

Research: What's Community Got to Do with It?



Toolkit for Community Organizations Interested in Research

Research Toolkit for Community Organizations | 2019

Are you part of a community organization? Do you have questions about your community you would like to investigate with research? If yes, then this toolkit is for you!

You can read each section on its own or out of order.
You don't need to have read one section to understand the next section.

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Produced by the Community Engagement and Collaboration Core, part of the Center for Clinical and Translational Science at the University of Illinois at Chicago, with greatly appreciated input from community partners. If you have any questions or comments, please contact us at toolkits@uic.edu.

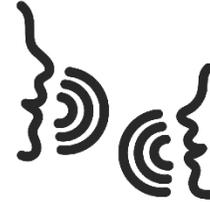
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1. Research Refresher

If you're already pretty familiar with research, feel free to skip to the next section. If it's been a while and you want to brush up your knowledge, read on.

What is research?

- It's an organized method and process to gain knowledge.
- It can take many different forms. Some of these include:
 - Interviewing people one-on-one
 - Talking with a group of people (focus group)
 - Having people fill out a survey, in-person or online
 - Looking at data other people have collected, like from the Census
 - Collecting blood or other samples from patients to do experiments
 - Giving people a pill or other treatment
- It can take a long time to do well
- Many of the things that have made our lives better – such as living longer – have come from research.



Research is NOT...

- It's not using people as guinea pigs. There are safeguards in place to protect people from harm. When there are risks, researchers explain them to participants.
- It's not perfect. There have been problems, both well in the past and more recently. That's why the safeguards are in place – to stop these things from happening again.
- It's not easy. But if it's done well, it can help us live better lives in our communities.

* Icons: talk by Mark S Waterhouse from the Noun Project, pills by Dima Lagunov from the Noun Project



2. Role of Community in Research

A. What does it mean to involve the community in research?

As someone in a community organization, having your voice heard in research is very important. Researchers, especially at a university or hospital, usually have their own ideas about what people need and want. They may not be what you know to be important.

What's a community?

- A neighborhood or town
- People with a certain condition (like diabetes or heart disease)
- Groups of people (like People with Disabilities)

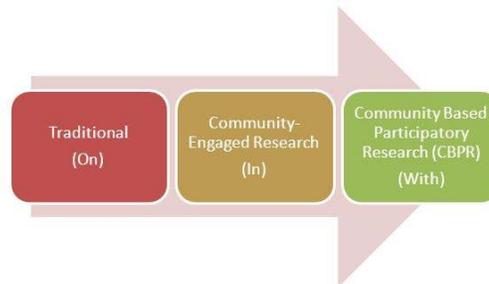
Being involved in research is not an easy decision. It can be time-consuming and difficult to see results. Nevertheless, research can have tremendous benefits for your community and society in the long-term. This toolkit is designed to give you information about research, particularly health research. This knowledge will help you decide whether or not you want to become a research partner, and if you do, give you tools that will help you meet your goals for engaging in research.

3. Power Sharing

In a research partnership, there are many different ways power can be distributed. It usually comes down to who makes the final decisions.

- In traditional research, most decision-making power lies with the researcher. It is research that “focuses on” the community.
- In community-engaged research, some power to make decisions is shared, but the final say stays with the researcher. It includes “targeted participation in” the community.
- In community-based participatory research and participatory action research, decision-making is shared equally between researchers and community organizations and members. It is “active involvement with” the community as equal partners.

Continuum of Community Based Research for Health



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Regardless of which model is chosen, conversations about how decisions are made and processes should take place before embarking on a project. These conversations should be revisited periodically to ensure everyone is satisfied with how the model of decision-making is serving the partnership’s needs.

Even if everyone agrees to a certain way of making decisions, that won’t make some things go away. Power and privilege related to race/ethnicity, sex, gender, class, and many other factors remain. Also, the researcher often has a place of privilege because they are often the ones obtaining grants and with access to the university’s resources. If issues come up, they should be discussed sooner rather than later so they can be resolved rather than getting worse.

4. Prior Experiences

Some examples of what's gone well:

- In Detroit, a partnership between community-based organizations, health services organizations, and the University of Michigan studied food access. The community partners collected data and helped make the tools used to collect data more responsive to what was important to them. This led to higher quality data.²
- In Chicago's Southwest Side, a community group contacted a UIC researcher to help them. More partners joined and helped do focus groups, surveys, and storytelling sessions. Everyone learned more about the community. Many people got to publish papers, and nonprofits were able to use the information in their grant applications.
- In Philadelphia, a group of community-based organizations and a researcher have worked together to identify the community's health priorities. Cancer was identified as a priority, and they developed educational programs that have increased public awareness of what to look for and a program to do more screenings.³

But, things can still go wrong. Be on the lookout for projects like these:

- Helicopter research is where a researcher comes into a community, gets help collecting data, and then leaves without ever sharing their results with the community. It happens way too often.
- Lots of health studies have had adult white men as the participants. That means we know what treatments work in adult white men but don't know if those treatments will also work in other groups, such as women, people of color, or children.
- Some researchers have come into a community and asked for help, but didn't offer anything of value (like paying for their time or helping with program evaluation for free) to the community organizations or members.

5. Ethical Violations in Research

Many research studies have had ethical problems. Below are a few examples to show what can go wrong.

Examples from the 20th Century:

What most people know as the Tuskegee Syphilis Study was a project that was run by a division of the federal government, the US Public Health Service. They monitored 399 African American men with syphilis and 201 men who did not have the disease between 1932 and 1972.⁴

What did the researchers do wrong? Many things, but a few include:

- Never telling the men with syphilis that they were infected
- Stopping them from getting treatment when penicillin became the standard treatment
- Running the experiment in the first place: we already knew how syphilis progressed, so the study wouldn't tell us anything new
- Singling out poor, Black people to be research subjects to study a disease that affects other groups, too

The Willowbrook Studies were problematic, too. Researchers conducted a series of experiments on mentally disabled children at the Willowbrook State School in New York. In some of the experiments, children who had been given hepatitis antibody injections were deliberately injected with a live form of the virus, to see how they reacted.⁵

What were some of the things they did wrong?

- Not getting freely informed consent: They made participating in experiments a condition of attending this desirable school. In other words, they coerced the parents into enrolling their kids in the studies.
- Conducting experiments on kids when they could have experimented on adults, who can give their own informed consent.

More recent example:

Even with the ethical standards of today, problems still happen. A professor from Southern Illinois University injected an experimental vaccine for herpes into participants. This happened in 2013 in Illinois hotel rooms and in 2016 on a Caribbean island. The Food & Drug Administration opened a criminal investigation in 2018.⁶

What did he do wrong?

- He never got any approval to do this research
- He knew it wasn't ok, so he tried to hide it in hotel rooms and going out of the country



Key points to remember:

There are now many protections in place to reduce the likelihood of these sorts of abuses happening. But, it's important to be aware of what has happened in the past. Also, it's important for you, as someone who may be participating in research, to be on the lookout for lapses in ethical behavior. Asking tough but fair questions of the researcher makes the research safer for everyone involved.

6. More Details about University Research

A. Research Options

Many types of research might be useful to you and/or reach out to you for partnership. While there are many important research projects in fields like education, history, and social work, our focus is on health research. A few of these areas include:

Clinical Trials: Clinical trials are research studies performed in people that are aimed at evaluating a medical, surgical, or behavioral intervention. They are the primary way that researchers find out if a new treatment, like a new drug or diet or medical device (for example, a pacemaker) is safe and effective in people. Often a clinical trial is used to learn if a new treatment is more effective and/or has less harmful side effects than the standard treatment. ⁷

Public Health / Epidemiology: Public health promotes and protects the health of people and the communities where they live, learn, work and play. Research studies in public health may include assessments of a neighborhood's health, programs to adopt healthy behaviors (like exercise or quitting using cigarettes), or identifying where disease outbreaks might occur. Environmental health and occupational health are specific areas of public health. ⁸

Program Evaluation: There is a good chance you've had to do this for grants. Program Evaluation looks at how a program operates and the impact that it has on participants. They are used by organizations and funders to determine whether a program is effective and how to improve it. Universities may have researchers (faculty and/or students) who are available to conduct an evaluation with you.

B. How research works at universities

University research works by its own unique timeline and system of rewards. Many health researchers receive funding from the National Institutes of Health (NIH), and most of NIH's grants are for one project that lasts 5 years. It's not unusual for a project to take 7 years from initial planning to completion.

The system of rewards and promotions at universities do not necessarily encourage community collaboration. Reviews for promotion and tenure typically look at research, teaching, and service. However, research, especially publishing articles in journals and obtaining grant funding, is usually seen as the most important. So, they are under pressure to produce articles, which may not seem useful for the community members, but are very important to their careers.

We're not saying these are good or bad things. What we are saying is that these are the realities of the situation for most researchers. Understanding the system they are in can make it easier to form and maintain partnerships, because there are fewer surprises and conflicts.

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C. Stages of Research: Research follows a specific series of stages. Not every project has all of these, but they generally follow along these lines.

Stage	Description	Example	How You Can Participate
Identifying a problem or issue	Looking at the world or previous research and finding a problem or issue that you want to investigate further.	High blood pressure continues to be an issue for many African Americans.	Your role here could be help the researcher identify the issue. Maybe a lot of your friends and family have high blood pressure, so you contact the university to see if someone can investigate this.
Developing a research question	Getting more specific about the issue.	What type of exercise works best at helping African Americans lower their blood pressure?	You could develop this question together. Maybe the researcher wants to test a drug, but you think people in the community would be more open to an exercise plan.
Creating a hypothesis	Making a specific prediction about what you think will happen. This has to be a prediction that can be tested.	Resistance exercise (like weights) will be more effective than aerobic exercise (like running) for helping African American adults lower their blood pressure.	Your role could be to refine the hypothesis. The researcher might want to use yoga, but if that's not popular in the community, you can let them know they would have a hard time convincing people to do it.
Designing the methods	Moving from ideas to concrete plans of how to test your hypothesis.	Create a plan to recruit African American and White participants who don't do a lot of exercise, randomly assign people to do resistance or aerobic exercise for 2 months, measure their blood pressure before and after.	You can tell the researcher about how people exercise and what makes someone sedentary versus active.
Preparing staff and materials	Anybody who helps out with the research – whether they are students, university staff, community health workers, or others – needs to be trained. Materials like surveys need to be created.	Making the forms to see if people are eligible, creating consent forms, training recruiters.	You can develop and/or review the materials to make sure they are relevant to your community.

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Recruiting participants	There are many different ways participants can be recruited – direct outreach to people you know, passive outreach like posting flyers, and online recruitment via websites and social media.	Posting flyers and purchasing Facebook ads to get people to sign up for the exercise study, setting up a table at a school, letting people who attend your programs know about the study.	If your organization has staff or volunteers with connections to the community, they would be ideal recruiters of participants.
Delivering the program	Turning ideas and plans into reality.	Getting participants started using the exercise program, monitoring to make sure they follow the plan.	If there is a gym in your building or nearby, you could have the program there to make it more accessible to participants.
Collecting data	Before, during, and after the program, you need to collect information from participants so that you can see whether your hypothesis was right.	Measuring blood pressure before, during, and after the workout program.	Staff and/or volunteers can work with university staff to collect the data.
Analyzing the results	Looking at the data to see what happened.	Figuring out how much blood pressure dropped for every group, comparing the results of different groups, determining whether the hypothesis was right or not.	You can look at the data as well, whether it's in a statistical program or in charts and graphs, to help interpret the results.
Sharing the results	Communicating your findings with different groups.	Publishing a paper about the study in a journal or having a community event to talk about blood pressure and exercise.	You can prepare brochures, host events, do radio interviews, etc. to help spread the word about what the study found.
Advocating for action	Developing policy recommendations and advocating for those to be implemented.	Lobbying the park district to install more exercise equipment at the fieldhouse and have fitness programs that meet residents' needs.	Your connections to community members are critical here, to inform them about the issue and encourage them to lobby for the policy change you want.

7. Risks & Benefits for Your Organization

Getting involved in research means risks and benefits.⁹

There are many potential benefits to participating in research:

- The research partnership is good for people who are directly involved
 - The researcher engages with you in the way you want them to
 - The researcher is respectful, truthful, and listens to you
 - Useful data and findings are shared with you
 - You are compensated adequately for your time
 - Staff, partners, and/or constituents have a positive experience
 - Participants may get access to health services, information, and other benefits they may not otherwise be able to access
 - You can get access to funding for your programs/services
- The research benefits the community
 - You participate in a high-quality, relevant project
 - The research is a springboard for funding and other resources
 - Your participation contributes to greater understanding of health and/or better therapies

Some, but not all, of the potential problems include:

- The research partnership is problematic
 - You may feel like your voice is not being heard
 - Data and findings may not be shared with you
 - Researchers may not understand or be responsive to community concerns
 - Participating may take up too much time, leaving less time for other activities
 - You may not be compensated for your time, or the compensation might be low
 - If you staff, partners, and/or constituents have a negative experience in the research project, that may hurt your relationship with them
 - If it's a bad experience, it may hurt your reputation in the community
- Other problems
 - You might feel like there is too much research being done on your community
 - The research might have little benefit to your community

There may be other risks and benefits not listed here; these lists are here as general guides to help you think about what could happen and what, for you, is most important.

8. Preparing for Research Worksheet

This section is intended to help you assess your organization’s readiness for research before you have in-depth conversations with a potential research partner. You don’t need to have everything listed here all ready to go, but it’s a good idea to think about each and either have it ready or think about how you will develop that idea/resource. This will help you go into the meetings with an idea of what to look and ask for during these conversations.

Questions	Answers	Tips
What do you hope to get from research in general?		<p>Some possibilities:</p> <ul style="list-style-type: none"> • understanding of the need for programs • effectiveness of programs, • impact of government policies • accessing funding • highlight work you’re doing • increase your impact • provide resources to participants • and others
How will your organization or the communities you serve benefit from participating?		<p>Example: Findings are relevant to the populations you serve</p>
What do your stakeholders think about participating in research?		<p>You can consider the opinions of clients/ participants/ members, staff, funders, etc. Do you have the buy-in from management and front line personnel to participate?</p>



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Questions	Answers	Tips
Does your organization have the staff capacity (in number of people with sufficient time, energy, and skills) to participate in research?		Your research partner and/or the grant may be able to help with this. Be sure to communicate your needs to your potential partner.
Does your organization have the facilities and equipment to participate in research?		You may be able to build these into the budget of the grant.
Does your organization have the time to participate in research?		Research takes time to do well! Consider all the people who may be involved and their workloads. Can some responsibilities (either related to the project or other tasks) be shifted around?
Is there anything else you would like to communicate to potential research partners?		



9. Is This Specific Opportunity Right for You?

Once your organization has a clear idea of what you want to get out of research, you might look into entering into a specific research partnership. Whether you or the researcher makes the initial contact, the following questions can help bring some clarity to the decision-making process.

- 1) **Do you and the researcher share the same goals?**
 - a) Is everyone clear on what the goals are?
 - b) How likely is it that the goals will be met?

- 2) **Do you and your team have the right skills?**
 - a) Can one or more people on your team engage with the researcher?
 - b) Will your staff people be able to fulfill the tasks of the project?
 - c) Will you and/or your staff need to complete ethics training (CITI or CIRTification)?

- 3) **Are the right resources in place?**
 - a) Do you and your staff have time for the project?
 - b) Do you have adequate funding (either from the research project or outside sources of funding) to cover costs?
 - c) Will you need to hire extra staff?
 - d) Will you need to purchase or otherwise obtain extra equipment?

- 4) **How will staff, partners, and constituents perceive the project?**
 - a) What is the reputation of the researcher, for the quality of their work and how they approach communities?
 - b) What is the reputation of the university, for the quality of their work and how they approach communities?
 - c) How will working with this researcher and university affect your reputation in the community?
 - d) How might your staff, partners, and constituents respond to the aims and methods?

- 5) **What will your relationship with the researcher and their team be?**
 - a) Will you primarily interact with the researcher or someone on their team?
 - b) How are decisions made?
 - c) Is there a process for addressing concerns and resolving conflicts?

- 6) **What happens when the research is done?**
 - a) Will you have access to the data and findings?
 - b) Will the collaboration continue after this project?

10. Finding Potential Research Partners

Many researchers are interested in working with community organizations. In Chicago, we have many universities with diverse research interests. Your best bet is to search some of the various universities here, such as UIC, Northwestern, University of Chicago, Rush, Loyola, DePaul, and others for the specific area you are interested in.

What's especially good is if you can find a whole school or department focused on what you want to study. For instance, if you are part of an organization that works with People with Disabilities, a fantastic resource is the Disability and Human Development Department at UIC's College of Applied Health Sciences, <https://ahs.uic.edu/disability-human-development/>. If you work with LGBTQ+ people, the Institute for Sexual and Gender Minority Health and Wellbeing at Northwestern is a good place to start: <https://isgmh.northwestern.edu/>. And, if you work with youth, Chapin Hall at the University of Chicago is a great resource: <https://www.chapinhall.org/>.

If you don't know where to start, there are two resources that can help guide you in the right direction. The first is the Community Engagement and Collaboration Core, the group that produced this toolkit. We're here to help! Please feel free to contact us at toolkits@uic.edu, and we will be happy to talk through your interests and connect you with the researchers and/or resources that can help you.

Additionally, The Chicago Department of Public Health (CDPH) Office of Research leads a range of initiatives to support strong collaboration between academic researchers and institutions and community stakeholders to improve the health and health equity of the city of Chicago. The office engages and serves as a liaison for research and evaluation efforts to advance [Healthy Chicago 2.0](#) priorities and support evidence-informed policymaking and practice.

Services and resources available from the Office include:

- Assistance with identifying partners and brokering partnerships with CDPH contacts, community partners, research/evaluation partners;
- Information about health research being conducted in Chicago by local academic institutions including dissemination of research findings; and
- Information about local funding and training opportunities and events related to community-engaged research and evaluation.

Contact: Rachelle Paul-Brutus, Coordinator of Research & Evaluation, Chicago Department of Public Health at Rachelle.PaulBrutus@cityofchicago.org.

Some places to find additional researchers include <https://www.researchmatch.org/>, <https://projectreporter.nih.gov/reporter.cfm>, <https://clinicaltrials.gov/>, <https://www.researchgate.net/>, and <https://scholar.google.com/>.

11. The Keys: A Reference Guide for Engagement Strategic Partners (ESP) for Academic Collaborations

The Keys is a set of principles developed by Le'Andre Moore and Project Brotherhood. They lay out principles that community organizations, as Engagement Strategic Partners, can adopt a condition to participating in research. These materials are © Le'Andre Moore and Project Brotherhood; please cite appropriately if reproducing.



The Keys: A Reference Guide for Engagement Strategic Partners (ESP) for Academic Collaborations.[†]

- I. **ESP** understands that adequate research is based on building relationships.
- II. **ESP** seeks communication, transparency, equality and a shared-decision making process for relationships/collaborations.
- III. **ESP** seeks to inform the Academic partner that we "serve" the community.
- IV. **ESP** seeks to ensure that the community voice is heard and considered in the decision-making process.
- V. **ESP** seeks to put mechanisms and systems in place that protect the community so that no harm knowingly or unknowingly will be inflicted on the community.
- VI. **ESP** understands that social science is just as crucial as evidence-based and/or clinical science.
- VII. **ESP** seeks to be an equal partner during the conceptual phase, writing, and physically present for the submission of a grant.

[†] © Le'Andre Moore and Project Brotherhood

VIII. **ESP** seeks to be an equal partner with approval or disapproval rights in the development of the budget, aims, IRB submission and the evaluation.

IX. **ESP** seeks to be included as an author in all publications related to the strategic partner.

X. **ESP** seeks to be involved in the development of all presentations as it relates to the strategic partnership.

XI. **ESP** seeks to be listed appropriately with acknowledgment of its contribution on all presentations as it relates to the strategic partnership.

XII. **ESP** seeks to be a Principal Investigator or Co-Investigator.

XIII. **ESP** seeks the University to follow the Principles of the Ethical Practice of Public Health.

XIV. **ESP** seeks to ensure that the University incorporates the social determinants of health when conducting research.

XV. **ESP** requires University partners to leverage additional non-financial resources for the ESP.

XVI. **ESP** encourages adapting evidence-based scientific research to allow for unique and innovative techniques.

XVII. **ESP** requires that the community's time be valued and respected by taking their needs, concerns, and obstacles into consideration during decision-making processes.

XVIII. **ESP** seeks to conduct research in an ethical and moral way that will ultimately assist in shaping policy.

XIX. **ESP** seeks to have the contact information of the proper authorities residing over the grant and official protocol in place if the ESP feels ethical and moral beliefs have been violated during the research project at the beginning of collaboration.

12. Grants

A. Statements from Funders about Importance of Community Partnership

Funders have begun to recognize the importance of community involvement in research. Here are a few examples:

“For many years the W.K. Kellogg Foundation has believed that communities, academic health programs, and health practitioners should be working together to promote the health and well-being of all members of the community.”¹⁰

“A fundamental belief of Community-Campus Partnerships for Health (CCPH) is that health equity and social justice need to be pursued both within partnerships and through them.”¹¹

“In CBPR, researchers and community participants seek to collaborate as full partners in every phase of the research process: from the definition of the problem to be investigated; through the design, implementation, and evaluation of the intervention; to the dissemination of study findings. A primary goal of CBPR is to increase a community’s capacity to address and solve its own problems through the development of effective and sustainable interventions.”¹²

B. Sources of Grants

One of the main sources of funding for health research is the National Institutes of Health (NIH). This program of the US Department of Health & Human Services funds a wide range of clinical trials and other health-related projects. You can search funding announcements at <http://bit.ly/2PIgzPQ>.

Other organizations that may be able to provide grant support for research include:

Aetna Foundation

<https://www.aetna-foundation.org/grants-partnerships/grants.html>

American Psychological Foundation Roy Scrivner Memorial Research Grants

<http://www.apa.org/apf/funding/scrivner.aspx>

American Psychological Foundation Wayne F. Placek Grants

<http://www.apa.org/apf/funding/placek.aspx>

CCTS Pilot Grant Program

<http://www.ccts.uic.edu/content/ccts-pilot-grant-program>

The Commonwealth Fund

<http://www.commonwealthfund.org/grants-and-fellowships/new-faq-page>

Disability and Rehabilitation Research Projects (DRRP) Program
<https://www.grants.gov/web/grants/search-grants.html?cfda=93.433>

Ford Foundation
<https://www.fordfoundation.org/work/challenging-inequality/>

GLMA Lesbian Health Fund
<http://www.glma.org/index.cfm?fuseaction=Page.ViewPage&PageID=922>

Jacobs Foundation Research Fellowships
<http://jacobsfoundation.org/what-we-do/research-funding/jacobs-research-fellowship-program/>

The Joyce Foundation
<http://www.joycefdn.org/apply/what-we-fund>

Paralyzed Veterans of America Research Foundation
<https://www.pva.org/research-foundation>

Patient-Centered Outcomes Research Institute
<https://www.pcori.org/funding-opportunities>

Point Foundation LGBT Scholarships
<http://www.apa.org/about/awards/point-foundation.aspx>

Robert Wood Johnson Foundation Research, Evaluation, and Learning Grants
<http://www.rwjf.org/en/how-we-work/rel.html>

The Society for the Psychological Study of Social Issues - The Clara Mayo Grants
<http://www.spssi.org/index.cfm?fuseaction=Page.ViewPage&PageID=727>

Tinker Foundation: Field Research Grants for Study in Latin America
<http://www.tinker.org/content/field-research-grants>

William T Grant Foundation Research Grants
<http://wtgrantfoundation.org/grants/research-grants>
<http://wtgrantfoundation.org/focus-areas/reducing-inequality>

The Williams Institute Small Research Grants
<http://williamsinstitute.law.ucla.edu/small-research-grants/>

13. Glossary of Research Terms

Adapted from CIRTification (Emily Anderson, PhD, Loyola University)¹³

Anonymous Data:

Information that cannot be linked in any way to the person who gave the information.

Beneficence (Benefit): The ethical rule that researchers should not harm subjects.

Confidentiality (also see Privacy):

It is a rule in research that the information about subjects that is collected for research purposes should not be shared with any people outside the research project.

Data Collection:

The process of getting information in research. Data collection can include direct contact with research subjects. For example, doing surveys and interviews involves interacting with subjects and asking them questions to get information. Data collection can also include observation. For example, research may involve watching people do something, such as grocery shopping, and writing down information about them and what they do. Data collection can also involve getting information about people from records that already exist, such as medical or school records.

Human Subject (Research Subject, Subject, Participant):

A living person about whom information is collected in research.

Human Subjects Research: A study that collects information from or about living people.

Identifiable Personal Information:

Data containing enough information to reveal the identity of the person who provided it.

Informed Consent:

A person's voluntary agreement to participate in research, based upon their understanding about the purpose, tasks, risks, and potential benefits of taking part. In most studies, research subjects are asked to sign a *consent form* to show that they understand the research and agree to take part. In other cases, subjects may provide verbal agreement only. Even when subjects are not required to sign a consent form, they must be told enough information about the study to help them make their decision.

Institutional Review Board (IRB):

A committee that reviews research involving human subjects to ensure that subjects will not be harmed. Any organization with researchers that conduct research with people must have an IRB or name one from another organization to review their research. IRB members include researchers with a variety of areas of expertise as well as people who are not employed by the

institution, including at least one community member. A research project must be approved by an IRB before it can start.

Justice:

The ethical rule that researchers should be fair in choosing subjects for their research so that all groups of people are included and can share risks and benefits.

Minimal Risk Study:

A study that does not involve any harm or discomfort that is more than what someone might face in their daily life.

Principal Investigator: The lead person who is responsible for the research project.

Privacy (also see Confidentiality):

It is a rule in research that people are allowed to decide if and when they are going to share information about themselves.

Recruitment:

The process of finding people to take part in research. It may involve sharing information in ways that will let individuals who are interested contact the researchers and/or it may involve directly inviting individuals to participate.

Research: A planned study to better understand a question or problem.

Respect for Persons:

The ethical rule for research that people should decide for themselves whether or not they want to participate in research. If people do not have the ability to decide for themselves due to their young age, mental disability, or some other disadvantage, then the person who makes the decision for them should be looking out for their well-being.

Risk: The possibility that harm may occur.

Study Sponsor (Funder):

The organization that financially supports the research through a grant or contract. Depending on the funder, the researcher may have to meet specific requirements (for example, a final report).

Voluntariness (Voluntary):

The decision to take part in a research study should be a subject's own personal decision. Subjects should know that nothing bad will happen if they do not want to participate or if they decide later that they want to stop. Subjects should not be persuaded to participate in research with large amounts of money or false promises.

14. Budgeting for Community/Academic Partnership

When putting together a budget for a research project, your academic partner will typically be the lead. As such, they should be able to help you with the forms and other necessities. The following are some things that will be helpful for you to be aware of as you plan out the budget with the partner.

Items to include in the budget:¹⁴

- Salary & fringe benefits of staff who will work on the project
- Stipends for temporary staff who may help with the project (example: community health workers)
- Equipment (printing cots, facility rental if needed, tablet computers, etc.)
- Meeting costs (food, materials, etc.)
- Travel costs if participants are far away
- Incentives for participants (see below)
- Indirect costs or overhead: These are costs that are not tied to one project or program but are shared across the organization. Examples include rent, electricity, etc. Whether you can include indirect costs, and what percentage of your total they can be, will vary depending on the grant source. Your academic partner should be able to help you determine how much you can include.

Information about paying participants incentives:

- Guidance for University of Illinois (including UIC)
<https://oprs.research.illinois.edu/guidance-payments-human-subjects>
- Additional guidance¹⁵
 - The amount of payment, if any, should be reasonable, based on the complexities and inconveniences of the study. The amount of payment should NOT be based on the risk of study participation.
 - The magnitude of the incentive and the proposed method and timing of its disbursement must not be coercive or present undue influence for initial or continued participation in the study.

If you are applying to the National Institutes of Health, specific budget information can be found at <https://grants.nih.gov/grants/how-to-apply-application-guide/format-and-write/develop-your-budget.htm>. Also see the next section for more information about the NIH.

15. Explaining Role of Research to Your Constituents

Videos explain the importance of research, answer basic questions, and provide links to further information. Some helpful ones include:

Participating in research: What is research?

<https://www.youtube.com/watch?v=4pLsHhP7yTw&list=PLr17E8KABz1Ex7n0cjhxVgGDDF7xWHpF1&index=1>

Participating in research: Clinical trials

<https://www.youtube.com/watch?v=5VCW31AnEpI&list=PLr17E8KABz1Ex7n0cjhxVgGDDF7xWHpF1&index=2>

Participating in Research: Questions to ask

<https://www.youtube.com/watch?v=0SgsWQWu1vc&list=PLr17E8KABz1Ex7n0cjhxVgGDDF7xWHpF1&index=3>

Deciding about participating in health research for children:

https://www.youtube.com/watch?v=6yaKwLG_vlE

Questions to ask when deciding whether to volunteer for research

English: https://www.hhs.gov/ohrp/sites/default/files/questions_full_list_v5-remediated_12222016.pdf

Spanish:

https://www.hhs.gov/ohrp/sites/default/files/questions_full_list_v5_sp_remediated.pdf

Common terms in research

English: <https://clinicaltrials.gov/ct2/about-studies/glossary>

Spanish: <https://salud.nih.gov/investigacion-clinica/glosario-de-terminos-comunes/>

Protecting research volunteers

Information from Health & Human Services: <https://www.hhs.gov/ohrp/education-and-outreach/about-research-participation/protecting-research-volunteers/index.html>

16. National Institutes of Health Information

A. Introduction to the National Institutes of Health (NIH)

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

The NIH provides leadership and direction to programs designed to improve the health of the nation by conducting and supporting research:

- in the causes, diagnosis, prevention, and cure of human diseases;
- in the processes of human growth and development;
- in the biological effects of environmental contaminants;
- in the understanding of mental, addictive and physical disorders; and
- in directing programs for the collection, dissemination, and exchange of information in medicine and health, including the development and support of medical libraries and the training of medical librarians and other health information specialists.¹⁶

The NIH is one of the main sources of funding for health research. If you're working with a university partner on a health project, chances are NIH will be funding the project.

B. Describing Your Communities & Services to Justify Your Role in Partnership When Writing Grants

When writing about your organization in grants to NIH, as with any funder, considering your audience is important. Some standard information – such as number of staff, number of clients served, mission statement, etc. – should be included. It will also be necessary to highlight the unique strengths you bring to the partnership. This will most likely involve some references to community-engaged research (CEnR).

The National Institutes of Health says the following about community-engaged research: “CEnR research methodologies are expected to result in more meaningful academic-community collaborations and relationships, which should also lead to sustainable interventions and improved health of individuals and communities. Investing in community and academic partnerships in research efforts will provide its greatest impact in translating established health care practices in health promotion and prevention and self and symptom management.”¹⁷

A few points are essential here. The NIH is interested in improving health outcomes by encouraging the discovery of improved health interventions. As such, CEnR is a path toward those end, not an end in itself. While it is important to describe your collaboration and the features of each organization, the most important information to include is how your organization is uniquely suited to answering this research question, and why answering it will lead to better health outcomes.

For example, if you are running a violence prevention program that works with gang-involved youth, you could talk about some of reasons why these youth face poor health outcomes: in addition to the direct consequences of violence, they may be unable to access facilities that are across gang borders. If you partner with a researcher who will provide healthcare in areas that are safe for youth in the program to access, your ability to connect the researcher with the youth is essential.

C. Creating an NIH Biosketch

In order to collaborate on a National Institutes of Health (NIH) grant, one form that is required is the NIH Biosketch. This form must be completed for Key Persons on the grant. For a community organization, this will likely be the program director overseeing the research project and/or the executive director. Forms and instructions can be found at [https://grants.nih.gov/grants/how-to-apply-application-guide/forms-e/general/g.240-r&r-seniorkey-person-profile-\(expanded\)-form.htm](https://grants.nih.gov/grants/how-to-apply-application-guide/forms-e/general/g.240-r&r-seniorkey-person-profile-(expanded)-form.htm).

Keep in mind that the NIH Biosketch is usually meant for university researchers to fill out. Some of the sections are very different from what you may have seen in other grant applications.

To fill out a biosketch, you will need an eRA Commons username. You can start the process at https://era.nih.gov/reg_accounts/register_commons.cfm.

In the introductory section, include your education, beginning with a bachelor's degree or professional training program, and continue through all degree(s) you have.

In the Personal Statement section, describe your position in the organization that will be part of the research project, along with any volunteer activities, such as being on a board of directors. Describe how your experience will help you contribute to research projects.

In the Positions and Honors section, list employers, volunteer leadership positions, and any awards you have received.

In the Contributions to Science section, describe how your organization can contribute to research. After the text in this section, list any papers in peer-reviewed journals where you were listed as an author. If you do not have any, that is ok, just state "none to report."

In the Research Support section, list any NIH grants you or your organization have received. If you do not have any, that is ok, just state "none to report."

Examples can be found on pages 91-95 of https://communityengagement.uncg.edu/wp-content/uploads/2014/07/CAGAT_Community_Partners_Guide_20160722.pdf.

D. Letters of Support

Letters of support are needed for National Institutes of Health (NIH) grants. Examples from previously funded research can also be found at <https://www.nichd.nih.gov/grants-contracts/process-strategies/process/samples>.

Your academic partner should be able to give you a template, and provide guidance if you need it.

- It must include your contact information. Ideally, it should be on your organization's letterhead.
- The letter of support should be addressed to the primary investigator (P.I.).
- State that you endorse the grant.
- Be sure to state the grant name and number clearly.
- Briefly describe your organization in one paragraph (about 3-5 sentences).
- Discuss how your organization will be involved in the grant, and why the research is important.
- Include a closing about how you look forward to working with the P.I., thank them for the opportunity, or something similar.
- At the bottom, include your signature and printed name.

An example can be found on page 87 of https://communityengagement.uncg.edu/wp-content/uploads/2014/07/CAGAT_Community_Partners_Guide_20160722.pdf.

17. References

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- ⁶ <https://khn.org/news/fda-launches-criminal-investigation-into-unauthorized-herpes-vaccine-research/>
- ⁷ <https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies>
- ⁸ <https://www.apha.org/what-is-public-health>
- ⁹ Many but not all of these risks and benefits come from the University of Washington course on CBPR: <https://depts.washington.edu/ccph/cbpr/u1/u13.php>
- ¹⁰ <https://www.wkkf.org/resource-directory/resource/2001/12/overview-of-the-community-based-public-health-initiative>
- ¹¹ <https://www.ccphealth.org/principles-of-partnership/>
- ¹² <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.93.5.803>
- ¹³ <http://www.cts.uic.edu/content/about-cirtification>
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- ¹⁵ <https://www.irb.pitt.edu/content/incentives-participation-research-studies>
- ¹⁶ <https://www.nih.gov/about-nih/what-we-do/mission-goals>
- ¹⁷ <https://grants.nih.gov/grants/guide/pa-files/pa-18-381.html>

18. Acknowledgements & Citing the Community Organizations Toolkit

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The **Community Engagement Advisory Board** at UIC

Any errors that remain are the responsibility of Kevin Rak, Research Specialist at UIC. If you have any comments or questions, please feel free to contact us at toolkits@uic.edu.

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