

Appendix C: Participant Materials

MODULE 1 HANDOUT: CASE STUDY OF CBPR



CASE STUDY EXERCISE

The National Institute of Environmental Health Sciences has announced a request for proposals (RFP) for community-based participatory research (CBPR) projects focusing on reducing environmental contributors to excess risk. The announcement states that “increasingly, environmental exposures are being linked to a wide variety of serious health problems in the US, with some communities experiencing higher exposures to environmental toxins and pollutants with adverse effects on health.” The RFP objectives specify the establishment of evidence-based CBPR interventions to reduce pollutants and/or reduce adverse health effects in communities facing disproportionate risk. The RFP requires a research design and outcome measures. It also requires that applicants demonstrate that they have established a community-academic partnership. Successful projects will be funded at a maximum total award amount of \$2 million and can last for up to five years. As researchers, public health practitioners, and community-based organization representatives you are very interested in addressing issues of environmental health in communities experiencing excess risk. While you have some experience working together on outreach and engagement efforts, you have not worked together as a partnership using a CBPR approach. You work in an area that includes several distinct low-income communities of color which have a strong sense of identity. You know from state health department data that almost all of these low-income communities have higher rates of mortality and morbidity that have been linked to environmental exposures, compared to the state overall.

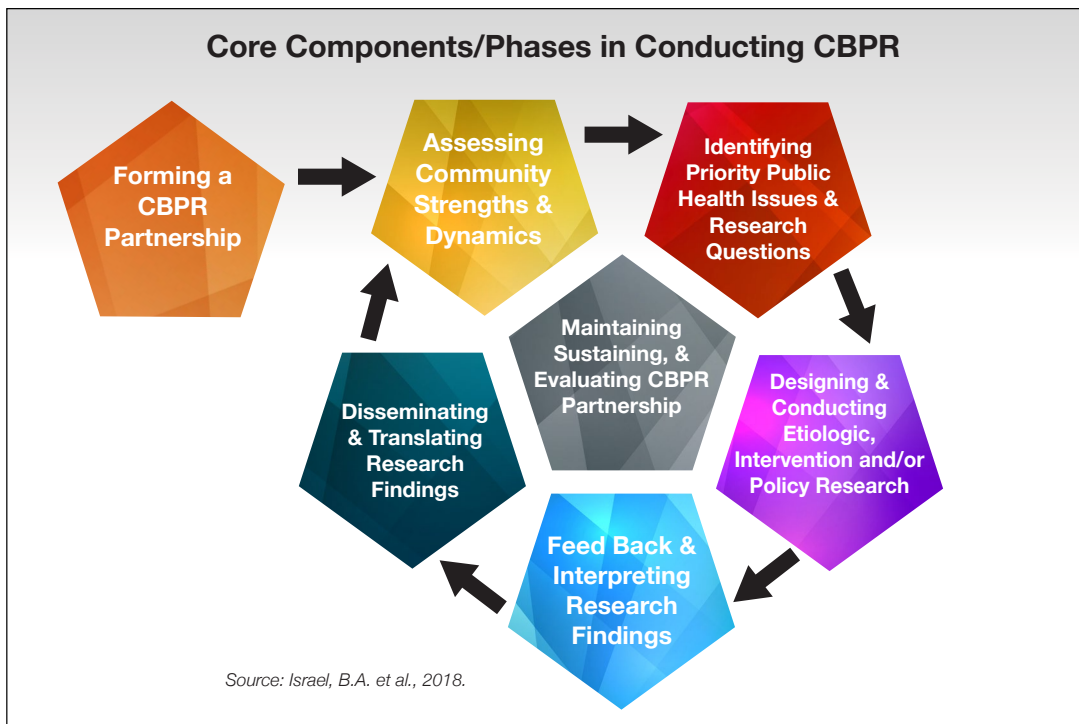
Your group decides that it wants to develop a CBPR proposal for this NIEHS funding opportunity, which is due in two months. Please discuss the following questions as you embark on your planning for this proposal:

Questions for discussion:

1. Who should be invited to partner on this grant application, and why (e.g., what academic departments, community-based organizations, government agencies, others)?
2. Who decides who is invited?
3. Is membership made up of individuals or organizations or both? What are the pluses and minuses of each?
4. How is “community” defined and who is able to “represent” the community (e.g., in terms of class, gender, race/ethnicity)?

MODULE 1 HANDOUT: CBPR PARTNERSHIP DEVELOPMENT WORKSHEET

The purpose of the Partnership Development Worksheet is to assist in setting goals and tracking the progress of your partnership as it develops. Each partnership team will use this document differently given that they are at different points in the development process. For example, some teams may only use select sections or may complete sections in non-sequential order. The worksheet is organized by seven core components or phases of CBPR partnership development as shown in the image below. We recommend that as a team you review this worksheet and fill out relevant sections periodically to assist in planning your strategies/activities as well as documenting your progress. Please keep in mind that this is a cyclical process, and that all of the specific phases/strategies listed may not be appropriate for all partnerships - recognizing that there is no “one way” to do CBPR. You may also find that there are other strategies/activities that you completed in addition to those listed on this worksheet – please insert accordingly.



Form a CBPR Partnership

- Identify potential partners
- Select mutually defined goals and objectives
- Jointly (community and academic) establish guiding principles for the partnership

- CBPR principles for partnership
- Operating norms
- Mission statement
- Ownership and use of data
- By-laws
- Determine an organizational structure including
 - Decision-making body
 - Group membership criteria
 - Affiliated projects
 - Staff roles and responsibilities
 - Develop group processes that put CBPR principles into practice such as
 - Equitable participation of members
 - Confidentiality
 - Shared leadership and power
 - Trust and relationship building
 - Decision making processes
 - Conflict resolution
 - Equitable sharing of resources
 - Communications
- Other?

Maintain, Sustain and Evaluate CBPR Partnerships

- Create a process for selecting and orienting new partners
- Create processes that sustain the partnership including
 - Processes that sustain relationships and commitments among partners
 - Processes that sustain knowledge, values and capacity
 - Processes that sustain funding, staff and programming
- Develop a process for regular and ongoing evaluation that involves all partnership members and incorporates regular feedback to the group. Consider the following when developing the process
 - Determine who should develop and carry out the evaluation
 - Clarify program objectives and goals
 - Establish overall plan and timeline for evaluation activities
 - Develop evaluation questions and indicators of success
 - Develop data collection methods
 - Conduct evaluation (e.g., conduct in-depth interviews, survey questionnaires, documentation)
 - Analyze evaluation data
 - Create process within the partnership to feedback and interpret evaluation results
 - Incorporate changes to the partnership based on evaluation results
- Other?

Assess Community Strengths and Dynamics

- Define the “community” by exploring all dimensions of the community including:
 - Historical
 - Physical/geographical
 - Demographic
 - Social
 - Cultural

- Political
- Economic
- Identify key community partners. Consider including the following:
 - Stakeholders, both beneficiaries of the work of the partnership and those otherwise affected by it
 - Opinion leaders/influential people within the community
 - Policy makers
 - Members of the community-at-large
 - Organizations that are influential/highly regarded in the community (e.g., community-based organizations, faith-based organizations)
- Assess the history of research conducted in the community
- Gather information on community assets, strengths, and resources. These may include:
 - Persons living within the community
 - Businesses
 - Non-profit and community organizations
 - A physical structure or place
 - Social networks
- Identify systems of power within the community
- Other?

Identify Priority Local Health Concerns and Research Questions

- Select and use methods for gathering information to prioritize community local health concerns, such as:
 - Use existing data
 - Listening sessions and public forums
 - Interviews
 - Focus groups
 - Direct and participant observation
 - Surveys
 - Asset mapping
- Identify and apply criteria for prioritizing a health concern as the focus of a project. Consider the following questions:
 - Is the issue significant enough to the community that members will want to address it?
 - Does the partnership have expertise in this area?
 - Would the partnership be able to achieve measurable change?
 - Is the issue important to a broad range of community members?
 - Will this issue help move the community toward its overall vision of a healthy community?
- Engage a representative and diverse group of community members in prioritizing health concerns
- Create a participatory process for determining priority health concerns
- Other?

Design and Conduct CBPR

- Create a structure for carrying out research including overall decision-making body and committees/working groups
- Ensure that both academic and community partners receive training in responsible and ethical conduct of research
- Obtain Institutional Review Board (IRB) approval for research project
- Determine theoretical framework

- Identify research questions
- Determine research design
- Determine and conduct data collection methods, such as:
 - Mixed methods design
 - Surveys
 - Focus groups
 - In-depth interviews
 - Observational data
 - Biomarker data
 - Exposure assessment data
 - Others?
- Develop measures and instruments
- Train and involve community members as data collectors
- Tailor language and data collection procedures to the local culture and community context
- Recruit participants
- Ensure informed consent and protections for research participants
 - Provide training for those collecting data
- Provide a community site for data collection, if relevant (e.g., for biomarker sampling)
- Other?

Feed Back and Interpret the Research Findings within the Partnership

- Develop procedures for feeding back results to the partnership
- Share analysis of findings
- Involve and engage partners equitably in evaluation, discussion and interpretation of findings
- Other?

Disseminate and Translate the Research Findings

- Create dissemination guidelines, including, for example:
 - Authorship/co-authorship: determine who disseminates results, that is, the role of community and academic partners in publishing the results
 - Develop procedures for determining representation at conferences and meetings
 - Develop protocol for how to respond to requests for information
 - Determine procedures for requests for use of data
- Determine what information is the most important to share with the community, such as:
 - Key findings
 - Conceptual framework
 - Process
 - Reflections/lessons learned
- Determine the audience for dissemination, such as:
 - Community members
 - Academic community
 - Participants
 - Key stakeholders
 - Policy makers
 - Others?
- Consider the mechanisms to disseminate findings, such as:
 - Fact sheets

- Individualized feedback
- Community forums
- Press releases
- Reports
- e-Newsletters
- Social media
- Determine where to disseminate information, such as:
 - Websites
 - Local news media
 - Popular press
 - Academic Journals
- Develop dissemination materials with input and feedback from community and academic partners
- Develop plan and distribute dissemination materials to relevant audiences using most appropriate media
- Other?

MODULE 2 HANDOUT: QUESTIONS TO ASK BEFORE GETTING INVOLVED



Is this Community-Based Participatory Research?

- Who chose the problem to be studied?
- Is there an intervention or policy change component?
- Who designed the intervention/policy change?
- Who made the research design decisions?
- Who writes papers/makes presentations?
- Where are the results communicated?
- To what extent are resources shared?

Questions to Consider before Getting Involved in a Research Project

Questions to ask about a potential research partner

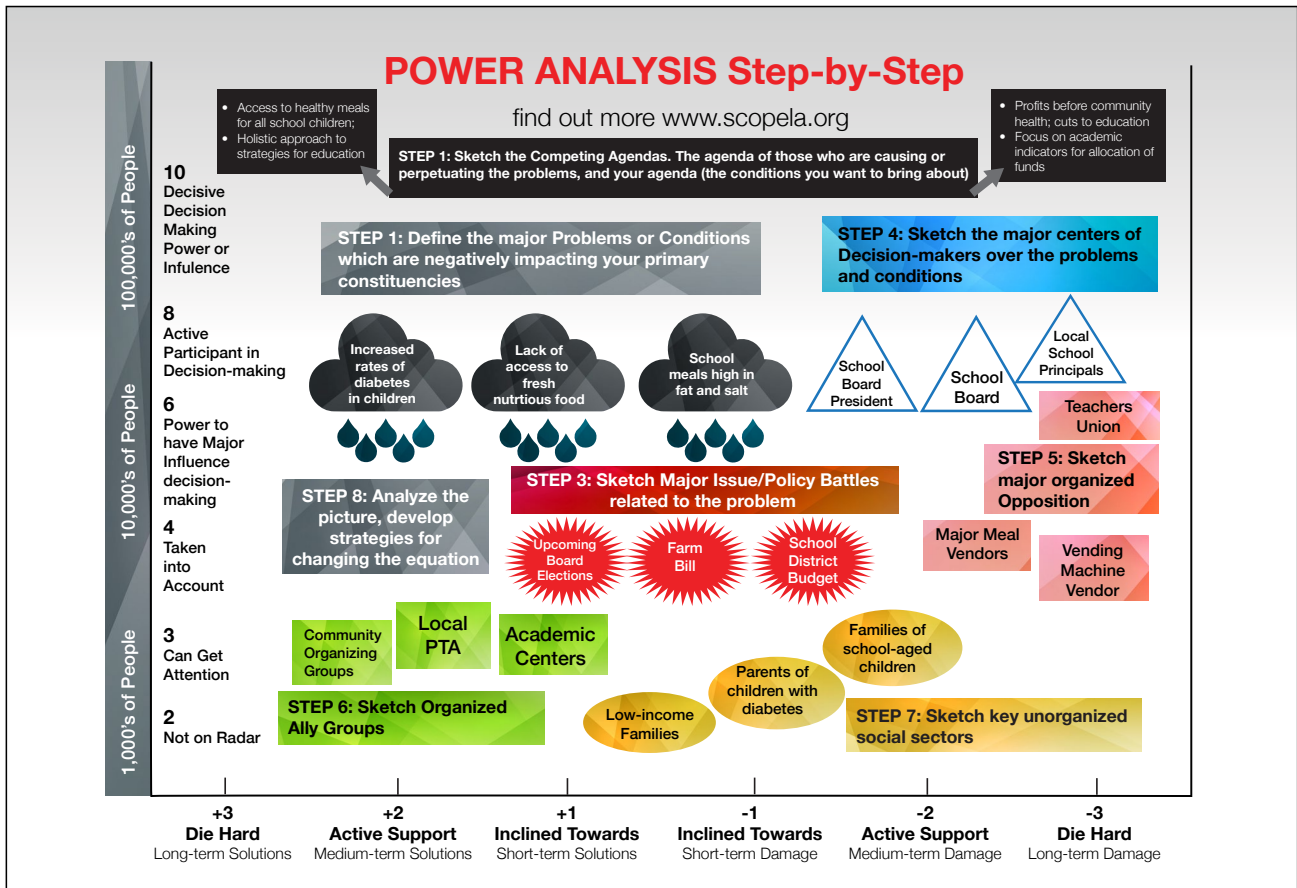
- What previous experience with collaborative research does the institutional researcher have?
- What funding and other resources (such as training, jobs) are there for your community?
- How will your organization's interests inform or drive the project?
- What skills for working with communities does the outside research team have?
 - Cultural humility
 - Communication and listening skills
 - Sharing power and control over decisions
- Are the institutional researchers/public health practitioners uncomfortable with changing methods and/or approach to working with participants?
- What if the outside researchers don't "buy into" collaborative research principles?

Questions for all potential partners to ask themselves

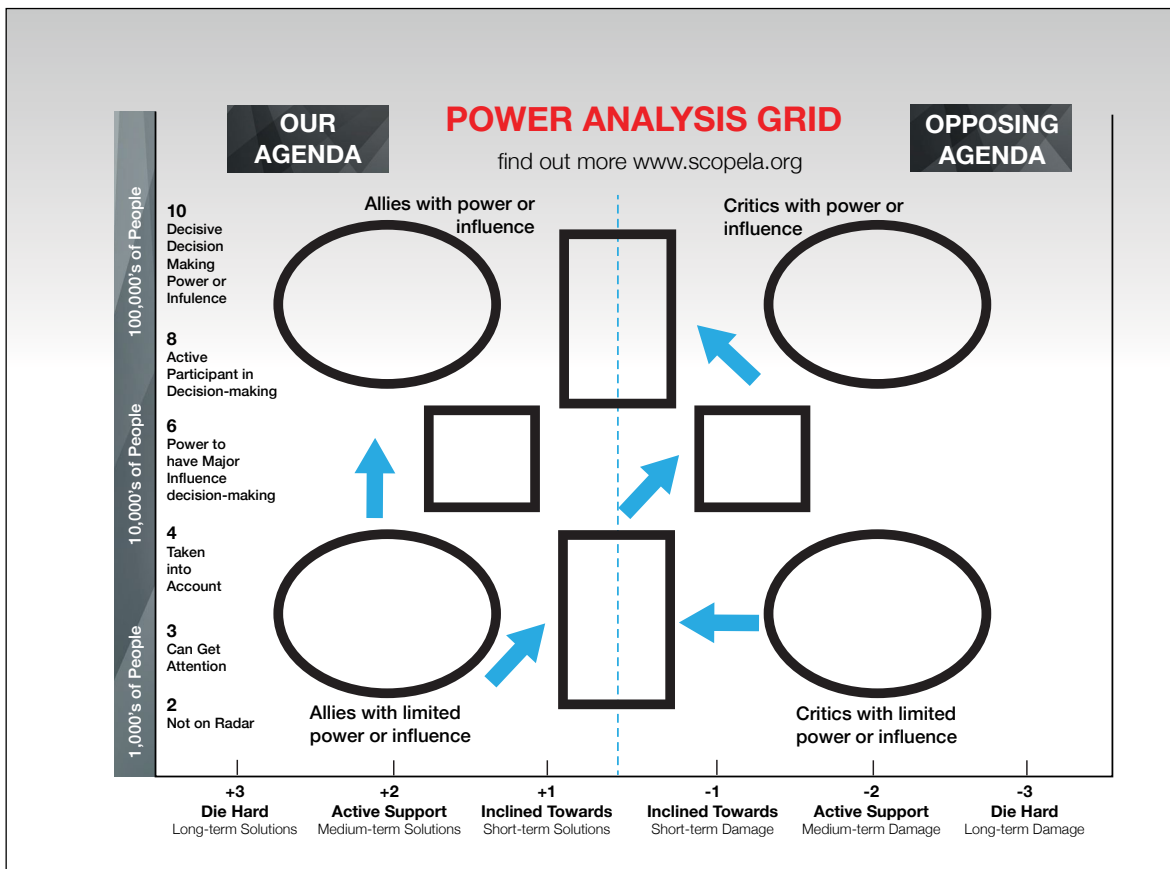
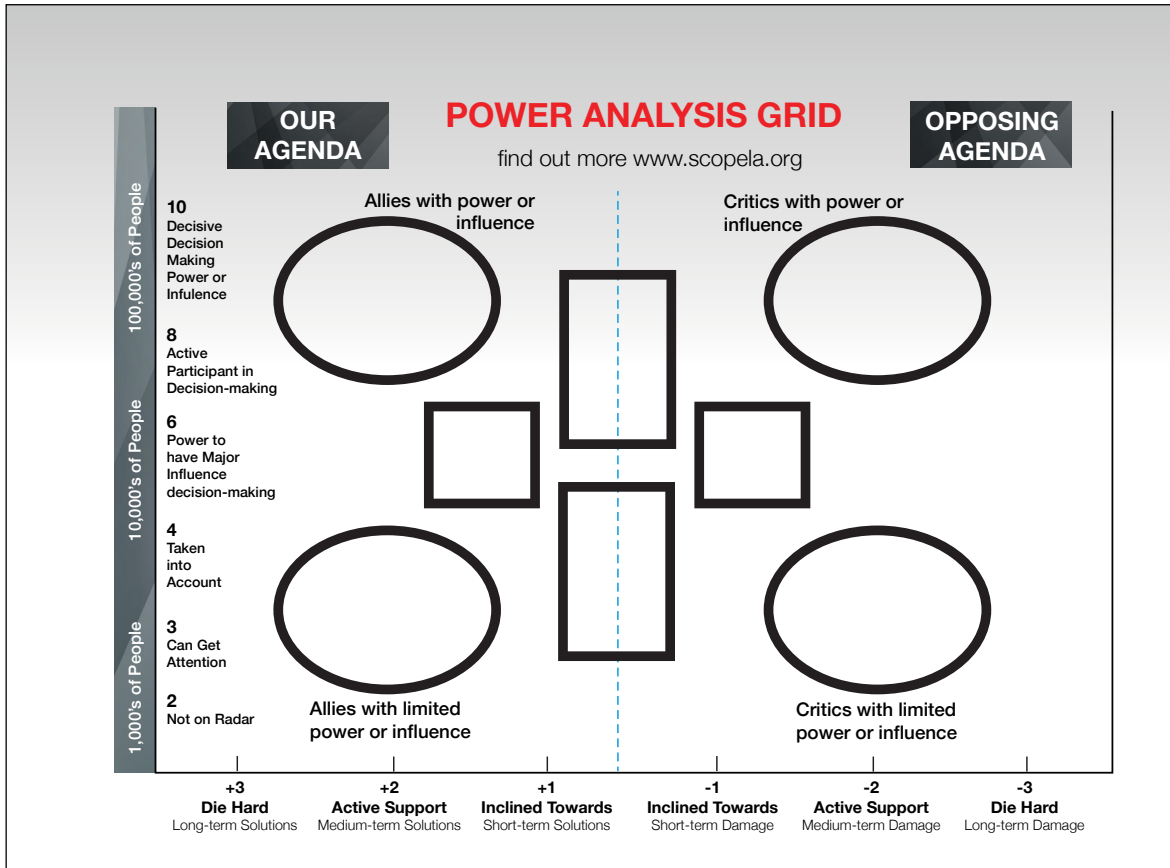
- What are potential benefits as well as costs of being involved in this research partnership, both to the organization and to the community? Short term and in the long run?
- How much time and resources will it take to participate?
- What expectations do we have of each other as partners?
- Are there common goals and objectives for the partnership?
- Is there enough initial mutual trust and respect to move forward together?
- When should we say no?

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MODULE 3 HANDOUT: COMPLETED POWER MAP EXAMPLE



MODULE 3 HANDOUT: NETWORKING POWER MAP HANDOUT



MODULE 3 HANDOUT: POWER MAP SCENARIOS

Use these sample issue scenarios to create your own Power Maps. Also, you can create your own issues scenario by following the template on the next page.

The use of agricultural pesticides is leading to increased health concerns and complaints in farm working communities in the San Joaquin Valley.

- Vision for change: Reduce the use of the most dangerous pesticides in California agriculture
-

A biomass facility, which emits high levels of air pollutants such as particulate matter (PM) 2.5 (fine inhalable particles), is expanding. It is located near a neighborhood where the majority of residents are low-income people of color.

- Vision for change: Approve policies that increase the regulations of existing biomass facilities, including stopping their expansion and prevent new facilities to be located near residential neighborhoods.
-

Construction of a new freeway has been proposed to support the development of a high-income suburban community.

- Vision for change: Decision makers refuse to approve the new freeway despite the pressure of developers.
-

Contaminated drinking water is making residents of small rural communities sick.

- Vision for change: Federal and state funds are invested to ensure that small communities have the infrastructure needed to access clean, safe drinking water.

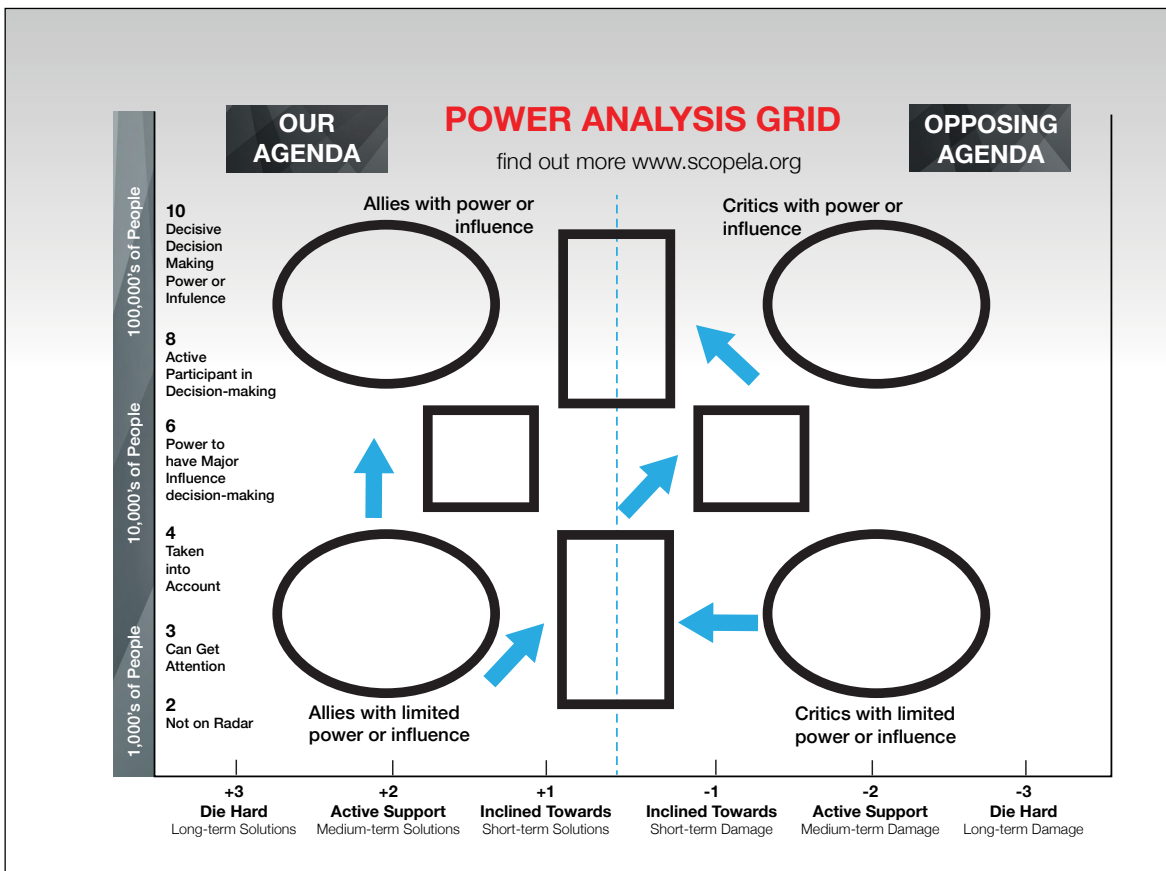
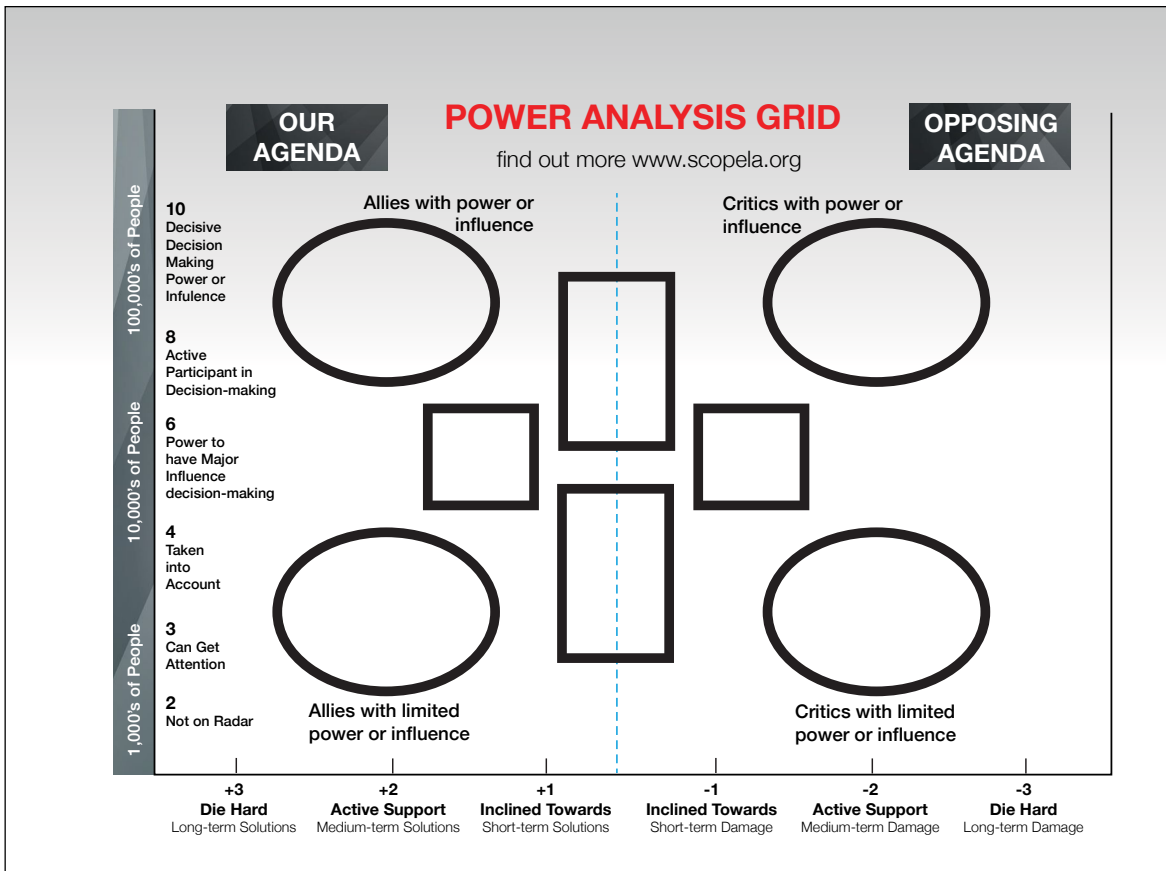
Create Your Own Scenario Template:

Issue Description: Write a description of an environmental issue that you are working on.

Vision for Change: Use this section to fill in what your group's vision is for changing the issue.

Participant Instructions: Power Mapping an Environmental Justice Issue

- As a group fill out boxes and circles in the Power Map to your best ability.
 - o Circles: Allies or critics
 - o Rectangles: Those who are on the fence and could be moved
 - o Squares: On one side of agenda and could be moved one way or another
- Focus on jotting down a big picture of the landscape you would be working on if you were to focus on the issue you have been assigned.
 - o It's ok to add other rectangles or squares as you see fit.
- As a group: have participants discuss and write how research can move any of these actors towards our siding with our campaign or issue change.
- If you can think of a particular research question to move a particular actor write it on a post it and place next to the actor its moving.
- If you can only see what direction research would move the actor that's fine, just draw an arrow.



MODULE 3 PARTICIPANT INSTRUCTIONS: MAPPING OUT RESEARCH NETWORKS IN RELATION TO AN ENVIRONMENTAL JUSTICE ISSUE (POWER NETWORK ANALYSIS)

In your groups, use the butcher paper, markers and post-it notes to create your own Power Network Analysis Diagrams.

Step 1: In the center of the butcher paper draw a circle and write on the center of that circle the issue you are working on. Write the vision for change underneath the issue.

Step 2: Map major institutions and/or researchers who work in areas relevant to the issue we are addressing.

- Brainstorm and map out who the major institutions, researchers, key faculty, or staff that you know are involved in this issue and/or are associated with the institutions the group has identified as crucial to its campaign.
- If you know it, include their expertise and/or type of research that they conduct that could advance our cause.
- Draw a circle at the edge of the issue circle with the name of the institution in the center.
 - o Can include:
 - Organizations
 - Agencies
 - Regulatory agencies and commissions
 - Universities and other research entities
 - o Example:
 - UC Davis (institution)
 - o Researcher "X"
 - Uses mapping tools to highlight places and communities that are in greatest need based on their proximity to pollution sites and social vulnerability
 - Community-Based Organization
 - o Lead Organizer
 - Community-based participatory research (CBPR) report detailing survey of drinking water in our area

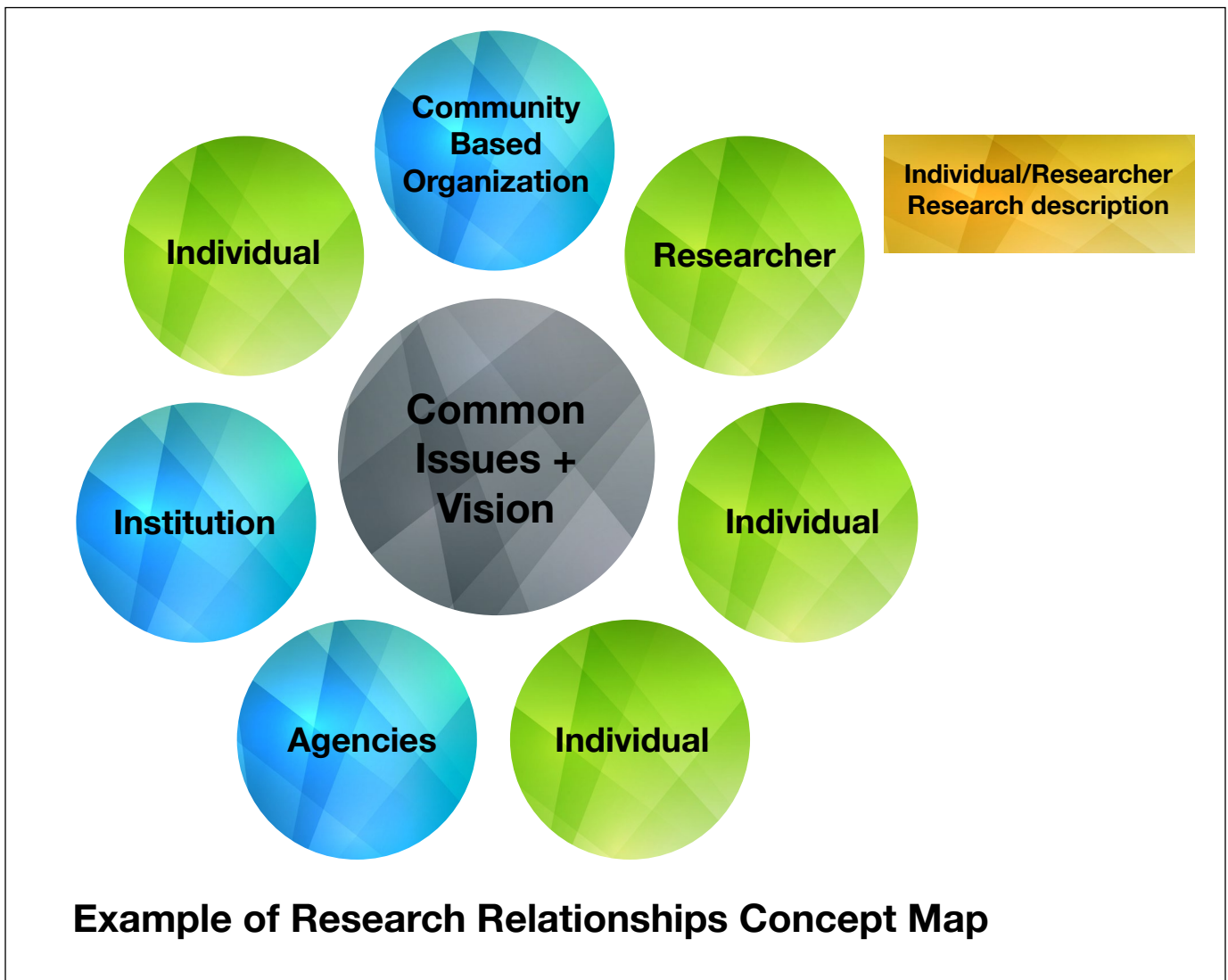
Step 3: Map Research Needs

- o Researchers in the group answer the following questions on a large Post-It Note and place the answers on diagram. It is ok to make new circles as necessary.
 - What is your research area(s)?
 - How does it impact this issue?
 - How do you envision your research being used?
 - If your research does not fall in this area, what general type of research approach, or specific research question, can you imagine applying to this issue?
 - What colleagues or research organizations do you think could conduct research on this topic?
- o Community-Based Organizations, Agencies, Regulatory Agencies/Commissions in the group answer the following questions on a Large Post-It note and place it on diagram. It is ok to make new circles as necessary.
 - What research are you conducting?
 - Whose research are you using?
 - How does it impact this issue?
 - What is your vision for this research being used?

- What types of research do you need to move your issue area?
- If you have not conducted research what general type of research approach can you imagine applying to this issue?

Step 4: What relationships do we have?

- o Analyze: based on the map, what relationships do we already have in place? Which did we identify as essential for this issue?
 - Draw a line connecting the relationships between people, institutions, or research ideas that can build on each other
 - Place a regular Post-It note on that line to describe the relationship
- o Place a Square Post-It note next to an institution, community-based organization researcher or body of research that you don't already have a relationship with and would want to further this issue.



MODULE 4 PARTICIPANT HANDOUT: CBPR STRATEGY CHART TEMPLATE

Long Term Campaign Goals: 1 year plus					
Mid Term Campaign Goals: 6-12 months					
Short Term Goals: 0-3 months					
<ul style="list-style-type: none"> Campaign Goals: 					
Targets	Constituents	Allies	Opponents	Tactics	Resources
Research	Research	Research	Research	Research	Research
Short-Term Research Goals:					
Mid-Term Research Goals:					
Long-Term Research Goals:					

MODULE 4 PARTICIPANT HANDOUT: CBPR STRATEGY CHART GUIDE

<p>Long Term Action Goals: (1 year+) Campaign Goals: Long-term goal of your efforts. What changes in environmental and/or social conditions are you trying to achieve? Note: Refer to vision statement developed in the Power Mapping activities</p>					
<p>Mid Term Action Goals: 6-12 months</p> <ul style="list-style-type: none"> Campaign Goals: This is the specific action goal of your campaign. You should choose something that can be done within a year and move you towards your long-term goal. 					
<p>Short Term Action Goals: 0-3 months</p> <ul style="list-style-type: none"> Campaign Goals: First steps that your group can take to get to your mid-term goal(s). This should be quick victory to gain momentum and inspire your members and the broader public around your campaign goals. 					
<p>Use the results of your power map to identify the following:</p>					
Targets	Constituents	Allies	Opponents	Tactics	Resources
<p>People and/or person who has the power to give us what we want.</p> <p>What is the relationship we have with them?</p> <p>What power do we have over them?</p>	<p>Who are the people, organizations, institutions, and communities that are on our side of the issue?</p>	<p>Who are the people, organizations, institutions that can align with our issue for reasons that may be different than ours?</p>	<p>Who are the people, organizations, or institutions that oppose us?</p> <p>What do they stand to lose?</p> <p>What are they capable of doing to oppose your work?</p> <p>How much influence or power do they have over our targets?</p>	<p>What steps can we take to influence our targets?</p> <p>List out potential Tactics</p>	<p>What information, funding, information or other assets do we have to help us succeed in our tactics?</p>
<p>Research: What types of research can help us move our targets closer to side?</p>	<p>Research: What research are we already using (from outside researchers or our own) organizations' research)</p> <p>What Research needs do we have?</p>	<p>Research: What can our current or potential partner researcher bring to the campaign?</p> <p>What research needs do we have in common with our allies?</p>	<p>Research: What research are our opponents using?</p> <p>Can we utilize their research to make a case for what we want?</p> <p>What research will help us move them closer to what we want?</p>	<p>Research: How will we utilize research in our strategy?</p> <p>What other research needs do we have to help us with our tactics</p> <p>Whose research can we utilize for our tactics?</p>	<p>Research: What relationships do we have to additional researchers?</p> <p>How can we get access to them?</p>
<p>Short-Term Research Goals:</p> <ul style="list-style-type: none"> Use existing research to inform "quick win" 					
<p>Mid-Term Research Goals:</p> <ul style="list-style-type: none"> Conduct our own research Build relationships with researchers and/or research institutions for additional support to help meet our goals Work on collaborative research design process and conducting of research with identified research partners. 					
<p>Long Term Research Goals:</p> <ul style="list-style-type: none"> Complete collaborative CBPR projects with research partners Utilize research to inform longer terms strategies Scale up existing research for broader impacts 					