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Cultural Competence in Research

Annotated Bibliography

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ABBREVIATIONS

AAMC	Association of American Medical Colleges
AHRQ	Agency for Healthcare Research and Quality
AIR	American Institute for Research
CBPR	Community Based Participatory Research
CCHCP	Cross Cultural Health Care Program
CCTC	Cultural Competence Training Center
CITI	Collaborative Institutional Training Initiative
CRECH	Center for Research on Ethnicity Culture and Health
ENACCT	Educational Network to Enhance Cancer Clinical Trials
HRSA	Health Resources and Service Administration
NES	Non English Speaking
NIH	National Institute of Health
NLM	National Library of Medicine
NMCI	National Multicultural Institute
OPSR	Office of Prevention Services and Research
SIS	Specialized Information Services
TLP	Tuskegee Legacy Project
TSUS	Tuskegee Study of Untreated Syphilis
UMHS	University of Michigan Health System
UMSPH	University of Michigan School of Public Health

INTRODUCTION

DEFINITION OF CULTURAL COMPETENCE

Cultural competence refers to awareness of unique, and defining characteristics of the populations for which health professionals provide care and from which they wish to enroll clinical research participants.¹ Cultural competence entails understanding the importance of social and cultural influence on patients' health beliefs and behaviors.² According to the literature, numerous terms have been used interchangeably to define cultural competence including awareness,³ responsiveness, safety⁴ and sensitivity.⁵ However, unlike cultural responsiveness, sensitivity or appropriateness, cultural competency moves beyond sensitivity or awareness to action.³ Therefore for purposes of this training module, cultural competence is considered a broad concept which encompasses not only a researcher's understanding of his/her study participants, but also expression of this awareness in his/her actions in research design, conduct and interpretation.

BACKGROUND

Over the past decade, the importance of cultural competence as a critical facet for the provision of high quality health care has risen. As such cultural competence has been defined in the context of health care delivery and providers, specifically focusing on the provider-patient interaction. However, research in the health sciences (e.g., biomedical, clinical, health services, and Community Based Participatory Research (CBPR)) has just recently begun to explore the importance and linkages between culture and research design, analysis and interpretation.

To date, use of the concept of cultural competence in the context of research, compared to its use in the context of health care providers in health care setting has been limited. However, with rapid changes in the cultural diversity of our country, it is anticipated that this transition will necessitate adjustments in how research that is designed to improve the health status of specific populations is conducted. These demographic shifts will increasingly require that researchers better understand the potential role of racial and cultural differences among population groups, how such differences

¹ O'Brien, R. L., Kosoko-Lasaki, O., Cook, C. T., Kissell, J., Peak, F., & Williams, E. H. (2006). Self-assessment of cultural attitudes and competence of clinical investigators to enhance recruitment and participation of minority populations in research. *Journal of National Medical Association*. 98 (5), 674-682.

² Betancourt, R. J., Green, A. R., & Ananeth-Firempong II, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports* 118, 293-302.

³ Shiu-Thronton, S. (2003). Addressing cultural competency in research: Integrating a community-based participatory research approach. *Alcohol Clin Res*. 27 (8), 1361-1364

⁴ Crampton, P., Dowell, A., Parkin, C., & Thompson, C., (2003). Combating effects of racism through a cultural immersion medical education program. *Academic Medicine*. 78 (6), 595-598.

⁵ Cook, C. T., Kosoko-Lasaki, O., & O'Brien, R. (2005) Satisfaction with and perceived cultural competency of healthcare providers: The minority experience. *Journal of the National Medical Association*. 97 (8), 1078-1087.

may impact their research study design, analysis and interpretation, and consequently how best to engage diverse populations in research. For the current work, the term cultural competence for researchers describes how researchers can be culturally prepared to consider some of the aforementioned issues.

DEFINITION OF CULTURAL COMPETENCE IN RESEARCH

Cultural competence in research is the ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population when developing research ideas, conducting research, and exploring applicability of research findings. Cultural competence in research plays a critical role in study design and implementation processes, including the development of research questions and hypotheses, outreach and recruitment strategies, consent activities, data collection protocols, analyzing and interpreting research findings, drawing conclusions and presenting the results. Altogether, cultural congruence in these research processes helps to ensure the research is applicable to diverse populations and if necessary can be adapted to meet the target population's social, cultural and linguistic needs. Depending on the type of research, cultural competence can be crucial to successfully recruiting and retaining diverse individuals as study subjects.⁶

It is important to differentiate Cultural Competence in Research from Community Based Participatory Research and Community Engagement. Cultural competence in Research is an overarching principle, which encompasses traditional modes of scientific research including, but not limited to, basic science research, clinical research (including clinical trials), community-based participatory research (CBPR), and community engagement. CBPR begins with a research topic of importance to a specific community, with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities⁷. Community engagement is a core element of any such research. It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment.⁸ An understanding of cultural competence in research is thus not only required for successful and culturally safe CBPR and community engagement, but also for effective research design, implementation, and recruitment of research participants.

According to the literature, most researchers do not understand or have not received training that enables them to work from and/or incorporate the perspective of minority populations into their work and thus assume the cultural perspective of the majority in the conduct of their work.⁹

⁶ O'Brien, R.L., Kosoko-Lasaki, O., Cook, C. T., Kissell, J; Peak, F., Williams, E. H. (2006). Self-assessment of cultural attitudes and competence of clinical investigators to enhance recruitment and participation of minority populations in research. *Journal of National Medical Association*, 98(5), 674-682

⁷ Kellogg Community Health Scholars Program, 2001.

⁸ Jones L, Wells K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. 297:407-410.

⁹ Rabionet, S. E., Santiago, E., & Zorilla C. D. (2009). A multifaceted mentoring model for minority researchers to address HIV health disparities. *America Journal of Public Health*. 99(S1) Supplement 1 S65-S70.

Cultural competence is critical for researchers to ensure: (1) effective communication and interaction between researchers and study participants; (2) adequate analysis and interpretation of results as they relate to the patient/population impact; and (3) appropriate engagement in study design and implementation for community/population based research. In addition, cultural competence could help to improve participation of minority populations in these studies, ensuring that different subgroups in the population are represented proportionally in research studies. Due to the limited availability of resources on cultural competence in research and the growing interest in this area by researchers, the need to develop an annotated bibliography was identified.

While developing Cultural Competency for Researchers Annotated Bibliography, it became evident that the literature on the subject is sparse. Most of the currently available resources on cultural competence are focused on the patient-provider interaction and reside within the CBPR literature. In addition, although there was some overlap between the CBPR literature and the broader work on cultural competence for researchers, there was limited information on cultural competence as it relates to researchers in the other health sciences (e.g., biomedical, genetics, clinical research).

The purpose of this annotated bibliography is to serve as a resource on cultural competence for researchers irrespective of the extent to which they interact with patients (i.e., from bench researchers to community based researchers). The bibliography is divided into five (5) sections. The first four sections are a review of the cultural competence literature with a focus on: (1) defining cultural competence for researchers, (2) mentoring and training, (3) developing methodology for clinical trials and recruiting study participants, and (4) delivery of healthcare to minority populations. The last (5) section provides information about available web resources on cultural competence for research and health care provision to culturally diverse and minority populations. These resources include links to other tools and references, publications, and training programs on cultural competence for researchers.

SEARCH STRATEGY

Through preliminary review of the literature, a list of MeSH (Medical Subject Headings) terms were identified and used to develop the search criteria (See appendix A for details). Using these criteria, the literature on cultural competence for researchers published by academic institutions, government institutions and foundations was reviewed. Letters, editorials and review articles that focused on cultural competence for health care providers were only included if they provided definitions for cultural competence, trainings on cultural competence and/or information on cultural competence in research. What follows is a list of resources identified with abstracts or summaries.

CULTURAL COMPETENCE FOR RESEARCHERS

The articles in this section provide information on the various definitions of cultural competence with respect to research, Community Based Participatory Research (CBPR), or providing health care to minority populations.

English, R., Lebovitz, Y., and Griffin, R. (2010). Transforming Clinical Research in the United States: Challenges and Opportunities: Workshop Series Summary: *Forum on Drug Discovery, Development, and Translation*. Institute of Medicine, 59.

Excerpt: The intent of the workshop was to engage stakeholders in an honest discussion of the state of clinical trials today and to gain an understanding of what has and has not worked in planning and executing trials. The workshop was focused on four disease areas: cardiovascular disease, depression, cancer, and diabetes. Although “clinical research” is a generic term, a clinical trial in breast cancer, with 5-, 10-, or 15-year outcomes, is quite different from a clinical trial in cardiovascular disease, where the outcome of interest may occur in a month or less. The disease being studied also affects the kind of patients needed and how they are recruited and retained.... also highlighted the success of NIH/NIDDK multicenter trials in recruiting racially and ethnically heterogeneous populations, suggesting that NIH studies have the advantage over industry-funded trials in this regard.

Wilson D, Neville S. (2009). Culturally safe research with vulnerable populations. *Contemp Nurse.*, 33(1), 69-79.

Abstract: Culturally safe research processes, methodologies, and mutually aligned research endeavors are a fundamental right of those being researched. Vulnerable populations are at risk of experiencing inequalities in health experiences and health outcomes, and research beneficial to those being researched is crucial to address disparities. Often vulnerable populations are exposed to research that is driven by dominant epistemologies, research methodologies, and socio-cultural lenses that can exacerbate their vulnerability, negating their socio-cultural reality. In this paper it is contended that researchers should review the way in which research is constructed and developed by creating a culturally safe space for research to occur with those who are vulnerable. A framework based on partnership, participation, protection, and power is presented as a way of creating culturally safe research.

Marshall, P.A. (2008). "Cultural competence" and informed consent in international health research. *Camb Q Healthc Ethics*, 17(2), 206-15.

Abstract: The notion of “cultural competency” in healthcare has gained currency in recent years. Health professionals are expected to be sensitive to the cultural backgrounds and language of their patients. Courses on cultural competency are now routinely offered to physicians, nurses, and

others working in health fields. Although the rhetoric of cultural competency has been applied to clinical contexts, little attention has been given to its applicability in health research generally or, more specifically, in international health research. This paper explores the relevance and limitations of cultural competency for informed consent to international health research, particularly in the context of low-resource settings. PMID: 18312735

Oscós-Sánchez MA, Lesser J, Kelly P. (2008). Cultural competence: a critical facilitator of success in community-based participatory action research. *Issues Ment Health Nurs*, 29(2), 197-200.

Excerpt: Familias en Acci'ón is a community-based participatory action research(CBPR) project with the goal of conducting and evaluating an elementary school-based violence prevention program in a predominantly Mexican community on the south side of San Antonio, Texas. The principal investigator of the project is Patricia Kelly, PhD, RN; Janna Lesser, PhD, RN is the site PI in San Antonio. In the summer of 2005 I (Manuel Osc'os-S'ánchez) joined Familias en Acci'ón as a co-investigator. Given my training and experience in ethnographic participant observation I was asked to contribute to answering one of the research questions of the grant: What are the feasibility, barriers, and utility of community-partnered research methods with low-income Mexican-American populations? Based on 20 months of field observations, I report here on critical aspects of cultural competence that facilitated the success of this CBPR project. A critical facilitator of success observed in this CBPR project was the cultural competence of the site PI. PMID: 18293225

Dein S. (2006). Race, culture and ethnicity in minority research: a critical discussion. *J Cult Divers.*, 13(2): 68-75.

Abstract: Race and ethnicity are terms commonly used in ethnic minority research. Both these terms present a number of problems in terms of definition and classification. It is argued here that there is a need to move beyond essentialised concepts of race and ethnicity to examine the socio-political processes which relate to their social construction and the ways in which these terms articulate with other categories such as social class and gender and structure social relationships. The implications of the social constructionist position are discussed specifically in relation to the use of interpreters and ethnic matching of researcher and respondent in qualitative research on ethnic minorities. PMID: 16856693

Israel B. A., Schulz A. J., Becker A. B., Allen III, A. J., & Guzman, J. R. (2005). Critical issues in developing and following community based participatory research principles. In *Community-Based Participatory Research for Health*, (Chapter 3, 53-76.).

Summary: This book chapter provides an overview of the challenges researchers face when addressing disparities in health care and how CBPR can be used to address social and cultural dynamics of the community. The authors outline the nine key principles of CBPR and research involving culturally diverse partners from different backgrounds. Specifically, the narrative on challenges faced by researchers is based on their experiences in a community initiative (i.e.,

Community Action Against Asthma project in Detroit), where cultural competency training was suggested as a way to address conflicts experienced by researchers. These conflicts resulted from the engagement challenges between individuals in a culturally diverse group of researchers working together in the community initiative. This article provides limited insight on the importance of cultural competence for researchers.

Betancourt, R. J., Green, A. R., & Ananeth-Firempong II, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports, 118*, 293-302.

Summary: The authors define cultural competence using a framework based on a literature review of the subject. A new framework for defining cultural competence in health care and how it interacts at the different levels of the health care delivery system: organizational, structural and clinical interventions, was developed.

Shiu-Thronton, S. (2003). Addressing cultural competency in research: Integrating a community-based participatory research approach. *Alcohol Clin Res., 27*(8), 1361-1364.

Summary: The author provides an elaborate definition of cultural competency—differentiating it from previously used terms such as cultural responsiveness, sensitivity or awareness. The author emphasizes that unlike cultural responsiveness/sensitivity/appropriateness, cultural competency moves beyond sensitivity/awareness to action. Shiu-Thronton also discusses five different core components of cultural competence: developing a value for diversity, conducting a cultural self-assessment, understanding the dynamics of difference, accessing cultural knowledge, and adapting to diversity. The content of this article was drawn from the author's dissertation.¹⁰

Fraser, I., Lanier, D., Hellinger, F., & Eisenberg, J. M. (2002). AHRQ Update: Putting practice into research. *HSR: Health Services Research, 37*(1), 1-14.

Summary: Developed by the leadership and staff at the Agency for Healthcare Research and Quality (AHRQ), this article provides information on the actions taken by the agency to ensure links between researchers and practitioners, to encourage collaborations and synergies across research projects, and bolster the infrastructure for research. The importance of cultural competence as a priority area of focus by the current turn around projects funded by the agency is highlighted.

¹⁰ Shiu-Thornton, S. (2001). *Culturally competent perinatal health care for Chinese and Mien refugees: Ethnographic narratives from Seattle's International district health clinic. University of Washington Seattle.*

Fisher, C. B., Hoagwood, K., Boyce, C., Duster, T., Frank, D. A., Grisso, T., Levine, R. J., Macklin, R., Spencer, M. B., Takanishi, R., Trimble, J. E., & Zayas, L. H. (2002). Research for mental health science involving ethnic minority children and youths. *American Psychologist*, 57(12), 1024-1040.

Summary: This article summarizes key recommendations on ethical decision-making for mental health research involving ethnic minority children and youth. A group of national leaders in bioethics, multicultural research, and ethnic minority mental health developed these recommendations in 2001. This article provides details on the relevance of cultural competence in research among minority populations.

Brach C, Fraser I. (2000). Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Med Care Res Rev.*, 57(S1), 181-217.

Abstract: This article develops a conceptual model of cultural competency's potential to reduce racial and ethnic health disparities, using the cultural competency and disparities literature to lay the foundation for the model and inform assessments of its validity. The authors identify nine major cultural competency techniques: interpreter services, recruitment and retention policies, training, coordinating with traditional healers, use of community health workers, culturally competent health promotion, including family/community members, immersion into another culture, and administrative and organizational accommodations. The conceptual model shows how these techniques could theoretically improve the ability of health systems and their clinicians to deliver appropriate services to diverse populations, thereby improving outcomes and reducing disparities. The authors conclude that while there is substantial research evidence to suggest that cultural competency should in fact work, health systems have little evidence about which cultural competency techniques are effective and less evidence on when and how to implement them properly. PMID: 11092163

Gil EF, Bob S. (1999). Culturally competent research: an ethical perspective. *Clin Psychol Rev.*, 19(1), 45-55.

Abstract: This article addresses the perspective of the Ethical Principles and Guidelines for Providers regarding issues affecting research with ethnic minority populations. Issues such as failure to report or give informed consent to research participants, lack of diversity among researchers, inappropriate study of ethnic minority populations, and culturally insensitive assessment instruments are discussed. Examples of recommended responsibilities and criteria for culturally competent research are provided, including increased involvement of minorities in research, both as investigators and concerned citizens. In sum, the recommendations address the larger problem of failure to acknowledge people in their cultural context. Finally, implications for the Ethical Principles and Guidelines for Providers are considered.

Fontes, L. A. (1998). Ethics in family violence research: Cross-cultural issues. *Family Relations*, 47, 53-61.

Summary: The author examines the different challenges faced by researchers in family violence research and suggests strategies for how researchers can balance the ethical challenges. Factors key to designing ethical cross-cultural research such as informed consent, definition of sample, composition of the research team, research methods, and potential harm and benefit to subjects are discussed.

Campinha-Bacote J, Padgett JJ. (1995). Cultural competence: a critical factor in nursing research. *J Cult Divers.*, 2(1), 31-4.

Abstract: By the year 2000, one in every third American will represent an ethnic minority. This statistic presents various challenges for healthcare providers. While cultural competence is examined in educational and practical nursing areas, nursing research is only beginning to view cultural competence as essential. This article explores various cultural issues embedded in the research process and provides readers with a conceptual model to enhance cultural competence in nursing research. PMID: 7663899

MENTORING AND TRAINING

This section focuses on issues of mentoring and training of researchers whose research studies focus on minority health issues, and/or whose study participants consist of primarily minority populations. The section summarizes articles on mentoring new researchers, and tools developed for assessing of cultural competence among researchers and health care providers.

No authors listed. (2010). Culture clash on consent [Editorial]. *Nat Neurosci.*, 13(7), 777.

Abstract: All research on human subjects requires their informed consent. Obtaining valid consent from isolated minorities can be particularly challenging, but scientists need to avoid the temptingly easy way out, so as to prevent further exclusion of these vulnerable populations from biomedical research. PMID: 20581808

Alegria, M. (2009). Training for research in mental health and HIV/AIDS among racial and ethnic minority populations: Meeting the needs of new investigators. *American Journal of Public Health*, 99(1), S26-S30.

Summary: The author draws upon years of experience in mentoring young researchers and describes the challenges experienced by young researchers as they embark on research on underserved, racial/ethnic minority populations. The author suggests that training new investigators should involve “atypical” research strategies such as CBPR and cultural competency. In addition, the adaptation of research training to the needs of racial and ethnic minority students and young investigators are discussed. Further, the author argues that the adaptation of research training would allow trainees to modify or translate traditional study methods, instruments and interventions allowing exploration of new innovative research methods and data collection methods to fit the needs of diverse multicultural populations.

Rabionet, S. E., Santiago, E., & Zorilla, C. D. (2009). A multifaceted mentoring model for minority researchers to address HIV health disparities. *American Journal of Public Health, 99*(S1), S65-S70.

Summary: Regarding cultural competence, the authors of this article provide a three step multifaceted mentoring model for minority researchers (i.e., establishing multi-institutional collaborations, offering systematic training based on competency development, and creating cross-disciplinary research teams in which mentors and mentees work together). They also state that most researchers had not received training to work from the perspective of minority populations and approached their work assuming the cultural perspective of the majority. They further note that understanding cultural competence was necessary in order to: (1) make health care services more responsive to underserved populations, (2) begin to shift the focus of research, and (3) redirect impact from a local response to a global one.

Bushy, A. (2008). Conducting culturally competent rural nursing research. *Annu Rev Nurs Res., 26*, 221-36.

Abstract: The face of America is changing. In efforts to provide services to and meet the needs of consumers of different ethnicities and cultures, cultural competence has become a driving force not only in health care but also in business, education, and research. Lack of cultural competence among caregivers has been linked to health disparities, decreased client satisfaction, and decreased client adherence to recommended medical regimens. The depth of rural research in general, and by nurse researchers focusing on rural cultural groups in particular, is limited. This chapter focuses on conducting rural nursing research with rural cultural groups, highlights methodological issues that are commonly encountered with rural populations, and proposes strategies to address them. Addressing methodological challenges will contribute to the limited knowledge base related to culture and ethnicity in rural nursing research. PMID: 18709752

O'Brien, R. L., Kosoko-Lasaki, O., Cook, C. T., Kissell, J., Peak, F., & Williams, E. H. (2006). Self-assessment of cultural attitudes and competence of clinical investigators to enhance

recruitment and participation of minority populations in research. *Journal of National Medical Association, 98(5), 674-682.*

Summary: This article describes a study and its findings on strategies necessary to enhance the abilities of study investigators to relate and communicate effectively about health and clinical research with members of minority communities. The authors of the article define cultural competence as awareness of unique and defining characteristics of the populations for which health professionals provide care and from which they wish to enroll clinical research participants. Using previously developed cultural competency instruments, investigators who had been enrolled in the study self assessed their levels of cultural competence for research, and reported on challenges faced in enrolling subjects. The authors found deficits in cultural competence among study investigators and made recommendations on how to address the challenges faced by study investigators. In addition, the need for effective cultural sensitivity training and a desire to communicate effectively with other cultural communities is suggested.

Crampton, P., Dowell, A., Parkin, C., Thompson, C. (2003). Combating effects of racism through a cultural immersion medical education program. *Academic Medicine, 78(6), 595-598.*

Summary: The authors of this article provide a definition of cultural safety, and how it differs from cultural competence. In addition, the authors provide an overview of cultural immersion in medical education as a strategy to ensure cultural safety of indigenous people in New Zealand. Authors explain cultural immersion (experienced by students in an one-week undergraduate cultural immersion program) as a strategy to enhance cultural competence among students.

Papadopoulos I, Lees S. (2002). Developing culturally competent researchers. *J Adv Nurs, 37(3), 258-64.*

Abstract: BACKGROUND: Whilst we live in multicultural societies most health researchers tend to take the cultural perspective of the majority ethnic group at the expense of the perspective of minority ethnic groups. AIM: This paper discusses the need for the development of culturally competent health researchers in all areas of research and proposes a model for the achievement of this. CONCLUSION: Current health policy in many developed countries focuses on inequalities of health and managing diversity, including ethnicity. Thus the authors conclude that the development of culturally competent researchers will lead to both valid research and culturally competent practice by health care professionals. PMID: 11851796

DEVELOPING METHODOLOGY FOR CLINICAL TRIALS AND PARTICIPANT RECRUITMENT

This section includes articles that focus on considering cultural competence when developing methodology for clinical trials. Specifically, the articles focus on previous studies that involved investigations among minority populations and increasing the participation of minority populations in research studies.

Chukwuneke FN, Umeorah OU. (2010). Enrolment and retention of African women in biomedical research: the challenges. *Niger J Med.*, 19(2), 132-5

Abstract: BACKGROUND: In Africa, women have had minimal participation in biomedical research especially in clinical trials despite the epidemiologic realities of the trends and burden of diseases in the continent. The purpose of this paper is to critically examine the challenges as well as suggesting ways of over-coming them in recruiting and retaining African women in biomedical research. CONCLUSION: Women need to participate in clinical trials because of their different biological and physiological make-up which require proper information about the effects of drugs on their bodies. A variety of harm may therefore ensue from failure to include adequate numbers of women in biomedical research such as exposure to ineffective treatment, occurrence of unexpected side-effects and delayed diagnosis and early treatment of disease. PMID: 20642074

Floyd T, Patel S, Weiss E, Zaid-Muhammad S, Lounsbury D, Rapkin B. (2010). Beliefs about participating in research among a sample of minority persons living with HIV/AIDS in New York City. *AIDS Patient Care STDS*, 24(6), 373-80.

Abstract: Despite substantial data documenting the challenges in recruiting racial and ethnic minorities into research studies, relatively little is known about the attitudes and beliefs toward research that are held by racial and ethnic minorities living with HIV/AIDS. The present study assessed the research attitudes and beliefs of a racially and ethnically diverse group of persons living with HIV/AIDS, with research broadly defined as either psychosocial, behavioral, or clinical. Also assessed were factors that would encourage or discourage them from participating in a research study. Six hundred twenty-two participants were recruited from 22 points of service in New York City; data were gathered through a single in-person structured interview conducted in Spanish or English. Findings from a series of quantitative analyses indicated that attitudes about research were primarily neutral or positive, and different attitude and belief patterns were associated with different preferences regarding what would or would not incline one to participate in a research study. Results suggest that minorities with HIV/AIDS are open to the possibility participating in research; however, they also suggest that receptivity to research may not be uniform and indicated a variety of specific research design and implementation options that investigators should consider in order to ensure sufficient access and interest in participation. PMID: 20515415

Grann VR. (2010). Erasing barriers to minority participation in cancer research. *J Womens Health (Larchmt)*., 19(5):837-8.

Summary: This article discusses the barriers to minority participation in Cancer research. The author focuses on participation in clinical research, which is more burdensome to low-income patients. The author posits that underserved groups may face psychosocial barriers to trial entry including language, cultural beliefs and mistrust of the healthcare system.

Hinton L, Carter K, Reed BR, Beckett L, Lara E, Decarli C, Mungas D. (2010 July). Recruitment of a Community-based Cohort for Research on Diversity and Risk of Dementia. *Alzheimer Dis Assoc Disord.*, [Epub ahead of print]

Abstract: We describe the history, development, and success of the recruitment and screening procedures used by researchers at the University of California, Davis Alzheimer's Disease Center (UCD ADC) to facilitate minority enrollment in research. After an initial, unsuccessful approach with satellite clinics in minority neighborhoods, the ADC shifted to an active community outreach approach. Multiple strategies were implemented to remove barriers to research participation such as providing transportation to clinical appointments and offering in-home cognitive screening. Considerable resources were directed toward hiring and training bicultural and bilingual individuals with knowledge of the target populations, both as recruiters and staff involved in clinical assessment. Implementation of these methods resulted in a dramatic increase in the number of ethnic minorities enrolled (and retained) in research protocols, including protocols that are complex and longitudinal. Diversity was achieved on other variables as well; years of education in the cohort range from 0 to 21, with 26% having 8 years or less. The community screen identified candidates for an in depth clinical evaluation and enrollment in longitudinal research, and we examined factors that predicted a positive response to invitation for the clinical evaluation. Individuals with a broader fund of knowledge were more likely to participate independent of other variables including ethnicity and education. When diversity is an important goal active outreach is far more efficacious than clinic-based and advertising-based approaches to recruitment. PMID: 20625273

Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. (2010). More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*, 21(3), 879-97.

Abstract: This paper describes results of a qualitative study that explored barriers to research participation among African American adults. A purposive sampling strategy was used to identify African American adults with and without previous research experience. A total of 11 focus groups were conducted. Groups ranged in size from 4-10 participants (N=70). Mistrust of the health care system emerged as a primary barrier to participation in medical research among participants in our study. Mistrust stems from historical events including the Tuskegee syphilis study and is reinforced by health system issues and discriminatory events that continue to this day. Mistrust was an important barrier expressed across all groups regardless of prior research participation or

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socioeconomic status. This study illustrates the multifaceted nature of mistrust, and suggests that mistrust remains an important barrier to research participation. Researchers should incorporate strategies to reduce mistrust and thereby increase participation among African Americans.

Shaw, M. G., Morrell, D. S., Corbie-Smith, G. M., Lowell, A., & Goldsmith, L. A. (2009).

Perceptions of pediatric clinical research among African American and Caucasian parents. *Journal of the National Medical Association, 101(9), 900-907.*

Abstract: Difficulty in recruiting African American adults for clinical trials is well documented, but there is no consensus on African American children. Responses of a survey completed by 90 African American and Caucasian parents from December 2004 to April 2005 were analyzed to determine if racial disparities exist in research participation interest in an academic pediatric dermatology clinic. The majority of questions (32 of 38) were answered similarly by subjects of both races. However, when compared to African Americans, Caucasians were slightly more trusting (84% vs. 65%) in regard to either total or moderate trust ($p = .03$). African Americans were 3 times as likely to feel that their child might be “treated like a guinea pig” if the child was a research subject ($p = .03$). Nearly a third more Caucasians than African Americans would be more inclined to enroll their healthy child in a research study if they had an established relationship with the health care provider informing them of the study ($p = .0001$). Caucasians had more exposure to research ($p = .03$). Nevertheless, there was no racial difference in the willingness to theoretically allow their child to participate in research studies. Accordingly, the possible lack of trust should not be used as the only reason racially representative recruitment goals are not accomplished.

Sheikh A, Halani L, Bhopal R, Netuveli G, Partridge MR, Car J, Griffiths C, Levy M. (2009).

Facilitating the recruitment of minority ethnic people into research: qualitative case study of South Asians and asthma. *PLoS Med., 6(10).*

Abstract: BACKGROUND: There is international interest in enhancing recruitment of minority ethnic people into research, particularly in disease areas with substantial ethnic inequalities. A recent systematic review and meta-analysis found that UK South Asians are at three times increased risk of hospitalisation for asthma when compared to white Europeans. US asthma trials are far more likely to report enrolling minority ethnic people into studies than those conducted in Europe. We investigated approaches to bolster recruitment of South Asians into UK asthma studies through qualitative research with US and UK researchers, and UK community leaders. PMID: 19823568

Braunstein JB, Sherber NS, Schulman SP, Ding EL, Powe NR. (2008). Race, medical researcher distrust, perceived harm, and willingness to participate in cardiovascular prevention trials. *Medicine (Baltimore), 87(1), 1-9.*

Abstract: Minority underrepresentation exists in medical research including cardiovascular clinical trials, but the hypothesis that this relates to distrust in medical researchers is unproven. Therefore,
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we examined whether African American persons differ from white persons in perceptions of the risks/benefits of trial participation and distrust toward medical researchers, and whether these factors influence willingness to participate (WTP) in a clinical drug trial... In summary, African American participants expressed markedly greater concerns about experiencing harm from participation in clinical trials and distrust toward medical researchers than white participants. These factors, in turn, appear to explain much of the resistance among African American persons to participate in clinical trials compared to white persons. PMID: 18204365

Gadegbeku CA, Stillman PK, Huffman MD, Jackson JS, Kusek JW, Jamerson KA. (2008). Factors associated with enrollment of African Americans into a clinical trial: results from the African American study of kidney disease and hypertension. *Contemp Clin Trials*, 29(6), 837-42.

Abstract: Recruitment of diverse populations into clinical trials remains challenging but is needed to fully understand disease processes and benefit the general public. Greater knowledge of key factors among ethnic and racial minority populations associated with the decision to participate in clinical research studies may facilitate recruitment and enhance the generalizability of study results... Participants associated enrollment with personal and societal health benefits, while non-participants were influenced by the health risks. In a step-wise linear regression analysis, the most powerful significant positive predictors of participation were acknowledgement of health status as important in the enrollment decision (OR=4.54, p=0.006), employment (OR=3.12, p = 0.05) and healthcare satisfaction (OR=2.12, p<0.01). Racially-based mistrust did not emerge as a negative predictor and subjects' decisions were not influenced by the race of the research staff. In conclusion, these results suggest that health-related factors, and not psychosocial perceptions, have predominant influence on research participation among African Americans. PMID: 18639652

Katz, R. V., Kegeles, S. S., Kressin, N. R., Green, B.L., James, S.A., Wang, M.Q., Russell, S.L., & Claudio, C. (2008). Awareness of the Tuskegee Syphilis study and the US Presidential apology and their influence on minority participation in biomedical research. *American Journal of Public Health* 98(6), 1137-1142.

Abstract: Objectives: We compared the influence of awareness of the Tuskegee Syphilis Study and the presidential apology for that study on the willingness of Blacks, non-Hispanic Whites, and Hispanics to participate in biomedical research. Methods: The Tuskegee Legacy Project Questionnaire was administered to 1133 adults in 4 US cities. This 60-item questionnaire addressed issues related to the recruitment of minorities into biomedical studies. Results: Adjusted multivariate analysis showed that, compared with Whites, Blacks were nearly 4 times as likely to have heard of the Tuskegee Syphilis Study, more than twice as likely to have correctly named Clinton as the president who made the apology, and 2 to 3 times more likely to have been willing to participate in biomedical studies despite having heard about the Tuskegee Syphilis Study (odds ratio [OR]=2.9; 95% confidence interval [CI]=1.4, 6.2) or the presidential apology (OR=2.3; 95%

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CI=1.4, 3.9). Conclusions: These marked differences likely reflect the cultural reality in the Black community, which has been accustomed to increased risks in many activities. For Whites, this type of information may have been more shocking and at odds with their expectations and, thus, led to a stronger negative impact.

Kennedy BM, Newton RL Jr, York-Crowe E, Walden HM, Ryan DH, White MA, Williamson DA. (2008). Recruiting African American girls and parents for a secondary weight gain prevention study. *J Cult Divers.*, 15(4), 181-6.

Abstract: This research report describes the process and results of recruiting African American adolescent girls and parents for a secondary weight gain prevention study. We sought to recruit 60 girls with equal representation of at-risk for overweight (BMI percentile 85-95) and overweight (BMI > 95th percentile), and at least one obese (BMI > 30 kg/m²) parent. A personal and individual recruitment approach was the sole method utilized for recruitment of participants into this two-year Internet-based study targeting weight gain prevention. Participants were randomized to either an interactive behavioral condition or a health-based education (control) condition. Fifty-seven African American adolescent girls and their parents were enrolled in the study conducted at a university-based nutrition research center. One hundred eight adolescent girls volunteered and met the study criteria on the first contact, 95 interviewed in the clinic, 64 were randomized, and 57 (89%) of those randomized began the study. Seven percent of the study sample was comprised of African American girls at-risk for overweight, while the majority (93%) of those enrolled were overweight (BMI > 95th percentile). Our study sample comprised an imbalanced number of overweight versus at-risk for overweight African American girls suggesting that perhaps a clinic-based secondary weight gain prevention study may be an inefficient and ineffective setting for recruiting this population. Although we were successful in recruiting a majority of overweight girls, we conclude that the imbalance in the number of participants recruited is likely related to the sociocultural environment that predisposes African American girls to obesity and a lack of awareness by the parents' of the consequences of being overweight. PMID: 19202720

Paskett ED, Reeves KW, McLaughlin JM, Katz ML, McAlearney AS, Ruffin MT, Halbert CH, Merete C, Davis F, Gehlert S., (2008). Recruitment of minority and underserved populations in the United States: the Centers for Population Health and Health Disparities experience. *Contemp Clin Trials*, 29(6), 847-61.

Abstract: OBJECTIVE: The recruitment of minority and underserved individuals to research studies is often problematic. The purpose of this study was to describe the recruitment experiences of projects that actively recruited minority and underserved populations as part of The Centers for Population Health and Health Disparities (CPHHD) initiative. CONCLUSION: Recruitment of minority and underserved populations to clinical trials is necessary to increase study generalizability and reduce health disparities. Our results demonstrate the importance of flexible study designs, which allow adaptation to recruitment challenges. These experiences also highlight

the importance of involving community members and reducing participant burden to achieve success in recruiting individuals from minority and underserved populations. PMID: 18721901

Mainous AG , Smith DW, Geesey ME, Tilley BC, (2008). Factors influencing physician referrals of patients to clinical trials. *J Natl Med Assoc.*, 100(11), 1298-303.

Abstract: PURPOSE: Initial trials in the NIH Parkinson's disease (PD) network (NET-PD) included 91% Caucasian non-Latino patients, although PD is thought to be as common among African Americans and Latinos. Our purpose was to assess physicians' attitudes and beliefs about patient recruitment, particularly minorities, into clinical trials. RESULTS: The TIMRS was lower among African-American physicians and physicians with high proportions of minority patients. Likelihood of trial referral was associated with previous referral to trials (OR=4.24, 95% CI: 2.09-8.62) and higher TIMRS (OR=1.06, 95% CI: 1.001-1.12). TIMRS results were similar among physicians not previously referring to trials. CONCLUSIONS: Study results emphasize the importance of developing a trusting relationship with local physicians if investigators expect these physicians to refer their patients to clinical trials. The trust-related barriers for minority-serving physicians, regardless of their own race/ethnicity, seem to mirror the trust-related issues for their minority patients. PMID: 19024226

Morgenlander KH, Winters SB, Lin CJ, Robertson LB, Heron DE, Herberman RB, (2008). Novel method for benchmarking recruitment of African American cancer patients to clinical therapeutic trials. *J Clin Oncol.*, 26(31), 5074-7.

Abstract: PURPOSE: The National Cancer Institute (NCI) has historically evaluated the participation of underserved minorities within University of Pittsburgh Cancer Institute (UPCI) clinical trials in relation to the proportion of African Americans in the general population of the UPCI primary service area of Allegheny County (12%). This standard seemed to be unrealistically high as a result of a younger age distribution of African Americans within the county. CONCLUSION: The method developed by UPCI is recommended as a useful mechanism for benchmarking recruitment of African American cancer patients to clinical therapeutic trials at other cancer centers. PMID: 18809610

Ogilvie LD, Burgess-Pinto E, Caufield C. (2008). Challenges and approaches to newcomer health research. *J Transcult Nurs.*, 19(1), 64-73.

Abstract: Newcomers include immigrants, refugees, or asylum seekers. Approaches to research in newcomer populations include consideration of the insider-outsider status of the researcher(s), sample selection and recruitment strategies, and attention to language barriers. Potential research participants need to be identified, approached, and made to feel safe before, during, and after participation in research. Interpersonal relationships need to be negotiated with awareness of potential power imbalances, institutional discrimination, and trauma associated with premigration,

migration, and settlement experiences. Embedded within these approaches should be awareness of the need to ensure the cultural safety of research participants through implementation of culturally competent research strategies. PMID: 18165428

Pinsky PF, Ford M, Gamito E, Higgins D, Jenkins V, Lamerato L, Tenorio S, Marcus PM, Gohagan JK. (2008). Enrollment of racial and ethnic minorities in the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial. *J Natl Med Assoc.*, 100(3), 291-8.

Abstract: BACKGROUND: Minority populations in the United States, especially blacks and Hispanics, are generally underrepresented among participants in clinical trials. Here, we report the experience of enrolling ethnic minorities in a large cancer screening trial. RESULTS: Among almost 155,000 subjects enrolled in PLCO, minority enrollment was as follows: black (5.0%), Hispanic (1.8%) and Asian (3.6%). This compares to an age-eligible population in the combined catchment areas of the PLCO centers that was 14.0% black, 2.9% Hispanic and 5.4% Asian, and an age-eligible population across the U.S. that was 9.5% black, 6.5% Hispanic and 3.0% Asian. About half (45%) of Hispanics were recruited at the center with the special Hispanic recruitment effort. Seventy percent of blacks were recruited at two centers; the one with the major special recruitment effort and a center in Detroit whose catchment area was 20% black among age-eligibles. Blacks, Hispanics and (non-Hispanic) whites were all more highly educated, less likely to currently smoke and more likely to get regular exercise than their counterparts in the general population. CONCLUSION: Significant efforts were made to recruit racial/ ethnic minorities into PLCO, and these efforts resulted in enrollment levels that were comparable to those seen in many recent cancer screening or prevention trials. Blacks and Hispanics were nonetheless underrepresented in PLCO compared to their levels among age-eligibles in the overall U.S. population or in the aggregate PLCO catchment areas. PMID: 18390022

Powell JH, Fleming Y, Walker-McGill CL, Lenoir M. (2008). The project IMPACT experience to date: increasing minority participation and awareness of clinical trials. *J Natl Med Assoc.*, 100(2), 178-87.

Abstract: OBJECTIVE: This study evaluated activities of Project IMPACT (Increase Minority Participation and Awareness of Clinical Trials), a National Medical Association (NMA) project chartered to identify ways to increase minority physician and patient involvement in clinical trials. Project IMPACT included physician education and training workshops, establishment of a physician-investigator database and other activities to facilitate minority-physician clinical trial participation. METHODS: A descriptive survey was used. The survey was distributed to 542 African-American physicians. Physicians were queried about prior involvement in clinical research, barriers and facilitators to clinical trial participation by patients and physicians, and perceptions regarding Project IMPACT. RESULTS: Two-hundred physicians responded to the survey. Common practice characteristics were self-employment (51%), solo practice (39%) and office based (58%). Prior involvement in clinical trials was generally low. Barriers to participation included lack of awareness

of clinical trial opportunities and lack of resources to conduct clinical trials. However, most respondents had referred patients to clinical trials. Project IMPACT participants who responded were highly satisfied with the project. CONCLUSIONS: Minority physicians are interested in participating in clinical trials. However, multiple barriers, including lack of awareness and lack of access to clinical research coordinators, continue to exist and must be addressed. Clinical trials training programs alone are not enough. PMID: 18300535

Branson RD, Davis K Jr, Butler KL. (2007). African Americans' participation in clinical research: importance, barriers, and solutions. *Am J Surg.*, 193(1), 32-39.

Abstract: Ethical and scientifically sound research requires that any sample population represent the population as a whole. African-Americans suffer disproportionately from cancer, hypertension, and heart failure compared with whites, but they are commonly underrepresented in clinical trials of these diseases. Failure to include African-American subjects in clinical trials prevents generalizability of the results to this population. African-Americans are often underrepresented in clinical research for numerous historic, societal, educational, and economic reasons. Efforts to improve enrollment of African-American subjects requires recognition of the problem, planning, educational efforts, and investigator training. The incidence of heart disease and prostate cancer in African-Americans dictates that these patients be targeted for clinical trials of surgical research. The research team must appreciate the importance of community involvement and support in recruiting African-Americans participants. Additionally, the continued effort to recruit and train African-American investigators must be a priority. PMID: 17188084

Corbie-Smith G, Williams IC, Blumenthal C, Dorrance J, Estroff SE, Henderson G. (2007). Relationships and communication in minority participation in research: multidimensional and multidirectional. *J Natl Med Assoc.*, 99(5), 489-98.

Abstract: We examined the range and nature of investigators' communication and relationship building as they recruit minority participants in their research. Semistructured, in-depth interviews were conducted with 33 investigators conducting research with human participants. The response rate was 77%. Investigators described several kinds of relationships that are formed or called upon when including minority participants in research. The relationships ranged from study-related, short-term interactions geared solely to facilitate recruitment to others that were longer term, extending beyond a particular project. The data suggest that a range of relationships is important as investigators seek to include minority populations in research. These relationships can both facilitate the recruitment process as well as aid in the interpretation of research findings. PMID: 17534006

Durant RW, Davis RB, St George DM, Williams IC, Blumenthal C, Corbie-Smith GM. (2007). Participation in research studies: factors associated with failing to meet minority recruitment goals. *Ann Epidemiol.*, 17(8), 634-42.

Abstract: PURPOSE: To determine the recruitment goals that investigators set for racial/ethnic minorities and the factors associated with failure to meet those goals. RESULTS: Ninety-two percent of PIs set goals for African Americans, 68% for Hispanics, 55% for Asian Americans, 35% for Native Hawaiians/Pacific Islanders, and 23% of PIs set recruitment goals for American Indians/Native Alaskans. Among those PIs who did set minority recruitment goals, the mean goal for the recruitment of African Americans was 31%, 16% for Hispanics, and 9% for Asian Americans. Twenty-seven percent of PIs failed to meet their recruitment goals for African Americans, 23% for Asian Americans, and 23% for Hispanics. After adjusting for multiple investigator and trial characteristics, the type of study (odds ratio [OR] 1.8; 95% confidence interval [CI] 1.2, 3.4 for observational vs. phase III trial) completion of study enrollment (OR 2.0; 95% CI 1.2, 3.4), and PI identification of a larger number of major barriers to participation (OR 1.8; 95% CI 1.1, 3.0) were all associated with failure to meet recruitment goals for African Americans. However, no factors were consistently associated with failure to meet recruitment goals across different racial/ethnic groups. CONCLUSIONS: Investigators often do not set recruitment goals for some racial/ethnic groups. Factors associated with failure to meet recruitment goals vary in the recruitment of different minority groups. PMID: 17531504

Garber M, Hanusa BH, Switzer GE, Mellors J, Arnold RM. (2007). HIV-infected African Americans are willing to participate in HIV treatment trials. *J Gen Intern Med*, 22(1), 17-42.

Abstract: BACKGROUND: Despite the high prevalence rates of HIV infection in the African-American community, African Americans remain underrepresented in HIV treatment trials. OBJECTIVE: (1) To develop a questionnaire that measures attitudes and concerns about HIV treatment trials among HIV-infected African Americans at a university-based clinic. (2) To determine actual participation rates and willingness to participate in future HIV treatment trials among HIV-infected African Americans at a university-based clinic. DESIGN: Questionnaire development and cross-sectional survey. CONCLUSIONS: Having never been asked to participate in research is a major barrier to the participation of HIV-infected African Americans in HIV treatment trials. African Americans who seek medical care for HIV infection should be asked to participate in HIV treatment trials. PMID: 17351837

Howerton MW, Gibbons MC, Baffi CR, Gary TL, Lai GY, Bolen S, Tilburt J, Tanpitukpongse TP, Wilson RF, Powe NR, Bass EB, Ford JG. (2007). Provider roles in the recruitment of underrepresented populations to cancer clinical trials. *Cancer*, 109(3), 465-76.

Abstract: BACKGROUND: Providers play a vital role in the successful recruitment of underrepresented patients to cancer clinical trials because they often introduce the opportunity of clinical trials. The purpose of the current systematic review was to describe provider-related factors influencing recruitment of underrepresented populations to cancer clinical trials.

METHODS: To find original studies on the recruitment of underrepresented populations to cancer clinical trials, electronic databases from January 1966 to December 2005 were searched; hand-searched titles in 34 journals from January 2003 to January 2006; and reference lists were examined of eligible articles. Title and abstract reviews were conducted to identify relevant studies. Potential articles were then abstracted using a structured instrument and a serial review process by 2 investigators. **RESULTS:** Eighteen studies were eligible for review: 13 targeted healthcare providers, 3 targeted patients/participants, and 2 targeted both providers and patients. The study designs included randomized controlled trial, concurrent controlled trial, case-control, descriptive, and qualitative. A lack of available protocols and/or a lack of provider awareness about clinical trials prevented providers from discussing the opportunity of clinical trials in 2 studies. In 14 studies, patient accrual was affected by provider attitudinal barriers relating to patient adherence to the study protocol, patient mistrust of research, patient costs, data collection costs, and/or patient eligibility. Providers' communication methods were barriers in 5 studies and promoters in 1 study. **CONCLUSIONS:** A heterogeneous body of evidence suggests that several provider-related factors influence recruitment of underrepresented groups to clinical trials. Future recruitment efforts should address these factors. (c) 2007 American Cancer Society. PMID: 17200964

Kennedy BM, Burnett MF. (2007). Clinical research trials: factors that influence and hinder participation. *J Cult Divers.*, 14(3), 141-7.

Abstract: The objective of this study was to examine factors that influence and hinder participation of African Americans in clinical research trials. Specifically, we examined and compared the perceived advantages and disadvantages to participation in clinical research trials, exposure to selected experiences prior to participation (i.e., who and what influenced the decision to participate or not), and perceptions regarding necessary preparation for participation in clinical research trials. Three hundred eighty six African Americans responded to the questionnaire that was administered in the study. As expected, African Americans who had previously participated in a clinical research trial agreed with factors perceived as advantages to participation, while respondents who had not previously participated endorsed factors perceived as potential disadvantages to participation in clinical research trials. PMID: 18314816

Lawsin CR, Borrayo EA, Edwards R, Belloso C. (2007). Community readiness to promote Latinas' participation in breast cancer prevention clinical trials. *Health Soc Care Community*, 15(4), 369-78.

Abstract: The high breast cancer (BC) mortality rates that exist among Hispanic women (Latinas) are a health disparity burden that needs to be addressed. Prevention clinical trials are a burgeoning area of cancer prevention efforts and may serve to promote parity. Unfortunately, Latinas, along with other ethnic minority women, continue to be under-represented in this form of research. Previous studies have examined individual barriers to ethnic minorities' participation, but none have assessed community factors contributing to Latinas' under-representation in these studies.

The present study addressed these limitations from a community perspective by exploring which factors might inhibit Latinas' participation in clinical trials, specifically BC prevention trials. Using the Community Readiness Model (CRM), 19 key informants were interviewed in four communities, two rural and two urban, in Colorado, USA. The key informant assessment involved a semistructured interview that measured the level of community readiness to encourage participation in BC prevention activities. The results reflected a community climate that did not recognise BC as a health problem that affected Latinas in participating communities. Compared to other healthcare priorities, participation in BC prevention clinical trials was considered a low priority in these communities. Overall, leadership and community resources were not identified or allocated to encourage the participation of Latinas. The results highlight the lack of awareness regarding clinical trials among both community members and leaders. According to the CRM, strategies to enhance awareness at multiple levels in the community are necessary. This study demonstrates how the CRM can be used to better understand a community's perspective on BC, and specifically, the under-representation of Latinas in clinical trials. PMID: 17578398

Linden HM, Reisch LM, Hart A Jr, Harrington MA, Nakano C, Jackson JC, Elmore JG. (2007). Attitudes toward participation in breast cancer randomized clinical trials in the African American community: a focus group study. *Cancer Nurs.*, 30(4), 261-9.

Abstract: Participation of African Americans in research trials is low. Understanding the perspectives of African American patients toward participation in clinical trials is essential to understanding the disparities in participation rates compared with whites. A qualitative study was conducted to discover attitudes of the African American community regarding willingness to participate in breast cancer screening and randomized clinical trials. Six focus groups consisting of 8 to 11 African American women (N = 58), aged 30 to 65, were recruited from local churches. Focus group sessions involved a 2-hour audio-taped discussion facilitated by 2 moderators. A breast cancer randomized clinical trial involving an experimental breast cancer treatment was discussed to identify the issues related to willingness to participate in such research studies. Six themes surrounding willingness to participate in randomized clinical trials were identified: (1) Significance of the research topic to the individual and/or community; (2) level of trust in the system; (3) understanding of the elements of the trial; (4) preference for "natural treatments" or "religious intervention" over medical care; (5) cost-benefit analysis of incentives and barriers; and (6) openness to risk versus a preference for proven treatments. The majority (80%) expressed willingness or open-mindedness to the idea of participating in the hypothetical trial. Lessons learned from this study support the selection of a culturally diverse research staff and can guide the development of research protocols, recruitment efforts, and clinical procedures that are culturally sensitive and relevant. PMID: 17666974

Movsas B, Moughan J, Owen J, Coia LR, Zelefsky MJ, Hanks G, Wilson JF. (2007). Who enrolls onto clinical oncology trials? A radiation Patterns Of Care Study analysis. *Int J Radiat Oncol Biol Phys.*, 68(4), 1145-50.

Abstract: PURPOSE: To identify factors significantly influencing accrual to clinical protocols by analyzing radiation Patterns of Care Study (PCS) surveys of 3,047 randomly selected radiotherapy (RT) patients. RESULTS: Overall, only 2.7% of all patients were accrued to clinical protocols. Of these, 57% were enrolled on institutional review board-approved institutional trials, and 43% on National Cancer Institute collaborative group studies. On multivariate analysis, patients treated at academic facilities ($p = 0.0001$) and white patients (vs. African Americans, $p = 0.0002$) were significantly more likely to participate in clinical oncology trials. Age, gender, type of cancer, and type of insurance were not predictive. CONCLUSIONS: Practice type and race significantly influence enrollment onto clinical oncology trials. This suggests that increased communication and education regarding protocols, particularly focusing on physicians in nonacademic settings and minority patients, will be essential to enhance accrual. PMID: 17418963

Robinson JM, Trochim WM. (2007). An examination of community members', researchers' and health professionals' perceptions of barriers to minority participation in medical research: an application of concept mapping. *Ethn Health, 12(5)*, 521-39.

Abstract: OBJECTIVE: Some of the most promising medical treatments are currently being developed and used in clinical trials. In the US, rates of chronic disease among racial/ethnic minorities are disproportionately high. Unfortunately, the rates of minority participation in medical research are low, and the reasons are unclear. This study seeks to contribute to the body of knowledge that is currently available relating to the specific barriers to racial/ethnic minority participation in medical research through the conceptualization and measurement of these barriers. RESULTS: The findings of this study suggest that there are two specific areas where barriers to minority participation may be addressed. The first area is the research system, specifically, the manner in which research studies are designed and implemented, including referral, recruitment and retention of racial/ethnic minorities. The data suggest that recruitment and retention will be aided by addressing patient concerns regarding the research process, and assuaging fears about clinical trials. The second area pertains to minority perceptions of the research process based on history and personal experiences. CONCLUSION: There appears to be a difference in the barriers to participation as defined by community members themselves, and health professionals' perceptions of these barriers. Increased inclusion of minorities in the design, management, and implementation of medical research studies would help mitigate negative perceptions of the research process, and serve to increase participation among racial/ethnic minorities. PMID: 17978947

Shaya FT, Gbarayor CM, Huiwen Keri Yang, Agyeman-Duah M, Saunders E. (2007). A perspective on African American participation in clinical trials. *Contemp Clin Trials, 28(2)*, 213-7.

Abstract: The relatively low participation of African Americans in phase III clinical trials has raised concerns about the appropriateness of generalizing study results to African American populations. If African American enrollment in clinical trials continues to be low, the society may continue to see disparities in the treatment of diseases as well as unanswered questions as to why the population fares less than others when diagnosed with certain diseases such as cancer and diabetes. Additionally, more clinical trials are needed to explicitly monitor the difference in outcomes across different populations. This article discusses the various reasons why African American patient recruitment and participation is sub-optimal; the critical role of clinical trials in therapies; recommendations by important authorities; and a new practice model (Collaborative Care Model) as an innovative strategy to augment participation rates of African Americans [and other minorities] in clinical trials. PMID: 17141575

Smith YR, Johnson AM, Newman LA, Greene A, Johnson TR, Rogers JL. (2007). Perceptions of clinical research participation among African American women. *J Womens Health (Larchmt)*, 16(3), 423-8.

Abstract: BACKGROUND: Recruiting minority women into clinical research remains a significant challenge to conducting ethnically representative research. The main objective of this Office on Women's Health, DHHS-funded e-health database evaluation project was to examine African American women 's thoughts and perceptions about the clinical research process and about participation in the University of Michigan Women's Health Registry research database. RESULTS: Ten common trends were identified. (1) Information about the Women's Health Registry is not reaching the community. (2) Research is perceived as biased to benefit Caucasians. (3) Community involvement by the research team is critical for trust to develop. (4) Research directly relevant to African Americans or their community will encourage participation. (5) Researchers should use existing networks and advertise in appropriate locations. (6) The community needs more information concerning research. (7) Compensation is important. (8) Research that addresses a personal or family medical problem encourages involvement. (9) Minority representation on the research team is a motivator to participation. (10) There is limited time for healthcare-related activities. CONCLUSIONS: Successful recruitment strategies for African American women should feature community-based, culturally appropriate approaches. Online research databases for subject recruitment will likely be successful only if implemented within a broader community-oriented program. PMID: 17439387

Zúñiga ML, Blanco E, Martínez P, Strathdee SA, Gifford AL. (2007). Perceptions of barriers and facilitators to participation in clinical trials in HIV-positive Latinas: a pilot study. *J Womens Health (Larchmt)*, 16(9), 1322-30.

Abstract: BACKGROUND: Women of color comprise a growing proportion of U.S. HIV/AIDS cases and are poorly represented in HIV/AIDS clinical trials. Improved understanding of reasons for low Latina representation in HIV/AIDS clinical trials is needed to promote participation and improve

study generalizability. We studied barriers and facilitators to HIV/AIDS trial participation in HIV-positive Latinas in the U.S.-Mexico border region. RESULTS: Latinas were Mexican born (70%), preferred health information in Spanish (62.5%), had a mean age of 38 years (range 21-60), had a household income \leq 15,000 dollars/year (62.5%), crossed the border at least once/month (45%), and reported residing in Mexico (15%). We found no significant differences between women who participated in a clinical trial (60%) and those who had not (40%) across language, age, education, and border crossing ($p > 0.05$). Sixty-three percent of Latinas perceived individual-level barriers (e.g., fear, shame, and stigma), and 10% mentioned system-level barriers (e.g., lack of transportation or language-appropriate services); 70% of providers mentioned system barriers. HIV stigma was not reported as a barrier by providers. CONCLUSIONS: The role of stigma in recruitment of HIV-positive Latinas into clinical trials and differences in perceptions of barriers between Latina participants and service providers merit further exploration. Improved understanding of individual and system barriers to clinical trials participation in a binational context is warranted.

Baquet CR, Commiskey P, Daniel Mullins C, Mishra SI. (2006). Recruitment and participation in clinical trials: socio-demographic, rural/urban, and health care access predictors. *Cancer Detect Prev.*, 30(1), 24-33.

Abstract: BACKGROUND: Recruitment and participation in clinical trials by minorities, particularly African Americans and rural underserved populations, are low. This report examines predictors of clinical trial recruitment and participation for adult Marylanders. RESULTS: 11.1% of the respondents had been recruited to clinical trials. In addition, 59.4% of the respondents recruited to clinical trials actually participated in a clinical trial. Among respondents recruited to clinical trials, black and middle income respondents were significantly less likely to actually participate in clinical trials; whereas, respondents who received information about clinical trials from their health care provider, who were knowledgeable about clinical trials, and those who had the time commitment were significantly more likely to participate in clinical trials. CONCLUSIONS: These results suggest serious gaps in efforts to recruit racial/ethnic minorities and residents of rural regions into clinical trials. The findings provide the basis for the development and implementation of community-based educational programs for both the general public and health care professionals, and to enhance availability of community-based clinical trials, especially in the rural areas of the state. PMID: 16495020

BeLue R, Taylor-Richardson KD, Lin J, Rivera AT, Grandison D. (2006). African Americans and participation in clinical trials: differences in beliefs and attitudes by gender. *Contemp Clin Trials.* 27(6), 498-505.

Abstract: OBJECTIVES: To explore gender differences in perceptions of 1) barriers and motivators to participation in clinical trials and perceived need of clinical trials and 2) perceptions of risks and benefits of participation in clinical trials in African American men and women. DISCUSSION: Focus

group results indicate that African American men and women present different preferences, beliefs and barriers to participation. Men expressed the desire to know information on funding issues, financial benefit and impact of the research. Women expressed the desire to be treated respectfully and as an individual as opposed to just a study subject. Integrating gender preferences into researcher-participant interactions, advertisement, informed consent delivery and advertisement of research studies may lead to increased participation rates. Discussing and presenting relevant information on clinical research funding mechanisms, and the business of clinical research with potential participants may be helpful in building trust with the researcher and the research team. Creating a process for information exchange and methods to minimize the power imbalance between the researcher and participant may also build trust and help participants feel more comfortable to participate in research. PMID: 16962382

Calderón JL, Baker RS, Fabrega H, Conde JG, Hays RD, Fleming E, Norris K. (2006). An ethno-medical perspective on research participation: a qualitative pilot study. *MedGenMed.*, 8(2), 23.

Abstract: BACKGROUND: Recruitment of racial/ethnic minorities for clinical research continues to be problematic, yet critical to ensuring that research data will be applicable to diverse populations. There is a paucity of information about culturally appropriate methods for recruiting and retaining racial/ethnic minorities in research. OBJECTIVE: To cross-culturally assess perceptions of research participation by African American and immigrant Latinos living in the inner-city community of Watts, Los Angeles, California, using qualitative methods. CONCLUSIONS: Using an ethno-medical science model, we demonstrated that it is possible to identify shared barriers and motivators to research participation between 2 distinct cultural groups. This approach can be useful in developing targeted community-based strategies to increase minority participation in clinical trials. PMID: 16926762

Hussain-Gambles M, Atkin K, Leese B. (2006). South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy.* 77(2), 149-65.

Abstract: There is little UK-based empirical research on South Asian participation in clinical trials. The predominantly US literature rarely engages with mainstream debates about ethnicity, diversity and difference. This study was prompted by a lack of knowledge about how South Asian people perceive trial involvement and the risks and benefits involved. Face to face interviews were conducted with 25 health professionals (consultants, GPs, nursing staff, academics, non-medically trained trial co-ordinators, LREC and MREC members) and 60 South Asian lay people (20 Indians, 20 Pakistanis and 20 Bangladeshis) who had not taken part in a trial. The study took place in the Leeds and Bradford areas of England. It was found that lay South Asian attitudes towards clinical trial participation focused on similarities rather than differences with the general UK population, suggesting that the relevance of ethnicity should be kept in perspective. There was no evidence of antipathy amongst South Asians to the concept of clinical trials, and awareness was a correlate of

social class, education and younger age. Lay factors that might affect South Asian participation in clinical trials included: age; language, social class; feeling of not belonging/mistrust; culture and religion. Approachable patients (of the same gender, social class and fluent in English) tended to be 'cherry picked' to clinical trials. This practice was justified because of a lack of time, resources and inadequate support. South Asian patients might be systematically excluded from trials due to the increased cost and time associated with their inclusion, particularly in relation to the language barrier. Under-representation might also be due to passive exclusion associated with cultural stereotypes. The paper concludes by applying the theoretical framework of institutional racism as a means of making sense of policy and practice. At the same time, caution is advocated against using ethnicity as the only form of discrimination facing minority ethnic populations. PMID: 16216378

Lindenstruth KA, Curtis CB, Allen JK. (2006). Recruitment of African American and white postmenopausal women into clinical trials: the beneficial effects of soy trial experience. *Ethn Dis*, 16(4), 938-42.

Abstract: OBJECTIVE: To describe the strategies and costs associated with recruiting both African American and White postmenopausal women into a randomized controlled trial. RESULTS: A total of 705 postmenopausal women (381 African American, 324 White) were screened, and of those, 217 were randomized (105 African American, 112 White), and 192 (91 African American, 101 White) completed the study. Direct mailings to targeted zip codes proved the most successful recruitment strategy for recruiting African Americans (52% of African Americans recruited) and the second most effective for recruiting Whites (32% of Whites recruited). Newspaper advertisements yielded the highest number of White participants (36%) but proved less successful for recruiting African Americans (8%). Airing advertisements on the radio was the second most effective strategy for recruiting African Americans (15%), yet it was one of the least effective approaches for recruiting Whites (5%). The total cost of recruitment was dollar 49,036.25, which averaged dollar 255.40 per participant who completed the study. The three most successful strategies, direct mailings, newspaper ads, and radio ads, were the three most expensive approaches but yielded 73% of all participants who completed the study. PMID: 17061750

Newlin K, Melkus GD, Jefferson V, Langerman S, Womack J, Chyun D. (2006). Recruitment of black women with type 2 diabetes into a self-management intervention trial. *Ethn Dis.*, 16(4), 956-62.

Abstract: The purpose of this study was to evaluate the relationship of recruitment methods to enrollment status in Black women with type 2 diabetes screened for entry into a randomized clinical trial (RCT). Using a cross-sectional study design with convenience sampling procedures, data were collected on recruitment methods to which the women responded (N=236). Results demonstrated that the RCT had a moderate overall recruitment rate of 46% and achieved only 84% of its projected accrual goal (N=109). Chi-square analysis demonstrated that enrollment outcomes varied significantly according to recruitment methods (P=.05). Recruitment methods such as

community health fairs (77.8%), private practice referrals (75.0%), participant referrals (61.5%), community clinic referrals (44.6%), community advertising and marketing (40.9%), and chart review (40.4%) demonstrated variable enrollment yields. Results confirm previous findings that indicate that Black Americans may be successfully recruited into research studies at moderate rates when traditional recruitment methods are enhanced and integrated with more culturally sensitive methods. Lessons learned are considered. PMID: 17061753

Williams IC, Corbie-Smith G. (2006). Investigator beliefs and reported success in recruiting minority participants. *Contemp Clin Trials*, 27(6), 580-6.

Abstract: PURPOSE: Attaining adequate minority participation in clinical trials has been challenging and limited by the lack of data on the role that investigator perceptions play in minority recruitment. We sought to determine what investigator and study factors were associated with investigators' reported success in recruiting minority populations in research. METHODS: Principal investigators (PIs) who conducted clinical research funded by the National Heart, Lung and Blood Institute in 2001 were surveyed about their success in recruiting minority populations, perceptions about the importance of minority recruitment, use of recruitment strategies, and barriers to minority recruitment. Logistic regression was used to identify factors associated with PIs' reports of success in minority recruitment. RESULTS: A total of 440 PIs completed the survey about minority recruitment. PIs who agreed more strongly about the importance of minority inclusion in their research reported being more successful in minority recruitment. PIs who reported midstream modifications to their recruitment strategies to increase minority participation and those who reported more barriers reported less success in recruiting minority populations. CONCLUSION: PIs' reports of success in recruiting ethnic/racial minority populations for research are associated with the value investigators place on inclusion of minority participants in their research. PIs' perceptions should be considered in minority recruitment efforts as they may influence minority participation rates. PMID: 16839822

Wilson JJ, Mick R, Wei SJ, Rustgi AK, Markowitz SD, Hampshire M, Metz JM. (2006). Clinical trial resources on the internet must be designed to reach underrepresented minorities. *Cancer J*, 12(6), 475-81.

Abstract: PURPOSE: Internet-based clinical trial information services are being developed to increase recruitment to studies. However, there are limited data that evaluate their ability to reach elderly and underrepresented minority populations. This study was designed to evaluate the ability of an established clinical trials registry to reach these populations based on expected Internet use. DISCUSSION: The Internet is a growing medium for registry into clinical trials databases. However, even taking into account the selection bias of Internet accessibility, there are still widely disparate demographics between general Internet users and those registering for clinical trials, particularly the underrepresentation of minorities. Internet-based educational and recruitment services for

clinical trials must be designed to reach these underrepresented minorities to avoid selection biases in future clinical trials. PMID: 17207317

Wood CG, Wei SJ, Hampshire MK, Devine PA, Metz JM. (2006). The influence of race on the attitudes of radiation oncology patients towards clinical trial enrollment. *Am J Clin Oncol.* 29(6), 593-9.

Abstract: OBJECTIVES: Enrollment of adult cancer patients in clinical trials remains low, particularly in the minority population. Understanding patient attitudes towards clinical trials during the recruitment process may enhance accrual. Unfortunately, data describing patient attitudes towards clinical trials are limited, particularly in the radiation oncology clinic setting. CONCLUSIONS: Minority patients historically enroll in clinical trials at a significantly lower rate. Our study of radiation oncology patients documents significant differences in attitudes towards clinical trials between Whites and non-Whites. Understanding the differences in attitudes may allow physicians to overcome barriers that would otherwise hinder the enrollment of non-White patients into clinical trials. PMID: 17148997

Wendler, D., Kington, R., Madans, J., Wye, G. V., & Christ-Schmidt, H. (2006). Are Racial and Ethnic Minorities Less Willing to Participate in Health Research? *PLoS Med.* 3(2), 201-210.

Abstract: Background: It is widely claimed that racial and ethnic minorities, especially in the US, are less willing than non-minority individuals to participate in health research. Yet, there is a paucity of empirical data to substantiate this claim. Conclusions: We found very small differences in the willingness of minorities, most of whom were African-Americans and Hispanics in the US, to participate in health research compared to non-Hispanic whites. These findings, based on the research enrollment decisions of over 70,000 individuals, the vast majority from the US, suggest that racial and ethnic minorities in the US are as willing as non-Hispanic whites to participate in health research. Hence, efforts to increase minority participation in health research should focus on ensuring access to health research for all groups, rather than changing minority attitudes.

Yonas, M. A., Jones, N., Eng, E., Vines, A.I., Aronson, R., Griffith, D.M., White, B. & DuBose, M. (2006). The art and science of integrating undoing racism with CBPR: Challenges of pursuing NIH funding to investigate Cancer care and racial equity. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 83(6), 1004-1012.

Abstract: In this nation, the unequal burden of disease among People of Color has been well documented. One starting point to eliminating health disparities is recognizing the existence of inequities in health care delivery and identifying the complexities of how institutional racism may operate within the health care system. In this paper, we explore the integration of community-based participatory research (CBPR) principles with an Undoing Racism process to conceptualize, Page 32 of 55

design, apply for, and secure National Institutes of Health (NIH) funding to investigate the complexities of racial equity in the system of breast cancer care. Additionally, we describe the sequence of activities and “necessary conflicts” managed by our Health Disparities Collaborative to design and submit an application for NIH funding. This process of integrating CBPR principles with anti-racist community organizing presented unique challenges that were negotiated only by creating a strong foundation of trusting relationships that viewed conflict as being necessary. The process of developing a successful NIH grant proposal illustrated a variety of important lessons associated with the concepts of cultural humility and cultural safety. For successfully conducting CBPR, major challenges have included: assembling and mobilizing a partnership; the difficulty of establishing a shared vision and purpose for the group; the problem of maintaining trust; and the willingness to address differences in institutional cultures. Expectation, acceptance and negotiation of conflict were essential in the process of developing, preparing and submitting our NIH application. Central to negotiating these and other challenges has been the utilization of a CBPR approach.

Ard JD, Durant RW, Edwards LC, Svetkey LP. (2005). Perceptions of African-American culture and implications for clinical trial design. *Ethn Dis.*, 15(2), 292-9.

Abstract: OBJECTIVE: To identify unique cultural variables for African Americans that might limit the effectiveness of behavioral interventions in clinical trials. DESIGN: Focus group discussions lasting 90 minutes. SETTING: Outpatient, clinical research center. PATIENTS: Twenty-six African-American men and women, who completed the screening process but were ineligible for the PREMIER study, participated in six focus group sessions. PREMIER is a multicenter, randomized clinical trial that studies the effects of three different lifestyle interventions designed to reduce blood pressure without medication. CONCLUSIONS: Cultural variables can affect African-American perceptions of the feasibility of certain behavior modifications as health interventions and their perceptions of clinical research. Using these themes, investigators can design trials and interventions that capitalize on certain cultural variables and avoid strategies that conflict with others. The identification of such cultural characteristics unique to African Americans may help to enhance the outcomes achieved by African Americans in clinical trials, improving the generalizability of results from behavior modification research. PMID: 15825976

Cook ED, Moody-Thomas S, Anderson KB, Campbell R, Hamilton SJ, Harrington JM, Lippman SM, Minasian LM, Paskett ED, Craine S, Arnold KB, Probstfield JL. (2005). Minority recruitment to the Selenium and Vitamin E Cancer Prevention Trial (SELECT). *Clin Trials*, 2(5), 436-42.

Abstract: BACKGROUND: Previous large chemoprevention studies have not recruited significant numbers of minorities. The Selenium and Vitamin E Cancer Prevention Trial (SELECT) is a large phase III study evaluating the impact of selenium and vitamin E on the clinical incidence of prostate cancer. Over 400 SELECT study sites in the USA, Canada, and Puerto Rico recruited men to this trial.

The SELECT recruitment goal was 24% minorities, with 20% black, 3% Hispanic, and 1% Asian participants. The goal for black participants was set at 20% because of their proportion in the United States population and their prevalence of prostate cancer. RESULTS: SELECT recruitment began in August 2001 and was intended to last five years, but concluded two years ahead of schedule in June 2004. Of the 35 534 participants enrolled, 21% were minorities, with 15% black, 5% Hispanic, and 1% Asian. CONCLUSIONS: Careful planning, recruitment of large numbers of clinical centers and adequate resources accomplished by the combined efforts of the National Cancer Institute (NCI), Southwest Oncology Group (SWOG), SELECT Recruitment and Adherence Committee (RAC), SELECT Minority and Medically Underserved Subcommittee (MMUS), and the local SELECT sites resulted in attainment of the estimated sample size ahead of schedule and recruitment of the largest percentage of black participants ever randomized to a cancer prevention trial. PMID: 16315648

Dwayne, T. B., Isaac, L. A., & LaVeist, T. A. (2005). The legacy of Tuskegee and trust in medical care: Is Tuskegee responsible for race differences in mistrust of medical care. *Journal of the National Medical Association*. 97(7), 951-956.

Abstract: Objectives: To examine race differences in knowledge of the Tuskegee study and the relationship between knowledge of the Tuskegee study and medical system mistrust. Methods: We conducted a telephone survey of 277 African-American and 101 white adults 18-93 years of age in Baltimore, MD. Participants responded to questions regarding mistrust of medical care, including a series of questions regarding the Tuskegee Study of Untreated Syphilis in the Negro Male (Tuskegee study). Results: Findings show no differences by race in knowledge of or about the Tuskegee study and that knowledge of the study was not a predictor of trust of medical care. However, we find significant race differences in medical care mistrust. Conclusions: Our results cast doubt on the proposition that the widely documented race difference in mistrust of medical care results from the Tuskegee study. Rather, race differences in mistrust likely stem from broader historical and personal experiences.

Lin JS, Finlay A, Tu A, Gany FM. (2005). Understanding immigrant Chinese Americans' participation in cancer screening and clinical trials. *J Community Health*, 30(6), 451-66.

Abstract: The purpose of this study was to identify potential barriers and facilitators to Chinese immigrant participation in cancer screening and clinical trials. A series of focus groups, in English, Cantonese, and Mandarin, were conducted with physicians, community leaders, and first generation members of the Manhattan Chinatown community. Participants were asked to discuss their beliefs about cancer, cancer screening, clinical trials, and cancer health education materials. Focus group data were stratified by respondent group and analyzed for thematic content. Eleven physicians, 15 community leaders, and 38 community members participated. Some community members were not familiar with cancer screening as a preventive measure and had not received common screens such

as PAP smears or mammograms. They described widespread misconceptions about cancer that act as screening deterrents, e.g. testing for cancer can cause cancer. Community members were unfamiliar with clinical trials and would not participate in a clinical trial unless "sick," and only on the recommendation of their physicians. Physicians did not see the relevance or value of clinical trials for their patients. Among first generation Chinese immigrants, there are many perceptual barriers to cancer screening and clinical trials recruitment. There is a need for effective culturally tailored health education on these health topics to address persistent misconceptions about cancer and to increase knowledge about cancer screening and clinical trials. Health education efforts and clinical trial recruitment in this community must involve community physicians. PMID: 16370055

Mason SE. (2005). Offering African Americans opportunities to participate in clinical trials research: how social workers can help. *Health Soc Work, 30(4)*, 296-304.

Abstract: Historically, African Americans have resisted participation in clinical trials and other research projects because of distrust of the mostly white research establishment. Although there are legitimate reasons for refusing to join clinical trials, most notably the abuses of the Tuskegee Syphilis Study, African Americans may be passing up opportunities to obtain needed medications years before they reach the market. This article analyzes 29 empirical articles from medical and mental health journals for their findings on recruiting and maintaining African Americans in clinical trials. Reasons for declining and accepting opportunities to participate are organized into themes that represent the salient findings of these reports. Suggestions for social work interventions and changes in research designs are intended to make the research process more welcoming to African Americans. Interventions are linked to the themes and incorporate social work ethics and values. The premise of this study is that African Americans should be offered realistic opportunities supported by sufficient resources to increase participation. PMID: 16323721

Warne, D. (2005). Genetics Research in American Indian Communities: socio cultural considerations and participatory research. *Jurimetrics J., 45*, 191-203.

Abstract: Genetics research has the potential to improve health care. American Indians (AIs) suffer from significant health disparities, including significantly higher incidence and prevalence of preventable diseases like diabetes, alcoholism, and their complications. Underfunding of health programs, including the Indian Health Service and lower socioeconomic status among AIs contribute to these disparities. Improvements in disease prevention and treatment potentially offered by genetics research could help to reduce health disparities. However, a history of nonparticipation in the research process and a history of dishonest research practices have raised barriers to conducting research in AI communities. A paradigm for research that includes the community as a full research partner may be necessary to promote research in AI communities and to translate genetics research into reductions in health disparities.

Bates, B. R., Harris T. M., (2004). The Tuskegee Study of Untreated Syphilis and public

perceptions of biomedical research: a focus group study. *J Nat'l Med Assoc.*, 96(8), 1051-64.

Abstract: Participate in biomedical research. Researchers often attribute nonparticipation to the "Tuskegee effect." Using critical qualitative analysis of focus group data, we examined the public's use of the Tuskegee Study of Untreated Syphilis (TSUS) to discuss biomedical research. Our participants articulated three primary themes in relation to TSUS: 1) that TSUS made them suspicious about biomedical research; 2) that other values had to weigh against concerns about TSUS; and 3) that African Americans could take steps to resolve their concerns about TSUS. African Americans were more likely to discuss TSUS than were European Americans. African Americans did not use TSUS to express simple fear. African Americans suggested issues other than TSUS that influence the decision to participate in research. African Americans indicated specific reforms that would increase participation in research. We discuss how a better understanding of African Americans' use of TSUS can enhance research participation and allay concerns about "another Tuskegee."

Hussain-Gambles M, Leese B, Atkin K, Brown J, Mason S, Tovey P. (2004). Involving South Asian patients in clinical trials. *Health Technol Assess*, 8(42), 1-109.

Abstract: OBJECTIVES: To investigate how South Asian patients conceptualise the notion of clinical trials and to identify key processes that impact on trial participation and the extent to which communication difficulties, perceptions of risk and attitudes to authority influence these decisions. Also to identify whether 'South Asian' patients are homogeneous in these issues, and which factors differ between different South Asian subgroups and finally how professionals regard the involvement of South Asian patients and their views on strategies to increase participation. CONCLUSIONS: Effective strategies for South Asian recruitment to clinical trials include: using multi-recruitment strategies; defining the demographic and social profiles of the population to be included; using focus groups to identify any potential barriers; consulting representative community members to provide assistance in the study; ensuring eligibility criteria are set as wide as possible; developing educational and recruitment approaches to attract ethnic minority health professionals; ensuring health professionals are adequately trained in culturally and ethnically orientated service provision; determining the most effective mass media to use in study promotion and recruitment; and targeting inner-city, single-handed practices likely to have high ethnic minority populations. Future research should consider: responses when invited to participate; the role of methodological and organisational barriers to recruitment; the complexities of recruitment from a health professional perspective; developing culturally sensitive research methods; the magnitude of the problem of under-recruitment; strategies to encourage inner-city, single-handed GP participation; and other factors affecting trial inclusion, such as age, gender, educational level and socio-cultural background. PMID: 15488164

Herring P, Montgomery S, Yancey AK, Williams D, Fraser G. (2004). Understanding the challenges in recruiting blacks to a longitudinal cohort study: the Adventist health study. *Ethn Dis.*, 14(3), 423-30.

Abstract: This paper presents findings from formative research exploring Black Seventh-day Adventist church members' attitudes about Black non-participation in past studies, and suggestions for recruiting 45,000 Blacks to an upcoming longitudinal cohort study. Data were collected in California and Pennsylvania, using 15 key informant interviews and 6 focus groups. Key findings supported and elucidated existing literature on the barriers to minority recruitment, and included: a general mistrust of the medical/scientific community; a perception that providing informed consent relinquishes, rather than protects, an individual's rights; a perception of being "studied" rather than "studying," due to the paucity of Black investigators; and a perceived lack of cultural sensitivity in the recruitment of Blacks, and in the conduct of the research itself. Building trust throughout the process, from clearly demonstrating the benefits of participation, at the individual and community level, to including Blacks in the study design from conceptualization to data analysis and presentation, emerged as a critical component in garnering Black participation in future studies. PMID: 15328945

Woods VD, Montgomery SB, Herring RP. (2004). Recruiting Black/African American men for research on prostate cancer prevention. *Cancer*, 100(5), 1017-25.

Abstract: BACKGROUND: Black/African American men die of prostate cancer at a greater rate relative to other males. During the period from 1992 to 1998, prostate cancer incidence rates in the United States were 234.2 per 100,000 persons among non-Hispanic black males and 144.6 per 100,000 persons among white males. The reasons for these increased rates of prostate cancer among black males are largely unknown, but increased mortality is associated with late detection. The authors conducted a longitudinal study of black men that investigated prostate cancer prevention behaviors within this population. The purpose of the current article is to identify successful recruitment strategies that were reported by participants in this study of prevention behaviors. METHODS: Qualitative research methods were used to elucidate men's thoughts, attitudes, beliefs, and practices regarding prostate cancer prevention behaviors and to identify strategies for attracting black men to research programs and retaining them in these programs. RESULTS: Ethnocentric recruitment strategies that were identified included the development of tailored printed materials; the use of targeted locations; and a personalized, participatory approach for engaging potential participants. We contacted 498 black men and enrolled a cohort of 277 non-Hispanic black males (75% of whom were recruited within a 9-week period) in the current study. CONCLUSIONS: Unlike other studies that reported difficulty in recruiting African American men, the current study did not encounter such difficulties. The authors attribute their success to culturally attractive Afrocentric materials; cultural sensitivity; a caring, professional, personalized ethnic approach; respect; and participatory involvement of the target population. Nonetheless, the authors did encounter barriers, such as lack of physician interest and lack of trust in quality medical care.

These barriers must be overcome before black males can be engaged and retained in research studies on prostate cancer prevention. PMID: 14983498

Harris KJ, Ahluwalia JS, Catley D, Okuyemi KS, Mayo MS, Resnicow K. (2003). Successful recruitment of minorities into clinical trials: The Kick It at Swope project. *Nicotine Tob Res.*, 5(4), 575-84.

Abstract: Ethnic minorities are often underrepresented in clinical trials, and their recruitment can challenge researchers. Developing and communicating effective and efficient recruitment strategies may help researchers enroll more minorities into research studies. Kick It at Swope was a double-blind, randomized trial that evaluated bupropion for smoking cessation among 600 adult African Americans who smoked 10 or more cigarettes a day. Proactive recruitment strategies (in-person appeals by study staff and health care providers) and reactive recruitment strategies (disseminating information that asked people to call a study hotline) were implemented sequentially in an additive fashion over 16 months. Resulting patterns of recruitment are described and the two phases are compared based on their relative effectiveness, efficiency, and cost. More enrollees were recruited in the reactive phase (n=534) than in the proactive phase (n=66). Those recruited in the reactive phase were more likely to be eligible (OR=4.8) and more likely to be enrolled (OR=4.2) than those recruited in the proactive phase. Participants recruited in the reactive phase reported significantly higher levels of education and income, better health, and significantly lower indicators of depression and life hassles, compared with those recruited in the proactive phase. The reactive recruitment phase was less expensive than the proactive recruitment phase (22 US Dollars/enrollee vs. 159 US Dollars/enrollee). Reactive recruitment strategies added to multiple proactive clinic-based recruitment strategies were more effective, more efficient, and less costly than proactive recruitment alone. Close monitoring combined with the use of multiple recruitment methods and flexible recruitment plans can lead to successful, efficient, and low-cost recruitment of minorities into clinical trials. PMID: 12959796

Story M, Sherwood NE, Obarzanek E, Beech BM, Baranowski JC, Thompson NS, Owens AS, Mitchell M, Rochon J. (2003). Recruitment of African-American pre-adolescent girls into an obesity prevention trial: the GEMS pilot studies. *Ethn Dis.* 13(1,S1), S78-87.

Abstract: OBJECTIVE: The objective of this report is to describe the methods used to recruit 8- to 10-year-old African-American girls into four 12-week randomized controlled pilot studies on obesity prevention. DESIGN: The Girls Health Enrichment Multi-site Study (GEMS) involved 4 field centers which independently developed and tested interventions designed to prevent excess weight gain in African-American girls. Each field center developed its own recruitment plan, but used a standardized recruitment reporting form. The goal was to recruit 40-60 girls, depending on the center. MEASURES: Recruitment yields were computed at each site. Socio-demographic data and weight status were collected for 210 African-American girls who were randomized into the

study, as well as for their parents/caregivers. Data were collected on the sources from which participants heard about the study, and the reasons for their interest in the project. RESULTS: The 4 field centers used multiple, but different, recruitment strategies. The most commonly used approaches were mailings, flyers, radio announcements, and group presentations. Caregivers were most likely to hear about the program from the radio (29%), a flyer from the school (23%), or from their child (18%). Among caregivers, the most common reasons for participating were: interest in health (56%), interest in diet/health (51%), and believing the program would be fun for their child (46%). The most frequent reason given by girls was that the program sounded like fun (70%). Three of the 4 field centers met their recruitment target goals. CONCLUSIONS: The GEMS experience demonstrates the feasibility of recruiting and enrolling African-American girls in short-term intervention studies of behavior change. The multiple recruitment strategies, which included developing trusting relationships in the respective communities, were considered critical to the success of recruitment. PMID: 12713213

Fulton P, Tierney J, Mirpourian N, Ericsson JM, Wright JT Jr, Powel LL. (2002). Engaging black older adults and caregivers in urban communities in health research. *J Gerontol Nurs.*, 28(2), 19-27.

Abstract: The under-representation of the Black population in research may lead to poor health outcomes for them and a decreased capacity to generalize results to Black populations. This article describes ways in which sensitivity to cultural distinctions of Black older adults and their current or future caregivers can enhance their recruitment and retention in research. Cultural mores play an important role in the shaping of one's perceptions, definitions, responses to disease, and participation in health regimens. Similarly, one's cultural orientation plays a role in how a person is effectively recruited and retained in research. Wenger's translation process model uses cultural meaning to inform research decisions. This model was used in a recent study of Black older adults and their caregivers and will be described in this article. Effectively engaging Black individuals in health research is essential for improving their health. PMID: 11846287

Shavers VL, Lynch CF, Burmeister LF. (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Ann Epidemiol.*, 12(4), 248-56.

Abstract: PURPOSE: The relative absence of racial/ethnic minorities among medical research subjects is receiving considerable attention because of recent government mandates for their inclusion in all human subject research. We examined racial differences in the prevalence of sociocultural barriers as a possible explanation for the underrepresentation of African Americans in medical research studies. METHODS: During 1998-1999, a total of 198 residents of the Detroit Primary Metropolitan Statistical Area (PMSA) participated in a survey that examined impediments to participation in medical research studies. Chi square tests and logistic regression analyses were used to examine the association between race, issues related to trust of medical researchers, and the willingness to participate in medical research studies. RESULTS: Study results indicate that

African Americans and whites differ in their willingness to participate in medical research. Racial differences in the willingness to participate in a medical research are primarily due to the lower level of trust of medical research among African Americans. African American respondents were also somewhat less willing to participate if they attribute high importance to the race of the doctor when seeking routine medical care, believed that minorities bear most of the risks of medical research, and if their knowledge of the Tuskegee Study resulted in less trust in medical researchers. CONCLUSION: These data reiterate the need for medical researchers to build trusting relationships with minority communities. Researchers can begin by acknowledging the previous medical abuse of minority research participants, discussing their specific plans to assure the protection of study participants, and explaining the need for the participation of racial/ethnic minorities including studies that specifically target or that are likely to result in disproportionate representation of racial/ethnic minorities among study participants. PMID: 11988413

Baker S. (2001). Black populations, human immunodeficiency virus/acquired immune deficiency syndrome, and research: implications for nurses. *Appl Nurs Res.*, 14(2), 94-9.

Abstract: Knowledge that is generated from research is critical toward understanding the prevention, impact, and treatment of human immunodeficiency virus (HIV) disease and acquired immune deficiency syndrome (AIDS). During the past several decades, the Black community has been disproportionately affected by the HIV/AIDS epidemic. Therefore, engaging their participation in HIV/AIDS research is necessary to understand the disease further and to develop strategies for nursing interventions. Many factors hinder Blacks from participating in HIV/AIDS research. This review provides information for nurses about problems related to recruitment and recommendations for recruiting Black participants for HIV/AIDS research. Copyright 2001 by W.B. Saunders Company. PMID: 11319705

Fouad MN, Partridge E, Wynn T, Green BL, Kohler C, Nagy S. (2001). Statewide Tuskegee Alliance for clinical trials. A community coalition to enhance minority participation in medical research. *Cancer*, 91(1 Suppl), 237-41.

Abstract: BACKGROUND: Cancer mortality rates for all sites are nearly 2.5 times greater for African-Americans compared with whites. In addition, there are data implying that cancer treatment outcomes for minorities are unfavorable compared with whites. Whether this is due to poor access to health care or a biologic property of malignancies occurring in specific populations remains to be determined. Because of these unknown factors, targeting minorities for clinical trials may contribute toward the reduction of the overall morbidity and mortality associated with specific cancers. CONCLUSIONS: The planning, development, and implementation of this conference provided a valuable experience for researchers and community members. It was discovered that community involvement in the early phase of this project contributed to its success. Furthermore, the partnership that developed between researchers (academic institutions) and communities

successfully provided an infrastructure that supported the interest of both groups. Copyright 2001 American Cancer Society. PMID: 11148586

Shavers VL, Lynch CF, Burmeister LF. (2001). Factors that influence African-Americans' willingness to participate in medical research studies. *Cancer*, 91(1 Suppl), 233-6.

Abstract: BACKGROUND: The underrepresentation of African-Americans among medical research participants is receiving considerable attention because of recent government mandates for the inclusion of all racial/ethnic groups in human subject research. Therefore, there is a need to determine factors that influence minority enrollment in medical research studies. METHODS: Between 1998-1999, 91 African-American residents of the Detroit Primary Metropolitan Statistical Area participated in a mail and telephone survey designed to examine impediments to participation in medical research studies. Chi-square tests and multiple logistic regression analyses were used to examine the association between race, issues related to trust in medical researchers, and the willingness to participate in medical research studies. RESULTS: African-American respondents were somewhat less willing to participate if they attributed high importance to the race of the physician when seeking routine medical care, believed that minorities or the poor bear most of the risks of medical research, and, most especially, their knowledge of the Tuskegee Study resulted in less trust in medical researchers. CONCLUSIONS: These data reiterate the need for medical researchers to build trusting relations with African-Americans and to conduct research in an ethical manner. This includes maximizing benefits, reducing risks, and assuring distributive justice to all medical research study participants. Copyright 2001 American Cancer Society. PMID: 11148585

Katz, R. (2000). Willingness to participate in biomedical research African-Americans vs. Whites. *Annals of Epidemiology* 10(7), 456-457.

Abstract: Purpose: The overall goals of this study were: 1) to determine whether (and if so, the extent to which) African-Americans differed in their willingness to participate in biomedical studies as compared to non-Hispanic Whites, and 2) to determine the influence that a range of demographic, psycho-social and medico-historical variables had on the comparative willingness of these groups to participate in biomedical research. This report will present preliminary findings on the first goal. Conclusions: The findings from this study show that African-Americans self-reported a lower willingness to participate in biomedical studies than did non-Hispanic Whites, and that African-American subjects were more influenced by the factor of 'who' was running the study than by the factor of 'what' they might have to do as study subjects. Study supported by grant P 50 DE10592 from the NIDCR at NIH.

Outlaw F. H., Bourjolly, J. N., Barg, F. K. (2000). A study on recruitment of Black Americans into clinical trials through a cultural competence lens. *Cancer Nursing*, 23(6), 444-453.

Summary: The authors relate findings on a study assessing major barriers experienced by clinicians in a cancer center, which hinder inclusion of minorities in clinical trials with findings from a comprehensive literature review on articles reporting the different barriers to enrolling minority populations in clinical trials. The study findings showed that the major barriers that hinder clinicians from recruiting minority populations include: the complexity of research, trouble seeing the value of research, fear of the health care system, and mistrust of research due to adversities experienced in the past by minority populations who participated in research (e.g., the Tuskegee research experience). These findings were consistent with findings from the comprehensive literature review conducted by the authors of the article. They further suggest identification of a core curriculum for health care providers aimed at enhancing cognitive and effective skills needed to communicate effectively across racial/ethnic, cultural, and socioeconomic differences. This was a first phase study and investigators plan for a second phase study, which would involve assessing barriers to recruitment of minority populations in research from the perspective of the community where the cancer center is located.

Corbie-Smith, G., Thomas, S. B., Williams, M. V., & Moody-Ayers, S. (1999). Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med, 14(9), 537-546*

Abstract: Objectives: To describe barriers to participation of African Americans in research. Design: Focus group interviews conducted in 1997. Patients: Thirty-three African-American adults presenting to an urban public hospital for outpatient medical care participated in one of five focus groups. Measurements and Main Results: African-American patients' attitudes toward medical research were measured. Mistrust of doctors, scientists, and the government was reported consistently by the participants. Many participants described concerns about the ethical conduct of clinicians and investigators when poor or minority patients are involved and cited examples of exploitation as supporting evidence for their mistrust of the medical establishment. While participants were clear about the violation of human rights in the Tuskegee Syphilis Study, all were misinformed of the historical facts of the study. Few participants understood the concept of informed consent. Participants saw signing the document as relinquishing their autonomy and as a legal protection for physicians. Despite these concerns, participants gave recommendations to improve minority participation in research. Conclusions: African-American participants in this study described distrust of the medical community as a prominent barrier to participation in clinical research. Participants described real and perceived examples of exploitation to support their distrust of researchers. The goal of the consent process, to inform patients of risks and benefits so as to facilitate self-determination, was misinterpreted by these participants. Understanding the importance of interpersonal trust within the clinical relationship may prove to be a significant factor in enhancing participation in clinical trials.

Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC. (1997). Why are African Americans under-represented in medical research studies? Impediments to participation. *Ethn Health*, 2(1-2), 31-45.

Abstract: OBJECTIVES: In accordance with the NIH Revitalization Act of 1993, the National Institutes of Health and the Alcohol, Drug and Mental Health Administration require grant applicants and cooperative agreement participants to include minorities in human subject research. In an environment characterized by diminishing research dollars, this mandate has increased the pressure on investigators to determine factors that impede minority participation and to develop strategies to overcome these impediments. METHODS: An extensive review of the literature was conducted to identify the factors possibly responsible for the low participation levels of African Americans in medical research studies and to highlight areas for further research. The items examined included the historical relationship between African Americans and medical researchers and the attitudes, perceptions and beliefs of potential participants and researchers as they relate to the low representation of African Americans in medical research. RESULTS: The factors identified as possible impediments to African American participation included distrust of the medical/scientific community, poor access to primary medical care, the failure of researchers to recruit African Americans actively, the alienation of minority health professionals, lack of knowledge about clinical trials, language and cultural barriers. CONCLUSIONS: Well-designed, relevant, ethical research in conjunction with an appreciation of the many barriers to participation are paramount to increasing African American presence in clinical research. PMID: 9395587

Frayne, S. M., Burns, R. B., Hardt, E. J., Rosen, A. K., Moskowitz, M. A. (1996). The exclusion of non-English speaking persons from research. *Journal of General Internal Medicine*, (11), 39-43.

Abstract: Objective: We sought to determine how often non-English-speaking (NES) persons are excluded from medical research. Design: Self-administered survey. Participants: A Medline search identified all original investigations on provider-patient relations published in major U.S. journals from 1989 through 1991, whose methodologies involved direct interaction between researcher and subject (N = 216). Each study's corresponding author was surveyed; 81% responded. Measurements and Main Results: Of the 172 respondents, 22% included NES persons; among these includes, 16% had not considered the issue during the study design process, and 32% thought including the NES had affected their study results. Among the 40% who excluded the NES (excluders), the most common reason was not having thought of the issue (51%), followed by translation issues and recruitment of bilingual staff. The remaining 35% (others) indicated that there were no NES persons in their study areas. Conclusions: NES persons are commonly excluded from provider-patient communication studies appearing in influential journals, potentially limiting the generalizability of study findings. Because they are often excluded through oversight, heightened awareness among researchers and granting institutions, along with the development of

valid instruments in varied languages, may increase representation of non-English-speaking subjects in research.

DELIVERY OF HEALTH CARE TO MINORITY POPULATIONS

The articles in this section focus on cultural competence and provision of health care to minority and culturally diverse populations. Although these articles are not all-encompassing, references identified that link to cultural competence in research are included.

Cook C.T., Kosoko-Lasaki, O., & O'Brien, R., (2005). Satisfaction with and perceived cultural competency of healthcare providers: The minority experience. *Journal of the National Medical Association*. 97(8), 1078-1087.

Abstract: It is well known that nonwhite minority participation in clinical research is lower than their representation in the community. The goal of this study was to assess satisfaction of minority community members in Omaha with the care received and cultural competency of healthcare providers. We sought input from Omaha minority communities on how to improve the care they received and asked why they did not participate in healthcare research. Seventy-two minority members representing African Americans, Hispanic Americans, Native Americans, Sudanese, and Vietnamese; and eight whites were surveyed. The results of this study indicated that the majority of our respondents were satisfied with the care they received, but for a small percentage, language, communication and/or culture contributed to dissatisfaction. In addition, some respondents did not think the provider was culturally competent, i.e., not sufficiently knowledgeable about their racial, ethnic and/or cultural background. Some participants indicated that they preferred a provider of similar racial, ethnic and/or cultural background, and/or thought some diseases were better treated by a provider of the same racial, ethnic and/or cultural background. Regardless of the cultural competency of the provider, the overwhelming majority of our respondents (with the exception of African Americans) indicated a willingness to participate in healthcare research. In conclusion, this study found that satisfaction with healthcare providers was not associated with perceived cultural competency and that the cultural competency of the provider did not affect patient willingness to participate in healthcare research; however, we acknowledge that the Hawthorne effect may be in operation.

Betancourt, J., Green, A. R., Carillo, J. E., & Park, E. R. (2005). Cultural competence and health care disparities: Key perspectives and trends. *Health Affairs*, 24(2), 499-505.

Summary: In order to indentify key perspectives and trends in cultural competence, the authors conducted interviews with experts in cultural competence from managed care, government, and academe. Among the findings from experts are that cultural competence is one step toward eliminating disparities, the need for outcomes research on cultural competence interventions, and

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cultural competence training to help reduce disparities. The authors further note how cultural competence appears to have caught the attention of federal policy makers as part of an effort to eliminate racial/ethnic disparities. Specifically, the authors note the recent trends in government interest in cultural competence including research and education in cultural competence funded by the Agency for Healthcare Research and Quality (AHRQ) and the National Institute of Health (NIH).

Snowden, L. R. (2003). Toward a culturally competent evaluation in health and mental health. *Multicultural Health Evaluation*.

Summary: This article outlines four main dimensions for assessing culturally competent treatment and care: (1) overcoming misunderstanding and miscommunication, promoting therapeutic alliances, (2) bridging divergent conceptions of health and illness, (3) understanding culturally sanctioned coping styles, and (4) recognizing the role of cultural groups, organizations and communities. In addition, the author indicates examples of available culturally responsive evaluation methods that evaluators may use in order to address research questions related to cultural sensitivity in program design and implementation.

WEB RESOURCES

This section provides links to resources on cultural competence in research and includes additional references, publications and training programs. The sources of these resources range from government institutions, to non-profit organizations, academic institutions, and private foundations. While most of the resources are available for public access, there are access restrictions (e.g., registration, membership) to some of these resources.

INSTITUTIONS/ORGANIZATIONS: GENERAL

Center for International Rehabilitation Research Information and Exchange

Summary: This site provides cultural competency resources, including past training and outreach programs as well as new initiatives. CIRRIE facilitates the sharing of information and expertise in rehabilitation research between the U.S. and other countries through a wide range of programs.

Website: <http://cirrie.buffalo.edu/cdresources.php>

The Joint Commission: Hospitals, Language and Culture

Summary: The Joint Commission provides links and resources regarding cultural competence in research and health care, in the context of patient safety.

Website:

[http://www.jointcommission.org/PatientSafety/HLC/HLC Resources and Links.htm](http://www.jointcommission.org/PatientSafety/HLC/HLC_Resources_and_Links.htm)

London Deanery: Cultural Competence Research

Summary: This site provides a worldwide perspective of cultural competence research. In addition to gaining an understanding of the current provision of cultural competence within London Deanery Trusts, best practice cultural competence research was also undertaken both in the U.K. and worldwide. The research aim was to identify and engage leading training providers and thought leaders. This resource provides findings on a study on cultural competence in both the U.K. and U.S.

Website: <http://www.londondeanery.ac.uk/var/equality-diversity/cultural-competence/cultural-competence-research>

INSTITUTIONS/ORGANIZATIONS: ACADEMIC

Center for Research on Ethnicity, Culture, and Health

Summary: The Center for Research on Ethnicity, Culture, and Health (CRECH) was established in 1998 at the University of Michigan School of Public Health (UMSPH). CRECH develops new approaches to research and research training relevant to the description and understanding of racial and ethnic health disparities.

Website: <http://www.crech-test.org/>

National Center for Cultural Competence

Summary: Based at the Georgetown University Center for Child and Human Development, the National Center for Cultural Competence through research, publications, and creation of tools provides national leadership and contributes to knowledge regarding cultural and linguistic competency within systems and organizations.

Website: <http://www11.georgetown.edu/research/gucchd/nccc>

The Cultural Competency Training Center of Central New Jersey

Summary: The Multicultural Family Institute of Highland Park NJ and the Office of Prevention Services and Research (OPSR) of University Behavioral HealthCare, University of Medicine and Dentistry of New Jersey have developed the Cultural Competence Training Center (CCTC) through the support of a NJ State-funded Division of Mental Health Services, Office of Multicultural Affairs contract. The aim of the CCTC is to provide training and technical assistance to agencies in central New Jersey. The Cultural Competence Training Center melds the expertise and resources of the Multicultural Family Institute (MFI) and the Office of Prevention Services and Research (OPSR).

Website: <http://www.cctcnj.org/>

University of Michigan Program for Multicultural Health

Summary: The Program for Multicultural Health was created in 1993. This program has a Cultural Competency Division that aims to improve accessibility, utilization, and the quality of care received by the diverse patient population. The Cultural Competency Division plays a vital role in implementing cultural competency in the University of Michigan Health System (UMHS) and in promoting good community health care practices. In addition, the program provides cultural competency training using audiovisual materials, clinical unit consultations, customized classes and workshops, educational seminars, and lecture series.

Website: <http://www.med.umich.edu/Multicultural/ccp/index.htm>

INSTITUTIONS/ORGANIZATIONS: GOVERNMENT

Office of Minority Health, US Department of Health and Human Services.

Summary: The U.S. Department of Health and Human Services Office of Minority Health aims to improve the health of minority populations and reducing health disparities experienced by these populations. In particular, this website has a cultural competency section that mainly focuses on issues concerning health care service provision to minority populations (e.g., the National Standards on Culturally and Linguistically Appropriate Services aimed at guiding health care provision to minority populations.).

Website: <http://www.omhrc.gov/> ; <http://minorityhealth.hhs.gov>

Cultural Competency CME Portal

<https://www.thinkculturalhealth.hhs.gov>

Health Literacy and Cultural Competency, Research Findings

<http://www.ahrq.gov/browse/hlitra.htm#Cultural>

Links for a comprehensive view of cultural competency

<http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=1&lvlID=3>

Health Resources and Service Administration, U.S Department of Health and Human Services

Summary: The Health Resources and Service Administration (HRSA) provide links to various resources on cultural competence including assessment tools, trainings, publications and services administration.

Website: <http://www.hrsa.gov/culturalcompetence/>

United States National Library of Health-Specialized Information Services, National Institutes of Health

Summary: The Specialized Information Services (SIS) Division of the National Library of Medicine (NLM) is responsible for information on resources and services in toxicology, environmental health, chemistry, HIV/AIDS, and specialized topics in minority health. Regarding cultural competence, SIS has a significant number of categorically grouped multicultural resources for health information.

Website: <http://sis.nlm.nih.gov/>

Clear Communication: A National Institutes of Health (NIH) Health Literacy Initiative

Summary: This site provides information on cultural competency including its definition, frequently asked questions, and links to web resources.

Website: <http://www.nih.gov/clearcommunication/culturalcompetency.htm>

Office of Women's Health, U.S Department of Human and Health Services

Summary: Besides serving as a federal government source for women's health information, this site also provides links to publications on cultural competence.

Website: <http://www.womenshealth.gov/health-professionals/cultural-competence/cultural-responsiveness.cfm>

PRIVATE FOUNDATIONS

American Institute for Research

Summary: The American Institute for Research (AIR) is the largest behavioral and social science research organization in the world. AIR was founded as a non-profit organization in 1946. This website provides general information on cultural competence including its definition, and how it is integrated into education.

Website: <http://cecp.air.org/cultural/default.htm>

Agency for Healthcare Research and Quality (AHRQ)

Summary: The Agency for Healthcare Research and Quality (AHRQ) and the Office of Minority Health (OMH) provide public access to a key report examining how cultural competence impacts health care. In this report, the authors explore the agenda for implementing cultural competence research and developing culturally competent interventions. The general AHRQ website has numerous resources on cultural competence for health care provision to minority populations. It also provides links to a number of assessment tools for cultural competence.

Websites: <http://www.ahrq.gov/research/cultural.htm>; General Site: <http://www.ahrq.gov>

Association of American Medical Colleges (AAMC)

Summary: In 2000, Association of American Medical Colleges (AAMC) developed the Tool for Assessing Cultural Competence Training (TACCT). TACCT is a self-assessment tool that was designed to enable medical schools to introduce cultural competence education in the undergraduate curriculum.

Website: <http://www.aamc.org/meded/tacct/start.htm>

The California Endowment

Summary: The California Endowment is a private statewide foundation. The foundation's site has publications and training materials on multicultural and culturally competent evaluations. This site also has a well developed annotated bibliography on multicultural health evaluation.

Website: <http://www.calendow.org>

Collaborative Institutional Training Initiative (CITI)

Summary: The Collaborative Institutional Training Initiative (CITI) was founded in March 2000 as collaboration between the University of Miami and the Fred Hutchinson Cancer Research Center to develop a web-based training program in human research subjects' protection. Available training modules related to cultural competence include: (1) Research with protected populations/vulnerable subjects, (2) Research involving minors, (3) Research with culturally or medically vulnerable groups, and (4) Group Harms: Research with culturally or medically vulnerable groups. It also has an international section for non-U.S. investigators collaborating on U.S. research-funded projects outside the U.S. This site has training modules translated in Chinese, French, Portuguese and Spanish.

Website: <http://www.citiprogram.org/>

The Cross Cultural Health Care Program

Summary: Founded in 1992, the Cross Cultural Health Care Program (CCHCP)'s work focuses on ensuring underserved communities' full access to quality health care that is culturally and linguistically appropriate through cultural competency trainings, research and provision of resources on cultural competency.

Website: <http://www.xculture.org/about.php>

The Cultural Competence Training Center of New Jersey

Summary: The Cultural Competence Training Center (CCTC) was developed by the Multicultural Family Institute of Highland Park New Jersey, and the Office of Prevention Services and Research of University Behavioral HealthCare, and University of Medicine and Dentistry of New Jersey through the support of a New Jersey State funded Division of Mental Health Services- Office of Multicultural

Affairs contract. The aim of the CCTC is to provide training and technical assistance to agencies in central New Jersey. Additionally, this site provides links to resources, publications and films on cultural competence.

Website: <http://www.cctcnj.org/>

Educational Network to Enhance Cancer Clinical Trials (ENACCT)

Summary: Educational Network to Enhance Cancer Clinical Trials (ENACCT) was founded in 2004 with support from the Lance Armstrong Foundation. ENACCT offers two interrelated cultural competency training programs with the purpose of improving recruitment, consent and accrual processes, for cancer clinical trials, especially among ethnic and racial minorities.

Website: <http://www.enacct.org/training-programs/clinical-trial-teams-training-program>

EthnoMed

Summary: This website was developed and is hosted by Harborview Medical Center, one of the hospitals affiliated with the University of Washington. The EthnoMed site contains information about cultural beliefs, medical issues and other related issues pertinent to the health care of recent immigrants to Seattle or the U.S., many of whom are refugees fleeing war-torn parts of the world.

Website: <http://ethnomed.org/>

Multiethnic Advocates for Cultural Competence

Summary: The Multiethnic Advocates for Cultural Competence recognizes the ongoing need for research and multidisciplinary learning opportunities in the area of cultural and linguistic competence. This organization recognizes a need for a committed group of individuals to investigate, analyze, and publish original research to assist agencies and systems in better understanding and accomplishing their work.

Publication: Statewide Cultural Competence "Learning Your Needs" Assessment Supplemental Report 2008: The Multiethnic Advocates for Cultural Competence updated a statewide 2006 Cultural Competence Needs Assessment previously conducted for the Ohio Department of Mental Health, thus producing the Cultural Competence Needs Assessment Report 2008 featuring new mental health information on the Somali community.

Website: <http://www.maccinc.net/>

National Multicultural Institute

Summary: Established in 1993, the National Multicultural Institute (NMCI) is a private non-profit organization. The mission of NMCI is to work with individuals, organizations, and communities to facilitate personal and systemic change in order to build an inclusive society that is strengthened and empowered by its diversity.

Website: <http://www.nmci.org/>

Unite for Sight: Cultural Competence Training Course

Summary: Cultural competence training and cultural awareness is of paramount importance for those working in any international or clinical setting. All Unite For Sight Global Impact Fellows are required to complete this Cultural Competency Online Course. This course is freely and publicly available.

Website: <http://www.uniteforsight.org/cultural-competency/>

CONCLUSION

As the diversity of populations studied in research increases, there is a growing appreciation that researchers should have a basic awareness or perhaps a deeper understanding of the role that

race/ethnicity or culture may play in their research. Hence, there is a growing need for researchers to consider how differences in culture can impact the conduct and interpretation of their research and perhaps equip themselves with skills to enhance their interaction and communication with diverse study subjects or populations. Cultural competence is critical for researchers to achieve these desired skills.

Although there appears to be limited resources and literature available on cultural competence for researchers, institutions including federal/state governments are becoming more aware of the importance of this issue. The US health care system is currently moving towards provision of culturally competent health interventions. However, these interventions can only be appropriately implemented with the contribution of research that has been developed and interpreted within the context of a diverse population. It is anticipated that this resource will make a meaningful contribution to researchers in this endeavor and build a solid foundation to advance cultural competence in research.

APPENDICES

APPENDIX A

Search Keywords:

Search keyword 1: Cultural, trans-cultural, culture or multi-cultural.

Search keyword 2: Competency, competence, diversity, responsiveness, cultural, cultural safety, appropriateness, humility, knowledge, dynamics, diversity, attitudes, or differences.

Search keyword 3: Researchers, research, evaluation, or assessment.

Search criteria

Criteria	A	B	C	D
Search keywords	1, 2 & 3	1 & 2	1 & 3	2 & 3

Search Engines: Medline, Pub Med, Google Scholar, Google, Hollis, Social and Science journals