Published in final edited form as:

Appl Nurs Res. 2016 November ; 32: 164–170. doi:10.1016/j.apnr.2016.07.009.

Guidelines for research recruitment of underserved populations (EERC)

Yui Matsuda, PhD, RN, MPH^{a,*}, Jada L. Brooks, PhD, MSPH, RN, BSN^b, and Linda S. Beeber, PhD, PMNCNS-BC, FAAN^b

^aSchool of Nursing and Health Studies, University of Miami, Coral Gables, FL 33124

^bSchool of Nursing, University of North Carolina, Chapel Hill, NC

Abstract

Purpose—Despite concerted efforts to establish health equity, significant disparities persist. One roadblock to eliminating health disparities is the inadequate recruitment of underserved populations, which prevents researchers from creating culturally-tailored interventions. To further develop the science of recruitment, we argue that a systematic approach should be applied to research participant recruitment. Given the lack of practical and comprehensive recruitment conceptual frameworks or guidelines in the literature, the authors propose newly synthesized guidelines for research recruitment of underserved populations: EERC (evaluate, engage, reflect, and carefully match).

Methods—The EERC guidelines are delineated, and the application of these guidelines is illustrated through a study recently conducted by the authors.

Results—The guidelines consist of the following four components: 1. **Evaluate** the composition of the research team; 2. **Engage** fully with the community by working with key informants and cultural insiders; 3. **Reflect** the unique cultural characteristics of the community in the research conduct; and 4. **Carefully** use a matching technique. The application component of the article demonstrates concrete examples of how the guidelines can enhance research recruitment for an underserved population.

Conclusion—The authors intend these guidelines to be broadly applicable for research teams regardless of research design or characteristics of the underserved population.

Application of these guidelines in nursing and health science will contribute to increasing research recruitment of underserved populations, with the goal of reducing health disparities and achieving health equity for all persons.

Keywords

Recruitment; Patient selection; Community-based participatory research; Health equity; Nursing

Disparities in health are defined as differences in health outcomes and their determinants between segments of the population, as influenced by social, demographic, environmental,

*Corresponding author. Tel.: +1 305 284 1056; fax: +1 305 284 4221. ymatsuda@miami.edu (Y. Matsuda).

and geographic attributes (Centers for Disease Control and Prevention, 2014). Determinants of health include age; sexual orientation; race and ethnicity; physical illness, mental illness, or disabilities; socioeconomic status; and geography of residence (rural or urban area as well as safety and access to health promoting facilities). The overlap of determinants among the underserved often results in differences, or disparities, that can impact an individual's level of resources, access to care, and quality of care. The ability to eliminate health disparities within underserved populations requires an understanding of not only the existing health disparities, but also of the social factors that largely influence these disparities. In order to examine these factors and ultimately eliminate the systematic disparities in health (Braveman & Gruskin, 2003), researchers must include adequate numbers from underserved groups in their research studies regardless of the study design or approach. Only then can researchers study health issues specifically affecting the sociocultural context of underserved populations to determine the most appropriate forms of intervention and health care delivery.

Racial and ethnic minority status comprises one of the most important and discussed determinants of underserved populations. Despite the increase of racial and ethnic minority composition in the U.S. and increasing need for their research recruitment, their recruitment rates continue to be suboptimal due to factors such as mistrust of authorities, fear, stigma related to the topic area, and immigration status. This creates a vicious cycle when researchers strive to create culturally-tailored interventions to improve the health of those experiencing health disparities. In 2001, the National Institutes of Health (NIH) published guidelines focused on increasing the recruitment of minorities into research studies. More than a decade later, these NIH guidelines have not been systematically approached, practically applied, or translated into research practice, with only anecdotal reports of successful minority recruitment strategies through working with communities (Wallerstein & Duran, 2010). What we lack is systematic efforts to advance the science of research participant recruitment.

When considering community engagement and success in research studies, the community-based participatory research (CBPR) approach has been used increasingly in recent decades (Wallerstein & Duran, 2010). The CBPR model is an approach in which community partners are equally involved in all stages of the research process and is believed to create social change, improve community health, and reduce health disparities (Israel, Eng, Schulz, & Parker, 2005; National Institutes of Health Office of Behavioral and Social Sciences Research, 2013). Although CBPR has been used with increasing frequency, the majority of research studies do not use the CBPR methodology: other than specific program announcements for CBPR, research funding applications ask for specific population and topics to study, thus may limit researchers' ability to use a CBPR approach. In addition, some studies do not lend themselves to CBPR. These non-CBPR studies lack appropriate guidelines to effectively recruit participants. Therefore, we propose newly synthesized guidelines for research recruitment, EERC (evaluate, engage, reflect, and carefully match). Application of these guidelines in the development of the recruitment strategy should prove helpful; however, we further recommend these guidelines be coupled with a community engagement approach for better results. Overall, we intend that the EERC guidelines serve as a way of operating a research process rather than presenting specific strategies to apply to recruitment alone.

The EERC guidelines contribute to the emerging science of research recruitment. The intent of these guidelines is to build the science of recruitment for non-CBPR studies, not to reduce the value of or replace CBPR. Our study, “A UNC [University of North Carolina] – Community Partnership to Enhance Outcomes for Infants and Toddlers with Suspected Disability who are Enrolled in Early Intervention Services” (Beeber et al., 2014) will be used to exemplify the implementation of the research recruitment guidelines. These guidelines aid researchers in meeting the challenges of recruitment and offer direction for designing research studies to test the efficacy of inclusive recruitment practices. Further, adopting these research recruitment guidelines is a critical step toward eliminating health disparities regardless of study design or approach.

1. Introduction to the EERC guidelines

The authors developed the research recruitment guidelines (EERC) using a systematic review of available literature on recruitment, discussion of direct experiences with recruitment and synthesis of the main components. The EERC has four components (see Fig. 1):

1.1. Evaluate the composition and dynamics of the research team

Team science is essential to effectively intervene in complex health issues (Falk-Krzesinski et al., 2010). For members to maximize their contribution to the team, an effective operation of team-based research collaboration is critical. In 2010, a science of team science (SciTS) concept map was proposed during the first annual international science of team science conference. This concept map identifies structure and context for teams, as well as characteristics and dynamics of teams as the nuts and bolts of team science (Falk-Krzesinski et al., 2011). Structure and context for teams include statements about abstract concepts leading to a successful team science approach (e.g., team dynamics can impact science, contextual/situational factors influence the effectiveness of team collaboration). Characteristics and dynamics of teams include more specific elements of team science. Teams are composed of personnel with unique professional and cultural backgrounds. Team members may have different communication styles and preferences depending on their cultural backgrounds, which includes difference in their academic disciplines. Status difference and power dynamics within the team must also be considered: One team member may occupy more dominant professional or social position than others (e.g., professor vs. students/early career individuals, male vs. female, racial/ethnic majority vs. minority) or possesses a dominant role within the team (e.g., principal investigator vs. data collectors). To improve the research process, it is essential to observe how power dynamics within the team facilitate or prevent full participation by members. A deliberate effort to create a particular team culture is needed. This team culture should embody practices that support the respect of all team members, the freedom to express their individual thoughts and opinions, and the ability to have meaningful input into decisions about the conduct of the research.

1.2. Engage fully with the community by working with key informants and cultural insiders

Key informants and cultural insiders are crucial components in developing community engagement. Researchers must identify key informants and cultural insiders, and must work

with them in partnership in order to build sustainable relationships. A key informant is a person who holds a formal role within the community and is able to communicate information about the community to researchers (Tremblay, 1957); a cultural insider is a person who belongs to or has significant involvement with the community (Ganga & Scott, 2006).

The term “key informants” originated from the discipline of anthropology and has been used to guide researchers about whom to contact in the target communities (Poggie, 1972). According to Tremblay (1957), the ideal characteristics of informants include a formal role in the community, possession of the information that researchers seek, and willingness and ability to communicate with researchers about the information in a reflective manner. However, key informants may not always be community members, and their views may not be accurate (McKenna & Main, 2013; Poggie, 1972). In previous studies, key informants were not aware of the underlying cause of a community problem and community members’ true feelings about resolving a problem, thus, they inaccurately represented the community (Marshall, 1996; McKenna, Iwasaki, Stewart, & Main, 2011). While there are potential drawbacks in relying on key informants, they also have important functions such as providing expert knowledge, setting research priorities, or functioning as gatekeepers to specific populations or information (McKenna et al., 2011; Pauwels & Hardyns, 2009).

In contrast, cultural insiders are accepted and trusted by the community members (Kahan & Al-Tamimi, 2009). Regardless of where the underserved populations are from, working with cultural insiders who have already been accepted and trusted with community members is critical to successful recruitment efforts (Beeber et al., 2010; Kahan & Al-Tamimi, 2009; Martinez, McClure, Eddy, Ruth, & Hyers, 2012). For example, Beeber et al. (2010) worked with the Early Head Start agencies to recruit participants for their intervention study to improve maternal depressive symptoms, and Martinez et al. (2012) worked with school systems and local organizations to recruit for their prevention study. Community members may not trust organizations such as government or health care systems due to past or present mistreatment, or fear of authority. Universities may also be perceived as unknown and untrusted organizations. In such cases, working with cultural insiders who have had intimate connections with the community is essential. Their contribution to research is critical in gaining information to engage the community and promoting research recruitment (Barnett, Aguilar, Brittner, & Bonuck, 2012).

One significant difference between key informants and cultural insiders is acceptance from the community. Key informants, by definition, do not have to be accepted by the community as long as they hold an official role in the community (McKenna et al., 2011). Research teams need to determine when and where in the research process they work with key informants and cultural insiders, depending on what they aim to accomplish. Key informants can function as a part of a community advisory board, or they may be interviewed in-depth to gain their perspectives on issues researchers are examining (McKenna & Main, 2013). The research team may work with key informants in the early stages to gain access to the community, and with cultural insiders during the recruitment process to inform potential participants about the study.

1.3. Reflect the unique cultural characteristics of the community in the research conduct

The EERC's third component is about learning the unique cultural characteristics of the community (i.e., socioeconomic status [SES], religious beliefs, sociocultural context of research topic) in order to incorporate appropriately tailored recruitment approaches when conducting research studies within the community. Current literature supports this component: Researchers have suggested multi-faceted ways to consider SES, cultural, and religious aspects of the participants (Ejiogu et al., 2011; Rooney et al., 2011; Rugkåsa & Canvin, 2011). However, study descriptions tend to focus on individual strategies or experiences facilitating recruitment of racial and ethnic minority populations (Yancey, Ortega, & Kumanyika, 2006). Therefore, they do not necessarily advance the science of recruitment by addressing cultural characteristics of the community on a conceptual level. There are two strategies that can successfully reflect and help incorporate unique characteristics of the community into the research process. One strategy is to do preliminary work with community members via focus groups to understand potential participants' sociocultural context and perspectives on the research topic (Matsuda, Martinez, & Beeber, 2014). The other strategy is to rely on the expertise of research team members/cultural insiders who have trust and ongoing relationships with the community. As discussed in component #1 of the guidelines, the process would be structured to ensure the research team members/cultural insiders actively participate in protocol development and research study operation.

1.4. Careful use of the matching technique

Matching refers to the systematic pairing of "like" characteristics in the research team and participants, most commonly race or ethnicity (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Cook, Godiwalla, Brooks, Powers, & John, 2010; Heiney et al., 2006; Yancey et al., 2006). Matching is frequently operationalized by selecting one or more qualities to match study participants to project staff who have direct contact with these participants. These staff members can include recruiters, interventionists, or data collectors. However, it has been documented that researcher-participant matching is more critical than project staff-participant matching (Yancey et al., 2006) since a project which has not been designed with a cultural understanding of the community has little chance of being successful. Levkoff, Levy, and Weitzman (2000) suggest an extended matching model that examines and identify barriers and facilitators related to recruitment beyond visible characteristics. The impact of matching on study recruitment has not been rigorously tested, yet the practice has become a requirement in health disparity research. As each person is composed of many characteristics (i.e. race, ethnicity, gender, SES, education completed, skill or experience in the role required), it is impossible to match all characteristics between research team members and study participants. Consequently, there is the need to consider what characteristics should be matched and the importance of scientific rationale made explicit.

2. The application of EERC guidelines

In order to facilitate the understanding of how the EERC guidelines can be used in a research study, the authors will illustrate the application of the EERC guidelines with the study "A UNC Community Partnership to Enhance Outcomes for Infants and Toddlers with

Suspected Disability who are Enrolled in Early Intervention (EI) Services” (Beeber et al., 2014; referred as EI study).

The authors implemented the EERC guidelines into the EI study to successfully recruit diverse families receiving EI service for their infant or toddler with developmental delays/disabilities. EI services are offered to children with suspected disability or developmental delay between zero and three years old and supported by the Part C of Ideal Education Act (United States Department of Education, n.d.). Thus, federal and state governments are involved, and the service is offered to all 50 states. As it is critical for children to receive developmentally appropriate services (i.e. speech, developmental, occupational and physical therapy), caretaker (commonly mothers) engagement with “routine-based care” is essential to the optimum use of EI services. “Routine-based care” means that mothers would reinforce skills children learned during their EI services into their daily routines; therefore, children can practice skills throughout the day, every day, through family interactions. However, while few, some studies have indicated high prevalence of depressive symptoms among mothers whose children are receiving EI service (Feinberg, Donahue, Bliss, & Silverstein, 2012; Hebbeler et al., 2007). When mothers experience depressive symptoms, implementation of routine-based care becomes difficult, as constant reinforcement of skills to children requires extra energy in addition to the need to care for children’s and families’ physical needs. Presently, there is no formal support to screen/refer/treat mothers’ depressive symptoms through the EI services. Mothers of children receiving EI services are clearly both high risk and underserved in being screened and receiving mental health care. The aim of the EI study was to describe depressive symptoms of mothers whose children have suspected disability or developmental delay and are receiving EI services. One hundred six mothers were recruited into the study, and the participants’ demographic characteristics are shown in Table 1.

In the following sections, four strategies proposed in the EERC guidelines will be explained based on how each point was implemented into the EI study recruitment.

2.1. Evaluate the composition and dynamics of the research team

The study team was composed of researchers from multiple disciplines, including nursing, psychiatry, public health, and developmental and clinical psychology, at a university and a private research firm, in addition to a EI service agency director, and bilingual (Spanish/English) specialists. The study team was composed of experts in maternal mental health, child development (in general and focused on developmental delay), providing context of EI services to the research team, and conducting research studies with both English and Spanish-speaking families.

The team leader (nurse researcher and the third author, L.S.B.) particularly ensured the following two points to maintain effective teamwork:

- 1a** The team leader ensured close communication and took the lead in building relationships among team members. The team leader made efforts to minimize logistical barriers by providing multiple alternatives to join team meetings (i.e., both via telephone and a video conference tool). This effort was particularly

useful as the community agency and the private research firm were located in a different area of the town away from the university. The team leader and each team member also discussed and mutually agreed on realistic expectations, time commitment, and involvement related to the research study. The EI service agency director's time and effort were not supported by an available funding mechanism due to her appointment as a state employee; therefore, the team had to understand that her time and involvement with the study were limited. Nevertheless, she was invested in the research project because she firmly believed that research work is beneficial to staff members in supporting the families receiving EI services.

- 1b** All team members were actively involved at all stages of research. The team leader played a critical role in establishing a respectful and safe environment, in which all team members could share ideas, issues, and concerns. The team leader maintained authority as a principal investigator to lead the team and at the same time was aware of the power dynamics present within the team. For example, an individual's relative social position (professors vs. postdoctoral fellows or students, individuals with research background vs. individuals with other professional backgrounds) may make one person feel weaker than others. However, the team leader set up a respectful group atmosphere so that everyone could voice their thoughts and opinions at the team meetings. In addition, during the research process, bilingual specialists were part of or invited to be part of data analysis, a stage of the research in which they do not traditionally participate. Bilingual specialists provided rich insight into the data interpretation of the study results.

2.2. Engage fully with the community by working with key informants and cultural insiders

The differences between cultural insiders and key informants make it critical to identify appropriate personnel to work with during a research project. For the EI study, the EI service agency director was the cultural insider and research team member. The director was a cultural insider who is immersed in the culture of the EI services and knows families who are receiving the services. During the research study, the team also worked with staff members of the EI service agency in various ways.

- 2a** At the suggestion of the EI service agency director, one office support worker was designated to call potential participants because direct contact with potential participants was not permitted. Phone invitation directly resulted in doubling the number of contacts to the office (10 calls in two weeks vs. 10 calls in a month, 200% increase). In addition, the office support worker mailed permission to contact form to potential participants. Having a permission to contact form mailed back to the research office allowed the team to directly contact mothers.

EI service agency staff members' duties included working directly with the families to coordinate therapies and ensuring that families received necessary admission paperwork, evaluations, and resources. The team conducted focus groups with staff members to increase their understanding about what families experience, how staff members could support

families, and what they felt was missing or how they wanted to be equipped. To thank the staff members and meet their educational needs, the research team conducted educational sessions on maternal mental health issues. As the staff members became more familiar with the study through contact with research team, they also provided permission to contact form to families when appropriate.

2.3. Reflect the unique cultural characteristics of the community in the research conduct

Culture is defined as ways of thinking and acting developed by a group of people and is not limited to race and ethnicity (Clark, 2015). For the current study, the culture explored was made up of mothers whose young children have developmental delays or disabilities. Researchers should identify and gain respective information on the cultural characteristics that might potentially influence study recruitment and data collection. To learn how to recruit and collect data from mothers and minimize burden for the EI study families, the research team conducted focus groups prior to recruitment. The focus group participants' concerns included location of interviews, fear of scrutiny, dealing with uncertainty, and perceived stigma because children are labeled "disabled" or "developmentally delayed," and ongoing implications associated with such labels or potential diagnoses. Based on the information gathered in the focus groups, the team attempted to address mothers' concerns in the process of study recruitment and data collection. For example, mothers chose the location for data collection, and childcare was offered as needed. In addition, mothers expressed fear about breach of confidentiality, particularly disclosure of children's information and its negative effects on their school admission. During the focus group, the team reiterated the confidentiality of research data to the mothers. Then, the team discussed and decided not to conduct objective assessment of children's development. Instead, the team collected information on child's development from EI agency's assessment and evaluation chart. The chart information was obtained after mothers signed permission to obtain records from the EI agency.

Participation incentives (\$30 per visit) were provided to participants. As the study progressed and the research team identified increased participant burden, the team consulted with the agency and decided to raise incentives to \$50 per visit. The greater incentives increased the number of inquiries received from 10 per month prior to the raise to 20 in the 2 weeks after (400% increase).

2.4. Careful use of the matching technique

After considering many characteristics that either limit or facilitate matching between data collectors and participants, the study team determined several characteristics necessary for matching. First, it was critical to match gender because data collectors often visit a participant's home alone, and mothers may be the only one at home during the day. Spanish fluency was another component that the study team made certain to match due to the large pool of potential Spanish-speaking participants. The team preferred native-born Latinas while also taking into consideration their English proficiency. The team ensured data collectors' proficiency of languages during the hiring interview and training, and incorporated role-playing to practice data collection. Additionally, data collectors' familiarity with research was a component considered when hiring. Although not required,

research experience was preferable because it reduced training time and orientation to human subject protection and other research specific concepts and procedures. The study team did not necessarily match race and ethnicity, which is commonly mentioned in the literature as a matching factor between data collectors and participants. However, because the team ensured the presence of critical matching characteristics, no problems were encountered that required a change in the protocol or compromised the data. The team ensured frequent and regular debriefings among data collectors to discuss the recruitment and data collection process and any opportunity for improvement.

Researcher–participant match was considered. In addition to having expert researchers in various content areas (psychologists with developmental delay and maternal mood disorders expertise, nurse scientist with mental health expertise), the team reached out to a nurse scientist who is a mother of child receiving EI services. Her participation and insight in research team meetings were valuable and augmented team discussion in examining the next steps in the research process. The concept of insider (i.e., membership in an oppressed group)/outsider (i.e., non-membership in an oppressed group) was first introduced by Narayan (1988), who states that there are experiences that only insiders experience first-hand. However, the outsiders may offer a broader perspective on the insiders' situation when they approach the subject with a willingness to learn. Moreover, one can often be an insider in one way of oppression (i.e. being a racial/ethnic minority) and an outsider in another way of oppression (i.e. being a male). Narayan (1988) described how outsiders should be sensitive and consider differences when working with insiders.

As a result of implementing the EERC, the best practice strategy guidelines for research recruitment, 127 mothers expressed interest to participate in the study within a ten-month timeframe. Out of the 127 mothers, 106 mothers (83%) were successfully recruited and completed the study. Twenty mothers (16%) expressed interest but did not respond to recruitment efforts, and only one mother chose not to participate.

3. Discussion

Application of the EERC guidelines was provided through examples of a study conducted in partnership with a community agency. Successful recruitment of participants was achieved by forming a strong partnership between researchers and a community agency, building a multidisciplinary research team including cultural insiders, and carefully considering the needs of the target population. Flexibility and close communication for problem solving within a research team were also essential to recruit participants for mental health research studies working with the EI service.

Several recent studies have examined ways to increase minority participants' recruitment in clinical trials (Durant et al., 2014; Rubin, 2014; Trevino et al., 2013). Rubin (2014) proposes that clinical trial nurses can assume an advocacy role for minority and culturally diverse research participants. Trevino et al. (2013) suggest a creation of toolkits to facilitate translation of material into Spanish language to increase recruitment of Spanish-speaking participants. Durant et al. (2014) conducted focus groups with key informants, researchers, and clinicians to explore ways to increase minority participant recruitment. We believe that

the EERC guidelines offer a practical framework to increase recruitment of research participants, including minority and culturally diverse participants, as opposed to the literature, which focuses on individual study experiences that do not systematically contribute to advancing the science of recruitment. In addition, reporting actual numbers related to recruitment, as shown in this paper (e.g. number of phone calls, number of participants recruited per month) should be recorded and incorporated into reporting of study results in data based manuscripts. Creating standards for quantifying and reporting data will allow for measurement of the degree of success in recruitment, and thus, will contribute in building the science of recruitment.

Working with a community advisory board (CAB) can be another effective strategy to obtain perspectives from community members possessing different characteristics. A CAB is composed of community members who may share a common identity, values, language, and/or culture (Israel, Checkoway, Schulz, & Zimmerman, 1994; Strauss et al., 2001). According to Strauss et al. (2001), a CAB can function as a liaison between researchers and community, advocate for minority research participants, and/or advise research protocol design and implementation. However, depending on the study, the function of a CAB is vastly different. In some cases, they meet infrequently and their involvement is limited (Wilkins et al., 2013). In contrast, some studies work intensively with a CAB, with the CAB having more authority in determining the next research agenda, almost like a community partner in a CBPR model (Cooper, 2015). On various occasions, researchers have raised ethical concerns when working with CABs (Flicker, Travers, Guta, McDonald, & Meagher, 2007; Pratt et al., 2015). Due to the diverse ways CABs are used in research studies, we purposefully did not include discussion about CABs in the research recruitment guidelines.

The authors believe that advancing the science of recruitment benefits all populations who are experiencing health disparities, including not only racial and ethnic minorities, but also other populations, such as the elderly, sexual minorities, people with mental illness or medical conditions, and caregivers.

4. Conclusion

Many barriers continue to hinder research to eliminate health disparities. As the Affordable Care Act has been implemented, health coverage has expanded to encompass an increasingly diverse population requiring partnerships with previously excluded communities to understand the newly insured (United States Department of Health and Human Services, 2014). Upcoming immigration reforms will also shift the dynamics of U.S. health care (White, Yeager, Menachemi, & Scarinci, 2014), requiring research on how the health care system can be extended to include the increasing numbers of newly immigrated U.S. residents and citizens. The EERC guidelines have been created to offer a practical guide to increase the research participation of communities where health disparities exist. It is the authors' intent that researchers use this tool to work with cultural insiders, listen to potential participants, and create the best recruitment strategies for accommodating the living context of the population from which researchers aim to recruit participants, whether the team is conducting clinical trials or qualitative studies or beginning to work with new or complex communities. The EERC guidelines should be incorporated into the planning phase of the

research process, executed throughout the research study, and included in the study report. We strongly believe that the application of these guidelines in research will contribute to enhanced study recruitment and assist in examining phenomena of interest, thus leading to disease prevention and improved health outcomes of vulnerable and underserved population. Ultimately, these guidelines contribute to reducing health disparities and results in health equity for all persons.

Acknowledgments

Funding sources

This manuscript was made possible by grant numbers 2T32NR008856 and T32 NR007091 from the National Institute of Nursing Research at the National Institutes of Health. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NINR.

The Early Intervention (EI) Study was supported by a NC TraCS Pilot award # 550KR41203. NC TraCS is the academic home of the NIH Clinical and Translational Science Award (CTSA) at the University of North Carolina at Chapel Hill (UNC-CH). Matching funding was contributed by the UNC-CH School of Nursing, the UNC-CH School of Medicine, Department of Psychiatry and the UNC-CH Center for Developmental Science.

Support for this research was received from the Center of Excellence for Health Disparities Research: El Centro, National Center on Minority Health and Health Disparities grant P60MD002266.

The authors would like to thank Dr. James Britton and Ms. April Mann for their editing support.

References

- Ashing-Giwa KT, Padilla GV, Tejero JS, Kim J. Breast cancer survivorship in a multiethnic sample. *Cancer*. 2004; 101:450–465. <http://dx.doi.org/10.1002/cncr.20370>. [PubMed: 15274058]
- Barnett J, Aguilar S, Brittner M, Bonuck K. Recruiting and retaining low-income, multi-ethnic women into randomized controlled trials: Successful strategies and staffing. *Contemporary Clinical Trials*. 2012; 33:925–932. <http://dx.doi.org/10.1016/j.cct.2012.06.005>. [PubMed: 22732312]
- Beeber LS, Holditch-Davis D, Perreira K, Schwartz TA, Lewis V, Blanchard H, ... Goldman BD. Short-term in-home intervention reduces depressive symptoms in Early Head Start Latina mothers of infants and toddlers. *Research in Nursing & Health*. 2010; 33:60–76. <http://dx.doi.org/10.1002/nur.20363>. [PubMed: 20043296]
- Beeber, LS.; Meltzer-Brody, S.; Mandel, M.; Wheeler, A.; Hubbard, G.; Mills-Koonce, R.; ... Alvarez, S. Children in the grey zone: Navigating undiagnosed developmental delays in infants and toddlers. Paper presented at the Council for the Advancement of Nursing Science: 2014 State of the Science Conference; Washington D.C. 2014.
- Braveman P, Gruskin S. Defining equity in health. *Journal of Epidemiology and Community Health*. 2003; 57:254–258. <http://dx.doi.org/10.1136/jech.57.4.254>. [PubMed: 12646539]
- Centers for Disease Control and Prevention. Health disparities: Social determinants of health. 2014. Retrieved from <http://www.cdc.gov/socialdeterminants/Definitions.html>
- Clark, MJ. Population and community health nursing. 6. Boston, MA: Pearson; 2015.
- Cook, SC.; Godiwalla, S.; Brooks, KS.; Powers, CV.; John, P. Recruitment and retention of study participants. 3. San Francisco: John Wiley & Sons, Inc; 2010.
- Cooper, LA. Using implementation and dissemination research methods to achieve equity in hypertension care and control. Paper presented at the National Institute of Minority and Health Disparities: Annual translational health disparities course; Bethesda, MD. 2015.
- Durant RW, Wenzel JA, Scarinci IC, Paterniti DA, Fouad MN, Hurd TC, Martin MY. Perspectives on barriers and facilitators to minority recruitment for clinical trials among cancer center leaders, investigators, research staff, and referring clinicians: Enhancing minority participation in clinical trials (EMPaCT). *Cancer*. 2014; 120(Suppl 7):1097–1105. <http://dx.doi.org/10.1002/cncr.28574>. [PubMed: 24643647]

- Ejiogu N, Norbeck JH, Mason MA, Cromwell BC, Zonderman AB, Evans MK. Recruitment and retention strategies for minority or poor clinical research participants: lessons from the healthy aging in neighborhoods of diversity across the life span study. *Gerontologist*. 2011; 51(Suppl 1):S33–S45. <http://dx.doi.org/10.1093/geront/gnr027>. [PubMed: 21565817]
- Falk-Krzesinski HJ, Borner K, Contractor N, Fiore SM, Hall KL, Keyton J, ... Uzzi B. Advancing the science of team science. *Clinical and Translational Science*. 2010; 3(5):263–266. <http://dx.doi.org/10.1111/j.1752-8062.2010.00223.x>. [PubMed: 20973925]
- Falk-Krzesinski HJ, Contractor N, Fiore SM, Hall KL, Kane C, Keyton J, ... Trochim W. Mapping a research agenda for the science of team science. *Research Evaluation*. 2011; 20(2):145–158. <http://dx.doi.org/10.3152/095820211x12941371876580>. [PubMed: 23223093]
- Feinberg E, Donahue S, Bliss R, Silverstein M. Maternal depressive symptoms and participation in early intervention services for young children. *Maternal and Child Health Journal*. 2012; 16:336–345. <http://dx.doi.org/10.1007/s10995-010-0715-3>. [PubMed: 21140201]
- Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: Recommendations for institutional review boards. *Journal of Urban Health*. 2007; 84(4):478–493. <http://dx.doi.org/10.1007/s11524-007-9165-7>. [PubMed: 17436114]
- Ganga D, Scott S. Cultural “insiders” and the issue of positionality in qualitative migration research: Moving “across” and moving “along” researcher-participant divides. *Forum Qualitative Social Research*. 2006; 7:1–12. (Retrieved <http://www.qualitative-research.net/fqs/>).
- Hebbeler, K.; Spiker, D.; Bailey, D.; Scarborough, A.; Millik, S.; Simeonsson, R.; ... Nelson, L. Early intervention for infants and toddlers with disabilities and their families: Participants, services and outcomes: Final report of the National Early Intervention Longitudinal study (NEILS). 2007. Retrieved from http://www.eittrainingcenter.org/pdf/resources/NEILS_Report_02_07_Final%20EI%20Study%202007.pdf
- Heiney SP, Adams SA, Cunningham JE, McKenzie W, Harmon B, Hebert J, Modayil M. Subject recruitment for cancer control studies in an adverse environment. *Cancer Nursing*. 2006; 29(4): 291–299. (Retrieved from <http://vb3lk7eb4t.search.serialssolutions.com/?sid=Entrez:PubMed&id=pmid:16871096>). [PubMed: 16871096]
- Israel BA, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education & Behavior*. 1994; 21(2):149–170. <http://dx.doi.org/10.1177/109019819402100203>.
- Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA. Introduction to methods in community-based participatory research for health. In: BAE; AJ; EA, editors. *Methods in community-based participatory research for health*. San Francisco: John Wiley & Sons, Inc; 2005. p. 3–26.
- Kahan D, Al-Tamimi A. Strategies for recruiting Middle Eastern-American young adults for physical activity research: A case of snowballs and salaam. *Journal of Immigrant & Minority Health*. 2009; 11:380–390. <http://dx.doi.org/10.1007/s10903-008-9117-7>. [PubMed: 18214678]
- Levkoff SE, Levy BR, Weitzman PF. The matching model of recruitment. *Journal of Mental Health and Aging*. 2000; 6(1):29–38.
- Marshall M. The key informant technique. *Family Practice*. 1996; 13:92–97. <http://dx.doi.org/10.1093/fampra/13.1.92>. [PubMed: 8671109]
- Martinez C, McClure HH, Eddy JM, Ruth B, Hyers MJ. Recruitment and retention of Latino immigrant families in prevention research. *Prevention Science*. 2012; 13:15–26. <http://dx.doi.org/10.1007/s11121-011-0239-0>. [PubMed: 21818583]
- Matsuda, Y.; Martinez, MM.; Beeber, LS. Caring through research study recruitment and retention in the community. Poster session presented at the 35th International Association of Human Caring Conference; Kyoto, Japan. 2014.
- McKenna SA, Main DS. The role and influence of key informants in community-engaged research: A critical perspective. *Action Research*. 2013; 1:113–124. <http://dx.doi.org/10.1177/1476750312473342>.
- McKenna SA, Iwasaki PG, Stewart T, Main DS. Key informants and community members in community-based participatory research: One is not like the other. *Progress in Community Health Partnership*. 2011; 5:387–397. <http://dx.doi.org/10.1353/cpr.2011.0053>.

- Narayan U. Working together across difference: Some considerations on emotions and political practice. *Hypatia*. 1988; 3(2):31–48. <http://dx.doi.org/10.1111/j.1527-2001.1988.tb00067.x>.
- National Institutes of Health. NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research – amended. 2001 Oct. 2001. Retrieved from http://grants.nih.gov/grants/funding/women_min/guidelines_amended_10_2001.htm
- National Institutes of Health Office of Behavioral and Social Sciences Research. Community-based participatory research. 2013a. Retrieved from https://obssr.od.nih.gov/scientific_areas/methodology/community_based_participatory_research/
- Pauwels L, Hardyns W. Measuring community (dis)organizational processes through key informant analysis. *European Journal of Criminology*. 2009; 6(5):401–417. <http://dx.doi.org/10.1177/1477370809337878>.
- Poggie J. Toward quality control in key informant data. *Human Organization*. 1972; 31(1):23–30. (Retrieved from <http://sfaa.metapress.com/content/6k6346820382578r/fulltext.pdf>).
- Pratt B, Lwin KM, Zion D, Nosten F, Loff B, Cheah PY. Exploitation and community engagement: Can community advisory boards successfully assume a role minimising exploitation in international research? *Developing World Bioethics*. 2015; 15(1):18–26. <http://dx.doi.org/10.1111/dewb.12031>. [PubMed: 23725206]
- Rooney LK, Bhopal R, Halani L, Levy ML, Partridge MR, Netuveli G, ... Sheikh A. Promoting recruitment of minority ethnic groups into research: Qualitative study exploring the views of South Asian people with asthma. *Journal of Public Health*. 2011; 33(4):604–615. <http://dx.doi.org/10.1093/pubmed/fdq100>. [PubMed: 21228023]
- Rubin SL. The clinical trials nurse as subject advocate for minority and culturally diverse research subjects. *Journal of Transcultural Nursing*. 2014; 25(4):383–387. <http://dx.doi.org/10.1177/1043659614523999>. [PubMed: 24595167]
- Rugkåsa J, Canvin K. Researching mental health in minority ethnic communities: reflections on recruitment. *Qualitative Health Research*. 2011; 21(1):132–143. <http://dx.doi.org/10.1177/1049732310379115>. [PubMed: 20682968]
- Strauss RP, Sengupta S, Quinn SC, Goepfinger J, Spaulding C, Kegeles SM, Millett G. The role of community advisory boards: Involving communities in the informed consent process. *American Journal of Public Health*. 2001; 91(12):1938–1943. <http://dx.doi.org/10.2105/AJPH.91.12.1938>. [PubMed: 11726369]
- Tremblay MA. The key informant technique: A nonethnographic application. *American Anthropologist*. 1957; 59(4):688–701. <http://dx.doi.org/10.1525/aa.1957.59.4.02a00100>.
- Trevino M, Padalecki S, Karnad A, Parra A, Weitman S, Nashawati M, ... Thompson IM. The development of a minority recruitment plan for cancer clinical trials. *Journal of Community Medicine & Health Education*. 2013; 3(5):1000230. <http://dx.doi.org/10.4172/2161-0711.1000230>. [PubMed: 25152846]
- United States Department of Education (d). IDEA 2004: Building the legacy. n.d. Retrieved from <http://idea.ed.gov/part-c/search/new>
- United States Department of Health and Human Services. Health Care. 2014. (Retrieved from <http://www.hhs.gov/healthcare/>)
- Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity. *American Journal of Public Health*. 2010; 100(S1):S40–S46. <http://dx.doi.org/10.2105/AJPH.2009.184036>. [PubMed: 20147663]
- White K, Yeager VA, Menachemi N, Scarinci IC. Impact of Alabama's immigration law on access to health care among Latina immigrants and children: Implications for national reform. *American Journal of Public Health*. 2014; 104(3):397–405. <http://dx.doi.org/10.2105/AJPH.2013.301560>. [PubMed: 24432880]
- Wilkins CH, Spofford M, Williams N, McKeever C, Allen S, Brown J, ... Strelnick AH. Community representatives' involvement in clinical and translational science awardee activities. *Clinical and Translational Science*. 2013; 6(4):292–296. <http://dx.doi.org/10.1111/cts.12072>. [PubMed: 23919364]

Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. Annual Review of Public Health. 2006; 27:1–28. <http://dx.doi.org/10.1146/annurev.publhealth.27.021405.102113>.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Fig. 1.
EERC research recruitment guidelines.

Table 1

Participants' demographic characteristics.

Sample characteristics (n = 106)		
Variable	%	Mean (SD)
Race and Ethnicity		
White	57	
Hispanic	22	
Black	13	
Multiracial	7	
American Indian	1	
Language of interview		
English	83	
Spanish	17	
Current work status		
Employed	39	
Actively seeking employment	4	
Not actively seeking employment	57	
Currently partnered	84	
Caregiver's age		32.92 (5.78)
Years of schooling		14.45 (3.55)
Average monthly income		3528.64 (3228.96)
Early intervention child age (first child, in months)		30.94 (4.77)