

Analyzing Perceptions of Community-Engaged Health Research Partnerships Comprising Hispanic Groups and Academic Allies in Indiana

Author

CINDY GIL, Office of Community Engagement, Indiana University-Purdue University Indianapolis (IUPUI)

KARLA ARMENTA, HealthLINK Center, San Diego State University Research Foundation

CAMILA ESPADA, Kelley School of Business, Indiana University-Purdue University Indianapolis (IUPUI)

LEONEL ONTIVEROS-SALINAS, Biology Student, Indiana University-Purdue University Indianapolis (IUPUI)

GERARDO MAUPOME, Richard M. Fairbanks School of Public Health, Indiana University-Purdue University Indianapolis (IUPUI)

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ABSTRACT

Objectives: To analyze perceptions about multiple community-engaged oral health research partnerships with various local Hispanic-serving institutions and community-based organizations occurring in Indiana from 2010 through 2020, via interviews with actors involved in those partnerships.

Methods: We designed key informant interview questions based on a literature review to inform the approach at synthesizing perspectives from community partners and academic allies. Statements were categorized using thematic analysis and grounded theory.

Lessons Learned: Forty percent of respondents stated that community-engaged research projects connect communities with educational information about dental care and low-cost resources. In terms of capacity building, about half of respondents felt these projects had a positive impact.

Conclusions: Community partners defined positive impact as increasing access to dental care educational resources, helping to enhance communication networks through social media with community partners, and contributing to local Hispanic health education through TV, internet, and radio partnerships. The partnerships uniting Hispanic groups and academic allies appear to have helped set a foundation of trust to support current and future efforts in Indiana.

INTRODUCTION

Community-based research is a collaborative approach to conducting scholarly investigations in which power is shared with, and engages, community partners in the process, always aiming to benefit the communities involved. This positive interaction may happen either through direct changes in the life of the community, and/or by translating research findings into subsequent interventions and policy changes (Israel et al., 1998).

There are several different types of evaluation—process, impact, outcome, participatory, formative, and summative evaluations—and multiple data collection methods—quantitative and qualitative—that can be used to evaluate community-academic partnerships (Israel et al., 2012).

The present manuscript describes the findings from key informant interviews conducted to estimate the impact of multiple community-engaged research (CER) partnerships developed between Hispanic community groups and one group of academic allies in Indiana. We consider key informant interviews to be qualitative interviews because they are conducted with people who know “what is going on in the community,” and are selected for their first-hand knowledge about a topic of interest (USAID, 1996). The main themes from the interviews purported to identify improved strategies for enhancing community partnerships, and further support a framework for the integration of findings into ongoing research projects.

METHODS

PROTECTION OF HUMAN SUBJECTS IN RESEARCH

Permission for data collection was approved by the Indiana University IRB (#1703740862, #1709401236). Key informant interview participants did not receive financial compensation for their collaboration.

METHODOLOGICAL CONSIDERATIONS

Various theoretical and conceptual models provide frameworks for understanding and assessing how community-engaged research (CER) partnerships operate, their impacts and their outcomes. Models such as “The Conceptual Logic Model of Community-Based Participatory Research” (Wallerstein & Duran, 2010) and other theoretical models (Lasker & Weiss, 2003; Schulz et al., 2003; Sofaer, 1999) outline how the structural characteristics of the partnership (e.g., attaining membership) influence the group dynamics of the partnership (e.g., communication, or conflict resolution). The partnership’s programs and interventions determine the intermediate measures or characteristics of partnership effectiveness (such as the

degree of member involvement), which in turn influence the extent to which a partnership achieves its ultimate outcomes or outputs (for instance, improved community health outcomes).

PLACING THE PRESENT ANALYTIC ENDEAVOR IN THE CONTEXT OF PRIOR APPROACHES

Our relationship with Hispanic-serving organizations developed through their involvement in past studies. Through these relationships, key leaders in the community were identified and asked to continue working with us to help disseminate resources and information (health education flyers and manuals) that emerged from our previous research projects. To determine the effectiveness of these partnerships we conducted evaluations to ascertain the effectiveness and sustainability of CER partnerships that may take different shapes and forms. Generally speaking, approaches that respect the types of interactions between partners, and that ensure balanced power relationships are preferred. One solid example of such an approach are key informant interviews as they may be used to explore in-depth perceptions and beliefs about CER. We summarize here salient CER experiences in the recent literature.

In one study, key informants shared their perspectives and impressions of medical research, as based on personal experiences or stories from other people (Rodriguez et al., 2013). Interview questions ranged from, “When I say the words ‘biomedical research,’ what do you think of?” to “Would you ever participate in this type of research?” Key informants were also asked if having this type of research was important in the community as well as if there were any group concerns about having this type of research in the community (Rodriguez et al. 2013).

The Tampa Bay Community Cancer Network (TBCCN), involving a cancer center and community-based

organizations is another example. It used a participatory evaluation approach to evaluate perspectives on adherence to CER principles, priorities for cancer education and outreach, and suggestions for sustaining TBCCN and its efforts (Simmons et al., 2015). Semistructured interviews were used to assess each organization's perceived role in the TBCCN partnership, both expected (e.g., "What were your expectations of TBCCN when you first became a partner?") and realized benefits of the partnership, and suggestions for network sustainability and partner capacity building (e.g., "In what ways do you think TBCCN can enhance efforts to improve community partner capacity/skills?") (Simmons et al., 2015).

We used both process and impact evaluation frameworks in a previous CER project which enabled community partners to reflect on the successes and challenges of the partnership. In that study, semistructured interviews were conducted with key stakeholders, revealing main themes relating to the process, quality, challenges and value of the partnership, including navigating and defining equitable roles, relationships, and expectations of the partnership and capacity building within community teams and with the university team (Stacy et al., 2014).

In another example, key informant interviews were used to measure the extent and impact of environmental change in three community-level obesity-prevention initiatives (Cheadle et al., 2010). Interviews with a range of community stakeholders were used as one of the short-term outcome evaluation methods. The interviews assessed the operations of coalition, documented the efforts made to change community environment, and assessed the impact of those changes on residents most directly exposed to obesity-prevention interventions (Cheadle et al., 2010).

In a case involving the Detroit Community Academic Urban Research Center (URC), the evaluation

subcommittee involved academic and community partner representatives. They designed and conducted in-depth, semistructured interviews to assess the process by which the URC had developed and worked toward meeting its objectives and to assess the impact of the partnership (Israel et al., 2012). The topics covered included expectations and hopes for the first year of the partnership and whether they were met; major accomplishments, barriers, and challenges and recommendations for meeting them; personal knowledge or skills gained; tangible benefits from an organization's affiliations with the URC; and examples of exchanges of information or assistance or support between partner organizations (Israel et al., 2012).

CHOICE OF ASSESSMENT STRATEGIES

Different approaches are used to design one-on-one qualitative interviews, varying with the degree of formality or informality required, the use of fully specified questions or topic guidelines, and the degree of flexibility in phrasing questions (Patton, 2002). Despite the different approaches, an emphasis is placed on asking open-ended questions, with follow-up probes as necessary, allowing a respondent to provide an in-depth explanation of the issues being addressed. Patton (2002) noted other aspects should be considered, including whom to interview, where to conduct the interview, recording, note-taking, informed consent, confidentiality, and approaches for data analysis. Furthermore, evaluation tools have assessed the effectiveness of CER projects using start-point, mid-point, end-point, and post-project evaluations. Examples of indicators used at start-point evaluations include community capacity, organizational capacity, and historical context of collaboration. Indicators in process evaluations could inquire about involvement in recruiting study participants, collecting data, and interpreting study findings. Indicators in output and outcome evaluations might include academic publications, community presentations, and community

and organizational development (Nash, 2016).

Our approach was simpler, aiming to incorporate a wider perspective of CER between long-standing community partners and academic allies that encompassed several projects carried out between 2010 and 2020. The academic allies have largely amalgamated around a research program led by Gerardo Maupomé. The various CER projects have focused on oral health, oral health knowledge, perspectives on dental care and access to dental treatment; general health and mental well-being; food/drinks/snacks choices; the architecture and evolution of social networks in well-established and in recent Hispanic immigrants to Indiana (Maupomé et al., 2016; Maupomé et al., 2016; Pullen et al., 2018; Lopez-Owens et al., 2018; Pullen et al., 2019) including various aspects of acculturation and integration, such as use of language, adherence to new and old social and cultural traditions, and psychosocial interpretation of the world; and socio-economic-demographic variables. Because of the diversity of CER projects over several years, it was unfeasible to conduct start-point, mid-point, end-point, and post-project evaluations for each project. A mosaic of projects were considered to estimate the perceptions of impact of outcomes over the 10 years of such CER collaborations (Appendix 1).

DESCRIPTION OF PARTNERSHIPS INVOLVED IN THE PRESENT ANALYTIC ENTERPRISE

We have gathered extensive data over 10 years of robust CER collaborations. While this poses a challenge for us to describe in detail each individual partnership, a content analysis following principles of grounded theory unearthed some common themes. Each partnership followed general features that have been replicated over discrete CER endeavors. Namely,

1. The academic allies maintained a fluid exchange and collaborations on non-CER related aspects, e.g., sharing information about funding resources that might be

attractive to community groups. The flow of information also included pieces relayed in the opposite direction, i.e., from community groups to academic allies.

2. Community groups encompassed multiple entities. Specifically, Hispanic businesses, employers with large Hispanic populations, parishes and temples with substantial Hispanic congregations, parochial schools affiliated with such parishes; community advocacy groups; informal and formal networks targeting recent immigrant families, with community workers and volunteers being charged with supporting assimilation of children to American education systems (academic level, remedial efforts, and language acquisition).

3. Community groups participated in various CER projects over the years – some only once, others multiple times. The availability of community groups' resources, transition periods, financial health, and other varying factors led to the opportunity and the willingness to participate.

4. Community members were always compensated for their time, with childcare and refreshments often being available.

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6. Community members had substantive input in the creation of scholarly products and chose whether or not to be part of the authors' line up.

Explicit efforts were always present to engage community groups on an equal footing for research design with academic allies. Some specific examples of this include monthly (for local partners) or quarterly (for partners throughout the state) visits to their community sites and communication via email on research progress.

STUDY DESIGN AND POPULATION

The key informant interview questions were developed based on a literature review and discussions with the team of community groups and academic allies. An interview script was created and translated into Spanish. Three areas were identified: research process evaluation, perceived value of research for the Hispanic community, capacity-building strategies to further engage community, and preferred research format for working with Hispanics. The team postulated that there are unique characteristics of Hispanic immigrants compared with other minoritized populations. It was our goal to gain greater insight into how to better design, cocreate, and conduct CER with Hispanics living in Indiana. The interviews focused on research programs involving Hispanic communities from Mexico, El Salvador, Guatemala, and Honduras, which made up most of the Hispanic population in the area during those years.

DATA COLLECTION AND VARIABLES

To collect data, two university students were trained to complete key informant interviews. The interviews were conducted over the phone in either English or Spanish. Eligibility criteria for interviewees were a) to be a leader in the Hispanic community or an academic ally, b) be of Hispanic ancestry, and/or c) to have participated in any of the CER projects. Twelve key informants were recruited through an email invitation, identified from a list of community partners and academic allies and having been involved currently or in the past as supporting programs addressing health and wellness of Hispanics. The phone interviews took place over a two-week period following the email invitation. If no response was received, a follow-up call was made to make sure questions or concerns were addressed. The original number of planned interviews was 12, and 10 were conducted. Interviews lasted 25 to 30 minutes and were audio recorded, and responses were transcribed.

INTERVIEWS

Key informant interview consent was obtained at the beginning of the interview. No personal identifiers were collected. Key informants were informed that the interview would be recorded to ensure the collection of accurate information. While most interviews were conducted in English a few key informants preferred conducting their interviews in Spanish. Using a prepared script (Appendix 1), participants were encouraged to expand their responses and provide details when appropriate and were allowed time to think about the questions and responses. The script presented questions related to capacity-building efforts, CER related to oral health, and practices for building engagement through CER. Each key informant was interviewed individually.

Interview core statements were categorized by staff. A number of the questions were met with a “Do not know” answer, or “I have no information specific to this question.” Rather than considering these categories as ambiguous, we believe respondents felt at ease to answer frankly during the interview. In this perspective, where respondents did answer the remainder of questions, that information did in fact signify first-hand experience, or carefully weighed responses to the standardized questions. Respondents were encouraged to speak about their experiences and recollections of the projects, and they were told to omit answers for any reason they felt appropriate (e.g., respondents were not involved in that aspect of the project or did not know about it).

DATA ANALYSIS

Transcribed interviews were thematically analyzed using grounded theory. We developed a codebook, with emerging categories driven by the narratives. Simple frequencies and proportions of categories were calculated from the aggregated collection of categories across all respondents.

Results

The following is a description of the key informant participants. A total of 10 participants (each representing a local Hispanic-serving institution or community-based organization) took part in the impact assessment study (seven female and three male). Five had directly worked as partners with the CER team, and all reported that they enjoyed working with the team. Below we present the themes that emerged during key informant interviews.

Most positive aspects of project

Forty percent of respondents stated that the CER studies mentioned served to connect communities with educational information about dental resources. Another 40% of respondents stated that the CER projects increased the Hispanic public's knowledge of dental care.

Project success

The CER projects had a positive impact among the Hispanic community in Indiana, according to 40% of key informants.

Feedback from community members

Forty percent of respondents indicated they received positive feedback from community regarding CER experiences. In fact, two respondents shared stories of clinicians making use of the educational material developed through an oral health education manual.

Contribution to building capacity

When asked if the CER studies contributed to building capacity in the Hispanic community, 60% of respondents confirmed they believed those projects in fact did so. Respondents were allowed complete control in describing how "building capacity" emerged from their views. Specifically, two key informants indicated that community members shared that the CER experiences helped to educate and connect the community to free or low-cost dental care services. We learned of the need for health educational resources

from previous research projects and materials were developed with the participation of community. These resources are now used by the community to share health knowledge.

Local assets and resources

Key informants pointed to the potential to collaborate with other projects or groups who have similar goals of advancing health education among the Hispanic community. Others indicated that concrete dental care resources were most helpful.

Activities you believe have increased a community's knowledge of health topics

Informants shared that the oral health manual was helpful in increasing the community's knowledge of health topics. Additionally, community partners recognized that the CER team has done strong work in outreach, promotion of findings from the studies, and recruitment of individual CER study participants.

Improved process of building capacity

Key informants had various suggestions for how the research team could continue to build capacity in the Hispanic community. In fact, 40% stated that the CER team could work more closely with community partners, and 50% stated that the best way to conduct CER data collection was face-to-face. This supports consistent use of surveys done one-on-one. It was reassuring to find that 60% of participants thought that community interests were represented throughout the CER projects.

Community partners would like to receive more information about the status of current CER projects. It is clear that community members see value in the approach and initiatives, thus supporting this involvement. Suggested ways to further involve the community include providing updates and information about the events the CER team will attend. 40% of informants shared they would like to receive updates about the progress of CER projects.

EDUCATION AND KNOWLEDGE

Increasing access to dental health education was identified as vital by many key informants. Forty percent of respondents shared that through the CER projects listed, the community was able to receive educational information about dental care. Specifically, the navigation manual was utilized by the community. Clinicians provided examples of how patients used this resource to advocate for themselves during dental visits. The value of having resources that speak to targeted Hispanic communities has proven effective, rather than attempting to provide ‘one-size-fits-all’ resources meant to address concerns across all Hispanic communities. In the case of the navigation manual, this resource focused on newcomers from Central American countries (Guatemala, El Salvador, and Honduras), utilizing language and cultural nuances specific to this population.



Figure 1: A guide for the care of teeth and mouth for communities from Guatemala, El Salvador, and Honduras. The guide currently is being used by community partners throughout the state.

Another common theme gathered from the key informant interviews is that in order to continue making

a difference for patients in dental care, Hispanic communities need to learn about dental care options. By collaborating with partners throughout the state, the CER team has compiled a list of low-cost or free dental care resources. This list is periodically updated, openly disseminated, and also provided to community members as requested. Key informants verified that this resource has been invaluable to increase the agency of individuals to have greater knowledge and advocacy tools to negotiate their way around dental care challenges

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DISCUSSION

This is a qualitative analysis of perceptions about various research projects. Based on the variety of impressions derived from the key informant interviews, we learned that community groups and academic allies are aligned in the process of CER knowledge and resource cocreation of dental health education and local dental care resources. The CER partnerships seem to have led to more Hispanics living in Indiana gaining greater understanding about access and awareness of dental care. Through shared CER involvement, community groups take part in the decision making and shaping of research agendas, and academic allies

gain greater clarity to guide future directions and engagement opportunities with the community. CER partnerships therefore can facilitate further engagement opportunities as directed by community leaders. Additionally, engagement should be sustainable through simple and accessible communication with community stakeholders, facilitated through paper and e-newsletters, open forums or roundtables, as suggested by community partners.

However important our estimates may be, some methodological considerations apply to the straightforward design we created. While key informant interviews provide rich information and contribute to an enhanced understanding of evaluating community-academic partnerships, they are labor and time intensive, requiring resources and skills on the part of the interviewer (Patton, 2002; Israel et al., 2012). Additional challenges include the time constraints on the community partners, the degree to which members of a CER partnership have input into the design, implementation and interpretations of the partnership's evaluation, and whether the evaluation should be led by an individual or team external and without a vested interest in the partnership (Israel et al., 2012). Perhaps of greater importance is the need to recognize that the

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evaluation methods used, and the questions asked in partnership and impact evaluation, may need to evolve over time as a CER partnership evolves. Tolma et al. (2009) describe how community-academic partnerships go through different phases or stages and the dimensions

that need to be evaluated change over time.

Within the constraints of our approach, it appears that shared power and capacity building can be estimated through assessment efforts such as the present perception analysis. CER lessons may be used to support the implementation of actionable processes where new knowledge can be generated by both academic allies and community members, leading to aligned and improved partner practices that support better health access and equity.

Together with other peer-reviewed and public announcements resources derived from the research enterprise under analysis, we aim to offer practical advice and real-world resources to support the acquisition of community-relevant tools. The following are the key takeaways from the present report:

1. Hispanic community partnerships can serve as a tool for enabling communities accessing resources.
2. Through key information interviews we learned how community – through descriptions in their own words – benefitted from past community-engaged research projects, and also about areas that need improvement.
3. Connecting to various levels of the community, above and beyond the specific goals of the research project, is a vital part of a community-engaged research partnership.

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APPENDIX 1

Key informant interview guide

Informant Code:

Interviewer Name:

Date:

Location of Interview:

Interview Start Time:

Interview End Time:

Introduction

Hello. Thank you for agreeing to participate in this interview to help us evaluate your partnership with a community-engaged research (CER) project. You are being asked to participate because you are a valued member of the community or an academic ally in current or past CER projects. The purpose of this interview is to facilitate a reflection and evaluation of the CER project and your partnership. We are asking these questions to learn about your experiences, so that we can better understand how the projects perform, and how it can be improved to better meet its mission.

Everything you say will be strictly confidential and anonymous. We value your insight and expertise, so we'd like you to share, in your own words, the successes, any challenges, as well as any outcomes that you feel may have come from this CER project and your role. There is no right or wrong answer to any of the questions that I will be asking today. The interviews will be audio-recorded and transcribed by a member of our research team.

Let's begin.

Demographics

1. Please describe your role in the community or the academic organization.

Process Evaluation Overall Assessment of the CER projects.

1. Could you briefly describe your knowledge of or role in the CER projects led by Gerardo Maupome, which you have collaborated with?
2. What were the most positive aspects of your involvement with the CER project?
3. In your opinion, how successful was the CER project in the community? Did it add to the Hispanic community's knowledge of health issues?
4. In what ways is the CER project benefiting the community, or has benefitted it? Probe: How could the CER project improve its benefits to or value in the community?
5. What feedback, if any, did you receive from community members regarding the CER project?

Capacity Building

1. Do you believe that this CER project contributed to building capacity in the Hispanic community? (capacity building: allows individuals and organizations to perform at a greater level)

Yes/No

Probe: Please explain. E.g. Increase knowledge

2. To what extent and how has the CER project helped community organizations and members recognize and work with their assets and local resources?
3. If applicable, which activities do you believe have increased a community's knowledge of health topics as a result of the CER project?
4. Looking forward, what suggestions do you have to improve the process of building capacity within your community?

Research

1. What do you believe is the best way to do CER with the Hispanic community?
2. Do you think that community interests have been represented and assured in the CER project?

Probe: Please explain why or why not.

Overall Impression

1. Given your experience with the CER project, what advice do you have for us in the future?
2. Do you have any other comments and/or questions you feel are important to you as a key informant of this impact assessment?

Probe: If yes, please describe.

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