u> symptoms listed. This will help us understand if there are differences in transmission between men with and without

Question	Acceptable Responses	Abstraction Instructions
		symptoms.
MHH.36. If yes, was there unprotected sexual contact while partner(s) had this illness?	No, Yes, Unknown	If yes above, choose one. This questions asks if unprotected sexual activity occurred while the partner had symptoms. Please also indicate 'yes' if sexual exposure occurred just prior to (within 2 days) of illness. This information might be found in the maternal H&P or prenatal visit note. This will help us understand if there are particularly high-risk periods of exposure.
MHH.37. Did partner have a test that demonstrated laboratory evidence of Zika virus disease?	No, Yes, Unknown	If mother reported sexual partners, choose one. Choose 'yes' if there was any laboratory evidence of Zika virus infection. Laboratory evidence includes PCR positive or positive Zika virus IgM with confirmatory PRNT. This information might be found in the maternal H&P or prenatal visit notes. Information might also be available through Health Department or commercial laboratory reporting. This will help us understand if testing is being offered and the relationship of test results to transmission risks.

Maternal Health History (*Underlying maternal illness*)

Question	Acceptable Responses	Abstraction Instructions
MHH.38. Diabetes	No, Yes, Unknown	Choose one. This section aims to collect data on maternal illnesses that were present prior to pregnancy. Please do not include Gestational Diabetes as an underlying maternal illness; only diabetes diagnosed prior to pregnancy should be included in this section. Look for terms such as diabetes mellitus (DM), Type I diabetes, Type II diabetes, insulin-dependent diabetes mellitus (IDDM), Class B diabetes, Class C diabetes, Class D diabetes, Class R diabetes, Class F diabetes, Class RF diabetes, Class H diabetes, Class T diabetes. This information might be found in the maternal H&P or prenatal visit notes and would likely be listed as past medical history.

Question	Acceptable Responses	Abstraction Instructions
MHH.39. Maternal Phenylketonuria (PKU)	No, Yes, Unknown	Choose one. Phenylketonuria (PKU) is a <u>rare</u> inherited disease requiring a protein-restricted diet of phenylalanine-free medical formula, with fruits, vegetables, bread and pasta. If diagnosis is not mentioned in past medical history, look for dietary restrictions that mention phenylalanine. This information might be found in the maternal H&P or prenatal visit notes. Most patients will not have this information in their medical records.
MHH.40. Hypothyroidism	No, Yes, Unknown	Choose one. This field is for a past medical history of hypothyroidism, not for a diagnosis of hypothyroidism made during the current pregnancy. This information might be found in the maternal H&P or prenatal visit notes and would be likely listed as past medical history.
MHH.41. High Blood Pressure or Hypertension	No, Yes, Unknown	Choose one. This field is for hypertension (HTN) diagnosed prior to pregnancy, not for hypertension which presented during the current pregnancy. This information might be found in the H&P or medical history. Look for chronic hypertension, high blood pressure prior to pregnancy. This information would likely be listed as past medical history.
MHH.42. Other underlying illness(es)	No, Yes, Unknown	Choose one. Please check 'yes' if there are other maternal conditions existing prior to pregnancy that are not listed above. The information would be likely listed as past medical history.
MHH.43. If yes, specify	Free text field	If 'yes' is marked for MHH.42, describe any other underlying illnesses. If there are multiple illnesses, separate each with a semi-colon and a space. Use this variable to document other chronic medical conditions and/or substance abuse disorders not mentioned above. This might be found in the maternal H&P, medical history, or prenatal visit notes. Please record what is in the medical record.

Pregnancy Information

Question	Acceptable Responses	Abstraction Instructions
MHH.44. Last menstrual period (LMP)	mm/dd/yyyy	Enter the first date of last menstrual period (LMP). This might be found in the maternal H&P or in the prenatal visit notes. This information is often used to establish the estimated date of delivery (EDD),

Question	Acceptable Responses	Abstraction Instructions
		although EDD might be confirmed or changed by ultrasound.
MHH.45. Estimated delivery date (EDD)	mm/dd/yyyy	Enter the Estimated Delivery Date (EDD) <u>as documented in the medical record</u> . For this question, please do not calculate the EDD yourself based on LMP or other information. This information might be found in the maternal H&P or prenatal visit notes. The clinician will calculate EDD based on LMP or ultrasound findings. Earlier ultrasounds provide more accurate estimates of EDD than later ultrasounds. A final EDD is very important to establish as it impacts assessment of infant measurements at birth.
MHH.46. Estimated delivery date based on	LMP (date), 1 st trimester ultrasound, 2 nd trimester ultrasound, 3 rd trimester ultrasound, Other, specify Free text field	Check all that apply. Select how the Estimated Delivery Date (EDD) was determined by the clinician. This information might be found in the maternal H&P or prenatal visit notes. EDD can be determined by LMP = last menstrual period or prenatal ultrasound. If the EDD was not determined by any of the above, enter free text describing how EDD was determined.
MHH.47. # pregnancies (including current pregnancy)	Whole number	The number of pregnancies is also known as gravidity and should <u>include the current pregnancy</u> . This information may be found abbreviated as 'G' (for 'gravida'), along with 'P' (for 'para') for data below (MHH.48–50). This is specifically asking for the 'G.' This information might be found in the prenatal visit notes and maternal H&P. For further information on Pregnancy History (e.g., Gravidity, Parity), please see Clinical Pearls in this document (page 62).
MHH.48. # living children	Whole number	This number should NOT include the outcome of the current pregnancy. This information might be found in the prenatal visit notes or maternal H&P. It may be listed as a number associated with parity (P). If the 'P' is listed as 4 numbers, this refers to the last number. For example, the number of living children would be '4' if 'P' is listed as P5014.

Question	Acceptable Responses	Abstraction Instructions
MHH.49. # miscarriages	Whole number	For this question, miscarriage is meant to include any past history of unintentional or spontaneous pregnancy loss. This includes spontaneous abortion or 'SAB.' Please include spontaneous pregnancy losses, i.e., both miscarriages in this number, but do NOT include the outcome of the current pregnancy. This information might be found in the prenatal record, hospital admission H&P, past medical or obstetrical history.
MHH.50. # elective terminations	Whole number	Enter number of elective terminations. This may be listed as therapeutic abortion, 'TAB', termination of pregnancy, 'TOP' or simply 'abortion', 'ab'. This number should NOT include the outcome of the current pregnancy. This information might be found in the prenatal visit notes or maternal H&P.
MHH.51. Prior fetus/infant with microcephaly	No, Yes, Unknown	Choose one. This information might be found in the maternal H&P or prenatal visit notes. This helps establish if the woman has an increased baseline risk of infant microcephaly outside of Zika virus. If the pregnant woman had a prior fetus/infant with microcephaly, she might be at higher risk for a fetus/infant with microcephaly. This information helps identify potential other causes or associations with birth defects.
MHH.52. If yes, cause genetic?	No, Yes, Unknown	Choose one. If there is a history of a prior infant with microcephaly and there is a known genetic abnormality (Down syndrome, trisomy 18, or other genetic condition), please check 'yes.' This information might be found in the maternal H&P or prenatal visit notes.
MHH.53. Gestation	Single, Twins, Triplets+	Choose one. This question is referring to the number of fetuses in the current pregnancy. The third choice is triplets or more and includes quadruplets and higher order multiples. This information might be found in the prenatal visit notes, ultrasound report, or maternal H&P.
Substance Abuse during this pregnancy: MHH.54. Alcohol use	No, Yes, Unknown	Choose one. This question asks about regular alcohol use during pregnancy. It does not include occasional use. This information might be found in the maternal H&P or prenatal visit notes. Possible other terms include ETOH, ethanol. This question is asked because regular alcohol use can be associated with birth defects.

Question	Acceptable Responses	Abstraction Instructions
MHH.55. Cocaine use	No, Yes, Unknown	Choose one. Choose 'yes' if any cocaine use during this pregnancy. This information might be found in the maternal H&P or prenatal visit notes. Cocaine use includes crack smoking. This question is asked because cocaine use may be associated with growth abnormalities and pregnancy loss.
MHH.56. Smoking	No, Yes, Unknown	Choose one. This information might be found in the maternal H&P or prenatal visit notes. Smoking includes tobacco-containing products and e-cigarettes. This question is asked because smoking may be associated with low birthweight and pregnancy loss.

Complications during current Pregnancy

This series of questions asks if a maternal infection was diagnosed during the **current pregnancy**.

Question	Acceptable Responses	Abstraction Instructions
MHH.57. Toxoplasmosis infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician's assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. Look for clinical diagnosis of maternal toxoplasmosis (toxoplasma) during pregnancy. Testing for maternal toxoplasma is not routine and would likely be triggered by a fetus with abnormalities detected on prenatal ultrasound or infant born with birth defects. This question is asked because this can be a risk factor for adverse pregnancy outcomes.
MHH.58. Cytomegalovirus infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician's assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. Look for clinical diagnosis of maternal cytomegalovirus (CMV) infection during pregnancy. Testing for CMV is not routine and would likely be triggered by a fetus with abnormalities detected on prenatal ultrasound or infant born with birth defects. This question is asked because this can be a risk factor for adverse pregnancy outcomes.

Question	Acceptable Responses	Abstraction Instructions
MHH.59. Herpes Simplex infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician’s assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. This question is asking about genital herpes simplex virus (HSV) infection. Look for clinical diagnosis of active genital HSV, especially in early pregnancy. This question is asked because this can be a risk factor for adverse pregnancy outcomes.
MHH.60. Rubella infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician’s assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. Important: pregnant women are routinely tested for <u>immunity</u> to rubella. Notation of ‘rubella–immune’ (‘RI’) or ‘rubella non-immune’ (‘RNI’) status is standard and may be written in as a note to the surveillance form, to distinguish this from potential rubella disease. A women who is rubella-immune cannot have rubella as a complication of pregnancy (Choose ‘No’). If the woman is rubella non-immune, had an equivocal rubella test result, or is rubella unknown, look for a diagnosis of maternal rubella infection in pregnancy.
MHH. 61. Lymphocytic choriomeningitis virus infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician’s assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. Look for clinical diagnosis of lymphocytic choriomeningitis virus (LCMV) infection. Testing for LCMV is not routine and would likely be triggered by a fetus with abnormalities detected on prenatal ultrasound or an infant born with birth defects. This question is asked because this can be a risk factor for adverse pregnancy outcomes.

Question	Acceptable Responses	Abstraction Instructions
MHH.62. Syphilis infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in MHH.63. This information should be based on the clinician's assessment and might be found in the prenatal visit notes, laboratory results, maternal H&P, or ICD codes. Look for clinical diagnosis of syphilis infection or syphilis treatment during pregnancy. If either maternal RPR and/or VDRL are positive, choose 'yes.' (RPR and VDRL are tests for syphilis.) This question is asked because this can be a risk factor for adverse pregnancy outcomes.
MHH.63. If yes for infection testing during current pregnancy, please describe the results	Free text field	This information should be based on the clinician's notes or laboratory records. Please include any information provided for each infection (MHH.57–62), including laboratory test dates and results, and any treatment.
MHH.64. Fetal genetic abnormality	No; Yes, describe (Free text field); Unknown	Choose one. If genetic abnormality is present, mark 'yes', and briefly describe genetic abnormality. If there are multiple, separate each with a semi-colon and a space. This question asks about genetic abnormalities in the fetus, which might cause a genetic syndrome (e.g., trisomy 21 (Down Syndrome)) with dysmorphic features. Information might be found in the prenatal visit notes, laboratory results, or consult notes for genetic evaluation. Genetic tests may be described as cell-free DNA, chromosome analysis, karyotyping, aCGH, or FISH (fluorescent in-situ hybridization). Details of genetic tests and abnormalities detected should be documented in MHH.215–228.
MHH.65. Gestational Diabetes	No, Yes, Unknown	Choose one. Look for diagnosis of gestational diabetes, often abbreviated as GDM or GD. If diabetes is managed with medication (e.g., metformin, insulin), please document medications in MHH.71. This diagnosis might be found in the maternal H&P or prenatal visit notes. This question is asked because this can be a risk factor for adverse pregnancy outcomes.

Question	Acceptable Responses	Abstraction Instructions
MHH.66. Pregnancy-related hypertension (HTN)	No, Yes, Unknown	Choose one. This information might be found in prenatal visit notes or admission H&P. Look for a diagnosis of gestational hypertension, pregnancy-induced hypertension (PIH), pregnancy-related hypertension (PRH), pre-eclampsia, or eclampsia. If managed with medication, please document medications in MHH.71. This question is asked because this can be a risk factor for adverse pregnancy outcomes.
MHH.67. Intrauterine death of a twin	No, Yes, Unknown	Choose one. This information might be found in the prenatal visit notes or ultrasound report. This includes death of a twin for any reason, including 'vanishing twin,' retained second twin, or multifetal pregnancy reduction. This question is asked because this can be a risk factor for adverse pregnancy outcomes.
MHH.68. Other	No, Yes, Unknown	Choose one. Please check 'yes' if there is any additional information about pregnancy complications. This information might be found in the prenatal visit notes, laboratory results, ultrasound or prenatal imaging reports, maternal H&P, or consult/referral notes. Describe the complications in MHH.69. These may be listed in a problem list in the prenatal record.
MHH.69. If yes, please specify	Free text field	Describe any additional complications that occurred during this pregnancy. This information might be found in the prenatal visit notes, laboratory results, ultrasound or prenatal imaging reports, maternal H&P, or consult/referral notes. These may include, but are not limited to: polyhydramnios, oligohydramnios, placenta previa, placental abruption (or abruption placenta), incompetent cervix (or cervical insufficiency).
MHH.70. Medications during pregnancy	No, Yes, Unknown	Choose one. This information might be found in the medication record, maternal H&P, or the prenatal visit notes. When reviewing the medication record, only indicate 'yes' if medications taken during this pregnancy have been taken at least once a week. Do not mark 'yes' for common pregnancy medications such as prenatal vitamins, anti-nausea medications (e.g., pyridoxine, doxylamine succinate, or Diclegis), iron supplements (e.g., ferrous sulfate), laxatives or

Question	Acceptable Responses	Abstraction Instructions
		stool softeners (e.g., docusate or Colace). This question is asked to see if any medications could be associated with the outcome.
MHH.71. If yes, specify	Free text field	Enter name of medications (or type of medications if actual name is unknown) taken at least once a week, preferably with dose and frequency. Do not include common pregnancy medications such as: prenatal vitamins, anti-nausea, iron supplements, laxatives, or stool softeners.

Pregnancy Losses

Question	Acceptable Responses	Abstraction Instructions
MHH.72. Did this pregnancy end in miscarriage (<20 weeks of gestation)?	No, Yes, Unknown	Choose one. Complete this only at the end of the pregnancy. This is an unintentional pregnancy loss not an elective termination. This information might be found in prenatal visit notes, ultrasound results, or maternal H&P. Terms or abbreviations may include miscarriage, spontaneous abortion, spontaneous ab, or SAB. This is important to record to help us understand if Zika virus infection is associated with miscarriage.
MHH.73. If yes, date or gestational age if date is not known	mm/dd/yyyy Whole number	Enter date. OR Enter gestational age in weeks at the time of miscarriage. This information might be found in the prenatal visit notes, ultrasound results, or maternal H&P.
MHH.74. Please describe any abnormalities noted	Free text field	Please list any abnormalities that were detected prior to or at the time of the miscarriage. This may include an abnormal head circumference, anatomic findings, or birth defects, and might be found on prenatal visit notes, prenatal imaging reports, maternal H&P, or autopsy or pathology report.
MHH.75. Did this pregnancy end in stillbirth (intrauterine fetal demise) (≥20 weeks of gestation)?	No, Yes, Unknown	Choose one. Complete this only at the end of the pregnancy. Chose 'yes' if pregnancy loss occurred at gestational age of 20 weeks or more. This information might be found in the prenatal visit notes, prenatal imaging results, maternal H&P, or delivery or operative note. Terms or abbreviations may include stillbirth, intrauterine fetal demise, or IUFD. This is important to help us understand if Zika virus infection is associated with stillbirth.

Question	Acceptable Responses	Abstraction Instructions
MHH.76. If yes, date or gestational age if date is not known	mm/dd/yyyy Whole number	Enter date. OR Enter gestational age in weeks at the time of intrauterine fetal demise. This information might be found in the prenatal visit notes, prenatal imaging results, maternal H&P, delivery note or operative note.
MHH.77. Please describe any abnormalities noted	Free text field	Please list any abnormalities that were detected prior to or at the time of the intrauterine fetal demise. This may include an abnormal head circumference or birth defects, and might be found on prenatal visit notes, prenatal imaging reports, maternal H&P, or autopsy or pathology report. Please also check 'Stillbirth' on NAD form and complete pertinent sections of NAD form if physical exam findings are documented.
MHH.78. Was this pregnancy terminated?	No, Yes, Unknown	Choose one. Complete this only at the end of the pregnancy. This is asking if the pregnancy was intentionally terminated for any reason. This information might be found in the prenatal visit notes or maternal H&P. Terms or abbreviations may include therapeutic ab, TAB, termination of pregnancy, TOP, elective abortion, EAB, or abortion.
MHH.79. If yes, date or gestational age if date is not known	mm/dd/yyyy Whole number	Enter date. OR Enter gestational age in weeks at the time of termination. This information might be found in the prenatal visit notes, operative note, or maternal H&P.
MHH.80. Please describe any abnormalities noted	Free text field	Please list any abnormalities that were detected prior to or at the time termination. This may include an abnormal head circumference or birth defects, and might be found on prenatal visit notes, prenatal imaging reports, maternal H&P, operative note, autopsy, or pathology report.

Maternal Health History Form

On the form is space to document three prenatal ultrasound studies. Each section repeats the same variables, thus they are combined in this guide. Please report each ultrasound study separately in the order in which it was performed. If additional prenatal ultrasound studies were performed, please enter into Supplemental Imaging Form (SIF). Ultrasounds that were performed only to document fetal heart rate or perform biophysical profile (BPP) do not need to be reported, as long as fetal measurements (i.e., head circumference (HC), biparietal diameter (BPD), abdominal circumference (AC), femur length (FL)) or fetal abnormalities were not recorded. This information is very important to help us understand how easily adverse outcomes associated with congenital Zika virus infection can be detected prenatally and when findings can be detected following Zika virus infection.

Question	Acceptable Responses	Abstraction Instructions
MHH.81, 114, 147. Date of ultrasound	mm/dd/yyyy	Enter date. This information might be found in prenatal visit notes or prenatal imaging reports.
MHH.82, 115, 148. Check if date is approximated	Check box	Check if date is approximated.
MHH.83, 116, 149. If date not known, Gestational age (weeks, days)	Whole number	Enter gestational age in weeks and days. This information might be found in prenatal imaging results or prenatal visit notes.
MHH.84, 117, 150. Overall fetal ultrasound results	Normal, Abnormal	Choose one. This information might be found in the prenatal ultrasound report, prenatal visit notes, or maternal H&P, or obtained by a healthcare provider interview. Try to use the ultrasound report directly if it can be obtained.
MHH.85, 118, 151. Reported by patient/healthcare provider OR Ultrasound report	Reported by patient/healthcare provider, Ultrasound report	Choose one. Report whether the result in MHH.84/117/150 is from the provider or from the ultrasound report.
MHH.86, 119, 152. Head circumference (HC) (cm)	Whole number	Enter head circumference in centimeters. This information will be located in the prenatal ultrasound report, and may be abbreviated as head circ or HC.
MHH.87, 120, 153. HC Normal/Abnormal (by physician report)	Normal, Abnormal	Choose one. This information will be located in the prenatal ultrasound report. Report whether HC was identified as normal or abnormal in the medical record.
MHH.88, 121, 154. Biparietal diameter (BPD) (cm)	Number (up to two decimal places)	Enter biparietal diameter (BPD) in centimeters. This information will be located in the prenatal ultrasound report. Include decimals.
MHH.89, 122, 155. Femur length (FL) (cm)	Number (up to two decimal places)	Enter femur length in centimeters. This information will be located in the prenatal ultrasound report. Include decimals.

Question	Acceptable Responses	Abstraction Instructions
MHH.90, 123, 156. Abdominal circumference (AC) (cm)	Number (up to two decimal places)	Enter abdominal circumference in centimeters. Include decimal to two digits if available. This information will be located in the prenatal ultrasound report.
MHH.91, 124, 157. Symmetric IUGR Asymmetric IUGR (HC%>AC% or HC%>FL%)	Symmetric IUGR, Asymmetric IUGR	Choose one, if applicable. This information will be located in the prenatal ultrasound report. HC = head circumference, FL= femur length, AC= abdominal circumference. Intrauterine growth restriction (IUGR) is defined as estimated fetal weight (EFW) <5%ile for gestational age. Look for terms such as intrauterine growth restriction, IUGR, GR, small for gestational age, SGA. If IUGR is stated, check either symmetric or asymmetric IUGR even if EFW is 5% or greater; there may be situations when IUGR is diagnosed based on different standards. IUGR is assumed to be symmetrical unless otherwise noted. Asymmetric IUGR is defined as EFW <5%ile for gestational age PLUS HC%>AC% or HC%>FL%. Look for terms such as <u>asymmetric</u> , plus intrauterine growth restriction (IUGR), GR, small for gestational age, SGA. It is important to document the measurements of HC, BPD, FL, AC in MHH.86–90, 119–123/152–156.
MHH.92, 125, 158. Microcephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Microcephaly is the finding of a small head when compared with fetuses of the same sex and gestational age, and is a sign that the brain is abnormally small. Please use the clinician's determination of microcephaly in the medical record; do not provide your own determination of microcephaly based on reported measurements. This information might also be found in the prenatal visit notes or maternal H&P. It may be helpful to obtain and securely transmit a redacted version of the prenatal ultrasound findings.

Question	Acceptable Responses	Abstraction Instructions
MHH.93, 126, 159. Intracranial calcifications	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Intracranial calcifications are accumulations or deposits of calcium within the brain tissue and are a sign of brain injury from infection, hemorrhage, or lack of oxygen. Look for terms such as intracranial calcifications or calcium deposits within the fetal brain. In the free text field below, it would be helpful to include the specific location of the intracranial calcifications in the brain if this is available.
MHH.94, 127, 160. Cerebral/cortical atrophy	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Cerebral or cortical atrophy refers to loss of cells within the two cerebral hemispheres (the main portion of the brain). Look for terms such as cerebral (or cortical, periventricular, white matter, gray matter) atrophy or brain dysgenesis.
MHH.95, 128, 161. Abnormal cortical gyral patterns (e.g., polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia)	No, Yes	Choose one. Lissencephaly is a smooth cerebral cortex. Pachygyria is a simplified gyral pattern and is considered a subset of lissencephaly by some. Microgyria and polymicrogyria are small cortical ridges. Schizencephaly is a cleft in the cerebral hemisphere. Look for terms such as lissencephaly, agyria, pachygyria, incomplete lissencephaly, microgyria, polymicrogyria, simplified gyral pattern, schizencephaly, gray matter heterotopia, neuronal migration/maturation disorder, ectopia, marginal glioneuronal heterotopia, leptomenigeal heterotopia, or minor cortical dysplasias.
MHH.96, 129, 162. Corpus callosum abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. The corpus callosum is a band of nerve fibers in the central brain that join the two cerebral hemispheres. Look for terms such as agenesis or missing corpus callosum, hypoplasia or thinning of the corpus callosum, dysgenesis of the corpus callosum.
MHH.97, 130, 163. Cerebellar abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Look for terms such as cerebellar atrophy, agenesis, hypoplasia, or dysplasia. Terms may include any part of the cerebellum including the olive, pons, (inferior)

Question	Acceptable Responses	Abstraction Instructions
		<p>vermis, or cerebellum in general, and may combine anatomical locations (e.g., olive + pons + cerebellum = olivopontocerebellar).</p> <p>Dandy Walker malformation, mega cisterna magna, tectocerebella dysgraphia, rhomboencephalsynapsis, and cerebellar cyst are included in this category.</p>
MHH.98, 131, 164. Porencephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Porencephaly describes a cavity or cyst in the cerebral hemisphere. Look for terms such as porencephaly, porencephalic cyst or cavity, encephaloclastic porencephaly, developmental porencephaly.
MHH.99, 132, 165. Hydranencephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. In hydranencephaly, the cerebral hemispheres are replaced by fluid-filled sacs. Look for hydranencephaly or hydroanencephaly.
MHH.100, 133, 166. Moderate or severe ventriculomegaly/ hydrocephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Look for terms such as hydrocephalus and large, enlarged, or dilated cerebral ventricles (which may be specified as lateral, third or fourth ventricles), or hydrocephalus. Specific types might include aqueductal stenosis, occlusion of the foramina of Monro, and communicating hydrocephalus. There are also ventricles in the heart; be sure this is a cranial and not a cardiac finding.
MHH.101, 134, 167. Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Fetal brain disruption sequence is a pattern of congenital abnormalities that include severe microcephaly, overlapping cranial sutures, prominence of the occipital bone, and scalp rugae (excessive folding of the skin). All components of the fetal brain disruption sequence (microcephaly, overlapping sutures, prominent occipital bone, scalp rugae) must be present for this to be checked.
MHH.102, 135, 168. Other major brain abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Other brain abnormalities might include intraventricular hemorrhage that occurs in utero, absence of septum pellucidum, Arnold-Chiari or Chiari malformation,

Question	Acceptable Responses	Abstraction Instructions
		septo-optic dysplasia, colpocephaly, bilateral or multiple unilateral (all on the same side) subependymal cysts or pseudocysts, periventricular leukomalacia (not due to prematurity), large or prominent cisterna magna, or atrophy, aplasia, hypoplasia, or dysplasia of any part of brain not listed above.
MHH.103, 136, 169. Anencephaly/acrania	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Anencephaly is partial or complete absence of brain and skull. Acrania is absence of skull bones with some brain tissue present. Look for terms such as anencephaly, acrania, absent brain, craniorachischisis, exencephaly, iniencephaly, holoanencephaly, meroanencephaly.
MHH.104, 137, 170. Encephalocele	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.
MHH.105, 138, 171. Spina bifida	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Spina bifida is incomplete closure of the vertebral spine through which spinal cord tissue and/or meninges herniate. Look for terms such as spina bifida, neural tube defect, myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, meningomyelocele, myelocystocele, myelodysplasia, myeloschisis, rachischisis, spina bifida aperta, spina bifida cystica. Although the spina bifida lesion will be located along the spine, spina bifida is often associated with a cranial lesion termed Arnold-Chiari II malformation involving downward displacement of the hindbrain and 4 th ventricle.
MHH.106, 139, 172. Holoprosencephaly/	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Holoprosencephaly is

Question	Acceptable Responses	Abstraction Instructions
arhinencephaly		failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
MHH.107, 140, 173. Structural eye abnormalities/ dysplasia	No, Yes	Choose one. Any structural eye abnormality should be recorded as 'yes.' This information will be located in the prenatal ultrasound report. Look for terms such as microphthalmos, microphthalmia, anophthalmos, anophthalmia, nanophthalmia, cataract, intraocular calcification, ocular abnormalities, and any abnormality of the eye, retina, choroid, lens, macula, or optic nerve, however even if the only information is 'abnormal,' please include.
MHH.108, 141, 174. Arthrogryposis	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Arthrogryposis refers to contractures (abnormal shortening and stiffness of the muscles, tendons, and ligaments/or) of the limbs that is present at birth. The contractures can be fixed or more flexible, and can involve all, most, or a single joint. Look for terms such as arthrogryposis, arthrogryposis multiplex congenita, congenital contractures, fetal akinesia sequence, limitation of movements, joint ankyloses, joint contractures, and decreased flexibility.
MHH.109, 142, 175. Clubfoot	No, Yes	Choose one. Clubfoot is a developmental deformity of the foot in which one or both feet are excessively plantar flexed. This information will be located in the prenatal ultrasound report. Look for terms such as clubfoot, talipes equinovarus, talipes.
MHH.110, 143, 176. Hydrops	No, Yes	Choose one. Hydrops refers to abnormal fluid collections in fetal soft tissues and cavities. This information will be located in the prenatal ultrasound report. Look for terms such as hydrops, fetal edema, or hydrops fetalis.
MHH.111, 144, 177. Ascites	No, Yes	Choose one. Ascites is accumulation of fluid in the abdominal cavity and can be detected on ultrasound. This information will be located in the prenatal ultrasound report. Look for terms such as ascites or abnormal accumulation of

Question	Acceptable Responses	Abstraction Instructions
		fluid in the abdominal cavity.
MHH.112, 145, 178. Other If yes, describe.	No, Yes If yes, describe: Free text field	Choose one. This information will be located in the prenatal ultrasound report. Describe any abnormal results that have not been described. If there are multiple abnormalities, separate each with a semi-colon and a space.
MHH.113, 146, 179. Description of abnormal ultrasound findings	Free text field	Describe any abnormal results verbatim from the prenatal ultrasound report including the actual description of any abnormalities noted in MHH.102, 135, 168 – MHH.113, 146, 179. If there are multiple abnormalities, separate each with a semi-colon and a space.
MHH.180. Fetal MRI performed	No, Yes (if yes, answer questions below)	Choose one. This information might be found in the prenatal visit notes or prenatal imaging reports.
MHH.181. Date of MRI	mm/dd/yyyy	Enter date. This information might be found in the prenatal visit notes or fetal MRI report.
MHH.182. Check if date is approximated	Check box	Check if date is approximated.
MHH.183. If date is not known, Gestational age (weeks, days)	Whole number	Enter gestational age in weeks and days. This information might be found in prenatal imaging results or prenatal visit notes.
MHH.184. Overall fetal MRI Results	Normal, Abnormal	Choose one. This information might be found in fetal MRI report, prenatal visit notes, or maternal H&P, or may be obtained from a healthcare provider interview. Try to use the MRI report directly if it can be obtained.
MHH.185. Reported by patient/healthcare provider OR MRI report	Reported by patient/healthcare provider, MRI report	Choose one. Report whether the result in MHH.184 is from the healthcare provider or from an MRI report.
MHH.186. Head Circumference (HC)	Number (up to two decimal places)	Enter head circumference in centimeters. This information will be located in the fetal MRI report, and may be abbreviated as head circ or HC.
MHH.187. HC: Normal, Abnormal (by physician report)	Normal, Abnormal	Choose one. This information will be located in the fetal MRI report. Report whether HC was identified as normal or abnormal in the medical record.
MHH.188. Biparietal diameter (BPD)	Number (up to two decimal places)	Enter biparietal diameter (BPD) in centimeters. This information will be located in the fetal MRI report. Include decimals.

Question	Acceptable Responses	Abstraction Instructions
MHH.189. Femur length (FL)	Number (up to two decimal places)	Enter femur length (FL) in centimeters. This information will be located in the fetal MRI report. Include decimals.
MHH.190. Abdominal circumference (AC)	Number (up to two decimal places)	Enter abdominal circumference (AC) in centimeters. Include decimal to two digits if available. This information will be located in the fetal MRI report.
MHH.191. Symmetric IUGR or Asymmetric IUGR (HC%>AC% or HC%>FL%)	Symmetric IUGR, Asymmetric IUGR	<p>Choose one, if applicable. This information will be located in the prenatal ultrasound report. HC = head circumference, FL= femur length, AC= abdominal circumference.</p> <p>Intrauterine growth restriction (IUGR) is defined as estimated fetal weight (EFW) <5%ile for gestational age. Look for terms such as intrauterine growth restriction, IUGR, GR, small for gestational age, SGA. If IUGR is stated, check either symmetric or asymmetric IUGR even if EFW is 5% or greater; there may be situations when IUGR is diagnosed based on different standards. IUGR is assumed to be symmetrical unless otherwise noted.</p> <p>Asymmetric IUGR is defined as EFW <5%ile for gestational age PLUS HC%>AC% or HC%>FL%. Look for terms such as <u>asymmetric</u>, plus intrauterine growth restriction (IUGR), GR, small for gestational age, SGA. It is important to document the measurements of HC, BPD, FL, AC in MHH.186–190.</p>
MHH.192. Microcephaly	No, Yes	<p>Choose one. This information will be located in the fetal MRI report. Microcephaly is the finding of a small head when compared with fetuses of the same sex and gestational age, and is a sign that the brain is abnormally small. Please use the clinician's determination of microcephaly in the medical record; do not provide your own determination of microcephaly based on reported measurements.</p> <p>This information might also be found in the prenatal visit notes or maternal H&P. It may be helpful to obtain and securely transmit a redacted version of the fetal MRI findings.</p>
MHH.193. Intracranial calcifications	No, Yes	<p>Choose one. This information will be located in the fetal MRI report. Intracranial calcifications are accumulations or deposits of calcium within the brain tissue and are a sign of brain injury from infection, hemorrhage, or lack of oxygen. Look for</p>

Question	Acceptable Responses	Abstraction Instructions
		terms such as intracranial calcifications or calcium deposits within the fetal brain.
MHH. 194. Cerebral/cortical atrophy	No, Yes	Choose one. This information will be located in the fetal MRI report. Cerebral or cortical atrophy refers to loss of cells within the two cerebral hemispheres (the main portion of the brain). Look for terms such as cerebral (or cortical, periventricular, white matter, gray matter) atrophy or brain dysgenesis.
MHH.195. Abnormal cortical gyral patterns (e.g., polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia)	No, Yes	Choose one. This information will be located in the fetal MRI report. Lissencephaly is a smooth cerebral cortex. Pachygyria is a simplified gyral pattern and is considered a subset of lissencephaly by some. Microgyria and polymicrogyria are small cortical ridges. Schizencephaly is a cleft in the cerebral hemisphere. Look for terms such as lissencephaly, agyria, pachygyria, incomplete lissencephaly, microgyria, polymicrogyria, simplified gyral pattern, schizencephaly, gray matter heterotopia, neuronal migration/maturation disorder, ectopia, marginal glioneuronal heterotopia, leptomenigeal heterotopia, or minor cortical dysplasias.
MHH.196. Corpus callosum abnormalities	No, Yes	Choose one. This information will be located in the fetal MRI report. The corpus callosum is a band of nerve fibers in the central brain that join the two cerebral hemispheres. Look for terms such as agenesis or missing corpus callosum, hypoplasia or thinning of the corpus callosum, dysgenesis of the corpus callosum.
MHH.197. Cerebellar abnormalities	No, Yes	Choose one. This information will be located in the fetal MRI report. Look for terms such as cerebellar atrophy, agenesis, hypoplasia, or dysplasia. Terms may include any part of the cerebellum including the olive, pons, (inferior) vermis, or cerebellum in general, and may combine anatomical locations (e.g., olive + pons + cerebellum = olivopontocerebellar). Dandy Walker malformation, mega cisterna magna, tectocerebella dysgraphia, rhombencephalsynapsis, and cerebellar cyst are included in this category.

Question	Acceptable Responses	Abstraction Instructions
MHH.198. Porencephaly	No, Yes	Choose one. This information will be located in the fetal MRI report. Porencephaly describes a cavity or cyst in the cerebral hemisphere. Look for terms such as porencephaly, porencephalic cyst or cavity, encephaloclastic porencephaly, developmental porencephaly.
MHH.199. Hydranencephaly	No, Yes	Choose one. This information will be located in the fetal MRI report. In hydranencephaly, the cerebral hemispheres are replaced by fluid-filled sacs. Look for hydranencephaly or hydroanencephaly.
MHH.200. Moderate or severe ventriculomegaly/ hydrocephaly	No, Yes	Choose one. This information will be located in the fetal MRI report. Look for terms such as hydrocephalus and large, enlarged, or dilated cerebral ventricles (which may be specified as lateral, third or fourth ventricles), or hydrocephalus. Specific types might include aqueductal stenosis, occlusion of the foramina of Monro, and communicating hydrocephalus. There are also ventricles in the heart; be sure this is a cranial and not a cardiac finding.
MHH.201. Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)	No, Yes	Choose one. This information will be located in the fetal MRI report. Fetal brain disruption sequence is a pattern of congenital abnormalities that include severe microcephaly, overlapping cranial sutures, prominence of the occipital bone, and scalp rugae (excessive folding of the skin). All components of the fetal brain disruption sequence (microcephaly, overlapping sutures, prominent occipital bone, scalp rugae) must be present for this to be checked.
MHH.202. Other major brain abnormalities	No, Yes	Choose one. This information will be located in the fetal MRI report. Other brain abnormalities might include intraventricular hemorrhage that occurs in utero, absence of septum pellucidum, Arnold-Chiari or Chiari malformation, septo-optic dysplasia, colpocephaly, bilateral or multiple unilateral (all on the same side) subependymal cysts or pseudocysts, periventricular leukomalacia (not due to prematurity), large or prominent cisterna magna, or atrophy, aplasia, hypoplasia, or dysplasia of any part of brain not listed above.

Question	Acceptable Responses	Abstraction Instructions
MHH.203. Anencephaly/ acrania	No, Yes	Choose one. This information will be located in the fetal MRI report. Anencephaly is partial or complete absence of brain and skull. Acrania is absence of skull bones with some brain tissue present. Look for terms such as anencephaly, acrania, absent brain, craniorachischisis, exencephaly, iniencephaly, holoanencephaly, meroanencephaly.
MHH.204. Encephalocele	No, Yes	Choose one. This information will be located in the fetal MRI report. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.
MHH.205. Spina bifida	No, Yes	Choose one. This information will be located in the fetal MRI report. Spina bifida is incomplete closure of the vertebral spine through which spinal cord tissue and/or meninges herniate. Look for terms such as spina bifida, neural tube defect, myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, meningomyelocele, myelocystocele, myelodysplasia, myeloschisis, rachischisis, spina bifida aperta, spina bifida cystica. Although the spina bifida lesion will be located along the spine, spina bifida is often associated with a cranial lesion termed Arnold-Chiari II malformation involving downward displacement of the hindbrain and 4 th ventricle.
MHH.206. Holoprosencephaly/ Arhinencephaly	No, Yes	Choose one. This information will be located in the fetal MRI report. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
MHH.207. Structural eye abnormalities/dysplasia	No, Yes	Choose one. This information will be located in the fetal MRI report. Look for terms such as microphthalmos, microphthalmia, anophthalmos,

Question	Acceptable Responses	Abstraction Instructions
		anophthalmia, nanophthalmia, cataract, intraocular calcification, ocular abnormalities, and any abnormality of the eye, retina, choroid, lens, macula, or optic nerve.
MHH.208. Arthrogryposis	No, Yes	Choose one. This information will be located in the fetal MRI report. Arthrogryposis refers to contractures (abnormal shortening and stiffness of the muscles, tendons, and ligaments/or) of the limbs that is present at birth. The contractures can be fixed or more flexible, and can involve all, most, or a single joint. Look for terms such as arthrogryposis, arthrogryposis multiplex congenita, congenital contractures, fetal akinesia sequence, limitation of movements, joint ankyloses, joint contractures, and decreased flexibility.
MHH.209. Clubfoot	No, Yes	Choose one. Clubfoot is a developmental deformity of the foot in which one or both feet are excessively plantar flexed. This information will be located in the fetal MRI report. Look for terms such as clubfoot, talipes equinovarus, talipes.
MHH.210. Hydrops	No, Yes	Choose one. Hydrops refers to abnormal fluid collections in fetal soft tissues and cavities. This information will be located in the fetal MRI report. Look for terms such as hydrops, fetal edema, or hydrops fetalis.
MHH.211. Ascites	No, Yes	Choose one. Ascites is accumulation of fluid in the abdominal cavity and can be detected on prenatal imaging. This information will be located in the fetal MRI report. Look for terms such as ascites or abnormal accumulation of fluid in the abdominal cavity.
MHH.212. Other If yes, describe.	No, Yes Free text field	Choose one. This information will be located in the fetal MRI report. Describe any abnormal results from that have not been described. If there are multiple abnormalities, separate each with a semi-colon and a space.
MHH.213. Description of abnormal MRI findings	Free text field	Describe any abnormal results verbatim from the fetal MRI report including the actual description of any abnormalities noted in MHH.192 – MHH.212. If there are multiple abnormalities, separate each with a semi-colon and a space.

Question	Acceptable Responses	Abstraction Instructions
MHH.214. Amniocentesis performed	No, Yes	Choose one. This information might be found in the prenatal visit notes, laboratory results, or there may be a separate procedure note. It might be abbreviated as amnio. Information on Zika virus testing on amniotic fluid from amniocentesis, record in the Laboratory Results form. If cytogenetic testing is performed from amniotic fluid from amniocentesis, enter in MHH.215–228.

Prenatal (Fetal) Cytogenetic Testing

Question	Acceptable Responses	Abstraction Instructions
MHH.215, 222. Prenatal (fetal) cytogenetic testing performed	No, Yes	Choose one. This information might be found in the medical records under genetic testing or the specific tests. If no, skip to MHH.229.
MHH.216, 223. Cytogenetic Tests	Karyotype, FISH, CGH microarray, Cell-free DNA, Other, specify Free text field	Choose one. If other, specify in the free text field. This information might be found in the medical records under genetic testing or the specific tests.
MHH.217, 224. Date of test	mm/dd/yyyy	Enter date of cytogenetic test. This information might be found in the medical records under genetic testing or the specific tests.
MHH.218, 225. Gestational Age (weeks, days) or Trimester	Whole number OR Trimester: 1 st , 2 nd , 3 rd	Enter the gestational age OR choose one trimester. This information might be found in the medical records under genetic testing or the specific tests. If not found, gestational age may be calculated based on the estimated date of delivery; an online pregnancy calculator (e.g., http://www.medcalc.com/pregnancy.html , http://www.calculator.net/pregnancy-calculator.html) OR pregnancy wheel (e.g., http://www.prokerala.com/health/pregnancy/pregnancy-wheel/) can help calculate gestational age.
MHH.219, 226. Specimen type	Amniocentesis, Chorionic Villus Sampling (CVS), Maternal Serum, Other, specify Free text field	Choose one. If other, specify in the free text field. This information might be found in the medical records under genetic testing or the specific tests.

Question	Acceptable Responses	Abstraction Instructions
MHH.220, 227. Test result	Normal, Abnormal, Unknown	Choose one. This information might be found in the medical records under genetic testing or the specific tests.
MHH. 221, 228. Description of abnormal cytogenetic testing findings	Free text field	If abnormal results indicated in MHH.220 or 227, describe cytogenetic testing findings. This information might be found in the medical records under genetic testing or the specific tests.

Health Department Information

Question	Acceptable Responses	Abstraction Instructions
MHH.229. Name of person completing form	Free text field	Enter the full name of the person completing the form.
MHH.230. Phone	Free text field	Enter the phone number of the person completing the form.
MHH.231. Email	Free text field	Enter the email of the person completing the form.
MHH.232. Date form completed	mm/dd/yyyy	Enter the date of form completion.

* Alabama (AL), Alaska (AK), American Samoa (AS), Arizona (AZ), Arkansas (AR), California (CA), Colorado (CO), Connecticut (CT), District of Columbia (DC), Delaware (DE), Federated States of Micronesia (FSM), Florida (FL), Georgia (GA), Guam (GU), Hawaii (HI), Idaho (ID), Illinois (IL), Indiana (IN), Iowa (IA), Kansas (KS), Kentucky (KY), Louisiana (LA), Maine (ME), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Mississippi (MS), Missouri (MO), Montana (MT), Nebraska (NE), Nevada (NV), New Hampshire (NH), New Jersey (NJ), New Mexico (NM), New York (NY), North Carolina (NC), North Dakota (ND), Northern Mariana Islands (MP), Ohio (OH), Oklahoma (OK), Oregon (OR), Pennsylvania (PA), Republic of Palau (RP), Rhode Island (RI), South Carolina (SC), South Dakota (SD), Tennessee (TN), Texas (TX), US Virgin Islands (USVI), Utah (UT), Vermont (VT), Virginia (VA), Washington (WA), West Virginia (WV), Wisconsin (WI), Wyoming (WY)

Neonatal Assessment at Delivery Form

Neonate Assessment

Question	Acceptable Responses	Abstraction Instructions
NAD.1. Infant's state/territory ID	Free text field	Enter the infant's jurisdiction ID. This is a jurisdiction-specific identifier chosen by the Health Department
NAD.2. Mother's state/territory ID	Free text field	Enter the mother's jurisdiction ID. This is a jurisdiction-specific identifier chosen by the Health Department.
NAD.3. Infant Date of Birth	mm/dd/yyyy Live birth, Stillbirth ≥ 20 weeks	Enter the infant's date of birth. For jurisdictions that cannot provide date of birth, please provide month and year of birth and gestational age at birth, and list date as '15'. Choose one: live birth or stillbirth. Information on liveborn or stillborn infants may be found in the delivery notes.
NAD.4. Sex	Male, Female, Ambiguous/ undetermined	Choose one. This information might be found in the delivery notes, first pediatric examination of the patient, or pediatric History and Physical (H&P).
NAD.5. Gestational age at delivery (weeks/days)	Whole numbers	Enter the weeks and days of the infant's gestational age at delivery. This information might be found in the delivery note or pediatric H&P. This may be abbreviated as GA or gest age.
NAD.6. Gestational age based on (<i>check all that apply</i>)	LMP Date mm/dd/yyyy, 1 st trimester ultrasound, 2 nd trimester ultrasound), 3 rd trimester ultrasound), Other _____ Free text field	Check all that apply. Select how the estimated date of delivery (EDD), and therefore the gestational age, was determined. This information might be found in the obstetric admission notes (H&P) or prenatal ultrasound. You may need to determine the trimester when the ultrasound occurred. If gestational age was based on LMP, enter the first date of last menstrual period (LMP). This might be found in the H&P or in prenatal visit notes. If none of these are available, please describe how the infant's gestational age was determined.
NAD.7. Maternal age at delivery (years)	Whole number	Enter the maternal age at delivery. This information might be found in the delivery notes or in the maternal history.
NAD.8. State/Territory reporting	Free text field (Drop down in PDF-fillable forms)	Enter the abbreviation for reporting jurisdiction.*

Question	Acceptable Responses	Abstraction Instructions
NAD.9. County reporting	Free text field	Enter the county of the reporting jurisdiction.
NAD.10. Delivery type	Vaginal, Caesarean section	Choose one. This information might be found in the delivery note, operative note, or pediatric H&P. Look for terms such as Vaginal or Caesarean section. Vaginal is often abbreviated as vag, NSVD (normal spontaneous vaginal delivery), SVD (spontaneous vaginal delivery, AVD (assisted vaginal delivery), VAVD (vacuum-assisted vaginal delivery), FAVD (forceps-assisted vaginal delivery). Vaginal delivery includes vaginal delivery assisted by forceps or vacuum. Caesarean section is often abbreviated as C/S, CD (cesarean delivery), or c-section.
NAD.11. Delivery complication	No, Yes	Choose one. This information might be found in the delivery note, operative note, neonatal H&P, or maternal or neonatal discharge summary. Look for terms uncomplicated delivery or delivery complicated by. Complications might include (but are not limited to): premature rupture of membranes (PROM), preterm premature rupture of membranes (PPROM), post-partum hemorrhage (PPH), preterm delivery, retained placenta, shoulder dystocia, birth injury, third or fourth degree laceration, deep vaginal laceration, uterine rupture, respiratory or cardiac arrest, meconium aspiration, or surgical complications during cesarean section (e.g., bladder, bowel, or ureteral injury).
NAD.12. If yes, please describe	Free text field	If yes marked for delivery complication (NAD.11), describe any complications that occurred during the delivery (e.g., postpartum hemorrhage, fetal distress).
NAD.13. Arterial Cord blood pH (<i>if performed</i>)	Number (up to 2 decimal places)	Enter the arterial cord blood pH if umbilical cord blood gas analysis performed. Umbilical cord blood gas is used to assess newborn metabolic condition at birth. This information might be found in the laboratory report, delivery note, or neonatal H&P.
NAD.14. Venous Cord blood pH (<i>if performed</i>)	Number (up to 2 decimal places)	Enter the venous cord blood pH if umbilical cord blood gas analysis performed. Umbilical cord blood gas is used to assess newborn metabolic condition at birth. This information might be found in the laboratory report, delivery note, or neonatal H&P.

Question	Acceptable Responses	Abstraction Instructions
NAD.15. Placental exam (based on pathology report)	No, Yes	Choose one. If there was an examination of the placenta by a hospital pathologist, select yes; otherwise, select no. This information might be found in a pathology report.
NAD.16. If yes,	Normal, Abruption, Inflammation, Other abnormality (please describe) Free text field	Check all that apply, if placental exam performed (indicated by 'Yes' in NAD.15). Describe any other abnormalities found on the placental exam. If there are multiple abnormalities, separate each with a semi-colon and a space. This information might be found on a pathology report. Look for terms such as placental implantation abnormalities, placental abruption, inflammation, circumvallate placenta, placenta accreta, multi-lobed placenta succenturiate, hydatidiform mole, velamentous cord insertion.
NAD.17. Apgar score 1 min / 5 min	Whole number	Enter the infant's APGAR scores for 1 minute and 5 minutes after delivery. This might be found in the delivery note, operative note, and neonatal H&P. Values range from 0 to 10.
NAD.18. Infant Temp (if abnormal)	Number (up to 2 decimal places)	If the infant's temperature (temp) was abnormal ($T \geq 38^{\circ}\text{C}$ (100.4°F) or $\leq 36^{\circ}\text{C}$ (96.8°F) at birth, please record the temperature. Please enter either $^{\circ}\text{C}$ or $^{\circ}\text{F}$, not both. This information might be found in the neonatal H&P.

Physical Examination

Question	Acceptable Responses	Abstraction Instructions
NAD.19. Birth head circumference	Number (up to 2 decimal places)	Record the infant's head circumference (HC). This information should come from the head circumference measured at or within 24 hours of birth. Please fill inches or centimeters, not both. This may appear in the medical record as Occipital-Frontal Circumference (OFC) or HC.
NAD.20. Molding present	Check box	Check if present. Check if delivery note or neonatal H&P indicates that molding was present at birth. Molding is a temporary asymmetry of the skull caused by overlapping or overriding of the sutures; molding might be caused by passage through the birth canal.

Question	Acceptable Responses	Abstraction Instructions
NAD.21. Physician Report	Normal, Abnormal	Choose one. This information should come from the neonatal H&P from the first infant exam. Use clinician's assessment of whether the head circumference was normal or abnormal as documented in the medical record. This might be abbreviated as OFC or HC or head circ.
NAD.22. HC percentile	Whole number	Using the intergrowth21st newborn standards (http://intergrowth21.ndog.ox.ac.uk/), determine head circumference percentile by using head circumference (NAD.19), infant sex (NAD.4), and gestational age at delivery (NAD.5). If this cannot be determined due to a missing variable, use the HC percentile documented in the medical record.
NAD.23. Birth Weight (grams or lbs and oz)	Whole number	Enter the neonatal weight at birth. Enter either in grams or pounds and ounces, not both. This might be found in the delivery note or neonatal H&P.
NAD.24. Birth weight percentile	Whole number	Using the intergrowth21st newborn standards (http://intergrowth21.ndog.ox.ac.uk/), determine birth weight percentile using birthweight (NAD.24), infant sex (NAD.4), and gestational age at delivery (NAD.5). If this cannot be determined due to a missing variable, use birthweight percentile documented in the medical record.
NAD.25. Birth Length (cm or in)	Number (up to 2 decimal places)	Enter the length at birth. Enter centimeters or inches, not both. This should be identified from the delivery note or neonatal H&P.
NAD.26. Birth length percentile	Whole number	Using the intergrowth21st newborn standards (http://intergrowth21.ndog.ox.ac.uk/), determine the birth length percentile using birth length (NAD.26), infant sex (NAD.4), and gestational age at delivery (NAD.5). If this cannot be determined due to a missing variable, use birth length percentile documented in the medical record.
NAD.27. Repeat head circumference	Number (up to 2 decimal places)	Record the repeat head circumference. This information might be found in the infant's progress notes. Enter cm or in, not both. This measurement should be performed at least 24 hours after birth.
NAD.28. Date performed or age in days	mm/dd/yyyy OR Whole number	Enter the date repeat head circumference performed OR the age of the infant at time of measurement in days. This information might be found in the infant progress notes.

Question	Acceptable Responses	Abstraction Instructions
NAD.29. Physician Report	Normal, Abnormal	Choose one. This information might be found in the clinician's assessment of the repeat head circumference and documentation of normal or abnormal in the medical record. Please do not make a personal determination based on reported findings.
NAD.30. Repeat HC percentile	Whole number	Using the intergrowth21st newborn standards (http://intergrowth21.ndog.ox.ac.uk/), determine the repeat head circumference percentile using repeat head circumference (NAD.27), infant sex (NAD.4), and gestational age at delivery (NAD.5). If this cannot be determined due to a missing variable, use repeat head circumference percentile documented in the medical record.
NAD.31. Admitted to Neonatal Intensive Care Unit If yes, reason	No, Yes Free text field	Choose one. If yes, describe the reason why the infant was admitted to the NICU. This information might be found in the progress notes and there may be separate notes from the NICU.
NAD.32. Neonatal Death	No, Yes	Choose one. Indicate if neonatal death (death <28 days) occurred. The information might be found in the infant's progress notes, death note or death certificate, or discharge summary.
NAD.33. Date or Age at death in days	mm/dd/yyyy Whole number	If a neonatal death occurred ('Yes' for NAD.32), enter the date of death OR the age at death in days. The information might be found in the infant's progress notes, death note or death certificate, or discharge summary.
NAD.34. Cause of death	Free text field	If there was a neonatal death ('Yes' for NAD.32), describe the cause of neonatal death. The information might be found in the infant's progress notes, death note or death certificate, or discharge summary.
NAD.35. Microcephaly (head circumference <3%ile)	No, Yes	Choose one. Please check 'Yes' if the health care provider reported microcephaly or small head in the medical records. If there is no record of microcephaly or small head, check 'No.'
NAD.36. Seizures	No, Yes	Choose one. This information might be found in the infant's progress notes or H&P.
NAD.37. Neurologic Exam: <i>check all that apply</i>	Check all specific findings that apply	Select whether the infant had a neurologic exam performed and document findings. This information might be found in the infant's H&P, progress notes, or consult notes.

Question	Acceptable Responses	Abstraction Instructions
	Not performed	Check if neurologic exam was not performed.
	Unknown	Check if it is unknown if neurologic exam was performed.
	Normal	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note.
	Hypertonia /Spasticity	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as hypertonia, hypertonic, spasticity, increased muscle tone.
	Hyperreflexia	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as hyperreflexia, hyperreflexic, increased reflexes.
	Irritability	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as irritable, excessive crying/fussiness.
	Tremors	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as tremors, jitteriness, jerking of arms/legs, myoclonus.
	Other neurologic abnormalities	Check if any other neurologic abnormalities are present that are not already specified. This information might be found in the infant's H&P, progress notes, or consult/referral note.
NAD.38. Please describe below	Free text field	If, 'Other neurologic abnormalities' is checked, describe the abnormalities found <u>on the neurologic exam</u> not already specified. If there are multiple abnormalities, separate each with a semi-colon and a space. This information might be found in the progress notes, consult notes or infant's H&P. Look for terms such as floppy, atonic, hypotonic, abnormal (as applied to flexor tone, extensor tone, pupillary response, blink reflex, doll's eye phenomenon, corneal reflex, response to noise, gag, moro, grasp, sucking, rooting, and stepping reflexes).

Question	Acceptable Responses	Abstraction Instructions
NAD.39. Splenomegaly <i>by physical exam:</i>	No, Yes, Unknown	Choose one. This information might be found in the infant's progress notes or H&P. Use clinician's determination of whether splenomegaly is present as noted in the physical exam and assessment. Look for terms such as splenomegaly, enlarged spleen.
NAD.40. Please describe	Free text field	If yes, describe any abnormalities found. This information might be found in the infant's progress notes or H&P.
NAD.41. Hepatomegaly <i>by physical exam</i>	No, Yes, Unknown	Choose one. This information might be found in the infant's progress notes or H&P. Use clinician's determination of whether hepatomegaly is present as noted in the physical exam and assessment. Look for terms such as hepatomegaly, enlarged liver.
NAD.42. Please describe	Free text field	If yes, describe the liver size or other abnormalities found. This information might be found in the infant's progress notes or H&P.
NAD.43. Skin Rash <i>by physical exam</i>	No, Yes, Unknown	Choose one. This information might be found in the infant's progress notes or H&P. Look for a maculopapular rash, exanthem, papules, or macules. Exclude common newborn skin conditions such as milia, pustular melanosis, erythema toxicum, melanosis, acne, mongolian spot, nevus, seborrhea, and dermatitis.
NAD.44. Please describe	Free text field	If yes, describe the skin abnormalities. This information might be found in the infant's progress notes or H&P.
NAD.45. Other abnormalities identified: <i>please check all that apply</i>	Check all specific findings that apply	Identify abnormalities on physical exam not already specified, including facial, cardiac, renal, respiratory, gastrointestinal, genitourinary, genetic, and chromosomal abnormalities. This information might be found in the infant's H&P, progress notes, or consult notes.
	Fetal Brain Disruption Sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)	Check if 'fetal brain disruption sequence' is listed in the medical record or if all the following are present: microcephaly, overlapping sutures, prominent occipital bone, scalp rugae. This information might be found in the infant's H&P, progress notes, or consult notes. In addition to listed terms, other possible terms include excessive and/or redundant scalp skin, thick scalp skin folds.

Question	Acceptable Responses	Abstraction Instructions
	Encephalocele	<p>Check if present. This information might be found in the infant's H&P, progress notes, or consult notes.</p> <p>Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.</p>
	Anencephaly/ Acrania	<p>Check if present. This information might be found in the infant's H&P, progress notes, or consult notes.</p> <p>Anencephaly is partial or complete absence of brain and skull. Acrania is absence of skull bones with some brain tissue present. Look for terms such as anencephaly, acrania, absent brain, craniorachischisis, exencephaly, iniencephaly, holoanencephaly, meroanencephaly.</p>
	Spina bifida	<p>Check if present. This information might be found in the infant's H&P, progress notes, or consult notes.</p> <p>Spina bifida is incomplete closure of the vertebral spine through which spinal cord tissue and/or meninges herniate. Look for terms such as spina bifida, neural tube defect, myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, meningomyelocele, myelocystocele, myelodysplasia, myeloschisis, rachischisis, spina bifida aperta, spina bifida cystica. Although the spina bifida lesion will be located along the spine, spina bifida is often associated with a cranial lesion termed Arnold-Chiari II malformation involving downward displacement of the hindbrain and 4th ventricle.</p>

Question	Acceptable Responses	Abstraction Instructions
	Holoprosencephaly/ arhinencephaly	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
	Microphthalmia/ Anophthalmia	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Microphthalmia is reduced volume of the eye. Anophthalmia is total absence of eye tissue or apparent absence of the globe of the eye in an otherwise normal orbit. Look for terms such as microphthalmia, small eyes, small palpebral fissures, anophthalmia, nanophthalmia. NOTE: if infant has eye abnormalities, please document name and contact information for ophthalmologist.
	Arthrogryposis (congenital joint contractures)	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Arthrogryposis refers to contractures (abnormal shortening and stiffness of the muscles, tendons, and ligaments/or) of the limbs that is present at birth. The contractures can be fixed or more flexible, and can involve all, most, or a single joint. Look for terms such as arthrogryposis, arthrogryposis multiplex congenita, congenital contractures, fetal akinesia sequence, limitation of movements, joint ankyloses, joint contractures, and decreased flexibility.
	Congenital Talipes Equinovarus (clubfoot)	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Clubfoot is a developmental deformity of the foot in which one or both feet are excessively plantar flexed. This information will be located in the prenatal ultrasound report. Look for terms such as clubfoot, talipes equinovarus, talipes.

Question	Acceptable Responses	Abstraction Instructions
	Congenital Hip dislocation/ developmental dysplasia of the hip	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Congenital hip dislocation results from abnormal development of the acetabulum and femur and is identified by mechanical instability of hip joint on exam. Look for terms such as congenital hip dislocation, developmental dysplasia of the hip, DDH, congenital hip dysplasia, teratologic hip dislocation.
	Other abnormalities	Check if there are other abnormalities on physical exam as described in the medical record not already specified. These might include colobomas, cataracts, or other abnormalities detected on physical exam. This information might be found in the infant's H&P, progress notes, or consult notes.
	Free text field	If yes, describe the other abnormalities. This information might be found in the infant's H&P, progress notes, or consult notes. Look for terms such as eye defect, hearing deficit, difficulty moving extremities, hemorrhage/excessive bleeding.
	Free text field	If yes, describe the other abnormalities. This information might be found in the infant's H&P, progress notes, or consult notes. Look for terms such as eye defect, hearing deficit, difficulty moving extremities, hemorrhage/excessive bleeding.
NAD.46. Please describe below	Free text field	If yes, describe the other abnormalities. This information might be found in the infant's H&P, progress notes, or consult notes. Look for terms such as eye defect, hearing deficit, difficulty moving extremities, hemorrhage/excessive bleeding.

Neonate Imaging and Diagnostics

Question	Acceptable Responses	Abstraction Instructions
NAD.47. Hearing screening: (Date__) or Age__day(s)	mm/dd/yyyy Numerical	Infants routinely undergo a hearing screening test at birth, and may be referred for audiologic testing if the screen is abnormal. Enter the date of the initial hearing screening OR age (in days) at hearing screening. This information might be

Question	Acceptable Responses	Abstraction Instructions
		found in the infant's progress notes or in a separate consult note.
NAD.48. Hearing screening result	Pass, Fail, Inconclusive/Needs retest, Not performed	Choose one. This information might be found in an infant's H&P, progress note, or consult/referral note.
NAD.49. Please describe	Free text field	If the infant hearing screening was abnormal, please describe the findings. This information might be found in a progress note or a separate consult note.
NAD.50. Audiological evaluation	Not performed, Auditory brainstem response (ABR) test performed, Otoacoustic emissions (OAE) test performed, Acoustic stapedius reflex (ASR) test performed, or Unknown	Choose one. Indicate which audiologic test was performed. This information might be found in the infant's progress notes or a separate consult note.
NAD.51. If performed, Date	mm/dd/yyyy	If audiologic evaluation was performed, enter the date the test was done. This information might be found in the infant's progress note or a separate consult note.
NAD.52. Audiologic evaluation result	Normal, Abnormal	Choose one. This information might be found in the infant's progress notes or a separate consult note.
NAD.53. Please describe	Free text field	Describe results of audiologic evaluation. This information might be found in the infant's progress notes or a separate consult note.
NAD.54. Retinal exam (with dilation)	Not Performed, Performed, Unknown	Choose one. This information might be found in the infant's progress notes or a separate consult note.
NAD.55. If performed: (Date__) or Age__day(s)	mm/dd/yyyy Whole number	If a retinal evaluation was performed, please enter the date of the exam or if unknown, enter infant's age in days. This information might be found in the infant's progress note, consult note, discharge summary, or outpatient visit note. The retinal exam might be performed as an outpatient and thus might be found in an outpatient visit note or consult note.

Question	Acceptable Responses	Abstraction Instructions
NAD.56. Please check all that apply	Check all specific findings that apply	Choose all types of abnormalities seen on retinal exam and please list other abnormalities that are not listed.
	Normal	If no abnormalities are described, choose normal.
	Microphthalmia/ Anophthalmia	Check if present. This information might be found in the infant's progress note, consult note, discharge summary, or outpatient visit note. Microphthalmia is reduced volume of the eye. Anophthalmia is total absence of eye tissue or apparent absence of the globe of the eye in an otherwise normal orbit. Look for terms such as microphthalmia, small eyes, small palpebral fissures, anophthalmia, nanophthalmia.
	Coloboma	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. A coloboma is an abnormality of the eye where pieces of the eye structure are missing. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as coloboma (of any part of the eye), ocular coloboma, uveoretinal coloboma.
	Cataract	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. A cataract is an opacity of the lens of the eye. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as cataract, infantile cataract, anterior polar cataract, lamellar cataract, nuclear cataract, posterior lentiglobus/lenticonus cataract, posterior cortical cataract, sectoral cataract, zonular cataract.
	Intraocular calcifications	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. These are abnormal deposits of calcium in the eye. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as intraocular calcifications, calcifications in the lens, vitreous, or other eye structure.

Question	Acceptable Responses	Abstraction Instructions
	Chorioretinal atrophy, scarring, macular pallor, gross pigmentary mottling, or retinal hemorrhage, excluding retinopathy of prematurity	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. These represent changes in the retina and/or choroid, and are a sign of injury from infection, bleeding, or hypoxia. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as abnormalities of the choroid, retina, or macula, including atrophy, hypoplasia, scarring, calcification, pigmentary mottling or clumping, hyperpigmentation, abnormal blood vessels, inflammation or infection. Other terms include chorioretinitis, retinitis, scarring, macular pallor, mottling, retinal hemorrhage.
	Other retinal abnormalities	Check if any other abnormal retina exam findings are present, not already specified. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note.
	Optic nerve atrophy, pallor	Check if present. This includes abnormalities of the optic nerve. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. Look for terms such as any abnormalities of the optic nerve, optic disc, or optic cup including atrophy, hypoplasia, or pallor.
	Other optic nerve abnormalities	Check if any other abnormal optic nerve findings are present, not already specified. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. Look for terms such as optic nerve abnormalities, double-ring sign, increased optic cup-to-disc ratio, increased optic disc cupping.
NAD.57. Please describe below	Free text field	Describe any abnormalities from retinal exam as recorded in the infant's medical records.
NAD.58, 62, 66. Imaging Study	Cranial ultrasound, MRI, CT, or Not Performed	Choose one. Indicate whether an imaging study was performed. If imaging was performed, record the type of imaging study, starting with the first study. This information will be found in the infant's imaging (radiology) results. Cranial ultrasound may be abbreviated to cranial US or u/s. MRI is the abbreviation for magnetic resonance imaging study. CT may also be referred

Question	Acceptable Responses	Abstraction Instructions
		to as CAT scan or computed axial tomography.
NAD.59, 63, 67. (Date:__) or Age__day(s)	mm/dd/yyyy Whole number	Enter the date the imaging study was performed OR if date is not known enter the infant's age in days.
NAD.60, 64, 68. Findings: check all that apply	Check all specific findings that apply	Check all abnormalities seen on imaging report.
	Normal	If no abnormalities are described, Check normal.
	Microcephaly	Check if present. This information will be located in the infant's imaging report. Microcephaly is the finding of a small head when compared with infants of the same sex and gestational age, and is a sign that the brain is abnormally small. This may be found in the imaging report. Look for terms such as microcephaly or microcephalic. Please use the radiologist's determination of microcephaly in the medical record; do not provide your own determination of microcephaly based on reported measurements. It might be helpful to obtain and securely transmit a redacted version of the neonatal imaging findings.
	Intracranial calcification	Check if present. This information will be located in the infant's imaging report. Intracranial calcifications are accumulations or deposits of calcium within the brain tissue and are a sign of brain injury from infection, hemorrhage, or lack of oxygen. Look for terms such as intracranial calcifications, or calcium deposits within the brain.
	Cerebral/cortical atrophy	Check if present. This information will be located in the infant's imaging report. Cerebral or cortical atrophy refers to loss of cells within the two cerebral hemispheres (the main portion of the brain). Look for terms such as cerebral (or cortical, periventricular, white matter, gray matter) atrophy or brain dysgenesis.

Question	Acceptable Responses	Abstraction Instructions
	Abnormal cortical gyral patterns (lissencephaly, pachygyria, agyria, microgyria, polymicrogyria, schizencephaly)	<p>Check if present. This information will be located in the infant's imaging report. Lissencephaly is a smooth cerebral cortex. Pachygyria is a simplified gyral pattern and is considered a subset of lissencephaly by some.</p> <p>Microgyria and polymicrogyria are small cortical ridges. Schizencephaly is a cleft in the cerebral hemisphere.</p> <p>Look for terms such as lissencephaly, agyria, pachygyria, incomplete lissencephaly, microgyria, polymicrogyria, simplified gyral pattern, schizencephaly, gray matter heterotopia, neuronal migration/maturation disorder, ectopia, marginal glioneuronal heterotopia, leptomeningeal heterotopia, or minor cortical dysplasias.</p>
	Corpus callosum abnormalities	<p>Check if present. This information will be located in the infant's imaging report. The corpus callosum is a band of nerve fibers in the central brain that joins the two cerebral hemispheres. Look for terms such as agenesis or missing corpus callosum, hypoplasia or thinning of the corpus callosum, dysgenesis of the corpus callosum.</p>
	Cerebellar abnormalities	<p>Check if present. This information will be located in the infant's imaging report. Look for terms such as cerebellar atrophy, agenesis, hypoplasia, or dysplasia. Terms may include any part of the cerebellum including the olive, pons, (inferior) vermis, or cerebellum in general, and may combine anatomical locations (e.g., olive + pons + cerebellum = olivopontocerebellar).</p> <p>Dandy Walker malformation, mega cisterna magna, tectocerebella dysgraphia, rhombencephalsynapsis, and cerebellar cyst are included in this category.</p>
	Porencephaly	<p>Check if present. This information will be located in the infant's imaging report. Porencephaly describes a cavity or cyst in the cerebral hemisphere. Look for porencephaly, porencephalic cyst or cavity, encephaloclastic porencephaly, developmental porencephaly.</p>

Question	Acceptable Responses	Abstraction Instructions
	Hydranencephaly	Check if present. This information will be located in the infant's imaging report. In hydranencephaly, the cerebral hemispheres are replaced by fluid-filled sacs. Look for hydranencephaly or hydroanencephaly.
	Moderate or severe ventriculomegaly/hydrocephaly	Check if present. This information will be located in the infant's imaging report. Look for terms such as hydrocephalus and large, enlarged, or dilated cerebral ventricles (which may be specified as lateral, third or fourth ventricles), or hydrocephalus. Specific types might include aqueductal stenosis, occlusion of the foramina of Monro, and communicating hydrocephalus. There are also ventricles in the heart; be sure this is a cranial and not a cardiac finding.
	Fetal brain disruption sequence (collapsed skull, craniofacial disproportion, overlapping sutures, biparietal depression, prominent occiput, scalp rugae, excess nuchal skin)	Check if present or if multiple contributing features are mentioned. This information will be located in the infant's imaging report. Fetal brain disruption sequence is a pattern of congenital abnormalities that include severe microcephaly, overlapping cranial sutures, prominence of the occipital bone, and scalp rugae (excessive folding of the skin). All components of the fetal brain disruption sequence (microcephaly, overlapping sutures, prominent occipital bone, scalp rugae) must be present for this to be checked.
	Other major brain abnormalities	Check if present and describe under NAD.61/65/69 below. This information will be located in the infant's imaging report. Other brain abnormalities might include intraventricular hemorrhage that occurs in utero, absence of septum pellucidum, Arnold-Chiari or Chiari malformation, septo-optic dysplasia, colpocephaly, bilateral or multiple unilateral (all on the same side) subependymal cysts or pseudocysts, periventricular leukomalacia (not due to prematurity), large or prominent cisterna magna, or atrophy, aplasia, hypoplasia, or dysplasia of any part of brain not listed above.

Question	Acceptable Responses	Abstraction Instructions
	Encephalocele	Check if present. This information will be located in the infant's imaging report. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.
	Holoprosencephaly /arhinencephaly	Check if present. This information will be located in the infant's imaging report. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
	Other abnormalities	Check if there are other abnormalities as described on imaging report not already specified and describe under NAD.61/65/69 below. Other abnormalities that might be detected in imaging include microphthalmia, anophthalmia, intraocular calcifications, or other abnormalities.
NAD.61, 65, 69. Please describe other abnormalities below	Free text field	Describe any abnormalities verbatim from the infant's imaging report, including the actual description of any abnormalities noted in NAD 60, 64, 68. If there are multiple abnormalities, separate each with a semi-colon and a space.
NAD.70. Was a lumbar puncture performed	Yes, No, Unknown	Choose one. Indicate whether a lumbar puncture (LP) was performed. This information might be found in the infant's progress notes, procedure notes, or laboratory results. Look for terms such as cerebrospinal fluid (CSF) or LP.
NAD.71. (Date:__) OR Age__day(s)	mm/dd/yyyy Whole number	If a lumbar puncture was performed ('Yes for NAD.70), record the date of the lumbar puncture (LP) or infant's age. This information might be found in the infant's progress notes, procedure notes, or laboratory results. Look for terms such as cerebrospinal fluid (CSF) or LP.

Postnatal Infection Testing (includes urine culture for CMV)

Question	Acceptable Responses	Abstraction Instructions
NAD.72. Toxoplasmosis infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Look for terms such as <i>Toxoplasma gondii</i> or toxo. Tests performed might include PCR, IgM, IgG.
NAD.73. Cytomegalovirus infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Tests might include cytomegalovirus (CMV) PCR, IgM, IgG, urine shell viral culture.
NAD.74. Herpes Simplex infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Tests might include HSV PCR, IgM, IgG, culture, direct fluorescent antibody testing.
NAD.75. Rubella infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Testing might include rubella PCR, IgM, IgG.
NAD.76. Lymphocytic choriomeningitis virus infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Testing might include lymphocytic choriomeningitis virus (LCMV) culture, PCR, LCMV- specific antibody testing, or immunofluorescent staining (IFA) for LCMV.
NAD.77. Syphilis infection	No, Yes, Unknown	Choose one. If testing was performed, indicate the result of laboratory test in NAD.78. This information might be found in the infant's laboratory results, H&P, or progress notes. Testing might include RPR (rapid plasma reagin), VDRL (venereal disease research laboratory), EIA (enzyme immunoassay), FTA-ABS (fluorescent treponemal antibody absorption), TPPA (treponema pallidum particle agglutination assay), or darkfield microscopy.

Question	Acceptable Responses	Abstraction Instructions
NAD.78. If yes for any postnatal infection testing, please describe results	Free text field	This information should be based on the clinician's notes or laboratory records. Please include any information provided for each infection (NAD.72–77), including laboratory test dates and results, and any treatment.

Postnatal (Infant) Cytogenetic Testing

Question	Acceptable Responses	Abstraction Instructions
NAD.79. Cytogenetic Test	Karyotype, FISH, CGH microarray, Other, specify _____ Free text field	Choose all that apply. If 'Other' is selected, please specify the cytogenetic test performed.
NAD.80. Date	mm/dd/yyyy	Enter date of specimen collection for the cytogenetic test(s) selected in NAD.79.
NAD.81. Infant Age ___ months	Whole number	Enter infant age in months at the time of cytogenetic testing.
NAD.82. Specimen	Cord blood, Peripheral blood, Tissue, or Other, specify _____ Free text field	Choose type of specimen. If 'Other' is selected, please specify the specimen type.
NAD.83. Test Result	Normal, Abnormal, Unknown	Choose one.
NAD.84. Description of cytogenetic test findings (verbatim)	Free text field	Enter verbatim description of findings of cytogenetic testing.
NAD.85. Other tests/results/diagnosis (include dates)	Free text field	Record abnormal radiologic or laboratory findings not previously reported. Include dates. Do not record results for complete metabolic panels (CMP) or complete blood counts (CBC) <u>unless</u> thrombocytopenia (low platelet count below 100,000 platelets per microliter) is noted. Include any abnormal findings from referrals, consultations, or pediatric evaluations. Include the dates of any test or evaluation that resulted in an abnormal finding.

All Birth Defects Diagnosed or Suspected (Including Chromosomal Abnormalities and Syndromes)

Please note: the following are un-numbered variables on the NAD form. Enter all diagnostic codes pertaining to diagnosed or suspected birth defects or associated diagnoses and obtained from the fetus/infant's delivery and/or hospitalization records or outpatient follow-up. If more than six codes exist, continue listing subsequent codes on a supplemental sheet.

Question	Acceptable Responses	Abstraction Instructions
Diagnostic code 1		Enter first ICD-10 code for birth defect of interest or associated diagnosis. ICD-10 codes are billing codes and should be prominent in the medical record (often in the front of the chart).
Certainty 1	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).
Verbatim Description 1		Record verbatim description of birth defect from medical record.
Diagnostic code 2		Enter second ICD-10 code for birth defect of interest or associated diagnosis.
Certainty 2	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).
Verbatim Description 2		Record verbatim description of birth defect from medical record.
Diagnostic code 3		Enter third ICD-10 code for birth defect of interest or associated diagnosis.
Certainty 3	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).
Verbatim Description 3		Record verbatim description of birth defect from medical record.
Diagnostic code 4		Enter fourth ICD-10 code for birth defect of interest or associated diagnosis.
Certainty 4	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).

Question	Acceptable Responses	Abstraction Instructions
Verbatim Description 4		Record verbatim description of birth defect from medical record.
Diagnostic code 5		Enter fifth ICD-10 code for birth defect of interest or associated diagnosis.
Certainty 5	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).
Verbatim Description 5		Record verbatim description of birth defect from medical record.
Diagnostic code 6		Enter first ICD-10 code for birth defect of interest or associated diagnosis.
Certainty 6	Definite, or possible/probable	Choose one. Indicate whether the diagnosis is confirmed (e.g., verified by exam, imaging, or other testing) or suspected (e.g., rule/out, possible or probable, one of several differential conditions).
Verbatim Description 6		Record verbatim description of birth defect from medical record.

Health Department Information

Question	Acceptable Responses	Abstraction Instructions
NAD.86. Name of person completing form	Free text field	Enter full name of the person completing form.
NAD.87. Phone	Free text field	Enter phone number with area code of person completing form.
NAD.88. Email	Free text field	Enter email address of person completing form.
NAD.89. Date of form completion	mm/dd/yyyy	Enter the date of form completion.

* Alabama (AL), Alaska (AK), American Samoa (AS), Arizona (AZ), Arkansas (AR), California (CA), Colorado (CO), Connecticut (CT), District of Columbia (DC), Delaware (DE), Federated States of Micronesia (FSM), Florida (FL), Georgia (GA), Guam (GU), Hawaii (HI), Idaho (ID), Illinois (IL), Indiana (IN), Iowa (IA), Kansas (KS), Kentucky (KY), Louisiana (LA), Maine (ME), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Mississippi (MS), Missouri (MO), Montana (MT), Nebraska (NE), Nevada (NV), New Hampshire (NH), New Jersey (NJ), New Mexico (NM), New York (NY), North Carolina (NC), North Dakota (ND), Northern Mariana Islands (MP), Ohio (OH), Oklahoma (OK), Oregon (OR), Pennsylvania (PA), Republic of Palau (RP), Rhode Island (RI), South Carolina (SC), South Dakota (SD), Tennessee (TN), Texas (TX), US Virgin Islands (USVI), Utah (UT), Vermont (VT), Virginia (VA), Washington (WA), West Virginia (WV), Wisconsin (WI), Wyoming (WY)

Infant Follow-up Form

Question	Acceptable Responses	Abstraction Instructions
Infant follow up	2 months, 6 months, 12 months, or _____ months Whole number	Choose One. Choose the timeframe closest to the infant's chronological age at the time of clinician's exam. Use ___ months (completing blank) when infant is seen for a visit other than 2, 6, or 12 months. If less than 1 month enter as a decimal, 15 days old becomes 0.5 months.
IFU.1. State/Territory Reporting	Free text field (Drop down in PDF-fillable forms)	Select the abbreviation for reporting jurisdiction.*
IFU.2. Date of infant examination	mm/dd/yyyy	Enter the date infant examined, which might be found in the visit notes.
IFU.3. Infant's State/Territory ID	Free text field	Enter the infant's jurisdiction ID. This is a jurisdiction-specific identifier chosen by the Health Department.
IFU.4. Mother's State/Territory ID	Free text field	Enter the mother's jurisdiction ID. This is a jurisdiction-specific identifier chosen by the Health Department.
IFU.5. DOB	mm/dd/yyyy	Enter the infant's date of birth. For jurisdictions that cannot provide date of birth, please provide month and year of birth and gestational age at birth, and list date as '15'. This information might be found in many locations in the medical record, including the patient registration form.
IFU.6. Sex	Male, Female, Ambiguous/undetermined	Choose one. This information might be found on the visit notes.
IFU.7. Infant Death	No, Yes	Choose one. This information might be found in the infant's outpatient visit notes, inpatient discharge summary, or death certificate. This information might not be in the visit notes and could require telephone consultation/confirmation with the provider's office if death is suspected.
IFU.8. If yes, cause of death	Free text field	If yes, enter cause of death. This information might be found in the infant's outpatient visit notes, inpatient discharge summary, or death certificate. This information might not be in the visit notes and could require telephone consultation/confirmation with the provider's office if death is suspected.

Question	Acceptable Responses	Abstraction Instructions
IFU.9. If yes, Date or Age at death	mm/dd/yyyy, OR Whole number OR Unknown	If yes, enter the date of death, OR enter infant age at death (in days), OR check the box if unknown. This information might be found in the infant's outpatient visit notes, inpatient progress note, death note, or discharge summary, or death certificate. This information might not be in the visit notes and could require telephone consultation/confirmation with the provider's office if death is suspected.
IFU.10. Weight (grams or lbs and oz)	Number (up to 2 decimal places)	Enter the weight of the infant either in grams OR in pounds and ounces measured at the visit of record. This might be found in physician or nursing visit notes.
IFU.11. Length (cm or in)	Number (up to 2 decimal places)	Enter the length of the infant either in centimeters OR inches at the visit of record. This might be found in the physician or nursing visit notes.
IFU.12. Head circumference (cm or in)	Number (up to 2 decimal places)	Enter the head circumference of the infant either in centimeters OR inches at the visit of record. This might be found in the physician or nursing visit notes.
IFU.13. Infant findings for corrected age at examination: (For infants born preterm, please account for corrected age: chronological age minus weeks born before 40 weeks' gestation)	Check all findings that apply	Check any abnormalities reported by the pediatric healthcare provider on the infant's physical exam. These might be found in the clinical note for the visit or in laboratory testing, diagnostic imaging and referrals that originated/ordered during or shortly after the visit.
	Normal	Check if no abnormalities are present and the report documents only normal findings. This information might be found in the radiology report.
	Microcephaly (head circumference <3%ile)	Choose one. Please check 'Yes' if the health care provider reported microcephaly or small head in the medical records. If there is no record of microcephaly or small head, check 'No.'

Question	Acceptable Responses	Abstraction Instructions
	Fetal brain disruption sequence (collapsed skull, craniofacial disproportion, overlapping sutures, biparietal depression, prominent occiput, scalp rugae, excess nuchal skin)	Check if 'fetal brain disruption sequence' listed in the medical record or if all the following are present: microcephaly, overlapping sutures, prominent occipital bone, scalp rugae. This information might be found in the infant's outpatient visit notes or consult notes. In addition to listed terms, other possible terms include excessive and/or redundant scalp skin, thick scalp skin folds.
	Anencephaly/ acrania	Check if present. This information might be found in the infant's outpatient visit notes or consult notes. Anencephaly is partial or complete absence of brain and skull. Acrania is absence of skull bones with some brain tissue present. Look for terms such as anencephaly, acrania, absent brain, craniorachischisis, exencephaly, iniencephaly, holoanencephaly, meroanencephaly.
	Encephalocele	Check if present. This information might be found in the infant's visit notes or consult notes. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.

Question	Acceptable Responses	Abstraction Instructions
	Spina bifida	Check if present. This information might be found in the infant's outpatient visit notes, inpatient progress notes, or consult notes. Spina bifida is incomplete closure of the vertebral spine through which spinal cord tissue and/or meninges herniate. Look for terms such as spina bifida, neural tube defect, myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, meningomyelocele, myelocystocele, myelodysplasia, myeloschisis, rachischisis, spina bifida aperta, spina bifida cystica. Although the spina bifida lesion will be located along the spine, spina bifida is often associated with a cranial lesion termed Arnold-Chiari II malformation involving downward displacement of the hindbrain and 4 th ventricle.
	Holoprosencephaly / arhinencephaly	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. Might be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
	Microphthalmia/ Anophthalmia	Check if present. This information might be found in the infant's outpatient visit notes or consult notes. Microphthalmia is reduced volume of the eye. Anophthalmia is total absence of eye tissue or apparent absence of the globe of the eye in an otherwise normal orbit. Look for terms such as microphthalmia, small eyes, small palpebral fissures, anophthalmia, nanophthalmia. NOTE: if infant has eye abnormalities, please document name and contact information for ophthalmologist.
	Hypertonia/ Spasticity	Check if present. This information might be found in the infant's outpatient visit notes or consult/referral note. Look for terms such as hypertonia, hypertonic, spasticity, increased muscle tone.
	Hyperreflexia	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as hyperreflexia, hyperreflexic, increased reflexes.

Question	Acceptable Responses	Abstraction Instructions
	Irritability	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as irritable, excessive crying/fussiness.
	Tremors	Check if present. This information might be found in the infant's H&P, progress notes, or consult/referral note. Look for terms such as tremors, jitteriness, jerking of arms/legs, myoclonus.
	Splenomegaly	Check if present. This information might be found in the infant's progress notes or H&P. Use clinician's determination of whether splenomegaly is present as noted in the physical exam and assessment. Look for terms such as splenomegaly, enlarged spleen.
	Hepatomegaly	Check if present. This information might be found in the infant's progress notes or H&P. Use clinician's determination of whether hepatomegaly is present as noted in the physical exam and assessment. Look for terms such as hepatomegaly, enlarged liver.
	Skin rash	Check if present. This information might be found in the infant's progress notes or H&P. Look for terms such as maculopapular rash, exanthem, papules, or macules. Exclude common newborn skin conditions such as milia, pustular melanosis, erythema toxicum, melanosis, acne, mongolian spot, nevus, seborrhea, and dermatitis.
	Swallowing/feeding difficulties	Check if present. This information might be found in the infant's outpatient visit notes, consult notes, or H&P. Look for terms such as poor suck, poor feeding, choking, difficulty swallowing, coughing/sputtering with feeds, dysphagia, not interested in feeding, difficulty feeding, decreased oral intake, decreased appetite, anorexia, presence of a gastric feeding tube.
	Arthrogryposis (congenital joint contractures)	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Arthrogryposis refers to contractures (abnormal shortening and stiffness of the muscles, tendons, and ligaments/or) of the limbs that is present at birth. The contractures can be fixed or more flexible, and can involve all, most, or a single joint. Look for terms such as arthrogryposis,

Question	Acceptable Responses	Abstraction Instructions
		arthrogryposis multiplex congenita, congenital contractures, fetal akinesia sequence, limitation of movements, joint ankyloses, joint contractures, and decreased flexibility.
	Congenital Talipes Equinovarus (clubfoot)	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Clubfoot is a developmental deformity of the foot in which one or both feet are excessively plantar flexed. This information will be located in the prenatal ultrasound report. Look for terms such as clubfoot, talipes equinovarus, talipes.
	Congenital hip dislocation/ developmental dysplasia of the hip	Check if present. This information might be found in the infant's H&P, progress notes, or consult notes. Congenital hip dislocation results from abnormal development of the acetabulum and femur and is identified by mechanical instability of hip joint on exam. Look for terms such as congenital hip dislocation, developmental dysplasia of the hip, DDH, congenital hip dysplasia, teratologic hip dislocation.
	Other abnormalities	Check if there are other abnormalities on physical exam as described in the medical record not already specified. This information might be found in the infant's outpatient visit notes, consult notes, or other notes. List findings in IFU.14.
IFU.14. Please list other abnormal findings	Free text field	If yes, describe the other abnormalities. If there are multiple abnormalities, separate each with a semi-colon and a space. This information might be found in the infant's H&P, progress notes, or consult notes. Look for terms such as eye defect, hearing deficit, difficulty moving extremities, hemorrhage/excessive bleeding.

Question	Acceptable Responses	Abstraction Instructions
IFU.15 Development assessment for corrected age at examination: (For infants born preterm, please account for corrected age: chronological age minus weeks born before 40 weeks' gestation).	Normal, Abnormal, Unknown	Choose one. Please check only one option based on the physician report; if the physician states that development is abnormal, check abnormal. If the physician states development is normal, check normal. If the physician documents only normal findings from the chart below, check normal. If there is no developmental assessment, check unknown. This information might be found in visit notes from pediatrician visits (developmental milestones are often noted at routinely scheduled pediatric visits). There might also be consult notes, referral notes (to specialists or early intervention programs), and intake assessments for evaluation of developmental delays.
IFU.16. If developmental delay, in what area? Please check all that apply	Gross motor, Fine motor, Cognitive (linguistic and communication), Socio-Emotional	Check all that apply. Please choose all areas where developmental delay was reported by the pediatric health care provider. This might be found in the visit notes or consultation. Use developmental chart to assess.

Special Studies Since Last Follow-up

On the Infant Follow-Up Form is space to document two imaging studies. Each section repeats the same variables, thus they are combined in this guide. Please report each imaging study separately in the order in which it was performed after the infant's birth. If additional studies were done, please write in the 'Other tests/results/diagnosis' section below (IFU.37–39).

Question	Acceptable Responses	Abstraction Instructions
IFU.17, 21. Imaging study	Cranial ultrasound, MRI, CT, Other, Not performed, or Unknown Free text field	Choose one. If other is selected, please indicate study performed. Indicate whether an imaging study was performed. If imaging was performed, record the type of imaging study, starting with the first study. This information will be found in the infant's imaging (radiology) results. Cranial ultrasound may be abbreviated to cranial US or u/s. MRI is the abbreviation for magnetic resonance imaging study. CT may also be referred to as CAT scan or computed axialtomography.
IFU.18, 22. Date	mm/dd/yyyy	Enter the date the imaging study was performed.
IFU.19, 23. Findings: check all that apply	Check all findings that apply	Check all types of abnormalities seen on imaging study and please list other abnormalities that not listed.

Question	Acceptable Responses	Abstraction Instructions
	Normal	Check if no abnormalities are present and the report documents only normal findings. This information might be found in the imaging report.
	Microcephaly	Check if present. This information will be located in the infant's imaging report. Microcephaly is the finding of a small head when compared with infants of the same sex and age, and is a sign that the brain is abnormally small. This may be found in the imaging report. Look for terms such as microcephaly or microcephalic. Please use the radiologist's determination of microcephaly in the medical record; do not provide your own determination of microcephaly based on reported measurements. It may be helpful to obtain and securely transmit a redacted version of the neonatal imaging findings.
	Intracranial calcifications	Check if present. This information will be located in the infant's imaging report. Intracranial calcifications are accumulations or deposits of calcium within the brain tissue and are a sign of brain injury from infection, hemorrhage, or lack of oxygen. Look for terms such as intracranial calcifications, or calcium deposits within the brain.
	Cerebral/cortical atrophy	Check if present. This information will be located in the infant's imaging report. Cerebral or cortical atrophy refers to loss of cells within the two cerebral hemispheres (the main portion of the brain). Look for terms such as cerebral (or cortical, periventricular, white matter, gray matter) atrophy or brain dysgenesis.
	Abnormal cortical gyral patterns (lissencephaly, pachygyria, agyria, microgyria, polymicrogyria, schizencephaly)	Check one. This information will be located in the infant's imaging report. Lissencephaly is a smooth cerebral cortex. Pachygyria is a simplified gyral pattern and is considered a subset of lissencephaly by some. Microgyria and polymicrogyria are small cortical ridges. Schizencephaly is a cleft in the cerebral hemisphere. Look for terms such as lissencephaly, agyria, pachygyria, incomplete lissencephaly, microgyria, polymicrogyria, simplified gyral pattern, schizencephaly, gray matter heterotopia,

Question	Acceptable Responses	Abstraction Instructions
		neuronal migration/maturation disorder, ectopia, marginal glioneuronal heterotopia, leptomeningeal heterotopia, or minor cortical dysplasias.
	Corpus callosum abnormalities	Check if present. This information will be located in the infant's imaging report. The corpus callosum is a band of nerve fibers in the central brain that joins the two cerebral hemispheres. Look for terms such as agenesis or missing corpus callosum, hypoplasia or thinning of the corpus callosum, dysgenesis of the corpus callosum.
	Cerebellar abnormalities	Check if present. This information will be located in the infant's imaging report. Look for terms such as cerebellar atrophy, agenesis, hypoplasia, or dysplasia. Terms may include any part of the cerebellum including the olive, pons, (inferior) vermis, or cerebellum in general, and may combine anatomical locations (e.g., olive + pons + cerebellum = olivopontocerebellar). Dandy Walker malformation, mega cisterna magna, tectocerebella dysgraphia, rhomboencephalsynapsis, and cerebellar cyst are included in this category.
	Porencephaly	Check if present. This information will be located in the infant's imaging report. Porencephaly describes a cavity or cyst in the cerebral hemisphere. Look for terms such as porencephaly, porencephalic cyst or cavity, encephaloclastic porencephaly, developmental porencephaly.
	Hydranencephaly	Check if present. This information will be located in the infant's imaging report. In hydranencephaly, the cerebral hemispheres are replaced by fluid-filled sacs. Look for hydranencephaly or hydroanencephaly.
	Moderate or severe ventriculomegaly/hydrocephaly	Check if present. This information will be located in the infant's imaging report. Look for terms such as hydrocephalus and large, enlarged, or dilated cerebral ventricles (which may be specified as lateral, third or fourth ventricles), or hydrocephalus. Specific types might include aqueductal stenosis, occlusion of the foramina of Monro, and communicating hydrocephalus. There are also ventricles in the heart; be sure this is a cranial and

Question	Acceptable Responses	Abstraction Instructions
		not a cardiac finding.
	Fetal brain disruption sequence (collapsed skull, craniofacial disproportion, overlapping sutures, biparietal depression, prominent occiput, scalp rugae, excess nuchal skin)	Check if present or if multiple contributing features are mentioned. This information will be located in the infant's imaging report. Fetal brain disruption sequence is a pattern of congenital abnormalities that include severe microcephaly, overlapping cranial sutures, prominence of the occipital bone, and scalp rugae (excessive folding of the skin). All components of the fetal brain disruption sequence (microcephaly, overlapping sutures, prominent occipital bone, scalp rugae) must be present for this to be checked.
	Other major brain abnormalities	Check if present and describe under NAD.61/65/69 below. This information will be located in the infant's imaging report. Other brain abnormalities might include intraventricular hemorrhage that occurs in utero, absence of septum pellucidum, Arnold-Chiari or Chiari malformation, septo-optic dysplasia, colpocephaly, bilateral or multiple unilateral (all on the same side) subependymal cysts or pseudocysts, periventricular leukomalacia (not due to prematurity), large or prominent cisterna magna, or atrophy, aplasia, hypoplasia, or dysplasia of any part of brain not listed above.
	Encephalocele	Check if present. This information will be located in the infant's imaging report. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.
	Holoprosencephaly /arhinencephaly	Check if present. This information will be located in the infant's imaging report. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as

Question	Acceptable Responses	Abstraction Instructions
		holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia, cebocephaly, ethmocephaly.
	Other abnormalities	Check if there are other abnormalities as described on imaging report not already specified and describe under IFU 20, 24 below. This information will be located in the infant's imaging report. Look for terms such as such as ocular or eye abnormalities.
IFU.20, 24. Please describe below	Free text field	Describe any abnormalities verbatim from the infant's imaging report, including the actual description of any abnormalities noted in IFU 19, 23. If there are multiple abnormalities, separate each with a semi-colon and a space. This information will be located in the infant's imaging report.
IFU.25. Hearing screening or re-screening	Not performed, Performed, or Unknown	Choose one. If hearing screening or re-screening was not performed, performed, or unknown, please check the appropriate box. This might be found in the outpatient visit notes or consult note.
IFU.26. If performed, date	mm/dd/yyyy	If hearing screening or re-screening was performed, please enter the date performed.
IFU.27. Result of hearing screening or re-screening	Pass, Fail or referred	Choose one. This information might be found in an infant's outpatient visit note, or consult/referral note.
IFU.28. Please describe	Free text field	If 'Fail or referred' was selected for IFU.27, describe results of test. This information might be found in the infant's outpatient visit note or a separate consult note.
IFU.29. Audiological evaluation	Not performed, Performed, or Unknown	Choose one. If audiological evaluation not performed, performed, or unknown, please check the appropriate box. This might be found in the infant's outpatient visit notes or a consult/referral note.
IFU.30. If performed, date	mm/dd/yyyy	If audiological evaluation was performed, please enter the date of the exam. This information might be found in the infant's outpatient visit note or a separate consult note.
IFU.31. Result of audiological evaluation	Normal, Abnormal	Choose one. This information might be found in the infant's outpatient visit notes or a separate consult note.

Question	Acceptable Responses	Abstraction Instructions
IFU.32. Please describe	Free text field	If audiological exam was performed, please describe, including test performed, test results, and follow-up tests performed or referrals ordered. This information might be found in the infant's outpatient visit notes or a separate consult note.
IFU.33. Retinal exam (with dilation)	Not Performed, Performed, Unknown	Choose one. This information might be found in the infant's outpatient visit notes or a consult/referral note.
IFU.34. If performed: Date	mm/dd/yyyy	If a retinal evaluation was performed, please enter the date of the exam. This information might be found in the infant's outpatient visit note or consult note.
IFU.35. Findings: check all that apply	Check all findings that apply	Check all types of abnormalities seen on retinal exam and please list other abnormalities that are not listed.
	Microphthalmia/ anophthalmia	Check if present. This information might be found in the infant's progress note, consult note, discharge summary, or outpatient visit note. Microphthalmia is reduced volume of the eye. Anophthalmia is total absence of eye tissue or apparent absence of the globe of the eye in an otherwise normal orbit. Look for terms such as microphthalmia, small eyes, small palpebral fissures, anophthalmia, nanophthalmia.
	Coloboma	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. A coloboma is an abnormality of the eye where pieces of the eye structure are missing. This might be found in the outpatient visit notes or a consult/referral note. Look for terms such as coloboma (of any part of the eye), ocular coloboma, uveoretinal coloboma.
	Cataract	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. A cataract is an opacity of the lens of the eye. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as cataract, infantile cataract, anterior polar cataract, lamellar cataract, nuclear cataract, posterior

Question	Acceptable Responses	Abstraction Instructions
		lentiglobus/lenticonus cataract, posterior cortical cataract, sectoral cataract, zonular cataract.
	Intraocular calcifications	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. These are abnormal deposits of calcium in the eye. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as intraocular calcifications, calcifications in the lens, vitreous, or other eye structure.
	Chorioretinal atrophy, scarring, macular pallor, gross pigmentary mottling, or retinal hemorrhage, excluding retinopathy of prematurity	Check if present. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. These represent changes in the retina and/or choroid, and are a sign of injury from infection, bleeding, or hypoxia. This may be found in the outpatient visit notes or a consult/referral note. Look for terms such as abnormalities of the choroid, retina, or macula, including atrophy, hypoplasia, scarring, calcification, pigmentary mottling or clumping, hyperpigmentation, abnormal blood vessels, inflammation or infection. Other terms include chorioretinitis, retinitis, scarring, macular pallor, mottling, retinal hemorrhage.
	Other retinal abnormalities	Check if any other abnormal retina exam findings are present, not already specified. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note.
	Optic nerve atrophy, pallor	Check if present. This includes abnormalities of the optic nerve. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. Look for any terms such as abnormalities of the optic nerve, optic disc, or optic cup including atrophy, hypoplasia, or pallor.
	Other optic nerve abnormalities	Check if any other abnormal optic nerve findings are present, not already specified. This information might be found in an infant's progress note, consult note, discharge summary, or outpatient visit note. Look for terms such as optic nerve abnormalities, double-ring sign,

Question	Acceptable Responses	Abstraction Instructions
		increased optic cup-to-disc ratio, increased optic disc cupping.
IFU.36. Please describe	Free text field	Describe any abnormalities verbatim from the infant's retinal exam, including the actual description of any abnormalities noted in IFU 35.
IFU.37. Other abnormal tests/ results/ diagnosis	No, Yes	Choose one. Record abnormal radiologic or laboratory findings not previously reported. Include dates. Do not record results for complete metabolic panels (CMP) or complete blood counts (CBC) <u>unless</u> thrombocytopenia (low platelet count below 100,000 platelets per microliter) is noted. Include any abnormal findings from referrals, consultations, or pediatric evaluations. Include the dates of any test or evaluation that resulted in an abnormal finding.
IFU.38. Date	mm/dd/yyyy	If 'Other abnormal tests/ results/ diagnosis' checked Yes, enter date.
IFU.39. Please describe	Free text field	If 'Other abnormal tests/ results/ diagnosis' checked Yes, please describe.

Health Department Information

Question	Acceptable Responses	Abstraction Instructions
IFU.40. Name of person completing form	Free text field	Enter full name of the person completing the form.
IFU.41. Phone number of person completing form	Free text field	Enter phone number of the person completing the form.
IFU.42. Email of person completing form Email	Free text field	Enter email of the person completing the form.
IFU.43. Form Completion Date	mm/dd/yyyy	Enter the date of form completion.

* Alabama (AL), Alaska (AK), American Samoa (AS), Arizona (AZ), Arkansas (AR), California (CA), Colorado (CO), Connecticut (CT), District of Columbia (DC), Delaware (DE), Federated States of Micronesia (FSM), Florida (FL), Georgia (GA), Guam (GU), Hawaii (HI), Idaho (ID), Illinois (IL), Indiana (IN), Iowa (IA), Kansas (KS), Kentucky (KY), Louisiana (LA), Maine (ME), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Mississippi (MS), Missouri (MO), Montana (MT), Nebraska (NE), Nevada (NV), New Hampshire (NH), New Jersey (NJ), New Mexico (NM), New York (NY), North Carolina (NC), North Dakota (ND), Northern Mariana Islands (MP), Ohio (OH), Oklahoma (OK), Oregon (OR), Pennsylvania (PA), Republic of Palau (RP), Rhode Island (RI), South Carolina (SC), South Dakota (SD), Tennessee (TN), Texas (TX), US Virgin Islands (USVI), Utah (UT), Vermont (VT), Virginia (VA), Washington (WA), West Virginia (WV), Wisconsin (WI), Wyoming (WY)

Laboratory Results Form

Mother's Zika Virus Infection

Question	Acceptable Responses	Abstraction Instructions
LAB.1. State/territory reporting	Free text field (Drop down in PDF-fillable forms)	Select the abbreviation for reporting jurisdiction.*
LAB.2. State/territory ID	Free text field	Enter the mother's jurisdiction ID. This is a jurisdiction-specific identifier chosen by the Health Department.
LAB.3. Mother's ArboNET ID	Free text field	Please enter if known.
LAB.4. Infant's State/territory reporting	Free text field (Drop down in PDF-fillable forms)	Select the abbreviation for reporting jurisdiction, either the state or the territory.
LAB.5. Infant's State/territory ID	Free text field	Enter the infant's jurisdiction ID. This is a state or jurisdiction specific identifier chosen by the Health Department.
LAB.6. Infant's ArboNET ID	Free text field	Please enter if known.
LAB.7. Specimen Type If other specimen type, please specify	Check boxes Free text field	Choose one. Check the appropriate specimen type. Select only one per lab form. If other, please describe.
LAB.8. Location of testing	Commercial lab, State PHL, CDC	Choose one. Choose the location where the laboratory testing was performed. Commercial laboratories include Quest, LabCorp, Mayo, etc.
LAB.9. Lab specimen collection date	mm/dd/yyyy	Enter date specimen was collected.
LAB.10. Zika IgM performed?	No, Yes, Pending	Choose one.
LAB.11. Zika IgM result:	Positive, Negative, Equivocal, Inconclusive	Choose one result. If additional tests were performed, please indicate them separately on an additional lab form.
LAB.12. Dengue IgM performed?	No, Yes	Choose one.
LAB.13. Dengue IgM result:	Positive, Negative, Equivocal, Inconclusive	Choose one. If additional tests were performed, please indicate them separately on an additional lab form. If testing was inconclusive, repeat testing is recommended.
LAB.14. Zika RT-PCR performed?	No, Yes	Choose one.

Question	Acceptable Responses	Abstraction Instructions
LAB.15. Zika RT-PCR result:	Positive, Negative, Equivocal, Indeterminate	Choose one. If additional tests were performed, please indicate them separately on an additional lab form.
LAB.16. Dengue RT-PCR performed?	No, Yes	Choose one.
LAB.17. Dengue RT-PCR result:	Positive, Negative, Equivocal, Indeterminate	Choose one. If additional tests were performed, please indicate them separately on an additional lab form.
LAB.18. PRNT performed?	No, Yes	Choose one.
LAB.19. Zika PRNT result:	Free text field	Enter specific result. Results are typically reported with a > (e.g., >1280). If additional tests were performed, please indicate them separately on an additional lab form.
LAB.20. Dengue PRNT result:	Free text field	Enter specific result. Results are typically reported with a > (e.g., >1280). If additional tests were performed, please indicate them separately on an additional lab form.
LAB.21. Zika immunohistochemistry (IHC) staining performed?	No, Yes	Choose one.
LAB.22. Zika immunohistochemistry (IHC) staining result:	Positive, Negative	Choose one.
LAB.23. Histopathology performed?	No, Yes	Choose one. This question refers to an exam performed by a pathologist on a specimen from a pregnancy. These test may be performed on placenta, cord tissue, or fetal tissue.
LAB.24. Histopathology results:	Free text field	Enter results provided from the pathology report.
LAB.25. Other test performed? (Including autopsy)	No, Yes	Choose one. This variable includes autopsy.
LAB 26. Other test results:	Free text field	Please list the type of test and the results. Please include any results of autopsy for fetal or neonatal death (verbatim).
Findings (verbatim)	Free text field	Enter findings from specimen testing report.

* Alabama (AL), Alaska (AK), American Samoa (AS), Arizona (AZ), Arkansas (AR), California (CA), Colorado (CO), Connecticut (CT), District of Columbia (DC), Delaware (DE), Federated States of Micronesia (FSM), Florida (FL), Georgia (GA), Guam (GU), Hawaii (HI), Idaho (ID), Illinois (IL), Indiana (IN), Iowa (IA), Kansas (KS), Kentucky (KY), Louisiana (LA), Maine (ME), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Mississippi (MS), Missouri (MO), Montana (MT), Nebraska (NE), Nevada (NV), New Hampshire (NH), New Jersey (NJ), New Mexico (NM), New York (NY), North Carolina (NC), North Dakota (ND), Northern Mariana Islands (MP), Ohio (OH), Oklahoma (OK), Oregon (OR), Pennsylvania (PA), Republic of Palau (RP), Rhode Island (RI), South Carolina (SC), South Dakota (SD), Tennessee (TN), Texas (TX), US Virgin Islands (USVI), Utah (UT), Vermont (VT), Virginia (VA), Washington (WA), West Virginia (WV), Wisconsin (WI), Wyoming (WY)

Supplemental Imaging Form

Question	Acceptable Responses	Abstraction Instructions
SIF.1. State/territory ID	Free text field	Enter the mother's jurisdiction ID. This is a state specific identifier chosen by the Health Department.
SIF.2. State/territory reporting	Free text field (Drop down in PDF-fillable forms)	Select the abbreviation for reporting jurisdiction.*
SIF.3. County reporting	Free text field	If possible, enter the reporting county.
SIF.4, 37. Date of ultrasound	mm/dd/yyyy	Enter date. This information might be found in prenatal visit notes or prenatal imaging reports.
SIF.5, 38. Check if date approximated	Check box	Check if date is approximated.
SIF.6, 39. If date is not known, Gestational age (weeks, days)	Whole number	Enter gestational age in weeks and days. This information might be found in prenatal imaging results or prenatal visit notes.
SIF.7, 40. Overall fetal ultrasound results	Normal, Abnormal	Choose one. This information might be found in the prenatal ultrasound report, prenatal visit notes, or maternal H&P, or obtained by a healthcare provider interview. Try to use the ultrasound report directly if it can be obtained.
SIF.8, 41/42. Reported by healthcare provider OR Ultrasound report	Reported by patient/healthcare provider, Ultrasound report	Choose one. Report whether the result in SIF.7/40 is from the provider or from an ultrasound report.
SIF.9, 43. Head circumference (HC) (cm)	Numerical only	Enter head circumference in centimeters. This information will be located in the prenatal ultrasound report, and may be abbreviated as head circ or HC.
SIF.10, 44. HC Normal/Abnormal (by physician report)	Normal, Abnormal	Choose one. This information will be located in the prenatal ultrasound report. Report whether HC was identified as normal or abnormal in the medical record.
SIF.11, 45. Biparietal diameter (BPD) (cm)	Number (up to 2 decimal places)	Enter biparietal diameter (BPD) in centimeters. Include decimals. This information will be located in the prenatal ultrasound report.
SIF.12, 46. Femur length (FL) (cm)	Number (up to 2 decimal places)	Enter femur length in centimeters. Include decimals. This information will be located in the prenatal ultrasound report.
SIF.13, 47. Abdominal circumference (AC) (cm)	Number (up to 2 decimal places)	Enter abdominal circumference in centimeters. Include decimal to two digits if available. This information will be located in the prenatal

Question	Acceptable Responses	Abstraction Instructions
		ultrasound report.
SIF.14, 48. Symmetric IUGR OR Asymmetric IUGR (HC%>AC% or HC%>FL%)	Symmetric IUGR, Asymmetric IUGR	<p>Choose one, if applicable. This information will be located in the prenatal ultrasound report.</p> <p>HC = head circumference, FL= femur length, AC= abdominal circumference.</p> <p>Intrauterine growth restriction (IUGR) is defined as estimated fetal weight (EFW) <5%ile for gestational age. Look for terms such as intrauterine growth restriction, IUGR, GR, small for gestational age, SGA. If IUGR is stated, check either symmetric or asymmetric IUGR even if EFW is 5% or greater; there may be situations when IUGR is diagnosed based on different standards. IUGR is assumed to be symmetrical unless otherwise noted.</p> <p>Asymmetric IUGR is defined as EFW <5%ile for gestational age PLUS HC%>AC% or HC%>FL%. Look for terms such as <u>asymmetric</u>, plus intrauterine growth restriction (IUGR), GR, small for gestational age, SGA. It is important to document the measurements of HC, BPD, FL, AC in MHH.186–190.</p>
SIF.15, 49. Microcephaly	No, Yes	<p>Choose one. This information will be located in the prenatal ultrasound report. Microcephaly is the finding of a small head when compared with fetuses of the same sex and gestational age, and is a sign that the brain is abnormally small. Please use the clinician's determination of microcephaly in the medical record; do not provide your own determination of microcephaly based on reported measurements. This information may also be found in the prenatal visit notes or maternal H&P. It may be helpful to obtain and securely transmit a redacted version of the prenatal ultrasound findings.</p>
SIF.16, 50. Intracranial calcifications	No, Yes	<p>Choose one. This information will be located in the prenatal ultrasound report. Intracranial calcifications are accumulations or deposits of calcium within the brain tissue and are a sign of brain injury from infection, hemorrhage, or lack of oxygen. Look for terms such as intracranial calcifications or calcium deposits within the fetal brain.</p>

Question	Acceptable Responses	Abstraction Instructions
SIF.17, 51. Cerebral/ cortical atrophy	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Cerebral or cortical atrophy refers to loss of cells within the two cerebral hemispheres (the main portion of the brain). Look for terms such as cerebral (or cortical, periventricular, white matter, gray matter) atrophy or brain dysgenesis.
SIF.18, 52. Abnormal cortical gyral patterns (e.g., polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia)	No, Yes	Choose one. Lissencephaly is a smooth cerebral cortex. Pachygyria is a simplified gyral pattern and is considered a subset of lissencephaly by some. Microgyria and polymicrogyria are small cortical ridges. Schizencephaly is a cleft in the cerebral hemisphere. Look for terms such as lissencephaly, agyria, pachygyria, incomplete lissencephaly, microgyria, polymicrogyria, simplified gyral pattern, schizencephaly, gray matter heterotopia, neuronal migration/maturation disorder, ectopia, marginal glioneuronal heterotopia, leptomenigeal heterotopia, or minor cortical dysplasias.
SIF.19, 53. Corpus callosum abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. The corpus callosum is a band of nerve fibers in the central brain that joins the two cerebral hemispheres. Look for terms such as agenesis or missing corpus callosum, hypoplasia or thinning of the corpus callosum, dysgenesis of the corpus callosum.
SIF.20, 54. Cerebellar abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Look for terms such as cerebellar atrophy, agenesis, hypoplasia, or dysplasia. Terms may include any part of the cerebellum including the olive, pons, (inferior) vermis, or cerebellum in general, and may combine anatomical locations (e.g., olive + pons + cerebellum = olivopontocerebellar). Dandy Walker malformation, mega cisterna magna, tectocerebella dysgraphia, rhomboencephalsynapsis, and cerebellar cyst are included in this category.

Question	Acceptable Responses	Abstraction Instructions
SIF.21, 55. Porencephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Porencephaly describes a cavity or cyst in the cerebral hemisphere. Look for terms such as porencephaly, porencephalic cyst or cavity, encephaloclastic porencephaly, developmental porencephaly.
SIF.22, 56. Hydranencephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. In hydranencephaly, the cerebral hemispheres are replaced by fluid-filled sacs. Look for hydranencephaly or hydroanencephaly.
SIF.23, 57. Moderate or severe ventriculomegaly/ hydrocephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Look for terms such as hydrocephalus and large, enlarged, or dilated cerebral ventricles (which may be specified as lateral, third or fourth ventricles), or hydrocephalus. Specific types might include aqueductal stenosis, occlusion of the foramina of Monro, and communicating hydrocephalus. There are also ventricles in the heart; be sure this is a cranial and not a cardiac finding.
SIF.24, 58. Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Fetal brain disruption sequence is a pattern of congenital abnormalities that include severe microcephaly, overlapping cranial sutures, prominence of the occipital bone, and scalp rugae (excessive folding of the skin). All components of the fetal brain disruption sequence (microcephaly, overlapping sutures, prominent occipital bone, scalp rugae) must be present for this to be checked.
SIF.25, 59. Other major brain abnormalities	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Other brain abnormalities might include intraventricular hemorrhage that occurs in utero, absence of septum pellucidum, Arnold-Chiari or Chiari malformation, septo-optic dysplasia, colpocephaly, bilateral or multiple unilateral (all on the same side) subependymal cysts or pseudocysts, periventricular leukomalacia (not due to prematurity), large or prominent cisterna magna, or atrophy, aplasia, hypoplasia, or dysplasia of any part of brain not

Question	Acceptable Responses	Abstraction Instructions
		listed above.
SIF.26, 60. Anencephaly/acrania	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Anencephaly is partial or complete absence of brain and skull. Acrania is absence of skull bones with some brain tissue present. Look for terms such as anencephaly, acrania, absent brain, craniorachischisis, exencephaly, iniencephaly, holoanencephaly, meroanencephaly.
SIF.27, 61. Encephalocele	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Encephalocele is a sac-like protrusion or projection of the brain and/or the membranes that cover it through an opening in the skull, resulting in an opening in the midline of the upper part of the skull, the area between the forehead and nose, or the back of the skull. Look for terms such as cephalocele, cranial meningocele, encephalocele, encephalomyelocele, encephalocystomeningocele, hydranencephalocele, meningoencephalocele, ventriculocele.
SIF.28, 62. Spina bifida	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Spina bifida is incomplete closure of the vertebral spine through which spinal cord tissue and/or meninges herniate. Look for terms such as spina bifida, neural tube defect, myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, meningomyelocele, myelocystocele, myelodysplasia, myeloschisis, rachischisis, spina bifida aperta, spina bifida cystica. Although the spina bifida lesion will be located along the spine, spina bifida is often associated with a cranial lesion termed Arnold-Chiari II malformation involving downward displacement of the hindbrain and 4 th ventricle.
SIF.29, 63. Holoprosencephaly/ arhinencephaly	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Holoprosencephaly is failure of the forebrain to fully divide into a left and right side. May be associated with mid-face deformities. Look for terms such as holoprosencephaly, arhinencephaly, holotelencephaly, cyclopia,

Question	Acceptable Responses	Abstraction Instructions
		cebocephaly, ethmocephaly.
SIF.30, 64. Structural eye abnormalities/dysplasia	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Look for terms such as microphthalmos, microphthalmia, anophthalmos, anophthalmia, nanophthalmia, cataract, intraocular calcification, ocular abnormalities, and any abnormality of the eye, retina, choroid, lens, macula, or optic nerve.
SIF.31, 65. Arthrogyriposis	No, Yes	Choose one. This information will be located in the prenatal ultrasound report. Arthrogyriposis refers to contractures (abnormal shortening and stiffness of the muscles, tendons, and ligaments/or) of the limbs that is present at birth. The contractures can be fixed or more flexible, and can involve all, most, or a single joint. Look for terms such as arthrogyriposis, arthogryposis multiplex congenita, congenital contractures, fetal akinesia sequence, limitation of movements, joint ankyloses, joint contractures, and decreased flexibility.
SIF.32, 66. Clubfoot	No, Yes	Choose one. Clubfoot is a developmental deformity of the foot in which one or both feet are excessively plantar flexed. This information will be located in the prenatal ultrasound report. Look for terms such as clubfoot, talipes equinovarus, talipes.
SIF.33, 67. Hydrops	No, Yes	Choose one. Hydrops refers to abnormal fluid collections in fetal soft tissues and cavities. This information will be located in the prenatal ultrasound report. Look for terms such as hydrops, fetal edema, or hydrops fetalis.
SIF.34, 68. Ascites	No, Yes	Choose one. Ascites is accumulation of fluid in the abdominal cavity and can be detected on ultrasound. This information will be located in the prenatal ultrasound report. Look for terms such as ascites or abnormal accumulation of fluid in the abdominal cavity.

Question	Acceptable Responses	Abstraction Instructions
SIF.35, 69. Other If yes, describe.	No, Yes Free text field	Choose one. This information will be located in the prenatal ultrasound report. Describe any abnormal results that have not been described. If there are multiple abnormalities, separate each with a semi-colon and a space.
SIF.36, 70. Description of abnormal ultrasound findings	Free text field	Describe any abnormal results verbatim from the prenatal ultrasound report including the actual description of any abnormalities noted in SIF.15, 49 –SIF.35, 69. If there are multiple abnormalities, separate each with a semi-colon and a space.

Health Department Information

Question	Acceptable Responses	Abstraction Instructions
SIF.71. Name of person completing form	Free text field	Enter the full name of the person completing the form.
SIF.72. Phone	Free text field	Enter the phone number of the person completing the form.
SIF.73. Email	Free text field	Enter the email of the person completing the form.
SIF.74. Date form completed	mm/dd/yyyy	Enter the date of form completion.

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Clinical Pearls

Pregnancy History

Pregnancy history may be recorded in the medical record using “Gravida/Parity” notation.

- This is often written in the medical chart as G_xP_y
- G = Gravida = number of times a woman has been pregnant. For a woman who is currently pregnant, gravidity includes the current pregnancy.
- P = Para = number of deliveries >20 weeks of gestation (20 wks). Parity is sometimes written in 4 numbers, which indicate pregnancy outcomes, in order: 1) full term infants, 2) preterm infants, 3) spontaneous abortions, miscarriages, and terminations (SAB=spontaneous abortion; TOP=termination of pregnancy), 4) living children.
 - The Parity count should not include the ongoing pregnancy.
 - The SAB/TOP number is a summation. Note that it may not always be possible to distinguish whether pregnancy loss was spontaneous or a termination, unless this is specified.

Notation example: G5 P3023

Interpretation: Five pregnancies, 3 full term infants, 0 preterm deliveries, 2SAB/TOP (i.e. 2 SABs; or 1 SAB, 1 TOP; or 2 TOPs), and 3 living children.

Estimated Date of Delivery (EDD)

For a given pregnancy, there should be an EDD established early in pregnancy, based either on the last menstrual period (LMP) or by ultrasound (U/S) measurements. Earlier ultrasound measurements generally have a smaller margin of error than ultrasounds performed later in pregnancy. Sometimes the EDD is re-assessed in pregnancy because LMP was felt to be unreliable and U/S contradicts this estimate. If discrepant EDDs are found in the medical record, work with the provider to determine which is the final EDD and how it was established.

The EDD is a key metric for the U.S. Zika Pregnancy Registry and Zika Birth Defects Surveillance because EDD is used to calculate gestational age and measurements (e.g., head circumference) are compared to standard growth measurements depending on gestational age.

Gestational Age and Trimesters

- Gestational age is calculated from the first day of the mother’s last menstrual period (LMP).
- The first trimester begins at 2 weeks after the last menstrual period (2 weeks’ gestation) and extends for 13 weeks and 6 days.
- The second trimester begins at 14 weeks’ gestation and extends until 27 weeks and 6 days.
- The third trimester begins at 28 weeks’ gestation and extends until delivery.

Conventions for gestational age notation are based on the 7-day week, e.g. gestational age of 25 4/7

means 25 weeks and 4 days. If needed, an [online pregnancy calculator](http://www.medcalc.com/pregnancy.html) (e.g., <http://www.medcalc.com/pregnancy.html>) OR [pregnancy wheel](http://www.prokerala.com/health/pregnancy/pregnancy-wheel) (e.g., www.prokerala.com/health/pregnancy/pregnancy-wheel) can be used to determine gestational age for a given date, based on the estimated date of delivery (EDD).

Developmental Milestones

	Gross motor	Fine motor	Cognitive, Linguistic and communication	Social-Emotional
2 months of age	*Lift head	*Follow to midline	*Vocalize	*Smile responsively
4 months of age	*Sit – head steady	*Grasp rattle	*Laugh	*Regard own hand
6 months of age	*Roll over	*Reach	*Turn to rattling sound	*Work for toy (out of reach)
9 months of age	*Stand holding on	*Pass cube (transfer)	*Single syllables	*Feed self
12 months of age	*Pull to stand	*Bang 2 cubes held in hands	*Imitate vocalization/sounds *Babbling	*Pointing to indicate object of interest *Play pat-a-cake

†More than 90% of children pass this item at indicated age. In infants born preterm, please account for corrected age [chronological age (in weeks) minus weeks born before 40 weeks gestation] when considering development.

Source: Child Development theme in Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition.