

# How NCCCP Outreach Efforts Help Reduce Cancer Disparities

Efforts to reduce cancer healthcare disparities are challenging and require multidimensional strategies and solutions. These efforts should be tailored to the demographics of each community and to specific priorities. NCCCP sites identified community outreach and screening events as critical to successfully engaging disparate communities for reducing cancer disparities. To that end, NCCCP community outreach programs involved the intentional and bi-directional process of building relationships in the community to facilitate access to information, education, services, and support for addressing community health and healthcare needs.<sup>1</sup> Together, NCCCP sites worked to develop tools and resources designed to improve, expand, and demonstrate the impact of outreach efforts. They shared best practices and tools, including:

- Cultural awareness webinars to provide education on how disparate populations' healthcare beliefs may influence interactions with the healthcare team.
- Case studies to share strategies for reaching under-

served populations (see pages 44-45) and to help identify promising practices, as well as challenges, related to increasing enrollment in clinical trials.

- A template for community outreach to guide outreach program planning with an overview of important considerations for how to develop, implement, and evaluate focused community outreach efforts (Table 1, at right).

Over the course of the NCCCP pilot, as sites planned and implemented new programs, they consolidated their collective experience into the Disparities White Paper. This article features content from the paper to offer guidance for other community cancer centers working toward the same goals.

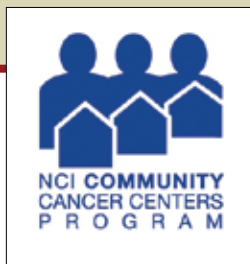
## Getting Started

To implement successful outreach projects, NCCCP sites found it helpful to first:

- Identify a specific targeted program (e.g., increase mammography for Hispanic women at risk for breast cancer)



Outreach coordinator draws blood from a local resident during a free health screening event, part of Community Health Day activities at NCCCP site Christiana Care.



- Establish clearly defined outcomes and metrics
- Ensure the collection of baseline data.

NCCCP sites recognized the importance of stakeholder engagement to project success. Key stakeholders included senior hospital administration, community health and outreach staff, nurse and patient navigators, registrars, and IT staff. A dedicated IT person helped NCCCP sites think about evaluation and data management to better analyze and track outreach data. For example, building an Access database helped incorporate important quality outcome measures into NCCCP outreach projects. The process of identifying outcome measures required input from nurse navigators and outreach staff.

### It Takes a Village—Partnerships

NCCCP sites found that partnerships were critical to the success of outreach projects. The collaborative efforts among NCCCP sites provided guidance in the develop-

ment and implementation of outreach projects. Partnerships and relationships with a variety of organizations—both large national organizations, such as the American Cancer Society (ACS) and community organizations—helped

bring screening and education to large numbers of underserved populations through local events such as Cultural Heritage Festivals. In addition, partnering with academic organizations, such as the Community Networks Program through NCI's Center to Reduce Cancer Health Disparities (<http://crchd.cancer.gov/cnp/overview.html>), opened doors to other partnership and grant opportunities.

Partnerships with community-based organizations offered numerous benefits—both to NCCCP sites and to their communities. Area residents gained a greater appreciation for the cancer center's mission and its ability to serve disparate and vulnerable populations. For many NCCCP sites, working with carefully chosen community and faith-based groups helped establish key relationships that opened avenues to collaboration on additional grant proposals and

**Table 1. NCCCP Disparities Community Outreach Template**

*Define target population and determine specific project activities:*

- Review community data, surveys, or other local or state processes to determine a significant unmet need (e.g., Hispanic women at risk for breast cancer and African-American men at risk for prostate cancer).
- Consider targeting the defined populations with specific cancer outreach, screening, and follow-up efforts. (Note: for Native Americans, NCCCP sites recommend that only one tribe be the focus for such an effort.)

*Determine partners and focus:*

- Define the goal and purpose of the partnership. Consider other community groups (e.g., Federally Qualified Health Centers, faith-based organizations) or efforts that serve the target populations and develop partnerships and/or form advisory groups.

*Define scope, objectives, goals, and expected outcomes:*

- Identify the scope (e.g., track screening through resolution of abnormal finding; track screening through treatment; promotion of clinical trials, follow-up care, and survivorship) and determine effective and measurable strategies and targets. Consider the following:
  - ✓ What information can be tracked
  - ✓ Community input and/or experience from other providers and community groups
  - ✓ The need for culturally appropriate material
  - ✓ Possible consultation with NCI CNPs, advocacy resources, or other NCI programs as needed.

*Develop metrics and proposed targets:*

- Determine baseline and change

metrics for the specific effort during the project time frame. The NCCCP breast screening tracking tool and the proposed colon cancer tool may offer useful templates.

*Document barriers:*

- Note strategies to overcome barriers specific to the project activity. Flag items for discussion with others on routine conference calls, initiate connections with other pilot sites, contact NCI as needed.

*Evaluate:*


- Assess effectiveness of the specific effort to make changes in interventions and to overcome barriers. Note ongoing barriers and share successes with other sites and NCI through quarterly reports, email updates, or agenda items for discussion on monthly calls.

## Factors to Help Ensure Successful Outreach Efforts

To create an effective outreach program infrastructure at a community cancer center, NCCCP sites recommend:

- Establishing support from physicians and senior hospital administration
  - Identifying internal (physician and administration champions) and external advocates to support outreach initiatives
  - Developing a multidisciplinary disparities committee made up of individuals representing appropriate clinical specialties and operating areas, such as patient registration, social services, and quality management
  - Conducting a needs assessment before beginning a project
  - Hiring a dedicated outreach coordinator (1.0 FTE is recommended) who is familiar with the targeted population
  - Considering whether a nurse or lay outreach worker is best for your efforts
  - Implementing a policy for accepting charity care
  - Working with hospital leadership
- to develop a plan to handle positive findings in the uninsured population
  - Building community partnerships that offer resources and credibility to your program and build trust within the community
  - Providing follow-up reports to the community partners
  - Ensuring that outreach staff is representative of the target populations (e.g., Hispanic outreach community worker)
  - Fostering community engagement through the use of volunteers to promote outreach initiatives and donations
  - Researching grant opportunities to support and sustain your outreach program
  - Implementing a plan to collect data, especially patient race and ethnicity data, in compliance with federal OMB guidelines
  - Ensuring timely data entry to promptly follow up on screening results and to document all services and issues in the disparities program database for tracking and reporting purposes
  - Identifying best practices and evidence-informed approaches to addressing cancer care disparities that are applicable to your community
- Creating a Disparities Dashboard to identify areas for intervention, such as common tumor sites (e.g., breast, prostate, colon)
  - Utilizing the dashboard tool to assess barriers to care, evaluate success reaching program goals, and ultimately measure quality indicators.

Staff resources may consist of a full-time community outreach coordinator who also serves as the patient care coordinator, a community educator, dedicated IT personnel, and administrative assistants. To meet defined goals and objectives, other staff can support program activities as appropriate. Bilingual capabilities are important for certain positions.

After identifying appropriate staff resources, offer education to ensure that personnel are equipped with proper training to implement a successful outreach program. Useful training modules include topics such as cultural sensitivity, health literacy, and race and ethnicity tracking. The NCI's Cancer Control P.L.A.N.E.T. (<http://cancercontrolplanet.cancer.gov>) is a resource to help planners, program staff, and researchers to design, implement, and evaluate evidence-based cancer control programs. 

expanded reach to more communities with trusted partners.

Another benefit to partnerships was the opportunity for NCCCP sites to add staff with specific skills, such as language translation. For example, bilingual staff in one partner organization helped translate educational information about the dangers of smoking to an underserved Hispanic population. Collaboration with experienced African-American outreach liaison staff helped NCCCP sites gain insight into new communities.

How might other cancer centers create such partnerships in their own communities? Try inviting the organizations to become members of a Community Advisory Council. Identify and reach out to church members or informal leaders to increase awareness of cancer services. Keep faith-based and community partners informed about hospital programs through ongoing communication, such as newsletters, a monthly calendar of events, or email alerts.

Many NCCCP sites collaborated with existing coalitions to bring services to large numbers of people in underserved communities. This strategy often led to support from other public health entities and cultural groups. Community partnerships should be ongoing relationships in order to sustain outreach projects and goals.

For community cancer centers that want to implement

or improve outreach efforts, NCCCP sites offer these key strategies:

- Engage your community in the initial design, development, and implementation of any outreach efforts.
- Conduct a needs assessment before planning a program. Ask key stakeholders: *What programs would be helpful to our community?*
- Take time to establish priorities and consider staffing capabilities.
- Incorporate your cancer team (nurses, patient navigators, and outreach staff) into activities. Include staff from your community partners.
- Stay flexible and adapt as necessary. Some organizations may experience funding cuts that reduce program staffing and disrupt the flow of projects.
- Identify dedicated IT personnel, data management, and evaluation requirements at the project's start to help analyze and track outreach data.
- Build a database that incorporates key outcome measures.

### Coordinating Resources for the Uninsured

Developing systems that work collaboratively to provide direct care and financial support to the uninsured is often

## Barriers to Successful Outreach Efforts

For community cancer centers looking to implement outreach programs, NCCCP sites identified these possible barriers to success:

- Lack of a consistent point person for various community organizations
- Diverse communication pathways that may occur when working simultaneously
  - with two or more cultures
  - Inability to identify key leadership within the faith-based community
  - Transportation and childcare challenges that must be met before attendees can participate in outreach programs
  - Multiple databases with no electronic connectivity
  - The ability to manage collected data (i.e., paper-based data)
  - Language differences
  - Preconceived notions and perceptions about the institution
  - Difficulties related to identifying additional funding to continue programs once they are established
  - The ability to gain trust from other organizations that have similar targets and intentions and to overcome skepticism from community members
  - Weather-related challenges (for outdoor events)
  - Time needed for staff training and development
  - Unanticipated interruptions, such as change in community leadership or loss of key staff members during implementation.

a challenge. In their efforts to reach out to the uninsured, NCCCP sites found three key strategies and offer these suggestions. First, establish a list of community resources and providers willing to deliver cancer services to the uninsured *before* starting a screening program. Second, agree on a plan with hospital leadership to handle positive findings in uninsured populations. Know your hospital's policy on charity care. Finally, ensure timely data entry. This strategy will allow expeditious follow-up of screening results and document services and issues in the disparities program database for effective tracking and reporting.

### Establishing Metrics

Various forms exist to capture and track data for measuring outreach program effectiveness. During the initial design of any database, quality metrics stratified by race, ethnicity, and abnormal findings can assist in improving overall quality and promoting equity. Having patients self-report by completing registration forms, pre- and post-tests, or surveys is an efficient way to collect information. While integrated IT programs are preferable, a simple Excel spreadsheet can also be created and easily modified to record collected metrics information for various types of outreach programs.

As part of their outreach efforts, NCCCP sites adapted several different tracking systems. Most sites used multiple databases to track their data. Having one database or interconnected databases will ensure compliance and assist with quality improvement.

In addition to demonstrating the impact of outreach efforts on targeted populations, tracking metrics specific to the cancer center are important for performance measurement, administrative justification, and budget justification. NCCCP sites suggest these metrics for outreach education or screening programs:

- Race, ethnicity, sex, and age of participants
- Zip code (to determine if outside the service area, rural or urban)
- Insurance status
- Number and type of screening events
- Number of patients screened by disease site (e.g., breast, cervical, prostate)
- Number of previous cancers and their disease sites
- Number of patients completing a screening for the first time

- Abnormalities found
- Number of patients lost to follow-up after an abnormal screening and reason
- Staff and volunteer hours
- Fixed and variable direct costs per screening event
- Number of screenings completed per provider per hour
- How the participant heard about the event (e.g., email, word of mouth, media, physician).

### Lessons Learned: The NCCCP Outreach Implementation Experience

The majority of NCCCP sites reported an overall positive experience implementing outreach projects. Benefits included:

- Increased awareness of the cancer center within the community
- More opportunities for collaboration with community organizations
- New opportunities to partner with public organizations (e.g., Health Department)
- Prospects for funding and donations
- Increased ability to identify and treat more patients whose cancer would have otherwise gone undetected
- Greater participation in screening events
- Improved credibility with diverse populations.

When NCCCP sites faced challenges to success, the primary obstacles were the lack of manpower and insufficient buy-in from private practice physicians. Outreach efforts to targeted populations require:

- Additional resources to maintain or enhance existing projects
- Dedicated outreach coordinators to locate, meet, and establish rapport with specific disparate populations
- Increased use of community needs data for planning
- The ability to provide ongoing outreach efforts for achieving long-term goals
- Internal support and cohesiveness among management and staff.

Communication barriers due to language, cultural beliefs or health literacy may influence whether minorities get high-quality healthcare. Identifying key members in the community who can help address these barriers is crucial to outreach

## CASE STUDY 1 Community Health Outreach and Education (CHOE) Program

At one NCCCP site, CHOE staff provided 225 public awareness and community-based screening programs reaching nearly 15,000 individuals annually. Success was achieved by planning programs that aligned with state and local initiatives, as well as careful review of evidence-based programs prior to initiating new programs.

The use of research-tested intervention programs (RTIPs) (<http://rtips.cancer.gov/rtips>) provided useful guidance. Through partnership with the NCI Cancer Information Service, CHOE used the “Using What Works” Program to assure that all staff had basic training for program planning, implementation, and evaluation. Through this program, staff learned about creating measurable goals and establishing a means to track success. Additionally, the NCCCP Disparities Community Outreach Template (Table 1, page 41) assisted with understanding how a program is developed, how it is implemented, and what steps are necessary to establish and attain measurable outcomes. All initiatives incorporated the best practices in patient navigation established by Dr. Harold Freeman.

From 2008 through 2009, this NCCCP site reached 2,254 individuals for breast, colon, prostate, and cervical cancer screenings. Of these, 1,288 persons were reached through a Combination Community Screening Program, which combines cholesterol, diabetes, and cancer risk assessment in an effort to draw in persons who may not come to a stand-alone cancer screening or

who do not understand the need for screening. The program started in 2005; it continued with funding from the Avon Breast Foundation for Women, Susan G. Komen for the Cure-Philadelphia Affiliate, the state Delaware Cancer Consortium, and the NCCCP. Screening venues included community and faith-based events and state service centers. Implementation of the Combination Community Screening Program required a full-time program coordinator to manage daily operations, arrange events to assist with meeting goals, track outcomes for each event, and organize follow-up for individuals requiring further assistance. The coordinator also targeted high-risk zip codes in an effort to touch never-screened residents, the uninsured, or individuals needing assistance to understand risk factors and the importance of cancer screenings.

An important step in development of this program was the establishment of, and the process for, the use of accurate forms to collect patient information for tracking purposes. The forms included demographic and medical history information, as well as clinical testing results. Recent changes incorporated information on smoking history, revised the race and ethnicity data, and added information on whether or not the person needs assistance to complete cancer screenings.

With a strong infrastructure in place, the Combination Community Screening Program was easier to expand through the development of alternative strategies. For example, “Health Information on the Go,” a program for blood pressure screenings, incorporates questions about cancer screening and allows individuals to provide information

that is passed on to a patient navigator. The navigator can contact the patient for additional follow-up.

These statistics clearly demonstrate the program’s success: Of the 1,288 who participated in the program, 588 (46 percent) were African Americans, 159 (13 percent) were Hispanic, and 320 were uninsured. There were 486 referrals for further assistance; 189 were referred for cancer screening assistance; 140 individuals were provided with further information on how to eliminate financial barriers; 74 percent actually completed screenings. Reviewing follow-up processes to encourage more screening completions remains challenging.

The major obstacles to this outreach effort included:

- Availability of staff during non-traditional working hours
- Additional bilingual staff required to focus on the Hispanic community
- Ensuring that the individuals served were not using the screening for second opinion or diagnostics
- Collecting data without an electronic data management system in place required manual tracking through spreadsheets and other databases
- Ensuring follow-up for individuals contacted by navigators and recommended for cancer screenings.

This program can be adapted and used by other community cancer centers as a strategy to serve hard-to-reach individuals, provide education, and deliver information. This type of setting is less threatening for some individuals than going to the doctor, and it allows screenings in a variety of community venues that provide easier access. 📌

efforts. A comprehensive outreach program should provide culturally sensitive and linguistically appropriate educational programs, including printed materials and hands-on training (e.g., breast self-exam models), and offer convenient cancer screenings within the community. Create an approach for how to best serve disparate groups by attempting to identify “at risk” populations within your community. Consider other community groups or efforts that serve these populations and develop partnerships. Endorsements from local community and faith-based leaders may also increase access

to disparate populations and secure additional resources, volunteers, or staffing. These collaborative strategies can enhance organizational credibility and trust, important factors to the success of the program.

Understanding the community’s perception of the cancer center is also important. Communities want to know that the cancer center is there for the long run, not just for one program or project. For example, navigating patients with positive screenings helps to ensure that the underserved are brought into the healthcare delivery system for

## CASE STUDY 2 Annual Minority Cancer Awareness Event

Using the NCCCP Disparities Community Outreach Template (Table 1, page 41), one NCCCP site designed an event to raise awareness in the minority community about the importance of being screened for cancer. Scheduled in conjunction with Minority Cancer Awareness Week, the event included screening for breast, skin, prostate, and colorectal cancers, as well as blood pressure and glucose screenings. Free food and children's activities,

including a clown and face-painting, were also offered. This NCCCP site used grant resources to underwrite the program and to promote the event.

The outreach event required six months of advance planning. The help of more than 100 volunteers and generous donations from the community were crucial to the successful implementation of this screening program. Success factors included a team approach to preparations, adequate planning time, and the involvement of the local community.

Obstacles included the weather

and the need for sufficient bilingual translators to assist at the event. An ideal addition would have been a bilingual physician or nurse practitioner.

Buy-in from the community included attendance by the city mayor, who also served as the event's Honorary Chairperson. Other cancer-related community-based organizations and health organizations were invited to participate in the health fair.

Through this one event, the NCCCP site is able to reach a large number of people and provide education for hundreds more. 📌



**Community member meets with cancer program representative during a screening event held as part of National Minority Cancer Awareness Week at The Cancer Program of Our Lady of the Lake and Mary Bird Perkins (NCCCP site).**

further diagnostic and treatment services. This process includes coordinating appointments with specific clinicians for consultation and procedures, offering referral to financial assistance programs as appropriate, providing follow-up support, and serving as a patient advocate.

Remember to provide evaluation and follow-up infor-

mation to community partners related to achievements of your joint efforts. Continue to foster these relationships, for example, by notifying community partners about events and screenings or by providing speakers for future community events. In an effort to build trust, it is important to consider community partnerships as long-term friendships that require nurturing. 📌

*Nora Katurakes, RN, MSN, OCN, is manager, Community Health Outreach and Education at Helen F. Graham Cancer Center, Newark, Del. Deb Hood, MBA, is director for the National Oncology Service Line for Catholic Health Initiatives, Colorado Springs, Colo. Mitchell Berger, MD, MMM, CPE, FACP, is medical director and principal investigator for NCCCP site The Cancer Program of Our Lady of the Lake and Mary Bird Perkins Cancer Center, Baton Rouge, La. Donna Costa, MA, MHS, is community outreach/program development manager at The Cancer Institute at St. Joseph Medical Center, Towson, Md. Renea Duffin, MPA, is vice-president of Cancer Programs at Our Lady of the Lake and Mary Bird Perkins Cancer Center, Baton Rouge, La. Delisa Simon-Dawkins, BLS, MT, is community outreach coordinator for Gibbs Cancer Center at Spartanburg Regional Hospital System, Spartanburg, S.C.*

*Additional contributors to this article acknowledged on page 52, the final page of the NCCCP Disparities White Paper feature.*

### References

<sup>1</sup>Gonzalez-Ramos G, Cohen E, Hagestuen R. *Health connect: A practical guide to community outreach*. Medtronic Foundation 2007.

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