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Q1: OPTIONAL: This recommendation was submitted by (please provide your first and last name, affiliation, and email address)

First Name	Ken
Last Name	Dunning
Affiliation	American Indian Community House, HIV/AIDS Program
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Q2: Title of your recommendation

Improve the accuracy of HIV/AIDS surveillance data on Native Americans

Q3: Please provide a description of your proposed recommendation

KEY BACKGROUND

- Historically, Native Americans have been mis-identified because of inaccurate identification and stigma/non-disclosure.

- What was historically a cloudy portrait of Native American HIV and AIDS incidence – both in New York State and nationally - became even harder to discern with the rise in the use of the “Multi-Race” category, with the reported cumulative number of AIDS cases among Native American in New York State actually declining significantly in recent years:

2005
- New AIDS diagnoses, Native Americans: 9
- Cumulative AIDS cases, Native Americans: 121

2006-2012
- New AIDS diagnoses, Native Americans: 30
- Cumulative AIDS cases, Native Americans (should be): 151
- Cumulative AIDS cases, Native Americans, reported: 88

It appears that AIDS diagnoses among 63 previously identified Native Americans have been re-classified into other racial/ethnic categories, coinciding with the increased use of the Multi-Race category; 63 of 151 previously identified AIDS cases among Native Americans (41.7%) are no longer reported as Native American.

- Who is considered to be Native American is a complicated issue. Each Native American nation/tribe has its own, separate criteria for member enrollment; blood quantum and lineage requirements vary. Some Native Americans having 50% or more blood quantum may not be considered Native American by their nations if the requirements for descent (e.g., matrilineal) are not met. The federal government considers members of

“federally recognize”’ tribes to be Native American. The Census includes all who self-identify as Native American. In many cases, however, multi-race Native Americans are often eligible/considered to be Native American.

- Long term anecdotal reports from Native American community based providers strongly suggest several trends:
• Native Americans have only recently started seeking HIV testing in larger numbers.
• Native Americans with and at highest risk for HIV face multiple barriers to seeking services, including stigma within the Native community, and not feeling comfortable to seek assistance outside of it.
• Many at-risk Native Americans do not seek medical care until they are really sick.

- Although Native Americans comprise roughly 1% of the population, and existing data samples are often not large enough to be statistically significant, there have nevertheless been key instances where the existing data has appeared to support anecdotal knowledge:
• In 2006 and 2007 combined – before the largest increases in the use of the Multi-Race category in 2008 and 2009 – 12 of 20 new HIV diagnoses among Native Americans were defined as late diagnoses. This rate of 60% was considerably higher – by a wide margin – than that of any other racial/ethnic sub-population.
• As of 2012, viral suppression among persons living with diagnosed HIV infection was lower among Native Americans than in any other racial/ethnic sub-population.

RECOMMENDATIONS

Revise and update the current methodology for identifying Native Americans for HIV/AIDS surveillance. Expand the definition of Native Americans to include those who identify as both Native American and Multi-Racial.

Continue to support Native American community based efforts to reduce stigma in the Native American community.

Q4: **For which goal outlined in the Governor's plan to end the epidemic in New York State does this recommendation apply? (Select all that apply)**	Identifying persons with HIV who remain undiagnosed and linking them to health care , Linking and retaining persons diagnosed with HIV to health care and getting them on anti-HIV therapy to maximize HIV virus suppression so they remain healthy and prevent further transmission

Q5: This recommendation should be considered by the following Ending the Epidemic Task Force Committee (Select all that apply)	Data Committee: Develop recommendations for metrics and identify data sources to assess the comprehensive statewide HIV strategy. The Committee will determine metrics that will measure effective community engagement/ ownership, political leadership, and supportive services. It will also determine metrics that will measure quality of care, impact of interventions and outcomes across all populations, particularly identified sub populations such as transgender men and women, women of color, men who have sex with men and youth. In addition, the Committee will evaluate to determine optimal strategies for using data to identify infected persons who have not achieved viral suppression and address their support service, behavioral health, and adherence needs.
Q6: Does this recommendation require a change to an existing policy or program, or the creation of a new policy or program?	Change to existing policy
Q7: Would implementation of this recommendation be permitted under current laws or would a statutory change be required?	Permitted under current law
Q8: Is this recommendation something that could feasibly be implemented in the short-term (within the next year) or long-term (within the next three to six years)?	Unknown

Q9: What are the perceived benefits of implementing this recommendation?

- This upgrade would move data surveillance on Native Americans forward to increase the level of its accuracy and completeness.

- More accurate and complete surveillance data will more effectively identify key needs (e.g., late diagnosis, lower rate of suppressed viral load, etc.) of HIV+ and highest risk Native Americans, and better inform the targeting of services for them.

- The Native American community will have a better glimpse of the full extent to which it is being impacted by HIV/AIDS, and more effectively inform the allocation of community based services and resources.

Q10: Are there any concerns with implementing this recommendation that should be considered?

The significant lack of complete and accurate data leaves a great deal of uncertainty. Infection rates and the level of associated issues could be higher than the existing data suggests.

Q11: What is the estimated cost of implementing this recommendation and how was this estimate calculated?

Unknown.

Q12: What is the estimated return on investment (ROI) for this recommendation and how was the ROI calculated?

While the costs associated with implementing this recommendation are not known, the perceived benefits of implementing it, which would ultimately facilitate greater engagement, linkage, and retention of HIV+ and highest risk Native Americans in care and/or prevention services, would help ensure the most cost effective approaches.

Q13: Who are the key individuals/stakeholders who would benefit from this recommendation?

- HIV+ and highest risk Native Americans, who will have better informed services targeted to their needs.

- Native and non-Native service providers looking to increase their long term engagement, linkage and retention of HIV+ and highest risk Native Americans.

- Native leadership, who will have a fuller range of data to underscore the full scope of Native community need.

Q14: Are there suggested measures to accompany this recommendation that would assist in monitoring its impact?

More complete and accurate data on Native Americans would include multi-race Native Americans who are:
• Enrolled members or eligible for enrollment in their nation/tribe.
• Children of enrolled members and/or have at least 25% Native American blood quantum.

Q15: This recommendation was submitted by one of the following Ending the Epidemic Task Force member