The Community Foundation *for* Greater New Haven

Imagine. Inform. Invest. Inspire.

Working together to build a stronger community – now and forever.

MAKING RESEARCH WORK FOR YOUR COMMUNITY:

- ☐ Do you conduct surveys to learn more about your community?
- ☐ Do you have participants fill out forms?
- ☐ Do you perform evaluations to figure out the impact of your activities?
- ☐ Do you have to report to your funders about outcomes?
- ☐ Are you thinking about doing any of these activities?
- ☐ Are you considering working with researchers or do you want to work more effectively with researchers?

A Guidebook to Successful Research Partnerships

About this guidebook

Since 2008, Natasha Ray, New Haven Healthy Start Consortium Coordinator and physician researchers from the Yale Robert Wood Johnson Clinical Scholars Program (YRWJFCSP) have partnered on a series of research projects to address maternal health issues in New Haven, CT. During these partnerships, Natasha Ray, Kenn Harris, Director of New Haven Healthy Start and community research faculty from the YRWJFCSP reflected on what they experienced as best practices in community partnered research.

An opportunity arose between these two long standing research partners to gain a greater understanding of and enhance the experiences of other community leaders (including other Healthy Start Programs) and university researchers in collaborative relationships. In 2012 Natasha Ray, BSc and YRWJF Clinical Scholar, Karen Wang, MD launched a qualitative study to gain insights from both community leaders in New Haven and university researchers on practices that would benefit both partners.

This guidebook was created as a result of their work together and the findings of their interviews with 20+ community leaders and university researchers. It is intended to help communities and community organizations in their decisions to:

1. Conduct their own research;
2. Work effectively with university researchers;
3. Maximize the value of community-university research relationships

Acknowledgements

The following research team, Advisory Committee and authors provided support leading to the creation of this guidebook:

David Berg, *Clinical Professor, Yale University School of Medicine*

Amy Carroll-Scott, *Associate Research Scientist, Community Alliance for Research and Engagement, Yale School of Public Health; Assistant Professor of Community Health, Drexel University*

Ann Greene, *Board Member, West River Neighborhood Services Corporation*

Kenn Harris, *Director, New Haven Healthy Start, The Community Foundation* for *Greater New Haven*

Georgina Lucas, *Deputy Director, Director of Community Research Training, Robert Wood Johnson Foundation Clinical Scholars Program, Yale University School of Medicine*

Marjorie Rosenthal, *Assistant Director, Co-Director of Community Research Training, Robert Wood Johnson Foundation Clinical Scholars Program, Yale University School of Medicine*

Barbara Tinney, *Executive Director, New Haven Family Alliance*

healthy NEW HAVEN START

Robert Wood Johnson Foundation Clinical Scholars Program

Yale School of Medicine

The Community Foundation *for* Greater New Haven

Table of Contents

A. What is research and why does it matter? 2
What is community-based participatory research? 3

B. The benefits to partnering with university researchers in research 4

C. How do you best represent the interests of your community when partnering with university researchers? 5

D. What are the necessary conversations to have with university researchers when considering my community's involvement in a project? 6

E. What does a research partnership involve? 7

F. How does my community create action from the research results? 8

G. Potential barriers to research partnerships 9

APPENDIX

Checklist 10

Resources 11

A

What is research and why does it matter?

Research is the systematic collection of information or data to answer a specific question that is of interest to a broad audience. Research is important because it can:

1. Be used to document a need for services or the effect of services.
2. Provide information to improve the quality of programs, services and outcomes for your participants.
3. Promote the work of your community.
4. Advocate for your work and secure support for your mission.
5. Tell a story in reports for funders and policymakers.

Common types of research:

1. **Clinical Trials**—studies that explore whether a medical strategy, treatment or device is safe and effective for humans.
2. **Program Evaluation**—the systematic collection, analysis, and reporting of information about a program to determine the effectiveness of the program and/or assist in program improvement.
3. **Needs Assessment or Community Assessment**—a process to collect information about the needs and assets of a particular community to help guide actions for program interventions for policy decisions of a target population to help guide the services and programs to address those needs and policy decisions.

Types of data collection methods commonly used in research:

1. **Interviews**—specific questions asked to individual people in a conversational format, led by a trained facilitator.
2. **Surveys**—specific questions of individual people in a written format. They can be interviewer-administered or self-administered on paper or online. They can include short answer or multiple choice questions.
3. **Focus Groups**—small group sessions led by a trained facilitator to obtain a group of participants' opinions about on a set of discussion questions. It is a way to capitalize on group dynamics and shared experiences.

The method(s) selected for a research project is dependent on the goals of the research and/or resources available for the research.

What is community-based participatory research?

Community-based participatory research (also known as CBPR, participatory action research, community-partnered participatory research) is an approach to research that is rooted in the principles of equality and aims to ensure that all the partners in a research project secure what they need from the project. Through this process, community organizations are involved ideally in all stages of the research rather than just a single aspect such as recruiting participants or offering advice.

The main characteristics of CBPR include, but are not limited to:

1. Recognizes that community as a unit of identify;
2. Builds on strengths and resources within the community;
3. Facilitates a collaborative, equitable partnership in all phases of the research, involving a power-sharing process that attends to social inequities;
4. Fosters co-learning and capacity building among all partners;
5. Integrates and achieves a balance between knowledge generation and intervention for mutual benefit of all partners;
6. Focuses on the local relevance of public health issues that recognize and attend to the multiple determinants of health;
7. Involves systems development using a cyclical and iterative process;
8. Disseminates results to all stakeholders and involves partners in the dissemination process;
9. Involves a commitment to sustainability.
10. Openly addresses issues of race, ethnicity, racism, and social class, and embodies "cultural humility."

B

The benefits to partnering with university researchers in research

Whether your community/organization is just beginning the process of data collection or already involved in research, it might consider working with a university researcher to:

1. **Gain knowledge** in the field of research.
2. **Increase your capacity** to do research and increase the capacity of the individuals involved in the research. Skills learned through this process can be applied to other aspects of your work.
3. **Provide more resources** for your community/organization.
4. **Increase the legitimacy** of your community/organization's work among existing and new audiences.
5. **Broaden the impact** of your community/organization's work by including researchers in your coalitions of stakeholders—unified to address a common mission.

"There is a wealth of knowledge, information and experience that is had when academic researchers and community members engage in authentic community-based participatory research."

—Community Leader

C

How do you best represent the interests of your community when partnering with university researchers?

Before agreeing to any research, there are a few aspects of research to consider. Research, though potentially rewarding, may be a labor intensive and time consuming process. It is important to know your goals and your limits. You should discuss these issues with your staff and research partners to decide whether a research project is worth your time and energy.

Three questions to ask before agreeing to work with university researchers:

1. Is the project in line with the mission of my organization/community?

- Does this information help to address your community needs and priorities? Will the research be conducted with awareness of the rights of the people involved?
- Will the type and amount of information you collect meet the needs of your organization?
- Is the timeline of the project and the production of results in line with your timeline? (for example: report deadlines)

2. What does my organization/community gain from the research project?

- What resources does the researcher provide for your participation in the project? (for example: data, funding, training, equipment)
- What products does your organization get from the research to help you achieve your mission? (for example: research reports, grant application)
- What is the plan for using the data from the research once the project is over? (for example: data ownership, results dissemination)

3. What does my organization/community have to give up to participate?

- Does it interfere with your organization's ability to carry out its daily work?
- Will participation in the research be practical, realistic, and achievable? (for example: staff time, administrative resources, organizational flow, client perception)

"Ask yourself: What does it mean to engage in a long-term partnership? What are you willing to give? What are you willing to give up? Know the interest of the University and decide on a project that has mutual interest."

—Community Leader

"So as long as you have a vision, know where you want to go, and you stick to your vision, your goals, you'll never have a problem."

—Community Leader

D

What are the necessary conversations to have with researchers when considering my community's involvement in a project?

Community organizations have had the experience of university researchers who "pack up and leave" after data collection is done to write their academic manuscripts. They don't share the findings with the community participants, and they don't give recognition to the community organization for its participation in the research. However, successful community-university partnerships exist, and two processes to improve your experience in research and prevent this type of exploitation are:

1. Engage in all parts of the planning process to ensure you are an equitable and empowered partner throughout the process.
2. Identify and articulate explicitly in the beginning of the partnership development and planning process what you expect to gain from this process, how involved you want to be, and what you want the next steps after data collection to be.

"You need to be very clear about who is going to keep the data, what's done with the data. There were times when there was a disagreement with that and then so we had to resolve that issue. Things ought to be negotiated and then clearly spelled out somewhere. The Memorandum of Understanding is where you capture everything so that everything is clear. You set up those parameters early on."

—Community Leader

"I said, 'I want you to make an investment. In the past, it's really been a colonial relationship. I mean you guys want something and what do we get?' We need to change the structure. There needs to be something that we derive directly from the research."

—Community Leader

Some community organizations require a **Memorandum of Understanding** that explicitly states the role, responsibilities, ownership of the data, plans for sustainability and other issues that need clarity throughout the project. **You have the right and responsibility to negotiate your needs and protect your organization and the community.** You don't have to answer only "Yes" or "No". Here are few issues you should discuss:

- Do not be afraid to **talk about history with the university researcher.** This conversation might include any personal history you have had with university research or any experience your organization may have had in the past. It might also involve talking about the historical relationship between the university and your organization and the larger community.
- **Equal representation of your community organization** on any product created from the research partnerships—Several products may be created, such as executive summaries, community or academic presentations, policy briefs, press releases or manuscripts. Make sure your organization's name, logo and staff members who worked on the project are represented on products created and mentioned in any public setting where applicable.
- **Ownership of the data.** At the start of the partnership, negotiate the use and storage of the data by both parties.
- **Use of data during or after the research project.** Researchers may be required by journal editors to keep certain results of a project private until the publication is printed. Be sure that you are able to use your data in reports to funders or promotional activities if needed before publication.
- **Your level of involvement.** There are many roles for community organizations in a research process. You can be involved along the continuum of research activities, from recruiting participants for a research study by putting up a flyer in a waiting room, serving as an advisor on research project, allowing researchers to conduct a study at your site with your clients, or being a co-researcher or lead research on a project. Your involvement will influence the intensity and content of your discussions about the research relationship between you and the university researcher.

E

What does a research partnership involve?

A good working research partnership occurs when there is an underlying trust and when the partnership is mutually beneficial to all partners involved. This type of partnership requires time and effort to begin, develop, and maintain. Community organizations have had variable experiences working with university researchers forming collaborations. Many community leaders would agree that the foundation for a good collaboration is based on equality, transparency, and clear communication.

How do you work towards a good research partnership?

Be clear about your expectations, your role and responsibilities in the research.
To ensure a good partnership, it is important to talk about your role in and your expectations from the research partnership, as well as your research partners' expectations of you from the beginning.

Be open about your needs.
Throughout the project, particularly in the beginning, you should negotiate what you want from the research project – for example, a report from the research, data to use for other reports and grant applications, research training for your staff, and financial and human capital resources to support your work on the research project.

Re-evaluate your role and needs during the process and at the end of the project.
Once the project begins, the community organization staff often gets so deeply involved in the day-to-day work that it is not uncommon to forget to reassess whether you are getting what you want from the project. Remember to get feedback from staff involved directly in the project and then give feedback to your research partners.

Know the goals of your university researcher partners.
University researchers engage community organizations in research for a variety of reasons, such as improving the quality of their research, fulfilling a requirement by funding agencies, or recruiting participants in a study to decrease health inequities. University researchers must also create products to succeed within the university, such as publications, presentations and getting grant funding. These goals can co-exist with your goals, so long as you are both up front from the beginning about what you need to get out of this partnership and project.

Expect and work through conflicts.
Issues arise in all working relationships, especially between organizations. Have a plan for conflict resolution.

What makes a good university collaborator?

Community organizations in New Haven have said that they want to work with university researchers who are:

- Able to balance their knowledge and skills with humility
- Good listeners
- Value the expertise of the community and community organizations
- Open to learning
- Flexible in their research approach
- Transparent in their goals for the research project
- Knowledgeable in principles of community-based research and community-based participatory research

"Any collaboration has to have a philosophical synergy, a programmatic and personal clarity and connection to the work. This synergy is usually beneficial to both groups."
—Community Leader

"Our challenge was getting to a place where there was true mutuality between researchers and community members. It took a while for the [academic] researchers to internalize a real sense of equality."
—Community Leader

"If there is an opportunity for partnerships, it should be understood that this is an "intersecting" and not a "merge". Each organization has its own culture, objectives and outcomes. There needs to be a clear understanding that these organizations intersect to interact, not to merge and that they need to embrace the diversity within the partnership."
—Community Leader

F

How does my community create action from the research results?

At the beginning of the project you should plan for the next steps following research completion, and identify the role(s) you and your research partners will play. Your plans may change depending on the research experience and results. However, identifying some of these next steps during the planning phase will ensure the project meets your organization's needs. Here are some examples of next steps after research:

"When we have a plan to disseminate this information to the community, it is the best. We can have an open talk and say, 'These are our findings. There's going to be a brochure, a DVD or a little card that says what we found or what people should do."

—Community Leader

"It would have been nice to have some sort of a follow up after the report to talk about, "How can I use the report?" Again, I would love to be educated by the researchers on how to take this info and turn it into a change in practice, creation of a new program, or a change in existing programs."

—Community Leader

"I would tell them to have regular communications meetings where you are building a relationship with the researcher to talk about how things are going, get feedback, and evaluate excitement level."

—Community Leader

Disseminate results

- Communicate research results to community members, partner organizations, advocates, policymakers, funders, and other stakeholders
- Promote your work through press releases, newsletters, local media, etc.
- Present at scientific or community conferences
- Publish in scientific journals

Plan for other possible next steps for your project

- Identify additional stakeholders, allies, or partners
- Identify program or service needs
- Identify necessary policy changes
- Identify further needed research or program evaluation activities
- Seek funding and apply for other grants
- Engage in policy change or advocacy efforts
- Mobilize leaders and residents around an issue
- Develop an on-going collaboration
- Design a longer-term work plan within the research partnership you created
- Institutionalize successful data gathering, analysis, or research processes into your organization's operations (for examples: create a research review committee)

Sustain relationships with research partners by maintaining communication

- Set up regular meetings to keep discussions ongoing
- Give and get regular updates from all research partners even after the data has been collected or funding period is over
- Share your progress regarding your work related to the original research project

G

Potential barriers to research partnerships

Community organizations that have worked with university researchers talk about the amount of work that goes into these partnerships. Here is a list of potential barriers to research partnerships that are good to be aware of.

Resources:
Conducting research can be resource-intensive, of both time and money. Here are potential investments:

- Ensuring the research process and research partnership doesn't compromise your work or community relations
- Investment of staff energies and any other in-kind support for the project that takes resources away from programs or other work
- Finding staff with the skills and interest to work on the project
- Supporting staff to take the time out of their work to go to meetings and work on the project

"The other challenge was the amount of time, investment and resources—not necessarily financial resources but human resources that one needs to put into a community-based participatory research process. It was quite demanding."

—Community Leader

Institutional Review Boards (IRB):
Any research conducted with an organization that has an IRB needs to go through what is called human subjects approval. The IRB is a body that ensures the research will be ethical, fair, and respectful of the individuals involved. The researcher needs to submit a written proposal describing the research to the IRB. This process minimizes risks and maximizes benefits, ensures confidentiality of participants, and seeks consent for participation. It is important to ask about the IRB process and start the process early so it doesn't hold up your work, since approval by an IRB may take a lot of time. . Special arrangements may need to be made for staff of your agency to be covered by the IRB. Every staff member involved in the research project must complete the human subjects protection training.

Administrative Hurdles:
There are many administrative steps to starting and completing a partnership research project between CBOs and university researchers, that may include:

- Getting approval from your board of directors, your research committee, and other key stakeholders, such as community members.
- Getting approval for subcontracts and the transfer of funds from university to CBOs to support research within the CBO
- Setting up correct process for payment of research staff within the CBO
- Ensuring that every member of the research team has human subjects training

"Talk about the money, get stipends for the participants. Make sure that it works for you in your organization. If it doesn't, there will always be more work than you thought there would be. There will always be twists and turns in the road that you or they didn't anticipate."

—Community Leader

APPENDIX

Checklist

- [ ] What do you want from the research? What are your priorities?

- [ ] What is your desired outcome from the research?

- [ ] What resources do you have to do the research?

- [ ] What resources do you need to do the research?

- [ ] What plan do you have in place to ensure that your needs are met?
(for example: human capital, training, financial resources, access to data, plan for after project is completed, MOU)

- [ ] What are the administrative hurdles that you need to get over to participate in research?

- [ ] What are the priorities of the university researcher?
(for example: publications, grant-funding, improvement of clinical practice and behavioral change)

- [ ] If you decide on a CBPR approach, how will you adhere to the principles of community–based participatory research?

Resources

The following list contains a few resources developed for community-university partnerships:

Local

Community and university researchers affiliated with YCCI (Yale Center for Clinical Investigation), CARE (Community Alliance for Research and Engagement), RWJFCSP (Robert Wood Johnson Foundation Clinical Scholars Program) developed *Principles and Guidelines for Community-University Research Partnerships* and *Beyond Scientific Publication: Strategies for Disseminating Research Findings,* both available online at *yale.edu*

- **YCCI** focuses on translating discoveries from laboratory into the clinic and then into community to improve care and outcomes for patients. One pillar of its mission is community research and outreach—training future researchers on community research, fostering interdisciplinary community-university collaborations, and providing skills and resources for community partners. *ycci.yale.edu*
- **CARE** aims to improve the health of New Haven residents through community engagement, collaborative community-based research, and dissemination of findings. *care.yale.edu*
- **CSP** trains university researchers on community engagement and community-based participatory research. The CSP program and its Steering Committee on Community Projects provide input for the university researchers interested in developing community-engaged projects. *rwjesp.yale.edu*
- **Center for Interdisciplinary Research on AIDS (CIRA)** is an AIDS research center at Yale that facilitates interdisciplinary research to advance science and improve outcomes for communities affected by HIV/AIDS. Community and university researchers affiliated with CIRA developed the *Community-Based HIV/AIDS Research: Guidelines for Successful Partnerships. circa.yale.edu*
- ***Making Research Work for Your Community: A Guidebook to Successful Reseacrh Partnership*** by Natasha Ray and Karen Wang, MD

National

Community-Based Public Health Caucus *www.sph.umich.edu/cbphcaucus*
This group, affiliated with the American Public Health Association, is guided by the belief that 'community lies at the heart of public health, and that interventions work best when they are rooted in the values, knowledge, expertise, and interests of the community itself'.

Community-Campus Partnership for Health (CCPH) *www.ccph.info*
CCPH is a nonprofit organization that promotes health equity and social justice through partnerships between communities and academic institutions. It hosts many resources including toolkits for research partnership and comprehensive list of more community-campus resources.

Detroit Community-Academic Urban Research Center (Detroit URC) *www.detroiturc.org*
The Detroit URC is a community-based participatory research (CBPR) partnership conducting research and interventions to reduce and ultimately eliminate health inequities in the city of Detroit. This website contains news and updates, networking opportunities, CBPR tools, policy advocacy resources and much more.

The Institute of Community Research (ICR) *www.incommunityresearch.org*
ICR is a nonprofit organization based in Hartford, CT whose focus is to use the tools of research to build community capacity and foster collaborative community-based partnerships.

Printed in 2014

Natasha Ray, BSc
Consortium Development Coordinator

c/o The Community Foundation
for Greater New Haven
70 Audubon Street
New Haven, CT 06510

nray@cfgnh.org
203-777-7087