Tools for Research Partnerships in Lawrence, Massachusetts

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 who 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.

The Research Process: An Example

> It is known that being overweight is common among senior citizens and that being overweight can cause health problems. Knowing this, researchers might want to find out good ways to get seniors to eat better and exercise. So, the researchers might come to Lawrence and try to get seniors to participate in an *intervention* research study—to answer questions about their health and behaviors and to try some exercise and diet programs. The researchers would carefully write down what the seniors said and what happened when they tried the programs. Then they would put together all the information (or *data*) from all the seniors who participated and see what they found. If enough seniors participated, then the research *findings* might be *generalizable*. That is, they would apply to the world in general and not just the Lawrence individuals who participated.

In 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. The glossary can help community members understand some of the words that researchers regularly use. (The words that we define in the glossary look like *this* in these documents). We hope you find these tools useful and that you will share your suggestions for how to make them better.

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, program and research projects?
- How will the partnership be sustained beyond the completion of the project?

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