

# CRN Connection

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## News from NCI

### Trans-DHHS Meeting on Improving Patient-Reported Outcomes Assessment and Measurement

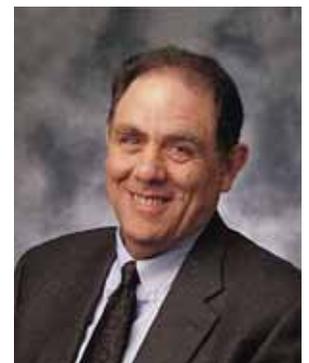
Representatives from Institutes, Centers, and Agencies across DHHS met on Feb. 24, 2004 to discuss their mutual interests in improving patient-reported outcomes assessment and measurement through new technologies and methods that have been successfully employed in other research fields. Topics discussed at this meeting included cognitive interviewing, computer and internet-based technologies, item response theory modeling, computerized-adaptive testing, and the importance of evaluating measurement equivalence when exploring group differences on measured traits such as depression, fatigue, pain, and physical functioning. This and subsequent meetings should serve to strengthen the "federal community" of outcomes researchers to support a research program that uses these methods to improve our ability to assess and measure a patient's health status.

-Martin Brown, NCI

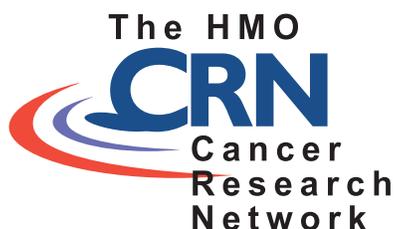
## Ed's Corner of the World

*News from the CRN PI*

Some recent events suggest that NIH research funding may change in significant ways. On the negative side, double digit NIH budget increases are history and there will be less money for the foreseeable future. The Breast Cancer Surveillance Consortium was not refunded, which may signal greater scrutiny of expensive, more general research resources. On the positive side, the new NIH Roadmap gives high priority to research that moves and evaluates innovations in actual practice. That should play to some strengths of the CRN. The net effect of all these changes remains to be seen, but it is clearly not a time to be complacent. For a large cooperative agreement like the CRN to survive in this era, we will have to demonstrate our value as a resource to researchers outside the CRN. The Steering Committee will be discussing how to approach this goal without lessening our value and commitment to our investigators and organizations. We will also have to keep promises made in our proposal—especially to create and use standardized data collection and data handling approaches. We need active involvement of all with the SDRC to meet this goal. Our work is cut out for us.



Thanks to the nearly 100 of you who have completed the CRN 2003 Evaluation survey, and a reminder to those that have not - the new deadline for completing the CRN Evaluation is April 1, 2004.



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.

## ***CRN Scientific Interest Groups***

The CRN Steering Committee has created Scientific Interest Groups in several areas to encourage the incubation of research proposals. Gene Hart has created listservs for each of these groups to facilitate and document discussion. The Scientific Interest Groups and conveners are listed below:

### **Prevention and Health Behavior Change**

**Convenor: Tom Vogt**

### **Health Services & Clinical Genetics**

**Convenor: Judy Mouchawar**

### **Health Disparities**

**Convenor: Terry Field**

### **Quality of Care**

**Convenor: Ed Wagner**

### **Survivorship**

**Convenor: Ann Geiger**

### **End-of-Life Care**

**Convenor: Chris Neslund-Dudas**

### **Cost Issues**

**Convenor: Mark Hornbrook**

If you would like to be a member of one of these groups and are not on the group's mailing list, please contact the Scientific Interest Group convenor to be included in the conference calls. Email Gene Hart, [hart.je@ghc.org](mailto:hart.je@ghc.org) to be added to the interest group mailing list.

If other CRN projects or interest groups would like their own searchable listserv list, please contact Gene Hart, GHC.



**DETECT members who attended The International Conference on the Scientific Basis of Health Services in September 2003: From L-R: Marianne Ulcickas Yood, Kevin Beverly, Laura Ichikawa, Steve Taplin, Wendy Leyden, Jane Zapka, Joyce Gilbert, Martin Brown**

## **Project Report:**

# **DETECT<sub>ing</sub> Progress**

During the first four years of the CRN Research Network, investigators from seven sites initiated a project to evaluate why invasive cervical and late-stage breast cancers occurred within their plans, since all women had access to screening. Called DETECT (Detecting Early Tumors Enables Cancer Therapy), this project included three major components: an organizational assessment involving an analysis of health plan screening policies, a survey of physicians regarding screening guidelines, and a survey of women who had positive screening mammograms and/or Pap tests, and three year retrospective chart reviews of invasive cervical cancer cases diagnosed from 1995-2000, and late-stage breast cancers diagnosed from 1995 through 1999.

One of the key aspects in the conceptualization of this project was that the care process involved both the types of care received and the transitions between them. How screening tests are performed, and the quality of diagnostic procedures are critical to the process but transitions between episodes are also critical. As a result we categorized potential breakdowns in quality at critical transitions and steps in care; 1) absence of screening suggest a problem with recruitment, 2) absence of detection meant that screening occurred but the cancer was missed, and 3) breakdown in follow-up meant that a positive screening test occurred but diagnosis was potentially delayed. The first and third failures suggest problems in transitions, while the second is a problem with

# DETECTing Progress

(continued)

the performance of the screening test.

Findings were amazingly consistent between the two cancers. More than 50% of both cervical and late-stage breast cancer cases were associated with an absence of screening during the period before diagnostic tests were initiated. About 35% of both cancers were associated with absence of detection, and the remainder raised questions about breakdowns in the follow-up process. The organizational assessment augmented these findings by showing strong support for screening within leadership but variation in how reminders for screening were implemented. Given our findings, direct outreach to patients may have advantages for those women who do not seek care. The patient survey also demonstrated important consistency between patient report of follow-up and what actually occurred, so studies in this area may rely on patient reports when automated data are not available. Finally, the team demonstrated that a little coffee and cajoling obtained outstanding response rates (91%) from primary care providers.

Results of the work were presented at the 5th International Conference on the Scientific Basis of Health Services in September 2003. The presentations synthesized various aspects of the project and entertained commentary from experts at the NCI (Rachel Ballard-Barbash MD, MPH and Martin Brown PhD) as well as two international experts

in screening, Peter Sasieni PhD from the United Kingdom, and Stephen Walter PhD from Canada. The biggest issue in the review was explaining and understanding that this work was about screening implementation, not screening efficacy.

There is a great deal of work left to do, and it can build on other work within the CRN. The main results of the late-stage breast analysis are under review, and two other papers are close to submission. The organizational assessment team has published four articles and has two more under review. The cervical cancer team is working on several pieces as well. Future clinical care and research priority should be given to reaching women who are not screened and improving the screening methods.

-Steve Taplin, NCI

## What's New on the Web?



KPNW will be presenting a poster at the HMORN conference on the Cancer Counter, how it functions, and its uses. KPNW will also be presenting an "interactive poster," with a laptop demonstration of the cancer counter available for viewing. The data on view will be fictitious, but will show the functionality of the counter.

-Gary Ansell, KPNW

## CRN NEWS & MILESTONES

- " Chyke Doubeni and Terry Field submitted a minority to NCI in February.
- " GHC submitted an application in response to the BAA. "Re-Engineering the Clinical Research Enterprise: Feasibility of Integrating and Expanding Clinical Research Networks" Eric Larson is the PI.
- " Group Health is in receipt of CRN Year 6 Notice of Grant
- " 2 PROTECTS abstracts accepted for HMO Research Network Conference, 1 PROTECTS abstract accepted for oral presentation at SGIM

## Calendar of Events

The NCI and the Drug Information Association are co-sponsoring a conference titled "Advances in Health Outcomes Measurement: Exploring the Current State and the Future of Item Response Theory, Item Banks, and Computer-Adaptive Testing."

**June 23-25, 2004**  
**Bethesda, MD**

For more information, please visit the NCI conference website: <http://outcomes.cancer.gov/conference/irt/>, or contact Bryce Reeve at [reeve@mail.nih.gov](mailto:reeve@mail.nih.gov).

## 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). All submissions are welcome!



## HMO RESEARCH NETWORK CONFERENCE

### CRN-RELATED MEETINGS

May 3-5, 2004 Dearborn, MI

#### **MONDAY, May 3**

8:30am-12:30pm  
9:00am-12:00pm  
9:00am-12:00pm  
12:00pm-1:00pm  
12:00pm-4:30pm  
1:00pm-4:00 pm  
1:00pm-5:00pm

DCIS Project Meeting  
IMPACT Project Meeting  
Ovarian End-of-Life  
Non-Electronic Data Committee  
HIT2 Project Meeting  
BOW Project Meeting  
MENu Project Meeting

#### **Room \***

Regency C  
Regency J&K  
Thomas  
Thomas  
Regency E&F  
Regency J&K  
Regency D

#### **TUESDAY, May 4**

8:00am - 9:30pm  
11:30am - 1:00pm

1:30pm-3:00pm  
1:30pm-3:00pm  
3:00pm-4:00pm  
4:00pm-6:00pm  
6:30pm-8:30pm

SDRC Leadership (*during breakfast*)  
Concurrent Session: Five Years of Data Collection & Management on the CRN: are collaboration and control incompatible? Regency A&B  
SDRC Implementation Meeting Regency G&H  
DTC Genetics Meeting Thomas  
Genetics Scientific Interest Group Thomas  
CARE Study Meeting Off-site  
CRN Steering Committee Giulios & Sons  
*Dinner & Meeting - Conference Hotel*

#### **WEDNESDAY, May 5**

1:00pm-2:00pm  
1:00pm-2:00pm

PROTECTS/PM Outcomes Meeting (*during lunch*)  
New Proposals Committee Meeting (*during lunch*)

*\* Rooms may be  
changed prior to  
the meeting*

## ***WE THOUGHT YOU'D NEVER ASK!***

### ***SDRC OFFERS TOOLS TO FACILITATE DATA COLLECTION***

The CRN has accumulated a lot of experience—and a few hard lessons—in its 5+ years of existence. One of the roles of the Scientific and Data Resources Core (SDRC) is to harness these experiences and share them with other projects. Several documents (some old, some new) have been prepared and uploaded to the CRN web site to help researchers make decisions about data collection strategies and anticipate potential pitfalls.

Recently, we undertook a comparison of the pros and cons of doing mailed survey data collection using a central site vs. having each site handle its own mailings. Balancing concerns in the era of stringent privacy regulations against the advantages of a consistently applied mailing protocol are among

the considerations. To find this document go the CRN web site under the Table of Contents/CRN Global Items/Notes and Memos: [Centralized vs. Decentralized Mailed Surveys](#)

Terry Field, co-leader of the SDRC interviewed several investigators and project managers across the CRN to capture the various lessons they learned in the process of implementing telephone surveys and chart abstraction. These practical recommendations are of benefit for anyone who is planning (or even in the midst of) data collection. To find these documents go to the CRN web site under Table of Contents/SDRC/Expert Teams-Survey Measurement:

[Lessons Learned from CRN Medical Record Abstraction Efforts](#)

[Lessons Learned from CRN Patient and Provider Survey Efforts](#)

Finally, the data cleaning process is a critical but time-consuming step. Based on the experiences of the CRN 1 projects, an offering of data cleaning guidelines were compiled, in hopes of making this process as efficient as possible. To find this document go to the CRN web site under the Table of Contents/SDRC/General/Policies: [Suggested Guidelines for Data Cleaning](#)

If you have any ideas for other “lessons learned” documents or other ways to synthesize and share experiences, we encourage you to contact the PI’s office.

*Sarah Greene, GHC*