



Race for Cures: Rethinking the Racial Logics of 'Trust' in Biomedicine

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Abstract

This article examines the normative underpinnings of 'trust talk', asking how biomedical discourse constructs racial group boundaries and what implications this has for our understanding of the politics of medicine more broadly. Drawing upon a 2-year multi-method study of the world's largest stem cell research initiative and extending key insights from the sociology of race–ethnicity and social studies of science and medicine, this paper identifies three ways in which discourse in the stem cell field constructs racial group boundaries – through diversity outreach, clinical gatekeeping, and charismatic collaborations. In so doing, the paper also explicates counter-narratives – medical racial profiling, subversive whiteness, and biopolitical minstrelsy – as forms of discursive resistance that challenge the normative underpinnings of recruitment discourse.

The organization that owns trust owns its marketplace.¹

The problem of distrusting citizens should be recast or reformulated as an issue of social justice.²

In the United States, African-Americans have historically been conscripted for experimental medical research while denied access to quality health care (Nelson 2011; Reverby 2009; Wailoo 2000; Washington 2007).³ As one informant aptly queried, “Why am I in such demand as a research subject when no one wants me as a patient?” Since the passage of the National Institutes of Health Revitalization Act, there exists a legal mandate to include a racially diverse population in medical research. This fuels a “vexing and time consuming body hunt” because researchers find it difficult to recruit a representative sample of participants (Epstein 2008, p. 806). This purported lack of racial representation is also cause for anxiety in fields that require human tissue samples to hone treatments. In the arena of human stem cell research, for example, some observers are concerned that the inability of stem cell banks to obtain tissue from a racially diverse population will ultimately make it harder for non-Whites to obtain a tissue match if and when therapies develop (Faden et al., 2003; Moller 2008). As one Hastings Center Report contends,

Stem cell therapies should be available to people of all ethnicities. However, most cells used in the clinic will probably come from lines of cells stored in stem cell banks, which may end up benefiting the majority group most (Greene 2006, p. 57).

While social scientists and human geneticists, alike, have demonstrated how this and similar statements mistakenly conflate racial classifications with genetic diversity, the following analysis raises a different set of issues with respect to such calls for 'stem cell diversity'. Often a primary reason that researchers and policy analysts provide for the low enrollment of African-Americans as clinical subjects or tissue donors is their tendency to distrust science and medicine. Hundreds of peer-reviewed papers have been written to discern why, under

what circumstances, and with what consequences Africans-Americans express distrust.⁴ In this way, ‘Black distrust’ circulates as a biomedical truism, an empirical curiosity, and a cultural trait unique to African-Americans – what sociologists of race call an ‘essentialist’ approach – with little interrogation of the wider discursive field in which it circulates. This article examines the normative underpinnings of trust talk, asking *how biomedical recruitment discourse constructs racial group boundaries* within the context of stem cell research and what consequences this discursive practice holds for our broader understanding of the politics of medicine.

By putting the sociology of race–ethnicity in conversation with the social studies of science and medicine, the following analysis extends our understanding of how epistemic and normative practices are inextricable. The attempts of well-meaning researchers to use science and medicine to redress prior forms of abuse and neglect are often based on assumptions of inherent racial differences (Bliss 2012; Braun et al., 2007; Fullwiley 2008; Fujimura et al., 2008; Kahn 2012; Montoya 2011; Ossorio and Duster 2005; Reardon 2004; Soo Jin Lee 2005). In particular, Pollock’s (2012) incisive analysis of Derrida’s *pharmakon* metaphor as simultaneously ‘cure’ and ‘poison’ best illustrates the tension herein: a *race for cures* resuscitates static group boundaries in the quest to produce novel medical treatments.⁵ But it is not only *biologically* reductive notions of race that are revived in stem cell recruitment discourse, but also culturally essentialist ideas about group traits – trusting versus non-trusting groups – that require critical attention.

In challenging biological determinism, extant scholarship in the social studies of science and medicine has focused less on the way that reified notions of culture are routinely employed as a lens to make sense of group differences (see Jenks, 2010 and Shim, 2010 for notable exceptions). For example, this Benjamin (2011, 2013) found that some clinicians and researchers routinely use generalizations such as “Asian-American science-philia” or “African-American fatalism” to explain why people choose to participate in experimental stem cell treatments or not. It is worth noting that, in these instances, racial logics are typically used in an attempt to include and represent a wider spectrum of the body politic, rather than to exclude and dominate, as in previous eras where eugenic ideologies were the norm. The current context is what Epstein has called the *inclusion-and-difference paradigm* whereby “researchers are enjoined to conduct subgroup comparisons by race to test whether treatments have different effects in different groups” (Epstein 2007, p. 813). In the process, many researchers often mistakenly come to believe that “medical ‘have-not’s’ [are] pounding on the walls of research institutions, demanding to be let into the experimental domain” (Epstein 2008, p. 806). Yet, they must routinely grapple with resistance or indifference to their solicitations, and often try to make sense of their difficulty through the idiom of ‘distrust’.⁶ By constructing trust as a cultural trait that some groups have more *or less* of than others, such discursive practices lead those engaged in trust talk to overlook differences *within* purported ethnoracial groups, disregard similarities *across* groups, and most importantly, ignore the larger institutionalized structures of inequality in biomedicine and beyond.

Drawing on a 2-year multi-method study of the world’s largest stem cell initiative, this article interrogates the normative underpinnings of biomedical recruitment discourse. Following a discussion of methods and relevant scholarship in this area, the article identifies three ways in which trust talk in the stem cell field constructs racial group boundaries – through *diversity outreach*, *clinical gatekeeping*, and *charismatic collaborations*. By exploring these practices through three ethnographic vignettes, the paper also explicates counter-narratives – *racial profiling*, *subversive whiteness*, and *biopolitical minstrelsy* – that challenge the normative underpinnings of trust talk in biomedicine. The analysis herein illustrates how biomedicine is a site of group-making, one that does not simply leave existing social arrangements in place, but potentially reifies or resists the racial status quo.

Methods and background

Inside the stem cell initiative

Stem cells have the potential to regenerate any tissue in the human body, that is, they are ‘pluripotent’. But due to the fact that many researchers utilize cells taken from the inner lining of a 5-day to 8-day old embryo to harness pluripotency, some techniques have proven extremely controversial in the United States. In over a dozen states, initiatives to fund or ban stem cell research have spurred legislative action or public referendum. Voters approved the single largest funder of stem cell research in the world, California’s Proposition 71 on November 2, 2004. Prop 71 authorized the sale of general obligation bonds to raise \$3 billion over 10 years to fund stem cell research, including contested methods that utilize human embryos to isolate stem cells. The Stem Cell Research and Cures Act, in turn, amended the state constitution to include a “right to research” (Brown and Guston 2005; Ganchoff 2004).

The following discussion draws upon findings from a 2-year (2005–2007) mixed-method study of the California Stem Cell Research and Cures Initiative and the California Institute for Regenerative Medicine (CIRM), which is the new state agency established by Proposition 71. Through a formal affiliation with the agency as part of its first cohort of “training fellows,” I observed institute board meetings, scientific retreats, academic courses, legislative and legal hearings, and biotechnology industry conferences. I also conducted content analysis of Prop. 71 campaign finance documents, CIRM press releases, and SCR media documents. Finally, I interviewed a purposive sample of 63 people actively engaged in advocating for, implementing, or critiquing CIRM in the regulatory, biomedical, and civic arenas. This included patients and their families, physicians, and other medical staff who utilized or provided medical services at an urban teaching hospital, the Garvey Research Complex (pseudonym). Garvey houses a cord blood bank and stem cell transplant program and a regional sickle cell clinic, as well as a number of other clinical and research departments.⁷

My fieldwork at Garvey entailed shadowing the head physician in the sickle cell clinic, attending medical rounds, observing patients in clinic visits, and observing discussions between physicians, nurses, and social workers, including discussions on patients’ medical and social histories. I was given access to cord blood program enrollees and observed the process by which parents of children affected by an ailment were instructed to collect and store blood for possible use in a stem cell transplant. Unlike other methods that use embryonic stem cells, this method for treating sickle cell disease and other blood-based disorders utilizes “adult” stem cells from a mother’s umbilical cord upon giving birth to a child who is not affected by the illness but might match the affected sibling. I observed patients and health professionals (including nurses, social workers, outreach workers, MDs, and researchers) in a number of settings including home visits with patients and their families, sickle cell community events, and community-based talks by scientists working on stem cell transplantation.

In telephone interviews with parents who had banked umbilical cord blood from an unaffected sibling at Garvey’s tissue bank for possible future use in a stem cell transfusion, I asked what factors they were considering as they decided whether and when to have their child undergo the transplant (Benjamin 2011, 2013). In examining their attitudes in relation to the broader context of recruitment, I came to understand that I, as well as those engaged in the new science of recruitment, tended to limit our unit of analysis to individual decision-making rather than investigating how institutional norms and discursive practices shape the larger context of meaning-making.

“Rights” that do wrong

The inclusion of racial-ethnic minorities in research is implicitly framed as a medical “right” – an extension of *biological citizenship* – which posits the body as a primary locus of political redress (Petryna 2002; Rose and Novas 2005; Roberts 2011). Scholars have detailed how a history of “deliberate neglect and medical abuse” (Nelson 2011, p.15) have led many Black health advocates to demand biomedical access even as they refuse to participate in experimental research. Thus, a “right” to access biomedical goods must be understood within a larger socio-historical context, in which such “rights” entail the potential to *be done wrong*. The racialized dimension of *rights that can do wrong* is particularly acute in the context of experimental stem cell treatments, where researchers seek diverse representation in tissue donation upstream *and* in clinical trials downstream.

The relationship between advances in the life sciences and new rights that lay claim to those advances is what Jasanoff terms bioconstitutionalism (Jasanoff 2011). Through bioconstitutional struggles, legal and social obligations become unsettled as the state’s political prerogatives are reworked in light of new demands such as “diverse stem cell lines.” Most importantly, the issue of what the state owes particular groups is intimately connected to biological definitions of what constitutes a group in the first place. Older forms of group-making, such as race, are not simply replaced by, but often resuscitated in service to new biopolitics. As in other social arenas, individuals’ racialized dispositions, and not institutional forms of racism, are typically the locus of concern in popular discourse (Bonilla-Silva 2009) surrounding trust in biomedicine.

The passage of the California Stem Cell Act can be understood as “a rethinking of law at a constitutional level. At these moments, the most basic relations between states and citizens are reframed through changes in the law” (Jasanoff 2011, p. 3). The Act was in essence a *bioconstitutional moment*, where struggles over ‘who we are, what we are owed, and what we are responsible for’, as both objects and subjects of scientific initiatives unfolded (Benjamin 2013). In California and a growing number of jurisdictions, representatives of various constituencies attempted to codify answers to these fundamental questions. In the process, histories of medical neglect and scientific abuse, as well as debates over ongoing racial health disparities were resuscitated and often quickly ‘reburied’ (Ossorio and Duster 2005) lest they slow the urgent race for cures.

Binaries and biopolitics

Discursive negotiations are fundamental for the mutual construction of reality (Mills 1940; Berger and Luckmann 1967; Goffman 1967, 1981), especially as it relates to racial discourse (Goodman and Burke 2010; Myers 2001, 2015; Pollock 2004; Reisigl and Wodak 2001; Wetherell and Potter 1992), and the construction of whiteness (Foster 2009; Hughey 2011, 2012; Picca and Feagin 2007; Riggs and Augoustinos 2004; Steyn and Foster 2008). The drive to include a diverse population in experimental treatments rests, in part, upon a culturally framed binary – White trust versus non-White distrust in biomedicine.⁸ This reproduces racial boundaries within a symbolic order in which consent and compliance are implicitly coded “White” while dissent and refusal are coded “non-White.” Thus, biomedicine seeks not only to ameliorate bodily suffering but ‘cure’ cultural attitudes that are rendered pathological. As such, researchers inadvertently extol trust as the desired attitude towards recruitment, even when this conceals the many shortcomings of biomedicine, most notably the vast ethnoracial inequities to which a distrusting attitude may be acutely attuned.

In the next section, the paper identifies three ways in which discourse in the stem cell field constructs racial group boundaries – through diversity outreach, clinical gatekeeping, and

charismatic collaborations. In so doing, the paper also explicates counter-narratives – medical racial profiling, subversive whiteness, and biopolitical minstrelsy – as forms of discursive resistance that challenge standard recruitment norms.

Recruitment and its discontents

Diversity outreach and racial profiling

On October 14, 2006, a group of scientists, clinicians, social justice advocates, health policy analysts, and academics participated in a conference in Oakland, California entitled “Toward Fair Cures: Integrating the Benefits of Diversity in the California Stem Cell Research Act,” sponsored by the UC Berkeley Project on Stem Cells and Society, Children’s Hospital of Oakland Research Institute (CHORI), and the Greenlining Institute (a national policy, grassroots organizing, and leadership training institute working for racial and economic justice). The purpose of the event was to “increase the understanding of the economic and medical potential of stem cell research among historically underserved minority communities and ensure that California’s stem cell research efforts serve our state’s diverse community.”⁹ A point of debate was the conference’s subtitle: “Addressing the *Lack* of Diversity in Stem Cell Research.” Organizers were forced to change this to the more upbeat title, “Integrating the *Benefits* of Diversity in the California Stem Cell Research Act”¹⁰ [italics added] when co-sponsor Robert Birgeneau, UC Berkeley’s Chancellor, implied it was “too confrontational.” However, key organizers maintained that reframing undermined the autonomy and agency of health policy advocates to address the historic exclusion and exploitation of racial-ethnic minorities in scientific and medical decision-making.

Chancellor Birgeneau’s intervention highlights a larger pattern that sociologists Bell and Hartman (2007) describe as the ubiquity of diversity “happy talk” in US discourse on race and ethnicity – a way of addressing race that is sanitized due to the “cultural blind spots” that reinforce White normativity and fail to consider the effects of the “unseen privileges and normative presumptions” of mainstream American culture (895). Attempting to unsettle this normative center, several conference participants underscored the fact that if tax-spending decisions were made in an inclusive way, and reflected the values, interests, and perspectives of truly diverse groups, stem cell research would not top the list. One conference participant observed that “all technology has power relations embedded in [it], [is] developed to benefit specific populations and [is] made available to specific populations [...]. If we were to go to minority communities and women’s communities and ask them how to spend \$3 to \$6 billion, it’s unlikely that they would say ‘on stem cell research.’”¹¹

Similarly, another participant urged attendees to shift the focus away from minority distrust in science to the “trustworthiness of institutions.”¹² But while this provocation was not taken up as a major locus of concern for participants, it serves as a window on to the way that discourses around trust in biomedicine typically pivot around the disposition of individuals and groups, rather than located in the norms and practices associated with institutions. From the latter perspective, what is often called outreach relies on group profiling, where the discourse surrounding trust is a major feature of constructing ethnoracial profiles.

Consider, for example, a Diversity Workshop at the Charles R. Drew University of Medicine and Science hosted by the state stem cell agency on February 26, 2010. Drew is a historically Black institution founded in Los Angeles’ Watts neighborhood in response to the 1965 urban rebellion sparked by social and economic inequities that Blacks faced and continue to face. Its mission today is to educate and serve the predominantly Black and Hispanic residents of the area. The goals of the Diversity Workshop were twofold: to “gain

a greater understanding of how population diversity affects, benefits and advances CIRM's mission" and "to use this knowledge to ensure that CIRM's funding initiatives support diversity in regenerative medicine." During this workshop, an invited speaker Dr. Maria Pallavicini explained how the University of California Merced had to "educate the population of this historically underserved population in the San Joaquin Valley about the nature and value of research." This, she said, had been "a challenge in a region with relatively high rates of poverty and low levels of educational achievement."

Another speaker, Dr. Keith Norris of Drew University, highlighted the importance of research scientists engaging with doctors and clinical researchers, and underscored that the goal of this interaction "should be to relate research to broader community health concerns."¹³ Reflecting a deficit framing of patient compliance and participation (i.e., focused upon what people lack), Norris observed that "functional illiteracy" ("48 percent of US adults cannot fill out a job application") limits people's ability to participate in research initiatives. He also mentioned other socioeconomic factors, such as "concerns about the time and expenses (travel, child care, and lost income)" that hinder participation in research studies. Accordingly, Norris suggested that "smaller mission-based and/or minority-serving institutions," like Drew University, could be a potential resource for increasing minority participation in research.

Relatedly, scientists at the CIRM Diversity Workshop emphasized the importance of developing a "diverse stock of cells" to ensure immune tolerability across the diverse population who will seek access to future cell-based therapies. Dr. Louise Laurent of UC San Diego presented "results from genetic analysis indicating there is restricted genetic diversity in established human embryonic stem cell lines." In other words, due to the fact that many stem cell lines are produced using eggs from fertility clinics whose donors are predominantly non-Hispanic Whites, the stem cell lines were said to disproportionately cater to that demographic. The UC San Diego team stressed it was "developing a genetically diverse collection of human iPS cell lines"¹⁴ ... The success of this effort depends, in part, on the ability to recruit a genetically diverse group of donors to participate in the project." Laurent's concerns drew on prior "considerations of justice in stem cell research and therapy" (Faden et al., 2003), which warned that a lack of ethnoracial diversity would necessarily result in a lack of genetic diversity and the subsequent exclusion of groups who were not well represented in basic research and tissue biobanks. One influential Hastings Center report had argued that "[u]nless the problem of biological access is carefully addressed, an American stem cell bank may end up benefiting primarily White Americans, to the relative exclusion of the rest of the population" (Faden et al., 2003, p.14).

Conference-goers, in turn, relied on cultural explanations for non-Whites' lack of participation. One CIRM study presentation entitled "Supporting Diversity in Research Participation: A Framework for Action" attributed nonparticipation to people of color's lack of understanding about clinical trials and their risks and benefits, literacy deficits, and finally, "a general lack of trust in the health care system and especially in clinical research."

African-Americans tend to have the lowest level of trust in the health care system because of historical abuses. Chinese-Americans also have trust issues, as well as problems with English and, ... older members of the community and recent immigrants [have] a lack of understanding of the underlying concepts of clinical research. Latinos also face language barriers, as well as a fear on the part of immigrants – legal or otherwise – that participation could bring negative consequences for them and their families [i.e., deportation]. Southeast Asians share many of these issues, along with, for many groups, a fear of authority bred by a variety of traumas.¹⁵

In short, while the White versus non-White boundary is implicitly reinforced by describing these groups as all having "trust issues", they are given distinct profiles in which history,

language, and education among other factors are used to make sense of their ambivalence towards biomedical recruitment. Thus, as in quests for diversity more broadly, inclusion rests upon reified notions of difference that often leave institutional structures unexamined.

Embedded in the “hard-to-reach” framing of minority recruitment was the idea that their relative proximity to biomedicine was a matter of self-selection, rather than systemic dispossession. While references to African-Americans’ “historic distrust” – particularly the oft-mentioned Tuskegee Syphilis Study (1932–1972) – suggested external justification for why some people might be “hard-to-reach,” issues of ongoing social marginality were largely absent from conference conversations. In particular, social production of distrust in minority groups’ daily encounters with the US healthcare system, and lack of access were rarely mentioned (Durant et al., 2011; Author Date). But whereas diversity outreach discourse obscures such inequities, the *unhappy* talk of medical racial profiling alerts us to the normative underpinnings of recruitment efforts.

Clinical gatekeepers and subversive whiteness

At Garvey Research Complex,¹⁶ a related dynamic ensued as primary care physicians – the “crucial mediators between patients and clinical researchers” (Epstein 2008, p. 816) – formed an intermediary tier of distrust that is all but invisible in the larger discourse of biomedical recruitment. Namely, some White clinicians are at odds with researchers, surgeons, and specialists over the efficacy of new high-tech treatments and expensive drugs. Therefore, they exhibit their own brand of ambivalence and can be described as subversive within the larger context of what sociologist Matthew Hughey terms “hegemonic whiteness” saying, “while there is no question about the political differences and individual heterogeneity of White actors in an array of settings, it is important to recognize that certain forms of whiteness can become dominant and pursued as an ideal” (Hughey 2012, p. 13). In this case, the idealization of trusting patients and compliant research subjects, implicitly coded White, is reinforced when recruitment discourse fails to adequately account for the ways that clinicians may subvert the dominant narrative about medical institutions as altruistic and trustworthy.

Take, for example, Tate Wright, who regularly attributes “patient noncompliance” to the stress of his patients’ daily lives and the ineffectiveness of prescribed treatments. As a member of a predominantly White clinical staff serving a Black patient population, he was acutely aware of racial and power asymmetries and how that could inhibit patient trust and compliance. He disagreed with other hospitals’ “behavior contracts” that are often selectively applied to young Black patients, in particular: the “zero tolerance” policies that maintained “Failure to comply with the following rules will result in your immediate discharge from the hospital and/or the intervention of law enforcement personnel.”¹⁷

One afternoon in the sickle cell anemia clinic, he shared a story of 15-year-old Tyrone Hemmingway. Tyrone and his family had elected to remove his spleen, because, as is common with sickle cell anemia, it became swollen as the sickled hemoglobin blocked the blood vessels. Wright explained

The doctor who performed the surgery decided to use some high-tech equipment that would allow him to do a laser surgery, which meant that he wouldn’t have to open Tyrone all the way up. But because Tyrone’s spleen was so big and they couldn’t finish the operation in a reasonable amount of time, they left him open, iced his stomach and wrapped him up. They brought him back to complete the surgery the following day, because they didn’t want to keep him under anesthetics so long in his condition. But in the second round they accidentally lacerated his stomach, although they didn’t yet know it. So they sewed him up and when he got back into his room, he was complaining

of pain. Staff thought it was just the post-op pain. Then he started peeing black urine and vomiting up blood. So they rushed him back into the operating room and opened him up and found the tear in his stomach. A few days later, Tyrone was still saying he was in a lot of pain, and it turned out that although they sewed the tear, he was digesting his pancreas.¹⁸

Wright recounted the half dozen surgeries in three weeks that were required to rectify the initial surgical damage. When he visited Tyrone after one of these surgeries, he “honestly didn’t think this kid was going to make it.” Wright further mused, “The family has been *so good* about it. I mean they are angry, but they’re not enraged like they *ought* to be. I mean it was an elective surgery, and the poor mom, every time she left the hospital, they called her to say that Tyrone was being rushed into the emergency room.”¹⁹

In a related fashion, Wright expressed his ambivalence towards the ‘newest technique on the block’ alongside his disdain for his colleagues’ career-advancing motivations. In one instance, in the midst of explaining that a new hemoglobin had been discovered at the Garvey Research Complex, he stated, “[The institution] is a little tacky since you’re supposed to name it after the patient, *not* the person who discovers it.” When a new medical student asked a round of questions about the discovery process, he said: “a lot of what’s driving the discovery of Hemoglobin types is scientists trying to get their report in *Blood* [a medical journal], even if it’s just based on one patient and the type is never seen again.” Finally, Wright and others at Garvey avoided referring patients to other specialists whose decisions they questioned and who were supportive of experimental procedures like the stem cell transplant that was then being offered in the research wing of the hospital. In all these ways, Wright exemplified what I am calling ‘subversive whiteness’ in so far as he used his position as clinical gatekeeper to question and circumvent the recruitment norms of biomedicine. As previously mentioned, his subversion can be understood in the context of what Hughey describes as hegemonic whiteness – an ideal which Tate Wright was deliberately subverting.

As Wailoo and Pemberton document in *The Troubled Dream of Genetic Medicine* (Wailoo and Pemberton 2006), the expectations of those affected by sickle cell disease have repeatedly been raised by pronouncements of ‘breakthrough’ cures such that, unlike other ailments for which stem cell cures are predicted, there exists an extremely ambivalent relationship between those affected by sickle cell and cutting-edge, high-risk medical research. Physicians like Wright are appalled at the “rollercoaster of unfulfilled therapeutic promises” (Wailoo and Pemberton 2006, p. 117).²⁰ Positioning themselves as allies to their patients, doctors like Wright act as “refusers” (Rapp 1999) of the allure of experimental treatments. Still, the cultural conception of distrust, as inherently pathological and pertaining to non-Whites, fails to account for Wright’s disdain for biomedical business-as-usual.

Whiteness – not only in terms of Wright’s ethnoracial identity, but even more so as it is exercised through the authority assigned to the white coat of medicine and science – allows for his distrust to go unmarked, thereby bolstering the binary opposition between non-White distrust and White trust. By focusing only on his role as gatekeeper, we may overlook the way in which he and other clinicians exercise forms of subversion that run counter to the recruitment norms of the stem cell field and other experimental life sciences.

Charismatic collaborations and biopolitical minstrelsy

The final vignette of biomedical recruitment examines charismatic research enthusiasts and the way that their advocacy resists the reification of group boundaries while simultaneously obscuring the power relations that characterize the recruitment process. Richard Gaskin,

an African-American stem cell activist who was paralyzed from a gunshot wound when he was 20 years old, publicly exudes trust, thus delinking the discursive association of blackness with distrust. Gaskin's rap moniker, "Professir X," [sic] draws upon the X-Men comic book series about mutant characters with physical characteristics that can be viewed as liabilities or powers. As with the fictional leader of mutants who trains those with seeming disabilities to transform their frustration into a resource, Gaskin set out to purposefully intervene in the 'stem cell battles' as someone who appears to fully support the new field. Since his injury, he has worked with Michael J. Fox, the late Sen. Ted Kennedy, and the late Dana Reeve (wife of the late Christopher Reeve) to generate awareness and funds for stem cell research.²¹

In a 2007 interview, Gaskin expressed the belief that his experience was representative of broader Black sentiment:

Before, there was nobody famous who represented me, except maybe Teddy Pendergrass. ... here was somebody who was going out there, fighting for a cure, advocating for better quality of life for people with disabilities, something I'd seen no one else do.²²

Following Christopher Reeve's death, Gaskin wrote a song entitled "Forever Superman," about his fellow enthusiast's search for a cure. His song inspired Dr. Wise Young, founder of the W. M. Keck Center for Collaborative Neuroscience, to recruit Gaskin to "[bring] a hip-hop vibe to the world of [spinal cord injury] education and advocacy."²³ Gaskin also traveled to China, as an SCR ambassador, and thereby aided Young and the CIRM establishment in framing participation in terms of access to SCR²⁴:

The cost of holding clinical trials – which includes admitting 240 people [the typical size of a phase 1 (clinical) trial] into the hospital, tests and treatments, and months of physical therapy – will be about \$32 million. So Young and others came up with the JustaDollarPlease.org campaign, asking families and friends of spinal cord injured [people] to give a dollar a day (\$365 a year) and everyone to give whatever they can.²⁵

Gaskin, also elaborated the day-to-day struggle of living with a disability in order to stand in for what he considered the community of patients in need.

The practice of speaking for others is not without its hazards because, as the sociologist of science Michel Callon puts it, "to speak for others is to first silence those in whose name we speak" (Callon 2005, p. 14–15). As such, spokesmen like Gaskin do not simply represent, but help to *produce* a normative ideal of trusting patients-in-waiting. Charismatic enthusiasts combine rhetoric and reality, along with the symbolic and the material world, effectively prioritizing the pragmatic requirements of basic research over Black recruitment concerns. For example, sociologist Steven Epstein recounts how one young African-American physician was "invited to be a co-investigator on a study, only to conclude eventually that what the senior investigator really sought was a 'black face' to display at community forums for purposes of reassuring potential participants" (Epstein 2008, p. 816). Indeed, Yancey and colleagues point out,

[a] common approach to building trust and alleviating attitudinal barriers was community involvement, particularly in the form of using lay outreach workers from the targeted population. Inclusion of minority ("cultural insider") investigators was also advanced as a community engagement strategy... [as was the use of] churches [that] provide captive audiences (Yancey et al., 2006, p. 9).

The use of in-group members as fronts and spokespersons for research initiatives emerges as a way to mitigate distrust and appear more 'culturally competent'. While superficial

approaches like this abound, we nevertheless find examples of stem cell recruitment that attempt to transform “the power imbalance between the researcher and the community under study” (Epstein 2008, p. 817) by involving community spokespeople at earlier stages of the research process to provide input in to research questions and protocol. However, in such cases, we are still confronted with difficulties plaguing other efforts at participatory science, many of which are tied to the politics of representation. After all, scientific knowledge “does not simply represent (in the sense of *depict*) ‘nature,’ but it also represents (in the *political sense*) the ‘social interests’ of the people and institutions that have become wrapped up in its production” (Hayden 2003, p. 21).

To the extent that charismatic collaborations between researchers and community spokesmen are forged mainly to celebrate and bolster science, without building in critical assessments of the impact and meaning of a given field on those targeted as prospective research subjects or tissue donors, then public displays of Black trust may enact a kind of *biopolitical minstrelsy*. Historical analyses of minstrelsy emphasize the “contradictory impulses at work”, rather than conceive such performances as “uncomplicated or monolithic”; so, too, does my use of the term signal the unsettled discursive terrain of charismatic collaborations. As Lott describes, “the minstrel show was less the incarnation of an age-old racism than an emergent social semantic figure highly responsive to the emotional demands and troubled fantasies of its audiences...[a] mixed erotic economy of celebration and exploitation, what Homi Bhabha would call its ‘ambivalence’” (Lott 1993, p. 6). So by ‘biopolitical minstrelsy’ I mean the “borrowing of Black cultural materials” [i.e. hip-hop aesthetics] in the service of powerful scientific and medical institutions, thereby obscuring the power relations between researchers and African-American communities, which make such performances necessary in the first place.²⁶

So like Tate Wright, whose own complex role within Garvey elides easy representation in the binary framework of Black distrust and White trust, so too does Professor X’s exuberant commitment to the stem cell cause challenge the epistemological bedrock of biomedical recruitment. These seeming exceptions to the discursive linkage between race and trust, and the fact that they stand out as such, serve to underscore both the power and limits of the assumptions that are often made about group dispositions towards experimental biomedicine.

Conclusion

Throughout this paper, I have argued that the cultural concept of trust is racialized in the context of biomedicine. Here we find a binary opposition between White trust and non-White distrust serving as the epistemological scaffold of recruitment discourse. Thus, not only do science and medicine tend to impact racially-defined groups differently, but racial logics help to define the norms and practices of science and medicine – a feedback loop which deserves critical attention. Drawing upon the classic article “Whiteness as Property” (Harris 1993), Reardon and TallBear (2012) explain that

[w]e live in times where for many, the relevant ‘civilizing’ project that shapes their lives is the development of the ‘knowledge society’ in which knowledge is a primary source of wealth. . .” (p. 235).

Ideas about ethnoracial groups that assume they are characterized by inherent biological or cultural differences, even in order to ultimately help underserved communities, is an extension of this civilizing logic. As an idea “that brings good things to all, whiteness itself becomes a thing of value that should be developed and defended” (Reardon and TallBear 2012, p. S234). Resistance to and distrust for biomedical recruitment, in turn, becomes a problematic attitude to be cured in the name of scientific progress.

“Buying in” to the value of research is not only or primarily about a philosophical commitment to defending the civilizing mission of biomedicine, but also a matter of practicality – that is, having the resources to spend on this increasingly costly ‘embrace’ of biomedicine. As Good (2001) declares,

While the world’s dominant economies invest private and public monies in the production of biotechnology and aggressively seek to integrate these advances into clinical practice – thereby reaping financial as well as scientific returns on [often tax-funded] capital investments – all societies are confronted with difficult questions about rationing biomedical interventions assumed central to competent clinical medicine” (p. 407).

Considering the costs associated with quality health care in the United States, an attitude of distrust casts a shadow over the logic of research subject recruitment. Again, whiteness is not simply tied to White bodies or an imagined White culture, but is a larger expression of a calculating modern rationality, which gave rise to *homo economicus*, that ‘anthropological monster’ (Bourdieu 2005, p. 209) who we might imagine as ‘objectively’ weighing the risks and benefits of a particular recruitment pitch. Yet, when this abstraction is faced with a reality in which research participants may not be able to access the fruits of stem cell research and other novel treatments, the possible ‘wisdom of distrust’ becomes apparent.

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Short Biography

Ruha Benjamin is an assistant professor of Sociology and African-American studies at Boston University. She earned her Ph.D. in sociology at UC Berkeley and completed a postdoctoral fellowship at UCLA’s Institute for Society and Genetics. Ruha was awarded an American Council of Learned Societies fellowship and a visiting fellowship at the Harvard Kennedy School of Government’s Science, Technology, and Society program where she completed her first book, *People’s Science: Bodies and Rights on the Stem Cell Frontier* (Stanford University Press 2013).

Notes

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¹ See Brownlie et al. (2008). *Researching Trust and Health*. New York: Routledge.

² Johnson and Melnikov (2009). Wisdom of Distrust. In: N.K. Denzin (ed), *Studies of Symbolic Interaction* Vol.33: 9–18.

³ The most well-known illustration of the tension between biomedical research and health care is the Tuskegee Syphilis Study, which “became a symbol of their mistreatment by the medical establishment, a metaphor for deceit, conspiracy, malpractice, and neglect, if not outright racial genocide” (Corbie-Smith et al., 1999, p. 542).

⁴ In a comprehensive review of recruitment studies Yancey et al. (2006) found that for African-Americans especially, “[...] perceptions of trust and mistrust of scientific investigators, of government, and of academic institutions were found to be a central barrier to recruitment” (9). Research reported that recruitment techniques targeting African-Americans (including mass mailings, media campaigns, physician referrals, support groups, health fairs, and community outreach in churches, beauty shops, and barbershops) typically focus on the discrete attitudes of individuals, as they work to extend the right of participation

to a racial-ethnically representative sample of the US population (Braunstein et al., 2008; Corbie-Smith et al., 2002; Dula, 1994; Gamble, 1997; Gorelick et al., 1998; Harris et al., 1996; Randall, 1995; Royal et al., 2000).

⁵ The notion that society (in the form of reified conceptions of race) and biology (in the form of stem cells that can regenerative human tissue) are 'co-produced' is central to the field of science and technology studies (Reardon, 2004, Jasanoff, 2005, Thompson, 2005).

⁶ Sociologist of science, Charis Thompson, aptly and succinctly describes trust as "what must be unquestioned for any system of truth to be sustained" (Thompson, 2005, p. 41).

⁷ Institutional Review Board human subjects approval #2007-007.

⁸ Analysts have long established trust "as a critical aspect of medical care...that includes perceptions of the health care provider's technical ability, interpersonal skills, and the extent to which the patient perceives that his or her welfare is placed above other considerations" (Halbert et al., 2006, p. 896). For example, Epstein (2008) emphasizes the "highly charged politics of trust and mistrust that characterize relations between researchers and many communities from which they hope to recruit" (Epstein, 2008: 803). Recent studies have gone on to distinguish between interpersonal and societal distrust (Durant et al., 2011), where *interpersonal* distrust is "based on personal experiences and interactions of individuals within health care or clinical research settings," and *societal* distrust is "characterized by a global negative outlook on clinical research based on perceptions of collective research entities or life experiences in society at large" (p. 124). While there are no significant racial differences in interpersonal distrust in clinical research, African-Americans are shown to express more societal distrust in clinical research than Whites (p. 128). So even if individuals trust their doctor, they may refuse to participate in clinical trials and other forms of experimental treatment due to their experiences with the medical establishment and other social institutions.

⁹ From the Toward Fair Cures conference publicity material.

¹⁰ Personal interview with main conference organizer, November 18, 2006. Berkeley, California.

¹¹ Field note entry, October 14, 2006: Toward Fair Cures conference, Oakland, California.

¹² Field note entry, October 14, 2006: Toward Fair Cures conference, Oakland, California.

¹³ Field note entry, October 14, 2006: Toward Fair Cures conference, Oakland, California.

¹⁴ "Induced pluripotent stem cells" are often abbreviated as iPS cells. They offer the same potential for tissue regeneration that embryonic stem cells do, but without the need for embryos. That is, by forcing the expression of particular genes, they can be coaxed in to differentiating.

¹⁵ Field note entry, February 26, 2010. CIRM Diversity Workshop, Charles Drew University of Medicine and Science, Los Angeles, CA, USA.

¹⁶ All names in this section are pseudonyms to protect confidentiality.

¹⁷ Field note entry. February 10, 2010.

¹⁸ Field note entry, October 31, 2005.

¹⁹ Field note entry, October 31, 2005.

²⁰ This is even more problematic given that such innovations emerge in a broader context of health care deprivation that disproportionately affects African-Americans: "Indeed, by the 1990s innovation in sickle cell disease care had come to be seen as a dangerous game – a tricky act of balancing promises of dramatic advances and the perils posted by extraordinary medical experiments against the difficulties of assessing standard medical care" (p. 119).

²¹ In many ways, Gaskins exemplifies what Nelson (2011) describes as "bio-cultural brokers", those individuals or groups who serve as a mediator between Black communities and mainstream medicine.

²² Douglas Lathrop, "The Education of Professir X." Available at: <http://www.newmobility.com/articleView.cfm?id=11582>.

²³ Douglas Lathrop, "The Education of Professir X." Available at: <http://www.newmobility.com/articleView.cfm?id=11582>.

²⁴ Gaskin and Young traveled to China to see up close some of Young's clinical trials that use umbilical stem cells and lithium. In Young's words, "This [is] unacceptable. How far have we declined in this country that we have to send people to China to participate in clinical trials of therapies developed in the U.S.? It isn't that umbilical cord blood cells and lithium are at all controversial. The only obstacle is money [to run the trials]." The reality that Americans must engage in medical tourism rather than have access to cutting-edge therapies at home motivates both Young and Gaskin's advocacy and fundraising.

²⁵ Douglas Lathrop, "The Education of Professir X." Available at: <http://www.newmobility.com/articleView.cfm?id=11582>.

²⁶ "Blackface minstrelsy was an established nineteenth-century theatrical practice, principally of the urban North, in which white men caricatured blacks for sport and profit. It has therefore been summed up by one observer as 'half a century of inurement to the uses of white supremacy'" (Lott, 1993, p. 3).

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