JUNE 2006 UPDATE

NCI INITIATIVES IN PALLIATIVE CARE

The National Cancer Institute (NCI) continues to support initiatives in research, education, and training to improve symptom management and palliative care in cancer. This update is to inform our colleagues, partners, and advocacy communities about our activities and encourage further collaborations and information exchanges where possible.

NCI's Strategic Plan

In January 2006, NCI published *The NCI Strategic Plan for Leading the Nation to Eliminate the Suffering and Death Due to Cancer*. This plan includes objectives and strategies directly targeted at improving palliative care, such as translating palliative care and symptom management research into interventions to improve care for patients and survivors and for those at the end of life. This publication is available online at cancer.gov or in print by ordering at 1-800-4-CANCER.

I. Research

Reducing Barriers to Symptom Management & Palliative Care

Fifteen applications were funded (7 R21s and 8 R01s) in response to the RFA (CA-05-013) announced in late 2004 and the amount allocated for 2006 is $5.2 million. All of the project abstracts, the original RFA, and additional opportunities continue to be updated and announced on NCI's palliative care funding opportunities Web page.

http://cancer.gov/researchandfunding/announcements/palliativecare

Some palliative care funding opportunities announced in 2006 included such areas as:

- Developmental Projects in Complementary Approaches to Cancer Care;
- The Influence of Religiosity and Spirituality on Health Risk Behaviors in Children and Adolescents;
- Research on Clinical Decision Making in Life-Threatening Illness;
- Methodology And Measurement in the Behavioral and Social Sciences;
- Research on Ethical Issues in Human Subjects Research; and
- Information Technologies and the Internet in Health Services and Intervention Delivery.

Platforms for Conducting Palliative Care Research

Several NCI-funded research platforms are available to investigators who wish to collaborate on research in the broad area of palliative care. Studies conducted in these platforms include:

- Health communication research being conducted in the Centers of Excellence in Cancer Communications Research.
- Health services research in cancer treatment, palliative care, and end-of-life care being conducted in NCI's HMO Cancer Research Network.
- Late and long-term effects of cancer treatment are being studied in the NCI-funded Childhood Cancer Survivor Study, coordinated at the University of Minnesota.
- Symptom management, health-related quality of life, and supportive care research conducted through the Community Clinical Oncology Program and the Clinical Trials Cooperative Group Program; trials open to accrual can be found using NCI's PDQ clinical trials database by searching for supportive care trials with NCI sponsorship.

Cancer Care Outcomes Research & Surveillance (CanCORS)

NCI's Cancer Care Outcomes Research and Surveillance (CanCORS) is a consortium conducting the largest observational study ever of cancer care delivered in diverse, population-based health care settings. In the past several months, approximately 5,000 patients with lung cancer and 5,000 patients with colorectal cancer were enrolled in this study. Patients, or their surrogates, were interviewed at 4–6 months after diagnosis and are now being contacted again to complete a follow-up survey. During the rest of the year, extensive detail about patients and their treatments, including palliative care, will also be collected from medical records of the specialists and non-specialists involved in caring for patient participants. Given that about one-quarter of colorectal and more than half of lung cancer patients have advanced stage of disease at initial diagnosis, CanCORS is providing a unique opportunity to comprehensively examine community practices regarding palliative and end-of-life care from the perspective of the patient, surrogate, and providers among a diverse group of patients followed over time. http://healthservices.cancer.gov/cancors/

CanCORS Caregiver Study

The caregiver supplement to CanCORS leverages this larger initiative to address critical information gaps relating to the role and impact of informal caregiving. More than 1,500 informal caregivers have been surveyed, the responses from whom will complement existing CanCORS data to provide a more comprehensive assessment of the relationship between cancer-related care and patient and family outcomes.

Cancer Survivorship Research

NCI's Office of Cancer Survivorship (OCS), in partnership with the American Cancer Society and the Lance Armstrong Foundation will hold its third biennial cancer survivorship research conference, "Cancer Survivorship: Embracing the Future ," October 4-6, 2006, in Bethesda, Maryland. Key aims of the conference are to: 1) identify future directions of cancer survivorship research, 2) examine advances in e-health and communications, 3) identify challenges to follow-up care for cancer survivors, 4) understand and address the needs of cancer caregivers and families, and 5) review research and strategies to address health disparities in cancer survivorship.

The OCS Web site includes an up-to-date portfolio of funded research in cancer survivorship and the October conference meeting information is available at: http://survivorship.cancer.gov/.

Centers of Excellence in Cancer Communications Research (CECCR)

This initiative is funding four major research centers focused on large-scale interdisciplinary studies in cancer communications to encourage the development of new health communication technologies, programs, message strategies, and interventions for reducing the cancer burden throughout the nation. The University of Wisconsin's Center of Excellence focuses on research concerning communication and coping with cancer. One of the major research projects in this center focuses specifically on evaluating communication strategies for improving palliative care for lung cancer patients and their families. A second clinical trial, funded by the National Institute of Nursing Research, was awarded to the Wisconsin team that focuses on improving communication strategies among patients, the healthcare team, and the family caregivers for end-of-life issues for patients with advanced breast or prostate cancer.

Complementary & Alternative Medicine (CAM)

NCI funds palliative care cancer research in CAM, which is coordinated through NCI's Office of Cancer Complementary and Alternative Medicine (OCCAM). Information for investigators and the CAM portfolio of funded grants are available at the OCCAM Web page. http://www.cancer.gov/cam

Patient-Reported Outcomes (PRO)

NCI is sponsoring a conference: *Patient-Reported Outcomes Assessment in Cancer Trials (PROACT): Evaluating and Enhancing the Payoff to Decision Making*. The purpose is to:

- determine what we know about the use and value of health-related quality of life (HRQOL) in clinical trials;
- identify the challenges to more frequent or extensive application; and
- identify studies that would enhance the decision-relevance of HRQOL measurement in cancer trials.

The conference will take place September 20–21, 2006, at the Marriott Bethesda North Hotel & Conference Center in MD near NIH. Registration is free and available online at: http://www.scgcorp.com/PROACT/,

NCI is participating in the *Patient-Reported Outcomes Measurement Information System* (PROMIS) initiative that establishes a collaborative relationship between NIH and individual research teams.

The broad objectives of the PROMIS network are to:

- Develop and test a large bank of items measuring patient-reported outcomes
- Create a computerized adaptive testing system that allows for efficient, psychometrically robust assessment of patient-reported outcomes in clinical research involving a wide range of chronic diseases
- Create a publicly available system that can be added to and modified periodically and that allows clinical researchers to access a common repository of items and computerized adaptive tests

More information available at: http://www.nihpromis.org.

Integrating PROs in Clinical Oncology Practice

The NCI funded two SBIR Phase I contracts to develop a software system to provide integrated, ongoing PRO measurements to provide timely, efficient, and individualized information for monitoring patient progress and improving decision making in routine oncology patient care. The long-term goal is to develop computerized PRO data measurement and information systems for use by clinicians and patients that include cancer-specific symptoms and quality-of-life domains using well-validated instruments or item banks and computer adaptive testing administration to gather patient-reported data for use in clinical practice. Such systems would provide as-needed reports to patients and treating clinicians to assist in informed decision making to improve cancer care.

II. Education

Health Professional Education

The EPEC-O (Education in Palliative and End-of-Life Care-Oncology) curriculum for oncology health professionals that was piloted as a train-the-trainer program in June 2005 via a collaboration between the American Society of Clinical Oncology (ASCO), the EPEC™ Project at Northwestern, NOVA Research, the Lance Armstrong Foundation, and NCI, is now being adapted to disseminate the curriculum for wider application.

- NCI is partnering with ASCO to educate clinicians, inside and outside of oncology, using DVD-based training with CME's available. December 2006 is the planned launch date.
- The IHS (Indian Health Service) and NCI are working to plan, implement, and evaluate a three-tiered training of the EPEC-O curriculum for health care providers within the IHS system.
- NCI is partnering with Medscape to explore the feasibility of offering parts of the EPEC-O material on their site and offer continuing education to physicians, NPs, and nurses who complete the module to further disseminate this palliative care education to an even broader audience of health care practitioners.

Patients, Caregivers, and Public Education

This past winter, NCI released updated versions of two patient education booklets, *Coping with Advanced Cancer* and *When Cancer Returns*. Both booklets now have an emphasis on palliative care, specifically in helping patients cope with physical and emotional needs during advanced or recurrent cancer. In addition, three new booklets for family caregivers are now available: *When Someone You Love Is Being Treated for Cancer*, *Facing Forward: When Someone You Love Has Completed Cancer Treatment*, and *When Someone You Love Has Advanced Cancer*. Each booklet addresses the needs of the caregiver unique to a given phase of cancer care.

They provide family caregivers with information about:

- Adjusting to caregiving
- Caring for your mind, body, and spirit
- Talking with the health care team
- Life planning

All publications can be ordered by calling NCI's Cancer Information Service at 1-800-4-CANCER, or online at www.cancer.gov/publications. Electronic versions of each booklet are also on the cancer.gov Web site. NCI continues to integrate more palliative care information based on deficits found in a palliative care content analysis of NCI materials, including revising three major booklets: *Pain Control*, *Chemotherapy and You*, and *Radiation and You*. All three will be available in the near future, and offer health professionals and patients updated information in more user-friendly formats.

NCI's Web Site: cancer.gov

The PDQ Supportive Care Editorial Board is drafting a summary on end-of-life care that will be a great addition for health care professionals and patients along with over 20 supportive care summaries.
http://www.cancer.gov/cancertopics/pdq/supportivecare

Results of newsworthy clinical trials in palliative care are highlighted under the section, Supportive Care Trial Results, in addition to disease specific progress in the clinical trials portal of cancer.gov at:

http://www.cancer.gov/clinicaltrials/ct-types-list

III. Training

NCI's Cancer Training Branch supports education and research dissemination concerning palliative care primarily through its Cancer Education (R25E) Program. There are other components of the NCI grant portfolio that could support research/career development in this area, e.g., the NCI Cancer Prevention, Control, Behavioral and Population Sciences (K07) Career Development Award; the NIH Mentored Patient-Oriented Research (K23) Career Development (K23) Award; the NCI Transition Career (K22) Award; the NCI Established Investigator (K05) Award in Cancer Prevention, Control, Behavioral and Population Sciences; and the NIH Mid-Career Investigator (K24) Award in Patient-Oriented Research. While as of fiscal Year 2005 these additional portfolios did not have grants in palliative care, the NCI did support 15 R25E programs focused on palliative care at a total cost of $4.6 million and 1 K05 focused on palliative care at a total cost of $0.2 million. These programs targeted diverse clinical audiences including oncologists, primary care and geriatric physicians, nurses, medical students, and nurses' aides working in hospices, nursing homes, cancer centers, and other settings. The goals of the grants range from the development of curricula for educating new clinical audiences to efforts to increase the dissemination of evidence-based practice findings using existing community networks.

More information about this and other funding mechanisms to increase the number of interdisciplinary trained researchers is available on NCI's Web page on training opportunities, which has been improved since last year.
http://www.cancer.gov/researchandfunding/training

NCI's Palliative Care Working Group

Division of Cancer Control and Population Sciences (DCCPS)

Neeraj Arora, Patient-Centered Communication Initiative
Linda Harris, Health Communication & Informatics
Arnold L. Potosky, Health Services & Economics Branch, Applied Research Program
Bryce Reeves, Outcomes Research, Applied Research Program
Julia Rowland, Director, Office of Cancer Survivorship

Division of Cancer Prevention (DCP)

Ann O'Mara, Program Director, Symptom Management Portfolio, Community Clinical Oncology Program

Division of Cancer Treatment and Diagnosis (DCTD)

Andrea Denicoff, Nurse Consultant, Palliative Care Initiatives Coordinator, Cancer Therapy Evaluation Program (CTEP)
Ted Trimble, HR-QOL Chair, Senior Investigator, CTEP

Office of the Director (OD)

Cheryl Arenella, Professional Education Branch, Office of Education and Special Initiatives (OESI)
Robin Baldwin, PDQ Supportive Care Board Manager, Office of Communications (OC)
Louise Cunningham, Cancer Education Branch, OESI
Annette Galassi, Cancer Information Service, OC
Lenora Johnson, Director, OESI
Belinda Locke, Minority Training Grants, Office of Centers, Training, and Resources (OCTR)
Rick Manrow, Office of Cancer Information Products & Systems, Office of Communications
Anita Ousley, Professional Education Branch, OESI
Carolyn Strete, Chief, Cancer Training Branch, OCTR
Jeff White, Director, Office of Cancer Complementary and Alternative Medicine