

# CRN Connection

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## *CRN NEWS & MILESTONES*

*We're pleased to announce...*

The DETECT team presented its findings at the International Conference on the Scientific Basis of Health Services in September.

Three new members have joined our Academic Liaison Committee:

- ◆ John Ayanian, Harvard
- ◆ Otis Brawley, Emory
- ◆ Gerry Riley, CMS

We received nine new pilot fund proposals, covering diverse research areas.

The PROTECTS team's publication of their article on the implementation of a computerized system for chart abstraction (*Cancer Causes & Ctrl* 2003; 14L469-476). The article is a good resource for teams writing proposals or implementing multi-site studies that involve medical record abstraction. Ann Geiger at KPSC and Roy Pardee at GHC are available to consult to provide scientific and technical consultation, respectively.



*The Cancer Research Network (CRN) is a collaboration of 11 non-profit HMOs committed to the conduct of high-quality, public domain research in cancer control. The CRN is a project of NCI and AHRQ.*

## **News from NCI**

### *30th Anniversary of SEER Program*

On October 16th, NCI celebrated the 30th Anniversary of the SEER Program. Information about the anniversary conference can be found at: <http://seer.cancer.gov/anniversary/>. At this site you will find information about the 30th Anniversary Program and Symposium, an electronic version of a pamphlet describing SEER Landmark Studies, and a search engine for all SEER publications. The scientific session for the 30th Anniversary Symposium focused on the role of cancer registries in health services research. The session was chaired by Martin Brown, with presentations by Colin Begg from Memorial Sloan-Kettering Cancer Center and John Ayanian from Harvard.

*-Martin Brown, NCI*

## **Ed's Corner of the World**

### *News from the CRN PI*

We were pleased to receive nine proposals in response to our call for pilot fund projects. Each proposal will be reviewed by three reviewers from a combination of the CRN community and our Academic Liaison Committee. As hoped, the proposals involve some new research areas and new investigators. The Steering Committee will make final funding decisions at our December meeting in Bethesda.

Several of you have suggested that we do not have enough opportunity to talk about science on the CRN, either the scientific issues involved in our projects, or new developments in cancer research and care. I agree with this observation, but I am not sure how widely this need is felt. To this end, we will add a few questions to our annual evaluation, which will assess interest and ideas for promoting dissemination and discussion of emerging and important topics in cancer research and care. The evaluation will take place in January 2004. We will look forward to your candid input.



### *In This Issue . . .*

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The Meaning of Simple Gestures

# STUDY FINDS HIGH RETENTION RATES AMONG CANCER PATIENTS

The Disenrollment Pilot Study, funded by a CRN administrative supplement, has completed analyses. Ultimately, we identified 132,590 enrollees in five HMOs who were diagnosed with invasive cancer from 1993 to 1999. Among those patients who remained alive at one year after diagnosis, 96% were still enrolled in their health plan. Among 5-year survivors, 84% remained enrolled. There was little variability in retention rates across the five plans and across the major cancers. These high retention rates encourage us to believe that the CRN can serve as a base for studies of quality of care and long-term outcomes. A complete report from the study will be available on the CRN website later this year. A summary manuscript detailing the results has been accepted for publication in the Journal of the National Cancer Institute.

Within this study we also focused on identifying characteristics of cancer patients associated with disenrollment during initial treatment, defined as the first year following diagnosis. Patients with the highest rates of disenrollment during this period were aged 20 to 44 years, non-white, or had short lengths of enrollment prior to their cancer diagnosis. Patients insured through Medicaid had the highest disenrollment rate. This suggests greater loss to follow-up for quality of care studies in these groups, although in most sub-groups retention rates were over 90%. Table 1 presents the results for several groups of patients.

The sub-groups with the highest rates of disenrollment were of special concern since these are the groups most often found to lose health insurance in surveys of the general public.

	% DISENROLLED	ADJUSTED HAZARD RATIO*	95% CI FOR ADJUSTED HAZARD RATIO
<b>Age</b>			
20-44	7.4	1.9	1.7, 2.1
45-54	4.0	1.3	1.0, 1.4
55 +	1.0	1.0	referent
<b>Race</b>			
Asian	4.4	1.3	1.1, 1.5
African-American	3.4	1.2	1.1, 1.3
Hispanic	3.6	1.1	0.95, 1.2
Non-Hispanic White	2.7	1.0	referent
Other/Unknown	6.7	1.8	1.4, 2.3
<b>Primary type of Insurance</b>			
Medicaid	16.5	3.5	2.9, 4.3
Commercial	4.0	1.5	1.4, 1.6
Self-pay	2.9	1.2	1.1, 1.4
Medicare	1.7	1.0	referent

*\*Controlling for age, sex, race, stage of cancer, prognosis, enrollment prior to diagnosis, CRN site, and year of diagnosis; censored at date of death or end of first year after diagnosis if still enrolled*

To follow-up on this issue, five CRN sites have submitted a proposal to the National Cancer Institute to interview both newly diagnosed cancer patients who disenroll from their health plan during the first year and a comparison group who remain enrolled.

Several developments that grew out of the pilot study may be of special interest to CRN investigators and staff:

Using compiled tumor registry data from multiple sites, we developed and tested a “cancer counter.” An updated version of the cancer counter, including data from all of the CRN-related tumor registries, is under construction and will be available on the CRN website later in the year.

The counter will support development of proposals by assisting investigators to

estimate sample sizes and describe samples in terms of characteristics, such as, age, race and gender.

The study used a detailed data dictionary that included data elements from the sites’ tumor registries and electronic enrollment and vital status databases. Multiple cross-site tests of missing data and cross-tabulations provided investigators and data analysts with better understanding of the inconsistencies and special problem areas that arise in merging frequently used data elements across sites. Thus, the study served as a pilot for the data-mapping initiative being conducted as a key element of CRN II.

- Terry Field, Meyers Institute

## NOTES FROM THE FIELD

# End-of-Life and Hospice Care for Ovarian Cancer

The project “Evaluation of End-of-Life Care for Ovarian Cancer” aims to understand the occurrence and management of pain and other major complications at the end of life and to examine referral and use of hospice among ovarian cancer patients in HMO environments.

This is a CDC-funded project (Steve Coughlin) administered through the Association for Community Health Plans (Cia Byrnes). It involves Group Health (Kari Bohlke), HealthPartners (Cheri Rolnick), Henry Ford (Chris Neslund-Dudas), KPNC (Lisa Herrinton, PI), and KPNW (Mark Hornbrook). It was built upon the successful work of Chris and Kari to examine prostate cancer care at the end-of-life. Some of you may remember that the ovarian study proposal was put together in one week—evidence of how this group of researchers benefitted from the cohesiveness and communication structures established by the CRN.

Data collection will be through medical record review and data linkage. During Year 1, we developed and piloted the abstraction instrument and learned a great deal about our electronic hospice data.

We spent the first part of the year discussing and refining the specific aims. Numerous data elements were wanted, but some could not be reliably recorded due to data quality and/or availability issues. We also made a major decision to record the medical record data using an encounter approach, so that every encounter would be noted. This would have the benefit of requiring minimal interpretation from the abstractors.

When we moved into the pilot study, we found that we had been too ambitious in specifying the level of detail for capturing ovarian cancer complications. In addition, we found that the encounter approach was unwieldy and that greater interpretation could be demanded from the abstractors.

Ultimately, we decided to obtain details for the major complications only: pain, nutritional management, effusion, and obstruction. In addition, we plan to train the abstractors to define episodes of care, so that one line of data may represent a two-month course of management for an episode of pain, for example.

The study has just completed Year 1 of its three-year plan. Regrettably, Year 2 budget constraints were such that data collection will occur at only three of the five sites, although all investigators will stay involved.

We are seeking additional funding from NCI to bring the two outstanding sites back into data collection. Moving into Year 2, we expect to conduct a bit more piloting before starting data collection in earnest. We look forward to better understanding the death experience in ovarian cancer and hope that this work ultimately will improve systems of care and increase the options available to dying women and their families.

- Lisa Herrinton, KPNC

## CRN ANNUAL STEERING COMMITTEE MEETING

BETHESDA, MD

DECEMBER 4 - 5, 2003

### AGENDA

Thursday, December 4, 2003 8:30am - 5:00pm

- Welcome & CRN Overview
- Opportunities for Collaboration within Cancer Control Spectrum
- New Projects – Presentations for ALC Feedback
- Project Reports – Discussion of Dissemination and Next Steps
- Translating Research into Practice: Diffusion and Dissemination
- Academic Liaison Committee Feedback – Vision for CRN III

Friday, December 5, 2003 8:30am - 12:30pm

- Pilot Project Proposal Review



## CRN Connection

CRN Connection is a publication of the CRN created to inform and occasionally entertain CRN Collaborators. It is produced with oversight from the CRN Communications Committee.

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Please send comments or suggestions on this newsletter to Chelsea Jenter, CRN Project Director, at [jenter.c@ghc.org](mailto:jenter.c@ghc.org). All submissions are welcome!

## PROJECT PROFILE

### Asian Women and Breast Cancer Clinical Trials

Cancer is the leading cause of death in Asian American women, and breast cancer is the most commonly diagnosed cancer among Asian American women. Findings from major cancer prevention or treatment trials often cannot be generalized to ethnic minorities due to their lower rates of trial participation. The National Cancer Institute funded an administrative supplement through the CRN entitled “Participation of Asian Women in Breast Cancer Treatment and Prevention Trials” to explore issues in research participation among patients and providers. This project is led by Tung Nguyen, M.D. at the University of California, San Francisco, and Carol Somkin, Ph.D. at the Kaiser Permanente Northern California Division of Research.

The project consists of two physician surveys, one of primary care providers and one of oncologists, to assess their participation in breast cancer trials and their reports of barriers faced by them and their patients. Patient perspectives were elicited through focus groups of Asian women in the San Francisco Bay Area community and through interviews of Asian breast cancer survivors.

We have completed data collection and are currently in the process of data analysis. For the primary care physician survey, 324 physicians replied for a response rate of 54%. We found that, in bivariate analyses, compared to non-Asian physicians, Asian physicians were less likely to have discussed a cancer chemoprevention trial with any woman patient as well as with any Asian women patients.

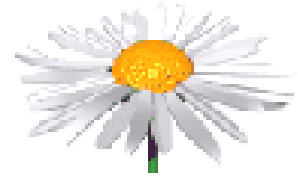
Physicians of all ethnicities identified language barriers; lack of culturally-relevant information on breast cancer; lack of adequate knowledge about research and research concepts; fear of experimentation;

complex trial protocols; and lack of communication about trials between providers and patients as barriers to the enrollment of Asian American women in chemoprevention trials. Asian physicians were more likely to identify these barriers. In addition, Asian physicians also chose lack of knowledge about breast cancer; lack of knowledge about preventive care; lack of transportation; fear of loss of time from work; fear that experimental treatment is inferior to standard treatment; concerns about personal modesty; and deference to other decision makers as barriers for Asian women. In addition, all physicians cited lack of information about trials; effort and time to learn about trial eligibility and treatment; and effort to explain risks and benefits as barriers to their ability to discuss trial enrollment with Asian women.

Preliminary analyses of the focus groups of Asian women (Vietnamese and Chinese) conducted in Vietnamese or Cantonese suggest that these women are aware of breast cancer and are concerned about it. They are also interested in prevention and many have obtained screening mammograms. However, a significant proportion lacks knowledge about research in general, with only 1/3 having heard of clinical trials. About 1/3 is interested in hearing more, but 1/3 is not interested primarily due to fear of treatment side effects.

Many patients cite competing interests such as childcare, work, or co-morbidities as reasons for not considering participation. Immediate future plans include completing the analyses and manuscripts for the primary care physician survey and the focus groups. Subsequently, we will analyze the oncologists’ survey and the breast cancer patient interviews.

- Tung Nguyen, UCSF



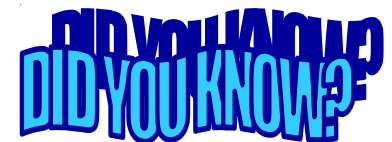
### The Meaning of Simple Gestures

Recently, I arrived in my office to find a half-dozen beautiful peach-colored roses accompanied by this note:

“Words can’t begin to explain how much I appreciated your referral. Corrective surgery done. Fantastic results. Thanks very much!!!”

This generous gesture of gratitude came from a KPSC study subject in the Prophylactic Mastectomy Outcomes project (often referred to as “PM Outcomes”). Weeks earlier our project manager, Carmen West, had brought me a note from this woman briefly describing the poor outcome of her surgery eight years earlier and inquiring if we could help. Immediately, I called the woman and arranged an appointment with a plastic surgeon; a simple gesture with no promise of improvement, which moved both the woman and her husband to tears. Our research results touch many individuals whom we will never know, but these simple gestures had a powerful impact on one woman and her husband and on our study team and me.

- Ann Geiger, KPSC



Do you ever forget to print out the call-in numbers and access codes for the Steering Committee Conference Call? Or do you need the dates for upcoming calls? Just hop onto the CRN website and click on the “Conference Call Schedule” on the left-side navigation bars, and open up the 2003 Conference Call Schedule. This document also has the times and dates of all of the core project meetings (though not all access numbers for those calls are available ahead of time).