

HEALING HANDS



Vol. 13, No. 3 ■ June 2009

Research in HCH Settings: Advancing Quality in Primary Care

Health Care for the Homeless (HCH) clinicians strive to provide integrated primary and behavioral care of high quality to a diverse clientele, many of whom have multiple and complex health problems that are exacerbated by their unstable living conditions and limited resources. Interrupted care, often provided in nontraditional settings, makes strict adherence to standard practice guidelines difficult. Moreover, patient populations for whom such guidelines are developed often differ from HCH patients. The following articles describe the research agenda of the National HCH Council, explore the history of practice-based research networks (PBRNs), and explain how such networks can foster collaboration among researchers, primary care providers, and patients to improve the delivery of care.

The National Health Care for the Homeless Council and the HCH Clinicians' Network have long promoted and facilitated clinical research by their members, recognizing the importance of research that is directly relevant to homeless health care and to public policies that disproportionately affect homeless people. In 2004, under the leadership of Susan Kline, DNP, MN, ARNP, and Aaron Strehlow, PhD, FNP, RN, the Research Coordinating Committee (RCC) of the Council and the Network launched an effort to develop an agenda for future research on homelessness and health. RCC members reviewed the relevant literature and interviewed experts in health care research from across the country.

These efforts culminated in a report that recommended a stronger research role for the Council in three areas:¹

1. *Facilitating ongoing research* by fostering collaboration of providers and recipients of homeless services with researchers interested in studying homelessness and health care;
2. *Building research capacity* in the field of homeless health care by supporting the training of such researchers, through post-doctoral fellowships or other means; and
3. *Increasing the impact of existing research* on clinical practice and public policy through publication and dissemination of research findings.

In 2000, Congress had charged the Agency for Healthcare Research and Quality (AHRQ) with the responsibility to “employ research

strategies and mechanisms that will link research directly with clinical practice.”² The aim was to provide better evidence about the best ways to organize, finance, and deliver health services to American communities. RCC recommendations are consistent with this goal.

The RCC research agenda emphasizes the use of qualitative, ethnographic, and community-based participatory research methodologies to better capture the diversity and complexity of the homeless population. This is hard to accomplish using quantitative research models, given the difficulty of enumerating the homeless population and obtaining representative samples with randomized controls. Investigative methods based on collaboration can include more qualitative descriptions of client behavior, which can improve understanding of variation in practice and outcomes. By eliciting client input and involvement they can also highlight the survival skills and resilience strategies of people who experience homelessness, important factors affecting the provision of health care.

Practice-based research networks (PBRNs) offer a promising vehicle to elicit questions from primary care providers and their clients that can generate studies more directly relevant to their concerns than research conducted in tertiary care settings. The capacity of PBRNs to study particular groups that are less well represented in research studies and to work collaboratively is especially useful to HCH clinicians and provides a successful framework for the HCH PBRN.

“A primary care practice-based research network, or PBRN, is a group of ambulatory practices devoted principally to the care of patients, and affiliated in their mission to investigate questions related to community-based practice and to improve the quality of primary care. There is ongoing commitment to network activities and an organizational structure that transcends a single research project. PBRNs often link practicing clinicians with investigators experienced in clinical and health services research, while at the same time enhancing the research skills of the network member.”

– Agency for Health Care Research and Quality (AHRQ)³

The RCC report acknowledged challenges often faced by clinicians who conduct research in community-based settings where homeless persons receive services. For example, there may be conflicting points of view between clinicians and researchers regarding the inclusion of client perspectives and priorities, a hallmark of homeless health care.

Researchers experienced in successful community-based investigation suggested that the RCC:¹

- Initiate better collaborations between providers and researchers
- Form an alliance with a research center or university
- Develop trust within community partnerships
- Increase the number of researchers interested in studying this field
- Be prepared to provide infrastructure (staff, space, administrative resources)
- Provide opportunities for input from homeless people throughout the process, from research design to assessment of results
- Obtain consent from participants respectfully without being exploitative, coercive, or intrusive
- Understand there will be delays related to inconsistent records, mismatched data, and staff turnover
- Realize that follow up of subjects can be extremely time-consuming and costly

HISTORY OF PRACTICE-BASED RESEARCH NETWORKS

Conducting clinical research in community-based settings is not a new concept—individual general practitioners conducted seminal family practice research during the late 1800s. Over 40 years ago, early primary care practice surveillance systems developed in the United Kingdom and the Netherlands and inspired other countries to establish clinical practice networks.^{4,5} In 1965, the Dutch government established the Netherlands Institute for General Practice under a permanent grant, which funded cooperative studies about general practice—in one instance a paper data collection system called the “weekly return” monitored more than 30 conditions.⁵

Regardless of successful practice-based research abroad, the academic model persisted in the United States, where research remained within the purview of institutes, hospitals, and universities. However, in the 1970s, the work of Dr. Curtis G. Hames in rural Claxton, Georgia, culminated in the famous *Evans County Cardiovascular Studies*, an observational study in which coronary heart disease appeared less frequently among blacks than whites despite the greater prevalence of hypertension among blacks and their high-fat diets. The fact that a single provider, Hames, achieved a 92% response rate from more than 5,000 community residents including every adult over age 40 amazed his academic partner John Cassel.⁵

Two regional primary care networks formed and collaborated in the 1970s: Family Medicine Information System in Colorado (FMIS) and Dartmouth Medical School's Cooperative Information Project (COOP) in New Hampshire. The results of these practitioners' research programs established the PBRN concept in America.

Today, PBRNs help to fill the gap between research and practice by applying research findings to real-life patient care, and by answering research questions providers ask about day-to-day practice. A PBRN provides a framework that allows collaboration between community-based clinicians

and researchers to design, implement, evaluate, and share practice solutions that are broadly relevant to primary care providers. The AHRQ has provided funding for PBRN studies as well as other support, such as a national PBRN resource center and annual PBRN conference. Over 111 networks in the U.S. represent close to 2,000 practices, 13,000 physicians, and 14.7 million clients among whom minority and uninsured groups are overrepresented, and have published over 600 articles in peer-reviewed journals.² These primary care PBRNs are on average five years old and pursue a variety of research questions, commonly in the areas of prevention, diabetes, cardiovascular risk factors, and mental health. Established PBRNs are readily able to support complex research models, including:

- Comparative case studies of specific health care needs
- Observational studies to evaluate practice variations
- Interventional studies and trials reviewing program effectiveness and cost analysis
- Quality initiatives related to policy and administration

PBRN STRUCTURE Pursuing the RCC's agenda to conduct community-based research, committee member **Barbara Wismer, MD, MPH** and **Suzanne Zenger, PhD**, then research specialist for the National Health Care for the Homeless Council, attended an AHRQ-sponsored *Introductory PBRN Seminar for Developing PBRNs* in December 2007. They were intrigued by the opportunity afforded by the PBRN model to link HCH providers with researchers to improve homeless health care and increase the capacity of HCH providers to be involved with research.⁶ “We were hooked,” Barb Wismer says. “Even though we understood the amount of procedural work ahead to establish an HCH framework that could support our clinicians and make the process easier, we realized the importance of moving ahead.”

Suzanne Zenger concurs: “We already knew from our literature scans that most research did not apply specifically to the homeless population. In addition, most of our clinicians lacked the resources and time to pursue individual research projects. But translational practice-based research [translating research into practice] looks like quality improvement to clinicians and their staff, so it seems both feasible and relevant to their practice. At the same time, the translational strategy appeals to researchers and funding agencies.”

The PBRN structure is fundamental to clinicians' desire to participate—it makes the research process doable despite their busy practices. PBRNs rely on a “bottom-up” approach that involves clinicians from the beginning in deciding “what to study, how to study it, and how to evaluate and present the results.”^{7,9} In a best-case scenario, academic colleagues and clinicians share equal footing, working together to design projects that solve problems and improve practice. All bring important perspectives, knowledge, and skills to the table. Partners focus on questions that are relevant to client care so that new practice guidelines can be tested in the field during development and account for financial and lifestyle barriers and comorbidities.

Paul Nutting, MD, has been involved in practice-based research since the early 1970s and encourages an ongoing interplay among all participants at each stage of the process (Steps for Practice-Based Research); indeed, he has found that sharing early data with the clinical partners who collected it can lead to “incredible insights.”^{7,10,11}

Continuous Cycle of Steps for Practice-Based Research¹¹

1. Identify from practice the translational gap between research and clinical care
2. Search for answers
3. Generate study questions
4. Design study
5. Analyze data
6. Implement results
7. Begin again

Linda Weinreb, MD, vice-chair and professor in the Department of Family Medicine and Community Health at the University of Massachusetts and a primary care clinician, describes her association with PBRNs as “a meaningful and creative relationship that provides a structure to do science in real-world settings. Partnering with clients and care delivery programs leads to research that provides corrective solutions and the things we need to focus on to improve care. Our clients have unique needs and face many demands; finding ways to develop and test effective primary and behavioral care can best be done in the settings where our clients actually receive their care. Conducting research in a large network of practices makes it possible to generate answers that are relevant and can work.”

COMMUNITY-BASED PARTICIPATORY RESEARCH In both community-based participatory research (CBPR) and research conducted by PBRNs, researchers and community partners collaborate fully—in selection of the research question, program design, data analysis, implementation of results, evaluation of outcomes, and dissemination of findings. While PBRNs tend to focus on health care delivery, a primary goal of CBPR is to develop sustainable interventions that will increase the community’s capacity to assess and resolve its own problems.^{12,13} Both types of research address health care issues, but CBPR promotes public health through the dissemination of knowledge

and action for social change to eliminate health disparities.¹³ Minkler and associates have worked with groups across the country, empowering them to speak up, engage the political system, and advance health within their communities. CBPR partnerships have helped hotel workers improve working conditions, and facilitated community-wide efforts to decrease smoking, change eating habits, and increase opportunities for exercise.

The National Health Care for the Homeless collaborates with the Council Community Campus Partnerships for Health (CCPH) to encourage partnerships between HCH projects and academic institutions (www.nhchc.org/Publications/HCHCampusStudy.pdf). CCPH is a strong advocate of community-based participatory research (http://depts.washington.edu/ccph/pdf_files/p-msu-cbpr.pdf and <http://www.ccphe.info/>).

Darlene M. Jenkins, DrPH, MPH, CHES, the Council’s new research director, has participated in research projects within communities where previous investigations had been conducted in a hit-and-run fashion that left a lingering antipathy for individual researchers and the institutions involved. “It is very important to make sure the consumer or community is involved from the very beginning,” she says. “When there is an equal partnership across the continuum of the project, including discussion of the results with clients, a win-win response is established that enhances the implementation and ongoing collaborations for the good of individuals and the community-at-large. There are communities and health problems that can benefit from a conceptual approach which combines the CBPR model with the PBRN model.” Drs. Rust and Cooper advocate “blurring the boundaries between community health and practice-based research” as one of 12 potential strategies that could help primary care researchers reduce health disparities: “Research must be conducted not only in community settings but in partnership with communities.”¹⁴

Evolution of the HCH PBRN

After attending the introductory workshop about PBRNs, Barb Wismer and Suzanne Zenger worked with the Research Coordinating Committee (RCC) to develop a governing structure for the HCH PBRN. The RCC became the academic advisory group to ensure that all PBRN research proposals are scientifically sound and relevant to homeless health care.

Members of the RCC include:

- RCC chair, jointly appointed by the National HCH Council Board president and the HCH Clinicians’ Network chair
- Council research director/PBRN coordinator
- Council and Network representatives experienced in research on health care and homelessness
- PBRN Steering Committee director
- Task Force chairs

The HCH PBRN Steering Committee grants approval for the involvement of PBRNs in proposed studies and trouble-shoots all approved projects. Its members include a director appointed by the RCC chair, Council research staff, two members appointed by the National Consumer Advisory Board, and eight to ten representatives of participating HCH organizations and clinicians.¹⁵

Barbara Wismer, MD, MPH, is the first director of the HCH PBRN Steering Committee. Currently medical director of the Tom Waddell Health Center and Homeless Programs in San Francisco, Wismer had previously worked as an epidemiologist doing prevention research at UC Berkeley’s Center for Family and Community Health.

“Throughout these initial steps, we have been careful to make sure that the

foundation of governance was inclusive and the structure provided the support HCH grantees would need to make the network easy to use, so its startup could be efficient and inviting. Over time, this will allow HCH clinicians to provide care that is grounded in results from our own practice settings, and produce research results more applicable to the broad population of homeless individuals,” explains Wismer. “We are also mindful of the importance of community input because of the Council’s strong commitment to involving consumers in the planning, governance, and evaluation of the care they receive. I am hopeful that many HCH grantees, clinicians, and clients will join our HCH PBRN to increase their capacity to do research and to improve the quality and quantity of homeless health care research.”

PBRN MEMBERSHIP It's easy to join the HCH PBRN! The only prerequisite is affiliation with a federally funded HCH grantee. Members are expected to complete a survey about their site, consider studies endorsed by the HCH PBRN, and assist with implementation of studies at their site. Members may propose research topics to the PBRN Steering Committee. More information about the HCH PBRN is available at www.nhchc.org/research.html.

Membership in the HCH PBRN helps advance the goal of the Health Resources and Service Administration's Health Care for the Homeless Program: To improve the health status and outcomes of homeless individuals and families through improved access to primary health care and substance abuse services. This is accomplished through outreach, case management, and by linking clients to mental health services, housing, benefits, and other critical supports (www.bphc.hrsa.gov/policy/pal9912.htm).

Creating new approaches through collaboration, delivery of comprehensive care, and integration of medical, behavioral, and human services are among the tasks that HCH providers pursue. A survey of initial HCH PBRN members showed research interests that included:

- Mental health and substance abuse integration with primary care
- Management of chronic illnesses (diabetes, cancer, asthma)
- Chronic pain management
- Services for women and children
- Challenges in providing services to undocumented people
- Infectious diseases
- Cognitive impairments
- Problems with recent veterans
- Problems of aging
- Challenges in providing services to transgender people

FINDING AN ACADEMIC PARTNER

The next step was to find an academic partner for the HCH PBRN. Linda Weinreb, MD, and Carole Upshur, EdD, also a professor in the UMass Department of Family Medicine and Community Health (DFMCH), generously volunteered their time and their organization's support to partner with the National Council and Network to complete the groundwork necessary to launch the HCH PBRN.¹⁶ The



This map shows the geographic placement across the U.S. of the 30 Health Care for the Homeless grantees or clinicians that currently comprise the HCH PBRN.

DFMCH has a growing health services research program focused on the primary care of vulnerable populations and considerable experience conducting research with homeless individuals and families. The department continues to be a resource and offers guidance and support for the young and growing HCH PBRN. In addition, DFMCH serves as academic partner to the New England Clinicians Forum PBRN and has established its own PBRN linked to primary care practices throughout central Massachusetts.

“We already had experience with PBRNs and understood the network as a vehicle that provides more strength to the research proposal. With multiple sites, the problem no longer can be viewed as unique and the results are more generalizable,” says **Carole Upshur**. “Folks in clinical practice become isolated, overworked, and burdened. A PBRN is a low-cost way to foster interaction among similar practices and initiate ideas. This model allows health centers to make enormous contributions. Currently we have a grant pending with the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to look at implementing brief interventions with women who have problems with alcohol. Three HCH PBRN sites will be involved—in Santa Clara, California; Springfield, Massachusetts; and Manchester, New Hampshire—and all are really excited.”

This grant is a good example of how PBRN research has the potential to improve practice. The brief intervention tool has been studied in

more mainstream populations and shown to be effective in reducing problem drinking. The study would look at the feasibility and effectiveness of this tool in HCH settings with homeless women.

The academic partner becomes the resident research expert overseeing the process and providing the institutional review board (IRB).¹⁷ **Cheryl Zlotnick, DrPH, MPH, MS, RN**, director of the HCH Center for the Vulnerable Child in Oakland, California, and a clinical scientist, emphasizes the importance of partnership in the PBRN structure. “The investigator with the study and the network members need to work collaboratively with the organizational IRB. All sides must be vigilant so that the original direction of the study is not altered and it continues as a truly collaborative initiative.”

THE FIRST PROJECT Collaboration among Drs. Lillian Gelberg, Linda Weinreb, and Barry Saver has marked the first official HCH PBRN research project. Gelberg and Weinreb have worked with homeless women for over 20 years as health care providers and academic investigators. Saver, the project's chief investigator, has also worked with vulnerable individuals in primary care settings over a number of years. Medical directors of PBRN member programs were asked to complete an online survey about contraceptive service provision. Based on the results, researchers plan to work with the HCH PBRN to develop and test interventions that will enhance contraceptive availability for homeless women.

Barry Saver, MD, found the 63% response rate from HCH PBRN members encouraging. “You’re really lucky to have a 50% response,” he says. “The surveys indicated that 17 of the 20 respondents are offering clients a range of contraceptives. However, over half reported barriers to IUDs, including lack of provider training, lack of coverage, and high cost of the device; and only three provided Implanon. This information is helping us target our efforts to improve homeless women’s access to effective, long-term contraception. I was pleased that the first project worked so well—it suggests that the network is really committed. That makes my work more meaningful because my goal in research is to make a difference in the lives of vulnerable patients, and collaborating with the HCH PBRN can really make that happen.” Because this study included practices scattered across the country, it illustrates how PBRN research can generate results that are more generalizable to homeless populations.

HCH PBRN STEERING COMMITTEE

Evan Howe, MPH, is a PhD candidate working with the HCH Care Alliance Health Center in Cleveland, Ohio, and a member of the PBRN Steering Committee. Howe has worked with underserved people since he was an undergraduate. He finds that practice-based research allows the clinician to be in the front seat gathering the data, and as others have noted, encourages retention of clinicians in underserved communities.¹⁸

“I find that I read the literature from a different perspective now, and that doing research in the clinic benefits my practice,” Howe says. “It’s a real boost to other clinicians to see how research can be applied to care; it highlights the importance of their work and elevates everyday activities. Everything is seen in a fresh light.” Howe helped formulate the HCH PBRN

Research Proposal Form, which leads the applicant carefully through the steps required to initiate a proposal by describing what will be needed in terms of background information, study aims and objectives, methods, site requirements, participant risks and benefits, and dissemination plan (www.nhchc.org/Research/PBRNResearchProposalForm_FINAL_51409.doc).

Erin Stringfellow, MSW, a research associate with the Boston HCH Program (BHCHP), has a slightly different point of view about research than some members of the PBRN Steering Committee. Boston has its own research program and is affiliated with several other academic and research institutions in addition to the HCH PBRN. “Many of our staff are interested in research and understand how it fits into the work they are already doing. Because the research program is right here, there is constant interaction between patients and clinicians, and our most curious providers regularly approach the research department with project ideas. Our new facility allows the behavioral health, medical, and specialty teams to interact and integrate care more than ever before; such integration has provided increased opportunities for pilot projects and evaluation. Our Consumer Advisory Board, composed of 14 currently or formerly homeless clients of BHCHP, meets monthly here in the center and provides input and encouragement to the research team.”

Serendipity in life following 9/11 brought **Amy Grassette** to the Family Health Center in Worcester, Massachusetts: www.nhchc.org/SuccessStory/agrassette.html. Now she is the center’s volunteer project coordinator, food stamp advocate, and part-time practice manager for the Mental Health Department, a role in which she triages

clients to other agencies in the community as necessary. Grassetto is pleased to give back to her community and learn new skills as part of an opportunity to work with practice-based research.

In addition to her work at the center, Grassetto chairs the National Consumer Advisory Board (NCAB) and is a member of the PBRN Steering Committee. For the past four years, NCAB has surveyed HCH clients nationwide about health care, homelessness, and service access. “This year, I encouraged a different focus—one with a more structured design and a scientifically rigorous process,” Grassetto explains. “Our topic concerns violence encountered while homeless: ‘Violence on the Streets.’ With the help of the Council’s research associate **Molly Meinbresse, MPH**, the seven NCAB executive committee members will be certified as principal investigators for this consumer research project. It is so exciting!”

Meinbresse confirms plans for a web-based training program on the protection of human research subjects. Such training is required of all primary investigators working with human participants. The Collaborative Institutional Training Initiative (CITI) was developed by the University of Miami and the Fred Hutchinson Cancer Research Center in Seattle. “The final design for this project is innovative and collaborative,” explains Meinbresse. “Research coordination will be provided by the National Health Care for the Homeless Council, a nonprofit agency; research oversight (IRB) by the Nashville Public Health Department; and consumer leadership by eight HCH projects that are receiving federal funding to guide the research process, from development through implementation. I agree with Amy—it’s so exciting!”

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This publication was developed with support from the Health Resources and Services Administration. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of HRSA/BPHC.