



Multistate Assessment of Public Health Surveillance Relevant to American Indians and Alaska Natives, 2007

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Abstract

Improving the health of American Indian and Alaska Native (AI/AN) populations involves multiple agencies, levels of government, and jurisdictions. We assessed collaboration between state health departments and AI/AN Tribes and agencies through an online survey of State Epidemiologists. Frequencies and percentages of responses were examined by univariate and bivariate analyses. Among 39 states with federally recognized or state-recognized Tribes or federally funded urban Indian health centers, 25 (64%) participated. Nineteen had discussed public health surveillance with an AI/AN government or nongovernment entity in the past 2 years (10 (53%) of these had ongoing, regular discussions about public health surveillance; nine (47%) had these discussions as needed). Nine (36%) responding states have a point person for working with AI/AN communities and/or agencies on public health surveillance. Four (16%) states have an active memorandum of understanding or other formal agreement with an AI/AN government or nongovernment entity regarding surveillance. To prepare for public health emergencies, six (24%) states involve the Indian Health Service, and eight (47%) involve another AI/AN entity. Functional relationships between state health departments and AI/AN agencies have not been consistently established. Strengthening these relationships will facilitate surveillance and response capacity to address continuing and emerging public health problems.

Keywords

Epidemiology; Indians; Indians of North America; North American; Public health surveillance

Cover Page Footnote

Disclaimer: The findings and conclusions in this paper are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention and the Indian Health Service.

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ABSTRACT

Improving the health of American Indian and Alaska Native (AI/AN) populations involves multiple agencies, levels of government, and jurisdictions. We assessed collaboration between state health departments and AI/AN Tribes and agencies through an online survey of State Epidemiologists. Frequencies and percentages of responses were examined by univariate and bivariate analyses. Among 39 states with federally recognized or state-recognized Tribes or federally funded urban Indian health centers, 25 (64%) participated. Nineteen had discussed public health surveillance with an AI/AN government or nongovernment entity in the past 2 years (10 (53%) of these had ongoing, regular discussions about public health surveillance; nine (47%) had these discussions as needed). Nine (36%) responding states have a point person for working with AI/AN communities and/or agencies on public health surveillance. Four (16%) states have an active memorandum of understanding or other formal agreement with an AI/AN government or nongovernment entity regarding surveillance. To prepare for public health emergencies, six (24%) states involve the Indian Health Service, and eight (47%) involve another AI/AN entity. Functional relationships between state health departments and AI/AN agencies have not been consistently established. Strengthening these relationships will facilitate surveillance and response capacity to address continuing and emerging public health problems.

Key words: public health surveillance; Indians, North American

INTRODUCTION

The collection, analysis, and dissemination of data to control disease through public health surveillance is an essential public health function (Principles and Practices of Public Health

Surveillance, 2000). Public health surveillance systems provide the data needed to promptly detect health threats, track ongoing threats, and target and monitor programs to improve the public's health. In the United States, state governments have the legal authority to conduct public health surveillance (Broome, Horton, Tress, Lucido & Koo, 2003). State governments work with healthcare providers, laboratories, and other government entities to collect public health data, and they base policy and initiation of actions to protect public health on these data. American Indian and Alaska Native (AI/AN) tribal governments are sovereign entities apart from states, with their own authority to enact laws and implement public health actions within their jurisdictions (Indian Health Care Improvement Act of 1976; Allison, Rivers & Fottler, 2007; Centers for Disease Control and Prevention, 2009). The 562 federally recognized AI/AN Tribes are distributed across 35 states, some with their own health codes and health departments, and most are affiliated with at least one regional Tribal Health Board or Tribal Epidemiology Center (Centers for Disease Control and Prevention, 2009) engaged in public health activities (Bryan, Schaefer, DeBruyn, & Stier, 2009). AI/AN Tribes are positioned to be an important part of the national public health surveillance and response network.

Previous evaluations of surveillance systems have indicated weaknesses in state-based surveillance systems for monitoring the health of AI/AN populations and have shown gaps in other essential public health activities with respect to AI/AN populations (Espey, Wu, Swan, Wiggins, Jim & Ward, et al., 2007; Puuka, Stehr-Green & Becker, 2005; Bertolli, Roussel, Harris, Lentine, Gable, Fichtner, et al., 2008). A 2001 assessment of Indian Health Service (IHS) facilities and a 2004 assessment of tribal and urban Indian health centers regarding surveillance practices for a group of infectious diseases found that the proportion of facilities participating in case reporting to state-based surveillance systems is suboptimal across both facility types and reportable diseases (Bertolli et al., 2008). This report is the first to quantify the extent of state collaboration with AI/AN tribes and organizations on public health surveillance.

Activities conducted in the planning phase of the Turning Point program, an initiative of the Robert Wood Johnson Foundation, an unrelated activity that predated the assessment described in this report and which was undertaken to transform and strengthen the public health system in the United States, demonstrated the unavailability and inadequacy of community-level health information related to AI/AN health status (LaFronza & Brown, 2001). The 2001 and 2004 assessments mentioned previously, as well as focus groups conducted during 2002–2003 involving staff of tribal, urban, and national AI/AN agencies, corroborated this description, documenting that public health surveillance data tend to be unavailable to tribal agencies that would use the information, and that consequently IHS, tribally operated, and urban AI/AN health agencies are not fully integrated into surveillance and other public health response networks.

The Council of State and Territorial Epidemiologists (CSTE) is a national organization that sets public health surveillance standards for the United States. CSTE recognizes the essential role of AI/AN Tribes in the network of government agencies addressing public health in the United States. Through its Tribal Epidemiology Subcommittee, CSTE is engaged in efforts to strengthen collaboration with AI/AN Tribes and health agencies. This subcommittee, which comprises state and tribal epidemiologists, was established after completion of an earlier evaluation of infectious disease surveillance from the perspective of AI/AN Tribes and health agencies. The Tribal Epidemiology Subcommittee wished to further describe the extent of collaboration between state health departments and AI/AN Tribes and health agencies. In 2007, the Subcommittee conducted a survey of state health department–based epidemiologists through the State Survey of Public Health Surveillance Activities and Relationships with American Indian/Alaska Native Communities.

METHODS

State health department–based epidemiologists were identified through the CSTE membership roster. CSTE sent an email to the chief epidemiologist in each state (State Epidemiologist) listed on the roster, requesting that the assessment be completed on behalf of the state public health agency. Topics covered by the assessment included states' public health surveillance processes and established agreements with respect to AI/AN Tribes and organizations. Information was requested about communicable disease outbreaks in AI/AN communities, and sources, collection, sharing, and dissemination of public health surveillance data about AI/AN populations. Questions about the involvement of AI/AN Tribes and agencies in emergency preparedness and response to health threats affecting AI/AN communities also were included.

CSTE's Tribal Epidemiology Subcommittee designed the questionnaire. Survey Monkey software was used to create a version of the questionnaire that could be completed online. A statement in the introduction to the assessment explained that it targeted states with federally recognized or state-recognized AI/AN Tribes or with a federally funded urban Indian health center(s). Although a list of states without any of these entities was provided, State Epidemiologists in these states were not discouraged from completing the assessment.

Potential respondents were contacted in February 2007 about completing the assessment, and reminder letters were sent in March and April 2007. The online data collection period ended May 31, 2007. In July 2007, individual states that had AI/AN populations >50,000 and had not previously responded were given another chance to participate. Data were analyzed using SAS statistical software (version 9.1, SAS Institute, Inc., Cary, North Carolina). Frequencies and percentages of responses were examined through univariate and bivariate analyses.

RESULTS

Among the 39 states with federally recognized or state-recognized Tribes or federally funded urban Indian health centers, 25 (64%) participated in the assessment; 22 states (88%) had federally recognized Tribes, nine (36%) had state-recognized Tribes, and 14 (56%) had urban Indian health centers. Together, the AI/AN populations of the participating states represent 85% of the total AI/AN population according to the 2000 United States Census; all states with AI/AN populations >50,000 persons participated (U.S. Census Bureau, 2002). Four (16%) responding states were located in the West; two (8%), in the Southwest; seven (28%), in the Northern Plains; three (12%), in the Southern Plains; and nine (36%) in the East. Six (24%) participating states had AI/AN populations <25,000 persons; four (16%), 25,000–49,999 persons; eight (32%), 50,000–99,999 persons; and seven (28%), >100,000 persons.

Nineteen (76%) responding states had engaged in discussions about public health surveillance with AI/AN tribal governments, tribal health departments, nongovernment AI/AN health organizations, urban Indian health centers, Tribal Epidemiology Centers, or IHS in the past 2 years. Four (16%) states had not engaged in these discussions, and two (8%) did not answer the question. The percentage of states engaging in these discussions did not differ significantly by region or by size of states' AI/AN population.

Of the 19 states engaging in these discussions, 10 (53%) had ongoing, regular discussions about public health surveillance, and nine (47%) had these discussions as needed; none engaged in these discussions only when a problem arose. Equal numbers of states (nine each) held these discussions with AI/AN tribal governments, tribal health departments, and IHS, respectively. Eight states held

surveillance discussions with Tribal Epidemiology Centers. Fewer states held these discussions with nongovernment AI/AN organizations or “other” organizations (three states) and/or urban Indian health centers (one state). (“Other” organizations included Tribal Head Start, Tobacco Coalitions, contract healthcare providers, state-recognized Tribes, and other health clinics.)

There were two questions about states’ use of staff or agreements to facilitate public health surveillance. State Epidemiologists of nine states (36%) reported having a point person for coordinating public health surveillance with AI/AN communities and/or Tribal Epidemiology Centers; 15 (60%) did not; and one (4%) did not answer the question. Four states (16%) had an active (unexpired) memorandum of understanding or other type of formal agreement with an AI/AN government or nongovernment organization to address public health surveillance. The various purposes of these agreements included sharing data, establishing case definitions, summarizing surveillance data, and sharing resources.

Five (20%) responding states identified one or more outbreaks that involved AI/AN reservations, rancherias, pueblos, villages, or other AI/AN communities during the previous 3 years, for a total of 14 outbreaks. For the 10 outbreaks for which information was available, four were first detected by IHS; two, by the state health department; and one each, by a tribal health department, county/municipal health department, urban Indian health center, or other organization. The agency first to respond was most often a tribal health department or urban Indian health center (three outbreaks each), followed by a county/municipal health department and IHS (two outbreaks each). Of the 20 states that had not had any outbreaks affecting AI/AN populations in the past 3 years, six predicted the state health department would be the most likely to respond first to an outbreak in an AI/AN community; three each predicted the county/municipal health department and the tribal health department would respond first; and one predicted IHS would respond first (respondents for seven states did not answer this question).

Reporting of notifiable diseases (Centers for Disease Control and Prevention, 2007) from AI/AN communities occurs through a variety of routes (Table 1). For approximately half of states, reporting occurs through IHS and tribal health departments; for about one quarter, reporting occurs through urban Indian health centers. In six states (24%), notifiable diseases are reported through only one of these sources; in seven states (28%), through two of these sources; and in four states (16%), through all three sources. Four responding states (16%) reported receiving reports of cases of notifiable disease from AI/AN organizations through county health departments, rather than directly to the state.

Table 1. Sources for notifiable disease reporting—Council of State and Territorial Epidemiologists State Survey of Public Health Surveillance Activities and Relationships with American Indian/Alaska Native Communities, 25 States, 2007

Reporting source	No. (%) states responding		
	Reporting	Not reporting	Not applicable
Indian Health Service	12 (48)	4 (16)	9 (36)
Tribal health department	13 (52)	3 (12)	9 (36)
Urban Indian health center	6 (24)	6 (24)	13 (52)

The questionnaire asked respondents to estimate the completeness of notifiable disease reporting by source (Table 2). Among respondents from states to which this question was applicable, 20%–32% indicated that the completeness of notifiable disease reporting to state/municipal health departments from IHS, tribal health departments, and urban Indian health centers is the same as from other reporting sources. Eight percent to 12% of respondents indicated that reporting from these sources was less complete than reporting from other sources.

Table 2. Comparison of completeness of notifiable disease reporting to state/municipal health departments, by source of report—Council of State and Territorial Epidemiologists State Survey of Public Health Surveillance Activities and Relationships with American Indian/Alaska Native Communities, 25 States, 2007

Reporting source	No. (%) states responding			
	Less complete than other sources	Same as other sources	More complete than other sources	Not applicable
Indian Health Service	3 (12)	8 (32)	1 (4)	13 (52)
Tribal health department	2 (8)	8 (32)	0	15 (60)
Urban Indian health center	3 (12)	5 (20)	0	17 (68)

Respondents indicated impediments to complete reporting of notifiable diseases among AI/AN populations by reporting source (Table 3). Staff turnover was mentioned most frequently in regard to reporting by IHS (32% of respondents); concerns about confidentiality (20%) and “reporting arrangements not established” (20%) were the most frequently mentioned barriers to reporting by tribal health departments; and “reporting arrangements not established” (16%) was the most frequently mentioned barrier to reporting by urban Indian health centers.

Respondents were asked to list five major surveillance summary reports issued by their state health department and to indicate whether these reports contained AI/AN-specific data. Sixty-five percent of the surveillance summary reports listed contained AI/AN-specific data; no reports contained Tribe-specific data.

States used various approaches to disseminate public health surveillance reports that included information about AI/AN populations. Some states tried specifically to disseminate data to AI/AN Tribes and health agencies: 44% of the major surveillance reports listed were sent to Tribal Epidemiology Centers; 43% to tribal health departments; 29% to tribal health facilities; 18% to tribal governments; and 12% to urban Indian health organizations. Other states made the data publicly available (e.g., on the Internet) but did not specifically attempt to target reports to AI/AN Tribes and health agencies; others used both approaches.

Table 3. Barriers to complete notifiable disease reporting to state/municipal health departments, by reporting source—Council of State and Territorial Epidemiologists State Survey of Public Health Surveillance Activities and Relationships with American Indian/Alaska Native Communities, 25 States, 2007

Reporting source	No. (%) states responding*				
	Patients do not accept testing/screening	Concerns about confidentiality	Staff turnover	Reporting arrangement not established	Other
Indian Health Service	2 (8)	4 (16)	8 (32)	4 (16)	3 [†] (12)
Tribal health department	3 (12)	5 (20)	3 (12)	5 (20)	6 [‡] (24)
Urban Indian health center	2 (8)	3 (12)	3 (12)	4 (16)	3 [§] (12)

*Responses to these questions were available for 24 states; percentages do not add to 100% because respondents were instructed to “check all that apply.”

[†]No legal requirement, staff time, and low priority; passive and voluntary from tribal health clinic service; small population.

[‡]Lack of dedicated staff, no legal requirement because of tribal sovereignty; data ownership concerns; lack of organized tribal health department.

[§]Not able to provide urban designation in our data; urban Indian health centers do not exist in the state.

The survey asked two questions about preparing for public health emergencies. Six of the 25 respondents said their states involved IHS in developing, testing, and/or implementing special disease/outbreak surveillance systems. Seventeen states gave responses to questions about involving other AI/AN agencies in these activities; of these, eight reported the state involved tribal health departments, Tribal Epidemiology Centers, tribal governments, or urban Indian health centers. Of the 25 respondents, five and seven, respectively, answered affirmatively to questions about the participation of IHS and other AI/AN agencies (i.e., tribal health departments, Tribal Epidemiology Centers, tribal governments, or urban Indian health centers) in special surveillance systems. These respondents indicated that IHS or other AI/AN agencies participated in at least one of the following special surveillance systems: symptom/syndrome surveillance, emergency services utilization, monitoring pharmaceutical sales, monitoring student or employee absenteeism, enhanced laboratory surveillance, or some other special surveillance system.

Two respondents each indicated that IHS participates in symptom/syndrome surveillance and emergency service utilization in their states, and one indicated that IHS participates in enhanced laboratory surveillance. No respondents indicated that IHS participates in monitoring the dispensation of pharmaceuticals or absenteeism monitoring of students or employees. Five respondents indicated that other AI/AN agencies or organizations participate in emergency service utilization; three indicated participation of these agencies in symptom/syndrome surveillance; two indicated participation in enhanced laboratory surveillance; and one each indicated participation in monitoring pharmaceutical sales and monitoring absenteeism of students or employees.

DISCUSSION

Our survey of State Epidemiologists completes an effort to describe public health surveillance of AI/AN populations from the perspectives of multiple stakeholders. The 2001 assessment involved IHS staff; focus groups and key informant interviews in 2002–2003 involved a cross-section of individuals across a wide geographic area, including tribal and urban Indian health center representatives, technical experts, leaders, and administrators; and the 2004 assessment involved staff in tribally operated health facilities (Bertolli et al., 2008). The findings of all these assessments indicate that health agencies serving the AI/AN population are not well integrated into established public health surveillance and response networks. Consequently, surveillance data for the AI/AN population are of inconsistent quality and availability, and response networks may be insufficiently prepared. Our results point to incompleteness of notifiable disease reporting; challenges related to inconsistency of reporting across multiple information sources used to identify cases of notifiable disease; variability in the existence and nature of communication about surveillance between state or municipal health departments and health agencies serving the AI/AN population; and limited participation of the latter agencies in special surveillance systems.

These problems with surveillance and response must be addressed to support the development of strategies to prevent and control disease in AI/AN communities and to reduce AI/AN health disparities.¹³ The need for improved surveillance data has been previously identified and expressed by AI/AN health professionals (Bertolli et al., 2008; Roubideaux & Dixon, 2001), the National Congress of American Indians (National Congress of American Indians, 1999), the American Public Health Association (American Public Health Association (1983), CSTE (Council of State and Territorial Epidemiologists, 1996), the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 2010), as well as the Indian Health Service through its support of Tribal Epidemiology Centers and surveillance demonstration projects (Indian Health Service, 2011; Bernard & Robertson, 1999). However, an organized national effort to strengthen public health surveillance for AI/AN populations has yet to develop.

A number of difficult challenges lie on the path toward such an initiative. Foremost is the post-colonial legacy of mistrust which continues to engender suspicion on the part of AI/AN people and governments about the uses of surveillance data (Bertolli et al., 2008; Marsden, 1998). Concerns about data ownership, privacy and data security are important issues to discuss and resolve, as they can supplant the political will to improve public health surveillance. The Turning Point Project, completed in 2006, resulted in the development of some important tools to guide such discussions, including a set of policy principles for advancing collaboration among and between tribal communities and surrounding jurisdictions (Turning Point Program, 2001). In addition, accumulated experience with community participatory research in AI/AN communities may provide some guidance (Matloub, Creswell, Stickland, & Pierce, 2009), and existing U.S. models of inter-governmental agreements related to data sharing and public health response activities may also help to point the way forward (Bryan et al., 2009; Wall & Lustig, 2001).

A key operational challenge to improving surveillance is the availability and quality of data identifying AI/AN people, a challenge which in part results from ambiguity about who should be counted as AI/AN (Burhansstipanov & Satter, 2000), and difficulties with carrying out the counting, stemming in part from the context of mistrust. Tribal leaders have expressed concerns about the confidentiality of tribal membership rolls and possible adverse consequences from publication of tribe-specific health data. The Northwest Portland Area Indian Health Board has demonstrated a successful process for addressing such concerns (Sugarman, Holliday, Ross, & Wilder, 1997). If adopted as a national standard, such a process might have potential to resolve an important barrier to the use of surveillance data to describe AI/AN population health, namely that tribal affiliation is

not routinely collected by public health surveillance systems

But until these issues are resolved, inaccuracies in both numbers of cases of reportable diseases and the total population size used to estimate rates of disease compromise the validity of surveillance results (Roubideaux & Dixon, 2001; Sugarman et al., 1997; Ericson, 1996; Bertolli, Lee, & Sullivan, 2007). In the meantime, epidemiologists are implementing a variety of alternative solutions, including analyses by county to include data on cases from federally recognized tribal lands or adjacent to tribal lands (Espey, Wiggins, Jim, Miller, Johnson, & Becker, 2008), linking case surveillance with the IHS national patient information and reporting system (Becker, Espey, Lawson, Saraiya, Jim, & Waxman, 2008), and linking case data with tribal membership registries on a geographically limited basis (Puuka et al., 2005). Although these approaches can provide useful data, they are not a substitute for a consistent national approach that produces accurate data on an ongoing basis.

Improvements in public health surveillance of the health of AI/AN people are not possible without the involvement of AI/AN tribes. For AI/AN tribes to lead the development of public health surveillance, there must be clear benefits to AI/AN people (Bertolli et al., 2008). Yet the population sizes of many AI/AN communities may be too small to produce stable estimates by state, let alone estimates for individual tribes. The value of public health data for broader aggregations of AI/AN people should be explored. A good recent example is the description of regional differences in cervical cancer incidence among AI/AN women (Becker et al., 2008). Although data from this analysis of surveillance data are not presented by tribe, but rather by IHS region, the results help to guide public health action, including at the tribal level.

Population mobility and isolation of relevant health data within state or tribal jurisdictional boundaries may hamper effective use of public health surveillance information in AI/AN settings. Outbreak detection and response involving AI/AN populations would be stronger and more efficient if they were supported by more systematic approaches and infrastructure that include formalized cross-jurisdictional partnerships (e.g., mutual aid agreements, data sharing agreements), official points of contact, standard operating procedures, and clear legal codification of public health authorities (Bryan et al., 2009; Bertolli et al., 2008). Again, some models exist which might be used as a blueprint from which to build (Bryan et al., 2008).

Our findings indicate that most recent outbreaks involving AI/AN populations were first detected by IHS staff and that outbreak responses were most often initiated by a tribal health department or an urban Indian health center. Historically, IHS has had fewer resources and less capacity to respond to outbreaks than a state or local health department (Marsden, 1998). However, some recent efforts have been made to strengthen epidemiologic response capacity with respect to AI/AN populations, including the creation of a State–Tribal Liaison position within some state health departments. In addition, IHS partnerships with CDC, reorganization within IHS to create the IHS Division of Epidemiology and Disease Prevention, establishment of Tribal Epidemiology Centers, and efforts by CSTE to increase and improve collaboration between Tribal Epidemiology Centers and state health departments have occurred. The TECs have an important role to play in strengthening AI/AN tribes' technical capacity to participate in the development, implementation, and use of surveillance systems for the benefit of AI/AN people, a role which was recently emphasized in the reauthorization of the *Indian Health Care Improvement Act* (included in the Patient Protection and Affordable Care Act of 2010).

The data from our survey of state epidemiologists may not be generalizable to all states with federally recognized or state-recognized AI/AN tribes or federally funded urban Indian health centers. However, the findings align with previous work indicating that Tribal, Federal, and state stakeholders believe that surveillance of AI/AN population health is both critical and currently suboptimal (Bertolli et al., 2008; Marsden, 1998; Roubideaux & Dixon, 2001). An organized national effort to strengthen

AI/AN public health surveillance is needed. Tribal public health infrastructure and epidemiologic capacity have advanced, and principles and methods for working collaboratively with tribes and for using data effectively have been established. Leadership is needed to capitalize on these developments to improve surveillance of AI/AN health and public health response. Lessons learned from similar efforts in Canada, particularly those to improve cancer surveillance among First Nations people, may be useful in this endeavor (Cancer Care Ontario, 2004).

CONCLUSION

Functional cross-jurisdictional relationships regarding public health surveillance and response involving AI/AN communities are limited. Although AI/AN governments; tribal organizations, such as Tribal Epidemiology Centers; and IHS are positioned to be an important component of the national public health surveillance and response network, they are not yet well integrated into this network. Strengthening these relationships will facilitate surveillance and response capacity to address continuing and emerging public health problems.

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