Reference for Identifying Pregnancy-Associated Deaths

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Accurately identifying deaths during and within one year of pregnancy (pregnancy-associated deaths) is a crucial first step for understanding leading causes of death, contributing factors, and opportunities for preventing pregnancy-related deaths. Relying on the information on the death record alone can both underestimate and overestimate the number of identified deaths that occurred during or within a year of the end of pregnancy.[1] To overcome these limitations, identification of these deaths requires use of additional data sources and linkage methods.

The purpose of this document is to describe best practices identified by the Workgroup for linking jurisdictional vital records data to identify 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 pregnancy-associated death 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

> Women ages 10-60 years <u>and</u>

> 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, <u>two</u> 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.
>
> Matches identified should be reviewed for accuracy.

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 methods using linkage software such as Link Plus, Match*Pro[2-3], or statistical software such as SAS.

> Blocking variables may include mother's first name, mother's last name, and mother's date of birth.
>
> Matching variables may 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.
>
> 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.
>
> Matches identified should be reviewed for accuracy.

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

This is not an exhaustive list of potential pregnancy-related keywords, and additional terms may be added based on review of death record data. If using software to identify keywords, adding common misspellings may improve identification of pregnancy-associated deaths. For example, "eclmpsia" or "eclampsa" for eclampsia.

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.

<u>Identification of Pregnancy-Associated Deaths based on Pregnancy Checkboxes on the Death Records</u>

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 errors. Records where a pregnancy check box on the death record indicates pregnancy, but there is no documentation of pregnancy in the year preceding death documented in the confirmation process are considered "false positives." 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] Catalano A, Davis NL, Petersen EE, et al. Pregnant? Validity of the Pregnancy Checkbox on Death

[2] CDC. Registry PlusTM 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.

[3] NIH. Match*Pro Software. Surveillance, Epidemiology, and End Results Program, National Cancer Institute, National Institutes of Health. https://seer.cancer.gov/tools/matchpro/. Accessed 12 June 2023.