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The Imperial Logic of American Bioethics

Holding Science and History to Account

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In 1974, the United States passed the National Research Act, which set the rules for the treatment of "human subjects" of research. The law pertained to both biomedical and social science research and it remains in place today, largely unchanged over fifty years, despite revisions in 2018 that nonetheless retained the basic structure and assumptions of the law. Those assumptions included a moral ontology organized around civic individualism and its safeguarding, as opposed to anticolonialism and its dismantling. In 1974, the immediate prompt for the law was the public revelation of the Tuskegee Syphilis Study: government scientists had been withholding a viable treatment for syphilis (penicillin) from people enrolled in the studies, who were low-income Black men in rural Alabama. The US government had been funding the Study for four decades; and scientists had been writing and reading about it in medical journals for just as long. Although the public exposure of medical suffering and abuse at the hands of the US government was the immediate prompt for the law's passage, the content of the rules – how procedural, government bioethics would work according to the law – had been two decades in the making within the National Institutes of Health.[1]

As a result, since 1970, a specific field known as modern American bioethics has dominated secular, English-language spaces of political power – the language of ethics as it is spoken in US domestic and foreign policy, international "medical diplomacy," global market regulation, and transnational corporations. It is the lingua franca of Euro-American science imperialism. It speaks louder and talks over the more context-informed, justice-based practices of science, making it easy to forget that this bullish and coercive variant of bioethics is a historical fluke.[2]

[1] Laura Stark, *Behind Closed Doors: IRBs and the Making of Ethical Research* (Chicago: University of Chicago Press, 2012).

[2] Jenny Reardon et al., "Science & Justice: The Trouble and the Promise," *Catalyst: Feminism, Theory, Technoscience* 1, no. 1 (September 8, 2015): 1–49; Jenny Reardon, "On the Emergence of Science and Justice," *Science, Technology, & Human Values* 38, no. 2 (2013): 176–200; Renee C. Fox and Judith P. Swazey, *Observing Bioethics* (New York:

Shortly after the law's passage in 1974, Carolyn Matthews, a white-settler free-spirit from Portland, Oregon, settled in her hometown and went back to college. In 1977, when she was in her late thirties and recently settled in Portland, she enrolled in a school that was designed for working adults. She could get course credit for her prior work experience, so she typed up her two decades of job experiences. She had worked a good deal in healthcare settings and been both a "human subject" of government medical research and a researcher of human subjects.

I met Carolyn after I put a description of my historical research in the Antioch College alumni magazine, and Carolyn got in touch with me. I was researching a program at the US National Institutes of Health (NIH), through which NIH "procured" healthy human civilians for medical experiments during the decades after World War II.[3] Across several conversations between 2016 and 2018, Carolyn relayed her life story. We talked by phone twice for official oral histories, we emailed updates about this project and our personal lives, and I visited her at her house in Portland, Oregon. Carolyn had been willing to tell me the story of her time at NIH's Clinical Center. But her NIH story extended into a longer, politically saturated narrative about bioethics – one that toppled the bookends of her NIH story and was impossible to ignore.

Carolyn shared with me the paper she had written in 1977 for course credit describing her job as a healthy human subject at the NIH Clinical Center (as well as her volunteer work as a lab technician there); she summarized the skills – and life experience – she gained as an x-ray technician in Arizona taking films of Akimel O'odham people; she listed her responsibilities as a research technician in Boston. It was her story – about her working life.

But woven into this 1977 story about her work life was another story – about her ethical awakening. This woven story compared her experiences as a human subject of NIH experiments to the experiences of the low-income hospital staff and patients whose organs she scanned in Boston after they received injections of radioactive tracers. The Akimel O'odham people, however, were absent. Whereas

Oxford University Press, 2008); Adriana Petryna, *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects* (Princeton: Princeton University Press, 2009).

[3] I am writing a book on the first healthy human subjects of NIH medical experiments from the time the agency's clinical research center opened, in 1954, until the death of the first "Normal" in 1980. The history of people's experiences and NIH's legal strategies to create what it called the Normal Volunteer Patient Program show that white bodies came to stand in for the "normal" body in postwar medicine – with ongoing effects. Carolyn was one of more than one hundred people with whom I created oral histories and archived photos, letters, and memorabilia from their time as "normal control" research subjects at the US National Institutes of Health. The collections are free and publicly accessible through the Vernacular Archive of Normal Volunteers. Laura Stark, *The Normals: A People's History* (Under Contract: University of Chicago Press), https://dataverse.harvard.edu/dataverse/vanv.

she inserted the Akimel O'odham people into the story of her working life, they were illegible as part of her bioethical understanding.[4]

This chapter tells Carolyn's story in two registers. It sets Carolyn's work experience prior to 1974 alongside her moral recounting of those experiences in her college portfolio – which she composed after the crystalizing moment of the Tuskegee revelations, which set the moral vocabulary and framework for research on people in terms of modern American bioethics. The point is not that Carolyn had a lapse in moral judgment in her practices or recall of her experiences. The premise of this chapter is that Carolyn perfectly articulated the logic of American modern bioethics. The insight of Carolyn's story is that the field of American bioethics operates with settler state presumptions. The question the chapter explores is how, specifically, the broad imperial logic of bioethics works – through what concepts, practices, and imperceptions.

The discourse of modern American bioethics is a geopolitical concern, and relationships across the Americas provide a special vantage on the field. Because of the coterminous geography, the history of science and ethics across the Americas points attention to the production of boundaries – to national borders, racial categories, citizenship status, and moral designations together through science.[5] For example, the same US government scientist who led the Tuskegee Syphilis Study from 1932 to 1972 also conducted related experiments in Guatemalan prisons during the 1940s, in which the research team intentionally infected incarcerated people with syphilis.[6] The production and enforcement of racial hierarchies within and between the US and Guatemala facilitated the research. In addition the research was predicated on logics of spatial containment and moral worth that justifies systems of incarceration and colonialism – within and between US, Latin American, and Native spaces (as also seen in Chapters 5 and 6). The study of science ethics across the

[4] There is large, excellent literature on the methods of oral history. As Spiegel explained in 2014, it nonetheless remains to be theorized "the materiality and reality of 'voices' from the past, without assuming the necessary truth of what they convey, at least in terms of the factuality of its content. In the end, however, what is at stake in not the epistemological question of 'truth' but an ethical response to the catastrophes of the last century." Gabrielle Spiegel, "The Future of the Past: History, Memory, and the Ethical Imperatives of Writing History," *Journal of the Philosophy of History* 8 (2014): 149–179.

[5] Megan Raby, "Science, the United States, and Latin America," in *The Routledge Handbook of Science and Empire*, ed. Andrew Goss (New York: Routledge, 2021), 264–274; Sandra Harding, "Latin American Decolonial Social Studies of Scientific Knowledge," *Science, Technology, & Human Values* 41, no. 6 (2016): 1063–1087; Eric V. Meeks, "Race and Identity across American Borders," *Latin American Research Review* 53, no. 3 (2018): 679–688; Eric V. Meeks, *Border Citizens: The Making of Indians, Mexicans, and Anglos in Arizona* (Austin: University of Texas Press, 2020).

[6] Susan M. Reverby, "'Normal Exposure' and Inoculation Syphilis: A PHS 'Tuskegee' Doctor in Guatemala, 1946–1948," *Journal of Policy History* 23, no. 1 (2011): 6–28; "*Ethically Impossible*": *STD Research in Guatemala from 1946 to 1948*.

Americas highlights how boundaries are strategically fabricated, not only *through* scientific efforts but also *for* science.

My intention as a white settler historian is to invoke the experiences of a fellow white settler knowledge maker – namely, Carolyn – in an imperfect effort to hold settler science (read: myself) to account.[7] My hope is to approximate Kim TallBear's technique of "studying up." While TallBear's standpoint, as a Sisseton Wahpeton Oyate scholar, in relation to white settler science is different from my own, the technique offers a way to study the (re) production of settler colonial structures within science and also to avoid co-opting and capitalizing on those injustices.[8]

The chapter follows Carolyn across three sites and over three decades. In 1962, Carolyn served as a healthy human subject at the NIH Clinical Center in Bethesda, Maryland, a time and place where Native people had a lively presence (second section). When she was not on study, Carolyn worked enthusiastically but without pay as a lab technician in the hospital. This volunteer work resulted in an offer to work for pay on an NIH research team collecting samples from a Native American tribe in Sacaton, Arizona, which she readily accepted (third section). After Sacaton, Carolyn worked as a scanning technician in Boston, Massachusetts (fourth section), before she returned after many years to Portland, Oregon, where she reflected on the ethical implications of her experiences in medicine (fifth section). The point of a critique of bioethics through the Americas is to strengthen existing alliances for justice-based science and to inform practices – in science, in history, and in transformative bioethics.

Bethesda, 1962: Carolyn as Research Subject

Carolyn enrolled in Antioch College in 1962 and arrived at the NIH Clinical Center three months later. The Clinical Center was the US government's main research hospital, located on what was called at the time NIH's "reservation" in Bethesda, Maryland. As part of its Congressional mandate, the Clinical Center could *not* admit people for treatment alone; everyone admitted to the hospital had to be a research subject (often as part of a treatment). For its part, Antioch

[7] Methodologically, scholars have improvised several anticolonial techniques for writing histories that highlight, then subvert, the structures of oppression built into many traditional archives, as well as the standards of professional history. See Marisa J. Fuentes, *Dispossessed Lives: Enslaved Women, Violence, and the Archive* (Philadelphia: University of Pennsylvania Press, 2016); Saidiya Hartman, *Wayward Lives, Beautiful Experiments: Intimate Histories of Social Upheaval* (New York: W. W. Norton, 2019); Kim TallBear, *Native American DNA: Tribal Belonging and the False Promise of Genetic Science* (Minneapolis: University of Minnesota Press, 2013).

[8] TallBear, *Native American DNA*; Eve Tuck, "Suspending Damage: A Letter to Communities," *Harvard Educational Review* 79, no. 3 (2009): 409–428.

College was one among a set of small colleges organized around a pragmatist pedagogy that prioritized "experiential learning." Every other quarter, for four years, students moved away from the tiny silvan town of Yellow Springs, Ohio, and took jobs anywhere they could imagine.[9] "I was very restless, even too restless for Antioch," Carolyn told me. "I just wanted to be on my own."

In the early 1960s, Antioch had a reputation for radical politics and drew students with a bent toward social activism. But Carolyn knew none of this when she was considering colleges. The hegemonic activism and what college histories called "militant intellectualism" was imperceptible from her high school in Portland, Oregon.[10] "It was a shock, and it was a good thing that I did not drop out right away."

"I was in a very conservative family, in a conservative town," Carolyn told me. Growing up, she was an only child and in 1951 her father's carpentry business went bankrupt. Her parents packed up their pickup truck with some clothes, the dog, their camping gear, and Carolyn. They let the bank have the house and drove east to the Rocky Mountains, stopping for a few weeks at a time for her father to do carpentry jobs and for Carolyn to go to school (Figure 7.1). When the weather turned cold, they crossed the Colorado border into Arizona and set up house for a few months in Phoenix. Carolyn's father worked, she went to primary school, and on weekends the family visited the national parks of the Sonora Desert (Figure 7.2).

For tribal members, the commodification of cultural authenticity offered one way of earning money out of the brutality of dispossession – turning the white American popular mythology into tourism dollars in the capitalist colonial structure that had long oppressed Indigenous groups. There was a way to look "Indian" to the white consumer eye that, in the postwar decades, reenacted a nineteenth-century fiction.[11]

While Carolyn and her parents were in Arizona, the latest US federal policy change related to Native Americans was emerging. In 1955, the Public Health Service, within the Department of Health, Education and Welfare (today's Health and Human Services), was handed responsibility for the Indian Health Service, formerly called the Division of Indian Health and located within the Department of the Interior's Bureau of Indian Affairs. The new Indian Health

[9] Burton R. Clark, *The Distinctive College: Antioch, Reed & Swarthmore* (Chicago: Aldine PubCo, 1970); Algo D. Henderson, *Antioch College: Its Design for Liberal Education* (New York/London: Harper & Brothers, 1946); Cary Nelson, "Antioch: An Education in the Real World," *The Chronicle of Higher Education* 53, no. 43 (June 29, 2007): B.5.

[10] Clark, *The Distinctive College*, 62.

[11] Philip Joseph Deloria, *Playing Indian*, Yale Historical Publications (New Haven, CT: Yale University Press, 1998); Philip Joseph Deloria, *Indians in Unexpected Places* (Lawrence: University Press of Kansas, 2004). Native people were also "supposed to" be poor under the white settler gaze. Alexandra Harmon, *Rich Indians: Native People and the Problem of Wealth in American History* (Chapel Hill: The University of North Carolina Press, 2010).

Figure 7.1 Carolyn Matthews, around age eight, and her father, circa 1951. Her dog Rip van Winkel (Rippy) is also in the photo. Roger Burmont Matthews stopped for food during a road trip to find work. The photo description on the back reads, "Chow time! On road/ between Boise Idaho & Salt Lake City." Photographer credit: Melba Cambridge Matthews. *Source:* Matthews Collection, VANV.

Service was a response to decades of federal cuts to Native clinics and reliance on private contractors, as well as state and local governments, to attend as they saw fit to the health needs of Native communities.[12] In Arizona as in other places, the poverty that caused poor health was not predetermined, but an

[12] Abraham B. Bergman et al., "A Political History of the Indian Health Service," *The Milbank Quarterly* 77, no. 4 (1999): 571–604; Betty Pfefferbaum et al., "Learning How to Heal: An Analysis of the History, Policy, and Framework of Indian Health Care," *American Indian Law Review* 20 (1995): 365. When Carolyn was in Arizona, a Cornell field hospital on the Navajo reservation was studying a new therapy for tuberculosis, while also trying to treat the disease. The study set up a wide net of surveillance in the name of public health. David Jones, "The Health Care Experiments at Many Farms: The Navajo, Tuberculosis, and the Limits of Modern Medicine, 1952–1962," *Bulletin of the History of Medicine* 76, no. 4 (2002): 749–790; see also Bergman, 583. Settler scientists had considered tuberculosis on federal reservations a key health problem since the late nineteenth century, attributing its prevalence to "race" rather than to the US state's past and continued discrimination. Christian W. McMillen, *Discovering Tuberculosis: A Global History, 1900 to the Present* (New Haven, CT: Yale University Press, 2015).

Figure 7.2 Carolyn Matthews in moccasins, Rippy, and her mother, circa 1951. Photographer: Roger Burmont Matthews. Carolyn's father wrote a description on the back around 1951: "Grain Grinder. Tonto National Monument." The Tonto National Park is in the Upper Sonora Desert, near the ancestral home of Akimel O'odham people. *Source:* Matthews collection VANV.

expression of political structures working against many Native people's desires.[13]

After Carolyn's stay in Phoenix, the family drove back to Portland and built a new house. When Carolyn arrived at Antioch College at eighteen years old, she was a curly-haired aspiring anthropology major with braces on her teeth. One of Carolyn's first experiences as an Antioch student was working a co-op term at NIH. At the time, NIH administrators had "procurement contracts" with several colleges, a few labor unions, and the national organizations of two Anabaptist churches, to supply "normal control" human subjects for medical experiments.[14] In addition, the federal Bureau of Prisons flew or bussed twenty-five men to the Clinical Center every five weeks for most of the 1960s in an arrangement akin to convict labor leasing.[15]

She got free room and board, and a small "stipend" from NIH funneled through the college. When scientists were not using students in medical experiments they were allowed – encouraged – to work unpaid in "career placements" designed to keep the Normals busy, away from mischief or rumination, and advertised by NIH as a way to boost their resumes through (unwaged) work experience at a prestigious institution. Importantly, she also got course credit from Antioch and a chance to see Washington, DC in her downtime. To get these resources, however, she also had to give.

She arrived at the Clinical Center in early October and was assigned a bed in the ward on 8 West, having been allotted to NIH's Institute of Arthritis and Metabolic Diseases. Each of the institutes that comprised NIH was given space at the Clinical Center for their "bedside" research – their studies on whole people. Based on the studies they had planned, the scientists forecasted their need for Normals and every three months sent their order to the administrator for NIH's "Normal Volunteer Patient Program," the hinge between Antioch and NIH. Carolyn's body was projected into a study on insulin clearance. She started on Tuesday morning.

Her room had a private bathroom, which she shared only with her roommate, a German Jewish grandmother from Brooklyn with thyroid disease, whom Carolyn adored. However, for the study, the nurses needed her to urinate, not inside the private bathroom, but in the open hospital room into a commode while they waited – and to do it every fifteen minutes. When

[13] Angela Garcia, *The Pastoral Clinic: Addiction and Dispossession along the Rio Grande* (Berkeley: University of California Press, 2010); Tuck, "Suspending Damage."

[14] Laura Stark, "Contracting Health: Procurement Contracts, Total Institutions, and Problem of Virtuous Suffering in Post-War Human Experiment," *Social History of Medicine* 31, no. 4 (2018): 818–846.

[15] Laura Stark and Nancy D. Campbell, "Stowaways in the History of Science: The Case of Simian Virus 40 and Clinical Research on Federal Prisoners at the US National Institutes of Health, 1960," *Studies in History and Philosophy of Biological and Biomedical Sciences* 48, Part B (December 2014): 218–230, https://doi.org/10.1016/j.shpsc.2014.07.011.

Carolyn and I met in 2016, I helped her get access to her NIH study record and she allowed me to see a copy, too. The study record includes a log of study procedures (researchers), social surveillance notes (nurses), and legal forms (administrators) for the autumn of 1962. It includes a note from Nurse Cushing the same day Carolyn started the study: "Unable to void @ prescribed times so test running irregularly."[16]

Her record does not include a consent form.[17] "Regarding informed consent: It's hard to tease out what I felt at the time, in 1962, from the perspective of 54 years later." Carolyn wrote me an email in the summer of 2016. "Although the NIH docs knew I had an interest in biology, I actually did not have much knowledge about it yet." She had two months of college course work at that point and told the doctor who admitted her that she was an anthropology major. "The docs may have credited me with a higher level of understanding than I deserved, and I wasn't assertive enough to say 'I do not understand'," Carolyn said. "I do know that I was very trusting of the whole thing, and it never occurred to me to question anything." She shared a sensibility with many white Americans of the early 1960s. The Cuban Missile Crisis took shape the week after she arrived, reinforcing public support for the sciences of national defense. A month later came the death of Eleanor Roosevelt, champion of social safety net programs as former First Lady and of international human rights as Chair of the United Nations Commission on Human Rights after World War II. Trust in authority – in government, in science, and in medicine – among middle-class white Americans would only unravel later in the 1960s. At the same time, sovereignty claims in the United States were being made ferociously by the American Indian Movement.[18]

While Carolyn was at the Clinical Center as a "normal" subject, there were also children from Native communities living in the research hospital as sick patients to study and treat. Irene was a thirteen-year-old Navajo girl who, in the summer of 1964, got a new roommate at the Clinical Center on the same floor where Carolyn had lived, the 8 West for insulin and diabetes. Irene's new roommate was a nineteen-year-old Normal from an Anabaptist college in Kansas who described her time with Irene in daily letters home to her boyfriend. "I had enjoyed being alone so much," the young woman wrote after Irene temporarily left, "but am glad she's back now since we still have not gotten the TV back (and I hope we never will)." Irene had a tracheotomy; she was shy and spoke little; the location of her family is unknown. Federal concern specifically with the health of children from Native communities is

[16] Carolyn Matthews Medical Record, "Nursing Notes," 10 AM, October 9, 1962.
[17] Carolyn Matthews Medical Record 1962. On the history of consent practices at the Clinical Center, see Stark, *Behind Closed Doors*.
[18] Elizabeth Rich, "'Remember Wounded Knee': AIM's Use of Metonymy in 21st Century Protest," *College Literature* 31, no. 3 (2004): 70–91.

a legacy of boarding school programs that removed Native children from their homes, cut them off from their families, and socialized them into white American habits, priorities, and networks.[19] Tuberculosis was a particular concern on reservations and in the total institutions of boarding schools especially. Irene's presence at the Clinical Center was likely an effect of the Bureau of Indian Affair's failures and Congress's reassignment of responsibility for Native health to the Public Health Service, which also subsumes NIH.

They developed a sweet intimacy. "Irene + I have been having a very good time together lately," the young woman wrote. "She acts so different around some people but not like a vegetable with me." The young woman was set to return to her Anabaptist college at the start of September. "She said she will miss me when I leave. I just hope I've been a good influence + have helped her see more in life than the TV set."[20] The following year, Irene was still living on the eighth floor of the Clinical Center, the young woman's boyfriend now living at the Clinical Center serving as a Normal himself. "I suddenly remembered you wanted me to look up Irene," he wrote to her the following year, "but she wasn't in." Irene was, however, still living on the same ward on 8 West.[21]

Another "normal control" Anabaptist young woman wrote to her grandparents about Native children at the Clinical Center. The young woman played with the children as part of her unpaid work assignment in the Clinical Center's recreation department, where she went during downtime from experiments. "[O]ne of my favorites is Alice [redacted], a 5 year old Am. Indian," she wrote to her grandparents, "I might have mentioned her before." Alice also lived on the endocrinology unit, 8 West. "Alice has a very rare condition, at least for a girl. Her blood does not clot," the Normal wrote. "I'm not positive, but I think she has to have transfusions something like every five days."[22] Like Irene, the nature of Alice's illness, the location of her family, or the condition of her assent are unclear.

The idea that it made sense to talk about "Am. Indian" as a group was a product of the US settler state. Until the American Revolution, settlers considered Indigenous people to be white, which was simultaneously a political and a biological statement. By the turn of the nineteenth century, however, white elites lumped various Native groups into the racial category of "red." When they were white, Native people were imagined as physically and mentally like white settlers, if socially different, and, therefore, capable of reform and worthy of assimilation. The contrast was with people whose families were

[19] David Wallace Adams, *Education for Extinction: American Indians and the Boarding School Experience, 1875–1928* (Lawrence: University Press of Kansas, 1995).

[20] Page 4 (MS page 10). August 1964 letter set, Reimer 2019, VANV.

[21] Keith Reimer to Susan (nee Stuckey) Reimer, June 1965 (page 19 of 89) and August 17, 1965 (page 80 of 89), Reimer letter set, VANV.

[22] Marnette (Bette) Hatchett to her grandparents. Marnette Hatchett Collection, VANV.

African, nearly all enslaved at the time. Ruling elites and citizens of a slave nation could better justify the institution by maintaining the strategic fantasy that any perceived physical differences between settlers (largely European descent) and the people they enslaved (largely African descent) indicated a physical incapability of adopting dispositions on which political rights rested.[23] When Native people became "red," they too were reimagined as biologically different from white settlers, politically intractable, and incapable of governance.[24] This recategorization justified explicit federal policies of termination starting in the early nineteenth century – including deportation, expulsion, and extermination.[25]

The political attitudes of the white settler state overlay a material need for territory – fields, mountains, water – and the resources they contained, as well as exigency of smooth travel that possession allowed. Thus, Native dispossession and scientific racism by the United States is always interdependent with Black subjugation.[26] After the Civil War, scientific racism, under the banner of social Darwinism, elaborated stage theories of society, including Lewis Henry Morgan's three-stage insult of savagery, barbarism, and civilization.[27] These stage theories were teleological, associating practices and people with a period in evolutionary time. The racial category of "red" was a political tool that built in the assumption of difference in social evolution and distance in

[23] Rana A. Hogarth, *Medicalizing Blackness: Making Racial Difference in the Atlantic World, 1780–1840* (Chapel Hill: The University of North Carolina Press, 2017).

[24] Alden T. Vaughan, "From White Man to Redskin: Changing Anglo-American Perceptions of the American Indian," *The American Historical Review* 87, no. 4 (1982): 917–953; Nancy Shoemaker, *A Strange Likeness: Becoming Red and White in Eighteenth-Century North America* (Oxford/New York: Oxford University Press, 2004). In his otherwise compelling, important, and no-doubt landmark study, Vaughan attributes the shift in settlers' visions of race to their ideas and attitudes, which he describes as "logical" extensions of settlers' experiences with Native groups. Vaughan admits the reasons for the shift in settlers' racial vision are obscure to him, and he is silent on material explanations, not least, settlers' forced relocation of Native people and seizure of Native lands, which the fabricated idea of racial difference helped justify.

[25] Claudio Saunt, *Unworthy Republic: The Dispossession of Native Americans and the Road to Indian Territory* (New York: W. W. Norton, 2020).

[26] Tiffany Lethabo King, *The Black Shoals: Offshore Formations of Black and Native Studies* (Durham, NC: Duke University Press, 2019).

[27] See especially chapter 6: Robert Bieder, *Science Encounters the Indian, 1820–1880: The Early Years of American Ethnology* (Norman: University of Oklahoma Press, 2003). Morgan introduced his three-stage (or "status") theory of the "Progress of Mankind" in the first chapter of Bieder, *Science Encounters the Indian, 1820–1880*; Lewis Henry Morgan, *Ancient Society Or, Researches in the Lines of Human Progress from Savagery, through Barbarism to Civilization* (Project Gutenberg, May 20, 2020), www.gutenberg.org/ebooks/45950; Yael Ben-Zvi, "Where Did Red Go?: Lewis Henry Morgan's Evolutionary Inheritance and U.S. Racial Imagination," *CR: The New Centennial Review* 7, no. 2 (2007): 201–229.

evolutionary time, which then prompted scientists to design studies that treated these assumptions as real.[28]

The US federal government introduced the category of "Indian" to the US Census in 1850 but the aim – and census-takers' activity – was to count only Native people who "renounced tribal rule" and "exercised the rights of a citizen." In the mid nineteenth century, the point was to track the settler-state goal of disappearance through "assimilation" and to count the number of people who needed to pay federal taxes particularly after the Indian Apportionment Act (1871) that parceled Native people's land for private ownership. The criteria for being "Indian" changed after the Dawes Severalty Act (1887), through which the US government took possession of Native land. After the Dawes Act passed Congress, people were required to register on tribal rolls (Dawes Rolls), which were based on ancestry. Thereafter, US census-takers were taught to count people as Native depending on their blood quota, not based on whether they renounced tribal rule (and were potential taxpayers). The addition, revision, and reintroduction of "Indian" into the census tracked the careening US policies toward Native groups.[29]

By 1962, the category of "Native American" lumped together the people that Carolyn had seen in Arizona as a child and the children from the Great Plains that lived in the Clinical Center in the 1960s, as well as many more groups – including Inuit people, Hawaiian islanders, and people who straddled the borders of settler states, like Mohawks (US–Canada) and Akimel O'odham (US–Mexico).[30] The creation of a bureaucratic category to capture a variety of Native groups suggested a coherent scientific racial grouping. It also suggested a homogeneity and commensurability, which belied a range of lifeways, lineages, and experiences under American Empire and global capitalism.

Although Carolyn was poor at being a "normal control" human subject, she was diligent in her career assignment as an unpaid lab technician. Dr. Jan Wolff was leader of the Clinical Endocrinology Branch, and supervisor of the

[28] Johannes Fabian, *Time and the Other: How Anthropology Makes Its Object* (New York: Columbia University Press, 1983); Michel-Rolph Trouillot, *Global Transformations: Anthropology and the Modern World* (New York: Palgrave Macmillan, 2004); Seth Garfield, *Indigenous Struggle at the Heart of Brazil: State Policy, Frontier Expansion, and the Xavante Indians, 1937–1988* (Durham, NC: Duke University Press, 2001).

[29] Kenneth Prewitt, *What Is Your Race?: The Census and Our Flawed Efforts to Classify Americans* (Princeton: Princeton University Press, 2013); Josh Pearl, "Native Americans and the Census," Journeys: Topics in Digital History, January 25, 2016, https://journeys.dartmouth.edu/censushistory/2016/01/25/native-americans-and-the-census/; Margaret M. Jobe, "Native Americans and the U.S. Census: A Brief Historical Survey," *Journal of Government Information* 30, no. 1 (2004): 66–80; Dan Bouk, *Democracy's Data: The Hidden Stories in the U.S. Census and How to Read Them* (New York: MCD, 2022).

[30] Audra Simpson, *Mohawk Interruptus: Political Life across the Borders of Settler States* (Durham, NC: Duke University Press, 2014).

young scientist who had enrolled Carolyn as a Normal. Together, they processed data for their endocrinology research in their laboratory.[31] Carolyn helped. How would people have perceived her then, more than fifty years ago, I asked in one conversation? "Oh, naïve," Carolyn told me, "Cooperative, except for not being able to pee on schedule, mostly cooperative."[32]

Hormones from the thyroid process iodine, and, troublingly, nuclear fallout sends out radioactive iodine. As of 1962, the United States was continuing a program of testing nuclear weapons in the ocean and upper atmosphere, as well as in the deserts of the American Southwest. Thus, the United States was funding both research on atomic science and research on the diseases that atomic science caused. Under its Atoms for Peace campaign, the US government paid the salary of Dr. Wolff, who was figuring out how to block the thyroid function in the event of a nuclear accident.[33] Another (paid) technician would stop at one of NIH's slaughter houses and bring thyroid glands from sheep, pigs, and other animals to the lab. Carolyn's job was to grind up the glands and prepare them for tests. She did not know what the researchers were trying to learn. "It had something to do with thyroid," she said. "It was very lofty and technical." She did not find her work interesting; she just wanted to do a good job.[34]

Interesting or not, she was happy. So it was easy to smile when the *Washington Post* photographer arrived at Dr. Wolff's lab (Figure 7.3). With Carolyn in a white lab coat, her situation was too delicious to resist: a human guinea pig doing research on other lab animals. The photographer snapped pictures of Carolyn rather than the scientists. Readers of the *Washington Post* were taught what it was like for her and other Normals to be subjects of NIH medical research. "Personal consent is essential," the article instructed. "No volunteer ever starts any test without first understanding its purpose, methods, duration, demands and inconveniences or discomforts." The people who served in medical research were portrayed as a type. "They are not daredevils, nor fools, nor even overly inspired idealists," the journalist wrote. "They're ordinary men and women, mostly in their twenties, who see a job

[31] Marvin C. Gershengorn, "History of the Clinical Endocrinology Branch of the National Institute of Diabetes and Digestive and Kidney Diseases: Impact on Understanding and Treatment of Diseases of the Thyroid Gland," *Thyroid* 22, no. 2 (February 2012): 109–111; Dewitt Stetten, ed., *NIH: An Account of Research in Its Laboratories and Clinics* (Orlando: Academic Press, 1984), 419.

[32] Matthews Oral History 2016, VANV.

[33] David V. Becker et al., "The Use of Iodine as a Thyroidal Blocking Agent in the Event of a Reactor Accident: Report of the Environmental Hazards Committee of the American Thyroid Association," *JAMA* 252, no. 5 (1984): 659–661; Kiyohiko Mabuchi and Arthur B. Schneider, "Do Nuclear Power Plants Increase the Risk of Thyroid Cancer?," *Nature Reviews Endocrinology* 10, no. 7 (2014): 385–387.

[34] Matthews Oral History 2016, VANV.

YELLOW SPRINGS, O., Feb. 1963 - Antioch College student Carolyn Matthews is pictured on her co-op job doing laboratory work in the Normal Volunteers program of National Institutes of Health in Bethesda, Md. Carolyn is in the unusual position of both dontaint research material - samples of her blood - and working on it in lab tests. She assisted Dr. Jan Wolff in a study of the circulation of anti-thyroid substances in the body.

Figure 7.3 Carolyn Matthews as "Normal Control," published in the *Washington Post*, 1963.
Source: Co-op Photo Collection, Olive Kettering Library, Antioch College, Yellow Springs, OH.

that needs to be done and offer to do it."[35] NIH strategically allowed access at the Clinical Center only to sympathetic journalists to manage its reputation.

In the evenings, Carolyn would get a pass from 8-West nursing station, trundle down to the first floor, and wait in the sweet autumn dusk for Jan Wolff's car. Wolff and the esteemed biochemist, Edith Wolff, who had married him, hired her as their babysitter. Word of Carolyn spread among the upper ranks, and she started babysitting for other scientists, too. Still, it came as a surprise when the doctor made a proposition. "[O]ne day when I was in my room on 8-West, another doctor who I'd never seen before came into my room – his name was Dr. William O'Brien – and said, 'Hey, I'm putting together a team to go to Arizona to take x-rays, to find the incidence of rheumatoid arthritis in this Indian population in Arizona. Would you consider coming?'"

Carolyn had never seen him before. He had just returned from a three-month stay at the Blackfeet Indian Reservation on the US border with Canada.[36]

"Me being this restless person I already told you about, I said, 'Are you kidding? I'd love to'."[37]

Sacaton, 1963: Carolyn as Research Technician

Carolyn arrived with the team in January 1963 and had ambitions of making an ethnological study of the Native community. It was a romance drawn from popular knowledge of the dominant school of cultural anthropology at the time, Claude Lévi-Strauss's *Structural Anthropology*.[38] Practitioners drew "plans" of space from a bird's-eye view, often Indigenous villages and tribal meeting places (Figure 7.4). Carolyn named the "dust, dirt, grit," and drew arrows to the world beyond the paper's edge as she imagined it. "The desert to infinity," they pointed. For structural anthropologists, it was unnecessary to learn of the world beyond the paper's edge because the "plans" of physical space corresponded to the social structure of a group, which itself could be "mapped" with ink and paper. Lévi-Strauss was credited with helping to dismantle the racist orthodoxy in mid-century Euro-American science. His target and that of many others was race science and eugenics, which claimed racial inequality was the natural consequence of biological difference, rather than the result of political oppression and discrimination, as the liberal academy agreed. In some camps, however, structural anthropology in general and Lévi-Strauss in particular were rebuked for replacing race science with a

[35] Patricia Griffith, "Conscientious Non-objectors to Important Medical Research," *Washington Post*, February 3, 1963.
[36] Anon., "Arthritis among the Blackfeet," *Modern Medicine* (February 4, 1963): 45–46.
[37] Matthews Oral History 2016.
[38] Claude Lévi-Strauss, *Structural Anthropology*, n.d.

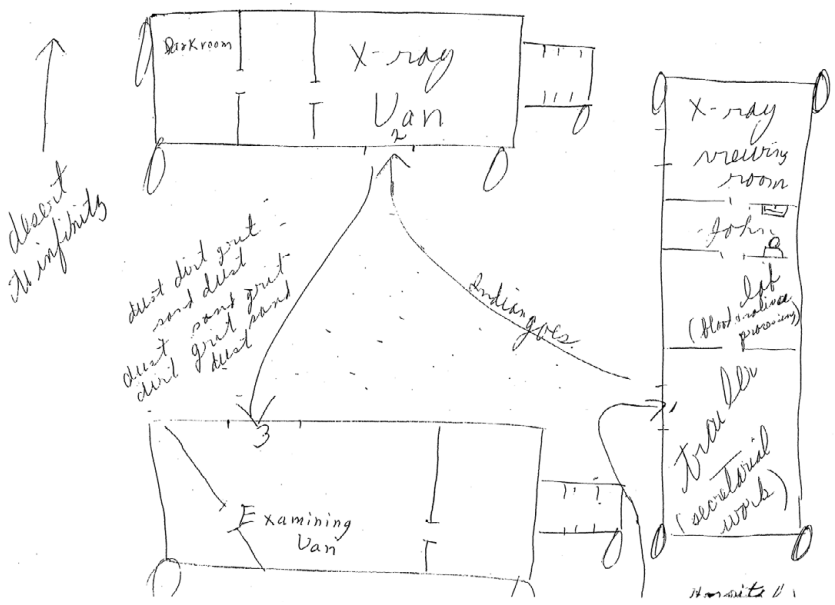

Figure 7.4 Carolyn Matthews's "plan" of field site, undated.
Source: Carolyn Matthews collection, VANV.

nonetheless essentialist and race-based concept of human difference. Essential racial difference was built into the visual grammar of structural anthropology. Its mapping method assumed that people with a different skin color also had within their bodies a fundamentally different social "structure" – where the white Euro-American experience was the unmarked category against which difference was compared. But Carolyn's amateurism left room for subversion. In drawing a plan of the NIH site, her untrained anthropology flipped a method and a viewpoint that scientists had originally developed on (and had used to discipline) Native groups back onto a scientific community.[39]

Soon Carolyn dropped her ethnographic ambitions as scores of people emerged out of the desert to infinity. That seemingly endless vacant sandscape was in fact striped with irrigation ditches and established villages.[40] People of

[39] Don D. Fowler, *A Laboratory for Anthropology: Science and Romanticism in the American Southwest, 1846–1930*, 1st ed. (Albuquerque: University of New Mexico Press, 2000); Nancy Parezo, ed., *Hidden Scholars: Women Anthropologists and the Native American Southwest* (Albuquerque: University of New Mexico Press, 1993).

[40] M. Kyle Woodson, *The Social Organization of Hohokam Irrigation in the Middle Gila River Valley, Arizona* (Sacaton, AZ: Gila River Indian Community, 2016); David

the Akimel O'odham tribe, known to settlers as the Pima Indians, had farmed the banks of Keli Akimel (the Gila River), which lent the people its name. The river also distinguished them from their kin, the Tohono O'odham (Papago), who lived to the south and migrated between desert and mountain, farming and hunting, depending on the season.[41] The Akimel O'odham, by contrast, were steady, resident agriculturalists. Until the late nineteenth century, they grew cotton, wheat, corn, beans, and melon for subsistence, often with surplus, which they traded or gave to neighboring tribes, to travelers en route to the Pacific coast's mineable mountains, or to administrators of the Mexican and American governments surveying the land and its resources. Mexico officially claimed the land after that colony itself gained independence from Spain, but the Mexican government still let the tribe govern itself as a matter of convenience.[42] Akimel O'odham land remained part of Mexico even after the Mexican–American War (1846–1848), when the United States claimed swaths of territory that it governs today as the states of the Southwest and Pacific Coast.[43]

The group's land remained part of Mexico – and its people effectively self-governing resident farmers – until the United States bought a bite of land south of the Gila River in 1854. Then the United States claimed much of the Akimel O'odham land as its own and pushed people into a newly parceled reservation, its linear borders drawn over a small section of their previous territory. The drive for railroads, mail service, and other accoutrements of national infrastructure hardened the US containment, as did US mining interests in the region.

In the 1950s, local scientists around Phoenix bemoaned the recent changes in the foods Akimel O'odham people ate. Where beans, tortillas, and chili

H. DeJong, *Stealing the Gila: The Pima Agricultural Economy and Water Deprivation, 1848–1921* (Tucson: University of Arizona Press, 2009).

[41] For an analysis of government-industry technology experiments on the Papago Reservation starting in the 19[80]s, see Jeremy Greene et al., "Innovation on the Reservation: Information Technology and Health Systems Research among the Papago Tribe of Arizona, 1965–1980," *Isis* 111, no. 3 (2020): 443–470.

[42] DeJong writes that "Mexican independence had little impact on the Pima . . . The arrival of Americans, however, did affect them. While Americans were prohibited from entering the country under Spanish rule, Mexican law was relaxed, and hundreds of American mountain men descended on the Gila River and its tributaries" (17). DeJong, *Stealing the Gila*.

[43] DeJong, *Stealing the Gila*; David H. DeJong, *Forced to Abandon Our Fields* (Salt Lake City: University of Utah Press, 2011); John P. Wilson, *Peoples of the Middle Gila: A Documentary History of the Pimas and Maricopas 1500s–1945* (Sacaton, AZ: Gila River Indian Community, 2014). At this moment, the Smithsonian Institution was created as an appendage of the US government and made responsible for collecting information on the land and people. See especially chapter 5, "The Great Surveys," in Fowler, *A Laboratory for Anthropology*.

peppers were staple for older folks, younger people bought packaged food at trading posts. "The Pima Indians are a southern Arizona tribe which has readily acclimatized itself to Western civilization through fairly close proximity to off-reservation urban communities," one local scientist explained in 1959. They were geographically near "civilization," the scientist said, and yet consumed "mostly non-perishable foods that are bought because of long distances traveled and lack of facilities for storage of perishable foods."[44] Scientific investigations left unremarked the relation between changes in the tribe's foodways and the United States' enclosure of the tribe in a reservation away from the Gila, the government's systematic denial of water for their irrigation systems that decimated their remaining farm lands, and federal policy on agriculture and economics favoring industrial capitalism. Left unremarked was the possibility that these changes in foodways were a political problem, not an outcome of nature (e.g., droughts), and therefore not natural and inevitable.[45]

When the new arrivals from NIH parked their trailers a short stretch from the US Public Health Service's Indian Hospital, they made their first discovery: they were far from the only scientists studying the local tribe (Figure 7.5.).[46] Inside the PHS Indian Hospital, a young clinician had been collecting information from Native medical records on a stack of index cards.[47] He was of the mind, as a colleague put it, that there was a "critical need for good health for Indian people if they were to take their rightful place in American Society."[48] The praise winced with settler assumptions and values. The clinician had first studied tribes in the area during the late 1950s under the auspices of the

[44] Frank G. Hesse, "A Dietary Study of the Pima Indian," *The American Journal of Clinical Nutrition* 7, no. 5 (September 1, 1959): 532–537.

[45] DeJong, *Stealing the Gila*. The US Indian Appropriation Act (1859) created reservations for "Pima" people. "Throughout the 1850s, the Pima continued to enjoy economic growth. While the Indians served notice that their land and resources were under their sovereign control, in the post-Civil War years the United States encouraged settlement of the territory, and by the end of the decade, the Pima stood on the precipice of far-reaching economic and political change. No longer did they control their own destiny, as the rapidity of change brought about by federal polices diminished Pima sovereignty and disadvantaged the Indians . . ." (56).

[46] On the NIH team's meeting of Dr. Maurice Sievers, see Stephanie Stegman, "Taking Control: Fifty Years of Diabetes in the American Southwest 1940–1990," PhD dissertation, Arizona State University, 2010, 88. Sievers would go on to coauthor many scientific articles with the NIH team, especially Dr. Peter Bennett. For analysis of the local scientific context and the NIH research team, as well as a comprehensive documentation of the 1963 field study on the ground, also see Stephanie Stegman, "Taking Control: Fifty Years of Diabetes in the American Southwest 1940–1990," PhD dissertation, Arizona State University.

[47] Maurice L. Sievers and James R. Marquis, "The Southwestern American Indian's Burden: Biliary Disease," *JAMA* 182, no. 5 (1962): 570–572.

[48] "Maurice Sievers: Obituary," *The Arizona Republic*, March 2020, www.azcentral.com/obituaries/par036229.

Figure 7.5 NIH trailers at data collection site, circa 1963.
Source: NIDDK, PowerPoint. Thanks to NIDDK Sacaton Branch.

National Cancer Institute, which was part of NIH. He interviewed and examined Navajo uranium miners who were digging radioactive materials.[49] Uranium is an essential building block of atomic weapons and nuclear states were the only buyers on uranium markets. The US government was spending money both to continue its nuclear weapons development program and to investigate the diseases that resulted from the program, especially cancer from exposure to uranium dust, nuclear waste materials, and fallout from test explosions.[50]

[49] Gabrielle Hecht, *Being Nuclear: Africans and the Global Uranium Trade* (Cambridge, MA: MIT Press, 2012). Through the study of French African uranium mines over the past six decades, Hecht examines the creation in the post–World War II period of a market for uranium, which, she shows, developed by creating risk for workers, not only producing a rhetoric of atomic threat for populations, raising questions of responsibility under global capitalism.

[50] The mines on the Navajo reservation were closed in 1986 by which point there were more than 500 mining sites run by private contractors of the Atomic Energy Commission and its incarnations. William L Chenoweth, "Navajo Indians Were Hired to Assist the U. S. Atomic Energy Commission in Locating Uranium Deposits," Arizona Geological Survey Contributed Report Series (US Department of Energy, September 2011); OECA US EPA,

By the time Carolyn arrived, she had gotten two weeks of official training at the NIH Clinical Center on how to use the equipment before flying to Phoenix with the team.[51] So with limited formal training, her working knowledge of making x-rays – how to arrange people's bodies like a portrait sitting, where to touch to tactfully drape the lead apron, when to swivel the machine like a carnival game – came from practice in conditions unlike those of the Clinical Center exam rooms.

Among other things, Carolyn was now standing inside a truck (Figure 7.6). When the door swung open it let in a burst of light and air – along with a person hoisting up into the vehicle. She took four pictures: neck, pelvis, hands, and feet. Then she stepped to the tail of the truck to let the films develop in the makeshift darkroom. At the end of January, she turned nineteen years old.

At first, the work was steady and manageable. Bernice, a member of the tribe, recorded each person's basic information in a mobile-home trailer when they arrived, then gave them a drink from the carton of Black Label beer. Bernice was hired as a temporary secretary for NIH, and her husband was hired too. He worked as a driver, one of the locals who knew the topography and motored around the reservation collecting tribe members for the study.[52]

"Case Summary: $600 Million Settlement to Clean up 94 Abandoned Uranium Mines on the Navajo Nation" (2017); Will Ford, "A Radioactive Legacy Haunts This Navajo Village, Which Fears a Fractured Future," *Washington Post*, January 19, 2020, www.washingtonpost.com/national/a-radioactive-legacy-haunts-this-navajo-village-which-fears-afractured-future/2020/01/18/84c6066e-37e0-11ea-9541-9107303481a4_story.html. See also DeJong, *Stealing the Gila*; Doug Brugge and Rob Goble, "The History of Uranium Mining and the Navajo People," *American Journal of Public Health* 92, no. 9 (September 2002): 1410–1419. See also Rafael Moure-Eraso, "Observational Studies as Human Experimentation: The Uranium Mining Experience in the Navajo Nation (1947–66)," *NEW SOLUTIONS: A Journal of Environmental and Occupational Health Policy* 9, no. 2 (1999): 163–178.

[51] NIH started offering regular training courses in x-ray technology. They took two years to complete. For example, "News from Personnel – X ray Technology Course," *NIH Record*, May 21, 1963: 2, https://nihrecord.nih.gov/sites/recordNIH/files/pdf/1963/NIH-Record-1963-05-21.pdf.

[52] This scene suggests how members of Native communities differentially adopted the vocabulary and skills of settler science – perhaps also adapting and co-opting its prestige in some circles for their own strategic purposes. My analysis is indebted to Gabriela Soto Laveaga's work documenting and showing how some Mexican peasants combine their own local knowledge of the (coveted) wild yam and scientists' chemical vocabulary (about progesterone) to produce themselves as local elites. The important insight is that Indigenous groups are internally stratified, that internal hierarchies are emergent (not preexisting and stable), and that people can use settler science as a resource to negotiate their own status in the broader context of citizenship. Gabriela Soto Laveaga, *Jungle Laboratories: Mexican Peasants, National Projects, and the Making of the Pill* (Durham, NC: Duke University Press, 2009). It would be interesting to develop further the suggestive parallel between Bernice in Sacaton and the legendary "Nurse Rivers" in the context of

Figure 7.6 Carolyn Matthews's NIH research team on location in 1963.
Photographer: Carolyn Matthews. Carolyn Matthews wrote a description on the back in 1963: "X-ray van / Joel [Silverman] + Dr. [Thomas] Burch / (pineapple juice used / for glucose tolerance test / is in Black Label beer / cartons)." *Source*: Carolyn Matthews collection, VANV.

When he pulled up to the site, he pointed his passengers to Bernice's trailer, who then directed them to Carolyn's truck. He waited as they crossed the sand to the last truck, where a member of the NIH team took their blood and saliva. The drink from the beer carton had been pineapple juice, not alcohol, and the needle in the vein allowed the researchers to test the level of sugar in their

the US Tuskegee Syphilis Studies. Susan M. Reverby, "Rethinking the Tuskegee Syphilis Study. Nurse Rivers, Silence and the Meaning of Treatment," *Nursing History Review: Official Journal of the American Association for the History of Nursing* 7 (1999): 3–28.

blood. Then he gathered his passengers to return them home. By late March, his trips were so frequent and his car so full, Carolyn was working ten-hour days.

In the evening, Carolyn and the rest of the NIH team drove to Chandler, the next town over from Sacaton and off the reservation. NIH had rented an old estate hotel, *La Hacienda*, with separate units for each of the families: Dr. William O'Brien, his wife, and two toddlers; Dr. Thomas Burch, head of the field unit; Dr. Peter Bennett and nurse Sally Bennett, his wife, both from the United Kingdom, and another young researcher also taking x-rays. Carolyn had a unit to herself as a family of one. Most nights, she cooked, cleaned herself, and promptly went to bed. On Sundays, the team cooked a communal meal in the central kitchen and ate together in the banquet hall.

At that time, there was a beguiling, and, to many researchers, highly suspect explanation circulating in the medical literature for a smattering of seemingly unrelated diseases: arthritis, diabetes, fever, and skin rashes.[53] These different conditions had a common cause, researchers argued, at least in some instances: an autoimmune disorder.[54] Before joining the NIH team, Bennett had done influential work in the UK to first argue that arthritis was often a sign of an autoimmune attack (rheumatoid arthritis), and not always the result of wear and tear on the joints (osteoarthritis). After his initial work, Bennett was keen to investigate whether genetics determined the autoimmune malfunction, but he conceded in a 1960 write-up: "No definite views on causation can be expressed on the evidence available."[55] Picking up the scent of a research question from across the Atlantic, NIH researchers got to work. In the fall of 1962, while Carolyn was serving as a normal control at the Clinical Center, O'Brien decamped for the Blackfeet Indian Reservation. He led a field team in the first of a two-phase study of the causes of autoimmune-based, rheumatoid arthritis. To help collect data from the Native community, NIH invited Bennett to Montana. Building on the work of the UK team, the NIH group wanted to find the "non-genetic etiology for

[53] In the late 1920s, a scientist in Norway was led to the seemingly improbable conclusion that diabetes might be caused by an antibody response (assumed to be an infection). Edvard Gundersen, "Is Diabetes of Infectious Origin?," *The Journal of Infectious Diseases* 41, no. 3 (1927): 197–202.

[54] The possibility of a common cause of disparate conditions also meant that diseases previously categorized together (diabetes, arthritis) were split and reshuffled. Some kinds of arthritis were now more akin to some kinds of diabetes than to diseases that shared the same name because they were both caused, endocrinologists claimed, by this autoimmune malfunction. Arleen Tuchman, *Diabetes: A History of Race and Disease* (New Haven, CT: Yale University Press, 2020).

[55] J. S. Lawrence and P. H. Bennett, "Benign Polyarthritis," *Annals of the Rheumatic Diseases* 19, no. 1 (March 1960): 20–30.

these conditions," namely, rheumatoid factor (an indicator of autoimmune disease). When O'Brien had come to Carolyn's hospital room at the Clinical Center, he had been a stranger to her because he had been in Montana gathering x-rays and blood from Native community members.

In addition to genetics, another possible cause of arthritis was climate. The NIH team designed their field survey in Sacaton to allow them to test the hypothesis that climate (hot/dry versus cold/moist) predicted a particular form of arthritis better than genetics ("heredity"). The logic of comparison articulates the racialized assumptions of NIH scientists. There are plenty of hot dry places in the United States. But scientists wanted to control for another key variable: race. By this logic, scientists needed, then, to pick people (a "stable population") in a hot dry place that were related to people thousands of miles away on the US–Canada border. There is little that is intuitive about the idea that a group of people in the Sonoran Desert were a "stable population" given migration and relationships across the US–Mexico border; there was little reason to imagine they were more closely related to people in Montana than to residents of Phoenix, where Akimel O'odham people moved, married, and worked. Through their logic of comparison it is possible to see how scientists imagined this political difference in how the US government treated groups as a biological reality.[56]

By April, the team had brought nearly all of the adults living on the reservation – one thousand in all – to the trucks for an exam, x-rays, saliva swab, and blood draw.[57] The team packed up the trailers and their families, said goodbye to Bernice and the other local workers, and went back to Bethesda. Carolyn returned to school.

Boston, 1964: Carolyn as Research Technician

In the spring of 1964, Carolyn decamped for another co-op assignment: in Boston, where she worked as a live-in cook for a communal home for the

[56] "Race" is a meaningful category in the modern United States, but that category has multiple meanings – political, biological, administrative, and more. As Steven Epstein writes, historically, the idea that "the categories of political mobilization and state administration also functioned as the categories of biomedical differentiation was given crucial support by federal health officials." As a result, "the question of why the categories of political mobilization and administration should also be viewed as the categories of greatest biomedical relevance was effectively bypassed." Steven Epstein, *Inclusion: The Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007).

[57] H. Bennett and T. A. Burch, "The Distribution of Rheumatoid Factor and Rheumatoid Arthritis in the Families of Blackfeet and Pima Indians," *Arthritis and Rheumatism* 11, no. 4 (1968): 546–553. The team examined 86 percent of adults on the "well-defined reservation communities" (551).

Quaker church.[58] At the end of the quarter, she decided to stay. She had gotten out of sync with her Antioch cohort when she skipped a beat to go directly from Bethesda to Sacaton. ("I was never one of the tribe," she said.) She also never fit the mold of the politically radical Antioch student. And the pacifist politics of her Quaker housemates had started to compel. US imperialism bore down in Southeast Asia and nuclear weapons enhanced its menace. Within American borders, the practice of nonviolent resistance of the mainstream Black Civil Rights movement aligned with the goals and philosophy of the Quaker church. In the early 1960s, only a few groups connected US imperial projects, on the one hand, and the Black Civil Rights movement, on the other hand, in a way that articulated the movement as a response to American imperialism via chattel slavery and its extensions.

As a result, it was possible for middle-class white Americans, like Carolyn, to miss imperial projects close to home. Like the Black Civil Rights movement, the Red Power movement mobilized in the late 1950s and 1960s.[59] Unlike the Black Civil Rights movement, however, the demands of Red Power were not for civil rights defined by liberal individualism. Native American sovereignty movements, contemporary with the nonviolent Civil Rights movement, demanded recognition of their full political authority over land and lives that the US claimed or presumed to control.[60]

With her NIH credentials, despite now being a college drop-out, Carolyn was hired as a scanning technician in the Radiation Department at Peter Bent Brigham Hospital, next to the Harvard Medical School. This steady job, one she had found herself not pointed at in a college binder, felt very good in concept. She wore a lab coat, fetched doctors to inject people with radioisotopes, and scanned their bellies with a new machine the department was testing. At the end of the week, she got her own paycheck.

In practice, the work felt considerably worse. Instead of sending radioactive atomic particles into the bodies of Akimel O'odham people (her job as an x-

[58] Carolyn lived and worked at the Beacon Hill Friends House, which still operates, at 6 Chestnut Street, Boston, MA. Oral History 2017. Carolyn also lived for a year in a small apartment with Sandy Calloway Ferguson, who had been a Normal at the US National Institutes of Health through the Antioch co-op program and also dropped out of Antioch. Sandy had severe reactions to the experimental drugs she was given at NIH. She had to leave NIH and take a term off from Antioch to recover at home in upstate New York. Ferguson Oral History 2019; Woods Oral History 2018.

[59] Rich, "Remember Wounded Knee."

[60] King, *The Black Shoals*. The US government's prior gestures toward Native sovereignty nonetheless held that Indian nations were not independent but "domestic dependent nations" according to the Marshall Trilogy. As Richard Scott Lyons writes, "It's a paradox: sovereignty produced by colonization." Scott Richard Lyons, "Actually Existing Indian Nations: Modernity, Diversity, and the Future of Native American Studies," *The American Indian Quarterly* 35, no. 3 (2011): 294–312.

ray technician with NIH), she was using a new machine that absorbed atomic waves from people's temporarily radioactive bodies. Carolyn worked under Dr. James Potchen, who got his medical training during the Eisenhower administration and the federal "Atoms for Peace" campaign, through which the Atomic Energy Commission urged researchers to find uses for atomic science beyond its use for weapons.[61] Under the Atoms for Peace program, the federal government made and mailed radioactive versions of molecules to scientists around the country, including the radioactive iodine used in Jan Wolff's lab at the NIH Clinical Center, where Carolyn had worked without pay when she was not serving in experiments. Radiologists like Potchen knew that when the radioactive version of a molecule, called radioisotope tracer, is put into the body (in a drink, or through an injection), it moves through the body just like a regular molecule, but it emits radiation. If researchers had a machine that could detect radiation as well as human tissues (x-rays are only good for bones), they could see how "normal" bodies work and where sick bodies are having problems. During his first year of residency, Potchen designed such a machine. Today he is credited with making the first radionucleotide image in the esteemed Harvard hospital system.[62]

To get clinicians beyond Boston to use his scanner – and, through the instrument, to extend the reach of his influence – he needed to show its usefulness. He corralled the experimental results of his scanner to get funding from the Atomic Energy Commission to continue testing the machine and to establish its precision.[63] He hired Carolyn to do the scans.

The work felt ethically wrong to Carolyn, and by Potchen's own admission it was. "That first image was produced at night somewhat surreptitiously," Potchen said, "because all clinical radioisotopes at the Brigham were in the domains of the departments of surgery, endocrinology, or hematology. Radiology did not have permission from the 'clinical chiefs' to be using isotopes on patients."[64] The Atomic Energy Commission had control over

[61] "Potchen, E James," in *American Men & Women of Science: A Biographical Directory of Today's Leaders in Physical, Biological, and Related Sciences*, 23rd ed., vol. 5 (Detroit, MI: Gale, 2007), 1191.

[62] E. James Potchen, "Reflections on the Early Years of Nuclear Medicine," *Radiology* 214, no. 3 (2000): 624.

[63] Potchen presented on new scanning techniques at a conference in Shaker Heights, OH, October 30–31, 1964, based in part on work that Carolyn had done for him. United States Atomic Energy Commission, "Isotopes and Radiation Technology," 2, no. 2 (Winter 1964–1965): 192–193. See also Teresa J. C. Welch, *Fundamentals of the Tracer Method* (Philadelphia, PA: Saunders, 1972); James E. Potchen and Alexander Gottschalk, *Diagnostic Nuclear Medicine*, Golden's Diagnostic Radiology Series; Section 20 (Baltimore, MD: Williams & Wilkins, 1976).

[64] Potchen told his story of derring-do and it became a favorite lore of the field of radiology. Potchen, "Reflections on the Early Years of Nuclear Medicine."

isotope distribution, and sent isotopes to medical departments for their exclusive use.

It was unclear what patients and healthy people knew about the injections they got and about the scans. Carolyn herself did not know much, nor did she ask. Sometimes she scanned patients for a diagnosis or to ready them for surgery. Other times she scanned the healthy hospital orderlies and janitors, her fellow low-skill laboring friends. Every few days, she carried the radioactive waste down the hall to an open storage room in the hospital.[65]

Years later, Potchen reflected on the ethics of his experiments in nuclear medicine to refine the scanner: "I am still not convinced that the early unregulated years inflicted any harm to patients." Ethically, the interest was whether scientists thought the procedure could harm, rather than whether a patient or a community had a right simply to know they were part of an experiment and to have the power to decide. The concern was with the result rather than with the ethics of the action. "Such an approach would be unthinkable today, and would require many years to reach the same conclusions." It is worth noting that Potchen's practices were not uniformly endorsed, even then. Carolyn lasted a year.

Portland, 1977: Carolyn as Story-Worker

In the thirteen years after Carolyn dropped out of Antioch, she moved more than a dozen times. After her year as a Boston lab technician, she moved to Switzerland as a nanny; later, she briefly took classes at Columbia University, where she watched the women's movement pulse into popular awareness on the streets of New York City. She kept her Boston connection to the Quaker church and, though she was not a religious believer, she took a job with the American Friends Service Committee in 1968 in San Francisco. Within months of Carolyn's arrival, an activist group, Indians of All Tribes, landed on Alcatraz Island in the San Francisco Bay. Just a mile offshore from the city's North Beach, the island was by 1969 a legendarily brutal maximum-security federal prison. The activists of Indians of All Tribes aligned with the Red Power movement. They organized to occupy Alcatraz to protest the US government's policies of termination of Native communities. They carried weapons and stayed for nineteen months. Carolyn's activist sensibilities were, however, elsewhere.

San Francisco was the context for what she came to see as her "political awakening." In that city and that year, the war in Vietnam was the dominant target of protest and the summer of love its emblem. Her work and social life

[65] At the time, the federal government did not require that people label radioactive material when it was being moved. United States Atomic Energy Commission, "Isotopes and Radiation Technology," 192–193.

was oriented around her Christian pacifist Friends, so it was the US proxy war on Red China, not the Red Power movement, which tuned her attention. She was involved in the Movement for a New Society, which opposed violence abroad and supported Black Civil Rights at home. Yet it had less to say about war as a strategy of continental American Empire or about Native sovereignty claims. In 1973, two years after the Alcatraz occupation ended, Native groups operating under the American Indian movement stood off with federal agents at Wounded Knee, the site of the US federal massacre of Lakota people in 1890.[66]

Through another antiwar job with the Quaker church, Carolyn moved back to Boston in 1974. The same year, the US Congress passed the National Research Act in the wake of public exposure of the Tuskegee Syphilis Studies, the four-decades long racist and exploitative study of African-American men funded by the US government. Federal health agencies, led by the National Institutes of Health, had been quietly working to write policies to guide research on "human subjects" since the mid-1960s.[67] When an enterprising journalist at the *Washington Star* finally followed up in 1972 on a tip about the Public Health Service-sponsored research on poor Black men in Tuskegee, Alabama, the agency had already drafted a set of policies for the US Congress to adopt as law. There were other options proposed, including a centralized federal ethics review office (to encourage consistent decision-making and transparency), rather than innumerable local Institutional Review Boards, modeled on the NIH Clinical Center's Clinical Review Committee. But Congress lined up behind the plan from the NIH proposal, to deflect legal responsibility away from the federal government and toward local research institutions.[68]

Thus, US federal protections for human subjects research – and popular knowledge of those protections (e.g., through the mass media) – bore the mark of the specific historical event that prompted the protections: the Tuskegee Syphilis Study. In the present day, American ethics training, as well as mass-market accounts of the importance of the field of bioethics, begins with Tuskegee.[69]

The essential feature of Tuskegee in its public iterations was that the human subjects racially identified as Black. They also lived in a rural area, earned less

[66] Dee Brown and Hampton Sides, *Bury My Heart at Wounded Knee: An Indian History of the American West* (New York: Holt Paperbacks, 2007).

[67] Stark, *Behind Closed Doors*.

[68] Ibid.

[69] John Hyde Evans, *The History and Future of Bioethics: A Sociological View* (Oxford: Oxford University Press, 2014); John H. Evans, *Playing God?: Human Genetic Engineering and the Rationalization of Public Bioethical Debate* (Chicago: University Of Chicago Press, 2002); Fox and Swazey, *Observing Bioethics*; Reardon et al., "Science & Justice."

money than they needed, and experienced structural racism, as well as casual prejudice and interpersonal discrimination. Yet, American law and ethics about human research was coded as a set of practices especially "protecting" people who were Black – which was important but also an insufficient recognition of the structures of injustice at play. The 1974 National Research Act, in addition to requiring regulation, also mandated that a committee of experts write ethical guidelines that would translate the regulations into useable language and a moral framework. This mandate resulted in the Belmont Report, following a four-year effort in the mid-1970s, through which a team of scientists, theologians, and ethicists gathered background papers and wrote a several-hundred-page manual. This influential report and its background papers discussed Black Americans in research, but failed to mention other racial-identity groups or the political dispossession that connects them.

Carolyn was in her early thirties when she moved back to Portland to be near her aged parents and the landscape that had raised her. In 1977, as the Belmont Commission completed its work and five years after the Tuskegee Syphilis Study had hit the headlines, Carolyn went back to school at Portland's Marylhurst Education Center (now Marylhurst University). With the hopes she might earn some course credit, Carolyn wrote up her past decade of transient work experience.

From the vantage point of 1977, she first explained her previous work at the NIH Clinical Center:

> Normal Voluntary Control (human guinea pig)
> National Institutes of Health
> Bethesda, Maryland
> Oct.-Dec. 1962
>
> I was an object of medical research, "employed" as a normal voluntary control. I lived in the Clinical Center, availing myself at all times for medical / experimental study. I understood very little of the research that was being done on me – partly because I was not informed of much, and partly because what was told to me was too complicated for me to understand. (I have since read parts of two articles [Carolyn's college advisor and friend] loaned me: "Accountability in Health Care" and "A Political Perspective on Accountability & Research on Humans," which confirm many of my principled questions on the subject, developed since my experience at the NIH.

Her "principled questions" were organized around whether she, as a human subject, had been on the receiving end of an adequate informed consent process. The write-up documents that the scholarly literature emerging in the late 1970s, as the field of American bioethics consolidated, informed Carolyn's bioethical vocabulary and analysis.

Carolyn also analyzed her earlier job as a research technician in Boston. Among other things, her responsibilities included:

> – Arrange for patient's departure (hospital orderly, taxi), making appropriate and sensitive response to patient's anxious questions (such as, 'you should ask you [*sic*] doctor, since I do not make diagnoses – he'll be looking at this test along with the other's you have had . . .')
>
> – [Participate] from time to time [in department"s] "research cases" to determine how fast a compound would concentrate in a given area of the body and how fast it would dissipate. Sometime these coincided with clinical cases, but often the "volunteers" were solicited. In my opinion, these people were not informed adequately what the procedure really was and what the possible risks were. In fact, my supervisor deliberately disguised what he knew to be certain facts of such a procedure in order to get volunteers, taking advantage of the fact that most of these volunteers were from the uneducated, lower echelons of the hospital hierarchy – orderlies and supply room workers.

Carolyn explained from the vantage of 1977 what she learned from the job in Boston. "This was one of my early exposures to medical deception," she wrote. "I did not at this time, link this up with my having been an ill-informed subject of medical experimentation at NIH." Carolyn affirmed that by 1977 she did not connect her earlier experience at NIH as a "human guinea pig" with that of her research subjects in Boston. Carolyn's 1977 write-up shows how she reframed her past with tools of the field of American bioethics that emerged in this decade.

Carolyn also thought back to her work in Sacaton with the Akimel O'odham people. What is worth noting is what was left unstated under the frame of American bioethics:

> X-ray technician
> NIH field survey
> Pima Indian Reservation
> Sacaton, Arizona
> Jan.-March, 1963
>
> I fell into this job accidentally, while at the NIH. I heard about a survey team that was going to Arizona to determine the incidence of rheumatoid arthritis in an Indian tribe. They were looking for a flunkie to take x-rays, and invited me along. So I went on an "own-plans" job with Antioch, and arranged to return to campus one quarter later.
>
> I was quickly trained to take and manually develop x-ray pictures of hands, feet, neck and pelvis on 1000 Indians in a portable unit right on the reservation. An Indian tribe was used because it was considered a relatively stable population; the family members do not move around much, so hereditary factors could be considered. Also, the results were to be compared with a previous survey done in Montana (on the Blackfoot [*sic*]

> Indians), the idea being to compare the effect of a hot-dry climate with a cold-dry climate on the incidence of arthritis. Interestingly, no significant difference was discovered. Plans were being made to go to Guam (hot-wet climate).
>
> I had hopes of being able to do some kind of anthropological study with the Pima Indians for some Antioch credit, but that soon proved impractical as we were working about ten hours each day.

Unlike her accounts of her experiences in Boston and Bethesda, Carolyn did not articulate her experiences in Sacaton in terms of questionable consent or possible coercion. Unlike the other two medical research experiences, she did not see a similarity between herself at the Clinical Center, her human subjects in Boston, and her research subjects in Sacaton – the Akimel O'odham people. In her 1977 report to Marylhurst, Carolyn described each of the three work experiences in chronological order. To draw the ethical connection between Boston and Bethesda as she did, Carolyn had to leapfrog her work with Native research subjects.

The puzzle is how it was possible for a person like Carolyn to fail to draw a connection. She was a deeply compassionate and educated person: she was informed about the ethics of research on people, had been employed in anti-imperial work for social justice, and was lucid in her memory of her part in research on the Akimel O'odham people ("Pima Indians"). Based on her 1977 account of her earlier experiences in Boston, Bethesda, and Sacaton, I want to suggest that Carolyn enunciated the formally sanctioned American bioethical frame. She is a best-case scenario not merely of what was allowable but what was perceptible under the dominant bioethical frame – which is a frame that set the structure of bioethical thinking that continues to dominate white American sensibilities today. To support justice through the work of history, it is important to precisely identify how and why the research setting that was most overtly characterized by racialist imperial power dynamics could be illegible within such a solid frame of ethical analysis. Carolyn is an indicator of what American bioethics made morally imaginable and legible as a matter of ethics.

Conclusion

Carolyn's story testifies to the embeddedness of modern American bioethics in a logic of colonialism. Dominant strains of modern science have invented and stabilized purportedly natural categories, such as race, which settler states and other global actors have used to naturalize difference, universalize place-specific relations, and justify political rule. No doubt, territorial expansion, forced labor, and violence are tactics shared beyond settler states; Indigenous groups have used these tactics, too. What is distinctive of Euro-American

settler states, however, is their enlistment of formal science in the service of setter logics and practices.

At the same time that settler states have operated through science, in the twentieth century, the field of bioethics has safeguarded the moral authority of science.[70] Instead of operating as place-specific, responsive practices of valuation, American bioethics reproduced the ontologies of the human sciences, life sciences, and clinical sciences that it claimed to hold to account. Bioethics functioned to uphold the settler logics of the sciences it claimed to regulate because it was a product of those sciences – designed to allow them to continue racialized, extractive practices without serious question or reform.[71] The implication is that research with people, even in the most formally ethical conditions among well-intended people, can enact this colonial logic.[72] To the extent that professional history has uncritically absorbed the discourse of modern American bioethics, the field – even in its best efforts – can rearticulate a colonial moral logic.

Carolyn's story materializes the perfect functioning of bioethics' settler logic. It reveals that the formally sanctioned and globally dominant American bioethical frame actively makes imperial situations illegible as such. In doing so, it defuses the settler past that structures the possibilities of action in a given situation, and the possibilities of scientific research in the first place. The imperial power dynamics of the Sacaton research situation was illegible in Carolyn's moral imagination, even from the vantage of 1977. With Carolyn as a guide, it is possible to recognize that the dominant American bioethical frame is marked by its origins in the US federal government – as a historically specific outgrowth of the Tuskegee exposé, which allowed elite actors to narrow ethics concerns, to emphasize racial discrimination as a preeminent issue, to organize ethics of race around a Black–white binary, and to exclude consideration of settler colonialism.[73]

This points to the framing of bioethics as an issue of safeguarding civic individualism, rather than dismantling anticolonial logics. It also suggests the bioethical frame is organized around expectations of citizenship and the demand that the state observe individual civil rights. Thus, the possibility that sovereignty is at stake, rather than civil rights, is not part of the officially sanctioned American bioethical frame. An imagination of the United States as

[70] Stark, *Behind Closed Doors*.

[71] Laura Stark, "Reservations," *Isis* 113, no. 1 (March 2022): 128–136.

[72] Tess Lanzarotta, "Ethics in Retrospect: Biomedical Research, Colonial Violence, and Iñupiat Sovereignty in the Alaskan Arctic," *Social Studies of Science* 50, no. 5 (October 1, 2020): 778–801; Joanna Radin, "'Digital Natives': How Medical and Indigenous Histories Matter for Big Data," *Osiris* 32, no. 1 (September 1, 2017): 43–64.

[73] Aileen Moreton-Robinson, *The White Possessive: Property, Power, and Indigenous Sovereignty* (Minneapolis: University of Minnesota Press, 2015).

an empire is inactive. Projects on research justice, such as CARE, as well as new critical histories of human experimentation, offer strategies reengaging research as an ethical relational practice.[74] In addition to promises that have not yet been met, there are solidarities yet to activate between movements for Native sovereignty and against anti-Black racism, both grounded in the bioethics of the US state.

[74] Cristina Mejia Visperas, *Skin Theory: Visual Culture and the Postwar Prison Laboratory* (New York: New York University Press, 2022).