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Practicing Community-engaged Research

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In 2006 the National Institutes of Health (NIH) instituted a new emphasis on **translational** research; this is research that focuses on the translation of scientific discoveries into practical applications that improve human health. A **community-engaged** research approach can enable researchers to strengthen the links between research and practice and enhance translational results. Yet in order to practice community-engaged research one needs to re-think the relationship of research and researchers to communities.

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Introduction

The Centers for Disease Control and Prevention (CDC) define community-engagement as:

" the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people."

This module presents an overview of community-engaged research. The Centers for Disease Control and Prevention (CDC) defines **community-engagement** as:

"*the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.*"

CDC/ATSDR Committee on Community Engagement, 1997

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Community-engaged Research

- **A framework or approach for conducting research**

- **May be used with both qualitative and quantitative methods**

- **Recognizes and builds on community strengths**

- **Characterized by principles that guide the research**

- **Requires partnership development**

Overview and Definitions

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.

Community-engaged research requires partnership development, cooperation and negotiation, collaboration with community partners and a commitment to addressing local health issues.

Lasker RD, Weiss ES, 2003; Minkler M. 2005

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Community

A group of people
- **Linked by social ties**
- **Sharing common perspectives or interests**
- **Who may or may not share a geographic location**

But what is a "community"? The term is commonly used but seldom defined. For this module the working definition of community is:

A group of people who are linked by social ties and share common perspectives or interests and may also share a geographic location.

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Community Members have Characteristics in Common:

- **Common culture or ethnic heritage**
- **Where they live**
- **Similar age**
- **Speak the same language**
- **Religion**

Communities are not homogeneous and seldom speak with one voice

Members of a community have some meaningful characteristics in common—usually where they live. However, they might not all live in the same area, or be of the same age, race or religion. Communities are not homogeneous and they seldom speak with one voice. Examples of communities include: senior citizens living in a retirement center; recent Mexican immigrants who have settled in a city; members of a state-wide disability rights group; and religious congregations, some congregations may include members from many different areas.

In this module "community" is used to mean groups outside of academia. Researchers conducting community-engaged research will work with community leaders, community organizations and agencies, and community members. These groups represent different aspects of a community and are likely to have different perspectives.

For example many African American congregations have been deeply divided over providing acceptance and assistance to gay or HIV+ members. In many Latin American communities in the U.S there is great distrust between Latino Catholics and Latinos who have become Protestant, leading to political and social divisions.

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1. Translational Research and the History of Community-engaged Research

2. Differences Between Research Approaches

3. Incorporating a Community-engaged Approach Into Traditional Research

4. Trials, Tribulations and Rewards

This module has 4 sections, each with learner objectives:

Section 1 provides background on NIH's increased emphasis on translational research and an introduction to the history and development of community-engaged research.

Section 2 describes differences between traditional research, a community-engaged approach and Community-based Participatory Research (CBPR).

Section 3 describes how the community-engaged approach to research differs from traditional research and how a community-engaged approach can be incorporated into the traditional research process.

Section 4 identifies some of the challenges and rewards which researchers may face when using a community-engaged approach. These include some of the complexities of partnership and the potential benefits of this approach.

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1. Translational Research and History Of Community-engaged Research

Background on NIH's translational research initiative

Learning Objectives

- **Identify reasons for NIH's increased emphasis on translational research.**

- **Recognize how community-engaged research fits into the NIH translational research initiative.**

In 2000 the leadership of the National Institutes of Health (NIH) confronted some longstanding issues in the conduct and use of biomedical research. Congress was asking why, even though the United States spends more per capita on health care than any other nation, US health outcomes were not better than those of other industrialized nations; instead they were worse.

Furthermore, although the U.S. is a leader in biomedical research, the link between research and clinical practice was weak. Ten to 25 years may elapse between research advances and their integration into clinical practice. Communication between communities and medical researchers was poor or non-existent, which left community concerns and interests out of the research agenda.

Westfall JM, Mold J, Fagnan L. 2007

NIH Roadmap

- **Long term plan**
- **Sets priorities for NIH**
- **Emphasizes strengthening links between research and practice**
- **Encourages improved communication and cooperation between researchers and communities**

In response to these issues and others, NIH developed a new long term plan, part of which included a focus on translational research. This plan, called the Roadmap, sets priorities for NIH. The section on clinical research emphasizes strengthening the links between research and practice and improving communication and cooperation between researchers and communities. This emphasis led to an increased interest in community-engaged research.

NIH Roadmap - http://nihroadmap.nih.gov/

http://copr.nih.gov/reports/public_trust.asp

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History and Development of the Community-engaged Research Approach

Learning Objectives

- Identify the historic roots and philosophical basis of community-engaged research

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,

•HIV prevention researchers 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.

•Beginning in the late 1980s at the Hispanic Health Council in Connecticut anthropologists have used a community-engaged approach to develop programs and services for injection drug users, pregnant women, and teens in the local Spanish speaking community.

Singer M. 1993; Campbell C. 2001

Israel BA, et al 1998

Wallerstein N, Duran B. 2003

Contributing Theories

- **Empowerment education**
  - **Equality and co-learning**
  - **Community problem solving**

- **Theories of different but valid perspectives on what is being observed**
  - **Role & experience of the observer**

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.

For example, since the 1930s the Highlander Center in Tennessee has used empowerment education to help coal miners, civil rights leaders and environmental activists learn how to organize communities and challenge policy.

Theories from philosophy, anthropology, community psychology and sociology contributed 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.

Adams, F. 1975; Morris, AD. 1991

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2. Differences Between Research Approaches

Learning Objectives

- **List the differences between a traditional research approach and a community-engaged approach**

- **Describe elements of community-based participatory research (CBPR)**

- **Explain how community-engaged research exists on a continuum**

How different is community-engaged research from traditional research?

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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 area of expertise.
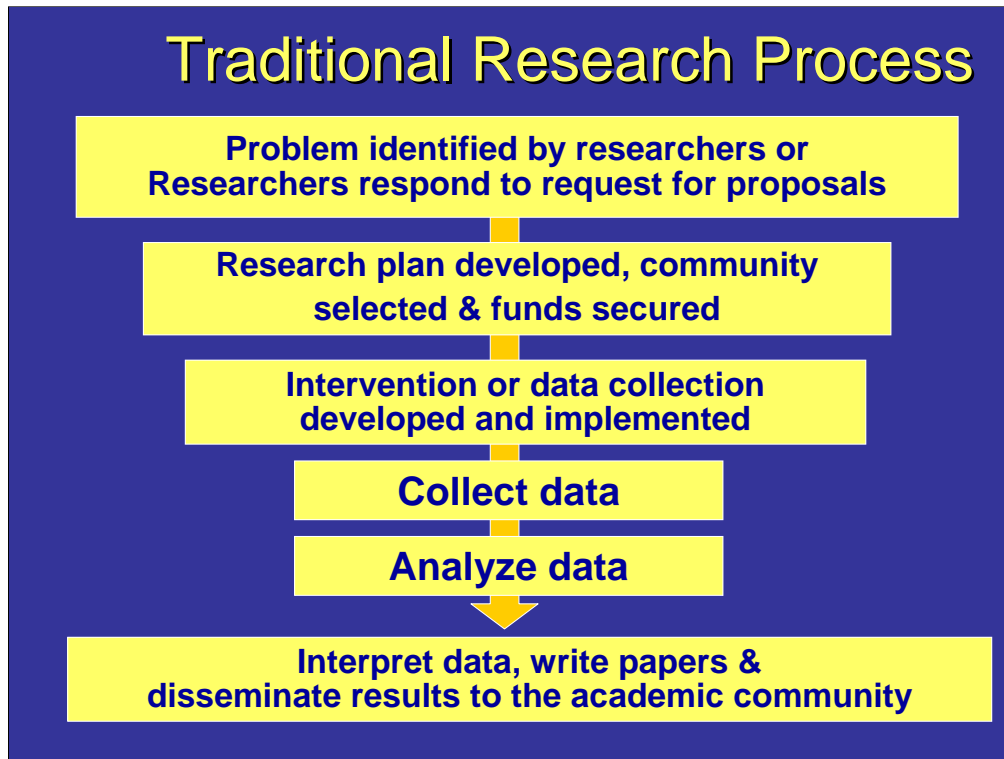
Lasker RD, Weiss ES. 2003

Being the **subject of** research is different from being a **participant in** research. With a community-engaged approach communities are seen as partners and collaborators and community members are viewed as research **participants**, not as 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 is 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 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.

Research terminology is changing and in current regulations and medical journals biomedical research "subjects" are now called "participants." The New England Journal of Medicine, the American Journal of Public Health and the International Committee of Medical Journal Editors use "participant."

Carlson, ED. 2004; Corbie-Smith, G. 1999; Freimuth, VS. et al. 2001; Lasker RD, Weiss ES. 2003; Minkler M. 2005

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Traditional Research Process

**Problem identified by researchers or
Researchers respond to request for proposals**

**Research plan developed, community
selected & funds secured**

**Intervention or data collection
developed and implemented**

Collect data

Analyze data

**Interpret data, write papers &
disseminate results to the academic community**

Different approaches

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 researchers 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 the research results.

For example, in California the Hotel Employees and Restaurant Employees union (HERE) was concerned about high rates of injuries and musculoskeletal problems among hotel cleaners. The union thought these problems were job related and contacted researchers at the University of California about doing a study. The union had identified research priorities and some of the research methodology: they wanted the hotel workers to be involved with data collection, and they also wanted the study to be scientifically sound. Researchers collaborated with the union and its members to identify potential risks and contributing factors; design a survey for hotel workers; and recruit and train a group of workers to administer the survey. After analysis of the survey results, researchers held focus groups with the hotel workers to examine the findings and solicit explanations and interpretations from the workers. Researchers wrote a report and the union was able to use it as a bargaining tool with management for improved work conditions.

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Community-engaged Research Includes the Full Spectrum of Research Involving the Community As Collaborators

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.

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Traditional Research Approach	Community-engaged Research	
	Research with the community	Community-based Participatory Research Approach
Researcher defines problem	Research IN the community, or WITH the community	Community identifies problem or works with researcher to identify problem
Research IN or ON the community	Research WITH community as partner	Research WITH community as full partner
People as subjects	People as participants	People as participants & collaborators
Community organizations may assist	Community organizations may help recruit participants & serve on Advisory Board	Community organizations are partners with researchers
Researchers gain skills & knowledge	Researchers gain skills & knowledge, some awareness of helping community develop skills	Researchers & community work together to help build community capacity
Researchers control process, resources & data interpretation	Researchers control research, community representatives may help make minor decisions	Researcher & community share control equally
Researchers own data, control use & dissemination	Researchers own the data & decide how it will be used & disseminated	Data is shared, researchers and community decide its use and dissemination

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. A detailed view of this table is available for download in PDF format: Traditional vs Community-engaged Research.pdf

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 show that it exists on a continuum: from low community engagement (left in dark blue) to high community engagement (right in light blue). Community-engagement exists on a continuum and there are many possible combinations.

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Community-based Participatory Research (CPBR):

- **Is a collaborative approach to research**
- **Equitably involves all partners in the research process**
- **Recognizes unique strengths that each brings**
- **Begins with a research topic of importance to the community**
- **Combines knowledge with action**
- **[Aims to] achieve social change to improve health outcomes and eliminate health disparities**

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 (below) 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**." (emphasis added)

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Community-based Participatory Research (CBPR)

- **Strong partnerships between researcher and community**

- **Community and researchers are equals**

- **Both share responsibility and control**

- **Community identifies problems**

- **Researchers work with the community**

- **Community organizations are experts on their community culture and health needs**

This module is intended for those who are new to community-engaged research and so concentrates on a basic community-engaged approach rather than the intense community partnership and equity necessary for CBPR. However, the term Community-based Participatory Research (CBPR) is often used as a label for projects which incorporate a wide range of community engagement, partnership and participation. Many of these projects incorporate some principles of community-engaged research, but would not meet the Kellogg Foundation's definition of CBPR (previous slide).

For example, researchers in an Arizona city implemented a program to increase physical activity developed for Healthy People 2000. They wanted to determine if the program was effective. They collaborated with a hospital and the city Parks and Recreation Dept. and created a steering committee. Teams were formed at workplaces, neighborhoods, senior centers, etc. Participants completed a pre- and post-questionnaire on physical activity.

Although this study worked collaboratively with community organizations to implement the intervention it would not meet the Kellogg Foundation's definition of CBPR. Researchers formed a steering committee for the study, yet the people in the study area did not request the program, nor did they contribute to its development or decide how it would be implemented. The collaborators had well defined tasks for organizing groups to participate, but tasks were not tailored to meet the interests or needs of this community. The study was implemented in the community and involved collaboration, but could not be termed CBPR.

CBPR requires strong partnerships between researchers and community. The community and the researchers are equals and share responsibility and control of the research process or components of it. Community organizations, who are experts on their community culture and health needs, identify problems and work with researchers as full partners to collaboratively develop proposals to study those problems. With a partnership based on trust and mutual understanding CBPR researchers and community organizations can negotiate during the development of a proposal to produce a project plan that all partners can agree on.

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Community-based Participatory Research Builds Community Capacity

- **Communities identify problems**
- **Communities develop solutions**
- **Shared decision making power**
- **Shared dissemination of data**

Building a strong partnership takes time, attention, and reflection

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 can be difficult to achieve. Researchers who have such relationships with community organizations have often worked with those organizations for ten years or more. For example, public health researchers from the University of Michigan have worked with community organizations in low-income Detroit since 1996 to address determinants of poor health.

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 sources and constrains of all the partners.

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3. Incorporating a Community-engaged Approach Into Traditional Research

Incorporating community-engaged practices into traditional research

Learning Objectives

- **Describe examples of how research projects could incorporate some principles of community-engaged research at different steps of the research process.**

- **Describe how the role of the researcher differs 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. The previous section of this module included examples of the role of communities in traditional research and in community-engaged research (including CBPR).

The following section gives examples of how community-engaged research practices can be incorporated into the steps of traditional research projects.

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Step 1, Problem Identification

- **Community members may approach researchers or**

- **Researchers may approach community with a proposal for research**

In **Step 1**, **Problem Identification**, 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.

Example 1: A group of clergy approaches a researcher with concerns about how many people in their congregations suffer from diabetes. They ask the researcher if there is anything that could be done to prevent diabetes.

Example 2: Researchers interested in diabetes prevention identify a section of the city with a high rate of diabetes. They contact community organizations and agencies to determine if there is community interest in participating in a research project on diabetes prevention.

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Step 2, Research Plan Developed, Community Selected & Funds Secured

- **Researchers may handle all these steps**
- **Community organizations may contribute**
  - **Research questions**
  - **Ideas on recruitment**
  - **Advice on logistics**
  - **Suggest other collaborating organizations**
  - **Advice on how to tailor for the community context**

Step 2, Research plan developed, community selected & funds secured, 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, suggest research questions, and offer ideas on recruitment. They can give advice on logistics, suggest other organizations to collaborate with, and advise on other aspects of the project.

Example 1: 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 a proposal and include these organizations as community partners.

Example 2: Researchers receive funding for a diabetes prevention project. They have not chosen a community site so they meet with representatives of local agencies and organizations to see if any local communities are interested in being the site for this research.

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To Build Trust, Researchers Should:

- **Share drafts of the research proposal (or the funded grant) with community partners**

- **Include funding for the work of community partners**

- **Share information on the project budget**

Community organizations should receive drafts of the research proposal for review. 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.

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.

Example 1: The 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 for the employee. All have copies of the final budget.

Example 2: Since the researchers had not worked with community organizations before submitting the proposal, they meet with community representatives and give them copies of the grant. The community representatives decide 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.

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Step 3, Begin Study in Community

Involve community members as
■ **Project staff, in the office or in the field**
■ **Advisors**

Involvement helps with
■ **Recruitment and retention**
■ **Community buy-in**

In **Step 3**, **Begin study in community.** Community-engaged research practice is 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.

Example 1: Researchers and Community Advisory Board (CAB) members hire project staff from the surrounding community.

Example 2: The study office is in the community where the research takes place, however the staff is small and the positions require specialized training and experience. Researchers cannot find anyone in the community who is looking for a job who has the appropriate qualifications and so cannot hire locally. To keep the community interested in the study, researchers meet with the CAB and develop ways to make the study accessible to community members and to enable researchers and project staff to maintain a community presence.

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Step 4, Develop & Implement Intervention or Data Collection Process

Community partners can

- **Help tailor the intervention**
- **Help tailor the data collection process**
- **Advise on problems**
- **Promote the study in the community**
- **Collect community's responses**

Step 4, **Develop & implement intervention or data collection process.** Community organizations can help tailor the intervention, advise when problems arise, promote the study and collect community responses.

Example 1: 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 for the study.

Example 2: 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.

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Step 5, Collect Data

Community members can be hired to:

- ■ **Administer questionnaires**
- ■ **Log participation**
- ■ **Read measurements**
- ■ **Make observations**

In **Step 5**, **Collect data**, community involvement would depend on the type of data needed. Community members can be hired to administer questionnaires, log participation, read measurement devices or make observations.

Example 1: 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.

Example 2: 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.

Step 6, Analyze Data

Office staff can assist in data cleaning
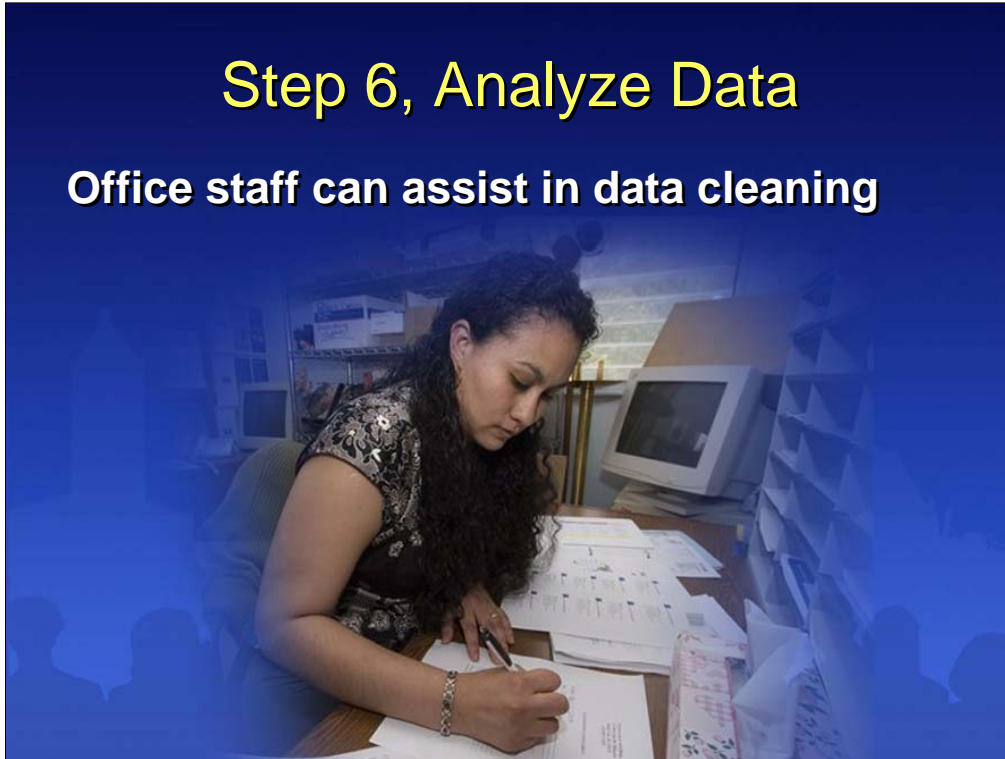
Step 6, **Analyze data**, is generally done by researchers.

Example: If the community office staff are familiar with the data, they can assist in data cleaning, a process of checking that data is correctly identified, complete and ready for analysis.

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Step 7, Report and Disseminate Results

Community may want to use

- **Meetings**
- **Radio programs**
- **Newspaper articles**

Researchers need to discuss how and when to present findings in the community

Step 7, **Report and disseminate results.** 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 the 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 JAMA, 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.

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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.

Example 1: After the data are collected and analyzed researchers and the chair of the CAB discuss preliminary results on local radio stations.

Example 2: The researchers do not feel that they can present preliminary results and want to wait until they complete the full analysis. They 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.

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Community Members and Community Partner Organizations Should:

- **Receive credit for their contributions**

- **Be included in press conferences**

- **Attend and present at meetings, if possible**

- **Be considered for inclusion as co-authors in papers**

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.

Example 1: 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.

Example 2: The project budget did not have sufficient funds for community partners to attend scientific meetings as co-presenters. Researchers and the CAB wanted to make sure that all community partners received recognition. They held a public reception to honor them and arranged for city officials to present certificates of appreciation to all organizations and CAB members.

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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, as in the examples of the two Diabetes Prevention Projects. 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.

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4. Trials, Tribulations, and Rewards

Learning Objectives

- **Describe benefits from collaboration between researchers and community partners.**

- **Describe possible complications when researchers and community partners collaborate.**

- **Identify challenges in the evaluation of community-engaged research.**

- **Discuss academic beliefs about conducting community-engaged research**

Community Issues

Time is a concern for all researchers and community-engaged research involves building partnerships, negotiating, planning and communicating. These are time consuming activities over and above regular research responsibilities. There are also rewards for researchers who use a community-engaged approach. While community-engaged research may be "messier" than traditional research, it is this messy complexity that makes it more representative of real world conditions and so increases its translational value.

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Benefits of Using a Community-engaged Approach

1. **Researchers can develop questions about health issues of concern to the community**
   - **Results likely to be translatable**

2. **Community partnerships can help participant recruitment**
   - **Community understanding can bring community support**

What are the concrete benefits for researchers of using a community-engaged research approach?

1) Researchers can develop research questions concerning health issues of concern the community. Since the research questions are studied within the community, results are likely to be translatable to similar communities.

2) Working in partnership with community organizations can help in recruiting participants and in obtaining informed consent. When people understand the purpose of the research and the results may affect them, they are more likely to support the research and the researchers.

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Benefits of Using a Community-engaged Approach

3. **Community-engagement can improve the reliability and validity of:**
   - **Measurement tools**
   - **Questions and study procedures**

4. **Can inform researchers of community interpretations of research results**

3) 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.

4) 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.

For example in Durham, North Carolina the African-American Health Improvement Partnership (AAHIP) is a collaboration between researchers and community organizations. The AAHIP research team developed a draft survey, then shared it with the full Community Advisory Board for feedback and worked with a subcommittee of the board to refine it. Board members helped to make some questions more comprehensible and added new questions (one of which proved to be the only useful question for understanding variations in the patient-provider relationship). The Community Advisory Board also provided advice on how to administer the lengthy survey in such a way that people would be able and willing to finish it.

The Community Advisory Board also worked to identify churches that would be interested in the project, represent a cross-section of the community and be interested in forming partnerships. They thought through how best to approach the churches and solicit their involvement and generated ideas for other recruitment venues.

Minkler (2005)

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Partnership is a central concept of community-engaged research. Like any relationship, partnerships may include complications. Whether in the lab or the community, research seldom proceeds without problems and unexpected events. This is especially true with community-engaged research which is affected by all the difficulties that beset any community. Political scandal can jeopardize funding for community organizations, floods and hurricanes can cost weeks of research time as the community recovers, budget cutting can cripple community partners and industry shut downs can wreak economic havoc.

For example, an occupational health project in rural North Carolina recruited women who worked at two poultry plants for a longitudinal study of musculoskeletal problems related to work duties. Since there was no union and the poultry processing company would not cooperate all enrollment was done outside of the plants. When the five year study was half completed one of the poultry plants closed unexpectedly. Many women who had been enrolled in the study were no longer employed as poultry plant workers—a condition for enrollment—and the number of study participants decreased by a third. Local study staff had to quickly recruit other women still employed at the remaining plant to replace those who were no longer working in poultry processing. Since the local staff had established community connections throughout the five county study area during their earlier recruitment work, they were able to quickly recruit additional poultry plant workers for the study.

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Agencies, such as the Health Department and community groups, service organizations, churches, etc. can be valuable community partners. Not only are they a resource for learning about community health concerns, they can provide information on local politics and relationships and a historical perspective on community problems.

Yet agencies and organizations have their own missions and mandates to fulfill and collaborating on research is often an additional responsibility for an already overworked staff. Researchers and community partners should discuss their commitments early and often and agree that all are receiving appropriate payment for their contributions. Even with careful planning unexpected situations can develop and community partners may be forced to cut staff, change focus and be unable to meet their commitments.

This is especially true for service organizations such as county Health Departments, who are generally understaffed. If there is an outbreak of hepatitis, or other contagious disease, in the population, staff who were collecting data or implementing an intervention for a research project will likely be reassigned for several weeks to help with the outbreak.

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Evaluation of Community-engaged Research

Community-engaged research:
- **Includes domains seldom found in health research**
- **Has few established evaluation scales or methods**

Researchers can include in research proposals:
- **Community-engagement goals & objectives**
- **Intermediate measures for these goals & objectives**

Evaluation of community-engaged research

The NIH Roadmap initiative is changing the criteria for some research funding and emphasizing the need for community-engaged research projects. As part of this initiative grant review committee members across disciplines will need to learn how to evaluate effectively research proposals incorporating a community-engaged approach. The Agency for Healthcare Research and Quality issued a report in 2003 which included recommendations for evaluating such proposals.

Community-engaged research includes domains not commonly found in health research. Some of these domains, such as forming community partnerships and building community capacity, do not have established evaluation scales or methods. However, researchers can include community-engagement goals in their research proposals and develop specific measurable intermediate objectives for them. In this way, the process of community engagement is incorporated into measurable research project goals.

For example, for a community-engaged research program on childhood asthma, any of these activities would demonstrate evaluative progress:
- development of an advisory board made up of community members
- meetings with families of asthmatic children to solicit and document advice on recruitment and to learn about barriers to participation
- documentation of how research activities had been tailored in consultation with community partners

http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf

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Community-engaged Research May Challenge Status Quo Beliefs

Academic issues

In "Overcoming Barriers to Effective Community-Based Participatory Research in US Medical Schools" Ahmed, Beck et al. show how the academic research paradigm can make community-engaged research appear less rigorous and can contribute to the undervaluing of researchers who use this approach. Historically, academic institutions have subscribed to established beliefs about the characteristics of good research, such as:

•Research areas are defined by the discipline and by individual researchers who identify research questions and conduct the research.

•Researchers are objective, while non-academics are subjective and have biases and political agendas.

•The most valuable research is based on theory and is broadly generalizable.

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A community-engaged approach to research may challenge these academic status quo beliefs. Research topics may be developed and refined in consultation with community partners and community members may be involved in gathering data and conducting research. Including community organizations as collaborators in research is a departure from the established research model and may be difficult for some academic institutions to understand and accept.

Yet Duke and other universities are committed to supporting the community-engaged research approach. Many are revising their tenure and promotion guidelines to accommodate the different challenges posed by community-engaged research. For example, guidelines can recognize the additional time often needed to establish community partnerships and to work collaboratively.

http://www.sph.umich.edu/cbph/office/committee.html

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Community-engaged Researchers

- **View community partners as knowledgeable & important contributors to research**

And may also

- **Acknowledge that they and community members bring their own beliefs to research**

- **Think beliefs and values should be recognized**

Community-engaged researchers view community partners as knowledgeable and as important contributors to the research endeavor. They recognize that both researchers and community members bring their own beliefs and values to the research and that these perspectives should be recognized.

For example, a group of researchers participate on a local obesity prevention committee. After the committee does a survey on availability of fresh foods, a member asks if they could apply for a local grant to work on this problem. Committee members decide applying for the local grant would be too difficult and time consuming. One researcher asks if the group would consider working with him to apply for a larger research grant. It would require more data collection, but would provide some funds for the kind of intervention the committee wants to try. Committee members agree and since they know the community will assist in developing the research proposal.
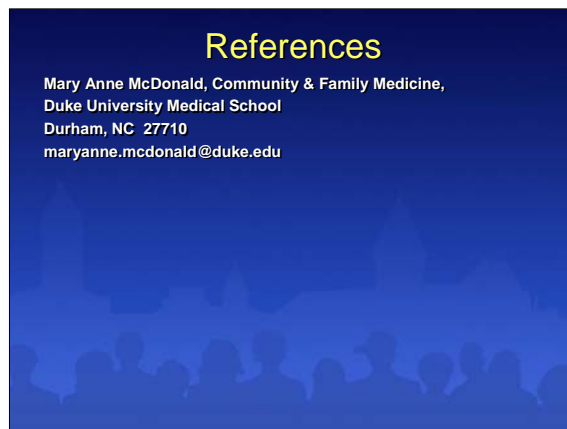
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Conclusion

Health problems exist within the context of people's lives, the solutions to such issues will likely be context specific as well.

A community-engaged research approach can enable researchers to conduct research and produce results which may be directly translated to improve human health.

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