'YOU OWE IT TO EACH OTHER': RACE & THE PRODUCTION OF KNOWLEDGE IN AIDS CLINICAL TRIALS (ACTs) RECRUITMENT

by

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ABSTRACT

'YOU OWE IT TO EACH OTHER': RACE & THE PRODUCTION OF KNOWLEDGE IN AIDS CLINICAL TRIALS (ACTs) RECRUITMENT

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This dissertation is based on an ethnographic case study of a public health intervention and research project titled "ACTPOC" (not its real name). ACTPOC's goal was to design, develop, and test a group-based standardized intervention to increase the interest in and enrollment of women and people of color living with HIV/AIDS in AIDS clinical trials (ACTs).

Following the NIH Revitalization Act of 1993, recruitment interventions such as ACTPOC draw upon a variety of ideological and material discourses to promote clinical trials participation. According to ACTPOC, the "underrepresentation" of people of color in ACTs results from the *social* conditions of racism that in turn denies their racial *biological* ontologies in medication development. ACTPOC designed the group-based educational intervention to remedy the absence of people of color from ACTs, with the hopes that their inclusion would improve drug development and help to mitigate some of the racialized disparities seen in HIV/AIDS. This dissertation explores the contradictions whereby ACTPOC acknowledged the social and institutional barriers that limit women and people of color's access to ACTs at the same that that it depicted race and gender as idioms of essential biomedical difference. Participants' accommodations to and reinterpretations of ACTPOC's efforts to socialize them into biomedical research norms illustrate the contingencies involved in even the most rationalized public health models.

This dissertation's ethnographic exploration of ACTPOC demonstrates how public health interventions to recruit people of color into biomedical research, while undertaken in part to reduce health disparities, may unintentionally yield the opposite effects.

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I feel so fortunate to have been able to undertake this project, and it could not have been finished—let alone started!—without the help of so many people.

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When I enrolled in my last graduate seminar, Professor Halliburton's "Science and the Politics of Knowledge" I had a dissertation proposal near completion, as well as some pilot data I had already collected, transcribed, and analyzed. His course proved to be a game-changer, as was his encouragement and support as I fumbled my way through a newfound fascination with AIDS clinical trials (ACTs). I am forever grateful to Murphy not only for his intellectual breadth, patience, and willingness to help, but also for his modeling a form of scholarship that is curious, intellectually fierce, and

compassionate all rolled into one. In a dominant culture that is very goal-oriented and rewards rational choices, I believe that Murphy's teaching inculcated in me a willingness to take risks and to embrace uncertainty, which has made this journey all the more fulfilling.

I've been incredibly fortunate to have also had the chance to work with Jacqueline Nassy Brown and Rebecca Jordan-Young. I've admired Jackie's excellent scholarship from afar, and quickly found out how she is equally dynamic in person! She has an uncanny knack for pinpointing the rabbit holes of confusion, and for guiding me out of them. Writing this dissertation gave me the opportunity to reflect upon the HIV/AIDS work in San Francisco, from 1994 until 2002. I recall one cold night, probably around 1995, that I spent sitting on the floor of the Women's Building for a noisy forum about lesbians and HIV. One of the bold presenters (whose name I can't remember) told us about some studies someone named Beck Young was doing in New York City, and I read one of her articles soon after. Beck's research helped me to begin making sense of scientific expertise, HIV/AIDS, gender, and sexuality almost twenty(!) years ago, and her present-day guidance and support have taken those lessons to new levels.

I want to give an incredible thanks to the "ACTPOC" research group for allowing me to extend my role as a qualitative consultant into an ethnographic study that is the basis for this dissertation. I doubt that there are many other researchers that would welcome a graduate student to study what they do and write an independent analysis that takes a different path from the research they are doing. ACTPOC's Principal Investigators engage a level of awareness of and commitment to issues of social justice and racial inequality even as the federal funding sources on which their research depends push forth a different agenda. I am especially grateful for the intentional messages and unconscious influences put forth by the primary PI towards HIV/AIDS intervention research. Her belief that we can only try our best, may change our minds later, and never stop learning pulled me out of paralysis on many an occasion. It is comforting to know that I will be able to revise my misinterpretations and develop my line of thinking into areas that I neglected.

I also owe thank yous to Kate Crehan, Michael Blim, and Louise Lennihan for helping me through the transition to the department and to NYC, and for making me feel welcome. No dissertation would be complete without a huge thank you to Ellen de Riso. She has thrown me a lifeline more times than I can count, and her kindness and sense of humor made the windowless Graduate Center a much more welcoming place.

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Despite their overloaded schedules, I was always spoiled with “NYC rehab”: trips to the local Farmer’s Market, bike rides down Valencia, home-cooked meals, updates on nonprofit gossip, and walks across San Francisco’s neighborhoods with stops for coffee along the way. The stories they shared of the plays they were performing, gardens they had planted, and classes they were teaching were important sources of inspiration and comfort. Thank you to Carrie Paff, Jeremy Sabol, Lorrie Tanioka, Trang-Ahn, Christy Ann Chavez, and Jason Luz! Your help and friendship are immeasurable.

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Melissa is an intellectual force like no other, and I have benefited from her insights in so many ways. Her willingness to talk through ethnographic topics and fieldwork challenges, pore over pages upon pages of drafts with her sharp mind and tidy handwriting, and be an all-around positive supporter leaves me awed and grateful.

She and Lenny, and Frankles the Hound-Dog, spirited me away from work for some fun adventures!

Kim Morland and Corinne Munoz-Plaza owe a special thank you for helping me through so many different aspects of this dissertation, from reminding me of the world outside my head to spending good times with the plucky puggle Luna.

I also owe my fellow Behavioral Sciences Training (BST) collaborators and public health rabble-rousers—Rebecca Tiger, Vivian (Pacheco) Johnson, Stephanie Campos, and Azure Thompson—a huge thanks for reading and rereading so many early drafts of this dissertation, and for giving me encouragement as I stumbled to write anything at all. Two BST postdocs also shaped this project: Hannah Cooper whose scholarship and presence was a model for me in thinking about how to do critical public health work. Luther Elliott shared his keen insights and sense of humor, too. There is also a special thank you for fellow predoc Kerwin Kaye, for his thoughtful feedback, extensive bibliography, and for allowing me to impersonate a sociologist and join a very helpful writing group he organized: thanks to fellow writers Alton Brown, Craig Willse, and Alison McKim.

At NDRI, Drs. Sam Friedman and Barbara Tempalski not only personally took time out of their busy schedules to offer me feedback on some chapters, but also served as intellectual forms of inspiration through their groundbreaking work in their research on social inequality, HIV/AIDS, and harm reduction. At NDRI and NYU, I have also had the pleasure of working alongside and under the direction of Angie Banfield, Noreen Boadi, DeShannon Bowens, Pablo Colon, Dr. Marya Gwadz, Dr. Noelle Leonard, Mindy Finkelstein, Zohar Massey, Maya Tharaken, Amanda Ritchie, Robert Quiles, and Professor Marion Riedel. They are not only great co-workers but friends too. Angie in particular has been a source of wisdom, encouragement, and inspiration throughout the projects we worked on together, and Noreen kept me laughing through malfunctioning tape recorders and coffee runs. Mindy was of enormous help not only keeping up my spirits but also proofreading and editing several of these chapters.

Writing a dissertation involves the generosity of people's labor, some of whom I do not know personally though I remain indebted to their help and assistance. A number of transcription staff typed out dozens of interviews with precision and care. The NYPL and GC libraries felt like second homes, and the ILL folks facilitated my access to books and articles from far away. The IRB patiently answered all my questions and clarified my confusion as I wrote and revised my consent forms.

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Sir Humphries and Bella Bean, my two diabolically wicked French bulldogs, perched on my lap like hood ornaments as I tried to write. In exchange for liver treats, they have agreed to take responsibility for all grammatical errors. Sir Humphries earned "mascot" status in my cohort, and Ellen de Riso promises that he will be given the honorary title of "Pup-h-D"! My fellow dog rescue volunteers on the website writers for the French Bulldog Rescue Network www.frenchbulldogrescue.org generously shouldered my share of writing up the weekly foster profiles and adoption stories as the dissertation demanded more of my time.

Finally, undertaking this lengthy ethnographic study and writing the dissertation would not have been possible without generous funding from the Dean Harris & University Fellowships, the NIH Behavioral Sciences Training (BST) Program on Drug Abuse Research Predoctoral Fellowship, and a Presidential Dissertation Fellowship.

Finally, I'd like to thank all the people living with HIV/AIDS (PLWHA) I have had the honor and privilege of learning from over the past twenty years. I am extremely grateful for the wisdom and perspectives they have shared, and especially for helping me to understand, through their anger and insights, the systems that have failed them. It is my hope that this work will contribute in some way to the dialogues and debates that aim to improve the health of PLWHA, and it is to them that I dedicate this dissertation.

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GLOSSARY OF ABBREVIATIONS & ACRONYMS

ACASI	Audio-Computer Assisted Self-Interview
ACTG	AIDS Clinical Trials Group
ACTs	AIDS Clinical Trials
ACTPOC	Pseudonym for ACTs recruitment project
ACT-UP	AIDS Coalition to Unleash Power
ACTU	AIDS Clinical trials Unit
AETU	AIDS Evaluation Treatment Unit
AHC	Academic Health Center
ARVs	Antiretrovirals
CASI	Computer-Assisted Self-Interview
CD4	T-cell, the cells that help prevent infection
CDC	Centers for Disease Control and Prevention
CHOW	Community Health Outreach Worker
CPCRA	Community Program of Clinical Research for AIDS
CRI	Community Research Initiative
DEBI	Dissemination of Evidence-Based Interventions
DHHS	Department of Health & Human Services
DTC	Direct-to-Consumer
EBBM	Evidence-Based Behavioral Medicine
EBI	Evidence-Based Intervention
EBM	Evidence-Based Medicine
EBP	Evidence-based Practice
EBPH	Evidence-Based Public Health
FDAMA	Food and Drug Administration Modernization Act
FTFI	Face-to-Face Interview
GAO	General Accounting Office
H/I	Hydralazine/Isosorbide Dinitrate (combination)
HAART	Highly Active Antiretroviral Therapy
HIPAA	Health Insurance Portability & Accountability Act
IAQ	Interview-Assisted Questionnaire
IDU/IVDU	Injection-Drug User/Intravenous Drug User
IGF	Intervention Group Facilitator
IND	Investigational New Drug
INDA	Investigational New Drug Application
IRB	Institutional Review Board
JAMA	Journal of the American Medical Association

LGBT	Lesbian, Gay, Bisexual, & Transgender
MMWR	Morbidity & Mortality Weekly Report
MPH	Master's of Public Health
MSM	Men who have Sex with Men
NEJM	New England Journal of Medicine
NDA	New Drug Application
NIAID	National Institute Allergies & Infectious Diseases
NIH	National Institutes of Health
NIH RA	National Institutes of Health Revitalization Act
NRTI	Nucleoside Reverse Transcriptase Inhibitor
ORMH	Office of Research on Minority Health
ORWH	Office of Research on Women's Health
PDI	Peer-Driven Intervention
PDUFA	Prescription Drug User Fee Act
PHS	Public Health Service
PI	Principal Investigator
PLWHA	People living with HIV/AIDS
pVL	Plasma Viral Load
RA	Research Assistant
RCT	Randomized Controlled Trial
RDS	Respondent-Driven Sampling
STS	Science & Technology Studies
VA	Veterans Administration
WHI	Women's Health Initiative
WSW	Women who have Sex with Women

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INTRODUCTION

San Francisco, 1996

The first wave of protease inhibitors marked an extraordinary transformation in HIV/AIDS. Before these medications became available, the time between infection and death was roughly ten years, and debilitating conditions, such as *Pneumocystis Pneumonia* (PCP), cervical cancer, and cytomegalovirus were common as the disease advanced. From 1987 to 1996, AZT was the primary treatment shown to delay viral reproduction,[1] albeit with many limitations: originally developed as a drug to treat cancer, it was powerfully toxic, poorly tolerated, and its benefits—if any—were often short-lived.

To say that these antiretroviral therapies marked an incredible shift in HIV/AIDS is something of an understatement. It is difficult to adequately convey what it was like to witness the transformations these new medications brought. I was working at an HIV/AIDS prevention and support organization in San Francisco during this time, and saw people living with HIV/AIDS (PLWHA) who had been quite ill—a few even incapacitated—undergo dramatic changes. Energy returned and lost weight was regained, and the chronic opportunistic infections that had long been a mainstay of living with HIV were less incapacitating and infrequent. Viral loads shrank to

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[1] The few other drugs available at that time (such as ddI, ddC, and d4t) are considered the "chemical cousins" to AZT; they all belonged to the same class of *Nucleoside Reverse-Transcriptase Receptors* (NRTIs).

undetectable levels and CD4 counts rose. Reeling in disbelief, many PLWHA resumed life activities, pursued new interests, and made future plans that extended beyond one month or six. Phrases such as "borrowed time" and "coming back from death's door" became catchwords people used to describe these radical changes in PLWHAs' quality of life and its length.

However, not everyone had access to highly active anti-retroviral therapy (HAART), and following these rigorous medication regimens proved to be difficult, especially for those who lacked stable housing and access to regular meals. Not all PLWHA who took these medications experienced the changes they had hoped for and others quickly developed drug resistance. Taking this medication changed lives in unwelcome ways too: there were painful side effects to endure and complicated pill-taking schedules to follow. The long-term effects of these drugs were (and many still are) unknown. These emerging biomedical remedies sparked a new optimism, albeit for treatments long overdue in an epidemic that had claimed the lives of so many. But these medications did little to address many of the ongoing, pressing problems that affected many PLWHA's health and overall wellbeing. The passing of the Personal Responsibility and Work Opportunity Reconstruction Act of (PRWORA) of 1996,[2]

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[2] The PRWORA ended Aid to Families with Dependent Children (AFDC), restricted many immigrants from benefits, and introduced "welfare-to-work" programs criticized for their low pay, lack of training for jobs that support a living-wage, and the absence of workplace protections. Sandra Morgen and Jill Weigt describe that the PWORA devolved income support to the poor to the state level (Morgan & Weigt,

severe cutbacks to Medicaid, and the explosion of mass incarceration fueled by the racialized and gendered war on drug users threatened the daily survival of many PLWHA. Medication alone is inadequate to address the "syndemic of violence" (Singer 1998:20) that is HIV/AIDS, for which weary immune systems are only one part.

The development of HAART has been nothing short of extraordinary, but it is not a panacea for the problems that affect the health and wellbeing of PLWHA. I share in the sense of relief that these pharmaceutical treatments are helping many live longer and healthier lives and I am equally encouraged by the efforts to facilitate greater access to these drugs. However, medication alone cannot address the complex issues that drive HIV transmission, nor does it intervene in how this disease intersects with multiple forms of marginalization to produce devastating results. The experiences of living with HIV/AIDS in poor communities of color—and especially among lesbians, gay, bisexuals, transgender (LGBT) people, and women in these communities—reinforce existing inequalities and generate new forms of suffering.

ACTPOC: An Ethnographic Case Study

This dissertation explores a public health project titled "ACTPOC,"[3] which aimed to develop and test strategies to recruit women and people of color to AIDS Clinical

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2001:152). For more on welfare reform and its relation to the minimalist state, see JoAnn Schneider (2001).

[3] "ACTPOC" is a pseudonym, as are all names of research participants. This issue of confidentiality is discussed in more detail in later in the Introduction.

Trials (ACTs), the studies that evaluate experimental treatments for HIV/AIDS. At first glance, an alliance between public health initiatives and pharmaceutical medication development might seem unlikely, given the former's historical commitment to social reform and prevention. ACTPOC's group-based educational intervention proposed that the lower rates of participation among HIV-positive people of color[4] in ACTs limited the development of scientific and clinical knowledge of how medications may affect them differently. Their participation in ACTs was urgently needed, ACTPOC stated, in order to ensure that claims of a medication's safety and efficacy applied to them. Moreover, ACTPOC pointed out that participants miss the chance to experience the potential benefits these studies may offer, such as specialized testing and monitoring by experts. Because women and people of color face barriers that limit their access to these studies (for example, numerous studies show that providers refer their white male patients in the greatest numbers) ACTPOC brought information about ACTs directly to them.

Drawing upon ACTPOC as an ethnographic case study, this dissertation explores the growing phenomenon of recruiting communities of color to biomedical

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[4] Similar to federal legislation that mandates their inclusion in clinical trials (and is discussed at length in Chapter three), ACTPOC's designated "target groups" were "women and minorities." Because virtually all of the women who participated in ACTPOC were in fact women of color, I drop the "women" as a separate category to ignore confusion. Gender was an important construct in ACTPOC, and to foreground this I follow the lead of ACTPOC's staff who often modified the language of the standardized interventions to say, "people of color and especially women of color." This issue is further discussed in Chapter One as well as other parts of the dissertation.

research studies. I argue that the "problem" of biological racial invisibility in clinical trials not only displaces the critical debates, resources, and strategies needed to address health inequalities, but also produces new kinds of racial personhood amenable to the deregulation of pharmaceutical markets and the privatization of the functions of the welfare state. According to ACTPOC, the "underrepresentation" of people of color in ACTs results from the *social* conditions of racism that in turn denies their racial *biological* ontologies in medication development. ACTPOC designed the group-based educational intervention to remedy the absence of people of color from ACTs, with the hopes that their inclusion would improve drug development and help to mitigate some of the racialized disparities seen in HIV/AIDS. This dissertation's ethnographic exploration of ACTPOC demonstrates how public health interventions to recruit people of color into biomedical research, while undertaken in part to reduce health disparities, might unintentionally yield the opposite effects.

Why AIDS Clinical Trials (ACTs)?

My interests in understanding the relationship of HIV/AIDS, biomedicine, and social inequalities had formed prior to my undertaking this dissertation project, but I knew very little about ACTs and even less about the efforts to recruit participants to these studies. I arrived at the topic of clinical trials by chance, while I was working for a study that was researching whether a particular therapeutic intervention helped HIV-positive mothers to reduce the harms of substance use. The Principal Investigator (PI) for that study (also the PI of ACTPOC) asked if I would be interested assisting in the evaluation of a smaller-scale, pilot version of ACTPOC, and I readily agreed. Unbeknownst to me at the time, my experience working as a part-time consultant for a few short weeks on this pilot intervention project was the beginning of what eventually grew to be a fascination with the relationships between ACTs, HIV/AIDS treatment, and biomedical and social scientific categorizations of race, gender, and evidence.

As the precursor to ACTPOC, the pilot project designed a series of educational groups about ACTs and tested whether participants in these groups developed knowledge about and interest in these research studies. At the conclusion of the pilot groups, I conducted semi-structured interviews with twelve participants, whose experiences with and understandings of biomedical research piqued my interest in the relationship of ACTs and HIV/AIDS clinical care. When I finished compiling these qualitative findings in a brief analytic report, I found myself wondering more about the PLWHA who take part in ACTs and the staff who conduct these research studies. A visit to the Rare Books and Manuscripts Division at the New York Public Library (NYPL) introduced me to some of the primary documents of the AIDS Coalition to Unleash Power (ACT-UP). I read the handwritten meeting minutes in which members discussed how HIV-positive women and people of color were excluded from ACTs, and pored over the creative flyers activists had created to bring awareness to this issue.

Additional sources explained some of the reasons why HIV-positive women and people of color were among those groups whose participation was routinely denied during the early years of the epidemic: many ACTs researchers assumed that women and people of color had a race and gender that would "complicate" their research findings (not surprisingly, the race and gender of the white male subjects were so normative as to be invisible; they were not similarly "raced" or "gendered"). My interest in the politics of HIV/AIDS medication development deepened as I studied the debates between "methodological purity" and "pressing social realities" (Epstein 1995:422) that transpired between the academic investigators affiliated with the AIDS Clinical Trials Units (ACTUs) and the community-based, clinically oriented researchers.

My ethnographic research of ACTPOC began in June 2008 and continued through June 2010, with numerous and ongoing follow-ups that extended into 2011. To study ACTPOC ethnographically, I spent hundreds of hours in the educational groups. I also talked informally with and conducted formal interviews with the group participants, the Intervention Group Facilitators (IGFs), the Research Associates (RAs), and the PIs. I also spent time in the ACTPOC office, attended staff meetings, observed how the RAs conducted their interviews with participants, and administered some of these same surveys. At the ACTU, I was able to observe some of ACTPOC's screening visits and had the chance to interview several of the clinical research staff. I also conducted textual analyses of ACTPOC's *Intervention Manual, Research Protocol*, and the

Intervention Group video and related texts. These documents alone would have been inadequate for grasping the rich subtleties and dynamic effects of ACTPOC's everyday practices, but they proved to be useful in mapping out its official aims and keeping the scope of its activities in view.

ACTPOC's primary goals were to: 1) develop and deliver a group intervention to provide information about ACTs and medical research among HIV-positive women and people of color; 2) conduct a rigorous study to determine if and how the group intervention worked; and 3) expand ACTs eligibility criteria through data collected at screening visits. This dissertation focuses on ACTPOC's first and second goals; due to time limitations, ACTPOC's third goal will be the subject of future work. ACTPOC hypothesized and hoped that the group-based educational intervention they had designed would facilitate participants' access to ACTs by offering them information about and facilitating their screening for these studies.[5] If deemed to be successful, the standardized curriculum ACTPOC designed might be classified as "evidence-based," which could result in its reproduction and dissemination in various public health settings across the U.S.

ACTPOC's everyday practices yielded a number of contradictory effects. From its official goals outlined in its grant award and research protocol to its everyday

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[5] ACTPOC's structured this ACTs screening visit as a conversation between the participant and clinical research staff regarding ACTs. The screening visit was made to resemble a medical history, and omitted all physical research procedures that could determine eligibility for these studies. The topic of screening is discussed more closely in Chapter Three and in other parts of the dissertation.

activities, ACTPOC proved to be both routine and unpredictable; creating an analytic tension that recurs throughout this dissertation. The participants embraced their experiences—though not always for the same reasons that the intervention group developers and researchers had intended. The IGFs' passions for social justice and commitments to participants' wellbeing at times collided with the narrow repetition of the standardized intervention they were assigned to deliver. Similarly, the RAs drew a great deal of satisfaction from their jobs and especially in their interactions with participants, but also faced conflicts with how their work addressed the social suffering they encountered. The possibility that the participation of HIV-positive people of color in ACTs might improve the efficacy of existing medications or help to develop more powerful antiretrovirals—a key message outlined in the intervention groups—clashed with the more immediate and treatable problems participants experienced that affected their health and wellbeing such as unstable housing; lack of access to health care (including medications); poverty; and other forms of structural violence.

Individual Empowerment, Collective Redress…and Biomedical Research?

ACTPOC's approach was unique: it did not promote a simple message of "You should screen for an ACT" but integrated multiple discourses and cross cutting explanatory frameworks. ACTPOC drew from the discourses of individual empowerment and collective redress to propose that these biomedical research studies could potentially yield solutions to the devastating racialized inequalities in HIV/AIDS. The following example highlights how ACTPOC's pedagogical approach circulated participants' experiences of social injustice into an affective domain of biomedical research possibilities.

ACTPOC's PIs and senior management, in collaboration with a television producer, created a documentary-style video about ACTs and people of color as part of the standardized curriculum for the group intervention. The video opens with a group of self-identified HIV-positive people of color, including several that are publicly known through their affiliation with a local community-based health and harm reduction organization. The group is seated around a table in an empty restaurant, against the backdrop of the city streets. Some are there to discuss their own experiences with ACTs while others are eager to learn more about them. Josephine expresses her skepticism towards ACTs. She says,

> I would be concerned 'cuz I know that if you're going to be screened they're going to ask you like a million questions. I come from a poor neighborhood. I have a history of substance abuse. I been incarcerated. Are they just using me? Or…you know, how much am I really going to get out of these? Because I do. I wanna learn. I want to survive. I have plans. But I don't want to be used.

Josephine references her racial subjugation and impoverished neighborhood; her histories of incarceration and substance use also add to and deepen her marginalization. She locates herself at the bulls-eye of potential exploitation, in which her body literally becomes an object of the medical experts: "These doctors over there—my doctor is a specialist on HIV/AIDS. Do they really know this information? All the new meds? And everything you know or are they just there to see your reaction and are really not sensitive with HIV and AIDS?"[6] Josephine wants to know: as a poor, recovering Latina living with HIV/AIDS, how can she be sure that ACTs researchers will not mistreat and mislead her? Alberta, who earlier had shared her own positive experiences with ACTs, responds to Josephine's questions slowly and deliberately. "They need you. They need you preciously. They will not do anything to hurt or harm you." Her voice softens as she enunciates each word with care: "The cure for AIDS will come from AIDS clinical trials." The camera pans Alberta's peers, who are intently following her declaration; their body language conveys anticipation and hope. The cure is a powerful symbol in its uncertainty, which, according to Charles Rosenberg only enhances its significance: "(A) lack of precise meaning has rarely interfered with the efficacy of appeals to science and the promise of its application" (Rosenberg 1995:150). Similarly, support for racialized biomedicine persists although it has not yielded the answers many have hoped because, "it is not the tangible results but the promise of potential [that] drives much of the research agenda and funding" (Stevens 2003:1039).

But while its potential solutions remain opaque, the drawbacks of racialized biomedicine are clear. The search for the "minute, insignificant biological differences"

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[6] What is also interesting about this exchange is that Josephine's assessment captures some qualities of actual research: experts *do* observe. They are (one hopes and expects) likely to care. And while there may be some secondary therapeutic benefit to trials, it is not their primary aim.

(Brawley 1995:223) among people of color threatens to shift attention from the social inequalities that are pervasive in HIV/AIDS. It is this flaw—along with several others—that makes racialized biomedicine especially amenable to and compatible with neoliberalizing trends in health and medicine, which are examined in the following section.

Public Health and Neoliberal Medicine

At the risk of oversimplifying a broad range of scholarship, molecular geneticists, epidemiologists, and physical anthropologists rebut racial biology with rigorous analyses that expose its flaws. These contributions are crucial to these debates; however, if we could discredit racial biology (again) by exposing its specious claims, then why is it still here?

One of the strategic moves undertaken by proponents of race-based medicine has been to shift the terms of the debate, arguing that the *lack* of research into race-specific biomedical solutions neglects the health needs of communities of color. In other words, the unknown possibilities of racialized biology and race-based medication development is health inequality that demands attention, alongside the more familiar issues readily recognized as health disparities—sub-standard health care, environmental pollution, and the proliferation of nicotine advertising.

Ethnography offers insights into the practices by which racial biology is constructed—and reconstructed. Not simply an abstract idea, ACTPOC sutured together race, biology, and medication development to invoke affective expressions and collective understandings. These claims did not emerge from a public domain, but a public health domain secured by material resources and structured by institutional authority. Yet it would be incorrect to label ACTPOC as simply a "top-down" intervention—its participants engaged with its messages, and often refashioned new meanings from it. By keeping the official representations of the group-based intervention in view with its on-the-ground practices, we can more firmly grasp the effects of racial biological claims. It also highlights some unexpected and practices that may be overlooked if we focus only on these formal debates.

The focus upon race and medication development is suited to the current proliferation of consumer-oriented, market-based models of health care and public health, which are unprecedented in the history of U.S. medicine. The privatization of public services, deregulation of financial markets, dismantling of the welfare state, and other features of neoliberalism are reinventing the concept of health care access and refashioning new duties of and identities for the patient. The Food and Drug Administration's (FDA) transformation as the "nation's food and drug watchdog," into an "under funded lapdog" (Goozner 2006:739); the massive public and private investment in biomedical research in search of the "biological bullet" to solve health problems (Navarro 2009:427); and the adoption of a Medicaid managed care model

(Maskovsky 2000) demonstrate that as the state's redistributive function shrinks, its role promoting and protecting the commoditization of health flourishes.

This dissertation asks: does the public health focus on minority participation in clinical trials naturalize the social conditions that give rise to racial inequalities in HIV/AIDS? Does this emphasis upon minority participation in clinical trials function as yet another way to "mask privatization and other means of restructuring or destructuring the welfare state" (Stevenson and Burke 1991:284)?

The promotion of minority participation in biomedical research studies conforms to several neoliberalizing trends in health care. Race-based biomedicine is linked to the emergence of new lucrative pharmaceutical markets (Kahn 2005; Duster 2005), and the disinvestment of state-supported health care facilitates participation in trials (Fisher 2009; Ayo 2012:100). The search to identify possible racial differences displaces attention from the resources needed to address the structural problems that are at the root of health disparities (Roberts 2011a).

A Note on Approach

There were a number of characteristics that made ACTPOC unique, such as its innovative approach to ACTs education, dynamic staff, eclectic group of participants, and seasoned investigators. On a daily basis, I was a witness to and participant in ACTPOC's numerous positive effects, from the participants who forged meaning in the intervention's messages to the inspirational staff and Principal Investigators (PIs) whose visions of racial equality and social justice fueled their work. ACTPOC assumed many risks and shouldered no small burden to make this ethnography happen, from the participants and staff that shared their life experiences and insights about race and HIV/AIDS research with me, to the senior management who integrated an anthropological research project into a demanding organizational structure, risking what an ethnographic gaze might reveal or more likely, misinterpret.

Anthropological traditions of ethnographic research encourage unexpected directions and serendipitous moments that alter the course of a study. The national health priorities and federal funding that shaped ACTPOC's goals and influenced its research design emphasized different epistemologies, such as hypothesis-testing and statistical significance. Although our formal priorities were largely determined beforehand, it seemed that we—that is, ACTPOC participants, PIs, staff, and myself—were constantly in the process of managing and engaging what our work meant, in terms of ACTPOC's official goals and more broadly, in relation to the overall health and wellbeing of people of color living with HIV/AIDS. It is my hope that this ethnography, as a "work-in-progress," upholds the spirit of self-reflection and dialectical engagement that the ACTPOC participants, staff, and PIs have contributed to my thinking and development.

Besides conducting this ethnography, there was another way in which I was able to experience and participate in ACTPOC. I was hired as a qualitative consultant to conduct semi-structured interviews with participants about their experiences with the intervention groups and explore their motivations screening for ACTs. I was part of a team that consisted of another qualitative consultant and the project director. Of the forty interviews, I conducted approximately twenty-five of them, all with participants that had been screened for an ACT. My co-consultant and the project director interviewed the remaining fifteen, none of whom had taken part in screening for an ACT. The idea behind this approach was to learn and compare what motivated the participants to screen for an ACT or what made them less inclined to do so. The forty participants that we interviewed were randomly selected from the two groups. No one who was asked declined to take part in an interview. Any interviews that I did not conduct myself are indicated with the pseudonym of the interviewer that conducted them.

Our qualitative team was concerned with learning how the ACTPOC group intervention worked—what conditions facilitated or deterred screening for an ACT? These findings have the potential to yield a direct application to increasing the recruitment and enrollment of people of color in ACTs, and perhaps biomedical research in general. While these contributions are important, it is from a different standpoint that this ethnographic project aimed to understand ACTPOC. If I were to approach the study of ACTPOC in relation to its aims and accomplishments—or adopt a primary focus on the wealth of insights, analyses and pearls of wisdom the team and participants shared with me—then it would have resulted in a different kind of dissertation. My research agenda and outlook were shaped by different concerns than those outlined in ACTPOC, and therefore, many of my critiques draw from questions and areas of interest that were unrelated to its official mission.

ACTPOC participants received $25 cash and a public transportation voucher for each research study visit they completed (including the qualitative interview) and for each intervention or control group they attended. If participants attended all research visits and groups to which they had been assigned, they could earn $150. They also stood to earn up to $85 if they recruited three peers for ACTPOC, and educated them using ten true/false statements (this method of recruitment, "Respondent-Driven Sampling" or RDS is the subject of chapter four). In describing that there is no compensation provided for the ACTPOC screening visit (other than a round-trip public transportation voucher), the PIs state, "This is a long-standing policy intended in part to gauge an individual's non-financial motivation to participate in an ACT or ACT screening" (Research Protocol:42). A few participants enrolled in two ACTs, and many more took part in observational studies, all of which offered various amounts of cash reimbursement.[7]

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[7] Per the official guidelines of the ACTPOC study protocol and consent forms, the language of "reimbursement" or "compensation" are used, not "payment." In his book on commodification and clinical trials, Abadie argues that the language of "volunteering" for research studies conceals the labor—

These details are significant. Payment was highly important to ACTPOC participants, most of who lived at or below poverty levels. David, one of the participants, describes his experience of deprivation and anxiety:

> The money doesn't hurt. A little bit of change always comes in handy. Because the little check we get every month, it ain't enough to live on, it wouldn't work for a squirrel…Basically, people are all strapped around a little pittance the government gives us at the beginning of the month, I live on less than $400 a month, after I pay my rent and my little phone bill, I'm on like three and change. And that's ridiculous, it's very hard to live on it.

David's narrative is revealing of the poverty and everyday financial struggles participants were constantly negotiating. It also points to what was a curious absence in ACTPOC, as further chapters will explore. While the intervention highlighted the concept of race—and to some degree, gender—issues of class and poverty were largely absent. ACTPOC made race and gender intelligible in terms of individual membership in groups and as biological properties, but these renderings did not inflect the mutual constitution of poverty and class, racialized and gendered oppressions and disease. Nancy Krieger and Mary Bassett argue that, "We must begin to develop an antiracist model of disease causation. Ultimately, to call for an antiracist science is to demand a class-conscious science" (Krieger and Bassett 1993:169). The visibility by which race

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and risk—that research participants undertake in Phase One safety studies (Abadie, 2010). However in the day-to-day operations of ACTPOC these formal descriptions of reimbursement were rarely followed, from participants asking their interviewer how much they will be paid for attending each group, to the RAs who left phone messages for participants that missed their appointments with reminders that they will be paid $25 for completing their visit. ACTPOC does not seem atypical in this regard; colleagues who work in other studies tell me they also use the language of "payment"; the same is true for the many other health behavior research studies I have worked on.

comes into view in ACTPOC brings the neglect of class and income into sharp relief. The question, how did ACTPOC participants become racially legible while class and income-invisible is a topic that emerged in the ethnography, which is discussed and analyzed.

All of the names referenced in this dissertation are pseudonyms, including the title of the project "ACTPOC."

Place, or where was ACTPOC?

Three book-length ethnographic studies of clinical trials served as guideposts as I pursued this project**:** Jill Fisher's *Medical Research for Hire: the Political Economy of Pharmaceutical Clinical Trial* (2009) Roberto Abadie's *The Professional Guinea Pig* (2010), and Adryna Petryna's *When Experiments Travel: Clinical Trials and the Global Search for Human Subjects* (2009). The politics of place and location are central to each author's ethnographic analysis of clinical trials participation. Philadelphia, the Southwestern U.S., Brazil, and Poland are no mere backdrops in these ethnographic studies, but principal actors. Abadie studied an organized network of predominantly white male anarchists, a group of self-identified "professional guinea pigs" who regularly enroll in Phase One clinical trials. Abadie's framing of the phenomena of "guinea-pigging" calls attention to Philadelphia's disinvestment of its public services and infrastructure, which occurred alongside the promotion of the new incentives to establish pharmaceutical-university partnerships, which made the area a veritable "hotbed" of clinical trials activities. The guinea pigs found that participating in Phase One clinical trials offered a viable alternative to the low-wage service economy, but not without the threat of unknown risk (Abadie 2010). Adryna Petryna studied clinical trials in part by their movement: she tracks the off-shoring of U.S.-sponsored clinical trials to select regions in Eastern Europe and Brazil, where "the bodies of people living marginally are being reconstituted into a labor force…subjects in a reserve army who will likely see no long-term benefit to their participation" (Petryna 2005:192). In her ethnographic study, Jill Fisher's analyses reveal how pharmaceutical companies, looking for the fastest, efficient, and most profitable trial venues, purposefully sought to conduct clinical trials in the southwest region, where "ready-to-recruit" groups were available (Fisher 2007; Fisher 2009). Fisher illustrates that the paradigmatic liberal, autonomous subject that freely chooses does not describe the people she encountered in her study, many of whom were poor Latinos, dependent on flexible wage-labor economies and in dire need of health care.

Fisher, Abadie, and Petryna each illustrate the significance of geographic location in understanding the circuits of power that structure biomedical research economies. These ethnographies highlight the widespread poverty, lack of health care, and unequal relations that divide the Global North and South—as well as the Southwestern and Northeastern U.S.

ACTPOC took place in a North American city with a sizable population of PLWHA. When undertaking this ethnographic project, I followed the standard non-disclosure agreement, which prevents ACTPOC's specific location from being part of this story. This type of arrangement is routine for many ethnographic studies of PLWHA, which must protect patient confidentiality. In the absence of developing the rich analyses of place that framed Abadie's, Fisher's, and Petryna's ethnographic studies of clinical trials recruitment, I began to wonder how the *absence* of place figured centrally in ACTPOC, and what significance, if any, might this have in my ethnographic analysis?

Furthermore, the concept of "the field" forms the cornerstone of ethnographic research; many consider it the bedrock of anthropology. Jaqueline Nassy Brown observes that, "no one traffics in the local like the anthropologist" (Brown 2005:6). Some core principles of anthropology have come under scrutiny in recent years as critics challenge how uninterrogated concepts of the local lead to the reification of people and places as timeless and bounded entities. Following Deidre McKay, how might anthropologists "continue to attend to the importance of locality through research that is place-based, without being place-bound" (McKay 2006:201)? Akhil Gupta and James Ferguson propose that, "The idea that anthropology's distinctive trademark might be found not in its commitment to 'the local' but to its attentiveness to epistemological and political issues of location" (Gupta and Ferguson 1997:39). How might we theorize "place"—particularly in the absence of a formal, geographically described space—to enable a better understanding of ACTPOC, its purpose and effects?

As I reread my field notes, I took care to extract any identifiers that could possibly be linked to this city. At first, it seemed like I was parsing out rich details, but eventually a different view of place began to take shape. ACTPOC, in explicit and subtle ways, engaged not so much in the "localizing" practices I had initially expected and assumed an ethnographic study would reveal. Instead, a concept of the "nation-state" emerged, and became an object of analysis in this study. As I sat in the ACTPOC groups, I followed the visual performances and textual narratives that displayed nationwide statistical data of HIV/AIDS and people of color. When I assisted the RAs with collecting survey data, I engaged participants in the mundane bureaucratic practices of recording race, ethnicity, and gender, "Pick the one you most identify with," I instructed them according to the guidelines I read from my computer screen. I also studied the federal legislation that mandates the inclusion of women and minorities in clinical research within the United States. ACTPOC was not rooted in its locality in the ways that I had expected. Instead, it was driven by, and constantly invoked *national* agendas: minority and women's inclusion in clinical research; the determination as to whether the outcomes associated with the intervention were significant, and if so, could this project be reproduced in a number of health locales across the U.S.? These national projects were enabled by the mundane bureaucratic state practices: the enumeration of populations, the standardization of the intervention groups, and the ongoing monitoring and surveillance by the state, which had funded ACTPOC.

The boundaries of the nation-state were securely drawn and transparently assumed, which left a gap in how ACTPOC's claims to the biological significance of race might be theorized. Pamela Sankar et al. argue that the genetic studies that aim to identify and explain the markers of racial disparities in health are problematic for several reasons. In this paradigm, race/ethnic identity stands for putative genetic ancestry; the authors then ask, why do blacks outside of the U.S. have lower rates of the common health problems experienced by American blacks (Sankar et al. 2004:2987)?

ACTPOC presents race as an unmarked, stable category. There is no acknowledgment of its transnational or historic dimensions. This seems to be a powerful omission, especially because clinical trials are increasingly being "outsourced" to bodies in the Global South. The eventual consumption of these (tested) drugs by people in Western and cosmopolitan settings does not call into question the concept of purportedly biological racial differences. ACTPOC presented a portrait of race that domesticated it within the boundaries of national belonging. Jodi Melamed points out that a function of neoliberal multiculturalism is to legitimate the hegemonic character of race, which "prevents the calling into question of global capitalism" (Melamed 2006:16).

ACTPOC deployed forms of racial personhood that were amenable to particular forms of governance and are explored in this ethnographic study. The racial-biological links of different bodies that ACTPOC constructed were secured within the particular geographic boundaries of the U.S., but did not extend beyond them. These observations of ACTPOC as embedded in national projects and guided by routine state practices seemed to transcend the local. However, the PLWHA of color that took part in ACTPOC were, in many ways, confined to a localized space. ACTPOC participants did not, for the most part, have the privilege of mobility. One example in particular helped me grasp this kind of confinement. I have heard, many times over the course of ACTPOC groups, participants describe their longing to return home to the South; however, they were unable to, as they would be unable to access the same level of health care and other services. The HIV and other drugs approved by Medicaid vary; some participants spoke of how their desire to return conflicted with their need for medication that was not on Georgia or Tennessee's formularies. As devolution shifts services from the federal to the state level, PLWHA find their movement limited.

Finally, ACTPOC had to shed its local dimensions in its potential to become an evidence-based intervention (EBI). Edward Trickett proposes that these "interventions have focused primarily on specific programs designed to change people, not on processes designed to change places" (Trickett 2005:4). What new spatial forms emerged in the "disappearance" of place-based practices in HIV/AIDS public health?

As part two suggests, these EBIs reinforce aspects of identity that appear stable across place—for example, interventions designed for particular groups such as "African American high-risk heterosexual women" and "gay and bisexual men fifteen to twenty-two years old." The localized characteristics of HIV/AIDS behavioral projects created figures now visible on the national stage.

Organization of the dissertation

This ethnographic study and analysis of ACTPOC hopes to contribute to the dialogue on HIV/AIDS health inequalities and knowledge practices in at least two ways. Framed in part by the national health policies that promote racial and gendered inclusion in clinical research, this dissertation engages the everyday practices of ACTPOC's group-based educational intervention. It explores the contradictions whereby ACTPOC acknowledged the social and institutional barriers that limit women and people of color's access to ACTs at the same that that it depicted race and gender as idioms of biomedical difference. ACTPOC elicited and embraced participants' racialized and gendered experiences living with HIV/AIDS, and organized these complex narratives into expressions of biomedical difference. Participants' accommodations to and reinterpretations of ACTPOC's efforts to socialize them into biomedical research norms illustrate the contingencies involved in even the most rationalized public health models.

Second, this ethnographic case study delves into some overlooked aspects of the fairly recent but well-established trends to develop and adopt "science-based" or "evidence-based" interventions in both clinical medicine and public health promotion (such as HIV/AIDS education). ACTPOC was not only a group-based educational intervention; it also studied if and how the intervention increased participants' knowledge of and interest in taking part in ACTs screenings. Patterns of funding for health services research now demand the kinds of methodologies most often associated with the rigorous—if not rigid—research design that is used to test experimental drugs, the randomized controlled trial.[8] The criteria typically used to evaluate behavioral science interventions—through data produced through standard tools such as surveys and Likert scales—no longer suffice, as public health researchers are expected to integrate control groups, measurable endpoints, and larger samples into their research design. Reflecting the broader commodification of health care, HIV/AIDS public health education is now dominated by an epistemology of outcomes, and research labor is being restructured to accommodate these shifts. However, with the exception of some attention to its impact upon clinicians and higher-status staff, the rise of "evidence-based" upon behavioral health staff has been largely unexamined. The perspectives of

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[8] Randomized trials research is an experimental treatment by way of randomly assigning two (or more) groups to either the experimental treatment or the placebo or "standard-of-care." ACTPOC tested its group-based standardized intervention against a "standard-of-care" series of three groups regarding HIV/AIDS care that included medication adherence, mental health, and medical support, including a brief (ten minutes) presentation of ACTs. ACTPOC's goal was to determine if participants in the experimental group screened for and were more knowledgeable about ACTs in greater numbers.

"non-elite" scientific labor—ACTPOC's non-PI, non-managerial staff members, which include the Research Associates (RAs) that collect survey data and the Intervention Group Facilitators (IGFs) that administer the standardized curriculum to the intervention groups—offer critical perspectives of evidence-based interventions.

This dissertation is organized into Part I (Chapters one through four) and Part II (Chapters five through seven).

Part I examines ACTPOC's group-based standardized intervention, which was composed of three groups.

Chapter one discusses the history of the NIH Revitalization Act, the mandate to include women and people of color in clinical research, which supported recruitment interventions such as ACTPOC. I situate the NIH RA and similar health policies that promote race-based medication development in relation to broader neoliberal trends such as welfare restructuring and federal deregulation.

Chapters two, three, and four each describe ACTPOC's intervention groups that form a complete cycle.

Chapter two examines some of the introductory exercises that introduced participants to several key themes of the intervention. It explores the particular means by which ACTPOC framed ACTs as a potential option to address the disparate health outcomes seen among PLWHA of color. This chapter discusses how concepts of gender and sexuality were deployed in such a way as to circumscribe and reinforce notions of race as immutable and fixed.

Chapter three's focus is on group two. This chapter describes ACTPOC's ACTs screening visit and examines several group exercises on research and clinical care to question whether the differences between them might have been minimized. It draws from secondary data analysis of ten HIV/AIDS clinicians working in busy public clinic settings to discuss how they employed caution in their referrals. Not driven by paternalism or stereotyping, many clinicians reported their dissatisfaction with the pharmaceutical HIV drug testing agenda.

Chapter four discusses group three, the third and last group in a cycle. This chapter describes how ACTPOC followed the lead of many other public health oriented research studies that are adopting a new recruitment method called "Respondent-Driven Sampling" (RDS). This chapter describes how RDS is replacing the outreach workers who until recently had served as the primary recruiters for health research studies. Framing RDS within a critique of neoliberal health policy, this chapter draws from participants' experiences with the cash-based "recruitment economy" to illustrate its problems.

Part II examines the "evidence-based" movement in HIV/AIDS behavioral interventions and draws from interviews, focus groups, and participant observation to explore the work involved with such an undertaking, focusing particularly upon ACTPOC staff, the RAs and IGFs.

Chapter five discusses ACTPOC from the perspective of the RAs who conducted survey interviews with participants. This chapter analyzes how staff negotiated the various roles their positions demanded of them, and the limits of the evidence-based enterprise for workers that do not share the status of physicians for example. Yet despite the charges of "de-skilling" that pervade the EBM and EBBM literature, standardization actually required more from them, even if their work "to make it work" was structurally invisible.

Chapter six examines the use of a new computer technology the RAs used to conduct interviews, which is being widely adopted in public health survey-based studies. A broader examination of this technology's epistemological implications is followed by ethnographic perspectives that illustrate how this new technology is reshaping RAs' relationships to participants, management, and their work overall.

Chapter seven explores the Intervention Group Facilitators' (IGFs) experiences with administering the intervention. What was it like for them to follow a standardized manual as facilitators of these groups? How did they come to view their work and what was required of them?

The conclusion summarizes the dissertation and its findings. It also suggests ways that further research might build upon this ethnographic research.

CHAPTER ONE:
The NIH RA & RACE-BASED MEDICATIONS

> And you need the clinical trials to be done on *all* types of human beings. You need young people, you need old people, you need working people, unemployed people, you need smokers, you need alcoholics,[9] you need drug users, you need prostitutes, you need homosexuals, you need atheists, you need Catholics, you name a person, that person is needed for a clinical trial. We need black women, and Puerto Rican women. We need Asian women, we need our communities. And our community is infused with *everybody*.
>
> *Alberta, ACTPOC intervention group video*

The camera slowly recedes from Alberta, enlarging the frame to depict the six individuals sitting around a bare table in an empty restaurant. Alberta's arms continue to gesticulate, and her mouth moves as if she is speaking. But her voice is now muted; replaced by an AIDS Clinical Trials Unit (ACTU) research nurse who describes the concept of eligibility for trials. This video is one presentation in ACTPOC's standardized group intervention, and I am watching it alongside nine other people in a dim, windowless meeting room that ACTPOC rents from an HIV/AIDS clinic that serves primarily low-income PLWHA in a large urban hospital. Chyna, a middle-aged black woman sitting across from me watches the screen intently, her pen poised to jot down the occasional note. To my right, Gus, a young Puerto Rican man, slouches in his

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[9] The statement that some studies "need" alcoholics has gained national attention, though not for the reason that Alberta mentioned. Carl Elliott and Roberto Abadie cite an article in the *Wall Street Journal* (Cohen 1996) that reported on Eli Lilly's practice to recruit homeless alcoholics from shelters to participate in Phase One safety trials of new drugs [(Elliott & Abadie 2008:2316) Cohen, 1996].

seat; his long, restless legs extend out into the semi-circle. The room is quiet until a voice pipes up from the outer edge of the circle. “Hey isn’t that Jeri?” Murmurs of agreement and responses of surprise follow as Jeri, a longtime HIV/AIDS and harm reduction activist and women’s health advocate, describes her positive experience screening for an ACT. The benefits of screening, Jeri says, meant that she received a superior level of care than the kind she received from her own doctor, including a test that revealed she was borderline diabetic.

ACTPOC argues that the limited enrollment of women and people of color in ACTs—a phenomenon referred to as their “underrepresentation”—hampered researchers’ ability to determine if and how HIV medication may have a different efficacy and/or safety profile for women and people of color. ACTPOC participants are told that the potential for these differences to be detected—and the opportunity to develop new and improved medications—will not be possible unless more women and people of color enroll in ACTs. Alberta pleads for viewers to consider these high stakes: “People of color, and especially women, are now the ones that are mainly infected and we don’t participate in clinical trials so the researchers don’t know how to treat us because we’re not participating. They have to know how our bodies work.”

Jeri and Alberta’s provocative claims raise a number of questions this dissertation explores. How was the concept of underrepresentation in ACTs for women and people of color in ACTs defined; why was it seen as a problem; and how was the concept of participation communicated by researchers and interpreted by participants? Why were biomedical solutions seen as crucial to addressing racialized and gendered inequalities in HIV/AIDS care? How did staff and participants alike respond to the fusing of racial and gendered inequalities in HIV with screening for ACTs? What are we to make of the fact that ACTPOC's call for the study of racial difference drew from standardized and precise classifications, which took on multiple and flexible meanings as they moved across different sites? How were constructs of sexuality used to mediate and manage racial differences?

In the Introduction, I proposed that ACTPOC needed to be framed in relation to the neoliberal contexts in which clinical trials participation occurs. This chapter adds to and extends that discussion by examining the contemporary health policies that institutionalize the study of racial difference. First, I place this ethnographic study of ACTPOC within the NIH Revitalization Act (referred to as the "NIH RA"), a policy that mandates the inclusion of women and minorities in clinical trials. This health policy has radically shifted the terms of how federally funded clinical research is conducted. Although no discussion about the NIH RA entered into the ACTPOC's intervention groups or the day-to-day practices of the study, the source of its funding was directly tied to the NIH RA's mandate to support the development and testing of scientific-based strategies to recruit women and minorities to clinical research. A brief historical outline of this policy change offers insight into the various agendas that led to its passing.

Next, I explore the story of BiDil, the first FDA-approved drug to treat heart failure in African Americans, to illuminate key issues that are largely absent from the mostly positive discussion of how race contributes to the knowledge produced in clinical trials. The weakening of the social service contract, teamed with the transformation of state institutions (such as the FDA) away from the public to support of capital projects, is highlighted to discuss the expansion of race-based pharmaceutical interventions.

ACTPOC has multiple genealogies, and the framing of this ethnography could have proceeded from any number of directions and indeed claims more origins that what I provide here. The cross cutting issues of racial biology, health disparities, and neoliberal health policies were especially salient in ACTPOC and help to explain its development. This chapter's examination of the NIH RA and BiDil's pharmaceutical development reveals insights that seem to apply to or at least have relevance for ACTPOC. However, ACTPOC framed its own goals and purposes quite differently. Some of these differences emerge in ACTPOC's day-to-day practices that shaped its meanings, purpose, and effects. The point is not to resolve the disparities among these accounts, but to explore the different actors and opposing stakes that shape the phenomena of racialized biomedicine, which is far less unified than it might appear.

Overview of Clinical Trials Inclusion Mandates

In 1993, Congress passed and President Clinton signed the NIH Revitalization Act Public Law 103-43, titled *Women and Minorities as Subjects in Clinical Research* (hereafter referred to "NIH RA"). The NIH RA introduced significant changes that affect the design, analysis, and operation of all federally funded biomedical and behavioral research. It requires that "women and minorities and their subpopulations be included in Phase III clinical trials in numbers adequate to allow for valid analyses of differences in intervention effects"[10] (Office of Research on Women's Health (ORWH) 2002:4). The same year the NIH Revitalization Act was introduced, the Food and Drug Administration (FDA) lifted the 1977 guideline that excluded most women "of childbearing potential" from taking part in clinical research (Merkatz et al. 1995:793). The FDA also specified that it could reject New Drug Applications[11] (NDAs) "that did not conduct adequate analyses of population subsets if there was insufficient evaluation for the safety and effectiveness of the intended population[12]" (Lee and Skrentny

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[10] There is an exception if data from previous studies "strongly support no significant differences of clinical or public health importance in intervention effect based on sex/gender, racial/ethnic and/or relevant subpopulation comparisons, then sex/gender and race/ethnicity will not be required as subject selection criteria" (NIH notebook, 2002:7). However, "the inclusion and analysis of sex/gender and/or racial/ethnic subgroups is still strongly encouraged" (ibid.).

[11] The Investigational New Drug Application typically follows preclinical animal testing. Applications for INDs must show a certain degree of efficacy to merit testing in humans. Once the INDA is approved, Phase One trials can begin. To obtain permission to market a new drug, the sponsor must submit a New Drug Application (NDA), along with research results of the clinical trials conducted and other relevant studies (Lurie and Zieve 2006:88).

[12] These requirements were opposed by profit-oriented pharmaceutical companies in contrast to NIH-funded PIs, note Catherine Lee and John Skrentny (2010:617). However, it also seems that the division

2010:634). In 1998, the FDA instituted the "Demographic Rule" that called for sponsors of Investigational New Drugs (INDs) and New Drug Applications (NDAs) to tabulate its' participants in clinical trials by "age group, gender, and race in their annual reports" (ibid.).[13]

As part of its mandate, the NIH RA allocates funds to develop and design outreach strategies to recruit minorities and women to clinical trials. In 2003, the NIH division that funds HIV/AIDS research (that includes ACTs, laboratory or bench science, and behavioral health sciences research) released a Program Announcement (PAS-03-168) titled "Enrolling Women and Minorities in HIV/AIDS Research Trials." Citing the NIH RA, the announcement reads, "While public law now mandates the inclusion of women and minority groups as subjects in clinical research, NIH acknowledges that barriers exist that affect adequate recruitment and retention of racial and ethnic minorities and women into clinical trials." ACTPOC was the result of a successful proposal to design and test an educational intervention for HIV-positive women and people of color to increase their knowledge of and rates of screening for these studies.[14]

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between pharmaceutical and NIH is weaker than ever, suggesting that significant overlap. But this does not distract from Lee and Skrentny's important insight.

[13] In 1997, the FDA Modernization Act (FDAMA) implemented similar requirements for non-federally funded biomedical research, i.e. pharmaceutical industries.

[14] The discussion here emphasizes the policies that support inclusion efforts. It should not be assumed that the PIs' interest in and concern for these issues mirrors that of the official declarations. In fact, in their own words, the PIs' describe their goals evolved from a slightly different set of concerns that match the goals of these policies but emerged from a commitment to access as was declared by one of their co-

Origins of the NIH Revitalization ACT to Include Women and Minorities in Research

Official NIH texts depict the origins of the NIH RA and its organized support as "an outgrowth of the women's health movements" (ORWH 2002:3) but this claim to the legacy of feminist health is somewhat misleading. Scholars argue that support for the NIH RA did not reflect the fundamental politics of the grassroots women's health movements that flourished during the 1960s and through the 1980s and beyond.[15] There are significant differences between professionals' calls for reform with that of feminist health rooted in social justice. This section discusses the NIH RA as the outcome of several interrelated social and historical processes, several of which seem related to concerns about gender, but none of which fully express the radical critiques at the heart of feminist health. The relatively late addition of "minorities" to this bill, which had initially named women as its focus, is also significant in the development of the NIH RA and is described here.

Social scientists trace the origins of the NIH RA to a 1985 report that was commissioned by the Public Health Service (PHS) and produced by the newly

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investigators that initiated their collaboration. In addition, ACTPOC's educational pedagogy to increase the participation of women and minorities in clinical research did not formally recognize the NIH RA in its group settings, but the Congressional Record and Department of Health and Human Services (DHHS) official texts suggest its relevance in the emergence of recruitment interventions.

[15] The purpose here is to question the narrative that women's health movements were the origins of the NIH RA. My reference to feminist health activism is intended to call attention to the broad differences that are not accounted for in official NIH RA publications. See Sandra Morgen (2002) and Carol Weisman (1998) for overviews of feminist health activism in the U.S. An excellent study of racism, classism, and heterosexism in the reproductive rights movement may be found in Dorothy Roberts' work (1999).

organized Task Force on Women's Health (Auerbach and Figert 1995; Ruzek and Becker 1999; Epstein 2007). The goal of the Task Force on Women's Health was to document women's health in an effort to mobilize federal attention to these issues. The first recommendation of the *Report on the Women's Task Force* outlined that laws be enforced and regulations developed "to ensure that all people, regardless of socioeconomic status, have a safe and healthful physical and social environment" (1985:79). However, as Judith Auerbach and Anne Figert note, their recommendations by and large "went unheeded, and the report itself received little, if any, public attention" (Auerbach and Figert 1995:117). There was one exception, but it was neither economics nor the environment that drew particular scrutiny and interest. Of the fifteen recommendations the *Report on the Women's Task Force* outlined, it was the call to expand biomedical and behavioral research studies to focus on "conditions and diseases unique to or more prevalent among women" that galvanized attention (1985:76). The rising interest in biomedical reform—and the subsequent displacement of the social causes of health inequalities—foreshadowed the events that were to unfold.

In response to the Task Force's report, in 1986 the NIH issued a policy "to *encourage* the inclusion of women in clinical scientific trials" (Auerbach et al. 1995:117). In 1989, the General Accounting Office (GAO) conducted a survey that showed "the NIH had failed to implement its policy to include women in study populations" (Ruzek and Becker 1999:6). The results of the GAO Report sparked consternation for many; it served as yet another reminder of widespread institutional neglect for women's health concerns.[16] The disappointing findings outlined in the report proved to be a driving force for women's health advocates, who, along with the Congressional Caucus for Women's Issues and other members of Congress, used the *Report* to publicize greater attention to women's health. Facing pressure from both Congress and the public, the acting director of the NIH William Raub created a new NIH Office for Research on Women's Health (ORWH) to state his commitment to women's inclusion in clinical trials (Epstein 2007:78). With the NIH budget up for reauthorization, members of Congress drafted a policy to include women in clinical trials, giving it the force of the law (Epstein 2007:79).

Scholarly critiques of NIH RA portray its supporters as professionals located in the centers of power, suggesting that the connections it claims with women's health activism might be overstated, as the next example suggests. Jean Hamilton, a NIH physician-investigator, offers a firsthand account of her involvement in the development of the NIH RA. She reports that attention to and subsequent funding for the GAO Report was the result of a "well-orchestrated effort" on the part of scientists such as herself, the Executive Directors of women's public interest groups, attorneys, and lobbyists. Hamilton's description of this group as "women's health advocates from all walks of life" does not quite seem to match its elite membership and professional

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[16] The GAO Report found that the 1986 policy on inclusion "had been poorly communicated even within the NIH and had been applied inconsistently" (Epstein 2007:77).

agenda that defined its goal to "chang[e] the climate at the NIH" (Hamilton 1994:15). Sheryl Ruzek and Julie Becker describe how this legislation gained organizational support from women in Congress, the biomedical professions, and health advocacy organizations (Ruzek and Becker 1999:6). Epstein describes the coalition supporting the NIH RA as a large contingency working from "the inside in" that represented "the elites of U.S. society"—professional organizations, supporters from within DHHS agencies, politicians, physicians and scientists, and even pharmaceutical companies (Epstein 2007:54).

Feminist health activism's challenges to medical authority and biomedical norms—as evidenced by its critical position towards paternalistic medicine, over-medicalization, and the neglect of social relations in shaping women's health—were largely absent in the NIH RA's supporters' vision. As research on women's health was gaining prominent visibility at the NIH and developing commercially for those who could pay, the Hyde Amendment;[17] the war on drugs; the adoption of managed care models in Medicare and private insurance; and devolution were wreaking havoc on the lives of women, and especially poor women, women of color, and their communities. NIH RA advocates called for biomedical research reform in terms of inclusion and funding, but other topics—the relation of biomedical research to the pharmaceutical industry, the current state of and access to health care, and the health problems rooted

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[17] The Hyde Amendment, which passed in 1976, prohibits Medicaid funding for abortions, except in unusual circumstances; for example, an exception is made when it threatens the woman's health.

in social inequality—did not occupy the agenda. Part of the reason for this, it seems, had to do with the noticeable shift to the Right that dominated the political climate of the 1980s and 90s. Adele Clarke et al. note that this was a time when women's health and HIV/AIDS movements were being co-opted into biomedical consumerism (Clarke et al. 2003:179). Sandra Morgen argues the development of profitable, specialized services "geared to affluent women" indicates this shift from the margin to the mainstream (Morgen 2002:233). The NIH RA, unlike most feminist health activist movements, offered little opportunity for involvement by women who were not scientific researchers or health policy experts—those outside the centers of power the NIH RA advocates occupied. Women were not invited to join supporters at the table or set the terms of the health agenda. The potential for most women's involvement set out by the NIH RA lay in their participation as *biomedical subjects* in clinical trials.

Ruzek and Becker describe the passing of the NIH RA as evidence of a transformation whereby "the women's health movement's critique of biomedicine and the call for demedicalizing health care was framed into a bipartisan agenda for equality" (Ruzek and Becker 1999:6). Funds to develop and launch the Women's Health Initiative (WHI), a longitudinal research study to examine cancer, osteoporosis, and cardiovascular disease, has been described as the NIH's demonstration of their commitment to women's health (Epstein 2007:81). But who stood to benefit? Adele Clarke and Virginia Olsen propose that the key research goals of the WHI may in fact be the "socialization of the costs of pharmaceutical testing" that transfers the burden of costs from pharmaceutical industries to the public (Clarke and Olsen 1999:16). Noting a similarity between the goals of the WHI and the "pacification stories of giving more drugs to women, which feminists critiqued decades ago" (ibid.), Clarke and Olsen insist that, "[W]e need to question why strategies for prevention are not also being pursued" (Clarke and Olsen 1999:17).

The NIH RA reflects a "new wave of women's advocacy," which sidestepped controversial efforts such as abortion, highlighted the importance of research and was less critical of pharmaceutical companies (Epstein 2007:80). The NIH RA's avoidance of the thornier issues related to women and health promoted its appeal to Democrats and Republicans alike. How gender-specific biomedical research would interact alongside—and in conflict with—longstanding commitments to addressing health inequalities in relation to social conditions such as racism, gender domination, and poverty were not, it seems, priority concerns. Feminist challenges to biomedicine were being replaced by calls for more equal distribution of its benefits.

Women…and Minorities?

Thus far, the inclusion of women in clinical trials and the resources for and attention to women's health were the basis for the development of the NIH RA. When did minorities join this legislation and what led to their addition?

Minorities did not garner much visibility among NIH RA supporters until several years after the release of the PHS Women's Task Force Report in 1985.[18] Scholars agree that the addition of minorities during the drafting of the NIH RA legislation occurred somewhat serendipitously; organizers' focus on gender did not, it seems, lead them to seek out allies who might have shared similar concerns regarding race. Epstein states that, "In 1990, as the NIH Revitalization Act was being drafted by Congress, some Black caucus members' interest in the legislation was met with favorable reception by the Congressional Caucus for Women's Issues. As a result, "the phrase 'and minorities' was added to the wording of women in research" (Epstein 2007:79). Drew Halfmann et al.'s study of minority health bills from 1975-2002 found that the NIH RA was part of the main group of proposals (fifty-seven percent), which were all attached to bills with a broader purpose than minority health. Noting that the category of "minorities" was added alongside the category of women in the drafting of the NIH RA, despite that the bill's supporters were not "specifically requested to do so by minority health advocates," lead Halfmann et al. to speculate that some NIH RA advocates viewed this addition as a strategy to strengthen their bill (Halfmann 2005:22).

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[18] Federal attention to racial inequalities in health gained official recognition with the first report commissioned in 1985 titled, "Task Force Report on Black and Minority Health." Margaret Heckler of the DHHS created a Task Force that was headed by Dr. Thomas Malone. The Task Force compiled a seven-volume report that identified significant racialized gaps in access to health care, disease incidence, and mortality rates. They analyzed a number of reasons for these inequalities, including poverty and lack of prenatal health care, but the Reagan-dominated Health Division cited "behavioral problems" such as smoking and obesity as the cause. Despite the downplaying of racial inequalities in health, this report did result in the creation of Minority Health Offices at the PHS and NIH (Halfmann et al. 2005).

In their discussion of whether minority communities find the principal arguments for inclusion mandates to be compelling, Mandy Garber and Ronald Arnold note that, "the rationales for increasing minority representation…did not originate in the minority communities" (Garber and Arnold 2006:17). Members of the National Medical Association (NMA), an organization of African American physicians, developed a *Consensus Statement* that is critical of the narrowness of vision in calls for "adequate representation" of minorities in clinical trials. They argued for greater minority representation not just as trial subjects but across multiple aspects of clinical research and health care, calling for the expansion of educational and training opportunities for minority physicians and clinical researchers and for greater equality in health care and advocacy in medical ethics (2000:464).

The problematic addition of minorities to women concurs with feminist critical race and sexuality scholar Lisa Bowleg's assessment of the NIH RA, which she maintains spuriously portrays race and gender as "mutually exclusive categories" (Bowleg 2008:313). The ontological constructions of race and gender will be further discussed; for the moment, the additive capacity of race to join gender transforms the dialectical relationship of racism and gender domination into a set of attributes or characteristics. The trope of "women and minorities" coheres with Lynn Weber's account of biomedical interventions, which typically "obscure the nature of race, class, gender, and sexuality as social relationships" (Weber 2006:37). The Office of Research on Women's Health (ORWH) and the Office of Research on Minority Health (ORMH), which were both mandated by the NIH RA, illustrate this institutionalized divide between race and gender. This separation leads Morgen to argue that this logic contributes to the "marginalization and invisibility" of women of color, who are often subsumed into one of two distinct categories: "minority" or "woman" (Morgen 2006:405).[19]

This discussion of the NIH RA has thus far outlined a few key points about its origins, described its alliance with biomedicine, and illustrated the tensions of race and gender in its organizing and outcome. The following section discusses social and biomedical scientists' critiques of the racialized and gendered biomedical research agenda and its neglect of the structural roots of health inequalities.

Race, Gender, and Biologies

ACTPOC's aims align it with a growing school of thought [WC] that seeks to detect the presence of (or potential for) racial biological differences that influence medication development, medical treatment, and clinical outcomes. This paradigm is supported by a mosaic of actors with a variety of interests, encompassing commercial venues and academic disciplines, as well as lay people and experts alike. But this paradigm has been met with equal opposition; among these critics are cultural

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[19] The NIH RA also secured permanent funding for the recently developed ORWH and ORMH at the NIH, and developed new professional opportunities to support women and minorities in biomedical research.

anthropologists and other social scientists that are wary of this burgeoning interest in the biologization of race, with some framing its resurgence within its problematic histories. Although it did little to mitigate the mass sterilization practices of primarily poor women, the majority of whom were black and/or Latina, the widespread support for racial biology receded in the mid-twentieth century as the exposure of Nazi atrocities helped to shift public consciousness.[20] Anthropologists and other social scientists' research, which debunked the myths of race biology, were instrumental to passing the landmark *Brown vs. the Board of Education* case (Baker 1998). It is now well known how tenacious racial inequality has proven to be—particularly as the concept of culture has taken on the ideological work race once enabled (Gregory 1998:10; Smedley 1993)—but this fact does not distract from the phenomenal discrediting of racial biology, which a few decades earlier had legally codified the "one-drop rule" as scientific fact (Somerville 2000:168).

Some scholars maintain that current efforts to study racial biologies represent a clear break from the pernicious histories of eugenics, anthropometry, and Social Darwinism. David Skinner argues that the new "biologism"—a term he coined to refer to "the growing ascendancy of biologically based accounts of human life" (Skinner,

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[20] Nancy Ordover (2003), Harriet Washington (2006), and other scholars urge us to keep the connections between Nazi eugenics and the eugenic projects in the U.S. Ordover points out that many Nazis were avid students of U.S. eugenic doctrines (Ordover, 2003:41). Harriet Washington offers a historical discussion of the involuntary surgical sterilization targeting poor women, women of color, and those with disabilities, which lasted well into the 1980s (Washington, 2006:202-205).

2006:461)—challenges “dystopian predictions of a revival of scientific racism” (Skinner 2006:475). A similar optimism is supported in the influential writings of Nikolas Rose, which convey that the debate regarding race needs to be located in the “biology of the present” (Rose 2007:161). According to Rose, this molecular genomic biology “is probabilistic not deterministic, open not closed, not identifying an essential racial truth that determines individuals to different fates but opening up the possibility of intervention and transformation” (ibid.). The anthropologist Nadia Abu El-Haj agrees that, “racial thinking in postgenomics diverges from a commitment to biological determinism” (El-Haj 2007:291). She argues that the interest in postgenomic medicine by people of color itself indicates a significant qualitative difference that sets it apart from the deleterious racial sciences of the past (El-Haj 2007:292).

Skinner, Rose, El-Haj, and other theorists remind us that the racial biology of the twenty-first century is not identical to that of the late nineteenth and early twentieth, cautioning against the tendency to ignore the specific contexts in which contemporary developments in racial biologies are emerging. However, I am less convinced that this break between contemporary and historic racial science is actually as substantial as they propose. Is the new biology really that novel and different from its harmful predecessors in its formulations of race and disease? Does the fact that some people of color support contemporary research into race-biology diminish its possible harms?

How is the growing emphasis upon the new biologies' transformative potential distracting us from the social structural causes of unequal health burdens?

Support for the study of racial biology and the development of racially-targeted medication resembles the perspectives put forth by Rose, Skinner, and El Haj—as its proponents maintain, the search for racial and gendered difference is grounded in *addressing* health inequalities, not reproducing them. Rejecting the notion that biological differences reflect positive or negative valuations, some maintain that the search for unbiased truths neutralizes any such distinctions. In fact, ACTPOC and other groups argued that ignoring what they describe as the strong possibility for or presence of biological racial differences only reinforces health disparities. Rebecca Dresser's critique of the "standard human"—a reference to the clinical trials subject as white, male, approximately forty years old or younger—is frequently cited in support of race- and gender-specific medical research. "Like the pronoun 'he,' it was taken for granted that the white male subject stood for all of us"[21] (Dresser 1992:27). Absent of the proportionate representation of women and people of color, Dresser and others argue, means that the benefits of publicly funded biomedical research is denied these groups. The implicit dominance of the universal (unmarked) white male subject studied in clinical trials neglects what some consider "physiological" racial difference as well as

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[21] As many scholars have pointed out, the idea that "the white male subject" has dominated clinical trials is not entirely correct, given that historically, the most politically marginalized and vulnerable—including poor people and/or people of color—have been the primary subjects of trials (Weinstein 2001:197; Ho 2008:39).

gender difference.[22] If "color-blind" science leads to the erasure of certain groups in biomedical research and medication development, ACTPOC and similar interventions promise to restore their visibility.

Given the relative success of HAART, the tragedies of racial biology, and the political-economic factors that contribute to poorer health among PLWHA of color we must ask why the topic of racial visibility in biomedicine is being embraced with such enthusiasm. What propels the scientific agenda that aims to discover racial differences in biological and physiological responses? Why has the search for race-based medicine reemerged in its present form and what does the attention to racialized biomedicine displace? On what bases does race-based medical research structure its claims to improve health? How do the assumptions that people of color embody different innate biological differences communicated by clinical researchers, and how do people of color living with HIV/AIDS respond to, challenge, and integrate these claims?

Kamala Visweswaran's analysis of Franz Boas' legacy, particularly the distinction he made between race and racism, is instructive for exploring the limitations of the racial-biological approaches that Dresser and NIH RA advocates support. Boas "sought to make race a scientific, biological, and therefore value-neutral fact" (Visweswaran 1998:73) where it "could be separated from racism or negative value

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[22] Krieger and Fee argue that the present focus on the "white male as norm" to understand lack of research is not accurate as "the health of women and men of color and nonreproductive health of white women [was] simply ignored" (Krieger and Fee 1994a:270).

through proper science" (Visweswaran 1998:71). Although a well-intentioned effort to undermine racist thinking, Boas created a specious divide between culture and race, abrogating the latter to the realm of biology that defined it as fixed and ahistorical. Visweswaran's critique of Boas' efforts to neutralize the purported links between race and biology offers a challenge to NIH RA advocates, who overlook how biology, race, and gender are mutually constituted in complex matrices of power. Visweswaran asserts that, "What we assign to the realm of biology has everything to do with the modernity of social classifications. Races certainly exist, but they have no biological meaning outside the social significance we attach to biological explanation itself" (Visweswaran 1998:77).

Critical Voices of Racial Biologies

Critical social and biomedical scientists outline how the purported biologies of race and gender are a kind of "false lead" that distracts from the work that needs to be done to address racialized and gendered inequalities in health. David R. Williams agrees, stating that, "reifying the concept of race can leave relevant aspects of the social environment unexplored…" (Williams 1997:329). Williams' perspective represents a larger school of thought among many social epidemiologists, anthropologists, and other social scientists: systems of power—including but not just limited to racial and gender stratification—are important to the study of and response to health inequalities.

Attributing these disparities to purported innate differences between races is a misguided effort; biological differences *embody* social inequalities; they do not cause them. Nancy Krieger and Davey Smith explain, "At issue is how social influences become literally embodied into physio-anatomic characteristics that influence health and become expressed in societal disparities in health" (Krieger and Smith 2004:92). In other words, there are indeed biological differences that can be linked to *racism*: unequal access to care, structural inequalities, and the burdens of oppression are all detrimental to health. "Race" is a socially constructed characteristic, not an innate force that causes or that accounts for these differences. One CDC study recently found that twenty-eight percent of Black MSM were HIV-infected; young black men had the highest rate of new infections, approximately fifty-two percent (MMWR 2008:985-989). These differences reflect pervasive social inequalities, such as racial marginalization and heterosexism/homophobia; they do not—as some might have suggested in a parallel example that has been widely discredited—point to purported differences in black bodies.[23]

The allure of biological racial claims is based in part on promises of their potential. Given that a body of rigorous research illustrates ways to address racial and gendered health disparities—from facilitating access to health care to promoting

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[23] In the case of HIV/AIDS, the argument that high rates can be attributed to purported differences in black bodies has been discredited, but these racist myths persist. See Charles Leslie (1990).

economic justice—why does the ambiguous call to racial science garner the most credibility? The claims that future genetic discoveries will one day address the pervasive, present-day health disparities are simply a detour to addressing the social structural problems that cause health disparities, according to Pamela Sankar et al., who argue, "Standardizing access to health care and reforming attitudes toward minority patients poses a far greater challenge than introducing new treatments facilitated by genetic research" (Sankar et al. 2004:2987).

A willingness to accept the possible harms of racial science under the guise of addressing health disparities is especially troubling. Linda Hunt and Mary Megyesi's study of geneticists reveals how they minimized the deleterious effects of their use of race in their work by subscribing to vague but powerful beliefs that science will ultimately correct any harms. Hunt and Megyesi conclude that, "While acknowledging that this practice [of using poorly defined racial categories] may have significant negative implications for racial/ethnic group members, most defended their use in pragmatic terms…an interim step in the march towards scientific progress" (Hunt and Megyesi 2008:499).

What Are these Categories? What Are the Effects?

The NIH RA requirements are operationalized through a formulation of racial classifications titled *Office of Management and Budget Directive* (OMB) *15*.[24] The official bureaucratic texts that outline the requirements for the measurement and collection of race emphasize an administrative and technical focus that forecloses a more critical reflection of them. Of course, standardized forms of measurement are among the vital tools needed to assess the prevalence of racialized and gendered health inequalities. The importance of population-level health data demands even greater attention to how these categories are defined and ultimately, interpreted. The application of the NIH RA categories does not however facilitate the greater care that is needed to conceptualize these categories and analyze their relevance. Even in the absence of the biologization of racial differences, the resulting reification of race and gender fuels their misinterpretation.

Newton Osborne and Marvin Feit point out that despite the ubiquitous number of studies that use race as a variable, it is rarely defined (Osborne and Feit 1992:275), which supports the "tendency to assume that the results obtained are a manifestation of

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[24] The standard categories the NIH, CDC, FDA, and other governmental agencies used to collect racial data are referred to as the *Office of Management and Budget's (OMB) Race and Ethnic Standards for Federal Statistics and Administrative Reporting* (Hunt and Megyesi 2008:495). These racial classifications are used in the Census and also in ACTPOC: Black/African American; Asian/Pacific Islander; Native American/Alaskan Native; and White (people also have the option of marking "Other" or "Refuse to Answer"). Ethnicity is designated as Hispanic or non-Hispanic white. In his discussion of how state public health agencies may adopt these requirements into their reporting mechanisms, Daniel Friedman cites *OMB Directive 15* that states, "the categories in this classification are social-political constructs and should not be interpreted as being scientific or anthropological in nature" [(Friedman et al. 2000:1715) Fed Register, 1997]. See Lee and Skrentny for a discussion regarding how the politicization of the category of race, which emerged from Civil Rights struggles, have been transformed into bureaucratic classifications (Lee and Skrentny 2010).

the biology of racial differences…that certain racial groups have a special predisposition, risk, or susceptibility to the illnesses studied" (ibid.). Catherine Lee describes a similar set of findings from a content analysis in which she explored the adoption and interpretation of race following the institutionalization of NIH RA requirements. In her review of over two hundred articles published in biomedical research journals that reported on studies funded by the National Cancer Institute (NCI) of the NIH, Lee found that "despite the frequent invocation of the terms 'race' and/or 'ethnicity,' authors rarely offered a definition or operationalization of the concepts" (Lee 2009:1187). Lee concludes that, "a growing faith in biomedicine and genomics and an uncritical acceptance of scientific studies of race or ethnicity may foster essentialized and biologically reductionist approaches" (Lee 2009:1189). Janet Shim uncovered similar findings in her ethnographic study of a group of epidemiologists, whose response to the NIH RA requirements led to "the ritualized inclusion of race as a taken-for granted and unexamined variable" (Shim 2005:427). Shim argues that the routine inclusion of variables such as race and gender "obscure considerable uncertainty over exactly *how* such inequalities are produced, that is, what exactly *about* race, class and sex/gender contributes to chronic disease" (Shim 2002:136). While there are a number of excellent studies that examine heath inequalities that discuss concepts of race, gender, and socioeconomic status, the routine adoption of race in research studies (Shim 2002, 2005) and its lack of definition (Lee 2009) indicates the absence of critical and rigorous examination of what these variables are supposed to measure and represent.

The many dialogues taking place among biomedical researchers have not prompted universal agreement regarding how race is measured and interpreted but indicate a shared concern regarding its problematic uses. These examples suggest how race and gender may be used to assess the prevalence of health disparities, and to avoid the specious claims of racialized biomedicine. Should research follow the Institute of Medicine's (IOM) recommendation that ethnicity be adopted as a category to document health disparities, in order to avoid perpetuating race as a biological construct [(Oppenheimer 2001:1049) IOM, 1999]? Are racial classifications in agreement with how participants in these research studies see themselves (Moscou 2003:1084)? Is the concept of race simply a proxy for socioeconomic status, as many have suggested (Winker 2004:1613)? How might we systematically explore the relation of racial and gendered stratification and health in a way that avoids essentializing these concepts (Mullings and Schulz 2006:9)?

Several leading biomedical journals have taken the lead in drawing greater attention to the epistemological relevance of race and question the uses to which it is being put. In 2003, the *Journal of the American Medical Association* (JAMA) featured an essay that documents common pitfalls that include constructing race as fixed and biological; and simplistically assigning it to be the sole cause of health disparities without adequate explanation (Kaplan and Bennett 2003:2711). In 2004, *JAMA* adopted a policy that includes the requirement for authors reporting race to specify its relevance "to facilitate critical evaluation of race and ethnicity as constructs within the study" (Winker 2004:1614). The *International Committee of Medical Journal Editors* recently published guidelines for manuscript submissions that specify, "When authors use such variables as race or ethnicity, they should define how they measured these variables and discuss their relevance" (ICMJE 2010:12).

Discourses of Gender & Biology

Race-based biomedical research and treatment is the focus of rigorous critique across the social and biological sciences, as well as in the fields of bioethics and humanities. This has not been the case with gender. Steve Epstein observes, "reports of biological difference by race have sparked a heated medical and public controversy about 'racial profiling,' but no corresponding debate seems to have arisen as yet with regard to biological differences by sex" (Epstein 2007:234). The absence of critical commentary regarding gender and/or sex as a category in health research may have to do with the fact that, "It seems so routine, so normal, to view the health of women and men as fundamentally different, to consider the root of this difference to be biological sex" (Krieger and Fee, 1994:266). Krieger and Fee argue that this perspective not only neglects the significant differences among women but also overlooks women's similarities to men: “Women are discussed as a single group defined by biological sex, members of an abstract (and implicitly white) category” (Krieger and Fee 1994:272). Donna Strobino et al. agree that the lack of women’s participation in clinical trials poses a challenge for researchers, but propose that the “major deficit in education of health providers has been the limited attention to how the social context of women’s lives affect their health” (Strobino 2002:845). Women’s multiple roles and stressors, relationships, and social and economic circumstances point to the need to develop health policy that draws from social policies to ensure economic security for women (ibid.).

Numerous scholars and activists have noted that women’s relationship to HIV/AIDS has been ignored on multiple levels, from prevention education to clinical knowledge (Triechler 1999; Patton 1993; ACT-UP NY 1990; Cohen 1999). Women’s exclusion from ACTs (a point I discuss more in chapter two) also contributes to their invisibility. Until 1993, the definition of AIDS did not include several characteristics of this disease that are absent in men but present in women, such as cervical cancer.[25] Lynn Weber states that, “the construction of AIDS based on symptoms and manifestations in men led to defining criteria of the disease that excluded numerous conditions noted in women, including cervical cancer, pelvic inflammatory disease, and human papillomavirus, until twelve years after the disease was diagnosed” (Weber

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[25] As a result, many women with AIDS could not access services and support associated with their (lack of) diagnosis, such as Social Security Insurance (SSI), supportive services, and other forms of care.

2006:28). The relationship of gender and biology has some explanatory value in a way that race does not; however, like race, the biologization of gender encounters many similar problems regarding how these assumptions deflect attention from the structural bases of women's health inequalities.

More recently, the issue of possible gender-based differences in responses to medication has again emerged in the biomedical literature on HIV/AIDS. In their study of racial disparities and HIV/AIDS, Carolyn Chu and Peter Selwyn note that while the relation of sex and HIV medication toxicities is a matter for further exploration, they argue that pharmacodynamic differences are most likely multifactorial (Chu and Selwyn 2008:4). Chu and Selwyn point out that similar to race, differences in health-related outcomes organized by sex can be largely attributed to "unequal insurance coverage and access to medical services, patterns of health care utilization, existence of other serious comorbidities, and uneven receipt of and adherence to antiretroviral therapy" (ibid.).

The story of BiDil

The NIH RA can trace its origins to the Reagan years, which Lisa Duggan describes as a time when "pro-corporate, 'free-market,' anti-'big government'" shaped Western national policy and dominated international financial institutions (Duggan 2003:10). The corporatization of the FDA's mission, as evidenced by policies such as the

Prescription Drug User Fee Act[26] (PDUFA) and the deregulation of pharmaceutical advertising, occurred alongside the adoption of managed care, the reduction of spending on public health, and a steep decline in NIH funding. How was the NIH RA able to mobilize support for legislation that introduced new regulations and allocated new federal grant monies at a time when clinical research and public health projects were facing federal deregulation and the systematic withdrawal of public resources? Recruiting a diverse group of participants and analyzing data according to gender and race require considerable time and energy, all of which interfere with the period of patent protection. Although the NIH RA and (some characteristics of the) FDA MA are framed as interventions to address health disparities, a drug called BiDil invokes a different story, one that is especially relevant to contextualizing the ethnographic study of ACTPOC in the chapters that follow. BiDil offers a case study in which to observe the unintended consequences and potential dangers of race-based medicine and examine the pharmaceutical markets that propel this research.

Racial biographies of medication

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[26] The PDUFA illustrates a clear "privatization of public services"—corporate fees are used to accelerate the FDA approval process, staff positions contingent on funds and measured by approval; funds do not support post-marketing studies; etc. The fees collected from the PDUFA apply to NDAs only (the amount is roughly $300,000 per NDA); generic drugs suffer in what is called the FDA "have and have-nots" (McCabe 2003:799). An IOM Report Brief, *The Future of Drug Safety: Action Steps for Congress* criticized the PDUFA as "excessively oriented toward supporting speed of approval and insufficient attention to safety" (IOM 2006:2).

Pharmaceuticals have biographies, according to Sjaak van der Geest et al. These biographies are comprised of stages in a pharmaceutical's life cycle—such as production and prescription—each of which are characterized by varying social contexts and peopled by different actors [(van der Geest et al. 1996:156) Kopytoff 1986]. These stages are organized by a different "regime of values" that expresses distinct ideas about medicine [(ibid.). Appadurai 1986]. Pharmaceutical biographies may soon include racial identities, following the unprecedented legal classification of a drug as "racial medication." In 2005, BiDil was granted FDA approval as a "race-specific" drug to treat heart failure in "self-identified Black patients" [(Kahn 2005:105) FDA News, 2005]. It was, as Dorothy Roberts explains, a historic decision with far-reaching effects; never before has the FDA granted approval for a medication indicated for a specific race (Roberts 2011a:1).

BiDil is a central force in the emerging phenomena of race-based medicine and offers insight into the relationship of race, health disparities, and medicine that is proposed by the NIH RA and FDA MA. First, we must briefly turn our attention to a few key features of contemporary pharmaceutical industry development: the strategies that are used to maximize the length of patents help to contextualize the emergence—or, as BiDil's case shows, the reintroduction—of profitable new race-based medicine.

Pharmaceutical patents

The late twentieth and early twenty-first centuries have witnessed the phenomenal growth of pharmaceutical markets and products, exerting global influence on a scale previously unseen. Worldwide, pharmaceutical sales in the amount of 466 billion dollars were reported in 2003 alone (Busfield 2006:297). George Flynn reveals that in 2005, pharmaceutical companies took in 230 billion dollars in the U.S. market, where 3.5 billion prescriptions were written for 130 million people (Flynn 2006:60). Pharmaceutical growth is fueled by and constantly demands the need for more research subjects—and more fast and efficient recruitment methods. According to industry analysts, every day that an experimental drug remains in trials results in a loss of over $1.3 million in sales (Drennan 2002:167).

To extend patent protection and profit, it is not uncommon for pharmaceutical companies to re-test existing drugs by designing new clinical trials in order to investigate the possibility of other applications. If successful, a new patent can be obtained for that purpose. The phenomena of "me-too" drugs—where existing medications undergo minor modifications to be re-patented, marketed, and sold at the name-brand price—are also widespread (Angell 2005:21). The *National Institute for Health Care Management* (NIHCM) conducted a study of FDA approvals to find that of all the approvals for new drugs, only thirty-five percent of applications related to new chemical entities—the remainder involved active ingredients already used in available products (NIHCM 2002:3). The biography of BiDil, as the following section shows, narrates how an effective generic medication with little market value was "reborn" into a name brand, patented, and more costly race-based drug.

The biography of race-based medication

How does a drug "become ethnic" (Kahn 2004:1)? The story is a complex one; the discussion presented here highlights some key events as they unfolded over a twenty-year period. BiDil is a combination of two generic heart medications, *hydralazine* and *isosorbide dinitrate* (H/I). From 1980 to 1985, university and Veteran's Administration (VA) researchers conducted clinical trials to test the generic combination, H/I, against a placebo and another heart failure drug to evaluate its efficacy in reducing mortality. The results, published in the *NEJM*, showed that "the H/I combination seemed to have a beneficial impact on mortality" [(Kahn 2004:7) Cohn 1986]. In 1987, Dr. Jay Cohn,[27] one of the leading PIs, applied for and was granted a patent for H/I, describing it as a "method of reducing mortality" that was associated with heart failure; race was not mentioned in his application [(Kahn 2004:13) U.S. Patent 4,868,179, 1989]. None of the publications that emerged from these studies broke down the data by race, nor were the studies themselves limited to members of one particular racial group (Kahn 2004:13). Both *hydralazine* and *isosorbide dinitrate* had been

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[27] Dr. Cohn had the advantages of patent-friendly legislation, such as the Bayh-Dole Act. "The 1980 University and Small Business Patent Procedures Act, also known as the Bayh-Dole Act, granted academic institutions and small firms the power to patent discoveries derived from research sponsored by the NIH and then to grant licensing rights to the pharmaceutical industry" (Petryna 2009:69).

generically available for many years before these large-scale studies had begun, and thus had limited value for pharmaceutical industry profits.

So how did these two generic drugs become an ethnic and profitable name-brand drug? In 1996, a company by the name of Medco Inc. (which had purchased the intellectual property rights from Cohn) submitted a NDA to obtain FDA approval to market and sell BiDil (the new name given to H/I, which they had developed in a single-dose combination for easier dosing of the two separate drugs). In 1997, the application for a NDA was rejected. According to Kahn, the FDA did not make this decision because they evaluated the drug as ineffective; in fact, many of the doctors on the panel agreed the drug in fact worked (Kahn 2005:111). The refusal to grant NDA status was due in part to the fact that H/I was a combination of two generically available drugs for anyone to use (ibid.). As a result, Medco's stock dropped and the intellectual property rights for BiDil, which had decreased in value, reverted back to Cohn.

The rejection of a NDA sparked BiDil's "ethnic rebirth" (Kahn 2004:16). Cohn and his colleagues conducted a retrospective data analysis from the two large-scale trials and aggregated findings by race. It is unclear if the data by race had been analyzed prior to this point; at least no racial analyses had appeared in any of their prior publications that reported on these studies' findings. In one article, the researchers referred to possible variables, such as gender and coronary heart disease, that they questioned might affect therapeutic response, but race was not mentioned [(Kahn 2004:16) Cohn et al., 1993]. A company named Nitromed acquired the intellectual property rights to BiDil in 1999, and in 2000, Cohn and another PI, Peter Carson, submitted a new patent application, which Kahn notes "appeared to be much the same as Cohn's original [1989] patent" (Kahn 2005:112). The significant difference, Kahn notes, is that the wording of the patent application describes that the "present invention provides methods for treating and preventing mortality associated with heart failure in an *African American* patient" [(Kahn 2005:112) U.S. Patent No. 6465463 2002]. In 2001, a clinical trial named "the African American Heart Failure Trial" or A-HeFT, began testing BiDil against a placebo among 1,050 self-identified African Americans with heart failure (concomitant medications were permitted; often BiDil or placebo was added to several other heart failure medications). The trial concluded in 2004, reporting a greater reduction in mortality among participants in the BiDil group (Kahn 2005:105). In 2005, BiDil was approved by the FDA for the treatment of heart failure as an adjunct to standard therapy in self-identified black patients.

Markets & Medicines

BiDil's origins may be traced to the 1980s clinical trials of H/I, which found the combination of two generic medications effective in treating heart failure. There were no chemical or molecular changes between H/I and BiDil, other than the development of the two generic drugs into the single-dose pill, BiDil. The absence of chemical change did not however limit BiDil's acquisition of its "ethnic[ity]" (Kahn 2004:11), which was instrumental to securing FDA approval and patent protection.

M. Gregg Bloche argues that BiDil exemplifies how "market and regulatory incentives shape research agendas" (Bloche 2004:2036). BiDil is part of the broader phenomena of patent extension strategies that drive the development of many, if not most "new" drugs that offer minimal clinical benefit over existing ones. While BiDil's biography is similar in some ways to the "me-too" counterparts, other elements set this drug apart. As Dorothy Roberts explains, BiDil's patent protection and FDA approval rested on its characterization as a drug specifically for African Americans, shoring up the possibilities to *patent race* itself (Roberts 2006:529). In a systematic review of patent applications, Kahn reveals a trend whereby race is invoked "in a strategically defensive manner to provide added protection against possible patent challenges" (Kahn 2006:1350).

By approving BiDil as a drug for African Americans, the FDA legitimized the use of race as a biological category. Kahn refers to the US Patent Trade Office (PTO) in his statement that, "when the federal government grants a patent to an invention that is based on an asserted or implied genetic basis for a particular racial group, it gives its imprimatur to a potentially inappropriate reification of race as genetic" [(Kahn 2006:1149) Duster 2005]. In his critique of the FDA's role in BiDil's approval, Sheldon

Krimsky states, "Despite all the reasons why 'race' has no role in science, it was a science-based agency that approved BiDil for a racial group"(Krimsky 2012:115). As previously noted, the NDA that was submitted for H/I in 1996 was rejected partly on the basis of scientific criticisms of the study design. According to the biostatisticians voting on approval, the data lacked clear variables and endpoints, limiting the certainty of their interpretations [(Kahn 2004:15) Minutes FDA meeting]. The FDA's decision to approve BiDil rejected conventional scientific standards; yet, the institutional weight of scientific authority validated race-based medicine.

In her examination of the heated exchanges at the FDA Advisory Committee Meeting that led to BiDil's approval, Roberts describes how references to racial disparities in heart failure were used to undermine scientific critique of the application. The main critique of BiDil's application was that its use of race as a proxy for "some undetermined genetic something" flew in the face of scientific reasoning that race is a social and political construct, not a biological essence or characteristic (Roberts 2011a:5). Concerns regarding the reliability of the statistical data in BiDil's application were summarily dismissed under the claim that the drug offered therapeutic benefit for "special populations" (ibid.). Advisory Committee members and members of the public that spoke at this meeting regularly invoked the high rates of heart failure, as well as the troubled history of racial discrimination and health inequalities among African Americans to support BiDil's approval.

Despite BiDil's designation as a "racial drug," it is of limited value for addressing health disparities, and even exacerbates these inequalities. Kirsten Bibbins-Domingo and Alicia Fernandez argue that by "invoking the rhetoric for health disparities and applying it to the drug approval process"—and summarily dismissing the wide body of research on the social causes of health inequalities—"the FDA actually aggravated the health inequalities that they claimed BiDil would treat" (Bibbins-Domingo and Fernandez 2007:55). In the words of Bloche, BiDil was not intended to address health disparities in heart failure; rather, he says, "race consciousness offered a faster way through the FDA's regulatory maze" (Bloche 2004:2036).

The commodification of social inequality proved to be a lucrative strategy for NitroMed, and presumably, other race-based medications in the pipeline. The racialization of BiDil was immensely profitable: H/I, which costs roughly forty-four cents per dose as two generic pills, costs a fraction of the price of the name-brand Bidil, which holds the market from generic fixed-dose combination until 2020 (Bloche 2004:2036). *Hydralazine* and *isosobide dinitrate* continue to be generically available as separate drugs, which if taken together are equivalent to BiDil. Clinicians do continue to prescribe the generic combination of H/I; the only difference is that patients must take two drugs instead of one. Roberts notes that by approving BiDil, "the FDA gave a huge commercial inducement to scientists to conduct race-conscious research on the treatment of diseases in particular racial and ethnic groups" (Roberts 2006:529).

Bibbins-Domingo and Fernandez summarize Bidil's commercial benefits, "The use of health disparities to justify the 'creation' of an expensive medication is perverse…[U]sing the health disparities argument to justify the creation of an expensive 'new' medication from 2 generic medications distorts the understanding of health disparities beyond recognition" (Bibbins-Domingo and Fernandez 2007:55).

The Tragic Narratives of AZT and People of Color

The NIH RA's argument that studies of medication need to be understood by the categories of race and gender fails to account for its historic (mis)uses, distracts from the social problems that create health inequalities, and supports the assumption that biomedical interventions yield solutions to social problems. The following example draws from a pivotal and problematic moment in the history of HIV/AIDS medication development to outline some of the deleterious consequences when racialized differences are assigned biologically deterministic meanings.

In 1991, the PIs of a Veteran's Administration (VA) study of AZT's effectiveness announced their preliminary findings, which suggested that AZT was less effective in black patients than whites. It was not long after that journalists' reports of this press conference appeared on the front page of the *New York Times* and the *Wall Street Journal*. Not surprisingly, these preliminary findings were eventually withdrawn, citing their clinical irrelevance, but by then significant damage had been done. It was reported that in response to this announcement, clinicians debated whether to prescribe AZT to their black and Latino patients, while others modified their prescribing practices and some even took their patients off the drug completely. The argument that AZT was harmful also prompted many PLWHA to decline this form of treatment. Harriet Washington explains, "The reputation of AZT was permanently tarnished in the minds of African Americans and, for a while, in the opinions of physicians that cared for them" (Washington 2006:341).

Criticisms regarding the VA study soon emerged, which reinterpreted the original data and found nothing to support racialized biological differences to AZT. In an editorial in *JAMA*, Mark Smith explains that "differences in survival observed between blacks and whites are shown not to be a consequence of differential effectiveness of zidovudine" but rather of the preexisting differences between the two groups, such as the more advanced stages at which Blacks and Hispanics presented at the outset of the study [(Smith 1991:2751) Easterbrook et al. 1991]. Smith cautions readers to avoid making similar assumptions as did the VA's PIs; he argues that even if race and/or sex differences are found in research data, "such differences should not automatically be attributed to biological differences" (ibid.). This point is supported by Patricia King, who argues "rather than trying to determine whether blacks and whites respond differently to AZT, attention should first be directed to learning whether response to AZT is influenced by social, cultural, or environmental conditions" (King

1992:37).

The following text from an interview with "Jeremy," an ACTPOC participant, foregrounds what is at stake for PLWHA of color and racialized biology.

> I've been positive twenty-two years. If I waited to listen to everybody else's opinion, I wouldn't have been here because ya know when—when I—like I said, I was taking that 1200 milligrams of AZT when they were telling you AZT kills black people. Ya know that was—that was what they were telling us, that AZT kills black people, don't take it. It only works for white folks. Don't take it. And I was sitting up there saying yeah, okay that's nice [*laughs*]. Alright you hold onto that. I'm staying alive. I don't know about you girls, I'm staying alive. And—and it—it's so sad when I tell you right now some of the people that we had that discussion with they're not here.

Jeremy's experiences with AZT also provide a sobering and tragic reminder of the stakes involved in attributing differences to innate racial biologies. The assumptions that the difference observed in clinical trials participants' responses were due to some undefined racial biological characteristics is a tragic distortion, for which the effects continue to be felt today. Even setting aside for the moment that race is a social construction, not a set of biological characteristics, the speed by which these researchers turned towards racial biology as an explanation illustrates several of the many dangers of race-based medicine. First, the knowledge of how racialized health inequalities affect care patterns receded in the speculation of the admittedly unknown. The remote possibility (not conclusion, as the VA researchers themselves noted) that racial biological differences might explain these differences contradicted with what researchers already knew in 1985—that HIV-positive blacks and Latinos entered care much later than white men, due in part the limited access these groups had to health care.

Michael Silverberg et al. (2006) report on the results of their large (N=1,910) cohort study that examined race and HAART effectiveness to find that there was no difference in HAART's effectiveness among whites and blacks. There were, however, important differences between the two groups regarding access to health care, which, much like the subsequent analyses of different responses to AZT, explained the unequal health outcomes between white and black study participants. In a review of ACTs that addresses the concept of generalizability, DAJ Moore et al. (Moore et al. 2000:153) cite a study by Galai et al. (1995), which examined findings from several cohort studies to illustrate that none found associations between ethnic group identification and disease progression [(Moore et al. 2000:153) Galai et al. 1995].

The NIH RA proposes that the inclusion of more women and people of color in clinical research will lead to biomedical innovation in addressing health disparities. However, the biologization of racialized disparities in health may exacerbate these inequalities, as demonstrated in the commodification of race to promote BiDil's "innovation" for patent purposes and subsequent approval by the FDA. BiDil's invocation of racial disparities in health also threatens to distort and undermine the rigorous studies that examine heath inequalities in relation to and as the outcome of social relations such as poverty, discrimination, and other forms of structural violence.

Paradoxically, BiDil's adoption of a language of health inequalities has had the effect of making this drug *more* expensive and *less* accessible for African Americans with heart disease.

This discussion highlights the complex phenomena of race-based medicine, as seen in the powerful alliances forged by institutions such as the NIH, FDA, and pharmaceutical industries. Dorothy Roberts argues, "It is critical to place race-based medicine into a political trend that extends beyond issues of health. This diversion of attention from social causes and solutions reinforces privatization, the hallmark of the neoliberal state that pervades every aspect of public policy" (Roberts 2008:542). Moreover, the NIH RA's depiction of the potential benefits of research inclusion for women and people of color obscure the opposite direction of this movement. Through their participation, women and people of color add to and expand pharmaceutical growth—both as research subjects and often later as patients (Fisher 2009:211). As mentioned in the Introduction, although the language of drug development typically draws upon notions of health "consumers," the research subjects of clinical trials also *produce* these pharmaceutical interventions.[28] Of course, biomedical research is necessary for the development of therapeutic treatments and requires human research subjects; however, participation (and the desire to participate) is mediated by numerous factors, including the access to and quality of one's health care, the persistence of

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[28] This is especially problematic when access to drugs once approved may be limited because of cost (Noah 2003:243).

racialized and gendered inequalities, as well as altruism and financial need. If we fail to locate clinical trials in relation to the circuits of capital that define pharmaceutical research agendas, select the sites for studies, and define the price of drugs, we may be in trouble.

What is the relation of the race-based medicine phenomenon to potential test subjects? As the forthcoming chapters will illustrate, some of the actors in ACTPOC offer different interpretations of race-based medicine and cast new light on this phenomena. The critiques presented in this chapter have relevance for understanding some of the forces that shape the development of research recruitment strategies for women and people of color. It shows the limits of notions of "visibility" or "representiveness" in addressing racialized health inequalities. These critiques are reinforced and extended into new directions by ethnographic analyses of ACTPOC, which outline the contingencies of race- and gender-based recruitment practices and alert us to its multiple uses.

This chapter illustrates some of the broader forces that prioritized the inclusion of women and minorities in clinical research as critical to the nation's health that drew from, and to some degree even co-opted, feminist health. The NIH RA introduced a landmark regulatory function for federally funded researchers (and similar legislation, the FDA MA, did the same for all researchers, including pharmaceutical developers). The NIH RA indicates a shift from the state's role to protect the public from potential research harms to that of protecting the public's right to participate in research.[29]

The NIH RA influenced many aspects of ACTPOC's design and development. However, no reference was made to the NIH RA or FDAMA, which seemed like a curious omission. One of ACTPOC's managers described that these regulations have little teeth, leading me to initially form the impression that the NIH RA was one of many bureaucratic requirements. But later, I heard that at least one ACTU (there are dozens of these sites across the country) had its NIH funding revoked because of minority under-enrollment (although these details were not clear to me). My search for an official mention of this did not yield any information, and the reluctance to discuss it that I encountered led me to drop the issue, so this point cannot be confirmed. However, the NIH RA guidelines indicate that the failure to diversify trial subjects and conduct sub-group analyses can lead to the withdrawal or non-renewal of grant monies. According to Vicki Shavers-Hornaday et al. (1997), the inclusion of minorities outlined by the NIH "has increased the pressure on investigators to determine factors that impede minority participation and to develop strategies to overcome these impediments" (Shavers-Hornaday et al. 1997:31). J. Taylor-Harden et al. similarly

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[29] As mentioned in the previous chapter, the NIH RA fails to recognize the many problems with pharmaceutical drug development. As these have been discussed extensively elsewhere, a few points are mentioned here, some of which are addressed in more detail in the dissertation. The practices of withholding results not favorable to the pharmaceutical company sponsor(s) are widespread (Steinbrook 2005:2160; Bodenheimer 2000:1542; Rettig 2000:131. Although required to conduct post-marketing research to assess and update drug safety, studies have found that only a fraction of pharmaceutical companies actually do (Fisher 2003:260; Angell and Relman 2002:109).

explain that, "Applications submitted to NIH are barred from initial funding, even with excellent priority scores, if the plan for inclusion of women and minorities is judged to be scientifically unacceptable by the initial review group" (Taylor-Harden et al. 2000:83).

To assist clinical researchers in meeting these new requirements to diversify the participants in their studies, the NIH RA mandates that funds and resources be set aside for "programs and support for outreach efforts to recruit and retain women and minorities and their subpopulations in clinical studies" (NIH ORWH 2002:4).[30] ACTPOC was developed in response to a Program Announcement titled "Enrolling Women and Minorities in HIV/AIDS Research Trials" (and was its source of federal funding). The *Outreach Notebook for the Inclusion, Recruitment and Retention of Minority Subjects in Clinical Research* is just one of several official documents produced by the ORWH of the Department of Health & Human Services (DHHS) to assist NIH-funded PIs adopt these new requirements. Addressed to the Principal Investigator (or grant applicant), the *Outreach Notebook* states, "The information in this notebook may be of assistance to you and your research team in fulfilling your responsibilities for proper conduct of clinical research under applicable federal laws and regulations" (ORWH 2002:iii). According to the *Outreach Notebook*, researchers who have been successful in

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[30] While this new federal requirement played a role in relegating funds for researchers to competitively apply for awards that addressed this very issue, ACTPOC's history reaches far beyond national funding priorities, reflecting the PIs' decades-long commitments and contributions to research that seeks to identify and address health disparities, HIV/AIDS, and social justice.

recruiting diverse population groups often begin with "culturally and racially sensitive outreach into the communities in which individuals reside" that require addressing two of the primary barriers to recruiting minorities, namely "the lack of trust towards and knowledge of research processes" (ORWH 2002:55-56). The ACTPOC Research Protocol states that "Misinformation and negative or ambivalent beliefs about ACTs are also commonly held among those in the social networks of minority and female PLHA" (Research Protocol 2008:3).

The following chapter explores the first of the three intervention groups to ask these and other questions: How did ACTPOC present and define clinical research, and how did they frame it as significant to HIV-positive women and people of color? Through what means was race made biological and what notions and assumptions did ACTPOC use to frame this connection? What kinds of affective social relations did ACTPOC deploy between the IGF and among members of the group? What sources did the intervention draw from? Was its instruction didactic or open-ended? How were HIV/AIDS and ACTs presented in relation to other forms of social inequality?

CHAPTER TWO:
ACTs RECRUITMENT, EXPERT LANGUAGE, & ALTERNATE UNDERSTANDINGS

The standardized intervention groups were at the heart of ACTPOC. This series of three two-hour groups had been designed by the PIs to provide education about clinical trials to women and people of color and to encourage their participation in screening for ACTs. One of the characteristics that "standardized" these intervention groups was the *ACTPOC Intervention Manual* (referred to now as *Intervention Manual*), which was developed by the PIs. The *Intervention Manual*, which totaled one hundred and twenty-two pages (that included thirty-nine pages of handouts each participant received in their packets), offered a step-by-step guide the Intervention Group Facilitators (IGFs) used to conduct each group. The *Intervention Manual's* presentation of the identical material across all groups was to make it a "comparable" object for the purposes of research, so that could be tested against the standard-of-care groups. Of course, no two groups were the same; each new cycle of participants and the IGFs shaped the group's tone, energies, and questions asked. The *Intervention Manual* detailed the entire content of all three groups. The *Intervention Manual* structured the order and set the timing of the group exercises, defined each group's goals, and provided the materials that were used (such as a video; passages of text that served as an outline for presentations; and visual materials, such as posters).

This chapter draws primarily from participant observation of the intervention groups. Excerpts from interviews also help to elaborate on participants' responses to and interpretations of this first group session. Following Charles Briggs, the focus of this chapter's analysis of ACTPOC is "to ponder not just the content of messages but how the ideological construction of their production, circulation and reception shapes identities and social 'groups' and orders them hierarchically" (Briggs 2005:275). Drawing from participant observation of the intervention groups, interviews with participants, and textual analyses of the *Intervention Manual*, I explore how ACTPOC's introductory exercise interpolated participants into groups (Latino, African American, white women, and women of color), which were set in contradistinction to their normative center: HIV-positive white participants in ACTs.

ACTPOC Intervention Group One, Part I

> This project came about because there are not enough women and people of color in AIDS clinical trials (ACTs). This causes problems and has been recognized as a national problem.
>
> *ACTPOC Intervention Manual, under the heading "Sample Presentation Points." Pp7*

ACTPOC participants are beginning to arrive in the meeting room where the intervention takes place, which is adjacent to a busy HIV/AIDS clinic in an urban public hospital. Each participant has been mailed a reminder of the date and time of the group, as well as detailed directions to the location. Arriving at the correct building may present a challenge: even with the information card that lists the group's address and room number, participants must navigate among several hospital buildings scattered over two city blocks.[31] Once participants find the right building, their journey continues. They pass through the automatic doors and the foyer where a uniformed security guard sits, avoid the common confusion of entering the visibly marked and bustling HIV/AIDS clinic, and follow a short corridor that leads to a plain-looking door with a flyer bearing ACTPOC's logo, an illustrated bridge with the phrase: *clinical trials—good for us too!*

The meeting room is bathed in bright florescent light and there are no windows. Above the large plastic trash can in one corner hangs a bulletin board, tacked with the previous month's schedule of programs and overlaid with colorful computer-generated announcements for a support group for PLWHA also living with Hepatitis C, and a website printout of a PLWHA's perspective of his anal cancer diagnosis. Several ACTPOC posters line the entire back wall, but just temporarily as we will remove them once the group is over. A collection of heavy tomes such as *The Physician's Desk Reference for HIV/AIDS* and medical manuals on infectious disease are stored in a locked glass cabinet. The chairs are identical and the TV/VCR is locked to its console.

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[31] The difficulties in accessing the physical sites in ACTPOC will be examined in more detail in Chapter three, where, in order to locate the ACTU for a screening visit, participants must follow a literal maze to reach the unit. The difficulty in locating the proper sites is important for the obvious reason that it presents a barrier for participants. Many discussions have taken place in ACTPOC staff meetings where this problem is discussed, but in the absence of institutional change on the part of the hospital, there is little to do except provide clear information to participants.

This afternoon a new ACTPOC intervention group cycle has begun. I have just finished assisting Barbara,[32] the Senior IGF, in preparing the room with materials we carried over from the main office in a wheeled suitcase, tote bag, and two plastic sacks. We have spent the past hour assembling snacks, napkins, and bottled water; cueing the educational video cassette in the VCR; positioning the flip chart; setting up the video camera; gathering an assortment of colored markers; and placing a folder on each of the participants' chairs that we arranged in a circle. Although the group is not scheduled to begin for ten more minutes, participants have already begun to arrive. Barbara greets each person as they enter the room, checking their names on a master list she has surreptitiously placed under a stack of her materials. She asks everyone to write their first names, or "what you would like to be called"[33] on the nametags that have been placed in each of their folders. At the request of the Research Assistants (RAs) who conduct the baseline and follow-up interviews with participants, Barbara asks participants to complete locator forms, which request participants to share their current address, telephone number, and the names and phone numbers of personal contacts, such as family members and case managers.[34] Barbara offers our help with locator forms and nametags to anyone who needs it.

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[32] As mentioned in the Introduction, all names are pseudonyms. This applies to staff and managers as well as participants.

[33] As Barbara explained to me, this was important for upholding participant confidentiality.

[34] I have asked ACTPOC participants to complete these forms when I have conducted their baseline research visit, which consisted of informed consent and surveys. I was surprised that no one has ever

At four o'clock exactly, Barbara announces to the group that we will begin in a few minutes, and to expect that a few more participants may join us. Barbara cues me to check the entrance to see if there are any participants who are waiting at the HIV/AIDS clinic by mistake. When the clock reaches five minutes past four, Barbara clears her throat and waits for the room to fall silent. She smiles broadly at the participants seated in a circle before her. "How's everybody doing?" she asks warmly. "Welcome to ACTPOC. We are here to learn about clinical trials. But let me say, right off the top of the bat, that this is not a clinical trial. Sometimes that confuses people. We are here to learn about clinical trials, to give you information and let you make the decisions of whether you want to screen for a trial. We'll be talking about screening later, but let me say that one of the things that we'll be doing over these next few groups is separating screening from joining a trial. It's easy for people to think, clinical trial, and automatically jump to joining, but we'll discuss screening and all the steps in between."

With ease, Barbara commands the attention of the group. She can be serious but is not formal, and her sense of humor is infectious. In addition to her many years

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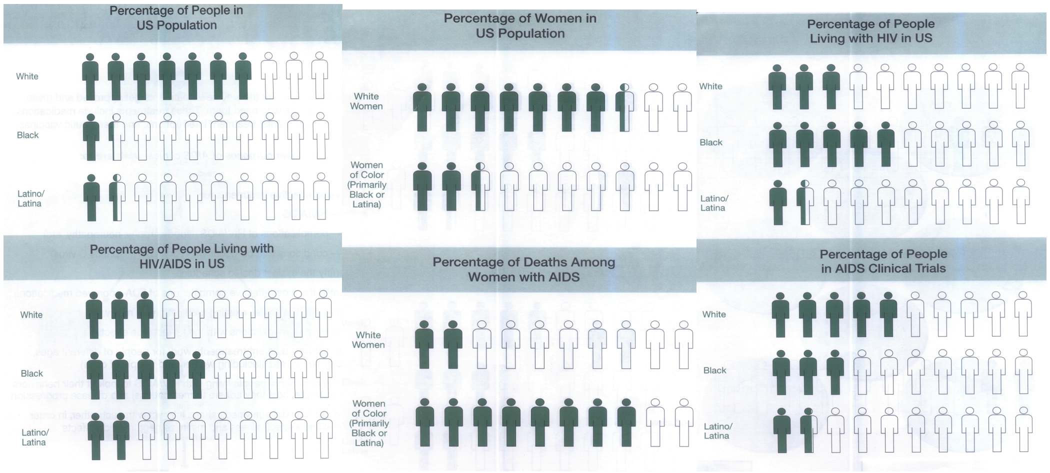
refused to share his or her name, address, phone number, and contact information of a friend of relative (although a few have asked if they absolutely must share their social security number). The accumulation of personal information is used as a tracking tool to send written reminders of upcoming research study visits, and to call participants' contacts if they miss their follow-up appointments and cannot be reached. Participants' disclosure of their personal information reveals their familiarity with such a request, which is routinely required to access Medicaid, apply for benefits, sign up for case management support, and obtain other services. The institutional demand for this personal information illustrates how thoroughly these surveillance techniques are embedded in poor people's lives.

working in public health settings (including earning an MPH) and her work with PLWHA in particular, she is also very active in her church and is studying to be a minister. Barbara is African American, born and raised in a historically black neighborhood where she now lives with her husband and their young daughter. This area is home to Barbara, as she has recounted to me in stories of her childhood and revealed in her relief returning to this neighborhood following her graduation from college outside of the city, one hundred miles and a world away. Barbara's work has been fueled by her concerns with racialized and gendered inequalities in HIV/AIDS, and she had been drawn to work for ACTPOC because of her commitment to its goals: promoting access to health information among people of color and women of color.

Barbara leads us through an icebreaker exercise where people introduce themselves, which is followed by a discussion where the group creates and agrees upon a set of ground rules. By the time we have finished, most of the participants seem to be sitting more relaxed in their seats than when they first arrived. Someone has removed the snacks from the side table, and the bowl of granola bars, nut packets, and raisin boxes is passed around the circle. It is almost four-thirty, and according to the *Intervention Manual* that estimates the length of time for each activity, our group is exactly on schedule.

Barbara introduces the first exercise, which sets the tone for the remainder of today's meeting and the two groups that will follow. As the next section shows, although this is the first time that many ACTPOC participants have heard of ACTs, it almost immediately grabs their attention. This framing of ACTs calls upon the higher rates of HIV/AIDS and poorer health outcomes in black and Latino communities. This exercise employs a powerful pedagogy that juxtaposes biomedical research, racialized inequalities, and potential remedies. It illustrates some of the characteristics of a manual-driven, standardized intervention that leads the group through a structured agenda set out by the *Intervention Manual*: while the IGFs encouraged participants to ask questions and share their thoughts and feelings to the material, the intervention was not dialogical.

Figure 1: **ACTPOC posters, designed for Exercise #4, titled "Disproportionality of women and people of color and medical research."**



Barbara directs everyone to look at the large laminated posters that are on the back wall. Rows of identical stick figures, which resemble the universal symbol for "male" usually seen on bathroom doors, are used to represent national census and epidemiological data. These posters depict one of three racial groups: blacks, whites, and Latinos; as well as two genders: male and female. The first poster titled "Percentage of People in the U.S. population" illustrates census data for whites, blacks, and Latinos, which depict whites as the majority (fifty percent) of the population, followed by blacks (fifteen percent) and Latinos (about twelve percent). The bottom half of the poster classifies the racial breakdown of PLWHA in the U.S., where blacks make up fifty percent of this group; Latinos are roughly twenty percent; and whites, thirty percent.

The next poster, titled "Percentage of Women in the U.S. population" portrays the majority of women, seventy-five percent of whom are white; the remaining twenty-five percent are organized under the heading "women of color (primarily black and Latina)." Directly below this census data is any image titled "Percentage of Deaths among Women with AIDS" illustrate that women of color make up eighty percent of these deaths; white women number twenty percent. "Even though blacks make up only fifteen percent of the population, we make up about half of all people with HIV," Barbara tells the group. "Latinos and Latinas are also overrepresented; you can see that they make up about twelve percent of the population, but are about fifteen percent of all people with HIV." As Barbara narrates the figures and numbers that appear on these posters, a few members of the group nod and one woman shakes her head in frustrated disbelief. "Of all the women with AIDS that died, eighty percent were women of color. Just think, eighty out of every hundred women that died from AIDS were women of color, mostly black or Latina." Barbara pauses and looks around the quiet room. She clears her throat, and cautions everyone to keep in mind that census data is never absolutely correct as it is impossible to count everybody, but that these broad estimates are helpful in seeing who is being affected by the epidemic in the greatest numbers.

Barbara introduces the term *disproportionality* to describe the higher rates of HIV infection in communities of color. "Blacks and Latinos are infected with HIV at rates *disproportionate* to overall census data. Women of color are disproportionately affected by HIV/AIDS compared to white women." The last poster reproduces a set of figures displayed in the first poster. "Percentage of People Living with HIV in US," which shows the racial breakdown of PLWHA, is an exact reproduction of the first poster. But, it now appears alongside a new set of epidemiological data: "Percentage of People in AIDS Clinical Trials." These two images—the racial breakdowns of both "People Living with HIV/AIDS in the US" and "People in AIDS Clinical Trials"—illustrate a stark contrast: the majority of HIV-positive people in the U.S. are African American, yet blacks make up a significantly smaller percentage of people in ACTs. The disparity is not so stark among Latinos, but it is also there.

Barbara turns and faces the group. “Given the high rates of HIV in communities of color, why aren’t more of us participating in ACTs? Why are we underrepresented in these studies?” she asks.

Statistical Constructions

At this first intervention group, participants were introduced to several of ACTPOC’s core themes, which helped to establish its foundation and tone. It was during this first group session that participants were given an overview of what they would learn in the three groups that make up a cycle. Participants were told to expect to accumulate a lot of information, and that given the restrictions on time and the dense volume of material, the groups would move at a fast pace.

Participants’ introduction to the intervention groups began with a visually arresting display of posters that covers the entire back wall of the room. Deceptive in its simplicity, this statistical data formed a powerful organizing principle for the themes that were to follow in the remainder of the intervention. Their identities—as women and men of color living with HIV/AIDS—became fathomable through the gaze of epidemiological experts. What kinds of knowledge did this group exercise privilege and what particular ways of knowing did it conceal?

This collection of U.S. based population health statistics posters identified these epidemiological data: percentages of the overall U.S. population; PLWHA; deaths from AIDS; and ACTs participation. Each of these segments was further broken down by three classifications of race (white, black, and Latino/a) and two classifications of gender (male and female).[35] Drawing from official statistical data produced by institutions such as the U.S. Census and the CDC, these posters portrayed the sharp differences in rates of HIV/AIDS, deaths from AIDS, and ACTs participation among various racial groups and between men and women from these groups. These narratives categorically linked race, gender, HIV rates, AIDS deaths, and ACTs participation to form a sequence that implied causality. This presentation of HIV/AIDS epidemiological data appeared fairly straightforward—these groups and their percentages were neatly arranged in identical rows of green and white stick figures, with citations to the CDC and U.S. Census at the bottom.

But statistical data also constructs the phenomena it represents, according to scholars such as Michael Bloor et al. who argue that "Statistics on AIDS represent the subject of AIDS: they themselves constitute sets of discursive practices" (Bloor et al. 1991:136). This perspective does not debate the veracity of the percentages and graphs

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[35] Population-based health statistics are, in my view, a necessary tool for broadly assessing the extent of heath disparities. A different setting might make these same statistical data a useful building block to organize a health and social justice campaign. The concerns I raise here are directed towards the epistemological authority that frames these statistics. What social arrangements are communicated in these depictions?

that refer to PLWHA and their rates of infection. Neither does it undermine the importance of assessing population-level racial and gendered differences in rates of HIV/AIDS, which are vital to developing public health responses to the epidemic. Like all forms of knowledge production—including ethnography—these statistical representations give shape to a particular worldview and put forth a certain kind of social relations. Epidemiological classifications of race and gender may appear self-evident, which belie their imbrications in the authority of classificatory systems and the uses to which they are put.

What do these statistics *not* tell us about the correspondence between PLWHA and HIV/AIDS? The social conditions that give rise to high rates of HIV/AIDS in communities of color were notably absent in this exercise. In the absence of a broader narrative to place ACTPOC's statistical data, what did this constellation of race, gender, HIV/AIDS, AIDS deaths, and biomedical research evoke? What possibilities did these discursive practices introduce and what did they foreclose? What did the straightforward tone that guided the presentation of people, percentages, and bureaucratic language in an informative but rather unremarkable manner tell us about ACTPOC's pedagogy; what did it reveal about the relations of participants to the intervention?

As many have argued, the conventional public health framework's focus on behavioral differences tends to neglect the situational and structural hierarchies—

poverty, racism, geography, and other forms of structural violence—foster radically different levels of risk and harm (or the absence of).[36] ACTPOC's portrayal is also a timeless one—while the CDC and the census data were only a few years old, they lacked the dynamic movement of history, and flattened out the particularities of social location. According to John Durham Peters, statistics enable "the possibility of envisioning spatially dispersed events in a single moment in time" (Peters 1993:78).

The absence of such movement calls forth Briggs' critique of the "objectification of social images in epidemiology" (Briggs 2001:694), that is divorced from "the social, political, and historical circumstances in which they are produced" (ibid.). ACTPOC's epidemiological representations are evidence of what Tukufu Zuberi sees as a common pitfall in statistics, whereby race is conceptualized as an individual attribute, taking on a "decontextualized racial identity" (Zuberi 2001:97) which is then interpreted as a *cause* of social phenomena.

In the following interview, Kimberly, my fellow qualitative consultant for ACTPOC, had been trying to jog Patricia's memory about the groups, which she had attended several months prior. Kimberly asked, "And do you remember learning about

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[36] For example, the risk of HIV/AIDS has little to do with individual behavior, argues Wafaa El-Sadr et al. who states, "(T)he extent of the risk if acquiring HIV in the United States today is largely defined by a person's sexual network rather than his or her individual behaviors" (El-Sadr 2010:2). In other words, sexual risk largely depends upon the prevalence of HIV/AIDS within one's social network. The behaviors that may be risky in a network where HIV prevalence is high poses little or no risk in a network with low prevalence. The differential rates of HIV and Hepatitis C in New York City versus San Francisco can be partially understood by the former's opposition to and criminalization of syringe exchange that did not materialize in San Francisco.

that a little bit in ACTPOC. How did that make you feel when you learned that information? What did you think about that?" Patricia replied, "I don't know. Just that Caucasian people is more informed and stuff than women and Blacks and Puerto Ricans." The following excerpt from my interview with Michael echoes Patricia's perspective, in which the responsibility of "underenrollment" is assigned to the very people that have historically been excluded from ACTs.[37] Michael explained how he liked learning new information about HIV/AIDS and ACTs, stating that "We learned about the percentage of people of color that actually do clinical trials, it's pretty mind-blowing…*That's why it takes forever for drugs to get approved*. So it was very informative." [Italics added]. Greer echoes this sentiment in his statement. "I don't know if it's good or bad, but it seems that—that for people of color, unless—unless it's really something to their advantage, that they don't—I ain't gonna say they—*we* don't volunteer for a lot."

These interviews suggest that ACTPOC's presentation of statistical data problematically linked people of color and the rates of HIV/AIDS and ACTs participation, reproducing a common tendency in HIV/AIDS research that Alisse Waterson explains, unintentionally "lapse(s) into blame the victim ideologies which help protect, maintain, and reproduce existing inequalities" (Waterston, 1997:1388).

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[37] As mentioned in the Introduction, most women and people of color were excluded from many ACTs because PIs wanted "clean data"—that is, data purportedly free of the variables of gender and race. Chapter three discusses this phenomenon in more detail.

Barry Adam points out the potential dangers in how research is translated on an individual and/or community-based level, arguing that, "Bringing population-level reasoning to grassroots practice can, at times, produce paradoxical or noxious results" (Adam 2011:4). Citing studies that find endless correlations between particular groups and HIV, absent of context, creates a logic and reasoning that further marginalizes these groups, "(s)toking racism, ageism, homophobia and AIDS phobia" (ibid.). Aileen Plant and R. Louise Rushworth's discussion of the ways people of Aboriginal descent in Australia relate to various kinds of health data offers further insight into ACTPOC's exercise and the implicit meanings that may be derived from it. They state, "People from indigenous groups frequently feel despair at the health statistics provided in formal settings, such as classrooms, and informal settings, such as casual conversation. At some level, to be part of a group that lives less long, can appear to be perceived as being less deserving of living" (Plant and Rushworth 1998:1150).

Whose Knowledge?

ACTPOC's visual arrangement of aggregate populations initiated participants into a particular hierarchy of knowledge. The presentation of these data—collected, defined, and organized by experts drew its authority from a certain distance and detachment. In this presentation, the "disproportionality" of women and people of color with HIV/AIDS, and those in ACTs, leave little room for participants' engagement and reinterpretation. Does ACTPOC's representations follow Ted Porter's point that statistics and calculation often serve to subdue public controversy, "[giving] the appearance, at least, of ideological neutrality, and hence identification with a community of researchers than a movement of activists" (Porter 1992:31). The *Intervention Manual's* guidelines for how IGFs might respond to group participants that challenge the accuracy of representation is telling: it describes "resistance" to the message as a technical problem, which, it seems to me, undermines the significance of critiques of accuracy and forecloses other possibilities for how this presentation might be reinterpreted and engaged. The *Intervention Manual* addresses this note to the IGF, as part of Exercise Four titled, "Disproportionality of women and people of color and medical research."

> The exact numbers are not as important as the over-representation in the disease and death rates as compared to the population and the under-representation in ACTs. Thus the emphasis in this exercise is not on the data or the ontology of high rates of HIV/AIDS, but the reasons why *under-representation* in ACTs is a problem.
>
> *ACTPOC Intervention Manual, Exercise 4:11*

ACTPOC's narrative followed a metonymic sequence, which began with U.S. population statistics, continued with the "disproportionate" rates of HIV/AIDS and deaths from AIDS among people of color and concluded with their "underrepresentation" in ACTs.[38] The social, historical, and political-economic contexts

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[38] The absence of context to accompany these statistical depictions makes the HIV-positive to AIDS deaths links calls attention to another disturbing point. During one group, this abstract data reminded

that foster racialized and gendered inequalities in rates of HIV/AIDS were absent in this exercise, as was the acknowledgment of the depth of suffering and affliction this disease has caused. The presentation of differences in death rates resembles a pattern of recitation and rhythm identical to the presentation of census-based population statistics.

Insights into the everyday practices involved with racial statistical data collection helps to elaborate on the broader purpose and implications of ACTPOC's epidemiological presentation. In a rare ethnography of census data collection—a phenomenon she describes as "where the state meets the nation at the doorstep" (Nassy Brown 2009:32), Jacqueline Nassy Brown analyzes the United Kingdom's first census that adopted questions regarding ethnicity. Brown critiques the notion that statistical data will supply the proof of racism necessary to combat it, noting that it places the burden on blacks "who are encouraged to exert their agency by submitting to their objectification" (ibid.). ACTPOC implied that screening offered participants the opportunity to establish a more equitable racialized representation in ACTs and thus intervene in the unequal burden of HIV infection and AIDS deaths among women and people of color.

ACTPOC invoked a democratizing language of representation, participation, and possibility. But the degree to which screening for ACTs constitutes a form of redress to

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me of actuarial practices a lone adjuster coldly and dispassionately calculated strangers' risks of modern life and assessed their insurance rates accordingly.

the invisibility and abandonment ACTPOC participants experience as poor people of color living with HIV/AIDS, was uncertain.

Counter-Narratives

In the dozens of groups I attended, this exercise proceeded as had been intended, but not always. Alan Peterson offers the reminder that, "Individuals creatively engage with expertise, taking from encounters what they wish and interpreting information within their own lay frameworks of knowledge" (Peterson 2003:197). Group participants complicated the seamless links by which ACTPOC drew together HIV/AIDS and communities of color by articulating their perspectives of the social contexts and conditions that fuel these statistics. The *Intervention Manual* did not pose the issue of why the rates of HIV and time to death are so racially disproportionate; why this is so was not part of the exercise. The intervention neither silenced nor did it encourage participants to engage with these racial and gendered inequalities in HIV infection rates. However, group participants, by inserting their voices into these racialized statistical discourses, confronted the abstraction and depersonalization of these high infection rates. These alternative narratives challenged "the logics that hold dominant explanations in place, sometimes by challenging the race-space-disease equation and sometimes by reversing their causal arrows" (Briggs 2005:279). For example, at one group Martin inserted a contextual understanding of what the epidemiological statistics did not convey: "The reason those numbers are so high for Blacks is that there's not enough drug treatment," to which others nodded in agreement, sparking a discussion on the widespread availability of drugs and prisons but few options for treatment. In another group, June put forth that HIV and Hepatitis C would not be such grave epidemics had there not been laws prohibiting syringe exchange and criminalizing drug use. While discussions that engaged the absent contexts that fuel HIV/AIDS were not typical, that they occurred at all suggests that the epidemiological hierarchies into which participants were assembled were neither seamless nor complete.

Martin, June, and other group participants who fashioned different interpretations from the epidemiological narrative they were given were neither cut off nor ignored by the facilitator. Following the *Intervention Manual*, Barbara acknowledged each individual's contribution to the discussion, though the kindness and respect with which she listens, nods in agreement, and encourages the participant to say more cannot be taught from a standardized manual; it is hers alone. But inevitably, the discussion must end. "Thank you for your comments but I need to put this on pause for now because we've got a lot to cover here, and we need to move forward." With a discreet glance of her watch, Barbara turns to the flip chart and, gripping a thick fragrant green marker writes **BARRIERS TO ACTs** in block capitals across the top of the paper. She turns to face the group: "What are some reasons you can think of why women and people of color aren't taking part in ACTs?"

These ethnographic data demonstrate how participants challenge this exercise, despite the credible, convincing, and authoritative representation of data in appealing visual form that Alan Peterson and Deborah Lupton argue is "central to the persuasive function of quantification rhetoric" (Peterson and Lupton 1996:38). Confronting the authoritative detachment of the exercise by engaging some of the reasons as to *why* this phenomenon occurs, participants reframe ACTPOC's narrative of population data to a discussion of the issues and problems that fuel the epidemic. They expose and challenge the ways that HIV/AIDS in communities of color is naturalized in its depiction as a stable, ahistorical phenomenon by calling attention to a range of issues, such as access to health care, language barriers, and substance use. Their challenges to the organized display of numbers and the classification of racial and gendered populations form an example of what Nancy Stepan and Sander Gilman call a "scientific counterdiscourse" in that "new interpretations, new narratives of self and identity" are formed against the prevailing scientific norms (Stepan and Gilman 1993:183).

The presentation of the high rates of HIV infection among people of color appears deceptively straightforward. Race appears first in the form of census data, an uncritical assemblage of categories of African American, Latino, white, and "other." The introduction of HIV/AIDS recalculates these census classifications—themselves signs of the power of the state to organize and administer these categories—to produce percentages and proportions that illustrate the racial differences in rates of infection and times to death. These representations of race and HIV/AIDS reflect ACTPOC participants to the extent that they have been classified, counted, and organized in this way. Yet despite the powerful portrayals of administrative categories, ethnographic research shows that participants enter into this discourse as both interlocutors and critics.

The problem to which the "disproportionality" refers is not the higher rates of HIV/AIDS, but *their lower rates of ACTs participation*. In other words, it is not the high rates of HIV/AIDS in black and Latino communities that are disproportionate, but the rates of their participation in ACTs. These rates of HIV infection among African Americans, Latinos, and women of color are preludes to the problem presented to them: their absence from ACTs, which depict participants as overwhelmingly white and male. The epidemiologist Sam Harper, along with his co-authors, argue that single measures of health inequalities, while not technically incorrect, are embedded with value judgments that designate "what the appropriate target of inequality reduction should be" (Harper et al. 2010:22). Harper's argument that "proportionality not equality" sheds light on the fact that this exercise *recontextualizes* the skyrocketing rates of HIV/AIDS among people of color as a problem of *under-enrollment* in ACTs. Epidemiological data that presents racial and gender inequalities in rates of HIV/AIDS and time to death alongside income differentials, experiences of gender violence, racial marginalization, and access to quality health care would identify a different set of problems that warrant intervention. Olivia Carter-Pokras and Claudia Banquet's analyses illustrate that how health disparities are conceptualized invoke "an ethical judgment of what conditions are considered unacceptable" (Carter-Pokras and Banquet 2002:428).

All ACTPOC participants have intimate knowledge of and the experience however varied—of living with HIV/AIDS. It shapes how they related to others and influenced their community affiliations and exclusions. This intervention group exercise yielded a decontextualized view of the epidemic; the opportunity to engage and reflect was limited. ACTPOC however offered one alternative to intervene in these disparities: by equalizing the rates of participation of women and people of color in ACTs so that they are *proportionate* to the rates of HIV infection. The strategy aimed to raise the participation of HIV-positive people of color in ACTs so they achieved parity with whites. But such an approach refrained from intervening in the racial inequalities that shape different health outcomes for PLWHA of color.

Dr. Mary Jones, the Director of the ACTU, appears briefly in ACTPOC's educational video, conveying a statement that reinforces the normalization of these high rates of HIV/AIDS. Donned in a crisp white doctor's coat, Dr. Jones is shown seated behind a large desk. "The rates of AIDS clinical trials participation are here," she holds her hand carefully in front of her. “And over time it has risen. But it needs it to be here to match,” she says slowly, raising her steady hand higher, “the populations that are currently infected.”

The intervention first circulated participants into expert and administrative views of the disproportionately high rates of HIV/AIDS in their communities; next, they were encouraged to consider screening for an ACT, a decision which, participants were told, had the potential to create better and more effective medications for people of color. The problem, then, was not the troubling rates of HIV/AIDS in communities of color, but one of their *biomedical racial invisibility* in ACTs. The racial inequalities that drive rates of HIV/AIDS were remade into the hallmark of neoliberalism: “responsibilization,” which, according to Thomas Lemke, involves “shifting the responsibility for social risks such as illness, unemployment, poverty, etc., and for life in society into the domain for which the individual is responsible and transforming it into a problem of ‘self-care’ [(Lemke 2001: 201) Teghtsoonian 2009:29]. Participants’ racial invisibility in ACTs can be corrected, ACTPOC suggested, if individual participants make the choice to undergo screening for an ACT.

The representation of this statistical data, especially its position as the introductory exercise of the three intervention groups, initiated participants to the authority of the intervention, framing their embodied, everyday experiences as PLWHA under the power of the state to measure and classify populations, and reinforcing the authority of biomedicalized solutions to respond to racialized and gendered disparities in HIV/AIDS: screening for ACTs. HIV/AIDS, an epidemic of inequality, was transformed into a problem of biomedical racial invisibility.

Race vs. Sexuality? Group One

> In the beginning, clinical trials were populated mostly by gay white men. But now the epidemic is hitting communities of color and women the hardest and trial participation has not increased along with the high rates of infection in communities of color, and especially among women of color.
>
> *ACTPOC Intervention Group*

> Originally, gay white men were the highest number of persons infected with HIV/AIDS. People of color and especially women are now the ones that are mainly infected, and we don't participate in clinical trials, so the researchers don't know how to treat us 'cause we're not participating. They have to know how our bodies work.
>
> *Alberta, ACTPOC Video*

The ACTPOC intervention group conveyed this to participants: because ACTs have primarily been conducted upon HIV-positive gay white men, the knowledge gained from this research may have little bearing upon their particular disease profiles. This message raises a number of questions the remainder of this chapter explores: How were gender and sexuality used to mark racialized biological differences between these two groups? Why did people of color lack the sexual identifications assigned to gay white men; why were there no gay people of color? And where were the women? How does the neoliberal public health model that structured HIV/AIDS contribute to the familiar notions of “gay white men” as distinct from “women and people of color” seen in ACTPOC?

ACTPOC’s depiction of gay white men as the original sufferers of HIV/AIDS is part of a broader and distorted narrative of the disease; these representations also reveal the paradigms that shape modern formations of sexuality and race. I argue that in the years following the formal recognition of HIV/AIDS, scientific constructions of “gay white men” were enabled in part by the practices that “darkened” drug use, a relation that proved to have traction. The constructions of “gay white men” and “people of color” as separate, even divisive groups were enabled, in part, by the state. These kinds of antagonisms reflect and extend neoliberalizing processes in health, cementing models of consumer-based care and the devolution of social services.

The processes of racialization and sexualization used to construct ACTPOC’s participants were not unique to this kind of public health project or even the HIV/AIDS epidemic: their deep and tenacious roots stretch back to the modern scientific formations of sexuality and race as mutually constitutive categories, necessary in part to construct the boundaries that regulate these groups.

HIV/AIDS Discourse and the Whitening of Gayness and Darkening of Drug Use

ACTPOC’s origin story of HIV/AIDS racialized gay as white, which conforms to the pervasive epidemiological categorization of risk group logic. ACTPOC’s racialization of gay as white conforms to the "risk group logic" that came to characterize popular understandings of the HIV/AIDS epidemic. The category of "Homosexual" was formed in relation to another risk group: "Heroin users" or rather, injection drug users, commonly referred to as IDUs. By the early 80s, the data indicating that this new immune disorder was not simply limited to gay men could no longer be ignored. The CDC designated these groups as high-risk for HIV/AIDS: homosexuals, Haitians, heroin addicts, and hemophiliacs, who came to be referred to as the "Four H's" by the media. The logic of risk group formation hinged on the idea that identification with and membership in one of these groups (as these groups did not intersect[39]) defined one's risk, irrespective of individual safer (or unsafe) sex and syringe sharing practices. Gerald Oppenheimer outlines that, "A further consequence of creating 'high-risk groups' was to reinforce the relationship between the disease and 'marginal' members of the population" (Oppenheimer 1988:283).

The following examples from leading AIDS scholarship illustrate the assumptions that undergird the powerful racializing processes that "whiten" gayness and "darken" drug use. Ronald Bayer collapses gay and white men, distinguishing them from the heterosexual black or Latino male IDU. In Bayer's teleology, HIV transmission among people of color begins with a male drug user, moves to his female

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[39] The separation of risk categories—the non-intersection of IDUs and gay and bisexual (let alone lesbian and/or transgender)—exemplifies how the construction of epidemiologic categories as separate and distinct prevents their overlap. See Rebecca Young (1994) for a discussion of women who have sex with women (WSW) and inject drugs, illustrating the synergistic effect of these identities that are lost when variables are additive.

partner(s), and results in the devastation of Black and Latino communities to which both he and partners belong, as the following statement illustrates: "With more than half of New York's addicts presumed to be infected, and with most addicted men having as their partners nonaddicted women, the implications were ominous for HIV transmission to the broader black and Hispanic ghetto communities" (Bayer 1989:229). In a similar example, Ronald Caplan et al. state, "Gay men and IVDUs (and their sexual partners) constitute separate at-risk populations. Gay men are typically white…IVDUs and their sexual partners are more often black or Hispanic" (Caplan 1989:152).

Nina Glick Schiller describes how the dominance of certain research strategies and designs construct "gay white men" and "Black and Hispanic IDUs" as discrete and separate groups. She states, "Most ethnographies of HIV-infected intravenous drug users have been conducted in inner-city neighborhoods, and most surveys of homosexual men have been done in the gay communities of major cities...As a result of this dichotomized research strategy, HIV-infected intravenous drug users and gay men are portrayed as racially distinct from one another" (Glick Schiller 1992:243). The durability of the trope of gay white men is discussed by Calu Lester and Larry Saxon, who point out how this construction neglects the multiple and intersecting forms of oppression. They state, "Gay men of color…did not share the wealth of information that has influenced change in the gay white community. Many gay men of color are isolated in the impoverished inner city and have not been provided with the basics about how to keep from being exposed to the virus or spreading it" (Lester and Saxon 1988:566).

These social scientific constructions were not limited to experts alone, but were made commonsense through mass media. For example, Harlon Dalton argues that the media focus on gay white men and neglect of gay men of color early in the epidemic reflected prohibitions on racial crossing, stating "Note that this argument assumes either that Black gay men do not exist or that they do not have sex with white gay men" (Dalton 1989:225). Cathy Cohen's careful archival analysis of the *New York Times* yields similarly disturbing findings: only three articles about Black gay men appeared during the years of 1981-1993, despite that the leading route of HIV transmission for Black men during this period was sex with other men (Cohen 1999:166). This lack of attention is all the more striking, Cohen notes, when compared to the publication of sixteen articles that appear in the New York Times in 1997 alone, stories which often "pitt[ed] gay white men and their demands against the increasing numbers of blacks and Latinos living with AIDS. Rarely were the intersections of these identities considered" (ibid.).

The Neoliberal Paradox: "Black" vs. "Gay" in the Science of HIV/AIDS

Lois Jackson reveals how the neoliberal reduction in public health funds in Canada supported the organization of identity-based groups such as "gay white" and "people of color," thus diminishing the potential for solidarity among affected groups (Jackson 1997:27). Maskovsky's ethnographic research of HIV-positive poor sexual minorities in Philadelphia uncovers similar strategies that "structured competing claims to political authenticity and community leadership that required the emphasis of key social markers (e.g., gay, black, Latino, women) in the name of communities affected by HIV" (Maskovsky 2001:331). The state's construction of these identity-based categories, which were the basis for how resources were allocated, limited how poor lesbian, gay, bisexual, and transgender (LGBT) people of color living with HIV/AIDS could politically mobilize:

> This selective, asymmetrical, and nonsensical emphasis on sexuality vs. race as the central political struggle affecting the provision of life-supporting AIDS services had a number of consequences for HIV-positive people, particularly the poor…(T)he state effectively forces poor lesbians and gay men to sacrifice their sexual identities in order to gain access to the political process as consumers (Maskovsky 2001:331).

These empirical studies support the thinking of scholars who, like Alan Sears (1992), who does not disagree with the significant role of civil society institutions in the early years of the AIDS epidemic, but argues that we must theorize power within in the state, and more specifically, the *capitalist* state (Sears 1992:79). ACTPOC's narratives of gay white men as distinct from the generalized "women and people of color" are in fact effects of the state's powerful interventions to subdue the effects of a withering welfare state and limiting the ways groups might mobilize.

ACTPOC created a historical narrative of ACT participation in which gay white men were positioned as racialized, gendered subjects within the taxonomy of sexual identity. Why are the genders and sexualities of people of color left unnamed, in contrast to the precise language of sexual identification for the *gay* white men?

According to Evelyn Hammonds, racial marginalization is evidenced in the constructions of the black woman as *already* sexualized, prior to her own definitions and expressions of it. She states, "black women's sexuality has been constructed in binary opposition to that of white women: it is rendered simultaneously invisible, visible (exposed), hypervisible, and pathologized in dominant discourses" (Hammonds 1997:170). Cathy Cohen's discusses how the degradation of sexuality functions as an effect of racism, while also expanding the racialized targets of such discourse.

> Many of the roots of heteronormativity are in white supremacist ideologies which sought (and continue) to use the state and its regulation of sexuality…to designate which individuals were truly 'fit' for full rights and citizenship…The stigmatization and demonization of single mothers, teen mothers, and primarily poor women of color dependent on state assistance has had a long and suspicious presence in American 'intellectual' and political history (Cohen 1997:453).

The preceding discussion takes note of how the development of the science of sexuality, and especially the taxonomy of classifications it produces, was integral to ACTPOC. Sexuality and gender were relevant to how ACTPOC delivered one of its key arguments that encouraged participants to consider screening for ACTs: the epidemiological classifications of HIV-positive people of color, women of color, and white women underscore their differences from and incommensurability with gay white men.

Racism intersects with sexuality in such a way that makes people of color both hyper- and in-visible. On the one hand, their sexualities are already deemed suspect by the powerful "culture of poverty" theses and for example, the stereotypical depiction of the "black matriarch" and "hypermasculine, aggressive black man." Under these terms, Black and other non-white sexualities become invisible; their representations are rarely (though not always) intelligible outside these tropes. In other words, to talk of black sexuality is redundant; by its very definition black is already sexualized.

ACTPOC's narrative regarding the emergence of HIV/AIDS in the U.S. reflects the popular depiction of gay white men as hit the hardest at the onset of the epidemic and of people of color and especially women of color as latecomers to the disease.[40] This historical retelling of HIV/AIDS places gay white men at the epicenter of suffering, until the sudden and unexplained shift that casts women and people of color—curiously absent of sexual identities—into this role. This narrative is deleterious to all involved—it ignores gay people of color, including women, at the outset of the epidemic, and dismisses how gay communities continue to be affected by HIV/AIDS—two claims that are simply untrue. These perspectives also have a particularly troubling

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[40] Of course, "gay white men" (as well as "women and people of color") is an oversimplification of a heterogeneous group fails to acknowledge the various levels of stratification among the people to whom is refers, especially those who are poor; rural; transgender; immigrant; injection drug users; working-class; disabled and/or elderly (to name a few). The gay white urban male model who I take as a symbol of privilege in this exercise (compared to women and people of color) is not necessarily inclusive of individuals from the list of groups described above, though whiteness still affords these men privilege denied to gay men of color who also face similar forms of stratification. The point here is not to confirm or dismiss these identities in relation to how people see themselves (and each other) or how they perceive others see them. Rather, it is to ask what kinds of thinking are enabled by these classifications? Occluded by them?

effect for lesbian, gay, bisexual, and transgender people of color, as their relations to and experiences with the disease are ignored in their racial exclusion from the classification of "gay." What historical contexts can help us to theorize why the people of color living with HIV are presented as incongruent with sexuality and/or sexual definition, unlike the gay white men to whom they are compared?

Science & Sexuality

The exclusion of certain groups from the classifications of sexuality and gender is a racially coded omission. However, the vocabularies of gender and sexuality ACTPOC used in constructing gay *white* men, a lexicon that was curiously absent among people of color, is far from unique. In fact, it remains very much embedded in the cultural landscape in which we live, and is continually reinforced through our practices.

These divisions between gay white men and racially marked "others" have powerful roots in the sexual sciences of the late nineteenth century. According to George Mosse (1985), in the late nineteenth and early twentieth centuries a new science of sexology emerged that made distinctions between "appropriate" and "inappropriate" men who have sex with men that depended on reproducing class and race distinctions. This new science, Mosse notes, "serve[d] to modify the boundaries between the norm and what was considered abnormal" (Mosse 1985:37) and legitimized homosexuality (to some degree) by drawing a strict division between what was viewed as congenital homosexuality and pseudo-homosexuals or, inverts and perverts. Kerwin Kaye's study reveals that in the early twentieth century, the formation of homosexuality depended on important divisions between the two, where "the boundaries of normative heterosexuality" would "condemn working-class perverts [which] helped to legitimize the call for compassion to middle-class 'inverts'" (Kaye 2003:6).

The modern development of a gay—or rather, homosexual—identity seems to have emboldened by class and race exclusions. The racialization of sexuality took on a Spencerian tone, according to Jennifer Terry, who explains that homosexuality could be understood in part by the placement of the European at the apex of civilization. The presence of homosexuality among the "intelligent women and artistic men of the upper classes was supporting evidence that this contrary sexual instinct was a troublesome side effect of European cultural refinement" (Terry 1995:132). Sexological science may have rebuked homosexuality because it removed him from his proper place in family and nation, but homosexuality itself, as an unfortunate outcome of an excessive European civilization, did not entirely exclude him from it (Mosse 1985:38).

Of course, it must be acknowledged that the modern sex-gender system and its identities of gay and heterosexual are not necessarily how people see themselves. But the exclusion of certain groups from the science of sexual classification is racially coded. In this introductory exercise, ACTPOC frames its points within dominant systems of scientific classification and organization, as evidenced in the epidemiology of population health in HIV/AIDS and ACTs statistics and demographics; the biologization of race in medicine development; and the dominance of pharmaceuticalized solutions to improve the health and quality of life for people of color. The absence of the modern taxonomy of sexuality to describe ACTPOC participants may not be so strange after all.

These recruitment exercises in the first ACTPOC group describe the pervasive racial and gendered disparities in ACTs research by way of visually appealing decontexualized statistical data. And while the very visible actors (the gay white men, women, and people of color) at least partly reflect meaningful affiliations and socially salient identifications, the racism, sexism, classism, heteronormativity and other pervasive structural inequalities that create massive differences in HIV rates remain for the most part, out of sight. The visual depiction of statistical representations and language of "disproportionality" in conjunction with the narrative of early ACTs as dominated by gay white men are compelling symbols. However, they offer little in the way of uncovering and critiquing how scientific and other kinds of expertise may contribute to—as well as undermine—the racial and gendered disparities in ACT research.

CHAPTER THREE:
"WHERE'S THE CLINICAL IN AIDS CLINICAL TRIALS (ACTS)?"

I am standing on the sidewalk, waiting. Finally, I see two men in scrubs approach the employee entrance of the large urban teaching hospital. One of the men opens the automatic door with his badge and I follow them inside. I pass the empty kiosk and enter the elevator that wheezes upward before it stops abruptly on the third floor. A middle-aged African American man is standing awkwardly in the empty hallway and I immediately recognize the familiar ACTPOC logo stamped on the paper he is holding. He looks quizzically from his paper to the cul-de-sac of identical closed office doors.

As I approach, Joe introduces himself to me and shows me his paper. Is he in the right place? He's supposed to be meeting with someone named Arturo at 1PM. I tell him my name and that I'm also part of the ACTPOC project—and that I work with Arturo, and the other intervention group and research staff. Joe smiles. "You know Lauryn then? Lauryn did my group. She was good, real good. Real nice girl." I show him where the buzzer is and explain that soon someone will respond and let us inside. Joe and I are the only people in the dim hallway, disconnected from the main arteries of the bustling urban hospital. Today's visit is just to talk about ACTs, right? Joe asks. He'll get a transportation card, but there's no money unless he actually joins a trial? Before I can respond, the heavy door opens and Tina, one of the Physician's Assistants

(PAs) who works at the ACTU, ushers us in with her trademark friendliness, "C'mon in! Hi Rebecca! What's your name? Joe? Joe, I'm Tina. I work here at the ACTU. Welcome to the ACTU Joe, c'mon, over this way, sit down, there's water if you like. Make yourself comfortable." Tina leads us past a row of unoccupied examining rooms to the waiting area, which consists of a few chairs and a water cooler. The assortment of colorful magazines such as *POZ* and *HIV Plus*[41] stand out against the drab carpet and the monotonous gray of the surrounding cubicles.

Arturo, ACTPOC's AIDS Clinical Trials Screener, has heard us arrive and emerges, smiling, from his nearby cubicle. He greets Joe and they shake hands. When Arturo asks, Joe tells him that he wouldn't mind me sitting in during his visit, and I join them in the narrow examination room. Arturo and Joe sit in the two office chairs, and I perch between them on the exam table. The room is similarly muted aside from a three-dimensional plastic replication of an HIV molecule that displays the pharmaceutical company name "Bristol-Meyers" on the stand that holds it. Arturo shuffles through the accordion folder on his lap to retrieve several forms, occasionally rolling on his squeaky stool to place other forms on the countertop that he uses as his desk. He tells Joe that any information he shares will be labeled with a number, and that nothing will have his name printed on it. Arturo asks if he has any questions about confidentiality and Joe

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[41] *HIV Plus* and *Poz* are two of several magazines directed to PLWHA audiences. They typically address any number of themes related to HIV/AIDS, from the importance of washing vegetables properly to tips on dating HIV-negative partners. These magazines are free, supported by ads, mostly for HAART.

shakes his head.

This is Joe’s first experience with screening for medical research, other than calling some of the advertisements featured in the free daily papers[42] and being told over the phone that he was not qualified. Arturo is friendly and welcoming, and tells Joe to interrupt if he ever has any questions. “If you qualify for an ACT—it’s up to you. It’s all up to you.” Arturo repeats ACTPOC’s message that participating in a screening visit for an ACT is completely voluntary and that he can stop the visit, and any future visits, at any time and for whatever reason. He reiterates that today’s screening does not mean he will join a trial; he is only there to have a conversation about these studies. Arturo asks Joe if he understands that and he nods. Arturo fills out the date and Joe’s patient ID number at the top of the form.

“Do you know your T-cell count?” he asks.

“Umm, I think six-something? Uh, six sixty-eight.” Arturo scribbles as Joe answers.

“And your viral load?”

“Undetectable.”

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[42] One ad retrieved from the *Village Voice* states “Feeling Depressed? A clinical research study for an investigational medication is currently enrolling people who are currently taking an antidepressant but still need additional relief or are not taking any antidepressant medications but think they may have depression…Receive study medication and study-related medical care at no cost. Compensation for time and travel may also be provided” (retrieved from www.villagevoice.com on 23 January 2013).

"When did you last have these tests done?" Arturo asks, looking up from his form.

"March, it was March this year," Joe replies.

"What's been your lowest T-cell count? And what's the highest?"

"The lowest? Uh, twenty-seven. That was back in '98, '99. Highest is right now." Joe's gaze shifts down to the paper where Arturo is scribbling his notes but looks back up before Arturo's eyes return to meets his.

Arturo asks Joe if he has ever been on anti-HIV medications, and if so which ones he has taken. Joe replies yes and laughs nervously when he tells us that he is blanking on the names of them. "I've got them all written down on a card in here," Joe opens his worn canvas bag. "Wait," Arturo tells him. "I've got a visual chart if you need it." His chair squeaks again and he hands him a laminated printout that depicts enlarged photos of various HIV medications and their chemical and brand names. Joe points at each colored pill as he reads, "Viracept…Viread…and Kaletra."

The remainder of the forty-minute visit consists mostly of Arturo asking Joe questions regarding his past and current medical history, which consists mainly of whether he has been diagnosed with particular diseases: Have you ever tested positive for TB before? Do you have or have ever had herpes or syphilis? When did you first test positive for HIV? Have you ever had any opportunistic infections, like PCP? Joe answers no to most of these questions. "Where do you go for your medical and do you like your doctor?" Joe tells him the name of the hospital where he receives his care, and says he is happy there and that he likes his doctor very much. "That's great," Arturo replies.

In response to a question about any drug or alcohol use, Joe replies that he has been several years clean and sober, to which Arturo stops writing and responds with heartfelt affirmation for his accomplishment. Arturo asks Joe what kinds of social support he has. Joe seems to perk up answering this question. "My family, my kids, my youngest is thirty-one, that's my baby boy," he says his son's name with pride in his voice. Joe uses both hands to count off the other members of his family that give him support. "And there's my mother and father, brothers, cousins, aunts."

Arturo's notes now cover both sides of the two-page fill-in-the blank screening form. "Okay, just off the top of my head, I think you might be eligible for a lung study. It's an observational trial, no medications. They're trying to observe the kind of bacterial pneumonia that HIV-positive people get, what the germ is." Arturo describes where the study is located, and that his involvement would include meeting with the Research Nurse for about an hour to do a breathing test, have his blood drawn and give a urine sample. "Then you would come back one time every four years and do the same. You'd get twenty dollars per visit, and a transportation voucher. And if you do get pneumonia in the next four years, they would schedule a bronchoscopy with you. A bronchoscopy is a test of the lungs," Arturo explains. "They'd anesthetize you, then put a tube down through your nose, and swab with a big giant Q-tip. You'd get two hundred dollars for the bronchoscopy, but only if you get pneumonia. But, there's a one in three chance that you'd get a bronchoscopy to begin with. Remember randomization?[43]" Joe nods. "One in three people who sign up for the lung study get a bronchoscopy right off the bat. But I don't want to build your hopes up, two hundred dollars is a good chunk of money. If you are randomized to get the bronchoscopy, then you have to do that. So if you like, I can do the referral if you want to do the HIPAA[44] forms. I'll give you some information, a copy of the consent form, and you'll need to sign and date it. That's one trial." Arturo's eyes continue to skim his clipped stack of papers, as he reads off why a particular trial might interest Joe or why it is not appropriate. Each page describes a current study and lists its inclusion and exclusion criteria, such as the parameters for CD4 count and viral load needed to qualify. A flu vaccine trial emerges as a possibility, but Joe will need to retrieve his vaccine history to see if he is eligible.

"So we have one trial and a potential second. That's good, some people don't hit any," Arturo tells Joe. "You have any questions about this?"

"No," replies Joe, slowly. "That's all the info I need."

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[43] Arturo is referring to the ACTPOC intervention group's brief discussion of randomization, and to the handout that offers a glossary of research-related terms.

[44] The "Health Insurance Portability and Accountability Act" or HIPAA, took effect in 2003. It is often referred to as the Privacy Law, and mandates that healthcare providers (and related entities, including health care research) implement policies to protect all health information concerning patients, including any identifying characteristics (such as telephone numbers).

"Good, I like to hear that," Arturo smiles. "If you think of anything, just give me a call. My number is right there on the card. Anything at all, you just ring up." Arturo says that if he can hang on a few more minutes, he will get all the information on the lung study ready for him. He hands Joe a transportation voucher.

Research & Clinical Care: An Introduction

Joe's hour-long ACTs screening visit highlights several features that were fairly typical for ACTPOC participants. ACTPOC PIs, staff, and participants alike encountered difficulties finding the ACTU. The ACTU's obscurity helps to protect patients' confidentiality, but the institutional anonymity also signals a less-than-welcoming introduction to the unit.[45] Like most of his counterparts in the ACTPOC intervention groups, Joe had neither been screened for ACTs nor recalls having ever heard about them from any of his primary care providers. While ACTPOC intervention group participants were encouraged to undergo a screening visit for an ACT, their participation in ACTPOC did not require it.

ACTPOC's intention was to create an intervention that above all aimed to eliminate the possibilities that participants would experience coercion or mild pressure to become involved with medical research. Throughout the intervention, ACTPOC

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[45] The difficulties of accessing the ACTU were described to me by one participant who recounted during an interview, "It's just this hole in the wall, you have to go through this maze to go over to the [ACTU], y'know what I'm saying?...You ask people that can't read or write, y'know, they're going over there and they're like, 'What building?' (*laughs*)."

reiterated and reinforced the differences between screening for a trial and actually joining one.

There was no single experience of screening; how participants presented to ACTPOC's Screener varied and their questions and needs shaped their visits. Some asked specific questions related to their health, unrelated to ACTs. Arturo, ACTPOC's Screener, was committed to addressing participants' health outside the stated purpose of the visit. In their interviews, several participants recounted how they gained insights and received referrals from Arturo and the other staff at the ACTU. Several others felt that talking to Arturo—and feeling listened to—were affirming, even therapeutic experiences for them.

These ACTs screening visits drew my attention to some of the paradoxes regarding research, clinical care, and standardization, which I came to view in other aspects of ACTPOC too. This statement about ACTs contrasts with the epidemiological model and language of underrepresentation and disproportionality presented in the first intervention group. There, the prevalence of HIV/AIDS among women and people of color was framed via expert scientific views, eclipsing participants' knowledge of this very phenomenon. Concepts such as underrepresentation and disproportionality evoked scientific domains of quantification and precision; by contrast, ACTPOC's paradigm of clinical care and research did not attain this semblance of specificity.

This chapter analyzes how ACTPOC's notions of clinical care and research were multiple and flexible, not only among the differently positioned actors, but also within ACTPOC itself. My initial efforts to make sense of these differences did not yield to the explanatory frameworks I tried to apply. As I came to learn (and relearn over the course of the fieldwork), my assumptions of standardization as a tidy object with uniform practices did not match what I was learning in ACTPOC's everyday practices. Moreover, while ACTPOC's slippages between research and treatment raised questions regarding the boundaries between the two, when I looked closer I found that ACTPOC's representations of these domains illustrate far more complex and interesting insights than the simple matter of some inconsistencies.

How were these different definitions of and relationships between clinical care and ACTs enacted and what kinds of effects were produced? To explore this question, this chapter draws upon these ethnographic sources: participant-observation of the intervention groups, ACTPOC's *Research Protocol*, *Intervention Manual* and participant handouts, participant interviews, and secondary data analysis of ten interviews that were conducted with HIV/AIDS primary clinicians working in public health clinics.

First, I briefly describe how AIDS activism led to a shift in the perceptions and practices of clinical research. I also discuss an important feature in the history of ACTs that is absent from the intervention groups: the *exclusion* of women and people of color (and other groups, including Injection Drug Users (IDUs) and hemophiliacs). The remainder of the chapter focuses almost exclusively on ethnographic material to describe how the group intervention presented HIV/AIDS primary care providers in something of a contradictory and conflicting role. On the one hand, participants were encouraged to form a partnership with ACTs researchers and their clinicians; but on the other, doctors' ACTs referral practices were opened to scrutiny as "gatekeepers." I focus on two characteristics of clinicians and publicly funded clinical care that receive somewhat dismal portrayals. Interviews with ACTPOC participants express different perspectives that did not match the motivations assigned clinicians in several group exercises.

Finally, the last section returns to a problem ACTPOC identified: many clinicians do not refer women and people of color to ACTs. A secondary data analysis of ten interviews conducted with HIV/AIDS primary care physicians point to some important issues that shape their decisions to refer (or not). Similar to issues raised by ACTPOC participants, these clinicians challenge ACTPOC's portrayals of the authoritative doctor. Their perspectives reveal how ACTs and clinical trials are embedded in a broader and more complex set of issues, including clinical care; research risks and benefits; and pharmaceutical agendas.

Research or Medicine?

"AIDS clinical trials study the newest *treatments* available. True."

> —One of ACTPOC's ten true/false core messages, printed on wallet cards and distributed at the last group. [Italics added].

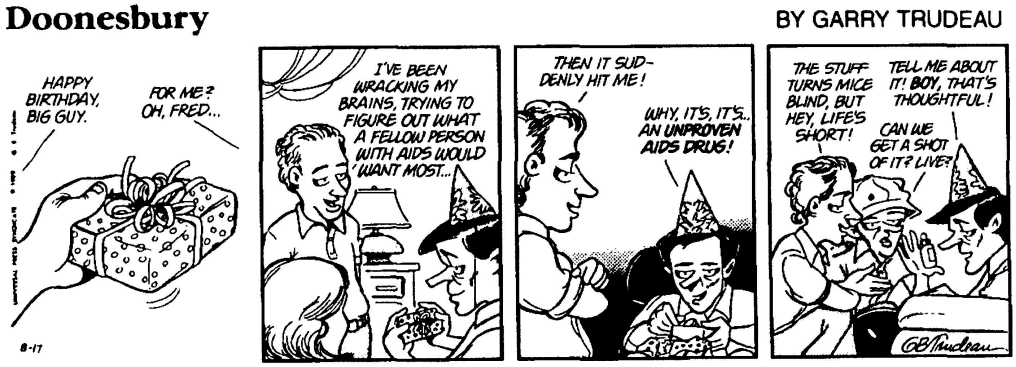

Figure 2: **Doonesbury comic, 1989:797.** ***Reprinted from*** **(Annas 1989:797).**

ACTPOC's language linked clinical care and medical research. The true/false statement above describes ACTs as treatment; while a seemingly minor detail, it does not convey the experimental nature of research. This reference to treatment obscures a key principle of clinical trials research: therapeutic equipoise.

ACTPOC's slippage between clinical care and research is not all that uncommon, due in part to the fact that, for many years, ACTs were the only place (besides some underground buyers' clubs) where PLWHA could access the possibility of pharmaceutical treatment (that is, if the experimental treatment worked; if they were eligible for the study; if they were not randomly assigned the placebo). As many scholars have noted, HIV/AIDS reinvigorated the conflicts regarding the definitions of and boundaries between the clinical and the scientific. HIV/AIDS activism makes this disease unique among modern epidemics: activists challenged some deeply rooted norms in what qualified as "science," and forged new epistemic meaning that altered how ACTs were developed and conducted. Until HIV medications became available, participation in an ACT held the only possibility of gaining access to (pharmaceutically-based) experimental therapies.[46] During these earlier years, the "gold standard" of the controlled randomized clinical trial design was challenged by activists' arguments that, lacking other (pharmaceutical) therapeutic options, ACTs *were* in fact clinical care. PLWHA demanded the right to risk taking unproven therapies, with many regarding it as a more promising alternative than *not* taking the risk.[47] Activists challenged that placebos, a standard feature of randomized design in a clinical trial when no "standard-of-care" existed, were in fact unethical.[48] It was ironic, Harold Edgar and David Rothman point out, that the AIDS activists "rejection of paternalism fits so perfectly

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[46] There also existed a thriving underground network of experimental drug distribution organized by PLWHA and their allies. This network enabled PLWHA to access (non-FDA approved) pharmaceuticals that were purchased abroad and smuggled into the U.S., as well as herbal prescriptions. See Epstein 1996.

[47] George Annas offers a thoughtful counter-perspective to these dominant representations of the PLWHA willing to undergo risky experimental trials. Annas is critical of the conflation of treatment and research in HIV/AIDS and points out that the image of a PLWHA willing to undergo great risk ignores that "terminally ill patients can be harmed, abused, and exploited" (Annas 1989:797).

[48] In 1997, international media brought to light ACTs in Uganda, most of which were funded by the U.S. government (Crane 2010:12) that sought to test a short-course of AZT against a placebo to interrupt mother-fetal transmission, despite that AZT had already been established as the standard of care. The sponsors claimed a local definition of standard-of-care in Kenya, igniting an international debate regarding clinical trials ethics. See Crane (2010); Petryna (2005); and Angell (2005).

with the pharmaceutical industry's complaints about the drug review process…Sick gay men, abandoned by a president who refused to publicly acknowledge their disease on all but one occasion, provided the shock troops to move forward his administration's deregulatory drug control program" (Edgar and Rothman 1990:123-24). Enrollment in the first AZT studies was indeed a matter of life and death for some; participants in the experimental arm lived longer and experienced fewer opportunistic infections (Broder 2010:5).

The bioethicist Robert Levine argues that the devastation of HIV/AIDS, its visible public activism, and the lack of pharmaceutical treatment challenged the protectionist approach to research, and contributed to public perceptions of clinical research as "benign and beneficial" (Levine 1994:93). However, not all ACTs were in fact "benign and beneficial." The fortunate few who had won the lottery to participate in the early AZT studies, were randomized to a clinically therapeutic amount, and who ultimately benefitted from the trial were not necessarily representative of many participants in the early ACTs. For example, an ACT that tested a drug called *Suranim* was halted when several study participants died. Other experimental treatments, such as Soluble CD4, were proven to have no therapeutic value or effect, much to the dismay and distress of the research participants (Epstei 1996). Another bioethicist, George Annas, argues that the declarations of untested, experimental drugs as treatment could only occur in the absence of societal and state support for life-saving measures, such as adequate nutrition, health care, and housing (Annas 1989). It bears stating the obvious that is often overlooked: HIV/AIDS clinical care *did* in fact exist prior to the development of anti-HIV pharmaceuticals. During this period, clinicians—along with other providers—offered various forms of supportive care to patients, which included nutrition, measures to prevent opportunistic infections, acupuncture and other alternative treatments, and stress management. These and other kinds of treatments challenge the equation of care with pharmaceuticals, ignoring other ways of relieving suffering.

ACTs Exclusion

Now criticized for these flaws, many early ACTs routinely denied most women, people of color, and IDUs from participating. Owing in part to the complexities of this new and poorly understood disease, many researchers viewed that race (defined as non-white) and gender (defined as women) would confound interpretation and interfere with the results of experimental AIDS therapies.[49] Peter Arno and Karyn Feiden describe that the researchers conducting the first Phase II AZT study enrolled a homogenous patient population of mostly gay white men, in order to "limit variables

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[49] In a sense, this view was not unlike several principles of the NIH RA, except it was "the other side of the same coin." The efforts to foster clinical diversity are different from the NIH's aim to include racially diverse groups. Two community-based AIDS research settings, the Community Research Institute (CRI) and the Community Program for Community Research on AIDS (CPCRA) argued that the common practices that excluded PLWHA with high liver values unnecessarily excluded people with hemophilia, as well as many IDUs whose use is often associated with these high values. The CPCRA sought to make their studies less like a laboratory, as it were, and develop findings that would be of immediate use to clinicians and patients. See Merton (1990) and Mueller (1998).

that might distort the data"[50] (Arno and Feiden 1992:47). Researchers' preference for white males was shaped in part by their stereotypical beliefs and discriminatory attitudes that assumed people of color would be unwilling to participate, or would not adhere to the requirements of a trial (King et al. 2007:561; Wendler 2006:208). HIV/AIDS advocates and activists struggled to address the blanket exclusions that left many PLWHA with little chance to access these studies.[51] The *FDA Action Handbook* produced by ACT-UP of New York states, "Women, IVDUs, hemophiliacs, children, and people of color have been systematically excluded from most experimental drug trials for AIDS therapies[52]" (Denenberg 1988:73). As Steve Epstein explains, "Activists demanded the inclusion of more women and racial minorities in clinical trials of experimental drugs, arguing that clinical trials served as an important means of access to otherwise unobtainable and theoretically helpful new therapies" (Epstein 1996:189). In 1988, ACT-UP organized a protest to call attention to the problems black and

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[50] The definition of people of color as the "racial variable" to a white "norm" accurately portrays of the ways people of color were marginalized in ACTs.

[51] Although the direct exclusion of women and minorities from research protocols is the focus here, HIV/AIDS treatment activists and advocates also called attention to a broad range of ways exclusion of these groups occurred. Mary Rose Mueller's archival examination of Congressional Hearings reveals the widespread criticism that ensued following the creation of the fourteen AIDS Treatment Evaluation Units (ATEU) sites, which did not include several of the cities with some of the highest prevalence rates and large communities of color, such as Atlanta, Houston, and Philadelphia (Mueller 1998a:90). In addition, many ACTs restricted PLWHA from taking concomitant medications—even aspirin! As Epstein summarizes, "(M)ethodological purity and cleanliness reflected a dangerous abstractedness from pressing social realities" (Epstein 1995:422).

[52] IDUs were also routinely excluded from ACTs, based on the unfounded assumption that they would not comply with research protocols (Kolata 1998:1). Numerous studies have refuted this belief both in terms of ACTs and medication adherence, and although this exclusion has considerably abated, unfortunately it does continue.

Hispanic patients in New Jersey faced in accessing these studies, and began compiling data on the sex, age, race, and ethnic distribution of patients in the clinical trials program sponsored by the NIH (*ACT-UP Mimeo*, cited by Mary-Rose Mueller, 1998b). In the days following the release of the GAO Report detailing the NIH's internal failure to include women in clinical trials as its 1986 guidelines had suggested, five hundred people blocked the streets outside the international AIDS conference in San Francisco to protest the exclusion of women from ACTs [(Epstein 2007:85) Del Vecchio, 1990]. In 1988, a "die-in" protest at the FDA headquarters in Maryland brought public attention to this fact, where activists created tombstones that read, "As a person of color I was exempt from drug trials" and "I got the placebo. R.I.P." [(Epstein 1996:225) *Gay City News* 1988].

"Direct-to-Consumer" (DTC)

> In part because of concerns about providers impeding access to care or research, fields including cancer clinical trials and pharmaceuticals have launched social marketing efforts 'direct-to-consumer,' bypassing medical providers (Kravitz et al., 2005; Zachry et al., 2003). On the other hand, PLHA's (people living with HIV/AIDS) relationships with their health care providers are often vital to their care and wellbeing. Thus there is also value in enlisting the support of PLHA's health care providers in ACT-related decisions. The present study will address the patient-provider relationship using approaches adopted from the direct-to-consumer model.
>
> (*ACTPOC Research Protocol*, 2008:4)

The ACTPOC group intervention was designed as a "direct-to-consumer" (DTC) intervention, bypassing (though not excluding) clinicians in addressing women and people of color living with HIV/AIDS directly. The model of DTC advertising has only recently been established as a pharmaceutical strategy for drug promotion. Jill Fisher and Lorna Ronald explain that until the deregulation of the pharmaceutical industries in the 1990s, prescription drugs were marketed almost exclusively to health care professionals (Fisher and Ronald 2008:32).[53]

The laws relaxing DTC stand out in the last century of mandates aimed to protect the consumer. The Pure FDA Act of 1906 curbed widespread advertisements for various drugs by limiting their placement to medical journals. While framed as necessary to protect the public from "quack" medicine, the delegation of prescribing authority to doctors displaced patients' use of the pharmacopeia, and supported the professional consolidation of physicians and drug companies.[54] Nevertheless, these regulations proved to have a beneficial public effect according to Paul Starr, who states

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[53] The language of "consumer" is a recent development in the history of medicine. Alvan Feinstein offers some historical context to the rise of the neoliberal health consumer. In his discussion of the transition of medicine "from a caring profession to a business" (Feinstein 2003:235), Feinstein, a physician and researcher, notes that this new language reflected the shrinking of clinical personnel and the addition of hospital administrators: "(T)he term doctors was replaced by 'health care providers'…patients became 'consumers'" (ibid.).

[54] Jonathan Libeneau points out how the Pure Food and Drug Act's mandate for drug companies to institute laboratories to measure and assess the accuracy of the chemical compounds of the drugs being sold drove the smaller drug makers out of business, and paved the way for large drug manufacturers. This American Medical Association and the Bureau of Chemistry both supported this decision. The new laboratories were also good for business; its association with science bolstered sales. (Liebenau, 19xx:4-7).

that, "the logic of the 1906 law was to improve the functioning of the market, making consumer information more accurate" (Starr 1982:133).[55]

Joy Fuqua argues that the language of "patient/consumer 'education'" amounts to little more than "brand-name recognition" (Fuqua 2002:662). A study conducted by the Canadian Health Services Research Foundation found little to support that DTC actually educated patients. Instead, this study found that many of these ads promoted the drug's emotional value, medicalizing regular conditions such as shyness, baldness, and premenstrual syndrome (Canadian Health Services Research Foundation, 2007).

The money spent on DTC advertising rose sharply since its inception: Morris Fisher points out that from 1997 until 2000, DTC advertising increased from $791 million to 2.5 billion (Fisher 2003:257). By 2009, spending on DTC advertising and related marketing reached 2.3 billion dollars for the first six months (Eberling 2011:826). Often portrayed as beneficial for the patient, proponents of DTC pharmaceutical advertising state that it increases patients' access to and knowledge of drugs and medical conditions through television, print, and other media—no longer do they have to rely upon doctors as the sole authority of information. ACTPOC's use of a DTC model did not, of course, engage in the direct promotion of any specific pharmaceutical

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[55] Of course, even when drugs were not publicly advertised did not mean that doctors were free of corporate pharmaceutical influence. See Oldani (2004) for a firsthand account of twentieth century "detailing" practices, which illustrate how pharmaceutical sales representatives, through a gift economy, influence doctors' prescribing practices.

drugs. The logic of DTC advertising has restructured the relations between doctor and patient.[56]

ACTPOC's DTC approach, which delivered the group-based intervention directly to participants, rather than to their clinicians, occurs within the broader neoliberalization of health care. As discussed in the Introduction, the decline of the welfare state shifts what had previously been the clinicians' labors onto patients, their families, and social networks. ACTPOC's approach to the individual consumer (rather than their physicians), is revealing of the tenets of neoliberal health: as Adele Clarke et al. (2003) describe it, health is paradoxically becoming more *and* less biomedicalized. Clarke et al. observe that activities once deemed medical are being redirected to non-medical settings such as the home; yet at the same time health care is "seemingly less medicalized as the key site of responsibility shifts from the physician/provider to include collaboration with or reliance upon patient/user/consumer" (Clarke et al. 2003:170-173).

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[56] Marcia Angell and Arnold Relman argue that the money poured into ads that instruct viewers to 'ask your doctor about' supports a model of "consumer-driven" health care, which, they argue, "contributes little or nothing to the quality of medical services" (Angell and Relman 2002:107). Julie Donahue et al. conducted a study of FDA and pharmaceutical industry practices to find that the FDA role in regulating drug advertisements is very limited, due in part to staffing levels that have not kept pace with the growth of these ads (Donahue 2007:679). As mentioned in Chapter one, the deregulation of the FDA has been a significant part of the overall neoliberalization of health care, and DTC is a major reflection of that shift. In their study of DTC discourse, Jill Fisher and Lorna Ronald conclude that the problem DTC advertising presumes to address is the patient's "inadequate access to information that would enable drug use" (Fisher and Ronald 2007:36). While some argue that DTC challenges medical authority by broadening access to the information contained in pharmaceutical ads, others put forth that they reduce protections and create new burdens and responsibilities for the public. From the latest antidepressant ads that instruct viewers to detect potential signs of depression in their everyday behavior and outlook to the depictions of active lifestyle for name-brand arthritis drugs, patients—now consumers—bear new roles of "responsibilization" for their health in late capitalism.

However, what Fisher and Ronald describe as the "empowered consumer" (Fisher and Ronald 2008:36) bears little resemblance to feminist activists' challenges to medical authority; it is more suited to the neoliberalization of health care and the rationalization of clinical care. As Briggs explains, "(T)he central role of mass media in health communication today attests to the increasing marginalization in the age of neoliberalism of the benevolent patriarchal authority symbolized in an early era by the image of the family physician" (Briggs 2007:51). Briggs' observation of the vanishing clinician is elucidated by Patricia Peppin and Elaine Carty, who note that the clinician has largely disappeared in drug advertising in part because, "the drug itself has assumed the role of healer" (Peppin and Carty 2001:569).

Discriminatory Doctors & Responsibilized Subjects

> Studies have shown that doctors are less likely to refer people of color and women to be screened for ACTs. Why do group members think this might be so? Discuss. The following points can be discussed:
> - Some health care providers tell their patients about AIDS clinical trials but many others do not.
> - For this reason, the [ACTPOC] Project goes straight to people living with HIV/AIDS to let you know about the opportunity to access AIDS clinical trials.
> - We also know that your health care providers are very important. We respect that relationship.
>
> *ACTPOC Intervention Manual, Exercise #4:*
> *"Talking to Your Doctor about ACT Screening and Enrollment"*

> "We do not take care from your primary."
>
> *Hilda, ACTU Research Nurse, ACTPOC Video*

> "Why do your doctors not refer you to ACTs?" Barbara asks the group before answering, "Doctors don't want to lose you. AIDS is a big business."
>
> "Doctors are not talking to people of color about ACTs. They are not giving you the chance to make that decision," says Lauryn.
>
> *ACTPOC Intervention Groups*

The stark terms in which this disparity was communicated—physicians do not refer women and people of color to ACTs as they do their white patients—naturally raised participants' concerns of and suspicions as to why many of them had not heard of these studies before. As several studies demonstrate, clinicians' racial stereotyping and other forms of discrimination towards their patients is one reason why some are not referred (Sullivan et al. 2007; Sheikh 2006:0167; Joseph et al. 2009:608). As one of the developers of ACTPOC's group intervention explained to me in an interview, "Your doctor doesn't refer you because they are racist." The act of situating discrimination and racial exclusion at the level of an individual encounter made it immediately relevant and deeply personal for most participants. However, localizing it at this interpersonal scale posed limits to how participants might learn about and engage racializing processes in ACTs. The focus on race and racism at the level of the individual encounter restricted the possibility for a broader discussion of its relationship to ACTs.

And while ACTPOC's presentation raised the possibility that some clinicians engage in possible discriminatory practices—due, perhaps, to "big business"—the question of why ACTs *researchers* were not subject to the same scrutiny remained unclear. ACTs were absent of any reference to business or profit-making interests. The suggestion that ACTPOC participants' *clinical* care follows a profit-making business model did not bring awareness to the fact that pharmaceutical medication development is perhaps the most market-oriented aspect of existing health care, with global profits tending towards the billions.[57] That many ACTs are pharmaceutically sponsored[58] did not sound the same alarms as did ACTPOC's focus upon particular clinicians who worked in busy publicly funded clinics.

The following intervention group exercise offers insights into the rather negative portrayal of doctors. Two participants are asked to volunteer to read the "Talking to My Doctor Script," out loud to the group, which is followed by a discussion.

"Talking to My Doctor Script"

Marta: So, doctor, I am thinking about getting screened for an AIDS clinical trial. Can I talk to you about this?

Dr. Lopez: Well you are doing ok. We finally got you stable. I don't think you need a trial.

Marta: Yes, I am doing well, but I have a lot of health issues and want to learn about what's new out there. I also like the idea that I may be able to help my community.

Dr. Lopez: The meds will come on the market in a couple of years and we can talk about them then, if you need them.

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[57] For example, worldwide sales of pharmaceutical medication amounted to 466 billion in 2003 alone (Busfield, 2006:297). In 2005, pharmaceutical companies took in 230 billion dollars in the U.S. market where 3.5 billion prescriptions were written for 130 million people (Flynn 2006:60).

[58] And, even those not pharmaceutically sponsored are still subject to the interests of the market. As discussed in the Introduction, publicly funded research is a misnomer with legislation such as the Bayh-Dole and Hatch-Waxman Acts, which assigns the intellectual property rights of publicly funded research to individuals and corporations.

Marta: Well, my hep C keeps getting worse and I have heard they might have a new trial for that. I would like to find out more. I'm curious. That's why I want to get screened.

Dr. Lopez: We have been working for a long time now and the new doctors won't know you as well.

Marta: Well I still want you to be my main doctor. Can't we still work together if I join a trial?

Dr. Lopez: Yes, we can do that.

Marta: If I am eligible to join a trial I will talk to you about it with you before I make a decision to join.

Dr. Lopez: Well, I know about the trials. I am not sure you can stick to the requirements of a trial. That's why I didn't suggest this to you.

Marta: I am just going to get screened. If they tell me I am eligible for a trial I will talk to you about it before I make my decision about joining one. I will find out what the requirements are.

Dr. Lopez: OK. Let me know what happens.

Marta: Thanks, I will.

THE END

—ACTPOC Intervention Manual, pp4

In every ACTPOC group I attended, participants' immediate responses to this exercise conveyed frustration towards Dr. Lopez. What seemed to rile people the most was Dr. Lopez' withholding information about ACTs to Marta because of the assumption that she would not be able to handle the requirements of a trial. Some recurrent descriptions ACTPOC participants used to describe Dr. Lopez's overt behavior included "bossy," "assuming," "know-it-all," and "annoying." The issue of access to ACTs was personalized, rooted in the influential racialized and gendered power dynamics that shape how some physicians interact with their patients. Participants viewed Dr. Lopez as paternalistic: Marta's desire to extend her care beyond the bounds the doctor had established was met with overt hostility.

ACTPOC was intentional in targeting women and people of color living with HIV/AIDS for ACTs education (rather than, for example, targeting HIV/AIDS clinicians on how to develop referral strategies and/or explore their discriminatory motivations for not referring). The decision to use this DTC model was due in part to what was described by the ACTPOC PIs as "concerns about providers impeding access to care or research…" (*Research Protocol,* 2008:4). Dr. Lopez is an example of a provider who impedes patients' access to ACTs as evidenced by his statement, "Well, I know about the trials. I am not sure you can stick to the requirements of a trial. That's why I didn't suggest this to you." The barriers Dr. Lopez conveys to Marta present the evidence supporting ACTPOC's DTC approach, by setting up an opposition between the paternalistic doctor that aims to subdue the patient to his/her authority. The doctor's responses seek to reinforce the medical authority and dismiss the patient's. "The new doctors won't know you (as I do)." The presentation and facilitation of this exercise clearly outlines the repressive "no" that reveals Dr. Lopez's assumption that Marta was not capable of adhering to a trial's requirements.

This dialogue does not consider the possibility for Dr. Lopez to be driven by a different set of motives, established, perhaps out of concern for Marta: Will the ACTs researchers be able to grasp all of Marta's complex history of HIV and Hepatitis C co-infection? Does the recommendation to wait for the drugs to reach the market have to do with a clinical preference for FDA-approved drugs that have completed testing in clinical trials and have demonstrated satisfactory findings?[59]

In addition to conveying Dr. Lopez's paternalism and authority, this script also demonstrates the role of the patient who addresses the barriers to her screening head-on. Marta patiently corrects Dr. Lopez's generalizations about ACTs and provides reassurance that their doctor-patient relation will continue. She also clarifies one of the main messages of ACTPOC that encourages screening for an ACT, which does not entail joining one. Marta exemplifies what John Coveney describes as a key feature of neoliberal public health, namely its ability to "govern[s] at a distance by ensuring that subjects are bound into the language of expertise at the very moment they are assured of their freedom and autonomy" (Coveney 1998:466). Marta articulates her challenges to Dr. Lopez, but what significance might we place on her adoption of ACTPOC's language to do so?

Bypassing the clinicians that engage in uneven referral practices, ACTPOC facilitated HIV-positive women and people of color's access to information about ACTs. But what burdens did this create for participants? How did the representation of the doctor as authoritative and paternalistic deflect attention from the many reasons (that range from stereotypical assumptions to clinical concerns) that may discourage

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[59] Donald Light, a professor of psychiatry, notes that the Health Research Group recommends waiting seven years to prescribe new drugs, unless no alternative is available, so that adverse events (AEs) to come to light that did not emerge in clinical trials (Light 2010:52).

clinicians from referring their patients to ACTs? Moreover, why is there not a script between participant and ACTs researcher for people to read out loud and discuss?

The ACTU vs. public clinics: "I hate waiting…(but I love my doctor)."

> **EXERCISE #5: "Expectations of Screening and the ACT Site(s)" (15 minutes)**
> *Teaching Objective: To raise awareness about that fact that systems of care can be very different. In particular, the ACT Site(s) differ from participants' typical health care venues. To successfully access ACT screening and trials, participants will need to understand this and adapt to it.*
>
> ACTPOC Facilitator Manual
> Session Two: Understanding the Screening Process

One of ACTPOC's powerful juxtapositions of research and clinical care had to do with waiting. This section illustrates that in matters of convenience, the ACTU emerged as the single-handed winner. ACTPOC's presentation outlined the differences in wait times that participants might expect at the ACTU. Participants were told that at the ACTU appointments begin at their scheduled time. The ACTU does not double-book, as is regularly the case with many clinics that routinely overbook their clinicians. In order to manage staff shortage, estimates that some number of patients will miss their appointments are routinely integrated into the schedule, so as to accommodate the clinic's caseload and stretch the clinician's time. As health care institutions devolve, the volume of patients and amount of need tends to be much greater than what available services can manage.

Participants were encouraged to arrive at the ACTU on time for their screening visit and to call if they needed to reschedule. This discussion of ACTs and clinical care had benefits for the ACTU and its potential participants. Participants may have felt less anxiety knowing something about the organizational norms of the ACTU, and awareness of the appointment scheduling likely helped them plan their visits. The ACTU also benefitted, as ACTPOC participants that undergo a screening will be socialized into the operation of the clinic, thus minimizing the interruptions of late patients.

The issue of waiting to see their regular clinicians—sometimes with delays that lasted hours past their scheduled appointment times—was a routine occurrence for most participants and the source of much frustration. This exercise regularly invoked ACTPOC participants' stories about the longest time they spent waiting and their strategies to alleviate this inconvenience, such as attempting to get the first appointment of the day or at least the earliest one. Some described setting aside the entire afternoon for this thirty minutes (or less) appointment, so as to avoid being late or missing another appointment or commitment that same day. Another was to bring reading material, or tackle a pile of household bills and budget. Many participants engaged in various forms of emotional self-management in anticipation of the long wait and submission to the institutional regimes over which they had little or no control.

Participants were surprised to hear, and responded favorably to learning that appointments at the ACTU involved very minimal or no waiting.

ACTPOC's comparisons between clinical care and research revealed stark and somewhat puzzling contrasts between them. Dr. Lopez was portrayed as the doctor who withheld information from Marta, brushed aside her own concerns and interests, and assumed she was unable to meet the requirements of an ACT. ACTPOC outlined the reasons AIDS doctors do not refer their patients, as described in these scenarios: doctors prioritize their financial interests over the needs of their patients, fearing they will lose them and withhold information from their HIV-positive people of color they treat. Now, participants' experiences of waiting to see their doctors at overburdened public clinics won't be an issue at the ACTU, who will be ready to see them at their specified appointment time, not thirty minutes or two hours later.

Waiting is especially salient in comparing the resources of ACTPOC and the ACTU to the publicly funded HIV clinics ACTPOC participants attended. Biomedical research (especially pharmaceutically-sponsored research studies) have a greater number of resources at their disposal than do state-funded health clinics that deliver primary care to people who receive Medicaid or who have no insurance. The latter operate on a base of shrinking city, state, and federal funds. Patients' needs are at an all-time high, and the range and depth of issues people present often exceed the typical standard of care as defined by the fifteen-minute routine medical check-ups that focus on quarterly diagnostic tests to measure CD4 count and plasma viral load test (pVL) (in the absence of signs of health issues, these visits function as "medication management"). While evidence-based guidelines affect the quality of and the interaction between doctor/patient, patients' care has not been standardized across the board. Research visits for ACTs do however follow standardized procedures determined by research protocols (this is another reason that visits are able to adhere to a schedule). While the particular ACTU with which ACTPOC had collaborated was committed to patient's health and regularly went above and beyond the protocol, this is not universally the case with clinical trials. For example, Jill Fisher found out through her ethnographic research that even when patients had health needs, these were not always addressed in the medical monitoring the research study offered (Fisher 2009). In addition, Mandy Garber and Robert Arnold challenge the argument that participation in clinical trials leads to improved outcomes, noting that any benefit is likely disease-specific and does not translate into primary care (Garber and Arnold 2006:16).

ACTPOC Participants and Clinical Care

ACTPOC's representations of Dr. Lopez did *not* reflect most participants' health care experiences with their HIV/AIDS clinicians. While ACTPOC participants had no small share of negative interactions with health care systems, the overwhelming majority spoke highly of their clincians. Jimmy described to me some of the differences between the HIV care he now receives and that is available to him in the urban area where he now lived, compared to the smaller and more geographically isolated city he had moved from. In fact, he had relocated to this particular city in part because he was in need of the publicly funded drug treatment and HIV care available in this area. Jimmy named the previous clinic he attended as "hit and run medicine." He says, "So the one I used to go to was like hit and run, in and out, bang, bang, bang, bang. You know, they didn't…bother to tell you nothing or explain anything to you, you know what I mean?"

ACTPOC participants, virtually all of who were on (or in the process of applying for) Medicaid must interface with a health care apparatus that is overburdened and underfunded. They described the considerable bureaucratic demands in seeking care; Medicaid reimbursement policies that delay necessary tests; and difficulty reaching providers immediately when they are trying to determine whether a high temperature is a sign to rest, or warrants a visit to the emergency room. The processes patients routinely undertake to facilitate and grant permission and other consent for their various health providers to speak to one another involved complex and demanding procedures (that might have been previously been undertaken by their case managers and social workers, no longer available as these and other forms of social services have shrunk). Obtaining refills for medications or arranging for a visit to see a specialist can present another set of hurdles. The reduction in social services has only intensified patients' needs. Poor people with HIV/AIDS who seek care at these centers may be in need of stable housing; treatment for co-morbid problems such as Hepatitis C, heart disease, and diabetes; assistance to apply for entitlements and access services such as mental health intervention, harm reduction and/or drug treatment services, family assistance, and more.

The economic and racial segregation between different care systems is staggering. In one of the buildings in the hospital where many ACTPOC groups were conducted, the main entrance opens up into a newly remodeled entry, designed as a welcoming space: tall green plants, natural light, and a wide space that may be full of people but not feel crowded. Soon, however, the familiar racial and economic order returns: one private wing features specialized labor rooms that can run into the tens of thousands, while several floors below poor PLWHA wait, in a drab windowless room far past the time of their scheduled appointments. Yet despite that these systems are underfunded and overburdened, the majority of ACTPOC participants spoke highly of their primary care physicians and nurse practitioners, especially those with whom they have built a quality relationship with over many years.

On an institutional level, the neoliberalization of health care and the introduction of a managed care model create delays, increase wait times, and add to the demands and frustrations for patients in need of care. It has also resulted (sometimes though not always) in a compartmentalization of clinical care, where issues not related to the physical checkup receive less time. However, the stresses upon the health care system are not the only determining factor in patients' quality of care. In fact, many—if not most—ACTPOC participants reported strong and supportive relations with their providers. Several even described them as their advocates and mentors in their experiences living with HIV/AIDS, addressing concerns that extended beyond "medical" domains according to the diagnostic checklist. Although several described disagreeing with their providers and occasionally butting heads regarding the course of their care, most felt that these differences were unified in support of the patient's health—not the result of a doctor's lack of concern or the assertion of authority over the patient.

Janine described her experience receiving high-quality care and dealing with a broken health system. She said,

> You know, […], she's a caring doctor, you know. She listen to you, you know. At the clinic, it was a different type of atmosphere because they're, okay, okay, well I gotta—you know, and they running back and forth. Nobody really cares at the clinic. Nobody really cares. Nobody cares about what's going on. You're just a person that got HIV and AIDS or whatever and boom, you know. They interested in charts. How many charts they do, you know, that was the impression I got, you know. So I don't need that. And then I was just, you know, coming to terms—I wasn't even coming to terms - I hadn't even got a grip on it yet. So I really felt like, you know, mm mmm, I can't do it.

Berta shared the similar experience of finding a good doctor whom she trusts. "What normally would take fifteen minutes in her office takes like a half an hour 'cause we just be talking. Mm-hmm. Yeah…She even told me that if I feel like she wasn't providing good enough service for me, I could move to the next doctor. She did—that I'd have her full support." Frank, who is one of a small handful of participants who had enrolled in an ACT (at a different site; not at the particular ACTU with which ACTPOC was affiliated) that was testing a drug for HIV-related fatigue, lamented to me that his long-term doctor just returned home to England. Frank said, "Yeah, I worked with him for probably a year and it was like instantly, y'know, instantly y'know, I understood. He cared about me too, but it seemed like he was really, really on point and he explained things to me in a way that I understood." Frank described that years before he had left the state, became homeless, and lost access to his medical care and his anti-HIV medications. When he returned to the area and to his regular care, his medications did not work as well as they had done so in the past. His doctor tinkered with his medications and Frank's CD4 counts began to rise again, much to his relief. Frank explained, "So he had me take a vacation from the medication and then he restarted on the exact same meds and they started working again, which some people—they say can't be done but it happened for me." Frank's experience speaks to the importance of the physician-patient relationship, as well as to his doctor's clinical vision, which was personalized and specific to his situation.

Jimmy, Berta, Janine, and Frank's perspectives are just a few of many that participants shared that depicted their supportive relationships with their primary care providers. ACTPOC's representation of Dr. Lopez and the portrait of AIDS as a big business do not seem to match participants' experiences with their doctors. Berta's statement that describes the promise of her physician's support—whether she chooses to continue under her care or select another doctor—contradicts ACTPOC's portrait of the possessive doctor who does not want to release their patient to someone else's care. Frank's experience with his doctors bears similarity to many other ACTPOC's participants' experiences, where they do not encounter responses of stigma or blame for stopping medication (many participants had stopped their meds at different times for various reasons, sometimes out of choice, but incarceration and homelessness also interrupted their adherence). Instead, as in Frank's case, his doctor attends to him with an individualized level of care with the goal of improving their health.

ACTPOC participants' encounters with health care systems are commodified (especially under the conditions of Medicaid and managed care), but by and large, their relationships with their clinicians did not fit this mold. While participants had to manage time spent waiting and endure—as Janine so eloquently expresses—feeling "like a chart" in the clinic, most had very positive experiences with their doctors in these systems. Participants were engaged with and valued the social relations that formed the core of their medical treatment, from being forthcoming with their doctors (especially with disclosing information, such as stopping medication and/or recent drug relapse, without fear) to the security many felt knowing they will be treated with competence and care.

Another important element of ACTPOC participants' description of their clinical care runs counter to the encounter between Dr. Lopez and Marta: in a declining welfare state, models of "responsibilization" instruct participants to be active in their care/self-sufficient, autonomous, decision-makers. Those qualities were indeed present in participants' valuations of their health care—no one wanted to be dominated or told what to do—however, many spoke highly of what appeared for the most part to be closer to a "less neoliberal" doctor-patient relationship. They wanted to be informed of what the clinicians were doing; encouragement to ask questions about their care was similarly important. But, they also equally wanted answers from experts, and looked to and held trust that their doctors would be forthcoming with their knowledge and direction regarding a path of care. Staying abreast of HIV information through their peer networks, service organizations, and publications geared to PLWHA was important for many, but not a substitute for their doctors, who held specialized knowledge of HIV/AIDS, valued their unique needs, responded to their questions, and treated them with integrity and respect.

Overall, participants' positive evaluations of and experiences with their doctors challenged ACTPOC's dominant representations of their clinicians as embodied in Dr. Lopez and whose interests conform to a "big business" model. In fact, a stronger connection could link the ACTs to the business model, besides the obvious links to the testing of pharmaceutical drugs. As ACTPOC taught participants, they are in the driver's seat—they have the ability to choose whether to screen for an ACT or decline to do so. But the limits of rational model of choice are evident—like good consumers, participants can take it or leave it. There is very little or no room to negotiate the conditions of their involvement; for example, participants cannot opt out of the placebo group or decline particular tests that studies require to determine eligibility. Many ACTPOC participants' relationships with their doctors offered up a wider range of possibilities. Kristen recalled her doctor strongly encouraging her to seek drug treatment to improve her deteriorating health, but at the time she was not interested. Her doctor asked her how what they could do to increase her CD4 and fight a spate of recent infections, and the two agreed upon a plan for her to cut back on her drug use and seek grief counseling. This was not exactly what the doctor had in mind, and the participant agreed with some reluctance. But Kirsten and her doctor, acting in partnership, reached a satisfactory compromise that helped to minimize the harms of her drug use without abstaining entirely.

What Do Clinicians Think?

ACTPOC attributed the uneven rates of participation in ACTs in part to the HIV/AIDS clinicians that withhold information about these studies from women and people of color. Under what circumstances do clinicians refer their patients to ACTs or decline to do so? This section draws from my secondary data analysis of nine interviews with HIV/AIDS clinicians that had been conducted by another interviewer for the pilot study of ACTPOC. These particular clinicians were a convenience sample of HIV/AIDS doctors that work in various clinics that primarily serve low-income people of color. All interviews but one were digitally recorded and transcribed verbatim.

The DTC model that ACTPOC used would most apply to the doctors that play gatekeeper with ACTs referrals, as evidenced by disparaging statements one physician, Dr. Sharpe, made towards some of the patients she sees, who she views as disinterested in ACTs due to their "laziness." The majority of the doctors who were interviewed used different criteria as to whether they would refer their patients to ACTs. These clinicians describe the processes by which they evaluate the appropriateness of whether and under what conditions they refer, which draw from both their assessment of the ACT's characteristics as well as the potential for their patients to experience clinical benefit and avoid harm. The following discussion suggests that these clinicians' ACTs referral practices were not embedded in the paternalistic outlook that Dr. Lopez demonstrates, nor did they convey racist motivations described to me by Dr. Greene, one of ACTPOC's Intervention Group developers, who stated, "What do I want people to learn? ...Your doctors may not be giving you information because your doctors may be racist too." The physicians did not harbor the "big business of AIDS" mentality that ACTPOC constructed. Rather, these clinicians' perspectives of biomedical research offer a complex picture that highlights these processes of ACTs referral are not executed lightly, but involve their assessment of the individual patient and the potential benefits, harms, and flaws of the clinical trial.

Reluctance to refer

There were several elements about ACTs that made clinicians reluctant to refer their patients. ACTs' narrow eligibility criteria restrict most potential participants from taking part in trials. Dr. Marotta was especially frustrated that the ACTs' research agenda did not address many of the problems among the patients he treats, particularly co-infection with Hepatitis C. Another did not want to refer her patients to placebo trials. The location of where the ACT was taking place made a difference in whether one doctor would refer, as many hospitals were not welcoming to the patients she sees, most of who are active drug users. Dr. Serra said, "But remember, it's not a harm reduction model in the hospital…Before you get [to the physician] you pretty much judged, condemned, and hung." Dr. Singh explained how clinical trials stereotype and judge participants: "Because I think people are stereotyping. You know, if you're Black, you're not gonna be adhering. You want your study to be nice and clean."[60]

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[60] Dr. Singh's reference to studies being "clean" point to a broader conflict within clinical trials research, efficacy vs. effectiveness: are experimental drugs being tested in "real world" patients, who sometimes miss doses? Or are clinical trials meant to approximate laboratory conditions?

Drs. Bernstein and Arnold discussed the challenges they faced in attending to the multiple issues their patients present. Many described the limits on the time they could allot to each patient due to their high caseloads, which made ACTs referrals a low priority. According to Dr. Bernstein, "Because when you're consumed into seeing patients thirty minutes apart, and sometimes some patients may be very ill compared to others and you spend more time with them. Sometimes you're so focused on making sure that they have all the vaccines in the past year, or did I make sure I covered this, and there are other issues that I have to take care of aside from their HIV issue, sometimes I wouldn't have time to actually think about it." Time (or the lack of) was also a consideration for the patients they treated. Dr. Arnold's statement conveys an understanding of his patients' needs with regards to their employment demands and scheduling needs. "The fact that employment hours now are so much worse than they used to be…horrible hours and minimal benefits." This physician pointed out that unless the ACTU extended their hours of operation, it was unlikely his clients would be able to take part in an ACT.

Despite some of the problems with ACTs these clinicians describe, they were supportive of the possible benefits patients could gain from their involvement with these studies. The possibility of access to salvage therapy—the experimental medication that may be helpful for PLWHA who cannot tolerate or no longer respond to existing medications (i.e. used for patients with no other pharmaceutical therapeutic options)—was the primary reason doctors would refer their patients. Several doctors also mentioned the important ways research benefitted the treatment they could provide patients, and were very supportive of the new knowledge that may emerge from ACTs that could improve the clinical care they offered.

ACTPOC did an excellent job meeting its goal to connect participants with the ACTU. Approximately eighty percent of ACTPOC's intervention group participants completed the optional screening visit, and participants rated these visits very positively. Nevertheless, there were certain aspects to ACTs referrals that participants' physicians seem best suited to do. For example, Dr. James described that she had once assessed that a particular patient could really benefit from being enrolled in a particular ACT, but this patient had been deemed ineligible according to the ACT's restrictive eligibility criteria. Dr. James called the ACTU and convinced the researchers to admit this patient into the study.

Dr. Arnold explained how she sees ACTs referrals as important for filling in the gaps for what her care is unable to provide. "I think it's just knowing what the patients' main problems are and saying what they might benefit from that I can't do for them already." Dr. Bernstein also plays "gatekeeper" but in a positive way that ACTPOC had overlooked. According to this doctor, there is no reason to refer patients to a flawed study, as this statement conveys: "I can tell you from my point of view why I am not going to enroll people in that study…I realized very early on that they are much more toxic drugs and I have just been using the other drugs." Dr. Bernstein's comments indicate the need to carefully examine the politics of pharmaceutical drug development and interrogate the politics of what kinds of drugs get studied and for what kinds of patients stand to benefit?

These comments from clinicians offer a wider set of concerns that shapes their referral decisions, and illustrates ways how referrals to ACTs involved patient advocacy. These clinicians raise important points regarding the problematic aspects of ACTs that limit the participation of women and people of color. ACTPOC's identification of clinicians that focuses on them as barriers to participation overlooks the important and critical role they play in trying to help the patient achieve the best level of care.

CHAPTER FOUR:
PARTICIPANT-DRIVEN INTERVENTION (PDI) & RESPONDENT-DRIVEN SAMPLING (RDS)

The group's facilitator, Barbara, is leading our group of ten adults through a review of ten statements about AIDS clinical trials (ACTs) that are listed on the laminated poster hanging on the bare wall behind her. Barbara occasionally points to the numbered statements to animate her presentation, though she barely glances at the list; she recites the statements from memory. "'More women and people of color are needed in AIDS clinical trials.' True or false?" She pauses, waiting for someone from the group to respond. Sherie, an African American woman in her mid-fifties speaks first. "True, yes we need more of us to do these studies," she replies, peering at the poster over the top of her glasses. "What do the rest of you think—do you agree?" Barbara's eyes scan the group. Her question is returned with a cacophony of affirmative replies. "True. Yes that's correct. Good." Barbara says firmly. "More women and people of color are needed in AIDS clinical trials." Barbara holds up one of the small green *Main Messages* cards each participant had been distributed in that day's packet of materials. "You can go ahead and mark true or false next to each statement on your cards. You need to get this right in order for the peers you recruit to get this right. And keep in mind, you will receive a dollar for each statement your peers answer correctly when they come in for their first appointment."

Next, Barbara demonstrates a practice recruitment encounter with a volunteer from the group and then rearranges everyone into pairs to practice with each other. Soon the room is abuzz with conversation. A few participants study the handout "Steps to Peer Education and Recruitment" which was organized into sections such as *Ask*, *Explain*, and *Educate*. Others prefer to test their opening lines with their practice partner, asking them, "Do you have a few minutes for me to tell you about a project where you learn about AIDS clinical trials and earn a little extra money?" or "Have you ever heard of the ACTPOC project?"

This chapter analyzes Respondent-Driven Sampling (RDS) and the Peer-Driven Intervention (PDI), the recruitment methods used to enroll women and people of color living with HIV/AIDS into ACTPOC. RDS and PDI have been widely embraced by researchers, who laud them for their efficiency, low expense, and scientific benefits. This chapter offers a counterpoint to these positive appraisals by bringing to light some of the problems that remain obscured in the literature: namely, that the institutionalization of RDS denigrates the significant contributions of outreach workers, further stratifies the research hierarchy by eliminating outreach positions, and creates new pressures and demands for research participants now charged with the task of peer recruitment.[61]

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[61] The word itself, "recruit" reveals an interesting choice of language to describe the process of clinical trials enrollment. A recruit refers to someone who has enlisted in or has been conscripted into the army or military. The standard dictionary definition, as well as common usage of the word recruit suggests not

Part one of this chapter discusses how outreach workers engaged people—many of who were involved in highly stigmatized activities such as drug use and sex work—in HIV risk-reduction activities such as syringe exchange and condom use. Taking notice of how outreach workers successfully engaged with people they had viewed as "hard-to-reach" and difficult to enroll into their HIV/AIDS prevention and biobehavioral studies,[62] researchers hired them to conduct recruitment for their projects.

But this changed in the mid-1990s, when RDS was introduced as a cost-effective research recruitment method, a point I explore in part two of this chapter. Its creators argued that RDS would improve the sampling of "hidden populations" as well as eliminate the need to employ outreach workers. I discuss how the benefits of RDS are framed through a hostile and, as I will show, distorted portrayal of outreach-based research recruitment. These representations deflect attention from the ethical problems that emerge in RDS/PDI methods, which seek to replace employed outreach workers with a cash economy organized on principles of social control and competition for scarce resources. Part two also summarizes the competing ontologies of outreach and RDS through a brief discussion of its sampling frames, labeled as targeted and random, respectively.

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so much a relationship between two people than an action that one person performs upon another. In literal terms, recruiters are active agents; recruitees are passive objects. In contrast, activists adopted the term outreach to connote the encounter where both parties are engaged. The concept of outreach rejects the militaristic qualities of recruit. Keeping in mind that decontextualizing language from its usage presents the danger of overreaching, the consensus of the term recruit in the literature on clinical trials speaks of a hierarchical feature of study enrollment.

[62] The "bio" in bio-behavioral refers to studies that involve HIV testing; it does not include medication-based studies, which I refer to in this dissertation as AIDS Clinical Trials or ACTs.

How did ACTPOC participants experience these forms of recruitment? Who stood to benefit and who was at a disadvantage within the new economy of peer recruitment and education? Drawing from participant observation of and interviews with ACTPOC participants and staff, Part Three highlights the conflicts, contradictions, and unintended consequences that emerge in daily practices with RDS/PDI. This discussion analyzes how neoliberal ideologies of choice and empowerment 1) disparage the social service and employment opportunities outreach work offers, and 2) conceal RDS/PDI's negative effects and potential harms upon PLWHA in marginalized communities. Finally, as a case study, RDS/PDI offers compelling insights into the effects of market-oriented solutions in public health that produce a "reserve army" of informational labor.

Part One: Outreach Work

Outreach work has a long history of facilitating health care access for people marginalized from mainstream health institutions. Jacqueline Azzarto outlines the rich tradition of outreach to the poor with its origins in the "days of friendly visitors and settlement houses" and other reforms of the Progressive Era (Azzarto 1995:58). Barbara Suczek and Shizuko Fagerhaugh describe the flourishing of outreach in the era of the Great Society where "social and governmental agencies sent workers into the field to discover and provide assistance to persons who cannot or who will not…locate and make use of the services available to them" (Suczek and Fagerhaugh 1991:162). In the 1960s, federal grants supported the creation of a corps of community health workers across the United States whose work expanding access to health care to underserved communities was deemed successful (Witmer et al. 1995:1055). HIV/AIDS outreach is also modeled upon a project that was developed to respond to the explosion of heroin use in Chicago during the 1960s. The "Indigenous Leader Outreach to IV Drug Users"[63] hired former heroin users to reach out to current heroin users in Chicago's drug market to encourage methadone maintenance, as well as to track heroin "outbreaks" [Needle et al. 2005:S46 (Hughes, 1977)].

The institutionalization of outreach workers to support and extend existing HIV prevention methods facilitates numerous positive effects in reducing disease transmission and promoting health and safety.[64] Outreach offers the advantage of

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[63] NIDA's "Manual to Reduce the Risk of HIV and other Blood-Borne Infections in Drug Users" offers a section on "Advantages of Indigenous Outreach Staff" that states "Community-based outreach to prevent HIV/AIDS among out-of-treatment drug users is typically conducted by individuals who are familiar with the drug use subculture and indigenous to the target community" (2000:19). I find the language of indigenous to describe the affinities often shared between outreach workers and clients to be problematic for a number of reasons. First and foremost, this use enervates the historical and political meanings of this language for dispossessed groups, such as Native Americans. I also question whether the language of indigenous is appealing in part because it 1) aligns outreach workers with racially marginalized groups (perhaps the least paid and under-recognized work in bureaucratic health institutions); and 2) deskills the challenges, experiences, and accomplishments of indigenous staff through the use of an identity label.

[64] The problem of developing appropriate interventions for illicit drug users was due in part to the organizing structure of the NIH and its distribution of funding. HIV/AIDS was designated as a health problem/infectious disease, despite that sharing syringes were identified as a risk of HIV transmission. NIAID had no formal relationship to NIDA until well into the 1980s. Many drug treatment programs also followed this model and were slow to integrate HIV prevention education. Moreover, many drug treatment programs promoted a model of abstinence that eschewed hard reduction approaches such as needle exchange.

addressing the range of complex needs that both add to and are exacerbated by HIV/AIDS. Although the definitions of outreach work in HIV/AIDS vary, an important feature is its adaptation to the needs of clients and their social contexts. Outreach work often rejected the traditional "client/provider" role to recognize multiple forms of expertise among users, an approach especially valued among people in need of HIV/AIDS information and support, yet frustrated with the myopic vision of public health to "Just say no" to drugs and to "Use condoms" irrespective of the challenges of doing so[65]. Aware of the powerful barriers that limit indigent IDUs' access to services, outreach workers arranged support and brought resources directly to them in various settings such as shooting galleries, sex work districts, and homeless encampments. Gerry Stimson et al. note, "Outreach was conceived as a means to reach out the people within their own communities or local settings, outside of the usual service settings" (1994:1603). While outreach work is adaptable, at its core is its face-to-face service delivery (Johnson et al. 1990:199).

The success of outreach programs is summarized in Richard Needle's analysis that "Evidence from more than 40 studies and additional unpublished reports indicate that community-based outreach reaches hidden populations vulnerable to HIV" (Needle 2005:S54). Needle's meta-analysis, along with numerous other studies have shown that outreach workers have contributed to reducing the transmission of HIV

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[65] See Kane and Mason (1992) for a discussion of risk behaviors as "interrelated survival techniques" (1992:220).

(Newmeyer 1989:3131); provided supportive care for people living with HIV/AIDS (Cabral et al. 2007); and facilitated broader access to drug treatment and other health services (Coyle et al. 1998). Some note a broader potential for HIV/AIDS outreach that expands individual-level interventions to include how "risk environments" are a result of social and political-economic changes such as forced migration and policing strategies (Rhodes et al. 2005). Outreach workers have contributed to a number of broader environmental and systemic changes that includes the establishment of safer injection spaces and syringe exchanges, the decriminalization of drug use and sex work, and opposition to police harassment.[66]

Outreach work is efficacious in supporting marginalized communities to reduce HIV/AIDS, Hepatitis C, and other harms and to promote health, but is not always easily measured according to conventional research instruments and/or outcomes. Serena Rajabiun et al. point out that the standard brief evaluations of interventions, which typically examine outcomes over the period of a few months, fail to properly capture

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[66] It is beyond the scope of this chapter to describe the adaptation of outreach work in HIV/AIDS in the detail it deserves, and therefore this brief review focuses on agency-based outreach, as this is the target of Broadhead and Heackathorn's criticisms. But suffice to say that this kind of support owes much to its origins in activist and informal community settings. For example, the first publicly advertised syringe exchange in San Francisco, which was organized by a group of activists that included both former and current syringe users as well as non-injectors. These activists brought packages of sterile needles and hazardous waste boxes to users who would exchange a used syringe for a new one, and would also be offered other items such as condoms, sterile wipes, and cotton to reduce the likelihood of abscesses and blood borne diseases such as Hepatitis C. These syringe exchangers knew where users were and reached them through shared social networks and familiar geographies. The goal for "activist providers" working with the exchange was to take on the role of "knowledgeable allies" and not reproduce the hierarchies and stigma that routinely denied injectors access to information, health care, and life-saving tools (Clark, Downing et al. n.d.). Long before biological advances aided in understanding HIV transmission, users themselves offered support and education to each other to minimize risk. A study showed risk reduction among groups of injectors in the Haight Ashbury district of San Francisco in the early 80s (Black et al. 1986:447) and in New York City, safer injecting behaviors and related activities first emerged in the "grass-roots, micro-social actions of many IDUs themselves" (Friedman et al. 2007:109).

the incremental yet significant changes that result. Drawing upon findings from their qualitative study of HIV-positive homeless participants and the outreach workers that served them, Rajabiun et al. demonstrate that considerable time and resources were required to form and sustain these partnerships that proved to be critical to their care (Rajabiun et al. 2007:28).

Similar studies support that outreach workers' effectiveness stem in part from the relationships they build with people, which integrate HIV/AIDS within a broader set of overlapping concerns (also suggesting that information alone is not enough to support change, a point that is explored in more detail in the discussion on the Peer-Driven Intervention or PDI later in the chapter). In his analysis of the Community Health Outreach Worker (CHOW), Eric Margolis states that:

> CHOWing in the Tenderloin is not simply a matter of handing out bleach and condoms. In order to establish the reputation of trust to make the educational message believable, CHOWs work to be 'neighborly.' They do what they can to intercede on behalf of their clients in their relations with the social service agencies that control and circumscribe their lives—housing, food stamps, detox programs, medical and legal systems, and so on (Margolis 1990:389).

A.C. Tomasello et al.'s study also found that the "caring reciprocal relationships" outreach workers developed with HIV-positive homeless persons led to greater access to and engagement with medical care (A.C. Tomasello et al. 2006:915). In a study of HIV-positive people of color that had dropped from medical care or had never accessed care following their diagnosis, Fred Molitor et al. concluded that the time and trust outreach workers developed were crucial factors for linking people into care. "It was not uncommon for a number of contacts to occur before the [outreach] worker referred a client to services. Establishing trust and making a proper assessment took time, and not all clients were willing to consider enrolling in needed services right away" (Molitor et al. 2005:409). Afsaneh Rahimian and Alfred Pach's ethnographic study of the Community Education Outreach Project showed the necessity of addressing HIV/AIDS holistically, suggesting its utility beyond how service is typically defined in institutional public health.

> Soon outreach workers discovered however that the IDUs and others they serve often face many barriers to healthful living and that at least some of these barriers must be addressed for meaningful HIV risk reduction to occur. As outreach workers began to help IDUs obtain housing, drug treatment, medical services, financial assistance, and the like, they began to realize that for many IDUs they have become important and increasingly trusted resources (Rahimian and Pach 1999:1999).

Given sufficient training and ongoing support, a flexible orientation, and a nonjudgmental approach, Nancy Stoller states that experiences of and/or familiarity with illicit drug use, homelessness, and incarceration are often beneficial to this work (Stoller 1998:131). Richard Pates and Virginia Blakely note that "indigenous workers" possess unique qualities that are of significant benefit to HIV/AIDS prevention, such as "knowledge of the culture and environment, and of access to groups who are often difficult to contact" (Pates and Blakely 1991:131). Some organizations hire active drug users as outreach workers, noting that their knowledge of and experiences in drug scenes helps to reach individuals that may otherwise be overlooked (Needle et al. 2005:S54). Outreach workers offer valuable knowledge that, "alert other program staff to changes in the drug use subculture that may influence the local epidemic" (NIDA 2000:8).

As noted in Chapter two, scholars have noted that the professionalization of HIV/AIDS support and care unwittingly reinforce the social inequalities that drive transmission. For example, many of the nonprofit agencies initially developed by activists now form bureaucratic entities that place undue demands on clients, only hire staff that possess advanced degrees, and reproduce evidence-based knowledge (to the exclusion of other kinds). The outreach worker position remains an (exceedingly rare) exception, as it generally employs people with considerable life experience but who in many cases do not possess advanced degrees. While guidelines for outreach are in place, outreach workers are not expected to follow standardized intervention manuals, as is the case for staff hired in the CDC Diffusion of Evidence-Based Interventions (DEBI) Program.[67]

"Hard-to-Reach" in HIV/AIDS Biobehavioral Studies/Recruiters

With the advent of HIV/AIDS, the concept of "hard-to-reach" was mobilized primarily to describe illicit drug users who were assumed to be indifferent to their

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[67] Evidence-based interventions are the topic of Chapters five and six.

health, though it eventually became a catchword to denote sex workers, transgendered persons, and some gay, bisexual, and MSM who typically did not seek out or lacked access to HIV prevention and support services. As discussed earlier, categorizations of "hard-to-reach" and "hidden populations" implied they were isolated from and resistant to the agencies that were charged with serving them.[68] While this term may tell us little about the people who are labeled as such, it speaks to the distance that separates social service agencies and the communities they are charged with serving. Rejecting the hard-to-reach label many researchers used to describe the people they sought to recruit into their HIV/AIDS studies, Claire Sterk-Elifson proposed it be replaced by the phrase "different-to-reach" and called upon researchers to adopt alternative methods such as outreach to connect with drug users whose illegal activities may place them outside traditional information channels (Sterk-Elifson 1993:63). Sterk-Elifson also notes that outreach workers' ability to listen, develop trust, and discuss

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[68] It is a bit of a contradiction that the most marginalized substance users are often *most* in public view (and would then be less "hard-to-reach"). White middle-class cocaine users have significant advantages that enable them to conceal their substance use and minimize potential harms their drug use may bring to their lives. With enough money, users can forego purchasing drugs on the street and thus avoid the police surveillance that is central to the War on Drugs. White middle-class cocaine users are not the victims of racial profiling, which means they are less likely to be subject to unwarranted stop-and-searches where their drugs may be discovered. Privileged cocaine users have access to private spaces in which to use illicit drugs, such as bar bathrooms, offices, private clubs, or their own homes. Treatment programs may be available to them through health insurance, and if charged with cocaine possession, they are less likely to face stiff penalties such as prison time due in part to the racially motivated differentials in sentencing—which is especially compounded by the lighter sentencing for cocaine possession (as opposed to a modified version of cocaine, crack, which brings a much heftier sentence). Moreover, if charged with the crime of possession, middle-class cocaine users will be able to hire their own attorneys who will have time to become familiar with and prepare their case. They will not have to rely on extremely overburdened court-appointed attorneys who may juggle dozens of cases and pleas simultaneously. If treatment is mandated, privileged users will have the opportunity to pursue private rehabilitation and not be mandated to the Treatment Communities (TCs) that limit their movement, extend the arm of punishment, and enforce rules and practices that are largely dehumanizing.

sensitive topics led many PIs to expand their outreach and recruitment roles to formalize their contribution to ethnographic research (ibid.). Suczek and Fagerhaugh note that HIV/AIDS outreach workers train themselves to be "close observers and to develop methods for collecting accurate ethnographic and statistical data from the field for the furtherance of the research that provides funding for their work" (Suczek and Fagerhaugh 1991:169). Cunningham-Williams et al. conducted a study in three major cities that illustrates the effectiveness of outreach workers' efforts to recruit active cocaine and heroin users in HIV prevention research (Cunningham-Williams et al. 1999:7).

In addition to the positive benefits outreach workers contributed to researchers and the people they served, these positions offer important opportunities for the people hired to conduct them. Jane Simoni et al. describe the contributions of Project STAR's interviewers, all HIV-positive women who lived in the communities that were the focus of their study, who recruited participants more effectively and served as an internal community board to the study (Simoni et al. 1999:87). Project STAR benefitted as a result of their labors, and so too did the interviewers themselves, as Simoni describes the value they placed on the training, work experience, as well as sense of accomplishment (ibid.)

Part Two of this chapter describes the theories and operations of RDS/PDI. It contrasts these features with the kinds of support and engagement outreach workers offered, which are formally absent in the RDS/PDI method.

Part Two: RDS/PDI

In 1995, Robert Broadhead et al. published an article titled "Drug Users vs. Outreach Workers in Combating AIDS: Preliminary Results of a Peer-Driven Intervention." It was followed in 1997 with Douglas Heckathorn's "Respondent-Driven Sampling: An Approach to the Study of Hidden Populations." Briefly, Respondent Driven-Sampling, or RDS is a form of research subject recruitment whereby study subjects recruit their peers through a coupon referral system.

Broadhead and Heckathorn's publications launched a major shift in how HIV/AIDS biobehavioral researchers recruited participants into their studies. Prior to RDS/PDI, most of the recruiting of participants to HIV/AIDS biobehavioral research—and in particular those studies that sought to enroll people that bore the label of "hard-to-reach"—were conducted by outreach workers. Robert Broadhead and Douglas Heckathorn claim that their methods offer significant advantages to hiring outreach workers, citing improvements in sampling strategy and reduced costs.

Drawing from textual analysis of the seminal articles on RDS/PDI and a review of the small but promising empirical studies of these methods, this section uncovers the assumptions that fuel Broadhead and Heckathorn's overstated claims. It asks: What can the redefinition of research recruitment tell us about changing social relations of researcher and researched? What effects do these methodologies produce beyond their intended goals? I examine these questions in relation to RDS/PDI with a focus on these four areas: 1) *Sampling* examines the distancing strategies RDS utilizes to obtain a representative sample; 2) *Dual-Incentive Structure* counters the assertion that RDS trumps outreach, which grossly mischaracterizes the latter; 3) *Peer-Driven Intervention* analyzes the theoretical underpinnings of this educational model; and 4) *RDS & Outreach* examines how RDS/PDI's mischaracterization of outreach work give support to Broadhead and Heckathorn's neoliberal arguments regarding RDS/PDI's benefits in the areas of cost savings and elimination of health resources. First, a brief overview of some of the features of RDS/PDI and their operation in ACTPOC introduce Part two of this chapter.

Brief Overview of ACTPOC & RDS

ACTPOC followed the tenets of RDS/PDI described by Broadhead, Heckathorn, and their colleagues. The ethnographic snapshot that began this chapter introduces the third and last group of the ACTPOC intervention, where participants received three coupons with instructions to distribute to their peers who might be interested in and eligible for ACTPOC. Peers recruit peers, and successive waves of recruitment continue until the ACTPOC's enrollment goal was reached. A small stipend of $15 was promised to participants for each new recruit enrolled in the project (for a maximum of three participants). These peer recruitment and education activities were short-term; each coupon had to be redeemed within a 30-day window from the date the ACTPOC participant received it, and no further coupons could be obtained. Physical possession of the coupons is of primary importance in RDS—lost coupons cannot be "voided" and replaced. At the beginning of the research visit, the peer who was recruited must present the coupon they were given; otherwise, the appointment is terminated and the person is told they can reschedule but must have coupon in hand. However, simply being in possession of the coupon does not guarantee eligibility. If the coupon-holder is found to be ineligible for the study the recruiter does not receive any of the incentive, nor can they obtain the original coupon for redistribution to another potential participant. To protect confidentiality, RDS coupons are assigned unique serial numbers that correspond to the recruiter, which are used to track the money (if any) the recruiter is owed for the peers that enroll.

The Peer Driven Intervention, or PDI often accompanies RDS activities, as it did in ACTPOC. The vignette that opened this chapter offers an example of RDS/PDI that I documented as part of my participant observation of ACTPOC groups, which briefly describes the training ACTPOC participants received in how to recruit their peers to the project and teach them the ten true/false statements about ACTs. In PDI, the recruiters also received one dollar for every one of the ten true/false answers their recruitees answered correctly at their baseline interview (for a maximum of $30 if all three recruits answered each question correctly). Participants' labors recruiting peers and educating them yielded them an amount that ranged from $0 to $85.[69]

RDS: 1) Representative Sampling

What is the basis for researchers' claims that their findings are not unique to the individuals they studied, but are reflective of larger patterns? RDS is said to offer a significant advantage to the researcher attempting to conduct a representative sample for which "no sampling frame exists" (Heckathorn 1997:174). Unlike existing sampling procedures, such as targeted sampling, which purport to estimate "hidden" populations, Heckathorn argues that RDS achieves a truly "representative" sample in its modification of a chain-referral procedure to produce a sample independent of the original subjects (Heckathorn 1997:183).

However, the concept of representativeness promulgated by RDS is by no means universal[70]. To illustrate this point, I contrast RDS with the sampling methods that were

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[69] Participants also had the option of not recruiting at all, in which case they could return all three coupons at their one-month follow-up and receive $15.

[70] Representativeness did not always mean random, a concept that did not take hold in the statistical domain until the late 19th century. Ian Hacking states "Most professionals now believe that representative sampling gives more accurate information about a population than an exhaustive census. That was unthinkable during most of the nineteenth century" (Hacking 1990:6). Hacking's historicization of the concept of representativeness encourages us to consider these concepts not as the timeless truths they are often purported to be, but to explore them as epistemologies distinct to certain worldviews. Talal Asad notes that a major shift in the development of modern statistics took place when probability sampling was introduced. Statisticians of the late 19th and early 20th centuries who used purposive (average) sampling methods were initially quite wary of the introduction of (probability/random) sampling (Asad 1994:71). In their efforts to construct representative samples through purposive sampling, early statisticians depended on notions of the average and "ideal types" (ibid.). Social interaction and activity were necessary to determine what persons fit the "ideal type" that statisticians would study to form generalizations about the whole, a decision that Asad describes was based in part on statisticians'

used to develop some of the earliest HIV/AIDS epidemiologic research of IDUs, which involved the labor of outreach workers (later in the chapter I show how RDS/PDI disparages outreach work in favor of a coupon economy). Rather than evaluate these methods in terms of their claims to representation and generalizability (an important inquiry)[71], this section explores the distinct epistemological orientations that frame representative and targeted sampling, which reveal conflicting worldviews regarding the study of stigmatized activities, knowledge of marginalized communities, and the professionalization of research.

Targeted-Sampling

As the relationship of injection drug use (IDUs) to HIV/AIDS transmission gained ground as a scientific and public health concern in the 1980s, there was discussion among researchers regarding sampling. Although there had been a long tradition of studying drug users as a largely "captive" population (those enrolled in treatment or incarcerated), many researchers felt strongly that this approach would overlook and misrepresent the HIV prevention needs of IDUs who were not in these

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"experience and intuition" (ibid.). Random sampling came to be seen as more reliable, Asad argues, when it made a "conceptual break with territoriality" (Asad 1994:74). In other words, the advent of probability theories that did not seek to eliminate chance meant that knowledge of regions and other social contexts were no longer required to conduct statistical activity. The representative sample, which had been viewed as a "microcosm" of the whole, was abandoned with the adoption of stratified sampling, which operated "according to *a priori* divisions of the (national) population" (ibid.). Whereas earlier statistical research necessitated face-to-face interaction, the random sample rendered this kind of encounter irrelevant. "The solution to the problem of representativeness did not depend on complete and certain knowledge of the entire geographical area under investigation. It was precisely uncertainty with which probability theory was designed to deal" (ibid.).

[71] See Heifer (2005) for discussion that questions the assumption that RDS produces random samples.

settings. But the stigma and criminalization of injection drug use meant that no sampling frame existed, which created a problem for these studies' claim that their findings could be generalized in order to address the HIV prevention and other health needs of drug users. In describing one of the first HIV/AIDS studies of IDUs in which they sought to identify the social organization of injectors' risk activities, John Watters et al. underscore the stakes involved in their selection of sampling strategy. They declare, "the problems of sampling difficult to study populations are not trivial and could impact public health policy developed to control the spread of AIDS in the United States" (Watters et al. 1989:418).

Watters and his team developed a plan of targeted sampling to reach IDUs not in treatment that included ethnographic mapping, the use of secondary data (such as number of overdoses in a particular area), and chain referral sampling. Outreach workers played an integral role in these mapping efforts as well as in the recruitment of IDUs into the survey. The aim of the ethnographic mapping was to study injection drug use and related activities across various neighborhoods they had selected. To do this, outreach workers and other research team members observed street activities and engaged in numerous conversations with a cross-section of inhabitants that included IDUs, clerks at single-resident occupant (SRO) hotels, store owners, drug purchasers and sellers, and the police (Watters et al. 1989:421).

Targeted sampling strategies have facilitated researchers' access to and study of "hidden populations" in HIV/AIDS research. In their examination of how they prepared for recruiting an "at-risk" sample of African Americans for an STD/HIV study, Chandra Ford et al. underscore the importance of simply "hanging out," which enriched their understanding of the communities they hoped to reach (Ford et al. 2007:179). In addition, through their project's visibility and involvement with the community, the researchers learned about existing efforts related to their long-term goal of developing an HIV intervention, and also exposed them to additional concerns not directly related to HIV/AIDS (Ford et al. 2007:181). The time and cost involved in these efforts led to their visibility in and reinforcement of their commitment to the community at large. This legitimacy, the authors note, was important not only for the more immediate goal of participant recruitment but also helpful for future plans to disseminate their research findings to improve HIV education and treatment access. Wayne Wiebel proposes that research projects attain some form of stability and presence in the areas they study, and recommends that researchers consider renting storefronts and employing neighborhood residents (Wiebel 1990:10). Robert Carlson et al. agree that these sampling strategies are time and labor-intensive, but conclude that this investment is necessary. In their description of a modified sampling strategy they used to identify and recruit crack-cocaine users and IDUs, Carlson et al. note that the success of their plan depended upon the employment of and collaboration with knowledgeable outreach workers, as well as the research team's overall familiarity with the region. The authors note, “The fact that most of the outreach workers who participated in the development of the plan had been working with us on a previous project, affirms the value of building long-term relationships and conducting extended field research in a regional context” (Carlson et al. 1994:285).

The sampling mechanisms of RDS are quite different from targeted sampling efforts. RDS involves the identification of a few initial “seeds” (which, in ACTPOC’s care, was undertaken by several HIV/AIDS service providers selected by the researchers) from which the waves of recruitment originated. As Greg Scott points out in his ethnographic analysis of RDS, “The participant, rather than the researcher, maintains responsibility for study participation” (Scott 2007:43).

If, as Ian Hacking suggests, statistical concepts are intimately tied to notions of what a society is (Hacking 1990:7), then what forms of social life do RDS and targeted sampling bring into being, and how are each different? Two themes emerge that illustrate the ontological differences between RDS and targeted sampling that I will attempt to summarize here: the role of the researchers; and the identification and definition of social phenomena.

Role of the researchers

In targeted sampling, researchers are more likely to be invested with the communities they study, through the visible storefronts, conversations with community residents, hiring of residents, and building relationships with the community-at-large. This level of presence allows community members to enter into dialogue with researchers regarding their ideas, concerns, suspicions, and more (as was the case with Ford et al., 2007). RDS does not propel researchers into these kinds of relationships, which Edward Trickett proposes are necessary to engage communities in interventions (Trickett 2005:23). They must only be present at two points: when the first wave of seed coupons are distributed and then again (indirectly) at data collection, when the research participant meets with the Research Assistant to submit their coupon and complete surveys.

Definition of social phenomena

In addition to the various researcher roles these methods employ, they also indicate contrasting ideas in identifying and defining social phenomenon. HIV/AIDS researchers have used targeted sampling methods to develop more expansive views of the phenomena they study, allowing them to go beyond documenting behavior or even practices to analyze these phenomena relationally. Philippe Bourgois' methods of researching the crack economy and the position of (predominantly) young Puerto Rican men working in the lower-ranks of it entailed time hanging out, observing, and taking part in community and neighborhood activities. These experiences allowed him to see the crack economy as part of a larger pattern of structural violence that occurred in relation to the social abandonment of East Harlem by New York City and the flight of union employment to the un-unionized Global South. RDS requires no such view.

The possibility for uncovering important links and including them in a sampling frame would be one example of how targeted sampling could introduce new avenues of inquiry, and further refine the research project's focus. As Watters et al. notes, "data are constantly analyzed and used to adjust the recruitment and sampling techniques" (Watters et al. 1989:421). If targeted sampling yields for example, very few Blacks in a Black neighborhood, this might lead to researchers' interrogation of their research premises and/or call their attention to the urgent issues this group faces that take precedence over research participation. On the other hand, RDS researchers can forego such engagement with critical issues like racial inequality and intersecting systems of power that shape the production of social scientific knowledge. In the absence of structural location, race is reduced to one variable among many; the labor of recruiting Blacks is ostensibly left to research participants. Broadhead and Heckathorn state, "a PDI offers a built-in accommodation to the cultural diversity in the user population: with IDUs accessing their peers, the recruitment effort is always couched in culturally appropriate terms for each subgroup" (Broadhead and Heckathorn 1998:55). The interconnected contexts that shape behaviors seem to be overlooked in RDS, where the social organization of groups is reduced to an aggregate of individuals.[72]

RDS. Part Two: Dual-Incentive System

In RDS, the dual incentive structure refers to the potential gains by both parties in the coupon transaction. The research participant stands to earn a referral fee for the peers they recruit; potential peers could gain access to a study where incentives are given for their participation. Heckathorn states that RDS and its "dual-incentive" system overcome the bias present in other sampling methodologies that favor "cooperative subjects" (Heckathorn 1997:179). Heckathorn states, "Individuals who resist field researchers' appeals may nonetheless yield to appeals from peers motivated, at least in part, by secondary incentives. Even the least cooperative individuals are not immune to social pressure" (ibid.). Heckathorn's suggestion that the participants who express disinterest to field researchers may respond to recruitment pressures via their social ties ignores the fact that institutionalizing "social control" seems to abrogate the minimum ethical requirement expected of researchers working with human subjects: a lack of coercion. Heckathorn not only dismisses how such forms of social pressure affect participants' social networks, but also neglects the problems that unfold when the

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[72] In his historical analysis of study design in psychology, Kurtt Danziger argues that a random selection of individuals came to be seen as representative because they were viewed as a *population* where their various histories, social relations, and other features could be controlled by random assignment. As a result, complex social groups became devoid of internal structure (Danziger, 2000:345).

peer recruiter is faced with *demand* for coupons, where the stakes are often escalated and the repercussions of social control intensify.

Greg Scott's ethnographic investigation into the use of RDS in a surveillance project of IDUs in Chicago indicates that the "dual-incentive structure" (and several other features of this method) produced troubling results. Scott illustrates how coupons stratified relations of dominations among coupon-holders (and people without coupons). And while RDS guidelines state that coupons are not supposed to be sold, they often are. Instead of distributing coupons to peers and receiving the referral fees from the research staff, some coupon-holders build an additional incentive into the system by selling coupons to peers and collecting referral fees. Scott takes note of these individuals' efforts to double the cash they stand to make along with others who work hard at recruiting, but for who no monetary benefit results. An example of the latter would be recruiting peers who turn out to be ineligible, or tracking down peers who take the coupon but don't complete their appointment, or are deemed ineligible to participate. This volume of work may yield very little results, in which case no compensation is given.

Scott learned that the pressure to participate in RDS was sometimes accompanied by threats, such as dealers withholding drugs for sale and preventing access to shooting galleries (Scott 2008:48). He also witnessed intimate partner violence, and narrates an experience where one woman's boyfriend verbally abused and threatened to punish her if she did not redeem her coupon or gives him the $10 recruitment bonus he felt he was owed (ibid.). As Scott points out, these and other forms of domination he observed existed prior to the creation of a coupon economy. However, the demand for the coupons—combined with their scarcity—reinforced existing hierarchies in problematic ways and exacerbated the potential for harm (as will be discussed in more detail in the next section, which describes ACTPOC participants' experiences with RDS). It also gives pause to reflect on the ethics of well-funded research studies that create economies of exchange where the stakes are high for participants, and they must compete with each other for them. What if these well-funded studies circulated a number of coupons that was more appropriate for and better suited to the community's needs?[73] What if coupons were not so scarce? Coupon distribution results from researchers' sample size and statistical power—they has little if nothing to do with the impact coupons make upon participants' social relations and their networks—connections that are often crucial to their survival.

Response to Scott

Scott's nine-page article was met with a thunderous response by Broadhead, Heckathorn, and other RDS proponents. The primary critiques of Scott's article are

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[73] Of course, public health research studies also suffer under neoliberalism and the contraction of the social compact. Regardless however research studies are well resourced in comparison to the people they often study.

centered on what his critics describe as a "flawed" methodology (Oullet et al. 2008), buttressed by claims that his ethnographic sample of informants was not "representative" of the study population[74] (Lansky et al. 2008). Broadhead even responds to Scott with a racialized epithet of sorts, "But his findings are all refried beans" (Broadhead 2008:236).

A great deal of response towards Scott's ethnographic findings was the insistence that RDS did not create these problems—a point that Scott himself makes clear. Broadhead claims these problems of "kickbacks" are not unique to RDS, but are present in other recruitment methodologies, such as chain-referral sampling (Scott 2008:235). That the problems Scott raised are present in other recruitment methodologies is used to legitimize the problems with RDS, rather than call into question the ethical problems of *all* these recruitment methods. In a rare rejoinder, several of the study's funders, including the CDC, chimed in to assert that the study in which RDS was used followed all required human research protections. Drawing upon generic bureaucratic language, the funders stated, "None of the local IRBs raised questions about the peer recruitment process" (2008:241); "all participants provided informed consent" (ibid.); and that the three coupon maximum allowed participants was a safeguard "to prevent coercion" (2008:242). While on the surface, these comments may not seem to offer much more than the standard rhetoric, in actuality, they are *very* revealing in their illustration of the

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[74] Scott himself points out that his decision was to focus only on successful recruiters, and notes this focus does not capture what are likely to be a range of experiences of RDS.

paucity of neoliberal notions of coercion and consent—a point that will be further explored in the conclusion.

RDS Part Three: Peer Driven Intervention Training (PDI)

In addition to the training participants undergo in RDS to recruit potential participants into ACTPOC, they also receive instruction in PDI. Paired with RDS, PDI is a process whereby the recruiter educates a peer by disseminating a series of statements. Upon enrolling in ACTPOC, the recruited peer is asked true/false questions about ACTs; for each correct answer, the peer's recruiter earned one dollar.

In ACTPOC, the PDI consisted of ten statements about ACTs. One of the ACTPOC group exercises involved participants learning and practicing these ten messages as part of their preparation to educate potential participants. It is explained they will receive one dollar for every statement the peers they recruit answer correctly.

ACTPOC MAIN MESSAGES CARD: TRUE or FALSE

1. **AIDS Clinical Trials study the newest treatments available.**
2. **Screening is a discussion to see if an AIDS clinical trial is right for you.**
3. **Screening does not mean joining a trial.**
4. **AIDS clinical trials can treat other health problems such as Hepatitis C.**
5. **People who use drugs or alcohol can participate in AIDS clinical trials.**
6. **Even if you never took anti-HIV medications, AIDS clinical trials can still help you.**
7. **People who feel good still get screened for AIDS clinical trials.**

8. **You don't have to change your current treatment to participate in AIDS clinical trials.**
9. **Every year thousands of women and people of color join clinical trials.**
10. **More women and people of color are needed to AIDS clinical trials.**

The information taught in this exercise is compensated only if it is reproduced, not if it is challenged with a response that goes beyond or contradicts the True/False model. In selecting one unambiguous answer, either true or false, participants must orient or even subordinate themselves to a particular knowledge system, one that erases opposing forms of knowledge and counter-views. The format of the PDI arranged in these ten true/false statements would seem to contradict a key argument of support for RDS, which claims its ability to help people be "active and individualistic, not passive and dependent" (Miller, 1993).

These ten statements, along with the true or false designations that accompany them, are fairly quick to administer and are easy to test. For example, the statement "People who use drugs or alcohol can participate in AIDS clinical trials" conveys that drug users are not categorically excluded from ACTs—an exclusion that was routine earlier in the epidemic. This statement is helpful in promoting the growing awareness that drug use itself does not automatically make people ineligible for ACTs. However, the actual history of ACTs' recruitment of people that use drugs and alcohol illustrates the predicament of a true/false designation of complex phenomena. The brevity of the

"People who use drugs and alcohol can participate in AIDS clinical trials" works on the level of communicating uncontested information in an easier-to-digest snippet, but the complex phenomena this statement indexes is obscured by it.

An example of this occurred one day when I was conducting ACTPOC's baseline survey interview with a participant who had been recruited into the study by their peer. I read the first four true/false statements about ACTs out loud and recorded each of the participant's responses into the computer. When I read the fifth statement, "People who use drugs and alcohol can participate in AIDS clinical trials" and asked her, is that true or false, she replied that it would depend—what kinds of drugs? How much alcohol? I did not respond to her questions. Following the guidelines for conducting interviews, I evaded her question by asking, "So are you saying that it's true or false? You also have the option of saying 'I don't know' too." I tapped the key with the one word response she offered gave, "False" and continued to read the remaining five statements to her. Similar criticisms could be applied to several other statements that appear on this list such as, "AIDS clinical trials study the newest treatments available"; "Screening does not mean joining a trial"; and "More women and people of color are needed in ACTs." These statements do not acknowledge the profit-driven agenda of pharmaceutical (including academic) medication development that has shaped the drive to develop "race-based" medicine as a potential solution to health inequalities. Likewise, the language of "treatment" overlooks the experimental nature of the drugs under study, and "newest treatments" may refer only to smaller changes in drug design.[75]

The structuring of these phenomena as true or false foreclose participants' opportunities to engage with these topics of medication development and racial disparities in HIV/AIDS as interlocutors and critics. The ideologies that underpin these true/false statements uphold biomedical expertise and dismiss the growing public awareness of and deepening concern towards the politics of profit-driven medication development. The ACTPOC discourse circulates participants into the role of laypeople who are expected to consume, not challenge, the knowledge of biomedical experts. Heckathorn offers an example of a PDI-statement that was used in a study of IDUs, which conveys a position of this abstract, top-down expertise. It states, "Rule #1: Never discard your set of works unless you know you have a fully functioning, clean replacement" (1995:544). What appears as a deceptively straightforward statement is in actuality a much more complex phenomenon. For example, Hannah Cooper et al.'s qualitative investigation of a police crackdown and its impact upon HIV risk led many residents to not carry their works for fear of arrest (Cooper et al. 2004:680). David Moore concurs with the potential of delivering statements independent of context in his

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[75] Of course, changes that appear small may indeed have significant effects for the people who take them—developing medications that involve fewer pills is important. Nevertheless, the description "newest" treatments also overlook the purpose of some trials to retest drugs in order to extend patents—and profits. See Angell, 2004.

argument that the "stability and orderliness that is assumed in guidelines for safer injection may in fact be harmful"[76] (Moore 2004:1550).

It has been widely shown that the concept of information, in and of itself, is not enough to address the multiple burdens that shape HIV risk. These PDI statements are insufficient at noting the complexities regarding medication development, the growing mandates to enroll women and people of color in ACTs, and the nascent markets and marketing budgets for race-based medicine. In ACTPOC's case these ten PDI statements socialized participants into a hierarchy of knowledge, where their roles were to consume information and follow the lead of experts, leaving them little opportunity to question the assumptions and underpinnings of clinical trials, access, and racialized disparities in HIV/AIDS.

RDS Part Four: Mischaracterization of Outreach Work & RDS

The appeal of RDS/PDI and its purported advantages in research recruitment and sampling support the overall theme of this dissertation, which is that ACTPOC is part of the broader neoliberalization of public health. RDS/PDI seeks to replace health service jobs (in this case, outreach workers) with market strategies that promote entrepreneurial identities among poor people. It fuels the broader impetus to

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[76] "True/false" statements about HIV/AIDS may work in some settings—for example, a list of statements to supplement HIV/AIDS 101 groups that include statements such as "HIV can be transmitted through breast milk" or "You can get AIDS from a toilet seat." But assigning true/false value to behavior independent of its contexts that shape its meanings and risks and dangers—such as syringe possession in a society that marginalizes drug users—seems misdirected, at best.

professionalize research and intensifies the view of health intervention as abstract, top-down knowledge. RDS supports neoliberal ideologies of welfare reform, which seek to “enfranchise the poor through the market” (Morgen et al. 2003:319) at the same time that the social contract withers. Broadhead et al. present RDS/PDI through the neoliberalizing language of empowerment, a lack of dependency, and an investment in intervention—mixing metaphors of social change and markets. According to neoliberal principles that guide the privatization of public services, Broadhead et al. argue that the coupon economy of RDS outperforms outreach work in sampling, efficiency, and ease of use, and participant satisfaction with and ownership of the process. Broadhead’s claims espouse neoliberal principles that support the privatization of public services, what Cori Hayden describes as “what the state has done the market can do better” [(Hayden 2003:49) Escobar 1996].

RDS/PDI may provide short-term, quick recruitment that produces data for researchers, but is absent of the engaged social relations (or rather created problematic social relations) and service provision facilitated by the outreach worker, who typically brought expertise, knowledge, and experience to the recruitment encounter. Even for outreach workers hired specifically to recruit potential subjects for HIV biobehavioral studies, some degree of support remained—a feature that is absent in RDS/PDI. As Martha Hill et al. note, “The provision of human services on an individual basis may become part of the conduct of community-based research and the investigators may find themselves attending to the community's priorities and needs, even if those are only tangentially related to the research questions" (Hill et al. 2010:229). William Elwood et al. argue that outreach-based research recruitment cannot be done without some degree of intervention, suggesting how it offers potential study participants something besides enrollment in a research study (Elwood et al. 1995:330).

Long regarded as a strength, outreach workers' social ties to the communities they serve are distorted and criticized by Broadhead et al. These seminal articles describing RDS/PDI form unrelentingly negative and overgeneralized conclusions that are based on prior observations they made, but lack further rigorous examination and analysis of these findings (Broadhead et al., 1995; Heckathorn, 1997). For example, Broadhead et al. state, "(S)ome of the credentials that outreach projects looked for in hiring outreach workers are the same kind that often keep people from getting a good job; e.g., a former drug habit, a prison record, socialization to lower class culture, street-smarts about hustles and con jobs, previous gang membership, or a former career in prostitution" (Broadhead et al. 1995:534). Broadhead's views of outreach workers' qualities as deficits not only echo problematic "culture of poverty" viewpoints, but also suggest that outreach workers are a class of "unemployable people" doomed from the start. In his discussion of outreach work hiring practices, Broadhead et al. suggest that simply *needing* a job is an indication of that applicant's unemployability:

> (A)pplicants who respond to job ads do not come from a random sample of all people who are qualified, because most such people are already satisfied with

> their current employment. Instead, most responses come from people who are unemployed or are in the process of losing their current jobs. This group contains a larger proportion of workers with problems in competence or reliability than the applicant pool at large (Broadhead et al. 1995:533).

According to Broadhead, the desire to leave a job necessarily reflects badly upon the worker—these reasons cannot include being laid off or forced out of work, unrelenting demands from management, low pay scale, discriminatory work practices, or even simply the desire to change jobs. Moreover, Broadhead neglects the work ethic and knowledge base that is required to have "street-smarts" as he generically describes it[77]. Outreach workers encounter formidable challenges in the multiple roles these positions require; as Suczek et al. point out, they must negotiate conflicting expectations such as fellow drug users suspecting them of being a narc and staff and supervisors scrutinizing them for signs of relapse (Suczek et al. 1991:169).

Broadhead's reluctance to acknowledge the well documented sources outlining outreach workers' contributions to HIV prevention and health promotion extends to his neglect of the personal risks and other sacrifices outreach workers make on the job. For example, Joann Schulte et al. conducted a study of HIV/AIDS and TB health outreach workers in three Texas cities to find that 16% had experienced physical attacks and/or weapons threats (Schulte et al. 1998:439). Describing the outreach work position in HIV/AIDS, Pates et al. note that, "It seems to demand an exceptional person. Such a

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[77] Broadhead's use of the term "street smarts" gives no distinction to the multiple kinds of "smarts" that outreach requires and the ability to "code-switch" among these various settings requires.

brief may be unrealistic and inappropriate, given the low pay of outreach workers and their present lack of career structure" (Pates et al. 1992:133).

However, far too many studies outlining the numerous benefits of outreach have been conducted, replicated, and published in a variety of peer-reviewed medical and social science journals for Broadhead et al. to dismiss them completely. How then does he reinterpret outreach work to cast it in such negative terms? Unable to dispute the documented decreases in episodes of injection and syringe sharing outreach workers facilitated, Broadhead et al. draw from several sporadic instances of IDUs assisting outreach workers in distributing bleach bottles and setting up information tables to dismiss outreach workers' labors (Broadhead et al. 1995:541). Citing these activities as evidence of "deep involvement" of clients, the authors suggest that RDS/PDI offers IDUs a "more collaborative role" (ibid.). Utilizing the powerful neoliberal ideologies of "responsibilization" in their commentary, Broadhead et al. state that in response to "the inertia" of outreach work, IDUs "went well beyond the role of being mere clients" and that PDI would "enhanc[e] the mutual opportunities and incentives for IDUs to work with their own peers, and to invest themselves in their own intervention" (Broadhead et al. 1995:532).

The authors' disparagement of being "mere clients" dismisses the hard work, conscious efforts, and commitment of public resources these encounters require.[78] Moreover, Broadhead et al. are not the first to suggest that IDUs have been invested in their own care—several studies convey similar perspectives regarding IDUs, their peers, and communities. But these studies' sociological and historical analyses contrast with Broadhead's hastily formed conclusions. One of the earliest examples of this scholarship was conducted by Don des Jarlais et al., who found that even prior to formal HIV prevention, there was "almost universal awareness of AIDS among IDUs in NY and a sustained reduction in needle sharing" (des Jarlais et al. 1985:757). Russell Rockwell conducted a series of oral history interviews with people about their experiences injecting illicit drugs during the mid-70s to mid-80s to reveal a number of ways that people were reducing harm individually and within social settings, as indicated by the transition from long-term, dropper-type syringes that were shared to individual disposable ones (Rockwell 2006). A study of IDUs in the Bushwick section of Brooklyn by Friedman et al. reveals various forms of care and cooperation among IDUs,

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[78] For example, in 1994 I had been newly hired as a case manager at a nonprofit that offered HIV and substance use/harm reduction services to women in San Francisco. In my orientation to and as part of my training for the job, I assisted Anita, a seasoned outreach worker on her rounds around the Mission and Tenderloin neighborhoods. As we traversed street settings, perinatal clinics, and needle exchanges, I saw firsthand the range and depth of outreach clients' emotional and sometimes even physical sacrifices in these exchanges. I can recall the sex workers that nonchalantly palmed the condom and lubricant kits we discreetly passed to them to the handful of "regulars" that greeted Anita and sometimes stopped her to talk. Strangers who knew of Anita would approach her, sick and needing a health referral. Volunteering at the syringe exchange, I regularly saw people experience the initial pangs of withdrawal discomfort as they patiently awaited their turn to discard and retrieve new syringes, and others that created complex organizational systems to exchange hundreds of syringes for neighbors living in their apartment building or SRO. These are just a handful of dozens of examples that illustrate that "being mere clients" involves active, hard work.

as well as to the larger communities in which they are also a part. Describing these efforts (that occur largely outside of though they may be related to public health institutions) as evidence of "collective cultural reinforcement of risk reduction," Friedman et al. propose that public health consider the potential of these allies to model their contributions in funded user groups and/or as paid consultants (Friedman et al. 2004:259). These studies offer insight into IDUs' collaborative role, but unlike Broadhead et al., they do not posit these efforts in conflict with supportive services such as outreach work.

In RDS/PDI, outreach services are substituted with neoliberalizing values of investment and incentive that reject the "provider-client model" to offer "new opportunities for the hard-to-reach IDU" (Broadhead et al. 1995:531). Not surprisingly, the more collaborative role that Broadhead et al. propose does not involve transferring the *resources* of this position, such as a steady paycheck and health care, to the collaborating, deeply involved IDUs.[79] Broadhead's failure to account for this fact reinforces his view of a hegemonic meritocracy where individual motivation—especially that which is amenable to market-based solutions as is the case with RDS—offers the best solution to any number of social problems.

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[79] Broadhead's call for the elimination of jobs in order to save on the costs of providing health care benefits—in the field of health care—carries no trace of irony.

Moreover, Broadhead et al.'s argument is a racially encoded one[80]—as seen in his statement that RDS contrasts with "the traditional model that turns IDUs into clients of, and dependent on, paid staff of outreach workers" (Broadhead et al. 1995:532). In their genealogical reconstruction of the word "dependency" Nancy Fraser and Linda Gordon illustrate how the meaning of this word shifted from an expression of relations of subordination (which did not carry stigma in preindustrial society) to an "inherent property or character trait" (Fraser and Gordon 1994:317) of marginalized racial groups. In the official and public discourse on welfare reform, the language of dependency is a thinly veiled reference to *poor Blacks and Latinos and especially women and mothers* who are viewed as stereotypically dependent.[81] Jeff Maskovsky describes that such calls to eliminate dependency are infused with "a moral and political imperative" (Maskovsky 2001:337)—not unlike Broadhead's criticisms—that serve as a powerful ideological frame in which devolution takes place.

RDS/PDI contributes to—and is supported by—post-welfare "reform" and the further deterioration of a social contract; no longer will IDUs be "dependent" on outreach workers, but instead will become self-empowered subjects. Broadhead's line of reasoning supports what Deborah Lupton describes as the "neo-liberal focus on the

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[80] For example, ideological support for U.S. imperialism was crafted through views that Third World peoples were dependent, unable to govern themselves. With the rise of psychiatry in the 1950s, the language of dependency was further "feminized" in its association with single unwed mothers, who were typified by the psychological register of "immaturity" (Fraser and Gordon 1994:325).

[81] See Ortiz & Briggs (2003) for a thoughtful discussion of how welfare "reform" of the 1990s produced images and narratives of pathological "welfare mothers" as non-heterosexually partnered black, Latino, Native American, and Asian women.

responsibility of citizens to support and better themselves with minimal help from the state" (Lupton 1999:297). The contradiction is that while RDS/PDI claims to foster independence, it actually *reduces* the capacity for participants' involvement. While studies of outreach have shown it to be flexible and adaptable to participants' needs, RDS/PDI propels participants into conducting a stripped-down, standardized version of the labors once undertaken by outreach workers—but with none of the assurances or benefits.

RDS and PDI's calls to eliminate outreach workers and replace them with incentive-based, "cost-effective" models reject the notion that access to health care and supportive services are a basic human right and responsibility of public institutions. The "peer" elements of RDS/PDI offer participants little more than a temporary foothold in a cash-based informational service economy where they are trained to repeat and recite researchers' standardized[82] scripts, as seen in the ten "True/False" statements about ACTs. RDS/PDI participants are caught in this conundrum: they should reject so-called "dependency"—support from resources such as outreach workers—to embrace neoliberal principles of opportunity, involvement, and responsibilization. Yet these same neoliberal advocates reject any responsibility towards this flexible labor force—peer recruiters experience none of the protections

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[82] In ACTPOC, researchers mobilized a "community board" to develop the 10 messages that that forms the core of PDI. "Community members'" participated in developing the messages, the actual format, in which 10 true/false statements are used as the basis of peer education, are drawn from PDI and are researcher-driven.

labor and union organizers have achieved for workers over the decades, nor do they experience its benefits. And, RDS/PDI's treatment of peer recruitment as uniform bits of "piece-work" presents a level of risk for the temporary laborer, who stands to earn nothing if peers do not cooperate—or in some cases, incur awkward obligations if they do.

The language of "peer-driven" and "respondent-driven" conceals how participants' decision-making processes are limited to whether they chose to conduct these recruitment and education activities or declined to do so. In ACTPOC, participants' autonomy did not extend to the ability to develop and define the conditions of their involvement, whether that was determining coupon availability, establishing who would be eligible, or crafting the messages regarding ACTs.

RDS/PDI claims that its methods will allow IDUs to break their "dependency" on outreach workers, and become self-empowered subjects. Yet, as the state withdraws its capacity of service provision, it plays an even *greater* role in governing subjects. No longer will knowledge belong to the mutually negotiated relation of outreach worker and client. Instead, true/false statements interpolate participants into a narrow frame of social reproduction [NEEDS clarification…better description]. Participants' limited capacity suits the goals of RDS/PDI: their unpaid and underpaid labors produce the "material" by which researchers will form and shape their claims. Rather than the empowerment it promises, RDS/PDI actually enforces *new* demands upon participants, who are subjected to (and subject others to) the authority of entrepreneurship in the coupon economy.

RDS/PDI & ACTPOC: Ethnographic analysis

Thus far, this chapter has examined the literature on outreach and RDS/PDI and explored some important differences between them. What are the experiences of the participants who are recruited by RDS/PDI methods (and also recruit others)? Part Three of this chapter discusses the ACTPOC participants' experiences with these methods, and the three themes are organized as follows. *Payment and Dual-Incentive Structure* and *Policing Participants* were two significant categories that emerged when coding the qualitative interview data. The third theme, *Vulnerability* was not uniformly present in most interviews as were the first two themes, but is nevertheless important to any discussion of RDS/PDI's effects upon participants.

The following section draws from participants' perspectives to suggest alternate views of RDS/PDI not currently represented in the literature about this method. Although some of these data overlap with Scott's findings, they also reveal new areas of concern. ACTPOC participants' roles in RDS/PDI were arranged prior to and without their involvement. Their activities related to these methods were regulated by the protocol, yet participants' engagement with this process did not seamlessly unfold. Alan Peterson's observation illuminates the schism between theoretical health models and their occurrence in everyday practices: "(A)lthough the available options for action in health care are often predetermined rather than 'invented' by consumers themselves, there is nothing inevitable about how individuals act" (Peterson 2003:196).

Payment & Dual-Incentive Structure

My observation at the ACTPOC groups, along with the interviews I conducted illustrate that ACTPOC group participants were overwhelmingly enthusiastic to learn about and practice peer recruitment and education. They seemed to enjoy engaging in the role-plays with a partner, where they practiced their approaches and shared feedback on one another's strategies. But, this excitement occurred among palpable anxieties as well, mostly with regard to the eighty-five dollars they stood to make, a significant amount of money for group participants, virtually all of who lived at and in many cases well below the poverty line. The following questions regularly emerged in some form at every group I attended: What if you lose your coupons? What if the person you recruit doesn't show up or what if they turn out not to be eligible—can you get the coupon back and recruit someone else? How should you decide who to give your coupon to since that person has to show up? Can you get more than just the three coupons, since you know a lot of folks who could do these groups? How long do you have to wait to be paid for your recruitment efforts? And can you retrieve the money as each recruited peer enrolls in ACTPOC, or do you have to wait for all coupon holders to finish enrolling before getting paid? These issues regarding payment were recurring themes throughout my ethnographic study of ACTPOC, both in participant-observation of groups and participant interviews.

Mathilda described that although her peers' interests in ACTPOC may have had something to do with wanting to learn about clinical trials, monetary need was the primary reason they wanted coupons. In our conversation about her experience conducting peer recruitment, Mathilda explained how her fellow participants at a drug and alcohol recovery program for PLWHA had approached her. "Everybody wanted it, well they claimed they wanted it…everybody was saying everyone else was getting tickets, so they were coming up to you 'Do you have a ticket?' So you know, that wasn't hard at all." When I asked if she could recall the reasons people wanted coupons, Mathilda replied quickly, "Money. They may have wanted more out of it, but we're living on a budget, welfare, SSI, SSD. So any money is helpful right now. I'm on SSD and I'm just making it—I was on welfare. So any little bit will help."

This monetary need seems to have also driven Mathilda's insistence on following the PDI guidelines for compensation. She explained to me how she instructed her peers in the ten true/false statements: "I told them, I said, 'You have to fill this out and let me know, and I'll give you the answer after you finish.'" Mathilda goes on to describe how this strategy was one she learned at ACTPOC's third intervention group session, which trains participants in RDS/PDI. "She [the group facilitator] did the same thing with us before we even got the coupons. And she said, 'Answer the questions,' and she told us what was right and what was wrong."

Marcus' experiences recruiting others was that once he stated the project was a way to make extra money, "Before I even got the sentence finished, they were like, yes." He says that the people he distributed the coupons to did not wait to hear his spiel, and seemed unconcerned when later he described the study's focus on ACTs and information about where the groups were located. The immediate response that Marcus and other ACTPOC participants received when recruiting demonstrates that people's need for money takes precedence over the intervention's content and its details.

Mathilda's and Marcus' comments underscore the unsuitability of the language of "choice" to describe their own situations, and that of their peers—if choice means the absence of coercion, then they, like all other ACTPOC participants, did indeed have choice whether to participate in RDS/PDI. But if choice is examined with regards to the fact that participants were poor and had difficulties making ends meet then choice seems like an insufficient concept to describe what took place.

Policing Participants

Some ACTPOC participants' experiences with peer recruitment and education involved exerting various kinds of pressure in their coupon distribution. Potential participants wanted the coupons that were required to take part in ACTPOC (which, if they were eligible and attended all intervention groups and research visits, could net them $275). Likewise, ACTPOC participants conducting peer recruitment also wanted to be sure they earn a return on their coupons. Jose points out that, "I think the coupon thing was a good idea because it made people—see—they—the—in order for me to make more money, I've gotta make sure I—I do all the groups myself. A—and the—that money—money—you know money is always in the center of it anyway [*chuckles*]". Jose adds that his recruitment style was informed by his need for the compensation. He recalls telling people, "You gotta make sure you know the answers to all these questions, 'cause you know the answers—I get more money."

Within the market-based model of peer recruitment and education, Jose acts in his own interest that aligns with the "rational choice theory" that was one of the primary theoretical foundations of ACTPOC. With a limited number of coupons, the instructions he gives his peers along with coupons reduce the risk that his labor will result in less cash. He optimizes his chances for a full return by eliciting peers' cooperation to answer the true/false statements correctly when enrolling in the study. RDS/PDI rewards approaches like Jose's. Compared to the open-ended engagement of outreach—which was less didactic, more conversational, and context-specific—"information" assumes the form of a commodity in which its exchange-value far exceeds its use-value.

Jake, who is in his early fifties and is a long-term survivor now living with AIDS, describes his criteria for evaluating whether a peer would make a potential study participant. Following his discussion of the clinic he attends that draw "mature people—everybody was mature, like in their 50s and all that," Jake goes on to say:

> You didn't see basically nobody too young. Because mature people that are HIV, they know a lot about their sickness already. I mean you don't have to be older to know about HIV because people who are older may have just gotten HIV. But those people, they are well known throughout the community, the places we go, they go to groups and all that, so they know about, they were gonna be responsible in order to get, for me to give them a coupon, for anybody to give them a coupon. That's the way it was said, y'know. If you say you have a study, a lot of people they take it but they don't show up.

Jake's evaluation of potential participants must meet his criteria for being responsible—that in his case correspond to being older and likely stable (as indicated by his reference to people well-known and regular attendees at certain groups). In addition to Jose's discussion of teaching his peers to perform correctly, he also described his process of selecting potential participants: "I don't know if you would call it a drawback or not, but because the coupons were going to make me some money, I tried to make sure that the people I gave them to were dependable and of sound mind, and would—would, you know come here."

RDS/PDI facilitates the kinds of exclusions that participants employ to determine suitability for ACTPOC that draw upon assumptions and stereotypes.[83] Jose and Jake, like all other ACTPOC participants (and those in other studies using RDS) have a finite number of chances to make use of their coupons. As Jake explains, a coupon that is distributed but not used—"a lot of people they take it but they don't show up"—allows no margin of error. The recruitment conducted by outreach workers did not face this problem—while goals for contacts often had to be met, these limits to their time are qualitatively (and quantitatively) different from the three coupons (chances) RDS/PDI participants have. The scarcity of the coupons makes their waste untenable, and the possibility of lost earnings result in pronouncements like Jose and Jake's.

Jose's embeddedness in a community of PLWHA with older members, and his reluctance to distribute a coupon outside his social group also complicates Broadhead et al.'s observations from a previous study that, unlike RDS coupon holders, outreach workers were reluctant to cross certain divisions, which reflected badly upon their work. Citing a statement from an outreach worker who told him, "'I only talk to people that I've been introduced to,'" Broadhead et al. argues that, "(I)t is hard for homeboys to adopt a friendly demeanor and talk to strangers about AIDS, or work the streets distributing prevention materials" (Broadhead et al. 1995:537).

Setting aside Jose's stereotypical views of youth, the fact that he is rooted in a

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[83] It is especially discouraging to consider this, given the fact that these and other forms of stereotyping have circumscribed their lives. As poor PLWHA of color, many of who have histories of drug use and incarceration, and whose sexuality is automatically deemed suspect (see Chap three), these ideological narratives of who is "worthy" or not have been destructive to their own lives in countless ways.

network of elders benefits RDS/PDI. The same argument applies to outreach work: As numerous studies have indicated, conducting outreach is not "cookie-cutter" work, but rather relies upon and is enriched by outreach workers' histories, former and current communities of practice, and more. One outreach worker might experience discomfort in an intergenerational shooting gallery, but be fluent with crack cocaine users across various geographies (and vice versa). Rather than view these particular features as strengths, Broadhead et al. depict these qualities as an indictment of outreach workers' failure to reach all individuals. The "glass half-empty" demonstrates a skewed understanding that neglects the historical, social, and political-economic complexities of how substance users create forms of social organization, which in part are a response to marginalization from the larger society, and that are often culturally meaningful. It also ignores the expertise of outreach workers' knowledge of these spaces, which suggests Broadhead et al.'s attempts to deskill the outreach worker to support their claims of RDS/PDI's advantages.

"Assessment" as Labor Practice

Moreover, Jose and Jake's assessment activities yield the invisible (or unspoken) support for the governing practices in the research enterprise. Judgments of which participants are "fit" for coupons may yield an assortment of subjects that are more likely to be "adherent" to the requirements of ACTPOC (of which there are many, including completing surveys that take anywhere from one to two hours; agreeing to share “locator” information such as the names of relatives and case managers; and arriving to appointments on time). These kinds of “pre-screening” eliminate some of the efforts that would be spent on tracking participants “lost to follow-up” over the course of a study—a time-consuming and overall demanding task. Of course, participants’ generalizations of “who will show up” may not necessarily correspond to what people actually do. But, it is often the case that people with long-term or frequent interaction with recovery centers, jail, or GED preparation, are familiar with the regimes of institutional compliance, making them well suited to the demands of research studies such as ACTPOC. The time spent waiting for an appointment is one example: upon receiving a coupon and calling ACTPOC’s 1-800 number, participants were told they would have to wait anywhere from five weeks to three months for the next available appointment. Another was the requirement to bring a copy of their M11Q or HIV medication with their name on it to “prove” their status. Participants’ “prescreening” by their peers (along with the encouragement that they recruit people from their support groups) seemed to yield a sample of participants who were familiar with the routines of waiting, accustomed to answering hundreds of questions using a scale of one to five, and socialized into the routine and impersonal management of their social suffering, such as documentation of HIV diagnosis.

Vulnerability

Some ACTPOC participants, though not all, experienced various kinds of vulnerability in the coupon economy. When Maria speaks about her experience distributing her coupons, she says that several people had approached her with requests for coupons, and so they were "spoken for" before she even received them (and completed the RDS/PDI training) in the third group. Why did people want the coupons? I asked. She replied, "Yeah they know about the study and the two hundred dollars, that's the most important for the people." Maria tells me with a hint of disappointment in her voice, "I didn't have a chance to pick the person." As she described the pressure she felt to distribute coupons, I asked Maria what made it difficult to tell the person no? For what reason was she compelled to give coupons to the people that demanded them? She explained to me that because she attended the same treatment and support program as these individuals, she felt unable to say no to them.

The possession of coupons—or even the perception that you will soon possess them—creates awkward situations for some participants. RDS/PDI capitalizes on participants' social ties to facilitate "group-mediated social control" which, according to Heckathorn, "alters interests through secondary incentives, i.e. rewards and punishments to a group based on performance of individual members" (Heckathorn 1995:541). Their argument gives little or no consideration for how the coupon economy may potentially harm these ties (which, in Maria's case, offer her nurturance and support). While participants' social networks are said to facilitate participants' RDS/PDI activities, in Maria's case her social ties make these situations uncomfortable.

Gilles' experience with RDS/PDI prior to his formal enrollment in ACTPOC brought to the fore his exclusion from the networks in the support program he attends. As we talked, Gilles' lifelong experiences of human suffering seemed very close to the surface, and over the course of the interview our conversation led into several painful areas: his family's abuse and rejection of him; experiences of enduring sexual violence while incarcerated; a childhood of deprivation; and the traumas he confronts from past experiences of trading sex for drugs. Gilles' recollection of these psychic traumas were *not* triggered by the coupon economy; as I understood it, these issues were part of his ongoing struggles that regularly surface in his everyday life. However Gilles also seemed to alternate the narrative of his coupon experience with some of the suffering he carries from two childhood events of devastating rejection: the intolerance he encountered from neighborhood kids towards his racially mixed parentage and his classmates' cruel responses when he was placed in Special Education to receive assistance with his learning disabilities.

Gilles elaborated to me some of the differences between the coupon economy and another kind of activity in the informal economy:

> But everyone does the [transportation vouchers] thing together but when it comes to other things like clinical trials, everybody, shh, don't tell nobody. Don't

> tell nobody. Give it only to so-and-so over there. Don't give it to him or don't give it—you know, what I'm saying…And see because—that's like people didn't want, like they don't want you to go nowhere, like some people, they just don't—I don't want you around. You're a nerd or you this or whatever…They're doing it out of I want money. Um I want money. I want my clique to have money. I want the people—my girls to have money and you can't get into this and I don't want you hanging around me no more.

Gilles encountered what he describes as "clique-ish" behavior in which some coupon-holders withheld coupons, distributing them only to people with a similar status. In Gilles' case, coupons had more than just monetary value—they accorded status value that affirmed belonging—and signaled exclusion. Gilles' experience suggests that the economies of coupon acquisition and distribution create new kinds of value that conflict with regular exchanges (such as making a few bucks from selling the surplus of transportation tokens) already present in the informal economy that seem to benefit everyone[84]. Susan Hyatt notes that, "(T)he assumptions underlying the execution of many of these programs actually violate those norms of reciprocity and mutuality that predate these policies and that have long sustained poor communities" (Hyatt 2001:213).

How Gilles eventually obtained a coupon to participate in ACTPOC further

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[84] According to Gilles and other participants I have spoken with, the informal transportation economy works like this: when participants attend a support group, they are given a round-trip, full-fare public transportation voucher. They may collect several of these over the course of a day. Many may not need them as they have purchased monthly passes (sometimes at a discount, as many are able to obtain the rate for disabled travel). Participants collect these public transportation vouchers before they sell them to a known local corner store (during a specific day of the week) for a fraction of their cost. Participants are paid in cash for these sales, and the store's workers and/or owners then re-sell them at their regular price, which yields them a considerable profit. Because these vouchers are sealed in plastic prior to their re-sale, the people that purchase them do not know the origins of their $4.50 round-trip fare.

underscores the vulnerabilities people may experience in coupon distribution. Gilles had actually offered to buy a coupon from someone, who agreed to the transaction. However, when Gilles found out that the person would receive money for enrolling in ACTPOC, he withdrew his offer of cash. The person gave him the coupon anyway, and in the process obtained his phone number so that he could call and remind him of his appointment. Gilles described to me the many phone calls that followed. "Well, see, the guy that told me about it, he kept calling me to get to go because he wants to get that, he gets an extra twenty-five dollars every time somebody joins." The man had received Gilles' phone number by way of the ACTPOC script that suggested recruiters ask for the phone numbers of the peers they distribute their coupons to, in order to remind them of their upcoming appointments (what Broadhead et al. would refer to as "secondary social control"). Gilles felt uncomfortable with this person who kept calling him, wanting to know if he had attended his visit yet. He said, "He was on the phone too long. He was trying to get to know me where he, I can tell he's still on drugs. And he wanted to maybe trick with me…Y'know when I get my money I can help him buy drugs or something like that." Gilles describes how receiving the coupon from this person directly exposed him to these harassing phone calls for "I wouldn't have gave him my number if he had asked me before."

Although Gilles' experience with the coupon economy intensified his preexisting vulnerabilities, he shared with me the satisfaction he felt creating thoughtful and supportive recruitment encounters that countered his own experiences of exclusion. When Gilles completed the ACTPOC groups and received coupons of his own, he was determined to seek out people to distribute his coupons to who would likely not have had access to a coupon otherwise. He recalls,

> I gave a guy a ticket who's very slow and another girl, this church person. And they both cried when I gave it to them. Because nobody would give them a ticket like me. And I told them, I said, I told them the story about it. I said, you know what? I felt the same way you did when I couldn't get a ticket. And, and I knew that, I said I can tell y'all are really good people and y'all deserve some kind of break too and I think you will enjoy this. It's, it's a conversation that goes along when you go into these groups, you would enjoy this.

ACTPOC Participants' Experiences with RDS/PDI Techniques

RDS/PDI are taught to participants as *techniques*, which downplay participants' lived experiences and shared social relations that facilitate recruitment. For example, in the third and final group that focuses solely on RDS/PDI, participants are taught "how to approach your peers" and form pairs to practice "good opening lines" to use in coupon distribution. Participants are encouraged to talk to their peers that attend their HIV support groups. The content of the presentation acknowledges people's social networks, but largely ignores the kinds of labors (including the work that comprises "personal experience") that are essential to participate in these networks. Attendance at a support group requires various kinds of work, including socialization into a particular set of group norms, disclosure of HIV status, and the time and emotional energy of participation. In ACTPOC, the presentation of PDI emphasizes "reimbursement for your time"—a ten to twenty minute conversation with peers. But, how is the "time" that is being compensated constructed in this description? And to what labors does "time" refer? First, not all time is reimbursed—as many people put effort into their recruitment that did not yield results—a disadvantage that outreach workers did not face in their role as employees, not contractors. Moreover, it is precisely participants' situated-ness in and involvement with their communities, the time they spend taking part in their social networks, the energy required to live with HIV and the efforts spent to make connections with and exchange support with others living with HIV that make RDS/PDI possible. "Reimbursement for your time" is not quite the oxymoron as the phrase "paid volunteer[85]" but nevertheless seems inadequate to describe participants' labors that are central to the research enterprise. Heckathorn's proud statement that RDS/PDI is cost-effective because participants, rather than staff, conduct the bulk of recruitment efforts indicate how the labors involved with research recruitment are devalued and deskilled in the contemporary research economy (Heckathorn 1997).

As Broadhead et al. promise, RDS/PDI did indeed create "new opportunities" for participants that recruited and educated their peers about ACTPOC. But these findings suggest the need for more careful examination of what these opportunities entail and

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[85] Roberto Abadie's ethnographic study of a group of self-professed "guinea pigs" reveals that pharmaceutical drug trial sponsors described research participants in Phase One clinical trials as "paid volunteers" so as to obviate the payment that was the basis for enrolling in these studies (2010).

what they foreclose. These selections of interviews call attention to how multiple forms of marginalization positions people unevenly with regard to choice, and thus discourages their engagement with and critique of information regarding ACTs. In order to make the money they need, participants cannot challenge or modify the information (statements) about ACTs—but must reproduce them as they were instructed—and convince others to do the same.

Concluding Remarks

RDS/PDI activities circulated ACTPOC participants—virtually all poor people of color—into an information-based service economy that is characteristic of neoliberalism's valorization of market-based solutions to public health needs. Once valued as part of the social contract necessary to both provide support and recruit potential participants to research studies, outreach work has come under intense scrutiny and critique with the advent of RDS/PDI, its discourse of empowerment and cost-effectiveness, and coupon economy of incentives, scarcity, and dual-incentive structure (or social control). These interviews and other ethnographic data provide rich examples of the ways RDS/PDI facilitated surveillance among ACTPOC participants and peers in order to ascertain normative qualities often associated with certain privileges, such as access to housing and the absence of drug addiction. Participants that lack certain forms of social capital (such as membership in certain cliques) or are deemed as belonging to particular groups labeled as irresponsible (such as youth) are also excluded from the coupon economy—and the intervention. If not outright excluded, participants may be forced to undergo additional burdens to obtain coupons, as demonstrated by Gilles' willingness to purchase a coupon following repeated refusals.

Based upon goals of harm reduction and broadening access to health care, outreach work traces its legacy in part to social reform movements such as the "War on Poverty." Outreach work bears an important resemblance to the idea of a social compact—even a fragile one. Outreach workers' connections to the agencies where they worked meant that they could offer more to the users they were recruiting for a research study than simply the invitation to participate. They could also serve as points of contact to access medical care, state benefits, emergency housing, syringe exchange, and detoxification. The relations of support forged in the model of HIV/AIDS outreach do not easily translate to the coupon-based recruitment that is at the core of RDS/PDI. Of course, this does not mean that the encounters between ACTPOC coupon-holders and potential participants were unsupportive or unhelpful. In fact, in many cases it was just the opposite. However, when sharing information and accessing resources occurs among peers in RDS/PDI, it is likely to be less streamlined than outreach worker referrals. "Hurley," one of the ACTPOC RAs, recalled to me his experience when he was hired as an outreach worker and conducted street-based study recruitment, years prior to the use of RDS/PDI. “At least when you’re right there in the street you’re geared up with information that could be made available, like right there on the street, if you need detox, if you need health services, you need case management services, you have those resources at hand that you can refer to.”

The emergence of RDS/PDI and its denigration of outreach work is part of the phenomena of post-welfare “reform” and broad economic restructuring where the state is seen to foster dependency and threaten individual responsibility. Yet at the same time that the state withdraws its capacity of service provision, it continues to, and may play an even greater role in governing subjects. No longer will knowledge be subject to the mutually negotiated relation of outreach worker and client; instead, reduced to its barest and most simple form, “information” interpolates its subjects into the role of passive consumer (and/or producer in the labor undertaken to socialize the “right kind” of subjects for research studies, i.e. those “fit to be participants”).

The format of RDS/PDI messages and the types of training (instructions/guidelines) that are involved are ontologically similar to the postindustrial service economies in which poor people work: the fast-food chains and “big box” retail cashier jobs. In these settings, workers’ labor is narrowly scripted to repetitive tasks. They face greater challenges to unionize and are woefully underpaid. While nonprofit public health is qualitatively different from McDonald’s, Wal-Mart, and other powerful players (such as nation-states) in the contemporary “global economies,” the use of

RDS/PDI to educate and recruit participants benefits from the inequalities and insecurities institutionalized within the system of advanced capitalism. Like Marx's reserve army of labor, participants are ready and well positioned to conduct recruitment and education. Yet these activities restrict the potential of developing a collective voice. The uncertainties of the informal economies ACTPOC participants are involved in, combined with shrinking entitlements (such as SSI) create high levels of coupon demand and a strong willingness to recruit and educate peers. Participants are less eager though to be expelled from the coupon economy upon distributing their three coupons, as indicated by their many requests to gain more coupons or assist their peers in recruitment.

RDS/PDI dramatically differs from the outreach work model it threatens to displace, which offered viable employment opportunities such as training in supporting clients, learning how bureaucratic health systems operated and making referrals, and conducting research recruitment. The adoption of RDS/PDI removes significant job opportunities that had tremendous value and mutual benefits for the outreach workers who very often belonged to the communities being studied. Outreach workers were compensated with an hourly or salaried wage and in some cases, health care, and other benefits. In their study of the use of community-health workers in research, Martha Hill et al. point out that, "Beyond the direct contribution to research, the use of community-health workers also has important economic and social consequences. Skill-building and on-the-job-training provide both employment and entry into health or other career paths"[86] (Hill et al. 2010:225).

In contrast, RDS/PDI presented ACTPOC participants with the option of conducting recruitment and receiving "reimbursement for your time"—an activity that undercompensates the experiences of living with HIV and their involvement with and expertise regarding the networks that researchers seek to study. RDS/PDI operates on a model whereby poor people must hedge their bets on granting coupons to the people most likely to bring the greatest returns—i.e., enrollment in ACTPOC and recitation of the correct answers to the ten true/false statements about ACTs. This language of "reimbursement" does not describe the act of labor—it diminishes its value and fails to recognize its important value to research economies.

According to Broadhead and Heckathorn, RDS offers many advantages over the typical outreach methods used to enroll "hard-to-reach" participants into studies, such as recruiting participants quickly and effectively. An example from a study conducted by Courtney McKnight et al. illustrates the efficiency of using RDS to successfully enroll drug users in a study of HIV seroprevalence in lower Manhattan. McKnight et al. state, "Utilizing RDS, we were able to recruit and interview 118 more drug users than originally proposed in one-quarter of the time. RDS was efficient with respect to time

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[86] Hill et al. note that while the possibility exists for the CHOW to transfer to another research project when the study ends, it is not a guarantee of secure employment. Hill et al. suggest that supporting CHOWs to plan for such a transition take place well before the study ends, and include help with resumes. (Hill et al. 2010:223).

and economics (we did not have to hire an outreach worker) and effective in recruiting a diverse sample of users" (McKnight et al. 2006:i54). The fast-paced recruitment maximizes the Research Assistants' labor and increases the number of study subjects, thus attaining greater statistical significance that lends greater support to the PIs' scientific findings. However, the RAs' perspective of RDS might tell a different story. Their workload *quadrupled* and very likely their employment, no longer needed once recruitment was completed, ended sooner than expected. The RAs' perspectives of RDS and their experience being part of a research team without an outreach worker do not even warrant mention.

Moreover, Broadhead et al.'s claims that the replacement of the outreach worker position with stipends disbursed to participants in RDS is cost-effective tell only part of the story of this transformation. While ACTPOC recruitment coupons and PDI function as an informal economy among participants, there is another important transformation that is tied to the elimination of outreach worker jobs. The creation of a coupon/cash-based recruitment system that offers small but badly needed financial incentives for participants in exchange for work not only displace outreach workers, but also facilitates and strengthens existing class- and race-based hierarchies: researchers professionally advance and even gain scientific prestige through the use of this lauded method. As entrepreneurs in this research economy, ACTPOC participants facilitate researchers' access to participants that allow them to develop new and innovative knowledge as well as involve themselves in the burgeoning scientific economies of RDS (through grants, RDS conferences, and special journal issues). In public health research, the introduction of RDS/PDI strengthens the professional identities for both the administrators that organize the logistics of this new recruitment and the biostatistician who analyzes the chain-referrals of coupon distribution. ACTPOC's management team of administrative professionals and statistical experts hone new skills, engage dynamic processes, and explore new arenas of knowledge making. RDS/PDI may lead to researchers' new technoscientific experience to list on their CVs and journal citations that circulate them into its growing field of RDS expertise.

The outreach worker who in the past might have fulfilled this role of study recruitment has been eliminated, replaced by participants who determinedly—and sometimes desperately—recruit their peers. The outreach worker's supervisor (and especially as the Principal Investigator or Co-Investigator) in years past likely gained insight into outreach clients' lives, their physical geographies, and emerging and changing directions of the epidemic. There is no counterpart for RDS statisticians to gain similar insight. The advent of RDS has slashed from research budgets the outreach workers who once gave accounts of people's lives, from their contextual understanding of abandoned neighborhoods to the insights they gleaned from changing drug practices.

There is an important similarity that draws together PDI and ACASI (the Audio-Computer Assisted Self-Interview) that is administered by RAs. Chapter seven explores the literature supporting the use of ACASI in interviewing and its claims to prevent the common errors and lost data that occur when RAs conduct paper interviews. The important similarity between the introduction of PDI via the loss of outreach worker jobs and ACASI via the shrinking job of the RAs is that the people who have labored in these roles have little or no power to identify the challenges and problems in their work and develop ways to remedy them. Instead, problems such as the occasional loss of interview data by RAs and Broadhead et al.'s anecdotal accounts of outreach workers running personal errands while not being monitored were tasked as problems that *researchers* set out to solve, with no input from the staff that know this work best, or from the clients and participants the RAs and outreach workers serve in their work. This point exemplifies outreach workers' abandonment from the labor force—the rules of the game have changed, and they are summarily expelled.

Despite the advantages RDS/PDI offer, some ACTPOC participants experienced mild coercion, possible breaches, or threats to confidentiality, and reinforcement of social hierarchies where some people are deserving of coupons while others are not. Researchers' use of RDS/PDI advances statistical science and offers them greater professional recognition and material rewards. These differences point to the urgency of engaging a conversation regarding RDS/PDI that goes beyond its social scientific dimensions of sampling, representativeness, and feasibility to interrogate the emergence and appeal of RDS in ethical terms: how is this method appealing to the contemporary post-welfare era that vilifies the marginal public resources once available to its poorest residents? David Hess asks, “Can one also set up criteria for the progress of science at the institutional level, such as the minimal maintenance of wages and resources at cost-of-living levels, or the increased amount of diversity and equity in the institutional organization of scientific and technical production” (Hess 1997:30)? This question is one that I believe staff, investigators, funders, and participants alike in the field of HIV/AIDS behavioral research urgently need to ask.

PREFACE TO PART TWO: EVIDENCE-BASED, NEOLIBERAL HEALTH, & KNOWLEDGE PRACTICES

> Evidence-based medicine creates a demand for clinical trials and thus the recruitment of patients into these trials.
>
> Eric Mykhaloviskiy and Lorna Weir 2004

Part one of this dissertation focuses primarily upon ACTPOC's intervention groups, which had been designed to increase the interest in and knowledge of ACTs among HIV-positive people of color. Chapters two, three, and four examine how the concepts of racialized and gendered under/representation and ACTs; the screening process and clinical care; and peer-driven education and recruitment were disseminated in an everyday public health setting. These ethnographic findings also discuss the processes by which participants both put to use and challenged ACTPOC's claims.

This Preface to Part two outlines some context to chapters five, six, and seven, which present ethnographic analyses that focus upon ACTPOC's research activities. ACTPOC's research structure and design were shaped in part by "the growing tendency to embrace experimental and comparative work—particularly RCTs (randomized controlled trials) as some sort of 'gold standard'—as the only appropriate way to evaluate HIV/AIDS interventions" (Van de Ven and Aggleton 1999:462). The evidence-based phenomenon is not limited to clinical medicine; public health is increasingly drawing from clinical trials data to develop guidelines and interventions. Evidence-based medicine (EBM) has spawned evidence-based behavioral medicine (EBBM), evidence-based practice (EBP), and even evidence-based public health (EBPH), which Jonathan Fielding and Peter Briss define as "the process of integrating science-based interventions with community preferences to improve the health of populations" [(Fielding and Briss 2006:970) N.D. Kohatsu et al. 2004]. The explosion of evidence-based has had the effect of devaluing those interventions that have not—perhaps because of cost, resources, and feasibility—been evaluated by randomized controlled trials.

Dave Holmes et al. asks, "What makes one piece of evidence so 'self-evidently' meaningful for us at this precise historical moment, while another appears so 'self-evidently' meaningless or non-sensical" (Holmes et al. 2006:182). Nadav Davidovitch and Dani Filc propose that evidence-based public health must be understood within the neoliberal era in which it has emerged. According to the authors, a body of knowledge had to be developed that would align clinical judgment and health practices—traditionally antithetical to reductions in health care costs and privatization of health care models—with the goals of cost-containment (Davidovitch and Filc 2006:300). Sandra Tanenbaum describes evidence-based practice as a movement of "scientists, public officials, private payers and advocacy groups that seek to establish a new knowledge regime in health services" (Tanenbaum 2005:163). Tanenbaum argues that

EBP is adaptable to "market and political goal setting" (Tanenbaum 2005:170), particularly managed care programs.

Recent empirical attention to EBM (and the evidence-based phenomena generally) has produced a plethora of critical insights, challenging the notion that the clinicians that use it are practicing "cookbook medicine" (Villanueva-Russell 2005:554; Berg 1997:1082). These studies indicate that EBM does not unambiguously resolve the contingencies and uncertainties that are present in clinical practice nor are they indiscriminately applied. David Armstrong's interviews with doctors illustrate the primacy of their clinical judgment in prescribing antidepressants, especially when choosing from the growing number of new selective-serotonin reuptake inhibitors (SSRIs) (Armstrong 2002). Pediatric residents integrate the research evidence drawn from computerized databases of evidence-based medicine with the clinical expertise of their supervising physicians (Timmermans and Angell 2001), and doctors negotiate patients' illness narratives with EBM's probabilistic outcomes (Tanenbaum 1994). Studies reveal that clinicians adapt EBM guidelines according to patients' interests and desire for information (Putnam et al. 2002). Eric Mykhalovskiy found that a group of cardiologists strategized how to preserve their clinical autonomy in the face of hospital administrators' attempts to standardize patient care during hospital restructuring (Mykhalovskiy 2001). Stefan Timmermans and Marc Berg explore the significance of labor hierarchies in their study of oncology staff's interaction with a research protocol for an experimental treatment for advanced lymphoma. Timmermans and Berg explore the uneven benefits the research protocol brings to the doctors and nurses in their study. Whereas the doctors experience professional opportunities such as an increase in status and opportunities to publish, the nurses bear an even greater burden of work (Timmermans and Berg 2003:289-293). Rather than showing a loss of professional status, these studies indicate that EBM enhances clinicians' authority.

But are these findings relevant to those workers who do not share the elite status of clinicians and other professional workers who have been the predominant focus of empirical analyses of "evidence-based" in practice? Were the ACTPOC staff—the RAs and IGFs—undergoing a "de-skilling process" as a result of the trend towards standardization, evidence-based, and meta-analyses of clinical trials? What brought the RAs and IGFs the greatest amount of satisfaction and the most conflicts in their work? In what ways did the RAs' perspectives differ and how did their work relate to ACTPOC as a whole? A key theme emerged in my ethnographic research that undergirds the analysis presented here: while some degree of "deskilling" was present, the staff re-skilled themselves, allowing them to adhere to the study protocol while creatively exploring its limits.

The authority upon which scientific foundations claim a universal objectivity face challenges from scholars in the field of science and technology studies (STS). It has democratized certain elements of science by broadening the ways laypersons and nonexperts contribute to its debates, yet critics note that its discussion upon scientific labor, beyond that of established and credentialed scientists, has been limited. Daniel Kleinman and Steven Vallas' analyses of the STS literature reveal "a highly selective focus on credentialed workers" (Kleinman and Vallas 2001:452) such that "institutionalized forms of legitimacy, such as advanced degrees, are valued much more than the less credentialed forms of expertise" (Kleinman and Vallas 2001:477). In his study of Robert Boyle, the seventeenth century chemist credited with the creation of the water-pump, Steve Shapin examines Boyle's published papers and other correspondence to reveal the central contributions technicians and workers made to this development despite the lack of acknowledgment they receive in the historical record (Shapin 1989). Noting that historians and sociologists who study science tend to neglect the role of technicians in their studies, Shapin urges that their invisibility not be reproduced lest they be seen as unimportant to science proper (Shapin 1989:563).

Finally, this ethnographic study of the ACTPOC staff's work activities in part two of this dissertation hopes to add to what some scholars describe as an underdeveloped area of STS. As Jill Morawski and others have noted, the field of psychology (evidence-based behavioral health interventions are included in this field) receives considerably less attention than the biological sciences among STS scholars. Morawski states, "(P)sychology has been examined less than any human science through the critical lens of difference theory, identity politics, and science studies"

(Morawski, 2005:78). Compared to the numerous ethnographic studies of biology and genetics laboratories, why is there relatively little attention paid to psychology as a science?

As scholarship in STS has outlined, science achieves its legitimacy in part through its concealment of the processes that lead to its development. In ways similar to laboratory and clinical studies of HIV/AIDS, evidence-based HIV/AIDS public health mainly appears in the forms of texts—peer-reviewed articles, standardized manuals, and meta-analyses. The following chapters attend to the less visible but very important labors that contribute to and shape these artifacts. ACTPOC staff's work activities are important to study in part because they illustrate the limitations and conflicts that are often absent in the "official" texts of the growing body of evidence-based HIV/AIDS public health. Too often, the recursive logic of scientists and scientific practices fail to account for the majority of people that labor under the banner of science. Lacking professional credentials, these technicians, support staff, and research assistants become invisible in the realm of the scientific, and especially within evidence-based HIV/AIDS public health.

But, to my knowledge, there are only a few empirical accounts of evidence-based behavioral medicine or evidence-based public health "in-the-making." There are however a few exceptions. Alison Hamilton Brown conducted qualitative interviews and focus groups with clinical and research staff of the "Methamphetamine Treatment

Project," a randomized controlled trial that tested two kinds of behavioral treatments (Brown, 2004). Brown's findings illustrate the RAs' frustrations with the research hierarchy, which they viewed as largely out of touch with the important concerns RAs faced regarding clients' needs (Brown 2004:106). A study conducted by Stefan Timmermans and Tara McKay examined a behavioral and pharmacologic clinical trial for methamphetamine addiction. Focusing primarily upon the research participants' experiences, Timmermans and McKay noted the significance of the RAs' non-judgmental and friendly approach in participants' satisfaction and retention in the project (Timmermans and McKay 2009:1789). While empirical approaches to behavioral interventions and especially to the "DEBIs" give insights into the experiences of health care workers that administer these interventions (Dolcini et al. 2010; Dworkin et al. 2008), these studies do not speak to the research and data-gathering processes that lead to their development.

Evidence-Based: Who is DEBI?

The field of HIV/AIDS prevention education and social support[87] is undergoing dramatic changes. The growth and expansion of scientific, evidence-based interventions have come to direct the HIV/AIDS public health agenda, displacing many grassroots health promotion efforts in the process. HIV/AIDS behavioral interventions

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[87] Some examples of prevention education and support might include "HIV 101" for high school youth and a substance reduction group for people living with HIV/AIDS.

are becoming increasingly dominated by randomized controlled trials, standardized measurement, replication and dissemination, and statistical power and significance. How have knowledge practices most often associated with testing medications come to be promoted as the highest form of evaluation for public health interventions (Victora et al. 2004:400)? Can group-based educational interventions—even those that use a standardized curriculum—be comparable objects in ways similar to experimental medication studied in a clinical trial setting? What kinds of social conditions make such possibilities knowable?

HIV/AIDS is unmatched in the history of modern epidemics, as no other disease has been the target of such vigorous challenges to medicine, science, and politics. "HIV brought to the surface questions about the nature of state power and authority, and the role and expertise of the medical profession" (Jackson 1997:21). Structural inequalities, such as racism, hetero/sexism, the criminalization of drug use, and poverty, which fueled (and were fueled by) the epidemic were made visible and publicly challenged. HIV/AIDS biomedical and behavioral research are unique sites of both conflict and collaboration among PLWHA, activists, researchers, clinicians, government regulators, and industry. From the struggles to include women's clinical characteristics in AIDS diagnoses to the distorted epidemiological analyses that failed to acknowledge gay, bisexual, and men who have sex with men who inject drugs, what counts as evidence has been subject to intense debate over the course of the HIV/AIDS epidemic. Edward

Trickett notes that an earlier period of HIV/AIDS research, which emphasized collaboration and context [(Herdt and Lindenbaum 1992; Treichler 1987); Trickett 2005:4], has been profoundly neglected in the current dominance of positivist approaches. The relationships of research to practice, and of grassroots to professionalism, have been contentious topics in the struggle to prevent HIV transmission and support the health of PLWHA. How the DEBI Program is shifting the terms of "evidence" in this highly charged epidemic, allowing some voices to be heard while silencing others, demands our attention.

In 2002, the CDC introduced a program titled the "Dissemination of Evidence-Based Intervention" or "DEBI" for short. According to Charles Collins of the CDC, the DEBI Program was initiated in response to the Institute of Medicine's (IOM's) report, which urged the CDC to facilitate the transfer of HIV prevention change research to community prevention practice (Collins et al. 2006:6).[88] Collins et al. states that its mission was to "ensure that communities benefit from the investment in prevention intervention research" (Collins et al. 2006:6). There are approximately forty-nine Evidence-Based Interventions (EBIs) in the DEBI Program that are available for dissemination, which "have been packaged for use in local HIV-prevention programs"

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[88] Interestingly, the IOM's report lists a number of obstacles to HIV prevention, including "social barriers, such as poverty, racism, gender inequality, and the stigma attached to HIV/AIDS" (2001:3), but **it** is the link of translating science into practice that captures most of the literature on EBIs. This bears an important similarity to the discussion of women's health in Chapter One, in which the *Report on the Women's Task Force* reported on several social and political economic conditions that shaped women's health, but it was their underrepresentation in clinical trials that galvanized attention.

(*Morbidity & Mortality Weekly Report* 2006:598). A community-based agency may apply for and receive funds to administer an EBI (although CDC funding is not a requirement to administer one).[89] A DEBI package includes a standardized manual that scripts how the intervention is to be delivered in community settings; visual materials, such as posters, pamphlets, and videos are also part of the curriculum.[90] Staff training and technology transfer are among the resources allocated to the dissemination of these EBIs. Agencies that receive funding to administer EBIs must agree to certain conditions, the primary one is to adhere to the standardized format of the intervention.

The processes involved to be selected for the DEBI Program are difficult and uncertain. Attaining the status of "evidence" is no small feat, but rather a mammoth scientific undertaking that requires intense preparation, planning, and execution; activities that are overwhelmingly, if not exclusively limited to health professionals. In the DEBI Program, the criteria for "best evidence" includes: testing in a randomized trial setting, demonstration of a statistically significant effect, the use of behavior change theory in intervention design, and a minimum of two articles that discuss research on the intervention, which must be published in peer-reviewed journals (Dworkin et al. 2008:52).

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[89] However, it seems to be more often the case that agencies' motivation for selecting DEBIs as a resource do so because of funding needs. Margaret Dolcini et al. (2010) conducted a qualitative study of several CBOs that implemented several EBIs and found that "an agency's need for resources to continue to support programs and staff played a significant role in seeking DEBI funding" (2010:1842).

[90] Info obtained from www.effectiveinterventions.org accessed on 01/26/11.

Likewise, testing interventions in a clinical trial setting requires extensive resources that are unnecessary to undertake the large-scale research needed to attain statistical significance. Bruno Latour points out that while individuals may debate scientific facts publicly, the *making* of scientific facts to counter existing scientific ideas is a costly undertaking and limited to a select few. Latour states, "The equal world of citizens having opinions about things becomes an unequal world in which dissent or consent is not possible without a huge accumulation of resources which permits the collection of relevant inscriptions" (Latour 1987:70). While there are many critiques of the DEBI Program, very few have the resources to create a program that challenge the tenets of what counts as—and is discounted by—evidence.

Few HIV/AIDS interventions could meet the DEBIs' criteria for evidence. Behavior change theories are those based upon individualized models such as rational choice theory, and are generally within the province of professional social science, not activism. For example, the ethos of one of the first community-based organizations, the STOP AIDS Project, was the *rejection* of formal health theory, an approach that proved to be successful in mobilizing gay and bisexual male communities and resulted in a sharp decrease in the rates of HIV infection (Wolfheimer 2001:i179). Influenced by feminist health activism's emphasis on community care and critique of medical neglect, these groups "developed a participatory, dialogic method of safe sex education, avoiding the individual behavior or rational health behavior models of many later professional programs" (Stewart and Rappoport 2005:62).

If shown to be effective, there is the potential for ACTPOC to be reproduced and disseminated as an evidence-based intervention.[91] ACTPOC meets all of the rigorous criteria necessary for consideration as "evidence-based": it used a randomized trial design to compare the standardized group intervention to the standard-of-care or control groups; demonstrates a statistically significant effect; drew from several behavior change theories, including rational choice theory; and its findings have already been published in peer-reviewed journals, with more soon to follow.

DEBIs, Evidence, & ACTPOC

ACTPOC's research design shaped the work that the RAs and IGFs did. The RAs conducted surveys and followed randomization processes according to a structured research protocol, which at times seemed counterintuitive or even irrelevant. The IGFs faced similar concerns regarding their adherence to the standardized intervention manual. The relationship between research participants and ACTPOC is complex one. Study staff had to "manage" (or discipline) people with complex subjectivities, whose concerns, interests, and desires extend far beyond their role as

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[91] According to ACTPOC's Research Protocol, "One long-term objective of the present study is to develop an efficacious intervention that can be disseminated to and implemented in AIDS clinical trials sites nationally" (*Research Protocol*:29).

research subjects in the clinical trial setting. The RAs and IGFs underwent their own socialization into the protocol. The RAs work was shaped by a particular set of data collection tools; the IGFs followed a standardized intervention manual. These ethnographic findings suggest that ACTPOC's protocol-driven research activities and manual-driven intervention groups do not simply ignore or erase participants' and staff's interpretations and values, but draw them into, and make them a part of, ACTPOC's discourses.

ACTPOC's everyday research activities were imbued with the science of adherence, standardization, and objective neutrality. These scientific discourses seemed to mediate, and at times contain, various conflicts and forms of social distress, as the ethnographic data in the upcoming chapters illustrate. Chapters five, six, and seven discuss the everyday work activities staff undertook to produce evidence-based knowledge, and by doing so, aims to crack open the black box of evidence. Chapter five discusses the ACTPOC RAs' experiences with the standardized protocols and their work conducting surveys with ACTPOC participants. Chapter six continues this discussion of the RAs and their work with a focus on the computer technology that regulates their interviews with participants. Chapter seven examines the IGFs experiences adhering to the intervention manual and describes some of the advantages and conflicts they faced.

CHAPTER FIVE:
DOING THE WORK OF MAKING IT WORK: EVIDENCE-BASED BEHAVIORAL MEDICINE AT THE SITE OF PRODUCTION

> We bring a certain thing to the interview whether you see it or not. We bring a quality of compassion to these interviews.
>
> *Hurley, ACTPOC Research Associate*

Evidence-Based Behavioral Medicine (EBBM) & Clinical Trials

As Hurley explains in the opening quote, the ACTPOC RAs brought a sense of compassion to their interview encounters with poor, HIV-positive people of color living with HIV/AIDS. The RAs' perspectives of their work evoke rich narratives of empathy and ethical commitment, and are also revealing of their frustrations with and skepticisms toward the broader research economy in which they labor. These chapters explore the RAs' activities phenomena of "deleted work" (Star 2009).

The RAs played a significant role in producing the data that is at the core of ACTPOC's scientific findings: they asked survey questions, elicited research participants' responses, and transformed it to fit the demands of the standardized protocol. The few empirical analyses to have emerged focus upon EBM and EBBM as they are adapted by and applied in clinical contexts (and almost all are medical settings). This chapter seeks to remedy this absence with ethnographic perspectives of the ACTPOC RAs at work.[92] This chapter examines *how* the RAs did their work and its relation to the broader study; and most importantly, explores what this work meant to them and to the people they interviewed.

The ACTPOC Research Associate and Research Assistant (RA) job descriptions formed a long list of work duties. The RAs' daily activities included determining participant eligibility using a screening instrument; conducting informed consent and HIPAA forms with participants; asking survey questions and recording responses; and monitoring the ACASI[93] section of the interview where participants answer questions directly into a computer. Alongside these activities were the constant and often immediate demands the RAs encountered in the course of a regular day, some of which required going back and forth between the field site and the main office two blocks away.[94] The RAs returned to the office where they returned participants' phone calls;

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[92] In their study of nursing clinical practice protocols, Geoffrey Bowker and Susan Star (1999) point out that making visible labor that is neglected is not necessarily the solution to its neglect as it has the potential to further regulate work. They state that, "So-called unskilled tasks may be taken out of their hands and the profession as a whole may suffer a loss of autonomy and the substitution of rigid procedure for common sense" (Bowker and Star 1999:30).

[93] ACASI stands for "Audio Computer Assisted Self-Interview" and is the topic of the following chapter. This software enables data collection to be done on the computer. The RA facilitates the first part of the interview, and participants have the choice as to whether to conduct the remainder of it themselves or for the RA to ask all questions and input their answers.

[94] Although the field site is where the RAs spent most of their day, the nonprofit agency that ACTPOC rented this space from limited the items they could keep there. The RAs had access to a small file cabinet in the middle office, where they stored the plastic water bottles, canvas bags, and money pouches printed with the ACTPOC logo and toll-free telephone number, which were distributed to each participant at each of their three follow-up research visits. Each RA coordinated with other staff to maintain their interview supplies, which they transported to and from the field site in a laptop case daily: their laptop computer, a mouse, computer cords, a USB drive, consent and HIPAA forms, cash and public transportation vouchers for research participants' reimbursement, a receipt book, appointment cards that

scheduled and rescheduled interviews; located participants who missed their appointments; sent letter reminders and made phone calls to confirm the date and time of upcoming appointments; downloaded the interview data to a protected server; updated a database with records of interviews completed; reconciled receipts and maintained a steady cash flow and supply of transportation vouchers; secured the informed consent and locator forms; and documented the written proof of HIV-positive status that ACTPOC participants were required to bring to their first research visit. With the help of a Project Manager and the IGFs, each RA also maintained and updated a calendar to schedule participants for either the intervention or control groups to which they have been randomly assigned. With the exception of the Tuesday morning hour-long staff meeting that takes place at the main office, these activities comprised most of the daily work routine of the RAs (five days a week for the two full-time staff and three days each for the two part-time staff).

This list offers a useful description of many of the RAs' work activities, but it is also limited in that it does not capture the complex interpersonal, social and intellectual labors they performed in order to get the job done. The RAs engaged in respectful and trusting encounters with participants, something the abstract formality of the survey

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list the study's name and toll-free numbers, a computer printout of referrals, headphones for the research participant to listen to the audio section of the interview, and a continually updated paper file that lists each participant's name, identification number, date of enrollment, and information regarding their assignment to the intervention or control arm of the study.

interview does not capture. This chapter explores the competing expectations the RAs encountered and examines how they managed these various roles, but not without considerable tension. The RAs' perspectives of and experiences with their work offer insight into the processes of evidence-based behavioral medicine (EBBM) at the site of production, during the clinical trial testing phase.

The data collected from RAs' interviews with participants formed the primary source upon which the Principal Investigators (PIs) construct their findings. When ACTPOC's enrollment drew to a close (having reached its target goal of 525 participants), many of the participants' sixteen-week and twelve-month follow-up visits continued. Preliminary analyses of the intervention's efficacy have been presented at international conferences, and papers are in progress for submission to peer-reviewed journals. These and other efforts highlight ACTPOC's original and significant contributions to how people think about the recruitment of "hard-to-reach groups." But scientific representations of these subjects reveal little about many of the day-to-day work processes that produce research findings, and thus further marginalize the scientific labor that are not part of a smaller group of higher-status scientific professionals.[95] Eric Mkyhalovskiy and Lorna Weir call for new research approaches to

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[95] Briefly, the conventions used to disseminate scientific findings, such as journal articles and conference presentations, typically follow what Bruno Latour and Steve Woolgar describe as the *de*construction of reality (Latour and Woolgar 1986:179) [italics added]. For example, the reporting of study methodology is a common and expected practice in conferences and journal articles, yet is curiously absent of the frontline research labor that helped to produce it. Latour and Woolgar argue that scientific facts are not

EBM, stating, "The 'work' of evidence along the course of its production, circulation, and consumption requires exploration. This need not focus only upon physicians and their economies of time and training but also on evidence at the *point of production* in clinical trials" (Mkyhalovskiy and Weir 2004:1066) [italics added].

The Interrogation?[96]

The ACTPOC data collection team was composed of two full-time and two part-time Research Assistants. Hurley and Julia worked every day, and were joined by Kate and Shannon, who each worked three days of the week. Together, the four RAs made up a friendly, down-to-earth group. At the field site, I arranged and conducted qualitative interviews with the ACTPOC participants, all of whom were interviewed by the RAs, and on occasion have filled in for another interviewer if they are out sick or if vacation schedules overlap.[97] There was a high level of cooperation among the RAs,

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simply socially constructed, but "*involve the use of certain devices whereby all traces of production are made extremely difficult to detect*" (Latour and Woolgar 1986: 176) [italics in original].

[96] This section of the chapter presents several of the main themes that emerged in the focus group and interviews I conducted with the RAs. I formed an initial set of questions for the RAs based on my views of this work that developed while observing their interviewing and talking to them informally, as well as reflecting on my own experience conducting similar interviews for other HIV studies. I asked general questions in the focus group and my line of questioning developed from the themes the RAs raised and discussed. A close reading of the data revealed a number of co-occurrences between various themes, and led me to ask additional follow-up questions and points of clarification. Fortunately for me, the RAs were very patient and extremely willing not only answering my questions, but sharing insights and perspectives that is critical to the analysis presented here.

[97] I was able to volunteer to do this because I had several years of previous experience as a Research Associate on various studies that examined topics such as HIV and substance use and was also a Qualitative Consultant on ACTPOC. My relationship to the team, combined with my familiarity with collecting survey data meant that I could step in and occasionally assist when needed. Ordinarily, the

and the group achieved a balance of efficiency and flexibility in organizing their appointments, arranging their complicated schedules, working quickly under mounting time pressures, and staggering their use of the shared interview space. They were quick to lend a hand to help one another, whether that was locating a participant or loaning cash and transportation vouchers to another RA who has exhausted their supply. Besides the relationships they have formed with each other, the RAs also interacted socially over the course of the many hours they spend together. They engaged in banter, teased one other, occasionally complained, shared reading materials and gossip, and organized coffee and bakery runs, all of which served as a temporary retreat from the demanding emotional and intellectual labors interviewing required.

I witnessed such shared understandings and mutual help among the RAs in the focus group that I conducted with them, and they were also described to me in the formal interviews and informal conversations. I also observed how the RAs related to one another at the main office and during the weekly meetings with the other staff. Despite the stresses they faced in their jobs, the RAs formed a collegial and supportive group, who extended themselves to me in numerous ways with their patience and willingness to help.[98]

ACTPOC management rigorously evaluates potential employees in various ways, including their ability to listen to participants non-judgmentally.

[98] I was surprised that the RAs were so willing to talk despite the possible risks this involved. I followed the same informed consent procedures as I did for other aspects of my study, though I took additional steps to emphasize that I would not publicly reveal my data to the rest of the team (especially

The ACTPOC field site consisted of three small rooms that were rented from a large AIDS service organization, and it is here that the RAs met with research participants to conduct and administer surveys.[99] A computer printout of the "ACTPOC" logo was taped to the doors of these identical windowless rooms; each one was lit by the glare of an overhead fluorescent light and contained a table, a few stained chairs, and a telephone. The walls were bare and the air circulation, poor. One afternoon, Kate and I were sharing lunch in one of the interview rooms when we began discussing our dislike of these offices: the cramped space, dingy carpets, scuffed walls, and hard chairs. We agreed that worst of all was the absence of natural light and fresh air; there were no windows in the offices or in the other areas of the building to which we had access. Kate pointed out to me how this setting must feel even worse for the participants. She waved her hand across the room and spoke excitedly, "Can you imagine discussing things you *never* talk about in a room like this? It's such a closed-in space where, it's almost like an interrogation. All we're missing is the single bright bulb

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management) before the completion of the study (when their jobs would end). I also pointed out that while I would assign pseudonyms to everyone, because there were only four RAs it would probably not be difficult for a manager on the team to figure out who said what. But everyone agreed to participate without hesitation, and a few even joked about their desire to talk. I felt satisfied that everyone was fully aware of the risks involved.

[99] The large non-profit behavioral health research organization that ACTPOC belonged to had a long-term lease in a building where interviewing clients was forbidden. Although there were some unusual circumstances (the sudden and unexpected loss of previous rental space) that prompted the research organization's move to this space, this rental condition further entrenched the labor stratification of the various studies: the research participants and interview staff were forced to meet elsewhere, whereas the higher-ranking researchers and administrators had access to comfortable and convenient offices to conduct their work. Moreover, the building's exclusion was based in part upon the (assumed) characteristics of participants in research projects that primarily studied contemporary health problems such as HIV/AIDS and substance use.

hanging down. It feels like an interrogation, you have to repeat the question, keep repeating the question if they don't understand. There aren't even any posters on the walls," Kate sighs and shakes her head. [*See Figure 3*]

[*Figure 3*. One of the offices at the field site where ACTPOC RAs interviewed participants.]

ACTPOC's physical space serves as a potent symbol for how Kate viewed the roles of RA and participant in the interview setting. Her comparison of the research interview to an interrogation by the police points to a key feature of the RA—participant encounter, in which the former is scripted into a position of authority over the latter. Kate's description of "you have to repeat the question" is also revealing of how RAs are instructed to adhere to these guidelines: they are not allowed to interpret or explain the questions when participants ask for clarification or are confused by them, despite the discomfort this brings both RA and participant. Encountering bureaucratized language in this institutionalized setting, at times participants experienced the repetitive questions as demands for answers.

The focus group and individual and informal interviews that I conducted with the RAs, in addition to my participant observation of their work, illustrate these and other conflicts the RAs faced. As researchers, they were instructed to refrain from intervening, despite participants' presentation of problems, which was sometimes accompanied by heightened emotional states during their interviews.

A primary area of discord lays in the structure and content of the standardized interview questions that RAs asked ACTPOC participants. On the one hand, RAs engaged in a form of affective labor by interviewing research participants about sensitive topics.[100] But on the other, the RAs were tasked with collecting precise data for the PIs, which demanded a high level of precision, narrow vision, and adherence to the study protocol. For the RAs, managing these dual roles involved careful and delicate negotiation between the needs of the participant and the data they collected for the PIs. That the RAs accomplished both does not resolve the various levels of uncertainties, anxieties, and conflicts they experienced having to do so.

The RAs' work experiences illustrate what Marc Berg and Stephen Timmermans refer to as "politics of standardization in practice" (Berg and Timmermans 2003:21), or what we might also call "the politics of evidence-based behavioral medicine in the making." These topics that emerged in my ethnographic exploration of the RAs' and their work are organized into the following sections: 1) Adherence to the ACTPOC protocol; 2) Volume of the work; 3) Follow-ups; and 4) Enumeration of social suffering. The analyses that follow examine these findings in relation to ACTPOC's goals and the larger research and knowledge economies of which they are a part.

Adherence to the ACTPOC Research Protocol[101]

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[100] Here are a few examples of some of the questions participants are asked: recent CD4 count and viral load; date they learned they were HIV-positive; number of medical visits they scheduled and the number they attended; if they are Hepatitis A, B, and/or C positive; level of formal education; monthly income; relationship status and partner's HIV status; if they are or were recently pregnant; if there are children in their care and how many; and current substance use.

[101] The NIH's definition of a protocol is a "Formal description and design for a specific research project. A protocol involving human subject research must be reviewed and approved by an Institutional Review Board (IRB) if the research is not exempt" (2002). The differences between clinical practice guidelines and protocols are not as significant in one essay by Marc Berg, where he states that the various terms used to

The ACTPOC protocol was a written document that outlined myriad aspects of the research and intervention activities. Research protocols are structured and written prior to data collection and offer a detailed plan of how the research will be conducted, which includes a timeline, recruitment plans, overviews of the surveys and the measures used. These protocols also describe the research hypotheses and plans for data analysis. The precision of the research protocol often makes adherence a challenge, and while protocols may be revised, these changes involve several steps that include gaining approval from the IRB and study sponsor (in this case, an institute of the federal funding source), a process that can take several weeks or more. The addition of research subjects, revision of a study instrument, and changes to the follow-up plans (from four months to six months, for example) all constitute modifications to the protocol that require these approvals.

Hurley describes his initial research training (which took place several years prior, on a different study) that instructed him to restrict and manage affective expressions and "keep that straight poker face." Hurley found the uncompromising structure and content of the interview guide contradicted his own experiences of interviewing participants.

If we're learning to do the interview, the first thing we are told, the *first* thing we

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describe protocols "have in common that they are to be read as a set of instructions telling medical personnel to do A in situation B. These instructions may be more or less elaborate, precise, or binding; they may be formatted in different ways …but they all share this common feature" (Berg 1997:1081).

> are told [*his voice rises and he pronounces every word*]: 'Read the question the way it is written.' Well suppose they don't understand? 'Read it again in a different tone.' And if they don't understand, 'Read it again a little slower. Do not change anything. Read the question the way it was written.' And sometimes it's the tone, how you read the question […] impacts the response that you get, but the question must be asked the way the investigator wrote it. According to them they spent endless hours developing and formatting these fantastic interviews! And then we have to like, present it the way they prepared it… I'm just here to collect data and I should show no ambiguity. I care, I don't care, I just have to keep that straight poker face, and just like [*taps his finger on the table, voice changes to monotone*] 'Answer the question please.' Don't deviate, just do what I ask you to do, yes or no, true or false, how often and that's it.

The PI's instructions to "read the question the way it was written" conform to a primary principle of standardization, which is to establish uniformity and prevent bias. That there can be little or no revision is revealing of the hierarchy of knowledge within the research economy. Hurley notes that while some PIs are "flexible and encouraging" not all are. The "difficult" PI Hurley had worked with in the past clearly ascribed to a top-down setting in which RAs were excluded from any discussion of the research questions, which the RA must administer according to her instructions. "'I'm the one who wrote that and that's the way it is.'"

While standardization is often seen as a distancing mechanism that abstracts people from their lived experiences, Kate's description of the relatively "mundane"[102] questions illustrates the opposite effect. Kate explained, "Like the question, 'Do you have any biological children and if so how many?' Someone will tell me about they're

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[102] As Kate points out, the questions are not ordinary, but given the volume of questions and the limited time RAs have to ask each one, it is expected they become routine.

totally exhausted, or their son is out there doing this, or 'I haven't told my children yet that I'm infected.'" The standardized quality of such questions, combined with their sheer number and the limited time that is allotted to complete them (there are several hundred questions in the initial baseline interview that lasts two to three hours), reflected what Trudy Dehue describes as the impersonal and efficient values of the randomized controlled trial (Dehue 2001:291). These survey questions, which are not atypical in health behavior research, pierced complex and intimate details of participants' lives, evoking responses that were incongruent with the narrow parameters of the question that sought Yes/No or a single number. Kate's insights illustrate that the standardization of these questions and the structure of the interview might render them routine, impersonal, and efficient, the actual practices shore up a wider range of possibilities.

Standardization supports the kind of scientific validity that is required of a large-scale clinical trial like ACTPOC, but the inflexibility of the standardized instruments is a source of frustration when they do not fit with the context of the interview. For example, Julia explains, "I hate not being able to clarify questions. I mean, they sit there, they read a question, they don't know what it means, they ask but we can't tell them what it is. I think the data is completely useless in comparison."

This research norm, which aimed to standardize the questions asked, was a point of frustration for the RAs and participants alike. An example of a question that provoked confusion was “How often have you felt blue (in the last 30 days)?” In staff meeting, the RAs conveyed that question was especially confusing to participants whose first language was not English. The RAs pointed out that “feeling blue” was a vernacular that not all were familiar with, and asked for permission to clarify the purpose of the question (which was one of several measures of depression). The standardized protocol was referenced to explain why the question could not be changed. As it was once explained during a staff meeting, RAs could not translate or adapt the questions to the participant, as the question would no longer be standardized across the sample.[103] It was recommended that RAs select the “Don’t know” option as a response and continue to note these problems they encounter with particular questions, which may be useful for PIs in determining whether to exclude a question entirely in the future. Because the questions were selected prior to the start of the study, they could not be changed without discarding the existing data; as any future data would be considered incomplete because it would not include responses from the entire group.

The RAs were tasked with managing participants to adhere to the limits that standardization imposes. In the following example, Kate shares the common experience of intervening in order to maintain the uniformity the survey interviews required. She explains how she was especially conscious of this on the occasions she

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[103] This approach is routine for most behavioral health surveys that rely upon aggregate responses. In other words, varying the question would make it “non-comparable” to the previous way it had been phrased.

forgot her flash cards (participants use these laminated cards to select their answers; for example, a Likert-scale of 1-5 where 1=Always and 5=Never).

> I think I notice that even more when I don't have my flash cards, 'cause I'm reading them the question, and they're about to actually answer with their own answer, and I'm just like, 'No no no, wait you have to use one of these' [*her voice changes as if she's reading off a list*]: 'Sometimes, always, never, rarely' and they were just about to say something—
>
> [*Shannon jumps in*]: Yeah, or they'll say something and you ask, 'Is that 'Sometimes'?

The following example reveals how Kate integrates her concern for the participant and their emotional response with her role as an RA, to interview and collect data. Kate says,

> Especially with the participant, in the beginning, depending on the participant, I know some questions that I'll ask, will get on their nerves or they'll give me attitude or something, even if I say, 'Look I'm going to do this interview, some of the questions may be repetitive or obvious, but I have to ask these questions.'

Kate's empathy with how the interview's repetitiveness affects participants is one of many examples of the RAs' efforts to minimize participants' possible discomfort and help them feel at ease. Kate prefaces the interview by conveying to the participant that she understands the questions may be "repetitive or obvious" but as the interviewer she "[has] to ask these questions." Kate could have just as easily noted these qualities of the questions and left it at that. However, she did not displace the participant's frustration onto the questions—the external object in their encounter—that might perhaps allow her some distance and relief from the participant's "nerves or attitude." Rather, her approach is empathetic and relational, one that accounts for her own role in "doing [the] interview," which involves both requesting the participant to endure its repetitiveness and sharing something of her own role as interviewer—she *has to* ask the questions. Kate did not attempt to conceal to the participant the fact that these relations—asking questions and answering them—are hierarchically structured: however, her comments hint at the roles that have already been created for them, which leave little room for either participant or RA to maneuver. Kate's approach is a relational one, a quality that is also conveyed by how she places herself in the encounter.

Kate's efforts exemplify how the RAs, in response to the constraints they encounter in these standardized interviews (i.e., asking obvious questions and repeating questions), *multiplied* their efforts, which helped participants to feel at ease and to get the job done. In other words, to argue that RAs are totally constrained misses the creative, empathetic, and affective qualities they employ in their work. While it seems that standardization would limit the RAs role to simply "reading the question," the RAs' perspectives also suggest how they crafted *new* strategies in order to meet the demands of the protocol.

The contingencies and variations the ACTPOC RAs described do not, I think, indicate their defiance towards or rejection of the prevailing standard scientific principles necessary for comparison. However, they do complicate the narrow aims of standardization and research norms in the health behavior sciences. As Timmermans and Berg state, "Universality through standardization is at the heart of medical and scientific practice…Standards aim at making actions comparable over time and space" (Timmermans and Berg 1997:273).

The PI to whom Hurley refers (who he had worked for many years prior; not an ACTPOC PI) seems to have missed that study instruments do not operate mechanistically. The alternatives the RAs develop to do their work support Susan Leigh Star and Martha Lampland's argument that the slippage between "a standard and its realization in action" (Star and Lampland 2009:15) is a crucial moment in which to study quantification and standardization. In other words, interviewing people involves much more than the rote asking of a question and the recording of an answer (even when the same questions are asked). Standardization does not restrict intervention and interpretation across-the-board; in fact, the examples presented here support Timmermans and Berg's argument that protocols *require* complex negotiations. In the following example, Hurley does not reject the PI's instruction to "read the question the way it is written"; rather, his example captures the broader—and often unrecognized—scope of work involved in standardized interviewing.

> We bring a certain thing to the interview whether you see it or not. We bring a quality of compassion to these interviews. There's certain questions that I may ask in a high tone. And in freestyle form. Y'know what I mean? And there's certain questions that I tone down to give the impression like, these are important and I need you to answer these, when we talk about gender differences, how do you identify yourself. For me that's a serious… Are you

> straight, you gay, you bi, you whatever. When we get down to the more serious stuff, I try and tone down the questions.

Volume of the Work

In the previous section, the RAs discussion of their work identifies a range of interviewer qualities that are essential in their jobs, alleviating possible discomfort and as Hurley describes it, "listenin' to what's goin' on with them." As some of the literature on empirical studies of EBM reveal, the physicians who draw upon these guidelines are not simply practicing a form of "cookbook medicine" nor are these RAs conducting "cookbook interviews." Adhering to the study protocol is a challenge, and the RAs maneuvered the standardized questions alongside their own judgment, experience, and understanding of the situation at hand.

The RAs' work duties were largely relegated to conducting interviews and maintaining the administrative tasks that go with it, such as those described in the opening of the chapter. The standardized interview questions were indeed repetitive, and so too were the other work activities that were organized to ensure data collection. The RAs' official daily activities rarely strayed from the broad goal of ACTPOC's research at a key point of its production: the gathering of data. The RAs' research-gathering activities were crucial to ACTPOC's primary aims, which were to rigorously test whether participants randomized to the intervention groups screened for ACTs at higher rates than did participants who were randomized to the control, or "standard-of-care" groups.[104] But on a day-to-day basis, the RAs rarely, if ever, came into contact with other aspects of the study. This isolation was a clear source of frustration for some of them, who imagined that a better understanding of and interconnectedness with the work of the other staff would allow them to see how their work was contributing to the broader goals of the research study: to improve the health of PLWHA.

Because they are extremely busy conducting interviews, follow-ups, and administrative work, the RAs' opportunity to embrace new challenges and develop innovative projects was limited. The RAs' workload, and the repetitive quality of it, sometimes invoked a feeling of weariness among them. They expressed regret that their busy schedules did not allow them the time to attend the trainings that were regularly hosted by the agency they work for (and, for which staff from other agencies traveled locally and regionally to attend). These trainings offered presentations and workshops on a host of public health concerns, such as HIV confidentiality laws, domestic violence in LGBT communities, substance use and harm reduction.

> JULIA: But speaking of trainings and stuff, [*name of agency*] has a lot of talks and stuff, I hear about trainings but we never get to go to them, I used to go but we're so busy with interviews—
>
> HURLEY: 'Cause we're so full of interviews! We don't have time to do nothing.
>
> SHANNON: We really are.

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[104] ACTPOC had many other research questions that related to this goal: for example, did intervention group participants' knowledge of ACTs change from their baseline visit to their follow-up visit, when they had completed all three groups? Did age, constructed as a variable, mediate whether participants were "more likely" or "less likely" to screen for an ACT in the future?

> HURLEY: There are new techniques that have been developed in interviewing that we could utilize ourselves.

The need for further training was also discussed in relation to their introduction to their jobs. Kate notes that she draws on training she learned at a previous RA job.

> JULIA: I don't think I did any training. Training, did you get trained? [*She turns to KATE*.]

> KATE: I got trained from you. Which is different from where we worked before. Of course ours, we were in a hospital, it's very much so…some of the things that I learned from there that Julia learned too.

The RAs' work was structured into the broader study in such a way that limited their opportunity for further training. None of the RAs spoke of opposition from management to attend trainings; they simply did not have the time to attend. The RAs worked exceptionally hard, and were more than capable at conducting survey interviews, locating participants, and completing related administrative tasks. Training activities that might expand upon their current skills were not structured into their jobs. In other words, these positions did not *require* additional training; the activities undertaken on the first day of work was much like their last. My impression was that some of the staff felt like they could not justify trainings within the context of their duties as an RA, and while none were directly discouraged, none pursued them. In this regard, the intense interview scheduling, combined with the standardized quality of it, may facilitate the de-skilling of their positions.

Julia pointed this out to me on a particularly hectic day. It was late afternoon, and she had just returned to the office from the field site where she had spent the day conducting back-to-back interviews. Spotting Julia from my cubicle, I wandered over to say hello. She was sitting at her desk tallying up the day's money and transportation cards she had dispersed to participants that day, at the same time eating a late lunch, having worked through her mid-day break. "What do we learn here that we can take elsewhere?" she shook her head and sighed. "It's like once you know the job, figure out the procedures, that's all there is to know. The only thing that changes is the participants who come through here. I get mad sometimes…" she paused as she clipped a stack of receipts together and took a bite from her styrofoam tray of food. "I think we need a little more than just interviews. We need to have more than just our interviewer role. To be able to, like, accumulate more info I suppose. We're all stuck. We all make calls, we all schedule interviews, we're all here doing interviews, there's nothing coming in from outside." Julia's perspective lends support to one of Berg's arguments, in which he points out that protocols can create new possibilities and opportunities for research staff (Berg 1997:1087), but cautions that "without specific attention to the acquisition of new competencies 'de-skilling' is inevitable" (ibid.).

Locating and Following-Up with Participants

When the RAs were not conducting interviews, they were busy calling participants, returning calls,[105] mailing letters with a reminder date of upcoming appointments, and retrieving confidential documents from a locked cabinet that stored participants' locator forms. One particular source of anxiety for the RAs was to obtain high follow-up rates by completing surveys with all (or most) of ACTPOC participants that had enrolled. These high follow-up rates are one criterion for how other scientists will assess the validity of ACTPOC's research findings. The achievement of high follow-up rates is looked upon favorably in the reports PIs submit to their funders, to peer reviewers evaluating their work for publication in a journal, and when competing for new grants. Follow-ups involved very labor-intensive activities that often required pursuing any leads and remaining persistent despite facing dead ends.[106] High-follow up rates also demanded that RAs be flexible, such as accommodating a participant who worked full-time by meeting in the evening or occasionally on a Saturday. The RAs were extremely good at conducting follow-up and tracing the whereabouts of participants, but the extensive amount of time and energies devoted to locating them

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[105] One morning I caught Julia as she was making her way to her cubicle and asked her if she could, on such short notice, schedule me into one of the offices that afternoon. Julia was scanning the room schedule on her computer screen when she paused to push the blinking light on her phone and punch in her code. The recorded voice said, "You have…thirty-two new messages." All calls using ACTPOC's toll-free number are routed to Julia's phone, and she receives and returns many of the calls. Julia disconnected her voice mail and sighed. I immediately assumed that Julia had been putting off checking her messages for some time. As if she could hear me thinking this, Julia turned to me and said, "That's just since I left at five o'clock yesterday," and explained that receiving that amount of calls, especially when an intervention cycle was complete and a new batch of recruitment coupons were distributed, was not unusual.

[106] At the end of the study, the RAs achieved a follow-up rate of approximately 90%, which is extremely high.

did not always bring the desired results. When participants missed appointments, the RAs' initial attempts to locate them sometimes resulted in the familiar recorded voice of a disconnected phone or the return of unopened letters stamped "Return to Sender." Calls to case managers, family members, and other contacts sometimes yielded little information as to the participant's whereabouts. Detailed messages (that included reminders of the cash reimbursement they will collect upon completing the visit) accompanied the requests for the participant to call and (re)schedule their interview. Sometimes, four or five phone calls and many messages to different sources were left before the participant was reached.[107]

Many of the ACTPOC participants' schedules were also quite full. On a daily basis, this included working and/or looking for work; attending doctor's visits and other medical appointments; taking care of themselves as well as children, grandchildren, spouses and partners, and elders; and negotiating complicated city bureaucracies to obtain benefits and access services.[108] In addition, many participants

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[107] Although follow-ups sometimes proved to be a tedious task, the RAs were not withheld their paychecks if they were unable to complete an interview with a participant. That the RAs were guaranteed their hourly wages regardless of the outcome of their efforts contrasts with the experiences of the ACTPOC participants, who despite time and energies recruiting potential participants had no guarantee of payment.

[108] For example, a hugely time-consuming effort for participants was using the public transportation van services for people with impaired mobility. The law guarantees that public transportation must be accessible to all persons, and several ACTPOC participants qualified for this much-needed service. However, the vans would arrange a long window of pick-up and drop-off, sometimes as long as ninety minutes in both directions. The long wait periods and the problems of unregulated drivers were even featured in a national newspaper article that described the staggering burdens disabled passengers experienced in making a doctor's appointment.

experienced HIV-related illnesses and side effects from HIV medications, as well as other health problems such as Hepatitis C, diabetes, and heart disease. Some active users spent time attended to their drug use and harm reduction support; while some participants in recovery from drugs and/or alcohol attended several 12-step meetings a week in addition to outpatient (and occasionally residential) detoxification and other forms of drug treatment. The qualitative interviews that I conducted with participants revealed two areas of concern: finding ways to supplement one's fixed income; and for those without stable housing, finding a safe and clean place to live in an overpriced housing market. The burden of traveling to the field site to complete a computer survey, sometimes several months following their last visit, often competed with other pressing needs (although many did because the $25 reimbursement was badly needed). When the RAs did reach participants that had missed appointments or with whom they have lost contact, they attempted to convince them to come to the field site and complete their follow-up appointment (within a window of time defined by the protocol). At the same time, they refrained from being unduly coercive. Sometimes the RAs felt uneasy in their efforts discerning the line between the two. All felt very strongly that they did not want participants to feel pressured and questioned how participants felt about their tactics. In the following quote, Kate imagines herself as the participant who is receiving follow-up calls, messages from friends and relatives, and reminders of cash compensation. The concept of choice does not adequately describe the context by which participants, receiving numerous calls and in need of money, agree to follow-up interviews.

> I feel like, y'know, I'm scared to think like, how many people end up thinking, 'Oh gosh they keep calling me, lemme just end up doing it.' Y'know? I would like for you to end up doing it because you want to do it, not because you're annoyed or irritated about the fact that you keep ending up getting these calls and this twenty-five dollars keeps getting waved in front of your face…Y'know, so, there's certain things where you wonder whether or not, y'know, I'm making this a choice for you, but if I'm calling you after a whole bunch of weeks of calling your parents, your grandparents and I'm calling like other people, like how much of a choice is it really?

Follow-ups were a recurring item on the weekly staff meeting agenda, which included a computerized list of follow-ups that needed to be completed. If the end of a window for a participant's follow-up was approaching, this was also emphasized. Together with a member of the management team, the RAs discussed their efforts to locate that person or, if they had been located and rescheduled, to provide the date of their upcoming appointment. It was only when a participant verbally said "No, please don't contact me" to an appointment (which, to my knowledge, happened only once during the study) were follow-up efforts withdrawn.

The topic of follow-up was not just limited to staff meetings either. During a follow-up interview, Kate had asked a participant, "Have you had thoughts of ending your life in the past thirty days?" Her response was "Yes." Kate brought her concerns regarding the participant's safety to a member of the management team, and recalls her ensuing discomfort when the topic of follow-up entered into the discussion.

> I did stop [the interview], yeah, I don't know if it was right or wrong, but y'know, "You're having these thoughts" and she's like yeah, so her husband relapsed after five years and she thought everything was okay, and then last week she had thoughts of ending her life. "I didn't want to live anymore. I didn't want to do this, I didn't want to do that." She's discussing this, and I'm letting her know, this is where I guess, where a little bit of your therapeutic role comes in and you're going to actually say something, like, do you have a plan, follow some kind of suicide protocol. "No I don't." So at the end of the interview I gave her the resource directory and asked her, "Do you want to speak with somebody?" and I was like, "Well here's the resource directory just in case." And so I gave it to her and so after, I just had a, y'know, uneasy feeling. You just had someone tell you that like y'know, you had somebody tell you this last week. But then here we go with the fact that we're in research—[SHANNON: It's counterintuitive.] Yes, exactly. It goes against what you know. So once I went back to the office, and it was like, [the manager asks]: "Okay, so when does her husband come in for a follow-up?" [*laughs*] Like she was talkin' about she was gonna commit suicide the week before! [*Kate's voice begin to tremble a little.*] Not when her husband is comin' in for a follow-up. Y'know? ... I was able to go and check up on her and I found out that she went for [an ACT] screening with Arturo and she's fine, but it's just like […] and it was just like left off, 'Oh, oh that was sad. But let's check up on the follow-ups.'

Kate's clipped tone, fast speech and body language were palpable in the room as she spoke. Describing this event made her uneasy and the anxiety she conveyed was unmistakable.[109] Her angst serves as a reminder that it was not only the participants, but also the RAs that were affected by the questions they asked and the responses they

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[109] The experience of "secondary trauma" results from listening to deeply painful experiences. Incidents such as hearing expressions of suicidal ideation often raise the specter of secondary trauma that is experienced when listening to deeply painful experiences. It is important to keep in mind that it is not uncommon for RAs to hear participants' anguish, which is part of the work.

received. This selection of narrative not only sheds light on the participant's crisis and her relationship to the study; it is also Kate's story as well.[110]

"[Going] against what you know" and introducing follow-up into the conversation illustrate "the protocol's structuring role" (Timmermans and Berg 1997:294), even in distressing circumstances. Clearly, both the RA and the manager were scripted by the protocol, but this should not neglect an important difference between them. The manager's responsibility was to regulate the RAs to meet the protocol's requirements (similarly, the manager faces the same pressures from her supervisor, and so on), while the RAs' jobs were to discipline the participants to complete surveys and return for follow-up visits.

In her distress, the participant who discussed her husband's drug relapse and her thoughts of suicide breached the interview's script, but her plight was eventually subsumed to the study's goals. Her despair became a springboard to discuss the need for her husband's follow-up interview. While on the one hand such a move seems to be reductive, it may also be instructive to think about its productive capacity as well, as it interpolates both participant and RA into an established trajectory in the protocol.

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[110] The focus here is on Kate's experience, and the discomfort she felt when the topic of follow-ups entered into the discussion regarding the participant's suicidal thoughts and distress. Of course, it goes without saying that the Project Manager might have experienced this encounter differently; and it is possible that her steering the conversation to the topic of follow-ups reflected her own emotional response to the situation.

"How many times have you injected in the last 30 days?" The Enumeration of Suffering

In the research interview, participants were asked to reveal certain kinds of information according to a standardized format, but their responses sometimes resisted the narrow responses they could choose from. It was not unusual for participants to modify the questions they were asked and/or to depart from the responses permitted in the interview structure, which were organized into "Yes or No"; "Sometimes, Often, Never"; or a single number. Hurley says,

> ...asking these questions kick up certain attitudes, certain fears, certain feelings or whatnot, and they may somewhere in the process get emotional [...] and you can see this stuff is starting to erupt inside of them, and to move them on would be really bad for the interview, y'understand, where you're forced to listen to some of this, y'understand? And sometimes I've had interviews, where they cry behind this here. Where, "I'm positive, I shot dope with my brother, and I got it from him, and he died, and then my younger brother shot dope with me now he's positive, so we gave it to each other, one of us died, and I'm next or he's next" and it's kickin' up all this emotional stuff inside of them leading from substance abuse questions, you need to slow down, allow them to feel what they feel and at least let them vent. Acknowledge that you understand, y'know, "I feel you, I know what's goin' on' and you're entitled to those feelings" and trying to find that line where you're not going to go into a […] counseling session with them, to try and stabilize them and get them to a point where they can answer these questions, for the remainder of it, as opposed to just like "[…] I'm not gonna answer that question 'cause it's kickin' up my feelings and whatnot." How many times have I injected heroin in the last thirty days? Did I share?

The standardized questions Hurley asked structured the encounter but did not wholly determine it. The participant did not yield to the question's aim to elicit the number of times he had injected drugs in the last thirty days, and Hurley did not demand an answer. Recognizing the participant's signs of emotional anguish that were triggered by the questions, Hurley anticipated that ignoring them would have negative effects for both the participant and the interview. Hurley's response to this participant in distress involved putting aside the interview to be present with him. "You need to slow down, allow them to feel what they feel."

Hurley's encounter offers a clear example of some of the contradictions RAs faced in their work, which is revealing of how he managed these competing demands with wisdom and compassion. The interview question facilitated the participant's recall of injection drug use; however, as Hurley illustrates the participant's response to this question and the emotions it evoked were occurring *in that very moment*, not as it were, a past event as the question framed it. On one hand, Hurley highlighted the importance of "at least let[ting] them vent…To try and get them to that point where they can answer these questions." But on the other, Hurley was also faced with the task of eliciting the participant's exact response to the question that aimed to standardize injection drug use by episode. The interview question triggered the participant's painful recollections; however, his expressions of social suffering were also obscured by the very same question.

There was no code for the young man's grief of losing his older brother who had transmitted HIV to him, nor was there any way to record the torment he feels having infected his younger brother. His expression of loss and guilt, as well as the tragic injustice that makes the provision of new syringes illegal and inaccessible is subordinated to the numerical answer that the question aims to record. The participant's narrative of overwhelming emotion, tragic injustice, and complex social ties was ultimately transformed into a different kind of story, one that aligned with the interview question, "How many times have you injected illicit drugs in the last thirty days?" This participants' suffering was enumerated, to serve as the basis for the knowledge claims of experts.

The assumption that standardized questions yield straightforward and transparent responses (as evidenced by the limited amount of time in which questions are to be asked and answered) did not always bear out in practice. In another example, Kate problematized how the standardized measure ACTPOC used to identify possible psychosis was incongruent with the affective setting in which these questions were asked.

> And it's just like—to me, it's the worse feeling. Especially for someone that you know needs that to be heard. Yes they need to be heard. Because a lot of times, even with interviews, you're asking questions about how they feel. And people never ask them before. They don't get asked this. Like even when you're asking about like, how you've been feeling over the past month, like y'know to just, y'know, check to see if there's any psychosis, they're just like, "Hmm…" Just to actually ask the story, there's so much, you can tell, when they build that comfort with you and they want to be able to express themselves but at the same time you're going to have to move on. At the same time, 'Okay, we're going to have to move on.'

The limitations Kate described are highlighted in Marc Berg's observation that silences are required for protocols to effectively operate. Berg states, "Similarly, bringing the patient's own voice back to either yes or no brings about the unequivocality needed for protocols to work…inevitably the requirement for stable and predictable elements predisposes the taming, or even silencing of these potential sources of contingency" [Berg 1998:241 (Star 1989)].

Hurley and Kate's descriptions of their experiences with the two participants in crisis were central to our focus group discussion, but should not give the impression that the RAs' interviews were composed only of such powerful and intense situations. Most of these interviews were mundane. On any given day, the RAs conducted two, three, sometimes even four near-identical interviews (the follow-up interviews are shorter than the baseline). The following example illustrates how managing participants' subjectivities to conform to the format of the interview became routine. In describing her work conducting interviews, Julia said,

> It's totally boring. It's just interviews and getting people. There is no rocket science to this. I mean, in fact I don't use my brain at all. In fact I could go on autopilot all day. [*Everyone laughs*.] I go in there, I dial my numbers, [*Speaking in a monotone voice*] "Hi, I'm Julia from the ACTPOC Project. We need to schedule you for an interview. Okay, 'bye." Hang up.

Julia's approach shows the possible advantages that the enumeration of social suffering might offer participants and research staff. Mykhalovskiy and Weir point out that medical humanism "interprets evidence-based medicine as erasing and ignoring the patient" but it is a mistake to assume that patients want or seek "deep disclosure" (Mykhalovskiy and Weir 2004:1063). The logic of the interview to classify, collect, and enumerate from a distance may come as a relief for both staff and participants who did not wish to be circulated into confessional and self-revelatory narratives (ibid.).

Science & Work

One aim of this chapter is to broaden theorize knowledge production as it relates to these less visible but no less important kinds of work the RAs did in the clinical trial settings at the heart of EBM and EBBM. It reversed the most visible forms of EBBM (that include the presentation of cohesive[111] data highlighted in a peer-reviewed journal or conference poster) to an earlier phase of its production: the research interview. The RAs' discussion highlighted the unpredictable moments and everyday routines of their interviews and other work activities, and revealed the strategies they undertook to manage the conflicts their work presented. These ethnographic findings highlight that despite the RAs' circulation into the demands of the standardized interview and study protocol, they resisted being fully reduced to them.

If this examination were to narrowly focus on the standardized instruments the RAs conducted with participants and the unvarying and even rigid processes they adhered to, it might lead to the erroneous assumption that their work is mechanistic, routine, and requires a minimum of skill. My ethnographic research shows that just the

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[111] This is not to say that the data itself is orderly (most biostatisticians would argue that these collections of numbers are themselves dynamic and open to multiple possibilities for analysis and interpretation), but that the disorder is framed within the body of data that is to be analyzed. The kinds of disorder and contingencies that precede the assemblage of data have been transformed, at an earlier stage in the process, at the site of the research interview.

opposite is true. The RAs' discussion of their work practices, coupled with my participant observation of the interview process, illustrate that uniformity and standardization were never fully closed. The RAs' clinical judgment, ethical assessments, interpretive skills, tacit and formal knowledge, and cultural and affective connections were present in their work practices and vital to what they did. These emotional, intuitive, and intellectual labors created a comfortable and encouraging setting for those who were interviewed, at the same time yielding the high-quality data that the PIs expected.

A great deal of insight, assessment, and negotiation was vital to the RA's role in administering surveys and collecting data. The repetition and routine in applying the survey instruments did not mean that the RAs operated mechanistically, and many would not have gotten very far if they had, as the RAs expressed. Overall, the RAs unhesitatingly describe the satisfaction they experienced in their work, but at times reveal frustration with the practices that structured their work in such a way that was incongruent with their interviews, participants' needs, and their own ethics. They question if and how what they do contributes to supporting the health of PLWHA, a distant and abstract idea that was largely disconnected from their everyday work activities.

During interviews, the RAs were often brought face-to-face with the pressures and challenges participants encounter at the same time they were tasked with mobilizing these participants to comply with the demands of the research survey. The RAs had to enforce survey norms ("please answer the question"); meet institutional mandates (managing the time allotted per participant in order to keep up with the demanding interview schedule); engage in nonjudgmental listening; suppress their own intuition; and occasionally, attend to participant breakdown or crisis. When viewed from a daily perspective, the RAs, much like the IGFs, spent a great deal of time and energy attempting to negotiate the differences between the standardized material and the participant who sat before them. Socializing participants into the framework of the study was an important part of what the RAs do; they served as a valuable bridge that linked the two.

For a variety of reasons, the RAs' efforts to form bridges with study management—bringing their own and participants' concerns to their attention—were not as productive. The RAs were unable to influence the course of the study or institute the changes they would like to have made. This is not because the ACTPOC management were not concerned or do not care—quite the opposite, in fact. They were extremely committed to supporting the staff, whether that was listening, addressing the intense workload (that led to the addition of another RA, Shannon), or encouraging open communication. The staff was far from ignored; the high quality of their work was often acknowledged and their labors were frequently recognized in staff meetings and emails. I am not alone in my interpretation of the ACTPOC management, especially the primary PI's openness to listen to and acknowledge the expertise of the non-managerial staff that worked for her. She had a strong and solid reputation among her staff, and they all spoke very highly of her.[112]

However, the fact remained that the norm of standardization in research protocol development restricted the RAs to conducting the interview; as is the case for most health behavior research studies, none took part in the planning stages. For example, all of the RAs agreed that if they could, they would have suggested revising the interview guide. Yet the preparatory activities involved in conducting a research study are often limited by the ways research studies apply for and receive federal funding. Many health researchers face the challenge whereby their employment (and their staff's employment) depends upon applying for and receiving grants. Proposing a research study involves a great deal of work, and PIs often begin this process before their funded grant runs out. This structure of funding does not permit PIs to assemble a team and recruit their input into study design.[113] This relationship of protocol to research workers

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[112] In fact, one of the stories that regularly circulated among RAs was of the primary PI who, during the pilot of ACTPOC many years before, had actually sat alongside staff and conducted interviews when the need arose, during a period of understaffing. The RAs' accounts of her doing so, without fuss, revealed how much they valued what they described as her willingness to conduct interviews when the situation demanded it. They also viewed that experiences such as this gave her insight into what their jobs were like, which contrasted with other PIs they had worked for (such as the PI Hurley described). She also listed staff's names as authors on a conference poster, something that was well-deserved and should be mandatory but more often than not credit is not shared with the staff whose roles are important but ignored. The fact remains though that these attributes reflect the individual characteristics of integrity and fairness of this particular PI, but are not structured into the research economy as a whole.

[113] It is beyond the scope of this study to explore the larger domain of research funding that executes this kind of labor stratification, which warrants closer and careful study. It would be an error to examine the

illustrates how the power of the former to determine the latter, but not the reverse.

EBM and EBBM are often heralded as promoting and expanding access to information. Stephen Timmermans and Aaron Mauck state, "EBM promises to create better-informed patients and clinicians by offering collectively agreed-upon and publicly available information about treatment options" (Timmermans and Mauck 2005:20). The hallmark of the DEBI is the translation of peer-reviewed studies that have demonstrated scientific efficacy into "packaged" interventions that would be adopted by health organizations. Such an effort seeks to expand the knowledge base of these interventions beyond individual scientific experts that read and critique each other's work. The institutionalization of the DEBI in the CDC's funding priorities elevates the randomized clinical trial above other kinds of research, arguing that this scientific approach benefits everyone. Some claim that EBM "levels the playing field" in that it offers access to information (basically, published literature), intervening in what was once seen as the province of doctors and professionals. On the one hand, EBM may undermine the exclusivity of the medical profession; however, Timmermans and Kolker argue that EBM creates a "new elite of clinical researchers in medicine" [(Timmermans and Kolker 2004:181) Hafferty & Light 1995].

RAs' experiences solely in relation to the study's management, for the research structure is far from ideal for its PIs, who must negotiate a research agenda in an increasingly lean funding environment that prioritizes "cost-effectiveness" at the expense of the research goals and the needs of staff and management. The limitations the RAs experience may be more accurately viewed in relation to the increased competition for ever-dwindling federal research funds, which are related to government funding mechanisms caught by broad neoliberal restructuring.

The benefits of the scientific information discount the RAs' activities to solicit and construct that evidence, which appear to have the *opposite* effect upon the workers who produce the information. The ACTPOC RAs sometimes experienced a sense of futility in their work—for example, as Julia explains in her frustration in not being able to communicate questions to participants, which conveys her own sense of powerlessness: "Why can't we explain it to them?" It is experiences such as these that contributed to the RAs' varying levels of disillusionment regarding how their labors contributed to improving the health of PLWHA. In a clinical trial setting, data collection rarely changes, a fact that minimized the RAs' access to new sources of information and knowledge. In addition to the immediate benefits such training would have brought to their work, they missed the chance to develop skills that could have expanded their future research and job opportunities. The experiences of the ACTPOC RAs suggest that EBM has contributed to an even more rigid division of labor in the workplace that disconnects them from other activities and broader perspectives of what they do.

The experiences of the RAs lend important insights to the body of empirical studies of EBM in practice, whose focus upon higher-ranking professionals tend to overlook the experiences of other staff. EBM and EBBM claim to increase access to information, which certainly seems to ring true for the medical residents in Timmerman and Angell's study, who drew from online databases to research medication interactions and the presentation of uncommon symptoms. (Timmerman and Angell, 2001). But the ACTPOC RAs had almost an opposite experience from the clinicians and other professionals who use EBM and EBBM. Research protocols for clinical trials depend upon large data sets, enough participants to assign to intervention and control groups, and statistical power, all of which require an intensified division of labor and the rigor and precision of standardized surveys. In terms of everyday practice, the RAs' interviews were indeed repetitive, and they had few opportunities to engage beyond their particular narrow scope of work. These characteristics of clinical trials contribute to the increasing standardization and repetitive quality of RAs' jobs: they conduct the same interview over and over; trainings are limited; and labor has become more stratified so that there is less cross-fertilization and exchange of ideas among various team members.

Concluding Thoughts

Latour and Woolgar's groundbreaking study of laboratory bench scientists offers a way of thinking about and theorizing the work that is rendered invisible in scientific economies. They argue that official representations of scientific work (such as journal articles and grant applications) involve processes that they refer to as social *deconstruction* (1986:179), which render absent the daily and routine labors of the "uncredentialed" lab technicians and secretarial pools that helped to produce it. The strength of scientific findings depends in part on a successful deletion.[114] Latour and Woolgar's findings help to explicate the position of ACTPOC RAs, who will disappear, along with the participants, in the official representations of research data. Along the way, RAs also deconstruct participants' complex realities to preserve the format and content of the standardized interview. Likewise, the RAs' work "making EBBM work" similarly recedes in the final outcomes ACTPOC produces.

The RAs and participants share what Thomas Gieryn describes as the "boundary-work" (Gieryn 1983) of crafting science: participants were asked to frame their responses to the demands of the Likert-scale; RAs listened to the narratives of social suffering and injustice but could only document the number of injection episodes. The RAs occupied a liminal space where they were tasked with maintaining scientific order—they had to move past the participant's breakdown and extract a number of injection episodes to satisfy the survey—at the same time their role in the research hierarchy prevented them from attending trainings and participating in conversations and exchanges regarding the broader goals of the study. Their integration into a highly regulated division of labor illustrates Gieryn's powerful example of "how the demarcation of science is accomplished in practical settings" (1983:781).

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[114] Latour and Woolgar do not suggest that their findings should invalidate the claims made by the scientists they studied, but rather to take note of the social processes that support this work. Similarly, these interviews and analyses of the RAs at work are not meant to doubt the credibility of ACTPOC data, but to expand our understanding of the processes that produce that data.

This chapter speaks to the intense demands the ACTPOC RAs experienced in their work, yet at the same time, none of the RAs were completely caught by it either. Neither the RAs—nor the participants—seemed to be fully governed by the standardizing processes they encountered in the interview. The RAs' analyses of and experiences with standardization suggest that while standardization is a powerful tool, it is never fully closed. The alternatives and oppositions the RAs employed in their work practices illustrate the significance of "articulation work" (Star, 1991:275) that is, the work that is invisible to rationalized models of work yet necessary for its completion.

CHAPTER SIX:
AUDIO-COMPUTER ASSISTED SELF-INTERVIEWING (ACASI) in the NEW RESEARCH ECONOMY

I tap on the half-open door to the office Julia is using at the field site.[115] Waving me in, she tells me her next appointment is not scheduled to arrive for a few more minutes. I sit down and watch as Julia counts bands of five and ten dollar bills and writes the amounts in her cash log. Next to the laptop computer and headphones is the single paper form for the sixteen-week follow-up visit, where Julia has filled in the participant's identification number in the space provided and checked the box noting their assignment to the intervention group arm of the study. As Julia sorts the money, she asks me if I've caught up with the latest episode of the British spy show we both follow and soon we are deep in conversation. Even as Julia relays her complex prediction regarding the hidden motives of one character that plays a double agent, her rhythms of counting and recording money remain constant.

A few minutes after eleven, a participant appears in the hall outside the doorway. "Hello there! Glad to see you," Julia beckons her inside the small room. "Come in, sit down." Julia introduces me to the participant, Sandra, who I recognize from an intervention group cycle that had taken place a few months before. Sandra and

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[115] A few minor revisions were made to modify the identities of the participant and staff but these do not change the interview's overall content and tone. I selected this encounter from my field notes because it is typical of many ACASI interviews I have observed and administered, and captures a bit of what happens at the field site where these interviews were conducted.

I exchange hellos while Julia types Sandra's four-digit identification number into the laptop computer. Julia tells Sandra, "This will be like your last visit, I'll ask you the first part and you can do the second on your own using the computer. It will last about an hour, maybe less."

Sandra nods. "Okay."

"Let's see, the last time you were here was—"

"Back in September I think," she replies.

"Yes, says here September 20th. Okay. Have you been enrolled in a clinical trial since you were last here?" As the participant shakes her head no, Julia states, "Have you been screened for a clinical trial? A screening is a discussion between you and a health professional regarding any interest you might have in clinical trials..." Julia's words are identical to the computer prompt that defines "screening" any time it appears in the interview. I notice Julia is not reading from the screen, but recites the text from memory.

Sandra pauses for just a moment. "I called some place on the back of weekly papers? It was one of those free ones—"

"A screening is an actual visit where you meet with a medical professional face-to-face to see if you may be eligible for a trial." Julia's voice softens a bit. "Have you done anything like that since you were here last, in September?" Before Julia finishes her question, Sandra shakes her head no.

After a few more questions, Julia tells Sandra that, just like the last time she came in, she can complete the remaining part of the interview herself using the computer. Julia says that today's visit is much shorter than her last one; she will probably be done within the hour. "Just let us know if you have any problems or questions, okay?" Sandra nods and says she liked using the laptop, that it went fine when she used it on her last visit. Did she want to use the headphones? Sandra declines, saying that she prefers to read the questions herself. I am relieved and I know that Julia is too; the headphones do little to muffle the computer's robotic monotone, a male voice of clipped speech that pauses abruptly between each word.

For the next hour, Sandra stares intently at the screen, her brow occasionally furrowing. Her lips move slightly as if she is reading but makes no sound. Occasionally she quietly yawns and shifts her weight on the hard chair, but her concentration remains steady. I doodle on my notepad while Julia puts checkmarks on a list of ID numbers to note the window of time she will need to schedule participants for their upcoming follow-up appointments.

Julia's whispers that she is thinking of ordering Thai today—did I want anything? I nod and she passes the worn menu to me. It is quiet again in the small room except for Sandra's steady clicks of the mouse. As I look over the lunch specials, I notice a slight change to Sandra's rhythm: her mouse clicks have sped up and I silently predict that she will finish soon. As if on cue, after a few more clicks Sandra sighs loudly, pushing back from the table. She stretches her arms straight out in front of her and I see a faint smile appear at the corners of her mouth. “Alright, I’m all done. That’s so many questions, all the same. Am I finished for today?” Julia nods, “Yup, we are all done here. How’d that go?” She hands Sandra a receipt along with $25 cash and a public transportation voucher for that visit. “Fine, just fine,” Sandra replies as she neatly prints her initials on the receipt. Julia tells her, “You’re not due back for an interview for a few more months, so I’ll be in touch so we can set that up.” Sandra folds the crisp bills into her purse and nods. She stands up slowly and tells us to enjoy our weekend. “Have a good rest of your day; see you next time,” Julia replies, looking up from her task backing up the data on an external drive that she has retrieved from her bag. As soon as Sandra leaves, Hurley sticks his head through the half-open door to tell Julia that her 2PM appointment has already arrived, and that she’s been sitting in the waiting area since 12:30, hoping she can be seen early. Hurley said that he told this participant that Julia might be able to see him at 1PM, but there was no guarantee. “Be right out there,” Julia calls out to Hurley as the sound of his footsteps recede in the hallway. Julia sighs and asks if I mind waiting to order lunch.

Description of ACASI and Overview of Chapter

ACTPOC research visits were conducted with a laptop computer and software program titled Audio-Computer Assisted Self Interview, or ACASI. As the vignette illustrates, ACASI had a central role in the research interview, directing how Julia posed her questions to the manner in which Sandra answered them quietly on her own. All of ACTPOC's research survey data were collected using the ACASI method.[116] ACTPOC participants were all presented with the option of forgoing use of the computer entirely. In these cases, the RA used ACASI to conduct the entire interview with them, asking each question and recording their responses. The face-to-face approach added about an hour to the two-hour baseline interview and roughly one-half hour to the follow-up.

The first part of this chapter critically examines some of the social science literature on ACASI, focusing on two influential peer-reviewed studies that compare it to the more conventional face-to-face interview (FTFI) approach. These widely cited studies claim ACASI has clear advantages over the FTFI, including greater accuracy and efficiency. But what exactly do these concepts of accuracy and efficiency mean, and more importantly, what do they obscure? What can concepts of "cost-effectiveness" tell us about contemporary research economies and how they operate?

The second part of this chapter explores how RAs experienced ACASI, and highlights its differences from the conventional FTFI approach. These findings indicate that ACASI made the RAs' expertise less visible, even as this new technology

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[116] ACASI was used for almost all of ACTPOC's data collection, with a few exceptions: the qualitative interview (conducted with about forty of the five hundred and twenty-five participants) and several questions asked during the baseline survey interview, regarding topics such as date of HIV diagnosis; CD4 and pVL, if known; current housing status; and number of medical appointments they had attended in the previous twelve months.

demanded more of their unique skill sets and abilities. Literature from STS and the anthropology of technology help to unpack the assumptions that the introduction and adoption of technology in work settings is uniformly beneficial. This section illustrates the reconfiguration of research epistemologies and labor arrangements that are not the direct cause of but are facilitated by the introduction of ACASI.

My interviews and focus groups with the RAs, along with the qualitative interviews and ACASI surveys that I conducted with participant illustrate some of the benefits of this new technology but more importantly, highlights the problems it creates. These ethnographic data illustrate the unintended consequences of ACASI's use in everyday settings and raise questions regarding how this method exacerbates some of the existing problems with public health research.

ACASI vs. Interviews Conducted with RAs

ACASI is a computerized tool used to manage the retrieval, processing, and storage of survey data. Interviews conducted with ACASI software involve the use of a computer (often a laptop), a mouse or similar device, and headphones. ACASI interviews are usually self-administered; that is, the research participant answers survey questions directly into the computer. As the opening vignette illustrates, Sandra spent most of her one-hour interview alone on the computer; as per the protocol, Julia remained in the office to answer any questions or attend to any problems.

ACASI has received an overwhelmingly positive reception since it was introduced in the mid-90s. Its appeal has steadily grown and it has become a mainstay for many, if not most, behavioral health research surveys. Two large-scale randomized HIV behavioral risk studies conducted by Metzger et al. (2000) and des Jarlais et al. (1999) compared the rates of reporting among participants using these two methods.[117] Metzger et al. and des Jarlais et al. had hypothesized that participants assigned to the ACASI group would report higher instances of unsafe sex and syringe sharing than the participants assigned to the control group, who were interviewed by RAs face-to-face. The results of these two studies demonstrated that reports of unsafe sex and syringe sharing were, for the most part, higher in the ACASI group, which seemed to confirm their hypotheses. However, des Jarlais et al.'s and Metzger et al.'s research design and interpretations of their findings raise a number of questions and expose several assumptions that require a closer look.

According to the des Jarlais et al. and Metzger et al., the higher rates of reported HIV risk behaviors in the ACASI group are evidence of its clear advantage over traditional interviewing methods. What led to the notions that the lower rates of

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[117] These articles were selected in part because the authors utilized a randomized trial design to study ACASI. The researchers for whom these articles were targeted would likely classify the study design as the "gold standard." Both of these articles attained wide circulation in high-ranking journals. Judging by the fact that these studies are routinely cited in other ACASI studies as evidence of its appropriateness and feasibility, it seems fair to say that these articles have played a central role in shaping the discourse on ACASI's use in studies of stigmatized behaviors. According to *Journal Citation Reports* (2009), the Impact Factor for *The American Journal of Epidemiology* was 5.589; and 30.8 for *the Lancet.* The *AJE* is ranked second among Public Health journals, and *TL* is ranked second in Medical journals.

syringe sharing and unsafe sex among the participants who completed their surveys with an interviewer revealed *under*-reporting? What did "under-" (as opposed to "over"-reporting assume)? Did study participants share the same interpretations of certain behaviors as socially stigmatized, as did the researchers? A large body of literature illustrates strong peer support for syringe exchange as well as the adoption of alternate methods (such as smoking) to avoid the risks injection poses.[118] It has also been well established that safer sex and drug use practices may be sanctioned in certain settings and with secondary partnerships but not with (for example) primary partners. Coupled with the widespread marginalization and criminalization of substance users, it seems reasonable to consider that the participants who, assigned to ACASI, disclosed higher and therefore more accurate rates of these behaviors. However, norms of safety and care are context-dependent, and may not be as evident as des Jarlais et al. and Metzger et al. assume them to be. It seems that the authors' arguments of ACASI's accuracy draws upon normative assumptions of reliability that fail to account for the context-dependent meanings of syringe-sharing practices and HIV sexual transmission.

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[118] Some excellent qualitative studies illustrate the contexts that underpin commonsense notions of safety to follow public health proscriptions. Hannah Cooper et al.'s qualitative investigation illustrates how syringe sharing increased following a crackdown in one NYC neighborhood; residents evaluated the potential for arrest as far more dangerous than the risk of sharing syringes, leading many to stop carrying their own works (Cooper 2004:680). Citing his ethnographic research that illustrates the possible dangers posed by fellow drug users who are not known to the user, David Moore argues that the "stability and orderliness that is assumed in guidelines for safer injection may in fact be harmful" (Moore 2004:1550).

des Jarlais and Metzger's large-scale research of ACASI enlisted a randomized controlled study design, which compared this technology to the traditional FTFI conducted with RAs. des Jarlais et al. describe that participants randomized to the ACASI group were given the use of a computer, a consent form, and a private space. The reader learns virtually nothing about the *interviewers* who conducted the face-to-face interview method, and who were compared to ACASI. des Jarlais et al. adopt the generic language of "fieldworkers" to describe the workers who conducted the FTFIs, characterizing them in such a way that conceals their individual characteristics, unique qualities, past employment, and other skills these positions require. What experiences and expertise did they bring to their jobs? What were their training needs? The language of fieldworker is vague; it could refer to a person with many years' experience working in substance use and harm reduction settings or to a recent college graduate with training in biostatistical analyses of infectious disease but who lacked experience with and understanding of injection drug use and HIV/AIDS issues.

The capacity to be nonjudgmental towards injection drug use, familiar and comfortable with needle exchange settings, and proficient at establishing rapport and conducting interviews about topics such as safer sex and needle use seem to be the very minimum of what is required of a competent interviewer asking needle exchange participants survey questions. Even the most seasoned RAs would likely need ongoing support and training in this setting, but these were minimally available to the RAs in the ACASI studies. As des Jarlais et al. note, "All fieldworkers had 2 days' training to explain the specific research aims, participant selection, informed consent, questionnaire content, traditional face-to-face interviews, and ACASI procedures" (des Jarlais et al. 1999:1658). Supervision and support for the fieldworkers was limited to a weekly long-distance phone call for the purposes of "quality control and resolution of any problems that arose" (ibid.).

The generic characterization assigned "the fieldworker" serves an important purpose in this research economy: it reduces their expertise and allows for them to become a "comparable object" to be studied in this research setting. The "fieldworkers" in these ACASI studies are not unlike the scientists in Karin Knorr-Cetina's (1992) sociological study of the laboratory, which reveals how these persons functioned as instruments and objects in the lab experiment. The RAs were made comparable to the ACASI technology; their value was assessed solely according to the rates at which research participants reported HIV risk. The higher the reports of HIV risk in the ACASI group served to lower the value of the fieldworkers.

The debates regarding accurate data notwithstanding, data *itself* is not a reliable source in which to assess quality, as noted by the ACTPOC RAs in the previous chapter, who expressed concern regarding the data quality upon observing participants barely glancing at the screen as they tapped computer keys. Metzger et al. (2000) and des Jarlais et al. (1999) dismiss the work processes undertaken to produce that data (both by the RA and participant in the FTFI, and participant in ACASI), a move that serves to reify or even fetishize data as an object separate from the relations that created it.

"ACASI Cost-Effective"

In addition to the effect of ACASI upon the quality of and satisfaction with employment, it seems likely that ACASI will reduce the number of job opportunities for RAs.[119] To my knowledge, there have been no systematic attempts to assess this, but several signs are present: a training document from Center Institute for Research on AIDS (CIRA) states that one of the advantages of using ACASI includes a reduction in personnel costs, including its allowance for simultaneous interviewing (2009). As Jennifer Brown et al. point out, "CASI-based data collection may yield considerable cost savings over time for some studies, because of increased administration efficiency, reduced duplication costs, and the elimination of staff time devoted to data entry" (Brown et al. 2008:2). ACASI's cost-effectiveness is also noted by Diane Morrison-Beedy et al., who state that "Face-to-Face-Interviews are labor intensive and costly" (Morrison-Beedy et al. 2006:542). Among the benefits of ACASI, claim Metzger et al., is its reduction in hiring research staff and training personnel. They state, "When IAQ [Interviewer-Administered Questionnaires] are used, the attainment of such standardization requires a significant amount of training and ongoing supervision"

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[119] The chapter on RDS/PDI illustrated the replacement of outreach workers with a minor economy of cash rewards.

(2000:105). Despite the job insecurities the RAs faced in anticipating ACTPOC's conclusion, all worked hard and maintained their employment until the study came to a close.[120] Presently, ACASI still requires a human worker to explain the survey procedures; however, its long-term effects upon RA labor are uncertain.

Privacy Concerns

According to des Jarlais and Metzger, the accuracy they associate with ACASI may be explained in part by the privacy the computer offered research participants. Privacy is an issue that many people take for granted, but is often denied to members of marginalized communities. The uneven distribution of privacy has been well documented, from the racial profiling that occurs on freeways and in labor delivery rooms to the scrutiny people encounter at homeless shelters for signs of drug use. The effort to afford research participants the privacy that is routinely withheld from them is undoubtedly important. However, what is to be made of the instances where participants' need for privacy is a response to the unwelcome scrutiny of the researcher's gaze or the intrusiveness of interview questions? Does ACASI's promise of privacy foreclose researchers' engagement with how their studies—the questions asked,

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[120] As of this writing, the ACTPOC project is close to fulfilling its goals to enroll 525 participants and deliver the intervention. With approximately one year remaining on the grant, several members of the staff were recently laid off (as had been expected), which included two RAs (one full-time and one part-time) and one of the intervention facilitators. All staff continued to work until their obligation ended with the completion of the grant, when their positions were eliminated.

the setting, even the purpose of the research itself—may be a source of discomfort for its participants? Does ACASI allow researchers to defer from critically engaging with the ways their research may in fact *create* the conditions that participants seek privacy from? The possibility that ACASI may minimize this stigma ultimately does little to address it. While research should not compound stigma, its purported elimination erases research participants from the social worlds in which they circulate and in which their behaviors are judged. The possibility for the RA and research participant to negotiate their research encounter (even one structured by standardized questions) is eliminated. However the ethnographic data of how ACASI was used in ACTPOC shows that despite the new forms of compliance this new technology engendered, research participants sometimes thwarted these intentions.

Accuracy and Data Collection

Developing accurate assessments of sexual and drug risks are crucial for developing ways to intervene in HIV transmission risk. Proponents of ACASI argue that this technology addresses one of health behavior researchers' key concerns: the reliability of their data. The employment and training of skilled research staff; triangulation of self-report data with other sources; and the development, piloting, and revision of surveys are examples of some efforts researchers undertake to increase data reliability. Some researchers view issues of data accuracy and overall quality as important, but extend beyond the focus on the interview encounter to grapple with (for example) the social conditions that compound the risks participants face in disclosing behaviors that may further stigmatize them. Amy Salmon and her team in British Columbia worked with First Nations women to consider the negative impact of a proposed study of Fetal Alcohol Syndrome (FAS). While still in the early planning stages, Salmon and her collaborators strategized ways to minimize the harm and maximize the benefits such a study might pose (Salmon et al. 2007). Of course, these approaches are not without problems, including assumptions regarding concepts such as community and representation. Nevertheless, these efforts offer a different register upon which to critically examine whose standpoint is invoked—and concealed—in claims of data reliability, accuracy and efficiency.

Metzger et al. argue that ACASI "removes interviewer-induced bias" (Metzger et al. 2000:100). Kurt Danziger notes, "There is the tendency to neglect the social aspect of psychological experiments to disturbances of the research process that do not belong. But human subjects in psychological experiments are in fact unable to behave simply as natural objects" (Danziger 1990:9). In his historical examination of psychological research, James Capshew asks how the interviewer's presence—which had once been viewed as necessary to the experiment—had to change in order to accommodate the growth of psychological testing and the development of a larger workforce. How were psychologists to preserve their authority with the new influx of and growing need for the new labor that was needed to take on the large-scale testing? It was during this time that the interviewer's presence in psychological interviewing became suspect. Whereas the psychologist's presence during interviews had helped to secure their claims and the scientific validity of their findings in the late nineteenth century, in order to accompany the new test administrators in the twentieth, the psychologist's presence was now considered suspect. The implications were significant in the development of psychology as a discipline, which aimed, as James Capshew describes, "toward eliminating or minimizing such experimental 'artifacts' through refinements in method rather than toward consideration of their epistemological implications" (Capshew 1999:224).

If ACASI proponents seek to eliminate experimental effect by distancing the RA and removing the possibility for "bias," it is important to ask, what new kinds of social relations does this technology introduce? How does technology mediate the social worlds of research subject, RA, and PI? The ACTPOC RAs have much to tell us about how the introduction of this technology reorganized their work.

RAs' Experiences with ACASI

Metzger et al and des Jarlais et al.'s seminal studies of ACASI argue that it improves accuracy, decreases cost, and eliminates the need for staff training. Missing from their analyses are perspectives from RAs and participants. The focus here is upon how did the RAs experience this new technology, and how did they evaluate its impact upon their work? With an emphasis on its storage capabilities and efficiency, ACASI literature neglects to account for the kinds of engagement and the subtle complexities that emerge in interviewing practices. In fact, the RAs' perspectives suggest that ACASI may further diminish the kinds of labors that interviewing requires. The ACTPOC RAs, together with participants, conceive more complex, intuitive, and relational meanings of accuracy than des Jarlais and Metzger's arguments allow. The RAs' reflections also bring this question to the fore: How might we evaluate ACASI in relation to the behavioral health research enterprise more generally, which seems to be establishing a greater distance from the very people they aim to study, and for whom their research aims to benefit? In the case of HIV/AIDS research, ACASI joins other technological apparatuses, such as DEBIs, which offer a scientific distance for administrators and researchers to manage what is at stake in this work: risk, disease, and inequality.

"Don't let them find the 'Don't Know' button!"

There is no single concept or analytic statement that neatly summarizes the RAs' experiences with ACASI. What is certain, though, is that ACASI shaped the quality of the RAs' interviews and influenced the varying levels of discontent and satisfaction all experienced with their work. The RAs' perspectives underscore the narrow and flawed visions of the ACASI social scientific literature, which failed to take into account the problems with this method that couldn't be extrapolated from the measures and surveys used. The RAs also discussed ACASI's flaws; namely, its inability to support the quality of data collected from participants. The RAs did not support a uniform view of ACASI, but all agreed that it was problematic in various ways, particularly in its effects upon participants' experiences, as well as data quality and satisfaction with their work.

One of the elements of ACASI that troubled RAs the most was seeing participants lose interest in the interview: many found it tiring; the density and repetition of the questions made focusing upon them a challenge. The baseline visits can run two or three hours. If some of the questions might spark interest for participants, the sheer number of them made them repetitive. For example, many questions were phrased the exact same way with a minor difference: "If the person screening you was of your race, would you be less likely or more likely to feel comfortable?" Pick from one of these six answers: 1=Not at all Likely; 2= Unlikely… A question that followed might ask, "How willing would you be to tell a peer or friend about ACTs if the person screening you was of the same race?"

> JULIA: Y'know there's a few people I've told, like [*Project Director*] about data that is completely useless. Because [that person's] sitting there going like this. [*She taps the table quickly and repetitively with her finger as if to imitate a participant completing their ACASI interview on the computer, hitting the same key, not looking at the question.*]
>
> HURLEY: That's what I was wondering. And if it doesn't get tossed out and it gets incorporated into actual data, what is it doing to the study? I mean, we're getting tainted stuff. We may be assuming that's what they're saying, but in reality—

> JULIA: It's not.
>
> KATE: And you always wonder, especially it reaches towards the end, these people have been on the computer for such a long time. And so, it's like you don't care anymore. No now you're just clicking, clicking. You're looking at the time and you have to go.
>
> JULIA: Once you realize what happens when you click—
>
> KATE: Don't let them find the "Don't know" button! [*the RAs laugh*]
>
> HURLEY: You get a lot of that.
>
> SHANNON: I wonder how much of this data gets tossed out…eventually.

Khalil Ghanem et al.'s research of ACASI at an STD clinic found that it "may reduce the ability to probe for clarification of responses given or elicit responses that require empathy. It may also enable a participant to 'surf' through a survey without seriously considering their responses" (Ghanem et al. 2005:421). The lack of empathy involved with answering questions directly into a computer evoked a sense of frustration for this ACTPOC participant named Mike, an African American man in his early fifties.

> It's one thing to ask the question in person. You have to do it on the computer again? You know what I am saying? It's like I am saying to myself…now I am on the computer and now you're asking me this question again. You know what, let me, let me start clicking whatever, whatever now, you know. Now you're trying to kick up my shit again. Here we go, you know, these conversations. So you know what, let me stop answering questions…So when you want me to talk about my past, I don't like my past. It's so much darkness and so much pain. So it makes me angry. So when you get me, when you get

> me riled up again and I'm thinking about my past and, you know what, here we go with this BS, bullshit again I have to deal with.

The RAs were sometimes frustrated with having to follow the research protocol, which meant that they could not ask questions other than how they were written, as the previous chapter showed. From the vantage point of fulfilling their RA duties, they had to follow the rules; but by doing so, they had to discard their own understandings and insight of the situation. Hurley's description of a research study that he had worked on several years prior, which took place on the street and involved the face-to-face interviews, sheds light on the significant changes ACASI has introduced.

> But we knew how to deal with that stuff when we were doing these interview 'cause a lot of times, like now it's like computer or whatnot, but we were workin' paper, and face-to-face, when there was no skipping out on anything unless it was major, if they said yes to this shit, you had a ton of questions you had to step into […]

It is these types of conflicts that seemed to facilitate a kind of detachment among RA staff. Having to following the protocol suspended them in a narrow contradiction. The inability to intervene left them with few options: by subscribing to a rational model of scientific principles, as they had been instructed to follow, meant they had to distance themselves from caring about the quality of the data, period. This approach foreclosed their opportunities to engage with the participant, follow up on their observations, or bring their intuition and expertise to the situation. Rob Kling and Suzanne Iacano argue that computer advocates routinely adopt scientific discourses in support of new technologies, which deflect attention from its impact upon the quality of jobs and employment (Kling and Iacano 1988:238).

Hurley describes ACASI's impact upon both RAs and participants.

> HURLEY: I've always been a believer in the interviewing, that an interviewer should do *interviews* [*taps the table as he speaks*], y'understand? When they came up with this ACASI and this self-interview, everybody was happy, myself included, I said 'Oh my God I can take a break from the interviewing, let them answer their own questions' but then seein' what goes on when they're answering their own questions [NO BO: Yeah.] you sit there as a researcher and you go, 'That's a crock of shit.' That's not so. Excuse my language.
>
> KATE: I've actually had interviewees tell me, 'I like it so much better when you ask me the questions.'
>
> HURLEY: Exactly, exactly. […] they're being honest, they probably don't understand the question, or maybe can't read it too well, or misinterpret the question altogether. But as an interviewer I always prefer askin' questions from A to Z, until the interview was done. Because when you askin' and we done interviews just checking responses or whatnot but when we were doing interviews back in the day they were open-ended stuff, there were paper, you probed, you got information, you did calculations, you forced them to put their mind to work. And give you responses that were suited for the questions that you asked. As opposed to just sayin' anything to skip through it, once they got hold of it, I come in here, I know that in an hour's time I'm outta here. I know that I can click these buttons and I get done.

The RAs engaged in work that rarely varied: they administered hundreds of identical surveys to participants and did the painstaking work of following up with all of them. The straightforward description of their duties—to ask questions, record answers, and document their follow-up efforts—did not speak to the range of daily practices they undertook, which were less visible but crucial to getting their jobs done. They entered into vertical hierarchies with the ACTPOC management and the PIs, who themselves were managing both the burdens and benefits of the trial design.

Internationally recognized as experts in the field of HIV/AIDS behavioral science by their peers, the PIs' research was heavily monitored, circumscribed, and regulated by the state.

The epistemology of standardization and the social relations it engendered emerged as a crucial topic in this ethnographic study, and proved to be an especially salient characteristic of the ACTPOC RAs' experiences. The RAs faced the greatest kinds of standardization in their work found ways to invest even its most restrictive forms with their creativity and energy. More often though, they found that the critiques and ideas for change that once animated them gradually gave way to occupying what felt like static work roles. In other words, with little power to change the conditions of their work, many staff uneasily adapted to this work that had changed *them*. The inflexible structure that shaped the organization, content, and delivery of the RAs' work demanded them to sacrifice or set aside their own concerns to adhere to the regularities of the protocol—although, as noted, this was not absent of their engagement.

However, as mentioned, not all RAs viewed ACASI in the same way. Julie viewed ACASI as an opportunity for relief from what she described as the drudgery of her work. She related strongly to the concept of privacy; as she described, she would not want a stranger asking her such personal questions. As she put it, "I'm so happy to not be doing the interviews, I can read a book or whatever."

Concluding Thoughts

This chapter argues that while ACASI represents a qualitative shift in how RAs conduct interviews, these changes are not simply the product of a technological object; ACASI's adoption into the research interview has been accomplished in part because it *extends* existing prior relationships of domination within research economies. These changes ACASI has engendered—its transformation of how interviews are conducted and how RAs do their work—are not a product of ACASI alone, but a manifestation of existing relationships of power that structure the PI/RA and RA/research participant relationships. Jeffrey Liker et al. affirm this point in their observation that, "The addition of technology depends on the job you start out with" (Liker et al. 1999:577). In other words, ACASI seems to have intensified some of the problematic values of the research economy: Whereas once RAs had met *with* research participants face-to-face to ask questions, probe their responses, and record their answers, with the advent of ACASI, RAs now administer surveys *to* participants.

The ACTPOC RAs' views of data quality and participant satisfaction provide a counter-point to des Jarlais and Metzger's analyses of these same issues. The growing use of ACASI in health behavior research illustrates that des Jarlais and Metzger's definitions of quality dominate. According to these researchers, ACASI outperforms FTFI in terms of accuracy, privacy, and efficiency. It is not their empirical data alone that supports their claims; their pronouncements are validated by the social arrangements in a research economy, where the absence of RAs' input into ACASI is so unremarkable that it has not gained notice. Pfaffenberg describes as "It could be objected, to be sure, that a technology either 'works' or it doesn't, but this objection obscures the mounting evidence that creating a 'successful' technology also requires creating and disseminating the very norms that define it as successful" [(Pfaffenberg, 1988:250) MacKenzie, 1987].

CHAPTER SEVEN:
THE INTERVENTION GROUP FACILITATORS (IGFs), ADHERENCE, & STANDARDIZATION

> They say the numbers are increasing. Well why not talk with people? [Part of the problem is] that you have this standard thing. [*emphatic*] Please.
>
> *Barbara, Intervention Group Facilitator*

The chapter begins by exploring the role of non-standardized knowledge—both that of the IGFs as well as participants—which was such a crucial part of the participants' overall ACTPOC experience. Those aspects of the group intervention that cannot be standardized call into question the centrality and force that matters of standardization have taken on in recent years. Within the evidence-based literature, for example, matters of adherence to the standardized manual and issues of intervention fidelity take on such importance.

The second part of this chapter, which is closely related to the first, proposes that these positive affective, relational connections the IGF worked hard to establish, and which participants helped to forge despite the personal risks of being misunderstood and judged also *validated* the standardized knowledge of the intervention. The standardized surveys ACTPOC participants completed reveal a wealth of data by which PIs will construct scientific claims regarding (for example) changes in participants' perceptions of ACTs screenings. As described in the Introduction, the intervention was designed in part to address barriers to ACTs, which the PIs describe to include "persistent ACT misinformation and ambivalent/negative attitudes" (*Research Protocol*, 2008:24). Putting aside the problematic implications of how these particular elements were identified as barriers to overcome, I question how scientific claims regarding changes in participants' attitudes will be ascribed to the standardized intervention itself, independent of the labor that played such an important part of these changes.

Finally this chapter briefly discusses the concept of "information" that was central to multiple parts of the ACTPOC group intervention, and outlines some of the contradictions that emerged with regards to information.

Non-standardized knowledge

I have experienced firsthand how ACTPOC participants connect easily with Barbara and the bonds between her and intervention group participants are palpable.[121] Due to scheduling conflicts, it was not uncommon for me to conduct qualitative interviews weeks and sometimes months after participants finished their group, but this seldom dissipated the energy with which participants described to me—without my

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[121] On several occasions, Barbara has received some of the highest praise at the last of the three groups, which, as one participant put it, "Barbara, you are the best counselor I have ever had." The description of Barbara as counselor indicates that although the interventions such as ACTPOC are defined as a standardized curriculum, in actuality the intervention is as much a part of (if not more) the facilitators that lead groups through the material.

prompting—Barbara's energy, passion, and kindness and most viewed this as the highlight of their ACTPOC experience.[122]

In conducting qualitative interviews for ACTPOC, I had the opportunity to listen to and learn from participants regarding their experiences with the intervention groups. The Intervention Group Facilitators (IGFs) were, as several excerpts from these interviews will show, key influences in participants' overall experience with ACTPOC. Without prompting, participants shared with me their positive experiences with their facilitators. The following quote from Mayla reflects several salient themes regarding participants' connections with the IGFs that emerged in my interviews.

> She's [Barbara's] open, too. She's friendly and she come in you know, people not saying oh all these people got HIV you know. It's — it's — it's the way you approach it you know. People — we already have that stigma, you know what I'm saying? And — and some people are — are knowledgeable about the stuff and other people are really naïve, you know what I'm saying? So you know — so that presentation, that warm feeling, just a little smile, you know what I'm saying?

Kimberly, my co-qualitative consultant, conducted an interview with Geene, and asked him what he thought of the groups and how they were run. He described to her that one of the things he especially liked was how Lauryn, the other IGF, elicited

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[122] Participants were equally enthusiastic when speaking about Lauryn, the other Intervention Facilitator. Lauryn was new to HIV/AIDS when she began as an Intervention Facilitator with ACTPOC. Her life's work focuses primarily on intimate partner violence, sexuality, and spirituality. She is also a writer. Lauryn's style of facilitation is hard to capture in words. I witnessed how her presence embodied a real sense of calm, peace, and confidence, which brought a sense of tranquility to her groups. Lauryn is African American, and is in a long-term relationship with her female partner. Like Barbara, Lauryn received high praise from participants that I interviewed, who spoke of Lauryn's kindness and compassion. While working at ACTPOC, Lauryn was enrolled in and graduated from a yearlong intensive training course in interfaith counseling and ministry.

everyone's participation, and had challenged him to not be a "wallflower," an experience he describes very positively, "It was cool, it was cool. Small class, we had a small class probably no more than ten or eleven people. The teacher was real knowledgeable…African American girl with an Afro, she was real informative and like a real schoolteacher, it was cool." Both Geene and Myla express the way that IGFs engage them with care and respect. Mayla's reference to her stigmatizing encounters with providers makes her statement regarding Barbara's supportive, non-judgmental approach especially poignant. And, even though several months had lapsed since he attended the intervention groups, Jason's clear recollection of Lauryn's encouragement to speak up and not be a "wallflower" suggests the meaningful impression this left on him.

These and many other ethnographic observations reveal several important forms of knowledge that are critical to standardized interventions such as ACTPOC, which call into question what exactly studies of standardized interventions actually measure. Are the "improvements in self-efficacy" that many CDC-established EBIs claim actually a measure of the standardized intervention curriculum? Or do they reflect these conscious and sometimes subtle connections, forged by skillful, caring, and empathetic IGFs? I propose that the basis for claims that of standardized interventions' efficacy—through survey measures that demonstrate statistical significance, for example—fail to capture what seem to be most crucial to participants' intervention group experiences.

For many ACTPOC participants, the information conveyed in their groups was inseparable from their perceptions of and relations with the IGFs, whom they saw as caring, insightful, and knowledgeable in their own right. I also argue that EBIs' manuals define knowledge, or in ACTPOC's case "information" as transparent and even narrow, existing at the level of concepts and ideas. However, as the interviews with and participant observation of the ACTPOC IGFs at work suggest, the knowledge conveyed by the intervention is much more relational and less easily defined than what proponents of evidence-based acknowledge. But it is these less easily defined practices that resist standardization and measures that the DEBI discourages. Charles Collins, Director of the DEBI Program at the CDC, critiques many prevention providers' preferences for the "homegrown interventions" (CITE). According to Collins, these homegrown interventions "typically have not been rigorously evaluated and often use informal methods passed through demonstration from seasoned employees to new employees" (Collins 2006:7).

For example, the literature on EBIs, which focuses primarily upon intervention fidelity, obscures the affective, relational connections between the IGF and the participants. While DEBI trainings pay attention to some vital aspects IGFs bring to interventions—such as listening and withholding judgment—standardized knowledge, that is based on a reproducible intervention manual that had been testing in a randomized controlled trial setting, is of primary value in EBIs. The less visible but very significant modes of shared and mutual understanding that the IGF established with participants are evidence of the kinds of knowledges that include but surpassed the exercises and materials. As Mayla pointed out above, she valued the intervention in part because of Barbara's welcome, which bore no trace of fear or judgment. Mayla made no mention of the intervention group's topic or a particular exercise that led her to feel comfortable in that setting. Her interpretation of Barbara was both abstract and embodied, departing from the valuation of conventional forms of expertise: (for example, "She demonstrated knowing this much about HIV, so she can be trusted"). Instead, as Mayla expresses: "So you know — so that presentation, that warm feeling, just a little smile, you know what I'm saying?" Standardizing the intervention is required if it is to meet the criteria of "science-based" or "evidence-based." But here lays the paradox: according to participants, some of the most significant aspects of their intervention experiences were in fact *not* standardized. Barbara, the Senior IGF, explains:

> It's things that are not—not just written. How could anybody do ACTPOC curriculum? It's mechanical almost. Anyone can read it and can get to know it and do the groups. But I think the focus should be on the facilitator or facilitators than the actual group. Focus on this curriculum than group. Move curriculum along. Be present in the group. The thing is, participants show up, they go through the groups, some may still get screened but it wouldn't really have impact that it could have, if have something that focused on curriculum but also focused on participants' needs at the same time.

Clearly, the IGFs were integral to the intervention. The PIs and staff of ACTPOC acknowledged this; however, the structure of evidence-based interventions does not.

For many participants, the facilitators *were* the intervention. In this sense, standardization is not a closed process—the information, attitudes, and knowledges facilitators possess matter greatly. There are multiple knowledges, tacit and otherwise, that cannot easily be documented or described in an exercise. Harry Collins explains, "All types of knowledge, however pure, consist, in part, of tacit rules which may be impossible to formulate in principle" (Collins, 1974:167). We must critically interrogate the purpose of "DEBIs" not only for what they aim to produce—standardized curriculums—but also for how this emphasis diminishes the significance of the labor in the process.

Information

> "What is screening?" Lauryn, one of the Intervention Facilitators, asks the group seated before her.
>
> A brief pause is followed by some murmurs. A few members of the group call out: "It's where you get information," says one. "Information," says another.
>
> "What is screening? I can't hear you." Lauryn turns her head and cups one hand behind her ear.
>
> "Information," replies the group in unison.
>
> *ACTPOC Intervention Group*

That the participants valued the IGFs and regarded them as trustworthy supported the intervention group's messages regarding ACTs. There was an obvious association between the IGFs and the curriculum, especially for the participants. The intervention groups emphasized "information," which presented this concept as straightforward and transparent. The problem, as I came to see it, was that participants trusted the information *because* of the IGFs. When I asked Gerald how he decided the information as trustworthy and worthwhile, he explained to me:

> I know because what they did as like they said it, all we're doing is giving you information about facts, you know what I'm saying, and so far I haven't seen anything to contradict that, ya hear me...As opposed to feeling from [*inaudible*] was like, you know what I'm saying, like as you say using you for a guinea pig, no…They was only asking us how much we knew about certain things and giving us information about things we had not heard of or knew about that exist, you know what I'm saying? And get—like I say, give you the option you know if you wanna participate, you can participate, you see, without going—break your arm if you know what I'm saying, bend it, you know what I'm saying?

The IGFs had nothing to do with writing the curriculum, and while they supported most of it, there were some parts that posed a conflict for them. ACTPOC's message was shaped by its delivery by a group of skilled, thoughtful IGFs, who shared similarities in geography, culture, racial, spirituality/religion, and class with participants. How was the presentation of this message by a group of IGFs a strategic one; in other words, what were the effects of selecting these particular IGFs to deploy this message? One possibility is that these kinds of "matching" added to the intervention's suitability and fit for many participants. This is fairly common practice in public health. However, the issues that emerge in evidence-based that seem especially problematic are that in a standardized intervention, the IGFs had very little control over the content of the message. The curriculum they presented was not their own. Yet participants' valuation and judgment of the intervention were not likely to have made a distinction between the two.

In the following example, Lauryn illustrates how she mediates her understanding of participants' vulnerabilities and needs with the messages in the curriculum. The approach that Lauryn describes below did not emerge from a line in the facilitation manual, but draws from a wide range of experience that includes (but is not limited to) her experience working in biomedical and social science research in communities of color. Lauryn says,

> Yeah, even with those words, the cure. Like just think of if you, depending on the type of facilitator you are, would say, "Look, the benefit of you participating in AIDS clinical trials is that y'know the cure could come from us." And there's all these different words you could use that could come across as sales-y. Like you're trying to convince. And people of color have been hoodwinked enough, and bamboozled and we don't need to do that when it comes to screening.

Information is not just something to be accumulated, as June points out: "I definitely like to end up providing the groups with information. But at the same time what got to me is that [while] you're providing them with info it's a limited time that they have for expressing their feelings and how y'know this is affecting them." June expresses what has been recognized as a conflict for facilitators of standardized interventions: "(T)he clinician is likely to possess skills that go beyond the scope of a particular intervention" (Johnson et al., 2003:353) and can lead to "conflict between the established scope of the research and the judgment of the clinician and their desire to help" (Johnson et al. 2003, 354). As Nadav Davidovitch and Dani Filc point out, the adoption of evidence-based strategies contributes to,

> [T]he polarization of the health care profession (and especially so the medical profession) into an elite, which manages the new techniques, and thus gains more power and authority, and the rank-and-file practitioners, who see their power and authority further restricted, since they have to adapt their practice to research performed by those professionals with access to resources, to analysis made by researchers with the appropriate skills, to guidelines written by experts (Davidovitch and Filc 2006:305).

As noted in earlier chapters, the ACTPOC PIs purposefully defined and arranged the intervention groups and the ACTs screening as "information-gathering sessions" separate from the process of actually joining an ACT. This was done for several reasons. By instituting interest in ACTs screenings as a step-by-step process, they hoped to allay the widespread fear that "there was no turning back" once a participant expressed interest in learning more about these studies. However, the relationship of biomedicine and public health was not so much marked by difference, but by similarity. In other words, the role of public health in supporting biomedical endeavors makes the strict distinctions that define them less relevant. Public health has indeed become more biomedicalized.

The concept of information was also vague. Ben, a long-term survivor with HIV, expressed how the lack of information was frustrating to him. When pressed, he describes in more detail his dissatisfaction.

> Well you know what? The material is good and if anything, my—my complaint about the material is that it's what makes it good. Is that it's kinda like it's—it's

> saying come and see Arturo, you can learn more. Basically that's all, but you set for three days, in my opinion. Come see Arturo, you can see—learn more and I was like I got that already. I got that already. Well come and see Arturo you—I said no. I got that already ya know. And it's like you just kinda like stuck to your guns. Well when you come to see Arturo you'll learn more. And I was like [*sighs*] oh God. I just said obviously I gotta go see Arturo if I want anything.

As noted, the IGFs did not create the intervention. Upon their hiring, they were handed the *Intervention Manual,* which had been approved by the funding source and IRB. Theirs was not a "word-for-word" script to follow; however, all of the group exercises were described and key points were highlighted. The IGFs firmly supported and believed in ACTPOC's goals to equalize access to information about ACTs. However they also found themselves, to varying degrees, "following a script," which was a source of discomfort. The frustrations IGFs experienced bear a strong resemblance to certain aspects of the service economy of contemporary labor. By this I mean that IGF's work is rationalized into cost-effective models, and for which they have little control over. Moreover, from most participants' standpoints, the IGFs and the material they presented seemed to be naturally interlinked, which did not acknowledge the divisions between the facilitators and the standardized intervention curriculum.

In the following example, June reveals the limits of the concept of information, and the contradictions it presented in an experience co-facilitating one of the control groups. June, along with several other facilitators, posed the challenge that information was not specific enough; what the concepts of information relayed did not stand up to the conceptual significance assigned to it.

> We were talking about some medication you can take that can cause lipodistrophy. And they were like "Well I'm not taking any medications!" and it was also on the basis of like that it happened to, it mostly happens to people of color. Now this just, it got everyone's attention. Everybody started to freak out and, "I'm deciding to not take any kind of medications" and yknow I think what happened the co-facilitator I was working with was like, "Oh, they're not really sure yet, they haven't really proven it," it's like, it's kind of like you gave them information and when they started to panic it was like, "Well we're still not sure" and I think it started to panic and confuse y'know the participants and it left me stuck like, y'know I don't want to end up y'know, steering anybody wrong… "I'm not taking any medications!" and "I knew those medications caused these side effects—" And it was like, 'Oh no no no. We're not sure yet." How do you end up just dealing with that? And they were like, "We use the same medication, this person has, that means I'm going to have, that means I'm going to stop using my medication." [Me: Oh wow.] And it was just like, it was a big group too. It was about ten to twelve people, and all of a sudden, people, little by little, just started having conversations like "Yeah you use that one? You use Reyataz?" "Oh no no no, I'm not using that anymore." And its just like, it's just starting to go. And what do you do?

June's description of this event, and her insights regarding it, bring to the fore what is at stake with information. Clearly, the debate regarding information is not simply a matter of posing some information as bold truth or patently false. Rather, it points to the problems that may emerge with making overly generalized statements while supporting access to information.[123] Participants naturally expected their IGFs to be informed about the claims they were making. This discussion regarding people of color, HAART, and lipodistrophy shares some commonalities with the AZT fiasco. Even when the researchers withdrew the claims that HIV-positive Black and Latinos

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[123] This is not to say that IGFs had ready responses to even a portion of the questions they were asked. In fact, the recommendation was that speaking to one's clinician was necessary. The point here is that information and claims about HAART are fragile—there is much at stake, to say the least.

did not in fact have some inherently different response to the drug, the connection had been made and had taken on a life of its own.

> BARBARA: What I always said, the control groups reminded me of the groups that our folks go to. [June: Yes, yes exactly.] All the time. And they still have questions right. And these are groups they go to all the time. So then they come in here hoping, yes, now they can get an answer. To these groups that they go to all the time. And to still be sent back out without an answer.
>
> LAURYN: That's a problem. 'Cause it's more than research. You're talking about people's lives.
>
> JUNE: (B)ecause control's like "You guys are teaching me about self-care, I'm assuming you guys already know this." So when you sit down there and say, "Well I don't know, you're gonna hafta ask your primary health care physician." "Well I tried asking but they gave me the roundabout story and so now I'm looking for the truth with you and you can't even answer it."

Whose information?

Barbara points out another interesting contradiction regarding information. Much emphasis was placed upon ACTPOC participants gaining access to information, overlooking how the researchers were also gaining information from participants. Barbara's insight affirms an earlier point regarding clinical trials: while participants are hailed as consumers of trials and beneficiaries of them, they are equally producers in the risks they embody.

> What is unfortunate about these interventions is that they're just that. It's just an intervention and it comes in and it's present for a little while and then it goes away...I enjoy the work but one of the many things I don't like about the work is that it ends. Researchers come in and they get the information that they need, they prove that something may work or may not work. And then it's gone. And then what happens to the community.
>
> —*Barbara, ACTPOC Group Facilitator*

Access to information about ACTs and screenings came up repeatedly in my discussions and interviews with the IGFs. The concepts of information helped to reaffirm that participants were not being asked to join a trial, but to learn about them. Yet despite this emphasis, the concept of information seemed to be presented and understood in very positive terms. In other words, there was no attention to how participants might evaluate information. What makes some information credible and others less credible? The group intervention was about "giving you the information so that you can make the decision about wanting to be screened" as was announced at the beginning of every group, and reinforced over the course of the group series.

Participants were drawn to information about ACTs because it helped them feel like they did not have to commit to anything. Information also proved to be an equalizer—according to the intervention, as women and people of color, they often did not have access to the same information as did others with HIV. Information was unequally distributed. Information was such a general term; its strength was in its ambiguous meaning. Information in and of itself was deemed to be positive. In these terms, information was self-evident, a matter of being in possession of information, or being denied it. One of the contradictions to emerge from this intervention's focus on information was that the IGFs did not have access to regular trainings and sources of information.

This chapter proposes that the logic of information underpinning the dominant model of intervention development and evaluation in public health conforms to the paradigm of advanced liberalism. This kind of teaching is appropriate to an information-based, service oriented economy in which many people who are poor, have few opportunities, and experience racism and other forms of oppression labor. As Keith Denny explains, "Capitalist economics at the end of the twentieth century are characterized at least in part by the 'knowledge worker' and the increasing significance of 'information,' both in the production and exchange of commodities and as a commodity itself" (1999:260). Denny argues that, "the construction of the need for 'information' serves to manage demands for more democratic health care, thus reinforcing a dominant scientific paradigm" (ibid.). The huge push to deliver health information, while undoubtedly useful in many respects, also deflects attention from issues of health generally. For example, facilitating access to information about ACTs is an important task, but perhaps best suited to a broader conversation regarding HIV/AIDS or health care. The narrow focus on ACTs and information potentially exclude the inclusion of certain areas of health that PLWHA might look to ACTs to treat, whether that is overloaded health systems or environmental causes. As Cindy Patton explains,

> People have more than the responsibility to know, more than the right to choose. People have the right to understand the ideologies of science and education…HIV/AIDS education either reinscribes the sexual, class, and racial ideologies that are propped up by moralism or science, or disrupts the hierarchical formations of knowledge (Patton, 1990:105).

Concluding Thoughts

In order to conform to the guidelines of science-based interventions, a great deal of the daily activities and broader goals of ACTPOC involved the regulation of its moving parts. The content and organization of groups must follow the intervention manual. Survey questions must be asked uniformly. The protocol for administering RDS restricts deviations—for example, coupons have expiration dates, and lost coupons cannot be voided. If the results from the surveys illustrate that ACTPOC has met its goals, the intervention manual may be eligible for reproduction as an evidence-based intervention (EBI). Formal knowledge, such as the kind that is contained in a forty-page manual, is privileged over other kinds. Informal knowledges (including embodied knowledge), are not outright excluded, but are necessary to make the intervention work. Generally speaking, the intervention manual cannot be altered mid-way through a study, and facilitators' adherence to the manual is regulated through video and audiotaping and clinical supervision meetings. Part of what is at stake in creating consistency is to maintain internal validity (or "intervention fidelity"). But what about the social relations that not only support the delivery of the written intervention, but were central to participants' experiences with the intervention? These ethnographic data support the importance of the IGFs in shaping the participants' standardized group intervention experiences, despite their absence from the "evidence" itself.

CONCLUSIONS

> We cannot treat our way out of this epidemic.
>
> Michael Merson et al. 2008:485

> Why agitate against the status quo if lab work is the salient determinant of our social and political future?
>
> Nancy Ordover, *American Eugenics*. 2003:123.

The development and improvement of anti-HIV therapies requires rigorous forms of testing. However, as many HIV/AIDS clinicians, social scientists, and PLWHA point out, medication development is just one of many issues that requires our attention. In addition to improving the safety profile of HIV medications and developing new kinds of therapeutic treatments, it remains imperative that complex understandings of and dynamic responses to this disease be embraced, not abandoned.

HIV/AIDS medication has progressed considerably since the 1980s, when the few pharmaceutical options that existed had quite severe side effects and limited long-term therapeutic benefit. In a twenty-five year retrospective essay of HIV/AIDS, Sam Broder, one of the lead researchers of the first AZT study, called HAART a "triumph of modern medicine" and describes the current range of therapeutic options as "an embarrassment of riches" [Broder, 2010:1 (Hirschel & Calmy, 2008) (Richman, 2009)].

ACTPOC highlighted the significance of medication development. Of course, these drugs are neither universally available nor equally efficacious. Developing resistance to these drugs' effects is also a real possibility. The side effects have indeed improved, but still remain a barrier to PLWHA who cannot tolerate their toxicities. HIV/AIDS also compounds existing co-morbidities, including those routinely seen among the growing aging population of PLWHA.

We can assume that ACTs will advance therapeutic possibilities for PLWHA and help people live longer and healthier lives. The experimental medications that are studied in ACTs offer the potential of "salvage therapies" for PLWHA who do not respond to current pharmaceutical treatments. One of ACTPOC's goals was to open up these possibilities for participants. Their dissemination of information about ACTs helped break down some of the barriers PLWHA of color faced in accessing these studies.

Studies of ACTs recruitment practices are primarily concerned with identifying the barriers to and increasing the rates of participation among women and people of color. Barriers to participation, such as physicians' uneven referral practices and the negative social norms regarding research among people of color are sometimes highlighted. Many researchers looking to diversify the participation of women and people of color in their studies find the recommendations and strategies these studies outline to be useful guides. Similar to the dominant model of HIV/AIDS behavioral research, these studies tend to focus on identifying individual behavior and group norms as the site of intervention. Most studies of ACTs recruitment and enrollment focus upon measuring the motivation and attitudes of PLWHA, with the help of standardized surveys and questionnaires. These types of approaches may yield insights into PLWHA's decision-making processes, but leave the contexts that shape these decisions under-analyzed.

This dissertation might have easily focused its attention upon ACTPOC's many positive effects. Instead, it adopted a different kind of approach, outlining the cross cutting and conflicted nodes of power that undergirded ACTPOC's practices. ACTPOC's framing of ACTs screenings as a vehicle to improve the health of PLWHA of color became a central point of exploration and critique in this ethnographic study. This dissertation joins the growing scholarship that engages the contemporary phenomena of minority participation in clinical trials beyond the terms (of its regulation determined) by which it has been defined by the NIH RA and recruitment strategies. ACTPOC was contextualized in relation to the historical and political-economic processes of racialization that fueled its purpose and pedagogy. Yet for all its material resources and scientific power, participants, staff, and PIs engaged with ACTPOC's official discourses and formidable protocols, revealing its limits.

In ACTPOC, racialized and gendered inequalities into a "moral economy of hope" (Rose 2007:27) by way of some powerful affective claims that called for the development of better HIV meds or perhaps even the cure. Depicted as a right, the message of inclusion in ACTs garnered enormous appeal for participants. What was perhaps most contradictory about this process was that ACTPOC participants, who faced the severe consequences of devolution and disinvestment, were made visible through the potential of racialized biomedicine. ACTPOC's adopted a powerful language of social change and democratic participation, frequently invoking concepts of "representation" and "community" to bolster its attendant claims of individual decision-making and racialized biomedical solutions.

The organization and structure of ACTPOC's research activities seemed deceptively straightforward; however, seeing the RAs and IGFs at work and talking with them quickly dissuaded me of that notion. My assumptions of standardization as a tidy object with uniform practices did not match what I was learning in ACTPOC's everyday practices. If this examination were to narrowly focus on the standardized instruments the RAs conducted with participants and the unvarying and sometimes rigid processes IGFs adhered to in the groups, it might lead to the erroneous assumption that their work is mechanistic, routine, and requires a minimum of skill.

Steve Epstein argues that despite its tendency to affirm biological meanings of race, the recruitment of women and people of color has led to the application of humanitarian discourse into biomedical clinical trials contexts (Epstein 2007). However, these ethnographic findings reverse Epstein's claim. As a case study, ACTPOC presents clear evidence that the social sciences are also becoming more biomedicalized. ACTPOC illustrates how scientific knowledge practices used to evaluate medications are increasingly being used to determine the efficacy of non-medical interventions. The "biomedicalization" of HIV/AIDS public health has had profound implications in the area of HIV education, care, and social support. Joao Biehl crafted the phrase "the pharmaceuticalization of public health" to refer to the phenomena whereby medication is prioritized to the neglect of public health infrastructures and a broader definition of clinical care (2007:12). In some cases, highly active antiretroviral therapy (HAART) is viewed as a replacement for public health responses (that focus on prevention). For example, it has been recommended that clinicians prescribe HAART to *all* PLWHA, regardless of CD4 count,[124] because it "maximizes the individual and public health benefit for those already receiving care without requiring additional investment in outreach and expanded testing" (Charlebois et al. 2011:1046). There are calls to adopt HAART as a widespread prevention tool by prescribing these medications to HIV-*negative* individuals—a strategy that earned it the title "Breakthrough of the Year" by *Science* (2011:1628).

This ethnographic study has several limitations. Due to time and other constraints, some important perspectives are absent from this dissertation. In addition to not integrating the perspectives of several of ACTPOC's PIs, as well as some of the main ACTU researchers I interacted with. Interviews with CDC officials would also

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[124] There is no widespread consensus regarding when to start ARVs. Current guidelines for when to begin ARVs: vary: the World Health Organization and European AIDS Clinical Society advocate beginning ARVs when the CD4 counts drops to 350, whereas in the United States the guidelines recommend beginning when CD4 is 500 (*Annals of Internal Medicine*, April 18 2011).

expand the perspective put forth here, especially with regards to its departure from typical HIV/AIDS interventions. I hope that future work might address this gap.

REFERENCES

Abadie, Roberto

2010 The Professional Guinea Pig: Big Pharma and the Risky World of Human Subjects. Durham, NC: Duke University Press.

ACT UP/NY Women and AIDS Book Group

1990 Women, AIDS, and Activism. Boston: South End Press.

Adam, Barry

2011 Epistemic Fault Lines in Biomedical and Social Approaches to HIV Prevention. Journal of the International AIDS Society 14 (Supplement 2):S1-S9.

Angell, Marcia

2005 The Truth About the Drug Companies: How They Deceive Us and What We Can Do About It. New York: Random House.

Angell, Marcia and Arnold S. Relman

2002 Patents, Profits, & American Medicine: Conflicts of Interest in the Testing and Marketing of New Drugs. Daedalus 131(2):102-111.

Annas, George

1989 Faith (Healing), Hope and Charity at the FDA: The Politics of AIDS Drug Trials. Villanova Law Review 34:771-797.

Appadurai, Arjun

1986 Introduction: Commodities and the Politics of Value. pp3-63. *In* The Social Life of Things: Commodities in Cultural Perspective. Arjun Appadurai, ed. Cambridge: Cambridge University Press.

Armstrong, David

2002 Clinical Autonomy, Individual and Collective: the Problem of Changing Doctors' Behavior. Social Science & Medicine 55(101):1771-1777.

Arno, Peter and Karyn Feiden

1992 Against the Odds: The Story of AIDS Drug Development, Politics and Profits. New York: Harper Collins.

Asad, Talal

1994 Ethnographic Representation, Statistics and Modern Power. Social Research 61(1):55-88.

Auerbach, Judith D. and Anne E. Figert

1995 Women's Health Research: Public Policy and Sociology. Journal of Health and Social Behavior (Extra Issue):115-131.

Ayo, Nike

2012 Understanding Health Promotion in a Neoliberal Climate and the Making of Health Conscious Citizens. Critical Public Health 22(1):99-105

Azzarto, Jacqueline

1995 Problems with Public Health Outreach. Social Work in Health Care 22(1):57-67.

Baciu, Alina, Kathleen Stratton, and Sheila P. Burke

2007 The Future of Drug Safety: Promoting and Protecting the Health of the Public. Washington, DC: National Academies Press.

Baker, Lee

1998 From Savage to Negro: Anthropology and the Construction of Race, 1896-1954. Berkeley: University of California Press.

Barker, Kristin

2011 Listening to Lyrica: Contested Illnesses and Pharmaceutical Determinism. Social Science & Medicine 73(6):833-842.

Berg, Marc

1997 Problems and Promises of the Protocol. Social Science & Medicine 44(8):1081-1088.

1998 Order(s) and Disorder(s): Of Protocols and Medical Practices. *In* Differences and Medicine. Marc Berg and Annemarie Mol, eds. Durham, NC: Duke University Press. Pp226-245.

Berube, Allan

2001. "How Gay Stays White and the Kind of White It Stays." *In* The Making and Unmaking of Whiteness. Birgit Brander Rasmussen, Eric Klineberg, Irene J. Nexica, and Matt Wray, eds. Durham: Duke University Press. Pp234-265.

Bibbins-Domingo, Kirsten and Alicia Fernandez
2007 BiDil for Heart Failure in Black Patients: Implications of the U.S. Food and Drug Administration Approval. Annals of Internal Medicine 146(1):52-56.

Bibeau, Gilles and Duncan Pedersen
2002 A Return to Scientific Racism in Medical Social Sciences: A Case Study of Sexuality and the AIDS Epidemic in Africa. *In* New Horizons in Medical Anthropology: Essays in Honour of Charles Leslie. Mark Nichter and Margaret Lock, eds. London: Routledge. Pp141-171.

Biehl, Joao
2007 Pharmaceuticalization: AIDS Treatment and Global Health Politics. Anthropological Quarterly 80(4):1083-1126.

2009 Will to Live: AIDS Therapies and the Politics of Survival. Princeton: Princeton University Press.

Bloche, M. Gregg
2004 Race-Based Therapeutics. The New England Journal of Medicine 351(20):2035-2037.

Bloor, Michael, David Goldberg, and John Emslie
1991 Ethnostatistics and the AIDS Epidemic. The British Journal of Sociology 42(1):131-138.

Bodenheimer, Thomas
2000 Clinical Investigators and the Pharmaceutical Industry. The New England Journal of Medicine 342(20):1539-1544.

Bowker, Geoffrey and Susan Leigh Star
1999 Sorting Things Out: Classification and Its Contents. Cambridge: MIT Press.

Bowleg, Lisa
2008 When Black + Woman + Lesbian ≠ Black Lesbian Woman: The Methodological Challenges of Qualitative and Quantitative Intersectionality Research. Sex Roles 59(5-6):312-325.

Brandt, Allan M. and Martha Gardner

2000 Antagonism and Accommodation: Interpreting the Relationship between Public Health and Medicine in the United States during the 20th Century. American Journal of Public Health 90(5):707-715.

Brawley, Otis W.
1995 Response to 'Inclusion of Women and Minorities in Clinical Trials and the NIH Revitalization Act of 1993—the Perspective of NIH Clinical Trialists'. Controlled Clinical Trials 16:293-295.

Briggs, Charles L.
2001 Modernity, Cultural Reasoning, and the Institutionalization of Social Inequality: Racializing Death in a Venezuelan Cholera Epidemic. Comparative Studies in Society and History 43(4):665-700

2005 Communicability, Racial Discourse, and Disease. Annual Review of Anthropology 34:269-291.

Briggs, Charles L. and Daniel C. Hallin
2007 Biocommunicability: The Neoliberal Subject and Its Contradictions in News Coverage of Health Issues. Social Text 93(25):43-66.

Broadhead, Robert S. and Douglas D. Heckathorn
1998 Harnessing Peer Networks as an Instrument for AIDS Prevention: Results from a Peer-Driven Intervention. Public Health Reports 113(1):42-57.

Broadhead, Robert S., Douglas D. Heckathorn, Jean-Paul C. Grund, L. Synn Stern, and Denise L. Anthony.
1995 Drug Users Versus Outreach Workers in Combating AIDS: Preliminary Results of a Peer-Driven Intervention. Journal of Drug Issues 25(3):531-564.

Broder, Samuel.
2010. The Development of Antiretroviral Therapy and Its Impact on the HIV-1/AIDS Pandemic. Review. Antiviral Research 85:1-18.

Brodkin, Karen
2000 Global Capitalism: What's Race Got to do with it? American Ethnologist 27(2):237-256.

Brown, Alison Hamilton

2004 Integrating Research and Practice in the CSAT Methamphetamine Treatment Project. Journal of Substance Abuse Treatment 26(2):103-108.

Brown, Jennifer L., Peter Vanable, and Michael D. Erikson.
2008 Computer-Assisted Self-Interviews: A Cost Effectiveness Analysis. Behavior Research Methods 40(1):1-7.

Brown, Jacqueline Nassy
2009 Racial State of the Everyday and the Making of Ethnic Statistics in Britain. Social Text 98(27):11-36.

Bull, Chris
1988 Seizing Control at the FDA. Gay Community News 16 October 1988, 1, 3.

Busfield, Joan
2006 Pills, Power, People: Sociological Understandings of the Pharmaceutical Industry. Sociology 40(2):297-314.

Cabral, Howard J., Carol Tobias, Serena Rajabiun, Nancy Sohler, Chinazo Cunningham, Mitchell, Wong and William Cunningham
2007 Outreach Program Contacts: Do they Increase the Likelihood of Engagement and Retention in HIV Primary Care for Hard-to-Reach Patients? AIDS Patient Care and STDs 21(Supplement 1):S59-S67.

Canadian Health Research Services Foundation
2007 Myth: Canada's System of Healthcare Financing is Unsustainable. Mythbusters: Using Evidence to Debunk Common Misconceptions in Healthcare. Electronic document, http://www.pnhp.org/single_payer_resources/mythbusters_by_the_canadian_health_services_research_foundation.php Accessed July 1, 2010

Capshew, James
1999 Psychologists on the March: Science, Practice, and Professional Identity in America, 1929-1969. Cambridge: Cambridge University Press.

Carbado, Devon W.
1999 Black Rights, Gay Rights, Civil Rights: The Deployment of Race/Sexual Orientation Analogies in the Debates about the "Don't Ask, Don't Tell" Policy. *In* Black Men on Race, Gender, and Sexuality: A Critical Reader. Devon W. Carbado, ed. Pp. 283-302. New York: New York University Press.

2000 Symposium Race and the Law at the Turn of the Century: Black Rights, Gay Rights, Civil Rights. UCLA Law Review 47 Rev. 1467:1468-1519.

Carlson, Robert G., Jichuan Wang, Harvey A. Siegal, Falck, Russel S. & Jie Guo
1994 An Ethnographic Approach to Targeted Sampling: Problems and Solutions in AIDS Prevention Research among Injection Drug and Crack-Cocaine Users. Human Organization 53(3):279-286.

Carpenter, Daniel P.
2004 The Political Economy of FDA Drug Review: Processing, Politics, and Lessons for Policy. Health Affairs 23(1):52-63.

Carter-Pokras, Olivia and Claudia Banquet
2002 What Is a 'Health Disparity'? Public Health Reports 117:426-434.

Center for Interdisciplinary Research on AIDS (CIRA)
2009 ACASI Training. Electronic document, http://cira.med.yale.edu/events/irmseminars/acasi_101609.pdf Accessed on February 1, 2010.

Charlebois, Edwin, Das Moupali, Travis Porco, & Diane Havlir
2011 The Effect of Expanded Antiretroviral Treatment Strategies on the HIV Epidemic Among Men Who have Sex with Men in San Francisco. Clinical Infectious Diseases 52(8):1046-1049.

Chu, Carolyn and Peter Selwyn
2008 Current Health Disparities in HIV/AIDS. The AIDS Reader 18(3):144-146, 152-158.

Clark, George, Moher Downing, Marcy Rein, Delia Garcia, and Sara Kershnar
Date Unknown. Prevention Point: Street-Based Needle Exchange. A Descriptive and Explanative Model. Mimeo.

Clarke, Adele A. and Virginia L. Olesen
1999 Introduction: Diffracting in Order to Revision. *In* Revisioning Women, Health and Healing: Feminist, Cultural, and Technoscience Perspectives. Adele A. Clarke and Virginia L. Olesen, eds. Pp. 3-48. New York: Routledge.

Clarke, Adele A., Janet K. Shim, Laura Mamo, Jennifer Fosket, and Jennifer R. Fishman
2003 Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine. American Sociological Review. 68(2):161-194.

Clinical Trials Consensus Panel
2000 Recommendations of the Clinical Trials Consensus Panel. Consensus Statement. Journal of the National Medical Association 92(10):464-471.

Cohen, Cathy J.
1997 Punks, Bulldaggers, and Welfare Queens: The Radical Potential of Queer Politics. GLQ: A Journal of Lesbian and Gay Studies 3:437-465.

1999 The Boundaries of Blackness: AIDS and the Breakdown of Black Politics. Chicago: University of Chicago Press.

Cohen, Jon
2011 Breakthrough of the Year: HIV Treatment as Prevention. Science 334(6063):1628.

Cohen, Laurie P.
1996 To Screen New Drugs for Safety, Lilly Pays Homeless Alcoholics. Wall Street Journal, Nov 14. A1 & A10.

Collins, Harry M.
1974 The TEA Set: Tacit Knowledge and Scientific Networks. Science Studies 4:165-186.

Cooper, Hannah, Lisa Moore, Sofia Gruskin, and Nancy Krieger
2005 The Impact of a Police Drug Crackdown on Drug Injectors' Ability to Practice Harm Reduction: A Qualitative Study. Social Science & Medicine 61:673-684.

Corrigan, Oonagh P.
2002 A Risky Business: The Detection of Adverse Drug Reactions in Clinical Trials and Post-Marketing Exercises. Social Science & Medicine 55:497-507.

2003 Empty Ethics: The Problem with Informed Consent. Sociology of Health & Illness 25(3):768-792.

Coveney, John
1998 The Government and Ethics of Health Promotion: The Importance of Michel Foucault. Health Education Research 13(3):459-468.

Coyle, Susan L., Richard H. Needle, and Jacques Normand
1998 Outreach-Based HIV Prevention for Injection Drug Users: A Review of Published Outcome Data. Public Health Reports 113(1):641-651.

Crane, Johanna
2010 Adverse Events and Placebo Effects: African Scientists, HIV, and Ethics in the 'Global Health' Sciences. Social Studies of Science 40:843-870.

Cunningham-Williams, Renee M., Linda B. Cottler, Wilson M. Compton, David P. Desmond, Wendee Wechsberg, William A. Zule, and Peter Deichler
1999 Reaching and Enrolling Drug Users for HIV Prevention: A Multi-Site Analysis. Drug and Alcohol Dependence 54:1-10.

Dalton, Harlon L.
1989 AIDS in Blackface. Daedalus 118(3):205-227.

Daniels, Jessie and Amy Schulz
2006 Constructing Whiteness in Health Disparities Research. *In* Gender, Race, Class, and Health: Intersectional Approaches. pp89-129. Amy Schulz and Leith Mullings, eds. San Francisco: Jossey-Bass.

Danziger, Kurt
1990 Constructing the Subject: The Historical Origins of Psychological Research. Cambridge: Cambridge University Press.

Davidovitch, Nadav and Dani Filc
2006 Reconstructing Data: Evidence-Based Medicine and Evidence-Based Public Health in Context. Dynamis 26:287-306.

DeHue, Trudy
2001 Establishing the Experimenting Society: The Historical Origin of Social Experimentation According to the Randomized Controlled Design. The American Journal of Psychology 114(2):283-302.

DeJong, Jocelyn, Ziyad Mahfoud, Danielle Khoury, Farah Barbir, and Rema Adel Afifi
2009 Ethical Considerations in HIV/AIDS Biobehavioral Surveys that use

Respondent-Driven Sampling: Illustrations from Lebanon. American Journal of Public Health 99(9):1562-1567.

Deneberg, Risa
1990 Treatment and Trials. *In* Women, AIDS, and Activism. ACT UP/NY Women and AIDS Book Group, ed. Pp. 69-80. Boston: South End Press.

Denny, Keith
1999 Evidence-Based Medicine and Medical Authority. Journal of Medical Humanities 20(4):247-263.

Dolcini, Margaret, Alice Gandelman, Stacy A. Vogan, Carol Kong, Tia-Nicole Leak, A.J. King, Linda DeSantis, and Ann O'Leary
2010 Translating HIV Interventions into Practice: Community-Based Organizations' Experiences with the Diffusion of Effective Behavioral Interventions (DEBIs). Social Science & Medicine 71(10):1839-1846.

Donahue, Julie, Marisa Cevasco, and Meredith B. Rosenthal
2007 A Decade of Direct-to-Consumer Advertising of Prescription Drugs. The New England Journal of Medicine 357(7):673-681.

Drennan, Kathleen B.
2002 Patient Recruitment: The Costly and Growing Bottleneck in Drug Development. Drug Discovery Today 7(3):167-170.

Dresser, Rebecca
1992 Wanted: Single, White Male for Medical Research. The Hastings Center Report 22(1):24-29.

Duggan, Lisa
2003 The Twilight of Equality? Neoliberalism, Cultural Politics, and the Attack on Democracy. Boston: Beacon Press.

Duster, Troy
2005 Race and Reification in Science. Science 307:1050-1051.

Dworkin, Shari, Rogerio Pinto, Joyce Hunter, Bruce Rapkin, and Robert Remien
2008 Keeping the Spirit of Community Partnerships Alive in the Scale-Up of HIV/AIDS Prevention: Critical Reflections of the Rollout of DEBI (Diffusion of

Evidence-Based Interventions). American Journal of Community Psychology 42(1-2):51-59.

Eakin, Joan, Ann Robertson, Blake Poland, David Coburn, and Richard Edwards
1996 Towards a Critical Social Science Perspective on Health Promotion Research. Health Promotion International 11(2):157-165.

Easterbrook, Philippa J., Jeanne C. Keruly, Terri Creagh-Kirk, Douglas Richman, Ricahrd E. Chaisson, et al.
1991 Racial and Ethnic Differences in Outcome in Zidovidune-Treated Patients with Advanced HIV Disease. The Journal of the American Medical Association 266(19):2713-2718.

Ebeling, Mary
2011 'Get with the Program!': Pharmaceutical Marketing, Symptom Checklists, and Self-Diagnosis. Social Science & Medicine 73(6):825-832.

Edgar, Harold and Donald Rothman
1990. New Rules for New Drugs: The Challenge of AIDS to the Regulatory Process. Milbank Memorial Fund Quarterly 68:111-141.

El-Haj, Nadia Abu
2007 The Genetic Reinscription of Race. Annual Review of Anthropology 36:283-300.

El-Sadr, Wafaa M., Kenneth H. Mayer, and Sally L. Holder
2010 AIDS in America—Forgotten but Not Gone. The New England Journal of Medicine 362(11):967-970.

Elliott, Carl and Roberto Abadie
2008 Exploiting a Research Underclass in Phase 1 Trials. The New England Journal of Medicine 358:2316-2317.

Elliott, Denielle A.
2007 Pharmaceutical Surveillance, Medical Research, and Biovalue among the Urban Poor. Ph.D. dissertation, Department of Sociology & Anthropology, Simon Fraser University.

Elwood, William N., Cheryl A. Dayton, and Alan J. Richard

1995 Ethnography and Illegal Drug Users: The Efficacy of Outreach as HIV Prevention. Communication Studies 46:261-275.

Epstein, Steven

1995 The Construction of Lay Expertise: AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials. Science, Technology, & Human Values 20(4):408-437.

1996 Impure Science: AIDS, Activism, and the Politics of Knowledge. Berkeley: University of California Press.

2004 Bodily Differences and Collective Identities: the Politics of Race and Gender in Biomedical Research in the U.S. Body & Society 10(83):183-204.

2007 Inclusion: The Politics of Difference in Medical Research. Chicago: University of Chicago Press.

2008 The Rise of "Recruitmentology": Clinical Research, Racial Knowledge, and the Politics of Inclusion and Difference. Social Studies of Science 38(5):801-832.

Fee, Elizabeth & Nancy Krieger

1994 Health, Politics and Power. The Women's Review of Books 11(10/11):4-5.

Feinstein, Alvan R.

2003 Scholars, Investigators, and Entrepreneurs: The Metamorphosis of American Medicine. Perspectives in Biology and Medicine 46(2):234-253.

Ferguson, Roderick A.

2005 Of our Normative Strivings: African American Studies and the Histories of Sexuality. Social Text 23(3-4):85-100.

Fielding, Jonathan and Peter Briss

2006 Promoting Evidence-Based Public Health Policy: Can We Have Better Evidence and More Action? Health Affairs 25(4):969-978.

Fisher, Jill A.

2006 Co-Ordinating 'Ethical' Clinical Trials: The Role of Research Coordinators in the Contract Research Industry. Sociology of Health & Illness 28(6):678-694.

2007 "Ready-to-Recruit" Or "Ready-to-Consent" Populations? Informed Consent and the Limits of Subject Autonomy. Qualitative Inquiry 13:875-894.

2009 Medical Research for Hire: The Political Economy of Pharmaceutical Trials. New Brunswick: Rutgers University Press.

Fisher, Jill A. and Lorna M. Ronald
2008 Direct to Consumer Responsibility: Medical Neoliberalism in Pharmaceutical Advertising and Drug Development. Advances in Medical Sociology 10:29-51.

Fisher, Morris A.
2003 Physicians and the Pharmaceutical Industry: A Dysfunctional Relationship. Perspectives in Biology and Medicine 46(2):254-272.

Flynn, George
2006 The NIH Ethics Crackdown: A Message to the Research Community. Annals of Emergency Medicine 47(1):57-60.

Food & Drug Administration
2005 FDA Approves BiDil Heart Failure Drug for Black Patients, FDA News, 23 June 2005

Ford, Chandra L., William C. Miller, Marlene Smurzynski, and Peter A. Leone
2007 Key Components of a Theory-Guided HIV Prevention Outreach Model: Pre-Outreach Preparation, Community Assessment, and Network of Key Informants. AIDS Education & Prevention 19(2):173-186.

Fraser, Nancy and Linda Gordon
1994 A Genealogy of Dependency: Tracing a Keyword of the U.S. Welfare State. Signs 19(2):309-336.

Friedman, Daniel J., Bruce C. Cohen, Abigail Averbach, and Jennifer M. Norton
2000 Race/Ethnicity and OMB Directive 15: Implications for State Public Health Practice. American Journal of Public Health 90(11):1714-1719.

Friedman, Samuel R., Wouter de Jong, Diana Rossi, Graziela Touze, Russell Rockwell, Don C. Des Jarlais and Richard Elovich
2007 Harm Reduction Theory: Users' Culture, Micro-Social Indigenous Harm Reduction, and the Self-Organization and Outside-Organizing of Users' Groups. International Journal of Drug Policy 18:107-117.

Friedman, Samuel R., Benny Jose, Bruce Stepherson, Alan Neaigus, Marjorie Goldstein, Pat Mora, Ric Curtis, and Gilbert Ildefonso
1998 Multiple Racial/Ethnic Subordination and HIV among Drug Injectors. *In* The Political Economy of AIDS. Merrill Singer, ed. pp. 105-127. Amityville: Baywood Publishing.

Friedman, Samuel R., Carey Maslow, Melissa Bolyard, Milagros Sandoval, Pedro Mateu-Gelabert and Alan Neaigus
2004 Urging Others to be Healthy: "Intravention" by Injection Drug Users as a Community Prevention Goal. AIDS Education & Prevention 16(3):250-263.

Fuqua, Joy V.
2002 'Ask Your Doctor about...': Direct-to-Consumer Prescription Drug Advertising and the HIV/AIDS Medical Marketplace. Cultural Studies 16(5):650-672.

Galai, N, D. Vlahov, JB Margolick, K. Chen, NMH Graham, and A. Munoz.
1995 Changes in Markers of Disease Progression in HIV-1 Seroconverters—A Comparison between Cohorts of Injecting Drug Users and Homosexual Men. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology 8(1):66-74.

Galen, Joseph and Daniel Dohan
2009 Diversity of Participants in Clinical Trials in an Academic Medical Center. Cancer 608-615.

Garber, Mandy and Robert M. Arnold
2006 Promoting the Participation of Minorities in Research. The American Journal of Bioethics 6(3):14-20.

Ghanem, KG, HE Hutton, JM Zenilman, R. Zimba and EJ Erbelding
2005 Audio Computer Assisted Self Interview and Face to Face Interview Modes in Assessing Response Bias among STD Clinic Patients. Sexually Transmitted Infections 81(5):421-425.

Gieryn, Thomas
1983 Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists. American Sociological Review 48(6): 781–795.

Goozner, Merrill

2004 The $800 Million Dollar Pill: The Truth Behind the Cost of New Drugs. Berkeley: The University of California Press.

2006 Conflicts of Interest in the Drug Industry's Relationship with the Government. Hofstra Law Review 35(2):737-748.

Gould, Stephen Jay

1996 The Mismeasure of Man. New York: W.W. Norton & Company

Gregory, Steven.

1988 Black Corona: Race and the Politics of Place in an Urban Community. Princeton: Princeton University Press.

Gupta, Akhil and James Ferguson

1997 Beyond "Culture": Space, Identity, and the Politics of Difference. *In* Culture, Power, Place: Explorations in Critical Anthropology. Pp 33-50. Gupta, Akhil and James Ferguson, eds. Durham, NC: Duke University Press.

Hafferty, Frederic and Donald Light

1995 Professional Dynamics and the Changing Nature of Medical Work. Journal of Health and Social Behavior (Extra Issue):132-153.

Halfmann, Drew, Jesse Rude, and Kim Ebert

2005 The Biomedical Legacy in Minority Health Policy-Making, 1975-2002. Research in the Sociology of Health Care 23:245-275.

Halliburton, Murphy

2009 Drug Resistance, Patent Resistance, Indian Pharmaceuticals and the Impact of a New Patent Regime. Global Public Health: An International Journal for Research, Policy, and Practice 4(6):515-527.

Hamilton, Jean A.

1994 Going to Extremes. The Women's Review of Books 11(10-11):15-16.

Hammonds, Evelynn M.

1987 Race, Sex, AIDS: The Construction of 'Other'. Radical America 20:55-62.

1997 Toward a Genealogy of Black Female Sexuality: The Problematic of Silence. *In* Feminist Genealogies, Colonial Legacies, & Democratic Futures. Alexander, Jacqui M. & Chandra Talpade Mohanty, eds. pp. 170-182.
New York: Routledge.

Harden, J. Taylor and Gertrude McFarland
2000 Avoiding Gender and Minority Barriers to NIH Funding. Journal of Nursing Scholarship 32(1):83-86.

Harper, Sam, Nicholas B. King, Stephen C. Meersman, Marsha A. Reichman, Nancy Breen, and John Lynch.
2010 Implicit Value Judgments in the Measurement of Health Inequalities. The Milbank Quarterly 88(1):4-29.

Harrison, Faye V.
1995 The Persistent Power of "Race" in the Cultural and Political Economy of Racism. Annual Review of Anthropology 24:47-74.

1998 Introduction: Expanding the Discourse on "Race." American Anthropologist 100(3):609-631.

Hayden, Cori
2003 When Nature Goes Public: The Making and Unmaking of Bioprospecting in Mexico. Princeton, New Jersey: Princeton University Press.

Haynes, M. Alfred and Brian D. Smedley, eds.
1999 The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved. Washington, DC: National Academies Press.

Heckathorn, Douglas D.
1997 Respondent-Driven Sampling: A New Approach to the Study of Hidden Populations. Social Problems 44(2):174-199.

Herdt, Gilbert and Shirley Lindenbaum
1992 The Time of AIDS: Social Analysis, Theory, and Method. Gilbert Herdt and Shirley Lindenbaum, eds. Newbury Park, CA: Sage.

Hess, David

1997 Science Studies: An Advanced Introduction. New York: New York University Press.

Hill, Martha N., Lee R. Bone, and Arlene M. Butz
1996 Enhancing the Role of Community Health Workers in Research. Image: Journal of Nursing Scholarship 28(3):221-233.

Hirschel B. and A. Calmy
2008 Initial Treatment for HIV Infection—An Embarrassment of Riches. Editorial. The New England Journal of Medicine 358(20):2170-2172.

Ho, Anita
2008 Correcting Social Ills through Mandatory Research Participation. American Journal of Bioethics 8(10):39-40.

Holmes, Dave, Stuart J. Murray, Amelie Perron and Genevieve Rail
2006 Deconstructing the Evidence-Based Discourse in Health Sciences: Truth, Power, and Fascism. International Journal of Evidence-Based Healthcare 4:180-186.

Hunt, Linda and Mary S. Megyesi
2008 Genes, Race and Research Ethics: Who's Minding the Store? Journal of Medical Ethics 34(6):495-500.

Hughes, Donna M.
1995 Significant Differences: The Construction of Knowledge, Objectivity, and Dominance. Women's Studies International Forum 18(4):395-406.

2010 Uniform Requirements for Manuscripts Submitted to Biomedical Journals: Writing and Editing for Biomedical Publication. Pp. 1-17 Electronic document, www.icmje.org/urm_full.pdf, accessed on 10 July 2011.

Hyatt, Susan Brin
2001 From Citizen to Volunteer: Neoliberal Governance and the Erasure of Poverty. *In* The New Poverty Studies: The Ethnography of Power, Politics, and Impoverished People in the United States. Pp. 201-235. Goode, Judith & Jeff Maskovsky, eds. New York: New York University Press.

Jackson, Lois

1997 Canadian Federal Government Policies and the Funding of HIV/AIDS Commuity-Based Groups: Changing Objectives in Times of Change. CRSP/RCPS 40:19-45.

Johnson, Jay, Mark L. Williams, and Joseph A. Kotarba
1990 Proactive and Reactive Strategies for Delivering Community-Based HIV Prevention Services: An Ethnographic Analysis. AIDS Education & Prevention 2(3):191-200.

Kahn, Jonathan
2004 How a Drug Becomes 'Ethnic': Law, Commerce, and the Production of Racial Categories in Medicine. Yale Journal of Health Policy, Law, and Ethics 4:1-46.

2005 From Disparity to Difference: How Race-Specific Medicine may Undermine Policies to Address Inequalities in Health Care. Southern California Interdisciplinary Law Journal 15:105-130.

Kane, Stephanie and Teresa Mason
1992 'IV Drug Users' and 'Sex Partners': The Limits of Epidemiological Categories and the Ethnography of Risk. Pp. 199-222. *In* The Time of AIDS. Gilbert Herdt and Shirley Lindenbaum, eds. Newbury Park, CA: Sage.

Kaplan Judith B. and Trude A. Bennett
2003 Use of race and ethnicity in biomedical publication. The Journal of the American Medical Association 289(20):2709–2716

Kaye, Kerwin
2003 Male Prostitution in the Twentieth Century: Pseudohomosexuals, Hoodlum Homosexuals, and Exploited Teens. Journal of Homosexuality 46(1-2):1-77.

Kent, James A. & C. Harvey Smith
1967 Involving the Urban Poor in Health Services through Accommodation—the Employment of Neighborhood Representatives. American Journal of Public Health 57(6):997-1003.

King, Patricia
1992 The Dangers of Difference. Hastings Center Report 22(6):35-38.

Kleinman, Daniel Lee & Steven Vallas

2001 Science, Capitalism, and the Rise of the 'Knowledge Worker': The Changing Structure of Knowledge Production in the United States. Theory and Society 30:451-492.

Kling, Rob & Suzanne Iacano
1988 The Mobilization of Support for Computerization: The Role of Computerization Movements. Social Problems 35(3):226-243.

Kohatsu, N.D., J.G. Robinson, and J.C. Turner
2004 Evidence-Based Public Health: An Evolving Concept. American Journal of Preventative Medicine 27(5):417-421.

Kolata, Gina A.
1988 AIDS Research on New Drugs Bypasses Addicts and Women. New York Times, January 5

1988 Recruiting Problems in New York Slowing U.S. Trials of AIDS Drug. New York Times, December 18

Kopytoff, Igor
1986 The Cultural Biography of Things: Commoditization as Process. In The Social Life of Things: Commodities in Cultural Perspective. Pp64-91. Arjun Appadurai, ed. New York: Cambridge University Press.

Krieger, Nancy
1987 Shades of Difference: Theoretical Underpinnings of the Black/White differences in the United States, 1830-1870. International Journal of Health Services 17(2):259-278.

2000 Epidemiology and the Social Sciences: Toward a Critical Reengagement in the 21st Century. Epidemiological Reviews 22(1):155-163.

Krieger, Nancy and Elizabeth Fee
1994 Man-made Medicine and Women's Health: The Biopolitics of Sex/Gender and Race/Ethnicity. International Journal of Health Services 24(2):265-283.

Krieger, Nancy and Mary Bassett

1993 The Health of Black Folk: Disease, Class, and Ideology in Science. Pp170-200. *In* The 'Racial' Economy of Science: Toward a Democratic Future. Sandra Harding, ed. Bloomington: Indiana University Press.

Krieger, Nancy and Davey Smith
2004 "Bodies Count" and Body Counts: Social Epidemiology and Embodying Inequality. Epidemiologic Reviews 26:92-103.

Krimsky, Sheldon
2012 The Short Life of a Race Drug. The Lancet 379(9811):114-115.

Latour, Bruno and Steven Woolgar
1986 Laboratory Life: The Social Construction of Scientific Fact. Princeton, NJ: Princeton University Press.

Lee, Catherine
2009 'Race' and 'Ethnicity' in Biomedical Research: How do Scientists Construct and Explain Differences in Health? Social Science & Medicine 68:1183-1190.

Lee, Catherine & John D. Skrentny
2010 Race Categorization and the Regulation of Business and Science. Law & Society Review 44(3-4):617-650.

Lemke, Thomas
2001 The Birth of Bio-Politics: Michel Foucault's Lectures at the College de France on Neoliberal Governmentality. Economy and Society 30(2):190-207.

Leslie, Charles
1990 Scientific Racism: Reflections on Peer Review, Science and Ideology. Social Science & Medicine 31(8):891-912.

Levine, Robert
1994 The Impact of HIV Infection on Society's Perception of Clinical Trials. Kennedy Institute of Ethics Journal 4(2):93-98.

Link, Bruce and Jo Phelan
1995 Social Conditions as Fundamental Causes of Disease. Journal of Health and Social Behavior 35:80-94.

Lowy, Ilana

2000 Trustworthy Knowledge and Desperate Patients: Clinical Tests for New Drugs from Cancer to AIDS. *In* Living and Working with the New Medical Technologies: Intersections of Inquiry. Pp. 49-81. Margaret Lock, Allan Young and Alberto Cambrosio, eds. Cambridge: Cambridge University Press.

Lurie, Peter and Allison Zieve

2006 Sometimes the Silence Can Be Like Thunder: Access to Pharmaceutical Data at the FDA. Law & Contemporary Problems 69(85):85-97.

Lynn, Lorna A.

1997 AIDS Clinical Trials: Is there access for all? Journal of General Internal Medicine: Official Journal of the Society for Research and Education in Primary Care Internal Medicine 12(3):198-199.

Maher, Lisa

1997 Sexed Work: Gender, Race, and Resistance in a Brooklyn Drug Market. London: Oxford University Press.

Mamo, Laura and Mary-Rose Mueller

2003 Confronting Inequalities of HIV/AIDS Care in the US: Suggested Lines of Investigation. Critical Public Health 3(14):347-356.

Marks, Harry M.

1997 The Progress of Experiment: Science and Therapeutic Reform in the United States, 1900-1990. Cambridge: Cambridge University Press.

Maskovsky, Jeff

2000 "Managing" the Poor: Neoliberalism, Medicaid HMOs and the Triumph of Consumerism Among the Poor in Philadelphia. Medical Anthropology 19:121-146.

2001 Sexual Minorities and the New Urban Poverty. *In* Cultural Diversity in the United States: A Critical Reader. Malden, MA: Blackwell Publishers. pp322-342.

2005 Do People Fail Drugs, Or do Drugs Fail People? The Discourse of Adherence. Transforming Anthropology 13(2):136-142.

McCabe, Alison R.

2003. A Precarious Balancing Act—the Role of the FDA as Protector of Public Health and Industry Wealth. Suffolk University Law Review 36(3):787-819.

McCarthy, Charles R.
1994 Historical Background of Clinical Trials Involving Women and Minorities. Academic Medicine 69(9):695-698.

McKnight, Courtney, Don Des Jarlais, Heidi Bramson, Lisa Tower, Abu S. Abdul-Quader, Chris Nemeth, and Douglas Heckathorn
2006 Respondent-Driven Sampling in a Study of Drug Users in New York City: Notes from the Field. Journal of Urban Health 83(7):i54-i59.

FINSH CITE LOOK FOR ORIG ARTICLE at HOME—may be wrong date for Merkatz.
Merkatz, Ruth
1995 Inclusion of Women in Clinical Trials: A Historical Overview of Scientific, Ethical, and Legal Issues. Journal of **????** 27(1):78-84.

Merkatz, Ruth, Linda Sherman, and Robert Temple
1995 Women in Clinical Trials: An FDA Perspective. Science 269(5225):793

Merson, Michael, Jeffrey O'Malley, David Serwadda, and Apisuk Chantawipa
2008 The History and Challenge of HIV Prevention. The Lancet 372:475-488.

Metzger, DS, B. Kobin, C. Turner, H. Navaline, F. Valenti, S. Holte, et al.
2000 Randomized Controlled Trial of Audio Computer-Assisted Self Interviewing: Utility and Acceptability in Longitudinal Studies. American Journal of Epidemiology 152(2):99-106.

Miller, Peter and Nikolas Rose
1988 The Tavistock Program: The Government of Subjectivity and Social Life. Sociology 22:171-192.

Mol, Annemarie and Marc Berg
1998 Introduction. *In* Differences in Medicine: Unraveling Practices, Techniques, and Bodies. Annemarie Mol and Marc Berg, eds. Pp1-12. Durham, NC: Duke University Press.

Molitor, Fred, Christina Kuenneth, Jenny Waltermeyer, Marisol Mendoza, Arthur Aguirre, Kama Brockmann and Carol Crump
2005 Linking HIV-Infected Persons of Color and Injection Drug Users to HIV

Medical and Other Services: The California Bridge Project. AIDS Patient Care and STDs 19(6):406-412.

Moore DAJ, R.L. Goodall, N.J. Ives, M. Hooker, B.G. Gazzard, and P.J. Easterbrook.
2000 How generalizable are the results of large randomized controlled trials of antiretroviral therapy? HIV Medicine 1(3): 149-154.

Centers for Disease Control and Prevention, Department of Health & Human Services
2006 Evolution of HIV/AIDS Prevention Programs—United States, 1981-2006. Morbidity & Mortality Weekly Report 55(21):597-603.

Morawski, Jill
2005 Reflexivity and the Psychologist. History of the Human Sciences 18(4):77-105.

Morgen, Sandra and Jill Weigt
2001 Poor Women, Fair Work, and Welfare-to-Work that Works. *In* The New Poverty Studies. Pp152-178. Goode, Judith & Jeff Maskovsky, eds. New York: New York University Press.

Morgen, Sandra
2002 Into our Own Hands: The Women's Health Movement in the United States, 1969-1990. Piscataway, NJ: Rutgers University Press.

Morrison-Beedy, Dianne, Michael Carey, and Xin Tu
2006 Accuracy of Audio Computer-Assisted Self-Interviewing (ACASI) and Self-Administered Questionnaires for the Assessment of Sexual Behavior. AIDS & Behavior 10:541-552.

Moscou, Susan, Matthew R. Anderson, Judith B. Kaplan, and Lisa Valencia
2003 Validity of Racial/Ethnic Classifications in Medical Records Data: An Exploratory Study. American Journal of Public Health 93(7):1084-1086.

Mosse, George
1985 Nationalism & Sexuality: Respectability & Abnormal Sexuality in Modern Europe. New York: Howard Fertig.

Mueller, Mary Rose
1998a "Women and Minorities" in Federal Research for AIDS. Race, Gender & Class 5(2):79-98.

1998b Physician Administrators and the Reorganization of Federally Sponsored Treatment Research for AIDS. Social Science & Medicine 46:1613-1622.

Mullings, Leith
2005 Interrogating Racism: Toward an Antiracist Anthropology. Annual Review of Anthropology 34(1):667-693.

Mullings, Leith and Amy Schulz
2006 Intersectionality and Health: An Introduction. *In* Gender, Race, and Class: Intersectional Approaches. Pp3-20. Schulz, Amy and Leith Mullings, eds. San Francisco: Jossey-Bass.

Mykhalovskiy, Eric and Lorna Weir
2004 The Problem of Evidence-Based Medicine: Directions for Social Science. Social Science & Medicine 59:1059-1069.

Mykhalovskiy, Eric and Marsha Rosengarten
2009 HIV/AIDS in its Third Decade: Renewed Critique in Social and Cultural Analysis—an Introduction. Social Theory & Health 7:187-195.

Mykhalovskiy, Eric
2001 Troubled Hearts, Care Pathways and Hospital Restructuring: Exploring Health Services Research as Active Knowledge. Studies in Cultures, Organizations, & Societies 7:269-296.

Murphy, Timothy F.
1991 Women and Drug Users: The Changing Faces of HIV Clinical Drug Trials. Qualitative Review Bulletin 17

National Institutes of Drug Abuse Research (NIDA)
2000 A Manual to Reduce the Risk of HIV and Other Blood-Borne Infections in Drug Users: The NIDA Community-Based Outreach Model. NIH Publication no. 00-4812. Washington, D.C.: U.S. Government Printing Office.

National Institutes of Health
2002 Outreach Notebook for the Inclusion, Recruitment, and Retention of Women and Minority Subjects in Clinical Research: Principal Investigators' Notebook. Bethesda, MD: US Department of Health & Human Services.

National Institute of Health Care Management (NIHCM) Research & Educational Foundation
2002 Changing Patterns of Pharmaceutical Innovation. Washington, DC: NIHCM Foundation.

Navarro, Vicente
2009 What We Mean by Social Determinants of Health. International Journal of Health Services 39(3):423-441.

Needle, Richard H., Dave Burrows, Samuel R. Friedman, Jimmy Dorabjee, Graziel Touze, Larissa Badrieva et al.
2005 Effectiveness of Community-Based Outreach in Preventing HIV/AIDS among Injecting Drug Users. International Journal of Drug Policy 16 (Supplement):S45-S47.

Newmeyer, John
1989 Outreach Education among Intravenous Drug Users: Use CHOWs. The Journal of the American Medical Association 262:3130-3131.

Noah, Barbara A.
2003 The Participation of Underrepresented Minorities in Clinical Research. American Journal of Law & Medicine 29:221-245.

Norsigian, Judy, Vilunya Diskin, Paula Doress-Worters, Jane Pincus, Wendy Sanford and Norma Swenson.
1999 The Boston Women's Health Book Collective and Our Bodies, Ourselves: A Brief History and Reflection. Journal of the American Medical Women's Association, Special Issue, 54(1).

Oldani, Michael
2004 Thick Prescriptions: Towards an Interpretation of Pharmaceutical Sales Practices. Medical Anthropology Quarterly 18(3):325-356.

Ordover, Nancy
2003 American Eugenics: Race, Queer Anatomy, and the Science of Nationalism. Minneapolis, MN: University of Minnesota Press.

Oppenheimer, Gerald M.

1988 In the Eye of the Storm: The Epidemiological Construction of AIDS. Pp267-300. *In* AIDS: The Burdens of History. Elizabeth Fee and Daniel M. Fox, eds. Berkeley: University of California Press.

2001 Lost Paradigm: Race, Ethnicity, and the Search for a New Population Taxonomy. American Journal of Public Health 91(7):1049-1055.

Ortiz, Ana Theresa & Laura Briggs
2003 The Culture of Poverty, Crack Babies, and Welfare Cheats: The Making of the 'Healthy White Baby' Crisis. Social Text 76(21):39-57.

Osborne, Newton G. & Marvin D. Feit
1992 The Use of Race in Medical Research. The Journal of the American Medical Association 267(2):275-279.

Paskett, Electra D., Katherine W. Reeves, John M. McLaughlin, Mira L. Katz, Ann Scheck McAlearnay, Mack T. Ruffin, Chanita Hughes Halbert, Christina Merete, Faith Davis, & Sarah Gelhert.
2008 Recruitment of Minority and Underserved Populations in the United States: The Centers for Population Health & Health Disparities Experience. Contemporary Clinical Trials 29(6):847-861.

Pates, R. and V. Blakely
1992 What should we be Looking for in Outreach Workers? International Journal of Drug Policy 3(3):130-134.

Patton, Cindy
1987 Resistance and the Erotic: Reclaiming History, Setting Strategy as we Face AIDS. Radical America 20:68-78.

1990 Inventing AIDS. New York: Routledge.

Peppin, Patricia & Elaine Carty
2001 Innovation, Myths and Equality: Constructing Drug Knowledge in Research and Advertising. The Sydney Law Review 23:543-576.

Petersen, Alan
2003 Governmentality, Critical Scholarship, and the Medical Humanities. Journal of Medical Humanities 24(3/4):187-201.

Peterson, Alan and Deborah Lupton
1996 The New Public Health: Health and Self in the Age of Risk. St. Leonard's, NSW: Allen & Unwin.

Petryna, Adriana
2009 When Experiments Travel: Clinical Trials and the Global Search for Human Subjects. Princeton, NJ: Princeton University Press.

Pinn, Vivian W.
1994 The Role of the NIH's Office of Research on Women's Health. Academic Medicine 69(9):698-702.

Piot, Peter
2008 Coming to Terms with Complexity: A Call to Action for HIV Prevention. The Lancet 372(9641):845-859.

Piven, Frances Fox & Richard Cloward [CITED in Mask 2000]
1997 Breaking of the American Social Compact. New York: The New Press.

Plant, Aileen J. & R. Louise Rushworth
1998 "Death by Proxy": Ethics and Classification in Epidemiology. Social Science & Medicine 47(9):1147-1153.

Public Health Reports
1985 Women's Health: Report of the Public Health Service Task Force on Women's Health Issues. Public Health Reports 100(1):73-106.

Putnam, Wayne, Peter Twohig, Frederic Burge, Lois A. Jackson, and Jafna L. Cox.
2002 A Qualitative Study of Evidence in Primary Care: What the Practitioners are Saying. Canadian Medical Association Journal 166(12):1525-1530.

ADD CITE [MAYBE] (PAS-03-168) titled "Enrolling Women and Minorities in HIV/AIDS Research Trials."

Rabinow, Paul & Nikolas Rose
2006 Biopower Today. Biosocieties 1:195-217.

Rahimian, Afsaneh and Alfred Pach
1999 Stories of AIDS Outreach and Case Management: Context and Activities. Substance Use & Misuse 34(14):1991-2014.

Reardon, Jenny
2006 Creating Participatory Subjects: Science, Race, and Democracy in a Genomic Age. *In* New Political Sociology of Science: Institutions, Networks, and Power. Scott Frickel and Kelly Moore, eds. pp 351-377. Madison, WI: University of Wisconsin Press.

Roberts, Dorothy
1999 Killing the Black Body: Race, Reproduction, and the Meaning of Liberty. New York: Vintage Books.

2006 Legal Constraints on the use of Race in Biomedical Research: Toward a Social Justice Framework. Journal of Law, Medicine & Ethics:526-534.

2008 Is Race-Based Medicine Good for Us?: African American Approaches to Race, Biotechnology, and Equality. Journal of Law, Medicine, & Ethics 36:537-545.

2011a Fatal Invention: How Science, Politics, and Big Business Re-Create Race in the Twenty-First Century. New York: The New Press.

2011b What's Wrong with Race-Based Medicine? Genes, Drugs, and Health Disparities. Minnesota Journal of Law, Science & Technology 12:1-22.

Rosenbrock, Rolf, Francoise Dubois-Arber, Martin Moers, Patrice Pinell, Doris Schaeffer, & Michel Setbon
2000 The Normalisation of AIDS in Western European Countries. Social Science & Medicine 50(11):1607-1629.

Rosenberg, Charles
1995 The Care of Strangers: The Rise of America's Hospital System. Baltimore, MD: Johns Hopkins University Press.

Ruiz, Rebecca
2011 Ten Misleading Drug Ads. Electronic document, www.forbes.com, accessed 10/02, 2011.

Ruzek, Sheryl Burt & Julie Becker
1999 The Women's Health Movement in the United States: From Grass-Roots Activism to Professional Agendas. Journal of the American Medical Women's Association 54(1):4-8.

Salmon, Amy
2007 Walking the Talk: How Participatory Interview Methods Can Democratize Research. Qualitative Health Research 17(7):982-993.

Saunders, Barry
2008 CT Suite: The Work of Diagnosis in the Age of Noninvasive Cutting. Durham, NC: Duke University Press.

Schiller, Nina Glick
1992 What's Wrong with this Picture? The Hegemonic Construction of Culture in AIDS Research in the United States. Medical Anthropology Quarterly 6(3):237-254.

Schulte, Joann M., Beverly J. Nolt, Robert L. Williams, and Spinks, Cynthia L. & James J. Hellsten
1998 Violence & Threats of Violence Experienced by Public Health Fieldworkers. Journal of the American Medical Association 280(5):439-442.

Scott, Greg
2008 'They Got their Program, and I Got Mine': A Cautionary Tale Concerning the Ethical Implications of Using Respondent-Driven Sampling to Study Injection Drug Users. International Journal of Drug Policy 19:42-51.

Sears, Alan
1992 "To Teach Them How to Live": The Politics of Public Health from Tuberculosis to AIDS. Journal of Historical Sociology 5(1):61-83.

ADD CITE Sengupta et al.

Shapin, Steve
1989 The Invisible Technician. American Scientist 77:554-563.

Sharp, Lesley
2000 The Commodification of the Body and Its Parts. Annual Review of Anthropology 29:287-328.

Sharav, Vera Hassner
2003 Children in Clinical Research: A Conflict of Moral Values. The American Journal of Bioethics 3(1):W12-W59.

Shavers-Hornaday, VL, Lynch CF, Burmeister LF & JC Torner
1997 Why are African-Americans Under-Represented in Medical Research Studies? Impediments to Participation. Ethnicity & Health 2:31-45.

Shim, Janet K.
2002 Understanding the Routinised Inclusion of Race, Socioeconomic Status and Sex in Epidemiology: The Utility of Concepts from Technoscience Studies. Sociology of Health & Illness 24(2):129-150.

2005 Constructing 'Race' Across the Science-Lay Divide: Racial Formation in the Epidemiology and Experience of Cardiovascular Disease. Social Studies of Science 35(3):405-436.

Silverberg, MJ, Wegner SA, Milazzo MJ, McKaig RG, Williams CF, Agan BK et al.
2006 Effectiveness of Highly-Active Antiretroviral Therapy by Race/Ethnicity. AIDS 20(11):1531-1538.

Simoni, Jane M., Weinberg, Beth A. and Dawn K. Nero
1999 Training Community Members to Conduct Survey Interviews: Notes from a Study of Seropositive Women. AIDS Education & Prevention 11(1):87-88.

Singer, Merrill
1995 Beyond the Ivory Tower: Critical Praxis in Medical Anthropology. Medical Anthropology Quarterly 9(1):80-106.

1998 Forging A Political Economy of AIDS. *In* The Political Economy of AIDS. Merrill Singer, ed. Amityville, NY: Baywood Publishing Company. pp3-32.

Skinner, David
2006 Racialized Futures: Biologism and the Changing Politics of Identity. Social Studies of Science 36(3):459-488.

Smith, Mark D.
1991 Zidovudine: Does it Work for Everyone? Editorial. Journal of the American Medical Association 266(19):2750-2751.

Smedley, Audrey

1993 Race in North America: Origin and Evolution of a Worldview. Boulder, CO: Westview Press.

Somerville, Siobhan

2000 Queering the Color Line: Race and the Invention of Homosexuality in American Culture. Durham, NC: Duke University Press.

Starr, Paul

1982 The Social Transformation of American Medicine: The Rise of a Sovereign Profession and the Making of a Vast Industry. New York: Basic Books.

Star, Susan Leigh and Martha Lampland

2009 Reckoning with Standards. *In* Standards and Their Stories: How Quantifying, Classifying, and Formalizing Practices Shape Everyday Life. Lampand, Martha and Susan Leigh Star, eds. Ithaca, NY: Cornell University Press.

Stepan, Nancy Leys & Sander Gilman

1993 Race and Gender: The Role of Analogy in Science. Pp 359-376. *In* The 'Racial' Economy of Science: Toward a Democratic Future. Sandra Harding, ed. Bloomington: Indiana University Press.

Sterk-Elifson, Claire

1993 Outreach among Drug Users: Combining the Role of Ethnographic Field Assistant and Health Educator. Human Organization 52(2):162-168.

Stevens, Jacqueline

2003 Racial Meanings and Scientific Methods: Changing Policies for NIH-Sponsored Publications Reporting Human Variation. Journal of Health Politics, Policy and Law 28(6):1033-1087.

Stimson, Gerry V., Gail Eaton, Tim Rhodes, and Robert Power

1994 Potential Development of Community Oriented HIV Outreach among Drug Injectors in the U.K. Addiction 89:1601-1611.

Suczek, Barbara & Shizuko Fagerhaugh

1991 AIDS and Outreach Work. *In* Social Organization and Social Process: Essays in Honor of Anselm Strauss. David Maines, ed. pp. 159-173.

Tanenbaum, Sandra J.

1994 Knowing and Acting in Medical Practice: The Epistemological Politics of Outcomes Research. Journal of Health Politics, Policy and Law 19(1):27-44.

Teghtsoonian, Katherine
2009 Depression and Mental Health in Neoliberal Times: A Critical Analysis of Policy and Discourse. Social Science & Medicine 69(1):28-35.

Terry, Jennifer
1995 Deviant Bodies: Critical Perspctives on Difference in Science and Popular Culture. Indianapolis: University of Indiana Press. Terry, Jennifer & Jacqueline Urla, eds.

Thomson, Reuters
2009 Journal Citation Reports. Retrieved January 15 2011.

Timmermans, Stefan and Alison Angell
2001 Evidence-Based Medicine, Clinical Uncertainty, and Learning to Doctor. Journal of Health and Social Behavior 45:177-193.

Timmermans, Stefan and Marc Berg
2003 The Gold Standard: The Challenge of Evidence-Based Medicine and Standardization in Health Care. Philadelphia: Temple University Press.

1997 Standardization in Action: Achieving Local Universality through Medical Protocols. Social Studies of Science 27(2):273-305.

Timmermans, Stefan and Emily S. Kolker
2004 Evidence-Based Medicine and the Reconfiguration of Medical Knowledge. Journal of Health and Social Behavior 45:177-193.

Timmermans, Stefan and Aaron Mauck
2005 The Promises and Pitfalls of Evidence-Based Medicine. Health Affairs 24(1):18-28.

Timmermans, Stefan and Tara McKay
2009 Bioethics and Health Care Disparities in Substance Dependency. Social Science & Medicine 69(12):1784-1790.

Tommasello, A. C., L. M. Gillis, J.T. Lawler, and G.J. Bujak
2006 Characteristics of Homeless HIV-Positive Outreach Responders in Urban U.S. and their Success in Primary Care Treatment. AIDS Care 18(8):911-917.

Treichler, Paula A.
1987 AIDS, Homophobia and Biomedical Discourse: An Epidemic of Signification. Cultural Studies 1(3):263-305.

1999 How to Have Theory in an Epidemic. Durham, NC: Duke University Press.

Trickett, Edison J.
2005 Community Interventions and HIV/AIDS: Affecting the Community Context. *In* Community Interventions and AIDS. Pp 3-27. Trickett, Edison and Willo Pequegnat, eds. New York: Oxford University Press.

van der Geest, Sjaak, Susan Reynolds Whyte and Anita Hardon
1996 The Anthropology of Pharmaceuticals: A Biographical Approach. Annual Review of Anthropology 25:153-178.

Victora, Cesar G., Jean-Pierre Habicht, and Jennifer Bryce
2004 Evidence-Based Public Health: Moving Beyond Randomized Trials. American Journal of Public Health 94(3):400-405.

Villanueva-Russell, Yvonne
2005 Evidence-Based Medicine and Its Implications for the Profession of Chiropractic. Social Science & Medicine 60(3):545-561.

Visweswaran, Kamala
1998 Race and the Culture of Anthropology. American Anthropologist 100(1):70-83.

Warner, John Harley
1995 The History of Sciences and the Sciences of Medicine Osiris 10:164-193.

Washington, Harriet
2006 Medical Apartheid: The Dark History of Medical Experimentation on Black Americans form Colonial Times to the Present. Random House: New York.

Waterston, Alisse

1997 Anthropological Research and the Politics of HIV Prevention: Towards a Critique of Policy and Priorities in the Age of AIDS. Social Science and Medicine 44(9):1381-1391.

Watters, John K. & Patrick Biernacki
1989 Targeted Sampling: Options for the Study of Hidden Populations. Social Problems 36(4):416-430.

Weber, Lynn
2006 Reconstructing the Landscape of Health Disparities Research: Promoting Dialogue and Collaboration between Feminist Intersectional and Biomedical Paradigms. Pp21-59. *In* Gender, Race, Class & Health: Intersectional Perspectives. Schulz, Amy and Leith Mullings, Eds. San Francisco: Jossey-Bass.

Weisman, Carol S.
1998 Women's Health Care: Activist Traditions and Institutional Change. Baltimore, MD: The Johns Hopkins University Press.

Wendler, David, Raynard Kington, Jennifer Madans, Gretchen Van Wye, Heidi Christ-Schmidt, Laura A. Pratt, Otis W. Brawley, Cary P. Gross, and Ezekiel Emmanuel
2006 Are Racial and Ethnic Minorities Less Willing to Participate in Health Research? PLoS Medicine 3(2):0201-0210.

Whippen, Deb
1987 Science Fictions: The Making of a Medical Model for AIDS. Radical America 20:39-54.

White, Evelyn C., ed.
1990 The Black Women's Health Book: Speaking for Ourselves. Seattle: Seal Press. First Edition.

Whyte, Susan Reynolds
2009 Health Identities and Subjectivities: The Ethnographic Challenge. Medical Anthropology Quarterly 23(1):6-15.

Williams, David R.
1997 Race and Health: Basic Questions, Emerging Directions. Annals of Epidemiology 7:322-333.

Winkler, Margaret A.
2004 Measuring Race and Ethnicity: Why and how? Journal of the American Medical Association 292(13):1612-1614.

Witmer, Anne, Sarena Seifer, Leonard Finocchio, Jodi Leslie, & Edward H. O'Neil
1995 Community Health Workers: Integral Members of the Health Care Work Force. American Journal of Public Health 85(8):1055-1058.

FINISH CITE no google search find article—maybe cited in Trickett? Wolfheimer, Dan
2001

Wolitski, Richard, Kidder, Daniel P., and Kevin A. Fenton
2007 HIV, Homelessness, and Public Health: Critical Issues and a Call for Increased Action. AIDS & Behavior 11(2):167-171.

Young, Rebecca
1994 The Scarcity of Data on Cunnilingus. The AIDS Reader 4(4):132-133.

Zierler, Sally and Nancy Krieger
1997 Reframing Women's Risk: Social Inequalities and HIV Infection. Annual Review of Public Health 18:401-436.

Zuberi, Tukufu
2001 Thicker Than Blood: An Essay on how Racial Statistics Lie. Minneapolis, MN: University of Minnesota Press.