

A Network of Community Partners Representing Multiple Communities: Developing a Tool for Matching Community-Engaged Scholars with Community Partners

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Abstract

The Community Partnership for Ethical Research (CPER) was a multi-faceted research project designed to test a model of community engagement using a network of community partners called Community Advocates for Research (CARs). The goals of the project included developing systems to sustain and expand the CARs network. This article presents one facet of this project—a method of effectively and efficiently managing data about the CARs. User-friendly surveys and a database were designed for the management of these data. The web-based survey allows data capture in the community. Moreover, the web-based database tools facilitate centralized data collection and management that will contribute to the sustainability of the network of CARs beyond the initial grant that provided the funding for its development. This article describes the surveys and database and their utility for other institutions desiring to establish similar networks of community partners.

Introduction

Finding investigators with an interest in a particular research area of expertise in a particular type of research can easily be facilitated by databases maintained by research organizations and institutions. For investigators in institutions interested in engaging the community in research, identifying and defining relevant communities and community members can be difficult. Conducting community-engaged research also requires investigators to address an implicit question: How do we define the communities with which we engaged? Conventional practices, particularly in public health, often lead us to view community in geographic terms—the state, a county, or a neighborhood. However, to truly partner with communities we must think more creatively and in ways that are meaningful to the people of the communities with which we partner. This paper describes a multi-stage process of tracking potential community partners for research that allows university investigators to extend beyond geography into more targeted and functional definitions of community. This method of data collection allows for relational definitions of communities in addition to tradition geographic definitions.

Background—Exception from Informed Consent

The model of university-community partnerships in this research was tested in the context of pre-hospital emergency medicine research. Pre-hospital emergency medicine research poses unique ethical questions related to the protection

of human subjects. The Belmont Report establishes three guiding principles of human subjects protection in research—respect for persons, beneficence, and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Embedded within the principle of respect for persons is the right of individuals to autonomously make decisions regarding participation in research through the process of informed consent. A special type of research conducted without informed consent, Exception from Informed Consent (EFIC) is emergency medical research that meets the following criteria: the patient is in a life-threatening situation where existing treatments are unsatisfactory; further research is needed to establish an experimental treatment's safety or efficacy; the patient is unable to consent due to the medical situation; the medical situation requires the patient to receive immediate treatment before a relative or legal representative can be reached; and protections such as community consultation have been conducted. Additionally, EFIC is only permitted in instances of equipoise, where there is uncertainty regarding whether alternative interventions will confer a more favorable outcome (Baren & Biros, 2007; Ernst & Fish, 2005; Merchant, Rubright, Pryor, & Karlawish, 2008; National Information Center on Health Services Research and Health Care Technology (2010); Pepe, Copass, & Sopko, 2009).

In order to facilitate this type of pre-hospital research, the Food and Drug Administration (FDA) issued regulations commonly known as the Final Rule, governing emergency research conducted

in circumstances where informed consent is not possible (Office of the Secretary, DHHS, FDA, 1996). Approval of EFIC studies requires that investigators work with their local Institutional Review Boards to protect the research participants who are unable to provide informed consent to participate in research. These protections include consultation with the communities from which participants might be drawn, public disclosure of the study and its risks and benefits, and, upon completion of the study, public disclosure of the results. These protections are collectively referred to as community consultation and public disclosure. Although the Final Rule requires that principal investigators plan and conduct community consultation and public disclosure for all research conducted without obtaining informed consent from participants, there are no guidelines for defining the communities with which to conduct the consultation or ways in which the consultation should be conducted. The model that was tested in this project used community consultation as a platform for exploring university/community partnerships. The model suggests an alternative to the more common investigator-driven methods of developing community consultation/public disclosure strategies (Ramsey, Quearry, & Ripley, 2011). This begs the questions of how investigators define the communities from which potential participants may come and how best to conduct community consultation and public disclosure with those communities.

The Community Partnership for Ethical Research

This research was a multi-faceted research project exploring innovative methods for university-community partnerships for community consultation and public disclosure in EFIC research. This model employed community-based participatory research (CBPR) strategies in developing these partnerships (Israel, Schulz, Parker, & Becker, 1998). One long term CPER goal was to create sustainable partnerships through which research projects other than EFIC research could emerge.

One facet of the project is the development of a network of community partners, CARs, who serve as bi-directional conduits of information between the community and the university. The initial cohort of 10 CARs developed a working definition of a CAR:

A CAR is an individual who is involved in his/her community and serves as a

catalyst as well as an effective conduit of information and experiences between CPER staff and the community in order to inform, educate, motivate, and engage the community in ethical research projects that will be used to best meet the needs and interests of the community.

The CAR model was designed to enhance the capacity of the community to influence the research agenda toward issues and needs within the community.

CARs had a dual role in the CPER study. One was as research participants. Their experiences and attitudes were examined to assess the effectiveness of the CAR model. They were given and signed informed consent documents. The university's Institutional Review Board approved this study. The other role was as active partners in the research process. Their research roles included (a) consulting on data collection strategies; (b) collecting data; (c) advising the investigators of two EFIC trials on community consultation/public disclosure strategies; (d) presenting at three national and international conferences; (e) serving as co-authors on publications; and (f) arranging community consultation and public disclosure events. Each CAR was provided an annual stipend for these activities. These research activities and the CAR model are described in greater detail elsewhere (Ramsey et al., 2011).

One of the many activities in which the CARs engaged was to advocate for their communities and present their communities' perspectives on ethics in research and on health research in general. A CAR, on behalf of his or her community, may initiate a dialogue with university investigators grounded in either community or university research interests. CARs may present the university with issues communities identify as important to research or, conversely, link university researchers with appropriate communities in which mutual interests can be addressed through research. The CAR model of collaboration between the campus and community has been designed and developed to promote sustainable relationships that build trust and respect between the various partners in accordance with the principles of community-based participatory research (Israel et al, 1998; Minkler & Wallerstein, 2008; Wallerstein & Duran, 2008).

Initial Definitions of Community for the EFIC Research

A recently conducted EFIC study at the university provided the opportunity to test the CAR model of community-university partnerships. One responsibility of the CARs was to assist with public disclosure for this particular EFIC study. The study to which CPER was attached involved research on pre-hospital emergency treatment protocol for seizures. The nature of seizures is one in which patients are not able to give informed consent to participate. The CPER management team recruited the first cohort of CARs as representatives of two types of communities representing potential participants in the EFIC trial, those at greater risk for seizures and the general population. Some of the potential participants have no previous history of seizures (Silbergleit, Lowenstein, & Durkalski, 2010). Therefore, four of the 10 CARs were recruited from the general community. The remaining potential participants have a history of seizures or a pre-disposing condition for seizures such as epilepsy or brain injury (Silbergleit et al., 2010). The remaining CARs serve as representatives of these communities.

The EFIC study had a catchment area defined by the service area of a metropolitan ambulance authority that serves a mid-sized city in the Mid-Atlantic region. Therefore, community was most broadly defined geographically to include the city limits. Approximately half of the study participants were anticipated to come from the general population in the geographic community including city residents, people who work in the city, visitors, and shoppers. From this perspective, geography served as a meaningful, although incomplete, definition of community.

The urban area in which the study was conducted is predominantly African American (51.8%), and 25.1% of the population lives below the poverty level (U.S. Census Bureau, 2010). The search for CARs to represent the general city population focused on the minority community. Minority and impoverished communities historically have been difficult to reach with effective community consultation (Holloway, 2006; Shah & Sugarman, 2003). Four CARs were recruited from the general geographic community—one from the faith community, two from voluntary social services agencies serving the minority communities of the city, and one from a local government agency serving the minority community.

Factors other than geography may be more

salient to the definition of community. In this case, certain sub-populations (i.e., the homeless, epileptics, or those with brain injuries) are at higher risk for the seizures than the general population. Therefore, the CPER management team identified community groups that would have access to people disproportionately affected by seizures. The CPER management team included a community liaison who identified and approached specific individuals within the designated communities. The liaison had significant experience in community organizing within the metropolitan area, was acquainted with various community organizations, and was well known in the community. Her insights into the broader community proved invaluable for identifying appropriate individuals to serve as CARs. Three of the CARs had ties to the epilepsy community, two worked with the homeless population in the city, and one worked with people with acquired brain injury. The definitions of community utilized to select these CARs were only tangentially related to geography; factors beyond geography (connections to communities that have the predisposing conditions) defined community in their cases.

BUILDING A NETWORK OF CARs

The long-term goal of this project extends beyond community consultation for EFIC research. It includes developing a network of CARs who can (a) advocate for research and their communities across the spectrum of scholarly inquiry impacting health; (b) inform investigators of research questions, problems, or concerns and interests of their communities; and (c) be active participants in the research process. CARs representing communities interested in education, social work, urban planning, business, advocates for groups within the larger community (e.g., mental health advocates or senior citizen advocates), and others were recruited. Regardless of the type of research in which CARs participate, they must have in-depth knowledge of their communities. The goal is to have CARs from all walks of life and assorted communities available to partner in nurturing campus/community connections.

Communities as Defined by CARs

The CARs in the initial cohort were selected because of their connections to specific communities relevant to this EFIC trial. However, people have multidimensional lives. They have connections to multiple communities—e.g., neighborhoods, work,

faith communities, volunteer organizations, and family. The definition of CARs in the CPER model allows CARs to represent various communities in their relationships with the university. They have the freedom to choose if and when they will share their access to the communities in which they have influence. The communities for which they advocate may shift over time based on the perceived needs of the communities and the university, as well as the preferences of the CAR. A CAR from the initial cohort illustrates this point. She was recruited as a CAR because of an interest in and connection to the epilepsy community. However, as she began her advocacy activities, she chose to conduct them in her neighborhood rather than through her connections with the epilepsy community. She is an active member of her neighborhood community and has considerable influence within her neighborhood. Her research activities included coordinating educational meetings, writing articles for the local newspaper, and conducting surveys. Her example illustrates that the CPER model is designed with sufficient flexibility so that CARs may work with multiple or alternate communities, depending upon the topic and design of the research.

A second EFIC study began in 2010 that required the community consultation process. As part of the process of developing an effective community consultation process, the principal investigator for the second EFIC study met with the CARs and requested their participation in community consultation activities. The CARs discussed the opportunity and came to consensus that they would assist with community consultation activities for the second EFIC study. Their participation provided another example of the flexibility of the CAR model and the necessity of understanding the communities that the CARs represent.

Sustaining the Network of CARs

Sustaining a network of CARs requires infrastructure at the university. The Center for Clinical and Translational Research (CCTR) served as the university host for the CARs. It provided the necessary university resources for the CAR network to expand and function. Among those resources is a method of tracking and managing information about the CARs and their respective communities.

CAR and Community Tracking Tool

Development

A functioning network of CARs requires efficient and effective management of information that can facilitate matching university investigators with CARs and communities whose interests correspond with those of the investigators' research interests. The CPER project was a multi-faceted project with both research and administrative components. Developing a tool for tracking CARs and their communities falls into the realm of developing vital administrative infrastructure for growing and sustaining the CAR model of community-campus collaboration.

The CARs began their research activities in December 2009. The original CAR and community tracking tool was developed through an iterative, collaborative process among the CPER staff and the CARs in early 2010. This process resulted in a tool with an entirely open-ended question format loosely based on the University of Kansas Community Toolbox (KU Work Group for Community Health and Development, 2010). The university team created an initial draft of the questions to be included in the CAR and community tracking tool. CARs reviewed and provided feedback through multiple drafts until the final tool was complete. While the open-ended tool provided the requisite information, the data collected through it lacked uniformity and could not be sorted or searched. The CARs expressed that the tool was time-consuming and difficult to complete. Moreover, it was not practical for an expanding network of CARs and communities.

These deficiencies in the functionality of the tool led to revisions driven by three goals: (a) make the survey easier for the CARs to complete; (b) enable the university to develop a searchable database of CARs for future research projects; and (c) construct a tool that is accessible and adaptable for other research institutions to use in adopting this innovative model for their own work.

A series of discussions resulted in a solution involving a five-step process of information-gathering that mirrored the initial tool process but was simpler to use. The process consists of a series of three computerized surveys, a biographical sketch, and an in-person interview of each new CAR by a member of the CPER management team. Table 1 presents each step and its purpose. Each segment of the process will be described in detail.

Web-Based Surveys as Instruments

Table 1. The Five-Step Process of Information Gathering

Step	Name	Purpose
Step 1	CAR Individual Survey	Gather contact and demographic information about the CAR
Step 2	CAR Community Survey	Gather information about the community or communities in which the CAR may advocate for research
Step 3	CAR Research Interests Survey	Gather information about the ways in which the CAR may be interested in participating in research
Step 4	Biographical Sketch	Facilitate interaction and collaboration between the CARs
Step 5	In-person Interviews	Clarify and expand information gathered in the initial surveys. Foster trust and rapport between the CAR and CCTR staff. Explore emerging interests.

for Gathering Information

The original open-ended survey incorporated information about the CARs as individuals, a section describing their communities, and questions about their interests in research. In the web-based version, three separate surveys replaced the original survey. The change was the result of input from one of the CARs, who felt it allowed for more clarity and made it easier to complete. The three surveys are the CAR Individual Survey, the CAR Community Survey, and the CAR Research Interests Survey.

In general, a web-based survey format offers several advantages. CARs can complete the surveys at a time and location that is convenient for them. Project staff can track completion of the surveys. Questions have been formatted with answers that are discrete variables (drop-down menu items and check boxes) or on analog rating scales. The data choice options allow for consistent data categories that can be aggregated and analyzed. Data can be maintained on a secure server owned by the university.

All surveys were constructed using Research Electronic Data Capture (REDCap), a centralized web-based electronic data capture platform (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009). REDCap offers several advantages to investigators, including secure data storage and an intuitive interface for easy data entry.

The surveys were constructed so that they can be easily used by individuals from all walks of life. The survey questions were formatted with check boxes and drop-down menu selections as much as possible to enable the CARs to complete the survey quickly and easily. Comment boxes were also included to allow CARs to provide any additional information or explanations they

deemed necessary. Additionally, for CARs who may not have the computer skills necessary to access the surveys, REDCap can create hardcopy versions of surveys. Project staff can manually enter handwritten information for any CARs who might prefer to complete the surveys on paper.

The REDCap surveys are linked with a REDCap database. This linkage allows the university to develop a searchable database of CARs for future research projects. CCTR staff will assume responsibility

for the ongoing administration of the CAR network. This staff will be able to link community-engaged investigators throughout the university with CARs and communities who share similar research interests using the CAR database. The ability to inform investigators about potential community partners is among the recommended guidelines for community-university research partnerships (Yale CARE Ethical Principles of Engagement Committee, 2009). The database has been designed so that investigators can request access to de-identified data and search for CARs who may potentially be interested in their project. The center’s staff determines which of the CARs chosen by the investigator is most appropriate and facilitate contact between the CARs and the investigator.

The survey templates may be requested by other institutions and adapted to fit institutional needs, thus fulfilling the third goal of the project. REDCap is not required to use the surveys. They could be readily re-created on other platforms. However, REDCap provides a platform to construct a tool that is accessible and adaptable for research institutions with REDCap who wish to adopt this innovative model for their own work. The information gathered in the individual and community surveys and the biography are sufficiently broad to be applicable to any scholarly discipline. The areas of research interest can be adjusted to reflect the research priorities of any institution.

Steps 1–3: Defining the CARs’ Communities of Influence

The community definition process begins with gathering information about the CAR as an individual, about his/her communities of

influence, and about his/her research interests through three REDCap surveys. Once an individual has agreed to serve as a CAR, the new CAR is emailed a link to the CAR Individual Survey, which provides information about the CAR as a person. The remaining surveys may be administered concurrently or later in the process. The survey consists of 24 questions covering general contact information, employment status, educational level, and any special needs the individual might have. Only name, address, and phone number are required fields. The information gathered through the CAR Individual Survey is linked in the database to information from the second and third surveys. In our initial testing of the survey, the average completion time for the CAR Individual Survey was less than five minutes.

CARs, like most people, have connections with multiple communities—e.g., workplaces, faith communities, family, neighborhoods, volunteer organizations. CARs will provide information about their communities through the CAR Community Survey. While CARs have connections with multiple communities and varying levels of influence in each of those communities, it is up to the individual CAR to determine in which communities he/she may be willing to function as an advocate for research. The communities may be formal, organized communities such as a social services agency or a church. However, CARs may also have connections to informal communities, e.g., parents of children with cancer or contacts within a given professional community like social workers in the metropolitan area. The survey allows the CAR to provide a description of up to three different communities.

The CAR Community Survey provides a general sense of the community and is the most extensive of the surveys, with up to 78 questions depending upon the number of communities described. The survey gathers information about the name, type, size, and purpose (if a formal organization) of the community. A series of drop-down menus, rating scales, and check box questions gather demographic information about the composition of the community by race, age, housing situation, educational level, languages spoken, and modes of transportation used. The final three questions are open-ended. They allow the CARs to reflect on the future of their communities and the potential impact of research on their communities. The first question asks for their thoughts about the changes they would like to see in their communities in the next five years and

how they envision those changes coming about. The other two questions ask the CARs to consider what types of information, training, or research would be helpful for their communities. In the initial testing of this survey, the CARs took an average of 10 minutes to describe one community and 17 minutes to describe two communities. No CARs described three communities.

The third web-based survey, the CAR Research Interests Survey, has 10 questions related to potential participation in research. The first asks for the CARs to describe any previous experience with research and, if so, to describe the experiences. Next, the CARs are asked through a check box list about areas of research in which they may be interested. The list includes (a) health, (b) business/economics/employment, (c) domestic/intimate partner violence, (d) education, (e) elder issues, (f) family issues, (g) gender issues, (h) homelessness/affordable housing, (i) race/ethnicity issues, (j) social justice, (k) transportation, (l) urban planning, (m) youth/adolescent issues, and (n) other. A text box appears if the “other” box is checked to describe any other areas of interest.

The next question explores interest in specific research areas such as physical activity for older adults or violence prevention in middle schools. If the respondent indicates that he/she has a specific interest, an open-ended response box appears where the specific area can be entered. The final questions explore specific ways in which the CARs may wish to be involved in research including authorship of peer-reviewed or community publications, serving as a community member of an Institutional Review Board or serving on the Community Engaged Research Review Panel. The CARs will also be provided an open-ended response box to indicate any other ways in which they may care to be involved with research.

Responses to the web-based survey have been overwhelmingly positive. The CARs unanimously expressed that it was easier to use and quicker than the previous open-ended questionnaire. One CAR stated that,

As a CAR, I believe that the revised assessment tool is much more user-friendly and less time consuming. It has served as a valuable tool in gathering information about the different CARs and their areas of expertise in the community.

Time is a valuable resource that CARs dedicate to advocating for research and an efficient

mechanism for collecting data that recognizes and honors the importance of the CARs limited time.

Step 4: Biographical Sketches

Each CAR is asked to write a biographical sketch describing his/her work, volunteer activities, educational background, contact information, and/or any other information the CAR considers pertinent. This information is captured in REDCap and, therefore, searchable by the CCTR staff. The biographical sketches are compiled into a CAR directory and, with each CAR's permission, distributed to the CARs and members of the center's staff. The primary purpose of the CAR directory is to facilitate collaboration and networking among the CARs. The CAR directories will not be distributed to the public or other investigators. The biographical sketch section of the CAR tracking tool and CAR directory remain unchanged from their initial inception other than placing it in REDCap. All CARs indicate the directory has been helpful in developing relationships with other CARs. The directory is seen as a valuable tool to provide not only contact information but also personal information about the CAR such as background, interests, and skills as well as information about their communities. It helped collaboration and networking.

Step 5: Individual Interviews

Individual interviews are the final step of the process. Interviews were conducted with the initial cohort of CARs at times and locations chosen by the CARs after they completed the original survey. We intend to continue this practice. As was done with the initial cohort of CARs, a member of the CCTR staff interviews each new CAR. These interviews are not intended for research purposes but simply to clarify and enhance the information gathered in Steps 1-4. The individual interviews have been designed to serve three primary purposes: clarifying or expanding the information provided through the web-based surveys, building trust and rapport, and exploring emerging interests. These interviews are intended to be conversational and informal. Since they are not intended for research, they will not be based on a structured interview guide but will be unstructured with the information in the web-based survey serving as the starting point of the interviews. In accordance with the purpose of building trust and rapport, no recordings of the interviews are done. The university staff member conducting the interviews takes notes and retains those notes for the files.

Next Steps

Involving communities in research is now an important part of clinical and translational research. This involvement can span from outreach to collaboration and shared leadership. The working definition of community engagement presented by the Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement speaks to the importance and impact of this partnership. It emphasizes,

the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interests, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as a catalyst for changing policies, programs, and practices (Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee, Task Force on the Principles of Community Engagement, 2011, p. 7).

The CAR model has the potential to enhance the ways in which campus-community partnerships can be formed, nurtured, and expanded. Past community engagement projects were often limited to a particular project and did not result in ongoing networking and partnership. The model provides a method of engaging community members on an ongoing basis. While the model is designed to facilitate bidirectional communication with the community regarding research, between and during research projects, CARs can also engage in education and public awareness initiatives as well as engage with students, faculty, and each other.

One potential use of the CAR tracking system is to connect faculty members who wish to have students engaged in service-learning with CARs. Faculty can use the same procedure to access the CAR database to search for community partners for community-engaged learning purposes. For

example, nine students from a community-based program planning and evaluation course within the public health master's program worked with four CARs and their community organizations. In this course the students partnered with the CARs to develop health promotion programs for the CARs' community organizations. This model of student-CAR engagement could be applied to any type of service-learning or civic engagement project for students in a wide variety of courses. This initial experience with student-CAR interaction suggests that such arrangements can be beneficial to both the CARs' communities and the students.

The CAR model and its associated tracking tool provide a highly flexible mechanism for partnering with communities across a wide variety of disciplines. It has the potential to serve as a mechanism for fostering cross-disciplinary research in large research institutions as researchers from various disciplines work with the same CAR and his/her communities. To date the CPER project has spawned several additional research projects developed in partnership with the CARs. One such project emerged from the interests of a CAR in the history of race relations among the local African American community and the university health care system. The project is collecting oral histories of the experiences of older African Americans with the health care system. Another proposed CBPR project involves using personal health records and lay health educators to help African American men manage their blood pressure. These projects center on medicine but bring together researchers from medicine and public health with CARs. Future CARs are being recruited specifically based on interest in women's health, substance abuse, and rehabilitation. However, CARs may be recruited from any community or based on any research interest.

While the initial cohort of CARs was selected based on an ongoing Exception From Informed Consent trial, these individuals helped to define and develop the initial CAR model. As stated above, the CAR model has been created in such a way that it allows for expansion of the CAR network. This expansion includes both a broader range of research projects and expanding CAR research participation. For example, after 18 months, at the end of the original grant, all CARs desired to continue in the CAR network. Individual CARs have subsequently engaged in other research projects, helped write a community newsletter, begun a community needs/health disparity survey, worked with students in service-learning

courses, and participated in community outreach educational programs. They are also serving as mentors for new CARs. While the CAR network is relatively new, the results and outcomes have surpassed the expectations of the university and community partners. The demonstrated feasibility of a multi-stage process of tracking potential community partners for research and its associated database can serve as powerful tools for expanding community participation in research. This process allows for engaging community partners according to community partners' relational definitions of their own communities however they envision their spheres of influence.

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