

COMMUNITY-ENGAGED RESEARCH



A RESOURCE GUIDE FOR RESEARCHERS AND COMMUNITY-BASED ORGANIZATIONS



COMMUNITY OUTREACH AND ENGAGEMENT PROGRAM
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TABLE OF CONTENTS

1 PREFACE

3 WHAT IS COMMUNITY-ENGAGED RESEARCH?

6 CHARACTERISTICS OF COMMUNITY-ENGAGED RESEARCH

7 KEYS TO BUILDING TRUST

10 KEY PRACTICES FOR RESEARCHERS

15 IMPORTANT CONSIDERATIONS FOR COMMUNITY-BASED ORGANIZATIONS

17 IMPORTANT CONSIDERATIONS FOR RESEARCHERS

19 AVOID COMMON PITFALLS

21 SUMMARY

22 RESOURCES

25 SUGGESTED READINGS

26 REFERENCES

About Us

As Georgia's first and only National Cancer Institute-designated Comprehensive Cancer Center, Winship Cancer Institute is a national leader in seeking out new ways to defeat cancer and in translating that knowledge into patient care. With over 250 active clinical trials, Winship researchers are dedicated to taking new cancer treatments from bench to bedside. Winship's Community Outreach and Engagement Program promotes and facilitates community-facing research and evidence-based program dissemination through programmatic initiatives across the state of Georgia. To fulfill our commitment to reduce the cancer burden in Georgia, the Community Outreach and Engagement Program:

- Engages with key stakeholders, including researchers, healthcare providers, educators, community members, advocates, and our Community Advisory Board for input, advice, and guidance
- Supports and facilitates community-engaged research through community-academic partnerships
- Disseminates evidence-based interventions and programs that promote healthy lifestyles, increase screening and early detection, and improve access to clinical trials
- Advocates for public policy and promotes systemic changes that advance health equity and cancer prevention and control in Georgia

About this guide

This resource guide is designed for researchers and community organizations that are considering entering into a research partnership, but have little or no experience in community-engaged research. The information provided serves as a starting point for developing a foundation for a strong community/academic partnership to support high quality research that benefits both the researcher and the community.

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- Smitha Ahamed, DrPH, MPH, CEO, East Georgia Cancer Coalition
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Preface

Cancer and many other public health concerns share a variety of lifestyle and social circumstances that influence disease outcomes. While scientific advances have led to increased knowledge regarding the causes, prevention and treatment of chronic diseases, those advances have not fulfilled their potential for optimizing community health (Fudge, et al., 2016). The transfer of scientific evidence into everyday practice is



necessary to mitigate health disparities and improve health outcomes. Developing effective community-academic partnerships and engaging local communities in research endeavors is an essential factor for the successful testing and implementation of promising interventions and programs, particularly those aimed at decreasing barriers and improving health in communities suffering health disparities.

Community stakeholders have valuable insights and understanding of the history, values, culture, social connections, and politics of their communities. These stakeholders, often representing community-based organizations, bring a unique perspective in helping researchers define research questions that are relevant to their communities; provide useful information on culturally-appropriate methods; help determine how study results can be translated to practice in ways that will benefit the community; and help shape future directions for research.

This guide promotes basic principles for effective and sustainable community engagement in cancer research. As defined by the Centers for Disease Control and Prevention, community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting the wellbeing of those people (CDC, 1997, p. 9). In general, the goals of community engagement are to build trust, enlist new resources and allies, create better communication, and improve overall health outcomes as successful projects evolve into lasting collaborations. (CDC, 1997; Shore, 2006; Wallerstein, 2002).

NCI's Mandate for Community Outreach and Engagement

While cancer mortality is declining in the United States, significant racial, ethnic, economic and geographic inequities persist (O'Keefe, et al., 2015; Gopal, et al., 2017). In 2016, to help address inequities in cancer treatment, care, support and research, the National Cancer Institute (NCI) instituted a community outreach and engagement mandate for NCI-designated cancer centers. Specifically, Cancer Centers are expected to conduct research projects that rely on catchment area data to establish priorities and that involve significant engagement of communities, resulting in high-impact science.

Winship Cancer Institute's Community Outreach and Engagement program is committed to fostering community-engaged research in Georgia. To that end, **this resource guide is designed for cancer researchers and community stakeholders who are considering entering into a research partnership, but have little or no experience in community-engaged research.** The information provided serves as a starting point for developing a foundation for a strong community-academic partnership that will support high quality cancer prevention and control research that benefits both the researcher and the community. To help build that foundation, this guide explores the following questions:

- What is community-engaged research and why is it important?
- How can working with communities to conduct research studies help advance research objectives and speed translation of results into practice?
- How can community-based organizations and the communities they serve benefit from engaging researchers to address issues of importance to their communities?
- How does one start a community-academic partnership for research?
- How can researchers build and maintain trust among community stakeholders?
- What questions should the researcher and community-based organization ask before entering into a research collaboration?
- What are some pitfalls to avoid in community-academic partnerships?

At the end of this guide, you will find a Resource section that provides links to data sources and program planning and evaluation tools. Also included is a Suggested Reading section that provides links to publications that provide more in-depth information on community-engaged research.


We hope you will find this guide useful in your journey toward creating and sustaining effective community-engaged research partnerships.

Theresa W. Gillespie, PhD, MA, BSN, FAAN
Associate Director, Community Outreach and
Engagement

Denise Ballard, MEd, Program Director
Community Outreach and Engagement

What is Community-Engaged Research?

Community-engaged research is conducted through partnerships with community stakeholders and researchers. The rationale for community-engagement in research is largely rooted in the recognition that lifestyles, behaviors, and the incidence of illness are all shaped by social and physical environments (Hanson, 1988; Institute of Medicine, 1988). While biology and access to healthcare influence health, health is also socially determined and rooted in larger socioeconomic and racial inequities (Healthy People 2020, Solar et al., 2010). Therefore, it follows that health issues are best addressed by engaging community stakeholders who bring their unique perspectives and understanding of the community to research endeavors.



“By jointly developing and conducting research projects with community members, I believe we increase the chances that our research makes a difference in people’s lives.”

Michelle Kegler, DrPH, MPH
Director, Emory Prevention
Research Center

Community engagement in research can take many forms. It can focus on complex systems such as healthcare systems, on social or political networks, on geographic areas, on individuals with a shared experience, or on virtual communities (e.g., social media groups). Partners can include organized civic groups, community-based organizations, patients, healthcare providers, the faith community, community residents, and other community stakeholders. Therefore, community-engaged research is not a one-size-fits-all proposition.

Community-engaged research is often viewed as a continuum (see Figure A), and levels of community engagement may vary depending on the nature of the research, funder requirements, the community of interest, resources available, and the availability of ready and willing collaborators. In the more traditional *community-placed* approach, while the research is conducted *in* the community, all phases of and most decisions about the research are driven by the researcher. The community serves as research participants and in some cases may be asked to help with study recruitment, but otherwise has no significant involvement. Community-engaged research, on the other hand, is conducted *with* the community, where community stakeholders are actively involved in various phases of the research, including some aspects of study design, implementation, and/or dissemination of results. On the far end of the community-engagement continuum is community-based participatory research (CBPR). CBPR is a form of community-engaged research in which community members are equal partners, sharing leadership with academic researchers throughout the entire research process.

Building strong community-academic research partnerships require time, experience, and trust. Therefore, most researchers and community-based organizations that are new to community-engaged research will not start with projects that use the full CBPR approach. This guide, therefore, focuses on the **moderate level** of community engagement. For those who are interested in further building their capacity for CBPR, see the “Suggested Readings” section of this guide.

Figure A – Community-Engaged Research Continuum

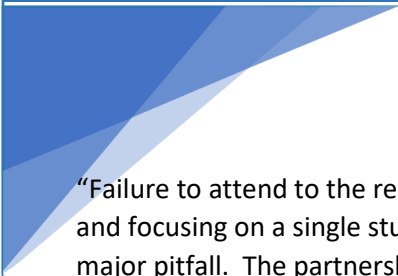


*The focus of this guide is the moderate level of community engagement. For information on the community-based participatory approach, see the Suggested Readings section.

Characteristics of Community-Engaged Research

Many factors characterize community-engaged research. Some are unique from the perspective of the researcher, and others from the community's perspective. However, following are a number of important factors that are shared by both the researcher and the community.

- The definition of “community” is understood by both the researcher and community stakeholders. The definition may be based on geography, socioeconomic status, ethnicity, or individuals affected by the health issue being addressed. The community may also refer to stakeholder audiences, such as policy makers, public health professionals, healthcare workers, community-based organizations, and other groups.
- Community stakeholders contribute to one or more phases of the research, such as the design, implementation, and/or dissemination of results (in CBPR, stakeholders contribute to most or all phases of research).
- Knowledge gained from research benefits both the researcher and the community.
- Purposeful and consistent efforts to build trust are implemented.
- Researchers and community stakeholders recognize one another's expertise, skills and assets, and the partnership provides opportunities for co-learning.
- Both the researcher and community stakeholders strive for a long-term partnership that allows for future collaboration (this is essential for CBPR partnerships).
- The collaboration speeds translation of results as policy, systems, practices, and/or environmental changes are adopted by community partners and other stakeholders.



“Failure to attend to the relationship and focusing on a single study is a major pitfall. The partnership should be treated like any other relationship. It requires an investment of time to continuously learn and respond to what each community partner values. Through give and take, trust-worthiness is built to sustain the relationship through fruitful and challenging seasons.”

Tabia Henry Akintobi, PhD, MPH
Associate Dean
Community Engagement
Morehouse School of Medicine

Keys to Building Trust

One of the most commonly cited barriers to public participation in research, especially among under-represented groups, is lack of trust (McCloskey, et al., 2011). Distrust is largely due to a history of unethical biomedical research practices suffered by vulnerable populations (Futerman, 2021). Today, while human research protections are in place for research participants, no such



institutional protections are in place to provide oversight for community stakeholders involved in research partnerships. Recognizing that there also is an inherent imbalance of power between the researcher/academic institution and community stakeholders, these vulnerabilities can lead to a lack of trust. Therefore, building trust between the researcher and community partners is essential for successful community-academic partnerships. Common practices for building trust in community-engagement include the following:

- **Maintain effective communication** – all parties should understand and agree on the goals of the research and share a basic understanding of the research methods. It is a good practice to communicate the goals and research aims frequently, especially during the early stage of the partnership. **Share information widely** – all parties involved in the research collaborative should receive the same information so that no stakeholder feels left out of the information loop. If for some reason the project cannot proceed as planned due to staffing issues, funding delays, etc., it is important to openly communicate the reasons

“Communication and transparency are essential to a successful partnership. Ensure responses are timely and make every effort to maintain regular communication.”

Smitha Ahamed, DrPH, MPH
CEO, East Georgia Cancer Coalition

to all parties to ensure that everyone understands the status of the project and future plans.

- **Demonstrate respect** – the tone and content of communications and the channels and methods used to relay information should consistently demonstrate respect for the individual, their input and expertise. For example, in meetings, the researcher and a community partner should share facilitation responsibilities. When partners make suggestions, it is important to act on them to the extent possible. If it is impractical to do so, a simple explanation of why the suggestion cannot be acted upon will usually suffice. All parties in the partnership should respect one another’s time constraints and ensure timely responses to requests for information. Finally, frequent communication between the researchers, particularly principal investigators and key partners, is one way of demonstrating respect for the partnership and is a practice that promotes equity.
- **Balance power dynamics by sharing responsibility and authority** – all parties should understand and agree on their roles and responsibilities, decision-making processes, data ownership, staff supervision, and other details. Consider drafting guidelines for collaboration or memoranda of understanding to communicate these agreements. Develop meeting agendas collaboratively and structure meetings to encourage input from all parties. Keeping in mind that the researcher is most often in a greater position of power, he or she should be prepared to shoulder the responsibility of addressing or preventing the occurrence of incidents that may cause a stakeholder to be skeptical about collaborating. Conversely, stakeholders should openly share with researchers any concerns they may have about power dynamics and demonstrate commitment to working together to solve problems as they arise.
- **Equitably distribute resources** – the allocation of resources should be negotiated between the researcher and community partners, based on their unique roles and responsibilities. Community stakeholders should advise the researcher of their financial requirements based on the scope of work. Rarely, however, will grant funding cover all costs incurred by the community partner, and the community partner is not usually motivated by funding alone. An organization typically agrees to collaborate when the research project is aligned with its mission and organizational goals. However, adequate funding is required to avoid overburdening the community organization and detracting from its core activities. It also is important that all parties agree on payment schedules and how costs are calculated (for example, a flat rate for specific activities, an

A literature review on building trust in community-engaged research found common characteristics of trustworthy researchers. They include being empathetic, accessible, approachable, honest, respectful, attentive, and humble (Wilkins, 2018).

hourly wage and benefits rate for key staff, or a combination of both). The parties should also agree on whether the community organization will be reimbursed on a particular schedule (e.g. quarterly) or on a fee-for-service basis as deliverables are met. These discussions should occur when the grant proposal and budget is being drafted and should be detailed in writing.

- **Maintain transparency** – the goals of the research, expected benefits to the community, motivations for engagement, and the allocation of resources should be openly discussed early in the partnership development process. It is important that the organization that receives grant funding (most often, the academic institution) reveal the total amount of the grant and how resources are allocated among the university, key partners and/or subcontractors. Community stakeholders may not be familiar with the academic institution’s grant policies (e.g., funding allocated for project staff salaries, or the percentage required for indirect costs), participant recruitment costs, and other direct costs. Sharing this information reduces the risk that community stakeholders feel exploited. Also, recognizing that changes to timelines are often inevitable, delays should be communicated among all parties in a timely manner to allow everyone to adjust their plans accordingly.
- **Engage community stakeholders in meaningful ways** – stakeholders appreciate being engaged in ways that support their interests, skills, resources and organizational objectives. Consider establishing a community-academic governance structure that include work groups charged with addressing key study objectives. Offering choices in workgroup participation encourages individuals to engage based on their backgrounds and interests. Workgroups may include communication, participant recruitment, data management, dissemination, or other project-related topics.
- **Hire staff members that reflect the community** – this practice can improve efforts to increase equity, supports cultural relevancy, helps build trust, and contributes to the community’s local economy. This is best accomplished through subcontract arrangements between the researcher and community organization(s).
- **Protect organizational reputations** – all parties should be mindful that individuals represent the organizations to which they are affiliated, and individual behaviors that damage trust in one collaborative research endeavor will likely result in distrust of the organization in future endeavors.

Trust is an essential ingredient for successful community-academic research partnerships. All efforts to develop and maintain trust contribute to increased credibility of the research community, encourages greater involvement in research by community stakeholders, and helps ensure sustainable improvements in community health.

Key Practices for Researchers

Researchers who have experience successfully working with community stakeholders recommend the following steps to build and sustain meaningful community-academic research collaboratives.

1. Get to know the community

If you are not very knowledgeable about the community you wish to engage in a research project, the first step is getting to know the community. Ideally, this should happen before you begin to approach stakeholders as potential partners. Review organizational websites, annual reports, strategic plans, newspapers, and other documents that might enhance your understanding of the community's history, values, social and cultural environments, political power structures and their interaction with health behaviors. Review other data sources, such as hospital discharge, cancer surveillance, and population data to get a better understanding of the segment of the community that will be the focus of the research (see sources of data in the Resource section of this guide).



2. Seek support of a mentor

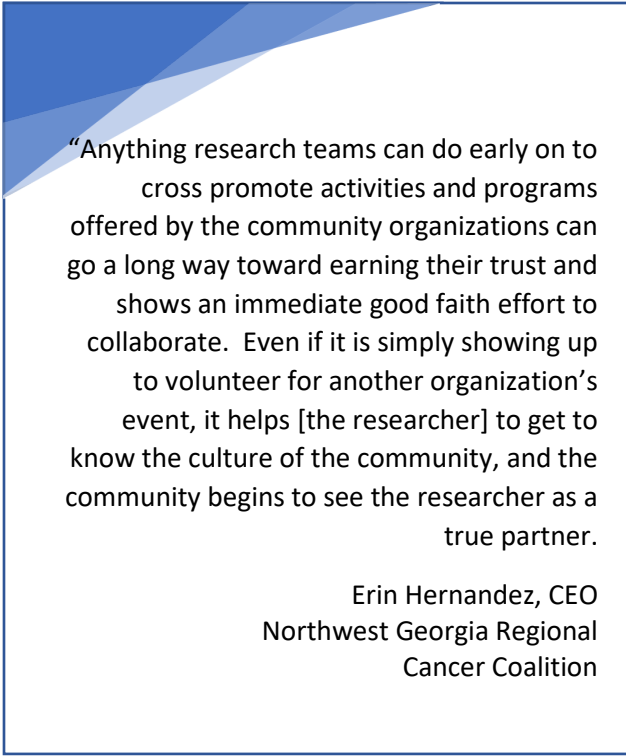
Another researcher who has experience in community engagement can provide valuable advice on working with communities. This experienced individual also may be able to introduce you to key community stakeholders, paving the way for your initial partnership development efforts.

3. Network

Gaining entrée into a community is the next step in the process. Ideally, you should start this process six months before developing a research proposal. Community-engagement is most effective when the researcher's interests are



aligned with the needs of the community. So start by casting a wide net to identify organizations and individuals who may share your interests. For example, if you are interested in research on primary cancer prevention strategies (e.g., tobacco control, obesity prevention, HPV vaccination, etc.), contact organizations that work in that space and those that serve the populations of interest. In Georgia, they may include regional cancer coalitions, public health district offices, school districts, hospitals, federally-qualified community health centers and other primary care clinics, and other health-concerned collaboratives. On the other hand, researchers who are interested in cancer patient care (e.g., treatment, palliative or supportive care) might start by contacting cancer centers, regional cancer coalitions, professional organizations (e.g., nursing associations), or cancer support groups.



“Anything research teams can do early on to cross promote activities and programs offered by the community organizations can go a long way toward earning their trust and shows an immediate good faith effort to collaborate. Even if it is simply showing up to volunteer for another organization’s event, it helps [the researcher] to get to know the culture of the community, and the community begins to see the researcher as a true partner.

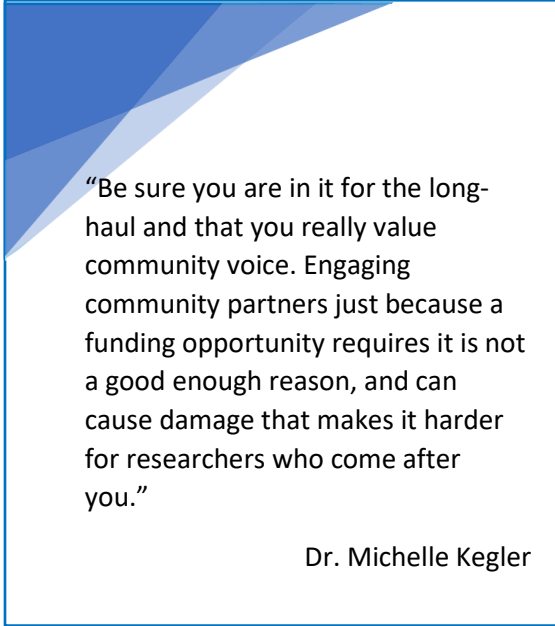
Erin Hernandez, CEO
Northwest Georgia Regional
Cancer Coalition

When possible, it is best to make these contacts through your own networks, including colleagues or friends. Ask those individuals to introduce you through an email or at an existing meeting. Seek community leaders and organizations that represent or serve individuals who can provide insights on the lived experience, such as individuals suffering from health disparities and those at high risk for cancer. Ask contacts about existing collaboratives and coalitions, and try to attend meetings of these groups or other local events to get to know others and to demonstrate genuine interest in the community. Try to determine who best represents the community, while gauging stakeholders’ interest in getting involved in research as partners.

4. Select partners

Now that you have conducted background research and networked with multiple stakeholders and organizations, it is time to hone down your list and select potential partners. Select those that best represent the community of interest, including those organizations that have the greatest influence on those who might participate in the study. Keep in mind that a community organization or key stakeholder might carry baggage that limit their ability to gain or maintain community trust. If you choose such an organization

or individual as a primary partner, you risk inheriting their reputation, so choose wisely. Also, be on the lookout for competing interests of organizations and community stakeholders, and select partners whose interests are most closely aligned with yours. Once selected, meet individually with representatives of these organizations to assess their interests in working with you, as well as their experience serving as research partners. Ask questions that will help you determine their capacity-building needs and offer support by sharing informational resources and offering training or other capacity-building assistance. It is common for community-based organizations to require information or training on human subjects protections, evidence-based strategies for cancer prevention and control, health equity, evaluation, qualitative data collection methods, grant writing and other topics. Collaborate with these partners to develop plans for capacity-building activities. Follow-up verbal agreements to collaborate with an email to document the agreement. Later, more formal documentation should be developed, such as a memorandum of agreement, or if funding will be shared, a contract executed by both partners.



“Be sure you are in it for the long-haul and that you really value community voice. Engaging community partners just because a funding opportunity requires it is not a good enough reason, and can cause damage that makes it harder for researchers who come after you.”

Dr. Michelle Kegler

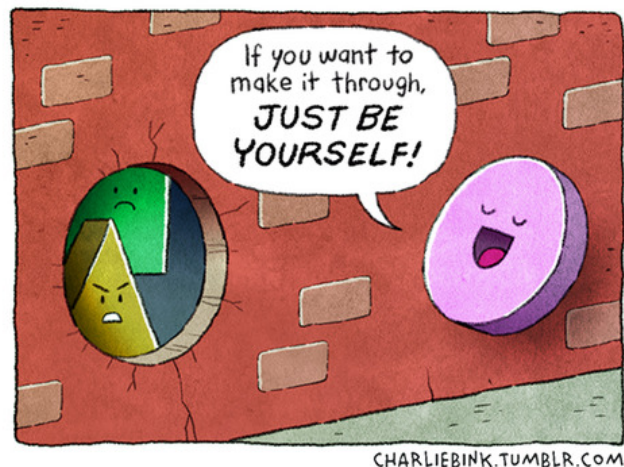
5. Collaborate with partners to define the organizational structure

Work with partners to determine what organizational structure is best suited for your partnership. For instance, will one or more organizations serve as primary community partners and be funded to assist in carrying out the research? Will you (the academic institution) hire staff who live in the community, or will the community partner employ such staff under a subcontract? Will the partnership benefit from a Community Advisory Board or Steering Committee? Will community members with lived experience be represented? Discuss these issues with your partner and create an organizational structure that you both agree will demonstrate power sharing, improve equity, build trust, and promote sustainability.

6. Embrace cultural humility

Embracing cultural humility is “a lifelong commitment to self-evaluation and critique, to redressing power imbalances . . . and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations” (Tervalon, et al., 1998, p 117). Cultural humility is an ongoing and critical process that aids in building trust and enables

partnerships to reach their full potential. Once you get to know the community stakeholders who are willing to serve as partners, have open discussions regarding the influence of history, culture, racism, and social class on health disparities and cancer outcomes. Involve diverse members of the community, including those with lived experience, in these discussions to get various perspectives. **Listen more than you speak** in order to gain a better understanding of the cultural realities of segments of the community that will be the focus of the research. For more information on cultural humility, see the Suggested Reading section of this guide.



7. Achieve a balance between research and action

Determine what the community hopes to gain from the partnership and build in activities that support their interests. Jointly consider how the results of the research will be used to change policies, practices or the environment, and help the community implement change based on study results. This activity is critical in speeding the translations of research results to practice. Collaborate with community partners to develop a sustainability plan to help ensure that the research advances will benefit the community indefinitely. While the partnership may focus on your research interests, it is important to cross promote programs and events offered by your partners to show support for other community health initiatives. This can be accomplished by sharing e-mail announcements, by allowing time for sharing at partnership meetings, or by highlighting partners in your program newsletter, etc.

8. Build trust by engaging in activities that support equity and power-sharing

It is important to engage in shared decision-making whenever possible. Include primary partners, including community advisory board or steering committee chairs, in planning, in problem solving and in important decisions. Maintain transparency by sharing information on how funds are allocated. Support equity by compensating community members and/or

organizations for the time they contribute to the project. Collaborate on meeting agendas and share meeting facilitation responsibilities. Seek opportunities for community partners and community members with lived experience to assist with data collection and interpretation of data, and involve them in disseminating research results.

9. Disseminate research findings to all stakeholders and provide opportunities for co-authorship

Share preliminary results as soon as available and disseminate final results to all stakeholders in the format(s) they prefer. This may include infographics, community events, websites, social media, and local mass media. Consider the language used in dissemination efforts – avoid jargon and use language that is familiar to the community. Involve partners in the dissemination process by offering opportunities for co-authorship of manuscripts, abstracts, posters and presentations.

10. Stay engaged with community partners after the project ends

Building sustainable community-academic partnerships requires nurturing of the relationship, even after the initial research project ends. Protect your investment by staying in touch with your primary stakeholders. Continue to share information that will benefit the partners and the communities they serve, including grant announcements, training opportunities, and other relevant resources and programs.

Important Considerations for Community-based Organizations

When deciding whether or not to collaborate with a researcher, the community-based organization should discuss with the researcher the following questions:

- What will be my organization's level of involvement in the project; what specific role will my organization play?
- How much staff time will be needed from my organization, and will that time be compensated?
- How will decisions get made?
- What influence will my community or my organization have on setting the research agenda?
- What skills will my organization need to serve as a research partner? Will the researcher help my organization build its capacity to serve as a research partner?
- Who will own the data?
- Will opportunities to co-author publications and presentations be offered?
- What benefits will the project leave behind for my organization? For my community?



The community organization should also reflect on its own unique assets, relationships, and organizational priorities and consider the following:

- Is research aligned with my organization's mission? Do I need Board approval?
- Does the proposed study address an issue that is important to my organization?
- Do I have time to invest in developing this partnership?
- Does my organization have the right connections to the community of interest, including those with lived experience?
- Will involvement in research negatively impact my organization's core mission?

- Do I know enough about the community (its history, experience with research, assets, culture) to provide useful information to the researcher?

Consider asking for advice from people you know who lead organizations that are similar to yours and who have been involved in research projects. They will likely be able to share important information to help you form a strong research partnership that benefits your organization and the community you serve.

Important Considerations for Researchers

Collaborating with community stakeholders on research efforts takes time and commitment to developing and maintaining mutually-beneficial and respectful partnerships. Researchers are wise to consider the following questions when considering community-engaged research partnerships.



- Do I know what it means to share power with community stakeholders, and am I willing and able to do so?
- Do I have the time and patience to get to know community stakeholders?
- Do I possess the interpersonal skills necessary to achieve lasting partnerships?
- Does my institution fully embrace and support community-engaged research?
- Am I willing to serve as a mentor for stakeholders on research practices?
- Am I eager to learn from community stakeholders?
- Am I willing to practice cultural humility?
- Do I plan to stay involved with this community for future projects, or am I looking to partner for a single, short-term project?
- Am I willing to invest in hiring community representatives who can guide me in the development of a community-engaged research plan and implementation strategy?

Depending on the nature of the research project and funding requirements, the researcher should also consider:

- What groups should be represented in the partnership?
- How will the partnership be structured? Will I need a community advisory board (C.A.B.) or a sub-contractual arrangement with one or more partners?

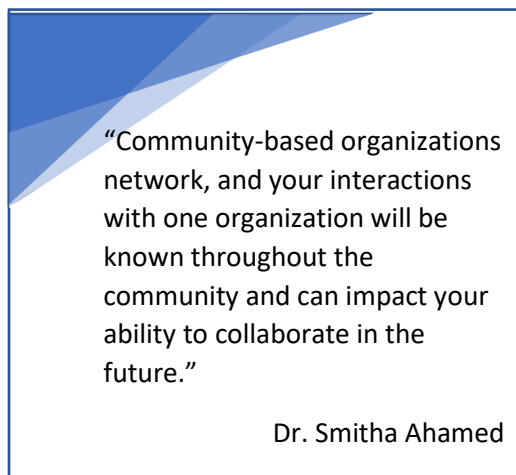
- If a C.A.B. is required, am I able to compensate members for serving?
- What resources can I bring to the partnership to support stakeholder capacity-building?
- Will my funding allow me to share financial resources with key partners through contractual agreements?

Consider seeking advice from a colleague who is experienced in community-engaged research. This person may be willing to serve as a mentor to help you get started working with communities.

Avoid Common Pitfalls

As with any relationship, there are a number of hot-button issues that may threaten community-academic research partnerships. It is important to plan ahead, as it is easier to avoid these risks than it is to resolve the issues once they occur. Common pitfalls include:

- **Unrealistic expectations regarding roles and responsibilities.** Both the researcher and the community partners should assume only the roles and responsibilities for which they have time and skills to execute. Once the parties agree on their respective roles, a memorandum of understanding should be drafted to articulate specifics of that agreement.
- **Lack of transparency regarding funding.** Define and communicate the specific resources each partner will contribute to the project, including in-kind services, and share information on how grant funds will be allocated among the researcher and community partner(s).
- **Failure to plan for and discuss the ongoing value proposition.** Community-academic research partnerships are sustained, in part, because of opportunities to build capacities and networks through training, workshops, other funding and connections. It is important that partners discuss the relationships, opportunities and resources that they can contribute, thereby making the value of the collaboration not limited to a single grant.
- **Researcher rushes in or out.** The researcher tries to quickly form a new partnership to meet an approaching grant deadline or disappears when the project is not funded or funding ends.
- **A leadership team member is inaccessible.** The Principal Investigator of the academic institution and a high-ranking leader of the community organization should communicate regularly to make sure the research plan is being implemented with fidelity and that any concerns other team members might have are appropriately addressed in a timely manner.



- **Slow response to requests.** Grant proposal submission deadlines, progress reports and other funder expectations often require timely responses. All parties must agree to respond to requests for information in a timely manner.
- **Lack of planning and skills in conflict resolution.** Even those who are experienced in community-engaged research partnerships sometimes experience conflicts. It is important to have a plan in place so it is clear to all parties how conflicts will be resolved and who will serve as mediators. Mediators should include team leaders who have strong conflict resolution, diplomacy, and facilitation skills. If the partnership includes a community advisory board, the chair should be among those involved in conflict resolution, as appropriate.



Summary

Community-academic partnerships are critical in designing and conducting research studies that address the needs of local communities, that improve equity, and that speed translation of science to community practice. Building productive partnerships between researchers and community stakeholders take time and requires power-sharing and commitment to collaborate on issues of interests to both the researcher and the community. Trust is an essential ingredient for successful partnerships, and all parties must take great care to consistently engage in activities that promote trust, including practicing transparency, joint problem-solving, and engaging in open, respectful and frequent communication. While community-academic partnerships in research require substantial investment from all parties involved, the rewards and most importantly the impact on community health, can be immeasurable.

Resources

Data

County Health Rankings & Roadmaps. A program of the University of Wisconsin Population Health Institute, the County Health Rankings are based on a model of community health that emphasizes the social determinants of health, using more than 30 measures that help communities understand their health factors and health outcomes and develop strategies for change. <https://www.countyhealthrankings.org/>

GeorgiaData.org. The Carl Vinson Institute of Government at the University of Georgia created compiled a variety of public sources and conveniently organized data by county and topic, <https://georgiadata.org/>

Georgia Health Data Hub. Created and managed by the Georgia Rural Health Innovation Center, this website blends powerful data tools in a single location. <https://www.georgiaruralhealth.org/rural-health-information/health-indicators-report/>

OASIS (Online Analytical Statistical Information System). The Georgia Department of Public Health's health indicator tool. OASIS provides a variety of health statistics and indicators from vital records, hospital discharge, ER visit, STD, Census population counts and other data in tabular, mapped, or charted form. <https://oasis.state.ga.us/>

State Cancer Profiles. National Cancer Institute and the Centers for Disease Control and Prevention. Cancer statistics, charts, and maps by data topic across the cancer control continuum. <https://statecancerprofiles.cancer.gov/>

U.S. Cancer Statistics Data Visualizations tool. The tool displays the official federal statistics on cancer incidence (newly diagnosed cases) from each cancer registry that met data quality criteria. The Centers for Disease Control and Prevention and the National Cancer Institute have combined their cancer incidence data sources to produce these statistics. <https://gis.cdc.gov/Cancer/USCS/#/AtAGlance/>

Program Planning Tools

Guide to Community Preventive Services (The Community Guide). A collection of evidence-based findings of the Community Preventive Services Task Force, the Community Guide is a resource to help practitioners select interventions to improve health and prevent disease in their state, community, community organization, business, healthcare organization, or school. <https://www.thecommunityguide.org/>

Evidence-based Cancer Control Programs (formerly known as Research-tested Intervention Programs), is a searchable database of evidence-based cancer control programs designed to provide program planners and public health practitioners easy and immediate access to program materials to speed the transfer of research results into clinical and community practice. Designed and managed by the National Cancer Institute. <https://ebccp.cancercontrol.cancer.gov/index.do>

Implementation Science at a Glance: A Guide for Cancer Control Practitioners.

Developed by the U.S. Department of Health and Human Services, National Institutes of Health, National Cancer Institute. Implementation Science at a Glance introduces core implementation science concepts, tools, and resources, packaged in a way that maps to the various stages that practitioners may find themselves in as they seek to use evidence-based interventions to meet the needs of patients, families, and communities.

<https://www.thecommunityguide.org/resources/implementation-science-glance>

U.S. Preventive Services Task Force. The U.S. Preventive Services Task Force is an independent, volunteer panel of national experts in disease prevention and evidence-based medicine. The Task Force makes evidence-based recommendations about clinical preventive services such as health screenings, counseling services, and preventive medications. <https://www.uspreventiveservicestaskforce.org/uspstf/>

Evaluation Tools

CDC Evaluation Resources. Evaluation planning tools, workbooks, logic models and other evaluation tools from the CDC Program Performance and Evaluation Office.

<https://www.cdc.gov/eval/resources/index.htm>

Centers for Disease Control and Prevention Framework for Program Evaluation. A practical tool designed to summarize and organize essential elements of program evaluation. The emphasis is on practical, ongoing evaluation strategies that involve all program stakeholders. <https://www.cdc.gov/eval/framework/index.htm>

Suggested Readings

Community-Engaged Research

Clinical and Translational Science Awards Consortium., United States, National Institutes of Health, Centers for Disease Control and Prevention & Clinical & Translational Science Awards Consortium. (2011). **Principles of community engagement**.
https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

Handley M, Potter M, Goldstein E. (2010). **Community-Engaged Research with Community-Based Clinicians: A Resource Manual for Researchers**. From the series: UCSF Clinical and Translational Science Institute (CTSI) Resource Manuals and Guides to Community-Engaged Research, P. Fleisher, ed. Published by Clinical Translational Science Institute Community Engagement Program, University of California San Francisco.
<https://ucsf.app.box.com/s/h9ta3pp0mggbtmy9kwa8jwfgie5gpm8>

Community-Based Participatory Research

Hacker K. (2013). *Community Based Participatory Research*. Sage.

Minkler M and Wallerstein N. (Editors). *Community-Based Participatory Research for Health: From Process to Outcomes*, 2nd Ed. Jossey-Bass.

Wallerstein N, Duran B, Oetzel J. (2018). *Community-Based Participatory Research for Health: Advancing Social and Health Equity* (3rd Ed.). Jossey-Bass.

Cultural Humility

Greene-Moton, E., & Minkler, M. (2020). Cultural competence or cultural humility? Moving beyond the debate. *Health Promotion Practice*, 21(1), 142–145.

Katherine Y, Bauer-Wu S. Cultural humility: Essential foundation for clinical researchers, *Applied Nursing Research*, Volume 26, Issue 4, 2013, Pages 251-256.
<https://www.sciencedirect.com/science/article/pii/S0897189713000669>

Tervalon M, Murray-Garcia J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, 9(2), 117-25.

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Futterman A. (2021, November). 5 Unethical Medical Experiments Brought Out of the Shadows of History. January 11, 2021. <https://www.discovermagazine.com/health/5-unethical-medical-experiments-brought-out-of-the-shadows-of-history>

Gopal S, Ahmedin J, "Socioeconomic and Racial/Ethnic Disparities in Cancer Mortality, Incidence, and Survival in the United States, 1950–2014: Over Six Decades of Changing Patterns and Widening Inequalities", Journal of Environmental and Public Health, vol. 2017, Article ID 2819372, 2017.

Healthy People 2020 [Internet]. Washington, DC: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion [cited October 23, 2021]. Available from: <https://www.healthypeople.gov/2020/leading-health-indicators/2020-lhi-topics/Social-Determinants>

McCloskey DJ, Aguilar-Gaxiola S, Michener JL. Principles of Community Engagement, 2nd ed Washington, DC: US Department of Health and Human Services; National Institutes of Health Publication; 2011:11–7782.

O'Keefe EB, Meltzer JP, Bethea TN. Health disparities and cancer: racial disparities in cancer mortality in the United States, 2000–2010. Frontiers in public health. 2015;3:51.

Shore N. Re-conceptualizing the Belmont Report: a community-based participatory research perspective. Journal of Community Practice 2006;14(4):5-26.

Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice), 2010.

Tervalon M, and Murray-Garcia J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, 9(2), 117-125.

Wallerstein N. Empowerment to reduce health disparities. *Scandinavian Journal of Public Health Supplement* 2002; 59:72-77.

Wilkins C. Effective engagement requires trust and being trustworthy. *Med Care*. 2018 Oct;56 Suppl 10 Suppl 1:6-8. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6143205/>