

Welcome to the Research Ethics Tip Guide!

Ways of doing research are dramatically changing. Conducting research used to be considered only a scientist's privilege; now research is being seen as the community's business as well. There is an increasing awareness of the importance of being respectful to the rights of participants not only as individuals and also as members of a community that may be affected by research.

As communities become more involved in research, ethical dilemmas come up at each stage in the research. These dilemmas include questions such as who decides what the research agenda will be, who has the power in the research relationship, how will a partnership be set up and how can it work fairly, and who owns data. All of these issues need to be addressed.

At the University of Massachusetts Lowell, we are working hard to build participatory research partnerships between the university and underserved communities. These tip sheets included in this manual were created as a part of workshops on *Ethical Issues in Partnership-based Research*. We hope that you find these tip sheets helpful in addressing some of the ethical questions that emerge in the partnerships. The topics of the tip sheets include:

- Initiating Partnerships: Gathering the Players
- Ethical Considerations in Participatory Research: The Researcher's Point of View
- Questions to Ask about Community Based Research Partnerships
- Partnership-Based Research: How the Community Balances Power within a Research Partnership
- Everything you always wanted to know about IRB's
- Overcoming the Roadblocks to Partnership
- "Science Shops" in Lowell?
- Knowledge Creation in Research Partnerships

Please feel free to use these tips for your purpose while mentioning the source. We would be more than happy if you could give us feedback to enrich them. Any concern or question should be emailed to Linda Silka (Linda_Silka@uml.edu, 978-934-4247). Thank You!

Initiating Partnerships: Gathering the Players

Darcie Boyer

So you've identified a problem or area of concern in your community that you believe warrants further study. You would like to get some feedback to see if others in the community feel the same, but you're not sure where to look or who to ask. The following steps may be helpful in starting to think about partnership development.

To illustrate the process, let's use an example:

Let's say that you have noticed that the use of bicycles as transportation has declined significantly over recent years, contributing to health problems, limited transportation options, and environmental concerns. How would you go about forming a partnership to discover if there is an interest in determining the causes of reduced bicycle use and in identifying possible solutions?



Identify people or organizations that will be impacted by the study or those who are influential in the community, such as health care providers, community activists, individuals without automobiles or licenses, environmental groups, school officials, city planners, etc. Ask yourself "Who has a stake in the research?"

To identify a possible research partner, you may want to find one that has already established a positive presence in the community. If that's not possible, access your local university and search for a researcher that has done work in this field or a related field.



Now that you have a list of potential partners, the next step is to invite them to join in a partnership with you and the others. Everyone has a different style of communicating; some may feel more comfortable on the telephone, while others prefer letters. Whichever form of communication you choose, there are some basic pieces of information that you may want to include:



Introduce yourself-let them know who you are and why you are interested in this project.


"My name is Darcie Boyer and I'm a parent living in the Lowell Highlands. I would like to encourage my children to ride their bikes to school and to the park, but I'm concerned for their safety. I'd like to explore how our community might increase safety and at the same time promote bicycle use."




Give some background on the research issue- show them that you have a genuine interest and have put thought into the issue. The trick is to give them enough information to get them interested, but not so much that they are overwhelmed. You don't want to give the impression that you have all the answers already.

" I have read about communities in Oregon that have implemented traffic-calming measures and believe that we could gain some valuable insight from their experiences,


but I would also like to make sure that this approach would work for our community. It may be that there are other strategies that would make more sense for us. This is what I hope to arrive at through a partnership!”

 Acknowledge their expertise- Site examples of some of their past work and illustrate what you think they would contribute to the partnership. Let them know what you want from them.

“Although my initial concern regarding this issue was safety, I am also very interested in the environmental benefit of increased bicycle use. You have done some wonderful work in the community increasing our awareness of solid waste issues and I feel that your experience in working with environmental issues would be an important asset to our partnership.”

 It may be helpful to present the situation as a problem in order to elicit excitement. There is a puzzle that needs to be solved and this person has some of the pieces that are needed to put it together.

“One of the biggest challenges I see facing this partnership is in moving people beyond the idea that bicycles are strictly for recreation. I believe that your success in the area of consumer waste reduction would help the partnership tackle the issue of behavior modification and perhaps help the partnership “sell” the idea of bicycle transportation to a society that is in love with the automobile.”

 List some possible goals of the research partnership, to illustrate the benefits of coming together as a team.

“Through this partnership I hope that our community can increase bicycle use and in the process reduce congestion, increase safety and improve air quality. How we get there will be determined by the insight and participation generated in this partnership.”



You’ve done such a wonderful job provoking interest in the research project that you now have a list of interested parties. It may be a good idea to have a small, roundtable meeting of these key figures before holding a larger meeting that is open to the community. This will enable the partnership to define some common goals, but it will also help ensure that different ideas and interests are expressed and represented in the community meeting. When organizing this meeting, try to find a time that works for everyone and a place that is neutral, comfortable and convenient.



Use the insight and feedback you received at the round-table meeting to draft an agenda for the community meeting. You might want to share it with the individuals who were at the initial meeting to give them an opportunity to comment on the content.



Now you’re ready to take it to the community. It’s time to get on that bike and ride!

Ethical Considerations in Participatory Research: The Researcher's Point of View

Maryjane Costello

One of the main issues -- if not *the* main issue --with which individuals and groups involved in community-based partnerships contend is power. In any relationship, the individual with the power determines who, how, what, and why a certain course is chosen and followed. In a research partnership relationship, power is demonstrated by control --who controls what is researched, why it is researched, how it is researched, and the outcome of the research. We need to realize, however, that each individual in a partnership has access to a source of power -- be it the traditional authority and knowledge base of the researcher or the access to and understanding of people, traditions, and culture of the community participant.

In order to ensure that issues of power are handled equitably in research partnership, each of the participants in community-based research partnerships must become sensitive to a wide range of ethical considerations that determine how a project is designed and implemented.

While each of us probably feels confident that we understand the obligations and responsibilities of ethical behavior, we may not be as confident if asked to define or explain the word "ethics". To paraphrase the Court decision on pornography -- we may not be able to define ethics, but we know what it looks like when we see it. In the Oxford Modern Dictionary, ethics is defined as a system of moral principles -- a definition vague enough to be of limited use. It may help to break down the idea of morality to phrases and keywords like a "causing no harm", a "concern with standards of general conduct", fairness, equity, respect, or dignity.

Each of us may respond to a different "ethical trigger" based on our own background and personal experience. If I were an elder homeless person, dignity might provide the foundation of my concept of ethics; if I were a feminist, equity might provide the ethical link to my worldview. We all must be sensitive to the fact that when we are working with issues of ethics, we need to embody an ongoing flexibility, openness and willingness to listen to all the points of view of all the participants.

But, in addition to an awareness of how we define the ethics inherent in our approach to research partnerships, we also need to look at the different places in the research cycle we come up against concerns that require us to be mindful of ethical concerns. To ensure that we match our research to our ethical responsibilities, we need to ask ourselves questions that will help us make sure that we are sensitive to the needs of our community partnerships. We need to maintain a high level of ethical awareness throughout the stages of the research cycle, not only as the project is initiated, but also on an ongoing process through project implementation.

One way to do this would be to map out the different stages of the research cycle and anticipate what questions we should be asking that will maximize our ability to work with the community-based partnership model. For example, we might want to ask:

In the project planning stages:

- At what point am I involving the community?
- How is the community approached?
- What's the benefit for the community?
- How are the cultures and traditions of the community respected?

In the information gathering stage of the project:

- How are participants recruited?
- How are (and by whom) are research questions selected?
- How is the privacy and confidentiality of the involved individuals and communities protected?
- What kinds of methods are being used (and how are they chosen)?
- How is the information gathered going to be used?

In the data analysis stage:

- How is the information gathered going to be analyzed or interpreted?
- What input does the community have in the analysis process?

At the end of the project:

- Is there going to be any sustainable change initiated by research results?
- What are the roles of researcher and community in determining what change looks like?

Asking any of these questions is not going to insure that the research that we do is ethical and integrated with a community-based research model. Asking questions does help us remain sensitive to the understanding that everything that we do during the research process affects our community-based partnerships. This process helps us create a research experience that fully reflects our intention of respecting the rights, privacy and dignity of the research participants alongside the researcher's goal of creative and scientific projects.

Questions to Ask about Community Based

Research Partnerships

Niem Kret



QUESTIONS FOR THE COMMUNITY








QUESTIONS FOR RESEARCHER

1. As a community member, have you been adequately informed about what a planned research study is all about?
2. As a community member, have you been invited to assist in the design of a research program and is that research program likely to be of benefit to the community?
3. Has consideration been given to how research can be designed so that the results are more likely to be directly applicable to pressing problems of concern to the community?
4. As a community member, have you been invited to participate in an equal way in all of the steps in a research cycle—from the development of the research focus to the application of the findings to addressing current problems?


Community members often hold schools, universities, institutions, and organizations in high esteem and believe that researchers are inevitably working to better the human lives and communities. In the absence of bad experiences with researchers or bad experience from participating in research, community members continue to want to be helpful in research studies.


















Community involvement in research design and development can have many benefits. These include











-  Community members have valuable knowledge and information of communities that can be very helpful for research studies. Examples include knowledge of community structures and makeup, local politics; long standing local issues or community evolutions and changes over the years.
-  A deep understanding of diversity within a culture
-  An understanding of how to enhance the usefulness and applicability of research done in the community
-  Knowledge of what the community needs and interests are
-  An ability to assist researchers in accessing the

1. What questions should you ask yourself before beginning a research study with underserved groups?
2. How do you access community resources and information? Are you planning to do so without involving community members or leaders?
3. What benefits might result from working w/ community members when you do research study? What obstacles might be overcome?
4. What ethical issues should you take into consideration before doing a research study?
5. Do you want to achieve a well balanced, well designed questionnaire and implementation?

These are just some questions that you may want to consider when you are preparing to do research. Different types of research will require different techniques but many will involve community members and communities. Partnerships may be difficult to achieve but at the same time partnership research can be very rewarding and has the potential to bring great benefits to researchers and communities. These benefits include

-  Data or research findings that more directly address the problems of greatest concern to those affected
-  Increased likelihood that disseminated research results will find a larger eager audience ready to implement the findings
-  Effective research study and continuity of research – the research is likely to be better designed when it involves all the stakeholders, including researchers, scientists, community members, community based organizations, institutions, universities, community leaders, key informant and individual participants
-  Effective research lead to direct community

<p>community and the community resources</p> <ul style="list-style-type: none">  An ability to increase access to community resources, services and information  A well balanced view of multiple needs that can add depth to a research study  The community members may be able to continue with the implementation and use the research study if they are involved in the research study. Examples, community members who are eating fresh water fish with toxic mercury may be willing to stop eating it to protective their health.  Community members can help research to designed better research planning, tools, evaluation and implementation  Partnership can increase community capacity by receiving training from the researchers  Community members who become involved in the planning and development of the research study will come to better understand research  What will impact the community members from the research  Build community capacity  Community developments  Community revitalization  Community finding out origins and causes of problems, issues or need of community  Build community relationship, socialization to reduce prejudices and misunderstanding between community and researchers  Link research to similar research in the other communities and need to know and consent of community members  Community members may be more willing to participate in prevention programs  Community members will understand the researchers prospective and researchers may understand the community and cultural events  Understand the right of the community members  What are the consequence of the research on the 	<p>benefits and greater chance for research implementation and community benefits. The implementation and research design will be well developed and take into consideration all of the ramifications, researchers aspects, community aspects, and all of the potential pros and cons of the research study</p> <ul style="list-style-type: none"> • What are the community cultures? Traditions? • What impact will the research have on the community? • Will the benefits be for the community? Or is it for myself or for researchers only? • Will I leave with positive changes in the community or negative changes? Will there be bias, stigma or prejudices because of the research? <ul style="list-style-type: none"> ☛ Researchers may have more insight and knowledge of community when it is a partnership. Example – community diversity, cultures, evolution or changes over the year. Such as more people with diabetes & obesity. Looking at the real needs of community. Community contributes values insight and knowledge or communities. ☛ Community Diversity may include different ethnic groups, cultures and practices – what are the community priorities and compromise to move forward to new ventures or impact on social changes and environmental changes ☛ Researchers may have better insight to identified problems or research issues. See larger picture, overview of the issues and a sense or moral and beneficial research study ☛ Researchers may understand the community values such as – job training is very importance to community members or that it is best for researchers to do their questionnaires in the afternoon because most of the community members are working in 2nd shift or 1st shift, etc. ☛ Researchers are accessing readily available information and resources from community members. Example – community members are knowledge of the social services they are accessing and why they are accessing services or why they are not accessing
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<p>community and the community members</p> <p> What are the community priorities that the researchers may need to understand and work with?</p> <ul style="list-style-type: none"> • Community may have ideas and solution to research study <p> What are all the community assets and liability?</p> <ul style="list-style-type: none"> • Community knowledge of new ideas for change? Understand the depth of the community issues and how researchers view issue as liability but community member views it as assets <p> What are the constraints on the research from the community prospective?</p> <ul style="list-style-type: none"> • Community members may have valuable and insight to research study from their previous experience with researchers or just for being in the community <p> Community members may be more willing to participate if they see the potential solutions to problems or issues</p>	<p>services. Community's members may see problems or issues in the communities that they live in all their life. Such as when the oil was dump on the ground or how the neighborhood became infected with rats or some unidentified disease or health issues about 50 or 60 years ago. How they are eating fishes with mercury or toxic chemical in the past ten years.</p> <p> Researchers may understand their roles, responsibilities and duties to community members and the community as a whole. Respecting the community, respect the people who live in the community and their life that you, as a researcher are invading and asking questions.</p> <p> Community feedback and input on:</p> <ul style="list-style-type: none"> • Research planning • Research types or issues • Research implementation • Evaluation of research • Research findings or result <p> Researchers can contribute to community by training community members, build collaboration and coalition with communities</p> <p> Researchers should give recognition of community input into research study</p> <p> Use research may be as simple as use vocabulary and terminology that community members understand</p> <p> Prevention focus</p>
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*Partnership-Based Research:
How the Community
Balances Power within a Research Partnership*

G. Martin Sirait

When we talk about power, we are raising questions about who controls whom and who controls what. Power issues in the research process deal with questions such as ‘Who decides on the agenda, data collection, and research methodology? ‘Who interprets the findings?’ Who owns the data?’ and so forth. When there are large power differences between communities and “researchers”—as there often are--the tips below suggest ways that the community can balance power in a research process.

Participate in research committee

Community members can play an active role by participating in research committees. In such a committee, community members can help to determine the agenda, the research method(s), the questions asked and so forth. As an example, The Wai’anae Cancer Research Program in Hawaii formed a community research committee composed of community representative, health professionals, and scientific researchers. They worked together to develop and seek funding for the project. In this case, the community have access to decision making from the very outset of the research.

Keep in Mind that community members are also researchers

Who is ‘researcher’ in partnership-based research? Basically, all parties involved in the research are researchers. A community can choose to have some of its members be trained and to become experts regarding community context. What can occur is a kind of human resources development through research process. Such an approach can increase internal capabilities of community. In turn, what can emerge is a new leadership within community. For instance, The *New Ventures* Partnership in Lowell young people are trained to be the “River Ambassadors” who then educate community members about environmental issues, using drama and interactive games.

Revitalize community value

Every community has important and unique values. Ideally, a program of research will be consistent with these values while, at the same time, serving as an internal impetus for social change. In turn, the research can then strengthen the community identity as well as dignity. Take an example from participatory research conducted in Hawaii; they used traditional Hawaiian values such as *Kokua* (a willingness to help without expecting back), *Aloha* (love), and *Lokahi* (harmony) as well as communication models as the basis of a curriculum to promote breast and cervical cancer screening.

Co-own data

Data are often collected within a community and community member play important roles in providing, gathering, and analyzing the data. Thus, it is only fair if community also possess the data. Control over findings includes inserting the name of community in a publication of findings. Co-owning data also means that community may interpret findings. Community

perspective in interpretation is also valuable. At this point, community can decide which finding is useful for them and which is not.

Set up Community-IRB or Community Research Board (CRB)

Most of the existing IRB (Institutional Research Board) deliberations deal with protection of human (individual) rights rather than protection of community rights. Moreover, the members of the IRB do not always include many community representatives. So we need another IRB (or modified IRB) which can accommodate the interest of community and protect the rights of community (Community-IRB/Community Research Board; *see also "Everything you always wanted to know about IRB's"*). For example, in the Genetic Research in Socially Identifiable Populations (Apache tribe, Oklahoma), the tribal CRB played significant roles from reviewing the treatment of blood samples to discussing findings and data storage.

Partnership-based research basically intends to empower community as well as other parties to gain power over their lives.



Everything you always wanted to know about IRB's



Sokmeakara Chiev

You might be saying, “What’s an IRB?” and wondering exactly what it is that you have always wanted to know about them! If you’re interested in forming a research partnership, or have already started working in one, then the answer is quite a bit. So we’ll start at the beginning.

IRB stands for Institutional Review Board. In 1974, a national act established that all research funded by the Department of Health and Human Services must undergo review by a board to make sure that research is conducted in an ethical manner. IRB’s are now found everywhere that humans participate in research (for example, hospitals, universities) to ensure that participants are not exposed to any unreasonable risk.

IRBs review all research plans to make sure they meet criteria for ethical research and assess the risks and benefits of participation.

The IRB’s role is to make sure that participants are not harmed *during* their participation in the experiment. IRB typically do not involve themselves with other ethical issues, such as:

- Who defines the research question? Is the community member an equal partner?
- How will the findings be brought back to the community? In a way that will benefit them?
- How does this research benefit the community?

As research partnerships become more and more common, many communities have started thinking about these issues, and about who is looking out for their best interests. This concern, tied with the recognition of the benefits research has to offer, has inspired many communities to form their own **Community IRBs**. These boards, consisting of members of the community, are very common among Native American communities, though others have started to form them as well. Community IRBs set up their own guidelines that a research protocol must follow, addressing such issues as:

- Benefit to the community
- Cultural sensitivity
- Data ownership

For more information about community IRB’s, check out:

- ✓ Detroit Urban Research Center at www.sph.uich.edu/urc
- ✓ Community Advisory Board at www.supreme.state.az.us/jjsd/cab.htm

Overcoming the Roadblocks to Partnership

Marie Martinelli

As a community leader, perhaps you are interested in becoming involved in a partnership, but you are not sure where to start. And, you've heard some good comments about partnerships, but other comments point to potential problems. Some people say that research partnerships are rarely successful. So, what are the obstacles and objections that you are likely to encounter and how can these be addressed? Below are some common questions and concerns many communities encounter when they begin to consider the idea of becoming involved in research partnerships. When you're faced with these roadblocks, how can you overcome them?

Objection 1

Will this partnership be of any benefit to the community?

☀ It's hard to anticipate all of the benefits partnerships might have on communities, but partnerships have worked in many communities and can be very beneficial. These benefits can be seen in many different communities, such as in Native American communities and the Native tribes in Hawaii. So where to start? Some steps to consider:

- ☀ Develop a Community-based advisory board
- ☀ Participate in the project planning
- ☀ Vocalize the community's concern and objections, if any
- ☀ Share knowledge and interventions for mutual benefit

Objection 2

As community leaders, how are we supposed to work with those researchers, when they seem to only want to collect their data and leave?

☀ It is not easy to form partnerships, especially when the groups contemplating the development of a partnership have different agendas, goals and objectives. Many times researchers can overlook important aspects of partnership, because they are so involved in their research. The challenge in working with traditional researchers is that researchers may be more focused on "benefiting humanity", advancing their own careers, and expanding scientific knowledge. The result can be that a particular community that provides the data to meet the above goals can end up feeling exploited. To overcome this, communities need to:

- ☀ Establish trust with researchers
- ☀ Be more involved in the planning process
- ☀ Meet with the researchers to see that the data are shared with the community or have researchers educate the community about how the data affects the community. These steps can ensure that data are used for program development to create policy and social change.

Objection 3

'Researchers do not know who we are. They don't understand our community and our culture. What do they know about our community's needs?'

🌟 To achieve a balanced partnership between researchers and communities, education and training should be developed.

Communities new to research partnerships may not yet have developed the experience needed to ensure that the full benefits of these associations are achieved. But other communities--such as the Native American tribes--have experienced various partnerships with researchers and have developed models that we can draw on for ideas and suggestions. These communities have been able to establish means of ensuring the community's ability to overcome obstacles and objections. It often isn't easy to join partnerships because you don't know where those partnerships will lead or indeed if it'll lead anywhere. And, it is even harder when the community is new to participating as a partner research. But like many other communities that have overcome the obstacles of partnerships, so will you and your community.

“Science Shops” in Lowell?

Kerrie Pharmer

As a member of your community, you may at some point have been the focus of a research project. Unfortunately, there have been situations where communities have been exploited by the research process. In contrast with this prevailing undemocratic model, "community-based research" is rooted in the community, serves a community's interests, and frequently encourages citizen participation at all levels. Community-based research aims not merely to advance understanding, but also to ensure that knowledge contributes to making a concrete and constructive difference in the world.

Sound Interesting?

- You see the benefits of research but want to take a more active role to make sure this research is being done ethically. You've created, or are part of a research partnership, but would like to explore further into the realm of community-based research centers?
- You may have heard of the so called “Dutch “Science Shops” but are not quite sure how they could work right here in the U.S or even in Lowell.

The following ideas may help you think about the possibilities.

What if the U.S. had an established network of several dozen community research centers (or “science shops”) associated them with universities, and conducted, coordinated, and summarized research in response to specific questions posed by community groups?

Start by looking at Universities.

- How is the Universities Research department organized?
- Work on developing partnerships or getting involved with partnerships that already exist.

How could this work within the Community?

- Gain recognition a “united community”.
- Build on strengths and resources in the community.
- Facilitate involvement of all partners in all phases of the research.
- Mutual benefit for all the partners.
- Disseminate findings to community involved.

No Additional Funding

- These new centers could provide community groups, local governments, and non-profit organizations with some of the support they will need to take up the slack when budget cuts exist.

- Because students are doing research and writing papers, and faculty are supervising and evaluating their work – extra cost is minimal.
- Sometimes research is persuaded by industry and funding sources, community centers may help balance this.
- Funding is now more available for Community-Based Research.

Where do these Community-Based Centers already exist in the U.S.?

- Some models already exist: the non profit Loka Institutes has begun compiling case studies of community –based research in the U.S. and elsewhere. You can check them out at www.loka.com.

Imagine this “community-based research” model working here in Lowell?

Lowell is an extremely diverse city, home to the largest Cambodian Community in the United States. One example of this “community-based research” in effect is the Southeast Asian Environmental Justice Partnership – leaders in the Cambodian and Laotian community, scholar-activists from the local university, and local health care providers came together to address environmental problems such as water problems environmental problems lead paint.

Knowledge Creation in Research Partnerships

Pascal Garbani

Two major aspects of creating successful partnership: **Sharing a common vision** of the future and **Creating Knowledge**. One major obstacle is how to get people grounded in different realities to get the ball rolling.

- Accept that you or the organization you represent have developed strong tendencies over the years about what constitutes Cooperation and Knowledge. Accept that these models may be self-constructed and therefore somewhat biased and subjective.
- Cooperate with the inevitable. Chances are the majority people will have a tendency at first to reject Partnership. Unlike the commonly used sport's metaphor. Better Team work does not necessarily come from more members conforming to a standard. Better Team work comes from accepting other's differences as a source of new knowledge and more perfect view of the whole.
- Use more Metaphors. By calling one entity by the name of another or substituting the parts for the whole, people can describe experiences or communicate ideas which are difficult to articulate. Metaphors help facilitate and shape change by making something strange look familiar. What is important is not so much which metaphor you use, but the fact that the group develops metaphors together to articulate a common vision of the future.
- Recognize that what constitute knowledge and how it is created is a very old debate which is not settled yet. Some consider knowledge the result of a mental process, based on theories and formulas – Rationalists. Others regard sensory experience, based on intuitions and hunches, as the fundamental source of knowledge - Empiricists.
- A Knowledge Creation Model to consider is one used by Japanese manufacturing plant in product development which requires a great deal of cooperation from parties that are not used to work together and are grounded in very different realities. The model acknowledges that for a group to create knowledge, it needs to create opportunities to share direct experiences (tacit knowledge) are a group through Socialization and Combine this tacit knowledge with theoretical frameworks (explicit knowledge). This interaction between tacit and explicit knowledge leads

Resources:

"The Knowledge Creating Company" I. Nonaka and H. Takeuchi, Oxford University Press, 1995

"Creative Organization Theory" G. Morgan, Sage Publications, 1989

"Organization Theory" D. Pugh, Penguin Books, 1997