


Appendix 2. Initial Causes of Fetal Death (INCODE)

 <small>Stillbirth Collaborative Research Network</small>	CAUSE OF DEATH REVIEW Version 04 / December 21, 2009	Form 91A	
Review Case ID	Member	Review Number	Form Completion Date
_____	_____	_____	____ / ____ / ____ mm dd yyyy

Instructions: Complete the Cause of Death (CoD) Review Form for each stillbirth case reviewed. For multiple births complete a separate form for each stillborn baby using the Member ID (e.g., 1, 2, 3) -- consistent with chart abstraction Member ID designation.

A. Reviewer

1. Reviewer category
01=Assigned team 02=Alternate team 03=Individual reviewer 04=Other
2. If other than team assigned by the DCAC (i.e., the assigned team), list last name of reviewers below.
 - a. _____
 - b. _____
 - c. _____
 - d. _____

B. Comprehensive Review of Findings Pertinent to Cause of Death

Instructions: Code findings according to the • designation where 01=present ; 02=possible cause of death; and 03=probable cause of death. Use the highest code for a finding with the criteria met. For example, if there is systemic lupus erythematosus disease activity (flare) during pregnancy and abruption placentae, the SLE should be coded as 1c3 (probable cause).	01=Present	02=Possible	03=Probable
1. Maternal Medical Conditions during Pregnancy			
a. Hypertensive disorder of pregnancy¹⁻⁴			
1) Hypertensive disease alone	•		
2) Hypertensive disease with <u>at least ONE</u> of the following (specify if present):		•	
a) SGA (<10%) 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
b) Absent or reversed end diastolic flow of umbilical vessels 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
c) Maternal hypertensive crisis 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
3) Hypertensive disease with [isolated clinical diagnosis of abruption (no retroplacental clot or pathologic evidence of abruption)] OR [hypertensive disease with isolated retroplacental clot or pathologic evidence of abruption (no clinical evidence of abruption)]		•	
4) Hypertensive disease with <u>at least TWO</u> of the following (specify if present):			•
a) SGA (<10%) 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
b) Absent or reversed end diastolic flow of umbilical vessels 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
c) Maternal hypertensive crisis 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
5) Hypertensive disease with antepartum clinical diagnosis of abruption and <u>at least ONE</u> of the following (specify if present):			•
a) Retroplacental clot 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
b) Pathologic confirmation with extensive parenchymal infarction 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			
c) Maternal blood transfusion 01=Yes, 02=No <input type="checkbox"/> <input type="checkbox"/>			

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Instructions:	01=Present	02=Possible	03=Probable
Code findings according to the • designation where 01=present ; 02=possible cause of death; and 03=probable cause of death. Use the highest code for a finding with the criteria met. For example, if there is systemic lupus erythematosus disease activity (flare) during pregnancy and abruption placentae, the SLE should be coded as 1c3 (probable cause).			
d) Massive bleeding with rupture of membranes noted in records..... 01=Yes, 02=No _ _			
e) Eclampsia..... 01=Yes, 02=No _ _			
Specify most appropriate category of the disorder from below _ _ 			
01=Preeclampsia			
02=Gestational hypertension			
03=Chronic hypertension			
04=Chronic hypertension with superimposed preeclampsia			
05=Eclampsia			
b. Diabetes during pregnancy⁵⁻⁸			
1) Gestational diabetes			
a) Abnormal 3 ^o GTT with FBS <105 or unknown with or without LGA (>90%)	•		
b) Abnormal 3 ^o GTT with FBS ≥105 and LGA (>90%)		•	
2) Pregestational diabetes (type 1 or type 2)			
a) HgbA1C unknown during pregnancy and normal fetal growth	•		
b) HgbA1C <6.5 during pregnancy and normal fetal growth	•		
c) HgbA1C ≥6.5 during pregnancy or unknown, abnormal fetal growth [SGA (<10%) or LGA (>90%)]		•	
d) Diabetic ketoacidosis			•
e) Diabetic embryopathy with lethal anomalies			•
3) Poorly controlled diabetes with majority of blood sugars > 250 mg/dl or if noted in clinical record			•
4) Diabetic fetopathy with significant birth trauma or fetal pathologic changes (e.g. islet cell hyperplasia)			•
c. Systemic lupus erythematosus⁹⁻¹² (SLE) (SLE diagnosed by ARA criteria)			
1) Diagnosed SLE, but no disease activity during pregnancy	•		
2) SLE disease activity (flare) during pregnancy		•	
3) SLE disease activity (flare) during pregnancy associated with <u>at least ONE</u> of the following (specify if present):			•
a) Antiphospholipid syndrome (APS) 01=Yes, 02=No _ _			
b) Abruption placentae 01=Yes, 02=No _ _			
c) Severe preeclampsia 01=Yes, 02=No _ _			
d) Eclampsia..... 01=Yes, 02=No _ _			
e) SGA (<10%) / oligohydramnios..... 01=Yes, 02=No _ _			
d. Intrahepatic cholestasis of pregnancy^{13,14} (Generalized pruritis with bile acids increased [≥40 μmol/L])			
1) Bile acids 40-70 μmol/L		•	
2) Bile acids >70 μmol/L			•
e. Thyroid disorders during pregnancy¹⁵⁻¹⁷ (Diagnosis of hyper or hypothyroidism)			
1) Medical management and clinically euthyroid	•		
2) Clinical symptoms of hyperthyroidism or hypothyroidism		•	
3) Thyroid storm			•

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f. Renal disease during pregnancy ¹⁸⁻²⁰ (<i>Elevated serum creatinine</i>)			
1) Serum creatinine 1.3-1.9 mg/dL without SGA (<10%)	•		
2) Serum creatinine >1.9 mg/dL without SGA (<10%)		•	
3) Serum creatinine ≥1.3 mg/dL with SGA (<10%)		•	
g. Severe maternal infection ²¹⁻²⁴ (<i>Maternal infection – examples: influenza, polio, varicella pneumonia, pyelonephritis, appendicitis</i>); Specify organism, if known _____			
1) Hospital treatment and fever >100.4 F, or IV antibiotics, or surgery, or ventilatory support >2 weeks prior to the stillbirth or timing not known	•		
2) Hospital treatment and fever >100.4 F, or IV antibiotics, or surgery, or ventilatory support within 2 weeks prior to the stillbirth		•	
3) Hospital treatment and fever >100.4 F, or IV antibiotics, or surgery, or ventilatory support within 48 hours prior to the stillbirth, or hypotension			•
h. Shock during pregnancy ²⁵⁻²⁷ (<i>Precipitating event leading to shock presentation not sepsis</i>)			
1) Corrected with fluid replacement		•	
2) Need for pressor agents			•
i. Asthma during pregnancy ^{28,29} (<i>Clinical diagnosis of asthma</i>)			
1) No evidence of exacerbation, with or without medications	•		
2) Uncontrolled exacerbation or uncontrolled asthma		•	
3) Status asthmaticus, with or without hypoxia documented			•
j. Seizure disorders during pregnancy ^{30,31} (<i>Diagnosed seizure disorder</i>)			
1) Seizure activity during pregnancy absent or ≤1 seizure/month, with or without anti-epileptics	•		
2) Seizure disorder not controlled by medications, occurring >1 seizure/month		•	
3) Status epilepticus			•
k. Maternal substance abuse ³²⁻³⁴ (<i>Evidence of substance abuse by history or laboratory evaluation</i>)			
1) Positive drug screen without SGA (<10%) or history of drug use with negative drug screen	•		
2) Positive drug screen with SGA (<10%)		•	
3) Narcotic withdrawal		•	
l. Other maternal medical condition (<i>Specific maternal condition</i>) Specify condition _____			
1) Condition is diagnosed with no consequences on pregnancy	•		
2) Condition is associated with possible fetal consequences		•	
3) Condition has clear pathophysiology that most likely caused fetal death			•
2. Obstetric Complications			
a. Fetal maternal hemorrhage ³⁵⁻³⁸ (<i>Kleihauer-Betke test positive or flow cytometry positive</i>)			
1) Positive Kleihauer-Betke or flow cytometry <5%	•		
2) 5% to <40% of fetoplacental blood volume		•	
3) ≥40% of fetoplacental blood volume with signs of anemia in the fetus or in the placenta (pallor)			•
b. Cervical insufficiency (<i>Sonographic evidence of short cervix or evidence on cervical examination</i>) with antepartum death	•		
c. Preterm labor (<i>spontaneous preterm labor diagnosed before or after antepartum fetal death</i>)	•		

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d. Preterm premature rupture of membranes (<i>PROM diagnosed before or after antepartum fetal death</i>)	•		
e. Clinical chorioamnionitis (<i>diagnosed before or after antepartum fetal death</i>)	•		
f. Intrapartum fetal death with labor –associated asphyxia (prior to or at 26 weeks) ³⁹⁻⁴⁴			•
Specify associated conditions present:			
1) Cervical insufficiency 01=Yes, 02=No..... __			
2) Abruptio placentae..... 01=Yes, 02=No..... __			
3) Preterm labor 01=Yes, 02=No..... __			
4) Preterm PROM 01=Yes, 02=No..... __			
5) Clinical chorioamnionitis 01=Yes, 02=No..... __			
6) Histologic chorioamnionitis 01=Yes, 02=No..... __			
g. Hypoxic intrapartum fetal death (after 26 weeks) ⁴⁵⁻⁴⁹ (<i>Intrapartum fetal death</i>)			
1) Clinical or pathology evidence of fetal asphyxia (by fetal heart rate monitoring or clinical evaluation) Specify any contributing maternal or fetal condition _____			•
h. Abruptio placentae ⁵⁰⁻⁵² (<i>Clinical diagnosis and/or retroplacental clot on pathology</i>)			
1) Retroplacental clot noted at any time, but no clinical diagnosis of abruption	•		
2) Clinical diagnosis without retroplacental clot or pathologic confirmation		•	
3) Antepartum clinical diagnosis of abruptio placentae with <u>at least ONE</u> of the following (specify if present):			•
a) Retroplacental clot 01=Yes, 02=No __			
b) Pathologic confirmation with extensive parenchymal infarction..... 01=Yes, 02=No __			
c) Maternal blood transfusion..... 01=Yes, 02=No __			
d) Massive bleeding 01=Yes, 02=No __			
i. Complications of multiple gestation ⁵³⁻⁵⁷ (<i>Clinical diagnosis of multiple gestation</i>)			
1) One or all fetuses dead, no SGA (<10%) or evidence of uteroplacental insufficiency, intervening membranes noted	•		
2) One or all fetuses dead, with SGA (<10%) and/or evidence of uteroplacental insufficiency, intervening membranes noted		•	
3) Complications of monochorionic multiple gestation (e.g., twin to twin transfusion syndrome, TRAP sequence, monoamniotic twinning)			•
j. Uterine rupture ^{58,59} (<i>Separation of uterine scar noted at surgery</i>)			
1) Uterine dehiscence with no extrusion of fetus or cord, no evidence of uteroplacental insufficiency	•		
2) Uterine dehiscence with no extrusion of fetus or cord, with evidence of uteroplacental insufficiency		•	
3) Uterine rupture			•
k. Maternal trauma during pregnancy ⁶⁰⁻⁶³ (<i>Maternal trauma documented in medical record</i>)			
1) No evidence of maternal or fetal injury from the trauma	•		
2) Evidence of maternal injury with no abruptio placentae, but with presence of fetal cephalhematoma or skull fracture		•	
3) Evidence of maternal injury with abruptio placentae or direct fetal trauma (e.g. subdural hemorrhage)			•

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I. Uteroplacental insufficiency⁶⁴⁻⁶⁶			
1) Isolated SGA (less than 10%)	•		
2) AGA (10-90%) with <u>at least ONE</u> of the documented findings specified <u>below</u>	•		
3) SGA (5-10%) with <u>at least ONE</u> of the documented findings specified <u>below</u>		•	
4) SGA <5% with <u>at least ONE</u> of the documented findings specified <u>below</u>			•
Specify documented findings present for 2-4 above:			
Sp_a) Oligohydramnios: AFI less than 5 cm with intact membrane 01=Yes, 02=No __			
Sp_b) Abnormal Doppler: Absent or reversed end diastolic flow of umbilical vessels 01=Yes, 02=No __			
Sp_c) Category III fetal heart tracing or a biophysical profile score ≤6 01=Yes, 02=No __			
m. Other obstetric condition (Specific obstetric condition) Specify condition _____			
1) Condition is diagnosed with no consequences on pregnancy	•		
2) Condition is associated with possible fetal consequences		•	
3) Condition has clear pathophysiology that most likely caused fetal death			•
3. Maternal or Fetal Hematologic Conditions			
a. Heritable thrombophilias⁶⁷⁻⁷¹			
1) Positive test only	•		
2) Positive test with SGA (less than 10%)		•	
Specify tests documented positive for 1-2 above:			
Sp_a) Factor V Leiden 01=Yes, 02=No __			
Sp_b) Prothrombin Gene 20210A 01=Yes, 02=No __			
Sp_c) Antithrombin III deficiency 01=Yes, 02=No __			
Sp_d) Protein S deficiency 01=Yes, 02=No __			
Sp_e) Protein C deficiency 01=Yes, 02=No __			
b. Antiphospholipid syndrome (APS)⁷²⁻⁷⁴			
1) Positive test for APS, no SGA (less than 10%) or oligohydramnios present		•	
2) Positive test for APS with SGA (less than 10%) or oligohydramnios present			•
Specify tests documented positive for 1-2 above:			
Sp_a) Lupus anticoagulant 01=Yes, 02=No __			
Sp_b) Anticardiolipin antibodies 01=Yes, 02=No __			
c. Red cell isoimmunization⁷⁵⁻⁷⁸ (Maternal antibodies against RBC antigen [1:16 or higher] except for any titer Kell antibody)			
1) No hydrops or fetal anemia	•		
2) Fetal anemia, without hydrops, extramedullary hematopoiesis present		•	
3) Hydrops fetalis			•

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d. Platelet alloimmunization ⁽⁷⁹⁻⁸¹⁾ (<i>Maternal antibodies vs. pertinent fetal platelet antigen present</i>)				
1) Parental platelet incompatibility with normal fetal platelet count and no fetal intracranial hemorrhage	•			
2) Fetal thrombocytopenia			•	
3) Fetal thrombocytopenia with intracranial hemorrhage				•
e. Other maternal or fetal hematologic conditions (<i>Specific maternal or fetal hematologic condition</i>) Specify condition _____				
1) Condition is diagnosed with no consequences on pregnancy	•			
2) Condition is associated with possible fetal consequences			•	
3) Condition has clear pathophysiology that most likely caused fetal death				•
4. Fetal Genetic, Structural, and Karyotypic Abnormalities				
a. Chromosomal anomalies ⁽⁸²⁻⁸⁴⁾				
1) Aneuploidy, specify : _____				•
2) Unbalanced translocation, deletions			•	
3) Confined placental mosaicism with SGA (less than 10%)				•
b. Autosomal recessive disorders ⁸⁵⁻⁸⁸				
1) Alpha thalassemia causing hydrops				•
2) Storage disease causing hydrops				•
3) Amino acid disorders				•
4) Peroxisomal disorders				•
c. X-linked dominant disorders in males ⁸⁹	•			
d. Structural anomalies without chromosomal anomaly ⁹⁰⁻¹⁰²				
1) Pentalogy of Cantrell/ectopia cordis				•
2) Cardiac anomaly with no hydrops	•			
3) Cardiac anomaly causing hydrops (structural defects/dysrhythmias)				•
4) Intrathoracic anomaly causing hydrops (neoplasia)				•
5) Urogenital anomaly causing anhydramnios (prune belly, bilateral renal agenesis, cloacal dysgenesis)				•
6) Non-immune hydrops (diagnosed prior to fetal death, any cause)				•
7) Lethal type skeletal dysplasia				•
8) Fetal or placental tumors causing hydrops, specify _____				•
9) Abdominal wall defects				•
10) Neural tube defects, with no evidence of brain stem compromise			•	
11) Neural tube defects, with evidence of brain stem compromise				•
12) Other structural neurologic abnormalities, specify _____			•	
13) Fetal lung abnormalities (CCAM, hypoplasia), with or without congenital diaphragmatic hernia			•	
14) Endocrine gland agenesis, hypoplasia, or dysfunction			•	
15) Neuromuscular disorders (myotonic/muscular dystrophies)			•	
16) Any structural abnormality without chromosomal anomaly (1-15 above) with hydrops (if not already specified) or major structural abnormality likely leading to death, specify _____				•

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e. Fetal metabolic disorders¹⁰³⁻¹⁰⁴; Specify _____			
1) Inborn errors of metabolism: systemic effects			•
2) Inborn errors of metabolism: degenerative neurologic disease			•
f. Other chromosomal, genetic or structural abnormality Specify, if known _____			
1) Condition is not likely associated with fetal consequences	•		
2) Condition is associated with possible fetal consequences		•	
3) Condition has clear pathophysiology that most likely caused fetal death			•
5. Placental and/or Fetal Infection (Excluding Fetal Membranes)			
a. Fetal infection involving vital organs: brain, heart, lung & liver¹⁰⁵⁻¹¹⁵ (Positive bacterial or viral culture, or viral-specific PCR – examples: listeriosis, group B streptococcus, Escherichia coli, other viruses, protozoa) Specify organism, if known _____			
1) Culture or PCR proven infection in vital organs with no documented histologic signs of infection	•		
2) Culture or PCR proven infection in vital organs with signs of infection in the placenta but not organs		•	
3) Histologic evidence of infection in vital organs without culture or PCR proven infection in vital organs		•	
4) Histologic evidence of infection in vital organs with culture or PCR proven infection in vital organs			•
5) Pathognomonic pathologic findings in fetus with or without culture or PCR proven infection			•
b. Fetal infection that causes congenital anomaly or other fetal condition¹¹⁶⁻¹¹⁹ (Fetal infection with a teratogenic organism – examples: parvovirus, varicella, CMV, toxoplasmosis) Specify organism, if known _____			
1) Organism known to cause fetal anomaly/condition, anomaly/condition is present, timing of infection not consistent with specific anomaly/condition	•		
2) Organism known to cause fetal anomaly/condition, anomaly/condition is present, timing of infection is unknown		•	
3) Organism known to cause fetal anomaly/condition, anomaly/condition is present, timing of infection consistent with expected anomaly (including neuronal injury or calcifications)			•
4) Pathognomonic pathologic findings in fetus or placenta with or without culture or PCR proven infection			•
c. Placental infection - organism likely to lead to decreased placental function¹²⁰⁻¹²³ (Maternal infection with organism known to decrease placental function - examples: malaria, syphilis) Specify organism, if known _____			
1) Culture or PCR proven infection without placental histologic changes characteristic of infection or in the absence of placental histology	•		
2) Culture or PCR proven infection and placental histologic changes characteristic of infection such as villitis and placentitis (minimal placental involvement)		•	
3) Culture or PCR proven infection and placental histologic changes characteristic of infection such as villitis and placentitis (extensive placental involvement)			•
4) Pathognomonic pathologic findings in placenta with or without culture or PCR proven infection			•

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d. Infection-related fetal death by other or unknown mechanisms (<i>placental or fetal infection, possible mechanism different from other categories</i>) Specify organism, if known _____			
1) Presence of maternal or fetal infection, no clear pathophysiologic sequence leading to fetal death	•		
2) Presence of maternal or fetal infection, plausible pathophysiologic sequence leading to fetal death		•	
3) Presence of maternal or fetal infection, likely pathophysiologic sequence leading to fetal death			•
4) Pathognomonic pathologic findings in fetus or placenta with or without culture or PCR proven infection			•
6. Pathologic Placental Conditions ^{124–136}			
a. Placental Disc ^{137–141}			
1) Implantation site abnormalities			
a) Placenta previa	•		
b) Placenta percreta, increta, accreta		•	
2) Abnormal development of villous parenchyma			
a) Delayed villous maturation		•	
b) Accelerated villous maturation		•	
c) Partial mole			•
b. Placental membranes ¹⁴²			
1) Circumvallate, velamentous, or furcated cord insertion with compromise		•	
2) Early amnion rupture sequence			•
3) Amnion nodosa	•		
c. Umbilical cord ^{143–149}			
1) Vasa previa			
a) With no bleeding	•		
b) With bleeding			•
2) Umbilical cord entrapment (includes nuchal cord, body cord, shoulder cord or other evidence that umbilical cord is constricted by the fetus)			
a) With no evidence of occlusion	•		
b) With evidence of cord occlusion		•	
c) With evidence of cord occlusion and fetal hypoxia			•
3) True knots, false knots, torsions, strictures			
a) With no thrombi or other obstruction	•		
b) With thrombi or other obstruction			•
4) Cord prolapse			•
d. Fetal membranes and placental inflammatory disorders ^{150–157}			
1) Histologic chorioamnionitis with antepartum fetal death	•		
2) Histologic chorioamnionitis and funisitis with antepartum fetal death		•	
3) Histologic chorioamnionitis and funisitis with intrapartum fetal death after 26 weeks of gestation		•	

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e. Circulatory disorders ¹⁵⁸⁻¹⁷⁷				
1) Compromised maternal circulation: vascular lesions				
a) Extensive decidual vasculopathy	•			
b) Extensive villous (parenchymal) infarcts				•
c) Extensive intraplacental thrombi (hematoma)				•
d) Massive subchorionic hematoma				•
e) Subamniotic hemorrhage	•			
2) Compromised maternal circulation: nonvascular lesions				
a) Minor perivillous parenchymal fibrin deposition	•			
b) Massive perivillous parenchymal fibrin deposition				•
c) Maternal floor fibrin deposition (maternal floor infarct: covers parenchyma with 1 cm or more deposition of basal plate)				•
3) Compromised fetal microcirculation				
a) Thromboembolism of umbilical vein or large fetal vessels, no evidence of or partial obstruction			•	
b) Thromboembolism of umbilical vein or villous fetal capillaries and avascular villi, with evidence of obstruction				•
4) Compromise of maternal/fetal circulations				
a) Placental and/or fetal hydrops				•
f. Other placental abnormalities (<i>Specific placental abnormality diagnosed</i>) Specify condition _____				
1) Condition is diagnosed with no consequences on pregnancy	•			
2) Condition is associated with possible fetal consequences			•	
3) Condition has clear pathophysiology that most likely caused fetal death				•
7. Other Pertinent Condition Not Specified in Sections 1-6				
Specify condition _____				
1) Condition is present that is pertinent to the evaluation of the fetal death	•			
2) Condition is associated with possible fetal consequences			•	
3) Condition has clear pathophysiology that most likely caused fetal death				•

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Version 04 / December 21, 2009

Form 91A

Review Case ID _____	Member _____	Review Number _____	Form Completion Date ____/____/____ mm dd yyyy
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C. Synopsis

1. **Review complete**..... 01=Yes, 02=No |__|__|
 If NO →
 a. Are there questions for the clinical site?..... 01=Yes, 02=No |__|__|

If YES → Specify

- b. Are there questions for a pathologist?..... 01=Yes, 02=No |__|__|

If YES → Specify

- c. Are there questions for a geneticist? 01=Yes, 02=No |__|__|

If YES → Specify

- d. Is any additional input required?..... 01=Yes, 02=No |__|__|

If YES → Specify

Dudley DJ, Goldenberg R, Conway D, Silver RM, Saade GR, Varner MW, et al. A new system for determining the causes of stillbirth. *Obstet Gynecol* 2010;116.

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2. Are there key data found in narrative reports that are not found or that are entered incorrectly in the SCRN database? 01=Yes, 02=No

If YES → Specify

3. Provide a narrative in the space below

Dudley DJ, Goldenberg R, Conway D, Silver RM, Saade GR, Varner MW, et al. A new system for determining the causes of stillbirth. *Obstet Gynecol* 2010;116.

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Narrative

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