

*Perspectives of Racial and Ethnic Groups
about Participation in Genomic Research and
Data Sharing*

Vence L. Bonham, J.D.

*Associate Investigator, Social and Behavioral Research Branch
Chief, Educational and Community Involvement Branch*

Community Genetics Forum



genome.gov
National Human Genome Research Institute
National Institutes of Health

Google™ Search

SEARCH

Research Funding

Research at NHGRI

Health

Education

Issues in Genetics

Newsroom

Careers & Training

About

For You

[Home](#) > [About](#) > [Organizational Structure](#) > [About the Office of the Director](#) > [Office of Policy, Communications and Education](#) > [Education and Community Involvement Branch](#) > [Community Genetics Forum](#)

Education and Community Involvement Branch

Community Genetics Forum

Family History Demonstration Projects

Community Genetics Forum

Share Print

The **Community Genetics Forum** is held annually and is sponsored by the [Education and Community Involvement Branch](#) (ECIB) at the National Human Genome Research Institute (NHGRI). The overall goal of each forum is to develop models of community engagement or to enhance existing models (i.e. previous forums or other community engagement projects) of public engagement and public participation within the geographic communities targeted for the project. It is also a goal to develop and evaluate genetics education and public participation supportive materials for the community that can be adapted by others wishing to plan, develop, implement and evaluate a public genetics forum with community engagement in their respective communities.



Each year, ECIB selects a different region of the country to host the forum. In May 2005, the [University of Washington](#) was selected to host the first forum, representing the Northwest region of the United States. In 2006, ECIB selected the Southeast region of the country to host the forum (Department of Health and Human Services (DHHS) regions IV and VI). The University of North Carolina was selected.

For the 2007 forum, ECIB selected the Midwest region of the country as host ([DHHS regions V and VII](#) [hhs.gov]). The University of Michigan was selected to host the 3rd annual Community Genetics Forum. Five concurrent Forums were held across the Midwest region, in Michigan, Minnesota, Iowa, Missouri, and Illinois. The five Forums were held on the same day and were connected to each other via video conferencing. For more information, please visit www.genocommunity.org

See Also:

[Community Genetics Forum 2005](#)

[Community Genetics Forum 2006](#)

On Other Sites:

[Community Genetics Forum 2007](#)

GenoCommunity, hosted by the University of Michigan

Keywords: [what's this?](#)

> [Community Genetics Forum](#)

Website :<http://www.genome.gov/19518473>

Racial and Ethnic Groups Perceptions of *Risk* of Participation in Genetic and Genomic Research

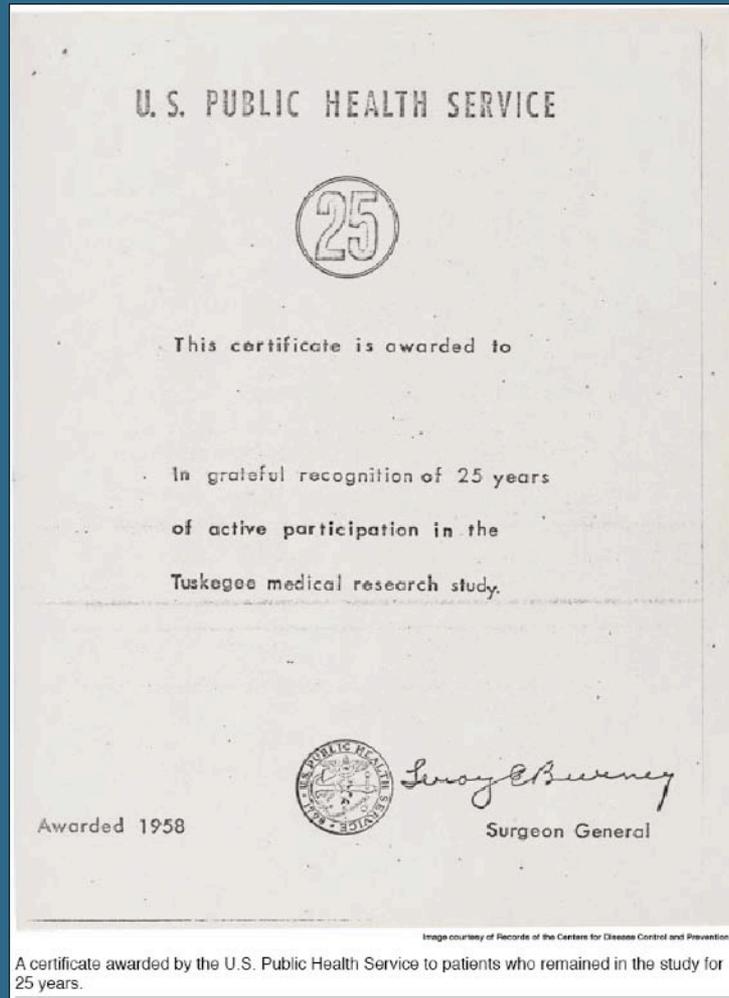
- Research Ethics Violations
- Unequal Treatment in the Health Care System
- Invasion of Privacy
- Stereotyping



Historical Basis for Racial and Ethnic Group Concerns



U.S. Public Health Services Syphilis Study “Tuskegee Syphilis Study”



Voices of the Community

Genetic Research

“I’m not trusting anything the government does that’s supposed to be helpful to black folks. I just don’t trust anything they do, and I would advise anybody that takes any advice from me... to not be involved [with] anything to do with the government until we know absolutely sure what they are going to do with it. I don’t want to have my information in any data bank. I am just very distrustful. We need to remember what they did to our men in Tuskegee.”

The U.S. Public Health Service STD Inoculation Study of 1946-1948

“This case of unethical human subjects research represents an appalling example from a dark chapter in the history of medicine.”

Francis S. Collins, October 1, 2010



Voices of the Community

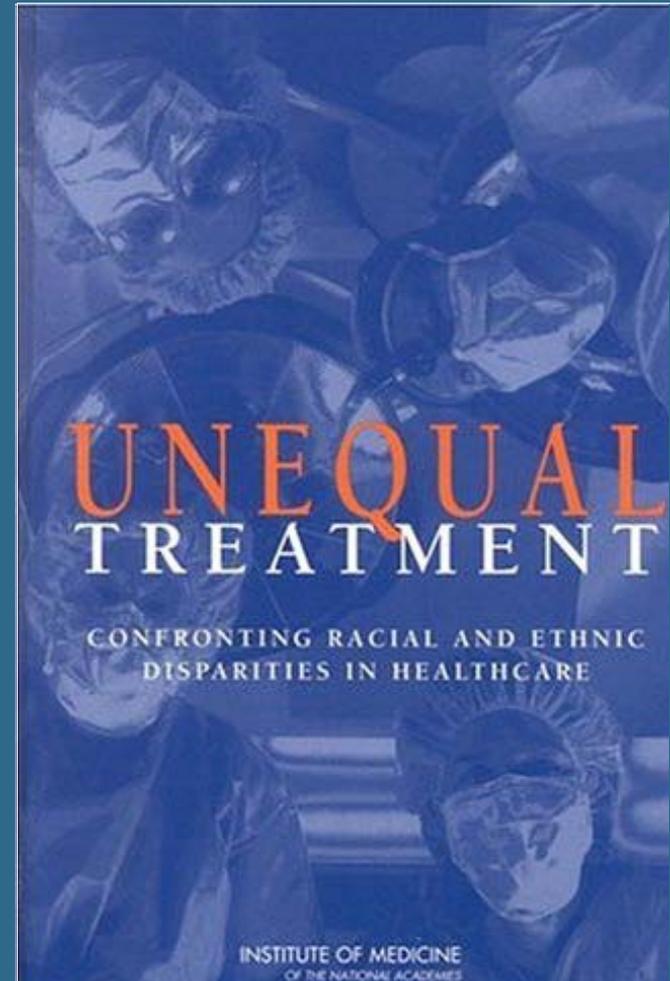
Genetic Research

“Historically it has always been the lowest person in society that gets tested. We’ve got to be wary as to who’s going to be the guinea pigs in this deal, it’s probably going to be us.”

History of Unequal Treatment

- “Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels...”

Unequal Treatment Confronting Racial and Ethnic Disparities in Healthcare, IOM, 2003



Willingness To Share Data



Table 2. Results of Multiple Logistic Regressions Examining Demographic Differences in Willingness to Share Data

	"I Would Allow These Researchers to Use My Samples and Information for Research."						"If I Could Not Be Identified, I Would Be Willing to Have My Information and Research Results Available on the Internet to Anyone."	
	Academic or Medical Researchers in the United States		Government-Funded Researchers		Pharmaceutical-Company Researchers		Agree^b	p Value
	Agree^a	p Value	Agree^a	p Value	Agree^a	p Value		
Gender								
Men	92%	0.23	81%	0.39	75%	0.95	53%	0.01
Women	91%		78%		73%		45%	
Household Income								
\$0–24,999	89%	0.004	77%	0.02	72%	0.47	49%	0.91
\$25,000–49,999	90%		76%		75%		47%	
\$50,000–74,999	94%		80%		75%		48%	
\$75,000+	95%		88%		77%		54%	
Education								
Bachelor's degree or higher	95%	0.01	87%	0.0004	74%	0.40	53%	0.39
No bachelor's degree	90%		77%		75%		48%	
Race or Ethnic Group								
Black, non-Hispanic	85%	0.004	71%	0.06	71%	0.07	49%	0.13
Hispanic	89%	0.47	78%	0.48	69%	0.04	46%	0.33
White, non-Hispanic	93%	reference	81%	reference	76%	reference	50%	reference

All findings are adjusted for general concern about medical privacy and for concern about protecting privacy in the study. All p values are based on results of multiple logistic regressions containing all covariates in the table, as well as age, which was entered into the models as a continuous variable.

^a Percentage of respondents who agree with the statement "I would allow these researchers to use my samples and information for research."

^b Percentage of respondents who agree with the statement "If I could not be identified, I would be willing to have my information and research results available on the internet to anyone."

Table 2. Results of Multiple Logistic Regressions Examining Demographic Differences in Willingness to Share Data

	"I Would Allow These Researchers to Use My Samples and Information for Research."						"If I Could Not Be Identified, I Would Be Willing to Have My Information and Research Results Available on the Internet to Anyone."	
	Academic or Medical Researchers in the United States		Government-Funded Researchers		Pharmaceutical-Company Researchers		Agree^b	p Value
	Agree^a	p Value	Agree^a	p Value	Agree^a	p Value		
Race or Ethnic Group								
Black, non-Hispanic	85%	0.004	71%	0.06	71%	0.07	49%	0.13
Hispanic	89%	0.47	78%	0.48	69%	0.04	46%	0.33
White, non-Hispanic	93%	reference	81%	reference	76%	reference	50%	reference

Source: Kaufman, DJ, Murphy-Bollinger, J, Scott, J, and Hudson, KL. *Public Opinion about the Importance of Privacy in Biobank Research*. The American Journal of Human Genetics 85, 643-654. November 13, 2009.

Invasion of Privacy

“Finally, 37% of respondents said that they would be afraid that the information collected by the study could be used against them. Black non-Hispanics and participants under the age of 60 were significantly more likely to share this feeling.”

Racial and Ethnic Groups Perceptions of *Benefits* of Participation in Genetic and Genomic Research

- Community Benefit
- To Understand Diseases that Burden their Communities
- To Use Genomics To Improve Health of their Communities



Community Benefit

“At a very broad level, everyone should benefit from genetic technology, especially those who have a specific need for this type of technology. I would hope the benefits are made available to all human kind and not just for the benefit of a specific population. It should benefit people irrespective of gender, social economic status, political affiliation, etc.”

The Moral Contract Between the Researcher and Participant



NATIONAL HUMAN GENOME RESEARCH INSTITUTE *Division of Intramural Research*



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES | NATIONAL INSTITUTES OF HEALTH | genome.gov/DIR