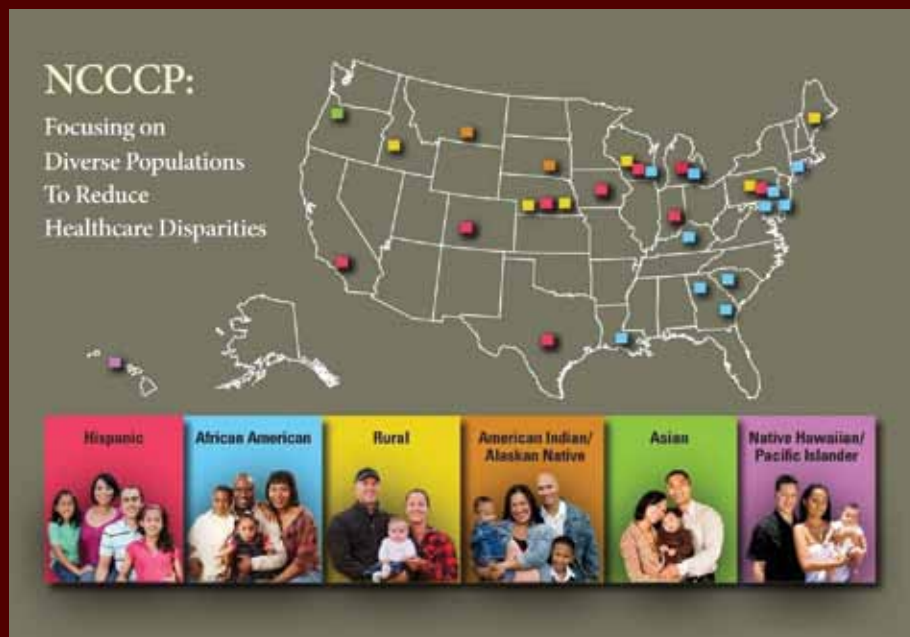


# Reducing Cancer Healthcare

## An overview of the NCCCP Disparities Subcommittee White Paper

The National Cancer Institute (NCI) launched the Community Cancer Centers Program (NCCCP) in 2007 as a three-year pilot, forming a public-private partnership with 16 community hospitals to explore the best methods to enhance access to care, reduce healthcare disparities, improve quality of care, and expand research within the community setting.<sup>1</sup> At the conclusion of the pilot period, the network sites collaborated to produce White Paper reports to document their experience addressing program deliverables in specific focus areas. A series about the NCCCP White Papers was introduced in the January/February 2011 edition of *Oncology Issues*.<sup>2</sup> This month's journal features the Disparities Subcommittee White Paper, divided into the following sections: Reducing Cancer Healthcare Disparities, Outreach Efforts, and Patient Navigation.

During the course of the NCCCP pilot, the 16 sites saw more than 27,000 new cancer cases per year and served diverse populations that included African American, Hispanic, Asian, and Native American peoples. In addition, many NCCCP pilot sites served rural and frontier populations—historically challenging areas for patients to access the full cancer continuum of services. The sites' efforts to address cancer healthcare disparities for underserved populations are discussed in this issue.



NCI launched the NCCCP pilot program in 2007 with 16 community hospitals. In 2010 NCI expanded the network and added 14 sites. Today, 30 NCCCP sites are working to reduce cancer healthcare disparities.

# Disparities at NCCCP Sites

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## Defining Disparities and Targeting Efforts

The NCCCP placed a strong focus on reducing healthcare disparities and dedicated 40 percent of program funding to this effort. At the start of the pilot, the 16 sites were using different definitions of disparities. Specific definitions were needed to help understand how to define disparate populations in their communities. The Disparities Subcommittee decided to use the Minority Health and Health Disparities Research and Education Act of 2000 definition for disparities, i.e., populations with differences in “the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates” as a basis.<sup>3</sup> The subcommittee further defined disparate populations to include not only racial and ethnic minorities, but also residents of rural areas, women, children, the elderly, persons with disabilities, the uninsured, the underinsured, and those who are socioeconomically disadvantaged. Each NCCCP site began to implement this definition to determine the priorities and focus for its own community.

Next, the subcommittee developed a Program Overview and Work Plan to provide NCCCP sites with specific direction about how to focus their disparities efforts for the remainder of the pilot. With input from all NCCCP subcommittees, a Disparities Dashboard (see pages 34-35) was developed. This tool included the program vision, a definition of disparities, metrics, and key pilot-wide disparities activities for each NCCCP focus pillar. The performance-based dashboard served as a management tool to improve the performance of NCCCP pilot sites in providing integrated cancer care and research to underserved populations, enabling sites to:

- Plan and manage an initiative to address cancer healthcare disparities
- Build skills
- Enhance the understanding of NCI to develop effective metrics to track cancer healthcare disparities efforts in community-based settings.

The complete listing of the disparities activities defined for each of the NCCCP program pillars are included in the Disparities Vision, Work Plan, and Dashboard, available online at: <http://ncccp.cancer.gov/files/NCCCP-Disparities-Dashboard-Combined.pdf>.

## The NCCCP Experience

Each NCCCP site needed a champion—typically the site’s representative to the Disparities Subcommittee—to translate the defined disparities work plan into action. Champions included physicians, dedicated outreach coordinators, cancer program administrators, and nurse navigators.

Outreach coordinators often worked with hospital committees to define the site’s focused activities. Some NCCCP sites formed a disparities taskforce or committee (e.g., Hospital Health Equity Committee). Other sites looked to their Diversity Council or cancer coalition to identify gaps in care. Still others interacted with parish nurse programs and departments of mission and ministry. Determining the focus of disparities activities required input from a wide range of participants, including administration, cancer physicians, hospital or cancer data analysts, outreach team members, and patients. Input from community partners, such as public health departments, clinics, advocacy groups, other providers, and state cancer coalitions helped accurately define the necessary work.

Standardized data collection was a crucial component for the overall effort. The Disparities Subcommittee identified end-result activities and methods to measure success. For many activities, these definitions and data requirements were specific to a particular work activity at an NCCCP site. The 16 pilot sites used various means of gathering data, including electronic capture, running reports from diverse hospital computer programs, and manual data entry; therefore, it was not possible to define a project that all 16 sites could complete in the same way. The Disparities Subcommittee, however, could be used as a forum to define both critical and desired data elements for capture. The subcommittee worked to discover and address deficiencies in collecting race and ethnicity data according to Office of Management and Budget (OMB) guidelines.

The NCCCP sites identified staff responsible for gathering and compiling the disparities data. While manual data entry often fell to outreach coordinators and nurse navigators, overall project analysis involved additional personnel. Due to the time constraints and logistics of manual entry, many NCCCP sites began developing electronic data collection solutions, ranging from Excel spreadsheets to Access databases and incorporation of data from cancer registry systems. Working with IT resources provided system-wide impact at their locations.

All NCCCP sites were able to:

- Develop a standard framework through the Disparities Work Plan and Dashboard
- Agree to common definitions
- Provide guidance, networking, and best practice sharing
- Collect data through periodic site assessments to measure the success of this work.

Baseline, interim, and final assessments were conducted throughout the pilot period. Data tracking included the



# NCCCP DISPARITIES VISION DASHBOARD

The NCI, through public/private partnerships with NCCCP pilot site community hospital-based cancer centers, will expand state-of-the-art cancer care continuum, from prevention and screening through treatment, follow-up and end of life care.

## Definition of Disparities

Health Disparities: "Different public and private agencies have different definitions of a 'health disparity' for their own program-related purposes, however these definitions tend to have several commonalities. In general, health disparities are defined as significant differences between one population and another. The Minority Health and Health Disparities Research and Education Act of 2000, which authorizes several HHS programs, describes these disparities as differences in "the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates." The Institute of Medicine publication, "Unequal Treatment" highlights inequities related to access and treatment as major factors in defining disparities.

NCCCP Disparities Dashboard	Overall Disparities Requirement: All patients screened and diagnosed with cancer		
	Clinical Trials	Biospecimens	Information Technology
<p><b>Consolidated disparities metrics from pilot sites by area of focus (OMB categories to be used for race and ethnicity metrics unless otherwise noted)</b></p>	<ul style="list-style-type: none"> <li>• % change minority patient accrual to pilot CTSU trials</li> <li>• % change minority accrual for NCI Cooperative Group and CCOP trials</li> <li>• % change in capturing data on race and ethnicity (e.g., decrease in missing data)</li> </ul>	<ul style="list-style-type: none"> <li>• # pilot sites that set up systems for special handling of specimens and consents for specific populations (e.g., Native Americans)</li> </ul>	<ul style="list-style-type: none"> <li>• % of sites (those participating in caBIG®) submitting race /ethnicity data to caBIG®</li> </ul>
<p><b>Key Disparities Activities/Overall Disparities Pilot Projects</b></p>	<ul style="list-style-type: none"> <li>• Minority accrual working group to develop recommendations for implementation by sites.</li> <li>• Track progress on race and ethnicity reporting</li> <li>• Track progress on role of navigators in accrual of patients to CT</li> </ul>	<ul style="list-style-type: none"> <li>• Education session on specimen and consent issues for special populations to be held for Biospecimen and other Subcommittees</li> </ul>	<ul style="list-style-type: none"> <li>• Support to be provided for multiple pilot projects</li> <li>• Work with vendors as opportunities arise on standardization of race and ethnicity data fields</li> </ul>

number of new community partnerships established, number of patients navigated, and number of community screenings and patients screened, as well as improvements in race and ethnicity measurements.

Comparing data across sites using these indicators was challenging, so the NCI and NCCCP sites worked together to develop a subset of data as metrics for each pillar on the Disparities Dashboard.

## Lessons Learned

NCCCP sites persist with efforts to improve data collection and data collection tools. The program's work aimed at reducing cancer healthcare disparities is ongoing and constantly evolving. NCCCP sites agree that it is important to:

- Understand and define disparate populations specific to each organization and community, while clearly identifying what makes the targeted group a disparate population.
- Identify and target efforts narrowly enough with a specific subpopulation to be successful and to measure change over time. While NCCCP's initial plan was to

look at all the disparate populations within a service area, the sites quickly realized the enormity of the work required to address all needs. Focusing on a particular subpopulation provides the chance to have a significant impact on eliminating healthcare disparities.

- Educate all involved cancer team members, regardless of what type of activities their work involves, about the importance of reducing disparities in cancer healthcare.
- Improve team members' understanding and knowledge of the best ways to make an impact on the defined disparate population.

This type of work requires continual and long-term efforts, and it is difficult to demonstrate measurable progress or change within a short time frame.

## Major Challenges

The program's efforts to reduce cancer healthcare disparities presented a few common challenges for NCCCP pilot sites:

*Understanding and defining the term "disparities."* The immediate interpretation is often that the disparate



and research to populations experiencing healthcare disparities (those with an excess burden from cancer) across the

For the NCCCP, we define the populations affected by health disparities to include racial and ethnic minorities, and other underserved populations: residents of rural areas, women, children, the elderly, persons with disabilities, the uninsured, underinsured and those who are socioeconomically disadvantaged.

### by the pilot sites are offered treatment— policies in place with annual confirmation

#### Quality of Care

- % pilot sites with improvement in completeness of race and ethnicity data for Commission on Cancer Quality of Care study (e.g., decrease in missing data)

#### Survivorship

- % of sites that have introduced tracking of race and ethnicity data in at least one of their Survivorship and Palliative Care programs

#### Disparities

- % change # of overall patients screened
- % change # of community partner organizations
- % change # of screening events by disease
- % change # patients navigated
- % change in number of pilot sites collecting race/ethnicity data

- Specific projects may emerge based on data collection and findings from quality of care initiatives
- Medical staff conditions of participation at pilot sites to include care of the uninsured

- Specific projects may emerge based on data collection and findings from Survivorship and Palliative Care initiatives

- Training modules/programs offered for race/ethnicity reporting
- Track progress on voluntary breast screening tracking tool for populations experiencing healthcare disparities
- Work with sites to track those never screened before, and those without a primary care physician

Approved by NCCCP Executive Committee – December 16, 2008

population is a racial or ethnic minority; however, disparities may include rural populations and other groups that require specific definitions for tracking (i.e., what constitutes a rural patient for cancer care in a specific market?).

**Time constraints.** Ongoing subcommittee calls placed multiple demands on staff members to participate. Many NCCCP sites did not have the resources or enough time to accomplish all the work given ongoing clinical responsibilities. For example, increasing and nurturing effective partnerships in the rural and Native American communities proved time intensive and long in duration.

**Data tracking and IT systems.** Hardware changes across organization enterprises were necessary to enhance race and ethnicity data collection to meet OMB guidelines.

**Limited resources.** Additional resources to screen and treat disparate populations were not included as part of the NCCCP project. To avoid overwhelming NCCCP sites and scattering efforts, the Disparities Subcommittee agreed outreach roles and responsibilities should be clarified, with goals prioritized. And while hospital marketing and public relations support for disparities activities can improve success, these teams are often focused on a variety of hospital

events and cannot provide adequate support to cancer center activities.

### Barriers to Success

Although NCCCP sites faced several challenges while trying to reduce cancer healthcare disparities, six major recurring themes surfaced. Creative strategies to overcome many of these obstacles emerged over time. Others, however, remain ongoing challenges.

**Cultural issues.** Chief among the cultural concerns were language barriers and trust issues. Reaching patients who spoke languages other than English presented challenges. Most often, NCCCP sites experienced a lack of bilingual staff or volunteers and translators available to assist with these patients. Educational materials had to be translated into the language of the non-English-speaking target population, which in most cases was Spanish. Another challenge: certain ethnic groups displayed a lack of trust in the medical system and its representatives. NCCCP sites spent more time and effort than anticipated to build a working rapport with African American, Hispanic, and Native American populations before disparities projects could be imple-

# Sustainable funding mechanisms are important for [disparities] long-term collaborations, and they help build the trust needed with different population groups.

mented. Faith-based community network models helped some NCCCP sites overcome these hurdles. Legal residency issues posed other problems, as services were often not available to patients who could not prove legal residency in the U.S.

**Staffing.** A few NCCCP sites lacked the key staff needed to conduct screening and education. Physician turnover and lack of nurses, patient navigators, and outreach staff contributed to this barrier. Instances of lack of buy-in and commitment from the host institution and physicians presented other challenges. Because these programs were often scheduled after normal working hours, it was sometimes difficult to convince qualified medical professionals to give up their valuable time off.

**Training and development.** Organization and time management issues ranged from deciding on which population to target to finding an appropriate time to hold training sessions for key staff. Often, NCCCP sites underestimated the time needed to develop and complete disparities projects and train staff.

**Partnership difficulties.** While NCCCP sites consistently acknowledged the many benefits of working with other organizations, these partnerships also created their own barriers to success. The most common challenge was the time necessary to establish trust with community members and community organizations, relationships that cannot be artificially rushed. Building relationships with several diverse communities at the same time could present additional challenges. At times, competing priorities within a partnering community or a faith-based organization created implementation problems for the projects. Not all community or public health organizations were able to deliver on the promises to support a project. Although participation in coalitions was a helpful strategy, large or complex coalitions might involve multiple agendas and deter focused action.

**IT.** Information technology barriers varied from site to site. It was sometimes difficult to collect accurate race and ethnicity data. Use of multiple databases that had no connectivity presented other challenges.

**Funding deficiencies.** A number of NCCCP sites had problems garnering consistent financial support for addressing cancer care disparities. At one site, patients who were diagnosed with cancer were supported by charity or community care within the hospital system, yet procedures had to be created to offer medication or equipment support from entities outside of the system. Financial assistance for treatment was an issue for undocumented patients who were often ineligible for governmental programs. Funding for specific outreach programs was frequently dependent on public or donor support that could be discontinued unexpectedly. Occasionally, state funding for existing

initiatives was withdrawn, requiring program adaptation. Sustainable funding mechanisms are important for projects that require long-term collaborations, and they help build the trust needed to develop programs with different population groups.

## The Importance of Improved Race and Ethnicity Data Collection

To ensure accurate reporting of information and accurate metrics to measure program effectiveness, NCCCP sites were expected to achieve compliance with OMB guidelines for use of race and ethnicity across multiple databases. These databases reside in many locations, including:

- Hospital financial systems
- Hospital inpatient and outpatient systems
- Cancer registries
- Hospital pathology systems
- Individual physician and practice office systems
- Community outreach activity logs.

For many healthcare organizations, the admission and/or registration process occurs via an automated software solution. This means that for most community cancer centers, changing data that is entered into the system is not simple. In addition, the cancer center is only one service line in an institution, and changes made in the cancer center can affect other parts of the organization.

To meet NCCCP goals for race and ethnicity data collection, sites secured buy-in from cancer services and hospital administration, admitting management and staff, IT teams, and patient support. An inclusive approach—identifying everyone affected by the project and involving all stakeholders early on—allowed NCCCP sites to define the project's scope, requirements, and planning phases.

NCCCP sites understood that accurate and standardized data would serve many purposes, including:

- Establishing common metrics and outcomes for tracking and reporting race categories and ethnicity
- Reporting accurate demographics of patients treated
- Analyzing outcomes to identify gaps in care related to race and ethnicity
- Providing culturally and linguistically appropriate care to patients
- Providing cultural awareness programs to staff based on patients treated.

A key resource outlined for OMB guidelines is available online at: [http://www.whitehouse.gov/sites/default/files/omb/assets/information\\_and\\_regulatory\\_affairs/re\\_app-a-update.pdf](http://www.whitehouse.gov/sites/default/files/omb/assets/information_and_regulatory_affairs/re_app-a-update.pdf). The minimum categories for data on race and ethnicity for federal statistics, program administrative reporting, and civil rights compliance reporting

# projects that require to develop programs

Table 1. OMB Categories for Race and Ethnicity Reporting

## Race

- **American Indian or Alaska Native:** A person having origins in any of the original peoples of North, Central, or South America, and who maintains tribal affiliation or community attachment.
- **Asian:** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent, including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- **Black or African-American:** A person having origins in any of the black racial groups of Africa.

- **Native Hawaiian or other Pacific Islander:** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White:** A person having origins in any of the original peoples of Europe, the Middle East, or Northern Africa. May include persons from Central or South America whose ancestors came from Europe.
- **More than one race:** A person whose ancestors are from different races (such as having one parent who is white and one who is black).
- **Other race.**

## Ethnicity\*

- **Hispanic or Latino:** A person of Mexican, Puerto Rican, Cuban, Central American, South American, or other Spanish culture or origin, regardless of race.
- **Non-Hispanic.**

\*The Ethnicity categories should be asked as two separate questions: 1) Do you consider yourself to be Hispanic or Non-Hispanic? and 2) What racial category best describes you? Thus, two separate data fields are required for this information. Other categories for “more than one race” or “does not want to respond” can be included.

Source. Office of Management and Budget (OMB). Revisions to the standards for the classification of federal data on race and ethnicity. *Federal Register*. 1997;62(210):58781-58790.

are defined in Table 1, above.

Data collection approaches for reducing cancer health-care disparities may involve modifications to existing processes. Consider incorporating information from the Health Research and Educational Trust (HRET) guidelines. The HRET Disparities Toolkit ([www.hretdisparities.org/](http://www.hretdisparities.org/)) is a web-based tool that provides information and resources for systematically collecting race, ethnicity, and primary language data from patients. HRET also provides a training deck to assist with staff training during implementation of the new collection process.

The NCCCP Disparities Subcommittee suggested that baseline metrics be collected at project implementation and quarterly thereafter. NCCCP sites used the following outcome measures for reporting over the course of the pilot period:

- Percentage improvement in race and ethnicity tracking in specific hospital and cancer program databases.
- Percentage of sites using OMB categories for tracking in specific hospital and cancer program databases.

## Implementation—Perspective from NCCCP Sites

Guiding principles to help implement race and ethnicity data collection include the following steps:

1. Review and standardize the definition and categories for race and ethnicity.
2. Educate and train staff on cultural awareness issues and information collection for race and ethnicity data.
3. Assess the cancer center’s process for tracking and data collection.
4. Avoid duplication of collection of race and ethnicity data.
5. Develop processes for tracking and data collection across the cancer program, including survivorship, quality, biospecimens, community outreach, and patient navigation.

Some community cancer centers may ask, “Given the complications of classifying and collecting accurate race and ethnicity data—should such data still be collected?” NCCCP pilot sites respond with a resounding “Yes.” The

## ...each cancer center needs to address cancer disparities specific to its community.

concepts of race and ethnicity create differential social, political, economic, and health-related realities for all people. These realities include the structures, beliefs, and practices of healthcare, medicine, and economics that contribute to health disparities for minority populations.<sup>4</sup> Continued collection of race and ethnicity data can help illuminate the historical contexts of health disparities and their impact on current populations.

### Recommendations and Conclusions

NCCCP efforts to reduce cancer healthcare disparities were the impetus for sites to: 1) review OMB categories and revise hospital registration processes, 2) establish patient navigation programs, and 3) expand outreach and screening activities. The NCCCP provided financial support for staff positions, such as outreach coordinators and nurse navigators, which may not have been funded otherwise. Quarterly reports from the NCCCP sites provided a comprehensive picture of the outcomes achieved over the three-year pilot, including an increased number of community partnerships for all sites.

For community cancer centers looking to reduce healthcare disparities, NCCCP sites offer these recommendations. First, understand that each cancer center needs to address cancer disparities specific to its community. Obtain input from organizational stakeholders, as well as community partners. Engage stakeholders who can offer financing solutions. Key community partners to consider are the agencies that generate the state's cancer control plan, the National Breast and Cervical Cancer Early Detection Program (NBCCEP), and the American Cancer Society.

Second, know that any disparities plan should include the population to be targeted, specific activities to address the disparities, and metrics to measure success. Before identifying a disparities project, community cancer centers should analyze and use available data to identify disparities that exist, review gaps in care delivery, and prioritize work. To help reduce cancer healthcare disparities, community cancer centers should also:

- Identify a disparities coordinator and team that can positively communicate the issues and impact change within the cancer center.
- Learn about the local community, its resources, and key members to help reach disparate populations. Engage members of disparate populations on outreach teams when possible. Consider forming a community advisory committee to gain ongoing input from the community.
- Use the tools developed and posted on the NCCCP website (<http://ncccp.cancer.gov/about/reports-and-tools.htm>).
- Collaborate, when possible, with NCI-funded Com-



**NCCCP site Billings Clinic holds a ceremony to present pink shawls to women who complete a breast cancer education program focused on Native American health.**

- community Networks Programs (CNPs) that focus on the targeted disparate populations.
- Learn from best practices that currently exist. Use existing education materials (evidence-based and tested). Be aware of health literacy concerns with patients.
- Keep stakeholders informed and communicate with them frequently. 🗣️

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

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