EXPLORING LEGAL ISSUES IN TRIBAL PUBLIC HEALTH DATA AND SURVEILLANCE

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INTRODUCTION

Tribes are sovereign nations with a government-to-government relationship with the United States.[1] Within the United States, there are 573 federally recognized Tribal nations[2] with distinct governments, cultures, and histories.[3] Each Tribe exercises both political sovereignty and cultural sovereignty through Tribal governance[4] and their unique cultural teachings.[5] As part of the exercise of this sovereignty, Tribes have the inherent authority to engage in public health activities that support the safety and welfare of their citizens.[6]

An essential component to public health practice includes the collection and surveillance of health data.[7] Surveillance data allows for the identification of health issues as well as instances in which certain populations are being disproportionately burdened by these health issues.[8] This data is essential to effective policymaking.[9]

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1 COHEN'S HANDBOOK OF FEDERAL INDIAN LAW, § 4.01[1][a] (Nell Jessup Newton et al. eds., 2012).

2 INDIAN ENTITIES RECOGNIZED AND ELIGIBLE TO RECEIVE SERVICES FROM THE UNITED STATES BUREAU OF INDIAN AFFAIRS, 83 Fed. Reg. 34863 (July 23, 2018).

3 NATIONAL CONGRESS OF AMERICAN INDIANS, TRIBAL NATIONS AND THE UNITED STATES: AN INTRODUCTION (2019), http://www.ncai.org/tribalnations/introduction/Tribal_Nations_and_the_United_States_An_Introduction-web-.pdf.

4 Cohen's Handbook, *supra* note 1, § 4.

5 Wallace Coffey & Rebecca Tsosie, *Rethinking the Tribal Sovereignty Doctrine: Cultural Sovereignty and the Collective Future of Indian Nations*, 12 STAN. L. & POL'Y REV. 191, 196 (2001).

6 Williams v. Lee, 358 U.S. 217, 271 (1959); United States v. Wheeler, 435 U.S. 313, 322–3 (1978); Aila Hoss, *A Framework for Tribal Public Health Law*, 20 NEV. L. J. (forthcoming 2019).

7 *The Public Health System & the 10 Essential Public Health Services*, CENTERS FOR DISEASE CONTROL AND PREVENTION, https://www.cdc.gov/publichealthgateway/publichealthservices/essentialhealthservices.html (last visited Aug. 21, 2019).

8 Samuel L. Groseclose & David L. Buckeridge, *Public Health Surveillance Systems: Recent Advances in Their Use and Evaluation,* 38 ANN. REV. OF PUB. HEALTH 57, 57-79 (2017).

9 *Public Health Surveillance*, WORLD HEALTH ORGANIZATION, https://www.who.int/ topics/public_health_surveillance/en/ (last visited Aug. 21, 2019).

Law is the foundation of public health practice, including the underpinnings of public health data collection and surveillance[10] and ensuring the privacy of such data.[11] Much has been written on public health data and surveillance at the state and local level.[12] Yet, Tribal law and the federal laws that define the relationships between Tribes, states, and the federal government add an additional complexity to the collection and surveillance of law for American Indian and Alaska Natives.

This article explores legal issues in Tribal data and surveillance. First, this article provides a summary of Tribal public health and health care systems. Next, it outlines surveillance laws and practical challenges in Tribal surveillance. Finally, it describes some of the legal strategies used to promote effective data collection and surveillance.

I. TRIBAL PUBLIC HEALTH AND HEALTH CARE SYSTEMS

Tribal public health and health care systems include a variety of entities across both various governments and nonprofits. Red Star Innovations modeled these entities in a report on Tribal public health, which includes (1) community health; (2) Tribal governments; (3) Tribal health departments and clinics; (4) federal agencies; (5) private industries; (6) local/state health departments; (7) Tribal colleges; (8) community leaders; and (9) Tribal-led organizations/Tribal Epi Centers (Figure 1).[13] This article will not be discussing each of these entities, although all are pivotal in Tribal public health practice. Instead, this article will discuss certain entities with emphasis on those with legal authorities related to public health data and surveillance. This section briefly discusses these entities below.

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10 Lawrence O. Gostin, et al., *The Law and the Public's Health: The Foundations*, LAW IN PUBLIC HEALTH PRACTICE 38 (Richard A. Goodman et al. eds., 2d ed. 2007).

11 James G. Hodge Jr., et al., *Identifiable Health Information and the Public's Health: Practice, Research, and Policy*, LAW IN PUBLIC HEALTH PRACTICE 246-52 (Richard A. Goodman et al. eds., 2d ed. 2007).

12 *See*, *e.g.*, Guthrie S. Birkhead & Christopher M. Maylahn, *State and Local Public Health Surveillance in the United States*, PRINCIPLES & PRACTICE OF PUBLIC HEALTH SURVEILLANCE 399-417 (Lisa M. Lee et al. eds., 3d ed. 2010); Chesley L. Richards, et al., *Advances in Public Health Surveillance and Information Dissemination at the Centers for Disease Control and Prevention*, 132(4) PUBLIC HEALTH REPORTS 403 (2017).

13 TRIBAL PUBLIC HEALTH INSTITUTE FEASIBILITY PROJECT, PROJECT FINDINGS REPORT 5 (2013), https://redstarintl.org/wp-content/uploads/2018/12/tphi_findings_report.pdf.

Figure 1: Tribal Health Systems, Red Star Innovations[14]

A. Tribal Governments

At the core of Tribal public health and health care systems are Tribal governments exercising their inherent authority to promote public health.[15] The structure of Tribal governments varies from Tribe to Tribe.[16] However, many Tribes maintain health agencies responsible for public health surveillance activities. For example, the Navajo Nation's Department of Health is responsible for the quality of the Tribe's health care and public health services.[17] As designated by the Navajo Nation Council, the authority of the agency includes "establish[ing] and operat[ing] an information system

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[14] *Id.*

[15] Hoss, *supra* note 6.

[16] MATHEW L.M. FLETCHER, FEDERAL INDIAN LAW 235 (2016).

[17] Navajo Department of Health Act § 1602 (2014), http://www.navajo-nsn.gov/News%20Releases/OPVP/2014/nov/Navajo%20Department%20of%20Health%20Enacted.pdf; *see also,* NORC AT THE UNIVERSITY OF CHICAGO, A PROFILE OF TRIBAL HEALTH DEPARTMENTS 16-17 (2012).

center to collect, manage, control and protect data related to health care, public health, epidemiological surveillance, research and disease investigations."[18] The mission of the Seminole Tribe of Florida's Health Department is to both provide quality health care and promote the health of the community.[19] Part of the duties of the Health Department include compilation of vital statistics, such as births and deaths, as well as the collection and analysis of health data.[20]

The Rosebud Sioux Tribe maintains a Tribal Health Board with the responsibility of developing and coordinating the Tribe's health and human service programming.[21] The Board, which includes members from the Tribal Council, the President, and two at large members, is responsible for "[g]athering information and data as to health, human services and home improvement resources and unmet needs in health, human services and home improvements of the Reservation Area."[22]

B. Inter-Tribal Health Boards

Many Tribes are members of inter-Tribal health boards, cross-Tribal organizations that promote health across regions.[23] For example, the Great Plains Tribal Chairmen's Health Board was founded in 1986 and represents eighteen Tribes across the Great Plains area.[24] The Northwest Portland Indian Health Board serves forty-three Tribes across Oregon, Washington, and Idaho.[25] The organization engages in health promotion, policy analysis, technical assistance, and surveillance.[26] Several Tribal Epidemiology Centers, discussed below, are housed within inter-Tribal health boards or other inter-Tribal organizations.[27]

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18 Navajo Department of Health Act § 1604(C) (2014).

19 *Health and Human Services*, SEMINOLE TRIBE OF FLORIDA, https://www.semtribe.com/STOF/services/health-and-human-services (last visited Aug. 22, 2019).

20 *Health Information Management,* SEMINOLE TRIBE OF FLORIDA, https://www.semtribe.com/STOF/services/health-and-human-services/health-information-management (last visited Aug. 22, 2019).

21 ORDINANCE NO. 93-05 ROSEBUD SIOUX TRIBE (November 3, 2004), https://narf.org/nill/codes/rosebudcode/Ord_93-05.pdf.

22 *Id.*

23 *NIHB Member Organizations*, NATIONAL INDIAN HEALTH BOARD, https://www.nihb.org/about_us/area_health_boards.php (last visited Aug. 22, 2019).

24 *About GPTCHB*, GREAT PLAINS TRIBAL CHAIRMEN'S HEALTH BOARD, https://gptchb.org/about/ (last visited Aug. 22, 2019).

25 *About NPAIHB*, NPAIHB: INDIAN LEADERSHIP FOR INDIAN HEALTH, http://www.npaihb.org/about-us/ (last visited Aug. 22, 2019).

26 *Id.*

27 TRIBAL EPIDEMIOLOGY CENTERS, BEST PRACTICES IN AMERICAN INDIAN & ALASKA NATIVE PUBLIC HEALTH 18-123 (2013), http://itcaonline.com/wp-content/uploads/2014/03/TEC_Best_Practices_Book_2013.pdf (listing the parent organizations of the TECs).

C. Indian Health Service

The foundations of modern day federal Indian health programming are based on treaties requiring the United States to provide health services to Tribes in exchange for ceded land.[28] While health services were originally provided to Tribal communities by military physicians,[29] the federal provision of health care to American Indian and Alaska Native is now principally offered by Indian Health Service (IHS).[30] IHS is an agency within the Department of Health and Human Services.[31] Its mission is "to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level."[32] IHS is a network of federal health care facilities and providers that serve 2.6 million American Indian and Alaska Natives[33] across twelve regions.[34] Despite being a legally required treaty obligation, IHS has never had enough funding to consistently provide quality health care to all American Indians and Alaska Natives.[35]

IHS also provides public health services such as health communications and education,[36] environmental health programs,[37] and injury prevention.[38] In the context of public health data and surveillance, IHS's Division of Program Statistics collects and measures health information across the agency's programs.[39] It publishes reports on various topics including behavioral health,[40] life expectancy,[41] and injuries.[42]

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28 NELL JESSUP NEWTON et al., COHEN'S HANDBOOK OF FEDERAL INDIAN LAW § 22.04[1] (2012).
29 *Id.*
30 *About IHS*, INDIAN HEALTH SERVICE, https://www.ihs.gov/aboutihs/ (last visited Aug. 9, 2019).
31 *HHS Agencies & Offices*, US DEPARTMENT OF HEALTH AND HUMAN SERVICES, https://www.hhs.gov/about/agencies/hhs-agencies-and-offices/index.html (last visited Aug. 9, 2019).
32 *About IHS*, *supra* note 30.
33 *Id.*
34 *Locations*, INDIAN HEALTH SERVICE, https://www.ihs.gov/locations/ (last visited Aug. 9, 2019).
35 Donald Warne & Linda Bane Frizzell, *American Indian Health Policy: Historical Trends and Contemporary Issues,* 104 AM. J. PUB. HEALTH 263 (Supp. 3 2014).
36 *Health Education Program*, Indian Health Service, https://www.ihs.gov/healthed/ (last visited Aug. 9, 2019).
37 *Division of Environmental Health Services*, INDIAN HEALTH SERVICE, https://www.ihs.gov/dehs/ (last visited Aug. 9, 2019).
38 *Injury Prevention*, INDIAN HEALTH SERVICE, https://www.ihs.gov/communityhealth/injuryprevention/ (last visited Aug. 9, 2019).
39 INDIAN HEALTH SERVICE, DIVISION OF PROGRAM STATISTICS, https://www.ihs.gov/dps/ (last visited Aug. 9, 2019).
40 *See generally*, INDIAN HEALTH SERVICE, REPORT ON BEHAVIORAL HEALTH (2018), https://www.ihs.gov/sites/dps/themes/responsive2017/display_objects/documents/IHS2018BehavioralHealth.pdf.
41 INDIAN HEALTH SERVICE, LIFE EXPECTANCY, AMERICAN INDIANS AND ALASKA NATIVES, DATA YEARS: 2007-2009 (2014), https://www.ihs.gov/sites/dps/themes/responsive2017/display_objects/documents/LifeExpectancy2007-09ReportMemo.pdf.
42 INDIAN HEALTH SERVICE, INDIAN HEALTH FOCUS: INJURIES (2017), https://www.ihs.gov/sites/dps/themes/responsive2017/display_objects/documents/Indian_Health_Focus_%20Injuries_2017_Edition_508.pdf.

D. Tribal Self-Governance

Passed in 1975, the Indian Self-Determination and Education Assistance Act (ISDEAA) promotes Tribal administration of federal programs including, among others, education and health.[43] In the context of health services, ISDEAA allows Tribes to contract with IHS to promote select programs and services or to compact with IHS to assume control of programming.[44] Tribal self-governance has given Tribes the flexibility to use federal funds to develop programming that is tailored and culturally-relevant for each Tribe.[45] Self-governance programs have been incredibly successful, with an increasing number of Tribes opting to administer their own health programs.[46]

E. Urban Indian Health Programs

American Indians and Alaska Natives living in urban areas can receive health care services at Urban Indian Health Programs (UIHPs) across the United States.[47] Authorized by the Indian Health Care Improvement Act (IHCIA),[48] there are currently forty-one UHIPs organized as nonprofit organizations.[49] UIHPs can include primary care, dental care, behavioral health, and immunization, as well as public health programming and surveillance activities.[50]

F. Tribal Epidemiology Centers

In 1996, Congress amended IHCIA to establish Tribal epidemiology centers (TECs) that would provide public health research and support to

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43 Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, § 207, 88 Stat. 2203-04 (1975).

44 *Office of Tribal Self-Governance: About Us*, INDIAN HEALTH SERVICE, https://www.ihs.gov/SelfGovernance/aboutus/ (last visited Aug. 9, 2019).

45 *Id.*

46 Geoffrey D. Strommer & Stephen D. Osborne, *The History, Status, and Future of Tribal Self-Governance Under the Indian Self-Determination and Education Assistance Act*, 39 AM. INDIAN L. REV. 1, 48-49 (2015).

47 *About Urban Indian Health Programs*, URBAN INDIAN HEALTH INSTITUTE, https://www.uihi.org/urban-indian-health/about-urban-indian-health-organizations/ (last visited Aug. 9, 2019).

48 Indian Health Care Improvement Act, Pub. L. No. 94-437, § 510, 25 U.S.C. § 1660 (1976).

49 *Office of Urban Indian Health Programs*, INDIAN HEALTH SERVICE, https://www.ihs.gov/urban/ (last visited Aug. 9, 2019).

50 *Id.*

Tribes.[51] There are twelve TECs located in each IHS region (Figure 2).[52] The functions of TECs include:

> (1) collect[ing] data relating to, and monitor[ing] progress made toward meeting, each of the health status objectives of the Service, the Indian [T]ribes, [T]ribal organizations, and urban Indian organizations in the Service area;
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> (2) evaluat[ing] existing delivery systems, data systems, and other systems that impact the improvement of Indian health;
>
> (3) assist[ing] Indian [T]ribes, [T]ribal organizations, and urban Indian organizations in identifying highest-priority health status objectives and the services needed to achieve those objectives, based on epidemiological data;
>
> (4) mak[ing] recommendations for the targeting of services needed by the populations served;
>
> (5) mak[ing] recommendations to improve health care delivery systems for Indians and urban Indians;
>
> (6) provid[ing] requested technical assistance to Indian [T]ribes, [T]ribal organizations, and urban Indian organizations in the development of local health service priorities and incidence and prevalence rates of disease and other illness in the community; and
>
> (7) provid[ing] disease surveillance and assist[ing] Indian [T]ribes, [T]ribal organizations, and urban Indian communities to promote public health.[53]

Many TECs are housed with inter-Tribal organizations[54] and all the organizations operate in consultation with their Tribal partners.[55] TECs take a leading role in the collection and analysis of Tribal health data.[56]

IHCIA's 2010 reauthorization sought to promote TEC access to health data by designating the organizations as public health authorities under the Health Insurance Portability and Accountability Act (HIPAA).[57] Public

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51 Indian Health Amendments of 1992, Pub. L. No. 102–573, 106 Stat. 4526, 4552 § 214(a)(1) (1992).

52 *Tribal Epidemiology Centers (TECs)*, INDIAN HEALTH SERVICE, https://www.ihs.gov/epi/tecs/centers/ (last visited Aug. 9, 2019).

53 25 U.S.C. § 1621m(b) (2012).

54 *See* TRIBAL EPIDEMIOLOGY CENTERS, *supra* note 27.

55 25 U.S.C. § 1621m(b) (2012).

56 *See* TRIBAL EPIDEMIOLOGY CENTERS, *supra* note 27.

57 25 U.S.C. § 1621m (2012); *see*, AILA HOSS, TRIBAL EPIDEMIOLOGY CENTERS DESIGNATED AS PUBLIC HEALTH AUTHORITIES UNDER THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (2015), https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf (summarizing the impact of this designation).

health authorities, including state, local, and Tribal agencies, are able to access identifiable health information despite being protected under the law, in order to prevent or control disease or injury.[58]

IHCIA also requires the federal government – through the US Department of Health and Human Services and the Centers for Disease Control and Prevention – to support TEC access to data within the agencies[59] and to provide technical assistance to TECs in performing their duties.[60]

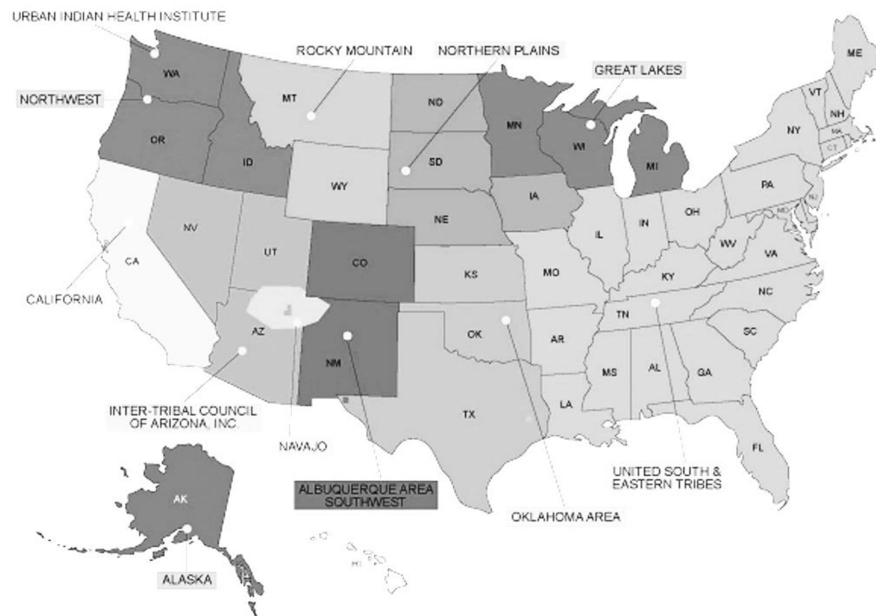

Figure 2: Tribal Epidemiology Centers, Indian Health Service[61]

G. State Law and Private Providers

Like all citizens, American Indian and Alaska Natives are also eligible to access health services through state programming and from private health care providers.[62] Because of this, relevant Tribal public health data can be collected through existing networks of state health care providers and state

58 45 C.F.R. § 164.512(b) (2016).

59 25 U.S.C. § 1621m (2012).

60 *Id.*

61 *Tribal Epidemiology Centers (TECs)*, *supra* note 52.

62 Jessica Schubel, *Coverage for American Indians and Alaska Natives at Risk Under Senate GOP Health Bill*, CENTER ON BUDGET AND POLICY PRIORITIES (Jul. 12, 2017), https://www.cbpp.org/research/health/coverage-for-american-indians-and-alaska-natives-at-risk-under-senate-gop-health.

health agencies. State Medicaid expansion, for example, has improved health care access for American Indians and Alaska Natives.[63]

II. PUBLIC HEALTH DATA AND SURVEILLANCE: LAWS AND PRACTICAL CHALLENGES

Given the complexity of Tribal public health systems, public health surveillance laws at the Tribal, federal, and state levels can all have implications on the surveillance of American Indian and Alaska Native health data. This complexity may also lead to practical challenges in accessing and using this data to promote public health.

A. Surveillance Laws

Some Tribes have exercised their public health authority by establishing infectious disease reporting laws.[64] For example, the Fort Peck Assiniboine & Sioux Tribal Code requires physicians to report communicable diseases or reportable diseases required by the Tribal Board of Health to the Tribal Health Officer.[65] Similarly, the Sac & Fox Tribe of the Mississippi in Iowa Code requires health care providers to notify occurrences of reportable diseases to the Tribal Health Director.[66] The report must include:

> (a) the name of the disease;
>
> (b) the approximate date the person with the disease is believed to have contracted the disease; and
>
> (c) all other information which would likely be of use to the Tribe to prevent the spread of the disease; provided that no client-identifiable information shall be disclosed.[67]

The code defines reportable conditions and includes various infectious diseases, vital statistics (births and deaths), and violent injuries.[68]

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63 *Id.*

64 AILA HOSS, MENU OF SELECTED TRIBAL LAWS RELATED TO INFECTIOUS DISEASE CONTROL 2, https://www.cdc.gov/phlp/docs/tribalidlaws-brief.pdf.

65 Fort Peck Comprehensive Code of Justice, Title XIV Health and Sanitation § 608, https://static1.squarespace.com/static/594c44e12cba5ec4cb294563/t/5995cef06f4ca34b2a759128/1502990064658/sec_608.pdf.

66 SAC & FOX Tribe of the Mississippi in Iowa Code, Article IV § 12–4203 (2007), https://drive.google.com/file/d/0B0BtqpQ32vW6OTRjLXBtLS1DNVE/view.

67 *Id.*

68 *Id.* § 12–4101.

Federal law also provides tools to support Tribal public health surveillance.[69] In addition to TECs, federal law authorizes the Centers for Disease Control and Prevention to assist Tribes with the collection of data related to adverse childhood experiences through various public health surveys.[70] IHCIA also authorizes funding to Tribes for the prevention of infectious disease that can include surveillance.[71] Tribes are often required to report health surveillance data to the federal government as part of their agreements to receive funding.[72]

Various federal laws require health data collection and surveillance in the context of Tribal health.[73] IHS maintains a Resource and Patient Management System[74] to maintain patient health records and immunization data.[75] Tribal self-governing health programs through ISDEAA are required to provide public health data to IHS as part of their agreements with the agency.[76] The Government Performance and Results Act requires federal agencies, including IHS, to report health data as a mechanism to track the quality of services provided by the agency.[77]

Each state requires the reporting of certain diseases and conditions by health care providers and laboratories to state and local health agencies.[78] For example, Oklahoma's law requires health care providers, laboratories, and hospitals to report various diseases, conditions, and injuries to the state health department.[79] Diseases such as AIDS and influenza are included, as well as injuries such as drownings and traumatic brain injuries.[80]

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69 *See*, *e.g.*, 42 U.S.C. § 242t (2018); 25 U.S.C. § 1621q (2012).

70 42 U.S.C. § 242t (2018).

71 25 U.S.C. § 1621q (2012).

72 *Grants 101*, GRANTS.GOV, https://www.grants.gov/learn-grants/grants-101/post-award-phase.html (last visited Aug. 22, 2019).

73 *See* WESTAT, DATA ON HEALTH AND WELL-BEING OF AMERICAN INDIANS, ALASKA NATIVES, AND OTHER NATIVE AMERICANS (2006) (providing a summary of data sources for American Indian and Alaska Native people).

74 *Resource and Patient Management System (RPMS)*, INDIAN HEALTH SERVICE, https://www.ihs.gov/rpms (last visited Aug. 22, 2019).

75 *See Webinar on Infectious Disease Reporting and American Indian and Alaska Native Populations: Law and Practice,* CENTERS FOR DISEASE CONTROL AND PREVENTION & AMERICAN BAR ASSOCIATION (Mar. 28, 2016), https://register.gotowebinar.com/recording/2419381152475160066 (Starla K. Roles presents on federal regulation of health data collection, including IHS management of patient health records and immunization data, at 31:06).

76 *Id.*

77 *GPRA and Other National Reporting*, INDIAN HEALTH SERVICE, https://www.ihs.gov/crs/gprareporting/ (last visited Aug. 22, 2019).

78 Richard N. Danila et al., *Legal Authority for Infectious Disease Reporting in the United States: Case Study of the 2009 H1N1 Influenza Pandemic*, AM. J. OF PUB. HEALTH 105(1), 13–18 (Jan. 2015).

79 Okla. Admin. Code 310:515-1-4 (2019).

80 *Id.*

B. Practical Challenges

In 2013, the twelve TECs published a report titled "Best Practices in American Indian & Alaska Native Public Health."[81] In it, the organizations identified various challenges in conducting Tribal public health collection and surveillance.[82] Specifically, challenges in accessing data across state and local agencies when data sharing agreements are not in place, when fees are required to secure the date, and when the data is not easily accessible across different software.[83] Additionally, some state and local agencies have refused to provide TECs access to this data on data privacy grounds[84] and state laws that provide additional protections for health data.[85]

Data quality issues persist in the context of American Indian and Alaska Native health data.[86] Small sample sizes create challenges in identifying statistically relevant trends.[87] Racial misclassification also leads to significant underreporting of health outcomes for American Indians and Alaska Natives.[88] This is particularly problematic within health systems that do not allow for patient self-identification, requiring health care providers to guess the race of the patient.[89]

Data usage presents unique challenges for American Indian and Alaska Native populations. There is a long history of governmental and researcher misuse of American Indian and Alaska Native data.[90] The *Havasupai Tribe of Havasupai Reservation v. Arizona Board of Regents* case provides a well-

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[81] TRIBAL EPIDEMIOLOGY CENTERS, *supra* note 27.

[82] *Id.* at 124-33.

[83] *Id.* at 124-26.

[84] JAMES G. HODGE ET AL., COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS, LEGAL ISSUES CONCERNING IDENTIFIABLE HEALTH DATA SHARING BETWEEN STATE/LOCAL PUBLIC HEALTH AUTHORITIES AND TRIBAL EPIDEMIOLOGY CENTERS IN SELECTED US JURISDICTIONS 11 (Nov. 8, 2011), available at http://www.cste2.org/webpdfs/LegalIssuesConcerningIdentifiableHealthDataSharingBetweenStateLocalPublicHealthAuthoritiesandTribalEpidemiologyCentersinSelectedUSJurisdictionsFINAL.pdf.

[85] *Id.* at 14-15; *see also* Jean O'Connor & Gene Matthews, *Informational Privacy, Public Health, and State Laws*, 101 AM. J. OF PUB. HEALTH1845 (2011).

[86] TRIBAL EPIDEMIOLOGY CENTERS, *supra* note 27, at 126-135; *see also* Wendy D. Roth, *Establishing the Denominator: The Challenges of Measuring Multiracial, Hispanic, and Native American Populations*, 677 ANNALS AM. ACAD. POL. & SOC. SCI. 48 (2018); Carolyn A. Liebler, *Counting America's First Peoples*, 677 ANNALS AM. ACAD. POL. SOC. SCI. 180, 180-90 (2018); Ursula E. Bauer & Marcus Plescia, *Addressing Disparities in the Health of American Indian and Alaska Native People: The Importance of Improved Public Health Data*, AM. J. OF PUB. HEALTH, Vol 104, No. S3 (Supp. 3 2014).

[87] TRIBAL EPIDEMIOLOGY CENTERS, *supra* note 27, at 131.

[88] *Id.* at 128-30.

[89] *Id.* at 128-29.

[90] *See* Rosalina James et al., *Exploring Pathways to Trust: A Tribal Perspective on Data Sharing*, GENETICS IN MEDICINE 16, 820–26 (2014), https://www.nature.com/articles/gim201447.pdf (discussing data-sharing procedures and tribal sovereignty).

known example.[91] In 1989, members of the Havasupai Tribes submitted blood samples to researchers from Arizona State University to study potential genetic links to diabetes.[92] The university subsequently used these samples to conduct a variety of studies, including alcoholism[93] and migration.[94] The Tribe had a particular interest in these issues given the stigma and stereotypes of American Indians and alcoholism and migration studies that undermine the Tribe's own origin stories.[95] The Tribe sued the university and the researchers for lack of informed consent.[96] The case ultimately settled,[97] but tarnished the reputation of the university and served as a reminder to Tribes of the risk of their health data being used to undermine their sovereignty.[98] Data usage raises issues regarding data sovereignty, a Tribe's "right . . . to govern the collection, ownership, and application of its own data."[99] Tribal data sovereignty seeks to prevent the continued colonization of Tribal data by other governments and entities.[100]

III. LEGAL STRATEGIES FOR PROMOTING SURVEILLANCE

Tribes and Tribal-serving organizations have relied on legal strategies to promote public health surveillance while ensuring Tribal data sovereignty.[101] For example, Tribes have passed Tribal data and research codes to protect Tribal interests during the research process.[102] For example, the Confederated Tribes of Siletz Indians has a research ordinance that ensures "all persons within the jurisdiction of the Tribe are free from

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[91] *See* Havasupai Tribe of Havasupai Reservation v. Arizona Bd. of Regents, 204 P.3d 1063 (Ct. of App. 2008).

[92] *Id.* at 1066-67.

[93] Robyn L. Sterling, *Genetic Research Among the Havasupai: A Cautionary Tale*, 13 AM. MED. ASS'N J. OF ETHICS 113, 113-17 (2011), https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-06/hlaw1-1102.pdf.

[94] *Havasupai Tribe*, 204 P.3d at 1067.

[95] *Id.*

[96] *Id.* at 1066.

[97] Amy Harmon, *Indian Tribe Wins Fight to Limit Research of Its DNA*, NY TIMES (Apr. 21, 2010), https://www.nytimes.com/2010/04/22/us/22dna.html.

[98] Sterling, *supra* note 93.

[99] *US Indigenous Data Sovereignty Network: About Us*, THE UNIVERSITY OF ARIZONA, http://usindigenousdata.arizona.edu/about-us-0 (last visited Aug. 9, 2019).

[100] Stephanie Carroll Rainie et al., *Policy Brief: Indigenous Data Sovereignty in the United States,* THE UNIVERSITY OF ARIZONA: NATIVE NATIONS INSTITUTE, https://nni.arizona.edu/ publications-resources/publications/policy-reports/policy-brief-indigenous-data-sovereignty-united-states; *see also* Stephanie Carroll Rainie et al., *Policy Brief: Data Governance for Native Nation Rebuilding (Version 2)*, THE UNIVERSITY OF ARIZONA: NATIVE NATIONS INSTITUTE (2017), https://nni.arizona.edu/application/files/8415/0007/5708/Policy_Brief_Data_Governance_for_Native_Nation_Rebuilding_Version_2.pdf.

[101] *Research Regulation*, NCAI POLICY RESEARCH CENTER, http://www.ncai.org/policy-research-center/initiatives/research-regulation (last visited Aug. 9, 2019).

[102] *See, e.g.*, Siletz Tribal Code § 9.100 (2015); 13 NAVAJO CODE § 3264 (2002).

unreasonably harmful, intrusive, ill-conceived, or otherwise offensive research and investigation procedures."[103] The ordinance established a permitting and contracting process to manage projects within the Tribe's jurisdiction.[104] Similarly, the Navajo Nation also requires a research application with their Research Review Board.[105] The research code establishes standards for informed consent,[106] confidentiality,[107] and requires regular reports on the status of the research.[108] Tribes have also passed health privacy protection for health data generated within their health facilities in their Tribal codes.[109]

Tribes and TECs have also entered into data sharing agreements to facilitate the sharing of health data.[110] Provisions within data sharing agreements that protect Tribal sovereignty can include (1) Tribal ownership of data or balanced ownership between the Tribe and researcher; (2) requirements for follow-up when exchange data for particular analysis; (3) ensuring Tribal access to data; (4) ensuring Tribal approval for the presentation of the data.[111]

CONCLUSION

Without accurate public health data, it can be challenging to identify urgent health issues and disparities. In turn, it becomes difficult to identify public health policy and funding priorities. Effective public health data collection and surveillance ensures that these public health goals can be met. While promoting the data collection and surveillance of Tribal health data is a worthy goal, the data must be collected and used in a method that promotes Tribal sovereignty. Law serves as a foundation for public health practice, including surveillance, but the complexities of Tribal health systems means that health data issues include a variety of actors and laws. Despite these

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103 Siletz Tribal Code § 9.100 (2015).

104 *Id.* §§ 9.100-9.111.

105 13 NAVAJO CODE § 3264 (2002).

106 *Id.* § 3266.

107 *Id.* § 3265.

108 *Id.* § 3267.

109 Starla Kay Roels, *HIPAA and Patient Privacy: Tribal Policies as Added Means for Addressing Indian Health Disparities*, 31 AM. INDIAN L. REV. 1, 30-38 (2006).

110 CENTERS FOR DISEASE CONTROL AND PREVENTION, OVERVIEW OF TRIBAL EPIDEMIOLOGY CENTERS 3, https://www.cdc.gov/tribal/documents/tec_overview.pdf.

111 Victoria Warren-Mears, *Principles and Models for Data Sharing Agreements with American Indian/Alaska Native Communities*, NATIONAL CONGRESS OF AMERICAN INDIANS, http://genetics.ncai.org/files/Principles%20and%20Models%20for%20Data%20Sharing%20Agreements.pdf. For a list of ethic codes and data-sharing agreements for tribal research, *see*, Anna Harding, Barbara Harper, Dave Stone, Catherine O'Neill, Patricia Berger, Stuart Harris, and Jamie Donatuto, Conducting Research with Tribal Communities: Sovereignty, Ethics, and Data-Sharing Issues, 120(1) Environmental Health Perspectives, page 8 (2012).

complexities, legal strategies can be implemented to promote public health and Tribal sovereignty.