



# The Data Drum

Supporting Sovereignty through Tribal Control over Tribal Data

February 2016

## Get to Know the Collaborative Research Center for American Indian's Health Methodology Core

The mission of the Collaborative Research Center for American Indian Health (CRCAIH) Methodology Core is to offer support for research projects involving American Indian health, and assist their tribal partners in North Dakota, South Dakota, and Minnesota in building their research infrastructure. Their assistance with research projects can involve support for the planning and design of research studies, data analysis, and interpretation and presentation of results. Key areas of infrastructure building include the development of research data storage and management plans, and trainings on research methods and software used for data storage and analysis. They have also worked with tribal partners to design, implement, and present results for community health assessments, and identify existing sources of data on American Indian health. Overall, the Core works with tribal partners to understand current research interests, identify needs, and build mechanisms that further support the tribal research process. To learn more about CRCAIH and the Methodology Core visit [www.crcaih.org](http://www.crcaih.org), and join the Quarterly Tribal Data Partners Call on March 9, 2016 at 1pm EST.

**Call-In Information: 1-888-244-8150 Code: 1017767**

If you would like to receive more information on the next Tribal Data Partners call on March 9, 2016 at 1 PM EST and other information related to this group, please contact Jalene Herron at [jherron@ncai.org](mailto:jherron@ncai.org).

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The Data Drum is a product of the Policy Research Center of the National Congress of American Indians. It is supported in part by the National Science Foundation under Grant No. SMA-143605. Any opinions, findings, and conclusions or recommendations are those of the authors and do not necessarily reflect the views of the National Science Foundation. If you have any content to suggest for future issues please send ideas to Jalene Herron at [jherron@ncai.org](mailto:jherron@ncai.org).

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## Revising the Policy for the Protection of Human Subjects in Research

In September 2015, a Notice of Proposed Rulemaking (NPRM) to revise the Federal Policy for the Protection of Human Subjects (the “Common Rule”) was published in the Federal Register by 16 federal departments and agencies. The Common Rule outlines basic requirements for Institutional Review Boards (IRBs), informed consent processes, and assurances of compliance with research regulations—including aspects of data sharing and use. There are significant implications for research with tribal nations and American Indian and Alaska Native peoples in the NPRM and, while the revision process has been ongoing since 2011, the federal government has not established a parallel process of tribal consultation. NCAI worked to ensure that the interests of tribal nations and peoples were represented in prior calls for public comment on research policies, and we continued to build upon these efforts in response to the NPRM.

The public was originally given 90 days to review the lengthy document (519 pages with 88 specific questions and cost evaluations), consider possible implications, and submit meaningful comments. NCAI worked diligently to draft comments for submission on behalf of tribal nations and citizens, and to raise awareness of the comment process among our various networks. A NPRM Comment Resource and Template Letter were available online to assist tribal nations and organizations in understanding the implications of the proposed revisions and develop their own comment submissions.

Following requests from multiple institutions for a deadline extension, the U.S. Department of Health and Human Services granted a 30-day extension to the comment period just prior to the Thanksgiving holiday, and in late-December a letter was distributed to tribal leaders to announce that a Tribal Consultation Call would occur one day prior to the new January 6, 2016 comment deadline. On the call, which included a presentation of the proposed revisions by Dr. Jerry Menikoff from the Office of Human Research Protections, several tribal leaders expressed concern for the lack of tribal-specific language within the revisions and reiterated the need for full, meaningful consultation on the NPRM. Dr. Menikoff was also invited to present information on this process at [NCAI’s Executive Council Winter Session](#) at the end of February.

NCAI’s NPRM comment submission seconded concerns raised on the call and highlighted concerns related to consent for secondary research with biospecimens, consent for research with biospecimens or other data from people who are no longer alive, research oversight by tribal Institutional Review Boards (IRBs) and other tribal regulatory bodies, and research oversight for categories of research and activities important in tribal contexts.

We were pleased to see several tribes and organizations engaged in research with tribal citizens join the Tribal Consultation Call and submit comments. View those comments here: <http://www.ncai.org/policy-research-center/research-data/priorities/fed-res-priorities>. All NPRM public comment submissions are searchable at [www.regulations.gov](http://www.regulations.gov) under Docket ID #HHS-OPHS-2015-0008. NCAI will provide additional updates on the NPRM as they unfold. For further information, please contact Dr. Deana Around Him at [daroundhim@ncai.org](mailto:daroundhim@ncai.org).

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## Census Tribal Consultations

The US Census Bureau has scheduled a number of tribal consultations on the 2020 Census. The first in the series was held in Morton, MN, on October 7th. Three more sessions will be held in 2016. Further information about these consultations is available at:

[www.census.gov/aian/census\\_2020/](http://www.census.gov/aian/census_2020/)

## Tribal Leader/Scholar Forum

The 11th Annual Tribal Leader/Scholar Forum will be held on Wednesday, June 29th in Spokane, WA, as a part of [NCAI's Mid Year Conference](#). Our Call for Proposals emphasizes one of the primary policy concerns of tribal leaders across the globe, and especially in the Pacific Northwest: **climate change**. We seek proposals that address the idea of 'climate change', in both a specific and broad sense, and that allow us to work together to generate healthy, affirming climates for our precious peoples. The deadline to submit a proposal is Friday, February 19. For more information and to view the Call for Proposals visit our website: <http://www.ncai.org/policy-research-center/initiatives/tribal-leader-scholar-forum>

## NCAI's National Science Foundation Project Update and NSF Tribal Data Partners Update

NCAI is stewarding a project funded by the NSF to meeting three specific objectives: to describe the current status of tribal data capacity nationally; to support a small number of tribes in improving their tribal data capacity and sharing insights from that work; and accessing Census Research Data Center information that would be beneficial to tribes. We are planning to begin a scan of tribal data capacity this year and to convene tribal data partners at [NCAI's Mid Year Conference](#) in Spokane, WA. For more information on this project visit our website: <http://www.ncai.org/policy-research-center/initiatives/data-quality>

## Tribal Data Partners - Thoughts from December 9th Call

NCAI held its second Quarterly Tribal Data Call on December 9, 2015. Eileen Briggs, the Executive Director of Cheyenne River Sioux Tribal Ventures gave a presentation on her research related to tribal workforce development. For more information and to read their entire report, please visit the Tribal Ventures website: <http://crtribalventures.org/strategies-initiatives/individual-social-cultural/>

Zach Scribner from the Chickasaw Nation Office of Self-Governance spoke about the Tribal Data Exchange which grew out of the need for a centralized system to hold tribal based data. For more information on this work please visit: <https://www.tribaldataexchange.net/>

Our next Tribal Data Call will be Wednesday, March 9 from 1:00 - 2:30 PM EST

**Call-In Information: 1-888-244-8150 Code: 1017767**

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