

CRN Connection

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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

A new report sponsored by NCI may be of interest to CRN members. The report by, Sam Harper and John Lynch at the Center for Social Epidemiology and at the Population Health University of Michigan, examines different ways of constructing population-based measures of cancer health disparities. The report shows that using different measures of disparities, e.g. relative vs. absolute measures, may result in different interpretations of whether health disparities are increasing or decreasing over time.

The full title of the report is:

Harper S, Lynch J. Methods for Measuring Cancer Disparities: Using Data Relevant to Healthy People 2010 Cancer-Related Objectives. NCI Cancer Surveillance Monograph Series, Number 6. Bethesda, MD: National Cancer Institute, 2005. NIH Publication No. 05-5777. A pdf of the report can be downloaded at: <http://seer.cancer.gov/publications/disparities/>

-Martin Brown, NCI

Ed's Corner of the World

News from the CRN PI

We hope that most all of you have heard the great news that the NCI Board of Scientific Advisors approved the issuance of the "concept" for CRN3. This concept approval was the necessary prerequisite for NCI issue the RFA. We expect that the RFA for CRN will come out in early May, and a proposal will be due in August or September.

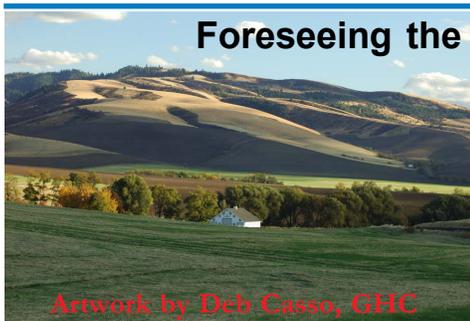


We have already received word that CRN3 will be much more explicit than CRN2 with respect to our collaboration with external partners—namely cancer centers. Related to this, the NCI is expecting us to work more closely with our delivery system oncologists.

To that end, the CRN is organizing a dinner of the HMO oncologists at this year's ASCO meeting in June. We will look to you to help us promote this dinner meeting as the details are firmed up.

See you in Boston!

Foreseeing the Quality of Care in the Inland Northwest



NCI is working with Group Health Cooperative to describe the quality of care received by typical cancer patients in several U.S. communities. The overall goal of NCI's project, "4CQuality: Quality of Patient-centered Cancer Care, Communication, and Coordination," is to provide a comprehensive assessment of the quality of American cancer care, especially quality as perceived and experienced by cancer patients and their families. Are patients and families getting the information and support as well as technical care that they need? To answer this question, we will review scientific evidence, conduct interviews with experts across the country, and gather and summarize the perspectives of patients and caregivers on the quality of cancer care in their community through site visits and focus groups. Specifically, we hope to illuminate the factors that facilitate or impede high quality cancer care in communities, as well as identify innovations that might improve disease outcomes and patient and family experiences.

The information we collect will contribute to the development of a conceptual framework that defines the characteristics of effective systems of cancer care. We hope this work will inform future quality improvement and

intervention research and practice. With light snowfall, March 13–14th, a team from the 4CQuality project visited with patients, families, oncologists, primary care providers, nurses, and local care centers in Eastern Washington State. From those on the frontline, we learned that overall they deliver quality care and are always trying to identify ways to improve the care they provide.

Generally, patients and families felt that they received high quality care from their providers in the Inland Northwest – very few said they would travel elsewhere for better care. However, they also expressed concern over long wait times for diagnosis and the lack of emotional support from providers. We also talked a lot about the influence of technology – particularly the Internet. Both patient and providers felt overwhelmed by the amount of information available online. They wanted straightforward, patient-friendly Web sites that could be trusted to provide accurate information. Providers were also concerned about financial reimbursement for drugs and care, and the lack of standardization of care, evidence-based outcome data, and integrated electronic medical records. However, Inland Northwest Health Services is leading an effort to introduce Information Technology solutions through developing partnerships between health care centers. We are looking forward to our next road trip to Central Massachusetts in April, then Detroit in May.

-Leah Tuzzio and Erin Aiello, GHC

IT'S IN THE RECORD BOOK

Last year, we published an article on Brittany Davidson, daughter of CRN Connection Editor, Maurleen Davidson. Brittany was ranked #1 in the nation in Western National gymnastics. This year, the Federation Incorporation of Gymnastics recently announced that the skill (front aerial two feet down) on the beam is called, "THE DAVIDSON", and is recorded in the book of records.

Brittany will compete in the Junior Olympic National meet next year. She will be judged on a different beam skill to be called the DAVIDSON#2. She would be the first junior olympic gymnast to have two skills named after her. Currently, Brittany is being scouted by colleges all over the United States.

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.

ContributorsErin Aiello, Gary Ansell, Martin Brown, Leah Tuzzio, Rita Williams, and Ed Wagner
Oversight Gary Ansell, Joann Baril, Martin Brown, Gene Hart, Judy Mouchawar, Dennis Tolsma, Leah Tuzzio, and Ed Wagner
Editor Maurleen Davidson

Please send comments or suggestions on this newsletter to Maurleen Davidson, CRN Connection Editor, at davidson.ms@ghc.org.

We would like to thank you for your comments and suggestions on the CRN 2005 Evaluation of the CRN Connection. We are very pleased with the survey results. This issue features one of the suggestions, which we are sure our readers will enjoy. Thanks!

An Interview with the Executive Committee: Program Testing Early Cancer Treatment and Screening (PROTECTS)

The PROTECTS investigators carried out 3 main studies related to breast cancer: the efficacy of contralateral prophylactic mastectomy in women with unilateral breast cancer (J Clin Oncol 2005; 23:4275-4286), the efficacy of bilateral prophylactic mastectomy in women at increased risk for breast cancer (Arch Intern Med 2005;165:516-520), and the efficacy of breast cancer screening in community practice, in women at average and at increased risk of breast cancer (J Natl Cancer Inst 2005;97:1035-1043).

The CRN PI's office conducted an interview with the Executive Committee of the PROTECTS study, including: Suzanne Fletcher, PI (HPHC); Ann Geiger (Wake Forest); Joann Elmore (UW) and Lisa Herrinton (KPNC). The interview focused on lessons learned: what went well and did not go well.

Q: *How did the Executive Committee develop a plan of operation?*

A: During the development of the initial CRN proposal, several investigators indicated interest in research related to breast cancer. Exploratory conference calls made it clear that the CRN sites could contribute useful and original research on three important areas in breast cancer. Suzanne Fletcher was asked to lead the project development. "Recognizing that this was going to be a big project, in fact, multiple projects, I asked several others to take the lead in

the different research areas. These people became the de facto Executive Committee that we created so the project would run smoothly. If I had been really smart, we would have had the Executive Committee from the beginning. As it was, there were several months of conference calls, which were pretty chaotic because the entire group of more than 10 people was developing every step and every data element. We were getting too little done. The Executive Committee took several steps "off-line" and developed drafts that were then vetted in the large-group conference calls. This approach helped the research team find the right balance between getting things done on the one hand and promoting democratic participation and creative chaos (crucial for good research) on the other."

Important keys in development of a project:

1. Coordinator

Having a coordinator to keep the group organized and coordinated was critical.

2. Small groups

Developing small work groups with a leader in each group kept the work on the projects moving forward, helped build enthusiasm for and participation in the work, and built in accountability for the team players. The Executive Committee provided the bridge between the small groups.

(Continued on next page)



WHAT'S NEW ON THE WEB

As of March, 7 2006, every person with CRN access can add files to the Web site! Now, you can add files using the new "Quick Post" function, which was implemented to broaden the scope of participation in content growth throughout the site.

It's quick and easy too! Go to the specific area of the Web site where you would like to add your document/file, and if you see a Quick Post icon (see icon below), you can post on that page. Then you can just as easily delete the file when you no longer want to have it display on the page.

To delete, you will see a red delete link beside the files you posted. If you would like to read the short instructions on how to Quick Post, please visit the Communications Committee page, and look for "Directions to Quick Post".

Please go to the site and post a file to share your knowledge and documentation with the rest of the members and let Gary Ansell know how the process went. You can reach Gary at gary.ansell @ kpchr.org with any questions.



- Gary Ansell, KPCHR

An Interview with the PROTECTS Executive Committee

(continued)

3. Flexibility

Establishing flexibility in trying different approaches for meeting our aims allowed for making mistakes and correcting them.

4. Interpersonal relationships

When we met at CRN meetings we each brought personal items that described who we were. Sharing our personal lives helped us to get to know each other better, and we became a “family.”

5. Two steps ahead

It was absolutely necessary for the Project Leader to be several steps ahead of the group to foresee any problems developing, to identify them quickly, and to develop a strategic plan for solutions.

6. Timeline and work plan

Early in project development, it was important to develop a work plan with deadlines and leaders assigned to each task. We rarely met our internal deadlines, but they helped us to stay on track and to make accountability clear.

7. Regularly scheduled conference calls with agendas, time allocations, multiple discussion leaders and action lists from the previous call

Early on, we had conference calls of the entire group twice monthly. We used an agenda that included multiple items on every call, with a designated amount of time for each item. The Coordinator would ask the group ahead of time for agenda items and would assign members on

the project to present so that they were engaged in the calls. We emailed attachments to give members a visual for the discussion. Each call began with a quick review of the action items from the previous call – thus building an ongoing connection to the overall work and to just-completed work. We encouraged laughter and small talk to nurture interpersonal relationships. Especially early on it was important to have calls more than once a month, to build a sense of community. We worked hard to start and end on time.

Q: *How was the budget developed and coordinated on a multi-site project?*

A: The major objective was to be transparent and open regarding the budget. This built trust in the group and transparency became an objective for all activities in the projects.

Q: *What was key to getting IRB approval across sites?*

A: Everyone involved in the project was committed and an advocate of the project. We explicitly discussed IRB issues unique to each site and attempted to create protocols that accommodated variation. We avoided iterative IRB submissions whenever possible, instead submitting final versions of everything simultaneously at all sites. Sometimes it was not easy to get all the IRBs to approve the same approach (See Greene, et al., *Ann Epidemiol* 2006;16:275-278).

Q: *With the focus being on more CRN publications, was this a factor in the project?*

A: Absolutely. We talked about publications at the very first meeting, and frequently thereafter. We created a manuscript-tracking document that listed potential papers, a lead author, and target meeting and submission dates. The lead author of each paper was rotated around so everyone on the team had an opportunity to be lead author on a paper. (See manuscript tracking document in the Projects: PM Outcome Study section on the CRN Web site)

Q: *In conclusion, what important information would you like to pass on to other projects?*

A: CRN is synonymous with collaborative research. It is good that the Connection is collecting experiences from projects to determine what works well (and what doesn't) in promoting useful research collaboration!



We would like to thank Suzanne, Joann, Ann and Lisa for participating in this interview. Stay tuned for more interviews with Principal Investigators and Project Teams.

- Maurleen Davidson and
Leab Tuzzio, GHC

CRN NEWS & MILESTONES

Clinical Trials in Kaiser Permanente Southern California



The Southern California Permanente Clinical Trials Group (SCPCT) is dedicated to advancing medical care and improving health outcomes. The SCPCT clinical trial investigators are physicians who bridge the gap between research and clinical practice. Their efforts combine the clinical expertise of the Southern California Permanente Medical Group and the Kaiser Permanente Health Plan and Hospital Network.

SCPCT provides regulatory and coordinating assistance with all research activities from pre-application to study completion. Support is available for the smallest pilot study to the largest multiple site trial such as the HIV AIDS Research Trials (HART), the Cancer Clinical Trials Access Program (CCTAP), the Surgical Radiation Oncology Clinical Trials Access Program (SROCTAP), or the Children's Oncology Group (COG). By the end of 2005, SCPCT had supported nearly 400 clinical trials with over 2,500 participants in more than 25 therapeutic areas.

Each year, more than 14,000 new cancers are diagnosed among KPSC members. CCTAP, under the direction of Jonathan Pollikoff, MD, enables KPSC medical oncologists to offer patients access to clinical trials and investigational therapies as a treatment option. And, in addition to benefiting KPSC members, CCTAP helps in recruiting highly qualified oncologists and provides physicians opportunities to maintain and expand their knowledge.

For more information about KPSC Clinical Trials, please contact Azucena Luna, MD, Practice Leader, (email: Azucena.D.Luna@kp.org). For information about the Cancer Clinical Trial Program (CCTAP), please contact Harvey Stern, Sr. Project Manager (email: Harvey.E.Stern@kp.org).



-Rita Williams, Sr. Project Manager, KPSC

- ▶ Two CRN posters were presented at the ASPO Conference on February 26-28, 2006 in Bethesda, MD.

1st place: "Diffusion of Aromatase Inhibitors for Breast Cancer." Authors: Erin Aiello, Ann Geiger, Roy Pardee, Diana Buist, Gene Hart, Sarah Greene, Lois Lamerato, Terry Field, Ed Wagner.

3rd place: "Predictors of Recurrence after Breast Cancer in Women Aged 65 Years and Older." Authors: Ann Geiger, Soe Soe Thwin, Diana Buist, Rebecca Silliman, Terry Field, Shelley Enger, Feifei Wei, Timothy Lash, Marianne Prout, Floyd Frost, Marianne Ulcickas Yood.

To view posters, go to the CRN Web site, publications and presentations.

- ▶ The "Forging Collaborations to Enhance Productivity: The HMO Cancer Research Network" abstract has been accepted for presentation at the Inventory and Evaluation of Clinical Research Networks (IECRN) May 31 and June 1. Authors: Sarah Greene, Leah Tuzzio, Gene Hart, Erin Aiello, Ed Wagner on behalf of the CRN.

