

Indigeneity, Data Genocide, and Public Health

Aila Hoss*

ABSTRACT: Public health datasets will often tell us nothing about Indigenous people. This type of data suppression has been described as data genocide and data terrorism, because it demonstrates the effort to erase Indigenous people. Even when data is available, Tribes and their partners are regularly denied access to public health data from other jurisdictions. The seemingly simple call for more accurate, comprehensive public health data regarding Indigenous communities butts up against complicated issues. Who is considered Native and thus captured in Indigenous data? Why is Indigenous data regularly excluded from datasets? Who gets access to Indigenous data? These questions implicate federal Indian law, colonization, and Tribal sovereignty. So, while better quality data and improved data access are important goals, there is no way to bifurcate the need for public health data with the systematic racism embedded into the laws that impact the analyzing, collecting, and disseminating of this data. This Article aims to outline how Indigeneity interfaces with public health surveillance systems, in the context of both the collection of accurate data and the access to such data. It summarizes existing law and policy that define “Indian” under various frameworks and explores the challenges and limitations of defining Indian, particularly for the purposes of public health surveillance. This Article ends with a series of considerations regarding public health surveillance reform to better support Indian country.

INTRODUCTION 1140

* Aila Hoss, J.D., is an Associate Professor of Law at Indiana University Robert H. McKinney School of Law. She teaches and researches at the intersection of federal Indian law and health law. This Article was written thanks to the support of several entities and individuals. First, this research was supported by a 2023 Indiana University EPIC Taking Action Challenge Grant. Second, the Author presented earlier drafts of this Article at the University of Cincinnati College of Law and Indiana University McKinney School of Law. She is grateful to these faculties for their feedback on the Article and for their rigorous discussion on the issues raised therein. Third, the Author thanks Sam Kalen, Heather Tanana, and Lauren van Schilfgaarde for their review and thoughtful comments on this Article. Next, the Author thanks her colleagues, Professors Benjamin Keele and Miriam Murphy, and her research assistant, Kristen Rue, for their research support. Most importantly, the Author thanks the editors of the *Iowa Law Review* for their excellent substantive and editorial support on this very long Article with a ton of footnotes.

I.	THE URGENT NEED FOR INDIGENOUS HEALTH DATA	1144
A.	<i>INDIGENOUS HEALTH INEQUITIES</i>	1145
B.	<i>THE INDIGENOUS DATA GAP</i>	1148
1.	Data Omission and Racial Misclassification	1148
2.	Failure to Collect Tribal Membership Data	1152
C.	<i>INDIGENOUS DATA ACCESS</i>	1153
II.	THE PUBLIC HEALTH SURVEILLANCE MAZE	1154
A.	<i>THE ROLE OF DATA</i>	1154
B.	<i>DATA COLLECTION SYSTEMS</i>	1157
C.	<i>INDIAN HEALTH SYSTEMS</i>	1164
1.	Federal Indian Health Systems.....	1164
2.	Tribal Health Systems	1167
3.	State Health Systems	1169
III.	DEFINING INDIGENEITY.....	1170
A.	<i>SELF-IDENTIFICATION</i>	1170
B.	<i>FEDERAL LAW AND POLICY</i>	1171
C.	<i>STATE LAW AND POLICY</i>	1181
D.	<i>TRIBAL CITIZENSHIP LAWS</i>	1182
IV.	INDIGENEITY AND DATA	1183
A.	<i>COMPETING DEFINITIONS</i>	1183
B.	<i>THE RIGHT NOT TO BE COUNTED</i>	1192
C.	<i>TRIBAL DATA SOVEREIGNTY</i>	1199
V.	CONSIDERATIONS FOR PUBLIC HEALTH SURVEILLANCE REFORM.....	1201
	CONCLUSION.....	1202

INTRODUCTION

“Do I look white to you,” asks Kenny Boy in a season two episode of the television show *Reservation Dogs*.¹ In answer, he was told, by a leader of a white supremacist cult, “Yes.”² This was the only time the critically acclaimed show directly addressed the uncertain claims of Indigeneity by Kenny Boy. The show does not provide the viewer with any definitive answer to the issue. Is Kenny Boy a Tribal member? Is he also white or are those two identities mutually exclusive? Is Kenny Boy Indigenous but not a Tribal member? Or, is Kenny Boy masquerading, perhaps very poorly, as Native? People on the

1. *Reservation Dogs: This Is Where the Plot Thickens* (FX on Hulu Sept. 14, 2022).

2. *Id.*

internet have theories.³ Yet, the uncertainty regarding Kenny Boy's identity neither impacts his storyline on the show nor the warm reception of the character amongst fans.⁴

For the Author of this Article, a public health attorney and law professor, Kenny Boy's identity matters. A lot. Which government or governments have regulatory jurisdiction over his scrap yard? Should Kenny Boy be prosecuted for his illicit drug operations, would he be subject to criminal jurisdiction under Tribal, state, or federal law, or some combination? Is Kenny Boy able to access health care at the Indian Health Service facility regularly featured on the show? If Kenny Boy is a Tribal member but presents as white, is he treated differently because of this fact? What box does Kenny Boy check when prompted to do so by the endless number of forms that ask people to select their racial identification? In short, Kenny Boy's identity implicates a myriad of issues across law, education, employment, housing, and health. It also intimates at a pervasive question in Indian country: Who is considered Indigenous?

If Kenny Boy is Indigenous, public health data suggests that he would experience worse health outcomes vis-à-vis white populations, including outcomes related to diabetes, certain cancers, and unintentional injuries.⁵ Public health data also indicates that American Indian and Alaska Native men have the lowest life expectancy when compared to all other race-gender categories at 61.5 years.⁶ This is more than ten years less than the national average for all men.⁷

Many times, datasets will tell us nothing about Indigenous people, with the COVID-19 pandemic offering a recent example of this. Amongst those who had tested positive for COVID-19 or those that had received a vaccine, an October 2021 study found that race and ethnicity data was unavailable for nearly forty percent of patients.⁸ Another revealed that American Indian and Alaska Native communities are among the most frequently omitted from

3. Havanalorraine, *Kenny Boy?*, REDDIT (Sept. 15, 2022, 11:54 AM), https://www.reddit.com/r/ReservationDogs/comments/xf1sa6/kenny_boy [<https://perma.cc/Q9KL-GS7W>].

4. See, e.g., Kaden Nanji, *The 10 Best 'Reservation Dogs' Characters Ranked by Likability*, COLLIDER (June 23, 2023), <https://collider.com/best-reservation-dogs-characters-likability-ranked> [<https://perma.cc/gGMS-BEPA>] (listing Kenny Boy within the top ten most likeable characters of the series); EmbarrassedToe627, Comment to *Kenny Boy?*, *supra* note 3 ("Whatever his ethnicity, he is [one hundred percent] bro."); Bosco3131, *Kenny Boy Rocks!*, REDDIT (Sept. 28, 2022, 5:07 PM), https://www.reddit.com/r/ReservationDogs/comments/xqppts/kenny_boy_rocks [<https://perma.cc/LR38-PPQK>].

5. See *infra* Section I.A.

6. ELIZABETH ARIAS, BETZAIDA TEJADA-VERA, KENNETH D. KOCHANEK & FARIDA B. AHMAD, CDC, PROVISIONAL LIFE EXPECTANCY ESTIMATES FOR 2021, at 2 (2022), <https://www.cdc.gov/nchs/data/vsrr/vsrr023.pdf> [<https://perma.cc/X3CF-6T9P>].

7. *Id.*

8. Cara V. James, Barbara Lyons, Philip A. Saynisch & Sarah Hudson Scholle, *Modernizing Race and Ethnicity Data in Our Federal Health Programs*, COMMONWEALTH FUND (Oct. 26, 2021), <https://www.commonwealthfund.org/blog/2021/modernizing-race-and-ethnicity-data-our-federal-health-programs> [<https://perma.cc/8VC6-QLSK>].

COVID-19 data.⁹ In a December 2021 review, sixty-four percent of states failed to report data on at least one COVID-19 metric regarding American Indian and Alaska Native communities.¹⁰ Eight states did not include Native communities in case and mortality data at all.¹¹ This type of data suppression has been described as data genocide and data terrorism, because it demonstrates the effort to erase Indigenous people.¹² Even when data is available, Tribes and their partners are regularly denied access to public health data from other jurisdictions.¹³ Former Centers for Disease Control and Prevention (“CDC”) Director Robert Redfield came under scrutiny for failing to give timely data access to Tribes and Tribal epidemiology centers during the COVID-19 pandemic.¹⁴ In addition, reports have found that states like Michigan,

9. See, e.g., Alexandra Skinner, Julia Raifman, Elizabeth Ferrara, Will Raderman & Talia M. Quandelacy, *Disparities Made Invisible: Gaps in COVID-19 Data for American Indian and Alaska Native Populations*, 6 HEALTH EQUITY 226, 226–27 (2022) (“Sixty-four percent of states do not report [American Indian]/[Alaska Native] data for at least one COVID-19 health metric: cases, hospitalizations, deaths, or vaccinations.”); Rebecca Nagle, *Native Americans Being Left out of US Coronavirus Data and Labelled as ‘Other,’* GUARDIAN (Apr. 24, 2020, 6:00 AM), <https://www.theguardian.com/us-news/2020/apr/24/us-native-americans-left-out-coronavirus-data> [<https://perma.cc/gF8g-UF2G>] (finding discrepancies in reporting Native status in race or ethnicity data for COVID-19 infections and deaths); Kate Conger, Robert Gebeloff & Richard A. Opiel, Jr., *Native Americans Feel Devastated by the Virus Yet Overlooked in the Data*, N.Y. TIMES (Jan. 3, 2021), <https://www.nytimes.com/2020/07/30/us/native-americans-coronavirus-data.html> (on file with the *Iowa Law Review*) (same); Stephanie Russo Carroll, Desi Rodriguez-Lonebear, Randall Akee, Annita Lucchesi & Jennifer Rai Richards, *Indigenous Data in the COVID-19 Pandemic: Straddling Erasure, Terrorism, and Sovereignty*, SOC. SCI. RSCH. COUNCIL (June 11, 2020), <https://items.ssrc.org/covid-19-and-the-social-sciences/disaster-studies/indigenous-data-in-the-covid-19-pandemic-straddling-erasure-terrorism-and-sovereignty> [<https://perma.cc/gT5M-722U>] (same); Aggie J. Yellow Horse & Kimberly R. Huyser, *Indigenous Data Sovereignty and COVID-19 Data Issues for American Indian and Alaska Native Tribes and Populations*, 39 J. POPULATION RSCH. 527, 528–29 (2022) (same).

10. Skinner et al., *supra* note 9, at 226.

11. *Id.* at 227.

12. See, e.g., SCOTT ERICKSON ET AL., URB. INDIAN HEALTH INST., DATA GENOCIDE OF AMERICAN INDIANS AND ALASKA NATIVES IN COVID-19 DATA 6 (2021), <https://www.uihi.org/projects/data-genocide-of-american-indians-and-alaska-natives-in-covid-19-data> [<https://perma.cc/T6JU-NFJU>]; Carroll et al., *supra* note 9.

13. See, e.g., U.S. GOV’T ACCOUNTABILITY OFF., GAO-22-104698, TRIBAL EPIDEMIOLOGY CENTERS: HHS ACTIONS NEEDED TO ENHANCE DATA ACCESS 12–13 (2022), <https://www.gao.gov/assets/D22/104698.pdf> [<https://perma.cc/LL98-H2JX>]; Joyce Hanson, *NM Sen. Demands CDC Transparency on Tribal COVID-19 Data*, LAW360 (June 22, 2020, 8:31 PM), <https://www.law360.com/articles/1285520/nm-sen-demands-cdc-transparency-on-tribal-covid-19-data> [<https://perma.cc/7JG8-WJ3X>]; Press Release, U.S. Senate Comm. on Indian Affairs, Udall, Murray, Pallone, Grijalva, Gallego Raise Concerns About Tribes Being Denied Access to Critical Federal COVID-19 Data (July 2, 2020), <https://www.indian.senate.gov/news/press-release/udall-murray-pallone-grijalva-gallego-raise-concerns-about-tribes-being-denied> [<https://perma.cc/PQ06-ADEN>].

14. Darius Tahir & Adam Cancryn, *American Indian Tribes Thwarted in Efforts to Get Coronavirus Data*, POLITICO (June 11, 2020, 11:45 PM), <https://www.politico.com/news/2020/06/11/native-american-coronavirus-data-314527> [<https://perma.cc/3DB5-MSKH>].

Massachusetts, and California denied Tribes access to COVID-19 data during the height of the pandemic.¹⁵

The seemingly simple call for more accurate, comprehensive public health data regarding Indigenous communities butts up against complicated issues. Who is considered Native and thus captured in Indigenous data? Why is Indigenous data regularly excluded from datasets? Who gets access to Indigenous data? These questions implicate federal Indian law, colonization, and Tribal sovereignty. So, while better quality data and improved data access are important goals, there is no way to bifurcate the need for public health data with the systematic racism embedded into the laws that impact the analyzing, collecting, and disseminating of this data.

This Article aims to outline how Indigeneity interfaces with public health surveillance systems, in the context of both the collection of accurate data and the access to such data. First, this Article describes the data gaps in public health regarding Indigenous communities. Part II provides background on the systems for public health data collection, sharing, and dissemination and the role of this data in public health practice. It also explains the complex health care systems that provide health care to Native people. Part III summarizes existing law and policy that define “Indian” under various frameworks. It presents the results of a review of all federal statutory and regulatory definitions. Part IV explores the challenges and limitations of defining Indian, particularly for the purposes of public health surveillance. Finally, this Article ends with a series of considerations regarding public health surveillance reform to better support Indian country. It is important to note that this Article does not attempt to, nor would it be appropriate to,¹⁶ proffer the “correct” definition of Indigenous for public health purposes.

This Article refers to the Indigenous people of the United States using a variety of terms, including American Indian and Alaska Native, Native, Indian,

15. *Tribes Face Barriers to Access COVID-19 Data*, RCAC (July 23, 2020), <https://www.rcac.org/native-communities/tribes-face-barriers-to-access-covid-19-data> [<https://perma.cc/8Y6D-CFMX>]; Kate Cimini, *We're Born Indian and We Die White: California Indigenous Fear COVID Deaths Undercounted*, CAL MATTERS (Mar. 3, 2021), <https://calmatters.org/california-divide/2021/03/california-indigenous-fear-covid-deaths-undercounted> [<https://perma.cc/6ALP-NEJ6>]. Local governments have also denied Tribes access to timely data. See Chelsea Curtis, *Hopi Tribe Releases ZIP Code Data, but COVID-19 Data for Arizona's 22 Communities Is Confusing*, AZCENTRAL (June 9, 2020, 3:05 PM), <https://www.azcentral.com/story/news/local/arizona-health/2020/06/04/coronavirus-arizona-indigenous-communities-cases-covid-19-data-hopi-navajo/3091650001> [<https://perma.cc/KXN9-HB2M>].

16. The Author is a non-Native scholar of Indian law. She does not represent or speak for any Tribe or Indigenous community nor is her Indian law scholarship informed by lived experience. She is not in a position to suggest what the “correct” definition of Indigenous should be.

and Indigenous.¹⁷ This Article capitalizes these terms and capitalizes “Tribe” and “Tribal.”¹⁸

I. THE URGENT NEED FOR INDIGENOUS HEALTH DATA

The field of public health works to promote health by preventing adverse health outcomes.¹⁹ One of the primary mechanisms in which public health goals can be achieved is through surveillance.²⁰ Public health surveillance is the “[m]onitoring of the distribution and trends of risk factors, injury, and disease in the population.”²¹ Epidemiology, in turn, studies “the distribution and determinants of health-related states among specified populations and the application of that study to the control of health problems.”²² *Public health, surveillance, and epidemiology activities all require data.* This Part describes the urgent need for more accurate and comprehensive public health data for Indigenous communities. It begins by discussing health inequities facing Indigenous communities. It then describes phenomena that lead the Indigenous data gap and ends with a discussion on access to Indigenous data.

17. See ICT Staff, *Native American vs. Indian*, INDIAN COUNTRY TODAY (Sept. 13, 2018), <https://ictnews.org/archive/native-american-vs-indian> [<https://perma.cc/39E5-DVU2>]; NAT'L CONG. OF AM. INDIANS, TRIBAL NATIONS AND THE UNITED STATES: AN INTRODUCTION 11, 24 (2020).

18. GREGORY YOUNGING, ELEMENTS OF INDIGENOUS STYLE: A GUIDE FOR WRITING BY AND ABOUT INDIGENOUS PEOPLES 77 (2018) (“Indigenous style uses capitals where conventional style does not. It is a deliberate decision that redresses mainstream society’s history of regarding Indigenous Peoples as having no legitimate national identities; governmental, social, spiritual, or religious institutions; or collective rights.”); Angeliqe EagleWoman, *The Capitalization of ‘Tribal Nations’ and the Decolonization of Citation, Nomenclature, and Terminology in the United States*, 49 MITCHELL HAMLINE L. REV. 623, 629–30 (2023). Many have adopted this capitalization practice. See, e.g., Aila Hoss, *Federal Indian Law as a Structural Determinant of Health*, 47 J.L. MED. & ETHICS SUPP. 34, 35 (2019); *About NIH/NHBL*, NAT'L INDIAN HEALTH BD., https://www.nihb.org/about_us/about_us.php [<https://perma.cc/S36D-V2K2>]; *About*, TRIBAL EPIDEMIOLOGY CTRS. (2024), <https://tribalepicenters.org/about> [<https://perma.cc/GLF7-FPMT>]. This convention was adopted by former President Biden’s administration. Exec. Order No. 13995, 86 Fed. Reg. 7193, 7195 (Jan. 26, 2021). Deviating from conventions in the American Medical Association or the Chicago Manual of Style citation styles is also best practice for researchers writing about other historically excluded communities. See *NABJ Style Guide: NABJ Statement on Capitalizing Black and Other Racial Identifiers*, NAT'L ASS'N BLACK JOURNALISTS (June 2020), <https://www.nabj.org/page/styleguide> [<https://perma.cc/HM67-PWSS>]; Kimberle Crenshaw, *Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color*, 43 STAN. L. REV. 1241, 1244 n.6 (1991).

19. CDC, Public Health 101 Series, Introduction to Public Health, at slide 5 (Oct. 10, 2014), available at <https://www.cdc.gov/training-publichealth101/media/pdfs/introduction-to-public-health.pdf> [<https://perma.cc/Y5JC-75SP>] (quoting C.E.A. Winslow).

20. Stephen B. Thacker, Judith R. Qualters & Lisa M. Lee, *Public Health Surveillance in the United States: Evolution and Challenges*, 61 MORBIDITY & MORTALITY WKLY. REP. 3, 3 (2012).

21. LAWRENCE O. GOSTIN & LINDSAY F. WILEY, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT 306 (3d ed. 2016).

22. CDC, Public Health 101 Series, Introduction to Epidemiology, at slide 8 (Dec. 22, 2014), available at <https://www.cdc.gov/training-publichealth101/media/pdfs/introduction-to-epidemiology.pdf> [<https://perma.cc/TZ8E-JRSg>].

A. *INDIGENOUS HEALTH INEQUITIES*

During the early months of the COVID-19 pandemic, American Indians and Alaska Natives experienced higher rates of COVID-19 in states like Arizona,²³ New Mexico,²⁴ and Wisconsin.²⁵ As the pandemic continued, more robust datasets show that, compared to white individuals, American Indians and Alaska Natives are more likely to be infected, hospitalized, and die from COVID-19.²⁶ These rates were higher than any other racial-ethnic group.²⁷

While the pandemic brought national media attention to Indigenous health inequities,²⁸ they have existed since European colonization began.²⁹ Infectious diseases, particularly smallpox, spread from English ships to Indigenous communities beginning in the early 1600s, greatly reducing the populations³⁰ across Tribes on the East Coast and eventually spreading with westward expansion.³¹ Smallpox transmission was even used as a tactical strategy by British military leadership.³² Following European contact, malnutrition and starvation were common and led to the deaths of thousands of Indigenous people.³³ This was the result of not only crop burning and game killing as a political and military strategy used against Indigenous communities but also

23. Emma Gibson, *Analysis: Native Americans Infected with COVID-19 at Higher Rates in Arizona*, ARIZ. PUB. MEDIA (July 10, 2020), <https://news.azpm.org/p/coronavirus/2020/7/10/176298-analysis-native-americans-infected-with-covid-19-at-higher-rates-in-arizona> [https://perma.cc/qJHQ-N9F5].

24. ABQ Journal News Staff, *'Huge Disparity' in COVID-19 Death Rates for Native Americans in NM*, ALBUQUERQUE J. (May 30, 2020), <https://www.abqjournal.com/1461218/huge-disparity-in-covid19-death-rates-for-native-americans-in-nm.html> (on file with the *Iowa Law Review*).

25. Danielle Kaeding, *Health Disparities Leave Native Americans More Vulnerable to COVID-19*, WIS. PUB. RADIO (July 13, 2020), <https://www.wpr.org/health-disparities-leave-native-americans-more-vulnerable-covid-19> [https://perma.cc/6HWT-6KCJ].

26. *Risk for Covid-19 Infection, Hospitalization, and Death by Race/Ethnicity*, CDC (May 25, 2023), https://archive.cdc.gov/www_cdc_gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html [https://perma.cc/9TGW-9QFK].

27. *See id.*; *see also* Samantha Artiga, Bradley Corallo & Olivia Pham, *Racial Disparities in COVID-19: Key Findings from Available Data and Analysis*, KFF (Aug. 17, 2020), <https://www.kff.org/report-section/racial-disparities-in-covid-19-key-findings-from-available-data-and-analysis-issue-brief> [https://perma.cc/US2E-6DHU].

28. Mark Walker, *Pandemic Highlights Deep-Rooted Problems in Indian Health Service*, N.Y. TIMES (Oct. 8, 2021), <https://www.nytimes.com/2020/09/29/us/politics/coronavirus-indian-health-service.html> (on file with the *Iowa Law Review*); Spero M. Manson & Dedra Buchwald, *Bringing Light to the Darkness: COVID-19 and Survivance of American Indians and Alaska Natives*, 5 HEALTH EQUITY 59, 59–60 (2021).

29. *See* ROXANNE DUNBAR-ORTIZ, AN INDIGENOUS PEOPLES' HISTORY OF THE UNITED STATES 69–70 (2014).

30. *See id.* at 68.

31. STEPHEN L. PEVAR, THE RIGHTS OF INDIANS AND TRIBES 4–5 (4th ed. 2012).

32. *See* DUNBAR-ORTIZ, *supra* note 29, at 68.

33. *See* RUSSELL THORNTON, AMERICAN INDIAN HOLOCAUST AND SURVIVAL: A POPULATION HISTORY SINCE 1492, at 41, 50, 124, 127, 146 (1987).

a more general consequence of colonization, violence, and displacement.³⁴ Forced removal and the establishment of the reservation system further interfered with food access for Indigenous communities, both by interfering with practices for access to traditional means of subsistence through hunting and gathering as well as the prescription of agricultural methods that did not adequately produce a sufficient amount of food.³⁵ The federal government also provided heavily processed foods to many reservations, often the primary source of subsistence for the communities.³⁶

The poor health outcomes experienced by Native people on reservations has been well-documented. The Problem of Indian Administration, more commonly known as the Meriam Report, was a federally commissioned report published in 1928.³⁷ It was produced to document the conditions in Indian country at the time.³⁸ Among other areas, it included detailed commentary on substandard health conditions.³⁹ At boarding schools,⁴⁰ “Indian children . . . are generally below normal in health as compared with standards for white children.”⁴¹ The food provided was insufficient for healthy children, “much less for children whose health is below normal.”⁴² In one case, a teenager spent two years without treatment for a health condition before being sent home at eighteen.⁴³ But medical services were inadequate across Indian country, not just boarding schools. “[T]aken as a whole practically every activity undertaken by the national government for the promotion of the health of the Indians is below a reasonable standard of efficiency.”⁴⁴ Indian country

34. See DUNBAR-ORTIZ, *supra* note 29, at 69–70, 92–94, 113, 125–28, 135, 152, 161, 166 (documenting examples of the use of food supply eradication as part of military strategy during the Tidewater War, and against the Pequot, Illinois and Indiana Territories, Cherokee, Chickamauga, Muskogee, Sauk, California, Dakota Sioux, Navajo, Lakota, Yurok, and Sioux).

35. Samantha Doss, Comment, *The Food Distribution Program on Indian Reservations: Past, Present, and Future*, 76 ARK. L. REV. 219, 223–24 (2023).

36. *Id.* at 223.

37. See generally LEWIS MERIAM ET AL., INST. FOR GOV'T RSCH., THE PROBLEM OF INDIAN ADMINISTRATION (1928) (surveying the economic and social conditions of the American Indians during the 1920s).

38. *Id.* at viii–ix.

39. *Id.* at vii, 189–345.

40. The federal government established Indian boarding schools to assimilate Indian children. Children were forcibly removed, often never seeing their families again, and were forced to give up their names, languages, and cultural practices. They were sites of significant violence and death. Press Release, U.S. Dep't Interior, Department of the Interior Releases Investigative Report, Outlines Next Steps in Federal Indian Boarding School Initiative (May 11, 2022), <https://www.doi.gov/pr/es/releases/departement-interior-releases-investigative-report-outlines-next-steps-federal-indian> [https://perma.cc/DN86-DVGB].

41. MERIAM ET AL., *supra* note 37, at 192.

42. *Id.*

43. *Id.* at 206.

44. *Id.* at 189.

experienced high rates of infant mortality,⁴⁵ tuberculosis,⁴⁶ and trachoma.⁴⁷ The staffing and facilities the federal government provided were wholly inadequate to meet the needs.⁴⁸ The report concluded that “[t]he fundamental explanation of these low standards in the medical work of the Indian Service is lack of adequate appropriations.”⁴⁹

More recently, the U.S. Commission on Civil Rights found a chronic federal funding deficit for Indian country in a 2018 report.⁵⁰ In *Broken Promises: Continuing Federal Funding Shortfall for Native Americans*, the Commission concluded that “[f]unding for the Indian Health Service [“IHS”] and Native American health care is inequitable and unequal.”⁵¹ Per capita health care expenditures at IHS, according to 2016 data, were at “\$2,834, compared to \$9,990 per person” for federal health care spending overall.⁵² Estimates suggest that IHS is funded at less than twenty percent of its need.⁵³ IHS also has difficulties recruiting and maintaining health care personnel,⁵⁴ further exacerbating poor health access.

Health inequities persist in Indian country today. For example, American Indians and Alaska Native people experience higher rates of high blood pressure, diabetes, certain cancers, unintentional injuries, and maternal and

45. *Id.* at 194.

46. *Id.* at 200–01.

47. *Id.* at 208.

48. *Id.* at 206, 228–59, 274.

49. *Id.* at 189.

50. U.S. COMM’N ON C.R., *BROKEN PROMISES: CONTINUING FEDERAL FUNDING SHORTFALL FOR NATIVE AMERICANS* 6 (2018), <https://www.usccr.gov/files/pubs/2018/12-20-Broken-Promises.pdf> [<https://perma.cc/8CJP-GZHL>].

51. *Id.* at 209.

52. *Id.* at 66; *see also* U.S. GOV’T ACCOUNTABILITY OFF., GAO-19-74R, *INDIAN HEALTH SERVICE: SPENDING LEVELS AND CHARACTERISTICS OF IHS AND THREE OTHER FEDERAL HEALTH CARE PROGRAMS* 8 fig.2 (2018), <https://www.gao.gov/assets/gao-19-74r.pdf> [<https://perma.cc/7GTZ-K5S7>].

53. U.S. COMM’N ON C.R., *supra* note 50, at 67 (“According to the Tribal Budget Workgroup, the 2019 IHS budget request of \$5.4 billion, which is \$413 million above FY 2018 annualized funds, would meet only a fraction of the Native American health care need. The Workgroup estimated that \$3.2 billion would be required to fully fund IHS based on health care need.” (footnotes omitted)); *see also* OFF. OF THE ASSISTANT SEC’Y FOR PLAN. & EVALUATION, U.S. DEP’T OF HEALTH & HUM. SERVS., HP-2022-21, *HOW INCREASED FUNDING CAN ADVANCE THE MISSION OF THE INDIAN HEALTH SERVICE TO IMPROVE HEALTH OUTCOMES FOR AMERICAN INDIANS AND ALASKA NATIVES* 15 (2022), <https://aspe.hhs.gov/sites/default/files/documents/1b5d32824c31e113a2df43170c45ac15/aspe-ihs-funding-disparities-report.pdf> [<https://perma.cc/8R9P-6CD5>] (“Although total funding for the agency has gradually increased over time, the overall IHS-wide Level of Need Funded (LNF) is 48.6 percent, according to the most recent calculation.”); U.S. COMM’N ON C.R., *A QUIET CRISIS: FEDERAL FUNDING AND UNMET NEEDS IN INDIAN COUNTRY* 42 (2003), <https://www.usccr.gov/files/pubs/nao703/nao204.pdf> [<https://perma.cc/VV82-65LJ>] (“IHS operates with an estimated 59 percent of what it needs to provide adequate health care.”).

54. *See* U.S. GOV’T ACCOUNTABILITY OFF., GAO-18-580, *INDIAN HEALTH SERVICE: AGENCY FACES ONGOING CHALLENGES FILLING PROVIDER VACANCIES* 9 (2018), <https://www.gao.gov/asset/s/gao-18-580.pdf> [<https://perma.cc/27EK-Q4LB>].

infant mortality as compared to whites.⁵⁵ American Indians and Alaska Natives have the lowest life expectancy as compared to any other racial group in the United States.⁵⁶

Many have aptly argued that race-based inequities are linked to racism rather than race.⁵⁷ Race continues to be used as a proxy for racism when identifying risk factors for disparities.⁵⁸ Thus, the collection of racial/ethnic information is essential to both documenting disparities and studying the impacts of racism. Much of these persistent disparities can be linked to the structural racism found in federal law and policy.⁵⁹ As described in more detail below, Indigenous health inequities also include lack of comprehensive and accurate public health data.

B. THE INDIGENOUS DATA GAP

The Indigenous data gap presents itself in a variety of ways. This includes omission of Indigenous peoples from data collection or results, data quality issues involving Indigenous people, and lack of Tribal membership information. This Section discusses each of these phenomena. The failure to collect meaningful data on Indigenous peoples may be emblematic of low or nonexistent priorities across governments.

1. Data Omission and Racial Misclassification

A CNN television report on the 2020 midterm elections showed a graphic regarding voter turnout based on race.⁶⁰ The graphic listed data for white, Black, Latino, and Asian voters plus a category labeled “something else,” which

55. See, e.g., Monique Adakai et al., *Health Disparities Among American Indians/Alaska Natives—Arizona, 2017*, 67 MORBIDITY & MORTALITY WKLY. REP. 1314, 1314 (2018); *Disparities*, INDIAN HEALTH SERV. (Oct. 2019), <https://www.ihs.gov/newsroom/factsheets/disparities> [<https://perma.cc/7YA5-NCC6>]; Rosalina James et al., *Assessing Social Determinants of Health in a Prenatal and Perinatal Cultural Intervention for American Indians and Alaska Natives*, INT’L J. ENV’T RSCH. & PUB. HEALTH 2–3 (Oct. 21, 2021), <https://www.mdpi.com/1660-4601/18/21/11079> [<https://perma.cc/WA5B-5VS7>].

56. Arias et al., *supra* note 6, at 2.

57. See, e.g., Elwin Wu, *Health Equity Research: A Clarion Call to Focus on Racism, Not Race*, 113 AM. J. PUB. HEALTH 604, 604 (2023); Claudia Wallis, *Why Racism, Not Race, Is a Risk Factor for Dying of COVID-19*, SCI. AM. (June 12, 2020), <https://www.scientificamerican.com/article/why-racism-not-race-is-a-risk-factor-for-dying-of-covid-191> [<https://perma.cc/Q5F5-WNA6>]; Paula Braveman & Tyan Parker Dominguez, *Abandon “Race.” Focus on Racism*, FRONTIERS PUB. HEALTH 4–6 (Sept. 6, 2021), <https://doi.org/10.3389/fpubh.2021.689462> [<https://perma.cc/S77B-A99N>].

58. Wu, *supra* note 57, at 604–05.

59. See, e.g., Hoss, *supra* note 18, at 38–40; Aila Hoss, *COVID-19 and Tribes: The Structural Violence of Federal Indian Law*, 2 ARIZ. ST. L.J. ONLINE 162, 164–66 (2020).

60. Laura Zornosa, *It Appears CNN Deemed Native Americans ‘Something Else,’ Sparking a Backlash*, L.A. TIMES (Nov. 5, 2020, 2:20 PM), <https://www.latimes.com/entertainment-arts/tv/story/2020-11-05/it-looks-like-cnn-called-native-americans-something-else-theyre-not-happy> [<https://perma.cc/5MEK-G7JF>].

apparently included Indigenous people.⁶¹ The graphic gained attention across social media.⁶² This anecdote offers just one of innumerable examples of data suppression impacting American Indians and Alaska Natives. Data suppression refers to exclusion of certain data due to lack of statistical reliability, data quality issues, or risks of identification.⁶³ American Indian and Alaska Natives are regularly excluded from data reports because of data suppression issues, often relegated to the “Other” category.⁶⁴

The Meriam Report also discussed in detail the lack of data regarding Indian country.⁶⁵ It found that Indian health “[v]ital statistics and records of medical activities at present are incomplete and as a rule unreliable.”⁶⁶ The report provided examples of inadequate data across censuses, birth records, death records, and infant mortality.⁶⁷ Although the report was written nearly a century ago, the data challenges described continue to persist.

Incomplete datasets regarding American Indians and Alaska Natives span a wide variety of urgent issues including HIV,⁶⁸ missing and murdered Indigenous women⁶⁹ and COVID-19.⁷⁰ In a survey of state and local governments conducted by the Council for State and Territorial Epidemiologists, the “overwhelming majority” of jurisdictions found it difficult to collect race and ethnicity data.⁷¹ When individuals indicate that they are more than once race, they will often

61. *Id.*

62. *Id.*

63. RICHARD J. KLEIN, SUZANNE E. PROCTOR, MANON A. BOUDREAULT & KATHLEEN M. TURCZYN, CDC, HEALTHY PEOPLE 2010 CRITERIA FOR DATA SUPPRESSION 1 (2002), <https://www.cdc.gov/nchs/data/statnt/statnt24.pdf> [<https://perma.cc/W4QK-AURT>].

64. See, e.g., Jennifer L. Wiltz et al., *Racial and Ethnic Disparities in Receipt of Medications for Treatment of COVID-19—United States, March 2020–August 2021*, 71 MORBIDITY & MORTALITY WKLY. REP. 96, 96 (2022).

65. MERIAM ET AL., *supra* note 37, at 266.

66. *Id.*

67. *Id.* at 266–68.

68. NAT’L CTR. FOR HIV/AIDS, VIRAL HEPATITIS, STD, AND TB PREVENTION, CDC, IMPROVING HIV SURVEILLANCE AMONG AMERICAN INDIANS AND ALASKA NATIVES IN THE UNITED STATES 9–12 (2013), <https://stacks.cdc.gov/view/cdc/13119> [<https://perma.cc/JV2H-T6SC>].

69. Braeden Waddell, *Incomplete Data Complicates the Search for Missing Native American Women*, U.S. NEWS & WORLD REP. (Nov. 1, 2021, 1:17 PM), <https://www.usnews.com/news/best-states/articles/2021-11-01/the-link-between-missing-indigenous-women-and-missing-data> [<https://perma.cc/Z3FX-L6ZQ>].

70. Jourdan Bennett-Begaye, Sunnie Clahchischiligi & Christine Trudeau, *A Broken System: The Number of Indigenous People Who Died from Coronavirus May Never Be Known*, HIGH COUNTRY NEWS (June 8, 2021), <https://www.hcn.org/articles/indigenous-affairs-covid-19-a-broken-system-the-number-of-indigenous-people-who-died-from-coronavirus-may-never-be-known> [<https://perma.cc/2LZE-5S85>]; Kimberly R. Huyser, Aggie J. Yellow Horse, Alena A. Kuhlemeier & Michelle R. Huyser, *COVID-19 Pandemic and Indigenous Representation in Public Health Data*, 111 AM. J. PUB. HEALTH S208, S208–09 (2021).

71. BROOKE BEAULIEU, CSTE, ADDRESSING GAPS IN PUBLIC HEALTH REPORTING OF RACE AND ETHNICITY DATA FOR COVID-19: FINDINGS AND RECOMMENDATIONS AMONG 45 STATE & LOCAL HEALTH DEPARTMENTS 5 (2022), <https://stacks.cdc.gov/view/cdc/117473> [<https://perma.cc/4Q4F-BGBA>].

be excluded from further studies because forms generally do not require individuals to indicate which races in which they identify.⁷²

Even when data is available, the data can be difficult to analyze⁷³ and researchers fail to utilize available tools to improve the quality of statistical analysis when studying groups with smaller populations.⁷⁴ In instances where racial–ethnic classification is collected by someone other than the individual, there can be instances of racial misclassifications based on perceived or presenting race.⁷⁵

Racial misclassification often occurs on death certificates, where funeral directors or medical examiners may determine the race of the deceased person.⁷⁶ A study by researchers from the Northwest Tribal Epidemiology Center and the Northwest Portland Area Indian Health Board reviewed a sample of Washington state death records from 1989 to 1997.⁷⁷ It found that nearly fifteen percent of American Indian and Alaska Native death records were not classified as such.⁷⁸ A 2019 survey conducted by researchers from the National Council of Urban Indian Health found that participating funeral directors relied on collecting information from family members or other informants verbally less than other methods when determining racial data.⁷⁹ Stereotyping based

72. Linda Charmaraman, Meghan Woo, Ashley Quach & Sumru Erkut, *How Have Researchers Studied Multiracial Populations? A Content and Methodological Review of 20 Years of Research*, 20 CULTURAL DIVERSITY & ETHNIC MINORITY PSYCH. 336, 337 (2014).

73. See, e.g., Curtis, *supra* note 15; TRIBAL EPIDEMIOLOGY CTRS., BEST PRACTICES IN AMERICAN INDIAN & ALASKA NATIVE PUBLIC HEALTH 8 (2013).

74. See, e.g., Marc N. Elliott et al., *Improving Disparity Estimates for Rare Racial/Ethnic Groups with Trend Estimation and Kalman Filtering: An Application to the National Health Interview Survey*, 44 HEALTH SERVS. RSCH. 1622, 1622–24 (2009).

75. See, e.g., Melissa R. Herman, *Do You See What I Am?: How Observers' Backgrounds Affect Their Perceptions of Multiracial Faces*, 73 SOC. PSYCH. Q. 58, 58–59 (2010); Aliya Saperstein, *Double-Checking the Race Box: Examining Inconsistency Between Survey Measures of Observed and Self-Reported Race*, 85 SOC. FORCES 57, 58 (2006); Aliya Saperstein, *Different Measures, Different Mechanisms: A New Perspective on Racial Disparities in Health Care*, 27 RSCH. SOCIO. HEALTH CARE 21, 22–23 (2009); NAT'L COUNCIL OF URBAN INDIAN HEALTH, WHAT IS RACIAL MISCLASSIFICATION ON DEATH CERTIFICATES, AND HOW DOES IT AFFECT AMERICAN INDIAN AND ALASKA NATIVE PEOPLE?, at 1, <http://ncuih.org/wp-content/uploads/Racial-Misclassification-on-Death-Certificates-for-Government-and-Policy-Stakeholders.pdf> [<https://perma.cc/6AJ5-ZY7Q>]; CDC, *Classification of American Indian Race on Birth and Infant Death Certificates—California and Montana*, 42 MORBIDITY & MORTALITY WKLY. REP. 220, 220–23 (1993).

76. *Health, United States: Race*, NAT'L CTR. FOR HEALTH STAT., CDC (Oct. 3, 2024), <https://www.cdc.gov/nchs/hus/sources-definitions/race.html> [<https://perma.cc/NQS2-5FRS>].

77. See generally Paul Stehr-Green, James Bettles & L. Dee Robertson, *Effect of Racial/Ethnic Misclassification of American Indians and Alaskan Natives on Washington State Death Certificates, 1989–1997*, 92 AM. J. PUB. HEALTH 443, 444 (2002) (summarizing findings from the Northwest Tribal Registry that “misclassif[y]ing” American Indians and Alaska Natives “on death certificates [leads] to an underestimation of overall and disease-specific mortality burden”).

78. *Id.* at 443.

79. Andrew Kalweit, Marc Clark & Jamie Ishcomer-Aazami, *Determinants of Racial Misclassification in COVID-19 Mortality Data: The Role of Funeral Directors and Social Context*, 44 AM. INDIAN CULTURE & RSCH. J. 15, 21 (2020).

on cause of death has also been found to be linked to racial misclassifications.⁸⁰ For example, people that died from liver cirrhosis were more likely to be classified as American Indian.⁸¹

Racial misclassification is not limited to death certifications, however.⁸² A study by Professors Grafova and Jarrín reviewed Centers for Medicare and Medicaid Services state-level administrative data.⁸³ They found significant variation between database racial and ethnic classifications as compared to self-identification data.⁸⁴ Research has found racial misclassifications in state cancer and other disease datasets.⁸⁵

Intentional self-misclassification of race can also occur when an individual believes that disclosing their race can disadvantage or harm them. Ponca attorney and activist, Brett Chapman, shared on X prior to a surgery that he was intentionally marking his race as Caucasian⁸⁶ to improve the quality of the services he receives post-operation.⁸⁷ Even Census data, based on self-identification, can lead to racial misclassification. The Census survey is completed by household unit,⁸⁸ meaning that one person may fill out the survey on behalf of all residents.

80. Andrew Noymer, Andrew M. Penner & Aliya Saperstein, *Cause of Death Affects Racial Classification on Death Certificates*, PLOS ONE 2 (Jan. 2011), <https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0015812&type=printable> [<https://perma.cc/YG9g-ZFX7>].

81. *Id.* at 1; see also Sherry Everett Jones & Delight E. Satter, *Implications for Coding Race and Ethnicity for American Indian and Alaska Native High School Students in a National Survey*, 33 J. HEALTH CARE FOR POOR & UNDERSERVED 1245, 1245 (2022) (discussing the impact of racial-ethnic coding on the precision of calculations of risk behavior prevalence among American Indian and Alaska Native students).

82. Emily A. Haozous, Carolyn J. Strickland, Janelle F. Palacios & Teshia G. Arambula Solomon, *Blood Politics, Ethnic Identity, and Racial Misclassification Among American Indians and Alaska Natives*, J. ENV'T & PUB. HEALTH 2 (Feb. 2, 2014), <https://doi.org/10.1155/2014/321604> [<https://perma.cc/M933-S2DW>].

83. Irina B. Grafova & Olga F. Jarrín, *Beyond Black and White: Mapping Misclassification of Medicare Beneficiaries Race and Ethnicity*, 78 MED. CARE RSCH. & REV. 616, 616–17 (2021).

84. *Id.* at 619, 621.

85. *Id.* at 623.

86. A term often used to mean “white.” This term has been used to define people belonging to a race native of Europe, North Africa, and southwest Asia. *Caucasian*, MERRIAM-WEBSTER (2024), <https://www.merriam-webster.com/dictionary/Caucasian> [<https://perma.cc/7J89-G63U>]. Although Caucasian is considered an obsolete and highly problematic term, it remains used in a variety of forms. Aksharananda Rambachan, *Overcoming the Racial Hierarchy: The History and Medical Consequences of “Caucasian,”* 5 J. RACIAL & ETHNIC HEALTH DISPARITIES 907, 911 (2018).

87. Brett Chapman (@brettachapman), X (Sept. 20, 2022, 3:08 PM), <https://twitter.com/brettachapman/status/1572316811336589313?s=11&t=N6Uo3FL7Fq4t8PHjKLuUXA> [<https://perma.cc/9CEC-B4JZ>].

88. *Families and Households*, U.S. CENSUS BUREAU (May 2, 2024), <https://www.census.gov/topics/families/families-and-households.html> [<https://perma.cc/Z3HX-HEUE>].

2. Failure to Collect Tribal Membership Data

Many but not all Indigenous people are citizens of one of the hundreds of Tribes within the United States. When public health data involving an Indigenous person is collected, it rarely includes Tribal membership identification.⁸⁹ This means that a Tribe will not be able to secure public health data about their own citizens. Instead, Tribes must rely on less accurate data based on racial/ethnic identifiers and zip codes as a proxy.⁹⁰ This can limit Tribes' ability to meaningfully engage in programmatic and policy work to respond to the public health considerations that the data reveals. As a hypothetical example, a Tribe like the Muscogee Nation, with an eleven-county service area,⁹¹ may want to assess influenza rates amongst their citizens. They may need to rely on influenza data from individuals that identify as American Indian and Alaska Native in certain zip codes. Those zip codes are also heavily populated with other Tribal citizens, like the Cherokee Nation, which has a fourteen-county service area that overlaps heavily with the Muscogee Nation.⁹²

It is *extremely* rare for institutions, health or otherwise, to collect Tribal-membership level data. Professors Small-Rodriguez and Akee conducted a systematic review of American Indian and Alaska Native decedents on all state death certificates.⁹³ They found no standardized collection method for Tribal membership.⁹⁴ They argue that “[t]he collection of [T]ribal enrollment data in vital statistics and health surveillance systems is necessary to identify and respond to health disparities among AI/AN subpopulations.”⁹⁵ It is by no means impossible to collect Tribal membership data. The University of Oklahoma's graduate admission application, for example, includes a field for racial self-identification.⁹⁶ For applicants indicating that they are American Indian or Alaska Native, there is a subfield to identify Tribal membership, if applicable.⁹⁷

89. AILA HOSS, STEPHEN MURPHY, EMELY SANCHEZ & CARRIE WAGGONER, *DISAGGREGATION OF PUBLIC HEALTH DATA BY RACE & ETHNICITY: A LEGAL HANDBOOK* 50 (2022), https://www.networkforphl.org/wp-content/uploads/2022/12/Network-for-Public-Health-Law-Data-Disaggregation-Handbook_FINAL.pdf [<https://perma.cc/F3VG-HD9P>].

90. *Id.*

91. MYSKOKE TOURISM, *ABOUT THE MUSCOGEE (CREEK) NATION GOVERNMENT* 1, https://vismuscogeenation.com/wp-content/uploads/2016/08/FactSheet_2sides_MCNT16.pdf [<https://perma.cc/J8VF-8SZV>]; *see also* *Careers*, MUSCOGEE NATION (2024), <https://www.muscogeenation.com/jobs> [<https://perma.cc/6DCF-UYWU>] (showing jobs in at least eleven different counties).

92. *Maps*, CHEROKEE NATION (Aug. 10, 2023), <https://www.cherokee.org/about-the-nation/maps> [<https://perma.cc/35B9-SRKS>].

93. Desi Small-Rodriguez & Randall Akee, *Identifying Disparities in Health Outcomes and Mortality for American Indian and Alaska Native Populations Using Tribally Disaggregated Vital Statistics and Health Survey Data*, 111 AM. J. PUB. HEALTH S126, S126 (2021).

94. *Id.* at S126, S128–30.

95. *Id.* at S126.

96. *Application for Graduate Admission*, U. OKLA. (June 1, 2008), <https://www.ou.edu/dam/CoE/AME/Forms/US-GRAD-APPLICATION.pdf> [<https://perma.cc/UD2U-EWXR>].

97. *Id.*

The Supreme Court's recent decision in *Students for Fair Admissions, Inc. v. President & Fellows of Harvard College* striking down the use of race in college admissions⁹⁸ may have broader impact in other areas such as employment.⁹⁹ Given this change, organizations may move toward collecting Tribal membership information. This would not be violative of *Students for Fair Admissions* since Tribal membership is a political classification subject to rational review, not a race-based classification.¹⁰⁰

Several organizations and scholars have made vocal calls for the inclusion of Tribal affiliation in health data collection.¹⁰¹ Yes, Tribal membership level data can support public health surveillance efforts; however, it also implicates issues regarding health privacy and Tribal data sovereignty. These critically important issues are discussed in Part IV below.

C. *INDIGENOUS DATA ACCESS*

One final overarching issue exemplifying the need for Indigenous health data is the lack of access to public health surveillance systems by Tribal governments. Public health datasets with racial identifiers include important information regarding Indigenous people. Most of these datasets are produced and housed by federal and state agencies. This means that non-Tribal governments have more access to information regarding Tribal citizens than Tribes do themselves. This undermines Tribal sovereignty.

During the COVID-19 pandemic, both the federal government and states failed to provide Tribes timely access to data implicating their citizens.¹⁰² Lack of access to timely COVID-19 data regarding Indigenous communities has garnered congressional attention. Lack of access to timely COVID-19 data regarding Indigenous communities has garnered congressional attention. Legislators have introduced bills to increase Tribal data access¹⁰³ and have

98. *Students for Fair Admissions, Inc. v. President & Fellows of Harvard Coll.*, 600 U.S. 181, 227–31 (2023).

99. Steve Friess, *Ending Affirmative Action Will Be an 'Earthquake' for Colleges, Companies*, NEWSWEEK (Nov. 16, 2022, 5:00 AM), <https://www.newsweek.com/2022/11/25/ending-affirmative-action-will-earthquake-colleges-companies-1759783.html> [<https://perma.cc/LR6C-RGK5>].

100. See *infra* Sections IV.A–B; see also Emma Hall, *For Native Students, the End of Race in Admissions Is Complicated*, CHRON. HIGHER EDUC. (July 14, 2023), <https://www.chronicle.com/article/for-native-students-the-end-of-race-in-admissions-is-complicated> [<https://perma.cc/5HH6-8AQV>] (describing the impact of *Students for Fair Admissions* on race-based admissions for Native students).

101. See, e.g., *Patient Demographic Information: Tribal Affiliation*, HEALTHIT.GOV (Apr. 29, 2022), <https://www.healthit.gov/isa/uscdi-data/tribal-affiliation> [<https://perma.cc/5FQX-P5AS>] (summarizing comments regarding the inclusion of Tribal affiliation information in health information technology).

102. Tahir & Cancryn, *supra* note 14; *Tribes Face Barriers to Access COVID-19 Data*, *supra* note 15; Cimini, *supra* note 15.

103. See generally Tribal Health Data Improvement Act of 2021, S. 1397, 117th Cong. (2d Sess. 2021) (expanding Tribal access to public health care data and public health surveillance programs, reauthorizing the National Center for Health Statistics, and requiring the CDC to

called for better Tribal data access from agencies like the CDC.¹⁰⁴ Tribal Epidemiology Centers, which provide public health surveillance support to Tribes, were also denied access to COVID-19 data despite clear federal statutory language requiring the federal government to do so.¹⁰⁵ This garnered significant attention, leading to the publication of a federal report on the topic.¹⁰⁶ When Tribes and their partners are unable to access timely and accurate data, this limits their ability to engage in public health programming. Examples of how governments rely on public health data are discussed in Section II below.

II. THE PUBLIC HEALTH SURVEILLANCE MAZE

Health data not only documents health disparities but also protective factors that make individuals and communities more resilient to health risks. Health data is generated through surveys, medical records, vital records, and research.¹⁰⁷ Data can travel across health systems, research institutions, health insurers, and government agencies. It can also be made available publicly. Understanding how data is collected, shared, and disseminated allows for better understanding of how the surveillance systems impacts Indigenous communities. Each of these are discussed in turn.

A. THE ROLE OF DATA

Public health data is used to respond to health crises and deploy health care resources.¹⁰⁸ It has a significant role in improving clinical outcomes. Surveillance systems supply information for public communications of current health priorities.¹⁰⁹ For example, a May 2023 report from the CDC regarding a salmonella outbreak included information regarding the source of the outbreak, raw cookie dough from a large chain restaurant.¹¹⁰ This information can be used to prevent others from eating the contaminated food and also getting

address the collection and availability of health data for American Indians and Alaska Natives); Tribal Health Data Improvement Act of 2020, H.R. 7948, 116th Cong. (2020) (expanding Tribal access to public health data, providing additional funding to Tribes, and establishing guidance to states to improve vital records for American Indians and Alaska Natives).

104. See Hanson, *supra* note 13; Press Release, U.S. Senate Comm. on Indian Affs., *supra* note 13.

105. 25 U.S.C. § 1621m(e) (2018).

106. U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 13, at 1–2.

107. Nat'l Libr. of Med., 3, *Health Data Sources*, NAT'L INST. HEALTH, https://www.nlm.nih.gov/nichsr/stats_tutorial/section3/index.html [<https://perma.cc/PWQ2-QN3E>]; GOSTIN & WILEY, *supra* note 21, at 308 tbl.g.2.

108. GOSTIN & WILEY, *supra* note 21, at 306–07.

109. See *Outbreaks*, CDC (Aug. 2024), <https://www.cdc.gov/outbreaks/index.html> [<https://perma.cc/44LJ-536D>]; *Disease Outbreak News (DONs)*, WORLD HEALTH ORG. (Sept. 20, 2024), <https://www.who.int/emergencies/disease-outbreak-news> [<https://perma.cc/CM37-CPQV>].

110. *Salmonella Outbreak Linked to Raw Cookie Dough*, CDC (July 13, 2023), <https://www.cdc.gov/salmonella/enteritidis-05-23/index.html> [<https://perma.cc/KgLQ-YLWG>].

sick. Health care providers, on notice of outbreaks in their communities, can use public health data to support diagnosis, treatment, and prevention.¹¹¹

Data is also essential for determining programmatic, policy, and funding priorities across all sectors.¹¹² As the Federal Reserve Bank of Minneapolis succinctly explains:

- A **worker** can get a sense of what wages are available in different occupations because the Occupational Employment Statistics provide up-to-date estimates. Before launching their careers, **families** and **students** can rely on American Community Survey (ACS) data to learn the range of salaries typically paid to graduates with different college majors.
- A **business leader** can use demographic data to tailor marketing strategies because the ACS contains a wide range of data for small geographic areas.
- A **policymaker** relies on the unemployment rates calculated by the Bureau of Labor Statistics to assess a labor market recovery and the need for monetary and fiscal policy action.¹¹³

At the state level, a Pew Charitable Trusts study found that data from administrative agencies informed policy decisions, service delivery, resource prioritization, and program evaluation.¹¹⁴ This could include, for example, determining health care service costs and coverage.¹¹⁵ Public health data is also needed to identify and respond to health inequities, particularly data disaggregated by race and ethnicity.¹¹⁶ “Disaggregated data refers to the

111. CDC, PUBLIC HEALTH SURVEILLANCE: PREPARING FOR THE FUTURE 17 (2018), <https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf> [<https://perma.cc/83ZE-RAT3>].

112. GOSTIN & WILEY, *supra* note 21, at 306–07; DEBORAH STONE, POLICY PARADOX: THE ART OF POLITICAL DECISION MAKING 183 (3d ed. 2012) (“One common way to define a policy program is to measure it.”).

113. Matthew Gregg, Casey Lozar & Ryan Nunn, *An Urgent Priority: Accurate and Timely Indian Country Data*, FED. RESRV. BANK MINNEAPOLIS (May 10, 2022), <https://www.minneapolisfed.org/article/2022/an-urgent-priority-accurate-and-timely-indian-country-data> [<https://perma.cc/2XYN-FP4Q>].

114. SALLYANN BERGH, ALYSSA DAVIS, AMBER IVEY, DAN KITSON & JENNIFER THORNTON, PEW CHARITABLE TRS., HOW STATES USE DATA TO INFORM DECISIONS 1–3 (2018), https://www.pewtrusts.org/-/media/assets/2018/02/dasa_how_states_use_data_report_v5.pdf [<https://perma.cc/4VTD-C9C8>]; *see also* COMM’N ON EVIDENCE-BASED POLICYMAKING, THE PROMISE OF EVIDENCE-BASED POLICYMAKING 4–10 (2017), <https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2019/03/Appendices-e-h-The-Promise-of-Evidence-Based-Policymaking-Report-of-the-Commission-on-Evidence-based-Policymaking.pdf> [<https://perma.cc/6923-SJLB>] (providing detailed survey results from federal agencies on how they use data for evidence-based policy development).

115. Beth A. Virnig & Marshall McBean, *Administrative Data for Public Health Surveillance and Planning*, 22 ANN. REV. PUB. HEALTH 213, 215–16 (2001).

116. Samantha Artiga, *Advancing Health Equity Requires More and Better Data*, KFF (Oct. 27, 2021), <https://www.kff.org/policy-watch/advancing-health-equity-requires-more-better-data> [<https://perma.cc/6923-SJLB>].

separation of compiled information into smaller units to elucidate underlying trends and patterns.”¹¹⁷ Categorizing data into overly large groups limits visibility of the communities within these groups.¹¹⁸

Federal programming also relies heavily on data to assess funding requests as well as the strength of the proposed intervention. A 2023 report from the Substance Abuse and Mental Health Services Administration (“SAMHSA”), *Developing a Competitive SAMHSA Grant Application*, refers to the need for data to strengthen funding applications.¹¹⁹ The Indigenous data gap in existing data systems means that Tribes and Tribal-serving organizations will have less available data to support their grant applications.¹²⁰ The U.S. Census data alone informed the use of 2.8 trillion dollars in fiscal year 2021.¹²¹

The Meriam Report devoted an entire chapter on gaps in data and statistics in Indian country and described how data could be used.¹²² It concluded that “[t]he lack of adequate accurate statistics and records regarding the Indians and the work done in their behalf has constituted a real handicap to every member of the staff of this survey of Indian affairs.”¹²³ The report indicated that the only way in which the federal government could provide services it is obligated

perma.cc/93YS-267L]; Alonzo L. Plough, *Using Data to Advance Health Equity in Your Community*, ROBERT WOOD JOHNSON FOUND. (Jan. 3, 2023), <https://www.rwjf.org/en/insights/blog/2023/01/using-data-to-advance-health-equity-in-your-community.html> [<https://perma.cc/N2D4-MULX>].

117. PAN AM. HEALTH ORG. & WORLD HEALTH ORG., WHY DATA DISAGGREGATION IS KEY DURING A PANDEMIC 2 (2020), <https://iris.paho.org/bitstream/handle/10665.2/52002/Data-Disaggregation-Factsheet-eng.pdf?sequence=19> [<https://perma.cc/G24U-7744>].

118. PAULA BRAVEMAN, ELAINE ARKIN, TINA KAUH & NICOLE HOLM, ROBERT WOOD JOHNSON FOUND., HEALTH EQUITY: EVERYONE COUNTS 11 (2022), <https://www.rwjf.org/en/library/research/2022/05/health-equity-everyone-counts.html> [<https://perma.cc/7N6L-2YQ6>]; VICTOR RUBIN, DANIELLE NGO, ÁNGEL ROSS, DALILA BUTLER & NISHA BALARAM, POLICYLINK, COUNTING A DIVERSE NATION: DISAGGREGATING DATA ON RACE AND ETHNICITY TO ADVANCE A CULTURE OF HEALTH 20 (2018), https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_o8_15_18.pdf [<https://perma.cc/8VGS-3H4N>].

119. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., DEVELOPING A COMPETITIVE SAMHSA GRANT APPLICATION 8, 10, 23–24, 29 (2023), <https://www.samhsa.gov/sites/default/files/developing-competitive-samhsa-grant-application-manual.pdf> [<https://perma.cc/XX5S-3PRZ>].

120. Mark Trahant, *Indigeneity’s Data Dilemma*, INDIAN COUNTRY TODAY (Apr. 11, 2023), <https://ictnews.org/news/indigeneitys-data-dilemma> [<https://perma.cc/C4RP-NCXX>] (describing how the formula for calculating Tribal employment rates in labor-related legislation requires data that Tribes do not have). Employment information collected by various organizations is not specific to Tribal members but, rather, American Indians and Alaska Natives generally. See, e.g., *Native American Labor Market Dashboard*, FED. RESRV. BANK MINNEAPOLIS (2024), <https://www.minneapolisfed.org/indiancountry/resources/native-american-labor-market-dashboard> [<https://perma.cc/WQ8L-28NZ>].

121. CECI VILLA ROSS, U.S. CENSUS BUREAU, USES OF DECENNIAL CENSUS PROGRAMS DATA IN FEDERAL FUNDS DISTRIBUTION: FISCAL YEAR 2021, at 41 (2023), <https://www2.census.gov/library/working-papers/2023/decennial/census-data-federal-funds-fy-2021.pdf> [<https://perma.cc/7LAD-2BG4>].

122. MERIAM ET AL., *supra* note 37, at 170–82.

123. *Id.* at 170.

to provide would require an accurate and detailed census.¹²⁴ In regards to health priorities, the report outlined, for example, lack of death statistics makes it impossible to track causes of death and craft effective public health programs accordingly.¹²⁵

These examples demonstrate the role of data in governmental and health care decision making. The Indigenous data gap leads to the lack of prioritization of Indigenous health issues and can limit the allocation of funding at the Tribal, state, and federal level. Tribes, in particular, are marginalized from engaging in the full breadth of their public health authority when they are denied access to data. Tribal citizens, in turn, are denied the opportunity to fully engage with and be served by their Tribes.

B. DATA COLLECTION SYSTEMS

Health data is typically coupled with demographic data to identify trends in health outcomes. The collection of race and ethnicity data is particularly fraught. Racial categories are not based on scientific distinctions.¹²⁶ Rather, “[r]ace is a socially constructed system of categorizing humans largely based on observable physical features (phenotypes), such as skin color, and on ancestry.”¹²⁷ Ethnicity, also, is “[a] social construct that divides people into smaller social groups based on characteristics such as shared sense of group membership, values, behavioral patterns, language, political and economic interests, history, and ancestral geographical base.”¹²⁸ Although social constructs, race and ethnicity have meaningful social and legal impacts, and definitions of race and ethnicity are not static under law and policy. For example, the Census Bureau considers race to be a personal identification to a certain social group¹²⁹ and ethnicity to include Hispanic or Latino.¹³⁰

Governments have the legal authority to collect data, including data based on racial and ethnic categories.¹³¹ There is no single mechanism in which public health data is collected nor a single entity that is responsible for its collection.¹³² One method of collection is through health care providers and

124. *Id.* at 170–71.

125. *Id.* at 172.

126. *Equity, Inclusion and Other Racial Justice Definitions*, ANNIE E. CASEY FOUND. (Apr. 14, 2021), <https://www.aecf.org/blog/racial-justice-definitions> [<https://perma.cc/8U7L-KJGM>].

127. *Id.*

128. *Racial Equity Tools Glossary*, RACIAL EQUITY TOOLS, <https://www.racialequitytools.org/glossary> [<https://perma.cc/Q628-X7NB>] (under “Glossary,” click the hyperlink labeled “Ethnicity” to expand the definition).

129. U.S. CENSUS BUREAU, RACE & ETHNICITY 1 (2017), <https://www.sanbenitocountyca.gov/home/showpublisheddocument/5935/637356700118370000> [<https://perma.cc/UBU2-UJUP>].

130. *Id.*

131. *See, e.g.*, *Whalen v. Roe*, 429 U.S. 589, 593 (1977); ROSS, *supra* note 121, at 41.

132. *See, e.g.*, CDC, Public Health 101 Series: Introduction to Public Health Surveillance, at slides 19–20, 24 (2014), *available at* <https://www.cdc.gov/training-publichealth101/media/pdfs>

health care facilities during clinical interactions with patients.¹³³ Every state requires providers, facilities, and laboratories to report certain conditions or events to health departments (Figure 2).¹³⁴ Reportable conditions and events vary from state to state but include infectious diseases—like influenza, HIV, or measles; non-communicable diseases like cancers, Lyme disease, or diabetes; and events like heart attacks and immunizations.¹³⁵ When reporting these communicable conditions and events, providers also include basic demographic information regarding the patient’s age, gender, race, and ethnicity.¹³⁶ There is no general federal requirement for states to report this information to the CDC.¹³⁷ But, many states do.¹³⁸ There is no consistency in the type, format, or timeline in which the CDC receives this data.¹³⁹

/introduction-to-surveillance.pdf [https://perma.cc/RJ8A-YYWg]; Aila Hoss, *Exploring Legal Issues in Tribal Public Health Data and Surveillance*, 44 S. ILL. U. L.J. 27, 27–28 (2019).

133. CDC, *supra* note 132, at slide 20.

134. *Id.*; see *infra* Figure 1.

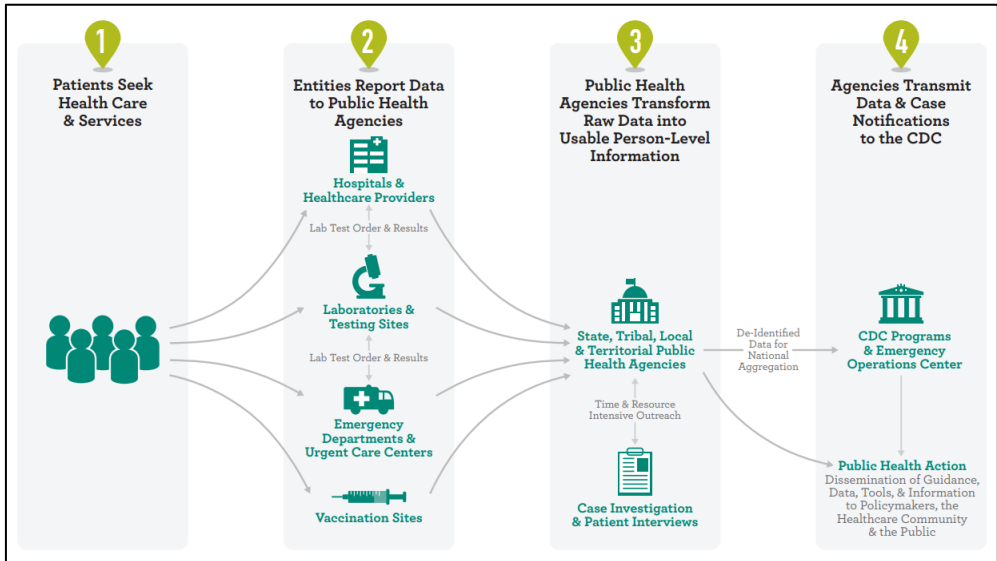
135. See, e.g., ALA. ADMIN. CODE r. 420-4-1-04, 420-4-1-A1 app. I (2024) (listing reportable conditions); FLA. ADMIN. CODE ANN. r. 64D-3.029 (2023) (same); 410 IND. ADMIN. CODE 410-1-2.5-75, -76 (2024) (same); COLO. REV. STAT. ANN. § 25-3-117 (West 2023) (heart attacks); OR. REV. STAT. §§ 444.300, .320 (2023) (childhood diabetes).

136. See, e.g., IND. DEP’T OF HEALTH, FORM 43823, CONFIDENTIAL REPORT OF COMMUNICABLE DISEASES 1 (2024), <https://forms.in.gov/Download.aspx?id=5082> [https://perma.cc/MR5B-VMCK]; GA. DEP’T OF PUB. HEALTH, FORM 3095, GEORGIA NOTIFIABLE DISEASE CONDITION REPORTING 3 (2011), <https://dph.georgia.gov/document/document/notifiable-disease-report-form/download> [https://perma.cc/T36G-F3EW]; *Oregon Notifiable Disease Case Report Forms*, OR. HEALTH AUTH., <https://www.oregon.gov/oha/ph/diseasesconditions/communicabledisease/reportingcommunicabledisease/reportingforms/Pages/index.aspx> [https://perma.cc/Z55T-23NC].

137. HOSS ET AL., *supra* note 89, at 19.

138. *Where Does Our Data Come From?*, CDC (May 17, 2023), https://archive.cdc.gov/www_cdc.gov/surveillance/data-modernization/basics/where_does_our_data_come_from.html [https://perma.cc/UQ2R-ZL9D].

139. *Id.*

Figure 1: Data Flow from Health Care to Public Health Agencies¹⁴⁰

States also collect information regarding births and deaths.¹⁴¹ On birth records, the races of the parents are usually provided by the birthing parent on the birth certificate.¹⁴² On death certificates, races are recorded by medical examiners, coroners, and funeral directors.¹⁴³ This is often done via perceived racial–ethnic identity.¹⁴⁴

The federal collection of data is governed by the Office of Management and Budget (“OMB”) Directive No. 15 categories of race.¹⁴⁵ It establishes seven categories of race/ethnicity: (1) American Indian or Alaska Native; (2) Asian; (3) Black or African American; (4) Hispanic or Latino; (5) Middle Eastern or North African; (6) Native Hawaiian or Pacific Islander; and (7) White.¹⁴⁶

140. HOSS ET AL., *supra* note 89, at 17.

141. Nat’l Ctr. for Health Stat., *supra* note 76.

142. *Id.*

143. *Id.*

144. *Id.*

145. Revisions to OMB’s Statistical Policy Directive No. 15, 89 Fed. Reg. 22182, 22194 fig.2 (Mar. 29, 2024); Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58782, 58788 (Oct. 30, 1997).

146. Karin Orvis, *OMB Publishes Revisions to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, WHITE HOUSE: OMB BRIEFING ROOM BLOGS (Mar. 28, 2024), <https://www.whitehouse.gov/omb/briefing-room/2024/03/28/omb-publishes-revisions-to-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity> [https://perma.cc/5J4M-9CRH].

Federal law and policy require health surveys sponsored by the Department of Health and Human Services (“HHS”) to use more detailed categories.¹⁴⁷

At the federal level, agencies engage in data collection through countless mechanisms. For example, the federal government engages in national-level health surveys.¹⁴⁸ Federal law sometimes establishes affirmative requirements for the federal government to collect public health data regarding Native people or to support Tribes in securing access to data.¹⁴⁹ The National Center for Health Statistics, for example, is required by statute to collect data regarding American Indians.¹⁵⁰

When the federal government is a direct provider of health services, as in the case for Veterans Health Administration and IHS, data collection is varied.¹⁵¹ Federal laws, like the Government Performance and Results Act of 1993 (“GPRA”), create reporting requirements for federal agencies to access

147. 42 U.S.C. § 300kk; *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*, U.S. DEP’T OF HEALTH & HUM. SERVS., OFF. ASSISTANT SEC’Y FOR PLAN. & EVALUATION (Oct. 30, 2011), <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability> [http://perma.cc/XDT3-DUDP].

148. The Behavioral Risk Factor Surveillance System is a national telephone survey administered annually. The questionnaire collects information regarding risk behaviors, chronic health conditions, and prevention services. *Behavioral Risk Factor Surveillance System*, CDC (Aug. 28, 2024), <https://www.cdc.gov/brfss/index.html> [https://perma.cc/BT4L-TV47]. The National Health and Nutrition Examination Survey is administered by the National Center for Health Statistics at the CDC. Data on health and nutritional information on U.S. children and adults are collected via in-home interviews. *About the National Health and Nutrition Examination Survey*, CDC (May 31, 2023), https://www.cdc.gov/nchs/nhanes/about_nhanes.htm [https://perma.cc/J75C-NDQJ].

149. See, e.g., 42 U.S.C. § 242k(m)(4)(A) (“[T]he Secretary, acting through the Center, shall collect data on Hispanics and major Hispanic subpopulation groups and American Indians, and for developing special area population studies on major Asian American and Pacific Islander populations.”); *id.* § 242t(d) (“The Director may, in cooperation with Indian Tribes . . . and pursuant to a written request from an Indian Tribe, provide technical assistance to such Indian Tribe to collect and report data on adverse childhood experiences through the Behavioral Risk Factor Surveillance System, the Youth Risk Behavior Surveillance System, or another relevant public health survey or questionnaire.”); 25 U.S.C. § 1621m(e)(2) (“The Secretary shall grant to each epidemiology center . . . access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.”); 25 C.F.R. § 900.67 (2024) (“IHS will work with Indian [T]ribe or [T]ribal organization representatives to develop a mutually defined uniform subset of data that is consistent with Congressional intent, imposes a minimal reporting burden, and which responds to the needs of the contracting parties.”); *Fast Facts: Preventing Adverse Childhood Experiences*, CDC (Apr. 6, 2022), <https://www.cdc.gov/aces/prevention/index.html> [https://perma.cc/NE3Z-MW9B].

150. 42 U.S.C. § 242k(m)(4)(A).

151. Cynthia Lucero-Obusan, Gina Oda, Anoshiravan Mostaghimi, Patricia Schirmer & Mark Holodniy, *Public Health Surveillance in the U.S. Department of Veterans Affairs: Evaluation of the Praedico Surveillance System*, BMC PUB. HEALTH 2–3 (Feb. 10, 2022), <https://bmcpubhealth.biomedcentral.com/counter/pdf/10.1186/s12889-022-12578-2.pdf> [https://perma.cc/A85A-GCKR]; Alec J. Calac & Aila Hoss, *Vaccine Passports and Indian Country: Nothing Fast About It*, 137 PUB. HEALTH REPS. 637, 638 (2022).

the quality of services they provide.¹⁵² For an agency like IHS, health data is both collected and reported for the purposes of GPRA.¹⁵³ IHS utilizes the Resource and Patient Management System, a decentralized software for the collection of clinical and administrative information.¹⁵⁴ This outdated system cannot easily meet the standards of the Federal Healthcare Interoperability Resources (“FHRI”) for exchange of information between computer systems.¹⁵⁵ Further, Tribal and urban Indian health organizations maintain their own electronic health systems, which also vary in their operability with the FHRI standards.¹⁵⁶ The National Patient Information Reporting System collects financial, environmental, and health care information across all facilities within the federal Indian health system, the Indian Health Service, Tribally-operated facilities funded under the Indian Self-Determination and Education Assistance Act (known as “638 facilities”), and urban Indian health centers (collectively referred to as “I/T/U facilities”).¹⁵⁷ But, not all Tribal facilities use an “electronic health record” system that is compatible with the central IHS system.¹⁵⁸ Thus, in summary, “there is no standardization or central collection of IHS health records.”¹⁵⁹

Some Tribes have codified their own health data reporting requirements.¹⁶⁰ Under the Sac and Fox Tribe of the Mississippi in Iowa’s code, health care

152. Government Performance and Results Act of 1993, Pub. L. No. 103-62, 107 Stat. 285 (codified as amended in scattered sections of titles 5, 31, & 39 U.S.C.).

153. *GPRA and Other National Reporting*, INDIAN HEALTH SERV., <https://www.ihs.gov/crs/gpra-reporting> [<https://perma.cc/ZTX2-5MYE>].

154. *Resource and Patient Management System (RPMS)*, INDIAN HEALTH SERV., <https://www.ihs.gov/rpms> [<https://perma.cc/8MC5-ANBD>].

155. U.S. DEP’T OF HEALTH & HUM. SERVS., STRATEGIC OPTIONS FOR THE MODERNIZATION OF THE INDIAN HEALTH SERVICE HEALTH INFORMATION TECHNOLOGY: FINAL REPORT 14 (2019), <https://www.hhs.gov/sites/default/files/ihs-hit-final-report-C-102019.pdf> [<https://perma.cc/Q7K2-8CXT>]; Ariz. Health Care Cost Containment Sys., PowerPoint Presentation: Tribal 638 Federally Qualified Health Center (FQHC), at slide 4 (May 2021), available at https://azahcccs.gov/Resources/Downloads/DFSMTraining/2021/2021_Tribal_638_FQHC.pdf [<https://perma.cc/99MJ-KXXY>]; Indian Self-Determination and Education Assistance Act, 25 U.S.C. §§ 5301–5423.

156. See U.S. DEP’T OF HEALTH & HUM. SERVS., *supra* note 155, at 12.

157. *National Patient Information Reporting System (NPIRS)*, INDIAN HEALTH SERV., <https://www.ihs.gov/npirs> [<https://perma.cc/SL6S-ZXZK>].

158. Kelly Sarmiento et al., *Traumatic Brain Injury-Related Emergency Department Visits Among American Indian and Alaska Native Persons—National Patient Information Reporting System, 2005-2014*, 35 J. HEAD TRAUMA REHAB. E441, E447 (2020).

159. Calac & Hoss, *supra* note 151, at 639.

160. See generally AILA HOSS, CDC, MENU OF SELECTED TRIBAL LAWS RELATED TO INFECTIOUS DISEASE CONTROL (2014), <https://www.cdc.gov/phlp/docs/triballidlaws-brief.pdf> [<https://perma.cc/5L7T-DJ4R>] (describing such laws); Danielle Hiraldo, Kyra James & Stephanie Russo Carroll, *Case Report: Indigenous Sovereignty in a Pandemic: Tribal Codes in the United States as Preparedness*, FRONTIERS SOCIO. 1, 3 (Mar. 15, 2021), <https://pmc.ncbi.nlm.nih.gov/articles/PMC8022763/pdf/fsoc-06-617995.pdf> [<https://perma.cc/8TUW-X2AM>].

providers¹⁶¹ are required to “provide a written report of each Disease Raising a Potential Health Emergency to the Health Director immediately upon becoming aware of facts indicating the existence of such circumstance.”¹⁶² As another example, the Navajo Nation’s HIV/AIDS Code requires that all providers that offer HIV/AIDS services within the Nation report HIV/AIDS surveillance data “to the Navajo Health Education and HIV Prevention Program.”¹⁶³

Surveillance systems are not perfect. A variety of factors can disrupt the collection of race/ethnicity data in the surveillance system. This can include patient hesitance to provide this information, data reporters failing to submit mandated reports, limitations in data technology systems, insufficient guidance on data collection, and insufficient staffing, among others.¹⁶⁴

Imperfect or not, public health datasets are made available to other governments and even publicly. For the purposes of this Article, data sharing refers to the sharing of public health data across governments and dissemination refers to public accessibility.¹⁶⁵ A patient’s health information is offered some privacy protections under the law. The Health Insurance Portability and Accountability Act (“HIPAA”) became federal law in 1996.¹⁶⁶ It requires the privacy and security of certain health information by covered entities,¹⁶⁷ generally health care providers, health insurers, and their business associates.¹⁶⁸ Under the Privacy Rule, covered entities may provide access to otherwise protected health information to “public health authorit[ies]”¹⁶⁹ for “public health activities.”¹⁷⁰ A public health authority is defined as

161. The code defines health care providers as:

- (1) physicians, dentists, medical residents or interns, hospital personnel and administrators, psychologists, psychiatrists, mental health professionals, nurses, home health aides, health care practitioners, chiropractors, osteopaths, pharmacists, optometrists, podiatrists, emergency medical technicians, ambulance drivers, undertakers, coroners, medical examiners, alcohol or drug treatment personnel, and other persons performing a healing role or practicing the healing arts;
- (2) organizations, institutions, or other entities or individuals, whether public or private (including [T]ribal, federal, state, or local departments, agencies, and instrumentalities) which furnish health-care services or resources; and
- (3) administrative or professional supervisors to any person or entity described in subsections (1) or (2) above.

SAC & FOX TRIBE OF THE MISSISSIPPI IN IOWA CODE § 12-4101 (a) (West 2011).

162. *Id.* § 12-4201. These diseases include cholera, measles, meningococcal disease, smallpox, tuberculosis, and yellow fever, among others. *Id.* § 12-4101 (d).

163. NAVAJO NATION CODE ANN. tit. 13, § 3207 (2010).

164. HOSS ET AL., *supra* note 89, at 31.

165. *Id.* at 48.

166. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 26, 29, & 42 U.S.C.).

167. *See, e.g.*, 42 U.S.C. § 1320d-2.

168. 45 C.F.R. § 160.103 (2024).

169. *Id.* § 164.512 (b) (1) (i).

170. *Id.* § 164.512 (b) (1).

an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian [T]ribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate.¹⁷¹

Public health activities include “preventing or controlling disease, injury, or disability.”¹⁷² These can include but are “not limited to [(1)] the reporting of disease, injury, vital events such as birth or death[; (2)] the conduct of public health surveillance[; (3)] public health investigations[;] and [(4)] public health interventions.”¹⁷³

Under the Privacy Rule, covered entities may only disclose the minimum amount of protected health information (“PHI”) necessary.¹⁷⁴ The rule permits covered entities to rely on the judgment of requesting public health authorities to determine the minimum amount of information needed for its public health activities.¹⁷⁵ “For routine and recurring public health disclosures, covered entities may develop standard protocols, as part of their minimum necessary policies and procedures, that address the types and amount of protected health information that may be disclosed for such purposes.”¹⁷⁶ HIPAA permits but does not require the sharing of data with public health authorities and in practice, jurisdictions are sometimes reluctant to share data.¹⁷⁷

171. *Id.* § 164.501.

172. *Id.* § 164.512(b)(1)(i).

173. *Id.*

174. *Id.* §§ 164.502(b), .514(d).

175. *Id.* § 164.514(d)(3)(iii) (“A covered entity may rely, if such reliance is reasonable under the circumstances, on a requested disclosure as the minimum necessary for the stated purpose when . . . [m]aking disclosures to public officials that are permitted under § 164.512, if the public official represents that the information requested is the minimum necessary for the stated purpose(s)”); U.S. DEP’T OF HEALTH & HUM. SERVS., DISCLOSURES FOR PUBLIC HEALTH ACTIVITIES 2 (2003), <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/publichealth/publichealth.pdf> [<https://perma.cc/LU9T-DDK3>].

176. U.S. DEP’T OF HEALTH & HUM. SERVS., *supra* note 175, at 2; *see also* OFF. FOR C.R., U.S. DEP’T OF HEALTH & HUM. SERVS., BULLETIN: HIPAA PRIVACY AND NOVEL CORONAVIRUS 3–5 (2020), <https://www.hhs.gov/sites/default/files/february-2020-hipaa-and-novel-coronavirus.pdf> [<https://perma.cc/UFL8-K9EY>] (discussing HIPAA in the context of COVID-19); 45 C.F.R. § 164.514(d)(3)(i) (“For any type of disclosure that it makes on a routine and recurring basis, a covered entity must implement policies and procedures (which may be standard protocols) that limit the protected health information disclosed to the amount reasonably necessary to achieve the purpose of the disclosure.”). *See generally* OFF. FOR C.R., U.S. DEP’T OF HEALTH & HUM. SERVS., PERMITTED USES AND DISCLOSURES: EXCHANGE FOR PUBLIC HEALTH ACTIVITIES (2016), https://www.healthit.gov/sites/default/files/12072016_hipaa_and_public_health_fact_sheet.pdf [<https://perma.cc/EgLA-RTYU>] (describing permitted disclosures to public health authorities).

177. For a discussion on facilitating access to data sharing, see JENNIFER BERNSTEIN ET AL., NETWORK FOR PUB. HEALTH L., PATHWAYS TO YES: A LEGAL FRAMEWORK FOR ACHIEVING DATA

Mechanisms for data dissemination include governmental publication of data or governmental release through requests from the public. These datasets contain de-identified data, which does not include individually identifiable information such as name, address, or social security number.¹⁷⁸ Government agencies regularly publish reports of the public health data they have collected.¹⁷⁹ The Freedom of Information Act allows for public access to records held by federal agencies unless exempted.¹⁸⁰ This can include public health data.¹⁸¹ Additionally, every state has its own public access law, although they vary in the type and format of data that can be made accessible.¹⁸²

As outlined, public health surveillance systems are complex. They are even more complicated when considering the idiosyncrasies of Indian health systems, which are described next.

C. INDIAN HEALTH SYSTEMS

American Indians and Alaska Natives people access health care across public and private facilities. These facilities are funded through public and private financing and are located across jurisdictions. This Subsection breaks down how federal, Tribal, and state health systems serve Indigenous people. This context is important because each system will utilize their own unique data systems, further complicating the public health surveillance maze.

1. Federal Indian Health Systems

In exchange for ceded territory, the federal government committed itself to provide health care services to numerous Tribes in treaties. These treaty obligations were eventually coupled with a congressional commitment for the provision of health care first via the Snyder Act in 1921¹⁸³ and subsequently

SHARING FOR HEALTH, WELL-BEING, AND EQUITY 35–36 (2022), https://www.networkforphl.org/wp-content/uploads/2022/10/DASH_NPHL-Pathways_to_Yes-FINAL-PDF.pdf [<https://perma.cc/SWYZ-CUPD>].

178. *Definition of De-Identified Data*, JOHNS HOPKINS MED. (Mar. 2003), https://www.hopkinsmedicine.org/institutional_review_board/hipaa_research/de_identified_data.html [<https://perma.cc/YLC5-LBR8>].

179. See, e.g., *Morbidity and Mortality Weekly Report*, CDC (Sept. 19, 2024), <https://www.cdc.gov/mmwr/index.html> [<https://perma.cc/S4B3-6YWW>]; *Indiana COVID-19 Home Dashboard*, IND. DEP'T HEALTH (Nov. 10, 2022, 10:51 PM), <https://www.coronavirus.in.gov/indiana-covid-19-dashboard-and-map> [<https://web.archive.org/web/20221214064640/https://www.coronavirus.in.gov/indiana-covid-19-dashboard-and-map>]; *CDC Wonder*, CDC (Aug. 21, 2024), <https://wonder.cdc.gov> [<https://perma.cc/3FK4-K3BA>].

180. 5 U.S.C. § 552.

181. Mitchell Berger, *The Freedom of Information Act: Implications for Public Health Policy and Practice*, 126 PUB. HEALTH REPS. 428, 428 (2011).

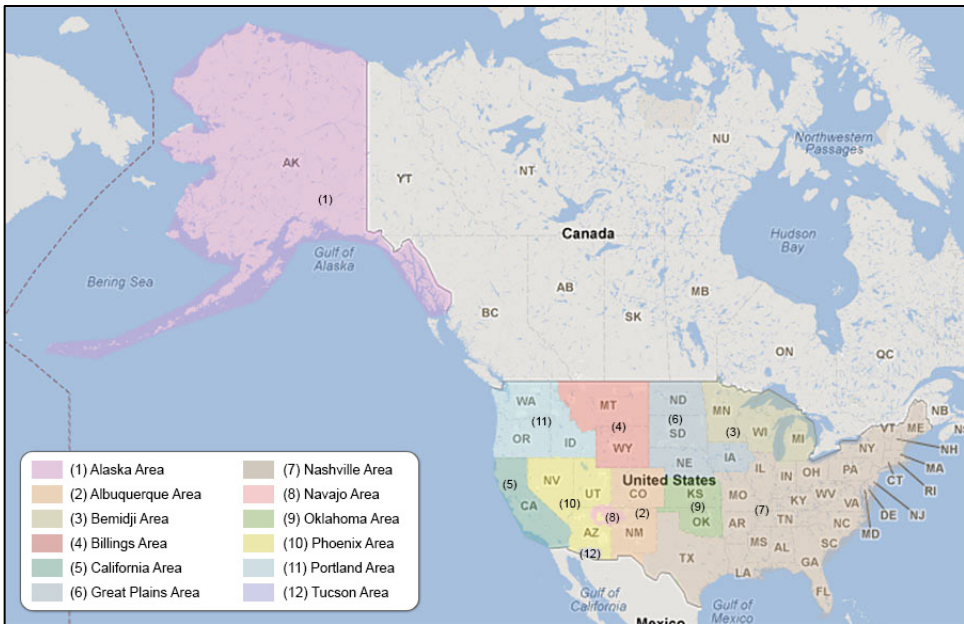
182. *State Freedom of Information Laws*, NAT'L FREEDOM INFO. COAL. (2024), <https://www.nfoic.org/state-freedom-of-information-laws> [<https://perma.cc/Y9AJ-DEPU>]; *State Open Data Laws and Policies*, NAT'L CONF. ST. LEGISLATURES (Jan. 25, 2022), <https://www.ncsl.org/technology-and-communication/state-open-data-laws-and-policies> [<https://perma.cc/M2FA-DFPN>].

183. 25 U.S.C. § 13.

via the Indian Health Care Improvement Act in 1976.¹⁸⁴ Although the legal obligation to provide health care to Indians is broad, the federal government has significant discretion in the scope, mechanisms, financing, and quality of health services it provides.¹⁸⁵ The result is a federal Indian health system that is underfunded and under-resourced, as discussed above.

The modern federal Indian health system is often referred to as the three tier Indian/Tribal/Urban (“I/T/U”) system.¹⁸⁶ This refers to government direct care through IHS, federally funded Tribal “638” health facilities, and federally funded urban Indian health programs.¹⁸⁷ IHS is organized into twelve regional service areas (Figure 2).

Figure 2: Indian Health Service Regions¹⁸⁸



184. Indian Health Care Improvement Act, 25 U.S.C. §§ 1605–1671.

185. See, e.g., *Lincoln v. Vigil*, 508 U.S. 182, 193 (1993) (“[T]o [that] extent,’ the decision to allocate funds ‘is committed to agency discretion by law.’ The Service’s decision to discontinue the Program is accordingly unreviewable . . .” (alterations in original) (citation omitted) (quoting 5 U.S.C. § 701(a)(2))); *Rosebud Sioux Tribe v. United States*, 9 F.4th 1018, 1025–26 (8th Cir. 2021) (finding that the Tribe’s claim against the federal government could proceed given the Tribe was seeking declaratory judgment and there was a fiduciary obligation established by treaty).

186. Aila Hoss & Michelle Castagne, *Public Health Law and American Indians and Alaska Natives*, in *PUBLIC HEALTH LAW: CONCEPTS & CASE STUDIES* 209, 209 (Montrece McNeill Ransom & Laura Magaña Valladares eds., 2022).

187. *Id.*

188. *Organizational Structure*, INDIAN HEALTH SERV., <https://www.ihs.gov/aboutihs/organizationalstructure> [https://perma.cc/85ZZ-BY8K].

The Indian Self-Determination and Education Assistance Act (“ISDEAA”) authorized Title I contracts,¹⁸⁹ allowing Tribes to administer their own health services directly using funds that would have been allocated to IHS direct care facilities.¹⁹⁰ ISDEAA’s 1994 Amendments authorized Title V compacts.¹⁹¹ It has higher eligibility requirements in regard to fiscal stability and advanced planning but allows for less oversight by the federal government.¹⁹² There is no performance monitoring for compacts.¹⁹³

The contracts or compacts identify the programs, services, functions, and activities (“PSFA”) in which the Tribe will administer.¹⁹⁴ Over half of IHS’s budget supports Tribal health facilities under ISDEAA.¹⁹⁵ As part of its 638 funding commitments, IHS provides mechanisms for contracting with third parties to provide services that the 638 is unable to.¹⁹⁶

Eligibility for services at direct care IHS facilities is limited to four categories: (1) Indians belonging to the Tribe that the facility serves; (2) non-Indian persons pregnant with an Indian child during the course of their pregnancy to postpartum; (3) non-Indian individuals that are members of an Indian’s household to control the spread of infectious disease;¹⁹⁷ and (4) individuals that are regarded as Indian by their community.¹⁹⁸ Generally, eligibility for services at 638 facilities are the same as direct care facilities, although 638 facilities can limit eligibility to Tribal members or area residents.¹⁹⁹ However, 638 facilities have the flexibility to serve non-beneficiaries so long as doing so does not compromise the level of care for beneficiaries.²⁰⁰

The federal government also funds Urban Indian Organizations (“UIO”) to provide health services in urban areas.²⁰¹ UIOs are nonprofit corporations

189. Indian Self-Determination and Education Assistance Act, 25 U.S.C. §§ 5301, 5321.

190. *Id.* § 5321(a)(1).

191. Indian Self-Determination Act Amendments of 1994, 25 U.S.C. §§ 5381–5399.

192. N.D. STATE UNIV. & AM. INDIAN PUB. HEALTH RES. CTR., SIX THIRTY EIGHT TOOLKIT 27 (2020), https://www.ndsu.edu/fileadmin/centers/americanindianhealth/files/638_Toolkit_Final.pdf [<https://perma.cc/D6GT-AGX3>].

193. *Id.* at 32.

194. INDIAN HEALTH SERV., PROGRAMS, SERVICES, FUNCTIONS AND ACTIVITIES (PSFA) MANUAL 3 (2002), https://www.ihs.gov/sites/selfgovernance/themes/responsive2017/display_objects/documents/2002-PSFA-Manual.pdf [<https://perma.cc/A7K7-ACSU>].

195. IHS PROFILE, INDIAN HEALTH SERV. 1 (2024), https://www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/factsheets/IHSProfile.pdf [<https://perma.cc/W4VA-TEQ4>].

196. *Contract Support Costs*, INDIAN HEALTH SERV., <https://www.ihs.gov/odsct/contract-support-costs> [<https://perma.cc/6EL6-MVRL>].

197. 42 C.F.R. § 136.12(a) (2024).

198. *Id.* § 136.12(a)(2).

199. *Id.* § 136.23.

200. *Chapter 1 - Eligibility for Services*, INDIAN HEALTH SERV. § 2-1.2(B), <https://www.ihs.gov/ihs/pc/part-2/chapter-1-eligibility-for-services> [<https://perma.cc/828T-6CZL>].

201. *Urban Indian Organizations*, INDIAN HEALTH SERV. (Oct. 2018), <https://www.ihs.gov/urban/urban-indian-organizations> [<https://perma.cc/NQ7Z-BU9K>]; 25 U.S.C. § 1652(a).

with a governing board of urban Indian directors.²⁰² IHS currently funds over forty urban Indian health programs.²⁰³ Any Indian residing in federally-defined urban centers can receive care at a UIO²⁰⁴ so long as they are a Tribal member, a descendant of a Tribal member “in the first or second degree,” or are considered an urban Indian by HHS.²⁰⁵

2. Tribal Health Systems

Exclusive of their 638 contracts, Tribes can and do engage in other health activities. Tribes have the inherent authority, for example, to engage in governmental public health activities.²⁰⁶ Tribal health departments vary in the services they provide.²⁰⁷ The COVID-19 pandemic provides numerous examples of Tribal exercise of their public health authority. Tribes have had highly effective COVID-19 vaccination programs.²⁰⁸ Tribes have used federal Coronavirus Aid, Relief, and Economic Security Act funding to build new

202. 25 U.S.C. § 1603(29).

203. *Urban Indian Health Program*, INDIAN HEALTH SERV., <https://www.ihs.gov/newsroom/factsheets/uihp> [<https://perma.cc/KM4M-8HUU>].

204. 25 U.S.C. § 1603(28).

205. *Id.* § 1603(13)(A), (C), 1603(28).

206. AILA HOSS, TRIBES ARE PUBLIC HEALTH AUTHORITIES: PROTECTING TRIBAL SOVEREIGNTY IN TIMES OF PUBLIC HEALTH CRISIS 3 (2021), <https://static1.squarespace.com/static/5930883f17bffc9debfd8d/t/5ff396bd9d513670e3c76471/1609799358131/Tribes+are+Public+Health+Authorities+FINAL.pdf> [<https://perma.cc/FT2L-B64T>].

207. ALANA KNUDSON ET AL., NORC WALSH CTR. FOR RURAL HEALTH ANALYSIS, A PROFILE OF TRIBAL HEALTH DEPARTMENTS 3-4 (2012), http://www.norc.org/PDFs/Walsh%20Center/Research%20Briefs/Research%20Brief_W18_KnudsonA_Profile_2012.pdf [<https://perma.cc/FQ3B-GTDG>].

208. See, e.g., Sarah Blake Morgan, *Native Americans Embrace Vaccine, Virus Containment Measures*, ASSOCIATED PRESS (Feb. 17, 2021, 12:10 AM), <https://apnews.com/article/native-americans-coronavirus-vaccine-9b3101d306442fbc5198333017b4737d> [<https://perma.cc/C9N5-DVF5>]; Kirk Siegler, *Why Native Americans Are Getting COVID-19 Vaccines Faster*, NPR (Feb. 19, 2021, 5:00 AM), <https://www.npr.org/2021/02/19/969046248/why-native-americans-are-getting-the-covid-19-vaccines-faster> [<https://perma.cc/NBC5-BR4U>]; Alex Brown, *In Hard-Hit Indian Country, Tribes Rapidly Roll Out Vaccines*, STATELINE (Feb. 9, 2021, 12:00 AM), <https://stateline.org/2021/02/09/in-hard-hit-indian-country-tribes-rapidly-roll-out-vaccines> [<https://perma.cc/GHR2-PBD8>]; Rachel Hatzipanagos, *How Native Americans Launched Successful Coronavirus Vaccination Drives: ‘A Story of Resilience’*, WASH. POST (May 26, 2021, 9:53 AM), <https://www.washingtonpost.com/nation/2021/05/26/how-native-americans-launched-successful-coronavirus-vaccination-drives-story-resilience/> (on file with the *Iowa Law Review*); *Alaska Native Vaccine Rollout: Commendation Not Condemnation*, VERA STARBAR (Jan. 30, 2021), <https://verastarbard.com/2021/01/30/alaska-native-vaccine-rollout-commendation-not-condemnation> [<https://perma.cc/HWN4-FT6C>]; Melina Delkic & Madeleine Ngo, *Covid-19: With Big Vaccine Push, Navajo Nation Has Tamed Virus*, N.Y. TIMES (Apr. 18, 2021), <https://www.nytimes.com/live/2021/04/04/world/covid-vaccine-coronavirus-cases/> (on file with the *Iowa Law Review*).

health facilities,²⁰⁹ distribute funds to citizens,²¹⁰ and create community gardens.²¹¹ For example, the Lummi Nation began building a field hospital in early 2020.²¹²

All public health systems coordinate and collaborate with other organizations and governments to promote their public health missions.²¹³ This is often especially true for many Tribal public health systems,²¹⁴ which have historically not received comparable levels of federal investment as other governmental services.²¹⁵ Intergovernmental agreements, like the ones entered into by Tribes and local governments across the Olympic Peninsula, describe mutual commitments between the governments to provide isolation, quarantine, and other forms of support in the event of an emergency.²¹⁶ Inter-Tribal health boards are generally operated as nonprofit organizations serving Tribes in a particular region.²¹⁷ The Southern Plains Tribal Health Board engages in a variety of activities serving forty-three Tribes across Kansas, Texas, and

209. Tyler Thomas, *Tribes' Use of CARES Act Funds Benefitting Citizens Now and Beyond*, CHEROKEE PHX. (Mar. 16, 2021), https://www.cherokeephoenix.org/opinion/tribes-use-of-cares-act-funds-benefitting-citizens-now-and-beyond/article_3df76ca0-8668-11eb-8b39-7bbf63c6724e.html [https://perma.cc/MTU5-F9H8].

210. Greg Kim, *'Are Stimulus Checks Allowed?' How Tribes Are Spending CARES Act Money*, KTOO (Aug. 13, 2020), <https://www.ktoo.org/2020/08/13/are-stimulus-checks-allowed-how-tribes-are-spending-cares-act-money> [https://perma.cc/6MFG-4MDY].

211. *The COVID Solution: How Montana's Indian Country Used CARES Act Relief Funds to Repair Reservations*, MISSOULIAN (June 11, 2021), https://missoulian.com/the-covid-solution-how-montana-s-indian-country-used-cares-act-relief-funds-to-repair/collection_2ff685c6f-2e4c-5025-a297-a653d2e22ce2.html [https://perma.cc/CM3Y-AB8Q].

212. Nina Lakhani, *Native American Tribe Takes Trailblazing Steps to Fight Covid-19 Outbreak*, GUARDIAN (Mar. 18, 2020, 1:25 PM), <https://www.theguardian.com/us-news/2020/mar/18/covid-coronavirus-native-american-lummi-nation-trailblazing-steps> [https://perma.cc/K2FM-Pg2C].

213. See, e.g., Timothy Jones & Craig Hedberg, *Coordination of Multiple States and Federal Agencies*, CDC: EPIDEMIC INTEL. SERV. (Dec. 13, 2018), <https://www.cdc.gov/eis/field-epi-manual/chapters/Coordinating-Agencies.html> [https://perma.cc/D2TA-YXEJ]; Niel E. Hann, *Transforming Public Health Through Community Partnerships*, PREVENTING CHRONIC DISEASE 1 (Nov. 2005), https://www.cdc.gov/pcd/issues/2005/nov/pdf/05_0072.pdf [https://perma.cc/P4R4-VVSA]; NAT'L ACADS. OF SCI., ENG'G & MED., COMMUNITIES IN ACTION: PATHWAYS TO HEALTH EQUITY 2 (James N. Weinstein, Amy Geller, Yamrot Negussie & Alina Baciu eds., 2017).

214. RED STAR INNOVATIONS, TRIBAL PUBLIC HEALTH INSTITUTE FEASIBILITY PROJECT: PROJECT FINDINGS REPORT 5 (2013), https://redstarintl.org/wp-content/uploads/2018/12/tphi_findings_report.pdf [https://perma.cc/H5RV-QQJM].

215. See, e.g., Heather Tanana & Aila Hoss, *Beyond the Pandemic: Historical Infrastructure, Funding, and Data Access Challenges in Indian Country*, in 2 COVID-19 POLICY PLAYBOOK: LEGAL RECOMMENDATIONS FOR A SAFER, MORE EQUITABLE FUTURE 82, 82–83 (2021), https://www.networfphl.org/wp-content/uploads/2021/05/COVIDPolicyPlaybook-v2_May2021.pdf [https://perma.cc/V36H-QUg6].

216. Hoss & Castagne, *supra* note 186, at 219.

217. See, e.g., *About Us*, S. PLAINS TRIBAL HEALTH BD., <https://spthb.org/about-us/who-we-are> [https://perma.cc/RHD5-A88A]; *Tribes Served by GLATHB*, GREAT LAKES AREA TRIBAL HEALTH BD., <https://glathb.org/tribes> [https://perma.cc/4DNY-RCVJ]; *About Great Plains Tribal Leaders' Health Board*, GREAT PLAINS TRIBAL LEADERS' HEALTH BD., <https://www.greatplainstribalhealth.org/about-us.html> [https://perma.cc/W76N-WYP6].

Oklahoma, including research, trainings, and advocacy.²¹⁸ Tribes often work with partners, like Tribal Epidemiology Centers (“TEC”), to conduct public health surveillance efforts.²¹⁹ There is a TEC in each IHS region.²²⁰ Several are housed within inter-Tribal health boards.²²¹

3. State Health Systems

I/T/U beneficiaries also receive care outside of the I/T/U system. Patients receiving care within the I/T/U system can be referred outside the system via contract health providers through the Purchased Referred Care Program (“PRC”).²²² These providers are private, non-I/T/U providers that are contracted to provide services to I/T/U beneficiaries by referral.²²³ The PRC program is essential to meeting the health care needs in Indian country yet accounts for only approximately sixteen percent of IHS’s total budget.²²⁴ There are insufficient resources within the PRC program, and services are regularly denied and deferred.²²⁵

Finally, there are other mechanisms in which Native people receive health care outside of the I/T/U system. For example, they have employer-sponsored health insurance plans, access direct care through the Veterans Health Administration, and access care through public health plans or marketplace plans. Access to these services and plans does not preclude the receipt of care directly from an I/T/U. Rather, it increases the options available for receiving health care. These options may include the receipt of care through facilities that are not part of I/T/U and are governed through a state-federal framework. Health care facilities, providers, and laboratories regularly collect health data from Indigenous patients that get reported exclusively through state health surveillance systems.

To summarize, Indigenous people receive care across many different health care facilities and are supported by many different programs. Each facility or program may be governed by different or multiple surveillance laws and policies. This means that Indigenous public health data is collected, analyzed, and utilized in uniquely fractured systems, if at all. And, it gets even more complicated when you consider how Indigeneity is defined across these systems.

218. S. PLAINS TRIBAL HEALTH BD., *supra* note 217.

219. *See Currently Funded TECs*, INDIAN HEALTH SERV., <https://www.ihs.gov/epi/tecs/currently-funded-tec> [<https://perma.cc/RQ39-GV7N>].

220. *See id.*

221. Hoss & Castagne, *supra* note 186, at 219.

222. *Purchased/Referred Care (PRC): History*, INDIAN HEALTH SERV., <https://www.ihs.gov/prc/history> [<https://perma.cc/J2GZ-S8Q2>].

223. *Id.*

224. ELAYNE J. HEISLER, CONG. RSCH. SERV., R47004, INDIAN HEALTH SERVICE (IHS) FY2022 BUDGET REQUEST AND FUNDING HISTORY: IN BRIEF 4 (2022).

225. U.S. GOV’T ACCOUNTABILITY OFF., *supra* note 52, at 19–20.

III. DEFINING INDIGENEITY

Indigeneity refers to “the state of being Indigenous.”²²⁶ There are differing perspectives on what makes a person Indigenous.²²⁷ This Section attempts to lay out the contexts and complexities in defining Indigeneity to set the foundation for how these complexities present themselves in the context of public health surveillance in Part IV. Modern day Tribal membership criteria can be impacted by the badges of colonization reflected in federal law and policy. Because of this, this Section ends, instead of begins, with a discussion on Tribal citizenship laws. But first, this Section discusses Indigenous self-identification. Next, it discusses federal and state law and policies regarding Indian status. This Part then ends with an overview of Tribal membership criteria.

A. SELF-IDENTIFICATION

In addition to the legal and policy mechanisms for establishing Indian status, self-presenting identification can impact constructions of Indigeneity. As Professor Joyotpaul Chaudhuri said, “[h]istorically, of course, Indians knew they were Indians.”²²⁸ Today, Indian identity can be more complex.²²⁹ Individuals self-identify as Indigenous based on a variety of factors including membership, descent, and connection to a Tribe.²³⁰ As discussed above, the U.S. Census uses self-identification for racial–ethnic identification.²³¹ In the 2020 census, 3.7 million people identified as American Indian and Alaska

226. OFF. OF INDIGENOUS INITIATIVES, *Decolonizing and Indigenizing*, QUEEN'S U. (2024), <https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/defintions> [https://perm.a.cc/F63R-MZ2T]. For a discussion on the history and origins of the term “Indigeneity,” see Tlakatekatl, *The Problem with Indigeneity*, MEXIKA (Dec. 18, 2019), <https://mexika.org/2014/09/17/the-problem-with-indigeneity> [https://perma.cc/DL3J-QZGR].

227. See, e.g., Angelina Newsom, *Opinion: The Real Problem with Jacqueline Keeler's 'Alleged Pretendian' List*, POWWOWS.COM (May 19, 2021), <https://www.powwows.com/the-problem-with-jacqueline-keelers-pretendian-list> [https://web.archive.org/web/20210520004237/https://www.powwows.com/the-problem-with-jacqueline-keelers-pretendian-list]; Jon Levine, *Activist Makes List to Bust Imposters Claiming to Be Native American*, N.Y. POST (Jan. 1, 2022, 12:24 PM), <https://nypost.com/2022/01/01/alleged-pretendians-list-exposes-allegedly-fake-native-americans> [https://perma.cc/TF64-SBS3]; Oyin Adedoyin, *Who Is Native American Enough?*, CHRON. HIGHER EDUC. (Sept. 14, 2022), <https://www.chronicle.com/article/who-is-native-enough> [https://perma.cc/PJR8-UY36]; KIM TALLBEAR, NATIVE AMERICAN DNA: TRIBAL BELONGING AND THE FALSE PROMISE OF GENETIC SCIENCE 31 (2013).

228. Joyotpaul Chaudhuri, *American Indian Policy: An Overview*, in AMERICAN INDIAN POLICY IN THE TWENTIETH CENTURY 15, 20 (Vine Deloria, Jr. ed., 1985).

229. Kyle Powys Whyte, *Indigeneity and US Settler Colonialism*, in THE OXFORD HANDBOOK OF PHILOSOPHY AND RACE 91, 91 (Naomi Zack ed., 2017).

230. Chaudhuri, *supra* note 228, at 21 (“[S]elf-identification is still a matter of great pride as identity is traced through descent, lineage, clan, and acceptance in specific [T]ribes.”).

231. *About the Topic of Race*, U.S. CENSUS BUREAU (Mar. 1, 2022), <https://www.census.gov/topics/population/race/about.html> [https://perma.cc/7ULV-F88K].

Native alone, and 5.9 million identified in combination with another race.²³² This totals 9.7 million people.²³³ This is a significant increase from the previous census.²³⁴ Self-identification is also used in a majority of federal, state, and institutional forms.

Self-identification is not the same as perceived or presenting identification, which refers to how others view an individual's race independent of their self-identification or other factors. Presenting identification can also be relative. In his 1964 essay, James Baldwin chronicles his experience being arrested, alongside a white friend, by police in New York City.²³⁵ The police officer was not aware that Baldwin's friend was white, thinking him Puerto Rican. This, Baldwin tells us, "says something very interesting . . . about the eye of the beholder—like, as it were, to like."²³⁶ Given that individuals may utilize differing criteria for self-identification, there can be tensions regarding who claims Indigenous identity and on what basis. This issue is discussed further in Part IV below.

B. FEDERAL LAW AND POLICY

Federal Indian law sets up the system in which the federal government has established definitions for Indigeneity. Federal Indian law refers to the body of law that governs the rights, relationships, and responsibilities between Tribes, states, and the federal government.²³⁷ Tribes exercise sovereignty, which is "the right . . . to make their own laws and be ruled by them."²³⁸ It is an inherent authority that predates the United States.²³⁹ The federal government recognizes the sovereignty of 574 Tribes.²⁴⁰ Federally recognized Tribes have a nation-to-nation relationship with the United States and other Tribes, and a

232. Nicholas Jones, Rachel Marks, Roberto Ramirez & Merarys Ríos-Vargas, 2020 *Census Illuminates Racial and Ethnic Composition of the Country*, U.S. CENSUS BUREAU (Aug. 12, 2021), <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html> [<https://perma.cc/WH93-T744>].

233. *Id.*

234. 2020 *Census: Native Population Increased by 86.5 Percent*, INDIAN COUNTRY TODAY (Aug. 13, 2021), <https://ictnews.org/news/2020-census-native-population-increased-by-86-5-percent> [<https://perma.cc/FG8C-DZXC>].

235. JAMES BALDWIN, NOTHING PERSONAL 17–20 (Beacon Books 2021) (1964).

236. *Id.* at 20–21.

237. MATTHEW L.M. FLETCHER, FEDERAL INDIAN LAW § 1.2 (2016).

238. *Williams v. Lee*, 358 U.S. 217, 220 (1959).

239. FELIX S. COHEN, FELIX S. COHEN'S HANDBOOK OF FEDERAL INDIAN LAW § 7.1, at 122 (1942) [hereinafter COHEN'S HANDBOOK] ("[T]hose powers which are lawfully vested in an Indian [T]ribe are not, in general, delegated powers granted by express acts of Congress, but rather inherent powers of a limited sovereignty which has never been extinguished." (emphasis omitted)); *Talton v. Mayes*, 163 U.S. 376, 384–85 (1896); *United States v. Wheeler*, 435 U.S. 313, 323–24, 332 (1978).

240. Indian Entities Recognized by and Eligible to Receive Services from the United States Bureau of Indian Affairs, 85 Fed. Reg. 5462, 5462 (Jan. 30, 2020).

government-to-government relationship with state and local governments.²⁴¹ However, the federal recognition process has not acknowledged the sovereignty of all Tribes. Historically, Tribes were recognized primarily by treaty and to a lesser extent executive order and acts of Congress. Today, the government has a rigorous administrative process for Tribal recognition.²⁴² It has used recognition, and its termination, as a political tool.²⁴³ Some Tribes have recognition via state processes, although it is not mutually exclusive with federal recognition.²⁴⁴ Some Tribes do not have any recognition.²⁴⁵

As an extension of colonization, the federal government both recognizes Tribal authority while limiting through the exercise of plenary power. Plenary power refers to the authority of Congress to legislate on all matters related to Tribes or American Indians and Alaska Natives.²⁴⁶ Congress has a history of exercising its plenary power to diminish Tribal jurisdiction,²⁴⁷ impede on Indigenous practices,²⁴⁸ and abrogate Tribal treaty rights.²⁴⁹ But, Tribes retain all aspects of sovereignty unless Congress has exercised its plenary power²⁵⁰ or an incident of sovereignty has been implicitly divested by courts.²⁵¹ More recent federal policy purports to exercise plenary power to advance Tribal sovereignty and self-governance.²⁵² The plenary power doctrine is the underlying authority

241. PEVAR, *supra* note 31, at 2–3; *Frequently Asked Questions*, BUREAU INDIAN AFFS., <https://www.bia.gov/frequently-asked-questions> [<https://perma.cc/6HRE-FTQ3>].

242. *Office of Federal Acknowledgment*, BUREAU INDIAN AFFS. (Oct. 4, 2024), <https://www.bia.gov/as-ia/ofa> [<https://perma.cc/ZGZ2-4PZJ>].

243. PEVAR, *supra* note 31, at 67–68, 273–74.

244. See Martha Saenz, *Federal and State Recognized Tribes*, NAT'L CONF. ST. LEGISLATURES (Mar. 2020), <http://www.ncsl.org/research/state-tribal-institute/list-of-federal-and-state-recognized-tribes.aspx> [<https://web.archive.org/web/20200324053337/http://www.ncsl.org/research/stat-e-tribal-institute/list-of-federal-and-state-recognized-tribes.aspx>].

245. U.S. GOV'T ACCOUNTABILITY OFF., GAO-12-348, FEDERAL FUNDING FOR NON-FEDERALLY RECOGNIZED TRIBES 7 (2012).

246. See, e.g., *Ex parte Crow Dog*, 109 U.S. 556, 561–62 (1883); *United States v. Kagama*, 118 U.S. 375, 383–85 (1886).

247. See, e.g., *Curtis Act*, Pub. L. No. 55-517, 30 Stat. 495 (1898); *Oliphant v. Suquamish Indian Tribe*, 435 U.S. 191, 212 (1978); *Montana v. United States*, 450 U.S. 544, 557, 565–67 (1981).

248. See, e.g., *Emp. Div. v. Smith*, 494 U.S. 872, 890 (1990); *Lyng v. Nw. Indian Cemetery Protective Ass'n*, 485 U.S. 439, 441–42 (1988); *Navajo Nation v. U.S. Forest Serv.*, 535 F.3d 1058, 1062–63 (9th Cir. 2008).

249. See generally *United States v. Sioux Nation of Indians*, 448 U.S. 371 (1980) (holding that Congress had effected a taking by abrogating a treaty and the Sioux Nation was entitled to compensation); *United States v. Dion*, 476 U.S. 734 (1986) (holding that Congress had abrogated the treaty rights via statute); *Hagen v. Utah*, 510 U.S. 399 (1994) (holding Congress had decreased the size of a reservation by allowing non-Native Americans to live in a particular part); *South Dakota v. Yankton Sioux Tribe*, 522 U.S. 329 (1998) (holding that the treaty had been abrogated by a statute that allowed non-Native American citizens to use the land).

250. *Santa Clara Pueblo v. Martinez*, 436 U.S. 49, 56 (1978); COHEN'S HANDBOOK, *supra* note 239, § 5.1, at 91.

251. COHEN'S HANDBOOK, *supra* note 239, § 3.1, at 35.

252. *Id.* § 4.16, at 85.

which allows the federal government to define Indigeneity. This reality is controversial. According to Professor Smith,

legislated identities which regulated who was an Indian and who was not . . . who had lost all status as an Indigenous person, who had the correct fraction of blood quantum, who lived in the regulated spaces of reserves and communities, were all worked out arbitrarily (but systematically), to serve the interests of the colonizing society.²⁵³

The federal government has relied on a variety of mechanisms in which to determine “Indian,” the primary legal term under federal law with respect to Indigenous peoples, status. In the infamous case of *United States v. Sandoval*, the Supreme Court considered whether Pueblos were Tribes under federal law.²⁵⁴ In arriving at its conclusions that Pueblos were Tribes, the Court compared, in its estimation, whether Pueblo members were like Indians.²⁵⁵ Essentially, were Pueblo members savage and uncivilized in the same way as other Indians? The language, although deeply offensive, is provided here:

The people of the pueblos, although sedentary rather than nomadic in their inclinations, and disposed to peace and industry, are nevertheless Indians in race, customs, and domestic government. Always living in separate and isolated communities, adhering to primitive modes of life, largely influenced by superstition and fetichism, and chiefly governed according to the crude customs inherited from their ancestors, they are essentially a simple, uninformed, and inferior people.²⁵⁶

253. LINDA TUHIWAI SMITH, *DECOLONIZING METHODOLOGIES: RESEARCH AND INDIGENOUS PEOPLES* 24–25 (3d ed. 2021). Smith continues:

Questions of who is a ‘real Indigenous’ person, what counts as a ‘real Indigenous leader’, which person displays ‘real cultural values’ and the criteria used to assess the characteristics of authenticity are frequently the topic of conversation and political debate. These debates are designed to fragment and marginalize those who speak for, or in support of, Indigenous issues. They frequently have the effect also of silencing and making invisible the presence of other groups within the Indigenous society like women, the urban non-status [T]ribal person and those whose ancestry or ‘blood quantam’ is ‘too white.’

Id. at 82. Professor McMillan Cottom also speaks to this issue in the context of Black identity: “[W]ho can speak legitimately about and for black people in the United States? For the record, there is no answer. At least there is no good answer. Because the truth is, black people can rarely gatekeep the boundaries of blackness.” TRESSIE MCMILLAN COTTOM, *THICK: AND OTHER ESSAYS* 148 (2019). Professor McMillan Cottom goes on to discuss how non-Black people “only had to convince white people” of their blackness. *Id.* at 148–49.

254. *United States v. Sandoval*, 231 U.S. 28, 45–48 (1913).

255. *Id.* at 39.

256. *Id.*

This analysis clearly demonstrates one mechanism which the federal government has relied on in determining Indian status. Namely, racism.²⁵⁷ The federal government has relied on various policy mechanisms, like Tribal rolls, blood quantum, statutes, regulations, and judicial definitions to define Indian status. The foundational underpinning of all these mechanisms, of course, is racism. This Subsection describes each of these mechanisms in turn highlighting some, but not all, of the commentary regarding the deeply problematic federal practices.

Native people are the most heavily regulated racial–ethnic group under federal law.²⁵⁸ This is largely due to the central role that law, and in particular Congress, has always played in furthering colonization policies. If differing rules apply regarding Indians for issues of jurisdiction, then there needs to be a definition of Indian. In the same vein, if certain services or benefits are only available to Indians, then there needs to be a corresponding definition.

The earliest colonial records regarding Tribal membership begin in the 1790s.²⁵⁹ The Spanish and Mexican governments took roll of Pueblo citizens.²⁶⁰ The federal government, in comparison, opted not to include Indians in the first census in 1790 based on the “Indians not taxed” provision of the Constitution.²⁶¹

References to Indians in the context of their blood status was frequent when referring to Indians of “mixed” status in treaties.²⁶² Blood status implicated both the rights of Indians as well as federal government policy. Were individuals of mixed status Tribal members entitled to full rights from the Tribe? And what responsibilities did the federal government have to individuals that were mixed? Were they United States citizens or noncitizen Indians? The federal government, when considering these issues, eventually adopted the practice of measuring blood quantum, which refers to the amount of Indian blood a

257. Racism played a role in the federal definition of “Native Hawaiians” in the Hawaii Homes Commission Act, as chronicled in Troy J.H. Andrade, *Belated Justice: The Failures and Promise of the Hawaiian Homes Commission Act*, 46 AM. INDIAN L. REV. 1, 18–19 (2022). The business interest of Hawaii’s white business elite also drove the crafting of this definition. *Id.*

258. See DAVID H. GETCHES, CHARLES F. WILKINSON, ROBERT A. WILLIAMS, JR. & MATTHEW L.M. FLETCHER, *CASES AND MATERIALS ON FEDERAL INDIAN LAW* 1 (6th ed. 2011).

259. See Paul Spruhan, *A Legal History of Blood Quantum in Federal Indian Law to 1935*, 51 S.D. L. REV. 1, 8 n.56 (2006).

260. *Census Enumeration of Pueblo Indians, 1790–1939*, NAT’L ARCHIVES, <https://www.archives.gov/research/census/native-americans/pueblo-enumeration.html> [<https://perma.cc/6LRS-FX25>].

261. See, e.g., BUREAU OF THE CENSUS, DEP’T OF COM. & LAB., *HEADS OF FAMILIES AT THE FIRST CENSUS OF THE UNITED STATES TAKEN IN THE YEAR 1790: RHODE ISLAND* 4 (1908), <https://www2.census.gov/library/publications/decennial/1790/heads-of-families-rhode-island.pdf> [<https://perma.cc/WHR8-4JLG>] (“Under [the First Census Act of 1790, the President directed] the marshals of the several judicial districts . . . to ascertain the number of inhabitants within their respective districts, omitting Indians not taxed . . .”).

262. Spruhan, *supra* note 259, at 9–12.

person has.²⁶³ This practice was originally established by the federal government as a mechanism to reduce Tribal populations, limiting exposure for federal funding.²⁶⁴ Blood quantum eventually became the primary identifying metric, over self-identification, in the federal context.²⁶⁵

Not until the passage of the Indian Citizenship Act of 1924 were all Native people born in the United States considered citizens.²⁶⁶ Until then, the federal government would allow for the renunciation of Tribal membership and Indian status to become a U.S. citizen, although the federal government still had to accept the individual through naturalization, treaty, or other act.²⁶⁷ Courts would also take into account whether an Indian was assimilated or unassimilated in adjudicating conflicts that depended on Indian status.²⁶⁸ In this way, Indian status was not static under the law.

The federal government also relied on Indian population counts, called rolls, to establish a list of members of individual Tribes. The General Allotment Act of 1887 authorized the checkerboarding of certain reservations.²⁶⁹ As part of the process of allocating allotted land, a comprehensive list of Tribal members was necessary.²⁷⁰ The federal government utilized blood quantum in making determinations for the Five Tribes: Cherokee Nation, Muscogee Creek Nation, Choctaw Nation, Chickasaw Nation, and Seminole Nation.²⁷¹ The Dawes rolls consisted of the list of individuals eligible for membership of the Five Tribes as determined by the Dawes Commission.²⁷² Inclusion in Tribal rolls varied significantly.²⁷³ Additionally, the required blood quantum for eligibility in roll inclusion and the process creating the rolls varied.²⁷⁴

263. Kat Chow, *So What Exactly Is 'Blood Quantum'?*, NPR (Feb. 9, 2018, 6:00 AM), <https://www.npr.org/sections/codeswitch/2018/02/09/583987261/so-what-exactly-is-blood-quantum> [<https://perma.cc/F2SP-5YJG>].

264. Spruhan, *supra* note 259, at 1–2; M. Annette Jaimes, *Federal Indian Identification Policy: A Usurpation of Indigenous Sovereignty in North America*, in *THE STATE OF NATIVE AMERICA: GENOCIDE, COLONIZATION, AND RESISTANCE* 123, 125–26 (M. Annette Jaimes ed., 1992); Ryan W. Schmidt, *American Indian Identity and Blood Quantum in the 21st Century: A Critical Review*, *J. ANTHROPOLOGY* 4 (Jan. 15, 2012), <https://onlinelibrary.wiley.com/doi/epdf/10.1155/2011/549521> [<https://perma.cc/EF7R-KZ2N>].

265. DUNBAR-ORTIZ, *supra* note 29, at 170.

266. Indian Citizenship Act of 1924, Pub. L. No. 68-175, 43 Stat. 25.

267. *Elk v. Wilkins*, 112 U.S. 94, 100–01, 116 (1884).

268. *See, e.g., Morton v. Ruiz*, 415 U.S. 199, 211, 238 (1974) (finding that unassimilated Tribal members living off reservation were still entitled to federal general assistance programs).

269. Indian General Allotment Act of 1887, Pub. L. 49-105, 24 Stat. 388.

270. *Dawes Rolls*, NAT'L ARCHIVES (Oct. 4, 2016), <https://www.archives.gov/research/native-americans/dawes/tutorial/intro.html> [<https://perma.cc/62AF-BWLN>].

271. Spruhan, *supra* note 259, at 10 n.66, 40. These Tribes were historically called the “Five Civilized Tribes.” *Id.*

272. *Dawes Rolls*, *supra* note 270; Spruhan, *supra* note 259, at 40–41.

273. Chaudhuri, *supra* note 228, at 21.

274. *See, e.g., Procedures Approved for Preparation of Roll of Delaware Indians*, BUREAU INDIAN AFFS. (Dec. 11, 1968), <https://www.bia.gov/as-ia/opa/online-press-release/procedures-approved-preparation-roll-delaware-indians> [<https://perma.cc/FR4G-DJ5P>].

In a 1919 Appropriations Bill, Congress provided the Secretary of the Interior with the authority to establish membership rolls for Tribes that included ages and blood quantum:

That the Secretary of the Interior is hereby authorized, wherever in his discretion such action would be for the best interest of the Indians, to cause a final roll to be made of the membership of any Indian [T]ribe; such rolls shall contain the ages and quantum of Indian blood, when approved by the said Secretary are hereby declared to constitute the legal membership of the respective [T]ribes for the purpose of segregating the [T]ribal funds . . . and shall be conclusive both as to ages and quantum of Indian blood²⁷⁵

The federal government continues to apply blood quantum in determining Indian status today. Blood quantum is a fraction calculated based on the amount of blood originating from designated enrollees.²⁷⁶ These designated enrollees are determined by designated Tribal census rolls.²⁷⁷ Blood quantum is reflected on Certificate of Degree of Indian Blood (“CDIB”) cards.²⁷⁸ The CDIB²⁷⁹ card has been issued by the federal government since approximately the 1970s.²⁸⁰ It is not mandated by Congress nor referenced in the federal code.²⁸¹ Instead it was established through Bureau of Indian Affairs (“BIA”) policy.²⁸² Bizarrely, the BIA maintains no information on its website on the CDIB card besides its application.²⁸³ In addition to blood quantum, the CDIB card includes the individual’s name, date of birth, the last four digits of the individual’s Social Security number, their Tribal ancestry, and a signature from a BIA official.²⁸⁴ The BIA has an application for individuals seeking a CDIB card.²⁸⁵ Blood quantum also serves as the basis for in federal laws related

275. Act of June 30, 1919, Pub. L. No. 66-3, 41 Stat. 9, 9. The Act did “not apply to the Five Civilized Tribes or to the Osage Tribe of Indians, or to the Chippewa Indians of Minnesota, or the Menominee Indians of Wisconsin.” *Id.*

276. Chow, *supra* note 263.

277. BUREAU OF INDIAN AFFS., CERTIFICATE OF DEGREE OF INDIAN OR ALASKA NATIVE BLOOD INSTRUCTIONS (2021) [hereinafter CDIB INSTRUCTIONS], https://www.bia.gov/sites/default/files/dup/assets/public/raca/online_forms/pdf/Certificate_of_Degree_of_Indian_Blood_1076-0153_Exp3-31-21_508.pdf [<https://perma.cc/UBX3-928R>].

278. *Id.*; BUREAU OF INDIAN AFFS. IN ANADARKO, OKLA., CDIB VS. TRIBAL MEMBERSHIP 1 (2010), https://www.hud.gov/sites/documents/DOC_8780.PDF [<https://perma.cc/3VNJ-B3K3>].

279. CDIB INSTRUCTIONS, *supra* note 277. The federal government also issues a Certificate of Degree of Alaska Native Blood. *Id.* For the purposes of this Article, CDIB will refer to both.

280. Paul Spruhan, *CDIB: The Role of the Certificate of Degree of Indian Blood in Defining Native American Legal Identity*, 6 AM. INDIAN L.J. 169, 177 (2018).

281. *Id.*

282. *Id.*

283. *Id.* at 178.

284. BUREAU OF INDIAN AFFS. IN ANADARKO, OKLA., *supra* note 278.

285. CDIB INSTRUCTIONS, *supra* note 277.

to land privileges.²⁸⁶ The continued prevalence of blood quantum as a measure for Indian status has been criticized as disrupting traditional mechanisms for cultural and community connections.

Largely following the passage of the Indian Reorganization Act and the Johnson O'Malley Act in the 1930s, federal programming in Indian country increased rapidly²⁸⁷ with a corresponding increase in definitions of Indian.²⁸⁸ Given the overwhelming complexity of federal Indian law and programing, it should be no surprise that there are numerous statutory and regulatory definitions of Indian under federal law. Congress has sometimes been inconsistent in these definitions.²⁸⁹

Under the federal statutory code, there are over eighty definitions of Indian.²⁹⁰ For the purposes of federal law, membership in a federally recognized Tribe²⁹¹ is the leading definition.²⁹² However, there are many provisions with more specific definitions.²⁹³ One provision defines Indian to include a "person recognized as being Indian or Alaska Native by an Indian [T]ribe, the Federal Government, or any State."²⁹⁴ In this provision, the definition includes members of state recognized Tribes.²⁹⁵ Another provision defines Indian more broadly than Tribal membership to include "a member of an Indian [T]ribe, and

286. Rose Cuison Villazor, *Blood Quantum Land Laws and the Race Versus Political Identity Dilemma*, 96 CALIF. L. REV. 801, 818–24 (2008).

287. COHEN'S HANDBOOK, *supra* note 239, § 4.16, at 83, 87.

288. For a robust historical discussion on definitions of Indian under the Indian Reorganization Act and the Johnson O'Malley Act, see Karl A. Funke, *Educational Assistance and Employment Preference: Who Is an Indian?*, 4 AM. INDIAN L. REV. 1, 3–4 (1976).

289. *Oversight Hearing on Federal Acknowledgment Process: Hearing Before the Select S. Comm. on Indian Affs.*, 100th Cong. 74 (1988) (supplemental report to statement of Hazel Elbert, Deputy to the Assistant Sec'y of Indian Affs., Dep't of the Interior). "Congress, also is inconsistent in defining Indians and Indian [T]ribes when enacting Indian legislation." *Id.*

290. Aila Hoss, *Federal Statutory and Regulatory Definitions of "Indian,"* 110 IOWA L. REV. ONLINE 117 app. 1 (2025).

291. The definition of "Indian Tribe" under federal law offers another area that has received significant attention from the courts. *See, e.g.*, *United States v. Sandoval*, 231 U.S. 28, 46–47 (1913); *Joint Tribal Council of the Passamaquoddy Tribe v. Morton*, 528 F.2d 370, 375 (1st Cir. 1975); *Yellen v. Confederated Tribes of the Chehalis Rsrv.*, 594 U.S. 338, 343–47 (2021); COHEN'S HANDBOOK, *supra* note 239, § 1.2, at 5. Generally, federal law considers membership in a Tribe to mean membership in a federally recognized Tribe. *See, e.g.*, 25 U.S.C. §§ 3703(8), 3703(10), 4103(10), 4103(13), 5304(d)–(e). However, this is not always the case and can, in turn, impact the definition of "Indian."

292. Hoss, *supra* note 290, at app. 1. *See also* the newly published RESTATEMENT OF THE LAW—THE LAW OF AMERICAN INDIANS, offering the following commentary on the definition of Indian: "For purposes of federal law, an 'Indian' is a member or citizen of a federally recognized [T]ribe . . . unless that term is defined differently in accordance with a specific federal statute for the purpose of applying that statute." RESTATEMENT OF THE L.: THE L. OF AM. INDIANS § 1 (AM. L. INST. 2024) (citation omitted).

293. *See* Hoss, *supra* note 290, at app. 1 (providing a list of the many definitions used to define "Indian" in statutes).

294. 12 U.S.C. § 1715z-13a(l)(3).

295. *Id.*

includes individuals who are eligible for membership in a [T]ribe, and the child or grandchild of such an individual.”²⁹⁶

Federal statutes and regulations also define terms like Alaska Native, Urban Indian, and Native American.²⁹⁷ There are over 220 Alaska Native Villages,²⁹⁸ each a federally recognized Tribe.²⁹⁹ Their members, Alaska Natives, are considered Indian under federal law.³⁰⁰ Urban Indians are defined under federal law as individuals living in an urban center who meet at least one of the following criteria³⁰¹:

(A) [] irrespective of whether he or she lives on or near a reservation, is a member of a [T]ribe, band, or other organized group of Indians, including those [T]ribes, bands, or groups terminated since 1940 and those recognized now or in the future by the State in which they reside, or who is a descendant, in the first or second degree, of any such member, or

(B) is an Eskimo or Aleut or other Alaska Native, or

(C) is considered by the Secretary of the Interior to be an Indian for any purpose, or

(D) is determined to be an Indian under regulations promulgated by the Secretary [of Health and Human Services].³⁰²

Under federal law, the term “Native American” is generally broader than the definition of “Indian.”³⁰³ It often expressly recognizes the Indigenous people of Hawaii,³⁰⁴ often includes Pacific Islanders,³⁰⁵ and does not limit Native American status to members of a federally recognized Tribe.³⁰⁶ Finally, some federal laws provide specific definitions for certain Indians like “California Indians,” Navajo Indians, and Indian of the Five Tribes.³⁰⁷ As another example

296. 25 U.S.C. § 2511(3).

297. Hoss, *supra* note 290, at apps. 2–4.

298. *Tribes Served by the Alaska Region*, BUREAU INDIAN AFFS., <https://www.bia.gov/regional-offices/alaska/tribes-served> [<https://perma.cc/S6NE-YD2G>].

299. Indian Entities Recognized by and Eligible to Receive Services from the United States Bureau of Indian Affairs, 85 Fed. Reg. 5462, 5462–67 (Jan. 30, 2020).

300. *See, e.g.*, 20 U.S.C. § 7491(3); 25 U.S.C. §§ 1603(13)(b), 1934, 2902(2).

301. 25 U.S.C. § 1603(28).

302. *Id.* § 1603(13).

303. Hoss, *supra* note 290, at app. 4.

304. *See, e.g.*, 25 U.S.C. § 2902(1); 20 U.S.C. §§ 7011(8), 7801(34); 38 U.S.C. § 3765(3); 42 U.S.C. § 9832(15)(A)(ii).

305. 20 U.S.C. §§ 7011(8), 7801(34); 25 U.S.C. § 2902(1); 38 U.S.C. § 3765(3); 42 U.S.C. § 9832(15)(A)(ii).

306. Hoss, *supra* note 290, at app. 4.

307. *See, e.g.*, 25 U.S.C. § 1603(3) (“The term ‘California Indian’ means any Indian who is eligible for health services provided by the Service pursuant to section 1679 of this title.”); 25 C.F.R. § 16.1(d) (2024) (“The term *Indian of the Five Civilized Tribes* means an individual who is

of certain Indigenous people being singled out in congressional action is the Ute Partition Act. It established a final termination roll of the Ute Indian Tribe,³⁰⁸ which subsequently resulted in lack of Indian status for descendants of those listed on the termination roll.³⁰⁹

When not statutorily prescribed, agencies often have significant discretion in determining Indian status. A Solicitor's opinion found that the Department of Labor could consider individuals without any Tribal affiliation Indians for the purposes of workforce reports.³¹⁰

Judicially prescribed definitions of Indian preceded statutory definitions in the context of criminal law. A Tribe, the federal government, or a state can all assert criminal jurisdiction depending on the identity of the accused, the identity of the victim, and federal statutes.³¹¹ In general, Tribes maintain concurrent jurisdiction alongside the federal government for crimes in Indian country³¹² unless federal law prescribes state authority or the defendant is a non-Indian.³¹³ Congress passed the Indian Country Crimes Act ("ICCA") in 1817 to authorize federal jurisdiction for crimes occurring in Indian country that involved a victim and defendant that were of differing Indian status.³¹⁴ The law, also referred to as the Interracial Crime Provision,³¹⁵ did not define

either an enrolled member of the Cherokee, Chickasaw, Choctaw, Creek, or Seminole Tribes of Oklahoma, or a descendant of an enrolled member thereof."); *see also* 42 U.S.C. § 280k(b)(1) (defining Indian under a health services related act); 25 U.S.C. § 415(d)(2) ("[T]he term 'Navajo Indians' means members of the Navajo Tribe."); 16 C.F.R. § 303.45(b)(8) (2025) ("The term Navajo Indian means any Indian who is listed on the register of the Navajo Indian Tribe or is eligible for listing thereon."); 25 C.F.R. § 91.2(d) (2025) ("*Tribal Member* means any person of Osage Indian blood of whatever degree, allotted or unallotted."). Federal law often includes Indians within the definitions of other statutory terms for the purposes of federal programming. 29 U.S.C. § 3102(24) ("The term 'individual with a barrier to employment' means . . . Indians, Alaska Natives, and Native Hawaiians . . ."); 26 U.S.C. § 7526A(e)(4) ("The term 'underserved population' includes populations of persons with disabilities, persons with limited English proficiency, Native Americans, individuals living in rural areas, members of the Armed Forces and their spouses, and the elderly."); 15 U.S.C. § 637(d)(3)(C)(ii) ("The contractor shall presume that socially and economically disadvantaged individuals include Black Americans, Hispanic Americans, Native Americans, Asian Pacific Americans, and other minorities . . ."); *id.* § 9501(15)(B) ("In carrying out this chapter, the Under Secretary shall presume that the term 'socially or economically disadvantaged individual' includes any individual who is . . . American Indian or Alaska Native . . .").

308. Act of Aug. 27, 1954, Pub. L. No. 671, ch. 1009, 68 Stat. 868.

309. *State v. Reber*, 171 P.3d 406, 409–10 (Utah 2007).

310. Chaudhuri, *supra* note 228, at 21.

311. COHEN'S HANDBOOK OF FEDERAL INDIAN LAW §§ 9.02–.04 (Nell Jessup Newton & Kevin K. Washburn eds., 2024) [hereinafter COHEN'S HANDBOOK (2024)].

312. 18 U.S.C. § 1152. Generally, Indian country is defined broadly to include the outer boundaries of the reservation. *Id.* § 1151.

313. Arvo Q. Mikkanen, *Indian Country Criminal Jurisdictional Chart*, U.S. DEP'T JUST. (Aug. 2020), <https://www.justice.gov/usao-wdok/page/file/1300046/download> [<https://perma.cc/DL75-R9AS>]; *Oklahoma v. Castro-Huerta*, 597 U.S. 629, 656 (2022).

314. 18 U.S.C. § 1152; Mikkanen, *supra* note 313.

315. GETCHES ET AL., *supra* note 258, at 472.

“Indian.” The Indian Major Crimes Act (“MCA”), passed in 1885,³¹⁶ was similar to the ICCA in that it also failed to define “Indian.” It provides for federal jurisdiction against Indian defendants for certain enumerated crimes, including murder, manslaughter, and arson.³¹⁷ The ICCA and the MCA set the stage for the confusion regarding the definition of Indian under federal law.³¹⁸ These laws have left a trail of judicial opinions that attempt to cobble together a framework.³¹⁹ The definition of Indian for purposes of criminal jurisdiction in Indian country continues to be a source of litigation³²⁰ as Congress has opted not to prescribe a statutory definition for these criminal laws, although it has for many other statutory schemes.

For the purposes of determining Indian status for criminal jurisdiction, Tribal membership alone is not sufficient. Early in its criminal jurisdiction in Indian country jurisprudence, the Supreme Court held that a white, adopted member of a Tribe could not be considered Indian.³²¹ A 2005 decision out of the Ninth Circuit, *United States v. Bruce*, established two prongs for determining Indian status.³²² The first, Indian blood “quantum.”³²³ The second, Tribal membership or affiliation.³²⁴ Both prongs must be met.³²⁵ Other factors that can be relevant, in declining order, are receipt of benefits of Tribal affiliation; enjoyment of benefits of Tribal affiliation; eligibility for membership; and ties to the Tribe.³²⁶ The Ninth Circuit applied this test in 2009, when assessing if a defendant meets the Tribal affiliation prong if the defendant had ties to a Tribe but otherwise did not receive benefits from the Tribe and was not eligible for employment.³²⁷ Here the court found that the defendant was not Indian³²⁸ and found that meeting the least important of the four factors was insufficient for meeting the *Bruce* test.³²⁹ More recently, in *United States v. Zepeda*, the Ninth

316. Act of 1885, ch. 341, 23 Stat. 3835 (codified as amended at 18 U.S.C. § 1153); *Duro v. Reina*, 495 U.S. 676, 680 n.1 (1990).

317. Act of 1885, ch. 341, 23 Stat. 3835 (codified as amended at 18 U.S.C. § 1153).

318. 18 U.S.C. § 1153.

319. *United States v. Bruce*, 394 F.3d 1215, 1223 (9th Cir. 2005) (“The term ‘Indian’ is not statutorily defined, but courts have ‘judicially explicated’ its meaning.” (citation omitted)).

320. FLETCHER, *supra* note 237, § 7.4, at 323–26.

321. *United States v. Rogers*, 45 U.S. (4 How.) 567, 571–73 (1846).

322. *Bruce*, 394 F.3d at 1223–24.

323. *Id.* at 1223, 1235 (Rymer, J., dissenting).

324. *Id.* at 1224 (majority opinion).

325. *Id.* at 1223.

326. *Id.* at 1224.

327. *United States v. Cruz*, 554 F.3d 840, 845–49 (9th Cir. 2009).

328. *Id.* at 848 (“[T]he evidence in this case, when taken in the light most favorable to the government, demonstrates that Cruz satisfies at best only a small part of the least important of the four *Bruce* factors. He does not satisfy any of the factors in full, and there is not even a scintilla of evidence suggesting that he satisfies a single one of the three most important factors.”).

329. *Id.* at 848–49 (“Were we to hold that evidence satisfying merely a portion of the least important *Bruce* factor is, in itself, sufficient to support a § 1153 conviction, we would be ignoring

Circuit held that the Indian ancestry-blood quantum requirement does not have to be from a federally-recognized Tribe.³³⁰ Finally, the Eighth Circuit has added a social connection to the Tribe as a factor relevant to Bruce’s second prong.³³¹ The Indian Civil Rights Act adopts this judicial definition for Indian. The law states that “‘Indian’ means any person who would be subject to the jurisdiction of the United States as an Indian under section 1153.”³³² Given that this Act implicates the rights of Indian defendants in Tribal court proceedings,³³³ it makes sense that it adopts a definition used in criminal cases.

C. STATE LAW AND POLICY

In addition to federal law, state laws also define Indian status.³³⁴ Their scope is limited to state services and programs, although some federal laws will provide program eligibility to members of state-recognized Tribes. Illinois’ Human Rights Act, for example, defines “American Indian or Alaska Native” as “a person having origins in any of the original peoples of North and South America, including Central America, and who maintains [T]ribal affiliation or community attachment.”³³⁵ Indiana law incorporates federal statutory definitions by reference when defining Native American for the purposes of the state’s Native American Indian Affairs Commission.³³⁶

Eleven states provide for Tribal recognition under state law.³³⁷ State recognition is not mutually exclusive of federal recognition and the rights and relationships related to state recognition vary significantly from state to state.³³⁸

Bruce’s mandate in various respects, including its requirement that the factors be considered ‘in declining order of importance.’ The first three factors could not realistically be deemed more important than the fourth if a partial satisfaction of the fourth could outweigh the complete failure to satisfy any of the first three.” (footnote omitted) (citation omitted)).

330. *United States v. Zepeda*, 792 F.3d 1103, 1113 (9th Cir. 2015).

331. *United States v. Stymiest*, 581 F.3d 759, 763–67 (8th Cir. 2009).

332. 25 U.S.C. § 1301(4).

333. *See* 25 U.S.C. §§ 1301–1304.

334. *See, e.g.*, CONN. GEN. STAT. § 47-63 (2023); FLA. STAT. §§ 285.08(2), 288.703(d) (2023); 775 ILL. COMP. STAT. 5/2-105(D)(1) (2022); IND. CODE ANN. § 4-23-32-2 (LexisNexis 2020); N.Y. TAX LAW § 470(14)–(15) (McKinney 2014 & Supp. 2024).

335. 775 ILL. COMP. STAT. 5/2-105(D)(1).

336. IND. CODE ANN. § 4-23-32-2.

337. These states include Alabama, Connecticut, Georgia, Louisiana, Maryland, Massachusetts, New York, North Carolina, South Carolina, Vermont, and Virginia. Martha Salazar, *State Recognition of American Indian Tribes*, NAT’L CONF. ST. LEGISLATURES (2016), <https://www.legislature.maine.gov/doc/5373> [<https://perma.cc/N3UK-AB6X>].

338. Alexa Koenig & Jonathan Stein, *Federalism and the State Recognition of Native American Tribes: A Survey of State-Recognized Tribes and State Recognition Processes Across the United States*, 48 SANTA CLARA L. REV. 79, 83 (2008); *see also* Eilis O’Neill, *Unrecognized Tribes Struggle Without Federal Aid During Pandemic*, NPR (Apr. 17, 2021, 7:00 AM), <https://www.npr.org/2021/04/17/988123599/unrecognized-tribes-struggle-without-federal-aid-during-pandemic> [<https://perma.cc/HA54-JRAU>] (explaining that state recognized Tribes will not necessarily be entitled to benefits under federal law).

A Tribe may have state recognition but not federal recognition;³³⁹ have federal recognition but not state recognition;³⁴⁰ or both state and federal recognition.³⁴¹ Some states define Indian to include members of both federally and state-recognized Tribes.³⁴²

Regardless of federal or state recognition status, Tribes also establish their own definitions for their membership.

D. TRIBAL CITIZENSHIP LAWS

Historically, Indigenous communities used a variety of mechanisms to establish membership, including ancestry, clan systems, and kinships.³⁴³ Modern citizenship laws vary significantly from Tribe to Tribe.³⁴⁴ Tribes have the sole authority to establish their citizenship criteria.³⁴⁵ The Supreme Court has acknowledged that federal interference with Tribal membership determinations would intrude on Tribal sovereignty.³⁴⁶ And yet, federal policies have left its imprint.

As discussed above, the federal government established Tribal rolls. Many Tribal laws establish their membership based on lineage from individuals listed on such rolls.³⁴⁷ The Muscogee Nation, for example, allows for citizenship based on lineal descendants listed on the 1906 roll.³⁴⁸ The Cherokee Nation

339. See, for example, the Eastern Pequot Tribal Nation, the Echota Cherokee Tribe of Alabama, and the Lumbee Tribe of North Carolina. See Martha Saenz, *Federal and State Recognized Tribes*, NAT'L CONF. ST. LEGISLATURES (Mar. 2020), <https://massnaela.com/wp-content/uploads/2023/06/FOR-WEBSITE-DEI-Native-Amer-Federal-State-Recognized-Tribe-List.pdf> [https://perma.cc/CUZ6-4NT4].

340. For example, the Mashpee Wampanoag Tribe and the Wampanoag Tribe of Gay Head. *Id.*

341. For example, the Pamunkey Indian Tribe, the Tonawanda Band of Seneca, and the Tuscarora Nation. *Id.*

342. See, e.g., CONN. GEN. STAT. § 47-63 (2023); N.Y. TAX LAW § 470(14)-(15) (McKinney 2014 & Supp. 2024).

343. COHEN'S HANDBOOK, *supra* note 239, § 7.4, at 135; see Gabriel S. Galanda, *The Indian Reorganization Act: Realigning Tribal 'Membership' with Kinship*, INDIAN COUNTRY TODAY (Sept. 12, 2018), <https://ictnews.org/archive/indian-reorganization-act-realigning-tribal-membership-kinship> [https://perma.cc/BS6G-NK63] (discussing the misalignment of Tribal citizenship laws and kinship). For a discussion on the "shift from defining Hawaiian identity by indigeneity to a definition based on race," see Andrade, *supra* note 257, at 19.

344. RESTATEMENT OF THE L.: THE L. OF AM. INDIANS § 18 (AM. L. INST. 2024).

345. *Santa Clara Pueblo v. Martinez*, 436 U.S. 49, 72 n.32 (1978) ("A [T]ribe's right to define its own membership for [T]ribal purposes has long been recognized as central to its existence as an independent political community. Given the often vast gulf between [T]ribal traditions and those with which federal courts are more intimately familiar, the judiciary should not rush to create causes of action that would intrude on these delicate matters." (citations omitted)).

346. *Id.* at 72.

347. Carole Goldberg, *Members Only? Designing Citizenship Requirements for Indian Nations*, 50 U. KAN. L. REV. 437, 467 (2002).

348. MUSCOGEE (CREEK) CONST. art. III, § 2; MUSCOGEE (CREEK) NATION CODE ANN. tit. 7, § 3-101 (West 2001).

requires lineal ancestry to a Cherokee citizen listed in the Dawes Rolls.³⁴⁹ The Native Village of Eklutna establishes base membership using the 1940 roll.³⁵⁰ Additionally, blood quantum policies are regularly part of Tribal membership criteria³⁵¹ and are closely tied to Tribal rolls.³⁵² The Pueblo of Isleta requires at least one quarter blood quantum to establish membership.³⁵³ The Constitution of the Kenaitze Indian Tribe provides base membership using the 1971 roll and one quarter blood quantum.³⁵⁴ Similarly, the Navajo Nation requires one quarter blood quantum.³⁵⁵

Tribes have also established other requirements for membership. The Pokagon Band of Potawatomi requires DNA testing as part of its enrollment application.³⁵⁶ Parental residency is a criterion for membership in some Tribes.³⁵⁷

This Part outlined the numerous ways in which Indigeneity can be defined across different individuals, legal schemes, and jurisdictions. The volume and complexity of these definitions impact public health practice and is analyzed below.

IV. INDIGENEITY AND DATA

The piecemeal definitions of Indian across a myriad of laws and policy inevitably creates complications in practice, including public health practice. Law, as discussed above, is not the only mechanism in which to establish Indigenous identity. This Part explores the impact of these numerous definitions on public health. First, it discusses how nuances across racial, ancestral, and political classifications fail to be captured and the impact of competing definitions. Next, it explores an individual's right to not be counted. It ends with a discussion on Tribal data sovereignty.

A. COMPETING DEFINITIONS

Part III discusses the many definitions and mechanisms for defining Indigeneity. The information generated in each definitional scheme can be relevant to public health but often do not align with the definitions used in

349. CHEROKEE NATION CONST. art. IV; *Registration*, CHEROKEE NATION, <https://www.cherokee.org/all-services/tribal-registration> [<https://perma.cc/6ZX5-97DN>].

350. *Enrollment Information*, NATIVE VILL. EKLUTNA TRIBAL GOV'T (2019), <http://eklutna-nsn.gov/departments/enrollment-information> [<https://perma.cc/6AR5-34AE>].

351. PEVAR, *supra* note 31, at 91.

352. Goldberg, *supra* note 347, at 467; Kirsty Gover, *Genealogy as Continuity: Explaining the Growing Tribal Preference for Descent Rules in Membership Governance in the United States*, 33 AM. INDIAN L. REV. 243, 259-69 (2008).

353. *Census Tribal Enrollment Office*, PUEBLO ISLETA, <https://www.isletapueblo.com/census-department> [<https://perma.cc/8ZU4-4F2Z>].

354. KENAITZE INDIAN TRIBE CONST. art. IV.

355. NAVAJO NATION CODE ANN. tit. 1, § 701 (2010).

356. *Enrollment*, POKAGON BAND POTAWATOMI (2024), <https://www.pokagonbandnsn.gov/citizens/enrollment> [<https://perma.cc/WQ7V-ZGCK>].

357. Gover, *supra* note 352, at 270.

public health surveillance systems. They also often fail to capture the mechanisms in which to base Indigenous identity: racial–ethnic, ancestral, political, and community. The impact of this is described via examples here.

A comparison of Indigenous population estimates serves as an initial example. Various census databases provide information regarding Indigenous populations in Indian country. My Community Explorer provides county-level racial–ethnic data³⁵⁸ and can be used to determine the Native population in a Tribe’s county service areas. The “Tribal Area” database includes population estimates of Indigenous people within a Tribe’s reservation and off-reservation trust lands.³⁵⁹ When comparing the population estimates from these two databases to published Tribal Membership numbers, the author found three distinct sets of numbers (Table 1). Tribal Membership will include all members regardless of where they live and their racial–ethnic self-identification. The Tribal Area database will only include American Indians and Alaska Natives, not all of whom are members, within reservation and trust lands. The Tribal Service Area will capture the Native population within a Tribe’s county service areas but not exclusive to their members. The two census databases both under capture and over captures relevant information. They under capture because it fails to include Tribal members living outside of a prescribed area. They over capture because it includes all Native people (i.e., members of other Tribes), not just a Tribe’s members.

Table 1

Population Estimate Comparison			
	Tribal Membership	Census Bureau “Tribal Area” ³⁶⁰	Tribal Service Area ³⁶¹
Cherokee Nation	450,000 ³⁶²	512,883 ³⁶³	133,700 ³⁶⁴

358. *My Community Explorer 4.3*, U.S. CENSUS BUREAU, <https://experience.arcgis.com/experience/13a111e0bad242fba0fb62f25199c7dd/page/Page-1> [<https://perma.cc/9GLL-U9T7>] (click “My Community Explorer,” then click “County: Race and Ethnicity,” then search).

359. *My Tribal Area*, U.S. CENSUS BUREAU, <https://www.census.gov/tribal> [<https://perma.cc/W4JA-LUV2>].

360. The U.S. Census Bureau Tribal Area estimates the American Indian and Alaska Native population living on reservation and off-reservation trust lands. *Id.* These estimates are not specific to Tribal members. *Id.*

361. A Tribal or Identified Service Area is a federally designated area where social services are provided for a Tribe’s members. 24 C.F.R. § 1003.4 (2024).

362. *Osiyo!*, CHEROKEE NATION, <https://www.cherokee.org> [<https://perma.cc/4GTP-4AT8>].

363. *My Tribal Area: Oklahoma, Cherokee OTSA*, U.S. CENSUS BUREAU, <https://www.census.gov/tribal/?st=40&aianihh=5550> [<https://perma.cc/BX5S-E6TW>].

364. The Cherokee Nation includes parts of fourteen Oklahoma counties: Adair, Cherokee, Craig, Delaware, Mayes, McIntosh, Muskogee, Nowata, Ottawa, Rogers, Sequoyah, Tulsa, Wagoner, and Washington. *Maps*, CHEROKEE NATION, <https://www.cherokee.org/about-the-nation/maps>

Population Estimate Comparison			
	Tribal Membership	Census Bureau "Tribal Area" ³⁶⁰	Tribal Service Area ³⁶¹
Cheyenne River Sioux Tribe	15,993 ³⁶⁵	7,221 ³⁶⁶	8,460 ³⁶⁷
Lummi Nation	5,000 ³⁶⁸	5,211 ³⁶⁹	4,801 ³⁷⁰
Navajo Nation	399,494 ³⁷¹	166,545 ³⁷²	287,200 ³⁷³
Yurok Tribe	5,000 ³⁷⁴	763 ³⁷⁵	8,003 ³⁷⁶

[<https://perma.cc/75SP-279E>]. Using the U.S. Census Bureau's My Community Explorer 4.3, the number of individuals that identify as American Indian and Alaskan Native only include: Adair: 8,700; Cherokee: 15,700; Craig: 3,100; Delaware: 8,900; Mayes: 8,400; McIntosh: 3,000; Muskogee: 11,900; Nowata: 1,600; Ottawa: 6,000; Rogers: 11,600; Sequoyah: 8,000; Tulsa: 34,300; Wagoner: 7,400; Washington: 5,100. *My Community Explorer*, *supra* note 358.

365. *Cheyenne River Agency*, BUREAU INDIAN AFFS., <https://www.bia.gov/regional-offices/great-plains/south-dakota/cheyenne-river-agency> [<https://perma.cc/8JYK-GU9N>].

366. *My Tribal Area: South Dakota, Cheyenne River Reservation and Off-Reservation Trust Land, SD*, U.S. CENSUS BUREAU, <https://www.census.gov/tribal/?st=46&aianihh=0605> [<https://perma.cc/RWU2-N375>].

367. The Cheyenne River Sioux Tribe's county areas include Dewey, Haakon, Meade, Lawrence, Perkins, Stanley, and Ziebach counties. *Cheyenne River Agency*, *supra* note 365. Dewey: 4,100; Haakon: 86; Lawrence: 509; Meade: 669; Perkins: 57; Stanley: 100; and Ziebach: 1,700. *My Community Explorer*, *supra* note 358.

368. *About Us*, LUMMI NATION, <https://www.lummi-nsn.gov/Website.php?PageID=388> [<https://perma.cc/3CPR-XP52>].

369. *My Tribal Area: Lummi Reservation, WA*, U.S. CENSUS BUREAU, <https://www.census.gov/tribal/?aianihh=2070> [<https://perma.cc/K6E6-PFCU>].

370. San Juan County, Washington: 101; Whatcom, Washington: 4,700. *My Community Explorer*, *supra* note 358.

371. Simon Romero, *Navajo Nation Becomes Largest Tribe in U.S. After Pandemic Enrollment Surge*, N.Y. TIMES (May 21, 2021), <https://www.nytimes.com/2021/05/21/us/navajo-choerokee-population.html> (on file with the *Iowa Law Review*).

372. *My Tribal Area: Arizona, Navajo Reservation and Off-Reservation Trust Land, AZ—NM—UT*, U.S. CENSUS BUREAU, <https://www.census.gov/tribal/?st=04&aianihh=2430> [<https://perma.cc/Q9WU-2MS8>].

373. Apache County, Arizona: 48,200; Coconino County, Arizona: 36,600; Navajo County, Arizona: 46,200; Bernalillo County, New Mexico: 33,200; Cibola County, New Mexico: 11,400; McKinley County, New Mexico: 55,000; Socorro County, New Mexico: 2,000; San Juan County, New Mexico: 48,100; San Juan County, Utah: 6,500. *My Community Explorer*, *supra* note 358.

374. *Yurok Tribe History*, YUROK TRIBE, <https://www.yuroktribe.org/our-history> [<https://perma.cc/5Q9V-EF7B>].

375. *My Tribal Area: Yurok Reservation, U.S. CENSUS BUREAU*, <https://www.census.gov/tribal/?aianihh=4760> [<https://perma.cc/2BK8-H5SR>].

376. The Tribal Surface Area for the Yurok Tribe includes the following populace in California: Del Norte County: 2,000; Humboldt County: 5,500; and Trinity County: 503. *My Community Explorer*, *supra* note 358.

Next, definitions of Indigeneity do not consistently capture or distinguish between racial and political contexts. Challenges defining Indigeneity present themselves in a variety of contexts outside of public health³⁷⁷ and have been explored by a variety of scholars.³⁷⁸ One primary tension is that between political identification versus racial–ethnic identification. Federal law has consistently recognized Tribal membership as a political classification.³⁷⁹ In the seminal case on this issue, *Morton v. Mancari*, the plaintiffs challenged the BIA hiring preference policy for Indian applicants as violative of the Fifth Amendment.³⁸⁰ The Supreme Court found that Indian hiring preferences were not race-based but instead politically based, subject to rational basis review.³⁸¹ The Court upheld the hiring preference.³⁸² Although Tribal membership is recognized as a political classification,³⁸³ racialized thinking has guided courts in recognizing Indian status. Professor Gerald Torres, in offering commentary on the *Sandoval* case discussed above, stated “that the racial condition of the Pueblos is what determines their legal status.”³⁸⁴ Additionally, federal definitions generally do not allow for clear distinctions between provisions based on race versus those that are based on political classification using Tribal membership. This is because so many provisions allow more than Tribal membership to determine Indian status.³⁸⁵

377. See, e.g., Adedoyin, *supra* note 227.

378. See, e.g., Julia Bello-Bravo, *When Is Indigeneity: Closing a Legal and Sociocultural Gap in a Contested Domestic/International Term*, 15 ALTERNATIVE 111, 111 (2019); Claire Timperley, *Constellations of Indigeneity: The Power of Definition*, 19 CONTEMP. POL. THEORY 38, 38–39 (2019); Rebecca Tsosie, *The New Challenge to Native Identity: An Essay on “Indigeneity” and “Whiteness,”* 18 WASH. U. J.L. & POL’Y 55, 55–56 (2005); Robert Maxim, Gabriel R. Sanchez & Kimberly R. Huyser, *Why the Federal Government Needs to Change How It Collects Data on Native Americans*, BROOKINGS (Mar. 30, 2023), <https://www.brookings.edu/research/why-the-federal-government-needs-to-change-how-it-collects-data-on-native-americans> [<https://perma.cc/VPV7-7R6K>].

379. See *Morton v. Mancari*, 417 U.S. 535, 553 n.24 (1974); *Moe v. Confederated Salish & Kootenai Tribes of the Flat-Head Rsrv.*, 425 U.S. 463, 480 (1976).

380. *Morton*, 417 U.S. at 537.

381. *Id.* at 555 (“As long as the special treatment can be tied rationally to the fulfillment of Congress’ unique obligation towards the Indians, such legislative judgments will not be disturbed.”).

382. *Id.*

383. Note that *Haaland v. Brackeen* challenged the constitutionality of Indian placement preferences under the Indian Child Welfare Act as violative of the Equal Protection Clause. See *Haaland v. Brackeen*, 599 U.S. 255, 291 (2023) (passing on this argument for lack of standing). A finding that this preference is discrimination based on race would have challenged the longstanding *Morton v. Mancari* holding and would have significantly disrupted federal Indian law. See *Morton*, 417 U.S. at 553 n.24 (holding that the Indian preference for employment in the Bureau of Indian Affairs was not a “racial” preference).

384. Gerald Torres, *Who Is an Indian?: The Story of United States v. Sandoval*, in INDIAN LAW STORIES 109, 132 (Carole E. Goldberg, Kevin K. Washburn & Philip P. Frickey eds., 2011).

385. COHEN’S HANDBOOK, *supra* note 239, § 1.2, at 3. This can create interesting Equal Protection Clause considerations. Provisions that rely on political classifications would be subject to rational basis review whereas racial classifications are subject to strict scrutiny. The hodgepodge manner in which Congress has defined “Indian” across the statutory code leaves significant vulnerability to much of federal Indian law.

Third, many federal statutory schemes define “Indian” as a member of a federally recognized Tribe. But, the “American Indian and Alaska Native” category under racial–ethnic data schemes does not prescribe the same membership requirement. Thus, someone that identifies as American Indian or Alaska Native may not be an enrolled citizen of a Tribe.³⁸⁶ Similarly, a person may be a Tribal citizen but not identify as American Indian and Alaska Native as their racial–ethnic identity.³⁸⁷

Similarly, political classifications may ignore ancestral ones. Blood quantum is only calculated from federally recognized Tribes.³⁸⁸ During the Termination Era, spanning roughly from 1940 to the early 1960s, over one hundred Tribes were stripped of their federal recognition,³⁸⁹ resulting in the loss of benefits and land.³⁹⁰ Most, but not all of the terminated Tribes were subsequently re-recognized by Congress.³⁹¹ The federal recognition process today is fraught.³⁹² The administrative process through the Department of the Interior involves a detailed application establishing seven criteria.³⁹³ Tribes can also secure recognition from an act of Congress or by implication from a judicial decision.³⁹⁴ DNA testing can provide information on Native ancestry but not on Tribal affiliation.³⁹⁵

Fourth, racial–ethnic categories in public health and health care settings are generally prescribed via self-identification or presenting identification.

386. *Id.*

387. D’Vera Cohn, *American Indian and White, but Not ‘Multiracial,’* PEW RSCH. CTR. (June 11, 2015), <https://www.pewresearch.org/fact-tank/2015/06/11/american-indian-and-white-but-not-multiracial> [https://perma.cc/JC9X-6TWK].

388. See generally CDIB INSTRUCTIONS, *supra* note 277 (providing instructions and materials for requesting a Certificate of Degree of Indian or Alaska Native Blood).

389. COHEN’S HANDBOOK (2024), *supra* note 311, § 2.10[3].

390. *Id.*

391. *Id.* § 2.11[6].

392. RENÉE ANN CRAMER, CASH, COLOR, AND COLONIALISM 5–8, 104–05 (2005); MARK EDWIN MILLER, FORGOTTEN TRIBES 74–78 (2004).

393. The seven criteria include: (1) “petitioner has been identified as an American Indian entity on a substantially continuous basis since 1900”; (2) “petitioner comprises a distinct community and demonstrates that it existed as a community from 1900 until the present”; (3) “petitioner has maintained political influence or authority over its members as an autonomous entity from 1900 until the present”; (4) “petitioner must provide . . . [a] copy of the entity’s present governing document”; (5) “petitioner’s membership consists of individuals who descend from a historical Indian [T]ribe (or from historical Indian [T]ribes that combined and functioned as a single autonomous political entity)”; (6) “petitioner’s membership is composed principally of persons who are not members of any federally recognized Indian [T]ribe”; and (7) “[n]either the petitioner nor its members are the subject of congressional legislation that has expressly terminated or forbidden the Federal relationship.” 25 C.F.R. § 83.11 (2024).

394. COHEN’S HANDBOOK (2024), *supra* note 311, § 5.05[1].

395. Nanibaa’ A. Garrison, *Genetic Ancestry Testing with Tribes: Ethics, Identity & Health Implications*, DAEDALUS, Spring 2018, at 60, 65; Jessica Bardill, *Tribal Enrollment and Genetic Testing*, GENETHERAPY.ME (Jan. 26, 2019, 8:48 PM), <https://www.genetherapy.me/genetic-testing/tribal-enrollment-and-genetic-testing-genetics.php> [https://perma.cc/825L-JC6Z]; Kim TallBear, *Narratives of Race and Indigeneity in the Genographic Project*, 35 J.L. MED. & ETHICS 412, 419–20 (2007).

The 1960 census was the first to allow for self-identification. Thus, comparing previous census data is impossible.³⁹⁶ Tensions can arise when ancestral connections, or alleged connections, lead to modern self-identification. Recently, several well-known public figures were exposed as faking their Indigenous identity.³⁹⁷ These individuals are sometimes referred to as “[p]retendians.”³⁹⁸ Senator Elizabeth Warren self-identified as Native in a variety of educational and governmental forms.³⁹⁹ Yet, she has never had any relationship or membership with any Tribe.⁴⁰⁰ Is she a relevant data point from a public health perspective? Or, is her self-identification skewing the data? Claims of Indigenous identity have been long-standing.⁴⁰¹ Furthermore, self-identification offers no insight on Tribal membership.⁴⁰² A person that self-identifies as Indigenous may present as another racial-ethnic group. Presenting as white may have protective factors⁴⁰³

396. Chaudhuri, *supra* note 228, at 22.

397. See, e.g., Sarah Viren, *The Native Scholar Who Wasn't*, N.Y. TIMES MAG. (June 15, 2023), <https://www.nytimes.com/2021/05/25/magazine/chokeberry-native-american-andrea-smith.html> (on file with the *Iowa Law Review*); Olivia Truffaut-Wong, *This Professor Reportedly Claimed to Be Indigenous for Years*, CUT (Dec. 1, 2021), <https://www.thecut.com/2021/12/carrie-bourassa-allegedly-fake-d-her-indigenous-identity.html> [<https://perma.cc/B75J-6E9A>]; Geoff Leo, *Birth Certificate Contradicts Mary Ellen Turpel-Lafond's Account of Her Father's Parentage and Ancestry*, CBC (Nov. 21, 2022, 4:37 PM), <https://www.cbc.ca/news/canada/saskatchewan/birth-certificate-contradicts-turpel-lafond-account-father-parentage-1.6657129> [<https://perma.cc/3PMU-C4MK>]; Ka'nhehs'io Deer & Jorge Barrera, *Award-Winning Filmmaker Michelle Latimer's Indigenous Identity Under Scrutiny*, CBC (Dec. 17, 2020, 3:54 PM), <https://www.cbc.ca/news/indigenous/michelle-latimer-kitigan-zibi-indigenous-identity-1.5845310> [<https://perma.cc/VXS5-ELSJ>]; Jay Caspian Kang, *Identity Crisis*, NEW YORKER, Mar. 4, 2024, at 12, 12 (discussing Elizabeth Hoover's Native identity).

398. Sam Yellowhorse Kesler, *The Race-Shifting of 'Pretendians'*, NPR (Feb. 23, 2022, 4:59 PM), <https://www.npr.org/2022/02/23/1082622851/native-american-communities-concerned-about-self-identification-wannabes> [<https://perma.cc/C4NE-JMTV>].

399. Ella Nilsen, *New Evidence Has Emerged Elizabeth Warren Claimed American Indian Heritage in 1986*, VOX (Feb. 5, 2019, 7:29 PM), <https://www.vox.com/2018/10/16/17983250/elizabeth-warren-bar-application-american-indian-dna> [<https://perma.cc/TD64-5XEG>] (finding that Warren self-identified as American Indian for the Texas State Bar registration card); Briahna Gray, *What Elizabeth Warren Still Doesn't Get*, INTERCEPT (Oct. 16, 2018, 1:37 PM), <https://theintercept.com/2018/10/16/elizabeth-warren-dna-video-native-american-harvard> (on file with the *Iowa Law Review*) (reporting Warren claimed to be Native American during her time at the University of Pennsylvania and as a minority on the Association of American Law Schools directory).

400. John Verhovek, *Sen. Elizabeth Warren Apologizes to Cherokee Nation for Taking DNA Test*, ABC NEWS (Feb. 1, 2019, 3:07 PM), <https://abcnews.go.com/Politics/sen-elizabeth-warren-apologizes-to-chokeberry-nation-taking-dna/story?id=60788103> [<https://perma.cc/PX3A-Y6BR>].

401. See, e.g., VINE DELORIA, JR., CUSTER DIED FOR YOUR SINS 2–5 (Univ. of Okla. Press 1988) (1969) (discussing claims to Indian ancestry).

402. MALIA VILLEGAS, AMBER EBARB, SARAH PYTALSKI & YVETTE ROUBIDEAUX, NCAI POL'Y RSCH. CTR., DISAGGREGATING AMERICAN INDIAN & ALASKA NATIVE DATA: A REVIEW OF LITERATURE 23 (2016), https://archive.ncai.org/DataDisaggregationAIAN-report_5_2018.pdf [<https://perma.cc/94VN-9KNB>].

403. Ashley Nicole McCray, *A Love Letter to My Fellow Light-Skinned Natives*, LAST REAL INDIANS (July 27, 2019), <https://lastrealindians.com/news/2019/7/26/a-love-letter-to-my-fellow-light-skinned-natives-by-ashley-nicole-mccray> [<https://perma.cc/DDK3-RBRN>].

that can be relevant to health outcomes. Put another way, presenting as white may lead to better quality of care in our health care systems.

Fifth, Freedmen, the descendants from individuals enslaved by Tribal members, have been frequently central figures in discussions regarding who is Native.⁴⁰⁴ Controversies regarding Freedmen highlight an instance in which Tribal ancestry may not align with Tribal membership or self-identification. Sometimes, a separate roll was created for Freedmen.⁴⁰⁵ It has resulted in significant litigation based on violations of constitutional and treaty language.⁴⁰⁶ In the Cherokee Nation case, the Tribe “concede[d] that its power to determine [T]ribal membership can be limited by treaty,” and when the district court found that the treaty required Freedmen membership,⁴⁰⁷ the Tribe brought a petition to the Cherokee Supreme Court to enforce the *Nash* decision.⁴⁰⁸ The Cherokee Nation Constitution was recently amended to ensure Freedmen citizenship.⁴⁰⁹ Other Tribes have not taken similar action. For Freedmen with Tribal membership but no Indian blood, they may be considered Indian under some federal laws but not others.⁴¹⁰

Sixth, increased instances of disenrollment provide another example regarding lack of alignment between Tribal law and self-identification. The Nooksack Indian Tribe disenrolled 306 members of the Tribe, resulting in significant litigation. In December 2012, the Tribal council determined these 306 members did not meet the Tribe’s membership criteria.⁴¹¹ It requires: (1) appearance on the 1942 census; (2) receipt of an original 1942 Tribal land allotment; or (3) be a descendant of someone who met either of those conditions.⁴¹² These disenrolled members likely identify as Indigenous but their

404. See, e.g., Jack Healy, *Black, Native American and Fighting for Recognition in Indian Country*, N.Y. TIMES (Sept. 8, 2020), <https://www.nytimes.com/2020/09/08/us/enslaved-people-native-americans-oklahoma.html> (on file with the *Iowa Law Review*).

405. Spruhan, *supra* note 259, at 40–41.

406. See, e.g., *Vann v. Kempthorne*, 534 F.3d 741, 745 (D.C. Cir. 2008) (challenging denial of citizenship based on the Thirteenth Amendment and the Treaty with the Cherokee, Cherokee Nation–U.S., July 19, 1866, 14 Stat. 799); *Graham v. Muscogee (Creek) Nation Citizenship Bd.*, SC 2020-01, 2020 Muscogee Creek Nation Supreme LEXIS 1, at *1–5 (Muscogee (Creek) National Sup. Ct. Sept. 17, 2020).

407. *Cherokee Nation v. Nash*, 267 F. Supp. 3d 86, 140 (D.D.C. 2017).

408. *In re Effect of Cherokee Nation v. Nash*, 16 Am. Tribal L. 268, 276 (Cherokee Sup. Ct. 2021).

409. Press Release, U.S. Dep’t of Interior, Secretary Haaland Approves New Constitution for Cherokee Nation, Guaranteeing Full Citizenship Rights for Cherokee Freedmen (May 27, 2021), <https://www.doi.gov/pressreleases/secretary-haaland-approves-new-constitution-cherokee-nation-guaranteeing-full> [<https://perma.cc/AT57-HZ99>].

410. See *Wilson v. Bridges*, No. 24-5041, 2024 WL 4132399, at *2–3 (10th Cir. Sept. 10, 2024) (finding that a Cherokee Freedman and citizen of the Cherokee Nation could be prosecuted by Oklahoma because he was not considered Indian under federal criminal law).

411. Gabriel S. Galanda & Ryan D. Dreveskracht, *Curing the Tribal Disenrollment Epidemic: In Search of a Remedy*, 57 ARIZ. L. REV. 383, 423–25 (2015).

412. *Id.* at 423–24 n.306.

political classification does not align. More frequently, Tribes are disenrolling existing members.⁴¹³ And per capita Tribes have been more likely to engage in disenrollment,⁴¹⁴ which may suggest that in some cases Tribal membership rosters cannot accurately reflect the self-identifying Indigenous population.

Seventh, tensions in defining Indigeneity have legal ramifications.⁴¹⁵ For criminal jurisdiction purposes, an individual can be considered an Indian without membership in a Tribe. At the same time, Black citizens of Tribes without Indian blood would not be considered Indian under federal law.⁴¹⁶ Information on Indian defendants and defendants in federal criminal cases can shed significant light on important public health issues including violence prevention, mental health, and substance use disorder. As *Bruce* and subsequent criminal law Indian status cases have established, holding yourself out to be Indian can be relevant to establishing “Indian status.” Adoption by an Indian Tribe by someone without Indian ancestry does not establish Indian status for criminal purposes.⁴¹⁷ But someone receiving benefits that are meant for Indians can possibly trigger criminal jurisdiction.⁴¹⁸

Eighth, the federal code sometimes directly conflicts in their definitions of Indian. Unlike the Indigenous Tribes of the contiguous United States and Alaska, Native Hawaiian sovereignty has not been recognized by the federal government.⁴¹⁹ Although Congress has acknowledged that “the political status of Native Hawaiians is comparable to that of American Indians and Alaska Natives,”⁴²⁰ Native Hawaiians do not have the same rights as other Indigenous peoples in the United States.⁴²¹ Federal law provides for some areas in which

413. See, e.g., Cecily Hilleary, *Native American Tribal Disenrollment Reaching Epidemic Levels*, VOA (Mar. 3, 2017, 10:38 AM), <https://www.voanews.com/a/native-american-tribal-disenrollment-reaching-epidemic-levels/3748192.html> [<https://perma.cc/B2KN-JCDV>]; Galanda & Dreveskracht, *supra* note 411, at 385–87.

414. Anna Malinovskaya, *Understanding the Native American Tribal ‘Disenrollment Epidemic’: An IV Approach* 29 (May 1, 2021) (unpublished manuscript), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3949116 [<https://perma.cc/KWE9-4EFY>].

415. See, e.g., Bethany R. Berger, *Race, Descent, and Tribal Citizenship*, 4 CALIF. L. REV. CIR. 23, 24–26 (2013) (offering an example regarding the exercise of special domestic violence jurisdiction under the Violence Against Women Act); Addie C. Rolnick, *Indigenous Subjects*, 131 YALE L.J. 2652, 2654–64 (2022) (discussing how race-based classifications undermine Indigenous rights).

416. Chris Cameron & Mark Walker, *Two Black Members of Native Tribes Were Arrested. The Law Sees Only One as Indian.*, N.Y. TIMES (June 6, 2023), <https://www.nytimes.com/2023/06/03/us/politics/freedmen-mcgrirt-ruling-oklahoma.html> (on file with the *Iowa Law Review*).

417. *State ex rel. Poll v. Mont.* Ninth Jud. Dist. Ct., 851 P.2d 405, 410–11 (Mont. 1993) (Trieweiler, J., concurring).

418. See *supra* notes 326–28 and accompanying text.

419. NATIVE HAWAIIAN LAW: A TREATISE 37–39 (Melody Kapilialoha MacKenzie, Susan K. Serrano & D. Kapua’ala Sproat eds., 2015).

420. 20 U.S.C. § 7512(12)(D).

421. FLETCHER, *supra* note 237, § 14.1, at 546–47.

Native Hawaiians can access unique programming.⁴²² Similarly, the inhabited territories of the United States have been colonized and are subject to a unique set of laws.⁴²³ The Indigenous people of the Pacific Islands are not considered Indians under federal law.⁴²⁴ Native Hawaiians and Pacific Islanders are Indigenous but are regularly excluded in federal definitions defining Indian. Often, there are distinct definitions for Native Hawaiians.⁴²⁵ As an example, federal law regarding housing for Native Hawaiians defines the term to include individuals that are:

- (A) a citizen of the United States; and
- (B) a descendant of the aboriginal people, who, prior to 1778, occupied and exercised sovereignty in the area that currently constitutes the State of Hawaii, as evidenced by—
 - (i) genealogical records;
 - (ii) verification by kupuna (elders) or kama’aina (long-term community residents); or
 - (iii) birth records of the State of Hawaii.⁴²⁶

This definition contrasts from the narrow definition under the Hawaiian Homes Commission Act, enacted in 1921, which established a race-based statutory scheme for access to homesteads.⁴²⁷ Here, Congress defined Native Hawaiian to include those of fifty percent blood quantum or higher.⁴²⁸ Although excluded from statutory definitions of “Indian,” Native Hawaiians are regularly included in federal definitions of “Native American.”⁴²⁹ As another example, the Code,

422. See, e.g., Act of Mar. 18, 1959, Pub. L. No. 86-3, § 5(f), 73 Stat. 4, 6 (establishing a public trust to support educational institutions for Native Hawaiians); Hawaiian Homes Commission Act, 1920, ch. 42, sec. 207, 42 Stat. 108, 110-11 (1921) (establishing a homesteading program for Native Hawaiians in designated areas).

423. See, e.g., Daniel Immerwahr, *The Greater United States: Territory and Empire in U.S. History*, 40 *DIPLOMATIC HIST.* 373, 385-90 (2016); *Territorial Federalism, in Developments in the Law—The U.S. Territories*, 130 *HARV. L. REV.* 1632, 1644-46 (2017); *Introduction, in Developments in the Law—The U.S. Territories*, 130 *HARV. L. REV.* 1617, 1617 (2017); Jon M. Van Dyke, *The Evolving Legal Relationships Between the United States and Its Affiliated U.S.-Flag Islands*, 14 *U. HAW. L. REV.* 445, 448-55 (1992); Tom C.W. Lin, *Americans, Almost and Forgotten*, 107 *CALIF. L. REV.* 1249, 1254-69 (2019).

424. Villazor, *supra* note 286, at 803-04.

425. See, e.g., 20 U.S.C. §§ 1070a-15(d)(2)(B), 7517(1); 25 U.S.C. § 4221(g); 29 U.S.C. § 3221(b)(3); 42 U.S.C. §§ 2545(c), 2992c(4); 34 C.F.R. § 647.7(b) (2024); 36 C.F.R. § 51.83(c)(4) (2024).

426. 25 U.S.C. § 4221(g).

427. Hawaiian Homes Commission Act, 1920, sec. 201(a)(7).

428. *Id.* For an account of the history of this legislative language, see Andrade, *supra* note 257, at 18-29.

429. Hoss, *supra* note 290, at app. 4.

at times, refers to Pacific Islanders as Native Americans.⁴³⁰ For public health surveillance systems, Pacific Islanders are usually incorporated in the “Native Hawaiian and Pacific Islander” racial category.

Finally, state definitions of Indian can also vary, creating legal conflicts. The Supreme Court considered the application of state excise tax law on reservations in *Washington v. Confederated Tribes of the Colville Indian Reservation*.⁴³¹ Here, non-member Indians were considered non-Indians for the purposes of state taxation.⁴³² Florida law establishes land and hunting and fishing rights to Indians, defined as members of a Tribe in one part of its code⁴³³ but uses a broader definition for accessing benefits in its minority-owned business programs.⁴³⁴

B. THE RIGHT NOT TO BE COUNTED

Parts I and II discussed the pivotal role of collecting and using data in public health practice. This Section provides a contrast to that proposition by discussing how work done to promote public health of Indigenous communities can still harm Indigenous people. This Section considers whether there may be a right not to be counted. The idea of the right not to be counted draws from a broad theory of privacy, “the right to be let alone.”⁴³⁵ This Section provides examples of ways in which some Native people are not left alone, despite their desires to the contrary.

First, Native people are regularly victimized by non-Native people and institutions simply for being Native. Throughout history, for many Native people, practicing their cultures, speaking their languages, dressing and adorning in traditional ways could be dangerous.⁴³⁶ In 1883, Congress criminalized the

430. 16 U.S.C. § 410qq-3 (“For purposes of this subchapter the term ‘[N]ative American Samoan’ means a person who is a citizen or national of the United States and who is a lineal descendant of an inhabitant of the Samoan Islands on April 18, 1900.”); 20 U.S.C. § 1059g(b)(3) (“The term ‘Native American Pacific Islander’ means any descendant of the aboriginal people of any island in the Pacific Ocean that is a territory or possession of the United States.”); 42 U.S.C. § 2992c(7) (“[T]he term ‘Native American Pacific Islander’ means an individual who is [I]ndigenous to a United States territory or possession located in the Pacific Ocean, and includes such individual while residing in the United States.”); *see also* 14 U.S.C. § 2131(b)(6)(A)(ii); 20 U.S.C. § 1070a-15(d)(2)(C); 34 C.F.R. § 647.7(b).

431. *Washington v. Confederated Tribes of the Colville Indian Rsrv.*, 447 U.S. 134, 141-42 (1980).

432. *Id.* at 161; PEVAR, *supra* note 31, at 17, 373 n.4.

433. FLA. STAT. § 285.08(2) (2023).

434. *Id.* § 288.703(4)(d).

435. Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 193 (1890).

436. *See, e.g.*, HIRAM PRICE, DEP’T INTERIOR & OFF. INDIAN AFFS., RULES GOVERNING THE COURT OF INDIAN OFFENSES 3 (1883), <https://commons.und.edu/cgi/viewcontent.cgi?article=1167&context=indigenous-gov-docs> [<https://perma.cc/V3XU-FZRP>] (prohibiting certain sacred practices under the Code of Indian Offenses); *Lyng v. Nw. Indian Cemetery Protective Ass’n*, 485 U.S. 439, 447-53 (1988); Rennard Strickland, *Genocide-at-Law: An Historic and Contemporary View of the Native American Experience*, 34 U. KAN. L. REV. 713, 726-28 (1986).

practice of sacred dances.⁴³⁷ The law remained on the books until the 1970s.⁴³⁸ In Indian boarding schools, Native children were prohibited from speaking their language or engaging in any cultural practices.⁴³⁹ Violent punishment was common for doing so.⁴⁴⁰ Indian children were often required to attend boarding schools and their parents could be held legally liable for not sending their children.⁴⁴¹ Being Native today, in quotidian life, can still be dangerous. Data from various sources show that Native Americans are three times more likely than white individuals to have a fatal encounter with the police.⁴⁴² Native women and girls are more likely to experience violence, including sexual violence.⁴⁴³ Native children are more likely to be victims of bullying in school.⁴⁴⁴

Second, Native people experience racism and discrimination in health care settings. Native women were targeted by the federal government for sterilization, often without consent.⁴⁴⁵ Physicians involved in sterilization of Native women believed that their conduct was ethical:

[T]he majority of physicians . . . believed that they were helping society by limiting the number of births in low-income, minority families. They assumed that they were enabling the government to cut funding for Medicaid and welfare programs while lessening their own personal tax burden to support the programs.⁴⁴⁶

More recent data demonstrates the role of racism in health care access. A 2008 study found that discrimination in health care to be the primary reason

437. PRICE, *supra* note 436, at 3.

438. American Indian Religious Freedom, Pub. L. No. 95-341, 92 Stat. 469 (1978) (codified at 42 U.S.C. § 1996).

439. DUNBAR-ORTIZ, *supra* note 29, at 150.

440. *Id.*

441. Robert Laurence, *Indian Education: Federal Compulsory School Attendance Law Applicable to American Indians: The Treaty-Making Period: 1857-1871*, 5 AM. INDIAN L. REV. 393, 395 (1977).

442. See MATTHEW HARVEY, CTR. FOR INDIAN COUNTRY DEV., FATAL ENCOUNTERS BETWEEN NATIVE AMERICANS AND THE POLICE 11 (2020), https://www.minneapolisfed.org/~/media/assets/articles/2020/fatal-encounters-between-native-americans-and-the-police/fatal-encounters-between-native-americans-and-the-police_march-2020.pdf?la=en [<https://perma.cc/V6BT-M4QE>].

443. See, e.g., ANNITA LUCCHESI & ABIGAIL ECHO-HAWK, URBAN INDIAN HEALTH INST., MISSING AND MURDERED INDIGENOUS WOMEN & GIRLS 2 (2018), <https://www.uihi.org/wp-content/uploads/2018/11/Missing-and-Murdered-Indigenous-Women-and-Girls-Report.pdf> [<https://perma.cc/7C83-Z6Y7>].

444. Evelyn M. Campbell & Susan E. Smalling, *American Indians and Bullying in Schools*, J. INDIGENOUS SOC. DEV. 10–11 (Aug. 1, 2019), <https://journalhosting.ucalgary.ca/index.php/jisd/article/view/63049/46994> [<https://perma.cc/Y8J7-65JK>].

445. BRIANNA THEOBALD, REPRODUCTION ON THE RESERVATION 155–60 (2019) (chronicling the federal sterilization campaign); U.S. GOV'T ACCOUNTABILITY OFF., HRD-77-3, INVESTIGATION OF ALLEGATIONS CONCERNING INDIAN HEALTH SERVICE 18–21 (1976) (finding that 3,406 Native women were sterilized between 1973 and 1976 at four IHS regions with “weaknesses” in obtaining patient consent).

446. Jane Lawrence, *The Indian Health Service and the Sterilization of Native American Women*, 24 AM. INDIAN Q. 400, 410 (2000).

that Native women were behind in their breast and cervical cancer screenings.⁴⁴⁷ Native women were also less likely to access dental exams, blood pressure, creatinine, and cholesterol screenings, and receive the pneumococcal vaccination due to discrimination in health care settings.⁴⁴⁸ In a 2019 study, researchers found that more than one in five Native people reported experiencing discrimination in health care settings.⁴⁴⁹ Fifteen percent reported avoiding health care to avoid discrimination.⁴⁵⁰ Importantly, research has also considered the biases of health care providers, not just the perceptions of patients, in finding discrimination in health care.⁴⁵¹ A 2020 report found that health care providers had negative perceptions of Native patients and that providers implicitly viewed these patients as noncompliant.⁴⁵² The beginning days of the pandemic were marked by egregious human rights violation implemented under the pretense of preventing COVID-19. An Albuquerque hospital implemented a policy intentionally separating Native mothers from their newborns.⁴⁵³

Third, researchers have a long history of exploiting Indigenous peoples and communities.⁴⁵⁴ As Professor Smith explains, “the term ‘research’ is inextricably linked to European imperialism and colonialism. The word itself, ‘research,’ is probably one of the dirtiest words in the Indigenous world’s vocabulary.”⁴⁵⁵ Here is one example: The University of California Berkeley kept

447. Kelly L. Gonzales, Anna K. Harding, William E. Lambert, Rongwei Fu & William G. Henderson, *Perceived Experiences of Discrimination in Health Care: A Barrier for Cancer Screening Among American Indian Women with Type 2 Diabetes*, 23 WOMEN’S HEALTH ISSUES e61, e64–e66 (2013).

448. Kelly L. Gonzales, William E. Lambert, Rongwei Fu, Michelle Jacob & Anna K. Harding, *Perceived Racial Discrimination in Health Care, Completion of Standard Diabetes Services, and Diabetes Control Among a Sample of American Indian Women*, 40 DIABETES EDUCATOR 747, 750–51 (2014).

449. Mary G. Findling et al., *Discrimination in the United States: Experiences of Native Americans*, 54 HEALTH SERVS. RSCH. 1431, 1434 (2019); see also Eric Whitney, *Native Americans Feel Invisible in U.S. Health Care System*, NPR (Dec. 12, 2017, 5:00 AM), <https://www.npr.org/sections/healthshots/2017/12/12/569910574/native-americans-feel-invisible-in-u-s-health-care-system> [<https://perma.cc/2SCX-52SM>] (“[A]bout a quarter of Native Americans reported experiencing discrimination when going to a doctor or health clinic . . .”).

450. Findling et al., *supra* note 449, at 1434.

451. See, e.g., Colin A. Zestcott, Lloyd Spece, Daniel McDermott & Jeff Stone, *Health Care Providers’ Negative Implicit Attitudes and Stereotypes of American Indians*, 8 J. RACIAL & ETHNIC HEALTH DISPARITIES 230, 232–35 (2021); Susan E. Puumala et al., *The Role of Bias by Emergency Department Providers in Care for American Indian Children*, 54 MED. CARE 562, 565–68 (2016); Ivy W. Maina, Tanisha D. Belton, Sara Ginzberg, Ajit Singh & Tiffani J. Johnson, *A Decade of Studying Implicit Racial/Ethnic Bias in Healthcare Providers Using the Implicit Association Test*, 199 SOC. SCI. & MED. 219, 224–27 (2018).

452. Zestcott et al., *supra* note 451, at 233.

453. Bryant Furlow, *Albuquerque Hospital’s Secret Policy Separated Native American Newborns from Their Mothers*, N.M. IN DEPTH (June 13, 2020), <https://nmindepth.com/2020/albuquerque-hospital-secret-policy-separated-native-american-newborns-from-their-mothers> [<https://perma.cc/FJY8-6YW3>].

454. SMITH, *supra* note 253, at 102–12.

455. *Id.* at 1.

an Indigenous man, Ishi, as a living exhibit at the university's anthropology museum.⁴⁵⁶ The arrangement was an alternative to incarceration or removal to Oklahoma.⁴⁵⁷ He remained there until his death.⁴⁵⁸ Even upon death, Ishi's humanity was ignored. He had requested a "traditional burial and no autopsy."⁴⁵⁹ Instead, his "brain was removed . . . and sent to the Smithsonian."⁴⁶⁰ A multi-year study on the impact of cold on thyroids was conducted by the federal government on Alaska Native individuals without informed consent.⁴⁶¹ In the infamous case of *Havasupai Tribe v. Arizona Board of Regents*, blood samples from members of the Havasupai Tribe were acquired for a study on diabetes conducted by Arizona State University.⁴⁶² The samples were subsequently used for other studies without consent from the participants.⁴⁶³ The Tribe sued the Board of Regents for a variety of causes of action including conversion, invasion of privacy, negligence, among others.⁴⁶⁴ The case ended up settling.⁴⁶⁵

Leaning heavily on the work of Professor Smith, there are a variety of issues with non-Indigenous research. It is almost exclusively conducted by non-Native people.⁴⁶⁶ The research is of "absolute worthlessness to us, the Indigenous world, and its absolute usefulness to those who wielded it as an instrument. It told us things already known, suggested things that would not work, and made careers for people who already had jobs."⁴⁶⁷ "The greater danger, however, was in the creeping policies that intruded into every aspect of our lives, legitimated by research, informed more often by ideology."⁴⁶⁸

Finally, data regarding Indigenous people can be exploited, manipulated, and used to stereotype and stigmatize. Although numbers are often presented as neutral, scientific measures to establish evidence, how something is counted,

456. *Ishi*, PHOEBE A. HEARST MUSEUM ANTHROPOLOGY, <https://hearstmuseum.berkeley.edu/ishi> [<https://perma.cc/DVRS-GERR>].

457. *Id.*

458. *Id.*

459. DUNBAR-ORTIZ, *supra* note 29, at 232.

460. *Id.*

461. NAT'L RSCH. COUNCIL, THE ARCTIC AEROMEDICAL LABORATORY'S THYROID FUNCTION STUDY: A RADIOLOGICAL RISK AND ETHICAL ANALYSIS 14–16 (1996); Robin Thompson, *Sins of the Past: The Iodine 131 Experiments in Alaska*, ANCHORAGE PRESS (Sept. 16, 2022), https://www.anchoragepress.com/news/sins-of-the-past-the-iodine-131-experiments-in-alaska/article_do8831ca-a79d-11eb-8caf-e738e4170dca.html [<https://perma.cc/P2M3-HRFN>].

462. *Havasupai Tribe v. Ariz. Bd. of Regents*, 204 P.3d 1063, 1066–67 (Ariz. Ct. App. 2008).

463. *Id.* at 1067.

464. Second Amended Complaint at 2, *Havasupai Tribe v. Ariz. Bd. of Regents*, No. cv2005-013190 (Ariz. Super. Ct. Feb. 22, 2006), 2006 WL 4642880.

465. Amy Harmon, *Indian Tribe Wins Fight to Limit Research of Its DNA*, N.Y. TIMES (Apr. 21, 2010), <https://www.nytimes.com/2010/04/22/us/22dna.html> (on file with the *Iowa Law Review*).

466. SMITH, *supra* note 253, at 49 ("Most Indigenous criticisms of research are expressed within the single terms of 'white research,' 'academic research' or 'outsider research.'").

467. *Id.* at 3.

468. *Id.*

are subject to biases and politics.⁴⁶⁹ Professor Smith notes that Indigenous people are “constantly fed messages about their worthlessness, laziness, dependence and lack of ‘higher’ order human qualities.”⁴⁷⁰ Professors Walter and Andersen state, “Indigenous statistics become intensely political.”⁴⁷¹ They argue they can be used to assimilate Indigenous communities by assessing “the ‘developmental lag’” as compared to non-Indigenous communities.⁴⁷² Some data presented as fact is actually not. The Meriam Report acknowledged this: “The statement is commonly made that venereal diseases are widely prevalent among Indians. No accurate facts are available to substantiate the assertions.”⁴⁷³ One report, in the context of child welfare programs, highlighted how program evaluations primarily focus on identifying deficits of Tribal programs while ignoring strengths.⁴⁷⁴ Essential information can also be omitted in study designs. For example, decades of research have studied alcohol use disorder in Indian country,⁴⁷⁵ advancing the stereotype of the “drunk Indian.”⁴⁷⁶ But, results from a 2016 report found that Native people and white people consume alcohol at comparable rates and that Native people abstain from alcohol use at higher rates.⁴⁷⁷ When data collection and analysis do not incorporate methodologies that protect Indigenous people,⁴⁷⁸ it disincentivizes wanting to participate in these surveillance systems both at the individual and community level. “Group privacy” refers to a right that is collective rather than individual in nature and that cannot be protected only by protecting individual privacy.⁴⁷⁹

469. STONE, *supra* note 112, at 183–87.

470. SMITH, *supra* note 253, at 4.

471. MAGGIE WALTER & CHRIS ANDERSEN, INDIGENOUS STATISTICS: A QUANTITATIVE RESEARCH METHODOLOGY 21 (2013).

472. *Id.* at 22.

473. MERIAM ET AL., *supra* note 37, at 216.

474. CHILD.’S BUREAU, A ROADMAP FOR COLLABORATIVE AND EFFECTIVE EVALUATION IN TRIBAL COMMUNITIES 17–18 (2013), https://www.acf.hhs.gov/sites/default/files/documents/cb/tribal_roadmap.pdf [<https://perma.cc/WH2M-75AX>].

475. Roxanne Dunbar-Ortiz & Dina Gilio-Whitaker, *What’s Behind the Myth of Native American Alcoholism?*, PAC. STANDARD (Oct. 10, 2016), <https://psmag.com/news/whats-behind-the-myth-of-native-american-alcoholism> [<https://perma.cc/BL3G-MTUR>].

476. See Malcolm D. Holmes & Judith A. Antell, *The Social Construction of American Indian Drinking: Perceptions of American Indian and White Officials*, 42 SOCIO. Q. 151, 154–56 (2001).

477. James K. Cunningham, Teshia A. Solomon & Myra L. Muramoto, *Alcohol Use Among Native Americans Compared to Whites: Examining the Veracity of the ‘Native American Elevated Alcohol Consumption’ Belief*, 160 DRUG & ALCOHOL DEPENDENCE 65, 66 (2016).

478. See, e.g., SMITH, *supra* note 253, at 4; Jason Edward Lewis, *An Orderly Assemblage of Biases: Troubling the Monocultural Stack*, in AFTERLIVES OF INDIGENOUS ARCHIVES 218, 218–27 (Ivy Schweitzer & Gordan Henry eds., 2019).

479. Luciano Floridi, *Group Privacy: A Defence and an Interpretation*, in GROUP PRIVACY: NEW CHALLENGES OF DATA TECHNOLOGIES 83, 85 (Linnet Taylor, Luciano Floridi & Bart van der Sloot eds., 2017); see also James G. Hodge, Jr. & Mark E. Harris, *International Genetics Research and Issues of Group Privacy*, 2001 J. BIOL. & BUS. (SPECIAL SUPPLEMENT) 1, 4–5 (suggesting methods for protecting group privacy in genetic group research).

Arguably, health privacy laws can offer protection to Native people within the public health surveillance system. Research has demonstrated skepticism in health data privacy in Indian country.⁴⁸⁰ Risks of re-identification even exist in datasets where personal identifiers are removed.⁴⁸¹ Disclosure of personal health care information can have serious impacts in employment, health care access, and personal relationships.⁴⁸² And, health privacy laws do not provide a mechanism to avoid being counted all together. HIPAA and the Privacy Rule, discussed above, permit the disclosure of protected health information to public health authorities and health care providers are obligated under state law to report health care data to these authorities. How often do health care records provide a “prefer not to disclose” category? Additionally, HIPAA’s privacy rule applies to covered entities when engaging in research activities; however, there are unclear distinctions between public health practice and research activities.⁴⁸³ Finally, most health-related data is not health care data and is outside the purview of health care privacy laws.⁴⁸⁴

Some Tribes have enacted research codes that can offer protection to their citizens’ health data privacy.⁴⁸⁵ The Navajo Nation’s Human Research Code

480. Riley Taitingfong et al., *A Systematic Literature Review of Native American and Pacific Islanders’ Perspectives on Health Data Privacy in the United States*, 27 J. AM. MED. INFORMATICS ASS’N 1987, 1995 (2020).

481. Brian Lee et al., *Protecting Privacy and Transforming COVID-19 Case Surveillance Datasets for Public Use*, 136 PUB. HEALTH REPS. 554, 560 (2021); Latanya Sweeney et al., *Re-Identification Risks in HIPAA Safe Harbor Data: A Study of Data from One Environmental Health Study*, TECH. SCI. 3 (Aug. 28, 2017), <https://techscience.org/a/2017082801> [<https://perma.cc/SYHF-WJ48>]; see also GEORGE T. DUNCAN, MARK ELLIOT & JUAN-JOSÉ SALAZAR-GONZÁLEZ, *STATISTICAL CONFIDENTIALITY: PRINCIPLES AND PRACTICE* 183–84, 193 (Stephen E. Fienberg & Wim J. van der Linden eds., 2011) (citing studies where re-identification risks are examined). For federal regulations regarding data privacy, see 45 C.F.R. § 164.514(a) (2024) (standard for deidentification); and Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82462, 82543 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160, 164).

482. See, e.g., *Humphers v. First Interstate Bank of Or.*, 696 P.2d 527, 533–34 (Or. 1985) (en banc); *Doe v. Medlantic Health Care Grp., Inc.*, 814 A.2d 939, 944, 948 (D.C. Cir. 2003). For a discussion on policy considerations regarding reidentification, see Daniel C. Barth-Jones, *Ethical Concerns, Conduct and Public Policy for Re-Identification and De-Identification Practice: Part 3 (Re-Identification Symposium)*, BILL HEALTH (Oct. 2, 2013), <https://blog.petrieflom.law.harvard.edu/2013/10/02/ethical-concerns-conduct-and-public-policy-for-re-identification-and-de-identification-practice-part-3-re-identification-symposium> [<https://perma.cc/HX6T-35VL>].

483. GOSTIN & WILEY, *supra* note 21, at 333–34.

484. See, e.g., Anya E.R. Prince, *I Tried to Keep My Pregnancy Secret*, ATLANTIC (Oct. 10, 2022), <https://www.theatlantic.com/ideas/archive/2022/10/can-you-hide-your-pregnancy-era-big-dat-a/671692> (on file with the *Iowa Law Review*); Andrea Peterson, *Privacy Advocates Warn of ‘Nightmare’ Scenario as Tech Giants Consider Fitness Tracking*, WASH. POST (May 19, 2014, 6:00 AM), <https://www.washingtonpost.com/news/the-switch/wp/2014/05/19/privacy-advocates-warn-of-nightmare-scenario-as-tech-giants-consider-fitness-tracking> (on file with the *Iowa Law Review*) (“[Health data is] the most valuable information in the digital age, bar none.”).

485. Stephanie Russo Carroll et al., *Using Indigenous Standards to Implement the CARE Principles: Setting Expectations Through Tribal Research Codes*, FRONTIERS IN GENETICS 7 (Mar. 20, 2022), <https://www.frontiersin.org/journals/genetics/articles/10.3389/fgene.2022.823309/full> [<https://perma.cc/KKX7-AM7C>].

applies to all human research activities on the Nation.⁴⁸⁶ It requires Tribal review and oversight on all research and publications.⁴⁸⁷ The Tohono O’odham Nation requires researchers to apply for permits from its Institutional Review Board before commencing activities. It also establishes a system for individuals to submit research complaints.⁴⁸⁸ These important requirements have not been adopted across all Tribes and are regularly ignored by researchers. And, the legal tests governing civil jurisdiction, in which surveillance, research, and privacy laws would fall, in Indian country are notoriously complicated. The general rule is that Tribal civil jurisdiction does not extend to non-members on non-member fee lands.⁴⁸⁹ Two exceptions exist to this rule. Tribes can extend civil jurisdiction over non-members within Indian country when there is a consensual relationship between the Tribe and the non-member or when the non-member “conduct threatens or has some direct effect on the political integrity, the economic security, or the health or welfare of the tribe.”⁴⁹⁰ Though the direct effects test reads broadly, federal courts tend to be hostile to extending Tribal jurisdiction to non-members and thus is a narrow exception.⁴⁹¹ Whether state surveillance laws apply within Indian country, is based on an even more complicated assessment of Tribal, state, and federal interests.⁴⁹² This *Bracker* balancing test provides an unpredictable analysis.⁴⁹³ This complicated application of civil jurisdiction means that there is pervasive uncertainty in regard to which and whether health privacy laws apply.

Despite the risks of being counted, there are repercussions for choosing not to be. The 2020 census questionnaire does not offer an option to opt out

486. NAVAJO NATION CODE ANN. tit. 13, § 3252 (2010).

487. *Id.* § 3260.

488. *Institutional Review Board*, TOHONO O’ODHAM NATION, <http://www.tonation-nsn.gov/to-n-irb> [<https://perma.cc/PCW4-4C8M>].

489. *Montana v. United States*, 450 U.S. 544, 559–60 n.9 (1981).

490. *Id.* at 566.

491. COHEN’S HANDBOOK (2024), *supra* note 311, § 8.06[3][b]; *Brendale v. Confederated Tribes & Bands of the Yakima Indian Nation*, 492 U.S. 408, 422–25 (1989); *Nevada v. Hicks*, 533 U.S. 353, 360–62 (2001); *Strate v. A-1 Contractors*, 520 U.S. 438, 445–60 (1997). But see *United States v. Cooley*, 593 U.S. 345, 347–51 (2021), for a recent decision that allows for Tribal jurisdiction under the direct effects test.

492. *White Mountain Apache Tribe v. Bracker*, 448 U.S. 136, 144–45 (1980).

493. Geoffrey D. Strommer, Starla K. Roels & Caroline P. Mayhew, *Tribal Sovereign Authority and Self-Regulation of Health Care Services: The Legal Framework and the Swinomish Tribe’s Dental Health Program*, 21 J. HEALTH CARE L. & POL’Y 115, 132–33 (2018) (“Due in part to its fact-specific nature, the outcome of the preemption test can be unpredictable.”); see also *Washington v. Confederated Tribes of the Colville Indian Rsrv.*, 447 U.S. 134, 160–61 (1980) (finding no preemption); *New Mexico v. Mescalero Apache Tribe*, 462 U.S. 324, 333–36 (1983) (discussing *Bracker*); *Atkinson Trading Co. v. Shirley*, 532 U.S. 645, 652–55 (2001) (noting the competing interests among the federal government, Tribes, and state government regarding the Navajo Nation’s imposition of a hotel occupancy tax on non-members).

or not disclose information.⁴⁹⁴ In fact, there are penalties for trying to avoid being counted in the census. Adults, for example, are required to fill out the census under federal law.⁴⁹⁵ Those that do not are subject to a criminal fine.⁴⁹⁶ Federal agencies regularly condition funding under grants and cooperative agreements on comprehensive reporting requirements.

Issues regarding consent appear frequently in issues related to research and data mismanagement in Indian country. Even the Indian Citizenship Act, valuable in its granting of voting rights, was passed during the assimilation era, a time of Indigenous erasure. Unsurprisingly, it was passed without individual consent.⁴⁹⁷

This Subsection describes the need for public health surveillance systems to protect individuals, the next Subsection describes the concurrent need for these systems to protect Tribal sovereignty. Here too, issues of consent are highly relevant.

C. TRIBAL DATA SOVEREIGNTY

Public health surveillance implicates the rights and jurisdiction of Tribal governments both in the form of data access as well as ownership and use of data. This Subsection considers how lack of access to data undermines Tribal sovereignty and how the public health surveillance systems often do not center Tribal sovereignty in the ownership and use of data. It also describes how existing jurisdictional frameworks fail to ensure Tribal governance of public health data.

Indigenous data includes “any facts, knowledge, or information about a Native nation and its [T]ribal citizens, lands, resources, cultures, and communities. Information ranging from demographic profiles, to educational attainment rates, maps of sacred lands, songs, and social media activities.”⁴⁹⁸ Indigenous data sovereignty refers to Tribal rights “to govern the collection, ownership, and application of their own data.”⁴⁹⁹

494. See U.S. DEP’T OF COM., OMB No. 0607-1006, 2020 CENSUS INFORMATIONAL QUESTIONNAIRE 1 (2020), https://www2.census.gov/programs-surveys/decennial/2020/technical-documentation/questionnaires-and-instructions/questionnaires/2020-informational-questionnaire-english_DI-Q1.pdf [<https://perma.cc/HCV5-7VU6>].

495. 13 U.S.C. § 221 (a).

496. *Id.*

497. See DUNBAR-ORTIZ, *supra* note 29, at 169 (“[T]he US government imposed unsolicited citizenship on American Indians with the Indian Citizenship Act of 1924, gesturing toward assimilation and dissolving the nations.”).

498. Stephanie Russo Carroll, Desi Rodriguez-Lonebear & Andrew Martinez, *Indigenous Data Governance: Strategies from United States Native Nations*, DATA SCI. J. 2 (July 8, 2019) (quoting STEPHANIE CARROLL RAINIE, DESI RODRIGUEZ-LONEBEAR & ANDREW MARTINEZ, NATIVE NATIONS INST., POLICY BRIEF: DATA GOVERNANCE FOR NATIVE NATION REBUILDING 1 (2017), https://climas.arizona.edu/sites/climas.arizona.edu/files/Policy_Brief_Data_Governance_for_Native_Nation_Rebuilding_Version_2.pdf [<https://perma.cc/9H7A-XFPY>]), <https://datascience.codata.org/articles/10.5334/dsj-2019-031> [<https://perma.cc/2E4T-2PDV>].

499. *Id.* at 3 (quoting RAINIE ET AL., *supra* note 498, at 1).

Tribes are regularly denied access to data.⁵⁰⁰ Although Tribes are public health authorities under HIPAA, neither HIPAA nor the Privacy Rule obligate covered entities to disclose PHI to public health authorities. Federal law only permits disclosure. State or Tribal law may provide additional obligations.⁵⁰¹ Even when federal agencies like the CDC attempt to improve access to data, challenges remain.⁵⁰² While federal Indian law would suggest that the federal government is obligated to provide data with Tribes, only TECs are guaranteed HHS data by statute.⁵⁰³

Federal law also requires states to report Indigenous data.⁵⁰⁴ Congress authorized states to apply for SAMHSA grants to engage in programming to reduce Indian youth suicide.⁵⁰⁵ A condition on the receipt of grant funds is to include data on regarding the Indian population to be included in state data system.⁵⁰⁶

As discussed above, under sampling and racial misclassification are common limitations in surveillance in Indigenous communities. Even when data is available, there are questions as to the utility of this data. Professors Walter and Andersen describe “that the quantitative methodologies that guide the collection, analysis, and interpretation of data about Indigenous peoples both reflect and constitute, in ways largely invisible to their producers and users, the dominant cultural framework of the nation-state within which . . . statistics . . . operate.”⁵⁰⁷ They argue that these statistics become the primary vehicle in which non-Indigenous communities use to form opinion of Indigenous communities; this is done without any critical analysis on the how the statistics were collected, analyzed, and interpreted.⁵⁰⁸ State and federal public access laws also facilitate broad access to all data,⁵⁰⁹ including Indigenous data.

500. See, e.g., Vickie M. Mays, Abigail Echo-Hawk, Susan D. Cochran & Randall Akee, *Data Equity in American Indian/Alaska Native Populations: Respecting Sovereign Nations' Right to Meaningful and Usable COVID-19 Data*, 112 AM. J. PUB. HEALTH 1416, 1418–19 (2022) (explaining that many Tribal epidemiology centers experienced problems accessing COVID-19 data).

501. See, e.g., 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) (“Tribes are thus, by virtue of their inherent sovereignty authority, in a position of determining what they want their privacy policies to provide, so long as that authority is not otherwise constrained.”).

502. *Tribal Public Health Data*, CDC (May 17, 2024), <https://www.cdc.gov/tribal-health/data-research/index.html> [<https://perma.cc/8SKB-GYXS>].

503. Aila Hoss, *Toward Tribal Health Sovereignty*, 2022 WIS. L. REV. 413, 435–37.

504. See, e.g., 25 U.S.C. § 1667c(a)(4)(B) (requiring states to disclose data relating to the Indian population of the state in order to receive grants).

505. *Id.*

506. *Id.* § 1667c(a)(4)(B)(ii)(II).

507. WALTER & ANDERSEN, *supra* note 471, at 9.

508. *Id.*

509. HOSS ET AL., *supra* note 89, at 38.

Misinterpretation of results can also be an issue.⁵¹⁰ The stakes can be particularly high for Tribes because data is weaponized to undermine Tribal governance. Given the anti-Tribe climate within many states and federal courts, adverse data can be used to challenge Tribal inherent authorities to exercise jurisdiction.

V. CONSIDERATIONS FOR PUBLIC HEALTH SURVEILLANCE REFORM

The volume and breadth of the issues raised in the preceding Part of this Article demonstrates the complexity in comprehensive public health surveillance system reform to support Indigenous health. This Part offers some potential, though incremental, paths to reform. To start, I categorize potential reforms into four broad categories: (1) definitional reform; (2) surveillance methodology reform; (3) supporting Indigenous health privacy; and (4) supporting Tribal data sovereignty.

In the context of definitional reform, the volume and inconsistency of federal Indian definitions is untenable. A more limited set of options would offer more consistency and stability in federal Indian law. This would require congressional action. The need for the collection of Tribal membership data is urgent, requiring the development of new systems to capture this information so long as it is in accord with Tribal sovereignty. Regarding surveillance methodology, epidemiologists, statisticians, and other experts have identified mechanisms to improve data quality in both the collection and interpretation of data.⁵¹¹ They need to be understood and adopted with the support of Indigenous researchers. In areas of high instances of racial misclassification, life death certifications, coroners and medical examiners need to rely on more than perceived identification. Through state law and policy, they can be required to do so.

Indigenous people must have access to more rigorous health privacy protections and methods to ensure that their data is used with their informed consent. A variety of frameworks have been developed to better support individual data privacy across multiple settings⁵¹² that could be adapted to

510. Farah Kader et al., *Disaggregating Race/Ethnicity Data Categories: Criticisms, Dangers, and Opposing Viewpoints*, HEALTH AFFS.: FOREFRONT (Mar. 25, 2022), <https://www.healthaffairs.org/doi/10.1377/forefront.20220323.555023> [<https://perma.cc/Z9L3-KTYN>].

511. See, e.g., U.S. GOV'T ACCOUNTABILITY OFF., *supra* note 13, at 21–23; WALTER & ANDERSEN, *supra* note 471, at 77–80. See generally Melissa L. Walls, Nancy Rumbaugh Whitesell, Allison Barlow & Michelle Sarche, *Research with American Indian and Alaska Native Populations: Measurement Matters*, 18 J. ETHNICITY SUBSTANCE ABUSE 129 (2019) (providing a framework for data analysis in Indigenous communities).

512. See generally *Principles on Personal Data Protection and Privacy*, UNITED NATIONS SYS. CHIEF EXEC. BD. FOR COORDINATION, <https://unsceb.org/principles-personal-data-protection-and-privacy-listing> [<https://perma.cc/LQ7X-S49G>] (establishing principles for the processing of personal data by, or on behalf of, the United Nations System Organizations in carrying out their mandated activities); *General Data Protection Regulation (GDPR)*, GDPR.EU, <https://gdpr.eu/tag/gdpr> [<https://perma.cc/BB4K-4WPQ>] (imposing obligations onto organizations that target or collect data related to people in the European Union).

ensure more comprehensive protection for Indigenous people. Tribes must also be afforded opportunities for both consultation and consent in the collection, use, and ownership of Indigenous data. As has been argued previously, Tribal consultation is pivotal to ensuring effective health policy,⁵¹³ including data surveillance policies. There must be multiple systems in place to account for the fact that each Tribe may have different perspectives on data sovereignty. Indigenous communities in some places abroad have seen more progress in terms of legal protections.⁵¹⁴ Additionally, public health surveillance systems need to appropriately consider jurisdictional conflicts when assessing the impact of surveillance on Tribal sovereignty. When do federal health privacy laws apply to Tribes? When a state and Tribe's surveillance or health privacy laws conflict, which laws control? These issues are highly fact-specific and dependent on the complex jurisdictional framework under federal Indian law. These are urgent issues, largely ignored in day-to-day public health practice.

CONCLUSION

Indigenous data is subject to a variety of dichotomies. It is both overanalyzed in predatory research that considers Indigenous communities problematic and ignored in the name of small sample sizes. Being Native is a racial classification in surveillance schemes but a political one under legal schemes. Some Indigenous people are considered too white or too black or too inauthentic and are thus omitted from important surveillance systems. The COVID-19 pandemic has centered these conflicts in public health discourse. It has demonstrated that Indigenous data quality, Indigenous data erasure, and Tribal access to health data continues to be a pervasive problem in American public health practice. This Article demonstrates how law and policy perpetuates these problems. Yet, it also acknowledges that there is no clear path to rectify these issues that reflect the diversity of Indigenous communities under existing law. What might a path forward look like? To answer this question, this Author proffers four categories in which to conceptualize the tensions ingrained within public health and federal Indian law that impact surveillance.

First, in the context of definitional reform, racial-ethnic classifications in public health surveillance systems must be reformed to capture more robust information regarding Indigenous communities, such as Tribal membership information. Second, surveillance methodologies must adapt to eliminate data suppression and racial misclassification of health data involving Indigenous people. Third, individuals, when interfacing with surveillance systems, must be afforded more opportunities to protect their data and its usage. Finally,

513. See Aila Hoss, *Securing Tribal Consultation to Support Tribal Health Sovereignty*, 14 NE. U. L. REV. 155, 160 (2022).

514. See generally INDIGENOUS DATA SOVEREIGNTY AND POLICY (Maggie Walter, Tahu Kukutai, Stephanie Russo Carroll & Desi Rodriguez-Lonebear eds., 2021) (highlighting some international victories in Indigenous data sovereignty to demonstrate the feasibility of implementing such protections).

Tribes must be given access to public health datasets and authority in determining how datasets implicating their communities should be used. Finally, while this Article makes suggestions for some areas for reform, advancements in public health surveillance must be made in lockstep with Tribally and Indigenous driven systems that protect sovereignty.