

A pragmatic view of community-engaged research: Case studies of multi-sectoral public health partnerships

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Abstract

Esistono vari approcci alla ricerca collaborativa, come la ricerca partecipativa basata sulla comunità, la ricerca-azione partecipativa, la Community-Engaged Research. Questi e altri paradigmi vengono utilizzati in base alla loro adeguatezza rispetto agli obiettivi di progetti specifici. In questo articolo si discutono tre progetti di salute pubblica che hanno utilizzato differenti modalità di collaborazione con i diversi *partner* di progetto in due contesti urbani negli Stati Uniti. Queste riguardano l'accesso e la fruizione dell'assistenza sanitaria presso ospedali pubblici e privati, problemi di salute e di sicurezza sul lavoro tra i lavoratori del settore alberghiero. Questi progetti hanno implicato la collaborazione con *stakeholders* di diversi settori e vari metodi di raccolta dati. Si analizza dunque il prezioso materiale raccolto, le intuizioni e le sfide per un rigoroso studio di progettazione e la validità dei risultati raggiunti grazie al coinvolgimento di diversi *partner*, e si avanzano suggerimenti per portare avanti simili ricerche collaborative.

There are various approaches to collaborative research, such as Community-Based Participatory Research, Participatory Action Research, Community-Engaged Research. These and other paradigms are used based on their suitability to the objectives of specific projects. We discuss three public health projects that employed different ways to partner with diverse stakeholders in two urban settings in the USA. They involved health care access and utilization at private and public hospitals, occupational health and safety issues among resort hospitality workers. These projects involved collaboration with stakeholders from different sectors and data collection methods. We discuss the valuable access and insights as well as challenges to rigorous study design and validity of findings presented by engaging with diverse partners, and provide recommendations for carrying such collaborative research forward.

Parole Chiave: Community-engaged research; salute urbana; ricerca con metodi misti

Keywords: Community-engaged research; urban health; mixed-methods research

Introduction

Various approaches to conducting collaborative research with academic researchers, community organizations, and other non-academic entities, such as governmental agencies and donors, have been carried out over the past several decades.

These projects have been variously referred to as community-based participatory research (CBPR), participatory action research (PAR), community-engaged/centered/involved research, community-academic partnerships, to name a few. Moreover, these paradigms have been informed by different conceptual or theoretical models and employ a wide range of methodological approaches, all of which have been described in detail in the literature. While some approaches, such as CBPR, have been very explicitly defined (Israel *et al.*, 1998; Israel and Schulz, 2003), other terms have been used interchangeably for projects involving academic and community partnerships to varying degrees.

Early on it was understood that community-engaged efforts could allow for research to be conducted in more culturally sensitive ways, such as addressing research questions of genuine interest to different communities, while potentially increasing the accuracy of the findings and the relevance of intervention approaches (Minkler, 2005). That said, communities are dynamic entities; thus, 'community-identified issues' may not necessarily be considered important to all or even most members depending on the process used to elicit information from the community (e.g., a few influential leaders vs. more inclusive participatory processes). This and a host of other *challenges* to this approach of health-related research have been extensively documented alongside a similarly impressive list of possible *benefits* (Mayan and Daum, 2016; Darling *et al.*, 2016; Horowitz, Robinson and Seifer, 2009; Minkler, 2005).

An important development along the way has been the expansion of this paradigm from use in intervention-oriented research emphasizing change in individual behaviors and settings to efforts more focused on higher level policy change. However, success in effecting change in policies is related to having partners with knowledge of local power structures and the type of evidence that can best support desired changes (Freudenberg and Tsui, 2014).

In public health, such collaborative relationships between community and academic partners have been increasingly used to examine health inequities and promote health equity (Coombe *et al.*, 2018; Collins *et al.*, 2018; Frerichs *et al.*, 2016; Cacari-Stone *et al.*, 2014; Israel *et al.*, 2010; Wallerstein and Duran, 2010; Wallerstein and Duran, 2006).

Yet, despite the increasing popularity of these partnerships, there is a lack of consensus in the field regarding what defines 'success' with community-academic partnerships and how to measure factors contributing to their possible success (Brush *et al.*, 2020; Sandoval *et al.*, 2012). In practice, developing specific measures of success may be a somewhat futile exercise since the nature and goals of community-engaged projects vary widely as is illustrated in the next section.

This paper describes experiences from three studies to illustrate the different ways in which public health researchers can carry out community-engaged research based on the topic of concern, stakeholders involved, external timelines and available resources. The key themes discussed pertain to: diversity and complexity of communities; establishment and negotiation of stakeholder roles; potential for multilevel (e.g., individual, community, policy) interventions/outcomes; adaptability of methodology to situational conditions and constraints; and, variation in measuring success due to the inherently different nature of community-engaged projects. Taken together, the 'lessons learned' from these case studies demonstrate how such research paradigms may, contrary to conventional scientific expectations, defy uniform classification. Indeed, 'achieving research impact through co-creation' in community-based health services research requires accepting the non-linear processes in this work and adaptability as the research or programmatic activities unfold (Greenhalgh *et al.*, 2016).

Case Studies in Community-Engaged Research

We have conducted numerous public health projects in collaboration with diverse stakeholders (i.e., members of relevant communities). The impetus for these projects has varied, which is largely related to the level of stakeholder involvement as well as the research methods used to carry out the projects. Moreover, the project goals, research questions, and time frame have generally informed *what* data get collected and which types of data collection *methods* are employed. As such, every community-engaged research project has been necessarily different and with its own unique set of challenges and opportunities.

This section describes three public health community-engaged research projects involving academic researchers at a public school

of public health (SPH) in partnership with different stakeholders in two urban settings in the United States. For the two projects in New York City, the researchers' pre-existing relationships with various health department, municipal, and community-based organizations were the basis for initial discussions that led to co-development of the collaborative research projects. With regard to the project in Las Vegas, one of the researchers (PV), an expert in organized labor and occupational health and safety at the SPH, initiated discussion among union and SPH colleagues to co-develop the research project. As researchers in community health at an SPH with an explicit mission to advance social justice, engagement in community-based collaborative projects is both valued and supported.

The case study descriptions focus on a) the main public health issue or topic that motivated the project and the way in which the community-academic partnerships came about; b) the research question or programmatic goal of the projects and methods employed; c) the level/nature of partner engagement; and d) the key findings and reflection on the partnership. Given that the focus of this paper is aligned with the journal's theme of «Overcoming and Challenges of Action-Research in Making Better Urban Worlds» we intentionally devote less of the discussion to the findings of the respective research projects and more to the nature of the community-engaged collaborations and ways in which they functioned and addressed their ostensible goals.

Case Study 1: A Public Safety-net Hospital Serving Diverse Immigrant Populations

Context and project initiation

The New York City (NYC) public hospital system (NYC Health & Hospitals) offers health care services through a dramatically reduced fee-for-service program called *Options* for those without private health insurance and ineligible for government-sponsored health insurance schemes (e.g., undocumented immigrants). Yet, the program had been under-utilized; thus, hospital administrators and community stakeholders wanted to know why and understood that participatory processes had been shown to be well-suited to use with immigrant groups (Vaughn *et al.*, 2017). An executive of the hospital system (NYC H&H) who

oversaw its department on community partnerships reached out to the city's school of public health to identify an academic research partner (this author). We worked together with more than 30 members of the hospital's community advisory board to determine the research questions and study design, develop the study proposal, and obtain funding. The project was funded by a private health-focused donor and was expected to be completed within one year.

Research questions and methods employed

There were three main questions we sought to address, which were developed through extensive collaborative deliberations involving the main partners: hospital administration, community leaders whose organizations serve the targeted immigrant groups, and the school of public health researchers (Romero and Flandrick, 2019). First, what was the level of awareness and knowledge of the *Options* program among members of the target immigrant communities in NYC? Second, why did people enroll or not enroll (if eligible) in the program? And thirdly, we sought to learn about enrollees' experiences with the program while asking non-enrollees what they would want from it *if* they participated. Thus, we developed a preliminary qualitative study design that we felt was best suited to elicit the factors driving participation in and experiences with the *Options* program. The hospital administrator convened the advisory board of community-based organizations (i.e., stakeholder groups) that serve immigrant populations to consider the proposed research questions and study design during a half-day meeting. This meeting involved much interactive discussion, including proposed revisions, resulting in the final research questions (above) and a qualitative study design comprising focus groups with community members and key informant interviews with organizational leaders.

Project implementation involved close collaboration with eight community-based organizations to conduct 21 focus groups divided between community settings and hospital facilities in all five New York City boroughs, and conducted in six languages with eligible users and non-users of the *Options* program. Figure 1 illustrates the complex sampling approach, which allocated four focus groups per city borough/immigrant group divided equally between community and hospital settings (to

stratify by *Options* program users and non-users) for a total of 20. Due to pressure from some community members, one more focus group was conducted to include an additional immigrant group; yet it was clear that it would not provide enough data to achieve saturation. The second phase of data collection involved compiling an extensive list from project partners of leaders of immigrant-serving organizations. We developed and applied a rubric to categorize individuals on the list to ensure that the final selection of key informants provided broad-based representation regarding immigrant groups, occupational, social and health-related services. A total of 15 key informant interviews were conducted. This allowed for approximately 3 to 4 interviews per category and saturation of themes in the data collected.

Level/nature of partner engagement

Our hospital and community partners were extensively involved in various aspects of the project. With regard to the sample, hospital administrators consulted utilization data to identify the newest linguistic groups that were using hospital services over the previous 6 to 12 months. They hypothesized that members of these groups (e.g., Fujianese speakers) would likely lack health insurance at higher rates than those from more long-standing linguistic groups (e.g., Spanish speakers). These data were then considered with on-the-ground knowledge from community leaders of recent arrivals to the country, such as Spanish-speaking immigrants from Central American countries as compared to members from more established Spanish-speaking groups such as those from the Dominican Republic. As experts in research methods, we guided our community and hospital partners through an extensive collaborative process to develop the complex sampling design described above. This is one place where community priorities for inclusion trumped sound research design in that the partners ultimately agreed to include a focus group for an immigrant group not among the key target groups.

Our partners co-developed the focus group and interview guides and translated them into the languages of the communities they served, while we orchestrated the forward-backward-forward translation process to ensure the integrity of the translations. We co-moderated all focus groups with the respective community

partner. And while we offered to engage in collaborative data analysis, all partners preferred that the academic research team undertake the initial analytic process and then convene to discuss the preliminary findings and provide feedback to be incorporated into the final results and recommendations. This is a common approach given that researcher partners typically bring data analytic skills to these collaborations while the community partners contribute their substantive expertise in review of initial findings. This often leads to additional analyses and more nuanced interpretations of the data. We then shared a draft of the near-final report and again elicited feedback from the community-based and hospital administration partners prior to its finalization.

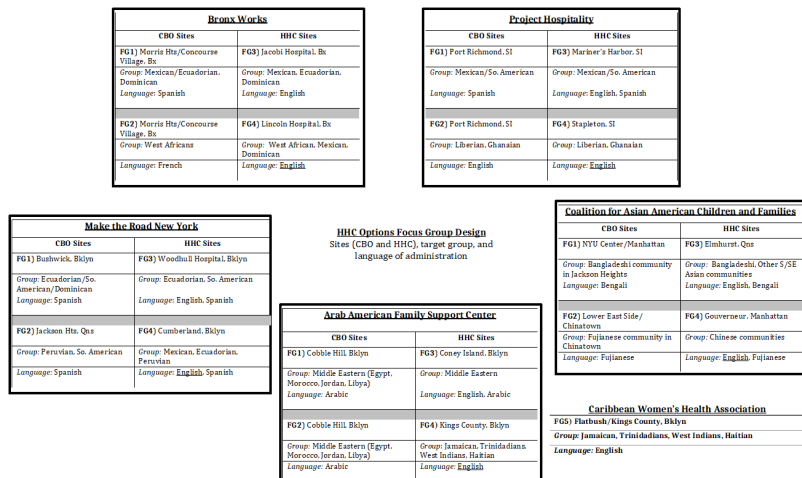


Figure 1. Community-based focus group sampling frame for the NYC H&H project (Permission to reprint from original journal of publication is pending.)

Main findings and partnership reflection

Key findings revealed low awareness of the *Options* program among eligible populations, the need for greater community-based outreach efforts that address concerns regarding immigrant status and potential discrimination, and fear of high medical bills and long-term debt associated with participation. This and the more detailed findings provided hospital administrators and collaborative partners with a deeper understanding of factors driving participation in the *Options* program, their experiences using it (e.g., satisfaction, discontent, services utilized), and how it could be improved – all of which can inform changes to the

program's policies going forward. From our perspective, the process was not researcher-driven – we followed the *initial* lead of hospital administrators in focusing on key populations from hospital utilization data, with the valuable corroboration (or not) of those data from community partners with on-the-ground knowledge. While deferring to our partners' respective expertise regarding the program and the target populations, we provided leadership in rigorous study design, sampling, field recruitment and data collection approaches and analysis.

Case Study 2: A Long-standing Private Safety-net Hospital Serving Low-income Communities

Context and project initiation

In 2010, St. Vincent's Catholic Medical Center (St. Vincent's) in NYC closed after 160 years of providing health care services to the community regardless of ability to pay. When St. Vincent's closed, the surrounding communities also lost an emergency room, in-patient hospital facilities, a Level 1 trauma center, several outpatient clinical services, and capacity to address widespread public health emergencies such as a natural disaster or act of terrorism. Even though health services were available from other health care providers in the community, local residents, elected municipal officials, and community-based service providers were concerned as to whether the hospital closure resulted in gaps in health care services. In response to pressure from myriad community groups to document the impact of the hospital closure, a Community Health Needs Assessment Steering Committee, comprised of diverse stakeholders, was formed by municipal leaders of the community boards from the two districts closest to the hospital. A lead elected official (i.e., Speaker of the New York City Council) on the Steering Committee reached out to the author and colleagues to contribute expertise in community health research to the project. Funding came from municipal funds accessed by this legislator as well as funds the researchers obtained from a NYC-based private philanthropy.

Research questions and methods employed

The objective of the project was to address the following four questions: what was the community's experience with health

care access, utilization, gaps, and quality prior to and post-closing; were there any unmet health care needs; what was the most significant effect of the hospital closure; and, what were key recommendations for improving health care in the community going forward (Romero, Kwan, Swearingen *et al.*, 2012; Romero, Kwan, Nestler *et al.*, 2012). A mixed-methods study design was developed, including 7 focus groups with residents and service providers in the community; 16 key-informant interviews with leaders of diverse community-based organizations representing residents and/or providing health and social services; and, an online community survey (n=1438) in English, Spanish, and Mandarin Chinese. The focus groups and key informant interviews were intended to collect data from two important perspectives (i.e., two units of analyses): *individuals* affected personally by the hospital closure and *organizations* (i.e., service providers) that were experiencing greater demand for services since the hospital closed.

Level/nature of partner engagement

In this community health assessment project, we were an integral part of the more than 40-member Steering Committee, which included four New York State legislators and four NYC elected officials, as well as representatives from residents' groups, health care providers, and advocates for people with special needs including those with HIV/AIDS, seniors, people with disabilities, mental health and substance abuse problems. We followed a community-based participatory approach from the outset seeking input and guidance from the Steering Committee with regard to the research questions, proposed data collection methodologies and instruments (i.e., interview guides; survey), data sources (i.e., key informants; focus groups), and sampling and dissemination strategies. This involved much discussion and negotiation; for example, given the short (6- to 9-month) time frame for the assessment and population-representative sampling challenges, our initial recommendation did not include a community survey. The Steering Committee, however, strongly advocated for an approach that would be more 'inclusive' of the community and result in a larger amount of data (i.e., a survey) to make a potentially stronger case for recommendations from the findings. We agreed as long as the scientific limitations that would accompany a non-

representative quantitative sample were understood.

With regard to the qualitative data collection, the Steering Committee members' deep knowledge of the community meant that they were able to identify a wide range of participants and informants for the focus groups and interviews. However, the number of focus groups and key informant interviews conducted were skewed toward the Steering Committee's preference to include as many voices from affected groups and stakeholders as possible. Thus, the design reflected a negotiation with community members and the data collected had more breadth than depth, affecting our ability to reach saturation across themes.

Finally, the combination of our partners' substantive knowledge with our research expertise resulted in a highly collaborative process to develop the data collection instruments. We had the main responsibility for data analysis but shared the findings to the Steering Committee as they were being generated at regular monthly meetings, which allowed for useful feedback and clarity to inform the final results. Overall, as a result of the high level of interaction with members of the community represented on the Steering Committee, the research process benefitted from their knowledge and expertise, including problem definition/issue selection, research design, and conduct of the research.

Main findings and partnership reflection

The findings from this project were extensive and reported in two related peer-reviewed reports, as well as via community-level dissemination modalities, such as in-person town hall meetings (Figure 2), and newsletters from community boards and elected officials to neighborhood residents. In short, respondents spoke positively of the hospital's accessibility, comprehensive, high-quality services, and the close relationship that it had with the community; the majority did not identify any unmet health care needs while the hospital was open. Conversely, experiences since the hospital closed were largely negative, including decreased access, interrupted care, and loss of emergency and specialty care, which appeared to be associated with a year-long state of 'limbo' and interrupted care described by many with chronic illnesses. A key cross-cutting issue was the concern for and potential impact of the hospital's closure on particularly *vulnerable groups*. We felt that the *expanded* study design resulting from Steering Committee

members' insistence on inclusion of a survey was incredibly beneficial. The survey findings both corroborated themes that emerged from the qualitative components (i.e., triangulation) as well as allowed us to study other important issues. Furthermore, its larger sample size certainly carried weight with policymakers who quickly acted on several key findings from the project, such as disseminating a guide to residents on area health and social services providers given the finding that many reported not knowing where to access such services.

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Figure 2. Example of ongoing public modes of dissemination of project activities
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Case Study 3: Occupational Health and Safety Issues Among Resort Hospitality Workers

Context and project initiation

In the United States, the services sector represented 81% of the workforce in 2015 and employees in the 'Leisure and Hospitality' segment of this sector are compensated relatively low compared to other type of service jobs. Low-wage jobs that lack benefits also face occupation-specific exposures to workplace hazards that vary by employment settings, such as industry sector and union presence. Non-union casino workers occupy a range of occupational categories and may be exposed to situations threatening their health and safety. A Las Vegas, Nevada-based local chapter of an international union representing workers in the casino industry sought to understand the health- and safety-related experiences of specific occupations among non-union casino hotel employees to identify processes leading to worker health and safety risks. A researcher colleague of this author, specializing in occupational health and safety and who had previous experience with the union, initiated discussions to collaborate on a study that could go beyond preliminary anecdotal data that they had collected (Romero, Flandrick *et al.*, 2018).

Research questions and methods employed

The key research question we wanted to answer was «what are the health- and safety-related experiences of hospitality workers in four occupational categories: porter, kitchen staff, hosts/servers, and guest room attendants»? This project fell into the paradigm of action research as the findings were intended to inform the worker organizing efforts of our one partner, the local union representing workers in several different occupations in the casino industry. The union staff had developed a topic guide and conducted a few focus groups, but they recognized the need to partner with researchers to produce more systematic and rigorous findings.

We developed a study design comprised of approximately 12 focus groups stratified by the four occupational categories noted above, which would allow three focus groups per category. An additional focus group was conducted to reach saturation of data

themes. Stratification by occupational group was maintained as that was the variable most strongly associated with different health and safety exposures. Further stratification, e.g., by gender, would have required double the number of focus groups, which was not feasible in light of limited resources. That said, a gender analysis was possible given the data collected; yet, occupational characteristics remained the key driver of health and safety risk.

Level/nature of partner engagement

Following our review of the data collection instrument and transcripts of the data collected from the initial focus groups that our partners conducted, it was clear that the questions in their original topic guide were not obtaining the type of rich data that is possible from a qualitative method like focus groups. As such, together we revised the topic guide questions so they would be more open-ended and yield richer data. In addition, we included a post-focus group survey to collect the categorical data on work activities that was more conducive to close-ended questions.

As our union partner had valuable, pre-existing trusting relationships with workers at different casinos in the community, they were ideally suited to recruit workers at non-union properties for the focus groups while ensuring confidentiality so as to not jeopardize their employment. The focus groups were jointly carried out by a union staffer with relevant training (MA in anthropology) and the public health researcher with expertise in occupational health and safety. As a group, we reviewed the important research elements associated with conducting focus groups to improve the quality of the data collected. Given our research expertise, we initially analyzed the data and then engaged in multiple, iterative discussions with our union partner regarding the emerging findings. The write-up of the final conclusions and report involved an *extensive* collaborative process.

Main findings and partnership reflection

The main findings from this project demonstrated myriad and ever-present adverse work conditions that threatened the health and safety of casino hospitality workers in four different

occupational groups. A framework (Figure 3) of non-union employee health and safety risk emerged, strongly implicating upper management’s overt lack of concern for employee health. Inconsistency in employer-controlled factors (e.g., work schedules, policy enforcement) perpetuated a lack of concern that played out in different levels of the work environment. For example, worker concerns about losing their jobs if they raised health and safety concerns led to their greater exposure to health and safety risks (e.g., reluctance to report injuries or request protective equipment or tools), which exacerbated already compromised health and safety conditions. Given the action-oriented goal of this research, our union partner used these findings to advocate for improved worker conditions with employers and for unionization among workers. They also provided support for two workers to co-present the project findings at a national public health conference and collect signatures for a union-related petition. The collaborative partnership in this project was mutually beneficial. It was clear from the pilot data collected by the union that their results would have been limited, hampering their ability to advocate from a solid evidence base. As public health researchers committed to applied research that can advance social justice, this work resulted in one of those rare moments when the findings were disseminated and resulted in a dialogue with employers as well as unionization of several properties.

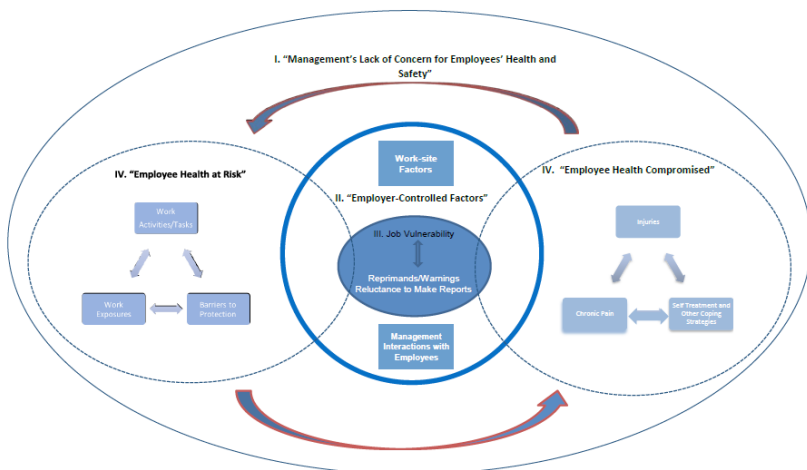


Figure 3. Framework of non-union casino employees’ health and safety risk (Permission to reprint from original journal of publication is pending.)

Discussion

The three projects described above are just a tiny representation of the wide range of health topics that can be addressed, and study designs and data collection methods that can be employed, for collaborative, community-engaged projects in urban settings. They also demonstrate that the types of stakeholders that public health researchers might engage with span across many sectors including governmental entities, health and social services departments, hospital systems and health care providers, and civil society groups such as community-based non-profit, trade, and other advocacy organizations. The main issues raised related to decisions concerning study design, partner involvement, and data integrity and ownership, such as the findings reported and means of dissemination.

As with other forms of research, the study design and data collection methods are usually based on those most appropriate to address the key research or programmatic questions. That said, community-engaged research may dictate that partnering researchers employ research methods *other than* what they might otherwise use. For example, when in-depth qualitative data is sought, one-on-one interviews might be the 'preferred method' for collecting confidential information on a sensitive topic. Yet, we might instead collaboratively conduct focus groups with our community partners following their guidance that the individuals they serve (e.g., immigrants with different cultural practices) would more likely provide the information in a group setting with others from their culture (as in Case Study 1). We have encountered situations like this on many occasions and have had to weigh multiple factors, such as the potential benefit of collecting more valid data versus being less able to protect the confidentiality of the data (as in Case Study 3), or adding another data collection modality (e.g., survey) because our partners want to include more of the community (as in Case Study 2), thus requiring more fundraising to support additional project components. Because our partners are typically experts in the substantive *topic* of inquiry, a key part of our contribution to these collaborations is providing instruction on the research process, methods of data collection, and factors that affect our confidence (or not) in the findings (Darling *et al.*, 2016; Mason *et al.*, 2013). Oftentimes this requires explaining *differences*

across methods and why some are better suited to addressing certain questions and issues than others, including the common misapplication of quantitative criteria (e.g., sample size and generalizability) to qualitative approaches.

Another important issue pertains to agreement on the findings, particularly those considered 'unwelcome' if they do not support the goals or mission (or contradict them) of our non-researcher partners. In Case Study 2, a major finding from the community was that they were most concerned with loss of an emergency department. Yet, when another hospital in the region announced plans to open a 'free-standing' emergency department, some partners challenged this research finding due to concerns that it could be used to support establishing the free-standing emergency department when they wanted an *entire* hospital.

Another common scenario regarding 'unwelcome findings' is when the project results might be equivocal. As researchers, we know that our studies do not always produce concrete results, particularly when a new idea is being explored. In an exploratory project that engaged diverse community stakeholders to consider the idea of establishing a structure for supporting primary-prevention community-health initiatives (Romero, Echeverria *et al.*, 2018), the donor that we collaborated with hoped for a definitive 'position' from the community. However, while there was certainly positive interest in the notion of such an initiative, the findings did not support our concluding that it was something the community *wanted* and was ready to undertake. While we understood the donor's desire for a clear indication of whether or not to move forward with this initiative, we had to remind them of our responsibility to be guided by the research results regardless of its outcomes.

A somewhat opposite situation is when the partner may seek to *minimize* the extent of the findings out of an abundance of caution. The study results from our project on occupational health and safety risks to casino workers (Case Study 3) were welcomed by our union partners but, as a business entity, all products of their work needed legal review. We agreed to the *review* but not to being bound by the legal approval decision given the principles of ethical conduct of research to which public health researchers are held. It was not surprising that such a legal review would tend to err on the side of caution and as such recommend that some 'emphatic' statements be 'toned down'

or deleted, presumably out of fear that they might be challenged by the casino industry. Thus, we engaged in an extensive process of negotiation and compromise with our partners in revising the report to produce a final version that we felt stayed true to the findings yet addressed their legal concerns.

Challenges and benefits in community-engaged work

There are a host of challenges and benefits associated with community-engaged public health research in addition to those noted above. A foremost challenge is the effort and time needed to establish meaningful and trusting partnerships (Drahota *et al.*, 2016). However, there is an inherent quandary that both researchers and community-based organizations face in that it is only in actually working together that most meaningful relationships develop, yet typically a *commitment* to partner together is first required in order to obtain funding for a *possible* future project. Thus, while relationships should ideally be established before proposing collaborative work they really require the extended time of working on a project together to take form. Once a project is underway, the time required to collect and analyze data and produce findings is usually longer than the amount of time available to inform decision-making around urgent issues. As a result, researchers must often concede some aspects of the study design to meet external timelines (e.g., policy decisions being made within a legislative session).

Dynamics and differences among collaborating partners can present different challenges. Researchers may worry about their credibility if, for example, the results of the collaborative work are reported by partners who may not present the findings with the scientific caveats or limitations that they feel are required. Conversely, non-researcher partners may feel that researchers are too 'neutral' and not appropriately committed to the issue to be a genuine 'partner' in the work, especially if it is action oriented. Moreover, when additional stakeholders are involved their naturally differing priorities and motivations for the work usually require careful planning and compromise to maintain trust in the relationship. For example, community-based service providers and advocacy organizations may prioritize actions to effect change, compared with the relatively

more limited (i.e., slower acting) bureaucratic and sometimes political governmental agencies, compared with time required for scientific peer-review prioritized by academic researchers. There are numerous benefits to conducting community-engaged research from the researcher's perspective. First, the very nature of the work is that it involves direct and intimate engagement with the communities of interest, which can serve to provide a deeper understanding of the issues of concern and the affected populations. Oftentimes *primary* data is collected, generally resulting in better quality data compared to using secondary data which 'trades' lesser quality (i.e., relevant) data for the sake of timeliness and convenience. Collaborating researchers can then use the process of reporting back preliminary findings to stakeholders (if they are not already involved in the analysis) as a 'validity check' to increase confidence in the findings. By extension, this can foster a more direct connection between studying a problem and effecting change to address it given the partnership with groups that presumably bring these diverse and complementary strengths to the collaboration. Ultimately, successful community-engaged *research* relationships can also serve as valuable partnerships in other ways, such as in the realms of educational and workforce development, for example: providing a conduit for community members to pursue academic goals; providing researchers with ways to provide service to the community; and, providing their student mentees with possible connections to post-graduate work placements in community-based and other partnering organizations.

Limitations

There are two main limitations to this paper. The first is that it is clearly written from the *researcher's* perspective. I recognize that the lens with which I consider community-engaged relationships in public health research juxtaposes the researcher with all others. While I recognize distinctions between different types of stakeholders and their respective motivations and priorities, I do not necessarily position the academic partner *within* the stakeholder groups but rather in some form of interaction with them, that is, researcher vis-à-vis 'others'. While it may accurately present the nature of the relationship from the researchers' perspective it likely limits my ability to know and

consider the complete nature of collaborative relationships involving a wide range of stakeholders that *includes* academic researchers. I hope to have at least provided a useful 'starting point' of issues for researchers to consider.

The second limitation of this discussion is that it does not present *all* of the beneficial and challenging issues to consider when participating in community-engaged research projects. While there are relevant issues that this paper does not discuss (e.g., funding and equitable compensation, publication and other modes of dissemination, tension between identity as 'researcher/scientist' and 'advocate/activist', ethical considerations (Wilson, Kenny and Dickson-Swift, 2018; Banks *et al.*, 2013), etc.), I suspect that it is likely impossible to address if not identify them all. Indeed, the field of collaborative and action-oriented research continues to evolve and with that new challenges and opportunities will likely continue to arise. With that in mind, I chose a case-study approach to highlight issues from actual projects, thus, utilizing more of an applied perspective. I hope that these 'lessons learned' are more relevant and useful to the reader.

Conclusions

The case studies presented illustrate the benefits as well as some of the complications inherent to community-engaged research. There are certainly some commonalities, such as use of mixed-methods study designs, and negotiation and compromise to navigate power dynamics. But as with all research projects, specific design elements (e.g., data collection methods, target populations), implementation, etc, will vary with the context. A community-engaged research approach is not appropriate for all projects, just as a specific study design (e.g., prospective randomized control trial) or data collection method (e.g., in-depth interviews) is not going to be suitable for *all* research questions (Firebaugh, 2008). The cases discussed above provide a sense of the range of topics and organizational structures for such collaborative work but it should be clear that there is no 'one size fits all' when using this paradigm. Over the past several decades the field of public health has witnessed great interest in and support for different types of community-engaged research (Elwood, Corrigan, and Morris, 2019). Indeed, some donors

have gone so far as to require that research proposals include a 'community partner' oftentimes specifying the nature of the partnership (e.g., serve as co-Principal Investigators, receive compensation at or above a minimum percentage of effort).

As a public health researcher in community health and who has worked on many projects with non-academic stakeholders, I applaud these efforts while flagging a concern. The fact remains that there are many ways in which research questions about social and health problems can be addressed. In fact, our fundamental inquisitiveness and creativeness leads to new methodological innovations from scientists curious about social phenomena and dedicated to working toward a better world. Thus, community-engaged research or partnerships are just one of many known and, as yet, unknown ways in which we may help to solve social-and health-related dilemmas. Requiring that increasingly more projects involve 'community partners' may seem uncontroversial yet the potential hegemony of *any* approach to research, community-engaged or otherwise, may be akin to expecting a mechanic to use the same tool for anything that needs repair. Even if a project is deemed appropriate for collaboration between academic researchers and community-based and other stakeholders, there are still pragmatic considerations that must be seriously weighed, including but not limited to the amount of time to completion and possible impact on time-sensitive outcomes; whether possible additional up-front costs involved would be offset or not by the ultimate cost of *not* engaging other knowledgeable collaborators; and, the possible impact on the *research* aspects of a project, including data control or ownership, that could jeopardize the validity of the findings and, thus, the overall project goals. Indeed, a systematic review of intervention studies using CBPR found research design in many of the studies was of questionable quality (Salimi *et al.*, 2012).

Public health is, by definition, an interdisciplinary field. Indeed, recently updated competencies for graduate public health education include 'inter-sectoral collaboration' (ASPPH, 2016). Thus, participatory research with community members and other relevant stakeholders will continue to be considered important notwithstanding the need for continued work to determine what makes for effective and successful collaborations. This includes ongoing deliberation and reflexivity by researchers of our positionality in these endeavors, what it means relative to that of

our partners and the ultimate project goals, and if a community-engaged approach is necessarily the best way to conduct research about a specific public health issue (Muhammad, Wallerstein and Sussman, 2015). Only after this calculus has been carried out should the decision regarding a study design be made, including whether or not it follows a community-engaged paradigm.

References

ASPPH (2016). *Teach and Research: MPH Core Competency Model*. ASPPH. <https://www.aspph.org/teach-research/models/mph-competency-model/>. Accessed 29/8/2020.

Banks S., Armstrong A., Carter K. *et al.* (2013). «Everyday Ethics in Community-Based Participatory Research». *Contemporary Social Science*, 8: 263–277. Doi: 10.1080/21582041.2013.769618.

Brush B.L., Mentz G., Jensen M. *et al.* (2020), «Success in Long-Standing Community-Based Participatory Research (CBPR) Partnerships: A Scoping Literature Review». *Health Education & Behavior*, 47: 556–568. Doi: 10.1177/1090198119882989.

Cacari-Stone L., Wallerstein N., Garcia A., Minkley M. (2014). «The Promise of Community-Based Participatory Research for Health Equity: A Conceptual Model for Bridging Evidence with Policy». *Framing Health Matters*, 104: 1615–1623. Doi: 10.2105/ajph.2014.301961.

Collins S.E., Clifasefi S.L., Stanton J. *et al.* (2018). «Community-Based Participatory Research (CPBR): Towards Equitable Involvement of Community in Psychology Research». *The American Psychologist*, 73: 884–898. Doi: 10.1037/amp0000167.

Coombe C.M., Schulz A.J., Guluma L. *et al.* (2018). «Enhancing Capacity of Community-Academic Partnerships to Achieve Health Equity: Results from the CBPR Partnership Academy». *Health Promotion Practice*, 21:552–563. Doi:10.1177/1524839918818830.

Darling M., Gonzalez F., Graves K. *et al.* (2016). Practical Tips for Establishing Partnerships with Academic Researchers: A Resource Guide for Community-Based Organizations. *Program Community Health Partnership*, 9(2): 203–212. Doi: 10.1353/cpr.2015.0042.

- Drahota A., Meza R., Brikho B. *et al.* (2016). «Community-Academic Partnerships: A Systematic Review of the State of the Literature and Recommendations for Future Research». *The Milbank Quarterly*, 94: 163–214. Doi: 10.1111/1468-0009.12184.
- Elwood W.N., Corrigan J.G., Morris K.A. (2019). «NIH-Funded CPBR: Self-Reported Community Partner and Investigator Perspectives». *Journal of Community Health*, 44: 740–748. Doi: 10.1007/s10900-019-00661-6.
- Firebaugh G. (2008). *Seven Rules for Social Research*. Princeton: Princeton University Press.
- Frerichs L., Hasmillier Lich K., Dave G., Corbie-Smith G. (2016). «Integrating Systems Science and Community-Based Participatory Research to Achieve Health Equity». *American Journal of Public Health*, 106: 215–222. Doi: 10.2105/AJPH.2015.302944.
- Freudenberg N., Tsui E. (2014). «Evidence, Power, and Policy Change in Community-Based Participatory Research». *American Journal of Public Health*, 104: 11–14. Doi: 10.2105/AJPH.2013.301471.
- Greenhalgh T., Jackson C., Shaw S., Janamian T. (2016). «Achieving Research Impact through Co-Creation in Community-Based Health Services: Literature Review and Case Study». *The Milbank Quarterly*, 94: 392–429. Doi: 10.1111/1468-0009.12197.
- Horowitz C., Robinson M., Seifer S. (2009). «Community-Based Participatory Research from the Margin to the Mainstream: Are Researchers Prepared?». *Circulation*, 119: 2633–2642. Doi: 10.1161/circulationaha.107.729863.
- Israel B.A., Schulz A.J. (2003). «Critical Issues in Developing and Following Community Based Participatory Research Principles. In: Minkler M., Wallerstein N. (eds.), *Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass.
- Israel B., Coombe C., Cheezum R. *et al.* (2010). «Community-Based Participatory Research: A Capacity-Building Approach for Policy Advocacy Aimed at Eliminating Health Disparities». *American Journal of Public Health*, 100: 2095–2102. Doi: 10.2105/ajph.2009.170506.

- Israel B., Schulz A., Parker E., Becker A. (1998). «Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health». *Annual Review of Public Health*, 19: 173–202. Doi: 10.1146/annurev.publhealth.19.1.173.
- Mason M., Rucker B., Reed M. *et al.* (2013). «'I Know What CPBR Is, Now What Do I Do?' Community Perspectives on CBPR Capacity Building». *Progress in Community Health Partnerships: Research, Education, and Action*, 7: 235–41. Doi: 10.1353/cpr.2013.0039.
- Mayan M., Daum C. (2016). «Worth the Risk? Muddled Relationships in Community-Based Participatory Research». *Qualitative Health Research*, 26: 69–76. Doi: 10.1177/1049732315618660.
- Minkler M. (2005). «Community-Based Research Partnerships: Challenges and Opportunities». *Journal of Urban Health*, 82: ii3–ii12. Doi: 10.1093/jurban/jti034.
- Muhammad M., Wallerstein N., Sussman A. (2015). «Reflections on Researcher Identity and Power: The Impact of Positionality on Community-Based Participatory Research (CPBR) Processes and Outcomes». *Critical Sociology*, 41: 1045–1063. Doi: 10.1177/0896920513516025.
- Romero D., Echeverria S.E., Duffy M., Roberts L., Pozen A. (2018). «Development of a Wellness Trust to Improve Population Health: Case-Study of a United States Urban Center». *Preventive Medicine Reports*, 10: 292–298. Doi: 10.1016/j.pmedr.2018.03.009.
- Romero D., Flandrick K. (2019). «A Focus Group and Key Informant Interview Study of Experience with the NYC Health & Hospitals Options Program». *Journal of Health Care for the Poor and Underserved*, 30: 310–328. Doi: 10.1353/hpu.2019.0023.
- Romero D., Flandrick K., Kordosky J., Vossen P. (2018). «On-the-Ground Health and Safety Experiences of Non-Union Casino Hotel Workers: A Focus-Group Study Stratified by Four Occupational Groups». *American Journal of Industrial Medicine*, 61: 919–928. Doi: 10.1002/ajim.22896.
- Romero D., Kwan A., Nestler S., Cohen N. (2012). «Impact of the Closure of a Large Urban Medical Center: A Quantitative Assessment (Part II)». *Journal of Community Health*, 37: 995–1005. Doi: 10.1007/s10900-012-9551-2.

- Romero D., Kwan A., Swearingen J., Nestler S., Cohen N. (2012). «Impact of the Closure of a Large Urban Medical Center: A Qualitative Assessment (Part I)». *Journal of Community Health*, 37: 982–994. Doi: 10.1007/s10900-012-9550-3.
- Salimi Y., Shahandeh K., Malekafzali H., *et al.* (2012). «Is Community-Based Participatory Research (CPBR) Useful? A Systematic Review on Papers in a Decade». *International Journal of Preventive Medicine*, 3: 386–393. PMID: PMC3389435.
- Sandoval J., Lucero J., Oetzel J. *et al.* (2012). «Process and Outcome Constructs for Evaluating Community-Based Participatory Research Projects: A Matrix of Existing Measures». *Health Education Research*, 27: 680–690. Doi: 10.109/her/cyr087.
- Vaughn L.M., Jacquez F., Lindquist-Grantz R., Parsons A., Melink K. (2017). «Immigrants as Research Partners: A Review of Immigrants in Community-Based Participatory Research (CBPR)». *Journal of Immigrant and Minority Health*, 19: 1457–1468. Doi: 10.1007/s10903-016-0474-3.
- Wallerstein N., Duran B. (2006). «Using Community-Based Participatory Research to Address Health Disparities». *Health Promotion Practice*, 7: 312–323. Doi: 10.1177/1524839906289376.
- Wallerstein N, Duran B. (2010). «Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity». *American Journal of Public Health*, 100: S40–S46. Doi: 10.2105/AJPH.2009.184036.
- Wilson E., Kenny A., Dickson-Swift V. (2018). «Ethical Challenges in Community-Based Participatory Research: A Scoping Review». *Qualitative Health Research*, 28: 189–199. Doi: 10.1177/1049732317690721.

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