

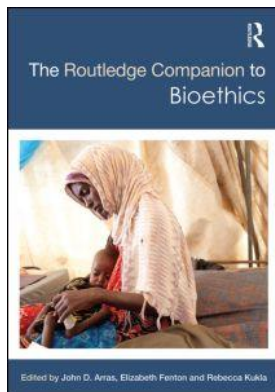
This article was downloaded by: 10.2.97.136

On: 30 Sep 2023

Access details: *subscription number*

Publisher: *Routledge*

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: 5 Howick Place, London SW1P 1WG, UK



## **The Routledge Companion to Bioethics**

John D. Arras, Elizabeth Fenton, Rebecca Kukla

### **Race and Bioethics**

Publication details

<https://test.routledgehandbooks.com/doi/10.4324/9780203804971.ch41>

Alexis Shotwell, Ami Harbin

**Published online on: 12 Dec 2014**

**How to cite :-** Alexis Shotwell, Ami Harbin. 12 Dec 2014, *Race and Bioethics from: The Routledge Companion to Bioethics* Routledge

Accessed on: 30 Sep 2023

<https://test.routledgehandbooks.com/doi/10.4324/9780203804971.ch41>

**PLEASE SCROLL DOWN FOR DOCUMENT**

Full terms and conditions of use: <https://test.routledgehandbooks.com/legal-notices/terms>

This Document PDF may be used for research, teaching and private study purposes. Any substantial or systematic reproductions, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The publisher shall not be liable for an loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

## RACE AND BIOETHICS

*Alexis Shotwell and Ami Harbin*

Racial difference has been of central concern in many canonical cases in bioethics. Consider two historical cases: Nazi medical experimentation and the now-infamous Tuskegee Syphilis Study. It was in response to revelations about Nazi experiments on human subjects that the Nuremberg Code was formulated. The Code sets out standards for informed consent, treatment of research subjects, and the necessity of predictable benefit from any given experiment. Nazi experimentation was based on an explicitly racializing notion: That Jews were a separate, and lesser, racial group and therefore appropriate subjects for experimentation. The Tuskegee Study of Untreated Syphilis (or “the Study”) was a 40-year (1932–72) clinical study that observed the progression of (mostly) untreated syphilis in a group of black men living in poverty in the U.S. These men were told that they were receiving free health care, when in fact they were not given effective treatment for syphilis even after such treatments were medically established. The Study was ended only when journalist Jean Heller broke the story. Responses to Tuskegee included the establishment in the U.S. of an Office for Human Research Protections, which aims to curtail the kinds of research abuses evident in the Tuskegee Study. In this chapter, we will use the Tuskegee Study as a touchstone for considering how racialization and bioethics matter to one another.

Racialization may be an unfamiliar word—it is less common, certainly, than *race*, or *racism*. We follow sociologists like Michael Omi and Howard Winant in thinking of race as “racial formation,” which they define as “the process by which social, economic and political forces determine the content and importance of racial categories, and by which they are in turn shaped by racial meanings” (Omi and Winant 1994: 61). This means that what we think of as “race” arises out of social relations, instead of coming from some biological reality “underneath” those social meanings. Racial formation is a way to understand the way that physical, social, and material things in the world are classified as racial—things like people’s hair, bodies, ways of speaking, and so on. This sort of conception of race as a dynamic, in-process social effect is also often termed “racialization.”

The Study is a useful starting point for thinking about racialization and bioethics for several reasons. First, reference to the Study has been important in formulating critical conceptions of the importance of informed consent in medical research and clinical treatment; talk of it circulates widely. Second, invocations of the Study within bioethics may well be deficient precisely in their considerations of race, and so extending the considerations of race in bioethics using the example of the Study may be instructive. As Susan Reverby writes in her exhaustive history of Tuskegee:

Bioethicists kept knowledge of the Study alive in research publications and teaching, but only in narrow ways . . . A survey of the key bioethics encyclopedias in their multiple editions and the major edited collections and texts reveals that the Study came in and out of use, primarily named as an example of the lack of informed consent and the ability of researchers to take advantage of the vulnerable. It provided a way to say that race matters and then to never really interrogate in what ways.

(Reverby 2009: 193)

So, centering on the Study can help us interrogate *in what ways* race matters to bioethics. In particular, the Study opens more adequate ways to understand the racial content of our bioethical judgments than can be encompassed by talk of consent in situations of inequality.

Yet taking the Syphilis Study as a touchstone for a discussion of bioethics and racialization may also problematically limit understanding. Much of the time, discussions of race focus primarily or exclusively on the U.S., and within that context, narrowing to a near-complete focus on black/white racial inequalities. For example, the promisingly titled but ultimately limited article “Why Bioethics Cannot Figure Out What to Do with Race” concludes that the main problem with the discipline of bioethics’ failure to adequately treat race is a failure to decide whether to include the (U.S.) Black Church in bioethical debates (Burton 2007: 10). While the specific historical context of the U.S. is very important for understanding the relation of race and bioethics, it would be a serious mistake to accept that the only forms of racialization relevant to bioethics arise from the U.S. black/white context. Our hope is that in taking the Tuskegee Study as a key example, the discussion below provides multi-use conceptual tools for thinking about racialization in many contexts, even while it skirts these dangers.

In looking at these early cases, we can see that some of the legal and cultural norms that established the professional and academic field of bioethics are entangled with race. And though it is not obvious that race is at work in every bioethical question we face, we will argue that race is intimately bound up in even the most everyday bioethical judgments.

### Race and Racisms

Although this chapter focuses on the question of how race matters to bioethics, from the start we need to think more clearly about the central concepts—“race” and “racism.” As described above, a commonsense way to think about race is as biological differences between people—and, indeed, historically this has been one way of understanding what race is. In this chapter, we reject the idea that there are bright lines of biological difference between groups that could delineate one race from another. When we say that we hold a racial formation or racialization view of race we don’t mean that there’s no such thing as race, or that race has no effects. We mean, though, that bioethicists should understand the effects and material realities of race as not biologically determined. Indeed, we agree with writers like Anne Fausto-Sterling, who argue that biology itself takes shape through and with social formations (see Fausto-Sterling 2005, 2008).

For its part, racism is often understood as the direct, explicit expression of interpersonal ill will, which can take the form of explicitly discriminatory policies or hateful speech (Garcia 2004). It is also seen as ignorance, whether actively shaped or passively absorbed (Mills 1998, 2007; Outlaw 2007; Sullivan and Tuana 2007; Types 2007). Of

course, even people with the best intentions can be racist. There are other sorts of racism that are not formulated in words. There is another sense altogether in which we might understand racism as not thoroughly described by explicit expressions of personal ill will or prejudice. Structural or systemic racism may never take the form of racist expression; indeed, perhaps more racial wrongdoing is effected by seemingly bloodless bureaucracy than self-proclaimed or subtle individual racist people (Arendt 2006).

### Interlocking Systems of Oppression

Whenever discussing the process of racial formation, we do best to also remember that other markers of social identity change the experience and meaning of the social dynamic we call “race.” Individuals’ experiences of gender, sexuality, class, disability, religious orientation, and more will shape their experience of race—and, indeed, attending to any of those axes of oppression and liberation requires concurrently attending to race. This mode of taking complex social relations into account in our theorizing and understanding is known as having an “interlocking oppressions” or “intersectional” analysis (see Collins 1998; Crenshaw 1991; Razack 1998). Because different forms of oppression and privilege are bound up with each other, we cannot think effectively about only one bit of the whole picture as though it is disconnected from others. In this chapter, we will for the most part use the phrase “interlocking oppressions” to name the relational co-production of social relations of inequality. This is a departure from some of the ways such analysis has been codified and made part of a feminist intellectual canon (see Carastathis 2008).

There are (at least) three levels on which we can see the importance of taking racialization into account in bioethics: Individual, group/collective, and systemic. At each level, many different social relations come together to shape the particular experience or problem under consideration. In thinking about racialization and bioethics it is particularly useful to note the ways someone may be harmed or oppressed in some ways while being benefitted or privileged in others. For example, someone may be harmed—or even oppressed—because of their gender, while receiving social goods because they are not disabled. Thus, people can be simultaneously, unevenly, oppressed and benefiting from oppression.

### Individual Experiences of Racialization

On an individual level, racialization matters to bioethics. Individual physicians and researchers may have responses and make medical decisions based on their and their patients’ racial position. After controlling for socioeconomic and access-related discrepancies between individuals belonging to different racialized groups, there remain significant disparities in health care across racial and ethnic lines. The Institute of Medicine (of the U.S. National Academy of Sciences) investigated these disparities and concluded that “racial or ethnic differences in the quality of health care” resulted at least in part from physician bias, stereotyping, or prejudice (Smedley et al. 2003; Balsa and McGuire 2003; Brody 2009). Current work on the concept of “implicit bias” indicates that even—and perhaps especially—people who do not believe they are discriminating based on race and other social identities actually do respond differently relative to these social categories (Wear 2003; Jost et al. 2009; Stivers and Majid 2007; Penner et al. 2010). More fundamentally, when discrimination based on race arises in health contexts,

whether treatment or research, it always manifests in individual people's actual bodies and experience. So we must think about racialization on what Brody et al. call the "micro-level," at the scale of people experiencing illness in part because of how they are racialized (Brody et al. 2012: 309). Although the force of racialization may be more obvious as it manifests itself in the lives of people of color, we could see every experience of health or illness as racialized—people who hold the social position of whiteness will have a different interaction with their doctor than will people of color. And other things being equal, a white patient's interaction will have more dignity and show more respect for patient autonomy (Cooper et al. 2012). A white patient's interaction will also likely produce better health outcomes. The U.S. Department of Health and Human Services' (2012) *National Healthcare Disparities Report* tracks specific disparities in acute preventive care for numerous conditions, by race and other markers. Of course, other things are rarely equal, and white people living in poverty, white people with disabilities, queer white people, will almost certainly have health outcomes worse than, for example, higher class, non-disabled, straight white people based on their entanglement with the harmful aspects of interlocking systems of privilege and oppression.

In the Tuskegee Study, recall, doctors followed a group of African-American men who had untreated syphilis in order to study the progression of the untreated disease. Participants in the Study were told they were signing up to receive free health care, and they were also guaranteed a funeral paid for by the Study. We can see that individual-scale racialization was manifest most obviously in the interactions between the doctors running the Study and the people participating in it. The black men enrolled in the Study were told that they were being treated, though not what for, when in fact they were being given merely aspirin and iron supplements. Most damningly for the doctors overseeing the Study from the Public Health Service (PHS), in cases when the men could have received effective treatment, they were not informed of these possibilities. For example, a number of the men enrolled in the Study pursued enlistment in the U.S. armed forces. Unbeknownst to them, the PHS had provided a list of their names to the Army with an explanation of their participation in a valuable medical study (Jonsen 2003: 148; Reverby 2009: 61). The U.S. Army had a policy of treating incoming recruits for syphilis, so when it rejected men from the Study we can see that they were directly denied treatment. Far more of the participants, along with their sexual partners, were indirectly denied proper treatment through relations of omission.

Race shaped the Study in terms of who was enrolled, how they were denied treatment, and how physicians, nurses, and researchers interacted with the participants. On an individual level, particular black men enrolled in the study were not treated for syphilis. The men who participated in the PHS Tuskegee Study were never provided with the opportunity to give anything like informed consent because they were not told that they had syphilis, or that they were not being treated for a disease they had, or that treatment was available, or a host of other salient facts. This failure to secure informed consent has been the central focus of much of the response in bioethics. The doctors, nurses, and researchers who participated in the Study were ignoring the broadest duty to provide a clear account of what facts were known, possible treatment options, and likely future results of engaging in the Study. In some cases their behavior exhibited disbelief that study participants were capable of understanding their situation (Reverby 2009: 55, 60, 116, 128; Brandt 1978).

How race and racism were involved in these ethical failures is not, however, as simple as it might seem. There were now-obvious problems with the failure to allow for informed

consent and with the exploitation of a vulnerable population for research purposes. There has been a temptation to tell the story of the Study as though the racial dynamics were simple: Bad, racist white doctors lied to and took advantage of illiterate Black sharecroppers to secure their careers (see Brandt (1978) for an early and important intervention in the racial dynamics of the Study). This story is accurate, but it is not complete. Not only was the Study hosted at the pre-eminent black research institution in the U.S. South, and not only were there black medical personnel involved all the way through, but the participants and practitioners were working within the constant background of everyday, unacknowledged racism. If, as we hope to show, health care and health research always function within the context of racialization, it will not be enough for medical ethics to ask about the intentional actions and omissions of “bad racist” practitioners. Bioethicists must consider the broader questions of ethical action in relation to group identity as well as in relation to systems of inequality.

### The Implications of Racialization for Groups

On a group or collective level, medical practice may be informed by racialization in harmful ways. In virtue of their group membership, and perhaps also in ways that define their group membership, racialized people can be picked out for differential treatment. For example, historically, racialization was involved in group-level decision-making in the form of eugenicist medical practices. Forced sterilization—and a concomitant valuing and encouragement of white women to have children—interact with racialization in the medical domain, and not only in terms of the individual-level effects to the women sterilized (Silliman et al. 2004; Smith 2005). Other invasions of women of color’s reproductive health include research informed by racialization, as in the case of Dr J. Marion Sims (1813–83), an Alabama surgeon who conducted experimental surgeries on black slave women in his development of treatment for vesicovaginal fistula (Axelson 1985; Wall 2006).

In much bioethics training today the way that students and clinicians are taught to engage with group differentiation uses the language of cultural competency for working with multicultural populations in health situations (Carrese and Sugarman 2006; Paasche-Orlow 2004; Washington 2009; Wear 2003). Although often there is some commitment to think about cultural competency as relevant to queer, disabled, non-majority language-speaking, or elderly patients, the term “culture” frequently supplements and, often, actually stands in for “race.” Although it is important for medical practitioners to be competent to treat people who come from various backgrounds, there is a difference between racialization and culture (or ethnicity). This is particularly the case in medical contexts in which researchers and medical practitioners believe that there are biological differences between races (Kahn 2012). An early, and still-important, definition set out cultural competency as “a set of congruent behaviors, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations” (Cross et al. 1989; cited in Brach and Fraserirector 2000: 182). Much racial grouping, even when it is framed as cultural, takes the form of treating people as though racial identity were a biologically determinable reality. Given this, it is striking that much clinical practice focuses on better managing the interpersonal manifestation of racialized group identities through increasing cultural competence in the medical professional. The PHS Syphilis Study should not be seen as primarily a failure of cultural competence.



As a paradigm of racialized wrongdoing, “Tuskegee” grouped black people in a particular place into a racialized group that was then understood as biologically distinct. A danger is that such clumping solidifies an implicit or explicit belief that there are biological differences between races. This was certainly a dynamic at the outset of the Study—researchers believed that African Americans had different (deficient) brains, and thus that the neurological effects of late-stage syphilis would be different by race (Reverby 2009: 45; see also Crenner 2012). Further, at least some of the individual wrong-doings on the level of consent and exploitation were the result of a perception that it was acceptable to sacrifice the interests of the men involved in the Study to the interests of black people in the U.S. more generally. At the time of the study, there was a belief that black people were biologically categorically different than white people, and therefore that it was medically beneficial to others to follow the progression of the disease (Reverby 2009: 159–61). Presumed group identity can, in cases like these, degrade the care individuals receive. The Study serves, in the present, as a short hand for talking about group-differentiated distrust of medical authority; racialized people in the U.S., especially black people, are represented as holding Tuskegee in mind (Brandon et al. 2005; Gamble 1997; Freimuth et al. 2001; W. King 2003). Some writers argue that medical practitioners should be knowledgeable about Tuskegee specifically in order to show knowledge of why race matters to medicine (i.e., as part of cultural competence) (Chiu and Katz 2011; Corbie-Smith 1999).

A perhaps surprising example of this is marked by the first drug approved by the U.S. Food and Drug Administration (FDA) for race-specific administration in the U.S., BiDil (two previously approved generic drugs, hydralazine and isosorbide dinitrate, which when combined are meant to treat heart failure in African Americans). As Johnathan Kahn has argued (see Kahn 2005, 2007), the specification of this drug as effective for, and only for, African-American patients with cardiac disorders has dubious beginnings and some pernicious effects. The dubious beginnings help us think about the difficulties in grouping people by racial group. The researcher who patented the BiDil combination re-examined past data, theorizing from a small (53-person) sample that the drug was more effective for African Americans. A second study was conducted with 1,050 self-identified African-American participants, and based on those data, the drug was approved for use in only African Americans. BiDil costs nearly six times its generic equivalents, leading some to believe that the re-patenting did not arise primarily out of a desire to benefit black patients with heart conditions. The pernicious effects of the approval include the medical reification of social groupings based on self-identification (Lee et al. 2001). Since there is no scientific definition of who, in BiDil’s terms, counts as “black people,” it is difficult to say who would be appropriate subjects for its administration. Since there is no biological test for racialization, there can be no biological ground for prescribing BiDil—leaving anyone from the patient’s doctors to their insurance company to the FDA responsible for their racial classification for medical purposes. As Kahn argues:

Researchers using race to develop drugs may be motivated by good intentions, but such efforts are also driven by the dictates of an increasingly competitive medical marketplace. The example of BiDil indicates that researchers and regulators alike have not fully appreciated that race is a powerful and volatile category. When used to bolster the commercial value of a drug, it can lead to haphazard regulation, sub-standard medical treatment and other unfortunate

unintended consequences. The FDA should not grant race-specific approvals without clear and convincing evidence of a genetic or biological basis for any observed racial differences in safety or efficacy. Approving more drugs such as BiDil will not alleviate the very serious health disparities between races in the U.S. We need social and political will, not mislabeled medicines, to redress that injustice.

(Kahn 2007: 45)

Kahn here points to a third way in which we can understand racialization as significant for bioethics: Health disparities arising out of systemic or structural inequality.

### Racialization and Systems of Oppression

Systemically, race, in concert with other systems of privilege and oppression, is one of the most significant determinants of health or illness. As Ruth Wilson Gilmore has argued, we can track racialization in part by examining the statistical likelihood of dying young; this political point is underlined by the now vast public health literature addressing health disparities (see Institute of Medicine 2002; Fiscella et al. 2002; Lasser et al. 2006). Racial and socio-economic status differentially shape the health of children (Chen et al. 2006), making it necessary to track both race/ethnicity and class status in giving an account of health inequalities (Kawachi et al. 2005; LaVeist 2005). As such, further close attention must be paid in bioethics to how multiple systems of inequality function together to affect health, with care to not neglect the importance of race in such processes.

We mentioned the U.S. Institute of Medicine's report on health disparities (*Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*) above; as Alan Nelson, a member of the committee that prepared the report said, the committee "finished its work convinced that the real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in the developing and implementing of strategies to reduce and eliminate them" (Institute of Medicine 2002: 667). However, the recommendations the committee makes remain at the level of improving doctor-patient communication, patient empowerment, allocating more resources for civil rights investigations about health wrongs, with relatively scant mention of changing the U.S. health system. To address the health disparities created and sustained by racialization, bioethics must take into account the complexities of racism at individual, group, and systemic levels.

### Future Directions

Encouragingly, bioethicists have begun to examine the impact of social and racial inequality on health. They have begun to highlight how the following kinds of questions must be asked in order to develop anti-racist approaches to bioethics.

#### ***How Can Bioethicists Address Racism Beyond Concerns about Informed Consent, Self-determination, and Autonomy?***

Patricia King (1998, 2004, 2007) argues that despite widespread recognition in U.S. bioethics that the Tuskegee Syphilis Study stands as a common trope for recognizing racism in medical research:



There has been inadequate attention paid to race, either in the sense of negative and differential treatment or in terms of pervasive scientific racism, in the construction of bioethics in the United States. American bioethics, from its inception, has resisted taking account of social context. In American bioethics, individualism, self-determination, and autonomy are paramount. Other values, and other ethical issues, have historically enjoyed lesser status. Even today, the failure to obtain consent from the Tuskegee subjects continues to receive greater attention than the social and economic conditions in which the subjects found themselves.

(P. King 2004: 149–50)

The central insight here is that all our ethical decision-making happens in a context of relations with other people and longstanding social realities (e.g., racism). Aiming to correct racism in health care practice by focusing only on the one-to-one level of interpersonal interaction (e.g., making sure that a physician is trained not to say anything racist) fails to attend to this broader social and historical context. In situations of systemic inequality, systems of oppression and benefit, all parties involved in health care practice would do well to take the social and historical context into account. Take the case of the Study, seen from a health equity perspective (and see Braveman (2006) on terminology). As even some doctors involved reflected, while they were not providing care to the men they studied, in some real ways focusing on their own individual wrong-doing is a red herring. Most, and perhaps all, of the men who participated in the Study lacked access to basic health care. With the exception of the men who could have joined the military, they would not have received care for syphilis even if they weren't enrolled in the Study. Would it have been better to not study (and not treat) people who were not being treated anyhow? (This argument fails at the point at which penicillin was available in public health clinics, from which many of the men seem to have been turned away.) Focusing on the ethical wrongdoing of the doctors and nurses leaves the ethical wrongs of an inequitable system uninterrogated. A focus on issues of informed consent and vulnerable populations obfuscates the bigger ethical problem, which is not seen as ethical at all: How can we have bioethical reasoning in a situation of fundamental inequity distributed by race?

***How Might Bioethicists be Well Positioned to Investigate the Ways Health Care, Economic, Educational, Criminal Justice, Carceral, and Other Systems Work Together to Harm Racialized Individuals?***

Bioethics might be well positioned to take a quite expansive role in redefining the meaning of race. We can think about race as a social fiction with material effects—a construct that becomes social reality. When we say “race” from this point of view, we mean “racialization.” Recall that *racialization* names the social process through which individuals and groups of people come to be defined as a racial group. This is a process that brings together ways of talking about people (or discursive practices) with material conditions in order to define a group of people as a race. Such ways of talking have used, for example, biological explanations (there are real biological differences between races); geographical explanations (where a group of people live shapes their racial ontology); phenotypic explanations (physical morphology makes someone “really” one race or another); social or cultural explanations (how people live either comes from or produces their racial identity). To use the concept of racialization is to see the production

of race *not* as a biological or cultural given, but rather as a social process through which people's bodies, cultural practices, and social/geographical locations come to carry and hold particular racial meanings. Bioethicists have the potential to be able to think relationally and holistically about how multiple social systems work together to harm racialized individuals—and about how multiple systems would need to coordinate to prevent harms or meaningfully benefit such groups.

***How Can Public Health Ethics Correct Narrow Understanding of Health Disparities and the Harms of Racialization in Health Care Practice, Research, and Theory?***

Many bioethicists write persuasively in the field of public health, some arguing compellingly for the need for bioethical accounts that focus on the way power dynamics shape relationships at all levels in health care (Fagan 2004; Baylis et al. 2008). Madison Powers and Ruth Faden argue that the health inequalities arising from “systemic patterns of disadvantage are the inequalities that are most morally urgent to address. Justice here demands aggressive public health intervention to document and help remedy existing patterns of systemic disadvantage and their detrimental consequences” (Powers and Faden 2006: 87). Annette Dula and Sara Goering's *It Just Ain't Fair: The Ethics of Health Care for African Americans* (1993) offers a sustained consideration of race and health disparities in the U.S. context, including discussions of infant mortality, HIV, rural health care, homelessness, black medical students, and surrogacy (see also Dula 2003, 2007). With increased focus on narrative medicine (Gotlib 2009), further attention should be paid to how narratives of experiences of racialization and racism could be important parts of improved health care. For example, when medical practitioners started listening to the people affected by the Tuskegee Study, they better understood the severity of harms experienced and could better anticipate where similar harms might be experienced in the future. The hope for public health ethics approaches is that they will begin already at a group level of understanding oppression in health care ethics, and so may be more able to resist reducing questions of race in health care practice to the imperative that individual racist health care providers become more racially competent.

***How Can Race and Racism Shape Diagnostic Categories, Including (and not only) in Domains of Mental Health and Illness?***

Bioethicists have worked from insights in science studies, biology, philosophy, and other domains to offer critical reflections on how classification systems can shape the health and lives of individuals subject to them. Of particular interest have been contentious diagnostic systems (e.g., classifications for sexual and reproductive illnesses; the Diagnostic and Statistical Manual of Mental Disorders). Bioethicists have highlighted the ways in which categorization and diagnosis have the power to shape not only the kind of treatment individuals receive, but the ways individuals perceive their own experience, and the possibility of individuals receiving care for conditions at all. Some bioethicists have investigated, for example, the ways perceptions of gender, class, and sexuality shape diagnoses of mental illness and the likelihood that individuals will be harmed by diagnostic categories. For example, bioethicists now know to be concerned about how readily characteristics of “sexual deviance” have been made diagnosable as mental illness (Martin 2001; Nissim-Sabat 2001; Potter 2004, 2005). New directions in

bioethics will further attend to the ways racialization has shaped diagnostic categories in ways that harm individuals subject to them.

***How Do Questions of Race and Racism Arise in the Development and Use of Medical Technologies?***

Bioethicists have become able to appraise technological advancements in medicine and health research with a critical eye to what drives the development of technologies, what populations they are meant to aid, and how they can be used for goals beyond those for which they were intended (Gillis and de Melo Martín 2010). Attention to racialization could be productive in further considerations of all these questions. For example, how do genetic technologies intersect with racialization (Braun 2002)? How can practices of “biobanking” biological samples for research harm racialized groups in ways not obvious to those whose specimens are taken (Halverson and Ross 2012; Tutton 2009)? If researchers discover differences in how diseases and illnesses affect people by ethnic group, will health insurance coverage for different groups be affected? How do reproductive technologies reinforce racialization (Russell 2010)? In the domain of public health, area-based research and technologies of “geo-coding” can investigate the ways location/place intersects with race, gender, and socio-economic status to lead to health disparities (Kreiger et al. 2003). Engaging further with the extensive literature on how medical technologies affect populations could facilitate future bioethical investigations of race and medical technologies.

***How Does Racialization Limit Communities’ Ability to Direct and Conduct Research to Reflect Their Needs?***

In questions of research ethics in medicine, bioethicists have been deeply critical of research conducted on communities that are not likely to benefit from the research, and of strategic neglect of the research questions of communities that are not likely to be profitable or universally relevant. Racialized communities have been harmed by both of these phenomena, and bioethicists could offer directions for highlighting the particular needs and vulnerabilities of racialized communities within public and private medical research agendas. How does racial grouping by researchers affect an individual participant’s willingness to participate in a given study (Goldenberg et al. 2011)? How can bioethics help clarify the successes and challenges of research directed by racialized communities themselves?

***Are Models Based on “Cultural Competence” Adequate for Understanding Race and Racism?***

There are numerous problems with “cultural competency” approaches as a way to engage group differentiation by race. (For critical assessments, see Kumagai and Lyson (2009); Beagan and Kumas-Tan 2009.) One problem is that in attempting to describe medically salient features of different cultures the full heterogeneity of those cultures is occluded; it can become received wisdom that all Native Americans prefer to not have end-of-life decisions talked about explicitly, when in fact that preference may be specific to one tribe or nation, or to non-Christian first peoples. Another problem arises from the documented prevalence of implicit bias and stereotyping among white, Christian, Anglo

nurses and doctors (Cooper et al. 2012) and how difficult it is to overcome bias even once it is made explicit. As we have discussed, perhaps the most significant problem with focusing primarily or exclusively on cultural competency training as a solution to the harms of racism in health care is when such a focus eclipses broader structures and systems that perpetuate inequality.

In sum, the challenge for bioethicists committed to developing anti-racist approaches in all domains of bioethics is to see racial inequities as a problem both perpetuated and partly addressable by clinical and theoretical bioethics. Bioethical thinking and practice can be improved, particularly with regard to the complex manifestation of race and racialization as health and illness. Doing justice to the individual, group, and systemic levels of racialization is difficult work, but both bioethics as a field and the lives of the people about whom bioethicists think and care would be better for it.

### Related Topics

- 
- Chapter 2, "Social Determinants of Health and Health Inequalities," Michael Marmot and Sridhar Venkatapuram  
 Chapter 14, "Biomedical Research Ethics: Landmark Cases, Scandals, and Conceptual Shifts," Jonathan D. Moreno and Dominic Sisti  
 Chapter 18, "Research Involving 'Vulnerable Populations': A Critical Analysis," Toby Schonfeld

### References

- 
- Arendt, H. (2006) *Eichmann in Jerusalem: A Report on the Banality of Evil*, London: Penguin Classics.  
 Axelson, D.E. (1985) "Women as Victims of Medical Experimentation: J Marion Sims's Surgery on Slave Women, 1845–1850," *Sage* 2 (2): 10–13.  
 Balsa, A.I. and McGuire, T.G. (2003) "Prejudice, Clinical Uncertainty and Stereotyping as Sources of Health Disparities," *Journal of Health Economics* 22 (1): 89–116.  
 Baylis, F., Kenny, N.P. and Sherwin, S. (2008) "A Relational Account of Public Health Ethics," *Public Health Ethics* 1 (3): 196.  
 Beagan, B. and Kumas-Tan, Z. (2009) "Approaches to Diversity in Family Medicine: 'I Have Always Tried to be Colour Blind,'" *Canadian Family Physician* 55: e21–8.  
 Brach, C. and Fraserirector, I. (2000) "Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model," *Medical Care Research and Review* 57 (4 Suppl.): 181–217.  
 Brandon, D.T., Isaac, L.A. and LaVeist, T.A. (2005) "The Legacy of Tuskegee and Trust in Medical Care: Is Tuskegee Responsible for Race Differences in Mistrust of Medical Care?" *Journal of the National Medical Association* 97 (7): 951.  
 Brandt, A.M. (1978) "Racism and Research: The Case of the Tuskegee Syphilis Study," *Hastings Center Report* 8 (6): 21–9.  
 Braun, L. (2002) "Race, Ethnicity, and Health: Can Genetics Explain Disparities?" *Perspectives in Biology and Medicine* 45 (2): 159–74.  
 Braveman, P. (2006) "Health Disparities and Health Equity: Concepts and Measurement," *Annual Review of Public Health* 27: 167–94.  
 Brody, H. (2009) *Race and Health Disparities in the Future of Bioethics*, New York: Oxford University Press, 138–41.  
 Brody, H., Glenn, J. and Hermer, L. (2012) "Racial/Ethnic Health Disparities and Ethics: The Need for a Multilevel Approach," *Cambridge Quarterly of Healthcare Ethics* 21: 309–19.  
 Burton, O. (2007) "Why Bioethics Cannot Figure Out What to Do with Race," *The American Journal of Bioethics* 7 (2): 6–12.  
 Carastathis, A. (2008) "The Invisibility of Privilege: A Critique of Intersectional Models of Identity," *Les ateliers de l'éthique* 3 (2): 23–38.  
 Carrese, J.A. and Sugarman, J. (2006) "The Inescapable Relevance of Bioethics for the Practicing Clinician," *CHEST Journal* 130 (6): 1864–72.

- Chen, E., Martin, A.D. and Matthews, K.A. (2006) "Understanding Health Disparities: The Role of Race and Socioeconomic Status in Children's Health," *Journal Information* 96 (4): 702–8.
- Chiu, C.T. and Katz, R.V. (2011) "Identifying the 'Vulnerables' in Biomedical Research: The Vox Populis from the Tuskegee Legacy Project," *Journal of Public Health Dentistry* 71 (3): 220–8.
- Collins, P.H. (1998) "It's All in the Family: Intersections of Gender, Race, and Nation," *Hypatia* 13(3): 62–82.
- Cooper, L., Roter, D., Carson, K., Beach, M.C., Sabin, J., Greenwald, A. and Inui, T. (2012) "The Associations of Clinicians' Implicit Attitudes About Race With Medical Visit Communication and Patient Ratings of Interpersonal Care," *American Journal of Public Health* 102 (5): 979–87.
- Corbie-Smith, G. (1999) "The Continuing Legacy of the Tuskegee Syphilis Study: Considerations for Clinical Investigation," *American Journal of the Medical Sciences* 317 (1): 5–8.
- Crenner, C. (2012) "The Tuskegee Syphilis Study and the Scientific Concept of Racial Nervous Resistance," *Journal of the History of Medicine and Allied Sciences* 67 (2): 244–80.
- Crenshaw, K. (1991) "Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color," *Stanford Law Review* 43 (6): 1241–99.
- Cross, T.L., Bazron, B.J., Dennis, K.W. and Isaacs, M.R. (1989) *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*, Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.
- Dula, A. (2003) "Racism and Health Care: A Medical Ethics Issue," in Lott, T.L. and Pittman, J.P. (eds.) *A Companion to African-American Philosophy*, Oxford: Blackwell Publishing.
- Dula, A. (2007) "Whitewashing Black Health: Lies, Deceptions, Assumptions, and Assertions—and the Disparities Continue," in Prograis, L.J. and Pellegrino, E.D. (eds.) *African American Bioethics: Culture, Race, and Identity*, Washington DC: Georgetown University Press.
- Dula, A. and Goering, S. (eds.) (1993) *It Just Ain't Fair: The Ethics of Health Care for African Americans*, Westport, CT: Praeger.
- Fagan, A. (2004) "Challenging the Bioethical Application of the Autonomy Principle Within Multicultural Societies," *Journal of Applied Philosophy* 21 (1): 15–31.
- Fausto-Sterling, A. (2005) "The Bare Bones of Sex," *Signs* 30 (2): 1491–528.
- Fausto-Sterling, A. (2008) "The Bare Bones of Race," *Social Studies of Science* 38: 657–94.
- Fine, M.J., Ibrahim, S.A. and Thomas, S.B. (2005) "The Role of Race and Genetics in Health Disparities Research," *American Journal of Public Health* 95 (12): 2125.
- Fiscella, K., Franks, P., Doescher, M.P. and Saver, B.G. (2002) "Disparities in Health Care by Race, Ethnicity, and Language Among the Insured: Findings from a National Sample," *Medical Care* 40 (1): 52.
- Freimuth, V.S., Quinn, S.C., Thomas, S.B., Cole, G., Zook, E. and Duncan, T. (2001) "African Americans' Views on Research and the Tuskegee Syphilis Study," *Social Science and Medicine* 52: 797–808.
- Gamble, V.N. (1997) "Under the Shadow of Tuskegee: African Americans and Health Care," *American Journal of Public Health* 87 (11): 1773–8.
- Garcia, J.L.A. (2004) "Three Sites for Racism: Social Structures, Valuings and Vice," in Levine, M.P. and Pataki, T. (eds.) *Racism in Mind*, Ithaca, NY: Cornell University Press.
- Gillis, M. and de Melo Martín, I. (2010) "Editors' Introduction: Biomedical Technologies," *Hypatia* 25 (3): 497–503.
- Gilmore, R.W. (2007) *Golden Gulag: Prisons, Surplus, Crisis, and Opposition in Globalizing California*, Volume 21, Oakland, CA: University of California Press.
- Goldenberg, A.J., Hull, S.C., Wilfond, B.S. and Sharp, R.R. (2011) "Patient Perspectives on Group Benefits and Harms in Genetic Research," *Public Health Genomics* 14 (3): 135–42.
- Gotlib, A. (2009) "Stories from the Margins: Immigrant Patients, Health Care, and Narrative Medicine," *International Journal of Feminist Approaches to Bioethics* 2 (2): 51–74.
- Halverson, C. and Ross, L. (2012) "Engaging African-Americans about Biobanks and the Return of Research Results," *Journal of Community Genetics* 3 (4): 275–83.
- Institute of Medicine (2002) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, London.
- Jonsen, A.R. (2003) *The Birth of Bioethics*, Oxford: Oxford University Press.
- Jost, J.T., Rudman, L.A., Blair, I.V., Carney, D.R., Dasgupta, N., Glaser, J. et al. (2009) "The Existence of Implicit Bias Is Beyond Reasonable Doubt: A Refutation of Ideological and Methodological Objections and Executive Summary of Ten Studies That No Manager Should Ignore," *Research in Organizational Behavior* 29: 39–69.



- Kahn, J. (2005) "From Disparity to Difference: How Race Specific Medicines May Undermine Policies to Address Inequalities in Health Care," *Southern California Interdisciplinary Law Journal* 15: 105–29.
- Kahn, J. (2007) "Race in a Bottle," *Scientific American* 297: 40–5.
- Kahn, J. (2012) *Race in a Bottle: The Story of BiDiL and Racialized Medicine in a Post-Genomic Age*, New York: Columbia University Press.
- Kawachi, I., Daniels, N. and Robinson, D.E. (2005) "Health Disparities by Race and Class: Why Both Matter," *Health Affairs* 24 (2): 343–52.
- King, P.A. (1998) "Race, Justice and Research," in Kahn, J.P., Mastroianni, A.C. and Sugarman J. (eds.) *Beyond Consent: Seeking Justice in Research*, New York: Oxford University Press, pp. 88–110.
- King, P.A. (2004) "Reflections on Race and Bioethics in the United States," *Health Matrix* 14: 149.
- King, P.A. (2007) "Race, Equity, Health Policy, and the African American Community," in Prograis, L.J. and Pellegrino, E.D. (eds.) *African American Bioethics: Culture, Race, and Identity*, Washington DC: Georgetown University Press.
- King, W.D. (2003) "Examining African Americans' Mistrust of the Health Care System: Expanding the Research Question. Commentary on 'Race and Trust in the Health Care System,'" *Public Health Reports* 118 (4): 366.
- Krieger, N., Chen, J.T., Waterman, P.D., Rehkopf, D.H. and Subramanian, S.V. (2003) "Race/Ethnicity, Gender, and Monitoring Socioeconomic Gradients in Health: A Comparison of Area-Based Socioeconomic Measures—the Public Health Disparities Geocoding Project," *Journal Information* 93 (10): 1655–71.
- Kumagai, A.K. and Lypson, M.L. (2009) "Beyond Cultural Competence: Critical Consciousness, Social Justice, and Multicultural Education," *Academic Medicine* 84 (6): 782–7.
- Lasser, K.E., Himmelstein, D.U. and Woolhandler, S. (2006) "Access to Care, Health Status, and Health Disparities in the United States and Canada: Results of a Cross-National Population-Based Survey," *Journal Information* 96 (7): 1300–7.
- LaVeist, T.A. (2005) "Disentangling Race and Socioeconomic Status: a Key to Understanding Health Inequalities," *Journal of Urban Health* 82: iii26–34.
- Lee, S.S.J., Mountain, J. and Koenig, B.A. (2001) "Meanings of Race in the New Genomics: Implications for Health Disparities Research," *Yale Journal of Health Policy Law & Ethics* 1: 33.
- Martin, N. (2001) "Feminist Bioethics and Psychiatry," *Journal of Medical Philosophy* 26 (4): 431–41.
- Mills, C.W. (1998) *Blackness Visible: Essays on Philosophy and Race*, Ithaca, NY: Cornell University Press.
- Mills, C.W. (2007) "White Ignorance," in Sullivan, S. and Tuana, N. (eds.) *Race and Epistemologies of Ignorance*, New York: State University of New York Press, pp. 11–38.
- Nissim-Sabat, M. (2001) "Review Article: Psychiatry, Psychoanalysis, and Race," *Philosophy, Psychiatry & Psychology* 8 (1): 45–59.
- Omi, M. and Winant, H. (1994) *Racial Formation in the United States: From the 1960s to the 1990s*, New York: Routledge.
- Outlaw, L.T. (2007) "Social Ordering and the Systematic Production of Ignorance," in Sullivan, S. and Tuana, N. (eds.) *Race and Epistemologies of Ignorance*, New York: State University of New York Press.
- Paasche-Orlow, M. (2004) "The Ethics of Cultural Competence," *Academic Medicine* 79 (4): 347–50.
- Penner, L., Dovidio, J.F., West, T.V., Gaertner, S.L., Albrecht, T.L., Dailey, R.K. et al. (2010) "Aversive Racism and Medical Interactions with Black Patients: A Field Study," *Journal of Experimental Social Psychology* 46 (2): 436–40.
- Potter, N. (2004) "Gender," in J. Radden (ed.) *The Philosophy of Psychiatry: A Companion*, Oxford: Oxford University Press.
- Potter, N. (2005) "Liberatory Psychiatry and an Ethics of the In-Between," in Shildrick, M. and Mykitiuk, R. (eds.) *Ethics of the Body: Postconventional Challenges*, Cambridge, MA: MIT Press, pp. 113–33.
- Powers, M. and Faden, R. (2006) *Social Justice: The Moral Foundations of Public Health and Health Policy*, Oxford: Oxford University Press.
- Razack, S. (1998) *Looking White People in the Eye: Gender, Race, and Culture in Courtrooms and Classrooms*, Toronto: University of Toronto Press, Scholarly Publishing Division.
- Reverby, S. (2009) *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy*, Chapel Hill, NC: University of North Carolina Press.
- Russell, C. (2010) "The Limits of Liberal Choice: Racial Selection and Reprogenetics," *The Southern Journal of Philosophy* 48 (Suppl.): 97–108.
- Silliman, J., Fried, M., Ross, L. and Gutierrez, E. (2004) *Undivided Rights: Women of Color Organizing for Reproductive Justice*, New York: South End Press.
- Smedley, B.D., Stith, A.Y. and Nelson, A. (eds.) (2003) *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Washington, DC: National Academies Press.



- Smith, A. (2005) *Conquest: Sexual Violence and American Indian Genocide*, New York: South End Press.
- Stivers, T. and Majid, A. (2007) "Questioning Children: Interactional Evidence of Implicit Bias in Medical Interviews," *Social Psychology Quarterly* 70 (4): 424–41.
- Sullivan, S. and Tuana, N. (2007) *Race and Epistemologies of Ignorance*, New York: State University of New York Press.
- Tutton, R. (2009) "Biobanks and the Inclusion of Racial/Ethnic Minorities," *Race/Ethnicity: Multidisciplinary Global Contexts* 3 (1): 75–95.
- Types, T. (2007) "Epistemologies of Ignorance," in Sullivan, S. and Tuana, N. (eds.) *Race and Epistemologies of Ignorance*, New York: State University of New York Press.
- U.S. Department of Health and Human Services (2012) *2012 National Healthcare Disparities Report*. Available at: [www.ahrq.gov/research/findings/nhqrdtr/index.html](http://www.ahrq.gov/research/findings/nhqrdtr/index.html) (accessed July 22, 2013).
- Wall, L.L. (2006) "The Medical Ethics of Dr J Marion Sims: A Fresh Look at the Historical Record," *Journal of Medical Ethics* 32 (6): 346–50.
- Washington, D.A. (2009) "Critical Race Feminist Bioethics: Telling Stories in Law School and Medical School in Pursuit of Cultural Competence," *Albany Law Review* 72: 961.
- Wear, D. (2003) "Insurgent Multiculturalism: Rethinking How and Why We Teach Culture in Medical Education," *Academic Medicine* 78 (6): 549.