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2007 Necessary Elements in the Fundamentals
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Disparity and diversity workshop

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Disparity and Diversity Workshop

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Program for the Elimination of Cancer Disparities

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 $\frac{1}{2}$ of the total workforce will be comprised of women and people of color.
- ◆ By the year 2050, $\frac{1}{4}$ of the total population will be Hispanic; $\frac{1}{2}$ of the population will be people of color.

Diverse Populations

Racial/ethnic minorities

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

Diverse Populations

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

Diverse Populations

Elderly

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

Diverse Populations

◆ 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, ½ 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)

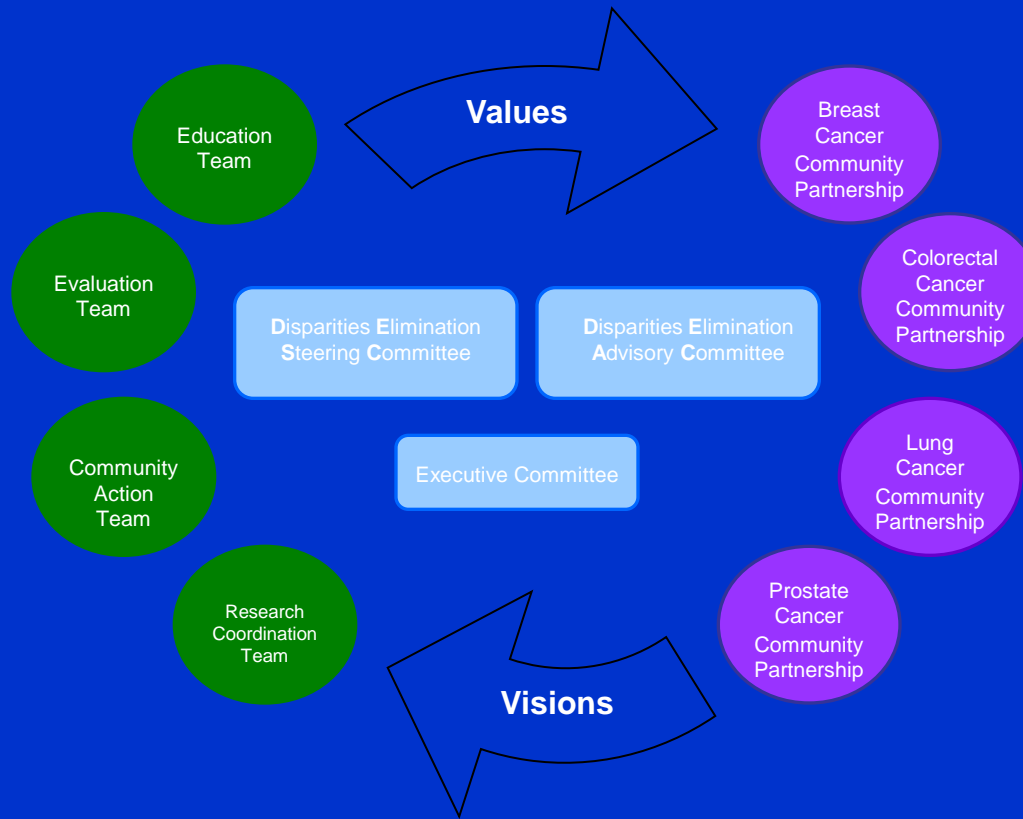
Mission

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