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The Recruitment to Dissemination Continuum in Community-based Participatory Research

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Abstract

Background: Dissemination of research findings to participants and communities, particularly among traditionally marginalized groups, is a systemic challenge. In community-based participatory research (CBPR), long-term partnerships may foster a link between recruitment to research studies, dissemination of results, and recruitment to future studies.

Objectives: To analyze the recruitment to dissemination continuum of a CBPR study and its potential impact on partnership processes and future research.

Methods: We conducted a qualitative study with four focus groups with community members and academic partners who participated in the recruitment and the dissemination of research findings from a study of Hispanic and Somali social networks in Rochester, Minnesota. Thematic analysis and coding of focus group transcripts was conducted by investigators. The CBPR conceptual model for this partnership guided the analysis.

Results: Trust, relationship building, and capacity building were key features for successful participant recruitment and

research dissemination strategies. Strategies, resources, and relationships used or developed during the recruitment phase of research were directly applied to planning a dissemination event. Participants and members of their communities said they were more likely to participate in future research studies as a result of attending a dissemination event.

Conclusions: This study demonstrated the ways in which recruitment of marginalized populations to research studies and dissemination of study results can manifest as a continuum. This continuum is nurtured by trust, longitudinal relationships, and robust partnership dynamics. These factors fit well within an existing CBPR conceptual model.

Keywords

community-based participatory research, community health partnerships, community health research, health disparities, health outcomes, health promotion, power sharing, process issues

The dissemination of research findings is a critical component of late translational research, but dissemination remains focused on academic audiences despite multiple studies demonstrating that research participants desire to know the key findings of studies in which they were involved.¹⁻⁴ This discord is related to a host of pragmatic challenges to dissemination, including time and financial constraints, meeting the needs and goals of various stakeholders,

literacy and cultural differences, and preserving the anonymity of participants while sharing meaningful results.^{1,5-7}

Dissemination is especially important in research involving racial and ethnic minorities where trust in research has been eroded by repeated research behaviors that have ranged from disrespectful to criminal. Immigrants and refugees, like other vulnerable populations, are at risk of being subject to unethical research behaviors.⁸

Community-based participatory research (CBPR) is a research approach that is uniquely poised to bridge this dissemination gap among marginalized populations. In CBPR, community and academic partners have an equitable relationship and share their expertise through all phases of research.⁹⁻¹¹ Collaborative dissemination of research findings to study populations and communities is a key principle of CBPR, and trust building is a critical element in developing a dissemination plan.^{9,11-13}

A variety of approaches have been utilized to disseminate research findings in a participatory context, including meetings, community forums, television programs, newspapers, phone calls, and e-mails.¹⁵ In all of these approaches, collaboration between community and academic partners was important in the development of a dissemination plan.¹⁴ Nevertheless, Chen et al.⁵ found that dissemination beyond scientific publication was reported in only 48% of 101 CBPR studies included in their systematic review.

A successful dissemination strategy may also have the potential to impact recruitment for future research. A single qualitative study with Hispanic, Marshallese, and African American participants examined perceptions and preferences regarding researching dissemination.³ A key theme was that dissemination of research findings encouraged participation in future studies because participants perceived a positive impact of research on the broader community. This recruitment to dissemination continuum is a potentially powerful mechanism to sustain CBPR partnerships and to iteratively follow a line of inquiry that addresses community priorities. This continuum and its perceived impact on partnership processes have not been explored previously.

In this article, we specifically address the link between recruitment of participants and dissemination of research findings in studies from a single CBPR partnership. We conducted a qualitative study of the complementary recruitment and dissemination processes surrounding a large cross-sectional social network survey study conducted by an established CBPR partnership.^{15,16} The aims of the current study were to explore effective mechanisms of participatory recruitment of research participants to the survey study and to a subsequent dissemination event, and to investigate the link between recruitment and dissemination.

METHODS

CBPR Partnership Description: Rochester Healthy Community Partnership

In 2004, a community-academic partnership developed between Mayo Clinic and Hawthorne Education Center, an adult education center that serves new immigrants. This partnership matured by formalizing operating norms, adopting CBPR principles, and adding partners from multiple sectors.¹⁷ The Rochester Healthy Community Partnership (RHCP) has developed an effective community-based research infrastructure that has facilitated extensive research training for community partners.^{18,19} RHCP has become productive and experienced at deriving health promotion interventions with immigrant and refugee populations.²⁰⁻²² Community and academic partners jointly conduct every phase of research, disseminate results together, and co-author scientific products.

In 2017, RHCP adapted an empirically derived CBPR conceptual model through an in-depth participatory evaluation process, which we have previously described (Figure 1).²³ The conceptual model domains articulate the contextual factors and partnership dynamics that underpin research processes and outcomes. RHCP uses the model to reflect on the partnership and the key factors that contribute to successful development of data-driven assessments and interventions in community-based settings.

Parent Studies: Healthy Immigrant Families and Social Network Survey

In 2015, RHCP completed the 5-year Healthy Immigrant Families study to improve physical activity and nutrition of Hispanic and Somali families after immigration, which showed improvements in the primary outcome of healthy eating.²⁴ Community and academic partners reflected on the high rate of obesity among study participants and the power of social network effects on health behaviors, and decided to explicitly address obesity in the next intervention iteration, Healthy Immigrant Community, by adopting a social network intervention for weight loss.^{15,16}

In 2017, RHCP partners conducted a social network survey among Hispanic and Somali adults to assess feasibility of a social network intervention. The survey collected data on

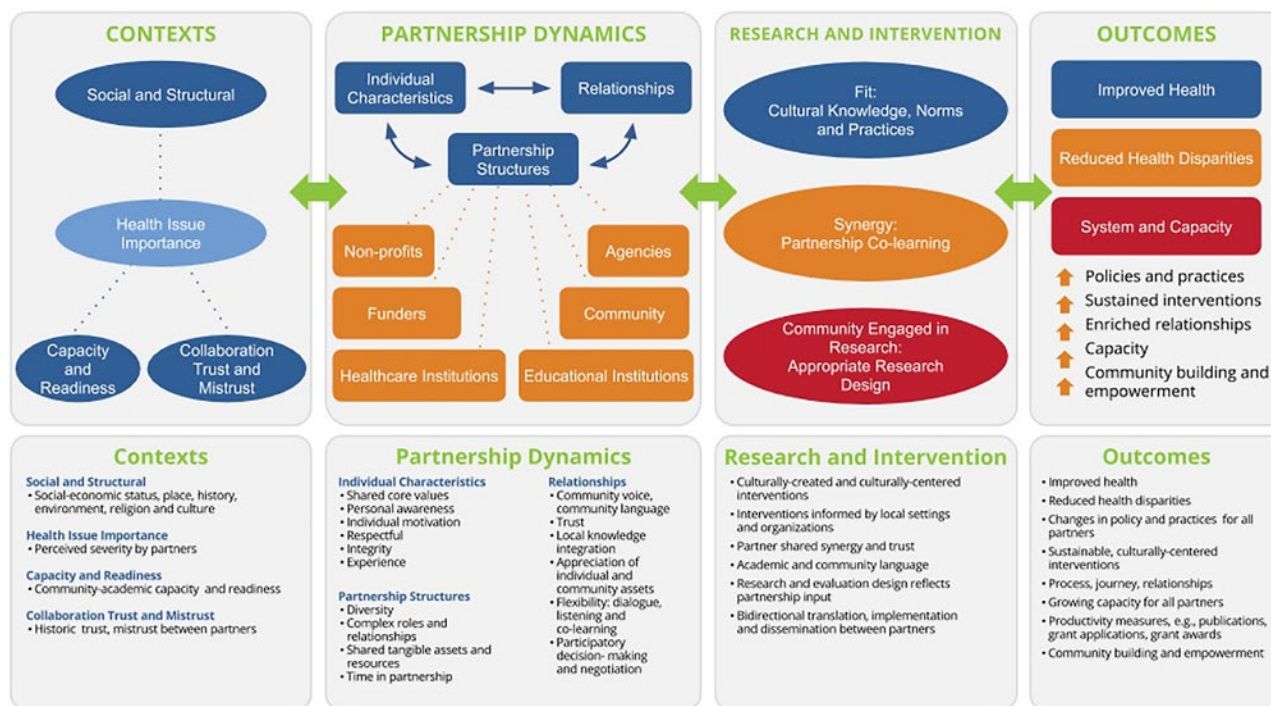


Figure 1. Rochester Healthy Community Partnership (RHCP) CBPR conceptual model. The original CBPR conceptual model was developed by Wallerstein N, Oetzel J, Duran B, Tafoya G, Belone L, Rae R. CBPR: What predicts outcomes?

In: Minkler M, Wallerstein N, editors. Community-based participatory research for health, 2nd. San Francisco, CA: Jossey Bass; 2008. pp. 371–392 and adapted for RHCP by Reese et al.²³

demographics, health behaviors, theory-based measures, and biometric measures (height, weight), and asked participants to identify members of their social networks. Participants (610 Hispanic and 646 Somali) were recruited by RHCP community partners and bilingual study staff through community organizations, religious institutions, community events, word of mouth, and referrals from participants of the Healthy Immigrant Families study. Study results confirmed the hypothesis that obesity clustered within social networks and that network factors were associated with weight loss intentions in both communities.^{15,16} The results of the Social Network Analysis study were shared among RHCP community partners then disseminated through a community-wide event attended by 150 community members held at a school. Data were presented in English, Spanish, and Somali.

Current Study: Recruitment to Dissemination Continuum

Participants in the current study included the community and academic partners who were involved in the parent

studies. The aim was to explore their experiences in the parent studies, especially their perspectives on recruitment and dissemination activities, in order to understand how the RHCP CBPR continuum impacted partnership processes and future research potential. Community partners were involved in the design of this study, including development of the data collection instrument. They also reviewed study results and gave input on interpretation. The study protocol was approved by the Mayo Clinic Institutional Review Board (ID: 18-006177).

Data Collection. Four focus groups were held between July 2018 and February 2019 with RHCP academic partners (*n* = 6), RHCP community partners (*n* = 8), and community members involved with study recruitment in the Hispanic (*n* = 8) and Somali (*n* = 9) communities. Participants were recruited by purposive sampling from RHCP members and volunteers who directly participated in recruitment of participants and dissemination of study results for the parent studies. Focus groups were conducted by an experienced language-congruent moderator. Written notes were taken and

focus groups were digitally recorded, transcribed, and where appropriate, translated, with permission from participants.

Focus group questions inquired about the research dissemination process in the context of CBPR, the extent to which there were links between dissemination and research participation, and recommendations for future dissemination events (Appendix 1). Some focus group questions were adapted from a previous qualitative study describing the process and community response to the dissemination of research results.²⁵

Data Analysis. The analysis used methods of directed content analysis, which is an analytic approach that employs existing theory in identifying topics or codes in the data as well as in discussion of findings.²⁶ The RHCP CBPR Conceptual Model served as a theoretical guide for analysis.²³ First, members of the study team performed an interpretive reading of the transcripts and identified manifest and latent content, including those related to recruitment strategies, barriers, and facilitators and excerpts that exemplified constructs of the conceptual model. They then developed a coding framework that was applied to transcripts and mapped categories onto broader themes, which were presented to the broader study team for discussion. Coding discrepancies were discussed as a team and consensus was reached. The study team also used group discussion to reflect on how the RHCP CBPR Conceptual Model helped explain RHCP's experiences recruiting community members to the survey and subsequent community dissemination event, as well as how the dissemination event may go on to subsequently influence future recruitment efforts.²³ RHCP community partners reviewed and revised the content of thematic analysis. Analysis and queries were facilitated by NVivo-11 software (QSR International, Pty. Ltd.).

RESULTS

The results are presented below using the RHCP conceptual model as a guide. Figure 2 portrays the recruitment to dissemination constructs within the model's domains.

Context

The model's attention to Context helped explain the successes and challenges of recruitment to the social network survey and community dissemination event. Contextual factors included political rhetoric on immigration, which

was both a barrier (mistrust) and an opportunity for fostering trust.

One of the biggest things, one that has already brought up, which was the timing of . . . this basically started after a major election in the United States that left immigrant and refugee communities with a sense of isolation and . . . mistrust of institutions. (Academic partner)

I think a nice sideline to this is that in spite of the election or in some cases because of the election, more trust was built where you would've thought it would be just the opposite. People in this room and elsewhere dove in and supported the community and said, 'we do not agree with what's been said and we're sorry. We are here and we stand with you,' sort of thing. (Academic partner)

Research that asked for personal information was also subject to community (mis)trust. Successful recruitment in this context was described as being built on trust.

[P]eople were scared that we can give this information about phone numbers, addresses. And I have to promise them that I will protect the information. (Community partner)

Context also included the existing relationships that underpinned capacity and readiness, especially the experience of community members who were previously involved in outreach for other RHCP health-related studies. They were confident that their community could enroll large numbers of people because of their past success. Their status in the community helped smooth recruitment for the study assistants.

Partnership Dynamics

In terms of Partnership Dynamics, the success of recruitment was often credited to individuals who were committed, experienced, and motivated, and who were able to connect with community members.

Every time that we went from one of those recruitment events, I would be surprised at just how . . . easily they were able to . . . break the barriers, talk to them, the

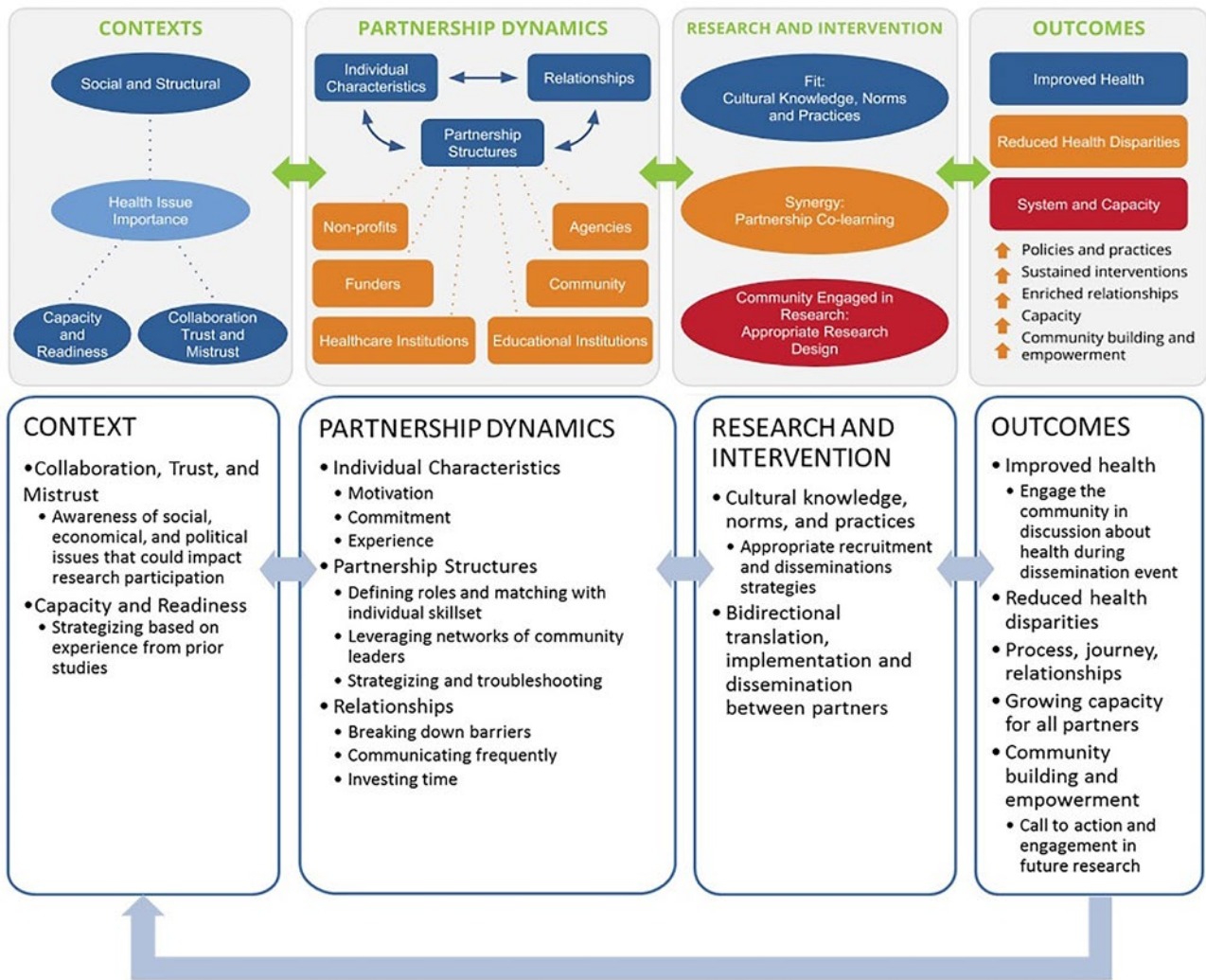


Figure 2. Mapping recruitment to dissemination constructs to the RHCP CBPR conceptual model.

participants, and within no time, we would be completing surveys. (Academic partner)

And kudos to the research directors because they got the right people for the job like [names of recruiters]. The right people that knew people. (Somali participant)

They also credited existing partnership structures and relationships. Participants spoke about the time they spent fostering relationships while troubleshooting recruitment issues. They also spoke about the process of learning from each other. Time in relationships was described as an investment. Researchers let recruiters develop flexible strategies and learned from them, holding frequent meetings to

discuss progress. Lessons were learned about time and place of recruitment and gender or age concordance for recruiters and participants.

Participants also described the development of trust in decision making between academic and community partners on the study team. A key example is when academic partners ceded control over survey recruitment strategies to community partners. Recruiters used their local knowledge to tailor recruitment strategies to “fit” norms and practices of unique communities. For example, they noted that they could leverage bigger events (e.g., church services) for the Hispanic community recruitment, but they needed more one-on-one approaches in the Somali community.

Sort of trusting their expertise . . . whereas I might bring some expertise about survey design to the table, they bring that expertise of . . . that recruitment piece. It would be silly for me to say ‘well, you should think about this kind of recruitment.’ So that’s really leveraging that expertise. (Academic partner)

People who were members of the community who helped specifically recruit females, so like [mentions names of recruiters] who has a store right next door to where [another recruiter] has an accounting business, so she would just bring people over to help that would come in her store. (Academic partner)

Research and Intervention

In terms of Research and Intervention, the research strategies had a high degree of fit with cultural knowledge, norms, and practices, and it was that fit which participants attributed to successful recruitment. There was also familiarity between research team members and potential participants; recruiters tapped into their personal networks, such that people approached for the survey were contacted by someone from the team who they knew. This was especially important for survey recruitment because the survey included personal and sensitive questions.

[W]hile you still had to explain to them what this project was about . . . that component of trust was already established. (Community Leader)

We trust each other since we are a community with connection. It is easier for us to, you know, to include people to participate during the recruitment. (Somali Participant)

Similar to the negotiation of partnership dynamics, the research was bidirectional. Community recruiters were instrumental in knowing when to use targeted strategies and when to build collaboration between communities. They used local knowledge to set the date for the event, so that it did not conflict with other important events, such as a wedding in another part of the state that would be attended by a large number of members of one community. Academic partners described being nervous about whether proposed strategies would work, but when they put their trust in

the community partners and recruiters, recruitment was successful.

I think it was also the idea to have that joint event came from the Community partners, so we didn’t float this idea at all. We thought we were going to do individual things for each group. (Academic partner)

And within the survey too, I mean, basically it just shows that both community have the same issues that we deal with. We have the same goals, same desires and all of that. . . . We might be a different culture, but at the same time, that we have a lot in common. (Community Leader)

Outcomes

In terms of the Outcomes construct of the RHCP CBPR model, the dissemination event was a strategy for sharing health information and engaging the community in conversations about health, which supports community building and empowerment. It served as a call to action for some participants. It also helped demonstrate the commitment of RHCP to stay in the community and continually engage the community in planning, recruitment, and dissemination activities.

We have to tell the community that it’s their community; it is their data. We are just facilitators. . . . It’s their information—that we were talking about . . . And it was worth it. But we still have to sell that. The data that we got is the most important thing. That now we know that, yeah, we need to do something about our health. (Community Leader)

One of the most important outcomes at the RHCP level was increased capacity-building for the partnership, and in fact a post-event survey found that the vast majority of attendees felt much more confident that people in their community can work together to improve the health of the community. That work may bolster context and partnership dynamics, setting RHCP up for success in future recruitment efforts. Finding new leaders and growing the RHCP network may create a more sustainable model. Through discussions about the survey or attendance at the dissemination event, recruiters engaged other community members with RHCP to become involve in other RHCP activities.

Some of the people who were involved in the dissemination now have come to RHCP meetings even after that has ended. I think identifying, too, leaders like [other participant] said and building relationships . . . and I think it gives some visibility to RHCP, including in the news media, which, I think, is overall good and may help in the future with recruitment for other studies. (Academic partner)

Likewise, those who attended the dissemination event and saw the study results as a call to action for the community were motivated to continue to be involved. The joint nature of the event was also hailed as an opportunity to grow local relationships between members of the research team, the Hispanic community, and Somali community.

It is good to know how our community can connect with each other . . . There is a lot of help in creating data for the community. There are contacts. The research helps the community in many ways, and now we have the connections and resources to solve the problems in the community. (Somali Participant)

The community can use this information to help the Somali community. There is not a lot of information available about the Somali community. Some other communities are well established. This fills gaps in the data about where the problems are. We have a lot of things that we need to track. It is hard to provide solutions through a lot of nonprofit that work with the Community that want to do the best they can but they reinvent the wheel and if you have data supporting the issues it is hard to . . . This is a very good first step. (Somali participant)

I was still interested in knowing what happened with the other part the study—with the Somali community. (Hispanic participant)

An extended group of, most of them were participants in the survey who were also seen of kind of as leaders within their communities, and that was a group of 20 some beyond the core group of community partners that really made this a more inclusive event, and we saw faces that we haven't seen before, and that really broaden the reach. (Academic partner)

DISCUSSION

The aim of this study was to explore the link between recruitment of research participants and dissemination of research results through a line of inquiry within a single CBPR partnership. The results of this study highlight the ways in which past collaborations impact the success of the recruitment process. Dissemination of research findings led community members to trust that RHCP will consistently share what it learns, making them more likely to participate in future studies. Study participants felt that they had individual and collective ownership of the data, so the dissemination of results gave them a sense of empowerment for next steps in building community health through CBPR. Dissemination of the social network survey study results have directly facilitated recruitment for the pilot social network intervention study, entitled Healthy Immigrant Community. This recruitment to dissemination continuum is shown in Figure 3.

Trust and relationship building were common threads. Trust built over time as relationships developed, and our data suggest that community members participated in large numbers because of trust in RHCP (based on past experiences) and trust in RHCP community partners. This trust was challenged by the timing of the study, which launched just prior to national election results that resulted in fear and mistrust of institutions among many immigrant communities. Possibly as a result of this fear and mistrust, the study team initially faced a challenge of low recruitment. Recruitment increased significantly only when community partners took complete control of survey recruitment and implementation strategy. This transition from collaboration to true power sharing was another manifestation of trust between community and academic partners. This is consistent with previous literature showing CBPR fosters trust since community members participate in all steps of the research process.^{13,27}

Dissemination in the context of CBPR can be a bridge-building exercise celebrating diverse participants and perspectives. The dissemination event for the social network study was unique in that it involved two distinct communities (Hispanic and Somali)—the approach was adaptable enough to tailor future recruitment by community-specific factors, but it also demonstrated the potential to find common purpose. While there are challenges to this format (e.g., linguistic,

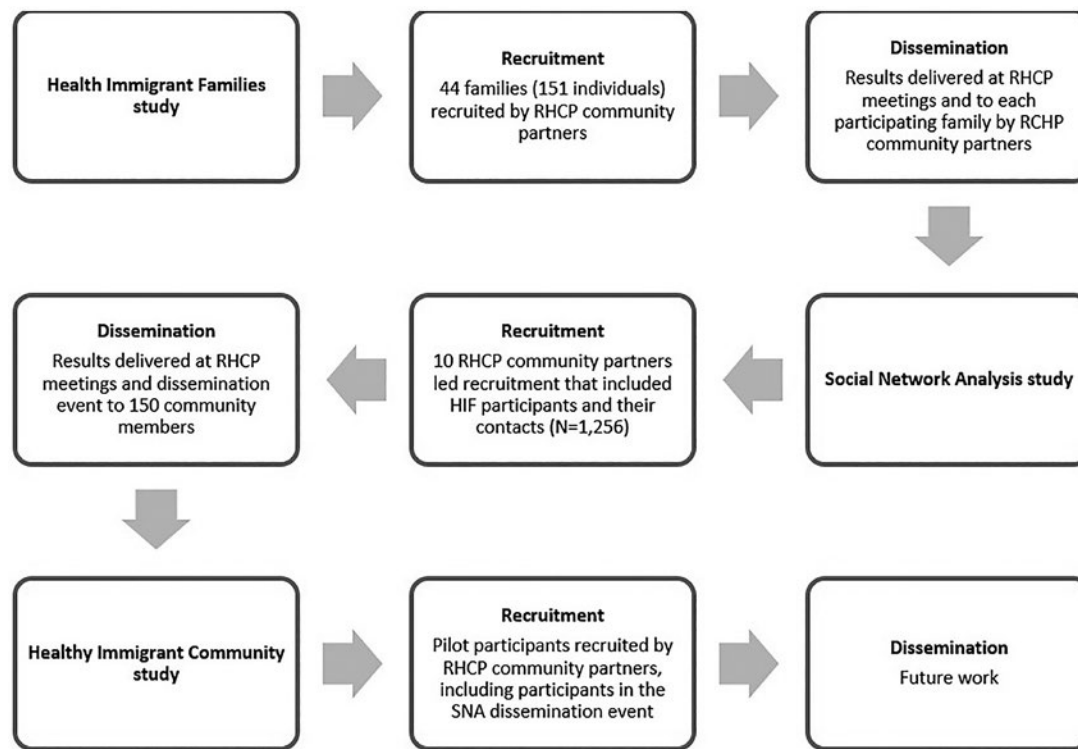


Figure 3. Example of RHCP recruitment to dissemination continuum.

religious and cultural heterogeneity), RHCP has operated from a position of strength through diversity of partnership participants.

The cyclical nature between dissemination of research findings and recruitment for future studies in a CBPR context may allow partnerships to more iteratively build on a line of inquiry that addresses community priorities, while growing the partnership through demonstration of on-going commitment. This suggests that the recruitment to dissemination continuum is a potential mechanism of sustainability of CBPR partnerships. Future research is needed to explore this interface between recruitment, dissemination, and sustainability for partnerships such as this one.

Sustained long-term relationships help to build equitable partnerships and promote mutual benefit.²⁸ Community partners in this study felt that they had an equal voice in research design and implementation decisions.⁹ These findings may also inform efforts to design and implement community interventions that meet the needs of community members and foster community capacity. Models that combine elements of CBPR and dissemination and implementation frameworks

may bridge the study of sustainable partnerships and intervention adoption and sustainability.⁶

Capacity building and community empowerment are central to successful community-engaged research,²⁹ and these processes are embedded throughout the CBPR continuum in a way that continually interweaves each initiative's success and challenges with the on-going capacity of the partnership. A community's capacity to conduct individual CBPR projects increases over time, which can lead to more efficient recruitment and dissemination processes for future work.³⁰ The community partners in this study highlighted the importance of strategizing and building on prior experience when recruiting participants. Relationships with community members who were recruited for past studies, in this case the Healthy Immigrant Families study, facilitated recruitment for the social network analysis study. The dissemination of results through this process and in such an event also serves to bring research concepts close to the community as a whole, highlighting the important role of the community as a research partner. This, not only has the potential of identifying new community champions or leaders, but the active involvement

of previous research participants in sharing results with the members of their own community, can serve to bridge the gap between research and communities.

The following recommendations emerged from the data of this study for fostering the recruitment to dissemination continuum within CBPR partnerships. First, during the dissemination of research findings, it is important to contextualize study results within the broader health and equity priorities for the community. Individual studies are often incremental, so it is critical to link them to the partnership's "big picture" goals. This approach also serves as a call to action for future research participation. Second, community and academic partners should incorporate dissemination planning in the context of recruitment for future studies from the outset. This planning may be achieved through a partnership work group dedicated to sustainability planning. Third, relationship building and trust are central to sustaining a viable recruitment to dissemination continuum. Relationship building helped RHCP bring new people into the group, which has grown its network of committed partners. This dedication to fostering partnership dynamics had led RHCP partners to conclude that process is their most important product.²³ It is notable that one of the parent studies used a social network approach, which is a study design based on interpersonal connections, for example, for information dissemination. This research approach may have contributed to higher levels of community trust, as well as helped build the social infrastructure that aided dissemination activities. While formal social network methods (e.g., relationship surveys and network statistical analysis) may not be part of all CBPR research studies, the approach to engagement of participants through personal connections in social networks is an important aspect of CBPR.

This study has several strengths, including the involvement of community members in study design and interpretation of findings. This study has limitations. It was conducted by a single community-academic partnership in one city, with implications for generalizability to different historical contexts, participant populations, and geographic regions. While the sample size was relatively small, the data were sufficient for a robust qualitative examination of the recruitment to dissemination continuum, which incorporated the view of multiple stakeholders. Furthermore, there are no long-term data yet on research participation from the dissemination

event attendees. Future studies should explicitly explore participant's intentions to participate in future research, and their motivational underpinnings.

CONCLUSION

This study demonstrated the ways in which recruitment of research participants and dissemination of study results can manifest as a continuum with the CBPR context. The extent to which recruitment of marginalized populations to research studies is successful, depends in part on the success of past dissemination activities. This continuum is nurtured by trust, longitudinal relationships, and robust partnership dynamics. These factors fit well within an existing CBPR conceptual model.

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THE RECRUITMENT TO DISSEMINATION CONTINUUM IN CBPR

| Focus Group Question Matrix | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|
| Question | Purpose/Intent |
| 1 What was your role in the Social Network Analysis study? | Introductions/get everybody to talk |
| 2 Let's start by talking about recruitment to the study. What was your experience like in recruiting community members to complete the survey? How did you go about that? | Identify extent of community participation in recruitment |
| 3 What recruitment strategies did you find to be most successful? Why? Did you change how you did things over time/how did you discover what was working well? What might you do differently next time? Why? How would you describe community involvement in recruitment? What lessons learned would you share with other communities that might want to do a study like this one? | Identify strategies/factors that led to successful participant recruitment |
| 4 Dissemination of research results is an important component of community based participatory research, meaning that when we finish a study, we want to share what we learned with the community. The results of the social network analysis were shared with community members at an event in May. What are your thoughts on this event? How well-received do you think it was in your community? Why? What would you describe as the outcomes of this event? | Identify extent of community participation in results dissemination |
| 5 What are your thoughts on whether we have been successful or not in terms of sharing of information in the community? | Determine if results dissemination was achieved in this study |
| 6 What did we do well? What work still needs to be done to share the results of this study? What could we do differently with future studies? | Identify strategies/factors that led to successful dissemination |
| 7 We've talked about community involvement in recruitment and community involvement in dissemination (or sharing) of the results. How do you think those two things are related, if at all? Was there anything about how we did recruitment that impacted how we were able to share results—good or bad? | Identify links between recruitment and dissemination |
| 8 How do you think the experience of this study might affect recruitment for future studies, if at all? (Probe for impact of recruitment and impact of dissemination) | Identify link, if any, between results dissemination and recruitment for future studies |
| 9 We talk a lot about "process" in community based participatory research, meaning that community members should be involved in all phases of the research and that researchers and community members should be continually going back and forth in working together. What are your thoughts on how this study has impacted the involved communities? | Identify any additional impacts of the dissemination of results to the community |