Considerations for Tribal Communities in the Collection and Security of Sensitive GIS Data

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The National Indian Justice Center, Inc. (NIJC) is an Indian owned and operated non-profit corporation with principal offices in Santa Rosa, California. NIJC was established in 1983 through the collective efforts of the National American Indian Court Judges Association, the American Indian Lawyer Training Program, and the Bureau of Indian Affairs in order to establish an independent national training and technical assistance resource for Native communities and tribal governments.

The goals of NIJC are to design and deliver legal education, research, and technical assistance programs which seek to improve the quality of life for Native communities and the administration of justice in Indian country.
NIJC currently administers the following training and technical assistance programs:

- Western TTAP – Tribal Transportation Training and Technical Assistance funded by FHWA and BIA
- CTAS Area 4 – Tribal Corrections and Alternatives to Corrections funded by DOJ
- Tribal Solid Waste Programs funded by RDU, USDA
- Native American Children Training Forum funded by the California Department of Emergency Management

NIJC conducts a regional training program for tribal government and particularly tribal court personnel

NIJC is also contracted to provide training programs about tribal jurisdiction to state and federal agencies.
NIJC staff participate on the following organizations and events:

- Transportation Research Board’s ABE80 - Native American Transportation Issues Committee
- Native American Advisory Committee to Caltrans
- California’s Administrative Office of the Courts Access and Fairness Subcommittee
- National Organization for Victim Assistance

Over the past 6 years, I have witnessed the following:

- Tribal leaders that share maps of their sacred sites in public forums not understanding the risks posed by audience members taking pictures of the screen.
- Academic researchers volunteering students to gather GIS data about tribal sacred sites but then publishing their findings without the consent of the tribe. In fact, the tribe did not know about the plans to publish.
- Caltrans requesting tribal GIS data to include in transportation planning and accidental turn over of more data than was requested including information about several sacred sites locations.
My Request

• Tribes and GIS personnel must develop security protocols and data use agreements that govern the gathering, usage, publication and sharing of tribal GIS data.

• Given the scope of the battle to strengthen and expand tribal jurisdiction; given the battles fought over research in tribal communities; these tools will help tribes prevent misuse of data and loss of important cultural information.

• Let’s begin with a the foundation for the development of such laws within tribal jurisdictions.

• We’ll discuss the cornerstones of Federal Indian Law, Research concerns in tribal communities, several of the more difficult research issues and strategies to employ GIS in ways that strengthen tribal communities.
Tribal Sovereignty and Jurisdiction

• Sovereignty is the Right of Self-Governance.
  • It is the right of an entity to make its own laws and to be governed by them.

• Jurisdiction
  • The scope of people, places and activities to which those laws apply.
  • It may be more than that which is within the mapped boundaries of tribal lands.
Sovereign Status of Indian Tribes

• Tribal Sovereignty was initially recognized by the U.S. as a result of having entered into treaties with Tribes.
  • The U.S. only negotiates treaties with sovereign entities.
  • The U.S. may expand or contracts its recognition of tribal sovereign authority.
Johnson v. McIntosh (1829)

- This case applied and adopted the Discovery Doctrine into U.S. case law.
- Discovery Doctrine gave the U.S. the exclusive right to extinguish the original tribal right of possession by purchase or conquest.
- Discovery Doctrine only left Tribes with the Right to Use and Occupy the Land.
- This theory gave the U.S. Government title to all land as a result of having arrived onto the continent.
- U.S. Supreme Court held that Indians did not have the power to give (nor could a non-Indian receive from an Indian) title to land upon which Indians lived.
- This case served to protect federal land grants (federal land patents) which the federal government used to settle the territories.
Cherokee Nation v. Georgia (1831)

- State of Georgia attempted to apply state law over Cherokee Nation in an effort to “annihilate the Cherokees as a political society.”
- Cherokee Nation filed suit as a foreign nation directly in U.S. Supreme Court.
- U.S. Supreme Court held that Cherokee Nation was not a foreign nation but a **Domestic Dependent Nation**.
Worcester v. Georgia (1832)

• Two missionaries were sentenced to 4 years hard labor by state of Georgia for residing in Cherokee Nation without a license and without taking oath to support the Georgia Constitution and laws.
• Worcester challenged the jurisdiction of Georgia Courts.
• U.S. Supreme Court held that Indian nations were distinct, independent political communities in which state law has no effect.
• President Jackson purportedly said Marshall has made his decision, now let him enforce it. No mechanism in place to enforce, South Carolina tries to leave the Union, Jackson begs Georgia to let missionaries go. Missionaries pardoned in 1883.
Trust Relationship

• Initially, the Federal government established an exclusive relationship with Tribes. This relationship excluded the states and state authority over tribes. This responsibility was described as the relationship of a “guardian to its ward.”
  • Now it is called the Trust Relationship.
• Pursuant to the Trust Relationship, the federal government owes a fiduciary duty to the tribes to protect the tribe’s beneficial interests in the lands and resources held for their benefit.
**Federal Tribal Trust Relationship**

**BENEFICIARY**
*Entity entitled to receive the principal and/or income from the trust*

**SETTLOR**
*Entity that creates a Trust*

**TRIBES**

**TRUSTEE**
*Creates Trust, Manages Assets, Holds Fiduciary Responsibility*

*Common law prohibits the settlor and trustee from being the same entity to protect against mismanagement of assets.*
Trust Relationship

Trustee = all federal branches of government

Res (lands and resources held in trust for Tribes or their members)

Beneficiary = Tribes and their Members
Intellectual Property

• Intellectual property (IP) refers to creations of the mind:
  • inventions, literary and artistic works, and symbols, names, images, and designs used in commerce.
Scope of IP Protection

- These rights allow artists to protect themselves from infringement, or the unauthorized use and misuse of their creations. Trademarks and service marks protect distinguishing features (such as names or package designs) that are associated with particular products or services and that indicate commercial source.

- HOWEVER, Tribal Cultural property is difficult to protect with the current array of federal and state IP laws.
  - Indian Arts and Crafts Act
  - NAGPRA
  - Tribal and Indian Health Services - IRB
A geographic information system (GIS) lets us visualize, question, analyze, interpret, and understand data to reveal relationships, patterns, and trends.
Problematic Research in Indian Country
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- Research with radioactive iodine (I131) early 1950s, USAF
  - "Do Alaska Natives survive the cold by having higher metabolism?"
  - Gave I131 to Alaska Native people
    - same amount as then used for thyroid scan
    - almost all AN did not speak English
    - long term effects of thyroid scan not then known
  - 3 AN women in the research were breast feeding children
  - (Research Answer: not higher metabolism; just better knowledge of how to dress)

- Navajo uranium miners, 1950s
  - dust in uranium mines known to cause lung cancer
  - AEC refused to regulate mining
  - PHS study, "natural history"
    - health exam Q2Yrs, tracked deaths
    - did not inform participants of known health effects or reason for study
  - Bodies piled up by 1960s, regulation started

- Kidney biopsies, children, & acute glomerulonephritis (AGN)
  - 2 epidemics of impetigo causing AGN on a Reservation, late 1950s
  - researchers did kidney biopsies on AI children with impetigo but who did not yet have AGN to see the earliest electron microscopic changes in AGN

- Barrow, Alaska study on alcoholism
  - 1970s, researchers from northeastern US announced findings in press conference held at their eastern institution
  - Internal stigmatization by people from Barrow & nearby communities
  - Bonds on Wall Street adversely affected

- Congenital syphilis epidemic, 1980s
  - Reservation not named in publication
  - Indian children taunted
  - Gas stations refused to let Indian people to use restrooms

- Hantavirus, summer 1993
  - 50% of infected people died
  - first recognized on the Navajo Reservation
  - CDC found cause <10 days (virus in deer mice)
  - helped NNDOH develop prevention programs
  - NNDOH asked CDC not to give Navajo place names in scientific articles
  - First 2 articles, CDC named the Navajo Chapters –where the people lived who were infected first and where the deer mice and other animals were trapped
  - Navajo approved no research for >13 months
Genetic Piracy:
The Havasupai Suit against Arizona State University
Genetic Research in Indian Country

- Researchers must take into account how the politics of tribal sovereignty can be affected by their research.
- No where is this more evident than in the debates within Native American communities, about medical research, particularly genetics research to address such issues as:
  1. diabetes
  2. alcoholism
  3. enrollment, and
  4. attempt to show that American Indians “were not the first Americans.”
- Generalizing about “tribal perspectives” on genetics research is very difficult, as there are varied and multiple responses. Some communities have chosen to actively engage in genetics research, and may even view it as an important future solution to the diabetes epidemic and now some Tribal nations are using it to address enrollment eligibility questions now be asked as a result of gaming revenue.
- Other tribal communities have placed strict moratoria on genetics research and will not approve any genetics research protocols.
- One of the fears often cited by tribal nations is that genetics research will be used to discredit tribal sovereignty because researchers will attempt to show that Native Americans “were not the first Americans.”
Genetic Research as an Advocacy Tool

- Tribes must clearly ask the question “what is the purpose of genetic research within our community?”
- Does the tribal membership support this research? Who has access to the data? How will the data be used?
  - **Local tribal rules must be developed to govern research and use of the data.**
- As tribes exert more control over the research and ownership over the data, they can partner with advocates to develop or change local, state and national policy.
- This in turn will increase ability to access more resources for their governmental programs and facilities.
- More importantly, tribal communities should drive the research to focus on the issues critical to their communities (i.e. SIDS, Cancer).
Havasupai: A Case of Genetic Piracy

- **A RARE GENETICALLY ISOLATED POPULATION...** The Havasupai Indian Tribe has had little contact with the outside world due to its rich traditional culture and the remote location of the Havasupai Reservation in the Grand Canyon.
- The Tribe is a rare “founder society” derived from a small group of individuals, and its geographic and cultural isolation have made Havasupai DNA less heterogeneous than the rest of the world.
- In addition, anthropological records have charted the genealogical history of nearly every adult member of the Tribe. As a result, access to the Havasupai’s genetic material and information is extremely valuable to genetic researchers.
A DEADLY DIABETES EPIDEMIC...

• The Havasupai Tribe suffers from a staggering diabetes epidemic.
  • A Professor of Anthropology at Arizona State University (ASU) who gained the trust of the Tribe after decades of work with the Tribe, offered to help the Tribe address the diabetes program.
  • A team of researchers at ASU designed a program to provide diabetes screening and education to the Havasupai Tribe. The ASU team met with the Havasupai Tribal Council and requested permission to enter the Reservation and draw blood from the Tribal Members to test for diabetes.
• The Tribal Council approved the diabetes program and encouraged Havasupai Tribal Members to submit to the blood testing to screen for diabetes.
• Over the course of several years, ASU drew the blood of nearly the entire adult population of the Havasupai Tribe.
RESEARCH WITHOUT CONSENT...

• Before ASU obtained approval from the Tribal Council to enter the Reservation, and before blood was taken from Tribal Members, ASU secretly applied for a grant to conduct research unrelated to diabetes using Havasupai blood samples. ASU conducted research to study schizophrenia and “inbreeding” in the Havasupai population using the Tribe’s blood samples, but never informed the Tribal Council or the Tribal Members of such research.

• The ASU researchers published research articles on schizophrenia and “inbreeding” in the Havasupai population, stigmatizing the Tribal Members.

• Then, Havasupai blood samples were transferred to the University of Arizona, where the blood samples were used in studies to support the “Bering Strait theory” of ancient human migration, which holds that American Indians are not indigenous to the North American continent.

• The Bering Strait theory contradicts the traditional spiritual beliefs of the Havasupai, which hold that the Tribe originated in the Canyon.

• ASU received lucrative grants and published numerous articles unrelated to diabetes using Havasupai blood samples and/or DNA.

• The ASU researchers created cell lines from the Havasupai blood samples and sent the Tribe’s DNA to research institutions and for-profit pharmaceutical laboratories across the world.

• ASU never informed the Tribe or its Members about these unauthorized activities and always represented its research as solely a diabetes program.
• After the blood samples were exploited for several years, an internal investigation was launched by ASU which resulted in a comprehensive report.
  • The report found that ASU failed to obtain written consent from tribal members as required by federal law, and concealed its unauthorized research from the Tribal Council.
  • Nevertheless, ASU never apologized for deceiving the Havasupai people.
• As a result, the Havasupai Tribe filed a lawsuit (Havasupai Indian Tribe v. ABOR, et al.) against the Arizona Board of Regents and several genetic scientists for fraud, negligence and other violations of state and federal law. A separate lawsuit (Tilousi v. ABOR, et al.) was filed by a group of Havasupai tribal members for lack of informed consent, negligence and emotional distress.
• The Havasupai cases have issues of great significance regarding genetic and indigenous rights.
  • The Havasupai defeated several attempts by the Defendants to dismiss the cases on technical and procedural grounds.
  • The Havasupai are encouraged by the support they have received from Indian Tribes and Inter-Tribal Organizations across the country including the Inter-Tribal Council of Arizona (ITCA), the California Nations Indian Gaming Association (CNIGA), the National Indian Gaming Association (NIGA), the Salt River Pima Maricopa Indian Community and the Navajo Nation.
Who provides IRB Approval?

- IRB of your own institution,
- IRB of tribe [if any],
  - "Tribal review" is not "Tribal IRB review"
  - Some tribes may have an internal IRB process (i.e., Cherokee Nation, Navajo Nation, Alaska Native Health Consortium)
- IRBs of IHS [if applicable], AND
  - if IHS is involved in any way
  - if tribe/clinic asks IHS IRB to do review
- Tribal government reviews & approves as well
- Structure: IHS IRBs
  - Based on IHS Areas
  - Alaska & Navajo Area IHS IRBs have dual authorization
  - IHS & tribe/Consortium
  - Two-tier, sometimes duplicate review
  - HIS Area Office, plus Headquarters
- Structure: implications
  - Complex, time consuming
  - Submit protocol concurrently, not sequentially
  - Submit at least 6 months before start date
Data Gathering to Implementing Change

- Quantitative evidence is necessary for obtaining legislative policy (which determines available resources) required for implementing change.
- The communities that want change must design the questions that are going to be asked, determine who is asking them and set forth why they are asking them in order to get the necessary data to implement change to their benefit. (education statistical, health care, environmental, telecom, etc...)
- Without this culturally sensitive approach to research, change and implementation may be difficult.
- We have to know:
  - how to define the problem,
  - the extent of the problem,
  - the resources that we have to address the problem,
  - the partners that we will need to address the problem.
NCAI PRC Guiding Principles

• Nationally focused;
• Resulting in improved quality of life for Native people;
• Timely, relevant and proactive, anticipating and addressing policy issues on the horizon;
• Advancing tribal discussion about policy options and future scenarios;
• Tightly aligned with Indian Country (e.g. information should flow from Indian Country to guide and inform the work of the Center, and information produced within the Center should flow back to Indian Country for use in local decision-making and national policy development);
• Honoring tribal ownership of data and the role of the community in research;
• From a Native perspective (e.g. tribally-driven);
• Credible (e.g. valid, reliable, using sound scientific standards, raising the standards for quality research in Indian Country);
• Building the capacity of tribal communities and Native scholars to determine local research agendas, collect and analyze data, and develop research expertise; and
• Leveraging partnerships and collaboration (e.g. rather than developing and relying solely on our own expertise, the Center collaborates in various ways with diverse partners to create networks of experts, leverage scarce resources, strengthen the feedback loop of new information to Indian Country, and add value to existing work).
NCAI PRC Core Values (excerpt)

• We believe that policy research should honor the government-to-government relationship and the sovereignty of American Indian and Alaska Native tribal governments. Policy research should facilitate the improved exercise of tribal self-determination. The goal of the Center’s work is to develop information that allows tribal communities to make more informed decisions about their own futures.
• We respect the sovereignty of tribal governments and believe that tribes own their data.
• We believe that the perspective of Native people and communities is important. Cultural understanding is essential for moving forward in exploring policy issues, research, and scenario development for policy solutions. Indigenous knowledge is as valid as academic knowledge. As Native researchers and policy analysts, we need to go back to who we are as Native people in order to be stronger in the future. Our work should be holistic and spiritually-rooted.
• We believe that research must preserve culture or it does not add value.
• We believe that policy research should honor Native values of sharing and respect. Research should respect the differences between and within tribal communities.
• We believe that policy research should focus, not on blame or bad choices, but on solutions. Policy research should be a paradigm shift that focuses away from reacting to the policy agendas of others outside of Indian Country to proactively developing a Native-driven policy agenda.
• www.ncaiprc.org
Security Measures – Key Terms

- **Data sharing**: Granting certain individuals or organizations access to data that contain personally identifiable information with the understanding that personally identifiable or potentially identifiable data cannot be re-released further unless a special data-sharing agreement governs the use and re-release of the data and is agreed upon by the receiving program and the data provider(s).

- **Data-sharing agreement**: Mechanism by which a data requestor and data provider can define the terms of data access that can be granted to requestors.

- **Data release**: Dissemination of data either in a public-use file or as a result of an ad hoc request which results in the data steward no longer controlling the use of the data. Data may be released in a variety of formats including, but not limited to, tables, microdata (person records), or online query systems.

- **Data dissemination**: Any mechanism by which data are made available to users. Includes mechanisms whereby data are released to users as well as mechanisms whereby data are made available without being released.

- **Sensitive Site Data - identifiable information**: As defined by (the Tribe), any information about an individual sacred site or other sensitive site, including (1) any information that can be used to distinguish or locate the site; and (2) any other information that is linked or linkable to a specific site, such as images, descriptions, surrounding markers.
Proposed Guiding Principles

1. Sensitive data should be acquired, used, disclosed, and stored only for legitimate purposes as endorsed by the tribes with interests in the data.

2. GIS programs should collect and report only the minimum amount of identifiable information necessary.

3. GIS programs should have strong policies to protect the privacy and security of site identifiable data.

4. Data collection and use policies should reflect respect for the rights of tribes and minimize undue burdens on the sites.

5. GIS programs should have policies and procedures to ensure the quality of any sensitive data they collect or use.

6. GIS programs have the obligation to use and disseminate summary data to tribal government stakeholders in a timely manner.

7. GIS programs should seek authorization to share data for legitimate environmental protection, site preservation, or public health and safety purposes and may establish data-use agreements to facilitate sharing data in a timely manner.

8. Sensitive data should be maintained in a secure environment and transmitted through secure methods.

9. Minimize the number of persons and entities granted access to sensitive site data.

10. GIS program officials should be active, responsible stewards of sensitive data.
Security Measures – Policy Structure

• **Scope**
  • Relevant data
  • Purpose of the data collection(s)
  • Terms of use and data sharing

• **Access and roles**
  • Level of access to confidential data by position (including staff who use the data daily as well as IT/data management staff)
  • Roles of persons who have/need access to data

• **Overall responsible party (ORP)**

• **Data release**
  • Rules governing release of data (with reference to a separate data release policy document)
  • Methods by which information will be disseminated and shared (including circumstances requiring a data-release agreement)

• **Data-sharing agreements/plans**
  • Procedures for implementing data-sharing agreements/plans
  • IRB procedures, if IRB approval required

• **Routine communications with confidential, identifiable data**
  • Procedures for communications requiring the sharing of confidential, sensitive site data with other project areas, both tribal, non-tribal providers, state and federal entities

• **Physical data security**
  • Procedures to ensure a secure physical environment (e.g., access to rooms, security screens, backup storage, file cabinets, storage of hard copies, use of shipping companies, opening of mail, and removal of information from secure areas)

• **Electronic data security**
  • Procedures to ensure a secure electronic environment (e.g., transfer and storage of electronic data, data backups, use of different media devices [PDAs, tablets, laptops, and thumb drives], and encryption requirements)

• **Transmission of data**
  • Procedures on transmission of data via physical mail, fax, e-mail, and other emerging electronic/wireless technologies

• **Investigation of suspected breaches and identification of jurisdiction should action be required**
  • Processes, tools, and forms to investigate and document suspected breaches of protocol and/or confidentiality
  • Chain of information/action/response

• **Training**
  • Requirements for annual, standard training on data security confidentiality policies and procedures, including a review of the written documents
  • Requirements for documentation of training

• **Appendix - Nondisclosure or confidentiality agreements**

• **Appendix - Glossary of terms**
Security Measures – Policy Structure

1. Data Sharing
   a. GIS personnel shall implement the requirements of reference (b) and share data across functional and organizational lines, with other Tribal agencies in accordance with applicable policy, regulations, Tribal and Federal laws.
   b. Tribal GIS Personnel shall ensure all spatial and geospatial data is secure and available for use by authorized personnel in accordance with the with the [computer network] architecture, except where specifically permitted or excluded due to classification restrictions or by policies established by the functional dataset leads.
   c. Release of geospatial information will be accompanied by a non-disclosure statement or agreement to ensure the receiving party understands and abides by the limitation and use of the specific geospatial information. At a minimum, all GIS data, reports and maps shall have a minimum classification of [“For Tribal GIS/Governmental Official Use Only”].
   d. All department personnel with management responsibilities will establish a data distribution policy that is centrally managed to ensure the controlled access to and distribution of geospatial data.

2. Data Security
   a. [Tribal GIS Dept.] will serve as the office of primary responsibility for geospatial information security policy. Functional dataset leads for each dataset will determine the classification level and access constraints for each dataset. Functional Dataset Leads will coordinate the classification level and access constraints for all assets designated as “critical” by the Tribal government.
   b. The Tribal GIS department will establish protocols for handling geospatial information and ensuring the appropriate protection of geospatial information.

3. Data Ownership
   a. All original data gathered by the Tribe, its GIS department and GIS consultants will be owned by the Tribe. All products produced using original tribal GIS data is the intellectual property of the Tribe and should be marked with a copyright and year to indicate intent of tribal ownership.
   b. Permission to use original tribal GIS data shall be obtained from the Tribal GIS department pursuant to policies adopted by the tribal government. Any use of original tribal GIS data without authorized permission shall be a violation of this policy and will be actionable in a court of competent jurisdiction.
Security Measures – Proactive Steps

- Buffer the points using large units and a random offset or centroid, only show or share the maps and not the raw data.
- Drop the point within the geometry and join the attributes with a larger parent polygon so that the site is somewhere within the shape.
- Row Level Security (RLS) - RLS implements privileges on the rows (GIS features) that individual users or user groups can select/update/delete. (Authorizes viewing of specific features on specific layers.)
References

• Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Injury Prevention


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