

“I Did It for Us and I Would Do It Again”: Perspectives of Rural Latinos on Providing Biospecimens for Research

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Recent breakthroughs in the fields of genomics, proteomics, and personalized medicine highlight the importance of acquiring a high volume of quality biospecimen samples for research. This need has garnered attention from major academic and research institutions, including the National Cancer Institute.^{1,2} Although advances present possibilities to improve individualized health care and to reduce the gap of health disparities, results are only generalizable if samples are comprehensive and representative of the population. However, racial and ethnic minorities continue to be underrepresented in biomedical research.³⁻⁶ Some researchers are not setting or meeting recruitment goals for minority groups.⁷ Simultaneously, inequalities in health care and health outcomes disproportionately influence racial and ethnic minorities, highlighting the importance of obtaining biospecimens from these groups.⁸

Currently, the 52 million Latinos in the United States are the largest and fastest growing ethnic minority.^{8,9} They experience a higher burden of chronic diseases than non-Latino Whites, with cancer as the leading cause of death among Latinos.^{10,11} Like other minorities, Latinos are less likely than non-Latino Whites to participate in biomedical research.^{5,6} Barriers to recruiting minorities into research studies—including participant fear and mistrust, sometimes because of a history of exploitation, lack of culturally appropriate strategies, and structural barriers—are well documented.^{10,12-19} Only recently have researchers explored the attitudes and beliefs regarding participation in biomedical research among Latinos and other minorities, noting that distrust of researchers and lack of understanding of biomedical research serve as barriers to participation.^{16,20,21} Some have examined public perception about establishment of biospecimens repositories and use of biospecimens for various research studies, noting concerns about the use of biospecimens.²²⁻²⁴ To our knowledge, however, no study has

Objectives. We elicited perspectives of rural Latino farmworkers and non-farmworkers about their participation in a community-based participatory pesticides exposure study in which they provided multiple biospecimens.

Methods. Between March and April 2012, we conducted semistructured, one-on-one interviews with 39 rural Latino farmworkers and non-farmworkers in Washington State (n = 39). Nineteen open-ended interview questions aimed to elicit participants' attitudes toward, expectations and experiences of biospecimen collection for research, and willingness to participate in future biomedical research studies. We reviewed and coded transcriptions using qualitative principles of grounded theory in which concepts were identified and themes derived from interview data.

Results. We grouped themes into 3 major categories: (1) motivation to participate, (2) challenges of participation, and (3) perceived rewards of participation. Many participants were motivated by the perceived importance of the study topic and a desire to acquire and contribute to new knowledge. Respondents said that the benefits of participation outweighed the challenges, and many expressed satisfaction to be able to contribute to research that would benefit future generations.

Conclusions. Our findings supported the use of community-based participatory research to engage minorities as participants and invested parties in such studies. (*Am J Public Health.* 2014;104:911-916. doi:10.2105/AJPH.2013.301726)

described the experiences of a minority population that has provided biospecimens for research.

A possible framework for overcoming the challenges associated with collection of biospecimens in minorities is the community-based participatory research (CPBR) approach, which promotes equitable exchange between researchers and community members, and can address barriers to minority recruitment and retention.²⁵⁻²⁸ Using these CPBR methods, the Center for Child Environmental Health Risks Research at the University of Washington and the Fred Hutchinson Cancer Research Center have explored the environmental health risks posed by pesticide exposure in Latino farmworker families for more than 13 years in the Yakima Valley of eastern Washington, an agricultural and predominantly Latino community. In 1999, investigators formalized partnerships with community organizations and individuals in the Yakima Valley and formed an 18-member

Community Advisory Board (CAB) to work specifically with the CBPR community project. The CAB has been maintained throughout the 13 years of the study and has contributed research questions and hypotheses, as well as addressed dissemination of study findings.²⁹⁻³⁶ The exposure study also employs bilingual *promotores*, who are trusted lay health workers from the community trained to deliver culturally appropriate messages and support participants throughout each phase of the study. At the conclusion of each phase of a study, the researchers and *promotores* hosted a Town Hall forum with CAB and community members to discuss study results and highlight the study's local relevance.

In this study, we examined the experiences of Latino farmworkers and non-farmworkers in the Yakima Valley who had participated in the CBPR-framed pesticide exposure study in which they were asked to provide multiple biospecimen samples over a year-long period. We used a qualitative approach to gather an

in-depth understanding of this population’s perceptions and experiences when providing biospecimens and to ascertain their willingness to participate in future studies involving biospecimen collection.

METHODS

The pesticides exposure study builds on 13 years of work to provide a comprehensive understanding of exposure to organophosphate pesticides among Latino farmworkers and non-farmworkers and their children in rural Washington state.^{15–17} The study followed a CBPR model, in which community members were participants in all aspects of the project. The use of CBPR made it possible to work on a project that addressed pesticide exposure, a contentious issue in the Yakima Valley. Formation of the CAB enabled the development of a project that met community needs and did not alienate the farmers who used pesticides.³⁴ As a result of this Valley-wide focus, we gained a great deal of credibility and participation from farmworkers, growers, and other community members. This enabled us to subsequently embark on a series of projects in which we collected many biospecimen samples—urine, blood, buccal cells, saliva, and dust—from both farmworker and non-farmworker community members.

Noting that few studies examined farmworkers and non-farmworkers living in an agricultural region, in 2005, we expanded our research to include 100 non-farmworker families in addition to the 100 farmworker families, hypothesizing that non-farmworker families might also be affected by the pesticides widely found in an agricultural community. In the present study, which began in 2010, we re-contacted 100 adult participants and 100 children from the 2 cohorts of farmworker and non-farmworker families. All families provided biological samples, completed surveys, and provided dust samples 3 times between March 2011 and January 2012. They were compensated \$250 for the year. Each sample and data collection period corresponded to an agricultural season that was characterized by specific types of pesticide application during the year. The first season (March to April) was when chlorpyrifos was sprayed on orchard crops; the second season (May through June) was when azinphosmethyl

was applied, and trees were thinned to enable the orchard crops to grow bigger and fuller; and the final season (December through January) was the no-spray season when crops were dormant. Table 1 describes the various data collection activities and demonstrates the demands of the parent study.

Participant Recruitment

During the pesticide biospecimen collection, participants signed a consent form that asked whether they would be interested in contributing to future research projects. All of the adults agreed to be re-contacted. In previous studies with rural Latinos in Yakima Valley, theoretical saturation—a point at which no new data emerges from interviews—was typically achieved at 30 to 35 interviews.^{37,38} To reach this number and to account for individuals who might not have been interested in completing an interview, the study team randomly selected 42 past participants and invited them by telephone to participate in a face-to-face interview.

Data Collection and Analysis

The project team developed a semistructured interview tool consisting of 19 open-ended questions to elicit participants’ attitudes toward

biospecimen collection for research, expectations and experiences of biospecimen collection for research, and willingness to participate in future biomedical research studies. The questions were first developed in English, translated into Spanish by a certified translator, and tested with *promotores*.

Three *promotores*, experienced in qualitative data collection, were trained by project staff to conduct the semistructured interview. One *promotora* visited each respondent’s home to conduct one-on-one interviews in the respondent’s language of choice (Spanish or English). Each interview lasted 20 to 25 minutes and was audio-recorded. Confidentiality and the voluntary nature of the interview were discussed with each participant, and each signed a consent form. Each participant received a \$20 gift card.

Three bilingual, native Spanish-speaking members of the project team transcribed each interview verbatim. Transcripts were uploaded into qualitative data analysis software, Atlas.ti version 7 (Atlas.ti, Berlin, Germany) for coding. To analyze the data, 2 bilingual researchers first applied an a priori approach, in which a startlist of codes was developed based on interview questions.^{37,39–41} Upon becoming

TABLE 1—Pesticides Exposure Study Biospecimens and Participation Over Three Seasons: Yakima Valley, WA, 2011

| Variables | Total Participants | | |
|----------------------|---|---|--------------------------------------|
| | Prethinning Season, Chlorpyrifos (Mar–May 2011) | Thinning Season, Azinphosmethyl (June–Aug 2011) | Nonspray Season, None (Nov–Dec 2011) |
| Baseline survey | 100 | 96 | 98 |
| Urine—day 1 | 100 | 96 | 98 |
| Urine—day 3 | 100 | 96 | 98 |
| Urine—day 5 | 99 | 96 | 98 |
| Urine—day 7 | 100 | 96 | 98 |
| Blood sample—day 1 | 100 | 95 | 97 |
| Buccal cell—day 1 | 100 | 96 | 98 |
| Buccal cell—day 3 | 100 | 96 | 98 |
| House dust—day 1 | 100 | 96 | 98 |
| House dust—day 7 | 100 | 96 | 98 |
| Vehicle dust | 96 | 92 | 94 |
| 3-day diet survey | 100 | 96 | 98 |
| 7-day activity diary | 100 | 96 | 98 |
| Follow-up survey | 100 | 96 | 98 |

Note. The sample size was n = 100.

familiar with the transcripts, the coders utilized an inductive, constant comparison approach, in which concepts were identified and themes derived from interview data.^{37,42,43} Through an iterative process, they met weekly to refine the codebook, adding, removing, and revising codes as needed, to address inter-rater reliability, and to compare new data with existing data. The coders consulted with the larger research team to build consensus around emergent themes throughout the coding and analysis process. The research team compared themes arising from the data and determined possible linkages across participants and thematic categories, and collaboratively selected exemplar quotes to represent each theme in the results. Salient quotes were translated from Spanish to English for inclusion in this article.

RESULTS

Of the 42 participants re-contacted, 41 agreed to participate in an interview, 2 of whom were later lost to follow-up and could not be reached. The remaining 39 participants were Latinos living in the reference area (Table 2) and were interviewed between March and April 2012. All but 2 respondents (92.3%) were born in Mexico. Twenty-four (61.5%) were farmworkers, and 32 (82.1%) were female, a gender distribution similar to that of the parent study (77% female). Nearly three quarters (71.8%) of participants reported having no health insurance.

We grouped emergent themes into 3 categories: (1) motivation to participate, (2) challenges of participation, and (3) perceived rewards of participation. Although farmworkers discussed concern about carrying pesticide residue home from the field—an issue not raised by non-farmworkers—motivations, challenges, and perceived rewards of research participation were otherwise shared between farmworkers and non-farmworkers in this sample.

Motivation to Participate

Personal connection to the study topic and opportunity for knowledge acquisition. All respondents described a personal relevance of the study topic as a reason for participation and discussed concerns about pesticide levels in their home and work environment. They hoped the study would reveal the risks of exposure to their families and communities. One female

farmworker exemplified this by stating, “This is important, especially because I live in an environment surrounded by orchards.” Most respondents expressed concern about their family’s—particularly their children’s—well-being in relation to pesticide exposure and hoped their participation would address these concerns, as illustrated by this male farmworker:

I decided to participate last year primarily because of my family. . . . I had to understand if I was carrying pesticide residue into my home or . . . my children could be affected by pesticides from work.”

Respondents indicated a major factor in their decision to participate was the expectation that they would be educated about issues connected to their well-being. Participants said they would be willing to provide biospecimens in the future if they knew they would receive generalizable information about their community when the study concluded. When asked why she decided to participate, this female farmworker explained:

We [Latinos] like to learn new things. . . . I can help my children, my grandchildren, or other people. . . . If they work in the field or something, one can explain to them about the pesticides that might do harm, and how they can protect themselves.

Advancing scientific research and global knowledge. Beyond their anticipation of self-enrichment, respondents hoped their participation would contribute to the creation of new general scientific knowledge, as well as that directly related to pesticides. All respondents asserted that biomedical research is important; they commonly reported that research can find “the causes of illnesses” and can determine if “something poses risks” or “does damage.” Exemplifying this sentiment, a female farmworker asserted that her participation would be “an aid for science to keep advancing,” whereas a male non-farmworker said of biomedical research:

It can help prevent certain diseases . . . like cancer. More than anything it can help us know what potential hazards there are in areas where pesticides are applied.

Expectations of participation. Regardless of occupation or health insurance status, participants widely held the expectation that they would receive individual information about their own health status and pesticide exposure levels, exemplified by this male (insured) farmworker who said, “Well, I hoped that they

TABLE 2—Characteristics of Interview Participants at Baseline: Yakima Valley, WA, 2012

| Variable | No. (%) or Mean (Range) |
|-----------------------------|-------------------------|
| Age, y | 38 (28–51) |
| Gender | |
| Female | 32 (82.1) |
| Male | 7 (17.9) |
| Language | |
| Spanish | 35 (89.7) |
| English | 4 (10.2) |
| Occupation | |
| Farmworker | 24 (61.5) |
| Non-farmworker | 15 (38.5) |
| Country of birth | |
| Mexico | 36 (92.3) |
| United States | 2 (5.1) |
| Refused | 1 (2.6) |
| Insurance type | |
| None | 28 (71.8) |
| Basic health care plan | 8 (20.5) |
| Private | 3 (7.7) |
| Household annual income, \$ | |
| < 5000 | 1 (2.6) |
| 5000–10 000 | 2 (5.1) |
| 10 001–15 000 | 7 (17.9) |
| 15 001–25 000 | 7 (17.9) |
| 25 001–35 000 | 14 (35.9) |
| 35 001–50 000 | 4 (10.3) |
| > 50 000 | 3 (7.7) |
| Don't know or refused | 1 (2.6) |

Note. The sample size was n = 39.

would give me a favorable result, right, like saying ‘Listen, your urine samples and the blood we took were perfect.’” Many respondents confused participation in biospecimen collection for the purposes of research with seeking clinical services. Illustrating this concept, a male (insured) non-farmworker said biospecimen research is carried out “to be able to detect an illness in the patient.” Similarly, another (uninsured) female farmworker saw her participation as an activity to take the place of clinical examinations: “I wanted to see if I’m well, because I am always working in the field . . . instead of going to do a check-up, I can do it with you.”

Confidentiality. Although participants asked for individual health results, respondents were

insistent that their anonymity as study participants be secured should any report of the study be distributed. Although most said their community would benefit from an article about pesticides in their area, respondents, like this female non-farmworker, wanted assurance that their names and identifying information could be removed from reports that might contain personal pesticide exposure levels: “I want to make sure that my information is not shared with anybody that doesn’t need that information.”

Challenges of Participation

When asked if they faced challenges during their participation, all participants’ initially responded “No.” However, further probing revealed difficulties and discomfort related to sample collection and storage and self-confidence about participation.

Sample collection and storage. The most often disclosed discomfort of participation was a fear of needles or reaction to providing blood samples, such as dizziness, bruising, and nausea. Despite this, as Table 1 indicates, the majority of participants provided blood in all 3 seasons and said they would do it again. Some participants also discussed difficulty with urine sample collection and storage. During the study, participants produced urine samples every other day for 7 days. They stored contained urine samples for 1 or 2 days in their refrigerator. *Promotores* collected the samples on days 3 and 7, and if requested, on day 5. Several respondents were nervous that they would forget to produce the samples at the appropriate times, exemplified by this female farmworker: “Well, it wasn’t difficult or uncomfortable. The issue is that sometimes I forget.” One female non-farmworker described her creative solutions to help herself remember: “At night, I would put the urine cup . . . there, next to the sink . . . because I had that little fear that I would forget . . . and in the morning I would wake up and see it.”

Women, such as this female farmworker, reported feelings of discomfort and embarrassment at having to provide urine samples to the *promotora*: “I met my goal; the [*promotora*] said it was good, that, whatever. . . . But, it [providing urine to the health worker] gave me shame.” Another female non-farmworker added that “having to hand that out to somebody else was . . . uncomfortable. . . . That’s part of who I am.”

Respondents occasionally noted that storing the samples in their fridge felt “strange,” but they mitigated the discomfort by designating a special place for samples away from food, and informing family members where samples would be stored. They did not mention any concerns about home and vehicle dust sample collection, and said that the buccal cell collection felt “easy.” All participants said the time requirements did not pose challenges to participation, but that occasionally, juggling work schedules around sample collection required extra effort and planning.

Meeting study requirements. A few respondents were preoccupied with their perceived abilities to meet study requirements. In addition to concerns about being able to provide samples when needed, respondents like this female farmworker also expressed uneasiness about completing the oral surveys: “I was nervous sometimes with some questions because I didn’t know how to answer . . . [so] I said ‘I don’t know because I don’t remember.’” A male non-farmworker shared similar sentiments: “Sometimes I was a little nervous. . . . You know, because of the questions, and especially when they ask a question and there is no adequate way to answer them correctly.”

Perceived Rewards of Participation

Positive experiences. Respondents reported positive experiences during their participation. They felt valued, respected, and cared about and expressed appreciation for the research as well as the institution conducting it. One female non-farmworker demonstrated this common sentiment in her response: “What I liked? I like that there are people working to give us questions and answers to certain things.” A male non-farmworker corroborated: “I liked that there is a company [Fred Hutchinson Cancer Research Center] that is concerned about the health of the population.”

Monetary incentives. Without prompting, fewer than a third of respondents discussed the \$250 monetary incentive as a reward for their participation. A few also speculated that a monetary incentive would motivate participation of family members. Most respondents who discussed money, however, said the extra cash was an added advantage, but other factors also compelled them to participate. When asked what she liked about participation, this female farmworker said:

Well, everything. Not just for the money, but for the experiences one learns . . . and continues to learn. And . . . If they (study participants) work in the field or something, you all explain about the pesticides and the things that do harm, and how we can protect ourselves.

Experience with promotores. All participants reported a positive experience with the *promotores*, often describing interactions as “friendly” and “familiar.” Respondents said the *promotora* put them at ease throughout the study, but particularly when challenges arose, as illustrated by this male farmworker:

The [*promotores*] are people who relate with you. . . . They make you feel like your participation isn’t something to make you tense or worry you. . . . I felt very comfortable with them. They were very attentive, very friendly, very sociable.

Contribution to future generations. Respondents consistently discussed the reward of being able to contribute to their community and to the well-being of future generations. All respondents said they would be willing to donate biological samples in future studies; for most respondents, their desire to participate was rooted in altruism, a theme summarized by one female non-farmworker as an opportunity to “serve the community.” Another male farmworker said of future participation:

Yes. . . . Well, if I can help research then I don’t think it’s an inconvenience. On the contrary, well, I feel very proud of myself to be able to collaborate in an investigation that will serve future generations.

Regarding participation in future studies, many respondents emphasized their expectation that the new knowledge would benefit the community. They felt their contribution of biospecimens was personally valuable and wanted reassurance that this sacrifice would make a meaningful contribution for the benefit of humanity, especially for that of their community. A female non-farmworker said:

I would . . . because the same fact that I would like to know how it (illness) was caused or, you know, to help other people . . . stop from causing it or to help them cure it in any way. . . . It’s going to benefit all of us.

Participants expressed pride at being part of a team that would answer questions and yield benefits for their community, illustrated by this female farmworker, who said “Together we are going to look for solutions. . . . We are not alone.”

DISCUSSION

Our study described the experiences of members of a rural Latino community who participated in a year-long study that included biospecimen collection. Despite demands of the study and challenges cited by participants with regard to sample provision and self-doubt about their abilities to complete all of the components of the study, participants all reported an overall positive experience. The 2% overall attrition rate demonstrated that participants were able to surmount challenges and complete the study. In addition, participants consented to the participation of their children in sample collection. We attributed this success to mutual trust and understanding built through CBPR methods.

Research conducted with Latinos has often been challenging because of researcher violation of normative cultural values such as *personalismo*—the desire to develop positive personal relationships—and *respeto*—deference to elders or authority figures.^{10,44,45} In our study, *promotores*, who were trained and trusted lay health workers from the community, served as a crucial link between participants and researchers. *Promotores* possessed both the ability to conduct research and to exemplify Latino normative cultural values, which enabled participants to complete the study requirements.

Kiviniemi et al.²⁶ contended that providing accurate information and improving knowledge about biomedical research in African American and Native American communities reduced anxieties and could lead to increased participation of these groups. Correspondingly, in the CBPR approach, study findings are delivered to the community along with educational messages and actionable interventions to improve health outcomes.²⁸ Not surprisingly, participants in our study expected to receive information about both general findings of the study as well as individual results. To address normative cultural values and to build trust, *promotores* explained the types of results participants would receive, such as individual exposure levels compared with the larger community and practical suggestions for how to mitigate exposure. Despite this, participants continued to conflate biospecimen research participation with clinical service, a phenomenon not uncommon among research participants

of all ethnicities.^{29,46,47} In addition to a Town Hall forum with CAB and community members to discuss study results, *promotores* returned to participant homes to deliver and answer questions about individualized information. This exchange benefited participants, the community, and the prospect for future research with minorities, who have been shown to be less likely to participate in research.⁴⁸

Although the survey tools from the parent study and interview guide for this study were developed with community members and pilot tested with the goal of being user-friendly, a few participants were preoccupied about their ability to “give the right answer” to survey questions. This phenomenon might be attributable to the cultural norms of *personalismo* and *respeto*, which could lead to participant reasoning that it was disrespectful to ask questions or clarify misunderstandings during the study.⁴⁵

Previous research showed that Latino respondents tend to score higher than non-Latino Whites on some measures of social desirability, which could have introduced bias in our sample.⁴⁹ Latino cultural norms of *personalismo*, or the desire to have positive interactions, might also have influenced the responses of our participants.^{45,50} Because 80% of the study participants were female, we might have missed aspects of the Latino male experience in participation of biospecimen collection studies.

Implications

The results from this study provided insight into the utility of CBPR as a mechanism for fostering the participation of a traditionally underrepresented population into a research study involving biospecimen collection. As a result, our follow-up study about participants' satisfaction with and attitudes toward biospecimen collection was relatively easy both in terms of recruiting participants and in eliciting information from them. We also noted that the informed consent process had to include clear language that explicitly outlined what participants would and would not receive as a result of taking part in the study. This information should include incentives, as well as information about which, if any, individual or general study results would be delivered. Without knowledge of the study and trust in researchers, this group would likely be unwilling to participate in research studies that require their

biospecimens. Our results illustrated that a trained lay health worker from the community is well positioned to deliver these messages, in effect bridging researchers and communities. Our participants faced some difficulties with sample collection, particularly, urine and saliva. Researchers should provide clear instructions about sample collection methods, both to build self-confidence and preserve the integrity of the samples. If CBPR approaches are not possible, the health provider or researcher must receive cultural sensitivity training to appropriately deliver clear messages about the study.

Conclusions

Advancements in biospecimen science and ubiquity of biospecimen collection for health care purposes necessitate understanding of how to best include minority communities in research. Our findings supported the use of CBPR to engage minorities as participants and invested parties in studies and highlighted the need to develop effective strategies for recruiting and retaining minority participants. It was therefore advantageous to utilize expertise of public health investigators with experience in the CBPR framework to recruit and retain individuals for these studies as a contribution to the larger biospecimen collection effort. ■

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Contributors

S.D. Hohl and C. Gonzalez led the data analysis and writing of the article. E. Carosso and G. Ibarra led the design and implementation of the biospecimen collection and the qualitative data collection, and contributed to the interpretation of the data. B. Thompson was the lead investigator and assisted in all aspects of the design, implementation, analysis, and writing.

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Human Participant Protection

All study materials were approved by the Fred Hutchinson Cancer Research Center Institutional Review Board (file #5946).

References

- Vaught JB. Biorepository and biospecimen science: a new focus for CEBP. *Cancer Epidemiol Biomarkers Prev*. 2006;15(9):1572–1573.
- De Souza YG, Greenspan JS. Biobanking past, present and future: responsibilities and benefits. *AIDS*. 2013; 27(3):303–312.
- James RD, Yu JH, Henrikson NB, Bowen DJ, Fullerton SM, Health Disparities Working Group. Strategies and stakeholders: minority recruitment in cancer genetics research. *Community Genet*. 2008;11(4):241–249.
- Grann VR. Erasing barriers to minority participation in cancer research. *J Womens Health (Larchmt)*. 2010; 19(5):837–838.
- Grann VR, Jacobson JS, Troxel AB, et al. Barriers to minority participation in breast carcinoma prevention trials. *Cancer*. 2005;104(2):374–379.
- Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA*. 2004;291(22):2720–2726.
- Durant RW, Davis RB, St George DM, Williams IC, Blumenthal C, Corbie-Smith GM. Participation in research studies: factors associated with failing to meet minority recruitment goals. *Ann Epidemiol*. 2007;17(8):634–642.
- Frieden TR, Centers for Disease Control and Prevention. Forward: CDC health disparities and inequalities report - United States, 2011. *MMWR Surveill Summ*. 2011;60 (suppl):1–2.
- Passel JS, Cohn D, Lopez MH. *Hispanics Account for More than Half of Nation's Growth in Past Decade*. Washington, DC: Pew Hispanic Center; 2011.
- Larkey LK, Ogden SL, Tenorio S, Ewell T. Latino recruitment to cancer prevention/screening trials in the Southwest: setting a research agenda. *Appl Nurs Res*. 2008;21(1):30–39.
- American Cancer Society. Cancer Facts and Figures for Hispanics and Latinos Available at: <http://www.cancer.org/acs/groups/content/@epidemiologysurveillance/documents/document/acspc-034778.pdf>. Accessed January 16, 2013.. 2012.
- Canales MK, Weiner D, Samos M, Wampler NS. Multi-generational perspectives on health, cancer, and biomedicine: Northeastern Native American perspectives shaped by mistrust. *J Health Care Poor Underserved*. 2011;22(3):894–911.
- Sheppard VB, Cox LS, Kanamori MJ, et al. Brief report: if you build it, they will come: methods for recruiting Latinos into cancer research. *J Gen Intern Med*. 2005;20(5):444–447.
- Katz RV, Green BL, Kressin NR, Claudio C, Wang MQ, Russell SL. Willingness of minorities to participate in biomedical studies: confirmatory findings from a follow-up study using the Tuskegee Legacy Project Questionnaire. *J Natl Med Assoc*. 2007;99(9):1052–1060.
- Hiratsuka VY, Brown JK, Hoelt TJ, Dillard DA. Alaska native people's perceptions, understandings, and expectations for research involving biological specimens. *Int J Circumpolar Health*. 2012;71:18642.
- Ulrich A, Thompson B, Livaudais JC, Espinoza N, Cordova A, Coronado GD. Issues in biomedical research: what do Hispanics think? *Am J Health Behav*. 2013;37(1):80–85.
- UyBico SJ, Pavel S, Gross C. Recruiting vulnerable populations into research: a systematic review of recruitment interventions. *J Gen Intern Med*. 2007;22(6):852–863.
- Khaliq W, Gross M, Thyagarajan B, Jones-Webb R. What motivates minorities to participate in research? *Minn Med*. 2003;86(10):39–42.
- Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27(1):1–28.
- Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med*. 1999;14(9):537–546.
- Corbie-Smith G, Williams IC, Blumenthal C, Dorrance J, Estroff SE, Henderson G. Relationships and communication in minority participation in research: multidimensional and multidirectional. *J Natl Med Assoc*. 2007;99(5):489–498.
- Hiratsuka V, Brown J, Dillard D. Views of biobanking research among Alaska native people: the role of community context. *Prog Community Health Partnersh*. 2012;6(2):131–139.
- Luque JS, Quinn GP, Montel-Ishino FA, et al. Formative research on perceptions of biobanking: what community members think. *J Cancer Educ*. 2012;27(1):91–99.
- Murphy J, Scott J, Kaufman D, Geller G, LeRoy L, Hudson K. Public perspectives on informed consent for biobanking. *Am J Public Health*. 2009;99(12):2128–2134.
- Christopher S, Watts V, McCormick AK, Young S. Building and maintaining trust in a community-based participatory research partnership. *Am J Public Health*. 2008;98(8):1398–1406.
- Kiviniemi MT, Saad-Harfouche FG, Ciupak GL, et al. Pilot intervention outcomes of an educational program for biospecimen research participation. *J Cancer Educ*. 2013;28(1):52–59.
- De Las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health Serv Res*. 2012;47(3 Pt 2):1363–1386.
- Horowitz CR, Robinson M, Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared? *Circulation*. 2009;119(19):2633–2642.
- Coronado GD, Holte SE, Vigoren EM, et al. Do workplace and home protective practices protect farm workers? Findings from the "For Healthy Kids" Study. *J Occup Environ Med*. 2012;54(9):1163–1169.
- Coronado GD, Thompson B, Strong L, Griffith WC, Islas I. Agricultural task and exposure to organophosphate pesticides among farmworkers. *Environ Health Perspect*. 2004;112(2):142–147.
- Curl CL, Fenske RA, Kissel JC, et al. Evaluation of take-home organophosphorus pesticide exposure among agricultural workers and their children. *Environ Health Perspect*. 2002;110(12):A787–A792.
- Strong LL, Thompson B, Coronado GD, Griffith WC, Vigoren EM, Islas I. Health symptoms and exposure to organophosphate pesticides in farmworkers. *Am J Ind Med*. 2004;46(6):599–606.
- Strong LL, Thompson B, Koepsell TD, Meischke H. Factors associated with pesticide safety practices in farmworkers. *Am J Ind Med*. 2008;51(1):69–81.
- Thompson B, Coronado G, Puschel K, Allen E. Identifying constituents to participate in a project to control pesticide exposure in children of farmworkers. *Environ Health Perspect*. 2001;109(Suppl 3):443–448.
- Thompson B, Coronado GD, Grossman JE, et al. Pesticide take-home pathway among children of agricultural workers: study design, methods, and baseline findings. *J Occup Environ Med*. 2003;45(1):42–53.
- Thompson B, Coronado GD, Vigoren EM, et al. Para niños saludables: a community intervention trial to reduce organophosphate pesticide exposure in children of farmworkers. *Environ Health Perspect*. 2008;116(5):687–694.
- Bernard HR. *Research Methods in Anthropology: Qualitative and Quantitative Approaches*. 4th ed. Lanham, MD: AltaMira Press; 2006.
- Sandelowski M. Sample size in qualitative research. *Res Nurs Health*. 1995;18(2):179–183.
- DeCuir-Gunby J, Marshall PL, McCulloch AW. Developing and using a codebook for the analysis of interview data: an example from a professional development research project. *Field Methods*. 2011;23(2):136–155.
- MacQueen KM, McLellan E, Kay K, Milstein B. Codebook development for team-based qualitative analysis. *Cult Anthropol Methods*. 1998;10(2):31–36.
- Miles MB, Huberman AM. *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
- Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Brunswick, NJ: Aldine Transaction; 2006.
- Sheikh A. Why are ethnic minorities under-represented in US research studies? *PLoS Med*. 2006;3(2):e49.
- Andrés-Hyman RC, Ortiz J, Añez LM, Paris M, Davidson L. Culture and clinical practice: recommendations for working with Puerto Ricans and other Latinas(os) in the United States. *Prof Psychol Res Pr*. 2006;37(6):694–701.
- Flores G. Culture and the patient-physician relationship: Achieving cultural competency in health care. *J Pediatr*. 2000;136(1):14–23.
- Luque JS, Quinn GP, Montel-Ishino FA, Arevalo M, Bynum SA, Noel-Thomas S, et al. Formative research on perceptions of biobanking: what community members think. *J Cancer Educ*. 2012;27(1):91–99.
- Halverson CM, Ross LF. Incidental findings of therapeutic misconception in biobank-based research. *Genet Med*. 2012;14(6):611–615.
- Wendler D, Kington R, Madans J, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2006;3(2):e19.
- Hopwood CJ, Flato CG, Ambwani S, Garland BH, Morey LC. A comparison of Latino and Anglo socially desirable responding. *J Clin Psychol*. 2009;65(7):769–780.
- Comas-Díaz L. Hispanics, Latinos, or Americans: the evolution of identity. *Cultur Divers Ethnic Minor Psychol*. 2001;7(2):115.