Published in final edited form as:

Nat Med. 2008 July ; 14(7): 704–705. doi:10.1038/nm0708-704.

Rotimi C (2008) Straight talk with Charles Rotimi. Interview by Charlotte Schubert

What will you be studying at the new center?

The way I see it, the mission is really to see how we can apply genomic tools to understand disease at basic scientific levels and to see how we can use that understanding to shed some light on the issue of health disparity. When you look at two groups, whether in terms of ethnicity, gender or socioeconomics, we ask the question, “Why do you see more disease in one group compared to the other? ”; that’s health disparity.

We focus on studying African-Americans and other African populations, and we do that in the context of what I call the triangular relationship between obesity, hypertension and diabetes. African-Americans have a much higher rate of obesity, and of course that also drives the rate of diabetes, heart disease and other diseases like stroke and hypertension. So right now we have major international projects in these three areas, and we plan to expand our studies to other ethnic groups in the future. We have a budget of \$1.7 million annually and will employ about 11 scientists when fully staffed.

What are some of the challenges of teasing out the influence of genetics from other factors that can lead to health disparities?

I will be the first to admit that for us to truly understand health disparity, we will need to understand the core issues—such as the poor social structures—that drive people toward poor health. When we develop models to test whether a particular gene is going to contribute disproportionately to disease risk within a certain group, we must make sure that we also capture those things in the environment that may be as or even more important than genetic factors.

What kind of information do you collect?

We collect demographic and migrational information from our study participants, including Africans and African-Americans. This information enables us to develop models to test how ‘old’ genes from Africa work in new environments such as the United States to increase our risk for diseases or to protect us from getting certain diseases. We also collect information on diet and data relating to education and income. But I would say that most of the very critical factors in term of health disparity are things to do with social structure, the communities where people live, and social factors such as racism. These are extremely difficult factors for a setup like ours to fully capture. But there are other groups we intend to collaborate with who can help address such questions.

You once said, “The only way we can get to the meaning of human genetic variation is by removing racial classification in biomedical research.” Can you please explain?

If we continue to label ourselves with racial terms, then we risk imposing racial perspective, consciously or otherwise, on the genome that does not necessarily hold.

Do you mean that people might not be treated appropriately because the doctor or researcher is biased?

Absolutely. There are examples where doctors and scientists make decisions based on phenotypic expression, and it results in very bad error, where people's lives are endangered. For instance, experiences where somebody is supposed to have sickle-cell disease but because of their phenotype—such as having fair skin — they were not diagnosed. Sickle [cell] is not a 'black' or 'African' disease. It is a disease found in human populations that have had to survive the ravages of malaria. This is why it is found in the Middle East and Greece but not in South Africa.

It seems kind of odd that you have to consider people in racial categories to consider health disparities, since, as you say, in the ideal world those categories might not exist

They would exist! But they would exist for the reason of social grouping. [G]enetically they are not that informative. For example, it is very difficult, if not impossible, to know how a person who self-identifies as African-American will respond to a particular drug based on that group label. My argument is not to eliminate groups; my argument is to define those groups in a way that is consistent with what the characteristics of that group truly are. Remove your stereotype and let the data inform you.

If there is not such a thing, genetically, as African-American, then what does it mean to belong to this group?

I never look at African-Americans from a genetic point of view as a uniform group. The only definition of African-American that I have that I can consistently defend is that these are descendents of the inhumane slave trade. That's it. And that's a social definition. At the genetic level, I think all bets are off, and the evidence that we continue to acquire shows that we are not studying a uniform group. African-Americans have ancestry from Africa, Europe, North America and Asia, among others. The combinations of these ancestries vary from person to person and from family to family.

You have criticized the FDA's decision to license the heart drug BiDil exclusively to African-Americans

First, and most importantly there was no genetics in the study that led to its approval in African-Americans. The authors only considered whether people who self-identified as African-American responded to the drug. Second, I thought that in this instance the FDA was sending the wrong message to the community. For a very long time in human existence, most of the drugs that were used on all human populations were mostly developed and tested on white European males. Now what kind of a statement does a nation like the United States make to its people when it says, "We tested this drug on African-Americans and not on other members of society and it is therefore not good enough to treat members of other ethnic groups?" Clearly, there is a genetic or environmental reason why some people respond to the drug—we need to find out what that is. Some European-Americans, for instance, are likely to benefit from BiDil. To label it as an African-American or even a black drug, to me, is really just doing an otherwise effective drug a disservice.

Many researchers have complained of difficulties in enrolling minorities in clinical trials. Do you come across that problem in your research?

No, we do not. I always maintain that if you approach people well—if you approach people correctly, with the right sentiments, and if you indicate to them why it is important to participate in studies, people respond. We have now close to 3,000 African-American participants in our studies of complex diseases.

What have you learned that other people could apply if they want more minorities in their trials?

Employ members of that community on your staff. Go to churches, make presentations about the study and interact with community leaders who can advise you. One of the things I say to my staff is, you are going to run into the issue of people saying things like “Tuskegee experiments,” and I say, “Do not run away from it.” You have to confront it. You have to explain to people and tell people that because of that experience, we have to be extremely critical, but that should not prevent them from participating.

One of your missions is to increase training opportunities at NIH for minority scientists and scientists from developing nations. What are some of the barriers to minority participation in science?

There is this issue of exposure, and then there is the issue of good mentorship. We can provide mentorship, and we can provide exposure. For instance, our researchers have developed programs that [educate] high-school students, and we have invited them to spend time in our lab when I was at Howard University [where he previously headed the school’s National Human Genome Center]. I intend to continue these types of programs [....] at NIH.

Some people have expressed concern that by studying genetics, you may be drawing attention to the least important factors contributing to health disparities. What do you say to your critics?

There are people who are extremely sensitive to hearing ‘health disparity’ and ‘genomics’ in the same sentence. It makes some people very uncomfortable, because people feel very strongly that you may take away from the most serious issues causing health disparities, such as social factors. What I tell them is that genomics is just one piece of the puzzle. It’s a small piece of the puzzle. But I think given how genetics underlies our most important health issues, we need to study it. Human diversity at both the genetic and social levels is not an illusion: We need to embrace it; we need to understand it, and, more importantly, we need to interpret it correctly.

Biography

Straight talk with...Charles Rotimi

When Charles Rotimi moved from his native Nigeria in January 1982 to study public health at the University of Mississippi, he came face to face with a startling problem. In his coursework and daily life, he grappled with the question of why some US groups—in particular African-Americans—suffered overall poorer health than others, such as those of European ancestry. He's now poised to help answer that question as the head of the new Intramural Center for Genomics and Health Disparities, launched in March in Bethesda, Maryland, as part of the US National Institutes of Health (NIH). **Charlotte Schubert** talked with Rotimi about how perceptions of race influence research and medicine—and how genetics can be used to help break down stereotypes.