# BETTER COLLABORATION IN ORGANIZED RESEARCH:

A Toolkit for Community Based Organizations and Researchers

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Institute for Health, Health Care Policy and Aging Research

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# INTRODUCTION

This document has been produced to give researchers and CBOs partnering in organized research the tools to work well together to do community research. The content was developed through a process of speaking to CBOs directly, hearing their recommendations and concerns, and providing background on basic terms, questions, and timelines of organized research.

While the toolkit is not exhaustive and many of its readers may have much more to add, it is the hope of its developers that this can be a pathway to better partnerships between CBOs and researchers as they jointly seek to do good research that fairly and respectfully engages with the community.

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## **COMMON DEFINITIONS OF RESEARCH**

- A formal controlled process to answer something you don't know
- Systematic data collection conducted to potentially get answers
- Modeling of prediction models to see if data can be used accurately to test improvements



Note: Not all research projects have the same structure and rules. To create this toolkit we assumed the guidelines that are in place for many organized research projects.

### **RESEARCH PROJECT ROLES**

- Sponsor the organization that's paying for the research. I.e. NIH, university, private foundation
- Institutional Review Board (IRB) A committee designed to review and monitor research for ethics
- Principal Investigator (PI) The person responsible for the research and overall project (Generally is a university professor). They work for the university and cannot work on another organization's behalf.
- Study Staff
  - Project Coordinator or Research Associate The person or persons who conduct the research and data collection and evaluate the project protocol
  - Research Assistant The person or persons who conduct daily project tasks such as data collection and general clerical work
- Research Participant A person who voluntarily participates in research to provide data to the study
- Other Partners CBOs, Consultants, Contractors,
- Fee-for-service



### **TIMELINE OF RESEARCH**

Typically, a research project spans 5 years. That includes the initial genesis of the idea through the reporting of results. An example of the 2 years between the finalization of an idea and the conducting of the research is displayed below:



Depending on when CBOs are engaged in the process, certain elements are difficult to alter.

INTRODUCTION

### TOP 5 SUGGESTIONS FOR COLLABORATIVE ORGANIZED RESEARCH PROJECTS



Relationship Building: Build a bi-directional relationship with the people you are studying that is based on trust and respect



Community Benefits: Share how the community served by the CBO can be improved by the process or outcomes of the research



Look like the Community: People that look like or are a part of the community being studied are more likely to be well received



Non-Extractive: Ensure research tactics are non-extractive and leave communities in a better place without doing any harm



Tap Trusted Sources: Rely on those who already have trusted relationships with the community

### TOP 5 COMMON ISSUES TO CONSIDER IN COLLABORATIVE ORGANIZED RESEARCH



No Translation: Certain topics do not "translate" into other cultures, languages, and settings



Poor communication: Researchers use the ineffective ways of communicating that ignores the culture of a group and relies on jargon that is not well understood



Rigid: Researchers and/or CBOs are not open to hearing real feedback that might change their methodology



Partnership Timeline: CBOs and the community are not considered to be partners in both the design of the research and in examining its results



Jumping in: Researchers come with good intentions, but may lack the patience to fully understand and engage with the community

How will you address this with your partners?

### FOR RESEARCHERS

## ANSWERS RESEARCHERS SHOULD PREPARE PRIOR TO APPROACHING A CBO TO PARTICIPATE IN A RESEARCH PROJECT

- How will the study benefit the community in the short-term and in the long-term?
- How will results be shared back to the community?
- How will the research acknowledge the history of systemic racism?
- How will the CBO be compensated?
- Will compensation really cover the CBO's costs?
- How will people be asked to participate?
- What project design and/or materials can a CBO provide input on? *I.e. Can a CBO review a flyer before it goes to the IRB*?
- Is there a plan for providing accurate translation of materials?



### WHAT COSTS ARE TYPICALLY ALLOWED ON A RESEARCH GRANT?

### ALLOWED

Fixed-rate participant-compensation Pre-Approved Supplies and equipment Salaries & Travel for University employees Consultant fee (for defined consultant work) Subawards/contracts

### **NOT ALLOWED**

Travel for non-university employees

Salary for independent contractors not through a subaward/subcontract

- Rent for community office space
- Training for community organization staff
- General operating or improvement costs for universities or CBOs
- Research costs not related to the funded proposal
  - Costs not permitted by local, state or federal laws
- X

Petty Cash/ Gifts

## ESSENTIAL RESOURCES FOR CBOS TO HAVE IN PLACE BEFORE DOING RESEARCH

- Executive buy-in and organizational support of the project
- Budget to be able to cover costs so folks can work
- Relationship with the community
- Understanding of research processes (what you are being asked to do)
- Staff capacity to do the work

### **POSSIBLE WAYS TO SHARE RESULTS**

- Aggregated results can be published or discussed
- Results that directly impact participant safety will be relayed directly to the participants according to ethical principles and law/regulations. For confidentiality reasons, these are generally not shared with CBOs.
- Individual results may or may not be returned to participants. Each study is different.
- De-identified data, tables, and graphs cannot be shared publicly until formal presentation or publication of results

## QUESTIONS A CBO SHOULD ASK ITSELF BEFORE AGREEING TO PARTICIPATE IN A RESEARCH PROJECT

- Who owns the information and how will it be used?
- What are the financial burdens we are being asked to take on?
- Can we request overhead costs or charges?
- What resources are being provided? What do we have to do on our own?
- How long is the total engagement with us?
- How can we work to help the people who participate in the project?
- Do I understand the research method and strategy being used in this project?

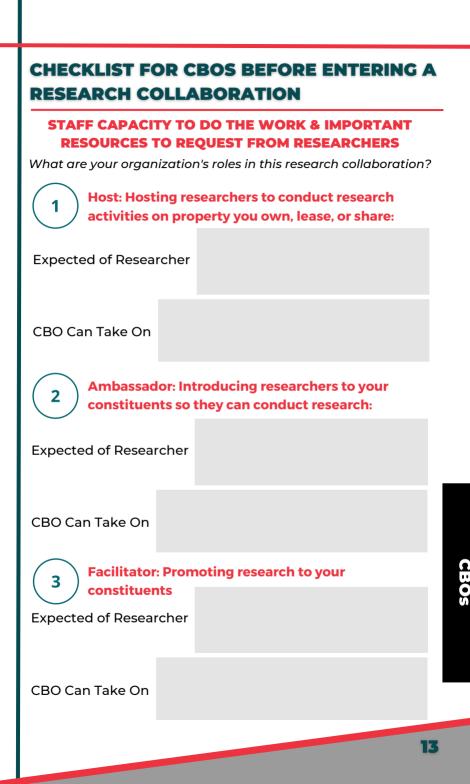


## CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

#### EXECUTIVE BUY-IN AND ORGANIZING SUPPORT OF THE PROJECT

People capable of making, approving, and executing organizational decisions regarding research collaboration:

		_ Support Y / N	
NAME	ROLE		
		Support Y / N	
NAME	ROLE		
		Support Y / N	
Staff responsible for the	research partnershi	p?	
Primary:			
NAME		ROLE	
Back-up:			
. NAME		ROLE	
BUDGET TO BE A	ABLE TO COVER CO	STS TO	
SUPPORT TH	IE WORK BEING DO	DNE	
hours per week of CBO staff whose job duties fit			
with research role			
hours per wee	ek of CBO staff who	se job duties	
can be modified			
hours per wee	ek of new hire need	ed	
\$ fo	r materials, etc.		



CHECKLIST	FOR CBOS BEFORE ENTERING A
RESEARCH	COLLABORATION

#### STAFF CAPACITY TO DO THE WORK & IMPORTANT RESOURCES TO REQUEST FROM RESEARCHERS

What are your organization's roles in this research collaboration?

**Recruiter: Committing to recruit a certain** 4 number of participants into research activities **Expected of Researcher** CBO Can Take On Advocate/guardian: Ensuring respect, equity, and 5 safety of your constituents who participate in research Expected of Researcher CBO Can Take On **Consultant: Providing feedback on research** 6 design, conduct, and dissemination **Expected of Researcher** CBO Can Take On

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### CHECKLIST FOR CBOS BEFORE ENTERING A RESEARCH COLLABORATION

#### **UNDERSTANDING OF RESEARCH PROCESSES**

Does your organization already host regular events during which researchers can present or engage your constituents?

YES NO

Does your organization conduct its own review of research

protocol (I.e., through an Institutional Review Board or a

Research Committee)? YES NO

If yes, what is the typical approval timeline?

Staff within your organization who has some familiarity with

research who will review the consent form:

Primary	_ (name)
······································	_ (

Back-up \_\_\_\_\_ (name)

Key Research Contacts

PI \_\_\_\_\_\_ (name)

Email/phone \_\_\_\_\_

Main staff contact \_\_\_\_\_\_ (name)

Email/phone \_\_\_\_\_

IRB email/phone \_\_\_\_\_

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