



From the Agency for Healthcare  
Research and Quality

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## AHRQ UPDATES ON PRIMARY CARE RESEARCH: MCC RESEARCH NETWORK DATA ARCHIVE

Scientists studying people with multiple chronic conditions (MCC) need new datasets and research methods to help them examine this growing population. The MCC Research Network data archive (<http://www.icpsr.umich.edu/AHRQMCC/>) from the Agency for Healthcare Research and Quality (AHRQ) seeks to fill this gap. Using datasets freely available in the data archive, researchers can investigate the interactions of chronic conditions, compare outcomes from different treatments, and discover the most efficient and effective methods of treating patients with MCC.

### Find Data

AHRQ's MCC Research Network data archive provides freely available datasets and documentation as well as additional MCC-related data. Data come from a rich range of sources, including: electronic medical record clinical data, multi-payer claims data, chronic disease registries, Medicaid claims, state psychiatric hospital inpatient data and outpatient mental health services, self-reported home blood sugar and blood pressure data, state cancer registry data, and quality-of-life and physical assessment data obtained from computer-assisted interviews. For many datasets in the archive, researchers can search for variables, studies, and bibliographies, as well as download data in SPSS, SAS, Stata, and ASCII formats.

### Share Data

In addition, investigators with MCC-related data are invited to share their data through the AHRQ MCC Research Network data archive. Data deposited in the archive will be freely available for download from the website until at least December 2015. After that time, the datasets will be accessible to Inter-university Consortium for Political and Social Science Research (ICPSR) members (which includes most institutions) and available for a cost to non-members. Shared data may include complete data sets, partial data, data documentation, and/or syntax files used to replicate findings. Data released for public dissemination can include: SAS, SPSS, and Stata data files, searchable PDF codebooks, and summary metadata records.

The website also includes a page for investigators to share code, syntax, software, methods, and other tools that they have used in their MCC research to help other investigators working on MCC research.

For more information on the AHRQ MCC Research Network and the data archive, please visit the AHRQ MCC website: <http://www.ahrq.gov/research/mccrn.htm>.



From the North American  
Primary Care Research Group

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## TELL US A STORY ABOUT WHEN PRIMARY CARE WORKED FOR YOU

The title above appropriately reflects the theme of the first Patient-Centered Primary Care Policy and Advocacy Preconference, held in conjunction with the 2013 NAPCRG Annual Meeting in Ottawa, Ontario, Canada, November 2013. This conference brought together 10 dyads, shown in Table 1, of patients and their primary care providers to learn about primary care, primary care research, and patient-centered outcomes research. The interactive conference included a full-day preconference, attendance at NAPCRG research presentations, and a second half-day debrief and learning group held towards the end of the NAPCRG meeting. The preconference featured several lectures from Perry Dickinson and Valerie Gilchrist, plenty of small group discussion and storytelling, and a lunch conversation with Joseph Selby, Director of the Patient-Centered Outcomes Research Institute (PCORI); David Meyers, Agency for Healthcare Research and Quality (AHRQ); and Nancy Mason MacLellan, Deputy Director, Program Delivery Research Capacity Development, Canadian Institutes of Health Research.

**Table 1. Patient and Provider Participants**

Ed Bujold, MD, and Ray Haeme
Kristen Dillon, MD, and Susan Lowe
Cynthia Krueger Wolff, MD, and Bethene Kay Ross
Tony Gerk, MD, and Christin Sutter, Ned Norman, and Maret Felzien, MA
Joesph Lemaster, MD, MPH, and Mang Sonna
Marilyn Fraser, MD, and Ruthann Taylor
Cleo Mavriplis, MD, and Madeleine L Champagne
Ann Macauley, MD, and Jean Légaré
Antoine Boivin, MD, and Jean Vocino

The goal of the event was to put a name and face to primary care research; to provide important stories to go along with the medical evidence for primary care. Policy makers like stories, and primary care research has not been effective at bringing these stories to our policy makers. The patient-primary care provider dyads agreed with the need for improved research policy and advocacy for primary care and patient-centered research. This combination of needs prompted the group to call for a series of patient engaged programs for long-term implementation within NAPCRG including: patient leadership within NAPCRG, broader patient involvement in NAPCRG strategic planning, program development, annual meeting participation, and patient-provider dyad advocacy work with research funders including elected officials, funding agencies, and academic research organizations.

The NAPCRG Patient-Centered Primary Care Policy and Advocacy preconference provided several new lessons. First, patients and their primary care providers are eager to work with each other on topics and areas outside of the individual direct patient care. We heard many stories from the patient/provider dyads about how they might impact their local community health. For instance, one patient and her primary care provider told about their work on identifying and mitigating radon exposure in their small rural Iowa farm town. They have now partnered with several researchers at the University of Iowa to further this research and disseminate it more widely throughout Iowa. Second, patients want to become more involved in the research agenda at NAPCRG. This spring, several participants from the conference will travel to Washington, DC, to share their experiences and needs at the annual Family Medicine Congressional Conference. Their trip will include an advocacy visit to discuss patient-centered primary care outcomes research with their federal legislators. Another patient will be joining the NAPCRG Board strategic planning retreat. Patients and providers want to judge posters at NAPCRG's Annual Meeting and present the "People's Choice Award" to the research with the most appeal to patients and primary care providers.

Third, the space where patients and their primary care provider interact is crucial to the translation and implementation of high quality health care. The participants were adamant that the most important research that might help them is research that provides information and tools for conversations, negotiations, and care between the patient and their primary care provider. Efforts that only engage the practice, the specialist, the physician are not adequate. Efforts that only target the patient may not be sufficient. We believe that the dyad is unique structure for enhancing patient-centered outcomes research.

NAPCRG planners started this process hoping to find patients and physicians willing to advocate for primary care research. What we got is a cadre of activated patients and physicians that want to be part of everything NAPCRG does. NAPCRG members can expect to see more patient engagement in the coming years, resources for patient engagement and participatory research, and patient and primary care provider leadership within NAPCRG. And they might even judge your research for the People's Choice Award.

*Jack Westfall, MD, MPH*



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## TASK FORCE PROVIDES UPDATE ON RESIDENCY ACCREDITATION TOOLKIT PROGRESS

The STFM Task Force has spent the first half of 2014 developing user-friendly tools, templates, checklists, modules, lectures, and more that residency programs will need to succeed in the Next Accreditation System environment and with the new program requirements. Both become active on July 1, 2014. The new outcomes-based accreditation process will be a drastic change, and residency programs across the country are preparing to transition to a continuous accreditation process.

"As we all continue to evolve our programs into the future of the NAS, we hope that this toolkit serves as a helpful reference for your journey," said Residency Accreditation Task Force Chair Ted Epperly, MD.

The STFM Task Force has focused on these following areas of toolkit development:

- Milestones: information, reporting, mapping, and gap analysis tools
- Milestones assessment and evaluation tools
- Clinical Competency Committee and how to make this hum
- Residents in difficulty and using the CCC
- New FM program requirements and toolkit items to help meet these
- Technology: needs assessment, tools, applications
- Milestones vignettes for program use
- Faculty development: Milestones, direct observation, feedback, entrusted professional activities tools
- Faculty survey and tips on how to use this
- Scholarly activity—what counts and what does not