

# CRN Connection

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**"What you do speaks so loudly that I cannot hear what you say."**

**- Ralph Waldo Emerson**



*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 -

### Strategic Plan for NIH Obesity Research

NIH Director Elias M. Zerhouni, M.D. announced on Tuesday, August 24, the release of the final version of the Strategic Plan for NIH Obesity Research, a multi-dimensional research agenda to enhance both the development of new research in areas of greatest scientific opportunity and the coordination of obesity research across NIH. The Plan calls for intensifying efforts along several fronts: behavioral and environmental approaches to modifying lifestyle to prevent or treat obesity; pharmacologic, surgical and other medical approaches to effectively and safely prevent or treat obesity; breaking the link between obesity and diseases such as type 2 diabetes, heart disease, and certain cancers research on special populations at high risk for obesity, including children, ethnic minorities, women and older adults; translating basic science results into clinical research and then into community intervention studies; and disseminating research results to the public and health professionals.

The report is available on the web at <http://obesityresearch.nih.gov>.

*-Martin Brown, NCI*

## Ed's Corner of the World

### News from the CRN PI

One of the original goals in our first CRN proposal was to increase our capacity by adding new members. Our first step in this direction was to add Kaiser Georgia. I am pleased to announce that the Lovelace Clinic Foundation (LCF) will join the CRN as an Associate Member, a temporary status allowing Lovelace to collaborate until funding is secured. Lovelace serves a highly diverse population based in New Mexico. We welcome the participation of Dr. Maggie Gunter, LCF Executive Director, and her research team.



CRN has had an unexpected windfall. It turns out that more money will be available to support pilot studies. As a result, we are again soliciting proposals for pilot projects. Details are available on the CRN website. As before, the primary goal of these funds is to enable CRN investigators to generate pilot data and experience to support the submission of a larger grant proposal.

A major advantage of the CRN, and integrated system research in general, is the opportunity to study the impact of centralized policies and programs on cancer care quality and outcomes. These studies require us to assess whether and how our organizations make decisions about various aspects of cancer care. In this vein, we very much appreciate the efforts of many of you in responding to our request for data about decision-making about drugs to prevent or treat cancer. These data will be crucial in interpreting variations in drug use across the CRN, an interest of many of us.

*Ed*

## FALL CRN STEERING COMMITTEE/ALC MEETING



### Meeting Sessions:

Friday, October 15 2-6pm CRN Strategic Planning Committee MENU Update
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Friday, October 15 7-9pm CRN Dinner
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Saturday, October 16 9am-1pm (working lunch) CRN Core Projects Presentations Scientific Interest Group Presentations SDRC Update
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\*1-3pm on Saturday is designated for breakout sessions/meetings

This year, our CRN Steering Committee meeting/Academic Liaison Committee is being held in conjunction with the 3rd Annual International Conference, "Frontiers in Cancer Prevention Research," located in Seattle from October 16-20. Many NCI staff attend this meeting.

Although the CRN is only in Year 2 of this four year cycle, planning for another renewal is already getting underway. The broader cancer research landscape has changed since we were funded in 1999, and the CRN is in the process of taking stock of its key strengths in order to best position itself for four more years of funding. So, a key element of this fall's in-person meeting will be a discussion of recommendations developed by the CRN Strategic Planning Committee, an ad hoc work group convened in May.

*-Maurleen Davidson/Sarah Greene, GHC*

## Scientific Interest Group Profile:

# Survivorship

Convener: *Ann Geiger*

The Survivorship Interest Group began meeting in March 2004. The Group, led by Ann Geiger (KPSC), meets monthly by telephone and shares information via email listserv. The Group includes representatives from multiple CRN sites, with frequent participation by Diana Buist (GHC), Terry Field (Fallon/Meyers), Mark Hornbrook (KPNW) and Marianne Ulcickas Yood (Henry Ford). We are currently expanding our group to include scientists from outside the CRN, such as Carolyn Gotay from the University of Hawaii.

Initial Group discussions featured several review articles summarizing the cancer survivorship field and sharing our individual interests in survivorship research. The field itself is broad, as are our interests. Examples include: prognosis (predicting survivorship and time to recurrence and death); secondary prevention and surveillance; clinical effectiveness as measured by quality of life domains; behavioral interventions to improve quality of life; and treatment patterns and long-term effectiveness. The Group assessed the CRN portfolio and identified eight funded and two proposed studies that fall under the rubric of cancer survivorship.

To help us explore ideas, the Group created a spreadsheet that combines information from the disenrollment study with treatment characteristics. This spreadsheet allows us to quickly estimate how many diagnoses of a specific cancer site might be available for study and what percent of those cases are likely to survive one or five years. In addition we can identify common treatment types and distinguish cancers found in children. We currently are using data from existing studies to understand challenges survivorship studies may face in using automated data, particularly in terms of assessing cancer treatments.

Recent discussions have revolved around the recent NCI symptom management RFA and other potential ideas that may evolve into grant proposals. We plan to nurture development of several proposals over the next six months by sharing information on the field and funding opportunities, and providing opportunities to discuss ideas and identify collaborators.

For further information or to join this Group, please contact Ann Geiger at [ann.m.geiger@kp.org](mailto:ann.m.geiger@kp.org).

*-Ann Geiger, KPSC*



# WHAT'S NEW ON THE WEB?

## CRN CANCER COUNTER

We successfully launched the CRN Cancer Counter on the CRN web site after rigorous testing for several weeks. We have uploaded data from five HMOs in this first version of the CRN Cancer Counter. Everyone who has access to the CRN web site has access to the new cancer counter through a link on the home page—see the CRN cancer counter navigation button. We think you will find it very helpful in developing site selection strategies for proposals, as one example. Variables included in the counter are counts on primary site, morphology, stage, and vital status, among others.

As you enter the Cancer Counter, you will be asked to specify a reason for your search query, which initiates a record of each visit to the cancer counter. The counter is virtually instantaneous for most queries.

As always, we would like to hear about any problems and challenges you may experience using the Cancer Counter, as well as comments on how the counter was helpful to you.

-Mark Hornbrook, KPNW

### Ten Ways to Increase Dissemination of CRN Research Results

Our work on the CRN is not complete until it is shared with other scientists and clinicians. Ideally, this should be done as rapidly as possible. Also, the number of publications is one yardstick by which the CRN will be judged. The CRN Publications Committee and PI's office humbly offer the following suggestions to help investigators and project teams produce and disseminate research findings more efficiently.

- 1 Develop a list of planned publications early in the life of the project, and update it regularly.
  - 2 Assign a lead author at the time a manuscript idea is added to the project team's list of papers.
  - 3 Monitor progress of planned publications, and be clear about expectations of progress.
  - 4 Look for opportunities to develop methodologic papers—don't wait for results to become available.
  - 5 Presentations should lead to publications within six months.
  - 6 Make data requests clear, focused and explicit, and supply table shells at the time of your request.
  - 7 Make project data available to others when the project team has developed its list of papers.
  - 8 Create a list of potential journals, so that if your submission is not accepted, you can quickly re-submit to the next journal on the list.
  - 9 Think globally, act locally. Support and enhance the efforts of your colleagues.
- And finally...*
- 10 Keep the PI's office informed about primary and spin-off publications. Every little bit counts!

-Sarah Greene, GHC

### CRN NEWS & MILESTONES

#### IMPORTANT DATES TO REMEMBER:

- CRN Pilot Fund Applications
    - 10/14 - Abstracts due
    - 11/12 - Full applications due
  - CRN Monograph
    - 12/15 - Manuscripts due
- Contact Chelsea Jenter, [jenter.c@ghc.org](mailto:jenter.c@ghc.org), for more information

AHRQ's co-sponsorship of the CRN offers additional confidentiality protections. However, it also requires that all CRN investigators and staff with access to CRN data sign a confidentiality agreement. This agreement is located on the CRN web site. We request the CRN Site Principal Investigators collect the agreements and send originals to the PI's office. Agreements are due by October 29, 2004. Thank you!

### CRN Connection

The *CRN Connection* is a publication of the CRN developed 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 Maurleen Davidson, CRN Connection Editor, at [davidson.ms@ghc.org](mailto:davidson.ms@ghc.org) or fill out feedback form on the web site. All submissions are welcome!

Special thanks to all for your contribution in the publishing of this newsletter. Special end of the year issue coming in December!

## PROJECT REPORT: *IMPACT – Cancer Surveillance Using Claims Data*

Clinical trials of cancer treatments have established approaches with proven ability to cure a large proportion of women diagnosed at an early stage of breast and cervical cancer. Treatment effectiveness is less clear in non-trial settings. Observational studies tracking patterns of treatment and outcomes can clarify these issues. The primary data source for these studies has been cancer registries—a source with limited information on treatment.

HMOs routinely collect data on patient encounters for administrative tracking, quality control, billing and reimbursement purposes. These electronic data systems can allow identification of cancer patients and offer extensive information on treatment patterns and outcomes. If these electronic data sources are found to be complete and accurate, they would provide the opportunity to broaden the population of patients that can be included in studies of patterns of care and outcomes.

The IMPACT study, a collaboration among four members of the HMO Cancer Research Network: Fallon/Meyers Primary Care Institute, Kaiser Permanente Northern California, HealthPartners Research Foundation and Henry Ford Health System, was funded by NCI to determine the completeness and accuracy of HMO electronic data systems to identify breast and cervical cancer patients, treatment received, and delivery system factors associated with differences in outcomes. Feifei Wei, from HPRF, is the Principal Investigator. Other investigators include Terry Field, Charles Quesenberry, Cheri Rolnick, and Marianne Ulcickas-Yood.

The specific aims of the IMPACT project are to:

- Determine the completeness and accuracy of HMO electronic data for identifying cancer patients, disease stage, and their treatment and outcomes among women age 55 or older with breast cancer and all women with cervical cancer.
- Determine the completeness and accuracy of claims-type encounter data for track-

ing treatment and outcomes among women age 55 or older with breast cancer and all women with cervical cancer.

- Analyze variations in completeness and accuracy of these data by patient characteristics and among different HMO's.
- Identify the biases associated with claims-type electronic data when they are used to characterize patterns of care and analyze the relationship between treatment and outcomes for women age with breast cancer or cervical cancer.



*IMPACT is developing and testing algorithms for identifying breast and cervical cancer recurrence*



IMPACT developed very broad patient selection criteria to identify all women who might have developed breast or cervical cancers during specific time periods. Criteria included codes from a variety of sources, including: ICD-9 diagnosis and procedure codes, CPT codes, ICD-O codes and pathologic topography codes. The women who met these initial criteria were randomized for chart abstraction. Chart abstracted data included details of diagnosis and initial treatment, outcomes and comorbidity. The study also pulled electronic administrative data on enrollment history, diagnoses, procedures, and dispenses of cancer-related drugs.

The IMPACT investigators are in the midst of analyses to produce a series of manuscripts. Among the planned topics are the following: development and testing of algorithms for identifying breast and cervical cancer patients in electronic administrative data; characterization of patterns of care and relationships between treatment and outcomes among women age 55 or older with breast cancer and among women of any age with cervical cancer; patterns of use of tamoxifen among women with breast cancer; ability of various comorbidity indices to predict treatment patterns and to modify the relationship between treatment and outcomes; development and testing of algorithms for chemotherapy and radiation therapy in women with breast cancer in electronic administrative data; development and testing of algorithms for identifying recurrence in women with breast or cervical cancer in electronic administrative data; patient and physician characteristics associated with treatment patterns' follow-up care for women age 55 or older with breast cancer.

Data collected for the IMPACT study are also serving as the base for an additional study by Dr. Chyke Doubeni, the recent recipient of a minority investigator research supplement from the National Cancer Institute.

*-Terry Field, Meyers Primary Care Institute*

### *The data collection for IMPACT is complete:*

Characteristic	Women with cervical cancer n (%)	Women with breast cancer n (%)
<b>TOTAL</b>	<b>823</b>	<b>910</b>
Age		
35 and under	473 (57%)	---
36-49	225 (27%)	---
50-54	39 (5%)	---
55-64	43 (5%)	331 (36%)
65-74	34 (4%)	310 (34%)
75 or older	9 (1%)	269 (30%)
Race		
White (non-Hispanic)	514 (62%)	746 (82%)
Black	100 (12%)	95 (10%)
Hispanic	33 (4%)	15 (2%)
Asian	42 (5%)	33 (4%)
Other	134 (16%)	21 (2%)
Charlson Comorbidity Index		
0	712 (87%)	579 (64%)
1	80 (10%)	191 (21%)
2 or greater	31 (4%)	140 (15%)