Successful Engagement of Minorities in Research:
A Building Trust Between Minorities and Researchers To Achieve Health Equity

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Architects of Community Engaged Research

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UMD Awarded $5.9M Grant for Health Equity Research

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College Park, Md. – African Americans in Maryland are three times more likely to die in infancy, twice as likely to die from diabetes, and much less likely to get flu vaccines than whites. The University of Maryland Center for Health Equity (M-CHE) is driving new efforts to eliminate such disparities—in the state and beyond—through a $5.9 million grant from the National Institutes of Health (NIH).

The new grant, awarded by the National Institute on Minority Health and Health Disparities (NIMHD), enables the M-CHE to conduct interventions designed to reduce racial and ethnic disparities in rates of diabetes, asthma, hypertension, infant mortality, obesity and vaccine preventable diseases. Based in the university’s School of Public Health, the M-CHE is leading multidisciplinary collaborative teams focused on understanding the root causes of racial and ethnic health disparities, designing innovative solutions that promote health equity and creating best practice models that could be used in communities across the country.
Building Trust for Engagement of Minorities in Human Subjects Research: Is the Glass Half Full, Half Empty, or the Wrong Size?

“An optimist will tell you the glass is half-full; the pessimist, half-empty; and the engineer will tell you the glass is twice the size it needs to be.”

—Oscar Wilde

In 1972, the longest running nontherapeutic research study ever conducted by our Public Health Service ended. The Tuskegee Study of Untreated Syphilis in the Negro Male (1932–1972) enrolled 399 poor, African American men with syphilis, watched as their syphilitic disease progressed, misled them, and denied them treatment. As one survivor said when President Bill Clinton apologized for the study:

We were treated unfairly and to some extent like guinea pigs. We were not pigs…. We were all

Tabatha Holley, aged 19 years, of Dawson, GA, looks at the sign she just made before joining a march in protest the day after George Zimmerman was found not guilty in the 2012 shooting death of unarmed African American teenager Trayvon Martin.

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First Look - Peer-reviewed, copy-edited articles published ahead of print
Current Issue - December 2013: Ethical Research and Minorities

External funding support for this issue was provided by grant # NIH-NIMHD RC2MD004766 to the Center for Health Equity, School of Public Health, University of Maryland (see http://www.healthequity.umd.edu).
THE OPPORTUNITY

Photo Credit: Sandra Quinn
AFFORDABLE CARE ACT of 2010
Maryland Health Improvement & Disparities Reduction Act of 2012

Signed into Law by Governor Martin O’Malley on April 10, 2012.
THE CHALLENGE

Photo Credit: Sandra Quinn
The Social Context of Health Disparities

The ultimate aim is to uncover social, cultural and environmental factors beyond the biomedical model and address a broad range of issues. This approach includes, but not limited to, breaking the cycle of poverty, increasing access to quality health care, eliminating environmental hazards in homes and neighborhoods, and the implementation of effective prevention programs tailored to specific community needs.
Because of historic inequalities and racism in the health care system, many African Americans may delay seeking health care. Beliefs about health and illness also influence community response to health communication messages designed to promote health and prevent disease.
History Matters
U.S. Public Health Service Syphilis Study done at Tuskegee (1932-1972)

A doctor draws blood from one of the Tuskegee test subjects

The Tuskegee Syphilis Study, described as arguably the most infamous biomedical research study in U.S. History
Cultural Memory
Health Disparities and Health Equity

According to *Healthy People 2020*

- A **health disparity** is “...a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage.”
- In contrast, **health equity** is “...the attainment of the highest level of health for all people.”
AIDS Cases Among Adults and Adolescents by Race/Ethnicity

Last Modified: April 28, 2011
Content Source: Divisions of HIV/AIDS Prevention
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Disparities in Breast Cancer Incidence & Mortality

Female Breast Cancer Incidence Rates by Race

Female Breast Cancer Mortality by Race and Ethnicity in US, 1999-2007

Source: Centers for Disease Control and Prevention
If You are Black:
Breast Cancer First Diagnosis at Stage 3 or 4

“Black women often arrive at the hospital with cancers so advanced, they rival the late-stage disease that doctors see among women in developing nations... 20% of African-American women with breast cancer did not learn of their disease until it had advanced to Stage 3 or 4. By comparison, only 11 percent of white women learn at late stages” (NYT 12-20-13).
Tackling a Racial Gap in Breast Cancer Survival

New York Times 12-20-13
THE FRAMEWORK

Photo Credit: Sandra Quinn
First Generation  Document the existence of health disparities

Second Generation  Explain reasons for health disparities

Third Generation  Provide solutions for eliminating health disparities

Toward a Fourth Generation of Disparities Research to Achieve Health Equity

Stephen B. Thomas,¹,² Sandra Crouse Quinn,¹,³ James Butler,¹,⁴ Craig S. Fryer,¹,⁴ and Mary A. Garza¹,⁴

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INNOVATIVE METHODS

Photo Credit: Sandra Quinn
Common Community Engagement Strategies

1. Hire people from the target population
2. Include minority investigators and staff on the research team
3. Develop a community advisory board
4. Sustain community partnerships once research and funding have ended

Harris et al., 2001; Horowitz et al., 2009
2001 FEDERAL DHHS

TAKE A LOVED ONE TO THE DOCTOR DAY

4th GENERATION APPROACH:

TAKE A HEALTH PROFESSIONAL TO THE PEOPLE
THE HEALTHY BLACK FAMILY PROJECT
(2004-2012)

A Community-Based Demonstration Project
Designed for Health Promotion and Disease Prevention

NIH-NIMHD PG60MD000207
HEALTHY BLACK FAMILY PROGRAM ACTIVITIES

Physical Activity
Nutrition Education & Guidance
Stress Management
Smoking Cessation
Family Health History
Self-Management of Chronic Disease
Referral to Medical Home

Health Advocates In-Research and Research (H.A.I.R.)
Network of Black Barbershops & Beauty Salons
DANGER AND OPPORTUNITY

Photo Credit: Sandra Quinn
The danger is to assume that:

1. racism is not relevant in the scientific pursuit of solutions for the elimination of health disparities;

2. that some populations will always suffer premature illness and death by virtue of their culture bound lifestyle choices; and thus,

3. that the elimination of disparities is impossible and health equity unachievable in a free market society.

The opportunity is to recognize health disparities as an issue of justice because specific groups were subjected to systematic racial discrimination and denied the basic benefits of society, a violation of the social contract.

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