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Cultivating Participant Relationships: The Ideal of Partnership and the Reality of Minority Communities' Participation in Biomedical Research

DISSERTATION

submitted in partial satisfaction of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

in Sociology

by

Vanessa Madden Kauffman

Dissertation Committee:
Professor Francesca Polletta, Chair
Assistant Professor Rachel Goldberg
Associate Professor John Billimek

2020

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DEDICATION

To

my husband, Niklas

and

my parents, Wendy and Fred

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ACKNOWLEDGMENTS

I would like to extend my gratitude to the members of my committee, Francesca Polletta, Rachel Goldberg, and John Billimek. I am so thankful to Francesca for her mentorship over the last six years and helping me grow as a scholar and sociologist. Her encouragement and thoughtful suggestions always pushed me to expand the boundaries of my thinking and develop a richer analysis. I am grateful to Rachel for sharing her expertise on health and the sociology of medicine, and for her kindness and support while I wrote this dissertation during a pandemic. I wish to thank John for his mentorship and our invaluable weekly meetings that kept me on track to finish this project. His humor and encouragement always lifted my spirits. I am incredibly thankful for the research and teaching opportunities that I have had at The Helios Lab, and for John's advocacy for me as a researcher.

I owe much to the memory of Jennifer Buher-Kane. Her insights were instrumental in the development of this project and she is greatly missed. I am also thankful to Ann Hironaka and David Snow for their mentorship. I wish to thank John Sommerhauser who was a constant source of support throughout graduate school and helped me navigate a challenging time. Thank you to Chuck O'Connell, my teaching mentor, surfing conversationalist, and the person who I can always count on to send me the best articles! I am so grateful to Chuck and to Marla for their friendship.

I am also thankful for the support and collaboration of many wonderful people at The Helios Lab. Many thanks to Jackie Chow for her enthusiasm for learning qualitative methodology, meticulous assistance on the study, and all-around excellence. Special thanks to Melissa Ramirez, Brett Cervantes, Alondra Salazar, Raquel Mireya Hidalgo, Raphael Natividad, John Robb, Leslie Martinez, Cintia Quan Kiu, Celeste Villegas, Javier Guerrero, and Adriana Orellana for their assistance conducting and translating Spanish interviews and focus groups. Emily Dow was a great support on this project and a huge help with recruiting participants. I am also grateful for the assistance of Robynn Zender and Adrijana Gombosev.

I would also like to thank my UCI graduate school friends and colleagues, especially Connor Strobel and Sofi Pedroza. And, Katt Hoban who was always a source of inspiration. I am thankful to Silvana Dillon and my wonderful friends on the East Coast. I will forever be grateful to the dedicated and innovative teachers at the Benchmark School who taught a quiet kid who couldn't read to love learning and to be a self-advocate. A special thank you to Renee Erickson.

To the participants of this study, thank you for your trust, kindness and generosity, and for sharing your stories.

I could not have completed this project without the personal support of my family. I am grateful for my beloved grandparents, Eleanor and Gerald Kauffman and Bill and Diane Wallenmeyer, who supported my goals, including adventures that took me to Baffin Island in the Arctic. They were a monumental influence on my life, and I still feel their love. I am grateful to my siblings, Elizabeth, Benjamin, and Madeline, who are my best friends, for their support, love, phone calls and epic family texts. They were always a source of encouragement. I extend many thanks and love to Ken, Ava and Trevor, Ida Wallenmeyer, and my Jensen family in Sweden.

I am especially thankful to my parents, Wendy and Fred, who sacrificed so much to ensure that when I was a child, I had educational opportunities and practical tools to succeed. They have always encouraged me to follow my dreams and have supported me in every way possible with their boundless love and encouragement. My parents inspire me, and I am so thankful and proud to be their daughter.

And finally, I am deeply grateful to my dear husband Niklas, who has walked along side me throughout this journey. Niklas encouraged me to keep going when everything felt hard and could always be counted on to make me laugh when I needed to take a break. From our daily afternoon dog walks with Penny Lane, to the kindness and love that he put into making our meals for over a year, Niklas' unending support, love, and faith in me helped me reach this goal. I cherish him and I am forever grateful that we are on this adventure together.

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2017 Outstanding Teaching Assistant Award, Department of Sociology, UC Irvine
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2017 Pedagogical Fellowship, Division of Teaching Excellence and Innovation, UC Irvine
2014 - 2016 Graduate Dean's Recruitment Fellowship, School of Social Sciences, UC Irvine
2012 - 2013 One-Third Tuition Merit Scholarship, The University of Chicago
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RESEARCH EXPERIENCE:

2020 - Assistant Specialist, Step I, Department of Family Medicine, UC Irvine

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A community-engaged, mixed-methods, longitudinal cohort study on how social and economic disruption impacts trust, solidarity, and risk-reducing behaviors among vulnerable Latinx residents of Orange County, CA from before to during the pandemic.

2019 Facilitator, Community Engagement Studio, Irvine Institute for Clinical and Translational Science (ICTS), UC Irvine, CA

Facilitated focus groups for health researchers interested in receiving feedback and guidance on study design from patients, providers, and community members.

2018 - 2020 Graduate Student Researcher, Department of Medicine, UC Irvine, CA

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Mentors and instructs undergraduate student researchers on qualitative research methods and currently supervises, trains and mentors a team of 4 student researchers.

2009 - 2014 Founder and Director of Big Blue Marble Inc., Washington, DC

Ran a federally registered non-profit researching the connection between digital media, art, and environmental action. Interviewed environmental artists and utilized visual ethnography and digital media to examine how art and technology impact environmental awareness.

Mar. 2013 Qualitative Interviewing Externship: National People's Action (NPA), Chicago, IL

Collected oral histories from leaders of a national social justice non-profit. Interviewed current and former leaders by phone and Skype, transcribed interviews, coded archival material, and wove together an oral history narrative that was used during the 2013 NPA National Convention in Washington, DC.

PUBLICATIONS:

Book Chapters

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2016 Bolzendahl, Catherine, Vanesa M. Kauffman, Jessica Broadfoot. "Coaching and Masculinity: A 'Natural' Combination? *Gender & Society Blog.* *https://gendersociety.wordpress.com/2016/08/12/coaching-and-masculinity-a-natural-combination/* Cross-posted: *Scatterplot* (https://bit.ly/3ioDuy2); and *Sociological Images* (https://bit.ly/2ZozOns)

2016 Bolzendahl, Catherine , Vanessa M. Kauffman, Jessica Broadfoot. "Constructing Gender, Creating Disparity: Justifying the Gender Gap in Coaching." Open Science Framework. osf.io/m7edz

CONFERENCE PRESENTATIONS & INVITED SPEAKING ENGAGMENTS:

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University of California, Irvine

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Pedagogical Fellow, Division of Teaching Excellence and Innovation — 2017
Studied and implemented research-based best practices for the integration of technology and active learning in the classroom and how to foster inclusive learning environments in higher-education.

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PROFESSIONAL ACTIVITIES AND SERVICE

2018 -	Research Mentor, The Helios Lab, University of California, Irvine
2015 - 2018	Peer Mentor, Department of Sociology, University of California, Irvine
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ABSTRACT OF THE DISSERTATION

Cultivating Participant Relationships: The Ideal of Partnership
and the Reality of Minority Communities' Participation in Biomedical Research

By

Vanessa Madden Kauffman

Doctor of Philosophy in Sociology

University of California, Irvine, 2020

Professor Francesca Polletta, Chair

Despite federal guidelines prioritizing the inclusion of minorities in clinical research, experts still struggle with how to convince people from underrepresented communities to volunteer in essential research. Motivated by ethical concerns and pragmatism, partnering with local communities is championed by recruitment experts as an effective strategy to address cultural and structural barriers to participation and encourage research enrollment among underrepresented racial and ethnic minority groups. In this study, I investigate how partnership, a key term in participatory research approaches, which emphasize the greater involvement of local people, is understood and enacted by biomedical researchers and ordinary people. I use qualitative methods to investigate how researchers' efforts to engender trust through partnerships with minority communities are experienced in practice by the people they aim to recruit. My analysis is drawn from 30 interviews with health researchers, a content analysis of public documents from a biomedical initiative using partnered approaches, and focus groups and interviews with 60 Latinx residents of Greater Los Angeles, California. I show that although partnering with local communities is a common method for involving minority groups in

research, partnerships are enacted and understood by researchers in varying and distinct ways, with partnership ideals often challenging to carry out. In all models of partnership, researchers assume that these relationships promote trust and encourage ordinary people to frame research participation as a form of civic engagement and social solidarity. However, this is rarely how vulnerable people frame research or why they volunteer. More often, I found that people do not draw a clear distinction between research and healthcare, with medical care experiences intimately connected to people's attitudes toward biomedical research. Community residents saw "participant partnerships" as confusing and tokenism to feign equality where it did not exist. Researchers and residents had drastically different understandings about what their obligations and entitlements were vis a vis each other, leading to conflicting relationship expectations and different symbolic valuations of monetary incentives. I conclude that increasing the participation of underrepresented groups in biomedical research depends on recognizing the different ways that people think about and act on relationships within the U.S. health care system.

CHAPTER ONE:
Introduction and Methodology

Daniel Chervoni, is a 62 year-old resident of Mott Haven, a low-income neighborhood in the South Bronx of New York City, who has lived with asthma for most of his life (Kilani 2019). Mott Haven, which goes by the nickname "Asthma Alley" has some of the worst pollution levels in the United States, with asthma hospitalizations at 5 times the national average and at rates 21 times higher than other New York City neighborhoods (Kilani 2019). The population in Mott Haven is 97% Hispanic or black, and the neighborhood is also home to numerous industrial plants (Kilani 2019). Minority communities like Mott Haven shoulder a disproportionate share of our country's environmental problems (Konkel 2015), with residents much more likely to experience environmentally related diseases than non-Hispanic whites (Forno and Celedón 2012). However, for people of color and residents like Daniel, they are much less likely to be included in biomedical research studies that address diseases such as asthma or diabetes that disproportionately affect minority populations (Burchard et al. 2014; Konkel 2015; Oh et al. 2015).

Biomedical research is the broad area of science that investigates how the human body works, seeking to improve societal health and discover new ways to prevent, treat and cure diseases. By analyzing genetic and environmental factors through experimentation, observation, laboratory work, and testing, biomedical scientists aim to understand the causes of disease and how to keep people healthy. However, biomedical research overwhelmingly lacks diverse representation, a problem that critics argue significantly limits our ability to understand factors that may lead to poor health and disease, and could exacerbate existing racial and ethnic health disparities if the people most affected by particular diseases continue to be left out of studies

(Konkel 2015). Despite requirements introduced nearly three decades ago from the National Institutes of Health to diversify and include minority populations in biomedical research (*National Institutes of Health Revitalization Act* 1993), fulfilling the mandate has proven difficult, with enrollment rates of racial and ethnic minorities still extremely low (Barrett et al. 2020). For example, although black and Latinx individuals account for 30% of the U.S. population, they make up just 6% of all participants in federally funded clinical trials (Konkel 2015). Additionally, while there have been over 10,000 cancer clinical trials funded by the National Cancer Institute, only 2% of these trials fulfill the NIH's diversity criteria (Oh et al. 2015).

The United States has a long and troubled history of mistreating racial and ethnic minority populations, including harm and abuse at the hands of the government and researchers within the health care system (Mitford 1971; Gamble 1997; Katz et al. 2006; Hornblum 2013). The past (and in some cases contemporary) actions of medical researchers have earned the mistrust of minority communities. The resulting mistrust from exploitive and unethical research practices poses a significant barrier for successful recruitment and retention of diverse participants. Biomedical researchers and recruitment experts have devoted considerable attention to understanding what holds racial and ethnically diverse communities back from participating in research, and what recruitment approaches are most effective in convincing ordinary people to volunteer (Katz et al. 2007; National Institutes of Health 1997; Wendler et al. 2005; Dancy et al. 2004; Haley et al. 2017; P. B. Gorelick et al. 1998; Epstein 2008).

Medical experts argue that if they are to be successful at delivering more personalized care to diverse patients and conducting state of the art research to understand genetic and environmental differences that shape health outcomes, research approaches and more broadly the

culture of medicine, has to change (Wilkins 2018; Berg 2020). This includes reimagining and reconstructing the kinds of relationships that are cultivated between professionals in medicine and research and ordinary people, where ideally these interactions are more transparent, collaborative, and trusting. For biomedical researchers, relationship building relates to the essential task of recruiting participants. The key questions researchers grapple with are how to enroll and retain diverse participants from underrepresented minority populations. What kinds of relationships foster trust, and keep people enrolled and engaged in research studies?

Participatory research approaches, where researchers and lay people from local communities collaborate on research, are considered the most effective approaches for conducting research with underrepresented minority populations (Chung et al. 2010; Katsanis et al. 2018; L. Jones et al. 2009; All of Us Research Program 2020). The approaches vary in methodology, but all participatory techniques emphasize developing trust with participants and local communities through reciprocal relationships and abolishing power imbalances through community partnerships. Most often, this is accomplished by developing research partnerships with community organizations. Partnering with individual participants as research "partners" is a participatory approach that researchers hope will foster greater levels of trust and positive relationships with minority communities (Berg 2020; L. Jones et al. 2009; L. Jones, Wells, and Meade 2009; NIH Community Engagement Team 2015; L. Jones and Wells 2007; All of Us Research Program 2020).

In this dissertation I use a sociological perspective to analyze how partnership, a key term in participatory research approaches, is understood and enacted by biomedical researchers and ordinary people. I investigate how efforts by biomedical researchers that use partnerships to engender trust with historically underrepresented minority communities are experienced in

practice by people they aim to recruit within those communities. My dissertation focuses on the experiences of Latinx residents within the Greater Los Angeles area of California, and medical and health research professionals throughout the United States who conduct research with underrepresented minority populations. My dissertation is guided by four central questions:

1) What are the ways that biomedical research is perceived and understood by Latinx adults in the Greater Los Angeles Area of California?

2) How do these perspectives, personal understandings, and attitudes towards research impact people's involvement in biomedical research?

3) What are the similar and different ways that biomedical researchers and Latinx community residents understand "partnership" in research?

4) And, to what degree do partnered recruitment and retention research practices align with ordinary people's attitudes and feelings about research participation?

Partnered research approaches with community members assume a particular kind of relationship between researchers and the partnered participant or community organization. Partnership suggests an egalitarian relationship with people motivated not only by self-interest but also by common goals. In this dissertation, I investigate this new approach and ask if researchers and ordinary people operate with the same ideas about partnership, and more broadly about research participation.

In brief, I show that although partnering with local communities is a common approach for involving minority groups in research, it is not a straightforward or singular practice. Rather, partnerships are enacted and understood in varying and distinct ways by biomedical researchers. In all versions of partnership, researchers assume that “partnering” develops trust and encourages ordinary people to frame participating in research as a form of civic engagement and social solidarity. However, I found that this is rarely the case for how ordinary people frame research participation. My interviews with low-income and recent Latinx community residents, show that their experiences with medical care are intimately connected to their attitudes toward biomedical

research. This dissertation addresses how socially-constructed relationships are vital in all aspects of how people understand, evaluate, and make decisions about biomedical research participation.

In chapter two, I explore how biomedical researchers understand and enact partnered relationships with local communities to encourage underrepresented racial and ethnic groups to enroll in research. I illustrate that partnerships take very different forms, ranging from rhetorical symbolic partnership to activist partnerships involving research participants. I show that different models of partnerships, including models that are more engaged with local communities, come with real challenges for involving minority communities in biomedical research. In chapter three, I discuss how partnerships are viewed by the people who are targeted by researchers. By comparing how biomedical researchers frame participant partnerships with the understandings of Latinx community residents, I show that ordinary people often do not distinguish between research participation and other forms of medical care. Lastly, in chapter four, I compare the distinctive ways that biomedical researchers and research participants symbolically and morally value financial research incentives. I illuminate tensions in the ways that researchers think about financial incentives and show that these understandings do not generally match how ordinary people view getting paid for research participation. I conclude that increasing the participation of underrepresented groups in biomedical research depends on recognizing the different ways that people think about and act on relationships within the U.S. health care system.

Review of Background and Conceptual Literature

Biomedical researchers wear many hats, as grant writers, protocol leaders, administrators, and as relationship experts. The arduous process of recruiting (also called enrolling or acquiring) and retaining research participants throughout a study is fundamentally about cultivating and

maintaining relationships. Convincing ordinary people to enroll as research subjects is an essential task for biomedical researchers who need individuals to donate their bodies and time to science in order to perform their studies (Epstein 2008). Equally as important, keeping a participant enrolled and adhering to the research protocol (often referred to as retention, compliance, or adherence), is vital for producing valid scientific results. Borrowing the French historian and philosopher Michel Foucault's (Foucault 1969) terminology, recruitment is a "human science," concerned with understanding and monitoring individual bodies, that uses frameworks from sociology, anthropology, psychology, and economics. Encouraging, managing, and maintaining relationships requires research teams to not only invest time to find the right people to volunteer as study participants, but also to know something about the communities that they hope to recruit from and build relationships.

In recent years, the practical challenges of finding and convincing individuals to join research studies have been complicated by guidelines, policies, and laws enacted and designed in the 1990s to diversify biomedical research (Epstein 2008). In 1993 Congress passed the National Institutes of Health Revitalization Act, which mandated the inclusion of women and minority groups in NIH-funded studies and clinical trials, and required that studies report differences between women and members of minority groups and other study subjects (*National Institutes of Health Revitalization Act* 1993). Additionally, in the 1990s, restrictions on the participation of women in clinical trials of pharmaceutical products were removed (Food and Drug Administration 1993), and new legislation mandated the inclusion of children in federally funded clinical research (*Food and Drug Administration Modernization Act of 1997* 1997). These regulations are tied to funding and compel industry and academic researchers to reflect on diversity from the beginning of their research programs. Federal agencies fund 22% of medical

and health research and development in the United States, with the NIH the largest public funder of biomedical research in the world (National Institutes of Health 2015), funding 82% of the U.S. federal investment in medical research (Research America 2019). Researchers seeking NIH-funding are required to break down recruitment targets by sex/gender, race and ethnicity, and if funded, provide annual reports to the NIH on current target levels and how the study stands to meet recruitment goals.

The institutionalization of inclusionary policies and monitoring systems in medicine has moved medical science from a one-size-fits-all model to a model focused on group identities (Epstein 2007). Researchers measure differences across and within groups with regard to medical treatments and disease progression, reflecting the shifts in policy, ideologies, and practice that sociologist Steven Epstein (2007) refers to as the "inclusion-difference paradigm." This push towards inclusionary requirements in medical research places pressure on pharmaceutical companies and scientists carrying out medical research on humans to recruit and retain a particular mix of bodies. In addition to satisfying institutionalized requirements, interests in inclusionary recruitment practices are also motivated by goals to eliminate health disparities, reverse past practices of minority underrepresentation, and advance precision medicine (Corbie-Smith, Moody-Ayers, and Thrasher 2004; Dancy et al. 2004). Precision medicine, sometimes called personalized medicine, refers to prevention and treatment health care strategies that take individual variability into account. While not a new concept (for over a century blood typing has been used to guide blood transfusions), recent technological developments, including large scale biologic databases and new computational tools to analyze big data, have made it possible to apply precision medicine more broadly (Collins and Varmus 2015). Diversity is crucial for the

advancement of precision medicine and understanding genetic differences that may shape health outcomes and be important for potential treatments (Berg 2020).

However, recruiting underrepresented minority groups to biomedical and clinical studies is difficult, with recruitment and outreach efforts being both extremely costly and sometimes ineffective (Daramöla et al. 2003; Gorelick et al. 1998; Epstein 2007). Reflecting the needs of distinctive study protocols and aims, study investigators employ myriad strategies to enroll participants in their research programs, acknowledging that there is no one strategy that fits all situations. Yet, given the expensive and difficult nature of finding and employing effective recruitment and retention techniques, researchers are increasingly interested in finding dependable answers to how to best enroll participants in their studies (Epstein 2008, 809).

Epstein (2007) calls the emerging applied science that produces and disseminates knowledge on recruitment, "recruitmentology." Recruitmentology attempts to address the most promising and successful ways of understanding, enrolling, and retaining "hard-to-recruit" populations, including underrepresented minority groups, into clinical and biomedical studies (Epstein 2007). Studies addressing barriers to minority recruitment point to a variety of overlapping factors including but not limited to: institutional and structural racism (Dancy et al. 2004; Brandon, Isaac, and LaVeist 2005; Gamble 1997), fear of experimentation and mistrust of researchers (Katz et al. 2006; 2007; Corbie-Smith, Moody-Ayers, and Thrasher 2004), unequal access to quality education, housing, employment, and health care (Ceballos et al. 2014; Haley et al. 2017), participant-researcher power differences and researcher conceptual frameworks (Dancy et al. 2004; Corbie-Smith, Moody-Ayers, and Thrasher 2004; Dancy et al. 2004), and the collective memory of historical exploitation and abuses in research (P. B. Gorelick et al. 1998; Shavers, Lynch, and Burmeister 2000). The formalization of recruitment, including meta-

analysis and formal comparisons of recruitment strategies (Chung et al. 2014), reflects the emergence of recruitmentology as a new specialty area pertinent to biomedicine that combines the natural and human sciences.

Epstein (2008) outlines several sub-genres of recruitmentology studies. One area of the literature seeks to determine and address the barriers that prevent ordinary people from choosing to participate in biomedical research. Often these studies are conducted through surveys (P. B. Gorelick et al. 1998) or focus groups (Haley et al. 2017; Kauffman et al. 2019) that aim to determine the reasons why people decline to participate in research. The second area of study focuses on culturally specific factors that impede recruitment, usually collected through observations from key informants, community leaders, or with researchers that have strong ties within the studied community (Epstein 2008, 811). Other recruitmentology studies focus on social relations, environmental factors (August and Billimek 2016) and networks (Philip B. Gorelick et al. 1998), and forging novel recruitment methods that best address the needs and available resources of the studied communities (Larkey et al. 2012; 2009). "Hard" recruitmentology studies borrow from economists and perform a cost-benefit analysis to deduce what recruitment strategies provide the highest yield: the ratio of enrolled participants to the total number of people screened (King, Harris, and Haskell 1994). Lastly, an entire sub-genre of recruitmentology scholarship focuses on the social and psychological impact of the Tuskegee Syphilis Study (Corbie-Smith 1999; Shavers, Lynch, and Burmeister 2000). This scholarship unpacks the legacy of the Tuskegee study but also moves beyond the single historical event in order to address the complicated ways that politics and racial justice in the U.S. affect attitudes towards medical research in communities of color. They examine systemic and institutionalized

racism, mistrust, collective memory, and power relations between researchers and participants (Gamble 1997; Brandon, Isaac, and LaVeist 2005).

In response to imbalances of power and models of research that have been criticized as "drive-by research" or "helicopter" and "parachute" studies with teams collecting data from minority communities and disappearing after the data collection is finished, study investigators and recruitmentologists have made concerted efforts to imagine and construct new models of trusted relationships. Participatory styles of investigation, emphasizing local peoples' involvement in research, have emerged as the most promising models for building trust. These models developed in the 1980s when AIDS and breast cancer communities and other advocacy groups lobbied for experimental treatments and greater involvement in the development of research agendas, study designs, and the drug approval processes (Dickert and Sugarman 2005). As bioethicists Neal Dickert and Jeremy Sugarman suggest, this was the beginning of an ethical shift in thinking, moving from a singular focus on protecting the rights and interests of individuals to considering the importance of involving communities in research development and approval (Dickert and Sugarman 2005).

Across the fields of medicine, the social sciences, and public health, there are numerous and novel partnership approaches to research. Often used interchangeably, these include "participatory-action," "community-centered," "community-engaged," "community-based," and "collaborative" research. All of these participatory research approaches are fundamentally focused on building mutual trust through transparent and reciprocal relationships, shared and re-directed power, and asset-based approaches that recognize the different but equally valuable assets of community members and academic research teams. Participatory recruitment strategies

promote collaboration and partnership between the researcher and the communities being studied.

Although partnership approaches aim to build trust and redirect power, they differ in practice with respect to who they involve, the duration of the partnership, and how power is shared. Some partnerships are developed with individuals, for instance partnering with local representatives on community advisory boards. These boards provide community leaders and representatives an opportunity to give feedback on a study and/or participate in the decision-making and management of the research (Dancy et al. 2004). Other partnerships are developed with community organizations, working with leaders and staff on a research project where the community organization may assist with recruitment. The duration of partnerships also greatly varies, with some relationships with communities being more consultative and short-lived, while others are sustained and collaborative relationships that evolve over time. Power-sharing can differ dramatically. In the most engaged forms of partnerships community members or organizational representatives may have a significant role in the development of research questions, the data collection, analysis and dissemination. Lastly, partnerships can be combinations of these different approaches. Community partnerships benefit researchers by providing valuable information about the community's primary health and social needs and helping to identify intra-community risks and effective community specific recruitment strategies that research outsiders might not be able to anticipate (Foster and Richard 2000). For communities, partnering with academics can be beneficial to strengthen or secure funding sources and assets, advocate for policy changes, and solve community problems (Carney et al. 2011).

Community-based participatory research (CBPR) is an institutionalized model of partnered investigation espoused by recruitmentologists that directly connects the issue of trust with investigator-participant power imbalances. The NIH National Institute on Minority Health and Health Disparities launched a CBPR program in 2005 to fund collaborative interventions that "involve scientific researchers and community members to address diseases and conditions disproportionately affecting health disparity populations" (National Institute on Minority Health and Health Disparities 2005). Additionally, CBPR was a core strategy discussed at the first national NIH Summit to Eliminate Disparities in 2008 (Dankwa-Mullan et al. 2010). The approach overlaps with many other collaborative research approaches, but what distinguishes it from others is the active involvement of community members in all phases of the research, including decision making, capacity building, and the dissemination of research findings (Riffin et al. 2016). Additionally, the approach is an iterative and cyclical process that provides practical and sustainable solutions aimed at improving health through long-term and enduring commitments by researchers and community members.

CBPR has been used as a paradigm for public health and investigators focused on eliminating health disparities. However in recent years it has gained traction in other areas of clinical and health services research (L. Jones and Wells 2007). For example, the National Cancer Institute (NCI), the Center for Disease Control and Prevention, and the American Cancer Society, have all sought to cultivate participatory research approaches, with the NCI funding 23 Community Networks Programs to support "community-based participatory education, training, and research" (Simonds et al. 2013). CBPR is not always applied in its purest form, where partnership is present in every aspect of the research process. However the partnership approach has been shown to be extremely successful as a recruitment and retention strategy (Epstein 2008;

Nueces et al. 2012; Riffin et al. 2016; Dankwa-Mullan et al. 2010). In addition to cancer research, examples of research that have used CBPR and more moderate partnership approaches include diabetes prevention research (Kitzman et al. 2017), palliative care research for minority individuals suffering from advanced illnesses (Riffin et al. 2016), primary and secondary stroke prevention and stroke recovery interventions (Springer Mellanie V. and Skolarus Lesli E. 2019), and in the design and implementation of randomized controlled trials to improve the quality of life of patients with immunodeficiency syndrome (AIDS) (Williams et al. 2005).

The publicly funded All of Us Research Program is the largest participatory research effort to date with the most fully developed rationale for adopting community-based approaches to recruiting and retaining underrepresented communities in research, and to establish partnered relationships with community organizations and participants. The program was first announced at President Barack Obama's State of the Union address in January 2015 (then referred to as the Precision Medicine Initiative cohort program). The near-term focus of the initiative centers on oncology research, while the long-term aims are to generate knowledge and applied practices to improve health and reduce disease. Diverse representation in biomedical research is central for the advancement of precision medicine, where the success of these efforts rest on the participation of individuals that reflect the diversity of the United States.

Participatory approaches to research, and specifically partnering with local communities, are frequently cited as the most advantageous approaches for the successful recruitment and retention of ethnic minority groups, vulnerable groups, and other populations that have been challenging to reach in the past (Nueces et al. 2012; Riffin et al. 2016; Dankwa-Mullan et al. 2010). By focusing on representation in research to advance precision medicine, All of Us aims to make health better for everyone by advancing precision medicine. Critics will point out that

health inequalities will persist, with the benefits of precision medicine still disproportionally aiding the more privileged in society (The All of Us Research Program Investigators 2019; Joyner and Paneth 2015). Yet, the All of Us Research Program represents a dramatic display of national scientific priorities to address disparity in research by using participatory approaches. The program was authorized $1.5 billion over 10 years through the 21st Century Cures Act and aims to enroll a research cohort of at least 1 million persons in the United States. As of July 2019, more than 80% of the 175,000 participants enrolled were from groups that have been historically underrepresented in biomedical research (The All of Us Research Program Investigators 2019).

The All of Us Research Program is interesting because it is a national example of biomedical researchers and recruitment experts adopting a partnered research approach to involve underrepresented minority subjects in research by implementing the most sophisticated and well researched partnership techniques. Additionally, distinctive from some participatory approaches to research that focus on forging partnered relationships with leaders, advocates, and representatives of respective communities, the All of Us Research Program treats each individual participant as a partner in research. While the aims of the All of Us Research Program are an exciting step towards greater diversity in biomedical research using a participatory approach, there are still many challenges more broadly related to this novel approach and difficult questions about how best to include communities in the research process (Dickert and Sugarman 2005). For example, what counts as a community and who is qualified to serve as a community representative? Often the direct benefits of research (for example, receiving a particular health intervention) are easy for investigators to articulate, but how are the broader concepts of community and societal benefits measured and what responsibilities do investigators have to the

communities they partner with to ensure that the research translates into tangible benefits for that community (Corbie-Smith, Moody-Ayers, and Thrasher 2004)? What does it mean to be an *individual* participant partner in research and what should this individual partnership with researchers look like? What responsibilities do individuals have as "partners in research" and how do ordinary people understand this relationship? And lastly, do all forms of partnership approaches to research necessarily lead to a more equitable power structure shared between communities and researchers, or is equity only legitimized with a particular kind of partnership?

Data and Methods

I use qualitative data sources and a grounded theory methodological approach to investigate the various ways that researchers and ordinary people enact research relationships, particularly how people understand "partnerships" in biomedical research. Grounded theory is a systematic strategy for theory development from the data (the ground) up, without a prior theoretical framework or use of hypothesis testing (Charmaz 2014a; Emerson, Fretz, and Shaw 2011). A grounded theory approach is particularly useful to explore relationships between social conditions and process because it is based on participants' meanings and experiences with both micro and macro contextual environments (Charmaz 2014a). My analysis draws on three types of qualitative data sources: focus groups with Latinx community residents, in-depth interviews with medical and health research professionals and with Latinx community residents, and a content analysis of a research study using a community partnered approach. Integrating mixed qualitative methods and speaking to people in their preferred language aided in my analysis of how ordinary people experience and understand partnered research participation and the extent to which these perspectives align with the understandings and goals of biomedical researchers that use a partnered approach.

I chose to conduct focus groups and interviews with Latinx community residents because this population is significantly underrepresented in biomedical research. Although 18% of the U.S. population identifies as Hispanic or Latinx, on average only 1% of clinical trial participants are Hispanic or Latinx. The focus groups and interviews with community residents were conducted in both Spanish and English, and all participants in this study were given pseudonyms to protect their identity. A common question asked among novice qualitative researchers is "How many people do I need to interview?" Rather than seeking a set number, qualitative researchers typically focus on continuous sampling and analyzing of the data until "saturation," where nothing new is being generated, at which point the sample is complete (Glaser and Strauss 1967). The exact number of participants needed to understand a complex social phenomenon depends on what is learned through interviews and field work, and how much information begins to be repeated (Charmaz 2014a; Glaser and Strauss 1967; Green and Thorogood 2009). In this study, I spoke with 60 community residents in interviews and focus groups, and 30 medical and health research professionals.[1]

Latinx residents were recruited from Community Health Clinic[2], a safety net health care clinic in the Greater Los Angeles area of California. Community Health Clinic is a Federally Qualified Health Center (FQHC) that provides primary care services to nearly 21,000 patients, 82% of which are at or below the federal poverty guideline.[3] FQHCs are nonprofit health care organizations that are located in medically underserved areas or in areas that have a shortage of health care professionals. Safety net clinics like Community Health Clinic provide high quality

[1] I collected in-depth interviews from 30 community residents. Half of these interviews were purposefully conducted in Spanish. The fact that I spoke to the same number of residents in 5 focus groups is purely coincidental.
[2] Community Health Clinic is a pseudonym.
[3] The federal poverty guideline for a family of four in 2020 is $26,200 (Department of Health and Human Services 2020).

primary care to patients regardless of if they have insurance, their ability to pay for services, or their legal documentation status. Payment for services is calculated using a sliding fee scale with discounts based on a patients' income and family size, in accordance to federal poverty guidelines. I recruited Latinx adults from Community Health Clinic with Spanish speaking bilingual research assistants. We spoke to patients before or after their clinical appointments, made announcements at health education classes, and used convenience and snowball (network) sampling strategies. After a focus group or interview was conducted, participants were asked if he or she might facilitate introductions to a friend, family member, or colleague who might be interested in participating in the study. Participants received a $30 gift card for participating in a 60 – 90 minute focus group, and a $25 gift card for participating in a 60 minute interview.

Although I speak some conversational Spanish, I am far from being able to speak the language fluently. This was a limitation conducting this research. I mitigated this challenge by collaborating with a superb group of 6 enthusiastic bilingual and bicultural undergraduate and post-baccalaureate students who provided invaluable linguistic translation and interpretation assistance. Collaborating with these students made it possible to collect and analyze data from Spanish-speaking Latinx residents. The 6 research assistants are students at UC Irvine who all grew up speaking Spanish with their families, and 2 of the students spent extensive time living in Mexico. The research assistants received formal training to facilitate focus groups and conduct in-depth interviews, which included opportunities to shadow interviews that I conducted in English. In addition to assisting with participant recruitment, the research assistants scheduled and conducted the Spanish interviews and facilitated the Spanish focus groups. Additionally, they translated and transcribed the individual and group interview data from Spanish to English. All focus group, interview, and recruitment materials were translated into Spanish by the

research assistants and were reviewed by bilingual community engagement staff members at The Helios Lab, a UC Irvine health services research lab, to confirm accurate translation of the documents. Two additional research assistants who spoke conversational Spanish but were not native Spanish speakers, also assisted on this study.

Much more than technical assistants, the research assistants that I collaborated with were a vital part of my research team. Given my own language and cultural limitations as an English-speaking American white woman, it was imperative to collaborate with bilingual and bicultural research assistants who interpreted more than just the literal meanings of words, but also contextual information (Green and Thorogood 2009). The research assistants meticulously translated as close as possible the exact words of participants, while also excellently capturing and conveying to me the emotional, cultural, and lexical implications of what the research participant said. The Spanish to English translated transcripts went through multiple rounds of evaluation to assure that our translations were as accurate as possible. The focus groups and interviews were audio recorded and later transcribed. The audio from the data collection with Spanish speakers was first transcribed from Spanish to English by the person who conducted the interview or focus group. Following this, another research assistant would review the translated document and audio file to check for translation accuracy and add any missing contextual information in brackets (for example, humorous uses of words, sarcasm, or metaphoric use). Lastly, before the document was considered finalized, I would read the translated documents and confer with the research assistants about any unclear parts of the transcript. All but one of the Spanish interviews and focus groups were translated using this system. The last focus group was translated and transcribed by a professional service.

We conducted 5 pilot focus groups with low-income Latinx residents of Greater Los Angeles, California. The focus groups were designed to garner information on people's attitudes towards biomedical research and what community residents experience as facilitators and barriers to participating in research. Additionally, we introduced an example of biomedical research where participants are research partners. In addition to general thoughts about participating in biomedical research, participants were asked to share what being a "partner" in research meant to them and what they would expect from this type of research relationship. Consistent with the advice of sociologist Robert S. Weiss (1995, 52) who counseled that "Eventually, it will be obvious what is important; initially it rarely is," the focus groups were a principle source of exploratory pilot research into the health concerns and social issues impacting community residents and their perspectives on research partnership. Focus groups are especially beneficial for collecting a significant amount of information in a relatively short time period (Green and Thorogood 2009) and in this case, hearing a broad range of perspectives on how partnership in biomedical research is understood and talked about. These early group interviews provided an environment to field test topics and questions that I would later explore during in-depth interviews, and to discover new lines of inquiry for further investigation.

The 5 focus groups, which in total had 30 participants, were held at Community Health Clinic. On average each focus group had 6 participants and lasted 77 minutes. The majority of the participants in the focus groups were of Mexican ethnicity (n=21) and first-generation immigrants. Although I aimed to recruit equal numbers of men and women to the focus groups, we spoke to more women (n=22) than men (n=8). Our challenges recruiting men may in part be attributed to the patient population at Community Health Clinic because close to three quarters of the patients that the clinic sees identify as female. Participants in the focus groups ranged in age

from 34 to 75 years old. Of the 5 focus groups, 4 were conducted in Spanish. It was particularly difficult to recruit participants for English-speaking focus groups because the majority of the patients that we came in contact with at the health clinic were more comfortable speaking in Spanish and/or were monolingual Spanish speakers.[4] As a result, we conducted more focus groups in Spanish. The focus groups in Spanish were facilitated by research assistants and were conducted in collaboration with The Helios Lab. During the Spanish-speaking focus groups, a research assistant interpreted the discussion to me in real time. I facilitated the English-speaking focus group and to ensure that we were sensitive to the cultural needs of all participants, Spanish-speaking research assistants were available to translate for participants if they needed help understanding a word or phrase.

Group settings are beneficial to hear from a spectrum of people but they are less useful for garnering in-depth accounts or hearing marginal opinions that may not have been discussed during the focus groups (Green and Thorogood 2009). To gain a nuanced understanding of how residents make sense of and experience partnered participation in biomedical research, I conducted semi-structured in-depth interviews with 30 Latinx residents living within Greater Los Angeles. During the interviews I asked people about their personal background, their experiences receiving medical care, and their experience with and views on medical research participation. I also provided an example of a biomedical research study that refers to participants as partners, and asked people what "partnership" meant to them, what they would expect out of being a partner, and if partnering with researchers would influence if they would theoretically participate in the study.

[4] Over 42% of the patients at Community Health Clinic speak a language other than English and are best served in their native language.

The majority of the community residents interviewed were of Mexican ethnicity (90%), and three individuals were of Puerto Rican, Salvadorian, or Venezuelan ethnic heritage. Half of the sample were 1st generation immigrants to the United States. Participants were never asked directly or indirectly about their documentation status. However, all but 4 participants openly shared this information during the interviews while discussing their personal background. Of the interviewees, 14 individuals were previously undocumented (n=6) or were currently undocumented (n=8), and 9 participants discussed having undocumented family members. The sample was predominantly made up of low-income individuals, with just under half of all participants reporting their household income as less than $30,000 a year. 43% of the participants had a form of public health insurance and 23% were uninsured, and the majority of people interviewed had no experience participating in research (67%). The interviews were conducted in public locations, usually at coffee shops, that were convenient to where the participant lived or worked.

Half of the interviews were conducted in English, with 9 women and 6 men. The average age of the interviewee was 35 years old. Bilingual research assistants conducted 15 additional interviews in Spanish with 10 women and 5 men. The average age of participants from the interviews that were conducted in Spanish was 48 years old. The interviews in Spanish were predominantly with 1st generation immigrants (87%) with low educational attainment. This was different than the interviews that were conducted in English, where I primarily spoke with 2nd generation immigrants (n=5) born in the United States to 1st generation immigrant parents, or 1.5 generation immigrants (n=6), who arrived in the United States as children. Among the English-speaking interviewees, 10 had taken college courses or had completed a higher education degree.

Please see Tables 1 and 2 in the Appendix for detailed demographic information on all community resident participants.

To better understand the characteristics of partnerships in research, the prevailing assumptions about partnership, and the effectiveness and challenges of establishing these relationships, I interviewed 30 medical and health research professionals. I used a snowball sampling strategy; 8 of the interviewees were recruited from my professional network and 11 interviewees were recruited from the 2019 Annual Meeting of the Society of Behavioral Medicine (SBM). The SBM conference brings together behavioral and biomedical researchers and clinicians to engage with the latest research and clinical and public policy concerns on health promotion, human behavior, health, and illness (Society of Behavioral Medicine 2020). The in-depth interviews were conducted with professionals from 20 research universities throughout the U.S. and 2 social service non-profit organizations in Southern California. The interviews averaged 46 minutes and were conducted in-person (n=15), over the phone (n=13), and on Skype (n=2) with academic medical researchers, clinicians, health services and health dipartites researchers, accrual and retention specialists, research assistants, clinical coordinators, and directors of research centers. Table 3 in the Appendix contains demographics of the research professionals that I interviewed.

Out of the 30 research professionals, 11 had personal experience conducting or supporting forms of participatory research. In the interviews, I asked people to discuss their perception of minority representation within their field of research, the strategies they use to recruit and retain participants to their studies, and social conditions that make recruiting underrepresented populations to their studies successful or more challenging. Additionally, I

asked research professionals to reflect on studies that they have conducted or know of that use partnership terminology ("participant partners" or "active partners").

Lastly, to explore one way that participant partnerships are currently enacted in a biomedical study and the broader assumptions about why ordinary people participate in research by biomedical researchers using partnered approaches, I turned to public information and organizing documents of the All of Us Research Program. I analyzed promotional videos, program announcements, the operational protocol, the Working Group final report (which developed the blueprint for the initiative) and other publicly available material from the NIH All of Us website (https://allofus.nih.gov). I particularly focused on how biomedical researchers talked about diversity and inclusion, recruitment and engagement approaches, and how participant partnership was defined and practiced. I treat All of Us as one, particularly large-scale and well-documented example of participatory research strategies that are being used by biomedical researchers around the country.

I analyzed the data using a grounded theory approach. This was an iterative process, going back and forth between the data and analysis, and using a comparative method through each step of the analysis to generate concepts and theory (Charmaz 2014b). Throughout the process of collecting data I wrote reflexive memos on what went well during interviews or focus groups, what questions needed improvement, and notes on my positionality in the research. I also wrote in-process analytic memos (Emerson, Fretz, and Shaw 2011) where I identified and elaborated on the theoretical implications of what I was hearing in interviews and focus groups. Writing analytic memos helped me uncover patterns and begin the process of developing new interpretations and understandings from the data.

I used Dedoose (Dedoose Version 8.3.36 2020), a qualitative coding software program to assist my analysis and to organize and store the data. To analyze the data, I used open and focused coding. Starting with open coding, I read the transcripts and documents line-by-line to identify important ideas or issues. Similar terms, events, ideas, phenomena, etc. were assigned a "code" and later were condensed into categories. Consistent with a grounded theory approach, these categories came directly from the data, not from my own preconceived concepts or hypothesis (Charmaz 2014b). I wrote code memos to elaborate and clarify codes and the assumptions underlying them, and to remove repetitive or ambiguous codes (Lofland et al. 2006). Following initial coding, I used focused coding to identify particular categories and themes. I also utilized additional forms of second round coding including in vivo coding (Saldaña 2013) to capture rich quotes and expressions from participants, and verses coding (Saldaña 2013) to explore binaries within and between how community residents and researchers talked about partnership. I identified the themes presented in this dissertation using this process of inductive and deductive coding approaches.

Chapter Outline

The rest of the dissertation uses data from medical and health research experts and community residents from an underrepresented population in research to understand how partnered research approaches are enacted and understood by biomedical researchers and ordinary people. In chapter two, I utilize interviews with research professionals to examine how experts view and enact academic-community partnerships. Although the term "partner" suggests egalitarian and reciprocal relationships, how partnership is understood and enacted by researchers varies dramatically. I compare three partnered approaches: 1) Symbolic partnership (rhetorical partnership talk); 2) Sustained, reciprocal, and egalitarian partnerships with

community organizations; and, 3) Partnerships with local individuals and study participants. I highlight tensions between different approaches and show that even the models that are more engaged with local communities come with significant challenges and may fall short of the ideals of reciprocity and equal power sharing that are often espoused in partnership models.

In chapter three, I focus on the experiences of low-income Latinx community residents of Greater Los Angeles and explore how residents understand research participation and what it means to be a "partner in research." I compare these understandings to how the All of Us Research Program frames biomedical research and "participant partners." I discovered that community residents relied on their relationships with health care providers to understand, frame, and evaluate new relationships with biomedical researchers. In other words, residents did not draw a clear distinction between research and healthcare. For most of the community residents that I spoke with being a "participant partner" in research was confusing because it did not match the relationship model that they used with health care providers. I found that a central barrier to research participation was in how ordinary people and researchers viewed appropriate relationships between researchers and research participants. I argue that the underrepresentation of some communities in research may be part of a more general failure by research teams to recognize the different ways that people think about and act on relationships.

In chapter four, I compare the different ways that researchers and study volunteers classify, use, and morally value monetary research incentives. I show that people's relational accounting of monetary incentives is significant for how relationships with study volunteers develop and how ordinary people and researchers understand these relationships. Community residents viewed incentives as a form of payment for their time and compliance in a study, while researchers did not view incentives as payments but rather as a gift of gratitude for participation

in socially valuable research. I found that researchers were primarily concerned that financial incentives that were a high dollar amount could potentially be coercive – as a result, financial incentives were often kept low. Community residents saw incentives as a straightforward payment for their time but worried that by accepting payment from researchers they would be entering into a potentially dangerous transaction where they could be exploited. I argue that how people personalize and symbolically value forms of money are important for understanding how researchers and ordinary people create and maintain relationships.

I conclude that the greater involvement of minority groups in research rests on recognizing how people frame and understand socially-constructed relationships. In all models of partnership, researchers assume that partnered relationships promote trust and encourage ordinary people to frame research participation as a form of civic engagement and social solidarity. However, this is rarely how people frame research or why they volunteer. Not drawing a clear distinction between research and healthcare, people's experiences of medical mistreatment, racial bias and discrimination, or being uninsured or underinsured, violate people's ideas of how they should be cared for by medical professionals. Research partnerships on an individual level (as "participant partners") do not match how people understand their relationships with medical professionals, or what they experience and expect from these relationships. Biomedical researchers frequently stress that distrust of research primarily stems from the legacy of unethical research studies and the continuation of poor research practices. Yet, I found that distrust from broken relationship expectations with health care providers and experiences with health inequities and disadvantages, are interwoven into people's skepticism and mistrust of biomedical researchers. Although there are significant challenges to developing sustained and equitable partnerships with community organizations, but these collaborations

often make it easier for vulnerable people to participate in research, using multifaceted strategies to mitigate barriers that impact health access and obstruct research participation. This study highlights how people's experiences within the U.S. health care system are intimately connected to people's attitudes of biomedical research.

CHAPTER 2
Community Partnerships: Strategies for Enrolling and Retaining Minority Participants

The dawn of the twenty-first century has been an exciting time for the improvement of health, with impressive developments in medical technology, advancements in biomedical research, and breakthroughs in understanding some of the genetic underpinnings of health and disease. And yet, a divide remains between the promise of evidence-based medicine and the challenging realities of community practice to provide primary and preventative medical care to people in the United States (Asch et al. 2006; L. Jones and Wells 2007). Although there have been significant medical and research advancements, health disparities affect every stage of life and particularly disadvantage racial and ethnic minority communities. The COVID-19 pandemic, which as of September 2020 has infected over 6.2 million individuals and killed over 187,000 people in the U.S. (Times 2020) has shone a spotlight on the systemic failures of the U.S. health system and the discrepancies in health outcomes for people of color and of lower-socioeconomic status. Racial and ethnic minority groups are more likely to be hospitalized and die from the novel coronavirus (Hopkins 2020), and Latinx and African American residents are three times as likely to become infected with the virus as white residents living in the United States (Jr et al. 2020).

As scientists scramble to examine the social, environmental, and biological factors that cause some people to be more susceptible to contracting acute infections like COVID-19, we also know that many chronic conditions including diabetes, asthma, and certain cancers have far worse outcomes and are disproportionately experienced among minority populations. For example, Hispanic women are 40 percent more likely to be diagnosed with cervical cancer, and 20 percent more likely to die from it, than non-Hispanic white women (CDC 2019). Experts

believe that to understand and effectively respond to acute and chronic disparities in health, biomedical research must include a more diverse populace. However, institutional efforts to include minority communities in research have so far come up short. For instance, in the last 20 years fewer than 5% of federally funded lung disease studies have focused on people of color, yet black Americans are a third more likely than white Americans to have asthma and over 3 times more likely to die from it (Konkel 2015).

Experts point to several overlapping possible factors for why minority groups are underrepresented in biomedical studies. Some of these explanations include: cultural and linguistic differences, socioeconomic constraints, and from the side of researchers, implicit bias and insufficient training to design and implement studies with minority communities (Haley et al. 2017; Konkel 2015; Corbie-Smith, Moody-Ayers, and Thrasher 2004). Overwhelmingly, experts contend that the poor representation of minority groups in research is partly attributed to fear and mistrust of medical authorities based on unethical research practices documented in past studies (Katz et al. 2007; 2006; Corbie-Smith 1999; Corbie-Smith, Moody-Ayers, and Thrasher 2004; Haley et al. 2017; Wendler et al. 2005). These challenges necessitate a fundamental change in how providers, researchers, and communities respond to resource constraints, the historical distrust of research and care professionals by some groups, and the social conditions and interrelated economic and social systems that shape health status and access to quality care.

Partnering with local communities may be one solution to address these challenges. Participatory research is the term used to describe research approaches that are carried out with and by local people rather than research conducted "on" them. The deliberate sharing of power between academic researchers and local communities is the key difference between participatory and conventional research methodologies (Cornwall and Jewkes 1995). In participatory research,

local knowledge forms the basis for research and planning. Research strategies that emphasize partnerships between academics and community organizations, leaders, and ordinary people, fall under the broad umbrella of participatory research methods which aim to include local people in research. Motivated by ethical concerns and pragmatism, partnering with local communities is championed by recruitment experts as an effective strategy to inspire ordinary people to participate in research but more specifically, to encourage underrepresented racial and ethnic minority groups to join research studies (L. Jones et al. 2009; L. Jones and Wells 2007). It is estimated that within 25 years, more than half of all Americans will belong to a racial and ethnic group other than non-Hispanic white (Colby and Ortman 2014). As the U.S. population becomes more diverse, garnering the participation of groups that are underrepresented in research is critical to limit the exacerbation of existing health disparities and equally vital for the successful development of large-scale research cohorts and clinical trials.

In theory, the idea of partnering with local communities sounds relatively straightforward, but I found that in practice partnerships are complicated and can take on very different forms. To examine the ways that investigators frame the development of community partnered relationships, I conducted 30 in-depth interviews with health and medical research professionals who were familiar with participatory approaches to research. In this chapter, I first review the prevailing assumptions for why minority groups participate less in research. Biomedical researchers frequently cite mistrust of health care and medical research institutions as primary contributing factors, pointing to historical abuses of power and research misconduct. I briefly address how racial politics and historical and social contextual factors are interwoven into tensions and mistrust of medical research by some communities. Participatory research methods have become a popular strategy for alleviating issues of mistrust and involving minority

populations in research. My interviews with research professionals revealed three distinctive partnered approaches: 1) Symbolic partnership (rhetorical partnership talk); 2) Sustained, reciprocal, and egalitarian partnerships with community organizations; and, 3) Partnerships with local individuals and study participants. I compare the different ways of "partnering" with local communities and illustrate through interviews with research professionals what these different forms of partnership look like, who researchers partner with, and what value researchers give back to community partners within each approach.

Investigators are still grappling with what counts as "true partnership," how individual participant partnerships with community residents can come to fruition, and what variations of partnership are best for different circumstances. My conversations with research professionals on the varied semblances of "partnering" with local communities and their different responses to the rhetorical and practical utility of participants as research partners, are representative of the relative infancy of participatory approaches in biomedicine. Although recruitment experts espouse participatory approaches as effective recruitment and retention strategies for diversifying research, my interviews with research professionals and with Latinx residents of Greater Los Angeles (discussed in chapter three), highlight the ways in which partnership is sometimes disputed by both research experts and ordinary people.

Lastly in this chapter, I discuss how health researchers presented ideal forms of partnerships, discussing the utility of reciprocal relationships for recruitment and retention, but also for the ethical importance of bridging community and academic knowledge to reduce disparities in health and increase minority group representation in research. I show how even in the more engaged models of partnership, which researchers argue are the best models for involving minority communities in research, there are significant challenges. Partnership ideals,

such as reciprocity and equal power sharing, are beneficial to both academic researchers and local communities, but it is challenging to achieve these ideals in practice.

Defining the Recruitment Problem

Recruitmentology (Epstein 2008; 2007), is a field of biomedical literature dedicated to discussing and researching why people participate in research, what stops them from doing so, and how to encourage people to participate in larger numbers. A significant segment of this literature focuses on overcoming and documenting challenges associated with recruiting and enrolling ethnic and racial minority groups to research studies. These challenges generally fall into three overlapping categories: Cultural dynamics, structural barriers including unequal access to health care, and mistrust of medical authorities.

One of the challenges of recruiting diverse populations to research studies is creating language-appropriate recruitment and informed consent material. Brochures, ads, and other study information need to be made available in multiple languages. Part of this task requires that researchers are sufficiently trained in the first place to be able to design and implement studies with diverse communities and that the research team involves culturally matched and bilingual research staff (Chen et al. 2014; Konkel 2015; Alvarez et al. 2006). Enrolling populations that have low educational attainment or speak a preferred language other than English requires extra time and resources to make sure that the way that study information is presented does not become a barrier for participation. Some studies suggest that informed consent information, even when designed and executed with culturally appropriate material and at an elementary literacy level, does not always come off as researchers intend. For example, particularly among individuals with low levels of education, people sometimes do not understand the information

they receive (Barr 2006), or have the ability to recall or use informed consent information in the ways researchers intended (Sugarman et al. 1999).

Biomedical researches also point out that the structural factors that shape health-seeking behavior among minority groups also impact exposure to and enrollment in research trials (Larkey et al. 2002). For example, studies addressing Hispanic communities have documented that poor access to health care, financial and time constraints (for example, lost time at work or needing childcare), and not having reliable forms of transportation limit people's chances to even come in contact with potential research opportunities (Larkey et al. 2002).

In addition to cultural and structural barriers to participation, distrust is overwhelmingly cited as a principal reason why some racial and ethnic diverse people decline to participate in medical research (Brandon, Isaac, and LaVeist 2005; Corbie-Smith, Thomas, and St. George 2002; Gamble 1997; Epstein 2007). Experts believe that unethical research abuses of black and brown communities have contributed to the mistrust of medical authorities (Johnson 2020b). In a recent example of research misconduct, a study team at Arizona State University collected blood samples from the Havasupai tribe to study genetic markers of diabetes. However, they also used the samples to conduct unrelated studies on schizophrenia and inbreeding, without the consent of tribal members (Drabiak-Syed 2010). An out-of-court settlement in 2010 required ASU to pay $700,000 to the Havasupai tribe and return all of the DNA samples collected from tribal members (Drabiak-Syed 2010). It is not surprising that some minority communities are skeptical about how the research outcomes might be used and how it will impact their community, particularly if they have felt pathologized, patronized, or exploited in the past by the academic university conducting the study (Benoit et al. 2005).

Substantial scholarship reports that fear of being an experimental "guinea pig" and concerns over government-sponsored research are leading reasons why minority participants withdraw or refuse to enroll in biomedical studies (Ceballos et al. 2014; Philip B. Gorelick et al. 1998). In both the academic and popular press, the Tuskegee Syphilis Study is referenced as one of the most predominant examples of research misconduct, where the legacy of the study continues to influence negative attitudes around medical research. In particular, the study is often cited as a contributing factor why some African Americans are skeptical and mistrustful of the U.S. medical and public health care systems (Gamble 1997; Philip B. Gorelick et al. 1998; Alvarez et al. 2006; Konkel 2015). The Tuskegee Study was a 40-year observational study (1932-1972) conducted by the U.S. Public Health Service in which nearly 400 African American sharecroppers from Macon County, Alabama were intentionally deceived and denied treatment for syphilis (J. H. Jones 1981). Fueled by popular eugenics ideology and racial politics, the study sought to investigate the natural history of syphilis and document racial differences in manifestations of the disease (J. H. Jones 1981). It was the longest non-therapeutic experiment on humans in the history of medicine (Corbie-Smith 1999). The legacy of the Tuskegee Study is often used to explain why minority communities continue to be reluctant to participate in medical research despite ethical research safeguards (J. H. Jones 1981; Corbie-Smith 1999; Shavers, Lynch, and Burmeister 2000; Corbie-Smith, Thomas, and St. George 2002). For example, it has been argued that ramifications of the study explain why during the height of the AIDS epidemic many African Americans opposed needle exchange programs, refused AIDs treatment with protease inhibitors for fear being used as "guinea pigs," and feared African American genocide at the hands of the U.S. government (Gamble 1997).

However scholars across numerous disciplines have also argued that relying on the Tuskegee Study to explain medical distrust neglects contemporary racial politics in the U.S. and the ways in which historical and social contextual factors are interwoven into medical distrust and skepticism of institutions and mainstream society (Gorelick et al. 1998; Epstein 2007; Gamble 1997). The exploitation of people of color in the U.S. can be traced back to the antebellum period where slaves and free black people were used as subjects for medical experiments (Gamble 1997). For example, the so-called father of modern gynecology, Dr. J. Marion Sims, experimented on Alabama slave women between 1845-1849, with each woman enduring up to 30 operations without anesthetics so that he could develop an operation to repair a bladder/vaginal disorder. Only after he was successful did he then operate on white women volunteers with anesthesia (Gamble 1997). Following the Civil War and emancipation, African American folklore was full of references to "night doctors," a term referring to doctors who would kidnap and murder African Americans to use their bodies for medical research (Gamble 1997). Perhaps these legends were not far from the truth; In 1882, grave robbing was documented in Philadelphia, in which a ring provided cadavers for the city's medical schools by stealing bodies from black cemeteries (Gamble 1997). Studies designed to specifically examine the relationship between knowledge of the Tuskegee Study and medical system mistrust confirm that historical and continuing patterns of negative interactions with the health care system are more important determinants of medical mistrust than actual knowledge of the Tuskegee Study (Brandon, Isaac, and LaVeist 2005; Shavers, Lynch, and Burmeister 2000)

The Tuskegee Syphilis Study authenticates already long-held beliefs and adds to a historical legacy and present day feelings that Americans value white lives more than the lives and humanity of people of color (Cary 1992). Throughout the 20th century federally funded

sterilization programs existed in 32 states as part of family planning and to control "undesirable" populations (e.g. immigrants, people of color, unmarried mothers, the disabled, etc.). California led the country with the highest number of sterilization procedures, accounting for one-third of all sterilizations (Ko 2016). The 1975 *Madrigal v. Quilligan* class action lawsuit brought public attention to the coerced sterilizations of Latina women and other poor women from minority groups who gave birth at Los Angeles County-USC Medical Center in the 1960s and 1970s (Tajima-Peña and Espino 2015). The lawsuit sought justice for Spanish-speaking women who, while in labor, were asked to sign papers, written in English, consenting to the cutting of their fallopian tubes. Some women signed the consent form but were unable to read English and did not know what they were consenting to. Others believed that the phrases "tying of the tubes" meant that fallopian tubes could be untied and that "sterilization" referred to a cleaning (Tajima-Peña and Espino 2015). Most of these women did not know they could no longer have children until many years later. The class action case prompted the federal government to make consent forms in Spanish and English, and to mandate bilingual counselors at county hospitals (Anderson 2015). Scholars argue that systemic institutional racism, such as the legacy of coerced sterilizations, is a possible contributing factor that helps to explain why Latinx individuals experience more fear and skepticism about biomedical research than non-Hispanic white individuals (Katz et al. 2007).

Participatory Research: Methodological Strategies to Diversify Participation in Research

Researchers have turned to participatory research approaches as a solution to address the distrust of medical authorities, structural barriers that impact people's access to health care, and informational and cultural barriers that together leave minority communities underrepresented in research trials. Participatory approaches to research are very different than conventional research

methodologies that typically follow a "top-down" process conducted and managed by academic researchers. Instead, participatory research advocates for academic-community partnerships, where researchers collaborate with local communities and power is shared (Cornwall and Jewkes 1995; L. Jones et al. 2009). The "bottom-up" approach of participatory research takes into account local priorities, processes, and perspectives by partnering with community organizations, leaders, and residents.

Participatory research focuses on the study community and aims to create relationships that address what holds people back from participating in research. This approach has gone hand-in-hand with institutional efforts to diversify medical research and encourage minority groups to participate in biomedical studies. For example, Cameron, an epidemiologist recounted:

> I would say maybe 10 years ago there was a big push for community participatory research. And that came from the realization that research needed to have community partners and needed to have engagement by the community in order to be effective. And there was a big push for the NIH to support and to sponsor a lot of this kind of research. And there were a lot of things that needed to be looked at, not just how can we recruit people into research, but specifically, how can we communicate with the community?

The institutional push towards participatory research reflects a shift in how researchers aim to understand and connect with a more diverse populace, and how experts address racial and ethnic health disparities. Developing partnerships, where researchers work "with" not "on" local communities, leverages the knowledge of locals to develop tailored strategies for involving a more diverse populace in research.

I interviewed 30 medical and health research professionals to examine how "partnership," a key term in participatory research approaches, is understood and enacted by biomedical researchers. The interviews with research professionals revealed three different variations of partnership with differing assumptions about partnering with ordinary people. In the next section I will compare what these forms of partnership look like, who researchers partner with in each

form of partnership, and what value researchers give back to community partners within each approach.

Variations of Partnered Research

Symbolic Partnership: "Even if it is nothing more than a label, I still think it's valuable."

The rhetorical use of "partners" or "active partners" to refer to biomedical study volunteers (rather than subjects, patients, or participants) was the most moderate approach of partnership that was discussed in my interviews with research professionals. The symbolic use of the term "partner" was often interwoven with professionals' discussions of recruitment and engagement strategies. For example, Aaron, the director of a research center, said:

> I believe that engaging participants to feel like stronger members of the research team is critical. I definitely have written about that. And I do believe that, and I have lots of little sort of catch phrases I use to recruit people that are utterly genuine! I tell people "When you enroll in a study with us, you're no longer a patient. You're the most important member of the research team." "You don't sit around in a waiting room waiting for us to call your name, you arrive, you're brought right back, you do what you came to do." We do treat people very differently than they're treated when they're getting their outpatient medical care.

For researchers like Aaron, partnership talk was meant to indicate to study volunteers that they were the "VIPs" of the research team, and that their participation was essential for the success of the research study. For other researchers that I talked with, like Abigail, the rhetoric of "participant partners" extended beyond a catchy recruitment phrase. Even though participants are not involved in the research process (more than being a study volunteer), Abigail argued that emblematic uses of partnership still matter. She discussed this by referencing the All of Us Research Program. As a well-known study using participatory research approaches on a national level, it was quite common for the professionals I interviewed to reference the All of Us Research Program while discussing partnerships.

> … I do think semantics are important. And I actually really appreciate that's an initiative that All of Us is following and they're recognizing the input and the value of providing information to a research study on the participants. And I think that labeling is really important, I just don't know enough about what it looks like in a practical matter. But, even if it is nothing more than a label, I still think it's valuable.
>
> - Abigail

Partnership talk suggests a particular kind of relationship that researchers want to develop with study volunteers. The language insinuates that an equal playing field exists between researchers and ordinary people. Mentioning researchers who use "active partner" terminology in IRB applications, Maya, a co-director of a clinical research recruitment and retention unit, said, "I'm not sure if that's more semantics or what, but I think in general [it is used] to convey that we're in this together, we're working together ... I think it's meant more philosophically than maybe practically." For Sophia, the solidarity that partnership talk is emblematic of, was a primary reason why her lab refers to study participants as partners.

> With our research we call them community partners. At the orientation we always call them "partners in research" and I think that gives people a sense that without them it cannot be possible … I think they get the sense like, "I'm doing this because I'm helping" … They're giving back to their community … Which draws a lot of people, they want to [participate]. Not only is this going to affect me and help me, but it's also going to help my grandkids, my children, our future generations, building a legacy. So that's how we talk about our research, how they're helping future generations. Sometimes they feel a little bit more empowered.
>
> - Sophia

Researchers used partnership rhetoric to advocate that research participation is part of civic engagement. The messaging of partnership talk was that by working together – in this case, simply having community residents volunteer to be a research subject – researchers and ordinary people could create a healthier society.

Additionally, symbolic partnership talk had important value for researchers to signal to volunteers what would *not* happen if they were a study partner. For example, Devin said,

> We actually are an All of Us Center here in [US city], which is kind of interesting. I agree with that approach [research participants as partners], and I think that maybe [it is used]

> to speak to the sensitivities of the studies in the past that have really, very wrongly approached this - the flagrant abuse of the researcher kind of participant thing. I think that [partnership] helps - it may help dispel some perceived notion of, "well they're just researchers, they're experimenting on me," so to speak. I like that idea, you know, this is truly a partnership. And then I guess the challenge is communicating that in a way that is valid, at least in the participants' eyes.

Experts believe that deep-rooted mistrust of health authorities is partly attributed to leftover historical residue from unethical experiments and the exploitation of people of color. Referring to research volunteers as "partners" rather than "subjects," is one way that researchers try to communicate with minority populations and other groups that have experienced abuse and mistreatment that research practices have changed. Devin's concluding remark, "communicating that in a way that is valid … in the participants' eyes," alludes to the challenges of using partnership only in rhetoric. Communicating "participant partnerships" is complex, even when partnership extends beyond rhetoric and reciprocal relationships are developed. As I will discuss in the next chapter, partnership talk (studies referring to participant volunteers as "partners" in research) was confusing for most of the ordinary people that I interviewed and was not the symbolic equalizer that researchers hoped it could be.

Partnerships with Community Organizations: "I'm still connected to the community"

While some research professionals used partnership talk symbolically and argued that rhetorical uses of partnership mattered, other professionals passionately argued that partnership without or with limited features of equal collaboration stripped the word of the intended meaning. Importantly, they argued that using partnership only in rhetoric could jeopardize the trust of community residents. Hector explained his view on the importance of equal collaboration and exchange in partnered research.

> I really like the idea of using words like "partner" because that implies a few things, but I also feel like the word partner is separate from "participant." A participant or subject … you're here to provide something for the researcher. Whereas partners you're in it together. So, if you're using that word, you can't expect the same thing as a subject

> because they're two different things. With the partner you should be giving back to that person because it's a reciprocal action. They'll give you something, [maybe] information and you have to give them something else. So, when using those words, it is important to act on them and figure out what they provided me with - the service – and what can I do for them?

Hector's comment illustrates a key feature of how most of the researchers that I spoke with discussed partnerships: Reciprocity. Frequently, reciprocity on the part of researchers was discussed as efforts by research teams to provide community partners with pertinent data and findings from the study or to help partners with other types of capacity building that would benefit the target community. Interestingly, although researchers were adamant that reciprocity was an imperative facet of ethical partnerships with local communities, stressing that you had to give something back, they were vague about what this actually required of researchers or what counts as a reciprocal action.

When research professionals referred to "partnerships" they were usually referring to the development of relationships with community organizations and the leaders and representatives of those organizations. As Julian stated, "If you told me about partners in the research or active partners, I would be thinking about community-based organizations. Not necessarily the participants themselves." Adam had a similar reaction, explaining, "So usually when I say "partner" I'm usually referring to a partner organization. And not that you can't have individuals that are partners - you always have a point of contact with an organization [that] can still be very personal." Research partnerships with community organizations are intentionally developed relationships with organizations that are reflective of the priorities of a community.

Similar to what the anthropologist Alan Page Fiske calls an equality-matching relationship schema (Alan Page Fiske 1991) – a particular frame for understanding a relationship where what people expect to give and get from the relationship is reciprocal – these kinds of

partnerships are ideally grounded in reciprocity and equality. Researchers and community partners are collaborators, each bringing particular skillsets to the relationship, and each partner benefitting equally but in different ways. In contrast to conventional styles of research where academic researchers often dictate the entire research process, in this "bottom-up" style of partnership, leaders from community organizations are instrumental in co-defining research priorities, sharing local perspectives, and collaborating on different parts of the investigation. For example, Abigail, an assistant research professor, explained:

> I've done some work [with] campus community partnerships, for example, where we'll have particular individuals from a community organization … on a particular project and they have just as much skin in the game and they have just as much voice at the table as anybody else. I cannot overstate the value of getting … those people involved. And you're still not necessarily getting the involvement of the particular individuals who are going to be the study participants … You're still getting the perspective of individuals in leadership positions … who may have more familiarity or comfort interacting with an academic environment.

Practitioners of this kind of partnered research involve local leaders of community organizations in the planning and implementation of research to share local knowledge and various perceptions of the community that the leaders represent.

There are a number of reasons why researchers might partner with community organizations to develop and conduct research. First, community organizations provide researchers with valuable "insider" knowledge, including what problems their residents face and what issues matter to local people. Researchers consult with community leaders and co-develop health initiatives that are important to residents within that community and argue that doing so makes recruiting local people easier because the topic matters to locals. For instance, Samantha said,

> I do believe that we need to more strongly involve the community in the kinds of science that we're doing. If we ask questions that are important to the community, if we design our studies in a way that make it feasible to the community, then they're more likely to

> buy in, and more likely to participate. If you're asking a question that just doesn't matter to anybody, or they don't see as relevant, you're going to have a high hill to climb.

Additionally, community partners play a very important practical role for recruitment, retention and developing trust. For example, Cameron said:

> We also have some community partners … like the Somang Society, which is an organization that helps recruit older Korean individuals into care for dementia. And they hold caregiving support groups, and they help recruit people to donate their bodies. There's a big body donation campaign … and it helped us to recruit individuals to sign up for [our studies]. Which is a big, big part of actually what [the Somang Society] organization does. And so, we partner with them. [My colleague] does a lot of talks and he presents material on what kind of trials are ongoing, and how best to connect with some of the research that's been ongoing at our university.

Trusted and respected community organizations that provide services to their residents can serve as liaisons for researchers to connect with potential participants. In some cases, partner organizations will recruit and enroll participants for researchers. Katherine said, "You need [community] brokers, because if you just walk in as a researcher who's an outsider to the community, they really don't have any reason to trust you. But if somebody they already trust …make[s] that connection for you, the trust can start to be built there." Community partners are instrumental in dispelling misinformation about medical research and helping researchers establish trusted relationships with community residents.

For researchers that conduct health research with vulnerable populations, community partnerships can be essential to address social and structural constraints that make it difficult to reach under resourced communities and very challenging to keep study participants from these communities enrolled as participants. Researchers that form partnerships with community organizations recognize that people who come to participate in research bring their whole life with them, not just their interest in the study. As Mateo mentioned, "if you want communities to be involved, you have to at least be ready to help address all of the other issues that come." This

philosophy significantly departs from more conventional research approaches that are often unidirectional in design and treat research inquires as separate from community needs. Samantha provided an excellent example.

> The more that you get community buy in, the door opens. And I mean this in a really good way. So, for example, with this weight loss intervention that we did, we were way under budget to do the study. It was a big study and … there are many barriers that [women in our study] encountered trying to come to the research, [such as] scheduling, time, transportation. How do you address weight loss when there are women who literally go hungry? They have food insecurity. What happens when you get a woman who comes to class, and you know [that] her spouse has left her and she's [in a difficult situation]? We partnered with AltaMed [a health care system providing medical, dental, and urgent care services in Greater Los Angeles] and they have a good reputation in the community. We got all of the services. AltaMed really committed to providing the support to finish the study. And, when there's a woman who doesn't have health insurance, we can connect them through AltaMed. When there's a woman who comes hungry, we can connect them through AltaMed to food services. They helped us to establish what do we do around domestic violence.

Researchers that advocate for partnering with community organizations stress that understanding health, health behavior, and health outcomes is complex and requires a team approach to be successful. They point out that models that focus on individuals (individual motivations or individual behavior change) miss and risk not being able to say very much about environmental and social influences of health. Partnering with community organizations allows researchers like Samantha, to tackle complicated social problems that not only impact the health outcomes that she's trying to address but on a more fundamental level influence the likelihood of individuals within this population of being able to partake in her study. Researchers that study health disparities often advocate for the development of community partnerships because communities that work with residents are intimately connected to the study population and can be influential in helping to develop multifaceted approaches to address particular barriers to research.

As examined earlier, reciprocity was a central feature in how researchers discussed partnerships with community organizations and leaders, advocating that partnered relationships

should be beneficial to both groups through the exchange of different resources, knowledge, and expertise. While for researchers the benefits of partnering with locals are numerous, how do community organizations benefit from this relationship? Recruitmentology literature emphasizes that community partners can benefit from working with academic leaders to obtain funding (L. Jones and Wells 2007). Although funding assistance was mentioned, more often the professionals I interviewed stressed sharing research results through easy to understand and accessible mediums as a primary benefit to partnered organizations (and more broadly, to the studied community). In the most ideal form, the research is directly connected to community needs, where community organizations are able to implement findings from the research into the services they provide. Samantha shared what she and her team did on a recent study:

> So, for me, it involves really a feedback loop back to the community [and] presenting our results back to the community. We will do a community forum where we present [what we learned]. [In my last community partnered study] … we went back and shared our results - we did a whole day with the clinic after the study ended. We brought back our study team and … half of the day was really around, what did we learn? And what do we share with the providers [of the health clinic we partnered with] on how to improve their care of Cambodian patients? We spent the other half of the day doing a healing ceremony in the community. It was shared hosted with us and the community, and the researchers could come. Part of it was a presentation from us, but more so the day was also about artistic expression. Different community groups could come. There was a dance presentation, food, a Buddhist monk came and led a meditation. So, it was really helping to close the loop, both from the science perspective, and then a celebration and recognition of the community contribution and strength that had helped to support this research. So that's a project that finished that we sort of went full circle.

Samantha's example of co-hosting a community celebration illustrates some of the best practices for how researchers can share their findings at the end of a study and honor the joint efforts that made the study possible. Natalie, provided another illustration:

> At the end of my study I went back … [and] had a presentation where I invited all the families back in to learn about the results of the study. And I think that's a place where researchers fall short because people want to know: Where did you go? What did you learn? What did my participation mean? And so, if that's something that we can do more

> systematically, particularly in [underrepresented minority] communities, we can reduce some of their stigma around research and the process.

Sharing research findings with study participants and partner organizations through accessible formats is a concerted effort to change how people view research participation and researchers. Although biomedical research is rarely immediately useful to study volunteers, researchers hope that by sharing the progress and research findings of a study they demystify the research process and provide ordinary people with a better understanding of how their participation mattered for the aims of the study. In interviews, researchers typically framed what they gave back to community residents or organizations by making comparisons to conventional research approaches which may not ever report findings back to local communities. By this comparison, doing something was better than nothing. In some cases, acts of reciprocity from researchers may have been more symbolically meaningful as an effort to shift the framing of research relationships with local communities away from unidirectional research models (even if these changes were incremental).

Additionally, research professionals discussed on-going efforts throughout the course of a research study to share their expertise and results with community partners. This included: Giving talks at community locations (for example, community centers, nursing homes and health clinics), holding public forums where community members could ask experts health related questions, offering free health education classes to community residents (this was often coupled with a behavioral health intervention study), presenting their research findings to clinical practitioners, and sharing information about university services or research that could be beneficial to community organizations and residents. Although making research findings more accessible and working with community organizations to implement the lessons learned were discussed as the benefits of partnering, researchers argued that these practices should occur

regardless of if a partnered approach is taken. As one researcher said, “There is a saying about [our university], it’s [that we are] the best well-kept secret, where people are not aware that we have a new university in our neighborhood … it’s a public university, you should have access to certain things. We need to be able to give [our community] something back for being here.”

Lastly, research professionals underscored that partnerships with community organizations ideally continue to grow following the conclusion of the research project. Directly after describing the community celebration, Samantha explained that completing the “circle” means that the relationship is iterative with the partnership continuing.

> And the last piece of that is I'm still connected to the community. When you participate meaningfully, you know, every year [my partner organization does] a fundraiser. I go to the fundraiser. I don't have a research study going now because my research hasn't spawned the next question, but I'm still engaged with the community. When it's time to do another study, it's not like I have to go back, I just have to reconnect … when somebody becomes part of your family you stay connected to them. But I think it is up to the researcher to make sure they close the loop. And certainly, at the end of the study by sharing what you learned and celebrating the effort that went into it.

To establish enduring community-academic partnerships, researchers emphasized meaningful dialogue and shared decision-making powers between community leaders and academics. As Sheila notes, “Shared decision-making is a huge part of being a community partner … yes, you have a researcher, yes, you work within a funding mechanism. But this is supposed to be a mutually beneficial project where the community feels like they're getting something out of it that is necessary and needed.” Lillian, a recruitment and retention specialists, was of a similar opinion:

> If you have a community partner, you want to hear what [they] have to say. So, for faculty researchers when they're calling somebody a partner, I think it would require them to meet [and] have regular meetings with these people so [community leaders] can provide their input on anything from study design, to recruitment, to dissemination, all kinds of things …where [researchers] really do care about what [the community] feels is important to them.

One way that researchers expressed trying to meet these ideals, was by creating a community advisory board (sometimes referred to as a steering committee) of community leaders, staff from the partner organization, and people from the research university. Advisory boards are a way for researchers to strategically organize projects and have leadership from the community. Representatives from partner organizations and residents in the neighborhood voice the perspectives and needs of their community and work with researchers to develop a research protocol to address these needs. Contrary to top-down models of research, open communication between researchers and community partners strives to equalize the research process through joint leadership. Ideally, partners develop a mutually beneficial investigation process and research goals that will positively impact wider community problems and continue to build capacity for the community partner.

Participant Partners: Community-based participatory research - "The Ultimate Next Frontier"

Although most of the research professionals that I interviewed discussed "partners" in research by referencing community organizations, they did believe that it was possible to extend the same notions of mutual exchange and learning, and collaborative decision-making and equality to individuals as research partners. However, this form of partnership meant something extremely specific for the researchers that I interviewed. For example, Alexa said, "Participants being active partners means something very distinct … participants as partners isn't a phrase that you should just throw around because it diminishes the importance of that partnership and the independence that participants have … It takes a trained researcher to truly come to the table with participants as equals. It's not an easy thing to do." Individual notions of partnership in

research were connected to community-based participatory research (CBPR) approaches. As Julian describes,

> …[There is a way to actually have people as partners [through] the whole CBPR approach where before [the research] is even getting started, [researchers and community members collaborate] getting input on what needs to be addressed. How should it be addressed? … It's not totally top down … To me just in the word "community" – it is in the title, right? Community-based. So, it's somewhat specific.

The approach overlaps with other forms of partnership discussed earlier where researchers partner with community organizations. Adam fleshes out the key differences:

> … The term community-engaged research came out … where [researchers] talk with community partner organizations and members of the community to get input. But [researchers are] still starting with a question that came from somewhere else … The ultimate next frontier is … called community-partnered research. Community partners support participatory research. And that's where the community says, we have a question … [and they have] relationships within the university to gather people and say, [will] you help us study this?

Similar to partnered approaches with community organizations and leaders, CBPR is an iterative and cyclical research process, ideally creating enduring relationships between partners and academic investigators. One of the central differences of the CBPR approach is that individual participants can be partners, involved in determining the research priorities and collecting and analyzing the data. Quite often the community also has joint ownership of the data with researchers. Cameron illustrates the intentionality behind the term "partner."

> The participant is not just an inactive entity that gets observed. It's not … that "guinea pig" mentality. That person is an active collaborator - an active person that collaborates with the researcher to learn something about the community. That is the whole goal that we want to accomplish … to have a participant feel like they are contributing something that is valuable and that it's not a one-way top down relationship.

This approach is a concerted effort to dismantle power imbalances between scientists and ordinary people through an egalitarian exchange and team approach that values the different contributions of community organizations, leaders, and residents.

Katherine, recounting her most recent CBPR study, shared with me what this approach to partnership looks like in practice, from start to finish. Katherine partnered with a non-profit organization that serves a Spanish-speaking Latinx immigrant population.

> My target population for all of my research has been Latino immigrants. So, in order for us to really achieve a true partnership and make sure the voice of the Latino community was heard, and that we were respecting Latino culture and the needs of the culture, we partnered with a community organization that already works in that community. This also allows us to work in a setting where participants like Latino immigrants already feel safe and feel trusted. The organization … [has] a health care center, a mental health program, a food pantry, a fruit store. Really, they're trying to provide a whole picture, a holistic health and wellness center. Most of their services are free … we have a lot of immigrants who are not documented. [The non-profit I partnered with] is a place where they never ask about documentation status and … they've been around for about 15 years, so they have built up their reputation as a place where people can go and feel safe. [It is a place] that they can trust.

By partnering with a trusted and respected community organization that has served this community for over a decade, Katherine garnered credibility. Importantly, for Katherine and other researchers that work with underrepresented minority communities, she was able to reach an undocumented immigrant population that investigators who conduct non-partnered research often have great difficulty accessing and gaining their trust. Katherine's partnered organization also benefited from working with her.

> What we had to do at the university side is bring in some expertise around strategic planning and organization, research and evaluation, so that we can help them make sure that they were achieving the goals that they wanted to achieve … and my research [which] they were a part of, the findings actually go back to them so that they can use [the findings] to improve their services for the mental health program there.

Forming relationships with community partners and developing trust takes an enormous amount of time. Katherine, who is an experienced health researcher, began developing a relationship with her partner non-profit organization when she was in her first year of graduate school.

> My advisor was already doing some work over there … it started out as me just going over there and helping out, volunteering, helping them do a little bits of program evaluation here and there. So, before I started [my most recent project] everyone there

> already knew me. I had to spend time volunteering, I had built a relationship of trust, which is a really big part of CBPR. The whole idea is that we develop long term relationships with our communities and with our partners, so we don't just drop in, do a study and leave. It's an ongoing process. We've been over there for several years.

A key aspect of CBPR, and how partnered relationships endure, is that communities identify the research problem and work with academic researchers to solve it. These are community-driven research projects where the ideal relationship is reciprocal, with academic and community partners bringing complimentary skillsets.

> [The non-profit I partnered with] had already identified mental health as the biggest problem for the community center because they had a health care coordinator … people were coming for [health problems like] diabetes or different physical health concerns and then once the doctors would talk to them, they were figuring out that [their patients] also had some pretty big mental health concerns too. So, they were referring [patients] for mental health care, but there was nowhere for [the community residents] to go get it because there isn't a viable form of [mental] health care here and [the patients] didn't have insurance. So, our partnership with [this non-profit] really started when they recognized this need [for] mental health services. My advisor and a couple other faculty worked to develop a mental health program over there, where students from our counseling and health psychology program were actually providing one-on-one counselling.

Katherine's CBPR study measured mental health resiliency and started with a feasibility evaluation that she conducted for her partner organization on how effective their newly developed mental health services were. The program provided training for university graduate students and filled a valuable need in the community. Katherine's study developed by working with community partners at the non-profit to see what else could be done to improve mental health for this community.

In addition to community-led research inquires, partnering with research participants is what distinguishes CBPR approaches from other forms of partnership that also strive to develop enduring and reciprocal relationships with community organizations. As discussed earlier, typically, partnered research begins with developing a community advisory. Katherine described what this looked for her study.

> Everyone on my community advisory board was Latino, and most of them were immigrants themselves. And they all spoke Spanish. … We started meeting way before the project ever actually got started. They were a part of every aspect of it. Developing a research question really came from the leadership of staff at [the partner non-profit] because they wanted to do more around mental health. Of course, I on the research side, I had to look at the literature and see how we can make sure that this is solid research protocols. But in terms of then designing the study, what kind of questions we were going to ask, everything from there on out, they were part of that process. I trained them on how to actually do the data collection. And they collect data instead of me.

This is where the CBPR methodology diverges from other forms of partnership with community organizations where leaders may give researchers their input on advisory boards, but their collaboration or influence may be more consultative rather than collaborative. CBPR differs by developing what some scholars refer to as "collegiate" partnerships (Briggs 1989; Cornwall and Jewkes 1995), where researchers and local people work together as colleagues in mutually beneficial research, with each bringing different skills. Additionally, CBPR treats ordinary people as partners. This means that community leaders, partner staff, and ordinary people in the community are all an integral part of forming and conducting the research. Researchers argued that involving individuals from the community in research was important for community engagement and respecting diverse backgrounds. For instance, Adam said,

> I think involving members of the study team from those communities is really powerful. [Having somebody] on the front line, knowing that there's somebody that speaks my language, I feel some connection to in terms of my own identity - I think that really seems to be one of the number one factors that really contributes to some of the interest [in participating in a study].

In Katherine's example, she trained community residents to collect face-to-face survey interviews in Spanish with other residents in the community. Community members who participated in her study also helped recruit other people to join. This is a strategy called respondent-driven sampling where research participants recruit people from their own networks and receive financial compensation for each person that they enroll into the study. For the vast

majority of the professionals that I interviewed, when they referred to "participants as partners," they were referring to CBPR methodology.

Passionate advocates of CBPR argue that the methodology is a panacea for many of the problems that often beleaguer researchers using conventional research approaches. Katherine summarized:

> If we [used a partnership approach with organizations and community residents] more often, we wouldn't see such a big disparity between research studies with minority and non-minority populations. I think the way we were able to do this was a way where people felt like they could trust [us]. So, the mistrust is an issue, the language barriers are an issue. We alleviated all of that. We conducted the research in a place that they already come to, that they already feel comfortable, they already feel safe. And have people who are part of their own community that they could sit there and have a conversation about, "Oh, which country did you come from? I'm from Mexico, I'm from here, I'm from there."

Proponents of participatory approaches that include ordinary people as participants and partners in research argue that researchers are able to more easily overcome recruitment hurdles, such as cultural and language barriers, misinformation, and mistrust of health professionals and government institutions. The approach values diversity and local knowledge and collaborates with leaders and lay people to create a research environment where people feel heard, welcomed, and respected.

Partnered Research as Activism: "Meeting people where they are"

At the end of the day, it's really just about listening to what people want, if you're truly interested in reducing health disparities. The solution is not going to come from my brain, it's going to come from engaging in discussions with community partners with different networks, different colleagues, and collaboratively coming up with a potential study that could have some impact on people. - Mateo

Partnering with local communities by collaborating with community organizations and/or extending collaboration to ordinary residents has great potential to ease recruitment and retention burdens. These kinds of partnered approaches are recommended by recruitment experts and, as

revealed in my interviews with researchers, are discussed as particularly effective techniques to involve minority populations in research. However, CBPR methodology and more moderate partnered approaches with community organizations and community leaders are more than just strategies for recruitment and retention. By challenging traditional power dynamics, building trust through community collaborations, and addressing structural inequalities, these approaches fundamentally aim to change the way research is conducted, particularly with ethnic and racial minority communities that are underserved and underrepresented in biomedical research. For these researchers, rhetorical and symbolic uses of partnership are superficial attempts at outreach and messaging and will not address the structural gaps that make it challenging for racial and ethnic minority communities to participate in research. In contrast, variations of equitable and reciprocal community partnerships are activist attempts to overcome structural barriers that underrepresented communities face when engaging in research and medical care.

Researchers that develop egalitarian collaborations, harnessing community and academic strengths, have a different outlook than researchers who discussed symbolic forms of partnership. For these professionals, reducing health disparities by engaging in forms of partnership was a personal and professional choice. For instance, Mateo shared, “For me, the intersection of what my professional research goals are and what my personal identity are, they're so intertwined. And that's intentional. So, I can't separate out what I value personally, politically, and then what my goals in my research are, so it's always been tied together.” Julie, a community health researcher and engagement specialist said, “I would say that people who do community engaged research are of a very particular ilk. And that it's some kind of undefinable quality. But you know it when you see it kind of thing, people who just understand how critical it is to make sure that whatever you're doing is relevant to the population.” My interviews revealed

that these researchers tended to see their work as a form of activism. Developing reciprocal relationships with under resourced communities was an intentional effort to support vulnerable and under resourced populations. For example, Katherine said,

> For me, it was important to work with this community because they're a high needs community and they are often forgotten or ignored … I wanted to be an advocate for people who maybe cannot always advocate for themselves. We were completely aware that white privilege exists and is a thing … I decided a long time ago that I accept that fact. And that I'm going to do something positive with my white privilege.

Forging community partnerships was a form of social justice advocacy and a more pinpointed effort to eliminate health disparities. Expressing professional humility was an important part of this advocacy work. For example, Mateo said,

> We do work with Latina trans women. And I'm a cisgender straight man … it's recognizing that I don't have the expertise, the knowledge or the capital to do this, but I want to help. We work with trans women who can conduct research – the research participants are very savvy, and they are very much active participants and partners in the research … they know more about their life experience than I do. And so, it's me recognizing that and always making sure that I'm checking in to say, am I dominating this relationship? … Or do you honestly feel like an active partner? And, that involves me talking with the team, who some of them are trans identified, and [asking] what would you like to see done? And are there methods that we can use? Are there questions that I'm not asking or that my team's not asking that you could help us identify? Because in the sense of active partnership, it's about saying, what are your needs and what can I do in my position of power to support those needs?

Activist forms of partnered research require researchers to be engaged in a kind of emotional labor (Hochschild 2012), where researchers strive to develop partnerships that can be characterized as being reflexive, flexible, and iterative (Cornwall and Jewkes 1995). This approach is drastically different than conventional or more linear forms of research and requires that researchers continually be reflexive on their positions of privilege and power.

Researchers that partnered with local community organizations, leaders, and community residents recognized that research in the conventional sense is often inconvenient and challenging for people to participate in (for example, needing to travel to a study location), and is

particularly difficult for low-resource communities. These individuals were committed to breaking down the structural barriers to research participation that are linked with more conventional approaches. For example, Mateo referencing his work with Latino gay men and transgender Latina women that are living with or at risk for HIV said,

> The Latino population is so big that there's always new possibilities to expand your work to this group, especially if you want to do it in Spanish, right? Which requires a whole different set of resources, a whole different set of personal labor workforce. And so, I've been trying to advocate that to do this work you need to bring people along with you who are capable and who understand the process of doing this. And so it's kind of been my goal that everywhere I've gone … [to] build awareness for the type of work that is required to reduce health disparities because you can't just take something that's worked in one place and expect it to work for this group with so many structural barriers to overcome.

Traditional models of research often require that people come to unfamiliar clinical settings during business hours. Among vulnerable populations, this can be a big ask of people, especially people who are under an incredible amount of financial stress, work long hours, struggle with childcare, or live far away from major metropolitan areas were medical research is often conducted. As Cameron said, “So not only do you have a gap in access, but for people here who are designing innovative technologies and innovative treatment interventions, those don't get disseminated to the populations most at need. You have [a] two-fold gap of accessing. Not being able to access [health services and research] and then because you don't have access, you don't get access to the new things that are out there in the world.” Collaborative partnerships work to change that by co-creating bespoke community-driven research initiatives and protocols, that make it easier for the most vulnerable to participate.

A very common refrain that researchers repeated during interviews with me was the importance of “meeting people where they are.” Discussing the latest trend to use social media as a recruitment tool, Alexa said that social media does not work for her study population in East

Harlem, New York. Instead she stressed, “meeting people where they are ... standing outside of Target, or Costco or bodegas in the neighborhood … Partnering with schools, churches … or community organizations who are holding events and overlapping with neighborhood events that are going on … meeting people where they are, environmentally. And for me, partnering with community-based organizations is so key.” Partnerships with community organizations is part of this idea of meeting people where they are – it is recognizing the need to do things differently and together with communities developing tailored approaches.

Lastly, the researchers that advocated for developing sustained and egalitarian partnerships with communities as a strategic effort to have greater minority group involvement in research, also advocated for diversifying the professional workforce. These two facets of diversity went hand-in-hand with their efforts to reduce health disparities and reach the communities that are most in need. Mateo explained his perspective:

> If you're going to be a champion for diversity [and] equity inclusion, really that needs to be sold as diverse people, people of color, have a different life course that is not better or worse than anybody else's, but they have a unique perspective to think about a medical problem from a different angle. And so, the idea with representation and why it's important is because people who are different than me, and how I am different from other people, we will inherently come up with interesting solutions to a problem. And so, this is why representation is important, because I can speak to some of the issues that maybe my colleagues can't … an affiliation with a community that gives you social capital to ask certain research questions, or to be the liaison between the community and the academic world.

Katherine was of a similar mindset, stressing that equity and representation in biomedical research needs to include institutional changes to the professional pipeline, where more people of color have the opportunity to be involved in research teams and professionally trained as investigators. Katherine argued that the “right way” to do ethical health research in an institutional system that currently hinders this, was to involve community organizations, leaders,

and ordinary people who had different experiences, life backgrounds, and social and cultural capital than she did.

> We still see such a low number of Latinos who are going through and getting master's degrees and getting PhDs. I think it's important for other people to be able to work with other communities and the way that we can do that appropriately is through CBPR, because the CBPR really acknowledges that you need to respect the culture, you need to respect the needs of that community, and that everything that you do should be about them and should be to benefit them … [People from the community involved in my research study] could just automatically bond and have these conversations that I could never have with [other community residents], because I'm not Latino or an immigrant. And I think that there's a level of appreciation that occurs there. They can appreciate that we see the importance of making sure that they're safe and comfortable, and that they can communicate. And it shows a level of respect … I wanted to do research with their community, but I also wanted to do it in the right way.

Researchers that adopted activist forms of partnership fundamentally believed that embracing novel community partnerships was essential for addressing complex health disparity problems. They advocated for partnered approaches that respected, valued, and made room for community forms of knowledge – where researchers were not always sitting in the driver's seat.

Tensions in Partnership Approaches and Applicability Challenges

My interviews with research professionals revealed three distinct types of partnership: Symbolic partnership (rhetorical partnership talk); Sustained, reciprocal, and egalitarian partnerships with community organizations; And, partnerships with local individuals and study participants. These variations highlight how partnering with local communities is anything but straightforward. Although the term "partner" suggests egalitarian and reciprocal relationships, how partnership is enacted by researchers varies significantly.

The symbolic use of partnership to involve minority communities in research was a point of particular contention among research professionals who collaborated with community organizations and/or with participant partners. Referencing egalitarian reciprocity as a key facet of partnerships with organizations or individuals, these professionals were particularly wary of

initiatives that were not transparent in how "participant partners" would be involved in the research process. For example, Abigail said,

> I don't know how much influence the participants/partners [of the All of Us study] have on [the] actual research design. Whereas when I think about community representatives in research and really more campus community partnerships … the individuals for whom a project is being developed … representatives from that population may be more actively involved in the researcher side of things as well as in the participation side of things.

For Alexa and other research professionals who conducted or were familiar with CBPR, the symbolic framing of participants as partners was an affront to the intentionality behind why researchers would strive to develop meaningful relationships with individual study participants. Interviewees often directed their criticisms to All of Us, mainly because of its scale and prominence, but the approach used by All of Us is used by other initiatives.

> I actually wasn't a fan of the All of Us project. In my opinion, that's not an active partner. The participants are giving all of their personal information. What are they actually getting in return? The ability to access their own data - that doesn't mean anything. If they were involved in looking at the data, analyzing data and interpreting the data, having a say on what that data means, and what are the implications then for treatment, for policy, for new programming, or budget allocations based on some health outcome or health need in a particular community, that is a partnership … my impression, and the reason why I hesitated to participate in it myself was because I didn't feel as if that was a partnership. I think that was marketing, to encourage as many people as possible to give up their personal health information.

Adam, was also skeptical of the All of Us Research Program's approach to participant partners:

> … There is research where you really do have partner individuals that are helping collect data … [for example a study has] residents taking air samples to determine air quality within their own homes and then the university will map that all out … that's true partnership … I don't feel like the participant, the people that are enrolled in the study, are all that involved in generating the questions. And I think that's what really distinguishes a partner from a participant … It just doesn't feel like those questions come out of the community members ... So, I think the partner term is a little more aspirational.

For Alexa, rhetorical forms of partnership are meaningless because there is no egalitarian exchange – research participants are giving but not getting anything in return. Collaborating with community organizations and involving community residents directly in research is part of an

effort to reconstruct new and positive relationships that address the mistrust of medical authorities that some communities harbor. Superficial partnerships threated to tarnish these relationships. Samantha said,

> The challenges is that researchers so often, even around here when I go to meetings, I hear people say things like, "Yeah, I just went down there and I asked this and then I left"... they don't think about the legacy or the impact. And, and I don't know if I do as good of a job as I should … but I do think that as researchers if we're not careful, we could slip into a tendency of using. Like, this is a commodity, I have a need, I'm going to use this product. Even though it seems well-intended, I don't think that's a good method for when you talk about human lives, right? Like, these are not commodities to be used.

Professionals who voiced concerns over symbolic forms of partnership worried that partnership rhetoric could be used to mask top-down research processes that co-opt local human resources into academic research agendas. A significant concern was that symbolic forms of partnership would harm efforts to develop new relationships with communities that have been mistreated in the past.

The concerns that research professionals raised relating to the marketing or aspirational uses of "partnership" also speak to challenges about developing reciprocal and sustained partnerships, and more broadly to the applicability of partnership approaches for national observational research or large-scale clinical trials. The first concern researches expressed was that in order to develop partnerships that extend beyond mere symbolism, there needs to be adequate funding to support the initiative. For instance, Abigail said, "I think one of the most valuable pieces is getting feedback from the target population … Before you start down that road, there's never enough funding … I think a lot of times that ends up being a barrier, just trying to get sufficient funding … everyone thinks what they work on is the most important thing and there is funding available. There's never enough funding." Developing community partnerships that are reciprocal relationships with research priorities tailored to community

needs, requires extensive groundwork and time spent within the community. These relationships develop over months and years. Often, the time needed to develop community relationships runs counter to the timelines of funding agencies. Shelia said, “Funding mechanisms are a lot harder, because again, these funding institutions have their own priorities. They're not realizing what the priorities of these communities are.” Time and funding constraints are significant challenges for developing academic-community relationships, and may be more difficult depending on the size and scope of the intended study.

A common criticism of partnered approaches is that relationships between academic institutions and community organizations are rarely as equal as advocates purport that they are. The archetypal partnerships with community organizations that professionals described were relationships that benefited community and academic partners, with each contributing different skills and know-how towards the success of the research program. However, in practice achieving egalitarian exchange may fall short. Julie said, “A lot of people think they do community engaged research, but maybe they actually don't. Maybe they are actually alienating themselves from the community by just utilizing patients at an agency and not developing a relationship with anybody and not sharing results back and that kind of thing.” Lillian observed, “We’ve had [conversations] with [community residents and community leaders from minority populations and] … they do feel sometimes taken advantage of, where universities or researchers come in and ask them for help and recruiting and then they get their patients and they never hear from them again.” The responsibility rests on researchers to ensure that partnerships are equitable where community partners receive equal benefit from the relationship. Some critics argue that not all researchers are trained adequately or equipped to properly ensure that community partners have a voice at the table. Other critiques maintain that researchers may

recognize the need to integrate local knowledge but continue to set research agendas and take responsibility for the outcomes of the research analysis.

Samantha suggests that funding also contributes to the potential unevenness between academic and community partners.

> We are human beings living on a planet and we're trying to solve complex problems … but you're not [financially] rewarded for doing [that]. So the back end community work that we did, none of that was paid for by the grant. All of that was paid for by the community and by me. If we really want to institutionalize sharing and community sharing, we have to put money as a nation into building the infrastructure in the community to match the infrastructure of the institution … You have to learn how to become a research participant. You're not born that way. And, coming to the table there needs to be some resources there to support you, just like everyone on the academic side got paid. But on the community side there's very little infrastructure and financial support. And if we're serious about it, we should probably do a more significant job there.

As Samantha points out, collaborative relationships require extensive time, effort, and funding, and more often this funding is funneled through academic institutions, where less resources are afforded to the community partner. It is much more common for clinical trials and other types of biomedical studies to use more conventional approaches than conducting research through academic-community partnerships. Researchers that partner with local communities may feel that they have to "prove" to the broader medical research community that this approach was worth the extra time and money spent. Along with funding challenges, community partnerships are hard to develop and sustain without institutional structures or pressure to incentivize academic researchers who might not be personally invested in issues of inclusion and diversity. For example, Julie runs a monthly meeting where she invites community leaders and academics to discuss relevant journal articles and participate in conversations about community engaged research. She said, "And as usual, we almost always have more community involvement than faculty. It's hard to get faculty to do anything." As Samantha alluded to earlier, the tangible benefits of partnered research are typically delayed (for example, it takes much longer to conduct

and publish partnered research). Significantly, this means that partnered approaches may conflict with the time pressure faculty feel to publish research or go up for tenure. Partnered research might be similar to other forms of academic community service (for example, faculty volunteering on academic committees) they are not as highly privileged or rewarded as other forms of institutional recognition (for example, publishing or being awarded a prestigious grant).

Nearly all of the researchers involved in partnerships with local communities argued for a concerted effort to make research more transparent, collaborative, and accessible. Most of the researchers that I interviewed contended that that begins with diversifying the research workforce. For example, Cameron said,

> I think [a partnered approach] still needs a lot of work. And it involves many things. For one thing, it involves a lot of participation of not just the [community] partner [but] the investigator to participate in the community. I think that their presence in the community is vital, but it also involves more diversity in investigators as well. We need to have people who know the community, who have lived in the community, who speak their language. And I think that that is a vital part of that process.

Julie and others argued that in addition to a more diverse research team, research results need to be transparent and accessible. She argued for a more institutional approach, suggesting that grant applications require budgets to have a line item describing what researchers plan to do with their results.

> I think every grant should have a [dissemination] requirement … What do you want to do? How do you plan on letting people know, not that just the ones that participate, but also the public? And how can you share it, because putting it in a scientific journal doesn't mean much … most people are not going to look through PubMed to try to find it.

For the researchers who saw community partnerships as a form of activism, community representatives are still not involved enough in the research process.

> I think we need to have more community leaders be a part of it. They're stakeholders in this research as well thing. They know the community and there has to be a lot of a lot more partnerships between academic researchers and community leaders … and a lot more communication. I [used a partnered approach on] a smaller scale in one study but I

> think it needs to happen on a more global scale. There needs to be a lot more communication between politicians as well, [where the] political system needs to be active in this … we tend at this point in time to work in silos. We go through a study, we collect the data, publish the results, and it stays there. There's no translation to the community, there's no policy activism involved. Nothing changes. So, it just ends up in a journal. And only academics can read and pay for the journal … the research might have cost, let's say, $500,000. It's wasted money because it ended up in a book and that's where it stayed. It needs to get translated. And that can only happen through communication – that can only happen if stakeholders are talking to each other about the research.
>
> - Cameron

Health researchers like Cameron, who advocated for sustained and egalitarian partnerships with local communities, prioritized research that generated "knowledge for action" by involving community organizations or local people as participants and partners in research. For Cameron, it was imperative that research be accessible to people outside of academia and be used to implement policy changes.

Lastly, researchers suggested that the challenges of using partnered research approaches may be exacerbated on a larger scale or the approach might not feasible. For example, Julian said,

> It's pretty personnel intensive, time and resource intensive. So, I'm not sure [about conducting individual partnered research approaches like CBPR on a national level] … In a way you have to start from scratch because you're working with that individual community to get their input and feedback on everything. But at the same time, if something's been done in a similar community in another part, then maybe that's a starting point that the investigator brings this type of thing to [that community] … I don't know.

Additionally, Alexa was skeptical if individual participants could be "partners" in large national studies.

> … Unless you're doing truly a CBPR project, which I don't know how much CBPR and RCTs [randomized clinical trials] overlap ... you can't truly have active partners … Unless you have a community board that's advising the RCT and you're sharing the results. And at the end of the day, there's going to be some population for some group that is not a partner because they are the participant in the study not [the] people who are being part of the data collection. I do think that there's opportunities for partnership in terms of, you received intervention, we collected data from you, we've analyzed it, and

> now we come back to you and [ask] does this make sense, or collecting [and] deidentify[ing the data] and then work[ing] together to analyze the data … I think that's feasible in RCTs, I'm sure it's been done. But it's obviously more time consuming.

CBPR was typically viewed as an unrealistic partnership technique for large-scale biomedical initiatives. Researchers conceptualized and operationalized individual notions of partnership very specifically compared to partnerships with community organizations that seemed to have more flexibility with regards to what counted as mutual exchange and what it means for community representatives to have a role in decision making. Often, researchers were skeptical that individuals could be intimately involved in large-scale research. Still others, contested that individuals be involved in this manner at all. For example, Aaron said,

> There's a movement to involve patients in the design of research. I admit to being a little less embracing of that because I think it's hard to design research. And you need a lot of years of training to be good at designing a research study. I think involving advocates, involving patients, understanding the barriers - that to me is very solid. Work groups that are designing a trial should include patients and family members, etc. so that their perspective is understood in the design process. But there's a slight difference between [that and] patient designed research.

Aaron was the only researcher who raised this perspective, but his skepticism and resistance to involving participants in the design of research, is more reflective of perspectives held by the larger scientific community. CBPR studies are difficult to enact and relatively infrequent compared to the majority of biomedical research initiatives that use conventional research methodologies or more moderate approaches to partnerships with community organizations. Some researchers may view partnerships with community organizations, or community leaders (such as developing an advisory board) as consultative, for instance, as Aaron said to understand the barriers to research participation, rather than as collaborative. Although reciprocity and equal power sharing were stressed as essential facets of partnerships with community organizations, there are significant challenges to enacting these ideals and likely these approaches range significantly in practice.

Discussion & Conclusion

In this chapter, I have used in-depth interviews with medical and health research professionals to examine the various ways that researchers enact and understand different forms of partnerships with local communities. Developing community partnerships is advocated as a promising approach for involving minority subjects in research. One of the greatest challenges for health equity and biomedicine is that the people who most urgently need or could benefit from medical advancements are the least likely to participate in biomedical research. Clinical trials to evaluate new drugs, medical devices, or biologics (such as a vaccine or blood product), have historically unrepresented minority groups. According to the FDA, in 2019 nearly 3 out of every 4 research subjects to test novel drugs were white individuals (Hopkins 2020).

Diversifying clinical trials is a scientific necessity, for instance, a vaccine for COVID-19 must be proven to work safely across all populations, but it is also a moral imperative. According to the Centers for Disease Control and Prevention, Latinx, Native American, and black residents in the United States are hospitalized for the novel coronavirus at rates that are nearly 5 times that of white residents (CDC 2020b). Although black residents comprise only 13% of the American population, they suffer nearly one-quarter of all COVID-19 deaths (Hopkins 2020; CDC 2020b). As researchers and drug companies race to develop a vaccine for COVID-19, experts argue that deep-rooted historical mistrust of health and medical authorities is the biggest problem contributing to the challenge of enrolling the racial and ethnic groups who are at the highest risk of contracting the virus (Hopkins 2020).

Experts say that of the thousands of participants volunteering in clinical trials to test vaccines for COVID-19, the volunteers are so far mostly young, white, and healthy Americans (Hopkins 2020). In a recent interview, Francis Collins, the director of the National Institutes of

Health, warned, “If this is a vaccine trial that enrolls a bunch of 20-somethings or white college graduates, it will not give us the information we need” (Johnson 2020b). As our nation also grapples with systemic racism, stoked by the killings of African Americans by police officers, most recently the murders of George Floyd and Breonna Taylor (Chughtai 2020), researchers are partnering with local community leaders, churches, and advocacy organizations, as a solution to address the problems of mistrust and representation in research. Partnering with organizations that work in communities with high minority populations, for instance, the collaboration between the National Black Church Initiative (which includes roughly 150,000 U.S. churches) and the drug maker Moderna Inc. (Hopkins 2020), are an effort to educate people on vaccines, encourage clinical trial enrollment, and importantly, to develop trust.

Partnerships with community organizations to enroll underrepresented groups into clinical trials, under normal circumstances would have developed over months and years. Now, these partnerships are being put together over the span of weeks (Johnson 2020b; 2020a). Partnered research approaches evolved out of efforts to make research and the benefits of research more equitable. Collaborations between researchers and local communities have potential to lifesaving partnerships. However, the normal constraints and challenges of establishing partnerships are exasperated during this unprecedented time, and it is equally possible that partnerships could drastically fall short of equitable ideals (as many do even during the best of circumstances). As data continues to surface, showing the exponential loss that communities of color are suffering, we need clinical trials that are representative of the American population. Partnerships that draw on community organizations and leaders that people trust, and that will communicate openly and acknowledge the layers of systemic inequalities that the pandemic has compounded, are likely to be incredibly important for enrolling diverse people into

COVID-19 trials. However, developing community partnerships is not a smooth and straightforward process. Although more engaged models of partnerships with community organizations seem to have the most promise for enrolling people from minority communities into COVID-19 clinical trials, my research highlights how these approaches come with real challenges.

As I discussed in this chapter, my interviews with health researchers revealed three approaches to partnering with local communities: 1) Symbolic partnership; 2) Sustained, reciprocal, and egalitarian partnerships with community organizations; and, 3) partnerships with local individuals and study participants. Researchers talked about types of partnerships in distinct ways and at times were skeptical of the potential utility or advantage of alternative applications of partnership. Symbolic partnership talk was the most contested approach. Advocates of symbolic forms of partnership argued that the semantics of calling research participants "partners" was meaningful for dispelling and moving past historical abuse and exploitation in research. The aspirational use of terms like "participant partner," were part of a concerted effort by investigators to develop trust and to unite people from diverse backgrounds that may be weary of researchers or medical authorities. However, using partnership symbolically was a point of contention among the researchers that I interviewed who highlighted multiple problems that stem from rhetorical partnership. First, is the problem of deception and mistrust. Recounting Charles Perrault's tale of "Little Red Riding Hood," symbolic partnerships are cloaked conventional top-down research agendas that use the term "partner" to feign equality where it does not exist. Using partnership symbolically risks exacerbating mistrust and skepticism by communities that have been (and in certain instances) continue to be mistreated by the scientific community. This leads to the problem of a tainted legacy and the continued difficulty for

researchers to enroll these groups into studies. Additionally, symbolic partnerships threaten the new relationships developed by researchers who conduct partnered research as an intentional form of activism to re-direct power and address issues of representation.

While some researchers were skeptical of the symbolic utility of rhetorical uses of "participant partnerships," others were unconvinced that more engaged partnership models could be applied successfully to large-scale studies, or that "participants as partners" should be involved in the design and application of the study at all. This critique was typically made towards the CBPR model of partnership, a time and labor-intensive partnership model that shares power with individuals and study participants. Interestingly, partnerships with individuals were conceptualized and operationalized by researchers in much more specific ways than partnerships with community organizations. For an individual to be a "true" partner in research, researchers needed to provide opportunities for lay people to be involved in the development of the research inquiry, data collection, analysis, and the dissemination of the study results to the broader community. For most of the people that I spoke with, individual forms of partnership that were conceptualized and operationalized this way, did not seem feasible. Partnerships with community organizations could involve community leaders in some or all of these processes but there was a broader spectrum of what counted as community involvement and what obligations researchers had to the community partner.

Ideal partnerships with local community organizations and individuals were characterized as enduring, collaborative, and reciprocal relationships. These forms of partnerships extend beyond mere symbolism, with researchers recognizing the value in local knowledge and a more flexible, collaborative, and reflexive research structure. Partnerships with individuals/study participants were discussed as much more challenging to enact in practice than partnerships with

community organizations. Yet, developing sustained, collaborative and mutually reciprocal relationships is extremely difficult, whether partnering with an individual or an organization. The different ways that researchers conceptualized and operationalized individual and organization forms of partnership, with greater flexibility on what obligations researchers had to partner community organizations, suggests that some partnerships may actually be closer to conventional research than the ideals espoused in partnerships.

My interviews with health research professionals revealed that the conceptual blurring of partnership terms (for example, what people purport by "partnering" with community organizations or enrolling "participant partners" in a research study) means that while there is a wide range of different applications in how people enact partnerships, there is also a lot of room for confusion and varied results for the success of reaching and encouraging the most vulnerable populations to enroll in research. Research initiatives that only use partnership symbolically, likely will continue to face an uphill climb to convince individuals from marginalized communities to enroll in biomedical studies. A significant advantage of community partnerships that are meaningfully developed and negotiated, is that they are more likely to address the structural barriers that stand between reaching the people who could benefit from research and better health services the most.

Conducting partnered research is incredibly challenging, and even when well-intended, meticulously planned, and generously funded, it can still miss the mark. For instance, often researchers in my interviews talked about working with "the community" as a homogenous and bound entity with defined problems and aims. However, this framing oversimplifies the great diversity and differences that are interwoven into heterogenous groupings of people that often get lumped into pan-racial and ethnic categories. Researchers did not talk about what happens

when partnerships with organizations (or community residents) fade. Commitment and interest, on both academic and community sides, is likely to wax and wane overtime, and is additionally complicated by the overturn and replacement of local leaders in a community. These are significant challenges in addition to the trials of securing adequate time and funding to develop partnerships.

Lastly, participatory approaches that treat individual participants as "partners" in research, either symbolically or actively through more engaged models, believe that ordinary people should be more involved in research decisions and implicitly assume that individuals *want to* and will *be happy* to be part of leading the charge. How much input and collaboration organizations or individual partners actually have could vary drastically. The democratic ideals that are represented in CBPR forms of partnership, where community participants are intimately involved as partners in a research study, may actually hold more significance and meaning to researchers (academic outsiders) than it does to ordinary people. My research suggests that inclusivity and diverse participation in biomedical research is more complicated than changing the social contract to prioritize collaborative participatory approaches with individuals. In the next chapter, I will discuss how "participant partnership" is complicated by people's lived experiences navigating health services in the United States, where for many low-income and recent immigrants, the differences between biomedical research and healthcare from a provider are blurred. For researchers wanting to form collaborative and egalitarian relationships with especially vulnerable communities that are underrepresented in biomedical research, they may find that people are not looking to be empowered by being a research partner, but rather they are looking for better access to immediate health services.

CHAPTER THREE

Making Sense of Biomedical Research Participation: How Ordinary People Understand Partnerships in Research

Having ordinary people participate in research as subjects or patients has always been an essential condition of biomedical research. However, up until the mid-90s, the majority of sponsored medical studies by the National Institutes of Health (NIH) centered on the health research priorities of white men. Critics argued that the findings from these studies were extrapolated across all social groups, reducing human diversity to a normative standard (Epstein 2007; Healy 2003). After the passage of the Health Revitalization Act in 1993, which mandated the inclusion of women and minority groups in clinical trials (*National Institutes of Health Revitalization Act* 1993) attention shifted towards addressing and eliminating health disparities, reversing the underrepresentation of groups previously excluded from research, and advancing precision (personalized) medicine. The institutionalization of these inclusionary requirements added a focus on diversity but also created different hurdles for recruitment to biomedical studies, which remains one of the most challenging phases in biomedical research (Rimer et al. 1996).

Since the passage of the Health Revitalization Act, considerable attention has been devoted to identifying and overcoming barriers to research participation that particularly impact the involvement of minority groups. There have been many sophisticated efforts to include underrepresented groups in biomedical research. The burgeoning field of recruitmentology, an area of applied social and human science, examines what stops people from choosing to participate in research and for those who do participant, what keeps them enrolled (Epstein 2008). Recruitment specialists publish a plethora of recruitmentology material and hold conferences to share research-based best practices and strategies that are designed to help

researchers enroll and retain research participants. For example, the Department of Health and Human Services (DHHS) has published numerous "how-to" books addressing recruitment and retention strategies for the inclusion of women and minority groups in research (Dankwa-Mullan et al. 2010; National Institutes of Health 1997; 2002). Furthermore, the NIH has sponsored summits on health disparities, which have in part focused on bridging gaps within health disparity populations through more inclusive research practices (Dankwa-Mullan et al. 2010; National Institutes of Health 2012).

As the culture of medicine continues to shift to prioritize the inclusion of diverse communities in research, new questions emerge about the kinds of relationships that investigators cultivate with study subjects. As part of ensuring that diverse groups are being represented, investigators have been experimenting with different ways to communicate and engage with participants. Recruitmentology experts have increasingly called for the adoption of participatory approaches to research that they argue are more successful at recruiting, retaining, and engaging with "hard-to-reach" populations (L. Jones and Wells 2007; Chung et al. 2010; Viswanathan et al. 2004; Nueces et al. 2012). Individuals who fall into hard-to-reach populations are not a homogenous group, but rather represent many different groups and subgroups within various contexts. Although social context matters immensely, the phrase is often applied as a catch-all term and refers to but is not limited to, racial and ethnic minority groups, migrants, newly arrived residents, and people living in vulnerable social and/or economic situations (Rockliffe et al. 2018). Participatory research differs in methodological approaches and techniques, but all forms hinge on research experts and laypeople (often community members or community-based organizations) sharing in the research process and abolishing the power

imbalance between researchers and the people studied (Riffin et al. 2016; Epstein 2008; Dancy et al. 2004).

Having participants be research partners is one way that traditional and unidirectional models of researcher-subject interactions are being re-imagined and rewritten. The language and practices associated with "participant partners," are representative of more widely held assumptions and beliefs shared by the scientific biomedical community on how to improve research. At the most fundamental level, partnership suggests a reciprocal relationship and a wiliness to learn from local communities. Establishing participant advisory boards, comprised of participant ambassadors for research in their communities, have increasingly become a common best practice among researchers. For example, Georgetown and Howard Universities' Center for Clinical and Translation Science established a Participant Advisory Board in 2017 to "to represent and promote the research participant's perspective in the planning, implementation, evaluation, and dissemination of the clinical research activities" (Georgetown University 2017). Collaborating and engaging with participants as research partners, through participant advisory committees, individual and community partnerships, or other novel approaches is thought to be a paramount way to encourage research volunteerism, foster trust, strengthen community ties, and to promote the adoption of research findings (Simonds et al. 2013; Epstein 2008; Corbie-Smith, Moody-Ayers, and Thrasher 2004). Scientists and recruitment experts hope that by conceptualizing participation through research partnerships between study participants and researchers, ordinary people will have a more significant stake in research, and underrepresented communities will feel welcomed and encouraged to participate.

Academic recruitment and engagement materials designed to provide tools and strategies for researchers are starting to incorporate more material on including participants as partners in

research, and more broadly to discuss variations of participatory styles of research (Viswanathan et al. 2004). For example, Stanford University's Research Participation Program, a center that provides engagement resources to Stanford investigators, offers "participant-focused" material and encourages investigators to "engage [with] participants as our partners in research" (Stanford Medicine Research Office Bulletin 2020). The peer reviewed *Journal of Participatory Medicine* is an academic journal entirely committed to providing an evidence base for participatory health, medicine, and research practices. Partnership is part of a larger cultural shift in medicine regarding the ways that researchers and practitioners interact with study volunteers and patients.

The language of "participant partners" has been used across a variety of biomedical research initiatives, including a recent genetic study with families of children with unexplained medical conditions (Katsanis et al. 2018). Additionally, academic partnerships with community representatives and organizations are growing, with these approaches particularly common in cancer research with patient advocates (Jernigan et al. 2019). The Community Partners in Care depression study, a 5-year community-based and led research project funded by the National Institute of Mental Health and the Robert Wood Johnson Foundation, is a prominent example of a participatory research initiative with community and academic partners working together to reduce instances of depression among vulnerable communities (Irwin 2014; Chung et al. 2010). The study is part of a larger decade plus effort by community leaders and researchers from UCLA and RAND to conduct 3 different community-engaged research projects to improve care for depression in low-income areas (Irwin 2014). The principle investigator of Community Partners in Care, Loretta Jones, who was also the chief executive of a non-profit health advocacy organization in Los Angeles County, said, "[Community Partners in Care] was successful because it was not done 'on,' 'to,' or 'for,' but 'with' the community."

The NIH-funded *All of Us* Research Program, is a leading example of a biomedical research initiative that is on the cutting edge of participatory recruitment and engagement efforts. The initiative treats research participants as active "partners" in the study. To examine if research partnerships between researchers and participants are better at encouraging underrepresented communities to participate in research, I analyzed official organizing materials and public documents from the All of Us Research Program. I compared this material with interviews that I conducted with mostly Mexican heritage Latinx residents of Greater Los Angeles on their perceptions of biomedical research and partnership. I chose the All of Us Research Program because as a national initiative it the largest research study that considers participants as partners in research and is arguably the most well-known and sophisticated initiative using a partnership approach. The All of Us Research Program has incorporated the most promising recruitment, retention, and participant engagement practices recommended by leading scientific experts. By analyzing the participant partnered practices of the All of Us study, I am able to better understand prevailing beliefs about why people participate in research that are more widely held by the biomedical research establishment.

My analysis of how people understand research relationships borrows from sociologists and social behavior scholars who note that schemas, our models for doing things, are cultural roadmaps that guide behavior. Relationship schemas are shared sets of expectations for different kinds of relationships (Alan P. Fiske, Haslam, and Fiske 1991; Alan Page Fiske 1991). Polletta (2020) argues that since relationship schemas are separate from actual relationships, they can be transposed from one setting to another (Sewell 1992). People can interact on the basis of relationships they imagine rather than actually have.

In this chapter, I expand on this scholarship to ask what happens when researchers and ordinary people understand and frame biomedical research through different relationship schemas. I suggest that people may choose to decline or participate in biomedical studies for reasons that study organizers often do not expect. Specifically, the relationship schemas that biomedical researchers and ordinary people draw on to understand, evaluate, and justify research participation are fundamentally different. Consequently, notions of partnership often don't make sense to ordinary people. I argue that the underrepresentation of minority groups in biomedical research may reflect the failure by research teams to recognize the relationships that people see themselves as having with researchers.

Literature Review

The prevailing belief within the biomedical research establishment is that recruiting ethnic minorities into clinical research is more difficult and more costly than recruiting non-Hispanic white individuals (Alvarez et al. 2006; Shavers, Lynch, and Burmeister 2000). However, research suggests that when study materials are translated or presented through culturally relevant content, individuals from ethnic and racial minority groups are just as willing to participate in research studies as their white counterparts when given the opportunity (Wendler et al. 2005). As discussed in chapter two, strategies to overcome structural and cultural barriers include providing free transportation to the study location, working with community leaders and bilingual or bicultural staff members, and developing community-academic partnerships (Alvarez et al. 2006; Haley et al. 2017; L. Jones and Wells 2007).

Community-academic partnerships take on many different forms. Some partnerships are structured with the community helping researchers gain access to potential research participants. In this example, community organizations that have experience and expertise working with

"hard-to-reach" populations spearhead recruiting and retaining participants for a study (Alvarez et al. 2006). In other kinds of partnership models, community leaders initiate research projects with the support of academics. Community leaders are involved in the research planning and process, and ideally the outcomes of the research directly impact policy action and changes that are beneficial to the partnered community. These two examples of community-academic partnerships are most typically forged with community organizations and with community leaders. Still, other models extend partnership to individuals, where participants in a study are also "partners in research." Partnered research models are thought to be more effective at ameliorating potential fear and mistrust, power differentials, mitigating cultural barriers, and at communicating the benefits of research participation (Alvarez et al. 2006; Benoit et al. 2005; L. Jones et al. 2009; L. Jones, Wells, and Meade 2009; L. Jones and Wells 2007).

These kinds of partnerships models are designed to be reciprocal relationships. Community members/organizations and researchers contribute different kinds of equally valuable knowledge and skills, and together learn with and from each other (L. Jones, Wells, and Meade 2009; L. Jones and Wells 2007). Partnered approaches suggest an egalitarian relationship between community and academic partners. Particularly important for recruitment and retention of research participants, partnerships also seem to suggest that people are motivated not only by individual self-interest but also by forms of reciprocity. Although not often explicitly discussed, "participant partnership" assumes a certain kind of relationship between research participants and investigators. This chapter focuses on what these assumptions are and asks if potential participants think about their partnership with researchers in the same way that researchers do. I came to realize that a central barrier to participation was in how potential participants and researchers viewed appropriate relationships between clinicians/researchers and

patients/participants. My interviewees had very different expectations for clinicians/researchers than what models of partnership suggest. To make sense of these differences and why they matter, I turned to a literature on the role of relationship schemas in social life.

Schemas, Imagined Relationships, and Decision Making

An intriguing topic of study for sociologists and scholars of culture is the boundless ways in which people use culture pragmatically and creatively. Culture, as defined in this dissertation, is the dynamic process and the results of creating shared meaning through social interaction. Culture shapes our sense of social reality, including the norms and value systems we live by, our behaviors and dispositions, and the perspectives we use to evaluate and understand our daily life and the relationships within it. Schemas sometimes referred to as scripts, are cultural models and playbooks for how to do things that guide behavior. They provide culturally and historically specific rules or generalizable procedures (patterns of thoughts, behaviors, and sets of expectations) that guide social behavior and how we interact (Sewell 1992). Additionally, schemas can be combined, diffused, or discarded altogether in favor of another schema. From how to shake someone's hand to how to bargain with a car salesperson, we have schemas for all types of interactions. Imagine the stress that you might feel if every time you encountered someone or something new you had to decode the encounter without scripts to help guide you and decide on an appropriate form of interaction. Without much individual effort, schemas help us quickly sort out and understand new perceptions or experiences and determine how we should interact.

Relationship schemas are shared sets of expectations for different kinds of relationships (Alan P. Fiske, Haslam, and Fiske 1991; Alan Page Fiske 1991; Alan Page Fiske and Tetlock 1997). We build our social relationships though our use of schemas as well as our understandings

of how various schemas exist in and through their difference from other schemas (Polletta 2020). For example, we can identify how a relationship schema for a physician-patient relationship is different from the relationship schema for a pupil-teacher relationship. Schemas are "virtual," meaning that they do not exist in a pure form but rather as ideals that can be modified and generalized to be used in a broad range of situations (Sewell 1992). Significantly, no matter the construction of the social relationship, we all rely on schemas to provide stability of expectations, a feature that becomes of particular importance when we encounter new or uncertain situations.

I frame my findings and discussion of the relationships forged between biomedical researchers and research participants in this chapter by borrowing from the expansive relationship schema theory developed by the anthropologist Alan Page Fiske (Alan Page Fiske 1991). Fiske developed a typology of four relationship models (schemas and models are the same) that individuals use as frameworks to guide and organize social action, including but not limited to shaping how people understand and evaluate each other's social behavior, decision making, and moral and political reasoning. The four relationship models Fiske describes are communal sharing, authority ranking, equality matching, and market pricing. The *communal sharing* relationship schema emphasizes collective identity and unity, the pooling and sharing of resources using a principle of "what's mine is yours, what's yours is mine," is consensus-oriented, and relationships value kindness, altruism, and generosity. This schema is typical of families and communes. Quintessential of the military, *authority ranking* relationships are linearly ordered and hierarchical with high-ranking people receiving greater social importance, power, and privilege. Lower-ranking people follow the authority of higher-ranking people but obtain protection and support from their superiors. *Equality matching* relationships, as often

experienced between colleagues, are egalitarian relationships among different but coequal individuals that emphasize balance and turn-taking, in-kind reciprocity, an eye-for-an-eye retaliation, and even distribution. Lastly, *market pricing* relationships are based on cost-benefit evaluations with interactions reduced to a single metric (often money, time, or utility). These relationships typically focus on evaluating other people's actions, products, or services relative to the rate that they could be acquired or exchanged for other commodities (Alan Page Fiske 1991, 15).

If we agree that people think about their social lives in terms of these four schemas, in practice relationships, institutions, and societies are typically built from a combination of the four types (Alan Page Fiske 1991, 155; Alan Page Fiske and Tetlock 1997). While any one schema may predominate in a relationship, people often structure each interaction or particular aspects of an interaction by referencing another model. For example, sociology faculty at a university department may have a sense of collective identity as faculty members at the university, and they may also make some kinds of decisions through consensus. At the same time, the department is organized through ranking hierarchy (from the Department Chair and tenure track rankings among faculty themselves, to graduate students and undergraduates, the department staff and maintenance workers). These forms of hierarchy are manifested through salaries and benefits, levels of prestige and work autonomy, job security, as well as in physical spaces, for example, the size and location of offices. At the same time, other parts of the department might be organized through egalitarian distributive justice, for instance, giving everyone the same allocation of discretionary printing. Faculty may take turns teaching unfavorable classes, reading each other's papers, or taking on burdensome administrative duties. Lastly, market pricing is part of departmental life through salary offerings to faculty, wages for

staff and graduate students, and purchasing departmental equipment (Alan Page Fiske 1991, 158). People understand and make sense of their social worlds through the seemingly innumerable combinations and composites of these four types. It is important to note that relationship schemas are defined by the relationship structure and process from the participant's point of view, not by an objective outcome that is externally defined (Alan Page Fiske 1991, 16).

So far, my discussion has centered around relatively straightforward relationships, but what happens when people invent and take action based on relationships not grounded in reality? Integrating Fiske's theory of relationship schemas with the work of history, sociology, and organizational scholars on how people combine and transpose schemas, Francesca Polletta (2020) argues that people imagine relationships that they do not have and use these imagined relationships in decision making. The use of imagined relationships leads people to make decisions that cannot be predicted or explained by self-interest, the demands of moral principle, or the structure of the relationships that they have. Additionally, Polletta shows that although people use schemas both creatively and practically, cultural scripts are constraining (with expectations about their use and potential risks and consequences from their usage), showing that cultural constraints not only stem from the top-down but also operate from the bottom-up.

In addition to people's use of imagined relationships, sometimes people apply the wrong relationship schema. Alan Page Fiske and Philip Tetlock call this a "taboo" relationship model (Alan Page Fiske and Tetlock 1997). This frequently happens in interactions between different cultures. If you have ever traveled abroad or encountered someone who is visiting from overseas, you are likely familiar with a time when you or your guest applied a different relationship model to a familiar situation or applied a familiar model differently (Fiske and Tetlock 1997). For example, on a hike in Sweden, I learned about "allemansrätt" (al:emansraet) or the right of

public access. An important part of Swedish culture since the days of Vikings, allemansrätt is an unwritten law that preserves the right of freedom of movement and the collective sharing of land and nature. People are free to hike through the woods and open landscape, to forage the land, and to camp anywhere for one night, even if your desired camping spot is your neighbor's yard. While Swedes may take for granted the collective sharing of land, imagine if while traversing the Pacific Crest Trail, a visiting hiker from Sweden decided that the best place to camp for the night was your front yard? You can imagine that you might react with surprise seeing someone hunkered down on your property and maybe even become worried, deciding that the best plan of action is to call the police (authority ranking). Or, perhaps you are an especially enterprising individual and choose to tell the hiker they can stay on your land, but only if they pay you $30 for the night (market pricing). With either response, the visiting hiker would likely be just as confused and upset as you would be!

Relationship schemas and the implementation of schema "rules" are deeply normative. When the wrong schema model is used people often have a strong emotional response to the breach of these norms because it throws "into doubt our fundamental assumptions about what each relationship *is* ... [and] without reliance on these assumptions, how can we sustain any meaningful interaction? (Alan Page Fiske and Tetlock 1997, 286)" Reactions to these transgressions range from anxiety and confusion to pure outrage. As a result of these breaches, people often want to punish the transgressor (to restore the social relationship) or distance themselves from the person responsible for the transgression (Alan Page Fiske and Tetlock 1997).

Biomedical research and the advancement of precision medicine is an especially interesting topic to investigate relationship schemas and the ways that schemas guide social

action and decision making. Schemas shape our expectations and our ideas about what we owe and what is owed to us vis a vis other people. There are numerous actors in research (investigators, participants, study personnel, community partners, etc.), yet people may organize, understand, and act on the same event in similar or very different ways. When people within an interaction operate different relationship schemas to understand a relationship, people may have conflicting expectations. I began this study by exploring how Latinx adults in Southern California conceptualize biomedical research and what factors are important to them when deciding to decline or participate in a study. If they did agree to participate, how did they make sense of their participation experience? Intrigued by partnered relationships, I wondered how did participants perceive and experience "partnership" in practice, and was this experience the same as how researchers had intended?

In this chapter, I will discuss the relationship schemas that the All of Us study uses to frame the research program and the ways in which All of Us imagines partnered relationships with study participants, including their hunches about why people may or may not participate in the program. By comparing these ideas of partnership with how Latinx community members framed and understood biomedical research, I aim to show that the underrepresentation of Latinx individuals in biomedical research is not the result of rational actors being uninformed or unincentivized. Instead, ordinary people are using different relationship frameworks to understand research that do not often line up with notions of partnership. Researchers and ordinary people use different cultural scripts that lead people to understand and experience the medical establishment differently, and to make decisions about biomedical research participation in distinct ways.

Biomedical Research Initiatives: Research Framed Through Solidarity and Partnership

"We are one nation, one people. When called upon to give from within, we come together and find that our capacity to help others is limitless. Here, we are fearless. What lies inside all of us is more than data. It's life. It's more than insight and medical research; it's vision and honor and compassion. What's flowing through America's veins is its' diversity. The next great breakthrough will be found in each and every one us. And what we find there will unlock mysteries, heal the sick and eradicate disease. We ask for one million individuals to come forward and stand on this landmark in history. We ask America to do, once again, what she has always done: lead the way forward. We're one nation. One people. But all of us are different, and it's those very differences that will lead to answers for generations to come."

- The All of Us Anthem

A quick YouTube search for the All of Us Research Program, and you'll likely find yourself on the program's homepage watching the 16-second promotional video that automatically begins to play. This shortened version of the "All of Us Anthem" may only be seconds long, but it is a powerful example of the kinds of relationships that biomedical researchers imagine building with ordinary people. Opening with an aerial view of an American city, the video evokes notions of unity and patriotism as split-second images of faces representing diverse ages, races, and ethnicities in America flash across the screen. The montage appeals to our shared humanity, our individual differences but collective identity, and promises that "it's those very differences that will lead to answers for generations to come." The initiative encourages research relationships with future participants by evoking a sense of civic duty through "honor and compassion" to "lead the way forward" as "one nation, one people" and to be part of a movement transforming medicine, health, and human existence (All of Us Research Program 2017b).

In Fiske's terms (Alan Page Fiske 1991), biomedical research initiatives like what is presented above use a communal sharing schema to imagine partnered relationships were all people – scientists and researchers, medical practitioners and ordinary individuals alike – are collaborating, sharing resources and working in harmony to create a healthier and more equitable

America. Like other biomedical initiatives, the All of Us study privileges altruism, volunteerism, and caring for future generations, suggesting that "by taking part, [participant partners] have a chance to support new discoveries that may help their families and communities" (National Institutes of Health 2020). The program is touted as being "a catalyst for positive change in research," whereby "working together, All of Us researchers, partners, and participants aim to build a better future for health care" (National Institutes of Health 2019a).

The keystone for all biomedical research is the advancement of health. For centuries we've retold legends about humankind's quest for health and longevity. From the mythologies of the ancient Greeks about ambrosia, the nectar of the Gods that was believed to heal scars, cure diseases, and even grant immortality, to the philosopher's stone which dates back to the Middle Ages, the idea of an "elixir of life" has been a constant throughout human history (Fantozzi 2017). Precision medicine, espoused by the All of Us Research Program, promises to be a modern-day key to unlock cures to illnesses and prolong life, holding the same kind of promise and hope for health and longevity as the fables of the past that have long captivated our attention. Biomedical research initiatives often operate assuming that health is a universal desire, with everyone sharing in the collective goal to improve health and work together to build a better future. As Francis Collins, the Director of the NIH explains and asks, "It's about health, it's about disease, it's about behavior, it's about environment. Why not? Why not participate? Why not be part of it?"

As Fiske would point out, communal sharing relationships are built on strong notions of collectivity with members thinking of their relationships as "natural." Decisions are shared and result in consensus, where people generally defer to the wisdom of the whole group even if they hold divergent views (Alan Page Fiske 1991, 74). Supposing that improving health is a universal

desire, biomedical researchers use notions of kinship and national belonging to imagine participant and researcher partnerships that are equally united in this struggle, even if the reality is that certain groups have been and continue to be sidelined and benefit unevenly from biomedical research. In a participant testimonial video from the All of Us program (All of Us Research Program 2019), Shantell Little addresses this tension:

> Personally, I wanted to become a participant in this program and be involved because as a black person living in America, I know that we've been left out of biomedical research largely in the past and this program is also looking to change that … I would say to anyone who has reservations about joining, that you could possibly be a part of medical breakthroughs in the future. Why would you not want to be a part of that?

Envisioning a more egalitarian future, biomedical researchers imagine the relationships with ordinary people and participants that they *want* to have. Researchers want participants to not only engender relationships with the scientific community but to also become part of a broader solidarity movement working to change the future of healthcare.

Relationship schemas, such as the communal sharing schema, are not mutually exclusive models for interpreting events. Instead, as cultural scripts, they can be combined, transposed in various settings, and even compartmentalized as different frames for the same event. All of Us is an excellent illustration of a composite of relationship schemas in action. While All of Us uses a communal sharing schema as a scaffolding for their study aims and to mold participant relationships based on shared notions of health, relationships between researchers and participants are modeled through equality matching scripts. Equality matching relationships are comprised of entities that are socially equated. The relationship stays in balance because people take turns, perform favors, and respond in-kind to restore imbalances.

Until recently, most research has not been structured using equality matching relationships with research subjects (with the exception of some feminist participatory action

scholarship and some grounded theory ethnographies). More commonly, researcher-participant relationships are modeled through authority ranking schemas where subjects obey directives given to them by researchers and researchers perform and evaluate the science. Studies that are using partnered research approaches envision a different kind of relationship between researchers and participants. "Whereas the majority of clinical research has been transactional in nature, with unidirectional data sharing from the individual to the study, the [All of Us Research Program] seeks true partnership between participants and researchers (Precision Medicine Initiative Working Group 2015, 39)." Biomedical research initiatives that are committed to involving minority populations believe that it is vital to change the way research is typically conducted to engender participant trust and encourage participation among groups that are often not heard from in research. "Coincident with advancing the science of medicine is a changing culture of medical practice and medical research that engages individuals as active partners – not just as patients or research subjects (Precision Medicine Initiative Working Group 2015)."

Relationships based on partnerships have increasingly gained traction within biomedical research as a way to encourage participation, foster trust, and to keep future participants engaged within the initiative. A public opinion survey completed by the Foundation for the National Institutes of Health reported that "71% of [surveyed] respondents agreed that participants and researchers should be equal partners (Precision Medicine Initiative Working Group 2015, 39)." However, what does it mean to be a "partner" in research from the perspective of biomedical researchers using these recruitment and engagement strategies? On the most foundational level, all participants in the All of Us Research Program are partners where they "have access to their information and a say in how the program is run." Although All of Us calls all participants "partners," there are different echelons of partnership, with the program incorporating various

approaches that have been proven effective. The research program was "developed using a highly interactive and proactive participation model, where participants … provid[ed] feedback and input during [the] planning and implementation phases of the cohort (Precision Medicine Initiative Working Group 2015, 2)." Some participant partners continue to be highly engaged in the study serving as participant ambassadors, on governance and oversight committees, and as part of advisory panels. However, for the vast majority of participant partners, the extent of participation is contributing health information to the study. By taking part in the program, partners answer surveys on different topics, are asked to share their electronic health records, and give samples of blood, urine, and saliva for lab and DNA tests (National Institutes of Health 2020). In this section, I will concentrate on the more typical relationships forged between researchers and greater numbers of participant partners whose participation is singularly based on the health information they provide to the study team.

All of Us imagines equality matching relationships with participant partners as distinct relationships but among coequals. The relationship stays balanced through an equal exchange. Significantly, what counts as the "same thing" is mediated and defined by the actors in the relationship (Alan Page Fiske 1991, 52). In these kinds of partnerships, it does not matter that participants may not have the same credentials as researchers; the relationship is balanced because participant partners contribute their health data (valuable in its own right but the value is compounded when combined with a million other individual health data contributions). Researchers promise compensation in equal measure through future discoveries and medical breakthroughs that may impact individuals, communities, and the medical establishment. In organizing documents for All of Us, researchers note that "…the paradigm is shifting: clinician, researcher, patient, and caregiver communities are increasingly engaged in active discussions

about ways to build *shared responsibility* (my emphasis) for health knowledge, empowering individuals, families, and communities to make the best decisions about their health and well-being (Precision Medicine Initiative Working Group 2015, 40).*"* Biomedical researchers want ordinary people to take equal responsibility for advancing health (for participants this means by sharing health data) and for their health knowledge. A key conjecture of biomedical researchers is that partnered research relationships and sharing health information back with participant partners will lead to the empowerment of individuals and their communities.

Research engagement and research partnerships are deeply intertwined with researchers' belief that people are more likely to participate and become engaged in something if it impacts them personally. Here is how All of Us answers why people should join the program (underlined emphasis is my own):

> By joining the program, you can: (a) Help represent your community in important studies that may lead to new research findings, treatments, and cures. (b) Learn about your own health, including risk factors that are specific to your family history or community. (c) Learn about additional research opportunities, such as clinical trials that may be relevant to you. (d) Leave a legacy for your children, your grandchildren, and future generations by supporting potential breakthroughs in areas such as cancer, diabetes, heart disease, dementia, depression, and chronic pain.

The diffusely defined idea of partnership encourages individuals to think about partnering in personal terms, directing people to see their involvement through potential benefits for themselves, their family, and their broader community. Shenela Lakhani, the Director of Genetic Counseling and Clinical Engagement at the Center for Neurogenetics at Weill Cornell Medicine highlights the importance of personal connection within the greater aims of the study saying, "It's amazing seeing the number of people from everywhere across the country coming together with ideas representing their communities, representing the people in their neighborhoods, and having a voice, and then reflecting that into the program." Partner relationships are designed to

encourage participants to feel that they are an essential part of a larger national community, helping to shape the program with each person's contribution to the study being equally valuable and potentially impactful on community and national levels.

Although biomedical initiatives like the All of Us Research Program strive to create a welcoming environment with relationships built on equality, these notions are not always mirrored in the lived realities of the ordinary people they hope to recruit. Biomedical researchers believe that discussions about diversity in research partnerships encourage underrepresented groups to feel included in a movement to create an equitable health care system. Emphasizing that participants "reflect the rich diversity in the United States" and that "having a diverse group of participants can lead to important breakthroughs," All of Us actively encourages diverse participation, recognizing failures to do so in the past and historical abuses of power and the exploitation of research participants.

> Some communities have not been invited to take part in research, or they were invited but were not told what was involved. For these reasons, we know very little about them. The All of Us Research Program has learned from this history. We want to be sure we do things right so that many different groups of people can join. We will tell you what we are doing. We will share results. And we will protect your data.

The All of Us Research Program is intentional about including communities of color into the study and addressing residual skepticism and mistrust of the U.S. medical and public health care systems that some individuals may hold. In a promotional video for the study, Patricia R. Butts, an African American community leader in Harlem, New York reminds viewers that, "It is important for minorities to be a part of this, or we will again be left with medications that are created for, really, other populations (All of Us Research Program 2017a)." Biomedical researchers believe that a primary reason why underrepresented minority groups participate less in research when presented with research opportunities is that clinical research in the past was

unidirectional, participants did not feel respected, and abuses from exploitive studies remain in the collective minds of the communities that were mistreated. However, researchers tend to pay less attention to how relationships developed through experiences attaining medical care influence perceptions about biomedical research. This is likely because although researchers tend to acknowledge that research and care are linked, they are viewed as distinct experiences. Advancements in research may lead to better care, but for medical and research professionals, healthcare and research are not one and the same. Research initiatives like All of Us hope to encourage participation by reframing the culture of medicine away from unidirectional authority ranking models towards relationships where participants are valued as equal "partners from the ground up" and are encouraged that their engagement in the study will contribute towards greater understandings about the nuances within the local communities that they are a part of.

Participant-researcher relationships built through mutual partnerships aim to foster transparency, inclusivity, and change how people view research enterprises. Connected to increasing diverse participation, biomedical researchers believe that transparency in what the study team is collecting, why they are collecting it, and how the information will be used, accessed, and stored will foster trust, especially among individuals who have previously had negative research experiences. As outlined in the data security and policy principles, All of Us "Strive[s] to build a system that participants trust. This means having a 'participant first' orientation … participants are the foundational stakeholders of all research activities (National Institutes of Health 2018b)." Part of developing trust for the All of Us Research Program is giving participants access to information. Participants have full access to data they share, which the initiative believes individuals may not otherwise have had access to, and that participant partners can "use their own health information to monitor and improve their quality of life

(National Institutes of Health n.d.; 2019b)." Particularly for diverse and underserved populations, All of Us assumes that increasing health literacy (through access to completed surveys and baseline health information that participants provide to researchers) will be empowering for the participant and lead to continued participation.

Through the equality matching relationships that All of Us imagines with partners, individuals provide health data to researchers and researchers offer educational resources to assist people in understanding their health information. In the All of Us study's own words dissemination of health information will, "empower [people] to make informed choices about their health and wellness (National Institutes of Health 2017)." In addition to individuals having access to the data they provide and the ability to modify what may be used in the All of Us study, participant partners are also informed about the study progression and of research findings. Participant partners are given aggregate participant data and information about other ongoing investigations. The study believes that these efforts to foster "active participant engagement" will:

> … raise potential participants' awareness of the benefits of generating, aggregating, and sharing data [since] many [individuals] may not realize … the critical role they can play by sharing that information for research. The [study team] can help communicate the importance of large, high quality datasets in understanding disease, and can potentially inspire individuals to want to become involved.

This quote (Precision Medicine Initiative Working Group 2015, 46) highlights the assumption that if ordinary people knew the potential benefits of the study and how these benefits could positively impact their lives and others, individuals as rational actors would be encouraged to participate. Although researchers imagine equality-matching relationships, the structured researcher-participant relationships that they have are more complicated. Researchers assume that participants will see the benefits of greater knowledge as a fair trade for their participation.

To summarize, the partnered relationships that biomedical researchers imagine are designed to encourage participants to feel connected to the scientific community and valued for their time and contributions. Biomedical researchers envision partnerships with participants as part of an equalizing measure to make research feel more appealing to diverse communities and safe to participate in. Re-envisioning researcher-participant relationships through communal sharing and equality matching relationship schemas are intended to emphasize how the scientific and medical research community have learned from past mistakes and are intentional about creating a research environment where participants are respected, appreciated, and intimately connected to medical solutions that are made for and with participants.

"We would like to make ourselves invisible": How Fear of Deportation and Medical Care Mistreatment Influence Community Perspectives of Biomedical Research

Partnered biomedical research initiatives, like the All of Us Research Program, frame the advancement of health and encourage research participation through the development of relationships grounded in equality and solidarity. The premise is that when everyone contributes to improving health through advanced research, together we all benefit. Many of the Latinx community residents that I interviewed in focus groups and in-depth one-on-one interviews (n=60) did not experience this patriotic notion of American togetherness and inclusion around health. Most importantly, they did not see themselves or their friends and families as included in these notions of equality based on national identity and shared goals. In this section, I discuss what holds Latinx (primarily of Mexican ethnicity) Southern California residents back from participating in biomedical research initiatives. I came to find that a significant barrier to participation is not only distrust stemming from previous mistreatment, but in many instances, a very concrete fear of being deported. Additionally, distrust of biomedical research is directly

connected to people's experience of being mistreated in medical care. Many of my interviewees did not differentiate between research and medical care, where people's negative experiences accessing and receiving health care drastically colored their perceptions and expectations of biomedical research and researchers in general.

I begin by first discussing how the residents that I interviewed do not typically see themselves and their community represented within the communal sharing and solidarity frames that researchers use to unite ordinary people and encourage participation. Following this, I discuss how medical care experiences and mistreatment significantly influenced people's perceptions of biomedical research. I show that ordinary people often understand and frame research using different relationship schemas than research investigators, and that these different framings are a primary reason why some especially vulnerable and marginalized communities are reluctant to join research studies.

Staying in the Shadows: Views on Race & Ethnicity, Immigration and Discrimination

Particularly among 1.5 and 2^{nd+} generation immigrants, the notions of togetherness and unity espoused in biomedical initiatives that use a partnership approach served more to remind participants of the gaps and asymmetries in the imagined relationships. As Isabella, a 24-year-old Mexican American observes, "The world isn't nice to minorities. And it's like, as much as you don't want to realize it, as much as I want to think that we're treated equally, we're kind of not." The adult children of 1st generation immigrant parents acknowledged the ideals of the type of overarching communal sharing relationship that All of Us and other partnered research initiatives champion but argued that Latinx communities are largely sidelined from this relationship. Reflecting on a psychology course that she took in college, Isabella addresses how structural

racism erodes the notion of an American communal sharing relationship because many minority groups have not been included in the first place.

> That's a big thing with the Latino representation too. Like, we're always in the shadows or we're the backstage people where we don't do anything up front … the main front of society is just black and white. I feel like Asians and Latinos and different nationalities are kind of left out of the spectrum because most studies are done with white people or black people … you don't hear anything about Latinos, you don't hear anything about Asians, or Native Americans. They're always left out. So, we're always in the background.

My interviews with Latinx adults confirm what researchers already widely acknowledge: that some communities have little contact with biomedical research. When I asked interviewees about biomedical research participation, they commonly said they had never encountered a research opportunity before. For example, Sergio responded in Spanish that he had never participated in a study "because no one has ever asked. I didn't even realize that that existed to research into medical issues." Raquel said, "I don't know. It never occurred to me [to participate in research] and no one has ever asked me until now." For the majority of the participants that I talked with, it was unsurprising to them that their community was underrepresented in biomedical research because they experienced marginalization, racism, and discrimination in many other aspects of their lives. When probed on why they thought they had not been asked to join research before or why they thought that their community was not well represented in biomedical research, frequently participants would respond with indignation that they had been systematically and purposefully excluded.

> They don't offer it to Latinos, they always offer it to other people who sometimes don't even want to help. They prefer that some die and others stay here … Perhaps they just select who they want and they just offer to those who they prefer to help. They tell them would you like to participate to see if this helps you or not? And those that they don't [want], well they almost just let you die [leaving you to take your own chances by luck] ... It makes you feel lesser because [some]one thinks that [your] life doesn't matter to them and feels that they don't want to help you for the same reason that you're an immigrant. The first word for some reason that comes to mind is racism.

– Sergio

> We are a minority group, you know talking about Hispanic, like Mexicans. I think [why no one has asked me before] has to do a lot with that. … I think they prefer to work with a lot of people like … not specifically white … I don't want to be rude or anything, but I think it's more reachable to them as white people.
>
> - Savana

In addressing diversity and inclusion in research, recruitment experts encourage building relationships centered around health promotion and research participation that are fashioned and upheld through compassion, generosity, and mutual support. Yet, the conditions of communal sharing relationships are only afforded to those who are *part* of the community. For individuals like Sergio and Savana who experienced forms of exclusion and rejection, notions of health solidarity are far removed from their lived experiences. For them, relationship frames that embrace notions of solidarity and reciprocity blatantly ignore significant structural inequalities that make health services and the benefits of biomedical research uneven.

Nearly all of the community residents that I spoke with did not see themselves represented in the communal sharing and American ideal relationships that biomedical initiatives like the All of Us Research Program imagine. However, they did see themselves in communal sharing relationships within *their* community – typically referring to participants' Mexican heritage. Participants advocated for general inclusion and improvements for the Latinx/Hispanic community. For example, Mariana, who described herself as a 28-year-old Chicana, asks, "How do we want to serve our people? You know, are we really serving them well? Are we just, you know, letting things happen like that where people are gonna go out and get medical care in their community, which was like [from] their neighbor?" Although not seeing themselves within the national solidarity framing used in some biomedical initiatives, participants like Sergio, Mariana, and Isabella vehemently argued that they should be included, and their exclusion was morally

wrong. As Isabella laments, “Whenever a study comes up, what happened to certain populations? It kind of feels like they’re excluding us from everything else. Are we not human beings too? We don’t go through this stuff too?” Isabella’s comment was a common refrain that I heard among the adult children of 1st generation immigrant parents. These young adults advocated for social relationships where their ethnic community is included, represented, and respected.

Framing health through a communal sharing script is successful in encouraging solidarity among individuals who already feel that they are part of a larger supportive network and will be afforded health advantages from the relationship. For many marginalized communities, including undocumented/unauthorized persons living in the United States, research relationships framed in communal sharing scripts are unrealistic as present and future health benefits are often not structurally available to these individuals. Of the 30 Latinx adults that were interviewed for this dissertation, 43% (n=13) of the participants self-identified as undocumented or previously undocumented and 60% (n=18) mentioned during our conversations that they had undocumented friends. Additionally, 2 participants were recent asylees from Mexico who escaped a cartel targeting their family; only part of their family had been granted asylum because other family members had been forced to flee across the Mexican-U.S. border without going through official immigration channels. The participants in this study were never asked directly or indirectly about their documentation status, yet surprisingly all but 4 participants openly shared this information when they discussed their personal background and their ability to access healthcare in the United States.

When I talked to interviewees about research initiatives that were particularly invested in encouraging members of their community to participate, they sometimes responded with confusion, quickly followed by skepticism. For example, Rod said, “We’re like the forgotten

culture. Nobody cared about us. And now they're focusing on us?" Rod wanted to know why researchers were only now interested in him and the Hispanic community. Compared to the ostracism he experienced in his daily life as an immigrant, what seemed like a newfound interest of Latinx people made this participant and many other interviewees feel extremely suspicious about research initiatives asking them to participate. This sense of distrust was directly tied to documentation status and fear of being deported. As Daniela explained during a group interview, "The government is scaring the community [by asking you to give up] names, addresses, [and] phone numbers. What about blood pressure numbers and the blood and the examination or that kind of information? [People don't want to participate in research because] they think what are they gonna do with my data?" When asked directly what she thought people were concerned about, she responded with a single word: "Deportations."

Most frequently, people discussed documentation status in interviews when they talked about central reasons why they believed people within their community decline to participate in research. For example, Alberto was born in the United States, but the majority of his family was not. He highlights how documentation status fundamentally shapes how people interact with institutions.

> The thing is that now [people are] weird about going to a doctor because when they're getting help or something [doctors] could call the [participant pauses] you know what I mean, the police or something … nowadays with the present situation, people talk [border] walls and then you're afraid to go to the hospital … afraid to talk to police. They're afraid if they're here illegally. They don't trust the government. All they hear is bad negative stuff. You don't hear the people that are all "we're here, we're here to help people." All you hear is about the wall [and] deportations. So, a lot of people that have [documentation] issues or families, even though they may have papers, they might not want to get involved [in research], because they don't want to put their families at risk that don't have papers. So, [taking] me [for example], half my family's illegal. More than half of them were. But they all got documented over the years.

Laura, a 20-year-old Deferred Action for Childhood Arrivals (DACA) recipient, reiterates how her undocumented status influences the decisions she makes.

> I definitely think [documentation status] influences … why people don't participate. And a lot of them. A lot of times I think [it is] just fear … It's kind of like, oh no, it's too good to be true. They're like, "no one wanted me for me [before]. No, I'm not gonna expose myself like that." I definitely fear from the government being close. And like I said, it's too good to be true. There's no way. Like, [maybe] they want to be able to expose me. Like they're going to take identifying information from me. So yeah, I definitely think it influences undocumented people.

Exclusionary and restrictive immigration policies that aim to emphasize the boundaries between foreign-born and U.S.-born residents influence how people feel they are perceived by others and their own perceptions of belonging within a community. The relationships that biomedical researchers imagine creating with ordinary people to encourage research participation are often not available as relationship scripts to individuals who are undocumented. For instance, one interviewee said, "Especially as Hispanics, we … would like to all of a sudden be invisible. Don't notice that I'm here. Why? Because of our legal status." Individuals in vulnerable communities, particularly people who are undocumented, are likely to be more distrusting of organizations. Even if organizations are well meaning, their efforts are overshadowed by fears and real threats of federal, state, and municipal practices that are designed to remove unauthorized individuals from the country. It is challenging, if not nearly impossible, to feel part of a larger health solidarity movement when the notion of American solidarity is not extended to people's daily lives and countrywide messaging and policies reiterate national difference and status illegality.

Research initiatives committed to addressing diversity and inclusion, often focus on establishing relationships with participants that mitigate forms of distrust that have been forged through negative research experiences or historical instances of unethical and exploitive research. However, perceptions of biomedical research, and more broadly of the medical establishment, do not operate in a vacuum. Xenophobia, nationalism, racism and discrimination,

are important contributors that mold cynicism and mistrust of organizations. As substantial scholarship has already concluded, these experiences and overlapping and shifting boundaries of intersectional forms of marginalization shape perceptions of institutions (Perreira and Pedroza 2019). I experienced the effects of anti-immigrant national rhetoric and Immigration and Custom Enforcement policies on participant attitudes towards research participation while collecting data for this study between January 2019 – February 2020. The majority of interviews with community members were conducted in Santa Ana, California, an ethnic enclave home to 77% of residents that identify as Latinx (U.S. Census Bureau 2019a). On June 17, 2019 President Donald Trump tweeted, "Next week ICE will begin the process of removing the millions of illegal aliens who have illicitly found their way into the United States. They will be removed as fast as they came in…" Between late June and September 2019, during the height of local and national ICE raid threats, I had 4 participants confirm for interviews, but not show up for the interview. The exact reasons why these individuals did not show are unknown (I was never able to get back in touch with 3 of them) and could have been attributed to normal challenges associated with conducting qualitative research. However, my interviews with health services researchers and other Latinx community members point to the equally likely scenario that people within this community were scared to take any unnecessary public risks and/or had been personally affected from policies enforcing the crackdown on unauthorized immigrants.

For example, in one of my interviews conducted with health service and research professionals, I met with a health provider from a Federally Qualified Health Center (FQHC) that had just had a training on what to do if ICE were to show up at her clinic. She told me that undocumented patients are afraid they will get picked up. When there has been a large ICE raid in the area, her clinic sees a dramatic decrease in patients showing up for appointments. When I

met with Viviana, an undocumented immigrant mother of two, she talked about how the recent ICE raids in her community have impacted her daily life.

> It affects us a lot, because a lot of people don't want to be known. A lot of people are trying to hide. The less [they] know their information, [the] better for you … They don't go to the supermarket … Because, you know how there have been raids? So, they rather be in their homes, or be places where they know that this is not going to happen … I know a lot of people that they don't go to the supermarket anymore … Stater Brothers [a supermarket] delivers. They would rather overpay [for] their foods and stuff, not to be out there.

Among the Latinx adults that I spoke with, documentation status and growing fears over recently shifting immigration policies were primary contributors towards distrust of outside communities. In this case, "partnerships" with study participants overlooks the socio-political and institutional structures that make opportunities for forging these relationships with vulnerable immigrant and undocumented communities very unlikely. While adverse research experiences do negatively influence views of the scientific community, the social and economic consequences of immigrant integration policies substantially influence how immigrant communities assess institutions and make decisions.

Furthermore, the chances of coming in contact with potential research opportunities are tied to health care access. Even in the absence of raids, deportations, and restrictive immigration integration policies, undocumented immigrant communities have low health care utilization rates (Garcini et al. 2016; Hacker et al. 2015; Perreira and Pedroza 2019) and have the lowest rates of health insurance coverage in the United States (Artiga and Diaz 2019; Kaiser Family Foundation (KFF) 2020). Most of my interviewees went to safety net health care clinics to receive medical care, and many discussed limiting their visits because they were worried about being detained by ICE officers. Laura and Isabella offer different examples related to these concerns.

> I think [research participation also relates to] whether or not people seek health care [or] seek help. Because a lot of times they might not have insurance. If they do go to hospital

> and [the doctors] like tell them, "Oh, you don't have insurance." And then [the doctors] scan your name, and then if they see like, “Oh, this person has a warrant out for their arrest,” they'll call whomever and then they'll see that that's because ICE is looking for them. And then ICE will show up to the hospital and from there it'll be like there is no escape … I think with everything that [undocumented people do] it's mainly that fear of coming into contact with ICE, or someone who can report them to ICE. And I think we try to stay as low profile as possible, reach out for the least amount [of help] probably that they can.
>
> - Laura

> I mean especially if they’re undocumented or if their parents are undocumented. … I have a friend who … went to apply for Obamacare. They’re asking about her parental history and if her parents were citizens. And she’s like, I can’t put that down. Because what if the [government] gets that and ICE comes after my parents? It’s a big concern because what if you put down the wrong information, they look you up someday, and then ICE shows up at your door? … I don’t want to give my information to anybody else. … How am I going to apply for Omamacare or go to a doctor without worry? It’s not safe. I don’t feel safe in my environment. And it causes a lot of stress because on top of that you’re in school and stress is a big thing. How can you take care of yourself? Selfcare is going to therapy. How can you afford therapy when you don’t have health insurance and you’re not documented?
>
> - Isabella

The socio-political and institutional structural constraints that contribute to low health care utilization among undocumented Latinx adults, significantly also contribute to low rates of participation in biomedical research. The combination of being undocumented and not having health insurance means that very often individuals in these communities come in less contact with research opportunities in clinical settings.

Making Sense of Medical Care & Research Relationships: Schema Mismatches & Taboo Violations

Although clinical practice and biomedical research are distinct entities, they are connected through many overlapping practices that include collaborations between researchers and practitioners, with biomedical studies often using clinical settings as primary grounds for recruitment. Research organizations often focus on the research experience; we can see this in

the efforts that researchers take to construct new and different kinds of partnered relationships with study participants to encourage involvement and retention. Yet, among my interviewees, health care access and medical experiences were more intimately connected to their views about research than any new forms of constructed relationship ideals with researchers. For example, when Raquel, who is undocumented and primarily gets her care through FQHCs, was asked why she thought she had never encountered an opportunity to participate in biomedical research she responded in Spanish saying:

> Because they are not interested in us, especially the Hispanic community … if they were interested, we would all have better medical attention … there would be somebody watching over us and they would advocate to give us insurance. There is no one here who is focused or interested in us. They're more interested in individuals who have the opportunity to get medical insurance.

When I interviewed Latinx community members about their perceptions of and experiences with biomedical research, I was surprised to learn that for the majority of the interviewees their experiences with healthcare professionals were interconnected, and at times not differentiated from their understandings and perceptions about researchers and biomedical studies. As Gabriela succinctly explained in her conversation with me, "It's like the same thing: medicine." The common practice of using clinical settings to recruit participants to biomedical studies may be one factor attributing to why the majority of community residents that I spoke with did not differentiate between research and health care practices.

Within the scientific community, research and healthcare delivery are linked as both are important for health promotion. However, they are distinct entities in the sense that researcher-participant and provider-patient relationships vary in norms and expectations. Relationship schemas help us understand different relationship structures, framing our normative expectations for how situations should unfold and how people should respond to us. However, people do not

always use the same relationship schemas to understand and organize social situations. A primary example of this kind of schema mismatch are the differences in how community residents most fundamentally thought about what constitutes as research and their expectations for research-participant relationships. Community residents, not differentiating between medical care and research, used the same relationship schema to understand both circumstances. Consequently, ordinary people had very different ideas than researchers about how the relationship should develop, and what their entitlements are as participants.

Of the 30 community residents that I interviewed, only 6 (20%) had direct experiences as current or previous research participants in a medical study. These individuals did not clearly differentiate their research experience from their experiences with healthcare professionals. For example, when asked to reflect on a recent study experience and what could be improved, one interviewee responded in Spanish, saying, "Well, since I've had good experiences with doctors … I can't ask for something better … Thank God I've had good experiences until now with the doctors I've had and the places I've been to." Even individuals with no previous research experience associated receiving health care services with participation in research. Explaining why she would consider participating in a biomedical study, Raquel said in Spanish, "I would like it if they sent us a copy of our results from the tests that they made on us … It would also help us see if there is anything that we need to go get checked out." Re-imagined communal sharing and equality matching relationships between researchers and participants did not typically resonate with the community members that I spoke with, and often were not available to them as scripts. More often, people counted on authority ranking schemas, the same relationship schemas they used with medical providers, to understand research opportunities and to make decisions about participating. The expectations for these types of asymmetric

relationships are that higher ranking people in knowledge or status will provide protection, care, and aid for the differentially ranked people below them (Fiske 1991). Viewing research as one and the same or as an extension of health services, the community members in my study expected that as patients or research participants they would be guided and cared for by medical experts.

For most of the people that I spoke with, biomedical research was seen as an extension of health care or another option that might provide access to better health care for them, their families, or for local communities. One such example is illustrated through an emotional and powerful story shared by Viviana, a 37-year-old single mother of 2 children who came to the United States with her parents from Mexico to escape social ostracization after it was discovered when she gave birth at age 10 that she had been sexually molested by her grandfather. Currently living undocumented in California and financially supporting her children and parents, Viviana lost her employer-based health insurance when the hotel she worked for changed ownership and the new owners began checking the legal status of employees. Viviana suffers from crippling migraines and has attempted to take her own life in the past. She is currently not being treated for her depression or her migraines, and she has had negative experiences with physicians during times when she was insured but her provider would not continue to prescribe her the antidepressant medication that she feels she needs. When I met Viviana and her 5-year old daughter at a café, I listened to her migration experiences and afterwards, using an example of biomedical research where participants are "partners," I asked her how she felt about the study and if she would ever consider participating in this study or another like it.

> It would be okay to me because I think I have my record … They can check [my health] record for new doctors [that I might see]. And then they can see like 'Oh look, for this person we should have had an alert because she was on her meds and then she was without them.' And then if you have it all, [my records], you can do a study so that way

> whatever happened with me, it's not gonna happen with someone else and then be something fatal. I mean, thank God I haven't done it, but I really need my meds for the depression … they could look it up [and give me my medication] and be alert of someone else [in a similar situation]. So, it won't happen. How many deaths do we have from people that nobody realized were under depression?

For Viviana, and other participants that I spoke with that were undocumented and/or experiencing extreme financial burdens and social stressors with very limited access to social service resources or health network connections, biomedical research participation was viewed as an extension of medical care and social resources. For Ava, 55 and originally from Mexico, she described her participation in a diabetes health education intervention study as informative because "I learn and have [access] to these resources, like where to go in case something comes up in the future." Rather than interpreting researcher-participant relationships through an equality matching schema, the interviewees that I spoke with more often understood research participation through authority ranking relationships with their health care providers. They did not distinguish providers and researchers but rather saw them as all part of the medical field. Additionally, although individuals framed research participation through the schemas they used to understand medical provider relationships, for some of the people that I spoke with these relationships were imagined – they did not have stable access to health care providers. The possible health resources that they saw as potentially coming from research participation were what they would *like to have* provided to them, *if* they were fortunate enough to have a structured relationship with a health care provider or biomedical researcher.

A central dilemma with framing the researcher-participant relationship as a partnership is that participants do not see their relationships with medical professionals as equal. Rather, participants are looking for and expecting to be taken care of. When asked about being a partner in research people like Mariana are reminded of the ways that the relationships that she has with

health providers are *not* on equal footing and of the times when she felt mistreated. Mariana, a 61-year-old immigrant from El Salvador who has lived in the U.S. for 30 years explains her thoughts about research partnership in Spanish:

> No, I do not feel like a partner. I am already contributing by teaching you all through my participation and [how I was treated] in the hospital. One time, they sent me to a nursing home, and they almost killed me because they are people who do not care about the patient. I went to another nursing home and they treated me like a person. So, if you study this, you'll see there is a difference. That's why I wouldn't feel like a partner.

Participants like Mariana see research and health care through authority ranking schemas that they experience as deeply flawed. As research participants or patients in these relationships, they are beholden to experts for their care. The most basic element of authority ranking relationships is that subordinate people are cared for. However, for many of the individuals that I spoke with, this relationship structure was inconsistent, damaged, and at times they felt it had been completely violated.

When people are faced with a relationship schema that violates deeply held norms, values or basic expectations for a relationship, they regard that schema transgression as a taboo violation (Fiske and Tetlock 1997). For example, Sofia comparing her interactions with her health care provider to her interactions with her dog's veterinarian, said, "…the veterinarian takes more time talking to me about my dog than my actual doctor talking to me! … but [the vet] actually cares about the animal and telling you what he thinks is in the best interest of the animal compared to us human beings and our doctors." When the individuals in my study felt that the normative expectations of the authority ranking relationships with medical professionals had been broken, they responded with outrage and disgust. It is taken for granted in authority ranking relationships between health providers and patients that the provider will treat and care for the patient because the relationship is based on deference and paternalism. However, when Isabella

shared with me how her family was not able to afford the cancer treatments for her uncle, and that he later passed away, she responded with moral outrage that health care for a dying person could operate along market pricing lines in the United States.

> It shouldn't be so expensive. You're putting a price on someone's life? I just think that's an injustice. You're kind of doing the survival of the fittest except it's someone who has the most money. It just feels wrong! Getting medical attention shouldn't be a luxury, it's a human right.

Isabella' story provides a powerful example of how offended and hurt people feel when the norms of one relationship type are seen as being inappropriately applied to another relationship type.

In addition to feeling profoundly hurt, people may feel skeptical or distrustful when they expect to be cared for in a relationship but feel that the conditions of the relationship have been violated. For example, Savana discussed the uneasiness she that feels accessing medical care because she is Hispanic:

> There is a lot of risk, you know. When you go to a place or office [and] they see you. "Oh, she's Hispanic." Even if you have a PPO, HMO, they look at [you] like that. They treat you that way – they look at you as a number, not as a patient … Some people might think, 'Oh they're Hispanic. They're not going to do nothing about it. They're afraid to look for a second opinion. I think this has a lot to do with it. "Oh they're just gonna believe what I'm saying."

Many of the participants that I spoke with, like Savana, were extremely wary of the relationships that they framed through authority ranking schemas, feeling that other actors in the relationship violated the unwritten rules of how they should be treated. Another participant expressed similar uneasiness saying, "I don't trust my doctor because he's not listening to me. I know my needs but he's not listening to me." Violations in how vulnerable communities expect to be treated can lead to skepticism that extends beyond patient-provider relationships. Since many individuals view research, health care practices, and medical care access congruently, mistrust stemming

from perceptions of broken promises or expectations is often woven through all forms of relationships pertaining to health. Camila, a 51-year-old immigrant from Mexico, recalled in Spanish one of her first experiences with medical professionals shortly after arriving in the U.S. 17 years ago.

> When my daughter was born, I was in a coma for a week and the doctor ended up sending me home. But there was another doctor that always went and stood at the [hospital room] door. The nurse told me "You cannot leave if the doctor does not sign the certificate giving you permission to leave." And I said, "What doctor?" She told me that she was referring to the doctor that was visiting me in the morning and in the night. But [the doctor she was referring to] never examined me. [The doctor by the door] never came to the bed to examine me or talk to me. That really hurt my feelings and that made me feel like something undesirable, something unworthy of living. It [was] difficult. I felt rejection. The situation made me feel like "you are not welcome here" [in America]. That is why I don't want to participate in anything with doctors.

Camila was steadfast that she would never participate in biomedical research. More than a single stand-alone horrible experience, for Camila her hospitalization was a humiliating breach of basic human dignity and an inexcusable violation of provider responsibility that shapes her perceptions of the scientific community.

Relatedly, socio-political policies of exclusion that may legitimize forms of discrimination and institutional racism foster fear and mistrust within immigrant communities. These policies and practices greatly impact immigrant integration, as well as the ease or difficulty in how people access health and social services. My interview with Jade, a 22-year-old Mexican American and her husband Sergio, an undocumented 24-year old 1st generation immigrant from Mexico, highlights how fear and mistrust are intertwined into health and research relationships. We began our conversation by talking about their respective families and where they go to get medical care.

> **Jade, speaking in Spanish:** My Mom won't let [American medical providers] do anything for the same reason. [She thinks] then I'll get sick … she always goes to Tijuana

> to address things … she doesn't like to have anything done [in the United States] … she doesn't believe the doctors here. My mom really believes the doctors in Mexico.
>
> **Sergio, speaking in Spanish:** [People like our parents] think that when they go to the doctor, they get more sick than when they don't go get things done. And they have their [own] remedies that they prefer because maybe they will end up injecting me with some kind of sickness or something. They would rather avoid that.

When our conversation switched to discuss perceptions of biomedical research, both Jade and Sergio continued expressing concerns of possibly being harmed or exploited.

> **Jade, speaking in Spanish:** I don't know what they'll do with the samples. Will they be used for good or for bad?
>
> **Sergio, speaking in Spanish:** Instead of helping them by taking their urine and blood samples they might be injecting them with a disease… the [researchers] pick the people that they want, and they'll see that their blood will benefit them [the researchers].

The relationships that research initiatives imagine establishing with ordinary people confront structural constraints (for example, English only laws) and restrictive immigrant integration policies that indirectly influence immigrants' feelings of exclusion. In response to the emotional stress and moral unease of schema transgressions, people often distance themselves from the person responsible for the transgression and negative relationship (Fiske and Tetlock 1997). With individuals viewing all experiences and relationships relating to health conjointly, mistreatment from health care providers is not distinguished from relationships with biomedical researchers (whether the latter relationship already exists or not). Significantly, this is a central reason why some of the community residents that I interviewed would decline to participate in biomedical research.

How community residents view partnership: "But somebody needs to be the professional"

A defining feature of the All of Us study is the notion of partnerships between researchers and individuals, where participants are "active partners" in the research study.

Participant partners have access to the health data that they share and the ability to learn about the research projects that are making use of this information. Experts believe that partnerships between researchers and participants generate a sense of connection between ordinary people and the scientific community, empower people with new knowledge, and nurture mutual appreciation and respect between partners. However, I found that for ordinary people the idea of being a "partner in research" is often cognitively confusing, particularly in relation to what ordinary people believe researcher-participant relationships should amount to. When I asked community residents what they thought partnership between researchers and participants meant, and I was met with a variety of responses ranging from assuredness in the answer they had given to bewilderment at what I was asking.

> A partner? Like me working with the nurse or something?
>
> – Gabriela

> Active participation? Well, I think that means they're constantly asking you questions or interviews or you are participating with them.
>
> – Raquel

> I think partner means … we're doing this together. … this is the relationship. You're providing us information. It makes me feel like that word is a little bit more fluffy. You know, it's a little bit more fluffy like, "Oh we're partners. We're going to work together." Nice case management. Social worker talk.
>
> – Mariana

To borrow a term from Fiske and his colleagues (Alan P. Fiske, Haslam, and Fiske 1991; Alan Page Fiske and Tetlock 1997), Gabriela, Raquel, and Mariana's reactions of confusion, uncertainty, and satire suggest that when asked to think about research participation through an equality matching schema this felt "taboo." When people are confronted with a relationship schema that seems wrong or incompatible with the norms of another relationship model used to guide interaction, people might experience a sense of anxiety or confusion, and often have to put in considerable effort to try and switch frames. Fernanda, a 22-year-old Mexican American,

provides another illustration. When asked how she felt about studies that call participants partners she paused for a few seconds before answering:

> I mean, I guess I agree. It is a partnership. You know, you're part of the whole research even if you're like one in a million … like I said, everybody's different. You might get something out of that one [participant] that you didn't get out of the rest. And that might be helpful for someone else. So, I agree. Yeah, it's a partnership.

Probed on what she would expect her role and experiences as a partner in research to be, she had difficulty framing her response:

> **Fernanda:** Mine personally? Just this exactly – to share my experiences, to answer questions whether it be [about] my experiences or … sorry, if you could just ask again? I kind of got lost in the question.
>
> **Researcher:** What does it mean [to you] to be a partner in research?
>
> **Fernanda:** So, to contribute to the research. You know, just sharing what you know, what you've seen, what you think, and how you feel about it.

Fernanda was not alone in having difficulty conceptualizing her part of the partnership and what she could expect from researchers. Again, participants provided a myriad of responses on what they expected out of research partnership relationships.

> I think for my wife and I, being a partner means being part of an investment and investing money or something. It wouldn't feel right for me to feel like partner.
>
> – Mario

> Partner in research. I'm going to put on a lab coat. I'm going to go and look into the microscope. I'm going to see the actions of the cells. Is that what it is? I don't think so [chuckling].
>
> – Rod

These perspectives and expectations from viewing partnership through an investment lens, to Rod joking at the superficial use of the word "partner," underscore how the partnered relationships espoused by biomedical researchers with participants are viewed skeptically or with confusion. For some, partnership talk does not mean anything because it runs contrary to how they view themselves and their relationships with researchers/clinicians. For them, the

relationship is fundamentally unequal, but this is a normal expectation for this kind of relationship where medical professionals/researchers oversee and care for patients/research participants. For others, like Mariana, partnership talk is a marketing strategy; partnership talk was a discourse used by professionals to feign equality where it does not exist. Since the concept of partnership did not match people's lives, talking about being "participant partners in research" was confusing to most ordinary people.

Although people can transpose schemas from one relationship to another, it is not certain that their preferred schema will stick. As Polletta explains, people are constrained in their creative use of relationship schemas because not all schemas are culturally familiar to everyone and even if a schema is culturally available it may be viewed as inappropriate for some people (2020). It is difficult for the equality matching relationships that biomedical researchers use to stick with participants because this relationship schema is not available to most people. Furthermore, people did not buy the idea of an equal "partnership" with researchers. For most ordinary people, they do not seem themselves on an equal playing field. Being told that they are ends up feeling superficial or confusing. Instead, ordinary people rely on more familiar relationship schemas, most often falling back on the schemas that they use with health care providers to understand and frame new relationships with biomedical researchers. For example, Savana explains how she imagines a research partnership working:

> An appointment to get my [information] and to always have a doctor, nurse, like a team that is going to help you. They're going to be with you [while] all this is going to happen with this medicine, if you're going to take new medicine … that person is going to help you. Like, "[Here] is the number if you need help. You can call this number whenever. We're going to answer you."

Participants more easily understood researcher-participant relationships through the relationship schemas that they used with health care providers. In these kinds of relationships community

residents were looking for a medical professional to provide therapeutic care and to guide them through challenging health decisions. In authority ranking relationships people follow the direction and guidance of individuals in more authoritative positions and in return receive care and protection (Alan Page Fiske 1991). I found that even when presented with examples of researcher-participant relationships framed in terms of equality and partnership, participants more clearly understood researcher-participant relationships through authority ranking scripts and had difficulty modifying the norms that they expected.

> It's kinda scary getting into something that you don't know nothing about. Like, okay we're going to be partners. Be partners and go through this journey. But, somebody needs to be the professional. Somebody needs to be the doctor. Somebody has to be in charge.
> – Savana

The notion of partnership only makes sense if viewed through an equality matching schema where both parties feel that they are on equal footing. The problem is that these norms of equality conflict with societal norms where the medical establishment is highly valued and revered, and clinical professionals and medical researchers retain high social prestige. As Savana shares, "somebody needs to be the professional," and it is implied that she thinks the person "in charge" should not be her. Trying to extend an equality matching schema to people who experience themselves as having lower status creates stressful situations and puts strains on an already imbalanced relationship.

Conclusion

As I have discussed in this chapter, partnered research approaches that frame relationships with researchers and study volunteers using notions of health solidarity and equality do not always map on to the relationships, understandings, and expectations about medical research that ordinary people have. These different understandings of researcher-participant

relationships help to explain why some people, such as the low-income, under-resourced and recent Latinx immigrants that I interviewed for this dissertation, may decline to participate in biomedical studies. Health solidary refrains such as, "we're all in this together," are thought to have broad appeal as an equalizing statement to unite diverse audiences around a common goal to improve health. Research initiatives often frame studies through communal sharing schemas where everyone is united regardless of social and structural factors that affect people differently. Among the Latinx residents that I interviewed, their experiences navigating the U.S. health care system did not mirror the models of health solidarity that are espoused in communal sharing relationship frames. Community residents, particularly low-income and undocumented individuals, felt left out of this relationship altogether. Rather than uniting people around the goal of health promotion, for vulnerable communities, solidarity refrains can be an unpleasant reminder of the ways in which they are excluded because of their legal documentation status, systemic racism, and a health care system with little to no public safety net.

Biomedical researchers stress that the historical residue from the exploitation and mistreatment of poor and minority communities negatively influences how some minority groups view biomedical research. In an effort to change attitudes, researchers believe that transparent relationships partnering with participants will foster trust, especially among groups that have been mistreated in previous research. Community residents in my study acknowledged these changes as important and positive but for most people, trusting researchers was not primarily influenced by whether they thought of themselves as "partner" in research. For most ordinary people "participant partnerships" were confusing. Partnerships with researchers did not match the relationship schemas that people used to make sense of research participation. Relationship schemas provide a structure and normative expectations for what will happen in a relationship,

including who does what and what is owed to each actor. Instead of reconstructing relationships with biomedical researchers through models of partnership, community residents sought out analogies from more familiar practices within medical care to serve as a model for their expectations and understandings of research. Moreover, people did not buy the idea that their relationship with researchers or clinicians could ever be equal or reciprocal. For some community residents, partnership talk was mere tokenism and a feel-good marketing strategy employed by professionals to feign equality where it does not actually exist.

Often viewing research as an extension of or the same thing as medical care, people's decisions about research participation were directly connected to their experiences with health professionals. Biomedical researchers frequently stress that distrust of research primarily stems from the legacy of unethical research studies and the continuation of poor research practices. This project highlights how distrust is interwoven into people's overall experiences with medical care and how they frame relationships. Relationship schemas shape people's understandings on what they owe and what is owed to them. Deep-rooted skepticism that researchers will not do what they say they are going to do stems from community residents framing research and medical care relationships with the same schema. Medical mistreatment and unmet relationship expectations with health professionals fundamentally impacted how community residents felt about their current or future relationships with researchers. The overall mismatch between the relationship frames that researchers and ordinary people use to understand biomedical research and each other, is a primary reason why some people may decline to participate in research opportunities.

This project highlights how educational efforts to clarify the differences between medical research and medical care to change ordinary people's attitudes about research or influence how

they make research decisions are not likely to be as effective a strategy as biomedical researchers would hope. People's decisions about research are not based on a pure cost-benefit analysis, as a rational actor model would suggest. Rather, the relationships people have and imagine are part of how ordinary people understand research and make decisions about participating. In communities that are especially vulnerable, where people are less likely to have a primary care physician or health insurance, people will likely frame new experiences with researchers through more familiar relationship models, such as the schema that they use within medical care settings. Rather than concentrating on symbolic partnerships with research participants, biomedical researchers should prioritize collaborations with clinical care practitioners, given that people's experiences with medical care drastically impact their attitudes of biomedical research.

Lastly, partnerships with research participants, even if only symbolic, assume that ordinary people want to be more intimately involved in health decisions and that this involvement will feel empowering. However, I found that particularly among the low-income and first generation immigrants that I interviewed, people might not want to be "placed in the driver's seat" of research activities (Adams and Petersen 2016). When asked to do so (even in a symbolic way), they may feel confused, skeptical, poorly prepared, or frustrated. Again, this relates to how people frame and understand relationships. Community residents framed research through schemas that they use with other medical care professionals. Researchers hoping to enroll vulnerable communities into research studies by framing participants as "partners" in research may find that people within these communities are not looking to be "empowered" by being a research partner, but rather they are looking for better access to immediate health services.

CHAPTER FOUR:
Incentivizing Research Participation: The Symbolic and Moral Meanings of Getting Paid to Participate in Research

Biomedical research depends on recruiting and retaining ordinary people as research participants. Requirements for the greater inclusion of women, minorities, and children in research have raised important and fundamental questions about enrollment in research, and how best to foster new relationships with groups that are underrepresented. A related issue that investigators grapple with is what kind of inducements work best to enroll and retain study participants. Paying people for their participation in biomedical research has become an integral component of many recruitment strategies. The models that scholars use to discuss why and how to pay people for participating in research, predominantly assume that people make decisions as rational actors analyzing the potential costs and benefits of participating in research (Dickert and Grady 1999). People are paid because it is believed that people view monetary incentives positively, and payments help to offset undesirable aspects of research (for example, time, effort, or enduring uncomfortable procedures). As a strategy to enhance recruitment, monetary incentives are offered to participants for taking part in a study, or as a way to guarantee that people can participate in socially valuable research without making personal financial sacrifices.

Although monetary incentives are commonplace in research with human subjects, the practice of paying people to participate remains contentious. The predominant concern expressed among investigators and institutional review boards is that the introduction of money may potentially unduly influence participation in research or be coercive. The argument that inducements can unduly influence participation, such as financial incentives that are overly high, contends that payments can cloud a person's judgment as they weigh reasonable or unreasonable choices, and consequently the individual may participate in something unreasonable, risky, not in

their best interest, or that they otherwise would not choose to do (Dickert and Grady 1999; McNeill 1997; Largent and Lynch 2017). Federal regulations and guidelines call attention to these concerns, but they do not offer investigators or institutional review boards substantive guidance on how to pay participants ethically. As a result, there is no consensus on how, when, and in what manner monetary inducements should be used to recruit participants.

In this chapter, I will address the practical applications of paying participants in research, and the different symbolic, moral, and social meanings attached to monetary research incentives. My analysis is drawn from in-depth interviews with medical and research professionals (n=30), and in-depth interviews and focus groups with Latinx residents of Greater Los Angeles (n=60). Throughout this chapter, I aim to show the ways that money is not just a fungible but a social medium, with monetary incentives having different symbolic and social values to community residents and research professionals.

Following a discussion of historical and contemporary applications and ethical considerations of monetary incentives in research, I address how researchers in my study predominantly viewed monetary incentives as fungible and practical forms of inducement. Without having clear regulatory guidelines on how much is "too much" to pay participants, researchers frequently worried that monetary incentives could appear coercive and impact the reasons why people participate. One of their concerns was that excessive monetary incentives, or people participating exclusively because of a financial incentive, could dilute civic and altruistic reasons for participating in research. Although there is no objective number at which a financial incentive appears to be or becomes coercive, researchers tried to predict the point at which an institutional review board might see the incentive that way. Compensating people with gift cards

to retail stores was one way that researchers got around uncomfortable tensions with a paying people to participate because researchers viewed the gift card incentive as a gift.

I then address how among low-income Latinx residents, research participation was viewed as a way to get paid in exchange for their time and cooperation, with monetary incentives helping to supplement other forms of income. Unlike my discussions with research professionals, residents viewed getting paid for their participation as a straightforward component of the research exchange. However, residents worried that by participating in research, which they saw as inherently risky, dangerous, and an unequal relationship with researchers, they could be physically harmed and exploited.

I argue that the tensions around monetary incentives presented in this chapter are much more than a debate over fungible accounting where ordinary people make decisions as rational actors. Elaborating on Viviana Zelizer's argument (1997) that not all money is the same, I show how people painstakingly negotiate the kinds of payments that are appropriate within the social context of research participation. My analysis shows how specific types of incentives (for example, cash vs gift cards vs in-kind incentives) have distinct meanings for researchers and study volunteers. The ways people personalize, use, and symbolically value various forms of money matter and tell us about how people construct, understand and work to maintain research relationships.

Paying people for their participation in research is often conceptualized in ethical discussions and formal research guidelines as a problem of voluntariness. The qualm is that money may pressure people into participating in something that they otherwise would not have or is not in their best interest. This strictly economic and rational actor view of money misses how interpersonal transactions are interwoven into all economic activity (Zelizer 2012). Moving

beyond the debates of what is an appropriate financial sum for a research incentive (where there is no objective number), a more pressing question to address is what kind of monetary incentive will a study offer and does the social and symbolic value of the incentive reflect the kind of relationships that researchers want to foster with study volunteers.

Historical Considerations: Paid Research Participation

Paying people for their participation in scientific research in the United States is a longstanding practice documented for well over 100 years (Grady 2005; Lederer 1995). For example, in the 1820s, the army surgeon William Beaumont paid a gunshot victim $150 plus food, clothing, and lodging to study the human digestive process and run experiments on the man's wounded stomach (Lederer 1995, 115). During the antebellum period, slaves were frequently the subjects of experimentation – of course, they were neither asked nor did they give consent to this request. Rather, slaveowners would receive compensation from physicians in exchange for allowing experimentation on their slaves (Lederer 1995, 115). In 1900, Walter Reed, the U.S. military physician who confirmed that yellow fever is carried and transmitted by a mosquito species, paid study participants $100 in gold if they allowed themselves to be bitten by infected mosquitos. If the volunteer subsequently contracted yellow fever (a life-threatening viral infection), Reed paid out an additional $100 – if the individual was still alive to accept the payment (Lederer 1995, 192).

Paying people to participate in research continued as a routine practice throughout the early to mid-1900s. In 1911 the Coca-Cola Company commissioned a study on the effects of caffeine on cognitive function, paying participants to perform a series of cognitive tests after ingesting various doses of caffeine (Lederer 1995). Interestingly, medical students have also long served as paid research subjects. Although both male and female students were study subjects, it

was particularly prevalent to pay female medical students for their participation because investigators often had a difficult time recruiting enough female participants to their studies (Lederer 1995, 120; Murphy, Shoemaker, and Rea 1934).

During World War II, American researchers increasingly used prisoners as subjects for medical experiments (Hutt 2003)[5]. After the war, ethical concerns about the ability of prisoners to freely consent to research participation, particularly if payment or rewards were offered, began to be more meaningfully explored. The trials of German Nazis in Nuremberg brought issues of voluntariness, grossly unethical medical experimentation and research, and human rights violations to a global stage. The Nuremberg Code, a set of research ethics regarding the human rights of research subjects, was never formally adopted in its entirety into law by any nation or significant medical association. Still, the Nuremberg Trials represented a global reckoning on human rights, and the resulting code has had a profound influence on medical ethics (Shuster 1997). After World War II, American researchers continued to use and pay prisoners for medical research but placed greater emphasis on informed consent and voluntariness. Rather than focusing on participant safety and health implications caused by early medical research experimentation with prisoners and other vulnerable groups, excessive payment was seen as the primary ethical concern (Hutt 2003). Part of researchers' apprehension about excessive research payments was that individuals influenced by high incentives might conceal symptoms or hide disqualifying factors, which could in turn jeopardize the validity of research results.

In the 1960s, it was a common practice among pharmaceutical companies to run drug-testing programs in American prisons (Hutt 2003). Jessica Mitford, an investigative journalist, presented a scathing account of prisoner experimentation in her 1971 book, *Kind and Usual*

[5] Vulnerable and ill-informed "volunteers" from mental asylums, orphanages, and hospitals, were also common subjects in early medical research (Stobbe 2011).

Punishment: The Prison Business, highlighting concerns of prisoner exploitation and the "pittance" payments of $1 a day that prisoners received from drug companies for more onerous experiments (Mitford 1971, 157). Other well-publicized studies that violated informed consent and ethical research practices, such as the now infamous government-sponsored Tuskegee Syphilis Study (J. H. Jones 1981; CDC 2020a; Newkirk II 2016), and the cancer experiments on non-cancerous geriatric patients in the Brooklyn Jewish Chronic Disease Hospital (Hornblum 2013; Langer 1964), prompted renewed ethical debates and the creation of formalized research guidelines.

The Belmont Report was issued in 1978 (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979), and has since served as the guiding principles for contemporary research practices and compensation approaches in human subjects research. The issues of incentives and financial compensation are framed through the principles of respect for persons and justice; autonomous individuals must provide informed consent to participate in research that is free from "coercion" and "undue influence." Coercion in research is best defined as a threat to violate someone's rights or to fail to follow through on an obligation to an individual in order for the person to comply in a situation where they would have no other reasonable alternatives but to comply (Largent and Lynch 2017). Alternatively, undue influence in research is best defined as providing an excessive reward or payment that results in a person making a choice that is unreasonably against their values or self-interests (Largent and Lynch 2017).

In 1991 the Federal Policy for the Protection of Human Subjects, known as the "Common Rule," set forth regulations addressing informed consent, and also clarified that payment to participants should be considered a recruitment incentive, not a benefit of research participation

(Code of Federal Regulations 2019). Institutional review board (IRB) approval for a study is determined if a study has a favorable risk-benefit ratio. This means that physical, social, and other risks to participants are minimized and outweighed by the social value of the study or the direct potential benefits to research participants (where payment to participants is not calculated as a benefit). The Common Rule also calls for appropriate "additional safeguards" to protect subjects that may be "vulnerable to coercion or undue influence, such as children, prisoners, individuals with impaired decision-making capacity, or economically or educationally disadvantaged persons" (Code of Federal Regulations 2019). However, what these safeguards are remains in question (Hutt 2003). Although both the Belmont Report and the Common Rule identify concerns about research incentives, the documents provide very little guidance on how to address concerns of coercion and undue influence from "excessive, unwarranted, inappropriate or improper reward[s]" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). Consequently, incentives and payment practices vary significantly in the United States (Grady 2005), as the specifics of these practices and what constitutes as coercion or undue influence are reviewed and left up to the discretion of institutional review boards (Largent and Lynch 2017).

Enrolling and Retaining Research Participants: Incentives, Motives, and Moral Qualms to Commodifying Research Participation

Behavioral and biomedical research depends on the participation of ordinary individuals. If researchers fail to recruit enough people to meet their projected sample size, researchers may not be able to answer the research question of interest. Equally important and just as challenging a task is keeping study volunteers as participants for the duration of a study. Failing to keep people enrolled can result in missing data. No matter how meticulously a research initiative is

planned or how carefully executed, insufficient recruitment and retention of participants threatens the internal validity of a study and places limits on scientific inferences that can be drawn from the results (Bernstein and Feldman 2015).

As discussed in an earlier chapter, recruitmentology is an emergent field dedicated to scientifically evaluating how best to convince people to not only become but to remain human subjects in research (Epstein 2008). Recruitment and retention specialists, consultants, communication experts, and increasingly community stakeholders, are frequently invited by investigators to assist in the development of the public image of a research initiative and to tackle how best to encourage and retain participants in a study. Often within recruitmentology literature, particularly when addressing recruitment strategies for "hard-to-recruit" populations in medical research, the scholarship has primarily focused on addressing barriers to recruitment or technical applications to boost successful recruitment (Dancy et al. 2004; Katz et al. 2007; Epstein 2007). These studies have shown that research incentives are an important mechanism for recruiting and retaining participants and that monetary payment may foment interest in participation (Grady 2005). However, recruitmentology studies have rarely addressed the social understandings that help to explain why underrepresented minority groups and other "hard-to-recruit" groups do enroll in biomedical research.

One of the more common recruitmentology applications of incentivizing research participation is paying people to participate. Monetary incentives are sometimes rewarded to participants in the form of cash or a pre-paid credit card, while other times participants are compensated through gift cards to commercial retail stores (Bernstein and Feldman 2015). Yet for some scholars, the idea of putting a price on research by paying people to participate feels morally murky. These scholars argue that research has been commodified through the growing

reliance on monetary incentives to solve social problems[6] (Sandel 2012), including the dilemma of how to motivate people to join research studies. Scholars from a variety of disciplines argue that markets can be destructive, and that the commodification of particular goods and services may be unjust. For example, the political philosopher Michael Sandel argues that when we decide that certain goods or services can be bought or sold, we are implicitly deciding to treat those goods and services as commodities and instruments for profit and use (Sandel 2012, 9). Sandel and other economic philosophers have argued that putting a price on certain things or particular features of human life potentially corrodes social rights. For example, the commodification of hospital care may leave some people unable or unwilling to pay for health services that they need, which under this reasoning would be an erosion of basic social rights and protections (Reich 2014, 1580). As a normative argument, the claim is that some things should not be bought or sold.

Within other fields of academic literature, particularly among bioethicists, discussions center on understanding the scope and nature of particular kinds of research incentives and minimizing the dangers of undue inducement that may be associated with some kinds of incentives. Although there is still debate on the moral grounds of monetary payment for research participation (McNeill 1997)[7], paying people to participate in social and biomedical research has

[6] School districts in the United States that pay children for getting good grades and/or pay teachers cash bonuses for improving student test scores are interesting examples of financial incentives in educational reform. For example, Roland Fryer Jr., an economist at Harvard, has been studying if financial incentives improve academic performance and motivate kids in poor performing urban schools to get better grades. He has been testing his idea in many of the largest school districts in the Unites States. In 2007 his project paid $6.3 million to students in over 260 urban schools. For example, in Chicago 9th grade high school students were paid $50 for getting an A, $35 for a B, and $20 for a C. In New York City if fourth graders performed well on standardized tests, they were paid $25. Fryer's studies have yielded mixed results: In New York City paying children for better test scores did not improve their overall academic performance, and in Chicago paying kids led to better attendance but little improvement on standardized tests. For more information see, "Financial Incentives and Student Achievement: Evidence from Randomized Trials" (Fryer 2011).

[7] In the published Report and Recommendations on Research Involving Prisoners for The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1976), Marx W. Wartofsky likens paid research participation to prostitution, arguing that human subjects are in effect selling their bodies for money.

become a widespread and normalized practice in the United States. Some scholars go so far as to argue that monetary incentives are a necessary and an inevitable feature of conducting scientific research with human subjects (Dunn and Gordon 2005). Although offering payment to research participants is a common practice, it is still a contentious issue. Over the last 40 years, scholars have grappled with the question of whether payments to research participants are coercive (Grady 2005; Heath 2001) or exploitive (Ashcroft 2001), or if payments jeopardize informed consent (Grady 2005). Others have explored why investigators might want to pay research participants (Grady 2005; Largent and Lynch 2017), and whether research participation is a form of labor where participants should be paid akin to other unskilled jobs (Lemmens and Elliott 1999; Grady 2005). More recently, while assessing how much to pay participants (Iltis 2009), scholars have also debated which payment structures minimize concerns about voluntariness and undue influence (Heath 2001; Largent and Lynch 2017).

Decision making and money are at the core these debates. What motivates people to join research studies? And, what is the role of monetary incentives in decision making, and more specifically for participating in research? As one behavioral medicine professional joked in an interview for this study, "If I knew that answer, I would be a bajillionaire!" To respond to these questions, scholars have frequently turned to investigating the production and consumption of material goods, as well as the science of human behavior. The simplest and most sweeping approach is that human behavior can be explained by assuming that people are rational actors. Motivated by self-interest, people will weigh the costs and benefits of different options, and they will choose the option that provides them with the greatest utility or benefit. The economist Gary Becker was one of the most ardent supporters of this approach, arguing that no matter what activity people are engaged in, they act to maximize their welfare (Becker 1976). For Becker,

people make decisions by calculating the costs and benefits of "shadow prices," the imaginary price attributed to intangible assets, implicit in the choices that we make and their alternatives (Becker 1976). For example, if a person was contemplating getting a divorce, Becker would argue that the person would consider the implicit price of leaving the marriage – the financial price and the emotional and social price – and make a decision based on if the perceived benefits of breaking up are or are not worth it (Sandel 2012, 61). For Becker, all human relations are market decisions. Monetary research incentives take Becker's "shadow prices" claim a step further by putting a monetary value on participating. The theory of rationality assumes that money is a neutral medium, facilitating the exchange of goods with people making decisions based on their self-interest. Although this model is used broadly and is often the default model in public policy debates, it is subject to frequent criticism as a simplistic carrots and sticks model that is devoid of the various facets of social complexity in decision making that cannot be explained by human selfishness.

While the theory of rationality assumes that money is neutral, other scholars have argued the exact opposite – that money can be a corrupting influence on people, their relationships, and social actions (Frey, Oberholzer-Gee, and Eichenberger 1996; Frey and Oberholzer-Gee 1997; Titmuss 1971). For example, Bruno Frey and Felix Oberholzer-Gee examined the influence that monetary incentives may have on acceptance of socially undesirable "NIBMY" (not in my backyard) projects (Frey, Oberholzer-Gee, and Eichenberger 1996; Frey and Oberholzer-Gee 1997). They conducted a series of surveys in a small Swiss village that developers had designated as a potential site for a nuclear waste repository. In the first survey, just over 50% of the residents said they would support the decision to have the waste repository in their village. In the second survey, Frey and colleagues asked the same question about support for the waste

repository but sweetened the deal by offering a financial incentive. Residents were told that the Swiss parliament would compensate residents yearly for the duration of the facility (the amounts ranged from $2,175 - $6,525). This time, support for the facility fell by half to just over 24% (Frey, Oberholzer-Gee, and Eichenberger 1996). Frey and collogues argue that introducing money can "crowd out" other forms of intrinsic motivation, like civic virtue. As an economist, Frey believes that people are rational actors, but he argues that people make choices based upon the kinds of incentives they are offered and decide how to act in accordance with the social system implied by the incentive.

In this way, markets not only allocate goods, but they also say something about the attitudes we have towards the goods being exchanged. Extending this argument further, commodifying certain things may undermine the intrinsic social value and integrity of these things (Reich 2014; Titmuss 1971). Medicine adherence provides a helpful case to apply this principle. Anywhere from one-third to one-half of patients do not take their medications as prescribed in the United States, with up to one-quarter never filling the prescription order (Kleinsinger 2018; Belluck 2010). Annually, we spend about $100 billion dollars in health costs that some argue are in part due to medication nonadherence and patients getting sicker (Kleinsinger 2018; Belluck 2010). To tackle this problem, researchers, doctors, insurers, and pharmacy companies have experimented with paying people to take their medicine, arguing that investing in small incentives amounts to much less than the cost of hospitalization. For example, researchers at the University of Pennsylvania Medical School used a computerized pillbox to record if people in their Philadelphia research study took their prescribed medicine (Volpp et al. 2008). Using a lottery system through the computerized pill box, people could win $10 or $100 each day if they took the prescribed pill (Volpp et al. 2008). Researchers found that the lottery-

based financial incentive was effective; people took their medicine correctly 92 – 100% of the time over a 3-month period, with only 0 – 8% incorrect pills taken per patient. Historically on average, 22% of people with the studied clinic population would take incorrect doses of their medication (Volpp et al. 2008). Scholars warning of the destructive power of markets towards social values would argue that cash incentives for achieving better health through medicine adherence not only bribe people to achieve better health, but incentivizing health through the chance of money changes attitudes towards achievement and health.

The social scientist Richard Titmuss applied this argument in his comparative study of blood supply systems in the United Kingdom and the United States (Titmuss 1971). Titmuss passionately argued that the UK system of voluntary blood donation was medically and morally superior to the blood supply system in the US, where often people are paid to give blood. He argued that the commodification of blood erodes social values and social institutions, and that when blood was given altruistically, these values were upheld. Furthermore, Titmuss found that when blood was voluntarily donated it was also of higher quality (Titmuss 1971). Relating the social values claim to research incentives, one could argue that the commodification of incentives might motivate people into doing the right thing (advance scientific knowledge and potential health improvements for individuals and society), but for the wrong reason (money).

Setting aside the moral unease of whether some facets of social life should be bought and sold, or the degradation of the social value and integrity of these things if they are commodified, there is still the question of how we value certain items and how we decide on a market price for them. In Adam Reich's study of the commodification of contemporary hospital organizations (2014), he shows how organizational environments (hospitals) are shaped and constrained by broader institutional environments (the U.S. medical practice). Reich argues that moral

understandings of market activity (for example, how we might value and commodify health care) are shaped historically and through the institutionalization of values within organizations. On a micro level, people struggle to reconcile their own moral-market understandings within the broader context of already moralized organizational and institutional contexts (Reich 2014). It is often quite challenging for people to assess the costs and benefits of the value of health through hospital care (Reich 2014). This is in part because there is a layer of uncertainty in the value of particular health treatments or interventions because patients are dependent on physicians to inform and guide them on health decisions (Alan Page Fiske 1991).

Economic and relational economic sociologists have long argued that to talk about the conditions of markets in the abstract, as many economists claim, misses the ways "economic transactions are fundamentally social interactions" (Zelizer 2012) and how social relations and values are "embedded" within economic life (Polanyi 1944; Uzzi 1997; Granovetter 1985). Embeddedness refers to how economic work is interwoven in networks of social relations (Granovetter 1985) and how these relationships are an important part of structuring economic action and economic outcomes (Granovetter 1985; Bandelj 2012). The concept of embeddedness highlights the importance of social networks in economic outcomes, but the approach has been critiqued for its insufficient attention to the role of culture, institutions, and power in influencing economic outcomes (Bandelj 2012). Relational economic sociologists, like Viviana Zelizer, expand on the concept of embeddedness, arguing that people attach distinctive meanings and understandings to symbols, practices, and different forms of media exchange, that are appropriate in some forms of relationships but not others (Zelizer 1997; Bandelj 2012; Zelizer 2012). Refuting the pervasive ideology that money is a single, interchangeable and impersonal instrument, Zelizer shows that money is a social medium. People use money in creative ways

through different payment systems and earmark money in different ways to express various social relationships (Zelizer 1997). “For each distinct category of social relations, people erect a boundary, mark the boundary by a means of names and practices, establish a set of distinctive understandings that operate within that boundary, designate certain sorts of economic transactions as appropriate for the relation, bar other transactions as inappropriate, and adopt certain media for reckoning and facilitating economic transactions within the relation” (Zelizer 2012, 146). Zelizer calls this process “relational work.”

Money is not merely an economic tool; it is influenced by cultural and social structures. There is a kind of “social accounting” in how people create and use monies, where people may “respond with anger, shock, or ridicule to the ‘misuse’ of monies for the wrong circumstances or social relations … such as tipping a restaurant owner” (Zelizer 1997, 19). As a social medium, money can be deeply subjective and subject to particular norms, morals, and values within different social networks. We see this in the ways that people earmark different kinds of money for many different social purposes. Zelizer’s relational theory underscores how money earned through research participation may be valued differently and perhaps used differently than for example, money won in a lottery, or money gifted for a birthday.

Symbolic and Moral Valuations of Monetary Research Incentives

Like other forms of monies, monetary research incentives have multiple meanings (Zelizer 1997; Bandelj, Wherry, and Zelizer 2020; Zelizer 2012). In this section, I expand on Zelizer’s relational work theory (Zelizer 1997) to underscore the different ways that research professionals and community residents in my study classify, use, and symbolically value monetary incentives. I begin with an analysis of health and medical research professionals. For research professionals, research participation has a moral value similar to other kinds of civic

duties associated with solidarity and bettering society. A central dilemma among research professionals is that if incentives are "too high" they appear coercive to IRBs and may weaken civic motivations for participating in research. Professionals struggle with the tension to recruit participants to studies by assigning a monetary value to participation while keeping participants safe from harm, and simultaneously trying to uphold research as a civic virtue. I contrast these understandings with the ways that Greater Los Angeles residents practically used and symbolically valued monetary research incentives. As a form of exchange for time and participation, monetary incentives were extremely important to economically vulnerable residents, but monetary payments also symbolized an unequal and dangerous power dynamic where residents feared that by accepting payment they could be exploited.

Medical & Health Research Professionals

In my interviews with professionals, researchers stressed that incentives were a particularly vital mechanism for enrolling low-income and vulnerable minority populations into research studies and keeping these individuals enrolled. There are many overlapping structural challenges that can make recruiting socio-economically vulnerable groups quite difficult, including keeping track of people over time. As one professional said of addressing these obstacles, "it's a full-time job!" Some of the common structural challenges that researchers mentioned include: participants not having a stable form of transportation or needing to rely on public transportation, phone numbers that change or are disconnected when data plans expire or if the bill couldn't be paid that month, parents lacking adequate childcare, housing insecurity, and individuals moving frequently. Successful recruitment and retention strategies with vulnerable and lower-income groups often rely on non-traditional methods. Valerie described a particularly effective and creative strategy working with community partners:

> My partners at a community health center are forever trying to find their people … what we did when we'd lose people … and we put [this in] our consent form, we'd use our community partners because [our patients/study participants] might be connected to our community partners [and we could] find out where they moved to. When [the patient would] go to the food bank to get their food, they have to update their address. So, the food bank would tell us where they were … we'd go poll the community partners – anybody know where family number six is?

Given the abundant structural barriers that impact individuals who may be recent immigrants and/or are experiencing food, housing, and financial insecurity, researchers rely on multilayered incentive strategies to help overcome these barriers to research participation. For example, it was common among the researchers that I spoke with to include reimbursements for public transportation in their study protocols and budgets, as well as to critically examine where the study would be taking place and if it was possible to run the study in or closer to the communities being investigated. For instance, Lillian said, "… [If] you get $20 for coming in [but] have to take a bus and take time off work or find childcare, those are all things that prevent [someone] from being able to come to the visit. So really, [researchers] would have to make it very easy for [study participants] to come to a location – maybe [do the study] in the community where it's easier for [participants] to get to." For some studies, like Martín's physical activity and nutrition intervention with school children, some of these considerations are more naturally built into the research protocol given the kind of research study that is being conducted.

> When you're embedded within the setting [and] you're asking [parents] to do some questionnaires …[because] we want to learn how the program works … [and] we want your feedback, [the parents are] just being nice … and they get like … $10 or $20 depending on how long [the survey] took … For us, it's a physical activity intervention … but for [parents] it's … a supervised [free] onsite program … parents work or have other things to do … I have three kids and somebody who you can rely upon to watch your kids and your kids are challenged and doing a good job … it's invaluable.

Factors like childcare and other social-structural considerations that make it easier for all people to participant in research are particularly impactful for more vulnerable groups. Transportation

and parking reimbursement, childcare, and the location of a study may incentivize some people to participate, but these kinds of compensations for time, inconvenience, or study-related expenses are different than monetary incentives, such as cash or retail gift cards, for participation in research.

Monetary incentives are presumed to be very motivating, particularly for lower income individuals that may not be well represented in biomedical research. Jun explains how she has experienced this in her work as a community engagement specialist:

> … People are either financially okay and they're almost well-to-do, and they have time and they have energy to [participate in research]. But, for the low-income [population], we do have some very low-income people call and they mostly ask about help [and] if there's any support or financial help, these kinds of things. They're not very likely to participate in the "no compensation" research. If there is some compensation, I think they probably will.

In addition to the prevailing belief that money motivates lower-income populations to participate in research, financial incentives are also sometimes used in conjunction with other study engagement practices to encourage long-term participation and help keep track of participants. For example, Valarie describes the incentive structure in one of her more recent studies:

> Everybody got a newsletter every other month. And part of the newsletter was a raffle. And so, if you sent back your [raffle ticket] that either confirmed your address and identification stuff, or gave us your new stuff, you got entered into a raffle and you could win money. That worked, that was helpful … people do things for money [or the] chance of money. It's amazing. You don't have to absolutely give them money, just the chance of money. And then we published in the next newsletter … congratulations to the winners of our raffle.

Unlike other forms of in-kind incentives or study related reimbursements that make participating in research easier, monetary incentives for research are less straightforward. A central challenge is that researchers must gauge what amount is an appropriate financial incentive that will not be coercive or an undue influence, and they need to receive the approval of an institutional review board (IRB). Although ethical practices guiding research incentives are institutionalized,

incentive structures are reviewed by IRBs on a case by case basis. An additional challenge is what form of payment to give out (cash, retail gift card, debit card, etc.). I'll address both of these challenges, starting with the former.

Research professionals discussed monetary incentives less in terms of whether a study would be providing a monetary incentive (one professional described including monetary incentives as a "given") but rather in terms of how great the financial incentive should be. One of the biggest concerns that researchers expressed when considering monetary incentives was the worry that incentives could seem or be coercive. Particularly when discussing working with vulnerable communities, researchers acknowledged that financial incentives can be an extremely valuable resource for low-income families and that these kinds of financial incentives make it easier to recruit participants from vulnerable and underrepresented communities into their studies. Alexa said, "… talking about the low-income population, gift cards totaling $100 dollars for participation in a six-week study means a lot … the way we worded the flyers it really attracted people who obviously looked at the dollar amount and the incentives were clearly on there." Research professionals consistently addressed how important it was to be mindful of incentives and not offer "too much," because an IRB may see the high monetary incentive as potentially coercive.

While concerned about potential coercion, some interviewees discussed growing up in similar circumstances to the communities they research and understood how impactful monetary incentives can be for families. In many of these cases, their career choices working to reduce health inequalities stemmed from personal experiences in under resourced communities. For example, Sophia describes what led her choose a professional research career working with underrepresented minority populations.

> Being Latino myself plays a big role [in the research and outreach that I do]. I've seen with not only my own family, but my community, how they struggle and sometimes they don't have access to the particular programs or the intervention or the knowledge not because they're not educated but [because] … a large portion are worrying about their basic needs … making sure that they have food on the table [or that] their rent is paid. … Coming from [an area] where it is so expensive to live … a lot of people have to work two jobs in order to make rent … it was really important to me to have the Latino representation and to try and break some of the stigmas and stereotypes and help people learn more about what it means to be part of research.

The researchers that I spoke with were extremely aware of the kinds of basic needs and struggles that particular communities face – often, these structural constraints impact access to healthcare and health resources, and are the same structural barriers that researchers are trying to mitigate and reduce. Yet, in discussing monetary incentives there was a tension between recognizing that vulnerable communities are often in desperate need of resources and determining "how much is too much" or "how high is too high" before a financial incentive seems or becomes an undue inducement. Conversations with Abigail and Natalie illustrate the challenge that researchers have in providing meaningful financial incentives that address structural constraints but without these incentives seeming or being potentially coercive.

> I'm an interventionist, so it's labor intensive studies but [also] the populations are out in the community … [there is a] recognition that the resources really need to be there in order to recruit and retain these families and make it worth their while … My study is very generous [with] compensation … for a one-hour interview … I'm giving the parents and adolescents $50 for the interview, and two or three movie tickets to the adolescent for their participation. … You have to be very careful of [generous incentives]. You don't want your incentives to be [coercive]. The IRB looks at whether they seem coercive or not. You have to be very sensitive to that. But I think they need to be worth people's time because these people are competing with a lot of demands. I mean, I'm a mom and I have a family now and I'm not even from a low resource family … and even I would have a hard time saying yes to a study at this point in my life. So, imagine what we're asking of families … families that are newly immigrated, families that don't have resources. Number one it's difficult, but if you make it worth their while this than becomes a resource for them, [and] you can increase participation.
>
> - Natalie

> I remember having a discussion around [different types of incentives and it was] a problem that remained unsolved … can we offer childcare? Because that was a frequently cited barrier to participation. So, can we tell people yes, you can bring your kids with you to participate in this study and we'll provide childcare for them while you're engaging in this research study? Ultimately, we were not able to find the way to [provide childcare] that was – ethical is the wrong word because it's not unethical – but, that was I guess appropriate. … Even things like providing snacks or providing [research participants] meals or things like that … there are oftentimes monetary incentives for participation in research [and] that is an incredibly tricky tightrope to walk. … If you're working with a low income population, you have to be very mindful that whatever is being offered is not coercive … you have to be mindful of that no matter what but I think you have to be particularly mindful of that when targeting low-income populations.
>
> - Abigail

Researchers talked about financial incentives as potential resources for low-income families. However, the most challenging task for researchers was navigating what it means for a financial incentive to become coercive. As Natalie said, "The IRB looks at whether [incentives] seem coercive or not. You have to be very sensitive to that." Yet, the choice between providing a meaningful financial incentive versus a coercive incentive is in practice not as obvious a choice as it may seem. What could be considered coercive varies from person to person. Researchers discussed how complicated incentive decisions are when working with low-income communities where families experience food, housing, and employment insecurity. Although researchers thought about incentives as helpful resources for the communities they studied, they were worried that their research would be in jeopardy if the IRB viewed the incentive as too high. Consequently, I found that researchers may not feel that they can offer important services like childcare, as Abigail discussed, or they may provide a lower monetary incentive than they think they should, so as to avoid conflict with the IRB.

Although the professionals that I spoke with were actively working to address communities that were underserved and they acknowledged that financial incentives from research participation could be significant resources for some participants, in interviews

professionals sometimes said that the introduction of money changed what they considered to be appropriate motives for research participation. For example, Alexa said:

> There [were] one or two parents that it was very clear they were driven by the incentive who might interrupt the interview we had with the child in the background and say, "Aren't you done yet? You're asking so many questions of my child" and things like that. It's a question about whether it's because … they're concerned about the questions versus they're trying to just get the money and they want to leave.

Implicit in this discussion is that people should not be volunteering only because they want to receive assistance – this feels unnerving to some researchers and implies that the individual was consenting to the study in order to receive in-kind services or money rather than participating for science and social benefit. As Lillian explains, "Some [participants] appreciate money. Of course, [the incentive] can't be something that's going to make them participate because they really need the money." Lillian's comment implies that researchers believe monetary incentives might cause people to participate in a study that they otherwise would not have, especially if the individual is in an economically vulnerable position. However, Lillian went on to explain that research incentives, particularly with low-income communities, need to cover study inconveniences, such as getting to the study visit, taking time off of work, or finding childcare. Research incentives that cover the costs of participation are seen as legitimate and an ethical component of conducting research with low-income and under resourced communities. If researchers were to accept that monetary incentives are the sole motivation behind why some vulnerable people participate, they may feel that they are "buying" research participants or worry that it would be perceived this way by the scientific community, harking back to exploitive studies that prompted the creation of regulatory guidelines for research.

Professionals in this project were painstakingly struggling with what constitutes as an appropriate payment for participating in socially valuable research. The dilemma for researchers

is that there is no straightforward answer for how to define when money becomes coercive. One of the ways that researchers got around the impossibility of defining when money becomes coercive is that they viewed particular kinds of payments to participants as gifts. Forms of payment and how a payment is labeled (as a gift, an entitlement, or reimbursement) signifies the character of a social relationship and designates what kinds of payments are accepted within particular social ties (Zelizer 2020). Money earned through financial incentives for participating in research is different than other kinds of payments. Among the researchers that I spoke with, incentives are not meant to be an income (although perhaps for some vulnerable people it is or at least functions as a supplemental income), nor is it a payment given for a merit, like a holiday bonus. Rather, as researchers in my study discussed, monetary incentives are optional (although a predominant practice), informal and variable, and when presented through gift cards they signify gratitude. For example, Hannah, described how her study provided incremental incentives between $10 and $20 for various data collection time points with participants. Discussing how her study team paid participants she said:

> They were store gift cards [to] local stores. And we did formative research with our intended population with other key stakeholders asking them, which stores, you know, do you shop at? Which stores, if you were to get a gift card, which store definitely, that you would like a gift card from? And so that was, all the way down to the actual store that we selected, and the incentive was informed by our community.

By paying people with a gift card, researchers saw it as a way to provide a gift and thank people for participating in the study. Researchers like Hannah who conducted formative research, wanted the gift card to be meaningful and useful to people but it still could not be too high, and it could not be cash. Payments in the form of gift cards to retail stores signify different kinds of relationships than cash payments. Cash payments to participants have a greater potential to be exploitive because by giving participants cash the relationship (Alan Page Fiske would refer to

this as a market-pricing relationship) treats study volunteers like commodities. Continuing our conversation, Hannah said, "Also, any time that [a participant] came to our study site, we reimbursed the participants for public transportation." Reimbursements for study inconveniences (transportation, parking, etc.) could be given as cash payments because the payment does not threaten to commodify the relationship between the researcher and study participant.

Financial incentives may be influential in bringing people to a study, but researchers are much more comfortable discussing altruism, health education, and benefits that may impact individual communities, as primary and appropriate motives for people participating in research. For example, Natalie said:

> Recruiting parents and children is more difficult. They're busy, they have a lot of competing things going on particularly if you're working with low income families. They're going to sometimes choose to do this study because of the monetary incentive that's involved. That's what is practical and a need for them at that time. But, you know, they have a lot of competing demands and so you really need to make sure that the study is worthwhile, and you present it as being something that's valuable to their community. Something I [try] to do is say that even though this is not going to have an immediate benefit for you, the information that you're providing is going to help other families just like you.

Incentives have tremendous symbolic value in defining the kinds of civic relationships that researchers want to foster with participants. Among the research professionals that I interviewed research participation carried a moral value similar to civic virtue. Researchers believed that all people should participate in research but especially underrepresented minority groups because it will "empower them," "change their lives," give them "education, knowledge … [and] a voice," be "valuable to their community," and as the All of Us Research Program touts, will improve the applications of science and health for all of us (National Institutes of Health 2018a). Among the researchers that I spoke with, the introduction of money can crowd out intrinsic motives that researchers and institutional norms associate with the production of science. This is in tension

with using monetary incentives for effective recruitment and retention, and recognizing that for many underrepresented groups, financial incentives are important and valuable fungible and social resources. Paying participants through gift cards to thank people for participating in socially valuable research was one way that researchers tried to mediate this tension and uphold civic values.

Community Residents

For the Greater Los Angeles residents interviewed for this dissertation, financial incentives received from participating in research were not discussed as symbols of gratitude from researchers or as forms of reimbursement for study inconveniences, but rather as a form of exchange. For many of the residents that I interviewed, financial research incentives were important fungible resources. This was particularly the case among undocumented and first-generation residents who worked in low-wage and in unstable jobs, such as selling food as a street vendor, working in a factory, or cleaning houses. A word about these interviews: Of the 15 interviews that were conducted in Spanish with monolingual Spanish-speaking residents, 12 of the interviewees (80%) had less than a high school education. The average household income of the 15 monolingual Spanish-speakers was between $18,667 - $28,666 dollars. The 15 additional interviews that were conducted in English were primarily with individuals who came to the United States during late childhood or were born in the United States.[8] Among these individuals 9 (60%) had taken some college courses or had earned a college degree. Among both groups, financial incentives were viewed as fungible resources exchanged for participating in a research study that helped supplement other forms of income. For instance, Isabella, a first-generation college graduate, discussed how she and her friends think about research participation.

[8] Please see Table 2 in the Appendix for a more detailed description of participant demographics.

> [My friends] they're just open-minded about stuff. You know, they have this thing like, "Oh, we're young. Why not try it?" They're more open to new things. And … a lot of us are really broke right now. So, if [research participation] came with a money thing, maybe they'll do it for that.

As with many students, recent graduates, and young adults, the opportunity to earn extra money from research can be especially helpful. Convenience sampling of university students has been a widespread practice for decades, especially in consumer behavior, social science, and medical research (Peterson and Merunka 2014; Christakis 1985). University students are often recruited as research subjects because students are easy to access and frequently willing to participate in research as part of the courses they attend (Berander 2004; Peterson and Merunka 2014; Leentjens and Levenson 2013). For other lower socio-economic and vulnerable groups, such as recent immigrants, monetary incentives are very valuable financial resources. This was especially the case for Viviana. Viviana is undocumented, a mother of two small children and is living with her parents in a shared residence. She supports her family by cleaning houses when the work is available. In a demographic survey, she listed her household income as between $0 - $9,999 dollars.

> I like to go to gigs … sometimes they pay you to do studies for this [or] studies for that. [Friends and other] people [I know] with low income, I told them … there's a resource where if you go, call the number and then [the researcher] will see. They can even help you with whatever you have, and they can even help you with your meds. And you can maybe get paid for that because it said on the ad. I mean, I don't know how true it is, or how you can get into it, but I say at least [try].

Community residents like Viviana who were struggling to get by saw research opportunities as part of the larger gig economy. Participating in research could provide financial assistance, but it could also help with accessing other health and social services that they needed. Ethical standards that guide research practices and the oversight of institutional review boards, like those presented in the Belmont Report and the Common Rule, are designed to keep research

participants safe and to avoid the reoccurrence of unethical research practices that have coerced, harmed, and exploited vulnerable persons. Researchers cannot "buy" or bribe participants to join their studies, nor can they persuade someone to join because that person has limited or few other options for the resource (either in-kind or monetary) that the study is offering. Yet, for many of the Latinx residents that I interviewed monetary research incentives were sometimes a primary reason why they participated.

Among my interviewees, research participation was primarily viewed as a form of exchange for their time and involvement in the study. Particularly for people who had very limited employment options or could not work in a traditional marketplace because of their documentation status or health status, participating in research was similar to another type of "gig" to make money where they would be paid for their time. One of the more candid presentations of this occurred when I was recruiting interview participants for this study at Community Health Center, a federally qualified health center in Greater Los Angeles. The health center network sees roughly 21,000 patients, with 72% of patients identifying as Hispanic/Latinx. In 2018, 82% were at or below the federal poverty guideline. Just over 11% were uninsured and 76% were insured through Medicaid, Medicaid Children's Health Insurance Program (CHIP), or other public insurance CHIP programs. I had been granted approval to talk with patients about my dissertation study while the patient waited in an exam room before being seen by a clinician. On one occasion when I was accompanied by a Spanish-speaking bilingual research assistant, we knocked and entered an exam room where a middle-aged man and woman were seated side by side in chairs waiting for their appointment. The man was holding a folded probing cane, often used by people who are visually impaired. Another probing cane was nearby that I assumed belonged to the woman. We introduced ourselves as researchers and students

from UC Irvine, speaking in both English and Spanish, and asked what language they preferred to continue with. Both of the individuals spoke Spanish but preferred to continue in English. I started to explain that we were conducting a study but before getting to discuss the topic of investigation or what we were recruiting participants for, one of the individuals interrupted and said, "How much? How much?" referring to the expected financial incentive for participating. I told the individual that participants would receive a $25 gift card for participating in a 60-minute interview about their health experiences and medical research. Immediately, the individual said "Ok. I'll do it," with the other patient chiming in that they also wanted to be interviewed. Although we collected their contact information (after continuing through the full study explanation and informed consent process), I did not interview either individual for this study because of scheduling conflicts and challenges reaching them by phone with the contact information they provided.

I left the exam room feeling troubled and concerned about what had transpired. As a trained researcher, I had the same concerns that many of the research professionals I interviewed for this study expressed – that it's inappropriate for people to participate in research if primarily motivated by a financial incentive. Financial incentives are an extremely common recruitment and retention practice but how does one gauge when an incentive becomes an undue inducement, particularly for socio-economically vulnerable individuals? I assumed that the individuals in my recent encounter were primarily interested in the $25 gift cards, and that made me feel uneasy. Ethical research guidelines are in place for important reasons, with plenty of historical breeches in ethical practices to remind us why they are vital. Ethical review boards shy away from accepting any instance where people may be primarily motivated by money because of fears (and valid concerns and consequences) of the potential for coercion, harm, and exploitation. Situating

research best practices in isolation from structural and cultural constraints, presumes that people should be volunteering for research because of altruistic or civic intentions. Using this moral framing, the inclusion of "too much money" corrupts or “crowds out” altruism and civic virtue (Titmuss 1971; Frey, Oberholzer-Gee, and Eichenberger 1996; Sandel 2012).

Similar to the research professionals who viewed volunteering for research as from of civic engagement, a small number of community residents that I spoke with also underscored a moral value to research connected to civic engagement and social solidarity. For example, one resident said, “I think it was very helpful. I felt good to donate my blood for it to be studied,” with another mentioning, “I felt good to be able to participate and contribute … a little bit of information.” A third resident, explaining why she would participate in biomedical research said, “Maybe you will find a cure [for an illness] in the future. Perhaps not for us but for our descendants.” However, for a few community residents these intrinsic motivations were in tension with being paid to participate. For example, Ava questioned why research participants should get paid to participate in something that benefits society and gives her an opportunity to learn more about her own health and strategies to improve her health.

> I’m interested and I like to learn what I don’t know …[and] I like to relearn what I might already know. A man was saying that he would like a higher compensation fee to increase participation. I told him that we’re so shameless … I truly feel shameless to ask for more money since you [researchers] are already giving me some in exchange for my participation. Why would you give me money if I’m the one who’s interested in learning? Of course, if you’re willing to give me some that’s fine, but if not, it isn’t time wasted for me. The man kept saying that more money should be given so that our society is more interested in letting you interview us – as a greater stimulus. It doesn’t sound right to me.

Laura was of a similar opinion:

> The [health education] classes I attend [at a health clinic] are called “Eating Healthy.” They first showed us how to cook in a healthy way and what to eat in order to be healthy … I took this class because I am diabetic. In addition, I took another course that was similar but in this course a doctor … would educate us about how to take our medications properly … the doctor in this class said we would receive a larger monetary

> compensation if we attended the classes. My personal opinion was that we did not need a financial incentive in order to learn something that may benefit us. After I made that comment there were many contradictions, some people said yes, others said no.

For community residents like Ava and Laura, paying people to participate in research commodified the relationship between researchers and participants. Getting paid to participate in research that could potentially benefit society and themselves did not feel right. Payment was problematic for them because instead of being an act of civic solidarity, research participation was a commercial exchange. Before Ava shared the story about the focus group she participated in, she mentioned that she enjoyed going to health talks and participating in focus groups because she has time and currently does not have to work. It may be that residents like Laura and Ava experience greater financial stability than other interviewees in this dissertation and feel more intimately connected and accepted within their local communities. As mentioned in an earlier chapter, researchers often frame biomedical studies through communal sharing relationships (Alan Page Fiske 1991) that privilege altruism and people participating out of solidary. It may be that the handful of interviewees that viewed research relationships through this same schema were better situated in their communities. Feeling accepted and cared for, they did not need supplemental forms of income.

The majority of the Latinx residents that I interviewed did not discuss research in social and civic solidary frames, and monetary incentives were straightforward and unproblematic. For community residents who emphasized that researchers are "paying for our time," gift cards in exchange for participating were not seen as corrupting their sense of civic duty. Rather, community residents viewed research incentives, such as gift cards, as payments. Residents did not explicitly discuss different forms of remuneration (for example, gift cards versus cash) but instead talked more generally about incentives and being paid. For community residents, gift

cards were like cash because it was redeemable to buy things that they needed, and the medium of the gift card reflected that they were getting paid for their time and participation in a study. Researchers wanted ordinary people to participate in research for the sake of science and they viewed gift cards as a gift. It is likely, that if researchers had paid community residents through a gift that residents could not easily exchange, residents would not have felt that the exchange was appropriate. Paying research participants through gift cards is a way to mediate the different desires and ideas of researchers and community residents. Participants still feel that they are being paid for their time and researchers avoid market-pricing relationships through a redeemable gift of gratitude and maintain that research participation should be tied to civic duty.

Significantly, when ordinary people frame and understand incentives as a form of exchange for time and compliance in a study, the symbolism of the incentive underscores for them how research participants and study investigators are not on equal footing. This is in direct contrast with research initiatives that frame participants as "partners" in research, where participants and researchers are equal collaborates working together. However, just as paying someone cash for intimacy signals a very different kind of relationship than giving a gift to an intimate partner, paying people for participating in research signals a different kind of relationship than a partnership based on equality. For example, Nina Bandelj (2012) reminds us of the "relational work" (Zelizer 2005) that Julia Roberts' character in the film *Pretty Woman* conveyed when after an argument she did not take the cash that Richard Gere's character left for her, but she took the clothes that Gere had bought for her as gifts. For community residents, payment for research participation highlighted power imbalances between themselves and researchers, and the impression that monetary payment in the form of research incentives is contractual with participation.

A significant theme in interviews with Latinx community residents was that even if people desperately needed financial, social, or medical help, they were extremely skeptical of the research process. They were overwhelmingly concerned, with some people staunchly asserting, that they would be exploited if they agreed to participate in research. Camila, who works as a promotora, providing basic health education to other Latinx residents in her community, explained in Spanish why she does not trust researchers.

> I like to help and support people, and I do not see that these studies are committed to doing that. I have seen research studies happen just for the sake of happening and they just leave. If there was an outcome, result, or consequence, we don't know about it … I feel like a lab rat … we volunteer to participate but then what do the researchers provide for us in return? For me, it seems like a double standard. I feel that the mentality on the part of researchers is, "I'm giving you this money, so you have no right to complain."

For Camila and other community residents, relationships with study investigators are exceptionally imbalanced. In her job as a promotora, Camila works closely with residents in her community and because she is involved in health promotion efforts she understood more than other interviewees how research typically works. Camila's discussion of "helicopter" research studies, where researchers conduct a study in a community but leave without informing residents or bringing benefits back to the studied community, highlight how people can feel used or betrayed. This is especially the case if researchers tell residents that their research will benefit their community because ordinary people are not seeing or experiencing these benefits. When asked what researchers could do to help people feel comfortable to participate in research, the resounding comment from community residents was that they wanted to trust researchers. Responding to this same question, one participant said, "I think above all honesty because if they tell you one thing and they do something else, where is the honesty? That's just a hook, nothing else." Additionally, by accepting payment for participating in a study, people felt like they were

entering into a contractual agreement but without any confidence the researcher would hold up their side of the bargain or without any recourse if the relationship went sour.

Distrust of biomedical research and more broadly of scientific professionals is interwoven with overall distrust of institutions. Many of the community residents interviewed for this dissertation were still learning the laws, policies, and cultural norms of a new country, and additionally worried whether they or their family members would get deported. These factors combined with people's lower levels of education and experiences with poverty, heightens people's awareness of their vulnerability. For example, Sandra stated:

> … Regarding scientists and studies, sometimes we get scared because we don't know what those words [that the scientists use] are meaning … there was this lady here at the clinic and she said that they wanted to give her injections so she could die. For real! So, she said "no, I'm not going to let them do that." And then [I] think about how they say that the sick is a burden for the government but that's not true because we work for our things.

Sandra's comment from a pilot focus group captures the complexity of concerns about research participation interwoven with systemic inequalities, socio-political context, and Sandra's personal experiences as an immigrant in the United States.

Many residents discussed working in low-wage jobs. As one resident said in a focus group, "You can say that we do the dirty jobs [that no wants to do]." Research participation was another kind of undesirable but supplemental low-skilled exchange (similar to other kinds of gigs in the gig economy) that people resorted to when they were in desperate need of financial or social resources.

> For us, our Hispanic community, it's very difficult to survive in this country given that food is very expensive, rent, services, everything. Not everyone has the means to buy, right? Or pay for it … they need help. They need a bit of help to get ahead. It's really unfair given that we are, as Hispanics, we come to work and, in many cases, we are a pillar for this community … We do the hardest work and we have the worst services. We have few places we can go to the doctor or few places we can go ask for a bit of help.

Participating in research was one strategy that residents turned to in order to get by in an American capitalist system that leaves people to struggle with minimal social safety nets to provide relief. However, participating in research was commonly seen by community residents as a risky, dangerous, and as a last recourse form of exchange. As one participant said in a focus group, "There is a bit of fear always because [I'm] afraid that they will treat us like a guinea pig." The metaphor of a guinea pig or a lab rat was used to describe the potential harm that people felt they might experience by participating in a research study, and the impression that people are exchanging their bodies (and potential safety and wellbeing) for financial compensation. For instance, Sofia and Gloria said,

> You know when scientists do those things with guinea pigs, they're using them to test certain things. I guess they don't really care about the guinea pig. Maybe the guinea pigs can go and die … [researchers] try things on rats too to see if it works out. Like out of 100 rats, 10 of them did this, 10 of them did that. They need to test it on somebody, right? When you test it on an animal it's one thing, but our bodies – human bodies – are different than an animal. It works on a rat but is it going to work on people? … That's why they pay you for these types of things. That's the only way they're gonna get people to try it, is the compensation. I don't think anybody would willingly do it for free.
>
> - Sofia

> Imagine if I tell someone that I got $25 for [answering] these questions. He or she wouldn't believe me. [They] would say no, it couldn't have been just because of that. There must be something else other [than] that. Something that could hurt me.
>
> - Gloria

Community residents such as Gloria and Sofia worried that researchers knew something that they did not. Residents were not so much concerned that researchers would not pay them, but rather that that researchers knew something that they did not, and what they did not know could harm them. Residents viewed getting paid as a necessary feature in order for scientists to convince ordinary people to participate in biomedical research studies. For community residents, the symbolic meaning of receiving a financial incentive was that they were being paid to participate in something that no one else wanted to do. And, they might get hurt doing by it.

Associated with being paid to participate in research was the feeling that because people were paid, researchers would treat their subjects as disposable. In pilot focus groups and during in-depth interviews, I described a biomedical study that framed participants as "partners." After describing the study, I would ask residents what their initial thoughts were about the program. Hector responded this way:

> You are saying that you will only take a small sample of my urine but what about later on? What if later you tell me take this or that? If that is the case, then no [I won't participate]. What we want is an explanation before they present us with something, or they give us something. Because something that helps one individual may harm me. And what is beneficial to me can kill someone else … I will not allow you guys to cripple me because you're giving me $25 dollars.

Hector's reaction was not unusual. For many residents being compensated symbolized an exchange whereby accepting the compensation they gave up their rights to their body for scientific experiment. As another participant in the focus group explained, "I'm not going to [participate] if someone asks me to participate in this study because [I] have arthritis, high blood pressure, or whatever … I would say no, I don't want to be the guinea pig." Furthermore, and as discussed in an earlier chapter, for many of the community residents interviewed for this dissertation, health care experiences were intimately connected and not always differentiated from scientific research. Alejandro's story of losing his wife illustrates how the root causes of distrust cannot be parsed out to a singular social factor.

> Everything in life is dangerous. In my experience, I've suffered, and I do not trust anyone because … my wife was told she had spots on her liver [and] it was cancerous. And on the day [that] she decided to operate, she never had problems. [My wife] went to the doctor … and there were college students there too with books. She was lying down for a while and then a lot of students told her, "sign this paper for a study," and she said yes. Well, I do not know what they did. After 15 days her stomach was filled with water … what did they do to her? … She wasn't sick before. Yes, she didn't feel well but her stomach was not filled with water. After the operation she went to the hospital every week. What did they do? Who knows … maybe it's an experiment for humanity but the bad thing is that they give [you] papers, by consent[ing] for blood, etc. and [I] don't know what they signed, so it could be [that] they took out a kidney. It's a thought."

It is unclear from Alejandro's story what led to his wife passing away, but most significantly from Alejandro's point of reference, his wife was mistreated and experimented on without being properly informed on what she was consenting to. For Alejandro, his wife's passing was another example of the scientific professional elite treating research subjects or patients as disposable.

Lastly, both research professionals and community residents discussed learning about health promotion in general and particular diseases as a benefit of research participation, and that this benefit may sway some people to join a research study. Frequently, research professionals framed learning as rooted in altruism. Studies could be intrinsically meaningful, and people wanted to learn more to better themselves, their communities, and society at large. This framing correlates with the way that researchers also often frame biomedical studies through a communal sharing schema (Alan Page Fiske 1991), where research participation is a form of solidarity that benefits all of society. However, for community residents learning health information that could be personally beneficial was not discussed as intrinsically meaningful (although it may have been). Instead, learning was predominantly discussed within the context of structural inequities that make it challenging for them to have opportunities to learn more about their health. People wanted to learn more about their health but lacked opportunities to do so.

While altruism and a desire to better society may be influencing factors, structural constraints and overlapping forms of inequality are directly connected to why residents discussed learning as a benefit of research participation. For example, Sofia said, "I think that we are all here so we can help others – to find better alternatives and to help people avoid reaching the point we reached because we did not have any information to help us." Participating in research to gain health information and resources was a common refrain among interviewees. For example, in a focus group on people's attitudes towards research, one woman said, "I come to

these [focus] groups to learn more because I have a child with a disability, and she takes medicine. She takes four medications daily and I told myself that I would come to learn more and see what you all tell me." Within the context of immigrant assimilation and underlying poverty, for these individuals research participation was an opportunity to get access to information, people, and services, that they otherwise would not to have access to. Rosie's story is a good illustration of this point:

> When I recently came to the US 17 years ago, they invited me to do a study for the [human] papillomavirus. I did not know much about papillomavirus, I did not have much information [on] what it is. After they gave me information what it is, how you can prevent cancer, I said "wow, I did not know this." So, I decided to participate in the studies because I saw the prevention for me. Participating in the study I'm not only doing it for the researchers, I am doing it personally as a prevention for myself. This was the [reason] that I got hooked to participate.

Scholarship addressing the "what" and "why" conundrums of people participating in research often discusses these issues through an individual perspective. For example, is the study intrinsically meaningful, where people's interest is rooted in altruistic motivations? Or are people driven by a particular project-related study, for instance diabetes research, where people are interested in the topic of the study? Framing the desire to learn through an individual lens can overlook the important structural factors that influence people's attitudes and opportunities. Lillian connected research participants' desire to learn targeted health information to structural opportunities, but her comment was unusual and stood out from most researchers who predominantly talked about learning as being intrinsically motivated and meaningful.

> What I've learned, which is not something I ever thought about, based on the [focus groups] we've done [and] some of the feedback we've received … from the Hispanic community is that they would participate because they want to learn. They have chronic illnesses [and] they don't know how to manage them. A lot of them don't have insurance. … It is difficult to make [or] get an appointment with a doctor who cares. So, they feel like if they were in a study, somebody would be able to sit down with them and provide them with information and that would improve their lives … Because they feel like …

> they do not have a good way to access it currently. So that was one of the reasons why they would join studies.

People may participate in research because they lack access to medical services and opportunities for health promotion. By primarily framing learning as another form of intrinsic motivation, scholars may miss the significant ways that for lower socio-economic and vulnerable populations, structural inequalities drastically limit people's access to health resources. This suggests that researchers may be overlooking important ways to both incentivize people to join their studies and to address health disparities by incorporating in-kind incentives that offer health education.

Conclusion

My interviews with community residents and research professionals tell a complicated story of how people symbolically understand different kinds of incentives and grapple with how to define research relationships. This project expands on our understanding of the different and resourceful ways that people identify and classify, create and use, and socially and morally value various kinds of money (Zelizer 1997; Bandelj, Wherry, and Zelizer 2020; Zelizer 2012). For economists, every dollar is the same as every other dollar but moving beyond the characteristic of fungibility, we see that money is fundamentally a social medium for how people understand and frame relationships. People have distinct understandings of different types of money. The context of where and how the money was received and what kind of money, influences people's evaluation and social understanding of money, the relationship between the giver and receiver of money, as well as the creative ways that people organize and use money (Zelizer 1997). This dissertation is an investigation into how people create and understand research relationships. Overwhelmingly, scholarship tends to focus on the appropriate levels of benefits or payments to

participants, and the ethical considerations when providing monetary research incentives. This work fails to recognize that researchers and their study participants do not always have the same symbolic valuations of research incentives. This chapter highlights how among economically and socially vulnerable immigrants, a $25 gift card given to participants from research professionals may symbolize a very different relationship structure than what professionals hope to foster.

The research professionals that I interviewed for this project were in a tough position. They wanted to provide financial incentives that would be a significant financial resource for the vulnerable communities they studied. At the same time, the incentive could not be too high, where it might pressure socio-economically vulnerable people into participating in something that otherwise they would not have done. Furthermore, researchers were more comfortable talking about intrinsic reasons why people *should* participate in research, discussing participation as a civic virtue, with potential benefits to individuals, their communities, and society at large, than they were in discussing the possibility that monetary incentives are sometimes a reason why some especially vulnerable individuals participate in research. Yet, my interviews with community residents highlight that people *do* participate in research studies to receive a financial incentive, where without a financial incentive they might not have volunteered. Investigators model research participation as a form of civic engagement that advances scientific knowledge and betters society. For researchers, a danger of people participating in research for money is that people participate for the "wrong reasons," which by this argument threatens to erode the social value of research. Gift cards as incentives are one way that researchers try to symbolically define the kinds of civic relationships that they want to foster with participants – gift cards are a gift to thank someone for participating in a socially valuable act (like an "I voted sticker"), not a payment. However, ordinary people do not typically frame research participation through civic

values. And rather than seeing incentives as a thank you gift, they view financial incentives as payment for their time and compliance in a study. Instead of contesting people participating in research for financial incentives, we should recognize that people already do and ask, if participating for a financial incentive really erodes the social value of research if ordinary people do not frame research that way in the first place. And lastly, the stories that community residents shared demonstrate the extreme inequalities in how racial and ethnic minority groups, recent immigrants, impoverished people, undocumented workers, and other vulnerable groups access medical care and experience the health care system in the United States. For these individuals, financial incentives from participating in research were extremely valuable financial resources, pointing to larger issues of social injustice.

Interestingly among the research professionals that I interviewed, individual potential benefits from research, such as health education and learning preventative health strategies, were mostly discussed as intrinsic forms of motivation without addressing the social and structural barriers that limit people's social networks and opportunities to social and health services. Framing the benefits of learning through an individual and intrinsic lens was especially surprising given that many researchers discussed research methodology, such as community-based participatory research (CBPR) models, that seek to mitigate structural barriers that often limit vulnerable people's ability to participate in research or access health services.

The Greater Los Angeles community residents interviewed for this project also viewed financial research incentives as important fungible resources, but the incentive was seen as a form of payment for their participation in the research. Paid research participation was a very important kind of exchange for time, particularly for individuals who experienced extreme financial duress or had limited employment options. Although some community residents did

morally value research participation in similar ways as research professionals (for example, as a civic virtue that should be upheld), overwhelmingly, this was not the central reason that people discussed participating. Rather, participation was another kind of gig that could help supplement other forms of income and provide opportunities for other forms of social and cultural capital. Significantly, payment for participation in research occurred within an unequal power structure. People participated because they needed the financial or social resource, but residents worried that in accepting the money, they would be exploited.

Future research should consider under what social conditions payment to research participants might be advantageous for fostering particular kinds of researcher-participant relationships. IRBs frequently keep payments to participants low in an effort to minimize the possibility of coercion and undue influence. This project and a growing body of scholarship (Largent and Lynch 2017), suggests that the link between payments that are "too high" and coercion might be overstated. Research professionals interviewed for this dissertation were extremely worried that their incentives may appear coercive, but community residents were much more concerned that they would be taken advantage of and harmed. When payments are appropriate, participants (and some scholars, see Dickert and Grady 1999; Grady 2005) underscore that research participation is a kind of exchange for time and study contribution. Payment conservatism, keeping research payments low, is a play-it-safe precautionary measure to avoid any possibility of coercion or undue influence. Instead of a predominant focus on payments that are "too high," IRBs and investigators should also be concerned with the ethical and practical concerns associated with keeping payments "too low," and what the social and symbolic value of low payments means for building relationships with study participants. Low payments may minimize the possibility of undue influence, but the social cost of low payments is

that some individuals may feel exploited, disrespected, or treated as disposable. If volunteering for socially valuable research is a form of exchange for some individuals, and morally valued as an act of solidarity and civic participation predominantly among the scientific community, we must reconsider what the social value of monetary incentives says about how we value and nurture these relationships.

Scholarship on research incentives discusses what are appropriate levels of incentives that limit the possibility for undue inducement (Grady 2005; Dickert and Grady 1999; Bentley 2004; Njue et al. 2015). However, a sociological perspective on this issue points to another important discussion: What kinds of relationships do researchers imagine having with their study participants, and are there certain types of incentives that are better at signaling and fostering these kinds of relationships? Financial incentives can be important fungible resources for socio-economically vulnerable groups, but beyond a fungible resource they have a more complicated symbolic value. Monetary incentives sometimes symbolize to people that they are being "bought" for their participation, or symbolize that as an individual research commodity, they are disposable. These concerns are especially prevalent when people already feel extremely constrained and positioned in an unequal social relationship. As discussed in earlier chapters, equalizing research through "partnerships" with participants and investigators has additional challenges. Ordinary people don't often relate to this kind of relationship framing.

Overwhelmingly, the residents that I spoke with wanted to be treated with respect, and they wanted better health care services. Community residents wanted opportunities to learn more about their health, how to eat healthy, and greatly wanted help with the U.S. insurance system and how to find and access affordable health care. These are problems rooted in structural inequalities. In-kind incentives, for example offering research-related medical benefits or health

education classes, may be more socially valuable to people. Additionally, these kinds of incentives address the structural landscape of communities by working with communities to together provide the social services that people are lacking. In-kind community wide benefits, combined with specific types of monetary payments, may help to foster greater trust with participants by changing the way people experience their relationship with researchers.

Researchers may want to consider using various types of monetary and in-kind incentives together but for different reasons. For example, cash to reimburse someone for study related expenses, a gift card to a community appreciated retail store to show gratitude, and in-kind incentives to establish a civic engagement model that is directly connected to community needs. Payments to research subjects are likely only to become more pervasive, as commercial funding for clinical research increases, the pressure for more inclusive research practices continues, and precision medicine is advanced and applied. It is easy to imagine different ideals and creative incentive possibilities that combine in-kind and monetary inducements, but the practicalities of enacting these suggestions are of course complicated, requiring extensive human, social, and financial capital, not to mention time. However, if committed to advancing ethical and socially valuable research, at a minimum we must consider how the social meanings of research incentives matter for the of relationships that develop between researchers and the people who volunteer.

CHAPTER 5
Conclusion

The insufficient representation of diverse research participants has been a longstanding problem in biomedical research. Despite federal guidelines passed over 25 years ago prioritizing the inclusion of women and minorities in clinical research (*National Institutes of Health Revitalization Act* 1993), experts still struggle with enrolling people from underrepresented communities in essential research. For instance, 18% of the U.S. population identifies as Hispanic or Latinx, yet on average they account for only 1% of clinical trial participants (U.S. Census Bureau 2019b; Aleccia 2020). Recruitment experts point to several barriers to participation, including that minority populations often have unequal access to health care centers that serve as referral sources for biomedical studies (Oh et al. 2015), financial constraints, competing demands of time, cultural and linguistic differences, fears of unintended outcomes and medical exploitation, and deep-seated distrust of medical authorities (Ceballos et al. 2014; Corbie-Smith, Thomas, and St. George 2002; Corbie-Smith 1999). Partnerships between researchers, community organizations and lay people are novel research approaches that aim to address mistrust and other barriers to participation by collaborating with underrepresented communities (Cornwall and Jewkes 1995).

When I began this dissertation research in the summer of 2018, I was intrigued by how "partnerships" were used to encourage people from diverse backgrounds to participate in biomedical research that sought to advance precision medicine. President Barack Obama had announced the Precision Medicine Initiative only a few years earlier (Obama 2015), and the All of Us Research Program, arguably the most expansive and sophisticated research effort to date utilizing participatory methods, had begun nationwide enrollment in May 2018. Up until roughly January 2020, diversity in clinical trials was a problem that was primarily discussed and confined

to people within the scientific community and within advocacy groups. The novel coronavirus (COVID-19) which evolved from an isolated disease in an area of China to a global pandemic, has changed that and just about everything else in our society (AJMC 2020). COVID-19 has pushed hospital systems to the brink, brought countries to a standstill, and in the United States, has laid bare the role of systemic and structural racism in health disparities. According to federal data, black and Latinx people are three times as likely as white people to become infected with COVID-19, and twice as likely to die from it (Aleccia 2020). The irony is that the people who are following the COVID-19 vaccine development, who have learned about the nuances of medical research, and have volunteered to participate in clinical trials, typically have privileges that make them much less likely to contract the virus (Johnson 2020b), while the communities that could most benefit from a safe and effective vaccine are among the least likely to be included in vaccine trials. The COVID-19 pandemic has forced a rethinking on how we socialize and work, how we conduct science and the speed at which it is possible to find a vaccine, and on the crucial need for diversity in clinical trials. Experts have turned to community organizations and community leaders, partnering in efforts to enroll minority participants in COVID-19 vaccine trials.

In this dissertation, I have analyzed how "partnership," a key term in a broader participatory approach to involve minority communities in research, is understood and enacted by research experts and people from underrepresented communities that researchers hope to enroll. I found that the socially constructed relationships that research experts draw on to understand, evaluate, and justify biomedical research participation are fundamentally different from those on which ordinary people draw. The low-income first and second generation community residents I interviewed for this study did not make a clear distinction between

research and healthcare. People's experiences with medical care were intimately connected to their attitudes toward biomedical research. Consequently, "partnering" in research as an individual "participant partner" was confusing for most ordinary people since notions of partnership did not match what people expect and want from their relationships with medical care professionals. This study highlights how the underrepresentation of minority groups in biomedical research is part of a more general failure by research teams to recognize the different ways that ordinary people think about and act on relationships.

I found that biomedical researchers frame research by privileging altruism, volunteerism, and caring for future generations. Participating in a research study is viewed as a form of civic engagement. Investigators suggest that research involvement will be empowering for individuals from underrepresented minority communities. Research participation is an opportunity for local people to learn about medical research, to feel connected to their community, and provide benefits to future generations. The spectrum of partnership approaches that researchers use, from symbolic rhetoric to reciprocal relationships, are efforts to foster trust and make research more democratic. Researchers imagine that partnerships signal to ordinary people that as study volunteers they are part of a broader health solidary movement, contributing different kinds of equally valuable information and skills where people learn both together and from each other. By framing monetary research incentives as gifts to thank study volunteers for their time and participation, researchers symbolically uphold relationships with ordinary people where the moral value of research is connected to civic virtue.

Significantly, for most of the low-income first and second generation community residents that I interviewed, research was viewed as an extension of or the same thing as medical care. Community residents relied on their relationships with medical providers to frame,

understand, and evaluate new relationships with biomedical researchers. Mistreatment by health care professionals fundamentally shaped how community residents felt about their current or potential relationships with researchers. Viewing research and medical care congruently, people's fear, skepticism and distrust of researchers was directly connected to people's experiences being mistreated while receiving care or not getting the kind of medical care that they thought they deserved. Although some community residents connected research participation to civic engagement, most people saw research participation as an exchange. Monetary research incentives were payment for their time and compliance participating in research. Overwhelmingly among the vulnerable population that I interviewed, participation in research was most often motivated by a desperate need for health and social services and getting paid. The most significant concern people had was that by accepting financial payment from researchers, they could be exploited. Negative medical care experiences, fears of exploitation, and among undocumented immigrants, a real fear of deportation, were primary reasons why people declined to participate in research.

Relationship schemas shape people's ideas about what their obligations and entitlements are to other people (Alan P. Fiske, Haslam, and Fiske 1991; Alan Page Fiske 1991; Alan Page Fiske and Tetlock 1997). The mismatch in how researchers and ordinary people from vulnerable economic and socio-political positions frame their relationships with each other is a primary reason why even when given the opportunity to participate in research, some individuals may choose to opt-out. Biomedical initiatives that involve participants as partners suggest an egalitarian and reciprocal relationship between ordinary people and researchers. However, community residents did not draw a clear distinction between research and healthcare. Experiences with systemic racism and discrimination, being uninsured or underinsured, or

receiving inadequate medical care, solidified to people in painful ways that their relationships with medical professionals were drastically imbalanced and that medical professionals were not providing the health benefits and care that people felt they were entitled to within the relationship. Community residents' mistrust of research did not primarily stem from past research experiences (most people had never participated in a research study). Instead, it came from people feeling that they were not being cared for by medical professionals and failures of the U.S. health care system to keep them safe and healthy. Community residents wanted to be respected and provided with safe and affordable access to health services, and for the people who were uninsured or underinsured, to have high-quality affordable health insurance.[9] Rather than being a "partner" in research, a relationship frame that did not make sense to most people, community residents wanted their relationships with medical professionals (which included biomedical researchers) to provide them with immediate health and social service assistance.

Researchers also talked about "partnership" in conflicting ways among themselves. Partnership talk, even when used symbolically to communicate research values, tends to be confusing, where research experts and ordinary people were skeptical about what the relationship actually entails or an appropriate way to enact it. This contrasts with partnerships that are developed with community organizations, where researchers agree on ideal characteristics and best practices for developing sustained, egalitarian, and reciprocal partnered relationships. Partnerships that are forged with community organizations are more successful at involving minority groups in research because they incorporate and respect local knowledge, and additionally recognize that the greater inclusion of minority groups is connected to broader aims

[9] This aligns with data on health care utilization and health disparities in immigrant and undocumented immigrant communities, where we know that stable health insurance is an important predictor in health care utilization (Kaiser Family Foundation (KFF) 2020; Artiga and Diaz 2019) and that undocumented immigrants are significantly more likely to be uninsured than U.S. citizens (Kaiser Family Foundation (KFF) 2020).

to eliminate health disparities. Researchers and community leaders use multifaceted strategies to mitigate structural barriers that impact health access and obstruct research participation. Yet, even in more engaged models of partnership that have greater promise for involving minority communities in research, there are significant challenges. Beyond securing adequate funding, researchers have to decide which organizations best "represent" the community, and how community representatives will have a role in decision making or shared power. Additionally challenging is deciding what kinds of investments researchers owe to community organizations and ensuring that these promises are fulfilled. The different ways that researchers thought about and operationalized organization forms of partnership, with a broad spectrum of what people gave back to local communities and how they did this, suggests that some claimed partnerships may actually be closer to conventional research relationships. My interviews with research professionals show that while partnership models emphasize fairness, egalitarian exchange and sustained relationships with community partners, fulfilling these ideals in practice is incredibly challenging.

In addition to addressing the structural barriers that impede access to care and participation in biomedical research, understanding how people frame and interpret relationships is vital for increasing the diverse representation of research participants. In the scientific community research and care are distinct yet linked practices, but this dissertation highlights how ordinary people do not always make this differentiation among the relationships with medical professionals that they have. This begs an important question: What advantages come from prioritizing the differences in medical care and medical research relationships? If people's experiences accessing and receiving medical care are intertwined with how they understand and make decisions about research, this suggests that rather than focusing on the differentiations

between these experiences, experts should pay more attention to the similarities in how ordinary people frame and experience these relationships. Changing people's attitudes on research participation and developing greater trust is connected to people's relationships with medical care providers. Research experts will benefit from developing sustained partnerships with care providers that extend beyond just recruitment assistance, but instead focus on people's experiences with the U.S. health care system and how to make relationships with health care providers better.

Study limitations and future directions for research

I have drawn on conversations with health and medical researchers and with ordinary people to examine how partnerships developed with minority communities are understood and enacted by both groups. As discussed in the methods section of chapter 1, not being able to speak Spanish fluently was a significant limitation for conducting this research. I mitigated this challenge by collaborating with an excellent team of Spanish-speaking bilingual research assistants. Their support on this project was invaluable. Even when working with your own language, we can assume shared means of words or phrases, but people may be using particular terms in different ways. Conducting qualitative research requires not making assumptions about shared meanings. Translating interviews from Spanish to English is not an easy task and exacerbates these challenges. Although conversations in Spanish were meticulously translated, some words may not have had a direct English translation and could have been interpreted in a different way than what the interviewee may have meant.

An additional limitation of this study is that the perspectives of leaders and advocates from partner community organizations are missing. This would have been helpful to examine how partnerships are negotiated between researchers and community leaders and analyzing what

community leaders value from these partnerships and what they receive. Additionally, it would be useful to examine the role that community advocates have in the development of research partnerships. For instance, Moderna, a Massachusetts based biotech firm, was the first to launch a COVID-19 vaccine trial in the United States. They partnered with the National Black Church Initiative (NBCL), a coalition of roughly 150,000 African American churches, to have support enrolling African American participants into the phase 3 trial. Anthony Evans, the president of the NBCL, was recently quoted saying, "It's not that the industry came to me, I went to the industry" (Aleccia 2020). It would be important to find out if this is typical, where community leaders and activists have a more concerted effort in the development of partnerships and advocating for diversity in biomedical research.

Future research would also benefit from investigating how partnerships are understood and experienced by ordinary people who are intimately involved as a "partner" in CBPR, a very specific model of partnership that involves local individuals in the research development, data collection, and analysis. The majority of the community residents that were interviewed for this project did not have experience participating in research and struggled with regular access and being able to afford health care. Are individual notions of "participant partnership" and research relationships understood in different ways by people from different socioeconomic or educational backgrounds? Are there social environments where "participant partnership" makes sense to people?

Looking forward

Focusing on partnered approaches to involve minority groups in research, this dissertation has been an investigation into how people create and understand different kinds of relationships. Not all research initiatives are suited for the types of community partnerships that

were analyzed and discussed in this project. However, conventional research can, and I would argue has a responsibility to, adopt key principles of broader participatory research approaches if committed to the inclusion of diverse communities in research. Ultimately, participatory research approaches acknowledge that local people are knowledgeable and have valuable forms of social and cultural capital that are instrumental for the success of biomedical studies. These approaches also recognize that the underrepresentation of minority groups in biomedical research is intimately connected to people's access to medical care services. In this project, I have argued that how people frame and understand relationships is as important as structural and cultural barriers in understanding the limited involvement of minority groups in research. The greater involvement of underrepresented populations in research requires that researchers address how people's experiences and understandings of their relationships with health care professionals fundamentally shape their expectations of research.

As vaccine clinical trials for COVID-19 get underway, only time will tell if these trials are successful at being inclusive. Scientists are under enormous pressure to enroll participants quickly, and although FDA guidelines for trials call for the diverse representation of racial and ethnic minorities, older people, and people with underlining conditions, ultimately these are nonbinding recommendations (Aleccia 2020). The FDA has said that they will still accept vaccine trial data that does not include diverse people (Shapiro 2020). Vaccine trials are being coordinated through the COVID-19 Prevention Network (CoVPN), drawing on four long-standing federally funded clinical trial networks (Aleccia 2020). Three of these trials targeted HIV and AIDS and developed collaborations and partnerships with community organizations that primarily represent black and Latinx communities.

COVID-19 has challenged nearly every aspect of research in the United States, from the scale and speed at which we coordinate studies, to how trials are conducted. Sweeping across nearly every country in the world, it has been suggested that COVID-19 is the greatest equalizer (Cuomo 2020), capable of infecting anyone, transcending wealth, fame, prestige or age (Mein 2020). A more accurate statement would be that COVID-19 is the great exacerbator (Thornton 2020). The coronavirus pandemic has amplified existing inequalities, disproportionately impacting poor and marginalized communities. As Steve Thornton, a journalist and activist recently said, "we are not all in the 'same boat,' but we are all in the same storm. If you are black or brown, you may be stuck on a raft without a life jacket" (Thornton 2020). Vaccine trials for COVID-19 are a monumental test to discover a safe and efficacious vaccine quickly, but they are also a test of how the scientific community develops partnerships with community organizations to enroll minority populations and those most vulnerable to contracting the disease. Calls for social solidarity to participate in COVID-19 clinical trials will likely not be successful at enrolling the most vulnerable and marginalized communities that have disproportionately suffered the most from the coronavirus. Rather, paramount to the success of enrolling volunteers from diverse backgrounds will be developing mutually beneficial community partnerships and understanding the ways that personal experiences and relationships with medical care professions and the health care system are intertwined with people's views of biomedical research.

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APPENDIX:
Participant Characteristics

Table 1: Characteristics of Community Resident Focus Group Participants (Focus Groups 1-5)

	Spanish Speaking		English Speaking		All Participants	
N	24		6		30	
Age, mean ± SD, years	54.6 ± 10.9		58.7 ± 8.4		55.4 ± 10.4	
Sex, no. %						
Male	6	25.0%	2	33.3%	8	26.7%
Female	18	75.0%	4	66.7%	22	73.3%
Ethnicity, no. %						
Mexican / Mexican American / Chicanx	10	41.7%	5	83.3%	15	50.0%
Peruvian	2	8.3%	0	0.0%	2	6.7%
Venezuelan	0	0.0%	1	16.7%	1	3.3%
Unknown or Declined to Answer	12	50.0%	0	0.0%	12	40.0%
Immigrant generation, no. %						
1st generation	10	41.7%	4	66.7%	14	46.7%
1.5 generation	1	4.2%	1	16.7%	2	6.7%
2nd generation	1	4.2%	1	16.7%	2	6.7%
Unknown or Declined to Answer	12	50.0%	0	0.0%	12	40.0%
Time in US (1st & 1.5 gen), mean ± SD, years	27.5 ± 3.9		36.0 ± 19.1		30.4 ± 11.9	
Primary Language at Home, no. %						
Spanish	24	100.0%	5	83.3%	29	96.7%
English	0	0.0%	1	16.7%	1	3.3%
English and Spanish	0	0.0%	0	0.0%	0	0.0%
Education, no. %						
Less than High School	8	33.3%	2	33.3%	10	33.3%
Some High School	2	8.3%	0	0.0%	2	6.7%
High School	4	16.7%	0	0.0%	4	13.3%
Some College	5	20.8%	3	50.0%	8	26.7%
Associate Degree	0	0.0%	0	0.0%	0	0.0%
College Degree	1	4.2%	0	0.0%	1	3.3%
Unknown or Declined to Answer	4	16.7%	1	16.7%	5	16.7%
Employment Status, no. %						
Full Time	4	16.7%	3	50.0%	7	23.3%
Part Time	1	4.2%	0	0.0%	1	3.3%
Unemployed and Looking for Work	1	4.2%	0	0.0%	1	3.3%
Disabled / Unable to Work	1	4.2%	0	0.0%	1	3.3%
Homemaker	3	12.5%	2	33.3%	5	16.7%
Retired	0	0.0%	1	16.7%	1	3.3%
Unknown or Declined to Answer	14	58.3%	0	0.0%	14	46.7%

Residential Status, no. %	5	20.8%	3	50.0%	8	26.7%
Apartment	4	16.7%	2	33.3%	6	20.0%
House	1	4.2%	1	16.7%	2	6.7%
Shared Residence / Bedroom	1	4.2%	0	0.0%	1	3.3%
Other	13	54.2%	0	0.0%	13	43.3%
Unknown or Declined to Answer						
Health Insurance, no. %						
Insured						
Private	1	4.2%	5	83.3%	6	20.0%
Public	4	16.7%	1	16.7%	5	16.7%
Uninsured	4	16.7%	0	0.0%	4	13.3%
Unknown or Declined to Answer	15	62.5%	0	0.0%	15	50.0%
Research Participation, no. %						
Current and Previous Participation	3	12.5%	2	33.3%	5	16.7%
Previous Participation	4	16.7%	4	66.7%	8	26.7%
No Participation	4	16.7%	0	0.0%	4	13.3%
Unknown or Declined to Answer	13	54.1%	0	0.0%	13	43.3%
Focus Group time, mean ± SD, minutes	94.5 ± 28.0		70.0 ± 0.0		89.6 ± 26.9	

Table 2: Characteristics of Community Resident Interview Participants

	Spanish Speaking		English Speaking		All Participants	
N	15		15		30	
Age, mean ± SD, years	47.6 ± 13.9		34.9 ± 16.9		41.3 ± 16.5	
Sex, no. %						
Male	5	33.3%	6	40.0%	11	36.7%
Female	10	66.7%	9	60.0%	19	63.3%
Ethnicity, no. %						
Mexican / Mexican American / Chicanx	14	93.3%	13	86.7%	27	90.0%
Puerto Rican	0	0.0%	1	6.7%	1	3.3%
Salvadorian	1	6.7%	0	0.0%	1	3.3%
Venezuelan	0	0.0%	1	6.7%	1	3.3%
Primary Language at Home, no. %						
Spanish	15	100.0%	7	46.7%	22	73.3%
English	0	0.0%	5	33.3%	5	16.7%
English and Spanish	0	0.0%	3	20.0%	3	10.0%
Immigrant generation, no. %						
1st generation	13	86.7%	2	13.3%	15	50.0%
1.5 generation	1	6.7%	6	40.0%	7	23.3%
2nd generation	1	6.7%	5	33.3%	6	20.0%
2.5 generation	0	0.0%	1	6.7%	1	3.3%
3rd generation	0	0.0%	1	6.7%	1	3.3%
Time in US (1st & 1.5 Gen), mean ± SD, years	21.1 ± 10.5		32.1 ± 17.1		25.1 ± 14.0	
Citizenship/Documentation Status, no. %						
Undocumented	6	40.0%	2	13.3%	8	26.7%
Previously Undocumented	4	26.7%	2	13.3%	6	20.0%
Undocumented or Prev. Undoc. Family Members	3	20.0%	6	40.0%	9	30.0%
Seeking Asylum	2	13.3%	0	0.0%	2	6.7%
Legal Immigration	0	0.0%	1	6.7%	1	3.3%
US Citizen (Naturalized or Native-born)	1	6.7%	8	53.3%	9	30.0%
Unknown Personal Status	2	13.3%	2	13.3%	4	13.3%
Education, no. %						
Less than High School	12	80.0%	0	0.0%	12	40.0%
Some High School	1	6.7%	1	6.7%	2	6.7%
High School	0	0.0%	4	26.7%	4	13.3%
Some College	2	13.3%	7	46.7%	9	30.0%
Associate Degree	0	0.0%	1	6.7%	1	3.3%
College Degree	0	0.0%	2	13.3%	2	6.7%
In School, no. %						
Yes	1	6.7%	4	26.7%	5	16.7%
No	14	93.3%	11	73.3%	25	83.3%

Employment Status, no. %						
Full Time	6	40.0%	7	46.7%	13	43.3%
Part Time	2	13.3%	5	33.3%	7	23.3%
Unemployed and Looking for Work	1	6.7%	0	0.0%	1	3.3%
Disabled / Unable to Work	3	20.0%	0	0.0%	3	10.0%
Homemaker	2	13.3%	1	6.7%	3	10.0%
Retired	1	6.7%	1	6.7%	2	6.7%
Unknown or Declined to Answer	0	0.0%	1	6.7%	1	3.3%
Household Income, no. %						
$0 - $9,999	4	26.7%	2	13.3%	6	20.0%
$10,000 - $19,999	4	26.7%	2	13.3%	6	20.0%
$20,000 - $29,999	2	13.3%	0	0.0%	2	6.7%
$30,000 - $39,999	2	13.3%	3	20.0%	5	16.7%
$40,000 - $49,999	2	13.3%	3	20.0%	5	16.7%
$50,000 - $59,999	0	0.0%	2	13.3%	2	6.7%
$60,000 - $69,999	1	6.7%	1	6.7%	2	6.7%
$70,000 - $79,999	0	0.0%	2	13.3%	2	6.7%
Unknown or Declined to Answer	0	0.0%	0	0.0%	0	0.0%
Residential Status, no. %						
Apartment	7	46.7%	5	33.3%	12	40.0%
House	5	33.3%	9	60.0%	14	46.7%
Shared Residence / Bedroom	3	20.0%	1	6.7%	4	13.3%
Marital Status, no. %						
Married	13	86.7%	5	33.3%	18	60.0%
Never Married	1	6.7%	8	53.3%	9	30.0%
Divorced	0	0.0%	1	6.7%	1	3.3%
Widowed	1	6.7%	0	0.0%	1	3.3%
Unknown or Declined to Answer	0	0.0%	1	6.7%	1	3.3%
Children, no. %						
Yes	14	93.3%	6	40.0%	20	66.7%
No	1	6.7%	9	60.0%	10	33.3%
Health Insurance, no. %						
Insured						
Private	2	13.3%	7	46.7%	9	30.0%
Public	7	46.7%	6	40.0%	13	43.3%
Uninsured	5	33.3%	2	13.3%	7	23.3%
Unknown or Declined to Answer	1	6.7%	0	0.0%	1	3.3%
Research Participation, no. %						
Current and Previous Participation	2	13.3%	4	26.7%	6	20.0%
Previous Participation	1	6.7%	3	20.0%	4	13.3%
No Participation	12	80.0%	8	53.3%	20	66.7%
Interview time, mean ± SD, minutes	56.4 ± 23.2		65.4 ± 14.3		60.9 ± 19.5	

Table 3: Characteristics of Medical and Health Research Interview Participants

N	30	
Age, mean ± SD, years	41.7 ± 11.6	
Sex, no. %		
Male	13	43.3%
Female	17	56.7%
Race, no. %		
African American or Black	1	3.3%
Asian		
Central Asian	1	3.3%
East Asian	3	10.0%
South Asian	1	3.3%
Caucasian (Non-Hispanic White)	13	43.3%
Caucasian and Hispanic or Latinx (Hispanic White)	2	6.7%
Hispanic or Latinx	8	26.7%
Native Hawaiian or Other Pacific Islander	1	3.3%
Interview Method		
In-person	15	50.0%
Phone	13	43.3%
Skype	2	6.7%
Interview Time, mean ± SD, minutes	45.5 ± 14.8	