

The Special Populations Networks for cancer awareness research and training

Abstract: The Special Populations Networks (SPN) project is widely regarded as perhaps the most successful in the history of the National Cancer Institute (NCI) at performing cancer awareness, research, and training activities within minority and underserved communities throughout the United States and its territories. Key to that success is the trust established among the community, its researchers and the NCI. Composed of 18 separate grant awards, the SPN project was implemented in April 2000 to integrate the communities' need for cancer information with the NCI's need to increase cancer awareness, perform new research, and train minority junior investigators for research in populations with a disproportionate burden of cancer. To date, the 18 networks have conducted more than 1,000 awareness events, trained more than 2,000 community health aides, won 135 grants to support pilot research projects, published 130 peer-reviewed papers, and raised another \$20 million to support SPN activities. Successful implementation of the SPN project required the principal investigators to establish and maintain close working relationships with key community leaders and organizations in cooperation with NCI.

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Introduction

The Special Populations Networks for Cancer Awareness Research and Training project is a major part of NCI's response to the disparately high rates of morbidity and mortality within minority and underserved communities. In April 2000, NCI issued 18 grant awards (See Table 1) to enhance its efforts to reduce the suffering and death due to cancer. The overarching goal is to establish a robust and sustainable research infrastructure to promote cancer awareness and to launch from these more research and cancer control activities aimed at specific population subgroups. The 18 SPNs comprise 6 programs focused on African-Americans, 3 on Hispanics, 2 on American Indians/Alaska Natives, 1 on Appalachian rural poor, 2 on Asian-Americans, 2 in multiracial/ethnic communities, and 2 on Pacific Islanders. The Appalachian program is the only SPN focused on the cancer health of a geographical area—not race or ethnicity. The Native Hawaiian-focused program in Hawai'i is the only SPN that is community-based, not run by an academic institution.

Methods/approach

The methods and approach for the SPN project are embodied in specific goals and phases.

The goals are:

1. Building infrastructure capacity by the grantee institutions;
2. Establishing academic and/or clinical partnerships between the grantee institution and cooperating institutions to support enhanced education about clinical trials and promote participation of minority scientists in research;
3. Promoting training opportunities for minority researchers and students while enhancing awareness and utilization of training opportunities;
4. Planning and instituting collaborative developmental projects with relevant NCI divisions and research partners, and
5. Developing with research partners competing grant applications that stem from the pilot projects.

These goals are fulfilled in three time-centered phases:

Phase I. Beginning in Year 1, SPNs were required to build infrastructure and capacity by establishing and maintaining a continuum of cancer awareness and education activities while organizing and building community infrastructure for research participation.

Phase II. Beginning in Years 2 and 3, SPNs were required to establish: 1) academic, clinical, and community partnerships, 2) enhance training opportunities for minority scientists, and 3) develop and implement pilot research projects.

Phase III. Beginning in Years 4 and 5, SPNs were required to emphasize research training and develop applications for investigator-initiated research in special populations.

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Table 1. Special Population Networks, 2000-2005

Population	Projects
African Americans	Arkansas Special Populations Access Network (ASpan), Arkansas Cancer Research Center, Little Rock, AR Deep South Network for Cancer Control, University of Alabama, Birmingham, AL East Harlem Partnership for Cancer Awareness, Derald H. Ruttenberg Cancer Center, Mt. Siani School of Medicine, New York, NY National Black Leadership-Cancer Control, Research & Training Network (NBL-CCRTN), National Center for Primary Care, Morehouse School of Medicine, Atlanta, GA Increasing Access to Clinical and Educational Studies (ACES), Thomas Jefferson University, Philadelphia, PA Special Populations Network for Cancer Control (SPNCC), Thomas Jefferson University, Philadelphia, PA
Hispanics	Latin American Cancer Research Coalition (LACRC), Washington Cancer Institute, Washington Hospital Center, Washington, DC Latino/a Research & Policy Center, University of Colorado at Denver, Denver, CO Redes En Accion, Baylor College of Medicine, Houston, TX
Native Americans and Alaska Natives	American Indian Initiative in Arizona, Arizona Cancer Center, Tucson, AZ The Network for Cancer Control Research Among American Indian and Alaska Native (AI/AN) Populations, Mayo Clinic Foundation, Rochester, MN
Pacific Islanders	ʻImi Hale, the Native Hawaiian Cancer Research & Training Network, Papa Ola Lōkahi, Honolulu, HI Pacific Islander Cancer Control Network (PICCN), Pacific Islander Cancer Control Network Department of Medicine, UC-Irvine, Orange, CA
Appalachia rural poor	Appalachia Cancer Network (ACN), Markey Cancer Center, University of Kentucky, Lexington, KY
Multiethnic minority focus	Cancer Awareness Network for Immigrant Minority Populations (CANIMP), Center for Immigrant Health, NYU School of Medicine, New York, NY Maryland Special Populations Cancer Network, Office of Research & Development, University of Maryland, Baltimore, MD

Results

A formal evaluation is being conducted of the SPN project. During the first four years of the five-year project, the work of each SPN was peer reviewed and rated either outstanding, excellent, very good, good, or fair. Technical assistance was provided by NCI upon request. The collective evaluation has yielded the following categorical summary of SPN achievements over their first four years of performance.

Cancer Awareness: More than 1,000 activities were conducted ranging from health fairs and various community events to participation in annual ethnic and cultural heritage celebrations. More than 2,000 community lay workers were trained as health advisors to inform their communities about cancer control. More than 300 partnerships were established, each with a formal Memorandum of Understanding (MOU). These MOUs were principally with local community-based organizations.

Training: More than 270 applications for pilot research projects were submitted to NCI, and more than 135 were funded. Of the applications, 225 or more were submitted by minority junior researchers, and more than 100 were funded.

This level of achievement provides a new model for involving minority junior scientists in research by having them plan and develop research proposals, compete for funding, implement their projects, and write up their results.

Research: More than 130 scientific publications have resulted from the SPNs. The topics deal with numerous issues and questions involving special populations ranging from the development of culturally competent materials to the development of models for performing research in a community-based setting. This achievement is a shining example of the ability of special-population researchers to impact the scientific literature.

Other achievements: The SPNs have been able to leverage their NCI funding by obtaining funding from other sources. More than \$20 million have been obtained collectively by the SPNs. This includes \$6 million for cancer awareness activities from organizations such as the Susan G. Komen Foundation, American Cancer Society, Avon Foundation, American Legacy Foundation, and many others. Seven million dollars have been obtained for research in special populations and another \$7 million for training minority researchers.

In the first three years of the project, several of the SPNs expanded their geographical coverage from a few counties to an entire state. Others expanded from a racial/ethnic community in one city, to like communities in other cities. These also had corresponding increases in staffing and funding.

At least two new community-based activities are being established that are directly attributed to the SPN project: 1) The Cancer Council of the Pacific Islands, a body to collectively address the cancer health needs in the 6 jurisdictions that comprise the US-associated Pacific; and 2) The Fanny Lou Hamer Cancer Foundation, named for the famed civil rights leader in the Mississippi Delta who died of breast cancer. These achievements are due to the competent and visionary leadership of the SPN principal investigators, their dedicated staff, and their ability to mobilize the community in support of project activities.

Eleven of the 18 SPN principal investigators (PI) are leaders within minority communities. One PI was awarded “Distinguished Faculty” status and was so honored at a gala fundraiser where her SPN accomplishments were profiled. Another PI has been awarded accelerated promotion towards the rank of full professor. Three are members of NCI’s most senior advisory group—the National Cancer Advisory Board—and nine are members of the Trans HHS Cancer Health Disparities Progress Review Group that produced the groundbreaking report “Making Cancer Health Disparities History.”

Discussion

The five-year performance period of the SPNs ends in March 2005. However, reports of residual program activity from various community sites suggest that it may be a while before the full measure of SPN achievements is realized.

The achievements of this project have been presented to the NCI governing bodies as the basis for competitive renewal and continuance of community interventions for another five years. Approval was granted along with a 30% increase in funding, and the resulting Request for Applications was opened to all eligible institutions. Programmatic emphasis during the next performance period will move from special-populations research to reducing cancer disparities in the community. This new program titled “Community Networks to Reduce Cancer Health Disparities” reflects this change in orientation.

The SPN project and its successor, the newly created Community Networks, represent the development of a new paradigm for research for and with underrepresented minority and medically underserved populations, integrating cancer education with community-based research and training. By engaging research leaders of these populations in aiding their own, training their own, and developing research to help their own, they have uncovered the power of their commitment to their own. The communities recognize this, and there is a bond growing among communities, SPN leaders, and NCI. Focus on trust-building and means of empowerment are key to the success of the SPN project.

More information about the Special Populations Networks can be found at <http://crchd.nci.nih.gov/spn/introduction/index.html>. ■

A sakau plant must not be placed vertically against the wall at a *kamadipw*. If the plant falls on you it will bring bad luck and even death. Also, bubbles in a cup of sakau will bring bad luck.

Pohnpeian beliefs