

Project CONNECT: The Bridge to Healthy Communities Through Research

Melissa Green, MPH-Project Coordinator

Carolina-Shaw Partnership for the Elimination of Health Disparities

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Why Worry About Minority Inclusion in Clinical Research

- Clinical research is the basis of advances in all areas of medicine
- Community-Academic relationships are essential to shaping research agendas that are responsive to community needs

A Disturbing Historical Perspective

- Medical and surgical experimentation on slaves
- Public Health Service Syphilis Experiment at Tuskegee
- Robbery of Black graves for cadavers used in medical education
- Fear of hospitalization

How Did We Arrive at Required Minority Inclusion in Research?

- Very public reports of ethical misconduct raised concerns about vulnerability in research
 - Nuremberg Trials
 - Willowbrook
 - Jewish Chronic Disease Hospital
 - Tuskegee
- Research guidelines had reinforced the need to protect groups considered vulnerable by physical, mental or social and economic circumstances

How Did We Arrive at Required Minority Inclusion in Research?

- Shift from clinical research being considered a risky burden to a prized benefit from which no one should be excluded
- Realization that some groups had been intentionally excluded from research
 - Leading to research findings that applied only to a small segment of the US
 - Research questions may not be relevant to the needs of some communities
- For these reasons researchers are now required to show how they will engage minority communities

Factors Contributing to Minority Under Representation

- Limited understanding of research
- Inadequate access to healthcare
- Provider beliefs and biases about research
- Fewer minority investigators in clinical research
- Concerns about research and unethical conduct of research
- People are not asked

Pastor Focus Groups

- Conducted July-August 2003 in designated priority regions in North Carolina
- Four focus groups, one in each region, conducted with a total of 30 African American pastors

Focus Group Themes

- Distrust
- Lack of awareness about research opportunities
- Pastor input in the research process
- Concern about access to and misuse of research results
- Researcher commitment to the community

Community

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Research

Minority Participation in Research

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- Build relationships with communities that will lead to meaningful participation in health disparities research
- Increase diverse participation in research to help improve health and quality of life for people of all backgrounds

Project CONNECT Goals

- Develop infrastructure to support registry of potential minority participants
- Pilot test recruitment of potential minority participants to the registry
- Build community networks to facilitate future recruitment efforts
- Conduct seminars/workshops for researchers on effective recruitment/retention strategies

The Volunteer Registry: How Does it Work?

- Project CONNECT maintains a private list of people who want to learn more about taking part in health-related studies
- List contains information such as one's contact information, age, race and basic health status

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Recruitment Methods

- 1. Community Outreach**
- 2. Participants in Current Research Studies**
- 3. Public Databases**
- 4. Email Announcements**
- 5. Internet**

Outreach Session Content

- Types of Health Research
- Research Protocols and Informed Consent
- What to Expect as a Research Participant
- Research Participant Protections
- How to Join Project CONNECT

Community Research Advocate (CRA) Project

- Outgrowth of Project CONNECT
- Purpose is to provide natural helpers in communities with information about research studies and participation

Community Research Advocates

■ Training:

- Roles of CRA in providing support
- Health Disparities 101
- Behavior Change Theory (Stages of Change)
- Outreach
 - 1:1
 - Community
 - Media
 - Medical/university

Project CONNECT Recruitment *

1. Community Outreach (295)
2. Current Research Studies (14)
3. Public Databases (74)
4. Email Announcements (207)
5. Internet (active method 9/2006) (15)

*As of 6/22/2007

Project CONNECT: Contact Us

- Toll Free: 1 (866) 849-1579
- Email: contact@connect.unc.edu
- Web: www.connect.unc.edu