



# **Catalyzing Trans-disciplinary Regional Partnerships to Eliminate Cancer Health Disparities**

**A Report from Cancer Health Disparities Summit 2007**

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**

**National Institutes of Health**





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# ***Letter From the Directors***

The Cancer Health Disparities Summit 2007 (Summit '07) provided a collaborative environment for researchers, community members, and health care professionals to promote cross-fertilization and resource sharing to address the elimination of health disparities. In planning for the Summit, we were pleased to bring together representatives across the National Cancer Institute, and also, from the National Center for Research Resources and the National Center on Minority Health and Health Disparities.

Building on the previous year's meeting, Summit '07 focused on the next steps in developing strategies to implement the recommendations from Summit '06, including increasing the sharing and utilization of resources in geographic regions and coordinating multiple research collaborations. Summit '07 outlined a range of strategies to guide programs, emphasized the need for greater collaboration, and drew attention to opportunities for developing partnerships within regions.

The Summit '07 report will be disseminated to other agencies and organizations working with public health professionals and the community in advancing efforts to reduce and eliminate health disparities. The report and conference resources are also available at: <http://www.cancermeetings.org/CHDSummit07>.

We thank you for your continued support and look forward to seeing you in 2008.

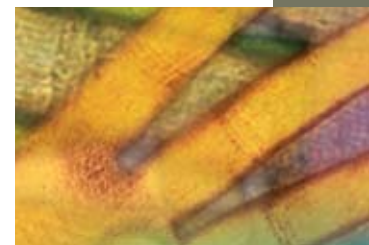
Sincerely,

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# ***Letter From the Summit Planning Committee***



Summit '07, held July 16-18, 2007 in Bethesda, MD was a jointly co-sponsored meeting by the National Cancer Institute (NCI), the National Center for Research Resources (NCRR) and the National Center on Minority Health and Health Disparities (NCMHD). The overall theme for Summit 2007 was Catalyzing Trans-disciplinary Regional Partnerships to Eliminate Cancer Health Disparities. The goals were to:

- Facilitate basic, clinical and community-based research collaborations within broad geographic regions across cancer health disparities research, training, education and outreach programs;
- Share best practices that will assist programs in addressing research and infrastructure needs, gaps analysis, areas of strength, and next steps to strengthen regional partnerships; and
- Identify critical elements required to develop and sustain regional capacity-building approaches.

We convened a Cancer Health Disparities Summit 2007 Planning Committee with individuals from the three Institutes/Centers representing large-scale NCI- NCRR- and NCMHD-funded research programs focused on eliminating health disparities. The Summit objectives were to:

- Capture snapshots of lessons learned and strategies used to overcome barriers in meeting research aims;
- Engage programs in developing additional comprehensive geographic strategies from broadly defined to more specific regions to eliminate cancer health disparities; and
- Develop tangible and comprehensive expectations of programs to increase collaborations and share resources.

At Summit '07, we welcomed over 750 attendees to participate in plenary sessions, concurrent sessions and workshops, debriefing sessions and poster/networking sessions. Participants interacted with other researchers, community partners and health professionals to share successful program strategies, accomplishments and challenges related to: Collaborations and Partnerships, Communications and Bioinformatics, Community Engagement, Managing and Sustaining Programs, and Training. We appreciate the support and participation of the various Centers, Divisions and Offices throughout NCI, NCRR and NCMHD. We especially want to commend all of the planning members for their diligent endeavors to make Summit '07 a success.

Sincerely,

Tarsha McCrae, M.P.H., CHES  
NCI

Shelia McClure, Ph.D.  
NCRR

Francisco Sy, MD, DrPH  
NCMHD



# ***Acknowledgments***

An endearing thank you to the following individuals for the participation in the overall planning of Cancer Health Disparities Summit 2007:

## **Cancer Health Disparities Summit 07 Planning Committee Co-Chairs**

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Shelia McClure, Division of Research Infrastructure, NCRR

Francisco Sy, Community-Based Participatory Research, NCMHD

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Mary Ann Van Duyn, Center to Reduce Cancer Health Disparities, NCI

Rosemary Wong, Division of Cancer Treatment and Diagnosis, NCI

## **Special Acknowledgments**

NOVA Research Company

Office of Communications, NCI

# Executive Summary



On July 16-18, 2007, the National Cancer Institute (NCI) partnered with the National Center for Research Resources (NCRR) and the National Center on Minority Health and Health Disparities (NCMHD) to host the Cancer Health Disparities Summit 2007: Catalyzing Trans-Disciplinary Regional Partnerships to Eliminate Cancer Health Disparities. The meeting brought together more than 750 researchers, public health professionals, and community health educators with an interest in eliminating cancer health disparities. Attendees participated in plenary and breakout sessions and an interactive grantee poster session.

Several Summit '07 plenary sessions featured presentations by grantees who have implemented successful program strategies related to the following key elements:

- Collaborations and Partnerships
- Managing and Sustaining Programs
- Communications and Bioinformatics
- Training
- Community Engagement

Following the presentations, Summit participants were organized into groups by geographic region—Northeast, Southeast, Central, and West—to discuss challenges and solutions related to these elements. The discussion outcomes were shared during plenary debrief sessions.

In another plenary session, Summit attendees were informed about potential funding opportunities through various NCI-, NCRR-, and NCMHD-supported programs. Participants also heard from a panel of media experts regarding the importance of and strategies for interfacing with members of media about health disparities.

A new feature of the Summit '07 agenda was concurrent small group sessions devoted to topics of special interest to meeting participants. These included:

- Ancestry Informative Markers: Genotyping as a Cancer Disparities Research Tool;
- Clinical Trials Education and Outreach: Strategies for Addressing Health Disparities in Medically Underserved Communities;
- Beyond Cowboys and Camels: A Community Networks Program Partnership to Examine Tobacco Message and Media Exposure to the Underserved;
- Patient Navigation in the Field; and
- Culturally Competent Education/Outreach Activities: What's Working in Communities.

Presentations by invited speakers were followed by questions and comments from Summit participants.

Participants also took advantage of the opportunity for one-on-one interactions with other attendees at the Grantee Poster and Networking Session, which featured posters on numerous aspects of cancer health disparities prepared by grantees from various NCI, NCMHD, and NCRR programs.

A detailed summary of Summit '07 and slides from plenary presentations are available at <http://www.cancermeetings.org/CHDSummit07/index.cfm>.

# Concurrent Sessions



## Ancestry Informative Markers: Genotyping as a Cancer Disparities Research Tool

The disparities in cancer burden between individuals of different racial and/or ethnic backgrounds have been well established. Some of these disparities persist even when factors such as socioeconomic status and access to high-quality care have been taken into account, suggesting that genetics and biology may play a role.

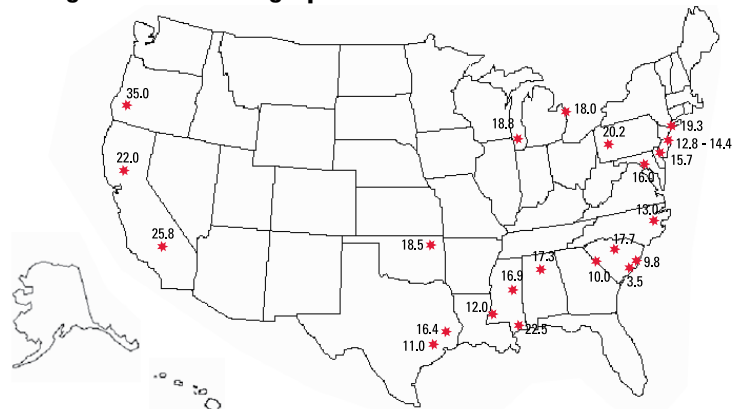
In the past, researchers have depended on “self-reported race” to try to identify relationships between race or ancestry and disease. This approach assumes that individuals are knowledgeable and open about their ancestry. However, studies have shown that this is often not the case, particularly in the United States where there has been extensive mixing of different racial and ethnic groups over the years. As a result, individuals who identify themselves as a particular race often actually have mixed ancestry without even being aware of it.

To help more accurately determine people’s ancestry, researchers have begun developing and using ancestry informative markers (AIMs). AIMs are variations in the genetic code that are commonly and predominantly found in people of one particular ancestry. For example, individuals of African ancestry may be more likely to have one form of a gene while individuals of European ancestry are more likely to have another form.

The goal of using AIMs is to be able to get a more accurate picture of an individual’s ancestry, rather than assuming that all individuals who identify themselves as one race are genetically similar. Being able to do this should help researchers more accurately identify genes that are associated with disease risk.

*Studies have shown that African Americans in the United States have from 3.5 to 35 percent European ancestry.*

### European Genetic Contribution in African-American Populations Living in Different Geographical Areas of the U.S.



References: Parra et al. AJHG 1998; Parra et al. AJPA 2002; Kittles et al. unpublished



## Breast Cancer in African-American Women

Although African-American women have lower incidence rates of breast cancer, they have higher rates of mortality from this disease than their white counterparts. Although differences in access to and delivery of care contribute to these disparities, they do not fully account for them. Many researchers have begun to investigate whether differences in tumor biology may influence differences in disease outcomes. Studies have shown that African-American women tend to be diagnosed with breast cancer at younger ages than white women—the median age for diagnosis is 62 for white women and 57 for African Americans. Furthermore, African-American women are at increased risk for so-called “triple-negative” breast cancers (little to no expression of estrogen receptor, progesterone receptor, or HER2), which are generally more aggressive than other types of tumors and less likely to

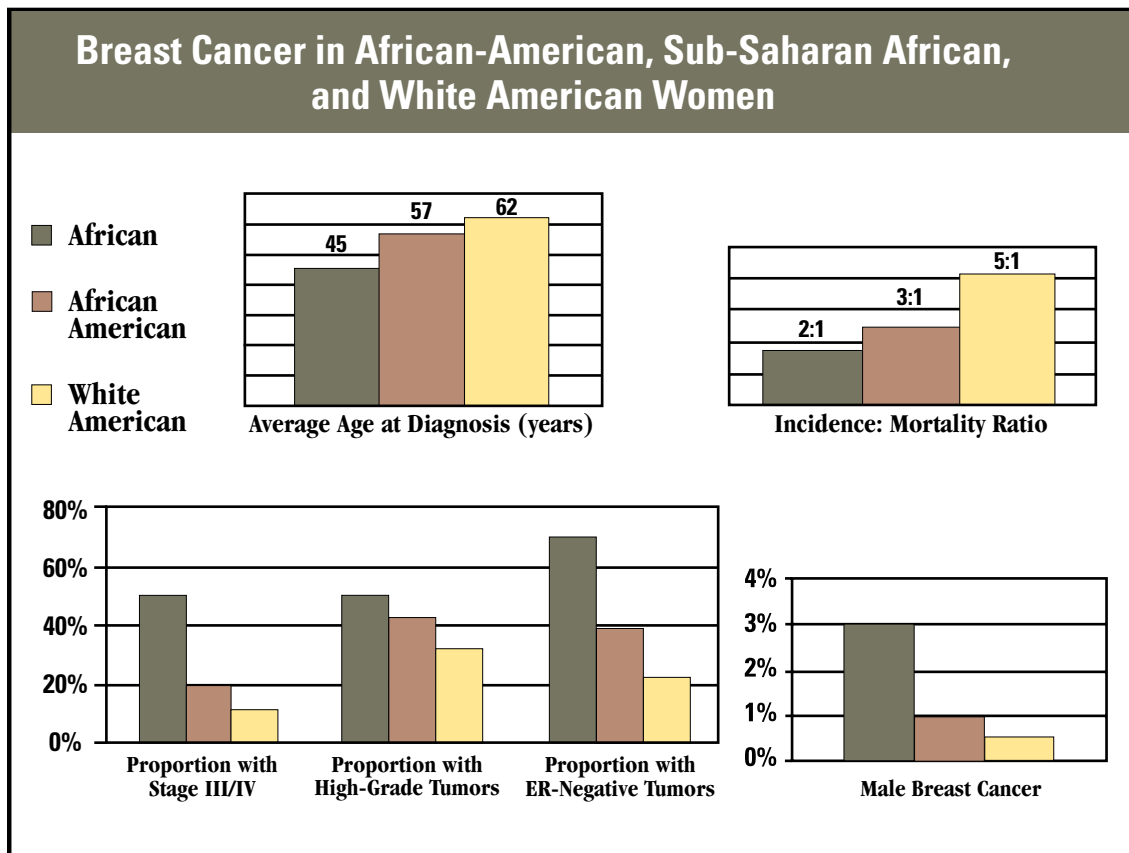
respond to existing treatments. Interestingly, sub-Saharan African women develop breast cancer at even younger ages than African Americans and have a substantially higher proportion of tumors that do not express estrogen receptor. These data suggest an association between African ancestry and increased risk for certain types of breast cancer, but better methods and tools are needed to verify this correlation.

### Presenters:

Lisa Newman, M.D., M.P.H., F.A.C.S.,  
University of Michigan

Jill Barnholtz-Sloan, Ph.D.,  
Case Comprehensive Cancer Center

*Of the 3 billion nucleotides that make up the human genome, only 0.2 to 0.5 percent (6 to 15 million nucleotides) vary between individuals*



## Clinical Trials Education and Outreach: Strategies for Addressing Health Disparities in Medically Underserved Communities

**Less than 5 percent of all eligible people with cancer participate in clinical trials.**

Clinical trials are research studies that cancer patients undergo to find out whether promising approaches to cancer prevention, diagnosis, and treatment are safe and effective. Less than 5 percent of all eligible people with cancer participate in clinical trials. Although the medically underserved experience a disproportionate cancer burden, they are even less likely to participate in clinical trials. The lack of participation by all groups has led to incomplete research findings.

There are many factors that hamper clinical trial participation.

*For patients, some of these factors include:*

- Lack of awareness about clinical trials
- Lack of access to clinical trials
- Fear/suspicion of research
- Cost
- Unwillingness to go against a physician's wishes

*For physicians, some of these factors include:*

- Lack of awareness of appropriate clinical trials

Phase	No. of Participants	Questions Asked
I	15-30	What dosage is safe? How should treatment be given? How does treatment affect the body?
II	<100	Does treatment do what it is supposed to? How does treatment affect the body?
III	100 to thousands	How does the new treatment compare with the current standard of care?
IV	100 to thousands	What is the long-term safety and effectiveness of the new treatment (usually takes place after drug is approved)?

- Unwillingness to “lose control” of a patient's care
- Belief that standard therapy is best
- Concern that clinical trials add administrative burdens

There are four different phases of clinical trials. These trials include different numbers of people and address different types of questions.

There are potential benefits and risks to participating in clinical trials.

*Potential benefits include:*

- Participants receive at a minimum the best standard treatment
- If a new intervention works, participants may be among the first to benefit
- Patients have a chance to help others and improve cancer care

*Potential risks include:*

- New treatments or interventions may not end up being better than, or even as good as, standard care
- Even if a new treatment has benefits, it may not work for every patient
- Health insurance and managed care providers do not always cover clinical trial participation



## ***Program Examples of Clinical Trials Education and Outreach***

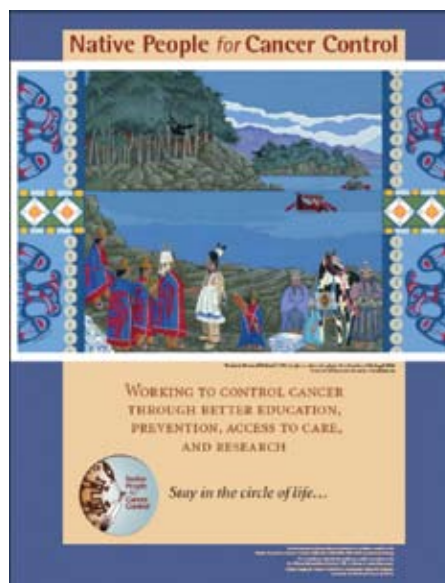
### **Community Networks Program: Native People for Cancer Control Art for Cancer Program**

The Art for Cancer program worked with a number of Native artists from across the country to design posters that utilize Native American art and contain information about cancer, including breast, cervical, colorectal, and lung cancers. The program also developed a brochure that provides background on types of clinical trials, risks, benefits, and barriers, and features a list of questions patients should ask when deciding whether to participate in a trial. Research has shown that when Native Americans participate in research, their primary motivation is the opportunity to benefit their community. Therefore, the brochure emphasizes this benefit of participating in clinical trials.

Visit the Native People for Cancer Control Web site at <http://depts.washington.edu/uwcccr/>.

### **Cancer Disparities Research Partnership Program: Singing River Hospital System**

Singing River Hospital System (SRHS) has developed a system and tools to improve accrual of underserved populations to clinical trials. A Clinical Research Associate reviews all new SRHS patients prior to their first scheduled visits. If the patient is potentially eligible for an open clinical trial, a blue sheet is attached to the patient's record to alert medical staff. A green Patient Fast Fact Sheet (PFFS) is also attached to the patient's record. The PFFS is designed as an introduction to a specific clinical trial and is used by the physician to initiate discussion regarding the option of clinical trial participation to the patient during treatment planning consultation. All PFFSs are Institutional Review Board (IRB)-approved at the time of study activation. Patients are also given a pamphlet on clinical trials. If a patient expresses interest in clinical trial participation, the patient's physician works with clinical trial personnel to further evaluate eligibility.



Once eligibility is verified, the informed consent process is initiated.

Find more information on SRHS at <http://www3.cancer.gov/rfp/CDRP/srhs.html>.

### **Project EXPORT: Carolina-Shaw Partnership for the Elimination of Health Disparities Project CONNECT**

Project CONNECT was created to build relationships with communities in order to spur meaningful participation of minority and underserved populations in clinical trials. To begin, focus groups were conducted in four priority regions in North Carolina with a total of 30 African-American ministers in order to gain insight into the low participation levels of minority/underserved populations in research. Using the information gathered through this process, Project CONNECT set out to develop an infrastructure to support a registry of potential minority clinical trial participants. The long-term goal is to build community networks to facilitate future clinical trials recruitment efforts. Project CONNECT maintains a private list of people who want to learn more about taking part in health-related studies. The list contains information such as contact information, age, race, and basic health status. Placing one's name on the list is not a requirement or agreement to take part in any study. Community members have been recruited to sign up for the list using a variety of methods, including:

- Community outreach
- Current research studies
- Public databases
- Email announcements
- Internet

For more information on Project CONNECT, visit [www.connect.unc.edu](http://www.connect.unc.edu).

## ***NCI Resources for Clinical Trials Education and Outreach***

### **Clinical Trials Education Series**

NCI developed the Clinical Trials Education Series (CTES) to help health care providers, patients, advocates, and others understand more about clinical trials. CTES resources are tailored to a variety of health literacy levels and some are available in Spanish. CTES consists of over 20 resources in a variety of formats, including: brochures, workbooks, web-based courses, slide shows, videos, DVDs, CD-ROMs and booklets.

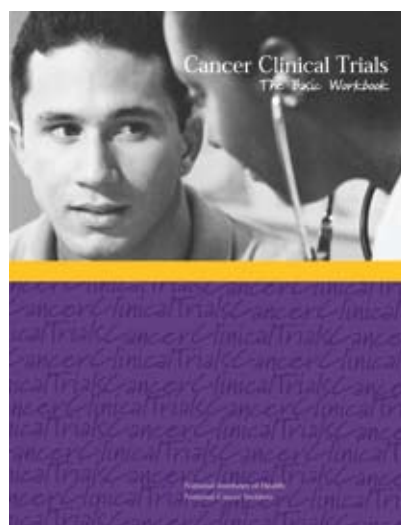
CTES also has a Trainer's Guide, a train-the-trainer program for those interested in or tasked with organizing targeted education and outreach programs. The Trainer's Guide includes diverse curricula and provides step-by-step instructions on how to conduct trainings.

To obtain free copies of CTES materials:

- Call 1-800-4-CANCER.
- Visit [www.cancer.gov/publications](http://www.cancer.gov/publications).

To access electronic versions of many CTES resources, visit

<http://www.cancer.gov/clinicaltrials/learning/clinical-trials-education-series>.



## Cancer Information Service

The Cancer Information Service (CIS) is made up of three components: the call center, the research group, and the Partnership Program. The Partnership Program is a nationally coordinated, regionally focused program committed to reaching minority and underserved populations that do not have adequate access to health information and services. Clinical trials are a major priority area of the program. Partnership Program staff are located in 15 regions representing the United States, Puerto Rico, and the Virgin Islands; service is provided to all 50 states. The Partnership Program works with organizations (rather than directly with the public) and provides support in a number of ways:

- Training
- Education and outreach support
- Assessments
- Media campaigns
- Presentation development
- Research

### Presenters:

Steve Charles, M.F.A.,  
Native People for Cancer Control, University  
of Washington

Maggie Clarkson, M.S.,  
Cancer Disparities Research Partnership Program,  
Singing River Hospital System

Evelyn González, M.A.,  
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Melissa Green, M.P.H.,  
Project CONNECT, University of North Carolina

Ryan Morigeau,  
Native People for Cancer Control,  
University of Washington

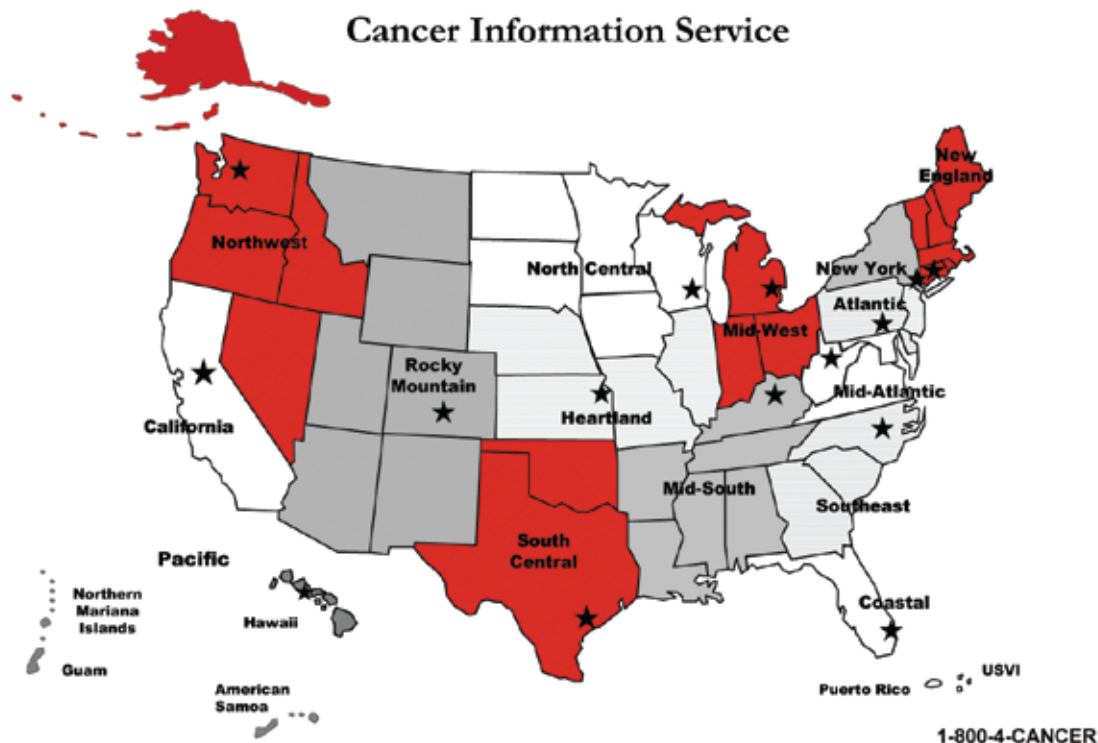
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Office of Communications and Education, NCI

Allison Zambon, M.H.S.,  
NOVA Research Company

*To reach your regional CIS office, call 1-800-4-CANCER.*

### National Cancer Institute's Cancer Information Service



## Beyond Cowboys and Camels: A Community Networks Program Partnership to Examine Tobacco Messages and Media Exposure to the Underserved

*The goal of TeRMM is to develop a set of valid measures of media and message exposure for application in future research.*

The Tobacco Research Network on Disparities (TReND) is a collaborative effort between NCI and the American Legacy Foundation. The mission of TReND is to eliminate tobacco-related health disparities through transdisciplinary research that advances scientific knowledge, translates the scientific knowledge into practice, and informs public policy. For more information on TReND, visit <http://cancercontrol.cancer.gov/tcrb/trend/index.html>.

One effort being conducted through TReND is the exposure to Tobacco-Related Messages and Media (TeRMM) project. TeRMM will investigate how people of diverse ethnic, racial, and socioeconomic groups are exposed to tobacco-related information with the goal of developing a set of valid measures of media and message exposure that can be used in future research and practice and can be applied to a range of populations and geographical areas. Several TReND members who are also Community Networks Program investigators are participating in TeRMM.

Implementation of the TeRMM project will take place in four phases:

- Phase I: Conduct focus groups to qualitatively explore exposure to tobacco-related messages.

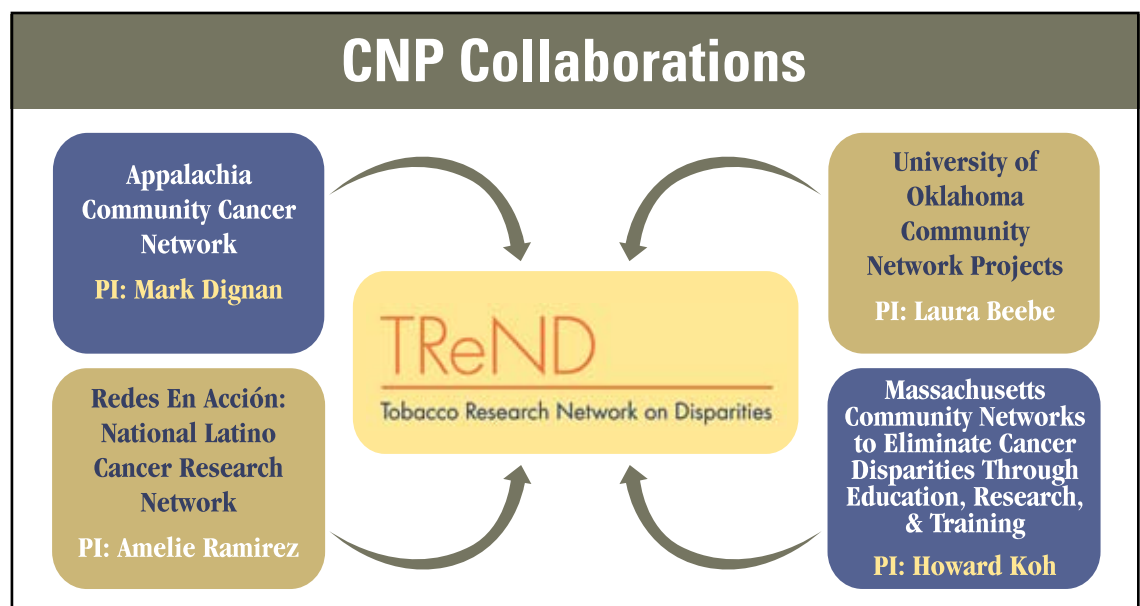
- Phase II: Develop the TeRMM index based on the results of the focus groups and conduct cognitive testing of the index.
- Phase III: Validate the TeRMM index in a large national survey.
- Phase IV: Disseminate the index and related data to the tobacco control field.

### Preliminary Results of TeRMM Phase I

TeRMM Phase I is being carried out by three Community Networks Programs (CNPs), each of which will conduct at least two focus groups. The University of Oklahoma CNP (OUCNP) will focus on Native Americans in Oklahoma, Redes En Acción: National Latino Cancer Research Network will focus on Hispanics in California, and the Massachusetts Community Network to Eliminate Cancer Disparities (MassCONNECT) will collect information on blue-collar African Americans and whites in Massachusetts.

### University of Oklahoma Community Networks Program

OUCNP has partnered with the Cherokee and Choctaw Nations using subcontracts. In addition to obtaining IRB approval from the University of Oklahoma for the program, IRB approval was also sought and granted from both Nations. Two focus groups will be held with each of these populations.



Focus groups with the Cherokee Nation have been held and preliminary results are available.

*Recruitment strategies include:*

- Onsite recruitment at clinic/community center
- Word-of-mouth
- Paid incentive for completing demographic form

*Preliminary results:*

- Internet and television were the most common venues for message exposure. Younger participants reported higher television exposure than their older counterparts. Radio offered “background” exposure. Most participants reported seeing print media such as billboards and flyers; exposure to newspaper ads was reported exclusively among older participants.
- Messages encouraging tobacco use were encountered in places of purchase and in magazines.
- Messages discouraging tobacco use were encountered through television, billboards, and flyers. Anti-tobacco messages focused on both prevention and secondhand smoke exposure.
- Warning labels were overwhelmingly perceived as ineffective. Participants recommended larger fonts and front-of-pack placement to improve them.
- Other approaches recommended to discourage tobacco use included:
  - Eye-catching messages that are direct and truthful (e.g., “Smoking will kill you”)
  - Higher prices for tobacco products
  - Positive messages that encourage patients

Visit the OUCNP Web site at  
<http://w3.ouhsc.edu/oucnp/>.

## **Redes En Acción**

Redes En Acción has completed two focus groups with Spanish-speaking participants and has planned one additional focus group for English-speaking Latinos.

*Recruitment strategies include:*

- Partnering with community organizations
- Encouraging word-of-mouth communication



- Attending community coalition meetings
- Distributing of flyers at clinics and other public places
- Providing paid incentives for participation

*Preliminary results:*

- Participants almost exclusively access Spanish-language media, with Spanish-language television being the most popular. Younger participants reported watching almost twice as much television as older participants. Radio was used primarily as background entertainment.
- Pro-tobacco messages were most evident on television and large billboards on heavily trafficked streets, particularly near the liquor stores that are abundant in the neighborhood. Magazine and newspaper advertisements were also mentioned. Advertisements featured typical “Marlboro Man” scenes with glamorous people in beautiful settings.
- Participants reported varying reactions to pro-tobacco advertisements, including a desire to emulate characters, indifference, anger, and concern for family.
- Most participants recalled seeing more anti-tobacco than pro-tobacco messages in recent times.
- The most effective anti-tobacco ads focus on the harmful effects of tobacco on general health and during pregnancy as well as the danger of secondhand smoke. The use of strong images (e.g., skulls) was also viewed as effective. The majority of participants viewed



warnings on pro-tobacco advertisements as ineffective.

- Participants suggested that anti-tobacco messages should be focused on smoking prevention and encouraging children to motivate their parents to quit using tobacco.

Visit the Redes En Acción Web site at <http://www.redesenaccion.org/>.

### **Massachusetts Community Network to Eliminate Cancer Disparities**

MassCONNECT partnered with the Boston Alliance for Community Health to recruit participants for four focus groups with African Americans in the Boston area.

#### *Recruitment strategies include:*

- Posting flyers through 11 neighborhood-based coalitions
- Local advertisements
- \$25 compensation and \$10 travel reimbursement
- Light dinner and refreshments

#### *Preliminary results:*

- Participants reported gathering news from local and national television outlets and newspapers. Some barriers to accessing these venues included cost, lack of credibility/trust, negative stories about particular populations, and outdated information.

- Advertising channels utilized by this population include word-of-mouth, coupons, transit advertisements, billboards, radio, and Internet. Effective attention-getting means cited were color, hip-hop music, and celebrities.
- Pro-tobacco messages were encountered from peers and family, in stores and gas stations, on radio and television, in movies, in email newsletters from tobacco companies, on Internet pop-ups, at baseball games, in promotional advertisements with celebrities, and in music and music videos. Participants also noted that tobacco companies target different groups with packaging, products, and sponsorship in other industries.
- Messages discouraging tobacco use came in the form of cessation aids, personal experience with illness/death of a loved one, “Truth” advertisements, and images of others’ experiences with smoking. Warning labels were considered ineffective and too small to be read by many adults.
- Participants suggested using more young people, celebrities, and hip-hop artists to publicly discourage smoking. They also suggested discouraging stores and gas stations from displaying tobacco advertising.
- Participants reported seeing more messages that discourage smoking and receiving information from employers, newspapers, doctors, family, and the media about smoking cessation.

Visit the MassCONNECT Web site at <http://www.hsph.harvard.edu/massconnect/>.



### Presenters:

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Project

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MassCONNECT, Dana-Farber Cancer Institute

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Sherrie Flynt Wallington, Ph.D.,  
MassCONNECT, Dana-Farber Cancer Institute

Anna Nápoles-Springer, Ph.D.,  
Redes En Acción: National Latino Cancer Research  
Network, University of California, San Francisco

Donna Vallone, Ph.D., M.P.H.,  
American Legacy Foundation

K. Vish Viswanath, Ph.D.,  
MassCONNECT, Harvard University and Dana-Farber  
Cancer Institute

## Patient Navigation in the Field

As patients enter health care systems for cancer diagnoses and treatment, many barriers can arise, particularly for those who are medically underserved. Some barriers that have been identified include lack of insurance, poor social support, inadequate coping styles, health beliefs, and low health literacy. Patient navigation programs have emerged as one way to address these barriers by assisting patients and their caregivers throughout the cancer continuum. Patient navigators:

- Identify client cases in need of navigation;
- Assess barriers to client care;
- Develop an action plan with the client to address barriers; and
- Track client through completion of care.

NCI created the Patient Navigation Research Program (PNRP) to support implementation and evaluation of patient navigation programs at nine sites across the United States. PNRP sites provide services to patients with abnormal findings or diagnosis of four screenable cancers—breast, colon, cervical, and prostate. Target populations

include African American, Hispanic, Asian/Pacific Islander, American Indian/Alaska Native, and people of low socioeconomic status. Navigator types vary across the sites and include lay navigators as well as social workers and nurses. PNRP outcome variables include diminishing time from abnormal screening to diagnosis, time from diagnosis to completion of treatment, patient satisfaction, and cost-effectiveness.

For more information on the PNRP as well as individual PNRP sites, visit

<http://crchd.cancer.gov/pnp/pnrp-index.html>.

## Work Design and Social Network of the Patient Navigator

A study being conducted at the Boston University Medical Center is analyzing data collected across the nine PNRP sites to explore a number of questions:

- How do navigators allocate their time?
- What tasks do navigators perform?
- With whom do navigators interact to accomplish these tasks (e.g., patients, providers/care sites, family, friends, community resources)?
- Are certain interactions more effective than others?

Observations will be linked to patient outcomes to identify the most effective navigation strategies. The results will be compiled in a structured observation guide.





### ***Case Study #1: Denver Health Medical Center***

A 61-year-old, homeless, alcoholic man presented with stage IV prostate cancer with metastases to the spine. The patient suffered with urinary tract infections, struggled to make copayments for twice-weekly hospital visits, and sometimes did not have enough to eat. The patient navigator helped the patient apply for a program that supplies prepared meals for cancer patients on a weekly basis. Social support was identified to provide financial assistance that has been used to purchase clothing and groceries and make copayments.

Although the patient did not initially want help, his attitude gradually changed as his needs began to be met. He is now more willing to ask for help. The patient navigator also coached the patient on treating the medical staff with respect, which has led to improvement of the patient's relationship with medical staff.

### ***Case Study #2: Moffitt Cancer Center***

A 52-year-old Hispanic woman presented with an abnormal mammogram. The patient was not insured, did not speak English, was unable to

read or write, and provided childcare for her grandchildren while other family members worked. She did not understand the meaning of the abnormal mammogram and had thus ignored the problem. A patient navigator visited the patient's home, explained the abnormal results, and described what the patient needed to do.

The navigator helped arrange transportation and find alternative childcare for the patient's grandchildren and also agreed to accompany the patient to her next doctor's appointment. The navigator also met with the patient's family in order to explain the cancer diagnosis and the need for further testing. The navigator also reassured the family that a cancer diagnosis does not mean certain death and described support that could be provided throughout treatment.

The navigator waited with the family during the patient's mastectomy and made additional home visits after the surgery to explain follow-up treatment and give the family Spanish-language cancer information brochures. Throughout the process, the navigator worked with the patient to help her take a more active role in her own care. For example, the patient was encouraged to understand and answer basic questions (e.g., her name and birth date) in English. Over time, the patient's confidence and self-esteem have grown tremendously.

### ***Case Study #3: Eastern Boston Neighborhood Health Center***

A 41-year-old Hispanic female presented with an abnormal Pap result and received a referral for a colposcopy. The patient spoke only Spanish, was illiterate, had no insurance, and lived with a brother on whom she depended for financial support. Numerous attempts by the patient navigator to contact the patient via phone and mail were unsuccessful; thus, the navigator met with the patient when she returned to the clinic for a follow-up appointment for an unrelated health issue. During the 1-hour meeting, the navigator learned that the patient had not understood what the doctor had told her and had decided to ignore the problem.

To address the barriers faced by this patient, the navigator made an appointment for the patient with a Spanish-speaking provider, provided a simplified explanation of the abnormal results, and made sure that an appropriate translator was available as necessary. The navigator also determined that the patient qualified for free medical care. The patient is currently undergoing treatment for moderate cervical dysplasia.

### ***Case Study #4: American Cancer Society***

A 64-year-old African-American female with a history of mental illness was diagnosed with endometrial cancer. The patient had significant trust issues and would not allow the medical staff to touch her on repeated visits. The doctor noted that the patient became upset and confrontational with family members, and it was decided that the patient navigator rather than a family member should accompany the patient on office visits. The patient navigator counseled the patient's daughter about giving her mother a sense of empowerment and avoiding the use of scare tactics, accompanied the patient on multiple hospital visits, and assisted in moving the patient into active treatment.

#### *Presenters:*

Elizabeth Calhoun, Ph.D.,  
University of Illinois at Chicago

Johanna Capo,  
Boston Medical

Jose Omar Esparza, M.A.,  
Denver Health Medical Center

Phyllis Ferguson-Collum, M.S.W.,  
American Cancer Society

Karen Freund, M.D.,  
Boston University School of Medicine

Yolanda Sarmiento,  
H. Lee Moffitt Cancer Center

## **Culturally Competent Education/Outreach Activities: What's Working in Communities**

It is widely recognized that addressing health disparities experienced by racial/ethnic minorities and other medically underserved populations will require culturally competent interventions. Organizations and people in the community are well poised to contribute to the development of effective education and outreach efforts because they are intimately familiar with the culture of their fellow community members.

### ***Face-to-Face Strategies***

#### **Home Health Parties to Improve Cancer Screening Among Hispanics**

Home health parties have been used to educate the medically underserved Hispanic population of the Yakima Valley of Washington State about the importance of cancer screening by the Hispanic Community Network to Reduce Cancer Disparities. These home-based cancer education discussions

*Home health parties have been used to educate medically underserved Hispanic populations.*



are initiated by community members, and at least one attendee must match the screening guideline demographics for the chosen theme of the party (e.g., colorectal cancer). A binder of educational flipchart sheets is taken to the party along with other visual aids and screening resource guides that list where people can go for free and reduced-cost screenings (all printed in Spanish and English).

Two baseline surveys are conducted at each party. The first is for all attendees and collects information about cancer prevention knowledge and activities. The second is for attendees who meet screening guideline demographics regarding their behaviors, attitudes, and family history. A 6-month follow-up survey is also conducted.

Over 250 parties have been conducted, reaching 1,100 people. Initial findings indicate that 25 percent of those meeting screening guidelines received screenings after the party. More than 25 percent reported thinking about screening and 25 percent asked their doctors about screening. Of those not already screened, more than 20 percent were considering being screened and an additional 20 percent already had an appointment.

## **Story Mapping to Engage Community Partners**

Story maps are one way to incorporate the community's point of view into the conceptualization and implementation of research studies. They are primarily used to initiate dialogue, create focus, integrate perspectives, create experiential learning, and move a group toward a comprehensive view of an important problem. Integrating community input can help improve study design and increase the likelihood that a study will yield meaningful results.

Story maps are pictorial representations of multiple facets of a topic that can facilitate communication among people in different roles. The creation of a story map begins with broad themes and narrows to specific scenarios that trigger stories. It is an iterative, participatory process that generally includes five or more steps; the first and final maps often look very different from one another. Story maps were used to incorporate both community and university input into the creation of the South Carolina Cancer Disparities Community Network.

## ***Image-Based Research***

### **Disseminating Body & Soul to African-American Churches in North Carolina**

Body & Soul is an evidence-based wellness program for African-American churches that focuses on healthy eating and involves pastoral leadership and peer counseling. The Carolina Community Network to Reduce Cancer Disparities (CCN) set out to increase awareness of Body & Soul among African-American churches in North Carolina. A secondary goal was to mobilize many Network members to focus on a single initiative.

The Southeast region of NCI's CIS trained two groups of volunteers on the Body & Soul program: community outreach specialists—community-academic research coordinators who bridge research and community needs—and lay health advisors from historically black colleges and universities. Letters were sent to churches in targeted CCN areas and information sessions on Body & Soul were conducted in churches. Church



responses were tracked via calls to the CIS toll-free number for further information and program materials. Post-information session surveys revealed several things, including:

- Seventy-six percent had not heard of Body & Soul prior to the information session
- Seventy-three percent said their church had an existing health ministry
- Fifty-nine percent strongly agreed that the content of the information session was relevant to their church's mission

Six-month follow-up calls to churches indicated five churches were interested in implementing the Body & Soul program. Lessons learned include the need for a better means of assessing state- or county-level calls to CIS regarding Body & Soul; the need for improved marketing of the program and its information sessions; and sending letters to churches was not sufficient.

### **Using Photovoice and GIS Mapping as a Tobacco Educational Approach for Asian-American and Pacific Islander Youth**

The WINCART—Weaving an Islander Network for Cancer Awareness, Research and Training—CNP at the University of California, Fullerton is exploring environmental influences on tobacco use in three Asian-American and Pacific Islander communities through the use of surveys, photovoice, and geographic information system (GIS) mapping techniques. Youth involved with a community-based organization in each community were trained to use photovoice to document influences on smoking behavior.

To collect place-based data, the project began with youth drawing maps of their communities. They were then given cameras and asked to photograph things they considered important and describe those images in words. Assessment of the narratives revealed that the youth recognized environmental influences on smoking behavior in their communities, with the top three being advertisements targeting teens (38 percent), cigarette sales in the community (32 percent), and litter and trash in the community (19 percent). Maps were created to plot the locations where the



photos were taken, with each location color coded as a positive, negative, or mixed influence.

Photovoice is a form of community-based participatory research (CBPR) that can influence community-level decision making. Community members are using photos from this project to promote legislative change. In one community, a tobacco vendor licensing law was passed, and the other two communities are working to achieve the same result.

### **Breast Health: Shared Stories from Women in Our Hawaiian Community**

*The 'Imi Hale* Native Hawaiian Cancer Network updated a 12-year-old American Cancer Society (ACS) breast health video targeting Native Hawaiian women. The updated version, entitled *Breast Health, Shared Stories from Women in Our Hawaiian Community*, was designed to meet the needs of health educators and empower viewers. *Breast Health* was filmed in Hawaii using real people (e.g., doctors, survivors, family members) and real stories. With \$20,000 from the Susan G. Komen Breast Cancer Foundation and a Safeway Foundation grant to cover postproduction costs, enough film was shot for a 4-hour documentary. This was edited into a variety of public service announcements, which were aired by two Hawaiian television stations the week before Mother's Day. A segment equivalent in length to a 30-minute TV show aired in June.

The video's dissemination plan is diverse and includes Native Hawaiian health care systems

and other health centers and health care service providers, television stations, the Association of Hawaiian Civic Clubs, patient navigator trainings, conferences, a medical library, and partners such as ACS, CIS, the Lance Armstrong Foundation, and the Susan G. Komen Breast Cancer Foundation. Feedback on the video has been positive. Lessons learned include the importance of being clear about the take-home message (in this instance, the importance of early detection), having a backup plan (locations are not always ideal and schedules change), realizing that not all people are equally filmable (and cutting footage for those who do not work out), and relying on experts (including a professional film crew and using actual survivors who share their personal stories rather than read scripts). *Breast Health* was awarded a Certificate of Merit in 2007 by the National Health Information Awards.

## Web-Based Communications

### Changing Physician Behavior with Web-Based Cancer Education

Several institutions in southeastern North Carolina, under the New Hanover Regional Medical Center site with the CDRP program, came together with the goal of increasing accrual of African-American cancer patients to radiation therapy clinical trials. One of many project activities directed toward this goal was the conduct of psychological research to examine factors that influence cancer treatment. Data were collected via a Health Awareness and Experiences Questionnaire. A total of 228 interviews were analyzed.

*Results indicated that those surveyed:*

- Are uncertain about their likelihood of having cancer, the effects of surgery on cancer, and the possibility of surviving cancer
- Believe in the power of prayer for healing
- Mistrust health care providers
- Expect racial discrimination from the health care system

These findings were particularly important given the lack of minorities in patient care positions in the area's health care system. Three interventions

were designed, one of which is an interactive, Web-based curriculum entitled *The Physician's Role in Reducing Racial Disparities in Cancer Outcomes*. This curriculum contains three 30-minute modules, all of which include interactive components such as tests and printable patient discussion plans:

- Disparities in health care and health outcomes (engages physicians intellectually and presents data on differential treatment based on race)
- African-American perspectives on health care (includes interviews with African-American individuals)
- Empathy and trust (designed to elicit behavior change)

### Online Community Tool for Engaging Diverse Communities in Cancer Health Disparities

The Arkansas Cancer Community Network received pilot funding to develop an online tool to enhance collaboration between the Arkansas Cancer Community Network and community partners (i.e., Cancer Councils). *CoalitionsOnline*, has enabled geographically dispersed partners to develop new relationships, provided opportunities to share knowledge, enabled creation of a social structure that fosters learning, and facilitated programming evaluation.

Features included on *CoalitionsOnline* include:

- Events calendar to which community partners can post
- Training materials
- Meeting materials, including agendas and minutes
- Legislative updates
- Membership directory
- Messaging/chat section
- Section for creating, posting, and administering evaluations
- Organization-specific pages for each Cancer Council

Lessons learned include the importance of training community partners in person rather than via phone if more than one partner is being trained at a time, providing hard copies of training

materials to community partners, training partners about the level of information to be shared (e.g., confidentiality), and determining up front who will have the right to post information (i.e., Cancer Council co-chairs). Next steps include developing a training guide and assisting other coalitions in establishing online collaborative space.

Visit *Coalitions Online* at

<http://coalitionsonline.mrooms.net/>.

### **Cancer.gov En Español—A Resource for Hispanic/Latino Communities**

Until recently, the NCI Web site (*cancer.gov*) included Spanish content, but was not presented as a unified Spanish-language site. Because *cancer.gov* receives 3 million visits per month and 10 percent of visitors identify as Hispanic, an NCI Spanish Web Site Committee was established. Formative research was conducted, including a needs assessment and literature review, interviews with 10 other Federal agency Spanish-language Web site developers, and focus groups with U.S. Latino Internet users.

Five issues were selected as critical to address during site formation:

- Equivalent and culturally relevant experience by Hispanic users
- Language and translation issues
- Content organization
- Design tailored to cultural preferences

Twenty-three new pages of content were developed, including information on cancer types and a dictionary of terms. Additionally, features were created to enable users to search, sort, and e-mail information in Spanish. The use of pictures of Latino families, content and images that address cultural perceptions, and a toggle feature that enables the user to alternate between Spanish and English versions of the same content created a culturally relevant experience. Literal translations and computer-aided translation were avoided, and plain language was stressed. Content was organized into fewer categories based on user-centered research. To tailor the design and address cultural perceptions (e.g., nothing can be done to prevent cancer),

a “myths and beliefs” section was added and images portraying cultural values were included throughout the site.

Since the site’s launch on April 2, 2007, *cancer.gov/espanol* has had 1.5 million visits, and visits by users in the United States have increased by 50 percent. Additional user research is planned to increase functionality and navigation, and new content continues to be developed.

#### *Presenters:*

Kathryn Braun, Ph.D.,

*‘Imi Hale* Cancer Network, University of Hawaii

Beti Thompson, Ph.D.,

Hispanic Community Network to Reduce Cancer Disparities, Fred Hutchinson Cancer Research Center

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Silvia Inéz Salazar, M.P.H.,

National Cancer Institute

Christine Ramirez,

Lockheed Martin

# Health Disparities in the News: Getting the Word Out



The media can be a powerful partner in the fight against cancer health disparities, but communication with members of the media requires different skills and knowledge than interacting with colleagues or the community. A diverse panel of media experts presented advice on how to effectively interact with media outlets and increase news coverage of health disparities.

## *Advice From Media Experts*

- Contact journalists to offer story ideas.
- Develop long-term relationships with journalists.
- Focus on media outlets that are familiar to and trusted by target populations.
- Target minority-oriented publications. They may be able to cover disparities-related topics in greater depth than mainstream populations.
- Promote stories that will give readers practical information about lowering cancer risk.
- Use plain language and avoid acronyms and jargon when talking to journalists.
- Personal stories put a human face on the problem of health disparities.

## **Media Panelists**

### **U.S. Medicine—Sandra Basu**

U.S. Medicine is an independent news organization that reaches about 40,000 readers through its *U.S. Medicine* newspaper and weekly electronic newsletter. The organization covers medical activities and policies of the Federal Government, including all aspects of American Indian and Alaska Native (AI/AN) health care. These populations are severely affected by disparities in a wide range of diseases, including cancer, tuberculosis, diabetes, heart disease, and depression. People on reservations are often wary of outsiders which make covering this population challenging. Finding sources willing to candidly discuss health issues is difficult. It is beneficial to journalists to develop relationships with professionals involved in community-based research because these professionals can refer them to community members.

Additional information about U.S. Medicine is available at <http://www.usmedicine.com/>.

### **Asian Fortune—Stella Choi**

*Asian Fortune* is an English-language newspaper that serves Asian Americans in the Washington, DC, area. Asian Americans face many barriers in gaining access to health care, including physical as well as language and cultural barriers. Many health education materials have been established for Asian Americans, but they are often not effectively distributed. Minority-oriented media can help disseminate health information to minority populations because they are conscious of cultural features of these populations. For example, *Asian*



*Fortune* is tailored to appeal to the family-oriented Asian-American culture.

Visit the *Asian Fortune* Web site at <http://www.asianfortunenews.com>.

### **National Newspaper Publishers Association—Hazel Edney**

The National Newspaper Publishers Association is a wire service comprising more than 200 African-American-owned newspapers around the country. African Americans experience numerous health disparities. A number of factors contribute to these disparities, including low high school graduation rates and high rates of unemployment, poverty, and uninsurance. Many African-American journalists are interested in communicating messages about cancer and healthy lifestyles to the African-American community. The most successful stories have been those that give readers practical information on how to lower their cancer risk. These stories are more likely to be picked up by other media outlets than stories that contain dry statistics. Health disparities researchers should focus on ways that African Americans can change behaviors associated with increased cancer risk and should provide this information to African-American journalists so it can be passed on to readers in the community.

Visit the National Newspaper Publishers Association Web site at <http://www.nmpa.org>.

### **New America Media—Viji Sundaram**

New America Media is a nationwide association of ethnic news organizations. It operates a Web site that also serves as a portal for stories about immigrant communities. Ethnic media outlets can be very effective for disseminating information to ethnic communities. However, ethnic journalists are not always well respected by the general public or people in leadership positions. It is important that ethnic journalists be recognized as legitimate reporters with important constituencies.

Visit the New America Media Web site at <http://newamericamedia.org>.

### **The Cancer Preventorium—Elmer Huerta**

Cultural factors influence health-related knowledge and attitudes; for example, some ethnic groups do not talk openly about disease and have a fatalistic outlook about cancer. Coherent, consistent, comprehensive, culturally appropriate media-based public education programs delivered through communication channels that are familiar to and trusted by minority populations can change knowledge and attitudes and empower people to reduce their cancer risk. The Washington Cancer Institute uses daily, weekly, and monthly radio broadcasts; weekly television segments; bimonthly columns in Spanish-language magazines; and a Web site to deliver health and prevention messages to the Latino community in the Washington, DC, area. The Washington Cancer Institute also encourages preventive medicine through its Cancer Preventorium, which provides screening of asymptomatic patients for conditions such as cancer, diabetes, and high blood pressure. The Preventorium engages in community outreach and also provides patient navigation services. More than 20,000 patients have been seen at the Preventorium since its inception in 1994.

Visit Prevension, Inc., at <http://www.prevension.org> to find more information on Spanish-language outreach efforts.

*The media can be a powerful partner in the fight against cancer health disparities.*



# Key Elements: Building and Upholding Successful Programs



Two plenary sessions and two breakout sessions during Summit 2007 focused on key elements for building and operating successful programs to eliminate cancer health disparities:

- Collaborations and Partnerships
- Community Engagement
- Managing and Sustaining Programs
- Communication and Bioinformatics
- Training

In the plenary sessions, invited speakers described best practices and lessons learned related to the five key elements. For the breakout sessions, participants were assigned to regional groups so that common concerns could be shared among programs in the western, northeastern, southeastern, and central regions of the country. Group participants and facilitators were provided with lists of suggested discussion topics and questions to consider. One participant from each region reported the key points of breakout group discussions in two plenary debriefing sessions.

## Collaborations and Partnerships

Interdisciplinary partnerships among research, academic, and community organizations that serve racial/ethnic minority and underserved populations are essential to improve the study of cancers that affect these groups and to increase the involvement of such entities and populations in scientific research.

*Plenary: Steven Patierno of the George Washington Cancer Institute (GWCI) in Washington, DC provided several examples of his organization's collaborations with community partners, including the Citywide Patient Navigation Research Program, the GW Mobile Mammography Partnership, the GWCI Men's Oncology and Prostate Cancer Outreach and Screening Program, and the DC Cancer Consortium.*

Breakout group members discussed novel and effective approaches that have been successful in developing mutually beneficial partnerships that incorporate diverse leadership and demonstrate significant community involvement; crucial factors in facilitating partnerships to bridge diverse populations; barriers to developing and sustaining truly diverse collaborations; balancing of rigorous scientific standards with substantial community involvement; benefits of encouraging collaborations among researchers who work with minority and underserved populations; best practices for forging new partnerships and expanding outreach to minority and other medically underserved communities;

and steps needed to increase availability of new technologies to facilitate collaboration.

## **Selected Key Points of Discussion**

- There are six keys to successful collaboration: overcoming misunderstanding; building trust in relationships through communication; sharing funding and other resources; evaluating the processes and outcomes of community-based research; recognizing the diversity of strengths and expertise among partners; standardizing IRB oversight across program sites; and engaging high-profile survivors as champions for programs.
- Provision of mentoring to minority scientists, inclusion of the community in the planning of research, and incorporation of economic policy and advocacy within the framework of the research program are essential to collaborative research.
- Obtaining treatment for uninsured patients identified through screening programs is an ongoing problem. Medical centers that participate in collaborative programs can provide care at no cost on a case-by-case basis, but most institutions place a limit on this practice.
- Collaboration among CBPR programs expands the options available to community members by creating regional networks of providers.
- The policy research components of collaborative programs are a potential avenue for changing the system to provide treatment for uninsured citizens.
- Partnerships can reduce budget constraints faced by researchers.
- NCI's Consumer Advocates in Research and Related Activities (CARRA) program can provide assistance to scientists who are interested in learning how to work with community-based organizations.
- Partnerships should be reciprocal, but partners must understand the limitations that constrain other parties. Partners may not be funded to support all activities, but they can

still make contributions in their areas of expertise. Service delivery is improved by eliminating duplication of effort.

- Rigorous scientific standards need to be reconciled with the concerns of the community. The community must understand the purpose of scientific method and IRB oversight, while scientists must understand that the community places a higher priority on its own needs.
- Requests for grant applications designed to address cancer health disparities should require applicants to clearly define the community organizations with which they intend to collaborate.

## **Community Engagement**

Addressing health disparities requires a collaborative approach to research that equitably engages all partners in the research process and recognizes the unique and considerable strengths that each partner brings to this process.

*Plenary: Mattie Woods of the Center for Healthy Hearts and Souls described a consortium of community hospitals in western Pennsylvania called Centers for Healthy Hearts and Souls, which has partnered with 81 churches and community organizations. The consortium is involved in the University of Pittsburgh's Community Research Advisory Board, which promotes bidirectional communication between researchers and the community.*

Breakout group members discussed key enablers of CBPR; developing and disseminating guidelines for CBPR; addressing barriers to participation in CBPR by community health care providers; focusing research on issues of greatest relevance to communities; designing intervention strategies that incorporate community norms; increasing culturally sensitive interpretations of research findings; identifying core research infrastructure needs for conducting research in community settings; leveraging existing infrastructure; and sharing effective approaches for designing training to promote community participation in research.

**Requests for grant applications designed to address cancer health disparities should require applicants to clearly define the community organizations with which they intend to collaborate.**

## ***Selected Key Points of Discussion***

- Programs must maintain consistency when communicating with communities, not only in the content of messages provided, but also in the individuals who reach out to the community. The group of professionals engaged in collaborative research should reflect the diversity of the community in which that research is conducted. Community gatekeepers should be enlisted by collaborative programs, especially as members of IRBs and advisory groups.
- Newspapers owned and operated by African Americans are trusted components of the community and very often serve as advocates and agitators. Collaborative programs should include these newspapers among their partners.
- Academic tenure requirements should be revised to place greater value on community engagement, rather than focusing on isolated individual accomplishments.

- Collaborative partners could use a central IRB as a neutral party in resolving issues that arise in the course of community-based research and service delivery programs, such as conflicts between researchers or institutions and community-based organizations. An IRB could also help clarify “ownership” of research projects and their findings.

- Communities need technical assistance to understand the purpose and expected outcomes of a research project and the importance of evidence-based interventions before they can be expected to make a decision to become involved.

- NIH funding mechanisms should allow support for building relationships necessary to incorporate community values and norms into the design of scientific studies. Staff time and resources

should be made available to help communities in tangible ways.

- Academia cannot ask communities to become partners if academic institutions maintain complete control and ownership of grant funds. Grants should be redesigned to include support for community-based programs.

## **Managing and Sustaining Programs**

Programs face constant financial and policy-related challenges in ensuring program continuity and securing reliable resources to meet program obligations. Evidence suggests that changes in health policy are critical to sustaining CBPR efforts over the long term.

*Plenary: Hugo Vilchis-Licon of New Mexico State University's Border Epidemiology and Environmental Health Center described a concept called REACH—Research, Education, And Community Health—as the core element required for program sustainability.*

Breakout group members discussed funding issues; examples of successful monitoring and implementation of recommendations and policies aimed at reducing cancer health disparities; working with legislators to evaluate local policies; increasing the potential for translating evidence-based research into sustainable community change; developing strategies for using research to influence legislation; and identifying data and training needs of decision makers to support implementation of public policy.

## ***Selected Key Points of Discussion***

- A lack of understanding of the value of community-based research on the part of academic institutions and peer reviewers is a barrier to establishing, managing, and sustaining collaborative programs. Many institutional leaders and reviewers feel that community engagement compromises scientific rigor and question the value of allocating resources to community groups.

***The increased interest within the National Institutes of Health (NIH) in expanding interdisciplinary clinical and translational research is an enabler that should facilitate the creation of collaborative research programs. Bringing broader expertise into cancer research will expand its focus to include social, economic, and political determinants of health disparities.***

- Academic institutions should help build infrastructure to provide ongoing support for community-based activities when Federal grants are no longer available. Communities need training in how to pursue funding opportunities from government and private sources and maintain programs after funding ends.
- Health-care cost reductions achieved through comprehensive community-based health and wellness programs could result in increased availability of funds for collaborative community-based programs.
- Research funding and protocol design must value indigenous knowledge and experience within communities and provide incentives to volunteers.
- A key element of ensuring sustainability is identifying the most appropriate data in the most appropriate format for presentation to policy makers.
- A central repository of existing policies is needed. The Cancer Control P.L.A.N.E.T. could house such a resource organized according to primary versus secondary prevention and by region.
- Health policy analysis is often not a strength of academic or community partners. Planning should include identification of expertise in this area.
- Bringing evidence-based interventions into the community requires increasing participation in clinical trials. Only 3 percent of the participants in clinical trials represent minority populations. Minority-Based Community Clinical Oncology Programs (Minority-Based CCOPs) provide an excellent model for addressing this problem. Policy makers need to be educated about the importance of improving access to trials for minorities. In addition, investigators involved in disparities-related collaborative programs should explore ways to participate in Minority-Based CCOPs.

## Communications and Bioinformatics

Computer networks underpin virtually all aspects of biomedical research, from the capture, storage,

and analysis of data to the dynamic modeling of disease epidemics. Powerful computers alone are not enough to exploit those opportunities. Researchers need comprehensive supporting infrastructure that integrates data-gathering facilities, computing hardware, data analysis and informatics tools, interoperable software, and expertise needed to build, manage, and utilize networks. Network connectivity is increasingly important for interdisciplinary team science because it allows collaborative sharing of valuable data, expertise, and other research resources.

*Plenary: John Carpten of Translational Genomics Research Institute (TGen) described his company's use of advanced bioinformatics to a wide variety of basic science and medical applications.*

Breakout group members discussed steps needed to enhance existing network infrastructure; processes and resources needed to facilitate interaction among grantees; use of existing resources to build bridges between academic health centers and community health care providers to stimulate CBPR; unique infrastructure needs of urban and rural/remote institutions; and strategies for meeting the costs of building and sustaining network infrastructure.

### Selected Key Points of Discussion

- Keys to enhancing existing network infrastructure include: strong IRB oversight and an emphasis on human subject protection; interdisciplinary training; linguistic cultural competency; education for researchers on the value of new technology; and availability of software to facilitate mining of data.
- Processes that may be required to ensure that existing network infrastructure facilitates

***A lack of understanding of the value of community-based research on the part of academic institutions and peer reviewers is a barrier to establishing, managing, and sustaining collaborative programs. Many institutional leaders and reviewers feel that community engagement compromises scientific rigor and question the value of allocating resources to community groups.***

interaction among regional grantees include: improvement of data management practices and development of compatible data management systems and standards; provision of information technology (IT) training to all partners; and memorandums of understanding to clarify roles and relationships.

- Programs need real-time data collection capability within clinical settings, with links to statewide and national hubs. This would accelerate and improve both care delivery and research collaboration.
- Actions that programs can initiate to increase the capacity of existing network infrastructure to bring academic and community-based partners together include making bioinformatics resources available to partners at distant sites to improve diagnostic procedures and implementing cross-training and community outreach. Bioinformatics and biostatistics core facilities, as well as teleconferencing and telemedicine facilities, could be established in academic settings and shared by regional partners.
- Data management systems used by various organizations in a region must be compatible so that information can be shared. Standardized guidelines for data management are needed.
- Information gained through research in the community must be translated into a form that can be delivered back to the community to improve outcomes.
- The costs of developing and sustaining network infrastructure can be met by: incorporating systems support and replacement costs into the planning from the beginning; building partnerships with local governments; advocating for policy changes; and leveraging the resources of partners. The costs of bioinformatics include not only equipment and software but also training and maintenance. Proposals to create collaborative programs must include strong justification for inclusion of IT staff.
- Programs need to integrate tools that can assist in patient enrollment by analyzing patients'

attributes and quickly indicating which patient populations are likely to benefit from a study.

- As the Cancer Biomedical Informatics Grid (caBIG) evolves, issues related to cancer health disparities should be addressed. The grid should be expanded to accommodate advocacy and policy issues, behavioral data, and information on community characteristics. In addition to working with caBIG, programs should explore other avenues for obtaining open-source software or GIS technology that can support their research activities.
- Development of a Web-based portal to share genomic and proteomic data with the public could take place rapidly if adequate funds were made available. The NCI Cancer Genetic Markers of Susceptibility Study and the Human Genome Project are two examples of NIH leadership in making data available to the public.

## Training

Reducing and eliminating cancer-related health disparities requires a well-trained, collaborative group of transdisciplinary researchers, health care professionals, and members of the community (both lay and other professional groups). It is important to provide specific training targeting senior researchers, junior investigators, and community members.

*Plenary: Estella Estape of the University of Puerto Rico described training and education initiatives used by the University of Puerto Rico to increase the number of minority and underserved investigators. These efforts focus on helping students become independent clinical researchers, conduct culturally appropriate and ethical studies, build and lead collaborative networks, and communicate effectively.*

Breakout group members discussed addressing critical training gaps for members of transdisciplinary research teams; promoting participation of cancer health disparities researchers on grant review committees; planning within regions to identify recruitment pools of

new investigators; ensuring a diverse workforce of investigators; and identifying best practices for working with junior investigators.

## ***Selected Key Points of Discussion***

- Success in mentoring depends on a good fit between mentor and student. Students should have the option of changing mentors, if necessary, to ensure development of positive and productive relationships. Mentoring practices must be tailored to individual institutions and their unique cultures. Students should have internal and external mentors to help them learn about different approaches to community-based research.
- Academic institutions should explore the role of community-based participatory research in developing tenure-track positions. Since CBPR investigators may produce fewer peer-reviewed publications than others, alternate measures of value for this work are needed.
- Formal programs are needed to increase awareness of CBPR training programs among high school and college students. Students with an interest in CBPR should evaluate academic institutions to identify those that provide the best opportunities to follow that career path. An important key to success in mentoring minority students is finding those who are passionate about making contributions to science and to their communities.
- Junior investigators should be given time off and other incentives to encourage participation on review panels. Community representatives should also be provided with the opportunity to serve as reviewers. In-house peer review for pilot projects can give junior investigators important first-hand experience in the peer-review process.
- Community-based cancer awareness programs should focus on recruiting young people for entry into academic career paths. Program directors who have access to training funds can use this as an incentive to encourage students to apply for training and prepare applications to conduct pilot projects.
- A centralized source of information on training opportunities is needed. Improved systems are also needed for tracking students once they enter the training system. A national or regional database system is needed to profile mentors, describe their best practices, and provide information on the careers of students with whom they have worked.
- Agencies that fund community-based research and those that fund education and training should be better connected so that scientists have input into plans for supporting career development.
- In academic institutions, appointment and promotions committees should consider community engagement and experience in evaluating junior faculty, in addition to teaching experience and publications. A community-based participatory research track could be established in addition to the traditional research and clinician-educator tracks.

***Academic institutions should explore the role of community-based participatory research in developing tenure-track positions.***



# Appendix A: Summit Agenda

Sunday, July 15, 2007									
4:00 a.m.–7:00 p.m.	<b>Registration</b>								
Monday, July 16, 2007									
7:00 a.m.–6:00 p.m.	<b>Registration</b>								
7:00 a.m.–8:15 a.m.	<b>Poster Setup</b>								
8:30 a.m.–8:35 a.m.	<b>Call to Order</b> <i>Tarsba McCrae, Center to Reduce Cancer Health Disparities, NCI</i>								
8:35 a.m.–9:00 a.m.	<b>Welcoming Remarks</b> <i>Barbara Alving, National Center for Research Resources, NIH</i> <i>Joyce Hunter, National Center on Minority Health and Health Disparities, NIH</i>								
9:00 a.m.–9:15 a.m.	<b>Sharing Our Vision: The New Center to Reduce Cancer Health Disparities</b> <i>Sanya Springfield, Center to Reduce Cancer Health Disparities, NCI</i>								
9:15 a.m.–10:15 a.m.	<b>Key Elements: Building and Upholding Successful Programs</b> Moderator: <i>Leslie Cooper, Center to Reduce Cancer Health Disparities, NCI</i> Panelists: Collaborations and Partnerships— <i>Steven Patierno, George Washington Cancer Institute</i> ; Community Engagement— <i>Mattie Woods, Centers for Healthy Hearts and Souls</i> ; Managing and Sustaining Programs— <i>Hugo Vilchis-Licon, New Mexico State University</i>								
10:15 a.m.–10:25 a.m.	<b>Q &amp; A</b>								
10:25 a.m.–10:30 a.m.	<b>Charge to Regional Breakouts</b> (Same Room Assignments for All Workshops) <i>Jamelle Banks, Office of Science Planning and Assessment, NCI</i>								
	<table border="1"> <thead> <tr> <th>Northeast</th> <th>Southeast</th> <th>Central</th> <th>West</th> </tr> </thead> <tbody> <tr> <td>Salon A or Salon B</td> <td>Salon C or Salon F</td> <td>Salon G or Salon H</td> <td>Brookside B or White Flint</td> </tr> </tbody> </table>	Northeast	Southeast	Central	West	Salon A or Salon B	Salon C or Salon F	Salon G or Salon H	Brookside B or White Flint
Northeast	Southeast	Central	West						
Salon A or Salon B	Salon C or Salon F	Salon G or Salon H	Brookside B or White Flint						
10:30 a.m.–10:45 a.m.	<b>Morning Break</b>								
10:45 a.m.–12:15 p.m.	<b>Workshops I</b> (Community Engagement)								
12:15 p.m.–1:30 a.m.	<b>Lunch</b> (on your own)								
1:30 p.m.–3:00 p.m.	<b>Workshops II</b> (Managing and Sustaining Programs)								
3:00 p.m.–3:15 p.m.	<b>Afternoon Break</b>								
3:15 p.m.–4:45 p.m.	<b>Workshops III</b> (Collaborations and Partnerships)								
4:45 p.m.–5:00 p.m.	<b>Break</b>								
5:00 p.m.–6:15 p.m.	<b>Debrief I: Bridging Resources to Maintain Program Efforts</b>								
6:15 p.m.	<b>Adjourn</b>								
6:30 p.m.–8:00 p.m.	<b>Grantee Poster and Networking Session</b>								

Exhibits Open



Tuesday, July 17, 2007	
7:00 a.m.–6:00 p.m.	<b>Registration</b>
8:30 a.m.–8:45 a.m.	<b>Opening Remarks and Administrative Notes</b> <i>Shelia McClure, Division of Research Infrastructure, NCRR</i>
8:45 a.m.–10:00 a.m.	<b>Key Elements: Building and Upholding Successful Programs</b> (continued) Moderator: <i>Jeremiah White, Jr., Osiris Group, Inc.</i> Panelists: Communications and Bioinformatics— <i>John Carpten, Translational Genomics Research Institute</i> ; Training— <i>Estella Estape, University of Puerto Rico</i>
10:00 a.m.–10:15 a.m.	<b>Q &amp; A</b>
10:15 a.m.–10:30 a.m.	<b>Morning Break</b>
10:30 a.m.–12:00 p.m.	<b>Workshops IV</b> (Communications and Bioinformatics)
12:00 p.m.–1:30 p.m.	<b>Lunch</b> (on your own)
1:30 p.m.–3:00 p.m.	<b>Workshops V</b> (Training)
3:00 p.m.–3:15 p.m.	<b>Afternoon Break</b>
3:15 p.m.–5:00 p.m.	<b>Concurrent Sessions</b> (Choose Topic)
5:00 p.m.–6:00 p.m.	<b>Debrief II: Accessing Innovative Tools and Strategies to Address Program Challenges</b>
6:00 p.m.	<b>Adjourn &amp; Poster Breakdown</b>

**Exhibits Open**

Wednesday, July 18, 2007	
8:30 a.m.–8:45 a.m.	<b>Opening Remarks and Administrative Notes</b> <i>Derrick Tabor, Office of the Director, NCMHD</i>
8:45 a.m.–9:45 a.m.	<b>Health Disparities in the News: Getting the Word Out</b> Moderator: <i>George Strait, Office of the Director, NCMHD</i> Panelists: <i>Elmer Huerta, MedStar Research Institute</i> ; <i>Hazel Edney, National Newspapers Publishers Association/Black Press USA</i> ; <i>Stella Choi, Asian Fortune Newspaper</i> ; <i>Sandra Basu, US Medicine</i> ; <i>Viji Sundaram, New American Media</i>
9:45 a.m.–10:00 a.m.	<b>Q &amp; A</b>
10:00 a.m.–10:15 a.m.	<b>Break</b>
10:15 a.m.–11:15 a.m.	<b>Funding Opportunities Announcements</b> Moderator: <i>Kenneth Chu, Center to Reduce Cancer Health Disparities, NCI</i> Panelists: Division of Cancer Control and Population Sciences (DCCPS)— <i>Vickie Shavers, NCI</i> ; Division of Cancer Biology (DCB)— <i>Suresh Mohla, NCI</i> ; Small Business Innovation Research (SBIR) and Small Business Technology Transfer Program (STTR)— <i>Michael Weingarten, NCI</i> ; Center to Reduce Cancer Health; Disparities Training Opportunities— <i>Nelson Aguila, NCI</i> ; National Center for Research Resources— <i>Michael Sayre, NCRR</i> ; National Center on Minority Health and Disparities and Across NIH— <i>Francisco Sy, NCMHD</i>
11:15 a.m.–11:30 a.m.	<b>Q &amp; A</b>
11:30 a.m.–11:40 a.m.	<b>Making the Connections to Eliminate Cancer Health Disparities</b> <i>John Niederhuber, National Cancer Institute</i>
11:40 a.m.–11:50 a.m.	<b>Q&amp;A</b>
11:50 a.m.–12:00 p.m.	<b>Closing Remarks</b> (Acknowledgments and Next Steps) <i>Sanya Springfield, Center to Reduce Cancer Health Disparities, NCI</i> <i>Sidney McNairy, Division of Research Infrastructure, NCRR</i> <i>Francisco Sy, Community Based Participatory Research, NCMHD</i>
12:00 p.m.	<b>Adjourn</b>

**Exhibit Breakdown**



# Appendix B: Workshop Descriptions

## Collaborations and Partnerships

Interdisciplinary partnerships among research, academic, and community organizations that serve racial/ethnic minority and underserved populations are essential to improve the study of cancers that affect these groups and to increase involvement of such entities and populations in scientific research. Workshops under this theme will showcase programs that have established effective and mutually beneficial collaborations and partnerships among cancer centers, academic institutions, community-based organizations, Federal agencies, students, and community members with the common goal of reducing cancer health disparities.

Major points of discussion will also include:

- Working with non-traditional partners such as corporations, insurance companies, and pharmaceuticals.
- Creating partnerships for the support and development of sustainable community-based networks for participatory research in areas of high cancer disparities.
- Providing regional opportunities for program networking across research disciplines.
- Enhancing the likelihood of the adoption of beneficial research results at the individual and community levels.
- Building and sustaining academic-community partnerships and community trust.
- Addressing the needs of trans-disciplinary research teams to tackle complex scientific problems and questions.

Strong partnership strategies are vital to the continuum of cancer care, and programs must be fostered that cultivate collaborative relationships between diverse representatives among decision-makers, community members, researchers, and other stakeholders.

*Questions to consider:*

- What novel and effective approaches have been successful in developing mutually beneficially partnerships that incorporate diverse leadership and demonstrate significant community involvement?
- What factors have been crucial in facilitating partnerships to bridge diverse populations by their commonalities?
- How do programs address barriers to developing and sustaining true diverse collaborations that link different segments (health care, social services, etc.) that advocate for minority and underserved health?
- How do programs balance rigorous scientific standards with substantial community involvement?
- What are the program benefits of encouraging collaborations among researchers who work with minority and underserved populations?
- What are the best practices for forging new partnerships and expanding outreach to minority communities and other medically underserved communities?
- What steps are needed to increase the availability of technologies and facilities conducive to producing more effective collaborative processes?

## Community Engagement

Addressing health disparities will require a collaborative approach to research that equitably engages all partners in the research process and recognizes the unique and considerable strengths that each partner brings to this process. Workshops will focus on barriers to and enablers of effective academic-community partnerships for community-based participatory research (CBPR) to address cancer health disparities. The goals of the workshops are to identify (1) strategies and best practices for conducting collaborative, community participatory clinical and translational research, particularly in minority communities and other medically underserved communities where cancer health disparities persist; (2) strategies and best practices for recruitment and retention of research participants; and (3) core infrastructure needs in communities that will encourage and enable community participation in research.

### *Key discussion topics will include:*

- Addressing racial, ethnic, and geographic disparities in clinical and translational research participation.
- Building community buy-in and trust to enhance recruitment and retention of research participants.
- Collaborative development of practical research protocols that work effectively in community health care settings and address questions of relevance to the community.
- Developing versatile and sustainable core research infrastructure (e.g., personnel, information technology, and informatics tools) to enable and encourage community participation.
- Leveraging existing infrastructure, including increasingly advanced clinical information systems, residing in safety-net community health center networks to facilitate CBPR.
- Sharing effective approaches in designing community action trainings to promote community participation in research.

### *Questions to consider:*

Barriers/enablers of effective academic-community research partnerships

- What are some of the key enablers of CBPR?
- How do we develop/disseminate guidelines and best practices for CBPR?
- What are some key barriers to community health care providers and community participation in research, and how can academic institutions overcome these barriers?

Facilitating collaborative development of practical research protocols

- What are some best practices for focusing research questions on health issues of greatest relevance to the communities at greatest risk?
- How do we develop intervention strategies that incorporate community norms and values into scientific approaches?
- What are the best practices for increasing accurate and culturally-sensitive interpretation of research findings?

Core infrastructure requirements for research in community settings

- What are the core research infrastructure needs for researchers, community health providers, and community participants?
- How do we identify existing infrastructure and leverage the infrastructure to increase CBPR?

Promoting educational training for community-based organization partners

- What are some successful examples from training modules for non-researchers on participating in CBPR to address cancer health disparities in their region?
- How do we facilitate the collaboration of regional trans-disciplinary research teams to work with the community to identify new opportunities and training needs in eliminating cancer disparities?

## Managing and Sustaining Programs

Workshops under this theme will focus on critical elements needed to develop a core process to ensure program continuity and identify and secure reliable resources to meet program obligations. Programs are constantly facing challenges in effectively moving research activities forward that include a lack of funding and resources and increased scrutiny of effectiveness.

Evidence suggests that health policy is critical to sustaining program efforts over the long term. Factors such as financial resources, program duration, and the process of project negotiation are a matter of policy. Grantees will discuss examining existing health policy models and determining how they may be adapted to address cancer health disparities-related gaps in the community, translate research findings into policy, and further engage local, state, and Federal policymakers.

*Key topics of discussion include:*

- Identifying the challenges in developing, implementing, and sustaining cancer health disparities programs.
- Working with individuals from multiple backgrounds to be able to interface and identify the needs, challenges, and strengths of the community in closing the cancer health disparities gap.

- Sharing effective processes to secure sufficient funding to implement new research policies and programs and to improve existing activities.

*Questions to consider:*

- How do we address inadequate funding issues to fully support infrastructure required to perform cancer health disparities research?
- What program examples have been instrumental in monitoring adoption and implementation of legislation and recommendations to reduce cancer health disparities?
- How have programs worked with local legislation to evaluate local policies?
- How do we increase the potential for translation of evidence-based research into sustainable community change that can be disseminated more broadly?
- What are successful processes that programs may adopt to effectively use research to influence legislation?
- What types of data and training are needed by decision-makers to implement public policy by creating legislation and regulation to eliminate cancer health disparities?

## Communications and Bioinformatics

High-speed computer networks are vital to biomedical research, yet the infrastructure supporting network connectivity remains unevenly distributed. Workshops will examine ways to implement networks that support research and communication. They will also serve to identify key needs and priorities for future infrastructure development.

Computer networks underpin virtually all aspects of biomedical research, from the capture, storage, and analysis of data to the dynamic modeling of disease epidemics. Researchers increasingly turn to computing power to conduct modeling and simulations of biological systems. Powerful computers alone are not enough to exploit those opportunities. A comprehensive supporting infrastructure (often termed cyber infrastructure) must be in place—one that



integrates data-gathering facilities, computing hardware, data analysis and informatics tools, interoperable software and middleware, and expertise needed to develop robust software applications and build, manage, and utilize networks.

Network connectivity is increasingly important, especially for trans-disciplinary team science, because it allows collaborative sharing of valuable data, expertise, and other research resources at optimal rates. Networks facilitate research collaboration and sharing of resources within geographical areas and beyond and also provide access for the conduct of telemedicine.

Academic health centers in some locations, as well as many physicians' offices, rural hospitals, and clinics, have poor connectivity, limiting their ability to participate in research networks. Shortcomings extend beyond the physical network, including adoption of policies and procedures for seamless interoperability and data standards and security for all participating sites. Overcoming these barriers will greatly expand access to research tools and health information for physicians, patients, and researchers, both in academic health centers and wherever researchers conduct community-based research. Enhanced connectivity will also broaden access to education and training programs that further national efforts to strengthen the clinical research workforce.

#### *Questions to consider:*

- What steps are needed to enhance the existing network infrastructure to adequately support interdisciplinary research and training of junior faculty and community program staff?
- What processes are required for the existing network infrastructure to facilitate interaction among grantees in geographical proximity and nationally?
- How can programs utilize their existing resources to increase the capacity of the existing network infrastructure to bridge academic health centers and community health care providers in order to foster

and stimulate community-based clinical and translational research?

- What are the needs of institutions in urban, rural, or remote areas, and how can these needs be addressed to enhance opportunities for communication and broader inclusion in biomedical and behavioral research?
- How will the costs of developing and sustaining network infrastructure that meets anticipated research needs and promotes collaboration be supported?

## **Training**

These workshops will address challenges and enhancement strategies to increase the recruitment, retention, and promotion of minority and underserved investigators in cancer health disparities research. Reducing and eliminating cancer related health disparities requires a well-trained, collaborative group of trans-disciplinary researchers and it is essential to provide specific training targeting senior researchers and junior investigators relating to the following points:

- Recruit and mentor junior minority investigators.
- Increase knowledge of the peer review process and how it plays an essential role in increasing the competitive pool of investigators working with diverse populations.
- Recognize the challenges and strengths confronted by the new investigator in identifying gaps in the field of cancer health disparities research.

#### *Key topics of discussion will include:*

- Describing the current pool of minority and underserved investigators in the area of cancer health disparities and why they are needed.
- Identifying challenges faced in both recruitment and retention of minority and underserved researchers in health disparities.
- Describing currently funded NIH programs that are available to facilitate increased recruitment and retention of minority and underserved investigators.

- Discussing study section participation and sharing approaches to promote peer review involvement.

*Questions to Consider:*

- What are the critical training gaps and needs for members of trans-disciplinary regional cancer health disparities teams?
- How do we encourage and promote the participation of cancer health disparities researchers on review committees to learn grant preparation nuances (e.g., individual reviewer qualifications and common critiques of research applications)?
- How do we engage in cross-talk and planning within a region to identify a recruitment pool of new investigators as well as training and recruitment/incentive needs?
- How do we ensure the inclusion of a more diversified pool of investigators to fill identified research gaps in new and emerging areas of science?
- What are some best practices to work with junior researchers in documenting the process to find the appropriate institution, mentors, and funding opportunities?



# ***Appendix C: Glossary of Acronyms***

<b>ACS</b>	<b>American Cancer Society</b>
<b>AI/AN</b>	<b>American Indian/Alaska Native</b>
<b>AIM</b>	<b>Ancestry informative marker</b>
<b>caBIG</b>	<b>Cancer Biomedical Informatics Grid</b>
<b>CARRA</b>	<b>Consumer Advocates in Research and Related Activities</b>
<b>CBPR</b>	<b>Community-based participatory research</b>
<b>CCN</b>	<b>Carolina Community Network to Reduce Cancer Disparities</b>
<b>CCOP</b>	<b>Community Clinical Oncology Program</b>
<b>CDRP</b>	<b>Cancer Disparities Research Partnership Program</b>
<b>CIS</b>	<b>Cancer Information Service</b>
<b>CNP</b>	<b>Community Networks Program</b>
<b>CRCHD</b>	<b>Center to Reduce Cancer Health Disparities</b>
<b>CTES</b>	<b>Clinical Trials Education Series</b>
<b>DRI</b>	<b>Division of Research Infrastructure</b>
<b>GIS</b>	<b>Geographic Information System</b>
<b>GWCI</b>	<b>George Washington Cancer Institute</b>
<b>IDeA</b>	<b>Institutional Development Award</b>
<b>IRB</b>	<b>Institutional Review Board</b>
<b>IT</b>	<b>Information Technology</b>
<b>MassCONNECT</b>	<b>Massachusetts Community Network to Eliminate Cancer Disparities</b>
<b>MI/CCP</b>	<b>Minority Institution/Cancer Center Partnership</b>
<b>MSI</b>	<b>Minority Serving Institution</b>
<b>NCI</b>	<b>National Cancer Institute</b>
<b>NCMHD</b>	<b>National Center on Minority Health and Health Disparities</b>
<b>NCRR</b>	<b>National Center for Research Resources</b>
<b>NIH</b>	<b>National Institutes of Health</b>
<b>OUCNP</b>	<b>University of Oklahoma Community Networks Program</b>
<b>PFFS</b>	<b>Patient Fast Fact Sheet</b>
<b>PLANET</b>	<b>Plan, Link, Act, Network with Evidence-based Tools</b>
<b>PNRP</b>	<b>Patient Navigation Research Program</b>
<b>RCMI</b>	<b>Research Centers in Minority Institutions</b>
<b>REACH</b>	<b>Research, Education, And Community Health</b>
<b>SRHS</b>	<b>Singing River Hospital System</b>
<b>TeRMM</b>	<b>Tobacco-Related Messages and Media</b>
<b>TGen</b>	<b>Translational Genomics Research Institute</b>
<b>TReND</b>	<b>Tobacco Research Network on Disparities</b>
<b>WINCART</b>	<b>Weaving an Islander Network for Cancer Awareness, Research and Training</b>





# ***Appendix D: Participating Programs***

## **National Cancer Institute**

### ***Cancer Disparities Research Partnership Program***

The National Cancer Institute's Cooperative Planning Grant for Cancer Disparities Research Partnership Program (CDRP) issued by the Radiation Research Program is an effort to strengthen the National Cancer Program by developing models to reduce significant negative consequences of cancer disparities seen in certain U.S. populations. The Program supports the planning, development, and conduct of radiation oncology clinical trials in institutions that care for a disproportionate number of medically underserved, low-income, ethnic, and minority populations but have not been traditionally involved in NCI-sponsored research. In addition, CDRP supports the planning, development, and implementation of nurturing partnerships among applicant institutions and committed and experienced institutions actively involved in NCI-sponsored cancer research.

<http://www3.cancer.gov/rrp/CDRP/index.html>

### ***Cancer Information Service***

The National Cancer Institute (NCI), the nation's lead agency for cancer research, established the Cancer Information Service (CIS) in 1975 to educate people about cancer prevention, risk factors, early detection, symptoms, diagnosis, treatment, and research. The CIS is an essential part of NCI's cancer prevention and control efforts.

<http://cis.nci.nih.gov/about/about.html>

### ***Community Networks Program***

The Community Networks Program (CNP) is designed to reach communities and populations that experience a disproportionate share of the cancer burden, including African Americans, American Indians/Alaska Natives, Hawaiian Natives and other Pacific Islanders, Asians, Hispanics/Latinos, and underserved rural populations. The overall goal of the program is to significantly improve access to and utilization of beneficial cancer interventions and treatments in communities experiencing cancer health disparities in order to reduce these disparities.

<http://crchd.cancer.gov/cnp/background.html>

### ***Minority-Based Community Clinical Oncology Program***

The Minority-Based Community Clinical Oncology Program (CCOP) will: (1) provide support for expanding clinical research in minority community settings; (2) bring the advantages of state-of-the-art treatment and cancer prevention and control research to minority individuals in their own communities; (3) increase the involvement of primary health care providers and other specialists in cancer prevention and control studies; (4) establish an operational base for extending cancer prevention and control and reducing cancer incidence, morbidity, and mortality in minority populations; and (5) examine selected issues in Minority-Based CCOP performance (e.g., patient recruitment, accrual, eligibility).

<http://www3.cancer.gov/prevention/ccop/>



## ***Minority Institution/Cancer Center Partnership***

Through planning activities dedicated to developing stable, long-term comprehensive partnerships that are mutually beneficial to Minority Serving Institutions (MSIs) and NCI Cancer Centers, the objectives of the Minority Institution/Cancer Center Partnership (MI/CCP) program are to increase the participation of MSIs in the nation's cancer research and research training enterprise, increase the involvement and effectiveness of the Cancer Centers in research and research training and career development related to minorities, and develop more effective research, education, and outreach programs that will have an impact on minority populations.

<http://minorityopportunities.nci.nih.gov/index.html>

## ***Patient Navigation Research Program***

The overall goal of the Patient Navigation Research Program is to develop effective interventions to reduce cancer health disparities by facilitating timely, continuous access to quality, standard cancer care for all Americans. Patient navigation for cancer care represents a new approach to providing individualized assistance to patients, survivors, and families. Navigation spans the period from cancer-related abnormal findings through diagnostic testing to completion of cancer treatment. Patient navigators are trained, culturally sensitive, health care workers who help individuals address patient access barriers to quality, standard cancer care.

<http://crchd.cancer.gov/pnp/pnrp-index.html>

## **National Center for Research Resources**

### ***Research Centers in Minority Institutions***

The Research Centers in Minority Institutions (RCMI) program enhances the research capacity and infrastructure at minority colleges and universities that offer doctorates in health sciences. To be eligible to apply for the RCMI grants, graduate institutions must have one or more underrepresented minority groups that comprise 50 percent or more of their student body representation. RCMI support is provided by the NCRR Division of Research Infrastructure (DRI) and provides funding to recruit established and promising researchers, acquire advanced instrumentation, modify laboratories for competitive research, fund core research facilities, and support other research. Because many investigators at RCMI institutions study diseases that disproportionately affect minorities, NCRR support serves the dual purpose of bringing more minority scientists into mainstream research and enhancing studies of minority health.

[http://www.ncrr.nih.gov/research\\_infrastructure/research\\_centers\\_in\\_minority\\_institutions/](http://www.ncrr.nih.gov/research_infrastructure/research_centers_in_minority_institutions/)

### ***Institutional Development Award (IDeA) Program***

The Institutional Development Award (IDeA) Program broadens the geographic distribution of NIH funding for biomedical and behavioral research. The program fosters health-related research and enhances the competitiveness of investigators at institutions located in states where the aggregate success rate for applications to NIH has historically been low. Supported by the NCRR Division of Research Infrastructure (DRI), IDeA increases competitiveness of investigators through support for faculty development and enhancement of the research infrastructure at institutions located in the currently eligible 23 states and Puerto Rico.

[http://www.ncrr.nih.gov/research\\_infrastructure/institutional\\_development\\_award/](http://www.ncrr.nih.gov/research_infrastructure/institutional_development_award/)

## **National Center on Minority Health and Health Disparities**

### ***Community-Based Participatory Research Program***

The goal of this program is to support community intervention research studies using community-based participatory research (CBPR) principles and methods to reduce and eliminate health disparities in any disease or condition of major concern to the community with emphasis on racial and ethnic minorities. This initiative has three phases: a 3-year research planning grant, a competitive 5-year intervention research grant, and a 3-year dissemination research grant.

*<http://ncmbd.nih.gov/>*

### ***Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training (Project EXPORT)***

The program aims to build research capacity at designated institutions enrolling a significant number of students from health disparity populations and to promote participation and training in biomedical and behavioral research among health disparity populations.

*[http://ncmbd.nih.gov/our\\_programs/project\\_export\\_awards/PrjExpFY03Awards.asp](http://ncmbd.nih.gov/our_programs/project_export_awards/PrjExpFY03Awards.asp)*





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