If we had time, we could talk about

community ethical review of research

if we all spoke the same language

A Conversation for Many Voices
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Some Useful Readings

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About the Authors

This report was produced by the Community Research Group of New York State Psychiatric Institute and Mailman School of Public Health of Columbia University, co-directed by Drs. Mindy and Robert Fullilove. Moriah McSharry McGrath and Molly Rose Kaufman contributed to this report. The exercises were developed by Molly Rose Kaufman, Kiara Nagel, and Brian Cheigh.

For the detailed description of the study and its findings, you cancontact us at community.research.group@gmail.com.

So how do we conduct "community ethical review of research"?

1. **Researchers should have the primary responsibility for protecting communities.**

Researchers should bear the ethical burden for protecting communities, just as they bear the ethical burden for protecting individuals. It is completely within the realm of possibility to teach researchers the issues that are at stake in studying communities, and ask that they address real and potential harms in developing their studies. Through conferences and training sessions, a discourse of community protection could be elaborated in a fairly short period of time. Such a task would not pose an enormous additional burden on researchers.

2. **Local wisdom should be incorporated at all stages of the research process.**

Developing research without adequate awareness of local wisdom introduces important scientific bias. Therefore, researchers should have the ethical and scientific obligation of working with local people to develop a shared understanding of the local areas.

3. **Community people who are willing to serve as ethical reviewers should be offered free science education.**

It is difficult to carry out the responsibility for reviewing science without adequate knowledge of what is being done. Universities should bear the costs of this science education. A masters degree in community ethical review, offered in exchange for service on a community review board or IRB panel, would be a fair exchange for all involved.

4. **Organizing the unorganized should be a priority of community activists.**

The neighborhoods that were the sites of research for this project lacked political power and therefore were in a poor position to protect themselves from the excesses of the grant plantation. Community organizers need to continue their efforts to organize the unorganized, creating social, economic and political power.

Overview

The Question: Is there an effective model of community ethical review of research?

Research can injure individuals and it can injure communities. In order to protect people, the US government has developed a system of review of research. Major research funders have also acknowledged that community representatives should be included in research projects. Representatives of communities are working together with researchers in many ways, ranging from informal advice to community-based participatory research. Is one of these models of cooperation more effective than others? In order to answer this question we conducted case studies of three different models of community-research collaboration to see what happens when people carry out community ethical review of research.

Our Method

We used situation analysis to examine the ways people worked together and the settings within which they carried out the work. We collected data from three different groups working at a research medical center in the Northeast. The first was a large research center that engaged community spokespeople in every phase of research, from formulating a question to carrying out analysis. The second, another large research center, got advice from community leaders as well, but they started getting advice after their study had begun. The third was a panel of the institutional review board for the protection of human subjects. As is the case for all IRBs, lay people, representing nearby communities, were members of the panel. We observed meetings of the three groups, and interviewed participants. We also examined materials from conferences at which researchers and community representatives were present.

Our Findings

Everyone involved worked hard: the researchers, the clinicians, and the people who represented local neighborhoods. Despite all this hard work we noticed recurring problems that stood in everybody's way. These were:

- The word "community" was used a lot but rarely defined;
- Scientists and community spokespeople differed in the kinds of knowledge they brought to the conversation, and inter-group exchange was difficult;
- Researchers, clinicians and community people also had different agendas that got in the way of cooperation; and
- Everyone complained about having too little time.

These recurring problems were set in the context of the massive system of research – the university-research complex – which drives production of knowledge at a very rapid pace and imposes real constraints on the process of community ethical review.

Our Conclusion

We found that these problems affected community ethical review in each of the three groups we saw in action. We think that these problems may well be universal to collaborations. Thus, we are not convinced that there is a perfect model of community ethical review of research. The many kinds of models that exist may each be useful in particular circumstances. However, we are convinced that collaborators can improve their ability to work together if they tackle the problems that interfere with the work. In the following sections, we examine these problems in more detail. We also offer exercises to help teams talk through the issues, considering ways in which their own work might be improved.

What's in a name? Examining our terms

Community

Sociologists and other students of community have documented that this word has many meanings. Communities are complex and vital organisms that emerge from the intersections people, places, things, ideas, understandings, ideologies, and an infinite number of other variables. O'Fallon and Dearry (2002), write on defining communities, "One of the greatest challenges to CBPR is defining 'community' because of its many socially constructed dimensions. For example, community could be defined as residents within a town, an ethnic population, a set of workers, or apartment building residents. Units of identity, such as family membership, social networks, or neighborhoods are created and recreated through social interactions. Because of its dynamic and diverse nature, no one definition of community can be applied to every situation."

We propose to simplify the task of defining a community by using just two key characteristics:

- Is the community located in a specific geographic area or is it a community that has something else in common?
- Is the community empowered because of its activism, political organization, status as a tribe or something equivalent or is it disempowered?

This strategy creates four groups and most communities can be assigned to one of these groups: located together with power, located together without power, dispersed with power, dispersed without power.

Our project examined community review based in disempowered minority neighborhoods, that is to say, communities that fit into the second group: located together but without power. Thus, this report will assume that "community" is a signifier for "poor people of color who live around here". The phrase "community ethical review of research" can be read as saying, "Let the excluded participate in ethical review of research".

Here is an exercise that your group can use to explore these definitions of community. Our goal in this exercise is to help each of us think, "What do *I* mean when I use this word?"

Exercise #1: What is Community?

Goals:
Examine the use (or overuse) of the term 'community' and the implications this has for research, consent, etc.

Materials:
Index cards or scraps of paper, pens, board or flipchart visible to the group.

Introduction:
Ask everyone to go around and introduce themselves and their work; ask them to describe why they feel their work is important.

During this part of the exercise, make note of the number of times the word 'community' is used, and how it is used (for example, geography, shared characteristics, class, race, neighborhood, etc.).

Activity: *Pass out index cards and pens to the group.*
Say to the group: Write down your definition of 'community' on the index cards.

ethics typically focuses on the role of the individual research participant and the process through which he or she consents to be in a particular study – the institution is not called in for review.

But when survey responses for all individual respondents are aggregated, the presentation of the data has the potential to stigmatize the neighborhood and/or community from which individual respondents were drawn. The study typically highlights the collective, not the individual. Thus, even residents who were not interviewed may be harmed in a variety of ways. Research findings that depict significantly high levels of violence, criminal activity, HIV infection, to name just a few, will either reinforce or create the general impression that the community that was studied is neither safe, nor desirable, nor worthy of the kinds of assistance that might alleviate the problems that are highlighted by the research. The final activity in this report is intended to guide a discussion of the ecology of community university research.

Exercise #5: Models and Ecological Health

Activity: *Consider the following questions with your collaborators. For every question, also ask,* "How could this process be improved?"

Models of community university partnerships – where do we fit in?

- What are the consequences of our work?
- How are we all part of one ecosystem?
- How do we rethink the role of universities?

What is our process for building relationships between partners? Who trusts whom?

Who owns the information/data collected/created?

- What is our process for disseminating results/information/results?

Who are the "gatekeepers" ? Who are the connecters/liaisons?

- How effective/important are they?
- How are they valued?

How do we develop real expectations for a project?

How is the process of consent revisited at different points along the project?

- How do we deal with controversy/complaints/problems/mistakes that arise?
- How do we adapt to change?
- How do we meet IRB guidelines? How do we go beyond them?

What are the responsibilities of:

- researchers?
- participants?
- community-based organizations?

How is good collaborative work recognized and rewarded?

Who wins?

Who loses?

Problems of the "Grant Plantation"

The urban university

As the leading producer of scientific research in the United States, US higher education is a fundamental contributor to the stunning power of American technology and basic science. Few would dispute the proposition that America's partnership with its research universities has contributed enormously to the shaping of modern life in the 20th century. Maintaining this position is not, however, without its costs.

The modern American research university is estimated to require a rate of growth of 2.5 million square feet every two years in order to create the laboratory and office space that must accommodate the ever-growing needs of the research enterprise. In urban universities, such as Columbia University, the University of Chicago, Johns Hopkins, or the University of Pittsburgh, the expansion of the surface area of the campus often comes at a cost to the residents of the poor communities of color that surround these institutions. Residents are often displaced in order to satisfy the demands for space, as the research being conducted is deemed more important than the lives in progress in the neighborhood.

Complicating the picture is the research that is frequently directed at these very same communities. The inner city and the myriad sets of conditions that are associated with urban poverty have been extensively studied by sociologists, psychologists, as well as medical and public health researchers, to name just a few of the relevant disciplines. The motivation for this research is ostensibly well intentioned: it involves naming the problems, understanding their causes, and proposing possible solutions. In occupying itself with these problems, the modern research university receives the necessary funding to maintain itself, its faculty, and its position as a producer of scientific knowledge.

Yet such knowledge has created an image of poor neighborhoods collapsing under the weight of problems and dysfunction. Furthermore, when universities propose expansion, it is the grim statistics of the crime and the poverty, and community morbidity and mortality that contribute to the view that rebuilding in the name of science kills two birds with one stone: advancing science and solving the problems of "the ghetto."

Spatial relations

George Evans, a councilman in Pittsburgh in 1943, summed up a view that prevails to this day when describing the need to clear a large, ghetto neighborhood on the borders of downtown Pittsburgh (and, coincidentally, a few blocks from the campus of the University of Pittsburgh): "Approximately 90 percent of the buildings in the area are substandard and have long outlived their usefulness, and so there would be no social loss if they were destroyed." Sixty years later, the continued razing of the Pittsburgh ghetto described by Evans continues, with homes, parking lots, large arenas, and university living facilities gradually replacing what was once a vibrant inner city community (Fullilove, 2004).

Devaluing the neighborhood

The more these issues are described, the greater the perception that the people and places that are caught up in these problems are social deficits rather than social assets. The problem with this kind of thinking is obvious: deficits deserve to be removed; assets deserve to be preserved. In too many instances the science that was designed to help such communities conflates the place and the problem. Since it is the people that make the space a place, it is not a far leap of logic to follow that the place and the problem would be better off without "those people."

If the university ultimately purchases the land and uses it for its own expansion and growth, its role in lowering the value of the land by inventorying the community's pathologies and gaining control of it through its research activities is, at best, ethically repulsive. This particular scenario is rarely examined, largely because the field of research

Collect the index cards.
Shuffle and redistribute the cards back to the group.

Say to the group: Read out loud to the rest of the group the definition on the card you received.

As definitions are being read out, write on the board or flipchart major themes or overlapping concepts that emerge from the definitions of 'community.'

Say to the group: As you can see, there are many ways of defining community.

Continue: Now, describe your community; define your community

Wait to see if people respond. If yes, have a few people to share their personal definitions. Allow the group to discuss these questions, asking them one at a time.

- What are some of the communities you are a part of?
- Can you speak on behalf of this group/ for this group? Can you give consent for them?
- Who represents your community (local/national)? Speaks on behalf of your community?
- What are some of the ways you use the word 'community' in your work (i.e., in grant writing, research questions, mission statements…)?

Say to the group: As we've seen, we've used community to imply many different things *(give specific examples from the group's previous discussion)*. The term can have vastly different meanings, and can also be used as a way to avoid using real terms to describe what we actually mean. In a book called "Science and Sanity," Alfred Korzybski suggested that tactics like these – whether accidental or intentional – can be harmful. He explained that people's mental health can suffer when there is lack of appropriate terminology for things. For example, we are all talking about community, thinking that everyone is using the same definition of the term. Yet, people actually have very different definitions, so we are constantly misinterpreting each other. It could just be enough to make you crazy!

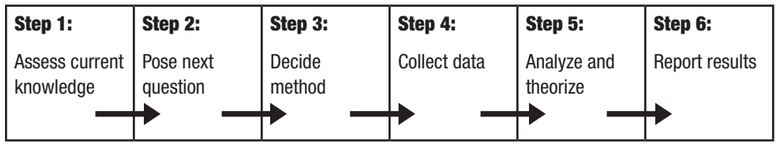
Ask the group: How is 'community' a codified term?

What are the some of the dangers of not clarifying the term 'community'?

Say to the group: Let's make a deal to raise our consciousness around the term community. For the rest of the workshop, whenever someone uses the general term 'community,' everyone has to say "CLARIFY!" and the person should reframe the phrase using different terms. Agreed? Let's practice: "I mostly work in the community" (group should respond with "Clarify!").

Research

Research is the activity of posing and answering questions about how the world works. Research follows a set pathway; it has six key steps.



In theory, anyone can do research, as long as they follow the rules. In practice, research takes a lot of money, and that money is given to a select group of people who have completed years of training and proven their ability to produce interesting results. Research is funded through the federal government and many private groups. Most of the money goes to universities. The people who practice science at the universities and the people who give out the money and the people who publish the journals and the industries that use the information are all interconnected, making up one big research-university-industrial complex. This exercise will help you think more about the basic questions that get asked in putting together a research study.

Exercise #2: Design a Study of Scientists

Goal: To examine the assumptions we bring to the table when we begin a research study.

Materials: Markers and a black/whiteboard or a flipchart

Activity: *Say to the group:* We have been asked by the Department of Scientific Inquiry (DSI) to design a study of scientists. This project is going to be an exciting opportunity to look at a population that has remained largely underserved by public health professionals.

Ask for a volunteer to take notes. Continue: To begin with, let's start by discussing what we already know about this group. *(Use the following questions as sample questions if the group needs additional ideas to get started.)*

- What are the demographics of this group?
- What do they look like?
- What do they eat?
- What are the problems this 'community' might face? (Use this question as a test to see whether the group has caught onto the idea of CLARIFY with the term 'community.')
- What kinds of stress do they face? What illnesses do they get?

Say to the group: So we already have significant information about this group. Now we must formulate a research question. What do you want to study about scientists?

- What about a research project that studies how they raise their kids? Infant care practices? Their diet? Stress levels?
- How would you design the research project?
- How would you create/choose a focus group?
- How would you get the participants to consent to be in your study?
- What are some funding streams that would support this study, be interested in the findings?

It is inherent to the nature of this institution. It is a grant farm. Grant plantation farming off of people of color. That is what this place is.

In this "grant plantation" metaphor, the production of knowledge is likened to the intensive production of sugar and cotton, a process that strips the environment of resources and fails to recycle constituent nutrients. Plantation agriculture ultimately desertifies the land and the people. If we follow this analogy it suggests that the knowledge production that takes from, but fails to return to, local neighborhoods contributes to their downfall.

At the same time, it encourages us to look at the conditions of the workers on the grant plantation, the scientists, who suffer from the conditions of their work environment: uncertain employment, constant pressure to accelerate production, and ruthless harvesting of the best fruit, without regard to a more ecological treatment of the product of the land. This is a dire picture, but one, we believe, that is in tune with the evidence. In this context, the researcher's comment that working with local representatives is "too costly" must be treated with respect as a true description of an exploitative system. This system, then, deserves further consideration.

Exercise #4: Working Under Extreme Pressure

Goal: Consider the ways in which the "grant plantation" affects community ethical review.

Materials: Pads for taking notes and markers.

Activity: *"Time is Money." Divide the participants into groups. Ask each group to consider the following question:*

What does it take to get money to support community organizations? What training does a community leader have to have? In what ways are community organizations stable or unstable?

What does it take to get money for research? What kind of training do researchers have to have? How is the work stable or unstable?

Ask each group to sort these realities into the following categories:

- Dependencies – what groups do community organizations depend on for their functioning? What groups do researchers need?
- Deliverables – What are products that must come from the work?
- Objectives – What are community groups trying to accomplish? What do researchers hope to achieve?

Ask each group to consider the following series of questions, and take notes:

- Knowing everyone's disparate dependencies, deliverables, and objectives, how could everyone work together? What are the processes that could make this ideal scenario happen?
- In reality, how are research projects actually conducted and how are each player's objectives actually achieved? What are some negative externalities that result?
- What are some small changes that each role could make to get from the reality of business-as-usual to the ideal process?
  What are more major changes that could happen?

Wrap-up: *Ask:* What did you learn from this exercise?

> There are things that I can point out depending on the study. If I think something is wrong, I am going to voice it strongly. Most of the time I feel listened to, but then they explain it's because I am not familiar with the scientific language.

What struck us about this comment is that lay people are appointed to the IRB because they don't know science. Yet this source of their authority is then held against them.

Ignoring local wisdom

Not everyone that we talked to or observed was as interested in working with community people was were the leaders of the Optional Center. Community people were very clear about the difference in attitude. They expressed the notion that although some researchers gave the illusion of respect, it did not seem to be accompanied by power to influence decisions: "... when it comes to what we know about, there's a lot of lip service. They say, 'Yes, we want to hear because this is what you know about.'" But representatives rarely saw the impact of their feedback. One community spokesperson, after years of experience collaborating with the university, had very clear ideas about how this dynamic operated:

> There is a difference between advice or feedback/input and the power to affect a decision. We've been asked for opinions and a different thing has been done. The extreme example is opinions are asked for and then completely discounted. I don't think there's malicious intent on the part of researchers. They have a sense that those opinions are really influencing their work. There is an assumption that hearing the opinions and knowing that that is somehow affecting my decision-making is enough. Which is different than the assumption on the part of the community people, which is "If I show up in the middle of a workday to give my two cents, you damn well better do something with it."

In addition to the Optional Center and the IRB, we interviewed people who worked with a group we called the Cohort Center. That group was conducting a long-term study focused on pollution and health and drawing its subjects from surrounding neighborhoods that had long histories of oppression. These histories, though similar on many counts, were not exactly alike. Some researchers in the Center argued that these different histories needed to be part of the Center's approach to data analysis. Leaders of the Center, however, did not agree to use this local knowledge. They preferred to use the race and ethnicity to examine their data.

If we had time...

These brief examples are meant to convey the strains that accompanied the effort to conduct community ethical review of research. Time was short, and the obstacles to communication were many, chief among them the power relationship between the research-university-industrial complex and the surrounding poor neighborhoods from which the subjects of research were drawn. Ultimately, taking the time to listen to poor people or their representatives was not worth very much in the economics of research. One investigator proposed a most surprising metaphor for the local research establishment:

> These communities are under great stress from all sides. Clearly the game plan is to move people of color out to the end of the train lines. Given that kind of relentless pressure on community groups — [the city authorities] don't put out the fires, they don't collect the garbage, they don't fund the schools, they don't fund the hospitals, the police are a brutal occupying army — given that pressure, it is a little much to ask community groups to closely monitor the research being done by the research plantation. It is an ethical responsibility of the researchers that are here to ensure that the community is properly treated. Otherwise it will continue to be an ethical failure.

Wrap-Up: *What are implications of this exercise? How is it that we make assumptions about 'subjects.'? Who has the power to create a research question?*

Ethics

Research contributes to our knowledge, but sometimes research has harmed the people who participated. Some of these stories are well-known, like the Tuskegee Syphilis Study, which asked the question: How are black men with syphilis different from white men with syphilis? In order to answer this question, researchers followed partially-treatment black men from 1932 until the study was shut down in 1972 because of public outrage. In order to protect people from being harmed by research, national and international commissions developed methods for review of research based on the ethical principles of justice, beneficence and respect for persons.

New issues are constantly reshaping how we think about these basic principles. For example, many people have pointed out the need for the protection of communities, which has been called the "4th principle of ethical research."

Communities, we know, can be harmed if information collected from their members creates stigma or other unwanted outcomes. In February, 2007, the *New York Times* reported a story about a professor who surveyed her students' perceptions of the local sororities. One sorority was described as "socially awkward." The national office of that sorority was so concerned about its image that they went to meet the young women; 23 of them were told to leave. This included every woman who was overweight, and the only black, Korean and Vietnamese members (Dillon, 2007).

Another concern is "bad science," which is considered highly unethical. Researchers are often socially distant from disempowered communities. They are unlikely to know the ins and outs of community life; in some cases, they don't care. This can lead to a serious problem with the accuracy of the research. Jason Corburn, a researcher who has worked closely with communities in Brooklyn, pointed out that communities have valuable knowledge that is essential if researchers want to get accurate results. Certainly, ignoring local wisdom is very bad science.

Exercise #3: Rethinking Local Knowledge

Goal: Understanding how different methods of data collection incorporate local knowledge.

Materials: Paper and pens. Pre-printed interview questions to be handed-out.

Activity: *Break the group into pairs.* [This exercise can also be done "fishbowl" style. In this scenario, three volunteers are selected to conduct interviews while the rest of the group observes and takes notes. One person is interviewed, first using the five questions and then again in the second style.]

Say to the group: Think of a place that is familiar to you, that you know very well, a place that you love. Now we are going to interview each other. Decide who will interview first. *Hand out these five questions (or write them up on the board), and ask interviewers to record the answers:*

1. *Where is the place?*
2. *Is it public or private?*
3. *How long have you been going there?*
4. *How often do you go there?*
5. *Which words best describe how this place makes you feel: happy, safe, calm, excited, other*

Say to the group: Now we are going to switch roles. The second interviewer is going to practice listening skills and is free to ask open ended questions. Ask the interviewee to describe the place. Listen and document the response. Questions that might be asked:

1. *Describe your place.*
2. *Why did you pick that place?*
3. *What are the smells? The colors?*
4. *What do you love about it?*
5. *What memories does it hold for you?*

Bring everyone back together. Ask the group:

What did people notice about the two interview styles? What information did each interviewer obtain?

What are the reactions from the people who were interviewed first?

What are the reactions from those who were interviewed second?

What are the implications of this exercise in our work?

Wrap-up: *Ask:* What examples do you have from your own work of the use of local knowledge?

Some real world examples

As we noted in the overview, we conducted three case studies in order to have some real world examples of what happens when community people and researchers get together to carry out community ethical review of research. Everyone involved worked hard, and cared about what they were doing. Much of the work went well. However, there were recurring problems that threatened the integrity of what they were doing. These were frustrating situations that involved not listening, not understanding, and not having enough time. For purposes of this conversation, we'll give some examples of what we saw or heard about.

Show us the product

In order to understand the world within which the researchers were functioning, we attended some conferences and listened to tapes of others. At one of these conferences, funder Gwen Coleman, from the National Center for Environmental Health Sciences, spoke quite frankly about the need for researchers to create products in exchange for funding for their work:

> We were pretty product driven so what could we do in a five year period that could really put the information out there to the people who really needed it? So I have spent the last four years worrying about this and probably, you know, badgering all of you to, you know, focus on the productivity, focus on the product… I would like to tell you that, you know, we are probably 600 or so publications and abstracts worth of research sitting in this room tonight… there has been numerous spin off grants and more money coming in, more research being done following the information to the next place and trying to do more work.

Coleman's admonition to produce was very real to the researchers in our study. One of the groups in our study, which we have called the Optional Center, was engaged in studies of the effects of environmental pollutants of people's health. The leader of the center believed in community engagement. Researchers and community people spent a good deal of time together and both sides reported that they had an excellent working relationship. They worked together to design and carry out studies that would help solve issues of importance to local people. Though this was all to the good, one researcher noted that it took a lot of time and not everyone in their research group was willing to work with the local community:

> It's not that [researchers are] not open [or] they don't see the need [for working with local groups]. We are all way too busy. We have way too much to do. Especially here where if you don't get grants you are out on the street. Even though I have tenure if I don't have grants I don't have a salary. There is a lot of pressure.

The "community" doesn't know science

One of the groups we examined was a panel of the institutional review board. This board examines research protocols to see if they are adequate to protect subjects.

Lay and university people serve on the panel. One of the university people told us:

> Generally our community members are wonderful for reviewing the consents forms, making sure they are readable etc. and they are wonderful at helping keep that perspective but they can't review the science or make a judgment about the safety issues. That is why we can't fill it with more community members.

One community member of the IRB had a parallel observation. Note how the community person describes this experience: