




**SURVEILLANCE OF MAJOR BIRTH DEFECTS IN NON-LIVE BIRTH PREGNANCY OUTCOMES**

**CASE IDENTIFICATION AND ABSTRACTION**

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National Birth Defects Prevention Network Surveillance Research Prevention

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**Objectives**

- Describe characteristics for birth defect surveillance of non-live births
- Identify components that make up the “Gold Standard” for case identification and abstraction of non-live births
- Describe data sources, case finding codes, and data elements
- Compare birth defect surveillance approaches for fetal deaths and terminations
- Discuss possible challenges

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**Characteristics for Surveillance of Non-live Births**

- Case finding codes are specific to the mother
  - Codes are broad and often not specific to fetal diagnosis
  - Case finding may be more time consuming and yield fewer reportable cases
- Programs may have limited access to complete prenatal records
- Confirmation of prenatal diagnoses may be difficult
  - Prenatal diagnosis may be impacted by gestational age
  - Confirmatory testing (genetic test results, postnatal evaluation) may be lacking
- Non-live births may occur outside of a healthcare facility

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**Gold Standard – What are the components?**

- Authority to monitor non-live births
- Access to multiple data sources, including those with needed case finding codes
- Data elements specific to non-live births
- Ability to conduct medical record review for confirmation

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**Authority to Monitor Non-live Births (sample language)**

- Legislation (Chapter 136A)
  - *The center for congenital and inherited disorders shall maintain a central registry or shall establish an agreement with a designated contractor to maintain a central registry, to compile, evaluate, retain, and disseminate information on the occurrence, prevalence, causes, treatment, and prevention of congenital disorders. Congenital disorders shall be considered reportable conditions in accordance with rules adopted by the department and shall be abstracted and maintained by the registry.*
- Administrative rules (Chapter 4 Iowa Administrative Code)
  - *The IRCID staff shall review hospital records, clinical charts, physician's records, vital records, prenatal records, and fetal death evaluation protocols pursuant to 641—1.3(139A), information from the INMSP, RGCS, NMP, and the IMPSP, and any other information that the IRCID deems necessary and appropriate for congenital and inherited disorders surveillance.*
- Institutional review board (IRB)

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**Data Sources**

- Vital records (fetal death certificates)
- Administrative databases (e.g. discharge data, payor databases)
- Healthcare facilities
  - Hospitals
  - Freestanding birth centers
  - Specialty clinics (e.g. Genetics, Cardiology)
- Healthcare providers
  - Primary obstetric providers
  - Maternal-Fetal Medicine/Perinatology
- Clinical laboratories
  - Maternal screening
  - Pathology

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**Case Finding Codes**

| ICD-10-CM Code | Code Description   |
|----------------|--|
| 035.0XXx       | Maternal care for (suspected) central nervous system malformation in fetus |
| 035.1XXx       | Maternal care for (suspected) chromosomal abnormality in fetus             |
| 035.2XXx       | Maternal care for (suspected) hereditary disease in fetus                  |
| 035.3XXx       | Maternal care for (suspected) damage to fetus from viral disease in mother |
| 035.4XXx       | Maternal care for (suspected) damage to fetus from alcohol                 |
| 035.5XXx       | Maternal care for (suspected) damage to fetus by drugs                     |
| 035.6XXx       | Maternal care for (suspected) damage to fetus by radiation                 |
| 035.8XXx       | Maternal care for other (suspected) fetal abnormality and damage           |
| 035.9XXx       | Maternal care for (suspected) fetal abnormality and damage, unspecified    |

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**“Core” Data Elements to Abstract**

- Delivery type (e.g. stillbirth, pregnancy termination)
- Date of pregnancy outcome
- Sex
- Gestational age at pregnancy outcome
- Demographic information
- Final diagnosis

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**“Recommended and Expanded” Data Elements to Abstract**

- Prenatal information
  - Last menstrual period (LMP)
  - Estimated date of delivery (EDD)
  - Gestational age at prenatal diagnosis
  - Date and result of prenatal tests (e.g. imaging, genetic testing)
- Outcome information
  - Date and result of postnatal evaluations (e.g. genetic testing, autopsy)

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**Ability to Review Medical Records (sample language)**

- Authority (Chapter 4 Iowa Administrative Code)
  - *The IRCID staff shall review hospital records, clinical charts, physician's records, vital records, prenatal records, and fetal death evaluation protocols pursuant to 641—1.3(139A), information from the INMSP, RGCS, NMP, and the IMPSP, and any other information that the IRCID deems necessary and appropriate for congenital and inherited disorders surveillance.*
- Access
  - Remote access or on-site review

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**Surveillance of Fetal Deaths vs. Terminations**

- Consider case definition
  - Reportable stillbirths vary by state
- Authority: Programs may be able to collect one and not the other
- Data sources may vary
- Case finding codes may vary
- Data elements may vary

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**Birth Defects in Fetal Deaths**

- Definitions
  - Spontaneous abortions/miscarriages <20 weeks gestation
    - Very large number of codes
    - May occur outside of source facilities
    - Difficult to identify prenatal diagnoses
    - Can have limited test results
    - For these reasons, will exclude from this discussion
  - Stillbirth
    - Definition varies by state
    - Model Law: Stillbirth  $\geq 350$  grams birth weight or  $\geq 20$  weeks gestation

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**Data Sources: Birth Defects in Stillbirths**

- Hospitals/birthing facilities
- Vital records: fetal death certificates
- Discharge data
- Clinical laboratories (Pathology/Autopsy)
- State-specific stillbirth programs

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**Data Sources: Birth Defects in Stillbirths**

| Source                          | Case finding source                 | Abstraction source                  |
|---------------------------------|-------------------------------------|-------------------------------------|
| Vital records                   | <input checked="" type="checkbox"/> |                                     |
| Discharge data                  | <input checked="" type="checkbox"/> |                                     |
| Payor databases                 | <input checked="" type="checkbox"/> |                                     |
| Healthcare facilities           | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Healthcare providers            |                                     | <input checked="" type="checkbox"/> |
| Clinical labs                   |                                     | <input checked="" type="checkbox"/> |
| Fetal death evaluation protocol | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| State perinatal program         | <input checked="" type="checkbox"/> |                                     |

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**Case Finding Codes: Birth Defects in Stillbirths**

| ICD-10-CM Code | Code Description                            |
|----------------|---|
| 036.4XXx       | Maternal care for intrauterine death        |
| Z37.1          | Single stillbirth                           |
| Z37.3          | Twins, one liveborn and one stillborn       |
| Z37.4          | Twins, both stillborn                       |
| Z37.60         | Multiple births, unspecified, some liveborn |
| Z37.61         | Triples, some liveborn                      |
| Z37.62         | Quadruplets, some liveborn                  |
| Z37.63         | Quintuplets, some liveborn                  |
| Z37.64         | Sextuplets, some liveborn                   |
| Z37.69         | Other multiple births, some liveborn        |
| Z37.7          | Other multiple births, all stillborn        |
| P95            | Stillbirth (newborn record only)            |

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## Birth Defects in Pregnancy Terminations

- May review for reportable birth defects at any gestational age
- Data sources useful in birth defect/pregnancy terminations
  - Healthcare facilities where pregnancy terminations are performed
  - Specialty clinics (e.g. Genetics)
  - Clinical laboratories (Genetic testing)
  - Discharge data

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## Data Sources: Birth Defects in Terminations

| Source                          | Case finding source                 | Abstraction source                  |
|---------------------------------|-------------------------------------|-------------------------------------|
| Vital records                   | <input type="checkbox"/>            |                                     |
| Discharge data                  | <input checked="" type="checkbox"/> |                                     |
| Payor databases                 | <input checked="" type="checkbox"/> |                                     |
| Healthcare facilities           | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Healthcare providers            |                                     | <input checked="" type="checkbox"/> |
| Clinical labs                   |                                     | <input checked="" type="checkbox"/> |
| Fetal death evaluation protocol | <input type="checkbox"/>            | <input type="checkbox"/>            |
| State perinatal program         | <input type="checkbox"/>            |                                     |

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## Case Finding Code: Birth Defects in Terminations

| ICD-10-CM Code | Code Description                                |
|----------------|---|
| 233.2          | Encounter for elective termination of pregnancy |

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**Challenges**

- Authority may vary from state to state
- Access to sources may vary, even within the same state
- Case finding codes are very broad, not specific to fetal diagnosis
- Case finding can be very time consuming with fewer cases identified
- Prenatal diagnoses may be difficult to confirm

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