
Reference Guide for Pregnancy-Associated Death Identification

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Every year, approximately 700 women die in the United States as a result of pregnancy-related complications.¹ Relying on the information on the death record alone can both underestimate and overestimate the identification of deaths that occurred during or within a year of the end of pregnancy.² To overcome these limitations, identification of these deaths requires use of additional data sources and linkage methods. Accurately identifying these deaths is a crucial first step for understanding leading causes of death, contributing factors, and opportunities for preventing pregnancy-related deaths.

The purpose of this document is to describe best practices identified by the Workgroup for linking jurisdictional vital records data to identify deaths to women during pregnancy and within the first year after the end of pregnancy (pregnancy-associated deaths). Vital records include data from registration of births, fetal deaths, and death reporting systems. Improved ascertainment of pregnancy-associated deaths may occur by linking death records of female decedents ages 10-60 years to pregnancy outcome information (birth or fetal death).

The following methods were developed by the Pregnancy-Associated Death Identification Workgroup, consisting of members from state departments of health and the Centers for Disease Control and Prevention (CDC). While these methods are considered best practices for case identification by the Workgroup, the order and exact process for completing this algorithm may differ depending on the resources and protocols within individual jurisdictions.

Data Sources

Death Records

Death records should be selected for linkage if they are for

Women ages 10-60 years and

Residents of your jurisdiction, regardless of where the death occurred

Provisional death files are preferred, and are sufficient, for more timely identification of deaths.

Birth Records and Fetal Death Records

To link births and fetal deaths occurring during the year prior to women's deaths, two calendar years of birth and fetal death record data are required. For example, if linking 2017 death records, birth and fetal death records from both 2016 and 2017 should be included to ascertain pregnancy outcomes in the year prior to death

Identifying Pregnancy-Associated Deaths by Vital Records Linkages

The application of both deterministic and probabilistic linkage is suggested by the Workgroup, as described below.

Deterministic Linkage Using Social Security Number

Death records of women ages 10-60 years are linked to birth and fetal death records using deterministic record linkage.

Files are matched on the mother's social security number (SSN).

Only matches where the death occurred less than or equal to one year from the date of birth and/or date of fetal death are retained. For example, a birth or fetal death occurred on June 30, 2017. This requires ascertainment for pregnancy-associated deaths through June 29, 2018.

Probabilistic Record Linkage

Death records of women ages 10-60 years that are not linked using deterministic linkage may be matched to birth and fetal death records using probabilistic linkage using CDC's Link Plus.³³

Blocking variables should include mother's first name, mother's last name, and mother's date of birth.

Matching variables should include mother's first name, mother's last name, mother's date of birth, mother's zip code, mother's social security number (if available), baby's last name, father's last name, and mother's maiden name.

The NYSIIS Phonetic System further increases linkages when applied to names

Link Plus guidance recommends a cut-off value of 7. This number may be adjusted depending on number of records included in the linkage and the available resources for manual review of uncertain matches.

Only matches where the death occurred less than or equal to one year from the date of birth and/or date of fetal death are retained.

Identification of Pregnancy-Associated Deaths based on Cause(s) of Death Information

Some pregnancy-associated deaths, such as those that occur early during pregnancy, will not have birth or fetal death registrations to link. Below are workgroup identified approaches for identifying pregnancy-associated deaths among those death records that did not link using the deterministic and probabilistic approaches.

Literal Cause of Death Fields in Death Record Data

Select death records where the literal cause of death fields contain any of the following pregnancy-related terms:

amniotic, chorioamnionitis, eclampsia, ectopic, intrauterine fetal demise, peripartum, peripartum cardiomyopathy, placental, postpartum, pregnancy, pregnant, uterine hemorrhage, and uterine rupture

ICD-10 Code

An ICD-10 code, if available, may be used to identify pregnancy-associated death using the ICD-10 codes related to pregnancy (A34 and O00-O99.9). To be comprehensive, all the cause of death fields should be examined for the ICD-10 codes related to pregnancy. O-codes are assigned based, in part, on the pregnancy checkbox on the death record, so these records should be confirmed with an additional information source to avoid misclassification. Examples of confirmatory sources are provided in the section on Additional Data Sources. Deaths identified only through ICD-10 codes need confirmation of pregnancy from the death certifier.

Identification of Pregnancy-Associated Deaths based on Pregnancy Checkboxes on the Death Records

Select death records where the pregnancy checkbox field indicates the woman was

Pregnant at the time of death

Not pregnant, but pregnant within 42 days of death

Not pregnant, but pregnant 43 days to 1 year before death

Selected records need to be confirmed with the death certifier, to identify potential pregnancy checkbox error. Examples of additional confirmatory sources are provided below.

Additional Data Sources Identified by the Workgroup that Can Help Confirm Pregnancy for Deaths Which Do Not Link to Birth or Fetal Death Records, But Have Pregnancy Indicated by Other Information on the Death Record (i.e. the Pregnancy Checkbox).

Hospital and Emergency Department Records: Pregnancy status may be confirmed in labs, physician narratives, surgical histories, ultrasound results, medication lists, etc.

Obituaries: Can be found on obituary and funeral home websites

Social Media: Facebook pages for both the decedent and family members, GoFundMe pages, etc.

Media and News Reports: Especially useful for deaths due to homicide, suicide, or motor-vehicle crashes. Helpful search terms include: decedent name, date of birth, date of death, cause of death, city of death, and/or county of death

Certifier Confirmation: Vital Records staff may be able to confirm pregnancy checkbox information with the certifier

Autopsy Reports: When available, these reports may provide information on pregnancy status

¹ CDC. *Pregnancy-related deaths*. Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, 26 Feb. 2019, <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-relatedmortality.htm>. Accessed 06 Dec. 2019.

² Catalano A, Davis NL, Petersen EE, et al. Pregnant? Validity of the Pregnancy Checkbox on Death Certificates in Four States, and Characteristics Associated with Pregnancy Checkbox Errors, *American Journal of Obstetrics and Gynecology* (2019), doi: <https://doi.org/10.1016/j.ajog.2019.10.005>

³ CDC. *Registry Plus™ Link Plus*. Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, 19 Nov. 2018, <https://www.cdc.gov/cancer/npcr/tools/registryplus/lp.htm>. Accessed 06 Dec. 2019.