



Published in final edited form as:

*Qual Health Res.* 2010 May ; 20(5): 697–706. doi:10.1177/1049732310361468.

## Using Focus Groups in Community-Based Participatory Research: Challenges and Resolutions

Christine Makosky Daley<sup>1</sup>, Aimee S. James<sup>2</sup>, Ezekiel Ulrey<sup>1</sup>, Stephanie Joseph<sup>1</sup>, Angelia Talawyma<sup>1</sup>, Won S. Choi<sup>1</sup>, K. Allen Greiner<sup>1</sup>, and M. Kathryn Coe<sup>3</sup>

<sup>1</sup> University of Kansas Medical Center, Kansas City, Kansas, USA

<sup>2</sup> Washington University, St. Louis, Missouri, USA

<sup>3</sup> University of Arizona, Tucson, Arizona, USA

### Abstract

A community-based participatory approach requires that community members be involved in all phases of the research process. We describe three focus group studies with American Indians in Kansas and Missouri, using a newly developed method of conducting and analyzing focus groups with community input (72 focus groups, 519 participants). We conducted two needs assessment studies focused on barriers to breast and colorectal cancer screening and one study focused on Internet use for gathering health information. Community members and researchers collaborated to develop guides for the focus group moderators. Community organizations and our community advisory board conducted recruitment, and we trained and employed community members as moderators, assistant moderators, and analysts. Our community partners also helped with dissemination of research findings to their constituents. The methodologic approach and data from these three studies will allow us to more appropriately address health disparities in the American Indian community, with full community support for our research.

### Keywords

cancer; community partnerships; disparities; racial; health care; race and racism; research participation; technology; use in research

---

Community-based participatory research (CBPR), which is “a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making and ownership” (Israel, Eng, Schultz, & Parker, 2005), is quickly becoming a common approach in a variety of settings. Key ways in which CBPR differs from other types of community-based research are the partnership between the academic institution and community, equitable distribution of all aspects of the research process (and monetary compensation), and shared decision making and ownership of data. Karnieli-Miller, Strier, and Pessach (2009) placed research partnerships and collaborative efforts as the most egalitarian of all types of research.

---

Corresponding Author: Christine M. Daley, University of Kansas Medical Center, Department of Preventive Medicine & Public Health, MS 1008, 3901 Rainbow Blvd., Kansas City, KS 66160, USA, cdaley@kumc.edu.

#### Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to authorship and/or publication of this article.

Researchers have used CBPR in American Indian communities to successfully address a variety of health issues including tobacco use, cancer prevention and control, elder abuse, youth wellness, genetic issues, environmental exposures, and mental health issues (Arcury, Quandt, & Dearry, 2001; Christopher, Smith, & McCormick, 2005; English et al., 2008; Forster, Rhodes, Poupart, Baker, & Davey, 2007; Holkup, Salois, Tripp-Reimer, & Weinert, 2007; Horn, McCracken, Dino, & Brayboy, 2006; Kaur, 2005; Letiecq & Bailey, 2004; Smith, Christopher, & McCormick, 2004; Teufel-Shone, Siyuja, Watahomigie, & Irwin, 2006). Numerous researchers have called CBPR a best practice in American Indian communities (Burhansstipanov, Christopher, & Schumacher, 2005; Caldwell et al., 2005; Coe, Wilson, Eisenberg, Attakai, & Lobell, 2006; Kaur, Dignan, Burhansstipanov, Baukol, & Claus, 2006; Noe et al., 2007; Strickland, 2006), largely because of historic abuses by medical and other researchers (Burhansstipanov et al., 2005). Many have asserted that the majority of American Indian communities prefer CBPR to other research methods, and some communities mandate its use.

From 2006 to 2008, our research team conducted three focus group studies with a total of 72 groups and 519 participants. During this time we developed a method of conducting and analyzing focus groups that included community members in all stages of research. Community members served in several capacities within the research team, including as paid research associates, paid community advisory board (CAB) members, and unpaid advisors from partner organizations. In this article we describe this CBPR focus group study methodology in detail and conclude with potential ramifications for health disparities researchers working in similar settings.

The research context for the development of our CBPR-based methodology involved the completion of two needs assessments focused on breast cancer and colorectal cancer screening in an effort to understand the abysmally low rates of screening among American Indians. Currently, only 34.4% of American Indians are up to date with colorectal cancer screening guidelines, including fecal occult blood test or endoscopy (American Cancer Society [ACS], 2008). Rates of mammography are likewise low, with 52% of American Indian women reporting a mammogram in the previous 2 years and 36.6% in the previous year (ACS, 2004). Preliminary results from our breast cancer and colorectal cancer needs assessments have been presented at several national and local conferences (Braiuca et al., 2008; Briscoe et al., 2008; Daley et al., 2007; Daley, Prue, Briscoe, James, & Greiner, 2007; Weir et al., 2008; Weir, Daley, Braiuca, Kaur, & Greiner, 2008) and are currently under review for publication (Daley, Filippi-Franz, James, et al., 2009; Daley, Filippi-Franz, Nazir, et al., 2009; Daley, James, et al., 2009; Daley, Nazir, Greiner, James, & Choi, 2009). Final analysis is pending. Our third study focused on use of the Internet for health information seeking and the desired characteristics for a culturally tailored Web site on smoking and lung health. American Indians currently have the highest rates of smoking of any ethnic group, at 41% vs. the next highest rate of 24% among Whites and African Americans (Okuyemi, Cox, Choi, & Ahluwalia, 2004). Results from this study are not yet available, though some preliminary data have recently been presented at the local level (Daley, 2009).

Although CBPR is becoming more common in research studies addressing specific health issues like those described above, most studies include community members in only certain aspects of the research. When conducting focus groups, community members are most often included in recruitment, conducting the groups, and dissemination of findings to the lay audience; it is less common for them to be involved in other aspects, most notably formal data analysis. Recent CBPR studies have used focus groups for the development of intervention materials or to guide topic selection or approaches in community health promotion work (Bogart & Uyeda, 2009; Cristancho, Garces, Peters, & Mueller, 2008; Johnson et al., 2009; Lutz, Kneipp, & Means, 2009; Ornelas et al., 2009). Our methodologic approach described

here involved community members in our formative research, study recruitment, conduct of focus groups, data analysis, and dissemination of findings.

## Formative Research

Beginning in 2004, we partnered with multiple community organizations serving the local American Indian community and colleges and universities in the area. In 2006, we formed the American Indian Health Research and Education Alliance, an alliance of organizations dedicated to promoting health and wellness among American Indians through quality participatory research and education. The creation of a formal alliance was a joint decision by academic researchers and community members and was done to put academics and community members on level ground rather than set up a hierarchy, as is common in research. Our community partners were wary of a partnership with academic researchers when we first began working together. By creating the alliance, we were able to assuage many community members' fears about academics taking over. The name of the alliance was used when collecting formative data, with partner organizations all acknowledged equally. While the American Indian Health Research and Education Alliance was being created, a joint decision was made to identify the greatest health concerns in the community. We began with informal meetings with partner organizations to identify a list of potential health concerns and locations at which we could talk with community members.

We used community events as primary locations for these informal meetings, specifically pow wows,<sup>1</sup> community dinners, and a local symposium held by one of our partner organizations, the American Indian Council, Inc., of North Kansas City. Both researchers and community members were present at events, demonstrating our partnership. Community members believed that it was very important for researchers to be present at community events on a regular basis to show commitment. They also believed that researchers should be accompanied by community members to obtain useful and truthful information. We had an information table at several pow wows each year, where we provided health information and asked people informally about their health concerns. In 2007 we held our own health and wellness pow wow, at which we provided health information and free health screenings such as serum glucose and cholesterol, blood pressure, vision, body mass index, and so forth. During this event we conducted surveys asking about preferences for health topics and how to address them. Each year we held a Christmas dinner at which we provided dinner for families and gifts for children under the age of 18 years, and a back-to-school barbeque where we provided a meal for families and school supplies for children under age 18. We conducted surveys and informal interviews at both of these events to learn more about what health topics were most interesting to community members. The American Indian Symposium is an annual event that addresses American Indian health, legal, and cultural issues and is attended by community members and health professionals who have an interest in cultural competency. We conducted surveys at the symposium, asking about health topics and how to properly address them in the American Indian community.

After identifying several topics, we paired research expertise with community member interest to determine which topics would be addressed in our first studies as a team. The researchers primarily wrote the grants but community members reviewed them and provided feedback prior to submission. Since our initial grant submissions, we now have community members who have begun helping draft our grant proposals and some who have begun drafting proposals for their own organizations. For our initial studies (the two breast cancer and colorectal cancer needs assessments) we chose to use both interviews and focus groups. We chose to begin with interviews with community leaders and health care providers because we believed that the one-

---

<sup>1</sup>A pow wow is an American Indian social gathering of music, dance, food, and arts and crafts, usually lasting from 1 to 3 days.

on-one format would help us delve into the greatest detail about needs and barriers (Daley, Filippi-Franz, James, et al., 2009; Daley, Filippi-Franz, Nazir, et al., 2009), helping us to develop guides for future focus group moderators. We chose focus groups for talking with community members because our community partners believed that it would be a safer environment for community members; it was believed that no one would meet with researchers alone and that people could come to the focus groups together. Community members requested that they be allowed to moderate the groups to ensure that participants would feel comfortable, but they also wanted at least one researcher available for questions during or, more importantly, after the groups.

Researchers and community members collaborated to develop moderator's guides for the focus groups based on the interview data for our breast cancer and colorectal cancer groups, data from a smoking cessation program we run, and several surveys we have done for the Internet use groups (Begaye, Deal, Braiuca, Daley, & Choi, 2007; Choi et al., 2004; Choi & Daley, 2006; Choi et al., 2010; Choi et al., 2006; Daley et al., 2005; Daley, James, McCloskey, Wilkett, & Choi, 2005; Daley, Cowan, Nollen, Greiner, & Choi, 2009; Seagraves, Choi, Daley, & Barnoskie, 2005). Researchers developed the scientific questions and community members addressed community concerns and the cultural appropriateness of questions. All team members (community and academic) completed human subjects training at the University of Kansas Medical Center; protocols were reviewed by both the University Institutional Review Board and the appropriate clinic or tribal board.

## Study Recruitment

Community members led focus group recruitment. The researchers identified potential human subjects protections issues and ensured that all recruitment methods and materials passed through the appropriate review boards. Recruitment strategies incorporated typical activities including posters, flyers, and word of mouth at locations identified by our community partners as places frequented by American Indians. We recruited at least half of our participants in each study by word of mouth, showing the benefit of respectful interaction with the community led by community members on the research team. Native-specific events, particularly pow wows, provided the majority of the rest of our focus group sample. At pow wows we used information tables and announcements by the emcee. In most cases, in return for table space and announcements, we sponsored a competition dance category—usually the women's or girls' jingle dress competition—because of their association with healing. In addition, native-specific listservs, particularly those of our community organization partners, and native social network listservs were more successful than posters and flyers. Additional recruitment efforts included working with native-specific housing authorities, student organizations at local colleges and universities, and religious organizations.

## Description of Focus Groups

Researchers formally trained nine community members as moderators and assistant moderators for the focus groups, all of whom were hired as paid research associates. Community members moderated all focus groups. In some cases the assistant was a researcher; in other cases a researcher was present but not involved in running the group. Moderators and assistant moderators were gender matched to groups that were gender stratified (breast cancer and colorectal cancer groups). Moderators collaborated to determine the format of the groups within research parameters. The first author approved the format of all groups prior to implementation to ensure fidelity to the research process and human subjects protections.

All focus groups began with an informal meal for participants. The moderator or assistant moderator individually brought participants into another room for informed consent. Most

often, for gender-stratified groups, we held two groups on the same evening, one with men and one with women, all within the same age stratification (appropriate to each study). By doing this, we allowed husbands and wives to attend groups at the same time; this strategy helped our recruitment dramatically, particularly in the recruitment of men. Meals included participants in both groups being conducted on a particular evening, allowing for a relaxed atmosphere. By the time the meals were completed, participants and moderators/assistant moderators felt comfortable with each other and the group members had established rapport with one another before the start of the focus group. After participants had eaten and completed the consent process, they split into two rooms for their respective groups.

The focus groups followed a semistructured format with open-ended questions, using a native ethnographic approach (Bernard, 2006) wherein a person from within a culture is used as the primary instrument of data collection. We audiotaped the groups and transcribed the tapes verbatim. Our community partners chose audiotaping as opposed to videotaping because they believed the participants would be more comfortable and would speak with more candor. In addition, they felt videotaping would not keep participants adequately deidentified, or that the participants would not perceive that they would be adequately deidentified.

## Data Analysis

Our approach to data analysis followed a combination of native and team ethnography, grounded theory, and the principles of CBPR (Bernard, 2006; Erickson & Stull, 1998; Israel et al., 2005). In native ethnography, individuals from within a culture conduct ethnographic study of that culture rather than the traditional anthropological approach of an outsider conducting the research (Bernard, 2006). In team ethnography, multiple investigators work together on the research rather than the traditional ethnographic approach of the lone researcher in a different culture (Erickson & Stull, 1998). By combining the emic or insider's perspective using an ethnographic approach, we were able to gain insight that an outsider would have missed. Likewise, by keeping the etic or outsider perspective through the researchers on the team, we gained insights that a community member might have missed because he or she was too intimately involved with the data. Although our analysis was in part ethnographic because we used the individuals responsible for collecting the data to also analyze it, we also followed a grounded theory approach in which we allowed the themes and theories to grow out of the data rather than analyzing the data with a theory already in place (Bernard, 2006). All of our analysis was done using the same cooperative principles of CBPR that our entire research project followed.

For each study, the primary investigator assigned five team members the roles of primary coder, secondary coder, tertiary coder, emic reviewer, or etic reviewer. All participants in the analysis of data were paid research team members, either community researchers or academic researchers. In each case, at least one coder and one reviewer were community members. Table 1 outlines the qualifications and responsibilities of each role. Initially, all coders and the primary investigator (also the etic reviewer) read through all transcripts and then met to inductively develop an initial code list. After the initial list was developed, the primary coder and the primary investigator created the codebook, and then met with the other coders to come to consensus on primary, secondary, and tertiary codes. After codebook development, all coders deductively coded the transcripts by hand, led by the primary coder, and meeting periodically to ensure that they were coding in a similar manner and making any necessary adjustments to the codebook. We chose coding by hand rather than using a computer program because we wanted to ensure that community members participated in the coding. We did not believe it would be of benefit to train community members in any of the available software programs because of the steep learning curve of those programs and the fact that the skills used for these programs are not transferable to anything other than qualitative data analysis. We also

believed that the use of computer programs might inhibit our ability to recruit appropriate community members into the analysis process.

After coding, coders individually wrote summary statements. The etic reviewer examined coded transcripts and summary statements and cross-checked approximately 10% of the codes to ensure intercoder reliability, and compiled the summaries into thematic statements. The etic reviewer returned these thematic statements to the coders for initial review, and then condensed them into more comprehensive statements. The emic reviewer assessed the condensed themes for “cultural match,” determining if statements accurately and respectfully interpreted and described things from within the culture. The etic reviewer then revised the themes again. The entire research team then received the new themes for review, after which the themes were finalized through a team meeting to achieve consensus on what the main themes were and how to interpret them. If a consensus could not be reached on a particular theme, the opinion of the community members outweighed that of the academic researchers.

## Dissemination of Research Findings

We have begun an extensive community dissemination process, including dissemination to both the regional and national scientific community and the lay community. Dissemination to the scientific community has included scientific articles and conference presentations. Every article and presentation has included both researcher and community member authors. Although our researchers have thus far provided the bulk of writing of articles and presentations, our community members have provided critical input on all of them and many are building their scientific writing skills. Our emic coders and reviewers have selected our exemplary focus group quotes for articles and presentations to ensure that the culture of the community is represented properly and respectfully. Community members have read all sections of articles and provided input and interpretation of findings.

We have developed our presentations through a similar approach. Both researchers and community members have presented material, sometimes in combination. Researchers have typically taken the lead on presentations at national scientific conferences, particularly for oral presentations, because of their relative comfort in that setting. Community members have presented at national conferences, but have been more likely to lead the local scientific conference presentations. Over time, our community team members have taken over parts of the writing process and are becoming more comfortable with scientific presentation. In each funded project, we are careful to allocate funds for community members to travel to national conferences along with our academic team members.

Community members of the research team have directed dissemination of research findings to the lay community. Our primary means of dissemination has been through our CAB and partner organizations. Our 40-member CAB meets quarterly; at each meeting we provide updates on our research and findings, along with copies of any publications. CAB members have assisted with dissemination of information to the community through word of mouth; they are integral members of their community and often hold positions of leadership in community organizations. We provide updates on research to our community partner organizations through project-specific monthly meetings, during which we also get additional input on the research process. We have presented our research at local community-oriented conferences as well, with community members of the research team taking the lead on presentations, often with the help of researchers. Our dissemination efforts to the community will increase dramatically with a quarterly newsletter and Web site that are currently under development.

## Challenges and Lessons Learned

Our CBPR approach has increased community investment in our research and research results dramatically. Our community partners are significantly more involved in and in control of the research and how it is used, as compared to prior projects with health care organizations and academics. As we have moved forward with including community members in all phases of the research, our recruitment efforts have increased exponentially and our results have increased in validity. Our CAB has quadrupled in size during a 2-year period, and we now have subcommittees within the board to address specific issues. We believe this has been made possible by the extensive involvement of our community team members and our inclusive CBPR methods.

We have encountered challenges in the conduct of focus groups with CBPR at each phase of the research process. Early in the formative research, we had problems choosing the appropriate health issues to address because researcher expertise (or funding) did not entirely match community members' interest. We found common ground on the issues we chose to address in these three studies, but are still determining how to begin to address some of the other health issues of interest to both community members and researchers. We have found this to be a continuing challenge, but respectful dialogue, collaboration, and occasional compromise have led to continued progress and considerable growth in programs and reach. Because we have uncovered several concerns raised by community members that would require additional, appropriate expertise to address, we have begun to recruit additional researchers to the team, particularly to address obesity and diabetes, both issues of great concern to members of the American Indian community. We have also talked with community members about research topics of interest that they might not have identified as problems, such as Alzheimer's disease, in which we have specific research expertise. Community members did not identify Alzheimer's disease as a health concern initially, but after learning more about it, agreed that it was an important issue to address. We have found that once there is a working relationship among partners and a mutual respect, it is relatively easy and often comfortable to discuss ways to address issues of importance to both researchers and community members.

### Human Subjects Training

In the early stages of our research, we also uncovered difficulty with our online and written human subjects training programs, which are written very much for biomedical researchers and often at a high level of literacy. Some of our community partners were less computer savvy and had fewer years of formal education than typical university employees. Our human subjects committee would not allow different training for community members; therefore, we paired a community member with a researcher who went through all of the training with the community member, explaining more as they continued. Although this approach took significant time (in some cases several days as opposed to a few hours), we believe it was appropriate because our community partners learned more about the research process, had a better understanding of human subjects concerns and legality, and emerged more self-confident and satisfied than if they had tried to get through the training themselves. Our community partners appreciated this approach and said that not only did they gain a better understanding of research and human subjects protections, but also got a chance to get to know and learn more about the different individuals on the research team who helped them through the training. What had started as a huge barrier to community member participation in research actually became a facilitator for better communication and closer relationships. An additional benefit to conducting the human subjects training in this manner was that our community researchers became more confident in their ability to consent research participants (the process of getting a participant's permission to be in a research study) because they had heard someone else explain consenting to them.

## Recruitment

We have had few problems with recruitment for focus groups because we have added more community members to our research team. Early problems with recruitment were largely because of the relatively few community members on the team, leaving community members wary of participation. Gaining the trust of several key leaders in the community who could help us recruit was of paramount importance. Our first 18 months of work as a team revolved around gaining the trust of key stakeholders in the local American Indian community. Recruitment became a nonissue; we have successfully recruited more than 3,000 individuals into our research projects since our team's inception.

## Conducting Focus Groups

Problems conducting focus groups centered on researchers initially being unwilling to give up complete control of their conduct. Researchers on the team had to stop thinking of themselves as the best people to conduct the groups or as knowing the best ways to ask a particular question (which in some cases was difficult). Ultimately, the few researchers who could not give up control were asked to leave the research team. We discovered that the reality is that researchers have their own styles and comfort levels and that some researchers are not well suited to CBPR because they cannot give up control of certain aspects of the research study. Our biggest problem with researchers who were unable to give up control was that we waited too long to ask them to leave the team, hoping that they would change or realize that their skills lay in different areas of research. Several community partners had to bring the problem before the team as a whole before we took action. We then spoke with team members who were having problems in an effort to address the issues, giving researchers time to determine if they wanted to continue to work on a CBPR team or if they preferred to work elsewhere. In the end, it became clear to us that our team could only function if we all wanted to conduct research using similar CBPR methods. Some of the individuals we lost in the process were excellent researchers who chose to work differently. Proper functioning of the team had to be of paramount importance, rather than just including people with the most research experience or the highest level of expertise in certain areas. It is possible that we damaged our relationships with certain community members by not taking action more quickly, but our long history of commitment to working collaboratively helped us overcome challenges and missteps.

Once the control issues were resolved, the focus groups ran smoothly, largely because of the ease with which our community researchers were able to conduct them. We had several community members with a natural ability to lead groups and were able to capitalize on their talents. Training community members to conduct the groups took little time (two to three sessions of training) and required only a few refresher sessions once the groups started. The main problem our moderators discussed was difficulty staying out of the conversation when they were passionate about it. This is a difficult task for even the most seasoned of moderators, and ours were no different. Each individual developed a way to stop him- or herself from entering the conversation, such as taking a drink of water to allow time for someone else to speak, writing down more notes when he or she wanted to speak, or repeating what was said rather than offering a personal opinion, among others. One other problem noted by a few of the moderators was familial ties to focus group participants. In the small American Indian community in our area, not only did most people in the groups know each other, but many were related in some way to each other or to the moderators. We could not avoid having family members in the same groups and this might have affected our results. This is an issue when conducting research in many close-knit communities.

## Analysis

In the analysis phase of research, the greatest challenge was convincing community members that their viewpoints mattered and that they could do analysis, which was daunting to some.



Several of our community researchers indicated that the most daunting aspect of the analysis, other than their own belief in the validity of their opinions, was the use of qualitative data analysis programs. Some of our analysts refused to conduct analysis on a computer. To ensure that community members with less formal education and less comfort using computers could still participate in the analysis, we conducted the analysis by hand. Most of our academic researchers believed strongly in the importance of community member input, though some had a difficult time accepting community member input as equal to their scientific perspectives. Our analysis began with both community members and academics still unsure of the usefulness of community input, but after coding was complete and thematic statements were developed, both sides realized the importance of including both outsider and insider perspectives.

Creation of the codebooks for our studies took several months each. We first had to train community members in codebook creation and its importance, and then began meetings with the entire research team to create appropriate codebooks for each study. The multiple training sessions and iterative process of codebook creation was tedious, but well worthwhile. After multiple training sessions and jointly creating each codebook, all members of the research team became more comfortable with each other; community members were more confident in their abilities and felt more equal to researchers because of the collaboration and because of careful and detailed code-book development. At the same time, researchers gained additional respect for community members who took the time to learn the process and whose opinions helped to create a much more useful codebook. During this process we learned the importance of jointly creating a codebook. Researchers and community members used different terms to define the same topic, and could read the same passage and think about it differently. By developing the codebook together, we were able to use terms that made sense to both academics and community members and could be used to code the same sections of transcript by both.

The extended period of time it has taken our team to analyze data in some cases (more than a year for the first study) has been worthwhile, though this has delayed academic dissemination, particularly through publication (causing more issues for the researchers than the community). We have succeeded with rapid dissemination to the scientific community through presentations, but these activities have still suffered because of the length of time it has taken to analyze the data. As we have completed analysis on successive studies, it has become quicker, but the reality for CBPR researchers is that getting study reports published in a timely fashion is difficult. Dissemination to the lay community has been easier because less formal analyses of preliminary data are more accepted, and have often been determined and distributed through our CAB and community outreach activities.

## Conclusions

Overall, we believe our methodology has resulted in a successful method for conducting focus groups in CBPR studies. Our strategies for involving community members in all phases of the research process can be used by other CBPR teams, particularly those teams working with underserved or traditionally marginalized communities. Our strategies for dealing with conflict and problems that arise when conducting CBPR are likewise transferable to other research teams. In many ways, though, techniques must be tailored to the community with whom you are working, and are an ongoing effort. Our success in growing programs and working with the regional American Indian community has resulted from continuous partnership across the research spectrum. We have placed a special emphasis on community member involvement in rigorous qualitative analysis. Our unique approach ensures that future activities will reflect appropriate interpretation of data, and we believe this will translate to highly successful health promotion work. Although time intensive, this approach might prove valuable to the development of sustainable and effective approaches to the embedded health disparities facing American Indians and other underrepresented groups across the United States.

## Acknowledgments

We thank our research assistants, community partners, and member organizations of the American Indian Health Research and Education Alliance for their contributions to the studies discussed in this article.

### Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article: American Cancer Society, American Lung Association, National Cancer Institute, and Susan G. Komen for the Cure.

## References

- American Cancer Society. Cancer facts & figures 2004. Atlanta, GA: Author; 2004.
- American Cancer Society. Cancer facts & figures 2008. Atlanta, GA: Author; 2008.
- Arcury TA, Quandt SA, Deary A. Farmworker pesticide exposure and community-based participatory research: Rationale and practical applications. *Environmental Health Perspectives* 2001;109(Suppl 3): 429–434. [PubMed: 11427392]
- Begaye, J.; Deal, A.; Braiuca, S.; Daley, CM.; Choi, WS. Strategies for involving youth in tobacco prevention in a Native community in the heartland. Poster presentation at the Spirit of Eagles 7th National Changing Patterns of Cancer in Native Communities: The Power of Partnerships; Minneapolis, MN. 2007 Sep.
- Bernard, HR. Research methods in anthropology: Qualitative and quantitative approaches. 4. Lanham, MD: AltaMira Press; 2006.
- Bogart LM, Uyeda K. Community-based participatory research: Partnering with communities for effective and sustainable behavioral health interventions. *Health Psychology* 2009;28(4):391–393. [PubMed: 19594261]
- Braiuca, S.; Choi, WS.; Nazir, N.; Yount, J.; Kaur, B.; Weir, M., et al. Patterns of breast and colorectal cancer screening among American Indians in Kansas and Kansas City, MO. Poster presentation at the University of Kansas Cancer Center Fall Symposium; Kansas City, KS. 2008 Nov.
- Briscoe, J.; Prue, R.; Weir, M.; Begaye, J.; Greiner, KA.; Daley, CM. Colorectal cancer screening barriers among American Indians in the Kansas City area. Poster presentation at the Kansas Department of Health and Environment, Center for Health Disparities, “Healthy Cultures, Healthy Kansas,”; Topeka, KS. 2008 Oct.
- Burhansstipanov L, Christopher S, Schumacher SA. Lessons learned from community-based participatory research in Indian country. *Cancer Control* 2005;12(Suppl 2):70–76. [PubMed: 16327753]
- Caldwell JY, Davis JD, Du Bois B, Echo-Hawk H, Erickson JS, Goins RT, et al. Culturally competent research with American Indians and Alaska Natives: Findings and recommendations of the first symposium of the work group on American Indian research and program evaluation methodology. *American Indian and Alaska Native Mental Health Research* 2005;12(1):1–21. [PubMed: 17602391]
- Choi, W.; Barnoskie, R.; Schupbach, R.; Wilkett, D.; Daley, CM.; Ahluwalia, JS. Focus groups of Native American smokers. Paper presented at the Indian Health Service Summit: Healthier Indian Communities through Partnerships and Prevention; Washington, DC. 2004 Oct.
- Choi, W.; Daley, CM. Creating a culturally-appropriate smoking cessation program for American Indians/Alaska Natives using CMA to tailor at all levels. Paper presented at the Annual Meeting of the American Anthropological Association; San Jose, CA. 2006 Nov.
- Choi, W.; Daley, CM.; Nazir, N.; Braiuca, SL.; Brokenleg, SL.; Talawyma, M., et al. Baseline characteristics of American Indian smokers in a pilot cessation study. Poster presentation at the Society for Research on Nicotine & Tobacco Annual Meeting; Baltimore, MD. 2010 Feb.
- Choi, W.; Daley, CM.; Segraves, M.; Barnoskie, R.; James, AS.; Schupbach, R. Addressing smoking cessation among Native Americans. Poster presentation at the Society for Research on Nicotine and Tobacco Annual Meeting; Orlando, FL. 2006 Feb.
- Christopher S, Smith A, McCormick AK. Participatory development of a cervical health brochure for Apsaa-looke women. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education* 2005;20(3):173–176. [PubMed: 16122366]

- Coe K, Wilson C, Eisenberg M, Attakai A, Lobell M. Creating the environment for a successful community partnership. *Cancer* 2006;107(Suppl 8):1980–1986. [PubMed: 16929483]
- Cristancho S, Garces DM, Peters KE, Mueller BC. Listening to rural Hispanic immigrants in the Midwest: A community-based participatory assessment of major barriers to health care access and use. *Qualitative Health Research* 2008;18:633–646. [PubMed: 18420537]
- Daley, C. American Indians & tobacco: Sacred use, abuse, and treatment. Paper presented at the Cancer Center Research Symposium; Kansas City, KS. 2009 Nov.
- Daley, C.; Choi, WS.; James, AS.; Schupbach, R.; Barnoskie, R.; Coachman, C., et al. A Pan-Indian smoking cessation program: Is this even possible?. Paper presented at the National Association for Native American Studies Annual Meeting; Houston, Texas. 2005 Mar.
- Daley, C.; Filippi-Franz, M.; James, AS.; Weir, MM.; Braiuca, SL.; Kaur, B., et al. Provider and community leader views of needs and barriers to mammography among American Indians. 2009. Manuscript submitted for publication
- Daley, C.; Filippi-Franz, M.; Nazir, N.; James, A.; Greiner, KA.; Choi, WS. Patterns of breast cancer screening among American Indians in the Midwest. 2009. Manuscript submitted for publication
- Daley, C.; James, AS.; McCloskey, C.; Wilkett, D.; Choi, WS. Challenges in developing an evidence-based smoking cessation program for a heterogeneous American Indian population. Paper presented at the American Public Health Association Annual Meeting; Philadelphia, PA. 2005 Nov.
- Daley, C.; James, AS.; Weir, MM.; Filippi-Franz, M.; Braiuca, SL.; Kaur, B., et al. American Indian community leader and provider views of needs and barriers to colon cancer screening. 2009. Manuscript submitted for publication
- Daley, C.; Nazir, NN.; Greiner, KA.; James, AS.; Choi, WS. Colon cancer screening behaviors among American Indians in the Midwest. 2009. Manuscript submitted for publication
- Daley, C.; Weir, M.; Prue, R.; Briscoe, J.; Casey, G.; Greiner, KA. American Indian community leader and provider views of needs and barriers to breast and colorectal cancer screening. Paper presented at the KUMC Faculty Research Day; Kansas City, KS. 2007 Nov.
- Daley CM, Cowan P, Nollen NL, Greiner KA, Choi WS. Assessing the scientific accuracy, readability, and cultural appropriateness of a culturally-targeted smoking cessation program for American Indians. *Health Promotion Practice* 2009;10(3):386–393. [PubMed: 18323536]
- Daley, CM.; Prue, R.; Briscoe, J.; James, AS.; Greiner, KA. Community leader and provider views of breast and colorectal cancer screening needs and barriers for Native people in the heartland. Paper presented at the Spirit of Eagles 7th National Changing Patterns of Cancer in Native Communities: The Power of Partnerships; Minneapolis, MN. 2007 Sep.
- English KC, Fairbanks J, Finster CE, Rafelito A, Luna J, Kennedy M. A socioecological approach to improving mammography rates in a tribal community. *Health Education & Behavior: The Official Publication of the Society for Public Health Education* 2008;35(3):396–409.
- Erickson, K.; Stull, D. Doing team ethnography: Warnings and advice. Vol. 42. Thousand Oaks: Sage; 1998.
- Forster JL, Rhodes KL, Poupart J, Baker LO, Davey C. Patterns of tobacco use in a sample of American Indians in Minneapolis-St. Paul. *Nicotine & Tobacco Research: Official Journal of the Society for Research on Nicotine and Tobacco* 2007;9(Suppl 1):S29–S37.
- Holkup PA, Salois EM, Tripp-Reimer T, Weinert C. Drawing on wisdom from the past: An elder abuse intervention with tribal communities. *Gerontologist* 2007;47(2):248–254. [PubMed: 17440130]
- Horn K, McCracken L, Dino G, Brayboy M. Applying community-based participatory research principles to the development of a smoking-cessation program for American Indian teens: “Telling our story. *Health Education & Behavior: The Official Publication of the Society for Public Health Education* 2006;35(1):44–69.
- Israel, BA.; Eng, E.; Schultz, AJ.; Parker, EA. Methods in community-based participatory research for health. San Francisco: Jossey-Bass; 2005.
- Johnson VA, Edwards KA, Sherman SL, Stephens LD, Williams W, Adair A, et al. Decisions to participate in fragile X and other genomics-related research: Native American and African American voices. *Journal of Cultural Diversity* 2009;16(3):127–135. [PubMed: 19824292]
- Karnieli-Miller O, Strier R, Pessach L. Power relations in qualitative research. *Qualitative Health Research* 2009;19:279–289. [PubMed: 19150890]

- Kaur JS. The promise and the challenge of the Spirit of E.A.G.L.E.S. program. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education* 2005;20(Suppl 1):2–6. [PubMed: 15916512]
- Kaur JS, Dignan M, Burhansstipanov L, Baukol P, Claus C. The “Spirit of Eagles” legacy. *Cancer* 2006;107(Suppl 8):1987–1994. [PubMed: 16944468]
- Letiecq BL, Bailey SJ. Evaluating from the outside: Conducting cross-cultural evaluation research on an American Indian reservation. *Evaluation Review* 2004;28(4):342–357. [PubMed: 15245624]
- Lutz BJ, Kneipp S, Means D. Developing a health screening questionnaire for women in welfare transition programs in the United States. *Qualitative Health Research* 2009;19:105–115. [PubMed: 18997152]
- Noe TD, Manson SM, Croy C, McGough H, Henderson JA, Buchwald DS. The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. *Ethnicity & Disease* 2007;17(Suppl 1):S6–S14. [PubMed: 17598311]
- Okuyemi, K.; Cox, LS.; Choi, WS.; Ahluwalia, JS. Smoking cessation in U.S. ethnic minority populations. Paper presented at the Vanguard Conference: Building on Success in Smoking Cessation; Washington, DC. 2004.
- Ornelas IJ, Amell J, Tran AN, Royster M, Armstrong-Brown J, Eng E. Understanding African American men’s perceptions of racism, male gender socialization, and social capital through photovoice. *Qualitative Health Research* 2009;19:552–565. [PubMed: 19201993]
- Segraves, M.; Choi, WS.; Daley, CM.; Barnoskie, R. A smoking cessation program for American Indians. Surviving disparities: Embracing community wellness. Paper presented at the Annual Region VII American Indian Council Symposium; Kansas City, MO. 2005 Nov.
- Smith A, Christopher S, McCormick AK. Development and implementation of a culturally sensitive cervical health survey: A community-based participatory approach. *Women & Health* 2004;40(2): 67–86.
- Strickland CJ. Challenges in community-based participatory research implementation: Experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control: Journal of the Moffitt Cancer Center* 2006;13(3):230–236. [PubMed: 16885920]
- Teufel-Shone NI, Siyuja T, Watahomigie HJ, Irwin S. Community-based participatory research: Conducting a formative assessment of factors that influence youth wellness in the Hualapai community. *American Journal of Public Health* 2006;96(9):1623–1628. [PubMed: 16873759]
- Weir, M.; Braiuca, S.; Casey, G.; Kaur, B.; Greiner, KA.; Daley, CM. Breast cancer screening barriers among American Indian women in the Kansas City area. Poster presentation at the Kansas Department of Health and Environment, Center for Health Disparities, “Healthy Cultures, Healthy Kansas,”; Topeka, KS. 2008 Nov.
- Weir, M.; Daley, CM.; Braiuca, SL.; Kaur, B.; Greiner, KA. Colorectal cancer screening barriers, attitudes, and knowledge among American Indian women over age 50 in Kansas. Poster presentation at the University of Kansas Cancer Center Fall Symposium; Kansas City, KS. 2008.

## Biographies

**Christine Makosky Daley**, PhD, MA, SM, is an assistant professor and director of the Program in American Indian Community Health in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas; an adjunct assistant professor in the Department of Anthropology at the University of Kansas in Lawrence, Kansas; and an instructor in the Department of Health, Sport, and Exercise Science at Haskell Indian Nations University in Lawrence, Kansas, USA.

**Aimee S. James**, PhD, MPH, is an assistant professor in the Department of Surgery at Washington University School of Medicine in St. Louis, Missouri, USA.

**Ezekiel Ulrey**, MPA, is a research associate in the Program in American Indian Community Health in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas, USA.

**Stephanie Joseph**, MLS, is a research associate in the Program in American Indian Community Health in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas, USA.

**Angelia Talawyma** is a research associate in the Program in American Indian Community Health in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas, USA.

**Won S. Choi**, PhD, MPH, is an associate professor and executive director of the MPH Program in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas; and an instructor in the Department of Health, Sport, and Exercise Science at Haskell Indian Nations University in Lawrence, Kansas, USA.

**K. Allen Greiner**, MD, MPH, is an associate professor and director of the Research Division in the Department of Family Medicine at the University of Kansas Medical Center in Kansas City, Kansas; and an associate professor in the Department of Preventive Medicine and Public Health at the University of Kansas Medical Center in Kansas City, Kansas, USA.

**M. Kathryn Coe**, PhD, is an associate professor in the Mel and Enid Zuckerman College of Public Health at the University of Arizona in Tucson, Arizona, USA.

**Table 1**

## Analyst Roles, Qualifications, and Responsibilities

<b>Role</b>	<b>Qualifications</b>	<b>Responsibilities</b>
Primary Coder	Formally trained in qualitative methods	Leads coding meetings
	Member of the research team who is not a community member	Responsible for codebook upkeep Responsible for formal drafting of initial themes and subthemes Participates in all coder activities described (Does not take part in the focus groups)
Secondary Coder	Formally trained in qualitative methods	Responsible for identification of representative quotes
	Member of the research team who is also a community member	Responsible for review of themes and subthemes prior to sending to reviewers Participates in all coder activities described Leads at least some of the focus groups
Tertiary Coder	Formally trained in qualitative methods	Participates in all coder activities described
	Member of the research team (might or might not be a community member)	Might or might not take part in the focus groups
Emic Reviewer	Formally trained in qualitative methods	Makes final determination on representative quotes
	Member of the research team who is a community member	Works with etic reviewer to finalize all themes and subthemes (Does not take part in the focus groups)
Etic Reviewer	Formally trained in qualitative methods	Leads overall analysis
	Member of the research team who is not a community member	Works with emic reviewer to finalize all themes and subthemes (Does not take part in the focus groups)