



Using Population-Based Data to Inform Fatality Review

National Center Guidance Report



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CDR and FIMR Overview

Each year, in the United States (U.S.), more than 35,000 children die before reaching the age of 18.¹ The loss of even a single child is devastating to families and communities, often leading to a search for answers about the circumstances surrounding the death. Fatality review teams play an important role in providing these answers by uncovering risk factors and community stressors that might otherwise go unnoticed. Child death review (CDR) and fetal and infant mortality review (FIMR) teams have a similar overarching purpose:

- To conduct comprehensive and multidisciplinary reviews of deaths that lead to a better understanding of how and why deaths occur, and
- To use findings to catalyze systems-level change to prevent future deaths, improving the health and safety of communities, families, parents, infants, and children.

Through their dedicated efforts, fatality review teams contribute significantly to understanding and addressing the complex, multidimensional issues surrounding stillbirth, infant mortality, and child mortality, ultimately working towards a future where fewer families experience such profound loss.

Purpose of This Guidance

Community health factors are the non-medical factors, such as access to health care services and community resources, that ultimately influence health outcomes for a variety of conditions.²

Figure 1. *Community Health Factors*³



There are geographic differences in life expectancy across the U.S., suggesting that where people live plays a role in shaping their health. Recognizing this, Healthy People 2030 prioritizes place-based approaches in its community health factors framework, highlighting the important role of “place” – where people live, work, learn, and play – in influencing health.⁴

Understanding the context in which a young person and family lived and how it impacted their health and wellbeing is crucial to making fatality review findings and elevating systems-level prevention strategies. While fatality review teams play a critical role in highlighting factors contributing to deaths, it can be difficult for them to identify the community and environmental

context in which the decedent and their family lived. For example, records traditionally accessed for the fatality review (e.g., vital records, death investigation records, medical records) often do not contain information about the community and environment. In addition, while fatality review teams attempt to conduct family interviews to gain these valuable insights, there are challenges with ascertaining critical information from families during a highly sensitive and emotional time.

One strategy to overcome these limitations and better understand the context in which a young person and their family lived is to use population data sources across the fatality review process. **The purpose of this guidance is to provide resources and ideas for how you can supplement your work by incorporating population data.**

Population Data

What is Population Data?

Population data is information about a set of individuals who share a characteristic or set of characteristics.⁵ Simply put, population data includes or represents everyone in a group. A population may be determined by geographies, such as all people living in a specific county or neighborhood.⁶ A population can also be defined in terms of demographic characteristics (e.g., race, ethnicity, age, sex).⁷

Examples of Population Data:

- [U.S. Decennial Census](https://bit.ly/4iP3PnP) (URL: <https://bit.ly/4iP3PnP>): includes all people or household in the U.S.
- [Vital records](https://bit.ly/3QZyN0l) (URL: <https://bit.ly/3QZyN0l>): include all deaths, births, and fetal deaths.
- [The Census Bureau's American Community Survey](https://bit.ly/3QWRYbf) (URL: <https://bit.ly/3QWRYbf>): represents all people, households, or workforce.
- [The Centers for Disease Control and Prevention's \(CDC\) Youth Risk Behavior Survey](https://bit.ly/3XKeAzn) (URL: <https://bit.ly/3XKeAzn>): represents high school students (grades 9-12).

Why is Population Data Important for Use During Fatality Review?

In fatality reviews, population data can provide advantages that improve both the process and the results.

- **Population data provides a broad, objective overview of the community in which the young person and family lived, helping to avoid discussions influenced by personal biases, assumptions, stereotypes, or anecdotal evidence.** By highlighting differences and challenging assumptions, utilizing population data promotes systems-focused reviews that ensure all demographic groups and communities receive appropriate attention.⁸
- **Population data facilitates data-driven discussions across sectors during fatality reviews.** It unites partners from law enforcement, child protective services, healthcare providers, and other fields, creating a common language among professionals from different backgrounds.⁹ By using population data, all team members can engage in evidence-based discussions that are informed by objective data, rather than opinions or isolated incidents. This cross-sector collaboration, supported by population data, leads to more comprehensive insights and solid conclusions.
- **Population data encourages multi-sector community and systems-level recommendations.** It helps identify broader, community and systems-level risk factors beyond individual children and caregivers, supports the development of specific interventions, and promotes collaborative solutions. This approach enables more effective resource allocation and enhances policy development by providing evidence to support community-wide change.

By leveraging population data, fatality review teams can conduct more comprehensive and impactful reviews. This approach not only improves individual case assessments but also contributes to broader systemic changes aimed at preventing future fatalities, ultimately leading to safer and healthier communities.

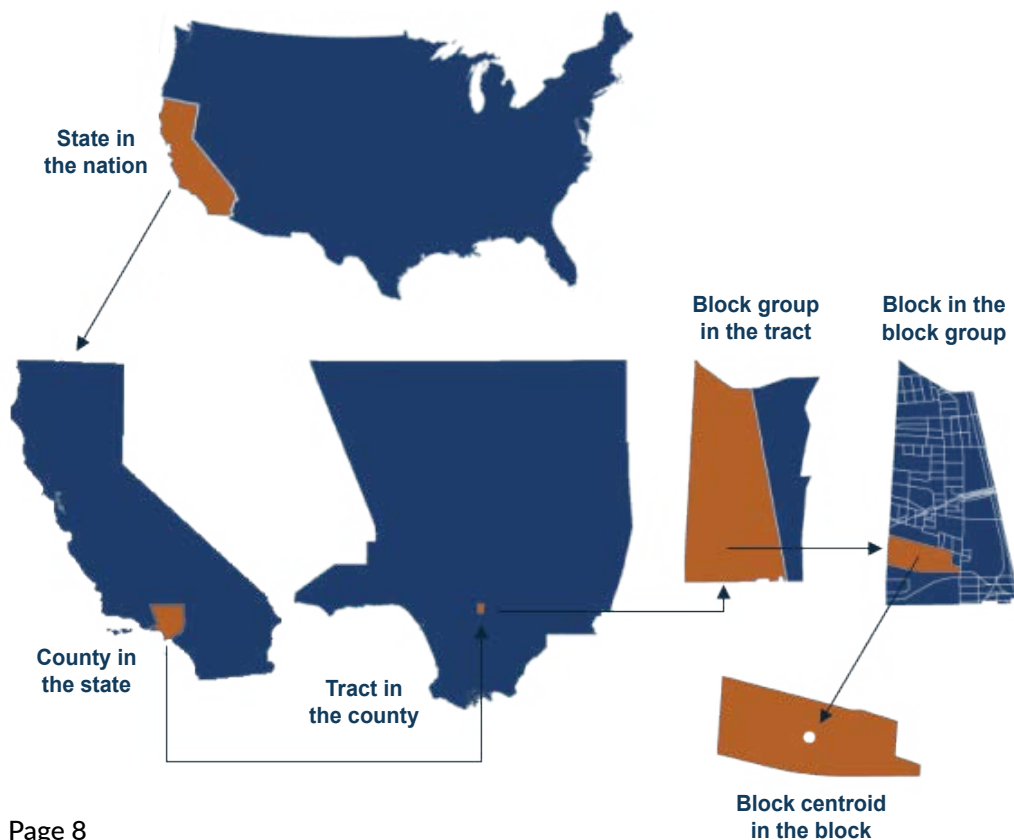
Considerations of Using Population Data During Fatality Review

Population data plays a role in understanding fatalities. However, its use must be approached carefully to avoid misinterpretations and assumptions leading to ineffective or misguided policy recommendations. This section outlines key considerations when using population data in fatality reviews.

Geographic Scale Matters

One important factor to consider is the geographic scale at which population data is analyzed. Different scales, such as census blocks, census block groups, census tracts, ZIP codes, or counties, can yield varying insights. For instance, census blocks or tracts may offer more detailed information unique to a neighborhood that could go unnoticed by larger aggregations at the ZIP code or county level.¹⁰ ZIP code data, on the other hand, could be more useful for putting policies into practice because ZIP codes are frequently used to assign services. Review teams should carefully select the scale that aligns with the goal of using each data source.

Figure 2. *Census Geographic Unit Relationships*¹¹



Avoid Ecological Fallacy

The ecological fallacy, first described in 1950, refers to the error of drawing conclusions about individual behavior or characteristics based on data or patterns observed at the group level.^{12,13} This concept is widely recognized in the fields of epidemiology and statistics.

For Example:

If a neighborhood has a high average family income, it would be false to assume that each individual family in the neighborhood has a high income. The neighborhood below has an average family income of \$86,000, but any assumption about individual families would be an ecological fallacy.



To avoid the ecological fallacy, caution is necessary when interpreting results. Place-based population data represent the characteristics of the decedent's geographic area and may not fully reflect the circumstances of the decedent or their family. Therefore:

- Be clear about the level of analysis (individual vs. group) in all reporting.
- Use phrases like "areas with high rates of X" rather than "people with X."
- Don't make assumptions about the child or family based on population data. Rather, use population data to consider the environment in which the child lived.
- Acknowledge the limitations of population-level data.

Example Population Data Sources

There are many population data sources that can be leveraged for use during the fatality review process. Three examples are detailed below, including steps to access the data and potential data points of interest. Visit [Appendix A](#) for a more comprehensive list of data sources.

American Community Survey

The American Community Survey (ACS) is a comprehensive, ongoing survey conducted every year by the U.S. Census Bureau.¹⁴ The survey provides crucial demographic, socio-economic, and housing data that informs the distribution of trillions of dollars in federal funds. This rolling sample survey reaches 3.5 million addresses yearly, successfully documenting about 2.2 million, and publishes its findings in two series: 1-year averages for areas with at least 65,000 people and 5-year averages for all geographic levels down to census block groups.¹⁵

To access data from the ACS, follow these steps:

- Navigate to the [ACS website](https://bit.ly/4jmBdm1) (URL: <https://bit.ly/4jmBdm1>) for an overview of the survey and available resources.
- Use the [Explore Census Data page on the United States Census Bureau website](https://bit.ly/3MhSRZT) (URL: <https://bit.ly/3MhSRZT>) to explore and filter ACS data by different topics (e.g., education, employment, housing, poverty) and geographic levels (e.g., state, county, ZIP code, census tract, census block). Customize and download data tables in formats like CSV, ZIP, and Excel.
- Create customized maps using the [mapping tool](https://bit.ly/3YiLgAb) (URL: <https://bit.ly/3YiLgAb>).

Example Data Points of Interest:

- | | | |
|--|--|--|
| <input type="checkbox"/> Education and school enrollment | <input type="checkbox"/> Poverty status of families by race and ethnicity | <input type="checkbox"/> Health insurance coverage |
| <input type="checkbox"/> Income | <input type="checkbox"/> Households receiving food stamps/Supplemental Nutrition Assistance Program (SNAP) | <input type="checkbox"/> Employment status |

View a [quick video tutorial on accessing and using the Census data tool](https://bit.ly/4iTVAAan) (URL: <https://bit.ly/4iTVAAan>) to explore ACS data.

Youth Risk Behavior Surveillance System

The Youth Risk Behavior Surveillance System (YRBSS) is a comprehensive tool designed to monitor health and risk behaviors among youth.¹⁶ YRBSS covers a wide range of topics including unintentional injuries, violence, physical activity, nutrition, weight status, tobacco use, alcohol and other drug use, and sexual behaviors. YRBSS gathers critical data on student demographics and experiences, providing valuable insights at national, state, and local levels. Its results are instrumental in tracking adolescent health behavior changes over time, identifying emerging issues, and guiding the planning and evaluation of youth health programs. Conducted both nationally by the CDC and at state, tribal, territorial, and local levels, YRBSS includes public and private high school students across the U.S., making it an essential resource for schools, communities, and partners striving to support and improve youth health.

To access data from the YRBSS, follow these steps:

- Go to the [YRBSS Explorer](https://bit.ly/40i9F8T) (URL: <https://bit.ly/40i9F8T>) for access to data on health-related behaviors among youth. You can filter data by demographic factors like sex, race, ethnicity, and grade level.
- [Download reports or datasets](https://bit.ly/4jktDII) (URL: <https://bit.ly/4jktDII>) for further analysis. Look for options to export the data in formats like CSV.
- Check your state's public health department website for local data and reports. Some states have their own modified versions of the YRBSS. For example, [Healthy Kids Colorado Survey](https://bit.ly/4iZoS7x) (URL: <https://bit.ly/4iZoS7x>).

Example Data Points of Interest:

- | | |
|---|--|
| <input type="checkbox"/> Unintentional Injuries and Violence (e.g., bullying, suicidal ideation and attempts, sexual violence, risky driving behaviors) | <input type="checkbox"/> Sexual Behaviors (e.g., unprotected sexual activity, early initiation of sexual activity) |
| <input type="checkbox"/> Tobacco Use (e.g., electronic vapor, cigarettes, cigars) | <input type="checkbox"/> Physical Activity (e.g., involved in sports team, had a concussion from physical activity) |
| <input type="checkbox"/> Alcohol and Other Drug Use (e.g., currently drank alcohol, ever used marijuana) | <input type="checkbox"/> Other Health Topics (e.g., social media usage, mental health, unstable housing, sleep, adult relationships, discrimination) |

View a [quick video tutorial on accessing and using the YRBSS Explorer](https://bit.ly/4i6dnd4) (URL: <https://bit.ly/4i6dnd4>).

Maternal and Infant Health Mapping Tool

The Maternal and Infant Health Mapping Tool, published by the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA), is an interactive resource that enables users to generate county-level maps.¹⁷ This tool allows for the visualization, exploration, and export of data related to maternal and infant health indicators, resources, and demographics. It integrates data from various sources, including vital statistics, the ACS, the CDC, and the National Survey of Children's Health (NSCH). Users can gain valuable insights by examining the relationships between health outcomes, resources, and demographics. The tool offers options for exporting customized maps, making it an asset for public health analysis and decision-making.

To access data from the Maternal and Infant Health Mapping Tool, follow these steps:

- Navigate to the [Maternal and Infant Health Mapping Tool website](https://bit.ly/4jeEhAg) (URL: <https://bit.ly/4jeEhAg>).
- Explore data related to maternal and infant health at the national, state, and local levels. You can map health indicators such as infant mortality, preterm births, and prenatal care.
- Use the interactive tool to filter data by specific health indicators and geographic areas (e.g., counties, states). You can layer multiple data points for a detailed analysis.
- Once you've customized your maps, you can export the data as a PDF or Excel file.

Example Data Points of Interest:

- | | | |
|---|---|--|
| <input type="checkbox"/> Infant Mortality Rate | <input type="checkbox"/> Preterm Births | <input type="checkbox"/> Hospitals with Obstetric Care |
| <input type="checkbox"/> Prenatal Care in the 1st Trimester | <input type="checkbox"/> Smoking During Pregnancy | <input type="checkbox"/> OB-GYN Provider Rate |
| | | <input type="checkbox"/> Rural Health Clinics |

View a [quick video tutorial on accessing and using the Maternal and Infant Health Mapping Tool](https://bit.ly/3YjUPim) (URL: <https://bit.ly/3YjUPim>).

Using Population Data in Fatality Review

Population data can be helpful throughout the fatality review process, starting from identifying deaths for review, all the way to developing and implementing prevention initiatives. The sections below describe examples of using population data at each step in the process.



Identification

Population data serves as a tool in the process of identifying deaths for fatality review. Many fatality review teams identify deaths for review using individual death certificate data. However, vital records data at the population level can also aid in identification, such as the Perinatal Periods of Risk (PPOR) approach. PPOR is often used by FIMR teams who may not have the capacity to review all stillbirths and infant deaths in their jurisdiction and therefore use population data to help prioritize the selection of deaths for review. Using population data in the case identification process allows teams to prioritize reviews based on higher mortality rates, key risk factors, or community needs. This approach leads to clearer and more actionable findings that address the root causes affecting specific populations.

To learn more about PPOR, visit:

- [Consulting Population-Based Data to Inform Fetal and Infant Mortality Review and Community Action Decisions](https://bit.ly/4i2WDn7) (URL: <https://bit.ly/4i2WDn7>).
- Gilbert, Carol. Fall 2012. [‘What is PPOR?’](https://bit.ly/3tqyekP) (URL: <https://bit.ly/3tqyekP>) CityMatCH CityLights PPOR (Perinatal Periods of Risk) 15 Years of Changing the Way Urban Communities Approach Infant Mortality. 20:3, pages 6-8.
- Peck MG, Sappenfield WM, Skala J. [Perinatal Periods of Risk: A Community Approach for Using Data to Improve Women and Infants’ Health](https://bit.ly/3MB6ErR) (URL: <https://bit.ly/3MB6ErR>). *Matern Child Health J.* 2010;14(6):864-74. doi: 10.1007/s10995-010-0626-3.
- Sappenfield WM, Peck MG, Gilbert CS, Haynatzka VR, Bryant T 3rd. [Perinatal Periods of Risk: Analytic Preparation and Phase 1 and 2 Analytic Methods for Investigating Feto-Infant Mortality](https://bit.ly/3MQmXkR) (URL: <https://bit.ly/3MQmXkR>). *Matern Child Health J.* 2010;14(6):838-50. doi: 10.1007/s10995-010-0625-4.

Review

Population data is a valuable resource to use during the fatality review meeting as it helps identify broader socioeconomic and environmental factors that may contribute to adverse outcomes. By providing insight into community factors like income levels, access to healthcare, and housing conditions, population data enable review teams to understand the contextual risk factors that may have been present for the young person and their family. Importantly, population data and community participatory sessions can also identify protective factors that could be leveraged to contribute to better outcomes. Without making assumptions about the child's experience, population data allows for a more comprehensive understanding of the community, highlighting specific subgroups or geographic areas where interventions could be prioritized to prevent future incidents. Population data ultimately guides the development of community- and systems-level recommendations that are tailored to address the root causes of identified risks, making prevention efforts more effective.

Explore the following mock death review scenario to see examples of using population data during the review.

Figure 3. *Mock Death Review Scenario*

Case Details

Jane, a 3-month-old Black female, was found unresponsive in an adult bed she was sharing with her mother. Jane's cause and manner of death are listed as accidental asphyxia. Jane's mom did not complete high school after becoming pregnant and works night shifts. Mom has difficulty paying rent and the family moves frequently. Mom told death investigators that she was unable to receive prenatal care because public transportation to and from the clinic was unreliable.

Population Data

The fatality review team used population data to understand the broader context of Jane's death and identify systemic factors that contributed to their obstacles. The review team integrated data from various sources, detailed below.

Population Data Source	Description	Insights
City Health Dashboard (URL: https://bit.ly/3Q3byS0)	<p>The City Health Dashboard can be queried on various health indicators at the city level.</p> <p>Jane's city of residence is represented in the dashboard, so the review team coordinator compiled a few measures to share with the review team.</p>	<p>Data highlight that in Jane's city/community:</p> <ul style="list-style-type: none"> • 68% of births received prenatal care in the first trimester, compared to 80% across all the Dashboard's cities. • The city had a neighborhood racial/ethnic segregation score that was double the score across all the Dashboard's cities.
Maternal and Infant Health Mapping Tool (URL: https://bit.ly/4jeEhAg)	<p>The Maternal and Infant Health Mapping Tool is a key resource for exploring data on maternal and infant health in communities.</p> <p>The review team coordinator used the tool to visualize information for Jane's community, including access to safe sleep resources. The map was shared with team members during the review meeting.</p>	<p>Data highlight that in Jane's community:</p> <ul style="list-style-type: none"> • 22% of families in Jane's community lived in poverty, more than double the national average. • The social deprivation index score was 90.
American Housing Survey (AHS) (URL: https://bit.ly/3R4Hcjc)	<p>AHS is the most comprehensive national housing survey in the United States.</p> <p>The review team coordinator wanted the team to know more about housing instability in Jane's community.</p>	<p>Data highlight that in Jane's community:</p> <ul style="list-style-type: none"> • 10% of renters missed at least one rent payment in the last year. • 8% of renters reported it was likely they would have to leave home within 2 months due to an eviction or foreclosure.

Recommendations:

When reviewing the case details alongside the population data, the fatality review team made the following recommendations:

- Advocate for policies that provide financial assistance, affordable housing, and rent stabilization programs to reduce housing instability for low-income families.
- Increase access to community programs providing safe sleep education and resources tailored to the cultural and economic realities of families in underserved areas.
- Ensure healthcare providers receive training on addressing community health factors and delivering culturally sensitive care.



Data Entry

Many fatality review teams utilize the Pediatric National Fatality Review-Case Reporting System (Pediatric NFR-CRS) to document information gleaned during the review process. Fatality review team members contribute information from their records to be documented in the Pediatric NFR-CRS. However, some important information is not typically included in these records and may not be known or shared by other team members. Using supplemental population data sources to obtain both person-level and place-based data can be helpful to complete data entry, fill in knowledge gaps, and improve data quality. See a few possible examples below. Although different from other examples in this guidance, the first two examples below show how population data can be used to find person-level information.

Immunization Registry

Many states keep a registry of immunization records. For some causes of death, like sudden unexpected infant death (SUID) and COVID-19, understanding if the infant or child was up to date on vaccines can be important. Explore a partnership (e.g., data sharing agreement) with your state's immunization registry to receive record-level data and fill in data gaps for the following items in the Pediatric NFR-CRS:

- A16: Was the child up to date with the Centers for Disease Control and Prevention (CDC) immunization schedule?
- I8e: Was the child eligible to receive a COVID-19 vaccination? If eligible, did they receive their first dose?
- I8f: For infants or fetal deaths only, did the mother receive her COVID-19 vaccination?

Child Welfare Information System

State child welfare agencies often have a centralized data system to house information about people who have had contact with the child welfare system. Experiences of child maltreatment have a large impact on health throughout the lifespan and is an important factor to understand in the context of child deaths. Explore a partnership (e.g., data sharing agreement) with your state's child welfare agency and information system to receive record-level data and fill in data gaps for the items in the Pediatric NFR-CRS, including:

- A23: Child had history of child maltreatment as victim?
- A24: Was there an open Child Protective Services (CPS) case with child at time of death?
- A25: Was child ever placed outside of the home prior to the death?
- F15: Did any investigation find evidence of prior abuse?
- F16: CPS action taken because of death?

HRSA's Health Workforce Shortage Areas

Sometimes, the circumstances of a death might lead fatality review teams to believe that the young person or their parent(s)/caregiver(s) were unable to access necessary health care. For example, a young person who died by suicide who could not access mental health care. Or a pregnant woman attempted to access prenatal care but there were unknown barriers in the way.

To better understand access to health care in specific communities, fatality review teams can use [HRSA's Health Workforce Shortage Areas tool](https://bit.ly/43LIXcz) (URL: <https://bit.ly/43LIXcz>). Plugging in a specific address will state if the area is a dental health, mental health, and/or primary care Health Professional Shortage Area (HPSA). If review findings align with HPSA designations from the tool, the review team can consider using the information to help complete items in the Pediatric NFR-CRS, including:

- A36: Issues prevented child from receiving mental health services?
- A51: Were there access or barrier issues related to prenatal care?
- I7b: Services not available.

Tip: A state or local fatality review coordinator should consider examining their jurisdiction's data quality summary with a lens toward where population data might be able to help. They may find an opportunity to leverage a population data source for data quality improvement. To view the data quality summary, refer to standardized report #33 in the Pediatric NFR-CRS.

Data Analysis

Population data enhances analysis by providing contextual information of the broader circumstances contributing to fatalities. It also enables fatality review teams to identify potential differences within specific populations or areas. By examining population data in partnership with data entered into the Pediatric NFR-CRS, teams can uncover systemic risk factors, such as socioeconomic stressors, healthcare access gaps, and community-level stressors, which may not be evident from aggregated Pediatric NFR-CRS data alone. There are two ways to incorporate population data in your analysis: 1) view the data side by side or 2) conduct a data linkage.

Side by Side

As you analyze your fatality review data, you might leverage population data to aid in interpretation and identifying potential differences by viewing it alongside your fatality review data. Many population data sources are accessible through public-facing interactive dashboards, enabling programs to query and analyze the information in real time.

One example is comparing the demographic make-up of the young people represented in the fatality review data to the demographic make-up of the population. Use tools like [CDC WONDER](https://bit.ly/311J8IX) (URL: <https://bit.ly/311J8IX>) or [KIDS COUNT](https://bit.ly/4lhMMMR) (URL: <https://bit.ly/4lhMMMR>) to retrieve the demographic data for the population of interest and then compare demographics of the fatality review data. If the proportions differ, an opportunity to improve health may have been discovered and should be investigated further. A [proportion plot](https://bit.ly/4ljnONj) (URL: <https://bit.ly/4ljnONj>) can be created to help visualize these differences.

Data Linkage

Another way to use population data during analysis is through data linkage. Data linkages can be resource intensive and won't be an option for everyone. However, if access to statistical software is available, try taking the data a step further through data linkage. This can be especially meaningful when connecting fatality review data to place-based data sources that can shed light on environmental and contextual factors, or to individual-level records (such as immunization data) that can provide missing context or additional variables.

For example, if there is access to address information for each death, data can be linked to records by various geographic levels (e.g., county, ZIP code, census tract) to other data from sources like the [American Community Survey](https://bit.ly/3EerG1e) (URL: <https://bit.ly/3EerG1e>) and [Social Vulnerability Index](https://bit.ly/42AydfY) (URL: <https://bit.ly/42AydfY>). See [Appendix A](#) for additional data sources available for linkage.



Success Story

The Utah Child Fatality Review Committee (CFRC) recognized that there were barriers to collecting community health data for deaths they were reviewing. Therefore, they decided to utilize Utah's Health Improvement Index (HII) in data analysis and reporting as a proxy way of highlighting community context.

Utah is made up of 99 small areas, created by combining neighboring ZIP codes.¹⁸ Those small areas are given an HII value based on important determinants of health such as economic inequality, resource availability, and opportunity structure.¹⁹ The higher the HII value, the more community stressors that area was found to have. Based on their HII value, small areas are grouped as very low, low, average, high, and very high in having opportunities to improve health. The higher the group, the more improvements and public health interventions the area may need.

During data analysis, the Utah CFRC links death data to HII values based on the small area the child lived in. Rates of injury death are calculated based on group. Visit page 11 of the [Utah CFRC 2023 Annual Report](https://bit.ly/42pNuiH) (URL: <https://bit.ly/42pNuiH>) to learn more and see how these data are visualized.

The first step to doing something similar in other jurisdictions is to identify a meaningful health index available for small geographies (e.g., small health statistics areas, ZIP codes, census tracts). Potential data sources include the [Area Deprivation Index](https://bit.ly/4lnAkLH) (URL: <https://bit.ly/4lnAkLH>) and [Social Vulnerability Index](https://bit.ly/42AydfY) (URL: <https://bit.ly/42AydfY>). Consider the resources needed for linking datasets and how the resulting analysis could be used for prevention.

Data Dissemination

Disseminating data and findings from fatality reviews is a crucial step to drive meaningful change. Effective communication of the fatality review data alongside population data allows review teams to share the broader implications of their findings, raise awareness about systemic issues, and advocate for specific prevention strategies. A few ways to leverage population data for dissemination include:

- **Highlighting Trends and Opportunities:** Population data can help highlight patterns that might not emerge from individual and aggregated case reviews. A common challenge in data dissemination is being able to share small numbers. Small numbers at the community level can introduce challenges in the ability to calculate reliable death rates and draw precise conclusions. To address this limitation, programs can consider aggregating data across multiple years to improve the reliability of death rate estimates and enhance the validity of their analysis. Additionally, programs can consider both the death burden (i.e., case counts) and rates, recognizing that the burden is a critical data point for state and local programs. Additionally, when paired with state or national level data, patterns that emerge from small numbers can still be meaningful and honor the lives of the young people they represent.

Mock Example

In my state, it is policy not to share data with a count of less than 10. This year, there were 7 suicide deaths among American Indian/Alaska Native (AI/AN) youth. Although we cannot share this data, I want to honor these young people and their families and bring attention to their deaths. To do so, I will reference national suicide rates from [CDC WISQARS](https://bit.ly/3EhZPgM) (URL: <https://bit.ly/3EhZPgM>) and state-level mental health indicators from [YRBSS](https://bit.ly/3XKeAzn) (URL: <https://bit.ly/3XKeAzn>). In my annual report, I will include the following text:

“To protect confidentiality, we are unable to share data on suicide among American Indian/Alaska Native (AI/AN) youth. However, it is important to note the potential misclassification of race and ethnicity of AI/AN people on death certificates. Given this limitation, it is important to highlight that nationally, AI/AN youth experience a significantly higher suicide rate when compared to all other races. Additionally, YRBSS data show that AI/AN youth report the highest prevalence of having attempted suicide when compared to their peers by race and ethnicity, a prevalence more than double that of state estimates.”



- **Providing Data Framing:** Using population data sources alongside fatality review data can help frame the data within community context. Providing context of community stressors helps to frame data with a narrative that leads with structural causes. Using this lens every time we communicate data helps to avoid perpetuating stigma and negative stereotypes.

Mock Example

In my county, we have significant racial differences in SUID rates. However, instead of just sharing the data on these differences in my report, I understand it is crucial to provide context of the systemic factors that contribute to them. I will use population data indicators from [American Community Survey](https://bit.ly/4cAWs1h) (URL: <https://bit.ly/4cAWs1h>) to help with this framing. Here is an excerpt from my upcoming data brief:

“The county observed a significant difference in the rate of SUID by race and ethnicity. The rate of SUID among non-Hispanic Black infants was 5 times higher than for non-Hispanic white infants. Black women have historically been disproportionately exposed to neighborhood poverty, a well-established risk factor for infant mortality. American Community Survey data show 25% of Black individuals in our county live below the poverty level, compared to 10% of white individuals.”



- **Strengthen Policy Recommendations:** Population-level insights help quantify the scope of issues, such as high rates of suicide or substance use in certain age groups. These data strengthen advocacy efforts by providing compelling evidence for policy changes or resource allocation. Visual tools such as heat maps, trend graphs, and infographics are particularly effective in highlighting opportunities to improve health for all, such as regions with elevated infant mortality rates or communities disproportionately impacted by systemic barriers. Geographic Information Systems (GIS) mapping adds another layer of clarity, offering powerful visuals to illustrate spatial differences and helping partners identify areas requiring focused attention.

Mock Example

My state writes an annual legislative report for child death review. This year, we have prioritized including a prevention recommendation about increasing access to telehealth services in rural communities. We added a visual next to this recommendation in the report to make a powerful impact on legislators viewing the report. The visual shows how higher SUID mortality rates map onto rural [Health Professional Shortage Areas \(HPSAs\)](https://bit.ly/42w8qo0) (URL: <https://bit.ly/42w8qo0>), drawing attention to the areas for improvement in healthcare access. We believe this will strengthen our recommendation about improving access to telehealth services.

- **Engage Communities:** Sharing localized data builds trust and transparency with community members. For example, if population data paired with fatality review findings reveals a lack of mental health resources for youth, it can be shared with schools, parents, and advocacy groups to mobilize support for comprehensive initiatives and to set the stage during community-participatory sessions.
- **Monitoring and Evaluation:** Dissemination efforts can include updates on how population-level indicators evolve over time, showcasing the impact of implemented recommendations and identifying areas still in need of attention.

By integrating population data into dissemination practices, fatality review teams can amplify the impact of their work, ensure findings are accessible to various audiences, and drive collaborative action to address the systemic factors influencing mortality.

Prevention

Population data sources can provide valuable insights to guide and focus prevention activities. Utilizing place-based population data provides a more nuanced and comprehensive understanding of community-level factors linked to stillbirth, infant, and child deaths, allowing for data-driven prevention discussions across multidisciplinary sectors. Though this information might not be reflective of the individual child and their family, this approach allows for a better understanding of the assets and vulnerabilities of the community where the family resides. By addressing community-level factors that contribute to health, prevention initiatives can be more impactful. This section offers guidance and key considerations for jurisdictional programs on leveraging place-based population data to focus prevention efforts in a way that will more effectively improve health for all.

Use Population Data Alongside Community Insights

Combining quantitative population data and fatality review findings with qualitative community feedback and insights can provide a more comprehensive understanding of fatality trends. It can be done through community-based participatory sessions, such as holding focus groups and conducting interviews. Another approach is collaborating with local and community-based organizations and coalitions to understand the perspectives of providers. Through multisector collaborations, programs can contextualize place-based health data alongside surveillance data and insights gathered from both the individuals and organizations serving the community. By integrating community contextual data with participatory feedback from disproportionately impacted communities, programs can develop prevention strategies that are more tailored, culturally responsive, and impactful. **This approach ensures that strategies align with the unique needs and values of the community while acknowledging the complex, multidimensional nature of health.** The combination of evidence-based strategies and community input ensures that prevention efforts are not only rooted in data but also reflect the voices and priorities of those most affected.

By combining population data with community insights, fatality review teams can:

- Contextualize data findings.
- Identify potential contributing factors not documented in quantitative data.
- Develop more community-specific and community-informed recommendations.
- Build trust and engagement with the communities they serve.



This approach helps ensure that data-driven decisions are grounded in the personal experiences of community members, potentially leading to more effective prevention strategies and policies. The tables below illustrate how data and community feedback can be combined for deeper insights.

Figure 4. Combining Data and Community Feedback for Deeper Insights (Example 1)

Data Source	Insights
Population Data Findings	There was a 25% increase in drowning deaths for census tract X over the past three years.
Aggregated Fatality Review Findings	Drowning reviews in census tract X in the last three years identified lack of supervision as a contributing factor in 80% of deaths. There was limited or no lifeguard presence at public pools where children were swimming. In addition, 75% of children who died did not know how to swim.
Community Feedback	<p>In speaking with a local community coalition, the review team learned that:</p> <ul style="list-style-type: none"> • Families haven't been able to find affordable swimming lessons because several lesson centers closed recently. • There has been an observed lack of lifeguards at the local public pools due to municipal budget cuts.
Recommendations	<p>Insights taken together from population data, review findings, and community feedback lead the review team to recommend:</p> <ul style="list-style-type: none"> • Increasing funding for staffing at public pools. • Exploring new partnerships for low-cost/free swimming lessons. • Implementing water safety campaigns in affected census tract X.

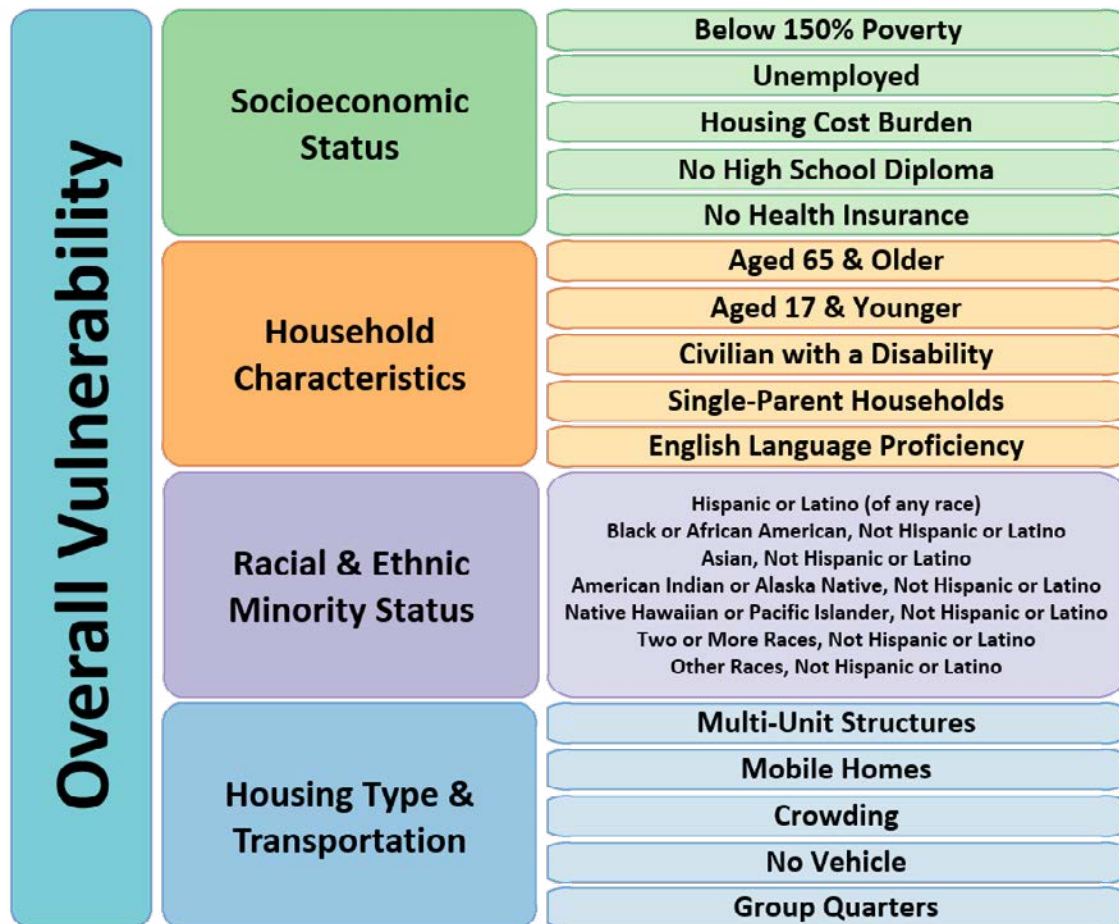
Figure 5. Combining Data and Community Feedback for Deeper Insights (Example 2)

Data Source	Insights
Population Data Findings	ZIP code X shows a 40% higher rate of sleep-related infant deaths compared to the county average last year.
Aggregated Fatality Review Findings	Reviews of sleep-related infant deaths in ZIP code X from the last year identified gaps in education on safe sleep from the nursing staff at the birth hospital. Findings also revealed that safe sleep education is not consistently integrated into home visiting services.
Community Feedback	<p>Through interviews with bereaved families, the review team learned that:</p> <ul style="list-style-type: none"> • Families are confused about safe infant sleep practices because they observed the nursery staff at the birth hospital serving this ZIP code using inconsistent infant sleep practices. • Families expressed that the messages in current safe infant sleep resources are confusing and unrealistic. • Black families have different cultural practices around infant sleep than what is recommended by the American Academy of Pediatrics. • Birth certificate data showed that 60% of Black infants were breastfed at discharge in the same year - a protective factor that supports infant health and can reduce the risk of sleep-related infant deaths.
Recommendations	<p>Insights taken together from population data, review findings, and community feedback lead the review team to recommend:</p> <ul style="list-style-type: none"> • Development of culturally sensitive safe sleep education programs in collaboration with the community. • Partnering with community leaders for outreach to birth hospitals and home visiting services on how to integrate safe sleep modeling, messaging, and education.

Using CDC's Social Vulnerability Index Data to Focus Prevention Recommendations

There are many place-based population data sources available. As one example, let's look at how the Social Vulnerability Index (SVI) can be used to focus prevention efforts. Social vulnerability refers to the capacity of communities to prepare for, respond to, and recover from external stresses on health.²⁰ It is shaped by factors that make certain communities more susceptible to harm from these events. The Social Vulnerability Index (SVI), created by the US CDC/Agency of Toxic Substances and Disease Registry (ATSDR), is a standardized, place-based metric that uses US Census tract- and county-level community health data to assess and compare levels of vulnerability to harm.²¹ The SVI organizes these factors into four main themes, each containing several domains that contribute to a community's overall vulnerability score.

Figure 6. Overall Social Vulnerability and Associated Themes and Domains, CDC's Social Vulnerability Index, 2018-2022





The SVI was originally developed to help public health officials identify and assist communities that are most vulnerable to external stresses, such as natural disasters. The SVI enables public health officials to prioritize efforts in areas that might have a harder time responding to or recovering from emergencies. More recently, investigators have broadened the use of SVI to examine the underlying factors contributing to worse health outcomes in communities.²²

State and local programs can consider the steps and considerations provided in the table below to illustrate how place-based community health data can be leveraged to more effectively focus prevention efforts. Visit [Appendix B](#) to view an example of how this step-by-step approach can be used in sudden unexpected infant deaths (SUID) prevention.

Figure 7. Action Steps and Considerations for Utilizing Place-Based Community Health Data to Focus Prevention Efforts

Action Steps	Considerations
<p>1. Identify geographic areas with the highest death rates for the health outcome in your jurisdiction.</p>	<ul style="list-style-type: none"> • Consider whether you have access to surveillance data for the health outcome for your jurisdiction (e.g., case registry, vital records data). • Assess if the available data are population-based, meaning they represent the entire group of interest. • Determine the geographic granularity of your data, including the level at which it can be analyzed (e.g., county, city, ZIP code, Census tract). Smaller geographic units are more likely to provide a precise approximation of community characteristics.
<p>2. Identify available, place-based community health datasets, their level of geographic granularity, and indicators. Determine which indicators are most relevant to the health outcome.</p>	<ul style="list-style-type: none"> • Consider the availability of public data sources, the presence of public-facing interactive dashboards, the geographic unit and its compatibility with your surveillance data, and the alignment of indicators with your health outcome. • These decisions should be made collaboratively as a group, such as with your FIMR or CDR team or a designated work group.
<p>3. Classify geographic areas by social vulnerability levels (e.g., using percentiles from the Social Vulnerability Index), grouping them into categories, such as quartiles. Identify geographic areas with high death rates for the health outcome you are investigating and that are also experiencing vulnerabilities to factors potentially influencing the risk for the health outcome.</p>	<ul style="list-style-type: none"> • Identify areas with both high incidence rates and high social vulnerability scores. • Describe observed geographic patterns between death rates and social vulnerability percentiles. • Assess how overlapping vulnerabilities might amplify the community’s risk and impact specific health outcomes.

Action Steps	Considerations
<p>4. Use data about the community context to enrich fatality reviews.</p>	<ul style="list-style-type: none"> • For each decedent that will be discussed at the fatality review meeting, gather information about the community characteristics. • Analyze community-level indicators that might be contributing to the health outcome. • Consider which partners need to be at your review and prevention meetings to help with community data interpretation and who can help move recommendations into action. • Develop prevention recommendations that are informed by both community-level data and the specific circumstances surrounding each death.
<p>5. Implement evidence-based community-participatory activities and initiatives in impacted communities.</p>	<ul style="list-style-type: none"> • Ensure active involvement of community members throughout the process. • Consider various formats, such as listening sessions, focus groups, surveys, and town halls, allowing for open dialogue and input. • The primary goal is to ensure that community voices are heard, respected, and integrated into the decision-making processes.
<p>6. Use information from multiple data sources and community-participatory activities to develop and enhance systems-focused prevention strategies.</p>	<ul style="list-style-type: none"> • Ensure community voices are embedded into prevention strategies. • Implement data-driven prevention strategies that center on the community and are tailored to the cultural and economic context of the community. • Develop a sustainability plan to ensure that successful programs, partnerships, and prevention efforts continue to positively impact communities.
<p>7. Evaluate impact.</p>	<ul style="list-style-type: none"> • Develop the evaluation plan at the start of the prevention strategy planning process. • Regularly evaluate the effectiveness of prevention strategies through feedback loops (e.g., plan-do-study-act cycles). • Engage the community in evaluating the outcomes and adjust strategies based on what is and is not working.

Using Population Data Within Pediatric Injury Extended Review

Pediatric Injury Extended Review (PIER) is a new process to identify risk factors for injuries and develop actionable recommendations. It brings together experts in injury surveillance, child fatality review, and policy advocacy. The process is designed to be sustainable and adaptable, offering a practical framework that other communities can implement. The PIER process involves 7 steps:

- Team identification.
- Population-level data preparation.
- Literature review for Extended Review Matrix.
- Case identification and review.
- Data review.
- Discussion of modifiable factors and recommendation development.
- Recommendation refinement, dissemination, and implementation.

Contact the National Center at info@ncfrp.org to learn more and create your own Pediatric Injury Extended Review.

The Role of Population Data in the Extended Review Framework

In step 2 of the PIER process, population data is gathered to help understand patterns of injury and identify upstream factors contributing to injury outcomes. This includes:

Preparing an Injury Data Summary

- **Aggregate Data:** Collect fatal and nonfatal injury data at relevant levels (e.g., state, city, county) and calculate rates per population.
- **Analyze Data:** Examine data by factors such as race, ethnicity, age, language, and environmental factors (e.g., rurality, neighborhood characteristics).
- **Incorporate Local and National Data:** Combine local data with national datasets like [CDC WISQARS](https://bit.ly/3EhZPgM) (URL: <https://bit.ly/3EhZPgM>) to address issues like small sample sizes or rare injuries.

Identifying Opportunities to Improve Health

- **Demographics:** Highlight differences in injury rates across groups (e.g., higher drowning rates in low-income or minority populations).
- **Environment:** Use indices like the [Child Opportunity Index](https://bit.ly/42gBTne) (URL: <https://bit.ly/42gBTne>) to assess risks based on socioeconomic and geographic factors.
- **Geographic Variations:** Examine differences across urban, suburban, and rural areas to identify areas with elevated risks or fewer safety resources.

Visualizing Data for Deeper Insights

- **Graphs:** Present rates in clear visual formats (e.g., bar charts, line graphs).
- **GIS Mapping:** Use spatial analysis to overlay injury hotspots with socioeconomic data or resource gaps (e.g., lack of swim lessons or traffic safety measures). See an example of [GIS mapping data](https://bit.ly/42HKrma) (URL: <https://bit.ly/42HKrma>).
- **Risk and Resource Maps:** Highlight neighborhoods with risk factors (e.g., unlit crosswalks) or limited preventive resources.

Iterative Refinement

- **Address Small Case Counts:** Aggregate datasets or use broader timeframes to enhance analysis.
- **Data Use Agreements (DUAs):** Establish agreements with public health entities to simplify data access.
- **Refine Analyses:** Regularly revisit analyses to explore emerging patterns, such as additional stratifications.



Conclusion

Fatality review teams play a significant role in understanding and addressing the factors contributing to child, infant, and fetal mortality. This guidance provides sources and ideas for incorporating population data into their work, enabling teams to achieve more comprehensive community and environmental contexts surrounding fatalities. By enhancing the objectivity of reviews and promoting systems-focused, data-driven collaboration across sectors, population data empowers teams to develop culturally responsive and impactful prevention strategies. Paired with community insights, this approach strengthens prevention efforts and supports the creation of healthier and safer communities for all.

Appendix A: Additional Sources of Population Data

Note: Since the publication of this guidance, some links may have changed or become inactive. Additionally, new data sources may be available, offering updated insights and information.

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
American Community Survey (ACS)	Census Bureau	Yes	States, county, ZIP code, census tract, census block and group, Public Use Microdata Areas (PUMAs), and more	https://www.census.gov/programs-surveys/acs/data.html	https://www.census.gov/programs-surveys/acs/data/data-via-ftp.html
American Housing Survey (AHS)	Census Bureau & Department of Housing and Urban Development (HUD)	Yes	States, county, metropolitan areas	https://www.census.gov/programs-surveys/ahs.html	https://www.census.gov/programs-surveys/ahs/data.html
Area Health Resources Files	Health Resources and Services Administration (HRSA)	Yes	National, states, county	https://data.hrsa.gov/topics/health-workforce/ahrf	https://data.hrsa.gov/data/download
Behavioral Health Workforce Tracker	George Washington University	No	States, HHS region, county	https://www.gwhwi.org/behavioral-health.html	N/A

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention (CDC)	Yes	States, county, city	https://www.cdc.gov/brfss/brfssprevalence/index.html	https://www.cdc.gov/brfss/annual_data/annual_data.htm
Bureau of Economic Analysis by Place	U.S. Department of Commerce	Yes	National, states, territories, county, metropolitan area	https://www.bea.gov/data/by-place-us	https://www.bea.gov/data/by-place-county-metro-local
Census of Employment and Wages (CEW)	Bureau of Labor Statistics	Yes	National, states, county	https://data.bls.gov/cew/apps/data_views/data_views.htm#tab=Tables	https://www.bls.gov/cew/downloadable-data-files.htm
Child Opportunity Index (COI)	Ohio State University	Yes	Census tracts, national, states, county, ZIP code	https://www.diversitydatakids.org/child-opportunity-index	https://data.diversitydatakids.org/dataset?_ga=2.48895589.237131468.1734993835-1152795890.1734993835
City Health Dashboard	NYU Grossman School of Medicine and Robert Wood Johnson Foundation	Yes	States, city	https://www.cityhealthdashboard.com/	https://nyumc.qualtrics.com/jfe/form/SV_8IZgcZ9tifgNibH

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Community Resilience Estimates	Census Bureau	Yes	Census tracts, states, county	https://www.census.gov/programs-surveys/community-resilience-estimates.html	https://www.census.gov/programs-surveys/community-resilience-estimates/data/datasets.html
Comprehensive Housing Affordability Strategy (CHAS)	HUD	Yes	National, states, county, Minor Civil Division (MCD), place	https://www.huduser.gov/portal/datasets/cp.html	https://www.huduser.gov/portal/datasets/cp.html
County Business Patterns (CBP)	Census Bureau	Yes	National, states, county, Metropolitan Statistical Area (MSA), ZIP code, Congressional District	https://www.census.gov/programs-surveys/cbp.html	https://www.census.gov/programs-surveys/cbp/data.html
County Health Rankings	University of Wisconsin Population Health Institute	Yes	States, county, ZIP code	https://www.countyhealthrankings.org/health-data	https://www.countyhealthrankings.org/health-data/methodology-and-sources/data-documentation
Economic Research Service (ERS) County Data	U.S. Department of Agriculture (USDA)	Yes	County	https://catalog.data.gov/dataset/county-level-data-sets	https://catalog.data.gov/dataset/county-level-data-sets

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Environmental Justice Index (EJI)	Agency for Toxic Substances and Disease Registry (ATSDR)/CDC	Yes	Census tracts, states, county	https://www.atsdr.cdc.gov/place-health/php/eji/eji-explorer.html	https://www.atsdr.cdc.gov/place-health/php/eji/eji-explorer.html
Fatality Analysis Reporting System (FARS)	National Highway Traffic Safety Administration (NHTSA)	Yes	National, states, county	https://cdan.dot.gov/query	https://www.nhtsa.gov/file-downloads?p=nhtsa/downloads/FARS/
Food Environment Atlas	USDA	Yes	States, metropolitan areas	https://www.ers.usda.gov/data-products/food-environment-atlas/go-to-the-atlas/	https://www.ers.usda.gov/data-products/food-environment-atlas/data-access-and-documentation-downloads/
Gun Violence Archive	Gun Violence Archive	Yes	States, city, county, address level	https://www.gunviolencearchive.org/charts-and-maps	https://www.gunviolencearchive.org/reports
HDPulse	National Institutes of Health (NIH)	No	States, county	https://hdpulse.nimhd.nih.gov/data-portal/home	N/A

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Health Information Exchange (HIE)	Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP/ONC)	Yes	National and regional patient-level, facility-specific	https://www.healthit.gov/data	https://www.healthit.gov/data/data
Health Professional Shortage Areas	HRSA	Yes	States, county, region, and Congressional District	https://data.hrsa.gov/topics/health-workforce/shortage-areas	https://data.hrsa.gov/data/download
Home Mortgage Disclosure Act (HMDA) Data	Consumer Finance Protection Bureau	Yes	Census tracts, county, ZIP code, loan-level data	https://ffiec.cfpb.gov/	https://ffiec.cfpb.gov/
Home Owners' Loan Corporation (HOLC)	National Community Reinvestment Coalition	No	Census tracts, metropolitan areas	https://ncrc.org/holc-health/#Map	N/A
HRSA Map Tool	HRSA	Yes	National, states, county, Medically Underserved Areas (MUA), Health Professional Shortage Areas (HPSA)	https://data.hrsa.gov/map	https://data.hrsa.gov/data/download

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
HUD Housing Data	HUD	Yes	Census tracts, national, states, county, core-based statistical area (CBSA)	https://www.huduser.gov/portal/pdrdatas_landing.html	https://data.hud.gov/data_sets.html
KIDS COUNT	Annie E. Casey Foundation	Yes	National, states, territory, city	https://datacenter.aecf.org/	https://datacenter.aecf.org/data#USA/1/0/char/1
Minority Health Social Vulnerability Index (SVI)	CDC and U.S. Department of Health and Human Services (HHS) Office of Minority Health	Yes	States, county	https://onemap.cdc.gov/Portal/apps/MapSeries/index.html?appid=3384875c46d649ee9b452913fd64e3c4&utm_medium=email&utm_source=govdelivery	https://minorityhealth.hhs.gov/minority-health-svi
National Center for Education Statistics (NCES)	NCES	Yes	National, states, school district	https://nces.d.gov/	https://nces.ed.gov/admindata/
National Health Interview Survey (NHIS)	CDC	Yes	National, states, county, metro area	https://www.cdc.gov/nchs/nhis/index.html	https://www.cdc.gov/nchs/nhis/documentation/index.html

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
National Survey of Children's Health (NSCH)	HRSA	No	States, HRSA region	https://www.childhealthdata.org/browse	https://www.census.gov/programs-surveys/nsch/data/datasets.html
Opportunity Atlas	Census Bureau	Yes	Census tract, county, city	https://www.opportunityatlas.org/	https://www.census.gov/programs-surveys/ces/data/public-use-data/opportunity-atlas-data-tables.html
PeriStats	March of Dimes	No	National, states	https://www.marchofdimes.org/peristats/	N/A
Picture of Subsidized Households	HUD	Yes	Census tract, states, city, county, congressional district, ZIP codes	https://www.huduser.gov/portal/datasets/assthg.html#data_2009-2023	https://www.huduser.gov/portal/datasets/assthg.html#data_2009-2023
PLACES	CDC	Yes	Census tracts, county, city, place, ZIP code tabulation areas (ZCTA)	https://www.cdc.gov/places/tools/interactive-map-tool.html	https://www.cdc.gov/places/tools/data-portal.html

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Pregnancy Risk Assessment Monitoring System (PRAMS)	CDC	Yes	National, state, county	https://www.cdc.gov/prams/about/index.html	https://www.cdc.gov/prams/php/data-research/index.html https://www.cdc.gov/prams/php/data-research/mch-indicators-by-site.html
Rural Health Information Hub	Federal Office of Rural Health Policy	No	National, states	https://www.ruralhealthinfo.org/visualizations https://www.ruralhealthinfo.org/data-explorer	N/A
School Climate Survey	GLSEN	No	National, states	https://www.glsen.org/school-climate-survey https://maps.glsen.org/state-research-snapshots/	N/A

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
School Health Profiles	CDC	Yes	National, states, large urban school districts, territories	https://www.cdc.gov/school-health-profiles/about/index.html https://profiles-explorer.cdc.gov/	https://www.cdc.gov/school-health-profiles/contact/index.html
Social Vulnerability Index (SVI)	ATSDR/CDC	Yes	Census tract, national, states, county, ZIP code	https://www.atsdr.cdc.gov/place-health/php/svi/index.html	https://www.atsdr.cdc.gov/place-health/php/svi/svi-data-documentation-download.html#cdc_generic_section_1-data
Uniform Crime Reporting	Federal Bureau of Investigation (FBI)	Yes	States, county, city, university, tribal	https://cde.ucr.cjis.gov/LATEST/webapp/#/pages/home	https://cde.ucr.cjis.gov/LATEST/webapp/#/pages/downloads
Web-based Injury Statistics Query and Reporting System (WISQARS)	CDC	Yes	National, states	https://wisqars.cdc.gov/	https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm

Data Source (A to Z)	Producer	Data Linkage Ability (Yes/No)	Geographic Levels	Website	Available Data Download, if Available
Wide-ranging ONLINE Data for Epidemiologic Research (WONDER)	CDC	Yes	Census tracts, national, states	https://wonder.cdc.gov/	https://www.cdc.gov/nchs/data_access/VitalStatsOnline.htm#Mortality_Multiple
Youth Risk Behavior Surveillance System	CDC	Yes	National, states, school districts	https://yrbs-explorer.services.cdc.gov/#/	https://www.cdc.gov/yrbs/data/index.html

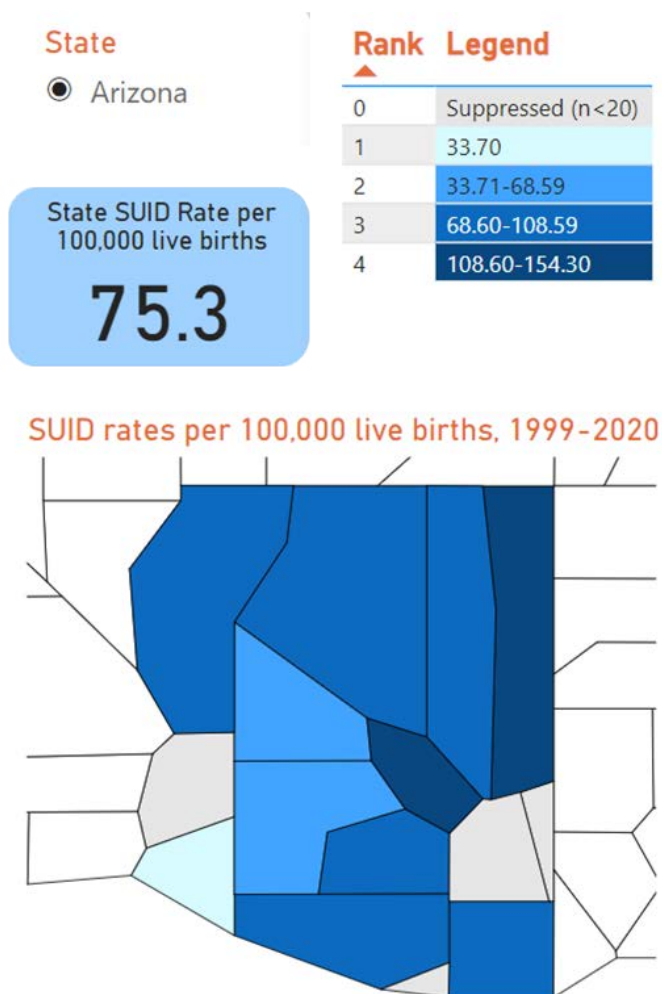
Appendix B: Application of CDC’s Social Vulnerability Index Data for SUID Prevention

Step 1. Identify geographic areas with the highest death rates for the health outcome in the jurisdiction of interest.

The figure below provides information on the rates of SUID per 100,000 live births across counties in Arizona during 1999-2020. SUID rates were divided into five categories using natural breaks according to the Jenks method in Python. Light blue (rank 1) represents the lowest rates, slightly darker blue (rank 2) represents low-to-moderate rates, medium blue (rank 3) represents moderate rates, and dark blue (rank 4) represents the highest rates. Rates where death counts were less than 20 were suppressed, shown as gray, because of the risk of decedent identity disclosure (death counts between 1 to 9) and because of the instability associated with those rates. State and local programs might apply a lower threshold for data suppression based on confidentiality rules and regulations specific to their jurisdiction.

County rates of sudden unexpected infant death (SUID) per 100,000 live births, Arizona, 1999-2020

This map shows that the highest SUID rates occurred in Apache County, located in the northeastern part of Arizona, and Gila County, situated in the central region of the state. Additionally, the counties of Mohave, Coconino, and Navajo in the north, as well as Pinal, Pima, and Cochise in the south-experienced SUID rates above the state average of 75.3 deaths per 100,000 live births.



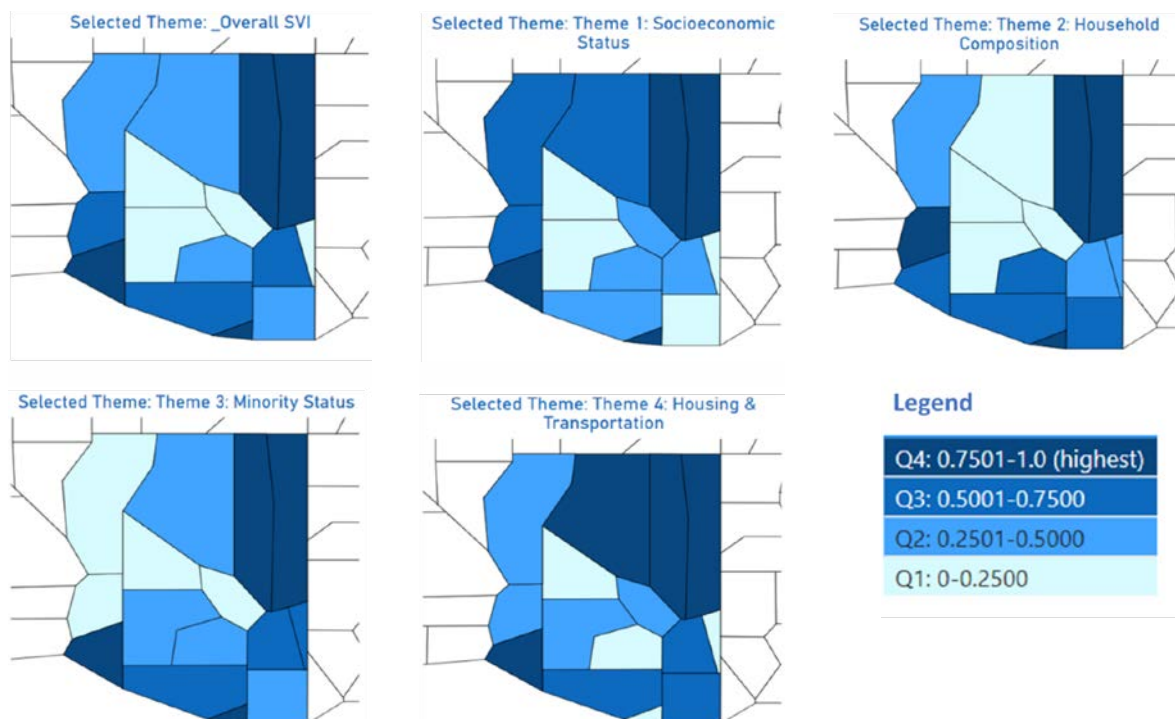
Step 2. Identify available, place-based community health datasets, their level of geographic granularity, and indicators. Determine which indicators are most relevant to the health outcome.

For this exercise, we will utilize the CDC's Social Vulnerability Index, incorporating the Overall SVI along with all associated themes and domains.

Step 3. Classify geographic areas by social vulnerability levels (e.g., using percentiles from the Social Vulnerability Index), grouping them into categories, such as quartiles. Identify geographic areas with high death rates that are also experiencing vulnerabilities to factors potentially influencing the risk for the health outcome.

Distribution of social vulnerability percentile quartiles according to the overall SVI and themes, Arizona, 2016-2020

These figures provide the distribution of SVI percentiles, both overall and by theme. Percentiles were grouped into quartile categories (0–0.2500, 0.2501–0.5000, 0.5001–0.7500, and 0.7501–1.0) to describe Least, Less, More, and Most Vulnerable counties, respectively. The first box shows that certain counties in the highest Overall SVI quartile also experienced the highest SUID rates, particularly in northeastern Arizona (Apache and Navajo Counties) and in Pima County, which is situated in southern Arizona. This alignment suggests systemic barriers within these counties that might impact their ability to adequately support residents.



Step 4. Use data about the community context to enrich fatality reviews.

Community context findings can inform fatality reviews by fostering data-driven discussions on multisector, systems-level approaches to addressing the health outcome. Integrating these data into the conversation helps mitigate potential biases that may arise when considering what is known about the community where the family resides. Additionally, prevention recommendations—traditionally focused on information specific to the child’s death and family circumstances—can be broadened to encompass community- and societal-level interventions.

Hypothetical example: A CDR team was reviewing a SUID case that occurred in Navajo County among an American Indian infant living in a single-parent household. On the day of the incident, the mother reported coming home after working long hours and sleeping in the same adult bed with her infant. Her infant died due to suffocation from overlay. The original recommendation before considering the community characteristics was to ensure safe sleep education during prenatal checkups.

The CDR Coordinator encouraged the team to consider the community and environmental factors that may have posed barriers for families in the county in accessing safe sleep resources. Analyzing the Household Composition theme revealed that Navajo County ranks in the 86th percentile for single-parent households with children under 18, meaning that 86% of counties in Arizona have a lower proportion of single-parent households than Navajo County. In other words, Navajo County has a relatively high proportion of single-parent families compared to other counties in the state. By incorporating SVI data into the fatality review process, the program is adopting a dual approach that not only continues to focus on safe sleep education efforts but also addresses the underlying vulnerabilities that affect safe sleep practices through systems-level actions. After incorporating SVI data into the CDR team discussion, the team updated the prevention recommendation to ensure safe sleep education is provided during prenatal checkups, that childcare options are available and affordable in the county, and that staff at prenatal care clinics and childcare centers are adequately and consistently trained to provide safe sleep education and can adhere to safe sleep practices.

Examination of the SUID Case Registry data for Navajo County revealed that a large fraction of cases occurred among American Indian infants in certain communities. The program decided to focus their safe sleep education and training in childcare centers, health care facilities, and community organizations serving American Indian communities within the county.

Step 5. Implement evidence-based community-participatory activities and initiatives in impacted communities.

This entails collaboratively engaging with communities disproportionately impacted by the health outcome, alongside public health professionals, caregivers, healthcare workers, and community-based organizations within the community. By doing this, programs can develop more tailored, culturally responsive, and impactful prevention strategies that resonate with the unique needs and values of the community. This combined approach ensures that strategies are evidence-based and rooted in the voices of communities that are disproportionately impacted. Prevention strategies are co-created giving everyone involved a sense of co-ownership over the process from start to finish.

A community participatory session is a collaborative meeting where community members share their experiences, perspectives, and insights on a specific topic to inform solutions that address the unique needs and challenges within their community.²³ These sessions can take various formats, such as listening sessions, focus groups, surveys, and town halls, allowing for open dialogue and input. The primary goal is to ensure that community voices are heard, respected, and integrated into decision-making processes. By involving the community in these discussions, the solutions developed are more likely to be relevant, effective, and culturally appropriate.

Using the same example, the program subcontracted with a Tribal-serving organization to host listening sessions in ZIP codes of Navajo County where the SUID rates were the highest. Community participants, including Tribal Elders, grandparents, and parents, were asked to provide their feedback on several safe sleep education materials as well as their perspectives on the barriers and protective factors families face when practicing infant safe sleep.

Step 6. Use information from multiple data sources and community-participatory activities to develop and enhance systems-focused prevention strategies.

The program compiled this information into a comprehensive summary report, convened a Community Action and Advisory Team made up of a multidisciplinary group of people with personal and professional experience, and integrated the findings from this report, the community context data, and the SUID data to develop and implement prevention strategies that were tailored to the unique needs of the community. The program also developed a Sustainability Plan to ensure successful programs, partnerships, and prevention efforts continue to positively impact communities.



Step 7. Evaluate the effectiveness of the strategy.

Evaluating prevention strategies is crucial because it helps programs see if their efforts are truly making a difference. Without evaluation, programs would not know which approaches are effective or how they are affecting disproportionately impacted communities. Evaluation also helps identify gaps in what programs are currently doing and make improvements that better serve the unique needs of different communities. Additionally, evaluation fosters trust and accountability with partners, families, and communities by showing measurable progress and ensuring resources are used responsibly. Evaluation aids in sustainability, for continued support and funding to ensure long-term success.

Evaluation planning should ideally begin during the prevention planning process to ensure that goals are clearly defined, and outcomes can be effectively measured from the outset. There are a variety of available evaluation frameworks, including the updated 2024 CDC Program Evaluation Framework, which supports the delivery of timely and high-quality evaluations, and the Plan-Do-Study-Act (PDSA) Framework, which is an iterative four-step process for improving processes, products, and outcomes ([CDC Program Evaluation Framework, 2024](https://bit.ly/42Hb4aF) (URL: <https://bit.ly/42Hb4aF>) and [PDSA Cycle - The W. Edwards Deming Institute](https://bit.ly/4IEfAiG) (URL: <https://bit.ly/4IEfAiG>)). The PDSA framework allows programs to evaluate strategies on a small scale, analyze findings, and refine the approach before broader implementation. Regardless of the evaluation approach selected, programs should prioritize developing their evaluation approach at the outset of their prevention planning work and actively engage the community in assessing outcomes to ensure prevention strategies are effective.

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