

# Challenges and Strategies in Recruitment of Ethnically Diverse Populations for Cancer Nursing Research

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**Purpose/Objectives:** To describe common barriers, identify challenges for researchers, and provide strategies for recruitment and retention of ethnic minority groups for cancer nursing research.

**Data Sources:** Computerized search of databases, published articles, abstracts, master's theses, and doctoral dissertations.

**Data Synthesis:** Social, economic, and cultural factors present challenges to recruitment of minorities into research. Knowing the culture of the target population, developing trust, engaging the community, and using tailored materials are strategies for recruitment and retention of minorities.

**Conclusions:** Knowledge of potential barriers and challenges to research with diverse populations provides the foundation for the development of strategies for successful recruitment of minorities in cancer nursing research.

**Implications for Nursing:** Increasing ethnic minorities in research will generate knowledge that will contribute to culturally competent cancer care.

## Key Points . . .

- ▶ The ethnic diversity of the U.S. population is growing and is predicted to increase in the coming decades.
- ▶ Social, economic, and cultural factors present challenges in recruitment of ethnic minority populations to research.
- ▶ Successful recruitment of ethnic minorities requires community engagement, knowledge of the target population, and culturally sensitive recruitment materials.

Recruitment of ethnically diverse populations for cancer nursing research is essential. The changing demographics of the population in the United States, the role of the societal mandate for nursing to understand human responses of all people, and disparate cancer outcomes for ethnic minorities provide a compelling argument to address the problem of under-representation of ethnically diverse populations in cancer research. As of 2004, Latinos and Hispanics accounted for 14% of the U.S. population, African Americans 12.5% of the U.S. population, and Asian Americans 4.1% (U.S. Census Bureau, 2004). In addition, Asian Americans are the fastest-growing minority population. For nursing to fulfill its societal mandate, nurses must understand cultural differences and ethnic diversity among those at risk for or diagnosed with cancer. Such knowledge is necessary to provide culturally competent care to patients (Oncology Nursing Society, 2000a; Parran, 2004; Phillips & Weekes, 2002) and to improve outcomes for populations at risk (Cohen, Phillips, & Palos, 2001; Flaskerud et al., 2002; Powell & Gilliss, 2003).

The etiology of cancer disparities is complex and includes social, cultural, environmental, biologic, and behavioral factors (Clanton, 2006; Polite, Dignam, & Olopade, 2006;

Underwood, 2000). Understanding the significance of cancer disparities and being able to identify factors that influence health outcomes in diverse populations are important (Kolb, Wallace, Hill, & Royce, 2006; Porter & Villarruel, 1993; Powell & Gilliss, 2003; Ward et al., 2004). Minorities' overall five-year survival rates are poorer when compared to those of nonminorities, and certain cancers are disproportionately higher in minorities, such as cervical cancer in Latina women (Giuliano et al., 2000; Howe et al., 2006). Among ethnic minority groups, African Americans have the highest risk of developing cancer and the greatest overall risk of dying from the disease (Kolb et al.; Underwood; Ward et al.). Poverty, lower educational levels, marginalized social status, and cultural factors of ethnic minorities are associated

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with decreased access to care, lower screening rates, more advanced cancer at diagnosis, less optimal cancer treatment, greater incidence of comorbidities, and poorer survival outcomes (Adams-Campbell et al., 2004; Kolb et al.; Ward et al.). Healthcare professionals must be knowledgeable about factors that contribute to disparate outcomes among minority populations (Williams & Jackson, 2005) and the relationship of those factors to recruitment of minorities in cancer research (Cabral et al., 2003; Polite et al.).

In summary, the population of the United States is rapidly growing more diverse, and insufficient data are available to support a full understanding of the experience of ethnically diverse people who are at risk for or diagnosed with cancer. Despite the federal mandate to include minorities in research, many studies fail to have sufficient numbers for subset analyses to explain similarities or differences. Oversampling of minorities into large trials and targeting studies with multiethnic or specific populations are needed to generate the knowledge necessary for culturally competent care and improved outcomes (Yancey, Ortega, & Kumanyika, 2006). Oncology nurse researchers have made substantial contributions to research of ethnic minorities in the area of screening and detection and the growing but smaller body of research with patients and families from ethnic minority groups who are surviving with cancer (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Aziz & Rowland, 2002; Culver, Arena, Antoni, & Carver, 2002). Despite the important contributions, much is unknown about how ethnic minorities respond to diagnosis, navigate the healthcare system, make decisions for treatment, cope with treatment, and live their lives after treatment. Thus, researchers must increase the number of ethnically diverse populations in their studies.

The purpose of this article is to describe common barriers to recruitment of ethnic minority groups, identify challenges for researchers in minority recruitment, and provide strategies for recruitment and retention of diverse populations (see Figure 1). The discussion of recruitment of African American, Latino or Hispanic, Asian American, and Native American populations for cancer nursing research will highlight common issues as well as unique cultural aspects across the diverse populations. The authors hope that the review will provide direction and guidance to researchers in their efforts to recruit under-represented populations.

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- Establish trust.
  - Develop an understanding of heterogeneity within and across diverse groups.
  - Dedicate adequate time for the prerecruitment phase.
  - Network in the community.
  - Build community relations.
  - Recruit and train ethnic research team members.
  - Establish respect and value for research team members.
  - Foster personal attributes of flexibility, sensitivity, and adaptability.
  - Provide adequate compensation for recruiters.
  - Develop multiple strategies for recruitment.
  - Tailor strategies to the study design.
  - Tailor materials to the target population.
  - Establish community reciprocity.
  - Research mentorship of ethnic minority nurses.
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**Figure 1. Strategies to Promote Recruitment and Retention of Diverse Populations**

## Barriers to Participation in Research Among Ethnic Minorities

Social, economic, and cultural (or ethnic) are the three major factors that explain cancer disparities among ethnic minorities (Ward et al., 2004); they also provide context for understanding common barriers to participating in research. Fear and mistrust are common attitudes among minorities and are particularly prominent among African Americans and Native Americans as a result of a history of oppression, slavery, forced acculturation, and unethical research (Daunt, 2003; Julion, Gross, & Barclay-McLaughlin, 2000; Lillington, Johnson, & Chlebowski, 2000; Underwood, 2000; Yancey et al., 2006). Socioeconomic status (SES) is separate from ethnicity (Gilliss et al., 2001; Ward et al., 2004), and low SES commonly is associated with less education, lower literacy, lower-paying jobs, inferior or no healthcare coverage, negative experiences with the healthcare system, and poorer health outcomes (Dirksen & Erickson, 2002; Giuliano et al., 2000; Hodge, Weinmann, & Roubideaux, 2000; Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services, 2005a, 2005b; Sudore et al., 2006). Lack of knowledge about cancer, inaccurate risk perceptions, competing life demands, limited resources, and financial concerns are related to lower SES. Lack of transportation (Brown, Fouad, Basen-Engquist, & Tortolero-Luna, 2000), lack of ability to pay for child care (Daunt), older age (e.g., greater mistrust, more comorbidities), and interference with work and family life for young and midlife people have been cited as common barriers to successful recruitment of people from low SES. A primary language other than English and the degree of English fluency pose challenges to recruitment. Language barriers and low literacy raise ethical issues for recruitment into research because of informed consent (e.g., need for translated materials or revisions for participants with lower reading levels) (Alvidrez & Arean, 2002; Daunt; Giuliano et al.; Heiney et al., 2006; Lee & Knobf, 2002; Sudore et al.; Yancey et al.).

## Common Challenges for Researchers Recruiting Ethnic Minorities

Community networking is critical to research with ethnic minorities (Alvidrez & Arean, 2002; Black, Frisina, Hack, & Carpio, 2006). A multicomponent plan with community involvement has been recognized as the most successful strategy to recruit diverse populations for research. Such a recruitment approach, however, is substantially more labor intensive because it requires community engagement, understanding of the culture of the target population, and development of tailored recruitment materials. Researchers often underestimate the time and money needed for community engagement during the essential prerecruitment phase (Banks-Wallace, Enyart, & Johnson, 2004; Black et al.; Brown, Long, Weitz, & Milliken, 2000; Daunt, 2003; Julion et al., 2000; Yancey et al., 2006) and therefore may fail to meet accrual goals. Time spent on community networking prior to recruitment will set a foundation for community engagement during and after a study.

Community engagement is essential but insufficient to fully understand the culture of those to be recruited. Researchers need to gain a solid understanding of the target ethnic group, which requires considerable time and effort. Heterogeneity

of broad ethnic populations and the sparse number of ethnic minority researchers further challenge these efforts. Level of acculturation, age, language, and SES may differ dramatically within and across ethnic groups. Knowledge of the ethnic identity and culture of the target sample is essential and may influence decisions on sampling, stratification, interpretation, and generalizability of results (Oncology Nursing Society, 2000b).

Study design may influence researchers' ability to recruit minorities. Recruitment for studies of cancer screening and detection may be difficult because of inaccurate risk perceptions and a less obvious benefit to those who are "healthy" (Gilliss et al., 2001; Lillington et al., 2000). In contrast, recruitment into exploratory studies with qualitative methodology may be facilitated by the fact that such studies provide people the opportunity to tell their stories and share their experiences and therefore may be less threatening (Ashing-Giwa, Tejero, & Kim, 2004; Cohen et al., 2001; Henderson, Gore, Davis, & Condon, 2003; Knobf, Erdos, Johnston, Johnson-Thomas, & Reynolds, 2003; Wilmoth & Sanders, 2001). Descriptive quantitative studies may promote recruitment because they communicate a sincere interest in wanting to learn about participants' experiences (Gibson & Parker, 2003; Lee, 2003). Intervention studies, especially those that involve randomization to experimental and control groups, may pose a significant barrier to recruitment because of mistrust and historical abuse in research (Yancey et al., 2006). Yet nurses generally are viewed by society as trustworthy and can use their perspective to diffuse mistrust inherent among minorities (Phillips & Weekes, 2002).

The use of tailored, culturally relevant materials for research with ethnic minorities is highly recommended (Ashing-Giwa, 1999; Ashing-Giwa, Kagawa-Singer, et al., 2004; Daunt, 2003; Heiney et al., 2006; Sheppard et al., 2005; Yancey et al., 2006). Although the technique is recognized as a strategic recruitment effort, researchers face many challenges. Many organizations have produced culturally relevant cancer materials that can be used for education, community outreach, and sometimes recruitment. Despite the availability of such materials, they may not meet the needs of a particular study. The task of tailoring materials for a specific study requires time, insight, and collaboration with members of the ethnic group (in creation, review, and feasibility testing). The reading level and complexity of data collection instruments also may affect retention of subjects. The availability of instruments that have been tested in targeted ethnic populations (with or without the need for translation) is limited.

## Strategies to Support Recruitment and Retention of Diverse Populations in Research

### Trust

Establishing trust is the most important factor in research with ethnically diverse populations (Daunt, 2003; Julion et al., 2000). Strategies for developing trust include community networking (commonly referred to as "getting to know" the community or "doing time" in the community), securing cultural knowledge of the targeted population, and establishing an ongoing relationship that fosters mutual trust and respect (Black et al., 2006; Daunt; Hodge et al., 2000; Sheppard et

al., 2005). Community involvement by the research team is essential to building trust and diffusing the tension between historically predominantly white academic researchers and minority participants from the community. The goal of the process is mutual respect between researchers and participants, which can be achieved only through the development of competence, understanding, and meaning from the perspective of the targeted group (Julion et al.).

### Community Engagement

The purpose of community networking is to begin to get to know the community and its members and identify key informants, community leaders, potential stakeholders, and sources of support (Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004; Daunt, 2003; Gilliss et al., 2001; Julion et al., 2000). Building community relations includes working with community members to establish feasibility and recruitment strategies and becoming involved in the community. Focus groups, local needs assessment, feasibility analysis, discussions with community-based support or social groups, and use of key informants are approaches that have been used to help determine how to reach target populations, provide insight into the culture of target groups, and begin to build ongoing relationships (Alvidrez & Arean, 2002; Baker, Homan, Schonhoff, & Kreuter, 1999; Julion et al.; Lee, 2003; Sheppard et al., 2005; Yancey et al., 2006). Community involvement includes community outreach, support, and education—acts of "good faith" as partnership between the research team and the community that is the target of the research. Involvement may include volunteering for health fairs, holding support groups, providing educational presentations, developing educational or resource materials, and disseminating health-related information of interest to the community, regardless of relevance to the specific research project (Heiney et al., 2006; Lee; Pletsch, Howe, & Tenney, 1995; Sun, 2006; Yancey et al.). Recruiting local businesses to endorse the study; using churches, schools, and support groups to disseminate information about the study; and creating a community advisory board are examples of seeking community support (Alvidrez & Arean; Cohen et al., 2001; Dancy et al.; Julion et al.; Yancey et al.).

### Research Team

Skilled recruiters are essential to research, regardless of design. They are especially critical in research with diverse ethnic populations. Identifying members of the community or institutional staff who share the same ethnic background as the target group has been a very successful strategy for community outreach, community education, recruitment, and data collection (Andrews, Felton, Wewers, & Heath, 2004). The time to recruit, educate, train, and routinely meet with such research team members is a considerable but essential investment. Community outreach and recruitment of ethnically diverse populations are labor and time intensive. Research team members responsible for this aspect have described their job as "working in the shadows" and not valued for the time and effort that is needed for community networking, building community relationships, and establishing trust (Brown, Long, et al., 2000; Daunt, 2003; Julion et al., 2000; Yancey et al., 2006). The principal investigator needs to foster an environment that communicates value and respect as well as appropriately compensates such workers for their time (Baker et al., 1999; Brown, Long, et al.; Yancey et

al.). Ongoing training of such research team members should include content on personal attributes that support their work in the field, specifically sensitivity, flexibility, and adaptability (Julion et al.). For example, asking sample participants their preferences for completing a survey by telephone or via written and mailed materials and persistent follow-up may improve data collection. Ethnically diverse populations often are underserved, and the barriers to participating in research pose unique challenges for the research team members who are building community relations, recruiting participants, and collecting data from those enrolled in the study.

## Recruitment Approach

A multidimensional approach is recommended in research with ethnic minorities to overcome the known barriers and challenges to recruitment. Mass mailings, personalized letters (targeted to the specific ethnic group), face-to-face recruitment, referral (snowball sampling), culturally tailored flyers and invitations, media presentations (e.g., radio, television), use of community agency endorsement, and tumor registries represent various ways to recruit, but their success varies with the specific ethnic population and type of study design (Ashing-Giwa, 1999; Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Brown, Long, et al., 2000; Cabral et al., 2003; Clanton, 2006; Daunt, 2003; Gilliss et al., 2001; Pletsch et al., 1995; Yancey et al., 2006). Knowing the community and cultural background of the target population will guide the team in tailoring recruitment strategies, which may need to be adapted over time.

## Insider-Outsider Debate

Matching the ethnic background of the research team and participants in research with diverse populations has been the subject of debate. The strategy has advantages and disadvantages for an ethnically matched (insider) and nonmatched (outsider) research team. Advantages to having insiders on the team include credibility, quicker access, and trust building; shared sociocultural experience; ability to communicate with participants who do not speak English as a primary language; and unique insight (Cohen et al., 2001; Haozous, 2003; Lee, 2003; Phillips & Weekes, 2002; Porter & Villarruel, 1993). Disadvantages to an insider-only team include threats to validity (e.g., researchers may fail to see important findings or take them for granted because of expectations), being from the same ethnic background does not ensure that one is an insider (especially if other factors differ, such as SES), trust from the community is not guaranteed even for insiders, and the strategy usually is impractical because of the shortage of ethnic minority nurse researchers (Julion et al., 2000; Phillips & Weekes; Porter & Villarruel; Powell & Gilliss, 2003). Advantages to the outsider approach include a larger pool of nurse researchers with expertise in research methods and content areas, potential for greater insight into findings that may be less explicit to insiders, more resources to fund and conduct studies, and the documented feasibility and success of conducting research as an outsider (Julion et al.; Phillips & Weekes; Knobf et al., 2003). The disadvantages of an outsider-only team include longer time to gain trust, issues of acceptance by the community, lack of a shared sociocultural background, and limited cultural insights. For practical and methodologic reasons, the ideal research team includes insiders and outsiders (Phillips & Weekes; Porter & Villarruel).

## Target Sample

A universal challenge in conducting research with ethnic populations is the sample. Significant heterogeneity exists in the broadly defined ethnic groups, which influences cultural context. Ancestral birth place, acculturation, SES, beliefs, values, and geographic location are some of many factors that delineate a sample within the larger ethnic group and are important to consider in recruitment, study purpose, design, and analysis. The Oncology Nursing Society (2000b) provides guidelines for conducting research with multi-ethnic samples that address the issues of heterogeneity of the sample and cultural sensitivity in detail. Accrual of a targeted sample may force researchers to use census data and recruit from areas where ethnic groups reside in greater numbers. Finally, estimating sample size may be challenging, especially if a sample is comprised of ethnically diverse people diagnosed with cancer, in which case accurate incidence data may be limited. The following sections provide insight into recruiting specific ethnically diverse populations for cancer nursing research. African American, Latino or Hispanic, Asian, and Native American populations were chosen because of the available literature and the significance of cancer disparities in those minority populations.

### African Americans

African Americans are the second-largest minority population in the United States and have the highest cancer incidence and mortality compared to other minorities and Caucasians. The birthplace of ancestors accounts for some of the heterogeneity in the group; many descending from Africa are comfortable with the designation of African American, but those who come from the Caribbean might prefer to be designated as black (Galasso, Amend, Melkus, & Nelson, 2005). The history of slavery and abuses in research have created a negative relationship between African Americans and researchers because of the power difference, and many are suspicious or distrustful of research in general (Dancy et al., 2004; Lillington et al., 2000).

As a culture, the group has shared values and beliefs, such as strong kinship bonds, interconnectedness to church and faith, and a strong bond among women, who commonly refer to each other as sisters (Ashing-Giwa & Ganz, 1997; Eng, 1993; Guidry, Matthews-Juarez, & Copeland, 2003; Knobf, Thompson, & Erdos, 2005; Newlin, Knafl, & Melkus, 2002). SES influences beliefs about health and research participation. Low SES among African Americans is associated with hopelessness and fatalism related to cancer, inaccurate perceptions of risk (e.g., breast cancer is a white woman's disease), lack of cancer knowledge, low literacy (which poses problems for informed consent), poor adherence to cancer screening guidelines, later stage at diagnosis, and poorer quality of life and survival outcomes (Ashing-Giwa, 1999; Ashing-Giwa & Ganz, 1997; Daunt, 2003; Giuliano et al., 2000; Heiney et al., 2006). Differences in SES among people of color influence recruitment strategies, reading level of promotional study materials and informed consent, and the type of incentives that might be considered.

In an attempt to address cancer disparities, cancer nurse researchers have made a substantial contribution in the area of recruitment of African Americans to studies of screening and early detection, specifically for breast cancer and prostate

cancer. A review of that body of literature is well beyond the scope of this article, but getting to know the community, engaging the community, using tailored materials, and establishing insider research team members were critical factors in successfully recruiting and retaining healthy at-risk African American participants. For African Americans diagnosed with cancer, the most studies have been conducted with breast cancer survivors and fewer with men with prostate cancer. Most researchers who target ethnic minorities use multiple recruitment strategies, including clinical sites, communities (e.g., agencies, churches, support groups), cancer support groups, and tumor registries (Ashing-Giwa, Kagawa-Singer, et al., 2004; Gibson & Parker, 2003; Henderson et al., 2003; Knobf et al., 2003; Wilmoth & Sanders, 2001). Despite efforts to recruit across the social strata, successful recruitment of women with lower SES is quite challenging and often unsuccessful (Gibson & Parker; Morgan et al., 2005; Northouse et al., 1999; Wilmoth & Sanders). Ethnicity also may influence ability to recruit for different types of research. Qualitative methodology with focus groups may be well suited culturally because African American women embrace a sisterhood bond that includes mutual sharing and support, and a group approach may decrease feelings of mistrust (Ashing-Giwa & Ganz, 1997; Ashing-Giwa, Padilla, Tejero, Kramer, et al., 2004; Henderson et al.; Knobf et al., 2003; Wilmoth & Sanders).

### Latinos or Hispanics

Latinos have become the largest minority group in the United States and represent more than 20 different countries of origin, the most common being Mexico, Cuba, Puerto Rico, and those in Central and South America. Immigrants from Puerto Rico tend to settle in the northeastern United States, Mexicans in the southwestern United States and West Coast, and Cubans in South Florida; employment opportunities, especially for day workers, influence where Latino immigrants and illegal immigrants reside. Although heterogeneity is recognized, Latinos tend to be foreign born, are more likely to speak a language other than English at home, have lower SES, are less educated, and tend to be younger, often with no healthcare coverage and no regular source of health care (Portillo et al., 2001). Latinos have a lower incidence of cancer, except for myeloma and liver, stomach, and cervical cancer, but they are less likely to be diagnosed with localized disease and have higher cancer mortality rates (Howe et al., 2006).

Factors that influence recruiting Latinos into research include language barriers, immigration status, low literacy, low SES, fear and mistrust, limited access to health care, limited knowledge of cancer and risk factors, and cultural values of familism and *machismo* (Giuliano et al., 2000; Naranjo & Dirksen, 1998; Sheppard et al., 2005; Stark et al., 2002). The cultural values relate to commitment and loyalty to family (familism) and husband (*machismo*) respecting the woman's wishes not to participate or related to competing demands to care for family (Dirksen & Erickson, 2002; Giuliano et al.; Naranjo & Dirksen). Factors associated with low SES significantly contribute to greater mistrust, cancer fatalism, high rates of refusal to participate in research, and a lower likelihood of completing the research even if they initially agree to participate (Ashing-Giwa, Kagawa-Singer, et al., 2004; Giuliano et al.; Naranjo & Dirksen; Stark et al.). Strategies to overcome recruitment barriers with Latinos include establish-

ing a bilingual research team (especially recruiters); developing trust; using tailored, culturally appropriate recruitment materials; giving verbal explanations of the study and reading the informed consent document; using sixth- to eighth-grade reading level materials; emphasizing the importance of the individual participating; and being flexible and adaptable in the recruitment process (Mandelblatt et al., 2005; Naranjo & Dirksen; Sheppard et al.; Zimmerman, 1997). Latinos have great respect for their physicians and healthcare providers. Partnering with care providers, getting their endorsement, and recruiting from care settings can facilitate participation rates (Ashing-Giwa, Kagawa-Singer et al.; Giuliano et al.; Mandelblatt et al.; Sheppard et al.).

### Asian Americans

Asian Americans include more than 25 groups that have been classified as a single group because of their common ethnic origins in Asia. Asian Americans are the fastest-growing minority population in the United States, predicted to constitute 10% of the U.S. population by 2050 (Giuliano et al., 2000). Although Asian Americans experience lower cancer rates overall compared with other minority groups, they experience higher death and incidence rates for certain cancers (Jemal et al., 2005). Asian Americans are culturally and experientially diverse, with inter- and intra-ethnic differences in degree of acculturation, culture values and beliefs, religion, primary language, income, education, and ethnic identity.

Chinese Americans constitute the largest percentage of the highly heterogeneous Asian American population (Alexander, Chu, & Ho, 2000). Immigration patterns influence access to ethnic minorities for research; Chinese Americans have immigrated predominantly to the East Coast (e.g., New York, New Jersey) and the West Coast (northern California). Similar to Latinos, common barriers to research participation for Chinese American immigrants include the language barrier, low literacy, low SES, limited healthcare access, level of acculturation, and cultural values (e.g., family). Chinese place value on the good of the family over the individual, which could influence the decision to participate in a study. Strategies to overcome recruitment barriers for Chinese Americans include using a bilingual research team, developing a personal connection with the community, and using multiple recruitment strategies and culturally and linguistically tailored study materials. Successful strategies to recruit a sample of 123 Chinese American breast cancer survivors included a year-long effort to get to know the community (e.g., making contacts, volunteering), to identify 33 sources of support and endorsement for the study, to identify Chinese-run healthcare clinics, to develop a breast cancer resource guide in Chinese, to advertise in Chinese newspapers, to employ snowball sampling, and to make face-to-face contact with potential participants (Lee, 2003). Because at least 40% of Asian Americans are not fluent in English (Giuliano et al., 2000), language may be a significant barrier to recruitment when researchers are not fluent in Cantonese and Mandarin. Lack of fluency in both Chinese tongues may require identification of a collaborator and education and training of that person (e.g., investigational review board certification, Health Insurance Portability and Accountability Act training, adherence to study protocol) (Lee; Sun, 2006). Similar strategies but less time in the local community may result in

a longer recruitment period and fewer participants accrued (Sun, 2002, 2006). Tumor registries provide a viable recruitment strategy for Asian Americans diagnosed with cancer, but multiple approaches are optimal, demonstrated by a study that accrued 30% of a sample of Asian Americans from local agencies and support groups in addition to those through a registry (Ashing-Giwa, Kagawa-Singer, et al., 2004). Inclusion of Asian Americans other than Chinese Americans (e.g., Japanese, Vietnamese, Korean) into future research is critically important because diversity is increasing with Asian immigration patterns. Yet this poses significant challenges to the research team related to cost, learning the cultural background of each group, recruitment of diverse Asian Americans on the research team, and the time and expertise for instrument translation and translation of qualitative data from a foreign language to English (Ashing-Giwa, Kagawa-Singer, et al.; Black et al., 2006; Lee & Knobf, 2002).

### Native Americans

Less than 1% of the U.S. population is Native American, but it is a poor minority group with significant healthcare disparities (Hodge et al., 2000). Cancer is the second-leading cause of death among Native Americans, and Native American women have higher morbidity rates from cervical cancer than any other ethnic group (Ward et al., 2004). The United States is home to more than 500 tribes, with more than 300 reservations in 35 states and a trend of migration from rural to urban areas. Tribes have distinct origins and cultural traditions that influence their beliefs, values, and attitudes toward health care and research. Some common barriers to recruitment for research among Native Americans are mistrust, distrust of dominant white people and institutions, prior negative experiences with research, low SES, low literacy, language, cancer fatalism, and the Indian Health Service (see description later in text) (Davis & Reid, 1999; Giuliano et al., 2000; Hodge et al.; Paskett et al., 2004). Language is a formidable barrier to recruitment and participation in research. Native Americans have traditions of oral history, their speech is less direct and slower with many pauses, and their words often have no direct translation to English (Davis & Reid). The Indian Health Service is a complex system with limited funding that is designed to provide primary care. Specialty care, such as oncology, often is contracted out, which creates further barriers in access to care, contributes to poorer outcomes, and further challenges recruitment efforts (Burhansstipanov & Hollow, 2001; Haozous, 2003). Study approval, including human subjects approval, is required by the Indian Health Service and may be required by individual tribes as well. Securing approvals is extremely time and labor intensive because the system is quite bureaucratic and complex.

Culturally, family has a central role in the lives of Native Americans, religion permeates their daily lives, the earth is highly valued, spiritual forces are respected, modesty and

privacy are important, and illness, including cancer, may be perceived as punishment or associated with guilt or shame (Burhansstipanov & Hollow, 2001; Davis & Reid, 1999; Struthers, Eschiti, & Patchell, 2004). An important cultural barrier to Native American participation in research is the widespread belief that cancer can be brought into being through discussion. The taboo effectively prevents many traditional Native Americans from engaging in conversations about cancer with researchers (Brant, Fallsdown, & Iverson, 1999; Carrese & Rhodes, 1995; Struthers et al.). Strategies to effectively recruit Native Americans into research include community networking to gain trust and ensure benefit to the community; familiarity with tribal traditions; ethnic researchers; engagement of tribal leaders; understanding of the significance of the connection among mind, body, and spirit; culturally tailored materials, knowledge and understanding of traditional Indian medicine; culturally sensitive communication (do not interrupt, and be patient with pauses and silence); and knowledge of and avoidance of conflicts with tribal events and time. Considerable time should be planned in the study timeline for community networking and the Indian Health Service and tribal approvals. Although many tribes have established research review committees, the committees may meet sporadically, and gaining insight into committee schedules can be challenging.

### Conclusion

The changing diversity of the U.S. population demands attention and commitment. The cross-cutting issues of minorities, such as low SES; low literacy; limited access to care; language, family, and community contexts; and attitudes about cancer and research, contribute to cancer disparities. If healthcare professionals are to improve cancer outcomes and provide culturally competent care, they must increase research targeted toward ethnically diverse populations, especially those who are more vulnerable. Research with ethnic populations poses formidable challenges. Strategies in addition to those discussed include education and recruitment of ethnically diverse nurses and nurse researchers (Leeman, Goepfing, Funk, & Roland, 2003; Powell & Gilliss, 2003), collaboration with ethnically diverse nursing associations (Parran, 2004), consideration of community-focused models of research in which researchers and participants share power and equality (Baker et al., 1999; Dancy et al., 2004.; Knobf et al., 2005), and more research with multiethnic samples to identify similarities and differences across minority populations (Ashing-Giwa, Padilla, Tejero, & Kim, 2004; Ashing-Giwa, Kagawa-Singer, et al., 2004; Culver et al., 2002).

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### References

- Adams-Campbell, L.L., Ahaghotu, C., Gaskins, M., Dawkins, F.W., Smoot, D., Polk, O.D., et al. (2004). Enrollment of African Americans onto clinical treatment trials: Study design barriers. *Journal of Clinical Oncology*, 22, 730-734.
- Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. (2005a). *National healthcare disparities report 2005*. Retrieved September 19, 2006, from <http://www.ahrq.gov/qual/Nhdr05/fullreport/Index.htm>
- Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services. (2005b). *National healthcare quality report 2005*. Retrieved September 19, 2006, from <http://www.ahrq.gov/qual/nhqr05/fullreport/Index.htm>

- Alexander, G.A., Chu, K.C., & Ho, R. (2000). Representation of Asian Americans in clinical cancer trials. *Annals of Epidemiology*, 10(Suppl. 8), S61–S67.
- Alvidrez, J., & Areal, P.A. (2002). Psychosocial treatment research with ethnic minority populations: Ethical considerations in conducting clinical trials. *Ethics and Behavior*, 12, 103–116.
- Andrews, J.O., Felton, G., Wewers, M.E., & Heath, J. (2004). Use of community health workers in research with ethnic minority women. *Image: Journal of Nursing Scholarship*, 36, 358–365.
- Ashing-Giwa, K. (1999). The recruitment of breast cancer survivors into cancer control studies: A focus on African-American women. *Journal of the National Medical Association*, 91, 255–260.
- Ashing-Giwa, K., & Ganz, P.A. (1997). Understanding the breast cancer experience of African-American women. *Journal of Psychosocial Oncology*, 15(2), 19–35.
- Ashing-Giwa, K., Kagawa-Singer, M., Padilla, G., Tejero, J.S., Hsio, E., Chhabra, R., et al. (2004). The impact of cervical cancer and dysplasia: A qualitative multiethnic study. *Psycho-Oncology*, 13, 709–728.
- Ashing-Giwa, K.T., Padilla, G.V., Tejero, J.S., & Kim, J. (2004). Breast cancer survivorship in a multiethnic sample: Challenges in recruitment and measurements. *Cancer*, 101, 450–465.
- Ashing-Giwa, K.T., Padilla, G.V., Tejero, J.S., Kramer, J., Wright, R., Coscarelli, A., et al. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13, 408–428.
- Aziz, N., & Rowland, J. (2002). Cancer survivorship research among ethnic minority and medically underserved groups. *Oncology Nursing Forum*, 29, 789–801.
- Baker, E.A., Homan, S., Schonhoff, R., & Kreuter, M. (1999). Principles of practice for academic/practice/community research partnerships. *American Journal of Preventive Medicine*, 16(Suppl. 3), 86–93.
- Banks-Wallace, J., Enyart, J., & Johnson, C. (2004). Recruitment and entrance of participants into a physical activity intervention for hypertensive African American women. *Advances in Nursing Science*, 27, 102–116.
- Black, M.E., Frisina, A., Hack, T., & Carpio, B. (2006). Improving early detection of breast and cervical cancer in Chinese and Vietnamese immigrant women. *Oncology Nursing Forum*, 33, 873–876.
- Brant, J., Fallsdown, D., & Iverson, M.L. (1999). The evolution of a breast health program for Plains Indian women. *Oncology Nursing Forum*, 26, 731–739.
- Brown, B.A., Long, H.L., Weitz, T.A., & Milliken, N. (2000). Challenges of recruitment: Focus groups with research study recruiters. *Women and Health*, 31, 153–166.
- Brown, D.R., Fouad, M.N., Basen-Engquist, K., & Tortolero-Luna, G. (2000). Recruitment and retention of minority women in cancer screening, prevention and treatment trials. *Annals of Epidemiology*, 10(Suppl. 8), S13–S20.
- Burhanstipanov, L., & Hollow, W. (2001). Native American cultural aspects of oncology nursing care. *Seminars in Oncology Nursing*, 17, 206–219.
- Cabral, D.N., Napoles-Springer, A.M., Mike, R., McMillan, A., Sison, J.D., Wrench, M.R., et al. (2003). Population- and community-based recruitment of African Americans and Latinos. *American Journal of Epidemiology*, 158, 272–279.
- Carrese, J., & Rhodes, L. (1995). Western bioethics on the Navajo reservation: Benefit or harm? *JAMA*, 274, 826–829.
- Clanton, M. (2006). The National Cancer Institute's Special Populations Networks for cancer awareness, research and training. *Cancer*, 107, 1931–1932.
- Cohen, M.Z., Phillips, J.M., & Palos, G. (2001). Qualitative research with diverse populations. *Seminars in Oncology Nursing*, 17, 190–196.
- Culver, J.L., Arena, P.L., Antoni, M.H., & Carver, C.S. (2002). Coping and distress among women under treatment for early stage breast cancer: Comparing African Americans, Hispanics and non-Hispanic whites. *Psycho-Oncology*, 11, 495–504.
- Dancy, B.L., Wilbur, J., Talashek, M., Bonner, G., & Barnes-Boyd, C. (2004). Community based research: Barriers to recruitment of African Americans. *Nursing Outlook*, 52, 234–240.
- Daunt, D.J. (2003). Ethnicity and recruitment rates in clinical research studies. *Applied Nursing Research*, 16, 189–195.
- Davis, S.M., & Reid, R. (1999). Practicing participatory research in American Indian communities. *American Journal of Clinical Nutrition*, 69(Suppl. 4), 755S–759S.
- Dirksen, S.R., & Erickson, J.R. (2002). Well-being in Hispanic and non-Hispanic white survivors of breast cancer. *Oncology Nursing Forum*, 29, 820–826.
- Eng, E. (1993). The Save Our Sisters Project: A social network strategy for reaching rural black women. *Cancer*, 72, 1071–1077.
- Flaskerud, J.H., Lesser, J., Dixon, E., Anderson, N., Conde, F., Kim, S., et al. (2002). Health disparities among vulnerable populations: Evolution of knowledge over five decades in *Nursing Research* publications. *Nursing Research*, 51, 74–85.
- Galasso, P., Amend, A., Melkus, G.D., & Nelson, G.T. (2005). Barriers to medical nutrition therapy in black women with type 2 diabetes mellitus. *Diabetes Educator*, 31, 719–725.
- Gibson, L.M., & Parker, V. (2003). Inner resources as predictors of psychological well-being in middle-income African American breast cancer survivors. *Cancer Culture and Literacy*, 10(5), 52–59.
- Gilliss, C.L., Lee, K.A., Gutierrez, Y., Taylor, D., Beyene, Y., Neuhaus, J., et al. (2001). Recruitment and retention of healthy minority women into community-based longitudinal research. *Journal of Women's Health and Gender-Based Medicine*, 10(1), 77–85.
- Giuliano, A.R., Mokuau, N., Hughes, C., Totolero-Luna, G., Risendal, B., Ho, R., et al. (2000). Participation of minorities in cancer research: The influence of structural, cultural and linguistic factors. *Annals of Epidemiology*, 10(Suppl. 8), S22–S34.
- Guidry, J.J., Matthews-Juarez, P., & Copeland, V.A. (2003). Barriers to breast cancer control for African American women: The interdependence of culture and psychosocial issues. *Cancer*, 97(Suppl. 1), 318–323.
- Haozous, E. (2003). *Cancer pain in Plains Native Americans*. Unpublished master's thesis, Yale University School of Nursing, New Haven, CT.
- Heiney, S.P., Adams, S.A., Cunningham, J.E., McKenzie, W., Harmon, B., Hebert, J.R., et al. (2006). Subject recruitment for cancer control studies in an adverse environment. *Cancer Nursing*, 29, 291–301.
- Henderson, P.D., Gore, S.V., Davis, B.L., & Condon, E.H. (2003). African American women coping with breast cancer: A qualitative analysis. *Oncology Nursing Forum*, 30, 641–647.
- Hodge, F., Weinmann, S., & Roubideaux, Y. (2000). Recruitment of American Indians and Alaska Natives into clinical trials. *Annals of Epidemiology*, 10(Suppl. 8), S41–S48.
- Howe, H.L., Wu, X., Ries, L.A., Cokkinides, V., Ahmed, F., Jemal, J., et al. (2006). Annual report to the nation on the status of cancer, 1975–2003, featuring cancer among Hispanic/Latino populations. *Cancer*, 107, 1711–1742.
- Jemal, A., Murray, T., Ward, E., Samuels, A., Tiwari, R.C., Ghafoor, A., et al. (2005). Cancer statistics 2005. *CA: A Cancer Journal for Clinicians*, 55, 10–30.
- Julion, W., Gross, D., & Barclay-McLaughlin, G. (2000). Recruiting families of color from the inner city: Insights from recruiters. *Nursing Outlook*, 48, 230–237.
- Knobf, M.T., Erdos, D., Johnston, R., Johnson-Thomas, D., & Reynolds, H. (2003). The experience of breast cancer survivorship in women of color [Abstract]. *Proceedings of the Eastern Nursing Research Society*, 70–71.
- Knobf, M.T., Thompson, S.A., & Erdos, D. (2005, April). *Connecting sisters: A community based participatory project*. Poster presented at the American Cancer Society Conference, Atlanta, GA.
- Kolb, B., Wallace, A.M., Hill, D., & Royce, M. (2006). Disparities in cancer care among racial and ethnic minorities. *Oncology*, 20, 1256–1261.
- Lee, S.C. (2003). *Treatment decision-making for the primary treatment among Chinese American women with early-stage breast cancer*. Unpublished doctoral dissertation, Yale School of Nursing, New Haven, CT.
- Lee, S.C., & Knobf, M.T. (2002). Validating equivalence and cultural relevance of Chinese-translated instruments for breast cancer treatment decision making [Abstract #34-18]. *Proceedings Department of Defense Breast Cancer Research Program Meeting, Vol III*.
- Leeman, J., Goepfinger, J., Funk, S., & Roland, E.J. (2003). An enriched research experience for minority undergraduates—A step toward increasing the number of minority nurse researchers. *Nursing Outlook*, 51, 20–24.

- Lillington, L., Johnson, I., & Chlebowski, R. (2000, September 14). African American women's perspectives on research participation. *Medicine of the Americas* 1.1, 20. *InfoTrac OneFile*.
- Mandelblatt, J., Kaufman, E., Sheppard, V.B., Pomeroy, J., Kavanaugh, J., Canar, J., et al. (2005). Breast cancer prevention in community clinics: Will low income Latina patients participate in clinical trials? *Preventive Medicine*, 40, 611–618.
- Morgan, P.D., Fogel, J., Rose, L., Barnett, K., Mock, V., Davis, B.L., et al. (2005). African American couples merging strengths to successfully cope with breast cancer. *Oncology Nursing Forum*, 32, 979–987.
- Naranjo, L.E., & Dirksen, S.R. (1998). The recruitment and participation of Hispanic women in nursing research: A learning process. *Public Health Nursing*, 15(1), 25–29.
- Newlin, K., Knaf, K., & Melkus, G. (2002). African-American spirituality: A concept analysis. *Advances in Nursing Science*, 25, 57–70.
- Northouse, L.L., Caffey, M., Deichelbohrer, S., Schmidt, L., Guziatek-Trojniak, L., West, S., et al. (1999). The quality of life of African American women with breast cancer. *Research in Nursing and Health*, 22, 449–460.
- Oncology Nursing Society. (2000a). Multicultural outcomes: Guidelines for cultural competence. Retrieved September 14, 2006, from <http://www.ons.org/clinical/special/multicultural.shtml>
- Oncology Nursing Society. (2000b). Multicultural toolkit. Part II: Nurse in research. Retrieved September 14, 2006, from <http://www.ons.org/clinical/special/multicultural.shtml>
- Parran, L. (2004). ONS makes the goal of diversity become a reality. *ONS News*, 19(3), 1, 4–6.
- Paskett, E.D., Tatum, C., Rushing, J., Michielutte, R., Bell, R., Foley, K.L., et al. (2004). Racial differences in knowledge, attitudes, and cancer screening practices among a triracial rural population. *Cancer*, 101, 2650–2659.
- Phillips, J., & Weekes, D. (2002). Incorporating multiculturalism into oncology nursing research: The last decade. *Oncology Nursing Forum*, 29, 807–816.
- Pletsch, P.K., Howe, C., & Tenney, M. (1995). Recruitment of minority subjects for intervention research. *Image: Journal of Nursing Scholarship*, 27, 211–215.
- Polite, B.N., Dignam, J.J., & Olopade, O.I. (2006). Colorectal cancer model of health disparities: Understanding mortality differences in minority populations. *Journal of Clinical Oncology*, 24, 2179–2187.
- Porter, C.P., & Villarruel, A.M. (1993). Nursing research with African American and Hispanic people: Guidelines for action. *Nursing Outlook*, 41, 59–67.
- Portillo, C.J., Villarruel, A., de Leon Siantz, M.L., Peragallo, N., Calvillo, E.R., & Eribes, C.M. (2001). Research agenda for Hispanics in the United States: A nursing perspective. *Nursing Outlook*, 49, 263–269.
- Powell, D.L., & Gilliss, C.L. (2003). Partnering in the cultivation of the next generation of ethnic minority nurse scientists: Responding to a compelling national agenda. *Journal of National Black Nurses' Association*, 14(2), 34–43.
- Sheppard, V.B., Cox, L.S., Kanamori, M.J., Canar, J., Rodriguez, Y., Goodman, M., et al. (2005). Brief report: If you build it, they will come: Methods for recruiting Latinos into cancer research. *Journal of General Internal Medicine*, 20, 444–447.
- Stark, N., Paskett, E., Bell, R., Cooper, M.R., Walker, E., Wilson, A., et al. (2002). Increasing participation of minorities in cancer clinical trials: Summary of the "Moving Beyond the Barriers" conference in North Carolina. *Journal of the National Medical Association*, 94(1), 31–39.
- Struthers, R., Eschiti, V.S., & Patchell, B. (2004). Traditional indigenous healing: Part I. *Complementary Therapies in Nursing and Midwifery*, 10, 141–149.
- Sudore, R.L., Landefeld, C.S., Williams, B.A., Barnes, D.E., Lindquist, K., & Schillinger, D. (2006). Use of a modified informed consent process among vulnerable patients: A descriptive study. *Journal of General Internal Medicine*, 21, 867–873.
- Sun, V. (2002). *Coping strategies and perceived stressors in Chinese Americans with cancer*. Unpublished master's thesis. Yale University School of Nursing, New Haven, CT.
- Sun, Y. (2006). *The decision making process of disclosing breast symptoms among Chinese American women*. Unpublished doctoral dissertation, Yale University School of Nursing, New Haven, CT.
- Underwood, S.M. (2000). Minorities, women and clinical cancer research: The charge, promise and challenge. *Annals of Epidemiology*, 19(Suppl. 8), S3–S12.
- U.S. Census Bureau. (2004). United States census 2004. Retrieved September 19, 2006, from <http://www.census.gov>
- Ward, E., Jemal, A., Cokkinides, V., Singh, G.K., Cardinez, C., Ghafoor, A., et al. (2004). Cancer disparities by race/ethnicity and socioeconomic status. *CA: A Cancer Journal for Clinicians*, 54, 78–93.
- Williams, D.R., & Jackson, P.B. (2005). Social sources of racial disparities in health. *Health Affairs*, 24, 325–334.
- Wilmoth, M.C., & Sanders, L.D. (2001). Accept me for myself: African American women's issues after breast cancer. *Oncology Nursing Forum*, 28, 875–879.
- Yancey, A.K., Ortega, A.N., & Kumanyika, S.K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health*, 27, 1–28.
- Zimmerman, S.M. (1997). Factors influencing Hispanic participation in prostate cancer screening. *Oncology Nursing Forum*, 24, 499–504.

## Call for Institutes and Open Sessions: 2008 ONS Institutes of Learning

The Institutes of Learning (IOL) Team invites ONS members to submit ideas for institutes or open sessions to be offered at the 2008 IOL. The conference will be held November 14–16, 2008, in Seattle, WA. The IOL Team will make decisions regarding institutes, content, and speakers at its January 2008 meeting. An institute provides three or six hours of intense training on a cutting-edge topic of interest, and the 90-minute open sessions focus on a variety of clinical and current healthcare issues. Selection of topics, content, and speakers is the sole responsibility of the IOL Team. Decisions of the IOL Team regarding content are based on identified ONS member learning needs.

**Requirements:** The IOL Submission Form requests the following: name of institute or open session, rationale, brief content outline, and identification of potential speakers.

To submit an idea for an institute or open session online, visit [www.ons.org/cecentral](http://www.ons.org/cecentral) in December for further instructions.