December 22, 2003

HIV/AIDS, STD, TB, and Hepatitis B and C Case Reporting Practices of Tribally Operated Health Facilities

Final Report

Prepared for

Centers for Disease Control and Prevention
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*RTI International is a trade name of Research Triangle Institute.

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INTRODUCTION

American Indian and Alaska Native (AI/AN) people are affected disproportionately by many infectious diseases, including human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS), sexually transmitted diseases (STDs), hepatitis B and C (HBV and HCV, respectively), and active tuberculosis (TB). Existing national surveillance figures indicate that, in 2002, the gonorrhea rate for AI/AN people was four times higher than the rate among non-AI/AN people, the chlamydia rate was six times higher, and the primary and secondary syphilis rate was twice as high (Centers for Disease Control and Prevention [CDC], 2003). The AIDS rate among AI/AN people aged 14 or older was 1.6 times higher than the rate among non-AI/AN people, and the TB rate was twice as high.

An HBV outbreak among injecting drug users in Montana, 1989 to 1990, linked injection drug use with HBV transmission in certain AI communities (CDC, 1992). Alaska has an HBV profile different from that of the lower 48 states; there, HBV is endemic among native people. Few data are available to describe the incidence and prevalence of hepatitis C among AI/AN people. However, preliminary findings from a recent study of pregnant women receiving prenatal care at an urban Indian health facility indicated an unexpectedly high HCV prevalence of 1.75 percent in this traditionally low-risk group (Indian Health Service [IHS], unpublished data).

National surveillance data often underestimate the number of AI/AN cases.

National surveillance data often underestimate the number of STD and HIV/AIDS diagnoses among AI/AN, for two reasons: (1) like other racial/ethnic groups, not all AI/AN persons living with these infections have been diagnosed, and (2) some AI/AN people who are diagnosed and reported to infectious disease surveillance systems may be reported to be of another race/ethnicity (Kelly et al., 1996; Hurlich et al., 1992; Thoroughman et al., 2002). Because of the sovereign status of tribal governments, tribally operated health facilities are not tied to the reporting requirements mandated by states. If some health care providers who serve AI/AN clients are not reporting cases to the surveillance system, this would contribute to underestimation of infection and disease prevalence.

In recent years, under the Indian Self-Determination and Education Assistance Act (1975), tribes are increasingly assuming more control over their resources for health care. More than 50 percent of federally recognized tribes have already participated, in some manner, in the movement toward managing health care for their members. Serious concerns have been raised regarding the impact on public health surveillance of recent changes in the way health care is delivered to AI/AN communities (see National Congress of American Indians, 1999). The effect of this decentralization of services originally provided by IHS on public health surveillance has not been studied.

This qualitative assessment is the second project designed to assess the status of public health surveillance for a related set of infectious diseases—HIV/AIDS, other STDs, TB, HBV and HCV—among AI/AN people. The first project assessed IHS facilities' participation in surveillance for these infections. This project solicited opinions from both tribally operated and urban Indian health facilities about surveillance's challenges and their unmet surveillance needs. The objective of the third project in the series will be to survey tribal and urban health facilities to describe their current participation in surveillance.

METHODS

Under contract with CDC, RTI International and Kauffman and Associates, Inc. (KAI) conducted a qualitative description of current and potential participation of tribal and urban Indian health facilities in HIV/AIDS, STD, TB, and HBV and HCV surveillance. As a first step, RTI and KAI met with stakeholders, including national and local AI/AN health and professional organizations, to obtain their perspectives on the project. Based on stakeholders' needs and expectations, we developed an evaluation design that guided our primary data collection efforts. We convened a series of focus groups and conducted personal interviews with a variety of individuals who have responsibility for ensuring the public health of AI/AN communities. We used convenience sampling to recruit key informants and focus group participants during existing conferences and meetings. The final sample included participants who represented a spectrum of knowledge about and engagement with surveillance. We asked questions about (1) sources, quality, and uses of surveillance data; (2) case reporting practices; (3) surveillance coordination with other entities; and (4) challenges to participating in surveillance. This report presents the results of our analysis of focus group and interview data.

RESULTS

Sources and Uses of Surveillance Data

Participants do not have good sources of surveillance data for risk behaviors.

All participants cited multiple sources of basic infectious disease surveillance data, including state and/or county health departments, CDC, IHS, or large national surveys. However, AI/AN people are often underrepresented in national surveys. Many participants identified sources of data that were sometimes used for surveillance but not necessarily designed for this purpose, such as in-house clinical or administrative databases, the IHS Resource and Patient Management System (RPMS), and anecdotal information. Participants do not have good sources of surveillance data for risk behaviors.

Participants expressed frustration that even when formal data sharing agreements with state/county health departments exist, the data are frequently not provided in a useful format. For instance, 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. Participants were also generally dissatisfied with the quality of surveillance data available to them. Respondents were concerned that AI/AN health issues stay "below the radar" because of underreporting, racial/ethnic misidentification, underrepresentation of AI/AN in some surveillance projects (e.g., national surveys), and a lack of protocols for tracking AI/AN people who migrate across jurisdictions.

Participants from both tribal and urban Indian health facilities reported that they use surveillance data for a variety of purposes, including applying for grants, planning prevention programs, monitoring disease trends, and guiding clinical practices. A few participants, however, were not knowledgeable about the uses of surveillance data. Also, some tribes closely guard surveillance data because they are concerned that information on native health or illness will contribute to negative views of the community.

Case Reporting Practices

Participants who provided comments about case reporting practices indicated that case reporting responsibility most often lies with physicians and nurses, although other entities, such as facility administrators and laboratories, also participate in reporting.

Migration Issues

Native people migrate frequently between urban centers and reservations, and their migratory patterns have implications for surveillance. Concerns about stigma and breaches of confidentiality may lead people to seek care off-reservation, which affects quality and completeness of tribal data as well as coordination of care. Most facilities lack protocols for tracking patients who migrate between tribal lands and urban centers. 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.

Coordination

Participants reported gaps in coordination of surveillance activities.

Participants from both tribal and urban Indian health facilities acknowledged the importance of collaboration with other AI/AN facilities to conduct surveillance; however, the extent to which they do so may be limited. Participants reported gaps in coordination of surveillance activities among tribal and urban Indian facilities and between tribal and urban facilities and federal, state, and local agencies. Lacking facility-to-facility connections, tribal and urban health facilities' primary link may be their patients. Organizations that might potentially serve in a coordinating role, such as the Tribal Epidemiology Centers and the IHS National Epidemiology Program, appear to be underutilized, perhaps because tribes are unaware of the type of support they can offer.

Surveillance Challenges

Jurisdictional confusion complicates coordinating a public health response.

Participants reported poor internal capacity to respond to health problems identified through surveillance and difficulties in eliciting assistance from state/county health departments. They find that jurisdictional confusion complicates coordinating a public health response. They noted that formal training and technical assistance; better sources of behavioral data; and strengthening relationships, communications, capacity, and infrastructure would help support enhanced surveillance and coordination.

CONCLUSIONS AND RECOMMENDATIONS

The findings in this report are meant to illustrate surveillance issues in tribal and urban Indian health facilities. How common these issues are will be assessed by a survey of tribally operated and urban Indian health facilities, to be conducted by the Council of State and Territorial Epidemiologists. Nevertheless, these results have provided critical information to guide the development of the subsequent survey.

In addition, these results suggest several considerations for addressing infectious disease surveillance challenges in tribally operated and urban Indian health facilities. First, development of a shared understanding of surveillance and its uses and objectives would support the development and strengthening of partnerships and collaborations among facilities and systems serving native people, including IHS, tribally operated facilities, urban Indian health facilities, and state and local public health systems. Second, there is a clear need for protocols and agreements to ensure cross-jurisdictional coordination. Finally, the role of Tribal Epidemiology Centers and the IHS National Epidemiology Program in coordinating and improving surveillance among AI/AN people should be explored.

1 Introduction

1.1 BACKGROUND

American Indian and Alaska Native (AI/AN) people are affected disproportionately by many infectious diseases, including human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS), sexually transmitted diseases (STDs), hepatitis B and C (HBV and HCV, respectively), and active tuberculosis (TB). Existing national surveillance figures indicate that, in 2002, the gonorrhea rate for AI/AN people was four times higher than the rate among non-AI/AN people, the chlamydia rate was six times higher, and the primary and secondary syphilis rate was twice as high (Centers for Disease Control and Prevention [CDC], 2003). The AIDS rate among AI/AN people aged 14 or older was 1.6 times higher than the rate among non-AI/AN people, and the TB rate was twice as high.

An HBV outbreak among injecting drug users in Montana, 1989 to 1990, linked injection drug use with HBV transmission in certain AI communities (CDC, 1992). Alaska has an HBV profile different from that of the lower 48 states; there, HBV is endemic among native people. Few data are available to describe the incidence and prevalence of hepatitis C among AI/AN people. However, preliminary findings from a recent study of pregnant women receiving prenatal care at an urban Indian health facility indicated an unexpectedly high HCV prevalence of 1.75 percent in this traditionally low-risk group (Indian Health Service [IHS], unpublished data).

IHS has been the primary provider of public health services to AI/AN people, since the enactment of the Indian Self-Determination and Education Assistance Act (1975), tribes are increasingly assuming more control over their resources for health care. More than 50 percent of the 562 federally recognized tribes have already participated in some manner in the movement toward managing health care for their members. Tribes may provide the services themselves with their share of IHS money (known as “compacting”) or use the funds to contract with IHS for provision of these services. Additionally, native people may access non-IHS Indian health facilities located in urban areas throughout the nation, as well as other public and private health care providers. IHS and its partnership with tribal and urban Indian health providers comprises a network of relatively independent hospitals, clinics, and health stations. The resulting decentralization of services has raised concerns about the potential for gaps in public health services.

Tribally operated health facilities are not tied to the reporting requirements mandated by states.

Against this backdrop of health care decentralization, native communities are challenged to protect the public health. Significant strides have been made in the past century to improve sanitation, water quality, and related public health concerns in Indian Country. Native communities’ role in providing other core public health functions, such as surveillance, health promotion, and disease prevention, is also in the midst of change. Infectious disease surveillance for AI/AN people in particular, especially on reservations, has been significantly affected by decentralization. Because of the sovereign status of tribal governments, tribally operated health facilities are not tied to the reporting requirements mandated by states. In Indian Country, providing direct patient care is often seen as a higher priority than conducting surveillance, given the limited resources available and the pressing health needs of the community. Surveillance’s purpose is misunderstood by lay people, and its benefits are not readily apparent even to front-line health care staff (Dixon & Roubideaux, 2001). Together, these issues have heightened the need for an integrated surveillance system.

1.2 CDC EFFORTS TO UNDERSTAND SURVEILLANCE CHALLENGES

Through contracts and cooperative agreements, CDC has supported a series of assessment projects (Phases I and II) which comprise an evaluation of the coordination of HIV/AIDS, STD, HBV, HCV, and TB surveillance between tribal and urban Indian health facilities and state, county, municipal and tribal public health agencies. (In the remainder of this report, “infectious disease surveillance” refers to surveillance of these particular diseases.) This Phase I evaluation, a qualitative needs assessment entitled *HIV/AIDS, STD, TB, and Hepatitis B and C Case Reporting Practices of Tribally Operated Health Facilities*, solicited opinions from both tribally operated and urban Indian health facilities about surveillance’s challenges and their unmet surveillance needs. Conducted by RTI and its partner, Kauffman and Associates, Inc. (KAI), under contract to CDC, the purpose of this project is to understand American Indian and Alaska Native tribal health agencies’ current and potential participation in HIV/AIDS, STD, TB, and viral hepatitis surveillance and to learn how to improve infectious disease surveillance systems for native people.

CDC and the Council of State and Territorial Epidemiologists (CSTE) are collaborating to conduct Phase III in 2004: *Survey of HIV/AIDS, STD, TB, and Hepatitis B and C Reporting Practices of Tribally Operated Health Facilities*. The objectives of Phase III are to assess surveillance practices among tribally operated health care facilities and to identify barriers and provider participation in surveillance. Qualitative information gathered during Phase II is guiding survey development for Phase III. The information gathered in these projects will be used to inform actions to strengthen national capacity for infectious disease surveillance among AI/AN.

As part of Phase II, the RTI/KAI team used input from stakeholders—individuals who have an interest in or are affected by the results of an evaluation—to inform primary data collection efforts. The remainder of this report presents findings from the evaluation. Section 2 focuses on the methods we used to collect and analyze qualitative data, and results are presented in Section 3. A summary and discussion can be found in Section 4.

2 Methods

This report is a qualitative assessment of surveillance activities and needs in Indian Country. As such, it is intended to be descriptive and illustrative, rather than representative and conclusive. RTI's approach to this project started with discussions with CDC staff and key stakeholders to define the scope of the project, identify the components of infectious disease surveillance to be addressed, and begin discussions of options for primary data collection. Working closely with CDC staff and stakeholders ensured that key needs and expectations were incorporated into the work. Information gathered during the stakeholder engagement process was used to develop methods for sampling and recruiting participants for focus groups and key informant interviews, discussion guides, and an analysis plan. In this section the approach used for engaging stakeholders is outlined, key findings from this process are detailed, and methods for conducting primary data collection and analysis are presented.

2.1 STAKEHOLDER ENGAGEMENT

Methods for stakeholder engagement are described in greater detail elsewhere (Harris, Roussel, & Fichtner, 2003). Briefly, RTI and KAI worked closely with the CDC technical monitor to select the stakeholders whose input would guide this evaluation. Stakeholders are persons who have an interest in infectious disease reporting at the tribal level, either because they use surveillance data or because they are in a position to act on the findings of this needs assessment. Stakeholders also included individuals with responsibility for surveillance infrastructure, opinion leaders, and people who are in a position to be influential regarding surveillance in tribal and urban Indian health facilities.

The process of identifying stakeholders proceeded iteratively, as our early experiences informed our subsequent thoughts and expectations about key groups or individuals to involve. This report is based on multiple interviews and discussions, including the following:

- kickoff meeting with steering committee of CDC staff representing HIV, STDs, TB, and viral hepatitis surveillance activities as well as key staff from IHS Headquarters East and the National Epidemiology Program and a representative from CSTE (which was considered a stakeholder group)
- group discussions at the annual meeting of the National Congress of American Indians (NCAI) health subcommittee and with the IHS area chief medical officers
- telephone interviews with representatives from Tribal Epidemiology Centers, urban Indian health facilities, state infectious disease programs, the National Native American AIDS Prevention Center, and the Association of American Indian Physicians

Our discussions with stakeholders were facilitated using interview guides that were developed based on the objectives for the stakeholder engagement activity. Topics covered in these discussions included the usefulness of the project, suggested areas of inquiry, strategies for approaching respondents, key issues in surveillance, and potential uses of findings.

During analysis, we focused on identifying patterns and common themes among stakeholders. We relied heavily on content analysis, which is a scientific approach to summarizing and categorizing the content of the interviews. This approach allowed us to carefully examine what different people said about the same topic.

Stakeholders indicated that the evaluation is needed to ensure that national surveillance systems support public health systems serving AI/AN people. Stakeholders were confident that evaluation findings would be a positive step toward building capacity and infrastructure to support participation in surveillance by tribally operated and urban Indian health facilities.

This stakeholder engagement enhanced the cultural competence of our approach. Stakeholders reminded us of the importance of such issues as stigma and confidentiality, stressed the need to convey openness and respect for participants' views and experiences, and noted that a project presented as a needs assessment would likely be more well received than an evaluation or a study.

Whenever feasible, we incorporated their recommendations for sampling, recruitment, and development of interview guides directly into our data collection protocol. These methods are described in greater detail in Section 2.2.

2.2 PRIMARY DATA COLLECTION METHODS

Methods for primary data collection included developing focus group and key informant interview guides, selecting locations for focus groups and coordinating their logistics, selecting and recruiting key informants, conducting focus groups and interviews, and performing analysis.

2.2.1 Instrument Development

For this evaluation, we developed two interview guides (standardized lists of open-ended questions designed to be covered in a particular order): one for discussions with persons representing tribal health facilities and the other for those representing urban Indian health facilities. These two guides were suitable for both focus groups and key informant interviews. (Interview guides are included in Appendix A.)

Topics covered in these guides included the following:

- sources, accessibility, quality, and usefulness of surveillance data
- case reporting practices
- surveillance collaborations with federal, state, and local governments and nongovernmental institutions
- challenges to participating in surveillance
- resources needed to increase participation level

While the topics covered in each guide were the same, the order of questions varied slightly based on stakeholders' priority information needs. Stakeholders acknowledged knowing very little about tribes' access to surveillance data, the quality of these data, and how the data are used for public health action; thus, our discussions with tribal respondents began with questions addressing these areas of interest. With regard to urban Indian health facilities, stakeholders prioritized the need for information on tracking infections among individuals who migrate between cities and reservations; thus, the discussion with urban facility representatives began with this issue.

Stakeholders suggested that it was important to assess general surveillance knowledge before asking in-depth questions about infectious disease surveillance. Therefore, the topic guide began with warm-up questions to assess familiarity with, access to, and uses and quality of diabetes data. (We chose diabetes as the topic of our introductory questions because of this disease's high prevalence among native people.) In most cases, we found that it was not necessary to ask these questions because stakeholders were generally aware of surveillance and comfortable with discussing infectious diseases.

2.2.2 Selection and Recruitment

RTI and KAI worked closely with CDC to select focus group venues and key informants for primary data collection. Selection was based in large part on the domains deemed important by stakeholders, as well as meeting organizers' and individuals' willingness and interest in participating. Selection domains and strata (in parentheses) included the following:

- facility type (urban, tribal)
- level of surveillance knowledge/engagement (low, medium, high)
- respondent type (technical expert, leader, administrator)
- geographic region (North, Southeast, Midwest, Southwest, West)

To aid in the selection process, we developed a system to track potential focus group opportunities and key informants by these domains and strata. This ensured that we captured viewpoints from a wide variety of respondents using criteria identified by stakeholders, even though the resulting sample was not random or representative of the entire population of tribal and urban Indian health facilities.

Level of surveillance knowledge or engagement was difficult to identify *a priori* for focus group participants, as was respondent type. Because we were not always certain who was going to attend sessions, we could not establish the general background of group participants until discussions began.

In accordance with stakeholders' suggestions, we sought to convene focus groups at previously scheduled national and regional meetings. We worked closely with meeting organizers beforehand to secure time slots, identify locations in which to hold discussions, and advertise focus groups to meeting participants. We convened focus groups at the following meetings:

- joint meeting of IHS and the Substance Abuse and Mental Health Services Administration (SAMHSA) titled "Building Partnerships to Meet Substance Abuse Prevention and Treatment Challenges in American Indian and Alaska Native Communities"
- joint meeting of the California Rural Indian Health Board and Northwest Portland Indian Health Board
- Aberdeen Area Tribal Chairman's Health Board
- annual meeting of the Association for American Indian Physicians

No more than nine individuals participated in each focus group. Participants included technical experts, tribal leaders, and health care administrators and providers.

After the focus groups, we identified nine key informants through professional networks and references from stakeholders, and we interviewed each by telephone. This final group of key informants included a broad cross-section of individuals representing the domains and strata stakeholders identified during the first phase of the evaluation:

- 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

The focus groups and telephone interviews ranged from 1 to 1½ hours each, depending on participants' surveillance knowledge and engagement.

2.2.3 Data Collection

Our focus group discussions and key informant interviews were guided by the instruments described in Section 2.2.1. Before initiating primary data collection, we received exemption from RTI's, CDC's, and IHS's Institutional Review Boards.

During focus groups and interviews, one member of the research team posed questions while the second member took notes on a computer. The interviewer followed up on potentially significant responses with probes designed to ensure that all critical issues were addressed.

After each group or interview, the interview team promptly reviewed the typed record for accuracy and completeness. These notes formed the raw data for our analysis. We also engaged in a structured debriefing process. This involved the use of matrices to integrate and augment notes taken during focus groups and interviews and to allow conceptualization of those data in terms of the objectives of this phase of the evaluation. The matrices listed participants in columns and the projects' objectives and questions in rows.

2.3 ANALYSIS

Our approach to the analysis of qualitative data flowed directly from the domains and objectives specified by stakeholders. We formulated an analytical coding structure to reflect these objectives and questions. Our analysis focused on identifying patterns and common themes across respondents. We relied on content analysis, which is a scientific approach to summarizing and categorizing the content of the interviews. This approach allowed us to examine carefully what different people said about the same topic.

The analysis was guided by the debriefing matrices we created, which enabled us to map each participant's remarks to our objectives and questions. This approach facilitated synthesis across respondents, allowing us to observe patterns of agreement and disagreement.

The presentation of findings that follows includes areas of agreement across participants, as well as topics for which there were conflicting perceptions. Whenever possible, we use participants' own words to illustrate a point or an issue.

3 Results

This section details our findings from focus groups and key informant interviews. We begin by highlighting respondents' experiences with surveillance data, followed by a discussion of their case reporting practices and migration issues. We then summarize how and to what extent tribally operated and urban Indian health facilities collaborate with federal, state, and local agencies as well as with each other to conduct surveillance. In closing, we present tribal and urban Indian health facilities' perceptions of surveillance's challenges and needs.

These findings are intended to illustrate some of the issues regarding surveillance in Indian Country. We present a range of perspectives; some may be complementary and some contradictory. Our analysis does not enable us to draw inferences about patterns in the broader population of tribal and urban Indian health facilities.

3.1 SURVEILLANCE DATA

Focus group participants and key informants discussed the availability of, access to, and quality of surveillance data in their facilities, as well as how these data are used.

3.1.1 Availability of and Access to Surveillance Data

All participants cited multiple sources of basic infectious disease surveillance data, including state and/or county health departments, CDC, IHS, or large national surveys. They noted that AI/AN people are often underrepresented in national surveys. Many participants mentioned sources of data used for surveillance but not necessarily designed for this purpose, such as in-house clinical or administrative databases, the IHS Resource and Patient Management System (RPMS), and anecdotal information.

The type of infectious disease surveillance data collected varies, particularly in tribally operated facilities. The majority of respondents said that only basic statistics, such as incidence rates and some demographic data (e.g., age, gender), were available in their facilities, and that these data can be queried to show year-by-year trends.

Routine collection of behavioral surveillance data is an anomaly rather than the norm. Its collection, particularly in urban facilities, is often contingent upon whether facilities receive governmental funding to do so. In some facilities, some behavioral surveillance data may be generated from risk assessments that patients complete at intake, which may ask about current alcohol or drug use. Numbers of sexual partners may be indirectly estimated from the partner notification process initiated after someone is diagnosed with an STD. However, this information is available only in some facilities and only for individuals presenting for treatment. These facilities generally lack systematic, population-based data on behavioral risk factors.

Obtaining local or facility-specific mortality statistics is also challenging for some facilities because data often are not current. As we learned from one respondent, “The hospital database is not always accurate as to who is alive and who is dead.” This makes thorough surveillance, coordination, and closing the gap challenging.

3.1.2 Quality of Surveillance Data

“Access to data isn’t a problem, but the data [quality] is questionable.”

Participants were generally dissatisfied with the quality of surveillance data available to them: “Access to data isn’t a problem, but the data [quality] is questionable.” Most participants believed that, at its best, available surveillance data yielded underestimates of the prevalence of disease among Native people due to multiple factors. One respondent put it this way: “For communicable diseases, we cannot rely on published accounts by state health departments of Native American disease due to too much underreporting. Often, Indian cases are not included. We see these disease rates among Native Americans as underestimates. It would be nice to have more accurate disease data."

Respondents believed that racial/ethnic misidentification is the primary factor affecting data quality. Misidentification occurs for interrelated reasons. First, Native people seeking care off-reservation may not self-identify as AI/AN, and providers in non-AI/AN facilities may assume race/ethnicity to be white or Hispanic.

Another issue affecting data quality is underreporting, which leads to underestimations of infectious disease burden among AI/AN people. As mentioned above, racial/ethnic misidentification, particularly for persons seeking care off-reservation, is one factor contributing to underestimation of disease rates among AI/AN people. We also learned that for some diseases, such as STDs, patients might receive medications for their sexual partners without the partners' having to come in for diagnostic and treatment services. Thus, any of these sexual partners infected with a reportable disease would likely not be counted in facility surveillance data, or in local or state surveillance data if the facility reports to these entities.

"I always wonder if the HIV cases we know about are an accurate picture of the actual cases of HIV in our community."

Data quality is also indirectly affected by concerns about stigma and breaches of confidentiality. Such concerns, particularly in small communities, may lead people to seek off-reservation health care. This issue is particularly pertinent to HIV and AIDS. As one respondent said, "I always wonder if the HIV cases we know about are an accurate picture of the actual cases of HIV in our community."

Abstracting local data from nonsurveillance databases, such as clinical or administrative ones, is unlikely to yield high-quality data. As one respondent said about obtaining data from RPMS, "This is not ideal because it was not designed as a disease surveillance system. It involved more work to get accurate information from it and there were other issues like diseases occasionally being miscoded."

3.1.3 Uses of Surveillance Data

Most participants were familiar with the many uses of surveillance data. For instance, both tribal and urban Indian health facilities use surveillance data to apply for grants, plan prevention programs, monitor disease trends, and to guide clinical practices as well as public health functions, such as partner notification. A few participants, however, were not knowledgeable about the potential uses of surveillance data and were uncertain about where to start.

3.2 CASE REPORTING PRACTICES

Participants informed us that case reporting responsibility most often lies with physicians and nurses, although other entities, such as facility administrators and laboratories, also participate in reporting. One respondent affiliated with a tribally operated facility mentioned that case reporting responsibility recently shifted from clinicians to the tribal health department; the impact of this shift is unknown at this time.

Tribally operated and urban Indian health facilities often report cases differently. Urban Indian facilities are mandated by law to abide by the reporting requirements set forth by their states, counties, and municipalities. Tribal facilities, on the other hand, are not required to report to state or local governments because they are operated by sovereign entities.

To varying degrees, tribes voluntarily report to local or state health departments as well as to IHS. For instance, this assessment found variability with regard to which tribal facilities report to their respective state health departments, to IHS, and to their local health department. One participant told us, “There is nothing really at the county level for us.” On the other hand, some facilities reported having better reporting relationships with counties and municipalities than with states.

We also learned that interpersonal relationships between tribal or urban Indian health facility staff and individuals from state or local health departments influence case reporting practices. Respondents who had established personal relationships with state or local individuals appeared more likely to report cases to their respective health departments than respondents who did not have such relationships.

“We just report data to the state, which is kind of this nebulous entity.”

Several responses indicated a lack of familiarity with the basics of surveillance. One participant said, “We just report data to the state, which is kind of this nebulous entity.” This person went on to highlight a need for “clearer understanding of what is under surveillance and what particular mechanisms one needs to follow.” On the other hand, some states ensure that reportable diseases and the processes for reporting them are widely disseminated (e.g., posted in clinics and emergency rooms).

Few respondents were able to provide specific details about their facilities’ case reporting processes. Those who were familiar with them identified laboratory-based systems as the means by which their facilities report cases to their various jurisdictions. Although this process ensures that surveillance data are transmitted to designated jurisdictions, facilities do not necessarily receive timely reports from laboratories.

“Surveillance does become a bit burdensome.”

The variability in case reporting practices may relate to the priority that facilities (particularly tribally operated ones) place on surveillance relative to managing chronic conditions that are affecting AI/AN people at disproportionate rates, such as diabetes or cardiovascular disease (CVD). While some felt that surveillance “complements direct care” and that it “fits comfortably with providing direct patient care,” others indicated that, in their facilities, surveillance is perceived as something that takes time away from providing direct patient care. This is less of an issue in facilities with a designated infection control staff (e.g., nurse); however, some facilities may lack that infrastructure. A clinician noted that “there is a lot of redundant paperwork…for multiple documentations. So surveillance does become a bit burdensome, rather than using our clinical time better.”

We also learned that some facilities may not know how to conduct surveillance or believe they are conducting surveillance when in fact they are not. As noted above, some rely on anecdotal information. Additionally, some respondents indicated that their facilities use nonsurveillance data systems for surveillance.

3.3 MIGRATION ISSUES

As we learned during stakeholder engagement, Native people migrate frequently between urban centers and reservations, and their migratory patterns have implications for surveillance. Concerns about stigma and breaches of confidentiality may lead people to seek care off-reservation, which affects quality and completeness of tribal data, as well as coordination of care. Migration to urban areas and receipt of clinical care in non-Native facilities increases the likelihood of racial/ethnic misidentification, which leads to undercounting of Native people in surveillance data. Migration may also disrupt the sequence of public health actions that follows an infectious disease diagnosis, either because cases are lost or because appropriate treatment is not initiated soon enough or continued long enough to prevent disease transmission. Migration can also result in multiple reports for a single person; however, it is difficult to predict the impact of duplicative reports on the completeness of surveillance data.

"Much of the time, people disappear and you can't really find them."

During primary data collection, we explored how tribal and urban Indian facilities track infections in persons who migrate, including the facilities' partnerships with each other and with state and local health departments. With few exceptions, we learned that there is little interjurisdictional or interfacility coordination when it comes to tracking cases, and "Much of the time, people disappear and you can't really find them."

Although urban Indian facilities tend to work with state and local health departments to track cases, this was not always the case for tribally operated facilities. Some of the tribes represented in this evaluation sought out or received support from state and local health departments to track cases. Conversely, tribes cited several reasons why they do not report cases to outside health departments, including concerns about violating the Health Insurance Portability and Accountability Act (HIPAA). Also, some participants felt that it was the patients' responsibility to coordinate their care if they move, or the clinicians', rather than viewing it as a facility responsibility.

Participants suggested that interfacility protocols for tracking infected persons who migrate between reservations and urban centers or vice versa are uncommon. Again, HIPAA concerns seem to be the primary deterrent to forging such collaborations. Additionally, respondents reported unsatisfactory experiences (e.g., lack of interest, unwillingness) when they tried to work in partnership with other facilities to track cases. The mention of

HIPAA suggests that education about its relationship to public health surveillance would be beneficial.

3.4 SURVEILLANCE COLLABORATIONS

"Tribes are very cautious about sharing information."

Participants described a range of collaborations among tribal and urban Indian facilities; federal, state, and local agencies; and other AI/AN health care providers or organizations. In general, "Tribes are very cautious about sharing information" with the state or with other tribes, perhaps because they are worried about "putting the community in a bad light."

3.4.1 State and Local Health Departments

Although respondents felt that it was important to work with state and local health departments to conduct surveillance, their perceptions of and experiences with these entities were often negative. For instance, some tribally affiliated participants expressed that state and local health departments do not seem interested in working with them: "I think we're [the tribe] willing to work with them, but they're not always willing to work with us." Similarly, both tribal and urban Indian participants said that data sharing tends to be one way; facilities may report to state and local health departments, but "they [states/counties] tend to keep information just to themselves." Other participants felt that "It's up to the states to work with tribes" and were unwilling to make the first move. This issue is made more complicated when tribal lands span multiple state jurisdictions.

Despite these perceptions and experiences, urban Indian facilities, and to a lesser extent tribally operated ones, do work with state and local health departments to conduct surveillance, but to varying degrees. This is particularly true for tribally operated facilities, which may voluntarily send surveillance data to state and/or county health departments whether or not a formal agreement exists. Such reporting relationships may not be sustainable in that they tend to rest on interpersonal relationships between individuals from tribal facilities and state and local health departments; thus, collaborations may terminate if one of the parties leaves his or her respective position.

"We need to have better document exchange, field records, and interview records exchange."

When formal data sharing agreements exist, as was the case with one of our respondents, tribal facilities rarely receive surveillance data back from states or counties; when they do, respondents reported that it is not necessarily useful to them. One respondent stated these needs: "We need to have better document exchange, field records, and interview records exchange." State and county surveillance reports do not contain tribal identifiers or present data by location (e.g., on- versus off-reservation). As one participant noted, "One of the problems that we have is identifying someone as a member of the community." Although this may not pose a significant problem in states with a limited number of tribes, the relevance and usefulness of surveillance reports are limited in areas with multiple tribes because individual facilities cannot tease out information related to their particular clinic population or area.

In addition to data, tribal and urban Indian facilities may receive other surveillance support from state and local health departments. State or local health departments may provide technical assistance, support in using computer-based data systems, or assistance with tracking individual cases who migrate.

3.4.2 IHS and Tribal Epidemiology Centers

Almost all participants' facilities work with IHS local area authorities to conduct surveillance. Most report surveillance data to their IHS area office and notify the nearest one if a known case is migrating to another area. Participants told us that, in return, IHS provides facilities with technical assistance and training, surveillance information, and assistance with tracking cases.

Unlike with IHS, collaborations with the network of Tribal Epidemiology Centers (TECs) are limited. (Tribal Epidemiology Centers which operate within tribal organizations such as regional health boards, were authorized by Congress to provide support to multiple tribes within IHS administrative areas.) Although one respondent indicated that the local TEC provides technical support, TECs are generally underutilized, perhaps because they are relatively new and tribes are unaware of the type of support they can offer. TECs are seen by some as having great potential to support surveillance.

3.4.3 Other AI/AN Facilities

"For continuity of care, I think that it is very important to keep in touch with [other facilities], but ultimately, it's the patient's responsibility."

Many tribal and urban Indian respondents acknowledged the importance of working in tandem with other AI/AN facilities to conduct surveillance; however, the extent to which they do so appears limited. Lacking facility-to-facility connections, tribal and urban health facilities' primary link is their patients. As one respondent phrased it, "For continuity of care, I think that it is very important to keep in touch with [other facilities], but ultimately, it's the patient's responsibility." Some respondents noted that potential for coordination may be limited, as in these remarks: "I don't think that keeping in contact with urbans [urban Indian health facilities] or other jurisdictions is very useful. The other day, I contacted another Indian health clinic and they don't keep records of ...members [from other tribes]."

Concerns about breaching patient confidentiality or a lack of interest or understanding of the usefulness of surveillance may also prohibit facilities from collaborating. For instance, one tribal health nurse told us that she tried to coordinate an intertribal response to a salmonella outbreak, but other tribes were not interested in cooperating. In contrast, one participant shared that his facility notifies the nearest urban Indian facility when a case migrates to a particular area.

3.5 SURVEILLANCE CHALLENGES

Several participants shared their difficulties in balancing surveillance with other priorities, especially since some were unclear about its importance, how the data are used, and what they will get in return for participating. Like other health care organizations, Indian facilities are overwhelmed by burgeoning rates of chronic diseases associated with obesity (e.g., diabetes, CVD) and are disappointed with the funding available to address these needs, let alone to conduct surveillance. As a result, facilities are often unable to secure the staff, facilities, and equipment needed to perform their clinical duties or to build their surveillance infrastructure and capacity.

Another challenge identified by participants, particularly tribally affiliated ones, is that most do not have formal relationships or clear lines of communication regarding surveillance with state and local health departments or with each other. One respondent, for instance, shared that his tribal health department tried to establish an intertribal Memorandum of Agreement (MOA) to increase communication but that nothing ever came of it. In other cases, participants reported that they attempted to establish relationships with outside entities, but the individuals with whom they communicated did not seem interested in working with them. Some respondents also felt that states and counties should initiate communication with them rather than the other way around.

Similarly, tribal and urban Indian facilities lack mechanisms for coordinating surveillance activities across jurisdictions, especially when cases migrate across county or state lines or from reservations to urban centers. Lack of coordination or willingness to collaborate seems to be rooted in a long history of AI/AN people's mistrust of federal, state, and local governments. Tribes in particular are concerned that if they ask states for help or share data, the community will be cast in a bad light. Although mistrust can be overcome through the establishment of interpersonal relationships, it takes time for these to develop. When coordination hinges on interpersonal relationships, it is often unsustainable because the responsibility lies with individuals rather than between jurisdictions.

3.6 SURVEILLANCE NEEDS

Participants identified several surveillance needs. For one, they expressed a desire for more training and technical assistance. In particular, they wanted more education about surveillance and felt that it would go a long way toward building capacity and participation level. Some examples included educating facilities about the basics of surveillance (i.e., who, what, where, when, and why to report) and teaching them how to use data to identify trends and respond to emerging health threats.

Participants identified the need for better behavioral surveillance data. Currently, most facilities do not routinely collect such data, nor do they have reliable outside sources for obtaining it. Data that are available tend to be fairly limited, unless facilities are receiving specific funding to collect information. Although large national surveys collect sociodemographic and risk behavior data, such as the National Survey on Drug Use and Health conducted by the Substance Abuse and Mental Health Services

Administration, results are not necessarily meaningful to individual tribes because data are presented for AI/AN people as a whole. However, respondents expressed skepticism that a tribal survey of behavioral risk factors would be successful: “Here in this community, many people don’t look favorably on surveys, because people are just trying to extract data from tribal members and they don’t benefit from this. While it would be good to track behaviors in tribal communities, like they do nationally, I see a resistance from the grassroots population.”

Many respondents also asked for help establishing processes or systems that yield meaningful data for AI/AN people. This may include assistance with building their facility’s infrastructure to diagnose and track individual cases or developing formal reporting agreements with state or county health departments that include channels for communication.

Participants also identified the need for timely and accurate data. Electronic reporting systems may ultimately increase the speed with which cases get reported and facilities receive data back from laboratories. One respondent described the process this way: “Clinicians report to the [tribal] public health department, who then reports to the state. Currently it is all on paper, but in the future, if we can have a secure reporting system, we could send the report electronically.” Several others noted the potential for human error in paper-based reporting systems. One respondent shared concerns about getting test results back from the state laboratory—and the implications for treatment and prevention as well as surveillance.

“Cross-jurisdiction tracking can be difficult.… If there was a database taking care of this, then these things wouldn’t happen.”

Respondents spoke to the need for a coordinated system. As one put it, “Cross-jurisdiction tracking can be difficult. We get lost in the shuffle sometimes and we don’t get good feedback and patients tend to be forgotten. If there was a database taking care of this, then these things wouldn’t happen.” Another noted that a coordinated surveillance system would alleviate some of the burdens each entity faces: “At this time, it is all left up to the local levels and individual health center clinics. It is very difficult for each individual tribe to invent the wheel. [We need] something at the national level and that has cultural sensitivity.”

Time and time again, participants cited a need for accurate racial/ethnic identifiers to address the health needs of native populations. The need for tribal identifiers was also clearly articulated by focus group and interview participants. As we learned early on, there is great heterogeneity among AI/AN people; thus, pooled surveillance data are not meaningful to individual tribes because they cannot estimate disease burden among their people. Respondents expressed that tribal identifiers may empower health officials to secure funding and plan programs that would address the public health concerns in their communities.

Similarly, participants were interested in identifiers that distinguish between persons living on reservations and those living elsewhere. This may require some capacity building: "We need to better educate the state and county health departments so that they can better identify which folks are the ones from [our] community by looking at their address." They thought that such an identifier would enable them to determine whether their facility or the state or local health department was responsible for tracking cases and ensuring follow-up care.

4 Conclusions and Recommendations

Findings from this report are meant to illustrate surveillance practices and experiences in tribally operated and urban Indian facilities. They are not intended to be generalized to these facilities as a whole; the Phase III survey should yield results that can be regarded as representative.

Clearly, there is a need to build on existing surveillance systems to make them inclusive of all AI/AN people. This will undoubtedly take time to accomplish, but there are several steps that can be taken in the short term to improve capacity and infrastructure for and participation in infectious disease surveillance among tribally operated and urban Indian health facilities.

First, it will be necessary to develop consensus about the place of infectious disease surveillance in serving the public health needs of AI/AN communities. Although some facilities understand the importance of surveillance and how to use data to protect and maintain the health of their people, this was not the case for all participants in this assessment. To build this shared vision, CDC, IHS or state and local health departments may wish to consider providing training and education to tribal and urban Indian facilities about surveillance's uses, how to conduct it, and how it will benefit their patients and facility.

For such efforts to be successful, it is imperative that tribal and urban Indian health facilities and state and local health departments work collaboratively to conduct surveillance;

however, this does not occur routinely. Tribal and urban Indian health facilities often believe that state and local health departments should reach out to them, yet these departments are not necessarily clear about their role in securing the health of Native people. CDC and IHS could help bridge this gap by working to develop stronger partnerships and collaborations between AI/AN health care facilities and state and local health departments that allow for cross-jurisdictional coordination for infectious disease surveillance. Partnerships and collaborations can take many forms and might be facilitated by the use of formal data sharing agreements, the establishment of clear lines of communication and authority (outlining who should respond or coordinate with others when surveillance data indicate a problem or an outbreak), and the enhancement of cultural competency at the state and local levels.

Along the same lines, the ability to respond efficiently and effectively to the public health needs of AI/AN people also rests on intertribal and tribal-to-urban Indian facility linkages. Open dialogue between tribes and tribal and urban facilities can perhaps be facilitated by federal agencies or AI/AN health organizations, such as the Association of American Indian Physicians or the National Council on Urban Indian Health. Once communication channels have been opened, there may be opportunities to establish intertribal or interfacility MOAs to formalize communication and enhance coordination within the Indian health care system.

Tribal and urban Indian health facilities also require more and better surveillance data, particularly for high-risk behaviors. CDC, IHS, and others can assist tribal and urban Indian health facilities in developing more efficient means for collecting and reporting surveillance data and in utilizing large national survey data to fill in any gaps. It is also possible that facilities could make better use of currently available clinical information systems, such as RPMS, to generate surveillance data, such as automated case reports. These in turn can be shared with state or county health departments or IHS. Additionally, when possible, increasing the timeliness of laboratory-based reporting would benefit facilities' disease prevention and control activities in that they could locate people more quickly for treatment (which is crucial in such a highly mobile population), thereby preventing transmission to others.

It will be equally important to establish communication and response protocols that clarify both tribal and urban Indian facilities' roles in responding to public health problems in AI/AN communities. It is not always clear which jurisdiction is responsible for coordinating a public health response that may cross city, state, or reservation boundaries.

Another way to improve surveillance capacity and infrastructure is to develop systems for tracking individuals who receive care from various providers, especially when individuals migrate between reservations and urban centers, while honoring expressed needs for privacy. As it stands now, many facilities are reluctant to discuss cases with other facilities because they are concerned about violating HIPAA regulations. Providing more education about HIPAA as well as assistance with developing confidential procedures for coordinating care may serve to alleviate this barrier.

Finally, it will be important to explore the potential role that TECs and IHS's epidemiology program may play in increasing surveillance capacity and data quality in tribal and urban Indian health care facilities. Both resources seem to be underutilized at this time, either because they are not perceived to be particularly helpful or useful or because their purposes are unknown.

5

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