II. How to Start a Local Homeless Mortality Data Report

The feasibility of a local homeless mortality count depends on factors including the availability of data, data analysis/programming expertise, and political/institutional support in each jurisdiction. This section describes a variety of methodologies, noting that the best-fit may depend on the resources, systems available, and the ease of access in each locality. Ultimately, the goals are to record deaths of people experiencing homelessness (PEH) and homeless status as comprehensively as possible, which may involve a combination of the following methods.

This section will provide a high-level overview of the most common mechanisms used for collecting and reporting on homeless mortality. We hope that health and housing advocates can learn from this information to inform their efforts to create and carry out ongoing homeless mortality data reporting efforts on a local, state, and national level.

Homeless Mortality Review Task Force/Working Groups

It is scarcely possible to initiate a homeless mortality report independently. Successful reports, rather, emerge from a collaborative task force or work group that focuses on accountability, brings in multiple points of view, provides partnerships and data-sharing, reviews results, and carries out recommendations. Such work groups must partner with health department leads.

Why Conduct a Homeless Mortality Count?

Each Homeless Persons’ Memorial Day, community members ask who died in homelessness, how many, how did they die, and how can these deaths be prevented. Many are surprised to learn that in most cities, counties, states, and indeed the federal government, there is no standardized reporting of people without homes who pass away. Homeless mortality reporting efforts on a local and state level vary greatly jurisdiction by jurisdiction, based on local circumstances. However, the most effective efforts have emerged from concerted organizing by advocates, health workers, researchers, health departments and local government officials who know that tracking and evaluating homeless mortality data is essential to develop health and housing strategies to save lives.
Health department and community partners appropriate for a task force/working group can include:

1. Medical Examiner/Coroner leaders
2. Health department, epidemiology, and public health leaders
3. City/County Homeless Department leaders
4. Health Care for the Homeless (HCH) programs or other health centers
5. Homeless Management Information System (HMIS) Continuum of Care leaders
6. Homeless services providers
7. Hospitals, health plans
8. People experiencing homelessness (PEH)
9. Community providers and advocates

Sources of Data that Capture Deaths and Their Causes

The first step is determining who keeps or owns data on homeless deaths. Mortality data in most jurisdictions reside with the Medical Examiner/Coroner (MEC), at the state level death certificate records systems, and – importantly – by community members themselves. Consider these sources of mortality data that tell us who died and how:

Coroner’s Office/Coroner’s Report

Coroners are elected or appointed county or state officials who are often situated in law enforcement without medical training. Each jurisdiction varies in the types of deaths their coroner’s office investigates and reports.

A coroner’s office typically only investigates deaths due to unusual or suspicious circumstances, violence (accident, suicide, or homicide), deaths that are sudden and without warning, or deaths that are unattended. This means that many “natural” deaths (such as those occurring in hospitals or care facilities) go unreviewed by a coroner. The political nature of the coroner’s office will impact relationship-building when conducting homeless mortality data research.

Office of Medical Investigator/Medical Examiner Report

A Medical Examiner is a board-certificated doctor in a medical specialty that works for a health department or district. Some states have a centralized state-wide medical investigator, while others have a county/district-based system (see the CDC’s resource on Death Investigations Systems for a state-by-state look!).

Similar to coroners, each state varies in the exact jurisdiction of deaths their medical examiner investigates; however, most investigate deaths “due to unusual or suspicious circumstances, violence (accident, suicide, or homicide), those due to natural disease processes when the death
occurred suddenly and without warning, when the decedent was not being treated by a physician, or the death was unattended.”

Neither the coroner nor medical examiner have records on all deaths in their jurisdiction. For example, in **Cook County, Illinois**, the medical examiner captures approximately 40% of deaths.

95% of medical examiner and/or coroner (MEC) systems nationwide are not accredited, and therefore have varied professional standards. Some localities, in fact, combine a coroner’s and medical examiner’s office functions.

**State Death Records**

In the U.S., each death generates a certificate. The death certificate is filled out by doctors and medical staff of hospitals and facilities, or by the coroner or medical examiner for accidental, suspicious, or unaccompanied deaths. Each state maintains death certificate records, which are public records and can be requested as such under the Freedom of Information Act (FOIA). Local public health departments enjoy unrestricted access to those records for surveillance purposes – for example, reviewing state death records to determine local homeless mortality. Most state death certificates lack searchable fields for homeless status, however, and ease of review and the amount and quality of death certificate information vary widely by state.

**Community-Based Primary Data**

In addition to these strategies, some pursue a community-based approach to mortality surveillance among people experiencing homelessness (PEH). This approach depends on a collection of reports of PEH by community reporters, informants such as people experiencing homelessness themselves, services providers, advocates, families, and through a review of news and social media for reports of homeless deaths. These community-based records of deaths are often used to honor the deceased in annual Homeless Persons’ Memorial Day events.

This approach is being utilized in **Nashville, Tennessee**, by a local homeless agency advocating for a systematic homeless mortality surveillance system managed by the city. One staff member notes:

> It is important to identify key stakeholders who are respected and trusted among the homeless community at hand. Identifying and communicating both a goal and dissemination plan for collecting this information is key in order to get buy-in from other nonprofits, organizations, and individuals with lived experience who may be weary of providing information about PEH that they knew. It is important to express and practice mindfulness regarding the information collected, such as cause of death, and to ensure that this data collection is not causing undue harm to PEH. Creating and consulting a community advisory board can promote community buy-in and prevent undue harm. The advisory board should consist of key stakeholders and, most importantly, those with lived experience.
Community-based approaches bear their own limitations. For example, they likely miss many PEH who are not connected or well-known among service providers, shelters, or community members. Communities should thus continue to advocate for other systematic reviews outlined in this report that captures all deaths, including in hard-to-reach subgroups, regardless of deceased individuals’ involvement with service providers. iv

Advocacy Spotlight: Sacramento

1. After Sacramento Regional Coalition to End Homelessness (SRCEH) Executive Director, Bob Erlenbusch, gave a report to the Sacramento Board of Supervisors in 2014 that identified the locations of the deaths of people experiencing homelessness, the Board of Supervisors voted to allocate $260,000 for additional nurse outreach to homeless encampments.
2. The Sacramento Continuum of Care (CoC) used the same report to focus street outreach efforts on the encampments along transportation corridors.
3. Through their homeless deaths report, SRCEH was able to show that the mortality rate for people experiencing homelessness was approximately 25% for each of the four seasons. In 2017, the city used this information to fund 24/7 low-barrier shelters year-round after years of shelters with limited hours only opening in the winter.
4. SRCEH’s homeless deaths reports inspired Joshua's House, a hospice house for terminally ill homeless men and women transferred from local health care partners. It is set to open in Spring 2021.
5. The SRCEH annual homeless deaths report has proved an invaluable public education tool, shattering the myths about homelessness and the causes of homeless deaths. For example, “don’t they all die in the winter?” No, 75% of homeless deaths are in the three other seasons. “Don’t a lot die of drowning in the American River.” No, only about 1% die of drowning. “Don’t most die of drug overdose?” No, about one-third die of substance use. Additionally, the community is shocked at the average age of death for homeless men and women is only 50 years of age. Finally, the annual report has helped the community understand how violent it is to live on the streets – about 35% of the deaths are violent deaths – gun shots, stabbings, and hangings.
6. The annual report is also cited by city and county staff in their briefings to the City Council and Board of Supervisors on the rationale for creating more shelter beds and affordable housing. The report is often cited in editorials in the Sacramento Bee to support the need for increased expenditures on issues pertaining to homelessness.
Sources of Data that Capture Homeless Status

The previous section described sources of death data, but many of these sources fail to specify if a decedent was experiencing homelessness. Local communities can also work with local partners who maintain data on people experiencing homelessness. The following sources of data and the development of info sharing relationships with these providers can create important ways to capture and verify homeless death reports.

Homeless Management Information System (HMIS)

Each jurisdiction belongs to a U.S. Housing and Urban Development (HUD) Continuum of Care (CoC), headed by a lead or coordinating agency. This agency often maintains a database of shelter/housing/outreach-based homeless service encounters for all HUD-funded agencies in their area, known as the Homeless Management Information System (HMIS). The CoC coordinates with community stakeholders and approves certain reports or data-sharing agreements that often help identify deaths and confirm homelessness status in the community.

CoC committees govern HMIS standard operating procedures, review local and federal reports, and create reports on demographics and utilization, including bi-annual Point-in-Time (PIT) Counts. These committees often consist of the service providers that enter data into the HMIS.

Each CoC uses a unique release-of-information (ROI) form with specific terms stipulating how data are collected and utilized. Clients may decline the ROI and still use agency services, in which case their encounter is still captured but not fully characterized. For the purposes of a homelessness mortality count, check with the agency that governs the HMIS to see if their ROI includes consent to share information for public health, program evaluation, and/or research purposes. If it does not, advocate to change the policy accordingly.

Partnering with HMIS systems for the homelessness mortality count provides two opportunities. First, death data may be already captured by programs in HMIS, and if not, it is possible to add a category of mortality as a program exit for HMIS services. Then, HMIS records can be reviewed to detect if death took place before (or after) housing placement. Secondly, it is possible to match HMIS records to coroner/medical examiner/state death records to improve the sensitivity of the surveillance effort overall. HMIS can clarify the housing/homelessness status of individuals who are identified through death records if there is no such status already noted.

Furthermore, building relationships with the CoC lead and member agencies will improve engagement with agencies that work with clients most consistently, which may create more informal channels for reporting deaths for the count.
Local Health Care and Social Services Providers

Health care and social services providers that may not enter data in the HMIS system are also helpful partners. Examples include: hospital systems; health centers, such as Health Care for the Homeless programs or other Federally Qualified Health Centers (FQHCs); health department-operated programs such as behavioral health, crisis response, street medicine teams, or emergency medical response providers; and shelter and service providers such as faith-based organizations and community groups that lack HUD funding.

Developing partnerships with service providers will improve the ability to share data in both directions, expand opportunities to confirm homelessness of people the HMIS may miss, and increase the access for community reporting. With health care and mental health providers, Due to restrictions from the Health Insurance Portability and Accountability Act (HIPAA) that affect health care agencies, it is generally best to partner with public health departments, which are better equipped to collect, store, and process sensitive protected health information.¹⁰

The longer and more precise the list of people experiencing homelessness, the more useful it is to compare to lists of people who have passed away in the same jurisdiction and thereby produce a more accurate homelessness mortality count.

Methods for Measuring Deaths Among People Experiencing Homelessness

Once the appropriate relationships are established, the next steps are to identify homeless deaths and access important information about these deceased individuals (e.g., circumstances of their deaths). These include the Medical Examiner/Coroner (MEC) Report, compiling HMIS Indicators of Death, search and review of MEC and State Death Records and data matching.

Medical Examiner/Coroner Report

Some MECs can provide either data or a compiled report on the decedents they have investigated or collected data on who were experiencing homelessness. While many homeless deaths are likely to be investigated by a MEC, not all homeless deaths will be captured (e.g. some deaths in hospitals), and while much MEC data is quantifiable (e.g. demographic characteristics, mode/manner of death) much of the data consists of descriptive/narrative notes such as scene investigation, toxicology, and/or contributory causes of death that may not be entered into an electronic database. Furthermore, MECs may not assess or document homeless status systematically.

If the local MEC does assess and document homeless status systematically, creating a homeless fatality count is easier. Many communities have established a relationship with the MEC to
provide data that community members analyze and publish. Some MECs carry out their own homeless mortality reports. Organizations that formed strong relationships with their MECs at the beginning of their homeless mortality data work have greater access to information.

Data Requests from MEC or State Death Certificate Data

Enabling ongoing access to data may be possible through a public records FOIA request, which can be expedited through a media/press request. A memorandum of understanding (MOU) or data use agreement (DUA) with the MEC allows access to their individual level data. Partnerships with the health department or a university for data requests consistently prove more effective.

Ideally, the data should include demographic characteristics and information about the mode and manner of death. Whether or not the MEC or state has an indicator for homelessness in their case data, case notes and descriptive fields are easier to search through using keywords. If individual level data from the local MEC are unavailable, aggregated data on the number of deaths they have investigated in the past year that have been flagged as homeless should be available (assuming they record homelessness in their investigation data).

Advocate at the local level for MECs to capture housing status. After years of statewide advocacy, for example, California recently developed new guidelines for determining and recording homelessness status in its Electronic Death Registration System, which should be fully operational in 2021 and will have a ripple effect through local communities that will help homeless mortality reporting.

Data Searching to Identify and Detail Homeless Deaths

While time-consuming, it can be fruitful to search through death records (by field or column-by-column) to search for data that can establish that a particular record is a homeless decedent. There is an art to these inquiries, which can include searches for common words connected with homelessness such as:

- indigent
- shopping cart
- homeless
- transient
- overpass
- freeway
- camp
- encampment
- tent
- body not claimed
- no next of kin
- camp
- dumpster
- unknown address
- exposure
- vagrant
- shelter
- car, van, trailer
- hypothermia
- hyperthermia
- dehydration
- bus bench/stop
- train tracks
- unsheltered

Evaluating the address can indicate that the decedent was homeless at time of death. Some states provide instructions to local death registrars regarding what to put in the address field if the decedent was homeless, such as looking at where GPS coordinates are entered instead of an address.
In searching MEC or state data, it is also helpful to become familiar with cemeteries or funeral homes where unclaimed persons are taken to, and search closely among this list. When reviewing these lists, differentiate “definitely homeless” and “maybe homeless” to help identify more information to validate for the latter category.

**Matching Datasets to Identify and Detail Homeless Deaths**

With access to death records and lists of people known to be homeless, it is powerful to use data-set-matching to identify homeless persons that have died, which can deduplicate multiple records for the same people and gain more data on decedents. This process is about “bumping” a list of known homeless persons (from HMIS or local health care or services providers) and/or PEH known to have passed away (from community reporters or media), or dates or locations where an unidentified person was known to have died, against a list of death certificate records, to find matches using common identifiers like first/last name, sex, date of birth, and date of death.

One can match lists of homeless-related addresses (e.g., shelters, mailing addresses, programs, etc.) to the death certificate records. **Los Angeles County** did this work illustratively in 2019.xiii While a full discussion of matching techniques is beyond the scope of this toolkit, the Homeless Mortality Data Work Group can provide contact information for work group members that have expertise in this area.

**Determining Cause of Death**

Methods to categorize cause of death depend on the type of homeless mortality reporting effort. While the Medical Examiner/Coroner (MEC) collects data on causes of death for the deaths they investigate, they usually do not code deaths using ICD-10 codes. However, they often collect detailed data on causes of death not deemed to be “natural” causes. These include drug overdoses, homicides and suicides, and other accidental deaths such as motor vehicle crashes. MECs may only have cursory data on sub-categories of natural-cause deaths (e.g., heart disease, diabetes).

If individual-level data from the MEC is available, it can be helpful to obtain a code book that explains the ways they classify, then stratify the mode, manner, and cause of death. If the MEC will not share individual-level data, seek aggregate data on numbers of homeless deaths by the top five causes of death.

Local data that quantify these mortality rate differences can be a powerful tool for advocating policy and programmatic action to reduce this disparity and support prevention efforts.

**State death files typically include International Classification of Diseases (ICD-10) cause of death codes entered into death certificates by doctors or medical professionals. This is the gold standard for classifying causes of death.** Local health departments should produce regular reports of mortality rates by cause of death for the general population. These reports use groupings of ICD-10 codes to report on common causes of death like coronary heart disease,
diabetes, cancers, motor vehicle crash, homicide, and drug overdose. Use these same groupings when analyzing ICD-10 codes on the death records of homeless decedents. The ideal way to determine ICD-10 cause of death is “bumping” MEC or community-reported data against state death records.

Creating a Homeless Mortality Report

Each jurisdiction’s homeless mortality report will differ. The NHCHC recommends a close review of the reports referenced in this toolkit (Appendix B) to find a format and method that works best based on the type of data available and the amount of work that can be put into the project. Key elements include:

1. Definitions
2. Categorizing causes of death by type and demographics
3. Locations of death
4. Focus on special issues (overdose, substance use, homicide, suicide, accidents)
5. Homeless mortality rates vs general population
6. Recommendations

Calculating Homeless Mortality Rates Among People Experiencing Homelessness

Evidence shows that people experiencing homelessness (PEH) have higher mortality rates than the general population. Local data that quantify these mortality rate differences can be a powerful tool for advocating policy and programmatic action to reduce this disparity and support prevention efforts.

To compare mortality rates across different populations, it is critical to adjust for differences in the age structures of the populations. This is because age is the single most important predictor of mortality. Furthermore, when one of your comparison groups is PEH it is also critical to adjust for gender distribution since men have higher mortality rates than women and they often make up a much higher proportion of the homeless population.

In order to compare age and gender adjusted mortality rates, you must have valid estimates of the age and gender distribution of your community’s homeless population. Continuum of Cares (CoCs) conduct quantitative and qualitative surveys to arrive at estimates of the percent of age, gender, and racial/ethnic groups. Some surveys also include additional items about living and health conditions and experiences of violence.

A comprehensive approach of calculating and comparing age and gender adjusted mortality rates is beyond the scope of this toolkit, however, below is a brief summary of the direct and indirect methods:
Direct Method

For this method you will need a “standard” population to which you apply age/gender specific mortality rates for your PEH population and your community population. It is common to use the 2000 US census population as your standard population. When you set up your calculations, you will need to base them on whatever age groupings your local homeless demographic survey uses to report its estimates.

For example, in Los Angeles County, California, the PEH demographic survey uses the following age groupings in its reporting: <18, 18-24, 25-54, 55-61, and 62+. Thus, to calculate age/gender adjusted rates in Los Angeles County it was necessary to create those same age groupings from the U.S. census (standard population) and Los Angeles County (comparison population).

Once you calculate adjusted mortality rates for each of your comparison populations, you can calculate a Mortality Rate Ratio (MRR), which is the mortality rate in the PEH population divided by the rate in the general community population. The ratio represents the number of times greater the rate is in the PEH population compared to the community population. Adjusted mortality rates and MRRs can be calculated for all causes of death combined and for specific causes of death. Cause-specific MRRs can only be calculated if you can determine causes of PEH deaths using the methods described in the section above.

Indirect Method

The indirect method is often used when numbers of deaths for each age-specific stratum are not available. In the context of homeless mortality, you would take the age/gender-specific mortality rates in the community-wide population and apply to each of those age/gender groupings in the homeless population.

This yields the number of deaths expected in each age/gender grouping of people experiencing homelessness if PEH had the same mortality rates as the general population. The total number of deaths observed among PEH divided by the number expected is called the Standardized Mortality Ratio (SMR). The SMR approximates the MRR described above.

Long-term Needs

The methodologies described in this toolkit represent some best practices at this time. However, communities across the country are relying on myriad local sources to estimate homeless mortality, including news media and other local reports gathered in conjunction with National Homeless Persons’ Memorial Day. Each community is also likely to have a range of options for progress at their disposal, which is why this toolkit lays out several ways to proceed. Even those communities that have been able to link MEC data with state death records can continue to expand and strengthen their homeless mortality surveillance systems.

The use of multiple linked sources of information is a tested method for improving the accuracy of surveillance systems. Accurate linkage and deduplication across data sources requires high-
quality data sources, standardized data labels, and variable formatting. While analytical options like imputation exist, the quality of available data ultimately depends on the way those data elements are collected in the first place.

The ability to obtain and link data on homeless deaths requires engagement with and commitment from the communities that produce the data, in addition to the organizations that manage the data. Through: 1) improved data standardization; 2) improved data quality; and 3) political will, these systems will continue to improve.

**Standardization**

To improve the accuracy of homeless mortality counts and help communities compare mortality rates, it is important to:

1. **Establish standard definitions and criteria for determining the size of a homeless population (i.e. the denominator) and the homelessness status of decedents (i.e., the numerators), and**
2. **Work with all stakeholders to adopt those definitions and criteria.**

**Homeless Status (Numerator):** The process by which identified decedents are labeled as homeless needs to be considered carefully. This applies equally to how MEC and state death records assign a label of homelessness, and how HMIS, hospitals, clinics, services providers, and community reporters assign that same label. In MEC records, the label of homelessness is typically applied to individuals that are either unsheltered or living in a homeless shelter (i.e., living in places not meant for human habitation, in emergency shelters, or have no regular residential address). This third category of no regular address may include individuals living doubled up with friends or family, residing in an institutional setting, or in temporary residences such as a hotel/motel, yet it may miss a number of individuals without homes. And while Transitional Housing is less common, these programs contribute to HUD definitions of homelessness in HMIS but would likely not count in some MEC criteria.

Additional data sources for identifying deaths among PEH (see “Data-Sharing” below and elsewhere) should also be evaluated for their definition of homelessness since health care organizations and housing agencies employ different definitions.

**Homelessness Data (Denominator):** This toolkit recommends the mid-year average of a community’s Point-in-Time Homeless Counts (PIT), which occur in January of each year. This effort relies on a particular application of the HUD definition of homelessness, which is somewhat unique to that count strategy. The PIT is widely recognized to be an undercount of the actual number of people experiencing unsheltered homelessness on a given night or over a year, but for now it offers the most standardized (i.e. generalizable) and reliable (i.e. consistent) opportunity to characterize homelessness in a jurisdiction. Ideally the criteria for assigning a label of homelessness status to a death record (numerator) should match the definition used in the denominator (number of PEH). This includes the geographic area for which deaths are identified and the area covered by the PIT.
Causes of Death

The process for coding and classification of cause of death currently relies on the International Classification of Diseases, 10th revision (ICD-10). This means that the terminology and associated codes for organizing causes of death should be consistent between local medical examiner records, state death records, and other clinical information sources. They should also provide consistency across different communities for comparison.

Not all sources for counting deaths will have a corresponding clinical classification. Of course, this standardized classification system is critical to establishing actionable and generalizable mortality counts. This is one important reason for linking additional community reports or housing agency data (HMIS) with death records whenever possible.

Data Quality

Missing or inaccurately recorded data reduces the successful ability to link or to use mortality surveillance data. Data cleaning procedures are a critically important part of data management. Inaccurate data is much harder to identify than absent data, particularly when errors in recorded data fall within the correct range. These types of errors cannot typically be corrected by data cleaning.

Improving data quality typically requires a continuous improvement that must move upstream from the data source to where the data is collected and captured. This often involves working with the messy, human elements of data collection.

Issues with missing data can also be corrected by the analyst once the full dataset is ready, using various analytical techniques such as single or multiple imputation procedures. These lie beyond the scope of this toolkit but are common practice in the statistical field.

Data Sharing

Limitations of a homeless mortality count commonly result in undercounting deaths. This is especially true when cases are thoroughly adjudicated by expert review of notes in a MEC record. One can be relatively sure that the final set of cases should be included, but it is harder to evaluate the number of cases that are missing from the list. Looking outside of standard systems for cases captured elsewhere improves the sensitivity of the system (i.e., the capacity for detecting deaths among PEH).

Sources of death data exist across sectors and across information platforms: housing and service agencies, health care organizations, academic researchers, and community-based advocacy groups. Each of these sectors may potentially contain unique contributions to the count. In turn, they may also present unique complications to partnership, which are beyond the scope of this toolkit.

In the most reductive sense, linking of records across systems requires a key that allows records to be matched. The simplest process requires a unique identifier that is applied in more than one
database (such as the MEC record number being stored in the state death record archive). In lieu of a shared identifier, names, dates of birth, social security numbers, and other personally identifiable data can be used to match records – when available. Whichever identifier(s) is used to support this process requires sufficient data quality and completeness. Otherwise, quality issues will directly impact the proportion of records that can be combined.

Once linkage is performed, records must be “deduplicated” by checking carefully for multiple entries referring to the same individual. Mismatches in data linkage can potentially result in two records for the same case. Therefore, the new combined dataset must be carefully reviewed for any records that match on multiple criteria (e.g. date and cause of death) but mismatched on the identifiers used to link the records.

References:

3. Alameda County Health Care for the Homeless (ACHCH) is a good example of this.
9. Alameda County Health Care for the Homeless (ACHCH) is an example of this.
10. Sacramento, California is an example.
11. Santa Clara County, California is an example of this.
12. In Albuquerque, New Mexico, Albuquerque Health Care for the Homeless began its work as a collaborative process with the state of New Mexico Office of the Medical Investigator, which has allowed Albuquerque to develop a shared process of homeless mortality data reporting.