A MANUAL FOR COMMUNITY-BASED PARTICIPATORY RESEARCH

USING RESEARCH TO IMPROVE PRACTICE AND INFORM POLICY IN ASSISTED LIVING

Dedication

We dedicate this manual to the diverse assisted living community including staff, family members, volunteers, advocates and others who help to enhance the quality of life for assisted living residents. We also dedicate this manual to assisted living residents themselves, who through their own life-long contributions, remind us why their ongoing quality of life is so important.

Acknowledgements

Many people gave freely of their time and expertise in conducting this project to create this manual. Thanks and appreciation go to the CEAL-UNC Collaborative partners for their commitment, expertise, and insights that enriched this project. Specifically, we thank:

Lastly, thanks to two silent but powerful contributors. To paraphrase, we stood on the shoulders of Barbara Israel and Meredith Minkler, giants in the field of community-based participatory research. We used the framework and understandings gained from their books in order to make our own intellectual progress.

Sheryl Zimmerman, PhD, Principal Investigator, University of North Carolina-Chapel Hill

Jane Tilly, DrPH Co-Principal Investigator, Alzheimer's Association

Lauren Cohen, MA, University of North Carolina-Chapel Hill

Karen Love, Center for Excellence in Assisted Living

Table of Contents

Preface

This manual serves as a "how-to" resource for researchers, practitioners, advocates, policy makers, and community members interested in the use of community-based participatory research (CBPR) to inform practice and policy. It conveys the experiences and lessons learned from a CBPR project conducted in the field of assisted living, with the partners being the Center for Excellence in Assisted Living (CEAL) and the University of North Carolina (UNC). The manual explains the principles and methods of CBPR gleaned from experts across the country, and illustrates and expands these points with examples from the CEAL-UNC medication administration collaborative research project.

While focused in the field of assisted living, this manual can be used by:

- Practitioners and other individuals interested in promoting better care and furthering knowledge by participating in applied research;

- Policymakers committed to using evidence-based research findings to inform policy decisions;

- Students attracted to the application of CBRP methods; and

- Researchers interested in using CBPR to better inform and shape their work so that it generates evidence that can further knowledge and inform practice and policy.

CBPR uniquely engages researchers and community members as equal partners in every aspect of a project.

Background of the CEAL-UNC Collaborative and Community-Based Participatory Research

In 2005, researchers from the Collaborative Studies of Long-Term Care based at the University of North Carolina at Chapel Hill (UNC) approached the Center for Excellence in Assisted Living (CEAL) to discuss collaborating on a research project. CEAL was interested in collaborating and the two entities decided to use an approach not yet widely applied in aging research known as community-based participatory research (CBPR). A grant proposal to study medication administration practices using this methodology was submitted to and funded by the U.S. Agency for Healthcare Research and Quality (AHRQ) in 2006. Both UNC and CEAL came to the project with extensive histories of collaborative work with diverse partners and unique expertise, but UNC did not have a formal collaboration with providers, policy makers, or advocates, and CEAL did not have a formal collaboration with researchers. UNC and CEAL partnered to conduct the two-year project they named the CEAL-UNC Collaborative, which began in September 2006.

The CBPR method was selected for a number of reasons including that compared to traditional research, CBPR results have an increased rate of knowledge translation and a shortened loop between research activity and community adoption of evidence-based practices. CBPR uniquely engages researchers and community members as equal partners in every aspect of a project including determining: the research topic and the questions to explore; the methodological design; instrument selection and development; documentation; data collection; data analysis and interpretation; and dissemination and application of results. The partners contribute expertise and knowledge and equitably share in project ownership and control of the research agenda.

The body of literature about CBPR in the field of aging is limited but plentiful for other disciplines. A sample of CBPR literature is included in the Appendix to provide readers a sense of what types of projects and disciplines have used CBPR.

The production of this Manual has been guided by two influential books on CBPR in the health field — Barbara Israel, Eugenia Eng, Amy Schulz and Edith Parker's *Methods in Community-Based Participatory Research for Health*, and Meredith Minkler and Nina Wallerstein's *Community-Based Participatory Research for Health* — as well as the CBPR Web-based listserv hosted by the University of Washington for the Community-Campus Partnership for Health. The chapters in this Manual are authored by various partners from the CEAL-UNC Collaborative in order to integrate their experiences and diverse perspectives into the writing.

Overview of Assisted Living and the Issue of Medication Management

Assisted living emerged in the 1980s as an increasingly popular alternative to the largely institutional environments of nursing homes. Assisted living experienced unprecedented growth over the next two decades, and by 2006 there were over 39,500 licensed assisted living communities with more than 900,000 residents nationwide (AAHSA, 2007). A recent definition of assisted living developed by AHRQ and CEAL referred to these settings as:

> **Assisted Living** — Residential long-term care options that are licensed, certified, or registered by states as assisted living or other residential care names. They combine housing and supportive services, which include at a minimum, assistance with activities of daily living and/or health care (such as help with medication administration). Assisted living settings have on-site staff who are available to meet both scheduled and unscheduled needs for assistance 24 hours per day, seven days per week. They also offer dining (two or more meals per day) and a variety of supportive services related to social and wellness activities. They care for individuals with a range of functional needs including dementia, and may provide a dedicated wing/area with additional

NOTES

security and cueing devices among other special services for those individuals. Assisted living units may be offered in free-standing communities or in a separate wing or building in a long-term care campus that provides other types of care. Assisted living does not include residential long-term care options that are licensed, certified, or registered by states as nursing homes, or those that exclusively serve persons with intellectual and developmental disabilities, the mentally ill (which is different than dementia), or persons with substance abuse diagnoses.

Assisted living is regulated at the state level and as a result considerable variation exists from state to state. Even the term "assisted living" is not consistently used across the country. Instead, there are over 30 different names states use to refer to assisted living including sheltered housing, domiciliary care, intermediate care, adult foster care and residential care facilities among others.

The types of services provided also vary. While all assisted living settings provide assistance with personal care needs such as bathing and dressing, as well as two or more daily meals and housekeeping, there are differences in other services, as well as differences in the residents for whom they provide care. For example, some settings do not permit individuals who have dementia to live there, while others specialize in the care of individuals with dementia. Some settings provide or coordinate medical services and employ trained clinical staff, while others depend almost entirely on unlicensed personal care aides to provide care.

A 1999 General Accountability Office (GAO) study of assisted living in four states raised concern that staff frequently did not provide residents the appropriate medications, stored medications improperly, and often employed insufficiently trained staff to administer medications (GAO, 1999). The issues described by this report have significant implications for medication management as resident acuity levels increase and an

NOTES

absence of any uniform standards of care across the states continues. Of note, whether or not nurses should be required to administer medications in assisted living has been a topic of national debate over the past few years. On the one side are individuals and groups who believe that assisted living residents require the clinical expertise of a licensed nurse; opponents argue that unlicensed medication aides can, with appropriate training and supervision, administer medications, and that allowing them to do so will reduce cost and improve access to care.

Although many states do not require assisted living settings to employ licensed nurses, almost one-half of all facilities, and three quarters of facilities with at least 11 residents, have a licensed nurse on staff (Zimmerman, 2005). Others contract with nurses to train unlicensed persons to administer medications. Thirty-five states allow unlicensed personnel to administer medications under varying delegation and training conditions (NCAL, 2007). Other states may limit medication administration to registered nurses (RNs) or licensed practical nurses (LPNs) or require assisted living residents to be able to self-administer their medications.

This manual provides a NOTES panel on each page to use for remarks or comments.

The Benefits of Using CBPR to Study Medication Management (and Other Issues) in Assisted Living

Using CBPR methods to conduct research in assisted living is especially desirable as this can be a confusing and complex field for researchers. Assisted living includes a diverse constellation of housing and services ranging from converted single-family homes with two or more unrelated residents to large high-rises housing 100 or more individuals in private apartments. In addition, assisted living is regulated on the state level, creating enormous variation in services and capabilities. Working within this diverse field, researchers strive to obtain knowledge that

NOTES

is useful, which is more likely if their work is under-taken in partnership with those who best understand the issues and will use the resulting findings.

From the perspective of operators and policy makers, the subject of medication management in assisted living is not well researched, leaving them with little to no evidence to inform their practices and policies. For these reasons, the partnership between CEAL and UNC was a prime opportunity to work together to craft the questions and develop the evidence that was of most relevance to medication administration. Similar partnerships between other community partners and researchers can answer questions in other areas, as CBPR is a method that lends itself to virtually any area of applied study. The partnerships can range from those between assisted living administrators and persons with research skills to those between assisted living organizations (such as the CEAL) and university researchers (such as UNC). The only requirement for CBPR is a desire to work together to obtain information that will inform policy and practice.

This manual provides a NOTES panel on each page to use for remarks or comments.

NOTES

Community-Based Participatory Research

1

To effectively use this manual, readers need to understand the basics of Community-Based Participatory Research (CBPR) as well as the roles of the researchers and the community being studied. This chapter will provide an overview of these issues by discussing the following topics.

What's Inside Chapter 1

- Overview of CBPR
- Community
- Researchers
- Origins and history of CBPR
- How CBPR works
- CBPR partnerships
- Partner objectives and expectations
- Partners or advisors
- Partner roles and responsibilities
- Institutional Review Boards (IRBs) and human subjects research

Overview of CBPR

Community-based participatory research is a unique method of research that partners researchers with community members of the topic being studied. Unlike other research approaches that may involve community members in an advisory capacity, CBPR actually creates partnerships between researchers and community members. Community members have equal voice, power and decision-making capacity in all aspects of a CBPR research project. In this way, CBPR bridges the expertise of researchers and community members through shared knowledge and experiences and leads to a more accurate basis for evaluating the issue under study and translating it into practice. Interest in CBPR has grown both nationally and internationally (Lantz, 2005) as experts from social science and other disciplines have come to recognize that traditional research methods do not always capture the dynamic and complex issues of the 21st century.

AHRQ describes CBPR as "an approach to research meant to enhance the value of studies for both researchers and the community being studied" (AHRQ, 2001). CBPR has been conducted in nearly all aspects of health care including primary, ambulatory and rural health care, mental and environmental health, health promotion, and health disparities. However, the use of CBPR is relatively new to the field of aging.

In 2001, AHRQ, along with several other federal agencies and the W. K. Kellogg Foundation, convened a forum to explore the use of CBPR as a resource for policymakers to help guide their program development and to develop strategies to advance CBPR. The outcome of the forum was the recommendation for one of AHRQ's Evidence-based Practice Centers (EPC) to develop a review and synthesis of the scientific literature regarding CBPR and its role in improving community health (AHRQ, 2001). As a component of this effort, the EPC developed a definition of CBPR that provides

NOTES

a uniform framework for using and understanding of this method of research:

> **Community-based participatory research** (CBPR) is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change (AHRQ, 2001).

The collaborative nature of CBPR provides a more comprehensive and therefore accurate framework for understanding, testing and evaluating the issues being studied which can lead to evidence-based interventions or policies that benefit the community. Other non-collaborative methods of research can produce outcomes that are not translatable or meaningful to communities. In contrast to research that is undertaken purely for academic pursuit, CBPR is undertaken to benefit both the community and to increase evidence-based knowledge.

Community

The majority of applied research is "**community-placed**;" that is, the project is conducted in the field (the "community"). If community members are involved at all, it is generally through participation in an advisory role. CBPR is different. It rebalances the control and decision-making capacity of community members to be equal partners. Therefore, CBPR projects are conducted in the community by community members — hence the term "**community-based**."

Webster's dictionary defines "community" as "an interacting population of various kinds of individuals

The collaborative nature of CBPR provides a more comprehensive and therefore accurate framework to study issues.

in a common area" (Merriam-Webster Online). The CEAL-UNC Collaborative struggled with defining the assisted living "community" for its project because it was challenging to determine whether the common area of assisted living constituted a narrow or global definition of community members. That is, in the broadest sense, the assisted living community includes a wide assortment of stakeholders from multiple levels — national, state, local — as well as numerous stakeholder categories including consumers, consumer advocates, providers (including but not limited to assisted living administrators, nurses, and medication aides), state regulators, health and allied health care professionals, and policymakers. In this way, it can be understood that defining the "community" may not be a simple effort.

Thus, one of the earliest tasks of the CEAL-UNC Collaborative was determining who constituted the community for the purposes of the medication study. The next task was coming to terms with the fact that because work on a CBPR project is not typically supported by a designated funding stream, not all community members have the time to participate. A notable example in this project was that while the CEAL-UNC project management team attempted to recruit an assisted living administrator and medication aide to participate in a partner capacity, the initial effort to do so was not successful because potential candidates declined due to their already busy workloads. The next invitee, who was also chair of the National Center for Assisted Living's Quality Committee, readily agreed and additionally made one of her assisted living company's medication aides available as well.

This experience exemplifies a common challenge encountered when community members are asked to participate in a CBPR project on an unpaid basis and/or as part of their already busy schedules: those working directly in the field (i.e., the administrator and a medication aide) may have more difficulty being involved in projects than

administrative or research personnel. Thus,
an early lesson is that it may be necessary to either:

- provide financial support for each
  member's time;

- incorporate this involvement as a component
  of a member's job description; and/or

- facilitate the focused involvement of those
  members whose time is more limited,
  and plan meetings around their schedules.

Based upon these experiences, the CEAL-UNC
Collaborative determined a definition for who is a
member of the assisted living "community":

Community — A stakeholder bound by a
common commitment and vision for the CBPR
project who brings relevant knowledge and
expertise; is not limited by geographic
boundaries; and has agreed to adhere to CBPR
principles for this project. Community members
may have different levels of awareness of the
details of the project, and their involvement
may vary depending on the stage of the project.

The community stakeholders for this project included
individuals who are involved in different facets of
assisted living such as consumers, owner/operators,
administrators and other staff, regulators, policy-
makers, state and national association
representatives, and others.

Researchers

Knowing who constitutes the "researcher" in a CBPR
project is a much easier task than setting parameters
around who is and is not a member of the community.
Researchers in externally funded CBPR projects are

NOTES

almost always academically based (i.e., affiliated with a college or university). Numerous articles in CBPR literature refer to "researchers" as academics and "community members" as non-academics. Not all researchers are affiliated with a college or university, however, so the academic/non-academic designation is not always appropriate.

> **Research Partner** — An individual who, regardless of his/her affiliation, brings to the partnership expertise to frame the research question(s), determine the research methods, collect and analyze the research data, and interpret the research results. The community partners have a role in these activities as well, as they have an insiders' view on matters such as collecting and interpreting the data. What they typically lack are the technical skills to conduct research, which is what the research partners provide.

Origins and History of CBPR

Conducting research in communities is not a new approach. For example, research has been conducted in communities for several decades to study the health and health care events common in primary health care through **practice-based research networks** (PBRNs). PBRNs actively involve primary care physicians in generating research ideas and conducting research in their practice settings. This research model differs from CBPR, however, in that it does not partner with other key stakeholders such as patients or community members (Westfall, 2006).

The roots of CBPR recognize the importance of these other community members, especially racial and ethnic minorities including African Americans,

Latinos, and Native Americans who have historically experienced marginalization both economically and politically. Based on their disadvantages, these communities had compelling reasons to be wary and distrustful of research and researchers. CBPR was developed and designed to engender trust and understanding between researchers and such populations. Partnering with members of these communities in all aspects of a research project not only enhances researchers' understanding and knowledge about the community, but also provides opportunities for researchers to form relationships with community members and so build trust.

In 1995, the National Institute of Environmental Health Sciences (NIEHS) was the first institute within the National Institutes of Health to undertake a CBPR project. Lawrence Green in "Tracing Federal Support for Participatory Research in Public Health" reports that this was because the public was more skeptical about the science of environmental health than about medical science (Green, 2003). NIEHS wanted to "establish methods of linking members of a community, who are directly affected by adverse environmental conditions, with researchers and health care providers and to enable this partnership to develop appropriate research strategies to address environmental health problems of concern" (NIEHS, 2000). As of 2003, NIEHS had funded fifteen CBPR projects at a cost of more than $6 million per year.

The National Institutes of Health (NIA) have increased their funding of CBPR projects dramatically, from two CBPR projects in 2000 to 51 in 2008 [see Table 1.1]. The table also shows that the NIA (one of the institute most likely to fund work related to assisted living) funded one CBPR project in 2006 and another in 2007. These figures may reflect the number of CBPR proposals submitted, the quality of those proposals, and/or how consistent they were with the mission of the NIH or the priority areas of the NIA.

NOTES

TABLE 1.1 Number of CBPR research projects funded by the National Institutes of Health Overall, and the National Institute on Aging, 1998-2008.

Year	NIH CBPR Research Projects	NIA CBPR Research Projects
1998	0	0
1999	0	0
2000	2	0
2001	5	0
2002	6	0
2003	11	0
2004	19	0
2005	34	0
2006	50	1
2007	56	1
2008	51	0

Source: CRISP (Computer Retrieval of Information on Scientific Projects). NIH, Washington, DC, on-line 7.07.2008

CBPR methods have also been practiced outside of the U.S. for many years, particularly in industrialized nations. For example, the Dutch government has funded a system of science shops at 13 universities. These science shops conduct collaborative research projects connecting community members and researchers. As another example, in 1991, the United Nations Development Program organized a conference, the African Informal Consultation on Behavior Change, to discuss and examine issues related to the HIV pandemic (Reid, 1993). The participants concluded that research in the field of HIV in Africa should be action-oriented and participatory-based. At a follow-up conference in 1992, participants stressed the importance of developing community-based monitoring, evaluation and program development methodologies. As the following additional examples illustrate, CBPR has been used for projects throughout the world with diverse populations and foci:

NOTES

- Intervention to improve food provision in a residential home for senior citizens in Guyana

- Study of the accessibility and relevance of sexual health services for diverse groups of urban youth in Toronto, Canada

- Project to improve sexual health in Arctic communities

- Intervention to manage tuberculosis among a high-risk group of poor farm workers in Cape Winelands, South Africa

- Intervention to improve newborn care in rural Nepal

The widening recognition of the benefits of CBPR has led to an increase in classes about this subject in U.S. colleges and universities, often in departments such as public health, nursing, sociology, social work and psychology (Israel, 2005). Workshops and sessions at regional and national conferences have also expanded over the past decade as interest grows and more people are presenting the outcomes of their CBPR projects.

NOTES

How CBPR Works

In CBPR projects, community members and researchers are equal partners. CBPR thus rebalances the traditional method of research in which the researchers determine what will be studied and develop the methods and interventions, so that in CBPR community members and researchers mutually decide upon these issues. This partnership is different than in traditional research where community members do not have a project leadership role and their insights and expertise are not considered by the research team.

Topics for research can develop in numerous ways. Community members might identify a need and search for researchers capable of conducting a study; this is not a common strategy, however, because funds are not typically available to conduct the research. Alternately and more often, researchers are interested in a particular topic, aware of a potential funder, and look for community partners. Research topics can also be explicitly proposed by a foundation or government agency consistent with their mission. In the CEAL-UNC Collaborative, the researchers were aware of a potential funder, and the topic for the project was jointly decided upon.

CBPR projects can be conducted in a specific geographic location (e.g., urban health in Detroit, maternal and child health in a Puerto Rican community), or cover a wide area (e.g., immunization of hard-to-reach children, pesticide exposure among migrant agricultural families). However, the more geographically dispersed the project partners are, the more challenging it is to maintain effective communication. Fortunately, partners who have access to technology as simple as the telephone and e-mail can sustain their collaboration across great distances.

While CBPR is still somewhat in its infancy for most disciplines other than public health, there are established principles that guide project formation and operation.

NOTES

The generally accepted **guiding principles** for CBPR (Israel, 2005), which will be discussed in detail in Chapter 3, include:

Guiding principles of CBPR —

- Recognize the CBPR partnership as a unit of identity;

- Build upon the strengths and resources of all partners;

- Equitably share decision-making and control over all aspects of the research process including project formation, research design, development and selection of instruments, field study process, interpretation and analysis of data, evaluation of findings, dissemination, and application of results;

- Implement an empowering and power-sharing process that addresses social and educational inequalities;

- Promote co-learning and capacity building among all partners;

- Ensure that a cyclical and iterative process to review decisions is employed throughout all phases of the project;

- Contribute to science while also integrating the knowledge gained with interventions and policies that benefit the community involved; and

- Commitment of all partners in disseminating the project results and findings.

Table 1.2 (on page 18) outlines potential benefits of CBPR to both community members and researchers.

NOTES

TABLE 1.2	Benefits of CBPR to community members and researchers.	
CBPR Component	Community Benefit	Research Benefit
Structure for collaboration to guide decision-making	Beginning of building trust and the likelihood that procedures governing protection of study participants will be understood and acceptable	Opportunity to understand each collaborator's agenda which may enhance understanding of the problem and recruitment and retention of study participants
Research question	Problems addressed are highly relevant to the study participants and other community members	Increased recognition by researchers of complex circumstances underpinning the problem and commitment to the research process by participants
Grant proposal and funding	Proposal is more likely to address issues of concern in a manner acceptable to community members	Funding likelihood increases if community participation results in tangible indicators of support for recruitment/retention efforts
Research design	Participants feels as if they are contributing to the advancement of knowledge as opposed to being passive research subjects and that a genuine benefit will be gained by their involvement	Community is less resentful of research process and more likely to participate
Measures, instrument design, and data collection	Interventions and research approach are likely to be more acceptable to participants and thus of greater benefit to them and the broader population	Quality of data is likely to be superior in terms of reliability and validity (defined later)
Intervention design and implementation	Participants feel the intervention is designed for their needs and offers benefits while avoiding insult; provides resources for communities	Intervention design is more likely to be appropriate for the study population, thus increasing the likelihood of successful implementation
Data analysis and interpretation	Community members who hear the results of the study are more likely to feel that the conclusions are accurate and sensitive	Researchers are less likely to be criticized for limited insight or cultural insensitivity
Research translation	Findings are more likely to reach the larger community and increase potential for implementing or sustaining recommendations	Increases dissemination of results

(Viswanathan et al., 2004)

CBPR Partnerships

In CBPR, partnerships offer an opportunity to bring together diverse participants who might not ordinarily have the opportunity to work together and also often increases partners' skills. In one CBPR initiative of Head Start programs (McAllister, 2003), parents of children enrolled in Head Start were trained to participate in data collection. While educating the parents took considerable time and effort, the CBPR project team found the investment rewarding. The parent interviewers were very knowledgeable and respectful of their fellow Head Start community members. The families being interviewed for the project trusted the parent interviewers and so shared information about personal situations. This helped improve the richness and quality of information gained for the study.

The first guiding principle of CBPR is recognizing the CBPR partnership as a unit of identity. This identity can be established as a condition of research funding, as occurred in the CEAL-UNC Collaborative. In this project, AHRQ provided a grant to UNC with a subcontract to CEAL. These relationships were legally binding and created a joint identity. Another strategy to develop a combined identity is to form a legal corporate entity. The CEAL-UNC Collaborative partnership did not pursue this path because they did not need to hire staff, sign rental space contracts, or conduct other activities more typical of a start-up organization.

Developing a unit of identity requires that partners commit the time and emotional energy necessary to establish inter-organizational and interpersonal relationships. Committing time can be a ticklish proposition, though, as even when funds have been received, they may not cover the time of all partners. Further, the time demands include not only those specific to the task at hand, but also the less specific interchanges that help to establish and cement relationships. Additionally, some of the community partners may be volunteering their time to participate on the project and adding time for the interpersonal

The first guiding principle of CBPR is recognizing the CBPR partnership as a unit of identity.

element adds more of an unfunded time commitment for them. These relationships are a critical element to successful CBPR projects, so those considering undertaking a CBPR project are urged to discuss this time element openly with all potential partner candidates and to determine the time investment and related role that is most feasible.

Of course, not all people have the disposition and personal skills to work well with others. Some prefer instead to work independently. Thus, one of the first considerations when choosing either research or community member partners in a CBPR project is determining their amenability to interpersonal relationships and working collabora-tively. Some potential partners will be known already, which makes this determination easy. Others will not be known, so subtle background work to determine their suitability will need to be conducted. This can take the form of a conversation with people who know the individual being considered to learn more about his or her ability to work well in group settings and knowledge of the topic being studied. Vetting potential partners to determine their suitability and expertise will involve extra work upfront, but is more than worth the time commitment to avoid conflict later.

As noted above, time also is needed to build informal relationships among the newly grouped partners. This is a critical element of the CBPR partnership, as strong relationships create the trust and flexibility needed to address complex issues that inevitably will occur during any project. Many experts in the CBPR field find that spending informal time together as a group over a meal is an excellent way for partners to get to know one another. One CBPR partnership of elementary school teachers and researchers in Colorado decided to begin each of their meetings with a pot luck dinner. While this commitment took time and money for both the community members and researchers, it became a fun and bonding activity.

The critical note here is that all partners participated in bringing food items, with a caution being that resentment might have built if some of the partners did not contribute.

For the CEAL-UNC Collaborative, CEAL board members drafted a list of assisted living community members to participate in the project, drawing from CEAL board members who were interested and able to commit to work on the project. In addition, the CEAL board considered what other assisted living expertise and experience would be needed for and valuable to the project and who these individuals might be. CEAL's list of proposed participants was discussed with, and approved by, the project's Principal Investigator (PI; the research partner who led the research activities) and each was invited to participate as partners. The UNC research partners were selected by the project PI and approved by the CEAL PI (the community partner who led the community efforts), although this approval was more a matter of faith because the CEAL team did not yet fully appreciate the different research skills and roles needed for such a project. The list of all project partners is in Appendix II.

While both CEAL and UNC had done collaborative work in the past, both were novices to CBPR. If they were more knowledgeable about the dynamics of CBPR when beginning their collaboration, they might have handled the partner selection process differently. For example, instead of each stakeholder group identifying its project members, it would have been more effective and bonding for the partners to conduct this process together.

The following two tables describe the partner expertise and knowledge the CEAL-UNC Collaborative identified as necessary for its project:

NOTES

TABLE 1.3   Research and field expertise needed for the project.

Participant	Responsibility/Role
Principal investigator	assures the scientific integrity of the project and that the aims will be met
Project coordinator	coordinates and oversees operational aspects of the project
Health care expert (in this case, a geriatrician/researcher)	has clinical knowledge about medications from a health care practitioner's perspective
Statistician	conducts the analyses
Pharmacist, academician	trains data collectors, consults on the data collection cycle, and provides pharmacy expertise
CBPR expert	provides information and coaching about the CBPR process
Data collectors	record field observations

TABLE 1.4   Assisted living community expertise needed for the project.

Participant	Responsibility/Role
Project manager	coordinates and manages the operational components of the project for CEAL's partners and helps with the development of the CBPR manual
Assisted living provider	has knowledge of operational practices in assisted living
Assisted living consumer	provides feedback about medication administration practices from a consumer's perspective
Assisted living nurse	has knowledge about the clinical systems, practices, and nurse delegation in assisted living
Assisted living medication aide	brings perspective about administering medications in assisted living
Consultant pharmacist with assisted living experience	has knowledge about pharmacy practices and medication protocols in assisted living
Geriatrician with assisted living experience	has knowledge about medication administration from a healthcare provider perspective
Gerontological nurse specialist	can provide feedback on the project design, tools, and practices

Once the partnership is formulated, CBPR partners should consider and discuss if there are any additional key people or stakeholders missing from the partnership composition. This and subsequent decision-making should be done through the whole partnership. This is a key element to establishing the trust and working relationships needed for an effective partnership, and it may require reminders to the project initiators who might have become acclimated to unilateral decision-making.

The formation and structure of the CEAL-UNC Collaborative reflects a combination of both deliberative and evolutionary processes as the partners' understanding of CBPR increased through project participation, discussion, and resolution of issues that arose. Thus, the structure, processes and outcomes of the CEAL-UNC Collaborative — as in all CBPR projects — inherently represent and reflect the unique collective interaction of the perspective, expertise and insights offered by its partners.

Partner Objectives and Expectations

Each partner will come to a CBPR project with his/her own objectives and expectations. Since these collaboratives are intended to benefit all partners, knowing what each person hopes to gain from his/her participation is important. Some may be more concerned about policy while others may be primarily interested in learning more about how a particular community operates from a practice perspective. While it is not realistic for all partners to have identical objectives, it is realistic to align all the objectives to best serve the project. An effective way to address differing aims is to candidly and openly discuss individual objectives and expectations from the outset and revisit the discussion periodically throughout the course of the project.

While it is not realistic for all partners to have identical objectives, it is realistic to align all the objectives to best serve the project.

Partners or Advisors

Approximately halfway into the CEAL-UNC Collaborative project, the working definition of project "partners" needed to be clarified because not all individuals were involved in the project in the same ways (which can be expected given the definition of "community" member). While the exact term applied to an individual might not be important, it does help to clarify how much time can be asked of that person in the context of his/her involvement in the project. Following a partner discussion, some of the individuals initially considered to be more in the role of project "advisors" were more appropriately determined to be "partners" because of their level of work and time commitment dedicated to the project. On the other hand, three individuals originally considered to be central enough to be "partners" felt that their involvement was more ancillary and better conceptualized as "advisor." CBPR teams are advised to discuss and define each individual's role at the project outset and then periodically throughout the project as roles and responsibilities may shift as the project plays out. At issue here is not an attempt to be exclusionary; instead, the matter is one of aligning roles with member expectations.

The CEAL-UNC Collaborative defined "**partner**" as —

> **Partner** — An individual who has committed through a Letter of Understanding [see Attachment III] to work collaboratively on the project, adhering to CBPR principles, and who is willing to commit intellect, time, and productive resources to the project as needed. A partner is a member of one or more Workgroups and participates in all partner calls and meetings (to the extent reasonably possible). A partner is able to describe the process and goals of the project, and has a clear sense of his/her role in attaining the project's goals. Each partner has one vote in decisions for the project.

NOTES

The CEAL-UNC Collaborative defined "**advisor**" as —

Advisor — An individual who brings expertise regarding a specific topic or issue to the CBPR project and participates in Workgroup and partner calls and meetings as needed. Advisors do not have a vote in decisions for the project.

Partner Roles and Responsibilities

Project partners' roles and responsibilities were not clearly explicated at the outset of the CEAL-UNC Collaborative. Instead, roles gradually evolved as it became clear how each person's expertise could best contribute to the project. This initial lack of clarity is not ideal because it can be confusing to participants and lead to ineffective use of time and energy. Still, it may be the nature of things as a new collaboration is developed. However, clarifying responsibilities early on regarding roles, as well as project processes, methods of communication, and project needs is essential. Recognize, however, that no matter how prepared one is about anticipating project needs, it is likely that some things will be overlooked. Therefore, the group process should include formal periodic opportunities to reassess all key components of the partnership. For example, the participant list should be revisited to examine if it is missing crucial members. Further, some participants might be more effectively involved as ad hoc experts, providing necessary input at select times as opposed to sporadic input throughout the entire process. Also, roles should be considered in relationship to stages in the project work and modified over time.

The CEAL-UNC Collaborative determined the following to be the roles and responsibilities of their partners. These items are included in the Letter of Partner

Understanding [provided in Attachment III] to which all partners agreed:

- Partners commit to learning and following CBPR guiding principles.

- Partners will read Chapters 1 and 2 of the CEAL-UNC Collaborative Manual as soon as possible.

- Partners will read the grant proposal for the CEAL-UNC Collaborative project as soon as possible.

- Partners commit to completing the required Human Subjects Training course (as per UNC's IRB) as soon as possible.

- Partners commit to sharing with the other CEAL-UNC Collaborative partners their relevant knowledge and information as it relates to the project.

- Partners commit to being an active participant in the project (i.e., active participation on one or more Workgroups [Workgroups described in Chapter 2]).

- Partners commit to participation in quarterly CEAL-UNC Collaborative partner meetings.

- Partners commit to help disseminate the project findings and to support initial next-phase efforts.

- And of special relevance for project integrity and success — partners commit to hold confidential all of the CEAL-UNC Collaborative materials and field study specific information. General information about the project such as what the project is about may be shared openly, but findings cannot be shared until approved by the project management team.

This last bullet highlights the fact that roles and responsibilities may be specific or unique to a given collaborative team. In the case of the CEAL-UNC partnership, there was concern that because of the

great interest in the topic under study, preliminary findings might be shared outside of the group before they were final. In this context, it becomes clear that the integrity of the message to be disseminated was of importance to the partnership.

Institutional Review Boards (IRBs) and Human Subjects Research

There is at least one more matter relevant to the topic of research integrity: the protection of human subjects. In order to ensure that research involving human subjects is conducted properly and ethically, research funders require that an Institutional Review Board (IRB), typically based at universities, authorize and provide oversight of a research project. Part of the authorization process includes the requirement that all the people with access to human subjects and the resulting identifiable data successfully complete an approved Human Subjects Research course. Traditionally, only the research team has access to human subjects and identifiable data, but in CBPR projects, the community members also have access to and make decisions regarding what will be asked of research subjects. So, all partners must understand what is involved in the ethical conduct of research.

The IRB language and requirements for uninitiated community members can appear adversarial and legalistic which can cause some tension among the community members for a newly formed CBPR partnership. CBPR project leaders are encouraged to use this as a co-learning opportunity and provide information and insights into the history of the need for IRBs and the value and benefit of human subjects training. Other project partners who have already completed the training can also contribute to this co-learning process.

For the CEAL-UNC Collaborative, the University of North Carolina at Chapel Hill's IRB required that all

NOTES

the project partners who would be involved in the conduct of the research project and have access to identifiable data complete a UNC approved program regarding Human Subjects Research. In the spirit of collaboration and joint-learning, the CEAL-UNC Collaborative decided that the training should be completed by all project partners, regardless their extent of involvement.

To meet this requirement, the CEAL-UNC partners were invited to either: a) complete the no-cost online Collaborative Institutional Training Initiative (CITI) course; or b) provide proof of completion for a similar approved human subjects research course. Some partners had previously completed this coursework in human subjects training at other research institutions and submitted the required proof to meet this requirement. Of the remaining partners, most completed the online CITI course. Given that the CITI on-line course required access to a computer, took numerous hours to complete, and was burdensome for some partners, the CEAL-UNC project management team sought information regarding alternatives and learned that the UNC IRB had recently approved an alternate training course for CBPR community members. Thus, a second option for completion was offered: an in-person PowerPoint presentation and short exam approved by the UNC IRB for use in CBPR projects. The in-person training was provided to all of the project partners who had not already completed the on-line training course.

Not all community partners in CBPR projects are computer literate and/or have access to a computer, and for some English is not their primary language, all of which make the conventional computer-based human subjects training especially challenging. Dr. Maghboeba Mosave conducted an informal Web-based survey of the Community-Campus for Partnerships in Health (CCPH) listserve participants in 2007 asking what approaches their institutions had taken to certify community members to conduct human subject research in CBPR projects. The following options reflect the diversity of approaches

NOTES

universities are taking to enhance the training experience for community members:

- Having a research team member conduct the training with tribal community members;

- Working one-on-one with visually impaired cancer survivors on the training;

- Requesting permission from the IRB to develop an interactive Spanish language training module that includes all elements and concepts of the CITI-approved human subjects training;

- Having the director of the Office of Research Affairs personally conduct training; and

- Offering several choices of methods, including the CITI training, a CD-based training that does not include tests, and in-person training.

Key Chapter Considerations

CBPR creates an equitable partnership between researchers and the community of the topic being studied; it is a dynamic relationship that reflects and adjusts actions as needed during the course of a research project.

CBPR requires significant time commitment from all partners. This may presents challenges in that time is as necessary for relationship building and process as it is for other aspects of research, such as securing funding or other resources for the project.

CBPR works best with sufficient advance planning regarding the roles and responsibilities of the various actors and formal understanding about these issues.

Flexibility is critical to CBPR because issues arise during project implementation which require all partners to discuss and come to agreement about how to address a particular issue.

NOTES

Developing a CBPR Collaborative

2

This chapter details how to develop a CBPR collaborative based on the literature and provides examples of how the CEAL-UNC Collaborative developed.

What's Inside Chapter 2

- Operational structure
- Leadership and management structure
- Expectations and research agenda
- Communication processes
- Workload structure
- Decision-making and conflict resolution processes
- Partner relationships
- Project closure and partnership dissolution
- Assessing the effectiveness of the partnership

Operational Structure

A well-defined operational structure is essential to an effective CBPR project. In addition to following the generally accepted CBPR guiding principles referenced in Chapter 1, CBPR projects also should develop their own operating guidelines. Drs. Macaulay and Nutting in an editorial in the 2006 January/February issue of the *Annals of Family Medicine* state that the experience of many [CBPR] partnerships is that the process of developing guidelines can strengthen both the partnership and the proposed research (Macaulay & Nutting, 2006).

Developing guidelines involves:

- Identifying and agreeing on project leadership, their responsibilities, and what decision-making authority is granted to them by the partners;

- Identifying and agreeing on project expectations including a detailed research agenda;

- Developing and agreeing on an effective process for communication of information throughout the project to the partners including level of detail to be communicated;

- Identifying and agreeing on how the project workload and management will be structured (e.g., workgroups, committees);

- Identifying and agreeing on decision-making and conflict resolution processes including what project decision-points require full partner discussion and agreement;

- Agreeing to commit the time and attention to develop, nurture and maintain relationships and trust among the diverse partners;

- Determining and agreeing on how and when the project partnership will dissolve and have closure; and

- Assessing the effectiveness of the partnership processes periodically, especially with regard to equitable decision-making and the power of the relationships and alliances.

NOTES

Leadership and Management Structure

Effective leadership is critical to the success of a CBPR project. With numerous partners from diverse backgrounds and communities as well as differing levels of knowledge and expertise, it could be easy in a CBPR project for issues to develop. An effective CBPR project leader needs to be "conductor-like" in simultaneously managing project progress, maintaining partner stability, and facilitating discussions among all parties.

Not everyone is a natural leader. Effective skills and an appropriate temperament and disposition are needed for successful leadership.

Leadership skills can be learned. However, having an appropriate temperament and disposition are largely innate traits. If the project leader is not naturally gifted with these attributes, then another person in a position of authority such as the project manager will need to possess them, as these attributes are critical to maintaining a CBPR project's equilibrium.

The project leader should ensure from the outset that all partners understand that their contributions to the project are equally important. Since CBPR partners bring diverse skills, knowledge, expertise and academic achievement to the effort, resentments could build if partners' perceptions are that not everyone is equally qualified.

The project leader should ensure from the outset that all partners understand that their contributions to the project are equally important.

Example of the need to stress equality — A less formally educated community partner could feel intimidated by a highly degreed research professional. The intimidation could take the form of the community partner weighing the researcher's input more importantly or else not being comfortable providing his or her own input. This outcome would defeat a critical aim of the CBPR methodology, which is to engage the community on an equal footing with the researchers and to let the research benefit from the deep experience and knowledge of the community members. ▪

The project leaders also need to ensure that discussions are ably facilitated. People who might be categorized as "dominant talkers," "ramblers," "shy persons," and "know-it-alls" can present challenges during discussions. A strong facilitator knows how to appropriately manage this so that open discussion does not get derailed.

The project leaders should ensure that all partners understand the role that their knowledge and expertise will have in the project and what contributions and responsibilities will be expected of them, including time commitment. As a project progresses, individual roles and contributions may shift and change so it is helpful to discuss this periodically throughout the project.

In the CEAL-UNC Collaborative, the leadership was structured by two main project elements: (a) research and field work; and (b) development of a CBPR manual. The UNC project leader (and principal investigator) was responsible for work related to the research and field work with the support of a project manager, and the CEAL project manager was ultimately responsible for work related to the manual development under the CEAL project manager. Thus, each project leader designated a project manager who worked with her. These four individuals comprised the project management team. Each CBPR project should dedicate sufficient time at the project outset to discuss and agree on what leadership configuration works best for them.

After determining the leadership structure, the project partners should decide and agree on what, if any, decision-making authority is to be granted to the project leaders. There is no one way of determining this element. The key, however, is for the partners to discuss and agree on the authority collaboratively.

The project management team structure in the CEAL-UNC Collaborative supported a balance between the research and community members as well as making it easy for the partners to know who to contact with questions or comments about various aspects of the project. Having four individuals on the project management team avoided any one person becoming overburdened with project details, yet was small enough to ensure that effective communication was maintained.

NOTES

Expectations and Research Agenda

Open and honest discussions among the partners to discuss project expectations and collaboratively define the research agenda are critical to the health of a CBPR partnership. Generally this involves multiple discussions, as an initial discussion only begins the conversation while subsequent ones help distill and define the issues and considerations. Allotting sufficient time for this is as important as the end products.

Research partners may have some differing project expectations than the community partners. This diversity is a healthy aspect of CBPR as long as the differences are openly expressed and understood. Problems arise when the expectation differences are not expressed and possible resentments or misunderstandings among partners simmer below the surface.

Open and honest discussions among the partners to discuss project expectations and collaboratively define the research agenda are critical to the health of a CBPR partnership.

Communication Processes

In the CEAL-UNC Collaborative, the UNC and CEAL management teams were physically located in different cities (Chapel Hill, NC and Washington, DC respectively). The majority of communication for the project was managed via emails and conference calls. The project management team had a monthly conference call as did two workgroups. All of the partners participated on a quarterly conference call so that everyone had a regular chance to talk together and discuss the project.

It is also important to bring all the partners and advisors together periodically for face-to-face meetings. The project budget for the CEAL-UNC Collaborative constrained the frequency of these get-togethers. The partnership met formally in person at the project outset, again once the field data were ready for initial analysis (at month 18), and lastly when the formal funding for the project ended.

The majority of the CEAL-UNC Collaborative partners were present at a symposium CEAL hosted during 2008, so the partners made it a point to informally get together over lunch during this event.

It would have been helpful to meet in person several more times during the course of the project, and this would have occurred if not for budget constraints. The frequency of in-person meetings is an important consideration when preparing the project budget and in discussions with funders. The in-person meetings provide opportunities for partners and advisors to informally get to know one another and build and nurture their relationships. As described previously, having good relationships among the partners is an important element in successful CBPR projects. While good relationships are beneficial in all research projects and processes, this is critical to the success of CBPR projects.

Effectively communicating information is crucial in CBPR projects because when information is not similarly understood by all partners, misunderstandings can easily arise and be magnified by each individual partner's misperception thus hindering the progress of the project.

Example of the importance of clear communication — In the CEAL-UNC Collaborative a number of the partners thought that the meaning of "equitable decision-making" as promoted in CBPR's guiding principles was decision-making that would equitably be made within each partner's fields of expertise; such as, the researchers would make decisions relative to the research project design, field study, and the evaluation elements of the project since these encompassed their fields of expertise. Other partner's perception of "equitable decision-making" meant that all partners, regardless of their fields of expertise, would be equitably involved in all decision-making as the co-learning element of CBPR anticipated that partners would need to educate one another as necessary throughout the project so all partners could make informed decisions. This issue was brought up for discussion during a partner conference call and the partners all agreed to adhere to the latter definition. ■

While good relationships are beneficial in all research projects and processes, this is critical to the success of CBPR projects.

An effective way to ensure that all partners understand information similarly is for the project leaders to regularly restate (during an in-person meeting or conference call discussion) key project decisions and ask if any partners have a different understanding. Inviting discussion is a helpful mechanism for different perceptions to bubble up and for everyone to feel comfortable discussing them.

Another area where communication can go askew is the terminology and language that the partners use. Researchers can use terminology that is familiar to them but perhaps not to the community partners. Similarly, community partners may use terms unfamiliar to the researchers. Open and effective communication fosters an environment where everyone is comfortable indicating if they are not familiar with some of the terms other partners are using, thus opening the way for establishing a common understanding of terms.

Example of misunderstanding of terms — During the CEAL-UNC Collaborative the research team used the term "pre-pour" to describe medications that are packaged off premises, such as bubble-packaging. The assisted living community partners mistakenly thought this meant "pouring" a liquid medication. The common term used by assisted living communities for medications packaged off site is pre-packaged. It was not until just before the field work began that this discrepancy in understanding surfaced. Because the term "pre-pour" was not commonly understood, the partners held different perceptions regarding what this meant in the context of the observations to be conducted. Fortunately the discrepancy was discovered in time to make adjustments to this aspect of the field work. ■

NOTES

There are numerous levels of communication needed in a CBPR project:

- intra-project leadership and management — communication between and among the project leadership and management

- intra-partnership — communication with the partners on a whole partnership level

- intra-workgroups or ad hoc groups — communication among subgroups of partners

Some levels of communication can be conducted informally such as by regular email updates. Other communications need to be formal such as written, disseminated notes from a workgroup meeting. While it is not necessary to detail how to specifically handle all levels of communication, it is important for CBPR project partners to understand the need for and importance of communicating effectively, including how to update partners who miss a meeting or call.

Lastly, CBPR partners need to understand the confidential nature of information learned or being evaluated during a project and not communicate this information outside of the project partners unless the information has been cleared for dissemination. There are two reasons for this. Often the tools and approaches used in a project have been developed by researchers and are part of their intellectual property. All partners need to understand and respect the confidentiality of discussions and not share details about discussions outside of the project. Secondly, preliminary research findings typically change at least a bit until the analyses are finalized. Thus, it is important not to release information until all agree that it reflects the final and accurate results.

The CEAL-UNC Collaborative included a separate item that all partners agreed to in its Letter of Partner Understanding [see Attachment III] that "Partners commit to hold confidential all of the project materials and field study specific information. General information about the project such as what the project is about may be openly shared."

NOTES

Once the analyses are completed and the work ready for dissemination, then the group decides on what will be disseminated. The ultimate goal of the Collaborative is to provide information that can be used to inform practice and policy, so dissemination is a key activity involving all partners.

Workload Structure

Generally the CBPR proposal to funders outlines how the project work will get accomplished. Once all the project partners have come together at the beginning of a CBPR project, how the workload will be structured is an important area for partners to discuss and reach agreement. The CEAL-UNC Collaborative decided to create two workgroups that relate to the two main project elements: (a) research and field work; and (b) development of a CBPR manual. The UNC management team was responsible for the research and field work in the context of the Medication Management Workgroup (in which CEAL members participated) and the CEAL management team was responsible for the Manual Workgroup (in which research team members participated). Generally, the CEAL-UNC workgroups met monthly by conference calls as well as communicated via emails as needed. Each project management team was responsible for:

- Scheduling conference calls

- Preparing an agenda and any materials needed for the workgroup discussion

- Facilitating the discussions

- Taking and distributing discussion notes

- Any follow-up work identified during the conference call

NOTES

Besides the standing workgroups, the CEAL-UNC Collaborative also decided to form ad hoc groups as needed to work on short-term projects such as developing a draft Memo of Partner Understanding for the partners' consideration. The combination of the standing workgroups and ad hoc groups ensured the flexibility to manage the project workload and unique needs as they arose. Each CBPR partnership will need to determine what system will work best for its needs.

Decision-Making and Conflict Resolution Processes

While CBPR has many benefits, it can create tension and potential for conflict because a diverse array of partners become involved in non-traditional roles. For example, partners participate in decision-making about aspects of the project that are outside their individual areas of expertise. This can result in some interesting group dynamics. Fortunately, the partners in the CEAL-UNC Collaborative were accustomed to working with others collaboratively either through academic and research pursuits, or through projects that involved multiple stakeholders, so tension was minimal.

A traditional research project may form an advisory group of community experts to provide background information and answer questions related to the topic being studied. The advisory group generally responds to questions posed by the researchers. In CBPR the community partners are just as likely to ask the researchers questions. Being asked detailed questions about the research design, instruments selected and data collection processes may be somewhat disconcerting for the researchers because this is not the traditional role of community participants. On the other hand, the researchers may welcome these questions, and in the CEAL-UNC experience, it became clear that such questions resulted in discussions that ultimately benefited the overall project.

NOTES

Effective group communication dynamics respect multiple perspectives and differences of opinion.

How decisions and conflicts that arise in CBPR projects are handled is significant to the outcome and success of a project. Discussions at the outset of a CBPR project about the fact that conflicts are a natural and expected occurrence during decision-making can help the partners perceive conflict as an opportunity to strengthen the project rather than as a negative outcome.

Effective group communication dynamics respect multiple perspectives and differences of opinion. While open communication is essential to CBPR, it is not without its challenges. Some partners may be passionate about an item of discussion and not be sensitive to the need of having all discussants involved. The "learning circle" technique is a communication process that provides equal opportunity for all participants in a discussion. Learning circles involve giving everyone in a group, either in a clockwise or counter-clockwise order, an opportunity to express their opinion about an issue without hearing rebuttals. More open discussion can occur after each person has had his or her say, with a moderator drawing out those who are somewhat hesitant to voice their opinions.

Coming to agreement on decisions can be challenging. The use of the concept "agreeing to disagree" establishes the fact that decisions do not have to end with one position winning out over another (Israel, 2005). This approach can help a group make a decision or resolve a conflict by mutually agreeing to something that everyone can live with. Alternatively, the partners may decide to revisit an item either later in that discussion or table it until the next discussion.

A partner may perceive a difference of opinion voiced by another partner as questioning his/her expertise and/or authority. A key feature of CBPR is the benefit derived from hearing and considering diverse perspectives. Hopefully a leader will note these undertones and help the partners clarify their meanings and perspectives.

A widely accepted format for reaching group decisions is by consensus. Consensus does not require unanimity but instead can be configured however the partners decide. For instance, partners may decide that consensus for its project constitutes 66% of partners' agreement. Rather than create tension for those partners holding a minority opinion, using consensus allows there to be differences of opinion among partners. The partners will need to be sensitive, however, to any significant decisions that do not have everyone's approval. It is helpful in these situations for everyone to commit to try to find common ground for the issue being discussed and come up with a decision that everyone can accept.

Other projects use a simple majority (51%) to make decisions. Whatever method is decided for a CBPR project, the critical element is that the partners as a whole agree to it. This is a decision that needs unanimous approval. Otherwise some of the partners will not be invested in the process and resentments are likely to form.

An issue might take time to resolve and involve various methods of communication including emails, phone calls and meetings. Working through differences to keep the lines of communication open and commit to working towards problem resolution is the goal.

In the CEAL-UNC Collaborative many of the project partners were accustomed to making decisions without always engaging in a deliberative process with others. Since the CBPR process requires that decisions be made collaboratively, agreement needed to be reached about what level of decisions required collaborative discussion and approval. The CEAL-UNC Collaborative decided that independence in decision-making would be necessary, as it was not feasible from a time or operational perspective to collaboratively decide everything.

NOTES

The Collaborative agreed to two levels of decision-making:

- **Routine decisions** not requiring discussion (e.g., how to format skip patterns on the data collection forms); and

- **Decision-points** requiring discussion (e.g., the qualifications to be required of data collectors).

In retrospect, the partners realized that some decision-points required more discussion than occurred at the time the decision was made. These incidents were brought to the attention of the partners and reviewed to improve future decision-making.

Example of a decision point — The partners realized mid-way through the project that the composition of partners represented by the assisted living "community" should have been more diverse. The partners decided what additional diversity was needed (an assisted living administrator and a medication administration technician) and upon a strategy to successfully recruit them. The community project manager was able to identify two candidates who the partners endorsed. ■

Partner Relationships

Establishing good interpersonal relationships among partners is a critical feature of CBPR. Building, nurturing and maintaining interpersonal relationships requires time and attention. This investment of time upfront later translates into the trust and flexibility among partners needed to navigate challenging and stressful aspects of a group-process project. The interpersonal relationship aspect is perhaps one of the most challenging of all CBPR elements because it is not a major focus in conventional projects yet it is an important aspect of effective CBPR partnerships.

Another challenge may be that the extra time needed for building and maintaining relationships in a CBPR project is not monetarily compensated. So, carving

out the needed time can present challenges for all the partners. Community partners may be participating on a CBPR project as an extension of their job. The CBPR project may represent work that adds to their existing responsibilities and thus the extra time commitment to the project may not be easy. The research partners may also already have demanding schedules and face similar challenges.

It is impossible to know exactly how much time and attention will be needed, as each CBPR project partnership is unique and distinct. Whatever the challenges, it is important to consider and address them when inviting partners to join the collaborative to ensure that those who agree to participate understand the time commitment they need to make.

Example of the importance of understanding the time commitment — A lack of understanding of the team value and time commitment by one of the project partners affected the CEAL-UNC Collaborative project. A key community partner agreed to participate in the project and then did so infrequently. It would have been helpful to the project to have this person's expertise and perspective represented consistently during discussions. If this partner had understood the time commitment and laid out his or her time constraints, the Collaborative would have approached another expert. Because of this situation, important expertise was missing for a period of time during the conduct of the project. ■

Relationship-building requires respect and trust. Besides creating a barrier to effectively navigate through differences and/or conflict, the lack of these basic relationship traits can negatively affect the outcome of the project.

In the CEAL-UNC Collaborative a number of the partners were already familiar with each other before the start of the project and thus already had mutual

NOTES

respect and trust for one another. However, not all the partners knew one another. In hindsight, the CEAL-UNC project leaders should have been more proactive at the project outset in helping create opportunities for the partners who did not already know one another to foster relationships. No major issues resulted from not being more proactive in this regard, but it did hinder some of the partners from feeling comfortable raising points and questions in the early stages of the project.

Project Closure and Partnership Dissolution

CBPR partnerships that form legal relationships will need to clarify partnership dissolution formally in their By-Laws with the help of an attorney. For CBPR partnerships that are informally formed and not legally-binding, the partners should determine and commit in writing the parameters for project closure and dissolution at the outset of forming the partnership. Of course, given the necessary flexibility of CBPR projects, the initial agreement about how and when to close and dissolve the project and partnership may change due to new considerations that arise during the project work. The key element is to keep discussions open and candid among the partners as new considerations emerge.

Assessing the Effectiveness of the Partnership

Decisions and modes of behavior established at the outset of a project can easily lead to establishing a routine that continues throughout the project. Over time, these decisions or the related actions may no longer be optimal. For example, a partner whose knowledge and expertise was not called upon initially or regularly may not feel integral to the project. His/her interest and commitment in the CBPR process

may wane. It is helpful, therefore, for the partnership to periodically evaluate its effectiveness especially so that elements about partnership equitability, decision-making, and power do not become unbalanced. Assessing the effectiveness of a CBPR partnership is discussed fully in Chapter 7.

Key Chapter Considerations

The CBPR process requires project leaders who have substantive knowledge, management expertise, and the ability to foster productive teamwork. Leaders and the rest of the team must agree on a management structure that spreads the workload and is flexible enough to meet project needs as they evolve.

Communication at the beginning of the project is critical to establishing expectations of partners and the research agenda. Communication processes must foster input from all stakeholders and lead to effective decision-making. Agreeing to disagree and reach acceptable compromises are critical to good team function.

Learning circles are a communication technique that can lead to resolution of differences and compromise. Learning circles involve giving everyone in a group, in a specific order, an opportunity to give their opinion about an issue without hearing rebuttals. More open discussion can occur after each person has had his or her say, with a moderator drawing out those who are somewhat hesitant to voice their opinions.

Partner relationships are key to the success of any CBPR project and sufficient time must be built into the project and budget to allow time for relationship-building.

Partners should establish upfront how and when the project will end and the partnership dissolve to prevent misunderstanding toward the end of the project.

NOTES

Putting CBPR into Action

3

The CBPR literature details the key elements of CBPR as it has been used in health care and other settings. This chapter restates the guiding principles introduced in Chapter 1 and applies each to the assisted living community.

What's Inside Chapter 3

- Guiding principles of CBPR
- Partnership as a unit of identity
- Strengths and resources of all partners
- Equitable decision-making
- Power-sharing
- Co-learning and capacity building
- Cyclical and iterative process
- Interventions and policies that benefit the community
- Dissemination of project results

As noted earlier, there are eight guiding principles of CBPR which provide the common framework to guide CBPR projects. Barbara Israel and colleagues (Israel, 2005) are credited for developing these generally accepted principles:

Guiding principles of CBPR —

- Recognize the CBPR partnership as a unit of identity;

- Build upon the strengths and resources of all partners;

- Equitably share decision-making and control over all aspects of the research process including project formation, research design, development and selection of instruments, field study process, interpretation and analysis of data, evaluation of findings, dissemination, and application of results;

- Implement an empowering and power-sharing process that addresses social and educational inequalities;

- Promote co-learning and capacity building among all partners;

- Ensure that a cyclical and iterative process to review decisions is employed throughout all phases of the project;

- Contribute to science while also integrating the knowledge gained with interventions and policies that benefit the community involved; and

- Commitment of all partners in disseminating the project results and findings.

It is crucial to understand that while these guiding principles help establish a common framework from

NOTES

which to guide individual CBPR projects, the elements should not simply be imposed on individuals partners. Rather, at the outset of each CBPR project, partners should take time to consider each element individually and discuss how these elements will be integrated into their individual partnership.

Partnership as a Unit of Identity

"Unit of identity" has already been discussed in detail in Chapter 1. An additional consideration is that involving all partners in creating a vision for the partnership will establish a common focus and understanding from which to launch the CBPR project agenda. Some say that the shared vision is a defining element of partnerships; otherwise the effort would only be a coalition or group with similar interests.

Strengths and Resources of All Partners

One of the fundamental values of CBPR is bringing together diverse people and resources to address community issues and research questions. How effectively diverse people and resources come together is important. While diversity among partners is desirable, the very nature of diversity presents potential challenges from the outset. Critical to the success of a CBPR partnership is recognizing and valuing the expertise and knowledge each individual partner brings to the project. It may be easier to readily perceive the value researchers bring with their academic credentials, but if CBPR is to be successful, the "field" credentials the community members bring to a project must be similarly valued.

Besides the need to recognize and value expertise and knowledge, CBPR partners need to be respectful and sensitive to one another's cultural beliefs and practices. Tervalon and Murray-Garcia (1998) created

The CBPR methodology instills a democratic approach to research in which all partners participate as equals and share control over the research process.

the term "cultural humility" to address the issue of outsiders' feeling they can master someone's culture. This has particular implications in a CBPR project, where researchers are outsiders to the community, and community partners are outsiders to the research community. Tervalon and Murray-Garcia caution people to practice "cultural humility" meaning that outsiders' should accept that they cannot master another's culture, but instead can commit to "self-evaluation and self-critique, to redress power balances and develop and maintain mutually respectful and dynamic partnerships with communities." As with other elements, being mindful of potential harm is essential.

During the partner selection process, individual strengths such as expertise, knowledge and resource potential are discussed. It is helpful to capture this information in a written list and share it with all the CBPR partners at the initial project launch meeting. This process allows everyone to understand what talent and resources have been assembled for the project and perhaps identify any key missing elements — a critical factor in beginning to establish the "unit of identity" of a CBPR partnership.

Equitable Decision-Making

The CBPR methodology instills a democratic approach to research in which all partners participate as equals and share control over the research process. This method varies significantly from traditional research methods where community participants are not involved as equal partners. Minkler (2003) uses the term equitable to qualify decision-making among partners to provide the latitude needed to encompass the diversity of the CBPR partners.

CBPR project partners should equitably be involved in all aspects of decision-making throughout every phase of the research process including:

- Identifying the topic to be researched

- Developing the research agenda and design

NOTES

- Developing assessment tools
- Collecting, analyzing and interpreting data
- Determining how data can be used
- Designing, implementing and evaluating interventions
- Disseminating findings

The partners may agree to delegate select decisions to internal groups such as ad hoc groups, topic groups or other workgroup structures. When delegating decision-making authority, the partners will want to clarify the conditions under which decisions are made and how this information is reported back to the full partnership.

The CEAL-UNC project defined equitable decision-making as:

> **Equitable decision making** — A group process whereby decisions are made only after equal opportunity for consideration and deliberation of, and input into, the topic has been given to all partners. Each partner has a vote in all decisions for the project; partners may seek the expertise of advisors in the decision-making process.

Power-Sharing

It is important to implement an empowering and power-sharing process that addresses social and educational inequalities. Power-sharing need not always be equitable as long as all the partners collaboratively agree on what arrangement works best for a specific aspect of the partnership/project. For example, it is unusual for community members to control the research process of a CBPR project. The research expertise and knowledge generally are found in an academic setting. The university

affiliation brings unique benefits such as an Institutional Review Board to critique project methods and ensure protections of participants in the research. This type of control exerted by the university milieu is typically unavoidable. CBPR partners will need to be candid about this dynamic and redress any discomfort that arises.

Co-learning and Capacity Building

CBPR partners share their individual knowledge and experience to create an environment of teaching and learning from one another. This approach meshes the collective knowledge capital of the partners to most effectively address tasks throughout the course of a CBPR project. The goal of co-learning is to increase one another's understanding to build capacity among all partners.

An example of co-learning and capacity building among CBPR partners is illustrated in the following example from the CEAL-UNC Collaborative.

> **Example of co-learning and capacity-building** — The CEAL-UNC team determined that a paper-and-pencil "knowledge" test would be appropriate for use in the study, to be completed by the licensed and unlicensed assisted living staff members who would be observed administering medications during the data collection phase of the project. To begin this task, a member of the UNC research team searched for and identified existing examples. The assisted living community partners reviewed these and found numerous issues with either the wording of items or with the applicability of some of the questions. Their input and the collaborative process strengthened the knowledge test while also teaching the researchers about the culture and norms related to medication management, as well as the expected knowledge base of staff in assisted living. ■

CBPR partners share their individual knowledge and experience to create an environment of teaching and learning from one another.

Cyclical and Iterative Process

Another departure from conventional methods of research is CBPR's iterative and cyclical process that involves revisiting decisions and other considerations throughout the course of the project.

> Once a project is underway, it might become apparent that a stakeholder with specific information is missing from the partnership composition. The partners may decide to reconsider the composition with the possibility of adding a new member who brings needed additional knowledge and expertise. ■

The iterative nature of CBPR allows flexibility to integrate new knowledge and learning gained during the project to better inform and shape subsequent decisions. This dynamic is an important element of CBPR and contrasts with conventional research, which may seek guidance from external advisors but is not bound to act on their guidance or report their decisions to the group.

Interventions and Policies that Benefit the Community

This principle to contribute to science while also integrating the knowledge gained into policies that benefit the community embodies a concept that the field of assisted living has underused. To date there has been comparatively little scientific research conducted in and about assisted living (especially compared to research conducted in nursing home settings). Further, little of the extant research has led to the development of interventions or policies nor been adopted into practice.

Medicine has long relied on using evidence-based knowledge to guide the development of clinical standards of care. Other fields where the margin

The iterative nature of CBPR allows flexibility to integrate new knowledge and learning gained during the project to better inform and shape subsequent decisions.

of error needs to be very small, such as aviation and pharmaceuticals, depend on evidence-based knowledge. The value of this knowledge in improving operational systems of care in assisted living is slowly gaining recognition.

Dissemination of Project Results

A CBPR project should not underestimate the value and importance of disseminating a project's results and findings. Dissemination of CBPR project results is included as a guiding principle to underscore its importance. Dissemination of the actual results and findings of a project naturally occur at the end stages of a project. The planning for how and where the information will be disseminated, however, should be done throughout the project and not left until the end. Part of the value and benefit of a CBPR approach is to influence policymaking as described in Chapter 6. To effectively broadcast the results and findings, the research results need to be disseminated thoughtfully and deliberately.

Dissemination efforts need to be tailored to various audiences. There is typically not a singular audience for the research results. Some key audiences include:

- The communities that are affected by the research outcomes at national, state, local and organizational levels;

- Policymakers at national, state, local and organizational levels; and

- Researchers interested in considering further studies in the field addressed by the research.

Making sure that the research results are accessible and disseminated to the communities the research addresses is essential in CBPR efforts. This is one of the key factors that can promote translation of research into practice. For example, if the assisted living community does not learn about the results of

To effectively broadcast the results and findings, the research results need to be disseminated thoughtfully and deliberately.

a medication research study, they may not know how they could improve their processes.

One effective means to disseminate findings to professionals, policymakers and researchers is through presentations at national and statewide conferences and meetings. Another key means to disseminate information is through published articles in peer-reviewed journals and in provider and other stakeholders' newsletters and periodicals. Academic researchers are expected to publish in peer-reviewed journals, and to date have not been "rewarded" for publishing or presenting in other venues. Further, the post production efforts of writing articles and presenting at conferences and other meetings are not typically included in the project funding, and so non-academic dissemination is perceived of lesser value and is often not done. Consequently, research results usually reside in academic journals that providers seldom read. This is an oversight that is remedied through the more expansive dissemination promoted by CBPR.

Another important point in dissemination relates to authorship. As Christopher et al. (2008) noted, "missing from most CBPR-based publications are the direct voices of community partners." Typically researchers write articles for publication and acknowledge community partners as participants in the CBPR project. In this case, the community partners are not co-authors of published articles about the project. While publishing is usually an essential aspect of professional life for researchers, such is not the case for community members. The limitations inadvertently imposed by community members not publishing results of their projects, however, can be significant. Not only does a community richly benefit from information shared directly by others within their community, but the body of literature about CBPR ends up uneven and reported through the singular voice and perspective of researchers. While writing for peer-reviewed publications may be off-putting for community members, the writing effort can and should be co-shared among partners thus integrating the diversity of voices and perspectives.

NOTES

Key Chapter Considerations

The Guiding Principles of CBPR are designed to foster a true partnership between the researchers and the community being studied. These principles, if followed, will lead to useful research results that can improve care delivery in the assisted living setting.

The process must engage all partners in creating the Partnership's own unique identity.

The strengths and resources of all partners must be nurtured in the implementation and completion of the research project.

Equitable decision-making and power-sharing are the hallmarks of CBPR, but this does not mean that all partners have an equal say in every decision that a Partnership makes. Rather, input is gathered for key decision points and consensus is reached. Partners with varying expertise in the community being studied or the research methods used may well have more or less influence depending upon the decision being made.

A cyclical and iterative process whereby all partners participate equitably in the project is critical to ensuring that the project benefits the community.

CBPR thrives on co-learning and capacity building so that all partners are equally vested in the success of the partnership's research project and dissemination of its results.

NOTES

Collecting and Analyzing Data in a CBPR Project

4

The processes of collecting and analyzing data in a CBPR project can represent new learning experiences for community partners and different operating procedures for researchers. This chapter reviews the major data collection and analysis tasks inherent in a CBPR project, and discusses how the involvement of all partners is essential to these activities.

What's Inside Chapter 4

- Study design
- Preparing for data collection
- Data collection
- Data analysis

Study Design

As reviewed in the Preface and in Chapter 1, the CEAL-UNC Collaborative partners jointly identified medication administration in assisted living as the area for study. However, once a research question has been identified, there is still much to do in terms of operationalizing that question and its components so that a scientifically rigorous yet practical study design can be achieved.

To operationalize a research question means to identify its main concepts and turn those concepts into specific, discrete, and measurable variables. For example, in the CEAL-UNC Collaborative, partners had to operationalize the concept of medication management. While seemingly straightforward, "medication management" includes many tasks, not all of which could be studied in a modest-size project. Thus, the first task was to set parameters around and define the scope of study. Among other areas, the Collaborative agreed to study medication administration, operationalized as the observation of medication passes to residents to assess whether the proper medications were given, as well as the accuracy of their route of administration, dosage, form (e.g., pill versus liquid), preparation (e.g., crushed versus not), packaging (e.g., stock bottle versus single-unit dose) and timing.

In addition to operationalizing the key concepts of a research question, partners must also identify and operationalize other concepts of interest. In the CEAL-UNC study, partners not only wanted to understand errors in medication administration, they also wanted to understand the cause of such errors. For example, the group theorized that characteristics that might affect medication administration included the training of the person administering the medication, the cognitive status of the person receiving the medication, and the form of the medication itself. The first was operationalized by specifying licensing and certification credentials and types and amount of training, the second was operationalized by incorporating a standardized measure of cognition into the research

NOTES

It is necessary that partners work together to identify the most important variables that can reasonably be measured within the boundaries of the study.

instrument, and the third by recording the form (e.g., liquid, pill) of each medication. Thus, CEAL-UNC partners met multiple times by telephone to brainstorm variables that should be measured as part of the study. This group iterative process was crucial to the success of the CEAL-UNC project. If — as is done in non-CBPR settings — the research members had taken sole responsibility for identifying the concepts to study, critical variables may well have been missed.

Because there are often numerous characteristics that could theoretically affect the phenomenon being studied, it is necessary that partners work together to identify the most important variables that can reasonably be measured within the boundaries of the study. Determining what is important is very much a collaborative process, as the different vantage points of each partner are needed to select those variables that might be the most influential and the most amenable to change; add to providers' knowledge of evidence-based practices; and/or have a large effect on outcomes. Without careful group consideration of the overall research question and its components, the resulting information might be incomplete and therefore not optimally useful.

In addition to specifying the research question itself and identifying the data that will be collected to answer it, there are many other preparatory decisions to be made. For example:

- Where will data be collected? In an industry that varies because of regulatory and cultural differences, it must be considered which states, locales, and types (e.g., urban/suburban/rural location, size) of communities to involve.

In the CEAL-UNC project, for example, a major decision was related to the selection of states in which data collection should occur. Because staff training was thought to be a key determinant of one's ability to successfully administer medications, the partners thought it wise to conduct the project in two states that had markedly different regulatory requirements for medication administration. The partners made an informed decision by compiling

information on state policies related to medication administration, and then, in a telephone conference, reviewing these policies together and discussing the two best states in which to collect data. The partners ultimately chose South Carolina and Tennessee. Tennessee stipulates that only licensed nurses can administer medications, while South Carolina allows unlicensed staff who have completed a training program to do so. In addition to having different regulatory approaches, these states were also adjacent to North Carolina (the research team location), and so fit within the practical boundaries of the project's budget.

Another question is how will potential participants who will be the focus of study be identified and accessed? Options included having the CEAL team do this through their informal networking or having the research team do it with their more formal strategies. In the end, both were tried, but given the potentially sensitive matter of observing medication errors, it was found that the more formal procedure yielded more participation.

There are a myriad of decisions to be made in the formation and daily conduct of a research project. The more that decisions are made as part of a team, the better they are — but the time demands on the partners and the overall project time must be respected as well. There needs to be clarification as to what decisions can be made by individuals, by subgroups, and by the entire collaborative.

CEAL-UNC partners initially struggled in trying to decide what decisions were "small" decisions that should be independently made, versus "larger" decisions that should involve input from the other community partners. As introduced in Chapter 2, the CEAL-UNC partners used the term **"decision-point"** to refer to key decision items that required discussion and agreement among all partners. Thus the term "decision-point" was coined, which is a unique contribution of this collaborative to the field of CBPR.

The CEAL-UNC partners used the term "decision-point" to refer to key decision items that required discussion and agreement among all partners.

Decision-point — A decision-point is a key decision that requires input from all partners. Some decision- points will be known at the outset of the project (e.g., identifying the subjects of study), however others will not be apparent until a partner is confronted with the decision. To the extent possible, partners should devote ample time at the project outset identifying decision-points. The early identification of them will help avoid confusion later in the project. ■

Identifying what does and does not constitute a decision-point will be somewhat individualistic for different projects. As a general rule of thumb, most of the activities related to identifying the research question, preparing for data collection, and interpreting the results are appropriate for group discussion; of these, all but the most straightforward, technical ones may be decision-points. Thus, for example, it is necessary to discuss and come to agreement as to who will be the subjects of study, how they should be approached, what information should be obtained, and how the results are to be interpreted and presented. Also to be discussed, but more for purposes of information rather than joint decision-making, are things such as the actual formatting of skip questions, procedures to work with the University Institutional Review Board (IRB), and how to use software to conduct the analyses. As a general rule of thumb, if the matter at hand is one for which discussion could affect the ensuing activities, then in the spirit of equitable decision-making that matter should be brought for group discussion as a decision-point.

Preparing for Data Collection

There are many activities that take place as part of preparing for data collection, such as data collector hiring and training, measure preparation and formatting, protocol preparation, database construction, and

IRB applications. In addition to ensuring partner cohesiveness, the identification of some of these activities as decision points (and therefore requiring partner discussion) is instrumental in canvassing partner resources. In the CEAL-UNC project, one preparatory task was to recruit assisted living communities in SC and TN to participate in the project. In a partner discussion of this decision point, it was revealed that several community partners had connections with desired communities, and thus could help with the recruitment process.

A second notable example is that of hiring and training data collectors. The CEAL-UNC project involved observing medication passes in assisted living communities. Specifically, data collectors were required to observe the passes and record the name and characteristics of the medications being passed. Because of the difficulty of this task, the partners spent considerable time deciding who would be able to reliably complete this task. The community and research partners ultimately decided that 3rd- or 4th-year pharmacy graduate students would have the necessary knowledge of medications to be able to complete this task. Based on this recommendation, the research team then identified and hired two pharmacy students. These students were trained in the observational protocol, and joined the monthly partner calls. However, because these students were transient, and only able to commit to the project for one summer, they were not identified as partners. Again, in ideal circumstances the data collectors of a CBPR project would be project partners. However, the practical needs of the project and the limited pool of qualified data collectors necessitated this approach.

Data Collection

As discussed in earlier chapters, one of the defining characteristics of CBPR is the equitable inclusion of all community members in all stages of a research project. In some cases, though, including certain community members can pose ethical concerns or

NOTES

other challenges. In the CEAL-UNC research project, the community partners recognized early on that members of the assisted living community should be a part of the Collaborative. That is, in ideal circumstances, the administrators, staff members, residents, and families of assisted living communities participating in the study should be included as a part of the research community. However, depending on the research question being examined, such inclusion can be difficult to navigate. In the CEAL-UNC study, the project was one of observing staff members administer medications to assisted living residents. Including these staff members and residents at the partner level would threaten both the integrity of the data collection and the unbiased nature of the research. For example, would staff members participate if they thought their supervisor could learn that an error was made? What if residents learned that an error had occurred? Would staff members change their behavior if they know exactly what data were being collected (i.e., would they be more careful than usual)? Therefore, in the CEAL-UNC project, the partners consulted with the local IRB and decided it would be best to include administrators and medication technicians from assisted living communities NOT participating in this study. This decision was appropriate in this case because of the sensitive nature of the topic being studied and the likelihood of subject reactivity.

Another point that is raised by this example is whether or not a supervisor or resident had the right to know about an error being made as soon as it was detected. IRBs (and common sense) demand attention to issues such as this, and the protocol for the CEAL-UNC study included an "adverse events" section, which required data collectors to respond immediately if they were aware of situations that could put someone in serious harm.

By collaborating in all phases of the project, the CEAL-UNC Collaborative came to understand the planning required, time involved, and details needing attention when conducting a research project. At first blush, the thought of studying medication

administration seemed rather simple and straight-forward to those who were not closely involved in research. By the end of the data collection period, however, they appreciated the many actions and decision points in the final research design. An example of the complexity of the final research design is made evident in the summary of the CEAL-UNC project below.

Example of a research design — In the CEAL-UNC medication administration study, data collection took place over the course of one summer. Data collectors traveled to 11 assisted living communities in SC and TN and spent two days in each community observing medication administration. In total, the data collectors observed 36 assisted living staff members administering 4,403 medications to 320 different residents. Data collectors also interviewed staff members to obtain demographic and training information, administered a medication knowledge exam to these staff members, and abstracted descriptive information from resident charts. The project manager interviewed the community administrator and obtained facility-level data related to medication practices. ▪

There are at least two additional steps between data collection and data analysis: data entry and cleaning. Every pencil stroke made by the data collectors must be entered into an electronic database and reviewed for accuracy. For example, a data collector might hurriedly enter a "9" referring to the code for "not applicable", but might have done so in a box designated for a numeric value (which would then be read as the number 9, as opposed to "not applicable"). In the CEAL-UNC project, some community partners expressed surprise over how long the entry and cleaning of data took after it had been collected. If not for regular monthly meetings, this minor point could have resulted in tension between the community and research partners. However, because

NOTES

the progression of the data entry was routinely discussed, all partners were aware of the timeline. This example is but one of many instances in which the community and research partners held different expectations based on their background, but through open and frequent communication were able to learn from one another.

Data Analysis

The data analysis phase of a research project can be the most challenging in terms of group involvement and co-learning, largely because of its technical and jargon-laden quality. Because of the diverse background of community partners, it is unlikely that all will be equally versed in even the basics of data analysis. Therefore, it is important to present background information to provide all partners with a common groundwork for the analyses, and to take the time necessary to explain results such that all can understand what they reveal. In the CEAL-UNC medication administration project, the research team introduced the topic of data analysis at an in-person retreat. This approach was especially beneficial because the research partners provided definitions for statistical terms, and were careful to present the analyses in non-technical language.

To quote one of the CEAL-UNC partners: "I believe the multi-step process of [reviewing findings] that began at our retreat was particularly helpful in regards to data analysis for non-research partners because it provided a strong learning structure that included research team teaching and group learning; individual reflection; and group discussion components."

The process proceeded as follows:

- The research partners prepared data tables in advance of the in-person retreat. At the retreat, the research partners presented and talked through each of the data tables, being careful to define all terms and explain the significance of findings.

- After the in-person retreat, the community partners took time to individually review the findings and carefully consider what elements stood out to them as important and what elements seemed unclear. The partners met by conference call the following week to answer questions and determine next analytic steps.

- Multiple conference calls (at least two per month) were then scheduled to review additional analyses and consider the over-arching questions. Along the way, community partners were provided with supporting material to aid in the digestion of the analytic tables.

Although decision points should be identified and discussed by all partners, the analytic phase of a project is one in which many technical decisions can likely only be made by the project analyst and research experts. Therefore, it is important that all partners come to agreement as to the intent of the analyses and the overriding questions that are to be answered. In the CEAL-UNC project, the partners had an open discussion about allowing the research experts to make independent decisions about some of the more intricate analyses, understanding that the rationale would be explained, and trusting that it was sound.

One suggestion made by many of the CEAL-UNC partners was to create a "glossary of terms" to ensure that the community and research partners understand the meaning of all words that are used during the data analysis phase. A glossary of terms that have been discussed during the conduct of this project is included at the end of the manual.

NOTES

Key Chapter Considerations

As with all other components of CBPR, collecting and analyzing data are collaborative processes.

Collaborative input is required as the research question is clarified and characteristics of interest are operationalized. Input also is needed as decisions are made regarding the research design and analyses to be conducted.

Given some of the technical components of data collection and analysis, once the team has come to an agreement on the key issues, experts may be charged with doing some work independently (as long as they report back and explain their decision-making to the group).

Because data analysis is technical and includes a language all its own, it is important that the collaborative use language that is understood by all and takes the time needed to explain the analytic process and results to all participants.

It is helpful to identify decision points that require input from the entire team.

NOTES

Evaluating CBPR | 5

This chapter describes the importance and benefits of conducting periodic evaluation in a CBPR project to ensure that the project and processes remain on a desired course.

What's Inside Chapter 5

- Purpose of an evaluation
- Types of evaluation
- Comparison evaluation of CBPR

Purpose of an Evaluation

Project and process evaluation is often considered as an afterthought because many view the actual work of a project as far more interesting than taking a step back to evaluate the process by which the work is being done. Ongoing evaluation, however, functions like a rudder — a guiding mechanism to enable those working on a project to determine whether or not they are on course and to take corrective actions as needed. Imagine if someone had a checking account where all he did was spend money (the fun part) and never stopped to determine whether he had sufficient funds to support all the spending. He could quickly end up knee-deep in overdraft notices. Unfortunately, the external signs that a project or process might be going off-track are not as tangible as overdraft notices.

The way to ensure that a project and processes remain on the desired course is to plan and factor in periodic evaluations. There are many ways to conduct evaluation including surveys and partner interviews. The first step, though, is to define the purposes of the evaluation such as:

- To learn how a project or process is operating;

- To assess outcomes;

- To document the progress of a project;

- To improve interventions; and/or

- To determine whether something works or does not work.

Types of Evaluation

An approach to project and process evaluation that is especially well-suited for CBPR is participatory evaluation. **Participatory evaluation** "...assumes that people can generate knowledge as partners in a systematic inquiry process based on their own categories and frameworks... producing richer and more accurate data; create active support for the

The way to ensure that a project and processes remain on the desired course is to plan and factor in periodic evaluations.

results of the process of inquiry; and therefore create greater commitment to change as well as the greater likelihood that the ideas will be diffused" (Minkler, 2003 p. 269).

Table 5.1 (below) outlines the key elements of both conventional and participatory evaluation. Conventional evaluation is much better suited for research requiring a high degree of scientific rigor such as double-blind studies (where neither the subjects nor the data collectors are aware whether an intervention is being given).

TABLE 5.1 Differences between conventional and participatory evaluation.		
	Conventional Evaluation	Participatory Evaluation
Who	External experts	Community and project participants
What	Predetermined indicators of success, primarily cost and outcomes or gains	People identify their own indicators, which may include outcomes and gains
How	Focus on "scientific objectivity" distancing evaluators from other participants; uniform; complex procedures; delayed, limited access to results	Self-evaluation; simple methods adapted to local culture; open; immediate sharing of results through local involvement in evaluation processes
When	Usually upon project completion; sometimes also midterm	Merging of monitoring and evaluation; frequent small-scale evaluations and reporting back to the group
Why	For accountability, usually summative, to determine if funding continues	To empower partners to initiate, control and take corrective action

Source: Melchior-Tellier (1991).

NOTES

The participatory evaluation approach embraces many of the same elements as CBPR: collaboratively conducted; co-learning among partners; co-development of instrument design; and iterative.

Participatory evaluation continues to grow and gain popularity especially in the fields of primary care, public health promotion in developing countries, and nursing research (Abbott, 1993). In the United States, a number of major foundations such as W. K. Kellogg Foundation are encouraging this approach.

Comparison Evaluation of CBPR

This section provides information as to how the process of a CBPR project can be evaluated. Because the authors of this manual have participated in only one CBPR project, the CEAL-UNC Collaborative partner demographics and survey evaluation responses are compared with the responses of a national survey of partners in other CBPR projects across the U.S. to provide readers a gauge of comparison on a wider scale. This larger survey was conducted as part of a doctoral dissertation at the Department of Psychology at the University of Illinois at Chicago, where Susan Staggs conducted a Web-based survey of members of the Community-Campus Partnerships for Health's (CCPH) CBPR listserve in 2008. Two hundred thirty-five people responded to the survey — 163 researchers and 72 community members.

The CEAL-UNC Collaborative partners were fairly similar in gender and education demographics as those who responded to Stagg's survey [see Table 5.2], but they were starkly different in terms of race. All of the CEAL-UNC Collaborative partners are Caucasian as compared to greater diversity in the national survey. Unfortunately the lack of diversity among community partners reflects the lack of diversity among the leaders and policymakers in assisted living, which to a large extent mirrors the residents of these settings, as the majority of assisted living residents are Caucasian.

	National Survey (N=234 projects) (Percent)	CEAL-UNC Collaborative (N=1 project) (Percent)
TABLE 5.2 Age and race of CBPR participants in a national survey and in CEAL-UNC collaborative.		
Age		
21–30	5	0
31–40	18	18
41–50	31	33
51–60	35	44
61+	11	5
Race		
American Indian	4	
Asian American	2	
Black/African Am.	9	
Caucasian	71	100
Hispanic	9	
Native Hawaiiain— Pacific Islander	.5	
Other	4	

There are 18 partners in the CEAL-UNC Collaborative which is not uncommon of CBPR partnerships; that is, in the national survey, one third of partnerships included 10 to 20 partners [Table 5.3, page 72]. Thirty-five per cent of the national survey partners were involved in partnerships of 21 or more partners.

As with the majority of national partnerships responding to the survey (91%), the CEAL-UNC Collaborative non-academic partners had a leadership role in the CBPR project. The majority (48%) of the national CBPR projects represented by the survey responses were funded by federal grants as was the CEAL-UNC Collaborative.

The CEAL-UNC Collaborative project was jointly initiated by the research and community partners.

NOTES

CBPR Project Characteristics	National Survey[1] (N=234 projects) (Percent)	CEAL-UNC Collaborative (N=1 project) (Percent)
TABLE 5.3 CBPR characteristics in national survey and CEAL-UNC collaborative.		
1 How many people work on your project?		
Less than 10	33	
10 – 20	32	X (18)
21 – 30	17	
31 – 40	5	
41 – 50	5	
more than 50	8	
2 Do non-academics have leadership roles on project?		
No	9	
Yes	91	x
3 What was the project's funding source?		x
Federal grant	48	
State grant	8	
City grant	2	
Foundation grant	15	
Multiple sources	27	
4 Who initiated the project?		
Academics	37	
Non-academics	20	
Both	41	x
Other	2	
5 In what stage is your project?	21	
Early	30	
Middle	27	
Late	21	x
Completed	1	
Not sure		
6 How many projects have you worked on?		
1	21	100
2	23	
3	20	
4	9	
5	5	
6 or more	22	
7 Is primary role academic or non-academic?		
Academic	69	35
Non-academic	31	65

[1] 235 people responded to the national survey: 163 academics; 72 community members. Not all respondents answered each question.

Forty-one per cent of those responding to the national survey noted that their CBPR projects were jointly initiated. The national survey found that 20% of community partners initiated their CBPR projects as compared to 37% initiated by research partners.

Thirty-six per cent of the national survey respondents had worked on four or more CBPR projects, while 64% had worked on three or less projects. This was the first CBPR project for all of the CEAL-UNC Collaborative partners. The national survey showed that 69% of CBPR participants were academics and 31% non-academics whereas the CEAL-UNC Collaborative was composed of 35% academics and 65% non-academics.

The CEAL-UNC Collaborative selected eight questions from the national survey questionnaire's 37 questions to survey its partner. Table 5.4 (page 74) shows the responses to these eight questions. The CEAL-UNC Collaborative experience was similar to the national survey respondents for the first six questions, but markedly different for the last two questions. The majority of respondents to the national survey (55%) reported that their CBPR projects had insufficient time to meet project goals as compared to none of the CEAL-UNC Collaborative partners. The majority of national survey respondents (62%) also felt that their projects had insufficient funding to meet project needs as compared to only 23% of the CEAL-UNC Collaborative partners. CEAL-UNC used the free on-line Survey Monkey tool in order to provide its partners confidentiality of their responses.

The CEAL-UNC Collaborative conducted two evaluations during its CBPR project using surveys; the first one was conducted three-quarters of the way through the project and the second one was conducted at the end of the project. The partners found both surveys to be informative wide-angle views into how aspects of the project were proceeding and to note project elements that needed addressing. Elements the first survey found that needed attention included: not all partners felt comfortable voicing a difference of opinion during discussions; the orientation process for new partners

NOTES

TABLE 5.4 Features of CBPR projects in national survey and CEAL-UNC collaborative.

	CBPR Project Features	National Survey (N=235) (Percent)		CEAL-UNC Collaborative (N=18) (Percent)	
		Agree	Disagree	Agree	Disagree
1	Project had agreed upon measurable outcomes	88	12	93	7
2	Project had resource sharing among partners	90	10	100	0
3	Project was effective in achieving its goals	90	10	100	0
4	Project met the expectations of community partners	88	12	100	0
5	Project met the expectations of academic partners	93	7	100	0
6	Project had a positive impact on the community	93	7	100	0
7	Project had insufficient time to meet project goals	55	45	0	100
8	Project had insufficient funding to meet project needs	62	38	23	77

joining the project after start-up needed to be expanded; and there was a need to discuss the budget with all partners. Once the evaluation brought these elements to light, the partners were able to discuss and resolve them.

Had the CEAL-UNC Collaborative not conducted the first evaluation, these issues would not have surfaced and possibly would have caused some partners to have long-term negative impressions about the CBPR experience. As the CEAL-UNC Collaborative was just learning the CBPR methodology, in hindsight the first evaluation should have been conducted sooner than three-quarters of the way through the project. There are no standards for when evaluations should be conducted during a CBPR project. Based on the CEAL-UNC partners' experience, conducting evaluations should be considered for the following project intervals: at the one-quarter mark of a project; two-thirds of the way to completion, and at the end of a project. For example, a three-year project could consider conducting evaluations at 9 months into the project, again at the 24 month mark and lastly at the end of the project.

The type of evaluation mechanism that a CBPR partnership uses should be discussed and determined by each partnership. Depending on the project specifics, some CBPR projects might be best served using face-to-face interviews while other projects can be effective using surveys. The specific questions and number of questions used for the evaluation are, again, project specific and should be mutually decided upon by the partners. This approach not only provides for a stronger process, but also invests all the partners in the usefulness of the evaluation.

Conducting the evaluation is only the first step. The next step involves analyzing the evaluation responses, followed by discussing the findings among the partners to determine what, if any, actions are needed. If there are project elements that need addressing, then the final evaluation step is to follow-up on whatever elements need addressing.

NOTES

Evaluation does require extra time during a CBPR project. The value, however, of being able to review periodically how a project is progressing to assess its functional effectiveness is one of the major benefits of CBPR. Imagine if a ship's captain never reviewed his or her navigation course during a trip and landed in China instead of Australia. The CBPR process prompts projects to continually assess their course and to make corrections as needed which is more than worth the added time expended!

Key Chapter Considerations

🔑 **Periodic evaluation** of a CBPR project functions like a rudder on a ship — a guiding mechanism to ensure the project is on course and to make corrective actions as needed.

🔑 **There are numerous ways** to conduct an evaluation. The first step is to define the intended purpose of the evaluation.

🔑 **Based on** the CEAL-UNC partners' experience, conducting evaluations should be considered at the one-quarter mark of a project, two-thirds of the way to completion; and at the end of a project.

🔑 **There are multiple steps** to CBPR project evaluation including conducting the evaluation, analyzing the results, discussing the findings among all the partners, determining what, if any, subsequent actions need to be taken, and lastly following-up on any needed actions.

NOTES

Translating CBPR Results into Policy, Advocacy, and Practice

6

This chapter details policy implications and advocacy efforts that relate to practice, based on CBPR project results.

What's Inside Chapter 6

- Policy considerations for CBPR projects
- History of CBPR in influencing policy and practice
- Identifying policy strands
- Translating policy implications into advocacy efforts
- Translating research findings

Policy Considerations for CBPR Projects

A unique feature of CBPR is that research findings are interpreted with regard to how they can benefit the community, including policy implications that will affect practice. For this purpose, once findings from a project have been determined, CBPR partners deliberately consider them from a framework of the implications they have on policy which in turn affects practices. There are multiple levels for policy considerations: organizational, community, and national. "Internal policy" is the process and procedures that guide how organizations, companies and other group-related units operate. "External policy," or public policy, is the process and procedures that guide how public entities such as local, state and federal governments operate. CBPR project findings, therefore, need to be considered from the perspective of whether or not there are policy implications at either the internal or external level, or both. Given the rigor of CBPR methods including the iterative discussion among partners and advisors, CBPR outcomes have the opportunity to influence policy from simply increasing community dialogue about a local topic, to bringing wider public attention to a pressing issue, to influencing federal legislation via public testimony.

History of CBPR in Influencing Policy and Practice

The Woburn case is one celebrated example of CBPR's impact on national public policy in the United States. Community members in Woburn, Massachusetts were concerned about the high rate of childhood leukemia in their town. After unsuccessful efforts to get the local government to test their water supplies, they appealed to researchers at Harvard's School of Public Health. Working collaboratively with community members, the researchers documented what was long suspected. A civil suit was filed by the Woburn township against

corporations that had been dumping toxic chemicals for years into the community's water supply. The community eventually won an out-of-court multimillion dollar settlement. The community members were credited with being a major motivation for reauthorization of the federal Superfund legislation (Sclove, 1997).

In another case, national welfare rights groups partnered with Virginia Polytechnic University researcher Susan Gooden to disseminate research findings on discrimination in workforce programs. Gooden's research documented what many welfare rights groups had experienced anecdotally; that women of color did not receive equal access to training, placement and employment services. Working together, the groups leveraged their efforts and mounted an intensive media campaign to educate the public about this disparity, pressuring the federal government to respond (Themba, 2000).

Identifying Policy Strands

The same strength and diversity of expertise and knowledge that the partners bring to inform and carry out the CBPR research project can be used to identify policy implications and subsequently to advocate for policy changes. The first step is to consider the findings from a policy framework by examining the "web of information" generated from the research project. The second step is to identify the policy strands based on the data. Consider a hypothetical CBPR research project that studied obesity in elementary school-age children over a ten year time period. The data indicated that obesity rates had increased by 25%. The partners examined the "strands" of information (i.e., the data and information) over the time span and noted that:

- Physical education programs in the schools were reduced as a result of budgetary limits;

- Fast food and soda vending machines were installed in the schools during year 3;

NOTES

- Suburban sprawl contributed to reduced exercise for the students as increased distances and a lack of sidewalks or bike paths necessitated driving instead of walking or biking; and

- The increased popularity of video and computer games meant that children were spending less time playing outside.

This information (i.e., the strands) provides the framework to consider policy implications regarding the state of the nation's elementary school-age children's health. Process and procedural recommendations include the need to restore and evaluate physical education programs; eliminate fast food and soda vending machines and replace them with healthy food choices; add safe pedestrian paths throughout the community; and implement a public awareness campaign about the causes of obesity and how the community can address them.

NOTES

Translating Policy Implications into Advocacy Efforts

Once policy implications have been determined, CBPR partners next decide what, if any, advocacy efforts towards implementing policy changes could/should be pursued. Funding of CBPR projects generally does not include the financial resources to support the efforts of translating findings in order to impact public policy. This valuable element is another benefit of CBPR — having community members involved and invested in the project who can carry the torch of policy dissemination that will affect practice; in fact, this is something they may be better positioned to do than their academic partners. While the project funding may not cover policymaking efforts, the community members may have either through their organizations or through their networks potential resources to pursue policymaking influence. The research partners may also be able to provide support, though often in a limited role. Researcher's support could take the form of writing testimony for the record or a policy brief, or participating in meetings with key policymakers.

It is difficult to outline what if any policy actions can or should be taken at the outset of a CBPR project, although the policy-relevance of a project may be known early on. Still, this level of information may not bubble up until the project data have been analyzed and evaluated. However, discussions among the partners in the early phases of a CBPR project about potentials for policymaking actions that will affect practice are encouraged as this captures the commitment of the partners to use the information they will obtain. It also will help direct data analysis toward the most relevant areas.

To provide some examples of the wide-ranging effects of CBPR projects, the following table (page 82) details four CBPR projects and their policy outcomes.

NOTES

TABLE 6.1 Sample CPBR projects and policy outcomes.			
CBPR Project Name and Location	Project Partners	Research Aim	Policy Outcomes
WE ACT Partnership – New York City, NY	West Harlem Environmental Action; Columbia Center for Children's Environmental Health	Study community-level exposure to diesel exhaust emissions and related air pollution	Conversion of New York City bus fleet to clean diesel
Southern CA EJ Collaborative – South Los Angeles, CA	Communities for a Better Environment; Liberty Hill Foundation; researchers from Brown University, Occidental College and University of CA/Santa Cruz	Examine environmental inequality in air quality and toxic exposure levels in Southern CA	Revision of CA Rule 1402 tightening emission standards and lowering MICR by 75%; changing policy language used by CA EPA from individual to cumulative risk exposure
Tribal Efforts Against Lead – Tar Creek, OK	Clan Mothers and Fathers; University of Oklahoma; University of New Mexico; Emory University; Ottawa, OK County Health Department	Assess lead exposure levels among local children and evaluate a lay health worker model	Helped get routine lead testing by Ottawa County Health Dept. for children in high-risk areas; helped stop use of chat (mine tailings) in construction and on roads without proper containment
CCT Partnership – Tillery, NC	Concerned Citizens of Tillery, NC; University of North Carolina; Halifax, NC County Health Dept.	Quantify disproportionate location of industrial hog operations in low-income/African Am. communities and their health effects	Passage of an intensive livestock ordinance by the Halifax, NC county commissioners; adoption of a statewide moratorium on corporate hog operations

Source: Minkler, Vasquez, Tajik, Petersen, 2006

Translating Research Findings

Looking at the CEAL-UNC Collaborative's two-year study of medication administration by licensed and unlicensed assisted living personnel, some of the project findings include:

- Medications administered outside the standard one-hour window time frame accounted for the majority of medication errors. Most all of the timing errors resulted in no clinically significant harm, however;

- The medication technicians (trained, unlicensed staff) had no higher medication administration error rate than licensed staff (nurses);

- The medication administration knowledge exam administered to all staff involved in either medication administration or assistance was a useful indicator to identify their competency; and

- The misadministration of limited drugs (such as warfarin and insulin) accounted for what could have led to serious medication errors.

Once the Collaborative's partners identified these research findings, the next step was to examine this information for public and assisted living industry policy implications; considerations for action and practice; and finally what possible advocacy actions the CBPR partners could pursue. The following table illustrates these steps.

NOTES

TABLE 6.2	CBPR policy and advocacy actions that will affect practice based on the CEAL-UNC project.		
Research Findings	Policy Implications	Considerations for Action	CBPR Partner Actions
Medications administered outside the standard one-hour window timeframe accounted for greatest number of medication administration errors.	Physicians who are less prescriptive regarding timing may allow for a lowered error rate.	Work with physicians to clarify which medications must be given strictly within a given timeframe.	1. Launch a public information campaign through print and on-line media to educate assisted living providers about this improved practice.
Trained medication technicians had no higher rates of medication errors than licensed nurses. The greatest likelihood of medication errors occurred with staff who were less trained and likely were assisting[1] residents to administer their own medications.	States that require nurses to administer medications may inadvertently be causing more medication errors when less trained staff assist residents.	Additional research is needed to identify the activities being undertaken by these untrained staff.	1. Inform states about research findings and advocate for a review of policies regarding who handles medications and their required training; standardize core curriculum and competency assessment. 2. Advocate for the training of all assisted living staff who handle medications.

TABLE 6.2   Continued from previous page

Research Findings	Policy Implications	Considerations for Action	CBPR Partner Actions
Medication administration knowledge and practice questionnaire functions as a useful tool in predicting the likelihood of staff medication errors.	Use of a knowledge exam could help reduce medication administration errors.	Consider on-going research to improve and make more comprehensive the existing self-administered knowledge and practice exam.	1. Discuss the possibility of creating a quality improvement tool to reduce medication errors.
The misadministration of a limited number of drugs has the greatest potential for medication errors causing serious harm.	Medication errors could be reduced by increasing staff, resident and family awareness and understanding of the potential for serious harm from the misadministration of a limited number of drugs such as warfarin and insulin.	Improve practice through an educational campaign about the potential for serious harm from the misadministration of a limited number of drugs such as warfarin and insulin.	1. Raise awareness and educate staff about this avenue to improve practice through a medication administration pocket guidebook that CEAL will produce. 2. Write articles in assisted living industry magazines about this serious potential for harm to residents and recommend improved practice.

[1]   The term administer medications generally refers to the actual administration of medications to a resident as opposed to assisting residents (e.g., opening pill bottle, reading pill bottle label, getting a glass of water) to self-administer their own medications. States and assisted living communities vary widely in how permissively the term assist is interpreted.

Key Chapter Considerations

🔑 **A CBPR project** does not end with the research findings, but rather continues through two additional phases: translating results into policy implications and actions; and dissemination.

🔑 **CBPR partners** have the potential to impact policy and practice on many levels ranging from increasing community dialogue about an issue to influencing state or federal legislation.

🔑 **Translating a project's** findings into policy and practice implications involves examining the layers of information generated from the research project and identifying the policy strands.

NOTES

Sustainability and Dissemination of CBPR Projects

7

This chapter details information about the sustainability and dissemination of CBPR projects.

What's Inside Chapter 7

- Dissemination of CBPR project results
- Sustainability of CBPR
- Selection of CBPR methodology
- Project impact

Dissemination of CBPR Project Results

Disseminating the results of CBPR projects is the final key element of CBPR. There are three major goals of disseminating CBPR study results: (1) to broadcast the findings of the study so that they will inform practice and policy; (2) to contribute to the knowledge of cultural norms and other important insights gleaned from the study to better inform the literature; and (3) to make people in general aware of CBPR methodology. Since CBPR is not widely known or used beyond the public health sector, dissemination to other sectors is critical to help more people become aware of its value and benefits. Widely disseminating this information is important not only to the research community but also to the general public as everyone is a community member of some kind. Community members can just as likely provide the initial impetus to investigate initiating a CBPR project. Hopefully this manual has sparked interest among community members and researchers alike to consider working together to strengthen the quality of studies and to discern understudied areas.

In conventional research, the typical avenues of dissemination are for the researchers to publish articles in peer-reviewed journals and present findings at conferences. Peer-reviewed journal articles are not typically helpful as a means to broadcast information to community members as they generally do not subscribe to them nor are versed in "research speak" in order to understand the information presented in the articles. Similarly, community members may not have an affiliation that sponsors conferences so conference presentations would not be helpful to them.

Disseminating information for a CBPR project incorporates a broader approach because its intent is to share information with community members as well as researchers. In CBPR projects, dissemination through publications is not limited to peer-reviewed journals. Instead, dissemination can include a wide

Hopefully this manual has sparked interest among community members and researchers alike to consider working together to strengthen the quality of studies and to discern understudied areas.

array of print, broadcast and on-line media including neighborhood newsletters; community weekly or monthly magazines; daily newspapers; and local radio or TV programs. Also, in-person presentations are not limited to conferences but also include local presentations to community members — perhaps in a school auditorium. Depending on the nature of the project, presentations might also be made to local, regional or state officials.

CBPR dissemination to community partners may create challenges because project funding does not usually cover dissemination efforts. For researchers, the quality of their work is justified by meriting publication in an academic journal. The added time for writing articles or being interviewed by media serving the community does not fall into the same professional obligation or advancement categories, although the importance of doing so is increasingly being recognized and rewarded. For community partners, many have become involved in a project because of an altruistic commitment to the community and may not be receiving much, if any, monetary compensation. The uncompensated time for dissemination can impose added responsibility they may not be willing to take on.

There are no clear cut solutions. The short-term answer is since broadcasting information gleaned from the study is a central tenet of CBPR, both community and research partners will likely need to commit to uncompensated time for this important element. The long-term answer is to educate funders of CBPR that the project does not end at the conclusion of the research phase, and that funding support needs to extend to all elements of CBPR.

NOTES

Sustainability of CBPR

Sustaining a CBPR partnership provides the opportunity to continue the benefits of having a network of partners with multi-faceted and broad expertise. The CEAL-UNC Collaborative partnership initially formed to work on the medication administration research project with no plans to sustain the partnership beyond the project. Once the partners began to consider the policy implications and dissemination plans, the idea to continue the partnership began to emerge. The relationships that had evolved over the two-year project were valued; the partners realized the benefits of continuing the partnership despite not having another project lined up. While the "sustainability" element is one of the guiding principles of CBPR, its true value was not realized by the neophyte CBPR Collaborative partners until the end of the project.

The CEAL-UNC partners decided to sustain its partnership and continue to hold quarterly conference calls. Conference calls were extensively and effectively used throughout the research phase of the project, and thus were a comfortable mechanism for continuing to maintain communication.

Both the CEAL community and UNC research partners felt that the project successfully accomplished more using CBPR than conventional means of research and unequivocally found the whole experience positive and educational. The partners' diverse expertise representing many disciplines better shaped and informed the project design, conduct, and data analysis.

There are many positive features of employing CBPR. In fairness, however, there are some challenges that impact on sustainability, the most notable being the increased time commitment required. The alternate side of having such wide and diverse partner expertise and input is the time required for partner discussions to explore, analyze, and synthesize data and other project related information. The CEAL-UNC Collaborative partners felt the extra time commitment was worth the effort because of the outcomes.

NOTES

Besides increased discussion time, another time intensive aspect over traditional research involved data analysis. During the data analysis stage, the statistician created information charts and accompanying text for each analysis session to help community members, unaccustomed to working with and translating data, contribute to discussions. This time consuming step is not typically needed in conventional research as researchers would have worked directly off their analytic printouts.

Another challenge to achieving sustainability is the potential to lose partners through job attrition and/or shifting job demands. Not only is institutional knowledge lost whenever an individual leaves a partnership, but the whole partnership relationship dynamic can be impacted depending on how key the individual was both formally and informally to the partnership.

There are many ongoing ways CBPR partners can continue to tap into one another's expertise and experience beyond the research project. Using the CEAL-UNC Collaborative partnership as an example, the following outlines a few symbiotic benefits of continuing to sustain the partnership:

- All partners can discuss other areas for potential research in assisted living where there are gaps in evidence-based knowledge;

- Community partners can review the researcher's draft articles to ensure the material appropriately addresses the cultural and operational norms of assisted living;

- Research partners can review the community partners' draft project articles for trade magazines to ensure the study details are accurately expressed; and

- Various partners can team together to conduct presentations both about the study findings and using CBPR methodology.

NOTES

Selection of CBPR Methodology

CBPR methodology is more appropriate for some studies than others. It is especially beneficial when exploring new areas and topics of study. Integrating the community members of a new area or topic being studied helps to ensure that the research being conducted is on target and of importance. Community members can shed light about topics including the cultural context that are often not yet available in the literature. There is little published research about medication administration in assisted living, thus CBPR was a desirable research method to use for the CEAL-UNC Collaborative's project.

One key criterion as to whether to use CBPR methods relates to whether the research intends to change policy and practice. If it does, then it is beneficial that it be conducted in partnership with the community who knows best about its policies and practices, and will be the ones to put changes into effect once they are found to be important.

Project Impact

It is too soon to judge the CEAL-UNC project's overall impact as affecting policy and practices takes time and this manual is being published shortly after the conclusion of the research phase of the project. While policy implications have been identified, the advocacy footwork that will change practices has yet to begin. Similarly, while plans for submission of peer-review journal articles and for assisted living trade publications articles are underway, nothing has been published to date. Still, based solely on the richness of the relationships that evolved out of the CEAL-UNC Collaborative, the project was a roaring success.

A potential barrier for sustainability and dissemination is that project funding generally does not include financial support for these efforts. Therefore, both the community and research partners are challenged to

NOTES

either find alternate funding sources or be able to self-support these efforts. It might be tempting to simply forego these efforts because of the financial challenge. However, disseminating the project's findings is a core element of the CBPR commitment to share knowledge and information with the broader community of the topic studied and thus should not be dismissed. It could be argued that all CBPR project funding should provide sufficient funds to cover all CBPR core elements.

Key Chapter Considerations

Sustainability is one of the guiding principles that CBPR partners must take into consideration. Whether to continue a CBPR partnership beyond the life of the project is a matter that each partnership needs to decide. Sustaining the partnership provides opportunities to continue benefits leveraged through the diverse array of partner knowledge, expertise and resources.

While the increased time commitment required of CBPR partners is a significant challenge, the CEAL-UNC Collaborative partners felt the extra time commitment was well worth the effort.

CBPR is appropriate when the project to be conducted aims to explore and affect policies and practices that will affect a community.

Disseminating findings from a CBPR project is important both to broadcast the study results and to spread knowledge about using CBPR.

A potential barrier for sustainability and dissemination is that project funding typically does not include financial support for these efforts.

NOTES

References

Abbott, K., and Duncan, S. (January 1993). Participatory research. Canadian Nurse, pp. 25-27.

AHRQ-Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. (2001) Conference on community-based participatory research: november 27-28, 2001. Sponsored in collaboration with the W.K. Kellogg Foundation, the Office of Minority Health, U.S. Department of Health and Human Services, and the Office of Behavioral and Social Sciences Research, National Institutes of Health.

Christopher, S., Watts, V., McCornick, AKHG., Young, S. (2008) Building and maintaining trust in a community-based participatory research partnership. American Journal of Public Health, 98(8):1398-1406.

Dick, J., Clarke, M., Van Zyl, J., and Daniels, K. (2007) Primary health care nurses implement and evaluate a community outreach approach to health care in the south African agricultural sector. International Nursing Review 54(4):383-90.

Felix, H.C. (2007) The rise of the community-based participatory research initiative at the national institute for environmental health sciences: an historical analysis using the policy streams model. Progress in Community Health Partnerships: Research, Education and Action 1(1):31-39.

Flicker, S., Guta, A., Larkin, J., Flynn, S., Fridkin, A., Travers, R., Pole, J.D., and Lavne C. (March 26, 2008). Survey design from the ground up: collaboratively creating the Toronto teen survey. Health Promotion Practice. Online at http://hpp.sagepub.com/cgi/content/abstract/1524839907309868v1.

Gesink, L., Rink, DE., Mulvad, G., and Koch, A. (2008) Sexual health and sexually trans-mitted infections in the north american artic. Emerging Infectious Disease 14(1):4-9.

Green, L.W. (2003) Tracing federal support for participatory research in public health. In Minkler, J., Wallerstein, N. (Eds.) Community Based Participatory Reserch for Health. San Francisco, CA: Jossey-Bass Publishers, 410-418.

Hewitt, G., Draper, A., Ismail, S., and Patternson, S. (2007) Improving food provision in a Guyanese home for the elderly: a participatory approach. Public Health Nutrition, 10(6):552-8.

Israel, B.A., Eng, E., Schulz, A.J., Parker, E.A., eds. (2005) Methods in community-based participatory research for health. San Francisco: Josey-Bass.

Lantz, P.M., Israel, B.A., Schultz, A.J., Reyes, A. (2005) Community-based participatory research: rationale and relevance for social epidemiology. San Francisco: Josey-Bass.

Macaulay, A.C., Nutting, P.A. (2006) Moving the frontiers forward: incorporating community-based participatory research into practice-based research networks. Annals of Family Medicine, 4:4-7.

Melchior-Tellier, S. (1991) Women, water and sanitation. Water International, 16(3):161-168.

Merriam-Webster Online Dictionary, www.merriam-webster.com/dictionary/community.

McAllister, C.L., Green, B.L., Terry, M.A., Herman, V., Mulvey, L. (2003) Parents, practitioners, and researchers: Community-based participatory research with early head start. American Journal of Public Health, 93(10):1672-1679.

Minkler, M., Wallerstein, N., eds. (2003) Community based participatory research for health. San Francisco: Josey-Bass.

Minkler, M., Vazquez, V.B., Tajik, M., Petersen, D. (2006) Promoting environmental justice through community-based participatory research: The role of community and partnership capacity. Health, Education & Behavior, 10:1-19.

Mollica, R., Sims-Kastelein, K., O'Keefe, J. (2008) Residential care and assisted living compendium: 2007. Prepared for the Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary of Planning and Evaluation, U.S. Department of Health and Human Services under Contract #HHS-100-03-0025.

Mosavel, M. Assistant Professor of Medicine, Center for Reducing Health Disparities, MetroHealth Medical Center, Case Western Reserve University, Cleveland, OH. Email correspondence 12.7.2008 (mxm5@po.cwru.edu).

National Center for Assisted Living. (2007) Assisted living state regulatory review: 2007. Washington, DC.

National Institute of Environment Health Sciences (2001) Successful models of community-based participatory research. Final report of a meeting sponsored by the Division of Extramural Research and Training, NIEHS on March 30-31, 2000. Online at www.niehs.nih.vog/dert/programs/translat/htm.

Osrin, D., Mesko, N., Shrestha, B.P., Shrestha, D., Tamang, S., Thapa, S., et al. (2003) Implementing a community-based participatory intervention to improve essential newborn care in rural Nepal. Transactions of the Royal Society of Tropical Medicine and Hygiene 97(1):18-21.

Reid, E. (1993). Inter-Country Consultation. AIDS Health Promotion Exchange 4:9-10.

Sclove, RE. (1997). Research by people, for people. Futures, 29:541-549.

Staggs, S. L. (2008). Intergroup relations in community-based participatory research. Unpublished doctoral dissertation, University of Illinois at Chicago, Chicago, IL.

Tervalon, M., Murray-Garcia, J. (1998). Cultural humility vs. cultural competence: a critical distinction in defining physician training outcomes in medical education. Journal of Health Care for the Poor and Underserved, 9(2):117-125.

Themba, MN., Delgado, G., Vribe, J., and Calpotura, R. (2000). Grassroots innovative policy program. Oakland, CA: Applied Research Center.

U.S. General Accounting (currently Accountability) Office, Report to congressional requesters (1999). Assisted living: quality-of-care and consumer protection issues in four states. GAO/HEHS-99-27.

Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K.N., Griffih, D., Rhodes, S., Samuel-Hodge, C., Maty, S., Lux, L., Webb, L., Sutton, S.F., Swinson, T., Jackman, A., Whitener, L. (2004). Community-based participatory research: assessing the evidence. Evidence Report/Technology Assessment No. 99 (Prepared by RTI-University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication 04-E022-2. Rockville, MD: Agency for Healthcare Research and Quality.

Westfall, J.M., VanVorst, R.F., Main, D.S., Herbert, C. (2006). Community-based participatory research in practice-based research networks. Annals of Family Medicine, 4:8-14.

Attachments

CEAL Partners	Representing	Domains of Expertise
Jane Tilly, DrPH, Co-PI	Alzheimer's Association	Dementia, long-term services and supports, public policy, research
Jan Brickley, RPh	North Carolina Div. of Health Service Regulation	Pharmacy, AL medication management, NC state regulation
Kathy Cameron, RPh., MPH	Consumer Consortium on Assisted Living	Pharmacy, AL consumer and disability advocate
Tom Clark, RPh, MHS	American Society of Consultant Pharmacists	Pharmacy, public policy
Sandi Flores, RN	American Assisted Living Nurses Association	Nursing, AL medication management
Pat Giorgio	Owner/administrator – Evergreen Estates	AL operations including medication management
Dan Haimowitz, MD	Pennsylvania Medical Directors Association	Geriatrician, serves clients in AL, public policy
Ethel Mitty, EdD, RN	Hartford Institute for Geriatric Nursing - NYU	Nursing, medication management, research
Karen Love	Center for Excellence in Assisted Living	AL operations, public policy, collaboratives
Jackie Pinkowitz	Assisted living consumer	AL consumer and advocate
Paul Williams	Assisted Living Federation of America	AL operations, public policy
Rebecca Youngblut	Medication aide – Evergreen Estates	AL operations including medication management

UNC Partners	Representing	Domains of Expertise
Sheryl Zimmerman, PhD, PI	UNC-CH	Long-term care research, research methods
Paula Carder, PhD	UNC-CH	Qualitative research methods, assisted living
Lauren Cohen, MA	UNC-CH	Project management
Jena Ivey, PharmD (as of 4/08)	UNC-CH	Geriatric clinical pharmacist, quality medication use research
David Reed, PhD (4/08 -)	UNC-CH	Statistics and data analysis
Philip Sloane, MD	UNC-CH	Geriatric medicine, long-term care research
Christianna Williams, PhD (9/06 – 3/08)	UNC-CH	Epidemiology, statistics, data analysis

CEAL-UNC Collaborative Advisors.

Geni Eng, PhD	University of North Carolina-Chapel Hill
Lynn Spragens, MBA	Spragens & Associates, LLC
Susan Reinhard, PhD, RN	Public Policy Institute-AARP

CEAL is a non-profit collaborative of eleven national organizations [see list below]. Each organization has one representative that comprises the 11-member volunteer Board of Directors. The organizations represent a unique balance of key stakeholders in assisted living including: four consumer advocacy organizations; four assisted living provider organizations; an organization focused on promoting the availability of affordable assisted living; a national assisted living nurse's association; and an organization focused on championing quality for aging services.

CEAL, incorporated in 2004, promotes high-quality assisted living, serves as a convener to bring together diverse stakeholders to discuss and examine issues related to assisted living as well as to help bridge research, practice and policies that foster quality and affordability, and maintains an objective national clearinghouse of information and resources about assisted living. CEAL's Web site is www.theceal.org.

An important part of CEAL is its Advisory Council. The CEAL Advisory Council was formed in 2005 to regularly bring together the wider assisted living stakeholder community to discuss and examine current topics from diverse perspectives and to facilitate the exchange of ideas and information. The volunteer Advisory Council meets four times each year in Washington, DC.

CEAL Board Member Organizations and Representatives

Organization	Representative
AARP	Don Redfoot, PhD
Alzheimer's Association	Jane Tilly, Dr.PH
American Association of Assisted Living Nurses	Sandi Flores, RN
American Association of Homes and Services for the Aging	Steve Maag
American Seniors Housing Association	Rachelle Bernstecker
Assisted Living Federation of America	Maribeth Bersani
Consumer Consortium on Assisted Living	Kathy Cameron
National Center for Assisted Living	Dave Kyllo
NCB – Capital Impact	Robert Jenkens
Paralyzed Veterans of America	Fred Cowell
Pioneer Network	Cathy Lieblich

About the University of North Carolina at Chapel Hill (UNC)

The University of North Carolina team that participated in this work is housed in the Cecil G. Sheps Center for Health Services Research. The assisted living research they conduct is done under the auspices of the Collaborative Studies of Long-Term Care (CS-LTC), a program of research on the quality of life, quality of death, and quality of care in residential care/assisted living communities, nursing homes, and other settings that provide long-term care. To date, more than 41 projects have been conducted under the auspices of the CS-LTC, which includes almost 700 settings in 14 states and data from more than 6000 residents and the family and staff who provide their care.

Dear [enter name of partner]:

Thank you for your interest in serving as a partner in the CEAL-UNC Community-Based Participatory Research (CBPR) Collaborative (Collaborative) on Medication Management in Assisted Living. The efforts of the Collaborative formally begin September 2006 and end August 2008, although it is expected that some work may continue after that time.

The UNC research team and CEAL project management team have been funded by the U.S. Agency for Healthcare Research and Quality to conduct this Collaborative. All reasonable and realistic travel expenses for Collaborative partners to participate in project meetings will be covered, however there is no remuneration for partner time.

Collaborative partner's roles and responsibilities:

- Partners commit to learning and following the CBPR's principles and partner elements
- Partners will read Chapters 1 and 2 of the CEAL-UNC Collaborative Manual as soon as possible.
- Partners will read the grant proposal for the CEAL-UNC Collaborative project as soon as possible.
- Partners commit to share relevant information they are aware of and their expertise for the project.
- Partners commit to be an active participant in the project (which generally means being an active participation on one or more Workgroups).
- Partners commit to participate in quarterly CEAL-UNC Collaborative partner meetings.
- Partners commit to completing UNC's Human Subjects Training as soon as possible.

And, of special importance for project integrity and success:

- Partners commit to hold confidential all of the CEAL-UNC Collaborative materials and field study specific information. General information about the project such as what the project is about may be shared openly.
- Partners commit to helping disseminate the project findings and to support initial next phase efforts.

I understand and agree to the above referenced roles and responsibilities outlined for the CEAL-UNC CBPR Collaborative partners.

_____   _____

Name and Organization   Date

We look forward to the opportunity to work together on the CEAL-UNC CBPR Collaborative. If you have any questions, please do not hesitate to contact one of us.

_____   _____

Sheryl Zimmerman, PhD   Jane Tilly, Dr.PH
Project Investigator   Co-Investigator
University of North Carolina   Chair, CEAL Research Committee

ATTACHMENT IV. Sample of literature on CBPR.

Aguirre-Molina, M. and D.M. Gorman. (1996). "Community-Based Approaches for the Prevention of Alcohol, Tobacco, and Other Drug Use." Annual Review of Public Health 17:337-58.

Ahmed S.M., B. Beck, C.A. Maurana, G. Newton. (2004). "Overcoming Barriers to Effective Community-Based Participatory Research in US Medical Schools." Education for Health 17(2):141-151.

Altman, D.G. (1995). "Sustaining Interventions in Community Systems: On the Relationship Between Researchers and Communities." Health Psychology. 14(6):526-536.

Ammerman, A., G. Corbie-Smith, D.M.M. St. George, C. Washington, B. Weathers, and B. Jackson-Christian. (2003). "Research Expectations Among African American Church Leaders in the PRAISE! Project: A Randomized Trial Guided by Community-Based Participatory Research." American Journal of Public Health 93:1720-1727.

Baker, E.A., S. Homan, R. Schonhoff, and M. Kreuter. (1999). "Principles of Practice for Academic/Practice/Community Research Partnerships" American Journal of Preventive Medicine 16(3 Suppl):86-93.

Baker, E. A., M. Kreuter, S.M. Homan, S. Starkloff-Morgan, R. Schonhoff, and A. Francioni. (2002). "Using Community-Based Participatory Processes to Bring Health Education Technology to Communities." Health Promotion Practice 3:83-94

Ball, J. and P. Janyst. (2008). "Enacting Research Ethics in Partnerships with Indigenous Communities in Canada: 'Do it in a Good Way.'" Journal of Empirical Research on Human Research Ethics 3(2):33-51.

Brown E.R., S. Holtby,E. Zahnd, G.B. Abbott. (2005). "Community-Based Participatory Research in the California Health Interview Survey." Preventing Chronic Disease [serial online] Available from: URL: http://www.cdc.gov/pcd/issues/2005/oct/05_0046.htm.

Casapia, M., S.A. Joseph, and T.W. Gvorkos. (2007). "Multidisciplinary and Participatory Workshops with Stakeholders in a Community of Extreme Poverty in the Peruvian Amazon: Development of Priority Concerns and Potential Health, Nutrition and Education Interventions." International Journal for Equity in Health 6:6.

Chávez, V., B. Israel, A.J. Allen, III, M.F. DeCarlo, R. Lichtenstein, A. Schulz, I.S. Bayer, and R. McGranaghan. (2004). "A Bridge Between Communities: Video-Making Using Principles of Community-Based Participatory Research." Health Promotion Practice 5:395-403.

Chigudu, H. (2007). "Deepening Our Understanding of Community-Based Participatory Research: Lessons From Work Around Reproductive Rights in Zimbabwe. Gender & Development 15(2):259-270.

Christopher, S., A.L. Gidley, B. Letiecq, A. Smith, and A. Knows His Gun McCormick. (2007). "A Cervical Cancer Community-Based Participatory Research Project in a Native American Community." Health Education and Behavior 0:1090198107309457v.1

Citrin, T. (2001). "Enhancing Public Health Research and Learning through Community-Academic Partnerships: The Michigan Experience." Public Health Reports 116(1):74-78.

Clark, N.M. (1999). "Community/Practice/Academic Partnerships in Public Health." American Journal of Preventive Medicine 16(3 Suppl):18-19.

Cristancho, S., D.M. Garces, K.E. Peters, and B.C. Mueller. (2008). "Listening to Rural Hispanic Immigrants in the Midwest: A Community-Based Participatory Assessment of Major Barriers to Health Care Access and Use." Qualitative Health Research 18:633-646.

DeBlasis, A.L. (2006). "From Revolution to Evolution: Making the Transition from Community Service Learning to Community-Based Research." International Journal of Teaching and Learning in Higher Education 18(1):36-42.

Eisinger, A. and K. Senturia. (2001). "Doing Community-Driven Research: A Description of Seattle Partners for Healthy Communities." Journal of Urban Health 78(3):519-534.

Felix-Aaron, K. and D. Stryer. (2003) "Moving from Rhetoric to Evidence-Based Action in Health Care." Journal of General Internal Medicine." Journal of General Internal Medicine 8(7):589-591.

Flicker, S. (2008). "Who Benefits From Community-Based Participatory Research? A Case Study of the Positive Youth Project." Health Education and Behavior 35(1):70-86.

Flicker, S., R. Travers, A. Guta, S. McDonald, and A. Meagher. (2007). "Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards." Journal of Urban Health 84(4):478-493.

Freudenberg, N. (2001). "Case History of the Center for Urban Epidemiologic Studies in New York City." Journal of Urban Health 78:508-518.

Green, L.W., M.A. George, M. Daniel, et al. (1997). "Background on Participatory Research." In: D. Murphy, M. Scammel, R. Sclove (Eds.), Doing Community-Based Research: A Reader (pp. 53-66). Amherst, MA: Loka Institute.

ATTACHMENT IV continued

Grinstead, O.A., B. Zack, and B. Faigeles. (1999). "Collaborative Research to Prevent HIV among Male Prison Inmates and Their Female Partners." Health Education and Behavior 26(2):225-238.

Harper, G.W., and L.J. Carver. (1999). "'Out-Of-The-Mainstream' Youth as Partners in Collaborative Research: Exploring The Benefits and Challenges." Health Education and Behavior 26(2):250-265.

Higgins, D.L., B. Maciak, M. Metzler. (2001). "CDC Urban Research Centers: Community-Based Participatory Research to Improve the Health of Urban Communities." Journal of Women's Health and Gender-Based Medicine 10(10:9-15.

Higgins, D.L. and M. Metzler. (2001). "Implementing Community-Based Participatory Research Centers in Diverse Urban Settings." Journal of Urban Health 78(3):488-94.

Horn, K., L. McCracken, G. Dino, and M. Brayboy. (2008). "Applying Community-Based Participatory Research Principles to the Development of a Smoking-Cessation Program for American Indian Teens: 'Telling Our Story.'" Health Education and Behavior 35:44-69.

Israel, B.A., R. Lichtenstein, P.M. Lantz, R. McGranaghan, A. Allen, J.R. Guzman, et al. (2001). "The Detroit Community-Academic Urban Research Center: Development, Implementation and Evaluation." Journal of Public Health Management and Practice 7(5):1-19.

Israel B.A., A.J. Schulz, E. Parker, A.B. Becker. (2001). "Community-Based Participatory Research: Policy Recommendations for Promoting a Partnership Approach in Health Research." Education for Health 14(2):182-197.

Israel, B.A., A.J. Schulz, E.A. Parker, and A.B. Becker. (1998). "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health." Annual Review of Public Health 19:173-202.

Jason, L.A., C.B. Key, Y. Suarez-Balcazar, R.R. Taylor, and M.I. Davis (Eds). (2004). Participatory Community Research: Theories and Methods in Action. Washington, DC: American Psychological Association.

Jordan, C., P. Lee, and E. Shapiro. (2000). "Measuring Developmental Outcomes of Lead Exposure in an Urban Neighborhood: The Challenges of Community-Based Research." Journal of Exposure Analysis and Environmental Epidemiology 10-6 Pt 2):732-742.

Kelly, J.A., T.G. Heckman, L.Y. Stevenson, P.N. Williams, T. Ertl, R.B. Hays, N.R. Leonard, L. O'Donnell, M.A. Terry, E.D. Sogolow, and M.S. Neumann. (2000). "Transfer of Research-Based HIV Prevention Interventions to Community Service Providers: Fidelity and Adaptation." AIDS Education and Prevention 12(5 Suppl):87-98.

Krieger, J., C. Allen, A. Cheadle, S. Ciske, J.K. Schier, K. Senturia, and M. Sullivan. (2002). "Using Community-Based Participatory Research to Address Social Determinants of Health: Lessons Learned from Seattle Partners for Healthy Communities." Health Education and Behavior 29:361-382.

Lantz, P.M., E. Viruell-Fuentes, B.A. Israel, D. Softley, and J.R. Guzman. (2001). "Can Communities and Academia Work Together on Public Health Research? Evaluation Results From a Community-Based Participatory Research Partnership in Detroit." Journal of Urban Health 78(3):495-507.

Lasker, R.D. and E.S. Weiss. (2003). "Broadening Participation in Community Problem Solving: A Multidisciplinary Model to Support Collaborative Practice and Research." Journal of Urban Health 80(1):14-60.

Leadbeater, B., E. Banister, C. Benoit, M. Jansson, A. Marshall, and T. Riecken, eds. (2006). Ethical Issues in Community-Based Research with Children and Youth. Toronto: University of Toronto Press.

Leung, M.W., I.H. Yen, and M. Minkler. (2004). "Community-Based Participatory Research: A Projising Approach for Increasing Epidemiology's Relevance in the 21st Century." International Journal of Epidemiology 33(3):499-506.

Malone, R.E., V.B. Yerger, C. McGruder, and E. Froelicher. (2006). "'It's Like Tuskegee in Reverse': A Case Study of Ethical Tensions in Institutional Review Board Review of Community-Based Participatory Research." American Journal of Public Health 96:1914-1919.

McAllister, C.L., B.L. Green, M.A. Terry, V. Herman, and L. Mulvey. (2003). "Parents, Practitioners, and Researchers: Community-Based Participatory Research with Early Head Start." American Journal of Public Health 93:1672-1679.

McCauley, L.A., M.R. Lasarev, G. Higgins, et al. (2001). "Work Characteristics and Pesticide Exposures Among Migrant Agricultural Families: A Community-Based Research Approach." Environmental Health Perspectives 109(5):533-8.

Metzler, M.M., D.L. Higgins, C.G. Beeker, N. Freudenberg, P.M. Lantz, K.D. Senturia, A.A. Eisinger, E.A. Viruell-Fuentes, et al. (2003). "Addressing Urban Health in Detroit, New York City, and Seattle Through Community-Based Participatory Research Partnerships." American Journal of Public Health 93(5):803-11.

Minkler, M. (2004). "Ethical Challenges for the 'Outside' Researchers in Community-Based Participatory Research." Health Education and Behavior 31(6):684-697.

Minkler, M. (2000). "Using Participatory Action Research to Build Healthy Communities. Public Health Reports 115:191-198.

Minkler, M., A.G. Blackwell, M. Thompson, and H. Tamir. (2003). "Community-Based Participatory Research: Implications for Public Health Funding." American Journal of Public Health 93(8):1210-3.

Minkler, M., V.B. Vásquez, M. Tajik, and D. Petersen. (2008). "Promoting Environmental Justice Through Community-Based Participatory Research: The Role of Community and Partnership Capacity." Health Education and Behavior 35:119-137.

Noe, T.D., S.M. Manson, C. Croy, H. McGough, J.A. Henderson, and D.S. Buchwald. (2007). "The Influence of Community-Based Participatory Research Principles on the Likelihood of Participation in Health Research in American Indian Communities." Ethnicity & Disease 17(1, Supp1):S1-3-S1-5.

O'Fallon, L.R. and A. Dearry. (2002). "Community-Based Participatory Research as a Tool to Advance Environmental Health Sciences." Environmental Health Perspectives 110(suppl 2):155-9.

Osrin, D. N. Mesko, B.P. Shrestha, D. Shrestha, S. Tamang, S. Thapa, et al. (2003). "Implementing a Community-Based Participatory Intervention to Improve Essential Newborn Care in Rural Nepal." Transactions of the Royal Society of Tropical Medicine and Hygiene 97(1):18-21.

O'Toole, T., K. Felix-Aaron, M.H. Chin, C. Horowitz, and F. Tyson. (2003). "Community-Based Participatory Research: Opportunities, Challenges and the Need for a Common Language." Journal of General Internal Medicine 8(7):592-594.

Parker, E.A., B.A. Israel, M. Williams, W. Brakefield-Caidwell, T.C. Lewis, T. Robins, E. Ramirez, Z. Rowe, and G. Keller. (2003). "Community Action Against Asthma: Examining the Partnership Process of a Community-Based Participatory Research Project." Journal of General Internal Medicine 18(7):558-567.

Parker, E., L.H. Margolis, E. Eng, and C. Henríquez-Roldán. (2003). "Assessing the Capacity of Health Departments to Engage in Community-Based Participatory Public Health." American Journal of Public Health 93:472-476.

Parker, E.A., B.A. Israel, M. Williams, et al. (2003). "Community Action Against Asthma: Examining the Partnership Process of a Community-Based Participatory Research Project." Journal of General Internal Medicine 18(7):558-67.

ATTACHMENT IV continued

Postma, J. (2008). "Balancing Power Among Academic and Community Partners: The Case of El Proyecto Bienestar." Journal of Empirical Research on Human Research Ethics 3(2):17-32.

Ritas, R. (2003). Speaking Truth, Creating Power: A Guide to Policy Work for Community-Based Participatory Research Practitioners. Seattle: Community-Campus Partnerships for Health.

Schulz, A.J., B.A. Israel, and P.M. Lantz. (2003). "Instrument for Evaluating Dimensions of Group Dynamics Within Community-Based Participatory Research Partnerships." Evaluation and Program Planning 26(3):249-262.

Schulz, A.J., B.A. Israel, S.M. Selig, I.S. Bayer, and C.B. Griffin. (1998). "Development and Implementation of Principles for Community-Based Research in Public Health." In: R.H. MacNair (Ed.), Research Strategies for Community Practice (pp. 83-110). New York, NY: Haworth Press.

Schulz, A.J., J. Krieger, and S. Galea. (2002). "Addressing Social Determinants of Health: Community-Based Participatory Approaches to Research and Practice." Health Education and Behavior 29:287-295.

Schulz, A.J., E.A. Parker, B.A. Israel, A. Allen, M. Decarlo, and M. Lockett. (2002). "Addressing Social Determinants of Health Through Community-Based Participatory Research: The East Side Village Health Worker Partnership." Health Education and Behavior 29:326-341.

Silka, L. G.D. Cleghorn, M. Grullón, and T. Tellez. (2008). "Creating Community-Based Participatory Research in a Diverse Community: A Case Study." Journal of Empirical Research on Human Research Ethics 3(2):5-16.

Sloane, D.C., A.L. Diamant, L.B. Lewis, et al. (2003). "Improving the Nutritional Resource Environment for Healthy Living Through Community-Based Participatory Research." Journal of General Internal Medicine 18(7):568-75.

Sullivan, M., A. Kone, K.D. Senturia, N.J. Chrisman, S.J. Ciske, and J.W. Krieger. (2001). "Researcher and Researched-Community Perspectives: Toward Bridging the Gap." Health Education and Behavior 28(2):130-149.

Vásquez, V.B., D. Lanza, S. Hennessey-Lavery, S. Facente, H.A. Halpin, and M. Minkler. (2007). "Addressing Food Security Through Public Policy Action in a Community-Based Participatory Research Partnership." Health Promotion Practice 8:342-349.

ATTACHMENT IV continued

Wallerstein, N.B. and B. Duran. (2006). "Using Community-Based Participatory Research to Address Health Disparities." Health Promotion Practice 7:312-323.

Williams, A., P.A. Selwyn, R. McCorkle, S. Molde, L. Liberti, and D.L. Katz. (2005). "Application of Community-Based Participatory Research Methods to a Study of Complementary Medicine Interventions at End of Life." Complementary Health Practice Review 10:91-104.

Williams, K.J., P.G. Bray, C.K. Shapiro-Mendoza, I. Reisz, and J. Peranteau. (2007). "Modeling the Principles of Community-Based Participatory Research in a Community Health Assessment Conducted by a Health Foundation." Health Promotion Practice 0:1524839906294419v1.

- Centers for Disease Control and Prevention — Prevention Research Centers (PRCs): The PRCs are a network of academic researchers, community members, and public health agencies that conducts applied research in disease prevention and control in their local communities. Sponsored by the Centers for Disease Control, PRCs have been established at 33 cities across the U.S. Funding for the development of this curriculum came from the PRC Program through a cooperative agreement between the CDC and the Association of Schools of Public Health. Examples in this curriculum are drawn from the Flint PRC and the Yale-Griffin PRC. www.cdc.gov/prc

- Community Tool Box. A product of the Work Group on Health Promotion and Community Development at the University of Kansas, the Community Tool Box contains an extensive collection of practical resources to support community health and community-based research, including information on leadership, strategic planning, community assessment, grant writing, and evaluation. http://ctb.ku.edu

- Community-Campus Partnerships for Health is a nonprofit organization that promotes health (broadly defined) through partnerships between communities and higher educational institutions. CCPH is a growing network of over 1,000 communities and campuses throughout the United States and increasingly the world that are collaborating to promote health through service-learning, community-based participatory research, broad-based coalitions and other partnership strategies. These partnerships are powerful tools for improving health professional education, civic engagement and the overall health of communities. CCPH advances its mission through information dissemination, training and technical assistance, research and evaluation, policy development and advocacy, membership development and coalition building. www.ccph.info

- The Community-Campus Partnerships for Health CBPR Resources Webpage includes CBPR definitions, tools, resources, course syllabi and web links. http://depts.washington.edu/ccph/commbas.html

- The Community Health Scholars Program is a post-doctoral fellowship program in CBPR in public health. The program is offered at three Schools of Public Health: The University of Michigan, the University of North Carolina-Chapel Hill and Johns Hopkins University. www.sph.umich.edu/chsp/

- The Community-Campus Partnerships for Health Consultancy Network helps community-campus partnerships to realize their full potential through presentations, workshops, and consultation. Consultants are "real life" practitioners with experience and expertise in service-learning, community-based participatory research and other pertinent content areas. http://depts.washington.edu/ccph/mentor.html

- The Federal Interagency Working Group on CBPR works to strengthen communication among federal agencies with an interest in supporting CBPR. www.niehs.nih.gov/translat/IWG/iwghome.htm

- Harlem Community Academic Partnership (HCAP) is committed to identifying social determinants of health and implementing community-based interventions to improve the health and well being of urban residents using a community-based participatory research approach. The geographical communities of focus are East and Central Harlem, areas where a substantial proportion of the residents are poor people of color. The HCAP is comprised of community based organizations, partners from academia, the health department, and the Center for Urban Epidemiologic Studies at the New York Academy of Medicine. www.nyam.org/initiatives/cues-research.shtml

- HIV/AIDS Community-Based Research Network is a network of community-based researchers on HIV/AIDS. The Network's website provides access to a library of community-based research posted by members. www.hiv-cbr.net

- Institute for Community Research (ICR) conducts research in collaboration with community partners to promote justice and equity. ICR publishes ICR-Abstracts, an electronic compilation of abstracts of recently published CBPR articles and reports. www.incommunityresearch.org

- Institutional Review Boards — A series of conference call was jointly sponsored by CCPH and the Tuskegee University National Center for Bioethics in Research and Health Care (the Bioethics Center) during January-June 2007. The call series sought to increase understanding of the role of IRBs and other mechanisms for assuring that human subjects research is ethical and appropriate - both at individual and community levels. Information from the call series can be accessed at http://depts.washington.edu/ccph.irbcalls2.html

- Living Knowledge: The International Science Shop Network enables science shops in Europe and beyond to share expertise and know-how with the aim of improving citizen access to scientific knowledge. The Network sponsors an annual conference, listserv, journal, and newsletter. www.livingknowledge.org

- Memos of Understanding — a sample selection of CBPR Memos of Understanding can be viewed on-line at https://depts.washington.edu/ccph/commbas.html#MOU

- National Community Committee of the CDC Prevention Research Centers Program is a national network of community representatives engaged in equitable partnerships with researchers to define local health priorities, drive prevention research agendas, and develop solutions to improve the overall health and quality of life of all communities. www.hpdp.unc.edu/ncc/

- PARnet aims to create a self-monitored, community-managed knowledge base and gateway to action research resources, connecting practitioners and scholars with each other, the literature, and other educational opportunities. It seeks to reflect the broad spectrum of approaches that characterize the international action research community. It turns to the community itself to define and shape the concept of action research, first and foremost, through the simple act of contribution. www.parnet.org

- Prevention Research Center of Michigan strives to embody excellence in public health research, practice, and policy through long-term partnerships based on trust and equality. The Center conducts community-based prevention research aimed at improving health status and reducing morbidity and mortality among populations experiencing a disproportionate share of poor health outcomes. www.sph.umich.edu/prc/

- Seattle Partners for Healthy Communities: Seattle Partners was established in 1995 as an Urban Research Center funded by the Centers for Disease Control and Prevention. It is a multidisciplinary collaboration of community agencies, community activists, public health professionals, academics, and health providers whose mission is to improve the health of urban, marginalized Seattle communities by conducting community-based collaborative research. www.depts.washington.edu/hprc/SeattlePartners

- The Wellesley Institute is an independent, self-sustaining not-for-profit corporation that is dedicated to building and strengthening communities though assisting coalitions, enhancing capacities and supporting community- and policy-relevant research. www.wellesleyinstitute.com

- Yale-Griffin Prevention Research Center is committed to research pertaining to the primary, secondary, & tertiary prevention of chronic disease that is responsive to the priorities of the Lower Naugatuck Valley residents, the residents of Connecticut's major cities, and other communities throughout the state. The center is dedicated to participatory research methods, to a robust research agenda inclusive of developmental/determinant, intervention, and translational research; to community involvement in public health; to the eradication of disparities in health and health care in the communities served; and to the dissemination of effective interventions in support of the national objectives of Healthy People 2010. www.yalegriffinprc.org

---

[1] Developing & Sustaining CBPR Partnerships: A Skill-Building Curriculum. http://www.cbprcurriculum.info, Appendix A.

- **ANOVA** (an abbreviation for Analysis of Variance) — this is a statistical test that compares the mean (averages) of groups, and determines whether they are significantly different (different enough to not have occurred by chance)

- **Beta or B** — in an analysis that is comparing one variable to another, B describes how much one variable explains another; for example, it can explain to what extent an individual's age relates to his/her likelihood of making a medication error

- **Bivariate analysis** — an analysis to examine the relationship between two variables (such as age and making a medication error)

- **Community-based participatory research (CBPR)** — a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.

- **CBPR advisor** — someone who brings expertise regarding a specific topic or issue to the CBPR project and participates in Workgroup and partner calls and meetings as needed. Advisors do not have a vote in decisions for the project.

- **CBPR community member** — a stakeholder bound by a common commitment and vision for the CBPR project who brings relevant knowledge and expertise about the subject being studied/researched. A community member is not limited by geographic boundaries, and agrees to adhere to CBPR principles for the project. Community members may have different levels of awareness of the details of the project, and their involvement may vary depending on the stage of the project. [Stakeholders for this project include individuals who are involved in some facet of assisted living such as a consumer, owner/operator, administrator and other staff, regulator, policymakers, state and national association representative and others].

- **CBPR partner** — someone who has committed through a Letter of Understanding [see Attachment III] to work collaboratively, adhering to CBPR principles on the project, and who is willing to commit intellect, time, and productive resources to the project as needed. A partner is a member of one or more Workgroups and participates in all partner calls and meetings (to the extent reasonably possible). A partner is able to describe the process and goals of the project, and has a clear sense of his/her role in attaining the project's goals. Each partner has one vote in decisions for the project.

■ **Correlation** — indicates the strength and direction of a relationship between two items; a positive correlation means that the two variables move together in the same direction, and a negative correlation means that as one variable goes in one direction, the other moves in the opposite direction. No correlation means that there is no consistent relationship between the two variables. In general, there is a positive correlation between height and weight (a taller person tends to weigh more), a negative correlation between age and health (older people to be less healthy), and no correlation between length of finger nails and number of teeth.

■ **Data cleaning** — the process of preparing data for analysis that involves activities such as checking questions for logical answers, converting months to years (when appropriate), and assigning "missing" values

■ **Data editing** — the process of preparing data for entry that involves assessing readability of answers, correcting coding mistakes, and performing preliminary data cleaning (when possible)

■ **Dependent or outcome variable** — the variable that is thought to be affected by the independent variable; in this case, medication errors are the dependent variables, and age or amount of experience are independent variables

■ **Descriptive analyses** — a summary of data to 'describe' the study sample and its findings; descriptive data include counts, frequencies, means, standard deviations, modes, medians; cannot be generalized beyond the sample

■ **External policy** — a process or procedure that guides how public entities such as local, state and federal governments operate. Also known as public policy.

■ **Independent or predictor or explanatory variable** — the variable that is thought to influence the dependent variable; in this case, medication errors are the dependent variables, and age or amount of experience are independent variables

■ **Inferential analyses** — statistical analyses that allow one to make inferences or generalizations to the larger population based on a small sample

■ **Internal consistency reliability** — the consistency of results across items within a given measure

- **Internal policy** — a process or procedure that guides how organizations, companies and other group-related units operate.

- **Mean or average** — As one type of average, a mean is a single number that best describes a series of scores. It is obtained by adding the scores and dividing by the number of scores.

- **Median** — the middle number in a series of sequentially ordered numbers. Example: the median of the ages 8, 8, 9, 10, 12, 14, 15 is 10.

- **Mode** — the most represented number in a series of numbers. Example: the mode of the ages 8, 8, 9, 10, 12, 14, 15 is 8.

- **Multivariate analysis** — an analytic method that enables one to examine the relationship between multiple independent and dependent variables

- **N** — This symbol represents the sample size or number of observations

- **P-value** (probability or significance value) — the probability of obtaining a value of the test statistic (such as the difference between the mean scores in two groups) by chance alone (if there is actually no difference between them). In the CEAL-UNC project, there was interest in learning whether the average number of errors made by unlicensed staff differed significantly from the average number made by licensed staff. Whether or not the difference was significant depended on exactly how different the two averages were, in relation to the number of staff being studied and the overall spread of their scores. Generally, p-values $<.05$ (meaning there is less than 5% likelihood of these scores being this different based by chance alone) are considered "significant"; in this case, the conclusion would be that one group did indeed experience more errors than the other.

- **Percent** — a way to express a number as a fraction of 100, to allow easy comparisons across numbers. Example: Five of ten men attended a dance (50%), while six of eight women attended (75%). Women were more likely to attend the dance than men.

- **Reliability** — the stability of a research measure; test-retest reliability measures stability over time and inter-rater reliability measures stability over different interviewers or raters

- **Significance** — there are two primary types of significance: statistical significance and clinical significance.

  Statistical significance refers to whether or not a difference between two groups exists by chance, or is large enough to indicate a real difference; see the definition of p-value for further discussion of this point. In very simple terms, it indicates (for example) whether the difference between four medication errors caused by one type of staff and five medication errors caused by another type of staff is a chance difference (not statistically significantly different) and might not be found in another sample, or whether it is a large enough difference that is likely to be found in other samples (statistically significant).

  Clinical significance refers to whether or not a difference that is detected between two groups is of clinical importance. In the example above, the difference between four and five medication errors might be statistically significant but not clinically significant if the errors were not likely to cause any harm.

- **Standard deviation** — The average spread of numbers around a mean, describing how closely grouped the series of scores are.

  Examples:

  a. The mean of 1, 2, 8, and 9 is 20/4 = 5. The standard deviation is 3.5, which means that on average, the scores differ from the mean by 3.5. If you take the mean (5) and subtract 3.5 (which equals 1.5) and add 3.5 (which equals 8.5), you can see that the spread of 1.5 - 8.5 is a good description of the series of numbers.

  b. The mean of 3, 4, 6, and 7 is 20/4 = 5. The standard deviation is 1.6, which means that on average, the scores differ from the mean by 1.6. If you take the mean (5) and subtract 1.6 (which equals 3.4) and add 1.6 (which equals 6.6), you can see that the spread of 3.4 - 6.6 is a good description of the series of numbers. The numbers in example b are more tightly grouped than those in example a.

- **T-test or Student's T-Test** — a statistical test that measures whether or not two means are different from one another

- **Validity** — the accuracy of a research measure in terms of whether it is measuring what it intends to measure

www.theceal.org
info@theceal.org

Collaborative Studies
of Long-Term Care
University of North Carolina
at Chapel Hill

A NATIONAL COMMUNITY-BASED PARTICIPATORY RESEARCH PARTNERSHIP