Orienting Issues: Research Ethics In Diverse Partnerships

1. **The rights of the individual versus the rights of the community**: Much of the existing structure for ensuring rights is focused on the individual (e.g., ensuring that the individual has been able to exercise informed consent), but increasingly it is the community that is affected by the research (e.g., an identifiable Native American tribe might be studied and found to have high rates of obesity). An individual might agree to be in the study but it is the community that receives the brunt of negative publicity from the findings. What strategies might we consider for balancing individual versus community rights?

2. **When various steps are taken in the research partnership**: The importance of what we do in research partnerships lies not just in the particulars of what we do (trying to address a particular hypothesis) but when we do it. For example, if the researcher decides on the area of study before consultation with the community, this is a problem even if the particular hypothesis is one with which the community might agree.

3. **Who decides on the research agenda and research questions**: Researchers and their community partners often disagree about who should set the research agenda. Researchers with a detailed background in a particular area (say, for example, water contamination) often assert that they should make the decisions about the agenda. Community members aware of the health costs in the community often assert that they should make the decisions about the research agenda. How can these differences be negotiated so that rigorous research is carried out that is helpful in addressing problems and answering basic research questions?

4. **The importance of solving a problem versus understanding the problem at a basic level**: Communities and researchers often have different goals for the collection of data. Communities may see a problem that is devastating their children and recognize the need to find a way to eliminate the problem. Researchers are often trained to try to get to the bottom of things and to leave no alternative explanation that might account for an effect. These differences in goals can fundamentally affect the partnership.

5. **When is enough known? When has enough research been done**: Many underserved communities have experienced being “studied to death.” They keep being studied and yet there is little to show in the way of benefits to the community. How are decisions made that there is sufficient information to focus on interventions as opposed to collecting more data? Who makes this decision?

6. **Who owns the data**: Research generally results in data. Questions are increasingly emerging about who owns these data. If studies are done on level of lead in the blood of young children, does the community own the data? The researcher?

7. **The press of time**: Everyone involved in research partnerships talks about the need to get more done and people worry about how long research takes. What differs is where people seem to think it is reasonable for delays to occur. For example, researchers will talk about how long it takes (and how effortful it is) to get a community on board in planning for research. Many researchers will say that as a consequence they can’t afford to get involved community-researcher partnerships. On the other hand, researchers think it is fine for delays to result from the need to get institutional review board approval, the need to do another study, or to have a review of the manuscript on the results take a long time. Both groups worry about time and talk about being frustrated by how long things take. What differs is which delays seem bothersome.

8. **Stereotyping**: Many researchers describe “the community” as if it were monolithic (that is, everyone in the community is the same). Community members often do the same with researchers. All researchers are alike and if you have had a bad experience with one researcher who is manipulative you can count on all others being the same way. The interesting question is now to reduce the stereotyping each group does of the other.

9. **Who can speak for the community**: Researchers have been called to task for assuming that anyone in lives or works in a community is qualified to serve as a spokesperson for that community. Such may not be the case. Individuals may promote
themselves as leaders but may not be viewed as leaders by the community. An informal
or unseen structure may determine who in the community is best qualified to provide
leadership.

10. **Community Institutional Review Boards**: Some areas such as tribal nations have
developed their own institutional review boards (IRBs). No research can be done on the
reservation without the approval of this local board. In the past, IRBs were typically
connected to the research institution. How does this shift the dynamic between
communities and researchers? Could such an approach be adapted to a situation where
no distinct geographic boundaries exist or where the leadership structure is informal?
What challenges would need to be overcome to do so?

11. **Is the purpose of the research to gain general knowledge (and the individual
    “subjects” are just a means to that knowledge) or is the purpose to gain
    knowledge that is intended to be useful to those who participate in the research.**
    Many researchers talk about individual communities as “laboratories.” For the
    researcher, a community near to his or her university is a place to test to test out
    hypotheses but those researchers might have relatively little interest in ameliorating
    problems in that community. Community members, on the hand, may be very concerned
    not about the generalizability of the findings but about whether the findings speak directly
to the kinds of problems in their community and what can be done about those problems.

12. **Confidentiality of the research**: Issues of confidentiality come up in many forms. If
    research partnership follow all of the confidentiality requirements set up by institutional
    review boards, will confidentiality be fully ensured? What about cases of small
    communities where everyone knows everyone else? What about cases where the
    problem being studied is unique to a particular community and thus confidentiality can not
    be ensured?

13. **Intrusiveness of research**: Research is often intended to help us understand problems
    that are very troubling: things like child abuse, alcoholism, poor family relations, post
    traumatic stress. Such research can involve asking sensitive questions and collecting
    information or samples that potentially intrusive. What problems arise here and how
    might such problems be addressed?

14. **Quality of the research**: Different audiences (e.g., different community leaders, different
    types of researchers) often find different types of studies to be accurate and reliable.
    Such differences often get discussed in terms of the quality of the research. Discussions
    about how the research will be carried out are often discussions about perceived quality.

15. **Should the community be able to approve research findings before they are
    submitted for publication**: Many researchers struggle with calls for the community to
give their approval before findings can be submitted for publication. Many communities
are puzzled by the lack of understanding on the part of researchers for the need for
careful consideration of how results are described and how the community is portrayed.
Researchers sometimes see the issue in terms of prior restraint of publication whereas
communities sometimes see the issue of one of respect and power sharing. What
strategies might overcome these differences?
Example One: Issues at the Initial Stages of Research

Who Decides What Will Be Studied?

This deceptively simple question lies at the heart of many of the disagreements that take place early in research partnerships. This question also gets at the heart of ethical issues that emerge in partnerships.

Too often in research, researchers already know what they want to study before they even contact the community. The researcher may have spent a great deal of time studying a particular problem (asthma, water contamination, gang violence, the homeless, poverty), knows the research literature, and knows which issues are seen in the research community as the most important to be studied now. Linda Silka here: As a researcher myself I like to think that I have much to offer based on past work I have done and based on my understanding of the literature. The problem, of course, for me and for other researchers is that we may be learning only from each other and not from the community. Our sense of the problems that need to be studied is being shaped by one perspective (that of researchers).

Consider what most graduate training is like: Many graduate students are in the process of thinking about doing a thesis or project. When they are deciding about a thesis topic and a research problem, we can look at who they talk to, where they get their information, and what literature they read. Chances are the graduate students are developing their ideas by immersing themselves in a research literature. Only after doing this and formulating a research problem (perhaps even a hypothesis) do graduate students start to think about who in the community might work with them on this research issue. The upshot: The structure of much research training often encourages researchers to get pretty far along in the research process before they consult those who might be “studied” in the research.

Consider a study we will call the “Vacuum Cleaner Study”: Below is an example to help us think about the issues that emerge at the start of partnerships in terms of hypothesis generation:

Suppose there is an asthma trigger study that involves the use of high tech vacuum cleaners as the intervention. In developing this study, researchers have seen that the literature points to the possibility that the use of an expensive HEPA vacuum cleaner used in a very specific way (vacuuming the child’s room) will reduce asthma triggers and will reduce asthma attacks among children living in poverty. The research hypothesis, informally stated, is that high tech vacuum cleaners used in a particular way will significantly reduce asthma triggers. If we step back from this hypothesis and imagine the partnership working differently, this framing of the problem of what causes asthma attacks:
1. Assumes that the families are not now using this kind of vacuum cleaner or something similar.

2. Assumes that the planned procedure makes sense to the families.

3. Assumes that children have their own bedroom and that this bedroom is separate enough that the cleaning of it can be maintained.

4. Assumes that families would have the time and resources to continue this procedure if it is found successful.

5. Doesn't develop the plan out of an understanding of the daily lives of the families.

6. Is focused on testing a hypothesis rather than testing an intervention that is robust, reliable, and works for the families involved.

The "million dollar" question, of course, is how to integrate good science and science that matters! Research training encourages scientists to move pretty far along in the formulation of the research problem before consulting the community. What is missing with many of these approaches is the partnering of community knowledge and research knowledge—and partnering these types of knowledge early and often. We should be talking to each other at the beginning, middle, and ends of research cycles, and continue to do so.

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So, let's approach this problem differently. In your partnership, which of the following might work to formulate the research problem so that it integrates good science and science that makes a difference? What would you change to make these work? What assumptions about partnership are you making when you assume that these would work?

1. Suppose a researcher made a presentation to a community about the latest research on asthma triggers and included in the presentation questions asking whether people thought this kind of intervention would work.

2. Suppose the head of public housing came to a group of researchers at a university to discuss worries about the high rates of asthma among children living in public housing.
3. Suppose an asthma coalition made up of community members and researchers meets regularly to talk about asthma problems in the community and decides together what needs to be done to address the problem.

4. Suppose a researcher held a focus group with parents living in public housing whose children suffered from recurrent asthma attacks in order to present a series of ideas about possible interventions.

From your perspective, which of these approaches captures the idea of research partnership? How would your partnership move toward the hypothesis generation stage?

Some “take home” points from Example One:

∎ In the past, it has usually been the researcher who has decided what will be studied.

∎ Because researchers are generally more focused on answering questions than on developing effective interventions, the research may neglect questions of whether the research lends itself to application.

∎ To put it colloquially, a lot of water has already gone under the bridge before researchers consult with the community. Most researchers are used to involving the community only after they have fully immersed themselves in the existing literature.

∎ Many opportunities are being lost because research is being generated without all of the knowledge that both partners (community and researchers) can bring to the problem solving enterprise.
Example Two: Initial Stages of Partnerships

Research Partnerships Start in Different Ways

Partnerships not only start for different reasons; they start in different ways. Do any of the examples below look familiar? Have you started a partnership for any of these reasons?

What are some of the ways that partnerships can start?

∗ A University might have service learning for students (in which they work with local health agencies) and through the placement of students over time faculty and agency personnel become increasingly aware of shared concerns (e.g., Why does there seem to be so much asthma among very young children in the community?).

∗ A community organization (such as a community development corporation) is starting an affordable housing campaign and wants to bring researchers into a partnership so that they can help look at some of the data that exists and that is needed to understand affordable housing issues.

∗ A community may have noticed something alarming: that there seem to be many cases of lupus and other autoimmune diseases and that the community also has many contaminated sites that are located near residents, schools, and parks. The residents approach a nearby university to see if researchers would enter into a partnership to study the problem and identify possible solutions.

∗ A University might have so many researchers that are interested in the same problem (for example, asthma in the community) that researchers decide to start a partnership that will enable them to work collectively with the same community groups.

∗ A number of different community groups realize that they are all working in different ways with the same university researchers and realize that a partnership will make it easier to share results and approaches.

∗ A group of researchers may realize that if results are to be implemented it will be important that the research be done in ways that may implementation easy. They form a partnership to achieve these aims.

∗ A University might have a Community-University Advisory Board that advises the university on emerging problems. The Board helps to implement partnerships that are needed to address these problems.
Clearly, some of these partnerships are initiated by the community and some by researchers. Some start as a result of a particular problem and some as a result of a relationship begun for other reasons. Partnerships also seem to start because there are structures in place that encourage partnerships and they start because some kind of other activity (such as setting up service learning for students) provide unexpected opportunities for communities and researchers to learn about each other.
Example Three: Issues in the Middle Stages of Research

Who Decides How a Topic Will Be Studied?

It is sometimes useful to break the research process into questions of "what" and "how." This example looks at "how." Please note that this example is not intended to capture all of the different ways that research can be done (qualitative approaches, quantitative approaches, etc). Here we are simply trying to raise some of the partnership issues that emerge when decisions are made about how a topic will be studied.

Hidden Partners: Many partnerships discover that when they talk about how research will be carried out there are often other hidden "partners" in the room shaping how decisions will be made. If the research is being done with funding from a foundation or federal source (in the United States such as the National Institutes of Health), the hidden partner is a review panel that often severely limits the options for what will be considered good science. Other hidden partners are often the peer reviewers at a journal where the researchers are aiming to publish the research.

Why keep these hidden partners in mind? Partnerships keep these hidden partners in mind because they are often flavor the discussion whether we realize it or not. Their impact can be especially great in terms of decisions about "how."

An example: Below is an example that can perhaps help partnerships think about this "how" issue. As with other examples, we have changed things a bit to protect the innocent (or guilty) without changing the essential points. So, here's the example.

- **Background:** The US Centers for Disease Control has a major multiyear research-intervention program going on in a number of cities across the United States. This program is a part of the CDC emphasis on reducing health disparities. The intent is to understand what kinds of disparities exist and what kinds of strategies might be successful among particular groups in reducing these disparities. In each city, the program is built on a partnership model whereby groups from health care centers, underserved community, and universities come together to first identify the most pressing health problem and then advance solutions.

- **The research approach:** CDC dictates that, as a part of the program, each participating community must carry out a survey of a
representative sample of individuals at risk for health disparities. The design of the survey should be based on the latest research on how people obtain their health information and surveyors must be of the ethnic group that is being surveyed. All must be thoroughly trained to follow the exact protocol. The results must be reported to CDC.

What happened: In one city where this surveying was done the targeted group reported feeling pretty demoralized. They were trained by researchers not of their cultural background to administer the survey. The training was detailed and rigorous and focused on how to do the surveying right. Little room was left for flexibility. Each surveyor had a list of addresses to go to and was expected to meet goals of the number of people who participated.

The result: Very nice information resulted from the study. The partnership had clear information about how people obtain their health information (as it turns out, from a local cable television show in their own language). Many questions were answered about the frequency of smoking and other behaviors. The information can be used to plan a variety of interventions. On the other hand, those who were recruited to collect the data felt that they were not treated like colleagues and were not given much room to comment on strategies for strengthening the ways that the research was carried out.

So partnerships are trying to think about how to approach this situation differently. What might your partnership see as the problems? Can they be solved? How would your partnership go about solving them?

The Upshot: Research partnerships create the opportunity to do good research that makes a difference. They also provide the opportunity for everything to fly out of control, for groups to find that they don’t work well together, and for groups to become alienated from each other. Your partnership is hopefully now on its way toward designing ways to keep these problems from happening.
Example Four: Issues at Middle Stages of Research

**Confidentiality and Other Ethical Dilemmas**

It is relatively easy to assert that all research partners should be involved in the data interpretation stage. Clearly it is important that all be involved, but partnerships are also beginning to reflect on the confidentiality problems that can emerge when all partners are involved. Consider the following:

ษา A dissertation student in psychology is doing collaborative research on depression and anxiety disorder in a very small tribal nation in the Northeastern United States. The tribe is very concerned about the devastation these psychological problems are having in the community; tribal leaders wanted this research to be done. The researcher has worked closely with the tribe in designing the research but she is not Indian and she did not grow up on the reservation. She knows how important it is that the data be collected and interpreted in a culturally appropriate manner. But, the tribe is small enough that everyone is likely to know what others have written and said in the study. *What to do?*

ياة In the house-to-house study in the Cambodian and Laotian communities, the interviews are carried out by individuals who—if they don't know each other—know friends of friends. Because the interviewers have intimate knowledge of the culture they are able to interpret subtle nuances of responses and views. But, confidentiality is more difficult to maintain because these same interviewers know the community. *What to do?*

نشأ In that same study, families want to participate together. They don't want a single person in the family to represent their views. They talk about their responses together. So, confidentiality was not maintained within the family in the way the data were collected. But, this was also the way that the families wanted to provide the data. *What to do?*

_again, in that same study, people were often insulted when they were asked not to put their names on the survey and were told that the survey would be anonymous. People asked the research team whether they were seen as not good enough to have their names attached to the study results. *What to do?*

Now, not all of the above points have to do with confidentiality as it arises in interpretation. But all of these examples speak to this general concern. Research partnerships (as opposed to studies carried out just be researchers)
are likely to raise more issues about confidentiality at all stages of the research cycle. Many partnerships are addressing this issue directly.

- They are talking together about best ways to ensure confidentiality with insulting participants.

- They are discussing together the dilemma of information being inadvertently shared throughout the community.

- They are developing protocols for the handling of sensitive information.

- They are talking with other partnerships about the strategies that they are using and whether those strategies have worked.
Example Five: Issues at the End of a Research Sequence

Research for Publication: Promise and Pitfalls for Partnerships

In the final stages of a research cycle, the publication of results can be useful to partnerships. Increasingly, partnerships are paying attention to what they want (and don't want from publication). Partnerships are also increasingly looking at the need for innovations in dissemination.

Research that is carried out under most kinds of US federal funding requires publication in “standard,” peer-reviewed journals. The partnerships that obtained such grants will generally be asked to describe where they have published the findings and this information will be taken into account when the funder decides whether the research partnership should be refunded in the future.

Partnerships have begun to look more closely at this emphasis on publication in scholarly journals and what they might gain and what they might lose through this emphasis. And partnerships are finding that this emphasis on dissemination can serve several purposes.

✦ Most journals have built in quality controls. Articles are not accepted for publication unless they have undergone rigorous review by other scholars and these scholars find that the studies are indeed original and meritorious. In other words, the conclusions that are drawn from the study are taken to be reasonable given the way in which the study was done. So, a study is assumed to have a stamp of approval once that study is published in a scholarly journal.

✦ There is another reason for funders to emphasize publication and that is related to the importance given to dissemination. The funders want the scholarship to be disseminated; they want others to learn about the research. Researchers read journals and so the best way for dissemination to occur among researchers is often to publish the results in journals.

Reminders of the Side Effects of an Emphasis on Scholarly Publications

This focus on publication also has various kinds of side effects. As many of us have found out, the extent to which a researcher is awarded tenure is often partly or largely decided by the number of publications he or she has produced. Publications serve as a short-hand way of ensuring that the work of this tenure candidate is of high quality and is productive. There are so few academic slots
around the country and universities have so little funding, that universities have come to count on the journals to do some of the quality control analysis for them. If a journal publishes the tenure candidate’s research, then it is assumed that the research is high quality.

Yet another side effect of the focus on journal publication is that while in graduate school, researchers learn to set their eyes “on the prize” of publishing and they tend to forget to look beyond publication to questions of what will be done once the results are in. It might sound strange, but questions of how the knowledge will be used just don’t come up very often (or certainly as often as they should).

So, these are benefits that journal publications bring in terms dissemination and quality control. But, are there things that scholarly publications don’t do well?

For the most part, journal publications:

- Do not reach nonacademic, non-research audiences
- Do not use language with which all readers are comfortable
- Do not focus on questions of dissemination
- Only report “significant” results so studies that don’t reach this criterion are not published but may have taken up lots of a community’s time to be carried out
- Often have a very long lag time between the completion of the research to its publication.

We need to think about other ways to get the word out about results. What might such strategies be?
Example Six: End of a Research Sequence

A Common Dilemma: Results that Reflect Badly On Community

It is not uncommon for results of research to reflect badly on a community. Has your partnership encountered examples of research that might be like this?

Studies might find, for example, that a particular community has an elevated rate of crime or gang violence. A community might be discovered to have high rates of chemical contamination, thus potentially reducing the market value of the homes of people in that community. Parents might be shown in a study to be uninterested in the schools or uninvolved in their children’s educations. A study might find high rates of corruption in the public sector. In short, there are many different findings that could reflect badly on a community, be it a community defined by geographical boundaries, ethnic links, religious bonds, or something else.

Because studies tend to be problem-focused, it should not be surprising that they often have bad news to share or present a community in a negative light. But what do we do about this?

First, it is important to realize that this problem of “bad news” is far from limited to communities. Right now there is a movement afoot among the editors of medical journals, to require that all drug trials being carried out by pharmaceutical companies and other groups be registered. Such a step will reduce the likelihood that companies won’t report the results from drug trials when those studies don’t show positive effects for the drug being tested. So, communities are not alone in being concerned about results that reflect badly on them.

So, what do partnerships do when results do reflect badly on the group being studies? The Massachusetts AFL-CIO statement on research partnerships, for example, says that they would not attempt to suppress data nor would they agree to participate in any research in which the company could have final say on the interpretation of the data or whether the data were made public.

What partnerships are searching for at this point is inventive ways to involve all partners—well before any data are collected—in thinking through what the results might look like and how those results could be used. A couple of considerations:
How would you overcome the obstacle of most partners having too little time? Talking about what the data would look like takes time. What strategies would you use?

Would you tie “next steps” to these discussions? In other words, would you consider facilitating a discussion in which partners were asked to think about the data in terms of how they would use them rather than merely in terms of what they said about the level of a problem?

Back to the Issue of Who Starts the Partnership

We are discussing here the difficult dilemma of findings that reflect badly on a community. Consider some of the work of WEACT, a community group. WEACT in Harlem, New York very much wanted to understand the level of the environmental health problems that existed in their neighborhoods. WEACT was, in effect, seeking to learn more about a problem that existed in the neighborhoods and was affecting the health of children.

One might look at this example and see that the information collected to reflect badly on the community. But, we may be missing something in that interpretation. Think a bit about the fact that is was community leaders who, in effect, started the partnership. They sought out the researchers. They (the community leaders) were focused on creating a plan for change.

Partnerships are starting to consider the possibility that who starts the partnership may be important in terms of responses to the data and uses to which the data are put.
Example Seven: Issues that Affect All Points in Research Cycle

Moving Beyond Institutional Review Boards: Community Advisory Boards

In many ways we are much better off having IRBs in place than not having these boards acting to evaluate whether proposed research is consistent with ethical guidelines. IRBs add an important layer of protection. Prior to their existence, researchers carried out whatever studies they judged to be scientifically significant and they often did so without obtaining informed consent and without adequately debriefing people or ensuring that their rights were protected. Many excesses occurred ostensibly in the name of science. So, IRBs add to the protections that now exist.

But IRBs are not designed to do everything that people assume they do. In particular, they don’t address many of the issues that are central to the concerns of community university research partnerships. These concerns include:

1. Community input on research design, study implementation, and data analysis.
2. Community oversight of the design to ensure cultural sensitivity and responsiveness.
3. Questions of who owns the data and what will be done with the data.
4. Questions about whether adequate attention has been given to whether the benefits for the community (as opposed to the individual) are sufficient.
5. Giving back to the community in any way or ensuring that the results are used by and useful to the community.

Suppose we designed a very nice car (bear with us on this—there is actually a point to this example!). The car may be great car (runs fine, gets good mileage, is just the right color) but that still doesn’t make it an airplane. If what we need is something that can cover great distances quickly then no matter how good the car is it still isn’t a plane. The same holds true of IRBs: when they run well they may be very good for what they
are designed to do but unfortunately they are not designed to do everything we need to ensure ethical research partnerships.

Many people are increasingly trying to solve this problem of how to have review boards that are better equipped to address the larger questions that are being raised about the ethics of research partnerships. In trying to solve this problem, people are focusing in on a number of issues with IRBs:

1. Is part of the problem one of composition of IRB boards? That is, IRBs are made up mostly of researchers and is this perhaps similar to “putting the fox in charge of the hen house”? If we change the composition of the boards, will this solve problems and, if so, which ones?

2. Is the problem one of focus: IRBs focus on the individual, on informed consent, and on the particulars of the research process. They don’t focus on how the partnership is set up (or even whether a partnership should be in place). They don’t concern themselves with questions about what will be done with the findings or who owns the data.

3. Is the problem a result of a focus on individual studies as opposed to multiple studies? Many proposals to IRBs (but not all proposals) focus on a single study proposed by researchers. There is often little in such a proposal that orients the reviewer to concerns about building long term relationships.

4. Is the focus too much on internal validity and not enough on external validity? In other words, is the focus too much on the quality of the design (and ensuring safeguards are in place given that design) and too little on what will be done with the findings and whether the findings speak to issues of pressing important to those in the community who will use the research?

5. Is the problem that IRBs do not give consideration to how the research will be used to make changes?

Innovations!

Where are innovations taking place? Important advances are being introduced in North American Native American tribal communities as well as the Detroit, Michigan Partnership in the United States. When we look closely at these examples we see some intriguing changes and new requirements that move much closer to some of the goals important to community university partnerships. When we look at these examples we see, for example, that the approval process has been transformed. Rather than the research institution providing the ethical stamp of approval, the community board does this. And the community boards put into place a different set of requirements, requirements that can include a focus on data ownership, on uses of data for amelioration and improvement, and on final decision making that is in the hands of the community.
Before we conclude that it makes sense to require community review boards everywhere and on all occasions, it is probably useful to think about what might be unique about these two situations (tribal nations and funded research centers). In both cases, one can get one's hands around the situation. A tribal nation can decide what it will do. As a nation it has defined borders. To some degree this is also true of the Detroit Center (with its defined roles and responsibilities). But, the Detroit, Michigan Center even adds to this. The Center example reminds us that part of what is workable about the model is that all the research, in effect, comes in through one door in the Detroit case. Anyone who wants to do research in that neighborhood and with the resources of the Center must receive the approval of the center board.

Most cities and communities face a far different situation. Researchers are coming in and out all the time. No one really knows when some new researcher has come to do research. The situation is highly fluid. We need, then, to design some strategies that might work in this more fluid situation (a situation which is very common). New possibilities need to be invented. What might they be? What might be some alternatives to institutional review boards that could realistically be implemented in many of the communities and situations with which you are familiar?

Expect that not everyone is going to embrace the idea of community advisory boards:

Consider this response on the part of researchers to institutional review boards and the like. In the journal *Psychological Science* (one of the leading journals for psychological researchers), a special issue was published in the last year or so that repeatedly made the point that some researchers believe that constraints on research have gone too far. In their view, less oversight of research is needed rather than more. In particular, these researchers object to nonpsychologists being allowed to assess whether proposed research has sufficient scientific merit; that is, whether it should be approved by an institutional review board. This example is fascinating and is probably worth keeping in mind. These researchers are focused on the obstacles they see as standing in the way of good science.
Example Eight: Issues in the Final Stages

*Strengthening the Final Stage of the Research Cycle: Creating Usable Knowledge*

You might be familiar with usability studies carried out by computer companies. Computer designers try not to go off into a corner and design a computer (or a piece of software) all by themselves. Instead they involve end users in testing various features of the computer design. Computer designers would probably not call what they do being a part of a research partnership but their approach does share common elements with what we have been calling research partnerships. The design is done in collaboration. They design for usable knowledge. Consider, below, some other examples that point to the increasing value being placed on usable knowledge.

**Best Practices**

The intriguing phrase “best practices” is now being used with increasing frequency in community university partnerships. The phrase “best practices,” like “science-based” interventions (another phrase increasingly occurring in the literature) reflects an innovation that is now taking place in how research is being carried out. When there is an emphasis on best practices, the focus is placed on how research can be useful, on how interventions can emerge out of research. The US National Institute of Environmental Health Sciences uses yet another phrase, that of “translational research,” to focus our attention on the importance of doing research in a way that leads directly to action and policy. The focus is on usable knowledge.

**The Research Cycle**

What does all of this have to do with strengthening the final stage of the research cycle? In partnerships people are talking about the importance of thinking about all of the stages of research together! The final stage--disseminating and using research--depends on a strong working research partnership being in place. Partnerships are finding that research is better designed if the end users are involved throughout the research. For example, if those who are going to carry out healthy homes interventions are involved in the design of research aimed at understanding contaminants in the home, then the contaminant research is likely to be more useful. Fewer steps may be needed to go from the basic research to the application of that research.

*Research that Fits the Community*
How do partnerships end up with usable knowledge? In the area of substance abuse prevention, the US federal agency CSAP (Center for Substance Abuse Prevention) has gathered together a vast body of research on what works to prevent substance abuse. A number of different models have been found to be equally successful in preventing substance abuse. The next step that CSAP has taken is to provide funding to community partnerships to look through the different models, learn about them, and then decide which of the various models has greatest applicability to their own community. Each community partnership is encouraged to consider their own situation in applying the research.

This CSAP approach is an intriguing one and represents an interesting innovation. The approach says that one of the important roles that community partners play is in evaluating the applicability of research to a particular set of circumstances. This is one example of how findings might be made usable.

Making Findings Usable

Partnerships are also looking other strategies for taking the results from studies and disseminating them in useful ways. Consider first some ways that might not work (and what we can learn from these). Consider the ways of making the dangers of mercury widely known. In other weeks, we have talked about mercury contamination of fish and my experience with researchers seeing the danger of mercury poisoning from eating fish as so serious that the researchers recommend that people be advice to stop eating freshwater fish. *What is the problem with this as a dissemination strategy? Why might this not work?* This strategy is certainly used—it was used on radio stations around the US this fall. The problem with advice giving—which is what this represents—is that it is too overarching and all-encompassing. It doesn’t provide alternatives. So, what do we do?

In one of our projects in Massachusetts we focused on fishing and understanding family traditions around fishing. The idea was to learn enough that we could figure out how as a partnership to disseminate findings about fish and mercury. We went to Buddhist temples and shared stories about family traditions of fishing (for example I shared stories about my farmer grandparents Orville and Velma and the fishing for bullheads they used to do in Iowa in their farm ponds) and Cambodian and Laotian shared stories of fishing in the Mekong and the Merrimack. We also shared fishing recipes. The result was that we all learned more about the roles of fishing and eating fish in different cultures and could then figure out how to talk about mercury contamination in ways that focused attention on the problem without assuming that people would change all of their traditions and entirely eliminate fish from their diet. Dora Tovar, a doctoral student working with us, put together fishing recipes from different cultures and then used this as a way to encourage people to also think about fish and mercury in a nuanced
way. Her advice: Don’t lose the complexity, either of the message or of the culture!

In Ohio, a group developed a heart attack prevention program for Asian families, many of whom do not speak English. The partnership that developed the program wanted to evaluate its effectiveness but traditional paper and pencil strategies didn’t work. The families were very uncomfortable with this part of the research procedure. So, the researchers developed this great board game that really fit with the culture of the participants and that provided opportunities for people to show what they had learned in different areas.

In Massachusetts, we used the concept of a teen “Envirocamp” as a way to assist teens in disseminating research (such as on healthy homes) to their community. The teens developed a cable television show, puppet shows, rap songs, and other strategies as ways to share findings with families in their community. In each case, the teens from our River Ambassadors Program focused on working with researchers to learn about the research, and then thought about the groups they wanted to involve in using the research, and then structured the presentations so that they would capture the audience’s interest and would be “sticky.” Sticky messages are ones that people don’t forget!

In Massachusetts we found that of all environmental issues in our community, purity of water tended to be the important gateway issue. This was the issue that everyone cared about. So as a partnership we thought about whether there might be ways to attend to the importance of this issue, its salience in various cultures, and share information about research. The Southeast Asian Water Festival, attended by thousands of people, has become one way of doing this. The Festival enabled the partnership to highlight research and show that cultural traditions are in “the driver’s seat.”

What can we conclude from these simple examples? They are intended to suggest that there is lots of important work yet to be done in thinking about how we bring research to application, how we disseminate findings. Journal articles serve many useful purposes, but usable knowledge has to go beyond written, scholarly words. The above are examples to help us start to think about what we as individuals and members of partnerships can contribute to the final stage of research, to the stage of having the research results become usable. The key is not just to finish the research but translate the research into usable community currency. Many challenges remain.