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2007 Necessary Elements in the Fundamentals of Human Subjects Research: Diversity and Disparity Workshop Series

Conferences

2007

Disparity and diversity workshop

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Disparity and Diversity Workshop

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Siteman Cancer Center
2007



Overview

- Why this course?
- Who are the diverse populations?
- Why is this issue important?
- What is PECaD's role?

Definition of Diversity

Many distinct characteristics that patients, researchers and staff bring to our institution and its programs. These include:

- Race / ethnicity / national origin
- Gender
- Age
- Sexual orientation
- Socioeconomic background
- Physical abilities
- Religion
- Other differences

Why Is This Important?

- Variations of thinking
- Beliefs and values
- Communication styles
- Behaviors
- Social customs

Understanding and appreciating these differences helps us achieve goals in health, health care, and research.

Why This Course?

- Diversity is widely-recognized as critically important
- Lack of available courses
- Differential awareness
- Internal and external pressures
- Modeled on Necessary Elements course
- Discussion and interaction
- Overview and tools

Course Overview

- Historical perspective
- Communication issues and strategies
- Informed consent issues
- Recruitment and retention strategies
- Community based participatory research

Planning Committee

- Washington University Human Research Protection Office
- Siteman Cancer Center
- General Clinical Research Center
- Center for Clinical Studies/Volunteer for Health
- Saint Louis University School of Public Health
- NCI Cancer Information Service
- Program for the Elimination of Cancer Disparities

Diversity Is Here

- Today, almost 1 in 3 Americans identifies as a racial or ethnic minority.
- Nearly 1 in 5 school-aged children speak a language other than English at home.
- By 2010, nearly ½ of the total workforce will be comprised of women and people of color.
- By the year 2050, 1/4 of the total population will be Hispanic; ½ of the population will be people of color.

Racial/ethnic minorities

- African-Americans
 - » 18% of catchment area
- ->50% of St. Louis City

Immigrants

- St. Louis is in top 10 for refugee resettlement
- 2nd highest concentration of newly arrived refugees and immigrants to native born residents
- ->27 languages in our schools

Elderly

 Represent 2/3 of cancer patients but only 20-30% of research participants (NCI)

- Low SES
 - Low income
 - Low health literacy
 - Poor education
 - No health insurance
- Rural
 - Transportation
 - Inconvenience
 - Poverty

Why Is This Important?

- Improves external validity
- Many diseases disproportionately affect minorities, elderly or low SES groups
- Different groups can have different outcomes
- NIH Revitalization Act

Barriers

Investigator-Related Barriers

- Lack of awareness
- Lack of effort
- Inadequate resources

Patient-Related Barriers

Distrust of Medical Community

Detroit study- 81% of 91 aware of Tuskegee study,
 1/2 would decrease willingness

Limited Resources

- Lack of reliable transportation
- Child care
- No insurance
- Inflexible work schedule
- Competing priorities

Patient-Related Barriers

- Poor Health Literacy
 - Limited understanding of clinical trials
 - Forms hard to understand
- English Language

Strategies

Special assistance

Community Presentations

Mass Mailings

Lay referral

Hiring special staff

Media

Program for the Elimination of Cancer Disparities (PECaD)

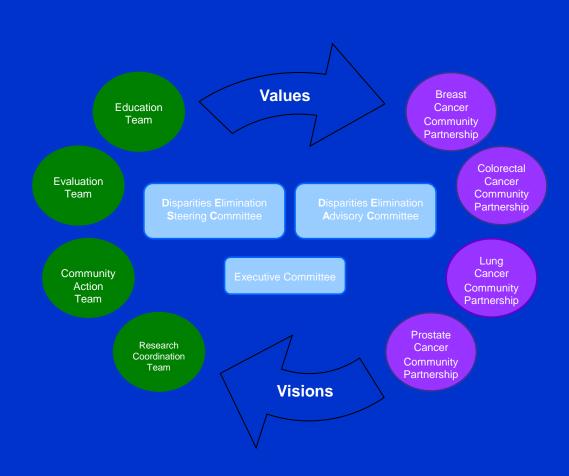
Mission

To bring state-of-the-art cancer care to the entire community

What is PECaD?

1 of 25 NCI funded Community Network Programs established to reduce cancer disparities

PECaD



Key Components

- Programs
- Policy
- Participatory research
- Pipeline
- Provider education

Community Initiatives

- Mammography Outreach Patient Registry
- Radio Education Program
- Prostate cancer screenings
- Partnership with Missouri Screen for Life
- Partnership with Young Choices, Inc.

Research Initiatives

- Trial Monitoring Program
- Disparity and Diversity Workshop Series
- Pilot Projects
- Community Protocol Review Committee

