Nepantla and Ubuntu Ethics Para Nosotros: Beyond Scrupulous Adherence Toward Threshold Perspectives of Participatory/Collaborative Research Ethics

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NEPANTLA AND UBUNTU ETHICS PARA NOSOTROS:
BEYOND SCRUPULOUS ADHERENCE TOWARD THRESHOLD PERSPECTIVES
OF PARTICIPATORY/COLLABORATIVE RESEARCH ETHICS

by

Monique A. Guishard

A dissertation submitted to the Graduate Faculty in Critical Social/Personality Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2015
This manuscript has been read and accepted for the Graduate Faculty in Critical Social/Personality Psychology to satisfy the dissertation requirement for the degree of Doctor of Philosophy.

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THE CITY UNIVERSITY OF NEW YORK
Abstract

NEPANTLA AND UBUNTU ETHICS PARA NOSOTROS:
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By
Monique A. Guishard

Adviser: Professor Michelle Fine

Participatory Action Research (PAR) refers less to a method and more to a continuum of approaches to collaborative inquiry. Within PAR, ideally, some phenomenon has been identified as a mutual area of concern to researchers and community members; working together they design, conduct, analyze, and disseminate the findings of a shared piece of research and coordinate action(s) aimed at using research to redress injustice. If PAR is embraced holistically boundaries inevitably blur as research team members become enmeshed in each other’s lives. This blurring while momentous can give rise to ethical quandaries that IRB centered research ethics are inadequate to engage or provide parameters for the conduct of ethical participatory research. Borrowing from Borderlands scholarship I conceptualized PAR stakeholders as nepantleras. PAR researchers and their community partners are nepantleras because their work is about unremittingly trying to co-create and co-nurture counter-hegemonic research relationships bridging racial, ethnic, cultural, and social class boundaries within their collaborations. Nepantla perspectives give rise to Ubuntu ethical stances. Ubuntu ethics involves evaluation(s) of how our PAR builds capacity, sustains transparency of project aims, gauges accountability, assesses inclusivity, demonstrates trustworthiness, and the preservation of dignity at each stage of the
research process. Using individual interviews and a longitudinal de-colonial ethnography of a community based ethical review board this dissertation attempted to understand how different nepantleras define the parameters of ethical conduct in research. In some ways I have accomplished this aim. I am in other respects left with the sobering realization that conducting ethical participatory research that embraces nepantla and Ubuntu ethics while working within the confines of conventional ethics is more difficult to conduct than I could have possibly imagined.
Dedication

This dissertation is dedicated primarily to my grandmother Eleanora Victoria Baltimore Smith and to my mother “Eunice” Naomi Williams. Granny, how I wish you were physically here to witness this moment with me. I feel your spirit always. Miss Eunice I hope this is an acceptable 76th birthday present. Thank you both for teaching me humility, dignity and for always feeding my incessant curiosity. I know my yearnings exasperated you.

For Roma, Arlene, and Desiree—my sisters; you are the reason I often describe things three different ways.

For my nephews Matthew and Aaron Guishard, my two favorite people in the world; this process hindered my ability to be the aunt and friend I wanted to be but could not for too many years. I finished this for us. Please don’t submit all of those rain checks at the same time.

For William, my sweetest adversary and greatest ally, I must have done something really amazing in another life to have been gifted with you. No one could ask for a better supporter, guardian, and friend than I have in you. Immense gratitude love for sleeping on the floor next to me as I wrote, for endless coke zero, seltzer water, Chipotle, and sometimes beer runs to the store—just for me, to lift my spirits and quite my inner critic. Thank you for countless other unexpected tokens, kisses, and hugs over these twenty years that conveyed your love without uttering a word. You will probably never read a word of this manuscript but you know its contents as much as I do. I am convinced the Wonder Woman socks with the tiny red capes sewn on the back helped me fly to the finish line.
For all of my students but especially for: Maricela Almonte, Marie New, Regina de los Santos, Alberto Salcedo, and Alexandra Sumner your finger prints are all over this thing. Deities know you have taught me far more than I have ever taught you. Ubuntu!

For Gloria Anzaldúa and Cynthia Chataway thank you for sharing mutual vulnerability, choques, nepantla, mestizaje, and conocimiento with the world. How I wish I could have met you both. See you next lifetime.
Acknowledgements

I would like to acknowledge my advisor and dissertation committee chair, Dr. Michelle Fine. Michelle, you took a giant chance on an outraged rejected applicant to our Social-Personality Psychology doctoral program. Thank you for your mentorship, for always advocating for me, for mothering mind from up close and far away. Being one of your students has been both a blessing and sometimes a formidable burden. The blessings are obvious, but the hindrances—not so much. Having you as a mentor has made me, perhaps naively, expect other distinguished scholars to share in your generosity, sense of ethics, integrity and sincerity—sadly that has not been the case.

I would like to acknowledge the support of my brilliant colleagues Jessica Eve Tuck, Maria Elena Torre, April Burns, Justin Brown, and Patricia Krueger-Henney. I am so appreciative of and humbled by your friendship. Our dinners, your comforting shoulders, constructive feedback and empathetic ears helped me in more ways than you know.

I would like to recognize the support of the other members of my dissertation committee Dr. Martin Ruck, my dude from day one, and Dr. Caitlin Cahill.

Many thanks to Dr. A.J. Franklin, Dr. Maureen O’Connor and Dr. Susan Opotow.

Ms. Judith Kubran I have told you this many times but it bears repeating—you are made of win and awesome-sauce.

I would like to acknowledge my research families: 1) the parent organizers from Mothers on the Move and the youth researchers (Christine Doyle, Jeunesse Jackson, Sati Singleton, Travis Staten, and Ashley Webb) from the Bronx on the Move project. 2) Peggy Shepard, Swati
Prakash, and Yolande Cadore from WEACT for Environmental Justice research. 3) Dr. David Fine and the youth researchers of the Investigating the History of Peekskill project.

I must acknowledge the support of the past and current members, project coordinators, and the principal investigator of the Bronx Community Research Review Board: SkaKing Alston, Michael Burke, Francisco Martin del Campo, Hetty Fox, Daniel Korin, Yvonne Long, Bianca Lopez, Kevin Montiel, Sandra Rodriguez, Barbara Salcedo, Hal Strelnick, and Bernice Williams. Thank you for welcoming me into such a sacred space.

Regina Wigfall, my other-mother. Thank you for your affectionate harassment, for staying at the college after hours with me so very many nights. I knew you didn’t always have work to do.

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Chapter 1: Nepantla and Ubuntu Ethics Para Nosotros: Beyond Scrupulous Adherence Toward Threshold Perspectives of Participatory/Collaborative Research Ethics

The ethical dilemmas that often surface in qualitative research are not put to rest by scrupulous adherence to the standard procedures for informed consent, anonymity, and confidentiality. “Who owns the data?” is an ethical question that participants in laboratory studies do not think to ask. Whose interpretation counts? Who has veto power? What will happen to the relationships that were formed in the field? What are the researcher’s obligations after the data are collected? Can the data be used against the participants? Will the data be used on their behalf? Do researchers have an obligation to protect the communities and social groups they study or just to guard the rights of individuals? Such questions reveal how much ethical terrain is uncharted by APA guidelines and institutional review boards. It is qualitative researchers who are wrestling with such ethical dilemmas, but the dilemmas are present in much psychological research regardless of the researcher’s methodological commitments.


Jeanne Maracek, Michelle Fine, and Louise Kidder’s (2001) work, their collective thoughts above have undeniably shaped this dissertation and my praxis as a de-colonial participatory ethicist. In the quote above they provoke us, social psychologists and qualitative researchers, to (re)consider how we define the parameters of ethical conduct in research. In the academy we are taught to subscribe to a posture of “scrupulous adherence” to federal ethical guidelines, ethical principles, professional ethical codes, and institutional review board (IRB) evaluations. We are encouraged to construe these sources as encapsulating the scope of ethical conduct in research with human participants. These yardsticks are instrumental in guiding a researcher’s thinking and actions, particularly with respect to avoiding the egregious ethical abuses of the past. Many others with Maracek, Fine, and Kidder (2001; Anderson et al., 2012; Blake, 2007; Boser, 2006; Bradley, 2007; Brydon-Miller, 1997; 2012; Brydon-Miller, Greenwood, & Eikeland, 2006; Cahill, 2007; Christians, 2007; Lincoln & Guba, 1987; Kuriloff, Andrus, & Ravitch, 2011; Malone, Yerger, McGruder & Froelicher, 2006; Mertens, Holmes, & Harris, 2009; Shore, 2008; Smith, 1999; Smith, 2005; Tuck & Guishard, 2013) have also critically questioned the limitations of these directives for how they attend to the ethical and
moral quandaries that often erupt in qualitative and participatory research. These feminist social psychologists have lastly charged us to trouble the notion that concerns about data ownership, the interpretation of a study’s findings, the self-determination of participants/co-researchers, and our responsibilities as social justice researchers only matter in alternative postures/methods of research (Maracek, Fine, & Kidder, 2001). To my knowledge using experimental design, random assignment and selection, simply tweaking the recipe and methods of research has never provided an escape from contemplating these issues.

Fundamentally, this dissertation was conceived to explore what I, and many others, have experienced as chasms between federal regulations, IRB checks and balances, and the ethical dilemmas academic scientists and their community partners struggle with in collaborative research. This is important work because we are living and working at a time when there is immense political pressure, public pressure, and growing federal support to produce collaborative, participatory, community engaged, community-based, translational, and/or patient-centered research in many academic disciplines (Bloomgarden & O’Meara, 2007; Driscoll, 2009; Green, 2003; Lauer & Collins, 2010; Minkler, Blackwell, Thompson, & Tamir, 2003; Minkler & Wallerstein, 2011; Van de Ven, 2007; Wallerstein & Duran, 2003; Woolf, 2008). Though these approaches to collaborative research are often conflated they are tied to different norms of participation, different epistemological and ontological beliefs systems. Though they are situated on different points on a continuum of collaboration these postures to research all seem to question: the nature of relationships between researchers and the researched, but also the purpose(s) of research. The point of this manuscript is not to spell out the differences between these approaches to research or to document the rise of citizen science. Other scholars have articulated the nature of the distinctions, the circumstances and events surrounding the shifts of
once marginalized stances to research moving toward the mainstream (Cammarota & Fine, 2008; Denzin, Lincoln, & Smith, 2008; Horowitz, Robinson, & Seifer, 2009; Kemmis & McTaggart, 2007; Kress, Malott, & Porfilio, 2013; Lorenzetti & Walsh, 2014; Minkler & Wallerstein, 2008; Trimble & Fisher, 2006). This dissertation does however aim to respond to the increasing interest in participatory approaches to research when PAR is considered as merely another method of social research that involves inserting more bodies into exploitative, non-transformative inquiry which serves the interests of researchers, institutions and funders but not communities (Kress et al., 2013; Krueger, 2010, 2011; Tuck & Guishard, 2013).

**Defining Participatory Research**

Participatory Action Research (PAR) is perhaps better understood as an orientation to collaborative inquiry than pigeon-holed as a particular methodology. It may be qualitative, quantitative, and/or employ mixed methods. PAR has varied characterizations, international and promiscuous disciplinary roots. It can be located in communities, the academy, or in co-constructed spaces. PAR embodies a continuum of research activities that utilize varying modes of participation (from low to high) and control between community-based entities and academic researchers (Brydon-Miller, 1997, 2012; Brydon-Miller et al., 2006; Chataway, 1997; Cornwall & Jewkes, 1995; Fals-Borda & Rahman, 1991; Gattenby & Humphries, 2000; Greenwood & Levin, 2005; Kemmis & McTaggart, 2000; Torre et al., 2012; Wadsworth, 1998; Wallerstein & Duran, 2003). Ideally, however, PAR aspires to initiate transparent, democratic inquiry; that is collaboratively designed, conducted, analyzed, and disseminated in the context of equal partnership with university scientists and members of disempowered groups.

Participatory Action Research (PAR) is counter-hegemonic to the hetero-patriarchal, imperialistic, and subtle (but sometimes overt) racist modus operandi of mainstream research. It
is not cooperative for the sake of cooperation but with the explicit goal of decolonizing and repatriating the knowledge production process (Chilisa, 2012; Guishard, 2005; 2009; Smith, 2005; Trimble & Fisher, 2006; Tuck, 2009a; Tuck & Guishard, 2013). In participatory research there are multiple transformations. Research as a self-interested enterprise, as a means of purely exploring testable hypotheses is transformed into a tool that can be used to illuminate systemic inequalities and achieve social justice. Rather than recreate and reify existing hierarchies of knowing, like erudite researcher and unwitting naïve subject, proponents of PAR engage in a process of iterative research, action and reflection. Personal narratives are combined with historical and structural analyses of the issue being studied. This aspect of PAR is pivotal as Martín-Baró (1994) notes the,

practical knowledge acquired through participatory research should lead toward the people gaining power, a power that allows them to become the protagonists of their own history and to effect change. (p. 30)

That is, in participatory research, the nonacademic research partners are not viewed as passive, unintelligent objects but as people who possess valuable insight and organic expertise into the conditions that affect their lives. PAR ideally, facilitates “the reciprocal exchange of knowledge and skills” (Israel et al, 2005) that builds capacities and critical consciousness for all contributors (Guishard et al., 2005; Guishard, 2009). It personally transforms the academic scientists as well (Brydon-Miller, 1997; Brydon-Miller et al., 2006; Chataway, 1997; 2001; Cornwall & Jewkes, 1995; Fals-Borda & Rahman, 1991; Cammarota & Fine, 2008; Fine et al., 2004; Guishard, 2005, 2008; Guishard et al., 2003, 2005; Guishard, 2009; Kemmis & McTaggart, 2000; Torre, 2009; Wadsworth, 1998; Watkins & Shulman, 2008). The research partners’ scientific knowledge and expertise are also interrogated regarding its insights and limitations. The extent to which the
researcher’s training, gender, race/ethnicity, social class, sexuality, and (dis)abilities shape their theoretical standpoints and analytical strategies is also analyzed (Baldwin, 1989; Chilisa, 2012; Dillard, 2000; Fine, 1994; Fine, Weiss, Weseen, & Wong, 2003; Fine & Wong, 1996; Guishard, 2009; Hurtado, 2003; Jordan et al., 2001). Collaborators use the data gathered to de-ideologize their realities, analyze the source(s) and contextualize the shared nature of their problems forming what Torre & Ayala (2009) characterize as participatory entremundos. I will later argue that PAR magnifies choques, nepantlera and Ubuntu ethical perspectives.

PAR projects have been highly successful in enhancing academic and lay understanding of social theory and practical problems. Participatory research has been shown to improve data collection, increase participation, yield research results, theories, and concepts that are more nuanced and culturally relevant (Banks et al., 2013, Bastida et al., 2010; Hatch, Moss, Saran, Presely-Cantrell, & Mallory, 1993; Jordan, et al., 2001; Mohatt & Thomas, 2006; Trimble & Fisher, 2006). Through the use of PAR, knowledge, materials, activities, trainings, and products have been developed that serve multiple audiences which fortify community capacity to understand and utilize research to advocate for their own issues independent of academic scientists. However, while PAR holds possibilities for restructuring and reshaping relationships between academe and the communities we serve; it is not a universal remedy for the multiplicity of isms that permeate much of academic research. Previously I have written that (Guishard, 2009), “action research methods are commodified when they are romanticized and touted as panaceas to institutional racism and structural injustice and when members of disempowered groups are superficially included in research” (p. 88). Jordan and Kapoor (2010) help us understand that this a not a new dilemma for participatory research,
since its inception almost half a century ago within anti-colonial movements in the global south, PAR increasingly has been subject to forces that have compromised its revolutionary potential as a transformatory methodology for subaltern and otherwise marginalized populations aimed at bettering their social and political conditions….the concept and practice of participation, unequivocally, has been subordinated to a neo-liberal agenda that in many respects mirrors the aims, objectives, and priorities of nineteenth and twentieth century colonialism. (p. 4)

As I reflect on the participatory action research projects I have directed, even years later, I cannot help but feel a mixed sense of pride, hope and uneasiness (Guishard, 2005, 2009; Guishard et al., 2003; Guishard et al., 2005). None of the participatory work I have been involved in was easy to initiate or complete, thus I am quite proud of what my research families and I have accomplished. Our work has troubled representations of Bronx residents, urban youth and has stimulated small actions. I still however, harbor palpable feelings of unease between the radical possibilities of PAR and the overt and covert attempts to subvert it. With Eve Tuck (Tuck & Guishard, 2013) I/we have posited that,

There is nothing about PAR that intrinsically serves as a cure-all or magic bullet for the many biases and moral quandaries that plague social science inquiry especially those that derive from complicity in relations of settler colonialism. There can be a general misconception that by simply building participation into a project—by increasing the number of people who collaborate in collecting data—ethical issues of representation and voice, exploitation, consumption, voyeurism and reciprocity are resolved. (p. 15)

In the quote above, Eve Tuck and I do not intend to come across as members of the participation police. What we intended to impart was that our own research, consultative work, and collective
experience as reviewers of action research manuscripts for publication taught us that participatory research has inherent ethics of participation that are too often left un-interrogated. Folks who look to PAR as a hip method of getting better data, rather than a process that is meant to decolonize research, frequently misconstrue participatory research with a tiny p for PAR with a capital P. I strongly suspect these misinterpretations can be traced to how the academy has primed researchers to think about the contours of their ethical conduct. In the next section I attempt to contextualize the representation(s) of ethicality I learned in formal research ethics training. I contrast these lessons with the embodied and relational stances to ethics that I acquired from my elders and from PAR.

A Social Scientist’s Prime Directive

The spaces between research methodologies, ethical principles, institutional regulations, and human subjects as individuals and as socially organized actors and communities is tricky ground. The ground is tricky because it is complicated and changeable, and it is tricky also because it can play tricks on research and researchers. Qualitative researchers generally learn to recognize and negotiate this ground in a number of ways, such as through their graduate studies, their acquisition of deep theoretical and methodological understandings, apprenticeships, experiences and practices, conversations with colleagues, peer reviews, their teaching of others.
—Linda T. Smith, On Tricky Ground, 2005, p. 85

Being ethical in mainstream social science research is often characterized as knowledge of and adherence to federal mandates, professional codes of conduct, and ethical principles (Cannella & Lincoln, 2007; Manzo & Brightbill, 2007; Martin, 2007; Mertens, Holmes, & Harris, 2009; Ross et al., 2010; Schwandt, 2007; Strohm-Kitchener & Kitchener, 2009; Tolich & Fitzgerald, 2006; Trimble & Mohatt, 2006; Tuck & Guishard, 2013). Many regulatory frameworks exist that detail the rights of individual human subjects and the responsibilities of academic scientists such as the Nuremberg Code, The Declaration of Helsinki, The Belmont Report, and The Common Rule (Beauchamp & Childress, 2001; King, Henderson, & Stein,
Novice academic researchers are taught, primarily through graduate ethics courses and online computer-based training, three guiding principles of ethical research: respect for persons, beneficence, and justice (Beauchamp & Childress, 2001; US DHHS, 2005). Respect for persons requires researchers to recognize and regard the autonomy of human research participants. This principle requires clearly informing potential participants about the purpose of research, the nature of potential risks and benefits of their participation, among other information (confidentiality and privacy procedures) which would assist them in deciding free from coercion or consequence whether or not they will participate in research. Under this principle, persons with reduced autonomy (ex. children, prisoners, and the mentally impaired) are afforded extra protections (Beauchamp & Childress, 2001; US DHHS, 2005). The principle of beneficence obligates researchers to protect participants from harm (non-maleficence) by minimizing risks and maximizing potential benefits of participation in research. Lastly, the principle of justice involves the expectation that researchers attend to how burdens and risks are equitably distributed in research (US DHHS, 2005). Beginning scientists are also educated in and required to comply with additional, albeit more practice-oriented ethical standards derived from discipline specific Codes of Conduct.¹ These codes are promulgated by professional research associations

¹American Education Research Association Code of Ethics and American Psychological Association Ethical Principles of Psychologists and Code of Conduct
that researchers are members of. Professional ethics codes must be obeyed by researchers who intend to present at conferences sponsored by these associations. In conjunction with a seemingly extensive, but at the same time shallow, education in ethical theory, neophyte researchers are socialized to construe concerns of Institutional Review Boards (IRBs) as comprising the entirety of concerns of ethical conduct.

IRBs panels are mandated by the U.S. Department of Health and Human Service to oversee research with human participants under the National Research Act of 1974. The Common Rule, the federal guidelines that direct the activities of the IRB define research “as a systematic investigation, including pilot research, testing and evaluation, designed to develop or contribute to generalizable knowledge.” (US DHHS, 2005) Because participatory research frequently does not endeavor to test hypotheses or contribute to generalizable knowledge per se, it is often not considered research by many review boards. IRBs are tasked with reviewing proposed research involving “human subjects” that is federally funded. Human subjects are defined, under the aforementioned guidelines, as living persons from whom a researcher will obtain “data” 1) through intervention or interaction with the individual or 2) identifiable private information (US DHHS, 2005). The function of an Institutional Review Board, is to protect research participants by a) making sure that the research is valid, b) ensuring that the risks are minimized or balanced by benefits or potential benefits, and (c) ensuring that potential participants are given information relevant to making an informed decision about participating in the research and about the choices involved in doing so. (Speigleman &Spear, 2006 p. 124)

Irrespective of review category (exempt, expedited, or full review), Institutional Review Boards have the authority to: approve submitted proposals, request revisions to study protocols and/or
materials and disapprove of a research project (Beauchamp & Childress, 2001; US DHHS, 2005).

This dissertation posits that the establishment of Institutional Review Boards (IRBs) to monitor ethical research practices with human participants in federally funded research is valuable and important. However it is critical to note that IRBs and other research ethics guidelines were created reactively in response to public exposure to instances of outrageous abuse such as the Nazi experiments, Tuskegee Syphilis Study (1932-1972), The Willowbrook Hepatitis Study (1966), and the deaths of Jesse Gelsinger and Ellen Roche (Jones, 1993; Stark, 2011; Tuck & Guishard, 2013; Wallace, 2006; Washington, 2006). The Declaration of Helsinki (The statement of Ethical Principles for Medical Research involving Human Subjects), was not advanced until 1964 after the Nuremberg Trials. The Helsinki Report was codified while the men, women and children of the Tuskegee Syphilis experiment were being denied penicillin and while Guatemalan prisoners were deliberated infected with STDs to investigate the effectiveness of penicillin (Reverby, 2011). The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and the Belmont Report were established after Peter Buxtum leaked the details of Tuskegee Syphilis Study to the press (Jones, 1993). The Secretary’s Advisory Committee on Human Research Protections, which conducts oversight of biomedical and behavioral research with special emphasis on vulnerable populations, was created subsequent to Jesse Gelsinger’s death. It was not until the National Institutes of Health Revitalization Act of 1993, as a result of organizing by women’s health groups in collaboration with activist researchers, that guidelines were created to address the exclusion of women and ethnic minorities from federally funded clinical trials (Freedman, Simon, Foulkes, Friedman, & Geller, 1995).
As Tuck & Guishard (2013) note, “IRBs, do not address the ways in which social science theory and methods are complicit in projects of settler colonialism and white supremacy” (p. 7). The institutional review process does not address how much of academic research is premised on the dehumanization of some colonized others to establish the superiority and betterment of settler colonizers. Interventions such as IRBs are reactive and incomplete rather than proactive and holistic. They represent a system of a priori checks without attempting to balance or disrupt asymmetrical power relationships in scientific inquiry. The institutional review process ostensibly addresses the symptoms of scientific racism and exploitation but not the causes.

**Dethroning Institutional Review Boards as the arbiters of ethics.**

The IRB framework assumes that one model of research fits all forms of inquiry, but this is not the case. This model requires that researchers fill out forms concerning subjects’ informed consent, the risks and benefits of the research for subjects, confidentiality, and voluntary participation. The model also presumes a static monolithic view of the human subject. Performance auto-ethnography, for example falls outside of this model, as do numerous interpretive paradigms such as reflexive ethnography, many forms of participatory action research, and all qualitative research involving testimonios, life stories, life-history inquiry personal narrative inquiry…In all of these cases, subjects and researchers developed collaborative, public, pedagogical relationships. The walls between subjects and observers are deliberately broken down.

—Denzin & Giardina, Ethical Futures in Qualitative Research, 2007 p. 20

Institutional Review Boards indisputably serve an important function within universities and research centers. However, they are primarily concerned with protecting the institution from litigation and claims of abuse (Speiglman & Spear, 2009). Vigorous, critical contemplations of ethical conduct in research are omitted if we construe the IRB approval process as being all encompassing (Blake, 2007; Brydon-Miller et al., 2006; Butz, 2008; Cahill, 2007; Cahill et al., 2007; Chávez, Duran, Baker, Avila, & Wallerstein, 2008; Detardo-Bora, 2004; Eikeland, 2006; Fisher, 1997; Larkin, Dierckx de Casterlé, & Schotsmans, 2008; Lincoln, 2005; Malone, et al.,
In truth the institutional review process is but a small component of what social scientists must contemplate when conducting ethical research. The utilitarian and Kantian principle based ethical frameworks (Beauchamp & Childress, 2001; Lincoln, 2005; Lincoln & Guba, 1987; Tong, 2002) that guide IRBs have been heavily criticized by proponents of virtue and communitarian ethics, indigenous, feminists, and critical race scholars for being:

1. Rooted in individualized, western, and white-privileged conceptualizations of risk which too often discount third party and community risk/stigma (Carrese & Rhodes, 1995; Flicker, Travers, Guta, McDonald, & Meagher, 2007; Maiter, Simich, Jacobson, & Wise, 2006; Ryan, 2004; Thomas, 2009).

2. More applicable to positivistic, biomedical, and clinical research designs than to social and behavioral, qualitative, and/or participatory orientations research (Ashcraft & Krause, 2007; Denzin & Giardina, 2007; DeTardo-Bora, 2004; Flicker et al., 2007; Lincoln, 2005).

3. Rarely inclusive of members of the populations under study in the ethical analyses of research risks, benefits, and burdens (Dickert & Sugarman, 2005; Israel et al., 1998; Myser, 2003; Lo & O’Connell, 2005; Quinn, 2004; Strauss et al., 2001).

4. Presumptuous about the moral superiority, knowledge and capacities academic researchers possess compared to the naivete and vulnerability of the researched (Fisher, 2006, 2007; Malone, et al., 2006; Quigley, 2006; Shore, 2008).

5. Inattentive to a “care perspective” on research ethics and thus prioritizing: general knowledge over nuanced knowledge, rights over responsibilities, impartial, formal, and abstract principles over subjective, “contextualized”, informal, intimate, and

Adherence to formalized regulations and professional codes of ethics cannot be interpreted as adequate touchstones for ethical conduct in participatory research. These guidelines and the review processes that follow them have persistently failed to ensure the well-being and/or respect the knowledge of indigenous people, people of color, the poor/working class and folks at the intersections of these heterogeneous communities (Chilisa, 2012; Fisher, 2007; Gamble, 1997; Smith, 1999; Tuck & Guishard, 2013; Wallace, 2006; Washington, 2006). Ethical participatory research necessitates a posture to ethics that frames discussions of ethics away from an emphasis on checklists that attempt to safeguard individual rights and autonomy toward an ethics of inclusion; of relational, dialogical ethics within which partnership, commitment, accountability and social justice are its central tenets (Khanlou & Peter, 2004; Larkin et al., 2008; Lofman, Pelkonen, & Pietilä, 2004; Maiter et al., 2006; Martin, 2007; Mertens, Holmes, & Harris, 2009; Torre, 2009; Torre & Ayala, 2009; Torre et al., 2012; Torres, 2005 ; Tuck, 2009b; Tuck & Guishard, 2013; Watkins & Shulman, 2008; Zeller-Berkman, 2007).

**Illuminating what’s ignored by the IRB process.**

Denzin (2008) notes that, “ethics are pedagogies of practice. IRBs are institutional apparatuses that regulate a particular form of ethical conduct, a form that may be no longer workable in a transdisciplinary, global and postcolonial world.” (p. 1). If deliberations about the ethics of a project by a novice or veteran researcher are only concerned with getting the project approved by an IRB, many important elements are overlooked:

IRBs/REB forms overwhelmingly operate within a traditional framework focused on assessing risk to individuals and not communities. They rarely take into account common...
CBPR (Community Based Participatory Research) experiences. Their noninterest in community level concerns, capacity building, and issues of equity situate them within a biomedical framework privileging ‘knowledge production’ as the exclusive right of academic researchers. Furthermore the lack of emphasis on action outcomes, dissemination, and decision making processes is antithetical to the goals of CBPR. (Flicker et al., 2007 p. 490)

From the perspective of participatory research, the institutional review process operates with narrow conceptualizations of respect. Respect for people in participatory research, for our collaborators encompasses more than monitoring informed consent procedures and documents. Respect in PAR subsumes the recognition of dignity, sacred knowledges and counter-storytelling. Researchers who attend to more rigorous notions of respect also appreciate that restorative justice is just as important as distributive justice, and that researchers are not the only people entitled to or capable of discerning risk:

- formulating regulations and ethical judgments solely on the basis of opinions expressed by experts in the scholarly community and IRB members risks treating subject like ‘research material’ rather than as moral agents with the right to judge the ethicality of investigative procedures in which they are asked to participate. (Fisher, 2006, p. 2)

Secondly, IRBs advance constricted perceptions about whom and what needs protection in academic research. Eve Tuck and Malia Villegas (forthcoming) have put forth recommendations for ethical and responsible research on indigenous land. Their research trouble the practice of anthropomorphizing in research ethics.

Thirdly, the institutional review process is inattentive to many central tenets of ethical participatory research: to reflexivity, to progressive notions of expertise, professional humility,
dignity, action, relationality, and trustworthiness in collaborative research (Tuck & Guishard, 2013). Lastly, IRBs can get in the way of a community’s research needs. This is because, IRBs provide guidance regarding ethical procedures when conducting research with individual participants not about an ethics of involvement or responsibility between scientists and communities (Banks et al., 2013; Bastida, Tseng, McKeever, & Jack, 2010; Brydon-Miller et al., 2006; Bradley, 2007; Butz, 2008; Cahill, 2007; Cahill et al., 2007; Cahill & Torre, 2007; Chavez et al., 2008; Fine et al., 2004; Fine & Torre, 2006, 2008; Manzo & Brightbill, 2007). Ethical PAR requires more pragmatic and less utilitarian ethics. Ethical PAR requires Ubuntu and nepantla ethics.

A recent account of how a university IRB hindered research in one community is Malone, Yerger, McGruder, and Froelicher’s (2006) Protecting the ‘Hood Against Tobacco (PHAT) project. The project began when university researchers conducted focus groups with community members in order to understand and document their reaction to tobacco industry advertising activities targeting residents of color in two African American neighborhoods in San Francisco. As is common in participatory research, participants were deeply affected by their participation in the focus groups, particularly the insight into the racist advertising strategies. Many wanted to share this information with neighbors and to cut down on their own smoking.

A community-university research partnership was established wherein, some participants agreed to serve as community researchers to investigate tobacco-caused harm in their backyards. The community partners were instrumental in co-designing the study and facilitating a town hall meeting where data detailing the health effects of tobacco use among African Americans was disseminated. A survey of the community’s perception of resources available to aid smoking cessation and impediments to quitting was also conducted. The results of the survey revealed
that the sale of loosies (single cigarettes) sold to residents illegally, was a major obstacle to quitting. This knowledge energized the community researchers who, “decided to conduct a systematic assessment of the proportion of convenience stores in the community that sold single cigarettes in 'violation of state law.”’ (p. 1915) An IRB protocol was submitted to the university to observe single cigarette sales among other activities. Later the community residents, more familiar with their neighborhood, felt that observation was an “inadequate methodology.” The community researchers’ reasoning was that it was potentially dangerous to loiter around stores and not practical to wait to observe loosen sales. The team wanted to actually attempt to purchase loosen from neighborhood stores. A modified proposal was submitted, which specified that identifying information would not be collected about the stores, employees, or business owners. It also specified that results would be presented aggregately. The IRB rejected the proposal, admonishing the PHAT proposed research design as one that would “entrap” store owners to commit an illegal act. The PHAT research team pushed back asserting that, it was important for the university to respect the community's knowledge and skills in this type of research and that—as community members had forcefully pointed out—it was impractical (and could in fact be even more dangerous) to conduct the study solely with the observational methods that had been originally approved. We produced relevant sections of the federal Code of Regulations that addressed research with human subjects to show the IRB that it did have the latitude to approve such a study. (Malone et al., 2006 p. 1916)

Sadly this is not the only instance of an IRB thwarting the efforts of a PAR project. I have encountered many other unpublished examples in my consultative work. Malone et al.’s. (2006)
research is however a powerful example of how IRBs and participatory researchers differ on how they evaluate risks, benefits, respect and protection in research.

This dissertation presumes that even scrupulous obeisance and adherence of IRB rules, professional codes of conduct, computerized ethical trainings, and the best of doctoral research ethics courses does not provide guidance in how to conduct ethical de-colonial participatory research. Extant founts of ethical information provide little advice for beginning (and even veteran) researchers about how to try out more democratic nonsexist, antiracist, non-homophobic relationships between the scientists and communities. The aforementioned frameworks are predicated on maintaining the divide between those who have the power to conduct research, to establish ethical norms and principles and those who are the subjects of research. Conventional ethical guidelines surreptitiously act to sustain white supremacy, hetero-normativity and patriarchy. Thus, conceptualizations of what constitutes ethical conduct in research that stem from these traditions are inadequate for many reasons:

First are the continuing stories of error and abuse in American research with human subjects, despite a nearly thirty-year experience in applying detailed federal regulations to shape and govern the design and conduct on that research (Advisory Committee on Human Radiation Experiments 1995; Faden and Beauchamp 1986, Rothman 1991). Next come the arguments played on in the international stage, that those American regulations—grounded in the principles of autonomy, beneficence, and justice—should not apply to all cultures… Finally comes the counterargument that regulations are not enough, that by virtue of their roots in acontextual moral principles that originated in the European Enlightenment, they fail to answer, and may even be incapable of asking, some intractable ethical questions. (King, Henderson, & Stein, 1999 p. 4)
What is desperately needed in these times, when many communities threaten (and others actually institute) moratoriums on research, are different perspectives on ethics; perspectives born of experience, of flesh, of urgency and not of abstract theory (Chilisa, 2012; Dillard, 2000; Hurtado, 2003; Smith, 1999; 2005). In solidarity with Hurtado (2003) and many other Black, Latina, and indigenous feminist scholars, I share the sentiment that I cannot use the oppressors’ knowledge validation process, or their ethical frameworks as my only ethical guides. This dissertation documents my attempt to gather counter-hegemonic ethical theories and practices. While reflecting on the aftermath of the trailblazing publication of Moraga and Anzaldúa’s *This Bridge Called My Back*, Hurtado credits Moraga, Anzaldúa and the other contributors for promulgating the radical notion that,

Theory, they claimed, should not come from written text only, but from the collective experience of the oppressed – especially that of women of Color. Theory, they continued, is for the purpose of ultimately accomplishing social theory should emanate from what we live, breathe, and experience in our everyday lives and it is only in breaking boundaries, crossing borders, claiming fragmentation and hybridity that theory will finally be useful for liberation. (p. 215-216)

This dissertation will detail the origins and contours of my own ethical praxis born from hybridity, from borderlands, of flesh and my attempt to document similar positions to research ethics within the participatory research community.

**Research Ethics Born from Flesh, from Experience, from Nepantlas**

I write to record what others erase when I speak, to rewrite the stories others have written about me, about you. To become more intimate with myself and you. To discover myself to achieve myself, to preserve myself, to make myself, to achieve autonomy. To dispel the myth that I am some mad prophet or a poor suffering soul. To convince myself that I am worthy and that what I have to say is not is not a pile of shit. To show that I can and will write never mind the admonitions to the contrary.
I understand why folk from “marginalized” groups discuss their positions to their work in their writing. The personal and the political are viscerally intertwined for many of us. Including a statement detailing our subjectivities serves many purposes. First, we reveal a bit of ourselves, as an act of self-preservation. Said in other terms, critical reflexivity is fundamentally a “critique of liberalism.” (Thomas, 2009) By sharing who I am from a position of pride I circumvent the inevitable attempts to erase, neutralize and whitewash me before they can begin to take root. We use critical reflexivity to rewrite and uproot the (mis)representations, (mis)construals—the seeds of racism and discrimination that are firmly supplanted within the listener/reader. In Yearnings hooks writes that,

Black folks coming from poor, underclass communities, who attend universities or privileged cultural settings unwilling to surrender every vestige of who we were before we were there, all “sign” of our class and cultural “difference,” who are unwilling to play the role of the “exotic Other” must create spaces within that culture of domination if we are to survive whole, our souls intact. Our very presence is a disruption. We are often as much an “Other,” a threat to black people from privileged class backgrounds who do not understand or share our perspectives as we are to uninformed white folks. Everywhere we go there is pressure to silence our voices to co-opt and undermine them. (p. 148)

Critical reflexivity as self-preservation and reaffirmation is a strategy used to resist these toxic pressures.

Experience has taught me that I might be understood by you if I make conscious attempt to scaffold your empathy by sharing realities with you that you might not be privy to. Critical reflexivity is a form of counter-storytelling. It speaks to multiple beliefs systems that pervade
research; to epistemology, ontology and axiology (Chilisa, 2012; Mertens, Holmes, & Harris, 2009). I suspect that marginalized scholars (or maybe it’s just me) conceptualize this type of disclosure as an invitation that will be answered by similar divulging gestures from scholars from dominant groups—but too often the invitation is ignored. It should be answered. It should be respected but too often these gestures leave us feeling more exposed, inspected, and appraised; placed upon a post-modern auction block for analysis and consumption. My colleagues Eve Tuck and K. Wayne Yang (Tuck & Yang, 2014) have often lovingly told me that the academy does not deserve our stories. Part of me agrees with them because I know the costs to our mental and physical health are not worth it. I will however continue this practice anyway for me and you, hopeful for the day it will be unnecessary.

**Hoglets and home spaces**

As radical standpoint, perspective, position, “the politics of location” necessarily calls those of us who participate in the formation of counter-hegemonic cultural practice to identify the spaces where we begin re-vision.

—bell hooks, Yearning: Race, Gender and Cultural Practices, 1990 p. 145

Hog ask he mumah wha mek she mouth so long. Mumah se –ah pickney when eh tun big you will know!

– Antiguan Proverb

As a Black feminist social psychologist from very penurious class origins, my knowledge of ethics and imperialistic research is personal, complicated, and at times dissociative. It predates but was also enhanced by gaps in my doctoral studies and by my own ethical missteps in participatory research. One major ingredient in the mélange of my posture toward ethical relationships in research is/was my grandmother. She was a Dominican and Antiguan immigrant to the United States by way of the Virgin Islands. My granny was formally uneducated but deeply wise. Before she joined the ancestors at 90 years old she wore many hats: mother to ten
children, grandmother and great grand to so many we’ve lost count, herbalist, orator, maid, and university custodian were a few. My granny was a housekeeper to one of the most powerful families in the Virgin Islands for over twenty years. Her employers affluence stemmed from their being direct descendants of Danish colonizers on the islands of St. Thomas and St. Croix. It is a position of power they still hold on to today. She loved the Lockhart family, but they chided her for her sass and wit. They dissuaded her from pursuing an education and from helping her children (and grandchildren to be) attain U.S. citizenship. Frustrated with their constant put downs, my granny left, somewhat regretfully, and took a position as a custodian at the University of the Virgin Islands (UVI) where she worked for thirty one years.

Deities know how she lived to 90 as she, like most Caribbean women of Color was wary of doctors. I grew up watching her expertly concoct poultices, teas and other salves for our family. She made them for other folks too; people who preferred her homeopathic treatments to long, unhelpful, and unaffordable waits at local hospitals. My granny was a great storyteller. They would come to Eleanora’s house for medicine as much as they came to listen to her yarns. A popular story was of rampant mis-pronouncements of death in Antigua’s public hospital. As my big sister Roma retells it, a child with croup was wrapped, tagged, and bound for the morgue refrigerator only to wake up and walk out of the waiting room a short time later startling the emergency room staff. That I have heard similar stories from Antiguans and St. Thomians unrelated to me is sobering.

Granny would also regale us with memories of the Lockharts before and after they were in positions of power. Some of her recollections were also of whispered and shouted conversations among the faculty; of how they otherized and looked down on the uneducated populace. While cleaning the halls and classrooms of the UVI and caring for the Lockharts’
household, Eleanora absorbed much, perhaps too much. She developed a situated perspective of privilege, education, medicine, and an ethics of care that I sometimes envy. She took delight in knowing and subsequently spilling the nuances of this knowledge to others. The narrative of my grandmother’s memories converged around themes: of expectations of care and respect, met with mistreatment, exploitation and disrespect. Through her I developed a complicated relationship with my schooling and to what it meant to be an educated person. She would tell me time and time again that, “study-a-tion was better than education.” This was a popular saying among Virgin Islanders; it is a seeming repudiation of intelligence that is made up of only book smarts. I have however never doubted that my grandmother understood the value of education as a means of achieving social mobility. During my adolescence I was sent to live with her in St. Thomas in order to finish high school. I rejected the move and chose to rebel by playing hooky. Ultimately the school board served me with a truancy warrant. I narrowly escaped a sentence at a juvenile facility for girls. In the aftermath, my granny damn near cattle prodded me to become as educated as possible, while simultaneously reminding me to stay grounded enough to absorb life’s lessons. As a child I didn’t appreciate or understand many of her cryptic lessons like the one about the hoglet. Now that I have ostensibly grown up, now that I have turned big, I don’t need to ask my mother why her mouth often appears long and anguished—I know.

Some of my grandmother’s experiences undoubtedly inculcated a deep sense of fear and suspicion of medicine in my mother, my granny’s eldest living child. My mother has a heightened skepticism of western medicine and research as a result of growing up in Antigua, of enduring humiliating and painful experiences in emergency rooms, and as a subject/patient of schools of dentistry. I vividly remember accompanying my mother to New York University’s College of Dentistry for an extraction of a badly decayed tooth. Before administering local
anesthesia to her gums, before discussing the state of her teeth, I watched as the dentist in
training shoved his hand in her mouth and asked if she could bring in her toothbrush for analysis
on her next visit. She never went back. For much of my life I have been a translator and
intermediary for my mother. I have been the bridge between her and medical personnel, in places
were many uninsured poor people turn to for healthcare after they’ve tried and failed to doctor
themselves. She recently chided me to remember “not to be too forward,” a popular reprimand in
the West Indies, very reminiscent of the admonitions in Jamaica Kincaid’s poem Girl.

The scolding was after two Columbia University researchers tried to recruit her into a
clinical trial at a time and manner she deemed inappropriate, when she was recovering from a
stroke at Isabella Geriatric Center and when I was not there to mediate. She doesn’t recall the
conversation but I am confident, in that moment, that my mother wanted to make sure I did not
behave similarly in my research endeavors. Reminding oneself “not to be too forward” is a
reprimand that many female scholars of Color have heard some variation of. It is a tension
between the privileges an education affords one, between obligations to community, serving as
an intermediary, mixed with forced humility and self-consciousness that I cannot fully name. I
do know that it has made me deeply introspective of my praxis. It has also motivated me to
immerse myself and consequently become deeply affected by academic writing that
contextualizes a history of racism, sexism, deception, inaction, and a lack of reflexivity in
primarily health but also social-behavioral research (Bishop, 1998; Chilisa, 2009; 2012; Gamble,
1997; Jones, 1993; Trimble & Fisher, 2006; Tuck, 2009; Tuck & Guishard, 2013; Varcoe, 2013;
Wallace, 2006; Washington, 2006).

My grandmother and mother may have taught me firsthand about imperialistic
relationships in medical research but many scholars from different disciplines, particularly
scholars of Color have validated their experiences pivotally moving Eleanora’s and Eunice’s private troubles to shared public inequities (Mills, 1959). Before I review the contributions of these theorists, it is important to note that I frame their writings as efforts to trace the roots and mechanisms of settler colonialism in scientific research. Elucidating this frame is important because rarely does research cast the heat of the magnifying glass on itself. As social scientists we are taught to study and particularize the shape and contours of oppressed thinking and behavior divorced from recognition of our complicity in maintaining the structures that requires their oppression (Tuck & Guishard, 2013).

In his introduction of settler colonial studies Lorenzo Veracini (2011) teaches us that colonialism and settler colonialism are intimately linked, “concomitant” manifestations of oppression but they are different. (pg. 2) Colonialism is an event, Veracini (2011) writes which is,

primarily defined by exogenous domination. It thus has two fundamental and necessary components: an original displacement and unequal relations. Colonizers move to a new setting and establish their ascendancy. (p. 1)

Said in other terms, the colonialist invades indigenous territory and says “you, work for me” however the settler colonialist says, “You, go away.” (Veracini, p. 1) Patrick Wolfe’s (2006) research provides another difference when he writes that,

the primary motive for elimination is not race (or religion, ethnicity, grade of civilization, etc.) but access to territory. Territoriality is settler colonialism’s specific, irreducible element. The logic of elimination not only refers to the summary liquidation of Indigenous people, though it includes that…. settler colonialism has both negative and positive dimensions. Negatively, it strives for the dissolution of native societies.
Positively, it erects a new colonial society on the expropriated land base—as I put it, settler colonizers come to stay: invasion is a structure not an event. (p. 388)

As Chilisa (2009, 2012), Guthrie (1976), Wallace (2006), Washington, (2006), Myser (2003), Smith, (1999, 2007), Dillard (2003), Bishop (1998) and countless others have pointed out, mainstream academic research operates in settler colonialistic ways. Research is too often conducted with a reductionist lens; it seeks discovery, and classification; imposing the scientist’s perceptions of order (of development) on objectified others. Research has frequently invaded and settled in indigenous people’s lives and land, and here I borrow Smith’s (2005) definition of indigenous people,

An assembly of those who have witnessed, have been excluded from, and have survived modernity and imperialism….they remain culturally distinct, some with their native languages and belief systems alive. They are minorities in territories and states over which they once help sovereignty. Some indigenous people do hold sovereignty, but of such small states that they wield little power over their lives own lives because they are subject to the whims and anxieties of large and powerful states. Some indigenous communities survive outside their traditional lands because they were forcibly removed from their lands and connections. (p.85)

Research historically has taken (and continues to take) knowledge, (physical, sexual, cultural/artistic) labor, literal territory, and terrain for theorizing from lesser others, particularly the materially poor, working class folks, people of Color, indigenous peoples, the disabled, and queer in order to develop theory, products, and practices for other settler colonists. Like settler colonialists, researchers aim to define what is dominant, calling it natural, neutral, unbiased and
normative repudiating and acting to “repress, co-opt, and extinguish indigenous alterities.”

(Veracini, 2011 p.3)

In his seminal work, *Even The Rat Was White* Guthrie (1976) details an early history of psychology you will not find in an introductory textbook. For Guthrie psychology materialized as a field inextricably shaped by zeitgeist:

By declaring itself the study of the *mind*, psychology claimed ownership of all that dealt with animal and human behavior. The new discipline cut a wide swath through the ivy halls of academia at a time when the Western Weltanschauung was infected by racism and social Darwinism and psychology eventually became an important contributor to the era. (p. 1)

This historical analysis is important because critiques of settler colonialistic relationships in research are/were thrust upon anthropology however, Guthrie’s works provides evidence of a cooperative research agenda between psychologists and anthropologists. This compromise gave psychology control over laboratory explorations of human behavior while the anthropology continued to investigate behavior in the field. As Guthrie (1976) notes, “anthropology provided psychology with the racial systems needed to justify intellectually the existence of differences among human beings.” (p. 3) Said in other terms, psychology emerged as a discipline concerned with amassing scientific evidence that justified racial hierarchies and social stratification in order to move beyond biblical explanations of physical differences.

Citing Guthrie (1976), Wallace (2006) highlights the connections between traditions of racist and sexist health research, legacies of fear of exploitation and lack of active consensual participation in research among African Americans, to a lack of a relational approach to ethical conduct in biomedical inquiry,
Medical and scientific history in the United States has a dark past when it comes to the professions’ involvement in and support for racist social institutions. Theories developed by the medical and scientific community were used to perpetuate stereotypes proposing the racial inferiority of African Americans (Guthrie, 1998). These scientific theories and studies were often used as justification for mistreatment and misuse of African Americans during slavery and the Jim Crow period (Guthrie, 1998; Shavers-Hornaday et al, 1997). (p. 68)

Harriet Washington (2006) similarly details the exploitation of African Americans in U.S. medical research from colonial times to today. In Medical Apartheid she provides, a “nuanced look at the calculus of racism’s effect on experimental practice.” (p.18) That is, her investigations have demystified the jargon-laden literature of medical research, and combined personal narratives of victimized African Americans with memoirs and academic writings of physicians, to reveal stories of mistreatment that would have otherwise never come to light (slave Betsey’s suffering in Marion Sim’s gynecological experiments, Henrietta Lacks’ stolen cancerous cells, Margaret Sanger’s Negro Project, Mississippi appendectomies, The Holmesburg Prison studies, The MK-ULTRA diseased mosquito exposure studies, among many others). Washington’s analyses redirect the causes of African Americans’ precarious health status; their “iatrophobia” (fear of medicine) away from theories that claim genetic inferiority, “putative biological dimorphisms” and unsubstantiated paranoia. It instead links the current appalling health profile of African Americans to settler colonialism—and research’s complicity in its maintenance:

When it comes to the abuse of African Americans, a different set of ethical standards has long prevailed and abusive researchers have historically been closer to the norm than we
would like to think. Conventional wisdom pins experimental abuses on the “Dr. Frankenstein” stereotype—a scientific outcast of dubious pedigree who harbors mental maladjustment. But historically, most perpetrators of ethical troubling experiments utilizing African Americans have been overarching adepts with sterling reputations sufficient to secure positions of great responsibility….in fact researchers who exploit African Americans were the norm for much of our nation’s history, when black patients were commonly regarded as fit subjects for nonconsensual, nontherapeutic research. (p. 13)

Catherine Myser (2003) critiques the lack of reflexivity in bioethics and the inattention to analyses of dominant, master narratives in our interpretations of “the cultural construction of bioethics.” (p.1) Myser (2003) defines whiteness and white normativity from a critical race perspective,

by talking about whiteness, I am talking about a marker of location, or position within a social, and here racial, hierarchy—to which privilege and power attach and from which they are wielded. (p. 2)

Her work provokes academicians to critically examine how and from whose perspectives we conceptualize what we mean by ethical conduct in research, to trouble traditions that obscure the connections between an ethics derived from white normativity and settler colonialism. Myser (2003) also warns bioethicists that by,

allowing the whiteness of bioethics to go unmarked, we risk repeatedly re-inscribing white privilege—white supremacy even—into the very theoretical structures and methods we create as tools to identify and manage ethical issues in biomedicine. In other words, by not seeing or locating the whiteness in bioethics, by theorizing from this un-self-
reflective white standpoint and by extending its cultural capital into bioethics policies and practices, we risk functioning as cultural colonizers who do violence to social-justice concerns related to race and class. (p. 2)

This dissertation similarly presupposes that Institutional Review Boards function to sustain white normativity, hetero-patriarchy, racism, sexism, and settler colonialistic relationships in research by controlling how ethical conduct is defined, who gets to define it. This dissertation presumes that IRBs promulgate: norms of participation, norms of interaction, and definitions of research, that are incompatible with participatory research. As I further reflect on my formal and organic ethics education and experiences with participatory research beyond weariness I have often felt lost (Guishard, 2005, 2009). Nothing I remember reading in my research ethics course or while completing recertification of the CITI modular ethical training required by my university helped me predict or avoid the ethical dilemmas I often encountered in PAR. I have often asked myself whether I was guilty of some ethical infraction when I made an conscientious effort to procure funds to finance fun activities because aspects of my PAR work with young people were not liberating and empowering but deeply depressing for the youth researchers. I have questioned whether I acted ethically by being responsive or should I have anticipated depression and planned for these outings when drafting my IRB proposal. I have spent much time wondering if I made ethical blunders by prioritizing hanging out and scaffolding trust between myself and my co-researchers over maintaining some semblance of distance and objectivity. Many of the casual conversations I have been fortunate to have with youth have often revealed different perspectives, novel ways of understanding the theories I was trying to contextualize (Guishard et al, 2003, 2005; Guishard, 2009). Was it unethical to include these moments, and stories as data, when I was not quite sure if I was Monique the friend or the researcher even if I did not attribute
name and intentionally blurred other characteristics in their retelling? Do participatory researchers undermine their responsibilities to safeguard the privacy and confidentiality of their co-researchers by recognizing and acknowledging the same folks as co-authors in writing or in conference presentations? I have also often pondered whether writing articles and presenting participatory research can be construed as producing real transformative social action.

I pursued this dissertation because it became important for me to document how common or not my personal experiences of feeling lost and in dire need of alternative ethical compasses were. I have struggled with how to name, for lack of better phrasing, the dissociative moments when for instance, ethical tenets like respect and justice had multiple, conflicting meanings in and outside the academy. It was while reading the work of Chicana feminist poet and activist Gloria Anzaldúa (1999) that I found the language to describe the disjointed sensibilities that were provoked as I moved between and within the academy and communities in which I conducted PAR. Two of Anzaldúa’s (Anzaldúa, 1999; Anzaldúa & Keating, 2002; Torre & Ayala, 2009) ideas that were instrumental in helping me name the clash of ethical spheres in this manuscript are choques and nepantla.

**Unearthing Nepantla Ethics Para Nosotros**

Caminante no hay puentes, se hace puentes al andar. Voyager there are no bridges, one makes them as one walks.

–Gloria Anzaldúa

In a chapter which fleshes out her ideas about mestiza consciousness, Anzaldúa (1999) powerfully describes a divided sense of being, which I speculate resonates with the hybrid consciousness many participatory action researchers encounter in their collaborative work,

In a constant state of mental nepantilism, an Aztec word meaning torn between ways, la mestiza is a product of the transfer of the cultural and spiritual values of one group to
another. Being tricultural, monolingual, bilingual, or multilingual, speaking a patois and in a state of perpetual transition, la mestiza faces the dilemma of the mixed breed: which collectivity does the daughter of a dark skinned mother listen to? El choque de un alma atrapado entre el mundo del espíritu y el mundo de la técnica a veces la deja entullada. Cradled in one culture, sandwiched between cultures, straddling all three cultures and their values systems la mestiza undergoes a struggle of flesh, a struggle of borders an inner war…the coming together of two self-consistent but habitually incompatible frames of references cause un choque, a cultural collision. (p. 100)

Drawing from Borderlands/Mestizaje scholarship further in this dissertation, I conceptualize action research as a process that provides safe spaces to re-theorize and transform choques. I firmly believe Anzaldúa (1983, 1999) would say in order to develop an ethical framework for participatory research, we need to critically analyze nepantlas and to listen to practitioners who struggle with tricky ethical situations every day; to nepantleras who are adept at forming nosotras. Nepantla in post-Borderlands scholarship is “a Nahuatl world meaning tierra entre medio” (Anzaldúa, 2002) or “in between space”. (Keating, 2006 p. 8) I make mention of it as a post-Borderlands term because it represents an expansion and deeper reflection in Anzaldúa’s Borderlands/mestizaje theorizing:

I found that people were using “Borderlands” in a more limited sense than I had meant it. So to elaborate on the psychic and emotional borderlands I’m now using “nepantla”…with the nepantla paradigm I try to theorize unarticulated dimensions of the experience of mestizas living in between overlapping and layered spaces of different cultures and social and geographic locations, of events and realities—psychological,
spiritual, historical, creative and imagined. (Anzaldúa, 2000 p. 176 as cited in Keating, 2006 p. 8)

As I understand it, nepantla refers to both physical and metaphorical spaces on the verge. Nepantla is part of a transformative, difficult birthing process. It is an identity in flux where one distances oneself from the restraints of what is, of forced upon compartmentalized identities, and from which one can imagine/work toward a synthesis of a hybrid, multi-dimensional self (or selves). Ortega (2005) furthers our understanding when she writes that nepantla is:

A space where one is not in one place or the other, one country or another, where countless travelers go through….but nepantla is not just a spatial region where faces are inspected, passports displayed; it is the very experience of those who live an in-between life because they are multicultural, multivoiced, multiplicitous, because their being is caught in the midst of ambiguities, contradictions, and multiple possibilities. (p. 79)

According to Keating (2006), an Anzaldúan scholar and biographer nepantleras are, in-betweeners’, ‘those who facilitate passages between worlds’ ‘(Un)natural Bridges’…nepantleras are threshold people; they live within and among multiple worlds, and develop what Anzaldúa describes as a perspective from the cracks. Nepantleras use their views from these cracks-between-worlds to invent holistic, relational theories and tactics enabling them to reconceive or in other ways transform the various worlds in which they exist. (p. 9)

I have looked long and hard for a concept that embodies the difficulty of being “multicultural, multivoiced, multiplicitous” person. I have searched, as have other nepantleras, for a notion that would assist me in representing my multiplicities, my seemingly discordant selves in a coherent respectful way. I am a Black woman, a Dominican woman, a graduate student and a professor
teaching at my alma mater viewed by my colleagues perpetually as a former student. I am a neophyte researcher without a Ph.D who is an expert in collaborative ethics. I am an insider with embodied knowledge of multiple and intersecting oppressions, who is often positioned as an outsider because of my academic credentials. I am an omnisexual person in a heteronormative world. I have achieved some level of social mobility but my Afrocentric physiognomy (skin color, hair texture, and broad nose) exclude me from experiencing many of the benefits of my middle class status (Cross, 2001). As it pertains to my work as a participatory researcher, I have struggled with the antiquated ethics I was socialized to internalize as appropriate guides despite finding them inappropriate and unhelpful in the field (Guishard, 2005, 2009). In some of my research endeavors I have been fortunate to receive warm kinfolk-like reception and unnerving open access to people’s lives and homes. I have also been regarded with intense apprehension and suspicion more than once while conducting research in communities that I share cultural values, vernaculars, social class, histories of oppression, discrimination, and passion for social justice. When confronted with either circumstance, I have tried my best to honor the trust and intimate knowledge I was privileged to witness and document. I made (and continue to make) every effort to keep my intentions and goals transparent while attempting to nurture respectful, accountable, and mutually beneficial relationships with my research partners. This is not easy work and many times I have felt squished at the intersections, marooned, alienated in limbo, very much like an interloper among people of Color, feminists, the LGBTQ community, academicians and community organizers even as I attempted to forge connections between these groups and my hybrid identities. Keating (2006) explains that
During Nepantla our worldviews and self-identities are shattered. Nepantla is painful, messy, confusing, and chaotic, it signals unexpected uncontrollable shifts, transitions and changes. Nepantla hurts!!! (p. 8, emphasis original)

I conceptualize PAR researchers as nepantleras because their work, our work is about unremitting trying to initiate and sustain counter-hegemonic and ethical research relationships which are difficult because in action research we are attentive to the clashes of race/ethnicity, culture, privilege and entitlement in our collaborations that the outside world homogenizes. Chavez et al. (2008) would say nepantleras/PAR researchers are practiced choreographers, Dancing provides a provocative analogy for exploring the interplay of ethnicity, racism, and privilege that often goes unacknowledged in community based participatory research (CBPR). The dance involves being aware of differences and respecting that although some people appear to be “natural” dancers, others need more time and instruction as they experiment with movement….dancers from different cultures must each other’s movements, rhythms, and meanings. To dance is to express our social and cultural context without imposing an absolute “correct way” to dance. (pp. 91-92)

Choreographing the dance of privilege, race/ethnicity, sexuality, physical and cognitive abilities is also difficult because the environments/institutions participatory researchers seek to transform through our interdependence, through implicating ourselves in each other’s lives, have vested interests in preserving asymmetrical power relationships (Ayala, 2009; Cahill, 2007; Cahill et al. 2007; Chávez et al, 2008; Krueger-Henney, 2010; 2011; Torre, 2005; Torre & Ayala, 2009; Torre et al.,2012). However, I would argue that nepantleras are proficient because of their in-betweeness to assist in constructing the scaffolding that unite nosotras. Nosotras is commonly understood as the feminine for “we” in Spanish. In This Bridge we Call Home Anzaldúa (2002,
p. 570) referred to nos/otras as “an alliance between ‘us’ and ‘others.” In nos/otras the ‘us’ is divided in to two, the slash in the middle representing the bridge—the best mutuality we can hope for at the moment.” In *Interviews/Entrevistas* Anzaldúa & Keating (2000) expanded our understanding of nos/otras asserting that,

> Living in a multicultural society we cross into each other’s world’s all the time. We live in each other’s pockets, occupy each other’s territories, live in close proximity and with each other at home in school, at work, we are mutually complicitous—us and them, white and colored, straight and queer, Christian and Jew, self and Other, oppressor and oppressed. We all find ourselves in the position of being simultaneously insider/outsider.

(p. 254)

Blurring the lines between us and other, forming alliances for a collective us using a relational approach to ethics, one that construes researchers and participants not as strangers but as people “situated…in complex, social, cultural, and political (Lo & O’Connell, 2005 p. 77),” “morally significant” and “interdependent” relationships (Larkin et al, 2008) is the vocation of a nepantlera. This is the work of a participatory researcher. In this dissertation I hope to learn much from nepantleras. I hope to glean as much information as I can about their private deliberations. I aim to learn about the tools and strategies that I imagine they have developed to surmount participatory choques; cultural collisions between the ethical commitments inherent in participatory research and biomedical centered ethical touchstones. This journey, the readings it inspired and my experience have made me realize that my desire to map the fracture points between multiple spheres of ethical teachings presumed that this was uncharted ground and subsumed the logic and language of imperialism. The truth of the matter is that many wise elders before me have more expressively theorized these apertures (Ortega, 2005).
Cahill (2007) while recounting her experiences within a PAR video project about barriers to undocumented students' entry into college captures the anxieties PAR researchers often confront while looking to narrow conceptualizations of ethics to guide their decisions,

Deep breath. Slow down. I have been here before. I remember this feeling.

This is familiar. ‘This’ referring to the ups and downs, the worries, the sleepless nights. This is the emotional engagement of doing participatory research. While I knew our research project was going to be political and possibly even controversial how could it not be? I had not thought through the implications of the project in terms of the emotional places we would be going together. And yet this is at the heart of our work. The questions I circle around are: how can I do this in a way that’s responsible? What are my responsibilities – our responsibilities? - to whom?

And what risks are involved? (p. 361)

Torre and Ayala (2009) have also built on the wisdom of Anzaldúa’s notions like choques, nosotras, conocimiento, mestizaje, and entremundos to enrich our understanding of participatory research,

We have found Borderlands scholarship invaluable in elucidating a liberatory PAR.

Challenging traditional notions of expertise, PAR assumes everyday people carry deep knowledge and analysis about the conditions of their lives and should lead in determining meaningful research questions, designs, methods, analyses and products (Torre and Fine, 2006). While our practice of PAR has been enriched by feminist, indigenous and critical race theorists (Lykes and Mallona, 2008; Matsuda, 1995; Smith, 1999), Anzaldúa’s work pushes our theorizing of a liberatory PAR in particular ways. (p. 388)
Respectfully retracing the footsteps of my elders and colleagues inspired me to focus my work on collecting stories of participatory choques from nepantleras. These testimonios (Brabeck, 2001; Perez-Huger, 2009) of the contemplations, strategies and tools PAR research teams develop to overcome the insufficiencies of conventional ethics, I hypothesize will reveal issues that are latent in and instructive to other research methods and to ethics training. In solidarity with Cahill (2007) I firmly believe that, “participatory research re-positions our understanding of ethics within the broader socio-political, global context of our everyday lives.” (p. 360)

**Ubuntu Ethics**

As I have grown to understand the concept, Ubuntu is borne out of the philosophy that community strength comes of community support, and that dignity and identity are achieved through mutualism, empathy, generosity and community commitment. The adage that ‘it takes a village to raise a child’ is an African wisdom borne from an understanding and way of being aligned with the spirit and intent of Ubuntu.

–Dalene Swanson, Where have all the fishes gone?, 2009 p. 10.

Ubuntu is an indigenous African worldview/philosophy of humanness and interconnectedness (Caracciolo & Mungai, 2009; Chilisa, 2012; Chuwa, 2014; Gade, 2012; Swanson, 2009; Tutu, 1999). The phrases, “I am because we are” and “we are because I am” both embody Ubuntu. Fundamentally, Ubuntu means that our humanity, our personhood, is interwoven. Cornell and Muvangua (2012) eloquently explain that our interdependence and obligations to each other begin at birth. They explain that it is through engagement and support of one another, through collaboration, that we are able to transcend our differences and be genuinely human,

In ubuntu human beings are intertwined in a world of ethical relations and obligations from the time they are born. The social bond, then, is not imagined as one of separate individuals…This inscription by the other is fundamental in that we are born into language, into kinship group, a tribe, a nation. But this inscription is not simply reduced
to a social fact. We come into the world obligated to others, and in turn these others are obligated to us, to the individual. Thus, it is a profound misunderstanding of ubunto to confuse it with simple-minded communitarianism. It is only through engagement and support of others that we are able to realize a true individuality and rise above our biological distinctiveness into a fully developed person whose uniqueness is inseparable from the journey to moral and ethical development. (p. 3, emphasis original)

Ubuntu has multiple dimensions: spiritual, ethical, historical and transformative action. Ubuntu is an ontologically, epistemologically, and axiologically distinct perspective. With respect to ontology Ubuntu holds that we can only know the world imperfectly because there are multiple, socially constructed situated realities. All knowledge, all perspectives are of importance, are equally valuable and necessary to understand the diverse, heterogeneous nature of humanity. From an Ubuntu worldview I can only understand the world and myself by understanding you. I can only transform unjust conditions by transforming myself and you. Our realities are only together.

With respect to epistemology or questions about the nature of reality Ubuntu rejects the notion of universal, generalizable principles because it embraces plurality not neutrality (Chilisa, 2012; Tutu, 1999). Threshold spaces, nepantlas, choques, border crossings are significant because they acknowledge and perhaps force us to perceive our interconnectedness. Ubuntu rejects attempts to separate, to form hierarchies, castes, and/or binaries. It rejects any attempt to obscure that which binds us, binds humanity together historically, spiritually, that which binds us to all things living, dead, flora and fauna.

With respect to axiology, Ubuntu appreciates that our values are inextricably tied to us, to our work, to how we see the world and treat each other. An Ubuntu worldview stresses the
interdependent nature of our value systems. We are in the predicament we are in because of our actions, inactions, what we placed value on, and what we ignored. We are mutually complicit; we are mutually implicated in our intersecting histories. With respect to research methods Ubuntu ethics call for emancipatory, participatory and indigenous methodologies. Methods that help us envision alternatives to deficit, damage centered, exploitative research, that problematizes evidence as solely cognitive, solely verbal, that resists one dimensional thinking and incorporates embodied practices are encouraged. From my perspective, Ubuntu pushes us to critically reflect on our values systems for how they impact our theories, our units of analysis, who include and exclude as potential partners/allies, our selection of research methods, and ethical conduct lest we commit epistemological violence (Teo, 2010). In other terms, Ubuntu pushes us to gauge, to consider how we are ontologically connecting our individual, dispositional analyses with societal, structural analyses but also how we contextualize the issue under study with respect to history. Embracing an Ubuntu ethical worldview, conceptualizing oneself as eternally connected to others is a perspective Chilisa (2012) suggests,

   calls on the researcher to see ‘self’ as a reflection of the Researched other, to honor and respect the researched as one would wish for self and to feel a belongingness to the researched community without feeling threatened or diminished. (p. 22)

Ubuntu moves beyond the western view of ethical research as an endeavor that protects individual rights and well-being. The “we” in, “I am because we are,” is a new entity that is greater than our individual particularities. Respect is not isolated to a fixed transaction at the beginning of research in Ubuntu ethics. I respect myself by respecting you. Your autonomy, your particularities, your self-determination, your sovereignty, and well-being are linked inextricably to my own. Ubuntu ethics is rooted in relationships, in genuine investment, shared power, shared
resources in reciprocity. An Ubuntu ethical perspective requires researchers and our collaborators to critically examine how our work builds capacity, remains transparent, includes a means of evaluating accountability, assesses inclusivity, demonstrates trustworthiness, and the preservation of dignity.

My thinking about Ubuntu ethics is admittedly in its nascent form. I did not start out this dissertation with any intent to incorporate it into my theoretical framework and ethical praxis. It was the work, particularly the de-colonial ethnography I stumbled upon the opportunity to conduct, that pushed me to embrace Ubuntu. I will clarify the research methods used in this dissertation in the next section. It is my position that excavating nepantlera ethical decision making and Ubuntu ethics will provide a more tangible, less antiquated, less classist, racist, sexist, and homophobic ethical compass for unsuspecting and suspecting researchers while conducing ethical participatory research. This dissertation was guided by following research questions:

1. What can nepantlas and nepantleras teach us about the contours of ethical participatory action research (PAR)?
2. How does the ethical training and IRB submission process prime doctoral students and members of IRB committees to conceptualize research ethics?
3. What navigational tools and guides do participatory researchers use to initiate and sustain ethical relationships between collaborators?

**Research Methods**

**Original Research Plan**

This dissertation aimed to document and analyze the ethical dilemmas that PAR practitioners wrestle while looking to narrow conceptualizations of ethics to guide their conduct.
I started from the position that analyses of the negotiations, strategies and tools PAR folks developed to overcome the insufficiencies of IRB ethics, research ethics courses, and computerized trainings were desperately needed. My aim was to conduct 24 semi-structured individual interviews using a convenience sample of: 8 academic researchers (comprised of graduate students and veteran researchers), 8 community/non-academic research partners, and lastly 8 interviews with members of IRB committees and/or Community Advisory Boards (CAB). I also planned to conduct 3 homogeneous focus groups of action researchers, community partners, and IRB or CAB members of, at most, 10 participants each.

**Original Recruitment Plan**

Respondents were recruited over May to August of 2013 in varying ways: in person, via email, flyer, listserv, website postings/forums, word of mouth, and telephone from various sources (articulated below). I essentially obtained the contact information (names, email addresses and phone numbers) of academic researchers and community based research partners (advisory boards, research review boards, and/or community based organizations) who have evaluated, conducted, and/or acted as a partner in a collaborative research project by:

1. Searching the published programs or web searchable programs of local seminars and national conferences that were geared toward participatory researchers as presenters and attendees such as: The Annual Meeting of the American Psychological Association, The Annual Meeting of the American Education Research Association, Teacher’s College Winter Roundtable, The American Studies Association Annual Meeting, The Public Science Project’s Participatory Summer Research Institutes, The National Community Partner Forum, and The Society for Community Research and Action.
2. Searching public databases/websites which list the recipients of participatory action research or community based participatory research grants, such as the National Institutes of Health Office of Behavioral and Social Sciences Research community-based participatory research grantees and National Institute for Environmental Health Science Environmental Justice and community-based participatory research grantees.

3. Exploring scholarly and popular education articles retrieved from using the CUNY Graduate Center and Bronx Community College library databases such as: ERIC, SocINDEX with Full Text, CINAHL, Health Source: Nursing/Academic Edition, EBSCOhost General Science Collection, MEDLINE, Science Reference Center, Academic Search Premier, Primary Search, PsycINFO, PsycBOOKS, PsycCRITIQUES, and Google Scholar. I entered the following search terms to find potential respondents who have written about: participatory research and ethics or ethical, community-based participatory research and ethics, challenges or obstacles and CBPR, issues or challenges or obstacles and action research, ethics and qualitative research, institutional review boards and participatory research, community involvement and ethics or ethics review; community consent and participatory or collaborative.

4. Searching web available content for the staff and community members of participatory research centers (such as the Public Science Project, The Institute for Community Research, The Community Campus Partnerships for Health community based participatory research and research ethics listservs).

5. Researching web and/or published proceedings for the staff and community representatives on community ethics review boards and community advisory boards (WEACT for Environmental Justice Community IRB, The Hispanic Health Council,

6. I also had access to other CUNY psychology doctoral students' email addresses through listservs.

**Speedbumps and Other Detours**

Most students’ research projects, theses, and dissertations are designed to meet the perceived needs of the student. The choice of the research topic and the conceptualization and the implementation of the study are, in most cases predetermined by the students, working within the boundaries of academic institutions’ standard procedures and regulations for research projects and thesis writing (Hodge & Lester, 2006). Such practices undermine attempts to decolonize research to ensure that fundamental issues such as research ownership and benefits of the research to communities are addressed.

–Bagele Chilisa, Indigenous Methodologies, 2012 p. 294

I have already described the methods I intended to use in this dissertation, however, in this section I will detail what actually occurred. Recruitment over the summer of 2013 seemed like a good idea in theory but it was rough in practice. Many academicians use their summers to travel. Many don’t keep up with their institutional email as often as they would during the academic year. I also experienced a lot of difficulty recruiting community research partners. If I could have delayed my recruitment until the fall I would have but I was working against an aggressively ticking dissertation clock; I was well into the uncomfortable territory of exceeding what the Graduate Center registrar’s office conceived as the maximum amount of time to earn my doctorate. Many respondents to my recruitment email expressed a preference to participate in focus groups over the individual interviews but I could not amass enough people who would agree to meet time at a common time or date to successfully run a focus group.
In my original dissertation proposal, I had hoped to relocate the often undisclosed, complicated, spontaneous, and disorganized deliberations PAR research teams have as they strive to build ethical relationships that transcend results, to wide-open-door analyses of ethical conduct. That is, I knew my participants would share a rather private part of their praxis. I carefully crafted a semi-structured interview protocol. I did not anticipate that the exchanges would feel and the text would read, less like inter-views, and more like I was bearing witnessing/gathering testimonios. Fine (2006) noted in introduction to an imaginary methods text for researchers studying oppression that, “if social psychologists take up the work of bearing witness to oppression and resistance, then we must rethink objectivity.” (p. 88) I have never been a proponent of objectivity as it conceptualized in experimental social psychology and other positivistic methods and epistemological traditions but I still heeded this advice. The truth is, there were very few degrees of separation between me and the participants of the interviews and the unplanned decolonial ethnography I conducted as part of this dissertation. Most people agreed to talk to me because they knew me, knew my advisors, were affiliated in some way with the Public Science Project, were alumni of my graduate school, and/or were members of the small community of participatory researchers, community engaged researchers and qualitative research ethicists. All volunteers were free in this study to share their experiences with PAR ethical dilemmas anonymously or with attribution to their identities. In this manuscript I have consciously decided to anonymize all responses. At times this was quite difficult to accomplish as blurring the details also obfuscated the ethical quandary I was trying to understand. I am sure some readers might construe this as paternalizing my research participants, or as disregarding their choice but this is not my intention. In future published work, after participants have had the opportunity to review the transcripts of their interviews and have edited or have declined to edit
their responses. I will include attributions to quotations. Because I did embrace feminist
objectivity (Harding, 2002) and critical reflexivity with respect to the personal, friendly,
sometimes intimate nature of the interviews, I turned to testimonios as my primary method.

Testimonios, testifying, and/or counter story-telling as research methods, as discursive
hermeneutics, have a rich history in white and Brown critical feminist writing (Brabeck, 2001;
Smitherman, 1986; Tuck, 2009a). There is hardly, particularly within Brown (Black, Latina, and
Indigenous) feminist writings, an agreed upon definition of testimonios. My use of the term here
refers to a form of truth telling (and conversely listening) that is intended to disrupt the
Whitestream status quo. Testimonios are private and public because the messages within them
are intended for audiences/listeners which are comprised of “cynics and non-believers” but also
the converted. (Hill-Collins, 1998 p. 238) Testimonios as counter-narratives function to convey
but also “create knowledge and theory through personal experience.” (Huber-Perez, 2009 p. 643)
Using testimonios, from my perspective, was also important to me analytically as a means of
locating myself as an empathetic witness rather than a detached unemotional expert/critic of
someone’s praxis. In the next section, I attempt to further explain the multiple methods I used to
understand nepantla ethics using testimonios.

A multitude of methods and results

I wanted to accomplish many things with my dissertation. Fundamentally, it was/is
important for me to document what I knew anecdotally about participatory researchers in and
outside the academy. Experience taught me that PAR has intrinsic ethical commitments to
change, to redressing exploitative research—what Chilisa (2012) and many indigenous scholars
frame as methodological and academic imperialism. These commitments are linked to
deportments that transgress the ethical principles, rules, requirements of current research ethics
guidelines. By documenting the praxis of action researchers using individual interviews I had
hoped in a small way to complicate widely held perceptions of PAR and to contribute to
decolonizing human research ethics.

By the summer of 2012, I was well into my analyses of the Belmont Report and 45 CFR
Part 46 using a hermeneutics of demystification (Josselson, 2004). I read and reread these
guidelines striving to document the ways in which they prime academicians to think about what
constitutes ethical conduct in research. I attempted to illuminate “what is unsaid and unsayable”
within these prescriptive rules and provide evidence of the link between bio-medically centered,
individualized ethical regulations with norms of participation and disengagement that were
incompatible with participatory research. (Josselson, 2004 p. 14) By the summer of 2012, I
stumbled upon the opportunity to learn about nepantla and Ubuntu ethics from the only
functioning research review board in New York City—the Bronx Community Research Review
Board (BxCRRB). I abandoned the ethics codes analyses and immersed myself into forging a
relationship with BxCRRB for several reasons. Firstly, I knew the interviews would yield
important insight to the perspectives of different stakeholders of in participatory and community
based research but I worried about not being able to include more grassroots, community
partners’ perspectives. I took seriously Fine and Weiss’ (1996) suggestions that:

As part of our theoretical and ethical commitment, we construct, at once, designs that
fracture ideological coherence and designs that document those spaces, relations and/or
practices in which possibility or critiques get heard. Our commitment to revealing sites
for possibility derives not only from a theoretical desire to re-view “what is” and “what is
could be,” but also from an ethical belief that critical researchers have an obligation not
simply to dislodge the dominant discourse, but to help readers and audiences imagine where the spaces for resistance, agency and possibility lie. (p. xxi)

I was confident that I would have encountered many sites of possibility, of radical ethical participatory research within the interview data but I also knew that I needed to delve deeply into a specific project/space to truly understand threshold research ethics. I have framed my work with the BxCRRB as a de-colonial ethnography. I fully understand how oxymoronic my framing is. On the subject of ethnography Clair (2003) notes that its racist, otherizing histories which grew out of a master discourse of colonization.” (p. 3) My work, with the BxCRRB, is a decolonial ethnography because I was not a detached observer to this work. I was not attempting to understand the proverbial other. I like, the members of the BxCRBB, am a Bronx resident, committed to interrupting pathological damage focused representations of the people and borough I have called home for most of my life. As a nepantla researcher who has partnered with three community based organizations (CBO), thus far, I am also fully aware of the tensions many CBOs have with academicians, particularly with parachute research. This is a de-colonial ethnography because I am at serious odds over pressures to deconstruct, analyze, classify, people and relationships as a means of earning a doctorate. I am at odds with what my schooling has taught me about the researched, methods, distance, and ethics and what I have learned from my experiences as a participatory action researcher and from other marginalized scholars within and outside of the academy. This is a decolonial ethnography because I/we are rejecting the norms of interaction and of participation the academy perpetuates; that is my relationship(s) with the board members, with the BxCRBB in whatever form it takes in the future, will transcend the results of this dissertation. I have never thought of the BxCRBB or its coordinators as my unknowing participants but as my colleagues, co-researchers and teachers. If a knowledge hierarchy exists
between me and the board I am most definitely on the lower rungs of the ladder. This is a de-colonial ethnography because I have endeavored to give as much as I have taken and I am committed to contributing to sustaining this space. With the end of the grant that has financially supported the BxCRRB in sight, while many key people have left to pursue other work, after the MOA I have with the board has expired, I will still be here doing anything I can to support the board.

In the pages that follow, I will attempt to explain the circumstances by which I stumbled upon the opportunity to document the work of the BxCRRB as a site of possibility. The primary finding of this de-colonial ethnography is that the Bronx Community Research Review Board has outgrown its prescribed frame. While this growth is a cause for much celebration it is simultaneous a source of great tension. In the pages that follow, I will attempt to organize the results of this work. I will try to speak to all of my suppositions, all of the things that were “predetermined” by me as I worked this process “within the boundaries of” the CUNY Graduate Center doctoral program’s “standard procedures and regulations for research projects and thesis writing.” (Chilisa, 2012 p. 294) The final product will be unconventional; there will be two semi-interdependent results sections. The first results section will detail the findings of the interview data I collected from 26 graduate students, veteran researchers, and community partners regarding their experience engaged in participatory research. The second results section, will detail the results of the de-colonial ethnography of the Bronx Community Research Review Board (BxCRRB). Using the analyses of the interviews and ethnography, I will attempt to document the nuances of nepantla and Ubuntu research ethics which both move beyond the scope of the usually relied upon sources for ethical direction, such as institutional review boards,
the ethical guidelines of professional organizations, research ethics classes and modular computerized ethics trainings.

The Individual Interview Data Methods

Participants

In all, I conducted 26 individual interviews over the summer of 2013 of people with varying experiences with participatory action research (N = 26). Participants identified themselves as graduate student researchers (n = 11), experienced academic researchers (n = 12) staff or members of community based organizations (n = 2), community advisory boards or ethics review boards (n = 4). All participants were English speaking adults (over the age of 21). Volunteers were not diverse in terms of gender identity. Participants identified themselves as women (n = 18, 69.2%), men (n = 7; 27%), and non-gender conforming (n = 1; 3.8%). In terms of race/ethnicity respondents categorized themselves as White/Caucasian (n = 16; 61.5%), Black/African American (n = 3; 11.5%), Latino/Hispanic (n = 2; 7.7%), Asian, South Asian, or Pacific Islander (n = 1; 3.8%), and Multi or Biracial (n = 4; 15.4%).

Procedures

Respondents were solicited using the recruitment plan I previously detailed and by word of mouth at conferences and participatory ethics workshops I facilitated. Many of the interviews


\[3\text{Participants were asked to check all that applied with respect to their relationship to research and thus some folks are members of more than one group.}\]
were conducted via Skype\(^4\), \((n = 11)\) or were face to face \((n = 2)\). The online interviews were conducted using the webcam on my password protected laptop and office computer. Face to face interviews were held within the Graduate Center’s thesis rooms or at my office at Bronx Community College. The remaining 13 interviews/survey participants were obtained via Qualtrics\(^5\). All volunteers consented to be interviewed and permitted me to record the audio of our conversations. After receiving recruitment flyers, participants emailed me regarding their interest in participating in the study. I subsequently emailed a scanned copy of the Graduate Center’s IRB approved consent form to the email addresses provided. I designed an electronic consent form but the IRB seal/stamp from the Graduate Center locked out the functionality of the document. Skype participants consented via email and I attached the emails within which requests were made to schedule interviews as evidence of their consent. I also read the complete informed consent document at the beginning of every interview and thus also have recorded audio consent. Some respondents consented to participate anonymously while others wanted to participate with permission to attribute their quotes to their names, schools, and/or organizations. The latter volunteers requested the opportunity to review, edit, or potential erase their transcribed interviews.

The Qualtrics respondents completed a web-based version of the consent form that was printable. These participants also had the choice to anonymously consent or consent with

\(^{4}\text{Skype is a free program that allows users to make video and audio calls online.}\)

\(^{5}\text{Qualtrics is a web based survey administration platform.}\)
attribution to their identities. At the moment, all of the transcribed data has been stripped of identifiers and replaced with pseudonyms. I have compiled a codebook of the initials of participants and their pseudonyms which is stored on an encrypted external hard drive that only I have access to. The online version of the interview was launched 24 times during May and August of 2013. Of the 24 launches, 45.8% (n = 11) were logged on/in to for less than 9 minutes, were incomplete and subsequently were not analyzed. The remaining participants’ surveys (n = 13; 54.2%) were completed at varying rates ranging from 10 to 89 minutes.

Drawings for opportunity to receive via email a $25 American Express E-Card for 10 participants and a $5 roundtrip MetroCard were the only forms compensation for participation offered to the individual interview participants.

**Inclusionary and Exclusionary Criteria**

Participants were required to be: English speaking adults, over the age of 21 experienced in participating, conducting and/or evaluating collaborative and/or participatory research. I excluded non-English speaking participants because while I am bi-lingual, I am not fluent enough in conversational Spanish or conversant in any other than language to conduct interviews or facilitate focus groups in those languages. Minors we also excluded as potential participants. While it is true that participatory research is often conducted with young people as research partners, I reasoned that issues surrounding the ethics of collaboration usually occur between the adult partnering bodies, between academics and administrators, principals and the staff of organizations and the like. Minors were also excluded as participants because there have been so few research studies conducted on this topic in psychology with adult volunteers that I surmised it might be difficult to judge potential risks and benefits among minor participants. I presupposed that it might be more appropriate after I have analyzed adult viewpoints of human research ethics
in research partnerships that I would explore a separate age-specific study on ethical perspectives of issues that arise Youth Participatory Action Research (see Guishard & Tuck, 2014).

The De-colonial Ethnography Methods

Participants

I do not have demographic data on all of the board members of the BxCRRB. I asked for brief biological sketches and background data to include in my dissertation on two occasions. My request was met with silence, a silence I have chosen to respect. The demographic data that is presented here is from the focus group conducted at Bronx Community College. Most of the active board members (N = 6) participated in the focus group. Two members were unable to attend due illness and personal emergency. Two additional members declined to participate. Of the focus group participants, these board members identified themselves as: a graduate student researcher (n = 1), staff or members of community based organizations (n = 2), and members of community advisory boards or ethics review boards (n = 4)6. All participants were English speaking adults (over the age of 21). Volunteers categorized themselves in terms of gender as women (n = 3; 50%) and men (n = 3; 50%). With respect to race and ethnicity, board members identified themselves as Black/African American (n = 2; 33.3%), Afro-Caribbean (n = 1; 16.7%) Latino/Hispanic (n = 3; 50%) and Multi or Biracial (White and Latino; n = 1; 16.7%).

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6Participants were asked to check all that applied with respect to their relationship to research and thus some folks are members of more than one group.
Procedures

I conducted a longitudinal de-colonial ethnography of the activities of the Bronx Community Research Review Board (BxCRRB) using a variety of methods: a focus group, fourteen months (March 2013 to July 2013 and September 2013 to June 2014) of participant observations at monthly meetings, retreats and a community outreach event. Additionally, I was granted permission to read, copy, and analyze the BxCRRB’s grant proposal, IRB protocol, recruitment and outreach materials, ethics training documents, meeting minutes, evaluations, and conference presentations. Though I met the BxCRRB during the summer of 2012 and attended several meetings afterward, it was not until February of 2013 that I was able to present a letter of intent and Memorandum of Agreement (MOA) to them. In the MOA I vowed that when facilitating focus groups or observing an activity, that I would always respect the dignity, rights, privacy and self-determination of the BxCRRB. Within the MOA, I also offered in exchange for the Bronx Community Research Review Board members’ assistance in collecting information that will be used in my doctoral dissertation and academic publications, my services as a writer, researcher, conflict mediator, exit-interviewer, and educator to support BxCRRB’s many scholarly and community outreach pursuits.
Chapter 2: Results of the Individual Interview Analyses

Searching for that extra good stuff with humility

I think one of the big lies in research and and I’ll maybe it was just me being in [location deleted] is that when people state I don’t know what I’m looking for [M: umm] there’s a piece of you or an and maybe as you smile now [M: *laughs*] maybe I’m f… maybe it’s something that when you’re a minority you know that because I heard Michelle say, the oppressed and poor people tend to know more than rich privileged people and they tend to know more than what’s going on with them and what’s going on with the other group and the rich privileged people only tend to know what’s going on with them and I’m not White so I don’t care to buy in to that so maybe that’s that’s a realm of discussion and information and pathways of knowledge and circuits of knowledge on its own [M: umm hmm] but for me as a Black man what I know is …..while I’m there I know what I’m looking for [M: umm hmm] I might not know the full truth or the depth of the situation but I have a very deep understanding of what’s the foundation I’m looking for where someone where ah colleague of mine would be like we’re going to examine what are the structures that would create the inequalities my thing is, I know the structures that’s creating inequalities! I’d rather have the discussion on how they see the structure, how they are dealing with it how they’re managing it how it’s is affecting them...and that’s one of the lies in research is that every researcher knows ...a good amount of what you’re looking for [M: hmm] and what it’s going to be and what it should look like and when you’re tapping into something truthful and that’s where I think the lie comes from is that fifty percent of research is you know what you’re looking for and then the other fifty percent is being smart enough to recognize when you found that extra good shit you didn’t know was going to come with what you were looking for....

Robert, African American, Male, Academic Researcher, Skype Interview

I attempted to write the results of the individual interviews I conducted during the summer of 2013 many times. Quite frankly too often I found myself treading quicksand rather than making confident strides. Part of my stagnation came from the stuff ABD students historically gripe about: insecurities about the amount of and quality of data I collected. I obsessively pondered those burning, obvious questions left unasked. I have/had intensified anxieties about what stories to tell and which to set aside for future analyses. I struggled most over which posture and voice I should adopt in detailing these results. Trevor’s words above; his admonition not to perpetuate the lie of naiveté is where I have decided to begin. I would not be
true to myself if I wrote in the vein of the vaguely familiar yet speculative neophyte researcher I suspect the academy wants me to. The reality is I do know a great deal about participatory and/or collaborative research ethics. I have read the literature widely and critically. I have directed several PAR projects, presented at and attended many academic conferences that have featured action research. I have also: written about my burgeoning ideas concerning nepantla and Ubuntu ethics, worked as a consultant, facilitated action research ethics workshops, and conferred with colleagues struggling with dilemmas in their collaborative work. It does not make sense to Columbus this work. I know that in choosing to write from a location of knowing that I risk many things. I risk losing perspective and objectivity as it is traditionally defined. I am a part of this community of scholars and community partners. I am deeply enmeshed in a shared mission to co-nurture participatory research as a rigorous, ethical and cultural responsive public science. While analyzing the choques and nepantlas my participants confronted I would be dishonest if I said that I did not often reflect and include in these analyses how our experiences have overlapped. I did however, make concerted attempts to acknowledge and document the particularities of each ethical dilemma I analyzed at the same time, because as Luow suggests “Ubuntu takes plurality seriously.” (as cited in Chilisa, 2012 p. 187) I also risk coming across as a pompous newbie whose a priori theoretical constructs might drown out what folks have shared with me. This is also not my intention. I have conscientiously tried to address this very real possibility by resolving to adopt an approach to writing and data analysis that is part confirmatory but also grounded theoretical analysis. This analytic strategy while humbly insightful is not all-knowing. This is an Ubuntu ethical stance. I am rejecting what I consider to be a tradition of categorizing myself as either novice or expert in academic writing. Beyond my own suppositions, several important articles and case studies of ethical issues in participatory
research have been published (Banks et al., 2013; Cahill et al., 2007; Flicker et al., 2007; Manzo & Brightbill, 2007; Minkler, 2004, Tuck & Guishard, 2013; Smith, 2008). I would be remiss not to explore points of convergence and divergence with my own suppositions, this growing body of work and the interview data because as Parker Palmer (1999 reminds us, “a scholar is committed to building on knowledge that others have gathered, correcting it, confirming it, enlarging it.” (p. 27)

**Answering my research questions**

This doctoral dissertation aimed to understand the nuances of ethical conduct in participatory research from the perspective and practices of nepantleras (stakeholders in PAR). This dissertation also endeavored to document the contours of Ubuntu and nepantla ethics. I used: focus groups, interviews, and participant observations to understand how researchers, community partners, members of community research review boards, and/or members of IRBs experiences’ conducting, participating in, or evaluating research shaped how they define what is and is not appropriate ethical conduct in action research.

The primary hypothesis of this dissertation was that the: private deliberations, ways of thinking, and practices nepantleras develop to engage in transparent, democratic research have the potential to be highly informative to conventional ethics because they are less utilitarian and consequentialist. Ubuntu ethical issues such as: concerns about ownership of research data, asymmetrical power relationships between collaborators, the self-determination of collaborators, and the social justice implications of study findings are present not just in collaborative research. They are latent in all types of scientific research. I speculated that nepantlas and nepantleras can assist social scientists in addressing and perhaps overcoming ethical challenges that are beyond
the scope of the usually relied upon sources. This dissertation attempted to answer the following research questions:

1. What can nepantlas and nepantleras teach us about the contours of ethical participatory action research (PAR)?

2. How does the ethical training and IRB submission process prime doctoral students and members of IRB committees to conceptualize research ethics?

3. What navigational tools and guides do participatory researchers use to initiate and sustain ethical relationships between collaborators?

In the sections that follow I will present findings of the individual interview data that addressed my research questions. I will also discuss what I learned about ethical predicaments outside of these questions and beyond the scope of the conventional ethics.

**What are Participatory Researchers’ Ethical Touchstones?**

It was important to me to capture the multiple founts of knowledge that researchers, community partners, and members of ethics review boards draw on when evaluating ethics in participatory research. I needed to show that collaborative researchers did not eschew research ethics. I presupposed that the usual ethical suspects would be mentioned: federal regulations, professional codes of ethics, ethical principles, graduate ethics classes, the IRB submission process, practice based ethics derived from experience, and their own personal moral compasses (Strohm-Kitchener & Kitchener, 2009). In the context of the individual interviews I asked participants if they completed any formal training in research ethics. I also asked respondents what specific sources guided their understanding and practice of ethics. Most participants reported obtaining training from multiple sources (80.8%, n = 21); the sources noted were graduate ethics courses (9.5%, n = 2), ethical requirements of funders (NIH and NSF; 9.5%, n =
and/or the history of unethical research, IRB mandated trainings/CITI, the Belmont Report
and the Helsinki Report (81%, n = 17). Four participants (15.4%, n = 4) did not specify the
trainings they completed and one respondent (3.8%, n = 1), an international scholar, said that she
did not complete any training in research ethics. Multiple ethical touchstones guided nepantlera
and Ubuntu ethical decision making. Conventional ethical guidelines such as IRB guidelines,
professional codes of ethics and benefit harm analyses were shared. However, very few
respondents were like Julia below, only mentioning conventional ethics, more specifically, IRB
regulations and APA ethics as the only standards that guided them:

Okay, well, I’m… I’m bound by that big, you know, all the federal regulations and I’ve
got this big thick book about, you know, IRB regulations that I read religiously [M: umm-
hmm] and I’m referring to it all the time, so I say first and foremost, it’s the federal
regulations [M: umm-hmm] and protection of human subjects. I mean, to me, part of my
role is protecting the researcher and the university from liability, but to me that’s all
secondary to protecting human subjects. That’s what really guides my ethics is all the
abuses in the past [M: umm-hmm] of vulnerable populations, of African-Americans, of
children with developmental disabilities, of people with mental illness, you know, of
political prisoners, like concentration camps, um, people in concentration camps and
people in prisons, you know, all those abuses in the past, you know, has kind of spurred
what all these regulations that we have today, which some people say are oppressive but
they are needed because we need to protect the rights of human subjects, especially those
who can’t protect themselves. [M: umm-hmm] …I’m bound by the APA code of ethics, so
when I teach research courses, I always speak about the APA code of ethics and how that
guides what I do. Um, I’m chair of the IRB in an institution that has a professional school
of psychology [M: umm-hmm] and so the APA ethics play a large role in… in that
program, but I have to review all IRB applications according to our entire
IRB…leadership school, education, human services, etc., but as a psychologist it’s just
hard for me to separate the APA guidelines from the HHS guidelines.

Julia, Multiracial (White & Latina), IRB Chair/Experienced Academic Researcher

Brian also mentioned the usual ethical suspects, but from his interview excerpt I also heard
frustration with how unhelpful they were in dealing with what he called the gray areas, or ethical
dilemmas, that often erupt in PAR,

Um, I have to say the only thing hardest is that wonderful CITI training, um…
[M: Is that “wonderful” with like quotations?] With quotations, yes! *laughing* Um, and
just, you know, like the Belmont Report, and you know all the old standard things. I think
for me it’s everything that’s…it’s it’s all bio-science based stuff, it’s nothing that I think
is really transcended over to social science. So it’s frustrating ‘cause I think that a lot of
the work that I like to do, and everyone I work with likes to do is in this gray area [M:
umm hmm] that cannot, so it can’t be so black and white. You know, so the only things
we have are old documents that are often times, um, I don’t wanna say misinterpret
but, um, probably not the best at getting at discussing the issues that we face when trying
to do the type of work we want to do, [M: okay] um, ethically.

Brian, Black Male, Graduate Student Researcher

The vast majority of participants cited multiple, intersecting, conflicting ethical guides. Below,
Jennifer talks about analyses of benefits and harms as her ethical guides alongside thinking
critically about participation as an opportunity to edify research volunteers and researchers.

For the me the question of ethics evaluates both the benefit and harm of participating in
research. I think it is our role not only to ensure that participants are not harmed, but
that the experience edifies participants. Through participation in research participants
can be provided a platform to address issues in their community that they would like to
address or change. A research participant can shine light on an issue that they feel that
the community, the academy, government or other powerful forces are ignoring.

Jennifer, White, Female, Graduate Student, Member CBO, Qualtrics Interview

I interpret Jennifer’s reflection on her role as a researcher here as encompassing Ubuntu ethical
concerns. It is important to Jennifer that participants get something for their experience in
research. She is not talking about monetary compensation here. It seems important to her that
participants’ agency, their perspectives and ability to use research as a tool to address their own
needs, guides her sense of ethics. Another researcher, Elena’s, ethical touchstones are equally
complex and also reflect nepantla and Ubuntu ethics. Elena’s “funds” of ethical knowledge are
multiplicitious. It is rooted in her experience: as a junior member of the IRB, as a PAR
researcher, her graduate work, through conferring with colleagues and the young people/co-
researchers she has collaborated with. Ironically, Elena feels insecure about what I interpret as a
profoundly rich nepantla and Ubuntu ethics lens:

You’d think as a junior faculty in training, someone would mentor me how to do...IRB
work...it’s serious, what we’re talking about an institution with more than 170 programs,
[M: yeah...yeah] academic programs. I’m the only representative in the College of
Education. [M: Damn] You’d think there’d be some mentorship and guidance and training for me to present and speak back to and respond to...in ethics and {inaudible} concerns. I am not prepared. Only because I’ve done a few PAR...you know, sort of collaborative, community-based, sort of research doesn’t make me the spokesperson of community-based research. [M: yeah] I find it really wrong and unethical, really. I have no soundboard. I’m the only one. [M: yeah] And I’m junior faculty, right? And I’m a woman of color. [M: yeah] I am, most of the time, really scared and intimidated with what I say is backfired later on when it comes to my review {yeah} of my material, so it’s really gross and yucky, I think. [M: yeah] Really gross and yucky, I don’t like it. I don’t like it...You know. Um, sometimes my funds of knowledge or who do I lean on, or who is sort of whispering in my ear [M: hmm-umm] is always, um, well it’s definitely everyone we have read at the GC, [M: hmm-umm] you know, the different courses and workshops and seminars we’ve attended and through the PSP and know where to go and that’s where and I don’t think I need to really repeat, um, I mean we share I think um, um, those funds of knowledge. But I...I...I mean it’s definitely the former PAR collective, all of us. [M: hmm-umm] They always draw on to...draw on all of our work everything that has been published, designed and I share that in class is what I teach and I’m so ready to drop these...all these articles on to IRB meetings, you know. [M: hmm-umm] And we’ll see. There’s just something about timing, but that’s definitely huge. Um, other fonts of knowledge is definitely, um, young...just my work; yearlong work commitment to young people. I still hear them when I write, right? When I converse with others, as I [M: hmm-umm] mentor others graduate students that...would like to do PAR for their dissertation research so I um, I...I quote my...my co-researchers all the time, you know [M: hmm-umm] for example, um, it’s definitely the fun...the treasures, right. Definitely the communities that I still belong to that I am profoundly connected with [M: hmm-umm] um, and who I run to all the time when I have questions.

Elena, Latina Female, Mid-Career PAR Researcher, IRB member, Skype Interview

Jennifer and Elena were not the only participants to reference some combination of text, nuanced experience and people as their ethical guides. April, Kenya and Yelena also seem to embrace multi-voiced ethical lens’,

I've taken the required Research Ethics course in the Human Development Track of the Psychology Program. Since I don’t have a thorough background in research, I tend to reference a great deal of the material from this course, especially when it comes to research with children and other vulnerable populations. I also took a Clinical Ethics course while I was in my MSW program, which was quite instructive on how to work with participants in more applied settings. I also rely on my academic advisor and fellow students that have a lengthier and more experienced background conducting research at the graduate level.

April, White, Female, Graduate Student, Qualtrics Interview

1. the codes of ethics for my two main fields, social work and psychology. 2. My personal values and ethics, which reflect considerable thinking and analysis over the years.
Kenya, Latina, Female, Experienced Academic Researcher, Qualtrics Interview

*Ethics in CITI, Helsinki, reading about Tuskegee and Guatemala, my experience in working as a researcher and as a community member, as well as community-researcher. Yelena, White, Female, Graduate Student, Qualtrics Interview*

Additional important themes emerged from analyses of this question. Many participatory researchers talked about relying on their praxis, their work, and unconventional sources to teach them ethical imperatives and ways of being. I interpret many of these examples as embodying Ubuntu because they make mention of the engagement, the “relationships” forged in PAR as a means of teaching them the importance of being “genuine”, of “reciprocity”, analyzing power differentials between research partners and “cultural differences.” It is difficult to separate out what I understand are nested Ubuntu ethical themes: more PAR than IRB, ethics of engagement, and relationships guide me:

*What...what guides my...I mean, I would basically say that um, that Freire’s *Pedagogy of the Oppressed* um, [M: umm hmm] is in many ways uh, particularly chapter 3 is in any ways, a document about how to.... um, how to communicate with community members um on at least a somewhat equal basis I think even that can be criticized by people, basically. Even then I think they’ll be criticized. My...my guidance, what guides me in terms of research is really more um, PAR than IRB. [M: Okay]*

Kevin, White, Male, Experienced Academic Researcher, Phone Interview

Um, well yeah, I think that, um, the reciprocity piece is...is again central to the ethics, at least in PAR, um, and I think in all research the idea of...of not being sort of imperialistic or not doing harm to people and engaging in power over in any way, um, and I think PAR is probably the most sensitive form of research to that. [M: Hmm] To the reciprocity of relationships and, you know, um, trying to democratize research, um, so I guess that’s kind of how I kind of approach it. I mean there are other like specific things that, you know, that come about in a...they’re not so different junctures at which you sort of ethical decisions to make specific ones at different points, um, I mean we...{colleague deleted} and I just working on a submission to AERA and...and we had a couple of paragraphs in there about {project deleted} thing and we suddenly realized we didn’t ask them if we could include that. [M: Yeah] you are constantly having to monitor yourself around like, you know, how do you make sure that you are like and in our case we meet, our group meets at {school deleted} and so, you know, we’re faculty and then you have like these other teachers there. So we had to constantly be sort of pulling back and remembering that, you know, they’re in control of the research, not us and it’s not...but...but...then the...the ethics of that is that it bring that they’re in control of the
research not us. It’s not...but...but...then the...the ethics of that is that it can take a very long time until each group figures out exactly what they want to get out of the project and sometimes that can be after a year of two; which is really, um, some of the really bigger PAR projects when you’re working on with university people and community people it can take a long time to build that kind of trust between those groups where they feel like there’s some genuine reciprocity built and, um, the problem the ethical problem with dissertation research in PAR is that students don’t have that time, you know, so they kind of sort of force the issue a bit...they have to generate their research questions and invite people to participate, and they become much more in control of it and I think it...that one of the constraints of dissertations here is so to speak, um, is to sort of skip some of those steps sometimes and that distorts the study in ways that some people have written about including like {colleagues deleted} and and others...

Michael, White, Male, Experienced Academic Researcher, Skype Interview

Um, probably doing it, I guess. Um, you know, having done it for years I think I’d have a sense of, um, some of where the pitfalls are where you can have, um, questions and difficulties and I think a lot of it has to do with, um, the initial relationships established, the initial communications that are established. And I think it grows from there, that that’s really the basis of research ethics in community-based research that it often needs to, um, people need to, um, kind of work out their differences [M: umm hmm] in a early part of the relationship so that that the demands on researchers around, um, ethics are understood by the community and that the community benefits and limitations and involvement and what what they’re really being asked to do and how they’re going to be involved is very clear [M: umm hmm] and there’s a fair amount of lead time to figure that out. I think when researchers go into communities, we...they don’t, they don’t have, um, a clue why we want some of the things we want [M: umm hmm] in terms of ethics or we’re not clear enough about how they might be implemented in this situation, so there’s a lot of sort of, I think, preliminary work [M: umm hmm] just, um, trying to understand each other’s cultures [M: umm hmm] and to understand, you know, the demands, um, I think practitioners when you’re a practitioners their sort of, um, everyday what they do, how they serve clients probably takes priority over, um, some of the demands that we have for, um, I don’t know very...very open relationships, very clear, um, consent forms [M: umm hmm] um, you know those lengthy consent forms when, you know, they would just go out and say “Do you want to do this or don’t you?” you know, we get into all these sort of lengthy, um, consent forms that sometimes we then have to translate to everybody else, but nevertheless kind of covers the areas of ethics that are important to um researchers or need to be filled by researchers. So there are cultural differences in in um what researchers understand to be ethics and often what the people in the community understand and we need to, we need to be pretty overt about those, um, and sort of built some clarity around what our cultures are [M: umm hmm] and what we, what we value and how we’re going to work together that kind of thing.

Marie, White, Female, Experienced Community Based Researcher, Skype Interview

The primary ideas that guide my pursuit of ethics in research are first and foremost a reckoning with the horrors that have been done in the name of research in the past. I seek, minimally, to not perpetuate those, but that is more of don’t than a ‘do’. More
generatively, I pursue ethics as an engagement with others about the values in deciding what is important and useful to know more about. This engagement is about personal, political, and social values and pursuing knowledge as a relational practice.

Yvonne, Female, Multiracial (South Asian & African heritage), Experienced Academic Researcher, Member of a CBO, Member of a CAB, Qualtrics Interview

Excerpts from Kevin, Michael, Marie, and Yvonne’s interviews above all reflect attempts to bridge the insufficiencies of IRB centered ethics with relational and Ubuntu ethics. Through unusual collaborations, it is the work that steers them to be reflexive, to self-monitor power and promises, to know when they need to pullback and respect their co-researchers contributions particularly when the world outside of PAR might disregard their work/perspectives. In these reflections I hear the work of nepantreras. I hear boundaries blurring. I hear that engagement redirected them to think about trust, anonymity alongside co-authorship, transparency, action and the timely return of research results as important contours of ethical PAR.

How do the Different Stakeholders in Community, Collaborative and/or Participatory Research Define What Constitutes Ethical Conduct in Research?

When I asked volunteers how they defined ethical conduct in participatory action research while piloting my interview protocol too often I received long pauses as answers. I changed my strategy and instead asked participants to free associate with me about their thinking of ethical conduct in research by creating their own ethics Wordles. A Wordle is a word cloud used to visually represent a multifacted concept and other nested ideas. Within the cloud the key ideas are represented as larger and bolder than lesser important ideas are depicted as small and unbolded. During the face to face and Skype interviews I held up an ethics Wordle I created as an example (see Figure 1) and asked respondents what might be important (both large and small) concepts be if they created their own research ethics in PAR Wordle. Participants who answered this question via Qualtrics, an online survey platform, saw the same image and typed their responses.
Figure 1. This figure is the research ethics Wordle example I shared with participants

Large Words.

I copied and pasted the text of participants’ responses in order to create a Wordle of their collective important/large research ethics concepts (See Figure 2). There were a wide variety of ideas mentioned, some of which referenced ethics of procedures while others pertained to ethics of shared engagement. The terms participants used most frequently were: action (catalytic, change, or impact), benefit (or beneficial), collaborative (or participatory), equity (or equal), non-maleficence (do no harm), negotiating (power and cultures), integrity, justice, open (doors, mindedness, and opportunities), relationships, respect and transparency. Taken together respondents perceived ethical participatory research as: beneficial, conducted with integrity, respectful, and transparent, sparking change/action, genuinely collaborative, equitable/just, not doing harm, and attentive to relationships. Participants’ large/important research ethics concepts Wordle provides a powerful, visual example of Ubuntu ethics.
In terms of lesser but still important ideas volunteers attached to their perceptions of ethical participatory research, three clusters of concepts stood out: the academy (including terms like institution, university, and administration), elevating evidence over the process of collaboration and compliance with institutional rules (best practices, consent, deception, IRB, privacy and procedures). I am cautious about how I re-represent the responses to this question. The most frequently shared small words pertained to compliance with homogenized ethical touchstones: consent/institutional, deception, rules, IRB, requirements, principal investigator, locked and secure, privacy, and procedures. For example, when participants like Jonathan shared that “legal requirements and institutional rules” would be his small words in a research ethics Wordle I can see where mainstream researchers might misconstrue what he and other participatory researchers are attempting to say in their responses to this question. I doubt that Jonathan is suggesting that research ethics are unimportant. He does however take a strong position with how ethics are defined and on the use of people, their experiences, and our interactions with them as a means of personal advancement. Jonathan’s suggestion to think about research as a conversation is also an interesting example of an Ubuntu ethical worldview. If we are indeed engaged in genuine dialogue with one another, participatory research ethics are not
about institutional rules they are collaborating in ways that are not reductive and complicit in the
dehumanization of others:

The biggest quandary for me is about the ethics and morality of using research subjects for my own (intellectual, personal, professional) ends. Treating research subjects (interview respondents, census enumerations, whatever) as "data" reduces humanity to statistics. When I benefit from this transformation through research publications and other institutionally approved requirements for professional advancement, I am instrumental in that dehumanization. This is not about rules and guidelines being "not helpful" in resolving an ethical dilemma. It's about those rules and guidelines producing and rewarding the ethical violation. [This is an ethical dilemma because]

Because it pertains to the nature, quality, and consequences of my interaction with other human beings. The solution is to think of research as a conversation with research subjects leading to an enlargement of knowledge for its own sake rather than the production of knowledge to be communicated to an external (external to the research/knowledge-creation process) audience.

Jonathan, White, Male, Veteran Academic Researcher, Qualtrics Interview

Figure 4. This figure reflects participants' small/less important ethics Wordle.

From my perspective there was a shared sentiment among many of the interviewees that procedural ethics were important but were not enough. Amy was the only person I interviewed to characterize her IRB’s handling of participatory research positively:

My IRB, at Syracuse University, takes participatory and community research very seriously. They also take working with graduate students to be at the core of their service, as educators. In fact, I think I have learned as much from the IRB chair and the
guiding questions she asks about my IRB and protocols as I have from my methods courses on the PRACTICE of thinking through the ethics of community-based research. I am in a very lucky situation, and I know this.

Amy, White, Female, Graduate Student, Qualtrics Interview

Amy describes herself as very lucky and I am inclined to agree with her. My own experiences and that of many of the participants of the Public Science Project’s ethics workshops I have facilitated over the past three years have taught me that Amy’s characterization of her university’s IRB is unusual. It is important to note she feels they respect collaborative research and in turn the committee members envision their work, their relationship with students, as integral to their roles as educators. I interpret this to mean that an IRB that adopts a relational ethical approach to their evaluations is more likely to respect the nuances of participatory research. More often, as is well documented in the literature (Ashkraft & Krause, 2007; Banks et al., 2013; Blake, 2007; Brydon-Miller, 2012; Butz, 2008; Cahill, 2007; Cahill et al., 2007, Denzin, 2008; Detardo-Bora, 2004; Flicker et al., 2007; Larkin et al., 2008; Lincoln, 2005; Malone et al., 2006; Manzo & Brightbill 2007; Martin, 2007; Schwandt, 2007) PAR researchers like Yelena, Yvonne, Barbara, Linda, April and Kenya lack confidence in IRBs. These participants all critically question the suitability of federal ethical regulations ability to evaluate participatory research:

IRBs seem to concentrate on protecting the institution now, not the individual or the community group. Also, they do not really understand CBPR (or PAR) and do not understand how a non-expert can be a participant in research. IRBs think science consists of very narrow and mechanistic questions, in many cases. Also, there is too much corporate involvement now in academia and other research institutions.

Yelena, White, Female, Graduate Student, Qualtrics Interview

I see IRB processes and PAR processes as genealogically and also contemporarily opposed to each other. In an IRB, knowledge is a product to be owned (whiteness as property) and PAR seeks to surface, build, and negotiate knowledge as between and as impermanent.

Yvonne, Female, Multiracial (South Asian and African heritage), Experienced Academic Researcher, Member of a CBO and CAB, Qualtrics Interview
With such adherence to the guidelines, the demands of ethical boards can be overly burdensome and also lack insight and understanding about collaborative and exploratory research designs.

Linda, Female, White, Experienced Academic Researcher, Qualtrics Interview

IRB’s do a lot to protect human subjects rights, but need to go a step further to include how the data will be used WITH the participants, and how it will benefit them.

Barbara White, Female, Community Psychology Consultant, Qualtrics Interview

I have heard stories from other students that describe insensitivities on the IRB’s part. I’m not sure that the IRB representatives always have the appropriate training to evaluate research studies.

April, White, Female, Grad Student, Qualtrics Interview

I have had positive experiences with our ethics board at my university. This has grown over the past 15 years. I find it ironic that our ethics board does not consider all CBR to be "research" and chooses to exempt some of the projects I have done.

Kenya, Latina, Female, Experienced academic researcher, Qualtrics Interview

Though they work in different fields, Kevin, Michael, Emily, and Robert all express yearnings for alternatives to checklist ethical review processes. For Kevin method and ethics are inextricably tied together in ways that existing forms of review do not capture because they tend not to integrate the two. He talked about the PAR involving different standards particularly as it pertained to accountability within a partnership,

Um, so as someone trained in [deleted] psychology, um, I sort of despised what, um, people traditionally conceived of as research ethics, I thought it was completely bureaucratic, completely unreasonable and, um, and unhelpful and, uh, conservative and uninteresting. Now later on, um, I started to become more interested in ethics generally outside of research ethics [M: umm hmm] and I think I started to realize that..... ethics is important and interesting and it’s kind of a shame that so much research ethics...it happens in institutional review boards, in universities umm is so...it is what it is, but um.... I think um... I mean I think the important thing for me as a [deleted] psychologist is that, uh, there’s sort of no distinction between, um, the ethics and the methodology of the process [M: umm hmm] that umm in [deleted] psychology they’re all a part of the same piece that I think in a traditional laboratory research setting, uh, the ethics and those who hold people accountable are completely separate from those who want to do the research and of course they work together and have to, um, agree and...and they sort of play off each other and make decisions but um, it’s a very different, I think that the seamless approach that sort of, um, involves that equal partnership with...with, um, the people in the community... I think some of those rules are very good and important. Um, I always sort of liked the historical material they used; something about STD, um,
{inaudible} the Nuremberg Trials, and um, I think generally they’re good I think, uh, the ways they’re set up immediate feedback {inaudible} go back through. Um, so I think they’re fine. I think, again, it’s sort of that...this idea that the IRBs are sort of, um, not integrated. Participatory action research, the ethics in that research really are one in the same [M: umm-hmm] those few...the research on one side and then here’s your rules on the other side. And um, I kind of think that’s important ultimately, um, ethical trainings are fine and um they have strengths and I don’t think they’re a bad thing to do...

**Kevin, White, Male, Experienced Academic Researcher, Phone Interview**

In an excerpt from my interview with William he too is troubled with the seeming lack of experience many IRBs have with participatory research. He talks also feeling disturbed by an invasive process that is unidirectional; one that requires transparency of procedures on the part of the researcher but not of Institutional Review Board committees,

> I don’t think that people know...I don’t think that the IRB gets it. I don’t think that those people that are sitting in those spaces have a clue what this work is about. I think this is ivory tower that where um, you know, this is what they say they do in prac...in...in...in their practice and this is what they say they do but they don’t really do it. And I don’t think they have the experience to do it, I don’t think they know. And I don’t think they connect and understand either um I don’t think they can empathize or empathize with what it means to be a part of those communities, um, that are really opening themselves up to this. Um, it’s almost like when I think about and this is actually to go back a little bit, to think about them in CITI training they’re doing work with prisoners you gotta have an advocate on the committee or whatever. [M: umm hmm] I mean...I think that that’s, I don’t think that the...the way IRB panels are made is fair and equitable. I don’t. I think who are these people? You know, give me a list, let me see whose names are on this, right? And I know that, well, even looking at like even though we now have access to say I’m gonna send something for this review and they’re some people I look for from there and I’m like they’re gonna have a conflict of interest about what I wanna do [M: umm hmmm] and it could be a personal thing because of who I am and my relationship with them, so I don’t think that they can be objective, but there needs to be another avenue through which we can actually call out the IRB and question them around um, the decisions that they make. So there needs to be some recourse of action that allows for us to get feedback, not about a paper or what’s on here but to really give them the hard line questions about who are these people and how did you go around the decision-making, um, them a part of this particular IRB.

**William, Black/African American, Graduate Student, Skype Interview**

Another graduate student researcher, Emily, detailed her attempt to attend to what Manzo and Brightbill (2007) frame as the social responsive nature of ethical PAR only to be thwarted by the IRB. Manzo and Brightbill (2007) explain that the fluidity, flexibility, “the very shifts in the
research process that participatory research requires makes PAR incompatible with institutional ethical review requirements that demand that we map-out research in its entirety to before we begin.” (p. 38) Emily conveys discomfort, anger and confusion. Her anger stems from not being able to be responsive, her work being dismissed and not considered research. She is confused because another PAR project within which, she partnered with formerly incarcerated persons to investigate the educational experiences of people with similar backgrounds, was deemed exempt by the IRB though participants shared their legal documents and other sensitive material. Emily’s frustration here is reminiscent of what the PHAT researchers (Malone et al., 2006) went through with their IRB. Emily didn’t understand how the same IRB could not see how it acted unethically to prevent her attempt to capture a movement organized against economic inequality,

I feel like well we had a bad experience with the IRB for the project which was that they just sat on our submission for over a year. [M: What?!] Yeah...yeah, um, and didn’t give us any reason for it and um, it was ridiculous because the whole occupy movement kind of came and went and we weren’t allowed to collect data [M: umm-hmm]. Um, so I think that was ridiculous and should never, ever, ever happen. Um, and that’s not about any of the issues that we talked about but I feel it was...it was connected to the fact because it was a PAR project [M: umm-hmm] and I think at the end they were like this isn’t even research. You know, I mean, you know, my IRB for the {name deleted} project was exempt [M: umm-hmm] um, which I thought was weird. [M: because it involved formerly incarcerated folks?] Um, yeah so I feel there’s not um, a lot of respect for research with human participants when there’s relationships and um, and I don’t feel there’s any guideline, for that I don’t feel like there’s any support for that. Um, I feel like we have to make it up as we go along. [M: hmm] And I think that’s a lot to do. [M: Um, this isn’t a question but it’s curious that you said that because...because you shared your IRB with me, I kind of wrote mine on top of it {E: umm-hmm} um, and initially the wanted to exempt me too, thinking that I was doing a PAR project. So I’m curious how you took being in the exempt category. Was it like a relief for you...?] I think both. I felt like, well my ass is covered because they are the ones who require this and they are the ones who said it was exempt [M: umm-hmm]. Um, and I don’t really feel like they have a lot to do with anything, so, um, but I also felt a little angry that, um, that they didn’t really see what we were doing as research [M: umm-hmm]. and also that it is extremely sensitive. [M: yeah] You know, but it’s extremely sensitive information that people are giving out [M: umm-hmm]. Um, and it is focus group and interviews so it is all it can be very closely connected to that person it’s not like it’s survey data, [M: umm-hmm]. So it was weird. I felt very uncomfortable.

Emily, White, Female, Graduate Student, Skype Interview
Emily and I are colleagues. I know that she has moved on from her feelings of anger and is eager to work with the aforementioned IRB to improve their understanding of participatory action protocols. The institutional review process as does the Belmont Report and the Common Rule presume hierarchal, distanced exchanges and transactional interaction between researchers and participants. Participatory research rejects many of these presumptions and as an approach to collaborative inquiry holds itself to a higher transformative, pragmatic ethical paradigm.

Unpleasant and dismissive encounters with the institutional review process do however have serious repercussions for action researchers who care about ethics beyond institutional liability.

Excerpts from my interview with Robert illustrate this point:

_The the other thing is when you’re dealing with ethics and and this from my standpoint as a Black man [M: umm hmm] is is anytime you have someone like in what I encountered a Black man going into a room of five White people [M: umm hmm ] that he needs to have access to his own community  [M: hmmm]...that’s weird! [M: yeah ]it’s it’s it’s inherently weird and it’s going to inherently be uncomfortable because let’s the the individuals who make up most ethics communities...ethics boards...aren’t that inclusive[M: right]...they’re not that worldly they you know for them...their expertise will be in, well I know what the Black community in Brooklyn needs because I read four articles [M: hmmm]......I didn’t really give a shit about IRBs [M:hmm] my thing I looked at them as here I am in {location deleted} and I have to pass through five sets like this [M:umm hmmm] group of five white people to tell me that I can now go and bring in the information that I’m already gathering [M:umm hmmm] they talked a lot about harm I’ve never harmed anyone and fifty percent of my IRB submission was what steps have I taken to be adequately prepared to communicate, effectively relate with this community and not show harm to them [M:umm hmmm] my thing was I’m not going to because that’s the community I live in that’s the community I work with I’m not a voyeur going into this....this seemed to be more like a porno disclaimer than an ethics disclaimer the other thing was once I get the information_.

**Robert, African American, Experienced Academic Researcher, Skype Interview**

In the excerpt of Robert’s interview above he problematizes the assumptions of the institutional review process about researchers and their relationships to participants. Robert is also critical of the lack of diversity and of the expertise of the IRB. He mentions feeling uncomfortable having
to ask permission to distanced others, whose knowledge of the Black community in most instances is based in theory, for access and permission to enter his community.

Jennifer’s experience below is another important example to reflect on. She seems wedged between biomedically centered definitions of research, of ethics, and a poorly designed PAR project:

*I have worked with a project that is engaging in participatory research and they have argued that our project does not have to apply to be a part of the IRB. I think because of they are less purposeful and clear about their procedure. I realized when going through this process the importance of a structured system to clarify your work. While, I know that no one was harmed through our work, I think the team leading the project did not think through every step of the process, because we were not asked to do so, and thus our results lacked some legitimacy. However, an argument could be made that the purpose of the work was to serve and organize the community, and the research results were secondary to this process. I considered it an ethical quandary because it was not following the existing protocol. However, I suppose if nothing is published as a result of the process it is not. I brought my concerns to the executives associated with the project and they said I did not need to be concerned. I suppose it remains as an ethical issue, if not a political one.

Jennifer, White, Female, Graduate Student, Member CBO, Qualtrics Interview

Participatory research does not equal the absence of theoretical frameworks, a scope of research methods or of research procedures though PAR is often characterized as such. Jennifer however, is seemingly viewing PAR through the lens of conventional ethics and thus interpreted the project’s lack of clarity on the purpose and procedures, prioritizing serving the community over results as detracting from the work’s legitimacy. Jennifer’s reflection is important to include because it assisted me in understanding two other participants: Elena and Robert below. In her interview Elena notes feelings of disempowerment and perhaps vulnerability as a new junior member of an IRB and participatory researcher:

*I sit now on the IRB board, at {location deleted}, between...so end of February/March beginning March, until the end of the academic year which was I think June, beginning June I was, um, an alternate non-voting member [M: hmm] I was being transitioned into being a voting member, so um, the representative of the college of education was transitioning out since she was getting tenured and she’d been on this board for a long
time and I was then replacing her so I am now officially a voting member, this will be now in August, we are meeting on Thursday actually and um, this August meeting is my third, no second meeting during which I am now officially able to vote [M: hmm-umm] on issues regarding ethical procedures. [M: hmm] Um, so I feel like I’m sitting on eggshells when I’m the IRB meetings just because for various reasons, nobody does PAR [M: hmm] or like work. A lot of the, um, applications that have been coming through are filed as community engaging research, right, [M: umm] for example, but it’s still a one person show in terms of design and logic and epistemology. I mean it’s very, very clear, um, and I would also say that other board members look at it, look at community engaging research they...{location deleted} is not ready, they’re ready...that’s not even it...of course there are ready to name anything whatever. But they’re not, um, I don’t think they really understand, um, the intimacy of PAR work [M: hmm]so they could say PAR, but I don’t quite understand...I mean I don’t think they understand what it really entails or what I would call the differences between let’s say community engaging research and PAR for example, right. [M: hmm] So, um, they look at it...look at engaging or collaborative research projects and has all ethical layers to it, right, they look through the standpoint from a very traditional, conventional, um, scientific, right, um, point of view. Um, so I’m still learning how to say what, when and what questions to ask. [M: hmm] So there’s a little of self-protection from my end ‘cause I don’t know who my allies are yet on the board. I’m still too new, so I’m learning how to work that, right.

From Elena’s perspective her school’s IRB is not ready to review PAR because they are unfamiliar with its intimate nature. She also talks about feeling apprehensive about the kind of critique she can offer as a junior faculty members who has not figured out who her allies are.

Robert mentions having to hide what he knew would not work based on his previous experiences as a Black man who has conducted collaborative research young Black men. He talks about feeling compelled to lie by omission in order to create a safe/cool space where the young men’s perspectives he had hoped to capture could be unearthed:

*The other thing was ...Michelle [Fine] had this paper called ah what was it it was on this notion of hot data in cool spaces [M: umm hmm] and my thing was....well I was always going to create a cool space [M: yeah] but I never put that.... in my IRB. So while I was in school, the traditional idea of collecting data in schools is it is always collected in the classroom ....you know what I mean? [M: umm hmm] it must always be collected in the classroom, the teacher is the head of this thing..my logic was well I gotta create a different scenario [M: umm] so in [M: umm] and will help them understand the history of violence and where it’s coming from by the way while I’m doing that I’m also collecting research data and taking and here’s the disclaimer, show it to the parents you handle all of that stuff for me so once I’m in the room half of this will be happening, the other half of this will be happening because my thing was going in straightly and telling the kids*
I’m here today to collect data from you …on this notion… was going to upset the apple cart cause because that’s too hot of a conversation and I wasn’t going to be able to create a cool space so some people might say I got unethical in that…to get my data I created the cool space and that the premise of collecting B I had to create A [M: hmm] and then while I would write it up I would write it up as well there are times where I tried to have the open conversation in the classroom with a teacher but I didn’t seem to be getting that conversation but I did notice that while the stress management exercise and the anger intervention exercise [M: umm hmm] this conversation appeared, and this data appeared and I found that in order for me to be ethical I had to get unethical because there brand of ethics wasn’t working for me because I was never going to be able to get a group of young juvenile Black men to discuss why they are angry in school in a in a room of thirty of them mixed with between them and AP students [M: umm] you know in that sample population with a with a white teacher of the school board’s choosing in the room. Or I’m never going to be able to to pull out ten Black men from a class… that that once they’re in the room together would be like why are we all being pulled out at this time….you know what I mean? [M: yeah] and then have them discuss openly their feelings on the discipline structure with the person who disciplines them in the room which is what which is what my ethics committee wanted [M: wanted hmm] me to do and my thing was well I’m not going to get the information I need...

Robert, African American, Experienced Academic Researcher, Skype Interview

To be clear I do not endorse withholding any information from IRBs purposefully or unintentionally. I do however understand and empathize with Robert’s choices particularly as think about Jennifer and Elena. I know, firsthand, what it feels to like to feel spread thin by efforts to nurture trust, attend to the ethical ethos of participatory research, and to be receptive to its ever-changing nature. I know that it is difficult to accomplish this while also handling what can be tedious, bureaucratic aspects of procedural ethics. The methodologies, aims, and products of participatory action research quite often deviate from what was initially proposed in our IRB packets. These deviations are to be expected because participatory research argues that knowledge of the risks and benefits of participation in collaborative research can not be wholly articulated before the work begins or be anticipated by the researcher alone. Many participatory researchers argue that our work should not be subject to IRB review for these and other reasons. Some participatory researchers, like myself, would argue exempting PAR research from IRB review is a strategy used to maintain a system of a priori checks without attempting to balance or
disrupt asymmetrical power relationships in scientific inquiry. Many PAR researchers interpret attempts to exempt PAR from IRB as a refusal to change their definition of research though post Belmont Report research is multi-methological, multi-theoretical and linked to multiple epistemologies. Divergences from the theoretical framework, procedures and aims as stated in IRB protocols occur in all research. Exempting PAR from institutional review is not the answer, transforming the entire review process toward something this is more iterative and inclusive is.

**What Can the Reflections of Community-Based Researchers, Participatory Action Researchers, and Community Partners Teach Social Scientists about Ethics?**

I asked participants to share an ethical quandary in their own work with me; a situation they construed as unique to participatory research and in which the ethical principles and rules they learned in graduate school or from federal guidelines were not helpful in guiding their next steps. In this section, I attempt to analyze these reflections for how they can further inform my understanding of nepantla and Ubuntu ethics and what they can potentially contribute to ethical review of all research. Based on my reading of the literature, correspondence with colleagues and my personal experience with PAR I anticipated, as the question suggests, encountering dilemmas around ownership, interpretation, self-determination, rights, and social justice. I did manage to gather examples of these predicaments, however, additional themes emerged from analyses of this research question namely dilemmas around: multiple roles and complicated relationships, quanderies around representation and attempts to subvert participation. In all the examples I will detail I hear the nepantla and Ubuntu. In all of the examples I recognize attempts to attend to institutional ethical rules while attempting to honor commitments to conduct research in ways that respects dignity, multiple perspectives, unusual relationships and a democratic process of knowledge production. Though I will provide examples of each of these themes in turn they
should not understood as mutually exclusive, they bleed into each because that is the nature of participatory nepantlas.

**Juggling multiple roles & complicated relationships**

Um, yeah, I think that a big one I talked...I talked about before, but um, I think how do you, how I think how can you switch roles [M: hmm] of being a researcher, um, and being, um, this kind of advocate and friend and kind of person that knows the population in terms of I know you, you know me and so now I wanna say, “I wanna study you.” How do you do that, you know? [M: right] Um, so for even like, okay I wanna test out a survey, right [M: hmm] and not even like PAR stuff. You know, I just wanna take and that’s a survey so um, to see if it’s actually valid or if I’m getting types of responses that I need, we don’t utilize, you know, we don’t do IRB review for those things. And so those people usually participating in it are our friends, like and we don’t go through the same process oh where something comes up for you then you need to see someone or talk to somebody [M: hmm] if there you feel you’ve been wronged in some way and I feel that that type of work that we do with that is like the type of work we do with PAR. [M: hmm] It’s honest, it’s true and I don’t think...I think it creates, I think these barr...these ethical guidelines create a lot of barriers to getting at the work we wanna do with the populations we wanna work with, because I don’t think that, um, I think that having these rules and regulations are almost create a lot of fear [M: hmm] and apprehension of like what are you gonna use this for or how is this going to get out there or you know, are you really protecting me? You know, am I really the one you’re trying to protect and...or are you trying to protect yourself for in the future, if something comes back oh, you can say, “Oh, you have this piece of paper you signed and so it’s okay.

**William, African American, Graduate Student, Skype Interview**

Um, conducting research with, um, {a vulnerable population} and um, having full-time staff members who were {in a similar situation as the participants}, [M: yeah] and having...um, there’s been instances of; um, a female co-worker who, um, was in an {unhealthy} relationship, [M: umm-hmm] another instance where, um...a good friend of mine {was in a compromising situation} And, um, so...those were difficult situations in terms of being a project director and having that occur within those people I was working with directly. ... in many ways, there was a decision made to hire them, um, [M: umm-hmm] to be a part...to help out with the project and to sort of be there all the way through to try to talk about.... to use their experiential expertise to guide the project? [M: umm hmm] And um, this was also the risk in their world and they also became close friends [M: umm hmm] and um, uhh...uhh...there was...there was concerns about IRB research ethics, but there was also the sort of, um, realization that....this happens all the time [M: umm hmm] people who are, you know, have been caught in a situation and that you know, our job to um {inaudible} and be supportive and try to, um, help them and not...the realization that firing them... is the last thing they needed at that point. [M: umm hmm] Um, so there was a lot...I’m sure there’s a lot, I mean the reason it’s ethics is because, uh.... there’s all sorts of selfish things I want. There’s all sorts of bureaucratic requirements [M: umm hmm] but then there’s also sort of the real human being element

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In the quotes above both William and Kevin share examples of juggling multiple roles, multiple responsibilities, and obligations in their respective projects. William is a LGBT organizer, researcher, and friend to his participants. He talked about how strange it feels to switch roles from service coordinator to researcher. In switching roles he finds it odd to have to seemingly push his prior relationships with LGBT youth to the background in order to be an ethical researcher. Within William’s quandary he discusses how bringing procedural ethics (consent forms and an IRB protocol) into spaces, into pre-existing relationships creates fear and apprehensive about his intentions, what the research will be used for and about who is being protected. In Kevin’s interview excerpt he discussed managing his roles as a project director and friend. In his example embracing the philisophy of participatory meant hiring and honoring the organic expertise of his co-researchers. From the perspective of bio-medical ethics his prior relationships, his knowledge of his coresearchers as members of the vulnerable group under study could all be interpreted as conflicts of interest. This was an ethical dilemma for Kevin because he was conflicted between his self interests, with how risk and conflicts of interest are defined traditionally, the nature of research outside of carefully controlled laboratories and human decency.

There were more examples of managing, switching, and walking the line between multiple roles and commitments among the interviewees. In my attempts to understand how participatory researchers conceptualize these sorts of predicaments I am not attempting to
document consensus. I intend by embracing Ubuntu, to explore both the particularities, the shared nature and divergent perspectives of the quandaries I examine. PAR researchers are as diverse as there are varied approaches to conducting collaborative research. Amy, a graduate student researcher, took a stronger position on relationships, her personal politics and ethical responsibilities in her participatory work. While juggling multiple positions as a trusted ally among youth, teachers and administrators in her work Amy talked about how PAR has taught her that ethically managing these relationships means being explicit about her ideological perspective and personal commitments than attempting to hide them. Amy’s reflection is a powerful example of the politics of participatory ethic of solidarity:

*I find that in my context, a high school, I become a trusted and relied upon "adult" by not only the youth I work with, but also by teachers and administrators. It is still difficult for me to walk the line between members of the community--researcher/change agent. I am not always sure how to relate to administrators. Taken into their confidence, I can help facilitate dialogue between students and administrators. However, at the same time, my commitment is to empowering youth, and, often times, I feel the administrators do not understand this/do not wish to understand this and so we are, in some ways, at odds. Interactions with other people are always at their core ethical. How we treat others, why we treat them this way, and what this relationship or interaction does have ethical implications. I want to be a partner with and advocate for youth, so how I position myself within a school, particularly in relation to administrators, is an ethical decision. It communicates my values, who I will side with, what I will stand with. This ethical dilemma will never be resolved. I will face it in every school context I work in…. I think research ethics, at least how they were taught in my methods courses, often look at researcher-subject dynamics, even in qualitative research courses. But participatory research often times, at least in my case, includes political and ethical commitments. As my four years as a doctoral student and now candidate have progressed, I have transitioned from trying to put my politics to the side to know saying very openly when I meet students, parents, teachers, and administrators I work with--I say explicitly what my goals are and why. My research looks at race/ethnicity and urban public schooling. There is always the chance that my positions will cause offense or alarm and lead others to not want to work with me, not to want to let me work with their youth. But for me this is a chance worth taking because it is essential that I be clear about my commitments.*

Amy, White, Female, Graduate Student Researcher, Qualtrics Interview
Quandaries about representation and reflexivity

As a white woman who researches health disparities, I often contend with the ethics of me doing this kind of work. I worry that my work is not benefiting people enough, or that I do not have a place to do this sort of research as an outsider to these communities. I am a junior faculty member and am trying to build more collaborative relationships, but it is difficult.

Amanda: White, Female Assistant Professor, Junior Faculty, Qualtrics Interview

“Yeah, um………well I think there were a lot of comments that were directed directly at me during focus groups. [M: umm-hmm] Um, because I was usually the only White person in the room [M: umm-hmm] and always the only person who hadn’t been to prison so there were a lot things that were maybe people made assumptions about me or, um, I didn’t…and then there was a question of I think for me, how much information about myself should I disclose and I have this tendency to say less about myself because I felt like this research isn’t about me [M: umm-hmm] that I don’t want to take up these people’s time by talking about myself. Um, and I realized, at one point, and this...this was an awkward moment..... But I also think that on other things: How do you know your group is representative? [M: yeah] I think that’s a really big question in whose on a PAR team because like you can’t really be representative because people are gonna have to commit to spending time [M: umm-hmm] um, and maybe reimbursing them somehow, [M: umm-hmm] which is great. We did pay people, I think very generously, um, I think that’s a really good question how can it be representative and I think that for vulnerable populations it seems harder but, you know.....they don’t even know what representative means. [M: yeah] Like, yeah, and I don’t think any of the like research methods can really help with that, ‘cause like you know we gonna do a random sample of like people who went to college after prison [M: yeah] There’s no such thing.

Emily, White, Female Graduate Student, Skype Interview

Graduate students Amy and Emily, along with researchers like Robert and Yvonne, can be considered somewhat outliers in the interview data because they are the only participants to explicitly express a critical race perspective on participatory research. Both women’s interview excerpts are critically reflective about their power and privilege in their collaborative efforts. When Amy says that she is attempting to develop more collaborative relationships I interpreted this as perhaps more diverse with respect to race/ethnicity, gender, and social class. As she noted, this is difficult work within and outside of participatory nepantlas. In Emily’s interview she was reflexive about her whiteness and her status as someone who has not been incarcerated within a team of mostly Black and Brown formerly incarcerated co-researchers. When she
questioned how much of herself to share in order to disrupt assumptions being made about her intentions while not detracting from the group I am reminded of the work of Cynthia Chataway and mutual vulnerability (Chataway, 1997; 2001; Guishard, 2014). Tied to her self-critique

Emily also questioned what representation and meaningful compensation mean in participatory research. I interpreted her “they don’t even know what representative means” as directed to her IRB and not to her co-researchers. Avery, another graduate student, below was critically reflective about potentially paternalizing one of their participant’s desire to continue their work. Avery also shared their introspections about the appropriateness of remaining silent or imposing their critique of another participant’s moral positions in her writing:

I can think of two examples. Umm one is connected to the issue of undocumented young people [M: hmmm] cause one of my participants was talking about her desire to conduct this kind of research and publish it, so its like this [inaudible] cycle, because she had heard some stories from some people... so she was asking me some advice on how to go about safely publishing and doing the same kind of work. Not within the university more like for Anarchy Press. I had lots of ideas but I was like fearful for her, and so there’s that sense of protection, which might be like really idealist or like paternalistic but I was scared for her to do it even though I was thrilled and excited about the project [M: umm hmm] and so I spent a lot of time like saying this is a great idea and here’s the things that concern me, and kind of like trying to offer that care, which ethics of care is like fascinating and like goes in lots of directions [M: yeah] So there is that, then I also had, I am working with human rights activist. So there is a huge disclosure of human rights and one of the young people I was working with was moralizing all over other people’s approaches to human rights activism, and that was, it was a rich intellectual space but it was complicated space because was I supposed to question like interrogate her judgment or just let her judgment stand? [M: umm hmm] and do I have to do it equally in comparisons to other conversations? [M: umm hmm] when not everybody was taking such a hard line? So then when I think about how I’m going to write about each participant, how colored is my perspective, by that knowledge, of you know what I would

20I have intentionally used their and they as gender neutral pronouns in deference to Avery.
say of the majority of the participants saying I’m the least judgmental person I know, and this one participant being like here’s all the things I think are bad and wrong [M: umm hmm] I wanted to push her, but that’s me, that’s not... there nothing unbiased about me saying like why are you being so moralistic? [M: umm hmm] but I am not saying that, I am not like {inaudible} ethical but that was a tricky one for me, both of those.

Avery, White, Non-gender conforming, Graduate Student, In-Person Interview

Subversions of Participation

Um, well I think...I think, um.....I think too often funding drives researchers’ interests [M: umm] and I think a lot of times they use participatory action research to um...to make...well they’re actually sort of predatory in the way they conduct the research. They use this to make them look like they’re, um.... that everybody’s...everybody’s common goals and this is helpful to everybody but the truth is...is it’s only helpful to the researcher. [M: umm] But I think that’s part of the problem, I think there are fewer ....research ethical dilemmas in research if it’s participatory, if it’s truly authentically participatory because if everybody’s equal as a part of the process than, um, and they’re all doing it together at absolutely every stage of the research project then I think, um...there’s a less less likelihood of accidentally doing harm to the community.

Kevin, White, Male, Veteran Academic Researcher, Skype Interview

The last recurrent theme of ethical dilemmas was about subversions of participation. In my work as a consultant to PAR projects, facilitator of ethics workshops, and reviewer of participatory manuscripts I have often felt like a member of the participation police. As I noted in the chapter one of this manuscript there is a range and continuum of participatory approaches to research. The p in participation is smaller to the left of the continuum, perhaps only participatory by way of consulting with a community based entity on the design or ascertaining the questions that should be asked and/or how to best phrase them—these mostly benefit the researcher and do not aspire to promote change. To the left of the PAR continuum the P is larger reflecting efforts to share power, co-design study methods, collaboratively collect data, and disseminate it back to people most affected in order to affect social change. In the latter, everyone benefits, everyone is transformed because there are shifts knowledge and new abilities are nurtured. In the latter, efforts are made to continue work ideally without the researcher. Of course there is also a middle ground. My analyses of subversions of participation as ethical quandaries here are not intended
to pass judgment on researchers and communities who choose to locate their work on any point of the continuum. My analyses here are about projects and circumstances that undermine self-determination and sovereignty—projects that pretend to be something they are not. Veteran action researcher, Kevin, in his interview excerpt above mentioned that funding for participatory and public science attracts researchers who see PAR as a means to an end, to publication and promotion—ways that are only helpful to the researcher. Robert, below, described additional ways that participation can be subverted. From his vantagepoint participation if manipulated when researchers perpetrate, with the guise of good intentions to get access to communities and when participation is scaffolded to be exclusively performative:

I got this thing one of the individuals I really don’t like is Malcolm Gladwell [M: umm hmm] and part of what I don’t like about Gladwell is I felt he created....this economy of stealing information [M: I see] where he uses access as both as a someone who can enter the Jamaican community or the poor community but someone who worked for the New York Times and who people just adore and feel safe around he took a lot of information about what happened at our dinner tables [M: hmm] at rum shucks or at cookouts and he found a way to place it in a very....misconstrued language where... insulated populations mostly privileged white people can now get their mind blown by something [M: hmm] and when you read Outliers and you read Blink and you read The Tipping Point you’ll see a lot of he said is stuff that old men in Jamaican rum shops and men in the ghetto have been saying from in the 60s and the 70s [M: right] I say that to say this I feel PAR in part....gave a lot of people...the chance to.... perpetrate a way in changing with the times [M: hmm] in that for a lot of time researchers never had to include their participants and when I say participants I’m going to go with poor people [M: okay] the the poor people their voice and what PAR did was PAR would give a racist white person who is already in the structure a way to slowly now say they’re incorporating that voice without having to fully incorporate it [M: hmm] ....because there are various degrees and ways in which you can institute PAR [M: sure] and and that’s what I’m upset about is that there’s not various degrees in which you can institute IRB [M: hmm right...] there’s not various degrees in which you can create the scientific method there’s not various degrees in which....what’s considered validity [M: hmm] you know what I mean? [M: yes.] We don’t get to sit down and go well oh well I reject your validity and I’m I’m going to create my own and the IRB look at you and go you’re going to give the traditional standing structures of what we find valid and what holds your information to be truthful but but when you look at PAR....[M: hmm] there are these various degrees in which...what is considered participation and for me this is where I go back and it’s like that vaccine thing to someone who is very smart and knows shit you know I don’t want to come off as a racist and I don’t want to come off insecure and I’m kind of worried in
you know talking to the Black and Latino community or I’m a bit homophobic and I gotta work with the LGBT community or I don’t want or you know I gotta talk to angry Black women but I don’t fully don’t want to talk to angry Black women let me dazzle a little PAR on them [M: umm] …and for me that’s where I feel the P is perpetrating you know….and and one of the signs for me in when the P is heavily perpetrated is when theatrics becomes the end sum of the study [M: yeah] when the end sum of the study is complete theatrics it hurts my heart because I feel that’s also a space where if it was done by someone else…. it would be valid [M: hmm] but when it’s done by someone who didn’t want to fully have to bring the voice of the issue it’s done to perpetrate like you did real work or you’re speaking for them and it’s also perpetrating because part of perpetrating is gaining access and impostering and PAR gives a lot of people to impost into a community

Robert, African American, Male, Academic Researcher, Skype Interview

Barbara’s and Natasha’s examples below, exemplify what Robert’s comments about performative PAR and cool spaces for hot data. Referencing her observations at a conference

Barbara provided an example of how participation can be subverted. From her interview I learned that participation can be undermined when: the ownership of collaborative work is not shared, when PAR research teams attempt to disseminate their work to audiences that are unreceptive to transgressive ways of being and knowing, and when it is used to maintain the status quo:

I recently attended a presentation of the results of a concept mapping exercise that was done with community members. The results suggested the community was interested in community transformation. The audience, composed of service providers, heard that they needed to better collaborate in providing services. Their interpretation was consistent with continuing to treat the community members as a big pool of clients rather than understanding that the community wants to get away from being someone’s "client" and have an empowered life like the providers experience. There were no community members in the room while the service providers planned for what they thought they should do to the community. I believe that ethically if we enter the community and collect data it is their data. Our role is not to use the information for our own planning, but to work with the community to help them to use the information to make the community the way THEY want it. We can show them how to use the results of PAR and projects such as concept mapping and photo voice to influence local, state, and federal policy decisions. Instead, all I ever see is the results being fed back to professionals who decide how they want to use it to get money, expand programs and create more clients.

[this is an ethical dilemma because] Because it's like data collected from communities is used to maintain the status quo (professionals get money, serve clients) rather than to organize for community transformation. Their voices are used to further careers... it has
not been resolved. It will be resolved when we move away from a "provide services" mentality in communities to transforming communities -- make them safer, make healthy food accessible, improve housing options, and create more economic opportunities.

Barbara White, Female, Community Psychology Consultant, Qualtrics Interview

While recollecting her previous position as a director of a research project Natasha shared a host of ethical quandaries around promises, project ownership, and returning results back to participants. I also recognize this as a profound example of a subversion of participation because people (students; teachers and parents) invested time to investigate injustice, in this case racial, gender, and social class disparities in student achievement and social outcomes, and the work was suppressed:

Um, sure. So when the Diversity Research Project sort of got shut down, um, the person who shut it down wouldn’t use that term but that’s what happen. Um, I...I feel like I was caught in the middle of a lot of things. So one. he’s my boss, right. [M: umm-hmm] I’m getting paid to do this, so I can’t just like keep carrying forward with the research when someone says you’re not allowed to do it. But I also know the little bit we uncovered there’s so much more there, so it feels like a cover up. [M: hmm] So I’m like but why, like if you already know...I mean like our question was about are there difference around race, class, and gender in student achievement and social/emotional outcomes at our school. [M: umm-hmm] Which is something you think you would actually wanna know. [M: umm-hmm] We have students involved and teachers involved, the people and parents like invested in finding out the answers to these questions. And so the fact that someone comes in and says no you can’t ask when we already know that there was a reason I started this project to begin with, like that’s really difficult. And then, so I sort of finished it up and I was forbidden to look in our...like our academic records and I have access to them because I am a teacher and I can input people’s grades [M: umm-hmm] and you can also search any other student’s grades. I ask can I look with my, you know, Diversity Research Project hat on. No. I’m like but I know what I’m gonna know and so like some of that ethical things are like whose data is it [M: umm-hmm] but I’m like if any other teacher can look at it and anecdotally that like the kids can come up repeatedly on the C- and below list [M: umm-hmm] the kids are getting asked to leave the school because in 8th and 9th grade and in the year I was doing it they were only 8 Black males in the class [M: umm-hmm], five of them left between the 8th and 9th grade and if you’re noticing these things, like and you’re paying me to do a diversity research project but you won’t let me actually look at the data! [M: hmm] That’s crazy! Um, and them...long story short, I finally finished up the report and he said I can’t sent it to anyone. I’m like
What about the people who are working on it and I’m like how can I...how can I tell them that we stopped it [M: umm-hmm] like the whole first year is was like meet with the board, meet with the parents, meet with each division whatever, so I had to announce that we were doing this to everybody and then they wouldn’t even do and I’m like should I go back and tell them that we changed directions and it was just like nope, don’t say anything. Nope you just write up what you have. And I’m like we don’t have...we just have a pilot.

Natasha, Black, Female, Grad Student, In-Person Interview

What Navigational Tools and Guides do Participatory Researchers Use to Initiate and Sustain Ethical Relationships Between Collaborators?

Well one thing we did do is the...the person who is sort of the director of {organization deleted} is really, um, kind of in charge of the research in some sense and is providing the direction and {colleague deleted} and I have kind of stepped back and are very intentionally being in a supportive role, because the kind of PAR that we’re doing...you know there’s this certain kind of PAR where you’re invited in by the community [M: umm-hmm] as opposed to, you know, you’re the research doing his or her dissertation and you’re inviting people to participate in your study, you know. So it’s like it the kind of, um, who’s inviting who and who’s in charge of the project and all that. So I think what the teachers and because of sort of the differences we’ve been very careful to be sort of be as useful and supportive as possibly but did not direct or guide by the project itself. And it’s worked out really well and the teachers themselves, um, have really stepped up and are, um, are are really doing the research and we’re supporting it. But I don’t know if that’s specific enough, you could like videotape one of our meetings and probably see a lot of interesting dynamics there although I would say that, um, because all the teachers are sort of activists and they’re pretty you know...they’re pretty aggressive in their views and stuff it’s not like they’re intimidated or anything. [M: Okay] So I think we have a pretty equal...we each bring different things to the table [M: umm-hmm] and I think that that negotiation works well and what we’ve done is taken a lot of time to...for people to sort of they get to know each other, you know, in terms of what do we bring to the table in terms of our different experiences and so forth. So, I don’t know...I don’t know if that if that’s kind of ...maybe you should give me the example that’d be ...example before I...

Michael, White Male, Experienced Academic Researcher, Skype Interview

After briefly discussing the work of my colleague Sarah Zeller-Berkman (2007) on the usefulness of Memorandums of Agreements (MOAs) I asked participants about other tools or activities that have used to sustain transparency, accountability and share power in their research. Many of the responses were like Michael’s above. It seemed difficult for most participants to disentangle the myriad of strategies they have used from the actual work. Michael discussed
taking a step back and allowing the community partner to drive the agenda as a strategy to maintain ethical research partnerships. For whatever reason, this question seemed to more easily answered, by the Qualtrics interviewees than it was for the other volunteers. I suspect there is something about being able to type and your reflections with room to save, and resume your progress in the interview lent itself to this question being easier to answer for these respondents. Jennifer echoed Michael’s sentiments about co-constructing an environment where everyone could feel that their contributions would be valued:

In most of the research projects I have led, we create a team of mostly youth researchers. We start with creating an environment where everyone can learn from one another and an aim to create an understanding that each member of the team brings different expertise. The group does receive some training about research methods, but the youth members are the ones who determine the direction of the research and design the research tools. I think creating a balance of power is difficult. While, I do think that our youth researchers feel empowered, it is difficult to say if there is ever a true evening of power within the group between adults and teens.

Jennifer, White, Female, Graduate Student, Member CBO, Qualtrics Interview

Amy talked about making her intentions, presence, and work transparent. She like Yvonne and April invited their co-researchers to engage in constant, mostly informal, but sometimes formal dialogue (as April suggests among researchers) with them about any areas of disagreement and concern:

I am still developing these tools, but I always make clear (1) why I am present/what my goals are (2) what I am doing and why and (3) what I will be doing with the information/products, etc. shared with me and (4) I share my research products and (5) invite the youth to develop the research products with me.

Amy, White, Female, Graduate Student, Qualtrics Interview

One of the ways of understanding that has been most helpful is initiate conversations about knowledge (what should we know more about? why? for whom?) as constant, ongoing questions. Framing these as collective unanswerable and therefore the most important questions has helped.

Yvonne, Female, Multiracial (South Asian and African heritage), experienced academic researcher, member of a CBO, member of a CAB, or CRRB
Unfortunately, many of my research collaborations have been with very small groups of researchers and the authority power dynamics in the relationships have limited the degree to which students can improve accountability. However, I have worked with researchers that attempt to disentangle the power differentials by meeting in more casual environments. For example, all of the researchers would equally participate in the discussion in a roundtable sort of environment.

April, White, Female, Grad Student, Qualtrics Interview

In the next chapter I will detail the results of my longitudinal de-colonial ethnography of the Bronx Community Research Review Board (BxCRRB).
Chapter 3: A De-colonial Ethnography of the BxCRRB

---------- Forwarded message ----------
From: Ceph <ccphirb@u.washington.edu>
Date: Thu, Jun 21, 2012 at 11:32 AM
Subject: [Ccph-ethics] Community-Academic Partnership in Research Review, June 22 from 12:30-2:30 pm in NYC
To: ccph-ethics@u.washington.edu

Dear CBPR ethics colleagues,

CASE STUDY: Community-Academic Partnership in Research Review

The forum will be presented by Bronx Community Research Review Board (BxCRRB) at Albert Einstein College of Medicine in the Bronx.

In the past many health researchers have not adequately discussed and engaged the community in planning, implementing, and sharing of their research results with the community. The BxCRRB represents the voices of the diverse communities of the Bronx, engaging researchers in conversations with residents on research projects in the borough so that research will benefit the community as a whole. The BxCRRB is one of 9 models featured in the forthcoming report, "Community IRBS & Research Review Boards: Shaping the Future of Community-Engaged Research" which will be announced shortly on this listserv! For more information about BxCRRB, visit http://bit.ly/KyUQpg

Field Notes 6/23/12.

A couple of days ago Catlin forwarded me this email from the Community Campus Partnerships for Health ethics forum about a community IRB in the Bronx who would be presenting their work at Albert Einstein College of Medicine (AECOM). I had not heard of these folks before Caitlin’s email and I jumped at the opportunity to learn more. I peeked at the website but there wasn’t a lot of stuff on it. I was able to jot down the name of the coordinator, Francisco Martin del Campo. I emailed him wanting to know if they were accepting new members and about how long they’d been around. This was like a gift from the deities man. I can’t even believe this; freaking serendipity AGAIN…first MOMs and now this BxCRRB) …is fate trying to tell me I’m destined to conduct research in the Bronx? Yesterday was D-day and my first time at Albert Einstein. Jesus Christo, Allah, Jehovah, Yahweh, and Confucius I didn’t realize how ginormous it was! It didn’t help that it was raining buckets either. I asked around and found the meeting space. After showing my ID I grabbed something to drink and sat in the rapidly filling conference room. There was food provided, which was nice. There were lots of young people, some older folks and some doctors or researchers. I couldn’t tell who was who because most of the audience had on lab coats. I think the young people were doing summer research at the College of Medicine but I could be wrong. The entire presentation was a little over two hours. I took copious notes.
During the first hour the chair of the Einstein Institutional Review Board (IRB) talked about institutional review boards in general, why they were established, and the issues IRBs often contend with: prospective research reviews, research oversight, conflicts of interest, and education. The organizational structure of AECOM IRBs was detailed. The requirements for membership on IRBs were also discussed. I know, from my own close readings of 45 CFR Part 46.107 that boards must be comprised of at least five people with differing expertise and competencies who can review research and act to safeguard the welfare of human participants in research. I know that IRBs should also be diverse in composition with respect to gender, race/ethnicity, and expertise (one member must be proficient in a scientific area, another member must be a nonscientist, and lastly one member should be unaffiliated with the host institution and unrelated to anyone affiliated with the host institution) among other nuances of membership requirements. One of Einstein’s IRBs (they have more than one) is comprised of thirty seven people: 21 scientists, 4 nonscientists, one community member and 11 alternates. Man I feel for that community member! The chairman also detailed the scope of research activities the Einstein IRB evaluates. He mentioned that were a few expert review groups that the IRBs consulted with or are engaging in talks to consult at AECOM. There apparently is a cancer research group in place but also plans for the development of a genetics and autism expert review groups. Under 45 CFR Part 46 a widely known requirement of IRBs pertains to research with people from vulnerable groups (children, prisoners, pregnant women, physical and/or mental impaired persons); a person with experience working with/in these groups or conversant with issues related to these groups should be included in assessments of the ethicality of research with these groups; this is particularly the case in research with prisoners. A lesser known clause in the Code of Federal Regulations regarding institutional review board membership and expertise states that,

(f) An IRB may, in its discretion, invite individuals with competence in special areas to assist in the review of issues which require expertise beyond or in addition to that available on the IRB. These individuals may not vote with the IRB.” (CFR Part 46.107)

I have often wondered about this clause, about what the discretion of the IRB means. I think this clause presumes that institutional review boards reflect on the expertise of the board. However I have to wonder what exactly is the point of this disenfranchised consultation? I think too much about these regulations... The chairman concluded his presentation by suggesting that evaluation/review of community engagement in research projects at the College of Medicine might be an area the BxCRRB could potentially contribute to Einstein’s IRBs. He also posed several questions. It was difficult to determine exactly who his queries were directed to. I wasn’t sure if they were being asked of the board members, the project coordinator, or the principle investigator. He asked about: When/where in the research review process would the BxCRRB community consultation begin? Whether they envisioned conducting an evaluation of community engagement before or after the institutional review process was complete. The chair inquired about the kind of research projects the board wanted to review, the volume of projects that was anticipated, and whether the members thought that community review should be mandatory or optional. Lastly, the IRBs chairman questioned the timeliness of
the Bronx Research Review Board’s review meetings noting that traditionally IRB operate year round.

During the second half of the meeting representatives of the BxCRRB spoke. Paco (I gather he doesn’t go by Francisco) gave an overview of the board’s presentation noting that an aim of the talk was to provide the audience with “an understanding of how unique a project” the BxCRRB is. He provided some background information about The Bronx Health Link (TBHL), the home of the board, a small “clearinghouse of health information” to Bronx residents and health care providers. TBHL is the community sponsor of the BxCRRB; Paco said that he planned to discuss the difficulties of performing that role in the context of a collaborative research project. The program coordinator shared TBHL’s mission, to “promote health equity and social justice, both [of which are] underpinnings of community engagement.” Apparently The Bronx Health Link’s executive board is comprised of medical providers, some of which, like the academic collaborator on this project are faculty at Einstein. TBHL has both policy and research initiatives but also experience participating on Community Advisory Boards (CABs). From their perspective TBHL’s contributions, their “voices” were construed as mere advice and lacking in actionable power as compared to the power of academicians on CABs. The organization was drawn to the platform that community engaged research would provide in elevating their agenda and the perspectives of Bronx residents. Paco talked about the rationale behind the BxCRRB, provided Bronx demographic data, he emphasized the significance of connecting this data to health disparities and health outcomes in the borough, such as rates of asthma, diabetes, cancer, obesity, and incidences of STDs. The BxCRRB was defined as, a community-based, community-driven structure that seeks to review research projects to make sure that the community: is engaged and informed; will benefit from said research; and that projects are sensitive to community’s culture and needs Additionally, the BxCRRB assures community input into research affecting Bronx populations by: voicing community needs and concerns about research; providing a feedback loop where research results will be disseminated to the community for its use and its benefit educating the community about research” (del Campo, Alston, Mcmullin, & Nation, 2012)

The board was framed as different from an IRB “because it creates a feedback loop whereby the results are disseminated into the community for use, who benefit and then voice their opinions back to the BxCRRB to bring it to IRB.” Recruitment, selection of members, compensation for participation, along with aspects of the board training curriculum was all explained. A few of the BxCRRB members (Roslyn, ShaKing, Bernice, and Karen) detailed the intricacies of the board’s research review process. What I gathered was that essentially researchers submit a copy of their curriculum vitae, informed consent documents, and a research review application prepared by the board in advance of a scheduled research review meeting. In the context of a monthly board meeting investigators formally present study protocols to the BxCRRB in jargon free, non-medical terms. After presentations the members of the BxCRRB provide recommendations to the researcher. The researcher is often invited back for further discussion on their research and findings which I gather are presumed to have incorporated elements of the consultation with the BxCRRB. This was beyond amazing. I have so many damn questions. Someone in the room asked about the utility of community
consent in given the rigors and bureaucracy of attaining IRB approval. I raised my hand and I identified myself as a Black/Brown feminist epistemologist excited about the prospect of meeting the BxCRRB and learning about their activities. I said that I thought IRBs were undoubtedly important but that they evaluate and are concerned with particular type of ethical concerns, forms of ethics that many would argue are more concerned with protecting institutions and researchers from liability, with assessing risks and benefits of individual research volunteers than with protecting communities, respecting the dignity of people and their experiential knowledge of risks and benefits. I asked if people in the room knew about the Havasupai nation and Arizona State University lawsuit. Unfortunately many of the attendees didn’t. The chairman chimed in and provided a brief synopsis. I said that a potential role for the role of the BxCRRB with respect to Einstein’s IRB might be to assist in attending to ethics of care and relational ethics. It was easy to talk about these things off the cuff when Eve Tuck and I had just presented our thinking on de-colonial ethics and participatory action research (PAR) at the Public Science Project’s Summer Participatory Action Research Institute a few weeks prior. The IRB chair thanked me for my comment and said that he could see from how I identified myself, where my thinking about research ethics came from and then fielded questions from the other attendees. I tried really hard not to laugh out loud or smirk at what I construed was a dismissal of my perspective. After the presentation some students from Einstein and I exchanged contact information. I also met Paco, Ms. Roselyn, Ms. Karen, Shaking, Ms. Bernice and Dr. Strelnick, the PI of the CRRB. Paco and I exchanged information and I emailed him today….I hope a potential collaboration on my dissertation works out but I’m just excited about a community IRB here in the Bronx....

Kanohi kitea & walking good.

…they are ‘factors’ to be built into research explicitly, to be thought about reflexively, to be declared openly as part of the research design, to be discussed back as part of the final results of a study and to be disseminated back to the people in culturally appropriate ways that can be understood.
–Linda Tuhiwai-Smith, 2013 p. 16

Before I detail the nuances of my longitudinal de-colonial ethnography of the Bronx Community Research Review Board there are a few matters that require clarification. There were many limitations, delimitations, tensions around critical reflexivity, mutual vulnerabilities, and relational ethics in this work. Though I promptly followed up the events of June 22, 2012 by contacting Paco and requesting to attend the next board meeting it would take several months of showing my face and walking good to gain the respect, trust, and acceptance of the coordinators, principle investigator, and members of the BxCRRB. Linda Tuhiwai-Smith (1999) explains that showing one’s face or He kanohi kitea encompasses a multitude of activities including attending
important events, active witnessing and/or participating in other ways that demonstrate trustworthiness and reciprocity. It is about authentically being present in order to learn “the protocols of being respectful, or accepting respect, and reciprocating respectful behaviours, which also develop membership credibility and reputation.” (Smith, 1999 p. 15) Showing face is not to be confused with academic voyeurism, with objectifying or exoticizing the practices of the researched. It is instead about learning from people, their histories, and the context of behavior/events in order to avoid transgressions. In the Caribbean we have a similar notion—walking good. When someone tells you to walk good—they are simultaneously bidding you farewell and admonishing you to be humble, respectful, and purposeful. Walking good and kanohi kitea are ethical commitments to de-colonial research the academy did not teach me and does not seemingly respect the time it takes to nurture.

**Pseudonymity, anonymity, units of analyses and observation…**

I struggled for a long time about how to write about my observations and attempt to document a living example of nepantla ethics. I struggled over whether pseudonymity would made sense in this write up. I could have muddied the identity of the BxCRRB and just said that I conducted an ethnography of the activities of a community based research review board in New York City; the only problem there being that this board is the only functioning community research review board in the city. Anonymity and pseudonymity also seemed silly when two articles (del Campo, Casado, Spencer, & Strelnick, 2013; Casado, 2013) have been recently been published about the BxCRRB. One of the manuscripts (del Campo et al., 2013) provides as a supplement, the original IRB protocol, recruitment materials, among other documents that many would construe as making rather private material public. The other piece is a rejoinder of sorts (Casado, 2013); it is the former executive director of TBHL, the community partner’s
perspective on the rationale for the board and on the breakdown of the research partnership. Both articles air out many of the issues that I address about what went wrong and what went wonderfully, right in the collaboration as contextualized within the framework of trying to understand nepantla and Ubuntu ethics in this dissertation.

Who the players are in the story of the evolution of the Bronx Community Research Review board matters. I am hyper-conscious that the readers of this dissertation might interpret my version of events as one that locates analyses in the bodies of and personal ethics of the principal investigators, the program staff, and/or board members. This is not my intention. Respecting the dignity of all parties is of paramount importance to me. I know that my telling will not please everyone. My analysis of the BxCRRB is limited because I did not have the opportunity to interview Joann Casado, the founding community partner of the BxCRRB and Bronx Health Link’s former executive director. Ms. Casado resigned from BHL in late 2011. The circumstances of her departure are unclear but I gather from many sources it was not pleasant thus I did not pursue interviewing her. I have instead opted to use her published account of BxCRRB as somewhat representative of her perceptions of the board and the community academic partnership (Casado, 2013). At the time of this writing I also have not interviewed the academic research partner, Dr. Alvin Strelnick, or any of the program coordinators of the research review board. I had planned to conduct an exit interview with Kevin Montiel, the outgoing and perhaps last program coordinator, at the behest of Mr. Montiel and of the board’s steering committee but that didn’t happen. I want to make it clear that my units of observation were the activities of people, the organizations, the group and inter-organizational dynamics, biomedical ethics, participatory/collaborative and community ethics. However, my unit of analyses are the intersections of the articulated and tacit ethos, ideologies, mission, values and
practices of the institutions (Bronx Health Link, Albert Einstein College of Medicine, the various medical schools and academic institutions that researchers represented) and the BxCRRB; a hybrid product of both of these entities.

In the pages that follow I will attempt to detail what I have learned about the evolution of the board from a feasibility study known as the CRAB and later the CRRB/BxCRRB (pronounced like crib). These shifts in designations are not superficial; they represent pivotal moments in the board’s development.

**Birth of the CRAB on Paper.**

Abuses committed against communities of color by researchers have eroded trust in research among these populations. Furthermore, it is argued that traditional research ethics fail to address needs of and protection due to communities. Building on community-based participatory research principles and methods, The Bronx Health Link, a community-based organization and Albert Einstein College of Medicine formed a community-academic partnership to pilot test a Bronx model of community consultation and consent. Through development of a research review board consisting of Bronx residents to review research proposals and provide a feedback process to inform the community of research outcomes, it is hoped that understanding of, trust and participation in clinical research will be promoted among low income, minority communities of the Bronx.

–Joann Casado, JD, A.H. Strelnick, and Jocelyn Camacho, 2007

On 161 Street and the Grand Concourse, on the ninth floor of the Bronx Supreme Court, within suite 916 of the Bronx Borough President’s conference room is meeting space of The Bronx Community Research Review Board (BxCRRB or CRRB). Where the BxCRRB convenes speaks to its mission, values and the role the board aspires to play between residents of the Bronx and academic scientists. The BxCRRB’s meeting space is across the street from Joyce Kilmer Park. The apartments facing the park and Bronx County Courthouse are a small strip of prewar, middle class apartment buildings and condos. Suite 916 is just a few blocks from Yankee Stadium. Visitors to the stadium and this area are often cautioned not venture too far from the
Concourse lest they encounter the crime ridden streets of Gerard Avenue, Walton Avenue, Concourse Village and Vietnam projects. The BxCRRB is at the intersection of social capital, poverty, crime, wealth (that is not accessible to Bronxites), and the battle for environmental, economic, and social justice in the Bronx. Where the board meets and its current stage of development speaks to nepantla, to a liminal, threshold spaces literally and existentially as they are, at least for the moment, renting this space from The Bronx Health Link (TBHL). The BxCRRB members are also struggling for autonomy as much as research participants in a study, dependent on the infrastructure and financial support of a principle investigator for sustainability can vie for independence.

The BxCRRB is/was the product of a community academic partnership between Ms. Joanne Casado J.D., former Executive Director of The Bronx Health Link (TBHL or BHL\(^{21}\)), and Dr. Alvin Strelnick M.D., Assistant Dean for Community Engagement, Professor of Clinical Family & Social Medicine at Albert Einstein College of Medicine (AECOM or Einstein). BHL defines themselves as, “a health education, research, and advocacy agency that engages Bronx residents, healthcare providers, schools, researchers, community-based organizations, and government officials in pursuing better health outcomes for the borough” (Bronx Health Link, 2014). Established in 1998 by Bronx Borough President, Ruben Diaz Jr., and officials from Bronx Lebanon Hospital Center, Montefiore Medical Center, the former Our Lady of Mercy

\(^{21}\) From 1998 to approximately December of 2012, while Joann Casado was its executive director (ED) the community partner of the CRRB feasibility study was known as The Bronx Health Link or TBHL. Subsequent to Ms. Casado’s resignation while Paulette Spencer was the interim ED and was later replaced Felix Urratia TBHL rebranded their logo and name to BHL.
Medical Center and St. Barnabas hospital, Bronx Health Link is the product of a borough wide community needs assessment (Casado & Strelnick, 2007). BHL’s mission is to assist Bronxites in realizing health equity by primarily forging connections between residents, healthcare providers, and policy makers. The Bronx Health Link provides health education, various community outreach activities, and conducts community based research with the goal of developing policy recommendations. BHL accomplishments and scope of work are much needed and impressive particularly with a staff of only eight people many of which are interns.

Albert Einstein College of Medicine (AECOM or Einstein) is the private nonsectarian medical and graduate school of Yeshiva University. AECOM is located in the Morris Park; a largely Italian American neighborhood of the Bronx. Einstein has come a long way and expanded greatly since its first class began in 1955 (Albert Einstein College of Medicine, 2014). Today it is the largest private employer and healthcare provider to Bronx residents. Montefiore Medical Center, the university/teaching hospital of AECOM is comprised of four hospitals (Montefiore Hospital, The Children’s Hospital at Montefiore, The Jack D. Weiler Hospital and Montefiore Medical Park), and 100 ambulatory and/or urgent care centers. The College of Medicine has a multifarious mission; chief among its objectives are to “welcome students, faculty and staff from diverse backgrounds who strive to enhance human health in the community and beyond” (Albert Einstein College of Medicine, 2014).

There are many stories about the birth of the Bronx Community Research Review Board, about the genesis of the community academic partnership between BHL and AECOM, and about its original purpose and vision. After reading the original grant proposal, almost 100 archived internal documents, academic publications about the BxCRRB (Casado, 2013; Martin del Campo et al 2013a), conference presentations, conducting a focus group with board members,
and listening to plain ‘ole office gossip I am not sure which version is true or that challenging the veracity of any of the versions matters. The most frequent telling of the origins of the board is that Ms. Casado and Dr. Strelnick were both thinking, around the same time, about submitting a small grants application to explore the possibility of establishing a community research review board in the Bronx. Whether they attempted, from the beginning, to partner as principal investigators on a federally funded community academic partnership project, or if they submitted separate grant proposals and were encouraged, later on, to collaborate is still debated.

Though some sources date the establishment of the BxCRRB as beginning in 2011, the idea and groundwork for the first cohort can be dated back to September of 2008. From an archived grant proposal I was able to discern that the Bronx Center to Reduce and Eliminate Ethnic and Racial Health Disparities (Bronx CREED)\textsuperscript{22}, established the BxCRRB as a five year feasibility study with four aims,

Aim 1. Collaboratively develop an independent Bronx Community Research Review Board at the Bronx Health Link that recruits, trains, and supports volunteer community residents and representative to pilot a model of community consultation, dialogue, and ‘informed consent’ for reviewing community-based research proposals.

Aim 2. Develop, implement and evaluate a training program in the protection of human

\textsuperscript{22} BxCREED is a federally funded center and program at Einstein with several aims, chief among them are creating collaborative researchers partnerships between academic scientists and community based organizations. (Albert Einstein College of Medicine, 2013)
subjects and communities for community residents and representatives to become BxCRRB members.

Aim 3. Develop appropriate qualitative and quantitative evaluation measures of the BxCRRB’s success in promoting community trust, community-academic research partnerships, and understanding of the clinical research process.

Aim 4. Increase the Bronx community’s understanding of and participation in research.

(Casado & Strelnick, 2007, p. 1)

The rationale for the creation of the review board was based on many things and events: the state of health disparities in the Bronx, an interdisciplinary literature review on: the disintegration of the public trust in clinical/health research, the historical context of egregious violations of the rights of indigenous people, communities of Color, and women of Color in research. The idea to establish the board was also influenced by the spirits of the time putting pressure on federal funding agencies to support initiatives aimed at repairing trust/fostering collaborations between academic scientists and the affected communities, focus groups of borough residents’ attitudes and opinions of scientific research, and analyses of the work of local and national community advisory boards. (Casado, 2013; Casado & Strelnick, 2007; del Campo et al 2013).

*A close reading of the theoretical framework for establishing the CRAB.*

The theoretical framework for establishing the BxCRRB was also rooted in analyses of the individualistic nature of American research ethics regulations and principles (Quigley, 2006; Weijer & Emanuel, 2000), models of community involvement/engagement in research including: community advisory boards, extant examples community research review boards, and community based participatory research (Carrese & Rhodes, 1995; Foster et al., 1999; Hatch et
al., 1993; Zambrana, 1994). While the grant proposal’s literature review is rich and spans many disciplines, references to three publications resonate most with me about the principal investigators’ hopes and dreams for BxCRRB. Firstly, Hatch and colleagues (1993) research on suggested models for collaborative research in African American communities and the related obstacles enacting these models might pose to communities and researchers seems to have been important in guiding the recruitment strategies for potential board members. Repeated reference to this work provides insight into more than just the strategy to recruit Bronx residents to the board but also to the imagined nature of the board members interaction with researchers,

Hatch et al describe four models of research in African-American communities: (i) where researchers consult peripheral members of the community cultural systems, often employees of human service organizations who live outside of the community in question; (ii) where researchers consult community leaders (e.g., clergy, elected officials, etc.) to obtain ‘community consent’ but retain complete control of the research project; (iii) where researchers contact influential community members and ask for support, advice, and guidance in hiring community residents as outreach workers, interviewers, and screeners; and (iv) where researchers seek community assistance in setting the direction and focus of the research, determining research questions constructing the design only after the community has been consulted for its own definition of the problem. In the latter recommended model the research builds upon the community’s knowledge and experience and, thus, becomes a full collaborator in the research, negotiating its goals, conduct, analysis, and use of its finding, that is not just ‘community based but community involved. What Hatch et al. described in 1993 as their fourth model is now
widely known as community-based participatory research. (Casado & Strelnick, 2007 p. 2)

The work of Hatch et al. (1993) is also an ostensibly important reference to the PIs shared conceptualization of Bronxites as profoundly knowledgeable about the conditions that shape their social and economic positions; this assets based approach and/or resilient prospective of the borough community is in stark contrast to the many deficit and pathological representations of Bronx residents that prevail in the media and in research (Cunningham, 2013; Kaplan et al., 2006):

For some, the South Bronx will always be a smoldering urban wasteland; however, it has always been more than that to those who live, work, and struggle there. We wanted to acknowledge and utilize an assets-based approach to the development of the CRAB, recognizing what the community brought to the table, assist them in understanding their strengths, and build on that to engender a dialogue for community development. (Casado, 2013 p. 353)

Secondly, references to Weijer & Emanuel’s (2000) writings which suggest that ethical regulations, like the Belmont Report, should extend protections to communities in research further solidifies the status/role the principle investigators imagined the Bronx Community Research Review Board would take on in the borough as facilitators of community consultation and not an entity that would provide community consent, They believe that a community ought to be accorded moral status over and above the respect owed to individual community members and argue (1) people view themselves as members of one or more communities that give them values and self-understanding, (2) community through public health and governmental authorities can make binding
decisions on behalf of individual members, and (3) the primacy of the individual versus the community varies from one community to the next and among cultural groups within geographic communities. They propose protections by consultation in research protocol development, providing and obtaining informed consent (at individual and communal levels), conducting the research, gaining access to data and disseminating findings. (Casado & Strelnick, 2007 p. 4)

Thirdly, in an attempt to elucidate the landscape of evaluations involved in community consultations the principal investigators also frequently refer to Quigley’s (2006) review of strategies that might improve ethical protection(s) of communities in health research. Quigley’s (2006) recommendations, which were a result of case study analyses of participatory public, environmental health, and environmental justice research with/in indigenous communities, also speak to the proposed training curriculum of CRRB,

these guidelines include the following components: (a) determining whether the investigator’s goals and community needs are compatible; (b) developing the collaboration of partnership with the community (including Community Advisory Committees, collaborative agreements and compacts, equity issues and cultural sensitivity); (c) informed consent issues (including education on risks and benefits, individual and community autonomy, and ‘voluntariness’); (d) community knowledge collection, (e) research data management (including confidentiality, control and ownership, interpretation, dissemination, and publication); and (f) sustainability of research efforts. (Casado & Strelnick, 2007, p. 4)

Upon reading one of the principal investigator’s vision for the board the linkages to Hatch et al. (1993), Quigley (2006), Weijer and Emanuel (2000) writings are obvious.
They believe that a community ought to be accorded moral status over and above the respect owed to individual community members. They propose protections by consultation in research protocol development, providing and obtaining informed consent (at both individual and communal levels), conducting the research, gaining access to data, and disseminating findings. Therefore, we started with a view that communities are to be respected, that they are complex, and that research could not engage vulnerable groups without according them special consideration. We also acknowledged that the issue of prior abuses—both real and perceived—exist in these communities and had to be addressed as a starting point to the work. We also defined community in broad strokes, going beyond the professional elite so often represented on boards, to a more representative community that envisioned inclusion of the poor, the less educated, and the marginally employed. The starting point was accepting the diversity of the community and ensuring that they were represented on the Board. The CRAB was intended as a structural approach to achieve community consultation in research. It would also create a platform for discussion about what research is needed to serve the community and meet its self-identified needs. (Casado, 2013 p. 353)

Fourthly, the design of the BxCRRB was also shaped by existing examples of community consultation to public health research locally. The work of Einstein’s Institute for Community and Collaborative Health Community Advisory Board is an example of how a local community advisory board influenced the research review process of the BxCRRB. The Hispanic Community Health Study also known as the Study of Latinos (HCHS/SOL) was a large federally funded epidemiological collaborative research project that explored the incidence of cardiovascular and other health conditions among Hispanics/Latinos in the Bronx, Chicago,
Miami, and San Diego (US DHHS NIH, 2013). Einstein’s Institute for Community and Collaborative Health Community Advisory Board (CAB) was instrumental in helping the College of Medicine with their application for establishing a field office in the Bronx. As I understand it, the principal investigators consulted members of the CAB very near the field center proposal deadline submission deadline. According to Casado and Strelnick (2007),

Because of the imminent deadline, late consultation, and ethical concerns regarding an observational study that did not offer services the discussion with the CAB was heated and challenging….CAB members raised many of the same concerns and generated a long list of questions and demands necessary for their support. These included clarification of the role of the CAB in the research study, the relationship between NIH’s interests and that of the community, how insured participants in the study would receive medical care, where the study site would be, and how resources would be distributed. (p. 4)

The Bronx field center’s coordinators took the recommendations of the CAB seriously. They subsequently drafted a written response to the board’s advice, included more Latino researchers in the study, involved a community liaison, and invited members of the CAB to continue their consultation to the project in varied ways. I gather that the principal investigators of the BxCRRB had high hopes that the board would function similarly. Einstein’s Institute for Community and Collaborative Health CAB was not the only model of community review the organizers of the BxCRRB learned from. Ms. Casado and Ms. Jocelyn Camacho, Bronx Health Link’s former coordinator of Community Research Initiatives also reviewed the work of other community advisory boards to obtain examples of strategies of recruitment, training of board members, and research review processes (Casado, 2013; del Campo et al, 2013).
Finally, the philosophy and dynamics of the board were also influenced at the same time by focus groups of Bronxites attitudes and opinions of scientific research conducted by The Bronx Health Link:

BHL’s research into other models of community research review occurred alongside a series of six focus groups conducted by BHL that investigated Bronx community perceptions of and attitudes about research. Focus groups participants said that, for them to participate in a clinical research study, they would need to know concrete details about the research design, background information about treatments that are already available, and more details about the risks and benefits of participation. Other participants stated that they already had enough trust in researchers and health care institutions to participate in a study. During the last two focus groups, participants frequently said they perceived discrimination in health care settings against ethnic minorities and people on public health insurance, resulting in substandard care and a lack of respect for their humanity, even when the discussion was specifically oriented toward research. (Pelto D. Beliefs and attitudes about health research in The Bronx, New York City. Unpublished manuscript. 2010; Joann Casado, written correspondence, January 21, 2013). (As cited in del Campo et al, 2013 pp. 343)

Articulating this nuanced understanding of the zeitgeist, socio-political context, and theoretical justification(s) for the establishing the BxCRRB are important to me. In order to understand the Bronx Community Research Review Board as a nepantla, an example of community-based threshold perspectives to research ethics, I felt an obligation to capture what was imagined for the board from the perspective of the principal investigators juxtaposed with what the board members envisioned as their own values, mission, and theory/ies of change. The adage, “if you
At times, the imaginings of the PI’s, project coordinators and board members for the BxCRRB coincided but quite frequently, and most recently, the differences between visions seem unnervingly wide. Recording this history slowly emerged as an ethical imperative for me. This de-colonial ethnography has taught me the significance of institutional memory in maintaining respectful community academic research partnerships. In the next section I attempt to document the intersections and sometimes collisions of the missions for the Bronx Community Research review board from the first cohort, the project evaluation, and the second cohort, up until June of 2014.

**In the beginning, there were transparent goals and responsibilities…**

In the original NIH grant proposal that funded the feasibility study the responsibilities of the academic and community partners were spelled out. It was the responsibility of the community partner, Bronx Health Link (BHL) to provide a salaried program coordinator/research assistant, coordinate recruitment of prospective board members, and “develop appropriate by-laws and procedures for the board’s operations.” (Casado & Strelnick, 2007 p. 5) The role of the academic partner in the collaboration was to provide “technical assistance” (Martin del Campo et al 2013a p. 341) in the form of bioethics training, research methods training, and to provide a pool of researcher trainees from Einstein’s Institute for Clinical and Translational Research program who would present their research projects for the board to review. It was proposed that once the BxCRRB became more experienced in the reviewing research projects, it would later shift to “review proposals from non-trainee investigators and from institutions other than Einstein and Montefiore as well.” (Casado & Strelnick, 2007 p. 7) The original recruitment plan was to solicit participation of at least 20
community representatives from the Institute for Community and Collaborative Health, The Hispanic Community Health Study/Study of Latinos community advisory board, the Borough President’s Office health and social services staff but also from other Bronx based community entities. Because board members would also be participants of a feasibility study, informed consent procedures were developed by the academic partner Dr. Strelnick and submitted to AECOM’s IRB. Participation was defined as the successful completion of bioethics training, active attendance and participation at 10 monthly meetings (skipping August and December) of two hours each. Board members also had to participate in individual interviews, three focus groups, nominal group sessions, and an on-line evaluation. Volunteers received $50 compensation for attending each meeting/training and $100 for facilitating a meeting.

Recruitment of the first cohort/the beginning and end of the Bx-CRAB.

The design of the CRAB was finalized in 2010. As spelled out in the grant proposal, The Bronx Health Link (TBHL) directed the recruitment efforts and interviewing prospective board members. Requirements for board membership were that participants had to be adults (at least 18 years old), residents of Bronx County, and the ability to both read and speak English. TBHL recruited from most of the Bronx Community Boards, “particularly to their Health and Human Services Committees” but also at health outreach events, and during their research efforts. (del Campo et al 2013a p. 343) Participation was also solicited from the TBHL website and through

23 Prospective board members were also recruited community based, faith based organizations, business associations, higher education institutions, labor unions, community boards, senior citizen centers, community boards and health centers in the borough.
electronic newsletters. In all, 19 people applied and 15 were selected. Of the 15 applicants that were ultimately selected, 13 would be full board members, while 2 applicants would be alternate members.

Many of the details about the early history of the first cohort of the CRAB were difficult to obtain. Much of the training materials have not been digitized; they are archived in The Bronx Health Link’s storage spaces or the whereabouts are unknown. I was able to discern from the published articles and random notes that Professor Esperanza Martel of Hunter’s College’s School of Social Work and Ms. Casado co-facilitated the training of the first cohort using participatory critical literacy, collective reflective and critical consciousness raising methods popularized by Paulo Freire (Casado, 2013; del Campo et al., 2013). As board members shared their collective experiences, learned about: research terms, the history of unethical research studies, and ethical guidelines, a transformed, politicized perspective on research ethics and a desire to act was imagined for participants,

It is a goal of popular education that the participant emerges from the oppressor–oppressed dynamic to create a new way of looking at the community and working to improving it. Our goal was to create the infrastructure for facilitating community involvement in reviewing research and influencing the research agenda of our academic partner by identifying topics that are considered a priority in the community. Using the Freire principles links knowledge to action so that participants actively work to change their societies at a local level and beyond. A predominant feature of Freire education is that people bring their own knowledge and experience into the process. (Casado, 2013 p. 354)
Training sessions were approximately 3 hours long, were meant to be a “safe space”, spaces for nurturing community and solidarity; they began with dedications, icebreakers, and the serving of a meal provided by the Bronx Health link. (Casado, 2013 p. 354)

Board members were given homework in the form of articles to read before meetings; these articles would be used to scaffold group conversations about research ethics, regulations, health disparities and health equity. Meetings concluded with board members evaluating the sessions and with suggestions for improvements. In addition to the lunches board members were reimbursed for travel expenses in the form of roundtrip MetroCards and were compensated for their participation. Most training sessions were facilitated by Martell and Casado but some meetings were facilitated by researchers and/or consultants.

From Casado (2013) published commentary on the CRAB it seemed that during the recruitment and training of the first cohort of the board there were differences with respect to the responsibilities, input, and participation of the research partners:

We recruited and then interviewed prospective members utilizing a group deliberation process. We developed all of the processes and reported on outcomes and products with no involvement by our AECOM partners. Although in hindsight the freedom from intervention from the academic partner was liberating we also missed several opportunities to engage the AECOM staff and faculty, who might have offered

recommendations. A true partnership requires discussion of ideas and engagement in the
development of a mutual product. Rather than engage in a participatory process, each
party operated in a void with little communication, discussion, or consensus building.
(Casado, 2013 p 354)

By February of 2012 the members of the CRAB, Joanne Casado, Alvin Strelnick, Jocelyn
Camacho, Esperanza Martel, and Paco Martin del Campo, despite many speed bumps on the
journey, had demonstrated that a community research review board in the Bronx was indeed
feasible. By February the CRAB had conducted community ethical analyses of six studies.
Researchers were master’s students, doctoral students, and junior investigators from Einstein and
Montefiore’s Institute for Clinical Training Research Program (CTRP). Prior to each research
review session academicians had to complete an application form accompanied by informed
consents documents and copies of their curricula vitae. Recruiting researchers was the
responsibility of Dr. Strelnick:

The academic co-PI, Hal Strelnick, asked investigators to make brief oral presentations
followed by discussion and questions for about 1 hour. Both the founder and director of
the CRTP observed one BxCRRB review each of their scholars’ research projects,
whereas the academic co-PI has observed all its reviews. After the first four presenters,

25 This form was created by Joanne Casado and contained questions about: the research study’s aims, the duration
of the research, participant recruitment, risks and benefits to individual research participants, the nature of the
any academic community partnerships, community involvement in the proposed study, risks and benefits to
communities, dissemination/return of results plans, and funding information.
subsequent investigators learned about the BxCRRB by word of mouth. (Martin del Campo et al 2013 p. 344)

The methods and community ethical concerns of studies reviewed varied widely. Two studies were clinical trials of buprenorphine and sodium bicarbonate respectively, two studies were focus groups of brain aging among older Bronx residents and Bronxites’ health literacy as it pertained to genetic research. The remaining research projects were about survival analyses of Latino Bronx residents with liver cancer and a survey of the Bronx community’s interest in research. In the next section I will briefly summarize the results of an external evaluation conducted to gauge the community academic partnership and the community consultation process.

360 Degree Evaluation of the 1st Cohort

Beginning in the Spring of 2011 the Irving Institute for Clinical and Translational Research at Columbia University conducted a 360 degree evaluation of the BxCRRB. Interviews were conducted with board members to evaluate their perceptions of the ethics training they completed, the research review process, and experiences in the feasibility study. Individual interviews were also conducted of the community and academic research partners in order to assess their collaboration. Lastly, focus groups with the researchers who participated in the community consultation sessions were also performed to assess their perspectives on the research review process. Preliminary analyses of the evaluation’s results were shared with board members of the second cohort on July 31st 2012 but the full report was not returned to TBHL or the board members until April of 2014.
Fieldnotes August 2nd, 2012.

Two days ago was my first BxCRRB meeting. It was almost three hours and so much happened ....I don’t know if I can remember it all. Thank the deities I have a copy of the agenda and took A LOT of notes. I sat in, in a purely observational capacity. The meeting informally started with lunch a little after 2 and formally began at 2:30. Most of the folks I met last month at Einstein were in attendance but there were also new faces. Anthony, Rosalyn, Bernice, Julius, Bianca, Yvonne, Michael, Daniel, ShaKing were the board members in attendance. Paco, Dr. Strelnick and Alejandra were also there. The meeting began with introductions and a reflection on whether folks that the board was focused, not focused or getting there. The schedule of facilitators, a DropBox account for board materials, Cornell University’s IRB training materials, an upcoming celebratory dinner and the September meeting were discussed. Paco also distributed drafts of an article about the BxCRRB which was slated to be published in Progress in Community Health Partnerships for member input.

The highlights of the meeting were informative presentations by Michael on epigenetics and epigenomes. It was proposed that the BxCRRB use their growing power to encourage researchers to conduct epigenetic research in the Bronx which might improve the quality of life for residents. The possibility of the CRRB organizing a one day epigenetics symposium was also discussed in order to educate the community about the benefits of this line of inquiry. Dude there is a chemist on the board...SWEET! I swear *cross my heart* that I understand epigenetics in a way I didn’t before this talk! Daniel, another board member I had not previously met, who is a pediatrician, talked about the Havasupai Nation vs. Arizona State University lawsuit. Dude a chemist and a pediatrician? Who are these folks? This is beyond rad!

Daniel contextualized the Havasupai nation’s relationship with Dr. Therese Markow and their request to understand more about diabetes among their people. He talked about the schizophrenia research that was conducted unbeknownst to the Havasupai and about the aftermath of hurt, disrespect, and mistrust for research this case has reinvigorated among Native people and racial/ethnic minorities. It turns out that a member of the board knows Carletta Tilousi, a member of the Nation instrumental in making this study’s ethical concerns public. The possibility of Ms. Tilousi coming to meet with the board was discussed.

Before Michael and Daniel spoke Alejandra, an external evaluator from Columbia University Medical Center returned the preliminary analyses of an evaluation of the board members experiences of the ethics review the training program, community research review sessions. The junior investigators perspectives’ on the usefulness of community consultation to their work was assessed. Lastly the experiences of the folks involved in establishing and implementing the BxCRRB was evaluated. The results were very interesting and a bit distressing....I will restrict what I learned to themes that emanated from the analyses of the individual interview with board members and the focus group of
researchers. Eleven the 13 original board members participated in the interviews. The protocol for the interviews were designed in part by the community partner—Ms. Casado, and the evaluator and was comprised of 18 open ended questions. The protocol for the purpose of the BxCRRB, 2) the community research review training, 3) the research review process and 4) the role of the BxCRRB in research.” (Aguirre, 2012) Regarding the protocol for the interviews were designed in part by the community partner—Ms. Casado, and the evaluator and was comprised of 18 open ended questions. The questions explored board members’ perceptions of: “1) the purpose of the BxCRRB, 2) the community research review training, 3) the research review process and 4) the role of the BxCRRB in research.” (Aguirre, 2012) Regarding the purpose and role of the board, many members expressed confusion about the goals of the CRRB. Some members thought purpose was to return research findings to the community. A few people thought they were to assist in health outreach and promotion, while two members understood the community consultation piece. Members also differed in their views of their role on the board. Concerns were conveyed about the board’s reputation, their posture and attitude toward the investigators who presented their projects. The focus group data of the researchers’ perceptions of the board echoed these concerns. A few of investigators perceived the board as “antagonistic” and “stern.” Researchers were also unclear about the purpose of the board and the role of community ethical review in addition to institutional review. Two researchers did not know what to expect from the board, as they rarely worked with community based groups. Both the academicians and the board members perceived the review sessions are vehicles to increase knowledge of community based and engaged research.

I wanted to ask to the current board members what they attributed the misperceptions of the mission, role of the BxCRRB and the reaction from researchers but I didn’t. It didn’t feel like the right time or place to do so. From my perspective this is not uncommon in participatory and in collaborative work. My own work and the work of my colleagues in the Public Science Project has taught me that these are things that constantly need to be restated, made absolutely transparent and continuously reflected upon. A part of me wonders if the varied responses reflect different visions that were conveyed by the community and academic research partners. The data about the study partners’ views of their collaboration and work to actualize the board was not discussed.

Alejandra’s presentation was almost an hour. During the Q&A one board members still concerned with the reputation of the Bronx Community Research Board recognized herself, recognized her words in an anonymized quote. She asked the evaluator if she could fix her grammar and the grammar of other respondents. I wondered how many people sitting around the room participated in these interviews. I wanted to know if the chemist and pediatrician were participants too. God I remember debating this very same delicate issue of representation, self-determination, and dignity years ago in my qualitative methods class many moons ago. This is one of the ethical dilemmas in community-based work that is not often discussed, or perhaps gets lost in the final products of research. Alejandra explained that even the researcher’s responses were sometimes not grammatically correct. She explained that in qualitative research it was important to capture what was said in exact terms, that it was alright and expected. At the moment I’m not sure if participants spoke or wrote their
responses. The board member agreed but still asked her to make amendments especially because Alejandra was scheduled to present these slides at Einstein son. She said that would consider it. Alejandra would be re-presenting the results of the evaluation at Einstein soon. The meeting concluded after Michael and Daniel’s presentations. MetroCards and stipends were distributed. Evaluations of Paco’s facilitation of the meeting were completed. We all shared one thing we would take with us and one thing we would like to see done differently at future meetings.

I can’t stop thinking about the board members request to fix her grammar. I am in no position to judge the evaluator but I would like to think that I would have handled that differently. I would have put something about the possibility of different interpretations of findings, about what would happen when my perspective as a researcher might clash with those of the board members. I have to include the prospect of this happening again in either my letter of intent to work with the board or in a memorandum of understanding (MOU). Do evaluators have MOUs? I hope that I am afforded to work with the CRRB but there sure are a lot of layers of research….or for lack of a better work—surveillance of the board’s activities going on that I was not previously aware of. Alejandra and I exchanged contact information. I hope that we can connect and I am invited back to this space. Exciting and important work is going on here…”

The CRAB becomes the BxCRRB

This is not a perfect example out of a text book. It is imperfect…but we have to keep moving forward…
— Daniel Korin, BxCRRB board member

Cradled in one culture, sandwiched between two cultures, straddling all three cultures and their value systems, la mestiza undergoes a struggle of flesh, a struggle of borders, an inner war.

—Gloria Anzaldúa, Borderlands/La Frontera: The New Mesitza

Between the successes of the first cohort in 2011 and the beginning of 2012 many things transpired which irrevocably shaped the future of the Bronx Community Research Review Board. Joann Casado, the community partner and director of The Bronx Health Link (TBHL) resigned. Paco (Francisco Martin del Campo) was promoted from a community health educator, to a salaried position as the program coordinator of the BxCRRB. Dr. Strelnick became the only principal investigator of the feasibility study. As mentioned previously I did not interview Ms. Casado or Dr. Strelnick. Archival documents, Casado’s published reflective essay (Casado,
2013) and the final draft of the evaluation of the feasibility study however all provide valuable insight into both partners’ perspectives on their collaboration and vision for the review board. Casado (2013) mentioned learning four lessons about ethical community engagement while nurturing the CRAB,

1. **Veracity**: There was a conceptual agreement with no real actualization on a shared vision for the work between TBHL and AECOM yet at the end, you had three silos with the CRAB caught in the middle of an ideological war between the two primary partners. There should be clearly stipulated expectations, a contract or memorandum of understanding clearly delineating the rights and responsibilities of each party to this type of work, and the designation of an outside arbitrator or negotiation process when there is disagreement.

2. **Limited funding**: It is impossible to have an equitable relationship when one entity in the partnership receives the lion’s share of the funding. It is difficult to talk about equity when there is no equality in funding.

3. **Sustainability**: The original funding for the CRAB ended and, although arrangements have been made to continue funding, monies must be enough to ensure independence and sustainability.

26 The academic PI and board members of the second cohort requested updates on the progress of the evaluation and a copy of the final product for almost two years. A physical copy was distributed to members of the BxCRRB in April of 2014.
4. *Use of Paolo Freire’s Popular Education* is recommended for those research review boards that will bring in community members from diverse educational backgrounds. Using the model of Popular Education is based on using the knowledge and experience that the members bring into the process on relies less on professional and educational credentials. (Casado, 2013 p. 355, emphasis original)

In this published commentary Casado (2013) provided important insight into a community partner’s standpoint on the conditions needed to initiate and sustain ethical community academic research partnerships (CAPs). I cannot help but read these lessons as a public explanation of the “ideological” reasons why she left TBHL and the CRAB project. (Casado, 2013 p. 354) The first lesson is about authenticity and intentionality. Casado (2013) conveyed that within ethical CAPs shared theoretical frameworks should translate into tangible collaborative action and responsibilities; the use MOUs, MOAs, and external arbiters are encouraged as tools which might scaffold accountability between research partners. We learned, from her reflection, that collaborators shared interests on paper however, within and beyond those interests there were philosophical and practical differences about how to realize the review board. There were no MOUs, MOAs or external arbiters in place between Einstein and TBHL. The second lesson is about equity. While there is a broad spectrum of participation and of conceptualizations of partnerships in collaborative research, Casado (2013), ostensibly maintains here that equity between partners is inextricably linked to equal decision making, to joint distribution of resources and jointly holding of purse strings. We learned that from the community partner’s prospective that this was not an equitable collaboration because the academic PI controlled the funding and therefore made most of the decisions. My observations and analyses did not reveal
evidence to support this however. TBHL was/is the financial conduit of the Bronx Community Research Review Board. TBHL procured lunch, dispensed travel reimbursements, paid for conference presentation costs, and stipends for board members and the program coordinators. After Casado resigned many of the nuanced financial details required to close out the grant and continue to have access to unspent funds were lost for a time. For the third lesson Casado (2013) charged that ethical CAPs should be forward thinking, planning for ways to continue the work after partnerships have ended. The sustainability of the BxCRRB is absolutely tied to its autonomy. In the last lesson suggested the use of Freirian strategies, which heavily rely on lived expertise to nurture abilities to perceive private issues as shared systemic injustice, rather than on depend on distanced academic knowledge. The last lesson, from my perspective, was about self-reliance and capitalizing on participation within the context of what Torre (2005) theorizes as the alchemy of integrated spaces of difference. I will discuss issues the BxCRRB’s sustainability and complex modes of participation at length in the next section.

Many other factors contributed to the breakdown of the research partnership. Some of the impediments not previously noted included: the complicated, multiple roles Dr. Strelnick juggled as co-principal investigator, chairman of the executive board member of Bronx Health Link, and the community partner’s inexperience with many bureaucratic facets of the federal granting structure (Irving Institute for Clinical Translational Research, 2014). I was also able to partly discern, from the evaluation report, aspects of the academic principal investigator’s, Dr. Strelnick’s, viewpoint on the research partnership between TBHL and Albert Einstein College of Medicine,

The partners had distinct visions for the purpose of the BxCRRB. Whereas AECOM preferred a broader review focusing on conversation between members and researchers,
TBHL strived for a community IRB. The AECOM PI attributed the difference in vision to their professional backgrounds (i.e., the TBHL PI is a lawyer and community advocate and the AECOM PI is a physician and researcher) yet neither partner indicated an attempt to bridge the perceived difference. Rather this difference of opinion was perceived as a strength of the partnership by the AECOM PI, he stated “even if we had a different notion on how broad, or narrow, or authoritarian, or conversational it would be that we both knew that as we did the work we would learn more about what would work best and how to do it better and it was good to have different points of the views. The difference of opinion was the strength. (Irving Institute for Clinical Translational Research, 2014 p. 27)

Research partnerships are not inherently strong because the collaborators often share divergent perspectives on common issues. Pairing an academician and a community based entity does not naturally produce stronger or better research no more than superficially adding more people to a research project makes the work participatory. In collaborative and participatory research choques, cultural collisions (Anzaldúa, 1999) are inevitable, can derail the best of work, but they do not magically resolve themselves without effort. Choques can be productive and transformative when they are met with attempts to bridge the ideological/cultural differences at the intersections and used to “analyze ways micro-tensions in the research reflect macro-level policies.” (Torre & Ayala, 2009 p. 390). In the collaboratively written published article about the development of the board I got the sense that both partners acknowledge that the obstacles to nurturing the BxCRRB and maintaining an equitable partnership were shared:

For the community partner, what tools and resources are needed for a CBO to successfully launch a project using the BxCRRB model? First, it is important for an
organization to have strong community networks, and ideally the organization would regularly serve vulnerable members of the community…Small organizations such as BHL (with only eight staff members) would also benefit from more training in qualitative and quantitative research methods. Last, it is clear that the community partner must be efficient and well-organized, because developing a board such as the BxCRBB is an extensive undertaking, which requires staff time and resources that are often scarce for otherwise ideal community partners. (del Campo et al., 2013 p. 350)

For the academic partner, other issues have arisen. Einstein has several CABs for different research centers (e.g., genetics, HIV/AIDS). Should the BxCRBB have a formal role within Einstein’s research review process, as the director of its IRB has offered? As a corollary, are there specific kinds of clinical research that the BxCRBB should concentrate on, or should it remain open to any clinical researcher requesting BxCRBB’s review and feedback? Because there is a large amount of research occurring in the Bronx, it would be helpful if academic partners assessed their internal needs for community input. (del Campo et al, p. 350)

Ms. Casado’s resignation from The Bronx Health Link (TBHL) overlapped with many other entrances and exits. TBHL would also have two more executive directors (Felix Urrutia and Barbara Hart) with little understanding of the scope of the board’s work, its complicated pseudo-participatory structure and early history. TBHL experienced additional programmatic changes including rebranding to BHL (Bronx Health Link), repositioning its outreach efforts, and foci in order to sustain itself. The BxCRBB would have two more coordinators (Sandra Rodriguez and Kevin Montiel) over the next year and a half. Initially the Rodriguez and Montiel were tasked with continuing to facilitate the activities of the board. However, with the rebranding
of BHL and the financial future of host organization/financial conduit of the board in doubt, the program coordinators were often reassigned to other work. In the midst of this instability the second cohort of the BRRB was established,

By January 2012, BxCRRB membership had dwindled to five. Some who left had wished to remain on the BxCRRB but had other obligations. BHL asked other members not to return after a summer break, because they were not preparing for or participating during meetings. BHL began recruiting a second group of BxCRRB members at community board meetings, health fairs, and related events in the Bronx. BHL received 17 applications from individuals living in nine of the Bronx zip codes. BxCRRB members participated in the majority of interviews and approved the selections of all nine new members, evaluating each by the same criteria as BHL did for the first round (e.g., community networks, lived experiences). After final selections, BHL and Einstein again designed a training syllabus that built on the first round training sessions. BHL scheduled six sessions during May and June of 2012, and each session lasted 3 hours (including half an hour for serving lunch). The subjects of trainings (bioethics, research methods, etc.) remained the same, as did the meeting structure for each session. However, much of the content differed during the second round of trainings (del Campo et al., 2013 p.344)

The content of the training for the second cohort of the BxCRRB was not all that was different about this configuration of the board. Compared to the applicants of the CRAB (the first cohort)
the BxCRRB was smaller with 9 primary and 8 alternate applicants. The CRAB had 13 primary member and 3 alternate applicants. The folks who applied and eventually came to comprise the BxCRRB were: slightly older (their ages ranged from 28 to 74 years of age and mean age was approximately 50), represented more Bronx neighborhoods, had higher levels of community involvement, were more formally educated\(^{27}\), and had more direct experience with public health research and research ethics than the previous board (del Campo et al., 2013). From the evaluation I learned that within the first cohort, “only one member stated prior involvement in research as a participant. Otherwise, members had no prior research experience.” (Irving Institute for Clinical and Translational Research, 2014 p. 3) I am not sure this iteration of the Bronx Community Research Review Board meshed with what was imagined by Ms. Casado and/or Dr. Strelnick however, the availability of members to attend meetings, trainings, and retreats while working full time was directly correlated with the level of educational attainment and relative financial security of the current board. From my perspective, because the second round of training relied less on outside facilitators and more on the professional and organic experience of the board members, because new board members possessed nepantla positions to public health research, the second cohort of the BxCRRB was more critical of their role as research participants in a feasibility study and gatekeepers to community engagement. The

\(^{27}\) 13 out of 17 or 76% of the applicants had graduate/professional degrees in this cohort compared to 3 people or 16% of the applicants.
second cohort of the BxCRRB as a consequence of the instability between BHL and Einstein was also more self-sufficient and self-governing.

Field notes from BxCRRB meeting November 21, 2013.

The agenda for today’s meeting was packed. Ms. Yvonne was the facilitator and she had her work cut out for her! This was the first time that I had the opportunity to observe the BxCRRB (Bronx Community Research Review Board) interviewing a researcher even though I’ve been coming to meetings since November of last year... I honestly didn’t know what to expect, particularly after hearing about the first cohort’s sometimes antagonistic posture towards researchers. Of course I know this current configuration of the BxCRRB is older, more formally educated and dare I say more diplomatic than their predecessors; still I was anxious about how the meeting would go down. I suspect the researchers were, too. LMAO! As I review the chicken scratches that are my notes I don’t know why I thought it of importance to note the shifting postures of the women scientists, which at first was seemingly relaxed, but later became what I interpreted as defensive. Toward the end of the meeting the lead principal investigator had her arms crossed in front of her. I doubt that she and her colleague anticipated the caliber and insightfulness of the questions the board members posed.

The study presented today plans to examine the neurocognitive effects of two forms of opioid addiction treatment: buprenorphine and methadone. Prospective participants will be randomly assigned to either methadone or buprenorphine treatment groups. The investigators hypothesize that buprenorphine’s chemical makeup as an opioid agonist, which is a fancy way of saying it mimics the shape of drugs like heroin and oxycodone, fools receptors in the brain and reduces feelings of withdrawal and cravings. The researchers also posit that the cognitive decline, the diminished capacity to think and reason that is often observed in prolonged opioid and with methadone treatment, will not occur in the treatment group that will receive buprenorphine. This second hypothesis is derived from reviewing research of a few human and animal trials of buprenorphine use.

To their credit the investigators shared a lot of their study materials with the BxCRRB. The IRB packet was almost two hundred pages. I’m glad to see that they made use of the revised research application Dr. Burke, the steering committee members and I worked on editing down from a longer, redundant format designed by Joann Casado. From their responses to this form I noticed that they have requested this meeting and the board’s service for assistance in recruiting Bronx residents as participants. The investigators have attempted triage recruitment by intercepting people who came in for treatment to the hospital they are affiliated with, but this was not always successful as people tended to come in with their minds made up about the kind of treatment they were seeking. The researchers are looking for people who are open to being randomly assigned to either a methadone or buprenorphine treatment group. This request for assistance in recruitment is a bit puzzling as the BxCRRB has repeatedly said that this is not and will not be their function in the Bronx. The board members are wary, as they should be, about being surreptitiously used by academic researchers to gain access to Bronx residents. They are cautious about being construed as a shortcut to obtaining
Bronxites’ perspectives, without genuine concerted efforts at community outreach and engagement. This second cohort of the board has positioned themselves as a research review board, open to assisting academicians, before and after their institutional review board applications have been submitted, to provide consultation on recruitment materials, consent documents and evaluate how community concerns, potential community risks and benefits are attended to in proposed research. The principal investigators talked for about a half hour and ceded the floor the board members for questions. I noticed that Daniel wasn’t with us today. I was looking forward to hearing the longtime community pediatrician’s reflections on this project. Still most of the core board members were present. Though I have recorded and transcribed the minutes of this meeting rather than include verbatim text of this exchange I am intentionally just including the questions posed and not the researcher’s responses:

Ms. Bernice asked whether participants would know which drug they were receiving and whether the researchers were having difficulty recruiting study volunteers. She inquired about how observed memory deficits would be isolated and only attributed to the type of addiction treatment given that so many factors might impact cognitive decline.

Barbara asked if the researchers knew of another scientist who was affiliated with the same hospital and was interviewed by the board in the past about a similar buprenorphine study...whether efforts had been made to reach out to him about sharing his resources and the agencies he partnered with. She asked about what was the point of having volunteers in the buprenorphine group, who would only be administered a dissolving tablet or filmstrip, come in as frequently for treatment as participants in the methadone group who required 21 weekly visits. Barbara also questioned the almost one hundred pages of questionnaires respondents had to complete. She asked whether they were to be self-administered or not and if the researchers thought about the likelihood of respondents experiencing burnout after answering the intense neuropsychological battery.

Dr. Burke asked about the chemical structure of buprenorphine versus methadone. He wanted to see evidence of the claim that the drugs were chemically distinct and evidence of the assertion that these drugs might have different impacts on cognitive decline. He inquired about the neurotransmission stories behind both drugs, about their agonist and antagonist properties. He asked about the acetalization effects (I have no idea what that is!) and whether there would be any brain imaging conducted or blood samples collected looking for particular protein synthesis in the study. Lastly he inquired about the role that HIV infection, about how the known decline associated with this condition, might influence the researcher’s hypotheses and findings.

Yvonne asked about people who were excluded during prescreening, about whether they might be offered an incentive for them to recruit other people. The P.I. said that each participant could recruit up to 20 people and would be compensated up to a certain amount for their recruitment assistance. Ms. Yvonne followed this up by asking whether the investigators had taken their recruitment efforts to the streets. Barbara dovetailed off of Yvonne’s questions and inquired whether the project employed outreach workers.

ShaKing asked about recruitment efforts for populations of opioid addicted Bronx residents who too often fall under the radar; people who might not hang around hospitals
or treatment centers or know of them. He asked about the services that might be provided to this group. The researchers kept saying the questions posed were excellent questions; the P.I. readily provided answers to the board’s queries, or noted that she wished the study could incorporate many of the concerns the members mentioned. There were some questions particularly about the neuropsychological assessments that would be conducted that the investigators admittedly said were difficult to answer because that part of the study was handled by another collaborator.

I was in awe of the board. I shouldn’t have been, not after the amount of time I’ve spent with these folks — but I was. I as reread my notes I can see the parallels between this review session and my school’s institutional review process. The BxCRRB members largely asked questions about the proposed methods, about prescreening procedures, elements of experimental design (the presence confounding/extraneous variables, about matched samples design), questions about the theoretical framework of the study, the distribution of risks and benefits. However the board also posed many concerns about: the nature of participation, about community outreach strategies, the effort the researchers have expended to take their recruitment efforts and understanding of opioid use outside of hospitals and treatment centers to the streets of the Bronx, the lack of sharing resources with colleagues in the Bronx and presenting at community boards. After the researchers left many of the board members, more knowledgeable about the NIH granting hierarchy than I am, felt the amount of compensation for participants, the lack of community outreach workers or activities was disproportionate to the amount of funding they presupposed the investigators were receiving for a RoI grant. This was a profound example of nepantla/threshold ethics to me because the questions posed addressed traditional ethical issues but also were concerned with dignity, capacity building, drawing on the experiential knowledge, community engagement and the return of results to Bronxites.

I have to admit that there were times that I yearned to ask a question. I consciously and perhaps unconsciously raised my hand eager to participate in the exchange between the investigators and the board. I could see that Ms. Yvonne was aware of this; she gave the evil eye several times but tactfully ignored me. I left feeling a little dejected as I frequently have felt uncertain about how the board conceptualizes me. I wonder whether they see me as an outsider/researcher or insider/fellow Bronx resident…as a member to be. I also left feeling overwhelmingly proud to just know these folks, to have the opportunity to witness and document the work they are performing for people who would never have the opportunity to ask researchers these kinds of questions…this was not my moment; in hindsight I realize how selfish of me it was to try to appropriate even a minute of it. It was the BxCRRB’s moment, they worked so hard individually and collectively to evaluate this protocol, to represent disempowered Bronxites with dignity thinking of their neighbors, children, clients, students and it was fantastic.

In the next section I will attempt to juxtapose what was envisioned for the BxCRRB with the board members mission and vision using excerpts from a focus group conducted in July of 2013.
You honor what has ended, say goodbye to the old way of being, commit yourself to look for the “something new,” and picture yourself embracing this new life. But before that can happen you plunge into the ambiguity of the transitional phase, undergo another rite of passage, and negotiate another identity crisis.

—Gloria Anzaldúa & Anna Louise Keating, This Bridge We Call Home: Radical Visions for Transformation, 2000, p. 547

The published articles and the evaluation previously mentioned capture the principal investigators’, BHL staff’s, and the first cohort’s reflections on the development of the Bronx Community Research Review Board. BxCRRB members read early drafts of these pieces. Daniel Korin and Michael Burke were specifically acknowledged as contributors to the editing of article (del Campo et al., 2013 p. 351). However apart from Dr. Korin and Dr. Burke other members ostensibly did not have the opportunity to convey their perspectives on the board²⁸, share their reasons for joining, vision for the future nor their complex feelings about their roles as research participants and evaluators of research.

I formally presented the theoretical framework and research methods of my dissertation to the board in November of 2012. Within the presentation I requested permission to facilitate two focus groups with BxCRRB members primarily about their attitudes and opinions regarding what it means to be ethical in community based health research. I asked for permission to conduct participation observations of activities of the BxCRRB in meetings and events. My

²⁸ Not outside of board meetings, conference presentations, and public outreach events.
request was debated over several meetings. It was not until February of 2013 that I was able to present a letter of intent and Memorandum of Agreement (MOA) which vowed that when facilitating focus groups or observing an activity, that I would always respect the dignity, rights, privacy and self-determination of the BxCRRB. Within the MOA I offered in exchange for the Bronx Community Research Review Board members’ assistance in collecting information that will be used in my doctoral dissertation and academic publications, my services as a writer, researcher, conflict mediator, exit-interviewer, and educator to support BxCRRB’s many scholarly and community outreach pursuits. (See Appendix C) The board was preoccupied with preparing for a major showcase of their work—The Borough President’s Health Summit at Fordham University, scheduled for that April. The MOA was signed by the board members, Dr. Sterlnick, and BHL personnel directly involved in the administration of the CRRB in June of 2013. The focus group was conducted in the President’s conference room at Bronx Community College in late July.

The original intent of the focus group was to understand how the CRRB as a nepantla, a threshold space, and the board members as nepantleras, people in transition between participants, health care workers, community members and ethics evaluators. I wanted to capture their attitudes and opinions about ethical issues in community based research and role of the BxCRRB. I intended to compare the focus group data with the individual interviews I had conducted. At the beginning of the discussion, just after we finished dinner I soon realized I had to abandon that plan and just listen because the board members had a lot to say. Paco had recently resigned. The new program coordinator could not make retreats and some meetings because they conflicted with her religious practices/beliefs. Albert Einstein College of Medicine and Bronx Health Link were both facing major financial crises and the future of the board was in
limbo. Four themes emerged from focus group which taught me important lessons about Ubuntu and nepantla ethics.

*My previous experience and frustrations with research motivated me to act.*

The board members’ past experiences with research spoke to complicated postures as former participants, research coordinators, a community pediatrician, graduate students, and an environmental justice organizer. Their collective experiences all inform rich threshold perspectives to research ethics. Because the members of the second cohort of the CRRB were not strangers to research they understood the process from multiple perspectives:

**P1:** Well for me I know that I participated in...in several research um with...one was with research on cholesterol because I have had um high cholesterol from the age of eighteen [M: umm hmm] until now another one was on um losing weight you know it was more like um a drink where I had to drink this um...like five times a day and um just trying to lose weight so I have participated in several research including um research on bipolar research on obesity...research on um hypertension um research on high cholesterol and that’...okay...So that’s. as as far as I’ve done with research

**P2:** So for me um in addition to what P1 had said I’ve had similar experiences uh I am I work for an organization that is establishing its own infrastructure in terms of creating research...so my role in that organization is a research liaison and now I am transitioning into coordinating research studies and...so...I do um grant...from eh input in the grant writing process to program design, data collection, and analysis and publishing. So that’s where I am right now in terms of that.

**P3:** So similar to P2 I actually have done...I’ve participated in some research qualitative research, like focus groups um and um I coordinate research studies and I’m also a graduate student um so I’ve done some work eh with some of my professors on a couple of their studies as well.

**P5:** Ehh my eh involvement with research formally is through the community campus partnerships for health and the...fostering of *coughs* eh community based participatory research where eh we really contribute to the advancement of the community component...and the ethical and including the political eh component of research as a physician I was interested in research because the research that I was seeing...did not match with the reality that I was seeing with [M: umm
my patients and that I have always worked in community health centers and in medically underserved areas... so eh I was always interested in that living knowledge that would help me contribute to the health of my panel of patients and the community formally one of the CBPRs that eh I participated was as a consultant for {organization’s name deleted} in eh a genetic literacy eh program {title deleted} that we identified two communities, one eh the Dominican community development corporation in upper Manhattan with {name deleted} and eh the other community was eh was an African-American community in {location deleted}. And for me it was.....very important because organization’s name deleted} .. is a very ...conservative institution in terms of research [M: umm hmm] so....I considered that a success to really move them [M: umm hmm] towards looking at eh genetics and to look at CBPR the importance was this was I think 2006 2007 was the eh the resistance from the establishment saying okay that you cannot teach genetics, what genetics is to eh community people [M: umm hmm] and so on but we did it so it’s eh really simply one of the major objectives was eh to inform them of what was the goods, the bads, and the neutrals....Okay for them and to....to be able to think okay how is it that this genetic research is going to impact... health insurance...whatever.

P6: I mean, just shortly, similarly working on community based participatory research was getting an environmental justice grant due to... to work with the South-East Asian community in {location deleted} because at the time we had researchers at the university working on ergonomics, epidemiology, cutting edge issues but from a labor and community based focus but yet in this local community there was no way to translate some of the cutting edge issues to action [inaudible] with the community so we formed a partnership bringing together these researchers, the city’s health department and local community based organizations to really redefine the way researchers practice and apply and as a result of that it lead to uh a series of different focus groups with um Cambodian and Laos women that do fishing in {location deleted} and what their experience is, so like working together and the challenges of domestic violence, a whole host of different issues that you normally wouldn’t hear discussed uh by this particular community as a result of setting up the framework and infrastructure it allowed them to talk about mental health issues and what it’s like being from Southeast Asia in communities where you are looked upon and issues of racism and different things we often forget that they have to deal with that was sort of one.

My own previous experiences with longitudinal participatory ethnography taught me that revolutionary love of one’s children and the community’s children can serve as powerful catalysts to social action (Guishard, 2009; Hill-Collins, 1998) I was still however, somewhat surprised to reencounter this theme again. Beyond and because of their work and experience with research the members of the BxCRRB felt compelled to act. The second cohort, from my
analyses, saw joining the board as an opportunity to: interrupt exploitation of their neighbors
they could no longer bear witness to, to become better advocates, to amplify community
perspectives, and to initiate dialogue with researchers that thus far they were excluded from
participating in. I interpret this is an instance nepantla perspectives engendering Ubuntu ethical
stances. The board members connected their own negative experiences with research, as
researchers, former participants, current participants, their observations and knowledge of
Bronxites of others, of us, being disrespected in research. What connected these encounters
was/is an external assault on our collective humanness that required action. One board member
specifically identified themselves as hybrid, as a nepantlera—grappling with multiple identities
to research as a physician, former medical administrator, former IRB member and Bronx
resident. While other members do not use these terms they also however echo the sentiment of
having sources of knowledge and experiences that collide—comfortably and uncomfortably,
ways of being that are polyvocal, identities that shift and intersect which inform their
perspectives to research. In the exchange that follows I hear attempts to bridge this polyvocality
(Koegeler-Abdi, 2013) through their work on the board:

P^3: When I worked at the {name deleted} the executive director at the time Joanne
was or ah er she was starting or building her collaboration with Albert Einstein
and she was um one of the community partners that they um engaged in order to
get this Study of Latinos...so it’s this Study of Latinos it’s one of about...four
projects across the country so it was a really big deal to have a site in the Bronx
and at the time I was working with her we started going to meetings with the
principal investigator and um she would give suggestions regarding the
community perspectives I mean ya know this was a clinical study but they would
engage community residents and they weren’t doing it through a hospital I mean
they were they were physically located, creating a study site on {location
deleted} so it didn’t necessarily have the auspices {organizations deleted}[M:
umm hmm] so I ah remember her just making suggestions about how um
patients should be recruited and having it fall on deaf ears [M: umm hmm] so I,
when you know and one of the things she started talking about was a community
institutional review board and I know... was doing some work with {organization
and project director deleted} who is very much about health equity so um I was
really interested. Um because obviously I went on to get a doctorate um or go on for my doctorate I asked did community research review board happen? [M: umm hmm] and he said yes, I was like, he said do you want to know more information and I was like sure I would love to know more because those are some of the issues that um the health equity and community research and making sure that we have um not only um participant ethics at the individual level but also look at the community impact [M: umm hmm] is something that really really really I’m passionate about [M: okay]

P1: I uh for me my story isn’t (inaudible laughs...no no no ...for me it was something different. you know um my friend and I run an organization that we do, we recruit um minorities for government jobs [M: umm hmm] so we um we write resumes and we ah inform them on how to dress and and help them land um jobs within the government ...agencies and then I said you know something I wanted to do something for my community. because everything we’re doing we do it Queens, [M: umm] or in Long Island so I thought this was a good opportunity for me to participate within my community so but everything else I used to do outside of my community so that’s the reason you know I ended up applying for the position

P5: For me it was em......I consider myself very much a hybrid because I’m not academic. I’m not ...completely community but I am in the (inaudible) [M: okay] but eh... in the trenches an eh *coughs* throughout my experience I have been very eh eager to make things happen [M: umm hmm] that why I ended up in medical administration not because I love medical administration [M: umm hmm] but it’s because it gave me the opportunity to do things that without an institution and so on I couldn’t do it and eh um.....there was ah I have little tolerance to abuse and I have seen that in eh a number of eh situations with eh our community, our patients and so on eh just to give some examples... eh why is it that..minority kids are so heavily medicated? [other participants : ummm] and okay they get the labels they get the labels and they are learned disabled or in special ed and so on and for me it’s extremely important to support the parents to really fight [M: umm hmm] even when they fight to fight the educational system to for example they.....um trying to um before it became something so routine...when kids were medicated with eh Ritalin [M: umm hmm] and so on I was pushing for why don’t you try stop the medication during weekends? Or during the summer time? then it became the norm . So for me the Bronx CRRB was really the eh opportunity to really go that step further [M: umm hmm] to eh bring it to the community...

P2: I...that for me it was and still is a personal....um...commitment, to wanting to um....correct the treatment of our residents, my neighbors because at the health center we have seen family members where they somehow ended up in study and they don’t know what they are on [M: umm hmm] or once the study ends their medication ends and they are not able to communicate effectively what they were on or not even understanding ah what happened in the end so for me....ummm what has always interested me about being on this board is that it is community members, Bronx residents and we are having that conversation that many people
I can have that conversation at my job because... I'm a collaborator but to have a researcher here from the community that's a totally that to me is so... hot that I'm like that to be, to have that conversation and that's what's always interested me about the CRRB. [M: okay... did you want to say anything or can I do on to the next question?]

**P6:** I just thought that it was important, in that we could really make a difference.

*Competing visions for the BxCRRB.*

Another major theme that emerged from the focus group concerned competing visions for BxCRRB. The two articles about the board previously discussed were in press at the time and to my knowledge had not been widely shared with BxCRRB members. The article drafts were available via Dropbox, which all members had access to. I was granted access to the original grant for the feasibility project and attempted to find out what the board members knew about the study’s aims versus the direction they envisioned for the BxCRRB as relatively more active participants in scaffolding the infrastructure of the board. The second cohort of the board articulated a mission, vision, and bylaws for the operations of the board. They also devised strategic goals for the upcoming year a short while before the focus group and a steering committee, comprised of four members as a means of expediting consultation with board and the principal investigator between monthly meetings. It is important to note that many of these activities were sanctioned by the academic principal investigator, Dr. Strelnick. Facilitators were paid and volunteered to instruct the board in further developing its organizational capacity. In the original grant the community and academic partners for the board is spelled out:

Our vision for the future is for a free-standing, independent, self-sustaining community research review board that may (or may not) take on full IRB status. We see our board members becoming community members of the Einstein, Montefiore, and other IRBs; participating in research as volunteer subjects and paid consultants, interviewers, and
outreach workers, and speaking out and advocating for better understanding and more appreciation of research that respects and engages their communities (Casado & Strelnick, 2007 p. 7)

From the conversation below it is clear that some members of the second cohort of the board did not share this vision. Some members noted that they would not have joined had they been informed of these intentions. From the conversation below I gather that members were frustrated, given their contributions to cultivating the board, and experience with capacity building about the ostensible lack of planning for the sustainability of the BxCRRB; there is also a shared apprehension about being subsumed by Albert Einstein College of Medicine’s IRB expressed:

**M:** I’m doing a little bit of like immersing myself in the history of the CRRB, right, um and as I understand it they’re two kind of like competing origin stories or maybe visions of what the CRRB should be, right. So one version that I kinda understand is that one person wanted to recruit Bronxites, um, and train them and how to become a community IRB with the hopes that they would that entity dissolve and, and take up positions as the community member of Institutional IRBs [All: um-uhm. Yeah]...and then another version I heard of that story was that it was about recruiting Bronxites to become a C-IRB that was very similar to like how tribal review boards function, is that right? So that it would be like, unattached, umm sovereign...

**P²:** Oh I don’t think this is going to be sovereign, sorry to interrupt you, but I don’t think this is going to be sovereign.[M: Okay]

**P³:** Yeah, there’s no way.

**M:** …So I guess my question, the first part of my question is, what’s your vision for the CRRB? Right. Is one of those three visions, um that I discussed or something else? Or maybe my question should be, “What did you understand when you signed up?” Does that make better sense?

**P²:** Well one of the things I have to say is that when we initially went through and I’m gonna just gonna say it cause I’ve been, I been very upset and angry with the recent event that happened at the Bronx CRRB. Um cause it hasn’t been, there wasn’t a vision and someone who comes from a community based organization a lot of us who have the first things we always talk about is sustainability. How is this going to work out afterwards? And it kills me to learn that there have been people who were in the initial stages of all this, cause this is maybe like the second, the second iteration of a grant or something. And they didn’t think far
enough, I have to tell you that all of us here, cause actually we’re all from the second cohort [All: yeah] so the second cohort I, because of the different recruiting mechanisms or tracks we can in we all had a different idea of what the CRRB was, what was the intent of the CRRB was and what was supposed to be doing its purpose. I didn’t know that I was going to get $50 at the end of a meeting, and that I was going to get a Metrocard. Some people knew a variation of that. So we ended up having to do, that’s why we ended up doing the whole mission and vision because you had twelve people in the room and each of us had a very strong, to some degree, relative idea of what the CRRB was supposed to do. The only origin story that I’ve heard is the first one where the vision of the of Joanne was that it was supposed to be Bronx community members, the 19 year old mom, single mom with the three kids to the 65-75 year old, um, grandfather who just retired. All of these people getting trained on human, you know, um, based, you know, protection of humans in research so that they then can be equipped to be able to be, to ...to hold a community seat in an IRB. Um I have had the privilege of being able to still communicate with Joanne and when I have shared with her where we are now we are totally different to what her vision was because we’re kinda getting to a point where we could become incorporated. I mean we’re working on a mission and a vision, recently worked on bylaws we even started thinking about seed grants or what have you. Totally different from what that vision was.

P3: Yeah

P5: I would like to...background on that...because I feel very much like um, like P2 and um, if that would have been the...the purpose of the Bronx CRBB, I wouldn't have joined.

M: Which one?

P5: The purpose of creating or training people to become IRB members and the reason is and here is where my hybrid knowledge comes. I know how the institution works and the institution really doesn’t have the Midas Touch. Look at what happens with Promotora de Salud that instead of really doing the work in the community they are really co-opted by the institution.

All: It's true.

Our conversation took an interesting turn after Promotoros, health promoters, were mentioned. The board members discussed their shifts, their training, the work they have accomplished, toward becoming the kind community research review board that ideally should have been the experience of the first cohort. From Alejandra’s PowerPoint presentation on the evaluation of the first cohort we all learned that the CRAB expressed frustrations with: the
disorganization of review sessions, the jargon laden documents they were tasked with reading in preparation for board meetings, the scarcity of review sessions and the board’s burgeoning combative reputation among Bronx researchers (Aguirre, 2012; Irving Institute for Clinical and Translational Research, 2014). In the excerpt of the focus group below members of the second cohort discussed their heterogeneity, the diversity of their expertise as strengths. At the same time they expressed a shared discomfort about their current positions, they questioned what can be accomplished given the funding for the BxCRRB is running out and institutional support of their efforts is in doubt. In a short span of time there is rejoicing, passion, hope and despair; this is nepantla:

**P5:** So how many community voices can you have in an IRB? Usually it's one or two people really sitting around all this ten thousand pound gorillas, most of the time, even myself, and I was directing one of the IRBs, um, I couldn't understand what they were talking about. When I reviewed the consent forms I couldn’t understand their English or their Spanish or whatever. *laughs* So the thing is that if that had been the case, I wouldn't have joined. They...I joined the process...and I think that...this cohort really helped move that process towards where I feel that...I feel comfortable. I would like more. I would like more independence. I would pray for us to become a community IRB, but we know that...that is a very long shot. But the thing is there is, eh, a lot of work that needs to be done and it's not just well the, this member and that member and that member but really going out into the community and saying, Okay we can help you with the education about, ok, what does it mean to do health research and what can your roles be on that.

**P4:** You know, just to add on, cause this is where it really gets to, I think, the subtleties about what we’re trying to do here because the initial idea around bringing together people to look at things is great but there was no foresight into when you bring together community, we are not all homogeneous, we all coming from different backgrounds, different perspectives and different experiences on how we relate to or understand the dynamics of different institutions. So, for us to be effective it's gonna be on how we define at we are capable of doing with respect to the given tools that we have that bring forth or that we get provided to us that's what it defines some level of our success but there's many levels and layer of complexities for us to truly be effective cause on one hand it’s, like you said, we sat in and we didn’t know, you said what's your mission, what's the purpose you get like twelve or thirteen different versions but you know we went through a process to really be able to collectively think about how we appreciate what we do and how we can be effective and now we are thinking about what are the practices or the procedures or the ways that we gonna be able to focus in on
what we think is a priority during a given period of time and get that done and then move on to the next because at any given time there’s so many external forces out there that can distract us that make us head in this direction, head in this direction that why we thought it’s so important about here’s our mission, this is our vision and these are the sort of values we bring together that’s gonna allow us to work and move forward and advance the notion of creating an entity that in essence we’re just trying to flip this over so that we don’t have these disparities in the Bronx, so we don’t have all these problems that because a couple of us, or a few of us or all of us what we bring to the table enough experience collectively of intellect to be able to say, we can change these power relationships between these institutions and our communities and stuff. We can make a better Bronx. We can make these disparities...be eliminated. We think we know what can be done to do that and that’s what we’re trying to do.

P2: Can I say one more thing about that? [M: Sure] and that’s what I saw, cause I’ve heard about the first cohort from people who were from the first cohort and like I said from one of the co-PIs that, uh, I’m not really sure what the vision was because, not to say, I think that when you have a 19 year old, people who are already feeling disenfranchised, people who are already feeling stigmatized, people who are feeling vulnerable and then here comes this researcher who is not taking a moment to not, definitely not speaking down, but to try to speak in layman terms that all that discord and whatever that not of...none of what’s happening right now would’ve happened in that first cohort because there was a lot of clashing. I mean I happen to brag about the fact that I’m like, you know, the board that I sit on that we have a doctor and we have a chemist. It’s just that we have to keep reminding the chemist to use his knowledge for the community. *laughing* ...to use his knowledge for the community because it’s, I thinks it’s amazing, I think that’s it, you know, and I and I don’t know again what was that what what brought this group together [M: um-huh] my loved co-members that I’m very happy and proud about because I think that the first cohort if they were around they would go like, Yeah, I think that’s what, I think that what we wanted to achieve, but because they were feeling like some people were talking to them in a in a bad way or they felt like they didn’t have the time or they felt like they didn’t have any expertise even after having gone through the same training that we did they still felt uncomfortable. So to me I feel like you know what I’m...I’m doing this here for myself and for my community but most I’m doing it for that first cohort [M: um-huh] because they didn’t get what they...that’s what we’re having now, I think is what was meant to happen, but that never really happened. I don’t know...

P3: It’s funny I think I can tell you from my perspective and it might be going a little bit off topic off the interview guide, the focus group guide, but I think that um that one of my perceptions was that when we first started doing this work you know I like, P5 had mentioned I was interested in the process I wasn’t interested in becoming a community member of the IRB but I was interested in how to reform a community IRB. I’m a researcher, I’m a student, I’m really interested in that, however when I got there I tried to take a step back because first of all I’m
employed by who I’m employed by so, second of all you know I felt maybe there’s a conflict of interest but let me think about it as being a student at a [name deleted] this can help feed into the type of research I wanna design, I wanna develop for my community so I was like interested, but what I couldn’t get my brain around was this and I know it’s important but the vision and the mission I was like OK we’re doing so much of the planning of who we’re going to be but we’re a, we’re a research study? We’re under...we’re under the Bronx Health Link? You know. And then the discussion of sustainability... It’s so many competing forces so how are we supposed to develop our identity when their saying that we have the capability and the capacity and they’re gonna listen to us but there’s the pessimistic side of me that rug is going to be pulled out. So I don’t know if I took this in a different area than what you wanted to go in but...

P5: Oh yeah, I agree.

P2: And I think basically we’re still defining who we are.

P3: Exactly.

P5: and it’s...I think that its ehh we get one meeting a month and a phone call and so on I think it’s such a drainage of our energy... to be thinking about ok the rug being pulled out and eh...

P3: Exactly.

Visionaries in limbo...

“It’s like one set of glasses you put ‘em on and we’re the research study but the other part...”
—BxCRRB board member, focus group excerpt

The sense that board members were eager to continue the work of the board but were anchored by uncertainty was another prominent theme that emerged from the focus group. Board members expressed feelings of uncertainty about the future of BHL and funds to support the BxCRRB. The exchange below also reflected the fallout of a sustainability meeting the steering committee members of the board, the principal investigator, program coordinator, and interim executive director of Bronx Health Link and I attended approximately two weeks prior to the focus group. The board traditionally had the summer months off, therefore this was the only opportunity to discuss the future of the board many members had in person. Meeting notes were shared via email but some of the elderly members of the board were not able to access them.
the meeting the steering committee inquired about the role of BHL and Einstein in sustaining the BxCRRB’s work in the upcoming year. More specifically, the board members called the meeting to ascertain how much funding remained to support the BxCRRB. They inquired about fundraising plans and whether they would be consulted and/or included in the future plans of either BHL or Einstein. The board was told that they should consider raising funds on their own. BHL’s own solvency at the time was contingent upon procuring funding to secure their operating budget. Without new funds the host organization would begin cutting programs and personnel that upcoming October. Members were told for the first time that the BxCRRB would likely be funded until December of 2014. The status of these funds was however in question as bureaucratic issues, namely the lack of a closeout report delayed NIH fund distribution. We were told that the Bronx Health Link had been paying the stipends, salary for the program coordinator and encumbered other costs to sustain the board which need to be repaid by whatever monies recovered. Dr. Strelnick mentioned that he was diligently working on writing grants wherein subcontracts between Einstein and BHL could be used to support the board. There was shock and anger from the board about being kept in the dark. There was anger about being surreptitiously disrespected and thrust into limbo between being members of an empowered research review board and passive research participants without agency:

**P2:** Uh unfortunately we learned, we learned recently that we know for sure that we are funded until December. What happened to the to the other six months we have no idea what happened to the other six months but whatever, so what has always killed me about this is that it’s almost like we are a fake…well no we’re not we are research…. a fake…we are a fake board because we’re participants so...

**P3:** Yes!

**P2:** We are rats in the maze who are cognizant that we are rats in the maze and that there are other rats and other mazes, we wanna make sure everyone gets their cheese at the end while we’re trying to get our own cheese so that’s why I’ve often
said to P⁵ I that I feel eh not psychotic, what’s the other word? Schizophrenic! And um...

P⁵: I’d rather be psychotic. *All laughing*

M: ...they’re the same...

P²: So we’re doing all this work and we’re spinning and we’re meeting people and just when we had a great event on April 6th, we had the IRB chairman who wants to meet us at Einstein we have other people who are interested in meeting with us and sending researchers to us but ... I come from a CBO, the clock is ticking on funding. And we just learned also on Friday that even for TBHL, their clock is ticking on funding too and they may end up losing personnel in October too, remember when...you were there too, remember? So and they are our current administrative financial conduit to keep us going, so we’re the next best thing since...since sliced bread in the community and the community wants our...our, us and we’re not... And I’m not hearing for me sustainability. How are we gonna continue to function? Because honestly I kinda don’t wanna keep spending time on working on a mission, vision...

P³: Yeah.

P²: ...or even engaging researchers, I don’t care about the money, I just...if we don’t know what’s gonna happen beyond December...

M: There’s so much out of that exchange that I have follow up questions to ask so I’m having a schizophrenic moment trying to like figure out which follow up question I wanna pursue. I guess...

P⁴: We can keep talking if you like.

M: Oh, okay. Well one thing I’m really interested in because, like, I been out hanging out for a while and I’ve been hearing but I’m a research participant, I can’t do that...right... So I’m interested in like the experience of feeling like you’re a participant but also a part of a project where you are supposed to be coordinating particular actions, does that make sense?

All: Yeah

P³: ...and this is, this is a process. They’re going...they’re...they have notes, they did transcripts. They’re going to, the study is the process and the process I feel this has been more about us creating the mission and vision than it is about reviewing research [M: uh-huh] and that is the problem that I can’t reconcile.

P²: I think that so two things; one I’m having a problem that we keep promoting ourselves as a model when we go to these organizations. I, as a model when what eh I went to, the thing that we went with Paco, I was there for other reasons but I was also there, since I was there I double dipped and I sat through the research review board uh presentation that Paco gave and present...he presented us as a
model and because I was in the room Paco then made the mistake of saying well, you know she’s a board member but I said, let me first say this, we are in a research study. So we are trying to understand, we’re developing the model, we’re trying to understand what it is. And then the conversation changes because all all all of a sudden we have all these people who are like wait a second let me take a step back because we’re still in development. [M: uh-huh] It’s not like something you can package. We were sitting there with a community IRB in Los Angeles, Eric Watts’ people, SSGA. We were with John from North Carolina, the…they are a community advisory board and then it was us. And it...and it...and it’s hard for me to say that we are we should stop presenting ourselves as being a model when we don’t even know how we are researching reviewers when we do do it.

P³: Yeah

P⁴: Yeah, I mean, you know I’m in agreement with everything that’s been said, you know um, one, you know, it’s like one set of glasses you put em on and we’re the research study but the other part is knowing that, you know, the sustainability of this does in some sense rest amongst them as starting this but it’s also we have the ability to decide this is the direction we wanna go that we think we wanna advance to. I mean if we wanna go the route of developing, you know, uh organization and having it fiscally sponsored we can do all of that [M: uh-huh] and it just mean it’s gonna like any other organization would get off the ground, it’s gonna take time, it’s gonna take a lot of commitment from a couple of dedicated people to do that and stuff. So in some sense we do have the ability to decide if that’s the direction we wanna go and focus our effort on on doing that. What that means is some of the immediate things we thought about engaging the researcher looking at all these other things gets put on the back burner. [M: uh-huh]

P¹: Yeah but you have to look at do you have the support...

P³: Exactly

P²: Which is...right...which is a thing to give then...I’m gonna answer that ‘cause it answers the ideal question which is I think that what happened also P³ was that because we, there were twelve people who didn’t know what the CRRB was about that’s why I know we went into mission and vision but I’m finding that this...these research participants we are that we are more visionary. We understand there’s a potential to this board to do really great stuff [P³: Agreed] and so we’re visionary and I think that’s what happened to we’re committed and so we’re in a quandary in terms of like so we’re gonna start engaging researcher so they can help us with letters of recommendation, reference letters when we go looking for seed money. Do we keep trying to figure out who we are as an organized entity and in the meantime support is dwindling its ticking away for us and even for the organizing body...
So much has occurred since that focus group in July of 2013. The BxCRRB members met with director of the Einstein IRB that August in an attempt to deepen the connection between the board and the medical school. BHL lost their executive director Mr. Urratia and gained Ms. Hart. The board continued to review research studies about obesity, Parkinson’s disease, and bio-banking. I should not be, but I am still astounded by the breadth of their expertise and resourcefulness. Kevin Montiel also left BHL and since his departure the board has not had a program coordinator. Mindful of this, not wanting to come off as unprepared or unprofessional, in preparation for the bio-banking research review meeting I was asked by the BxCRRB to present a mini-lecture on ethical issues in genetics research in communities of Color. Barbara however, did extensive research. She compiled and distributed a series of articles for the board to read to ensure they could understand genetics terminology and additional hot button issues around ownership of banked tissue, among other topics. Core membership has continued to shrink due to illness, loss of loved ones, conflicts with new positions and a need to just move on. Some of the NIH monies were recouped.

There are intentional and unintentional gaps in my account of this de-colonial ethnography. Intentional elements of the story are withheld because I have refused to engage in a certain level of deconstructing, analyzing, and classifying, people and relationships that are important to me as a means of earning a doctorate. Revealing these missing elements might make my account more understandable. I will not however, disrespect or sacrifice this space to further enlighten the readers of this manuscript. Last Spring, the board members and I, co-presented a symposium at the 13th Annual Conference for the Community Campus Partnerships for Health. Last summer Daniel and I co-presented parts of a paper we are in the process of writing at the inaugural What Went Wrong Conference in Minnesota. BHL paid for the travel expenses of the
board members who were co-presenters. In the past year the steering committee members
developed an ambitious logic model of the board’s future plans and forwarded a draft
Memorandum of Understanding (MOU) to address what they have framed as systematic
disrespect between the Bronx Health Link, Dr. Strelnick, and the board. The MOU was
forwarded in April of 2014 and was formally responded to in writing this December. My own
MOA with the board has expired and I am now a member. We do not receive stipends for
participation any longer. Lunch was still provided by Bronx Health Link for a while, as was a bit
of administrative support but those have also stopped. I have missed two meetings this fall
because they conflicted with my teaching schedule and completing this dissertation; other
members are experiencing similar conflicts. Meetings were in the process of being rescheduled
to reinvigorate board participation but last week we learned that the NIH has asked for monies it
paid BHL to support the BxCRRB to be paid back. It is difficult to predict the future of the
board at the moment. We are weighing our options and are seeking independent funding. It
might be easier for me to help by obtaining a grant through my job at Bronx Community College
but I don’t want my actions in this vein to be considered as an attempt to coopt the board. One
board member was recently asked to join one of Einstein’s IRBs and has accepted the position.
Perhaps the community and academic principal investigators knew that all of this would happen.
In the original grant the board was intended to disband. Board members were supposed to join
institutional IRBs as community representatives. Perhaps Casado and Strelnick (2007) knew that
it was more feasible to subvert the institutional review process from the inside, by having the
BxCRRB dissolve and join other IRBs, than to continue the difficult work to sustain an
alternative to IRBs.
Final Thoughts

Participatory Action Research (PAR) refers less to a method and more to a continuum of approaches to collaborative inquiry. Within PAR, ideally, some phenomenon has been identified as a mutual area of concern to researchers and community members; working together they design, conduct, analyze, and disseminate the findings of a shared piece of research and coordinate action(s) aimed at using research to redress injustice.

Drawing on the work of Chicana feminist theorist Gloria Anzaldúa (Anzaldúa, 1983, 1999; Anzaldúa & Keating, 2002; Keating, 2005, 2006), I began this dissertation by framing the messy, uncertain terrain that participatory research often ventures into as participatory nepantlas. Nepantlas are spaces of confluence between worlds that quite often exist in opposition to each other (like academy and the community). Participatory research occurs in—but also sparks the creation of literal in-between spaces, betwixt and between not just academia and communities but also between race, ethnicity, social class, ability, gender, &/or sexual orientation. The nepantlas of PAR unite people who might never interact with each other outside of participatory research.

Embracing Anzaldúa’s theories further I also positioned people who partner with each other PAR as nepantleras, cultural border crossers. Nepantleras are unconventional architects who are skilled at constructing bridges para nosotras (bridges for us and others; bridges for us all). I conceptualized participatory researchers, as nepantleras, because their work, the onus of PAR, is concerned with both beginning, and sustaining unconventional relationships between research partners.

While working together in partnership, borders that ordinarily divide collaborators are intentionally crossed and demolished. Within this crossing there is a painful and energizing
dismantling. Part of the pain is the deconstruction of the contradictions: the falseness of dichotomies, the multiplicities within us. Within these crossings there is a growing politicized consciousness of the borders imposed, from the outside, forces that are determined to divide us because they are invested in maintaining asymmetrical power relationships in research (Anzaldúa 1987; 2002; Keating, 2005, 2006). Part of the pain is also rebirth and catalyzing energy.

In PAR a new entity, a “we” is formed. This rebirth and unification embodies Ubuntu. Ubuntu is a multifaceted African philosophy and worldview which fundamentally means I am because we are. Recognizing that I am because we are is about understanding what Chuwa (2014) calls “the tension” between individual, community, and universal rights (p. 33). From an Ubuntu worldview I can only understand the world and myself by understanding you. I can only transform unjust conditions by transforming myself and you. Our realities are only transformable together. Threshold spaces, nepantlas, choques, border crossings are all significant to Ubuntu because they are the mechanisms that assist us in perceiving our interconnectedness. Ubuntu teaches us that we are mutually complicit; we are mutually implicated in our intersecting histories. Ubuntu ethical stances push researchers to critically reflect on our values systems for how they impact our theories, our units of analysis, who we include and exclude as potential partners/allies, our selection of research methods, and our ethical conduct. Ubuntu ethics are important because they prevent us from committing epistemological violence (Teo, 2010). In other terms Ubuntu pushes us to critically assess how we are connecting our individual, dispositional analyses of social psychological phenomenon with societal, structural analyses but also how we contextualize the issues under study with respect to history.
I conducted individual interviews with researchers, community partners and members of institutional review boards (IRBs) in an attempt to understand the role that conducting, participating in, or evaluating PAR potentially played in shaping nepantleras definitions appropriate ethical conduct. I also wanted to learn about the ethical quandaries these folks encountered particularly the points of resonance and discordance with existing ethical rules.

Secondly, I conducted a longitudinal de-colonial ethnography of the activities of the Bronx Community Research Review Board (BxCRRB) using a variety of methods: a focus group, fourteen months of participant observations at monthly meetings, retreats, community outreach events, and textual analysis of the project’s archived materials. The primary hypothesis of this dissertation was that the private deliberations, ways of thinking, and practices that nepantleras (the individual interview participants and the members of the research review board) developed to engage in transparent, democratic research, have the potential to be highly informative to conventional ethics because they are less utilitarian and consequentialist. Ubuntu ethical issues such as: concerns about ownership of research data, asymmetrical power differentials between collaborators, the self-determination of our co-researchers, and the social justice implications of study findings are present not just in collaborative research. They are latent in all types of scientific research.

From the interview data I have learned that nepantleras did not eschew research ethics. Nepantleras perceived PAR as: beneficial, conducted with integrity, respectful, and transparent, sparking change/action, genuinely collaborative, equitable/just, not doing harm, and attentive to relationships. I also learned that among my interviewees terms like the academy, evidence, and compliance with institutional rules were less central to their perceptions of ethical PAR. A second finding from this data was that multiple ethical touchstones guided nepantlera ethical
decision making. Conventional ethical guidelines were mentioned but many participatory researchers talked about relying on unconventional sources to teach them ethical imperatives and ways of being. It was largely the work that steered nepantleras to develop Ubuntu ethical stances; to be reflexive, to self-monitor their privilege, power, and promises, to know when they needed to pullback and respect their co-researchers contributions particularly when the world outside or PAR might disregard their work/perspectives. Thirdly, I learned that participatory researchers frequently encountered situations in which the ethical principles and rules they learned in graduate school or from federal guidelines were not helpful in guiding their next steps. I gathered examples of dilemmas around: multiple roles and complicated relationships, quanderies around representation and attempts to subvert participation. In all the examples I heard nepantla and Ubuntu. In all of the examples I recognized attempts to attend to institutional ethical rules while attempting to honor commitments to conduct research ways that respects dignity, multiple perspectives, unusual relationships and a democratic process of knowledge production. Lastly, it seemed difficult for most participants to separate the myriad of strategies they employed to establish, nurture and sustain ethical and equitable research partnership from the actual work. Some tools shared were exercising humility in the form of taking a step back and allowing the community partner to drive the agenda and engaging in constant mostly informal but sometimes formal dialogue with members of the research team about any areas of disagreement and concern.

From the de-colonial ethnography I learned about nepantla ethics and additional insight into Ubuntu ethics. Through the ethnography I learned that Ubuntu ethics involves making “relational accountability” and “reciprocal appropriation” transparent in my work (Chilisa, 2012 p. 22). Relational accountability fundamentally acknowledges that all phases of research, from
proposing questions, deciding methods, data analysis, interpretation and dissemination are all connected. It also means that researchers should be held responsible to their interrelations. Reciprocal appropriation concedes that research, as an enterprise, is a form of appropriation therefore it should be conducted in ways that are mutually beneficial and nurture shared ownership of the process and products of research. I described my collaboration with the BxCRBB as a de-colonial ethnography because I was not detached observer in the project work. I talked about being fully aware of the tensions many community based organizations have with academicians, particularly with research that takes without attempting to reciprocate what was gleaned. My work with the BxCRBB taught me the essence of Ubuntu because I/we are rejecting the norms of interaction and of participation the academy perpetuates; that is our relationship(s) will transcend the results of this dissertation.

The interview and ethnographic data have convinced me, more than ever, that scrupulous obeisance and adherence to IRB rules, professional codes of conduct, computerized ethical trainings, and the best of doctoral research ethics courses does not provide adequate guidance with how to conduct ethical participatory research. Conducting truly ethical collaborative research, embodying relational approaches to ethics like nepantla and Ubuntu is difficult, but nevertheless, necessary work. It involves the construction of tenuous bridges between our moral compasses, between normative ethical theories, principles, institutional review processes and pragmatic, relational ethics. I see this dissertation as the prologue to my life’s work of finding ways to shift the research ethics training discourse to include alternative ethical stances like Ubuntu and nepantla.
This work and its results are limited in many ways. Firstly my understanding of nepantlas and nepantleras was initially restricted to Anzaldúa’s writing in Borderlands. My use of nepantla is divorced from her writing about it as one of a series of several transformational stages of conocimiento (Koegeler-Abdi, 2013). Part of me feels like nepantla is not a category, state of thinking, or identity that can be thrust upon anyone. Part of me feels that it is something that you have to claim for yourself. The results of this dissertation are also limited by small sample size of participants, the recruitment efforts occurring over the summer of 2013 and the fact that there were few degrees of separation between myself and most of the people I interviewed. There are intentional and unintentional gaps in my account of this de-colonial ethnography. Intentional elements of the story are withheld because I have refused to engage in a certain level of deconstructing, analyzing, and classifying, people and relationships that are important to me as a means of earning a doctorate. Revealing these missing elements might make my account more understandable. I will not however, disrespect or sacrifice this space to further enlighten the readers of this manuscript.

I am not as excited about the enterprise of ethics as I was when this journey began but I am still hopeful. This project was a huge, labor of time consuming love. It took me a while to: rein everything in, to realize that this piece of writing did not have to be my magnum opus and to confront my naïve ambitions of decolonizing research ethics in one dissertation. I had hoped that in analyzing the ethical dilemmas that collaborators in participatory and community based research wrestled with while looking to narrow conceptualizations of ethical conduct to guide their footprints would allow me to theorize back to bio-medically centered research ethics. I have written with my friend Eve Tuck (Guishard & Tuck, 2014) that theorizing and/or researching back is not,
about rejecting theories but of critically assessing ideas in order to discern and articulate what aspects do and do not mesh/resonate with our current work. The goal of theorizing back is not resolving sour notes or mending the divergence between what parts of an idea survive reflective analyses and resonate in particular contexts. Theorizing back is about naming and articulating the unlike parts and placing value in the in-commensurabilities. (p. 192)

However, at the time of the writing/speaking there is a part of me that feels that articulating what is incommensurable between IRB centered ethics and threshold Ubuntu ethical positions is just not enough. I yearn to advance some kind of resolution; I wanted to end on am more optimistic note. I had presupposed that excavating nepantlera ethics would provide a more tangible inclusive but at the same time less antiquated, androcentric, racist, sexist, ableist ethical compass for unsuspecting researchers and community partners to use while traveling what can be “tricky ground” in collaborative research (Smith, 2005). In some ways I have accomplished this by unearthing some landmines and suggestions for detours on to terrain that is more respectfully traversed between academic scientists and communities. I am in other respects left with the sobering realization that conducting ethical participatory research that embraces nepantla and Ubuntu ethics while working within the confines of conventional ethics is more difficult to conduct than I could have possibly imagined.
Epilogue

“Life can only be understood backwards; but it must be lived forwards.”

— Søren Kierkegaard

Compañero/as, I imagine that you are reading this dissertation because you were interested in participatory and or collaborative research ethics. I also imagine that you are reading it because you are in the midst of a dilemma or dilemmas and are searching for examples of how other nepantleras have surmounted them. Part of me feels like this manuscript ended on pessimistic note. It does, but I try every day to be hopeful. I have decided to write you a letter to further explain myself. I remember how meaningful Gloria Anzaldúa’s letter to third world women writers was to me (Anzaldúa, 1983) and I want to pay her generous, vulnerable offering, forward. My theory of change at the beginning of my dissertation journey was perhaps what contributed most to my pessimism. I presumed that illuminating the insufficiencies within deontological normative ethical paradigms, would be enough to spark a debate and action about how this enterprise needs to be revolutionized. I hope that I have convinced you that your CITI ethics training, the work that you have accomplished in your graduate research ethics class, and what you have learned from undergoing the IRB review process, are all important—but they are not enough gente. I want to encourage you to reread Beauchamp and Childress (2001), Sales and Folkman (2000), and the Belmont Report (US DHHS, 2005) through the lens of a participatory researcher. I want you to read those texts alongside many of the counter-hegemonic and de-colonial critiques of research that can be found in the literature review of this manuscript. Sara Banks, Caitlin Cahill, Bagele Chilisa, Cynthia Chataway, Michelle Fine, Linda Tuhiwai Smith, and Eve Tuck’s work are all necessary readings companero/a. I want to ask you after all of this reading to think about whether research is the activity that you want to engage in
(Tuck & Yang, 2014). Unfortunately there are more questions I want to encourage you to ponder like: Why participatory action research? Why this approach to inquiry? Do you think PAR is a method? Regarding the issue you have decided to focus on, what is your relationship to this problem? How do you see yourself in this work? In the literature? With respect to approaching potential community partners, who are you to them? Are you an outsider, insider, insider-without, or an outsider-within? I want you to think about what they know that you don’t. Ask them or research the work that they have accomplished. Document their lived expertise. Think about who else needs to be in the room if you were to schedule a meeting to talk about collaborating. Please also think together about who might need to be excluded/not invited for now. Please ponder what is the work and what will be the actions. Companeros, what are your units of observation and analyses? Really ask yourself whether you have committed epistemological violence (Teo, 2010.) Please discuss, reflect, and discuss some more, what the collaborators theories of change are and your plan to transfer sufficient skills so that you are no longer needed apart from future consultation. Don’t just think about the ways in which you might not intend to harm, to tread on the dignity of your partners companero/a. Be demonstrable in your ethical practice; be genuine, trustworthy, and develop shared means of evaluating transparency, shared power, shared resources and the benefits of this work. I know this sounds onerous. I am actually okay with contributing to making participatory research harder to conduct particularly in communities that are over-researched. You can do this companero/a! I have not met you yet, but I believe in you. I only ask that you remember that de-colonial stances to research requires de-colonial ethical theories and practices.

¡Nos Vemos Pronto!

Monique
Appendix A. Interview Protocol

Greeting:
Thank you so much for consenting to participate in an interview about your experiences conducting, participating in or ethically evaluating collaborative and/or participatory action research. As I mentioned in my email/or in our previous phone call, this interview is expected to last between 30 minutes to an hour. I will ask you some questions about your experience with collaborative &/or participatory research and about any ethical dilemmas encountered while conducting, participating, or ethically reviewing this type of research. I would also like to learn about any practices or activities people have used/developed to sustain ethical relationships between collaborators in research. During our interview, if this is okay with you I will take some notes of the things you say and will also audio record the interview in order to record the details accurately.

In my experience as a participatory/collaborative researcher discussing the details of a research project with an outsider sometimes means revealing intimate and sacred; I want to assure you that I deeply appreciate your willingness to talk to me; though I am recording our interview today I will be the only one who listens to and transcribes it. After I’m sure I’ve captured everything accurately I will delete the recording and remove any identifying information from the transcripts and share text of the transcripts with my advisor and two student researchers.

I know I’ve just said a mouthful and I repeated a lot of the text of the consent form, but do you have any question for me or about the nature of the study before we begin?

Views of Participatory and/or Community Based Research

1. Tell me about your experience with participatory and/or community based research.
   a. Tell me about a project you’ve been involved in and your role in it.

2. Sometimes I have difficulty explaining to people exactly what PAR/CBPR research is and what it entails. On that note, if someone on the street came up to you and asked you to describe what participatory research is what you would say to them?
   a. What would you say about the aims of this type of research?

3. What do you think are some of the benefits of PAR over other types of research?
   a. What are some challenges to participating in PAR?

4. What does the P in participation mean to you or stand for to you?

Views of Ethics in Research

1. What guides or informs your understanding and practice of ethics in research?
2. I’d like to ask you what being ethical in research means to you but that seems like a really HARD thing to answer…in a coherent way. Instead I would like to ask you to look at this Wordle. If you had to make a world salad/Wordle like this what would it look like?

![Wordle Image]

a. Which words would be LARGE/most important in your Wordle?

b. Which words would be smaller and less significant?

3. What do you think are some ethical issues that can arise when conducting Participatory Research?

ONLY READ IF SOMEONE REQUESTS AN EXAMPLE

a. If I may give an example; several years ago I directed a PAR project that investigated the ways in which grassroots parent organizing on the academic achievement gap nurtured critical consciousness among poor and working class mothers, fathers and grandparents in the South Bronx. I collaborated with five youth researchers to design, conduct, and analyze oral history interviews of parent activists, many of whom were the youth researchers’ family members. Toward the beginning of the project I remember hanging out at the community based organization that sponsored the project and meeting one of the parent organizers. A week prior I had read an article which detailed this young woman’s efforts to organize tenants in her building to withhold rent until their landlord agreed to schedule and complete much needed repairs. She asked me for an example of the kind of participatory research we were hoping to conduct. My own project was being still being developed so I told her about Dr. Caitlin Cahill’s Fed Up Honeys (http://www.fed-up-honeys.org/) research group. Within the Fed Up Honeys group youth researchers created stickers that featured stereotypes about young women of color. The intent of the stickers and their stereotypical messages was to spark conversation, upset young women but at the same time inspire young women to defy them. I’ll send you the link if you’d like to see the stickers but basically they said stuff like: In abusive relationships, burden to society, lazy and on welfare, likely to become teen moms, and uneducated. I had some of the stickers with me while I was talking so I pulled them out. The young mom took them from me and started to stick them on her very pregnant belly while saying that she thought most of the stereotypes were true about her.
It was a moment I’ll probably never forget. How do I write about this I remember thinking. What did this observation teach me about the theories I was trying to understand? Did I have the right to include this observation as data? Who was I in that moment? Was I a researcher, a fellow Bronxite, a casual acquaintance, a potential friend? Would including this story disrespect the dignity of this fierce insurgent young activist even if I never used her name? Would this observation re-humiliate this young woman of Color in a world that already views her as damaged? How would my writing about this affect my relationship with the organization and the sense of trust I worked so hard to build? How can I and should I ask her permission to retell this story?

If you were in this situation what would your understanding of ethics in human research guide you to do?

4. I have experienced many moments while conducting participatory research when I felt I was in the midst of a quandary or a critical decision in which the ethical principles and rules I learned in graduate school or from the IRB were not all that helpful in guiding my next steps. I suspect many action researchers have encountered similar dilemmas because or work centers around relationships. My experiences and that of many of my colleagues have motivated me to collect and analyze stories of tricky ethical situations. I’d like to ask you to share an ethical quandary you’ve faced in your own work. A time when you felt confused maybe or unsure of what to do regarding writing, presenting, trust, relationships, accountability, responsibility or anything you’re comfortable sharing. You may of course be as vague or as specific as you like. If places and names are mentioned I will replace them with pseudonyms to respect your contribution and right to privacy
   a. If this seems difficult to answer off the cuff you can of course email me a response later it you’d like.

5. Why do/did you consider this situation you shared an ethical quandary?

6. Was your ethical dilemma resolved? (Please elaborate) If not why? Please include any tools or ways of understanding you might have developed as a result of this work.
   a. For example my colleague Dr. Sarah Zeller-Berkman has done a lot of writing about memorandums of agreements. She thinks about them as a living, evolving document that outline the goals of a project and the role of all of its participants. I’m interesting in understanding what other tools or activities maybe that PAR researcher and participant researchers have used to improve their collaboration.

7. What kind of ethical training have you completed in order to conduct in research?
   a. What is your opinion of this (these) training(s)?

8. What are your thoughts about the strengths and weaknesses of established ethics review processes for dealing with the quandaries you mentioned before?
a. If perceived inadequate move on to next concluding script.
b. If perceived inadequate ask → If you could imagine a different kind of human research ethics review process what would it look like?
c. If you could make changes to research ethics education would you change or add?

Thanks again for your participation. I just have a few background questions for you to answer that would help me compare the responses of different groups of participants.

1. You are:
   ___ A graduate student researcher
   ___ An experienced academic researcher
   ___ Please specify your field of expertise____________
   ___ Staff of a Community Based Organization
   ___ A member of a Tribal/Indigenous Research Review Board
   ___ A member of a Community Based Organization
   ___ A member of a Community Advisory Board or Ethics Review Board.
   ___ Other

2. Have you completed any type of ethical trainings in order to participate in research? ___ Yes ___ No
   a. If Yes please specify the type of training you completed:__________________________

3. You are
   ___ A woman
   ___ A man
   ___ Transgendered
   ___ Non-gender conforming
   ___ Other
4. What is your race and/or ethnicity? (check all that apply).
   ___Black or African American
   ___White
   ___Latino/Latina or Hispanic
   ___Afro Caribbean
   ___Middle Eastern
   ___Native American, American Indian, or Alaskan
   ___Asian, South Asian, or Pacific Islander
   ___Other (please specify) ____________________

That was my last question! I can’t thank you enough for agreeing to participate and for helping me gather a much needed insider perspective on ethics in participatory and/or community based research. I’ve tried to ask pointed questions, that weren’t too long but I might have left some things out. Would you like to ask me a question or add anything you thought I left out?

If you would like a copy of the study, please provide me with your address and I will send you a copy in the future. If you have any questions about this research, you can contact at the number and email I provided on the information sheet. You may also contact my advisor, Dr. Michelle Fine at (212) 817-8710 or Mfine@gc.cuny.edu. If you have questions about your rights as a participant in this study, you can contact Kay Powell, IRB Administrator, The Graduate Center/City University of New York, (212) 817-7525, kpowell@gc.cuny.edu

Thank You Again. Be Well
Appendix B. Letter of Intent with the BxCRRB

Date: January 14th, 2013

TO: The members and staff of the Bronx Community Research Review Board (BxCRRB)

RE: Letter of intent to establish a mutually beneficial collaborative research relationship

Greetings members of the Bronx Community Research Review Board (BxCRRB): Shaking Alston, Michael Burke, Heddy Fox, Russell Gordon, Daniel Korin, Yvonne Long, Bianca Lopez-Bakke, Karen Nation, Barbara Salcedo, Julius Torres, Bernice Williams, Kevin Montiel, Sandra Rodriguez, and Dr. Alvin Hal Strelnick,

After I presented at the board meeting last November I agreed to draft a Memorandum of Agreement, which would clearly articulate the purpose and scope of a mutually beneficial collaborative research partnership between myself and the members and staff of BxCRRB. In brief terms, I would like to facilitate two focus groups with BxCRRB members primarily about their attitudes and opinions regarding what it means to be ethical in community based health research. I would also like to conduct participation observation of the practices and activities of the BxCRRB. Participant observation is a research method in which a researcher does not merely observe and document a group’s practices and activities, but also participates in the group, working toward becoming a potential member, in order to gain a deeper, nuanced understanding of the group. In other terms, I would like to learn about the many perspectives and activities of the Bronx Community Research Review Board by observing and participating in meetings and events. Whether facilitating focus groups or observing an activity, I will always respect the dignity, rights, privacy and self-determination of the BxCRRB. In exchange for the Bronx Community Research Review Board members’ assistance in collecting information that will be used in my doctoral dissertation and academic publications, I offer my services as a writer, researcher, conflict mediator, exit-interviewer, and educator to support BxCRRB’s many scholarly and community outreach pursuits.

In my many attempts to compose to a MOA I referred to colleagues, my advisors, indigenous research review boards and other sources for existing examples of similar agreements that might guide my writing, only to be disappointed with the distant, cold, legal and jargon rich wording of many of these examples.

Attached is my imperfect, one-sided attempt at spelling out the terms of our proposed collaborative research partnership. It is imperfect and one-sided because it is not co-constructed and only represents my individual academic intentions. My draft is intended to be followed up by revised goals and responsibilities identified by members of the BxCRRB, working toward establishing a shared vision of our collaboration.

Monique Guishard

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Appendix C. Memorandum of Agreement

I. The purpose of this Memorandum of Agreement (MOA) is to clearly delineate the roles and responsibilities of Monique Guishard, members of the Bronx Research Community Review Board (BxCRRB), the Principal Investigator, and Program Coordinators in achieving a mutually beneficial and transparent research partnership.

II. Time Frame

This agreement is effective as of _______________ and is valid for a period of one year, approximately until _______________________. When this agreement expires it can be renewed and revised with the consent of all parties.

III. Monique’s Dissertation

My doctoral dissertation aims to explore what it means to be ethical in research from the perspective and practices of different stakeholders in community based participatory research, and from the unusual spaces that collaborative research travels to. I plan to use focus groups, interviews, participant observations, and anonymous reflections to understand how researchers, community partners, participants, members of community research review boards, and/or members of institutional review boards’ experiences conducting, participating in, or evaluating research shape how they define what is and is not appropriate ethical conduct in research. Overall I hope to collect data from:

A. 24 in person and online interviews:
   a. Eight interviews with participatory and community based researchers from multiple academic disciplines
   b. Eight interviews with community-based/nonacademic research partners.
   c. Eight interviews with current or former members of human research ethics review boards

B. Three focus groups:
   a. One with participatory &/or community based researchers from multiple academic disciplines
   b. One with community-based/nonacademic research partners.
   c. One with current and/or former members of human research ethics review boards

With respect to the Bronx Community Research Review Board (BxCRRB) it is my belief that perspective of a community based research review board is missing from my proposed analyses. I believe that people who collaborate with each other to evaluate community based research possess an intimate perspective on human research ethics that is different from that of members of institutional research review boards (IRBs). I believe that this perspective is different because it is rooted in lived experiences with research, with disparities and born from frustration with how researchers have historically treated people of color, poor and working class folks, the LGBTQIA community, prisoners, and disabled folks in research. It is my position that if gathered and analyzed the deliberations, negotiations, and activities of a community research review board can teach social scientists much about ethical conduct in research outside of IRB
centered ethical guidelines, research ethics classes and computerized research ethics trainings. My primary hypothesis is that analyzing the work of community based ethical review boards and of community based scientists has the potential to teach academic scientists about how to address ethical concerns about ownership of research data, interpretation of research results, self-determination of research participants/community groups and social justice that are present in all types of scientific research.

The title of my dissertation is “Nepantla Ethics Para Nosotros” which means “In-betweener Ethics For Us and Others.” Nepantla is an Aztec word that roughly translates to mean a third space, a space between worlds. Philosopher Mariana Ortega (2010) teaches us that nepantla is

“A space where one is not in one place or the other, one country or another, where countless travelers go through….but nepantla is not just a spatial region where faces are inspected, passports displayed; it is the very experience of those who live and in between life they are multi-cultural, multi-voiced, multiplicitous, because their being is caught in the midst of ambiguities, contradictions, and multiple possibilities.

(p. 79)

In many respects the staff and members of BxCRRB are nepantleras. Nepantleras are “cultural border crossers” people who know what it means to live between worlds---worlds that might be combative and in opposition to each other (like living and working in the academy and in communities at the same time; some people find it is difficult to serve the interests of both equally). Nepantleras also live between identities (academics, community organizer, person of Color, poor and working class, queer, feminist etc). Nepantleras are unconventional architects, people who live on the verge, who are skilled at constructing bridges para nosotras (bridges for us and others, toward a collective we). I think about the members of BxCRRB as nepantleras because the work of this board, as I understand it, is about trying to start and sustain unconventional relationships with academic researchers and the residents of the Bronx in a world that too often seeks to divide scientists from people who live in the communities they serve. The work of BxCRRB as consultants and gatekeepers can assist researchers in interrupting historically exploitative and oppressive relationships between the academy and people from economically and politically disempowered groups. To be clear here, I am interested in capturing moments when the board advises and ethically evaluates the work of researchers like Abby Batchelder and Gabrielle Long; within this context the BxCRRB functioned as nepantleras.

The Bronx Research Review Board is also a nepantla, a literal in-between space, betwixt and between the geographic community of the Bronx, between regular folks and academic scientists in which people from different walks of life, different types of expertise, and varying identities join together to discuss and evaluate research that is being proposed and conducted in their backyards. I am interested in learning about how people with particular experiences and histories think about human research ethics, BUT I am also deeply interesting in learning about nepantlas; spaces that are bridges/thresholds between different identities, spaces that are like jazz: a mixture of sounds that are dissonant and jarring but together make a beautiful harmony. I suspect my desire to understand the BxCRRB as a Nepantla may be confusing so I’d like to
include an example from the last meeting. If you all recall I asked the board members if I could have permission to take a picture of the community agreements because they represented, from my perspective, an example of a *Nepantla* ethical artifact or tool. Researchers need to see and learn from tools like this, which are developed to: ensure respect, transparency, shared values and accountability in collaborations. I hope to learn about and document many other *Nepantla* artifacts.

**IV. Questions and Research Methods**

Through our potential collaboration I would like to conduct participant observation and audio taped focus groups with members and staff of the Bronx Community Research Review Board to explore and attempt to answer the following research questions:

1. What can the reflections of the members of a community based ethics review boards teach social scientists about human research ethics outside of academic IRBs?
2. What can nepantlas and nepantleras teach researchers about ethical concerns regarding ownership, interpretation, self-determination, rights, and social justice that are present in all scientific inquiry?
3. What tools, ways of thinking, and guides do community ethical review boards use to both establish sustain ethical relationships between collaborators?
4. What potential do these beacons hold to improve transparency, balance power, develop shared conceptions of respect and accountability in collaborative research?

Focus groups are a research method in which a researcher or a member of a group moderates a group discussion about a topic. A focus group is similar to an interview but it is different. The emphasis is not on individual people but on capturing a diversity of perspectives within a group. I would like to conduct two focus groups with the members of the BxCRRB about their: perceptions of ethics in health research, experiences reviewing protocols, and experiences with research as participants. I would also like to attend meetings and board presentations to learn about the BxCRRB’s: history, goals, and collaborative process about the tools and ways of thinking that have been developed to sustain ethical relationships between
board members. In writing this I realize that much of this research might have been collected by former program coordinators and by evaluators thus I am also requesting permission to reread and analyze interviews and focus groups that have already been conducted by other parties. I do not want to waste time or valuable resources in asking questions that might have already been answered.

V. Risks & Benefits

The risks from participating in this study are minimal, meaning that they are no more than what is normally encountered in everyday life. It might be upsetting for some people to discuss the challenges they encountered while participating in or while reviewing research. As compensation for participating in focus groups with me I will provide board members dinner and reimburse travel expenses. Beyond these small benefits the information gathered from focus groups and participant observations will help me gather a much needed insider perspective on what it means to be ethical in collaborative and community based research. My writing (alone or with the members of the board) about our collaboration will directly contribute to the scarcity of knowledge on this topic and help researchers improve their practice.

VI. Assurances

I will write up field notes. I will listen, transcribe, and store all recordings on a password protected iPad mini. I will never use anyone’s real names or any identifying information about any of the members of the BxCRRB unless the group would like me to quote them directly. After I transcribe and verify the accuracy of the audio-taped focus groups, original recordings will be deleted and all potentially identifiable information will be removed from transcripts and substituted with pseudonyms. Interview transcripts stripped of identifiers will be backed up on an encrypted external hard drive with secure padlock pin access.

My doctoral advisor (Dr. Michelle Fine) and my dissertation committee members (Dr. Martin Ruck and Dr. Caitlin Cahill) will be the only people who will have access to the text of the recordings in order to guide my analyses. The data will be retained for a minimum of five years after study results are published, or at least three years after project completion if the study’s results are not published, in keeping with the ethical guidelines detailed in the 6th edition of the American Psychological Association’s Publication Manual.

VII. Interpretation

Whether facilitating focus groups or observing an activity, I (Monique) will always respect the dignity and rights of the BxCRRB. I promise to share my interpretation of the focus group data with the members of BxCRRB. If, for some reason, the group disagrees or has a different interpretation of my findings I promise to include both my interpretation and interpretation and that of the board’s in any academic writing. If I use the focus group data in any academic papers I promise to present a draft to the BxCRRB prior to submitting it for publication for review and with the goal of incorporating the board members’ perspectives.

VIII. Reciprocity in Collaboration
In exchange for the Bronx Community Research Review Board members’ assistance in collecting information that will be used in my doctoral dissertation and academic publications, I offer my services as a researcher, conflict mediator, exit-interviewer, and educator to support BxCRBB’s many scholarly and community outreach pursuits for one year to commence after the BxCRBB has reviewed, revised and articulated the specifics of its’ collaborative needs and planned activities that I may be helpful in.

By signing below, the parties listed enter into this memorandum of Agreement.

**Board Members**

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<td>ShaKing Alston</td>
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**BxCRBB Staff and Advisors**

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<td>Outgoing Program Coordinator, Sandra Rodriguez</td>
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<td>Incoming Program Coordinator, Kevin Montiel</td>
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<td>Principal Investigator Dr. Alvin Hal Strelnick</td>
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<td>Monique Guishard</td>
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Biblography

http://www.einstein.yu.edu/about/


Banks, S., Armstrong, A., Carter, K., Graham, H., Hayward, P., Henry, A., Holland, T., Holmes,


http://www.bronxhealthlink.org/tbhl/about/


Driscoll, A. (2009), Carnegie's new community engagement classification: Affirming higher
education's role in community. New Directions for Higher Education, 5–12.

doi: 10.1002/he.353


Guishard, M. (2005). *See some people they don’t have…the people or the organization who’s interested to educate people and to let them know what does justice mean: Lived critical consciousness within and across contexts: Community organizing and participatory research.* (Unpublished master’s thesis). The Graduate and University Center, New York.

Guishard, M. (2008). *Participatory and community based research ethics: Lessons social*
psychologists can learn from environmental health researchers and environmental justice organizers. (Unpublished second doctoral thesis). The Graduate and University Center, New York.


Schwandt, T. A. (2007). The pressing need for ethical education. A commentary on the
growing IRB controversy. In N. Denzin & D. Giardina (Eds.). *Ethical futures in qualitative research*. Walnut Creek, CA: Left Coast Press. (pp. 85-97).


public science. In H. Cooper (Eds.) APA handbook of research methods in psychology
(Vol. 2: Research Designs: Quantitative, Qualitative, Neuropsychological, and
http://dx.doi.org/10.1037/13620-011

Keating (Ed.). Entremundos/Amongworlds: New perspectives on Gloria Anzaldúa (pp.


culture. In J. Trimble and C. Fisher (Eds.). The handbook of ethical research with
Publications.

79(3), 409-427

Tuck, E. (2009b). Re-visioning action: Participatory action research and indigenous
theories of change. The Urban Review, 41(1), 47-65.

Tuck, E. & Guishard, M. (2013). (Un)collapsing ethics: Racialized sciencism, settler
coloniality, and an ethical framework of de-colonial participatory action research. In T.
Kress, C. Malott, & B. Porfino (Eds.). Challenging status quo retrenchment: New
directions in critical qualitative research (pp. 3-27). Charlotte, NC: Information Age
Publishers.

Tuck, E. & Villegas, M. (forthcoming). A statement on research that takes place on
indigenous land.


http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html


http://ohsr.od.nih.gov/guidelines/45cfr46.html


http://www.hhs.gov/ohrp/international/intlcompilation/intlcompilation.html


