

# THE STATE OF TRIBAL DATA CAPACITY IN INDIAN COUNTRY: KEY FINDINGS FROM THE SURVEY OF TRIBAL DATA PRACTICES

National Congress of American Indians
October 2018

# INTRODUCTION

Like other nation states, American Indian and Alaska Native (AI/AN) tribes are decision-making entities that need reliable information for planning and development. In the age of big data, tribes still rely on incomplete or inadequate data about their citizens and resources (Rodriguez-Lonebear, 2016). This lack of reliable planning data is only one symptom of the data gap in Indian Country. AI/AN populations remain both hard-to-count and hard-to-reach. They experience vast data inequities, such as being notable for the largest census undercount of any racial or ethnic group (U.S. Census Bureau, 2012), misidentification in vital and administrative records (Graber et al., 2005; Bertolli, 2007), and a persistent digital divide (Parkhurst et al., 2015).

Over the past two decades, there has been a mounting call by Indigenous scholars, tribal nations, and national organizations to address data access, ownership, and equity in Indian Country. The National Congress of American Indians (NCAI) passed several resolutions calling for access to quality data from various federal entities, including the U.S. Census Bureau (NCAI, 2017). Since 2001, the Native American Research Centers for Health (NARCH) initiative, administered by the National Institutes of Health and the Indian Health Service, funded numerous tribal academic research partnerships. The goals of the NARCH initiative are to increase the capacity of tribes and academic centers to conduct research, reduce distrust, and provide training to reduce health disparities in AI/AN communities while also building tribal research capacity and oversight (NIH, 2018). Tribal Epidemiology Centers, established under Section 214 of the Indian Health Care Improvement Act reauthorization in 1996, work to collect, analyze, and monitor health data on behalf of tribes, tribal organizations, and urban Indian organizations to help address data gaps (Tribal Epidemiology Centers, 2013).

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Many tribes now are interested in conducting their own surveys and censuses for local planning and governance. The demand for *Indigenous data sovereignty*: "the right of a nation to govern the collection, ownership, and application of its own data," is a growing effort (USIDSN, 2017). While the number of tribally-driven data projects has increased over time, from comprehensive tribal surveys to the development of tribally-led research review boards and data repositories, a comprehensive review of the extent of tribal data practices does not currently exist.

In order to better understand the landscape of individual tribal data practices across Indian Country, NCAI conducted a Tribal Data Practices Survey (TDPS). The overall objective of the TDPS was to assess current tribal data capacity and future needs. Specifically, the TDPS sought to understand: 1) the types of data or information tribes currently use; 2) how tribes access, collect, manage, and report these data; and 3) what types of data tribes need. This report includes the methods and key findings from the TDPS.

# **METHODS**

# **Setting**

NCAI is the oldest, largest, and most representative national organization serving the broad interests of AI/AN tribes, and it works to protect the inherent and legal rights of tribal governments in the U.S. (NCAI, 2018a). The NCAI Policy Research Center was established by NCAI in 2003 as a national tribal research and policy center. It is focused on developing research and data that support and inform the policy efforts of tribal leaders and others to promote proactive, future-focused strategy and decision-making (NCAI, 2018b). This project was completed as a part of a National Science Foundation (NSF) grant to NCAI with the aim to improve tribal data quality and capacity for data-intensive research by building a community across tribes, social scientists, and federal agencies committed to the collection and dissemination of data on AI/AN populations.

# Survey Design and Sample

The TDPS instrument was developed and informed by a series of stakeholder interviews at the 2016 NCAI Mid Year Conference during which input was gathered on a draft survey instrument. Two group interviews were conducted with representatives from five tribes that received pilot grants from NCAI to conduct their own censuses and surveys. Individual interviews were conducted with eight attendees at the 2016 NCAI Mid Year Conference, and they represented a mix of tribal leaders, tribal staff, researchers, and employees of tribal organizations. A total of seventeen individuals provided feedback on the draft survey instrument and topic areas.

The TDPS was conducted between October 2016 and April 2017. The population of interest for this survey was all AI/AN tribes. At the time, there were 567 federally recognized AI/AN tribal

nations (U.S. Bureau of Indian Affairs, 2017), nearly 100 state recognized tribes, and numerous tribes seeking federal and state recognition.

Since the TDPS was both an exercise in collecting information from tribes and in evaluating the best methods for doing so, examining the response patterns among as many tribes as possible was important. The goal was to invite all 567 federally recognized tribes to complete the survey.¹ The complete list of 567 federally recognized tribes, including contact information for the officially designated leader, from the Department of Interior's Bureau of Indian Affairs website was used. The information was cross-checked with the NCAI tribal membership list.

To maximize survey response, TDPS utilized a mixed-mode survey collection approach: in-person, online, and by mail (Dillman et al., 2014).

- In-person survey: Surveys were collected in person on project iPads during the NCAI 73<sup>rd</sup> Annual Convention & Marketplace from October 10-14, 2016 by ten trained survey assistants and project staff. The survey assistants were recruited from the University of Arizona and Arizona State University. Each survey assistant was trained on research ethics and survey research. On site recruitment during the Convention was utilized with TDPS signs and banners featured throughout the site. A dedicated survey collection space was also prominently positioned outside the Convention's General Assembly room, and announcements to complete the TDPS were made during General Assemblies. Anyone attending the Convention was allowed to complete the survey.
- Online survey: The online survey was advertised to launch at the 2016 NCAI Convention
  and an online link to the survey remained open through April 2017. Individuals were
  recruited to complete the online survey through email messages from NCAI's "Constant
  Contact" marketing platform with the headline "Complete the Tribal Data Survey Today!"
  which were sent three times in November 2016, December 2016, and January 2017. Online
  responses spiked following the mass emails.
- Mail survey: In order to increase response rates following the in person and online surveys during the NCAI Annual Convention in November 2016, a hardcopy survey and stamped return envelope were sent by mail to all tribal leaders of federally recognized tribes that were not documented to have completed an in person survey at the Convention or an online survey as of that date. Leaders of state recognized tribes that were members of NCAI and who did not complete a survey at the Convention were also included in the mailing. NCAI's internal mailing list was used for tribal contact details.

<sup>&</sup>lt;sup>1</sup> We also invited responses from representatives of state recognized tribes who are members of NCAI using a write in option.

#### Measures

The TDPS survey included 25 questions on selected topics related to tribal data capacity. The survey began with a request for the respondent to identify for which tribe he/she was completing the survey. A drop-down menu was used in the online version that listed each federally recognized tribe in the U.S., as identified from the U.S. Bureau of Indian Affairs website. Respondents were also asked to identify the approximate number of enrolled tribal members, the role of the respondent (elected/appointed tribal leader, tribal staff member, or other), and a scale to rate the level of knowledge of the respondent about the tribe's efforts to collect data.

Information collected on the survey about the tribe's data capacity included the following: groups on which they collected data (enrolled members living on or off the reservation/homeland; other Indians or non-Indians living on the reservations/homeland); whether the tribe has conducted its own census or survey of tribal members in the last 5 years; sources of funding for these efforts; whether they are interested in conducting their own tribal census or survey in the next 5 years; whether they have or are interested in having a central data office or hub to manage data; what kinds of data the tribe has already; and what barriers they experience to the collection and/or use of data on tribal members.

The survey also included questions on current use of data, including whether tribes collected specific types of data, such as tribal enrollment data and tribal program data, how they funded this collection of data, and whether tribal program data is shared among other programs. The survey questions asked if tribes have an Institutional Review Board or committee that approves research conducted on tribal lands or with tribal members, and how the tribes protect the privacy of information they collect on individuals. The respondents were asked if and how they use certain sources of federal, state, county, and other data, in which areas they need more information on tribal members, and various concerns they might have about the U.S. Census and the accuracy of federal data sources. The final question asked the respondent to rate the importance of tribes collecting or having access to data on their tribal populations for governance purposes.

# Analysis

A total of 253 surveys were completed: 207 surveys were collected on iPads during the NCAI Annual Convention; 43 surveys were collected online; and only 3 were returned by mail. After an initial analysis of all respondents, the survey team decided to only include those individuals who identified as an elected or appointed leader or staff designee of a federally recognized tribe in the analyses. Other individuals were excluded because the survey team took the position that only tribal leaders or staff are able to complete a survey on behalf of a tribal

nation.<sup>2, 3</sup> Further, while representatives of state recognized tribes who are members of NCAI were invited to respond, only 11 responses were collected and the decision was made to exclude these responses from this analyses due to the low response rate. A summary of the survey findings for state recognized tribal respondents is available upon request. Future tribal survey projects may want to consider developing a targeted outreach and collection strategy for state recognized tribes.

Of the 253 unique responses, 40 respondents who identified as someone "other" than a tribal leader or tribal staff designee were excluded from analyses. As mentioned above, 11 state-recognized tribal respondents were excluded from analyses. Two respondents who did not indicate their role were also excluded from analyses. Lastly, three respondents who did not indicate their tribe were excluded from analyses. The final sample included 197 responses from federally recognized tribal leaders or tribal staff who provided a valid tribal name and who consented to take the survey. More than half of participants (57 percent) were elected or appointed tribal leaders and 43 percent were tribal staff members. However, as a result of the open recruitment of respondents at the Convention, there were in some cases multiple responses from individual tribes. This result was not consistent with the goal of the survey to assess tribal data capacity at the level of the tribe.

Therefore, in this analysis, individual survey respondents (tribal leaders or tribal staff) were clustered within the tribe with which they identified and were not treated as independent observations. To obtain appropriate statistical estimates for tribes, a weight was created to adjust for the fact that 30 tribes had responses from more than one individual. For example, the weight applied to responses in the analysis was 0.5 for all tribes with responses from two individuals. The final effective sample includes 122 tribes represented by 197 individuals who completed the surveys. These probability weights were used to calculate descriptive statistics and inferential analyses at the tribal level.

<sup>2</sup> In order to restrict responses to these individuals, the survey instructions stated: "We request that elected or appointed tribal leaders, or their designees, complete this survey. Completing the survey may require input from multiple tribal staff members, such as those responsible for tribal enrollment data or tribal program oversight. You are encouraged to consult with others to best answer these questions."

<sup>&</sup>lt;sup>3</sup> Among the 40 respondents who identified as someone other than a tribal leader or tribal staff designee, specific roles such as researcher, former tribal president, and tribal member were listed.

# **RESULTS**

# Respondents

The TDPS respondents account for a broad sample of tribes with representation in all Bureau of Indian Affairs regions as illustrated in Table 1. In each region, 11 to 44 percent of tribes participated in this study.

Table 1: Regional Representation of TDPS responses4

BIA Region	Total Number of Tribes (#)	Number of Tribes Responding (#)	Percent response in region (%)
Great Plains	16	7	44%
Midwest	30	13	43%
Southwest*	25	10	40%
Western	42	15	36%
Northwest	45	14	31%
Rocky Mountain	8	2	25%
Eastern	30	7	23%
Pacific	104	23	22%
Southern Plains	24	4	17%
E. Oklahoma	20	3	15%
Alaska	227	24	11%
Total	577	122	21%

Note: in order to maintain the anonymity of all tribal responses, the Navajo and Southwest regions were combined. As the Navajo region is only affiliated with one tribe, and maintaining the separate Navajo BIA region would violate the guarantee of tribal anonymity.

In addition to geographic diversity, the tribes represented in the TDPS analysis varied in size as depicted in Table 2 below. The majority of tribes who completed the survey had 5,000 or fewer tribal citizens (68 percent).

 $<sup>^4</sup>$  Tribal classification by BIA region was obtained through the BIA's Tribal Leaders Directory Map, which can be found at www.bia.gov/sites/bia.gov/libraries/maps/tld\_map.html?utm\_source=Gen-l%20Master%20List&utm\_campaign=26644776c3-WHTNC\_2016\_Blast8\_4\_2016&utm\_medium=email&utm\_term=o\_c456a66794-26644776c3-112872621&ct=t%28WHTNC\_2016\_Blast8\_4\_2016%29&goal=o\_c456a66794-26644776c3-112872621&mc\_cid=26644776c3&mc\_eid=da24845cb4

Table 2: Population Size of Tribes Responding to TDPS

Tribal Size	Number	Percent
1,000 or less	35	29%
1,001-5,000	48	39%
5,001-10,000	16	13%
Larger than	21	17%
10,000		
Missing	1	1%
I don't know	1	1%
Total	122	100%

# Experience conducting tribal censuses and surveys

The overwhelming majority (96 percent) of respondents indicated that they were at least "somewhat knowledgeable" about the survey's subject matter. Eighty three percent of the tribes who responded to the survey indicated that it is extremely important for tribes to collect or have access to data on their tribal populations for governance purposes.

Almost half of tribes have conducted a tribal census or survey of their members in the last five years (43 percent), and three quarters of tribes (75 percent) were interested in conducting their own tribal census or survey of tribal members in the next five years. The majority of tribes currently collect or use data on their tribal citizens living on tribal lands (85 percent), and slightly less (72 percent) for tribal citizens living off tribal lands. Fewer tribes are collecting or using data on other Indians and non-Indians living on their tribal lands (51 percent and 38 percent respectively).

#### **Data Use**

Tribes indicated that the primary use of tribal data on members was to complete grant or other required reporting (76 percent). Other frequently identified uses of data include communicating with tribal members (69 percent), service delivery (61 percent), and setting tribal priorities and strategic goals (60 percent) (Table 3).

Table 3: Tribal use of data on its tribal members

Response	Frequency	Percent
Complete federal grant or other required	149	76%
reporting		
Communicate with tribal members	135	69%
Service delivery	121	61%
Set tribal priorities and strategic goals	118	60%
Develop a budget	110	56%
Communicate with others outside the tribe	74	38%
Other	11	6%
I don't know	7	4%
Missing	5	3%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages total over 100 percent because respondents can select more than one response option.

Tribes indicated use of a variety of external sources of data on its tribal members. The U.S. Census Bureau data was reported to be the most commonly used data source, followed by the U.S. Bureau of Indian Affairs, and the U.S. Department of Housing and Urban Development (Table 4).

Table 4. Tribal Use of External Data Sources

Data Source	Frequency	Percent
U.S. Census Bureau	139	70%
Bureau of Indian Affairs	134	68%
HUD – Department of Housing and Urban	120	61%
Development		
State Agency	60	30%
County Agency	41	21%
University and Colleges	47	24%
Other Federal Agency	28	14%
Pantribal Organizations (e.g. tribal	26	13%
epidemiology centers)		
Other Source	19	10%
Missing	14	7%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages total over 100 percent because respondents can select more than one response option.

# **Data Funding**

The TDPS survey included questions on the source of funding for various tribal data practices. Tribal money and federal grants and contracts appear to be the main sources of funding for the three types of tribal data practices reviewed in this survey (Table 5). Of the tribes who indicated they had conducted a tribal census or survey in the last five years, the majority used tribal money (64 percent) and federal grants and contracts (45 percent) to fund the project. Tribes that collect and maintain tribal enrollment data are also mainly using tribal money (71 percent) and federal grants and contracts (39 percent). Similarly, tribes that are funding the collection and maintenance of data for service delivery most frequently use tribal money (73 percent) followed by federal grants and contracts (61 percent), among other sources.

Table 5: Funding Sources for Three Tribal Data Practices

Funding Sources	Conduct Tribal Census or Survey # (%) *	Collection and Maintenance of Tribal Enrollment Data # (%) **	Collection and Maintenance of data on participants in service programs # (%) **
Tribal money	54 (64%)	141 (71%)	145 (73%)
Federal grants and contracts	38 (45%)	77 (39%)	121 (62%)
State grants and contracts	5 (6%)	14 (7%)	49 (25%)
Foundations, companies, non-profit organizations, universities, colleges, etc.	o (o%)	5 (3%)	25 (13%)
Other	2 (%)	3 (1%)	7 (4%)
I don't know	6 (7%)	o (o%)	o (9%)
Missing	112 (57%)	13 (7%)	13 (7%)

<sup>\*</sup> Note: number of respondents=197; number of tribes=122. The denominator for all census or survey funding sources is 85, the number of tribes who indicated they had completed a tribal census or survey in the last 5 years. Percentages are weighted for response at tribal level. The denominator for missing is 197. Percentages total over 100 percent because respondents can select more than one response option.

# **Data Management and Privacy**

Some tribes indicated that they do have formal mechanisms to approve research conducted with tribal members or conducted on tribal lands, such as an Institutional Review Board (IRB) or committee (28 percent). Many tribes are taking control of data management through other strategies. Nearly three quarters of the tribes (74 percent) have a data hub or central data

<sup>\*\*</sup> Note: number of respondents=197; number of tribes=122. Percentages are weighted for accurate tribal response. Percentages total over 100 percent because respondents can select more than one response option.

office where tribal data is managed. Another 64 percent reported that service programs participant data is being shared between tribal departments (Table 6).

Table 6: Tribal data management

Response	Frequency	Percent
Tribe has a central data office or hub – a main office where the tribe's data are managed	145	74%
Data sharing about participants in service programs occurs between tribal departments or tribal agencies	127	64%
Tribe has an IRB or committee that approves research conducted with tribal members or conducted on tribal lands	55	28%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level.

Tribes are often concerned with protecting the privacy of their tribal citizens with regard to data collection, management, and use. In this survey, the most frequently identified means of ensuring privacy of data that the tribe collects from individuals is employee confidentiality training (64 percent), followed by obtaining the authorization of individual tribal members (52 percent), and tribal ordinances or codes (49 percent) (Table 7).

Table 7: Tribal data privacy

Response	Frequency	Percent
Employee confidentiality training	127	64%
Authorization by tribal members	102	52%
Tribal ordinance or code governing tribal data and information	96	49%
Data security infrastructure	95	48%
No privacy protection is currently in place	6	3%
I don't know	19	9%
Other	11	6%
Missing	5	3%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages total over 100 percent because respondents can select more than one response option.

#### Data Needs

Tribes expressed a wide range of areas in which they need more or better tribal data on their tribal members. The most frequently identified need area is tribal language fluency and/or other cultural information (61 percent), followed by education level (58 percent), health (57 percent), housing (57 percent), demographics (57 percent), and employment status (56 percent) (Table 8).

Table 8: Tribal data needs

Response	Frequency	Percent
Tribal language fluency and/or	120	61%
other cultural information		
Education level	114	58%
Health	112	57%
Housing	112	57%
Demographics (age, gender,	111	57%
household composition, etc.)		
Employment status	110	56%
Income	102	52%
Current contact information	96	49%
(mailing address, email and/or		
phone)		
Date of tribal enrollment	46	24%
Other	20	10%
Missing	14	7%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages total over 100 percent because respondents can select more than one response option.

#### Concern about Government Data Collection

Tribes have significant concerns about government data collection on their populations. Tribes were specifically asked about the U.S. Census because the 2020 Census is quickly approaching and Al/ANs have been undercounted in each decennial. Not surprisingly, a little over 80 percent of tribes indicated they were concerned or very concerned about the accuracy of U.S. Census tribal population data, the usefulness of Census data to tribes, how the federal government uses Census data on tribal populations, and tribal input into Census decision-making. Beyond the U.S. Census, 89 percent of tribes are concerned about the accuracy of other federal, state, or local government data on tribes (Table 9).

Table 9: Concern about issues with the U.S. Census data on the tribal population (%)

Issue	Very	Concerned	Not very	Not at all	I don't	Missing
	concerned		concerned	concerned	know	
Accuracy of the	50%	32%	11%	3%	2%	3%
count						
How the federal	47%	34%	12%	3%	2%	3%
government uses						
Census data						
Usefulness of	42%	41%	10%	2%	3%	3%
Census data to the						
tribe						
Tribal access to	39%	32%	16%	6%	4%	3%
Census data						
Tribal input into	53%	29%	8%	4%	4%	3%
decision-making						
about Census data						

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages may total over 100 percent due to rounding.

In addition, 90 percent of tribes indicated concern about the accuracy of federal, state or local tribal population data other than the U.S. Census (Table 10).

Table 10: Concern about the accuracy of federal, state, or local government tribal population data (other than the US Census)

Response	Frequency (#)	Percent
Very concerned	122	62%
Concerned	54	28%
Not very concerned	10	5%
Not at all concerned	4	2%
I don't know	1	1%
Missing	6	3%

Note: number of respondents=197; number of tribes=122. Percentages are weighted for response at tribal level. Percentages may total over 100 percent due to rounding.

# **DISCUSSION**

Overall, 83 percent of survey respondents acknowledged that it was extremely important to collect or access data on their tribal citizens for governance purposes. However, the results of this survey paint a varied landscape of data experiences in the ways tribes are engaging in data access, development, and management. Almost half of the responding tribes have conducted a survey or census of their tribal members. The majority of these tribes paid for these surveys or censuses with tribal money, and almost half were funded by federal grants and contracts. These same sources of funding were also used for collecting and maintaining tribal enrollment data, and collecting and maintaining data on participants in tribal service programs. The costs for collecting and reporting federal program data can be a very high cost for tribes (NCAI Policy Research Center, 2017a).

Further, not all tribes have the resources to invest the substantial funding required to conduct these types of data activities. While there is a need for tribes to prioritize tribal funding to support data development, targeted funding specifically for tribal censuses, surveys, and data practices from non-tribal sources, such as federal, state, and local governments, the private sector, and foundations, is also of great importance. The experiences of tribes conducting surveys and censuses themselves have revealed a number of barriers and challenges, including the need for adequate staffing and funding (NCAI Policy Research Center, 2017b). The need for resources for tribes to collect their own data presents an opportunity for mutually beneficial partnerships between tribes and external data experts across the academic, corporate, and government sectors.

The survey results found that many tribes are taking action to manage and protect the privacy of their data through the use of central data offices or data hubs (74 percent). However, far fewer tribes have established an IRB or committee to review and approve research conducted with tribal members or conducted on tribal lands (28 percent). Many of the tribes that have taken action to manage and protect the privacy of their data are documenting their efforts, presenting their best practices at conferences, and increasingly publishing resources on the development of tribal IRBs, research codes, and review committees. In this survey, tribes also indicated which strategies they are using to protect the privacy of tribal member data. These findings are in line with existing research on the emergence of data governance mechanisms in Indian Country (Rainie et al., 2017c). As more tribes are exercising their sovereign right to control data and research in and about their communities, the number of tried and tested mechanisms for tribal data governance is sure to grow. Recommended strategies include growing tribal data champions, focusing on good data stewardship practices across tribal and urban communities, and creating intertribal connections.

Tribes indicated a wide range of data needs to support their ability to govern. They particularly expressed concerns about federal, state and local data sources, with the U.S. Census and other federal data sources being of most concern. These concerns are significant since these data

sources influence so many different resources and funding streams that may disproportionately benefit tribes depending on their accuracy (NCAI Policy Research Center, 2017c). The ability to conduct their own tribal censuses and surveys may help confirm or replace some of this data, but the accuracy of federal sources of data also needs to be addressed given the potential impact on current and future resources for tribes and their citizens.

The TDPS is the first national survey of tribal nations focused on assessing tribal data capacity related to tribal censuses, surveys, and use of data for tribal governance purposes. Nearly one quarter of all federally recognized tribes across the country participated in the TDPS (22 percent), which marks one of the highest response rates of a national survey of AI/AN tribes. Though not every tribe in the U.S. participated, the respondents were from every region of the country. The results provide the most comprehensive baseline information to date on tribal data practices related to tribal censuses, surveys, and practices beyond individual tribal case studies.

A scan of AI/AN research suggests that surveys of tribal nations on this topic are uncommon. AI/AN individuals are typically the targeted respondents of most surveys, and a case study approach is often used in research with tribal nations. Most of the surveys identified in this review involving tribal nations were conducted by federal agencies. These include the 2002 Bureau of Justice Statistics' Census of Tribal Justice Agencies and the 2017 Department of Housing and Urban Development's Assessment of Native American, Alaska Native, and Native Hawaiian Housing Needs. The scope of federal program surveys, however, is different than standard social surveys because they are closely linked to grant compliance and funding.

A recent non-federal survey of tribal nations was identified - the 2016 California Tribal Gaming Impact Study - which included 14 tribes in California (Beacon Economics, 2016). Another large national survey of tribes was conducted by the National Indian Health Board (NIHB) and reported in 1998. The NIHB survey aimed to assess tribal perspectives on self-determination and self-governance in healthcare of 587 tribes and tribal organizations, and this included the 554 federally-recognized tribes at the time (Shelton B.L.et al, 1998). A total of 210 tribes and tribal organizations participated in that study, which included 38 percent of federally recognized tribes. The respondents included tribal leaders and health directors who were asked about a broad range of questions on their perspectives of federal vs. tribal management of healthcare. The only questions relating to tribal data capacity were related to assessing the quality of care and the need for more funding to measure quality. In the NIHB survey, the invited respondents were only one tribal leader and one health director from each tribe and their responses were analyzed separately. As a result, the NIHB survey did not have the challenge of multiple respondents per tribe as was present in the TDPS survey and did not require a weighted analysis.

The status of tribes as sovereign nations has been reaffirmed by the Supreme Court, Congress, U.S. Presidents, and hundreds of treaties. In exchange for ceding millions of acres of land to the U.S., tribal nations received, among other guarantees, the right of continued self-

governance on their own lands as stipulated in numerous treaties and laws. While tribes have increasingly worked to build their data capacity and practices, more work is needed to help tribes receive the training, technical assistance, and resources they need to fully practice sovereignty with regards to data about their tribe and its members. Efforts in the U.S. and abroad towards promoting indigenous data sovereignty hold promise to create a movement further towards this goal (Kukutai & Taylor, 2016).

# **LIMITATIONS**

While a census of all 567 federally-recognized tribes was attempted, the TDPS did not achieve a complete response. After controlling for the occurrence of multiple responses for some tribes, the final sample included 197 individuals from 122 federally recognized tribes. Therefore, the results are not representative of all tribes across the country. The regions with the lowest representation in the survey were Alaska, Eastern Oklahoma, and Southern Plains regions. Feedback from Alaska Native respondents suggests that an Alaska-specific strategy is needed with questions and wording tailored to the unique relationships Alaska Native communities have among each other and with other sovereigns. Though not representative of the entire population of 567 federally recognized tribes (now 573 as of March 2018), the key findings provide an informative snapshot of the state of tribal data practices and needs across much of Indian Country.

Regarding methods, the TDPS experience demonstrated the challenges in administering a survey to all tribes, and the differential response rates of various survey modes, including inperson, on-line, and mail surveys. In particular, the mail survey yielded very few responses even after a significant amount of national advertising for the Convention and a personal letter of invitation. Mail surveys have typically lower response rates compared to other survey modes (Dillman et al., 2014). One reason for the low mail response to the TDPS may be that the surveys were mailed at the end of November, during the start of the holiday season. Specific reasons are unknown, but it is clear that the low TDPS mail response did not justify the expense and effort of a mail survey mode. The results were not analyzed by recruitment method to determine if there were differences in responses.

Another limitation of this survey was that the specific tribal leader or tribal staff member respondents were not further categorized as to their power over decision-making or whether they truly could speak for the tribe on this topic. However, 96 percent did indicate they were at least somewhat knowledgeable about the topic. It is unknown if the responses would be different if the survey was administered to just one person designated by the tribe to answer, or just one tribal leader since about one quarter of the tribes had multiple respondents. The survey team was not able to confirm or validate answers on respondent category, which were self-reported. Methodological limitations common with most survey research include self-selection bias, measurement error due to different interpretations of survey questions, and non-response bias.

# RECOMMENDATIONS

- Ensuring accurate, relevant, and timely tribal data should be considered part of the federal trust responsibility. Federal agencies should provide technical assistance and direct financial support for tribal data practices through official government-to-government consultation.
- Building data infrastructure and capacity in Indian Country presents opportunity for mutually beneficial partnerships between tribal nations and academic, corporate, nonprofit, and government sectors.
- 3. Engaging in tribal data practices is costly. Cost sharing between tribes, perhaps regionally, and exploring other funding mechanisms is an important catalyst in this work.
- 4. Federal agencies, particularly the U.S. Census Bureau, need to build trust as they engage with tribes. Agencies should focus efforts on ensuring tribal input into decision-making, and improving the accuracy of federal data and tribal access to this information.
- 5. Tribes need to expand their data collection efforts to include non-Indians and non-tribal members living on reservations and tribal homelands. With the extension of tribal jurisdiction over non-Indians in certain criminal and civil circumstances, it is imperative that tribes have information on all people living within their lands.
- 6. To grow a data workforce in tribal communities, tribes should prioritize the development and incorporation of data science curricula in local schools and tribal colleges and universities.
- 7. Intertribal collaboration is critical to sharing best practices and facilitating tribal data innovation. Tribes should also look to partner with organizations serving urban Indian populations.
- 8. Continued support for building tribal data capacity utilizing existing successful initiatives across Indian Country is essential, including support for tribal and urban programs, such as the Native American Research Centers for Health or the Tribal Epidemiology Centers.
- 9. Tribes need to continue to assert control over research and data efforts in their lands, with their citizens, and about their resources.
- 10. In addition to collaboration among AI/AN tribes, tribes can also engage in international collaboration with other indigenous communities on data governance to share best practices.

# ABOUT THIS PUBLICATION

This publication was produced as part of a series of monographs from the NCAI Policy Research Center's project "Using Science to Build Tribal Capacity for Data-Intensive Research." This material is based on work supported by the National Science Foundation (NSF) under Grant No. 1439605. Any opinions, findings, and conclusions or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of NSF.

The NCAI Policy Research is grateful for the collaborative work of the NSF project team members: Desi Rodriguez-Lonebear, Malia Villegas, Yvette Roubideaux, Amber Ebarb, Deana Around Him, Sarah Pytalski, Norm DeWeaver, Gregory Hooks, and C. Matthew Snipp. As an NCAI Doctoral Data Fellow, Desi Rodriguez-Lonebear led development of the Tribal Data Practices Survey in collaboration with Dr. Malia Villegas and the NCAI Policy Research team, and supervised and participated in all aspects of its design, conduct, analysis of the data, interpretation of results, and writing of the report. The authors wish to thank the survey assistants from the University of Arizona and Arizona State University, Dr. Stephen Cornell, Dr. Tahu Kukutai, Dr. Jane Zavisca, Dr. Daniel Martinez, Elijah Moreno, and all of the AI/AN tribal leaders and staff members who participated in this project.

Suggested Citation: NCAI Policy Research Center (2018). The State of Tribal Data Capacity in Indian Country: Key Findings from the Survey of Tribal Data Practices. Washington, D.C.: National Congress of American Indians.

# **HUMAN SUBJECT PROTECTION**

This study was approved by the Indian Health Service Institutional Review Board (#N16-N-06) and the University of Arizona Institutional Review Board (#1609856985).

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