Community-Driven Research Agenda to Reduce Health Disparities

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Abstract

This paper describes how a new regional campus of an academic health center engaged in a community-based participatory research (CBPR) process to set a community-driven research agenda to address health disparities. The campus is situated among growing Marshallese and Hispanic populations that face significant health disparities. In 2013, with support from the Translational Research Institute, the University of Arkansas for Medical Sciences Northwest began building its research capacity in the region with the goal of developing a community-driven research agenda for the campus. While many researchers engage in some form of community-engaged research, using a CBPR process to set the research agenda for an entire campus is unique. Utilizing multiple levels of engagement, three research areas were chosen by the community: (1) chronic disease management and prevention; (2) obesity and physical activity; and (3) access to culturally appropriate healthcare. In only 18 months, the CBPR collaboration had dramatic results. Ten grants and five scholarly articles were collaboratively written and 25 community publications and presentations were disseminated. Nine research projects and health programs were initiated. In addition, many interprofessional educational and service learning objectives were aligned with the community-driven agenda resulting in practical action to address the needs identified. Clin Trans Sci 2015; Volume #: 1–6

Keywords: behavioral studies, methodology, translational research

Background

In 2008, the University of Arkansas for Medical Sciences (UAMS) established UAMS Northwest (UAMS NW) as a regional campus in Fayetteville, Arkansas, a more rural but rapidly growing area of the state. The campus is located approximately 200 miles from the main UAMS campus in Little Rock. The UAMS NW campus builds upon UAMS's strong primary care presence in the northwest region of the state, which was established in 1973. The regional campus increased the university's capability to train physicians, pharmacists, nurses, and other health care professionals. The new campus began its first academic year in July 2009 with a strong commitment to interprofessional education and now serves approximately 200 students and residents per year. While the tripartite mission of an academic health center is teaching, research, and patient care, initially, UAMS NW had no focused research activities. UAMS NW recognized a need for research in the region and the need for faculty and students to engage in scholarly activity. The UAMS NW campus is situated among the largest number of Marshallese and Hispanic residents in the state. These populations are rapidly increasing in the United States and in Arkansas, and they experience significant inequalities in health care access and health status. The establishment of the UAMS NW regional campus provided expanded opportunities for research with these underserved populations. In 2013, with support from the Translational Research Institute at UAMS (established through a Centers for Translational Science Award), UAMS NW began building its research capacity in the region with the goal of developing a community-driven research agenda for the campus that is fully integrated into our interprofessional education program.

Introduction

Community-based participatory research (CBPR), also referred to as community-engaged research, action research, participatory action research, community-based action research, patient centered participatory research as well as other terms,[1–7] is promoted as a way of addressing health disparities in disenfranchised communities.[1–3,5,7–12] The Association of American Medical Colleges, in a letter to the National Center for Advancing Translational Sciences, has stated, "Successfully engaging local communities in all aspects of the translational research enterprise including dissemination and implementation is vital to not only developing drugs and devices, but also to reducing and eventually eliminating health disparities and inequity."[13] Several translational research centers, funded through the Centers for Translational Sciences Award, are working to engage communities in research.[14,15] CBPR uses participatory approaches to engage nontraditional partners (patients, nonprofits, disenfranchised communities) in the research process. CBPR honors the unique contributions these stakeholders bring to problem/question identification, research design, research conduct, data analysis, interpretation, and dissemination.[2,3] As Gaventa[16] describes, CBPR turns the traditional research paradigm upside down. Traditionally, a principal investigator within an academic institution determines the research questions, tools, methods, and intervention, as well as the outcomes that are valued, documented, and disseminated; however, CBPR shares the power and responsibility for these processes with community stakeholders.[1–3,7,17] CBPR can be conceived on a continuum (see *Figure 1*) that on one end includes community involvement in a more limited manner and at the other end involves full community engagement. CBPR with full community engagement is community-driven and involves community stakeholders in all aspects of the research process from setting the research agenda and identifying the research questions to interpreting and disseminating the results and making policy recommendations.[1–3] It is also important to note that the community-identified research agenda is often

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DOI: 10.1111/cts.12350

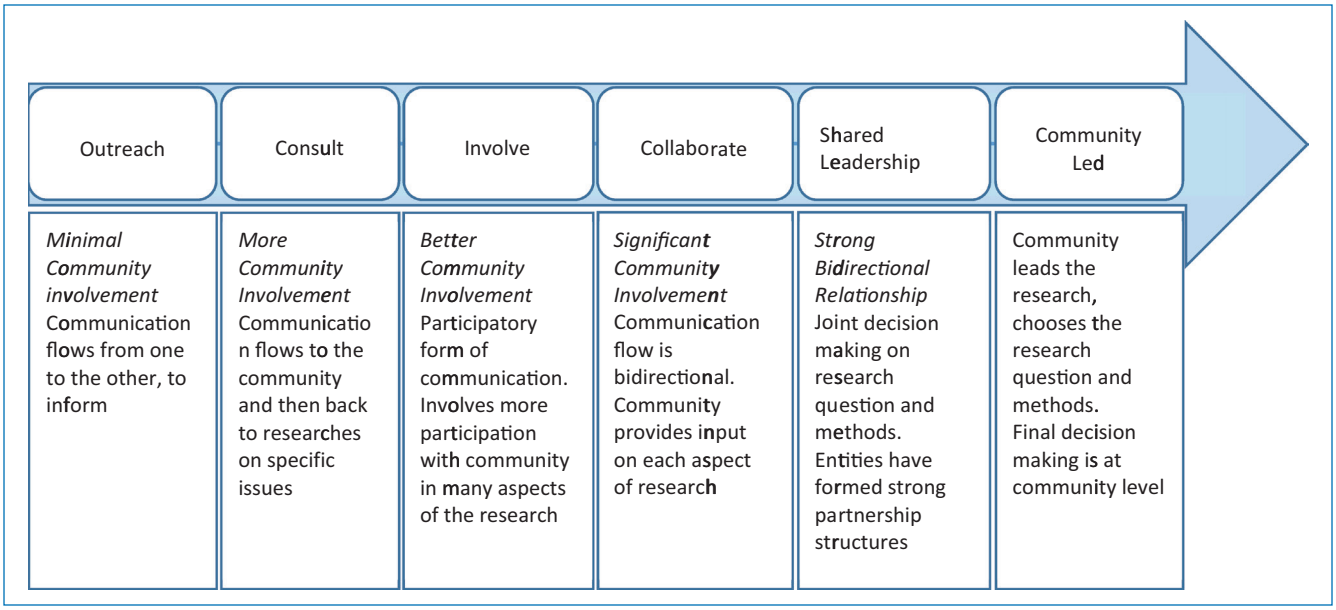

Figure 1. Community Engagement Continuum, adapted from Collman, GW. Community-based approaches to environmental health research around the globe. *Reviews on Environmental Health* 29(2) 125–128. March 2014. And Principles of Community Engagement – Second Edition. *ATSDR*. http://www.atsdr.cdc.gov/communityengagement

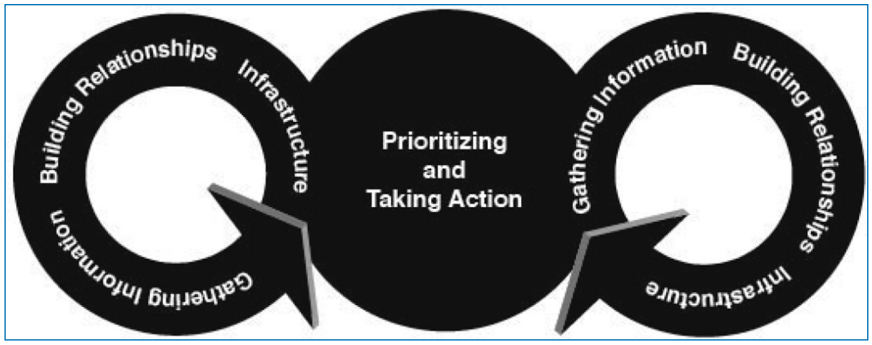

Figure 2. Intensive Community Engagement Process.[25]

tied to broader policy and programmatic priorities within the community. While many researchers practice some form of CBPR,[18] UAMS NW is the first campus to set its research agenda for the entire campus using a community-based participatory approach that also integrates student interprofessional education. As a branch campus of the larger UAMS medical school system, UAMS NW is positioned well to cultivate unique and intimate relationships with the local community that ensure the success of the CBPR research agenda.

Method

In 2013, UAMS NW hired a director of research with expertise in community-based participatory approaches, and began facilitating an intensive community engagement process to set a community-driven research agenda for the campus. The method of setting a community-driven research agenda included simultaneously gathering information and building relationships and infrastructure, with intermediate periods of prioritizing and taking action. As illustrated in *Figure 2*, while the process progressed in a somewhat linear fashion, the individual elements intertwined creating both synergy and constraints.

Information gathering

As a first step, UAMS NW began a concerted effort to better understand the health inequalities of the Marshallese and Hispanic communities. Traditional field work focused on understanding the histories and cultures of these specific communities.[14,19–25] Community members were asked to share their history, stories, and perspectives on health and research. During that time, UAMS NW also compiled and reviewed secondary data from the census, local schools, adult and youth Behavior Risk Factor Surveillance System (BRFSS), Arkansas Department of Health Vital Records, and needs assessments conducted in 2004 and 2010 by the local hometown health coalition and community foundation. Members from the community were asked to join with UAMS NW in the review of this data. Then, semistructured qualitative interviews were conducted with community members. During these interviews, structured, yet open-ended, questions were used to better understand the most pressing needs of the community. Next, primary data collection using a mixed-methods needs assessment was conducted with the priority populations. Approximately 3,000 participants were surveyed with both quantitative and qualitative questions. The survey included questions regarding self-reported health status, health research priorities, and perceptions regarding participation in research. Simultaneously, we collaboratively conducted a gaps analysis of services and an environmental scan of policies and systems related to the needs identified by community members. Community members worked alongside the principal investigator and community coinvestigators during the information gathering stage. As *Table 1* outlines, community members were involved in each step of the process.

Process	Who participated
Understanding the histories and cultures of the communities	UAMS NW investigators and three community coinvestigators
Gathered and reviewed secondary data	UAMS NW investigators and three community coinvestigators along with 38 community stakeholders from diverse communities
Semistructured qualitative interviews	UAMS NW investigators and three community coinvestigators conducted interviews with more than 50 community members. Reviewed with community stakeholders
Mixed-methods needs assessment	UAMS NW investigators and three community coinvestigators and 19 interprofessional students conducted assessment with ~3,000 community members participating. Reviewed with community stakeholders
Gaps analysis of services and an environmental scan of policies and systems	UAMS NW investigators and three community coinvestigators
Qualitative focus groups were held with the priority communities	UAMS NW investigators and three community coinvestigators led sessions with 32 members from priority communities
Planning sessions to review the interpreted data summaries	32 members from priority communities with UAMS NW investigators and three community coinvestigators
Set broad research priorities	UAMS NW investigators and three community coinvestigators led sessions with ~50 members from priority communities

Table 1. Community members engagement.

Priority setting

To set priorities, community members, community coinvestigators, and UAMS NW researchers reviewed the information gathered. Additional qualitative focus groups were held with the priority communities to collaboratively interpret the data. We then held planning sessions to review the interpreted data summaries with priority community members and broader community stakeholders and set the research priorities. As discussed in the results section, the research priorities set by the community are broad. As additional data was gathered through pilot research projects and as funding opportunities were announced, we held intermediate sessions with community stakeholders to prioritize specific research projects within the larger priorities set by the community.

Infrastructure

CBPR requires building both community and university infrastructure to support the nontraditional research process. Simultaneous with the information gathering, UAMS NW began building the infrastructure needed to implement a community-driven research agenda.

Relationships building

The principal investigator and other members of UAMS NW leadership have long-standing relationships with the priority communities and significant time was allocated to deepen those relationships. Formal relationships were built with nonprofits and leaders within the communities, and informal relationships were built with the community by attending cultural events, birthday parties, and religious services upon the invitation of priority community members.

Building a CBPR board

Community advisory boards or CBPR boards govern a community-driven research process. UAMS NW chose to partner with existing coalitions within the priority communities (Arkansas Coalition of Marshallese, Gaps in Services to the Marshallese Taskforce, League of United Latin American Citizens, and Hometown Health Coalition) rather than develop new coalitions. The CBPR board is composed of multiple members from each of these coalitions. It is important to note that these coalitions are made up of multiple community members and organizations. This approach of working with existing coalitions rather than creating new ones was requested by the community, and provides an important balance of power between the university and community. When a university develops a community advisory board by selecting the members and the criteria for membership, it unnecessarily puts the university in a greater position of power. By working with existing coalitions, power is more balanced and the coalition is more sustainable because the coalitions have a history and commitment to ongoing operations that are outside their partnership with the university. In addition, it is the community rather than the university that selects those who will serve. The UAMS NW CBPR board includes representation from four existing community coalitions. In addition, there are lay community members who serve on the advisory board. This provides a structure that can function effectively and allows for broad-based input from the community.

Community infrastructure: research capacity within community

Many community-engaged research programs cite the importance of building the capacity of the community to engage in research by educating community stakeholders on research methods and research processes.[2,3,9,10] While we did spend time educating the CBPR board members about research design and sampling when collaboratively making decisions concerning proposed studies, the learning was bidirectional and far more time was spent on the community members teaching academic researchers what needed to be studied and how to research the topic appropriately within the community. The education continues to be bidirectional and participatory in nature. Educating the CBPR board about research is achieved primarily through truly engaging them in all aspects of research (see action discussion below).

University capacity and connecting with researchers

A community-driven research agenda requires identifying and connecting researchers who have expertise in the areas of community-identified needs and priorities. This is the inverse of the traditional research process, where the researcher drives the research question and then may or may not seek community members input on how to conduct the research. Because community members identified the research priorities and

questions, much effort is required to find, connect, and facilitate researchers who can and will partner with the community in addressing these priorities. The principal investigator sought out researchers on the UAMS NW campus, the main UAMS campus, and even nationally who could help address the questions. Interdisciplinary teams of experts from across campuses were assembled to work with the community on the priority areas identified. The principal investigator maintained a facilitation role throughout.

University infrastructure: alignment with other priorities

UAMS NW, like many academic health centers, operates in an environment of increasing demands on time and budget, including less funding for research and nonclinical programs. Activities that are nonrevenue generating, such as community-based research and health programs, have seen significant budget cuts. Furthermore, CBPR is often cited as being more time consuming and more costly. To facilitate a community-driven research agenda within these constraints, the vice chancellor of UAMS NW, regional campus deans, faculty for the College of Pharmacy, and the principal investigator worked together to align the regional campus' service learning, community outreach, and interprofessional education experiences with the community-driven research priorities. An additional benefit to this approach is an increase in students' and residents' exposure to health disparities, cultural awareness training, and field research experiences.

Taking action

A primary concern of the CBPR board, as well as the larger input from community members, was that the research lead to action and that action be taken quickly. Therefore, action was taken concurrently with information gathering and infrastructure building. This action included conducting pilot studies, seeking funding for research and programs, writing both scholarly and community publications,[26–29] and partnering to implement programs to meet the needs identified by the community.

Each time the community prioritized a major issue, we wrote a pilot research protocol and concrete action steps were taken. These were often small studies in the form of focus groups, survey research, or secondary data analysis of health systems data. The pilot projects provided opportunities to discuss research design and methods as well as research ethics with the CBPR board and other community stakeholders. The process provided ongoing learning opportunities for both the CBPR board and researchers.

A significant amount of time was spent grant writing. Over a period of 18 months, 10 grant proposals were submitted. The CBPR board members determined the focus of the grants and gathered letters of support from the community. However, all of the writing responsibility fell to the university.

Preliminary data from the pilot studies is being used for publication in both community and scholarly mediums. Scholarly publications always include community authors. Action was also taken by partnering to find programmatic and policy solutions to meet the needs identified. These programs include access to diabetes care, healthy food access, and training of community health workers. In addition, a new UAMS NW interprofessional student clinic was opened to see patients who had diabetes, but lacked insurance or a healthcare provider.

Results

UAMS NW has achieved dramatic results in 18 months. Using a CBPR process, we established a community-driven research agenda for the UAMS NW campus. The community chose three broad areas: (1) chronic disease management and prevention (type 2 diabetes mellitus in particular); (2) obesity and physical activity; and (3) access to culturally appropriate healthcare. Ten grant proposals were submitted, five (50%) were funded (three small pilot awards, one Patient Centered Outcomes Research Institute [PCORI] contract, and one Center for Disease Control and Prevention [CDC] program grant). As directed by the community, these projects focus on chronic disease management, healthy food access to reduce diabetes, and access to culturally appropriate healthcare. Five scholarly articles were collaboratively written with community coinvestigators. In addition, more than 25 community publications and presentations were disseminated. Seven pilot research projects were also initiated. One large research project (PCORI funded) has just started and one multipronged collaborative program focused on policy, systems, and environmental (PSE) improvements (funded by the CDC) has also begun. Many interprofessional education (IPE) and service learning objectives of the UAMS NW campus were aligned with the community-driven agenda resulting in practical action to address the needs identified. These actions included interprofessional health screenings for chronic disease and the creation of an interprofessional student-led clinic focused on addressing diabetes within the priority populations, and cultural awareness training for all healthcare providers in the catchment.

Discussion of Lessons Learned

In the initial 18 months of this community-driven research agenda, much has been learned concerning the community-driven research process, building alignments and synergy with other priorities, and the constraints of a traditional research paradigm.

Community-driven research process: information, prioritization, infrastructure, and action

The process of information gathering, prioritizing, infrastructure building, and action is not a purely linear process, but an incremental and intertwined one. While a more comprehensive, rational, and staged approach to planning and agenda-setting might be desired, the reality of environmental constraints (funding and busy community stakeholders) required an incremental planning process. In addition, community stakeholders value action in the form of programs and policies above all else and are willing to engage in more comprehensive information gathering and research planning if iterative action is taken. In the words of one stakeholder: "*We know we are sick; we know we are dying. We don't need research to tell us we are sick. We want you to work with us to do something about it. We want to see change! We want to be able to go to the doctor, and we want to be healthy. We want our children to be healthy; we want our elders to live a long life.*" While taking action on preliminary community input may seem counter-intuitive to the CBPR process, this early action meant stakeholders were willing to engage in more time-consuming and intensive research planning. Universities have long focused on research that informs programs and policy, but have limited focus on direct program and policy implementation. However, it is the program and policy efforts that communities really desire. Consistent with the CBPR approach, we have balanced our efforts among research, programs and policy.

Community-driven, university facilitated

While the principal investigator facilitated the process, the community stakeholders drove the focus areas and priorities. "*We told you we wanted to do diabetes and you helped us do [research on] diabetes. We told you we needed health workers and you wrote a grant to try and get them. You told us you would listen, and you did.*" This more facilitative process meant giving up control and trusting the community process.

Constraints of conducting research in a traditional institutional research paradigm

The traditional model of research is driven by the principal investigator and his or her specific expertise. While community-engaged research often seeks input from communities in multiple phases of the research, the initial area of research focus is often constrained by the expertise of the investigators engaging the community and then further constrained by the specific community members the investigator chose to engage. UAMS NW engaged in a disease-agnostic approach, going into the field without a predetermined research agenda. This approach required a different type of investigator, one with facilitation and community engagement skills. The approach also required the willingness of researchers with expertise in the areas chosen to engage with the CBPR effort that they did not initiate themselves. This facilitated team approach crosses departmental boundaries that have traditionally governed the way that research is supported, conducted, and rewarded. Infrastructure support is designed within this traditional academic model, and research is incentivized (via bonuses, promotion, and tenure) based on this traditional model that promotes a principal, independent investigator. While UAMS NW has successfully navigated this community-driven model, it has been difficult and often stretched the traditional institutional boundary. Increasing flexibility will be required for sustained success.

Alignment with other priorities

One of the most unique and important elements of the UAMS NW program is the alignment of student-service learning, interprofessional education activities, and the community-driven research. This approach significantly increases the students and residents exposure to health disparities, cultural awareness training, and field research experiences. In addition, it has allowed students to take direct action in meeting the health disparities identified by the community. As a student-led, interprofessional clinic was being planned, the CBPR process and gap analysis that was conducted allowed UAMS NW to determine that a clinic to address chronic disease was more urgent than an acute care clinic. Students and residents attended cultural training and presentations concerning the CBPR research results. These sessions were coled by an interprofessional team of clinicians and community members, integrating the community-based participatory approach in to the education of new health professionals.

Conclusion

As academic health centers seek to expand their goals to embrace a model that promotes health as well as health care, it is imperative to integrate community-engaged research. This paper describes how one small, regional campus engaged in a CBPR process to set a community-driven research agenda. While many researchers engage in some form of community-engaged research, using a CBPR process to set the research agenda for an entire campus is unique. The process requires simultaneously gathering information, setting priorities, building infrastructure, and taking action. This process also requires a principal investigator willing to act as a facilitator as well as additional researchers willing to partner in the specific areas chosen. Expanded colearning and community health benefits can be gained by aligning student service learning and interprofessional education activities with community-based research. While this process may not be practical for a large, established university, there are lessons that can be learned and integrated into any program. Communities are dynamic and community-driven research must be dynamic as well. Academic literature often cites the difficulty and constrains of community-based research with the assumption that it is communities that need additional training to engage in research effectively. While additional community training may be needed, many of the constraints are due to an academic system that is not designed to facilitate community-based research. Increasing community participation in research will require universities to consider a new type of facilitative researcher and will require addressing the institutional barriers that constrain community-based research.

Acknowledgments

The authors acknowledge the community partners who continue to make our community-driven, collaborative research possible and fun. The authors thank: Arkansas Coalition of Marshallese, Gaps in Services to the Marshallese Task Force, ROaC Board, Hispanic Women's Organization, Washington and Benton County Hometown Health Initiatives of the Arkansas Department of Health, Feed Communities, Springdale School System, and the League of United Latin American Citizens.

Funding/Support

The project described was supported by the Translational Research Institute (TRI), grant UL1TR000039 through the NIH National Center for Research Resources and National Center for Advancing Translational Sciences. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Other disclosures

None.

Ethical approval

Not applicable.

Disclaimer

None.

Previous presentations

None.

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