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Building partnerships in community-based participatory research: Budgetary and other cost considerations

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Abstract

Community-based participatory research (CBPR) is an important framework for partnering with communities to reduce health disparities. Working in partnership with community incurs additional costs, some that can be represented in a budget summary page and others that are tied to the competing demands placed on community and academic partners. These cost considerations can inform development of community-academic partnerships. We calculated costs from a case study based on an ongoing CBPR project involving a Community Planning Group (CPG) of community co-researchers in rural Alaska and a bicultural liaison group who help bridge communication between CPG and academic co-researchers. Budget considerations specific to CBPR include travel and other communication-related costs, compensation for community partners, and food served at meetings. We also identified sources of competing demands for community and academic partners. Our findings can inform budget discussions in community-academic partnerships. Discussions of competing demands on community partners' time can help plan timelines for CBPR projects. Our findings may also inform discussions about tenure and promotion policies that may represent barriers to participation in CBPR for academic researchers.

Keywords

participatory research; Alaska Native people; community advisory board

INTRODUCTION

Community-based participatory research (CBPR) is a framework for improving health in communities and reducing health disparities. CBPR seeks to involve all partners in the research process to combine knowledge and action to achieve social change to improve health outcomes (Kellogg Health Scholars Program, n.d.). Participatory research has emerged as a preferred process for research with communities facing health disparities to study and reduce these disparities (Minkler & Wallerstein, 2008). The advantages of research partnerships are well known and include enhanced usefulness, quality and validity of the research; engaging partners who can influence policy; building capacity among partners; and the potential to overcome distrust of researchers (Israel, Schulz, Parker, & Becker, 1998).

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Collaborative and equitable partnership is a core principle of CBPR (Israel, Schulz, Parker, et al., 2008). The project discussed in this paper is also informed by a concept of "responsive justice" in which justice is seen as encompassing recognition of others and responsiveness to their concerns, as well as fair distribution of benefits (Goering, Holland & Fryer-Edwards, 2008). In this framing, partnership development processes may vary, but the norms of CBPR partnerships remain "mutual respect; recognition of the knowledge, expertise, and resource capacities of the participants in the process; and open communication" (Detroit Community-Academic Urban Research Center, 2011). Inclusion of community partners in each step of the research is recommended (Israel, et al., 2008). Enacting this precept may include discussions during research planning concerning where and how community partners prefer to get involved. Dialogue with communities can help adapt principles of CBPR to fit the community's culture and context (Israel, et al., 2008) and may lead to innovative methods such as photovoice, digital archiving, storytelling, collage and oral history (Springett & Wallerstein, 2008). More time is needed for CBPR compared with traditional research (Agency for Healthcare Research and Quality, 2002), to allow for benefits of co-learning between community and campus partners and ultimately more relevant research programs and communication (Gray, Ore de Boehm, Farnsworth & Wolf, 2010).

Building effective, sustainable partnerships, however, brings additional costs, primarily to allow partners to spend time learning about one another, developing trust, and developing processes for working together. Although both monetary and time-related costs have been recognized (Williams, Shelley, & Sussman, 2009), there is a dearth of data in the literature documenting their scope. One previous study assessed costs of recruitment when done in partnership with community-based organizations (Mendez-Luck, Trejo, Miranda, et al. 2011), but did not assess costs throughout the partnership. Our paper highlights the variety of additional costs that arise when working in partnership with community co-researchers.

As the nature and frequency of contact is defined by the local community context (Christopher 2007, CTSA 2011, Mendez-Luck, et al. 2011), costs associated with doing partnership work will likely vary in the same way. This case study focuses on a partnership with rural Alaska Native communities facing health disparities while also including a bicultural liaison group to guide discussions when working across sociocultural differences. The case explores costs of partnership, including costs in a budget summary page along with less often discussed costs of time spent in partnership activities for community and academic partners. The partnership primarily involves the Center for Alaska Native Health Research (CANHR) at the University of Alaska Fairbanks and rural communities in the Yukon-Kuskokwim (YK) region in Southwest Alaska, This partnership between predominately Yup'ik communities in the YK and CANHR is more than 10 years old (Allen, Mohatt, Rasmus et al., 2006; Boyer, Mohatt, Lardon et al., 2005; Boyer, Mohatt, Pasker, Drew, & McGlone, 2007), builds on relationships extending back much further, and has been strengthened by the addition of colleagues from the University of Washington (UW) over the past 3 years. The case study focuses on relationships developing with a recently formed Community Planning Group (CPG) of past Yup'ik participants in genetic studies at CANHR.

CASE STUDY

Projects

The case follows the Ethics of Dissemination (EoD) project (HG005221-01) which focuses on appropriate ways of returning research progress and results from genetic studies. CANHR is involved in two genetic studies: the Genetics of Obesity project (DK74842) which focuses on gene-environment interactions in relation to obesity, and the Northwest-

Alaska Pharmacogenomics Research Network (NWA-PGRN) (GM092676-01), which evaluates genetic contributors to drug response.

All projects were reviewed by the Yukon-Kuskokwim Health Corporation Human Studies Committee and university-based Institutional Review Boards.

Partnership

A central activity of the EoD project is a series of in-person meetings with 10 CPG co-researchers. Meetings last approximately 2 days in addition to travel time, and are held approximately 3 times per year. CPG members assisted in planning and implementing focus groups to elicit community views and are now assisting in data analysis. The project also formed the Ciuliat group ("leaders" in Yup'ik), consisting of 5 urban Yup'ik bicultural liaisons who serve as a cultural bridge between the CPG and academic partners and assist with language translation. Others attending the meetings include an anthropology consultant with experience in the YK and researchers from CANHR and UW with expertise including anthropology, bioethics, genetics, medicine, and pharmacology. The partnership thus includes individuals with Yup'ik, non-Yup'ik, and academic worldviews.

Most meetings with the CPG and Ciuliat are held in Bethel, Alaska – the regional hub in the YK. Costs for a Bethel meeting are slightly higher than at Fairbanks but this location was preferred by the CPG. Meeting in Bethel allows CPG co-researchers shorter travel times and an environment that more closely matches that of life in rural communities in the YK. Travel to Bethel allows academic researchers to step away from competing demands at the university, get outside their comfort zone, and meet the CPG at a tempo closer to that in their communities, but involves lengthy travel. CPG meetings are planned to offer enough time to process and communicate about topics, while not taking a burdensome amount of the community partners' time. Academic partners communicate with the CPG and Ciuliat between meetings. Communication methods include telephone, email, text messaging, and mailed letters. Five academic-community partners also met separately in Bethel between larger CPG meetings to discuss focus group data.

Budgetary costs

We calculated budgetary costs associated with the partnership process, including travel and communication costs related to partnership activities, compensation for community partners, and food served at meetings. Documents from the first 1.5 years of the project were reviewed to establish estimates. Documents included travel expenses to CPG meetings and focus groups, phone and email logs, records of mail correspondence, CPG and Ciuliat honoraria, and food and catering costs. Communication costs were estimated based on averages of 10 minutes per letter and 15 minutes per email and telephone contact. Personnel costs of communication were calculated based on estimated salaries for individuals contacting the CPG and Ciuliat. Long-distance telephone charges to academic institutions were aggregated from estimated minutes in contact with the CPG and Ciuliat. Texting and in-person contact between meetings were not included in the estimated communication costs, as they were often mixing communication of a personal nature with more project-related communication.

Travel and other communication-related costs—Communities in the YK lie off the road system, involving one flight to Bethel. Some CPG members may travel by boat or snow machine depending on the weather and snow conditions. Seattle and Fairbanks researchers travel on two flights to reach Bethel. The isolation imposed by this lack of ready access to the world outside dominates every aspect of daily life, limiting availability of services and products, and restricting economic opportunities, while acting as a protective barrier against

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the final erosion of cultures and languages that until recently thrived in this often harsh environment. Yup'ik people are caught between two worlds: traditional subsistence hunting and fishing and the cash economy which remains limited in these remote communities. Basic travel costs are aggregated in Table 1, including flights, gas for other transportation, lodging, ground transportation and per diem.

Among the CPG and Ciuliat there are a diversity of options and preferences for communication including landline telephone, cell phone, texting, mailed letters, and email. Some CPG members prefer communication in Yup'ik. The CPG and Ciuliat also vary in their ability to receive attachments by email and participate in teleconferencing. Communication costs with the CPG and Ciuliat between meetings are aggregated in Table 1.

Compensating community partners—The EoD project offers CPG and Ciuliat partners an honorarium based on their time involved with the project at and between meetings (Table 1).

Food at meetings—Sharing food at meetings was viewed as culturally appropriate and therefore an essential component of meetings. Consulting with the CPG and Ciuliat about the menu was an important preparation step. Confirmation of this approach came near the end of a meeting 6 months into the project when a Ciuliat partner mentioned that trust had developed within this group the night before when we shared a meal of mostly Yup'ik food. Yup'ik food may include seal, various dried fish, tundra greens, berries from the tundra, and other subsistence food. Sharing subsistence food opens opportunities to connect within the partnership on a more personal level. Subsistence foods strengthen the Yup'ik communities' connections to a culture of sharing and spiritual connection to the land and animals. Learning about these connections and the richness of a subsistence way of life is vital to the partnership, as outsiders sometimes mistakenly view gathering subsistence foods as purely about physical survival. Sharing food with elders in a respectful way is also an important way to honor elders and the knowledge they share.

The value of gifts shared from home, including food, cannot be quantified yet is important to partnership development. Yup'ik partners share subsistence food, while academic partners have shared fish they or a close friend caught, along with other food they make or bring from home. These items supplement the grant-purchased food that is quantified and reported in Table 1.

Opportunity costs of partnership

We also identified sources of opportunity costs resulting from partnership activities for both community and academic partners. Opportunity costs are defined as the value forgone by not doing the next best activity (Hutton & Baltussen, 2002), here the costs of time and energy put into partnership activities instead of into other valued activities. We present a qualitative list of these opportunity costs of partnership activities based on the authors' experiences in the EoD project, including conversations with community partners.

For Yup'ik partners, competing demands may involve time away from families, jobs, activities with the church and tribal government, and a subsistence way of life (Table 2). Time away from work may require taking vacation days that would otherwise be saved for subsistence hunting and fishing. Time away may also require finding someone to substitute at work or help take care of family. Subsistence activities, teaching, running a business, and caring for family are thus among the opportunity costs of their time spent in partnership. Academic partners similarly may need to defer work-related activities or seek coverage from colleagues and may need to limit family obligations to create time for partnership activities. Opportunity costs specific to academic partners include time deferred from preparation of

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papers and grant applications (Table 2). Ciuliat, some of whom are also working in academic research and leadership positions, may face all these competing demands as they navigate a liaison role as Yup'ik partners.

DISCUSSION

The Ethics of Dissemination (EoD) project addresses how to return information about genetic research studies to the community. In-person meetings allow time for developing relationships and a mutual understanding of communication differences between communities in the YK and academic centers. Indigenous communities are familiar with 'helicopter' research where researchers drop in, collect data and then are not heard from again, failing to return with study results (Boyer, Dillard, Woodahl, et al., 2011). In-person meetings ensure time for group members to speak on issues and for contemplation and are important when working with Alaska Native communities (Mohatt, Hazel, Allen, et al., 2004). Meetings also allow researchers to share more about themselves and their research in a way that may strengthen ties with the community (Hiratsuka, Brown, Hoeft, & Dillard, 2012). While our findings are specific to work with particular indigenous communities across large geographic distances, this case study offers a look at costs involved in building and sustaining a CBPR partnership that may be applied to other partnerships with isolated, rural communities in the U.S. or work with other communities globally. In these settings, in-person meetings facilitated by cultural liaisons may benefit both new and established partnerships.

Culturally appropriate practices, including sharing food and gifts at meetings, develop relationships. Sharing is an important community value in indigenous communities where gifts may be offered when seeking counsel from an elder (Gone, 2006) and where sharing and giving is considered an honor (Shutiva, 2001). Thus gift-giving is part of the cultural rules of visits in some communities (CTSA, 2011; Substance Abuse and Mental Health Services Administration, 2009). Catering and other grant-purchased food are aggregated in Table 1 and presented as a necessary item in CBPR. Complementing grant-purchased meals with small gifts, including food, is also important for building social connections. These gifts are meaningful partly because they are not compensated, making them truly a gift. Subsistence foods in the YK have additional meaning by giving partners a common dialogue and helping academic partners understand Yup'ik ways of living and being (Hensel, 1996; Thorton, 2001). With subsistence, "it is not only about how much you take from the land, but where you take it from, whom you take it with, whom you share it with and in what context" (Thorton, 2001. p. 89). Thus sharing food in the YK is unique in ways specific to subsistence, but the importance of giving and the respect connected with this tradition can be found in many other cultures.

Travel costs may be higher in rural Alaska as communities lie off the road system, yet other partnerships may use these budget items to assess their own travel needs and costs. In some projects this may be a 200-mile drive to the community (Christopher, 2007), or involve community partners at 40 sites across the U.S. spanning a greater distance than those within Alaska (CTSA, 2011). In urban areas, commutes may add up with regular visits with community through the CBPR process (Mendez-Luck, et al., 2011). In all community contexts travel costs reflect the face-to-face time in the community needed to develop relationships, which may be complemented by other forms of communication between meetings.

Time spent traveling and attending meetings, however, is time away from competing demands for both Yup'ik and academic partners. Subsistence activities are an important competing demand for Yup'ik partners, while writing publications and grant applications are

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more specific to academic partners. The opportunity cost of participation will thus differ among partners. A diversity of community partners is valued in CBPR (Green & Mercer, 2001), thus funding ways to accommodate these different competing demands is critical to the partnership. Community-academic partnerships should discuss the costs and benefits partners face and work together to find solutions to reducing these costs, including adjusting timelines of research. CANHR typically schedules data collection trips to avoid summer months when subsistence activities are at their peak, despite teaching schedules for academic partners which favor travel at that time. Discussing the competing activities faced by community partners can be helpful to the partnership process, though differing timelines may remain an issue (Minkler, Fadem, Perry, et al., 2002).

While compensation for community partner involvement does not reflect the opportunity cost of their time, both monetary and non-monetary compensation offset some costs of partnership and convey respect for community expertise. Non-monetary strategies may include opportunities for social interaction, access to information, influence on decision making, and recognition of contributions directed to community partners, their supervisors and the broader community (Newman, Andrews, Magwood, et al., 2011). CANHR offers an honorarium to the CPG and Ciuliat while also finding other ways to recognize community contributions. Minkler, Blackwell, Thompson, and Tamir suggest community partners may be offered monetary compensation at the level of graduate students working on the project to show respect for their time while helping cover expenses such as child care (2003). Monetary compensation may differ across partnerships, and at times community partners might suggest areas where compensation may be declined by some participants, for example with stories of sobriety (Allen, et al., 2006). Conversations with community partners during the planning stages of grant application development about appropriate compensation should lead to more equitable and sustainable partnerships.

For academic partners, efforts to influence policies for promotion and tenure at academic centers may help to offset some of the opportunity cost of time in partnership. As mentioned, adjusting timelines of CBPR projects may run counter to schedules for academic partners. Repeated visits to communities are essential in developing and maintaining trust with communities facing health disparities. Communication between academic researchers and their institutions may help develop policies for promotion that acknowledge community engagement in CBPR. For example, most institutions view community-related work as community service, which is not rewarded the same as other academic work in tenure evaluations (Ahmed, Beck, Maurana, & Newman, 2004).

This study offers information about cost considerations within the EoD study, but could not fully account for opportunity costs experienced by the partners in the study. Further research could focus in greater depth on this aspect of CBPR partnership work. Some community collaborators report feeling that their time spent on a research project, time taken from important work in their organizations and community, may be worth far more than they have gained from the partnership when compensation on the project is modest (Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2001). When individuals face many competing demands in their communities, these research relationships may not be sustainable. More research with community leaders to help assess the value of their time and balance of other activities is recommended. Interviews with key community leaders could more fully characterize the impact of competing demands on community involvement in research. In this project, for example, co-researchers hoped for involvement of community health aides in the CPG but the health aides approached were busy with other commitments. Research may focus on competing demands for health professionals and recommendations for including this valuable perspective within a CPG.

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Additionally, future research involving multiple CBPR partnerships, in particular from researchers working actively in assessing outcomes related to CBPR (Wallerstein and Duran 2010, Khodyakov, Stockdale, Jones, Ohito, Jones, Lizaola, et al. 2011), may be poised to assess costs of partnership work as they align with outcomes of such work.

CONCLUSION

The data presented here can provide other CBPR projects with insights into the budgetary costs of partnership and competing demands affecting project timelines. Findings may be relevant to other partnerships working across sociocultural differences, and represent an important component of efforts aimed at health promotion – from foundational research to implementation efforts – in disadvantaged communities in the U.S. and globally. Understanding costs and benefits of partnership work for community partners may lead to more sustainable partnerships. To the extent that partnership building is a necessary component of effective community-based research in health promotion, institutions should look to lower opportunity costs to researchers in CBPR to increase the number of academic partners in this important field.

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Table 1

Additional budgetary costs attributed to working in partnership in a CBPR project (first 1.5 years of project)

Travel	**Costs ($)**
CPG meetings	
CPG community-based co-researchers	25,140.34
Ciuliat and non-Yupik anthropology consultant	12,738.67
CANHR university-based co-researchers	19,136.78
UW collaborators*	14,453.94
Smaller working meeting	
CPG community-based co-researchers	159.14
Ciuliat and non-Yup'ik anthropology consultant	1,477.20
CANHR university-based co-researchers	840.10
UW collaborators	1,556.78
Genetics training	
Two trainers	3,590.65
Community travel to focus groups	
CPG community-based co-researchers	607.00
Communication with the CPG and Ciuliat (estimates)	
Letters (time)	529.17
Letters (postage)	151.52
Emails (time)	1,907.63
Phone calls (time)	2,388.50
Phone calls (charges)	747.00
Compensating the CPG and Ciuliat	
At meetings and co-facilitating focus groups	24,700.00
Between meetings	537.50
Food served at meetings	
Catering, restaurants and groceries	4,798.90
Sharing of Yup'ik and non-Yup'ik food at meetings	Costs cannot be quantified

*Does not include participation covered by NWA-PGRN parent grant at UW.

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Table 2

Types of opportunity costs attributed to working in partnership in a CBPR project

To CPG co-researchers and Ciuliat	
Type of Deferred Activity	***Example from Case Study***
Responsibilities with immediate family	Caring for children, grandchildren, and elders
Helping extended family & community members	Sharing Yup'ik foods with extended family and elders
Salary/hourly paid work	Teacher, Office Assistant
Self-employed work	Running a small business
Leadership positions in community	Work and meetings with Tribal Government
Subsistence way of life	Hunting, gathering and processing fish, berry-picking
Community events	40-day feast after the death of a community member, basketball tournaments
Church commitments	Activities related to serving as a deacon, lector, choir member
To academic co-researchers and some Ciuliat	
Type of Deferred Activity	***Example from Case Study***
Responsibilities with immediate family	Caring for children, grandchildren, and elders
Salary paid work	Teaching classes, other research projects
Leadership positions in community	Work mentoring younger researchers
Other activities in community	Volunteer activity in the community
Other academic endeavors	Preparation of papers and grant applications, presentations of work at conferences, academic service activities