Researcher Trustworthiness in Community-Academic Research Partnerships: Implications for Genomic Research

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Abstract

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For many communities, health research exists on a backdrop of distrust of research institutions. Decades of harmful experiences across many types of health research have contributed, including studies of genetics, infectious diseases, therapeutic drug trials, social-behavioral phenomena, and environmental exposures, such as unconsented exposure to radiation in Alaska Native communities. In addition to historical harms, ongoing policies and norms signal disrespect and untrustworthiness to communities that might otherwise be interested in research.

Distrust born out of this harm has led to a lack of participation in health research, which threatens to deny these communities potential benefits from large public research investments, and to increase existing disparities in health and health care. However, research is often

recognized as potentially beneficial to communities, and many communities would like to participate on their own terms.

Novel approaches to research with communities have developed in recent decades, founded on the idea that the affected or studied community should be an equal partner in the research. Community-academic partnerships taking approaches such as community-based participatory research (CBPR), have become increasingly prevalent, and funding for large clinical research programs, such as the Patient-Centered Outcomes Research Institute (PCORI) have stipulated that grantees have community co-investigators in their studies.

Throughout the community-academic research partnership literature, building trust is seen as essential to meeting partnership goals, and to upholding CBPR principles. Given the checkered institutional history, academic researchers hold a responsibility to cultivate their own trustworthiness with regard to communities, in order to build trust and start to overcome these barriers. Few partnerships have described how they have built or evaluated trust and even fewer have described researcher trustworthiness in their partnerships.

I employed a mixed-methods approach to address three key aims: 1a) To characterize trustworthiness within community-academic research partnerships, and b) to identify institutional barriers to trustworthiness encountered by such partnerships, and approaches taken to overcome those barriers; 2) To develop a measure of researcher trustworthiness in community-academic research partnerships; and 3) To identify opportunities to cultivate trustworthiness within a case of genetic research, APOL1 testing for End-Stage Renal Disease risk in African American communities.

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DEDICATION

This work is dedicated to all those who are working on the ground to improve community health, promote respectful community engagement among institutions, creatively navigate community and scientific cultures for direct community benefit, and to keep us honest.

Chapter 1. INTRODUCTION

1.1 BACKGROUND

1.1.1 *Legacy of harm and distrust*

"Research is a four-letter word." (Ball & Janyst, 2008)

Biomedical research has led to vast improvements in life expectancy, morbidity and mortality in the last century. However, these advances have relied, in part, on research conducted with varying degrees of ethical oversight and accountability. Questionable research practices have included exploitation of some populations for the benefit of others, deliberately in some cases, and more implicitly in others (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999). These studies were often conducted with minority or vulnerable populations, often involving deception, inappropriate or harmful practices (Beecher, 1966) and led to a persistent legacy of distrust.

Table 1.1 summarizes several key cases of health research that have contributed to this legacy of distrust, including harms to the physical body, as well as dignitary, cultural, and economic harms. This distrust of research may have been augmented by distrust of health care systems that have not always benefitted patients. For example, many women who accessed health care through the Indian Health Service were deceived into receiving involuntary sterilizations in the 1960s and 1970s (Lawrence, 2000). There is well-documented distrust of health care systems—whether they conduct research or not—among many minority communities, due to harmful research as well as associations with institutions perceived to be untrustworthy (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Kennedy, Mathis, & Woods, 2007).

Table 1.1. Examples of research that resulted in harm to the community being studied.

Study	Community	Research Institution	Type of research	Harmful outcomes	Study dates	References
Havasupai: genetics studies	Havasupai Tribe, of Supai Arizona	Arizona State University	Genetic research; Diabetes, and then other topics.	Data used without consent for broader topics; stigma and contrary to cultural beliefs. Multiple law suits; 8 major claims.	1989-2003	(Dalton, 2004)
Nuu-chah-nulth: genetics studies	Nuu-chah-nulth First Nation, British Columbia	University of British Columbia, Univ Utah, Oxford Univ	Genetic research on rheumatoid arthritis.	Data shared without consent; focus on individual over community ownership conflicted with community's values.	1980s	(Wiwchar, 2004) (e.g. Atkins et al., 1988)
Barrow Alaska: alcohol use study	Barrow, Alaska	University of Pennsylvania	Evaluation of village administration's alcohol program.	Despite community concerns with study methods, researchers publicized stigmatizing results; led to decrease in town bond rating.	1979-1980	(Foulks, 1989)
Karitiana: genetics studies	Karitiana Indians, the Amazon	U.S. researchers, non-profit Coriell Cell Repositories	Genetic research.	Researchers never delivered promised medicines to the community; allegedly sold samples for profit.	1970s, 1996	(Rohter, 2007)
U.S.P.H.S. Syphilis Study at Tuskegee	Black men in Macon County, Alabama	U.S. Public Health Service	Natural history of an infectious disease, syphilis.	Deception; withheld treatment of black men with syphilis, despite the discovery of penicillin.	1932-1972	(Gamble, 1997; Gray, 2013)
U.S. Arctic Aero-nautical Laboratory Thyroid Function Study	Alaska Natives from 7 communities	U.S. Air Force	Radioactive iodine used to study role of the thyroid in cold acclimatization, as part of Cold War effort.	Individuals given radioactive iodine without consent; deceived to believe that the pills would improve their health.	1956-1957; surfaced in 1993	(National Research Council, 1996)
Henrietta Lacks case	African American populations	Johns Hopkins University	Cell line developed for wide range of studies.	Tissue taken without consent from a black woman in a segregated hospital; used for many health care advances over decades, while her family has limited health care access, little benefit from these research advances.	1950s-present	(Skloot, 2010)
U.S.P.H.S. Sexually Transmitted Diseases Inoculation Study	Sex workers, prisoners, mental health patients in Guatemala	U.S. Public Health Service	Sexually transmitted disease prevention.	Purposeful and deceptive infection of vulnerable populations. No informed consent, and withheld known treatment.	1946-1948	(Rodriguez & García, 2013)

While these cases would fail to meet today's ethical standards, many of them were not considered outside of the standards for research at their time. Nevertheless, when brought to public attention, they sparked a reevaluation of these standards. In some cases, the communities and researchers involved did not share common expectations for the research, although the researchers may or may not have been aware of the community's views. Research standards have shifted over time, as have social norms, and communities have also responded by taking more control over the approval of any research conducted with their members. Still, researchers and communities operate under different sets of knowledge and worldviews that influence their expectations, interpretations and values within research. The impacts of these differences can only be anticipated with deep, on-going relationship-building, and lacking this, may lead to further harm and distrust.

1.1.2 *Participation rates, outcomes of low participation*

The distrust among minority communities in biomedical research is associated with a reluctance to participate (Braunstein, Sherber, Schulman, Ding, & Powe, 2008; George, Duran, & Norris, 2014; McDonald et al., 2012). Lack of participation is particularly prominent in genetic research, likely related to research missteps in well publicized studies like the Havasupai case, resulting in a diminishment of institutional trustworthiness (Johnston, Banerjee, & Geller, 2015). For example, in 2002, the Navajo Nation instituted a complete moratorium on genetic research with its members, in response to genetic studies conducted elsewhere, without community consent (Garrison, 2013). The low diversity of participation is evident in currently available genomic datasets, for which study participants are overwhelmingly of European descent. A review of genome-wide association studies (GWAS) showed that 96% of such studies were limited to European ancestry, which raised awareness of the issue (Need & Goldstein, 2009). Since then, there has been some increase in sample diversity, but a more recent review has shown improvement in minority participation to be minimal, with most of the increase attributed to the recruitment of participants of Asian ancestry (Popejoy & Fullerton, 2016).

There are scientific reasons for wanting to diversify participation in health research in general, including identifying a broader range of human variation in disease, genetics, and phenotypes, to understand disease mechanisms. These insights could inform new potential treatment targets, for individuals within a biomedical model, community-level interventions or policies for population health. Greater diversity in research means greater potential for understanding disease and advancing medical practice.

There are also ethical concerns regarding lack of minority participation, as there are biomedical implications for population differences. While self-identified race does not track reliably with genetic ancestry due to admixture and the social nature of racial identity (Mersha & Abebe, 2015), there are rare variants that are more prevalent in or unique to some ancestral populations, that show up in racially defined groups. Such population-specific genetic variants will not be identified in those ancestral populations that do not participate, and any medical advances that would develop from such research in European-ancestry populations will not benefit individuals of non-participating ancestry groups. For example, pharmacogenetic studies have demonstrated that population-specific variants have important implications for individuals' medication dosing needs. Studies of warfarin treatment response genotypes with Yup'ik and African-American populations have found variants that are private to these populations, and common variants that are uncommon in other study populations (Fohner et al. 2015; Cavallari and Perera 2012). As a result, genetic tests based on research in largely European-American populations lead to a greater likelihood that minority populations will receive uninterpretable genetic test results known as variants of unknown significance (VUS) (Forman & Hall, 2009), or worse, be harmed by the clinical use of genetic results that inaccurately represent an individual's genotype, as found in the COAG trial of genotype-driven warfarin dosing among African Americans (Kimmel et al., 2013). The lack of usable data could potentially exacerbate disparities within health care (Sankar et al., 2004). Further, studies that do not account for specific experiences and environments of minority populations will result in inaccurate research interpretations and could heighten stigma or beliefs of genetic determinism.

Thinking beyond genetics, research into community exposures and other social or environmental factors, paired with action, could potentially reduce health disparities. Health disparities in minority communities have gained recognition and are widely considered to be unjust (WHO Commission on Social Determinants of Health, 2008). Approaches to reducing health disparities require attention to the range of social and environmental factors experienced by these communities (Braveman, Egerter, & Williams, 2011; Marmot & Allen, 2014). Lack of participation in relevant research may contribute to a failure to eliminate health disparities.

1.1.3 *Community-academic research partnerships*

One approach to overcoming lack of community participation in research is partnering of researchers with communities on studies that matter to the community members. Community-based participatory research (CBPR) is one such approach often described in health research. CBPR has been defined as:

> *A collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and wellbeing through taking action, including social change.* (Viswanathan, et al., 2004)

Key aspects of this definition that set CBPR apart from more typical approaches to research include, a) collaboration with community members who are affected by the issue, rather than simply treating community members as subjects; b) community input in all aspects of the research, rather than just in the data collection phase or to rubber stamp an already-developed study plan; and c) efforts following the research study to improve health and wellbeing through action and social change. This contrasts with the Western science approach to focusing the research effort on the production of generalizable knowledge, with the researcher as the expert determining the course of research, and bearing no responsibility for the outcomes of their research. The CBPR approach acknowledges the value of various expertise, including community knowledge that does not derive from graduate education and training, as well as mutual learning, decision-making and shared ownership. It also values action and making changes that are not limited to health care interventions. Importantly, Holzer and colleagues describe how this approach to research can “help to remedy shortfalls of community trust, participant enrollment, and uptake of research findings” (Holzer, Ellis, & Merritt, 2014, p. 851).

Israel and colleagues proposed nine principles that have been widely disseminated, cited and generally accepted in the CBPR literature (see Table 1.2) (Israel, Schulz, Parker, & Becker, 1998). They also described these principles in action, including some common challenges and tensions that can arise, as these principles outline a set of values and commitments, rather than a how-to checklist (Israel et al., 2003).

Table 1.2. CBPR principles as described by Israel and colleagues, 1998.

Nine CBPR Principles
1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community
3. Facilitates collaborative partnerships in all phases of the research
4. Promotes co-learning and capacity building among all partners
5. Integrates and achieves a balance between research and action for the mutual benefit of all partners
6. Emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease
7. Involves a cyclical and iterative process
8. Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process
9. Involves a long-term process and commitment

Several similar approaches have developed in various research fields. While my own scholarship has focused on CBPR, I have chosen to adopt a broader term for my dissertation work, “community-academic partnerships,” as recommended for consistency across literatures by a research team that conducted the first systematic review of these approaches (Drahota et al., 2016). This broader term encompasses similar collaborative research approaches that have been described in the literature but do not derive from the same traditions as CBPR, such as Participatory Action Research, Critical Action Research, Collaborative Action Research/Emancipatory Research.

Empirical research has shown that trust and reciprocity are essential prerequisites to a cooperative relationship (Walker & Ostrom, 2009). Likewise, a key theme throughout the growing community-academic partnership literatures captures the importance of building and maintaining mutual trust (Mikesell, Bromley, & Khodyakov, 2013). Despite its apparent importance, there are few studies that describe the meaning of and evaluate trust in these partnership literatures. In the following pages, I review the concept of trust, and its antecedent trustworthiness, as discussed in other literatures.

1.1.4 *Trust*

The concept of trust has been debated in the Philosophy literature over the past three decades. Trust had previously been described uncritically, primarily in terms of contracts or relationships between two individuals of equal power and status (Hardin, 2002). In the mid-1980s, philosopher Annette Baier identified the lack of critical discussion within Philosophy addressing trust between non-equals, namely, including women as agents within the trust relationship (1986). Baier's critique and account of trust opened debate within the field, which is still active today, incorporating accounts of trust, trustworthiness, group- and institutional trust. The concept of trust has been taken up and furthered in the Organizational research literature as well.

Baier defines trust as, "letting other persons (natural or artificial, such as firms, nations, etc.) take care of something the trustor cares about, where such 'caring for' involves some exercise of discretionary powers" (1986 p. 240). The general form of trust is A trusts B with valued thing, X (Baier, 1986; Hardin, 2002). In this form, A is the trustor, B is the trusted, and X is something that A values and entrusts B to take care of in some way. Essential to this is the element of choice, known as discretionary power, that B takes on when deciding how to care for X. Because A values X, A takes a risk and becomes vulnerable to B and B's discretion in caring for X. This allows B the opportunity to harm X, but in trusting, A expects that B will not take that opportunity. X might be tangible (one's home) or intangible (one's personal safety), an action (to deliver a package, to provide truthful information), all aspects in a domain (in marriage, in teaching), a person (one's child), or any other valued entity.

There is consensus within the otherwise lively Philosophical debate that trust is *relational*; that is, the type of and context for the relationship are key elements of trust. The literature addresses dyadic relationships between parents and children or a person and god (total trust), (Hardin, 2002), intimate partners, friends, strangers, professionals/clients, people/governments (Jones, 1996), and in group relationships including among strangers in groups (Foddy & Yamagishi, 2009), in institutional settings (Hardin, 2002), and others. What the trustor can reasonably expect of B is necessarily context-dependent.

Motivations for trust have been a key element under debate. Hardin describes his account of trust as “encapsulated interest,” where A trusts B because B’s interests are encapsulated in A’s interests, due to the on-going nature of their relationship. If B wants to maintain a relationship with A, (or alternatively, to maintain B’s reputation in their social group) then B will fulfill their commitment to A in the care of X. If B does not care for X properly, then A will no longer trust B, and their relationship will be compromised, or X will be harmed, both of which hurt B’s interests (Hardin, 2002). Baier’s account attributes the motivation of B to care for X to having good will toward A, and claims that it is important that if A knew B’s reasons for wanting to earn A’s trust, this knowledge would enhance, rather than undermine, A’s trust (Baier, 1986). Likewise, Jones’s early account considers A’s attitude of optimism about B’s good will toward A as central to trust (Jones, 1996), but later shifts to responsiveness over good will (Jones, 2012). Alternatively, McLeod posits that B’s moral integrity, rather than good will, is the important motivator for A’s trust (McLeod, 2002). This refers to having shared moral commitments, and views on the nature of the relationship. Wright rejects the importance of good will, in favor of a “participant stance,” which does not require two individuals to care about each other in order to trust, citing enemies trusting each other, given a white flag in a war (Wright, 2010). The nature of the motivation for trust is a point for debate in the literature, and an empirical question in the context of research partnerships.

Several theorists claim that trust has a cognitive component, grounded in A’s knowledge and a rational assessment of B to determine whether or not to entrust B with X, (Baier, 1986; Hardin, 2002; Jones, 1996). This assessment includes incorporating A's knowledge of B and B's past behavior in determining whether it is reasonable to trust B. Jones also includes as a central element, an affective component, that is A's optimism about B's future behavior toward A, and expectation of a favorable outcome (1996). Either having shared values, or in the absence of this, expectations of the trusted's moral commitments, are crucial to trust. Key elements of trust are summarized in Table 1.3.

Table 1.3. Key elements of trust, per the Philosophy literature

- A's acceptance of some risk and vulnerability to B (from the definition)
- B's discretionary power regarding X (from the definition)
- Relational nature of trust and the importance of context
- Some motivation for B to be trustworthy toward A
- A's rational cognitive assessment of B, possibly combined with an affective assessment (optimism about future behavior)

Several additional elements are described in the literature, expanding on these core elements:

- B's competence to fulfill A's expectations for care of X, and A's corresponding confidence in B's competence. It is not reasonable to trust someone who is not competent to care for X appropriately (Hardin, 2002; Jones, 1996). For example, one would not trust a mechanic to perform an appendectomy, nor would one trust an untrained student to perform complicated data analyses for a publication.
- A's confidence that B will not act beyond what B has been trusted to do (Hardin, 2002). For example, one would trust a babysitter to attend to the children in his charge and not to repaint the bedroom, if not expressly asked.
- Trust, as an affective attitude, can be cultivated but not willed (Jones, 1996). Simply, if A has

reason not to trust B, the attitude of trust toward B will not exist, and cannot be forced.

- Trust is dynamic throughout a relationship, growing imperceptibly, and generally not explicitly (Baier, 1986; Potter, 2002). As Baier says, "trust is much easier to maintain than it is to get started and is never hard to destroy" (p. 242).

Another way to consider trust is to point out what is *not* trust. Distrust is a belief or pessimism by A about B's good will and/or competence, or expectation that B would harm X either maliciously or through prioritizing other interests over A's interests (Jones, 1996). There is also a neutral option, which is largely accepted within the Philosophy literature. A might simply not have any attitude toward B, as Jones states, "the absence of trust is not to be equated with distrust," (1996, p. 16). Several discussions also distinguish between trust and mere reliance (Baier, 1986; Hardin, 2002; Jones, 1996; McLeod, 2002). A can rely on B without trusting B. The key distinction between trust and reliance is the possibility of A being betrayed by B. In the absence of potential for feeling betrayed, A simply relies on B to act as expected. Two examples of reliance illustrate the scope of this concept: we may have reason to distrust the owner of the only grocer in town, but have no choice but to continue to rely on him for our food supply; or, if we know that the mail carrier arrives at the same time every day, we can rely her to pick up an important letter. Should she arrive early one day and collect the mail before we have set out the letter, we might be disappointed or inconvenienced, but we will not feel betrayed.

1.1.5 *Trustworthiness*

Considering the question of how researchers might go about establishing trust, it is useful to turn the question around and ask how researchers might go about cultivating their own trustworthiness. Drawing from the Philosophy literature, an individual is trustworthy only if the trustor (the community partner, for my dissertation) perceives the other (the academic researcher) as embodying those characteristics of trustworthiness in a manner that the trustor values. Hardin suggested that "commonly, the best device for creating trust is to establish and support trustworthiness," (2002 p. 30). Virtue- and feminist ethicist, Potter, agrees that "one way to responsibly cultivate trust is to develop a trustworthy character," (2002 p. 12), and argues that one can theorize about a trustworthy character, however conceptualizing trustworthiness depends on the relationship between the relevant parties. She adds that power and privilege can create misunderstanding and uneasiness, and can interfere with perceptions of trustworthiness. This idea has been tested through research in Applied Psychology, which found trustworthiness to be an important antecedent to trust, distinct from, and a stronger predictor of trust than, a trustor's propensity to trust (Colquitt, Scott, & LePine, 2007; Heyns & Rothmann, 2015).

Potter focuses on this side of the equation, examining what it means to be B in the trust relation. She says, "trust in another changes relations of power in that the trusting person becomes vulnerable to another with respect to that valued thing…Our moral responsibility to cultivate trust leads to the need for us to cultivate a trustworthy character…" (Potter, 2002, p. xv). Her definition of trust builds on the above 3-part relation, accepting many of Baier's elements. She adds a specific discussion on the impact of power imbalances as a primary hindrance to trust. This is particularly relevant to the consideration of community-academic research partnerships as typically, the research relationship between academic and participant has been one of substantially imbalanced power in favor of the researcher.

In the context of virtue ethics, Potter's description of trustworthiness goes beyond the three-part trust relation. She says, "A trusts B to be X sort of person with regard to Y; where X= a positive quality of character (from A's perspective) or way of performing an action; and where

Y= something good that A values" (2002 p. 17). Her model puts forth 10 key elements of responsibility for trustworthiness that take into account differential power within the relationship. For example, she claims that we must give signs and assurances of our trustworthiness, develop sensitivity to the particularities of others, respond properly to broken trust, work to ensure our institutions and governing bodies are virtuous, and that we recognize the importance of being trustworthy to the disenfranchised and oppressed (2002, p. 26-30). These responsibilities have also been echoed in community-academic partnership reports, although not necessarily described as elements of trustworthiness, and thus, this model appears highly relevant to my study.

Other theorists also provide accounts of trustworthiness that are worth noting, as these accounts all relate to the building of trust in relationships. Jones agrees that trustworthiness is a characteristic of the one being trusted, and provides the nuance that B's weighing of competing interests matters, as "one is not trustworthy unless one is willing to give significant weight to the fact that the other is counting on one, and so will not let that consideration be overruled by just any other concern one has" (1996 p. 8). She notes that another complication for trustworthiness is the challenge of understanding for what the trustor is counting on the trusted, as this requires B to have some background knowledge of what A generally values, and of A's culture, enough to know how to fulfill A's trust. Further, institutions can influence the perception of trustworthiness of those affiliated with them, and can either offer structures that promote trustworthiness (e.g. reducing the possibility of conflicts of interest) or hinder trustworthiness (Hardin, 2002; Jones, 2012). Several philosophers recommend attending to the structures of institutions as another strategy for developing trustworthiness (Jones, 2012; Potter, 2002), which is also applicable to considering the community-academic partnership context.

1.1.6 *Trust-enhancing practices in community-academic partnerships*

Conceptual descriptions of trust have largely been established based on relationships that do not include community engagement in research. A growing literature on community-academic research partnerships includes claims for the importance, and discussions, of trust within that type of relationship as well (Schulz, Israel, & Lantz, 2003). Still, there remains ambiguity within the community-academic partnership literatures regarding what trust and trustworthiness denote, thus making a systematic review of the literature challenging. Many reports use the term "trust" without definitional clarity, and others do not explicitly use the term but describe practices that could meet some definitions of trust.

When reviewing the literature on assessing trust within community-academic partnerships, I limited my search to reports that explicitly use the word "trust." I have observed that partnerships have reported the following practices to have enhanced trust. Many of these practices contribute to a cycle of trust, in which building trust facilitates work and practices that then deepen trust. While not specifically described as such, these practices (if performed by the researcher) could be considered demonstrations of a researcher's trustworthiness; as has been theorized above, cultivating trustworthiness can lead to trust. The practices reported to build trust include:

1. Adhering to the principles of community-based participatory research (CBPR) (Israel et al., 2003, 1998). Only one report explicitly called out these principles as a whole (Christopher, Watts, McCormick, & Young, 2008), but many of the practices described in the following points reflect CBPR principles.
2. Establishing long-term relationships: including face-to-face time and visibility within the community, holding research meetings within the community, participation in community events, genuine caring and without substantial turnover in the partnership (Ahmed et al.,

2011; Baquet, Bromwell, Hall, & Frego, 2013; Christopher et al., 2008, Maciak, Guzman, Santiago, Villalobos, & Israel, 1999; Roe & Roe, 2004; Taylor-Powell, Rossing, & Geran, 1998).

3. Acknowledging the institutional-, personal- and social historical contexts of the partnership, including historical trauma, research-related harms, previous research conducted in the community and/or experiences with the institution, and avoiding recreating harm (Baquet et al., 2013; Christopher et al., 2008; Voyle & Simmons, 1999).
4. Being attentive to the process of partnership: dialoguing to lay groundwork, having structures and principles for ongoing collaboration, holding trainings, taking steps to safeguard partners and lower the community's sense of risk; evaluating the partnership using methods that are not overly technical, and are comprehensible to community members (Baquet et al., 2013; Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2001; Maciak et al., 1999; Roe & Roe, 2004; Taylor-Powell et al., 1998).
5. Communicating effectively, clearly setting shared expectations and intentions. These can start with establishing clear roles, and drawing from community codes (such as tribal codes), and also include providing research information back to the community and being responsive to community needs and priorities (Christopher et al., 2008; El Ansari, 2005; Maciak et al., 1999; Taylor-Powell et al., 1998; Wagemakers, Koelen, Lezwijn, & Vaandrager, 2010).
6. Sharing power, control, input, ownership and credit; acknowledging community expertise, community priorities and sharing funding (Christopher et al., 2008; El Ansari, 2005; Maciak et al., 1999).
7. Practicing reflection about one's own assumptions and biases (Christopher et al., 2008).
8. Demonstrating accountability, commitment and sincerity by following up on promises and

agreements, acting in accordance with stated intentions, and providing the community assurances of researchers' commitments (Christopher et al., 2008; Voyle & Simmons, 1999).

The concept of rebuilding trust when there is a prior history of a breach adds an additional dimension to this discussion. When first building trust, it is possible that A would hold no *a priori* knowledge or expectations about B. However, unknown individuals are often judged on the basis of their group membership, and A's knowledge of B's group(s) relative to A's own group(s) (Potter, 2002). Stereotypes about another's group and that group's reputation based on prior behavior can precede individuals' involvement with one another. When group identification sets up suspicion or taps into a history of harmful relationships between the groups, a repair of trust might be warranted from the start of that relationship. Rebuilding trust after a direct betrayal between individuals might look similar to building trust anew between individuals from groups who have experienced harm at the hands of the other's group leading to a deficit of trust at the start. I draw from the Philosophy literature to describe this further.

To rebuild trust, B has several responsibilities. B must acknowledge and accept responsibility for the breach of trust, and accept that A is being rational by not trusting B (Potter, 2002). B must attempt to repair that broken trust, by trying to understand from A's perspective, what the unmet expectation was and the root of the breach, to set new expectations with greater insight regarding what B can be expected to do, especially in the face of conflicting responsibilities (Jones, 1996; Potter, 2002). If institutional or social structures were found to impose constraints on B's ability to fulfill A's trust, then B must work to change those structures. But central to all of this effort is cultivating a sensitivity to A's needs, the satisfaction of which can only be determined by A. Sharing power, such that B becomes vulnerable to A can lead to greater mutuality and leverage for A to take on risk once again (Potter, 2002). These elements are not necessarily fully distinct from the building of new trust, but there is a higher bar for B's responsibility for a commitment to both *being* trustworthy vis-à-vis A, and *signaling* that B can be trusted after a breach.

Finally, these descriptions of trust enhancing practices and discussion of responsibilities to rebuild broken trust are largely reflective and theoretical. There has been little formal evaluation or attempts at measuring the effects of these efforts. Next, I discuss the task of evaluating trust and trustworthiness.

1.1.7 *Trust & trustworthiness evaluation*

While much has been theorized and debated in other fields, there is limited discussion and a lack of conceptual clarity on trust and trustworthiness in the community-academic partnership literatures. There is a similar lack of consensus regarding the terms partnerships use to describe their relationships, and the type of evaluation conducted. Further, there is no consensus on partnership process evaluation methods, and most of these evaluations have relied on qualitative methods, leading to a call for valid, reliable quantitative partnership process measures (VanDevanter et al., 2011). This complicates any systematic approach to the literature, including on evaluation of any aspect of community-academic partnerships. Despite searching with many synonymous terms, I observed that there are few explicit evaluations of partnership trust, and none about trustworthiness, in the community-academic partnership literatures.

Considerable heterogeneity exists across approaches to evaluation that have been employed. Methods have included social network analysis (Luque et al., 2011), quantitative surveys (Ahmed et al., 2011; Schulz et al., 2003), qualitative approaches (Christopher et al., 2008; Wong et al., 2011), and mixed-methods (Pivik & Goelman, 2011). Qualitative interview-based evaluations generally did not specifically ask about trust, rather allowed it to arise as a theme in participants' responses (Wong et al., 2011), making direct assessment of trust somewhat elusive, but contextualized, enabling the reader to glean the emerging meaning of trust. An earlier review of quantitative partnership evaluation metrics concluded that the literature "is a fragmented collection of tools," with a need for theory and operational definitions of constructs as well as validity and reliability assessments of evaluation measures (Granner & Sharp, 2004 p. 517). Several years later, another team applied Wallerstein and colleagues' CBPR logic model, to assess the existing evaluation measures (Sandoval et al., 2012). Their study found that there is still a lack of psychometric data on evaluation metrics. From an academic perspective, the lack of these data means that we cannot necessarily know how well the items are measuring the construct of interest, but is also a reflection of the field's relatively early stage of development.

An additional challenge of assessing the explicit partnership trust measures is that there is a lack of clarity of constructs, and agreement about what kinds of items belong in a trust construct. Some quantitative items include the word "trust" without clarifying, as in, *Sense of trust* (Pivik & Goelman, 2011), *and Over the past year, has the amount of trust between group members increased, remained the same, or decreased?* (Schulz et al., 2003). As the latter was a participatory evaluation, there may have been mutual understanding on the meaning of trust in their partnership, but this was not described.

Here I mention two examples of partnership-specific trust constructs that include differing elements. The B Free CEED partnership evaluation included items on respect and comfort-level in their trust construct: *I feel comfortable talking openly and honestly [in] B Free CEED partnership meetings; I am comfortable bringing new ideas to the B Free CEED partnership meetings; Partnership members respect each other's points of view even when they disagree* (VanDevanter et al., 2011). Ahmed and colleagues' partnership evaluation survey included a combined construct on trust and communication, measured by items that were developed through interviews with community members. Their items include, *There is a high level of trust among partners; There is clear and open communication among partners; Membership reflects the diversity of the community's population and organization; New members are actively recruited; There is a process for integrating new members into the group; Partners are committed to making the collaborative an on–going effort* (Ahmed et al., 2011). These items are similar to items measuring different (non-trust) constructs in other measures, demonstrating lack of consensus in the field. They report a combined construct signaling an implicit definition of trust as being connected to collaboration. These surveys were deployed only to the partnerships for which they were developed, and so metrics may not be transferable to other partnership settings.

Community-academic partnership evaluations reviewed here are published within the peer-reviewed literature, so are necessarily academic and do not include other assessments of trust that might be considered valid by the community. Even with extensive community input, the evaluation process and reporting must adhere to standards of peer-reviewed publication, and as such, will be somewhat skewed toward the academic perspective and approach. Because of the lack of conceptual clarity on trust in this context, both in the writing of an evaluation tool and in the responding to evaluation questions, the lack of validated tools, and context-specific reality of the trust relationship, the most thorough means for assessing trust is currently through the narrative descriptions available.

Christopher and colleagues offer a structured way for considering their qualitative descriptions of how they recognized trust at multiple levels in their partnership—between academic and community partners, and then between the initial partners and the larger community and academic setting (Christopher et al., 2008). Rich descriptions can help communicate the context-specific factors that are not included in quantitative approaches, and narratives are often more comfortable for community members to provide and use. Certainly, differing goals for evaluation lead to different needs for metrics. There is room for qualitative, quantitative and mixed approaches in the partnership evaluation literature, but in all cases, this literature is young.

While trust is the primary outcome of interest for measuring the state of the partnership, *perceived trustworthiness* is a modifiable antecedent of trust, whose clarification could help identify ways to build trust. Measuring *trust* only offers information about the partnership status, but evaluating *perceived trustworthiness* may inform more specifically how the researcher can contribute to trust building. However, in the community-academic partnership literatures, there are no evaluations of trustworthiness. I found a set of very few measures claiming to evaluate public perceptions of researcher trustworthiness (Platt, Bollinger, Dvoskin, Kardia, & Kaufman, 2014), but these were directed toward general and abstract perceptions of researchers. I found no measures that were used within a particular relationship, nor that described any development or validation process. To find examples of trustworthiness measures within relationships, I turned to scholarship on organizations.

Three scales, each composed of three dimensions (or constructs) of trustworthiness, have been validated in the Organizational Research literature. McAllister's scale includes the constructs *competence, responsibility* and *care/concern* in his definition (1995); Mayer and Davis similarly include *ability*, *integrity* and *benevolence*, in their scale (1999); and Cummings and Bromiley include *honesty, good-faith effort* and *limited opportunism* in their scale (1996). Each scale includes nuanced differences in their constructs and applications, as well as the relationships considered (see Chapter 3). However, in all cases, the contexts studied were limited to professional relationships within workplaces, and not community-academic partnerships.

1.2 GAPS IN THE LITERATURE

Integrating the various literatures described, I identify several gaps. Trust is integral in community-academic partnerships, and trustworthiness is an essential antecedent to trust that can be modified by the would-be trusted. Yet, there is limited discussion on what constitutes trustworthy character and actions, in this context. Further, there are very few tools for evaluating trust and no tools for evaluating trustworthiness in this literature. There are a few high quality evaluation tools in the Organizational Research literature, although the state of that field is considered fragmented and lacking cohesion (McEvily & Tortoriello, 2011). As the Philosophy literature has recognized, these concepts are context-dependent. Therefore, the Organizational Research tools, which have been validated in employment relationships, are not readily applicable to evaluation of trustworthiness in community-academic partnerships without further validation.

For this project, I aimed first to clarify the concept of trustworthiness in the community-academic partnership setting, through conducting in-depth interviews with individuals involved in community-academic research partnerships. This approach offered a breadth of experiences and perspectives on what may be considered important for researcher trustworthiness, and offered examples of these concepts in their context. I then created and assessed an evaluation tool to be used to measure the perceived trustworthiness of a researcher in such a partnership. This tool can be used to examine correlations between institutional factors such as university policies or practices, and perceived trustworthiness, to inform institutional policy changes to remove problematic constraints from researchers. Or, an evaluation of trustworthiness could simply inform a discussion within the partnership that could, for some, enhance the development of trust. Finally, the details of any situation are fundamentally important for cultivating trustworthiness; I applied the concepts that I described in my first two aims to a case in genomic research, APOL1 genetic testing of African Americans. I used lessons about researcher trustworthiness within community-academic partnership, to frame a critical discourse analysis about genomics and health disparities, weaving together the current state of the science and needs for community engagement. This analysis highlights opportunities for cultivating trustworthiness in genomic research.

Chapter 2. TRUSTWORTHINESS IN COMMUNITY-ACADEMIC RESEARCH PARTNERSHIPS: CONCEPTS AND INSTITUTIONAL FACTORS

2.1 INTRODUCTION

"Trust is much easier to maintain than it is to get started and is never hard to destroy."
(Baier, 1986 p. 242)

Community-academic research partnerships have gained popularity in recent decades, as a response to a history of missteps committed by researchers, as well as to ongoing policies, practices and norms that perpetuate harms. This legacy of harm includes cases of disrespect, deception, racist research premises, studies without consent, infecting healthy people with diseases, allowing disease courses to continue and devastate participants after treatment has been developed, using research information to stigmatize communities, as well as economic and cultural harms (Dalton, 2004; Foulks, 1989; Lawrence, 2000; McDonald et al., 2012; Rohter, 2007; Wiwchar, 2004). Many minority communities have learned from these experiences to distrust researchers and their institutions, and have demonstrated a reluctance to participate in research.

Community-academic research partnerships, such as in community-based participatory research (CBPR) and similar approaches, have developed as a way for researchers and communities to work collaboratively, so that communities who want to participate in research can do so. Core to this approach is a commitment to equitable community participation in all aspects of the research process, to ensure that the community benefits from these efforts (Israel et al., 2003). The growing community-academic partnership literature highlights the importance of building and maintaining mutual trust within research partnerships (Mikesell, et al., 2013).

However, given that researchers operate within these institutions that have shown themselves to be untrustworthy, trust cannot be built or repaired without researchers attending to their own trustworthiness.

There is consensus in the Philosophy and Organizational research literatures that trustworthiness takes on different meanings in varying contexts. Trustworthiness in several other types of relationships has been described, such as between peer managers of organizations, between top management and employees, and between boundary roles persons across organizations (Cummings & Bromiley, 1996; Mayer & Davis, 1999; McAllister, 1995). While there may be similarities between the organizational setting and the community-academic research partnership setting, there are key differences in goals, norms, expectations, power dynamics, timelines, funding sources, and other factors that likely impact the relationship. Given that expectations for and assessments of trustworthiness are context-dependent, it is not clear that what has been learned from research on trust and trustworthiness can be applied to community-academic partnerships. Further, structures exist within research institutions that perpetuate distrust, and hinder researchers from being able to fulfill community's expectations, making it hard to operate truly equitably, according to CBPR principles (Israel et al., 2003). In this qualitative study, I aimed to a) characterize researcher[1] trustworthiness in community-academic research partnerships, b) identify institutional barriers to this trustworthiness encountered by those involved in such partnerships, and c) collect approaches taken to overcome those barriers.

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[1] I acknowledge the need for researchers to trust communities, as trust within a partnership must be mutual. However, I focus on what researchers can do to build trust in the context of a legacy of research harms, that researchers must overcome to demonstrate that they are trustworthy. Being in positions of traditionally greater power than communities in these partnerships, the responsibility is on the researcher, more so than community partner to be trustworthy, and so attention to these concepts is warranted.

2.2 METHODS

2.2.1 *Sampling and study population*

Individuals who have experience as a community partner, academic partner, or who identified with both community and academic roles (termed “bridge” partners, based on one participant’s self-identification,) within research partnerships were included in this study (n=31). The types of research undertaken by the partnerships varied, but all had some health-related focus. I used a combination of purposive and snowball sampling approaches to reach potential participants in each of the stakeholder groups, beyond my own network (Patton, 2002). I also recruited participants at two research partnership-focused professional conferences, Community-Campus Partnerships for Health Conference (May 2016), and the PCORnet Building Trustworthiness Conference (March 2016); and I posted on social media and email listserv announcements. Some authors of relevant papers to whom I had no apparent connections, were invited directly. Potential participants were invited to participate in a research study exploring what it means to be a trustworthy researcher, based on their roles in a research partnership. Participants were also asked to provide contact information for, or share the study information with, their research partners, and others who might be interested in participating.

Participant demographics are described in Table 2.1. There was a large range of ages represented, particularly among community partners. The racial/ethnic makeup of the sample was 51.6% white, and 48.4% people of color, including Native/Indigenous, African American, Hispanic/Latino, and Asian. Most (75%) of the white participants were academics, and the bridge participants were all people of color. There was a range of racial and ethnic concordance reported between participants and their partners: Just over a third (35.5%) reported they did share racial/ethnic identity with a research partner; the same number reported they did not, and just under a third (29.03%) reported they shared a racial/ethnic identity with some of their research partners but not all. The vast majority of participants were female, and all held a bachelor's degree or higher. All participants are located in North America, and their research partners are located mostly in North America, but some are located elsewhere in the world.

Table 2.1. Participant demographics

	Age	**Gender**		**Race/Ethnicity**					**Racial/Ethnic Concordance with Research Partner***			**Education Completed**		
Stakeholder Group	**Average / Range**	**Female**	**Male**	**White**	**Native / Indigenous**	**African American**	**Hispanic/Latina/o**	**Asian**	**Yes**	**No**	**Mixed**	**Bachelors degree**	**Masters degree**	**Terminal Degree**
Community (n=8)	48 / 28-71	6	2	4	1	0	2	1	3	1	4	3	3	2
Bridge (n=9)	54.5 / 40-66	8	1	0	4	2	1	2	7	0	2	0	5	4
Academic (n=14)	44.5 / 34-56	13	1	12	0	0	2	0	1	10	3	0	1	13
Total (n=31)	**28-71 years**	**27**	**4**	**16**	**5**	**2**	**5**	**3**	**11**	**11**	**9**	**3**	**9**	**19**

*Racial/ethnic concordance includes large racial/ethnic categories. Some participants were tribal members, partnering with tribes, although those might not have been their own tribes. Those were counted as "yes" for concordance. The "mixed" category indicates the partner is a racially/ethnically diverse community or research team.

2.2.2 *Data collection*

In-depth interviews were conducted between October 2015 and September 2016, by phone (n= 28) and in-person (n=3). The open-ended interview guide addressed each participants' concept of trustworthiness, which actions or factors demonstrate a researcher's trustworthiness within a particular partnership, what kinds of institutional barriers or facilitators influenced their experiences of trustworthiness within the partnership, and how the partnership has overcome any challenges to trust. Community partners were asked about characteristics of their academic partners; academic partners were asked about their own trustworthiness and that of other researchers; and bridge partners were asked about academic partners and their own sense of trustworthiness and responsibility in their unique roles. Additionally, I collected participants' demographic information, and background about the partnership they were describing. Interviews lasted 60 minutes on average, were audio recorded, and professionally transcribed. I reviewed each transcript for accuracy, and redacted identifying information. I sent transcripts back to each participant for their review and any further redaction of identifying or sensitive information.

2.2.3 *Data analysis*

I conducted a multiple phased coding process, based on grounded theory coding practices (Charmaz, 2008) using Atlas.ti (version 7) qualitative data analysis software. After several reviews of each transcript and open coding three transcripts by hand, I developed the codebooks iteratively, first using an inductive approach and included code names with brief definitions, full definitions, examples of when to use (MacQueen, McLellan, Kay, & Milstein, 1998). I then combined initial codes into code families, that reflected the main sections of the interview guide. Codes corresponded to types of responses in each aim based on early reviews of the transcripts. For example, for the trustworthiness concepts section, codes included: *definition, demonstrating trustworthiness, indicators, conflicts, compromise, power dynamics, rebuilding, risk, facilitators, distrust* and *solutions*. For the institutional factors section, codes included: *funding, history, constraints, barriers to community participation*, and *creative approaches*. This codebook was used for the first phase of coding, for all the transcripts.

Quotations from each code family were exported together, by stakeholder group, for a second phase of coding. I then used these exported data to create separate projects for each code family and further analyzed, using a fully inductive coding process to capture the details within each, relevant to each stakeholder group. I made connections between these detailed-level codes, creating the subthemes and examples, using networks. I reorganized coded quotations into matrices to capture sub-themes for each dimension. I kept analytic memos throughout the entire process, to track developing themes.

To ensure consistency and fidelity to the data, I recoded each transcript as a third phase of coding. After completing the thematic analysis in for each code family, these new codes were imported into a new codebook and applied to the again-whole transcripts (rather than the exported code family sections) to verify that all subthemes were captured, and nothing was missed in the exported data used in the second phase coding.

I asked three research questions of my data, corresponding to the three aims for this qualitative study. I identified themes for each of the three aims, and report them as Part A, for the question regarding characterization of trustworthiness, and Part B for the questions regarding institutional barriers and approaches to overcoming these barriers to trustworthiness.

2.3 RESULTS: PART A

Based on data from community, academic, and bridge partners, I identify four major dimensions of trustworthiness in the community-academic research partnership setting: *ethical*, *competent, caring,* and *vulnerable*. Each dimension has several subthemes, and a cross-cutting theme, *respectful* (see Figure 2.1). I highlight key aspects of each dimensions below.

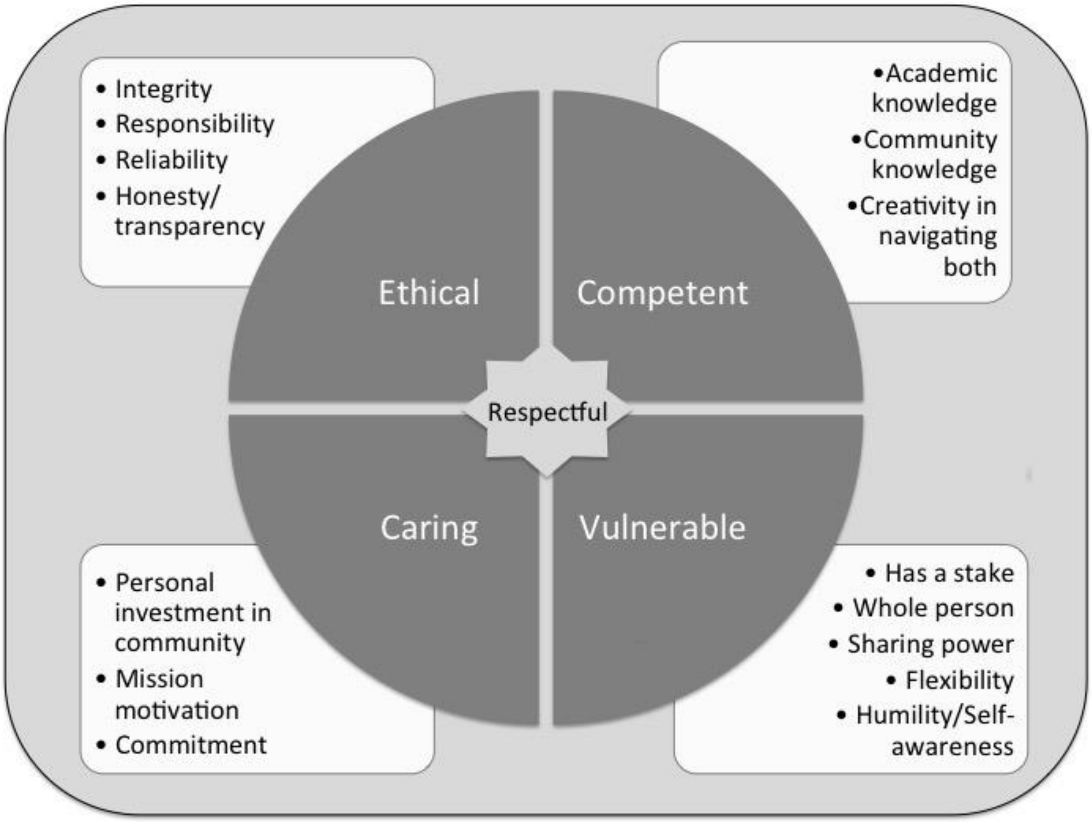

Figure 2.1. Dimensions of trustworthiness in community-academic research partnerships with subthemes and cross-cutting theme.

2.3.1 *Ethical*

The *ethical* dimension refers to an overall sense that the researcher operates from a set of principles and commitments that are either shared with or accepted by the community, and acts consistently with these principles and commitments. This sense of ethics was seen as important for guiding the trustworthy researcher’s actions, even when faced with a situation that has not previously been discussed in the partnership. Several sub-themes were identified as part of the *ethical* dimension: integrity, responsibility, reliability, and honesty.

Integrity: The idea of integrity relates to a sense of fairness, consistency, and ensuring that values and principles drive actions. As several participants explained:

> "You know, that word 'integrity,' it relates to 'integrated.' Your values are integrated throughout what you do and they're consistent…Of course there's all kinds of value systems, but I think integrity involves or implies a value system that is honest and doesn't have—how shall I put it, there's a double standard. What I expect of others, I expect of myself." (Bridge 17)
>
> "Consistency of my actions and behaviors…Underneath, that's the piece about being consistent. I'm not erratic. They know if they need something from me…that it will usually happen in a very consistent manner…there's some integrity in how decisions are made. I don't play favorites and I tell everyone the same story…There's consistency across partners and then consistency over time in my actions and words." (Academic 6)

For some, it was important that a researcher would adhere to rules, and also maintain the wholeness of the intention behind the rules. For example,

> "If you have an IRB in place, the researcher's academic partner isn't say, 'Yeah, that's what that says, but we don't really need to follow that.'" (Community 8)
>
> "That fine line between the drive for inclusion and then the safety of the patients and the compliance part. There needs to be a balance…It's inclusion, but not at all cost…It needs to be tempered by making sure the consent process…You need to get down, simplify it, and not lose the integrity of the facts… It's a regulatory piece of paper, so we need to do that because we're bound by the rules, but we also need to communicate in English without leaving out the facts so that people can understand this." (Bridge 20)

Responsibility: Participants in all stakeholder groups discussed acting responsibly as a core demonstration of a researcher's ethics or integrity. This ethical stance includes a strong sense of responsibility to the community, both in communication and accountability. Responsibility in communication extends to not assuming that the community members will speak up if they are not comfortable with something; instead, researchers might invite the community partner to interrupt, or might suggest specifically negative feedback, to offer community partners a genuine invitation to ask questions or reject an idea. This was seen as especially important when there is a power differential or cultural tendency to be deferential to authority. A community partner shared her discomfort in speaking up during research meetings, offering a responsibility for the researcher, for improving the dynamic:

> "If the [research team] had a protocol for checking in with [community] partners to say, 'hey, how are we doing,' we would've had this conversation already 'cause that's something I've been thinking about. I hadn't felt comfortable enough to initiate the conversation, but if we had check-in that would've come up." (Community 19)

Another bridge partner recognized that, in his community, it is culturally appropriate to agree with someone in a position of some power, and as such, sees a responsibility of the researcher to be pro-active in soliciting a negative response:

> "I think what that [the cultural issue of people tending to say 'yes' even if they don't mean it] means is that the onus is on me [the researcher] to really push that, and to give people the 'out' when we're having those conversations, to say, 'I know we talked about this before, and you expressed interest, but we're getting to the point where we have to sort of make a real final decision, and final commitments.'...You tell them that it's truly voluntary; …I can always check in with [the coalition director] and say, 'you know, that organization, they said "yes," but…do you think that that's a real "yes,"?'" (Bridge 2)

Several suggested that a trustworthy researcher will take responsibility for their own mistakes, continuing to show up and trying to repair any harms from those mistakes, with the community in the lead. Participants suggested that, particularly in the early stages of partnership development, it is advisable to talk through how situations will be handled if something goes awry, and to ensure all partners have input. It is important for the researcher to provide updates and preempt issues before it seems necessary.

> "It's about nipping things in the bud and also alerting people to, 'Okay, I've encountered this challenge at the university. Here's how I'm trying to deal with it, and stay tuned for an update.' I think it was just me regularly letting people know, 'Oh, my God, this is happening now, and I'm trying to deal with it. As soon as I get resolution, I'll let you know what's happening.'" (Academic 25)

For bridge partners working with their own communities, these responsibilities are heightened. Several reported feeling a strong sense of personal accountability to the community for any researchers coming in to work with the community. This was their role, and their own reputations were at stake.

> “I've been put in a gatekeeper position not really intending for that to be the case. … It puts us… in a pickle because then it's about personal trust and that trust then transfers to the project. We need to be careful… to make sure that we really, really believe in the work and …that you would be okay with your sister participating the research.” (Bridge 20)

Several also felt responsibility to make structural changes to decolonize the institution, and to advocate for CBPR and train researchers accordingly.

> “Decolonizing in a way that the university recognizes that the tribes, that we do have true traditional knowledge that is a valid knowledge…It's trying to build within the institution, mechanisms for recognition of traditional knowledge, how do we make that inclusive into the western educational system, and how do we change the thought that, for our Indian people who go into western education, that they are smart, that they are successful, and that they don't have to measure against those western standards.” (Bridge 14)

Reliability: Nearly every participant mentioned that following through and being counted on to do what one says, is necessary for trustworthiness. This also includes acting appropriately even in the absence of an explicit promise, meaning the researcher takes action with integrity to fulfill what they know the community expects, rather than justifying acting in another way because the researcher did not specifically promise to avoid doing so. One community partner described a counterexample to this reliability:

> “As I went through the for-profit world, one thing that I saw that there was a lot of lip-service being given in terms of really wanting to make difference and change outcomes, but they were not carrying out. Their actions did not match up.” (Community 26)

Also, keeping confidences whether specifically asked or not, was often mentioned among all stakeholder groups, as an important part of reliability.

> “Well, at a very basic level…that they won’t betray confidences, and that they can be counted on.” (Community 16)

Honesty/transparency: While honesty is easy to define, it was described as challenging to practice, even for highly ethical researchers, because it requires a great deal of reflection, knowledge, awareness of one's own relative social position, and also of one's own limitations, to be able to tell meaningful truths. It includes being realistic about one's own ability to commit, based on an understanding of institutional processes, timelines, and likelihood of receiving grants. Importantly, researchers must be careful to avoid over-promising, and building expectations that won't be met.

> "Plan A didn't work out, but Plan B has a little lag to it, so it creates a disturbance. Then you need to say to your community group—I say this because any time with grant writing, you may write five grants, and maybe one is funded, is truly funded. You tell 'em the odds, and the odds are of getting funded are not that high." (Community 9)

Honesty was also described as being accurate and not misleading, readily answering questions, having open organizational processes, and no hidden agendas**.** In order to make true statements about one's own intentions, action is needed.

> "I would think of trustworthy, is you tell people what your goal is, and you do that….You just be honest and open about the potential of the research, or the potential of the research to do good, but then also be honest about the potential of the research to maybe not find anything, or to maybe find something not good…not oversell the research… I think just being pretty transparent is important in trustworthiness...not trying to be very constantly positive…but I also just try to remain as open about it as I can, that 'We hope that this will have value, but we cannot say that for sure.'" (Academic 21)

Different interpretations of a statement or plan can lead to perceptions of dishonesty. While a researcher might not consider underestimating a project timeline to be a serious offense, to a community partner who has experienced many broken promises, this could be considered an unacceptable untruth. This was seen as both hugely important and also a place where many researchers were tripped up, in part because of their own passion and enthusiasm about their research, but also because of confusion about community expectations that were based on what the researcher had communicated. One academic partner described a miscommunication about the research timeline that resulted in a substantial breach of trust with the community partner:

> "Qualitative research can take a while to analyze sometimes…We had a lot of stories to tell…The timing of the data to collect it, you have to have time to analyze it. You have to figure out what the stories are, and then you write the papers. [My community partner] didn't understand that. It's, 'If the data's collected, so let's tell our story now…' I think when I'm talking about my limits and building relationships…that I would include those other commitments as well, which I didn't do the first time with them. That was a big lesson for me, and something that I need to tell people I'm working with." (Academic 7)

2.3.2 *Competent*

My data describe the *competent* dimension as comprising three main areas of knowledge that a trustworthy researcher needs: academic expertise (including both content and processes); understanding of the community's values, norms, histories, and practicalities; and importantly, using this knowledge to creatively navigate institutional constraints for the community's benefit.

Academic knowledge: Participants expected that researchers would be experts in their fields, highly skilled in conducting quality research and knowledgeable about methods to address the community's interests, as well as navigating academic institutional processes and requirements, and practicalities involved in conducting research. One community partner described assessing the research partner's knowledge:

> "Well, I felt safe, in her—the decisions that she was making about the work, because she obviously knew more about the research process than I did... This is her field and her area, and so she guided us along...Knowing that [the researcher] is an experienced researcher, and having been in conversations with her where I felt that she had familiarity with the community; All of that put together boosted my confidence that—and helped me feel comfortable with how she conducted the project." (Community 16)

Community-focused knowledge: Research partners were also expected to understand the community's history, what matters to the community, how the community interprets and conceptualizes respect, betrayal, benefit, risk, health, data and stewardship, and what the community would consider relevant information. This also has implications for the honesty sub-theme. Several participants stressed the importance of knowing and not repeating the negative history many communities have experienced:

> “It's absolutely critical to understand the historical context. I think anytime that you are saying you're doing work that is about social change or creating a more just process, you need to think about the historical context and get at some of the root issues as to what's created that context.” (Academic 3)

It is necessary for the researcher to learn what the community’s expectations are, what is needed for the community to feel respected by the researcher/institution, what kinds of benefits the community might perceive to be part of the research relationship, that the researcher might not consider. It includes recognition of the different views of what is considered “research” and knowing what would constitute a betrayal for the community, to avoid missteps. One bridge partner raised the need to build awareness of all of these issues:

> “Meaning if you work with somebody and you trust them, and you tell them all your secrets or all the things that you wouldn't want advertised, and then somehow they use that in a way you wouldn't want them to use. From the eye of the person who is betrayed, that would be a betrayal…. I think as researchers sometimes we do that, and we don't see it as betrayal.” (Bridge 27)

A community partner noted a common concern he has with researchers engaging communities without understanding what the community members actually care about or need:

> “I think with academia you just have people go in with the best intentions, but it doesn’t always come out that way. They don't fully understand the needs of the community.” (Community 26)

Knowledge to creatively navigate systems: The *competent* dimension describes a balancing act, knowing the research process and standards well, doing what is needed to keep one’s academic job and secure funding for the project, but balancing that with the community’s priorities and protocols they would find acceptable, or the needs they have from the research project that may not be publishable. Having deep knowledge about both areas enables (and perhaps obligates,) the researcher to navigate the institutional constraints on behalf of the community. Researchers can leverage their role in the university to push back against policies or structures that harm or otherwise don't suit the community's needs. Examples include buying ceremonial tobacco as gifts for participants instead of gift cards, negotiating for better indirect rates on community subcontracts to increase the funding flowing to the community, and arguing for why data collection had to stop during a community festival.

> "It's also this continuous navigation about trying to bridge those worlds in ways that make sense and hold you accountable. Accountable to the law and to your community and to your values. My community partners have seen me go to bat over and over and over, so that also kinda builds trust." (Academic 13)

2.3.3 *Caring*

For many participants in all three of the stakeholder groups, it is not enough that a researcher does high-quality, ethical work, and respects the community's values and priorities. The researcher should also have a *personal investment* in the community, meaning they care about the community beyond seeing them as research subjects or even work colleagues. Most participants, across all stakeholder groups, felt that a trustworthy researcher was someone who genuinely cares about the community, and "has my back," (Bridge 20). Many described their partnerships as friendships, or even like family.

> "[Community partner] was like, 'You're like one of my daughters, I feel like.' And I was like, 'Oh, my God…' that one sentence meant the world to me." (Academic 7)

Mission motivated: Many participants shared that they thought it was important for the researcher to be a team player, and motivated by the mission of the partnership, rather than his or her own ego. This was very clear to one community partner:

> "I think within the non-profit world and within academia, if faculty and academics are more engaged in showing up to things where there's not the promise of a publication to

> be developed, or any other ulterior motives, and they just want to help, I think that means a lot. The genuineness of that person, you can tell if somebody is on the right page and if they're mission motivated." (Community 26)

This dedication to mission includes not pushing one's own agenda or ego, but caring about the community's priority and benefit, and establishing a relationship before entering into research together. One academic partner conveyed a story of having to overcome skepticism over her intentions early in the relationship:

> "The first question I got asked very pointedly, 'why do you wanna work with our community? This isn't a savior project. We're not a group that needs to be fixed. We don't want any of that, save your colonial projects. We've had enough damage done in the name of helping. Unless you're here to do this *with* me and do this together and figure this out in a really collaborative way that supports Indigenous peoples' sovereignty and self-determination, don't bother.'" (Academic 13)

Giving back to the community was often considered an imperative, but it was also important that doing so comes from a place of good will, not simply obligation. This giving back can also be broader than just returning research results or employing community members on research grants. For the academics, it means treating their research partnership as more than just a job. It means drawing from one's own array of capabilities to contribute to whatever effort the community might need at the time, focusing less on the confines of professional roles and more on beneficial outcomes. It can mean helping to build capacity in the community to extend beyond the life of the grant, helping with a non-research related community effort, or providing a service without expectation of receiving something in return. One bridge partner explained why she felt comfortable connecting a researcher with her community, despite his lack of prior experience conducting community-engaged research:

> "[The researcher] didn't have the one-directional mindset. He really wanted to partner and not just take but actually—I think in one meeting he said, 'Maybe I have something that I could offer that will help.' He really wants to see providers have expanded capacity to do this [health] screening…He was very open to figuring out how this could be done…

> Even though he didn’t initially know what he had to offer, he was committed to exploring what he had to offer and committing to that.” (Bridge 30)

Commitment: A mutual understanding that the researcher was committed to working with the community was seen as essential for trustworthiness, across stakeholder groups. It signals that the researcher cares about the long-term benefit of the community, not just the scope of the current grant dictates. A bridge partner shared how she responds to researchers wanting her to connect them with the community:

> “I ask, ‘Well, what is your long-term commitment?’ Because this is a long-term commitment. This is not a two- or three-year, just going and doing your research and get back out. I says, ‘What is your long-term commitment? Why?’ I ask them why. I mean I’m pretty direct because I’m not gonna invest energy if you’re just gonna do a grant.” (Bridge 12)

2.3.4 *Vulnerable*

The concept of caring leads into the fourth dimension, *vulnerable.* When researchers get outside of their comfort zone, and share experiences with the community, they can enhance trustworthiness and give a deeper sense of who the researcher is as a person, not just a professional. While sharing one’s own fallibility, and giving up some level of control over the research can be seen as risky by academic professional standards, perhaps counter-intuitively, doing so can enhance the perception of researcher trustworthiness.

Has a stake: Participants across stakeholder groups mentioned that a trustworthy researcher is willing to risk something of value for the community, thus having a stake in the relationship. Researchers risking something of their own, especially early in the relationship, can show a level of commitment to the community, that the researcher is serious about the partnership and the work, enough to put something of value on the line. When researchers become vulnerable in this way, it can indicate that they trust the community enough to take a chance on them, or care enough about the work to risk something. When offered in advance of gaining the community's trust, this can give assurances of the researcher's own dedication, and so, their trustworthiness.

> "You need to build relationships. You need to start with smaller things and maybe in research-wise just, 'Here, I'm just going to give you access to this [research] paper that I've written to share with your members. I'm going to pay my own way to come to your [community] conference so that I can meet all of you and we can just kind of chat and you can see that I'm a nice guy.' …By building relationships, by offering things that [the researcher has] that [I] might like, without asking for anything in return, then I think that builds trust so that I can release something that I hold dear into your care." (Community 22)

Whole person: The vulnerability dimension can be demonstrated by showing up as a whole person, meaning bringing one's complex identity to the work with the community, attending events, and going above and beyond one's professional boundaries to participate in the community, as invited. In this way, it is important to graciously accept community invitations to activities and events, for both partners to learn more about each other. For some, this includes the researcher's willingness to show a very personal side of themselves, not just in their role as a researcher. This can be a very vulnerable position, that many researchers are not accustomed to taking, such as accepting emotional support from community members when dealing with difficult personal circumstances:

> "When I went through my divorce, I can tell you, those women out in [the community] were just phenomenal. They supported me. They sent me home with food. I didn't ask for that. They just, you know, they were concerned. It was really nice. It was very heartwarming." (Academic 5)

Sharing power: Shifting the balance from a traditional academic concentration of power to sharing power of decision-making and resources with the community, was considered necessary for trustworthiness. In the research partnership context, sharing power might include ensuring that the community will own their data, or the partnership will follow protocols such as community partners reviewing all manuscripts ahead of submission for peer review. For example, in order to work with one community group, researchers must agree to the community's parameters:

> "In essence, that's how we approach research a different way... You already have it set up that the data is owned by the community…When you work with a community, it's community involvement with this, the community owns the project." (Community 9)

For some, the community controls the funding and a researcher would have to comply with community guidelines in order to receive a share of the funding. In these cases, the researcher risks their own productivity by not being free to use the data for whatever purpose they would like, or risks the community rejecting the publication, which could harm the researcher's career by dimishing the number of articles they publish. This was seen as demonstrating commitment to the community, as well as being respectful of the community. A community partner, negotiating on behalf of her rare disease community established a power-sharing process with researchers:

> "In the past when I've mediated discussions…first of all calling it for what it is and saying, 'I understand that these are your parameters. This is your reality, and this is what our families want…you still have some rules that you have to follow with the university and I will try to respect those as much as possible. How can we stretch this so that we're involving our families as well and it's not just a drop it and go?' That takes a lot of commitment…The main ones have really put in a lot of their own personal time over and above what their grant is covering and reached out and made those personal connections and shown up in person and phone calls and things like that." (Community 22)

Flexibility, openness: Most participants talked about a need for the researcher's flexibility, and prioritizing the community's needs over the researcher's own priorities, including willingness to change one's schedule at the last minute, spend time on community needs rather than writing one's own papers, accepting unexpected research outcomes, and sometimes even missing time with one's family. Much work and communication is accomplished outside of typical work hours and often requires travel to the community and some personal sacrifice.

However, one academic researcher suggested that accommodating the community's needs didn't feel like a sacrifice, because the community's needs were such a high priority for her, personally.

> "I think of how many times that I'm not at my family's supper table because I'm responding to a community priority. To me, that's really critical. My family, thank goodness, gets it. …I guess it's because for me the lines blur a little bit. It's work, yes, but it's part of being there and being a good partner in this work. It becomes as important to me, I think, as the [community] women that…asked me to work with them on it." (Academic 25)

A bridge partner recounted an engagement process that resulted in a very different outcome than what the academic partners had envisioned— a stronger relationship that laid groundwork for future work, rather than a tangible product— but credited the team for openness to the process:

> "What I think is one of the outcomes I'm proud of, that the academic group was gonna be building in a planning group for all their grants, that they felt so strongly that this had informed priorities and future projects and research, and vice versa. The community felt strongly they wanted to keep working with this particular academic group. I think that's pretty important…In the end we didn't have a Power Point that was magical that you'd go out into the communities and everybody would clearly understand what it is you're doing research on…and speak it in their language and providing a truly informed opinion and feedback on it. That's not what happened. I would say, however, elders…had clear understanding that that wasn't going to happen. They were totally okay with that. They really were just…'if this has real meaning and use in our community we'll find a word for it. We'll figure out how to talk about it.' I thought that was profound." (Bridge 12)

Humility, Self-awareness: An important aspect of vulnerability is humility, along with reflection and self-awareness from the researcher. Trustworthy researchers are aware that their methods and tools are important but limited, that communities know what they need, and what they need might not actually be research or the researcher's methods. Humility includes the researcher accepting not being the only expert, and recognizing there is plenty that the researcher does not yet know that they do not know, or that the community members can offer insights from their own expertise, including lived experience. Having awareness of their own positionality as a researcher, and mitigating that effectively, is key. Two academic partners described their self-reflection:

> "I'm definitely hyper-vigilant about how am I being in community, especially as an outsider, and wanting to do things in a way that's, like I said, respectful and useful." (Academic 25)
>
> "Even before I sat down to say, okay, I want to partner with Indigenous communities, the key was a big responsibility of saying, okay, then I need to do my homework. I need to acknowledge what I know, what I don't know. Where I come from, and where we all come from. Show a real commitment to traveling down this road together, right?" (Academic 13)

One academic partner acknowledged that the requirements for humility and self-reflection, flexibility and openness are not suited to everyone:

> "I think that for some people, that type of research and work is not necessarily for them. Because I think it takes a lot of open-mindedness and …face-to-face time, and some researchers don't have time…But I think it's so important for researchers to look at their partnerships as much more than just they're getting tenure, they're making the research projects, etcetera…Because I think it changes you, as a researcher, if you are able to open up and really work with the community…And realize it's not about you. A lot of time researchers think it's about them. It's not about you, it's about the community and what their needs are and what works. It's their lives. We are coming in for just a brief time in their very busy lives." (Academic 5)

2.3.5 *Respectful*

The theme that pervades all of the dimensions is being *respectful*. Participants described this theme as the researcher valuing the community partner's culture, knowledge, opinions, timelines and priorities; signaling that they understand the community is their equal, and striving to fulfill the community's expectations of trustworthiness. It also means recognizing the community members' sacrifices when doing research, even if they are being paid for it, as they may leave other jobs and family obligations when they contribute to research. Like most of the concepts described, there is intuition involved, and respect is more than just about a narrow, clearly defined scope. Successfully embodying each trustworthiness dimension requires genuine respect for the community.

Respect includes paying community partners for their contributions, asking permission to come to the community, to publish, and take other steps in the research process. Community partners often voiced frustration with lack of compensation for their contributions to the research, or lack of acknowledgement of what kind of burden they bear when contributing to research:

> "A problem with the [research institution] also was where they give us a really small amount of money and expected us to do a lot of work. They did a ridiculous thing, where they were—they were trying to help community groups apply for research grants... They had originally wanted a plan to give out five grants, but they had so many good applications, that they decided to give out six grants…They only had money for five grants, so that meant that they gave less money, but they still wanted you to do as much work. That was one where I, later, wished I had actually turned it down… They say, 'Oh, well, you know, it's a small grant, but, oh, it can lead to a bigger grant later.' Well, it didn't lead to a bigger grant later…The whole thing feels patronizing sometimes." (Community 16)

Respect also includes responsiveness, or changing how researchers operate based on community needs and requests. This includes incorporating what is learned from the community, making accommodations to ensure the community has a genuine opportunity to provide substantive input.

> "Trustworthiness really requires…a lot of listening. Being attuned to the situation so that you can adjust, and adjust honestly and truly, and not just adjust for the surface effect of buy-in from other people…They [community partners with physical needs] just want people to be aware of the needs and make sure that those needs are met so that the research environment—so participating is conducive to it, it's inviting. If it's not inviting, do I trust you?...Do I wanna do this again with you if you can't respect my needs?" (Community 23)

2.4 DISCUSSION: PART A

2.4.1 *Dimensions of trustworthiness*

Researcher trustworthiness comprises four dimensions, being *ethical*, *competent*, *caring* and *vulnerable*, as well as the cross-cutting theme of *respectful*. With the exception of *vulnerable*, each of the dimensions has been discussed in the literature on trustworthiness, but because these concepts are contextual, there are details and applications of these concepts that are specific to the community-academic research partnership setting and worth their own study.

There are a multitude of perspectives on what is considered “ethical” or having “integrity” even within a research context, and using this as a metric or characteristic is not very specific. Therefore, the subthemes and exemplars are crucial for understanding how ethics and integrity fit in with researcher trustworthiness. For example, much has been described in the Philosophy literature about reliability; relying upon someone is written about as distinct from trusting that person, because one can be coerced to rely on someone they do not trust, in situations where there is a need, and the untrusted person is the only available means of fulfilling that need (Hardin, 2002). While perhaps the converse is not true, my study participants were clear that reliability was necessary for trustworthiness. It holds that if a person cannot be relied upon to keep their word, they cannot be trusted. Further, honesty is essential, yet complicated because it requires ethically using complex knowledge, which leads to the dimension of competence.

Competence has been identified in other literature as a key dimension of trustworthiness (Mayer, Davis, & Schoorman, 1995), however it takes on more complexity in my data. Scales based on this and similar constructs of trustworthiness address only an individual’s ability to effectively carry out their job roles. In my data, a researcher’s competence includes standard academic job roles, but also goes beyond what the researcher’s employer expects. In order to be trustworthy within a community-academic research partnership, the knowledge and ability around community's interests and how to effectively navigate those multiple, often competing interests, adds complexity to previously described constructs. This raises questions about whether or not students who are still training can be trustworthy researchers, if competence is a core requirement. Questions remain whether expectations of researcher competence apply to students as well as faculty, or whether there may be other kinds of benefit to the community and partnership of training a student, that could outweigh this need for full scientific competence.

There is much debate within the Philosophy literature around whether or not an individual's intentions or motivations matter. For some, having benevolent intentions or good will for the trustor, are important aspects of being trustworthy (Baier, 1986), while for others, there is no requirement for good will as long as the actions are appropriate (Wright, 2010). In the Organizational research literature, good will or at least benevolence are considered part of trustworthiness (Mayer et al., 1995). In my data, the researcher's motivation, and genuine care for the community were considered important aspects of trustworthiness, as the personal relationship between the community and academic partners is often highly valued. My data align with the Organizational research literature, and the pro-good will philosophers on this point.

Sharing power is a key principle of CBPR and discussed at length in the literature, however, in conversations about trustworthiness, sharing power went beyond sharing budgets and decision-making to specifically giving the community power over something that matters to the academic partner. My data highlight the quality of power sharing that lends it to a demonstration of trustworthiness. Humility—both cultural humility and general— is also often described in the CBPR literature (Wallerstein & Duran, 2006). Here I frame it as part of trustworthiness by clarifying what humility and self-awareness offer to the community, and how a shift from a researcher-as-expert mindset to sharing the role of expert and awareness of how research has harmed communities in the past can improve the researcher's trustworthiness.

In other literatures, vulnerability is generally seen as related to *trust*, rather than *trustworthiness*, as the trustor must become vulnerable in some capacity to the other party in whom they are trusting (Jones, 1996, Rousseau, Burt, Sitkin & Camerer, 1998). However, in my data, vulnerability was described as part of trustworthiness, perhaps because mutuality of trust is necessary in this context, and so trusting the other is part and parcel of being trustworthy. If the researcher does not trust the community, there cannot be mutual trust, and thus the researcher is not seen as trustworthy.

2.4.2 *Comparing stakeholder groups*

Academic partners who participated were recruited because of their substantial involvement in community-academic partnerships, which were generally considered successful partnerships, measured by their long-term continuation. They all had experience dealing with institutional constraints, and most felt that they had seen their relationships shift over time, feeling a sense of trust within their partnership, although they often noted that they could not speak for their partners on whether their partners actually perceived them as trustworthy.

Bridge partners often shared views with both academics and community participants. Their sense of responsibility to the community was more complicated, compared with academic partners. They had deep connections to the community that went beyond the research relationship, and thus perhaps had more to lose in the case of a research misstep. They described their own sense of trustworthiness as an academic, and also that which they would expect from an academic researcher.

Community participants in this study tended to be interested in and supportive of research, but only if it offered some benefit to their community. Those participants who identified as part of rare disease communities were highly interested in research to find a cure for their condition, and in a timely manner, often outweighing a sense of risk from participating, which might have influenced their perceptions of trustworthiness. Still, even those for whom the potential benefit was extremely high (e.g. finding a cure for a devastating disease), the concern about losing control over their data, having their data used for purposes not related to their disease, and the value of feeling respected by researchers mirrored those who had relatively more skepticism of, and less immediate expected benefit from, research. For those communities who were dealing more with social determinants of health, or who have been systematically oppressed in our society, there may be even larger risks relative to expected benefit. For these groups, trustworthiness of a researcher seemed to be imperative to their involvement; the likelihood that participating in research would address their health concerns is more incremental, and there are many other ways to do so, that do not involve participating in research.

Another interesting point in my data, that did not rise to the level of a theme, was that, while there are many ways to find common ground between researchers and community partners, sharing a marginalized identity was one way that community and bridge partners found to judge whether a researcher might be a good fit.

> “Just the fact that [the researcher] is a Hispanic, and she’s interested in doing research on Latinos and HIV prevention, that was 80 percent of the way there…I mean, cause there’s so few. Then just having a conversation with her…and hearing her speak and getting the sense that she understands the challenges…and the cultural issues that go on in the community, and those kinds of things. Those were signals…that she would handle these issues with cultural sensitivity and understanding.” (Community partner 16)

Given the competence dimension, it is not surprising that a community would initially consider someone sharing the community’s identities to be more trustworthy. Still, the underlying issues of trustworthiness remain, and although sharing social identity could help open conversations, it did not seem to reduce the importance of the other dimensions of trustworthiness.

2.5 RESULTS: PART B

In the second two analyses, I identified institutional barriers to researcher trustworthiness that community-academic research partnerships face, and approaches that researchers have used to find solutions, or work through these barriers and cultivate trusting partnerships.

2.5.1 *Institutional barriers*

There were five key themes regarding institutional barriers within community-academic partnerships, each containing several subthemes (see Table 2.2). These included issues with funding, academic pressures on researchers, problematic academic norms, rules and procedures, negative history with institutions, and issues specific to the role of bridge partner.

Table 2.2. Institutional barriers that have arisen in community-academic partnerships.

Money, Funding	Academic Pressures	Problematic Policies, Norms	Negative History	Bridge-Specific Burdens
• Project sustainability • Limits on grant targets/what can be funded • Institution's payment structures don't translate to community context • Power dynamics associated with which entity has the money • Mismatch of payment with work • Value of and commitment to community through funding • Conditions of grants can conflict with community interests	• Promotion and tenure criteria (e.g. only peer-reviewed publications are considered scholarship, not community reports) • Prioritizing publishing, over community benefit • Pressure for short timelines hinder community collaboration • Academic silos and need to develop independent scholarship may limit community benefit • Limits to academics' allowed action can conflict with community needs	• Research designs that are acceptable to the community may not be "the best science" • Burden and learning curve on community • Research protections often misaligned with community's priorities • Publication, and authorship rules misaligned with community's views • Limited institutional capacity to meet community needs • Privilege to academic hierarchy, approaches, and power dynamics • Community ownership is in tension with academic norms; • Sense of transience, community feeling used, and negative narratives • Biased metrics and limitations of peer review for CBPR	• Institutional reputations precede individual researchers • Healing needed • Researchers' responsibility for their institution's behavior, and broken trust—prior to and during partnership work	• Limited diversity in institutions results in added burden of addressing many community issues, taking on uncredited work, mentorship • Educating preparing academics for community research, but often not compensated appropriately • Safeguarding relationships with community, gatekeeping • Role affiliation can strain own community relationships

2.5.1.1 Money and funding

Issues regarding money and funding became the largest, most complex theme in my data. This theme includes issues of project sustainability, including short grant cycles and shrinking funding agency budgets, and increased competition that can lead to less funding for projects. Partnerships that rely on grants can find themselves putting in great effort to build relationships and to launch a program addressing a community concern, which then disappears when the grant runs out. For many communities, this can feel like a betrayal, and that harm can outweigh the good that the program was designed to offer. One bridge partner explained:

> “An argument is made for serving the community, but the organization that secures those dollars are not in the community…this community is often used as a test ground…There's a sense of—a feeling of being used…Versus the ideal would be to really take that information and become a hub. Become a true resource. Garner more resources for that community…There's a sense of—There's temporary resources. Then they're gone.” (Bridge 31)

Additionally, university payment structures do not always translate to community contexts, as many communities involved in these partnerships are located in rural areas with little or no access to banks and stores, or in systems that do not operate as university structures were designed to serve. Several academic partners described their struggles with having to follow university policies in a rural context where these policies do not make sense:

> “My university didn’t want me giving out honoraria to people in cash. They wanted to use bank accounts. A lot of the youth we work with didn’t necessarily have bank accounts. Then some of the elders we worked with they didn’t have SIN numbers…because they’ve been out of the colonial system. Maybe they’ve lived on reserve and never had a job that required those kinds of tax numbers.” (Academic 13)

> “In [community] culture, it’s trust, and it’s handshakes. I take your word for something. But in the university culture, everything has to be signed, documented, W-9s filled out, receipts given. I think that has been really difficult for one thing. I think that people look at you like, ‘We trust you. You don’t trust me? Why do you have to have a receipt?’” (Academic 5)

> “We're used to paying the [rural community partners] their honorarium in cash so that they can go to the grocery store and spend some of it on their way home [from the meeting location, in a town with stores]… University policy would be you send them a check for their honorarium a couple weeks after they've participated…Nobody wants a check two or three days or two or three weeks later. There's a benefit to them to say, ‘Here's your $400.00 for the two days that you've shared your knowledge with us.’ They go straight to the grocery store with that money. It's a benefit to them and their families.” (Academic 1)

There is a great deal of power associated with funding, in terms of who has decision-making power, whose work is valued, how money is used to signal value of and commitment to community interests, and who bears the burden of much of this kind of work. Several community and bridge partners shared their frustrations with this:

> "I sat on a panel reviewing stuff like a year and a half ago and just shocked everyone and said, 'Okay, I want you to turn to the person next to you and talk about what you're getting paid to be here. What's your salary? Now, look at your patient panel up here. We'll tell you what are we getting paid. You're saying our contribution is valuable… How do we express appreciation for value in our society? That's through pay. The pat on the back doesn't work.'" (Community 23)

> "A researcher was holding focus groups in our community…genetic testing in Latinos. Wanted me to be in the focus group, but they didn't have money to pay people stipends to pay for their time. She said, 'Oh, but we will feed you.' I said, 'That's great, yes; the focus group is during work hours…you're asking me, as well as other folks, to take time'—'cause these were going to be like, two or four-hour sessions. That's very long, right? I said, 'You're asking me and others who have very busy jobs to take time…to sit in on your focus group, and you're not going to pay a stipend…In those eight hours I could be writing grants to help sustain the work of this coalition. Thanks but no thanks.'" (Community 29)

> "You need staff that's representative of community… But then when it comes to budgets…which is when it comes to trustworthiness…then where you preserve your line items and for what purpose, it matters…My PI is not securing the line item [for my position for the next] three years that were funded…A PI shows up not knowing the community or the protocol…I've done three years' worth of work, so much so that we got competitively renewed because our work is good. *My* work is. …Then there's no appreciation in terms of where you preserve your line item. I'm at this point feeling used." (Bridge 20)

> "Well, in particular with [research institution]…trying to deal with their diversity issue, and they have this program that's been running for a few years now, and I think that they think that they're doing great things. They give out these really small grants, and I think if you are trying to do something serious, you need to give out larger pots of money. Plus, they make you go to this two-day workshop. You have to sit there for two entire days, which is a lot to ask, especially people that work in the nonprofit, cause you tend to be pretty busy. They expect you to sit there for two entire days to have them explain to you how research works. I mean for me it wasn't—maybe that's useful for somebody, but I just couldn't find it to be that helpful." (Community 16)

2.5.1.2 Academic pressures on researchers

Participants from all three of the stakeholder groups cited concerns with how academic researchers are incentivized to work, and what the constraints of their jobs do and do not support. A common complaint was that promotion and tenure criteria dictate which research products are considered part of a researcher’s scholarship and productivity, and valuing journal articles that the community often cannot access, over the benefit a researcher contributes in a community.

> “There’s a lot of knowledge within communities about…why the disparity, the access issues, are happening…Fixing them may not be easy in the first place, which is why they’re there…You keep defining it, or you can propose research or other ways of approaching it, like maybe even just programming and resources towards that to do something about it. Unfortunately, the latter is not part of many people’s jobs in academics. That is where, I think, the institution fails people who wanna do this work and do it right…but because the universities and the academic systems will not necessarily promote based on how much good you do in a community, versus how much you publish in top-tier journals or get NIH grants.” (Bridge 12)

> “I also think that there's a lot of work out there that speaks to just how the university system has a bias…if you're going out for tenure and promotion, that you need to have first authored manuscripts or you need to be sole authorship…authorship issues are a big deal. You also have sort of, a hierarchy in terms of what are the best journals that would be best for you, in terms of your tenure/promotion process. And those are the journals that might not be accessible to the community groups that you work with.” (Academic 3)

> “It's not intentionally that people say ‘No, don't do that’ [report to the community] it's just that it becomes such a low [academic] priority, as compared to everything else, that has much more of an urgency to it…it's hard to find the time to do it. But I think that's a problem, because I feel like we should not only fulfill our own, sort of drawn out expectations to begin with, but also, it's just a smart practice, no matter what.” (Bridge 2, junior faculty)

These pressures discourage collaboration with other researchers who might be able to complement each other’s work, and could lead to greater benefit for the community. One community partner described behavior that she observed from researchers who feared getting scooped, that she saw as harmful to her community:

> “Well, I mean this whole thing of publish or perish, right? You have to keep what you're learning pretty close to your chest so that somebody else doesn't steal it. 'Cause ideas are free, it's what you publish about the idea that gets you your grant money. That stops communication with the [community] because you can't freely have this conversation…I mean that—just that structure alone I think does quite a bit of damage.” (Community 22)

Additionally, pressure for meeting short grant application deadlines and other timelines was noted as conflicting with community needs and precluding equitable community collaboration that necessarily takes more time:

> “I feel like academics…are sometimes pressured by their academic institutions to hurry up and secure research grants, right? You couple that with trying to build these relationships, again, which takes a lot of time…I think some of this has really been because at the federal level there’s been just tons of this, community-engaged research. Some academic institutions are…coming around, but that’s only because they were mandated to, by the feds.” (Community 29)

Some of these pressures on academics included limits to what kinds of action they are allowed to take in their roles as faculty, and this can conflict with community expectations:

> “Part of our partners couldn’t engage fully based on the constraints of our academic roles and inability to advocate…but talked generally about evaluating policy on its merit, and used [our project] as a case study in teaching about policy evaluation [in a university class]. They got into 2 undergrad classes by couching it as a case study for policy evaluation. Faculty don’t want to be vulnerable.” (Academic 24)
>
> “Another challenge is when you're doing community-based work and trying to build trust, you have to spend time in that community. I've gone to weddings, I've gone to soccer games, banquets…Your time is tracked more closely, which makes sense. This is the taxpayer money that's paying your salary and if it's discovered that you're going to soccer games and banquets and weddings, I don't think that would be widely supported by most people who feel like they're paying for your salary. There's less time available to connect with community in a way that's more focused on relationship building and less focused on the work.” (Academic 6)

2.5.1.3 Problematic academic norms, policies, procedures

Participants shared many highly-regulated aspects of conducting research, and other norms that have become part of academic culture and training, yet do not meet communities’ expectations or serve their interests. Some of these norms can be invisible to researchers, and simply part of doing business as usual. However, these structures can hinder or even preclude community participation in research, preventing partnership success. Research protections, and publication/authorship guidelines do not always align with community's interests and priorities. Several academic partners shared their experiences with these issues:

> "The problem is that the policy always has unintended consequences. Some of the unintended consequences are that each research ethics board…they interpret the policy differently. If they have no experience working with the Indigenous peoples, then they will tend to interpret the policy to the letter of the law…without understanding community dynamic and the way things happen in community, then you tend to get held up at ethics…It can be very prescriptive and paternalistic the way that you're asked to address things like a consent form or your information sheet or how you're gonna collect or analyze data or how you're going to share your results, whether you name people or not. I know that it is always a big thing, and now people are starting to recognize that Indigenous peoples want ownership over their own intellectual property and to be acknowledged." (Academic 25)

> "We definitely didn't follow the authorship guidelines for manuscripts, in that we felt like [community] collaborators who helped develop an intervention…should be included as coauthors, because they had a significant role in the actual development of the program, and even if they were less involved in actually drafting a manuscript, that their contribution was significant and should be recognized as more than an acknowledgement in the manuscript." (Academic 15)

For several participants, their partnerships found that standard research designs were not acceptable to the community, or conversely, that the community's favored design was considered "not the best science." One academic explained:

> "It was also gonna be…an intervention and a control group... There was gonna be classes on mental health for one group of women and then I wanted the other group of women to get classes about something else, but it still be meeting in a group because I wanted to control for that. I had an idea about these tech classes that another [university] student had done there and I thought those would be great for a control and I took that back to staff…They were like, 'Well, we're not really sure we like those tech classes…if the women don't get to do this project, we want the other women to get this.' I basically changed the study design to fit this other thing…In my opinion…it wasn't the best control, but I was able to write it by being a little vague in my grant…in a way I thought I could sell it to the funder." (Academic 11)

Additionally, several academics lamented that while promotion and tenure criteria pressure academics to publish and receive grants, there are many within the peer review system that devalue CBPR, or do not understand how to review it appropriately:

> “The notion of having people who are, quote/unquote, your ‘peers’ review your work. If they really don’t understand what it is that you do, they’re not really your peers…not just at tenure and promotion. I would apply that to having peer review when you’re submitting grant applications...as well at publication and having journals get peer reviewers to review your work. If they don’t get it right, it becomes really problematic.” (Academic 25)

In many research partnerships, the academic partner’s institution may not have the capacity to meet community needs, such as not having anyone with specific expertise to effectively answer the community’s questions. For some, *research* in general, was actually a limited approach that might not address the community’s priorities adequately:

> “We do this [research] in a very idealistic environment…There's just unrealistic concepts depending on which perspective of academia you’re coming from. Are you approaching it from the public health angle? Are you approaching it from the individual health care practitioner angle?…When I try to speak to the universities, they’re looking at, ‘Okay, we’re helping in this capacity,’ and I'll try to share with them the idea that, ‘You’re helping in a very minutiae amount that’s not going to be something we can build off of. There needs to be more of a commitment in order to do things different, but, yes, you get to publish a paper saying how you surveyed all these patients and found this information out, but what good is it doing to the community that you surveyed them and you put a paper out?’” (Community 26)

For one graduate student, working within her own community, the project that the community wanted was held up in the academic process. Because the project was a dissertation, specific research components were required by the academic team that the community did not value; rather the community favored the intervention proposed in the study for their own purposes, regardless of the academic value or rigor of the project.

> “There were times when there have been people who said, ‘[Interviewee], just drop it. Don't try to do [the research]...Just you go ahead and do the community project [intervention]’…In fact, independent of me, other community members…really wanted to do that...They started talking to each other...One of them contacted me…I'm also participating in that because the community want it, I want it, and this has nothing to do with research.” (Bridge 27)

There is often tension over the university having most control, and community ownership is often favored both for signaling respect to the community and for sustainability of the project.

Without community ownership, there is often a sense of transience, and negative narratives can arise. One bridge partner explained the value of the data to the community:

> "Thinking about it in partnership, what might that community do with the data?...What it means to them. If the media or the policymaker were to…repeat this in a way it wasn't meaningful, at least the community could have some way of telling a different story; Changing the narrative…Looping back around so it's not just the information was provided, the community didn't have any ownership of it…The researcher has the information, is gonna do X with it. We have the same information, and we're gonna do Y with it." (Bridge 31)

The data ownership issue intersects with the theme of funding issues, as data ownership and control issues can conflict with conditions of funding. One community partner explained that not owning their data is a non-starter, and they are willing to forego grants that require the university to own the data:

> "We had been very sensitive about data and who owns the data…Other projects, where they wanted to own the data, and we said, 'No.' Yeah, we've had that problem with a huge funder who gives millions dollars to the University... They wanted the data, and we had to say, 'No.' Of course, when you get the 'no,' you don't get the money either." (Community 9)

2.5.1.4 Negative experiences with institutions

Participants explained how academics' institutions' reputations precede them, and can influence the community's expectations of the researcher to perpetuate harms. Several participants shared:

> "Some really not-so-good experiences, right? …In fact for the most part they were pretty negative. A lot of the communities we work with want no part of research, have very little respect for research as an idea. Unless you start with that history and that understanding you're doomed to just fail and replicate old colonial models." (Academic 13)

> "I had a student who worked with me for the summer…to explore the [community] neighborhood and its historical issues and the relationship with the university…finding out that there's an incredible lack of trust between [community] and the university for many years because a lot of the land and the parcels would be taken over by the university for university buildings, with not a lot of respect and not a lot of timing for the families to relocate…I realized that this really was a group that had not necessarily been

> treated that well by the university, and I was from the university, kinda nosing around, to try to build a partnership." (Academic 10)

> "When I'm teaching this to students or faculty, I always tell them, 'When you're meeting a partner, get a sense of what their experience has been with [the university] or academia before…because maybe…you're walking into somebody that has already a bad attitude because of past experiences, and really use that as a place where you can begin to develop a relationship, or maybe even they have a misunderstanding about the organization.'…In the community's mind, when you say [University], it could be the hospital, it could be the children's hospital, it could be the academic—their whole experience as a patient, or what they heard a patient's experience, was what they were basing their perception of [research university]." (Bridge 30)

Healing is needed from the harms that have been committed in the name of research, and academics must take responsibility for this history, as a member of that sector. A bridge partner explained:

> "Starting to meet with a tribal organization or a group of people, when you're first getting to know each other… you always get to hear about all the terrible things the researchers have done. That's part of your role, is to listen to that and recognize it… Scientists are not always focusing on the right questions or the right methods for…many of the health problems that come from practices that are colonizing…the way research has been used to take things away from people rather than heal people..." (Bridge 12)

A couple of counter-examples were offered, in which the community partner had positive experiences with the institution, helping to facilitate trust. For example, one young community partner noted,

> "I went into it really positive I guess. The belief that it was going to be a positive experience and that these institutes were doing good and that I could contribute to that and make it even better. I know I'm kind of coming in opposite of—I guess I missed the community abuse era a bit." (Community 19)

These institutional harm issues can also occur and cause rifts in trust while an established partnership is collaborating.

> "We don't control the data systems, we're trusting our own system to do that appropriately. It's sort of like some of this that I think of as trust, is a little bit of 'wait and see.'…If something happens we are untrustworthy because we're part of the system that

> did something terrible. It's definitely just, I don't know how to mitigate that except it's a risk and we've done the best we can and we also hope it doesn't happen…It's so personal…They're not going to differentiate between you losing your [research program] data and clinical data it's all going to be "[institution] lost my data." (Academic 18)

2.5.1.5 Bridge-specific issues

For individuals who both hold academic positions, and are members of the communities involved, there can be additional challenges. These include burdens of representation, whereby, with so few people of color within academic institutions, they end up doing the job of several people, including educating other academics, and affecting structural changes in the university. Several bridge partners explained:

> "Academia needs to realize that and when you get a diverse person in there,…do they have *support*, support?... In addition to bearing the burden of handling more issues than other academics, bridge individuals often have to educate academics about how to engage with communities. This is not a problem across-the-board, but when the academic has not done their homework, it can be an undue burden." (Bridge 4)
>
> "One of the things that I push in my guidances is that the tribes have every right to say no, and that the identified need for the research has to be identified by the tribe. You can come with all the great ideas, but no longer are researchers gonna go in and say, 'We're coming in to save you. This is a great idea that you guys need.' It's gonna be, now collaborate with the tribes…make them true collaborators in the project…The [university's] response was what resulted in all of the research coming through my office." (Bridge 14)

Bridge partners explained that they often find themselves in gatekeeping roles, being asked to connect academics to community, which can be a large burden on their personal relationships, with so much at stake.

> "Often I get approached [by researchers] to connect people, because they have a grant they want to go for… and I feel a little safer [to them] than going straight to the community. Sometimes, just by the way they frame their idea, their question, and how they came about it, I feel like giving them a whole course, to go and learn it online themselves first…because the investment of my time or other people's time may not be worth it at that point…You have to actually personally go out and meet people and listen to them and you may not come back with the same research question. If that's a problem, then you need to do more work before I support or guide you." (Bridge 12)

2.5.2 *Approaches to overcoming barriers*

When discussing issues arising from the institutional policies and practices that hindered the researcher's ability to fulfill community's expectations of trustworthiness, participants were also asked for the ways in which they overcame these challenges, if they did at all. In these cases, the actor is the researcher, and these approaches are reported from all three stakeholder groups (Table 2.3).

Table 2.3. Types of approaches used by academics encountering institutional barriers, with examples of each approach.

Advocate/ Educate	Find an Alternative	Personal Effort	Apologize/Explain	Resign from Job
• To funding agency to justify travel budget • To university financial office about essential research expenses that are not typically supported • To IRB about community's protection needs, and conflicts with standard protocols • For exception to university payment processes, to ensure community partners can genuinely benefit from payment • For changes to promotion/tenure criteria; which research products are given credit • Speak up when institution breaks community trust	• Use discretionary funds for necessary community expenses • Find funders who accept community organization as primary grant applicant • Creatively write community partners into grants that fulfill both needs • Seek academic jobs within institutions that do not value being primary grant applicant • Cut ties with researchers that do not comply with community protocols; find alternative academic partners • Build community accountability into job description • Academic as data steward not owner	• Self-pay for research expenses the funder or financial office will not reimburse • Self-pay when documentation would be too cumbersome • Use personal time to create community reports that university does not value • Use personal time to find grants that suit community's needs; adapting community project to suit funder goals • Ensure community benefit by providing non-research services, such as mentorship and training, supporting community efforts • Use personal time to attend events	• Communicate early and often about any institutional issues that arise • Ask for understanding and forgiveness when grant is not funded; when grant will not allow researcher to attend important community events • Up-front transparency about what the researcher needs to meet academic job criteria • Explain what constraints are and why the research cannot do as community would like, but keep advocating against constraints	• Seek another department if own department does not support CBPR • Seek another job with a better-funded institution • Seek a higher-level job to have greater power within institution to support community work • Leave to separate self from institution that severely harmed community during partnership work • Leave to focus on community benefit, and not be constrained by academic position

2.5.2.1 Advocate/educate for exceptions or revisions to policy

By far, the most frequently reported approach to overcoming institutional barriers included a combination of educating and advocating to institutions for which the institutional policy does not suit community needs. These institutions include funders, institutional review boards (IRBs), financial services offices, departments and administrators. Academic partners educated about the community context and realities they face, and argued for exceptions to a given policy or to change the policy altogether. One such example includes a researcher who motivated a change in university policy that kept her from being able to use grant funds to buy items not considered standard research expenses, but necessary for conducting respectful research with her community partners. She reported:

> "I had regular frustration with dealing with questions that made me feel that I wasn't trusted as a researcher by my own institution. It got to the point with the financial people that I contacted my vice-president and said, 'Look, if you don't help me do my job, I'm sending the money back because I can't spend all of my time fighting to get reimbursed for things that are legitimate research expenses. I can't get any research done.'" (Academic 25)

Another academic has expended much effort to explain to the university that their policies do not make sense in the community context, and can contribute to negative perceptions of the university:

> "…the university, who operates in this very bureaucratic tax model that's beholden. I spent a long time trying to get my university to change its policies, and to explain why...It's very frustrating in the moment when you're in a middle of a community…'Cause they just did the work, and the norm in the community is to just hand them the money. It's not to say, 'oh okay, let's wait for your check,' or …'I'm gonna put in a requisition form'…It's certainly not the way it's done in [rural community]. They're just like, 'what in the world are you talking about?'" (Academic 13)

At times, the best route is to convey the community realities to a potential funder. One researcher found that taking the grant agency's program officer to visit the community helped him to understand why the researchers' grants budgeted so much for travel:

> "A long time ago, our program officer—I took him out to one of [the communities], and he actually saw what it was like. I think that really helped him to see that, 'Oh, we are way far out.' Then we almost didn't get out because the weather had turned and the plane wasn't gonna come. He was like, 'We're gonna get stuck in the village!'…Actually having your program officer come out. That was one of the best things you can do, because it's, like I said, eye-opening experience for them." (Academic 5)

Another found that she had to explain in her grants why the protocol included aspects that may seem inappropriate to reviewers:

> "I think what you try to do is explain to the funder what the community has said. You try to show preliminary data, what worked or didn't work. You try to tell the funder…'the community has been engaged in the development of this intervention and this is what the community has said will work or won't work.' A lot of funders were probably anticipating seeing…that the promotores would be staff of [community partner organization] and that would be the best model in a lot of reviewers' eyes, but I wrote in the proposal that that was not actually what they [community] wanted." (Academic 11)

Instead of directly advocating on behalf of the community, sometimes the better option is to advocate to connect the community leaders and the university administrators, so the community leaders can speak for themselves. One researcher whose institution broke promises to her community partner, having nothing to do with her research, said,

> "I was able to put him in a meeting with some of the upper administration, so he could talk to them about his frustrations about those things…who might be able to address some of his larger concerns…He's the director of tribal health, and I think he was happy to be talking to people more at his level… I also kind of said to my upper administration that not having this meeting could adversely affect my own research." (Academic 21)

A bridge partner leveraged her position at the university to ensure that sustainability of funding would not be a problem in their community-facing programs. She ensured that there would be a base of funding that was not dependent on grants, to build up their infrastructure and ensure the basic programs' sustainability before securing more temporary supplementary funding from grants.

> "My goal in my work has been to try to really institutionalize change…Because I've observed so many universities where, oh they'd get a grant and they'd provide certain services to maybe students or tribes. Then four or five years, it's ended and that's it. We're building from a base here that it's one hundred percent state-funded. Now just in this last year…Now we are at a place where I feel comfortable to start going after grants ourselves that will just build on what we already have…My own position has been I'm not going out asking the tribes for anything until we've shown that this university is serious about what they're doing." (Bridge 17)

2.5.2.2 Take an alternative route

When advocating for exceptions or changes to a policy are not efficient or realistic options, some partnerships sought alternative ways to meet research goals by circumventing problematic policies. This included seeking funders that allow the community partner to be the primary institution on a grant, or setting up agreements and structures that enable the community to own their data. For example,

> "Our partnership, I think, was unique in that the original funding was from [agency]. We were one of the few partnerships where the community-based organization was the principal investigator. We did a lot of subcontracts with all the other partners, including the university partners. We had Memorandums of Understanding and things like that." (Community 8)

Some PhD-level researchers opted for faculty positions at a non-research-one university, or avoided tenure track positions, to allow for the flexibility needed to spend time on relationship development. Two participants explained:

> "I chose not to go tenure track because that would've just killed me. I did not want to get into the rut of trying to produce, publish and still maintain my relationships." (Bridge 4)

> "I'm fortunate in that, I am not at a research-one institution, so the pressures that some people might have at research-one institutions weren't my reality…There was no push-back about…'why isn't my university the lead applicant on the grant?'…I don't know if other institutions would have felt some heat in terms of having the grant go through their

> university versus going through, you know, the other organization that was involved." (Academic 3)

2.5.2.3 Personal effort

For some, the best alternative approach was to circumvent funding and documentation policies altogether by paying out-of-pocket for legitimate research expenses that the institution did not recognize as legitimate, or when the system for paying would not fit the community's needs. For example, some travel expenses in rural communities are outside of the standard economy. One researcher described paying a community member for a ride when there are no commercial travel options:

> "If someone's giving me a ride across the river in their boat, and they were just being kind, but I'd like to give them something to say 'thank you, I know this is gas money for you.' I don't stop and get a receipt. I just do it out of my pocket, because it's too awkward sometimes." (Academic 5)

In one case, a community partner also described making personal sacrifices to be able to partner on the research, as the project was important to her:

> "I had to change jobs because I couldn't do a 40-hour workweek anymore and this [research project]. I sell advertising space in a magazine and make commission so that I can have very unlimited flexibility with my schedule." (Community 19)

2.5.2.4 Apologize and explain

If no other options exist for handling an institutional issue, it is sometimes necessary to simply be honest about the issue and how efforts to address the issues have failed, then ask for the community's understanding and forgiveness. However, the researcher must have the integrity and track record in the relationship to back up the apology. This option was mostly used either when setting initial expectations in advance of deciding whether to partner, or when a relationship has been well-established. For example, there is no avoiding some kinds of documentation, so the researchers must be honest, recognize the awkwardness, and hope for understanding from the community when imposing institutions' rules on the community:

> "When I have to get W9s for everything…I kind of try to make light of it, but I say, '…They [university] wanna make sure that I'm not taking the money, and going on vacation somewhere.' Everyone usually laughs, and it's okay. It diffuses some of that tension of like, 'Well, why do I have to sign this and fill out a W9 and report this to IRS.'" (Academic 5)

For others, letting the community know what the blocks are, as the researcher is working to change them, while validating the community's request and frustration, is essential:

> "A lot of people want [their own] information back…Right now we can't do that for a thousand logistics reasons. It's tough because it's hard to say that's a completely legitimate request and…we couldn't be better positioned to do this, but we still can't… It's just having to tell people: 'You know what, that's a totally legitimate request and I can do nothing about it'…The best we can do is bring it up all the time [with the institution] and say, 'don't forget, our community really wants this and every time we talk about it they bring this up'…So we can definitely advocate for them but it's gonna be a huge organizational change." (Academic 18)

> "I think the fact that we've now put in several grants that haven't gotten funded…it's hard for me to keep going up and asking, 'I need *another* letter. We have *another* grant that we're putting in.'…It's hard to explain why we're not getting these grants…I feel I'm disappointing them, that things are slowing down, and think they understand, but also, if you're not in the grant world, it's just a little difficult to understand why grants are so hard to come by." (Academic 21)

2.5.2.5 Resign from academic position

Unfortunately, in extreme situations, several researchers reported that their only option could be to leave their faculty positions. For some, that meant leaving a poorly funded institution to find a better funding environment to support community-based research; for others, it meant leaving an academic department that did not recognize or value community-based research. For example,

> "One of the things that I was told early on, when I said that, 'you know, the kind of research I do, it just kind of takes more time,' was 'maybe you have to change how you do your work.' I thought well now I don't really want to change *how* I do my work, I

> might need to change *where* I do my work because it just, it pushes me in a way that is a kind of a compromise of my values."   (Academic 28)

For a bridge partner, leaving the academic research model altogether enabled her to prioritize the work that matters to the community, regardless of whether research was primary:

> "The idea there's a bad model in place for actually using research and the kinds of skills and resources we have in academics to make a difference socially. I left the university, for now, because I think I can find a better model…Because I'm not tied to a certain set of criteria in order to keep my job or be promoted... I am able to go for funding sources anywhere I want and with whatever partners I want, and even small partners which are many of the groups doing the most progressive work in communities, even those partners, I'm flexible enough to work with." (Bridge 12)

One researcher left her job when the university deeply harmed the community through a decision regarding funding, and did not feel that she could continue the program she had started for the community, as a university employee under the university's new conditions:

> "I was invited to go to the new center and provide the same type of service, and I said no. I couldn't do it. I couldn't do it. The project ended, and I ended up taking a different position somewhere else. I was really affected by it…That certainly broke trust. Again, I was helpless. I was a part of that labeled group, and it happened, and there was nothing I could do." (Academic 10)

2.6 DISCUSSION: PART B

There is much interest in community-based participatory research, and other similar engagement approaches from researchers, communities, funders and research institutions alike. Despite calls to include community voices in grant applications and to diversify research participant pools, institutional policies and practices remain that pose barriers to community participation at various levels. Academic structures are built for individual career advancement, valuing academic knowledge and expertise above other types of knowledge, and making a career through small incremental additions to generalizable knowledge, rather than impact on community outcomes. There are few consequences for those who exploit communities in this system, and damage the names of our institutions within those communities. This study contributes to the CBPR literature a consolidated catalogue of institutional barriers, with creative approaches to addressing these barriers, drawn from individuals involved in three positions within community-academic research partnerships: academic partners, bridge partners, and community partners. I also offer a new study context to the literature on trust and trustworthiness.

While many academics who genuinely wish to do right by community partners have found creative approaches to overcoming these structures, the fact that this must be done on a case-by-case basis, and puts increased demands on already busy academics, raises questions of how our academic systems might be restructured to support the work that may have great public health impact. My data show that academic partners are not just operating as researchers, but they are positioned within their institutions to advocate for changes that are in the community and partnerships' interests. While this is likely to be necessary indefinitely, perhaps there is a way to relieve some of this burden, through greater flexibility, and recognition by the institutions that the policies that were created for standard research practices do not necessarily apply to, or support community-based research. Academic institutions might engage with researchers, community partners, funding agencies, members of IRBs, and other administrators, to examine their own structures and policies at multiple levels to figure out what is and is not working and what might be changed to support community-based work. Simply raising awareness that ingrained structures and norms can constrain researchers and reproduce harms to communities, could be a first step.

The key institutional barriers that arose in my data are consistent with reports in previous literature. One theme that arose across all stakeholder groups was the pressures on academic researchers to publish and write grants that will allow them to keep their academic appointments. There are many responsibilities for academic partners to meet community expectations, that are not considered part of their academic scholarship. However, as has been pointed out in the past, this does not have to be the case. Nyden catalogued a system of incentives that could be employed to promote CBPR in institutions (Nyden, 2003), and my data demonstrate that these issues remain salient today. Tensions regarding the limits of the current peer review process to effectively evaluate CBPR projects and publications has also been described previously (Castleden, Sylvestre, Martin, & McNally, 2015). Despite funding for community partnership in research, a study of several Clinical and Translational Science Award programs (CTSAs) showed that only about a third of respondents felt their institutions valued community engagement for promotion (Marrero et al., 2013). Further, other research has shown that those researchers who do conduct CBPR are more likely to be female, African American or Latino than male, or white (Chung et al., 2015). It is possible that institutions that modify their promotion and tenure criteria to account for and reward CBPR, might create pathways for more diverse faculty to be successful within their institutions.

In all approaches to overcoming institutional barriers, the researcher must expend substantial effort beyond their standard research duties and relationship-building efforts with the community. They do this through taking on a role of educator and advocate within their own institution, finding non-standard ways to meet community goals that avoid running into academic policy barriers, using personal resources and time to solve issues, pro-actively communicating with the community about barriers that cannot be avoided, or even finding a new job. While the idea that community-engaged research takes a long time and a lot of effort is not new to the CBPR literature, I offer a set of categories as well as specific issues in each, that can help prepare researchers for potential realities of this approach.

It is possible that these barriers, when dealt with to the community's satisfaction, could actually increase the trustworthiness of the researcher, as a means of demonstrating one's dedication to work on the community's behalf within the institution. More research would be needed to determine if this is true. Still, given the number of participants in my study who suggested they would leave or have left their jobs due to institutional barriers to meeting community partners' expectations for the research partnership, attention to making these changes is warranted.

2.7 LIMITATIONS

This study has several limitations. First, the sample was skewed toward more educated individuals (all participants had a least a college degree), and is largely female. However, the field of CBPR is skewed female relative to other research approaches as well, so this is similarly representative of the field overall. The education-level bias is likely related to the study's inclusion requirement that the academic and bridge participants would have academic research jobs, (which usually require advanced degrees) and that the community participants be partners in the research project, not just participants in the studies. While there was no requirement for community partners to hold employment positions that require degrees, the research partner criterion drew largely individuals who hold leadership positions in community-based organizations, and so these participants also had high levels of education. The overall level of education in this sample is likely not representative of all communities who might participate in research, and the voices of those with less formal education are not included here.

Further, all of the participants were currently or previously members of multi-year research partnerships, and so the perspective represented here is generally of those who have had at least some positive research experiences. However, even in the course of a long-term, successful partnership, most had negative experiences, compromises or challenges to trust, or experiences from other partnerships in their past that had not gone well. While they were asked to generally consider one partnership, stories based on other partnerships were welcome if the participant deemed them relevant to the interview. In general, each participant shared a mix of successes, challenges, and failures, but they do not represent the views of communities who have only experienced failures, or have never entered into a partnership, including those who have avoided research for distrust reasons. Additional research is needed to understand the views of those who do not partner in research.

While trustworthiness within dyads is a worthwhile locus to explore, having two partners represented in the sample was not a criterion for inclusion, as I focused on an individual's perspective on the meaning of trustworthiness. This meant that the academic partners spoke to their own perspectives on other researchers' and their own conduct and commitments, but these views were not compared with their community partners' perspectives on their conduct. Participants were asked to invite their research partners, and in a few cases, those partners did participate. More often, however, partners did not participate. While I did not collect data on why, I can speculate that it could be because of privacy and confidentiality concerns, or concerns about potential impact on the relationship. Alternatively, partners might have been too busy or simply not interested in participating. Thus, this analysis does not take a paired approach to compare and contrast multiple perspectives on the same partnership. This inquiry would be worthwhile future research.

As this is a dissertation study, the interviews and data analysis were conducted independently, rather than using a team-based approach. To ensure consistency and strength of themes, fresh coding of the full data set was undertaken multiple times across different periods of time. For example, after themes were developed from the first rounds of coding, the entire data set was recoded using those themes and their subthemes to ensure all data were captured and themes reflected the data after a period of time away from the initial coding process. Key themes and subthemes were reviewed by a member of the thesis committee with qualitative research expertise (Dr. Edwards), then also by participants in the second aim study, who participated in cognitive interviewing. Dimensions and subthemes were modified slightly based on this feedback. This approach is consistent with the principles and goals of qualitative research, to develop interpretive frameworks that capture the breadth of a concept. Multiple coders is one way to meet these goals, however, not necessary if care is taken to meet these goals (Barbour, 2001).

2.8 CONCLUSIONS

> *"Community research here is a live, living entity. It's a force, and you have to treat it that way. You have to care for it…Maybe, at times, you adjust it. You've got to feed it. You've gotta talk to it. Community research is something you go into knowing full well it's like raising a plant. It's like raising a child. It's a living entity, and it has needs. You need to be aware of these needs and take care of it, as soon as it appears, because if you let it go, there's gonna be injury. There's gonna be suffering, and who knows? That community partnership or that research project could be irreparably harmed, or it could die." (Community partner 9)*

The concepts of trustworthiness presented in this exploratory study are not wholly surprising, but the details included make this a new contribution to the literature on trustworthiness. The meaning of each of the terms and dimensions may differ across contexts, and if building trust is as essential as it is generally taken to be in the community-academic research partnership context, then tending to the specifics of each dimension of trustworthiness will be needed. Existing literature concurs that trustworthiness includes competence/ability, a sense of ethics or integrity, and (however less universally accepted,) good will or caring toward the trustor. In my study, these three dimensions arose although it is in the details that the contextual factors become clear. Diverging from the extant literature, I found a fourth dimension, vulnerability, that also rose to the level of an important dimension of trustworthiness in this context, as well as a large emphasis on respect, that intersected the four dimensions.

I report themes gathered from interviews with academic, bridge and community partners with experience in community-academic research partnerships, on institutional factors perceived as barriers to researcher trustworthiness, as well as approaches that researchers have taken to mitigate these barriers and fulfill their partners' expectations. These factors included a range of funding issues, pressures felt by academics trying to keep their jobs, academic policies and norms that do not translate to the community context, history and reputation of the researcher's institution or research in general within the community, and bridge-specific issues. In many cases, the appropriate approach to dealing with these issues was to spend a great deal of personal effort in trying to change these policies or norms, seeking out other ways to meet their goals, taking on personal expense, nurturing the relationship when no alternatives could be found. In a surprisingly large number of cases, the researcher determined that the most ethical approach was to separate from the institution whose policies, norms, or actions caused harm in a community, or prevented their own successful CBPR, by resigning from their job.

Future research includes investigating whether these concepts also resonate with those community members who have had no experience or only negative experiences with research; to see how these dimensions apply to student researchers and in other research settings; and assessing the scope of the impact of each of these institutional factors on perceived trustworthiness, to suggest priority areas for institutions wishing to remove these barriers to conducting equitable, ethical community-engaged research. Interest in engaging communities in research partnerships to address health issues relevant to them is increasing, and new funding is becoming available to support these efforts, in theory. However, the success of these projects, defined in part by the communities' perceptions of researchers' trustworthiness, depends on researchers being less constrained by their institutions to fulfill their community partners' expectations of respect and ethical engagement, in addition to satisfactory impacts on health.

Chapter 3. DEVELOPING A MEASURE OF PERCEIVED RESEARCHER TRUSTWORTHINESS

3.1 INTRODUCTION

Trust is widely accepted as essential for successful community-academic research partnerships, such as community-based participatory research (CBPR) (Pivik & Goelman, 2011; Schulz et al., 2003). Several partnerships have documented the trust building process, and indicators of trust (or distrust) within their partnerships (Ahmed et al., 2011; Christopher et al., 2008; Luque et al., 2011; Voyle & Simmons, 1999). Wilkins and colleagues have developed a conceptual framework for measuring trust in biomedical research that can be used in community-academic partnerships, as it takes into account dimensions relevant to racial and ethnic minorities (Wilkins et al., 2015). However, the empirical study of trust within community-academic research partnerships has been limited.

Scholarship on trust is substantially more developed in fields such as Philosophy and Organizational Research, with definitions and aspects of trust debated over the past few decades. There is cross-disciplinary consensus that trust is both multi-dimensional and context-dependent (Hardin, 2002; McEvily & Tortoriello, 2011; Rousseau, Sitkin, Burt, & Camerer, 1998).The bulk of the empirical work on trust has been conducted within Organizational Research, between players such as managers and employees, managers at the same level, or boundary role persons across organizations. Mayer and colleagues presented a widely cited integrated model, in which they described trustworthiness as an antecedent to, and not interchangeable with, trust. The other key antecedent to trust is the trustor’s propensity—or personal inclination— to trust others (Mayer et al., 1995). A metaanalysis on the effects of trust propensity and trustworthiness (examined as its three component parts, based on Mayer and colleagues' model, *Ability*, *Benevolence*, and *Integrity*), found that trustworthiness was more strongly related to trust than to trust propensity (Colquitt et al., 2007).

As trustworthiness is strongly related to trust, it is a characteristic that researchers can develop to build trust within their partnership. Doing so requires understanding what the trustor (here, the community partner) cares about and considers valuable, and acting in a way that meets their expectations for the researcher's motivation, process and outcome. Additionally, it is important to identify factors that may hinder this development for researchers who are trying to meet their community partner's expectations. Although ultimately, the goal is to support the building of trust within these partnerships, for the aforementioned reasons, I focus my work on the concept and measurement of trustworthiness, as an important antecedent to trust.

To advance the empirical studies complementing the theoretical work on trustworthiness, high-quality measures of trustworthiness are needed (Bijlsma-Frankema & Rousseau, 2012). A recent systematic review found 5 high-quality scales developed to measure trust within organizational settings (McEvily & Tortoriello, 2011). Of these, three scales specifically measured perceived trustworthiness, or beliefs about the character of another individual or team. All scales reflected a multi-dimensional concept of trust, and demonstrated high psychometric properties (see Table 3.1). Each scale was tested in application to a distinct relationship context with little overlap between scales. Lists of items included in each scale are presented in Appendix A. I present a summary of the constructs in Figure 3.1, comparing the constructs covered in each scale, and the sub-themes from my data (Chapter 2).

Table 3.1. High-quality trustworthiness scales from the Organizational literature, recommended by McEvily & Tortoriello (2011).

Scale citation	**Relationship assessed**	**Trustworthiness constructs**	**Construct definitions**	**Psychometrics reported**
(McAllister, 1995)	Peer manager dyads (similar power)	Cognition-based Affect-based	*Cognition-based*: competence, responsibility, reliability, dependability *Affect-based*: expressions of care and concern for welfare, emotional bonds	Model fit CFI= .90 Reliability for 4 subscales: α= .69-.87 Validity assessed: Discriminant= all significant (t >1.96) Convergent Nomological
(Cummings & Bromiley 1996)	Inter-organization (between groups), peer boundary role persons	Trustworthiness is a belief in another's character: Good-faith effort Honesty Limited opportunism	3 dimensions of each construct of belief: affective, cognitive, intent to behave.	Bentler fit test= .94, .92, .89 Reliability (α): Good faith effort= .95 Honesty= .95 Limited opportunism= .94 Validity assessed: Face Convergent Nomological
(Mayer & Davis 1999)	Managers and employees (unequal power); although designed for multiple organizational relationships	Ability Benevolence Integrity	*Ability*: group of skills, competencies, characteristics that give one influence within some domain. Perceptions of others' ability, formal and informal. *Benevolence*: extent to which a trustee is believe d to want to do good to the trustor, aside from egocentric profit *motive*. Caring about the other's interests. *Integrity:* trustor's perception that trustee adheres to a set of principles that the trustor finds acceptable. Both espousing and acting upon those values.	Reliability (α): Ability= .85-.93 Benevolence= .87-.95 Integrity= .82-.96 Validity assessed: Convergent Discriminant Nomological

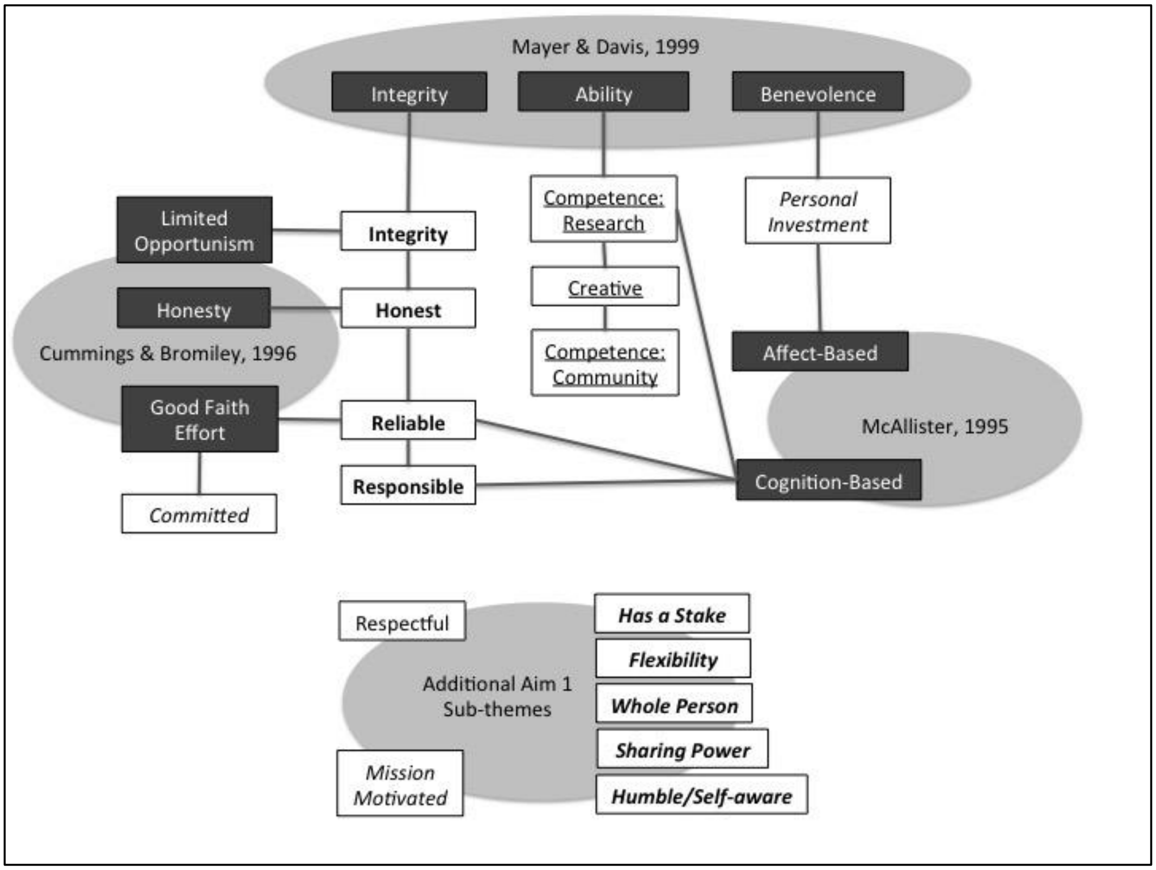

Figure 3.1. Existing trustworthiness constructs compared with Aim 1 sub-themes. Dimensions are as indicated: Ethical (bold), Caring (italics), Competent (underline), Vulnerable (bold italics), Respectful (plain font).

While there is a growing body of scholarship on trustworthiness in other fields, study of this concept within community-academic research partnerships is lacking. As trustworthiness is highly contextual, and the specifics of the relationship matter greatly, measures developed for one type of relationship cannot be assumed to be appropriate for another relationship context. Studies on what this means in the community-academic partnership context are warranted to support the development of trustful partnerships. While qualitative studies are immensely instructive for gaining insights into specific factors relating to individual partnerships, and a holistic understanding of trust and trustworthiness within a partnership, this work is time- and labor-intensive, and requires technical training to administer. By contrast, a simple quantitative scale, once validated, can be administered quickly and easily by anyone, and results can be tabulated simply, offering immediate and on-going information for a partnership.

Such a scale could be used in multiple ways. One example would be for leaders of a community organization to gain a sense for how their members perceive the research partner(s), the results of which could set up rich conversations within the community or organization and support their process for determining whether and how to work with a researcher. Another use in a research context would be to associate the results of this measure with potential factors that might influence perceptions of trustworthiness, and determine which factors are most salient for the community partners. These results could help an institution prioritize policy and practice changes within their own institution, to support community-academic partnerships.

The goal of this study is to develop and validate a high-quality quantitative measure of perceived researcher trustworthiness that could be easily used within community-academic research partnerships. There are no measures of perceived trustworthiness that have been developed and validated within this type of relationship; it is unclear whether scales that have been developed in other relationship contexts can be used in the community-academic research partnership context. This study drew from those existing scales as well as the new dimension and subthemes that were found to be relevant in my previous qualitative study (Chapter 2), to develop and test the psychometric qualities of a scale to be used in this relationship context.

3.2 METHODS

3.2.1 *Scale development*

A new scale was developed following steps outlined by Hinkin and colleagues (Hinkin, Tracey, & Enz, 1997). I previously conducted semi-structured interviews with individuals from community-based and academic-based groups involved in research partnerships, and individuals who have roles in both (n=31). Eligible participants had participated in at least one community-academic health research partnership. I conducted thematic analyses of interview data to identify salient components of trustworthiness (Chapter 2). This analysis yielded four key dimensions, each with multiple subthemes and a cross-cutting theme that participants considered to be part of researcher trustworthiness in their partnerships. I also identified five key themes regarding institutional factors that were considered barriers to trustworthiness in these partnerships (Chapter 2). Table 3.2 presents the themes from both of these prior qualitative analyses.

Development of the initial item bank followed a series of steps. First, I compared the themes identified in my qualitative study with the high-quality, validated scales of trustworthiness from the literature described above (see Figure 3.1). These scales were selected based on previously published criteria (Gillespie, 2012), however, none fit the criteria perfectly. I compared the constructs in each of these scales to each other scale, then to the dimensions that emerged in my data; three of my dimensions overlapped conceptually with existing constructs in the literature. I compiled these existing items into an item bank and slightly edited each to apply to community-academic research partnerships. For example, “top management” was modified to “my research partner,” so that the item would make sense to respondents. Second, I created additional items that represented each of the subthemes from my qualitative data, using words from my interviews, and added these to the item bank. Third, I created a new set of items for the two additional concepts that emerged in my data, the dimension, *vulnerable* and theme, *respectful*. This initial set of 93 items was reviewed independently by one academic researcher and one community member, and revised for wording clarity. See Appendix B for the full item bank.

Table 3.2. Trustworthiness dimensions and institutional barriers, resulting from qualitative analysis (Chapter 2).

Trustworthiness Domains	Subthemes
Ethical	• Has integrity • Honest • Responsible • Reliable
Competent	• Skilled in research • Knowledgeable about community's values and interests • Able to creatively navigate institution to support community's needs
Caring	• Personally invested in community • Mission motivated • Whole person
Vulnerable	• Humble • Self-aware • Has a stake, taking risks within partnership • Committed
Respectful	• Cross-cutting through all domains
Institutional Barriers	**Subthemes**
Money, Funding	• Project sustainability • Limits on grant targets/what can be funded • Institution's payment structures don't translate to community context • Power dynamics • Mismatch of payment with work • Value of and commitment to community • Conditions of grants can conflict with community interests.
Academic Pressures	• Promotion and tenure criteria • Prioritizing publishing, over community benefit • Pressure for short timelines hinder community collaboration • Academic silos and need to develop independent scholarship limit community benefit • Limits to academics' allowed action can conflict with community needs, • Biased metrics and limitations of peer review for CBPR
Problematic Policies, Norms	• Research designs that are acceptable to the community "not the best science" • Burden and learning curve on community • Research protections often misaligned with community's priorities • Publication, and authorship rules misaligned with community's views • Limited institutional capacity to meet community needs • Privileging the academic hierarchy, approaches and power dynamics • Community ownership is favored but in tension with academic norms; • Sense of transience, community feeling used, and negative narratives
Negative History	• Institutional reputations precede individual researchers • Healing is needed • Researchers' responsibility for their institution's behavior, and broken trust
Key solution: Advocate/ Educate	• To funder and university financial office to justify budgets and legitimate expenses • For exception to university payment processes, to ensure community partners can genuinely benefit from payment • To IRB about community's protection needs, conflicts with standard protocols • For changes to which products are given credit for promotion • When institution breaks community trust

3.2.2 *Q-Sort process and cognitive interviews*

I conducted a combined process of Q-sorting (Block, 1961) with cognitive interviewing (Napoles-Springer, Santoyo-Olsson, O'Brien, & Stewart, 2006), to a) validate that each item in the item bank was generally interpreted as representing the appropriate dimension or construct, and b) gather interpretations of items and categorizations to guide item reduction and clarification. This process occurred between December 2016 and January 2017, with diverse community members in Seattle (n=7). Participants were recruited through social media and word of mouth, and included 2 U.S. immigrants who speak English as a second language (one from Africa, one from Europe) and others who could provide feedback on cross-cultural applicability of the items. Researchers were purposely excluded, but all participants had at least some college education. I previously knew 3 of the participants, and had never met 4 of the participants prior to the interview. One additional participant conducted the Q-sort process but did not complete the interview, and so those data are not included here.

Each participant was interviewed individually, without discussion with any other participant. After providing informed consent and completing a short survey of demographic information, participants sorted the 93 items into 5 categories, corresponding to the dimensions and theme from my qualitative analysis. Participants took approximately 20 minutes to complete this task, without my intervention. Every individual made notes on items that were unclear or required multiple readings. Each item was assigned a random number, to use for reference to compare with my intended categories for the items. After the participant completed sorting all items, I compared his or her responses with my categorization. I discussed any discrepancies and any unclear items, starting with open-ended questions about the participant's interpretations, followed by more specific questions referring to my own intention for and interpretation of the item. Interviews lasted approximately 1.5 hours, and took place in person (n=6) or by phone (n=1). Five participants received paper versions of the items and sorting task, and two received electronic versions, completing the sorting task in Microsoft Excel. There were no discernable differences in the performances between the two types of administration. Each participant received a $40 gift card to Amazon.com upon completing the interview. This study was considered exempt by the University of Washington Institutional Review Board.

Upon participant feedback, I reworded confusing items and replaced items in the bank with the edited versions for future participants to review. I used an Excel database to track and compare responses, notes from discussions, and to highlight items that were consistently confusing or consistently interpreted as referring to the same categories. After the first five interviews, I began asking about discrepancies among interpretations of different participants, in addition to discrepancies with my interpretations. That is, if I had an item with agreement across the first 5 participants, and the next participant sorted it to a different category, I would ask them more detailed questions about why they chose their category, to see if they were really disagreeing with the other participants or if they actually saw it the same way I did. For some items, the group of participants was split between 2 categories, so I asked the next participant to comment on/weigh those two categories and explain why they would choose one over the other. For some that were highly mixed across participants, I asked the participant to talk about why that may be, or what is potentially confusing about the item.

To reduce the pool of items, I considered each item individually, discarding any that were consistently confusing among participants, or whose categorizations conflicted among participants, while ensuring that all dimensions and subthemes were addressed by retained items. As perceived trustworthiness is the variable to be measured, these constructs were prioritized for cognitive interviews. Fifty-three perceived trustworthiness items were included in the survey to be deployed. I added demographic items to mirror those collected in my qualitative interviews (Chapter 2). I created a list of items based on the themes regarding institutional factors, and a summary item to capture each theme. These were reviewed by an academic and non-academic for clarity, but due to time and resource constraints, I did not repeat the cognitive interview process for these items. The survey was created in Research Electronic Data Capture (REDCap) (version 7.1.2), and pilot tested with 15 individuals to ensure usability and a realistic estimate of time-to-complete.

3.2.3 *Initial scale description*

The survey involved 53 self-report items to assess each respondent's perception of their research partner's trustworthiness. All items were written as statements, and participants were asked to rate how strongly they agreed with each statement on a 5-point Likert scale set of response options (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). Ten items were reverse coded. Twenty additional items inquired about demographics and partnership characteristics, and 6 additional items inquired about institutional factors, with responses including yes/no options, as well as "check all that apply" options. Throughout the survey, text boxes were included for optional open-ended comments. Appendix B contains the set of 53-items retained for the survey.

3.2.4 *Sample*

The target population was community members who were partners in research studies, including community leaders, members of community-based organizations, community advisory boards, and other individuals in partnership roles. They were recruited through posts to email listservs known to include many such partners, through community partner-focused newsletters, social media, direct invitation, and word of mouth. Because of the unstructured nature of recruiting efforts, it is impossible to calculate a meaningful response rate. A total of 34 individual responses were recorded; of these, 23 met eligibility criteria; 19 completed all sections of the survey. Table 3.3 includes a summary of the final sample's demographics.

Table 3.3. Participant demographics, and partnership information (n=19)

Age			Duration of relationship	
Average 51.7	Range 28-74		Under 1 year	0
Gender			1-3 years	26.3% (5)
Female	84.2% (16)		4-6 years	42.1% (8)
Male	15.8% (3)		7-9 years	5.3% (1)
Transgender; Prefer not to say; or to self-describe	0% (0)		10 or more years	26.3% (5)
Education			**Duration of research together**	
High school diploma, GED, or less	0% (0)		Under 1 year	15.8% (3)
Some college	15.8% (3)		1-3 years	47.4% (9)
Associates	5.2% (1)		4-6 years	15.8% (3)
Bachelors	21.1% (4)		7-9 years	5.3% (1)
Masters	42.1% (8)		10 or more years	15.8% (3)
Terminal degree (e.g. MD, MFA, PhD, JD)	15.8% (3)			
Race/Ethnicity	**(check all that apply)**		**Research partner's Race/Ethnicity**	**(check all that apply)**
American Indian/ Alaska Native	5.3% (1)		American Indian/ Alaska Native	5.3% (1)
Asian	15.8% (3)		Asian	15.8% (3)
Native Hawaiian, Other Pacific Islander	0% (0)		Native Hawaiian, Other Pacific Islander	5.3% (1)
Black or African American	36.8% (7)		Black or African American	36.8% (7)
White	47.4% (9)		White	52.6% (10)
Other race	5.3% (1)		Other race/ethnicity	0% (0)
Hispanic or Latino	26.3% (5)		Hispanic or Latino	21.1% (4)
Prefer not to say race	5.3% (1)		Unsure	10.5% (2)
Prefer not to say ethnicity	10.5% (2)			
Primary language(s)	**(check all that apply)**		**Does your research partner speak at least one of the same languages as you?**	
English	94.7% (18)		Yes	89.5% (17)
Spanish	10.5% (2)		No	5.3% (1)
Vietnamese	5.3% (1)		Unsure	5.3% (1)
Portuguese	5.3% (1)			
Tswana, Hlubi, Sesotho, Xhosa	5.3% (1)			

Location (n=18)			**Research partner’s location (n=17)**	
Urban	63.2% (12)		Urban	73.7% (14)
Rural	21.1% (4)		Rural	21.1% (4)
Suburban	10.5% (2)		Suburban	5.3% (1)
United States	94.7% (18)		United States	63.2% (12)
Outside of USA	0% (0)		Outside of North America	5.3% (1)
Type(s) of research conducted by the partnership			**How did you hear about this survey?**	
Community health promotion	52.6% (10)		Academic partner	31.6% (6)
Individual behavior change program	47.4% (9)		Another community member	5.3% (1)
Genetics/Genomics	15.8% (3)		Email/Listserv	42.1% (8)
Basic science	10.5% (2)		Social Media	0% (0)
Clinical trials	15.8% (3)		Other	21.1% (4)
Diet/nutrition	21.1% (4)			
Social science or qualitative research	57.9% (11)			

3.2.5 *Survey procedures*

All participants responded via the REDcap electronic data capture tool (version 7.1.2), between February 20, 2017 and March 23, 2017. Prior to beginning the survey, instructions and information were presented on the screen, and eligibility questions were answered. If participants were not eligible based on their responses, a message thanking them for their time, and informing them of the eligibility requirements was presented. Eligible participants went on to provide consent for the survey, then respond to demographic and partnership questions, followed by trustworthiness items, and institutional factors items. For those completing all survey sections, a link to an external survey was offered, in which they could choose to enter their name and contact information, to be entered into a random drawing for one of three $50 Amazon gift cards. These identifiers were not connected to the main survey responses, to maintain anonymity of the main survey. Twelve individuals chose to enter their contact information. Gift card winners were chosen using an online random number generator. Gift cards were distributed on

March 31, 2017. This study was determined to be exempt, by the University of Washington Institutional Review Board.

3.2.6 *Data analysis*

3.2.6.1 Exploratory factor analysis

To evaluate the psychometric properties of a new scale of *perceived trustworthiness* for community-academic research partnerships, I started with two phases of exploratory factor analysis using principle components analysis (PCA) (Floyd & Widaman, 1995). I started with a PCA on the 53-item scale, designated my “primary PCA,” and then conducted a “secondary PCA,” on a smaller set of items, described below. My goal was to reduce the large number of items and create valid summary indices with the smallest number of items possible. This approach to exploratory factor analysis does not typically start with *a priori* hypotheses about the factors that will emerge from this analysis. Although I did have expected constructs based on dimensions in my qualitative analysis, I opted for an agnostic approach, to allow for the data to reveal the underlying structure of my instrument.

Given the small sample size, I included all of the items in the primary PCA, regardless of data distribution patterns. I used IBM SPSS (version 24) to run the PCA, with varimax rotation to enhance interpretation of the extracted data. I included a scree plot test to assess strength of the factors. I set my inclusion criteria to a minimal factor loading score of |0.60|, with no other factors loading at |0.40| or greater. After excluding items that did not meet the minimal cut off threshold, I considered the factors that included at least 3 items meeting my inclusion criteria to be robust subscales, to reduce the risk of testing too-short subscales.

I conducted the secondary PCA after removing the items in those initial subscales from the analysis, to identify any additional patterns in the remaining variables, again using the varimax rotational method. I then applied the same exclusion/inclusion criteria to this set of values, and at least 3 items per factor, to derive additional robust subscales. I created new summary variables for each subscale by computing the unweighted average of an individual's responses on all items within that subscale.

I examined my resulting subscales and remaining items that did not meet criteria for inclusion in a subscale, using the theoretical framework from my qualitative analysis (see Table 3.2). I added individual items representing concepts from my qualitative data that were considered important but were not empirically associated with a robust factor. These were included as items outside of a subscale and not used in further analyses.

3.2.6.2 Psychometric properties

To evaluate the reliability of the subscales, I calculated raw Cronbach's alpha values and item-total correlations for each subscale (Falk & Savalei, 2011). I considered acceptable minimums to be coefficient alpha >.80, and item-total correlation $r > .70$. Low alpha values could indicate a scale that is too short, poor inter-relatedness among items or that the assumption of construct unidimensionality is violated. Alpha values > .90 could indicate redundancy in the scale, so for each subscale with an alpha of >.90, I examined item-total correlations to find items that could be removed while maintaining subscale reliability of >.80. To minimize the number of items included in the final scale, I removed items with relatively low item-total correlations, and recalculated the subscale alpha (Tavakol & Dennick, 2011). However, I retained at least 2 items in each subscale, even for those whose Cronbach's alpha values exceeded .90 at this stage.

I used summary measures for each subscale that obtained an alpha of >.80 in further analyses. Because I aimed to create an overall measure of perceived trustworthiness, I computed an unweighted average of the summary values of these reliable subscales for each respondent. I then calculated a Cronbach's alpha to measure the reliability of the whole scale of perceived trustworthiness. The items that I added outside of subscales are not included in the overall perceived trustworthiness summary score, as additional information is needed to determine whether these items should be included in subscales, and if so, which ones.

I addressed multiple forms of validity in my scale (Aday & Cornelius 2006). To examine content validity, I started with items from previously validated scales, added new items that addressed each of the dimensions of trustworthiness that I derived from my qualitative data, and that were sorted into those corresponding dimension categories during the Q-sort process. As there is no "gold standard" against which I could measure criterion validity, I addressed construct validity by examining relationships between the measure and an expected outcome, based on my qualitative data. I hypothesized that if my perceived trustworthiness scale is valid, then I would expect trustworthiness scores to be lower among respondents reporting having a negative history with institutions, and among respondents reporting difficulty with the institution in their partnership, but positively associated with those communities who own their data. I conducted linear regression analyses to evaluate these relationships.

Stratification on demographics: To compare the key demographic groups and subscale/overall measure responses, I report means and standard deviations across demographic groups. Key demographics examined include age, dichotomized into two roughly similarly sized groups of "younger adults" and "older adults," gender, which was dichotomous in my sample, location (a trichotomous variable), and racial concordance with research partner, defined as having at least one racial or ethnic identity in common with their research partner. To look for significant differences between demographic groups, I conducted independent-sample t-tests for each set of demographic groups and the overall perceived trustworthiness score, setting significance at $p<0.1$.

3.3 RESULTS

3.3.1 *Exploratory factor analysis*

The primary PCA returned 9 factors (see Table 3.4). After applying my exclusion/inclusion criteria to this initial set of values, five factors retained at least 3 items each, and were considered robust subscales: primary factors 1, 2, 3, 4, and 7. The initial Eigenvalues indicated that these factors explained 39.6%, 14.1%, 9.1%, 9.0% and 5.5% of the variance, respectively. After removing the 19 items loading into these 5 factors from the data set, I ran the secondary PCA on the 34 remaining items using the same parameters, and with the same inclusion criteria. This resulted in 8 factors, of which secondary factors 1, 3 and 5 included 3 items each with acceptable loading patterns and were considered robust as subscales (see Table 3.5). The initial Eigenvalues indicated that these factors explained 39.0%, 10.8%, and 6.5% of the variance, respectively. The 5 robust factors from the primary analysis and the 3 robust factors from the secondary analysis are displayed as subscales, with new names, based on the theme resulting in each subscale (see Table 3.6).

Appendix C presents comments justifying decisions on each item retained or not during the theoretical review process. Three items were included to address the two aspects of the *competent* dimension that were not already captured; other important concepts included honesty, reliability, commitment and risk.

Table 3.4. Primary principle components analysis factor loading values.

Factor 1: Retained	**Assigned Dimension**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Sound principles seem to guide my research partners behavior.	Ethical	**0.947**	0.075	0.062	-0.027	0.226	-0.004	0.198	0.025	-0.029
I feel that my research partner tries to get out of his/her commitments.**	Ethical	**0.947**	0.075	0.062	-0.027	0.226	-0.004	0.198	0.025	-0.029
I think that my research partner succeeds by stepping on other people.**	Ethical	**0.844**	0.077	-0.028	0.091	0.16	0.353	-0.07	-0.287	0.186
Factor 2: Retained										
Who my research partner is as a person is a mystery to me.	Vulnerable	0.066	**0.919**	0.051	0.114	0.313	0.047	0.189	-0.008	0.012
My research partner ensures that any new team members will abide by partnership agreements and expectations.	Ethical	0.021	**0.908**	0.03	0.012	0.286	-0.058	0.081	0.085	0.272
My research partner knows his/her own limits and strengths.	Vulnerable	0.004	**0.837**	-0.136	0.368	-0.289	0.135	0.187	0.066	0.005
My research partner is aware of his/her impact on the community.	Competent	0.396	**0.672**	0.375	0.18	0.231	0.234	-0.272	0.137	-0.135
My research partner asks questions, rather than always just telling.	Respectful	0.396	**0.672**	0.375	0.18	0.231	0.234	-0.272	0.137	-0.135
Factor 3: Retained										
I am more likely to think a researcher is trustworthy if they reflect the same race/ethnicity and/or language as me, than if they do not.	General	-0.075	-0.084	**0.88**	0.162	0.077	-0.255	-0.224	0.073	-0.063
Knowing my needs and desires is very important to my research partner.	Caring	-0.232	0.118	**0.829**	0.066	0.215	0.369	-0.121	-0.058	-0.199
My research partner frequently does extra things to make our partnerships work more productive, that they know they won't be rewarded for.	Caring	0.177	0.183	**0.815**	0.155	0.341	0.051	0	0.34	0.104
My research partner makes sure community members are truly included in research decisions.	Respectful	0.326	0.013	**0.669**	-0.169	0.038	0.367	-0.107	0.352	0.375
Factor 4: Retained										
My research partner admits when he/she makes mistakes.	Vulnerable	0.353	0.287	0.106	**0.746**	0.26	0.125	0.282	0.198	-0.103

My research partner is not afraid to share control over decisions with the community.	Vulnerable	-0.004	0.273	0.399	**0.681**	0.209	0.276	-0.264	0.264	-0.195
My research partner takes responsibility for things that others do, even if it's out of their hands.	Ethical	-0.35	0.08	0.072	**-0.815**	-0.362	0.067	0.008	-0.19	-0.146
I do not have a good sense of whether or not my research partner plans to work with our community beyond the current grant.**	Caring	0.395	-0.219	-0.034	**-0.805**	-0.075	-0.083	-0.092	-0.26	-0.073
Factor 7: Retained										
My research partner updates me before I feel the need to ask.	Respectful	0.315	0.262	-0.129	-0.086	0.13	-0.043	**0.875**	-0.101	-0.115
My research partner is careful when other researchers want to use his/her relationship with our community to work with us.	Ethical	0.241	0.052	0.305	0.3	0.306	0.263	**0.736**	0.161	0.148
My research partner and I would both feel a sense of loss if we could no longer work together.	Caring	0.335	0.338	0.285	0.155	0.395	0.044	**-0.601**	0.035	-0.347
Factor 8: Not retained										
My research partner does not spend as much time in the community as I would like.**	Caring	-0.027	0.184	0.137	0.277	0.019	0.294	0.156	**0.823**	0.283
My research partner takes a personal interest in our community.	Caring	-0.194	-0.232	0.28	-0.008	0.096	0.272	-0.139	**0.808**	0.274
Factor 5: Not retained										
My research partner is very guarded around me or my community.**	Vulnerable	0.254	0.094	0.224	0.108	**0.897**	-0.004	0.029	-0.033	0.239
I feel like I know who my research partner is, as a person.	Vulnerable	0.116	0.193	0.372	0.192	**0.873**	0.011	0.023	0.063	-0.086
Factor 6: Not retained										
My research partner is very knowledgeable about what is important to the community.	Competent	-0.133	0.302	0.121	0.11	0.082	**0.819**	0.007	0.153	-0.134

**denotes reverse-coded. items. Items are displayed according to each largest factor loading value.

Table 3.5. Secondary principle components analysis factor loading values.

Secondary Factor 1	**Assigned Dimension**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
My research partner ensures that our community members are paid for their time and contributions to the research. (Paid could mean money or something else the community member values.)	Respectful	**0.906**	0.059	0.156	-0.054	0.262	-0.150	0.201	0.025
My research partner is willing to comply with our community's rules and norms.	Respectful	**0.801**	0.378	0.270	0.031	0.189	0.221	-0.140	-0.138
My research partner gets out of his/her own comfort zone.	Vulnerable	**0.828**	-0.085	0.027	0.034	0.136	0.150	0.29	0.243
Secondary Factor 3									
I often find that community members have to clean up messes left by my research partner.	Competent	0.097	-0.258	**0.806**	0.332	0.178	0.259	-0.213	0.020
I feel like I know who my research partner is, as a person.	Vulnerable	-0.053	0.037	**0.882**	0.030	0.369	0.122	0.072	0.185
My research partner is very guarded around me or my community.	Vulnerable	0.005	0.077	**0.933**	0.035	0.130	0.081	0.262	-0.059
Secondary Factor 5									
My research partner respects our community's knowledge and worldview.	Respectful	0.299	0.058	0.27	0.322	**0.791**	0.153	0.167	-0.05
My research partner actively seeks the community's criticism of the research.	Respectful	-0.083	0.281	0.339	-0.098	**0.759**	0.358	-0.197	-0.069
My research partner really looks out for what is important to me.	Caring	0.194	0.244	0.227	0.044	**0.827**	-0.167	-0.03	0.347
Secondary Factor 6									
My research partner takes time to listen to our community's problems and worries.	Caring	-0.044	0.254	0.257	0.156	0.033	**0.867**	-0.015	-0.034
Secondary Factor 7									
I often wish my research partner would ask for negative feedback or criticism.	Respectful	0.111	0.355	0.263	0.206	-0.144	0.137	**0.637**	-0.31
Secondary Factor 8									
My research partner recognizes his/her own position, as an outsider, as someone of a different	Respectful	0.359	0.063	0.346	-0.019	0.287	-0.186	0.02	**0.696**

race/ethnicity, gender, socioeconomic status, or other.									
My research partner shares characteristics with our community such as race, ethnicity, language, gender, health status, social groups.	Social Similarity	0.219	0.256	0.103	-0.093	0.087	-0.1	0.082	**-0.874**
Secondary Factor 2									
I believe my research partner intends to work with our community for a long time.	Caring	0.353	**0.719**	-0.267	0.287	-0.017	0.174	0.236	0.047
My research partner does not spend as much time in the community as I would like.	Caring	0.067	**0.798**	0.021	0.084	0.397	0.091	0.082	-0.196
Secondary Factor 4									
I consider my research partner to be trustworthy.	Ethical	-0.081	0.369	0.152	**0.874**	0.183	-0.068	0.092	-0.084

Highest loading values per factor are indicated in bold.

Table 3.6. Subscales based on factors resulting from primary and secondary principle components analyses, with subscale item-total correlations.

Subscales	Items	Item-total correlation
Primary Subscale 1: Ethical	**Sound principles seem to guide my research partner's behavior.**[#]	**.875**
	I feel that my research partner tries to get out of his/her commitments.** [#]	**.829**
	I think that my research partner succeeds by stepping on other people.** [#]	.692
Primary Subscale 2: Open to community	**Who my research partner is as a person is a mystery to me.****	**.943**
	My research partner ensures that any new team members will abide by partnership agreements and expectations.	.662
	My research partner knows his/her own limits and strengths.	**.757**
	My research partner is aware of his/her impact on the community.	**.747**
	My research partner asks questions, rather than always just telling.	**.741**
Primary Subscale 3: Caring	**Knowing my needs and desires is very important to my research partner.**[#]	**.809**
	My research partner frequently does extra things to make our partnerships work more productive, that they know they won't be rewarded for.[#]	**.822**
	My research partner makes sure community members are truly included in research decisions.	**.716**

	I am more likely to think a researcher is trustworthy if they reflect the same race/ethnicity and/or language as me, than if they do not.	**.704**
Primary Subscale 4: Accountable	My research partner admits when he/she makes mistakes.	.285
	My research partner is not afraid to share control over decisions with the community.	.353
	My research partner takes responsibility for things that others do, even if it's out of their hands.	.130
	I do not have a good sense of whether or not my research partner plans to work with our community beyond the current grant.**	.533
Primary Subscale 5: Responsible/Caring	My research partner updates me before I feel the need to ask.	.355
	My research partner is careful when other researchers want to use his/her relationship with our community to work with us.	.335
	My research partner and I would both feel a sense of loss if we could no longer work together.[#]	.010
Secondary Subscale 6: Community First	**My research partner ensures that our community members are paid for their time and contributions to the research. (Paid could mean money or something else the community member values.)**	**.833**
	My research partner is willing to comply with our community's rules and norms.	.622
	My research partner gets out of his/her own comfort zone.	**.841**
Secondary Subscale 7: Respect	**My research partner respects our community's knowledge and worldview.**	**.885**
	My research partner actively seeks the community's criticism of the research.	**.862**
	My research partner really looks out for what is important to me.[#]	.862
Secondary Subscale 8: Self-aware/Vulnerable	I often find that community members have to clean up messes left by my research partner.**	.571
	I feel like I know who my research partner is, as a person.	**.877**
	My research partner is very guarded around me or my community.**	**.856**
10 additional items, with theoretical category	My research partner is very capable of performing his/her research.[#] (Competent)	
	My research partner knows how to advocate on behalf of the community to get the university to change their ways, when needed. (Competent)	
	My research partner has learned the about our community's past research experience(s). (Competent, Caring)	
	My research partner checks in to see if the community members think the researcher or institution has done something wrong. (Respectful)	
	My research partner truly listens, with a willingness to take feedback. (Respectful)	
	My research partner is willing to risk something he/she cares about for our community's benefit. (Vulnerable)	

	I think my research partner sometimes misleads me or my community members. (Ethical: Honesty)	
	I feel that my research partner will keep his/her word. (Ethical: Reliable)	
	I believe my research partner intends to work with our community for a long time. (Committed)	
	I consider my research partner to be trustworthy. (General)	

**Denotes reverse-coded items; # denotes items derived from existing scales. Shaded subscales and items indicate an acceptable reliability score (Cronbach's alpha >.80). Items retained in the final scale and summary measure of perceived trustworthiness are denoted in bold. Items that I added outside of a subscale are listed at the bottom of the table.

3.3.2 *Reliability*

The item-total correlations for each item in the subscales meeting my initial inclusion criteria, and those subscales meeting the Cronbach's alpha cut-off of .80 (indicated in shaded rows) are listed in Table 3.6. I report each original subscale's alpha value and range of inter-item correlations, and the corresponding edited subscale values, after removing redundant items, in Table 3.7. The overall perceived trustworthiness score for each respondent, using averages of the 6 subscale summary values, resulted in Cronbach's alpha=.894 with item-total correlations of .671-.834 (see Table 3.7). I retained all 6 subscales in the overall scale, despite one subscale (*vulnerability*) having an *r* value <.70, because the Cronbach's alpha remained high when including that subscale, removing it did not substantially improve the overall scale's reliability, and nor was it redundant with other subscales. The final list of 16 items included in 6 subscales (in shaded rows) and the 10 additional retained items (26 items total) are shown in Table 3.6.

Table 3.7. Internal reliability for initial trustworthiness subscales and edited subscales, after reducing the number of items.

Subscale	No. items	Cron-bach's α	Range of item-total correlations	Edited Subscale	No. items	Cron-bach's α	Range of item-total correlations
Primary Subscale 1: Ethical	3	.888	.692-.875	Primary Subscale 1: Ethical (edited)	2	.957	.918-.918
Primary Subscale 2: Open to community	5	.904	.662-.943	Primary Subscale 2: Open to community (edited)	4	.902	.718-.900
Primary Subscale 3: Caring	4	.891	.704-.822	No change in alpha with edits.	4	.891	.704-.822
Primary Subscale 4: Accountable	4	**.526**	.130-.533	Eliminated	n/a	n/a	n/a
Primary Subscale 5: Responsible and Caring	3	**.347**	0.010-.355	Eliminated	n/a	n/a	n/a
Secondary Subscale 6: Community first	3	.856	.622-.841	Secondary Subscale 6: Community first (edited)	2	.891	.882-.882
Secondary Subscale 7: Respect	3	.926	.862-.885	Secondary Subscale 7: Respect (edited)	2	.888	.862-.885
Secondary Subscale 8: Self-aware/Vulnerable	3	.860	.571-.877	Secondary Subscale 8: Vulnerable (edited, renamed)	2	.911	.869-.869
Overall perceived trustworthiness score	6 (sub-scales)	.894	.671-.834	Not edited.	n/a	n/a	n/a

Bold values indicate initial alpha <.80, not meeting criteria for use.

3.3.3 *Validity*

The Q-sort process of categorizing items into dimensions informed content validity of my scale. Resulting categorizations of the full item bank and the 53-item survey are included in the Appendix B. To address construct validity, I examined associations between perceived trustworthiness (dependent variable) and institutional factors (independent variables) that I expected would be associated. Two expected associations were suggestive of significance with p-values < 0.1. Community data ownership was associated with a slight increase in perceived trustworthiness, at beta= 0.412, and p= 0.07. Having a previous negative experience with the research institution was associated with decreased perceived trustworthiness, at beta= -1.849, and p= 0.07. The remaining institutional factors (1. Negative history with other institutions—government, education and health care institutions, research in general; 2. Existence of problems with the institution; 3. Specific issues with institutional practices including how funding is distributed, academic pressures, academic ethical standards or rules, research study designs, kinds of projects undertaken, and data ownership) were not significantly associated with perceived trustworthiness.

3.3.4 *Demographic stratification*

To examine potential demographic patterns in the data, I stratified the data on key demographic variables (see Table 3.8). Only individual respondents who completed the entire survey are included in these analyses. The age variable was defined to create two similarly sized groups, “age 50 or younger” and “over 50.” Although more inclusive options were offered, respondents selected only female and male gender identities, and therefore gender was considered a dichotomous variable. Location was analyzed as a dichotomous variable as well, because one of the three response options had only one response (suburban), and was dropped from the analysis. Racial concordance with research partner resulted in mostly concordant responses, including pairs of varying races and ethnicities; those that were not concordant were also varied in both the community- and academic- partners’ races/ethnicities. Independent-samples t-tests for the overall trustworthiness score based on racial concordance status, dichotomous age, yielded no significant results. An independent-samples t-test for overall perceived trustworthiness based on urban vs. rural location yielded significant results (t= .632, p=0.004), despite the rural group being relatively small.

Table 3.8. Summary values for retained subscales, stratified on key demographic variables.

	Scale	Overall trust-worthiness	Subscale 1: Ethical	Subscale 2: Open to comm-unity	Subscale 3: Caring	Subscale 6: Comm-unity first	Subscale 7: Respect	Subscale 8: Self-aware/ Vulnerable
Variable	**Response option**	**Mean St Dev**	**Mean St Dev**	**Mean St Dev**	**Mean St Dev**	**Mean St Dev**	**Mean St Dev**	**Mean St Dev**
Age	**50 or under (n=9)**	.73 .61	.25 .46	.66 .68	1.16 .96	.75 .85	.69 .53	.88 1.03
	> 50 (n=10)	.85 .79	.56 .73	.66 .84	1.19 .80	1.00 1.20	.38 .88	.94 1.10
Gender	**Female (n=16)**	.78 .71	.43 .62	.57 .67	1.20 .88	.84 1.04	.50 .73	.91 1.07
	Male (n=3, n=1 complete)	1.04 n/a	.00 n/a	2.00 n/a	.75 n/a	1.50 n/a	1.00 n/a	1.00 n/a
Racial Concor-dance	**Yes (n= 12)**	.86 .78	.55 .69	.66 .73	1.2 .98	.75 .99	.64 .81	1.13 1.15
	No (n= 5)	.51 .41	0 0	.56 .97	.88 .32	.88 1.03	.38 .48	.38 .48
Location	**Urban (n=14)**	.62 .49	.30 .48	.50 .65	.93 .65	.55 .72	.35 .41	.73 .88
	Rural (n=4)	.92 1.41	.67 1.15	.92 1.38	1.25 1.30	1.00 1.73	.83 1.44	.83 1.44
	Suburban (n=2)	1.33 .35	.25 .35	.88 .18	2.38 .53	2.00 .71	.75 1.06	1.75 1.77

3.4 DISCUSSION

3.4.1 *Measure of perceived trustworthiness*

I conducted a two-phased principle components analysis (PCA) to examine the structure of my newly created perceived trustworthiness scale, tested in a sample of community members involved in health research partnerships. There is consensus in the literature that *trustworthiness* is a multidimensional concept. My prior qualitative data suggested some nuanced differences from other empirical studies of trustworthiness, as well as additional concepts that were not explicitly captured by existing high-quality scales. I expected that my PCA data would show at a minimum, the three previously reported, and likely the five dimensions resulting from my qualitative analysis (including the cross-cutting theme). Interestingly, the empirical data returned 10 factors, six of which comprised reliable subscales, that did not exactly reflect these initial dimensions as I had derived them. Two of the reliable subscales did not correspond to my theoretically derived dimensions, but subscales "Ethical," "Caring," "Respectful" and "Self-aware/Vulnerable" each reflected one of my dimensions. The only theoretical dimension not represented by a subscale is "Competent." The two other subscales that were considered reliable only collectively addressed limited components of trustworthiness, such as one or two subthemes within a dimension. It is possible that with more responses, additional subthemes or dimensions would become reflected in the empirical data; or it is possible that my theoretical framework would not hold up to empirical testing. More research with a larger sample is needed to clarify these results.

As this is an exploratory analysis with a very small sample size, I added to the full instrument items that corresponded to my dimension "Competent," and other important subthemes, even without meeting factor loading criteria for inclusion. I had employed fairly conservative standards to the first two phases of factor analysis resulting in my subscales. A further point to consider is that the two subscales that were eliminated from further analysis, due to low reliability scores, were both highly important concepts as well: Responsibility and Accountability. I would include these items in further research.

The initial 93-item bank with which I started this process, contained items from three existing high-quality scales, supplemented by items that I created based on language from my qualitative analysis. Of the 16 items retained in my 6 subscales, 3 items were derived from existing scales, and 13 were items that I had created. Only 1 additional item was retained from existing scales in my 10 added items, for a total of 4. Nearly all existing items were edited to fit the community-academic research partnership context; most were edited to change the original party to “my research partner” but some were substantially modified, while maintaining the essence of the item (e.g. “I frequently do extra things I know I won’t be rewarded for, but which make my cooperative efforts with this person more productive,” (McAllister, 1995) became “My research partner frequently does extra things to make our partnerships work more productive, that they know they won’t be rewarded for.”) It is possible that most of the existing items were not retained because either my edits invalidated previous psychometric work on those items, or more likely, because the partnership context is unique enough that items validated within the Organizational Research context would not apply to the community-academic partnership context. In either case, my data show that existing scales cannot be used validly within community-academic research partnerships.

There were no significant differences in perceived trustworthiness between most of the demographic groups I compared. There was a significant difference between urban and rural respondents, with the rural respondents expressing lower perceptions of researcher trustworthiness. It is possible that this reflects larger social trends, or that urban partners may be more familiar with the university than rural partners, thus having greater perceptions of researcher trustworthiness. More research is needed to understand this association.

3.4.2 *Institutional factors*

Although my regression analyses returned two suggestively significant results for institutional factors, most expected associations were not significant, only lending suggestive support to construct validity of this scale. This could be explained by the underpowered sample size (as little as n=11 in some cases), which could obscure any associations, even if they exist.

Alternatively, it is possible that over time, partnerships face challenges of all kinds, that if overcome, can strengthen trust within the partnership; it could be that institutional barriers to partnership building are among these types of challenges, giving researchers an opportunity to prove themselves as trustworthy to their community partners. A study by Hicks and colleagues suggests this might be possible: they described lessons about "honoring each other," in which they found trust to be strengthened when respectfully and openly working through likely inevitable institutional issues (referred to as "contextual" issues), such as budgeting (Hicks et al., 2012). To test this, both larger sample sizes, as well as data from those partnerships that were attempted but not successful, are needed. Because failed partnerships are difficult to identify, and so it would be highly difficult to find a large enough sample, this question may go unanswered.

Finally, it is possible that the institutional factor items were not clear, or do not reflect the issues I had intended. I created summary items for themes that emerged in my qualitative analysis, rather than including several detailed items, as potential subscales, to represent each institutional factor theme. These items were not subject to the cognitive testing that the perceived trustworthiness items underwent, and thus might be of poor quality. This is a consideration for any future use of the perceived trustworthiness scale, and should be considered when using the scale to determine any such associations with factors that might influence perceived trustworthiness.

3.4.3 *Limitations*

The major limitation in the development of the perceived trustworthiness scale is the small sample size. As such, I consider this analysis to be preliminary, and the final scale to require further testing. In general, factor analyses assume that the data are distributed in a multivariate normal pattern. Given my small dataset, not all of my data exhibited this pattern. As I continue to collect more data, this assumption will become less and less important. There is debate within the field of Psychology, in which these methods have been developed, regarding the ideal sample size for an exploratory factor analysis. Some suggest 5-10 responses per variable, which would amount to 265-500 for my project-- a range that I would be highly unlikely to obtain given the small population of interest and difficulty in reaching eligible respondents. Others have shown that solutions would be stable with relatively large factor loadings even in smaller samples (n=50 for factor loadings of .80). For a confirmatory factor analysis, 10 responses per parameter is considered sufficient (Floyd & Widaman, 1995), which would amount to 50 responses for my model—a reasonable number for my population and recruitment constraints. Without substantially more data, the psychometric properties that I report cannot be fully accepted.

Even after obtaining a large enough sample to address the power issue mentioned above, several unresolved issues must be addressed before this scale will be ready for implementation. A confirmatory factor analysis is an important next step to address the question of whether my theoretical framework is supported by my empirical survey data. Additionally, some items that were part of highly important themes in my qualitative data might not come up in some partnerships, and so, while very important to some partnerships, the item would not be a good metric for all; thus a response option that includes “this is not relevant to my partnership” would likely be helpful for differentiating between items on which a researcher might score moderately (“neither agree nor disagree”), versus when the respondent would not agree because the question does not apply. This is an important distinction when using the scale for its numerical values alone, as in to compare, or create cut-off decisions, although perhaps less so when using the scale to support discussion within the partnership, in which case, “not applicable” responses would be washed out in conversation.

3.5 CONCLUSIONS

I have created a measure of perceived trustworthiness for use among community members in community-academic research partnerships. Preliminary psychometric analyses demonstrate a high level of reliability for six subscales within this measure— *Ethical*, *Caring*, *Respectful* and *Self-aware/Vulnerable*, *Community First* and *Open to Community*, and of the overall summary value of *perceived trustworthiness*. However, these preliminary results do not exactly align with my, nor others', theoretical work on the topic, and were based on a very small sample size. Additional items related to institutional factors are included in the survey without information about which factor(s) they would load, with more data. There are unanswered questions about the construct validity and potentially the applicability of all items to every partnership. Therefore, the measure should not be deployed without further research. Next steps include collecting additional data on the full 53-item measure and repeating all of these analyses to reach more robust results, and capturing all aspects of the trustworthiness constructs, followed by a confirmatory factor analysis.

Chapter 4. CULTIVATING TRUSTWORTHINESS IN GENOMIC RESEARCH

4.1 INTRODUCTION

Recent calls for investigators to include racial and ethnic minority populations in genomic research have noted a lack of diversity in such studies (Need & Goldstein, 2009; Popejoy & Fullerton, 2016). There is a concern that if those populations do not participate in research, they will not receive the benefits from medical advances that use genetic data. Further, there are well-recognized disparities among minority populations for many health outcomes. A social gradient exists (Marmot, Shipley, & Rose, 1984), in which health status has been correlated with socioeconomic status, throughout time and geography. Importantly, race/ethnicity is associated with socioeconomic status, and so this gradient holds for race/ethnicity as well (Braveman et al., 2011). Bustamante and colleagues argue for greater diversity in genomic research, to ensure that those experiencing health disparities do not miss out on technological advances from genomics due to lack of data relevant to their ancestries. They say, "those most in need must not be the last to receive the benefits of genetic research," (Bustamante, Burchard, & De la Vega, 2011, p. 165).

In addition to the need to design studies that would appropriately include diverse populations and to do the often challenging work of recruiting members of these populations, it is also important that researchers consider why those individuals might choose not to participate, even if well aware of available genomic studies. A history of research missteps has resulted in distrust of health care, genomics, and research in general (Kennedy et al., 2007; McDonald et al., 2012). It is also becoming more and more clear that to overcome distrust, researchers must be trustworthy, and support community interests in research oversight and direction. For example, a new paper published in *Nature* described a recent effort by the San people, an indigenous group in South Africa, to institute a code for conducting genetic research with their members (Callaway, 2017). This is just the latest in an increasing list of communities that want a genuine say in how research is conducted, to ensure their data are used appropriately and respectfully, according to their own values. More and more genomic studies are being conducted within community-academic research partnerships, which demands researcher trustworthiness.

I previously studied the concept of trustworthiness in community-academic partnerships (see Chapters 2-3). My qualitative study identified four key dimensions of trustworthiness: *ethical*, *competent*, *caring*, and *vulnerable*; and a cross-cutting theme of *respect*. In order to demonstrate the *ethical* dimension, genomic researchers must exhibit honesty, integrity, reliability, and responsibility. Demonstrating the *competence* dimension requires an awareness of both the science and also the larger context of community concerns. Honesty and responsibility require communicating proactively and accurately about the potential that the research offers; identifying a promising pathway to benefit for the community, and along this pathway, recognizing the areas of uncertainty and the resources or steps needed to effectively reach benefit within a realistic context. It is important for researchers interested in engaging communities in genomic research to embody these characteristics. However, the scientific discourse touting the benefits of genomic research to minority communities experiencing health disparities may inadvertently prevent such trustworthiness. Common claims regarding the need for minority communities to participate in genomic research often fail to acknowledge relevant context, thus potentially threatening the development of trust among those communities that researchers wish to engage.

In this study, I examine scientific claims about genomic research for health disparities in the context of a single case, in an effort to inform how researchers might advance key aspects of trustworthiness. I use critical discourse analysis to identify how scientists are characterizing the implications of genetic research for African American populations and assumptions made regarding the expected pathway to benefit. I weave into this discussion what is known and uncertain about the science, and a greater context that takes into account possible areas of interest for communities.

4.1.1 *Case introduction: Chronic Kidney Disease and APOL1 genetic variants*

A highly compelling example of genetics informing a condition that is also a health disparity is the association with end stage renal disease (ESRD), of APOL1 genetic variants found almost exclusively in individuals with sub-Saharan African ancestry. Type 2 Diabetes Mellitus is considered the leading primary cause of ESRD in all racial groups (United States Renal Data System, 2014), and there is no evidence of any association with APOL1 variants for this etiology (Parsa et al., 2013). However, for other primary causes of ESRD, there is a substantial population attributable risk (that is, the proportion of cases that would be eliminated if the high-risk genotype were eliminated). For focal segmental glomerulosclerosis (FSGS), the PAR is 68% for (Kopp et al., 2011), indicating potential for improving kidney health in this population if the mechanisms by which APOL1 risk are better understood. Nephrologists are aware that social factors remain crucial (Williams & Pollak, 2013), and there is still much to be understood about ESRD disparities. Molecular technology and the ability to study genetic associations, including the quality of testing, have outpaced our understanding of what associations mean for patients (Freedman, Divers, & Palmer, 2013).

Still, this case is often held up as an example of genomic research helping to reduce a health disparity. APOL1 testing for kidney disease risk has been touted as a “large advance toward combatting renal disease among black patients” (Williams & Pollak, 2013), with substantial rhetoric in scientific discussions around expectations for the reduction of health disparities. Health disparities are an urgent concern for health research and policy, and the communities facing the burden of these disparities. In light of the distrust that exists, it is worth considering what constitutes trustworthy claims for research on the APOL1-ESRD association.

4.1.2 *Chronic Kidney Disease as a health disparity*

Chronic Kidney Disease (CKD) encompasses renal diseases with a range of etiologies. For most epidemiologic studies, CKD is defined as albuminuria (kidney damage) or glomerular filtration rate (GFR) of <60mL/min per $1.73m^2$ for 3 or more months (Levey & Coresh, 2012). Estimated GFR (eGFR) is used in most studies examining kidney function and as a case definition, or a quantitative trait in genetic studies. There are five stages of CKD, based on severity of decreased GFR, from 1 being the mildest stage, to 5 being the most severe, known as End-Stage Renal Disease (ESRD). This fifth stage requires dialysis or kidney transplant for patient survival. These treatments have substantial impact on individuals and their families. Dialysis impacts quality of life, as it often requires lengthy and frequent stays at dialysis centers, preventing some from being able to work, and limiting other life activities. Kidney transplantation provides relief for patients on dialysis, however, this option is not readily available to all, in part, because compatible donor kidneys are particularly scarce for African American patients.

African Americans comprise 13% of the U.S. population, but bear 32% of the burden of ESRD (National Institute of Diabetes and Digestive and Kidney Diseases, 2014). African Americans have a 3- to 4-fold greater risk of ESRD than Whites[2] (United States Renal Data System, 2016). While ESRD constitutes an important health disparity as a whole, the individual

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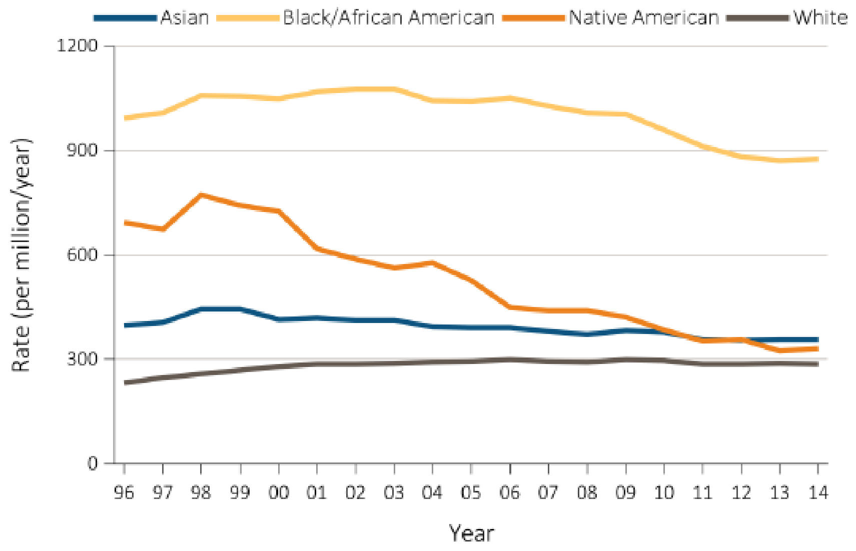
[2] African Americans bear a 3.1-fold greater incidence, and 3.7-fold greater prevalence compared with whites (adjusted for sex and age, standardized to the 2011 U.S. population). Hispanics and American Indians/Alaska Natives also bear an elevated risk of incident ESRD compared with Non-Hispanic whites, at 1.35-fold and 1.2-fold risk, respectively (United States Renal Data System, 2016).

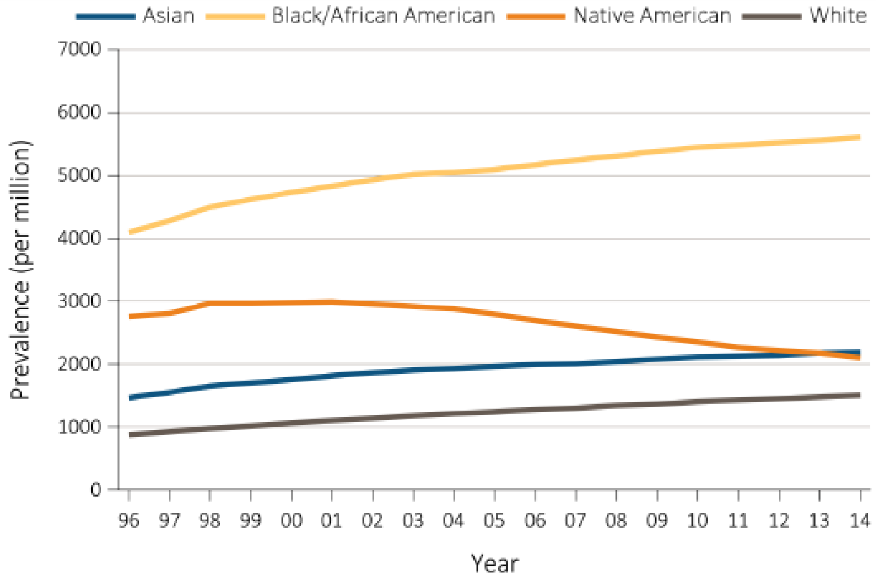
causes differ in their burden. Diabetic nephropathy is responsible for approximately 45% of ESRD cases in the U.S. (Ghaderian, Hayati, Shayanpour, & Beladi Mousavi, 2015). Diabetes is 60% more prevalent in African Americans than whites (United States Renal Data System, 2016). By contrast, African Americans have lower rates of immune-mediated IgA nephropathy (IgAN) compared with European and Asian populations (Freedman et al., 2013). Overall, ESRD disproportionately impacts African Americans in the U.S. compared with other racial/ethnic groups (see Figures 4.1 and 4.2).

These numbers should be taken with some caution, however, because the primary causes of ESRD are noted by physicians, and the reliability of this method of reporting is not clear (United States Renal Data System, 2016). Further, diagnoses regarding kidney disease are often made without kidney biopsy or standardized criteria, and with some racial bias among physicians (Freedman et al., 2013). Recently, Williams and Pollack have suggested that a subset of cases that have been attributed to hypertension are actually more likely to be related to variants in the APOL1 gene that have received increasing attention over the past several years (Williams & Pollak, 2013). While ESRD is treated similarly regardless of cause, the etiology of disease has implications for research and clinical prevention.



*Data Source: Reference Table A.2.2 and special analyses, USRDS ESRD Database. *Adjusted for age and sex. The standard population was the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease.*

Figure 4.1. Trends in adjusted ESRD incidence rates by race, U.S. population 1996-2014 (United States Renal Data System, 2016).



*Data Source: Reference Table B.2(2) and special analyses, USRDS ESRD Database. *Point prevalence on December 31 of each year. Adjusted for age and sex. The standard population was the U.S. population in 2011. Abbreviations: Af Am, African American; ESRD, end-stage renal disease.*

Figure 4.2. Trends in adjusted prevalence for ESRD by race, U.S. population 1996-2014 (United States Renal Data System, 2016).

4.1.3 *Genetic associations with ESRD*

Two coding variants (G1 and G2) in the apolipoprotein L1 (APOL1) gene, on chromosome 22, have been associated with a 10-fold increased risk of ESRD (Genovese et al., 2010). The G1 allele is a pair of nonsynonymous amino acid changes and G2 is a six base pair deletion. The two variants are mutually exclusive, meaning a single chromosome will have one or the other, but not both (Reeves-Daniel et al., 2011). These high-risk alleles exhibit a recessive pattern of inheritance and have been found to be common in individuals of sub-Saharan African ancestry, with 13% of African Americans harboring the high-risk genotype (Limou, Nelson, Kopp, & Winkler, 2014). While the APOL1 variants have not been shown to be associated with diabetic nephropathy, there are substantial odds ratios for these variant associations with non-diabetic types of kidney diseases: HIV-associated nephropathy (HIVAN)= 29, FSGS= 17 (Kopp et al., 2011, p. 2011), and hypertension-attributed end-stage kidney disease= 7.3 (Genovese et al., 2010). It should be noted that HIVAN has been nearly eliminated among all races, since the advent of antiretroviral therapies (Chaudhary et al., 2015), thus the large odds ratio for this form of ESRD has only minimal impact on current burden of disease.

The initial research on this genetic risk came from mapping of admixture linkage disequilibrium (MALD) technology, which identified the MYH9 locus to be associated with FSGS and non-diabetic kidney disease (Kao et al., 2008; Kopp et al., 2008). Later, APOL1 was found to be in linkage disequilibrium with MYH9, then shown to be the causal gene (Genovese et al., 2010). The APOL1 protein functions in mammals to lyse the parasite, *Trypanosoma brucei* (Pollak, Genovese, & Friedman, 2012). Resistant sub-species, *T. brucei gamiense* and *T. brucei rhodesiense* can evade APOL1 lysis, causing two forms of African sleeping sickness. The acute form caused by *T. brucei rhodesiense* is common in sub-Saharan Africa and produces serum resistance-associated (SRA) factor that binds to the APOL1 protein and prevents lysis. SRA does not bind with the G2 form of the APOL1 protein, enabling lysis, and thus protecting against parasitic infection (Pollak et al., 2012). The mechanism behind resistance conferred by the G1 form is not clear (Limou et al., 2014). These observations, combined with haplotype tests, have been suggested as evidence for a selective advantage for the G2 and G1 variants of APOL1, a relatively recent evolutionary adaptation in an environment with a high risk of *T. brucei rhodesiense* infection (Genovese et al., 2010). The advantaged conferred in this ancestral environment is not realized in an environment without risk of infection.

While APOL1 variants have been shown to increase progression to ESRD, the mechanisms that might inform potential treatment options have not been determined (Pollak et al., 2012). APOL1 variants were found to predict progression to ESRD despite aggressive blood pressure control and use of angiotensin-converting enzyme inhibitors among patients with hypertension in the African American Study of Kidney Disease and Hypertension (AASK) study. This finding suggests a potential mischaracterization of some CKD as hypertension-associated when it is actually APOL1-associated and not responsive to aggressive blood pressure control (Freedman, 2015). Given that no treatments have been shown to effectively reduce progression in APOL1 high-risk individuals, at this time, a patients' APOL1 status does not provide information that could guide targeted management of CKD.

The one area in which knowing a patient's APOL1 status has been shown to have some potential near-term benefit is in kidney transplantation. APOL1 is expressed in the cells of many tissues, although found in particular patterns of expression within kidney tissues (Pollak et al., 2012). One study showed that kidneys donated by deceased individuals with the high-risk APOL1 genotype experienced graft failure at a significantly faster rate than those with one or no risk alleles (Reeves-Daniel et al., 2011). Despite the strong association, the study authors were careful to withhold any suggestion of changes in kidney donor selection until the results are replicated. Furthermore, the kidney recipient's APOL1 genotype does not predict graft failure (Lee et al., 2012). With more data, it may be possible to better inform potential donors and make better allocation decisions, in the face of kidney shortages that disproportionately impact African Americans.

4.2 METHODS

4.2.1 *Critical discourse analysis*

I conducted a critical discourse analysis to examine peer-reviewed literature describing uses of APOL1 genetic information in African Americans, for health disparities. Critical discourse analysis assumes that "language is an irreducible part of social life, dialectically interconnected with other elements of social life, so that social analysis and research always has to take account of language," (Fairclough, 2003, p. 2). There is a reciprocal relationship between micro events such as speech or text, and the macro structures in society, in which macro structures pattern micro events, and micro events reproduce macro structures. The goal of critical discourse analysis (as distinct from descriptive discourse analysis) is to make visible and denaturalize the taken-for-granted, including highlighting assumptions that underlie claims (Fairclough, 1985). As Fairclough argues, individuals within social institutions (of which I consider research to be one) typically become unaware of their own way of seeing the world and speaking, through their own process of becoming the role that they play within the institution (in this case, researcher). This is not a criticism of the individual, but rather, an observation about how we tend to take on particular ways of interacting, as part of qualifying for the roles that we play. In this sense, the discourse that exists within an institutional community, such as genetic research, is separate from discourses in other communities, and not always in obvious ways. Fairclough puts forth the idea that ways of talking and ways of seeing are linked. Because in my work on trustworthiness, competence could be described as including an understanding of the community's perspective, it is important to surface assumptions present in how researchers write about issues that a community might find relevant to their own decision-making regarding research participation in studies related to a problem like the APOL1-ESRD association.

The specific analytic framework that I applied is based on Bacchi's approach to policy analysis (2009). Although my goal was not to analyze a specific policy, this framework is useful for my case because of the many decisions made in the course of conducting genetic research, including funding allocations, research questions studied, study design, and recommendations for action that may arise from these decisions. Given the scope of this project, I omitted two of Bacchi's six key questions,[3] and specified the questions to suit my particular goal. I included the remaining questions:

- What is the problem represented to be?
    - How is the term "health disparities" (or its variations) used in the paper? What are the context, and any definitions (implied or explicit)?
    - What predictions do the authors make about the benefits of genetic research for health disparities? How is the "promise" described?
- What assumptions underlie this representation of the problem?

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[3] Omitted questions include: #3 "How has this representation of the problem come about?" This question requires consideration of the history of the representation, and power relations that entered into this shaping of the problem; also #6. "How/where has this representation of the problem been produced, disseminated and defended? How could it be questioned, disrupted and replaced?" This question asks for searching beyond the scope of our literature of interest, to determine how the discourse examined here has been perpetuated. These questions would be appropriate for further research, but did not align with the immediate goal of this project to investigate researcher trustworthiness.

  - What is the implicit pathway to benefit for health disparities via APOL1?
- What is left unproblematic in this problem representation? Where are the silences?
  - What is unknown or uncertain in the scientific literature?
  - What are the obstacles (explicit or implicit) to benefit?
  - What other literature or evidence is relevant?

I coded text of each data source based on the key analytic questions, using Microsoft Excel. I then analyzed this coded text for themes within and across each category. I added an intertextual analysis, informing my analysis of the discourse in the health disparities articles, with papers reporting the basic science of APOL1 and kidney disease. Bacchi's last question cannot be effectively addressed in this analysis, so is included as part of the discussion:

- What effects are produced by this representation of the problem?
  - What is the relative benefit of this work, compared to other sources of health benefit?
  - What does this representation mean for trustworthiness?

4.2.2 *Data sources*

To keep my analysis sufficiently focused, I analyzed peer-reviewed journal articles from the scientific literature on APOL1 genetic testing in African Americans, and health disparities. I searched Pubmed and Web of Science databases for key terms *APOL1*, and *health disparity/ies* anywhere in the article entry. Appendix D presents the process of article screening, exclusion and inclusion, based on PRISMA standards for reporting (Moher, Liberati, Tetzlaff, Altman, & Group, 2009). The final list of articles included in the analysis are summarized in Table 4.1 (n=7).

Table 4.1. Peer-reviewed literature included in this discourse analysis.

Title	Journal	Authors	Date	Key topic
The African diaspora: History, adaptation and health	*Current Opinion in Genetics & Development*	Rotimi, Tekola-Ayele, Baker, & Shriner	2016	Review: of African ancestries and impacts on disease etiology, proposed as resulting from mismatches between ancestral and modern environments.
Using genetic technologies to reduce, rather than widen, health disparities	*Health Affairs*	Smith, Fullerton, et al.	2016	Policy recommendations: for the importance of racial/ethnic diversity in genetic research, to avoid increasing disparities in health care technology.
Kidney disease Genetics and the importance of diversity in precision medicine	*Pacific Symposium on Biocomputing*	Cooke Bailey, Wilson, Brown-Gentry, Goodloe, & Crawford	2016	Scientific study: to genotype 10 kidney disease polymorphisms to characterize variants across racial/ethnic groups.
APOL1 kidney disease risk variants: An evolving landscape	*Seminars in Nephrology*	Dummer, Limou, et al.	2015	Scientific study: to understand potential mechanisms for APOL1 in kidney disease.
Increased burden of cardiovascular disease in carriers of APOL1 genetic variants	*Circulation Research*	Ito, Bick, et al.	2014	Clinical scientific study: to determine association of APOL1 risk alleles and development of CVD.
Genome science and health disparities: A growing success story?	*Genome Medicine*	Rotimi, Shriner, & Adeyemo	2013	"Musings:" Reviews the state of science, using genetic technology to inform population differences in pharmacogenetics.
Health disparities in kidney disease — emerging data from the human genome	*The New England Journal of Medicine*	Williams & Pollak	2013	Editorial: Discussion of what is known and unknown about APOL1 and kidney disease

The additional scientific data about APOL1 discovery and clinical implications were drawn from highly cited articles, and suggested articles and advice from the Scientific Advisory Board of an on-going NIH-funded study (*Community-Based Evaluation of APOL1 Genetic Testing in African Americans*; NHGRI 1R01HG007879, Young/Burke, principle investigators). This board comprises experts in nephrology, epidemiology, genomics, clinical and public health practice.

4.3 RESULTS

4.3.1 *Problem representation: Health disparities are a genomic problem*

In this literature, health disparities are largely considered to be a problem of genetics. Although most of the authors I reviewed mentioned that social determinants of health are also important, and some noted the potential pitfalls of focusing on genetics, they maintained that genetics are important for informing health disparities, leaving the relative weight of these sets of factors unmentioned.[4] Williams and Pollak introduced the idea of health disparities as differences across populations that have largely been studied in terms of social determinants (2013), implying that genetics is an inappropriately under-studied area that could have an important impact on this health disparity.

Smith and colleagues (2016) claim that the fact that genetics play a role in disease manifestation supports the need to study genetics related to health disparities, kidney disease in particular. Rotimi and colleagues suggest that because genetic factors contribute to disease etiology as well as drug response, “the potential of genetics and genomics to shed light on health disparities must be considered,” (2013, p.1). Both sets of authors offer the association of APOL1 variants with kidney disease as an example to illustrate their points. Cooke Bailey and colleagues also justify their genomic study of APOL1 with mention of health disparities: APOL1 is the missing link, partially responsible for the “tremendous health disparity that exists even after accounting for socioeconomic status in kidney disease” (2016, p. 286).

The assumptions built into this characterization of health disparities as an important problem for genomics include: 1) the term, *health disparities,* is broadly defined, and APOL1 variants in

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[4] Reducing health disparities has been identified as an important policy goal for the nation’s health agenda. The CDC’s Healthy People program has stated this goal for the past two decades. While the necessity of reducing health disparities is an additional assumption embedded in the claims about the importance of genetics for health disparities, given the extensive literature and general consensus on the topic, I do not analyze this claim further.

African ancestry populations are evidence that health disparities such as kidney disease may be caused by genetics; 2) the genetic information that can be gained from studying this population can lead to health disparities reduction through health care advances; 3) this benefit is significant and urgently needed, (enough to warrant priority over other non-medical solutions).

4.3.2 *Underlying assumptions*

4.3.2.1 Assumption: The basis of health disparities is largely genetic.

The first assumption suggests that health disparities can be defined broadly and descriptively as population differences, and these patterns may be caused by many factors, including genetics. However, there is consensus in other areas of health sciences that a defining characteristic of health disparities is that they are specifically rooted in social inequity (Braveman, 2014; Phelan, Link, & Tehranifar, 2010). The Secretary's Advisory Committee on Health Promotion and Disease Prevention defines *health disparity* for Healthy People 2020, as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion," (The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020, 2008, p. 28), taken from Carter-Pokras (2002), and echoed by Braveman (2014).

Rotimi and colleagues provide a definition that does not directly mention social inequity: "Health disparities are differences in health status (such as incidence, prevalence, and mortality rates) between population groups. Health disparities depend on many factors, including age, gender, income, geography, ethnicity, and race," (2013, p.1). They then go on to describe the causes of health disparities in accordance with other authors: "Overwhelmingly, disparities in health are the result of sociopolitical structures that drive some members of a society towards poorer health." They note that health disparities are observed population differences, mostly caused by social inequities. This is a nuanced, but important, difference compared with definitions in the broader health disparities literature. Rotimi and colleagues' description leaves room for genetic factors to play a significant and potentially dominant causal role, while the health disparities literature incorporates the social inequities causes in the definition.

Rotimi and colleagues go on to provide examples of what they call health disparities, all cases of population differences in pharmacogenetic responses to drugs, that could potentially lead to different health care needs or algorithms. The common definitions of health disparities would have us consider current differences in risk of disease to be the relevant disparity, rather than the differences in outcomes due to health care treatments—particularly given the limited number of pharmacogenetic tests currently in clinical use, and substantial challenges to implementing new tests in the clinic (Relling & Evans, 2015). Furthermore, pharmacogenetic differences are simply examples of differences across populations, for which there is no inherently better or worse status. These differences may be useful for knowing how to effectively treat patients but having one variant or another does not necessarily confer better or worse health outcomes, if there is adequate knowledge of these variants for clinical application.

In a later paper, Rotimi and colleagues call APOL1 a "striking example" of the "evolutionary importance of genetic variants in populations of the African Diaspora, with implications for health disparities" (2016, p. 79). Despite their earlier stated understanding of health disparities as primarily resulting from sociopolitical structures, they use the existence of high-risk genotypes only found in populations with sub-Saharan African ancestry, that may have conferred an evolutionary advantage in the parts of the world where African sleeping sickness is a risk, as evidence that reducing health disparities depends on genetic research. As they state, "the discordance between ancestral genetic background and modern-day environmental exposures became pronounced in the African Diaspora, contributing to the disproportionately high burden of some chronic diseases and health disparities in these groups" (Rotimi et al., 2016, p. 79). This statement implies that the APOL1 case is likely one of many such effects that we could expect to see, but instead, it remains a rare case. It also implies that the only populations that would be expected to have near-private, deleterious genetic variants would be those experiencing health disparities, due to evolutionary mismatches. However, population genetic differences such as those Rotimi and colleagues mention, exist across populations, even those not experiencing health disparities.

Williams and Pollak (2013) and Smith and colleagues (2016) similarly seem to subscribe to the same concept of health disparities, although neither set of authors offers a definition. Williams and Pollak emphasize the genetics of kidney disease, while acknowledging social determinants: "Certainly, all racial disparities in kidney health are not attributable to APOL1 variation," citing additional phenotypes that have not been explained by APOL1, implying additional genetic cause(s) remain to be discovered. They then note, "we should not dismiss the role of socioeconomic factors, referral patterns, and access to the best practices for renal-replacement therapy" (Williams & Pollak, 2013, p. 2261), but return to the idea of needing to explore genetics to understand the problem. Smith and colleagues start their article with a statement of health disparity causes: "Health disparities between whites and vulnerable social groups such as racial/ethnic minorities are *often* rooted in nonbiological factors, such as socioeconomic status" (Smith et al., 2016, p. 1367) (emphasis added). Both papers use diminishing language, with "often," and "should not dismiss," down from Rotimi and colleagues' term of "overwhelming" to describe the social causes of health disparities.

The basic and clinical science articles do not provide a definition for their use of *health disparities*. Ito and colleagues use the term within their abstract only, regarding the association they found with APOL1 variants and cardiovascular disease: "APOL1 variants contribute to atherosclerotic CVD risk, indicating a genetic component to cardiovascular health disparities in individuals of African ancestry" (2014, p. 845). They do not mention the term in the body of their paper, and they use the term inaccurately to refer to a disparity within individuals; health disparities are patterns across groups, so it is unclear from the context how they would define *health disparities*. Dummer and colleagues simply name kidney disease as a health disparity, as justification for their study in their introduction and do not mention it again (2015). Their mention includes the observation of differential disease burden between African Americans and other groups, but there is no additional clarity. Interestingly, "health disparities" is one of their key words, despite the lack of discussion of this concept, signaling that they consider the concept to be of central importance to their work, but not in need of further definition.

Cooke Bailey and colleagues call the "higher prevalence and incidence of kidney disease among African Americans compared with other racial/ethnic groups in the United States" a "tremendous health disparity that exists even after accounting for socioeconomic status, as evidenced by reports that have evaluated varying degrees of kidney disease and have detected significant risk in African Americans compared to European Americans even when distinct methods are implemented and when income is taken into account" (2016, p. 286). They go on to suggest that "large prospective studies and clinical-based repositories will be required to realize the vision of precision medicine particularly for health disparities across diverse populations" (Cooke Bailey et al., 2016, p. 290). Here, they are using the term "health disparities" implicitly to refer to differences in how clinical applications of genetic tests might apply across populations of patients.

A key point that has been left unrecognized in this literature is that although ESRD is considered a health disparity, the APOL1 variants are only relevant to some etiologies of ESRD, not including the most common cause of ESRD, diabetic nephropathy. It cannot be assumed that non-specialists, including patients and communities, would understand this distinction. Because genomic information allows researchers to subcategorize conditions, (a boon, from the precision medicine perspective), addressing any given subcategory may serve to reduce the burden of that subcategory, but the overall disease burden may not be reduced as much as communities may expect when the benefit is communicated in a general way.

It is reasonable to suggest that knowing about genetic variants that are specific to racial/ethnic populations will be relevant to the application of precision medicine, eventually. If health care providers increasingly use genetic testing to inform clinical decision-making, then indeed, genetic information for diverse populations is necessary to ensure that all patients who see a provider receive useful information for their condition and their ancestry's variants and allele frequencies. As my colleagues and I describe elsewhere, this research effort is important, but it is not about health disparities (West, Blacksher, & Burke, 2017); rather, it relates to ensuring that genetic tests are equally informative for all populations, and thus to equity in access to high quality health care.

4.3.2.2 Assumption: Genetic research will lead to benefit for health disparities.

There is an empirical gap between identifying genetic associations with a disease that exhibits a health disparity pattern, and providing benefit to those individuals and communities bearing the burden of these diseases. Here, I trace the ways in which the authors I reviewed describe the pathway to benefit: some discuss better understanding of kidney disease; others mention the potential to address the health disparity through precision medicine, given greater inclusion of diverse populations in genomic research.

Pathway to benefit claim: Genomic research will help us understand diseases that constitute health disparities. Williams and Pollack reasonably claim in their high-profile commentary: "The first step in alleviating a problem is to understand it" (Williams & Pollack, 2013, p. 2261). They argue that research into APOL1 risk genotypes is likely to clarify the name and pathophysiology of a new kidney disease subtype. As they explain, "CKD that is attributed to hypertension or hypertensive nephrosclerosis may be a misnomer, and the molecular classification of black patients at least partially according to the APOL1 status may eventually supplant such nomenclature" (Williams and Pollack 2013, p. 2261). To take their point a step beyond their text, more accurate parsing of subtypes of disease falls in line with the goals of precision medicine (Collins & Varmus, 2015), and may point to treatments that would be appropriate for those patients with the APOL1-attributed CKD subtype, in contrast with the current practice which has been less effective in patients with APOL1 high-risk genotypes. Their points are appropriately specific and aspirational.

Others also tout the potential for genomic research to help improve our understanding of a health disparity condition such as CKD. For example, a genomic research team set out to elucidate mechanisms of APOL1 variants, to understand ESRD (referred to in their paper as

ESKD,) as a health disparity (Dummer et al., 2015). Rotimi and colleagues concluded, “in time, we will have sufficient knowledge to disentangle the genetic influences from the other broader behavioral, social, cultural, and health care access aspects of disparities in health outcomes” (2013, p. 2). In this way, understanding the genetics could remove that variable from the complex equation, leading to potentially greater ability to understand the rest of the factors. They offer several cases to support their claim that genomic research has successfully addressed health disparities, the first of which is APOL1 and kidney disease. In their discussion, which follows immediately after their definition and acknowledgement of substantial pitfalls of looking for genetic causes of health disparities, there is no mention of realized benefit from genomic research in the case. Rather, they imply benefit from the observation that genomic technology has contributed to the ability to find associations between diseases and genetic loci that are largely limited to one population; a population that also happens to be burdened with health disparities. They assume a high likelihood of benefit from understanding this relationship, in their characterization of these advances as “successes” in their title. Later, they discuss the ancestral environments in which these variants might have arisn as further evidence that there are genetic causes of health disparities, however, again, downplaying the social causes and without specifying the benefit to be derived from understanding the genetics (Rotimi et al., 2016).

The link between understanding mechanisms and benefit is not certain. In the APOL1 case, while there is a strong and likely causal association with disease, there is substantial yet incomplete penetrance of the risk variants. This penetrance is estimated at 20% (J. Kopp, personal communication, April 27, 2017), meaning that additional factors are at play, which could be social-environmental, or other gene interactions. Peralta and colleagues have demonstrated that there remains an important racial difference in rate of kidney function decline in the absence of high-risk APOL1 variants (Peralta et al., 2015). These points indicate that there are other factors that still need to be clarified before any such targeted treatments might be effective, and that a disparity remains among non-APOL1-related kidney disease. Understanding the APOL1 mechanism may be informative, but that information is likely to be limited to APOL1-associated nephropathy, not to the overall ESRD health disparity.

Understanding mechanisms is, indeed, an early step in reaching the goal of finding effective treatments, and it is reasonable to claim that understanding the genomics of ESRD will get us closer to being able to develop treatments for the disease. Although this molecular understanding is potentially helpful to explain how social factors are embodied and become pathogenic, however, it does not inform the broader root causes of a health disparity. The unspoken goal is to find medical interventions to treat a disease that is also a health disparity, supported by a commitment to health care justice, as distinct from the goal of reducing the causes of a health disparity.

Pathway to benefit claim: Genomics can help us address health disparities. Smith and colleagues go a step beyond, to claim that “genetic approaches and tools hold great promise for understanding *and addressing* the roots of these disparities” (Smith et al., 2016, p. 1369) (emphasis added). Their exemplars include APOL1 and kidney disease, and hereditary and sporadic breast cancers. Their approach to addressing health disparities in these cases is highly speculative and requires a great deal more research on a range of topics — including reduction in data gaps across populations (discussed more below) and on clinical utility and implementation of, as yet, undetermined interventions based on genomic information— as well as large educational efforts among patients and providers, attention to ensuring access, third-party payment, and avoiding stigmatization.

The eventual targeted treatments may either be developed based on improved understanding of the disease mechanisms, or used for genotype-informed clinical decision-making. Smith and colleagues assume that understanding molecular mechanisms of APOL1 can lead to efforts to reduce ESRD risk among those with the high-risk genotypes, with hypothetical future clinical treatments and lifestyle changes (2016). Drummer and colleagues similarly assume that understanding disease mechanisms might inform new treatment possibilities, implications for kidney donor screening, and “provide hope for millions worldwide” (2015, p. 232). The challenge is a current lack of clarity regarding what kind of treatments might be possible and effective.

For these claims to be realized, not only must the assumption hold that there are genetic roots of health disparities, but expectations of actionability must be fulfilled. As Rotimi and colleagues explain, "such [genomic] studies can find actionable observations that can be translated to treatment guidelines that maximize individual response while avoiding side effects and adverse drug reactions" (Rotimi et al., 2013, p. 2). There is an expectation of inevitability about the pathway from basic research to "actionable observations" to translation to "treatment guidelines" for drug dosing, but this pathway requires strong testable hypotheses that do not yet exist, and then many years’ worth of incremental research, with resources prioritized to support that work.

Potential for actionability in genomics is also limited to the health care setting, focused on treating individual patients on a micro-level (Collins & Varmus, 2015). There are two main problems with this focus. First, health care plays a limited role in health status. Attempts to quantify this effect have placed health care at 10-25% of health (Booske, Athens, Kindig, Park, & Remington, 2010; Mechanic, 2002), and statistical experiments have shown the substantially greater effect of increased education and rising incomes on positive health outcomes and reducing health disparities, compared with better health care (Woolf et al., 2010; Woolf, Johnson, Phillips, & Philipsen, 2007). Second, even if effective treatments or guidelines are developed, they must also be accompanied by an equitable distribution of health care services in order to make any impact on "addressing" disease once underway. Not only does work not have any ability to remove the fundamental social causes that lead to the onset of chronic kidney disease that would set an individual up for risk of ESRD in the first place, it does not address inequitable access to health care that disproportionately affect populations experiencing health disparities.

Pathway to benefit claim: Genomics will reduce health disparities as long as there are data to inform precision medicine across populations. Several authors observed that participant diversity in genomic research is needed to ensure that this research leads to identifying and including relevant genetic variants, to apply genomic medicine to individuals from all populations. Cooke Bailey and colleagues note, "ideally, genetic variants selected for clinical genotyping are relevant to all populations tested, and therefore efficient in providing potentially health care-related data even at the individual patient level. To achieve this goal, it is crucial that variants selected for genotyping have relevancy to traits in multiple populations, not just European-descent individuals" (2016, p. 290). They justified their own research into the identification of additional SNPs associated with kidney disease risk in the NHANES data set, using this claim, "research such as this is necessary to systematically characterize genome-wide and candidate gene identified genetic variants across diverse populations" (Cooke Bailey et al., 2016, p. 290). Rotimi and colleagues share this concern about diversity in study samples: "Given the central role of treatment with pharmaceutical agents in modern medicine, it remains crucial to study multiple global populations as well as more drugs" (2013, p. 2). They make an urgent call for more genomic research in populations of African ancestry because there is disproportionately more genetic diversity among those with African ancestry, and not enough data to be able to implement genomic medicine for African Americans (Rotimi et al., 2016). The subtext is that there is great benefit being offered by genomic medicine and the lack of data is the primary obstruction to those with African ancestry sharing this benefit.

Indeed, the data gaps that exist in current genomic research studies due to lack of diverse participation may preclude or limit the relevance to diverse populations of any new medical intervention that is developed from this research. The BRCA1/2 genetic test is an example. African American women receive uninterpretable results of variants of uncertain significance (VUS), more frequently than European American women. Laboratories report varying rates of VUS, and these have decreased in the last decades with additional research, but recent estimates are that 5-6% of European American women and 21% of African American women receive VUS results (Eccles, et al., 2015). There are strong justice arguments to support filling these data gaps. However, filling the data gaps would still only solve one of the many barriers to implementation of precision medicine that exist for all populations.

Examples can help consider more specifically the benefit that genomics might offer. For one, Cooke Bailey and colleagues suggest that genetic testing may help identify high-risk patients, to intervene and prevent/reduce CKD before it develops, thus reducing ESRD cases. Because kidney disease is generally asymptomatic until there is significant damage to kidneys, identifying patients early would indeed be beneficial if there were an effective follow-up treatment for those with positive genetic test results (Cooke Bailey et al., 2016). To realize this benefit, substantial research is still needed to identify the appropriate treatments that would lead to reduced CKD among those patients with high-risk genotypes; and there is no certainty that such treatments will be identified. Further, complex health service delivery issues would also need to be addressed, including how to determine whom to screen, payment allocation of resources, and access to both the screen and treatment.

The language used in the scientific articles signals a clear expectation of benefit. In their discussion, Cooke Bailey and colleagues suggest that genomics "will"- not might- streamline processes in identification of health risks. The reality is aspirational, and even if realized, would not necessarily constitute a benefit, in absence of available follow-up. Further, they set out to “determine the utility of these variants for precision medicine settings,” by examining genetic associations and allele frequency questions (2016, p. 286). They claim to be assessing utility of the discovered variants, but there are no data addressing outcomes of testing or suggesting that these variants have any utility in precision medicine. Their methods enable them only to assess clinical validity in various populations, as distinct from clinical utility (Burke, 2009); again, a reasonable goal for current research, but not directly about community health benefit.

A study looking at APOL1 associations with atherosclerotic cardiovascular disease (CVD) risk found a 2-fold risk, “indicating a genetic component to cardiovascular health disparities in individuals of African ancestry” (Ito et al., 2014, p. 845). They hypothesized that the high-risk APOL1 alleles associated with ESRD would also be associated with CVD, given that CKD is a risk factor for CVD and there is biological plausibility to support this idea. They explain that they demonstrated a causal relationship, “that APOL1 risk alleles impact CVD among participants in the Jackson Heart Study,” and in another cohort, show the association of these risk alleles with CVD independently of CKD. They conclude that their “data support epidemiological evidence that the differential burden of CVD in African Americans is based on ancestry that is unexplained by physiological risk factors" (Ito et al., 2014, p. 849). They attribute racial disparities in CVD (in addition to CKD) to APOL1 risk variants, despite the presumably low attributable risk for all of CVD in this population. They conclude that "the considerable population of African Americans with two APOL1 risk alleles may benefit from intensive interventions to reduce CVD" (Ito et al., 2014, p. 845). Their prediction is aspirational rather than definitive, positing that intensive treatment *might* be beneficial, however, they offer no further indication that this possibility is under study, or to what degree there are data to support their expectation of improved outcomes from genotype-specific intervention. Given data suggesting that intensive blood pressure control did not affect ESRD risk related to APOL1, a cautionary approach to this question might have been prudent. Instead, the lack of specificity or cautionary language serves to reify the sense of benefit on the horizon.

At this point, the anticipated benefits to precision medicine from APOL1 testing are limited to identifying high-risk patients (for CKD or CVD) for some undefined future clinical use of that information, and a somewhat more immediate expectation of benefit of APOL1 testing for kidney transplantation—although the latter discussion is largely absent in the literature I reviewed. There is evidence that donor kidneys from deceased individuals with two APOL1 risk variants are twice as likely to fail within a 2 year follow-up than those without the risk variants (Reeves-Daniel et al., 2011). Although the reason for graft failure is unclear, this information could be informative for kidney allocation decision-making. Recipient genotype does not appear to influence graft survival (Lee et al., 2012). There remains uncertainty about both the graft survival of kidneys from living donors, and the risk to the living donor with a high-risk APOL1 genotype of donating a kidney, but some bioethicists have argued that the donor's genotype should be tested and the results provided, to assist them in making an informed decision about donation in light of their potential risk (Ross & Thistlethwaite, 2016).

4.3.2.3 Assumption: There is an urgent need for genomic research on health disparities, potentially of greater priority than researching the social determinants.

Despite overwhelming evidence for the causal role of social determinants of health (Braveman et al., 2011), the fact that genetics clearly influence individual risk for disease within populations can lead to the conflation of health disparities with population health differences. As Williams and Pollack explained, observations of familial aggregation of diseases “have led to the pressing question of whether there were undiscovered genetic determinants” (Williams & Pollack 2013, p. 2260), despite the fact that families often also share social exposures. They also frame the evidence showing the role of APOL1 in ESRD as an important contribution to reducing ESRD among African Americans (Williams & Pollack 2013). However, as noted above, the evidence provided is limited to the “understanding” stage in the translational pathway, not yet in use to *combat* renal disease.

The language used in these articles regarding APOL1 and health disparities: “pressing question,” (Williams & Pollak, 2013), “necessary for” (Cooke Bailey et al., 2016), "urgently needed" in order to "benefit from genomic medicine” (Rotimi et al., 2016), all suggest a sense of urgency to understanding the genomics of APOL1 and ESRD. However, none of these authors provide an example of a demonstrated use for this information that could lead to prevention or improved outcomes at the population level.

The high burden of ESRD among African American populations is indeed, a notable health disparity. This fact has been used to justify the funneling of resources into genomic research, with the long-term goals of identifying and eventually treating high-risk individuals. While the rhetoric suggests there is a likely benefit to African American patients from using genotype data, this benefit is speculative and if realized, undoubtedly a long way off. Grams and colleagues report data from the large-scale longitudinal Atherosclerosis Risk in Communities (ARIC) study, showing that the rate of decline in a key measure of kidney function was highly variable in African Americans, regardless of APOL1 status, and thus do not recommend screening all African American individuals for APOL1 (2016). There is no clear understanding of what the high-risk genotype might mean for the individual and a conspicuous absence of hypotheses about the use of that information to reduce population health disparities. In short, there is no clinical utility to APOL1 genetic testing outside of kidney transplantation—and even that utility is provisional. Cohen and colleagues argue for screening of potential living kidney donors, on the grounds that those with the high-risk APOL1 genotype would likely be ill-advised to give up a kidney when they are at elevated risk of needing a kidney transplant at some time in life. However, they recognize that the evidence base is not yet robust enough to warrant contraindication of the high-risk APOL1 genotype in living kidney donors, and doing so could needlessly diminish the already small pool of kidney donors for African American patients (Cohen, Mittalhenkle, Scott, Young, & Norman, 2011).

In fact, there exist many questions to be resolved before APOL1 research can yield tests or interventions with clinical utility. Dummer and colleagues describe an extensive list of issues that remain, including a great deal more research needed to clarify the mechanisms regarding the APOL1 risk allele cytotoxicity, how APOL1-related diseases might be best managed, identification of the evidence needed to implement genetic screening and prevention for high-risk individuals, and how high-risk potential kidney donors ought to be counseled about their risks (Dummer et al., 2015). The Genetic testing to Understand and Address Renal Disease

Disparities (GUARDD) study is under way to examine some of the implementation issues, as well as African American community perspectives regarding testing, should clinical utility become apparent (Horowitz et al., 2017; Horowitz et al., 2016). Substantial implementation issues remain to be addressed to meet both patient and provider expectations for effective implementation of APOL1 testing.

4.3.3 *Caveat: Use of new advances to increase/reduce health disparities*

Developing a treatment for a disease that constitutes a health disparity is not the same as addressing the health disparity. Rotimi and colleagues claimed a role for pharmacogenetics in health disparities—to explain different responses to drugs and potentially to inform treatment differences. As they note, "scientists are now beginning to document how pharmacogenomics variants can explain disparities in health outcomes…Allele frequency differences between populations translate to poor performance…We are just beginning to appreciate the potential role of pharmacogenomics in health disparities" (Rotimi et al., 2013, p. 2). Again, while there is potential for pharmacogenetics to be used in a treatment to be applied to a condition for which there is a health disparity, as my colleagues and I have argued elsewhere, clinical care advances do not lead to an appreciable reduction in health disparities (West, Blacksher & Burke, 2017). As Smith and colleagues explain, "new genetic technologies such as next-generation sequencing may be implemented in ways that perpetuate and even widen health disparities" (2016, p. 1367). The assumption that treatments for diseases that constitute health disparities will be applied in a way that will reduce the health disparity is faulty—as it would require the treatment to be widely available to those with the greatest burden of disease, possibly less available to those populations with less disease burden. As previously shown with other new medical interventions, these treatments are often more readily accessed by those who do not identify with a community experiencing a health disparities, and so advances in health care can, in fact, widen health disparities (Chang & Lauderdale, 2009).

4.4 DISCUSSION

4.4.1 *Discourse analysis*

I employed a critical discourse analysis method to examine claims about health disparities and genomics, focusing on APOL1 risk variants and ESRD. My analysis revealed the normalization of the idea of importance, and even urgency, of studying genomics to address health disparities, as part of a dominant discourse within the research community. This discourse neither aligns with more a widely-accepted concept of health disparities, nor positions researchers to consider their work in the larger context that might interest communities. There is an assumption that benefit will come from focusing research on identifying the genetic contributions to diseases such as ESRD, that comprise health disparities, and erroneously, that this benefit will reduce the health disparity through applications within health care. The representation of health disparities as a problem for genomics to solve, at least in large part, has been used to introduce and justify genomic research, as well as draw important attention to the issue of disparities. However, I have shown that the more widely accepted conceptualization of health disparities as well as the state of the scientific knowledge and projected benefits of genomic research do not align with this dominant discourse within genomics.

4.4.2 *Cultivating our trustworthiness*

For researchers who wish to answer the call for increasing diversity in genomics, cultivating trustworthiness is as much a part of the task as is conducting sound science. As researchers affiliated with academic institutions, and/or paid by government-funded grants, researchers must recognize that many of the communities who would be participating have learned to distrust these institutions and their affiliates. As many of these communities also experience health disparities, communicating about the potential benefits of genomic research is one area of opportunity for cultivating trustworthiness. From the institutional level, honest assessment of our research tools, and competence to present our tools in the context of community health concerns can support this effort, in conjunction with self-reflection, and learning and acknowledging a community's history with research or other institutions. Speaking honestly within the field might shift the dominant discourse that would position researchers to take this more measured approach in their communication outside the field.

4.4.3 *The larger context*

As Bacchi's framework suggests, a critical look at a policy or recommendation would include consideration of the effects of a problem's representation. Similarly, in my trustworthiness framework, demonstrating honesty requires the incorporation of knowledge about what a community might consider to be relevant. I suggest that a reasonable guess would be that a community considering participating in genomic research, such as that related to APOL1, would be concerned about how we make the decisions about putting resources into community-based interventions, larger social policies, or genomics. Many communities are aware of the impacts of larger social forces on their health, and would likely want to know how well social determinants of kidney disease have been incorporated into any conceptualizations of APOL1 research and kidney research priorities in general. And for many, failure to consider genomics in their environmental context would be a perplexing idea. While researchers understand the technical challenges in conducting gene x environment interaction studies and measuring complex social factors, these challenges cannot become justifications for ignoring (or controlling for) these highly relevant forces. We risk perpetuating racist and inaccurate views if we look for and measure biological factors by race, without their social contexts. Data do not exist in a vacuum and publishing associations without including key contextualizing data may be seen as misleading, and doing so thus may undermine trustworthiness.

Why might we see so many claims about genomic technology and health disparities? There could be political value in over-promising the benefits of a particular kind of research. Researchers needed public support and political will to gain funding for the Human Genome Project, and as public research funding becomes more scarce, there is great need to justify on-going research, arguably incentivizing researchers to overestimate benefit. While the social determinants of health disparities have been studied for decades and much is known about the potential for benefits from interventions to address deleterious social factors, the political will remains limited for large-scale programs to address income inequality, homelessness, under-resourced education, and universal access to high quality primary care. While there is evidence to suggest that addressing these social factors would lead to substantial reduction in health disparities across many diseases, the more individual-focused, health care-centric orientation of our current cultural and political systems may explain the neglect of these issues and the emphasis on benefit from understanding genetic contributions to diseases and relying on high-tech health care approaches. The potential to reduce health disparities—a stated national priority— would likely be greatest by taking the social approaches for which we do not need to understand molecular mechanisms; however, some may argue that a more realistic approach (as unrealistic and futuristic as it may be,) might be to funnel the funding from the Precision Medicine Initiative and any other genetic funding to address conditions for those communities that experience health disparities. In all, however, this fragmented solution is likely a less effective, if more politically expedient approach.

4.4.4 *Limitations*

This study has several limitations. I limited my discourse analysis data sources to those articles that included discussion of APOL1 testing with mentions of health disparities. Other articles that address genetics and health disparities were not included; nor were papers that did not mention health disparities, but perhaps addressed the concept in other terms. I limited my analysis to highlighting the dominant discourse within the scientific community, in the peer-reviewed literature; this does not include representations of the problem to other audiences, namely community members who might be recruited to research or affected by its outcomes, health care providers, or policy-makers. A future discourse analysis examining communication to community members, patients, or prospective research participants regarding the benefits of APOL1 testing (or other genetic research) could examine whether, and if so, how the dominant discourse shapes communication to communities and prospective research participants. Research to determine how this communication impacts community and prospective research participants' views on research institution trustworthiness and research participation is also warranted.

4.5 CONCLUSIONS

My discourse analysis examined a core set of literature for several key questions: How is the problem of health disparities conceptualized in this discourse? What are the key assumptions? And what is left unproblematic? In the literature reviewed here, health disparities are conceptualized as simply population differences in health that can be addressed through health care advances and diversifying genomic research to ensure these advances will apply to all populations. Although social inequities are acknowledged as important, these inequities are not considered an essential part of the definition or relevant to the genomic research agenda. This departure from the robust literature on health disparities fundamentally changes the narrative, and coopts the justice arguments behind health disparities work to rationalize genomic research, potentially to the detriment of social action or community-based policies that would substantially reduce health disparities broadly. A more trustworthy approach would be to ensure that researchers are competent in other disciplinary knowledge; that is, social determinants researchers should have an understanding of biological/genetic factors, and genomic researchers should genuinely appreciate the weight of the role of social determinants and the importance of including them in explanatory models. Trans-disciplinary research can help to ensure that complex issues such as health disparities are understood in context.

Key assumptions that are made throughout the discourse include that genomics are fundamentally important for understanding, and then addressing health disparities, through improved health care. I have highlighted the shortcomings of these assumptions, in the leap between understanding a problem and deriving actionable treatment; in the gap between availability of treatment and its use among those who experience health disparities; then between improvements in health care and actual health disparity reduction. These assumptions allow a lack of accountability, and a lack of estimation of reasonable timelines, for benefit.

The assignment of urgency to the problem of genomics for health disparities is left unproblematic throughout this discourse. Language indicates that there is an immediate need for this information, and lack of genomic knowledge informing health disparities is framed as a justice issue. However, even in our most promising case study of a health disparity, APOL1 and ESRD, there is any pathway from genomic discovery, to individual health improvements, to reduction in health disparity is speculative, at best. While there may be benefits in the long run, improvements in health outcomes for those experiencing health disparities require attention to more immediate factors. While medical progress is a good thing, it does not address the root causes of these disparities, and is not likely to substantially reduce population health disparities. In my qualitative research, the different expectations among community members and researchers for the timeline between research discovery and health improvement came up as a persistent challenge to trustworthiness (Chapter 2). The more reflective, realistic and accurate researchers, funders and policy makers can be about the potential benefits of participating in large research investments, and the expected timelines to changing outcomes, the more worthy they will be of communities' trust. Without such honesty, researchers risk perpetuating the harms that have kept many communities out of research.

Chapter 5. CONCLUSION

5.1 PROJECT SUMMARY

Cultivating researcher trustworthiness is a necessary part of building ethical and strong community-academic research partnerships to improve community health and reduce health disparities. However, the relevant aspects of trustworthiness and what trustworthiness means in community-academic research partnerships have not been well characterized in previous literature. This mixed-methods study aimed to characterize researcher trustworthiness; develop and evaluate the psychometric properties of a quantitative measure of researcher trustworthiness; consider these concepts in action, through application to a case of genomic research.

In my qualitative aim, I interviewed 31 individuals with experience in community-academic research partnerships, to learn about their perspectives on what trustworthiness means to them in the context of their partnerships, what enhances or hinders trust and trustworthiness, and how they have dealt with institutional barriers to researcher trustworthiness. This analysis resulted in 4 dimensions of trustworthiness in this context, (*ethical, caring, competent, vulnerable*) each with important sub-themes, plus a cross-cutting theme, *respectful*, that arose in all four dimensions. Two additional thematic analyses resulted in five categories of institutional barriers, and five categories of approaches that researchers have taken to overcome these barriers.

I then translated the 4 dimensions and cross-cutting theme to Likert-scale survey items. I edited additional high-quality items that have been validated in other relationship contexts, for use in the community-academic partnership context, combining them with my items into an initial item bank. I used a Q-sort process and cognitive interviewing to clarify, validate and reduce the number of items, then pilot tested an online survey of these items, with demographic items and institutional factor items. After deployment of the final survey, nineteen respondents completed all sections. These responses comprised the sample of community partners for my two-phase exploratory factor analysis to examine underlying survey structure, additional validity, and reliability characteristics, and associations between institutional barriers and the measure of perceived trustworthiness. The analyses were underpowered to provide robust results; however, the exploratory factor analysis resulted in 6 reliable subscales that could be combined into a single computed perceived trustworthiness score. These subscales tracked largely, but not completely, with the dimensions and theme resulting from my in-depth qualitative analysis, and displayed moderate content validity. The empirically-derived subscales did not address all of the theoretically-derived dimensions of the concept of interest, so I retained several items from the item bank, in the revised survey for further evaluation with more data. Further, the linear regression analyses resulted in only two suggestively significant associations. There are many potential reasons for these unexpected results, however, I anticipate that the primary reason is a lack of adequate power to be able to see any potential associations.

I drew from the qualitative results to frame my third aim, the application to genomic research. Community-academic partnerships are increasingly considered necessary for conducting health research that benefits communities, especially those who experience health disparities. As precision medicine and genomic research gain more and more public resources and attention, there are legitimate concerns that those populations who are left out of research will not benefit from these investments. I asked how the fields of Genomics could cultivate its own trustworthiness to be worthy research partners of communities that have not participated, or have experienced negative repercussions from research or other institutions, through an honest characterization of the power of genomic research to reduce health disparities. Because relatively new research has pointed to strong associations between variants in the APOL1 gene and end-stage renal disease, I used this as a case study.

My discourse analysis of 7 peer-reviewed publications that link APOL1 genetic variants with health disparities revealed a great deal of language around the urgency to understand the genomic contributors to health disparities, with an assumption that this will lead to benefit for those communities experiencing the health disparity. Comparing this discourse to the state of the science in this uniquely promising case, I highlight the gaps between “understanding” and “benefit,” understood as reduction of health disparities. The overemphasis on genetic factors in much of the genomics-related literature discussing health disparities, perhaps inadvertently, downplays the role of social determinants, and may contribute to public perceptions of being misled about the actual potential for investments in genomic research to solve the social issue of health disparities.

Further, my first aim revealed that honesty about timelines matters for trustworthiness, and has caused serious rifts in relationships when communities expect immediate return on their investments of time and resources to address urgent health matters, and academic researchers have a longer view of the scientific process, and potentially greater tolerance for incremental increases in knowledge. Perceived dishonesty about such issues is not likely the result of purposeful deception, but rather the result of unrecognized differences in understandings and expectations. I argue that a commitment to trustworthiness requires improved communication regarding the points that communities value; understanding those values requires engagement with communities, either as co-researchers in the process if that is what they prefer, or as informants to guide messaging from the scientific community; and that as researchers, we cannot rely on our institutional structures such as ethics review boards, to adequately safeguard our trustworthiness.

5.2 CONTRIBUTIONS TO THE LITERATURE

In this study, I have described three core literatures relevant to the study of trustworthiness. First, the Philosophy literature has defined, debated and theorized concepts of trustworthiness in various types of relationships, converging on the idea that trust and trustworthiness are contextual. My qualitative study contributes a new relationship context to this discussion: community-academic research partnerships. This setting contains particular power dynamics, historical experiences, and differences in values and goals that set this relationship apart from other types of trust relationships. It demands a particular focus on respect as well as an additional dimension, vulnerability, that is often associated with trusting rather than trustworthiness. In my data, the mutuality of trust depended on the researcher taking on some risk, sharing power, embodying humility and self-awareness, which indicated that they might be trusted. This dimension has not been previously acknowledged in the literature as a component of trustworthiness, however, because of the primacy of this characteristic for being perceived as trustworthy, I offer vulnerability, as a positive characteristic that can contribute to the community-academic partnership relationship.

The second important body of trust literature is Organizational Research, to which I add an additional provisional tool to measure perceived trustworthiness relating to trusting beliefs, as one of the three main trust loci that have been developed in the literature, describing a judgment of another’s character (Jones & Shah, 2016). Each existing tool in this literature defines the relationship or relationships with which the tool can be used. Because none of the existing tools were validated in community-academic partnerships, I endeavored to validate existing items alongside new items in this relationship context. Most of the items from previously validated scales were rejected in my tool development process, and I speculate that we can expect the same in the other direction—that is, the tool developed here may not translate to the organizational setting. However, with some editing and pilot testing, my scale might be useful to organizations that are characterized by expectations of mutuality and equitable partnership in a context of some negative history, potential cross-cultural differences, and differences in social power or access to resources. Further research is needed to determine how my new tool might be used in this way.

To the third body of literature, the action and praxis-oriented literature on community-academic partnerships, I add a relevant framework of researcher trustworthiness, with examples and details that are derived from this type of relationship. I offer a tool that can be used by partnerships to self-evaluate, or to communicate to institutions about how the institution's policies and practices might be affecting the community's perceptions of the researcher. One way this could happen is for the community partners to take the survey about the academic partner; any low scores on the scale could be used to frame conversations about what is going wrong, what is constraining the researcher's ability to meet expectations, or whether an item matters to that particular partnership. Then, if institutional factors are identified as leading to these constraints, this tool can offer a set of data to support the need for institutional change.

A new study was published as I was completing my study, regarding stakeholders' views on building trust in community-academic research partnerships (Frerichs et al., 2017). The authors asked community partners, academic partners and health care providers in their sample, to weigh the relative importance of various antecedents of trust, and concluded that different groups placed different importance on some, but shared views on the most important antecedents (authentic communication and reciprocal relationships). I did not aim to evaluate the relative importance of these antecedents, however, my characterization of trustworthiness is compatible with their results.[5]

5.3 IMPLICATIONS FOR RESEARCH POLICY AND PRACTICE

As a researcher asking what it means to be trustworthy, I hope to contribute to bridging a divide that persists between communities and those researchers hoping to engage communities. I offer a message to genome scientists and other researchers, funders and policy makers about the importance of honesty about the practicality, scope, and timelines of benefits promised by investing in genomic research, especially with minority communities. Over the last decade, more and more community-academic partnerships are taking on genomic research. Given the history of broken promises and harms from research, equitable partnerships and trustworthy researchers are necessary for successful research investments. Thus, it is especially important that research messaging remain honest and not misleading—and this requires public and community engagement to understand both what communities value relevant to the research, and how messages are interpreted.

For example, new research efforts such as the All of Us cohort should be designed with a lens of trustworthiness to support on-going engagement. Reconsidering research participation as a long-term respectful partnership, rather than a unidirectional effort to bring individuals in donate their data to research may lead to better science, and greater willingness to be involved in research, especially among those who have previously shunned participation for reasons of

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[5] The antecedents of trust are from their previous concept mapping: “The final labels were (1) communication, credibility, and methodology to anticipate and resolve problems (27 statements; e.g., “memorandums of understanding outlining roles, responsibilities, data sharing/ownership . . .”); (2) authentic, effective, and transparent communication (37 statements; e.g., “honesty and full disclosure”); (3) mutually respectful and reciprocal relationships (31 statements; e.g., “assuring a mutual “win” for all at the table”); (4) committed partnerships (17 statements; e.g., “institutional concern for greater community”); and (5) sustainability (13 statements; e.g., “availability of funding”)” (Frerichs et al., 2017, p. 184).

distrust. Recruitment posters, other public communications and direct engagement efforts should be reviewed for scientific honesty and community interpretations.

The framework that I developed can offer a common language for communities and researchers to communicate concerns, establish shared expectations, and engage in a more respectful process, that can promote participation, even if a full community-academic partnership is not the goal. A trustworthiness orientation makes room for sharing control with communities, such as supporting community-owned projects, that could support the advancement of the science, while demonstrating mutuality and trust in the community, to enable participation. One example of such an effort is the Bio-Repository for American Indian Capacity, Education, Law, Economics and Technology with the Lakota community (BRAICELET) project, establishing the first tribally-run biobank. Shifting our lens from "ethical" research, as guided by institutional review boards and research regulations, to "trustworthy" research as co-defined by communities and researchers in partnership, could open the possibilities for communities to participate in research that matters to them.

5.4 LIMITATIONS

It is clear that mutual trust and reciprocity are considered important in community-academic research partnerships (Frerichs et al., 2017). Although both community- and academic- partners ought to be committed to cultivating their own trustworthiness, I limited my study to the trustworthiness of the researcher. This choice was rooted in two core reasons: 1. Academic institutions are responsible for a history of negative experiences and harms regarding communities, and thus are generally the ones who must rebuild trust, as an extension of their institution or scientific field; and 2. The power dynamic is generally assumed to be in favor of the researcher. Potter's theory of trustworthiness places the responsibility for cultivating and demonstrating trustworthiness on the party with relatively greater power (2002). Undoubtedly, there are other important features of building a trusting relationship that deserve attention that my study was unable to address.

A second key limitation in my study was a small or biased sample. My qualitative study was adequately sized but included mostly female participants, and all participants in both the qualitative and quantitative studies had at least some college education. These characteristics are likely reflective of the makeup of the population involved at the level of partner in the research, however, may not include the views of other genders and education levels of individuals who wish to become involved, or may be involved at different levels. As noted, the quantitative survey sample was diverse, but too small to provide adequately-powered results.

5.5 FUTURE DIRECTIONS

I would like to extend this work by including applying my trustworthiness framework and institutional barriers categories to conversations with institutions about structural or policy changes that would support community-academic research partnerships. I will continue to recruit survey participants to enable a confirmatory factor analysis, and improve the quality of my scale. Finally, I would like to study how community-facing communication around genomics impacts participation in both community-based, and large cohort studies.

It is not enough for researchers to conduct quality research, while staying out of policy issues. We must realize that what our institutions do– over which we may have no control– influence how communities perceive researchers. We would be wise to consider our work within larger social and political contexts, and how we communicate publicly, especially with communities who have been harmed by institutions. If we do so, we may ask better questions, build better tools, allocate resources more efficiently, and produce more just science.

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APPENDIX A

High-quality survey items in the literature, by dimension of trustworthiness.

Citation	Dimension (Construct) Measured	Perceived Trustworthiness Items
McAllister (1995) Notes: 7-point Likert scale; assesses theoretical framework	Affect-based items	• We have a sharing relationship. • We can both freely share our ideas, feelings and hopes. • I can talk freely to this individual about difficulties I am having at work and know that (s)he will want to listen. • We would both feel a sense of loss if one of us was transferred and we could no longer work together. • If I shared my problems with this person, I know (s)he would respond constructively and caringly. • I would have to say that we have both made considerable emotional investments in our working relationship.
	Cognition-based items	• This person approaches his/her job with professionalism and dedication. • Given this person's track record, I see no reason to doubt his/her competence and preparation for the job. • I can rely on this person not to make my job more difficult by careless work. • Most people, even those who aren't close friends of this individual, trust and respect him/her as a coworker. • Other work associates of mine who must interact with this individual consider him./her to be trustworthy. • If people knew more about this individual and his/her background, they would be more concerned and monitor his/her performance more closely.
	Affiliative (Organizational) citizenship behavior (OCB)	• I take time to listen to this person's problems and worries • I have taken a personal interest in this individual • I frequently do extra things I know I won't be rewarded for, but which make my cooperative efforts with this person more productive. • I pass on new information that might be useful to this person • I willingly help this individual, even at some cost to personal productivity. • When making decisions at work that affect this individual. I try to take his/her needs and feelings into account. • I try not to make things more difficult for this person by my careless actions.
Cummings and Bromiley (1996) Notes: 7-point Likert scale. Assesses 3 components for each dimension. Respondents fill in the blank spaces with the department being evaluated.	Keeps commitments	• We think that ___meets its negotiated obligations to our department. • In our opinion, ___ is reliable. • We feel that ___will keep its word. • We feel that ___ tries to get out of its commitments.
	Negotiates honestly	• We think the people in ____ tell the truth. • We feel that ____negotiates with us honestly.

		• We think ___does not mislead us. • We feel that ___negotiates joint expectations fairly.
	Avoids taking excessive advantage	• We think that the people in ____succeed by stepping on other people. • We feel that ___tries to get the upper hand. • We think that ____ takes advantage of our problems. • We feel that ___takes advantage of people who are vulnerable.
Mayer and Davis 1999 Note: 5-point Likert scale	Ability	• Top management is very capable of performing its job. • Top management is known to be successful at the things its tries to do. • Top management has much knowledge about the work that needs done. • I feel very confident about top management's skills. • Top management has specialized capabilities that can increase our performance. • Top management is well qualified.
	Benevolence	• Top management is very concerned about my welfare. • My needs and desires are very important to top management. • Top management would not knowingly do anything to hurt me. • Top management really looks out for what is important to me. • Top management will go out of its way to help me.
	Integrity	• Top management has a strong sense of justice. • I never have to wonder whether top management will stick to its word. • Top management tries hard to be fair in dealings with others. • Top management's actions and behaviors are not very consistent. • I like top management's values. • Sound principles seem to guide top management's behavior.

APPENDIX B

Initial complete item bank, with original domain assignments and sources for the original items including those that were edited. Items retained for the survey are denoted in shaded boxes.

Item Text	Assigned Domain	Subtheme	Source
My research partner graciously accepts invitations to community events.	Caring	Care/Whole Person	Aim 1
My research partner takes a personal interest in our community.	Caring	Care/Whole Person	(M95)
My research partner frequently does extra things to make our partnership's work more productive, that they know they won't be rewarded for.	Caring	Care/Whole Person	(M95)
My research partner takes time to listen to our community's problems and worries.	Caring	Care/Whole Person	(M95)
My research partner and I would both feel a sense of loss if we could no longer work together.	Caring	Care/Whole Person	(M95)
Knowing my needs and desires is very important to my research partner.	Caring	Care/Whole Person	(M&D99)
My research partner's heart is in their work with our community.	Caring	Care/Whole Person	Aim 1
I feel like I know who my research partner is, as a person.	Caring	Care/Whole Person	Aim 1
My research partner really looks out for what is important to me.	Caring	Care/Whole Person	(M&D99)
My research partner gives more to the community than just what is needed for the research project.	Caring	Care/Whole Person	Aim 1
My research partner does not spend as much time in the community as I would like.	Caring	Care/Whole Person	Aim 1
I do not have a good sense of whether or not my research partner plans to work with our community beyond the current grant.	Caring	Commitment	Aim 1
My research partner is very knowledgeable about what is important to the community.	Competent	Community	(M&D99)
My research partner has learned about our community's past research experience(s).	Competent	Community	(M95-O)
I am not sure that my research partner understands what the community needs.	Competent	Community	Aim 1
My research partner knows how to advocate on behalf of the community to get the university to change their ways, when needed.	Competent	Creative	Aim 1
My research partner(s) is very capable of performing his/her research.	Competent	Research	(M&D99)
I often find that community members have to clean up messes left by my research partner.	Competent	Self-aware	Aim 1
I am more likely to think a researcher is trustworthy if they reflect the same race/ethnicity and/or language as me/my community than if they do not.	Competent	Social Similarity	Aim 1
My research partner shares characteristics with our community such as race, ethnicity, language, gender, health status, social groups.	Competent	Social Similarity	Aim 1

I think my research partner tells the truth.	Ethical	Honesty	(C&B96)
I think my research partner sometimes misleads me or my community members.	Ethical	Honest	(C&B96)
Sound principles seem to guide my research partner's behavior.	Ethical	Integrity	(M&D99)
I think that my research partner succeeds by stepping on other people.	Ethical	Integrity	(C&B96)
My research partner truly listens, with a willingness to take feedback.	Ethical	Integrity	(M&D99)
My research partner makes sure community members are truly included in research decisions.	Ethical	Integrity	(M&D99)
I feel that my research partner will keep their word.	Ethical	Reliable	(C&B96)
In my opinion, my research partner is reliable.	Ethical	Reliable	(C&B96)
I feel that my research partner tries to get out of his/her commitments.	Ethical	Reliable	(C&B96)
My research partner ensures that any new team members will abide by partnership agreements and expectations.	Ethical	Responsible	Aim 1
My research partner updates me before I feel the need to ask.	Ethical	Responsible	Aim 1
My research partner is careful when other researchers want to use his/her relationship with our community to work with us.	Ethical	Responsible	Aim 1
My research partner takes responsibility for things that others do, even if out of their hands.	Ethical	Responsible	Aim 1
I consider my research partner to be trustworthy.	General	none	Aim 1
My research partner often comes across as arrogant, or a know-it-all.	Respectful	None	Aim 1
My research partner checks in to see if the community members think the researcher or institution has done something wrong.	Respectful	None	Aim 1
My research partner tries to find a balance between involving, and over-burdening community members.	Respectful	None	Aim 1
My research partner is willing to comply with our community's rules and norms.	Respectful	None	Aim 1
My research partner respects our community's knowledge and worldview.	Respectful	None	Aim 1
My research partner asks questions, rather than always just telling.	Respectful	None	Aim 1
My research partner actively seeks the community's criticism of the research.	Respectful	None	Aim 1
My research partner ensures that our community members are paid for their time and contributions to the research. (Paid could mean money or something else the community member values.)	Respectful	None	Aim 1
I often wish my research partner would ask for negative feedback or criticism of what he/she is doing.	Respectful	None	Aim 1

I believe my research partner intends to work with our community for a long time.	Vulnerable	Committed	Aim 1
I believe my research partner trusts me.	Vulnerable	Has A Stake	Aim 1
My research partner is willing to risk something he/she cares about for our community's benefit.	Vulnerable	Has A Stake	Aim 1
My research partner is not afraid to share control over decisions with the community.	Vulnerable	Has A Stake	Aim 1
My research partner is aware of his/her impact on the community.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner gets out of his/her own comfort zone.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner is very guarded around me or my community.	Vulnerable	Whole Person	Aim 1
Who my research partner is as a person is a mystery to me.	Vulnerable	Whole Person	Aim 1
My research partner admits when he/she makes mistakes.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner recognizes his/her own position, as an outsider, as someone of a different race/ethnicity, gender, socioeconomic status, or other.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner knows his/her own limits and strengths.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner is a team player.	Caring	Mission Motivated	Aim 1
My research partner passes on new information that might be useful to me/our community.	Caring	Personal investment	(M95)
My research partner makes friends with community members.	Caring	Personal investment	Aim 1
If I shared my problems with my research partner, I know he/she would respond constructively and caringly.	Caring	Personal investment	(M95)
My research partner will go out of his/her way to help me.	Caring	Personal investment	(M&D99)
My research partner is very concerned about my and the community's welfare.	Caring	Personal investment	(M&D99)
My research partner frequently does extra things to make our partnership's work more productive, that they know they won't be rewarded for.	Caring	Whole Person	(M95)
My research partner brings all aspects of him/herself, not just his/her researcher role to our work together.	Vulnerable	Personal investment	Aim 1
My research partner and I have both made considerable emotional investments in our working relationship.	Caring	Personal investment	(M95)
My research partner willingly helps us, even at some cost to personal productivity.	Caring	Personal investment	(M95)
My research partner would not knowingly do anything to hurt me.	Caring	Care/Whole Person	(M&D99)
My research partner and I have a sharing relationship. We can both freely share our ideas, feelings, and hopes.	Caring	Personal investment	(M95)

I can talk freely to my research partner about difficulties I am having with the partnership and know that (s)he will want to listen.	Caring	Personal investment	(M95)
My research partner is primarily motivated by his/her dedication to the community partnership, rather than his/her own individual benefit.	Caring	Mission Motivated	Aim 1
My research partner makes an effort to know the history of research in the community.	Competent	Community	(M95)
My research partner is very knowledgeable about the work that needs done.	Competent	Research	(M&D99)
If people knew more about my research partner, they would be more concerned and monitor his/her performance more closely.	Competent	Research	(M95)
Given my research partner's track record, I see no reason to doubt his/her competence and preparation for the job.	Competent	Research	(M95)
I feel that my research partner negotiates with me/my community honestly.	Ethical	Honesty	(C&B96)
I think my research partner does not mislead me/my community.	Ethical	Honesty	(C&B96)
I like my research partner's values.	Ethical	Integrity	(M&D99)
I feel that my research partner negotiates joint expectations fairly.	Ethical	Integrity	(C&B96)
My research partner has a strong sense of justice.	Ethical	Integrity	(M&D99)
My research partner genuinely values the community and demonstrates that through ensuring opportunities to truly be included.	Ethical	Integrity	(M&D99)
My research partner tries hard to be fair in dealings with others.	Ethical	Integrity	(M&D99)
I feel that my research partner takes advantage of people who are vulnerable.	Ethical	Integrity	(C&B96)
I feel that my research partner tries to get the upper hand.	Ethical	Integrity	(C&B96)
I think that my research partner takes advantage of our problems.	Ethical	Integrity	(C&B96)
My research partner's actions and behaviors are not very consistent.	Ethical	Reliable	(M&D99)
My research partner follows through on promises, and communicates appropriately when something comes up that makes it impossible to follow through.	Ethical	Reliable	(M&D99)
I never have to wonder whether my research partner will stick to their word.	Ethical	Reliable	(M&D99)
My research partner is accountable to our community.	Ethical	Responsible	Aim 1
My research partner takes responsibility for him/herself when in our community.	Ethical	Responsible	Aim 1
My research partner knows when it is not their place to make decisions on behalf of the community about any other researchers that the community works with.	Ethical	Responsible	Aim 1
My research partner genuinely values our community members' time.	Respectful	None	Aim 1
My research partner listens and is responsive to our community.	Respectful	None	Aim 1

My research partner values our community’s input.	Respectful	None	Aim 1
My research partner tries to learn from community members.	Respectful	None	Aim 1
My research partner shows genuine interest in our community members’ ideas.	Respectful	None	Aim 1
My research partner makes accommodations to ensure that the community has genuine opportunities to contribute to the research.	Respectful	None	Aim 1
My research partner asks the community what we actually want/need before proposing a research project.	Respectful	None	Aim 1
I believe my research partner is committed to our partnership.	Vulnerable	Committed	Aim 1
My partner takes on some level of risk in our relationship.	Vulnerable	Has A Stake	Aim 1
My partner shares control over things that matter to him/her (e.g. data ownership, community approval of publications) with our community.	Vulnerable	Has A Stake	Aim 1
My research partner generally knows enough to be able to make true statements about his/her own abilities.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner is open with community members about things he/she doesn't know.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner understands the limitations of research tools to address community needs.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner is aware of his/her own position relative to community members.	Vulnerable	Humble/Self-Aware	Aim 1
My research partner sees the community members’ knowledge as equal or more valuable as his/her own.	Vulnerable	Humble/Self-Aware	Aim 1

Abbreviations indicating sources of the items: Qualitative data (Aim 1), Mayer and Davis, 1999 (M&D99), Cummings and Bromiley, 1996 (C&B96), McAllister, 1995 (M95).

APPENDIX C

Items not meeting inclusion criteria in primary or secondary PCA. Comments describe the theoretical examination of each item, and my decision to add the item to the scale as an individual item (shaded rows), or fully eliminate the item.

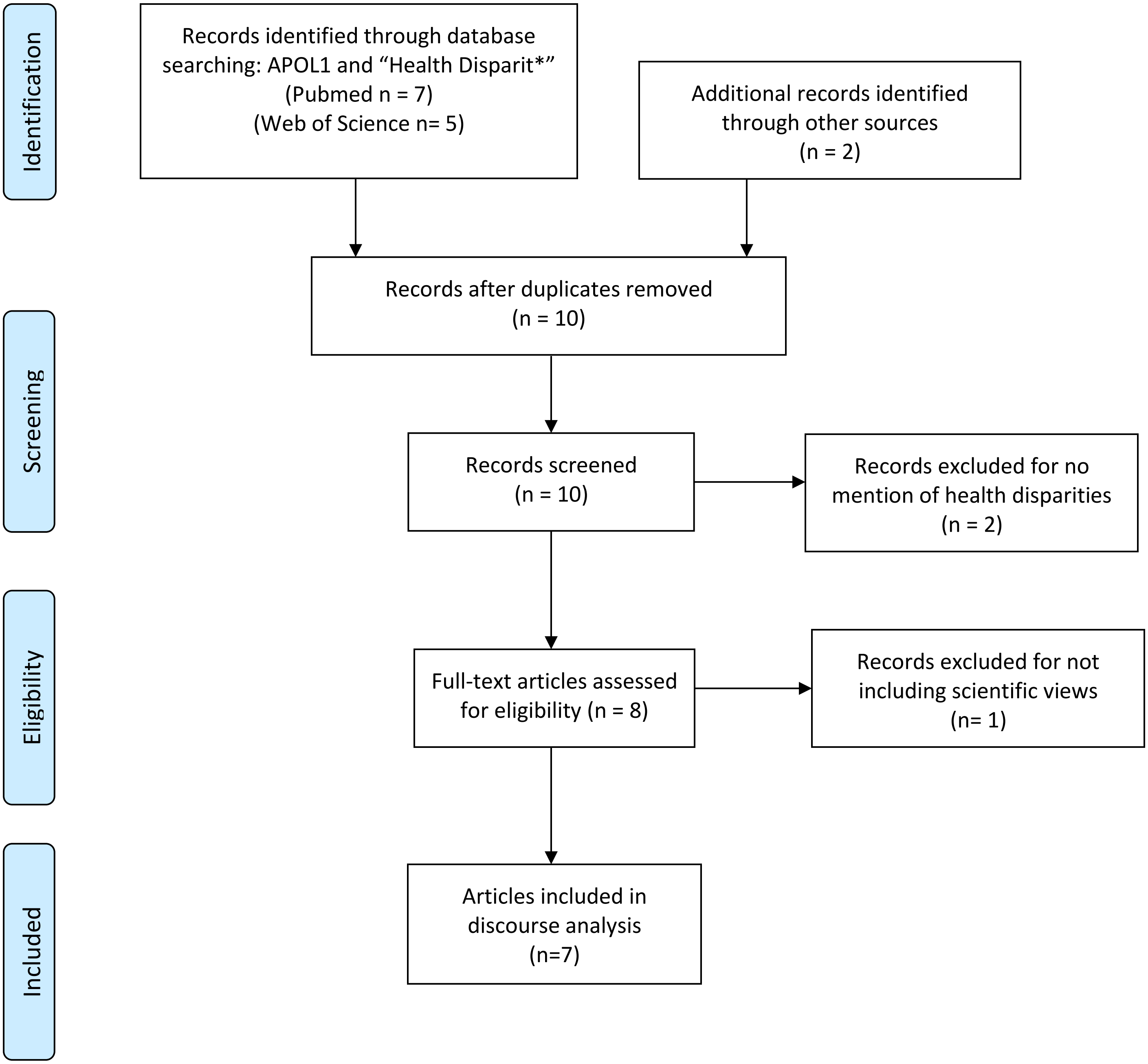
Items	Comments
I am not sure that my research partner understands what the community needs.	This is an important part of competence, but it seems to be sufficiently captured in other items. It is simply the negative of the included variable, so it is possible that the reverse does not indicate as much about trustworthiness as the positive—I eliminated it.
I believe my research partner intends to work with our community for a long time.	The idea of commitment or long-term intentions to work together was highly important in my qualitative data. I retained this item.
I believe my research partner trusts me.	This is a statement about the level of mutuality of trust in the partnership, less than perceived trustworthiness of the researcher. The item derives from the idea that if the researcher trusts the community first, that can enhance the community's willingness to trust the researcher. It might be an indicator of another antecedent, willingness to trust, rather than a researcher's trustworthiness. I eliminated this item.
I consider my research partner to be trustworthy.	Loaded highly into its own factor during secondary analysis. This item is a very general item, that could be instructive for future analyses; I retained this item.
I feel that my research partner will keep his/her word.	The exclusion of this item was surprising, as it is similar to other concepts that did exhibit high and moderate factor loading. This one loaded highly into a factor in the secondary analysis, with only one other item, and moderately on another factor Similar to the item about "misleading" the community; moved to a factor with moderate loading. Also moderately loaded on another factor, but when putting all similar items together in this factor, all reached the cut off of .60 for the factor, although several also met the .40 cut off for exclusion. Given the small sample size, I recommend retaining this factor.
I often wish my research partner would ask for negative feedback or criticism of what he/she is doing.	This item performed poorly and was similar to other items; I eliminated it.
I think my research partner sometimes misleads me or my community members.	This item scored moderately on several factors. It reflects a level of honesty, and was specifically considered highly important in my qualitative data. Strangely, none of the items in the sub-theme category of "honesty" reached high factor loading levels; however, honesty including not misleading the community, was nearly ubiquitous across qualitative participants. For this reason, I retained it.
I think my research partner tells the truth.	Similar to the item about "misleading" the community; also moderately loaded on another factor, (both loadings were close in magnitude,) so I retained the other item instead.
In my opinion, my research partner is reliable.	This item loaded moderately on several factors, including over .60 in 3 factors. It was close enough to the other ethical items "will keep his/her word," so I eliminated this item.
My research partner checks in to see if the community members think the researcher or institution has done something wrong.	This item indicates a proactive seeking of knowledge and self- recognition that the researcher might not know when they have offended the community, and cares to be sure they do know if something goes awry—an important topic in my qualitative data, so I retained it.
My research partner does not spend as much time in the community as I would like.	This performed highly under the dedication subscale during the secondary analysis, which was not considered reliable. I eliminated this item.

My research partner gives more to the community than just what is needed for the research project.	This item is similar to an included item and this one performed moderately on two factors, so I eliminated it.
My research partner graciously accepts invitations to community events.	A trustworthy researcher was described in my qualitative data as someone who would be glad to attend community events, as it is both a demonstration of respect, and interest in the community as more than just research subjects; it is possible that is not the same as trustworthiness; so I eliminated this item.
My research partner has learned the about our community's past research experience(s).	This idea was described as an essential starting point for those communities who had negative previous research experiences. It is possible that for those communities who do not have negative prior experiences, this item would be irrelevant. Still, given how important it is for those with negative experiences, I retained it in the scale for further evaluation.
My research partner is very capable of performing his/her research.[#]	This is one of the *competent* items, none of which loaded heavily. This was from a previous scale, and is one of the core dimensions of trustworthiness that exists in all of the previous high-quality scales I found, as well as a generally accepted component in the theories of trustworthiness. I included this item as an extra item outside of a subscale.
My research partner is very knowledgeable about what is important to the community.	It surprised me that this item performed as poorly as it did, because it seems like the more general *competent* question in the pool, however, several other items performed more strongly and addressed several aspects of this idea. I eliminated this item.
My research partner is willing to risk something he/she cares about for our community's benefit.	This concept was highly important in my qualitative data, but it is possible that the wording (e.g. the language of "risk") does not capture the essence of the idea as reflected in my previous data. I recommend reworking this item and retesting in future work.
My research partner knows how to advocate on behalf of the community to get the university to change their ways, when needed.	This item loaded moderately into several factors. This concept showed up many times in my qualitative data, as an important part of the "competent" domain. However, it is possible that out of context, this item did not elicit the same ideas, as it was not preceded by any mention of institutional policies that need to be changed to help the partnership. More evaluation is needed; I added this item to the scale.
My research partner often comes across as arrogant, or a know-it-all.	It is possible that this concept does not reflect on trustworthiness, so I eliminated it.
My research partner recognizes his/her own position, as an outsider, as someone of a different race/ethnicity, gender, socioeconomic status, or other.	This item performed poorly and was similar to other items; I eliminated it.
My research partner shares characteristics with our community such as race, ethnicity, language, gender, health status, social groups.	This is similar to another item that did load highly. It is also not necessarily an indicator of trustworthiness per se, but rather could be an independent variable for testing correlations with other trustworthiness indicators.
My research partner takes a personal interest in our community.	This item performed scored highly/moderately on two subscales. Other similar items scored more highly, so I eliminated this item.
My research partner takes time to listen to our community's problems and worries.	This item performed poorly and was similar to other items; I eliminated it.
My research partner tries to find a balance between involving, and over-burdening community members.	This may not be as essential, as it is a somewhat subtle idea, and perhaps not relevant to all partnerships; I eliminated this item.

My research partner truly listens, with a willingness to take feedback.	This concept was highly important across my qualitative data. It loaded heavily and moderately on factors that were not retained as subscales. It is possible that while crucially important for a researcher to demonstrate these actions, it is not actually a reflection of their trustworthiness, *per se*. More evaluation is needed on this item, so I added it to the scale.

APPENDIX D

Data source selection for discourse analysis, reported based on PRISMA standards (Moher et al., 2009).



VITA

KATHLEEN MCGLONE WEST

Education

• Ph.D. Public Health Genetics **Dissertation:** Researcher trustworthiness within community-academic research partnerships: Lessons for genomic research	University of Washington, Seattle School of Public Health, 2017 Advanced to Candidacy 2015
Alene Morris National Education for Women's Leadership Institute	University of Washington, Seattle, 2016
• M.S. Biology Center for Alaska Native Health Research Resilience and Adaptation Program, IGERT **Master's thesis:** Lessons from the River: Identifying Factors that Influence Comprehension of Genetics Research in a Yup'ik Eskimo Community.	University of Alaska, Fairbanks, 2009
• B.A. Politics, minors in Economics, Environmental Studies	Oberlin College, 2003

Research and Field Experience

- Pre-doctoral Research Associate, UW Departments of Bioethics and Humanities, and Biomedical Informatics and Medical Education Seattle, WA 2015-present
  - *Community-Based Evaluation of APOL1 Genetic Testing in African Americans* (Young/Burke, Co-PIs)
  - *Ethically responsible clinical decision support for Lynch Syndrome screening* (Korngiebel, PI)
- Research Analyst, UW Center for Genomics and Healthcare Equality, Seattle, WA, 2010-2015
- Project Consultant, UW Center for Genomics and Public Health, Seattle, WA 2013
- Research Consultant, Interdisciplinary Center on Epigenetics, Science & Society, Oregon Health Sciences University, Portland, OR, 2010-2012
- Graduate Research Assistant, Center for Alaska Native Health Research, Fairbanks, AK 2007-2009
- Intern, Center for Genomics and Healthcare Equality, University of Washington, Seattle, WA 2007
- Research Assistant, Bonanza Creek Long Term Ecological Research, Boreal Ecology Cooperative Research Unit, UAF, Fairbanks, AK 2006
- Health Educator and Reproductive Health Specialist, (full-time staff) Planned Parenthood of Alaska, Fairbanks, AK 2003-2006
- Intern, Guttenberg for State House Campaign, Fairbanks, AK 2002
- Student, Field Course, *Tropical Ecosystems*, James Cook University, Queensland Australia 2001
- Intern, Office of Senator Ted Kennedy, Washington DC 2001

Peer Reviewed Publications

- West, Kathleen McGlone, Erika Blacksher, Wylie Burke. (2017) *"Genomics, health disparities, and missed opportunities for the nation's research agenda."* *JAMA- The Journal of the American Medical Association.* Published online ahead of print: doi:10.1001/jama.2017.3096.
- West, Kathleen McGlone, Wylie Burke, Diane M Korngiebel. "Identifying "ownership" through role descriptions to support implementing universal colorectal cancer tumor screening for Lynch Syndrome" (in press, *Genetics In Medicine*)
- Bowen, Deborah, Travis Hyams, Melody Goodman, Kathleen West, Julie Harris-Wai, and Joon-Ho Yu. "Systematic review of quantitative measures of stakeholder engagement" (in press, *Clinical and Translational Science*)
- James, Rose, Kathleen McGlone West, Teresa Madrid. (2013) "Launching Native Health Leaders: Reducing Mistrust of Research Through Student Peer Mentorship." *American Journal of Public Health*.103(12): 2215-9. PMC, NIHMSID 554147.
- Walker, Lorelei, Helene Starks, Kathleen M. West, Stephanie M. Fullerton. (2011) "dbGaP Data Access Requests: A Call for Greater Transparency" *Science Translational Medicine*, 3(113).
- West, Kathleen M., Scarlett E. Hopkins, Kim J. Hopper, Gerald V. Mohatt, Bert B. Boyer. (2011) "Found in translation: decoding local understandings of genetics and heredity in a Yup'ik Eskimo community" *Public Understanding of Science*, March 14 DOI: 10.1177/0963662510397224.
- Boyer, Bert B., Gerald V. Mohatt, Renee L. Pasker, and Elaine M. Drew, and Kathleen K. McGlone (2007). "Sharing Results from Complex Disease Genetics Studies: A Community Based Participatory Research Approach" *International Journal of Circumpolar Health* 66(1).

Conference Presentations

- West, Kathleen M. *Researcher trustworthiness in community-academic research partnerships: What does it mean for genomics?* ELSI Congress, Jackson Laboratory, Farmington CT, June 2017 (accepted).
- Young, Bessie, Ebele Umeukeje, Kerri Cavanaugh, Deborah Davies, Stephanie M. Fullerton, Kate West, James Wilson, Wylie Burke. *Clinician Attitudes Toward Use of APOL1 Genetic Testing in Kidney Transplantation*. ELSI Congress, Jackson Laboratory, Farmington CT, June 2017 (accepted).
- West, Kathleen M. *Our hands are tied: Institutional barriers and creative remedies to foster researcher trustworthiness in community-academic partnerships*. American Public Health Association Annual Meeting, Denver CO, November 2016.
- Yu, Joon-Ho, Kathleen M. West, Julie Harris-Wai, Sandra Soo-Jin Lee. *The Ethics of Assessing Group Benefits and Harms in the Age of Precision Medicine*. Program workshop presentation at the American Society of Bioethics and Humanities, Washington DC, October 2016.
- West, Kathleen M. *What does it mean to be a trustworthy researcher in a community-academic research partnership? Repairing distrust of research institutions through advocacy and action.* Community-Campus Partnerships for Health, 14th International Conference, New Orleans, LA, May 2016.
- Korngiebel, Diane M., Kathleen M. West, Wylie Burke. *Clinician stakeholder views on implementing universal colorectal cancer tumor screening for Lynch Syndrome.* NHGRI Research Training and Career Development Annual Meeting, Washington DC, April 2016.**Award winner
- Tsosie, Krystal, Kathleen West, Joseph Yracheta, Keolu Fox. *Invited Session: Research Partners, Not Subjects: Engaging Indigenous Peoples in Genetics.* 65th Annual Meeting of the American Society for Human Genetics, Baltimore, MD, October 2015.
- Yracheta, Joseph, Kathleen West, Chad Uran. *Conversations about Genomics*. Affiliated Tribes of Northwest Indians Winter Conference, Ferndale, WA, February, 2014.

- West, Kathleen M., Lorita Clough, Rosalina James, Kelly Edwards, Scarlett Hopkins, Susan Brown Trinidad. *Collaborative tools for process evaluation of developing community-university partnerships.* International Congress on Circumpolar Health, Fairbanks, AK, August, 2012.
- James, Rose, Polly Olsen, Kathleen M. West. *Shifting tribal mistrust of research: Native student peer mentorship and exposure to CBPR concepts*. Native Health Research Conference, Seattle, WA, July 2012.
- Walker, Lorelei, Helene Starks, Kathleen M. West, Stephanie M. Fullerton. *Evaluation of dbGaP data access requests: A call for greater transparency*. 61st Annual Meeting of the American Society of Human Genetics, Montreal, Canada, October, 2011.
- West, Kathleen M., Scarlett E. Hopkins, Kelly A. Edwards, Kim J. Hopper, Bert B. Boyer. *"Passed Down Through Our Blood:" Developing Common Language for a Cross-Cultural Genetic Research Partnership.* Exploring the ELSI Universe: Ethical, Legal, Social Implications Research Program Congress, Chapel Hill, NC, April, 2011.
- Walker, Lorelei, Helene Starks, Kathleen M. West, Stephanie M. Fullerton. *Database for Genotypes and Phenotypes dbGaP: Who is using it?* Exploring the ELSI Universe: Ethical, Legal, Social Implications Research Program Congress, Chapel Hill, NC, April, 2011.
- Starks, Helene, Kathleen M. West, Lorelei Straub. *Stakeholder Views on Data Sharing Policies: Who Wins, Who Loses, and Why?* Exploring the ELSI Universe: Ethical, Legal, Social Implications Research Program Congress, Chapel Hill, NC, April, 2011.
- James, Rosalina, Lisa Rey Thomas, Cynthia Pearson, Myra Parker, Kelly Edwards, Michelle Montgomery, Dana Gold, Kathleen McGlone West, Robbie Paul. *Advancing Indigenous Research Ethics in Practice and Policy: A NW Tribal Research Review Mapping Project*, NW Tribal Health Conference, March 2011
- West, Kathleen M., Kim J. Hopper, Scarlett E. Hopkins, Kelly A. Edwards, Gerald V. Mohatt, Bert B. Boyer. *Learning my Lessons: Strengths and Challenges of Conducting Graduate Research from within a Community-Based Participatory Research Partnership*. Community Campus Partnerships for Health, 11th Conference, Portland, OR, May, 2010.
- West, Kathleen M., Scarlett E. Hopkins, Gerald V. Mohatt, Bert B. Boyer. *Stories from the River: Using Metaphor to Examine How Yup'ik Eskimo Community Members Comprehend Genetic Research Information*. Native Health Research Conference, Portland, OR, August 2009
- West, Kathleen M., Kim J. Hopper, Scarlett E. Hopkins, Eliza M. Orr, Kelly Fryer-Edwards, Gerald V. Mohatt, Bert B. Boyer. *Stories from the River: Using Metaphor to Examine How Yup'ik Eskimo Community Members Comprehend Genetic Research Information*. University of Alaska Biomedical Research Conference, Fairbanks, AK, May 2009
- West, Kathleen M., Kim J. Hopper, Scarlett E. Hopkins, Eliza M. Orr, Kelly Fryer-Edwards, Gerald V. Mohatt, Bert B. Boyer. *Stories from the River: Using Metaphor to Examine How Yup'ik Eskimo Community Members Comprehend Genetic Research Information*. University of Alaska Fairbanks Student Research Symposium, Fairbanks, AK,April 2009
- West, Kathleen McGlone. *Sharing Results from Complex Disease Genetics Studies: A CBPR Approach.* 57th Annual Conference, American Society for Human Genetics, San Diego, CA, October 2007

Academic and Professional Service

University of Washington

- School of Public Health Diversity Committee, inaugural member 2012-2017
  - Curriculum workgroup chair, 2015-2016
  - Undoing Racism Training workgroup chair, 2016
  - Student sub-committee co-chair, 2012-2013

- School of Public Health Curriculum and Educational Policy Committee, University of Washington, graduate student representative 2015-2016
- School of Public Health Undergraduate Major Curriculum Development Committee, member; SPH481 *Ethics, Social Justice and Policy* course development, 2013-2014
- Student Public Health Association, board member, 2013-2014
- Renal Disease Determinants Working Group, co-chair, 2012-2014

Other Professional Service

- Peer reviewer: *Progress in Community Health Partnerships*, 2016-present
- Peer reviewer: *Public Understanding of Science*, 2013-present

Courses Developed and Taught

University of Washington

- Contributor to redesign of Public Health Major core course, and guest instructor, SPH481: *Ethics, Social Justice and Policy*, 2013-2016
- Workshop developer and facilitator, *Teaching Your Own class: The First Day and Beyond Workshop.* TA/RA Conference, 2014-2016
- Lead instructor/Course developer, *Ethical Issues in the Food System and Public Health*, BH597. 3-credit graduate course, Spring 2014

University of Alaska Fairbanks

- Instructor/Workshop developer, Atlas.ti Qualitative Data Analysis Workshop, May 2009
- Teaching Assistant, Fundamentals of Biology II, BiolF106X, Spring 2007
- Teaching Assistant, Fundamentals of Biology I, BiolF105X, Fall 2006
- Adjunct Instructor, Beginning Swimming, RecrF110A, Spring 2006

Oberlin College

- Instructor/Course developer, Water Safety Skills, Swimming and CPR for Adults, Exco999, Spring 2003

Academic Lectures

- *CBPR Part 2: Intersection Values with Science.* Master's Program in Maternal and Child Health Systems, Bastyr University, February 2017.
- *Staying for Tea: An Introduction to Community-Based Participatory Research.* Master's Program in Maternal and Child Health Systems, Bastyr University, January 2017.
- *Introduction to Public Health Genetics: Ethical Case Study*. Upward Bound course, University of Washington, July 2014, July 2015.
- *Epigenetics and Embodiment of Life Experiences*. Social Justice, Power and Health Care, Nursing and Health Studies, BHLTH 497E, University of Washington, Bothell, July 2014.
- *Writing the Discussion*. Indigenous Wellness Research Institute, MSW trainees seminar, University of Washington, May 2014.
- *Ethics at the Intersections of Food and Genomics*. Public Health Genetics 512, University of Washington, February 2014.
- *Introduction to Ethical Frameworks*. Public Health 481, University of Washington, October 2013, & January 2014.
- *Ethical Dimensions of Genetically Modified Foods*. Public Health Genetics 200, University of Washington, December 2013.

- *Expanding Ideas of Community Engagement in Genomics Research and Training*, presentation to Ms. Paula Berg, Legislative Aide to Senator Patty Murray (D., WA), August 2013
- *Crawling the Talk*: *Lessons Gained as a Student within a Community-Based Participatory Research Partnership.* Critical and Indigenous Methodologies, Bioethics and Humanities 497, University of Washington, May 2013
- *Sustainability of Health in Rural Alaska.* Leadership Seminar, Rural Development 697, College of Rural and Community Development, University of Alaska Fairbanks, Chukchi Campus, Kotzebue, AK April 2008
- *Abortion and Contraceptives in Interior Alaska*. Human Sexualities Across Cultures, Psychology 333, University of Alaska Fairbanks, November 2005
- *Contraceptives and Sexually Transmitted Infections.* Psychology of Women Across Cultures, Psychology 360, University of Alaska, Fairbanks, April 2005

Student Supervised

- Samantha Torres, University of Washington Masters of Public Health Practicum, 2013

Professional Organization Memberships

- Member, American Public Health Association, 2016-present
- Member, Community Campus Partnerships for Health, 2009-2011, 2016-present
- Member, Oregon Public Health Association, Adolescent Health Section, 2009-2010
- Member, American Association of Sex Educators, Counselors and Therapists, 2004-2005

Honors and Awards

- Husky 100 Nominee, University of Washington, 2017
- First place, post-graduate trainee poster category, NHGRI Research Training and Career Development Annual Meeting, Washington DC, April 2016
- UW Health Sciences Martin Luther King Jr. Community Service Award to the School of Public Health Diversity Committee, 2016
- Achievement Rewards for College Scientists (ARCS) Foundation Fellowship winner, 2011 http://www.arcsfoundation.org/seattle ($17,500 grant, declined)
- Resilience and Adaptation Program, University of Alaska Fairbanks, NSF/IGERT fellowship program, 2006-2009
- Institute of Arctic Biology Summer Graduate Research Fellowship ($5,000 grant), University of Alaska Fairbanks, Summer 2007
- Cole Scholar Program, Department of Politics, Oberlin College, 2002
- Junior Honors Program, Department of Politics, Oberlin College 2001-2002

Software Skills

- Atlas.ti qualitative data analysis software
- REDCap electronic data capture tool
- Stata, SPSS statistical analysis software
- Microsoft Office
- Mac and Windows operating systems