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Putting the Community-Engaged Research Framework into Practice

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Introduction

Community-engaged research is an approach to inclusive and equitable research[i] where researcher-community partnerships form to conduct a study, project, or evaluation.[1–4] Researchers, community members and organizations (CBOs), and other partners work collaboratively throughout the full cycle of the research process.

This Toolkit for **Putting the Community-Engaged Research Framework into Practice** provides strategies for conducting research and evaluation with community members and partners, using a culturally responsive lens. Each section of this toolkit aligns with a phase of the research process listed in the Community-Engaged Research Framework (the "Framework") and includes strategies researchers can take to reflect community-engaged principles and foster a researcher-community partnership. Researchers can use this toolkit to review tools and resources for conducting culturally responsive, respectful, and attentive community-engaged research.

Tools researchers can use to guide their thinking and work on community-engaged research studies

Resources including links to relevant public documents and resources.

This Toolkit is a starting point to encourage researchers to ask questions about how to engage with community members and partners throughout the research process. Each partnership will be different in terms of composition, purpose, and collaboration approach. While we use the terms "research" and "study" throughout, the Toolkit can apply to social science, clinical, and applied research studies as well as to program evaluations.

What is Community-Engaged Research?

Community-engaged research, which joins researchers and communities as partners throughout the full research cycle, is not a specific method but an outlook and approach to research.[1–4] The emphasis is on the research team's[ii] relationship with the community.[3,4] Various methodological approaches and methods, including qualitative, quantitative, and mixed methods approaches, can be used. Conducting research *with* rather than *on* communities has many benefits: partners develop a mutually beneficial relationship that enhances each's capacity to conduct research; the research is culturally and logistically appropriate and provides information that is useful to community members and their

[i] Inclusive & Equitable Research are "the methods of practice for Equity Science that is collaborative research embracing a range of theoretical frameworks and mixed methods that are focused on centering and empowering people and communities under inquiry and democratizing the research process to promote equity." Johnson-Turbes, A., Jones, C., Johns, M.M., & Welch, V. (2022). Inclusive and Equitable Research Framework [Unpublished Manuscript]. Center on Equity Research, NORC at the University of Chicago, Chicago, Illinois.

[ii] A "team" consists of individuals, community-based organizations, researchers, evaluators, community leaders, and other key individuals or entities partners as determined by the research effort.

communities; it improves validity, relevance, enrollment, retention, interpretability of results, and contextualization of findings; and it enhances the use of the data to create behavioral, social, services, or policy change.[3,4] Community-engaged research exists along a spectrum of community involvement from community-informed (with minimal community input) to community-driven (community-led research)[1–5] (**Exhibit 1**). Even if a full community-driven approach is not possible (e.g., due to lack of time or resources), researchers can apply principles of community-engaged research in various aspects of research.[3–6]

Exhibit 1: The Continuum of Community Engagement in Research

Increasing levels of community involvement, communication, trust, and ownership

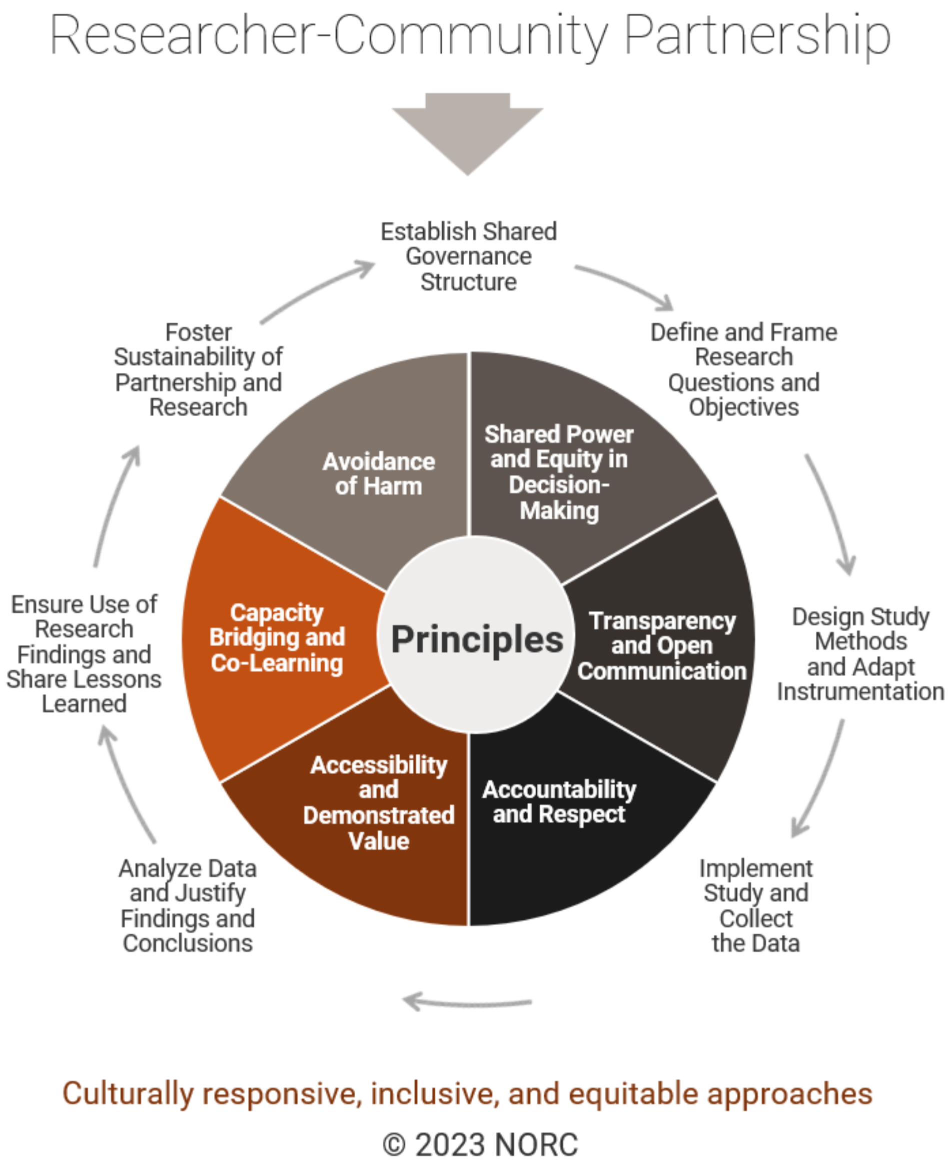
Community informed	Community involved	Shared Leadership	Community led
Community as advisor	**Community as collaborator**	**Community as equal partner**	**Community as leader**
Researchers drive the study questions, design, and implementation with some community involvement to seek feedback at discrete steps. Relationships and communication are largely uni-directional.	Researchers design the study with some community involvement, for example with a community advisory board. Researchers establish bidirectional communication channels and start to build partnerships and trust.	Researchers and the community work together to design and conduct research, and leadership and decision-making activities are shared. There is strong, bi-directional, and sustainable partnership and decision-making and trust. Community informs dissemination and sharing results.	Community defines and drives research efforts with researcher support. Community owns data and findings.

Source: Adapted based on ATSDR Principles of Community Engagement and Wilder Involving Community Members in Evaluation A Planning Framework

The Community-Engaged Research Framework

In 2023, NORC developed the **Community-Engaged Research Framework**, a conceptual model to guide researchers' thinking around community engagement in research (**Exhibit 2**). In sum (**Exhibit 3**), the Framework consists of six principles for community engagement and actionable strategies that teams can use to apply the principles to their research. We describe the Framework, its principles, and strategies in the Community Engaged Research Framework Equity Brief.

Exhibit 2: Community-Engaged Research Framework



Adapted from the Culturally Responsive Evaluation Framework and based on Principles adapted from various frameworks for community-engaged research.

Exhibit 3: The Community-Engaged Research Framework Principles and Actionable Strategies

Principle	Actionable Strategies
Avoidance of Harm: Ensure all members of the team understand the immediate and broader implications of the research in context and actively avoid further harming or marginalizing the communities in which the research is embedded.	• Understand historical and contemporary contexts and their impact on community(ies). • Implement strategies to mitigate harm. • Maintain community-researcher relationships beyond one study or funding period.

Principle	Actionable Strategies
Shared Power and Equity in Decision Making: Ensure all members of the team participate collaboratively, equitably, and cooperatively in all decisions.	• Create a diverse and inclusive team. • Establish governance structures that eliminate non-participatory power hierarchies that de-value community experience and expertise. • Discuss up front what communities want to contribute and ultimately get from the research.
Transparency and Open Communication: Ensure researchers and community partners communicate openly and honestly about power dynamics and decision-making processes around research objectives, resources, challenges, and limitations.	• Collaboratively establish open communication approaches and channels. • Minimize hierarchy in communication processes, "gatekeepers," and barriers to lines of communication.
Mutual Accountability and Respect: Ensure the team has developed an equitable structure for incorporating input into research and decision-making processes and addresses discord directly.	• Collectively develop charters and establish ground rules. • Establish procedures to overcome discord.
Accessibility and Demonstrated Value: Ensure time and contributions of all members of the team are valued, and methods of engagement are flexible and equitable.	• Acknowledge all team members and value their expertise, skills, and contributions. • Demonstrate cultural responsiveness and inclusivity.
Capacity Bridging and Co-Learning:[iii] Ensure all members of the team are learning from each other and engaging in bi-directional feedback and conversation.	• Facilitate the reciprocal transfer of knowledge, skills, and capacity. • Translate knowledge into action. • Affirm community strengths and assets.

[iii] Capacity building refers to building capacity, knowledge, and skills, of someone, usually a community person, to a research team.[39] Capacity bridging expands this notion to acknowledge that one person can bring many things to their position on a team[39] It also acknowledges the reciprocity of knowledge sharing between academics, researchers, community-based researchers, and individuals – so that all members are learning from each other.[39] This term was coined by the AHA Centre.

Phase 1: Establish Shared Governance Structure

SECTION AT A GLANCE

Strategy 1.1 Identify and engage community partners

- 1.1a Identify individuals, organizations, and other entities in the community of interest
- 1.1b Develop and implement an engagement plan

Strategy 1.2 Determine the nature and scope of the partnership

- 1.2a Work with community members to define their "community"
- 1.2b Establish ground rules for the partnership
- 1.2c Define the scope of the partnership
- 1.2d Ensure the research and partnership team represents the community

Strategy 1.3 Establish a shared governance structure

- 1.3a Determine where the study is on the community-engaged researcher continuum.
- 1.3b Implement the governance structure

Strategy 1.1 Identify and engage community partners

Nurturing researcher-community partnerships takes time, effort, intentionality, and resources. Ideally, partnerships develop organically based on common interests and continue beyond one study. However, sometimes partnerships develop within the context of a specific study.

1.1a Identify individuals, organizations, and other entities in the community of interest

Researchers may build connections with community-based partners by attending community meetings, events, and forums or participating on organizational boards, advisory councils, coalitions, or networks. They may also engage individuals from personal or professional networks. Researchers can conduct an environmental scan to identify local organizations and trusted community leaders, absent existing connections. Community-based partners may also themselves engage researchers directly or through contacts.

1.1b Develop and implement an engagement plan

Develop an engagement plan that lays out a clear purpose, approach, and timeline for engagement. Reach out to potential partners. Schedule an introductory meeting to get to know each partner, identify each other's strengths and assets, understand potential facilitators or barriers to partnerships, and establish a plan for follow-up. If appropriate, develop reference materials in advance of meetings with general information about your organization, its initiatives, and contact information. Promptly follow up with potential partners, share any agreed upon or requested resources, and complete any determined next steps for the partnership. Keep all parties up to date on the status and notify all parties about the outcomes. When partnerships are not good fits, acknowledge this and thank partners for their time and engagement.

TOOL: QUESTIONS TO CONSIDER

Developing an Engagement Plan

- What is the purpose of the partnership? Who are the potential partners? Which partners are prioritized for engagement and why?
- What is your plan for outreach, including outreach goals, logistics, materials (e.g., emails, pitch deck, meeting agendas)? What is your plan for follow up?
- What is the timeline for engagement? Have you accounted for internal preparation and coordination with researchers, outreach to partners for introductory meetings, and any post meeting follow-up and relationship building in your timeline?
- What are unique areas of expertise each organization has or is looking to expand? What are each organization's guiding principles and objectives related to pursuing strategic partnerships?

TOOL: QUESTIONS TO CONSIDER

Developing an Engagement Plan

- What are areas of study collaboration each organization is interested in and history of collaboration, including past challenges and lessons learned?
- What are ways in which a strategic partnership could promote equitable, culturally responsive research and evaluation and community interests?
- How does each organization work directly with the community? How will each party engage with each other and with the research?

Strategy 1.2 Determine the nature and scope of the partnership

Researchers and community partners should work together to determine a scope for the partnership.

1.2a Work with community members to define their "community"

Work with community partners to define community, relying on how they think about and define their own communities. Members of a community can have various characteristics in common (e.g., culture or ethnic heritage, where they live, age, language, religion) and be linked by social ties, perspectives, identities, residence, or interests.[3,4] Communities are diverse in terms of their beliefs, values, practices, and aspirations (for both themselves, their families, and their communities as a whole). Individuals are often part of multiple communities. Community can also include professionals and policymakers.[4]

1.2b Establish ground rules for the partnership

Determine how each partner wants to engage. This includes roles and responsibilities, mode and frequency of communication, compensation structure and amount, and the logistics of meeting coordination. Discuss and address barriers to engagement (e.g., concerns about time commitment or staff skills, limited capacity, language, transportation, or childcare barriers). For example, conduct meetings in multiple languages or provide interpretation or other accessibility services; engage at times and in places convenient to the community; provide transportation or childcare services; and offer tablets or other ways for members to access meetings.[7]

1.2c Define the scope of the partnership

Work collaboratively with community partners to develop a partnership agreement (e.g., memorandum of understanding [MOU], charter) that all parties can reference based on agreed upon ground rules, roles, group norms, responsibilities, and scope. Specify data ownership and outline plans for sustainability.

1.2d Ensure the research and partnership team represents the community

Assess the composition of the communities in which the research is taking place. Ensure that teams reflect the community in its characteristics, experience, and perspectives. For example, consider race and ethnicity, geography, gender identity, age, physical ability, language, education, and labor sectors. Avoid tokenism and including individuals, particularly from marginalized and minoritized groups, as a symbolic effort to give the appearance of diversity, inclusivity, or equity.[8] Ensure each member of the team has agency and voice, create bi-directional flows of information, input, and feedback, hold space for all team members to generate and contribute ideas, and respect the value of lived experience.[9]

Strategy 1.3 Establish a shared governance structure

Collaboratively determine the governance structure of the partnership and roles for each partner.

1.3a Determine where the study is on the community-engaged research continuum

Community-engaged research occurs along a continuum (Exhibit 1). Set expectations for level of engagement at the outset and understand its implications for how the partnership is structured. Be clear about what type of approach the partnership will take.

RESOURCES

Forming Partnerships

The Center for Community Health and Development at the University of Kansas' Community Toolbox includes resources for partnerships:

- Creating and Maintaining Coalitions and Partnerships
- Increasing Participation and Membership

Yale's Equity Research and Innovation Center (ERIC) CBPR Guidebook includes a section on forming partnerships.

The Clinical & Translational Science Institute at the University of California San Francisco (UCSF) developed a guide for developing partnerships with CBOs.

The Greenways for Pittsburgh Community Engagement Toolkit includes sample community meeting materials.

The Center for Health Care Strategies developed an brief on Engaging Community Members: A Guide to Equitable Compensation.

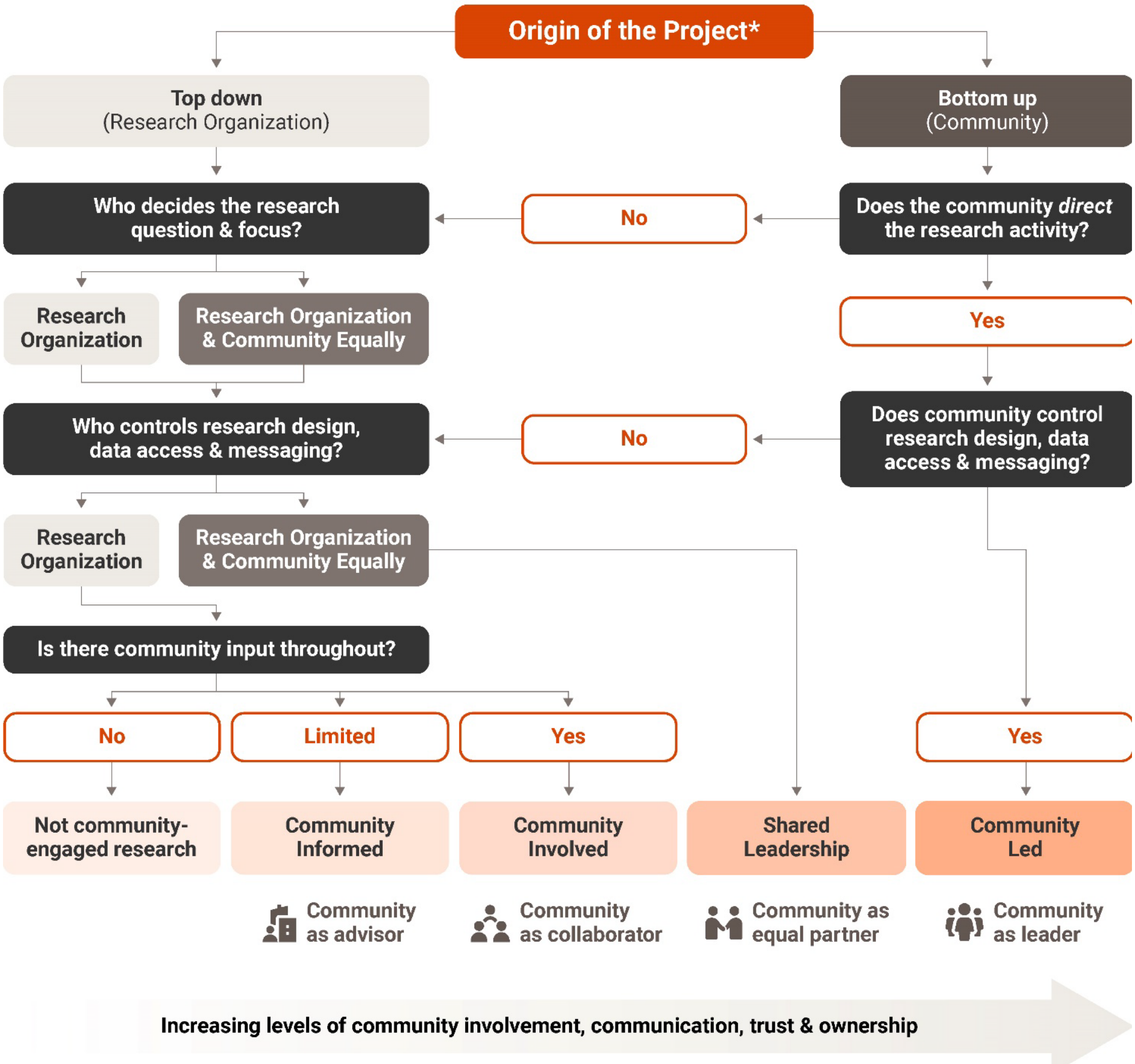
Developing Partnership Agreements

Yale's ERIC CBPR Guidebook includes a process for creating an MOU.

The American Psychological Association Practice Organization developed a guide on writing an MOU with community partners.

TOOL: DECISION TREE

Where Are You on the Engagement Continuum?



*Funders may be the originator of research questions; they are captured in the top-down category.

Developed by James Iveniuk, Petry Ubri, Sabrina Avripas, and Anmol Sanghera as a product of NORC's Research Innovation Projects and Center on Equity Research.

1.3b Implement the governance structure

The governance structure will vary by partner, study, needs, capacity, and available funding and resources. For example, shared leadership structures may name researcher and community co-investigators or establish a steering committee comprised of representatives of each partner while community-involved structures may establish a community advisory board to advise and inform on research efforts. Determine how and at what research phase the study can involve community partners, in line with the community's desired level of involvement. Partnerships or studies may employ varying approaches depending on the phase of research.

RESOURCE

Community Advisory Boards (CABs)

The Urban Institute has a toolkit for planning, forming, and operating a CAB.

The Center for Health Care Strategies developed a report Community Advisory Boards: A Close Look at One Strategy for Engaging MassHealth Members in Program and Policy Decisions.

TOOL: PLANNING FRAMEWORK

Community-Engaged Research Approaches, by Research Phase

Research Phase	Community informed Community as advisor	Community involved Community as collaborator	Shared Leadership Community as equal partner	Community led Community as leader
1: Establish Shared Governance Structure	Researcher-led governance structure. Researchers direct study; community advises (e.g., onetime input, no or limited decision-making control)	Researchers direct study and make final decisions, but have consistent community input, e.g., community advisory board.	Both community and researchers share decision-making authority (e.g., both researcher and community co-principal investigators; steering committee comprised of both researchers and community).	Community drives study, sets timelines, and makes final decisions with some researcher support or input
2: Define and Frame Research Questions and Objectives	Researchers define research questions and objectives with some community input	Researchers define research questions and objectives in collaboration with community	Community and researchers unanimously define research questions and objectives	Community defines research question

Research Phase	Community informed Community as advisor	Community involved Community as collaborator	Shared Leadership Community as equal partner	Community led Community as leader
3: Design Study Methods and Adapt Instrumentation	Researchers define study methods and develop tools with <u>some</u> community input	Community <u>reviews and gives input</u> on data collection strategies, tools; facilitate connections	Community and researchers <u>together</u> determine methods and co-create tools	<u>Community determines</u> approach, creates tools with some researcher review and input
4: Implement the Study and Collect the Data	<u>Researchers</u> conduct data collection	Researchers conduct data collection with <u>help of community</u>	<u>Community members and researchers</u> jointly conduct data collection (or jointly make decisions about who collects data)	<u>Community members</u> conduct data collection (or makes decision about who collects data)
5: Analyze Data and Justify Findings and Conclusions	Researchers develop analysis measures and tools and analyze data with <u>some</u> community input	Researchers analyze data. Community <u>reviews</u> analysis tools, provides context or interpretation of findings	Community <u>participates</u> in data analysis, raises new questions, interprets meaning	Community <u>leads</u> analysis, raises new questions, interprets meaning
6: Ensure Use of Research Findings and Share Lessons Learned	Community members review and provide <u>some</u> feedback to drafts and researchers reconcile the feedback, may <u>advise</u> on dissemination strategies and participate in sharing of results or lessons learned	Community <u>provides feedback and contributes</u> to drafts and interpretation of findings, <u>share ideas on</u> dissemination, are acknowledged in reports, publications, shared panel discussions, presentations, etc.	Community and researchers <u>together</u> develop recommendations, decide best modes for reporting, <u>co-present</u> findings, determine key audiences, share information in their networks, etc.	Community <u>writes reports or develop</u> other materials or approaches for reporting Community <u>decides</u> audience(s); presents findings
7: Foster Sustainability of Partnerships and Research	Community members <u>may</u> take part in other studies in similar roles	Team <u>discusses sustainability of partnership throughout</u> and defines continuing relationships before the study ends	Sustainability is <u>established as part of the shared leadership structure</u>. Team explores continuous collaboration opportunities.	<u>Community decides the needs for sustainability</u> and guides the expansion or continuation of the collaboration with the researchers.

Developed by Petry Ubri, Sabrina Avripas, and Anmol Sanghera as a product of NORC's Research Innovation Projects and Center on Equity Research. Adapted based on the <u>CRE Framework</u> and the <u>Wilder Planning Framework for Involving Community Members in Evaluation</u>.

Phase 2: Define and Frame Research Questions and Objectives

SECTION AT A GLANCE

Strategy 2.1 Understand community needs, strengths, and interests

- 2.1a Conduct an assessment to understand community interests, knowledge, and needs
- 2.1b Affirm community strengths
- 2.1c Practice cultural humility

Strategy 2.2 Develop research questions that reflect the interests, needs, and values of communities

- 2.2a Define research objectives and develop research questions
- 2.2b Reconcile discordance in partner objectives
- 2.2c Garner community buy-in early and often

Strategy 2.3 Identify and collaboratively pursue funding

- 2.3a Identify and apply for funding opportunities

Strategy 2.1 Understand community needs, strengths, and interests

Understanding community needs, strengths, and interests helps define research objectives.

2.1a Conduct an assessment to understand community interests, knowledge, and needs

Understand and acknowledge communities' political and social history, values, and relationships using a community assessment. This includes understanding the historical and contemporary context of the community and partners' mission and research goals. It also includes understanding who makes up the community and their culture, languages, religion, background, and practices, relevant local policies or laws, and past and existing research efforts, initiatives, and partnerships. This is particularly important when working with marginalized or minoritized populations who are often underrepresented in research due to historical and contemporary biases. It is also imperative to avoid harm and not further perpetuate distrust in researchers and systems. When possible, use existing community data to inform context.

Methods for conducting an assessment include:

- **Site Visits:** Visit the community and note observations to better understand the built environment and physical context in which the community functions (if relevant). Talk to community members and community leaders. Attend local community meetings and events.
- **Surveys:** Systematically collect data on community characteristics, perspectives, and input (or review existing data).
- **Interviews and Focus Groups:** Gather in-depth insights of community member perspectives.
- **Windshield and Walking Surveys**: Make systematic observations from a moving vehicle (windshield) or by foot (walking) to get an overview of the community.
- **Document Reviews**: Review existing community documents (e.g., public meeting notes, publications). Review community archives, histories, and material culture based on how local individuals and organizations have record their own stories.

RESOURCES

Understanding Community Needs and Strengths

The CDC developed a workbook for conducting a Community Needs Assessment.

The National Assocation for State Community Serviecs Programs developed a Community Action Guide to Comprehensive Community Needs Assessments.

The Rural Health Information Hub includes resources and tools to Identify Community Needs and Assets.

The Community Tool box includes:

- Developing a Plan for Assessing Local Needs and Resources
- Surveys
  - Conducting Surveys
  - Conducting Needs Assessment Surveys
  - Windshield and Walking Surveys
- Qualitative Research
  - Qualitative Methods to Assess Community Issues
  - Conducting Public Forums and Listening Sessions
  - Conducting Focus Groups
  - Conducting Interviews

TOOL: QUESTIONS TO CONSIDER

Conducting Community Assessments

- How is power distributed in the community? What power differentials exist?
- Which relationships are prioritized? Which ones are discouraged?
- How does the community like to be approached? Who are the gatekeepers and community leaders?
- How do you refer to individuals and community members?
- What are historical and cultural antecedents of the community?

Source: Child Trends: How to Embed a Racial and Ethnic Equity Perspective in Research

2.1b Affirm community strengths

Community-engaged research recognizes the strengths of communities, its members, and its institutions and connects existing resources and relationships to build solutions. Strengths-based approaches put *"the strengths and resources of people, communities, and environments, rather than their problems and pathologies, at the center of the helping process" and emphasize "resilience, resistance, courage, thriving, and ingenuity."*[10] For example, *Positive Marginality*[11] promotes the concept that injustice is rooted in structural determinants rather than personal or community behavior. The idea is that *"belonging to a non-dominant cultural or demographic group can be advantageous rather than oppressive."*[11] Research questions should also acknowledge the ecological context of the topic, with a focus on the importance of structural systems, racism, and other determinants like social, economic, and built environment, and the role of family and social connections.

RESOURCES

Community Assets

The National Center for Farmworker Health, Inc. developed a Community Asset Mapping Guide for community and migrant health centers.

The Preston City Council has a Community Mapping Toolkit.

The Community Tool Box includes resources and tools for:

- SWOT Analysis: Strengths, Weaknesses, Opportunities, and Threats
- Identifying Community Assets and Resources

Examples of ways to identify community strengths include:

- **Community Asset Maps** identify existing services, capacity, programs, resources, and other protective factors within a community. They can provide a snapshot of local demographics and information about the physical, social, and economic environment. They can map both needs and strengths and assets, including the resources and expertise of community organizations.
- **SWOT (Strengths, Weaknesses, Opportunities, Threats) Analysis:** SWOT analysis identifies an organization's or community's weaknesses, threats, strengths and opportunities.

2.1c Practice cultural humility

Cultural humility is the practice of self-evaluation and reflection to examine your own biases, acknowledge and shift power dynamics and imbalances, and held yourself and your organization accountable.[12] This includes humility about one's own expert knowledge, which should be interrogated (although not necessarily discarded) when it comes in conflict with community opinions and insights.

Researchers can:

- Conduct self-reflection, including on their own implicit biases, power, and privilege.
- Ask questions to understand where power interlocks and intersects.
- Take time to understand local ways of knowing. Do not assume that community members produce or consume knowledge through the same means as you.
- Learn from local knowledge-keepers (e.g., community elders) on acceptable cultural practice and epistemologies, as well as for insight on local politics and social structure.

RESOURCES

Practicing Cultural Humility

Project READY's (Re-imagining Equity & Access for Diverse Youth) training module on Cultural Competence & Cultural Humility.

UCSF's Power-Privilege Resource List.

Brandeis' list of tools for Engaging in Self-Reflection.

Strategy 2.2 Develop research questions that reflect the interests, needs, and values of communities

Involve communities in the design of research objectives and questions, reconciling discordance between funder and community objectives, and garnering community buy-in for the work.

2.2a Define research objectives and develop research questions

The origin of the study and its development process often determine the research approach and objectives. Consider what the purpose of the research is for the community. Actively seek community input to ensure that the research represents the values, needs, and interests of the community. Research questions should achieve a balance between research and data for knowledge generation with the need to advance local interests, partnerships, programs, policies, interventions, and services. To understand community needs and preferences, teams can:

- **Engage in intentional dialogue with community partners** around research questions, including through facilitated meetings with CABs or other partners, ranking exercises, consensus building exercises, working sessions, etc.
- **Collect background data on the community** and neighborhood from publicly available datasets, reports, media (see section **2.1a**).

- **Talk to community members** through dialogue, interviews, focus groups, or other approaches to understand their perspectives about the issue.
- **Review documents** related to legislation, policies, and regulations, public meeting notes, publications, and other available documents related to the topic of interest.

TOOL: QUESTIONS TO CONSIDER

Defining Research Objectives

- What value would addressing this topic or issue bring to the community?
- How does the community view the topic? Why? Is this topic of importance to the community? Will understanding more about this topic or issue help the community (e.g., inform development or enhancement of programs, services, policies)? If so, how?
- What language does the community use to discuss the topic?
- Who does the topic affect? Are there some groups in the community that are more affected by the issue than others? Which groups?
- What are the root causes and determinants of the issues? Acknowledge that there may be several and some causes may go beyond the field of influence of the researchers, funders, or community.
- How does the cultural and historical context of the community influence the topic?

Source: Adapted from Child Trends: How to Embed a Racial and Ethnic Equity Perspective in Research

RESOURCE: Root Cause Tree

2.2b Reconcile discordance in partner objectives

Research questions and objectives should stem from community needs, when possible. Researchers should help align their and any funders interests to community needs and integrate these needs into research questions and objectives. Depending on the study's and funder's purpose, teams may need to reconcile research objectives to align across interested parties.

TOOL: QUESTIONS TO CONSIDER

Reconciling Differences in Research Objectives

- Consider who determines the final research objectives based on the type of community-engaged approach and governance structure used in the partnership or study (see **Where are You on the Community Engagement Continuum?** Tool).
- Determine what the purpose of the research is for the community(ies), for the funder(s), and for the research organization(s).
- Determine: Where is there overlap in interests, needs, and values? Where are there differences in framing, perspectives, or focus?

TOOL: QUESTIONS TO CONSIDER

Reconciling Differences in Research Objectives

- Where there are differences:
  - Communicate the importance of the community perspective to the funder and all members of the research term and communicate the interests of the funder and research team to the community
  - Invite the funder and all members of the research team to be part of conversations with communities so they can hear directly from each other, when appropriate
  - Determine where there are priority areas for each party
  - Build consensus around the key questions

2.2c Garner community buy-in early and often

Having community buy-in for the research at the outset will facilitate research efforts and partnership sustainability. The community beyond will need to have a space in which it can openly talk about this topic and its long-term effects.

TOOL: QUESTIONS TO CONSIDER

Garnering Community-Buy In

- **Engage grassroots organizations and key community leaders** (e.g., faith-based organizations, local community centers, advocacy groups, etc.) beyond those actively participating as partners early in the research process to further elucidate community context and build trust. For particularly sensitive issues or in communities with a longer history of experiencing extractive research, grassroots groups and community champions can promote open discussion so the work becomes an ongoing conversation and not a one-time data extraction.
- **Consider sharing one-pagers** of the work and its value for the community, holding 1-1 or small group discussions, or providing other materials organizations may need to share and disseminate with their board, leadership, or networks.
- **Hold community forums and listening sessions** to hear directly from community members. Encourage them share their feedback on the topic, who it affects, and how the work can impact the community. This is also an opportunity for teams to share early iterations and thought processes for the research and provide a timeline for the work. Be honest about what can happen if the work does not come into fruition (e.g., the work is not funded), what challenges the team is experiencing or may experience, and what the team is doing to overcome those challenges. Be ready to respectfully listen if there is pushback or resistance and note how the team is responding to that resistance.
- **Maintain avenues of transparency and continued feedback** for appropriate progress and conversations to occur throughout the study. This may include regular updates at events or meetings or hosting a research website where anyone can find further information about the study, materials, and points of contact.

Strategy 2.3 Identify and collaboratively pursue funding

Ideally, researcher-community partnerships develop prior to preparing a response to a specific funding opportunity. During discussions, teams may develop priority areas or research objectives that may require additional funding.

2.3a Identify and Apply for Funding Opportunities

Both researcher and community partners should track potential funding opportunities or seek out foundations in line with the research topic and with community interests and values. Meet regularly to discuss fit of potential opportunities. Develop a one-pager that lays out the research objectives and value of the work that the team can use to have conversations with potential funders or serve as a basis.

Some researchers and community partners may be working together in response to a specific funding opportunity or announcement. Once teams have identified potential funding opportunities, researchers should work closely with community partners on developing the proposal.

RESOURCES

Applying for Funding

The Research Partnership for Healthy Chicagoland Communities developed a presentation on Community-Engaged Research Funding & Grantwriting Tips and Strategies.

Tufts Clinical and Translational Science Institute developed a Community Members' Guide to Submitting A Community-Engaged Research Federal Grant Application.

The CBPR Hub maintains a resource hub of vetted resources to support community-engaged research projects, including tips and strategies for grant budgets and grant writing.

Phase 3: Design Study Methods and Adapt Instrumentation

SECTION AT A GLANCE

Strategy 3.1 Collaboratively select a study design that is responsive to community context

- 3.1a Select study designs that community partners have found successful
- 3.1b Develop a sampling frame based on community context

Strategy 3.2 Collaboratively develop data collection instruments and protocols

- 3.2a Develop and assess data collection instruments to ensure responsiveness to community culture and norms
- 3.2b Establish protocols that reflect community context
- 3.2c Consider the amount and mode of incentive payments for research participants.

Strategy 3.3 Consider the implications of IRB and informed consent

- 3.3a Develop informed consent processes and forms that are responsive to a group's culture and norms, and accessible to people with different abilities
- 3.3b Develop and submit IRB application.
- 3.3c Develop a data management plan for protecting data and personally identifiable information (PII)

Strategy 3.1 Collaboratively select a study design that is responsive to community context

Consider methods that enable more in-depth understanding of contextual factors that inform people's experiences and include populations often underrepresented in research. This approach may take more time but requires establishing trust and rapport, and meeting community members where they are.

3.1a Select study designs that community partners have found successful

Explore how community partners successfully reach community members and how their resources and methods can enhance the study design. Mixed methods research captures not just the extent of a belief, opinion, or need, but also individual voices, stories, and context to explain nuances and trends. For example:

- **Narrative and storytelling** can provide holistic views of communities and people's lived experience.[13]
- **Photovoice** creates a narrative and documents reality through images.[14–16]
- **Ethnographic studies** collect data through observation and interviews.[17]
- **Social listening** uses social media data to understand how individuals are talking about key topics.[18]
- **Community mapping** provides detailed information about trends within maps.[19]

Each type of design will have its benefits and limitations. Consider the implications of each approach, relative to available resources and time, to determine which is the most appropriate for the study.

TOOL: QUESTIONS TO CONSIDER

Selecting Study Methodologies

- How do communities provide and communicate information?
- How do community members prefer sharing their stories or information? In person? Via paper? Via phone? Online? A mix?
  - What is the digital literacy of the population? Will using web-based approaches exclude key populations that are part of the community?
  - What venues provide sites of congregation for the community? Who is typically included and excluded at these venues? These could be online spaces or physical spaces.
- What kinds of leadership exist in the community, and is the leadership respected by the community at large? Will entry into the community (e.g., for recruitment) be helped or hindered by partnership with specific leaders, depending on their reputation?
- What capacities already exist in the community for partnership on research practices (e.g., are there people who could work with the team on recruitment, and the formulation of

TOOL: QUESTIONS TO CONSIDER

Selecting Study Methodologies

questionnaires, interview guides)? What capacities could be built by the research team that *stay* in the community afterwards, depending on the research design?

- Can the phenomena of interest be studied quantitatively, qualitatively, or both? If you could field a survey in this environment, who would you likely recruit, and would you produce the sample you need?
- What archives exist in the community, either written or oral? That is, what kinds of records do people keep in this community of the experiences of various cohorts past and alive today?
- What kinds of experiences do you want to focus on? Are you seeking a diversity of experiences, or very specific experiences? If diversity, what limitations would you encounter if these diverse peoples were in the same room for a focus group? Or are experiences better captured in individual, one-on-one conversations?

3.1b Develop a sampling frame based on community context

Consider the sampling frame from which the study will draw participants. In addition to probability sampling methods (e.g., random sampling) that achieve representative surveys, consider the inclusivity of populations that are often underrepresented in research. This includes "oversampling" to capture key data about U.S. racial and ethnic groups that are often excluded from or underrepresented in research.[20] Consider the use of nonprobability sampling approaches that reach these populations, such as community-based sampling. Teams will have to work closely with their community partners and statisticians to define an appropriate approach for their study. This requires having strong connections to community partners, building trust, and employing key methods for ensuring privacy of community organizations' and individuals' information. Understand the benefits and implications of each approach in representativeness of the research and potential biases.

RESOURCES

Sampling Considerations

The University of North Carolina has a presentation on Sampling Racial and Ethnic Minorities.

The University of Arkansas and Kansas State University have a presentation on Community-based Sampling Techniques: Leveraging Available Archival Data to Drive Research.

The North Carolina Center for Public Health Preparedness has a Guide to Sampling for Community Health Assessments and Other Projects.

TOOL: APPROACHES TO CONSIDER

Examples of Sampling Approaches

- **Community-based sampling**. This can include both convenience or purposive sampling (e.g., from existing relationships, community partner listservs or membership lists, community events) or more random sampling approaches (e.g., door-to-door surveys).[21,22]
- **Venue-based sampling (VBS)** identifies days and times when the population of interest gathers in specific venues, constructing a sample frame, and randomly selecting and intercepting individuals to gather consent and collect data.[23–25]
- **Respondent-driven sampling (RDS)** or **snowball sampling** where people who participate in the research refer other members in their network or community or based on referrals where a small number of people recruit others with similar characteristics from their network or community.[24,26,27]
- **Hybrid approaches** integrate multiple sampling frame methods to reach community members and optimize the inclusion of often underrepresented groups.

Strategy 3.2 Collaboratively develop data collection instruments and protocols

Factor in cultural context, perform cognitive testing of the instruments with community members, and consider the language needs of the community.

3.2a Develop and assess data collection instruments to ensure responsiveness to community culture and norms

Incorporate questions and measures that acknowledge community strengths. For example, strengths-based questions and measures that assess community competence, resources, promise, and resiliency can better reflect community values and principles while maintaining statistical rigor.[28] Incorporate frameworks that acknowledge community context, and multiple levels of influence and structural factors. For example, the socio-ecologic model acknowledges that individual, interpersonal, organization, community, and societal level factors, and their interaction, affect health.[29]

RESOURCES

Strengths-based Approaches

High 5 Test defines strength-based approaches, principles, and examples: What is a Strength Based Approach?

The National LGBTQIA+ Health Education Center developed Cultural Adaptation of Measures and Tools for Sexual Orientation and Gender Identity (SOGI) Data Collection.

RAND developed the Community Learning and Outreach Toolkit for Countering Anti-Asian Hate.

Consider the language needs of the community and translate data collection instruments and other research materials (e.g., recruitment flyers, study information forms, resource lists). Include resources and time for translating data collection materials into multiple languages reflective of community needs. The number of languages can be determined based on available resources and community needs. The specific translation languages should be informed by the demographic makeup of the community you are trying to reach.

TOOL: APPROACHES TO CONSIDER

Translating Data Collection Instruments

- Work with certified translation vendors to translate data collection instruments and other study materials. Work with community partners to review translations for quality assurance and accessibility. Consider having multiple people review each translation and reconcile feedback to achieve a harmonized instrument.
- Consider whether to build the data collection instrument in a language that is not English. Teams often default to developing data collection instruments in English and then translate into other languages.
- When developing English language instruments and then translating them, reassess the English language version of the instruments to ensure it aligns with any updates and changes made to the translated instrument.

Evaluate and cognitive test data collection instruments. Assess data collection instruments for cultural appropriateness based on the community, either when developing new instruments or using existing, validated instruments.[30] Cognitive test instruments with community members to understand how they interpret questions, instructions, and answer choices (if applicable).

3.2b Establish protocols that reflect community context

Work closely with community-based partners to develop a tailored, culturally responsive approach to data collection and protocols based on the needs and context of the community.

RESOURCES

Evaluating Research Instruments

The Michigan Public Health Institute (MPHI) has a working tool for determining if an evaluation practice is culturally responsive.

The University of Michigan Institute for Social Research has steps for developing a cognitive interviewing protocol. The National Center for Education Statistics (NCES) as a protocol for Adapting Cognitive Interview Techniques for Use in Pretesting Spanish Language Survey Instruments.

TOOL: QUESTIONS TO CONSIDER

Developing Data Collection Protocols

Recruitment

- **Where are you recruiting and how** (e.g., online, social media, phone, from community organizations' networks, individuals' homes [e.g., in person visits or mailings], physical flyers placed around the community)? Where do people gather?
- **Who is doing the recruiting** (e.g., researchers, community partners, other community-based organizations, trusted voices in the community)?
- **When are you recruiting** (e.g., time of day, time of the year)?
- **How inclusive are recruitment materials?** Are recruitment materials in plain language? Are they visually inclusive of diverse populations? Are they accessible to individuals of different capacity (individuals who are deaf, blind or have other physical or developmental disabilities? Are they translated in multiple languages reflective of the community in which the recruitment is taking place?
- **What are community partners' capacity to support with recruitment?** Do they have connections to other CBOs that can help support recruitment?

RESOURCE: The University of Illinois Chicago's Center for Clinical and Translational Science provides sample recruitment materials.

Data Collection

- **Where is the data collection taking place** (e.g., at a research facility, at a community organization, etc.)?
- **How are you facilitating access to participation?** Are you providing support for language, childcare, transportation, etc.?
- **What are community partners' capacity to support data collection?** Do they have staff or other members that can serve as data collectors? Can they refer the team to community members who can serve as data collectors? Do they have access to tablets or other necessary instruments to carry out data collection?

Develop supplemental materials to support community partners and data collectors. This includes job aids, adverse events protocols, troubleshooting guides, recruitment materials (e.g., flyers, social media posts, etc.), and other materials. Developing a list of resources to provide participants, depending on the topic, can help provide participants with additional supports.

3.2c Consider the amount and mode of incentive payments for research participants

Determine the appropriate amount and mode of incentives to encourage participation. Work closely with community partners and with the Institutional Review Board (IRB) to determine the appropriate incentive amounts based on burden estimates, and accessibility of incentives based on the restraints and parameters of the funding. Consider if there are other ways to alleviate the burden of participation for community members in addition to an incentive payment. For example, providing toys, crayons and coloring books, or childcare for participants who have kids (when collecting data in person), providing transportation support (e.g., metro cards, gas cards), and providing access to tablets for individuals to complete web surveys.

TOOL: QUESTIONS TO CONSIDER

Determining Incentives

- **How much are you providing in incentives?** Is the amount sufficient to adequately compensate individuals for their time and commensurate with length of time needed to collect the data? Is the amount compelling individuals to participate only for the compensation?
- What type of incentives are you providing? Each has its pros and cons:
  - **Virtual incentives** (e.g., e-codes or gift cards) can provide faster distribution of funds but can pose challenges for individuals with limited digital access or if they are restricted to specific stores that may not be readily available.
  - **Money or checks** allow participants to use the funds to purchase whatever benefits them. In person, it is easier to provide an envelope with cash. However, sending an individual cash or check via email may create opportunities for money to be lost in the mail or have further need for documentation (e.g., W9 considerations).
- **Who distributes the incentives?** Transferring funds to community partners may make it easier for partners to be more flexible in the mode of incentives they provide. However, it requires establishing systems of tracking incentive payments and ensuring the partners have sufficient funds to cover the cost of incentives.

Strategy 3.3 Consider the implications of IRB and informed consent

Teams should submit IRB applications for review of any data collection and research and develop accessible informed consent forms.

3.3a Develop informed consent processes and forms that are responsive to a group's culture and norms, and accessible to people with different abilities

When developing informed consent, work closely with community partners and the IRB to determine the right level of information to assure research participant comprehension. Consider:

- literacy level of the form (e.g., 4th grade reading level) and whether the consent form is in plain language that is accessible to the community and translated into predominant languages in the community.
- the need for additional supplemental materials (e.g., FAQs) that help reinforce understanding of the informed consent process.
- using additional probes that assess comprehension of the informed consent form, e.g., including open-ended questions that assess understanding of study, having guides or checklists to track the discussion, asking participants to paraphrase or repeat points.

3.3b Develop and submit IRB application

Discuss with community partners whether they need additional IRB review or approval or if they can use a reliance agreement that allows them to rely on your

RESOURCES

Supplemental Materials

The Aultman Health Sciences Library provides tips for Conducting Research Interviews.

Cross-cultural Survey Guidelines includes Interviewer Recruitment, Selection, and Training.

The National Instute of Mental Health has resources for Caring for Your Mental Health.

IRB Resources

The University of Minnesota has an IRB Toolkit Library.

Northwestern has an Observation of the Consent Process Checklist.

The UCSF Office of Ethics and Compliance has a quick guide on how to assess comprehension of informed consent and consenting non-English speakers.

Tribal IRB & Data Sovereignty

The Native American Center for Excellence has Steps for Conducting Research and Evaluation in Native Communities.

The Center for Native Heallh Partnerships and the National Cogress of American Indiancs developed Building Research Relationships with Tribal Communities.

The Partnership for Native American Cancer Prevention developed How to Conduct Research in American Indian and Alaska Native Communities.

The White House released Indigenous Knowledge Guidance for Federal Agencies.

The National Institute of Justice has resources for Embracing Tribal Culture to Build Research Partnerships.

organization's IRB for data collection. Also consider whether community partners have their own IRBs that need to be considered in the research process. For example, some Tribal communities have formal protocols or processes through which non-Tribal individuals wishing to partner on research can approach Tribal leaders, explain their interests and benefits to the tribe, and get permission to engage in the study.[31] When working with community IRBs, build in sufficient time and resources to acquire approval.

3.3c Develop a data management plan for protecting data and personally identifiable information (PII)

Work collaboratively with community partners and IRB to develop a data management plan that documents processes, roles, and responsibilities for data collection, storage, and sharing to ensure protection of PII, if applicable to the study and based on the sensitivity of the content. Ensure systems researcher and community partners work in meet requirements and standards for data security**.** Review external data sharing and storage policy to determine the appropriate system and tools to use for data sharing, storage, and transfer and confirm that they align with specific data management plans and data use agreements that may be in place, including when working with external vendors like transcription companies and vendors.

RESOURCES

Protecting PII

NIH provides best practices for data management. NIH also provides Certificates of Confidentiality (CoC) to protect the privacy of research participants by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research except when the participant consents or in a few other specific situations.

Phase 4: Implement Study and Collect the Data

SECTION AT A GLANCE

4.1 Recruit a community-based workforce for data collection

- 4.1a Identify and recruit community members as data collectors
- 4.1b Train a community-based workforce for data collection

4.2 Implement community-centered data collection protocols

- 4.2a Meet potential participants “where they are” and ensure data collection is appropriate and relevant for the intended group
- 4.2b Provide data collectors with technical assistance and support
- 4.2c Monitor data collection for privacy protections and to track progress
- 4.2d Implement data collection closeout procedures

Strategy 4.1 Recruit a community-based workforce for data collection

Engaging community in data collection helps overcome challenges of trust between researchers and community, increases credibility, minimizes barriers to participation, and helps enhance the capacity of both community partners and researchers.[3,4,32,33]

4.1a Identify and recruit community members as data collectors

Community partners can recommend individuals from the community and from their networks to support data collection efforts. The team can also identify organizations and networks that may have reach into the populations and communities of interest. Prepare recruitment materials (e.g., a one-pager that clearly defines the role of the data collector and expectations, compensation structure, and timeline for engagement). Collaboratively with community partners, establish eligibility requirements and criteria for interviewers and establish a process for interviewing potential data collectors. Community partners should have a key role in defining this role and in the selection of interviewers. When possible, incorporate data collectors early in the process to inform the study design and research questions.

RESOURCES

Engaging People with Lived Experience

The Office for the Assistant Secretary for Planning and Evaluation (ASPE) developed resources for engaging people with lived experience, including:

- Infographic: What is Lived Experience?
- Recruiting Individuals with Lived Experience

4.1b Train a community-based workforce

Establish processes to ensure all members receive adequate training to conduct data collection.

Human subjects research training. Most IRB policies require that anyone who will have a significant role in the conduct of a study that is human subjects research (including individuals overseeing the study, interacting with research participants, or analyzing data that contain PII) complete human subjects protection training.

Community partners may have varying levels of experience with research methods and practices. Many of the standard human subject research training programs are designed for professionally trained researchers with an extensive understanding of research methods and practices. They are not geared towards the nuances and understanding of community-engaged research. As such, community partners may consider these training programs to be dense and not culturally sensitive. Consider options for human subjects training that are designed specifically for community partners and not only for researchers. Which training program to use should be determined in conjunction with the IRB.

Study-specific training. Develop and conduct study-specific training with all members of the team involved in data collection and analysis and interacting with research participants. Consider:

- the appropriate length (e.g., full day, across multiple days), mode (e.g., in-person, virtual), type (e.g., live training, self-completed modules), timing (e.g., only before or throughout data collection, considerations for holidays, etc.), and accessibility and language needs.
- incorporating adult learning principles[34] into training and processes for interviewers needing additional support (e.g., office hours, supplemental training). Training should include sufficient time for role play and practice.
- whether there may be a need for additional site-specific training or protocol adaptations to fit the unique needs or workflow of their organization.

Clearly communicate expectations for completion of training and certification at the outset (e.g., number of hours of training requirement, any assessment or certification requirements). Provide a certificate of completion of training or other forms of acknowledgment of the learnings gained throughout the training process. Work closely with community partners to review the training for accessibility.

RESOURCES

Human Subjects Research Training

The U.S. Department of Health and Human Services has a Human Research Protection Training.

The Collaborative Institutional Training Initiative (CITI Program) has a Trusted Standard in Research, Ethics, Compliance, and Safety Training.

The following organizations have community-based research trainings:

- The All of Us Research Program has a Citizen Science Training with modules on Citizen Science, data literacy, and contributing to citizen science projects.
- The UIC Center for Clinical and Translational Science has a CIRTification: Community Involvement in Research Training available in English and Spanish and designed especially for community partners.

TOOL: QUESTIONS TO CONSIDER

Study-Specific Training

Consider including the following modules in study-specific training:

- Overview of the research and topic area
- Context of the community in which the work is taking place, e.g., community history, culture, and broader political and social context, power structures, norms and values, prior studies and research efforts, and administrative and management skills
- Detailed walk-though of the data collection protocol, including site-specific processes or protocol adaptations
- Best practices and techniques for data collection (e.g., interviewing, gaining cooperation, listening intently and collecting credible evidence, cultural responsiveness in interacting with research participants)

TOOL: QUESTIONS TO CONSIDER

Study-Specific Training

- Processes for adverse events reporting, if applicable
- Administrative protocols for handoff between recruitment and interviewing, input of data, follow up, and expectations and cadence for reporting
- Technology training if using tablets, online website, survey software, etc. for data input
- How to reduce power differentials and dynamics
- How to look for and interpret both verbal and nonverbal cues, challenge personal assumptions and biases, take note of behavioral or verbal nuances

Prepare for data collection and design the protocol and training, including promoting cultural sensitivity when interviewing or engaging with a research participant.

TOOL: QUESTIONS TO CONSIDER

Cultural Sensitivity in Training

When data collectors interact with community members to collect data and in general, it is important to acknowledge local community context and culture and to engage with participants in a culturally responsive way. It may be helpful for researchers to work with community partners to identify key strategies for engaging with community members during data collection. Consider the following:

- How do community organizations/community leaders engage with clients and community members? What approaches can data collectors use when engaging with community members?
- What are things a data collector should do or acknowledge when engaging with participants in data collection? What are some things they should NOT do?
- How have past and recent social or political events (e.g., COVID-19, recent national, state, and local level policies) impacted the community? Are there related circumstances that data collectors should keep in mind when talking to individuals from the community? When developing supplemental materials or providing resources to the community?
- What are some of the key cultural differences or cultural nuances that data collectors should keep in mind during the data collection process?

Strategy 4.2 Implement community-centered data collection protocols

Work with the community-based workforce to implement the data collection protocols. Throughout data collection, teams should be available to data collectors for support and technical assistance and to troubleshoot issues and concerns.

4.2a Meet potential participants "where they are" and ensure data collection is appropriate and relevant for the intended group

Recruiting research participants who are reflective of the demographics of the community and who are often underrepresented in research requires intentional efforts and culturally responsive practices. A community may have a history of abuse, discrimination, or misrepresentation in research that contributes to distrust of research processes and institutions. When recruiting potential research participants:

- be flexible and include approaches that meet community members "where they are." Make efforts to literally meet research participants "where they are" (e.g., based on literacy levels, in places where individuals are likely to congregate, in languages community members speak, in the modes preferred by individuals).
- coordinate with trusted community-based partners to place research touchpoints (e.g., data collectors, survey distributions, etc.) along public transport routes, in grocery store parking lots, or other places that groups congregate.

RESOURCES

Best Practices for Reaching Specific Communities

Child Trends Hispanic Institute and the Crimsonbridge Foundation developed a guide for Reaching and Engaging with Hispanic Communities: A Research-Informed Communication Guide for Nonprofits, Policymakers, and Funders

The HHS Office of Minority Health developed the Community Engagement Resource Guide: Advancing Equity for Asian American, Native Hawaiian, and Pacific Islander (AA and NH/PI) Communities in COVID-19 Response Efforts.

4.2b Provide data collectors with technical assistance and support

To support data collectors:

- **Identify clear points of contact and methods for communication.** Create a study email inbox and number that multiple members of the team have access to for troubleshooting questions and sending study materials. Delineate roles and protocols for responding to questions and for data collector needs outside of business hours (e.g., evenings, weekends, and holidays), and establish alterative points of contact when main points of contact are not available.
- **Develop troubleshooting protocols** that are accessible and readily available to use as needed. Consider including frequently asked questions and study contact information.
- **Establish back up technology and other supports (**e.g., tablets, incentives) in case of technology malfunction or issues during implementation.
- **Establish processes and platforms for sharing best practices across data collection teams**. This can include regular cross-site meetings for peer-to-peer learning and establishing platforms for data sharing so all partners have access to the latest materials.

4.2c Monitor data collection for privacy protection and to track progress

Monitor progress towards achieving data collection goals. This may include:

- Having regular check-ins and reporting of progress. Use and review tracking documentation and share monitoring reports and progress with community partners on an ongoing basis to keep all parties informed of progress. Continuously discuss and reinforce the importance of data monitoring and reasons for needing to ensure data quality.
- Developing and implementing quality assurance processes to ensure the collected data is systematic.
- Reviewing and updating troubleshooting processes as needed (e.g., points of contact for questions and for reporting of adverse events, having study inbox and phone number, updating FAQs, etc.).
- Supporting partner needs with reporting progress updates to other community partners.

Monitor data privacy protocols**.** Touch base regularly with data collectors about data storage. Store PII needed for recruitment, scheduling, or incentive payment separate from respondent data to ensure privacy. When using RDS or snowball sampling, provide participants with code words to offer to referrals rather than linking the referral to a participant's name or contact information. De-identify transcripts as needed and follow IRB and data management protocols for saving audio or video recordings, transcripts, or survey responses. When physical data storage is needed (e.g., of paper-based surveys), ensure that community partners have access to locked and secure file cabinets or storage units. Provide community partners with small, locked safes they can use for data storage if they lack access to their own. If data are particularly sensitive, work with community partners to establish additional protections to ensure all individuals interacting with the research and data sign non-disclosure agreements (NDAs) or memos of understanding.

4.2d Implement data collection closeout procedures

Work with community partners to establish processes to close out data collection per study requirements, e.g., data closeout instructions, checklist documentation. Debrief with data collectors and community partners to discuss the experience, challenges, successes, and lessons learned to improve future research efforts for both researchers and community partners.

TOOL: QUESTIONS TO CONSIDER

Debriefing from Data Collection

- Knowing what you know now, what would you have wanted to be trained on? What parts of the training were most and least valuable to you? Were there any training topics you'd like to have covered more or less thoroughly?
- What worked well and what didn't work well about [gaining cooperation; recruitment; data collection process; data storage; data reporting; paying incentives]? If we did the study again, what else should be considered?
- What were the pros and cons of conducting this study using [study approach]? What were considerations for specific populations?
- To what extent were [job aids; participant resources; adverse event protocols; useful? What was missing that would have been helpful?
- What surprised you about the process? What was the best part and what was the hardest part about working on this study? What made you a successful [interviewer/data collector/recruiter]?
- What would you like to see happen with the results of this data collection?
- Overall, what has this study meant for your community?

Phase 5: Analyze Data and Justify Findings and Conclusions

SECTION AT A GLANCE

5.1 Conduct participatory analysis and data interpretation

- 5.1a Analyze data in partnership with community members and partners
- 5.1b Where possible, disaggregate data

5.2 Promote community ownership of its own data

- 5.2a Early on, have discussions to determine who will own the study data

Strategy 5.1 Conduct participatory analysis and data interpretation

Participatory analysis integrates study participants and community members into the analytic process to ensure their community voices are heard when making judgments about findings. Participatory analysis 1) ensures better interpretability of results within community context, 2) sustains engagement with community members throughout the full research process, 3) creates buy-in for later implementation of findings, 4) increases audience's ownership of the data, 5) helps develop more realistic recommendations, and 6) identifies what other day may still be needed. Sensemaking gives meaning to data based on people's lived experience to highlight cultural, structural, and contextual factors.[17]

5.1a Analyze data in partnership with community members and partners

Throughout the analysis and sensemaking process, engage community partners in data analysis activities to identify which findings are most meaningful. Facilitate workshops and working sessions where community members code, categorize data, and develop themes in partnership with researchers. Conduct sessions where teams discuss findings and interpret results within community context.

RESOURCES

Participatory Analysis

The Office of Planning, Research, and Evaluation has a guide for Culturally Responsive and Equitable Data Parties: A Method for Participatory Analysis and Sense-Making in Virtual Spaces

The UNC North Carolina Translational and Clinical Sciences Institute has a TraCS CaSE program published Data Party Planning Guide

Depict Data Studio developed Data Placemats: A 3-Step Process for Increasing Data Use

The Urban Institute developed Data Walks: An Innovative Way to Share Data with Communities

Evergreen Data has tools for data engagement

Public Profit developed Dabbling in the Data: A Hands-On Guide to Participatory Data Analysis

The Brown School Evaluation Center developed a guide to Virtual Data Parties

Learning for Action has facilitation guidelines for Participatory Analysis

TOOL: QUESTIONS TO CONSIDER

Participatory Analysis

When conducting participatory analysis, consider:

- **Who will be involved in participatory analysis?** Participatory analysis can include members of a community advisory board, a subset of study participants, community data collectors, and others in the community both involved and not involved in data collection.
- **What data will be included in the participatory analysis approach?** Analysis may include the full set of data, preliminary data or findings, a subset of findings, or may occur at several stages to facilitate interpretation of:
  - general preliminary findings
  - full general findings
  - findings for a subset of groups or locations

  In all approaches, researchers should make adjustments to interpretation and analysis based on community input.
- **What approach will the analysis approach take?** There are many ways to conduct participatory analysis, including data parties. Choose an approach that aligns with the goals of the study and the preferences of community partners.
- **Ask community members:**[35]
  - What is the data telling you? What is missing from the data?
  - What surprises you about the data? What stands out for you?
  - What do you think is occurring here and why? What other meanings do you see in the data?
  - What is one step we should take based on this data?
  - How might we best communicate these findings?
  - How do community interpretations differ from researcher interpretations? Why?
  - What are the next steps for the data?
  - What questions should we ask about the data?

5.1b Where possible, disaggregate data

Conduct analyses that can reveal and highlight specific differences that may exist for some individuals and groups within particular contexts. Conduct data disaggregation by key demographics (e.g., race and ethnicity, other factors) to uncover differences within groups. This includes ensuring the methods of measurement selected for the study can best serve the purpose of providing multiple ways of measuring key concepts, the study design allows for sufficient sample size for data disaggregation, and that community partners are key voices informing the research process.[36,37]

RESOURCES

Data Disaggregation

The Association of Asian Pacific Community Health Organization's Data Disaggregation Principles, Promising Practices, and Lessons Learned to Advance Health Equity

PolicyLink has several resources for Making the Case for Data Disaggregation to Advance a Culture of Health

The UCLA Center for Health Policy Research has workshops on advancing health equity through data disaggregation and mitigating disclosure risk in disaggregated racial/ethnic data

TOOL: QUESTIONS TO CONSIDER

Data Analysis

- Who is conducting the analysis? In what form?
- What are the potential cultural implications of the data analysis approach?
- Is it possible to disaggregate data by race and ethnicity? If so, how? Is it possible to disaggregate data at the community level without risking the privacy of research participants?
- Is it possible to disaggregate the data by other factors that shape experiences (e.g., nativity, county of origin, citizen or immigration status, gender, neighborhood, positions of power, socioeconomic status)?
- Who is your comparison or reference group? Why is this the reference group?
- What are the biases in the way primary data was collected? In the way secondary data was collected?
- Why are trends occurring?

Strategy 5.2 Promote community ownership of its own data

Work with community partners to determine who owns the data stemming from the research and promote community ownership of its own data.

5.2a Early on, have discussions to determine who will own the study data

When working with non-community-based funders who are likely to want sole ownership over the data, have early discussions with both the funder and communities about what it would be helpful to provide back to the community and why. While funders may not grant access to data ownership, they may consider other approaches in collaboration with communities, including providing community-level data; providing infographics and other easily interpretable findings and results; working with communities to identify variables and analysis of interests, and providing back data tables based on those interests. Set up expectations for data ownership and use in partnership agreements.

RESOURCES

Community Ownership of Data

GWI provides information on Civic Data Trusts – What are They and Why, and how they promote community ownership of data about a city.

The Urban Indian Health Institute provides a toolkit and guidebook for Decolonizing Data.

The Engagement, Governance, Access, and Protection (EGAP Framework) outlines guiding principles for rights of communities to access their collective data.

The Build Healthy Places Network has resources for Shifting Power to Communities through Data.

Phase 6: Ensure Use of Research Findings and Share Lessons Learned

SECTION AT A GLANCE

Strategy 6.1 Tailor dissemination of findings to community needs

- 6.1a Collaboratively determine key audiences and dissemination approaches
- 6.1b Tailor dissemination products to community context
- 6.1c Develop feedback mechanisms to share data back to communities under inquiry

Strategy 6.2 Use inclusive language in reporting

- 6.2a Words matter so be intentional about carefully selecting language

Strategy 6.1 Tailor dissemination of findings to community needs

Research teams should engage in conversations with community partners early and often to define dissemination strategies that meet community needs.

6.1a Collaboratively determine key audiences and dissemination approaches

Include dissemination back to the community in the scope of work and in partnership agreements. Have conversations with funders at study outset (and as part of the proposal response when possible) to set expectations about community needs for the data and how to share data back with the community. At study outset and over the course of the study period, research teams should have conversations with community partners about dissemination of research updates and findings back to the community.

RESOURCES

Dissemination of Findings

The University of Minnesota developed a Community-Centered Dissemination Toolkit

The Stanford Our Voice Initiative developed a Dissemination in Community-Engaged Research: Guidelines for Practice

The CDC provided guidance on Dissemination as Dialogue: Building Trust and Sharing Research Findings Through Community Engagement

NORC developed a brief highlighting Translating Research into Practice: Using Women's Health Needs Study Data to Inform Local Community-Based Efforts

6.1b Tailor dissemination products to community context

It is important to consider dissemination products beyond academic publications and reports. Communities may benefit instead from fact sheets, infographics, community events, webinars, or other types of dissemination approaches. Research teams should work closely with community partners to tailor the dissemination of study results to the needs of the community, including in type and format of the product, language, accessibility, forum, etc. Ensure that any recommendations included in reporting of findings are generated through an inclusive process that involves community members. Highlight the role of community involvement in the research in all reporting.

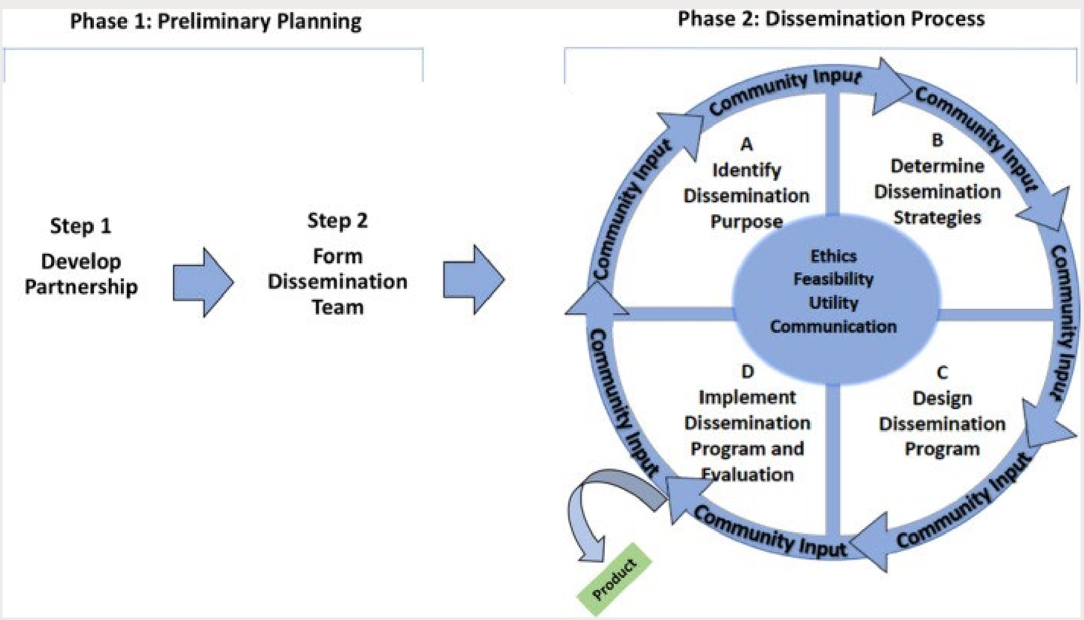
TOOL: QUESTIONS TO CONSIDER

Dissemination

When conducting participatory analysis plan development, consider and have discussions on the following:

- Who are the key audiences for dissemination of research findings?
- What is the best mechanism for dissemination? How does the community like to receive data and information?
- What are the key mediums for data dissemination (e.g., in-person events, data walks, infographics, local events of forums, local media)
- What type of information is most useful to community partners and community members?
- When is the best time to release results to the communities? Are there considerations around specific programs, initiatives, or policies that teams should keep in mind?
- Who are the right people to do the sharing of results back with the community?

In addition, Cunningham-Erves et al developed a Community-Engaged Research Dissemination (CERD) Framework for Research Findings:[36]



Source: Cunningham-Erves J, Mayo-Gamble T, Vaughn Y, et al. Engagement of community stakeholders to develop a framework to guide research dissemination to communities. Health Expectations. 2020;23(4):958-968. doi:10.1111/hex.13076

6.1c Develop feedback mechanisms to share data back to communities under inquiry

Collaborate with community partners to understand their data needs to ensure that the data being collected can inform community-level activities and interventions. This may include sharing raw data files or topline results of data analysis. Provide community-level data back to the community, including sub-analyses of interest to the community (e.g., by specific variables or crosstabs). Ensure that any recommendations included in reporting of findings are generated through an inclusive process that involves community members. Adequately explain the limitations of the research, data, and findings.

Strategy 6.2 Use inclusive language in reporting

Using inclusive language in reporting ensures that everyone who was part of the research feels included and respected, and helps avoid stereotypes and biases.

6.2a Words matter so be intentional about carefully selecting language

Consider the role of language in how results and data are presented and communicated back to community members, policymakers, academics, non-community-based funders, and other audiences. Use person-first and inclusive language in reporting. Ensure the language used to explain the findings acknowledges the structural issues contributing to individuals' behaviors or experiences by providing contextual information that explains the data.

RESOURCES

Inclusive Language

APA has the following resources:

- Bias-Free Language guide
- Inclusive Language Guide

The CDC developed the following inclusive language resources:

- Preferred Terms for Select Population Groups & Communities | Gateway to Health Communication | CDC
- Health Equity Guiding Principles for Inclusive Communication

The Center for Racial Justice Innovation developed a Race Reporting Guide

Racial Equity Tools provides a glossary

The Indigenous Journalists Association provides Reporting Guides

Phase 7: Foster Sustainability of Partnerships and Research

SECTION AT A GLANCE

Strategy 7.1 Establish group norms for sustainability at study outset

- 7.1a Create rules for research conduct that advance sustainability
- 7.1b Regularly discuss strategies and avenues for sustainability with community partners
- 7.1c Share resources that may be of interest to community members and partners
- 7.1d Engage with partners outside of a specific study or topic area

Strategy 7.2 Track funding opportunities for additional partnership

- 7.2a Maintain processes for identifying funding opportunities beyond the end of the study
- 7.2b Seek collaborative opportunities for moving forward recommendations and findings from the study

Strategy 7.1 Establish group norms for sustainability at study outset

Sustaining relationships with community partners can include an explicit intention to establish group norms that maintain connections beyond a project period or more information channels of engaging with community partners.

7.1a Create group norms for research conduct that advance sustainability

Create structures that nurture sustainability, including “group norms” or formal memorandums that lay out expectations for the partnership, not just during the study but beyond. See Section 1.2c for information on MOUs. This can include having “group rules” or formal memorandums that lay out expectations for research team and community roles and relationship. Group norms should address processes and strategies for addressing changes in team members, changes in or loss of funding, or changes in the scope of activities or research efforts. When possible, ensuring the long-standing presence of partners and team members could promote sustainability and serve as a stabilizing foundation for the partnership.[37] However, partnerships should maintain processes and flexibility for expanding or growing the partnership structure and its composition over time as the partnership and research efforts evolve.[37] Establishing collective principles that each partner commits to and agrees with helps establish expectations for partners and team members and provide a foundation for the partnership. Communicate frequently and openly with all partners.

TOOL: QUESTIONS TO CONSIDER

Partnership Sustainability[37]

- To what extent do we consider ways to develop and sustain relationships among the partners including orienting new partners and recognizing departing partners?
- To what extent and in what ways would the partnership continue if funding were no longer available?
- If the partnership ended, how could members of the partnership continue to work together?
- What abilities or resources have been gained through the partnership that would facilitate partners to engage in community-engaged research efforts after the formal partnership is over? This might involve things like knowledge, skills, networks, funding, or organizational capabilities that would support sustainment of the research efforts.
- How should unanticipated changes (e.g., transitions in group membership, loss of funding) be handled that might threaten the work of the partnership?

Source: Paul Chandanabhumma P, Gabrysiak A, Brush BL, et al. *Cultivating an Ecosystem: A Qualitative Exploration of Sustainability in Long-Standing Community-Based Participatory Research (CBPR) Partnerships*.

7.1b Regularly discuss strategies and avenues for sustainability with community partners

Meet regularly about not just research-related communications but also opportunities to continue to get to know each other and build rapport. Establish ways to keep communication channels open between partners to continue to build trust and rapport and find additional opportunities to collaborate. Evaluate the partnership or research effort and use lessons learned to inform future efforts and adapt existing strategies.

7.1c Share resources that may be of interest to community members and partners.

Share resources and materials of potential interest with each other, regardless of if they are related to the research efforts or study. This can help support community members and researchers continued learning and capacity building. Consider whether there are additional opportunities for mutual capacity building and co-learning, including outside of the study period. Enhancing the capacity of all partners and team members can help promote sustainability of the partnership.[37] This includes identifying and securing diverse resources to support the activities, research, and work of the partnership, capacity-bridging activities that enhance skills, expertise, and visibility of each partner, and advocating for the needs of partners to institutions, funders, and policymakers.[37] Continue to ask what would be helpful or valuable. For example, study letters of support or recommendation, certificates of completion of training, or support with their resume building may be helpful for community members and partners engaged in the research.

RESOURCES

Fostering Sustainability of Partnerships

Community Toolbox has several toolkits to promote sustainability of efforts and partnerships:

- Building and Sustaining Relationships
- Applying for Grants
- Evaluating the Initiative
- Sustaining the Work or Initiative
- Influencing Policy Development
- Advocating for Change

FSG has a toolkit for Sustaining and Scaling Health Equity Impact.

Recommend ways to work together on other studies. Engage in discussions about expertise and offer each other unique skills and resources, whether they are related to the study or research effort.[38] Offer and listen to ideas of how each partner can help each other (e.g., applying for funding, supporting dissemination of materials and resources, etc.).[38]

7.1d Engage with partners outside of the research context

Fostering meaningful connections that extend beyond the research can also help promote sustainability of partnerships. Researchers and community partners can engage outside of a specific study or topic area. Hold check-ins with community that include communication about the study, but also to build and maintain effective relationships after the study ends.[37] Attend local events and community forums, conduct trainings, or invite each other to webinars or lunch and learns (as participants or presenters). Discuss areas of interest and assess opportunities for collaboration on other topics and in other similar communities.

Strategy 7.2 Track funding opportunities for additional partnership

Sustainability of partnerships can continue beyond that of a specific study or research effort. Often, relationships with community partners end when a study ends, often due to lack of funding. Researcher-community partnerships should ideally extend beyond a single study. Partners can continue to work together towards mutual goals or a collective vision. See Section 2.3 for additional information on funding.

7.2a Maintain processes for identifying funding opportunities beyond the end of the study.

Partners can seek opportunities to secure resources to sustain a "partnership core" as opposed to or in addition to securing funding and resources for specific research efforts. Partnerships should maintain a list of organizations or funders that support community-engaged research, or that provided funding related to their areas of interest and need. Partners can support each other in identifying webinars, workshops, resources, and other opportunities to enhance skills related to seeking and applying for funding opportunities.

7.2b Seek collaborative opportunities for moving forward recommendations and findings from the study.

Include community recommendations in the final report and ideas for future research or funding and discuss strategies and ways to actively work towards implementing those recommendations. This includes opportunities to disseminate the results, work with policymakers, or other ways to support communities. Monitor other funding opportunities that may expand the partnership and share relevant funding opportunities with community partners to consider.

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