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Be Selfish Insights into Data Ownership within Community-Researcher Partnerships involving Studies on Asian American Public Health

Author

Nguyen, Alex

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Insights into Data Ownership within Community-Researcher Partnerships Involving Studies on Asian American Public Health

A thesis submitted in partial satisfaction of the requirements for the
degree of Master of Arts in Asian American Studies

by

Namanh Alexander Nicholas Le Nguyen

2020

ABSTRACT OF THE THESIS

Be Selfish

Insights into Data Ownership within Community-Researcher Partnerships Involving Studies on Asian American Public Health

by

Namanh Alexander Nicholas Le Nguyen

Master of Arts in Asian American Studies

University of California, Los Angeles, 2020

Professor Natalie Masuoka, Chair

This thesis seeks to understand how community-researcher partnerships negotiate ownership and control of data within community-based public health research projects conducted in Asian American and Pacific Islander communities. 10 semi-structured in-depth interviews were conducted with 11 participants, 6 researchers and 5 community members. While the literature generally centers the academic perspective, this project, rooted in Asian American Studies, strays away from the literature and centers the community's voice. The interviews reveal that community members define data ownership as possessing access to and control over data. In the various models of data ownership, these partnerships reveal data's ability to empower the community to (re)claim narratives and legitimize the community's voice. Additionally, this project concludes that community-researcher partnerships must build trust and recognize the community’s value through proper compensation. Ultimately, the community must “be selfish” in order to work towards an equitable community-researcher partnership and an equitable model of data ownership.

The thesis of Namanh Alexander Nicholas Le Nguyen is approved.

Jennifer Chun

May Sudhinaraset

Natalie Masuoka, Committee Chair

University of California, Los Angeles

2020

To bố mẹ,

To the community,

and

To those that made this possible

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Acknowledgements

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To my community, thank you.

Introduction

Introduction

During my field studies internship for my MPH, I worked on a project that, from the outside, appeared to disrupt conventional norms of public health and health research. The project attempted to create new evidence-based practices to improve the mental health of minority populations around California. I jumped at the chance to do something that I perceived to unsettle the status quo that focused explicitly on minority populations. In my case, the team I joined worked with and for the various Asian and Pacific Islander community organizations that created new, interesting methods for improving mental health in communities that previously might have never even considered their own mental well-being as a priority. However, after working on the project over the course of three months, I realized that, while the funders called this work community-based research, it did not match what I had learned about in my classes. While I assumed that not everything I learned in the classroom would wholly transfer to the real world, what I envisioned versus what I saw differed drastically. Both the community and my preceptors wrestled with the funders over who had the right of ownership over the data these communities collected and produced. The issue did not resolve in a way that I found equitable nor fair to community. However, the funders, as well as the literature, appeared to take for granted the issue of data ownership.

This project has revealed that those in power within public health possess the implicit assumption that data belongs to the researcher that collects it. While the funder in this case believed that they conducted community-based research, they also assumed they had sole ownership over the data. This view contrasts with much of the literature on community-based research in that the field believes in the partnerships defining for themselves ownership, often utilizing some model of co-ownership. However, in this project, the imbalance in data ownership diverged from the tenets of community-based research. Data has the power to transform communities. Therefore, the perceived inequity during my fieldwork made the issue of data ownership linger in my mind and became the impetus for this project.

I set out to investigate what it meant to own data. I searched the literature for a definitive answer on who should own data. I found examples of norms, regulations, and rules that dictated who did own data within community-based research. However, I found myself searching for something different. In the literature, I envisioned I would find reflections from researchers and community members on how they might have negotiated and/or shared data ownership in their community-based research partnerships. Yet, much of the literature described methods of data storage and took for granted defining data ownership as co-owned or merely researcher owned. The literature lacked examples of how communities and researchers defined data ownership.

The following research questions guided my inquiry about data ownership within community-based research.

(1) How do community-researcher partnerships develop trust in their relationships?

This question seeks to understand the particular dynamics of building trust within what I term community-researcher partnerships. As Nina Wallerstein and Bonnie Duran, the recognized founders of Community-Based Participatory Research (CBPR), detail, “CBPR facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequalities” (Wallerstein & Duran, 2006, p. 50). However, these collaborative and equitable partnerships do not instantaneously manifest. Therefore, I set out to discover how these relationships form partnerships over time.

(2) How do Asian American and Pacific Islander communities and researchers negotiate data ownership and control in community-based public health research?

This project seeks to understand data ownership within community-based public health research in Asian American and Pacific Islander communities. Ultimately, this project focuses on the ownership and control of data because of data's transformative power. Data provides not only researchers but also communities the tools they need to advocate for any type of social change they deem necessary. In order to improve and enhance society, communities need data to help them enact change. Therefore, understanding data ownership, as well as the rights and privileges pertaining to the data, provides insights into how data can empower the community.

(3) How can models of data ownership within community-researcher partnerships inform and improve future community-based public health research in Asian American and Pacific Islander communities?

The answers to the following two questions provide insights into past partnerships and collaborations. This question seeks to examine the past in order to inform the present and the future. The lessons gleaned from the interviews conducted can aid researchers and communities alike in their endeavor to conduct research that is collaborative and equitable that provides data that unlocks the ability to advocate for change. By using data collected about the past, I hope to better inform the future.

In order to answer these questions, I conducted semi-structured qualitative interviews to gather insights from both community members and researchers and asked them to reflect on and analyze how these relationships form trust. The interviews yielded many insights into the issue of data ownership within community-researcher partnerships. However, I make a distinct departure from much of the literature on community-based research and data ownership. In this project, I seek to center the community's perspective and advocate on behalf of the community. This focus on the community veers away from the literature focusing on the researcher's perspective in favor of the community’s. This project finds that communities and researchers have significance influence over one another in defining and practicing data ownership. However, some community members have drastically different perceptions on who should own data and how to effectively and equitably practice data ownership. Additionally, the partnerships interviewed for this project emphasize access to and control over data as keys to data ownership. Finally, this project presents ways in which the community can work with researchers to achieve a more equitable partnership and work towards an equitable model of data ownership. Before embarking on this project, I wish to emphasize that this project grounds itself in Asian American Studies and not Public Health.

A Project from Asian American Studies

The focus on the centering the community comes from a distinctly Asian American Studies and Ethnic Studies perspective. While I am a dual-degree student, earning an MA in Asian American Studies and an MPH in Community Health Sciences, this project is about public health but with an Asian American Studies lens. This project, much like community-based research, lies at the intersection of both fields. I first learned about community-based research in a public health class when the professor described the practice as treating the community as both experts and consultants on research. Coming from an Asian American Studies background, this seemed not only revolutionary but also the approach that almost all public health research should take. However, much of the literature on community-based research centers around what the researcher can do. Many books and articles provide road maps for the researcher on how best to incorporate the community into the research. However, very little of the research talks about nor centers the community. This project intends to change that.

In applying an Asian American Studies and Ethnic Studies lens to a public health issue, looking towards the origins of Ethnic Studies provides a key insight into the purpose of the field but also the purpose of community-based research. The movement for Ethnic Studies began at the then San Francisco State College by the collective known as the Third World Liberation Front (TWLF) in 1968 (E. Lee, 2015). The TWLF launched the longest student-led strike in American history asking for not only a curriculum that reflected the student body's various histories taught by scholars of color, but also, to borrow from the Black Panther Party across the San Francisco Bay, to "serve the people" (E. Lee, 2015). The TWLF wanted to help the community that surrounded the university. The strikers intended to use the knowledge they gained in academia in order to better the communities from which they came. The guiding ethos of "serve the people" not only guided the TWLF in 1968, but also influences community-based research as a whole. This project seeks to borrow from the TWLF and center the community. While much of the literature centers the researcher and their approach to community-based research, this project examines how community-researcher partnerships can and should center the community in community-based research projects and in models of data ownership.

Public Health and Asian Bodies

In considering how public health should interact with and collaborate with the community, I contemplate here how historically those in power have used public health as a tool of oppression. This brief historical analysis juxtaposes history with the efforts and aims of community-based research. While public health has been used as a tool of biopolitical control, community-based research then seeks to repair this fraught relationship. This project furthers the aims of community-based research by considering and expressing, through the community's voice, how public health can best "serve the people." By understanding how public health has wielded biopolitical control, I seek to underscore how public health community-based data can serve as a tool for empowering the community.

Biopolitics and Biopower

Michel Foucault's concepts of biopolitics and biopower help to frame the historical relationship of public health with Asian bodies. Foucault introduces both terms in his book, *A History of Sexuality Volume 1: An Introduction,* in which he first describes the difference between biopolitics and, what he terms, the anatomo-politics of the human body (1978, p. 139). Both of these terms arise from what Foucault calls the rise in "power over life" beginning in the 17th century (1978, p. 139). Rachel C. Lee describes the two as, "… biopower is sometimes used as an umbrella term for two kinds of manifestations of power, a disciplinary "anatomo-politics of the human body" and a regulatory "biopolitics of the population" (2014, p. 41). But sometimes "biopolitical" simply stands as an adjectival form of biopower" (R. C. Lee, 2014, p. 41). Lee's key delineation comes a few pages later when she describes biopolitics as "a more *top-down managerial perspective employing a calculative logic in assessing population-aggregates comparatively*" (2014, p. 45). In reviewing Foucault's writings and Lee's summations it becomes clear that biopolitics identifies when institutions exert their authority over people's ability to care for and regulate their own bodies on a large, more ecological scale. In turn, biopower appears to be a more general term that includes both institutions exerting influence as well as other forms of attempting to control the bodies of others.

Public health as a field has historically exercised biopolitical control over Asian bodies. Two examples, one domestically in San Francisco Chinatown in the late 1800s/early 1900s and during the conflict in Southeast Asia during the 1960s and 70s, highlight how the U.S. has used public health to racialize and kill Asian bodies. The exertion of biopolitical control results in a debilitating harm that only recently has public health attempted to remedy.

San Francisco Chinatown

In the early 1900s, San Francisco public health officials blamed Chinese residents for several outbreaks of infectious diseases, including bubonic plague, to justify exerting biopolitical control over the budding Chinatown. Nayan Shah writes, in his book *Contagious Divides,* that public officials in San Francisco at the time "conceived of Chinatown as the preeminent site of urban sickness, vice, crime, poverty, and depravity" (2001, p. 1). Public health officials accomplished this biopolitical control through "practices of race-making to the regimes of knowledge and discourses that g[ave] them legitimacy and plausibility" (Shah, 2001, p. 5). The classic public health technique of surveillance gave rise to these "regimes of knowledge" that harmed the Chinese in San Francisco.

Under the direction of then Mayor Kalloch, public health officials surveilled Chinatown and utilized maps as visual evidence that contributed the perception of San Francisco Chinatown as a cesspool of sickness. Investigators "catalogue[d] dozens of health ordinances that the "Chinese people" habitually violated" (Shah, 2001, p. 35). In creating this log of supposed violations, the investigators overtly surveilled the Chinese in the name of "scientific" observation. However, in this instance, nothing distinguished between "scientific" observation and racist surveillance tactics. In fact, they were exactly the same.

The maps made by public health officials visually displayed the racist data used to justify the biopolitical control that would follow. Maps have been a tool of public health practice since the time of Jon Snow, the grandfather of public health (Gordis, 2014). While Snow's maps helped stop an outbreak, the maps made in San Francisco hurt the Chinese. The maps succinctly visualized the supposed filth and squalor that the investigation found in Chinatown. Shah writes, “The maps and inventories were the products and tools of extensive surveillance, but they also ensured that more intensive surveillance would occur in the future” (2001, p. 38). Using the maps as justification, the public health officials began changing Chinatown.

San Francisco public health officials did not attempt to control Chinese bodies. Instead, as Foucault’s definition and Lee’s interpretation of biopolitics indicate, the state, in this case the city government, “employ[s] a calculative logic” in order to exert control (R. C. Lee, 2014, p. 45). The biopolitical control here manifests as an ecological mode of control. San Francisco public officials enacted discriminatory and exclusionary zoning legislation deemed “necessary to prevent health catastrophe for the entire population” (Shah, 2001, p. 53). These zoning laws mirrored the racial covenants occurring throughout the United States which prohibited people of color from moving to white-only neighborhoods (Rothstein, 2017). The San Francisco zoning ordinances exercised biopolitical control through dictating where the Chinese residents could be. These ordinances stripped away the privilege of movement and the freedom to live anywhere without consequence. Instead, these laws relegated the Chinese to spaces that officials deemed as sources of illness subjecting them to conditions that could potentially kill them. These “regimes of knowledge,” or data, created a toxic, antagonistic relationship. The Chinese community bore the brunt of public health officials wielding data to harm communities. Community-based research and this project intend to shift this paradigm

The U.S. in Southeast Asia

Similar to San Francisco Chinatown in the late 1800s and early 1900s, the U.S. military exercised biopolitical control through providing public health services. These services appeared innocuous. However, by inserting U.S. military personnel into Vietnamese communities, the

U.S. military gained the ability to surveil and collect data on potential enemy combatants. The data collected contributed to the knowledge the U.S. military used to kill.

The U.S. engaged in several attempts to not only provide relief from the trauma and horrors they contributed to, but also to collect data. According to a study produced by the RAND Corporation[1], the U.S. military and government charged the United States Agency for International Development (USAID) with "the task of nation-building, turning economic aid into a tool of counterinsurgency by strengthening recipient countries against subversion" (Elliott, 2010, p. 15). While this task of nation-building is not an overt act of violence and is not seemingly malicious, USAID worked in concert with other agencies, through the coordination of the Defense Department, in order to engage in "military civic action" also known as "winning hearts and minds" (Elliott, 2010, p. 15). Additionally, in his book *Soldiering Through Empire*, Simeon Man describes Operation Brotherhood and the Freedom Company which both utilized Filipino doctors, nurses, and veterans to "perform[] different kinds of intimacies, such as caring for the body and other convivial encounters" (2018, p. 51). Man terms these encounters as colonial intimacies (Man, 2018). These colonial intimacies and "winning hearts and minds" appear similar to the process of building trust within community-based research. However, while most researchers use community-based research to uplift and empower the community, the U.S. military sought to use this knowledge for nefarious purposes.

By building trust as a means of psychological warfare, the U.S. military gained the knowledge and data of who was where and when. This led to the ability to snuff out potential

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[1] Ironically or not the RAND corporation still holds a very tight and long-lasting partnership with the UCLA Fielding School of Public Health (FSPH). The report cited here is distinctly about the RAND corporation's involvement in the war effort. As such, many FSPH professors have had or continue to have appointments at both institutions highlighting the revolving door between the private sector aiding in a war effort and supposed public institutions. As this chapter shows, public health researchers and other social scientists are not immune to engaging in systems of oppression.

insurgents through friendly, non-adversarial relationships developing a collective knowledge of the people they “served.” Medical professionals and public health officials never appear threatening under the guise of caring. However, surveillance for the purpose of knowledge building, in this case to aid the military, can have and have had malevolent motivations.

In both of these examples, the U.S., domestically in San Francisco Chinatown and internationally in Southeast Asia, exercised forms of both biopolitics and biopower. The act of surveillance produces a voyeuristic gaze. San Francisco public health officials, through surveillance and maps, infiltrated Chinatown in order to collect data on supposed disease and illness. Only then did they have the justification to exert biopolitical control through zoning laws in order to maintain the Chinese as the Other and Chinatown as a space for Otherness. In Southeast Asia during the military conflict of the 1960s and 1970s, the U.S. military sent medics and supplies as a way to mend the wounded, to heal the sick. However, these missions of medication gave rise to the designation of Southeast Asians as the Other, Southeast Asia as a landscape of Otherness, and an opportunity to enact this voyeuristic gaze. The U.S. used body counts to track the progress of the war (Espiritu, 2014, p. 2). This effort to quantify the Other as a palatable manner is no different than the maps made of San Francisco Chinatown. In both cases efforts to surveil Asian bodies with the intent to control and/or kill are enactments of both biopower and biopolitics. Therefore, the relationship between public health and Asians and Asian Americans has been harmful since the origins of Asian America. While these examples are historical, they serve as a reminder of the destructive potential that public health data possesses. Contrastingly, community-based research upends the paradigm by collecting data intended to aid the community. Furthermore, community-based research allows the community to contribute to public health knowledge. This project, then, seeks to further contribute the community's voice by centering the community.

A Roadmap

What follows this chapter is the product of research conducted specifically to center the community's views on community-based research and data ownership. The first chapter reviews the literature on data ownership, community-researcher partnerships, and community-based public health research as a foundation for this project. The chapter uses indigenous data sovereignty as a way to understand how to center the community when understanding data ownership. The chapter then introduces the term community-research partnerships as an alternative to academic-community partnerships in an effort to center the community through the vocabulary used to describe these partnerships. Finally, the chapter concludes with a discussion on approaching public health research from a community-based orientation.

The next chapter describes the methods for this project. I conducted 10 semi-structured in-depth interviews with 11 participants. The participants included 5 community members and 6 researchers in order to gain perspectives from both parties in these community-researcher partnerships. These interviews yielded transcripts that served as the dataset for this project. The following chapters outline the conclusions reached after analyzing the transcripts.

"Definitions and Models of Data Ownership" describes the definitions and models of data ownership that the interviewees offer. Most of the interviewees offerred definitions that emphasized access to and control over data. However, one outlier considered whether or not data should be owned at all. In order to understand data ownership, I turn to land ownership from an indigenous perspective. As the forceful taking of land uses *terra nullius* as a justification, I consider whether or not *data nullius* exists through the definitions that the community members offer. The chapter then shifts its focus from defining data ownership to considering how these community-researcher partnerships operationalize ownership. In this section, the chapter explores how the partnerships interviewed work towards equitable models of data ownership. Understanding how best to work towards an equitable model provides the community with access to and control over data, something they indicate they desire through their interviews. The prioritizing of access and control surfaces throughout all of definitions and models of data ownership. The next chapter considers the why and how community-researcher partnerships might give access to and control over data to the community.

"(Re)Claiming Narratives and Legitimizing Voices" focuses on how access to and control over data empowers the community. I frame the chapter through two results of the community having access and control over data. First, I argue that through access and control, the community is able to (re)claim narratives. Data's potential is its ability to describe phenomena occurring in communities so that the communities can in turn advocate for changes they wish to see. Previous data either might have inaccurately described conditions in communities or lacked any data on certain communities. By the community gaining access to and control over the data produced by these partnerships, they can tell their own stories. Second, I argue that this access and control over the data legitimizes the voice of the community. While institutions such as universities do not realize the inherent value and knowledge that the community brings in these partnerships, by the communities demanding access and control over data, they can prove their value to these institutions. The ethos of community-based research respects the community as an expert. However, with data in hand, the community can then prove their expertise to others. This chapter highlights the power the community can wield with data.

“Improving Community-Researcher Partnerships” describes my observations on how future community-researcher partnerships might learn from these examples in order to work towards equitable models of data ownership. I offer three intertwining analogies where I liken building trust in these partnerships to sharing a meal, establishing the relationship to dating, and negotiating data ownership to throwing a birthday party. These three analogies describe how best to serve the community in future partnerships. These are recommendations present in the literature. However, as the literature focuses mainly on the researcher’s perspective, this chapter intends to encapsulate lessons gleaned from the community’s perspective.

The conclusion of this project offers my own reflections and commentary on my project. While I synthesize the findings from this project in the conclusion, I acknowledge how, while studying community-based research, this project does not engage in community-based practices. I also ponder future potential avenues of research related to the various topics brought up in this project. It is my hope that this project offers an insight into the community’s perspective on community-based research and forming equitable models of data ownership.

Literature Review

Introduction

This project seeks to understand how community-academic partnerships negotiate ownership and control of data within community-based public health research projects conducted in Asian American and Pacific Islander communities. No literature exist that fully encapsulates the aims of this project. Scholars have written about the component parts: data ownership, academic-community partnerships, and community-based research within the field of public health. While this project focuses on community-researcher partnerships, mostly only researchers publish and read the body of literature on these particular subjects. Therefore, in order to understand each component parts, this chapter synthesizes the literature to provide a baseline understanding of each part. The context provided through examining the researcher-written, existing literature then underscores how this project attempts to move away from a researcher-centered project towards a community-centered one.

This chapter consists of three distinct sections. The first section describes different views on the ownership of data within the field of public health. Data ownership is not a major area of focus for researchers nor is it a topic frequently discussed within the literature. Instead of literature on this subject, I turn to how researchers practice data ownership through the lens of funder requirements. To contrast this view and in order to understand data ownership from a more community-centered lens, I then borrow from indigenous scholars in the Pacific and in the U.S. in their conceptualization of indigenous data sovereignty as a way in which to understand how communities own data. Next, the second section surveys academic-community partnerships as a way to unpack the relationship between community and researchers in general. Academic-community partnerships are not unique to public health as a field. A review of the literature outside of public health provides insights into how academia in general approaches working with communities. Finally, the third section narrows from academia working with the community to understanding how public health approaches community-based research. Public health researchers utilize a number of modalities under the umbrella of community-based public health research. In order to synthesize and understand the umbrella of community-based research, this chapter uses Community-Based Participatory Research (CBPR), a popular approach to research, as an example. These interrelated areas provide a foundation for this project's aim of analyzing both community-based public health research and data ownership.

Data Ownership and Control

As this project centers around data ownership and control within community-based public health research, it is important to parse different conceptions of data ownership. Data's potential as a tool to empower communities through community-based public health research requires a slightly different understanding than more established methodologies of research, such as a cross-sectional survey or a double-blind research study. Data's power in the hands of communities is key in my understanding of data ownership. However, as funders play a key part in the ability to conduct this type of work, scrutinizing how funders envision data ownership sheds light on how public health as a field approaches the topic.

The NIH and Data Ownership

The National Institutes of Health (NIH) are one of the largest funders of public health researchers in the U.S. According to the NIH website, the federal government appropriates approximately $41.7 billion annually for medical research, under which public health falls (*Budget*, 2020). While the funding for community-based public health research out of this budget is infinitesimal, understanding the NIH's policies on data ownership shed light on how public health understands the issue.

The NIH policies for data ownership have multiple deficits. According to their guidelines, the NIH requires grantees who receive over $500,000 for one year’s worth of research to formulate a data sharing policy and encourages all grantees to have some sort of data sharing policy (NIH, 2003). However, the NIH’s concern over data sharing and not data ownership points to the first deficit. While the subfield of community-based research might require separate guidance on data sharing and/or data ownership, I could only find this policy. Therefore, this policy does not adequately serve the complexities of community-based research. The lack of any community-based research specific guidance implies that the researchers own the data. This guidance describes how the primary investigators should prepare for and enact a data sharing policy in the event that researchers external to the original research team wish to use the data. No such policy exists to guide any potential joint, shared, or otherwise negotiated model of data ownership. The implicit understanding of researchers as the sole owners of data indicates researchers misunderstanding or devaluing the contributions of community members in the research process. NIH policies and guidelines do not mention any rights for community members nor even the rights of the subjects of research. As discussed later, community-based public health research values community members as equals in the research process. However, the NIH, one of the largest funders of all research including public health research, does not acknowledge the value of community. Therefore, this lack of acknowledgement of the value of the community demonstrates that public health as a field operates with the understanding of researchers as the sole owners of data. Requiring a peer-to-peer sharing policy demonstrates how researchers value one another, but do not value the subject or the community.

The second deficit of this policy stems from its publication date. I found the most recent policy around data sharing and ownership published by the NIH in 2003. I hesitate to call this policy antiquated. However, given the research and progress of the field of public health in including community perspectives and the advent of community-based research as a popular modality since that time, it is a failure of the NIH to not update its guidance. While the NIH is the largest funder of all public health researcher, it is not the only one. The NIH’s hyper-focus on results and not necessarily the protection of those involved nor the subject points to a deficit in funding models and funder requirements in all public health researcher including community-based public health research. I want to note here that I use the NIH here as a proxy for funders and that certainly there might be some funders who do have guidance for their grantees on the sharing data ownership. However, due to the large dollar amount the NIH grants annually, the impetus for updated guidance or lack thereof should originate from the funder.

Models of Data Ownership

While funders might not concern themselves with issues surrounding data ownership, within public health research, there have been some attempts to define data ownership. However, these definitions are more abstract and do not adequately define what ownership is and how to best implement it. For example, early writings on data ownership in research came from sharing data with other researchers and not necessarily with community. Hilgartner and Brandt-Rauf, in describing data access for research projects and what they term “science policy,” believe in the right to accessing data but are unclear on what level of access and what access might look like (1994). They believe that data access should follow a data stream model, meaning that data includes everything from the mundane to the novel with the stream evolving over time to tell a continual story (Hilgartner & Brandt-Rauf, 1994). Not surprisingly, as the NIH uses essentially this model in all of their guidance on data ownership and access, the NIH helped to fund this article. Access can come in many forms, but the question remains how much access. Concern over access does not allow for all parties involved, including the subjects of research, to have a modicum of ownership or control. In this model, the subjects are merely subjects and do not possess any claim to the data that is ostensibly about them. This is the view of more traditional definitions of data ownership and perhaps contributed to the “current” NIH guidelines described previously. However, this line of outdated thinking is discordant with the efforts of this project.

Turning to more recent examples of data ownership could prove helpful. A contemporary example comes from the United Kingdom’s national health system. In this system, the government provides and grants all citizens healthcare through a nationalized health care system. Yet, the UK’s system does not utilize a centralized electronic health records (EHR) system. EHR systems store valuable and confidential patient medical information. These systems are commonly housed in local offices and in the UK healthcare system is decentralized. However, there have been attempts at open data initiatives in order to make access to data easier (Kostkova et al., 2016). These initiatives are driven by the questions: “by whom and for what purposes are shared citizens data used and how could decisions be effectively controlled by citizens themselves?” (Kostkova et al., 2016, p. 2). The main concern with this attempt at democratizing and decentralizing data is the trust of the users.

The UK’s potential centralized EHR system could make users wary of the health system’s ability to protect their data over which they should have ownership. The most important issue with this proposed model of data sharing and ownership is a renegotiation of rights to this data (Kostkova et al., 2016, p. 4). However, Kostkova et al. does not describe how this renegotiation occurs. Many of the models of data ownership that are found in the literature are in fact not about data ownership. These models hint at potential ways to own data. Yet, these discussions occur in the abstract or merely in the call for further research. These issues of trust and no concrete, actionable understanding of data ownership means makes this model, among many others, difficult to understand at best and moot in implementation. Understanding data ownership requires an actual definition and description of what data ownership looks like, especially for communities in community-based research.

One model that does describe how researchers conceptualize ownership of data collected in a community-based research comes from the American Indian and Alaskan Native communities. In this project, the researchers and community members engaged in a strategic data planning process that allows for communities to plan how to use data responsibly and in a culturally authoritative manner (Schultz & Rainie, 2014). The authors showcase how power is imperative in its ability to craft narratives and how some communities have even taken up the task of collecting their own data sans researchers (Schultz & Rainie, 2014). The re-narration of stories through data empowers these communities. However, this article again lacks concrete definitions of shared ownership of the data. By turning to other indigenous scholars, I attempt to borrow their definitions to better understand data ownership from a community perspective.

Indigenous Data Sovereignty

I borrow from indigenous scholars who globally have thought of and conceived of a different model of data ownership. This concept, called indigenous data sovereignty, redefines data ownership that centers indigenous communities. Indigenous data sovereignty provides a model for a community-centered approach to data ownership due to a lack of an Asian American definition of data ownership. Indigenous data sovereignty is an important step in understanding how Asian American and Pacific Islander communities can and might think about data ownership within community-based public health research projects.

The concept of data sovereignty is not new. Data sovereignty means "managing information in a way that is consistent with the laws, practices and customs of the nation-state in which it is located" (Snipp in Kukutai et al., 2016, p. 39). This definition privileges nation-states, many of whom historically have oppressed indigenous communities. The tie to nation-states indicates the importance of the actions of the nation-state over those who produce and use the data. In an effort to wrest ownership and control over data from a nation-state context, indigenous scholars have defined indigenous data sovereignty as indigenous peoples' rights to "maintain, control, protect, and develop their cultural heritage, traditional knowledge, and traditional cultural expressions as well as their right to maintain, control, protect, and develop their intellectual property over these" (Kukutai & Taylor, 2016, p. xxii). The ties to culture and a people are perhaps the defining hallmark of indigenous data sovereignty. In the more broadly understood definition, the invocation of the nation-state supports the notion of data as a tool for state apparatuses to function and not something of value tied to the people. Indigenous data sovereignty centers people and not governments as owners of data.

Indigenous scholars utilize a key document in rationalizing indigenous data sovereignty. These scholars draw upon the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) as justification for their definition of data sovereignty. Drawing upon Articles 3 and 4 from the UNDRIP, these articles assert that indigenous peoples have the right to self-determination, self-government, and autonomy (Davis, 2016). These articles point to indigenous peoples' rights to "maintain, control, protect" that are outlined in the previous definition of indigenous data sovereignty. While this justification allows for this new understanding of data sovereignty, using the UNDRIP comes with some flaws. First, the UNDRIP is non-binding and soft-law meaning it is unenforceable (Davis, 2016). This points to the broader criticism of the

United Nations as lacking in power. Therefore, while these scholars point to UN permanent forums and multiple declarations to hold their power in their hands and justify their needs, the façade of the UN as a governing body makes it abundantly clear that real change must come from the people it directly affects, the community. While this definition might work for indigenous communities, and perhaps for the purposes of this project Pacific Islander communities under the settler-colonialism of the United States, this definition, and the justification of the definition that indigenous scholars provide, does not function for Asian American communities.

There are no distinctly Asian American definitions of data ownership hence the turn towards indigenous scholars' definition of data sovereignty. Therefore, it is important to understand the key differences between Asian American and indigenous communities. In an American context, Asian Americans have been and continue to be settlers on indigenous and native lands. Asian Americans engage with the U.S. as a colonial nation-state as subjects of the state. Some Asian Americans historically have been settlers due to their interactions with the U.S., such as Southeast Asian refugees. While others have made the conscious decision to settle in the U.S. Asian Americans do not necessarily normally engage with what it means to be a settler on indigenous lands. However, the difference of indigeneity, as well as land ownership and similar yet differing histories of American oppression and imperialism are enough to distinguish a slightly altered understanding of data ownership and control. Pacific Islanders within this framework occupy an interesting position. While in the U.S., Asian American and Pacific Islander communities are often lumped together, they are different. Pacific Islanders in some cases, such as Native Hawaiians or their preferred term of Kanaka Maoli, could be categorized as indigenous. Similar categorizations for Pacific Islanders might include groups such as Samoans on whose land America still occupies. In any case, while this project focuses on both Asian American and Pacific Islander perspectives, the application of data sovereignty from indigenous scholars will only apply to an Asian American context. This project does not seek to reinvent nor redefine data sovereignty. Nor does it seek to formulate an Asian American definition of data ownership. Instead, this project seeks to understand how Asian American and Pacific Islander communities define and operationalize data ownership.

Academic-Community/Community-Researcher Partnerships

Understanding models of data ownership in community-based public health research come from what the literature terms academic-community partnerships. Examining the relationships and partnerships between researchers and communities is paramount in knowing how best to improve these dynamics with respect to data ownership and control. Academic-community partnerships are any time researchers, generally from academic research institutions, engage the community to accomplish any goal. The label of academic-community partnerships covers a vast swath of different types of partnerships. On the spectrum of academic-community partnerships, there exist very superficial partnerships akin to partnerships only in name. On the other end of the spectrum there are equal and equitable partnerships that pursue a common goal. A variety of academic fields, from education to public health, utilize these partnerships in an acknowledgement that academia needs community to carry out their projects.

These partnerships arise out of a need and want to work together. Generally, researchers partner with community because there is something, whether it be connections, networks, legitimacy, or knowledge, that researchers lack. Similarly, the community might partner with researchers because of a researcher's expertise or something that the community finds they lack. These conceptions of how best to work with community take into consideration the politics and ethics of research as a way to protect against the fear of exploitation. However, using the term academic-community partnerships does not accomplish what researchers claim as the purported goal of these unions.

In order to center community more clearly in these partnerships, I intend to the use the terms community-researcher partnerships. This term emphasizes the importance and value of the community and community agency within these partnerships. By using the term academic-community partnerships, I acknowledge the literature's descriptions of these relationships. Due to the centrality of the community to this as well as these partnerships, going forward I use community-researcher partnerships in order to describe projects and partnerships that are community centered, focused, and driven.

Academic-Community Partnerships

Multiple fields, including public health, utilize and have subsequently described academic-community partnerships in a wide body of literature. However, the articles published on the subject generally lack specifics about the politics of these partnerships. By using the word politics, I invoke the ways in which power influences the relationships between community and researcher as well as between community and institutions. Most of the writing occurs in the abstract concluding with more calls for researchers and institutions to engage community. Yet, the literature does not attempt to understand nor critique the relationships and negotiations within these partnerships. How researchers and community members relate and negotiate with one another brings about an intimate politics reliant on vulnerability and trust. However, the following examples of academic-community partnership literature fail to capture the nuance of the politics of working with community with few exceptions.

The definition of who counts as a community member varies. In some cases, researchers do not define who the community is. For example, one article discusses an attempt to partner with the community to improve oral health (West & King, 2019). However, the authors do not explicitly define who comprises the community. The researchers work with community clinics and dental providers in close proximity. However, when the authors suggest utilizing data sharing agreements, they only indicate that they would share data across medical providers. Therefore, this article frames the only community worthy of working with as these medical providers. Surely, the patients themselves have not only a right to their own data, even if aggregated and de-identified, but also could only aid in this partnership's efforts to improve community oral health. By merely defining medical professionals as the community, the authors do not "address fundamental deficiencies" within academia as they claim, at least not to the extent that they could by including more than just clinics and providers (West & King, 2019, p. S26). The article not only lacks specifics on who the community is but also how best to work with their "community." These deficits showcase that some researchers fail to understand the implications of working with community. This article clearly describes an academic-"community" partnership and not a community-academic partnership.

While not all examples of academic-community partnerships are as egregiously lacking as the previous one, a common partnership between academics and non-academics are between academics and schools. Public health utilizes partnerships with primary education schools often in order to implement interventions aimed at improving the community. For example, Caron et al. describes their evaluation of the efficacy of what they term academic-community partnerships between schools of public health and local schools (2015). The article calls for more of these partnerships in order to expand the reach of public health at the local level. The assumption of this article is that local elementary, middle, and high schools represent the community. This begs the question: who counts as the community? It is not the purpose of this project to attempt to answer this abstract question. However, I point to this because of the differing definitions of community within the literature. It appears that most academics merely mean non-academics when attempting to label people or a group as part of the "community." The concept of community is not defined, nor should it only have one definition. However, these inconsistencies within the literature highlight a lack of understanding of what the community is.

Critiques of academic-community partnerships are necessary to protect the community and improve the overall quality of research. There have been some attempts to be more evaluative of these partnerships. For example, Chou and Frazier analyze and then present recommendations for improving academic community partnerships (2019). This article acknowledges that these relationships between academics and community can be fraught with difficulties due to a potential power imbalance (Chou & Frazier, 2019). The community might view the researchers as experts and therefore only do what the researchers want resulting in an unbalanced partnership. In order to address these difficulties they propose the 4R framework, which stands for Respond, Record, Reflect, and Revise, in order to improve the research process (Chou & Frazier, 2019). Based on the American Psychological Association's Code of Ethics, the authors present these recommendations solely for when responding to ethical dilemmas between community and researchers. In other words, this framework only serves to respond if someone believes they witnesses something unethical. While this proposal on how to deal with ethical dilemmas is admirable, the actual proposal is problematic. These recommendations are only meant to stymie any potential conflict. The authors propose a very reactionary and reflexive approach rooted in panoptic and surveillance techniques rather than unpacking relationships of power and trust in order to resolve conflict. For example, the authors propose that researchers "privately document ethical concerns… with detailed field notes" in order to "provide more complete documentation and allow for cross-validation in discussion" (Chou & Frazier, 2019, p. 4). It appears that this framework only concerns itself with the protection of the researcher and not the community. Even during a critique of the process and the authors understanding the precarity and potential volatility of these relationships, the authors clearly only want to offer ways to protect the researcher and not community members.

More recent literature describes a different approach to evaluating academic-community partnerships. Teeters and Jurow offer a framework to evaluate what they term equity-oriented partnerships (2019). The framework includes five ways in which equity can be achieved: establishing partnerships, developing trust, working with language differences, planning for action, and outcomes and sustainability (Teeters & Jurow, 2019, p. 28). In contrast to the previous model of evaluation, this model attempts to center the partnership in an effort to develop equity. Equity, according to these authors, is amorphous and a "fluid and shifting aim" (Teeters & Jurow, 2019, p. 27). This evaluation is a vast improvement over the previous. The article also points to specifics on how to develop and evaluate each step in a way that centers both the community and the researcher. By offering specifics, this article upends the previous critique of most of the literature lacking specifics. As the authors published the article in 2019, perhaps this signals an acknowledgement by researchers that the politics of these relationships, in this case with respect to equity, needs further thinking and study.

Another example of an evaluation of the politics between researchers and community members comes from a professor's reflections on how they teach students to work within communities. The perspective of how researchers teach students to conduct research, especially within communities, is important due to who actually provides labor in these research projects. Lead researchers generally do not engage in these community-based projects alone. The term academic-community partnerships, then, accurately describes how, from the academic side, performs the labor. Generally, researchers include the lead researcher as well as ancillary researchers like students. By saying academics or researchers, it involves the students, both undergraduate and graduate, who provide their labor for the enterprise of research. In this article, the author calls for students to turn towards more asset-based thinking when working in communities and outlines key steps as to how to accomplish this type of thinking and work (da Cruz, 2017). This is an exception to the previous critique of the literature. This article views the community as an asset and provides examples of ways in which students can unpack these relationships. The article provides teaching cases as methods for students to learn how to understand the politics within a community-researcher partnership.

The last example shows the thinking of what I believe to be a community-researcher partnership. To reiterate, these partnerships center community in the research process and emphasize the importance and value of the knowledge that community brings. Additionally, these partnerships treat community as equals and work towards an equitable partnership. This general ethos of community-researcher partnerships stems from public health’s practice of community-based research. As discussed in the next section, public health utilizes community-based research and community-researcher partnerships quite often to achieve the goals of eliminating health disparities and achieving health equity.

Community-Based Public Health Research

Researchers use the term community-based research to encapsulate many different practices, methodologies, and orientations to conducting research with a particular community. A multitude of labels exist to describe different types or aspects of community-based research. Some include Participatory Action Research (PAR), Community Partnered Research (CPR) and Community-Based Participatory Research (CBPR). All of these labels possess a shared code of equally and equitably treating researchers and community members alike as experts contributing to a common goal: to eliminate or reduce a health disparity. Some have pointed to these different labels as differing methodologies that run counter to more established types of research. Historically, these established types of research treat researchers as the experts studying populations as subjects and have banned subjects from involvement in the research process. However, the advent of different types of community-based research has signaled a shift within the field to acknowledge community as a knowledge base that can be instrumental to discovering and eliminating health disparities.

I want to note here the link between the previous section on academic-community/community-researcher partnerships and the umbrella of community-based research within public health. Community-researcher partnerships are the direct products of and help to drive community-based research projects. The two terms are not exactly the same, but they share the same goal. The differentiation is that community-based research is an approach to research whereas community-researcher partnerships execute the research. While the aim of this project is to study community-researcher partnerships, the aim of this section is to understand where these partnerships emerge from: community-based research.

Power and Privilege within Community-Based Research

Before delving into community-based research as a whole, it is important to note that researchers bring with them a certain level of power and privilege into communities and community spaces. This privilege, left unchecked, could potentially corrupt, corrode, and destroy the delicate relationship within community-researcher partnerships. Foucault posits that power is "a web of discourses and practices found in institutions, communities, and families and exercised through actions in multiple relationships" (Foucault in Wallerstein & Duran, 2008, p. 34). In community-researcher partnerships the power lies in the relationship itself (Foucault in Wallerstein & Duran, 2008, p. 34). Community-based research unpacks these relationships with regard to power and privilege in order to work together so that these collaborations benefit all involved. Ultimately the goal of community-based research is "for members of the community to do things themselves and become self-sufficient knowledge providers and social change producers" (Stoecker citing Gaventa in Wallerstein & Duran, 2008, p. 108). In other words, the goal of the researcher and community members should be to make the researcher no longer necessary. However, in order to achieve this goal, community-researcher partnerships must be willing to build up the capacity of the community in order for them to lead their own projects for their own self-interest. Community-Based Participatory Research (CBPR) is one orientation to research that has been used successfully in community-research partnerships, particularly in the field of public health.

Community-Based Participatory Research

With the potential for community-researcher partnerships to be fraught, it is helpful to understand the source of these partnerships. The most commonly cited and used community-based research label is Community-Based Participatory Research (CBPR). Due to its popularity within public health, examining CBPR allows for a broader understanding of community-based research and community-researcher partnerships. By understanding CBPR and the broader umbrella of community-based research, I can begin to unpack the processes, the relationships, and the negotiations that occur in community-based research projects.

Nina Wallerstein and Barbara Duran are largely credited with establishing CBPR. In their book, Wallerstein and Duran define CBPR as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities” (2008, p. 6). This definition upends the paradigm of public health research drastically through the inclusion of community members within the research process. Traditionally, community members nor subjects of research did not participate in the research process beyond the collection of data from them, never mind the new status as equals in CBPR. Wallerstein and Duran’s emphasis on the strength of community recognizes the knowledge and power that communities can bring to the research process, perspectives that might have never been considered before this approach to research.

In considering the origins of community-based research and CBPR, Wallerstein and Duran point to a spectrum of traditions of theory that greatly influence community-based research. This spectrum of theory juxtaposes two traditions: Northern and Southern traditions. These traditions refer to the ideas of a Global North and a Global South that arose during a post-WWII Cold War era. The North traditions prioritizes systemic improvement through collaboration (Wallerstein & Duran, 2008, p. 27). Scholars of the North tradition that introduce community-based research foundations include Kurt Lewin and Talcott Parsons among others (Wallerstein & Duran, 2008, p. 27). The influence of the North tradition on public health community-researcher partnerships manifest through the collaborative effort to reduce and eliminate health disparities caused by social systems. The South tradition “challenges the historical colonizing practices of research and political domination of knowledge by the elites”

(Wallerstein & Duran, 2008, p. 27). Scholars that provide a foundation to the South tradition include José Ortega y Gasset and Paolo Freire, particularly Freire’s *Pedagogy of the Oppressed* (Wallerstein & Duran, 2008, p. 28). While the North tradition clearly influences CBPR, Wallerstein and Duran indicate that the South tradition has a much larger sway in the conceptualization of CBPR. This spectrum influences community-based research as a whole.

Out of the tension between North and South traditions of community engagement, community-based research develops into its own spectrum with its own tensions. The community-based research spectrum, like the North/South spectrum, juxtaposes action-oriented models of research against emancipatory models. The linkages between action-oriented models and the North traditions and emancipatory models and the South traditions are very strong. As the North traditions emphasizes collaboration, the action-oriented models of research prioritize inquiry followed by action. The South traditions seek to challenge forms of oppression and colonialism and the emancipatory models of research emphasize a move away from the “’colonizing’ nature of research and stem from Feminist, postmodern, and postcolonial theory” (Wallerstein & Duran, 2008, p. 10). The larger umbrella of community-based research then sits in between the ends of action-oriented versus emancipatory models. Wallerstein and Duran categorize CBPR as an orientation to research drawing from more South traditions, emancipatory models of research. With CBPR’s theoretical underpinnings of anticolonial practices, it becomes clear why Asian American and Pacific Islander communities and researchers choose to participate in this mode of research. CBPR allows for these communities to wrest control over their own data and narratives in a way that more established forms of research do not. While it might be hasty to say that CBPR is a decolonizing practice, the ways in which certain projects are implemented and executed provide an avenue for researchers and community members alike to combat stereotypes and institutions that previously did not hold the community in high esteem. However, in this effort to decolonize research and to regain autonomy as subjects of the nation-state, former victims of public health as a tool of statecraft can also alienate authority and institutions who seek to dismiss or invalidate this type of work. Community members must then partner with researchers, as representatives of the elites, in order to validate their own work.

Conclusion

This chapter provides a foundation for understanding data ownership with community-based public health research. While the field of public health generally understands data ownership as sole researcher ownership, new definitions of data ownership, such as indigenous data sovereignty, attempts to center the community. In revisiting "Introduction," centering the community is not only the aim of this project, but also the aim of all Asian American Studies. A recent publication of *Amerasia Journal* published a call-to-action for the field, "we urge Asian American studies and like-minded academic endeavors to "serve with community" through a renewal of engaged scholarship and epistemological projects centering thoughtful development of university-community partnerships that account for complex organizational structures" (Poon & Villanueva, 2018). This project answers the call to "serve with community" by centering the community. While this chapter mainly focus on the researcher's perspective, this project unpacks community-researcher partnerships' understandings of data ownership and community-based research. Ultimately, the findings of this project will hopefully lead to community-centered models of data ownership and improved community-researcher partnerships.

Methods

Introduction

This project used semi-structured in-depth interviews as its methodology. These interviews attempt to answer the following research questions: 1) How do community-researcher partnerships develop trust in their relationships? 2) How do Asian American and Pacific Islander communities and researchers negotiate data ownership and control in community-based public health research? 3) How can models of data ownership within community-researcher partnerships inform and improve future community-based public health research in Asian American and Pacific Islander communities? In the pursuit of answers for these questions, I conducted 10 interviews with community members and researchers to ask them to explain the foundations of these partnerships and to attempt to comprehend their individual models of data ownership within their projects. Through careful analysis of the transcripts, the interviews and partnerships demonstrate how understanding the negotiations around data ownership can aid in improving these relationships in the future. This chapter discusses the process of recruitment and eligibility, the interview process, the participants, the analysis, and limitations for this endeavor.

Eligibility & Recruitment

I intended to interview pairs of community members and researchers about projects they conducted together. Community members and researchers could participate if they had conducted or were currently conducting a community-based public health research project within an Asian American and/or Pacific Islander community. At least part of the project had to have occurred sometime within the last 10 years. Pairing the interviews provided an opportunity to examine different perspectives about the same project and partnership. The separate interviews did not intend to look for differences between responses. Instead, the separate interviews tried to understand how both viewpoints approached and understood the partnership and data ownership.

Participants were recruited through two main strategies. The first was by general word of mouth. I sought recommendations from colleagues on researchers who fight the eligibility criteria. The second strategy was using the National Institutes of Health's (NIH) Research Portfolio Online Reporting Tools (RePORT) database. This database provides all grants and grantees, as well as publications and other information, on projects funded by the NIH. The search terms used in a variety of combinations were "Asian," "Asian American," "Pacific Islander," "community-based research," "public health," and "CBPR." The search parameters set the search to results from the last 10 years.

Potential participants from recommendations from colleagues as well as the NIH RePORT searches received an email detailing the project and an ask to participate in an interview. Additionally, the email asked for recommendations for other potential participants and researchers were asked to recommend any community members that might be willing and able to participate. Coming from academia, finding researchers as the first point of contact was easier than finding community members who might have participated in a community-based research project. Once participants agreed to participate via email, times for interviews were coordinated.

Interviews

Interviews were scheduled and conducted over the span of approximately six months (September 2019 to February 2020). All interviewees identified their projects as community-based research prior during the pre-interview process. Each interview ranged from approximately 30 minutes to slightly over 60 minutes depending on the availability of the interviewee. Interviews were conducted in person as much as possible or over Zoom, a video conferencing platform, when preferred by the interviewee. Interviewees were sent the consent form prior to the interview. Prior to interview, I reviewed the form with the interviewee and asked for verbal consent as per UCLA IRB guidelines. Interviews were audio recorded for reference.

I conducted a total of 10 interviews with 11 total participants. 4 total pairs were interviewed with two researchers without community members interviewed due to constraints on availability from the community members. For one interview, I interviewed 2 community members who both wanted to be interviewed together because they had both worked on the project in similar yet distinct capacities. Interviews were timed so that community members and researchers were interviewed as close together as possible. After the interview, recordings were transcribed for analysis.

Interviewees were asked questions as outlined in the Schedule of Questions. The main themes of the questions asked were demographic and program specific information, the community and community-based research, data and data ownership, and the benefit of the program and advise for the future. The specific questions can be seen in Appendix 1.

Participants

In subsequent chapters, participants are identified by their initials and the projects where I could interview both the community member and the researcher are grouped together. To ensure anonymity, all participants' initials have been changed. The following are brief descriptions of each interviewee, details about the partnerships, and short descriptions of the projects. Where appropriate, initials will have parentheses to provide context such as T.R. (community member, 2-year partnership, Pair 1). The projects are organized visually in Appendix 2.

Pair 1 includes the community member, T.R., and the researcher D.R. who worked on a project that sought to discover problems and issues affecting local Southeast Asian youth. The project allowed the youth in the community to drive not only the study design and collection of data but also the analysis. The partnerships consisted of D.R. and a community organization that served Southeast Asian youth. T.R. served as the executive director of the organization. D.R. used to work at the organization prior to attending graduate school and sat on the board of the organization after going into academia. The organization applied for funding in collaboration with D.R. The partnership then received funding from a funder explicitly looking to fund community-based research. The project and partnership lasted approximately 2 years.

Pair 2 worked together in a collective that attempts to study and provide support for Filipinx mental health. The pair includes the community member, Z.B., who brought in the researcher, N.R., when the collective decided they needed an academic to collect and analyze data. Prior to the interview, the collective and N.R. had been working together for approximately a year, and the partnership is ongoing as of this writing.

Pair 3 is in fact a triad. Pair 3 includes two community members, U.C. and M.K. who were interviewed together as well as the researcher P.L. Pair 3 developed and implemented an intervention aimed at caregivers who tended to family members who had issues with memory loss and cognition within the Southeast Asian community. P.L. began the project and sought out community input for the project. P.L. partnered with multiple community organizations, including the community organization at which U.C. and M.K. worked. U.C. and M.K. both worked on the project but in different capacities. The partnership has worked together for approximately 2 years and is ongoing as of this writing.

Pair 4 is a partnership that has worked in Asian American and Pacific Islander communities to raise the awareness and implement interventions mainly around cancer. Pair 4 includes the community member, N.B.E., and the researcher, T.S. This partnership began outside the range of this project over 20 years ago and since then has worked together on a number of projects and issues. I spoke to them specifically about their cancer work, particularly in the Pacific Islander community. The project the interviewees discussed lasted approximately 10 years from conception to conclusion. Currently, N.B.E. serves as the Executive Director for a community organization where T.S. serves on the board of directors. The partnership continues to work together on a number of issues as of this writing.

The two researchers I interviewed where I could not interview a corresponding community member are Q.J. and F.B. Q.J. studied cancer and implemented an intervention in Pacific Islanders communities. The partnership Q.J. worked on lasted approximately 5 years. F.B. studies obesity with a particular geographic region where mostly East Asian communities reside. F.B.'s partnership began over a year ago and continues as of this writing.

Analysis

Each interview yielded a transcript for analysis for a total of 10 transcripts. The coding procedure for these transcripts combined descriptive and in vivo coding, outlined by Saldaña (2016, p. 102-110). The descriptive codes highlighted different themes across the different transcripts whereas the in vivo codes highlighted similar phrases shared across each transcript. In the analysis, quotes in which the similar phrases denoted by the in vivo codes were present were aggregated to look for themes across the interviews. For example, while not explicitly asked about in the interviews, multiple interviewees mentioned the IRB as a barrier or cumbersome. Those quotes were then highlighted as an in vivo code and then aggregated together for analysis. Transcripts were coded by hand, on paper, and annotated when appropriate.

Limitations

This project has a number of limitations. First, all the partnerships interviewed conducted their research in California. The only regional differences were between Northern and Southern

California. While there are many different Asian American and Pacific Islander communities across the United States, this project, due to availability of interviewees and other factors, only includes projects conducted in California. Second, all the researchers interviewed for this project work at public California universities. The job requirements of these researchers as well as the educational backgrounds are very similar and therefore do not include any perspectives of projects conducted with researchers from private universities and/or researchers from outside of California. Third, this project, while about Asian Americans and Pacific Islanders, only includes 2 projects involving the Pacific Islander community out of 6 potential projects. Ideally there would have been a balance between research conducted in Asian American and Pacific Islander communities. The projects including working with 3 Asian American communities, 1 Filipinx community, and 2 Pacific Islander communities. Finally, ideally this project would have interviewed an equal number of community members and researchers. However, due to the availability and desire on the part of some community members, I could not interview an equal number. In total 6 of the interviews were conducted with researchers while only 4 were conducted with community members. These limitations should be taken into consideration when reading the following chapters.

Conclusion

The methodology of semi-structured in-depth interviews provides a detailed yet flexible medium for investigating this topic. As much as possible, pairing the community members with the interviewees allows for all involved to provide their own perspective. Additionally, any discrepancies between the interviews can allow for points of examination or clarification that could potentially yield more nuanced and differing understandings about any of the topic. I would be remiss to not acknowledge that this project while studies community-based research as an approach to research, it is more so community-informed research rather than community-based. In this project, the community provides their perspective which usually does not occur within the literature. Often when the community does speak, the researcher and community speak as one. While this project couples together the community and the researcher, it also pulls their voices apart, looking for insights and observations that only the community can provide. In the spirit of Asian American Studies and Ethnic Studies, the following chapters describe the findings from these interviews and transcripts with the intention of centering and amplifying the community perspective. Since much of the literature around community-based research approaches the issue in an attempt to inform and change the researcher's perspective, the following chapters will seek to demonstrate how the community thinks and feels about data ownership in an effort to show how communities and researchers can improve their partnerships in the future.

Definitions and Models of Data Ownership

Introduction

Outside of community-based research, academics take data and data ownership for granted. Most researchers believe that data belongs to the collector of data and that the relationship between researcher and subject is purely transactional. Researchers simply extract data. Within public health research, data can take many forms not limited to but including beliefs, behaviors, and even biospecimen. The National Institutes of Health's (NIH) policies around data ownership demonstrate how most researchers outside of community-based research think about data ownership. As one of the largest funders of not only public health research but also all medical research, the NIH requires researchers to be ready to share out data to other researchers with little to no regard to any potential rights or claims to ownership on behalf of the subjects (NIH, 2003). In fact, the NIH policy for data and data ownership states: "Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data" (NIH, 2003). While data being widely and freely available is commendable and important, the policy elevates data as equal to the participants with no regard for participant rights. In a rebuke of this avenue of thinking, some scholars of community-based research, including public health research, have offered alternatives to these more "traditional" notions of data ownership.

An alternative to these "traditional" understandings of data ownership, indigenous data sovereignty arises from a group of indigenous and native scholars from around the globe, but mainly from the Pacific and the Americas. These researchers describe data sovereignty as "indigenous peoples' right to maintain, control, protect, and develop their cultural heritage, traditional knowledge, and traditional cultural expressions as well as their right to maintain, control, protect, and develop their intellectual property over these" (Kukutai & Taylor, 2016, p.

xxii). This definition of data sovereignty drastically differs from the commonly held belief that data belongs to the researchers who collected it, as per the NIH policy. Indigenous data sovereignty's emphasis on indigenous peoples' rights to own and control data collected about them demonstrates a community-centered approach to data ownership. While issues of data ownership are prevalent in community-based research literature, and in particular Community-Based Participatory Research (CBPR) literature, indigenous data sovereignty presents the closest definition to the desires expressed by the community interviewees. This project does not offer a new, distinctly Asian American model of data ownership akin to indigenous data sovereignty for indigenous communities. That is simply outside the scope. Instead, this chapter encapsulates what it means to own data, and how partnerships practice data ownership.

This chapter aims to center the community's voice in both the definitions and models of data ownership. With respect to defining data ownership, many of the interviewees presented very similar definitions regardless of their status as either community member or researcher. Overwhelmingly, the definitions offered by the interviewees for this project emphasized access to and control over data as a key component of data ownership. However, a certain outlier in the definition offers a way to inject nuance into the slight differences in the interviewees' definitions. After discussing the definitions, the chapter then describes the models of data ownership that each partnership practiced. In analyzing the various models of data ownership, the transcripts suggest that some partnerships worked towards an equitable model of data ownership more successfully than others. However, regardless of the closeness to equity in the models of data ownership, one observation remains: communities value access to and control over data in community-researcher partnerships because of its potential to empower communities.

Definitions of Data Ownership

Almost all of the definitions by the interviewees shared the same ethos of having access to and/or control over data. For them, data ownership comes from the ability to dictate what happens to the data. There are slight variations in the definitions offered as to what comprises data ownership. Some focus on data ownership from a physical standpoint. These definitions consider where the partnerships might house the data. Whereas others focus on intellectual ownership. These definitions contemplate which individuals should have some sort of power over the data. However, the similarities in these definitions outweigh the differences.

The focus on the physical ownership of data demonstrates the importance of access. For example, P.L. (researcher, ongoing partnership, Pair 3) defined data ownership as "… whoever physically hold the data and scientifically owns the data. So they will be in charge of the data collection, data dissemination, what happens with the data, if it gets published… I feel like that's what data ownership is: being able to control what happens to it." In this definition, P.L. discusses where the partnership might house the data as well as who has control over it. The differences in this definition between physical ownership and intellectual ownership align with the connections between access and control. Access to data dictates the ability to use the data but not vice versa. For instance, the community can access the data either physically or electronically, but the community might not possess the ability to interpret and/or analyze the data. In an example from Pair 1, D.R. (researcher, 2-year partnership) mentions that the community had both the electronic and physical copies of the data but that they "didn't want to ask the staff to learn SPSS or STATA" because of the burden that would impose on the community. D.R. (researcher, 2-year partnership) wanted to make the data "accessible to the youth and to the staff and the organization." If the community has access to the data, that does not automatically imply that they know how to use the data. Therefore, the ability of the researcher to interpret the data and make it accessible to the community serves as a benefit to community-researcher partnership and community-based research. However, the community still believes in access to the data.

Since controlling the data requires access to it, the community defines data ownership through the lens of control as well. The ability to control manifests in the definitions as an intellectual ownership of data. For example, P.L.’s definition above mentions “being able to control what happens to” the data. This idea of control appears in other definitions. N.B.E. (community member, 20+ year partnership, Pair 4) defines data ownership as “Because I think that having data ownership means that we have control over who publishes the data, who gets to analyze it.” Additionally, Q.J. (researcher, 5-year partnership), whose community counterpart was not interviewed, defined data ownership as “Um, data ownership means you have the you get a say and how the data is used you get a say and who uses the data. Another good term is stewardship of data. You kind of oversee it, you're the guardian of it.” While P.L.’s definition mentions ownership as physical and “scientific” or intellectual, these definitions focus on who has a right to and/or over the data. N.B.E.’s definition defines control as over publication and analysis. Q.J.’s definition defines control as “get[ting] a say” or “stewardship.” The language might differ but each definition echoes that those involved with the collection of the data should have a measure of control over it. Community members and researchers alike value access to and control over data. However, one definition is an outlier to those focused on access and control.

While the previous definitions defined data ownership as having access to and control over the data, one community member upends the entire notion of data ownership. Z.B. (community member, ongoing partnership) from Pair 2, defines data ownership as “data should not really be owned by anyone. I mean, you're collecting it to be shared for the use of everyone, right?" This definition, states that data should merely exist for the sole purpose of use. The implications of this definition fall outside the scope of the literature on data ownership. Therefore, the following discusses the implications of data ownership, by borrowing from the scholarship on land ownership.

Land Ownership and the Implications of Data Ownership

Land ownership has been studied and written about far more than the ownership of data. Within land ownership discourses, land exists as a finite resource. As land cannot be created, it requires protection from destruction. In a similar sense, many of the interviewees believe data as an entity requiring protection. However, a difference exists between protection and ownership. Through the lens of settler colonialism, land must be claimed. Settlers, through their conquests, demand ownership and control over the land. This claim to ownership comes from the concept of *terra nullius*. In her book *The White Possessive: Property, Power, and Indigenous Sovereignty*, Aileen Moreton-Robinson defines *terra nullius* as "land belonging to no one" and if land belongs to no one, then it must belong to someone (Moreton-Robinson, 2015, p. xx). Therefore, someone must claim it to warrant protection. Moreton-Robinson describes possessive logics as the justification for *terra nullius* in which possessive logics are a "mode of rationalization, rather than a set of positions that produce a more or less inevitable answer, that is underpinned by an excessive desire to invest in reproducing and reaffirming the nation-state's ownership, control, and domination" (2015, p. xii). This idea of possessive logics then implies that protection of an entity, whether land or data, compels ownership.

While the ideas of *terra nullius* and possessive logics provide insights into the justification for land ownership, multiple problems arise in applying that justification to data ownership. In land ownership, settler-colonizers stumble across a piece of land and then claim it as under their dominion. However, the data that many of the interviewees in this project discuss are data that they collect. These community-researcher partnerships do not merely stumble across some quantitative data set or pieces of qualitative data. They engage in targeted efforts to collect new data. The issue of new data here becomes paramount. As discussed later, the new data that these partnerships collect have the potential to empower the community to describe the problems they face. However, these problems do not manifest solely because the data describes them. The land that settler-colonizers claim existed far before they arrived and staked claims. Similarly, the community faces these problems daily and the collective knowledge that these problems exist serve as a form of not-yet-documented data. Community-based research and CBPR acknowledge that the community possesses an expertise (Israel et al., 2008). Yet that expertise exists prior to these projects. The knowledge base the community possesses on the not-yet-documented data serves itself as a form of data. Since the definitions described concern solely collected data, perhaps conversations around data ownership should then extend prior to and past the point of collection.

While not explicitly addressed by the definitions of data ownership provided by the interviewees, the data they collect through surveys, biospecimen, or other measures, are not the sole types of data generated in these projects. Access to and control over data after collection appears as the focus of the definitions. However, the community has a role to play before the data collection process begins. In some of the projects, the community serves as the drivers of the research. For example, in both Pairs 1 and 2, the community noticed a problem and sought out to collect data about the problem. In these cases, the community observations of the problem serve as the very first points of data that go unacknowledged. The community then understands that they need the data and therefore recruit researchers for their cause. In Pair 1, T.R. (community member, 2-year partnership) states that the community "needed data to determine what kind [indiscernible] of program would want to work on in relation to the issues that are impact them or creating barriers… for them to be healthy" and brought in D.R. to help collect the data. Similarly, in Pair 2, Z.B. (community member, ongoing partnership) "felt that the community needed" the data. Therefore, Z.B. sought out and incorporated N.R. (researcher, ongoing partnership, Pair 2) to help collect the data. While the community did not initiate every single project that these partnerships worked on, these two examples demonstrate that the community has knowledge, and therefore a form of data, prior. The ability to then shape the formation of the project, what types of data to collect, the data collection process, the analysis of the data, and then the dissemination of the data demonstrates the community's power within the entire research process in community-based research. Data ownership does not begin at the data collection process. In fact, data ownership might begin before the projects even commence.

Community ownership of data might begin before starting these projects and partnerships; however, another issue arises after collecting the project data. In returning to land ownership, once the partnerships collect new data, according to the definitions data requires protection. As seen in land ownership, protection begets ownership. While Z.B.'s definition in a way negates the issue of data ownership, the other definitions imply data as an entity to be owned. If data must be claimed, protected, and owned, then perhaps *data nullius* exists. A potential *data nullius* would be defined as data belonging to no one. Under the same logics as land ownership then, the data must belong to someone. Of course, the differences between land and data still apply. Also, I do not advocate for the existence of *data nullius*. However, *data nullius* proves useful in understanding why communities value access to and control over data.

The end of Z.B.'s definition, which is the outlier to the rest of the definitions, says, "But for me, it's like the important thing is getting the data." By "get[ting] the data" Z.B. does necessarily repeat the previous definitions' call for data ownership, but rhymes with them. By saying the community needs to "get" the data, Z.B. desires a means through which to collect and access the data. Again, the data has existed in the collective minds of the community. The new data generated by these partnerships then should not only belong to the community, but the community should have a sense of control over it. The ability to control what happens to the data and the ways in which communities have gained that power in their partnerships manifests in the models of data ownership.

Models of Data Ownership

Whereas the interviewees defined data ownership relatively abstractly in the previous section, this section focuses on the models of data ownership that each partnership practiced. These models fall into three distinct categories: codified agreements, informal agreements, and researcher owned data. These categorizations indicate the degree to which each of these partnerships move towards equitable models of data ownership. As previously stated, the goal of community-based research is an equitable partnership, and by extension an equitable model of data ownership. Therefore, utilizing an evaluative framework for equity and health equity, this section investigates whether or not indicators of equity exist in the models of data ownership demonstrating the various ways and levels to which these partnerships empowered the community. The framework, while not explicitly about equity in models of data ownership provides a structure to assess how these partnership share, or not, the data they collect.

While the literature review offered some frameworks to evaluate community-researcher partnership and/or CBPR projects, Ward et al. proposes a framework with specific indicators to demonstrate the effectiveness of CBPR partnerships as a whole. This framework has five dimensions of equity: "1) a focus on equity in partnership processes; 2) a focus on addressing health equity; 3) capacity and ability of communities facing health inequities to engage in future partnerships and decision-making; 3) shift in power benefitting communities facing inequities; and 4) reductions in health inequities and inequities in the social and environmental determinants of health"[2] (Ward et al., 2018). Since these seek to address CBPR projects and partnerships as a whole, not all of these dimensions of equity will apply to data ownership. However, the dimensions that do apply, focus on equity in partnership processes, capacity and ability of communities to engage in decision-making, and shift in power benefitting communities facing inequities, have various indicators that the authors of this framework utilize in order to determine whether these dimensions of equity exist within the partnership. The article provides various methods of data collection that would reveal how these indicators lead to the dimensions. These methods of data collection include document review, field notes, and in-depth interviews among others (Ward et al., 2018). While this project only conducted in-depth interviews, the transcripts provide insights into whether or not these indicators point to equitable models of data ownership.

Codified Agreements of Data Ownership

While not as common as informal agreements, two partnerships used codified agreements of data ownership. These models had formal documentation, in the form of Memoranda of Understanding (MOUs), that detailed how the partnership would practice data ownership including issues such as storage, rights of analysis, rights of dissemination, rights of sharing the data with other researchers, and others. The following examples describe how two different partnerships operationalized data ownership through MOUs in order to not only formalize their

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[2] There is a typo in the copy of the article. The number 3 is repeated twice so the numbering should reach 5 instead of 4.

models but also serve as potential prototypes for future community-researcher partnerships to use. These models, based on Ward et al.'s criteria, have several indicators that show these partnerships promote equity within their data ownership practices.

The first example partnership, Pair 1, used an MOU to detail the permissions around data and data ownership. However, the researcher, D.R., seems to couch the use of the MOU in language that obfuscates the formality of the agreement. When describing the partnership's approach to data ownership, D.R. (researcher, 2-year partnership) states that they did not have any "hard or fast rules." However, D.R. also states, "we had developed MOUs to, for me, in terms of data use and certain parameters around that." Additionally, T.R. (community member, 2-year partnership) said that the data "belonged to [the community organization] … there was an agreement that we had that [D.R.] could write about that that was research … but it was owned by the organization."[3] In this case, these two quotes demonstrate how much control that the community had over the data. The community outlined the terms of agreement. D.R. merely had permission from the community to utilize the data. D.R.'s description of their model of data ownership as lacking "hard or fast rules" might have stemmed from the partnership's lack of rigidity around the storage of data. D.R. stated that they had the data electronically while the community had the physical copies of the questionnaires they collected and copies of the electronic dataset. However, these quotes clearly show many indicators of equity.

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[3] Full quote: "I mean, it was very clear that it belonged to [the organization]. I mean, that was in the beginning. And that it belongs to [the organization]. And and that was who were doing it for, but it didn't mean that [D.R.], and there was an agreement that we had that she could write about that that was research that she could read literature on as well as [another PI] had needed to, but it was owned by the organization." T.R.

In this equitable model, the partnership fulfilled all three dimensions from Ward et al. that would apply to data ownership. First, the community had decision-making power in that the community, in the MOU, had to grant permission to the researcher to use the data. Clearly, the data collected belonged to the community. The community owned the data. By requiring the consent of the community, this model not only gives decision-making power to the community, but also shifts the power to benefit the community facing inequities. While the partnership sought to address health inequities they saw in their own community, the community organization's power in giving permission to the researcher demonstrates a different way of correcting a previous inequity. As seen with the NIH model of data ownership, in other research projects, only the research owns the data creating an inequitable data ownership model. As is the goal of community-based research and CPBR, the community not only are the subjects of the research but also, they lead the research and co-own, or this case just own, the data. The MOU in this partnership is tangible proof that, in negotiating the politics of belonging for the data that this project generated, the community owned the data. Therefore, not only does this partnership fulfill the dimensions of community engaging in decision making and shifting the power to benefit communities facing inequities, this partnership also demonstrates its focus on equity in the partnership process by claiming and codifying ownership of the data.

In a very similar instance to Pair 1, Pair 4 also utilized an MOU to describe their model of data ownership. As mentioned previously, Pair 4 have worked together for over 20 years. This has influenced their model of data ownership greatly. According to the community member, N.B.E., "we created a policy that the data is co-owned, but that anybody who wants to use it needs to come back to [the organization] to develop a short proposal about how they're going to use the data." Not only did the partnership use an MOU to codify the data ownership agreement, but also, this MOU has shifted into an organizational policy that dictates data ownership for not only the projects the pair works on, but all projects conducted in conjunction with other researchers. However, the partnership realizes how different this type of formal agreement is. T.S., the researcher said, "… that's really depending on each partnership, but the principles are out there. And what should be reflected in these agreements, however you end up doing the agreements should be, you know, in there." In acknowledging the distinctive nature of this partnership and their agreement, T.S. understands that not every partnership can or wants to operate in this fashion. However, if the goal of community-based research and CBPR is to promote equity and empower the community, then the MOUs that this partnership and Pair 1 have proven that they have and can do so.

The rationale for how Pair 4's model of data ownership promotes equity is very similar to that of Pair 1. Both require the consent of the community for the use of the data that shifts the decision-making power to the community. While Pair 1 defines data ownership as the data belonging solely to the community, Pair 4 has a model of co-ownership. By co-owning the data with the researchers, the community does not necessarily cede control nor decision-making power. However, Pair 4's model might not shift the power to the community entirely. In Pair 1, the model gives all the power to the community whereas in Pair 4 the community still has to consult with the researcher. The community still provides consent over the data's use. Yet by requiring the researcher's approval, the shift is only partially complete. Nevertheless, both partnership's use of a codified agreement shows how focused all involved are on equity within their work. It is important to note that both partnerships say that they practice CBPR specifically for the equity that this approach to research provides. Therefore, partially using Ward et al.'s criteria makes it evident that both of these pairs practice equitable models of data ownership.

While these partnerships operate with equity in mind, some partnership have only some of the indicators of equity in their models of data ownership.

Informal Agreements of Data Ownership

Unlike the codified models of data ownership, the informal agreements do not all have the same indicators of equity. These informal agreements share many aspects in common with the codified agreements. However, the differences point to a potential lack of protection for the community and a question of whether or not co-ownership really means co-ownership. Due to these risks, the informal agreements may not possess similar indicators of equity.

Due to the lack of specificity with informal agreements, describing models of data ownership becomes difficult. For example, while Pairs 1 and 4 had specifics within their MOUs about data ownership, consent, and control, others, such as N.R. from Pair 2, did not offer as exact descriptions of their models. N.R. (researcher, ongoing partnership) described the model as "a partnership control. It's almost like a lock and key, like a double bolt." Similar to Pairs 1 and 4, Pair 2 has a model that requires consent. While Pair 1 only requires the community's consent, Pairs 4 and 2 require both party's consent. In this way, the community provides a check on the researchers and vice versa. Through utilizing unanimous consent, the partnership empowers the community, involves it in the decision-making process, and has a focus on equity. Through these three criteria, it might seem that Pair 3 also have the same indicators of equity. However, the lack of a formal agreement could also potentially harm the community.

In another example, a researcher provides even less specifics. Q.J. said, "It's more of the community owns the data, collectively, no one person owns the data. So it's a community group that owns it." While this appears similar to Pair 1's model of data ownership, Q.J. does not describe any requirements of consent nor control. The lack of consent or control does not empower the community in the same way that previous models have. The community has no decision-making power, no shift of power to the community. It is unclear whether or not the partnership focuses on equity in the partnership processes. While the community owns the data, they have no recourse for control. A lack of specificity in this instance demonstrates a rift between the previous models of data ownership and this one. This rift between models indicates an inequity between the models of data ownership and the partnerships themselves. If only some but not all partnerships emphasize all the indicators that apply to data ownership that Ward et al. use to evaluate CBPR projects in general, then an inequity exists. While T.R. acknowledged that each partnership must define their own model of data ownership in their own way, the underlining emphases of focusing on equity, giving the community decision-making power, and empowering the community through this project should remain constant in order to promote equity. Additionally, the lack of specificity on the part of Q.J. and the lack of a codified agreement for both Q.J. and Pair 2, strands the community in terms of the recourse they might take against the misuse of data. The misuse of data comes up as a concern in the next chapter. However, here specifically, without a codified agreement, the community has no tangible evidence of what the researcher or anyone else involved with access can do with the data. At least with the MOUs, Pairs 1 and 4 can point to specific details written down that protect them, and to an extent protect the researcher, from misuse. This inequity might not necessarily be harmful due to the trust and success of the partners within these pairs. However, in order to achieve equity, community must be centered and empowered.

While some might argue that in the previous examples the community might not have cared about or known about the power that ownership of data can bring, in F.B.'s interview, the community member brought up the issue of ownership. The community member asked F.B.

(researcher, ongoing partnership), “Do we have ownership of the data? Is this go?” to which F.B. replied, “Yes. Yes, we do. Absolutely.”[4] In this case, the community member had to ask the researcher for clarification on ownership. Because this partnership still had not conducted its full intervention yet, the in-depth conversations that say Pair 4 might have had over the course of years might not have yet occurred. However, again the lack of a formal, codified agreement could potentially work to the detriment of the community. The community needing to ask about data ownership demonstrates a possible lack of focus on equity. Due to the tenets of community-based research and CBPR, the researcher might have assumed that the community either owned the data outright or co-owned it. However, the community, probably less familiar with the theoretical underpinnings of community-based research and/or CBPR, implicitly felt the inequity of the researcher solely owning the data and sought out to change the paradigm themselves by asking for ownership. As these examples have strayed further and further away from the codified agreements, it is important to note that these models of data ownership have worked for these partnerships. Not once did any interviewee in these pairs express disappointment with either the model of data ownership or the partnership. However, it is clear that these informal agreements do not possess the same indicators of equity as the codified agreements. This is not to say that the lack of indicators of equity have been detrimental in any case. Nonetheless, the varying presence of indicators of equity among these informal agreements show that not all models of data ownership equally nor equitably empower the community. In contrast to these models that did empower the community, in an outlier, one community did not receive any power at all.

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[4] The full quote by F.B. states: “Yes. Yes, we do. Ab-absolutely.” The slight stutter in the word “absolutely” is taken out of the quote in the text for clarity.

Researcher Owned Data

In contrast to the codified and informal agreements of the previous models of data ownership, one partnership did not practice a model that had outright community ownership, co-ownership, nor required the community's consent. In Pair 3, the partnership collected questionnaires to measure the effectiveness of their intervention. The pair, really a triad, appeared very in sync through their descriptions of their models. The researcher, P.L. stated, "we own the data here at [the institution], that it was our data, my data." One community member. U.C. who worked on the research team helping to implement the intervention, said, "all my notes are on the research team research system all the notes are stored in the same [cloud platform] with a limited access. And then for data, for example, I collect the data in paper. And I think [P.L.] she, she needs to follow the guidelines or the procedures at [the institution] how to store the data and I never asked her." The other community member, M.K. also understood that "[P.L.] has control over the data, meaning from beginning to tend, she was able to pull the data, research it, analyze it, decide." This model in which only the researcher, and partially the institution, owned the data stands in contradistinction to the previous models.

Clearly, by not having any level of community ownership nor control over the data that the partnership collected, all involved did not prioritize equity. Including U.C. on the research team could be interpreted as focusing on equity in partnership processes, this application of some of Ward et al.'s indicators of equity strictly applies to data ownership. Even with U.C. on the researcher team, U.C. did not own any of the work. P.L. and the institution made U.C. store her work on servers and ways that indicated that the institution and the researcher solely owned the data. The community expressed slight frustration with this model as M.K. stressed that "I think data should be available." However, the lack of a more explicit critique of this model of data ownership might indicate a reluctance on the part of the community to scorn the researcher and the model. The community could have been perfectly content with this model of ownership. Yet, this partnership, while saying they conducted a community-based research project, did not adhere to the principles of “joint community and academic leadership and ownership” that defines community-based research (Jones et al., 2008). This project does not wish to evaluate whether or not Pair 3 conducted a community-based research project. Instead, the point of presenting this outlier within the dataset is to showcase all various types of models of data ownership that exist underneath the umbrella of community-based public health research.

Models of sole researcher ownership and control of data present a fascinating conundrum within the sub-field of community-based research. Clearly, this model does not adhere to CBPR, as that approach to research has strict guidelines. Yet, this example demonstrates that, even underneath the larger umbrella of community-based public health research, variance exists with regards to models of data ownership, and to an extent community-based research as a whole.

Conclusion

In assessing these definitions and models of data ownership, one observation remains clear: one definition nor model exists within community-based public health research in the Asian American and Pacific Islander communities. These partnerships can increase the indicators of equity in their practices of data ownership in order to empower the communities. The absence of any access to or control over data means that these projects revert to more “traditional” modalities of research, something that community-based research actively wishes to disrupt. Instead of being subjects, and being subjected to the actions of researchers, community members now have the chance to exert power over the data that they not only have a part in collecting but also have a part in sharing out. Some even have concerns within the realm of community-based research. In this case, one community member had warned that “there’s a lot of researchers how think they’re doing CBPR… But they really have to monitor themselves because I’ve observed people, groups who think they’re doing CBPR but the community sitting on the table silent and not having a voice… So, I think that there’s groups who think they’re doing it, but they’re really not.”[5] This fear of abuse on the part of the researchers of the label CBPR extends to all community-based research. For too long, communities have been subjugated to the whims of researchers. Therefore, it becomes clear why these communities fight for ownership of the data, for the access to it and the power to control it. Data has the power to lend legitimacy to the community. The community can use this data to prove that they can conduct thorough, sound research and then use the findings to (re)claim the narratives about them perpetuated by these “traditional” research modalities. The definitions and models of ownership in this chapter only prove how valuable the communities see ownership and control over data. With it, they have the potential to enact visible change for their own communities.

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[5] Full quote: “I think there's a lot of researchers who think they're doing CBPR. And so, um, and so it's really defining it further because they think, “Oh, well, the community's here at the table, they're listening.” But they really have to monitor themselves because I've observed people, groups who think they're doing CBPR but the community sitting on the table silent and not having a voice. They're just listening and the researcher saying, “well, you're going to do it this way.” I've had researchers who think they're doing CBPR but then yell at the community say, “hey, all, all these surveys are in the same writing, that means you're falsifying information.” And I'm like, “No, that's really disrespectful for to ask the seniors to fill it out. And it you know, as a young person, you have to help them out. And yes, in all the writing, but it's the answers are accurate.” So, I think that there's groups who think they're doing it, but they're really not. And so they have to really understand what is true CBPR? And what does it mean? What does it truly mean to have the community at the table and for it to be equitable? And that means also looking around the table about who's talking, who's leading? Are they there for the whole process, from developing the tools to developing the budget to helping to write the proposal to you know, the policies that are developed to getting the funding to analyzing the data to do you know, disseminating the data, are they there from start to finish And is there trust built? So I think that people have to constantly do self evaluation of where they're at and how to improve.” N.B.E.

(Re)Claiming Narratives and Legitimizing Voices

Issues of Access to And Control Over Data in Community-Researcher Partnerships

Introduction

As seen through the interviewees' definitions of data ownership, these community-researcher partnerships emphasized access to and control over data. These partnerships reflected the importance of access to and control over data through most partnerships utilizing a co-ownership model of data ownership. The models of co-ownership largely required the consent of all parties involved for anyone, including members of the partnership, to use the data. Even though some did not practice a co-ownership model, these partnerships still emphasized the importance of access and control through both their definitions and models of data ownership. While understanding who owns the data and what constitutes ownership is important, the goal of this chapter is to understand interviewees view access to and control over data as paramount to the success of their work. In this endeavor, understanding the value of data will indicate why communities more so than researchers desire access and control.

Each of the partnerships have generated data that provide a snapshot of the state of the community. In the community's hands, the data from these projects serve two interconnected purposes. First, the data allows community members to (re)claim their narratives. Previously the corpus of scholarship might not have included data about these communities and specific issues. Conversely, the literature could have included data that misrepresented the community or data that were wrong. Therefore, with this new data in hand, communities can (re)claim their narratives. Second, the data lends legitimacy to both communities and researchers. As seen in the introduction, public health and Asian and Pacific Islander communities have historically had a fraught relationship. Community-based research intends to upend that paradigm by empowering the community through ceding decision making power to the community as well as collecting data as evidence for future changes. However, institutions like the university do not realize the value of the community. Data, then, legitimizes the community as researchers in the eyes of institutions and the university. Data serves as evidence not only for future change, but also as proof of the community's ability and expertise. In summary, this chapter finds that community-researcher partnerships value access to and control over data due to data's ability to enable communities to reclaim their own narratives and provide legitimacy to the community's voice.

(Re)claiming Narratives

Throughout the course of a semi-structured interview, tangents arise. Although not explicitly one of the goals of the interviews, many interviewees discussed the community-researcher partnership's motivations for conducting these projects. The partnerships felt a necessity to the data they collected. The (re)claiming of narratives told by the data previously collected stood out as a main motivation. By saying that these partnerships can claim the narratives supported by this data indicates a lack of data previously.

Lack of Data

While these partnerships might not say so, all of them produce new community-informed knowledge about their respective communities. As even with this project, most research requires a review of previous work done on the subject. However, more often than not with Asian American and Pacific Islander communities, data either does not exist or is not sufficient for the needs of the project. A few interviews highlighted the lack of data as a key motivator for conducting this research and these projects.

Within the first minute of the interview with T.R. from Pair 1, the community member mentioned this lack of data as both an obstacle to this research and a motivator. T.R. (community member, 2-year partnership) states that during the inception of the program "there really wasn't a lot of data about" the target population "during that time and" the partnership "needed data to determine what kind [indiscernible] of program would want to work on in relation to issues that are impacting the, or creating barriers for, they're creating barriers for, for them to be healthy and to improve their access to things." T.R., among others, highlights the need for data. Since they cannot find the data within the body of scholarly, peer reviewed literature, they needed to collect the data themselves. Community-informed data can exist at multiple levels. Oftentimes these community-researcher partnerships are the union of a community-based organization and a researcher, as with Pair 1. The community organization represents the community in the partnership as well as leverages their relationship with the community for the benefits of the partnership. In the case of Pair 1, in order to better serve the clients of the organization, they made a conscious effort to not only collect data they needed as a partnership, but also strove to include the participants/clients in the analysis of the data. T.R. (community member, 2-year partnership) later on in the interview says "it was creating data that didn't exist. It was empowering those who don't have information about their community that it is." This quote demonstrates how the lack of data in this case, and in other cases, served as motivation for the work. However, the lack of data is not the sole motivator for collecting new data.

In contrast to T.R. and Pair 1, F.B. describes a different motivation for data. In F.B.'s project, the partnership strove for "ethnic specific data. And we need localized data." The problem in F.B.'s partnership is not the lack of data but in fact the aggregation of data. The term "Asian American" that Yuji Ichioka defines in the late 1960s/early 1970s arises out of political necessity in order to rebuke earlier, racist terms such as Oriental (Lee, 2015, p. 304). One of the unintended consequences of this new term is the aggregation of dozens of Asian ethnic groups which ignores the diversity within the political category. For instance, N.B.E. saw differences between the published data and "what we were seeing on the streets." The diverging realities between the data and the community that N.B.E. and others such as Q.J. witnessed resulted from public health, in collecting large data sets, often aggregating Asian ethnic groups together and does the same to Pacific Islander groups. As early as 2000 and possibly earlier, scholars called for disaggregation (Srinivasan & Guillermo, 2000). However, not until 2016 did then Governor Jerry Brown of California sign the first law to disaggregate health data for Asian and Pacific Islander groups (Fuchs, 2016). F.B.'s struggle to attain disaggregated data exemplifies the need for data disaggregation. The lack of disaggregated data, both ethnically and geographically, is another type of lack that provides motivation for these partnerships. Absence here necessitates invention and creativity in community-based research.

These examples show how a lack of data or a certain type of data can motivate these projects. These new projects create new data that communities can use to claim unknown narratives, to tell new stories. The generation of data requires ingenuity in research, consultation of community, and the expansion of knowledge. This empowerment, as T.R. terms it, compels communities towards new goals. While interviewees pointed to a lack of data as a concern, others pointed to the fear of misuse or misunderstanding as equally as concerning.

Data Misuse

As some partnerships began with concern about the lack of data, others stated a concern around the misuse or misunderstanding of data. If the lack of data allows for these partnerships to claim an unknown narrative, worry about misuse indicates a project of reclamation. The word "reclaim," then, indicates a past in which the data collected did not reflect what the community saw or understood. Additionally, while "reclaim" implies a past, it could also denote more contemporary concerns about current scholarship. While this project does not seek to discredit previous or current research, the interviewees state that some works on these communities might have been or might be insufficient or misrepresentative. In the following examples, interviewees express apprehension around the misuse of data collected on the communities they represent.

These community-researcher partnerships did not explicitly identify their projects as ones of direct reclamation. Instead, some of the interviewees expressed a desire to protect their data against hypothetical misuse and misrepresentation of the communities through the data. Some of the interviewees articulated more current concerns for potential misuse. For example, P.L., a researcher, believed that their own awareness has increased around potential data misuse and that data “should not get into the wrong hands. I think it has to be protected.” This quote sits within a longer answer around data ownership. P.L. discusses how technological changes and advancements cause privacy requirements to grow. P.L.’s description of these new considerations does not appear onerous or cumbersome. In fact, P.L. “like[s] making sure that the data is like protecting the research participants.” By viewing the data as an extension of the participants, P.L. expresses a responsibility to the community to protect against misuse.

While P.L. does not explicitly name a potential abuser of the data, D.R does and points to a more recent example of abuse. D.R. (researcher, 2-year partnership) describes the hypothetical abusers as “people with perhaps not so good intentions.” D.R. then continues with an example of a researcher from the London School of Economics publishing racist studies roughly 10 years ago. This example serves as evidence that researchers can interpret data and imbue assumptions and implications that can harm the participants of a study. Therefore, by conducting community-based research these partnerships intend to prevent any misuse. The issue of misuse worried D.R.’s partnership so much so that they partnership agreed to not “use the data in such a way that would sort of be exploitative, that we would be responsible.” While D.R. points to a relatively recent example, other interviewees pointed to more historical concerns.

Within the same partnership as D.R., T.R. provided a historical perspective. This partnership worked in a predominantly Southeast Asian community. Given the history of colonialism, imperialism, and U.S. military intervention in Southeast Asia, T.R. (community member, 2-year partnership) worried about the misuse of data due to “the history of communities being objectified by science or being painted in a certain way, without control or power on how, how data is used.” Other interviewees, such as Q.J. and N.B.E., expressed similar sentiments on behalf of community members who felt that researchers previously had taken advantage of or used the community for their benefit. By speaking on behalf of these community members who felt used, these interviewees ground their concerns that come from real people who faced real historical problems and traumas. Previous researchers who collected the data on these communities misused the data by misrepresenting the community. The misuse of data and misrepresentation of the community can have deleterious effects as change makers can use it to affect policy, funding, and a whole host of other unintended consequences. Additionally, stereotypes can begin to emerge and seep into the collective consciousness of the field. These concerns grounded in historical basis contribute to the concerns that these partnerships possess about data misuse. Therefore, the new data generated by these partnerships supplants the data collected that initiated the concerns over misuse and misrepresentation.

Overall, these concerns over data misuse, linked with the lack of data previously discussed, exemplify how these community-researcher partnerships conduct a (re)claimation of narratives. Some interviewees presented concerns about a lack of data indicating a motivation to collect data about their communities. In this way, these partnerships claimed new narratives about communities absent from the scholarly literature. Other interviewees expressed concerns about the literature containing published data with analyses that misrepresented communities.

These concerns over the misuse of data caused the community-researcher partnerships to enact models of data ownership that protect their data. The valuing of access and control over data in the definitions and models of data ownership, which is how the partnerships protect their data, demonstrate how these partnerships actually (re)claim narratives.

Legitimizing Voices

In addition to (re)claiming narratives, by valuing access and control over data when negotiating data ownership, community-researcher partnerships gain legitimacy through the data they collect. Through this collection and analysis of data, the partnerships create new knowledge. Armed with this new knowledge, these partnerships, perhaps more importantly the communities, can then use the data as justification when arguing for funding or policy changes. However, even with this legitimacy that data provides, the community-researcher partnerships must still work to prove their worth, especially to academia. Several structures within the institution of the university do not value community-based work. These structures do not see the worth in several central tenets of community-based work such as the knowledge of the community nor the investment that researchers make into communities through their time and labor. Researchers, through these interviews, expressed frustration with appropriate means of compensation. Some pointed to monetary compensation while others acknowledge alternative means. However, while researchers can discuss compensating the community, institutions must still recognize the community’s value. A lack of recognition makes the community distrustful of institutions requiring researchers to serve as intermediaries between academia and the community. It is through these struggles of deciding compensation and advocacy that the community-researcher partnership then can gain the legitimacy they seek. This legitimacy allows for both community and researchers to apply for more funding and advocate for change.

Compensation and Investment

Several partnerships discussed the importance of different ways of compensating both the community and researchers. Compensation must come as a result of an investment and interviewees discussed investing more so through time than through money. However, money still reigns supreme in considering not only investment but also compensation. As N.R. (researcher, ongoing partnership) states, “money is power, and like I just told you, data is currency. So hence data is power.” This quote encapsulates the entirety of the notion that data provides legitimacy, or in this case power. Power and legitimacy are very similar. However, communities and researchers must wield data as a source of power in order to gain legitimacy. While this quote captures the ethos of the relationship between data, compensation, and legitimacy, the community-researcher partnerships view compensation and investment in two different yet related veins.

The first angle that these partnerships view compensation and investment is obvious: money. Community-based research projects have received some recognition in the field of public health more so in recent years. However, N.R. (researcher, ongoing partnership) points out that “one of the challenges of CBPR that’s a problem, though, is money.” While, as stated previously, the National Institutes of Health (NIH) appropriates approximately $41.7 billion annually for medical research, public health in general, and community-based public health research, receives merely a sliver (*Budget,* 2020). While the NIH does not disaggregate their grants and other funding they give to researchers by the type of research, the difficulty of finding partnerships for this project serves as evidence of the lack of funding going towards community-based research projects. Researchers seemingly not only have an easier time receiving money for this type of work but also the time needed to conduct these projects.

Researchers have an ease with which they can engage in this type of work professionally due to their educations and their occupations. All of the researchers interviewed for this project worked as professors at institutions of higher education. All of them had doctorates in social science fields that allowed them to work in positions that not only required them to conduct research but also gave them the resources needed to do so. A quote from Q.J. exemplifies this dynamic: "… realize that when I do research, or you do research, it's part – it's built into our schedule which, which part of our job or we're paid to do so, right? It's part of our 40-hour work week." As Q.J. indicates, academia has adapted to the capitalistic system of linking time to labor. In addition to teaching, mentoring students, participating in departmental meetings, and a whole host of other responsibilities, these professors also must conduct research. Q.J.'s quote acknowledges the researchers' ability to conduct this work with relative ease. As universities require research as part of their job description, the work these researchers conduct on these projects fulfill part of their job requirements. Due to this fulfillment, these employers compensate the researchers for their work. If not the employers, then usually funders compensate the researchers as funders generally see the labor, knowledge, and time that the researchers provide as valuable. However, the community lacks compensation and investment for their labor.

Generally, community-researcher partnerships operate between a researcher and a community organization. The community organization represents the community and has had a long-term investment in the community it serves. However, while the researcher receives compensation for their work through their employer, oftentimes funders provide unequal payment for the labor that the community provides. After working for 20 years in the same partnership, N.B.E. emphasized the importance of the community receiving equal funding from funders: "… really look at getting fair share. And that means equal money or more money, value, your work in the community, value your knowledge, that community is just as much of a researcher." The partnership regularly works on obtaining sustainable, long-term funding and submits budgets together that respects and compensates the community to their value. This unique partnership within this dataset demonstrates how the importance that the community places on monetary compensation. Without this partnership, N.B.E. says that they would "never have access to research funding" which could hinder their growth and sustainability as an organization. While monetary compensation is important, the predominant concern among these partnerships with regard to compensation and investment is time.

Since researchers receive monetary compensation from their universities for their work as well as partially from funders and since communities also might receive monetary compensation from funders, the interviewees also dwell on time as an investment. The amount of time spent by all members of these partnerships demonstrates the investment each makes. Q.J.'s partnership "would meet once a month, or once or twice a month for four hours" each so that the community and the research team could work together to improve and strengthen the project. While this is the only explicit mention of how many hours a partnership might have spent together, others like Pair 1 mentioned that D.R. (researcher, 2-year partnership) embedded themselves into the community organization by sitting in on weekly meetings, spending time to talk to organization staff informally, and meeting with the Executive Director often. The researchers can make this investment because of their pay structure. Spending time at a certain place or with a certain people indicates not only an investment in the project, but an investment in the people. Numerous partnerships stay in contact long after the project concludes. The ability of this project to reach out to researchers who nearly immediately had community members not only able but willing to speak on their experiences highlights the impact that the investment of time has both professionally and personally. However, certain researchers worry not only about the investment of time that the community makes, some with little compensation for their own work, but also the burdening of the community through attempting to build the organization's capacity during these projects.

Due to a lack of proper compensation in some cases, researchers are wary of asking too much of the community. Most of the time, these community-based research projects not only seek to conduct community-informed public health research, but they also intend to build the capacity of the community to conduct their own research. In the edited volume by Wallerstein and Duran, Randy Stoecker titles a chapter: "Are Academics Irrelevant?" (2008). In attempting to answer the question posted in the title of the chapter, Stoecker points to the original goal of community-based research in general as "the members of the community to do things themselves and become self-sufficient knowledge providers and social change producers" (2008, p. 108). Additionally, the article continues with the notion that "Doing research" is not, in itself, the goal" (Stoecker, 2008, p. 111). Stoecker's chapter demonstrates an understanding in the literature that community-based research does not solely focus on nor value the production of research. As many of the interviewees echo, the investment on the part of both community members and the researchers results in both professional and personal gains. However, in the interviews for this project, some interviewees expressed concerns over burdening the community.

Both researchers and community members acknowledge the investment that both make. However, some researchers either wish to protect their role and not make themselves obsolete, or genuinely worry about overburdening the community with labor without proper compensation. For example, in Pair 1, D.R. discussed the process of data entry in order to prepare for the community's analysis of the data. D.R. (researcher, 2-year partnership) did not want "the staff to learn SPSS or STATA," two statistical software, as they did not want to add any extra steps or labor for the community members. A community member even mentioned the burden that the researcher might place on them through this work. Z.B., when discussing N.R.'s asks for feedback on the surveys responded, "And for me, it's like, okay, that's your specialty. Go ahead and do it. And then, but then [N.R.] needs my feedback. It's important for her to get my feedback and sometimes it's like I don't have time to do that, and it shouldn't get so long. And then we're going to discuss this and it's life, yeah, let's figure it out later after we're done…" The community appears in this instance to focus solely on serving the community through the intervention and wants the researcher to take care of the research aspects. It is important to note the value of the community and the community organizations.

These community organizations serve the people and have deep investments in the communities they serve. The organization and partnership in Pair 4 had served the community for 20+ years, the organization in Pair 1 had served the local community for over 25 years, and the organization from Pair 3 has served the local community for more than 40 years. These investment in time, money, resources, and personal and social capital demonstrate both the amount of trust and equity these organizations have built over time as well as the reasons why they work in these partnerships. These researchers and community organizations in particular work together because the organizations understand how to build equity within their own communities. Researchers wish to duplicate that process in these partnerships and in the community-based research. As Israel et al. state, part of community-based work is to build on the strength of the community (2008). However, similar to the quote towards the beginning of this sub-section, Q.J. offers a slight difference focusing on the community: "So we are an extra layer of work for them. And hence, it takes a little longer because they're not paid to do it. I mean, we do pay them eventually. But it's not part of their 40 hours, right? So, some people would say, it's long." As the community and researchers both realize the potential burden that the extra labor might impose on the community through these projects, these partnerships understand the importance of compensation.

Some partnerships stated their attempts to compensate the community. P.L. mentioned how their partnership made sure to "compensate[] [the community] for their time" and tried their best to "make the intervention as convenient as possible to be able to, yeah, to meet their needs." As stated previously, Pair 4 works on their budgets together and submits them so that each party receives equitable funding for their amount of labor. While these two partnerships explicitly mentioned their attempts to compensate community for their labor, taking into consideration the investments that communities make indicates that perhaps more partnerships should work towards compensating communities for their labor and personal investment. While the researchers and community members understand the value of working together, others might not. The data that these partnerships produce lend legitimacy to both community and researchers. However, as seen through the previous examples, the lack of funding indicates that some still do not understand the value of community. Therefore, communities must work harder to prove their value. Yet, some institutions still question the value and the need for compensation requiring researchers to serve as advocates for the communities with which they work.

The IRB and Community Mistrust

The university as an institution only seeks to satisfy its own aims. While some universities, such as the University of California (UC) and California State University (CSU) systems, state community service as part of their mission, the policies and governance of the university does not reflect this aim (California State University Office of the Chancellor, n.d.;

University of California Office of the President, n.d.). An example of this dissonance between aims and practice is the Institutional Review Board. Researchers must work with the IRB to obtain approval for their research, including community-based research projects. Therefore, the IRB serves as a site to examine how the university might use the IRB as a gatekeeper that unintentionally builds and strengthens community mistrust. In order to gain the trust of the community and continue the work that the partnerships embark upon, the researchers must then serve as both representatives of the university and advocates for the community. Ultimately, the community must work with and lobby the researchers for the legitimacy that is necessary for the community to accomplish its goals.

Multiple researchers cited the IRB as a cumbersome part of the research process. As conducting these projects as soundly as possible lends legitimacy to the project and therefore the data and community, gaining IRB approval for any research study is absolutely necessary. The IRB mainly attempts to protect the subjects of these research studies. However, when the subjects become part of the research team, the IRB is woefully equipped to handle the nuance. For example, P.L., while describing the community's involvement in the project, says that the community collecting the data or administering the measures "would be an IRB violation." However, the research team in Pair 3 included U.C., a member of the community. P.L. included U.C. specifically for a community perspective, for community input. In order to include U.C., P.L. had to receive special consideration from the university and had to put in special protections for the storage of the data. Similarly, F.B. struggled with the IRB's requirements of the community that participated in the collection of data. F.B.'s institution "requires everyone who touches the data, not just the PI sub-awardee, but the people who like the moderators, etc., they have to do a CITI, CITI human subjects protection training."[6] The community and F.B. perceived this requirement as cumbersome and burdening as it was another barrier to research that the institution implemented. Some groups realized the complicated nature of the IRB in advance. Q.J., in discussing creating the measures for the intervention while revising with the community's input, said, "So instead of having to go back and doing an addendum in terms of an IRB, or whatever, we want to do it right from the beginning." Q.J. and their partnership understand how much the IRB can disrupt the flow of research. T.S. summarizes the relationship between the IRB and community best: "I have found that as the universities that are more challenged, then by far the communities." These examples demonstrate how intrusive the IRB can be within the research process. The IRB serves an important purpose. However, as in the case of Pair 3, the other examples, and the tenure process, universities are not built in their governance nor do them emphasize working with community and community-based research as a priority or a value. Communities often carry the brunt of the extra labor that universities and IRBs require. Due to this additional load, communities have become wary of institutions.

One pair exemplifies the distrust that communities have of institutions. While other interviewees mention the distrust of institutions, such as N.B.E. mentioning that the partnership "didn't want the community used" due to past experiences of "people use[ing] us and then they say what they want about us," Pair 1 struggled a lot with the IRB process throughout their research and the community began and grew more distrustful of the institution. The partnership worked with a specially protected population as defined by the IRB and thus needed special permission and special approval on their work, particularly their measures. D.R. discussed how in "going through IRB approval, and then also having to navigate that with the organization"

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[6] CITI stands for The Collaborative Institutional Training Initiative which universities partner with to certify researchers have a basic understanding of the protections of human subjects among other IRB concerns.

certain members questioned “why do we need to get approval from [the institution]? Why can’t we just do this on our own” to which D.R. (researcher, 2-year partnership) replied, “we have to wait for IRB.” The organization staff who had an equal part in forming and implementing the intervention and measures constantly expressed frustration with seeking IRB approval. At one point the staff wanted “to sneak in some questions to the survey, and it wasn’t IRB approved” per D.R. However, the team worked their way around these requirements and ultimately received IRB approval. In discussing this experience, T.R. (community member, 2-year partnership) mentioned how “what was harder for the staff to feel comfortable working with institutions, because they had a philosophy and belief that it needs to [indiscernible] and questioning why we need it and validate [indiscernible] with us on a project that is community based.”[7] T.R. also brings up how “the idea around social justice work is that you’re challenging institution” and therefore “there’s always tension” and difficulties. Through this pair’s example, it becomes clear how the rules and regulations of the IRB can become in some ways oppressive and preventative to the real work that these communities conduct. Additionally, the tenure process can also contribute and exacerbate these tensions between the community and institution. Because without approval from the IRB and without professional stability for the researcher, tensions can flare to the point of conflict. Therefore, in these partnerships, the researchers had to act as advocates for the community. The ways in which researchers can take tangible steps to support the community are discussed in the following chapter.

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[7] This interview was conducted over video conference and therefore because of internet connection interviews part of the audio cut out and was not salvageable. However, the quote still provides insight into the community’s thinking. Additionally, for privacy, the video portion of the call was not recorded, only the audio.

Conclusion

This chapter seeks to highlight why communities, in their definitions and models of data ownership, emphasize and value access to and control over data. Access and control provide communities the opportunity to (re)claim narratives and gain legitimacy in the eyes of universities, funders, institutions, and most importantly the community itself. Simply put, access to and control over data gives communities a power that they previously did not have. Data as a form of empowerment seeks to echo one of the goals of this project: to follow in the tradition of Asian American Studies and study and give voice to those who previously lacked one. Data is the way that communities gain a voice. Data is the way that they can tell their own stories. While each partnership is not made equally, and that these partnerships can vary, even internally over time, each of these projects provide an insight on how community-researcher partnerships might work. The next chapter describes how these partnerships function in order to provide insights on how to improve community-researcher partnerships and models of data ownership.

Improving Community-Researcher Partnerships

Introduction

As seen in the previous two chapters, each partnership must work together to formulate and operationalize a definition and model of data ownership that functions for them. The needs and wants of each community and each researcher will vary from project to project. While each partnership must conceive of and implement their unique version of data ownership, all the partnerships included in this project emphasized access to and control over data for the community. While the previous chapters described why communities value access to and control over data, this chapter seeks to describe the best practices or lessons learned that I gleaned from the interviews. I do not present a perfect or one-size-fits-all model for approaching data ownership. However, what follows is what appears to have been successful in the partnerships interviewed for this project so that future projects might adopt these approaches.

The following findings are not necessarily new. Much of the community-based research literature describes much of what is described in this chapter. However, as with much of this project, I strive to center and give voice to the community. Since academics generally speak to other academics through the body of community-based research literature, this chapter hopes to upend that trend and speak with and for the community.

The structure for this chapter somewhat follows the arc of a relationship. Most relationships begin over a shared experience. In the case of community-based research, many community members and researchers working in Asian American and Pacific Islander communities share meals in order to build trust. This trust can then develop into a period of sustained partnership. One community-researcher partnership likened community-researcher partnerships to dating. Once the partnership builds trust, a courtship and a tension develop that strengthens the bond and can lead to a successful partnership. Finally, as this project focuses on data ownership, the negotiation over data ownership has been a site of analysis for this project. To conclude, I use one community member's metaphor of throwing a birthday party as the entry way into discussing the negotiations over data ownership within community-researcher partnerships. These different touchpoints in the relationship between the community and researchers hopefully demonstrate how empowering the community and treating them as equals can improve these partnerships and the knowledge they produce. These are not the only ways in which these partnerships can operate. However, these are practices that these community members have engaged in to yield fruitful, productive, and lasting partnerships.

Building Trust (Over Food)

"It's hard to quantify how you develop trust among friendship" T.S.

At the beginning of any relationship, whether it be a friendship, romantic relationship, or professional partnership, the two parties must build trust in some way, shape, or form. The above quote by T.S. comes after a long partnership that began as professional and evolved into a personal, lasting friendship. While this might be the outlier outcome for community-researcher partnerships, the foundation of building trust between the two parties is paramount to the successful negotiation of data ownership and to an overall successful partnership. Some trust can originate from a sense of pedigree. For example, M.K. centers their trust in P.L., the researcher through, "… her education, background, and she [taught] me a lot." Additionally, trust can come from the researcher's previous relationship with the community. For instance, D.R. from Pair 1 and P.L. from Pair 3 had both formerly worked in the community organizations that they partnered with for these projects. While some interviewees cite these reasons for having pre-established trust before beginning the partnership, all of the partnerships mentioned sharing food as a key step towards building trust.

By using the sharing of food as the site for building trust within Asian American and Pacific Islander communities, I do not mean to essentialize nor stereotype. However, food has a distinct position in building trust through shared vulnerability. In most cases, these partnerships sat around tables sharing meals which developed the partnership. Since eating is generally a messy activity, then sharing a meal invites a vulnerability over a common experience. The act of sharing a meal not only makes those at the table vulnerable, but it also opens up the opportunity to address larger issues such as working styles, privileges, and motivations. For example, N.R. (researcher, ongoing partnership) mentions building trust with the community through vulnerability: "you have to put yourself vulnerable so that they see that you're vulnerable in return. And I think that with the trust building and all these dinners or lunches and coffee breaks that we've had… it really was just talking shop … it really is about just know who you are…" Community members such as Z.B. discovered "[the researcher] was very intent on really doing good for the community" after sharing meals together. The shared base of understanding, through being vulnerable with one another, exposes each person's motivations as well as acknowledges various privileges. In Pair 4, T.S. would invite N.B.E. to their home where the two of them would "meet at [the] kitchen table… how we built trust was, there was – they just listened." The actions partnerships can take to build trust, such as listening, repeatedly arises within the literature on community-based research. Also, the literature includes extensive writings on how privilege and power operate within these partnerships (Chávez et al., 2008). However, for Asian American and Pacific Islander communities, the act of sharing a meal with researchers aids in displaying vulnerabilities, uncovering motivations, and addressing issues of power and privilege.

In some instances, interviewees have pointed to food as a means of compensation. The previous chapter touched on the necessity of compensation for the community due to the community's investment in these partnerships and projects. Some researchers, then, pointed to food as a method of compensation for the community. N.R. (researcher, ongoing partnership) talked about food as a distraction in the sense that "we would kind of bamboozle them in some sense with food." This distraction also served as compensation for the time that the community members invested. P.L. says, "We always made sure that we fed our community advisory board, and we compensated them for their time." This notion of compensation is important in that the researchers acknowledge the investment of the community. As seen in the previous chapter, the community deserves proper compensation. Yet, these quotes demonstrate the lack thereof. The community deserves more than just food. Because, while food sustains for a moment, money and other actions can empower the community to make their own decisions and actions.

Some actions that the community and researchers have taken to empower the community include publishing together. N.R. likens data to currency. As publications serve as a form of academic currency, by publishing together, the community gains legitimacy from academia as well as tangible proof to show other community members as the products of the project. Publishing together can provide a legitimizing form of sustenance that food does not provide.

Additionally, some community-researcher partnerships list both the researcher and the community member as Principal Investigator (PI). Some in this project listed the community member as Co-PI elevating the community as equals on paper codifying within the eyes of the rest of the research community their status. Therefore, in addition to food as compensation, the community receives a monetary value in addition to the recognition that this brings akin to publishing jointly. Food begins to break down barriers and build trust. However, these actions sustain the health of the community. Furthermore, sharing meals serves as the beginning of the relationship. Community-researcher partnerships need time to develop into productive unions.

The necessity of an investment in time equals the necessity of exchanging vulnerabilities and motivations. The repeated sharing of meals serves as the site through which these partnerships choose to build trust through vulnerability and conversation. Sharing a meal, just like trust building, requires an investment of time. One researcher made a massive investment in the community and the community's time. Q.J., in order to build trust, went to monthly meetings that lasted nearly 4 hours in most instances. While 4-hour long meetings might seem arduous and inefficient, Q.J. grew to like them stating "we have open discussions, everyone gets to talk and then we eat… so certain things take time, and you just have to build in some cushion room." The cushion room described by Q.J. allows for the breakdown of barriers. This cushion room is exactly the time in which communities can learn more about the researcher in order to begin to trust them. Additionally, these meetings demonstrate tangibly the willingness of both researchers and community members to continue this partnership. While not every partnership has the capacity for four-hour monthly meetings, and others go about forming trust over food in different ways, it is clear that food has been and will continue to be a site of vulnerability and exchange. To provide a solid foundation for a community-researcher partnership seeking to engage in community-based research within Asian American and/or Pacific Islander communities, communities should share meals with researchers to uncover their motivations and build trust.

Community-Based Research is Like Dating

"This whole – it's almost like blind dating for a while and really knowing whether or not we want to be working together and developing that trust that way"- M.S.

Community-based research is like dating. In dating, two people use a series of questions that supposedly reveal the character and the intentions of a potential partner. The answers to these questions allow one person to assuage any anxieties they might have. Questioning is part of the courtship process. Due to the inherent tensions between communities and researchers, each must go through a process of not only building trust but learning to collaborate with one another. Therefore, this section will delve into the various questions communities might ask researchers to build trust and to gauge investment. As D.R. says, community-researcher partnerships are "kind of like dating… you have to be invested, not only do you have to like each other, but you have to be invested in the relationship... You don't have to do it together. But we recognize there was value synergistically to this relationship into the collaboration…" While it is not solely through questioning researchers that the communities can begin to feel comfortable in these partnerships, asking questions allows for answers that provide insight into who the researcher is. What follows are questions that community members posed in their interviews that the community can ask researchers when "dating." These questions give the community insight into the researcher's investment and motivations in order to build a stronger partnership.

"Are You Ready for Community?"

One of the first questions the community can ask researchers is whether or not they are prepared to work with and within the community. The community realizes that these partnerships drastically depart from more "traditional" or "normal" modes of research. For example, Q.J. spent "the first month or two just going everywhere to meet people… So I went there and she said "Are you ready for community?... because some people don't like it honestly, it's not for everyone… It's just because it's a different type of work." By the community asking this question of the researcher, this community member implicitly understands how community-based research severely diverges from the norms. While the literature acknowledges the move away from the subjectivities imposed upon the community by previous methodologies of research, this community member recognizes a different necessity when working with the community. Being ready for community-based research in some ways requires answering all of the following questions first in order to answer this question. Implicit in Q.J.'s quote is this notion of time which the community must question the researcher about before the researcher can answer if they are ready for the community.

"How Long Are You Going to be Around?"

The issue of time has continued to come up in all the aspects of this research. Discussing time within the context of both community-based research and data ownership indicates how integral communities view time. To the community, time exists as a resource. If the researcher willingly spends a lot of time in a community, it indicates how much the researcher values the work that the partnership conducts together, much like a dollar amount indicates how much confidence a funder has in a particular project. While the community might view the researcher's time as an investment, the community members themselves do not have the same luxury to only dedicate part of their time to the problems that the community faces. The community members live and breathe the problems they investigate through these partnerships. For them, these projects and partnership are not merely an adventure in problem solving. Instead, community members take active roles in crafting what they want the community to be. These projects allow community members to redefine what it simply means to be in their environments. Therefore, when a community member asks a researcher such as T.S. "How long are you going to be around?" the researcher must answer as N.R. (researcher, ongoing partnership) did, "I'm in it for the long haul."

The researcher’s answer is critical to demonstrating buy-in. Asking researchers if they are ready, if they are willing to invest the same amount of time into changing what it means to be in a certain community is not only a very simple step in verifying this relationship, but also crucial to breaking any tension between the community and the researcher. Researchers that do not have a vested stake in the community might simply parachute in for the length of the project. By declaring that the researchers have as equal an investment as possible in the community and its problems, the community members are able to shed any skepticism. The community now has faith in the researcher – both are ready to jump off a cliff, together.

“Why Are You At The Table?”

In addition to requiring an investment in time, the community must also evaluate why they choose to partner with the researchers. The researchers bring their bona fides and their institutional power to the partnership. However, that creates an imbalance with the institution valuing the researcher over the community as seen previously. Therefore, the community must investigate the motivations of the researchers and whether or not they value the community.

Researchers may explicitly state their motivations and what they value from the community. For example, P.L. stated that “We’re going to them because they know the community.” Additionally, N.R. said that the community is “the expert and this is why” they brought the community “to the table.” These quotes acknowledge verbally the value that these researchers see in the community. These researchers approach the table and sit down to engage in this partnership because they see that the community brings a unique aptitude to the table. To continue the food metaphor, the community and the researcher both bring dishes to the potluck to share the meal. In continuing the dating metaphor, the researchers and community members both see something attractive about the other. The question that prompts this subsection does not appear explicitly in the transcripts for this project. Instead, I surmise the question from N.R.'s quote as the table is a site of exploration, of trust building, and of examination. By asking why the researcher has approached the table and sat down, to share a meal and/or to engage in a dialogue with the community, the community gains insights into the motivations of the researcher and what they value in the community.

The greatest affirmation of the researcher's motivations and valuing of the community comes from a community description of the researcher. Z.B., a community member, described N.R.'s, the researcher, motivations of working with the community as saying, "I saw that [they] [were] very intent on really doing good for the community… really the intent to like understand what the community is all about." In this quote, Z.B. attests to both the motivations of N.R. and the value that N.R. sees in the community. These values are integral to community-based research in general. Treating the community as experts is nothing new. However, this project identifies the recognitions that community members have given to the researchers. The community also sees the value in, as T.R. puts it, "collaborating as equals."

Can You Meet Me Here?

Before answering whether or not researchers are ready for community, the community should ask the researcher to meet them where they are. Part of community-based research is providing a service to the community. In some ways, the researcher as a partial servant for the community in addressing problems that the community sees continues the ethos of community-based research by upending "traditional" research norms. However, in order to serve, the researcher must meet the community where they are. The following examples demonstrate how the researchers have been of service to the communities in which they conduct research. Only through being in the space of the community, can the researcher begin to help change what it means to be in that community.

By being present in the community, the researcher is able to serve and show community members evidence of their investment. For example, T.R. (community member, 2-year partnership) praised D.R. (researcher, 2-year partnership) in Pair 1 by saying that D.R. “was willing to come all the way out from [the institution] to meet with [the community] … and have a discussion and was very friendly and approachable and open.” D.R. traveled many miles in order to be physically present. By being physically present, D.R. strengthened the bond with the community and provided whatever services the community might need. In this case, D.R. provided their presence as well as their expertise as a service for the community. This not only strengthened the bond between community and researcher but also improved the quality of the project. While D.R. met the community where they were physically, other researchers have opened their homes to the community.

As mentioned, Pair 4 has been a long, dedicated partnership working towards health equity for Asian American and Pacific Islanders across a variety of issues. However, their foundation starts around a kitchen table. N.B.E. describes the beginning of their relationship as “It was never, “hey come to [the institution] and try to find parking” … it was “come over and let me cook for you.” A large amount of the metaphors for this chapter, and the extrapolations that follow, come from this one quote. This quote demonstrates what I perceive to be the pinnacle of community-researcher partnerships. Through asking the community to meet at the kitchen table, over food that the researcher cooked, the researcher invites the community into their own home, into their domain indicating that the community deserves to be in that space. The move away from the institution, away from the university, demonstrates an understanding that while the university might not recognize the value of the community, this particular researcher does. Additionally, the act of cooking, the act of providing sustenance for the community sends an explicit signal about the type of investment the researcher is willing to make for the community. In returning to the question of this subsection, asking the researcher to meet somewhere, anywhere allows the community to see what type of investment the researcher is willing to make for the community. Not every partnership will be able to make the same investment as Pair 4. However, replicating even slightly the level of generosity and service that T.S. gives to the community will improve future partnerships.

In summary, I want revisit the original question of this section: Are you ready for community? The questions that follow the first one pursue the ability to answer that question. Just like dating, both people, or both the community and researcher, must be ready for the partnership. These questions reveal the types of commitment that the researcher will give. In asking these questions, the community then will receive answers in both words and actions that demonstrate the researcher's ability to engage wholeheartedly in the partnership. The inherent tension between the community and the researcher can be eased by strong, emphatic answers expressing a willingness to work with and for the community when asked the above questions. However, the community must first ask the questions to yield the answers. Community-based work is like dating in that it is an exploration into a partnership. If the end result of dating is a long-lasting romantic partnership between people, then the result of community-based work is a partnership seeking to better the community. While discussing dating as a metaphor works for the umbrella of community-based research, throwing a birthday party is an apt metaphor for negotiating data ownership within these partnerships.

Happy Birthday!

"When you ask, "why do we engage communities?" It's because we're going to develop progress for community, the people who know communities best are them" – Q.J.

Negotiating data ownership within community-researcher partnerships should be like throwing the community a birthday party. This analogy comes from Q.J. who not only works with the community but also teaches students on best practices for working within communities. Q.J. likens community-based work to throwing a birthday party:

> "So the people who know themselves best are communities right? If I was going to throw a birthday party for you, Alex, the best person to ask is you. Like "Hey Alex, what types of food do you like? What type of music? Who do you want me to invite?" Right? I can't just go "You know, I, I think – I've been throwing enough birthday parties in my life. I want to throw you a birthday party, but I won't engage you." I will even ask you what you like. Right? So most likely if I did that, it might not be a birthday party that suits your fancy, you might not like it at all. So it's very simple. When you ask, "why do we engage communities?" It's because we're going to develop progress for community, the people who know communities best are them"

In this analogy, the process of planning for the birthday party is the constant negotiation of data and data ownership. While partnerships can agree on a model of data ownership in principle, the everchanging nature of research requires a continual process of consent and approval. Data ownership might merely be defined as a physical or intellectual control after collection. However, as demonstrated previously, community members want and should require access to and control over the data. Communities should have continual access and control over data from conception, implementation, collection, storage, analysis, dissemination, and everything in between. Therefore, researchers and community members must constantly engage in a negotiation over the data to achieve an equitable model of data ownership. If in the analogy of a birthday party the negotiation is the community and the researcher planning the party together, then the actual party is the equitable model of data ownership through which the partnership can share out the data. Then, achieving a continual equitable model of data ownership requires a feedback loop that emphasizes consultation between both the community and the researcher.

The process of defining this equitable model beings with setting expectations for roles and guidelines. In this equitable model, each person brings a particular expertise that the partnership utilizes collectively. Therefore, as T.R. (community member, 2-year partnership) points out, "I think it was important that we clarify what everyone's roles are, and then who the decision makers are because we didn't want to go into the agreements that we would be doing research" for them and without the community's input. T.R.'s concern stems from the devaluing of the community by institutions and the historical relationship of public health with Asian American and Pacific Islander communities. As a result, defining who makes decisions allows the community to not only prevent a potentially inequitable dynamic, but also allows the community to define as much access and control over the project and the data as they want. The birthday person should get as much say in their birthday as possible. So, the community should be able to define and redefine roles and give decision-making power as they see fit.

Once the partnership defines roles and decision-making power, they can continue the project, which should include some vehicle for feedback. N.R. (researcher, ongoing partnership) describes feedback as "giving, allowing ample time for people to respond in a way that is going to responsible." In unpacking this quote, it becomes apparent that feedback denotes a level of respect on the part of the researcher towards the community. The researcher could easily ask for the community's opinion and then disregard it. However, in N.R.'s case, the point about ample time allows the community weigh options and make an informed decision. One of the main critiques about community-based research in general is that it takes time. Admittedly, community-based research does take a long time, not only to conduct, but also to form the partnerships and bonds necessary to carry out the work. What critics might fail to realize in commenting that this type of work takes too much time, is that the community becomes empowered to alleviate their concerns about working with institutions and public health. Asking for feedback and providing the community enough time to respond, therefore, is a crucial part of creating a healthy, equitable relationship.

Given the importance of feedback many of the researchers value it and seek it out. Some, like F.B. built feedback "into the structure. So we're getting feedback at every angle." Others, like P.L. desired as much feedback as possible, stating "everything that I could get feedback on, I did. If I could implement it, I would." The use of feedback demonstrates a consultative and collaborative relationship within the partnership. Researchers, coming from the background of training in community-based research as an orientation to research, see the value in the community and believe that any and all feedback will only benefit the project and will help to strengthen the partnership. Since the philosophy of community-based research views the community as experts providing invaluable insights into this work, then it is clear why the researchers come to the community to conduct this work and for their feedback. However, some community members might view feedback as burdensome.

Some community members expressed that the constant ask for feedback hindered their ability to do the work. The staff members in Pair 1, as T.R. (community member, 2-year partnership) expressed, were "constantly frustrated about what the point was." Additionally, Z.B. said "it's important for her to get my feedback and sometimes it's like, I don't have time to do that and it shouldn't get so long… but yeah she's very consultative and that, that should be appreciated." The community in these cases convey a message of, "just let me do the work," in which case the researchers in the partnerships have the freedom to make changes at the margins.

However, by expressing a frustration with the researchers constantly asking for feedback, the community shows its implicit trust in the researcher. Any concerns they might have, they can voice. But the lack of an antagonistic relationship within the partnership only furthers the idea that the community and researcher have entered into a true, equitable partnership built on mutual trust, respect, and faith in both one another and a common goal. To return to the birthday party analogy, in a sense the community and researcher are best friends that will make decisions that will benefit everyone.

Defining data ownership in an equitable fashion should follow this process of establishing roles and asking for feedback. This negotiation empowers the community as part of the decision-making process. Also, while asking for feedback might be cumbersome, it allows the community to provide continual consent through which they can determine how much access and control over the data is appropriate for them. Combining all three: sharing meals, "dating," or throwing a birthday party together hopefully culminates in an equitable model of data ownership and an equitable community-researcher partnership.

Conclusion: "Be Selfish"

"I mean, be selfish. You should be in the driver's seat… Be selfish. Find the right researcher" – T.S.

T.S.'s quote essentializes the how communities should approach not only community-based research but especially data ownership. The community possesses the power and the leverage to demand that the research be conducted however they see fit. This project and chapter seek to center the community. However, it additionally partially places the onus on the community. Sharing meals means spending time with researchers to vet them and to build trust all with food as the mere compensation. Additionally, lacking compensation even further, the community must "date" the researcher in order to build a partnership together. This courtship process gives the community further insight into the researcher and establishes a foundation of mutual respect and faith. However, the community can then claim the power through throwing a birthday together, constantly negotiating data ownership in order to gain access and control over the data. Borrowing from T.S. in all these steps the community must be selfish. The community's selfishness helps to strengthen the partnership and creates an equitable model of data ownership.

Conclusion

Synthesis and Reflection

To conclude, I want to offer a brief reflection on this project while also synthesizing my findings. This project uses an Asian American Studies lens on issues within Public Health. Borrowing from the mantra of "serve the people," this project intends to center the community's perspective. However, while this inquiry provides commentary on community-based research, it in fact does not utilize a community-based approach. In some ways this project continues the trend of academics seeking information from the community for the gain of the academic. Whereas the field of public health explicitly states that it engages in community-based research, Asian American Studies does not commonly explicitly state practicing community-based nor community-engaged research. This project, from a public health lens, might have focused more on the academic perspective, using concept models and other tools to explain how best to form equitable models of data ownership. However, in utilizing a community-centered lens, I hope to have elevated the community's voice and perspective to shed light on how community and researchers can work towards more equitable models of data ownership and community-researcher partnerships. What follows are my personal reflections on the subjects that the interviewees bring up throughout this project in an effort to both synthesize my findings and begin to think about possible futures.

I began this project with an Asian American Studies lens. The introduction mentioned how the origins of Asian American Studies and Ethnic Studies emphasized not only changes within the academy but also the ability to use the knowledge created in the ivory tower to enact change in the community. This project utilizes this dual and interrelated purpose by advocating for changes that researchers can make. Additionally, this project tries to use the community's perspective as often as possible. As community-researcher partnerships are bridges between the community and the institution, these partnerships serve to erase the historical relationship between public health and Asian and Pacific Islander communities. Admittedly, the introduction only offers two examples, one Chinese and one broadly Southeast Asian, which does not encompass all of the different ethnic groups under the umbrella of Asian or Asian American. Also, these examples do not include Pacific Islanders at all. Yet, these examples of the U.S. exerting biopolitical control over Asian bodies demonstrates the complicity of public health in perpetuating Yellow Peril and U.S. imperialism. Early San Francisco Chinatown in the late 1800s/early 1900s served as the basis for U.S. perception of the coming Asian population. The allure of the illusion that is American Dream ultimately denies Chinese immigrants life, liberty, and the pursuit of happiness. Similarly in Southeast Asia during the 1960s, the oxymoronic military beneficence of providing inoculations serves as means of surveillance to gather intelligence about the South Vietnamese. Both of these examples demonstrate how the U.S. is able to exert biopolitical control. Additionally, these examples remind me of Sylvia Wynter’s dichotomy of the Man versus the Other as well as Edward Said’s Orientalism, but those ideas are outside the scope of this project (Wynter, 2003; Said, 1978). In sum, the introduction served to showcase the oppressive potential of public health and its data. Therefore, in direct opposition to this oppressive potential, community-based research gives the community the opportunity to contribute their insights, knowledge, and expertise into the corpus of public health knowledge and literature. Additionally, this project extends the power of the community further by examining how these community-researcher partnerships, which conduct community-based research in tandem, can work towards more equitable models of data ownership.

In the literature review, I then provide a base understanding of the following areas: data ownership and control, academic-community/community-researcher partnerships, and community-based public health research, specifically Community-Based Participatory Research (CBPR). By understanding these three areas and what parts of these areas inspire my work, I lay the foundation for how this project both supports many of the findings of these three areas as well as disrupts them. For instance, I use indigenous data sovereignty as a way to understand data ownership from a community perspective. However, this project does not propose a distinctly Asian American model of data ownership. Instead, indigenous data sovereignty underscores how other communities feel the need to reconfigure "traditional" models of data ownership for ones that benefit them. Also, by introducing community-researcher partnerships as an alternative to academic-community partnerships which the body of academic literature has termed these relationships, this project makes a conscious effort in putting the community literally first syntactically. Finally, by outlining what CBPR is and its theoretical underpinnings as an example of all community-based research, I demonstrate where the researchers' perspectives originate in this project. Many of them have had training in specifically CBPR. Therefore, understanding that perspective only seeks to contrast against the community's perspective in the latter chapters.

While "Methods" includes a summary of the methodology used for this project as well as some limitations, I want to include here not a limitation but perhaps a bias to this data. All of the partnerships I interviewed are successful. Nearly none of the interviewees expressed any difficulties or hardships about their partnerships or their projects. The positivity from the interviewees, the success of the partnerships, and the willingness to speak about their experiences might have skewed the data. The interviewees might have not spoken about a potentially bad partnership or project. Therefore, the data I collected possess a bias towards positive responses and successful partnerships.

In “Definitions and Models of Data Ownership,” I compare and contrast the differences in defining data ownership as done by the researchers and the communities as well as examine the various models of data ownership employed by the partnerships interviewed. With respect to the definitions, the researchers all provide very similar definitions as do most of the community members. The section, Definitions of Data Ownership, focuses on the outlier of Z.B. who does not necessarily believe in data ownership as a construct. I propose thinking of data generated in community-based research as similar to thinking about how society discusses property or land ownership. While data and land are not the same, they share qualities in that their ownership has been the justification for the U.S.’s oppression of different communities. For land, the U.S. violently erased indigenous peoples. For data, the U.S. used it to subjugate Asian bodies as seen in the introduction. Since the justification for owning land comes from the concept of *terra nullius*, I contemplate the existence of *data nullius*. As stated in the chapter, this project does not advocate for *data nullius* nor does project decide whether or not data should be owned. However, perhaps the decision to own data, to share it, to co-own it, to steward it, or to have any other formation of ownership or lack thereof might be a worthy avenue of discovery in the future. The second section of the chapter, Models of Data Ownership, describes the partnerships’ agreements for owning data as well as how some might work towards equitable models more so than others. Using a framework proposed by Ward et al. (2018) for evaluating the health equity of CBPR projects as a whole, I adapt the criteria for the purposes of this project, namely data ownership. The codified agreements on data ownership lend themselves more so to equitable models of data ownership with informal agreements possessing a detrimental potential for the community. The outlier of researcher-owned data only highlights the necessity for community-centered, equitable models of data ownership. The next chapters outline how community-researcher partnerships might achieve these equitable models of data ownership through giving the community access to and control over their data, something they continually mention as valuable.

In “(Re)Claiming Narratives and Legitimizing Voices,” I consider the positive potential of data for communities. The empowerment of the community by data provides two possibilities. First, data can allow the communities to (re)claim narratives. The impetus behind putting (re) in parentheses is the heterogeneous nature of the term Asian American and Pacific Islander. As the term Asian American arises as a political identity during the San Francisco State College Ethnic Studies Strike, it both encompasses many different ethnic groups as well as unites them (E. Lee, 2015). As there are many ethnic groups underneath the term Asian American and Pacific Islander, some have been studied by public health whereas others have not. However, the research that does exist generally comes from a non-community-informed perspective. Also, this project of (re)claimation comes from both a lack of data as well as the community’s fear of misuse. The concern over misuse derives from both previous experiences as well as historical experiences such as the ones mentioned in the introduction. Therefore, community-based research and these projects in particular generate community-based data which can either allow the community to claim new narratives about themselves, reclaim narratives once skewed by non-community-informed data, and/or accomplish both. Second, data has the power to legitimize the voice of the community. Community-based work does not necessarily accurate compensate the community for its investment creating an inequity within the partnership. Therefore, data allows communities to prove their capability and legitimacy. Additionally, as the community worried about misuse, they worry about the institutions the researchers represent. The institutions de- or mis-value the community. Through the IRB process, it becomes evident that the university is not set up to work with the community. Therefore, the researcher must take tangible steps, such as publishing together, listing the community as a Co-PI, and others in order to establish and maintain the legitimacy of the community as fellow researchers and experts. Additionally, these two potentials further highlight how the community values access to and control over data. By empowering the community through data, these partnerships give the community access and control, allow them to (re)claim narratives, and legitimize the community's voice.

Finally, the last chapter, "Improving Community-Researcher Partnerships," examines how community-researcher partnerships can establish trust, build a strong relationship together, and create equitable models of data ownership. I liken these three areas of focus to sharing a meal, dating, and throwing a birthday party respectively. These three analogies come directly from the interviewees in an effort to uplift their voices. While these metaphors do not entirely come from community members, the chapter attempts to center the community in considering how the community can best be served and serve within these partnerships. In this conclusion, I want to dwell a bit more on the conclusion of the previous chapter. One of the researchers, T.S., says "Be selfish" and I believe that entirely encapsulates the ethos of this project. The community has the leverage and the power in these partnerships. No matter which party approaches which first, the community should be able to exert their will because they should have at minimum equal decision-making power, if not have the power outright. If the guiding principle of community-based research is to treat the community as experts, then entering into the domain of the physical community should yield all the power and leverage to the community and its members. While the previous sentence distinguishes between the physical community and the people that make up the community, they are intertwined. Therefore, in order to safeguard against misuse, in order to prove legitimacy on their own terms, in order to protect themselves from harm, in order to create equitable models of data ownership, the community must “be selfish.” It is only to their benefit.

Where Do We Go From Here?

In considering different points of departure for this project, there are multiple avenues of exploration that this project can yield. First, this project could be larger in scope and include community members to make it truly community based. By engaging the community in this fashion, a future project could not only discover more researchers’ and community members’ perspectives on data ownership within community-based public health research but also a future project could leverage connections that community members possess encompassing a wider array of perspectives geographically, by racial/ethnic groups, by field of study, and others. Second, this project could consider the ramifications of data ownership for large, mainly quantitative datasets. Some examples of these large datasets include the California Health Interview Survey (CHIS), the National Latino and Asian American Study (NLAAS), the National Health Interview Survey (NHIS), and others. Within the realm of community-based research a model of shared ownership or mainly community ownership aligns with the ethos of the practice. However, researchers and policy makers rely on these larger surveys to set policy and to enact changes they see fit. From a community perspective, or even a subject perspective, considering any potential rights or desires on the part of the community/subject could yield interesting and nuanced understandings of data ownership. Third and finally, future projects could consider not only issues of data ownership but also issues surrounding the storage of data in a quickly advancing technological age. With increasing frequency, issues of data privacy from social media companies like Facebook appear in the news. While this project briefly touches on the physical storage of the data in the models of data ownership section of “Definitions and

Models of Data Ownership," considering the implications of privacy with respect to data storage in specifically health research projects could have infinite areas of discovery. Considering whether or not data will ever be truly secure could be an interesting point of analysis. However, based on merely anecdotal evidence, I believe that data can never be secure. In which case, considering its security is not as pressing as considering the potential misuse of the data and safeguarding against it in not only public health research, but all health research. Evaluating the guarantees that studies make to their participants and how well they safeguard against breaches in privacy digitally or otherwise might prove fruitful as a further area of study. These future possible research projects however only underscore how much further these lines of inquiry must go before fully understanding the issue of data ownership.

Researchers and community members might never fully understand the issue of data ownership. In fact, many may not care and merely take it for granted. However, as this project points out, the community still must fight for and attain equity within community-researcher partnerships, specifically around data ownership, if the goals of community-based public health research is to be achieved. The stated goal of CBPR is to utilize a "collaborative approach" in order to "combin[e] knowledge and action for social change to improve community health and eliminate health disparities" (Wallerstein & Duran, 2008, p. 6). However, achieving equity to eliminate health disparities is a continual struggle for these community-researcher partnerships. Hopefully, this project has provided some insight in how to work towards more equitable partnerships and models of data ownership in the future. To end, I combine and amend some statements given by the interviewees. The community should remember to "Be selfish – and Happy Birthday!"

Appendix 1

Schedule of Questions

Section 1: Demographics

1. Can you state your name?

Section 2: Project Involvement

1. Can you briefly describe the project for me?
2. Can you describe your overall involvement for me?
3. How did you first become involved in this project?
4. What do you remember was the original goal of the project?

Section 3: Community-Based Research

1. What did the researchers tell you about the research process?
2. Did you receive any training from the researchers?
    a. What did that look like?

Section 4: Community

1. How did you first meet the researchers?
2. How did they build trust between themselves and community?
3. How did you first become involved in this community or organization?
4. How did you and the researchers decide who you would study for the project?
    a. Did you feel that this included everyone it should have, or did it leave out anyone?
5. Throughout the project, what was the relationship between the researcher and community like?
    a. Did you feel any tension?

Now I want to talk a bit about the role of data in your project…

Section 5: Data

1. What types of data did you collect in this project?
    a. How did you decide what data to collect?
2. What was the community's role in terms of data collection?
3. What was the community's role in terms of analysis?
4. What was the community's role in terms of the dissemination, spread of data?
5. Did the researchers talk about the issues surrounding data with the community?
    a. Did you have a discussion around data ownership and/or control?
    b. Did you have an idea of how data should be owned and/or controled?
6. Throughout the project, did the issues of data ownership and/or control change or evolve in any way?
7. How much ownership and/or control did you feel the community had?

Section 7: Project Considerations

1. Within your project, did you do anything specifically catered to your community (Asian American, Pacific Islander, or more granular)?

    a. Did you bring up any cultural considerations to the researchers?
        i. How do you think they felt reacted to it?
        ii. Can you describe a specific instance related to culture in this project?
2. Did the researchers often ask for feedback?
    a. How did you feel giving feedback?
    b. How do you think the researchers perceived feedback?
        i. Was there any sort of disconnect between the community and researchers?
    c. Was there a dedicated avenue for feedback?
    d. Can you describe a specific instance related to feedback and how the researchers either or did or didn't incorporate the feedback?
3. Was there anything that caught you off guard? Anything that you were not prepared to encounter that arose throughout the research process?
    a. What was it?
    b. How did you resolve this?

Section 8: Community Benefit
1. When the project started, what did you think the community benefit would be?
2. Did the community benefits in your mind change over time?
3. What did the community gain from the project?
4. What did you gain from the project?

To close, I would like to talk about the future…
Section 9: Advice and the Future (5 minutes)
1. What would you recommend future community-based research projects do to include community more?
2. What would you recommend future researchers do to improve community-based research projects?
3. What advice would you give someone conducting another community-based research project?
4. How do you think this project has transformed your perspectives on community-based research?
5. What will you take (lessons learned, best practices) from this project that will influence your future work?

Is there anything we didn't talk about today that you would like to talk about?

Do you have any final comments?

Appendix 2

Pair	Researcher	Community Member	Community	Project Length	Ongoing?	Brief Project Description
1	D.R.	T.R.	Southeast Asian youth	2 years	No	This youth-led project sought to discover and intervene on issues facing local Southeast Asian youth.
2	N.R.	Z.B.	Filipinx	> 1 year	Yes	This project works to collect data on and intervene on Filipinx mental health. This pair works with and in a collaborative seeking to address mental health stigma, knowledge, and access.
3	P.L.	U.C. and M.K.	Southeast Asian	2 years	Yes	This project developed and implemented an intervention aimed at caregivers who tended to family members who had issues with memory and cognition within the Southeast Asian community.
4	T.S.	N.B.E	Pacific Islanders	10 years	Yes	While this partnership has worked on a variety of projects, the particular one they discussed in the interview was a cancer intervention within the Pacific Islander community.
N/A	Q.J.	N/A	Pacific Islanders	5 years	No	This project implemented a smoking cessation intervention linked to cancer outcomes within the Pacific Islander community.
N/A	F.B.	N/A	East Asian Americans	> 1 year	Yes	This project studied and collected data on obesity within a particular geographic region where predominantly East Asian Americans live.

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