Reviewing and Considering Research Requests from Academics

This document includes:

- examples of questions that communities can use to determine if they are interested in partnering or participating in a research requests or proposals that academic or other partners bring
- sample form for academic or other researchers to fill out to request community participation
- two sample forms for community partners reviewing research requests submitted by academic or other researchers.

Useful information on this topic can also be found at:

- UCSF Resource Manual for CBOs: http://accelerate.ucsf.edu/files/CE/manual_for_agencies.pdf
- http://www.catie.ca/en/pif/spring-2013/what-ask-when-researchers-come-knocking
- Article about Galveston Island Texas Community Research Advisory Committee: http://caps.ucsf.edu/wordpress/wp-content/uploads/2013/05/NIH-proposal-development.pdf

It may also be helpful to review resources for connecting and building relationships with academic partners.

Questions to Guide Review of Research Proposals in the Community

Compiled from Galveston Island Texas Community Research Advisory Committee guidelines, article by Strike and Guta (http://www.catie.ca/en/pif/spring-2013/what-ask-when-researchers-come-knocking), and input from ARCC staff and partners.

Community partners can choose some or all of the questions that are relevant and/or important to you.

Who?

1. Who is asking to conduct research in our community?
2. Do any of us know the person(s)? Do any of our partners know the person?
3. What is their research interest? What do they want to study?
4. What have they published, on this issue or other issues?
5. Can we get copies of their published work?
6. What school is involved? More than one school? What is their school/university's reputation in the community?
7. What is their position at the school? How long have they been there?
8. What department are they in?
9. What is their experience working in the community?
10. With which communities (in our area or elsewhere) do they have a history in the community?
11. Are any other organizations, churches, or community groups involved?
12. Are we the only ones who got the letter?
13. How is the study funded? By the school, by the government, by other funders?
14. What role, if any, will community members or community organizations (leadership, staff) be asked to play? Access to the organization information/clients for recruitment? More collaborative involvement e.g. setting goals, developing research questions and study design, collecting and analyzing data, and disseminating findings?
15. What resources will come to our organization for our involvement? Money, staff, space, training?
16. Will any community members be involved with planning and implementing the study?
17. Will community organization staff be need to complete any research tasks (e.g. collect or administer surveys, enter or submit data, etc.)? Will staff or the organization be compensated? Who will research staff report to? Will staff have opportunities to develop their research skills?
18. Will external research staff or other researchers working with the faculty be involved in the research team (faculty, students, staff, fellows)? Will they work onsite at our community organization? If so, who will they report to?
19. Is there a collaborative? How were they chosen? Are they representative of our community? Are they representative of the people being studied?
20. Can we have representation on the collaborative?

Compiled by the Alliance for Research in Chicagoland Communities (ARCC) www.ARCConline.net

21. What are their plans to include community in the study?
22. Can the group have input in study design and implementation?
23. What is the study procedure?
24. What are the expected outcomes?

What?
1. What is the purpose of the study?
2. What is the proposed research question?
3. What do they hope to find out?
4. Is this of concern to us?
5. Is it a significant or pressing concern to the community?
6. Is this a concern for our organization?
7. Will it help us plan or evaluate programs? Will help us understand changes in our community? Will it provide evidence for policy changes that benefit our community? Will it help us make the case of need or impact for funders?
8. What do we think is important to study in our community? Is this issue important enough to study and important enough to study *now*?

Where?
1. Where will they conduct the study? In the home? At the university? Somewhere in the community?
2. Who decided the study location? Did participants or community members have input on the location?
3. Is it convenient for community members?
4. Will transportation be a problem? Is there a transportation cost to participants?
5. If so, will the researchers help with the cost of transportation?
6. Will researchers need to provide child care, car seats?

When?
1. What is the status of the study/proposal? In design, submitted, funded, started?
2. If the research has already been submitted/funded, can we have a copy of the research proposal/budget? Is there an opportunity to make changes to the proposal/budget?
3. When will the study be conducted? How long will it take to complete the study?
4. Does this give us time to review the study?
5. Is there time for us to become involved, on the study collaborative or on the planning of the study?
6. Is the time good for the community? Is it a convenient time? For example, is it after school is out or around a holiday, important church dates (i.e bible study, a pastor's anniversary) or in the evenings?
7. Do the times of participation effect who can participate in the study,e.g., it is during work hours or at night or on the weekends?

How?
1. How do they plan to approach the research? What model of research do they plan to use? Are they using a traditional investigator-driven model or a more community-based or community-engaged approach or something in between?
2. What decision making process will be used for this research? Consensus? Majority rules? Researchers makes all decisions?
3. What do they want to do?
4. With what group(s)? Parents, women, men, seniors? Why?
5. How will they do it? By phone? In person? In groups?
6. Is it a survey or a face-to-face interview or group process?
7. How long will it take?
8. What steps are being taken to ensure the research is done in an ethical manner? What ethical principles will guide the project? How will the privacy and confidentiality of participants be ensured?
9. Will it be tape recorded? What will be done with the tapes?
10. Who will hear them?
11. Where will they be kept? Under lock and key?
12. What questions will be asked? Can we see them? Are we comfortable with them? Is the language understandable? Can we have input on the language and/or questions?

13. Do we know why these particular questions are being asked?
14. Are any of the questions offensive to us?
15. Are any of the questions embarrassing?
16. Is there a good reason for asking these questions?
17. Who will be asking the questions? For example, will men be asking men and women asking women? Will the people asking the questions be students? Will they be the same race as the participants?
18. How and who will be asked to participate in the study? Is anyone excluded? If so, why?
19. Will participants be compensated?
20. Will they be protected otherwise?
21. What happens to study results? Will they be published? If so, where?
22. Will data be accessible to our organization or community members?
23. Will there be a press release in the local paper(s)?
24. Are community members involved in the writing of the final report or article?
25. Will results be presented to the community? Where and how?
26. Are participants involved in the presentation?
27. Can participants have input on where and how study results are made public?
28. Will results affect the participants and/or the community? How?
29. Who else will the results be disseminated to, e.g., city government, local organizations, churches, other interested parties?
30. What happens after the study is over? Will the collaborative be disbanded? Will there be an intervention? If so, who will do it, where, when, with whom? Will community members be involved?
31. Do community members have input on the design and implementation of the intervention? Will researchers continue to work with the community?
32. Do the researchers have plans for more research with the community or other interventions?
33. Will the researchers support the community's efforts if the community continues to work on the research issue or intervention?

Research Request Form
(To be submitted by academic researcher)

From Galveston Island Texas Community Research Advisory Committee

Name of Principal Investigator (person responsible for the grant or project):_____
Affiliation:_____
Name of Co-Principal Investigators and Co-Investigators:_____

Address of Principal Investigator:_____
Street:_____
City and State:_____
Zip Code:_ _____
Phone Number:_____
Fax Number:_____
Email:_____

Title of grant or research project:_____

1. Please attach an abstract or brief summary of your project (e.g. purpose of the study, hypotheses, methods, implications, plan for dissemination of research findings, etc.)
500 word limit
Abstract Attached? ___Yes ___No

2. Why are you requesting to partner with ___your organization_____?

3. If funded, how will your work improve the quality of research to address health issues in the African American or potentially other underserved communities?

4. Please list the efforts you have made to ensure that the research team has the sensitivity to understand the social, cultural, and environmental context of the community of focus?

5. What is the racial and ethnic composition of your community of focus?

6. Are you or anyone on your team a member of our organization? If not, how did you learn about our organization?

Research Request Evaluation Form
(To be completed by the review committee)

From Galveston Island Texas Community Research Advisory Committee

Principal Investigator:_____

Project Name: _____

Type of Study: _____

Target Population: _____

Request submission date: _____

Notification date: _____

The evaluation score provided by each member of the GICRAC IWG will assist in determining whether research partnership, letter of support, etc. is appropriate.

<u>To be completed by each member of review committee</u>
Scoring (Scale ranges from 0 to 5)
Question #1: How closely is the proposed project matched with GICRAC's Mission Statement?
    5-Close match with our mission statement.
    3-Partial match with our mission statement.
    0-Inconsistent with our mission statement.
    Not applicable/Other

Comments:_____

Question #2: Are the reasons for requesting a letter of support convincing?
    5-Very convincing
    3-Somewhat convincing
    0-Not convincing
    Not applicable/Other
Comments:_____

Question #3: Does the research/grant project have the potential to advance the health in the community of focus?
    5-Highly likely to advance the field of <u>*our population's*</u> health.
    3-Likely to advance the field of <u>*our population's*</u> health.
    0-Probably not likely to advance the field of <u>*our population's*</u> health.
    Not applicable/Other
Comments:
_____

Question #4: Are efforts to ensure sensitivity to understand the social, cultural, and environmental context of the community of focus convincing?
    5-Very convincing
    3-Somewhat convincing
      0-Not convincing

Not applicable/Other

Comments: _____

Total Average Score:_ _____

Please send completed forms to _____. Scores will be tallied and sent to _____ to guide discussion on projects that were submitted for review.

      3.5 to 5.0: Very acceptable

      3.0 to 3.4: Acceptable

      Less than 2.9: Marginal/Not Acceptable

RESEARCH PARTNERSHIP AGREEMENT CHECKLIST

From Pacific Aids Network (http://pacificaidsnetwork.org/wp-content/uploads/2011/10/PAN-RESEARCH-AGREEMENT-CHECKLIST.pdf**)**

These guidelines are intended for agencies who may be partaking in community-based research for the first time and want to know some of the questions to ask in order to ensure proposed research projects are suitable to their organization's needs and capacity levels, and that research partnerships are respectful and mutually beneficial.

These guidelines may be used as an informal guide to help you assess whether a project is the right fit for you and your organization, or it may be used as a template for a questionnaire administered to potential research partners as part of a formal approval process. Please note this template is intended only as a guide, and should be adapted according to the specific needs and interests of your organization.

Study Background

➢ What is the name of the study?_____ _____

➢ What is the time frame for completion?_____

➢ What other sites, groups or organizations have been approached for this research?_____

➢ Who is on the research team? [Please list the names and credentials/affiliations of each member of the investigative team]_____

➢ Please describe the nature of the proposed partnership and the expected contributions of our organization. _____

➢ What are the proposed funding sources of this project? What is the current status of the grant application? _____

➢ What are the action- or policy-oriented objectives of this project? _____

➢ How will my organization benefit from this research?_____

Methodology

➢ Please attach copies of your research tools (interview guide, focus group guide, surveys, etc.)

➢ Please explain in detail the following methodological steps AND how community members will be integrated into these processes:

o Development of research questions _____

o Development of research tools _____

        o Participant Recruitment _____

        o Analysis _____

        o Knowledge translation and exchange activities _____

➢ Please describe the plan for communicating the results of the study to the participants and contributing community organizations. _____

Confidentiality and Support for Participants

➢ What participation and time commitment is expected of our organization's members who take part in the study? _____

➢ Explain the project's commitment to confidentiality and anonymity. _____
➢ Has the study been accepted by an ethics review committee?_____
➢ If there are personal or potentially triggering questions being asked of organization's members, is there a justified and logical reason for asking these questions? Please explain in detail. _____
➢ Please describe the plan in place for counseling/debriefing for participants once the interviews, focus groups, surveys, etc. have been completed.**_____**

Compensation
➢ What is the honoraria amount offered to the participants and peer researchers?_____
➢ What is the amount of the child care subsidy offered to the participants?_____
➢ What travel expenses will be provided (bus tickets, parking, mileage, etc.)? _____
➢ Is there an administrative fee or honoraria available for our organization?_____
➢ Is there any other additional, relevant information about this study our organization should be aware of?

Thank you.

Community Criteria for Research Participation

In August 2012, AAPCHO and its partners developed a set of research criteria that community health centers (CHCs) and communities could use to evaluate their participation in research studies. The criteria is rooted in the model of research known as Community-Based Participatory Research, in which communities actively and equitably engage in the research process. The criteria was designed to ensure that research on target communities was relevant and directly beneficial to the community being studied.

IMPORTANCE OF CBPR

- Research findings can be utilized in the development of interventions specifically for underserved communities facing health disparities.
- Traditional research is often done without community involvement and thus does not have relevance for communities. There is a greater need for education on how research can be appropriately conducted in partnership with community members.
- CBPR benefits not only researchers, but also the community under study by empowering it with the knowledge and tools to implement changes.
- CHCs and community-based organizations can engage in research that more-effectively address locally identified needs.[1]
- Significant community involvement can lead to scientifically sound research.[1]
- CBPR has the potential to build greater trust and respect between researchers and communities.[1]

For more information, please refer to the "CBPR Toolkit" at http://www.aapcho.org/resources_db/cbpr-toolkit/.

PARTNERS

We gratefully acknowledge the following organizations that contributed to the development of the Community Criteria for Research Participation:

- Community Health Applied Research Network
- University of California Los Angeles, Los Angeles, CA
- Asian Health Services, Oakland, CA
- Charles B. Wang Community Health Center, New York, NY
- Waianae Coast Comprehensive Health Center, Waianae, HI
- Waimanalo Health Center, Waimanalo, HI
- Kaiser Permanente Center for Health Research, Portland, OR
- Alliance of Chicago Community Health Services, Chicago, IL
- Bay Clinic, Hilo, HI
- Ko'olauloa Community Health and Wellness Center, Kahuku, HI
- Waikiki Health Center, Honolulu, HI

This project was made possible by the generous support of the Department of Health and Human Services, Health Resources and Services Administration (Grant No: UB3HA20232).

1. Examining Community-Institutional Partnerships for Prevention Research Group. Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum. 2006. www.cbprcurriculum.info

PARTICIPANT INSIGHT

A COMMUNITY MEMBER EMPHASIZED COMMUNITY ENGAGEMENT IN RSEARCH:

"If the problem is in the community, the solution is in the community. Understanding the community is essential. We need to recognize the role of the community in research, and we need to change the metrics of research to capture the value of research in the community."

A CHC ADMINISTRATOR COMMENTED THAT RESEARCH DONE AT CHCS NEEDS TO BE FLEXIBLE:

"At a CHC, everything always comes in secondary to patient services. Learning to be patient and flexible was hard but it's helped to garner better results. Most of the work from a new research grant will fall on the front line staff. We really need to acknowledge the way new programs will impact the way we operate."

AN ACADEMIC RESEARCHER SUGGESTED THAT CHCS SHOULD HAVE THEIR OWN ROADMAP OF RESEARCH PRIORITIES:

"Research is asking the right question. Making something better can only happen if we ask a question. CHCs should have their own roadmap to let outsiders know what their research priorities are."

MORE INFORMATION

For more information, please contact Research Manager Hui Song, MPH at hsong@aapcho.org.

COMMUNITY CRITERIA FOR RESEARCH PARTICIPATION:

COMMUNITY INVOLVEMENT IN DESIGNING THE COMMUNITY PROJECT

1. Recognizes community expertise, gives voice and value to the community
2. Community is engaged throughout entire research process such that equal value is placed in community vs. academic expertise
3. Has clear, specified community relevance and impact
4. Includes processes collaboratively developed with the community that includes protections for both researcher and the researched
5. Includes investigators who have previous experience working within the community, and who have a true desire to learn from the community
6. Includes plan for community training and monitoring of "knowledge gain," capacity building
7. Includes appropriate language of the community (e.g. "participants" instead of "subjects")
8. Includes CHC staff, including front-line staff, and/or community members in planning and all phases of research
9. Includes CHC or community principal investigator in research

ALIGNMENT WITH THE MISSION OF THE CHC AND ITS CONSUMERS

1. Research plan is included in CHC executive priorities or organizational roadmap
2. CHC / consumer is an equal partner in the proposed research
3. Designed in a way that will be sustainable to the CHC
4. Includes goals of value to CHC and community to extent that CHC is committed to investing in it in the future, even after project ends
5. Includes training to raise capacity of staff and community

EQUITABLE AND BALANCED BUDGET ALLOCATION BETWEEN PARTNERS

1. Includes a balanced budget that reflects the strengths and expertise of CHCs and consumers
2. Includes allocation in budget for community advisory group or community member FTE support
3. Includes allocation in budget for dissemination to the community
4. Includes allocation in budget for indirect costs for space for research implementation

ACCOUNTABILITY TO THE COMMUNITY AND NOT JUST THE FUNDING AGENCY

1. Research will make a contribution and prove value to community, not just value to research world
2. Research is pertinent to and reflective of lived community experiences
3. Includes clear plan for how knowledge is shared with the community
4. Includes plan for how to mobilize the community for social change (training for "change agent" skills)
5. Incorporates community events and initiatives and popular and ethnic media and literature, not just peer-reviewed publications and conferences, in its dissemination strategy
6. Includes plan for research funder to visit and better understand the community
7. Includes a mechanism for community to reach out to funders in case of unresolved issues, if the main study contact is not the community
8. Includes plan for how research will be used for social change to inform practice and policy and improve health equity

MUTUALLY AGREEABLE STANDARDS FOR RESEARCH COLLABORATIONS BETWEEN PARTNERS

1. Includes a Memorandum of Agreement (MOA) between all partners in the project (e.g., the CHC, academic institution), not just a letter of support
2. Roles and responsibilities are clearly laid out in a manual of operations that is available in case of staff turnover
3. Includes plan for orientation for all staff involved that includes sharing of history and values
4. Minimizes disruption of clinic workflow and thus patient direct care
5. Includes a mutually acceptable plan for monitoring/evaluating partnership development and project advancement
6. Includes plan for project risk management (e.g. how to resolve specified potential challenging issues that arise)
7. Includes plan for workforce development including training on project management, contract negotiation, and conflict resolution