



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,

Sanya A. Springfield, Ph.D.
Director
Center to Reduce Cancer
Health Disparities
National Cancer Institute

Barbara Alving, M.D.
Director
National Center for
Research Resources

John Ruffin, Ph.D.
Director
National Center on Minority
Health and Health Disparities

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

Tarsha McCrae, Center to Reduce Cancer Health Disparities, NCI

Shelia McClure, Division of Research Infrastructure, NCRR

Francisco Sy, Community-Based Participatory Research, NCMHD

Planning Committee Members

Jamelle Banks, Office of Science Planning and Assessment, NCI

Dionne Burt, Center to Reduce Cancer Health Disparities, NCI

Kenneth Chu, Center to Reduce Cancer Health Disparities, NCI

Leslie Cooper, Center to Reduce Cancer Health Disparities, NCI

Roland Garcia, Center to Reduce Cancer Health Disparities, NCI

James Hadley, Office of Liaison Activities, NCI

Kimberly Henderson, Center to Reduce Cancer Health Disparities, NCI

Belinda Locke, Center to Reduce Cancer Health Disparities, NCI

Francis Mahaney, Center to Reduce Cancer Health Disparities, NCI

Worta McCaskill-Stevens, Division of Cancer Prevention, NCI

Sonja Roberson, Division of Extramural Activities, NCI

Shobha Srinivasan, Division of Cancer Control and Population Sciences, NCI

Fred Taylor, Division of Research Infrastructure, NCRR

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

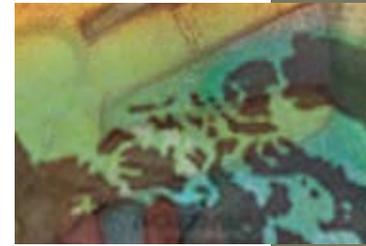
Rosemary Wong, Division of Cancer Treatment and Diagnosis, NCI

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.

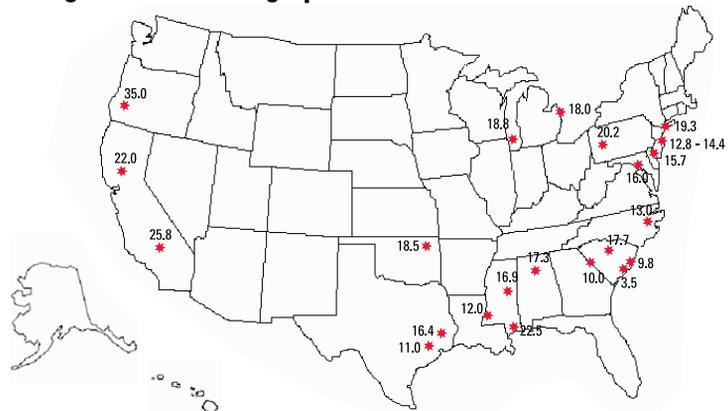
In the past, researchers have depended on “self-reported race” to try to identify relationships between race or ancestry and disease. This approach assumes that individuals are knowledgeable and open about their ancestry. However, studies have shown that this is often not the case, particularly in the 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.



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

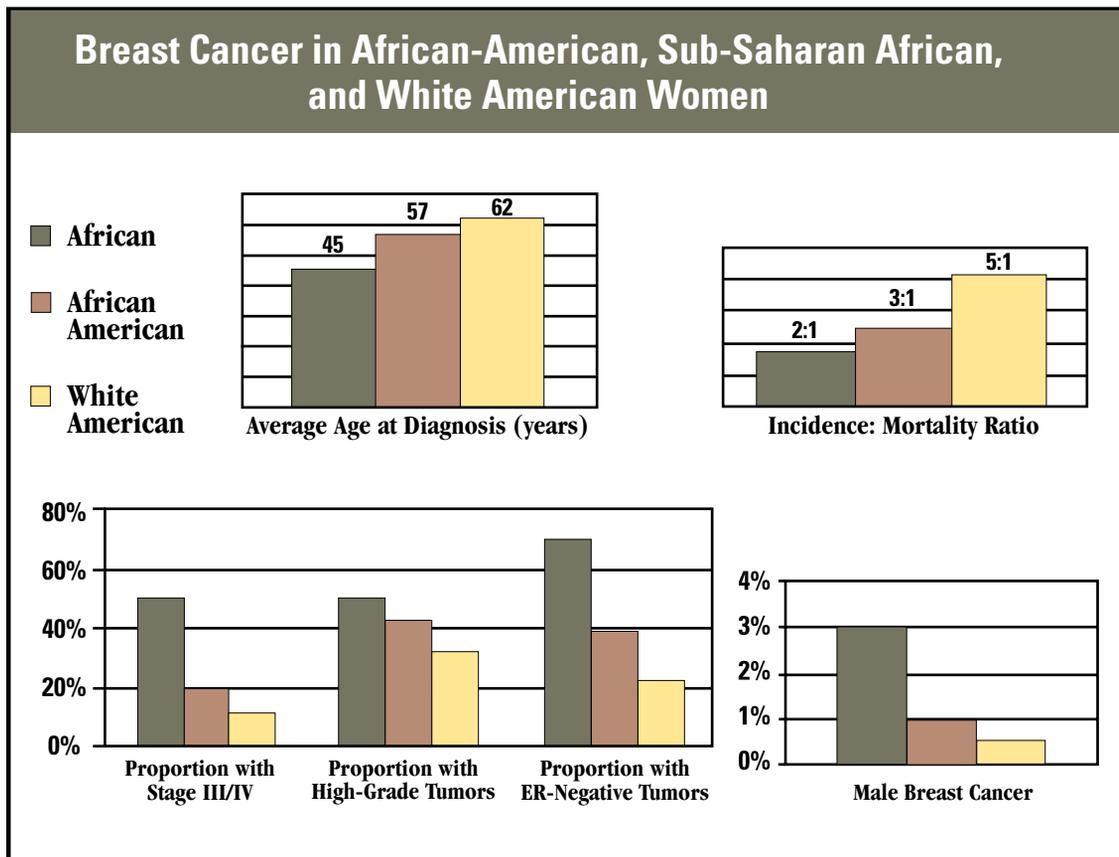
respond to existing treatments. Interestingly, sub-Saharan African women develop breast cancer at even younger ages than African Americans and have a substantially higher proportion of tumors that do not express estrogen receptor. These data suggest an association between African ancestry and increased 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

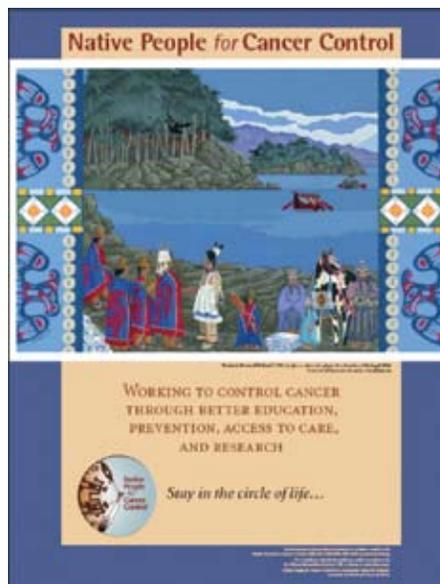
Community Networks Program: Native People for Cancer Control Art for Cancer Program

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.

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.

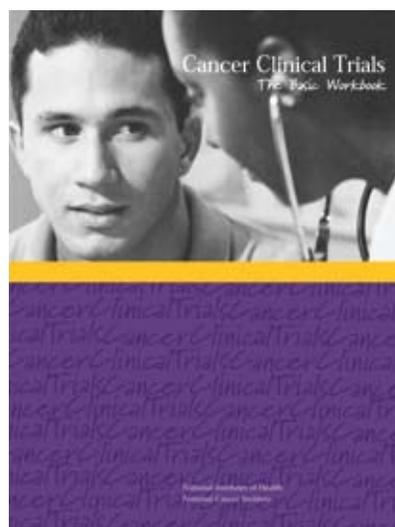
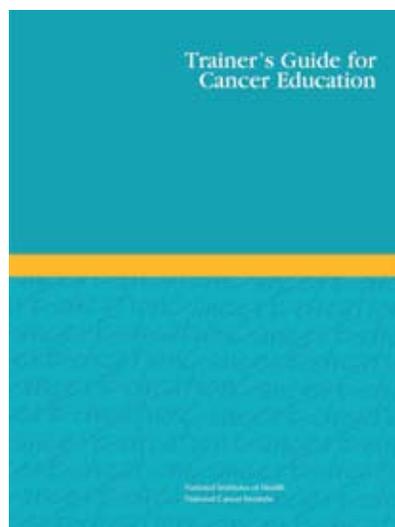
CTES also has a Trainer's Guide, a train-the-trainer program for those interested in or tasked with organizing targeted education and outreach programs. The Trainer's Guide includes diverse curricula and provides step-by-step instructions on how to conduct trainings.

To obtain free copies of CTES materials:

- Call 1-800-4-CANCER.
- Visit www.cancer.gov/publications.

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.,
Cancer Information Service, NCI

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

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

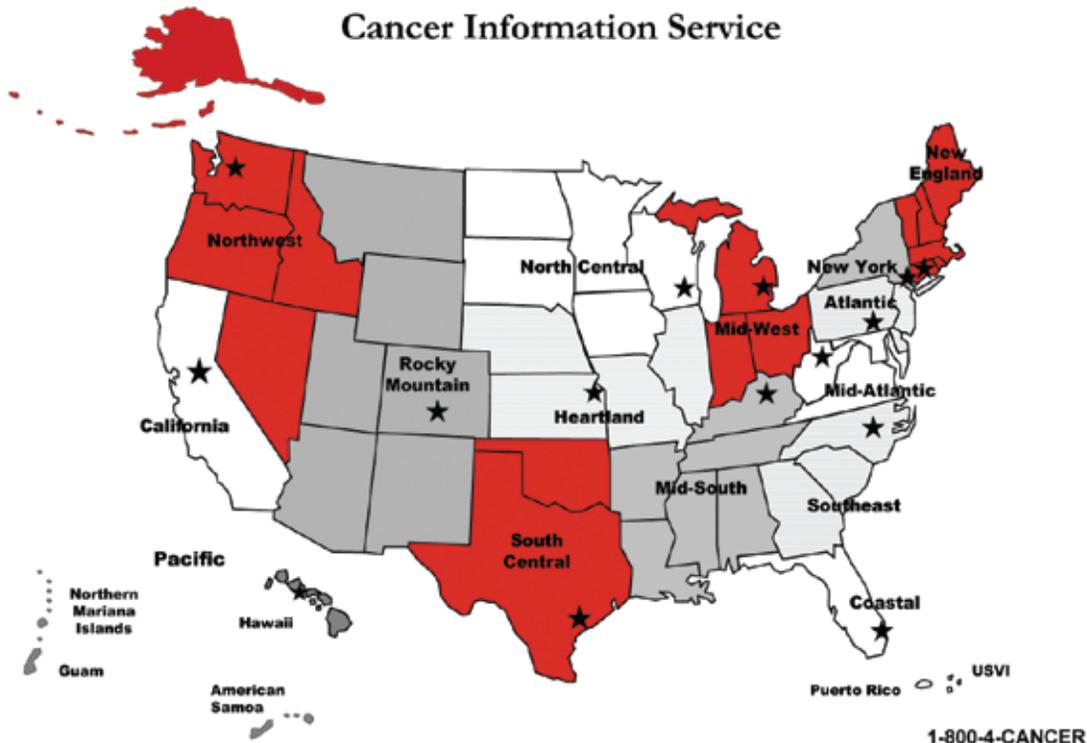
Felicia Solomon, M.P.H.,
Office of Communications and Education, NCI

Sona Thakkar, M.A.,
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.

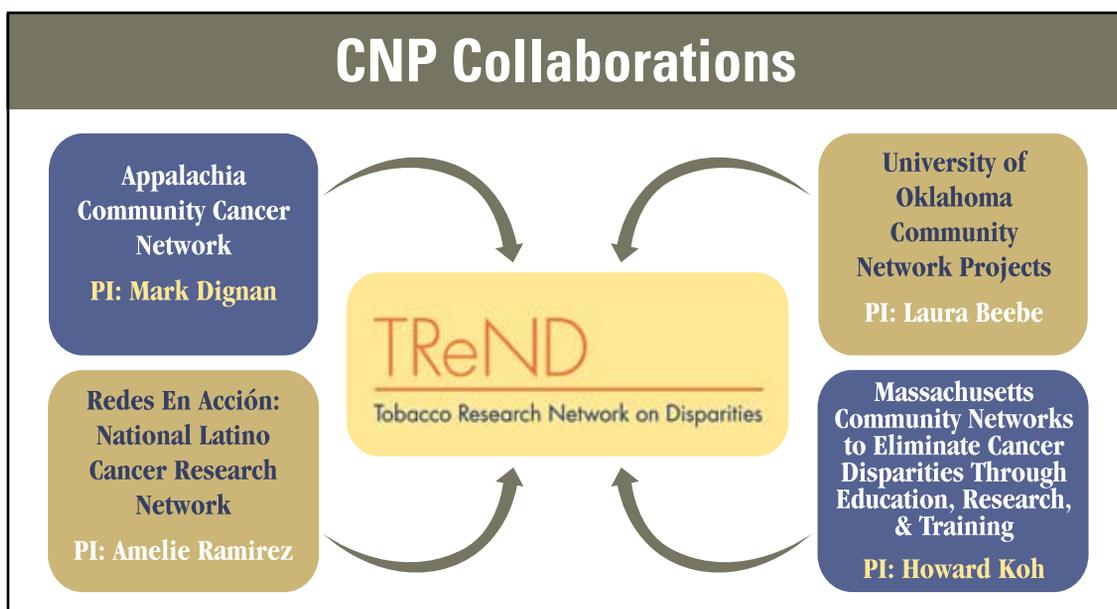
- Phase II: Develop the TeRMM index based on the results of the focus groups and conduct cognitive testing of the index.
- Phase III: Validate the TeRMM index in a large national survey.
- Phase IV: Disseminate the index and related data to the tobacco control field.

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:

Laura Beebe, Ph.D.,
University of Oklahoma Community Networks
Project

Josephine Crisostomo, M.P.H.,
MassCONNECT, Dana-Farber Cancer Institute

Pebbles Fagan, Ph.D., M.P.H.,
Division of Cancer Control and Population
Sciences, NCI

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://crcbd.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.



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