Module 6: Research to Practice – Community-engaged Research

Slide 1: Introduction
Hello. My name is Anh Tran. I am an Assistant Professor in the Dept of Community and Family Medicine at Duke University School of Medicine. Today I will be presenting Module 6: Research to Practice. This module is comprised of three sections, and this one covers the topic of Community-engaged Research. This Research to Practice module is one in a series created through funding from the Centers for Disease Control and Prevention and the Association for Prevention, Teaching and Research.

Slide 2: Acknowledgements
APTR wishes to acknowledge the following individuals who developed this module:
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- Duke University School of Medicine
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Slide 3: Presentation Objectives
The objectives of this module are the following:
1. Identify the historical and philosophical basis of community-engaged research (CeR).
2. Describe the principles of CeR.
3. List the differences between a traditional research approach and a CeR approach.
4. Discuss how research can benefit from collaboration between researcher and community.
5. Explain how CeR exists on a continuum.

Community-engaged Research
- CeR represents the opinions of the author(s) and does not necessarily represent the views of the Centers for Disease Control and Prevention or the Association for Prevention Teaching and Research.
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**Slide 4: Community-engaged Research – Overview and Definition**

First, let us provide an overview and definition of CEnR. Community-engaged research is a framework or approach for conducting research, not a methodology. A community-engaged research study may incorporate both qualitative and quantitative methods. This approach encourages recognition of the strengths of community institutions and individuals and encourages people and groups to build on those strengths. What characterizes community-engaged research is not the methods used, but the principles that guide the research and the relationships between researchers and the community. Finally, community-engaged research requires partnership development, cooperation and negotiation, collaboration with community partners and a commitment to addressing local health issues.

**Slide 5: Community-engaged Research – History and Development**

There are different approaches to conducting medical and health research in communities: community-engaged research is one of many. Since the 1980s the fields of public health, medicine, nursing, sociology, anthropology, social work, psychology and others have incorporated the community-engaged approach into research programs. By 2000 the community-engaged approach to research was widely discussed within many disciplines and incorporated into both domestic and international health projects and research programs. For example, some HIV prevention researchers have spent time with a group of sex workers in South Africa to learn the kind of intervention these women could realistically use to protect themselves from contracting HIV. The sex workers collaborated with researchers to develop a peer education program which provided information on protection methods they could use without losing customers and earnings.
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Slide 6: Contributing Theories

Community-engaged research has a rich tradition of theory and practice. A range of disciplines have contributed to its development. Psychologist Kurt Lewin used the term “action research” to describe the iterative process of communities identifying their problems, planning, taking action and then evaluating the results. In the 1970s, adult educators from Latin America and the United States developed “empowerment education,” a process that emphasizes both the equality of teachers and learners and the co-learning process (learning from each other). Empowerment education also incorporated principles of social justice and empowerment for marginalized communities. Furthermore, theories from philosophy, anthropology, community psychology and sociology have contributed to the concept that there are different ways to understand and portray what is being observed, depending on the role and experience of the observer. These philosophical developments inform the belief that researchers and communities may have different views of community health issues and that the “unscientific” knowledge of communities is both valid and valuable. Since the 1980s, some practitioners and researchers have incorporated these theories into community-engaged research.

Slide 7: Difference Between Approaches

In this section, we will discuss how community-engaged research is different from traditional research. We will also elaborate on the elements of community-based participatory research (CBPR) and how CEnR exists on a continuum.
Slide 8: Research “Subjects”

Health researchers have been working in communities for decades. Researchers have traditionally turned to communities to recruit research “subjects” or to conduct a study on a community. Communities, particularly minority and low-income communities felt that they seldom received benefits from this type of research. They expressed anger and frustration that researchers completed their research and left, without sharing their findings or creating a mechanism to continue successful programs. Research topics were selected by researchers without determining whether those topics addressed the perceived needs or concerns of the community, adding to the sense that research was not intended to help communities address problems, but rather was based entirely on the researcher’s idea of expertise.

Slide 9: Common Language for Community Engagement

Researchers and community members can sometimes have different perceptions of what is taking place when they interact with one another. They can come with different agendas, priorities and pre-conceived notions of one another. Thus, it is important to find a common language or point of understanding with one another.

Slide 10: Research Participants

Being the subject of research is different from being a participant in research. With a community-engaged research approach, communities are seen as partners and collaborators and community members are viewed as research participants as opposed to research subjects. Community members who have not worked on the planning of the research or been involved in any way, but who volunteer to enroll in the research, are still called participants rather than subjects. In medical research, subject has been the term used for people enrolled in a study, and this term institutionalized within many Institutional Review Boards. However, with a community-engaged approach the term participant is standard. One reason for using the term “participant” is that many communities, especially minority communities, do not like the term “subject.” Research shows that this word makes people think of being
powerless or feel like guinea pigs in an experiment. Since researchers are forming partnerships with community organizations and working to build trust in the community, it is important to use terms that are appropriate to the setting.

Slide 11: Traditional Research Process

Traditionally health researchers have used a research approach common throughout scientific disciplines. Researchers develop research questions, write proposals, secure funds, conduct the research and analysis and write papers. This slide shows the traditional research process. Community-engaged research builds upon the established steps of traditional research. The difference is the relationship between the community and the researcher and how the community participates throughout the research process. In community-engaged research, researchers and community agencies or groups form a partnership. The strength and intensity of this partnership varies by project and participants. Communities and researchers may collaborate in many different ways, including defining the problem, planning the research, making decisions about elements of intervention implementation, and sharing the presentation of research results.

Slide 12: Community-engaged Research

The term “community-engaged” is broad and includes the full spectrum of approaches that involve the community in the research process. It includes research that incorporates only a few elements of community engagement and minimal collaboration to research in which community organizations and researchers are equal partners throughout the process. The extent of the collaboration, when it occurs in the research process and the relationships among researchers and community organizations may be very different from project to project.
Slide 13: Traditional Research Approach V. Community-engaged Approach

This table illustrates the main differences between a traditional research approach and a community-engaged approach which includes the Community-based Participatory Research (CBPR) approach. Within the community-engaged approach, CBPR appears at the end of the spectrum since it embraces the greatest degree of relationship building, strong community partnership and collaboration throughout the research process. The gradations within community-engaged research shows that it exists on a continuum: from low community engagement (left side in the dark gray) to high community engagement (right side in the light gray). Community-engagement exists on a continuum and there are many possible combinations.

Slide 14: Fundamentals of Working With the Community

The following slides summarize seven fundamental concepts for working with the community. They include detailed information as well as actions which will help outsiders become more familiar with how best to work in a community.

Slide 15: Community-based Participatory Research (CBPR)

The WK Kellogg Foundation has been a leader in the development and funding of the contemporary practice of community-based participatory research (CBPR). Their definition of CBPR is widely used: Community-based participatory research is a "collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. . . . It begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities."

Ultimately, CBPR aims to improve health outcomes and eliminate health disparities.
Slide 16: CBPR Builds Community Capacity

Community capacity is the ability of a community to identify problems and work together to build skills and develop solutions. With CBPR, both community organizations and the research team should be concerned with building the community’s capacity. Decision-making power is shared equally, and research data is disseminated by the researchers and by the community. The CBPR ideal of full partnership, equal control and community participation is an important and worthwhile goal for some projects, but it can be difficult to achieve. Researchers who have such relationships with community organizations have often worked with those organizations for ten years or more. The community-based participatory research (CBPR) model is not appropriate for all research endeavors. A community-engaged approach with more limited community participation may be more effective for many research projects. Whether using a community-engaged approach or implementing full-scale community-based participatory research, to work together effectively all groups involved need to learn about the mission, history, funding resources and constraints of all the partners.

Slide 17: Benefits of Using a Community-engaged Approach

What are the concrete benefits for researchers of using a community-engaged research approach? First, researchers can develop research questions concerning health issues of concern in the community, results are likely to be translatable to similar communities. Secondly, working in partnership with community organizations can help in recruiting participants and in obtaining informed consent. When people understand the process of the research and the results that may affect them, they are more likely to support the research and the researchers.
Slide 18: Benefits of Using a Community-engaged Approach

Third, the reliability and validity of measurement tools can be improved when community members assist in designing and testing study instruments. Community members can help researchers compose questions and design procedures which will be culturally sensitive and also produce accurate and valid measures. Fourth, community involvement in the analysis and interpretation of findings can provide important and culturally sensitive explanations for results. Community members may view the results differently than researchers, and local interpretation may provide ideas researchers had not considered. These are some of the advantages of working with community organizations. A community-engaged approach can enable researchers to gain support from community organizations, improve study instruments, devise culturally sensitive interventions and interpret research results.

Slide 19: Community-engaged Research Exists on a Continuum

The community-engaged research approach does not require that community members or organizations be involved in all aspects of the research project, but the community needs to be involved in some meaningful ways. Researchers and communities may work together during one or two steps of the research process or during many steps. Each partnership will develop ways of working together. The funding source, community history, nature of the problem under study, methods used for the research, the type of community organizations involved and the local political climate will shape the research and the partnership. As partnerships evolve and researchers and community organizations gain experience working together, there may be more opportunities for collaboration.

Slide 20: Studies Which Lend Themselves to Community-engaged Research

In choosing to partner with community stakeholders, you may be able to address more effectively certain types of research questions. First, through epidemiological or descriptive studies, you can explore what particular health characteristics, needs or disparities exist. To study
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evidence based practices, you can examine to what extent evaluated programs or treatment approaches are applied in an actual or different community setting. How do they need to be changed to be effective in community practices or organizations? For evaluation or practice-based evidence investigations, you can study whether community programs meeting are their goals or are they effectively addressing patient and community issues and needs.

Slide 21: Incorporating a Community-engaged Approach into Traditional Research

How does the researcher role different in community-engaged research compared to traditional research? Community-engaged research exists on a broad continuum with great variation in how, when, and to what degree communities become involved. How can projects include some principles of community-engaged research (CEnR)? A previous slide included examples of the role of researchers in traditional research and in community-engaged research (including CBPR).

Slide 22: Steps to Incorporate Community Engagement into Traditional Research

The following section outlines 7 steps (and examples) of how community-engaged research practices can be incorporated into the steps of traditional research projects.
Slide 23: Step 1. Problem Identification

In Step 1, community members may approach researchers with a specific problem on which they want help or researchers may approach a community and propose working with them to research a specific disease or issue. For example, a group of clergy approached a researcher with concerns about how many people in their congregations suffer from diabetes. They asked the researcher if there is anything that could be done to prevent diabetes. Another example is when researchers interested in diabetes prevention identify a section of the city with a high rate of diabetes. Then, they contact community organizations and agencies to determine if there is community interest in participating in a research project on diabetes prevention.

Slide 24: Step 2. Community Selected, Research Plan Developed & Funds Secured

Step 2, may be handled by the researchers: they draft the proposal; develop the research design, and secure the funds. However, in community-engaged research, community organizations may contribute to the proposal draft as co-authors and/or suggest research questions, offer ideas on recruitment, give advice on logistics, suggest other organizations with whom to collaborate and advise on other aspects of the project. For example, researchers work with representatives of two large churches, the county health department and members of a diabetes support group to develop a participant recruitment plan and to tailor the proposed intervention to be appropriate for the selected community. Researchers use this information to develop the proposal and include these organizations as community partners.
Some standard research methods may look very different from the community perspective than they do from the perspective of trained scientists. For example, community organizations and agencies commonly refuse to participate in research that involves control groups who do not receive treatment or intervention. They may view excluding a control group from receiving a potential benefit as unfair to members of that group. Resources are scarce in many communities and research resources can be viewed as a kind of service which should be available to everyone. Secondly, sometimes using a design where the control group receives a delayed intervention or treatment is a compromise that researchers and community organizations can accept. Finally, this community view may also apply to studies that provide different treatments or interventions to groups for comparison and to studies that use random assignment of participants.

To build trust, researchers should first share drafts of the research proposal with community partners or co-author proposal with them. Secondly, researchers should include funding for the work of community partners. Funding the work of participating community organizations is important in order to build trust and establish an atmosphere of fairness. Organizations need to receive payment for their contributions of staff time, space, and other project-related expenses. They need to be paid fairly, rather than with only a token fee. Next, researchers should share information on the project budget. When developing the project budget with community organizations it is not necessary to reveal individual salaries, but overall personnel costs and other project costs should be discussed openly. If possible community organizations should contribute to budget development. One example scenario of building trust is the following: A proposal is funded and researchers work with the Community Advisory Board (CAB) to begin work. The community partners and researchers had already determined an appropriate rent for the space and salary of the employee. All have copies of the final budget. Another example of building trust is when researchers have not worked with community organizations before submitting the proposal, but then they meet with community representatives and give them copies of the grant. The community representatives then decide if their community will want to participate in the study. Researchers and community representatives work together to develop plans to hire staff from the community at appropriate salary levels.
Slide 27: Memorandum of Understanding

Because there is no established protocol for obtaining community or community organization consent, researchers and community organizations and agencies have looked for other means to address these issues. The Memorandum of Understanding (MOU) can help researchers and community organizations think through some ethical issues. A MOU does not need to cover explicitly ethical concerns, but it can specify how researchers and communities will work together and determine how decisions will be made.

Slide 28: Institutional Review Board (IRB) Approval

If the project involves research then it must be submitted to the Institutional Review Board (IRB) for approval, like any other research project involving human participants. CEnR projects are governed by the same ethical standards and regulations. In 1979, the Belmont Report was developed in response to the discovery of research abuses. Scientists, ethicists, funders, the Federal Government and others concerned with research realized the need for agreed upon fundamental ethical principles guiding research with humans. The Belmont Report established the ethical principles of respect for persons, beneficence and justice as the core values that should guide how researchers conduct research. They are the foundation for human research protections and for the development of regulations that apply to community-engaged research as well as to traditional biomedical research. When community partners work with study participants, or have access to study data, they will need to receive ethics training that is accepted by the institution’s IRB. IRBs differ by institution and some are familiar with CEnR while many others are not. Researchers should work closely with IRB leaders to develop a protocol that satisfies the IRB’s rules and regulations. There are articles and materials available on-line that explain how IRBs successfully approve CEnR projects.
Community organizations may also develop standards for research partnerships to establish acceptable practices and procedures. Examples of community partners with separate research approval processes include the following: First, organizations for members of ethnic or language groups. El Centro Hispano is a community-based organization in North Carolina which develops and provides services to and represents the Latino community. They require researchers to submit proposals to the El Centro Board of Directors and receive approval before the organization will work with them. Secondly, Native American Tribal Organizations. The Akwesasne Mohawk Nation in northern New York state established a Research Advisory Council (RAC) in 1995 to review and comment on research proposals. They developed standards for research protocols with requirements to help researchers collaborate with the Native American community. Third, county health departments. Many county health departments require that all research proposals which involve them as partners be approved by their Board of Health before the proposals are submitted to funders. Fourth, school boards and school administrators generally have a stringent review process for research done in the school.

It is common in community-engaged research practice to involve community members as project staff in the office, in the field, or as advisors whenever possible. The research can be strengthened by involving community members. Their presence can help with recruitment and retention of study participants, and secure community support, which will help the research endeavor. Sometimes it is not possible to involve community members directly with the study. In this case researchers may develop other ways to promote community involvement. One example is when researchers and Community Advisory Board (CAB) members hire project staff from the surrounding community.
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**Slide 31: Step 4. Develop and Implement Intervention or Data Collection Process**

In step 4, community organizations can help tailor the intervention, and data collection process, advise when problems arise, promote the study and collect community responses. For example, researchers, CAB staff and others work closely to fine tune their intervention. The CAB and office staff organize community meetings so that residents can ask questions about the project and make suggestions. When the intervention is launched community staff and the CAB use their own social networks to recruit participants to the study. In another example, two months into the implementation of the intervention, project staff ask whether the intervention could be modified in order to be more appropriate for the participants. The researchers meet with the CAB and partner agencies to modify the intervention to be more culturally appropriate.

**Slide 32: Step 5. Collect Data**

Community members can be hired to administer questionnaires, log participation, read measurement devices or make observations. One study example is where one of the measures the researchers use for diabetes prevention is weight loss. Community staff are trained to weigh participants and enter the data. A registered nurse in the community is hired part-time to take other measurements which require more training. In a second example, all of the measures needed for the research must be taken by an experienced registered nurse (RN). Although there are several RNs in the community, they are all employed and not interested in leaving their current jobs. Researchers include community representatives in the interview process and hire an RN who has no history in that community, but has worked with similar groups.

**Slide 33: Step 6. Analyze Data**

Step 6, is generally done by researchers. That said, if the community office staff are familiar with the data, they can assist in activities such as data cleaning, which is a process of checking that data is correctly identified, complete and ready for analysis.
In step 7, traditionally, researchers report study results by publishing papers in academic journals. With a community-engaged approach, dissemination of results to the community may take different forms. Community organizations and leaders are often more interested in how many people participated and benefited than in academic study results. Community groups are also more likely to want a radio program, newspaper article, public meeting or other event to present the information they think will interest community members. Depending on the sensitivity of the topic, the CAB may want the data presented publicly in a manner that will help community members understand the results and avoid potential embarrassment. Researchers should note that some medical journals, such as the New England Journal of Medicine and Journal of the American Medical Association, will not publish articles whose findings have previously been published in the newspaper, released on TV or in other popular media, unless the journal, after accepting the article, had agreed to release the information to the press.

Remember that the sense of timing in community settings may be different from that in academia. Community organizations and the public generally expect to hear about results as soon as possible. Waiting for results to appear in an academic journal, which may take years, can be disappointing. Researchers should discuss when and how the findings will be released, including what conclusions can be shared with communities and the press without compromising the researcher’s ability to present findings in academic venues. Some examples of different methods of data dissemination include the following: after the data are collected and analyzed, researchers and the chair of the CAB could discuss preliminary results on local radio stations. Secondly, many researchers do not feel that they can present preliminary results and want to wait until they complete the full analysis. What they can do, in the meanwhile, is to meet with the CAB to find out what the community is most interested in hearing about and develop a presentation that will be interesting to community members, but will contain only trends and preliminary outcomes.
Slide 36: Credit and Collaboration

Community partner organizations should be given credit for their contributions and attend and present at conferences when appropriate. Any press or local meetings on the research should include the voice of community partner organizations. If possible, consider including key community members who are active in the research as co-authors on papers. As an example, in order to disseminate the research results, CAB members develop a program for churches and community groups. They produce display materials to use at festivals and other local events. Researchers accompany them in order to hear community reactions to the research results. Two CAB members join researchers at a scientific meeting to present the community’s views of the research process.

Slide 37: Summary

In summary, CEnR approach encompasses a range of possibilities for research conducted with community partner participation. In CEnR, researchers and community groups or agencies form a partnership, and the intensity of this working relationship varies by project and participants. Nevertheless, the partners are committed to a mutual research vision and can collaborate on the research process in many different ways, such as defining study questions, writing funding proposals, designing the methods, implementing the research project, analyzing the results and disseminating the findings. Secondly, health problems exist within the context of people’s lives and the solutions to such issues will likely be context specific as well. By developing research questions around the health issues most important to the community and by empowering community partners to be involved in the research process, a CEnR approach can enable researchers to incorporate critical insights into their research questions and interpretation of their data. In addition, the results can translate more easily to real world settings and impact community health.
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