


Participatory Action Research from A to Z

A Comprehensive Guide

Principal Investigators Association™

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Dr. Jo Anne Schneider is the author of this report. Dr. Jo Anne Schneider has developed participatory action projects since the late 1980s. Her work with training and community organizations in Philadelphia led to changes in training contracting and the state TANF plan. The Kenosha Conversation Project, a community process to understand policy implementation, received national attention and was featured on National Public Radio. She has advised on participatory action projects in multiple settings and published widely on this and related topics. A former American Association for the Advancement of Science Policy and Technology Fellow at NIH, she is currently an Associate Research Professor at George Washington University.

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Best Regards,

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Introduction

Participatory action research (PAR) involves the community targeted for research or intervention as partners in all phases of the project, from planning to implementing outcomes. PAR projects ideally develop long-term relationships with communities that lead to an iterative process of defining needs, planning, research, and development of interventions that empower and change the community. As such, PAR is not a technique or method used as part of a toolkit of research strategies, but an approach to working with a community that involves rethinking the relationship between researchers, health institutions and the communities they serve. This guide is meant to provide an overview of the process for creating an effective PAR project, and addressing the challenges involved in each aspect of the project. The guide relies on examples from a wide array of projects to discuss what works and provide strategies to address common problems. It focuses primarily on health related research given the special issues associated with using PAR in health research, but includes examples from projects on other topics.

This form of research is most often associated with high poverty communities, international development, education, or health disparities. PAR was initially designed to level the playing field between researchers and the community. To accomplish this, researchers developed projects with community partners that would change the power balance in at-risk communities. While some forms of action research have existed since the 1940s, PAR evolved in the social sciences in the 1970s and 1980s to address a variety of social problems. It is widely used in development, social sciences, education, urban studies, and some forms of policy research.

Health research discovered PAR through social scientists working on related issues. Interest in PAR by the health research community developed in the 1990s, with most activity occurring after 2000. In 2001, the National Center for Minority Health and Health Disparities convened a workshop on community partnered research along with the National Institute for Nursing Research, which led to a series of research projects using PAR. AHRQ convened a two day workshop in 2001, commissioning an evidence review on PAR that appeared in 2004 (Viswanathan et al 2004). While much PAR research in health care comes out of social science research, there is increasing interest in using PAR in translational research or as a mechanism to enhance recruitment for clinical trials. At NIH, the Office of Behavioral and Social Science Research (OBSSR) and National Institute for Minority Health and Health Disparities (NIMHD) particularly promote PAR, but it is funded by a number of institutes (see http://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/index.aspx). AHRQ also actively promotes PAR for both research and evidence

End of Intro Preview

Section 1: What is PAR?

Hallmarks of PAR

- The project is developed in partnership with the community to meet community members expressed needs
- Community members participate in planning, research, analysis and implementation – not simply as advisory committee members but active participants
- The project engages with the community toward positive social change or empowering community members in their relationship to the institution
- The project develops a long-term relationship with the community that leads to implementation of findings and/or potential future projects

Throughout this guide, discussion distinguishes between PAR projects and projects that involve the community, but do not meet all of the criteria for PAR outlined as hallmarks of PAR. PAR is defined as *research that comes out of a long-term active collaboration with the community that involves community members in all phases of the research and implementation.* In contrast to other projects that involve community members in some aspects, PAR is designed specifically to meet the community's expressed needs and empower community members through the research process. One early social science definition of PAR describes it as, "In PAR, some practitioners in the organization studied team up with professional researchers in designing projects, gathering and analyzing data, and utilizing the findings in action projects" (Whyte 1989:368). The research process is meant to lead to long-term collaborations, with the results of the research institutionalized in community practice.

Take for example the Ask Me! project, an annual survey of Maryland residents with developmental disabilities conducted by the Arc of Maryland and sponsored by the Maryland Developmental Disabilities Administration. The project came out of a series of discussions between disability community advocates and officials from DDA, the state government office that administered funding for people with developmental disabilities. In addition to the Arc of Maryland and several other disability advocacy organizations, People on the Go, a self-advocacy organization of adults with developmental disabilities, was an active part of the discussion. These discussions led to a DDA funded Quality of Life survey that was developed by Arc of

Maryland in partnership with People on the Go and other disability organizations. People with developmental disabilities were hired as interviewers for the project, performed data entry, and participated in the analysis. The Arc of Maryland was the primary lead for the project and was responsible for interpreting data, with a subcontract to a survey research firm that developed the samples and ran statistics. Findings were fed back to both government and private organizations serving people with developmental disabilities, leading to positive changes in services and expectations of people with disabilities. The entire project empowered the disability community to play a more active role in determining rights and appropriate service goals. When the state decided to use a national survey instrument instead of Ask Me!, they insisted that people with developmental disabilities serve as interviewers, continuing the community role in annual evaluations of quality of life for people with developmental disabilities in Maryland.

In this project, as with other true PAR projects, the genesis of the project is often the community itself. Community members play an active role in setting project goals, developing the questionnaire, carrying out the research, and implementing results. Ask Me! continued for over 10 years before the state moved on to join many other states in using a common instrument, but many of the community participation goals of the project continued even after the project itself ended. This institutionalization of community participation is one hallmark of a PAR project.

Contrast this to community outreach projects that create community advisory committees, but only use them as a conduit to conduct research in the community. These projects may have buy-in from some aspects of the community, but are rarely institutionalized once the project is over. The same is true of many of the initiatives to engage communities in increasing intake of fruits and vegetables, smoking cessation, or other health initiatives by providing curricula and resource kits to faith communities and community based organizations to present to their members. These organizations may present the programs they are offered as long as funding continues, but the initiatives rarely continue after institutional support is withdrawn. Communities report feeling used by researchers or health institutions to do their work for them, with little input.

History

Participatory action research has a long history, but it is best known as a response to positivism in the 1960s and 70s. Theorists and researchers from a number of disciplines protesting the view of the researcher as an outside expert who provided unbiased data suggested that researchers should work closely with communities to conduct research. These changes came from an understanding that the form of a research study, questions asked and methods reflect the biases of the researcher. These scholars suggested that expanding the inputs into a research study would lead to more accurate data. This combined with radical thinkers such as Freire (1972) and others protesting the power relationships in research, which stressed that studied populations should be active participants in developing knowledge. As the basic assumptions of science as unbiased observation were shaken, the research community increasingly felt that research subjects should become partners in the research process. Particularly in health care, consumer participation has grown in importance until many funders require consumer advisors to research projects. For example, Blank et al (2003:53) mentions that the National Institute on Disability and Rehabilitation Research includes performance indicators for inclusion of people with disabilities for its rehabilitation research and training centers. In mental health, and to a certain degree disability, researchers who are also consumers receive special preference for some grants.

PAR developed along two strands. The more radical forms coming out of education, anthropology and some other disciplines saw the researcher as a catalyst for community action, working as the servant of the community following the works of radical educator Pablo Friere. In these studies, the community sets the tone, creates the research questions, collects the data, and uses the results to meet local goals. The researcher works with the community as an advisor and technical consultant. Study results are owned by the community. One of the risks of this kind of PAR is that the researcher may become an activist exclusively taking the view of the community they work with. On the other hand, this type of PAR has evolved into local actions like successful community initiatives to document public health risks from chemical waste disposal sites and a wide range of other local community improvement initiatives.

In more mainstream sociology and some other disciplines, PAR saw the researcher advised by community partners to develop studies that met community needs. This form of PAR research began to gain currency in the late 1980s, following several major pieces in major Sociology journals. An influence piece by Whyte (1989), uses cases from industrial research (Norwegian shipping, Xerox, worker cooperatives in Italy) to describe practitioners as advising researchers as projects develop. Two of the projects describe organization staff carrying out data collection and analysis as well as advising the researcher. It is important to note that Whyte primarily views practitioners as advisors, not co-researchers, a strategy that significantly influences the direction of most PAR projects as the research method evolved. This led to the community participation projects that placed the community in an advisory role.

Another example shows how this kind of participatory action research works. The Faith and

Section 2: Developing Relationships with a Target Community – Do's and Don'ts

Effective Community Outreach

- Works with the community to achieve goals
- Learns about the community culture and its beliefs about healthcare
- Understands the history of the institution in the community
- Identifies key individuals and networks to effectively reach targeted community members
- Crafts messages and outreach strategies with these partners
- Maintains continuing communication with outreach partners

Initial Community Outreach

The most delicate part of developing a PAR project involves fostering a respectful, collaborative relationship with the community you plan to study. Regardless of whether community representatives contact you or your institution identifies community based organizations to participate in a project, the initial interactions can frame the entire relationship. For this reason, it is important to know the community before you begin working with them. It is also essential to view the community as the experts in understanding their needs, not the other way around.

There are several ways to get to know a community. Most institutions maintain demographics on their surrounding communities and the people they serve. Learning this information is an important first step. Learning the history of a community and its institutions provides a better sense of major players, its current issues, and how it approaches problems. Historical information is often available at local libraries and through talking with key community leaders. For example, in Kenosha the Latino community initially consisted of agricultural migrant workers who settled out after the intervention of Catholic church initiatives to move migrants from farm to factory. Due to this history, the church remains a critical player in any initiative involving this community. Later, immigrants came directly to Kenosha from several Central American countries, developing an ambivalent relationship with the already established community. Understanding the relationship between the early farm worker population and the newer migrants was critical to determine what organizations could do to best reach new migrants.

In Kenosha, the project worked closely with the Kenosha County Job Center and several Latino serving organizations, including a Catholic church ministry run by the Latino community. These organizations provided information on where new migrants worked and lived. This led to developing a project to sign people up for Medicaid and Chip by using a trusted community based organization as a conduit. Another successful initiative allowed government enrollment specialists to go to firms that hired many Latinos to sign people up for health insurance, with no questions asked about the firms' policy regarding hiring undocumented workers. Without understanding the history and developing relationships with key organizations, these kinds of initiatives would not have been possible.

A different set of issues became important when working with the African American community because of a different history. Kenosha's African Americans were brought to Kenosha from Detroit and several other northern industrial cities to fulfill a government contract with the local auto industry that required a diverse workforce. This stable working class, highly unionized workforce came to a segregated community where they had relative job security, but faced discrimination everywhere else that continues to a large degree today. Given this history, the union hall became as important a partner as the local black churches that are usually central to African American communities.

Another important first step involves simply becoming comfortable in the community and its institutions. Regularly walking through the community, shopping in its stores, eating in its restaurants, and so forth, gives researchers an understanding of the community and allows community members to become familiar with researchers. Going out to local community based organizations, recreation centers, faith communities and other institutions simply to introduce yourself and the institution with no agenda is another important first step to begin to develop a relationship with the institutions. These initial conversations should focus on the researcher learning about the organization, its view of the community, and its needs. Those involved with outreach for the institution should also provide information on the research institution and current initiatives it has that could benefit the organization and community. This begins to develop a two-way relationship.

Outreach to peers already established in the community is another important way to develop relationships with a community. Sometimes these organizations or individuals are well known to the institution already, like an established community health clinic or well-known physician in the neighborhood. It is also important to ask people at other community organizations who the well-respected health providers in the neighborhood are, and use this list to find connections. Sometimes the most visible practices are not the ones trusted by the community. Developing care relationships with these providers may be an important first step for future PAR projects. For example, placing interns in these practices and developing partnerships to provide specialty or high technology care for patients served by these practices.

Mapping Community Networks

- Advisory committee member insights
- Key constituencies
- Key organizations
- Program users
    - GIS mapping of patients
    - Social mapping of referral sources and talk to them about networks

One goal of your outreach to the community should be to understand its networks and how key institutions lead to each other. While talking with community members and organizations, ask them about networks and key network leaders. Organizations should be asked who they work with and why, as well as who they don't work with. All of this information should be developed into a chart that shows the relationships among people and institutions in the community.

While this network mapping can be done by hand, a number of computer programs exist to show social networks. In very large communities, doing these kinds of network analysis can be helpful. Often, it is more important to combine computerized mapping with conversations with people about how networks develop. For example, the Silver Spring Neighborhood Center project mapped the home addresses for people in various programs. Finding very different patterns among those involved in youth programming, adult programming, food pantry users, and day care users led to conversations about how referral sources developed. This information proved important in helping the agency further market its services.

Mapping can be done with hospital patients or for clusters of diseases using information available through administrative databases and the local health department. This mapping can be used to identify areas the project wants to investigate or coupled with information on referral sources to understand an organization's footprint in its community. In either case, mapping information provides important data to understand a community and its needs.

Community Culture

All of the organizations approached for a project should be asked about the community culture and culture of health care in their communities. Each community is unique and researchers can not presume that they understand a particular neighborhood or community because they know something about people from that group. Beliefs about health care may be very specific to a community. Do community members believe that chubby babies are healthier or know that playing outside can be dangerous? In situations like this, nutrition and obesity projects will need to address local beliefs about health. Physical activity programs may need to be modified to keep programs indoors if the streets or local air quality are dangerous.

Community culture also includes understandings about institutions. For example, a community that was denied access to local hospitals in the past may be suspicious of them. A key health clinic that provided free immunizations and gift cards for holiday food may lead community members to expect that other health institutions will provide these kinds of services. Knowing these concerns or expectations up front will help frame the way an organization approaches a community to partner with it on PAR projects.

Getting to know these institutions is the first step in developing relationships with the community. Communities should not be approached about collaborating on a project until key personnel have started relationships with their peers and key local institutions like community based organizations, faith communities, day care providers, and schools. The types of institutions will vary depending on the nature of the community. In communities based on a particular disease or diffuse population (people with diabetes, cancer survivors, LGTB communities, people with disabilities), working with membership organizations or self-help groups may be a key way to learn about the community and develop relationships.

PAR Do's and Don'ts

DO:

- Develop a good understanding of the community and its needs before developing a project idea
- Bring the community into the process BEFORE developing a project proposal
- Keep lines of communication open at all times
- Check with all community factions about all aspects of the project
- Understand that you are a bridge between the community and your institution

DON'T:

- Presume that you are bringing something important to the community that they want
- Forget that your project is not the only, or even a primary, priority for the community
- Tell the community what to do or presume you know better
- Go native or take sides with any faction in the community
- Disappear once the project is over

Key Do's and Don'ts

This initial groundwork sets up the relationships that will be necessary to develop a project. As outlined in PAR Do's and Don'ts, researchers should develop a good understanding of the community and its key players before any project starts. This may lead to community members contacting you to initiate a project instead of the other way around. It is also helpful for the institution to make a practice of playing a role in the community by supplying people to serve on boards, developing volunteering relationships in local institutions, prioritizing hiring from the community, or develop an internship or job shadowing program with local schools or training programs.

Part of getting to know a community is understanding the sub-groups and factions within it. Representatives from all of these constituencies should be included in a project for it to succeed. For example, the Silver Spring Neighborhood Center project started through a request from the agency to a local organization that supported nonprofits and a local university. The agency executive director was particularly concerned with the public housing project surrounding the organization and encouraged the research team leaders to work with tenant organization leaders. However, preliminary background research in the community revealed a Catholic church with members both from the neighborhood and those who had moved away that remained interested in playing a role in the neighborhood. In addition to the mostly African American housing project, the surrounding neighborhood included a significant Asian refugee and immigrant community that was beginning to develop businesses in the area, as well as people from other city neighborhoods and African migrants who settled in the homes and apartments theoretically also served by this center. The project team intentionally reached out to all of these various communities in developing the project.

Section 3: Identifying Problems and Developing Research with the Community

Initial Outreach Steps

- Focus group or needs assessment in community to identify needs or get a sense of interest in your project
- Develop one page project description
- Get feedback from a wide range of people, organizations in the target community

Few researchers go to a community without an agenda, however vaguely defined. For a health outreach project, the goal may be as simple as to establish a presence in the community, improve community health, or addressing high rates of high blood pressure and diabetes. For example, in the Kenosha Conversation project, the university wanted to develop a project to understand the implementation of welfare reform. The researcher's role in the project is to help the community determine the specific problems it wants to study and craft research questions that can reasonably address those problems.

When a community comes to an institution to start a project, the goals may be equally vague. For example, the goals of the Faith and Organizations project initially presented by faith community leaders included understanding the role of the faith community for established FBOs and determining how to interact with FBOs to ensure that they upheld the faith community's values. For the Silver Spring Neighborhood Center project, the agency wanted to know the impact of welfare and child welfare reform on its community and the agency itself. Ask Me! wanted to create research to improve the quality of life for people with developmental disabilities.

Researchers going out into a community must be prepared to throw away their own agenda or significantly modify it depending on community needs. Take, for example, the hypothetical project to bring down high blood pressure and diabetes rates in a low income urban community. Before any project begins, the researchers or outreach staff at the medical center would have done their homework on the community and established contacts with a few community leaders. The first step would involve conversations with these leaders about the concern – health statistics that show high rates of high blood pressure and diabetes in the community. Despite clear data on the problem, the community leaders may counter that their primary concern is lack of affordable health care in the neighborhood. High blood pressure and diabetes are very low on their list of concerns, which also include lack of employment, adequate food, and a list of other basic needs. The project leaders may change their goals to creating affordable health care options that would monitor high blood pressure and diabetes rates, as well as research ways to provide adequate and healthy nutrition to neighborhood residents.

These conversations may take a long time. The Faith and Organizations project met at professional meetings and in small meetings sponsored by the leading faith communities for several years to develop the research questions and overall goals of the study. In other cases, one exploratory project could lead to others. For example, the Kenosha projects started with a project to start a conversation among community stakeholders in order to determine the impact of welfare reform on the community and what other programs were needed to help families move toward self-sufficiency. This led to program projects to create day care for sick children and a second research project focused on the needs of the African American and Latino populations in this small city. The initial project took approximately six months and developing and finding funding for the second one took another year.

The goals of these conversations should be to develop a one page project description that outlines the primary goals of the project and those involved. This statement would then be circulated to others in the community for comment and to develop relationships with others that want to be involved in the project. The statement would be modified based on these conversations and circulated again until all of the major factions in the community can come to an agreement about what they would like to have studied.

Given these time frames, it is important to start developing relationships long before any particular Request for Proposals (RFP) or Request for Applications (RFA) comes along. That way, the community and organization have relationships in place and can respond to a funding opportunity. The organization should also be prepared to pass by RFPs that do not meet the community's goals. For example, a community interested in providing basic health care may find a request for proposals related to obesity beside the point. Putting energy into developing this project may hurt the development of nascent trust and relationships with this community. Often, it may be important to find local sponsors – in the form of local foundations, businesses or the institution itself, to fund exploratory relationship building and formation of project ideas. This suggests that the institution is looking toward establishing a long-term relationship and wants to involve those already invested in the community in the process.

Community Needs Assessments

Another strategy to generate community involvement and identify community needs is to develop a needs assessment for the community. Usually the needs assessments are focused on a particular problem like health care, increasing employment, or addressing food insecurity. However, these needs assessments can also be very broad, simply to identify the key needs in the community.

There are several ways to conduct community needs assessments. One model involves doing focus groups in the community. The focus group questions would be developed with your initial community contacts and be conducted in a variety of community settings. Sometimes they can be done with a variety of stake holders. For example, the Kenosha Conversation project started with focus groups with county politicians and leadership of the county human services and employment sectors, frontline workers, community based agencies, and people receiving services from the community. These focus groups were used to identify five major areas of concern that were then discussed in a conference that led to the development of other projects.

A second strategy involves creating a series of town hall meetings to ask people about their major needs. These meetings should be conducted in already existing venues and be co-led with community leaders. For instance, holding town hall meetings with interested church members at key congregations, meetings with local school PTAs, and the members of a local service organization. In projects interested in working with local businesses, asking to do a focus group or town hall event at staff meetings or in the company lunch room is another option. In all cases, these events need to be well publicized in advance and their goals clearly stated at the outset. Like the focus groups, these meetings should be used to develop a short list of projects or problems to address.

The community should be involved in developing needs assessments as much as possible. Several strategies can achieve this goal. Listening projects are one well-tested option. This model is used by a variety of organizations and was institutionalized by the Alinsky sponsored community involvement projects like the Gamaliel Foundation, Industrial Areas Foundation, and several other similar groups (see http://www.gamaliel.org/). Listening projects involve training community members to conduct open ended one-on-one conversations with others in their community to ask about their needs, concerns, or beliefs about a set of issues. Community members conduct these conversations both to gather information on community needs and develop relationships with other community members. Information from the conversations are

Section 4: Including the Community in the Research Team

Hiring and Training Community Members to Perform Research

- Select community members with research training if possible
- Include people from all groups in the community
- Look for marginal insiders
- Provide mini research methods courses for all researchers on the team
- Shadow all team members
- Carefully review data collected for thoroughness and bias

One of the hallmarks of a true PAR project is that community members participate in conducting the research. This could be volunteer opportunities, like having members of a church youth group conduct interviews with church members. Or it could be a structured part of a study, as when researchers give people cameras to record their experiences in a community. One community based organization I worked with recruited volunteers to oversee an evaluation, only to learn that advisory committee members were expected to conduct surveys that the professional evaluator developed. While each of these examples qualify as PAR, the benefits of community participation is only fully realized when community members also participate in the development of the research protocols as well as conducting the study.

This process often starts with the advisory committee before the research team is hired. Just as the advisory committee participated in developing the research questions, they should participate in developing research instruments and determining criteria for staff. This will be discussed in more detail in the next section. Advisory committee members may also suggest people who may work well as research team members.

Hiring Community Members for the Research Team

There are many reasons to hire people from the community beyond the important issue of empowering the community through their participation in collecting data. Community members may be able to talk with people or go into settings that outsiders would have a hard time getting access to. Other community members may trust them more than outsiders. Community members may understand the dynamics of the community and help the research team develop research strategies that best reflect the community. They may also have a nuanced ability to interpret data and explain community culture to the rest of the research team.

Several issues influence who to consider hiring from the community from a particular project. In cases where a project is designed to work with a specific group, like members of a service club or high school youth, the bigger issue may be identifying someone who can supervise these teams adequately to ensure confidentiality and data quality. In this case, it is helpful to identify someone in the organization with previous research training and a strong understanding of the community. For example, does the church have a minister who had research training as part of a degree program? This person should be vetted to ensure that they have a good reputation with the community and are not considered a member of a particular faction.

These same criteria go into hiring research team members directly from the community. Ideally, someone from the community either has research training or an understanding of the research process. For example, the Faith and Organizations project hired a well known community member with a PhD in community psychology, similar training as other professionals on the research team. College students from the community are often excellent researchers, and can be chosen from applicants who have completed research methods or similar courses. For example, the Kenosha teams included a number of local students as researchers.

Other criteria may depend on the nature of the research. For example, the Ask Me! study recruited researchers from members of the self-advocacy organization People on the Go as well as people with developmental disabilities known to the key community based organizations with the contract for the study. They looked for an ability to listen and understand questions, as well as the ability to discern answers from potentially non-verbal respondents or those with limited capacity to communicate. Not everyone needed to know how to read or speak.

When Maryland changed to a much more complex survey, the criteria for staff changed to those who could read at an 8th grade level and write. This significantly changed the applicant pool, but the criteria of hiring people with developmental disabilities remained. The organization with the contract to carry out the study hired someone who had worked on Ask Me! as the key person to develop the research team. She, in turn, contacted the major organizations in the development disabilities community to find staff. As this example suggests, it is important for researchers to think through ahead of time what characteristics they value in their research team before sending out a call for applicants.

From the community means the specific community that is the target of study, not someone with similar background characteristics. Researchers need to be careful when selecting people who appear like community members but do not have a history in the community. For example, the Kenosha projects hired a young African American man from Chicago with similar religious and class background to the target population. He was met with suspicion by local residents because he was attending college and not from the community. Ultimately he was transferred to two different sites before dropping out of the project.

Researchers also need to be careful about hiring people with biases that would influence their research. For example, the Faith and Organizations project chose not to hire a young man with an evangelical background who had left the church and held strong views about the moral stances of the evangelical community. Sometimes someone within the community cannot see some of the nuances because they are so familiar to them. Presumptions that everyone does things a certain way may lead to information being left out of the study that would be important to record.

The social characteristics of the researcher may limit where they can go and who they can talk to. In many cases, male researchers can not work with women. For example, the Changing Relations project, a study of the interaction between immigrants and other community residents in Philadelphia, hired a Korean PhD student who lived in the immigrant community as a core member of the research team. While the data he collected was valid, he was not able to get into some parts of the community because of his own characteristics. When he left the project and was replaced with a white, female researcher, the project was able to learn about the experiences of women. For this reason it is important both to match researchers to the groups they will be working with and to have teams of people working on the project that complement each other.

Selecting community members as researchers also means carefully understanding that person's place in the community. It is not helpful to hire someone that is considered part of a particular faction or has a strong reputation in the community, either good or bad. The better choices are people known in the community but who are not considered major players in any way. For this reason, someone from the community who has gone away to study or work and has now returned is a good choice. These people would not be considered part of the current dynamic in the community and may have a broader view from their wider experience.

People who are both from the community and can step outside of it are called marginal insiders. These people understand the community well, but also have a broader understanding that gives them perspective

Section 5: The Research and Analysis Process with the Community

Research Process

- Use your expertise to develop the research plan, but work with the advisory committee to develop specific research methods, protocols, etc.
- Always keep the community informed about what you are doing
- Pre-test all research instruments with a wide range of community members or in all key settings
- Keep the advisory committee informed throughout the research process

PAR projects differ from other research projects because research is always an ongoing negotiation and collaboration with the community. Each step of the research process should be developed with the advisory committee, full research team and other community representatives with insights into a particular topic.

Take the Faith and Organizations project as an example. The study involved a combination of observation in agencies and faith communities, interviews with organization leaders, and development of a planning tool for CBOs and faith communities. The advisory committee and research team worked together to identify sites for initial study, with the community leaders providing introduction to agencies that eventually participated in the process. These agency leaders were invited onto the advisory committee.

Questions for more formal interviews were initially created by the research team and then shared with the advisory committee. The advisory committee added topics and suggested re-arranging the interviews for different faiths given the different ways they approached faith based activities.

Advisory committee members were also part of team meetings where initial findings were discussed. They played a role in determining issues for analysis. As the study progressed, they helped understand findings and outlined additional topics to pay attention to in both research and analysis.

Developing the final planning tool became even more of a collaborative process. Advisory committee members took part in outlining what should be in the questionnaire that served as the basis of the planning tool. During a project retreat, they sat with teams of researchers designing the tool and reflected on drafts. Advisory committee members and the research team both recognized that the project would need to create three separate instruments that reflected the different styles and issues for Jews, Evangelicals, and other Christian denominations. Advisory committee members from these faiths worked with small groups of research team members to draft the questionnaire. Then the advisory committee found people from their boards or organizations to pilot the planning tool. Feedback from these pilots from community members that participated combined with an open discussion between the advisory committee and research team to lead to the final versions of these planning questionnaires and the guides that accompanied them.

As in this project, community members play an active role throughout the project, shaping each step. Their guidance is essential to each step. Every research instrument is developed with the participation of these community members. They are then piloted with a broad range of community members representing each subgroup within the community. In the Faith and Organizations project, the subgroups were different faiths. In the Kenosha project, interview guides for family interviews and a needs assessment were developed with the community and piloted in several venues in both the African American and Latino communities. The same was true with all other PAR studies. In the Ask Me! project, new questionnaires were tried out in a percentage of interviews the next year, throughout the state.

Maintaining Communications

Part of the process of community research involves keeping the broader community informed about the project as it develops. This can be done in a variety of ways. The first and most obvious strategy is to develop written material about the project. Each project should develop a one page description of the project, its goals, who is involved, and who to contact that is written at a level appropriate for the community. These information sheets should also suggest ways that interested community members can become involved. These information sheets can be produced as a one page summary or a flier. These materials should be given to everyone on the advisory committee, each agency hosting the project, and everyone on the research team to hand out to anyone interested in the project.

In projects involving an organization, the research team leaders usually introduce the project and talk about its process before it begins at board meetings. They return to report on its progress to the board or at broader community events like an annual meeting or holiday celebration. Coalition projects include regular updates on the project at coalition meetings.

Projects involving a range of venues can be kept informed in a variety of ways. For instance, presentations about the project can be done at participating faith communities or member benefit organizations. Researchers participating in the project can schedule regular discussion forums at organizations in the community like a library or school. In all cases, the point of these events is to keep the entire community up to date on the progress of the project. These forums are also places to respond to rumors or concerns about the project.

Project leaders should be prepared to answer questions about the project outside of their normal business hours. This may involve using a cell phone as the contact number for the project so that questions can be answered on evenings or weekends. Researchers should also be prepared to respond to questions as they work in the community. In some cases, it may be important to set boundaries on when the project can be a topic of conversation. For example, one researcher participating in a project in a small town asked that community members not ask about the project in the grocery store or in evenings when the researcher was out in the community for entertainment. Most community members will honor these boundaries, but the researcher may need to bend when necessary.

Websites can also be used as a way to share ongoing information on a project. At the very least, the project website should include the informational flier, a list of the advisory committee and any participating organizations, and a list of researchers. The website should also provide a communications link as well as suggest ways that the community can get involved in the project. It can also be a place to post information on informational forums, project events, findings, etc. Other new media like Facebook and blogs can be used to share information on the project or provide a way for people to connect with the project.

Communications Strategies with Key Stakeholders and Advisory Committees

- Regular conference calls with key stakeholder participation
- In person meetings at regular intervals
- Email and phone calls to address specific issues
- Create sub-teams of community members and researchers for specific topics

Communications with the advisory committee and other organizations actively involved in the project should be frequent and on a regular schedule. Most of my project teams have weekly meetings by conference call, and advisory committee members were invited to attend once a month. Large projects had quarterly

Section 6: Creating Products Useful to the Community

PAR projects will create a variety of products for several audiences: the community, sponsors, the researcher's institution, and potentially policy or academic publications. The types of products you ultimately plan to create should be laid out in the initial project proposal, with the expectation that the list will be modified as the project progresses. As with other aspects of the project, these products should be developed with the community in order to serve their needs.

Community members will need to know about all publications that relate to their community, regardless of where they appear. This can avoid problems down the line. For example, one set of researchers published their findings in an academic journal without sharing the manuscript with the community first. A community member found the publication and wrote both the researchers and the journal with concerns that the publication was inaccurate. The researchers ended up offering a public retraction and apology to the community.

This section addresses two issues – 1) the process of creating products with and for the community and 2) ownership issues related to data created by the project. I start with ownership issues as they are critical to creating any sort of product from the project.

Who Owns the Data from a PAR Project?

Data ownership from a PAR project or any project done for a community organization can vary from the community organizations having all rights to the data, to complete ownership by the researchers, to partnership ownership with rules for publications and other uses for the data. I advocate the third option as the most equitable and fair to all parties involved. Efforts for sole community ownership of project data can backfire. For example, one community based organization insisted that the researcher turn over all data to the sponsoring organization. The researcher did as requested, but then refused to conduct anything more than preliminary analysis. The agency was left with a half-finished product and had to seek help from other researchers to complete the project.

While the researchers should have the ability to use the data from the project in publications for academic audiences and others, they should have an obligation to inform the community about any publications or presentations. Otherwise, the community may rightly feel that the researcher has used them to further his or her own career and has abandoned the community once the project is over. This should be avoided in order to protect the potential for further research with the community for this researcher and others. It also avoids embarrassing situations like the request for retractions discussed above.

Publications shared with the community may occur long after a project is over. For example, I published a book using data from a number of projects conducted over 12 years, approximately four years after the final project was over. I had returned to the community two years into writing the manuscript to collect some final data. I shared key chapters with organizations profiled in them for their feedback. This process was helpful in clarifying points in the book as well as generating ongoing relationships with these organizations. I have continued to return to these agencies for feedback years after projects ended and I moved away.

Ingredients for Ownership and Publication Agreements

- Any funder specifications for data ownership, publication, or funder acknowledgements
- Requirement to share all drafts of any publication other than student papers for class with key stakeholders, but stipulating no veto rights
- Who has access to and rights to use data
- Rules for using data for publications
- Authorship rules and rules for acknowledging community member and team participation in data collection
- Copies of all key publications must be shared with advisory committee and community members who ask

Ownership agreements should be in place before research begins. They can be fairly simple statements or drawn up by the legal department of the institutions involved. In either case, they should include the ingredients outlined above. Funder specifications for data ownership will be in the initial funding agreement. For example, some foundations will want to review publications before they go out. Funders may have specific ways that the grant is mentioned in a publication. Government entities may also claim some ownership of the data, even for PAR projects. All of this should be spelled out in the ownership and publication agreement.

Particularly for PAR projects, community stakeholders should see any product before it goes out for either review or dissemination. This should also be a required element in the ownership agreement. This should include the right to comment on drafts, request certain information not be revealed, or provide rebuttal arguments. However, these agreements should not give the community the right to veto a publication or a line of argument. The researcher needs the freedom to present analysis that may contradict widely held beliefs in the community, show aspects of the community they would prefer not be revealed, or offer a broader analysis of the events. In cases where the researcher and community agree, they should work together to present the data in a way that is appropriate for the community. For example, in the Faith and Organizations project, an advisory committee member active with evangelicals suggested the project use the term “sharing faith” rather than “proselytizing” in order to more accurately present the community’s view of its activities.

These ownership agreements are not only between the community and the researcher, but also set out rules for the research team. Rules for authorship and specifying who has access and use of the data include laying out how junior team members can use data for their publications. This will be discussed later in this section. In PAR projects, community members active in the project should also have permission to use the data for their own products and publications. Often these are done with the researchers. For example, Ask Me! publications were co-authored by key agency personnel and the PI. The agreement should spell out how access is given and the researcher’s role in these efforts. For example, it may be wise to request that the research team review community publications just as community members review products created by the research team.

These written agreements provide the ground rules for products and publications. As with anything else on a PAR project, they should be discussed before they are developed. They should be used to help the project figure out how to develop products and its review process. Refinements may need to be added to them after the project goes into the dissemination phase, but these can be added in addenda or other informal mechanisms.

Section 7: Maintaining Relationships After a Project Ends

PAR projects should develop long-term relationships between the community and the institution. Ideally, this will lead to future projects involving other researchers from the institution as well as translational projects that put findings from research projects into practice. Institutions involved in PAR should anticipate a long-term commitment to the community and spell out the multiple ways that they intend to stay involved with the community.

Efforts to continue relationships should start before the project nears a close. Institution officials should be involved in discussion of dissemination strategies and uses of the data for future partnerships. This may include a commitment of resources or promises to seek funding for future collaborations. It may also include creating stronger relationships to the community by offering training opportunities for community members that participated on the research team or jobs for community members. Depending on the nature of the project, it may involve creating collaborative efforts to better serve the community at the research institution. It may also mean creating outreach centers to offer services in the community.

In either case, it is important that the institution clarify their expectations regarding their relationship to the community and the organizations participating in the project after it ends. This may be done by informal conversations, offering institution staff to sit on agency boards, or program development. In either case, it involves working with the community to see how the institution and community can best work together in future.

This should involve discussions with the key community organizations involved in the PAR project about what worked about the project and what they would like to see done differently next time. It should also include brainstorming about future partnerships and other arenas where the institution and community can work together. As with initial outreach, the institution leadership should go out into the community and ask them how they would like to see the relationship progress. Community leaders may have learned more about the institution and have different ideas of its role in the community. They may also want to continue work on their own, but draw on institution resources as they develop the next phase of their own work.

In the best case scenario, key research team members will have stable employment at the institution and will want to continue working with the community in PAR projects. As the project moves into the analysis phase, project leaders should discuss next steps and ways they can work together. If project leaders have other projects and obligations, they should clearly state the boundaries for future collaborations. They should also be prepared to hand off an ongoing relationship to other researchers at the institution or other members of the research team.

PAR research team members may be junior agency staff or students who will move on to other positions. Here too, it is helpful to try to maintain connections with the project. For example, toward the end of the Kenosha projects, I left Wisconsin for a position in another state. However, I consciously maintained contact with key staff involved in the PAR projects for over 10 years after they ended. These relationships involved sharing publication drafts and simply talking about changes in the community. I offered occasional advice to the agencies based on new developments in the field.

Maintaining a relationship is important both for the integrity of the project and to remain true to the goals of PAR to empower the community. It is extremely important that the researcher not simply leave after the project is over. If the researcher stays in the community but moves on to other employment, relationships can continue through volunteering or otherwise engaging with the community.

PAR projects can create a bridge between the community and the wider world. This can occur through an ongoing process of presenting information on the project at conferences that involves community participants after the project ends. It may involve referring other external organizations interested in the same community to the community partners in the PAR team to discuss future projects. Individual community participants may be encouraged to explore careers in research and practice through participating in city-wide forums or professional organizations in opportunities sponsored by the research institution.

In all cases, the idea is to create enduring links between community and external institutions interested in working with the community. These partnerships should be strategic commitments on the part of both community and research institution. They are designed to enhance the activities of all partners involved by creating research that responds to realities in local communities and makes a commitment to work with them toward social change.

About the Author —
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Dr. Jo Anne Schneider has developed participatory action projects since the late 1980s. Her work with training and community organizations in Philadelphia led to changes in training contracting and the state TANF plan. The Kenosha Conversation Project, a community process to understand policy implementation, received national attention and was featured on National Public Radio. She has advised on participatory action projects in multiple settings and published widely on this and related topics. A former American Association for the Advancement of Science Policy and Technology Fellow at NIH, she is currently an Associate Research Professor at George Washington University. She also has an international reputation for university/community involvement, serving as a PennServe Community Based Fellow for Service Learning involving community/researcher partnerships. Recent major projects include developing a model to reach at-risk communities for NCI, the Faith and Organizations Project (www.faithandorganizations.umd.edu), and multiple projects related to social welfare and human services (see home.gwu.edu/~jschneid).