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PRACTICAL TOOLS

A Method for Achieving Reciprocity of Funding in Community-Based Participatory Research

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Abstract

Background: The St. Louis Komen Project was conceived to address disparities in breast cancer treatment and outcomes between African-American and White women in St. Louis, Missouri. Our goal was to apportion tasks and funding through a process to which all researcher partners had input and to which all could agree, thus eliminating institutionalized inequalities.

Methods: This paper describes the collaborative process and resulting division of responsibilities, determination of costs, and ultimate allocation of funds and resources, as well as the documentation employed to achieve funding reciprocity and equal accountability.

Results: Both communication and documentation are critical. Although the Memoranda of Understanding employed are not a panacea, they codify roles and expectations and promote trust. The process of developing financial transparency set the tone for subsequent steps in the research process.

Conclusions: The exhaustive planning process and projectspecific procedures developed by its partners have helped the project foster reciprocity, facilitate participation, and equitably distribute resources.

Keywords

Community-based participatory research, reciprocity, partners, cancer, allocation of funds

Rew would argue that maldistributions of power and resources contribute to health disparities in the United States. Yet, little attention has been paid to how these maldistributions are reproduced in community and academic research partnerships that are developed to address those very health disparities.¹ Maiter and colleagues² note that ethics of responsibility alone fail to fully protect against well-intentioned but deleterious or even malfeasant actions on the part of academic researchers. They advocate instead for project-specific procedures to afford such protection.

Israel and colleagues³ point out that true shared ownership

and control of the community–academic research process implies equal access and control of funds. This determination is confounded by the requirement by some funders that universities be the direct recipient and fiduciary of funds. Furthermore, although both academic and community partners must account for all the funds that they receive, the oversight of those funds often remains with universities.

Whether funds go to universities and are distributed to community partners or are provided directly to academic and community collaborators by funders, Maiter and colleagues'² advice to establish project-based procedures remains salient.

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Research funds are awarded based on the costs associated with proposed specific aims and anticipated products. Tying proposed costs to funding received is not always straightforward and may change as a project progresses. This is especially the case with community-based participatory research (CBPR), because the direction of research may shift based on the dialogue between academic and community partners.

Mutually determined project-based procedures help to ensure that a project's specific aims are achieved, research partnerships remain balanced, and partners are satisfied with their relationships. Yet, despite cautions to develop project-based procedures, few of these procedures have been developed to guide CPBR partnerships in achieving equitable funding. Herein, we have described a concrete set of projectspecific procedures developed by the four community partners and one academic research partner of the St. Louis Komen Project to both foster reciprocity and equitably distribute resources from the project's funder.

OBJECTIVE

There is broad agreement that improving the nation's health depends on the ability to translate research findings from the biological, behavioral, and social sciences into practices that can be disseminated and implemented in communities. Yet, poor progress has been made in achieving such translation,^{4,5} with only half of recommended health care practices ever being implemented.⁶

Translation of research findings into practice is best achieved when investigators work in partnership with community stakeholders to ensure that the context, value system, and needs of each affected community, whether the population is defined by race or ethnicity, age, or geographic area, are considered. Partnerships are most effective when a balance can be achieved between the unique expertise of community and academic partners. This balance relies on transparency of the research process,7 which we define as operating in such a way that all involved see what actions have been performed. Yet, transparency is not easily achieved and requires significant investment from all partners. Because financial reciprocity is among the most sensitive issues in community-based research, a major objective of the St. Louis Komen Project was to establish a transparent process of financial reciprocity that would form the basis for achieving transparency in subsequent steps in the partnered research process.

BACKGROUND

Although the overall incidence of breast cancer is approximately 10% lower among African-American women than White women, African-American women have a 37% higher death rate from the disease nationally.⁸ The Surveillance Epidemiology and End Results data collected by the National Cancer Institute indicate that whereas 126.5 per 100,000 White women are diagnosed with breast cancer per year, 118.3 per 100,000 African-American women are diagnosed per year. Yet 22.8 per 100,000 White women died from the disease in 2006 compared with 32 per 100,000 African-American women.⁹ The fact that the African-American and White disparity varies markedly by city within the United States suggests that social factors at the local level contribute to the disparities.¹⁰

The St. Louis Komen Project was funded by Susan G. Komen for the Cure in 2009 as part of its Vulnerable Communities Project. The five community and academic partners that form the project initially came together to address the disproportionate deaths from breast cancer of women living in the predominantly African-American neighborhoods of North St. Louis City and County. Three partners are providers of care to women through Show Me Healthy Women (SMHW), Missouri's version of the Breast and Cervical Cancer Program, and two are community-based organizations that focus on the health of vulnerable St. Louis residents. The academic partner is a major university and its main hospital affiliate.

The five partners are drawn together by an interest in the health and welfare of racial and ethnic minority women in St. Louis. One of their first decisions was the choice of a geographic area of focus that would allow them to affect breast cancer mortality with the resources available. The group decided to focus their efforts on the eight ZIP Codes in North St. Louis that have the lowest life expectancy at birth in the St. Louis region and the highest rates of cancer mortality (Table 1).

COMMUNITY AND ACADEMIC PARTNERS

The Betty Jean Kerr People's Health Centers (PHC) is a trio of clinics serving as a federally qualified health center that has been providing health care services to the medically uninsured and underinsured in St. Louis for more than 38 years. The three PHC sites provided services to 37,000 individual patients in 2010 over the course of 163,000 patient visits. PHC has mammography capacity at two North St. Louis sites, both of which have designated breast cancer navigators and participate in the SMHW program. As a member of the Integrated Health Network, a group of St. Louis' federally qualified health centers, they also serve as a Komen project liaison to other Integrated Health Network members.

Committed Caring Faith Communities is the local arm of an interfaith, tax-exempt organization that aims to bridge faith and prevention, treatment, and health recovery, and is part of a robust network of 22 churches in St. Louis. Committed Caring Faith Communities serves as a liaison to local churches and their members in North St. Louis.

The Women's Wellness Program of the Saint Louis Effort for AIDS has provided services in North St. Louis since 2007. Its case managers and prevention specialists target neighborhood and community venues in North St. Louis as part of Saint Louis Effort for AIDS's outreach efforts to African-American women.

Christian Hospital, a 485-bed nonprofit acute care facility, is located in North St. Louis County and serves patients from North St. Louis City and County. Christian Hospital's Cancer Care Center provides patients with a comprehensive program of education, early detection, advanced treatment, and follow-up care in breast and other cancers. Christian Hospital's involvement in the SMHW program helps to ensure the participation of lower socioeconomic status women.

The academic partner is Washington University in St. Louis through its Program for the Elimination of Cancer Disparities at the Alvin J. Siteman Cancer Center, the only National Cancer Institute-designated cancer center in Missouri. Its clinical affiliate is the Barnes-Jewish Hospital and its physicians provide services to women in the SMHW Program through the Joanne Knight Breast Health Center.

AIMS AND ASSUMPTIONS

In attempting to understand and address the disproportionate breast cancer mortality of African-American women in North St. Louis, the five partners of the St. Louis Komen Project made the decision to examine the contribution of systems-level factors. The group realized that no single partner had a broad picture of how women in North St. Louis moved through the existing system of care after diagnosis. The objective of the St. Louis Komen Project, then, was to develop a systematic method of identifying barriers in the breast cancer care continuum of African-American women in North St. Louis, with an ultimate goal of decreasing St. Louis' alarming African-American and White disparities in breast cancer mortality, and to address deficiencies in the current delivery of care.

The project's hypothesis is that poorly managed intraand inter-organizational referrals for North St. Louis women enrolled in the SMHW program contribute to their inability to complete prescribed breast cancer treatment and thus to the African-American and White breast cancer mortality disparity. The project's specific aims are to 1) use Missouri Tumor Registry and Komen Project partner data to identify women diagnosed between 2000 and 2008 while living in the eight high-mortality ZIP Codes; 2) interview a sample of the women identified to obtain and document their breast cancer treatment histories in their own voices; and 3) simultaneously increase trust among ZIP Code residents through establishing a drop-in center in the ZIP Code with the highest breast cancer mortality rate, and using it to provide services to women and their families.

Achieving the specific aims of the St. Louis Komen Project depends on achieving a balance of control among partners.

Table 1. Life Expectancy at Birth and Cancer Mortality per 100,000 Residents for Eight ZIP Codes in the St. Louis Komen Project ^a								
ZIP Code/ Geographic Area	Life Expectancy at Birth	Cancer Mortality per 100,000						
63101 ^b	72.1	472.3						
63113	69.8	349.9						
63106	69.2	336.4						
63115	71.7	280.2						
63107	70.5	268.2						
63147	74.9	265.2						
63104	77.1	256.8						
63120	70.2	255.7						
St. Louis	74.9	440.0						
State of Missouri	77.4	197.7						

Adapted from "Understanding Our Needs," released by The City of St. Louis Department of Health and based on 2006-2009 data.

^b Small population, interpret with caution.

Reciprocity of funding is an important aspect of achieving this balance. Although the funder required the award to go to the academic partner, it was important to devise a plan by which all partners could be compensated for the expertise that they brought to the project. This paper describes the initial, detailed, collaborative planning process undertaken by the partners and the resulting division of responsibilities, determination of costs, and ultimate allocation of funds and resources, as well as the documentation employed to achieve funding reciprocity and equal accountability across the stakeholders.

METHODS

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The group of five partners developed a four-stage process for assigning funds to achieve the aims of reciprocity and to support the tasks involved in accomplishing the project's three specific aims. The four stages are 1) articulate the tasks that must be executed to achieve the projects' specific aims, 2) assign a cost to each task, 3) decide which partner would assume the task, and 4) prepare a memorandum of understanding (MOU) for each partner to reflect its contribution and the funding assigned.

In the first stage, the group articulated all tasks that must be fulfilled to achieve each of the three specific aims. The first specific aim, for example, entailed developing a list of the types of information that we needed to secure from the Missouri Tumor Registry on each woman in the study population, meeting with Missouri Tumor Registry staff, and preparing an application for permission to conduct human subjects' research. The second aim entailed developing an interview survey and recruitment plan, staffing the recruitment team, and scheduling interviews with women who met the project's inclusion criteria. Achieving the third specific aim included tasks such as establishing an office in one of the ZIP Codes, locating and securing office space, setting up utilities, helping to plan community presentations, and advertising events.

In the second stage of the process, a representative from the university's research administration office met with the group and assigned a cost to each task that had been articulated by the group of five partners.

The function was unusual for research administrators, who were unaccustomed to this new approach to reciprocity. The grants administrator assigned to the project was reluctant to engage in a process that was so unusual to the modus operandi of his office. Three of the partners requested and were granted a face-to-face meeting with the university's Assistant Vice Chancellor for Research Services to discuss the process and its rationale. This person, who had prior experience with CBPR, then encouraged the grants administrator to move ahead with the process. A secondary gain of the process thus was more fully exposing the university research administration to the basic tenets of CBPR.

Next, the partners met to decide who was in the best position to assume each task. Some were straightforward; for example, statistical analysis of data was assumed by the academic partner, with assistance in interpreting results from the community partners. Committed Caring Faith Communities and the Women's Wellness program were in the best position to advertise the services of the Community Partnership Center within the community, based on their existing ties. PHC and Christian Hospital were best positioned to interpret women's clinical data and understand features of the clinical environment that helped to interpret how women moved between provider sites.

To facilitate this task, we wrote each task and its associated cost on a separate piece of single-sided, adhesive paper. The sheets of paper were attached to a wall so that partner representatives could visualize the entire constellation of tasks. Through active discussion, the group was then able to move tasks into five groups representing the five partner sites. In some cases, the partner who assumed a task asked for a renegotiation of the cost for a task. In these cases, the group discussed the type and amount of work that the task likely would entail and discussed the case until consensus was reached. This was possible in all cases, with some give and take among partners.

Last, the group prepared MOUs that articulated the tasks assigned to each partner and a budget that included final costs for each task. These MOUs and budgets were reviewed by each partner until agreement was achieved on their content (Table 2 provides sample tasks and their division among the St. Louis Komen Project partners and Appendix 1 [online] for access to an entire sample MOU).

LESSONS LEARNED

The St. Louis Komen Project has made great progress toward achieving its goals in its first 1.5 years of operation. We have prepared an overview of the more than 900 women who were diagnosed with breast cancer between 2000 and 2008 while living in the eight ZIP Codes and interviewed more than 98 survivors from the group, toward a goal of 100 interviews. We have presented a number of community programs and offer daily educational and support services through the Community Partnership Center. The success of these efforts is due in part to the time that the partners took at the project's inception to set the tone of transparency that has influenced our interactions since that time. Although the topic of this article is financial reciprocity, it is almost certain that the mode of shared decision making that led to the development of our MOUs has diffused to other areas of the team's functioning. Although the process is far from

	Academic _		Community Partners		
Responsibility	Partner	Α	В	C	D
Project Development/Management					
Formulate research questions	×	×	×	×	×
Develop task list, assess costs, and divide tasks/costs among partners	×	×	×	×	×
Complete course on human subjects research		×	×	×	×
Manage institutional review board reporting/compliance	×				
Analyze data	×				
Attend monthly partnership meetings	×	×	×	×	×
Grant Administration					
Manage accounting/bookkeeping	×				
Oversee budget	×				
Logistics					
Draft contracts	×				
Hire staff	×				
Find location for Community Partnership Center		×	×	×	×
Choose focus group(s) location/content	×	×	×	×	×
Recruiting					
Conduct recruiting activities		×		×	
Place targeted ads for recruitment, meetings, focus groups, and community research course		×		×	
Survivor Brunch					
Organize, invite, and plan		×	×	×	×
Community Partnership Center Activities					
Solicit needs of community		×	×	×	×
Recruit community residents to new programs		×	×	×	
Reporting					
Prepare reports for funders	×	×	×	×	×
Disseminate results (multiple channels/venues)	×	×	×	×	×

Table 2. Sample Responsibilities and Their Division Among the St. Louis Komen Project Partners,

^a Please note that this list is illustrative, not exhaustive.

conflict free, we have a culture of negotiation that allows us to use conflict productively to achieve the best possible results for our shared project.

Although community and academic partnerships may be begun with the best of intentions, the differences in perspective that are an underlying strength of CBPR can, in time, produce the disagreements that are inherent in all partnerships. Funding is one such point of disagreement if plans are not outlined clearly when partnerships are begun. Some funders mandate that a certain percentage of funds must go to community partners. Although this is a step toward reciprocity, disputes may arise if the task required to ensure that specific aims are achieved are not tied to those funds.

We have found that communication is critical, and must be followed by documentation of agreed-upon functions and responsibilities. The St. Louis Komen Project used a four-stage process to distribute tasks and funds to cover those tasks, resulting in the aforementioned MOUs. These MOUs are important documents for furthering the goal of equalizing responsibility, access, and control of funds and resources. The knowledge that all partners were actively involved in formulating the MOUs was instrumental in building the transparency that is essential for the goals of CBPR to be achieved. Because CBPR is an iterative process of decision making, the original MOUs needed to be adjusted as plans shifted to accommodate community and research realities. This could be done with minimum energy because agreed-upon MOUs were in place to provide a framework. Although MOUs do not eliminate all inequalities, they do help codify roles and expectations, promote accountability and trust, and as such, minimize conflict. Perhaps more important, the process of communication that was established early in the St. Louis Komen Project set the tone for the decision making that followed.

CONCLUSIONS

By implementing project-specific procedures developed by its five partners, the St. Louis Komen Project has sought to foster reciprocity, facilitate participation, and equitably distribute resources from the project's funder. These measures have helped to further the ethical and functional principles of CBPR, and have cultivated an atmosphere of trust and equal engagement.

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Appendix. Sample Memorandum of Understanding: Memorandum of Understanding for Community-Based Participatory Research Agreement St. Louis Komen Project

The University seeks in this Memorandum of Understanding ("Memorandum") and the specific agreements arising from it to forge a collaboration with # community organizations (together with the University, the "partners" or the "partnership") to address [Insert project focus]. By setting forth the principles of community-based participatory research that are generally applied in projects between academic and community researchers, the partners intend this Memorandum to establish the general guidelines that will be considered in creating specific agreements for the implementation of the project principles and objectives set forth below. It is contemplated by the partners that any such agreement will empower Community Partner A to act as liaison between the University and those communities to be served by this project, to work with the University to ensure substantial adherence to the research principles set forth below, and to facilitate the meaningful participation of individual members of the community and the community organizations acting as partners in order to ensure full community participation in the project.

PART I: PARTNERSHIP: PRINCIPLES AND PROCEDURES

Community-Based Participatory Research Principles

This project will follow principles of community-based participatory research set forth in Minkler and Wallerstein, *Community-Based Participatory Research for Health* (2011).⁺ The underlying principles will include:

- 1) The project will seek to enhance the community's welfare by empowering the community and its members to address their own health issues;
- 2) The project will be designed to increase breast cancer awareness in the community and to increase community knowledge of the breast cancer issues that are specific to the community;
- 3) Community and academic partners will work together in all phases of the project, including planning, implementation, research and evaluation, analysis, interpretation, and dissemination. In particular, the partners will seek community participation in the following respects:
 - a) Community and academic researchers will work together to define the issues to be addressed by this project and to shape the scope of the project to best serve the community;
 - b) Community and academic researchers will work together to solicit the meaningful input and participation of members of the community in the research process;
 - c) Community and academic researchers will work together to ensure that project membership remains open and inclusive, admitting as many community members and organizations as can be reasonably accommodated by scope of the project's funding and objectives;
 - d) Community and academic researchers anticipate that the partnership's regular meeting site will be rotated among the partners to ensure the broadest possible community participation;
 - e) Community and academic researchers acknowledge that each of the partners brings its own specialized knowledge and expertise to the medical issues facing the community and further acknowledge that each has demonstrated a high level of commitment to finding solutions to the particular medical issues confronting the community;

^{*} Minkler M, Wallerstein N, editors. Community-Based participatory research for health: From process to outcomes. San Francisco: Jossey-Bass; 2008.

- f) It is the academic researchers' intent to include community partners in the analysis, synthesis, interpretation and verification of all results and conclusions of the project, and it is the intent of the community partners throughout the term of the project to support the research and scientific process as needed;
- g) Community partners will collaborate with academic researchers to identify medical issues and project outcomes of particular relevance to the community; and
- h) Partners will meet periodically to assess the experience of both community and academic researchers, to address any concerns that may arise in the course of the project, and to ensure the meaningful participation of all partners in the project.
- The partners understand that the project may entail a consideration of social, economic and other cultural factors contributing to the prevalence of breast cancer in the community;
- 5) The partners will adopt mutually agreeable mechanisms to voice and resolve differences of opinion or concerns about the fairness of the research process, and the partners acknowledge that such issues would best be resolved by a majority vote of the partners.
- 6) The partners understand that dissemination of the research results will be the responsibility of all project participants, and that academic and community partners alike should be afforded ample opportunity for presentations and publications, subject to the conditions of the partnership set forth in this Memorandum and any agreements arising from it.

Financial Arrangements

Community and academic researchers will work together to assess the financial needs of each partner in relation to the activities each proposes to undertake in connection with the project. The partners understand that high-quality research evaluations of community projects may help the partners obtain future funding for medical research or other projects of value to the community. The partners understand that the ultimate sustainability of the collaboration will require development of a funding plan.

Institutional Review Board Responsibility

It will be requested that each participating community partner designate at least one of its members to complete a course in human subjects research and obtain a certificate of completion of such training through the University's Institutional Review Board (IRB) website (_____). Each participating partner should determine the status of its own IRB board, and develop plans to coordinate any IRB review through its agency with the review(s) of other participating IRBs.

PART II: PROJECT DESCRIPTION

The project is intended to establish a collaborative research infrastructure between the University, community agencies such as Community Partner A, and community health care of [see below]. The anticipated project period as submitted [Insert funding entity] is ______ through ______, 20__.

The long-range objective of the partnership is to develop an infrastructure founded on a community-based participatory research (CBPR) model that will serve as a platform for [Insert aims]. This objective can only be achieved if we are able to develop the infrastructure for a strong, balanced, and effective collaboration between two worlds, namely community stakeholders and academic researchers. The present application involves (1) community-stakeholders from four organizations who are aware of the health problems and strengths of their communities, expert in the contingencies imposed by being part of those communities, and represent the voices of those communities, and (2) academic investigators who possess the requisite knowledge to address these health disparities in a scientifically rigorous manner. Four robust community organizations will collaborate with their academic partners from Washington University to form the core collaboration referred to sometimes herein as the "partnership." Two of the five partners represent health care organizations familiar with [insert research focus] area of [Insert

location] (Community Partner B and Community Partner C) and one represents women's wellness (Community Partner D). The fourth collaborating organization, Community Partner A, is [Insert description of organization]. An additional goal is to document the methods, processes, and outcomes of the project, through the rigorous application of scientific method to the community-based participatory research framework.

The responsibilities and roles of partner A are as follows:

- 1. Partner A will receive \$XXXX per year for the Partner A representative's (or designee's) attendance at monthly partnership meetings, the site for which will be rotated among partners.
- 2. Availability by E mail of the partner representative to respond to questions that arise in between meetings (e.g., determining if an invitation by a community group for us to speak is appropriate, looking over flyers that the CBPR coordinator drafted to provide feedback).
- 3. Help in recruiting [Insert specific, measurable partner A recruiting goals]. Partner A will be reimbursed \$XXXX per year for a representative or representatives to [insert specific, measurable recruiting activities].
- 4. Provision of # representatives to help plan the meetings that are to be held one time per year and reviewing their agenda. These individuals will be reimbursed \$XX per hour for approximately XX hours of work a person.
- 5. Help with choosing the location and content of focus group meeting to be held ______. A representative will help with this planning for which they will be reimbursed \$XX per hour for approximately XX hours.
- 6. Analytic review of the transcripts of the meetings to identify themes and assisting with preparing a report for distribution. For this, XX representatives will be paid \$XX per hour a person for approximately 40 hours of work per year.
- 7. Partner A will coordinate and place flyers in church bulletins [Insert target area]. Partner A will be reimbursed \$XX per church flyer for a flyer placed once per month for XX months in XX church bulletins.
- 8. In addition, Partner A will locate and oversee the work of a caterer from a member church for the meetings and focus groups. For each of two meetings, the caterer will provide coffee and snacks for __attendees per year at a total cost of \$XXXX (\$XX per attendee for XXX attendees). For the focus groups, the caterer will be reimbursed \$XX per person for XX persons for a light snack and liquid refreshments (\$XXX total).
- Partner A will take responsibility for placing ads for recruitment for participation of women from the target sample in the project, as well as the meetings, focus groups, and community research course in church bulletins and the [Insert publications].
 \$XXX per ad for approximately XX ads will be designated to Community Partner A for these important advertisements.
- 10. It is anticipated that a cost-reimbursable subcontract will be set up between Washington University and Community Partner A for the activities performed. As awarded by ______, 20% indirect costs will follow the costs detailed above; provided, however, that Washington University's obligations under any such agreement shall be contingent upon the University's receipt of reimbursement from ______, and that in the event such funding should cease or otherwise become unavailable to the University, the University may cancel any the agreement and shall have no more obligations under the contract.

PART III: MISCELLANEOUS

- 1. The partners understand and agree that they are not agents, employees, partners or joint ventures, and none of them shall have the authority to bind the others, or to incur any obligations or debts on behalf of the others, or take any actions that attempt or purport to bind the others whether in contract or otherwise.
- 2. The partners may only alter or amend the terms of this Memorandum of Understanding by mutual written agreement of the authorized officials of each partner.
- 3. This Memorandum of Understanding shall be governed and construed in accordance with the laws of the State of Missouri,

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and the partners agree that any dispute arising out of or relating to this Memorandum shall be filed and litigated in the Circuit Court of ______, _____.

- 4. The partners understand and agree that nothing in this Memorandum shall be construed in a manner that would require any partner to act in violation of any local, state or federal law.
- 5. The partners understand that this Memorandum is a statement of principles and preliminary understandings only, and that the terms of any specific agreement arising out of this Memorandum shall supersede any statements, representations or other indications of intent contained herein, and that nothing contained herein may be used to contradict, alter or vary the terms of any specific agreement the partners may subsequently enter into.

PART IV: SIGNATURES

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A. Academic partner. The following party represents the primary academic partner in this Memorandum of Understanding. The signature indicates the University's general agreement with the *understandings set forth in this Memorandum*.

Washington University

By:	(DATE	

_____, Senior Contract Manager

B. Participating Community Partner. The following community partner is participating in the project described in this agreement as a voting member of the partnership (or in some other major role designated in the project). The signature indicates that the terms of the agreement have been reviewed and will be adhered to while participating in this project.

Community Partner A

By: ____

____, Chairman of Board of Directors; Community Partner A

C. Academic partners. The following academic partners have read, understand and acknowledge the terms of this Memorandum of Understanding:

____ (DATE) _____

__(DATE)___

_____, Principal Investigator