

The Cancer Research Network Connection

News from Ed, Larry, and Mark

Update from the CRN Executive Committee

The CRN has an opportunity to increase input from our clinical and health plan leadership in formulating CRN research and disseminating CRN research results. As we integrate the research and clinical arms of our organizations, we must build stronger relationships with and knowledge of our stakeholders. In the era of comparative effectiveness research (CER), we need a better understanding of the clinical impact CRN work has had, how CER can influence evidence-based medicine and clinical practice, what are the high-priority CER questions from the leaders of our cancer care programs, and what it would take for CRN sites to conduct large, pragmatic comparative

effectiveness trials. As we begin Year 12, fourth of five years of funding in CRN3, we plan to engage in dialogue with our stakeholders to lay the foundation for this basic understanding. Stakeholder engagement will help us conduct CER and improve care. Some of our oncologists have indicated strong interest in becoming more informed about the CRN and more involved in cancer epidemiology, clinical trials, and health services/comparative effectiveness research. We welcome opportunities for bridging between our research centers and clinical oncology departments.

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

News from NCI

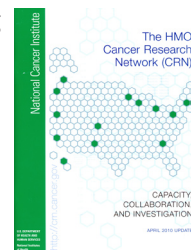
Update from the CRN Program Director

We are pleased to announce publication of the updated booklet, *The HMO Cancer Research Network: Capacity, Collaboration, and Investigation*. First published in 2008 and expanded and updated in April 2010, this booklet serves as a "user's guide" for potential collaborators. The updated version contains a new section describing CRN's comparative effectiveness research. It also highlights the CRN Scholars Program, showcases the CRN's many fruitful collaborations, and summarizes the diverse projects that this group of investigators is working on, including those

that received stimulus funding from the American Recovery and Reinvestment Act.

Visit www.crn.cancer.gov to view or download the PDF file. A maximum of three printed copies of the publication can be obtained at no cost by calling 1-800-4-CANCER or by ordering online from the NCI Publications Locator at www.cancer.gov/publications (search by keyword in the publication's title.)

-Martin Brown (NCI)



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.

In this issue ...

Stakeholder engagement in cancer research: what is it and why is it important?... page 2

What are others outside the CRN doing to engage stakeholders? ... page 2

The benefits of involving others in our research: report from a CRN intervention study ... page 3

Lessons learned from CRN studies: tips and tricks on engaging stakeholders in research ... page 4

We can't do it without them: stakeholder partnerships and difficult research topics ... page 6

Stakeholder engagement in research

The Who, What, When, Why and How

Our health care delivery systems and research centers have a long history of working together to identify and test strategies and innovations to improve care delivery and health outcomes. The national focus on health care reform has heightened attention to “rapid learning health care systems.” Such systems intend to more formally organize stakeholders to work together on developing ways to provide care that is evidence-based and patient-centered and to conduct research that is relevant and meaningful to advance science. By meaningfully engaging stakeholders in these learning health care systems we can conduct research that is driven and supported by those who ask important questions and can help advocate for sensible research and health care improvement.

Engaging health care delivery system staff, patients, families, caregivers, and patient advocates in research operations is important for several reasons.

- Stakeholders can collaborate on **developing, prioritizing, and refining research questions and methods.**
- Stakeholders can provide a **front-line, local perspective and context** on what is **logistically feasible** and **acceptable** to study and implement
- **Funding agencies and health care reformers are beginning to expect** the researchers to engage stakeholders throughout the research process from inception to implementation to sustainability.

Researchers can engage stakeholders anywhere along the continuum of improving health and

care delivery, for example:

- ✓ When developing specific aims or designing an intervention to make sure it covers all important bases and doesn’t duplicate other work.
- ✓ Before fielding, to ensure the intervention mirrors or can be integrated into a “real world setting” so that if it’s successful it can be scaled up easily and effectively.
- ✓ When developing surveys and study materials, pre-testing with stakeholders can affirm that the questions are understandable, meaningful and you’re not missing anything important.
- ✓ When you are writing a manuscript to help you understand the limitations and next steps.
- ✓ When you have results or an update to share so that you give back and sustain your stakeholder partnership.

CRN research provides many approaches and opportunities for engaging and learning from stakeholders. The following articles give some detailed insight from empirical studies on pragmatic strategies for effective engagement.

-Leah Tuzzio (GH)

Stakeholders are:

- researchers
- funders
- health care delivery system colleagues, including:
 - physicians
 - physician assistants
 - nurses
 - pharmacists
 - behavioral health providers
 - medical technicians
 - clinic support staff
 - administrative leaders
 - social workers
- health plan/ insurers
- patients
- family members
- caregivers
- community services
- patient advocates

What are others outside the CRN doing to engage stakeholders in research?

In the U.K.: INVOLVE is a national advisory group, funded by the National Institute for Health Research (NIHR). Its role is to support and promote active public involvement in NHS, public health and social care research, in order to improve the way that research is prioritized, commissioned, undertaken, communicated and used. <http://www.invo.org.uk/>

In San Francisco, CA: Seva is a partnership of community residents, neighborhood leaders, service providers, medical doctors, educators, and others who are listening to one another and working together to improve care and policy for those most vulnerable. <http://www.sevpartnership.org/>

The benefits of involving others in our research

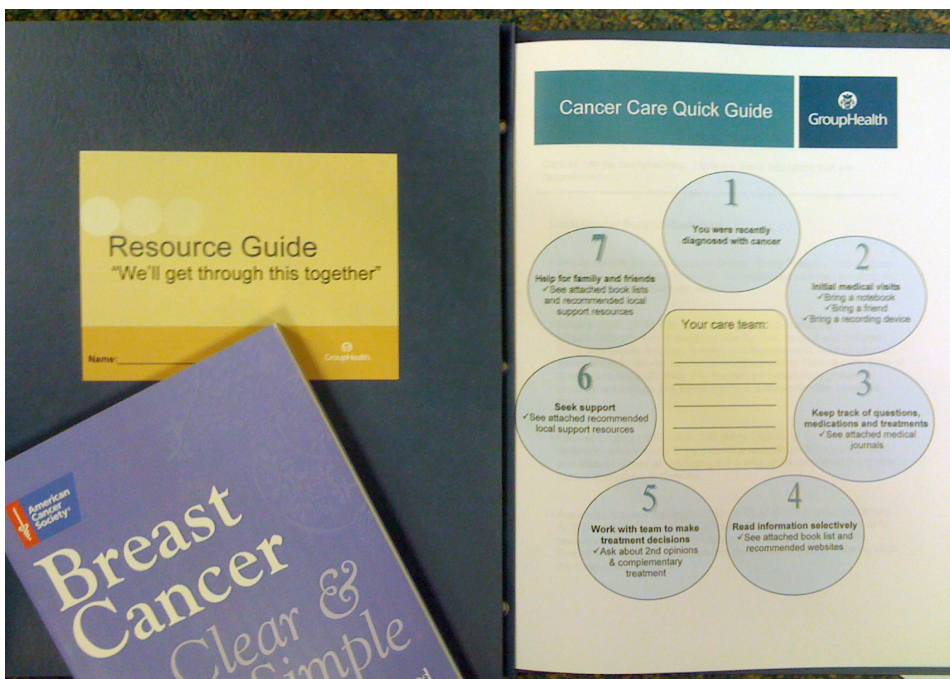
Engaging stakeholders in research requires time and commitment which can easily be shuffled to the bottom of the priority list after other project constraints. But for studies that test interventions and for researchers who aspire to translate findings into use, this initial energy focus may be especially beneficial. I am the project manager for a number of studies at the Group Health Research Institute. Before this work, I implemented quality improvement projects and evaluated community health clinics. I've learned that the work to gather people around a table is labor-intensive, but the benefits outweigh the effort.

One of my projects is the Oncology Nurse Navigator clinical trial, which is part of the CRN Cancer Communication Research Center (CCRC). The goal of our trial is to implement an oncology nurse navigator program for patients newly diagnosed with cancer and compare its effectiveness with enhanced usual care. The Principal Investigator is Ed

"I've learned that the work to gather people around a table is labor-intensive, but the benefits outweigh the effort."

Wagner. In the past year and a half, we have reached out to stakeholders including patients, our community organizations, and our delivery system—and their input has benefited our study tremendously. Highlights from stakeholder engagement to date include:

1. All study participants are mailed an "enhanced" packet of information about their cancer, but we didn't know what this packet should include or look like. We convened an advisory group by reaching out to a Group Health cancer support group and talking with colleagues and community organizations. Everyone appreciated being involved, especially when we showed them the final products and they saw that we incorporated their input into our materials. In fact, one patient said the packet was, "Perfect!"
2. Our Oncology Nurse Navigators have exceptional credentials, but we wanted them to understand the emotional distress that a cancer diagnosis often triggers. During one of our training sessions, a handful of patients and caregivers joined us to describe their experience of being told that they or their loved one has cancer. The RNs described the session as an "Aha!" moment. They learned how a little thing, such as asking a patient how they are doing, is critical before launching into providing in-depth educational information.
3. The conceptual framework for our Oncology Nurse Navigator trial hasn't changed, but we continually learn how to better implement the model. We modified our protocols over time to reflect lessons learned. We convened meetings to gather feedback from our delivery system partners to improve our program. Yes, we heard constructive criticism, which we are now incorporating into our protocols. In addition, we heard that the delivery system wants to be more involved.



Some materials from the enhanced cancer care information packet used in the Oncology Nurse Navigator study. The "Quick Guide" was developed by members of our Advisory Committee.

Recently, I organized a meeting suggested by a local medical chief to tackle an aspect of our Oncology Nurse Navigator trial. Nobody showed up. After initial thoughts of self-doubt, I emailed the providers asking if they still wanted to meet, and they all said yes! The moral is that even the most engaged stakeholders can't join every meeting and this shouldn't discourage your efforts.

-Kathryn Horner (GH)

Lessons learned from CRN studies

Researchers share tips and tricks for effective stakeholder engagement

Opportunistic colorectal cancer screening: providing FIT with annual flu shots

In this CRN pilot study, researchers worked with clinic staff to develop and implement a “FLU-FIT” campaign to provide colorectal cancer screening by fecal immunochemical test (FIT) during flu vaccine clinics.

Stakeholders: Clinicians and clinic staff

Lessons learned:

- Getting early input from clinical partners on the design of the intervention was essential for its success. Clinical partners helped design an intervention that was much more effective in the clinic setting than researchers could have designed on their own.
- The research team and clinical partners made compromises to accommodate each other’s perspectives. Our clinical partners were most concerned about reaching as many people as possible with the services our pilot offered, and our research team was most concerned with showing program efficacy and effectiveness before scaling it up.
- Based in part on the work of this pilot study, co-investigator Dr. Michael Potter was awarded a 4-year ACS Research Scholars Grant to collaborate with us to further test the effectiveness of the FLU-FIT Program and disseminate it to other KP Northern California settings.

- Carol Somkin (KPNC)

Health literacy and cancer prevention: do people understand what they hear?

This CRN research project focuses on comprehension of spoken messages about cancer prevention and screening.

Stakeholders: Health plan members

Why engage stakeholders? Our team feels it is important to engage health plan members throughout this project because we need them to tell us what they find confusing or hard to understand.

Lessons learned:

- We have found that many health plan members are extremely generous with their time, and enthusiastic about the opportunity to improve communication about health. They’ve been eager to share their views, worked hard at whatever we’ve asked them to do, and often volunteered to come back again!

- Kathleen Mazor (Meyers/UMass)

Chemotherapy and coinsurance: the effect of cost sharing on cancer care

Research on the effectiveness of advanced cancer treatments (REACT)

Researchers at KPCO have engaged a medical oncologist as a consultant and collaborator on two retrospective, observational studies of patterns of cancer care at CRN sites.

Stakeholders: Clinicians

Lessons learned:

- Come to the table with examples of how a collaboration would be of value to the clinician. In our case, we were able to use standard VDW data extracts to help inform the Oncology department about different ways of looking at the variation in incident cancer cases over time and within and across clinician practices.
- Engage and involve the clinician collaborator early and often. If you don’t understand a clinical issue that may inform a data extract or analysis, ask first before going down a naïve, uninformed path. Community practice doesn’t always follow published clinical trials. Ask for examples of typical patterns of care, share preliminary data extracts. Be open to starting over from scratch.
- Be flexible – the patient comes first. If we scheduled a meeting a month in advance and a patient or practice issue emerged, that had to take precedence. If we were drafting a proposal, we needed to make sure we had a solid draft available for review on the day and time the clinician had time to review it.

- Deb Ritzwoller (KPCO)



Preventing errors in the home care of children with cancer

This CRN and CRN Cancer Communication Research Center pilot study at Meyers and KPGA characterized home medication errors in children with cancer.

Stakeholders: Parents and health care providers of children with cancer

Why engage stakeholders? From this experience, we learned it is essential to understand the breadth and depth of the problem from the stakeholders before developing interventions.

Lessons learned:

- We approached parents in our study as experts, as we sought to learn about difficulties in the home care of children with cancer.
- We tried in every way possible to respect parents' time in arranging home visits. For focus groups we provided dinner and babysitting. We also had a Spanish speaking nurse so we could do home visits in Spanish.
- The home environment was chaotic, compared to a research setting, and data collection needed to be as simple as possible. However, the information we gathered was rich.
- We streamlined recruitment so that it minimized the time, space, and effort from the clinical staff. We met with the physicians and the rest of the care team to share results prior to presentation and publication.

- Kathleen Walsh (Meyers/UMass)

Media coverage and direct-to-consumer advertising of genetic tests

One of the aims of this CRN pilot study was to conduct focus groups with KPCO members and primary and specialty care providers, to elicit their knowledge, beliefs and attitudes about genetic testing for common disease risk and the direct-to-consumer (DTC) advertising of such genetic tests.

Stakeholders: Health plan members and clinicians

Why engage stakeholders? If we don't engage these stakeholders, we risk creating costly interventions and providing information to people that is unimportant or irrelevant to them and in the end will show no improvement in whatever outcomes we as scientists are measuring.

Lessons learned:

- Be willing to engage with the stakeholders and talk with them on their level. Find the angle on

your questions that helps them engage in the conversation.

- Be open to the opportunities they present when they show you a completely different perspective on the issue than what you were expecting.

- Alanna Kulchak Rahm (KPCO)

HealthPartners Cancer Connect

HPRF has created the Cancer Connect Newsletter to help keep HealthPartners oncology clinic staff, and others with whom we collaborate, informed of cancer-related work in care delivery, research, the CRN and the Minnesota Cancer Alliance.

Stakeholders: Clinicians

Why engage stakeholders: Involving providers in research may make it more likely that study methodology uses clinic resources appropriately and that lessons learned will result in system improvements. Our goal of making clinicians aware of the wider context of HealthPartners' cancer-related activities via Cancer Connect complements specific project involvement. Sharing this information may help to break down the perception of researchers and clinicians working in silos and may spark connections that might never have occurred if people were not aware of the broader scope of cancer activities.

Tips for Newsletter Development & Distribution:

- Emphasize all local cancer activities (not just those related to CRN).
- Highlight people as a means to facilitate connections (e.g., we include "Meet the Clinic Person" and "Meet the Research Person" sections and emphasize staff names in project summaries.)
- Make communication bi-directional by soliciting input on newsletter content.
- Expand the audience beyond the "usual" colleagues and collaborators (e.g., include nursing and support staff.)
- Clinicians are strapped for time so may not read the newsletter. We try to make the content as inviting as possible by focusing on people. Finding the balance between the right amount and too much information is a challenge. We think a two-pager is ideal.

- Jody Jackson and Cheri Rolnick (HPRF)

Continued on page 6



We can't do it without them: stakeholder partnerships and difficult research topics

Communication is vitally important to people facing cancer as they contend with a complex and often anguishing experience. This is only intensified if something goes wrong during the course of care, such as a medical error or other adverse event. What are they told? How does the event, or how it's handled by the medical personnel, affect them? With colleagues at Meyers Primary Care Institute, Kaiser Permanente Georgia, and University of Washington (UW), we're exploring the occurrence of and communication around adverse events in oncology. The NCI-funded project is part of the CRN's Cancer Communication Research Center grant, and is led by Kathy Mazor (Meyers) and Tom Gallagher (UW.) Data collection includes semi-structured phone interviews with patients (done!) and provider focus

groups (in progress).

Mounting this study has been an extraordinary experience, and we've benefited tremendously from involving stakeholders outside of our research team. With such a sensitive topic, it felt risky to open this black box — we were asking patients things like, "What went wrong during your care?" "Could it have been prevented?" "Did you take any action?" For those of us new to research on medical errors, we worried this might spur people to (re)consider taking action against the health plan. Thus, support of key stakeholders from among health system leadership (e.g., chief of oncology, head of risk management) was essential. At each site, we met with and listened carefully to leaders, and refined the protocol to proactively address their concerns. For example, we ensured that each

site had appropriate "triage" for interviewees who became distressed, or wished to share their concerns with customer service or other quality oversight personnel.

Health plan leaders ranged in their degrees of buy in for the study, but ultimately, we developed tactics to ensure that the interview protocol met the objectives of the research team and the health plans, while maintaining our goal of hearing the patient's perspective on whether something went wrong. We recognized that patients' perceptions and health plan definitions of problems might differ markedly. But that was what we wanted to learn, since research is sparse in this area.

We've since interviewed 78 patients, and analysis of 1200(!) pages of qualitative data is in progress. During the interviews, we sought participants' suggestions about improving communication about cancer, both in general, and when something goes wrong. We found that there were many invested and articulate folks in our study population, and that they could be an invaluable resource as we develop educational materials to aid both patients and providers in knowing what to say if a problem in care occurs. As such, we added an interview item asking people if they'd be willing to help us downstream as we develop approaches to meet patients' (and providers') communication needs. It strengthens the study and the products of our research to incorporate all of our stakeholders' voices throughout the process. Looking back, I can't see how we would have done this any other way.

- Sarah Greene (GH)

Lessons learned

Continued from page 5

Specimen Collection within the CRN: A Critical Appraisal

As part of the CRN Pharmacovigilance study, the genomics working group surveyed researchers at eight study sites to learn about recruitment procedures and participation rates from past studies that collected biological specimens.

Stakeholders: Researchers

Lessons learned:

- It worked best to have someone locally on the study team who

could identify the appropriate people to complete our survey, and who could follow-up with non-respondents and to answer questions. The respondents were more likely to answer if the request came from someone they knew.

- You may as well give people short deadlines. The extra time doesn't help — either they are going to do it relatively soon, or not at all. Then, you can follow-up sooner with the non-responders.

- Katrina Goddard (KPNW)

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 (Martin Brown, Terry Field, Alyssa Grauman, Reina Haque, Cheri Rolnick, Deb Ritzwoller, Nirav Shah, Leah Tuzzio, Ed Wagner, Robin Yabroff.)

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