Conducting Ethical Community-Based Research
Office of Community Engagement

What is Community-Based Research (CBR)?

There are multiple models and roots for CBR, but all involve research that is conducted by and for “ordinary people.” In some cases, a problem is identified by a group of people on the fringes of an organization or society, and the research is meant to clarify the problem’s roots and potential solutions, as well as to build some community around the problem. In other cases, an organization is interested in gathering information that will help its members better serve its community. CBR has many different names, including participatory action research, community research, action research, etc. Each has a slightly different root and purpose, but all focus on needs identified and researched by people with a stake in the issue and on addressing those needs as a community.

What is Service-Learning?

Like CBR, service-learning has multiple models and roots. Each institution that uses service-learning in its classroom settings defines it slightly differently. The University of Minnesota, Morris defines Service Learning is a classroom experience that utilizes community service, community-based research, or other civic engagement activities along with regular reflection to meet course goals and community needs.

The service-learning advisory board, comprised of students, faculty, staff, and community partners, wrote the above definition in 2005. The group also identified the following five goals for service-learning students. The goals were created to reflect the goals of a liberal arts education as well as the goals of service-learning articulated in the field of community-based learning.

- Increased understanding of how theory, knowledge, and skills learned in the classroom can be used to meet a range of community needs.
- Increased understanding of human diversity, including concepts of privilege and oppression and an improved ability to work collaboratively with diverse groups of people.
- Improved leadership skills, including effective communication and collaboration skills necessary for working in a variety of settings.
- Improved critical thinking and problem solving skills.
- Increased commitment to and understanding of civic engagement and improved skills and knowledge relevant to effecting social change.
What Makes CBR Service-Learning?

**Service-learning needs to meet a real community need, identified by a member of the community.** Often, community needs are identified by service providers—i.e., a teacher is aware that a fourth grade student is struggling in math and needs a tutor, or an organizer of the Special Olympics needs volunteers to assist with an event, or a community organization is in need of funds to better serve its constituents. When students are tutoring children, or volunteering at an event organized by a social service organization, or conducting a fundraiser, it is a bit easier to determine exactly what the need is and what the student’s role in meeting that need is. It is also easier to measure the results—for instance, the student’s grades may get better after tutoring, a person with developmental disabilities may complete the event successfully, a fundraiser brings in a clear dollar amount to meet an agency’s goal. With CBR, the student’s role, and the need itself, may be a bit less clear. CBR is intended to listen to the needs of groups of citizens, even if they are not organized into “agencies” or “organizations.” It is intended to address root causes of a problem along with individual people’s needs. CBR has the potential to create more substantial, long-term change, depending on how the community responds to the research. Key questions: Who is being “served”? What is the community need, and who identified it. Why are you (as a UMM student) in a position to provide this service better than others? What are the potential community benefits, and how can they be measured?

**Service-learning needs to help students learn the course goals and course material.** Key question: What will you learn that will enhance your understanding of the course goals and course material?

**Service-learning should help you meet secondary program goals listed above.** Key question: How do you anticipate this course project helping you to meet those goals?

CBR is Research

CBR was designed for community groups or organizations to do research that would be practical and beneficial to them. CBR has been used by groups of people who have gathered informally to address a particular problem (crime in their community, unmet needs of a new group of immigrants) or a specific event that indicates a larger problem (an incident of police brutality, a hate crime). Research can help groups make sense of the root causes of a problem or event and to determine next steps in solving the problem or addressing the incident. CBR has also been used by social service and other kinds of community organizations to better address needs of their clients or consumers. For instance, a nursing home might organize dialogues for their residents to determine how to make their lives in the nursing home better. Or, the county Human Services office might send out a survey to all foster parents to determine what they could do to better support their parenting.

Often, however, community groups want to partner with colleges and universities on such projects, because faculty, staff, and students may possess resources, expertise, or time that the group members do not have. Once you are involved as a member of the UMM community, you must follow the guidelines for ethical research that the University of Minnesota (and all universities) require. Sometimes these guidelines feel like barriers
to the completion of research that is quick and useful—but the reality is, they were designed to ensure that researchers treated their “research subjects” with dignity and respect.

As you may have learned in other classes, researchers have mistreated their research subjects throughout the course of history. There are some horrific examples, such as the Public Health Service Syphilis Study that lasted from 1932-1972, in which multiple African-American men were enrolled in the study without informed consent and then, when medical breakthroughs found a cure for syphilis, they were denied penicillin that could have saved their lives. At this point, you are probably thinking, my study is going to involve some focus groups or interviews—I am not messing around with people’s lives. Also, you might realize that CBR is based on a much different model that traditional research, and that there is a less clearly defined difference between the researcher and the research subject. However, the response to these horrific examples, and the laws and guidelines that have followed, are useful for ALL research projects. There are still subtle ways that you could, without intention, compromise the dignity of the people who are part of your research—and it is important to understand the ethical research guidelines that govern ALL research projects, and consider how they are useful in the context of CBR specifically.

The Belmont Report

In 1979, the United States Department of Health and Human Services (then called the Department of Health, Education, and Welfare) published the Belmont Report. The report is a statement of the basic ethical principles and guidelines to be used to resolve the ethical problems that surround the conduct of research with human subjects. It was published in response to examples like the syphilis study, but its principles are useful for any type of research.

The Belmont Report identifies three basic ethical principles for conducting research with human subjects. These principles are commonly called the Belmont Principles. The Belmont Principles are respect for persons, beneficence, and justice.

Respect for Persons

The first principle, respect for persons, essentially requires researchers to treat individuals as autonomous human beings who can make their own decisions. This means that people must consent to be a part of any research process, and to understand the purpose of the research and their role in it. In cases in which knowing the specific purpose of the research might change the way the research subject behaves (something not likely to occur in the context of CBR), the “subjects” must at least know generally that the study is related to, say, anxiety or personality. In other words, you can’t use a person in order to get an answer to a question unless that person understands how what s/he is going to do—talk in a focus group, talk to an interviewer, complete a survey, etc.—will lead to an answer to a research question for the researcher (and, in the case of CBR, the broader community).
In practice, the principle of respect for persons involves creating a consent process. Research subjects must have all the information they need to decide whether they want to participate, and they must be able to decide at any time that they no longer want to participate.

The principle also provides extra protection to those with limited autonomy, such as people with limited abilities to reason or make their own decisions or who are more likely to be swayed by the influence of others. These elements of autonomy are called mental capacity and voluntariness. Children, for instance, are considered part of a protected class of research subjects because they are easily influenced by adults and, depending on age, may not be able to make their own decisions. People with dementia, and people with developmental disabilities, are considered part of a protected class of research because their disabilities limit their ability to make their own decisions. So, if you are going to work with children or with people in protected classes, you must be able to explain how you will preserve their dignity and empower them to speak and act on their own behalf as much as is possible. Children must have permission from a parent or guardian to participate in a research project.

**Beneficence**

The second principle, beneficence, requires researchers to make sure that the research will pose as few risks as possible to the research subjects. The principal also suggests that the benefits should outweigh any risks. Researchers have to consider both the potential harm that could occur and the likelihood that this harm would occur. Harm does not just include physical harm, but also any legal, social, or economic repercussions. In some cases, answering certain kinds of questions, if a person were to be identified, could compromise how he or she is viewed by others (including potential clients or business partners), which could cause social stigma or even economic repercussions. And, if a research subject disclosed criminal activity and is identified, she or he could be subject to legal repercussions.

In most CBR situations, beneficence can be ensured if research subjects are treated as privately as possible. The fewest possible people should be able to connect a specific comment spoken in an interview or focus group or written on a survey with a particular person. And, anyone with access to the identity of research subjects should be aware of his or her responsibility to maintain confidentiality. Finally, any identifying information in a final report should be disclosed only when necessary. Remember, in small communities, what is considered “identifying information” may be different than in larger communities. For instance, in Morris, there may be a small number of parents of autistic children, or people of the Jewish faith, whereas in larger communities, if a subject was identified with one of these “labels,” he or she would have a much lesser chance of being identified.

Because CBR is meant to directly benefit the community, CBR researchers sometimes feel they are “off the hook” in terms of the benefits outweighing the risks. However, this is not always true. CBR is sometimes conducted both with and for an oppressed group of people, so while that group may benefit a great deal from the research, some people in power may not consider the research as beneficial. And, if those people are interviewed or surveyed, their privacy and dignity must be protected just as
the oppressed group would be. CBR is also sometimes conducted on behalf of an agency, with the consumers or clients of that agency acting as research subjects. In these cases, even if the agency will benefit from the information the study will give them—and that benefit will “trickle down” to consumers—the research subjects themselves must still be protected.

**Justice**

According to the Belmont Report, "Just as the principle of respect for persons finds expression in the requirements for consent, and the principle of beneficence in the risk/benefit assessment, the principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects." In other words, researchers should design research studies so that those who are “studied” will also benefit from the research as much as possible. And, people should be selected based on criteria that are in line with the purpose of the study, and not just because they are available. Researchers need to make sure they are not exploiting their subjects, and that the subjects are able to, and know they have the right to, say no at any time during the research process.

In CBR, justice is likely to happen naturally to some extent, because usually the research subjects and the researchers are one and the same—or at least, the research subjects or people who directly serve them came up with the idea for the project, even if the researcher acts more like an academic researcher and simply shares the final report. Still, again, some CBR requires the researcher to get information from subjects that are not in the “close circle” of the study, and justice needs to be considered when these subjects enter the project.

**The Role of the IRB**

The Institutional Review Board (IRB) is an all-university committee that reviews research projects conducted by students, faculty, or staff associated with the institution. Even if the research is being conducted with and for a community organization or a group of citizens, if the researcher is a student at or employed by the university, she or he is bringing his or her “university resources” to the project; this is especially true in small towns like ours, where we are often identified first as our roles as UMM professors, staff, or students.

Students and faculty who apply for IRB approval must choose the type of approval they wish to have depending on the type of research subjects who will be involved and the risk to those subjects. There are a variety of “levels” of approval, and it is important to read the guidelines carefully to determine which forms must be completed. Once forms are completed, the board reviews the forms and provides feedback, often requiring changes or conditions to the forms. Finally, projects are either approved or denied approval. Once a project has been approved, work on the project can begin.

Many community-based research projects at UMM are conducted under an IRB approval for community-based research that is campus-wide. Argie Manolis, coordinator of the Office of Community Engagement, is the PI on this IRB. The IRB was written in 2007 and has been continually renewed since then. If your project falls under this IRB
approval, you will need to read it carefully to ensure that you follow its constraints. Some projects have required their own IRB proposals; for instance, recent community-based surveys conducted by public health, economics, and psychology courses for community groups went through their own IRB processes. Again, whichever process your project falls under, you are responsible for understanding the specific requirements or guidelines for the study.

Below are the guidelines, word for word, which the IRB uses when making its decision. Reading them carefully will help you to understand how the particular provisions of your approval were determined.

**Beneficence**

- Risks to participants are minimized by using procedures that are consistent with sound research design and that do not unnecessarily expose participants to risk.
- Risks to participants are reasonable in relation to anticipated benefits, if any, to participants, and the importance of the knowledge that may reasonably be expected to result.
- Risks to participants are minimized whenever appropriate, by using procedures already being performed on the participants for other purposes.
- When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of participants.
- When appropriate, there are adequate provisions to maintain the confidentiality of data.

**Justice**

- Selection of participants is equitable.

**Respect for Persons**

- Informed consent will be sought from each prospective participant or the participant’s legally authorized representative, in accordance with, and to the extent required by the regulations.
- Informed consent will be appropriately documented in accordance with, and to the extent required by the regulations.
- When appropriate, there are adequate provisions to protect the privacy of participants.
- When some or all of the participants are likely to be vulnerable to coercion or undue influence, additional safeguards have been included in the study to protect the rights and welfare of these participants.
Ethical Issues Involved in CBR

CBR presents its own ethical issues which must be considered. Below are some questions to consider, in addition to consideration of the three larger principles of ethical research, when your research will be conducted with or for a community group or in response to a problem identified by a community group.

**Who identified the need, and what is this person or group’s “agenda”?** Every research project has an agenda, of course, which is often articulated in the form of a hypothesis. In “traditional” research, the “agenda” is often the researcher’s. With CBR, the “agenda” belongs to both the researcher and the community members/group with or for whom the researcher is conducting the research. It’s important to make sure the “root” of the identified problem that the research will address is clear. For instance, is an agency asking for research that will help their bottom line but not their clients? Are the clients involved in shaping the research questions that are being asked as much as they can be?

**How will “hostile” or “enemy” groups or individuals be protected during the research process?** To research sexism or racism or homophobia in a community, you may have to talk with sexist, racist, or homophobic people. To determine why a local agency isn’t adequately serving elderly people, you may have to talk to the agency’s staff. How will you frame the questions you ask, and how will you gain their trust? And then, if you are able to get information from them, how will you ensure that the information is presented in a way that provides those who spoke with you with the same protections other research subjects receive?

**How will research results be disseminated, and why?** The community-based IRB guidelines require that final reports be only submitted to those who were directly involved in the research; i.e., the research subjects themselves and the agency or agencies that requested the research in the first place. Therefore, it is important that everyone understand those requirements, so that the community members who have access to the information do not use it in a way that is not consistent with this requirement. In some cases, research could benefit a broader community, and it may be “worth it” to seek approval to disseminate it more widely. Again, it’s important to balance the three principles of ethical research with your desire to ensure the research is used when it is complete.

**How will researchers use the information provided?** What will researchers do if information indicates that the problem is not what they perceived? If the information indicates that they themselves are part of the problem? What process will those invested in the research use to follow up on the problem? Answers to these questions could not only compromise the three elements of ethical research, but could also simply make you more or less interested in taking on the time and energy required to complete the study. To ensure you are comfortable with the project, it’s important to discuss these questions ahead of time with the community members with whom you are working.
Some Scenarios

NOTE: NONE of these scenarios happened at UMM/in Morris; they are simply scenarios meant to prepare you for potential ethical issues that might arise when conducting community-based research.

You are working with a community organization that works for human rights. The group, with which you are affiliated, wants to get a better handle on the level of racism in the community, as well as its roots, in order to organize an anti-racist educational campaign. Some of the survey responses are very offensive to you personally and feel like personal attacks; many write that people of color are overreacting or that there is no problem with racism in your community. Because your community is small, you are able to identify some of those who responded by their handwriting and the demographic information they disclosed. What risks are presented here? What will you do to deal with your frustration, anger, and pain, to ensure that confidentiality is maintained at all costs during the process, and to accurately report the results of your work?

Consider the above scenario, only this time, you are conducting interviews instead of a survey, and you are hearing these offensive opinions in person. How, if at all, will your course of action differ?

You conducted the study above, and most of the results suggested there was no problem with racism and involved frustration or anger at the fact that the subject was being studied. Local schools and social service agencies are interested in the results of the study, though you are working on it with a community organization that works for human rights. Do you give the results to the local schools and social service agencies? If so, how do you present it?

In the middle of an interview, the interviewee says she does not like your question and refuses to answer it. How do you respond?

You realize you forgot to bring a consent form with you to an interview, but you traveled over an hour to conduct the interview. The subject is about local foods and community-based agriculture; you don’t feel any question is sensitive, as you are trying to determine how farmers could best work together to maximize the positive effects of community-based agriculture while remaining viable businesses. The research subject, a local farmer, has cleared two hours during a busy time of her work season to meet with you, and she is very eager to talk to you and excited about your project. What do you do when you get inside her home and realize you’ve forgotten the consent form?

A participant in a focus group walks out of the room in the middle of the focus group. What do you do?

You are certain that children with disabilities in your community are treated unfairly by teachers because of anecdotal stories you have heard from your neighbors and friends. You are working with a group of disability rights activists to gather systemic proof of this
mistreatment. You follow protocol and recruit participants—parents of children with disabilities—by using a list available in a public record, and sending them a letter. About 1/3 of the parents reply and consent to participate. After interviewing them, your data suggests that there is no problem with treatment of children with disabilities in the schools. What do you do next?

You find your roommate reading your notebook for class, which includes notes from some interviews you conducted. When you ask him what he is doing, he says he was looking for an assignment in the class you shared. What do you need to do next? What should you have done to avoid this situation?

You are interviewing the director of an agency that handles recycling in your town to better understand how recycling works. When you tell him that previous research suggests residents want recycling to be picked up more often, he says, “I thought you said this was a STUDY. I signed something saying I was part of a STUDY. I didn’t know you had an AGENDA. I’m not answering any more questions, and if you publish something that makes us look bad, I’ll sue you!” What do you do?