

Embedded Research to Improve Health

The 20th Annual HMO Research Network Conference, March 31 – April 3, 2014, Phoenix, Arizona

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The HMO Research Network (HMORN) is a member-based network of 17 research centers affiliated with not-for-profit health care systems across the US with an eighteenth site in Israel. These health care organizations all provide comprehensive medical services to enrolled members and patients. Though not all HMORN members are Health Maintenance Organizations (HMOs) most are integrated delivery systems, and most of the member research centers reside within the organizational structure of the health system itself. This ‘embeddedness’ of the research center within the health plan creates a natural opportunity for direct interactions between health care leaders, clinicians and staff, patients/members, and research investigators from HMORN member sites. Both organizational and member stakeholders are essential collaborators in the new model of patient and provider engaged research envisioned by the National Institutes of Health (NIH) Health Care Systems Research Collaboratory,¹ the Patient Centered Outcomes Research Institute (PCORI),² as reflected in recent funding opportunities published by NIH, PCORI and the Agency for Healthcare Research and Quality (AHRQ).^{3,4,5,6,7,8}

The theme of the 2014 HMORN annual conference, *Embedded Research to Improve Health*, was especially timely as the US research environment shifts toward increased stakeholder engagement. The conference included several new features: a poster contest, an award for the best thematic abstract, an investigator development program, project and scientific interest group working meetings, and numerous sessions devoted to sharing methods, best practices, processes, and other information to engage a variety of stakeholders in research and research processes.

The 20th annual conference of the HMORN was held in Phoenix, Arizona between March 31 and April 3, 2014. The

event was hosted by Kaiser Permanente Colorado with Heather S. Feigelson, PhD, MPH as scientific chair and Sarah Madrid, MA ABD PhD as conference manager. The event marked two decades of sustained and productive collaboration across member sites. The State of the Network Address by the 2013-2014 HMORN Governing Board chair, Dr. John Steiner of Kaiser Permanente Colorado, celebrated this longevity, identified essential elements of network sustainability, and discussed the skills necessary to practice “leadership without control” in decentralized, collaborative research environments such as the HMORN. The keynote address was delivered by Patricia Gabow, MD, the recently retired chief executive officer (CEO) of Denver Health, a nationally prominent, integrated safety-net delivery system. She discussed research-operations partnerships, and presented the Denver Health experience in using Lean⁹ approaches to improve organizational efficiency and control costs. Senior staff from PCORI offered two luncheon addresses and participated in panel sessions. Four early career investigators awardees shared findings on studies of patient satisfaction, lifetime cancer care costs, breast cancer prevention, and nursing home discharge outcomes. Two poster sessions, numerous sessions for research administrators and IRB officials, and opportunities for informal networking rounded out this year’s event.

State of the Network Address

John Steiner, MD, MPH is senior director of Kaiser Permanente Colorado’s Institute for Health Research and chair of the HMORN Governing Board. He delivered the annual State of the Network plenary address to begin the meeting. His remarks celebrated new shared infrastructure for the Network over the past year, including creation of an IRB reciprocal reliance agreement for ceding processes, revised pre-negotiated subaward and data use agreement

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templates, the launch of a new Web site, best practices for collaborating with funders and project data sharing policies, and guiding principles relating to de-identified data containing small cell sizes. Two manuscripts describing the HMORN Virtual Data Warehouse (VDW) will also be published shortly after the 2014 conference.^{10,11} The remainder of Dr. Steiner's remarks focused on assuring the sustainability of the HMORN in changing times as the Network enters its third decade. Considering network sustainability to be the development and enhancement of shared research assets and a community of researchers to use and further develop those assets, he identified essential elements he feels have led to the HMORN's 20-year record of sustainability – most notably the community of researchers and organizational culture of the Network.

Researchers in the HMORN have chosen to work outside both conventional academic research settings and private sector organizations. They are naturally allied with their host health system, and have a deep understanding of what a “system” is. They typically receive their own and their family's health care within the care systems they study. In addition, the HMORN itself is not a corporate entity and does not receive external funds to support its operations. Rather, the Network has a decentralized organization largely driven by volunteerism and a common mission, with emphasis on consensus-building, alignment, and respect for autonomy. In this decentralized model of organization, leaders of the HMORN and its scientific networks lack “command and control” authority and must instead practice “leadership without control.” This leadership model is not a challenge unique to the HMORN. Dr. Steiner shared guiding principles that Tom Clark, CEO of the Metro Denver Economic Development Corporation had articulated with regard to a highly successful 30 year regional development effort across 9 counties and 70 towns and cities in metropolitan Denver – each with its own government and priorities. An underlying theme of these guiding principles is the need for establishing and maintaining trust based on transparency and accountability. In the medium- to long-term, the true source of sustainability for the HMORN will not be its data assets, but its strong community and collective culture.

Early Career Investigators

Four early career investigators (ECI) received this annual HMORN honor and the opportunity to present their research during a plenary session. Awardees were selected through a competitive evaluation process co-led by the scientific committee chair, Heather S. Feigelson, PhD, MPH of Kaiser Permanente Colorado Institute for Health Research and Robert Steiner, MD of Marshfield Clinic Research Foundation.

Laura Panattoni, PhD, a research economist at the Palo Alto Medical Foundation Research Institute (PAMFRI) presented, *Patients Report Better Satisfaction with Part-Time Primary Care Physicians, Despite Less Continuity of Care and Access*. This work assesses the implications of the increasing number

of both male and female primary care providers opting to practice part-time. Her analysis identified a trade-off between higher patient satisfaction and lower care continuity and access that calls for additional study.

The second ECI awardee was Matthew (Mateo) Benegas, PhD, MPH, from the National Cancer Institute's Division of Cancer Control, Population Sciences Health Services & Economics Branch. He participates in the HMORN Cancer Research Network (CRN) Scholar Program. His presentation entitled, *Renal Cell Cancer (RCC): A Shift in Approaches for Treatment of Advanced Disease in the United States*, examined trends in systemic therapies for advanced RCC in the US. His future studies will include trends in surgical management of RCC patients and lifetime costs of cancer care among patients in integrated health care settings.

Hazel Nichols, PhD, who also participates in the CRN Scholars Program, is an assistant professor in the Department of Epidemiology at the University of North Carolina Gilling's School of Global Public Health. Her talk, *Discontinuation of Tamoxifen for Primary Prevention of Breast Cancer in the Sister Study*, summarized findings from a cohort of women at risk for breast cancer who began taking a 5-year course of tamoxifen as a chemopreventive measure. Her future work will look at more recent time periods, other measures of adherence, and expanded patient populations.

The final awardee was Ning Zhang, PhD, a health services researcher from Meyers Primary Care Institute of the University of Massachusetts Medical School and with the University of Massachusetts Amherst. Dr. Zhang's work focuses on the intersection between obesity and aging and her ECI presentation, *Does Weight Status of Short Term Nursing Home Residents Affect Discharge Outcomes?*, examined the challenges and care implications created from the increasing prevalence of obese nursing home residents. Her findings called for interventions, policies, and training to enhanced preparedness for the anticipated increase in obesity in nursing homes.

Keynote Address

The keynote plenary of the 20th Annual HMORN Conference was delivered by Patricia A. Gabow, MD, MACP. Dr. Gabow was CEO of Denver Health from 1992 until her retirement in 2012, transforming it from a department of city government to a successful, independent governmental entity. She presented *The Intersection of Health Care System Redesign and Research in the Safety Net*. In her remarks, she championed embedded research that addressed system redesign issues as a path to addressing the health care issues of cost, quality, patient and employee engagement, and empowering the transformation of systems and culture. She outlined the challenges and opportunities for research in safety net institutions. She gave particular emphasis to Denver Health's rationale for selecting Lean¹² as a vehicle for organizational change. After reviewing the basic operational principles of

Lean she described a number of highly successful applications within Denver Health and the notable reductions in waste and improvements in cost savings, process efficiency, and patient outcomes that resulted. She argued that Lean is applicable to the entire research enterprise due to the push for research to be faster, cheaper and better; the applicability of Lean principles and tools to pragmatic and process oriented research; and the emphasis of Lean on respect for people – including patients and clinicians.

PCORI 101 and 201 Sessions

Three PCORI staff presented at two luncheon plenaries. Sarah Greene, MPH, a senior program officer in PCORI's comparative effectiveness research (CER) methods and infrastructure program led off the first session with the rationale for establishing PCORI, their approach, and what differentiates PCORI from other funders. A snapshot of PCORI's research portfolio, tools and resources was also presented. Core attributes central to PCORI's mission include broad patient and stakeholder engagement, an emphasis on patient-centered CER, and PCORI methodology standards. PCORI's multi-stakeholder merit review process was reviewed and ongoing refinements to this process were briefly outlined.

As of January 2014, PCORI has made 279 research project awards in 38 states totaling \$464.2 million. This includes 50 pilot projects; 54 comparative studies of prevention, diagnosis and treatment options; 41 projects aiming to improve health care systems; 31 projects to inform the choice of strategies to eliminate disparities; 25 projects addressing communications and dissemination among patients, caregivers and clinicians; 30 awards to accelerate methodological research; and 29 networks (11 clinical data research networks, 18 patient-powered research networks) and a coordinating center to establish a national patient-centered clinical research network, known as PCORnet.¹³

Guidance available to grant applicants was reviewed, including tools to support researchers and partners such as applicant training, sample engagement plans, and other materials accessible at pcori.org. Researchers and others are invited to serve on application review panels (2 year term) or one of PCORI's six advisory panels, to suggest patient-centered research questions online, and to participate in new mechanisms such as the Eugene Washington PCORI engagement awards and PCORI's ambassador and matchmaking programs.

The second session was presented by Steven Clouser, PhD, MPH, program director for the improving healthcare systems program. His presentation entitled, *PCORI's Approach to Providing Support for Comparative Effectiveness Research: How to Improve your Likelihood of Success*, outlined essential characteristics of funded patient-centered outcomes research studies, and what types of projects lie outside of PCORI's funding mandate and priority areas. He remarked that

effectively engaging patients and stakeholders in research is an evolving science. To help with the process, he noted that PCORI has recently released the engagement rubric which gives guidance to investigators on how to structure patient and stakeholder engagement in their applications and in the conduct of their research. The engagement rubric also will be used by PCORI's merit review panel in the evaluation of applications going forward. He also urged applicants to adhere to PCORI's methodology standards which can be found on their Web site.

PCORI is building a diverse portfolio addressing high priority questions by offering three pathways to funding: targeted announcements that dictate the specific research question(s) to be answered, broad announcements that allow the investigator to specify the topic and research question(s), and new "hybrid" pragmatic clinical studies announcements that dictate the topic but allow the investigator to specify the research question(s). Dr. Clouser noted that many of PCORI's targeted funding initiatives are done in collaboration with other funders, such as NIH and AHRQ and briefly outlined the process by which these joint requests for applications are developed.

He concluded by outlining strategies likely to be successful when seeking PCORI funding in 2014, including comparing clear clinical or health system options and being wary of 'usual care' comparators, ease of replicability and dissemination, being mindful of engagement, ensuring that outcomes are meaningful and that both benefits and harms are addressed, examining potential differences in patient subgroups, and covering all the applicable methodology standards.

Looking Ahead

Little has been published about the conduct of embedded research, the topic of the 2014 HMORN annual conference. Like their academic counterparts, HMORN researchers must learn "on the job" how to build successful research partnerships with health system leaders, clinicians or patients. Many researchers have historically been encouraged to create research protocols in parallel with rather than in concert with health care operations to reduce burden, disruption, and costs to the system in carrying out research. New partnership models between HMORN researchers, the delivery systems with which they work and the patients who receive care in those systems provide an important opportunity for research in their own right. The findings of this research can lead to the development of new training models to develop a cadre of health research investigators and stakeholders that can continue to transform the field.

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