



Surveillance of Infectious Diseases Among American Indians and Alaska Natives

Journal of Health Disparities Research and Practice

Volume 2 | Issue 2

Article 7

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2008

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Recommended Citation

Bertolli, Jeanne; Roussel, Amy; Harris, Jennie; Lentine, Dan; Gable, Julia; Fichtner, Ron; Kauffman, JoAnn; Landen, Michael; and Bryan, Ralph T. (2008) "Surveillance of Infectious Diseases Among American Indians and Alaska Natives," *Journal of Health Disparities Research and Practice*: Vol. 2: Iss. 2, Article 7. Available at: <https://digitalscholarship.unlv.edu/jhdrp/vol2/iss2/7>

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Abstract

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Keywords

Communicable diseases – Reporting; Indians; North American; Indians of North America; Public health surveillance

Cover Page Footnote

The authors acknowledge participants from the National Congress of American Indians, National Indian Health Board, National Council on Urban Indian Health, the Tribal Epidemiology Centers, the California Rural Indian Health Board, the Northwest Portland Indian Health Board, the Aberdeen Area Tribal Chairman's Health Board, the Association of American Indian Physicians, the Indian Health Service, and tribally operated and urban Indian health facilities. 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.

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Abstract

We assessed participation in public health surveillance networks among Indian Health Service, tribal, and urban (I/T/U) Indian health facilities for a group of infectious diseases, and barriers to participation. We conducted surveys of I/T/U facilities and key informant interviews with representatives of tribal, urban, and national American Indian/Alaska Native (AI/AN) agencies. For the surveys, frequencies and percentages of responses in each response category were calculated. Qualitative methods were used to analyze interview content. The proportion of facilities participating in case reporting is suboptimal across facility types and diseases. Even when reporting is occurring, there is little feedback to tribal agencies. Lack of trust between tribal authorities and state/local governments, lack of feedback on surveillance efforts, and gaps in coordination of activities were identified as barriers to participation in surveillance. Our findings indicate weaknesses in surveillance systems for monitoring infectious diseases among AI/AN people, and have implications for addressing health disparities.

Key Words: public health surveillance; communicable disease; Indians, North American

Introduction

Health care providers and facilities are a critical link in the public health surveillance chain: to detect reportable health conditions, surveillance efforts depend on diagnoses and reporting by clinicians and health care facilities. The Indian Health Service was established in 1955 to be the principal federal health care provider for AI/AN people.¹ The original IHS system was highly centralized, which facilitated collection and reporting of public health surveillance data from the AI/AN population. However, profound changes in health care delivery to the AI/AN population in the past 30 years have affected the capacity for and coordination of public health surveillance among AI/AN.

In 1975, the Indian Self-Determination and Education Act (PL-93-638) was passed, giving tribes the option of staffing and managing the Indian Health Service (IHS) programs in their communities under Title I (self-determination contracts) or Title III (self-governance compacts).² The urbanization of the AI/AN population has also changed the provision of health services to AI/AN people. The 2000 U.S. census documented that more than half (62%) of the AI/AN population does not live on or near a reservation.³ In recognition of this fact, programs to improve health care access for AI/AN people living in urban areas were established, through Title V of the Indian Health Care Improvement Act (PL 94-437), passed in 1976.^{4,5}

With the growth in self-determination contracts and self-governance compacts since the 1990s, and the establishment of urban health programs to serve the growing AI/AN urban population, IHS and its partnership with tribal and urban Indian health care facilities now represent a network of relatively independent hospitals, clinics, and health stations, resulting in many more points of contact from which to obtain and aggregate information for surveillance of AI/AN health.^{1,2} Complex jurisdictional and capacity issues raise questions regarding tribal, state and federal authority and responsibility for surveillance of notifiable diseases required by state laws.^{1,2} With the transition from federal to tribal management of health services, whether and how tribally operated facilities are participating in public health surveillance is unclear.^{2,6}

The changes in delivery of health services for AI/AN people have called into question the completeness of infectious disease reporting from some of the health care systems serving this population (IHS, tribal, and urban Indian health facilities),⁷ but there has been no systematic assessment. We describe the results of a three-phased assessment of case reporting for a set of infectious diseases: HIV/AIDS, sexually transmitted diseases (STDs, comprising Chlamydia and gonorrhea), tuberculosis (TB), and Hepatitis A (HAV), B (HBV) and C (HCV). These conditions were selected because they share

modes of transmission, because national surveillance of these conditions is well established,⁸⁻¹⁴ and because of concerns about the impact of these conditions on AI/AN people.

Methods

The objectives of the project were to 1) assess surveillance practices among IHS, tribally operated and urban (I/T/U) Indian health care facilities, and 2) identify barriers to I/T/U participation in surveillance. CDC funded and coordinated the project. The first phase, conducted by RTI International, was an assessment of IHS facilities' participation in public health surveillance of the infectious diseases of interest. The second phase, conducted by RTI International and Kauffman and Associates, Inc. (KAI), involved eliciting opinions from stakeholders in tribal, urban, and national AI/AN agencies about the challenges of public health surveillance and their unmet public health data needs. The third phase, conducted by the Council of State and Territorial Epidemiologists (CSTE) and KAI, included a survey of tribal and urban health facilities to describe their current participation in public health surveillance.

The project was designed to answer the following questions:

- 1) What do stakeholders see as the primary challenges and unmet needs for infectious disease surveillance among AI/AN people?
- 2) What are the practices of IHS, tribal, and urban AI/AN health care facilities regarding infectious disease reporting to state/county health departments?
- 3) Do tribally operated facilities follow reporting practices different from those supported by IHS policy?
- 4) Are there any differences in reporting practices across the diseases of interest?
- 5) Do IHS, tribal, and urban agencies analyze aggregated surveillance data and generate their own reports, or receive surveillance reports from state/county or tribal public health agencies?
- 6) How are the responses to public health problems identified by surveillance data coordinated between federal, state/county, and tribal and urban AI/AN agencies?

Phase 1: IHS Survey

The first phase of the assessment was a survey of case reporting practices in IHS facilities. The purposes of this phase were to assess and document current processes of surveillance data collection and data flow from IHS facilities, and the interactions between IHS and state and tribal health departments, especially with regard to case reporting.

Instrument Development. Two questionnaires were developed, one targeted to Clinical Directors, and the other to key staff. Both questionnaires asked the participants to describe relevant clinical practices (i.e. diagnostic testing) and disease reporting procedures followed in the IHS facility in which they work. CDC and RTI International developed the instruments in collaboration with IHS staff, and the questionnaires were then pilot-tested by IHS clinicians. The questionnaires were revised based on the results of this pilot testing; circulated for review and comment by HIV, STD, TB, and viral hepatitis experts at CDC and IHS; and finalized based on additional suggestions.

Sampling. All IHS service units (networks of local health care facilities that include hospitals, community and school health centers, and health clinics) identified in the IHS telephone directory were chosen for participation. The questionnaire was mailed to Clinical Directors and other senior staff (Nursing Directors, Infection Control Practitioners, Laboratory Directors, and Environmental Health Directors, the latter because they sometimes have a role in surveillance) in the 68 IHS service units.

Data Collection. Questionnaires were mailed to staff at IHS facilities in January 2001, with a request to return the completed questionnaire in a pre-addressed, stamped envelope to RTI International. Following the initial mailing in January, reminder postcards were sent. To boost response rates, the questionnaire was mailed again to nonrespondents in April 2001, and follow-up contacts were made with nonresponding facilities by telephone. Responses were collected through July 2001.

Analysis. For questions about case reporting practices, frequencies and percentages of responses in each response category were analyzed by facility for each health condition (all respondents combined). If at least one respondent indicated that a case reporting practice was being followed, the facility response was considered positive for that question; selected analyses were restricted to Clinical Director respondents only. All analyses were performed using SAS statistical software, version 8.02 (SAS, Cary, North Carolina).

Phase 2. Qualitative Assessment Involving Stakeholders

The second phase of the evaluation was a qualitative assessment of the challenges public health surveillance poses for urban and tribally operated health facilities, and their unmet needs for surveillance data. The purposes of the second phase were to engage stakeholders, assess and document their need for information and expectations of this evaluation, and to elicit information from them to focus the design of Phase 3.

Instrument Development. Investigators met with stakeholders to obtain their perspectives on the project. (We defined stakeholders as persons who have an interest in case reporting of infectious diseases among AI/AN, either because they use available surveillance data or because they are in a position to act on the findings of our assessment.) We created interview guides (lists of open-ended questions designed to be covered in a particular order) for the focus group discussions and key informant interviews, tailored for either respondents from tribal health facilities or from urban Indian health facilities. Stakeholders' needs and expectations guided the content of the interview guides. Topics addressed in the guides included sources, accessibility, quality, and usefulness of infectious disease surveillance data; case reporting practices; public health surveillance collaborations with federal, state, and local governmental agencies and AI/AN organizations, the challenges of public health surveillance; and resources needed to increase participation in public health surveillance.

Sampling. We used convenience sampling to recruit key informants and focus group participants. Nine key informants were identified through professional networks and references from other stakeholders. Four focus groups were conducted, one at each of four existing AI/AN-focused conferences and meetings; each focus group had 9 or fewer participants. Selection of focus group venues and key informants was based on several domains (including type and geographic location of agencies represented, role of agency/individual in addressing health or public health among AI/AN, and level of engagement of the agency/individual in public health surveillance activities) to ensure that we captured viewpoints from a wide variety of respondents using criteria identified by federal stakeholders.

Data Collection. Data collection included in-person focus groups and personal interviews by telephone. The focus groups and telephone interviews ranged from 1 to 1½ hours each, depending on participants' public health surveillance knowledge and engagement. Focus groups and key informant interviews were conducted from November 2002 through October 2003.

Analysis. We formulated an analytical coding structure to reflect the primary research domains and questions. All coding and analyses were done manually. To ensure that the data were accurately coded, two RTI International staff members performed the coding, and intercoder reliability checks were conducted. Our analysis focused on identifying patterns and common themes across respondents through content analysis. The analysis was guided by analytic matrices we created, which allowed mapping of each participant's remarks to our objectives and questions. This approach facilitated synthesis across respondents, and revealed patterns of agreement and disagreement.

Phase 3. Survey of Tribally Operated /Urban Health Facilities

Phase 3 involved a self-administered survey about case reporting in tribally operated and urban Indian health facilities. The purposes of the tribal/urban health facility survey were similar to those of the IHS survey: to assess and document current processes of surveillance data collection and data flow from tribally operated and urban facilities, and the interactions of tribally operated and urban facilities with state health departments, tribal health departments, and Tribal Epidemiology Centers, especially with regard to case reporting.

Instrument Development. The instrument for the tribal/urban health facility survey was based on the instrument from the IHS survey, and included additional questions designed to address issues identified by the focus groups and key informants during the qualitative assessment.

Sampling. A comprehensive list of tribally operated health facilities, including 105 facilities, was developed from information provided by the Office of Tribal Programs, IHS. In addition, from an IHS list of 36 federally funded urban Indian health programs, 15 were identified that offer direct medical care, and these 15 were added to the list of tribally operated facilities, for a total of 120 tribal/urban facilities. All facilities on this list were approached to participate in the survey. Because tribal/urban facilities tended to be smaller than IHS facilities, in contrast to the IHS survey, only the Director of each health facility was asked to complete the questionnaire.

Data Collection. Survey respondents were able to complete the survey online or by hard copy (according to their preference) from April to June 2004. Follow-up email messages and faxes were sent, and phone calls were made to encourage participation. To encourage candor, the survey was anonymous; to complete the questionnaire online, respondents were asked to enter a unique username and password. This password feature helped to ensure confidentiality of responses while preventing more than one response from a facility. Responses to the online questionnaire were automatically entered into a database created using Access software (Microsoft Corporation, Redmond, Washington). As hard copies of questionnaires were returned by mail or fax, they were also entered into the survey database. To lower the risk of data entry errors, the database was constructed to accept only valid responses to questions.

Analysis. Analysis was performed using SAS statistical software, version 8.02 (SAS, Cary, North Carolina), and involved creating frequency distributions for most survey items, because most of the variables were categorical. Means were calculated for questions in which respondents were asked to rank the importance of a list of items, or to give an opinion on a predefined scale (e.g., very useful to not useful at all).

Results

IHS Survey—Response Rate and Respondents' Characteristics

Of the 68 IHS service units, receipt of the questionnaire was confirmed for 60 and 45 (66%) participated in the survey. The IHS facilities that provided information were largely located on rural AI/AN reservations (only 2 (5%) were located in a city with population larger than 50,000). The geographic distribution of respondent and nonrespondent IHS facilities is presented in Table 1. The IHS facilities had a median outpatient usage of 8,213 users per year and a median inpatient usage of 600 persons per year. For 12 facilities, data on whether inpatient services are provided were missing (e.g., the Clinical Director did not respond to the survey or did not respond to the question). However, 17 of the 33 facilities (52%) providing information indicated that they offer inpatient services.

Table 1. Number and Percentage of Respondent and Nonrespondent Facilities, By Geographic Region, Indian Health Service (IHS) Survey, 2001, and Tribal/Urban Survey, 2004

IHS Region	IHS Survey		Tribal/Urban Survey	
	Respondents N(%)	Non-respondents N(%)	Respondents N (%)	Non-respondents N(%)
†Alaska	0	0	4 (57)	3 (43)
*East	4 (67)	2 (33)	20 (63)	12 (38)
§Northern Plains	18 (86)	3 (14)	15 (63)	9 (38)
Pacific Coast	9(64)	5 (36)	19 (41)	27 (59)
**South-west	14 (52)	13 (48)	8 (73)	3 (27)
Total	45 (66)*	23 (34)	66 (55)	54 (45)

*Data on location was missing for 15 respondent facilities. †Alaska Region = Alaska.

*East Region = Kansas, Texas, Oklahoma, Louisiana, Mississippi, Alabama, Tennessee, Florida, South Carolina, North Carolina, Pennsylvania, New York, Maine, Rhode Island, Massachusetts. §Northern Plains = Montana, Wyoming, North Dakota, South Dakota, Nebraska, Minnesota, Iowa, Wisconsin, Michigan, Indiana. ||Pacific Coast = California,

Washington, Oregon, Idaho. **Southwest = Nevada, Arizona, New Mexico, Utah

As mentioned above, for the IHS survey, more than one staff person was asked to respond in each facility. The total number of respondents was 171. Of the 45 IHS facilities for which a response was obtained, the Clinical Director responded for 43 (96%), the Nursing Director responded for 36 (80%), the Laboratory Director responded for 34 (76%), the Infection Control Practitioner responded for 33 (73%), and the Environmental Health Director responded for 25 (56%). The distribution of number of years worked at the facility is shown in Table 2. Approximately 65% of those who responded had worked more than 5 years in the same facility. However, 32% had worked in their current location less than 5 years, and of these, about 40% (12 overall) had worked 2 years or less in the same facility.

Table 2. Number and Percentage of Respondents by Staff Type, Indian Health Service (IHS) Survey, 2001, and Tribal/Urban Survey, 2004

Years Worked	IHS* N (%)	Tribal/Urban N (%)
Less than 2 years	21 (12)	8 (12)
2-4 years	34 (20)	11 (17)
5-9 years	39 (23)	17 (26)
10-14 years	32 (19)	10 (15)
15 years or more	39 (23)	12 (18)
Missing	6 (4)	8 (12)
Total	171 (100)	66 (100)

*For all 171 respondents

Qualitative Assessment—Respondent Characteristics

Focus group participants included technical experts, tribal leaders, and health care administrators and providers. The key informants included a broad cross-section of individuals representing the domains and strata identified by federal stakeholders: five tribal and four urban Indian health representatives; two individuals who were very knowledgeable/engaged with surveillance, four with an intermediate level of surveillance knowledge/engagement, and three who were not very familiar or engaged with surveillance; four technical experts and five leaders or administrators; two persons from northern states, one from the Southeast, three from the Midwest, and three from the Southwest.

Survey of Tribally Operated /Urban Health Facilities—Response Rate and Respondents' Characteristics

Of the 120 tribal/urban facilities, 66 (55%) participated in the survey; 7 (11%) identified themselves as working at an urban Indian health center and 59 (89%) identified themselves as working at a tribal health facility. Due to the relatively small number of urban Indian health facility respondents, results were combined for urban and tribal facilities. Two respondents who submitted statements indicating that the survey was not applicable to their facilities were not included. In addition, two respondents who returned the survey several days after data analysis had been completed were not included.

Fifty-three of the 66 respondent facilities (80%) provide only outpatient services; 13 (20%) provide inpatient services as well as outpatient services. Data on service usage were obtained from 49 of the 66 respondent facilities (74%). The median outpatient usage among the 49 facilities was 4,000 users per year. Among the 13 facilities that indicated they provide inpatient services, the median inpatient usage was 1,500 users per year.

The geographic distribution of respondent facilities is presented in Table 1. The duration of employment in the each facility is presented in Table 2 for the 58 tribal/urban survey respondents who answered this question, and indicates that approximately one-third have worked in the facility for 4 years or less, another third for 5-9 years, and the remaining third for 10 or more years.

Findings

This section summarizes findings across the three-phased assessment, organized according to four main issues identified by stakeholders in Phase 2: reporting relationships, concerns about data quality, getting surveillance information to those who need it, and coordination of public health action in response to surveillance data. Stakeholders' descriptions of each of these issues and findings from the IHS and tribal/urban surveys that relate to each issue are presented below.

Issue 1—Reporting Relationships

According to stakeholders, lack of trust, particularly between tribal authorities and state or local government, influences the extent to which tribal/urban facilities report cases of infectious diseases to state and county agencies (or share data with other tribal agencies). Some stakeholders felt that this absence of trust stems from limited knowledge of AI/AN tribes about surveillance. Instead of seeing surveillance as a benefit, AI/AN tribes may view

it as a way for government, particularly states, to monitor them. Stakeholders reported that because tribes tend to be protective of their communities, they would rather maintain data on cases themselves than report them to a state or county agency. For example, tribes may be more willing to report cases of infectious disease to a Tribal Epidemiology Center.

The surveys of IHS and tribal/urban facilities evaluated the extent to which these facilities participated in public health surveillance through reporting of cases of STD, HIV/AIDS, TB and viral hepatitis. Our results demonstrate that case reporting to state or county agencies varied by type of facility and infection (e.g., HIV/AIDS vs. STDs, viral hepatitis, and TB).

Among the IHS facilities surveyed, all 43 that had diagnosed cases of HIV/AIDS stated that they report cases of HIV/AIDS to the state health department, and two facilities indicated that they had not diagnosed a case of HIV/AIDS, but had a plan in place to report if a case were diagnosed (Table 3). Reporting of the infectious diseases of interest to a state surveillance system occurred less frequently in tribal/urban facilities compared with IHS facilities. Among those facilities that had diagnosed cases of HIV/AIDS, 85% said that case reports were sent directly to a state surveillance system, or to a county/municipal health department that feeds data into a state surveillance system. Twelve of 14 facilities (86%) that had not identified a case of HIV/AIDS said that their facility had an HIV/AIDS reporting plan. For eight facilities (15%), the respondent did not know whether HIV/AIDS was reported to state, county, or municipal agencies.

Most IHS facilities indicated that they reported cases of STDs (98%), active TB (96%), hepatitis A or B (both 93%), and hepatitis C (91%) to their state health department. When asked whether they reported cases of HIV/AIDS to tribal authorities, only 22% of IHS facilities answered affirmatively, and about half indicated that they reported each of the other conditions to tribal authorities.

Fewer tribal/urban facilities reported cases of STDs (71%), hepatitis C (67%), hepatitis B (65%), or hepatitis A (62%) to state or county agencies. For tribal/urban health facilities, the specific health department or other authority to which cases were reported differed for HIV/AIDS and the other infections. Of the 52 respondents from tribal/urban facilities that had diagnosed and reported HIV/AIDS, 44 (85%) indicated that their facility reported diagnoses of HIV/AIDS to a state health department, a county or municipal health department, or both. Only 1 (2%) reported to both a state or county/municipal health department and a tribal agency, and 8 respondents (15%) did not know where HIV/AIDS case reports were sent. Although lower percentages of these facilities reported STDs, TB, and viral hepatitis to state/county/municipal health departments than reported HIV/AIDS to these health

departments (data shown in Table 3), 4 facilities (6%) reported the latter group of infections only to a regional Tribal Epidemiology Center or Indian Health Board, whereas none reported HIV/AIDS to a Tribal Epidemiology Center or Indian Health Board. The question about case reporting to a Tribal Epidemiology Center or Indian Health Board was not explicitly asked in the IHS Survey; rather, IHS respondents were asked if they reported cases of the infectious diseases to tribal authorities (as noted above).

Table 3. Number and Percentage Participating in Case Reporting, by Infection and Facility Type, Indian Health Service (IHS) Survey, 2001, and Tribal/Urban Survey, 2004

Cases reported to state/ county agencies	IHS Survey (%)	Tribal/Urban Survey (%)
HIV/AIDS		
Never diagnosed	2(4)*	14(21) [†]
Yes	43 (96)	44 (67)
No	0(0)	0 (0)
Don't know/missing	0 (0)	8(12)
STDs		
Yes	44 (98)	47 (71)
No	1 (2)	1 (2)
Don't know/missing	0	18 (27)
Hepatitis A		
Yes	42 (93)	41 (62)
No	2 (4)	2 (3)
Don't know/missing	1 (2)	23 (35)
Hepatitis B		
Yes	42 (93)	43 (65)
No	2 (4)	0 (0)
Don't know/missing	1 (2)	23 (35)
Hepatitis C cases		
Yes	41 (91)	44 (67)
No	4 (9)	0 (0)
Don't know/missing	0 (0)	22 (33)
Active Tuberculosis		
Yes	43 (96)	47 (71)
No	2 (4)	0 (0)
Don't know/missing	0 (0)	19 (29)

*Two facilities had not diagnosed a case of HIV/AIDS but had a reporting plan in place should a case be diagnosed. †Fourteen facilities had not diagnosed a case of HIV/AIDS; 12 had a reporting plan in place should a case be diagnosed.

Issue 2—Concerns about Data Quality

Key informants and focus groups contacted during the qualitative assessment raised issues with the quality of surveillance data available to them. These stakeholders described Native peoples' frequent migration between urban centers and reservations, and the implications for public health surveillance. Specifically, facilities may lack protocols for tracking patients who move back and forth between tribal lands and urban centers, and migration to urban areas may increase the likelihood of racial/ethnic misidentification, which may lead to undercounting of native people in surveillance data. Migration may also lead to multiple reports for the same patient. The stakeholders also mentioned that concerns about stigma and breaches of confidentiality may lead people to seek care off-reservation, which affects the quality and completeness of tribal data as well as coordination of care.

This concern was supported by the findings of both the IHS survey and the tribal/urban survey. High percentages of IHS and tribal/urban health facility staff (74% and 78%, respectively) who participated in the survey reported that their facility's clientele seek testing at alternative testing and treatment sites sometimes, often, or always for "sensitive conditions" like STDs or HIV. Fifty-two percent of IHS respondents and 54% of tribal/urban respondents believed that this practice interferes to a great or moderate extent with accurate estimation of HIV/AIDS case counts, while 38% and 40% of IHS and tribal/urban respondents, respectively, believed this practice interferes to a great or moderate extent with accurate estimation of Chlamydia or gonorrhea case counts.

Issue 3-Feedback: Getting Surveillance Information To Those Who Need it

Key informants and focus group participants contacted during the qualitative assessment expressed frustration at the lack of availability of surveillance information, and emphasized that even when formal data sharing agreements with state/county health departments exist, the data are frequently not provided in a useful format. Stakeholders pointed out that tribe-specific data are generally not available from outside sources, and tribes may not have the capacity to produce these data, as responsibilities for patient care take priority over public health functions such as surveillance. Also, some tribes closely guard data because they are concerned that information on native health or illness will contribute to negative views of the community.

The extent to which tribal or urban health facilities feel ownership of or see the value in surveillance was viewed by stakeholders as a key surveillance issue. If these facilities do not think surveillance data can benefit their

programs, they will be less likely to report cases to the state and/or county. However, stakeholders expressed the opinion that the perceptions of tribes may be changed by states' willingness and efforts to share surveillance reports with them.

In the IHS survey, less than 30% of Clinical Directors and other staff gave an affirmative response when asked if the facility receives an HIV/AIDS surveillance report from the state health department (slightly more than this (31%) said they did not receive a report and approximately 40% said they were not sure if the facility received a report or not). Similarly, although most surveyed tribal/urban facilities sent HIV/AIDS case reports to municipal/county/state surveillance systems, few of these facilities reportedly received state or county/municipal surveillance summaries for HIV/AIDS (24% received state summaries and 16% received county/municipal surveillance summaries; 71% said they did not receive a report, and 6% didn't know). Half of the IHS respondents and 41% of the tribal/urban respondents felt that HIV/AIDS surveillance reports would be, or were, "very useful" for educating staff. Well over a third of IHS and tribal/urban respondents also felt that HIV/AIDS surveillance reports would be, or were, "very useful" for securing additional funding (40% and 42%, respectively) and planning programs (39% and 33%, respectively). More than a third of IHS respondents but only a quarter of tribal/urban respondents felt that HIV/AIDS surveillance reports would be or were, "very useful" for allocating funding (38% and 26%, respectively), and performing clinical evaluations or service provisions (35% and 24%, respectively).

As for the other diseases of interest (STDs, viral hepatitis, and TB) results from both the IHS survey in Figure 1a and the tribal/urban survey in Figure 1b show that 63%-68% and 73-79% of respondents in the IHS and tribal/urban surveys, respectively, indicated that their facility did not receive surveillance reports from state health departments for the infectious disease listed. In the tribal/urban survey, 84%-89% of respondents indicated that their facility did not receive surveillance reports for the listed conditions from a county/municipal health department.

In the tribal/urban survey, for both HIV/AIDS and for the other surveyed diseases, only four respondents (6%) reported that their facility received tribe-specific information on case numbers from state/county/municipal health departments. For HIV/AIDS, 23 respondents (36%), and for other surveyed diseases, 35 respondents (53%) agreed that tribe-specific information would be useful. Respondents in five tribal facilities in the tribal/urban survey indicated that a facility-specific summary was prepared on HIV/AIDS among their clientele for internal use, and of these five, two shared the reports with the tribal government, and two shared them with IHS.

Figure 1a. Percentage of respondents reporting that their facility received a surveillance report from a State health department, IHS Survey, 2001. HIV, human immunodeficiency virus; STDs, sexually transmitted diseases (includes Chlamydia and gonorrhea); TB, tuberculosis; Hep A, hepatitis A; Hep B, hepatitis B; Hep C, hepatitis C.

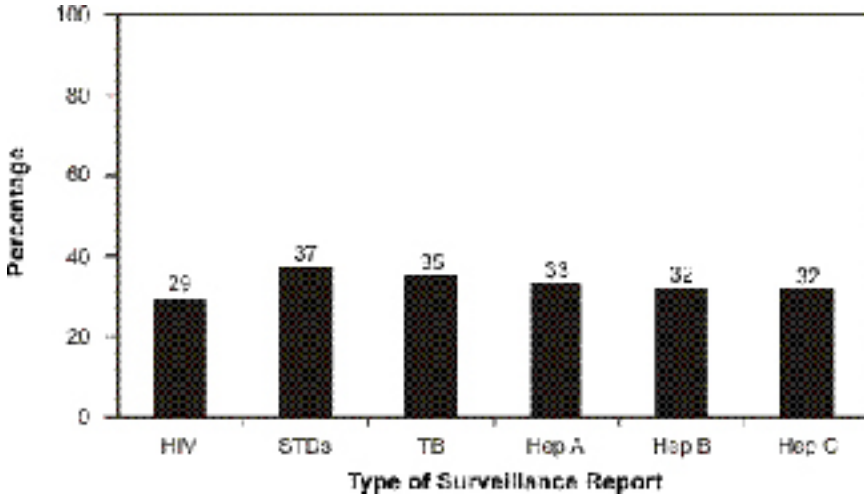
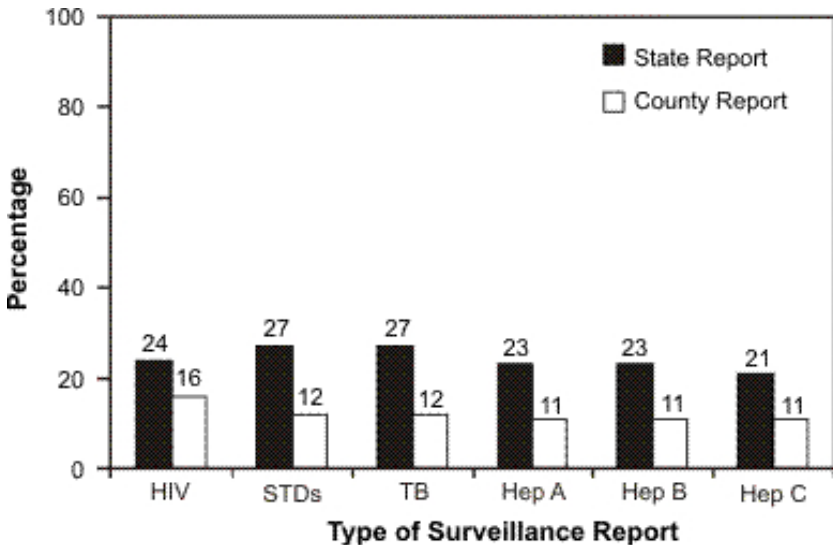


Figure 1b. Percentage of respondents reporting that their facility received a surveillance report from a State or County health department, Tribal/Urban Survey, 2004. HIV, human immunodeficiency virus; STDs, sexually transmitted diseases (includes Chlamydia and gonorrhea); TB, tuberculosis; Hep A, hepatitis A; Hep B, hepatitis B; Hep C, hepatitis C.



Issue 4—Coordination of Response to Surveillance Data

Some reservations border multiple jurisdictions (counties, states, or other tribal lands) and stakeholders contacted during the qualitative assessment noted that coordination among and between states to track diseases involving reservations has not worked well, citing examples in which individual states did not recognize a cluster of illness occurring within a reservation. Key informants from both tribal and urban Indian health agencies acknowledged the importance of collaboration with other AI/AN agencies to conduct surveillance; however, the extent to which agencies collaborate may be limited. These stakeholders reported gaps in coordination of surveillance activities among tribal and urban Indian agencies and between tribal and urban agencies and federal, state, and local agencies. They also pointed out the lack of facility-to-facility connections between tribal facilities and urban health facilities.

Only 15 of 66 respondents (23%) in the tribal/urban survey reported the existence of a process for the facility to address public health surveillance issues with the state health department or the county/municipal health department, 34 (52%) indicated that a process did not exist, and 17 (26%) were unsure.

Focus group participants and key informants contacted during the qualitative assessment reported poor internal capacity to respond to health problems identified through surveillance and difficulties in eliciting assistance from state/county health departments. They have found that jurisdictional confusion complicates coordinating a public health response.

The survey of tribal/urban facilities also collected information about coordination with other types of agencies to respond to public health problems. As many as 49 (74%) of 66 respondents in the tribal/urban survey reported that state/county/municipal health departments communicated with their facilities about possible exposure or risk to the patient population during outbreaks (8 answered “don’t know” and responses were missing for 3). Tribal/urban health facilities appeared to partner with a wide range of agencies to investigate or manage STD, HIV/AIDS, TB, or viral hepatitis cases: 39 (59%) partnered with county/municipal health agencies to investigate or manage STD, HIV/AIDS, TB, or viral hepatitis cases, 29 (44%) partnered with state health agencies, 14 (21%) partnered with tribal agencies, 6 (9%) with urban Indian health centers, and 1 (2%) with officials from a country outside the U.S. Thirty-one (49%) of respondents indicated that in an outbreak, other tribal/urban facilities communicated with their facility about risks and possible exposure of their clientele (8 answered don’t know, and a response was missing for 3).

Discussion

The Healthy People 2010 initiative emphasizes ensuring that federal, tribal, state and local health agencies have the infrastructure to provide essential public health services (including monitoring health status to identify and solve community health problems).¹⁵ The assessment described here was conducted to address concerns that the movement from a centralized IHS system to a decentralized I/T/U system, and the urbanization of AI/AN have affected surveillance systems monitoring infectious diseases among AI/AN. The findings suggest that reporting relationships that support surveillance systems, data quality, feedback of surveillance data to those who need it, and coordination of responses to surveillance data require attention.

Reporting Relationships and Data Quality

Before the trend toward compacting and contracting began, IHS had established relationships, rooted in law and policy, with both the health facilities diagnosing infectious diseases in the AI/AN population and the state health agencies collecting surveillance data. With IHS' decentralization into an I/T/U system, there is no longer a uniform policy to coordinate the case-reporting process, and surveillance functions have been shifted to tribal entities in many cases lacking legal and public health infrastructure to participate in public health surveillance networks.² These changes have implications for data quality, particularly the completeness of data.

IHS serves only a subset of the overall AI/AN population and AI/AN people often have multiple sources of health care, with up to 49% having insurance through their employer, other private insurance, or Medicare.¹⁶ Whereas most facilities supported by IHS are found in rural and reservation areas, the majority (62%) of the AI/AN population resides in off-reservation and urban areas.^{3,17,18} Overall, approximately 46% of AI/AN have no access to IHS facilities.¹⁹ Although IHS retains some centralized data functions for the I/T/U system, the IHS data warehouse excludes members of state-recognized tribes and urban AI/AN if they do not access IHS-funded urban clinics, and relies on the voluntary participation of health care facilities operated by federally recognized tribes.²⁰

State surveillance systems and the county/municipal surveillance systems that they encompass are designed to include all AI/AN people, regardless of where they may reside or seek care, and therefore retain the potential to serve as the most complete sources of data on infectious diseases affecting AI/AN people across the United States. However, completeness is dependent on case reporting, and our assessment points out weaknesses with regard to case reporting to state surveillance systems for a group of infectious diseases among AI/AN.

Case reporting appears to be occurring more frequently from IHS facilities than from tribal/urban facilities, and more frequently for HIV than for the other infections from both IHS and tribal/urban facilities. But according to our data, the proportion of facilities participating in case reporting is suboptimal across facility types and diseases. Lack of trust between tribal authorities and state/local governments, lack of feedback on surveillance efforts, and gaps in coordination of activities were identified as barriers to participation in surveillance.

AI/AN governments exist as separate governmental entities with sovereign status, and did not participate in the development of surveillance systems in the U.S., which evolved from systems initially developed by states to national systems with voluntary participation of the states.²¹ It is clear that efforts to include IHS and tribal / urban Indian health facilities in surveillance systems and other public health response networks are needed. Some tools exist or are being developed to guide these efforts, e.g., a technical assistance document developed by the National Alliance of State and Territorial AIDS Directors which outlines strategies for building trust between state public health agencies and AI/AN tribes, agencies, and communities, and for data quality, among other issues.²²

Feedback: Getting Surveillance Information to Those Who Need It

Even when reporting is occurring, there is little feedback to tribal agencies that would use the information for action. In addition, some tribal agencies have limited capacity to respond to public health problems identified through surveillance, and confusion about authority and responsibility to respond to public health problems on tribal lands may hamper the state/county health department response. These findings are consistent with findings from the Turning Point program, an initiative of the Robert Wood Johnson Foundation undertaken to transform and strengthen the public health system in the United States. Activities conducted in the planning phase of the Turning Point program demonstrated the unavailability and inadequacy of health information related to AI/AN health status at a community level.²³

Coordination

Shifts toward decentralization, such as the one that has affected the IHS, necessitate the integration of public health-related activities, management responsibilities, and services to ensure efficient public health practice.²⁴ Although our findings document some integration of public health activities of federal and state/county agencies with tribal and urban AI/AN health facilities, they also reveal that IHS, tribally operated and urban AI/AN health

agencies are not fully integrated into surveillance and other public health response networks. To affect this integration, tribal health codes and other laws affecting public health services may need updating.

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule recognizes Tribes as public health authorities. Disclosure of protected information to public health authorities, such as sharing of infectious disease case reports collected by state health departments with tribal government agencies, is specifically permissible under HIPAA, but only if the public health activity for which information is to be disclosed is “authorized by law,” i.e., general authority to conduct public health surveillance must exist.²⁵ However, a 1999 survey by the Intertribal Council of Arizona (ITCA) found that only 8 of 14 (57%) ITCA member tribes surveyed have a health code, that the health codes were at various levels of development, ranging from minimal to fully active health codes, and none of the 14 Tribes had a formal written agreement with an adjacent state(s) to allow enforcement of state health codes on tribal lands.²⁶ Some efforts have been made to work with Tribes to develop health codes through the Turning Point program^{27,28} and an assessment of the current status of these efforts is needed.

Through its Tribal Epidemiology Work Group, the Council of State and Territorial Epidemiologists (CSTE), the guiding body for public health surveillance in the U.S., is engaged in efforts to reach out to and include tribal entities. At each of the last five CSTE annual national conferences, the CSTE Tribal Epidemiology Work Group has hosted a forum to enhance collaborations between state health departments and Tribal Epidemiology Centers. The Work Group has been addressing the gaps identified in the assessment reported here. As mentioned above, the Turning Point program has also addressed both statutory authority for public health functions and integration of public health functions between state, county, and tribal agencies.^{23,29} In addition, the National Alliance of State and Territorial AIDS Directors has published guidance for state health departments for working with Native American communities to address HIV/AIDS.³⁰

An effective surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs.³¹ Our assessment suggests a need to build or strengthen relationships and processes for collecting, managing and sharing infectious disease information. To be most useful, the system must be accessible, accurate, timely, and clearly state and adhere to strict confidentiality standards. The system must be linked with other data systems and integrated at the federal, tribal, state, and local levels.¹⁵ Mutual aid agreements between tribes and states that specify uniform data standards, communications networks, how data access and data collection burdens will be shared, and how confidentiality will be protected

may prove useful in formalizing these linkages. A number of collaborative arrangements between and among tribal and non-tribal governments and organizations are available as models, including one which addresses shared responsibilities for public health surveillance.^{23,32}

In addition, Tribal Epidemiology Centers, which were originally authorized under Section 214(a) (1), Public Law 94-437, Indian Health Care Improvement Act, as amended by P.L. 573, and operated under cooperative agreements with IHS, are emerging as important links between tribal/urban facilities and surveillance networks of non-tribal public health authorities. Under the law, Tribal Epidemiology Centers “may collect or receive protected health information for the purpose of preventing or controlling disease...including but not limited to...the conduct of public health surveillance.” Innovative solutions like the use of Tribal Epidemiology Centers for increasing capacity for public health surveillance among AI/AN fit with the general movement from traditional and fragmented approaches to surveillance to a coordinated and flexible public health surveillance system for the 21st century.³¹

Implications

Our findings raise important questions about how AI/AN communities can monitor the impact of infections like STDs, HIV/AIDS, TB, HAV, HBV, and HCV, which are clearly important health problems among AI/AN people.⁸⁻¹⁴ Further, how can they predict trends and assess control efforts? How can state surveillance programs perform these same key tasks without the full picture of AI/AN infectious disease incidence and prevalence? It is clear that without public health surveillance data, it will be difficult to determine the need for public health action and assess the effectiveness of programs.

The implications of our findings for infectious disease control are serious. The identified weaknesses, singly or in combination, may result in failure to recognize or respond effectively to control an outbreak on tribal lands or that involves AI/AN people across geographically proximal but governmentally distinct jurisdictions, and may perpetuate health disparities with respect to endemic infections like STDs and viral hepatitis.

Furthermore, the implications for the national surveillance network are clear: a gap anywhere in the surveillance network has the potential to undermine the effectiveness of the entire surveillance system, and to result in failure to initiate timely public health action, whether the threat to the health of the population be from known organisms, previously uncharacterized disease, or bioterrorism.³³

Limitations

We acknowledge that the primary limitation of the IHS and tribal/urban health facility surveys is their reliance on respondents' self-reporting of their surveillance and reporting practices. Some results from these surveys, such as the proportion of facilities reporting cases to state health departments, may underestimate actual case reporting rates because reporting of AI/AN cases directly from contracted clinical laboratories was not assessed. CSTE is currently undertaking a survey of state health departments about participation in case reporting by tribal health facilities, which will provide some additional information on this topic.

The relatively low response rate of 55% in the tribal/urban survey and the large percentage of missing values for survey questions about case reporting were additional limitations affecting the tribal/urban health facility survey. Although these data provide a baseline for future evaluations, they may not be generalizable to all tribal and urban Indian health facilities.

Conclusion

Our findings showing weaknesses in public health surveillance for a group of infectious diseases among AI/AN people call attention to a gap in the United States' public health preparedness, have implications for addressing health disparities among AI/AN people, and highlight the need for state and local public health entities to build trusting working relationships with AI/AN tribes, agencies, and communities.

End Note

The applicability of human subjects regulations was determined separately for each of the three phases of the assessment. All three phases were determined to be nonresearch because of their classification as program evaluations involving collection of data about health facilities which are not identifiable persons. This determination was made by both the Associate Director for Science, National Center for HIV, STD, and TB Prevention at CDC and the Chairman of the IHS National Institutional Review Board (IRB) for the IHS survey and the qualitative assessment, and by these CDC and IHS authorities as well as the Cherokee Nation IRB for the tribal/urban health facility survey.

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Acknowledgements

The authors acknowledge participants from the National Congress of American Indians, National Indian Health Board, National Council on Urban Indian Health, the Tribal Epidemiology Centers, the California Rural Indian Health Board, the Northwest Portland Indian Health Board, the Aberdeen Area Tribal Chairman's Health Board, the Association of American Indian Physicians, the Indian Health Service, and tribally operated and urban Indian health facilities.

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.

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