

CREATING COMMUNITY-BASED PARTICIPATORY RESEARCH IN A DIVERSE COMMUNITY: A CASE STUDY

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ABSTRACT: COMMUNITIES STRUGGLE TO CREATE research guidelines for ethical collaborative research within their locale. In Lawrence, Massachusetts (USA) a collaborative group of community members and academic researchers, known as the Mayor's Health Task Force Research Initiative Working Group, took on the challenge of creating guidelines for ethical community-based research. This case study of the Task Force's work addresses questions of research ethics in a diverse community where families struggle with few resources and face many health disparities, under the often-intrusive and unhelpful scrutiny of researchers from the many nearby major research universities. Representatives from the city, community organizations, and research universities developed a set of core ethical principles for research partnerships, a list of criteria for agreements between partners, and a model to help guide researchers and community members toward equitable and mutually beneficial research. This model can be generalized to similar other communities.

KEY WORDS: community research guidelines, communities as partners, shared decision making, overcoming differences

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THE PROBLEMS THAT RESULT WHEN COMMUNITY-based research is nonparticipatory have received much attention (Bell & Standish, 2005; US DHHS: Agency for Healthcare Research and Quality, 2003), and are now well-documented (Green & Mercer, 2001). But how do we move beyond recognition of these problems to the creation of an ethical approach to community-based participatory research (CBPR) (Israel, Schultz, Parker, & Becker, 2001)?

Leaders in the creation of CBPR approaches have included tribal nations and research centers (Macauley, Cross, & Delormier, 1998). The Akwesasne, as a tribal nation, has been at the forefront (Srinivasan & Collman, 2005). The University of Michigan's Detroit Center for Urban Academic Studies is also known for its widely-respected model (Metzler, Higgins, Becker, Freudenberg et al., 2003; Srinivasan & Collman, 2005). What these leaders have in common, despite their many differences, is that they control their borders. A tribal sovereign nation can control who is allowed to do research on tribal land. A research center can maintain authority over who is allowed to do research in the name of the center and can ensure that the research is consistent with CBPR principles.

In contrast, many communities face a vastly different situation. In effect, they have no front door through which all researchers must enter and be guided toward ethical research. Researchers can arrive from different universities, contact different people in the community, and shop neighborhood groups and community organizations until they find groups willing to participate in research on the researchers' own terms. In contrast to a sovereign tribal nation or a research center, the community typically lacks gate keepers who have the authority to say what kinds of research or research partnership will be tolerated in the community.

With increased funding for research on health disparities and with more money directed at translational and community-based research, investigators are turning their

attention to poor communities and communities of color (Two Feathers et al., 2005). Conducting their studies within such communities is perhaps rightly perceived as increasing the likelihood that grant applications will be successful (Seifer & Calleson, 2004). The concentration of health problems in some poor communities of color makes them attractive “laboratories” for study (Srinivasan & Collman, 2005). How then can ethical approaches to CBPR be undertaken (Schulz, Krieger, & Galea, 2002)?

These issues are not idle ones in Lawrence, Massachusetts or in similar cities (Sullivan, Kone, Senturia, Chrisman, Ciske, & Krieger, 2001). Lawrence is within easy driving distance of perhaps the greatest concentration of research universities in the United States. Residents in Lawrence are largely Spanish speaking and families struggle with high levels of poverty, limited access to jobs, and limited access to the resources families need to prosper. The health problems are significant: much of the housing was built before lead paint bans, many of the waste incinerators in Massachusetts are concentrated near Lawrence and affect Lawrence’s air quality, and many families work at jobs that can compromise worker health. As the most Latino city on the east coast north of Miami and as one of the poorest communities in Massachusetts and in the United States, Lawrence has become a focus of researcher interest.

How then can such a community control the research agenda (Gilbert, 2006; Minkler, 2004; Shore, 2006)? What steps are communities using? While tribal nations as sovereign entities have developed various model practices, and some individual research centers such as the University of Michigan Detroit Center for Urban Academic Studies have developed plans and model practices (Srinivasan & Collman, 2005), few communities have attempted to develop research guidelines that can be used throughout a whole community and with diverse research partnerships (Macaulay et al., 1998; Santiago-Rivera et al., 1998; Brugge & Missaghian, 2003; Metzler et al., 2003). Lawrence’s approach to solving this problem can serve as a model for the many other communities that have begun to seek ways to advance ethical community-based participatory research.

In this case study, we describe how a community and its university partners can develop a set of guiding principles for research. Since there are no borders that will make these principles enforceable, we have sought to build principles and practices that can be the basis for community practice, with benefits both to the community and to researchers, thus making them advantageous to both (Blumenthal, 2006). While there are no quick fixes, common ground can be found so that both community and researchers will be motivated to

build an ethical, nonexploitative relationship. Through many meetings, consideration of models from many sources, and discussion of local research experiences, representatives of a community and many interested universities have built a shared set of principles and practices.

Lawrence: A Community Inundated with Researchers

Lawrence, Massachusetts, just 30 miles from Boston’s major research institutions, is attractive to researchers. In the past, the researchers who came to Lawrence to collect data made few attempts at collaboration. As a result, Lawrence’s experience with researchers has often been negative, as the following two cases illustrate.

In 1999, unbeknownst to people in Lawrence a Boston-based research institute took it upon itself to apply for funding to study Lawrence and its gang violence “problem.” The Lawrence community was not consulted about gang issues prior to the submission of the grant nor was the community made aware that this research was about to be undertaken once this grant was received. The investigator rented office space, and hired community residents and several noncommunity researchers to collect data on gang members and gang activity in Lawrence. What might have served as an opportunity for community residents to have access to training in research, such as training in the ethical conduct of human subjects research carried out in the community, did not occur. In fact, the researcher failed to complete the research. After several months the research project was abandoned, the office was closed due to non-payment of rent, and the community residents hired to conduct interviews were not paid for their services. The result was heightened distrust in the community of researchers and the research enterprise.

Well over a decade later, little had changed. In 2006, another national research group came to Lawrence, again having developed a research plan without consulting the community. The intent this time was to measure the health effects of high levels of pollution. The researchers had decided that they would do so by gathering saliva samples from Lawrence residents. Given the very grave concerns in Lawrence about high levels of pollution and their potential health impacts, the researchers simply assumed that community residents would provide any data needed. The team, when questioned, was

unprepared to answer the community's questions, such as why this research approach was selected, who would receive the results, who would own the data, and what would be done with the residents' saliva samples. In the face of so many unanswered questions, many within the community became concerned and unwilling to cooperate.

Two subsequent research projects differed from unilateral research practices described above and their success suggested the need for alternative approaches to research in Lawrence. These two projects, REACH2010 and Lawrence Latino Diabetes Prevention Project,² involved community members in developing practices consistent with CBPR (Khanlou & Peter, 2005). In both projects, community members were involved from the very outset and continued to play central leadership roles throughout the projects; the community provided resources and also received resources to conduct the studies, and many community members were hired as community experts. The focus in these research projects, moreover, was not simply on documenting problems; an equal emphasis was placed on interventions aimed at improving community health outcomes. The results emerging from these projects show improved health care and health outcomes for individuals who live in Lawrence. For example, as a result of the REACH 2010 Latino Health Project, which involved multiple interventions, outcomes on 15 health care and health status indicators improved significantly.

Following these two successful projects, and in response to many requests from federal, state and national research institutes, several community members came together to discuss the constant requests for permission to study the community. These community members were employed within the community and some also were members of civic groups (e.g., YWCA, Lawrence Environmental Action Group (LEAG), Asociación de Ministros Evangélicos Del Area de Lawrence, Council on Aging, Lead Prevention Program). The first meetings were held at the Community Development Department, the public library, and non-profit organizations. Community members led the group until a VISTA volunteer was hired to facilitate the process along with a community leader. The volunteers helped to organize evening meetings to accommodate community members who were unable to attend morning meetings.

²See http://www.cdc.gov/reach/community_profiles/index.htm for the REACH2010 Project and www.umassmed.edu/uploadedfiles/LawrenceDiabetes.pdf for the Lawrence Latino Diabetes Prevention Project.

It was evident from the very beginning that this core group of people needed the assistance of professionals who are conscientious and respected the community. This opened a door for the formation of a group of concerned citizens of Lawrence, which became known as the Research Initiative Working Group (RIWG) to learn more about community-based participatory principles and approaches. As the group studied approaches to community-based participatory research in order to decide on an approach for Lawrence, decision making was shared among those who actively participated, mainly community members. Lawrence is known for its commitment to voluntarism, and the RIWG operated solely on a volunteer basis as no funding was received to support the group. The goal of the RIWG, begun under the Mayor's Health Task Force, was to create a process that would reshape the relationship between communities and researchers and to develop a set of Guiding Documents that establish standards for research practices in Lawrence. Throughout the rest of this case study, we highlight key aspects of the participatory approach that established these standards, describing the group involved, the process they followed, and the products they created. Our intent is to provide sufficient detail that other communities working with multiple universities can replicate the Lawrence model.

A Model for Community Process Engaging Researchers

The Mayor's Health Task Force was begun under the auspices of the City Government to bring diverse groups together to address pressing health issues in Lawrence. The RIWG, a subgroup of the Task Force, brought together many individuals and organizations. Represented at the RIWG table were life-long community members, the Mayor's Health Task Force, Greater Lawrence Family Health Center (GLFHC), Lawrence Council on Aging, Greater Lawrence Community Action Council, Health Care for All, Massachusetts Department of Public Health, City of Lawrence Board of Health, Harvard School of Public Health, University of Massachusetts–Lowell, University of Massachusetts Medical School in Worcester, Tufts University, and Notre Dame High School students who live in the community. The RIWG discussions, facilitated by community leader/Chair of the Mayor's Health Task Force (Milagro Grullon) and a Massachusetts Campus Compact AmeriCorps*VISTA at the University of Massachusetts–Lowell (Craig Thomas), began to meet monthly and has continued to do so. Each representative brought extensive experience in a variety of domains, including the conduct of research,

advocacy for community needs, and knowledge of Lawrence's history and politics.

The Creation of an Approach

It might be assumed that individuals with good intentions and a common vision could quickly coalesce around a set of workable principles and practices and move on. However, communities embarking on this process need to know that this process is neither quick nor uncomplicated. The group, with much deliberation, began a step-wise approach with commitment to diversity at its heart. Drawing on previous work in the field of community-based participatory research (<http://depts.washington.edu/ccph/index.html>; Silka and Renault-Caragianes, 2007), the RIWG immersed itself in past examples of research partnerships and looked at how these examples could be adapted to an ever-shifting community context. The RIWG carried out a needs analysis in which health research needs in Lawrence were identified (including instances in which health research had been completed but in which the community had not been consulted about the need for the research, the results had not been disseminated, and the results had not been used to alter programs and practices). The RIWG then identified and discussed barriers to and opportunities for collaborative research in community settings. Based on this analysis of the need for new forms of research collaboration in Lawrence, the RIWG moved to identify and evaluate models that followed community-based participatory research, including materials from Community-Campus Partnerships for Health (cf. <http://depts.washington.edu/ccph/index.html>), the Navajo Nation Human Research Code, and the Akwesasne Task Force on the Environment (Santiago-Rivera et al., 1998; Brugge & Missaghian, 2003). After much discussion, the group reached consensus on principles of community-based participatory research that would be workable in the Lawrence community setting. RIWG then devoted much effort to considering how the principles might be promoted between researchers and community in a community where a particular approach could not be mandated. The decision was made to create a series of Guiding Documents that would guide collaborative research between academic researchers and the community. These documents reflect a concern with each kind of misunderstanding about research that had been experienced in Lawrence by the diverse members of the RIWG. (Please see Appendix I and III for examples.) The intention was not to "police" or censor research efforts in the City, but to promote a workable town-gown relationship.

THE CHARACTERISTICS OF THE GUIDING DOCUMENTS

Three Guiding Documents were developed to support collaborative research between researchers and community. These three documents included:

1. A set of core principles describing the overarching philosophy of collaborative research and questions collaborators should answer together to ensure that projects align with the principles. (See Appendix I.)
2. A glossary defining research terms used in the other two documents. (See Appendix II.)
3. A model that organizes the questions and processes according to the stages of a research project and the nature of the tasks or discussions. (See Appendix III.)

These entire documents are included in the Appendices so that other communities can use them. Case studies are now being developed to illustrate examples of research projects and how they have either benefited from following the core principles, or how they might have benefited if greater attention had been given to them.

These documents evolved from a series of drafts that slowly emerged as individual members volunteered for editing assignments between monthly meetings. After the content was agreed upon, great effort was devoted to framing to ensure that the documents would be useful to researchers and community members alike. One challenge, for example, was deciding how to use technical research language. Although the RIWG desired documents that would be accessible to community members with a wide range of reading skill levels, the group also wanted to retain use of research terminology since it is the currency of research. A glossary of the research terms was thus developed so that community members could learn from the documents and participate on equal footing in discussions with researchers. This glossary reflected the RIWG's sensitivity to the needs of the community in term of literacy levels. An assessment of the glossary using the Fry readability formula indicated a 10th grade readability level. While not ideal for a document intended for all in the community (although close to the average reading level of Lawrence adults), the higher readability level was driven by the complexity of the words defined in the glossary.

Educational Implications: The Continuing Process of Developing Ethical Research Partnerships

Effort aimed at maintaining ethical research engagement across a broad and diverse community is work that does not reach some natural ending point. Once the

core documents were agreed upon, the RIWG turned its attention to seeking endorsements of key groups to ensure broad support for the research principles. The Lawrence Board of Health has endorsed the guiding materials and the Mayor's Health Task Force has been tireless in its efforts to bring these issues to the awareness of those in city government offices that receive many unsolicited requests from researchers.

We returned again and again to the point that there is no single research gateway into the city nor can there be. Given this important point, the RIWG has devoted much attention to how the Guiding Documents can best be introduced to researchers and community members so that the documents impact research in Lawrence. It turns out that a handful of organizations in Lawrence has been fielding many of the health study requests from researchers. Health-related researchers often contact one of two groups: the Mayor's Health Task Force itself or the Greater Lawrence Family Health Center. Thus, educating people having contact with these two groups has the potential to impact many research projects and help establish community standards for research. Educational outreach to other groups is also important. The Research Initiative Working Group has begun to disseminate the research principles and model among all Lawrence community members and researchers across Massachusetts, and universities and community organizations have begun educating others about this approach.

A continuing challenge is how to find these others before they approach Lawrence community groups. One way has been to pay close attention to important processes where citizen participation happens. Lawrence holds several citizen participation meetings in which many of the residents help with prioritizing the needs of the community. These processes have included the development of the Five Year Consolidated Plan (HUD), the City's Five Year Health Plan, the Yearly Action Plan (HUD), and many other Community assessments. These activities can attract researchers who approach the community through hospitals, non-profits, and grassroots organizations. The Mayor's Health Task Force and the RIWG have a strong partnership base with 95% of the non-profit organizations in the City of Lawrence. These organizations have begun to contact the RIWG when they hear about research that needs community involvement, providing opportunities to share the Guiding Documents.

An important next step now underway is to find a good "home" for the Guiding Documents to promote and sustain collaborative research partnerships. Possibilities include an organization that would take

responsibility for assuring access to the documents and for bringing the principles to the attention of new researchers. The creation of a Lawrence Research Advisory Board to fulfill these functions has been suggested and is under consideration. The RIWG continues to shape the ultimate structures and methods that will facilitate collaborative research that leads to direct community benefit. Although much work remains, the Guiding Documents provide the architectural design for collaborative research in the Lawrence community.

Discussion

Leaders in the CBPR movement have spoken with eloquence about the problems that researchers and the community must overcome if they are work together successfully (Gilbert, 2006; Glass & Kaufert, 2007; Minkler, 2004; Malone, 2006). Among those who have been most persuasive about these problems has been Loretta Jones (2006) who, through her keynote address to the 2006 Community Campus Partnerships for Health (CCPH) Conference, used vivid metaphors to reflect on the nature of these problems. In her presentation, Jones likened community research to a journey by bus in which people not only climb on and off the bus at different times but use that same bus to go to very different locations. She pointed out that often researchers and community members envision vastly different destinations for their journey: the researchers might focus on testing scientific hypotheses, whereas the community might be intent on ensuring that the findings result in programs that improve community health. At the CCPH conference, images that likened community research to bus journeys resonated with conference attendees and the metaphor of the shared bus journey became a shorthand used by attendees to frame the problems they were encountering in their collaborations. For example, conference attendees called attention to problems arising when researchers decide which issue will be studied before the community is consulted (that is to say, researchers have already decided on where the bus will go before the community members are even on the bus). They called attention to the fallout when researchers fail to involve community members in thinking about how problems should be investigated. And they pointed to the difficulties caused when researchers study a problem without considering the use to which the findings would be put to solve that problem (i.e., the "bus journey" not only may end too soon but may end at the wrong "location").

In the Lawrence Research Initiative, we have all been trying to get "on the bus" at the same time and learn

how we can agree upon a shared destination. Many lessons about the shared research journey are emerging from these efforts and we end by pointing to four challenges that we have encountered and that other communities are likely to confront as they develop their own indigenous approaches.

COPING WITH CHANGING COMMITTEE MEMBERSHIPS

Who is at the table is inevitably in flux in community-university research partnerships. While a community's borders are porous, it is important to keep in mind that membership in community committees is equally permeable. In the Mayor's Health Task Force and in the Lawrence RIWG, people come and go; some individuals and organizations participate for a while and then drop out due to other priorities in their lives. In addition, new individuals may join once discussion is underway and after some decisions are already made. Most community-university research partnerships will face the challenge of achieving sustainability and consensus in the face of shifting involvement and sometimes in the face of the loss of institutional memory. The Lawrence Research Initiative models an important strategy for addressing this challenge via a set of Guiding Documents that will remain in place regardless of who is involved.

DEALING WITH THE CHALLENGES OF MULTIPLE LAYERS OF PARTNERS

Lawrence shares with many communities multiple, overlapping layers of research partnerships. There is no one-to-one relationship; it is not the case that one community works with just one university. Instead, many different community groups may work with a single university, and many universities may work with the same community partner. At any one time, members of the community may be involved with multiple research partnerships that entail varying levels of participation and commitment. The non-centralized nature of this "porous" community makes it difficult to ensure that all of the collaborations conform to CBPR principles. We chose the approach of the Lawrence Mayor's Health Task Force acting to unite these diverse efforts, not just in building the Guiding Documents, but in bringing together a diverse group to develop an overarching strategy for improving health in the city. The Mayor's Health Task Force, as a neutral convener, is able to avoid the threat of the agenda being controlled by a single group or perspective. We have frequently heard that it is unusual to have municipal government serve as the convener and champion; in Lawrence, given the multiple arrangements, this has worked with great success.

Drawing from and using examples from the work of others. We sought to draw on the lessons from other groups (e.g., research centers and tribal nations) who are struggling with community-researcher partnership questions, but we found that many of their ideas (such as that of setting up an community institutional review board) were not a good fit with our context. While some of the ideas will work in communities such as Lawrence, others will not. The continuing challenge is to draw on others' approaches for what will be valuable, while also developing an approach that grows out of the local context, culture, and relationships.

Moving ahead creatively in the face of scarce resources. Like many such community efforts, the Lawrence RIWG had few dedicated resources with which to achieve its goals. It had neither grants nor people paid to carry out the work generated by its decisions. However, members of the RIWG had common interests, a frank assessment of the problems with past research practices, strong leadership, and a commitment to finding alternative ways to work together. Groups embarking on efforts such as these will need to look creatively for resources if they are to achieve their goals in the face of such obstacles. In our case, we looked for ways that tasks could be designed so that they could be done as a part of people's existing work positions, and we wrote a grant proposal to fund an Americorps VISTA volunteer to assist us. The downside of our dependence on individual and volunteer efforts to keep the group work moving ahead was that such efforts took longer without dedicated resources. The unexpected positive consequence was that, because this work was not grant dependent, it became increasingly clear that it was not going to disappear simply because a particular grant came to an end. The struggles to do this work without funding have the potential to overwhelm tentative efforts at partnership, but that same lack of funding can also be an opportunity for building partnership resilience. We have found that the struggles have become a source for building partnership and overcoming obstacles.

Best Practices

We hope that other communities will consider adapting the RIWG Guiding Documents for their own use. As noted in this narrative, the initial development of guiding documents of this sort takes a long time. Now that these guidelines are in place, they can provide a starting point for other communities. Their availability could shorten the time needed by other communities to arrive at a set of community-guided ethical guidelines suited to their particular and unique needs.

Research Agenda

The aim of any research agenda in this area must be to ensure that community-based participatory research overcomes past barriers and continues to strengthen and grow. Two next steps will be important in such a research agenda. The first would be to compare and contrast various approaches to CBPR and to the extent to which various approaches impede or enhance community-based efforts to use guiding documents such as those described here. A second, equally important step would be to investigate the ways in which communities draw from various aspects of guiding documents such as these and how particular kinds of borrowing affect the success of communities in overcoming chronic problems with research carried out in their midst.

Educational Implications

The educational implications of the approach reported here are straightforward. Our experience repeatedly showed the importance of joint and bidirectional educational opportunities. Community leaders and researchers need to come together and learn together. By sharing their perspectives and concerns, they can operationalize CBPR in ways that will lead to rigorous research that meets community standards and needs. Our experience also points to the need for graduate education of future researchers to include an in-depth introduction to community-based participatory research. If future researchers complete their graduate studies without exposure to CBPR, they would appear to be much less likely to understand shared decision making with the community as a necessity and not a mere luxury.

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Appendix I: Tools for Research Partnerships in Lawrence, MA

Lawrence has become a magnet for health research studies. Researchers from universities and the federal government are coming to Lawrence to ask people to take part in studies, such as by taking surveys, so that the researchers can learn more about people in general. In the fall of 2006, the Mayor's Health Task Force decided that they wanted to encourage research in Lawrence, and they wanted to make sure that research in Lawrence benefited the Lawrence community. In the past, some community members had felt that they had been taken advantage of as research subjects and were never given any useful results. The Task Force members also thought that researchers could be more successful in their research if they were able to connect with some of the City's great community resources, such as organizations that could help researchers *recruit* research participants. It seemed to the Task Force, that a "partnership approach" should be promoted between researchers, Lawrence community organizations and the City.

In an effort to promote a research partnership approach, the Task Force set up a "Research Working Group" of researchers, City officials, and people from community groups. The group talked about how to make sure that research in Lawrence would meet community needs as well as the needs of researchers. The Research Working Group came up with four "tools" for researchers and Lawrence community groups to use when they are thinking about working together and as they go through the research process. These tools include some core principles, a list questions to be answered in agreements between researchers and community partners, a step-by-step chart to help guide research partners through a fair and successful research process, and a glossary of research words to help community members understand some of the words that researchers regularly use.

Core Principles

- Research is helpful to community development.
- Working with community members makes better science.
- Researchers and members of the Lawrence community can and should create good partnerships based on fairness and positive exchanges.

Questions for Research Partnership Agreements

The Research Working Group recommends that research projects in Lawrence have formal agreements between participating community organizations and researchers. If the City of Lawrence is also participating, the City should also have an agreement with researchers. The following list of questions can help guide research partnerships toward best practice for research in Lawrence.

- Who are parties to the collaboration?
- How will each party and the City of Lawrence benefit from the research?
- How will funding be shared?
- How will the parties communicate and understand each other?
 - How will language translation be accomplished?
- What will be each party's responsibility for communication about the project to the public and other parties?
- What will be the opportunities for mutual education about the parties' motivations, interests and background?
- What will be each party's role in identifying, defining and prioritizing research questions?
 - If the research involves an intervention or a project to change people, organizations or environments, what will be each party's role in designing that intervention?
- What will be each party's role in designing the overall research protocol and deciding how the research questions will be answered?
- How will the ethical basis of the research be assessed and assured?
 - Which Human Subjects Review Boards will review the proposed project and how will each party contribute to that process?
 - How will community ethical standards and concerns be represented in the research protocol and human subjects reviews?
 - How will it be assured that informed consent forms and procedures are understandable to potential research subjects?
- What will be each party's role in the recruitment of participants?
 - How will recruiters, liaisons and participants be compensated?
- What will be each party's role in collecting data?

- What will be each party's role in analyzing data?
- Who will have access to the data and who will have control and/or ownership of the data?
- Who will be able to propose changes to the research protocol and what will be each party's role in approving changes?
- Who will be able to propose that a project end before its completion and what will be each party's responsibility in deciding to end a project before its completion?
- What will be each party's role in disseminating and sharing results with other researchers, funders, government agencies and representatives, and community members?
- What will be each party's role in using results to support new policy, programs, and research projects?
- How will the partnership be sustained beyond the completion of the project?

See Appendix III, "Steps to Building Research Partnerships in Lawrence," for an overview of how a research project following the core principles might progress over time.

Appendix II: Glossary of Research Terms

Since researchers use terms that laypersons may not understand, we have developed the following glossary so that community people can understand what they might hear when talking to researchers or reading their proposals.

Analysis: Researchers analyze data to get research results. For example, you might use a survey to ask 100 people their age, whether they were male or female, and whether they had a flu shot last year. The answers the 100 people gave you would be your data. Your analysis could tell you what percent of people got a flu shot. You might also analyze the data to see whether men or women were more likely to get a flu shot. You could also see if older or younger people were more likely to get a flu shot.

Collaboration: Researchers usually collaborate with others. A true collaboration provides benefits to everyone included. Collaboration typically involves planning together, sharing resources, and managing resources together. Collaboration is best when all groups understand each other's point of view, communicate openly, and trust each other.

Community: A community is a group of people who have something in common. You might be a member of a variety of communities. As a resident of your city, you are part of the "Lawrence community." Some neighborhoods in Lawrence might also be considered "communities." Communities may also result from a shared interest or practice, like a community of soccer players or the Catholic community. People who share a race or ethnicity might also make a community, such as the "Latino community" or the "African-American community."

Data: Information or evidence of any kind that is written down or recorded. In research, data is analyzed to draw conclusions. Examples of data include answers to survey questions, blood samples, counts of how many people use the emergency room, or recordings of focus group discussions.

Data analysis: The process of breaking data down into smaller parts to pull out useful information and draw conclusions.

Database: A collection of data that can be easily accessed and analyzed. Databases are usually stored on computers.

Data-collection plan: A written plan describing exactly how the researchers will collect information. The plan usually describes who collects the information, when, where, and how.

Dissemination: Dissemination is another word for spreading the news about how a research project was done and what was discovered. The purpose of dissemination is to make sure that research is useful to many people, not just the ones who did the project. People might use information that is disseminated to make decisions, plan policy changes, or take action. When a research project is planned it is important to think about how the results will be disseminated to the people who are most likely to benefit from it.

Human Subjects: A "human subject" is a living individual about whom an investigator obtains either data through interaction or intervention with the individual, or identifiable private information. People who volunteer to participate in a scientific study, also known as human participants or human volunteers.

Human Subjects Protection Certification: All investigators conducting research with humans are required to complete an education program and become "certified" in human subject protections. In addition to principal investigators, members of the research team, and all other individuals (faculty, staff, or student) who have contact or interactions with research subjects or with their private, identifiable information; faculty supervisors of student research projects; investigators who are not affiliated with the research institution conducting the study but who are engaged in the research study are also required to take this certification.

Hypothesis: When researchers plan a project, they usually have a hypothesis they want to test. In community research, a hypothesis often predicts how or why a program will cause a result. For example, a researcher may want to test the hypothesis that providing tutors to students with low grades will improve their test scores. The data collected through research can be used to test hypotheses. To be a research hypothesis, a statement must be clear enough that it can be tested. For example, "TV news is more interesting than comedies" is not a hypothesis, but "Most Americans think that TV news is more interesting than comedies" is a hypothesis.

Informed Consent: Researchers need informed consent from people before they can include them in their research. After a researcher has explained the purpose, the type of information being collected, and the way the information will be used, the person can then freely choose to be in the research study. If, after the explanation, the person freely chooses to be in the research study, they have given informed consent. Informed consent is usually recorded on a signed document, but occasionally it is a verbal agreement.

Instrument (Data Collection Instrument): Researchers often call the ways they collect data “instruments.” What they mean is anything they use to collect and organize information such as surveys, intake forms, attendance records, or tests. Instruments may be written for a project or instruments from a past project may be used. Instruments from past projects are often used when the researcher wants to compare results from different projects.

Intervention: A word for any program that tries to make a change, such as improving heart health, decreasing hospitalizations from falls, or increasing the skills of hospital interpreters.

IRB (Institutional Review Board) or Human Subjects Committee: Most research projects need to be reviewed by an IRB. An IRB is a committee made up of researchers and community representatives who make sure that research projects will not hurt anyone and adhere to ethical guidelines. Universities and many hospitals have IRBs.

Peer Review: Researchers often seek to publish the results of their work in “peer reviewed journals” (scholarly publications). A researcher will write an article describing some part of a research project and send it to a journal. Other researchers, or peers, then make comments about the article, which is the peer review process. If the other researchers think the work is good—meaning it is scientifically sound and contributes significantly to knowledge—then the article gets published. Researchers at universities publish articles in peer-reviewed journals to share information about what they learned in the research projects. The information can be used by others to advocate for policy changes, and to support new programs and their funding. Journal articles can stimulate ideas for new research studies, they may help researchers get additional funding, and they contribute to researchers getting promotions.

Protocol: A protocol is the action plan for a research project. A protocol should tell what the project will do, how many people will be in it, who is eligible to participate, what interventions they will be given, what tests or surveys they will be asked to do and how often, and what information will be gathered.

Research: To understand researchers, it is important to think about what research really is. At the most basic level, research is the search for knowledge. The knowledge gained from research can help us to understand and solve problems. There are many ways to do research. You can do research in a library or on the Internet to learn specific information about the world. But research is not limited to looking up information that is already available. In fact, research can help discover new information and create new knowledge.

Often the information we need to address problems we care about is not known. Over the years, researchers have developed ways of collecting information to answer questions. When research is done well, the results can provide powerful evidence to prove that problems exist and to make positive changes.

When researchers try to answer questions about people’s health or behaviors, they often need “research participants,” people who are willing to answer questions, provide access to their medical or school records, or have physical exams. Only people who want to should participate in research; nobody should ever be pressured, forced, or tricked into participating. Some research, such as medical research testing a new treatment or community research testing an educational program, might directly benefit the person who participates in the research. However, often research does not directly benefit the individual, but provides information to answer questions about the community and inform programs and policies that the individual may benefit from in the future. Participating in research can be satisfying because you contribute to knowledge.

Research Design: A research design is the overall plan for a research project. Research designs tell what data will be gathered, from whom, how and when, and how the data will be analyzed.

Research Question: Research questions reflect the problem that the researcher wants to investigate. They can be based on theories, past research, previous experience, or the practical need to make data-driven decisions. The questions are important because they dictate the type of research design and statistical analysis that is appropriate.

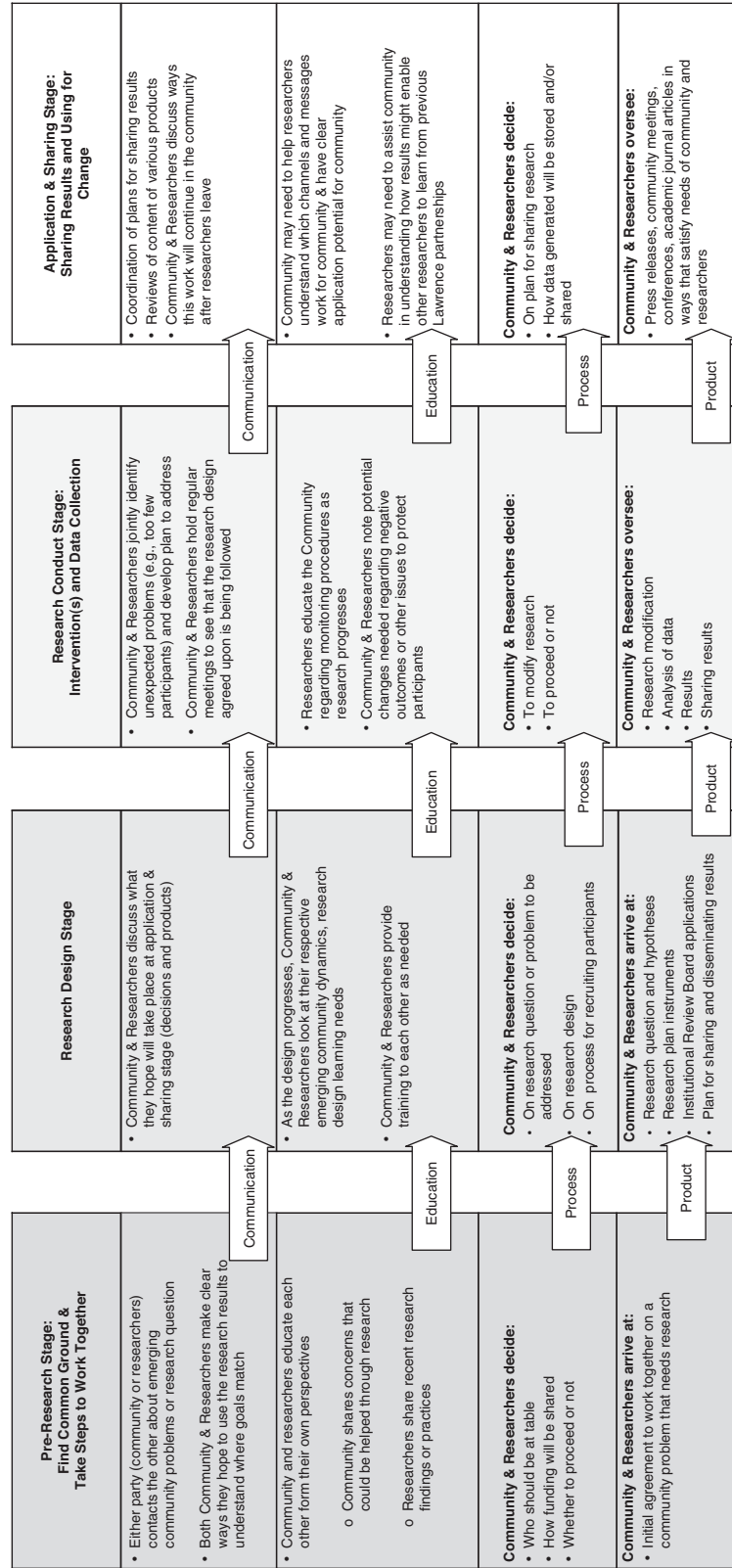
Voluntary Participation: When researchers try to answer questions about people’s health or behaviors, they often need “research participants,” people who are willing to participate in a research study. Participants may be asked to answer questions, complete forms, do tasks, participate in programs, take medications, provide access to their records (such as school or medical), and have medical tests or physical exams done (such as blood tests and body measurements). Only people who want to participate in research should participate. Nobody should ever be pressured, forced, or tricked into participating. Also, a person who gives informed consent can later decide not to continue to participate in the research study.

Web glossaries of research terms:

- http://www.cdc.gov/tobacco/evaluation_manual/glossary.html
- <http://www.ojp.usdoj.gov/BJA/evaluation/glossary/index.htm>
- <http://www.athabasca.ca/policy/research/preambleanddefinitions.htm>
- http://www.hhs.gov/ohrp/irb/irb_glossary.htm
- dir.niehs.nih.gov/dirosd/ocr/irb/irb_definitions.html
- www.umich.edu/~newsinfo/Releases/2001/Aug01/glossary.html

Appendix III

Working Together for Research That Matters
Steps to Building Successful Research Partnerships in Lawrence



The *Working Together Model* captures the flow of activities in building research partnerships where shared and equal decision making are the goals and where the findings are brought back into the community to create change and improve community conditions. The *Working Together Model* is intended to be used with worksheets, templates, and other supporting materials created by Lawrence leaders.