NCCCP PILOT DISPARITIES VISION AND PROGRAM OVERVIEW

This Disparities Vision, Program Overview, and Dashboard have been developed to provide an overview of all NCCCP pilot-wide disparities efforts that are underway in each of the sub-committees and to define the metrics that will be able to be tracked by the pilot sites from the baseline year to the end of the 3 year pilot. Because the NCCCP pilot program is a public/private partnership, the success of its initiatives is dependent upon guidance from NCI and the pilot sites (through the sub-committees). This program overview will enable the Disparities sub-committee to serve in an oversight and coordination role for all disparities related activities by organizing the activities in one document which the sub-committee can monitor and it will assist with communication and coordination for all of the sub-committees disparities efforts. Specifically this will:

- present a framework for the disparities efforts and provide a summary of activities
- assist with coordination and minimize duplication of effort
- serve as a planning tool so that the work of the pilot activities are noted on a timeline
- note the technical support that is needed to support activities
- track specific activities by pilot pillar
- provide a set of standard metrics across all pilot sites

DEVELOPMENT PROCESS

In May of 2008, a Disparities Vision Planning Group was established with representation from the NCCCP Program Advisory Committee (NPAC) and all key staff of the Center to Reduce Cancer Health Disparities (CRCHD), Co-Chairs of the Disparities sub-committee (pilot site representatives), and representatives from the NCCCP Evaluation Oversight Committee (EOC). Based on the recommendations of the Vision Planning Group, a draft framework and initial program overview was presented by the Director of the CRCHD at the NCCCP annual meeting. Across the Fall, this program overview was expanded to include specific activities and proposed timelines. It was reviewed with each NPAC member for each pillar and with the Vision Planning Group. It was presented to the Disparities Sub-committee for review and input and is scheduled to be presented to the NCCCP PIs for final input and approval at their December 16, 2008 meeting.

OUTLINE

NCCCP PILOT DISPARITIES VISION
NCCCP PROGRAM OVERVIEW

SECTION 1:
DISPARITIES PRIORITIES FOR NCCCP PILOT

A. Education
   i. Definition of Disparities
   ii. Educational Resources and Materials
B. Data Collection
   i. Data Reporting and Tracking on Racial and Ethnic Data
   ii. Data tracking across settings and private practice settings
C. Partnerships with local, state and national organizations
D. Prioritization

SECTION 2:
PILOT SUBCOMMITTEE CROSS-CUTTING EFFORTS

A. Disparities
B. Clinical Trials
C. Quality of Care
D. Survivorship
E. Biospecimens
F. Information Technology

SECTION 3:
OVERALL COORDINATION AND TRACKING OF DISPARITIES CROSS CUTTING PROGRAM

Appendix 1 Template for Community Outreach

NCCCP PILOT DISPARITIES VISION AND PROGRAM OVERVIEW

Topic	Recommendations	Next steps	Timeframe
Disparities Vision			
	• Finalize Vision and recommend where it needs to be posted in addition to the web site ***The NCI, through public/private partnerships with NCCCP pilot site community hospital-based cancer centers, will expand state-of-the-art cancer care and research to patients experiencing healthcare disparities (those with an excess burden from cancer) across the continuum, from prevention and screening through treatment, follow-up and end of life care.***	• Post to web site as part of Disparities program overview when finalized	Fall 2008
Section 1. Disparities Priorities			
A. EDUCATION			
Definition of Disparities	• Post definition on web site and on documents for all NCCCP initiatives. Provide education for pilot sites and subcommittees on this definition. Since the passage of U.S. Public Law 106-525, many agencies have incorporated this definition into their own materials, such as this excerpt from the U.S. Department of Health and Human Services' *Office of Minority Health* website: *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*	• Reinforce definition in planning all disparities-related pilot activities • Plan agenda item to note this definition for each pilot sub-committee so the definition is used across all pillars • Add definition to pilot monthly sub-committee update for September	Ongoing Fall 2008 November 2008

Topic	Recommendations	Next steps	Timeframe
	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 report entitled, "Unequal Treatment" highlighted inequities related to access and treatment as major factors in defining disparities. *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.*		
Educational Resources And Materials	• List educational needs related to disparities and develop a plan which prioritizes them and designates target subcommittees and a timetable for each. Much work has been started by some subcommittees so these efforts should be coordinated by the pilot leadership. • Develop lists of currently available resources and materials from NCI, other organizations, including NCCCP sites.	• Promote awareness of disparities resource page with resources links on NCCCP web site. Recommendations on improved navigation for this site and addition of information at the end of Year 1 of the pilot are in process. • NCCCP Intranet launched in September 2008 and will add site material related to disparities in Phase 2. Intranet has library of reference material and articles • FAQs and Talking Points on Disparities for the NCCCP pilot will be developed by the Communications sub-committee • CIS Training module on race/ethnicity to be posted to public web site and pilot intranet	Fall 2008/Winter 2009 Fall 2008/Winter 2009 Fall 2008/Winter 2009 Fall 2008
B. DATA COLLECTION			
Data Reporting and Tracking on Racial and Ethnic Data	• Develop plan, short term and longer term, to address this issue so that	• One training session provided to Disparities sub-committee by CIS in	August 2008

Topic	Recommendations	Next steps	Timeframe
	reliable metrics for the pilot can be established and tracked. Plan should include training options and availability of modules for staff to improve identification of race and ethnicity. Utilize OMB categories.	August 2008. Ask each site to designate a staff person for a "train the trainer" session. Determine additional training needs/opportunities. Incorporate training on specific issues for specific disparate population (e.g. Hispanic, Native American).	Plan "train the trainer" session Dec2008/Jan2009
	The ethnicity is either Hispanic or Latino versus Non-Hispanic or Non-Latino. This question is asked before the race question. Race can be one or more of the following races: o ***White*** o ***Black or African American*** o ***American Indian or Alaska Native*** o ***Asian*** o ***Native Hawaiian or other Pacific Islander*** ***For more than one race: use a category "more than one;" if responder does not wish to give their race, use "would not respond."***	• All NCCCP Pilot activities should use OMB categories, to the extent possible, for race and ethnicity reporting • In order to meet deliverable of increasing programs and services to disparate populations, NCCCP Pilot sites should strive to track race and ethnicity data in the programs they are able to influence (especially new programs) following OMB categories. Examples of activities/programs that may be able to be influenced over the course of the pilot are: cancer center patient registration/EHR, breast and colon screening, genetic counseling service or referrals, patient treatment summaries, patients seen in MDCs, patients seen by navigators, etc.) • An education session will be provided for Disparities sub-committee on ways/opportunities to approach the task of improving race and ethnicity reporting.	Ongoing Ongoing through pilot end with quarterly report updates from pilot sites December 2008
Develop guidance on tracking other underserved populations (e.g. rural, uninsured, underinsured, elderly)	A working group of the Clinical Trials sub-committee has been formed to consider these issues and to develop guidance or recommendations on categories and definitions. Include consideration of tracking distance patient lives from cancer centers.	• Invite Disparities subcommittee and others to give input and recommendations of the working group should be sent to the Disparities sub-committee for review.	Winter 2009

Topic	Recommendations	Next steps	Timeframe
C. PARTNERSHIPS WITH LOCAL, STATE, AND NATIONAL ORGANIZATIONS			
	• Share information on approaches to effectively engage potential partners • Based on site work plans and subcommittee projects, identify partners for pilot sites that can include NCI programs such as CIS, CNPs, NCI Designated Cancer Centers, other cancer organizations such as ASCO, CoC, Advocacy groups, other pilot sites, etc. • Prioritize partnerships based on likelihood of making progress on specific projects to be identified by NPAC, subcommittees, individual pilot sites.	Targeted overall pilot partners include the following: • American Cancer Society (ACS) for patient navigation-training program funded for NCCCP pilot sites. Administer an evaluation form to each of the participants in this ACS training to elicit feedback on its value for the NCCCP program. Send questions to be answered by attendees before the meeting. Organize an NCCCP navigator meeting at the ACS training so the representatives can meet one another. • Cancer Information Service (CIS) – with all pilot sites • State Cancer Plan/program linkages (e.g. breast and cervical programs). Plan discussion to compare information on different state plans and relationships. Pilot sites to identify strategies to push for policy change in entitlement programs or coverage expansion/mandates for cancer screening or treatment • Community Networks Program (CNP) – plan population-theme based presentations by CNPs for Disparities (other sub-committees to be invited) sub-committee. Deep South Network presented in August 2008. Presentations to include a report on successful strategies for engaging different populations. Explore CNP evaluation metrics for applicability to NCCCP program efforts • CNP/NCCCP relationships-invite NCCCP sites with agreements or in discussions with CNPs to describe scope,	Ongoing over pilot November 2008 Ongoing Discussion item at PI meeting - December 2008 Coordinate through CRCHD to plan and schedule over pilot Spring 2009

Topic	Recommendations	Next steps	Timeframe
		goals and potential synergies of/barriers of relationships as follows: o Towson-Univ of Maryland MRCN ***Underserved*** o Colorado Springs-Univ of Colorado CFRLCN- ***Hispanic/Latino*** o Spartanburg-South Carolina SCCDCN- ***African American*** o Orange-UCDavis AANCART ***Asian*** o Orange-Cal State Fullerton WINCART- ***Pacific Islander*** o Hartford-Harvard MASSCONECT-***Underserved*** o Sioux Falls-Univ of Washington Regional Native American CNP ***American Indian/Alaska Native*** o Delaware-Temple ATECAR- ***Asian*** • Patient Navigation Research Program (PRNP). Set up meeting to explore synergies with PRNP program and to learn about evaluation metrics and different models for navigation. Based on expertise and needs of the NCCCP, invite recommended PRNP PIs to present to the Disparities subcommittee • Develop presentation on effective strategies, mechanisms and tools for effective partnerships to include: o Letters of Agreement, MOUs, etc o Medical provider agreements (Avon requires) o Expected outcomes	NCCCP to coordinate meeting with PRNP program reps. NCCCP/Pilot Reps to Plan for early 2009

Topic	Recommendations	Next steps	Timeframe
D. PRIORITIZE EFFORTS FOR DISPARITIES ACROSS PILOT			
	• Educate pilot sites with the *Template for Planning Community Outreach (see Appendix 1),* and consultative assistance as needed to focus their disparities efforts for outreach, treatment, research, quality of care, and survivorship/palliative care. Data collection efforts will need to be coordinated across areas to avoid duplication and to reduce reporting burden. • Offer support for these efforts with community data sources through NCI-CIS, and educational resources for staff or for community members/patients through NCI or other organizations (e.g., Native Americans). • Coordinate efforts with other pilot subcommittees (i.e., QOC, Survivorship, IT, Executive Committee).	• Develop a workshop for pilot sites on how to use the *Template for Planning Community Outreach* efforts (see Appendix 1). This will include the 9 principles of Community Based Participatory Research (CBPR), how to set measurable objectives, data collection and metrics, useful tools and resources, etc.	NCCCP and CIS to work with pilot volunteers to develop workshop with target date of the February 2009 Disparities sub-committee meeting.
Section 2 Pilot Subcommittee Cross-Cutting Efforts			
A. DISPARITIES			
	• Recommend topics and format for best use of subcommittee meetings. • Develop a cross-cutting pilot report (a dashboard) so this subcommittee can serve as a clearing house and monitor the pilot disparities initiatives.	• Several presentations are scheduled for each sub-committee meeting • To be competed for presentation at the November Disparities subcommittee and the December Pilot PI meeting	Ongoing Nov-Dec 2008

Topic	Recommendations	Next steps	Timeframe
	• Develop pilot-wide approach to coordinate navigation to include monitoring and improving navigation for disparate populations. • Monitor voluntary effort for breast screening tracking. Consider adding whether a patient has been screened before and if a patient has a medical home • Identify topics which would be most valuable for subcommittee members for future meetings. *Priority topics from annual disparities sub-committee* • *Patient Navigation - outreach focus and cross-cutting navigation* • *How to form Community Advisory Committees* • *Outreach programs* • *Evidence-based practices to reach disparate populations for outreach* • *Screening programs (including for lung)* • *CNP linkages* • *Race/Ethnicity Awareness and training* • *Needs Assessments* • *Prevention* • *T2 Research*	• Form Navigation workgroup to develop a matrix on the role and functions of NCCCP patient navigators and to make recommendations to the NCCCP Program and pilot sites • Reporting on Quarterly reports and discussion at Disparities subcommittee • Some topics have been scheduled with others TBD	January 2009 Ongoing TBD
B. CLINICAL TRIALS			
	• Develop tracking of patients on trials with race and ethnicity data to confirm specifics of issues that preclude CT participation across sites. For the trial accrual log project, decrease the amount of missing data on race and	• Race and ethnicity data is collected on the CTSU NCCCP log. Race and ethnicity is also collected on NCI Cooperative Group and CCOP Trials. As part of a pilot wide effort to improve collection of race and ethnicity date using OMB categories,	Ongoing

Topic	Recommendations	Next steps	Timeframe
	ethnicity for all screened patients and monitor the percent change in capturing complete data sets on race/ethnicity	pilot site will report on progress toward implementation.	
	• Describe strategies used to improve minority/underserved accrual and track if they are successful or not. • Track barriers across sites and identify common issues.	• A Minority Accrual working group has been formed to address this issue and the next item on training and education needs.	Launched Sept 2008
	• Develop targeted efforts for staff training and education of the population in programs on culturally competency. • Research insurance coverage issues and develop recommendations for follow up with Advocacy subcommittee.	• Pilot sites organized effort to explore this and other issues	Ongoing
C. QUALITY OF CARE			
	• Coordinate with cross-cutting issues on data collection for race and ethnicity	• Consistent with pilot wide efforts, sites to report progress on implementation of race and ethnicity tracking for NCCCP QOC initiatives. CoC utilizes OMB categories for race and ethnicity	Ongoing
	• Consider disparities-related QOC information learned from the sites through the CoC breast and colon cancer initiative.	• Sites to consider follow up as appropriate based on site specific data.	After CoC reports are given to sites.
	• Sites to consider findings on patient reported outcomes on patient survey as race and ethnicity will be tracked	• Sites to report findings and any disparities related quality improvement plans after baseline CoC survey results are released	After CoC reports are given to sites
D. SURVIVORSHIP AND PALLIATIVE CARE			
	• Determine priorities for disparities-related Survivorship and Palliative Care efforts and propose projects or initiatives	• Subcommittee to discuss ways for disparities issues to be considered in Survivorship and Palliative Care activities.	TBD
	• Sites to consider findings on patient	• Sites to report findings and disparities	Upon release of

Topic	Recommendations	Next steps	Timeframe
	reported outcomes on patient survey as race/ethnicity to be tracked. • Discuss capacity of pilot sites to collect demographic data (race, ethnicity, elderly, uninsured, distance from cancer centers) in their survivorship programs and activities. Program modifications or accommodations could be developed based on this information (e.g. provide a DVD for distant patients) • Identify disparities-related educational needs for Survivorship and Palliative Care activities.	related quality improvement plans after baseline survey results are released • Plan subcommittee discussion • Work with DLCG or other NCI programs for education on Native American Survivor issues and challenges and other population specific groups as needs are identified.	patient survey results TBD Spring 2009 and ongoing
E. BIOSPECIMENS			
	• Education is needed across the pilot on specific cultural issues related to specimen collection and consents (noted under education). • Provide guidance on adding options for disposal or handling of specimens after testing	• OBBR to conduct an education session on this topic for Biospecimen, CT and Disparities subcommittees or others as requested. • GAFAT survey has added question on whether sites have policies on handling specimens from specific religious or population groups (e.g. Native Americans) • A recommendation for drop down menu categories for the handling of specimens has been developed and sent to NCCCP pilot sites	TBD Completed Completed/track follow up
F. INFORMATION TECHNOLOGY			
	• IT involvement in problem solving of data-related issues for short and long term solutions (e.g. clinical trials accrual log) including consistent race and ethnicity reporting • Link with vendors whenever possible to promote solutions to incorporate tracking of disparities through clinical and research programs (e.g. ASCO	• IT is consulted on related projects • Continue to promote	Ongoing Ongoing

Topic	Recommendations	Next steps	Timeframe
	EHR effort • Outcomes data base project under consideration would include race and ethnicity tracking tied to patient outcomes. This longer term potential project would drive clinical and research decision making to improve patient outcomes and clinical effectiveness, including tracking for race and ethnicity.	• Under consideration	TBD
Section 3 Overall Coordination, Communication, and Tracking of Disparities Workplan			
	• Discuss processes and communication for working across pilot areas. • Identify and prioritize disparities projects and metrics for tracking – develop and populate a NCCCP Disparities dashboard. • Finalize NCCCP Pilot Disparities Program Overview.	• Consult communications subcommittee to develop a communications plan for NCCCP Disparities Program Overview for review by NPAC. Plan to include communication across pilot sites and across the program pillar areas within NCI. • Finalize Disparities Dashboard • Monitor Disparities Program	TBD December 2008 Pilot Executive Comm. Ongoing monitoring by Disparities Subcommittee

Template for Planning Community Outreach

- Define target population and define targeted project activities
  - Through a review of community data, surveys, or other local or state processes, a significant unmet need is determined (e.g., Hispanic women at risk for breast cancer and African American men at risk for prostate cancer). Note that CIS can assist with data for this type of assessment.
  - Cancer outreach, screening and follow up efforts for the NCCCP project would target these populations and *this specific effort*. (Note: for Native Americans, it is recommended that only one tribe be the focus for such an effort.)
- Determine partners and focus – For *this specific effort,* consider which other community groups (e.g., an FQHC, faith-based efforts) or efforts serve these populations to develop partnerships and/or to form an advisory group. Define the purpose/goal of the partnership.
- Define scope, objectives/goals and expected outcomes – For *this specific effort,* determine scope (e.g. track screening through resolution of abnormal finding, track screening through treatment and follow up care/survivorship), effective strategies and targets. Consider how patients will obtain needed healthcare resources - diagnostic tests, treatment, and/or clinical trials, follow up care, etc. Consider what information is able to be tracked. Consider community input and/or experience from other providers/community groups. Consider the need for specific culturally appropriate material. Consider consulting NCI Community Network Programs (CNPs) with a particular focus, or other NCI or Advocacy resources as needed.
- Develop metrics and proposed targets – to determine baseline and change for *this specific effort* during timeframe of pilot (e.g. the breast cancer tracking tool and the proposed colon cancer tool may offer a useful template).
- Document barriers – Note strategies to overcome barriers for *this specific effort.* Flag items for discussion with others on monthly calls or initiate connections with other pilot sites or NCI as needed.
- Evaluate – Assess progress and effectiveness of *this specific effort*, highlighting changes to improve interventions and to overcome barriers. Note ongoing barriers and share successes with other sites and NCI, through quarterly reports, e-mail updates, or agenda items for discussion on monthly calls.

NCCCP DISPARITIES VISION DASHBOARD

NCI COMMUNITY CANCER CENTERS PROGRAM

The NCI, through public/private partnerships with NCCCP pilot site community hospital-based cancer centers, will expand state-of-the-art cancer care and research to populations experiencing healthcare disparities (those with an excess burden from cancer) across the 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.

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.

NCCCP Disparities Dashboard

Overall Disparities Requirement: All patients screened and diagnosed with cancer by the pilot sites are offered treatment– policies in place with annual confirmation

	Clinical Trials	Biospecimens	Information Technology	Quality of Care	Survivorship	Disparities
Consolidated disparities metrics from pilot sites by area of focus (OMB categories to be used for race and ethnicity metrics unless otherwise noted)	• % change minority patient accrual to pilot CTSU trials • % change minority accrual for NCI Cooperative Group and CCOP trials • % change in capturing data on race and ethnicity (e.g. decrease in missing data)	• # pilot sites that set up systems for special handling of specimens and consents for specific populations (e.g. Native Americans)	• % of sites (those participating in caBIG™) submitting race /ethnicity data to caBIG™	• % 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)	• % of sites that have introduced tracking of race and ethnicity data in at least one of their Survivorship and Palliative Care programs	• % 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
Key Disparities Activities/Overall Disparities Pilot Projects	• Minority accrual working group to develop recommendations for implementation by sites. • Track progress on race and ethnicity reporting • Track progress on role of Navigators in accrual of patients to CT	• Education session on specimen and consent issues for special populations to be held for biospecimen and other subcommittees	• Support to be provided for multiple pilot projects • Work with vendors as opportunities arise on standardization of race and ethnicity data fields	• 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