



SUICIDE SURVEILLANCE STRATEGIES

FOR AMERICAN INDIAN AND
ALASKA NATIVE COMMUNITIES



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OVERVIEW



This is good, noble work that we're doing. It's easy to get discouraged . . . And I get there about once a week. But this is good work, and we need to tell our people that are working in the field . . . that their work matters.”

—KEY INFORMANT



The Suicide Prevention Resource Center (SPRC) is pleased to present this report, which highlights a collective effort to better understand how American Indian and Alaska Native (AI/AN) communities can gather information about suicide—in ways that are feasible and culturally appropriate—to assist in planning and demonstrating the success of their suicide prevention efforts. The purpose of this project is to support tribal Garrett Lee Smith grantees in their data collection efforts, but we also hope that the strategies and successes offered here will be helpful to any AI/AN prevention effort.

Gathering data, stories, and information about suicide in AI/AN communities can help provide a better understanding of the nature and extent of the problem, guide strategic planning and decision-making, and help with measuring the effectiveness of suicide prevention programs. While the span of a three- or five-year grant may not allow enough time for concrete reductions in suicidal behavior, this kind of data collection can enhance the community's ability to know over time whether their prevention efforts are effective and lives are being saved.

The Garrett Lee Smith program includes diverse cohorts of Substance Abuse and Mental Health Services Administration (SAMHSA) funded tribal and tribal-serving entities. All of these entities are working on preventing suicide among AI/AN youth through unique efforts developed and implemented in one or multiple AI/AN communities located in vast geographic areas throughout the United States, including Alaska. Garrett Lee Smith grantees receive funding for a period of three to five years and are required to use data-driven approaches to demonstrate their success in reducing suicidal behaviors through project activities.

One of the roles of SPRC is to provide technical assistance to Garrett Lee Smith grantees, including support for suicide data surveillance and monitoring systems, by identifying resources, strategies, and success stories that can help grantees overcome common barriers and implement effective prevention programs. State and tribal Garrett Lee Smith grantees are required to demonstrate their impact in reducing suicide deaths and attempts in the populations they

are working with. Tribal Garrett Lee Smith grantees include federally recognized tribes, tribal organizations (as defined in the Indian Self-Determination and Education Assistance Act), Alaska Native entities, and urban Indian organizations (as defined in the Indian Health Care Improvement Act) that are actively involved in the development and continuation of a tribal youth suicide early intervention and prevention strategy (SAMHSA, 2015).

This report's in-depth inquiry looks at an array of challenges, successes, and innovative ways that AI/AN communities are engaging the sensitive topic of suicide data collection with an understanding of the uniqueness of each American Indian and Alaska Native community. It is our hope that we have captured a unique and foundational base of information that can be useful in the conceptualization, design, and implementation of current and future suicide data collection, prevention, and evaluation efforts.

This report briefly summarizes findings and recommendations from SPRC's exploration of suicide surveillance among AI/AN communities across the country. Each section describes challenges, provides strategies, lists resources, and highlights community examples as available. We are grateful for the contributions of our colleagues who shared their knowledge, stories, and experiences from the field. By sharing the knowledge gained through this inquiry, we acknowledge, honor, and appreciate the AI/AN communities, community members, key informants, and tribal Garrett Lee Smith grantees who are deeply engaged in and committed to the work of preventing suicide in AI/AN populations.

Because suicide rates among different AI/AN populations and regions vary over time (Chandler & Lalonde, 2004), gathering local data on suicidal behaviors and associated risk and protective factors is key to understanding the unique circumstances surrounding suicidal behaviors for each community. It is also important to consider local cultural protocols and areas of sensitivity when collecting data on suicide, as well as recognizing that tribal communities have other ways of knowing, including oral histories, storytelling, and spiritual traditions that perpetuate indigenous knowledge systems. The cultural knowledge and traditions of each AI/AN community should always be considered when thinking of other ways of measuring impact.

Many AI/AN communities face significant infrastructure challenges to data collection, such as a limited public health infrastructure, limited information technology resources and connectivity, and a lack of staff with experience and expertise in data collection and surveillance. Lack of transportation and a limited number of, or a long distance to, health facilities may prevent at-risk individuals from accessing services. And individuals who do not access health services are less likely to be screened. Many grantees and key informants noted that they rely on screening and/or assessment results to track, monitor, and refer at-risk individuals.

There is no one-size-fits-all approach related to best practices for developing or improving AI/AN suicide surveillance systems. Each tribe is different and has its own unique culture, so what works in one community might not work in another. Tribal surveillance systems also vary from urban to rural to frontier settings. Collecting data on Native populations has many challenges, including whether a person lives on or off a reservation and/or whether they identify

as AI/AN or are enrolled in a particular tribe. Surveillance systems that gather data on AI/AN populations may be housed within tribal or non-tribal government agencies, clinics, schools, and/or nonprofit organizations. These systems may cover individual communities, tribal consortiums or networks, counties, or regions. For organizations serving multiple sovereign nations, efforts can be complicated by the fact that each nation owns its own data, and each has its own decision-making groups and processes.

Despite these challenges, suicide prevention practitioners in AI/AN communities have found innovative ways to collect, share, interpret, and use data to enhance prevention efforts and meet funding requirements to demonstrate outcomes, while maintaining respect for cultural traditions. SPRC sought to explore all approaches in the hopes of offering diverse strategies for collecting this data in a way that can be useful for all parties involved.

METHODOLOGY

This inquiry began with a systematic review of the literature using key terms related to tribal suicide surveillance. An environmental scan of tribal Garrett Lee Smith grantee program proposals and detailed monthly conference call agendas were then conducted to see what the SAMHSA-funded projects proposed for their suicide surveillance efforts. Next, key informant interviews were conducted with 29 national experts with established careers in tribal suicide data collection, including Garrett Lee Smith project staff and AI/AN prevention professionals and community members. Key informants were interviewed via telephone or face-to-face. Finally, a quantitative survey of current tribal Garrett Lee Smith grantees was sent out via e-mail, with questions related to the challenges and successes of collecting data and establishing surveillance systems for suicide in the communities they were working with. All 17 tribal Garrett Lee Smith grantees responded to the survey.

RELATIONSHIPS ARE KEY



Like any long-term initiative, there must be strong, vocal and persuasive advocates from within the community who can rally leadership to put something sustainable in place, make sure there are people and funding to do the work despite the many, many other priorities.”

—KEY INFORMANT



Development and maintenance of AI/AN suicide surveillance systems should be driven by local needs, resources, and readiness (May, Serna, Hurt, & DeBruyn, 2005; Mullany et al., 2009). A crucial factor stressed repeatedly by key informants is the need for relationship building between researchers, tribal leaders, providers, prevention specialists, and community members. Data sharing takes time and requires communication, transparency, and trust. There must be dialogue about the importance of the data and how it will be used and shared.

RELATIONSHIPS WITH LEADERSHIP

CHALLENGE: Sometimes tribal leaders and health directors are elected or appointed. They may not have backgrounds as health professionals or a solid understanding of issues related to suicide—making it difficult to get leadership buy-in for prevention efforts.

STRATEGIES:

- » Build community support around the importance of suicide surveillance systems. Use word of mouth and find respected, trusted, and prominent community members who will vouch for the data needs. This can be done through existing connections or by joining other committees or groups working on similar issues.
- » Help tribal leadership get on board by showing how tribally owned data can be used and why it's important to have tribally overseen surveillance and prevention efforts. Share data on community-level suicidal behaviors to justify the need for resources and collaborative prevention efforts. Share data on local risk and protective factors for suicidal behaviors to help drive strategic planning.
- » Get on the agenda of a tribal council, school board, or health committee meeting to get connected to leaders in the local area.

CASE STUDY:

The White Mountain Apache community in Whiteriver, Arizona, has successfully implemented a suicide surveillance system. After a string of completed suicides by young tribal members, community members turned to tribal leadership for help in addressing suicide in their community. As a result, tribal leadership mandated all school, medical, social service staff, first responders, and community members to report all suicidal behaviors to local suicide prevention program staff. The data are entered into a secure database, and the results provide vital information back to the community that helps to inform prevention and postvention activities. The data have also shown a decrease in suicide deaths since implementation of the surveillance system. (Cwik et al., 2016)

RELATIONSHIPS WITH DATA KEEPERS

CHALLENGE: Some data keepers are reluctant or unwilling to share their data due to privacy, confidentiality, or other concerns.

STRATEGIES:

- » Reach out to off-reservation providers (including non-tribal emergency rooms, first responders, police, fire personnel, teachers, and off-reservation counselors and traditional healers) to encourage them to work cooperatively with your suicide prevention program. Find out how you can support their efforts and how they can support yours. Develop memoranda of understanding (MOUs) so that everyone has a clear vision of what the expectations are of all parties involved.
- » Partner with your regional Tribal Epidemiology Center, which receives funding to assist tribes and tribal-serving organizations to develop data and surveillance systems. Meet with data keepers in person initially to build relationships versus simply calling or emailing with requests for data.
- » Go out and make connections with advocates who can provide access to records and data systems. Consider creating limited data use agreements with partners to ensure data protections (see case study on page 21 for more details).
- » Network with other professionals who may be able to share tips or contact information for data keepers at meetings, conferences, summits, and training events.
- » One former Garrett Lee Smith grantee participated in a county-wide suicide prevention coalition that was made up of Native and non-Native representatives, creating a broad-based group with more collective leverage across their state and region for requesting and accessing data through establishing collective partnerships.

“The important first step is to make sure the community is ready. To have staff that are willing to go out and help educate the community about what the tribal suicide surveillance system is about, and what exactly they’re wanting to do with that information, who has access to that information. The community buy-in really needs to be there. Community support needs to be there from all levels as well. If it’s another agency that’s coming in and wants to implement this, they still have to work closely with the tribe because at the end of the day that data needs to belong to the tribe.”

—KEY INFORMANT

RESOURCES

Prevention Collaboration in Action Toolkit—Provides success stories of collaborating across communities and behavioral health fields

SAMHSA’s Center for the Application of Prevention Technologies (CAPT), [n.d.]

Available at <https://pscollaboration.edc.org>

SPARK Talk: Prevention Paradigm for Native Americans—Addresses community involvement in suicide prevention
Suicide Prevention Resource Center, 2015

Available at <http://www.sprc.org/video/native-americans>

SPRC Substance Abuse and Suicide Prevention Collaboration Continuum—Provides stages and strategies for building partnerships

Suicide Prevention Resource Center, [n.d.]

Available at <http://www.sprc.org/collaboration-continuum>

Surveillance Success Stories: White Mountain Apache Tribe—Describes the White Mountain Apache Tribe’s efforts to identify patterns of suicidal behavior

Suicide Prevention Resource Center, 2016

Available at <http://www.sprc.org/resources-programs/surveillance-success-stories-white-mountain-apache-tribe-wmat>

Transforming Communities: Key Elements for the Implementation of Comprehensive Community-Based Suicide Prevention—Provides models and guidance for community suicide prevention

National Action Alliance for Suicide Prevention, 2017

Available at <https://theactionalliance.org/sites/default/files/transformingcommunitiespaper.pdf>

Tribal Epidemiology Centers—Help tribes and tribal-serving organizations in data and surveillance infrastructure development, 2018

More information available at <https://tribalepicenters.org/>

‘Walk Softly and Listen Carefully’: Building Research Relationships with Tribal Communities—Provides information on community-based participatory research and fostering effective partnerships

National Congress of American Indians (NCAI) Policy Research Center and Montana State University (MSU) Center for Native Health Partnerships, 2012

Available at http://www.ncai.org/attachments/PolicyPaper_SpMCHTcjxRRjMEjDnPmesENPzjHTwhOIOWxIWOIWdSrykJuQggG_NCAI-WalkSoftly.pdf

[SpMCHTcjxRRjMEjDnPmesENPzjHTwhOIOWxIWOIWdSrykJuQggG_NCAI-WalkSoftly.pdf](http://www.ncai.org/attachments/PolicyPaper_SpMCHTcjxRRjMEjDnPmesENPzjHTwhOIOWxIWOIWdSrykJuQggG_NCAI-WalkSoftly.pdf)

CULTURAL CONSIDERATIONS



I wish there could be a little bit more understanding of the complications, that a person is being asked to be involved in even doing surveillance—because of the conflict about knowing that much information about one’s own community. Sort of knowing who the players are, and a closer knit community where you are related to people, that’s a hard role to do. And so what kind of preparation and professional development comes along with that, and not just how do we get people to do it but also buffer their sense of dual role—family protection vs. community protection vs. surveillance. I think there is an ethical challenge there in what you are asking people to do.”

—KEY INFORMANT



Because every tribe is different, a one-size-fits-all approach to interventions such as uniform policies and procedures meant to serve all Native communities will not work. Further, not all AI/AN communities experience high rates of suicidal behaviors. Those that have reduced rates or have maintained low rates of suicide may have indigenous knowledge and best practices that can help Native communities struggling with high rates. Research literature on best practices can inform, but not replace, indigenous knowledge shared across Native communities (Chandler & Lalonde, 2008).

“How a community measures success is important. There are different kinds of proof.”

—KEY INFORMANT

KNOWLEDGE TRANSFER

CHALLENGE: The research literature largely focuses on Western ways of knowing and top-down transfer of knowledge from researchers to communities. To be most effective, evaluation should acknowledge local and indigenous knowledge systems and incorporate this knowledge into prevention programming and measures of success.

STRATEGIES:

- » Incorporate other ways of knowing in addition to surveillance, including observing behavioral responses such as increased expression of loss and grieving in the community, community activism, talking with elders, increased participation in prevention activities, and increased willingness from community members to talk about issues previously not discussed.
- » Use community-based participatory research (CBPR) approaches (Minkler & Wallerstein, 2003) to foster co-learning and co-ownership of the program and evaluation activities. One grantee used CBPR by involving tribal leadership, youth, and all community members in their program development and implementation activities. They also trained youth from the community to do data collection and dissemination, which helped with community buy-in and ownership.
- » Present at major conferences on alternative, community-driven measures of success to create education and awareness opportunities for professionals and community members.

“Funders want to see an outcome change for a rare event in three to five years. It’s impossible to show effect. Everybody wants suicide numbers to decline. But it may not be possible within the project’s scope. You need intermediate outcomes that are more in line with the project’s scope and timeline.”

—KEY INFORMANT

ADAPTATIONS

CHALLENGE: Some grantees noted that standard questionnaires and existing instruments were not relevant to their community, with deficit-based questions that did not necessarily capture impact in a way that was sensitive to the traditions of that community. A key informant noted that tribes' ability to adapt tools may be limited by the Institutional Review Board (IRB) or other bodies where the approval process can take a long time.

STRATEGIES:

- » Before piloting, a tribal review committee recommended vetting survey scales with local experts.
- » Pilot survey scales with youth or other target audiences to ensure the questions don't set off any negative feelings or reactions, and that the questions are understood. One key informant noted: “Generally the reaction from students is that they were happy they were asked those questions, and they have never been asked those questions before. It's reassuring then when you are going to give it in a survey.”
- » One grantee described how they used another tribe's screening measures. The grantee made them relevant to their community by changing the vignettes but keeping the survey questions as they were.
- » Several tribal Garrett Lee Smith grantees are currently working with their colleagues at White Mountain Apache and Johns Hopkins University to learn how they set up the White Mountain Apache Tribe surveillance system. The tribal Garrett Lee Smith grantees plan to adapt the tools their colleagues used to fit with their own communities.

TABOOS

CHALLENGE: Both grantees and key informants noted stigma and cultural taboos related to talking about and/or measuring death and suicide. For example, some tribes do not talk about a person once they are deceased. Another tribe does not believe in counting deaths or how many children they have lost.

*“[There are] beliefs that talking about suicide will lead to suicide.” “There is reluctance to share shameful, embarrassing information with outsiders.”
“Suicide is a very taboo topic. We have to be strategic on how to discuss and bring it up with families.”*

—TRIBAL GARRETT LEE SMITH SURVEY RESPONDENTS

STRATEGIES:

- » Only collect as much data and information as you need.
- » Engage and consult with elders to help make the case for suicide surveillance that is culturally appropriate.
- » Use the platform of cultural preservation to create an opening for discussion. One tribal Garrett Lee Smith grantee used the following language to frame the need for data: “Suicide surveillance requires communication and is a form of preservation of our culture and people.”
- » One grantee community uses their local Native language to talk about how to notice when a person is not well and to use a strengths-based approach of talking about reasons for living.
- » Engage Native youth and local community members to help guide the evaluation so that any unintended issues can be addressed before moving forward in the community.
- » Get proper approvals from tribal leadership to ensure community buy-in and enhance sustainability.
- » Some Native communities have passed executive orders requiring all programs to collaborate on suicide prevention efforts.

CASE STUDY:

One key informant said, “One of the things we learned early on is that working on suicide prevention was going to be difficult because it’s considered taboo within our community. So one of the things we decided would be really important for us to do is work with our elders because we needed their support and guidance to work on something like this. We were being told ‘you can’t do this, you can’t do this’ and so we needed someone to say ‘we know we’re not supposed to talk about this or have conversations about this, but somebody needs to do something about this and yes we’ll support you.’ And so that’s where our elders’ council came in.”

RESOURCES

American Indian and Alaska Native Culture Card: A Guide to Build Cultural Awareness—Can be ordered free of charge online

Substance Abuse and Mental Health Services Administration, 2009

Available at <https://store.samhsa.gov/product/american-indian-alaska-native-culture-card/sma08-4354>

Community-Based Participatory Research for Health: Advancing Social and Health Equity—Provides guidance for development and implementation

Nina Wallerstein, Bonnie Duran, John Oetzel, & Meredith Minkler, (3rd edition), 2017

Available at <https://www.amazon.com/Community-Based-Participatory-Research-Health-Advancing/dp/1119258855>

The Cultural Connectedness Scale and its Relation to Positive Mental Health among First Nations Youth—

Provides a validated tool for measuring cultural connectedness

Angela Snowshoe, 2015

Available at <https://ir.lib.uwo.ca/etd/3107/>

The Elders' Report into Preventing Indigenous Self-harm and Youth Suicide—Provides strategies from elders and community leaders throughout Australia

Australian Government: Australian Institute of Family Studies, [n.d.]

Available at <http://apo.org.au/system/files/40060/apo-nid40060-46356.pdf>

The National Tribal Behavioral Health Agenda—Collaboratively developed document that addresses cultural considerations and the importance of surveillance

Substance Abuse and Mental Health Services Administration, Indian Health Services, and Indian Health Board, 2016

Available at <https://store.samhsa.gov/product/national-tribal-behavioral-health-agenda/pep16-ntbh-agenda>

SPARK Talk: Prevention Paradigm for Native Americans—Addresses community involvement in suicide prevention

Suicide Prevention Resource Center, 2015

Available at <http://www.sprc.org/video/native-americans>

To Live to See the Great Day That Dawns: Preventing Suicide by American Indian and Alaska Native Youth and Young Adults—Addresses culture, prevention, and breaking the silence around suicide

Substance Abuse and Mental Health Services Administration, 2010

Available at <https://store.samhsa.gov/product/live-see-great-day-dawns-preventing-suicide-american-indian-alaska-native-youth-young-adults>

RISK AND PROTECTIVE FACTORS



Data on ideation and attempts are only a small part of the picture. They don't tell everything that's going on. What does the community look like? What are the differences between communities with high vs. low suicide rates? Is it history, socioeconomic status, luck?"

—KEY INFORMANT



Researchers focused on AI/AN suicide prevention recommend looking at community-level determinants of health and an array of risk and protective factors that can have cumulative effects (Borowsky, Resnick, Ireland, & Blum, 1999; Bossarte, 2015; Freedenthal & Stiffman, 2004; May et al., 2005; Mackin, Perkins, & Furrer, 2012; Wexler et al., 2015). Building or enhancing protective factors can be as important in reducing suicidal behaviors as reducing the number of risk factors. Analyzing data on AI/AN adolescents from a statewide youth health survey, Mackin et al. found that for every additional risk factor, a young person is 1.4 times more likely to attempt suicide, and each additional protective factor decreases the likelihood of a suicide attempt by 50% (Borowsky et al., 1999; Freedenthal & Stiffman 2004; Mackin et al., 2012).

PROTECTIVE FACTORS

CHALLENGE: Several key informants pointed to a lack of existing data on protective factors. Also, sometimes the line between risk and protection was gray. One key informant noted: *“Connection and bonding to family is a protective factor, but often family is the problem.”* While connectedness can be a strong protective factor, some research has shown that peer connectedness can sometimes be a risk factor (Kaminski et al., 2010).

STRATEGIES:

- » Fifty-nine percent of current tribal Garrett Lee Smith grantees collect their own data on cultural protective factors, and another 12% use a combination of primary data collection and existing data.
- » Two grantees collect data on cultural protective factors through their community readiness assessments (surveys and interviews). One site collects these data as part of their intake process, and another tracks youth participation in tribal best practice activities.
- » For a comprehensive approach to suicide prevention, consider implementing programs and curricula that enhance protective factors, such as healthy family relationships and positive parenting.

RISK FACTORS

CHALLENGE: AI/AN communities are often leery of sharing data on risk factors that may reflect negatively on the community. Because many community problems are interrelated, efforts to address one problem at a time can make it difficult to collectively “move the needle” on any single outcome.

STRATEGIES:

- » Key informants mentioned that trauma and adverse childhood experiences are important indicators that should be tracked to assess the impact of these in relation to suicide.
- » Look at significant life stressors in the six months prior to a suicide attempt or death. Some stressors faced by youth today may differ from stressors faced by youth historically.
- » One key informant found that many American Indian youth who died by suicide were also involved with law enforcement in the weeks before their death. They established emergency residential care in order to observe those involved in the criminal justice system over a 48-hour period.
- » Youth in one community stated that collecting data only on risk factors made them feel bad, so they added strengths-based wrap-up questions to their Garrett Lee Smith screening instruments to promote positive feelings following questions related to depression and suicide.

RESOURCES

American Indian/Alaska Native Settings: Data Sources—Web page with sources of data on American Indian and Alaska Native demographics, socioeconomic status, geography, disability status, and risk status
Suicide Prevention Resource Center, [n.d.]
Available at <http://www.sprc.org/aian/data-sources>

From the Field: NARA NORTHWEST: Risk and Protective Factors among AI/AN Youth in Oregon—Identifies strategies for enhancing youth protective factors
Juliette Mackin, Tamara Perkins, & Carrie Furrer, 2016
Available at <http://www.sprc.org/news/nara-northwest-risk-and-protective-factors-among-aian-youth-oregon>

Suicide among Racial/Ethnic Populations in the U.S.: American Indians/Alaska Natives—Presents information on suicide deaths, attempts, ideation, and risk and protective factors among American Indians/Alaska Natives
Suicide Prevention Resource Center, 2013
Available at <http://www.sprc.org/resources-programs/suicide-among-raciaethnic-populations-us-american-indiansalaska-natives>

Understanding Risk and Protective Factors: A Primer for Preventing Suicide—Provides a list of major risk and protective factors for suicide
Suicide Prevention Resource Center, 2011
Available at <http://www.sprc.org/resources-programs/understanding-risk-and-protective-factors-suicide-primer-preventing-suicide>

INS AND OUTS OF DATA SHARING



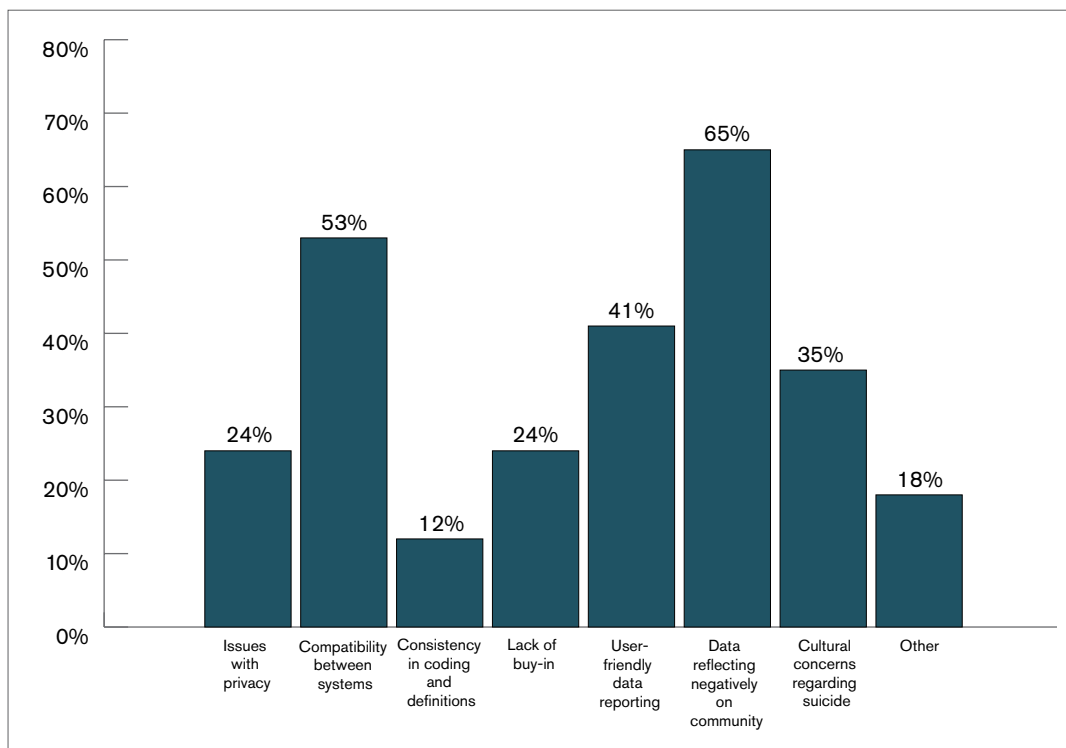
Anything elaborate, anything complicated is not going to work. The big wins we've had is I go out and meet people and shake their hand and we get the data. That's what it takes."

—KEY INFORMANT

TRUST

CHALLENGE: Many Native communities have significant concerns about what data are collected, how data are collected, how data are shared, and who owns the data. Historically, external researchers have collected data from Native communities for their own purposes, and have held and owned that data without benefiting the AI/AN communities who participated (NCAI, 2012). Among current tribal Garrett Lee Smith grantees surveyed, 65% ($n = 11$) were concerned about data reflecting negatively on their communities (see Figure 1).

Figure 1. Tribal Garrett Lee Smith Grantee Challenges Related to Data Sharing, 2016



STRATEGIES:

- » Consult closely with tribal leadership and follow their decisions about how data will be shared, and with whom.
- » Develop data-sharing agreements, MOUs, resolutions, letters of support, and reporting protocols and policies that are clearly written and understood by all partners so that data can be shared easily, and confidentiality concerns are addressed ahead of time.
- » Provide site-specific data to communities when the sample size is large enough. If numbers are too small, provide communities with regional data to protect confidentiality.
- » Share data with community advisory boards. The boards can in turn use the information to advocate for community needs.
- » Ensure that data sharing is mutually beneficial. Be willing to help answer the questions that your partners have as well as your own questions. One key informant noted that an MOU with the schools allowed them access to attendance and Youth Risk Behavior Survey data, and also helped them contact at-risk youth and their families.

RESOURCES

Surveillance Success Story: The Fort Peck Indian Reservation—Describes efforts to identify patterns of suicidal behavior on the Fort Peck Indian Reservation
Suicide Prevention Resource Center, 2016

Available at <http://www.sprc.org/resources-programs/surveillance-success-stories-fort-peck-indian-reservation>

CASE STUDY:

The Fort Peck Indian Reservation, home to the Assiniboine and Sioux Tribes, has collaborated with the University of Montana in establishing the foundations of a suicide surveillance system since 2011. The Tribal Council authorized the collection of data from local schools and behavioral health and health care providers, which helped to build trusting relationships. With their Garrett Lee Smith funding, the University of Montana's National Native Children's Trauma Center and the Fort Peck Sioux Tribes were able to develop and maintain partnerships with the local hospital providers, emergency departments, law enforcement, tribal programs, and schools to collect data on behaviors related to suicide. The data was used to identify risk factors relevant to their local population. The Garrett Lee Smith program provides training and support to increase knowledge about suicide prevention among community service providers and tribal community members.

CONFIDENTIALITY

CHALLENGE: Many grantees and key informants described barriers to sharing and accessing confidential data due to HIPAA regulations. Others spoke about concerns regarding limiting the amount of information collected on individuals and families in small communities where everyone knows each other. Of the 17 tribal Garrett Lee Smith grantees surveyed, 4 (24%) reported privacy issues as a challenge to data sharing (see Figure 1).

STRATEGIES:

- » Conduct assessments in places where there is privacy and individuals feel comfortable so that they can be open about what is going on in their lives.
- » Consider engaging trusted community health aides or other community members to help collect sensitive data. While this is a strategy used by some communities, others acknowledged that this can be difficult in small communities where everyone knows each other.
- » Be sure that when collecting sensitive information, a family's comfort level always takes precedence.
- » Build good relationships with coroners and medical examiners in order to find appropriate ways to collaborate while ensuring confidentiality.
- » One community only publicly reports the number of suicidal behaviors and doesn't provide any other information that might be used to identify the individuals or families. A key informant noted: *"So this is something that we looked at in trying to give the individual or survivor or family of the victim some type of confidence that we're not going to publish that information, pinpointing what is going on or happening in their life. We don't want to cause any more trauma."*
- » Explain to stakeholders that surveillance is a public health tool for tracking health trends and not a tool for monitoring individuals' behaviors.

CASE STUDY:

One key informant developed limited data use agreements to obtain detailed but de-identified patient information. The information received is detailed enough to cross-reference with de-identified 911 dispatch system information coming from schools, hospitals, and emergency departments in order to eliminate duplicate cases. When discussing cases with partners, case numbers or pseudonyms can be used. Stating in the agreements that information identifying individuals should not be included eased the process of data sharing. It also helped to agree not to share the identity of the community in which the individuals reside unless the tribal nation agrees that the information can be made public.

PROCESSES

CHALLENGE: Among current tribal Garrett Lee Smith grantees surveyed, 53% ($n = 9$) identified lack of compatibility between systems as a data sharing challenge. One factor involved is the lack of consistent coding and definitions. The ways in which data are collected, coded, defined, and operationalized vary from system to system (e.g., behavioral health, primary care, juvenile justice), making it challenging to share data across divisions or from one electronic health records system to another.

STRATEGIES:

- » Create standardized screening tools to be used across all programs and health systems.
- » Cross-walking data gathered from one system and comparing it to others has helped to reduce duplication across systems.
- » One grantee in Alaska gets daily state trooper reports that highlight any suicides, individuals with ideation, or mental health crisis-related transports made to local hospitals or behavioral health centers.

RESOURCES

Accessing Data about Suicidal Behavior among American Indians and Alaska Natives—Provides information about data sources and includes links

Suicide Prevention Resource Center, 2012

Available at <http://www.sprc.org/resources-programs/accessing-data-about-suicidal-behavior-among-american-indians-and-alaska-natives>

CSTE Tribal Epidemiology Toolkit—Includes tools and resources related to data sharing

Council of State and Territorial Epidemiologists, [n.d.]

Available at <https://www.cste.org/page/TribalToolkitLanding>

Principles and Models for Data Sharing Agreements with American Indian/Alaska Native Communities—

Includes an example of a data-sharing agreement

Victoria Warren-Mears, [n.d.]

Available at <http://genetics.ncai.org/files/Principles%20and%20Models%20for%20Data%20Sharing%20Agreements.pdf>

Recommended CSTE Indicators for Suicide among American Indian and Alaska Natives—Identifies and describes indicators of suicidal behavior and associated mental health and substance abuse risk factors that can be used for routine surveillance

Jennifer Major, Petra Vallila-Buchman, & Mary Byrne, 2018

Available at https://www.cste.org/resource/resmgr/publications/Tribal_Suicide_Indicators-Fi.pdf

DEALING WITH DATA QUALITY ISSUES



It's hard to say a lot with very small numbers, but people feel misrepresented when there's a state-level, aggregated report on American Indians in [State]."

—KEY INFORMANT



The research literature describes numerous challenges faced by tribal communities engaged in surveillance, research, and evaluation. Challenges include small sample sizes, low base rates, needing to combine multiple years of data to achieve reliable rates, challenges in determining populations to use for calculating rates, and issues of racial misclassification (Allen, Mohatt, Ching, Henry, & People Awakening Team, 2009; Centers for Disease Control and Prevention, 1998; Mullany et al., 2009).

CODING

CHALLENGE: Existing surveillance systems that track suicide attempts and ideation may be limited by patient willingness to report, patient understanding of terminology, providers not systematically asking about intent or not knowing how to respond to suicidal intent, coder ability, and system capacity. Key informants noted that some deaths are not coded as suicides by law enforcement, medical examiners, or coroners in order to protect the families. Coding, even in the same system, can vary greatly from person to person, depending on their training and experience, and different systems may have different levels of training and guidance for coding suicidal behaviors.

STRATEGIES:

- » If possible, check other sources of data, such as emergency department and hospitalization records, that might reveal previous suicide attempts and/or multiple injuries reported as accidental injury by the family.
- » Look at public safety data on single-occupancy vehicle accidents. These are not often counted as suicides although further investigation may reveal them to be.
- » Suicide death rates are subject to under-reporting, and ideation may be over-reported. Attempt rates may be a more reliable measure as they often produce physical evidence or involve witnesses.
- » Ensure standardized and consistent training for coders. Develop codebooks that can serve as guidance documents.

MISCLASSIFICATION AND DUPLICATION

CHALLENGE: Many informants spoke of data sources (such as hospital discharge data) that often don't include race/ethnicity or sources in which a person's race/ethnicity is determined by the person recording the data, rather than the decedent's family or the client themselves. Other times, multiple sources may report the same death.

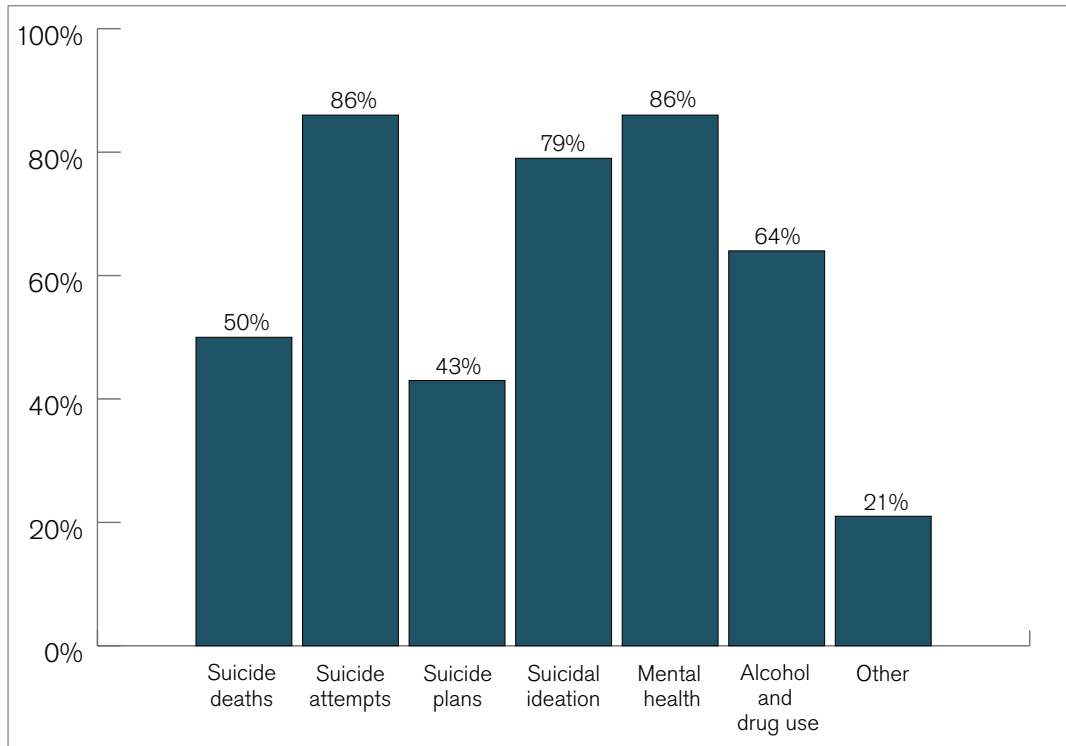
STRATEGIES:

- » Small community sizes and small numbers of events make it easy to identify duplicate records:
 - Use tribal ID numbers to match and track cases.
 - Work with law enforcement and first responder staff to cross-check existing data with electronic health record data.
 - One grantee simply looks at the dates listed on death records. As this respondent states, “[There’s] no magic procedure.” If dates from multiple sources line up, they’re able to identify duplicates.
- » Use geographic information from existing data sources to assess tribal-level suicidal behavior:
 - Use zip codes and self-reported race/ethnicity data from public health registries and vital statistics to estimate rates by tribal boundaries.
 - Use a similar process to mine hospitalization data for suicide-related emergency department visits.
- » Crisis response teams can match the data they collect with information that law enforcement has on crisis calls received.
- » Work collaboratively with other tribal departments, the Indian Health Service, the tribal police department, and the Bureau of Indian Affairs to confirm cause and intent when there is a death in the community.

DATA ON SUICIDE DEATHS VS. ATTEMPTS VS. IDEATION

CHALLENGE: Generally, data on suicide deaths are more readily available through public data collection systems and are collected more often than data on suicide attempts or ideation. Often suicidal ideation may not be reported if the person does not seek medical care or crisis services. To gain a better understanding of the different types of suicidal behaviors, tribal Garrett Lee Smith grantees reported collecting various types of data related to suicide in their communities (see Figure 2). Many tribal Garrett Lee Smith grantees are able to collect suicide-specific data through their programs and services; however, full-scale community-wide surveillance systems are not yet fully developed.

Figure 2. Types of Primary Data Collected by Current Tribal Garrett Lee Smith Grantees, 2016



STRATEGIES:

- » Death review teams can be used to research factors that led up to a young person's suicide.
- » Individuals who have attempted suicide can be interviewed about what happened. Providers may be able to ask about their specific plans and reasons.
- » The Youth Risk Behavior Survey, or other student surveys, can be used to assess self-reported suicidal ideation and history of attempts.

RESOURCES

Best Practices in American Indian & Alaska Native Public Health (2013)—Includes a chapter on data challenges and strategies, including misclassification, small population sizes, and other data quality considerations
Tribal Epidemiology Centers, 2013

Available at <http://www.glitc.org/forms/epi/tec-best-practices-book-2013.pdf>

CSTE Tribal Epidemiology Toolkit—Includes tools and resources related to data linkage
Council of State and Territorial Epidemiologists, [n.d.]

Available at <https://www.cste.org/page/TribalToolkitLanding>

Improving National Data Systems for Surveillance of Suicide-Related Events—Provides recommendations for improving national public health data systems for suicide

Ikeda, R., Hedegaard, H., Bossarte, R., Crosby, A. E., Hanzlick, R., Roesler, J., . . . Warner, M., 2014

Available at [https://www.ajpmonline.org/article/S0749-3797\(14\)00245-1/pdf](https://www.ajpmonline.org/article/S0749-3797(14)00245-1/pdf)

Interpreting Suicide Data: Special Considerations for Small Populations—Provides additional strategies for dealing with small sample sizes

Suicide Prevention Resource Center, [n.d.]

Available at <http://www.sprc.org/resources-programs/interpreting-suicide-data-special-considerations-small-populations>

Practice Manual for Establishing and Maintaining Surveillance Systems for Suicide Attempts and Self-Harm—

Includes tools for countries to use in setting up hospital data collection for attempts and self-harm

World Health Organization, 2016

Available online at: http://www.who.int/mental_health/suicide-prevention/attempts_surveillance_systems/en/

APPROACHES TO DATA COLLECTION



Collecting data, collecting quality data, is important and it's part of the overall surveillance. You want to collect the data, you want to use the data for identifying risks, and then you want to minimize the risks through education, treatment, or whatever. It's all part of the system. It's just getting people in that mindset . . . But to collect that information is valuable.”

—KEY INFORMANT

SURVEILLANCE FORMS

CHALLENGE: Some tribal partners are not aware of existing suicide surveillance forms or processes. Some partners may not have the time, training, or willingness to accurately and adequately complete surveillance forms or submit data.

STRATEGIES:

- » Train law enforcement officers, school staff, health care workers, and other community stakeholders to collect data and make referrals.
- » Support a tribal resolution that mandates the reporting of suicidal behaviors and self-harm to the suicide prevention program by all community members.
- » Create standard, easy-to-use data collection forms that can be used by multiple organizations.
- » Reach out to other tribal Garrett Lee Smith grantees to ask what they are using and whether their templates can be modified for your project.
- » Contact the Tribal Epidemiology Center in your region. They may be able to provide training on setting up databases, provide data collection tools and resources, and share best practices related to data collection and surveillance.

CASE STUDY:

One tribal nation adapted the CDC's Self-Directed Violence Surveillance tool, vetting several iterations with Indian Health Service staff, people working on suicide prevention, law enforcement, criminal investigators, community health representatives, and emergency medicine technicians. One key informant noted: *"When we started going through that surveillance tool it was just too much information so we had to kind of break it down to what is going to benefit us to report."*

The tool is used by community-level crisis response teams to collect data on types of suicidal behavior (i.e., threat, attempt, death), injury method, substances involved, number of past attempts, demographics, who notified the team, location, time, and date. The instrument identifies risk and protective factors, such as suicidal behaviors among family and friends, psychiatric history, or issues that the person may be having in school. If there were prior suicidal behaviors, they collect information on any referral and follow-up that took place. The crisis response team also makes note of anything important they observed at the location—about the victim, family, and environment.

When called to respond to a crisis, team members gather as much information as they can through conversations with family and friends, being careful to not probe more than necessary. Once all data are collected, the team determines whether home visits or welfare checks should be made, as well as the frequency of those visits. They also decide whether a referral should be made for counseling, inpatient treatment, and/or traditional or faith-based practices.

Crisis response team members and other key stakeholders (i.e., law enforcement, hospital and mental health staff) collectively populate an electronic version of the tool after the event, and then report the data to tribal nation prevention staff. Each person contributes information, from the initial dispatch call to information gathered during the crisis response to the review of medical records. Completing the instrument together is helpful because information shared by one person often reminds other members of details that may have initially been overlooked.

MEDICAL RECORDS

CHALLENGE: Not all suicide prevention practitioners have access to electronic health records (EHRs) in order to monitor suicide attempts and ideation. Further, some community partners use different, non-compatible EHRs.

STRATEGIES:

- » Use EHRs. Eight of the 17 current grantees use EHRs to track individuals who are at risk for suicidal behaviors or who have been seen for suicidal behaviors.
- » Establish buy-in with health systems by showing them how EHRs can be used to quickly analyze trends, query indicators, create flags on charts, and support multiple users.
- » The Fort Peck Tribes created a HIPAA compliant, de-identified, protected data-sharing agreement with their National Native Children's Trauma Center, local IHS hospital providers, and county sheriff's office, and then cross-walked data to flag duplicates.

CASE STUDY:

One tribal consortium pulls data from their own EHR to develop suicide risk reports. If any internal medical staff see a patient presenting with suicidal ideation or behaviors, an alert is triggered. A separate behavioral EHR produces reports on anyone seeking/needing psychological emergency services or crisis intervention. The consortium does routine depression, anxiety, and trauma screening. Anyone flagged as warranting further follow-up is included in the risk report. During weekly behavioral health meetings they ask for verbal information about any potential suicide risk in the community. They flag any domestic violence, sexual assault, rape, or sexual abuse. As one key informant noted: *“Not that we’re saying absolutely all of them are at risk for suicide, but we want to be able to follow up on those sooner rather than later to kind of reduce the trauma that could then fester and turn into suicidal behavior.”*

The consortium also has an agreement with an area hospital. Any consortium beneficiary coming into the emergency department is flagged, and consortium staff receive a daily report. They pull data on anyone being admitted to the mental health floor and persons who are directly listed with a diagnosis of suicidal ideation or attempt. They compile and cross-reference all of the data from each of these sources weekly, reconciling any duplications in the suicide risk report. In addition to monitoring risk, they also include a flag if there hasn’t been any follow-up. Quarterly, they review their records using search terms like “suicidal” or “overdose” to see if anything was missed when compiling the regular weekly reports.

SURVEYS, FOCUS GROUPS, AND INTERVIEWS

CHALLENGE: Although surveys can be an excellent source of surveillance data, they can be expensive to conduct. It can be challenging to reach individuals in rural and frontier areas through traditional data collection methods. In urban settings, it can be challenging to reach Native Americans using a randomized approach. Finally, many grantees and key informants shared that their communities are fatigued by excessive data collection efforts across multiple programs and health priorities.

STRATEGIES:

- » Conduct an annual survey at a local conference or event when many people from the community come together at once. If such a survey already exists around another health topic, explore adding questions about suicide rather than creating a separate survey.
- » Train youth to help with data collection and have them share data back with the community.
- » Heavily vet data collection tools and questions through the tribal government or council to ensure appropriateness.
- » Consider using encrypted wireless tablets with software designed to store and analyze data. This allows authorized project staff access to real-time data.
- » Collaborate with local universities and tribal colleges, hiring or otherwise involving trained evaluators and epidemiologists to assist in conducting rigorous local surveillance and program evaluation.

RESOURCES

Challenges and Recommendations for Evaluating Suicide Prevention Programs—Lessons learned about evaluation, data, and surveillance from two Garrett Lee Smith Communities of Learning
Suicide Prevention Resource Center, 2016

Available at <http://www.sprc.org/resources-programs/challenges-and-recommendations-evaluating-suicide-prevention-program>

Finding Help with Evaluation—Provides guidance for recruiting evaluators with the appropriate skills
Suicide Prevention Resource Center, 2014

Available at <http://www.sprc.org/resources-programs/finding-help-evaluation>

Self-Directed Violence Surveillance: Uniform Definitions and Recommended Data Elements—Provides best-practice surveillance definitions, questions, and response options

Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, 2011

Available at <https://www.cdc.gov/violenceprevention/pdf/Self-Directed-Violence-a.pdf>

Surveillance Success Stories: Fort Peck Indian Reservation—Describes how Fort Peck collected data from multiple sources to initiate a response following a suicide cluster

Suicide Prevention Resource Center, 2016

Available at <http://www.sprc.org/resources-programs/surveillance-success-stories-fort-peck-indian-reservation>

DISSEMINATING YOUR DATA



People may not relate to data. Bringing meaning to data is a big challenge.”

—KEY INFORMANT

USER-FRIENDLY FORMATS FOR DIFFERENT AUDIENCES

CHALLENGE: Forty-one percent of current tribal Garrett Lee Smith grantees said they lacked user-friendly means of reporting data.

STRATEGIES:

- » Methods for sharing data reported by current tribal Garrett Lee Smith grantees included group discussions, published articles, posters, reports, presentations, and fact sheets. Specific strategies included:
 - Producing regional suicide fact sheets, pulling data from multiple sources on factors that put individuals at increased risk (e.g., age, gender, lethal means).
 - Convening coalition partner groups to help make meaning of the data in order to gain a community-wide picture of prevalence and trends.
- » Hold a community gathering or health fair to share data. Provide a meal and door prizes to keep it engaging rather than just presenting the data.
- » One key informant described a day-long forum at which staff presented on different health-related projects and their outcomes. Community members were able to share feedback on how the projects related to their personal health status and the health of the community at large via audience response system (clicker) technology.

CASE STUDY:

In one community, youth received one-week training on data collection and interpretation, facilitated by an area university. The youth were then well positioned to talk about data and trends in the community. One key informant noted: *“When youth share data with community members, the community is more likely to listen. Youth and staff share data through presentations and infographics. This has resulted in productive dialogue between administration and school staff.”*

COMMUNITY PERCEPTIONS

CHALLENGE: Sixty-five percent of current tribal Garrett Lee Smith grantees expressed concern about data reflecting negatively on their community.

STRATEGIES:

- » Share data with the community first and ask how they would like the data to be disseminated. Use their feedback to develop a data dissemination plan and process.
- » If working with multiple communities, create one combined report with de-identified data for all communities along with customized reports for each community that are not shared widely. The combined report also serves as a comparison point for each unique community when reviewing their own data.
- » On the topic of disseminating data on risk and protective factors, one key informant shared that protective measures resonate more with community members who are focused on the positive aspects of their community: *“When I’m working with communities, youth survey data are particularly important because you can show how strongly protective factors are associated with [reduced] suicidal behaviors.”*
- » Talk about the relationship of the data to what the community is doing or can do to change the situation. Community members can see what impact prevention activities have on the data and work to see that the data improves next time.
- » Incorporate data on program successes (e.g., how many people have been trained, how many youth are involved, how many have been referred for help or support) to instill hope and model prevention actions.

“Find out what the community wants, what they’re interested in, and how they want it shared.”

—KEY INFORMANT

CASE STUDY:

Staff from one community's suicide prevention program share information through a local radio station. Once a month, the radio station gives the program one hour of airtime, with the prevention staff hosting the show themselves. They describe current surveillance and prevention efforts, prevention successes (including data on decreasing rates of suicidal behaviors), and planned prevention efforts.

RESOURCES

Action Alliance Framework for Successful Messaging—Includes resources on using data to convey a positive narrative and safe ways to communicate information about suicide
National Action Alliance for Suicide Prevention, 2014
Available at www.SuicidePreventionMessaging.org

Alaska Native Epidemiology Center—Compiles regional and statewide Alaska Native health profiles and fact sheets, including fact sheets on suicide
Alaska Native Tribal Health Consortium, [n.d.]
Available at <http://anthctoday.org/epicenter/healthdata.html>

Data Walks: An Innovative Way to Share Data with Communities—Describes an interactive approach for sharing findings with your community
Urban Institute, 2015
Available at <https://www.urban.org/sites/default/files/publication/72906/2000510-Data-Walks-An-Innovative-Way-to-Share-Data-with-Communities.pdf>

Icons for Everything—Offers free icons that can be used in infographics
Noun Project, [n.d.]
Available at <https://thenounproject.com/>

The Online Chart Building Tool—A free online tool for designing charts
ChartBlocks, 2017
Available at <http://www.chartblocks.com/en/>

Piktochart—Free tool for developing infographics, 2018
Available at <https://piktochart.com/>

Suicides in Colorado: An Overview—Provides statistics from the Colorado Violent Death Reporting System, Colorado Center for Health and Environmental Data, 2015
Available at https://cohealthviz.dphe.state.co.us/t/OPPIPublic/views/CoVDRSSuicideData/Story1?embed=y&:showShareOptions=true&:display_count=no&:showVizHome=no

Tableau Public—A free tool that helps turn data files into interactive data visualizations, 2018
Available at <https://public.tableau.com/s/>

CONCLUSION



Information about suicide deaths, attempts, and ideation can be useful in helping prevention programs and communities better understand the challenges and needs of their communities so that limited resources can be targeted to save lives. Over time, these data can also help communities and leaders understand whether prevention efforts are successful or whether changes are needed.

This report represents a snapshot in time of the state of suicide surveillance in AI/AN communities and highlights some challenges related to the establishment of suicide surveillance systems. Both Garrett Lee Smith grantees and key informants present some creative and culturally appropriate strategies for collecting suicide data. When developing suicide surveillance systems in AI/AN communities, it is important to recognize and honor the local customs and values of each community. Although cultural taboos exist in tribal communities, tribal Garrett Lee Smith staff have found innovative ways to address culturally sensitive issues in their communities.

It is important to note that suicide data collection and the evaluation of suicide prevention programs are relatively new in tribal communities. Additional supports are needed for fostering creative ways to measure risk and protective factors in AI/AN populations and to develop community-driven programs that address values, culture, fit, and sustainability. When tribal leaders and community members are included in data collection efforts, there is increased opportunity for cultural sensitivity, community buy-in, and successful collaborations for suicide prevention initiatives. Although there are data collection systems in place in the United States, many tribes are still working on building the infrastructure and capacity for collecting data on suicide while addressing unique cultural considerations.

The findings from this project suggest that when working with American Indian and Alaska Native populations, relationships are key, and there is no one-size-fits-all approach. It is important to keep it simple and to identify what success looks like within each unique community. Even small successes in collecting data on suicide should be celebrated as contributions to this important work.

LIMITATIONS

Results presented in this report are from a small number of tribal grantees and therefore are not generalizable to the greater AI/AN population.

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