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Who is sovereign and how? Informing data sovereignty initiatives beyond borders through analysis of autonomous health movements

Leah M. Friedman, Arizona State University, US, lfriedm5@asu.edu

In response to the increasing harms of large-scale data collection, a range of practices and technologies have been proposed to move towards increased data sovereignty. Broadly, data sovereignty is intended to create conditions that consider the social and collective setting in which individuals can claim control over their data, aiming to mediate between collective and individual interests when it comes to data management, generation, collection, and use. However, data sovereignty literature has rarely engaged with the question of who is included in the boundaries of a sovereign group outside of nation-states. This paper examines what binds sovereign groups together by putting data sovereignty in conversation with the operationalization of “sovereignty” in autonomous health movements. I review two historical case studies of self-managed abortions and the Black Panther Party’s organizing of free independent health clinics and identify four factors that allow autonomous health movements to maintain shared connections between their members: ideological or political identity, shared cultural or identity-based experiences, connection to place, and control over physical infrastructure. Based on this analysis, I propose ways that designers and researchers of data sovereignty can support these shared bonds of sovereignty, especially by designing culturally relevant data consent systems, redesigning data infrastructures, creating political coalitions, and navigating the blurry legal boundaries of sovereignty. This paper is as much a practical exercise in informing health data sovereignty as it is a creative exercise that thinks outside the possibilities of nation-state sovereignty to imagine how people can meaningfully manage themselves and their data.

1. Introduction

Digital technologies have enabled and encouraged a culture of data collection on an unprecedented scale by governments, corporations, and other organizations.[1] Mass data collection has increased surveillance, especially of people navigating heavily scrutinized public services,[2] while simultaneously making it significantly harder for individuals to know when their data is being collected, by who, and for what means. As a result, governments and corporations know more and more about individuals while individuals know less and less about the state.[3] In the domain of health, which is the focus of this paper, the imbalance of knowledge is further exacerbated by U.S. public health departments pushing to minimize barriers to data sharing between state and municipal departments with minimal consent for how data gets used.[4] Issues of consent are, in turn, complicated by data storage facilities, such as Amazon Warehouse Services buildings, or data collection systems, like Electronic Health Records, that often have their own inflexible privacy agreements yet provide valuable services such that states rely on these corporate partners for data management and storage.[5]

There are a range of practices that have been proposed as countermeasures to alleviate the power imbalances and harms of large-scale data collection. These practices are referred to under a collection of terms including data sovereignty, data justice, data autonomy, data privacy, data solidarity, and more; they include anything from improving individual consent for data use, to limiting corporate data collection, to creating data cooperatives where people can pool data and make collective decisions. Data sovereignty, specifically, aims to alleviate harms by considering the social and collective setting in which individuals can claim control over their data.[6] It is often (though not always) invoked as part of digital sovereignty, which includes infrastructural calls to minimize reliance on multi-national corporations, create more

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[1] Sandra Braman, *Change of State: Information, Policy, and Power* (Cambridge, Mass: MIT Press, 2006).

[2] For an example of surveillance of those most vulnerable, see Virginia Eubanks, "High-Tech Homelessness," *American Scientist* 106, no. 4 (2018): 230, https://doi.org/10.1511/2018.106.4.230.

[3] Braman, *Change of State*.

[4] For a description of how public health handles consent, specifically in HIV/AIDS data, see Stephen Molldrem and Anthony K J Smith, "Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response: Toward HIV Data Justice," *The American Journal of Bioethics* 20, no. 10 (October 2, 2020): 10–23, https://doi.org/10.1080/15265161.2020.1806373.

[5] Jose Van Dijck talks more about the implications of corporate/government partnerships. Jose Van Dijck, "Datafication, Dataism and Dataveillance: Big Data between Scientific Paradigm and Ideology," *Surveillance & Society* 12, no. 2 (May 9, 2014): 197–208, https://doi.org/10.24908/ss.v12i2.4776.

[6] Patrik Hummel et al., "Sovereignty and Data Sharing," no. 2 (2018): 20.

localized digital platforms or internet infrastructures, and give users a better sense of control of their digital selves. As data increasingly compose the basis of media and digital technologies, alleviating data harms has become a central issue in media studies.[7]

However, data sovereignty literature has rarely engaged with questions of who is included in the boundaries of a sovereign group outside the boundaries of nation-states: What and who is sovereign? Is sovereignty reserved for governance within the borders of nation states? Is data alone being governed or is there something else, like culture or identity, at stake?

This paper aims to speak to such questions about what sovereignty means and who can claim it, specifically in health, by reviewing two historical case studies of autonomous health movements (AHMs) and identifying four factors that allowed these AHMs to maintain shared connections between their members (which I call binding dimensions of sovereignty). AHMs are experiments in more collective, anti-state healthcare that have sought to recreate people's relationships to health, their bodies, and their communities especially in cases of stigmatized healthcare.[8] AHMs are concrete and under-examined examples of groups seeking sovereignty beyond the nation-state. In the following sections, I review historical case studies of self-managed abortions and the Black Panther Party's organizing of free independent health clinics. I ask: what are the relational features of AHMs and how do they translate to the pursuit of health data sovereignty beyond borders? From these case studies, I identify four binding dimensions of sovereignty: ideological or political identity, shared cultural or identity-based experiences, connection to place, and control over physical infrastructure.

When discussing data sovereignty, this paper conceptualizes health data broadly. Instead of examining a particular kind of data that AHMs engage with, I start with questions about how sovereignty is constituted in and by AHMs through these four binding dimensions. From there, I consider how those relationships of sovereignty affect design considerations for data systems downstream. This approach is both an extension of and departure from Critical Data Studies (CDS) approaches. It extends CDS' call for situated and context-specific ways of understanding the

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[7] See the following for a comprehensive review of media theory and datafication: Mirko Tobias Schäfer and Karin Es, Van, eds., *The Datafied Society. Studying Culture through Data* (Amsterdam University Press, 2017), https://doi.org/10.5117/9789462981362.

[8] Naomi Braine coins the term AHMs, and I primarily draw on her definitional work. However AHMs have been covered by different names by other authors. Naomi Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action," *Health and Human Rights Journal* 22, no. 2 (2020): 85–97.

implications of Big Data (i.e. data collected at mass volume, velocity, variety, and scope from digital devices), eschewing "theory-free" categorizations made by large-scale data analysis and algorithms.[9] However, I depart slightly from CDS' examination of "data assemblages," or "the technological, political, social, and economic apparatuses… that constitute[s] and frame[s] the generation, circulation and deployment of data."[10] I pay attention to how people group themselves rather than how they are grouped by algorithms. I do not wish to make visible how people at the margins are affected or constituted by Big Data but rather how they function independent of Big Data and can therefor inform a new imagination of what data sovereignty is. The intention is to reimagine possibilities for data management. I start with sovereignty, rather than data, to avoid being locked into current configurations of data sovereignty.

I argue that data sovereignty praxis must engage with different components of sovereignty and the question of who forms a collective (and how) to assess which routes are available to promote autonomy, sovereignty, and self-determination in data collection and use. I conclude with a discussion of alternative pathways for data sovereignty researchers, technologists, and designers of health data management systems to strengthen theory and practice by engaging more with collective identity and drawing inspiration from Indigenous Data Sovereignty. These alternative pathways include designing data consent and sharing systems according to cultural principles, co-opting and redesigning data infrastructures based on relationships, creating political coalitions and data service hubs, and navigating the blurry boundaries legal rights to sovereignty.

2. Contextualizing Health Data Sovereignty

2.1 AHM Engagements with Health Data

Even though I start with the configurations of people in health organizations rather than data, it is still useful to briefly discuss the kinds of platforms that health data is collected through and where they may be stored to understand the downstream implications for sovereignty. Health data, defined as data that conveys the health status of an individual, is increasingly widespread and can be collected both in healthcare and non-healthcare settings. Lämmerhirt and Schubert specifically

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[9] See the following for a definitions and implications of big data: Rob Kitchin, "Big Data, New Epistemologies and Paradigm Shifts," *Big Data & Society* 1, no. 1 (April 1, 2014): 2053951714528481, https://doi.org/10.1177/2053951714528481.

[10] Andrew Iliadis and Federica Russo, "Critical Data Studies: An Introduction," *Big Data & Society* 3, no. 2 (December 2016): 2053951716674238, https://doi.org/10.1177/2053951716674238.

delineate between personal data, generated from popular devices, and professional data, generated by engagements with the formal medical system.[11]

Both personally and professionally generated data are often maintained and controlled by software platform providers, their partners, or, in rare cases, the institutions using those platforms. In healthcare settings, professional data are often collected and stored in Electronic Health Records, which store data either locally at hospitals or with cloud-based storage providers.[12] The federal Health Insurance Portability and Accountability Act (HIPAA) is colloquially considered the privacy-protecting law for personal health information. However, HIPAA regulations do more to regulate how information is shared amongst 'covered entities' like healthcare providers, health insurance plans, and healthcare clearinghouses that process and store electronic records.[13] Professionally collected data may also include public health data stored by government departments or their corporate partners. Outside of healthcare settings, personal data may be collected through self-tracking tools or the willing sharing of health data in online support groups or forums.[14] Both personal and professional data can be sold anonymously with relative ease to data brokers and accessed with minimal regulations by law enforcement, though it is beyond the scope of this paper to discuss access in detail.[15]

AHMs function within this landscape of personally and professionally collected data; since they work with populations or health care that is more stigmatized, AHMs are typically more subject to surveillance and stigma themselves. Furthermore, as experiments in collective and anti-state healthcare, AHMs likely manage their own information. AHMs might be fighting against the location surveillance of people who use drugs, seeking to protect the electronic health records of people seeking abortions or gender-affirming care, or collecting data like demographics or citizenship status on a community's health for policy advocacy.

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[11] In their work, these authors speak to the implications of different data types for patient/provider relationships. Danny Lämmerhirt and Cornelius Schubert, "Old Data in New Devices? Problematic Popularizations of Digital Health Data and Consumer Devices," 2024, https://nbn-resolving.org/urn:nbn:de:0168-ssoar-93706-7.

[12] Denita Neal, "Choosing an Electronic Health Records System: Professional Liability Considerations," *Innovations in Clinical Neuroscience* 8, no. 6 (June 2011): 43–45.

[13] Zubrzycki has an excellent legal review of the implications of HIPAA in the context of U.S. abortion data regulations in the early 2020's. Carleen M Zubrzycki, "The Abortion Interoperability Trap," *The Yale Law Journal Forum* 132 (2022), https://www.yalelawjournal.org/forum/the-abortion-interoperability-trap.

[14] I draw this definition of health data from James Shaw and Sharifah Sekalala, "Health Data Justice: Building New Norms for Health Data Governance," *Npj Digital Medicine* 6, no. 1 (February 28, 2023): 30, https://doi.org/10.1038/s41746-023-00780-4.

[15] Again, see the following for a legal review: Zubrzycki, "The Abortion Interoperability Trap."

AHMs may also find themselves engaging with data that is somewhere between personally and professionally collected; they may run autonomous clinics outside of formally constituted institutions, they may work with traditional medicine or healers, or may run distributed networks of home healthcare that use personal devices in a pseudo-professional capacity. In this landscape of engagement with personally to professionally collected data, the intention of this paper is to understand how data management strategies implemented by designers of health data-based software can align with the pursuit of sovereignty by organizations like AHMs.

2.2 Definitions of (Data) Sovereignty

Clarifying the concept of sovereignty is important because there is still little agreement as to how data sovereignty should be defined and who should hold the power to manage data.[16] In international law and politics, sovereignty has traditionally been referred to as the ability of a nation, state, or region to self-govern and manage information consistently with that nations' law and customs.[17] In legal definitions, sovereignty is placed within geographical bounds of a nation-state, especially in the European Union where countries in the union are often negotiating their ability to self-govern. Digital sovereignty has become increasingly relevant in the discussion of nation-state power and is commonly used in political discourse to elevate the nation state's control of technology, data, and media communications.[18] Therefor data sovereignty often falls under the umbrella of digital sovereignty in nation-state discourse.

Digital and data sovereignty of nation states is discursively argued to underpin and individual's power for self-determination by supporting the human rights

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[16] Hummel et al. provide an extensive literature review through 2018 that demonstrates the wide variety of meanings that data sovereignty has been assigned. Patrik Hummel et al., "Data Sovereignty: A Review," *Big Data & Society* 8, no. 1 (January 2021): 205395172098201, https://doi.org/10.1177/2053951720982012.

[17] The following articles speak to legal sovereignty both in Western nation-states and Indigenous nations. Carol C. Gould, "Self-Determination beyond Sovereignty: Relating Transnational Democracy to Local Autonomy," *Journal of Social Philosophy* 37, no. 1 (March 2006): 44–60, https://doi.org/10.1111/j.1467-9833.2006.00302.x; Hurst Hannum, *Autonomy, Sovereignty, and Self-Determination: The Accommodation of Conflicting Rights* (University of Pennsylvania Press, Inc., 2011), https://doi.org/10.2307/j.ctt3fh82n; Tahu Kukutai and John Taylor, "Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs," in *Indigenous Data Sovereignty: Toward an Agenda* (ANU Press, 2016), https://www.jstor.org/stable/j.ctt1q1crgf.8.

[18] Julia Pohle and Thorsten Thiel, "Digital Sovereignty," *Internet Policy Review* 9, no. 4 (December 17, 2020), https://doi.org/10.14763/2020.4.1532.

doctrines of a given nation.[19] However, the value of state sovereignty for individual members of the public is complicated by the recent turns of global democracies toward nationalism.[20] These nationalist turns create deep divides between the interests of states and the people residing in them. Cybersecurity efforts within nation-states have arisen alongside nationalist moves towards border control,[21] and national data sovereignty is often used as justification for centralizing the power of nation-states over data as an economic resource. [22] Although these data localization efforts intend to give residents better control over their data[23] they backfire if a region does not govern in its citizens' best interest. Furthermore, the internet has complicated the locus of control for data sovereignty by weakening the ability of states to control information flow between borders,[24] rendering many of these efforts performative in nature.

In the domain of health, data sharing is often prioritized within and across nation-states for better outcomes in research, public health, and even individual self-improvement.[25] I do not wholeheartedly critique data sharing efforts becausee data sharing efforts can help to progress treatment options and assess urgency of public health emergencies. Instead, I call on public health and health researchers to consider the groups that are affected by this data sharing and consider how they can better side

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[19] Pohle and Thiel, "Digital Sovereignty."

[20] In her book, Walia describes global trends in nationalism in the late 2010's and early 2020's, extensively detailing nationalist turns across the world. Harsha Walia, Robin D. G. Kelley, and Nick Estes, *Border and Rule: Global Migration, Capitalism, and the Rise of Racist Nationalism* (Chicago: Haymarket Books, 2021).

[21] See the following for a discussion of the co-evolution of cybersecurity and nationalism: Ronald J. Deibert and Louis W. Pauly, "Mutual Entanglement and Complex Sovereignty in Cyberspace," in *Data Politics: Worlds, Subjects, Rights*, Routledge Studies in International Political Sociology (London ; New York: Routledge, Taylor & Francis Group, 2019).

[22] See the following for a discussion of data as an economic resource: Arne Hintz, "Data and Policy," in *Data Justice* (London: SAGE Publications Ltd, 2022), 89–104; Teresa Scassa, "Designing Data Governance for Data Sharing: Lessons from Sidewalk Toronto," *Technology and Regulation*, 2020, 44–56, https://doi.org/10.26116/techreg.2020.005.

[23] See also for definitions of data localization: Hintz, "Data and Policy."

[24] Braman, *Change of State*; Kukutai and Taylor, "Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs."

[25] See for a discussion of data the purposes of self-improvement: Btihaj Ajana, "Digital Health and the Biopolitics of the Quantified Self," *DIGITAL HEALTH* 3 (January 2017): 205520761668950, https://doi.org/10.1177/2055207616689509; See for a discussion of data cooperatives for the purposes of data sharing: Alessandro Blasimme, Effy Vayena, and Ernst Hafen, "Democratizing Health Research Through Data Cooperatives," *Philosophy & Technology* 31, no. 3 (September 2018): 473–79, https://doi.org/10.1007/s13347-018-0320-8.

with communities of marginalized patients, especially in situations of stigmatized healthcare (e.g. abortions or HIV treatment).

The other end of the data sovereignty spectrum often disregards legal definitions of sovereignty and borders in favor of data sovereignty increasing the ability of individual ‘consumers’ to control their data through legislation and/or IT infrastructure.[26] These efforts rely on strengthening individual autonomy, defined as an individual’s ability to freely manage their own behavior, bodies, and enforce claims to power over data. In the domain of health, some literature calls on designers of health technology to prioritize the “digital sovereignty” of their users by creating more transparent approaches for users to understand and control their data.[27] Individual self-determination is a newer approach to data sovereignty but is present, nonetheless.[28] An overreliance on individual sovereignty, however, can be as problematic as state sovereignty because an individual’s ability to resist platform privacy policies and surveillance is limited, even with transparently designed platforms.[29]

Some of the confusion about the definitions of sovereignty arises from vague terminology and conflation between the ideas of sovereignty, autonomy, and self-determination. Typically, self-determination is a philosophy that refers to the right of all people to freely pursue political, social, economic, and cultural development.[30] Meanwhile, autonomy is broadly used to describe an individual’s free decision making or the collective autonomy of local self-organized/self-governing groups. The term “data autonomy” has been used to refer to the mediation of individual and collective interests when it comes to managing and governing data.[31] The question arises, then, of why this term is not more commonly used, because it would be particularly helpful

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[26] Hummel and collegues’ two papers speak to sovereignty as both an individual and state quality Hummel et al., “Data Sovereignty”; Hummel et al., “Sovereignty and Data Sharing.”

[27] Paola Pierri and Bianca Herlo, “Exploring Digital Sovereignty: Open Questions for Design in Digital Healthcare,” *Design for Health* 5, no. 1 (May 2021): 161–75, https://doi.org/10.1080/24735132.2021.1928381.

[28] Pierri and Herlo, “Exploring Digital Sovereignty,” discuss discursive constructions of digital sovereignty.

[29] Van Dijck mentions this limitation in Van Dijck, “Datafication, Dataism and Dataveillance.”

[30] Gould gives this definition of self-determination in a paper that tries to argue that self-determination can happen beyond statehood by looking at local autonomy. It is a similar argument that I am developing in this paper, although I am looking to propose different concepts of sovereignty rather than shift the focus to the terminology of “self-determination”. Gould, “Self-Determination beyond Sovereignty.”

[31] See Oskar J. Gstrein, “Data Autonomy: Beyond Personal Data Abuse, Sphere Transgression, and Datafied Gentrification in Smart Cities,” *Ethics and Information Technology* 26, no. 3 (September 2024): 61, https://doi.org/10.1007/s10676-024-09799-x.

for defining data controllability for collectives that are not necessarily legally self-governing. It is also a legitimate ask for the word "sovereign" to remain reserved for legally recognized self-governing entities, especially as tribal governments fight for land back and a return of culturally important information to the stewardship of Indigenous people.

However, data autonomy is not as frequently used, nor does it commonly refer to an already-defined collective looking to manage their data in community. Data sovereignty, on the other hand, is a widely recognized and clearly disagreed upon term that warrants attention in a changing landscape of what it means to have digital and data sovereignty. Pohle and Thiel argue that the term 'data sovereignty' is more of a discursive tool than a legal or organizational tool;[32] it is a term that has come to refer to individuals, states, and intermediate groups such as unions, cultural minorities, or other sub-communities, and is worth clarifying. Therefor I maintain focus on data sovereignty in this paper because of its wide use in the field, its discursive (rather than legal) nature, and its new digital conceptualizations that cannot be contained to the geopolitical borders.

There have been practices suggested to mediate tensions across all possible spectrums of sovereignty. Data governance practices, like increasing data collection transparency and implementing meaningful informed consent to the use of data, are intended to support individual sovereignty in the context of state needs.[33] Other approaches are intended to support collective decision making outside the state through data stewardship, cooperatives, and trusts.[34] These practices usually pool data and delegate decision making about that data either through voting, deliberation between members, or a trusted/elected leader. In health, data cooperatives are sometimes suggested for special-interest patient groups, or broadly for anybody interested in pooling data for research purposes.[35] Yet a recent study has found that data cooperatives have failed to maintain ethics standards and attract co-op

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[32] See the following for a full explanation of their argument: Pohle and Thiel, "Digital Sovereignty."

[33] Lauri Goldkind, Lea Wolf, and Walter LaMendola, "Data Justice: Social Work and a More Just Future," *Journal of Community Practice* 29, no. 3 (July 3, 2021): 237–56, https://doi.org/10.1080/10705422.2021.1984354; Stephen Molldrem, Anthony K J Smith, and Vishnu Subrahmanyam, "Toward Consent in Molecular HIV Surveillance?: Perspectives of Critical Stakeholders," *AJOB Empirical Bioethics* 15, no. 1 (January 2, 2024): 66–79, https://doi.org/10.1080/23294515.2023.2262967.

[34] See the following for a rich breakdown of data trusts and the forms they can take. Stuart Mills, "Who Owns the Future? Data Trusts, Data Commons, and the Future of Data Ownership," *SSRN Electronic Journal*, 2019, https://doi.org/10.2139/ssrn.3437936.

[35] Blasimme, Vayena, and Hafen, "Democratizing Health Research Through Data Cooperatives."

members.[36] Furthermore, it is often impossible to actually give members of a data trust true autonomy because the custody of data flows are mired by unclear territories and ownership rules.[37]

Indigenous data sovereignty (IDS) is one of the few initiatives with socio-cultural and political cohesion, as well as one of the most coherent definitions of data sovereignty, because it considers itself as continuous with other forms of tribal sovereignty.[38] IDS is focused not on data for its own sake, but rather data to preserve cultural practices, maintain community relationships, and to rectify marginalization, power asymmetries, and injustices of colonization.[39] In an article discussing Indigenous health sovereignty in Māori communities, Jansen starts their definition of data sovereignty with an assertion of sovereignty, writing: "I assert that Māori sovereignty is informed by knowing about ourselves. Knowing who *we* are, where *we* are, what *we* do, when *we* do it, how *we* do it or how much *we* do what *we* do."[40] By starting with a definition of sovereignty, rather than data, Jansen sets up a continuity with the idea of sovereignty and the needs of a collective. This is not to say that it is always possible to reconcile the needs of an individual with that of a collective, even with cultural cohesion; in the case of genomic data, for instance, an individual's choice to share genetic data can implicate an entire community in genomic surveillance.[41] However, creating guiding principles based on cultural and political cohesion can assist in managing such tensions.

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[36] Tempini and Doughty presented these early findings on data cooperatives at the 2024 Society for the Social Studies of Science conference. Their paper is still forthcoming. Niccolò Tempini and Tom Doughty, "Still Unproven: Are Data Cooperatives Ever Going to Come of Age?" (Society for the Social Studies of Science and the European Association of Science and Technology Studies, Amsterdam, July 18, 2024), https://nomadit.co.uk/conference/easst-4s2024/paper/85505.

[37] Van Dijck, "Datafication, Dataism and Dataveillance."

[38] See Hummel et al., "Data Sovereignty." It is not clear if Hummel and coauthors are Indigenous, so their ability to speak to IDS comes specifically from the literature review they conduct and the ways they contextualize IDS in other data sovereignty work.

[39] Kukutai and Taylor, "Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs." To be clear, IDS is not a monolith; Kukutai and Taylor work reviews IDS in an introductory book chapter, tying together many common threads across different Indigenous tribes globally.

[40] Rawiri Jansen, "Indigenous Data Sovereignty: A Māori Health Perspective," in *Indigenous Data Sovereignty: Towards and Agenda* (Canberra: The Australian National University Press, 2016), 193–212.

[41] See the following for a description of risks associated with individual consent in Indigenous genomic data. Krystal S. Tsosie, Joseph M. Yracheta, and Donna Dickenson, "Overvaluing Individual Consent Ignores Risks to Tribal Participants," *Nature Reviews Genetics* 20, no. 9 (September 2019): 497–98, https://doi.org/10.1038/s41576-019-0161-z.

Despite its strengths, IDS is barely referenced in Western data sovereignty literature.[42] Kukutai and Taylor (2016) critique broader data sovereignty debates for their over-reliance on legal jurisdictions of national governments or multinational corporations. An overreliance on legal jurisdiction, they write, leads nation-states to be more concerned with "populations" than "people", reducing people to their identity as citizens rather as wholistic, culturally embedded agents. To strengthen initiatives outside of IDS, we must look at other spaces where people have strong conceptualizations of sovereignty, autonomy, and self-determination.

3. Case Studies: Autonomous Health Movements

Autonomous health movements are a kind of social movement that aim to fill systemic gaps in healthcare and pioneer new public health approaches.[43] AHMs are characterized by 1) de-medicalizing issues, meaning empowering people who are not socially sanctioned medical authorities to care for themselves; 2) shifting power away from centralized control and 3) a willingness to work around or outside the law. Autonomous health movements often arise from contexts where health issues have been stigmatized, institutionally neglected, or criminalized, so AHMs often function outside of institutional boundaries by necessity. AHMs fight for policy changes but their focus is implementing community-based health. Braine uses self-managed abortions (SMA) and harm reduction (HR) as examples of AHMs.

Braine writes that the boundaries of autonomous health movements are still porous at this stage of their conceptual development. For this reason, I provide some more clarity on what it might mean to promote autonomy outside of large institutional control. Autonomy might be signaled by an organization's mutual aid ethos, where mutual aid aims to provide assistance horizontally out of solidarity rather than charity.[44] Autonomy is also closely tied to an organization's funding structure: an organization cannot be fully autonomous if it is over-reliant on a single funder and therefore tied to that funder's goals. Some schools of thoughts on social movements argue that crowdsourced funding is the only way to minimize reliance on agendas of powerful organizations and increase self-reliance.[45] Yet, data sovereignty mostly

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[42] Hummel et al., "Data Sovereignty." Slightly tongue-in-cheek, Hummel and co-authors write that German publications do not mention IDS even in passing.

[43] See the following for original AHM definitions: Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action."

[44] Alex Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health," *Coils of the Serpent* 11 (2023): 120–47, https://doi.org/https: //doi.org/10.17613/agcb-7392.

[45] The following compilation from a collective of community organizers speaks to the non-profit industrial complex, arguing for social movements to be self-sustained in their funding rather than

engages with questions of funding on the periphery of the literature, often in the context of poorly sustained data management initiatives.[46] I include decentralized funding as a criterion for case studies of autonomous health movements.

AHMs are situated in long histories of social movements. Social movements play a big role in changing cultural attitudes, informing policy, and pioneering new governance approaches.[47] In health, social movements have led to changes in healthcare/public health delivery, changes in drug approvals, increased research funding, and changes in civil society.[48] For instance, demands for universal health care have largely been seeded by social movements and the movement for a treatment for HIV/AIDs has significantly changed institutional attitudes about patient credibility and increased cultural acceptance of LGBTQ+ people.[49] As fights over data sovereignty increase with the rise of nationalist states, expanding internet access, and wide-spread adoption of data-reliant Artificial Intelligence systems, social movements and AHMs will be critical in defining governance and cultural attitudes.

3.1. Self-Managed Abortion and The Black Panther Party's People's Free Medical Clinics

The following two historical case studies on the Black Panther Party's People's Free Medical Clinics (PFMCs) and the SMA movement are used in this paper to illustrate how AHMs sustain themselves and shape the boundaries of "who" is sovereign. I use

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relying on big doners. INCITE! Women of Color Against Violence, *The Revolution Will Not Be Funded* (North Carolina: Duke University Press, n.d.), https://www.dukeupress.edu/the-revolution-will-not-be-funded.

[46] Heeks and Shekhar review various data justice initiatives and mention, very briefly, that none of the initiatives were sustained long-term because sponsoring organizations pulled out funding. Richard Heeks and Satyarupa Shekhar, "Datafication, Development and Marginalised Urban Communities: An Applied Data Justice Framework," *Information, Communication & Society* 22, no. 7 (June 7, 2019): 992–1011, https://doi.org/10.1080/1369118X.2019.1599039.

[47] Jennifer Earl, "The Cultural Consequences of Social Movements," in *The Blackwell Companion to Social Movements*, ed. David A. Snow, Sarah A. Soule, and Hanspeter Kriesi (Oxford, UK: Blackwell Publishing Ltd, 2007), 508–30, https://doi.org/10.1002/9780470999103.ch22.

[48] See Phil Brown and Stephen Zavestoski, "Social Movements in Health: An Introduction," *Sociology of Health and Illness* 26, no. 6 (September 2004): 679–94, https://doi.org/10.1111/j.0141-9889.2004.00413.x; Robert H. Keefe, Sandra D. Lane, and Heidi J. Swarts, "From the Bottom Up: Tracing the Impact of Four Health-Based Social Movements on Health and Social Policies," *Journal of Health & Social Policy* 21, no. 3 (June 27, 2006): 55–69, https://doi.org/10.1300/J045v21n03_04.

[49] Beatrix Hoffman, "Health Care Reform and Social Movements in the United States," *American Journal of Public Health* 93, no. 1 (2003); Steven Epstein, "The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials," *Science, Technology, & Human Values* 20, no. 4, (1995): 408–37.

historical case studies because they allow for a "close examination of people, topics, issues, or programs."[50] I write about and analyze PFMCs and SMAs specifically as AHMs, choosing my cases based on the research question and guiding theory of sovereignty beyond borders. Since I am interested in describing how these projects can inform data sovereignty, rather than the projects themselves being the primary object of study, I use secondary sources that have already framed these two cases as autonomous movements through extensive primary research. These secondary sources help to "contextualize the research setting" and "offer alternative views on the events explored."[51]

These two case studies are chosen because they represent how AHMs can diverge in format, size, and political alignment while still maintaining bonds between their activists and constituencies. I briefly discuss the history of these movements then describe their specific features in the next section in service of defining four binding dimensions or factors that allow autonomous health movements to maintain shared connections.

The U.S.-based Black Panther Party was founded in 1966 in California by Huey Newton and Bobby Seale with the initial mission to protect Black communities from police brutality. The party then expanded to difference state chapters, all of whom were pursuing Black liberation in the United States under a guiding 10-point program.[52] First and foremost, the 10-point program called for the power to determine the destiny of the Black community. While many know the Black Panther Party for their stances on policing and civil rights, they also developed a robust stance on healthcare that involved opening many free clinics for Black Americans. In fact, their emphasis on healthcare strengthened as their emphasis on armed resistance decreased over the party's history, aiming to reframe their mission and appeal to the masses.[53] In 1970, then-leader Bobby Seale issued a directive for all chapters to work towards opening People's Free Medical Clinics in their neighborhoods. The PFMCs were

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[50] See Dominic Detzen and Sebastian Hoffmann, "Methodological Reflections on Historical Case Study and Interpretive Accounting Research," *Accounting History* 26, no. 4 (November 2021): 665–75, https://doi.org/10.1177/10323732211053899.

[51] See again Detzen and Hoffmann, "Methodological Reflections on Historical Case Study and Interpretive Accounting Research."

[52] Roland Martin, "Black Panther Ten-Point Program," in *Encyclopedia Britannica*, September 22, 2023, https://www.britannica.com/topic/Black-Panther-Ten-Point-Program.

[53] I rely heavily on Alondra Nelson's extensive history of the Black Panther Party and their People's Free Medical Clinics. The book is a deep review of primary sources, arguing that the Black Panthers commitment to healthcare was both practical and ideological, creating a lasting legacy of change in the healthcare system. Alondra Nelson, *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination* (Minneapolis: University of Minnesota Press, 2011).

framed as part of the Black Panthers' "serve the people" or "survival" programs that were grounded in meeting community needs. The party's 10-point program was revised in 1972 to include "completely free healthcare for all black and oppressed people," indicating a commitment to health as part of a movement for liberation.[54] Unfortunately, by the late 1970's, much of the Party's activity ceased due to a combination of leadership changes and an extreme targeted effort by the U.S. Federal Bureau of Investigation to surveil, jail, and sometimes kill party leadership.

I use the PFMCs as a case study of autonomous health movements because they 1) worked on de-medicalizing issues that commonly affect Black communities, 2) aimed to level the power imbalances between doctors and patients, and 3) often worked in contention with legal systems and under conditions of high state surveillance. De-medicalization, or what the Black Panthers called "self-health," was heavily promoted. Women that attended and worked at the clinics were taught to do Pap smears and would practice on themselves and each other.[55] The clinics worked to demystify medical authority by allowing patients to challenge the behavior of doctors (most, if not all, of whom were volunteers); sometimes doctors were let go if they received too many patient complaints.[56] PFMCs leveled the power hierarchies of patients and providers through political education initiatives that asked volunteer medics to read the Black Panthers' core political theory. The clinics filled structural gaps in healthcare and became a local option in Black communities that were often far from other health centers. They were imagined as an alternative to profit-driven healthcare and were sites of larger social agendas where people in the community could go for housing assistance, legal advice, and more. In her exhaustive history of the PFMCs, Alondra Nelson (2011) alternates between describing the PFMCs as pursuits toward "community control," "self-determination," "locally controlled alternative institutions," "communities' self-empowerment," and "social, political, and economic autonomy."[57] All the verbiage indicates an autonomous movement in health.

The second case of SMA care is a decentralized international movement that mobilized around offering women safe and accompanied at-home abortions. Chicago-based Jane Collective is said to be an SMA pioneer; opening in 1969 first as a referral clinic, the group went on to offer sliding scale fee abortions in response to a lack of accessible and safe abortions in the U.S..[58] In 1971, Lorraine Rothman and Carol

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[54] Nelson, *Body and Soul.*

[55] Nelson, *Body and Soul.*

[56] Nelson, *Body and Soul.*

[57] Nelson, *Body and Soul.*

[58] Barksdale provides an excellent review of reproductive and trans healthcare from the lens of autonomy. Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health."

Downner invented an abortion technique called menstrual extraction that offered a more DIY approach.[59] Then, the discovery of misoprostol and mifepristone (originally ulcer medication that was discovered to be effective for abortions) in Brazil in the 1980s catalyzed the SMA movement by allowing SMAs to take place on massive scale, especially in Latin American and African countries.[60] In 1999, Women on Waves began to offer abortions on board a Dutch ship that would anchor in international waters to give abortions to people from countries where it was highly illegal.[61] In 2005, Women on Web brought the process online to offer consultations and send medications by mail.[62] Unlike the Black Panther Party, the SMA movement remains very active today, therefore I use present tense when discussing its features. Braine characterizes SMAs as an autonomous health movement because of 1) the movement's attempts to de-medicalize pharmaceuticals for use by people with no professional training, 2) its ability to shift power to people who need abortions, and 3) the willingness of SMA activists to work peripherally to the law, sometimes without a license or in subversive ways (as with Women on Waves).[63]

The two case studies are chosen based on Braine's criteria for AHMs and for their critical differences and similarities. The two movements have different intended audiences: SMAs are highly global and networked in structure while the Black Panthers' PFMCs were opened by a top-down directive from Party leaders and specific to the U.S. However, the differences between these movements make their similarities starker. Despite structural differences, SMA and PFMC activists have similar political ideologies, parallel struggles and success with infrastructures, and shared experiences of discrimination against their constituents. Both cases of AHMs function in a hostile context that continues to neglect care for people seeking abortions, profit off ineffective treatments, and discriminate against Black Americans in both older medical practices and newer machine-assisted medical decision making[64]. Despite their different cultural contexts, SMAs and PFMCs arose out of a

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[59] Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health."

[60] Braine's book is one of the foremost sources framing self-managed abortions as an autonomous movement and documenting its global history, with a specific focus on Latin America. Naomi Braine, *Abortion beyond the Law: Building a Global Feminist Movement for Self-Managed Abortion* (London New York: Verso, 2023).

[61] Braine, *Abortion beyond the Law*.

[62] Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action."

[63] Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action."

[64] See the following for a description of how racism comes to play out in present-day devices: Sarah El-Azab and Paige Nong, "Clinical Algorithms, Racism, and 'Fairness' in Healthcare: A Case of Bounded Justice," *Big Data & Society* 10, no. 2 (July 2023): 20539517231213820,

need to fill the gaps where state healthcare was neglected or even criminalized. The two case studies, while not covering the data management practices of each group, provide a guidepost for data sovereignty to ground itself in bigger visions of sovereignty, especially in contexts of intense surveillance or neglect.

4. Findings: The Four Binding Features of Sovereignty

Based on the SMA and PFMC case studies, I propose four binding dimensions that allow autonomous health movements to maintain shared connections and a shared vision for sovereignty. These are intended to provide a starting point for data sovereignty researchers and technologists who are looking to identify audiences and visions for sovereignty initiatives outside the confines of nation-state borders. These four factors that emerge from an examination of autonomous health movement can help define who are the "agents" of sovereignty.[65] These four factors are not likely exhaustive; they are intended to demonstrate how conceptualizing sovereignty in a broader sense can inform data-intensive technological initiatives.

The four binding factors of sovereign groups that I identify are: a group's ideological or political identity, their shared cultural or identity-based experiences (including, but not limited to, experiences with state oppression or neglect), their connection to place, and their control over physical infrastructure. These four dimensions not only maintained connections between AHMs but also grounded them in a shared vision of sovereignty that moved beyond the immediate health-related goals of each movement.

4.1 Shared Ideological or Political Beliefs

First, shared ideological or political beliefs bind together a group of people who are asserting their autonomy. Both SMAs and PFMCs engaged in providing political education to their constituents, building capacity to sustain themselves and bringing in politically informed leaders. Both groups also unified under an ideologically explicit commitment to mutual aid and community care. The politics of SMAs were/are determined locally whereas the Black Panther Party issued national directives.

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https://doi.org/10.1177/20539517231213820; Darshali A Vyas, Leo G Eisenstein, and David S Jones, "Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms," *The New England Journal of Medicine*, 2020, 9.

[65] Hummel and coauthors propose that, in order to clarify definition of data sovereignty, authors should seek to emphasize exactly who is the agent of sovereignty. I take their note here to bring clarity to my own writing about data sovereignty. Hummel et al., "Data Sovereignty."

The Black Panther Party unified under radical political theory and an ideological commitment to community survival programs. Politically, The Black Panther Party drew inspiration from the writings of Karl Marx, Mao Zedong, Ernesto "Che" Guevara, and Frantz Fanon.[66] The 'trusted experts' that volunteered at the PFMCs were expected to partake in political education and read these theorists. The party ran extensive political education programs in their clinics; however, the PFMCs were still open to anybody who needed their services. In addition to political theory, the PFMCs were a manifestation of the party's belief in "community action projects" and sustained an ideological commitment to an ethic of caring for their people.[67] The Black Panther Party explicitly committed to an ideology of community survival, integrating the PFMCs with other social services like housing and legal advice. The Black Panthers formed a part of their political identity through their opposition to mainstream American policies and politics. The Black Panther Party's political identity was sometimes fragmented by party members who were dissatisfied with the hierarchical nature of the party's politics,[68] bringing to question whether autonomous health movements must also be decentralized.

The SMA movement has a less hierarchically dictated but equally active political identity. Much like the Black Panther Party, activists in SMA movements are retained in the movement through a political commitment to feminist theory and/or through an ideological commitment to care. The SMA movement has identified loosely with feminist, lesbian-feminist, and anarcho-feminist political theory,[69] with many activists seeing their work in connection to histories of activists and community-based healers who dealt with health issues beyond abortion. Simultaneously, like the Black Panthers, SMA functions to meet material needs of ordinary people and to stay accessible to activists who prefer not to engage in political theorizing. These activists instead prefer working on SMAs out of an ethic of mutual aid and care.[70] SMA activists have been committed to *acompañamiento*, or accompaniment: the idea that all women must be physically accompanied through an abortion because nobody should have to go through something alone. Throughout Latin America today, SMA collectives will integrate feminist political education into

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[66] Nelson, *Body and Soul.*

[67] Nelson, *Body and Soul.*

[68] Dana M. Williams, "Black Panther Radical Factionalization and the Development of Black Anarchism," *Journal of Black Studies* 46, no. 7 (October 2015): 678–703, https://doi.org/10.1177/0021934715593053.

[69] Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health."

[70] Braine, *Abortion beyond the Law.*

workshops on safe medication use for abortion, but people do not need to join the movement as activists to receive or administer abortions.[71]

4.2 Shared Cultural or Identity-based Experiences

The second binding feature of AHMs is shared cultural or identity-based experiences. Despite political unity amongst activists, people who engaged with SMAs or the PFMCs were not required to have a shared politic, instead having shared experiences and culture that sometimes emerged from regional, gender, racial, or ethnic identity. In the case of PFMCs, patients had varied experiences with medical discrimination, living in remote areas without medical access, struggles with over-policing, etc. At the very least, constituents of PFMCs were bonded through the shared experiences of Black Americans living in the 1960s/70s United States.

In the SMA movement, shared experiences emerged from literally obtaining or administering abortion services. As far as culture, SMAs took on the regional identities of the places in which they functioned. In the U.S., SMA activists are especially fragmented in identity; Black women have been at the front of reproductive justice in the U.S. and leave their own heavy legacy in SMA, yet legacies of white feminism often function to exclude Black women from movements.[72] Today, white activists in U.S.-based SMA movements are beginning to acknowledge and reconcile these divisions. SMA movements and The Black Panther Party both had constituents that participated heavily in protests. These protest identities that emerge out of shared experience are described by new social movement theory as the development of "oppositional" identity, where movements and the people within them come to define themselves by what they oppose.[73]

4.3 Connection to Place

The third binding feature that brings sovereign groups together is connection to place. The establishment of PFMCs was only possible due to the presence of regional chapters and the clinics were often especially important in areas that were remote

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[71] Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action."

[72] Braine, *Abortion beyond the Law*.

[73] See the following for explanations of oppositional identity in harm reduction movements: Neil Weiloch, "Collective Mobilization and Identity from the Underground: The Deployment of 'Oppositional Capital' in the Harm Reduction Movement," *The Sociology Quarterly* 43, no. 1 (2002): 45–72.

from other healthcare facilities. Even more than the PFMCs, SMA movements have taken on the regional identities of the places in which they function. Connection to place has been critical for establishing the infrastructure that these movements needed for their services. SMAs have rooted themselves in regions and use interpersonal connections to support in-person *acompañamiento* that enabled carrying out their ideology of care. Similarly, the infrastructure of PFMCs relied on interpersonal connections with regional donors to donate money, supplies, and medical labor.

Connection to place is intimately tied with the bonds of shared culture, experiences, and infrastructure. However, connection to place does not alone create culture or infrastructure, so I keep it as a separate category to emphasize that 1) culture can exist across a diaspora of people that don't necessarily live in the same place and 2) infrastructure is not necessarily place-based, as in the case of using telecom services.

4.4 Shared Physical Infrastructure

Finally, shared ownership over physical infrastructure and/or the ability to co-opt that infrastructure solidified the ability of SMAs and PFMCs to maintain autonomous or sovereign operations. Both movements relied of the co-opting of existing infrastructures as well as donated supplies and labor from trusted medical experts. The PFMCs would not have been possible without the control of physical spaces in which the clinics operated, and an inability to obtain space was often their downfall. Each chapter found their own clinic locations, often renovating storefronts or trailers. The search for clinics was made especially challenging by ongoing police surveillance and confrontation, making clinic security a key issue.[74] Some clinics never succeeded, such as the Milwaukee chapter, but others were foundational in creating today's free clinics and in kicking off life-long commitments to health equity by former Black Panther Party members.[75] Funding for PFMCs was scattered and decentralized; the clinics relied on the donation of supplies, even by pharmaceutical companies in Oregon and Washington state chapters. Religious organizations and universities also donated supplies, money, or labor, as was the case of University of New Haven donating money to the Connecticut PFMC. Some Black Panther chapters received federal grants but most did not. The clinics relied on volunteer labor from 'trusted experts' or medical doctors that had radical politics.

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[74] Nelson, *Body and Soul.*

[75] Nelson, *Body and Soul.*

SMAs have relied on more distributed infrastructure, repurposing phone, internet services, and, in the case of Women on Waves, ships. Early SMA services in Ecuador used phone hotlines to provide referrals and medications.[76] These hotlines were paired with interpersonal networks of care that provided women *acompañamiento*. Now, SMAs often combine telemedicine with community-based accompaniment strategies.[77] In the U.S., SMA networks are highly distributed. Braine describes this as a "cell-like structure" that keeps the network running even if one node is down.[78]

Access to the abortive drug misoprostol represented another instance of infrastructural access through volunteer labor. When Brazilian activists first discovered that misoprostol can be used to as an abortion medication, the medication was obtained with relative ease because it was a common ulcer medication.[79] Access was further facilitated by many SMA activists holding day jobs as medical professionals; Women on Waves/Web, for instance, is run by doctors without other institutional affiliations. SMAs have influenced medicalized abortion practices and public health approaches; shortly after the Brazilian discovery of misoprostol, French researchers developed mifepristone to be taken with misoprostol the combination of the two medications is now the most prescribed combination for early-stage abortion.[80] Such access to shared physical infrastructure and material needs supported the functioning of SMA movements.

5. Discussion: Integrating Sovereignty Theory with Data Practices

The boundaries of how sovereign groups come together in both SMAs and PFMCs are porous. Both movements were unified by political beliefs and shared experiences. However, neither movement excluded people from receiving services based on their politics. Instead, they provide(d) political education to their volunteers and constituencies. Both movements served people who were tied together by shared experiences of stigmatization and marginalization, as well as trouble accessing necessary health services. However, their focus was on providing care, with only a

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[76] Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health."

[77] Braine, "Autonomous Health Movements: Criminalization, De-Medicalization, and Community-Based Direct Action."

[78] Felicia Kornbluh, "Making Abortion Safe Outside of the Legal System: A Q&A on Self-Managed Abortion," *The Nation*, January 30, 2024, https://www.thenation.com/article/society/self-managed-abortion-naomi-braine/.

[79] Barksdale, "Anarchist-Feminist Perspectives on Autonomous Reproductive and Trans Health."

[80] Britannica, The Editors of Encyclopedia, "RU-486," in *Britannica*, June 6, 2024, https://www.britannica.com/science/RU-486.

secondary focus on protesting state neglect. Furthermore, both movements co-opted existing infrastructures but relied on a distributed network of telecom servers and/or donors to do so rather than purchasing their own buildings, internet servers, or land. These bonds of identity, politics, experiences, places, and infrastructures supported the missions of SMAs and PFMCs.

The next question is how to chart a path from these binding dimensions of sovereignty to more specific data sovereignty initiatives. One approach is to make connections between Indigenous Data Sovereignty movements that share many features with AHMs and have already begun charting a path for self-managed data. There is also the possibility of reimagining existing data sovereignty initiatives that are already underway according to the four binding principles of sovereignty. Drawing connections between AHMs, IDS, and other data sovereignty initiatives, I propose ways that technologists and researchers can design for data sovereignty beyond borders by bolstering shared experiences and cultural principles, redesigning and co-opting infrastructures based on relationships, creating political coalitions and data service hubs, and navigating the blurry boundaries of legal rights to sovereignty. I target these recommendations in tandem at researchers and technology designers because of the ways that digital health systems mediate patient, system, and provider needs.[81]

5.1 Bolstering Shared Culture

Based on the analysis of SMAs and PFMCs, one of the primary considerations when designing infrastructures is how to create decision making mechanisms for data that account for cultural principles. Specifically, data sovereignty initiatives can bolster cultural sovereignty by preserving a group's right to self-knowledge, aiding them in accessing, storing, and collecting health information that would typically be under collected or stored with EHRs or public health departments. The Black Panther Party emphasized "a knowledge of self" in their 10-point program and implemented self-health initiatives to de-medicalize certain systems of health. Self-knowledge is also core to the rights of Indigenous people to be sovereign over data. In the United States, tribal governments have a practical need for knowledge of self to be able to govern

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[81] See the following for a more nuanced discussion of how design ethics play a role in improving individual data sovereignty for digital health devices. Pierri and Herlo, "Exploring Digital Sovereignty."

meaningfully, determine citizenship, administer justice, set taxation, and more.[82] Knowledge of self is also a political stance because self-knowledge is a demand to settler states to return that which was once stolen: culture, community, and land.[83]

In IDS, the practice of data sovereignty not only involves reclaiming data collected by non-Indigenous institutions but also building tribal capacity to collect data that is "culture-smart" to improve internal decision making.[84] Data sovereignty initiatives can aim to understand what kinds of data are culturally important for the groups they are being designed for and can create culturally-relevant guidelines for negotiating data use. Examples to learn from include groups like the Metro Auckland Data Stewardship group, which uses a set of guidelines negotiation by leaders and members of the trust to decide how data gets shared with healthcare providers across the greater Auckland area, protecting patient confidentiality and surpassing the need for legally recognized sovereign territories.[85] This could translate to creating guidelines across AHMs or culturally-specific groups to manage consent to data sharing in public health, EHRs, or commercially available software.

To add another layer, technologists and data sovereignty researchers might consider how to design for distributed (or non-place-based) groups that morph in culture depending on region the way that SMA movements do. A fluid identity is also common in many social movements, where groups converge around identity and goals as needed and morph into some other form when the former convergence ceases to be useful or satisfying.[86] One step in the direction of data sovereignty that is flexible based on region and culture are data portability efforts, or the ability to move data from one storage location to another. The European General Data Protection Regulation takes initial steps towards enabling portability.[87] However more work is

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[82] See the following for a discussion of how the internet plays a role in self-knowledge: Marisa Elena Duarte, *Network Sovereignty: Building the Internet across Indian Country* (University of Washington Press, 2017), http://ebookcentral.proquest.com/lib/asulib-ebooks/detail.action?docID=4987329.

[83] See the following for a powerful stance on how calls for decolonization must involve a material return of land to Indigenous people: Eve Tuck and K Wayne Yang, "Decolonization Is Not a Metaphor," *Decolonization, Indigeneity, Education & Society* 1 (2012): 1–40.

[84] Kukutai and Taylor, "Data Sovereignty for Indigenous Peoples: Current Practice and Future Needs."

[85] See Jansen, "Indigenous Data Sovereignty: A Māori Health Perspective."

[86] Cristina Flesher Fominaya, "Collective Identity in Social Movements: Central Concepts and Debates: Collective Identity in Social Movements," *Sociology Compass* 4, no. 6 (June 2010): 393–404, https://doi.org/10.1111/j.1751-9020.2010.00287.x.

[87] See the following for more GDPR information: Hintz, "Data and Policy"; Hummel et al., "Sovereignty and Data Sharing."

needed to develop data potability that emphasizes collective, rather than individual, control.

5.2 Co-opting and Redesigning Relational Infrastructures

The infrastructures of AHMs and other autonomous movements are another important design consideration for technologists and researchers wishing to move beyond borders. Some infrastructures are specific to place and land ownership; this is another commonality AHMs share with IDS movements. For example, the Native BioData Consortium, the first Indigenous-owned infrastructure for the storage of genetic data, seeks to keep storage and decision-making power with Indigenous people by keeping genetic data on Native American land, specifically that of the Cheyenne River Sioux Tribe.[88] Unfortunately, although many American Indians now reside in cities outside of reservation lands, legal jurisdiction and bureaucratic regulations prevent meaningful data control outside of legally recognized sovereignty territories.[89] This is a problem that AHMs will continue to face as well.

Some IDS initiatives are aiming to bypass centralization and balance individual and collective needs in practice by implementing "community consented data", again charting a path for other distributed groups. Boscarino and colleagues (2022) have been developing a computing system that allows both individuals and tribal governments to consent to data use, allowing data to still be mobilized for use even if one individual does not consent to use.[90] This approach to distributed consent serves as an excellent data sovereignty model for AHM groups that are coherent in identity but distributed in place. It is an especially strong model for SMA movements that rely on distributed networks; if one person must drop out of consenting, the whole system will continue to function.

Boscarino and colleagues (2022) rely on a relational approach to make up for connection to place. This aligns with feminist arguments that meaningful consent relies on the ability of people to negotiate directly with each other.[91] Relational theories can be applied to infrastructures like data trusts, stewardships, cooperatives,

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[88] See "Native BioData Consortium," 2021, https://nativebio.org/.

[89] C Matthew Snipp, "What Does Data Sovereignty Imply: What Does It Look Like?," in *Indigenous Data Sovereignty: Toward an Agenda* (ANU Press, 2016), https://www.jstor.org/stable/j.ctt1q1crgf.8.

[90] Nima Boscarino et al., "Federated Learning and Indigenous Genomic Data Sovereignty," *Nature Machine Intelligence* 4, no. 11 (November 15, 2022): 909–11, https://doi.org/10.1038/s42256-022-00551-y.

[91] See Kovacs and Jain for a breakdown of feminist principles of consent and how they can be extended to data management. Anja Kovacs and Tripti Jain, "Informed Consent - Said Who? A Feminist Perspective on Principles of Consent in the Age of Embodied Data," *SSRN Electronic Journal*, 2020, https://doi.org/10.2139/ssrn.3788322.

or collaboratives, that are already being developed, by reshaping digital consent. One article by Mills (2019) has created a solid foundation for assessing the structure of data trusts and commons based on who generates and collects the data. He proposes that trusts can be designed in ways that benefit the collectors of data, the generators of data, or those who the data is about.[92] These designs could further be assessed for fit with infrastructures already available to autonomous movements.

Whether distributed or place-based, AHMs often gained access to infrastructure by coopting existing materials and everyday technologies, with SMAs using phone lines and the PFMCs reclaiming trailers and storefronts. Data sovereignty initiatives can think creatively about the infrastructures already available to them. Rather than building from scratch, existing infrastructures like cloud storage can be repurposed in new ways to give control to collectives or be physically moved to new data storage places.

5.3 Creating Political Coalitions and Data Service Hubs

Funding and coalitions are another important consideration for data sovereignty practices beyond borders. SMAs tapped into global feminist coalitions for resource support while the Black Panther Party worked with other Black power movements for building power during the Civil rights era. Borrowing again from social movement theory, coalitions go a long way to bridging collective identities even when groups vary widely in their context and culture.[93] In this vein, technologists and researchers looking to side with non-institutionalized groups may look to coalitions of organizations or alternative funding pathways.

At their core, approaches to data autonomy should draw on practices of existing social movements and grassroots organizations who already think about autonomy.[94] SMAs and PFMCs alike were not stand-alone initiatives but rather rooted in bigger efforts of feminist and Black liberation movements. Instead of reinventing the wheel, health data trusts should be integrated into larger organizational structures like autonomous health organizations, coalitions, or even unions and neighborhood associations.[95] Though these groups may not be legally sovereign, they represent important communities of interest. One Baltimore-based

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[92] See Mills, "Who Owns the Future?"

[93] Flesher Fominaya, "Collective Identity in Social Movements."

[94] Molldrem and Smith make a similar argument in: Molldrem and Smith, "Reassessing the Ethics of Molecular HIV Surveillance in the Era of Cluster Detection and Response."

[95] Igor Calzada, "Data Co-Operatives through Data Sovereignty," *Smart Cities* 4, no. 3 (September 5, 2021): 1158–72, https://doi.org/10.3390/smartcities4030062.

organization, B-CIITY, is paving the way for a community data cooperative that is intimately tied in with their neighborhoods' needs.[96] They have embedded their data sovereignty work by holding ongoing visioning and brainstorming sessions with their constituents.

If plugging into initiatives proves difficult, data sovereignty initiatives can create standalone community hubs for data services that follow the model of place-based autonomous movements. SMAs and PFMCs both created in-person support hubs in their communities where people could physically go for advice on health or other services. Today, an example of digital hub that follows this model is the Community Technology Collective, which works to provide communication and internet sovereignty toolkits around the U.S..[97] The collective has coalitions around the U.S. that serve different non-tech focused movements by teaching about network sovereignty and providing network toolkit trainings.

Critically, SMAs and PFMCs demonstrate the importance of plugging into broader political analysis while also meeting community needs. The SMAs sustained significant activist participation through a feminist politic and PFMCs brought their trusted experts into political consciousness through required reading for volunteers. In the same vein, data sovereignty initiatives or scholars can work on raising political consciousness or even discussion amongst technologists and non-technical partners. For instance, despite distinct needs of different tribes, Indigenous data sovereignty has created guiding CARE data principles (standing for Collective Benefit, Authority to Control, Responsibility, and Ethics).[98] These principles emerged from a global workshop of Indigenous groups, especially from New Zealand, Australia, United States, and Canada, to determine principles of IDS. Data sovereignty can seek to do the same by developing guiding political principles or taking the lead of groups that have already created them, such as the Feminist Data Manifest-no. Data sovereignty is a political pursuit, whether it is attached to geopolitical borders, individuals, or self-organized groups. Political analysis across disciplinary fields can support data sovereignty's integration with other movements.

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[96] See "Cooperatives & Liberation," B-CIITY Baltimore City Intergenerational Initiative for Trauma and Youth, 2023, https://www.bciity.org/upcoming-events/coops-and-liberation.

[97] See "About CTC," Community Technology Collective, 2020, https://www.ctcollective.org/about.

[98] See the following for an explanation of these principles and how they came to be: Stephanie Russo Carroll et al., "The CARE Principles for Indigenous Data Governance," *Data Science Journal* 19, no. 1 (November 4, 2020), https://doi.org/10.5334/dsj-2020-043.

5.4 Navigating Legal Rights to Sovereignty

The question of legal recognition and self-governance poses a challenge to creating data sovereignty for collectives like AHMs. AHMs at their core have a willingness to work at the boundaries of the law, especially since they are often neglected by the state or heavily surveilled. Indigenous movements depart slightly from AHMs in AHM's willingness to work outside the law. In the United States, tribal governments have legally recognized sovereignty over certain lands that allows them to make decisions about all things that concern their people in that territory. Maintaining legality is an important element of Indigenous sovereignty, though this is a larger discussion outside the scope of this paper. The open questions of legal jurisdiction in Indigenous sovereignty, especially for American Indians residing in cities outside of reservation lands, brings into question who is and is not included in Indigenous sovereignty decision making.[99] As a non-Indigenous person, I cannot and will not attempt to answer the question of who is or is not Indigenous. Rather, I wish to point out that Indigenous data sovereignty initiatives confront the question of "who" head on, finding ways to negotiate decision making about data both in and outside of legal geographical borders.

While legal rights to self-governance may bolster sovereignty, they do not single-handedly determine the possibility of autonomy. The Black Panther Party was not a legally recognized self-governing entity, but they maintained internal governance mechanisms for the party. SMAs were, and are, highly distributed, but still manage to self-govern regionally and maintain the movement through connected networks. Examples like the Zapatista movement in Mexico are also worth examining because the movement has never received legal recognition yet has maintained highly autonomous systems.[100] This begs the question of how technologists and researchers can support sovereign data systems at the boundaries of the law.

To be very clear, I do not believe that the work of data sovereignty lies solely with autonomous movements or non-institutionalized initiatives led by technologists and researchers. There are very valid reasons that the state should bear the burden of redressing data harms and implementing better systems of control over data. That said, the United States has tended to outsource responsibility for serious public health problems to private organizations or individuals rather than tackling them through

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[99] Snipp, "What Does Data Sovereignty Imply: What Does It Look Like?"

[100] See Rodriquz' work for a clearer description of the Zapatistas work. Chris Rodriguez, "Another Way of Doing Health: Lessons from the Zapatista Autonomous Communities in Chiapas, Mexico," 2013.

public systems[101]. State neglect has also tended to replace social support systems with increased policing and criminalization, a phenomenon described by abolitionist Ruth Wilson Gilmore as "organized abandonment".[102] The *Dobbs v. Jackson* case in the United States, which struck down federal protections for abortion care, is a prime example of the state removing protection for critical health care and replacing it with the threat of prosecution. The case studies reviewed here are also examples of where criminalization of abortion or intense policing of Black Americans during the civil rights era (that continues today) led to the development of autonomous health movements. In response, autonomous practices emerge to fill the gaps left by state neglect.

Sovereignty, furthermore, often relies on fraught legal claims to property ownership or borders to assert control over digital data. On one hand, treating data as personal or state property helps with legal arguments for digital rights. On the other, arguments that claim data as property or a feature of citizenship are rooted in racialized, queer, and class-based histories of exclusion that have denied marginalized groups the right of property ownership or citizenship or, worse, treated people as property.[103] In the absence of arguments that rely on claims to property or geographical borders for managing data, AHMs, and the aforementioned examples of initiatives rooted in shared culture, politics, experiences, places, and infrastructures, provide guideposts for imagining data sovereignty in new terms.

6. Conclusion

In this article, I argue that identifying shared ties within organizations is foundational for the assertion of sovereignty. In her book on internet sovereignty in Indian Country (Native American reservation land in the U.S.), Marisa Duarte writes that "infrastructures are the crystallization of institutions, and that institutions emerge from the human relationships that form around common goals."[104] Duarte places common goals of human relationships at the heart of infrastructural crystallization; without relationships, there are no infrastructures. The taxonomy of what becomes

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[101] See Steffen Böhm, Ana C. Dinerstein, and André Spicer, "(Im)Possibilities of Autonomy: Social Movements in and beyond Capital, the State and Development," *Social Movement Studies* 9, no. 1 (January 2010): 17–32, https://doi.org/10.1080/14742830903442485.

[102] See Zahra H Khan, Yoshiko Iwai, and Sayantani DasGupta, "Abolitionist Reimaginings of Health," 2022, https://doi.org/10.1001/amajethics.2022.239.

[103] Lim and co-authors make this argument in their manifesto to abolish claims to privacy that are based in oppressive claims to property. Elisha Lim et al., "Abolish Privacy," *First Monday*, February 5, 2025, https://doi.org/10.5210/fm.v30i2.13671.

[104] See Duarte, *Network Sovereignty: Building the Internet across Indian Country*.

possible for health data sovereignty is dependent on the relationships a group has around common goals, making nation-state sovereignty only one possible route for data sovereignty initiatives.

Drawing from two case studies of autonomous health movements in self-managed abortion and the Black Panther Party's People's Free Medical Clinics, I assert that data sovereignty praxis must engage more with the question of who forms a collective (and how) to assess which routes are available to promote autonomy, sovereignty, and self-determination in data collection and use beyond borders. Future research in this domain can focus on interviewing activists in autonomous movements to understand needs around data and technology, as well as understanding ways that data sovereignty efforts have or have not emerged in these movements. Important questions remain about the boundaries of these groups, how big a group can get before losing its unity, and whether there is ever a clear boundary between a community and its surroundings. That said, the hope is not to define a clear boundary around who is included in a sovereign group but to inform how data sovereignty initiatives can become more rooted in community goals and identities outside of geopolitical boundaries and property-based arguments.

Whether the field continues with the broadly defined concept of data sovereignty or delineates a new concept for sovereignty beyond borders and property, new visions of possibilities are important for continuing to redress data harms. As movements that aim to affirm agency and self-reliance, AHMs can be consulted to set priorities both for working within and outside of institutional boundaries. From SMA movements to the PFMCs, to additional examples of Zapatista autonomous zones, the radical political imaginaries of autonomous health movements can help envision more effective and sustainable bottom-up practices in health data sovereignty.

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