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On behalf of the American Indian and Alaska Native Health Research Advisory Council (HRAC), it is my pleasure to offer recommendations regarding research priorities for the various Health and Human Services (HHS) Operating and Staff Divisions. As we embark on serious discussions on health care reform in the United States, we have a unique opportunity to transform the Indian health system, including the manner in which research is carried out.

Since the HRAC's inception in the spring of 2006 and its official charter in June 2008, Tribal leaders have developed and provided input on health research priorities and needs of American Indians/Alaska Natives (AI/ANs). The HRAC serves three primary functions:

1. Obtaining input from Tribal leaders on health research priorities and needs for their communities for the purpose of developing an HHS wide AI/AN research agenda.
2. Providing a forum through which HHS operating and staff divisions can better communicate and coordinate AI/AN health research activities; and
3. Providing a conduit for disseminating information to Tribes about research findings from studies focusing on the health of AI/AN populations.

Representatives from several HHS operating and staff divisions participate in the HRAC including: the Office of the Assistant Secretary for Planning and Evaluation (ASPE), the Office of Intergovernmental Affairs (IGA), the Agency for Healthcare Research and Quality (AHRQ), the Indian Health Service (IHS), the National Institutes of Health (NIH), the Secretary's Office of Minority Health (OMH)/Office of the Secretary, and the Centers for Disease Control and Prevention (CDC).

In my limited time this morning, I would like to share concerns raised by the HRAC concerning the National Children's Study (NCS), general research recommendations, suicide in Indian Country, and the need for the development of Tribal consultation policies.

National Children's Study – While the HRAC fully supports the intent and purpose of the National Children's Study and its long-ranging impact on health care in the United States, the HRAC has identified several areas that could greatly benefit the study and more accurately reflect the American Indian/Alaska Native population.

The current NCS sampling frame anticipates inclusion of 2,000 American Indian children, primarily from the following areas:

- Arizona – Apache, Maricopa, and Pinal Counties
- Utah – Salt Lake County
- New Mexico – Valencia County
- Oregon – Marion County
- Washington – Grant County
- Arkansas – Benton County

While the 2,000 American Indian children is a reasonable representation of the total sampling frame and the selected counties do offer valuable information regarding the American Indian population, it does not sufficiently depict the true health picture of Indian Country. During the November 12, 2009 HRAC meeting, representatives highlighted the need to target areas suffering from the worst childhood health conditions in the United States. Specifically, the HRAC representatives cited Shannon and Buffalo Counties in South Dakota, which are located within the Pine Ridge and Crow Creek Reservations, respectively, and are rampant with poverty and poor health outcomes. Additionally, the HRAC identified the need to include Alaska Native communities that more accurately reflect the population.

The HRAC proposes a parallel study that directly targets additional counties and American Indian/Alaska Native (AI/AN) populations, which would compliment the current NCS sample. The HRAC would also like to offer the following regarding the AI/AN population within the NCS:

- Health research participants defined as American Indian or Alaskan Native must present proof of enrollment from a Federally-recognized Tribe as provided in the current 'Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs' or meet the BIA definition of American Indian or Alaskan Native as provided by a 'Certificate of Degree of Indian Blood.' Self-identification is inadequate and could potentially be inaccurate.
- Sampling protocols that promise to include preservation of DNA and tissue samples must be followed and Tribal Nations educated before, during and after as an on-going partner.

- Special consideration must be given to the treatment of blood and tissue samples.
 - Such samples should be treated as “non-renewable resources” and should not be used to develop cell lines to be used or shared in the future without prior consent of AI/AN participants and Tribal Institutional Review Boards (IRBs).
 - Further, researchers must consider the unique practices of Tribal Nations regarding blood and tissue sample disposal. Researchers must work in collaboration with Tribal Nations to develop protocols on collection, utilization, and disposal in a culturally appropriate manner.
- Commitment to Tribal sovereignty and consultation must be maintained.
- Commitment to honoring all necessary protocols regarding research in Indian Country, including review by all appropriate Institutional Review Boards (IRBs).
- De-identification of data must be reviewed with Tribal Nations.
- A data sharing agreement with Tribal Nations must be established in partnership with the Tribe before the local study commences.
- Study centers yet to be named could target Indian Country.

General Research Recommendations – The HRAC is acutely aware of the high and disproportionate rates of morbidity and mortality experienced by American Indians/Alaska Natives, therefore many of the recommendations focus on addressing the health disparities that continue to plague Indian Country. Additionally, the HRAC would like to recommend that HHS increase its activities to address the suicide epidemic in American Indian/Alaska Native communities.

In order to address the health concerns identified by the HRAC, research should focus on: data quality and accuracy to address under-representation of American Indians and Alaska Natives in population health data, the lack of access to health care services for AI/ANs in both rural and urban settings, lack of incorporation of traditional health care practices and traditional diets, the efficacy of health promotion/disease prevention activities, and the lack of health insurance coverage for AI/ANs. The HRAC has identified and recommends several research priorities (list is not prioritized), including:

- Quantification of Chronic Disease prevalence (e.g., cancer, heart disease, diabetes) and associated risk factors (e.g., obesity, diet, physical activity) through sustained support of prospective studies among AI/AN populations
- Chronic disease risk factor reduction
- Intentional and unintentional injuries
- Hypertension – evaluating methods to improve awareness and treatment of hypertension
- Stroke Prevalence/Prevention
- Methamphetamine Prevalence/Prevention

- Evaluation of the use of emerging technology (such as telemedicine, electronic health records, health information exchange, etc.) for the provision of care
- Health Services Research (such as utilization of prenatal care; preventable hospitalizations, emergency room utilization, etc).
- Auto Immune Disorders
- Suicide Prevention

In addition, efforts should be made to support research aims that attempt to understand exposure to risk and vulnerability over the lifespan to American Indian health due to social determinants such as social exclusion, marginalization and inequality. Research should address the complex interactions between health determinants and long term exposure to risk unique to American Indians and Alaska Natives as an Indigenous population.

It is important to stress that all research conducted should be evidence-based and to the extent possible, community-based participatory. Tribal governments are the rightful owners of their respective data and therefore all efforts should be undertaken to ensure Tribal governments are consulted before such data is shared with any entity. In addition to health concerns and research priorities, many barriers exist regarding research activities in Indian Country. These barriers could be addressed by:

- The elimination of impediments for collaboration, including information sharing, between Tribal Epi-Centers and HHS
- Increasing cultural sensitivity among researchers
- Increasing the number of AI/AN researchers. A possible avenue is through additional funding through the IHS Health Professions Scholarship Program and Loan Repayment Program specifically for research positions
- Improving the accuracy of data related to AI/ANs and the interoperability of data among HHS operating and staff divisions
- Increasing the amount of available comparative data: When research includes a comparison of racial or ethnic data that does not include American Indians and Alaska Natives, we recommend that HHS make oversampling a priority to provide this data for comparison.
- Improving infrastructure among AI/AN Tribal governments to increase Tribal capacity to carry out research and/or implement recommendations identified through research
- Increasing the amount of community driven research
- Providing Indian Health Service with a research funding line item to support research by and for American Indians and Alaska Natives
- Additionally, one of the most beneficial improvements would be the establishment of single data sources. As an example, the federal government maintains several AI/AN data sources through IHS, Bureau of Indian Affairs, Centers for Medicare & Medicaid Services, Centers for Disease Control and Prevention, National Institutes of Health, Substance Abuse and Mental Health Services Administration, U.S. Census Bureau, and several others. A single,

integrated internet accessible website with data available to calculate simple statistics, such as incidence and prevalence rates etc. would assist in identifying areas of focus within AI/AN communities. Additionally, the resource could provide access to published data as well.

While the HRAC would like to see more grants awarded directly to Tribal governments, we realize that academic institutions and research organizations are often the most suitable awardees for certain highly technical and advanced research grants. Unfortunately, when academic institutions and research organizations are awarded grants for research affecting AI/AN communities, no uniformity or requirements exist for collaboration and cooperation with Tribal governments. The HRAC recommends that grant requirements include demonstrated cooperation and collaboration with Tribal governments. While some grant awardees may consider such a requirement too burdensome, numerous resources exist to reduce any burdens on grant awardees. Resources that are readily available to assist include the HRAC, other AI/AN federal advisory bodies, area Indian health boards, Tribal epidemiology centers, and numerous others. We offer this recommendation not only because it is the right thing to do, but we have seen too many times where a research project has been rendered useless by the AI/AN community because it was conducted without adequate collaboration, or relied on illegitimate AI/AN expertise.

In addition to requiring Tribal collaboration and cooperation as part of grant funding requirements, it is important to have grant reviewers that have demonstrated experience with Tribal governments and are culturally sensitive. Such reviewers can ensure that grant applications adequately include collaboration and cooperation components, as well as evaluate grant applications from the AI/AN community which may have extensive subject matter experience but less academic credentials and degrees.

Suicide and Suicide-related behavior – I would now like to focus on an issue that continues to plague AI/AN communities; suicides and suicide-related behaviors. For too long, we have witnessed the toll suicide and related behaviors have taken on our communities. Unfortunately, the resources to address the problem, including research, has been lacking in Indian Country. We can no longer allow this to happen.

On a national level, many American Indian and Alaska Native communities are affected by very high levels of suicide, poverty, unemployment, accidental death, domestic violence, alcoholism, and child neglect. Suicides and suicide-related behaviors exact a profound toll on American Indian and Alaska Native communities. Suicides reverberate through close-knit communities and continue to affect survivors many years after the actual incident.

Using the latest information available, the American Indian and Alaska Native suicide rate (17.9) for the three year period (2002-2004) in the IHS service areas is 1.7 times that of U.S. all races rate (10.8) for 2003. Sadly, American Indian and Alaska Native young people ages 15-34 make up 64 percent of all suicides in Indian Country. (Trends in Indian Health).

According to the Institute of Medicine, an estimated 90 percent of individuals who die by suicide have a mental illness, a substance abuse disorder, or both. According to a 2001 mental health supplement report of the Surgeon General, “Mental Health: Culture, Race, and Ethnicity”, there are limited mental health services in Tribal and urban Indian communities. While the need for mental health care is great; services are lacking, and access can be difficult and costly.

Suicide is complex, and there is no single reason, cause, or emotional state that directly leads to suicide. Substantial research has been conducted on suicidal behavior, risk factors, and trigger events in the general population, but research within American Indian and Alaska Native communities is comparatively weak.

While the HRAC has focused on numerous health issues causing the high and disproportionate rates of morbidity and mortality in Indian Country, the HRAC has placed a priority on addressing the suicide epidemic in American Indian/Alaska Native communities. The HRAC has placed an emphasis on research that focuses on understanding exposure to risk and vulnerability over the lifespan and how it affects health due to social determinants such as the lack of incorporation of traditional health care practices/ traditional diets, social exclusion, marginalization and inequality.

The mental and behavioral health disparities that exist in American Indian and Alaska Native communities demonstrates a clear need to develop and implement strategies to begin to close the gap in research and access to services. The Department of Health and Human Services has a critical role to play in addressing these disparities including the lack of research on suicide in Indian Country. The Health Research Advisory Council recommends the following:

- American Indian and Alaska Native communities need to be involved at all levels of research, planning, and service delivery to create prevention programs that are truly community led and driven. This recommendation addresses both the considerations of sovereignty and the development of best practices for suicide prevention.
- Suicide prevention research needs to be framed to address and understand the issue of suicide from an Indigenous perspective, looking for cultural strengths and commonalities. Training also needs to be provided to support cultural competency and the development of research best practices, including qualitative methods.
- Funding agencies need to support long-term initiatives for suicide research efforts to be more successful in American Indian and Alaska Native communities.
- Discussions need to happen with Tribal and community leaders around the research, publication, and the use of data, establishing clear understanding and agreement around the release of the final data.

- Capacity-building needs to happen at all levels to inform researchers, funding sources, and government agencies of specific competencies needed for working with American Indian and Alaska Native communities; and to provide training and information for community members on the resources, skills, and strategies available for building program services.
- Support for community-driven program development to create prevention programs that are culturally relevant and successful and for evaluation for American Indian and Alaska Native communities to validate promising practices was recommended, along with the continued sharing of best practices and models between Indigenous communities.
- Increase collaboration across federal funding organizations involved in research to support the research priorities identified by Tribal leaders.

National Institutes of Health Tribal Consultation Policy – In closing, the HRAC remains concerned at the delay in the development of a Tribal consultation policy within the National Institutes of Health (NIH) in compliance with: U.S. Health and Human Services (HHS) Tribal Consultation Policy; Executive Order 13175, “Consultation and Coordination with Indian Tribal Governments;” and the November 5, 2009 Presidential Memo “Tribal Consultation For The Heads Of Executive Departments And Agencies.” NIH is mandated to develop its own policy to ensure meaningful and timely input by Tribal officials in the development of policies that have Tribal implications.

Tribal consultation policies have been effectively used by other HHS Operating and Staff Divisions to increase communication between Tribal Nations and the federal government and a policy within the National Institutes of Health could have a profound positive impact on the development of research policy to address serious medical and behavioral health issues plaguing Indian Country. The HRAC urges NIH to move forward in this effort.

In closing, it is important to stress that Tribal governments are the rightful owners of their respective data and therefore all efforts should be undertaken to ensure Tribal governments are consulted before such data is shared with any entity. The HRAC looks forward to continued collaboration with the various HHS operating and staff divisions to improve research activities affecting Indian Country. Thank you for the opportunity to offer remarks.