

The Cancer Research Network • Connection

News from Ed, Larry, and Mark

Update from the CRN Executive Committee

At the 2011 CRN Research Project Summit in Denver, several CRN project teams held in-person working meetings to review data and results and to discuss dissemination of results and preparing manuscripts. After the project meetings, over 40 people discussed ways to support and improve multi-site research. We made progress in expanding our definition of what CRN proposals and manuscripts are, as we have historically been undercounting our accomplishments. We agreed that the CRN leaders need to do a better job at informing colleagues to submit CRN proposals and manuscripts to

the CRN PI office for review and tracking. We also learned the importance of Knowledge Management in a complex enterprise like CRN, and discussed some of the work under way to help us better document and integrate lessons into our projects and infrastructure. This discussion led to a presentation from the Breast Cancer Surveillance Consortium (BCSC) on their approach to creating publicly accessible BCSC data. We acknowledged that many of the CRN projects have prepared and others want to prepare their project data for additional analyses. We learned about the challenges (e.g., programming and statistical time, funding to sustain reviewing and tracking functions) and the incentives (e.g., more analyses, support of external and junior investigators) to making limited data from CRN projects into a more accessible resource.

- Ed Wagner (GHC),
Mark Hornbrook (KPNW),
Larry Kushi (KPNC)



Sarah Greene, Ed Wagner, Kenneth Adams, and Martin Brown at the CRN Research Summit

News from NCI

Update from the CRN Program Office

NCI recently announced funding of the Population-based Research Optimizing Screening through Personalized Regimens (PROSPR) initiative. PROSPR is a research network consisting of a data coordinating center and seven grants that will collect community-based data for cervical, colorectal and breast cancer screening. Two of the research sites, both researching colorectal cancer screening, are HMO research centers affiliated with the Cancer Research Network. Douglas Corley (KPNC) leads a research team that will identify failures

throughout the screening process, develop corrective strategies and compare the relative benefits, harms, and effectiveness of alternative strategies including those based on individualized risk. Co-PIs for this project include Theodore Levin (KPNC) and Chyke Doubeni (MPCI.) Carolyn Rutter (GHC) leads a research team that will identify low-risk groups that might benefit from less intensive screening and evaluate the potential mortality impact of risk-based screening.

- Martin Brown (NCI)

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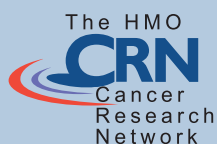
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The Cancer Research Network (CRN) is a collaboration of 14 non-profit HMOs committed to the conduct of high-quality, public domain research in cancer control. The CRN is a project of NCI and AHRQ.

Harvard Pilgrim Health Care Institute, Department of Population Medicine

CRN Site Profile

The Department of Population Medicine (DPM) is an unusual CRN HMO research unit because it was created by both an HMO and a medical school. Sponsored by Harvard Pilgrim Health Care (HPHC) and Harvard Medical School, the DPM core mission is to improve the health of individuals through research and teaching focused on patient populations and the health systems affecting their care. DPM has a broad portfolio of clinical epidemiologic and health care research. Cancer research conducted at DPM spans from cancer prevention, screening and surveillance to diagnosis, treatment, survivorship and palliative care. DPM is unique in that all its investigators are faculty of Harvard Medical School.

Like other CRN sites, DPM researchers

have access to patient populations of both an HMO and a health care delivery system; however, the two are distinct from one another. Harvard Pilgrim Health Care is a large non-profit health plan with over 1,000,000 diverse enrollees across New England. HPHC data available to researchers includes enrollment, outpatient and inpatient claims, and pharmacy utilization. Tumor registry data are available through an annual linkage of HPHC membership with the Massachusetts Cancer Registry. Together, these data are incorporated into the CRN Virtual Data Warehouse. Harvard Vanguard Medical Associates (HVMA) is a large multi-specialty

medical group practice of 300,000 members receiving care at a range of practice environments in the greater Boston area, now part of a larger practice network of Atrius Health. Harvard Vanguard Medical Associates was a pioneer in the use of electronic medical records; most of these are accessible for research.

See HPHCI, page 3



From left: Larissa Nekhlyudov (Associate Site PI), Suzanne Fletcher (Site PI)

HPHCI involvement in CRN-affiliated projects and initiatives

<p>CRN and CRN Collaborative Studies</p>	<p>CRN Center of Excellence in Cancer Communication Research</p>
<ul style="list-style-type: none"> • CanCORS Lung/Colon Cancer Outcomes • HIT 1 and HIT 2 (tobacco control studies) • PROTECTS (prophylactic mastectomy and effectiveness of clinical breast examination) 	<ul style="list-style-type: none"> • Stage One Feasibility Test of the Cancer Survival Query System (CSQS) • Assessing Patient-Centered Communication during Cancer Care (MapCare)
<ul style="list-style-type: none"> • Patient-Oriented Outcomes of Prophylactic Mastectomy • Clinical and Pathological Predictors for Recurrence after DCIS • Diffusion of Hormone Therapy • Diffusion of Breast MRI Technology in Community Clinical Settings • Diffusion of Ovarian Cancer Treatment • Building a Pharmacovigilance Population-Based Laboratory • INFORMED (Melanoma and skin cancer curriculum for primary care clinicians) • ABC (Anti-Depressants and Breast Cancer Pharmacoepidemiology) • SEARCH (Screening Effectiveness and Research in Community-based Healthcare) • SCHOLAR (Effectiveness of Screening Colonoscopy in Reducing Deaths from Colorectal Cancer) • ARRA DEcIDE (Comparing the Long-Term and Real World Effectiveness of Initial Management Strategies for DCIS) 	<p>CRN Scholars Program</p> <ul style="list-style-type: none"> • Developed and directed by Drs. Suzanne and Robert Fletcher, the program has provided young investigators with a unique opportunity to develop both research independence and productive collaborative research.
	<p>Cancer Survivorship Scientific Interest Group (SIG)</p> <ul style="list-style-type: none"> • Led by Dr. Larissa Nekhlyudov, meets monthly by conference call to discuss ongoing studies and explore research ideas. The SIG allows CRN and academic investigators to develop collaborative research and has led to recent proposals, projects and publications.

Building a Population Laboratory for Pharmacovigilance Studies in Breast Cancer

In 2008, the CRN received an administrative supplement to launch the Pharmacovigilance study. This complex and ambitious project pulled together four multi-site networks – the CRN, CVRN, CERT, and Pharmacogenomics SIG – with the goal of creating a population-based research laboratory to conduct pharmacoepidemiologic and pharmacogenomic studies. We collected administrative data on over 13,000 women diagnosed with incident breast cancer between 1999-2007 at eight CRN sites.

Our primary aims included both infrastructure and a proof-of-principle analysis. Activities included:

- Validating VDW procedures, pharmacy administrations, and diagnoses to identify:
 - Chemotherapy infusion data
 - Cardiotoxicity (including congestive heart failure and cardiomyopathy diagnoses)

- Exploring strategies for assembling biological specimens and collecting DNA
- Estimating the risk of cardiotoxicity associated with chemotherapy administration – specifically anthracycline and/or trastuzumab use – in a population-based cohort of women diagnosed with invasive breast cancer

Several manuscripts have been submitted, or will be submitted shortly, to peer-reviewed journals. As part of our project, we reviewed medical charts for 400 women. We plan to publish papers demonstrating the validity of administrative claims for chemotherapy infusions (led by Tom Delate, PhD at KPCO), and an administrative algorithm to identify heart failure diagnoses (led by Larry Allen, MD at the University of Colorado). A third paper (led by Katrina Goddard, PhD at KPNW) is examining the use of human

epidermal growth factor receptor 2 (HER2) testing and concordance with trastuzumab administration (all women who are HER2 “positive” should receive trastuzumab). And a fourth paper (led by Erin Aiello Bowles, MPH at GHC) is our proof-of-principle analysis evaluating the association between chemotherapy use and subsequent heart failure diagnosis.

All of these papers are products of an extensive amount of work and collaboration among the Pharmacovigilance investigators, programmers, and project staff. However, these papers represent a small portion of the work that could be accomplished with this dataset. Since our overarching goal was to create a population-based research laboratory to conduct pharmacoepidemiologic and pharmacogenomic studies, we have developed a proposal form for investigators to use if they are interested in working with the Pharmacovigilance dataset. This form and corresponding guidelines have been vetted by the CRN Steering Committee. We hope that this will serve as an example for other multi-site studies where there may be additional analyses that can be completed using existing data; therefore, creating efficiencies and maximizing our ability to conduct new, exciting research in the CRN.

To view the proposal form and guidelines please see:

<https://appliedresearch.cancer.gov/crnportal/projects/pharmacovigilance/>

-Erin Bowles and Ed Wagner (GHC)

HPHCI

DPM has a strong history of collaborations with the Dana-Farber/Harvard Cancer Center (DF/HCC) and is the home of the DF/HCC Community Practice Research Core (led by Dr. Nekhlyudov). The only such core in U.S. cancer centers, it exists to encourage and enable collaborative research between 800 members of the Cancer Center (from 6 major Harvard-affiliated hospitals, Harvard Medical School and Harvard School of Public Health) and researchers in DPM and throughout the CRN. Successful DF/HCC - CRN collaborative projects have included Drs. Jane Weeks (CanCORS, REACT), Nancy Rigotti (HIT1 and HIT2), Karen Emmons (Prophylactic Mastectomy Outcomes), and Stuart Schnitt (DCIS Predictors and ARRA DeCIDE DCIS Task Order). The close affiliation

between DPM and the DF/HCC has served as a model for other CRN sites aiming to foster similar collaborative relationships.

The DPM Cancer Program includes eighteen faculty members who are engaged in cancer research, and have active collaborations with other organizations positioned at the forefront of epidemiological and health services cancer research, such as the NCI-funded Cancer Intervention and Surveillance Modeling Network (CISNET), state registries, and NCI directly. HPHCI was a founding member of the HMO Cancer Research Network and has continued to lead and be involved in numerous CRN-affiliated research projects and initiatives.

- Larissa Nekhlyudov (HPHCI)

The CRN Connection is a publication of the CRN intended to inform and occasionally entertain CRN collaborators. It is produced with oversight from the Communications & Collaborations Committee.

Please send comments and suggestions on this newsletter to Sarah McDonald, mcdonald.sj@ghc.org

Health Literacy and Cancer Prevention: Do People Understand What They Hear?

Health literacy has received a lot of attention in recent years, but most health literacy research has focused on print materials. The Health Literacy and Center Prevention team realized that much health information is conveyed orally (for instance, in discussions with physicians, or the evening news), so we set out to study how well people understand spoken information related to cancer prevention and screening. We started by recruiting health plan members to watch short video clips from television and the Internet, and asked them to paraphrase key points. The team found that many people were confused about concepts central to cancer prevention, such as risk. We then created the Cancer Message

Literacy Test-Listening, an instrument which assesses how well people understand spoken information related to cancer prevention and screening. Over 1,000 health plan members from four CRN sites took the test. Manuscripts on reporting on test development, psychometric analyses and validity studies are under review. We also collected data on screening utilization and many other measures (including self-efficacy, ambiguity aversion, trust, and cognitive functioning, to name just a few.) Manuscripts exploring the relationships between these variables, health literacy and screening utilization are currently underway.

In September 2011, the team began



Kathy Mazor and Sarah Cutrona

to collect data for the final phase of this project. About 400 members will return for a second study session. In these sessions, participants will listen to three vignettes on PSA screening, colorectal cancer screening, and tamoxifen for breast cancer prevention. The vignettes vary in how the information is presented, which will allow the team to begin to isolate the factors which affect comprehension.

Recently, Sarah Cutrona joined the health literacy team. She received CRN pilot funding to explore ways in which existing peer networks have the potential to transmit effective cancer prevention messages. Peer networks can be an effective way to reach underserved groups, but to date, there has been little research on using these networks to increase cancer screening rates. Data collection for this pilot has been integrated into ongoing health literacy study sessions. This will allow the team to take advantage of the rich data already available on these participants. The questions which have been added for the pilot study focus on whether (or how) people communicate about screening within their social networks, and whether they view themselves as a source of health information for others in their network. She also asks participants for feedback on how to phrase emails about colorectal screening, and on whether they would be willing to send such emails. So far, the response has

see *Health Literacy*, page 5

Recent Findings from CRN Scientists

High-volume flu clinics offer a venue for increasing colorectal cancer screening in a managed care setting. ([Potter MB](#) in *Am J Managed Care*)

The influence of family and friends is a motivator for people who seek information about how genes and habits affect their health. ([Hay J](#) in *Public Health Genomics*)

Patients who believe that something went wrong in their cancer care often don't report their concerns to anyone in the health care organization, and may have unmet needs for information, support and understanding. ([Mazor KM](#) in *Patient Educ Couns*)

Among older women with early-stage breast cancer, age is the primary predictor of receiving less than definitive therapy, placing them at higher risk for cancer recurrence. ([Field TS](#) in *J Am Coll Surg*)

Older women who receive radiation therapy for left-sided breast tumors may be at increased risk for cardiovascular disease. ([Hague R](#) in *Cancer Epidemiol Biomarkers Prev*)

Webinar training was an acceptable, feasible and effective approach to assist in standardizing medical record review across multiple study sites. ([Avila CC](#) in *BMC Research Notes*)

Neighborhood socioeconomic inequalities lead to large disparities in risk of premature mortality among healthy US adults but not among those in poor health. ([Doubeni CA](#) in *Am J Public Health*)

Neighborhood socioeconomic deprivation and other unexplained geographic differences are associated with lower rates of survival from colorectal cancer. ([Lian M](#) in *Am J Epidemiol*)

SEARCHing for an Effective Data Transfer Process

CRN GO grant finds a way to improve multi-site research collaboration

The Data Use Agreement (DUA) process has a reputation for being arduous, so when it came time to put DUAs in place for the Cancer Screening Effectiveness and Research in Community-based Healthcare (SEARCH) project, I steeled myself for the impending misery. Add to the usual DUA challenges, eight participating research sites and well, it's enough to take a project manager's breath away.

Initially SEARCH had hoped to use de-identified data sets for all cross-site work, eliminating the need for DUAs, but we realized early on that this would not be possible. Given the number of SEARCH sites, we felt the traditional DUA process was not going to work and/or be efficient in helping us meet our project goals. We needed a DUA that helped facilitate the work we were funded to do – create a multi-disciplinary, multi-site team for comparative effectiveness research (CER) focused on the delivery of cancer screening in community-based settings and develop methodological capacity for future large-scale, population-based CER studies. We needed one DUA that allowed data transfer among all the SEARCH sites.

We started work on the first draft of our multi-site DUA in January 2011. I met with Tom Dundon, the GHRI contracts service manager, and described what we were looking to do. He took that information and drafted a document that was circulated to the sites for review in February 2011. The first review took the longest. Some sites were quick to get their edits back to us, others weren't. Delays were due to varying institutional policies around DUA review and the size of a site's contracts queue, among other things. Our second draft of the multi-site DUA was circulated for comments in

May 2011. This document included sites' comments and edits from the first round of review at the beginning of the year. This round was much quicker. The third and final draft of our multi-site DUA was circulated for signature in July 2011 and fully executed in August 2011.

So it only took 8 months! Yes, it took us a long time to execute our multi-site DUA, but everyone on the project

– the project managers, programmers and investigators –all feel it was worth the time and (at times) the heartache. Not only do we have a document that meets the needs of our project, but it could also serve as a model and potential template for future HMORN/CRN multi-site work.

- Gabrielle Gundersen (GHC)



Members of the SEARCH team after their meeting in Denver. From left: Andrew Williams, Mary Ann Blosky, Eric Johnson, Carolyn Rutter, Christopher Owens, Azadeh Stark, Terry Field, Chyke Doubeni, Aruna Kamineni, Kenneth Adams, Paul Doria Rose, Bob Greenlee, Jessica Chubak, Diana Buist



Health Literacy

been overwhelmingly positive. The vast majority (85%) of those asked say they would be willing to pass along a message encouraging colorectal cancer screening to friends and family members, and most of these people (78%) would be willing to do so via email. Sarah is already starting to talk to healthcare systems about actually using email to encourage cancer screening!

The Health Literacy and Cancer Prevention study is a core project of

CRN3. Kathy Mazor (MPCI) leads the team, which includes co-investigators Doug Roblin (KPGA), Andrew Williams (KPHI), Bridget Gaglio (formerly at KPCO, Bridget recently moved to Washington DC and joined KPMA), Terry Field (MPCI), Sarah Greene (GHC), Paul Han (Maine Medical Center), Mary Costanza (University of Massachusetts Medical School) and Sarah Cutrona (MPCI).

- Kathy Mazor (MPCI)

Honors and Awards

On September 26, **Chyke Doubeni, MD**, a CRN Scholar from the University of Massachusetts/Fallon, was honored by President Obama as an Outstanding Early-Career Scientist. This is the highest honor bestowed by the United States government on science and engineering professionals in the early stages of their independent research careers. The special honor reflects highly on Dr. Doubeni's achievements as well as on the CRN.

On October 2, **Jody Jackson, RN** (HPRF) gave the keynote address at the Scripps Cancer Center Oncology Nurses Symposium in San Diego, CA. Jody's talk was titled "Empowering Patients Through Survivorship Care Plans" and was based on work done with Dr. Cheri Rolnick, formerly CRN site PI at HPRF. Jody and Cheri presented this work at the CRN Scientific Webinar in October 2009.

Data Developments

Researchers at Meyers Primary Care Institute (MPCI) are looking forward to increased availability of cancer data. In **August 2011**, the Massachusetts Department of Public Health granted permission to establish a link from Fallon Clinic's data to the state cancer registry. Data will be available for the CRN cancer counter, the VDW tumor file, and prep-to-research analyses. MPCI was profiled in the September 2009 issue of this newsletter.

July 2013 is the target date for Henry Ford Health System's full deployment of Epic. Researchers and analysts will bid adieu to homegrown codes and say hello to Clarity tables! HFHS was profiled in the May 2011 issue of this newsletter.

What Happens in Denver... Stays with the CRN Forever!

During a long day of productive meetings on October 25, CRN colleagues relaxed and caught up with each other on breaks, at a reception hosted by KPCO's Institute for Health Research and after the business dinner.



Tom Delate, Mark Hornbrook, Larry Kushi



Gene Hart, Sarah McDonald, Sally Vernon, Heather Clancy



Heather Feigelson, Joan Holup



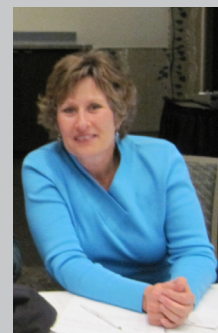
Terry Field, Katrina Goddard, Pam Pawloski



Ed Wagner, Sarah Greene, Jessica Chubak, Leah Tuzzio



Virginia Quinn



Kim Bischoff



Joanna Bulkley, Mark Hornbrook, Becky Silliman, Diana Buist, Andrew Williams



Laura Coleman