Participatory Development and Implementation of a Community Research Workshop: Experiences From a Community-Based Participatory Research Partnership

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Participatory Development and Implementation of a Community Research Workshop: Experiences From a Community-Based Participatory Research Partnership

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Abstract

Background: Although community-based participatory research (CBPR) principles stress the importance of “equitable partnerships” and an “empowering and power-sharing process that attends to social inequalities,” descriptions of actual projects often focus on the challenges confronted in academic—community partnerships. These challenges occur in the context of economic and power inequities and the frequently limited diversity of researchers. Less often does this discourse attend to the link between the principles of CBPR and their empowering potential for community members who internalize and use these principles to hold outside partners accountable to these ideals.

Objectives: This article documents the participatory development and implementation of a community research workshop, the community and organizational contexts, the content of the workshop, and lessons learned. Workshop objectives included increasing community knowledge of the research process, positively impacting community members’ perceptions and attitudes about research, and improving researchers’ understanding of community knowledge, perceptions, and experiences with research.

Methods: This project was conducted as a part of the larger United States Department of Agriculture, Agriculture Research Service (USDA ARS) Delta Nutrition Intervention Research Initiative (Delta NIRI). The workshop was developed by a joint academic–community team in partnership with a community-based workshop advisory committee (WAC) and implemented in three rural communities of the lower Mississippi Delta. Development included a dry run with the WAC, a pilot workshop, and a focus group to refine the final content and format.

Conclusions: Applying participatory principles to the development of the community research workshop resulted in the creation of a mutually acceptable workshop and co-learning experience that empowered community members in their involvement in other community research projects.

Keywords
Community-based participatory research, community health partnerships, health disparities, power sharing, public health, rural health, health care

Is participation the same thing as empowerment? Just because we participate, doesn’t mean we are empowered.
—Community WAC Member

Embedded within this quote lies an insight into a reality that is perhaps not uncommon in the context of CBPR. Although CBPR principles stress the importance of “equitable partnerships” and an “empowering and power-sharing process that attends to social inequalities,” descriptions of actual projects often focus on the challenges confronted in academic—community partnerships. These challenges occur in the context of economic and power inequities and the frequently limited diversity of researchers. Less often does this discourse attend to the link between the principles of CBPR and their empowering potential for community
members who internalize and use these principles to hold outside partners accountable to these ideals.

The current public health focus on behavioral risk reduction, disease prevention, and health disparities has generated many health initiatives targeting underserved populations. CBPR is an approach that is increasingly being promoted to increase community participation vital to the success of these efforts.5 As CBPR gains recognition in the health field, funders are increasingly demanding community engagement in all phases of the research process.6,7 These requirements have the potential to empower community members—even when CBPR is initiated by outsiders—if community members are aware that these requirements for their participation exist and understand the power this gives them. Changes in knowledge, critical awareness, and willingness to “ask why” are practical means to empowerment.8–11 These concepts were the focus of this project, which was funded by the USDA ARS and implemented within the context of an existing CBPR initiative known as the Delta NIRI.

This article documents the participatory development and implementation process of a community research workshop, the context within which this work was accomplished, the workshop’s content, and lessons learned. Three objectives of the project were to increase community knowledge of the research process, positively impact community members’ perceptions and attitudes about research, and improve researchers’ understanding of community knowledge, perception, and experience with research.

**DELTA NIRI**

In 1995, Congress enacted legislation to address nutritionally responsive diseases in the Lower Mississippi Delta region of Arkansas, Louisiana, and Mississippi through nutrition intervention research. Congress charged that the research be community based and that interventions be sustainable in these communities. The ARS and a consortium of universities established the Delta NIRI and chose CBPR as the methodology most likely to improve the health and well-being of Delta residents and to sustain the interventions. Formative research documented community residents’ perceptions of food, nutrition, and health problems, how to approach solutions, and how to get “buy in” from communities to participate in research.12–14 A series of meetings with key informants, community members, and health and political leaders led to the selection of three research sites: Marvell, Arkansas; Hollandale, Mississippi; and Franklin Parish, Louisiana. In 2003, local Delta NIRI research groups, composed of community and academic partners, were formed. These groups developed organizational structures, and planned and implemented nutrition interventions, including the following.

**Marvell**

The Will Try Program encourages children to try new fruits and vegetables. The Boys Girls Adults Community Development Center Summer Day Camp increases physical activity and builds self-esteem through noncompetitive activities. The Walking Club sets daily and weekly goals to encourage physical activity. Monthly, a healthy breakfast is served where attendees receive a nutrition lesson; an existing walking trail was refurbished to provide a place to walk. These interventions are increasing exercise and providing social and emotional support for those who are changing behaviors.

**Hollandale**

The Walking Intervention15 teaches adults maintenance of good health by eating and exercise. The School Kids Access to Treats to Eat (SKATE) provides elementary students with fresh fruits, vegetables, and nutrition lessons. The Soccer Program, now incorporated into the public school, gives students the opportunity to learn the game, compete in championships, exercise, and obtain nutritional food information.

**Franklin Parish**

People United to Sustain Health is a faith-based program that offers nutrition classes and cooking demonstrations designed to increase fruit and vegetable consumption and exercise among adults. The Children and Nutrition study provided in-class lessons to fourth-grade students on how to increase fruit and vegetable intake and exercise. Similarly, Camp SHINE (Sharing Healthy, Innovative Nutrition Experiences) provided fourth and fifth graders with fun, interactive lessons on how to adopt healthy lifestyles during their summer break. Figure 1 shows the Delta NIRI region and lists characteristics of the research partnering communities.
Figure 1. Delta NIRI Region (light shading) and Target Counties/Parishes (dark shading) in Arkansas, Louisiana, and Mississippi, With Initial Partners and County/Parish Characteristics (inset table).
Origins of the Workshop Project

In 2005, a Delta NRI academic partner perceived the need for Delta NRI community partners to learn more about the research process and research ethics. This idea was discussed among NRI partners, who agreed such training would be beneficial. The University of Arkansas for Medical Sciences (UAMS) College of Public Health Office of Community-Based Public Health (O-CBPH) was asked to develop a community research workshop with NRI partners. An O-CBPH workshop team (Stewart, Colley, and Felix) was formed. The O-CBPH maintains partnerships with several Arkansas community-based organizations (CBOs) to serve as model programs for CBPH and CBPR. Anna Huff, the executive director of the Mid-Delta Community Consortium, a nonprofit, CBO, was added as a paid member to the workshop team to provide a community perspective.

METHODS

Process of Workshop Development

In keeping with the community-based focus of the Delta NRI, the community research workshop was developed using a participatory approach. The team met with the three local NRI research groups to discuss their interest in a community research workshop. Once each community’s interest was confirmed, a subcommittee from each of the NRI research groups was formed to serve as a WAC for the workshop team. The workshop team met with the three WACs in 13 face-to-face meetings and 7 conference calls, and communicated regularly through e-mail.

The Community’s Role

Because of its geographic proximity and past working relationship with workshop team members, the Marvell WAC served as the principle community partner with the workshop team during development. Initial discussions focused on the workshop’s usefulness and content areas of greatest interest. Marvell WAC shared their thoughts on community participation and empowerment, and how these concepts manifest in their interactions with researchers, all of which informed the final workshop content. The Marvell WAC advised on workshop objectives, content, format, length, attended a dry run of the workshop, and gave feedback for improvements. They also approved a presentation abstract about the workshop for a national conference.

Workshop Content

The identified workshop content areas focused on CBPR, the history and ethics of research, Institutional Review Boards (IRBs), and IRB review processes. With this list of content areas, Colley reviewed the literature, gathered unpublished examples of curricula related to these topics, and contacted others who carried out similar trainings. A critical source for the final workshop curriculum was Family Health International’s Research Ethics Training Curriculum for Community Representatives. After compiling these sources, Colley developed two draft workshop outlines, one with multiple interactive activities and the other with traditional lecture presentations.

Workshop Dry Run

The Marvell WAC made several suggestions for improving the workshop content and process after participating in a dry run of the interactive version of the workshop, including simplifying the language used to describe technical concepts, adding more graphics to presentation slides, giving participants small gifts and completion certificates, and holding the workshop in a neutral location where community members would feel comfortable gathering. They also suggested giving participants a glossary of common research terms, research ethics guidelines, a sample consent form, and an Internet research resources list. The workshop’s final content was organized into two modules, each with three sections (Table 1).

Workshop Pilot

After these revisions, an 8-hour, 1-day workshop was piloted in Marvell, with the Marvell WAC assisting in workshop scheduling and participant recruitment. The pilot was attended by 28 community members, the majority of whom had been involved in the Marvell NRI. Many participants expressed in a pre-workshop survey (completed by 28 [100%] workshop participants) that they attended the workshop to improve their knowledge of health research and believed the workshop would build their capacity and skills. A few said they participated because they felt it was their duty as community members to be involved.
In a post-workshop survey (completed by 26 [93%] workshop participants), participants said the content was appropriate and that what they learned would be “most useful,” but they wanted additional information on how to participate as research partners and/or research subjects in community research projects. Suggestions for improvement included increasing the use of graphics in the presentation slides and holding the workshop in a place that was less busy. Overall, the responses were very positive and indicated participants would recommend the workshop to other community members.

Focus Group Discussion Methods

Two months after the pilot workshop, 12 participants were recruited by the Marvell WAC community members to participate in a focus group facilitated by Colley. A question guide was used to obtain feedback on the following: the workshop content, interactive activities, and what information was most helpful and least helpful to participants. Participants were also asked to give suggestions about how to improve the workshop overall.

RESULTS

Findings From Focus Group Discussion

Two key themes emerging from the focus group discussion included the appropriateness of the workshop content and structure, and empowerment.

Workshop Content and Structure. Most participants agreed the workshop topics were important and relevant to some of their experiences working in a research project. Some commented the workshop was “too long,” with one commenting the length was not good for older persons. A couple of the participants suggested that the workshop be conducted in two shorter days instead of one long one.

Table 1. Workshop Content and Corresponding Learning Objectives

<table>
<thead>
<tr>
<th>Content</th>
<th>Learning Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Increase Community Knowledge About Health-Related Research</td>
</tr>
<tr>
<td>Module I</td>
<td></td>
</tr>
<tr>
<td>Health Research</td>
<td>Define health research √</td>
</tr>
<tr>
<td></td>
<td>Define clinical and policy benefits of research √</td>
</tr>
<tr>
<td>Community Participation</td>
<td>Define community √</td>
</tr>
<tr>
<td></td>
<td>Define special research communities √</td>
</tr>
<tr>
<td></td>
<td>Explain importance of community participation in research √</td>
</tr>
<tr>
<td></td>
<td>Identify differences between traditional and CBPR √</td>
</tr>
<tr>
<td>Research History</td>
<td>Understand research history that influenced development of key research ethics documents √</td>
</tr>
<tr>
<td></td>
<td>List the research √</td>
</tr>
<tr>
<td>Module II</td>
<td></td>
</tr>
<tr>
<td>Ethics Principles</td>
<td>Learn three fundamental principles of research ethics √</td>
</tr>
<tr>
<td></td>
<td>Identify vulnerable research participants √</td>
</tr>
<tr>
<td>IRB</td>
<td>Define the role(s) of the IRB/Ethics Committee √</td>
</tr>
<tr>
<td></td>
<td>Explain the difference between medical and behavioral research √</td>
</tr>
<tr>
<td></td>
<td>Describe who makes up IRB committees √</td>
</tr>
<tr>
<td>Research Process</td>
<td>Identify basic components of the research process √</td>
</tr>
</tbody>
</table>
Empowerment. Nearly all the participants said they gained more tools to ask questions when called on the phone about participating in a survey; by knowing more about research, they lessened their chances of being “a guinea pig.” One person stated, “People have rights about how you collect and gather information—researchers are in and out of the community.” The workshop provided information that participants equated to knowing their rights as citizens; “rights that everyone doesn’t know,” as one participant stated.

Focus group participants were continually challenged by a few members to really think about what CBPR means, to take advantage of what was presented at the workshop, and to “truly become partners and build knowledge.” One participant suggested that, to improve the community, researchers working within the community need to be challenged. This discussion led to participants reflecting on their past and present experiences with research projects. They openly discussed positive and negative reactions to these present experiences.

Final Revisions and Implementation

Changes made to the workshop after the Marvell pilot and focus group discussion included the addition of small group exercises, use of examples from local NIRI studies the participants were familiar with, and shortening the time participants had to attend by splitting the workshop into two separate sessions.

The final workshop is organized into two “stand-alone” modules that can be delivered jointly or individually, with Module I requiring 3 hours and Module II requiring 5 hours to complete. See Table 1 for module content and Appendix A for the full workshop guide. The format includes traditional lectures using presentation slides, discussion prompts, and a limited number of interactive exercises.

This revised version was used in both Hollandale and Franklin Parish, where the local WACs recommended that the two modules be offered on separate evenings to accommodate community members’ schedules and to increase participation. These WACs also assisted with logistics and recruitment. Table 2 describes workshop participant demographics.

DISCUSSION

Challenges and Lessons Learned

A major challenge in this project was balancing desires for the workshop to be content rich, participatory, and interactive, with the communities’ requests to limit the workshop’s length. This tension was highlighted by WAC members during workshop development. For example, during the dry run, role plays,

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Marvell Pilot</th>
<th>Hollandale</th>
<th>Franklin Parish</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>(n = 25)</td>
<td>(n = 19)</td>
<td>(n = 11)</td>
<td>(n = 55)</td>
</tr>
<tr>
<td>18–29</td>
<td>8%</td>
<td>5%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>30–50</td>
<td>20%</td>
<td>37%</td>
<td>45%</td>
<td>31%</td>
</tr>
<tr>
<td>≥51</td>
<td>72%</td>
<td>58%</td>
<td>45%</td>
<td>62%</td>
</tr>
<tr>
<td>Gender</td>
<td>(n = 25)</td>
<td>(n = 19)</td>
<td>(n = 11)</td>
<td>(n = 55)</td>
</tr>
<tr>
<td>Female</td>
<td>96%</td>
<td>95%</td>
<td>91%</td>
<td>95%</td>
</tr>
<tr>
<td>Male</td>
<td>4%</td>
<td>5%</td>
<td>9%</td>
<td>5%</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>(n = 25)</td>
<td>(n = 18)</td>
<td>(n = 11)</td>
<td>(n = 54)</td>
</tr>
<tr>
<td>African American</td>
<td>88%</td>
<td>100%</td>
<td>82%</td>
<td>91%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>12%</td>
<td>...</td>
<td>18%</td>
<td>9%</td>
</tr>
<tr>
<td>Education level</td>
<td>(n = 25)</td>
<td>(n = 18)</td>
<td>(n = 11)</td>
<td>(n = 54)</td>
</tr>
<tr>
<td>High school or less</td>
<td>4%</td>
<td>16%</td>
<td>...</td>
<td>7%</td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>16%</td>
<td>28%</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>College or more</td>
<td>80%</td>
<td>56%</td>
<td>82%</td>
<td>72%</td>
</tr>
</tbody>
</table>

Note. Demographics only available for those completing an evaluation form.
storytelling, interactive exercises, and small group activities were used to increase participant engagement. However, these time-intensive methods did not allow the community-desired content to be included in a 1-day period. As a result, traditional lectures using presentation slides, discussion prompts, and a limited number of interactive exercises were used in the pilot. Participation in workshop discussions was fairly good and overall feedback was very positive, although several respondents felt the workshop was too long and required too much sitting. Subsequent workshops were delivered in two sessions on separate evenings with small group exercises and local examples. This format seemed to be more amenable to the participants’ needs and resulted in fewer complaints about length.

Several factors, including the participatory approach used in developing the workshop and the relationship between the facilitators and workshop participants, were keys to the success of the project. WAC members provided critical input and continued to be engaged in the project throughout development, implementation, and in dissemination (some are co-authors on this paper).

Workshop participants were primarily African American. All three workshops were conducted primarily by Colley, a mature African-American woman with years of experience working in rural, grassroots, predominately African-American communities, communities similar to the three involved with this project. Colley also had primary responsibility for communications between the workshop team and the community partners, allowing her to establish a good rapport with the communities before the workshops. One participant stated that she was “proud” that an African American was leading the workshop and this made a difference in her attending the workshop. These factors are believed to have contributed to the extent to which participants showed interest in the topics and engaged in workshop discussions.

Development of this workshop was accompanied by interesting discussions regarding empowerment. According to anecdotes from community members who co-authored this paper, the workshop and the focus group stimulated discussions among Marvell community members about how to ensure all community partners’ voices are heard when NIRI decisions are being made. This dialogue resulted in the community’s decision to meet separately before the full NIRI research group meetings attended by academics and agency partners to allow them to discuss things more freely, hear all voices, develop community consensus, and speak with a united voice. Other benefits have included their decision to revitalize plans for a school-based parenting group and for a self-education effort to increase community understanding of the terminology and implications of CBPR.

Likewise, in Hollandale and Franklin Parish, the workshops generated discussions about additional research issues of community interest to pursue through future CBPR activities.

**CONCLUSION**

The field of public health is increasingly acknowledging the importance of community participation in developing and implementing research to change health behaviors, prevent diseases, and reduce health disparities. Community members involved in CBPR projects have expressed an interest in gaining more knowledge about CBPR, the research process, and research ethics. Applying participatory principles to the development of the community research workshop resulted in the creation of a mutually acceptable workshop and co-learning experience that empowered community members in their involvement in other community research projects.
REFERENCES


Appendix A. Additional Resources

Research Definitions

Assent: when child agrees to participate in research; assent is generally necessary beginning at age 7.

Autonomous: independent; self-directed; has freewill.

Behavioral research: studies how people act as individuals and with others and then relates this to interventions; researchers may use interviews, focus groups, or surveys to get information about the knowledge, attitudes, experiences, or perceptions of individuals or groups.

Belmont Report: a cornerstone document of ethical principles and federal regulations of protection for research subject or participants; based on respect for persons, beneficence, and justice.

Beneficence: one of three research ethics principles; makes the researcher responsible for the physical, mental, and social well-being of the research subject or participant; two general rules are “do not harm” and “protect from harm by increasing benefits and decreasing possible risks of harm.”

Biomedical/clinical research: study that examines the medical results of using different drugs/medicines that have a possibility of helping make diagnosis or prevent disease; the idea is to measure how effective the outcome of the drug/medicine will be.

Collaborative: working together with others; shared or joint participation.

Community-Based Participatory Research (CBPR): collaborative approach to research that involves all partners equally in the research process and recognizes the unique strengths that each brings.

Confidentiality: how someone treats information that a person has revealed in a relationship of trust and believes that it will not be revealed to others without their permission.

Declaration of Helsinki: code of research ethics developed by the World Medical Association in 1964; focus was on true medical research with a healing/beneficial intent.

Emancipated minor: individuals under the age of 18 who are legally able to make decisions for themselves; they are living on their own, financially independent from their parents, have a child; or are married.

Exempt (excused) review: type of research study that involves educational tests, surveys, interviews, or observation of public behavior and does not require approval by the IRB; research using existing information on records, samples of body material if publicly available or unidentifiable; written consent is usually not required.

Expedited review: type of research study that does not have to be reviewed by the entire IRB committee; study may be approved by the IRB chairperson or one of the members of the IRB committee; examples of expedited studies include records, specimens, or documents not used for research and information from voice video, digital, or image recordings made for research purposes.

Experimental research: study where researchers assign research subjects or participants to receive an intervention or not receive an intervention at random; the highest standard of research.

Equitable: equal; fair; as it relates to research the fair and equal sharing of benefits and risks in a research study; recruitment and selection of research subject or participants must be done in a fair and equal manner.

Focus group: a research method that looks at peoples ideas and attitudes in a small group setting (usually 6–12 people); used to identify problems, educate or give knowledge to participants, and plan and evaluate programs.

Full/standard committee review: type of research that does not qualify for expedited or exempt review; research study will be reviewed at the full committee meeting and the study must receive the approval of the majority of those members present at the meeting; quorum is met.

Funder/sponsor: an organization or institution that provides funds and other resources needed to do research.

Guardian: individual who is authorized under state or local law to consent on behalf of a child for general medical care.

Guinea pig: a plump, short-eared, furry, tame animal that is larger than a hamster and used as a subject in scientific experiments; sometimes used to describe human subjects or participants who are in a research study against their will and without full knowledge.

Informed consent process: when a person or group of people are informed about a study, the information is understood and a decision is made without pressure, undue influence, or intimidation; during the study, the subjects or participants and community members understand what is happening; consent must be in writing.

Institutional Review Board (IRB) or Ethics Committee: a group of people from different backgrounds (religious, community, science, or research) who carry out an independent review of proposed studies on human subjects or participants; they are of different ages, genders, and racial backgrounds.

Justice: one of three ethics research principle; requires fair and equal sharing of benefits and risks of subjects or participants in a research study; recruitment and selection of subjects or participants must be done in a fair and equal manner.

Medical/clinical research: involves research on human subjects or participants; designed to answer questions about health and disease.

Nuremberg Code: rules for how subjects or participants in research are treated; standards of research that came about because of the abuses in research; adopted at the end of World War II (1946).

Observational research: the researcher measures but does not intervene; a study of something that can be observed as it really is and there is no attempt made to change the subject or participant in the research process.

Parent: federal regulations define this as a child’s biological or adoptive parent.

Permission: the agreement of parent(s) or guardian to the participation of their child or ward in research.

Protocol: a detailed research plan that gives information about how the research will be done; includes purpose of the research, the research question, why the study is important, anticipated results, and all materials that will be used in the study (questionnaires, surveys).

Quasi-experimental: a study design in which two groups of subjects or participants are studied but not randomly assigned.

Appendix continues
Research: an organized way to gather information about question that researchers do not have the answers to; especially refers to health-related issues that affect a lot of people.

Research participant or subject: any one whom information is gathered about.

Researcher: person who asks a question and carries out research to find the answer; investigator; responsible to protect research subjects or participants.

Research process: the series of steps which make up research from the development of an idea to the completed research project: (1) turn your idea into a research question, (2) review the literature about the topic, (3) design the study and develop measurement instruments, (4) write a proposal, (5) collect the data, (6) examine the data and interpret findings, and (7) report on the study and distribute the findings.

Respect for persons: one of three ethics research principles; recognition of a person as an autonomous (independent), unique (one of a kind), and free individual; recognizes that each person has the right and ability to make her or his own decisions.

Risks: are minimal when a person experiences what he/she might during a routine physical or mental examine or test; risks are greater than minimal when harm is higher than what he or she might experience during a routine physical or mental examine or test; however, the research may be helpful to the research subject or participant or provide knowledge about an illness or condition.

Scientific rigor: widely regarded as being exemplified by the randomized controlled trial (RCT); the RCT is termed the "gold standard" of research; proceeding in a systematic and methodical way; controlled; precise; rigor = accuracy; thoroughness; strictness.

Special research communities: research participants or subjects who belong to a special community of people; persons with the same disease (breast cancer or AIDS), profession, (teachers or health providers), or from a certain populations (older persons, teenagers, prisoners); persons living a specific geographic community (rural towns or urban cities).

Study design: a plan that researchers use to answer questions about what causes disease, what cures disease, what kinds of interventions or programs can prevent disease; a plan that is used to answer questions like what characteristics may be related to particular health issues.

Study protocol: a research project or investigation designed to discover facts about something; a report describing a piece of research.

Survey: a way to gather information from a large number of people; surveys may include polls, mailed questionnaires, telephone interviews, or face-to-face interviews.

Vulnerable persons: people who may be easily persuaded; people who have a decreased ability to make decisions for themselves; examples include children, pregnant women, prisoners, or the physically or mentally challenged.

Research-Related Resources Available on the Internet

- Council for International Organizations of Medical Sciences: http://www.cioms.ch
- Center for Health Professions at the University of California San Francisco: http://www.futurehealth.ucsf.edu
- Federally approved IRBs by location: http://ohrpr.cit.nih.gov/search/aerach.asp#ASUR
- Internet-based Medical and Healthcare Training Programs Provided by NIH: http://www.nihtraining.com
- Program on Ethical Issues in International Health Research at the Harvard School of Public Health: http://www.hsph.harvard.edu/bioethics/
- President’s Council on Bioethics: http://www.bioethics.gov/
- UAMS’s Office of Research Compliance: http://www.uams.edu/orc/
- UAMS’ Online Training on Human Subjects Research and HIPAA: http://www.uams.edu/orc/Training/Training.htm
- World Medical Association Declaration of Helsinki http://www.wma.net/e/ethicsunit/helsinki.htm
Several events have led to the development of guidelines and regulations for research ethics:

- The illegal experiments performed on concentration camp prisoners by Nazi doctors during World War II and later the Nuremberg Trials in 1946 gave birth to the Nuremberg Code, which states that “voluntary informed consent is absolutely necessary.”
- The Declaration of Helsinki of 1964 stressed the importance of written consent forms.
- The 1974 Belmont Report highlighted the three fundamental principles of respect for persons, beneficence, and justice.

The field of research ethics and human research protection currently rests on three fundamental principles (respect for persons, beneficence, and justice).

1. Many people have heard about the way the Nazi regime treated the Jewish people. One particularly horrifying part of that history is what some of Hitler’s doctors did to prisoners of war during World War II. One experiment was called the freezing experiment; prisoners were immersed into tanks of ice water for hours at a time, often shivering to death, to discover how long German pilots downed by enemy fire could survive the frozen waters of the North Sea. It was generally known at the time that human beings did not survive floating in the North Sea for more than 1 to 2 hours.

2. Doctor Sigmund Rasher attempted to duplicate these cold conditions at Dachau, and used about 300 prisoners in experiments, recording their shock from the exposure to cold. About 80 to 90 of the subjects died as a result.

3. In 1946, at the end of World War II, 23 Nazi doctors and scientists were put on trial for murder of concentration camp inmates who were used as guinea pigs. As a result of these horrifying experiments, there was a military tribunal, known as the Nuremberg Trial. When the facts came out several people got together to make the Nuremberg Code. These standards are basically rules for how we treat participants in research and during the 1950s and 1960s were widely recognized. However, this document was often ignored in the United States. Most scientists and doctors felt that points outlined were common sense and were written more as an argument to be made about the crimes committed by the Nazi doctors.

In 1964, the World Medical Association developed a code of research ethics call the Declaration of Helsinki, which was based on the principles set forth in the Nuremberg Code. At the heart of the declaration is the statement that the “the well-being of the human subject should take priority over the interests of science and society.” The focus of this document was on true medical research with a therapeutic intent. These principles became the required method of conducting human subject research in an ethical manner. Basically, this declaration became the forefather and paved the way to set up the IRB. It also gives special attention to the importance of written informed consent.

The Declaration of Helsinki has been revised five times, most recently in 2001, to include issues such as the use of a placebo (given to research subjects who are participating in a clinical trial but has no effect). It proposes that any new method should be tested against the best current proven drugs, procedures, or beneficial healing methods. The revised declaration also states that “medical research is only acceptable if there is a reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research.”

Research History in the United States

From the 1950s to the 1970s in the United States, there were a number of abuses of human subjects committed by U.S. researchers that came to public attention. These included:

- The Wichita jury study: Six jury rooms were bugged to study how juries deliberate. The violations included lack of consent, deception, and violation of the juror’s rights.
- The Munson Jewish Chronic Disease Study (1963): Senile patients were injected with live cancer cells to study a person’s immunity to cancer without any notification or consent of the patients.
- The Public Health Service Syphilis Study of “Tuskegee Study” (1932–1971): The Tuskegee Syphilis Study continues to emerge again and again as an example of research gone wrong. From 1932 to 1972, 399 poor, Black sharecroppers in Macon County, Alabama, were denied treatment for syphilis and deceived by physicians of the U.S. Public Health Service. As part of the study, designed to document the natural history of the disease, these men were told that they were being treated for “bad blood.” In fact, government officials went to extreme lengths to ensure that they received no therapy from any source. On July 26, 1972, The New York Times described the study as “the longest no therapeutic experiment on human beings in medical history.” The disclosure of this study by the press was a major scandal in the United States.

As a result, in 1974 congress authorized the formation of the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research. This commission wrote the Belmont Report, which they issued in 1978. This is a cornerstone document of ethical principles and federal regulations of protection for research participants based on respect for persons, beneficence and justice.

Stewart et al.
Appendix C. Community Research Workshop Pre-Workshop Questionnaire
Version 2, April 3, 2006

1. What is your age group?
   a. 18–29 years
   b. 30–50 years
   c. 51 years or more

2. What is your gender?
   a. Female
   b. Male

3. Do you identify yourself as:
   a. African American
   b. Caucasian
   c. Other—please specify:

4. What is your highest level of education:
   a. Less than high school graduate
   b. High school diploma or GED
   c. Any college or more

5. Do you agree or disagree with this statement: “Medical research is done for the benefit of humankind.”
   a. Agree
   b. Disagree
   c. No opinion

6. Have you ever participated in a study as a research subject or participant?
   a. Yes
   b. No (If no, go to Question 8)

7. In general, would you say most of your experiences as a research subject or participant have been:
   a. All positive
   b. Some positive/some negative
   c. All negative

8. Are you involved as a community partner in any research projects?
   a. Yes
   b. No (If no, go to Question 15)

9. How would you rank the importance of your role as a community partner to the research in which you are involved?
   a. Very important
   b. Somewhat important
   c. Not at all important

10. Do you think your participation and input as a community partner is valued by the academic research partners the same as that of the academic research team members?
    a. Yes, by all academic researchers
    b. Yes, by some academic researchers
    c. No
    d. I don’t know

11. Which best describes what you would do in your role as a community partner if you had a good idea or information you thought was relevant or helpful?
    a. I would tell the group about it.
    b. I would tell it to an individual I trust in the group and ask or hope they would express it.
    c. I would not do anything.
    d. Other—please specify:

12. Which best describes what you would do in your role as a community partner if you did not understand something an academic research partner was saying or doing?
    a. I would ask the academic researcher to explain it.
    b. I would ask another community partner to find out for me.
    c. I would not do anything, but I would keep participating.
    d. I would not do anything, and I would stop participating.
    e. Other—please specify:

13. Which best describes what you would do in your role as a community partner if you did not agree with something an academic research partner was saying or doing?
    a. I would always confront the person involved.
    b. I would confront the person involved, if I thought it was important enough.
    c. My reaction would depend on my relationship with the academic researcher.
    d. I would talk to a community partner about it.
    e. I would not do anything, but I would keep participating.
    f. I would not do anything, and I would stop participating.
    g. Other—please specify:

14. In your role as a community research partner, how comfortable are you with your level of knowledge about the research process?
    a. Always comfortable
    b. Sometimes comfortable
    c. Never comfortable

15. Have you ever had the opportunity to participate in a research study as a community research partner?
    a. Yes
    b. No

16. How interested are you in learning more about the research process?
    a. Very interested
    b. Somewhat interested
    c. Not at all interested

17. How important do you think it is for people to understand about research in order to participate in research as a community partner?
    a. Very important
    b. Somewhat important
    c. Not at all important

18. How important do you think it is for people to understand about research in order to participate in research as a research subject or participant?
    a. Very important
    b. Somewhat important
    c. Not at all important

19. How likely are you to participate as a research subject or participant in the future?
    a. Very likely
    b. Somewhat likely
    c. Not at all likely

Appendix continues
20. If you answered “not at all likely” in participating as a research subject or participant, can you explain why you would not be likely to participate?
21. How likely are you to participate as a community partner in community research in the future?
   a. Very likely
   b. Somewhat likely
   c. Not at all likely
22. If you answered “not at all likely” in participating as a community partner in community research, can you explain why you would not be likely to participate?
23. Why did you decide to participate in this workshop?
24. What are your expectations of this workshop?

Appendix D. Community Research Workshop Post-Workshop Questionnaire
Version 3, September 7, 2006

1. Which of the following workshop topics were new information for you? CHECK ALL THAT APPLY
   a. Benefits of research
   b. Types of research studies
   c. Clinical and behavioral research
   d. Importance of community participation in research
   e. History of research (e.g., Tuskegee, Belmont Report)
   f. Institutional Review Board or Ethics Committee
   g. Research ethics principles
   h. Informed consent
2. Which of the following topics had you heard about before but the workshop helped you understand them better? CHECK ALL THAT APPLY
   a. Benefits of research
   b. Types of research studies
   c. Clinical and behavioral research
   d. Importance of community participation in research
   e. History of research (e.g., Tuskegee, Belmont Report)
   f. Institutional Review Board or Ethics Committee
   g. Research ethics principles
   h. Informed consent
3. Do you agree or disagree with this statement: “Medical research is done for the benefit of humankind.”
   a. Agree
   b. Disagree
   c. No opinion
4. Has this workshop made you more or less likely to participate in the future as a research subject or participant in the future?
   a. More likely
   b. Less likely
   c. Same as before
5. Has this workshop made you more or less likely to participate in the future as a community partner in community research?
   a. More likely
   b. Less likely
   c. Same as before
6. Are you involved as a community partner in any research projects?
   a. Yes
   b. No (If no, go to Question 14)
7. How would you rank the importance of your role as a community partner to the research in which you are involved?
   a. Very important
   b. Somewhat important
   c. Not at all important
8. Which best describes what you would do in your role as a community partner if you had a good idea or information you thought was relevant or helpful?
   a. I would tell the group about it
   b. I would tell it to an individual I trust in the group and ask or hope they would express it.
   c. I would not do anything.
   d. Other—please specify:
9. Which best describes what you would do in your role as a community partner if you did not understand something an academic research partner was saying or doing?
   a. I would ask the academic researcher to explain it.
   b. I would ask another community partner to find out for me.
   c. I would not do anything, but I would keep participating.
   d. I would not do anything, and I would stop participating.
   e. Other—Please specify:

Appendix continues
10. Which best describes what you would do in your role as a community partner if you did not agree with something an academic research partner was saying or doing?
   a. I would always confront the person involved.
   b. I would confront the person involved, if I thought it was important enough.
   c. My reaction would depend on my relationship with the academic researcher.
   d. I would talk to a community partner about it.
   e. I would not do anything, but I would keep participating.
   f. I would not do anything, and I would stop participating.
   g. Other—Please specify:

11. In your role as a community research partner, how comfortable are you with your level of knowledge about the research process?
   a. Always comfortable
   b. Sometimes comfortable
   c. Never comfortable

12. If so, how would you rank the importance of your role as a community partner to the research in which you are involved?
   a. Essential
   b. Very important
   c. Important
   d. Sort of important
   e. Not at all important

13. Do you think your participation and input as a community partner is valued by the academic research partners the same as that of the academic research team members?
   a. Yes, by all academic researchers
   b. No, by some academic researchers
   c. No
   d. I don’t know

14. Which two presentation messages do you think will be most useful to you?

15. What additional information would help you or other community members to participate as a community partner in community research?

16. What additional information would help you or other community members to participate as a research subject or participant in research?

17. What part of the presentation, if any, should have been excluded? (Please specify)

18. What comments would you like to make about the workshop?

19. Please respond to each of the following statements by marking “x” in the box that best describes your feelings:

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The information presented was very easy to understand.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>b. The information presented was relevant to community representatives.</td>
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<td></td>
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<tr>
<td>c. The information was organized in a logical, easy-to-follow manner.</td>
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<tr>
<td>d. Participants had opportunities to ask questions.</td>
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<tr>
<td>e. Participants’ questions were clearly answered.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>f. The presenters used participatory activities to make the learning easier.</td>
<td></td>
<td></td>
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<tr>
<td>g. The handouts given during the presentation were useful.</td>
<td></td>
<td></td>
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<tr>
<td>h. The length of the presentation was appropriate.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. How could we improve the workshop next time?

21. Would you recommend this workshop to others? Why or Why not?