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Supplemental Case Report. Community Involvement in a Practice-Based Research Network

The High Plains Research Network Community Advisory Council

CORRESPONDING AUTHOR
John M. Westfall, MD, MPH
University of Colorado
Health Sciences Center
UCHSC at Fitzsimons
PO Box 6508 - Mail Stop F496
Aurora, CO 80045-0508
jack.westfall@uchsc.edu

ABSTRACT

Community-based participatory research (CBPR) has become an important method in primary care to improve the relevance of clinical research. The purpose of this article is to describe community involvement in the High Plains Research Network (HPRN), an integrated PBRN in rural Colorado. The HPRN Community Advisory Council (CAC) consists of local community members (farmers, ranchers, school teachers) that has met regularly for 2 years to help guide HPRN research. The necessary ingredients for our CAC included community members committed to improving the health of their community; a meeting space that was centrally located; a small amount of money to pay for travel, meals, and meeting costs; willingness from the academic researchers to travel; and an intentional plan for community member education and research flexibility. Most importantly, our CAC members agreed to participate because they believed the work would benefit their rural community. One unique challenge has been the tension between the community members desire to move quickly on projects and the research staffs' need to follow research protocols. The willingness of the research staff to incorporate CAC ideas, comments, and concerns into grants, manuscripts, and research products and the flexibility of our community members to slow down have lead to a close trusting relationship. The CAC has actively participated in research design, qualitative analysis, interpretation of results, and dissemination of findings. Community members can make an important contribution to PBRN research, and the use of a CAC is one method for successfully involving community members in a PBRN.

INTRODUCTION

Practice-based research networks (PBRNs) are common laboratories for describing primary care, disseminating practice innovation, and conducting intervention trials to improve care.[1] PBRNs have asked and answered important clinical questions on a host of clinical topics including: diagnosis of headache, management of miscarriage, improving patient safety, competing demands in diabetes, and the content of the primary care encounter.[2-7]

Community-based participatory research (CBPR) has become an important method in primary care to improve the relevance of clinical research.[8,9] CBPR is a collaborative process between academic researchers and community members, actively involving patients and community members in research design, implementation, analysis, and interpretation.[10,11] CBPR aims to be a "systematic investigation, with the collaboration of those affected by the issue being studied."[12] One practical goal of CBPR is to ground clinical research in real-life patient experience.

While many PBRNs have actively involved practicing physicians in research, few have involved patients and community members in their research.[13,14] The purpose of this case report is to describe how the High Plains Research Network began involving community members in PBRN research. This report will outline the steps we took to begin community involvement in the HPRN; the needs, barriers, and challenges we faced; and the value community members have had on the research conducted in the High Plains Research Network. Members of the HPRN Community Advisory Council were invited to provide input into this report, review drafts, and approve the final version.

High Plains Research Network

The HPRN is an integrated practice-based research network in rural northeast Colorado consisting of all the locations where doctors work; hospitals, emergency departments, ambulatory practices, and nursing homes. The HPRN is largely rural and frontier, includes nearly 20,000 square miles, and has a population of about 90,000. There are approximately 60 family physicians, 5 internists, 12 nurse-practitioners, and 15 physician's assistants. Founded in 1997, the HPRN has conducted research in ambulatory settings, hospitals, emergency rooms, and nursing homes.

A Brief History of the HPRN Community Advisory Council

In response to the AHRQ requirements to assure, "a mechanism (such as a community advisory board) is in place to solicit advice/feedback from the communities of *patients* served by the PBRN clinicians," we decided to start a community advisory council.[15] The research team of the High Plains Research Network developed a list of what we thought were the necessary components for a community group: people, events, research projects, money, space, travel, administrative support, flexibility, and leadership. In the next few paragraphs we briefly outline the history of our community advisory council, the challenges we faced, and the successes we encountered along the way.

Because the HPRN staff already knew many professionals and community members in the HPRN communities, the director of the HPRN simply began making telephone calls to persons we believed might be interested in participating. Table 1 outlines the community members identified, their community, their occupation, and how we first got their name and contact information. We decided early on that we would attempt to recruit some couples. We believed that in so doing, we would assure at least one of them could attend most meetings, they could discuss HPRN issues together, and it might be an enjoyable activity to do together. The HPRN staff knew several of those invited to participate. Others were referred by physicians, hospital administrators, and other community members. We actively sought to identify members of various ethnicities, socioeconomic levels, occupations, sexes, and regions within the HPRN. Several recommended community members could not be reached even after multiple attempts. We had no outright refusals. We had no idea of the correct size for a group and invited new members throughout the first 4-6 months of meetings. We called our group the High Plains Research Network Community Advisory Council (HPRN CAC).

As a first meeting, we invited all CAC members to the 2003 Colorado Convocation, the annual meeting for the Colorado PBRNs. We wanted to give them an immediate introduction to the research of the networks, to provide some basic education about PBRNs, and to get them excited about being part of a larger group. Our next meeting was several months later and consisted of a full-day retreat in a rural community in the HPRN. The goals of this retreat were to meet the group, build community, teach about research, begin

developing a mission, solicit research ideas, and identify the community members' priorities. Figure 1 is the CAC logo. The CAC generated a list of health topics they believed were important in northeast Colorado.

We hoped that involving the group early on in an ongoing research project might give them a better sense of research, methods, analysis, and interpretation. The HPRN had several projects in various stages, including a physician-nurse survey on palliative care that was awaiting analysis and writeup, and a 4-year project on patient safety. At our second and third quarterly meetings, we brought results of the palliative care survey for the group to review. The CAC helped us interpret the results of a finding that 60% of survey respondents reported good or excellent palliative care in their facility. The CAC then assisted in writing a press release about our study finding that appeared in several of the local newspapers.

While discussing the study we were conducting on patient safety and harm from medical mistakes, the CAC members became interested in definitions of harm from a medical mistake and what patients thought about medical mistakes. The CAC decided to participate with the research staff on a study of community members' definitions of harm from a medical mistake. This study was a truly collaborative effort, with the CAC participating in the methods (a survey questionnaire insert in 4 rural newspapers), data analysis (formal qualitative analysis), and dissemination (2 CAC members presented a poster at the 2005 North American Primary Care Research Group Meeting in Quebec). A manuscript is underway with several CAC members assisting as coauthors.

During our second year we invited Dr Ann Macaulay to attend a CAC meeting in rural Colorado. Her stimulating talk helped our CAC members gain a broader sense of the importance of participatory research. She consulted with our CAC and offered insights and suggestions to keep us on track. Her statement that "the community is always right" has helped us many times as we faced our frequent challenges.

The Centers for Disease Control and Prevention released a request for community-based participatory research on colon cancer prevention. While colon cancer had not been a top priority, the CAC decided this request might provide a great opportunity to work together on an important health topic. We were awarded a 4-year grant with the aim of increasing colon cancer screening in rural Colorado. We invited 8 medical professionals and public health workers to join the CAC to create the Joint Planning Committee (JPC) specifically for this project. The JPC began meeting regularly in person, with twice-monthly telephone conferences. The study, "Testing to Prevent Colon Cancer" has energized the JPC, bringing a focus to their energy and creativity.

The CAC helps guide the overall research of the HPRN. Because the HPRN now has multiple studies underway, we have developed smaller ad hoc working groups to maximize involvement and communication while not overburdening all CAC members (Figure 2). In addition to the colon cancer prevention project, we are just starting the Joint Arthritis Committee to work on a project to increase exercise among those with osteoarthritis. We continue to seek funding for a project to decrease methamphetamine abuse.

The CAC has been meeting regularly for nearly 2.5 years. We communicate every several weeks by e-mail, have quarterly face-to-face meetings, and hold conference calls when necessary. We send out printed materials (drafts of manuscripts, surveys, and research ideas) with postage paid return envelopes for rapid response. The CAC reconsiders the size of the group and discusses inviting new members at our regularly scheduled meetings. The CAC attends each yearly Colorado Convocation, and several members have presented our research and methods. We regularly address funding opportunities and discuss local health concerns.

What Does a CAC Need?

The following section provides some of the essential components identified by the HPRN researchers and CAC members. While not exhaustive, components provide what we believe are the basic infrastructure needs. We include barriers and challenges to obtaining and maintaining these components.

People

"The essential components are, first of all, a group of people representative of the varying populations in the rural areas, who are involved in their communities." – CAC member

We identified folks from our communities in many ways. Most were referred by someone the HPRN had previously worked with. Our committee members kept asking, "Am I supposed to represent my community?" We thought that, although we had attempted to identify members with varying backgrounds, it was unrealistic to expect a "representative" outlook from each individual member. CAC members are community experts who, and as one CAC member reminds us, can help provide a "path of least resistance." In addition to guiding the research toward specific needs of the community, the community members can act as a locally

attuned marketing firm to help design community-relevant methods and disseminate results. We expected CAC members to bring that expertise to bear on the health needs of their community and the research of the HPRN. While initially hesitant to accept the role of "expert," the CAC members now understand their knowledge of the local community is essential to our research. Having community members bring their local expertise to bear on research may be even more important in networks where many different communities are involved.

Money

Money immediately became a major issue to the success of the CAC. Fortunately, the Primary Care Research Unit (a collaboration between family medicine, general pediatrics, and general internal medicine at the University of Colorado School of Medicine) provided 10% full-time equivalent coverage for our research assistant to support CAC activities. We used money left over from several small evaluation contracts to pay for mileage reimbursement and meeting costs (meals, space rental). When we began the patient harm study, we were able to collaborate with the Applied Strategies in Patient Safety project, which provided some research funding. We were unable to identify any specific funding opportunities for community-based participatory research infrastructure support, particularly within a PBRN. The CDC grant provided funds to pay our community members a small amount of money to cover their time, travel, and work. Funding the basic infrastructure support for CBPR will continue to be a local challenge and is an opportunity for state and federal funding agencies to consider.

Travel

The HPRN includes 11 counties in eastern Colorado and includes nearly 20, 000 square miles. It stretches 100 miles from east to west and nearly 200 miles north to south. We have minimized travel by holding full-day retreats, and using e-mail and telephone conferences to communicate between meetings. We meet in Denver for our annual convocation and several other meetings. The remainder of the meetings we hold in various rural communities. No matter where we meet, members of the CAC must travel from 50 to 150 miles each way. When possible, they have worked out carpooling arrangements on their own. We are lucky that our community members have committed to participating and are willing to travel great distances to participate. CAC members have mentioned how important face-to-face gatherings are to allow for brainstorming, understanding the process, nurturing, mentoring, and establishing trust within the group.

Space

We used many different spaces in rural communities in the HPRN. We rented space from the community colleges and several churches, and we hosted several meetings in our department building in Denver. We have finally settled on a centrally located meeting space in a local church.

Benefits to the CAC members

"We are involved in the CAC because it provides an opportunity to help our community." – CAC Member

We have tried to identify benefits for participating in the community advisory council. Certainly, the standard academic benefits also apply to the CAC members; they travel to national meetings to present papers and visit exotic locations, coauthor peer-reviewed research papers, author newspaper articles, and receive financial compensation when specific projects make that available. But we were told early on that the CAC members would only participate if they believed that what they were doing might make a difference, that what we all did was important, and that the work of the HPRN helped rural people live a healthier life. A crucial benefit to participation has been to know that the work of the HPRN CAC matters to rural Colorado.

Challenges

There have been a number of barriers and challenges over the 2 years. The issues noted above are general infrastructure issues related to starting and maintaining a community group. The following are a few of the specific challenges we have faced in conducting the research of the HPRN.

Slowing Down

The CAC wants to move quickly. The researchers want to create new knowledge. Research requires moving more slowly to be certain we use appropriate research methodology, conduct precise evaluations, and make

reasonable interpretations. We regularly spend meeting time to openly address timelines and research methods. The CAC members now mostly understand, have been polite in accepting the research aspects of what we do, and keep pushing us to get moving. This tension between rapid turnaround and methodical research continues to be a balancing act that requires frequent attention.

Reciprocity

Along with making it clear that the work we do must matter, the CAC holds the research staff to a high standard for completing our tasks. The research staff knows that the CAC members expect us to get our portion of the work done and disseminate it back to the CAC members. Timely completion and dissemination have been a challenge when research staff have multiple projects. We find that openly talking about the demands of our department and other research effectively communicates this challenge to the CAC. They have been gracious in accepting this challenge.

This concept takes another form in the matter of decision making. Members report that involvement means they want to help with decision making as well as provide footwork and dissemination of findings. One member reported that because we trusted their input into critical research decisions, they in turn trusted our work, our timetable, and our ideas. This shared decision making serves as a motivating factor for continued community member involvement.

Linking the CAC With Our Physicians in the Network

The CAC is going very well, but physician involvement in the HPRN has dropped off somewhat. After we began the study on community members' definitions of harm from a medical mistake, we were confronted by the physicians in one community who thought we were undermining their professional position in the community. Resolution required many telephone conversations and an editorial in the local newspaper outlining the project and assuring the community and the local physicians that this study was not the result of concern about the local medical care.

Having an active community group involved has focused much of the research on community projects and broader interventions. Although this idea may be good from a public health aspect, it has moved some of the work of the HPRN away from the ambulatory settings. Maintaining active involvement in the physicians' offices and with the physicians will continue to be a challenge. The HPRN has recently reinvigorated our Medical Advisory Council and is attempting to communicate with all our physicians on a more frequent basis. Many of our CAC members report discussing the HPRN research with their doctor, which we believe helps maintain the interest and involvement of community members and physicians. Even though community involvement in HPRN research is still in an early phase, we can see some potential linkages between community groups and health care clinicians that will not only affect our research but may also have a positive impact on clinical care, chronic disease management, and public health programs.

Evolution of the CAC

The CAC has undergone a steady progression in its ability to participate fully in HPRN research. In the first few months, the group struggled with what qualities and skills they might bring to the research projects. We were able to use some completed projects to involve the CAC early on in dissemination of our findings into the rural communities. Toward the end of the first year, taking on a smaller project that was part of a larger multiyear study gave them a further sense of action and accomplishment. Finally, leading the CDC study on preventing colon cancer has provided a sense of full involvement, ownership, accountability, and expertise.

CONCLUSION

The CAC has been actively involved in research in the HPRN. They have helped interpret results and write newspaper articles; have modified research methods and plans; have conducted their own project, including participating in a formal qualitative analysis; and helped disseminate our results. The mission of the CAC is, "to help inform and guide research in real patient experience and assure information garnered returns to and improves the quality of health care in individual rural communities." Based on the several projects completed with the CAC, we believe that we are fulfilling this mission. We hope that this collaboration will ultimately improve the health of the people living in northeast Colorado cared for by the medical providers in the High Plains Research Network. One member states that "we have the opportunity to voice the concerns and issues of people on the eastern plains of Colorado. To be able to have research done in the rural area is a true

blessing." Another member wrote, "We can see that our involvement can assist the research, can bridge the gap between the researcher and the patient and can be a useful partnership."

Our CAC has radically altered the research in the HPRN. Table 2 describes some of the work of the CAC and its impact on our research. By involving community members, we believe our research is more grounded in the real-patient experience that will lead to more effective interventions and sustainable change. The CAC provides new research ideas, a fresh look at study methods, and a creative energy. They have provided public relations support in the local communities, talking with physicians, community members, newspapers, and local leaders. The CAC reminds us why we do research. It is not about papers or travel or promotion. Excellent medical research is about helping local people live a healthier life. The CAC understands that, models that, and challenges us all to remember that we do all this for our patients.

Key words: Practice-based research network; community-based participatory research; health services research

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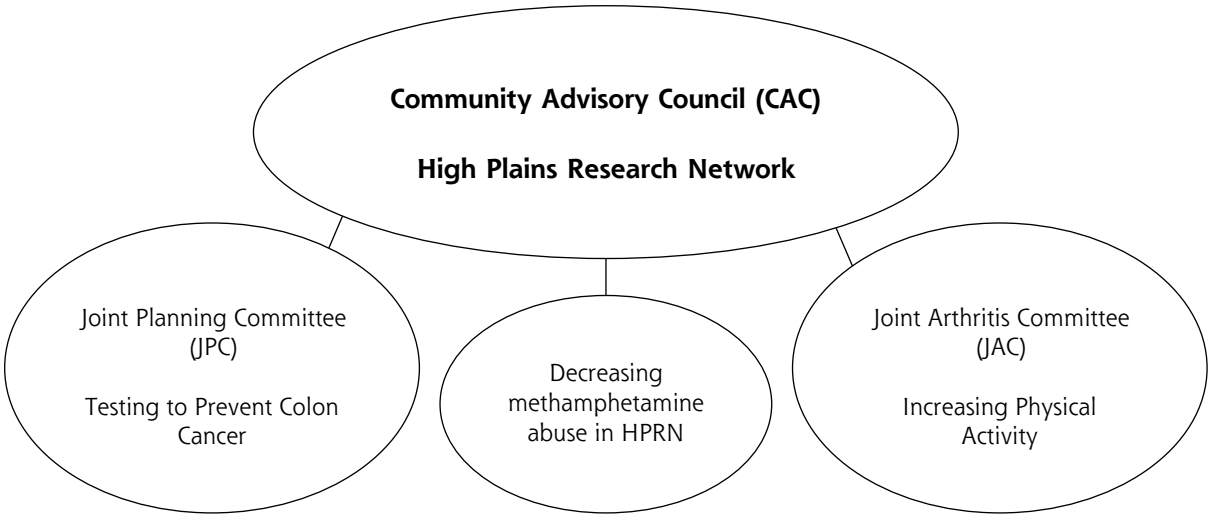
Supplemental Case Report Figure 1. High Plains Research Network Community Advisory Council logo.

Supplemental Case Report Figure 2. Structure of the High Plains Research Network (HPRN) Community Advisory Council.



Supplemental Case Report Table 1. HPRN Community Advisory Council Members

Name	Community	Occupation	How We Made Initial Contact
Maret Felzien	Sterling	Community college professor	Acquaintance of HPRN director
Ned Norman	Sterling	Rancher	Acquaintance of HPRN director
Kathy Winkleman	Limon	Elementary school teacher	Patient of HPRN director
Steve Winkleman	Limon	Farmer/rancher	Patient of HPRN director
Shirley Cowart	Yuma	Retired executive secretary	Referred by community member
Mary Rodriquez	Ft Morgan	Home visitation paraprofessional	Referred by a community organization
Connie Haynes	Haxtun	Retired teacher	Referred by hospital administrator
Gary Haynes	Haxtun	Retired teacher and farmer	Referred by hospital administrator
Mike Hernandez	Ovid	Teacher, Department of Corrections	Referred by CAC member
Cameron Walsh	Sterling	College student	Spoke to CAC about medical topic and invited by CAC to join
Becky VanVorst	Denver	Professional research assistant	HPRN coordinator, 1998-2005
Jack Westfall	Denver	Family medicine researcher	Director of the HPRN
Linda Zittleman	Denver	Professional research assistant	HPRN coordinator, 2005 to present
Joint Planning Committee			
Arlene Harms	Holyoke	Hospital CEO	Known to HPRN staff
Kindra Mulch	Burlington	Public Health Department	Referred by community member
Saeid Ahmadpour	Cheyenne Wells	Family physician	Known to HPRN staff
James Miller	Ft Morgan, Sterling	Internist	Referred by CAC member
Denise Hase	Sterling	Public Health Department	Known to HPRN staff
Kaia Gallagher	Denver	Consultant	Known to HPRN staff
Fred Grover Jr.	Denver	Family physician	Local expert in cancer prevention guidelines
Tim Byers	Denver	Physician	Local expert in colon cancer prevention
Rodrigo Araya-Guerra	Denver	Professional research assistant	Research assistant for Testing to Prevent Colon Cancer project
Steve Coughlin	Atlanta	CDC project officer	Project Officer at CDC
Deborah Main	Denver	Outcomes researcher	Local expert in program evaluation
Elizabeth Staton	Denver	Writer	Faculty in family medicine

HPRN – High Plains Research Network; CAC = Community Advisory Council; CDC = Centers for Disease Control and Prevention.

Supplemental Case Report Table 2. The Work of the CAC on HPRN Research

Research Project	Impact of the CAC on the Project
Palliative care	Helped interpret results of a survey question that found 60% of respondents felt palliative care was excellent
	Wrote newspaper articles about the palliative care study
Patient safety	Changed survey language from "patient safety event" to "medical mistake"
	Rewrote survey instrument
	Determined the survey instrument distribution method in 4 weekly newspapers
	Participated in qualitative analysis of survey results
	Presented poster at 2005 NAPCRG
	Coauthors on manuscript
Colon cancer	Changed name of study from "Increasing Colorectal Cancer Screening Rates," to "Testing to Prevent Colon Cancer"
	Determined the 4-part message and dissemination method
	Identified our catch phrase, "got polyps?"
Methamphetamine	Invited a recovering methamphetamine user to discuss drug issues
	Submitted a grant to provide broad-based education to health care clinicians, community members, and students
	Studied a video for youth about the seductiveness and dangers of methamphetamine use
	Researched current education programs in the local schools regarding the dangers of methamphetamines
CBPR	Co-presented a workshop at the 2005 Annual Convocation of PBRNs on community-based participatory research
	Two members attended the National Rural Health Association to learn about rural health issues
	Two members co-presented a poster at the 2005 NAPCRG
	Identified potential members for study-specific subcommittees

CAC = Community Advisory Council; HPRN = = High Plains Research Network; PBRN – practice-based research network; CBPR = community-based participatory research; NAPCRG = North American Primary Care Research Group.