

CRN Connection

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News from NCI:

We at DCCPS are sorry to announce that Barbara Rimer, Director and Bob Hiatt, Deputy Director, will be leaving NCI around the turn of the year. We will miss their leadership and vision, both of which have been major factors in building research resources like the CRN. However, they are both moving on to important positions in cancer control research, Barbara at the University of North Carolina at Chapel Hill and Bob at the University of California and the national office of Kaiser, which will ensure their continuing contributions to this field.

NCI has approved for funding a CRN supplement for a study of HRT use prior to and subsequent to the announcement of the results of the Womens' Health Initiative trial. We are also having ongoing discussions with NHLBI, AHRQ, NCHS and the Office on Women's Health, all of whom have expressed considerable interest in supporting extensions of this study or complementary studies.

- Martin Brown, NCI

Ed's Corner of the World

News from the CRN PI

We have received final guidance from the reviewers and NCI about revisions to our renewal proposal. We will submit our modified proposal and budget in early November. The good news is that our overall budget will be about what we requested, but the projects and infrastructure will change in accord with the feedback.

Does the CRN work? Consider the following chronology:

Monday, Sept. 9 - All CRN HMOs receive notice of a CDC task order for a study of end of life (EOL) care in ovarian cancer.

Tuesday, Sept. 10 - Rumbblings of interest, since the task order is unmistakably similar to our existing study of prostate cancer and EOL care.

Wednesday, Sept. 11, 12 noon, PDT - Task order discussed with CRN Steering Committee and interested HMOs urged to have a call.

Wednesday, Sept. 11, 2PM, PDT - Representatives from five CRN sites confer and agree to apply.

Saturday, Sept. 14 - Proposal and budgets completed and forwarded for review.

Monday, Sept. 16 - Proposal preliminarily approved pending budget modifications.

Tuesday, Sept. 18 - Proposal formally approved along with first year budget of \$310,000.



The Cancer Research Network (CRN) is a collaboration of 10 non-profit HMOs committed to the conduct of high-quality, public domain research in cancer control. The CRN is a project of the National Cancer Institute (NCI).



Four More Years for the CRN!

CRN Renewal Application rated "Excellent"

CRN News & Milestones

An administrative supplement on HRT initiation and cessation following results from the **Women's Health Initiative** was submitted to NCI and has been **approved for funding**.

The **Early Screening study's paper** on the effectiveness of **masking** medical record abstractors has been **accepted for publication** in the *American Journal of Epidemiology*.

Four CRN sites participated in a Center of Excellence in **Cancer Communications Research** grant, submitted on August 15.

An R01 on the etiology of **pancreatic cancer** is slated for an October 1 submission.

The fate of the CRN has been decided by a study section panel that was convened by NCI in late June. We are excited to report that we will be funded for four more years. Many changes are on the horizon, and plans are already under way for implementation of these changes.

Overall, our application received a qualitative rating of "Excellent," and a priority score of 171, which is in the fundable range. The critiques were generally very thoughtful, and give us clear messages about what we need to do to bolster the CRN as a research program during the next cycle. The next step will be to respond to the major criticisms and suggestions that emerged from the study section review. We will submit a so-called "best and final offer" to NCI, along with revised budgets, in early November.

The "take-home messages" from the Summary Statement are described below for our Infrastructure. Future issues of this newsletter will provide comprehensive features on each of the new projects.

CRN Infrastructure

We were commended for achieving a successful collaborative model, and for the great potential generated by the size and diversity of this network. Reviewers took note of the several new projects that have taken root in the CRN, and commended us on assembling a well-credentialed multi-disciplinary team. Several times throughout the infrastructure critique, the evidence of our synergy and integration was highlighted. Most importantly, the CRN was recognized as having significant potential to advance scientific knowledge and research on cancer care.

Glowing compliments aside, we have a great deal of work ahead of us in the next four year cycle. Our two major shortcomings were lack of data standardization, and insufficient connectivity between the Infrastructure and the Research Projects. We did emphasize these facts in the application, (perhaps giving them too much emphasis). Nevertheless, since we recognize these

weaknesses and the reviewers recognize them as well, it is definitely time to start working on ways to overcome them.

Data Standardization

We need to consider a constellation of factors as we undertake data standardization initiatives, including:

- what "place" a standardized data warehouse will occupy in the CRN (i.e., its purpose)
- ambitious nature of constructing virtual data warehouses
- data compatibility
- clarity about who leads, develops, and populates our virtual data warehouses
- reaching agreement about where data reside and who can access them
- priority order for standardizing different types of data
- how our experiences on the current projects can inform this process
- privacy issues (HIPAA, state laws, HMO policies, human subjects, etc.)

Better Connectivity between Projects and Infrastructure

Notably, one reviewer states, "Not one of the proposed projects mentions any support to be received from the Infrastructure core." There are other similar statements along these lines, although the whole of our collaboration is still viewed as greater than the sum of the parts. How do we go about increasing connectivity? For starters, we are launching the Project Leaders' Forum, and establishing a Scientific and Data Resources Core. Other strategies will be debated at the October meeting of the Steering Committee and Academic Liaison Committee at NCI.

Once again, our thanks go out to all of you for helping us achieve the aims of our first cycle. We are enthusiastic about applying what we've learned so far, and improving on the synergy and capacity of the CRN.

- Sarah Greene, GHC

Pilot Study Yields Better Understanding of Disenrollees

The disenrollment pilot study was undertaken with support from an administrative supplement to the CRN. The project had several aims. The first was to support CRN proposal development by pooling data about enrollees from five CRN sites who were diagnosed with cancer between January 1, 1993 and December 31, 1998, with follow-up through 1999.

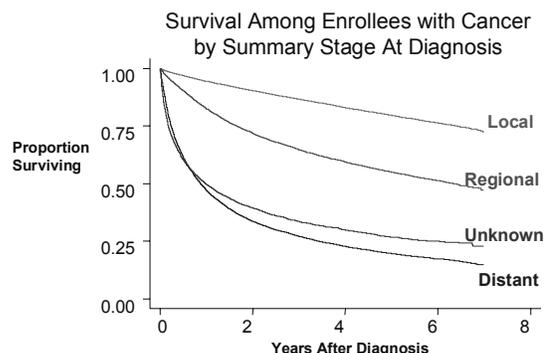
Using a common data extraction protocol and standardized data dictionary, we have assembled data from tumor registries and enrollment and vital statistics files on **122,841 individuals** with newly diagnosed invasive cancers, and followed them for 1 to 6 years, tracking their survival and continued enrollment in the HMO. Our primary focus for this part of the study was on estimating the number and percent of enrollees with various types of cancer who remained alive and enrolled at 1 to 5 years after the initial diagnosis, with the expectation that this information would provide solid evidence for planning studies and estimating sample sizes. We are preparing a report for CRN investigators that will summarize these results in detail (the table below presents one example.) Since some tumor registries also capture information on *in situ* cancers, the report will include data on enrollees with *in situ* cancers of the breast, bladder, and colon. The disenrollment study team and the CRN Steering Committee are reviewing options for making these data available to investigators on an on-going basis with the opportunity to request summary information on specific populations and issues.

Continued Enrollment of Enrollees with Newly Diagnosed Breast Cancer

Year of diagnosis	Total #	% alive and enrolled at end of each year after diagnosis				
		Year 1	Year 2	Year 3	Year 4	Year 5
1993-1994	6871	93%	86%	80%	74%	69%
1993-1995	10618	93%	86%	80%	75%	
1993-1996	14633	94%	87%	80%		
1993-1997	18915	94%	87%			
1993-1998	23398	94%				

The second aim of this pilot study is to identify and study enrollees who disenroll during the first year after a cancer diagnosis. Disenrollment during this critical treatment period threatens continuity of care, may have a negative impact on access to insurance, and may lead to increased out-of-pocket expenditures for care. Such a disruption in care might be triggered by patient dissatisfaction with the HMO, such as perceived problems with the quality of cancer care or inadequate access to special forms of treatment. However, some cancer patients may not disenroll by their own choice, but as a result of changes in the insurance coverage that gave them access to the HMO. This could result if the individual or family moves, changes or loses a job, or ceases being able to pay for insurance. The first step toward better understanding which of these possibilities need our attention, is to identify the characteristics of cancer patients who disenroll in the first year of treatment. We have completed initial, univariate analyses and are building multivariate models to clarify this issue. Our results

will be described in a manuscript that we will submit for publication this winter. We will also build on these results with an RO1 proposal to NCI in 2003. Several of the investigators who have participated in this project are planning additional manuscripts analyzing areas such as racial disparities in survival among enrollees with cancer and patterns of cancer detection among new enrollees.



Review of the pooled data reinforces our belief that the CRN includes a large and broad sub-set of the U.S. population with cancer. During 6 years in 5 of our sites, even cancer types with moderate incidence rates accumulated substantial numbers of new cases: invasive cancer of the bladder was newly diagnosed for 2,930 enrollees, for kidney cancer the total is 2,816, for oral cavity 2,124, for ovary 2,670, for pancreas 2,395, for stomach 2,237, and for uterus 4,100. Rare cancers are also well-represented in the pooled data with 867 enrollees with cancer of the esophagus and 1,671 of the liver, 895 enrollees with Hodgkin's Lymphoma and 1,600 with multiple myeloma. With pooled data we also find that there are substantial numbers of cancer patients with special characteristics: 1,442 under the age of 20 and 4,210 aged 85 or older; 29,838 are non-white.

The process of constructing the pooled dataset provided an opportunity for several CRN investigators and members of the Data Resources Coordinating Center to work jointly on a project with direct, tangible results. We have developed a better understanding of each site's issues in acquiring and interpreting specific data elements and have established many components of a virtual tumor registry including the data extraction protocols and common definitions for a number of critical variables. The study has greatly enhanced our readiness to provide support to future CRN projects. - Terry Field, Meyers

CRN Connection

The *CRN Connection* is a regular publication of the Cancer Research Network developed to inform and occasionally entertain CRN collaborators. It is produced with oversight from the CRN Communications Committee.

Contributors Martin Brown, Terry Field, Sarah Greene, Mark Hornbrook, and Ed Wagner.

Oversight and Production Robin Altaras, Gary Ansell, Terry Field, Sarah Greene, Mark Hornbrook, Virginia Quinn, Cheri Rolnick, Vic Stevens, and Ed Wagner.

Please send comments or suggestions to Robin Altaras, at altaras.r@ghc.org.

CanCORS - Cancer Care Outcomes Research and Surveillance Consortium

Five CRN sites (KPHI, GHC, KPNW, HFHS, and HPHC) are participating jointly as one of the Primary Data Collection Research sites (PDCRs) in CanCORS under the outstanding leadership of Jane Weeks from the Dana-Farber Cancer Institute. The CRN/CanCORS site PIs are Tom Vogt, Meg Mandelson, Mark Hornbrook, David Nerenz, and Bob Fletcher. The CanCORS Statistical Coordinating Center is at Harvard University under the leadership of David Harrington.

Other CanCORS PDCRs include Harvard/Northern California Cancer Registry Consortium, UCLA/RAND, University of North Carolina, University of Alabama, and University of Iowa. Interestingly, Kaiser Permanente members are included in the Harvard and UCLA/RAND study populations because the KP Northern and Southern California Regions participate in the respective regional community tumor registries.

The CRN/CanCORS site is conducting a special study on the economics of lung and colorectal cancers to examine patterns of resource use and costs for each cancer by stage and mode of treatment. This study is feasible because of the sophisticated electronic clinical, cost management, and claims information systems in our HMOs. The only resource information that can be consistently collected by the other PDCRs is Medicare claims (assuming permission is obtained from each Medicare respondent to access their Medicare claims files).

CanCORS is being designed to collect data prospectively on patients with histologically confirmed lung or colorectal cancer. Two waves of patient surveys are being planned, as well as medical record abstraction of the cancer episode,

and a survey of physicians. We are in the process of conducting cognitive tests and pilot tests of the patient questionnaire.

The Iowa site covers the entire state in order to collect sufficient number of cases to meet recruitment goals. The Alabama and North Carolina sites cover large portions of the rural areas in their respective states. When the CanCORS data base is completed, we will have detailed information on patterns of lung and colorectal cancer treatment and outcomes for a wide variety of geographic areas, urban and rural locations, fee-for-service and managed care systems, federal (Medicare and Medicaid) and private (commercial group and individual) health insurance coverage as well as the uninsured, diverse racial and ethnic groups, and persons with diverse socioeconomic status. We are planning analyses on access, quality, and outcomes of care for the two cancers.

One of the major design issues is at what point after diagnosis should the first patient questionnaire be administered. About 40% of lung cancer cases die within the first six months of diagnosis. Some cancer registries do not receive notice of a new case until 4 to 6 months after diagnosis. The PDCRs are looking into ways of identifying cases earlier, but the large tumor registry consortia will not likely be able to accelerate their case ascertainment processes.

One of the most interesting aspects of CanCORS, from the perspective of being in the HMO setting, is how much easier, cheaper, and faster it is for HMO-based investigators to collect data compared to University-based investigators working with community resources. We expect to begin formal recruitment in April 2003.

-Mark Hornbrook, KPNW

In the Spotlight



Donna Eubanks, CRN Web Developer, has worked behind-the-scenes on the CRN web site since its inception. She has made innumerable contributions and enhancements, and we thank her for her outstanding work!

Congratulations to **Lois Lamerato**, Henry Ford epidemiologist, on successfully defending her dissertation!

What's New on the Web?

One of the most popular web site features, "**Find People**," has been enhanced! Have a look!

If your information needs to be updated, contact your site data manager.

Users can now search for a certain **File Type**. A link appears on the Search Content page and at the top of each project and committee home page.

<https://secure1.kpchr.org/crn>

Calendar of Events

October 7-8, 2002

CRN Steering & Academic Liaison Cmtes
National Cancer Institute
Rockville, Maryland

October 9-11, 2002

CanCORS Meeting
San Francisco, California