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## *Appendix: Identification of Pregnancy-Associated Deaths with a History of SARS-CoV-2 Infection*

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### Background and Purpose

A study analyzing US national COVID-19 case surveillance data showed an increased risk of death among pregnant women with COVID-19 compared with non-pregnant women with COVID-19.<sup>1</sup> Standardized identification of SARS-CoV-2 infection among pregnancy-associated deaths could help to improve understanding of maternal mortality associated with COVID-19 in the United States. Maternal mortality review committees (MMRCs) are well-situated to play a key role in identifying pregnancy-associated deaths with a history of SARS-CoV-2 infection because of their existing processes for comprehensive identification of pregnancy-associated deaths. Systematic ascertainment of SARS-CoV-2 infection history among pregnancy-associated deaths can support MMRC reviews of individual deaths and contribute to broader surveillance of maternal mortality associated with COVID-19.

State and local MMRCs comprehensively identify and review pregnancy-associated deaths within their jurisdictions to determine factors contributing to the deaths and develop recommendations for preventing future deaths. MMRCs conduct rigorous processes to identify pregnancy-associated deaths within their jurisdictions, including linkages of death records with birth and fetal death records; using cause of death and pregnancy checkbox information from death records; direct reports from hospitals, providers, medical examiners, and coroners; and using publicly available online sources (e.g., obituaries, news reports, social media); see [Reference Guide for Pregnancy-Associated Death Identification](#).

This appendix provides information on data sources and methods that MMRCs can use for systematically identifying SARS-CoV-2 infection history among pregnancy-associated deaths. It builds upon an established process for identifying pregnancy-associated deaths detailed in the [Reference Guide for Pregnancy-Associated Death Identification](#). The methods in this appendix were shared by 9 jurisdictions participating in the Workgroup for the Identification of Pregnancy-Associated Deaths with a History of SARS-CoV-2 Infection. Workgroup members consisted of jurisdiction representatives who lead maternal and child health COVID-19 surveillance activities and/or who lead MMRC pregnancy-associated death identification, as well as representatives from the Centers for Disease Control and Prevention (CDC).

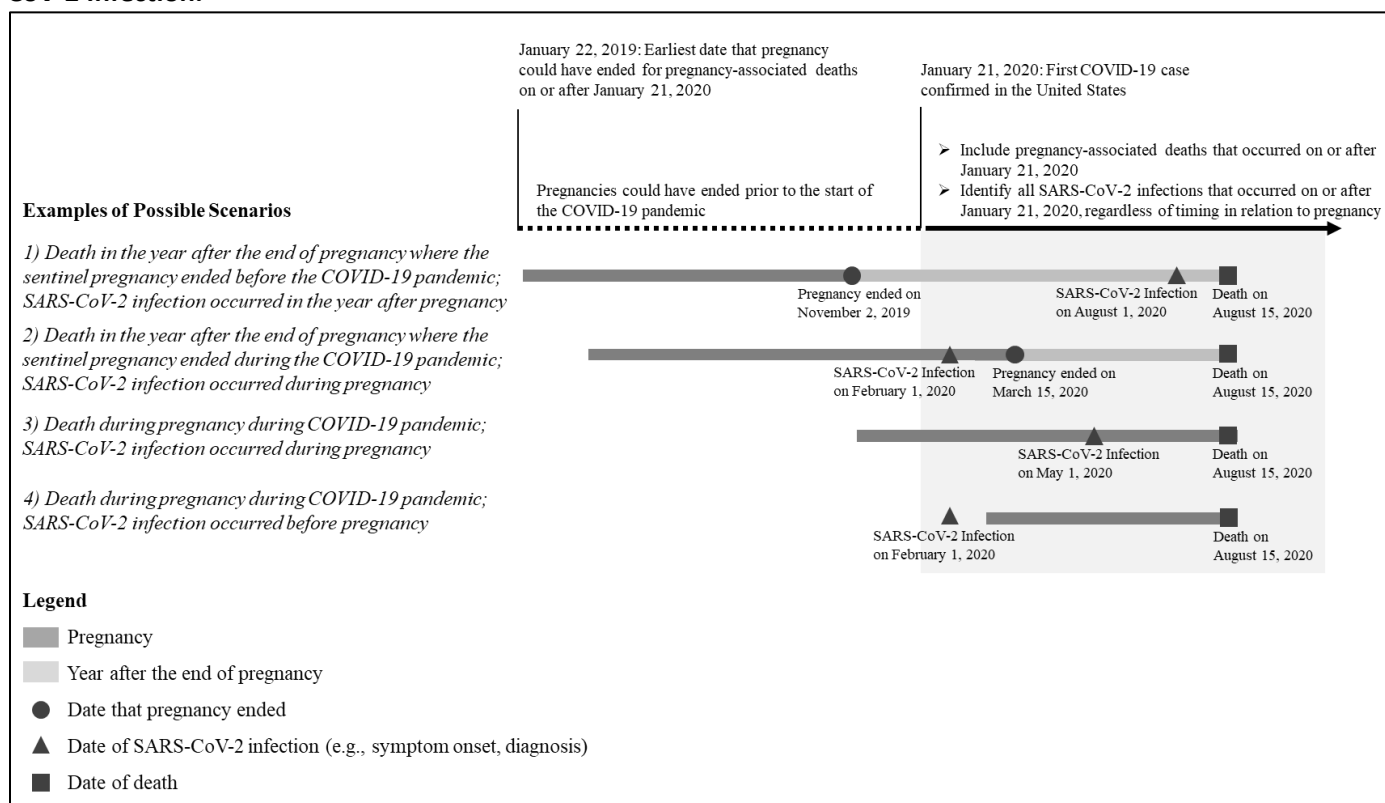
The key data source for identifying SARS-CoV-2 infections is jurisdiction-level COVID-19 case surveillance databases. These databases contain line-level information on COVID-19 cases reported to jurisdictions and allow for ascertainment of confirmed and probable COVID-19 cases as defined by the Council of State and Territorial Epidemiologists (CSTE). MMRCs may also be able to determine whether there was a history of SARS-CoV-2 infection from cause of death information on death records or by searching electronic health records or administrative data. It is possible that cases identified by MMRCs from death records, electronic health records, or administrative data may meet criteria for confirmed or probable cases; however, these case classifications should not be assigned unless available from the jurisdiction-level COVID-19 case surveillance database.

## Population of Interest

### **Which pregnancy-associated deaths should be included when MMRCs ascertain SARS-CoV-2 infection history?**

MMRCs should include all pregnancy-associated deaths that occurred during the COVID-19 pandemic regardless of the cause of death, starting on or after January 21, 2020 when the first COVID-19 case was confirmed in the United States (Figure 1). Because pregnancy-associated deaths are defined as deaths that occur during pregnancy and up to 1 year after the end of pregnancy, for the earliest possible death on January 21, 2020, the end of pregnancy could have been as early as January 22, 2019. For example, a person who gave birth on January 22, 2019 and was positive for SARS-CoV-2 infection when they died on January 21, 2020 would be included in the cohort.

**Figure 1. Inclusion Criteria for Identification of Pregnancy-Associated Deaths with a History of SARS-CoV-2 Infection.**



### **How long should MMRCs continue to determine SARS-CoV-2 infection history for pregnancy-associated deaths?**

Jurisdictions may continue to apply these methods until the end of the public health emergency or until they determine that it is no longer necessary or feasible to identify SARS-CoV-2 infection history.

### **Should MMRCs ascertain SARS-CoV-2 infection history only during specific time periods such as during pregnancy?**

No. The Workgroup recommends ascertaining all history of SARS-CoV-2 infection. This may include infections before, during, or after pregnancy at any time during the COVID-19 pandemic.

## Leveraging Existing Pregnancy-Associated Death Identification Processes

### ***At what point in the pregnancy-associated death identification process should MMRCs ascertain SARS-CoV-2 infection history?***

MMRCs can build in a step of determining SARS-CoV-2 infection history at any point during their existing case identification or abstraction process. See Box 1 for an example from a Workgroup jurisdiction.

MMRCs identify some pregnancy-associated deaths only through the pregnancy checkbox and/or International Classification of Diseases, Tenth Revision (ICD-10) codes related to pregnancy on the death record (see [Reference Guide for Pregnancy-Associated Death Identification](#)). Pregnancy status for these deaths needs to be confirmed (e.g., with the death certifier or in medical records) to avoid misclassification. This process can sometimes be burdensome, especially if the MMRC is not able to confirm with the death certifier and needs to begin requesting and abstracting records in order to confirm pregnancy status. MMRCs might choose to determine SARS-CoV-2 infection history before or after confirming pregnancy status depending on internal processes and resources. It is possible that information may be found in COVID-19 case surveillance data to confirm pregnancy status.

## Ascertainment of SARS-CoV-2 Infection History from Jurisdiction-Level COVID-19 Case Surveillance Data

### ***What are jurisdiction-level COVID-19 case surveillance databases?***

Jurisdiction-level COVID-19 case surveillance databases are the key data source for identifying SARS-CoV-2 infections. These databases contain line-level information on COVID-19 cases reported to the jurisdiction, including case classification (i.e., confirmed, probable, suspect), laboratory test results, and other information such as specimen collection date, how the case was identified, symptoms, and date of symptom onset. MMRC staff should become familiar with their jurisdictions' case definitions for confirmed and probable cases and how they have changed over time. Standard case definitions from the Council of State and Territorial Epidemiologists (CSTE) are included at the end of this appendix. The case definitions were first approved on April 5, 2020 and then updated on August 5, 2020. Jurisdictions apply the case definition that is in effect at the time that the case is classified; they do not retroactively change case classifications to align with updated case definitions.

### ***Which COVID-19 case classifications should be included?***

The Workgroup recommends ascertaining both confirmed and probable SARS-CoV-2 infections among pregnancy-associated deaths. Including both confirmed and probable cases casts a wide net for capturing SARS-CoV-2 infections, especially given potential differences across states in SARS-CoV-2 testing at the beginning of the pandemic and recent increases in antigen tests. Data quality for confirmed cases is expected to be more consistent across jurisdictions. Data quality for probable cases may vary both across and within jurisdictions due to differences in how and if probable cases are identified and reported, which also may have shifted across the course of the pandemic. Jurisdictions may need to assess the quality and completeness of probable cases before including them as part of identifying SARS-CoV-2 infection history for pregnancy-associated deaths. Reported data should be

stratified by confirmed and probable cases. Jurisdictions may consider ascertaining suspect SARS-CoV-2 infections, but this was not identified as a high priority by the workgroup.

***How can MMRCs use COVID-19 case surveillance data to ascertain SARS-CoV-2 infection history?***

The Workgroup recommends two methods for ascertaining SARS-CoV-2 infection history among pregnancy-associated deaths using jurisdiction-level COVID-19 case surveillance databases: linkage between the jurisdiction's cohort of pregnancy-associated deaths and the COVID-19 case surveillance database, and manually searching the COVID-19 case surveillance database for each pregnancy-associated death. Deciding between which method(s) to use may depend on resources and the burden of pregnancy-associated deaths within the jurisdiction. See Box 2 for examples of methods used by Workgroup jurisdictions. It is important to note that due to limitations of cross-jurisdictional data sharing for both pregnancy-associated deaths and COVID-19 case surveillance data, these linkages may miss SARS-CoV-2 infections where the case was reported in a different jurisdiction from where the person resided.

- **Linkage between pregnancy-associated deaths and COVID-19 case surveillance data**
  - Select all pregnancy-associated deaths that occurred on or after January 21, 2020. Per the [Reference Guide for Pregnancy-Associated Death Identification](#), this cohort should include all pregnancy-associated deaths of residents of the jurisdiction, regardless of where the death occurred.
  - Conduct computerized linkage between pregnancy-associated death cohort and the jurisdiction's COVID-19 case surveillance data. Specific methods will vary by which fields are available for both the pregnancy-associated death cohort and the case surveillance database. If possible, the Workgroup recommends using both deterministic and probabilistic linkages to maximize matches.
    - Deterministic linkage: Strategies that could be used include matching files on the mother's social security number (SSN); matching files on both SSN and mother's date of birth; and matching files based on first three letters of mother's first, last, and maiden names, mother's date of birth, and mother's address.
    - Probabilistic linkage: Blocking variables may include (if available) mother's first name, mother's last name, and mother's date of birth. Matching variables may include (if available) mother's first name, mother's last name, mother's maiden name, mother's date of birth, mother's address or zip code, and mother's phone number.
- **Manual search of COVID-19 case surveillance database for pregnancy-associated deaths**
  - Select all pregnancy-associated deaths that occurred on or after January 21, 2020. This should include all deaths of residents of the jurisdiction, regardless of where the death occurred. Search entire case surveillance database for each pregnancy-associated death. Specific methods will vary by which fields are available for both the pregnancy-associated death cohort and the case surveillance database. Below are examples of search strategies/combinations of fields used by Workgroup jurisdictions.
    - SSN
    - Mother's last name and mother's date of birth
    - Mother's last name, mother's first name, and date of birth
    - Mother's last name and mother's first name
    - Mother's maiden name and mother's first name
    - Mother's date of birth and city of residence

- Workgroup jurisdictions observed that sometimes first and last or maiden names are switched in case surveillance data, and that names may be misspelled. To maximize matches, the Workgroup recommends using multiple search strategies and allowing for partial or fuzzy matching if possible. For example, portions of names can be used in searches rather than requiring a match on the full name. Using Soundex or other phonetic algorithms when searching for names can allow for matches of names that sound alike even when they are misspelled.

In addition to ascertaining whether there was a history of confirmed or probable SARS-CoV-2 infection, MMRCs may also be interested in collecting additional detailed information on the COVID-19 case from the case surveillance database. Fields that may be available include how the case was first identified, date of first positive specimen collection, exposures in 14 days prior to illness onset (e.g., travel, workplace, contact with another COVID-19 case), laboratory test type(s) and result(s), symptoms and clinical course, and date of symptom onset.<sup>2</sup>

***What are the limitations of COVID-19 case surveillance data for ascertaining SARS-CoV-2 infection history among pregnancy-associated deaths?***

Some limitations of COVID-19 case surveillance data must be acknowledged. First, many persons who are infected with SARS-CoV-2 have mild or no symptoms and therefore may not have sought laboratory testing or medical care. These persons are less likely to be reported as cases in COVID-19 case surveillance data.<sup>3</sup> Second, the methods recommended in this appendix may miss scenarios where a person had a reported COVID-19 case in state other than their state of residence. Each jurisdiction will likely only be able to search its own case surveillance database for records that match pregnancy-associated deaths of their residents. It is possible that residents of a jurisdiction may have sought SARS-CoV-2 laboratory testing in another jurisdiction. In that situation, testing data may or may not be shared back with the jurisdiction where they were a resident.

***How can an MMRC get access to their jurisdiction's COVID-19 case surveillance database?***

The Workgroup recommends that MMRC staff seek direct or indirect access to their jurisdiction's COVID-19 case surveillance database. Direct access refers to MMRC staff being granted access to the database to be able to manually search the line list of cases or link the line list with their pregnancy-associated death cohort. Indirect access refers to MMRC staff being granted access to a data extract from the case surveillance database on a routine basis but not being able to directly access the database themselves. Among the Workgroup jurisdictions, MMRCs varied in terms of how they were able to get access to case surveillance databases. MMRC staff in most jurisdictions were able to get direct access to their jurisdiction's case surveillance database; a few jurisdictions needed to request data extracts.

Some Workgroup jurisdictions needed to establish or amend formal data use agreements between maternal and child health (MCH) and communicable disease departments to access COVID-19 case surveillance data for use in maternal mortality surveillance. Agreements between MCH and communicable disease departments may already be in place for surveillance systems such as Surveillance for Emerging Threats to Mothers and Babies (SET-NET) programs conducting surveillance of infections during pregnancy. Jurisdictions may need additional permissions to access communicable disease data covering all infections that could have occurred prior to, during, or after pregnancy among persons who experienced a pregnancy-associated death. Additionally, new agreements may need to be established if any of the maternal mortality review data will be shared back with communicable disease staff. Jurisdictions executing new data use agreements between MCH and communicable disease

departments may wish to consider keeping the data use agreement broad enough to include data on infections beyond COVID-19, if possible, in order to cover data access for future emerging threats.

Other Workgroup jurisdictions did not require a formal data use agreement for granting MMRC staff access to case surveillance data because such access was covered under broad public health authority for health department staff to use their jurisdiction's COVID-19 case surveillance data for surveillance purposes. Across all jurisdictions, a common lesson learned was the value of ongoing communication and relationship building between MCH and communicable disease departments particularly around public health preparedness. Several jurisdictions reported that it was helpful that MCH staff had participated in COVID-19 response efforts and had gained familiarity with their jurisdiction's case surveillance database. At least one jurisdiction reported that the relationships built between MCH and communicable disease departments for the SET-NET program were invaluable. See Box 3 for examples from Workgroup jurisdictions.

When MMRCs must request a data extract rather than having direct access to the case surveillance data, the Workgroup recommends the following specifications/considerations for the data extract:

- Persons ages 10-60 years whose sex is indicated as female, other, or unknown.
- Confirmed and probable cases at a minimum. Inclusion of probable cases may be dependent on data quality and completeness. Jurisdictions may also consider requesting data on suspect cases (recognizing that positive antibody tests may reflect prior vaccination or infections), negative SARS-CoV-2 laboratory tests, contacts of confirmed cases, etc.
- Not time bounded, so that infections that occurred at any point in time during the COVID-19 pandemic can be ascertained.
- Specific data fields for linkage or search purposes: First, middle, maiden, and last name; date of birth; residential address (street, city, zip code, county), SSN, and phone number. Available fields will vary by jurisdiction.
- Additional fields to provide more detailed information on SARS-CoV-2 infection history, e.g., how the case was first identified, date of first positive specimen collection, exposures in 14 days prior to illness onset (e.g., travel, workplace, contact with another COVID-19 case), laboratory test type(s) and result(s), symptoms and clinical course, and date of symptom onset.<sup>2</sup>

## Ascertainment of SARS-CoV-2 Infection History from Death Record Cause of Death Information

### ***How can MMRCs use death records to ascertain SARS-CoV-2 infection history?***

History of SARS-CoV-2 infection may be ascertained directly from the death record using ICD-10 mortality codes and literal text fields for immediate, intermediate, and underlying causes of death and other significant conditions contributing to the death. Because this information is limited to scenarios where COVID-19 contributed to a death, identification based on death records will likely be biased towards capturing more severe cases of COVID-19. Depending on the volume of pregnancy-associated deaths, jurisdictions may review each death record manually or automate a search of cause of death fields for specific COVID-19-related terms. Using loose or partial keywords or allowing for misspellings may enhance matching because there may be misspelling in cause of death fields. See Box 4 for an example from a Workgroup jurisdiction. Because death record data are limited to scenarios where COVID-19 contributed to a death, death record data should be used as a supplement to the previously described methods, but not as the sole source of ascertaining SARS-CoV-2 infection history.

**Which ICD-10 mortality codes or terms related to SARS-CoV-2 or COVID-19 should MMRCs search for on death records?**

- **ICD-10 mortality codes**
  - U07.1 (2019-nCoV acute respiratory disease; implemented on April 1, 2020)
  - B97.29 (Other coronavirus; not exclusive to SARS-CoV-2 or COVID-19)
  - J12.89 (Other viral pneumonia; not exclusive to SARS-CoV-2 or COVID-19)
- **Literal cause of death fields**
  - *More specific to SARS-CoV-2*
    - COVID-19 (e.g., “Complications of COVID-19”, “Probable COVID-19”, “Sequelae of SARS-CoV-2”)
    - Coronavirus disease
    - SARS-CoV-2
    - 2019-nCoV
  - *Less specific to SARS-CoV-2 but useful for identifying recent infection, especially early in the pandemic before widespread testing was available*
    - Respiratory failure
    - Asthma
    - Pulmonary embolism (PE)
    - Pneumonia/Bronchopneumonia
    - Acute respiratory distress syndrome (ARDS)
    - Sepsis/Septic shock
  - *Note that for individual deaths where there were only ICD-10 mortality codes or literal cause of death terms not exclusive to SARS-CoV-2 or COVID-19, these may need to be investigated further to determine whether to include as having a history of SARS-CoV-2 infection.*

## Ascertainment of SARS-CoV-2 Infection History from Electronic Health Records or Administrative Data

**How can MMRCs use electronic health records or administrative data to ascertain SARS-CoV-2 infection history?**

History of SARS-CoV-2 infection may also be ascertained through linkage of the pregnancy-associated death cohort with electronic health records or administrative data such as hospital discharge, emergency department, and ambulatory data. One Workgroup jurisdiction used hospital discharge data to ascertain history of SARS-CoV-2 infection among their pregnancy-associated death cohort. This jurisdiction identified pregnancy-associated deaths in hospital discharge data using a linkage on mother’s SSN and mother’s DOB, and then searched within the linked hospital discharge records for COVID-19-related ICD-10 diagnosis codes. See Box 5 for more details.

Depending on the volume of pregnancy-associated deaths that link to a medical record, jurisdictions may review each medical record manually or automate a search for a COVID-19 diagnosis.

**Which ICD-10 diagnosis codes related to SARS-CoV-2 or COVID-19 should MMRCs search for in electronic health records or administrative data?**

- **ICD-10 diagnosis codes**
  - U07.1 (2019-nCoV acute respiratory disease; implemented on April 1, 2020)
  - B97.29 (Other coronavirus; not exclusive to SARS-CoV-2 or COVID-19)
  - J12.89 (Other viral pneumonia; not exclusive to SARS-CoV-2 or COVID-19)

- *Note that for individual deaths where there were only ICD-10 diagnosis codes not exclusive to SARS-CoV-2 or COVID-19, these may need to be investigated further to determine whether to include as having a history of SARS-CoV-2 infection.*

### **What are the limitations of electronic health records or administrative data for ascertaining SARS-CoV-2 infection history among pregnancy-associated deaths?**

One limitation of administrative data is a potential delay in receipt of records. For example, one Workgroup jurisdiction was initially only able to access the first 6 months of hospital discharge data for 2020. Because of these delays, linkage with electronic health records or administrative data should be used as a supplement to the previously described methods, but not as the sole source of ascertaining SARS-CoV-2 infection history.

## Other Data Sources

### **What are other possible data sources for ascertaining SARS-CoV-2 infection history among pregnancy-associated deaths?**

**Ad hoc reporting from medical examiners or coroners:** Some jurisdictions, especially those with a state medical examiner, may learn of pregnancy-associated deaths with a history of SARS-CoV-2 infection directly from medical examiners or coroners. In one Workgroup jurisdiction, the MMRC sometimes learned of pregnancy-associated deaths with a history of SARS-CoV-2 infection directly from their Office of the Chief Medical Examiner prior to identifying those cases from case surveillance data or other sources.

**COVID-19 fields added to the jurisdiction's birth certificate:** Some jurisdictions have added fields to their state birth certificate to capture confirmed or presumed COVID-19 during pregnancy. These data are being used by some jurisdictions for reporting of COVID-19 cases during pregnancy to the National Center for Health Statistics.<sup>4</sup> Most of these jurisdictions added COVID-19 to the list of infections during pregnancy that are ascertained on the birth certificate; others asked about COVID-19 as part of items on obstetric procedures or characteristics of labor and delivery.<sup>4</sup> For pregnancy-associated deaths that link to a birth certificate, MMRCs could use the linked birth certificate as an additional source of COVID-19 infection data. Data quality on maternal COVID-19 infections on the birth certificate is unknown; jurisdictions should verify this information using additional data sources such as medical records or case surveillance data.

## Definitions

**Pregnancy-Associated Death:** Death during pregnancy or within one year of the end of pregnancy from any cause. All deaths that have a temporal relationship to pregnancy are included.

**Pregnancy-Associated Death with a History of SARS-CoV-2 Infection:** Pregnancy-associated death where there was evidence of confirmed or probable SARS-CoV-2 infection (per CSTE case definition below) before, during, or up to 1 year after the end of pregnancy.

### **CSTE COVID-19 Interim Case Definitions:**

- Approved August 5, 2020: See <https://ndc.services.cdc.gov/case-definitions/coronavirus-disease-2019-2020-08-05/>
- Approved April 5, 2020: See <https://ndc.services.cdc.gov/case-definitions/coronavirus-disease-2019-2020/>



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The findings and conclusions in this report are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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**Box 1. Building Ascertainment of SARS-CoV-2 Infection History into Pregnancy-Associated Death Identification Process**

In **Tennessee**, case identification of maternal mortality review cases occurs monthly. The manual search for SARS-CoV-2 laboratory results occurs after the monthly case identification process but before case verification by the Maternal Mortality Review (MMR) Program Coordinator. This enables rapid identification of potential COVID-19 pregnancy-associated deaths and informs prioritization strategy by the MMR Program Coordinator.

**Box 2. State experiences using COVID-19 case surveillance data to ascertain SARS-CoV-2 infection history among pregnancy-associated deaths.**

The **Louisiana** Pregnancy-Associated Mortality Review (PAMR) works to identify and review all deaths that occur during or within one year of the end of pregnancy, regardless of cause of death. To date, 78 confirmed pregnancy-associated deaths in 2020 have been identified. While the majority of 2020 cases have likely been identified, 2020 case identification will not be completed until the summer or fall of 2021. The Louisiana Department of Health, Office of Public Health, Bureau of Family Health is working to identify COVID-19 infection among pregnancy-associated deaths. In Louisiana, the state administrative code requires that all laboratory results of COVID-19 tests are reported to the state in an electronic laboratory reporting (ELR) database. Staff members from the Louisiana Pregnancy-Associated Mortality Review (PAMR) manually searched this database for all confirmed 2020 pregnancy-associated deaths. SAS was used to search for the first name of the decedent to identify all cases in ELR that had the same first name. This process was repeated for the last name and social security number. No methods were used to account for misspellings. Through this process, Louisiana identified a number of matches of both positive and negative test results between the pregnancy-associated case list and the ELR data.

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To identify pregnancy-associated deaths with a history of SARS-CoV-2 infection, **Massachusetts** performed deterministic data linkages between infectious disease case reports (n=137,418) for females of reproductive age (defined broadly as 11-59 years) with laboratory-confirmed SARS-CoV-2 infection and provisional data on pregnancy-associated deaths (n=24) occurring during January-June 2020. Pregnancy-associated deaths were identified by linking birth and fetal death records to death certificates, and through information related to pregnancy on the death certificate (checkbox indicating pregnancy, the literal cause of death field, and/or ICD-10 mortality O-codes related to pregnancy). Deterministic data linkages were performed using the following matching variables: first, last, and maiden name (using the first three letters and the Soundex function), maternal date of birth, and address. Through this linkage, Massachusetts identified three matches. These pregnancy-associated deaths were all identified only by ICD-10 mortality O-codes and the pregnancy checkbox on the death certificate (none linked to a vital record). False positives (i.e., deaths where the person was not actually pregnant within one year of death) can occur among pregnancy-associated deaths identified only by ICD-10 mortality O-codes and the pregnancy checkbox. Therefore, this number of matches may decrease after the MMRC completes pregnancy status confirmation for the identified deaths. Massachusetts also performed a manual search of all 24 pregnancy-associated deaths in their infectious disease reporting system. Searches were performed using exact first, last, and maiden name and date of birth, and fuzzy first, last, and maiden name and exact date of birth. Through this manual search, Massachusetts identified the same three individuals who matched through the linkage process.

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In **Tennessee**, case identification of maternal mortality review cases occurs monthly. The Maternal Mortality Review (MMR) Epidemiologist then sends the new case identification list to the Viral Hepatitis Special Projects Coordinator, who manually searches Tennessee's surveillance registry, the NEDSS Base System (NBS), for COVID-19 laboratory results. Key search terms include: first name, last name, date of birth, and social security number. To help with matches, partial first name was used. The manual search found the same matches as the linkage algorithm; however, the manual search saved a considerable amount of time. Because Tennessee conducts pregnancy-associated death identification on a monthly basis, the volume of deaths for manual look-up is small and manageable each month compared with completing a formal linkage each month. Information provided back to the MMR Program, includes COVID-19 case status (confirmed, probable, not a case) and COVID-19 specimen collection date, if applicable.

**Box 3. State experiences gaining access to COVID-19 case surveillance data for ascertaining SARS-CoV-2 infection history among pregnancy-associated deaths.**

At the **California** Department of Public Health (CDPH), the MMRC (called the California Pregnancy-Associated Mortality Review) and the Coronavirus Science Branch (CSB), which manages the CDPH COVID-19 Case Registry (including laboratory testing data), reside in different divisions and centers. Thus, to obtain laboratory testing data extracts from the CDPH COVID-19 Case Registry, the MMRC needed to enter into a data sharing agreement with CSB. The process for establishing the data sharing agreement, called a Business Use Case Agreement (BUCA), involves submitting a proposal that describes the project for which the registry data are being requested (e.g., project objectives, methods, IRB status, justification for the data need), list of data elements needed, time frame and frequency of data extracts, information privacy and security safeguards, and how the data will be used and/or shared as well as identifying project representatives responsible for managing the data.

The process to establish the data use agreement can be lengthy, and MMRCs should get started early. At CDPH, CSB provided a proposal template, instructions to complete and submit it, and data dictionaries. The MMRC team reviewed the data dictionaries to identify all potentially useful data elements for inclusion with the proposal. The MMRC coordinator also reached out to colleagues for examples of executed BUCAs to help draft the proposal. Once drafted, the BUCA proposal was reviewed, revised, reviewed again and finally approved by senior leadership at both centers. Altogether, this process took approximately seven weeks, not accounting for the time it took to draft the proposal.

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In **Massachusetts**, the Maternal Morbidity and Mortality Review Initiative (MMMRI) was able to build on an existing foundation of data access for Massachusetts' CDC-funded Surveillance for Emerging Threats to Mothers and Babies (SET-NET) program. At the start of SET-NET funding, a data use agreement (DUA) was established among the Bureau of Infectious Disease and Laboratory Sciences (BIDLS), Registry of Vital Records and Statistics, Universal Newborn Hearing Screening Program, and the Center for Birth Defects Research and Prevention (CDBRP), with the purpose of "1) identifying the proportion of pregnancies that experience infections with a reportable disease, and 2) better understanding and monitoring of adverse outcomes (e.g., stillbirth, birth defects, and hearing loss) that may occur with certain infectious diseases." With the start of the COVID-19 pandemic, the DUA was updated to have a broader scope and purpose: "The purpose of this data sharing agreement is to facilitate rapid surveillance of infectious diseases that the Department has deemed of concern or emerging threats to pregnant women and infants. The intended uses are: 1) Rapid surveillance for infectious disease that may put pregnant women and infants at risk; 2) Mutual sharing of data on possible cases identified by either the CDBRP or BIDLS that the other entity does not have information on; and 3) Participation by Massachusetts in national surveillance efforts (e.g., national registries led by CDC)."

The updated DUA was reviewed by the various programs' legal counsels and approved. From start to finish, the updating of the DUA and legal review took approximately one month. Updating the DUA to add new staff or additional variables not considered identifiers or restricted-access variables (e.g., HIV infection status) would not need additional legal review in the future, thus allowing for quick and seamless coordination and data sharing between all parties. For example, when the COVID-19 Maternal Mortality Workgroup was initiated, Massachusetts was able to quickly add MMMRI staff and additional variables needed for linkage.

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In **New Hampshire**, positive COVID-19 labs are reported either electronically through the New Hampshire Electronic Disease Surveillance System (NHEDSS) or via fax. As reports are received, NH case investigators interview cases using the NH COVID-19 Case Report Form. This form instructs investigators to collect pregnancy status and estimated due date if not already reported in the initial case report. The NH Bureau of Infectious Disease Control (BIDC) and Maternal and Child Health (MCH) staff conduct weekly exports of pregnant cases and initiate enhanced investigations. Through review of vital records data, case investigation notes, birth record abstractions and proactive reporting by birthing hospitals, enhanced surveillance is performed, in alignment with CDC's efforts to detect the effects of COVID-19 on pregnant women and their babies. NH also has a (daily) COVID-19 death monitoring protocol in place. This, combined with monthly maternal death surveillance

performed by NH's MCH section, allows for timely identification and enhanced investigation of COVID-related pregnancy-associated deaths if they are to occur.

Access to COVID-19 surveillance data for MCH staff was initially questioned in the absence of routine collaboration between the MCH and BIDC. The only other significant experience of MCH and BIDC working together closely in recent memory was in relation to Zika. Staff relationships built at that time provided connections and a framework upon which to build for COVID-19 collaboration. Citing [the portion of NH law](#) that describes "Acquisition of Information Related to Maternal Mortality" resolved data access concerns quickly.

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In 2019, [Tennessee](#) was a funded partner to address the impact of emerging health threats during pregnancy as it related to hepatitis C virus (HCV) infection. The existing HCV infrastructure provided a population-based mother-baby linked longitudinal surveillance approach that allowed for rapid adaptation to COVID-19. To address COVID-19, Tennessee leveraged its staff from the existing HCV project and maternal and child health (MCH) staff from the Division of Family Health and Wellness. The Viral Hepatitis Epidemiologists had access and familiarity with NBS, which is the database that also stored the COVID-19 laboratory and interview data. The COVID-19 pregnancy project is listed in Tennessee's Incident Command Structure for COVID-19 Response, which provides structure and maintains leadership communication pathways.

In the COVID-19 pregnancy project, there is information collected on adverse maternal outcomes, including maternal death. The MCH staff leveraged their relationships with the MMR Program and the Office of Chief Medical Examiner to identify and investigate pregnancy-associated deaths due to SARS-CoV-2 infection and prioritize them for review. These relationships were critical in building out capacity to identify and review maternal mortality cases and gather information on previous COVID-19 testing. COVID-19 cases have been prioritized for review starting in September 2020. Due to the existing HCV project, Tennessee already had access to needed surveillance data, and no data sharing agreement was required.

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Through the COVID-19 Maternal Mortality Workgroup convened by CDC, [Wisconsin](#) was able to gain access to and incorporate COVID-19 surveillance data as part of their MMR data collection and abstraction activities. Because Wisconsin typically has fewer than 50 pregnancy-associated deaths per year, it was determined that it would be best to request direct access for the MMR epidemiologist to manually look-up pregnancy-associated deaths in the Wisconsin Electronic Disease Surveillance System (WEDSS) for history of COVID-19 infection. This had the advantage of reducing the burden that would be placed on communicable disease partners who already have many demands on their time for COVID-19 related data requests. Additionally, MMR data staff were already familiar with searching in WEDSS from their participation in contact tracing and case follow-up for the COVID-19 and Zika responses. MMR data staff presented their request for WEDSS access for MMR to the internal Data Governance Board where it received approval from both the Bureau of Communicable Disease and Division of Public Health Leadership. By utilizing a manual case lookup, the MMR team is able to maximize the amount of COVID-19 information that is captured, including confirmed, suspect, and probable cases and negative COVID-19 tests. The WEDSS data may also identify additional providers or facilities where a woman received care that were not previously identified by other MMR records. This may allow for more complete records gathering, especially with relation to COVID-19 infection. Wisconsin hopes to use this experience with WEDSS data for MMR to identify additional opportunities to incorporate communicable disease information into the case abstraction and review process in the future.

#### **Box 4. Using Death Record Cause of Death Information to Ascertain SARS-CoV-2 Infection History among Pregnancy-Associated Deaths**

In [Louisiana](#), state staff use the pregnancy checkbox along with linkages of death records to live birth and fetal death records and pregnancy-related inpatient hospital discharge records to identify pregnancy-associated deaths. After pregnancy-associated deaths are identified, they are sent to the Maternal and Child Health (MCH) Coordinators, a team of nurses who confirm that a pregnancy occurred within one year of death and then complete case abstraction using vital records, medical records and other records as available. Some of the identified pregnancy-associated deaths had COVID-19 listed as a cause of death on the death certificate. The

MCH Coordinators started exploring medical records to find additional documentation to confirm COVID-19 infection in medical records, and already identified this information for some of the cases.

In spring 2021, Louisiana compared their current list of pregnancy-associated deaths with history of SARS-CoV-2 infection between those identified using death record cause of death information and COVID-19 laboratory test results from their electronic database (ELR). The cases identified based on death certificate cause of death information were the same cases identified as having had positive test results in the ELR search. Louisiana plans to continue doing this comparison moving forward as more pregnancy-associated deaths are identified for 2020 and 2021.

#### **Box 5. Using Hospital Discharge Data to Ascertain SARS-CoV-2 Infection History among Pregnancy-Associated Deaths**

The **California** Pregnancy-Associated Mortality Review has access to statewide provisional and final Patient Discharge Data (PDD), Emergency Department Data (EDD), and Ambulatory Surgery Center Data (ASCD) – collectively referred to as hospital data – from the California Office of Statewide Health Planning and Development (OSHPD), established through a Memorandum of Understanding. PDD consist of records for all inpatients discharged from California-licensed hospitals. EDD include encounters from all hospitals licensed to provide emergency medical services, and ASCD include encounters from general acute care hospitals and licensed freestanding ambulatory surgery clinics. After pregnancy-associated deaths are identified, they are linked to hospital data by social security number and date of birth to obtain all patient hospital encounter records within one year of the date of death. All diagnosis codes from linked hospital data are then scanned for ICD-10 codes U07.1, B97.29, and J12.89 to identify a patient’s history of SARS-CoV-2 infection. Diagnosis codes are also scanned for ICD-10 code Z20.828 (Contact with and (suspected) exposure to other viral communicable diseases) to screen for potential exposure to SARS-CoV-2. This code is used is when a patient is not diagnosed with COVID-19 but the exposure remains suspected.

OSHPD releases provisional hospital data with a time lag of 3 to 12 months, depending on the type of data file. Provisional EDD and PDD are available quarterly and semi-annually, respectively, whereas ASCD are released once per year (no provisional files).