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## Mixed Race: Understanding Difference in the Genome Era

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### Abstract

This article presents the findings of a qualitative study of multiracial individuals' understanding of identity, race and human genetic variation. The debate regarding the correlation between race, genetics and disease has expanded, but limited empirical data has been collected regarding the lay public's perspective. Participants in this study explore their identity and its relationships to their health care interactions. Participants also share their views on race-based therapeutics, health disparities and the connections between race, ancestry and genetics. Their voices highlight the limitations of racial categories in describing differences within our increasingly diverse communities. The genomic era will be a pivotal period in challenging current understandings and uses of racial categories in health.

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### Unraveling the Relationships between Race and Genetics

Race has long been used as a human label with far reaching implications in many aspects of our research, health care and society. Throughout history people have been classified into racial groups numbering from 3 to more than 50 (Barbujani 2005). Still, there has been no consensus reached on the definition and utility of race as a concept and the biological significance of racial categories across natural and social science disciplines.

In 1998, the American Anthropological Association's statement on race declared, "the idea of 'race' has always carried more meanings than mere physical differences; indeed, physical variations in the human species have no meaning except the social ones that humans put on them." (AAA 1998) In 2002, the American Sociological Association published, the *Importance of Collecting Data and Doing Social Scientific Research on Race*, a statement emphasizing the social foundation of race. The association noted, "although racial categories are legitimate subjects of empirical sociological investigation, it is important to recognize the danger of contributing to the popular conception of race as biological." (ASA 2003)

The completion of the Human Genome Project in 2003 opened the door for better understanding of genetic components of disease that will shape the future practice of medicine. The Human Genome Project detailed the map of our DNA sequence allowing researchers to develop tools to further explore genetic variation across the globe (International HapMap Consortium 2003). Built on the foundation of this knowledge researchers are continuing to uncover how genetic information can be used to screen, diagnose and treat disease. We learned

from the Human Genome Project that we are all genetically 99.9 percent alike. However, given that each person's genome contains 6 billion bases of DNA, a 0.1 percent difference represents 6 million locations that differ between two individuals' DNA (International HapMap Consortium 2003). The vast majority of these differences in sequence are "neutral," they do not change gene function.

Our knowledge of human genetic variation and its correlation with race and ethnicity is growing with our knowledge of the human genome. As biomedical and genetic research continues to propel us into the genomic era, in which researchers investigate the functions and interactions of all genes and environmental factors, the debates regarding the utility of racial and ethnic categories in the study and understanding of genetic variation will continue to increase (Bamshad et al. 2004; Cooper et al. 2003; Jackson 2004; Risch et al. 2002; Royal and Dunston 2004).

## Race and Multiracial Individuals in the United States

Race is a relatively recent concept in human history (Smedley 2007). This modern phenomena of classifying people was initially attached to a biological basis. People assumed that race was fixed or "rooted in nature" and physical appearances provided clues to qualities within individuals (Omi and Winant 2003). Conceptualizations of race often conflate biology and culture to place social meaning on ascribed physical characteristics (Holt 2000). Current social scientists and race theorists consider racial formation to be a "process by which social, economic and political forces determine the content and importance of racial categories." (Omi and Winant 2003)

In the United States, categories of race have always been fluid. In 1790, the U.S. Census categorized people in terms of "Free" and "Slave." In 1850 categories described people as "Black," "White" and "Mulatto;" and by 1890 census definitions had changed to "White, Black, Mulatto, Quadroon, Octoroon, Chinese, Japanese and Indian." (Nobles 2000) These changes highlight the struggle to categorize people of mixed racial backgrounds. The influence of the historical "one-drop rule" and the anti-miscegenation laws that prohibited interracial marriage in several states until 1967 created challenging and unique circumstances for multiracial persons of African decent (Roth 2005).

The United States continues to struggle with the use of racial classifications. In March 1994, the Office of Management and Budget established the Interagency Committee for the Review of Racial and Ethnic Standards, composed of representatives from 30 federal agencies. After a series of debates evaluating categories such as "Other" and "Multiracial," the OMB settled on the option to allow respondents to choose more than one race (OMB 1997). This option was available for the first time in American history during the 2000 U.S. Census.

Although the United States experienced a "biracial baby boom" during the late 1960s (Root 1992), multiracial individuals have only recently been given the tools to represent their ancestral heritage. When the U.S. Census Bureau acknowledged the growing population of multiracial individuals and allowed them to choose more than one race, 6.8 million people, or 2.4 percent of the population, indicated that they belonged to more than one racial group in the year 2000 (Grieco and Cassidy 2001). It is predicted that this number could reach 21 percent by the year 2050 (Lee and Bean 2004).

Multiracial persons are often confronted with issues surrounding visual ambiguity, identity confusion, rejection from familial or ethnic groups, and inability to identify with every component of a diverse racial background due to societal pressures (Deters 1997; Harris and Sim 2002). These challenges are often exaggerated in the lives of multiracial persons with some African American background. The views of laypersons with recently mixed ancestry,

each with distinct historical, socioeconomic and political backgrounds have several implications on the continued use and interpretation of research using self-identified racial categories to understand genetic variation. This qualitative study of multiracial individuals explores their identity, health care experiences and presents a valuable lens in analyzing the construct of “race” and its relationship to human genetic variation.

## Human Genetic Variation

The sequencing of the human genome has provided both natural and social scientists the opportunity to gain new knowledge about the complex relationships between our socio-politically constructed definitions of race, human genetic variation and health differences. Both race and ethnicity carry connotations that reflect culture, history, socioeconomic and political status, as well as an important connection to ancestral geographic origins (Collins 2004). Humans are genetically less diverse than many other mammalian species including chimpanzees (Fischer et al. 2004; Kaessmann et al. 2001). It is difficult to define human populations of significant genetic variation because of the clinal nature of our diversity (Long and Kittles 2003). Only 5 percent to 15 percent of genetic variation occurs between continental populations leaving the majority of diversity within these groups (Jorde et al. 2000). Additionally, the significance of this diversity is blurred by inconsistencies in the definition and inclusion parameters that are used to classify populations (Long and Kittles 2003). There are no gene variants that are present in all individuals of one population group and not in individuals of another. No sharp genetic boundaries can be drawn between human population groups (Bonham et al. 2005; Race Ethnicity and Genetics Working Group 2005).

The highest level of genetic diversity exists within African populations, reflecting the original groups of modern humans that migrated out of Africa to inhabit the rest of the world (Gabriel et al. 2002; Tishkoff and Verrelli 2003). Although genetic diversity within the human genome is small, these differences have some correlation to broad continental geographic groupings (Bamshad and Wooding 2003). Some researchers argue that these patterns support a biological basis to traditional racial categories that roughly correspond to groups from Africa, Asia, Europe, Oceania and the Americas (Risch et al. 2002). However, others contest the validity of the study designs, highlight the limitations of the sample selections and reassert that human genetic variation does not cluster into distinct groups (Frank 2007; Serre and Paabo 2004).

The concept of human genetic variation is further compounded by our simplistic view of the world in black and white. Genetic variation across the genome correlates to ancestral geographic origins which have often been associated with specific diseases. Self-identified racial and ethnic identity can correlate with ancestral geographic origins, but many individuals do not trace all of their ancestors to one place (Collins 2004). Self-identified ethnic and racial identity often does not reflect the totality of one’s inheritance. Most individuals emphasize selected aspects of their ancestry, have a limited knowledge of their complete ancestral lineage and live within an imposed social and political parameter of race and ethnicity.

## Role of Race in Genomic Medicine and Health Disparities Research

The emerging debate in the field of genetics over the use of race vs. ancestral labels highlights the importance of finding the best proxies for describing genetic population groups (Bamshad 2005; Tang 2006). The connection between race and genetics is tied to the understanding that race reflects ancestral geographic heritage. This connection is weakened among admixed populations, such as African Americans, that have a clear history of diverse ancestral background. On average, African Americans have about 80 percent West African ancestry with ranges from 20 percent to 100 percent (Bamshad 2005). Ancestry correspondence with geography is also less apparent in many Latin American countries that have European, African and Native American admixture (Santos and Maio 2004). Some geneticists therefore argue that

ancestry is a much more reliable marker of an individual's genetic makeup than race (Jorde and Wooding 2004). This debate is influencing the societal use of race as a category to describe differences in efficacy of drug therapies.

In June 2005, the U.S. Federal Drug Administration approved the first and only race-specific drug, BiDil, for the treatment of congestive heart failure among self-identified blacks (Temple and Stockbridge 2007). BiDil, a combination of two generic drugs, Isorsorbide Dinitrate and Hydralazine, was shown to successfully reduce mortality and hospitalization rates and increase quality of life among hypertensive black patients in the African-American Heart Failure Trial (Taylor et al. 2004). The approval of BiDil solely for "self-identified Blacks" has been widely debated. No data on genetic variants responsible for the proposed racial differences in response to the drug have been reported. Duster (2007) and other scholars have argued that BiDil has raised a number of concerns about the future direction of health disparities research and role of race in clinical decision making (Kahn 2004; Sankar 2006).

The genomic era will generate questions surrounding race, difference and health that will challenge us to evaluate the best methods for teasing apart the social, environmental, biological and genetic components that affect individual and population health. Genetic factors (Leroi 2005) and non-genetic factors such as, socioeconomic privileges and racial discrimination have all been proposed explanations for racial and ethnic health disparities (Krieger 2005). Growing multiracial populations with unique ancestry and social experiences provide opportunities for new areas of interdisciplinary research on racial and ethnic health disparities. Contact and interaction with multiracial populations contest other individuals' and social institutions' current construction of race (Johnson 1992).

There is very limited research that is focused on the attitudes and opinions of recently mixed populations and their understanding of race, ethnicity, ancestry and health (Snipp 2003; Sondik et al. 2000; Tashiro 2002). Condit (2004; 2005) and colleagues' study on the lay public's attitudes on race and genetics messages included several multiracial individuals but did not report their perspectives or concerns. Research on the layperson's perspective on genetics, race and health has shown that people have complex understandings of genetics research that warrants further exploration (Bates et al. 2005). Tashiro (2005) highlighted the need for qualitative research that transcends the "categorization of people into precise racial combinations and thoroughly explores the complexity of the lives and social locations" of mixed people. The leader of the International Human Genome Project, Francis Collins (2004), called for more "anthropological, sociological and psychological research into how individuals and cultures conceive and internalize concepts of race and ethnicity." Data from these types of studies can provide valuable information to clinicians and clinical researchers who frequently encounter multiracial and multicultural patients.

This study explored the views and experiences of individuals whose parents are from different racial backgrounds. The objective of the study was to learn about the participants' perceptions of their identity, their social and clinical experiences as multiracial individuals and their opinions on the debate regarding the importance of human genetic variation in understanding health disparities and use of race-based therapies. We investigated their attitudes towards the future of genomics and personalized medicine and the use of race as a heuristic in clinical decision making. We hope data from this study will challenge race scholars and other social and natural scientists to further investigate how human genetic variation research interacts with the social constructions of race.

## Methods

This qualitative research study utilized in-depth, semi-structured one-on-one interviews to gather information about racial and ethnic identity, ancestry, genetics and health care experiences of multiracial individuals. The study population was comprised of adults at least 21 years of age with one parent of African ancestry and the other parent of European ancestry. While there are numerous individuals who identify as multiracial, our participant pool was limited to individuals of African and European backgrounds. These individuals have a parent who identifies as a member of a racial group with well-documented health disparities, and another parent who identifies as a member of a majority racial group with typically better health outcomes. Only one participant from a family was eligible to participate in the study. A total of 22 interviews were conducted in two metropolitan areas: Washington, DC and Atlanta, GA. A pilot interview was performed in each location followed by 10 interviews, each lasting approximately one to two hours.

## Recruitment and Interviews

Several recruitment strategies were implemented to recruit participants for the study. Notice of the study was sent to national and local multiracial identity organizations in each geographic location via electronic mail. The research team also provided recruitment letters, detailing information about the study to colleagues and listserves for distribution. Lastly, a snowball sampling method was used to recruit additional people to participate in the study from individuals who had already been interviewed.

The interviews were held in Atlanta, GA and Bethesda, MD. A trained interviewer with a multiracial background concordant with the participants conducted the one-on-one interviews. The interviews were led in a semi-structured manner to allow for a natural flow of conversation. An interview guide provided the interviewer with a framework for discussion on the domains of identity, family ancestry, physician-patient interaction and understanding of genetics. Each interview was audio recorded and transcribed verbatim. Research protocol was reviewed and approved by the National Human Genome Research Institute's Institutional Review Board for Human Subjects Research.

## Data Analysis

Data analysis proceeded in several stages. First, a coding tree that depicted all codes and their definitions was created to guide data analysis and ensure that codes were appropriate and representative of important and salient ideas, themes and phrases in the transcripts. Second, two members of the research team used the created coding tree to code two selected transcripts independently. Third, to establish inter-coder reliability, they met to review their coding patterns and verify consistency. After coding differences were clarified and the coding tree was revised, the two research team members independently coded the 20 remaining transcripts using the finalized coding scheme. After subsequent meetings by the independent coders, all transcripts were reviewed and differences in coding patterns were reconciled to create a final dataset. Finally, this final dataset was reviewed to identify the most salient concerns, beliefs, and experience relating to the questions. NVivo 7 qualitative research software was used to support the coding and analyses of the data. Socio-demographic information was obtained from each of the participants at two points during the interview.

## Results

Our participant pool was comprised of relatively young individuals from educated backgrounds. The mean age of participants was 29 but ranged from 21 to 51. Of these participants, 82 percent were female and 42 percent had a master's or doctoral degree.

Consistent with interracial marriage patterns, 82 percent of the participants had white mothers and black fathers.

## Identity

Interviews began with questions about a participant's family history and personal identity. There were a variety of factors that affected how participants identified themselves. It is important to remain cognizant that our public categorizations have an impact on personal racial identity (Brunsma 2006). People may change how they report their race and ethnicity over time depending on age, marital status, parental race, geography or perceived benefit of reporting one way over another (Lee and Bean 2004; Roth 2005; Williams and Jackson 2000).

Consistent with other findings, this study found that participants' identity was influenced by a number of personal, social and contextual factors (Harris and Sim 2002). It was frequently noted that their personal identity was affected by their physical appearance and the racial labels that others placed upon them. A third of the participants identified as black usually in response to how they felt they were perceived by others.

Well, I consider myself black. Even though I'm multiracial, I consider myself black, because when people see me, that's what they see. So I figured to make things simple, I'm black. 208

Well, I mean I think most biracial people probably always straddled the, like, black identity even if they do generally call themselves mixed or biracial because most of the time you are still perceived as being black by other people. 102

Participants were also conscious of the past experiences of multiracial individuals in the United States with specific reference to the one-drop rule. While they recognized the opportunity to acknowledge both sides of their heritage they also understood that socially and historically they are grouped into the "black" race.

When I mark it generally, it's black. Growing up, my daddy kept telling me it's that one-drop theory – you're black. It doesn't matter if you're half white. They don't care. You're black. And it wasn't really in a negative way, but it was kind of like the way it is. 204

Some participants were very content with this modern hypo-decent while others thought it was important to identify as multiracial. Their diverse ancestry was a source of pride and they did not want to deny either side.

Racially? I always tell people I'm mixed. You know I don't really, I never say I'm one or the other. 106

A short pre-interview survey requested that participants report their race using standard OMB categories. At the end of the interview participants were given a second survey that allowed them to report their race using an open-ended question. In general, a third of the participants identified as black and 15 percent of all participants changed how they reported their race when allowed to write in a response.

## Health Care Interactions

Participants were asked how race and ethnicity information was collected in health care environments. While many of them understood that race could be a sensitive topic, they also admitted that personal and uncomfortable information was often discussed in health care settings. The interviewer asked them to remember how many times they had been directly questioned about their racial background or ancestry. Interestingly, the vast majority of participants reported that questions about race were included on in-take forms, but health care

providers rarely had conversations about their background or followed up on what was recorded on the forms.

Unless it was like the checkmarks that you just gave me that might be on, once again, I still put black and white on it, but I don't think I've ever had to, but it's definitely never come up in conversation. 201

Several of the participants also admitted that they identified themselves as black on medical forms and suggested that their health care provider had no knowledge of their European ancestry.

The people I usually see usually know my parents or have met them. So they know that I'm mixed. But I think on paperwork I'm black. 205

Interviewer: And so do you think that your health care provider knows about your European ancestry at all?

Participant: I don't think I put that on the form. No, probably not. 208

Participants were also asked if they thought health care providers assumed their race without asking them. Again, the majority of participants felt that their race was commonly assumed to be black, and they noted that this assumption was often transferred to their medical records.

But I don't feel like they have to ask me my race because they look at me and they automatically make a determination. 202

So my father being black and taking me to the doctor's office and everything, they would always assume that I was black. And I almost remember -- I do remember on at least one occasion when, I guess, when you go to the doctor's office and they bring somebody in first before the doctor gets there and asks you a series of questions, that when the doctor came back after they had left the room, my father noticed, I guess, that it was on the form, that it was bold, and that I was black. And he was, like, "No, that's not right. His mother's white." And they had to change it. And I just thought at that time I was, like, wow. 'Cause my dad's here and I'm here, they must think I'm black. And so generally whenever I go into a doctor's office, that's how I'm perceived. 103

Interviewer: And how many times do you think that they just assumed what your race is?

Participant: Oh, the majority of the time. 107

The consequences of race collection became apparent when the participants were then asked if they thought physicians and health care providers used their race when making decisions about their care. Some participants thought that race was completely irrelevant to health which may account for the lack of conversation about their racial background. Others thought that providers could offer more culturally appropriate care based on the patients' race (perceived or confirmed) and agreed that it should be considered when making health care decisions.

No, I don't think, not unless it came to, no I really don't think it would matter, like, for like, health-care wise, like what they would need to treat differently or what they would need to do. I don't think it would be that different if I was another race.-206

I would think that they have to sort of tailor things to the individual and that's, you know, part of, you know, sort of what's culturally appropriate for someone. I mean, people aren't going to adhere to things that contrast with their culture they're comfortable with or things of that nature. And that's sort of a real phenomenon, so I think it does, yeah. 108

Several of the participants thought that family health history, information that nearly all of them remembered being collected, was far more important and relevant to decisions about their care. They agreed that family health history was a more specific and accurate tool to guide health decisions. Race represented a complex and dynamic construct that did not possess the stability to inform medical decisions.

I would think they would use family health history more than they would race because I think – well, I guess it’s just coming from me. Family makes up what you are and it makes up everything about you. Race doesn’t tell everything about you. 104

Do you think they’re making decisions based on my race? I think that, well would hope that if they were they would be confirming my race before they, you know before they made those decisions. 106

## Race-Based Therapeutics

Conversations about the collection of race and use of race in health care decision-making led to more broad questions about race-based medicine. Participants were presented the BiDil example and asked to comment on drugs indicated for specific racial groups. While the reaction to race-based care was mildly accepted especially in reference to culturally competent practices, the development of race-based therapeutics provoked a largely negative response. Participants were suspicious of the science behind these types of drugs. They wanted to know exactly how the medication would benefit one race over another and struggled with the suggestion that they could take a pill developed for “black patients.” There was a general disconnect with the idea that drugs could treat one group better than another because in the participants’ experiences, they could be considered black or mixed in healthcare settings. It made them uncomfortable to think their personal identity decisions could influence how drugs are prescribed.

My next question is why is it only for black people? Is there something only in our heritage? And since I’m half white, would it only work half way for me? Things like that don’t necessarily sit well with me. 204

It seemed weird to me for several reasons. Once again, I just never heard of medicine working better for some than others. I mean, because although you know that there are some diseases that affect some people more than others, I still kind of operate under the assumption that we’re all the same on the inside. You know? 102

Participants also seemed concerned about the social implications of creating race-based therapeutics. They questioned if these drugs supported the concept of a biological or genetic basis to race. Participants thought that complexities surrounding race and identity made it impossible for drugs to treat groups of people based on race.

It’s a slippery slope, and it’s dangerous for people to try to treat by race because race, once again, is a social construct. There’s no biological basis. I mean there’s more genetic variation within a racial group than between, I mean, often times. 107

Yeah, just because of, I understand on a pure level, like even if you could resolve it, like scientifically, and say, “Yes, this helps this race more. It should be used for this race,” I don’t know how you deal with the social aspect of it, how people would actually interpret that and understand it. 109

Discussion about race-based therapeutics stirred new questions about identity and pushed participants to conceptualize how they connect race to genetics and health. It was often mentioned that many people in America have a mixed ancestry, and therefore invalidated the idea that race could be used as a heuristic for treatment decisions. Their personal experiences



had illustrated the inconsistencies of racial identity and they therefore concluded that race was not an appropriate tool to guide medical decisions.

I mean, I think especially in this country, as people are multi-racial, you know, we sort of, as a race of people, are dwelling on proportionality, that it sets up for major gaps. And I think, you know, one of the big concerns for physicians is that they, mean, beyond the limited time they have with somebody, they don't get all the information. And part of it is because they don't ask the right questions. 108

I mean, what specifically are they targeting that only makes it available, or good or useful for black people? Then, as scientists, they need to specifically identify what makes you black. 205

Yeah, so when someone says, self-, like, identified as African American, there is so much variation within that group. You have someone from the Caribbean and then, you know, someone who's like from West Africa within this category, and there's a variety of different types of genetic components that make up an individual. So, I don't know if people really have accounted for different side effects or how people respond to it. 107

## Health Disparities

Some participants liked the idea of drugs made for specific minority groups because of the history of health disparities in this country. They thought that drugs such as BiDil were a necessary response to the higher prevalence of diseases in minority populations such as African Americans. These participants thought that race provided a useful link to genetics that could help researchers identify treatment options for different groups.

I think they need to do more determination for the African American groups and the Latino groups and the other minority groups. The reason why is because the majority of the medications that they do test on, they've probably done more tests on Caucasian medication or Caucasian descent than anybody else. So they've already got medications that they've decided or worked out that satisfy that particular genetic make up or ancestral make-up. They need to do more on the African American side because hypertension is killing more African Americans than it is whites. 202

Others commented on the political and social power of the race construct. They mentioned that our current research and medical systems reinforce the use of race.

Well, for one, I mean, if you're not educated then you may not think those things in those terms. So you may think that there are biological or genetic differences between races. Or if you're in a position of power and may have certain political agendas then you may push those factors, such as genetics or something, to very much differentiate the races. 110

Discussion of race and medicine also prompted numerous comments about social and environmental factors that affect health. Participants acknowledged health disparities as a problem that should be addressed, but contested the idea of improving these disparities through race-based therapeutics. They thought that social factors such as diet, education, income or discrimination were far more pertinent contributors to health disparities. These participants thought that genetics played a minor role in differences in health outcomes by race.

But I think it's ridiculous really. I mean I don't think, I feel like any disease or health issue that's gonna come predominately to one race you have to look at the social factors that may be contributing to this. I don't think it has anything to do with genetics at all. 110

But as far as society goes it's like if they see an overweight black woman, she probably has high blood pressure and she's out of shape and blah, blah, blah, blah, blah. And I just think that's just because of the foods she eats. She must eat a lot of fried chicken. It's stuff like that that I disagree with. That it's not so much about your physical characteristics as far ethnicity and genetics. It's more about how society views you and the problems that you're going to get because of the way that you look and not so much about your actual DNA. 201

I just feel like class and just environment in general really informs how, your well-being, and definitely your social experiences would impact your well-being. And so that I see kind of a more definitive connection than the racial component if that makes sense. But again it is not to say that there isn't a racial component there. But I just don't know if my mind is willing to embrace that wholeheartedly. 203

## Race, Ancestry and Genetics

When participants were questioned about how they connect race, ancestry and genetics, many of them could construct a correlation among the concepts. However, ancestry was seen to be more closely related to genetics than race and therefore served as a more accurate reflection of their genetic make-up. Race was typically connected to genetics through physical characteristics that serve as important identifiers in racial categorizations. Several participants thought there may be some connection between race and genetics, but they struggled to decipher the strength of the relationship.

How would I describe the relationship between race, ancestry and genetics? I think they're all linked. I think that, I mean, ancestry and genetics are very closely linked obviously, because, you know, it's from where the genetics comes from. I think they're more closely linked than they are to race. But I think they all sort of envelop each other. 108

I think ancestry has a lot to do with your genetic make up. But I also think it has more to do – I think ancestry has more to do with your genetic make up than your race does. Because I just think of when I think about what makes up me, I think of everybody behind me and everybody that's come before me and whatever problems they have had whether they're white or whether they're black. Because I know that's what's ultimately who I am and what kind of medical issues I may have. 104

I mean, when I think of genetics, obviously I'm thinking of your DNA and, you know, you get 23 from Mom and 23 from Dad and that makes you.

So part of that is one of the things that you inherit is the color of your skin, which is part of what it means to have racial identity. So I think there's some link between genetics and race in how we frame what we mean by race. 108

I think that there is, but I don't know to what degree that it – it's hard to separate out the environmental factors from the genetic factors, and so, because you can't do that, it's hard to tell, like, you know, whether genetics is like 90 percent, and environmental is 10, or whether environmental is 10, and – I mean 90, and genetics is 10. So I think that there are connections. I just don't know how strong connections they are. 209

## Vision of Race, Health and Identity in the Genome Era

After participants were questioned about their personal identity, health care interactions, conceptions of race and race-based therapeutics, they were asked how they envision genetics affecting the use of race as an indicator of genetic difference in the future. There was a wide range of responses; some predicted an increased use of race while others thought genetics might phase out the use of racial categories. Participants' responses were founded on how closely

they linked race and genetics. However, many of them anticipated that technological advances and personalized medicine will focus on an individual's genetic make-up rather than his or her racial background.

I think it's going to go more towards ancestry and less towards race. Because I think, it's like I said, you have to be treated as an individual. You can't be treated as a race. I just think that's a big message I want to get across. 103

I don't know, I mean I think it's really unrealistic to expect that every human being that walks in a doctor's office would have a genetically tailored therapy. It's just too expensive and would take too much time. I think that race based genetics has a role but it's – be it limited – in medicine. 108

Well, I mean I guess I see race already impacting healthcare. And so if anything I think it will just sort of intensify the boundaries and sort of cement differences that may or may not be real. And so I think it may be used as an excuse to provide care differently to different groups or different populations. 203

I could say that since it's [genetics] more science based, I could say that it would phase out the use of that question. Because if we see that I identify myself as black, but half of me or half of my genetics is white, me checking black will give you a skewed representation of my medical history or my family history. So I could see that I would say that the race question could be phased out to something else more specific targeting genetics. 204

I really believe that – and perhaps the genetic piece will show us more of how – we're alike and how we're different from each other. Because they say that, like, 99 percent of the human genome is the same. And then there's just, like, this little bit that's different. And so I really hope that the more that that is understood, the better we can bring people together and say that, "I'm gonna treat you from a personal level as opposed to a racial level." And that that will actually be more effective. 207

Throughout the interviews, participants offered their thoughts for the future direction of research and medical care. Their comments generally addressed the importance of race in this country and simultaneously suggested the need to control the future use of racial identifiers. As our population continues to diversify, the issues that these multiracial individuals voiced will be relevant to all people.

But I don't think it's a good idea to just, you know, group people into races. I think that doctors need to get the memo that they need to test the person for a specific mutation. 209

I think that we have a unique perspective. And maybe since you brought it to my attention, but I think because we'd be caught in the crosshairs of a race-based medical system. 'Cause what would they do with us? You know what I'm saying? That that's how we can see the weaknesses in that system. It all – we can see the shortcomings... And so in all kinds of ways, we would put a challenge to trying to have a race-based health system. 207

## Discussion and Conclusions

The voices of the study participants illustrate diverse perspectives on topics of identity, race, genetics and health. While opinions about personal racial identity were varied, there was a general consensus that individual identity cannot be captured with the limited constructs of race and ethnicity and should therefore not be interpreted as such. Participants' healthcare experiences were also different, but the overwhelming majority noted that they had never been directly asked about their ancestral background in a health care setting. This trend is juxtaposed

to the fact that several participants thought that race was used by their provider when making clinical decisions. Although some discontinuity existed within opinions about race-based care, most of the participants objected to the development of race-based therapeutics. Many cited social and environmental factors as sources of health disparities and disliked the idea of creating drugs that would treat social groups of people. The majority of participants struggled to articulate their understanding of race, genetics and health. Most of them could draw strong connections between ancestry and genetics, but admitted weaker links existed between race and genetics. Many participants appreciated the potential for genetics to improve healthcare, but hoped that improved technology would allow health providers to assess them individually and not as part of a racial group.

The results of this study are limited to the sample of 22 individuals from two geographic locations. Our participant pool lacked age, gender and education diversity, and the majority of our participants were healthy individuals who often experienced minimal interaction with the health care system. Their voices cannot be extrapolated to experiences of all biracial people. However, to our knowledge, this is the first qualitative study of a multiracial population to investigate their attitudes regarding race, genetics and health. More empirical data is needed on the lay public's understanding of race and its relationship to human genetic variation. Untangling the web of identity, ancestry and genetics requires that more attention be paid to the diversity that exists not only within the racial spectrum of humankind, but also within the culture, behavior and privileges that define who we are.

Racial and ethnic health disparities are strongly associated with social determinants and individual behaviors (Shavers and Shavers 2006; Williams and Jackson 2005). Genetics is one of a multitude factors that may help explain differences in the incidence of certain diseases within racial groups. We must, however, be cautious not to over exaggerate genetics in the study of health disparities (Sankar et al. 2004). Despite the blurry correlation between race, genetics and ancestral geographic backgrounds, researchers and clinicians use race as a proxy for genetic disease risk (Kittles and Weiss 2003; Royal and Dunston 2004). Evaluating the genetic contribution to disease will also demand that more is understood about gene-gene and gene-environment interactions (Manolio and Collins 2007; Sankar et al. 2004).

Genomics research is quickly moving health services towards personalized medicine where patients' genetic profiles will be used in combination with behavioral and environmental factors when determining the best clinical treatment. However, the technology and financial feasibility for this type of care is not available for most people today. Until each individual has his or her genome sequenced and we understand it, we will remain dependent on group heuristics. Social and natural scientists must conduct interdisciplinary research to bridge the chasm that currently exists in order to move forward our understanding of race and the social and genetic basis of disease. Developing new analytical frameworks will require the expertise of social science researchers who understand the molecular biology of genetics and geneticists that understand the social theories of race and identity.

We cannot discount or exaggerate the correlations between genetics and social racial groups. Self-identified race can correlate with human genetic variation. Race, as a social construct, matters in the lives of people. There are dangers in having a society that doesn't recognize race and racism. Color-blindness can promote continued racial inequalities and create an illusion that race is no longer an issue (Gallagher 2003). This can be especially detrimental for individual health outcomes (Williams and Jackson 2000).

What can we learn from the voices of these multiracial individuals? Race, identity and genetics are complex constructs that should encourage us to continually and critically evaluate their significance and appropriate applications to healthcare and biomedical research. The

recognition of individuals of diverse ancestry challenges our conception of race and its connection to genetic group differences. This is more clearly illustrated in the experiences of people with a multiracial background, but is true for people of all backgrounds.

I think in some ways having a parent who's white and a parent who's black, I understand the sort of surface genome type. That because of those two – that union, I have the skin color I have and the nose, I have the lips, and I have this of my mother's and this of my father's. I mean, I get that, but I think I also realize that race – because I have parents of different races, that race is probably so much more than just genetics. I mean, that realization is probably more had by me than maybe someone who has parents of the same race. 108

Researchers and health professionals need to move beyond using race as “the best proxy” for genetic variation. Our society is diverse in culture, diet, language, faith and other characteristics outside of race. Improving health will demand that individuals are evaluated within the unique circumstances in which they live. Their health is affected by many factors including their individual genome as well as their education, household wealth, social status, social race and experiences of racism. The perspectives of multiracial individuals charge researchers to address the challenges that we face within our current racial classification system and biomedical research. Their voices demand a paradigm shift in the way we define and use race in the genomic era.

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Table 1

Participants' Demographic Characteristics

	TOTAL (N = 22)		DC (N = 11)		Atlanta (N = 11)	
Age	N	(%)	N	(%)	N	(%)
21-23	8	36	4	36	4	36
24-30	8	36	5	45	3	27
31-51	6	27	2	18	4	36
<b>Gender</b>						
Male	4	18	4	36	0	0
Female	18	82	7	64	11	100
<b>Education</b>						
High School	2	9	1	9	1	9
Undergraduate	11	50	4	36	7	64
Graduate	8	36	5	45	3	27
Doctoral	1	5	1	9	0	0
<b>Marital Status</b>						
Single	16	73	9	82	7	64
Married	6	27	2	18	4	36
<b>Income</b>						
Unemployed/Student	4	18	3	27	1	9
< \$15,000	1	5	0	0	1	9
\$15,000 - \$24,999	2	9	0	0	2	18
\$25,000 - \$49,999	7	32	4	36	3	27
\$50,000 - \$74,999	5	23	4	36	1	9
> \$75,000	3	14	0	0	3	27
<b>Insurance</b>						
Uninsured	4	18	2	18	2	18
Commercial	14	64	8	73	6	55
Medicare	1	5	1	9	0	0
Other	3	14	0	0	3	27
<b>Primary Care Provider's Race</b>						
No PCP	4	18	2	18	2	18
Asian	3	14	2	18	1	9
Black/African Am.	4	18	2	18	2	18
White	9	41	4	36	5	45
Other	1	5	0	0	1	5
Don't know	1	5	1	9	1	5
<b>Primary Care Provider Trust</b>						
Very much	10	45	5	45	5	45
Somewhat	12	55	6	55	6	55
Not very much	0	0	0	0	0	0
Not at all	0	0	0	0	0	0
<b>Doctor visits in the past year</b>						
0-2	7	32	3	27	4	36
3-6	13	59	7	64	6	55
7-10	2	9	1	9	1	9

**Table 2**

Participants' Self-Reported Race, Pre- and Post-interview

Pre-Interview (OMB Categories)	Total		Post-Interview (Open-ended)			
	n	%	Mixed/multi/bi-racial		Black/African-American	
			n	%	n	%
Black/African Am	7	32	2	9	5	23
Black/White	11	50	10	45	1	5
Black/White/Native American	2	9	2	9	0	0
Other	2	9	2	9	0	0
<b>Total</b>	<b>22</b>	<b>100</b>	<b>16</b>	<b>72</b>	<b>6</b>	<b>28</b>