

RESHAPING RESEARCH

A Guide to Enhancing Cultural Considerations into Research

Module 4: Recruitment and Retention



Case Center for Reducing Health Disparities

ABOUT THE CENTER

About the Center

In January 2004, the Center for Reducing Health Disparities was created by Case Western Reserve University and the MetroHealth System. In 2007, the Center received a P60 grant from the National Institutes of Health, which allowed the Center to pursue new projects related to hypertension, kidney disease, and organ donation. The Center also links students to mentors who have interests in health disparities to foster awareness of and interest in the issues of health equity in Cleveland.

The Center helps to direct the Community Research Partnership Core of the Clinical and Translational Science Collaborative involving Case Western Reserve University, MetroHealth Medical Center, University Hospitals of Cleveland, the Cleveland Clinic, and the Louis Stokes Cleveland VA Medical Center. The aim of this Core is to facilitate community based research among faculty, students, community organizations, and community residents. The Center is under the direction of Ashwini Sehgal, MD and J. Daryl Thornton, MD, MPH.

MISSION STATEMENT

To reduce health disparities through (a) research on root causes, mechanisms, and interventions, (b) education of students, providers, and policy makers, and (c) partnership with community organizations and government agencies.

LONG-TERM GOALS

- To create a durable academic-community partnership to develop innovative interventions that achieve measurable reductions in health disparities in the greater Cleveland area.
- To promote successful intervention strategies that can be replicated in other regions.
- To train a new generation of health activists committed to eliminating health disparities

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PREFACE

There have been significant demographic shifts in the United States in recent years. The U.S. Census projects that by 2060, minorities, now 37 percent of the U.S. population, will comprise 57 percent of the population.¹ The widening racially, ethnically, and culturally diverse population in the United States present unique challenges to human service practitioners and organizations.² Cultural competence has been defined in the context of health care delivery and providers, specifically focusing on the provider-patient interaction. It has also captured the attention of health care policymakers, providers, insurers, and educators as a possible strategy to improve quality and eliminate racial and ethnic disparities in health care.³ The executive summary of the national standards for culturally and linguistically appropriate services in health care states that cultural competency training should be integrated into health professions education and training at all levels, including academic and functional.⁴

While cultural competency education for clinicians is becoming widespread, little is being done to provide cultural competency education for clinical researchers. A lack of cultural competence on the part of researchers may hinder their ability to engage certain communities, such as minority or non-English speaking individuals, and may lead researchers to unknowingly impose their beliefs, values, and patterns of behavior upon those from other cultural backgrounds.⁵ A recent survey of clinical researchers found that they wanted to learn more about the needs and perspectives of different groups.⁶ In response to these needs, the Case Center for Reducing Health Disparities has developed this guide to fill gaps in cultural competency education training for researchers.

Research in the health sciences (i.e. biomedical, clinical, health services, and community-based participatory research) has only recently begun to explore the importance and linkages between culture and research design, analysis and interpretation.⁷ There is a growing need to develop and implement research studies that are culturally relevant to the needs of various groups. It appears that there are substantial participant barriers to research among minority populations, which have negatively impacted enrollment and retention rates of minorities in research studies.⁸ In addition, there are researcher, structural and organizational barriers that contribute to low recruitment and retention of minority groups.⁹ In order to address these barriers and to engage, recruit, and retain certain demographic populations, cultural considerations need to be integrated into the research process. Starting with the planning stages of the research study, researchers must ask whether they are using the appropriate constructs, measures, and

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methodology in relation to their target population. This enables researchers to move beyond between-group comparisons and examine within-group competence. This requires a dual commitment, which includes respecting and honoring cultural values, beliefs, and needs, without sacrificing scientific rigor.¹⁰ This guide is designed to assist researchers in their efforts to conduct quality research in a culturally appropriate manner.

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LEARNING ICONS

Learning Icons

Cultural competence begins with awareness, grows with knowledge, enhances with specific skills, and is polished through cross-cultural encounters. There will be a review at the end of the guide, which will be based on the following concepts:

<p>Awareness</p> 	<p>This section will encourage you to assess your personal awareness of the information and how it relates to your role as a researcher.</p>
<p>Knowledge</p> 	<p>Knowledge is obtained through continuing education and cross cultural encounters as it relates to conducting research. This section will include a brief summary of important key concepts.</p>
<p>Skill</p> 	<p>Skill building includes the ability to apply knowledge learned in a way that is culturally appropriate. This section will focus on how you can integrate the information within this guide into your current research efforts using a culturally sensitive approach.</p>

Pesquera, M., Yoder, L. & Lynk, M. (2008) Improving cross-cultural awareness and skills to reduce health disparities in cancer. *MEDSURG Nursing*, 17 (2), 114-120.

Overview

This is not an all-inclusive resource for researchers. This is designed to help researchers begin the process of learning more about the cultural background and considerations of the individuals, groups and populations they encounter, and how these factors impact how research is conducted.

The primary purposes of this guide are to:

- ✓ Assist researchers with increasing knowledge, skill, and confidence in working with diverse populations.
- ✓ Guide researchers in the process of integrating cultural considerations into the research process.
- ✓ Increase awareness and sensitivity during the process of developing research studies and engaging with diverse populations.

MODULE 4: RECRUITMENT & RETENTION

Module 4: Recruitment & Retention

UPON COMPLETION OF THIS MODULE, YOU SHOULD BE ABLE TO:

- Recognize the barriers that affect minority recruitment.
- Identify culturally appropriate methods to recruit and retain research participants.

INTRODUCTION

The NIH Revitalization Act of 1993 authorized that minorities and women be appropriately represented in clinical trials. However, minorities continue to have lower enrollment rates in research when compared to non-minority groups.^{1,2} The adoption of successful recruitment and retention strategies is important throughout the entire research process, especially in relation to data collection and analysis.⁶ Increased proportions of minorities in all studies may allow sufficient sample size for ethnicity specific analyses and data presentation. Subgroup specific data is needed when ethnicity can modify the outcome. This data is also useful to strongly document that the results are applicable to diverse groups.^{6,7} In addition to compromising generalizability, lack of inclusiveness may overestimate effects by creating a best case scenario. In prevention research studies, a lack of inclusiveness may actually underestimate effects because more advantaged participants may have a diminished capacity to benefit from preventive interventions.^{6,8}

It is important to offer community members fair and equitable opportunities to participate in research. Recruitment of participants from underserved and underrepresented minority groups remains one of the greatest challenges in conducting research.^{1,3,5} Corbie-Smith et al. (1999) found that African American responses to a question about what comes to mind with the term medical research included the following: being lied to, corruption, deception, negligence, using people, sacrifice, cruelty, and being a guinea pig.³ Multiple factors such as culture, gender, age, socioeconomic status, and trust may affect whether people are invited or choose to participate in research. Even though the National Institutes of Health has guidelines for inclusion of minorities, researchers continue to have difficulty in enrolling minority populations.⁴ Recruiting and retaining participants for participation in research has proved to be a challenging task. Attitudes toward research, the researcher, and beliefs about the benefits and risks of involvement in research remain critical factors to be explored.^{3,5}

MODULE 4: RECRUITMENT & RETENTION

Participant Recruitment

Recruitment is the dialogue which takes place between an investigator and a potential participant prior to the initiation of the consent process. It begins with identifying, targeting and enrolling participants for a research study. It involves providing information to the potential participants and generating their interest in the research study. There are two main goals of recruitment: 1) to recruit a sample that adequately represents the target population 2) to recruit sufficient participants to meet the sample size and power requirements of the study.⁷ The existence of poor relationships between minority populations and the medical research communities is well-known. This history is often symbolized by the Tuskegee Study of Untreated Syphilis in the Negro Male study. From 1932 to 1972, the U.S. Public Health Service conducted a study involving 600 African American men. Of the 600 participants, 399 had syphilis and 201 did not have syphilis. Most of these men were poor sharecroppers and were not informed that they had syphilis. When penicillin became the standard of care, the men were prevented from receiving treatment, so that researchers could learn longitudinally more about the effects of the disease over time.^{9,13}

Harm from research studies is not limited to adverse effects to individuals from clinical studies. Harm may also result from research that reinforces negative stereotypes of communities and further stigmatizes poor and/or minority communities.^{9,14} Studies have examined the influence of the Tuskegee Syphilis Study on public attitudes toward research participation, particularly among African Americans. For many African Americans, the Tuskegee study became a symbol of their mistreatment by the medical system, a metaphor for deceit, conspiracy, malpractice, and neglect, if not outright racial.³ However, the distrust caused by the Tuskegee study or similar historical events may be only one of a host of determinants of recruitment and retention of minority participants.⁶ Therefore, it is important that researchers actively engage with communities in order to build trust, dispel myths, breakdown barriers, and establish and maintain meaningful relationships.

Several barriers specific to minority recruitment have been identified. Barriers at the institutional level include provider time constraints and competing service demands. Barriers at the individual level include distrust of research, mistrustful attitudes based on personal experiences with staff and physicians at local institutions, problems with health and research literacy, and transportation issues.^{3,5} Researcher barriers include cultural differences, lack of knowledge, and bias against research leading to inactive recruitment. Despite ethical standards that would prohibit such actions, researchers may limit minority participation in research studies, particularly clinical trials, because of their beliefs that there is greater difficulty in

MODULE 4: RECRUITMENT & RETENTION

obtaining compliance with a study protocol and that minorities have higher attrition rates.^{3,6,9} Additional researcher barriers include: failure to accommodate cultural and economic diversity of potential study participants, claims that statistical power will be reduced if women and minorities are included, inaccurate beliefs that certain populations are not at risk for specific conditions or illnesses, and failure to establish research clinics in minority institutions.^{3,4,6,9} Researchers use a common excuse for exclusion of minorities in research when they describe them as “hard to reach.” This characterizes the population as difficult as opposed to taking the time to understand the broader context in which the community lives^{6,9} Additional barriers to research participation are described in **Table 1**. These barriers are divided into four categories: participant barriers, researcher barriers, protocol/eligibility barriers, and funding barriers.

MODULE 4: RECRUITMENT & RETENTION

Table 1: Barriers to Research Participation

Participant Barriers

- Fear of being a “guinea pig”
- Lack of knowledge about research studies
- Fear and mistrust of the health care system and medical research
- Illiteracy
- Practical obstacles (i.e. transportation, lack of time due to family/work responsibilities)
- Lack of access to health care and poor quality of health care
- Cultural and religious beliefs

Researcher Barriers

- Lack of minority researchers to recruit minority patients
- Failure to build rapport with communities
- Lack of awareness of ongoing research studies
- Bias or stereotyping toward ethnic minority groups

Protocol or Eligibility Barriers

- Complexity and stringency of the study
- Innapropriate exclusion critieria
- Negative media attention about the study

Funding Barriers

- Administrative issues
- Ethical Issues: includes translation and interpretation of consent forms and employing staff with cultural and linguistic skills

Recruitment & Retention Key Strategies

As barriers to recruiting minorities have become more clearly understood, there has been increased interest in designing recruitment interventions to overcome them.^{2,9} Below, are a strategies to effectively recruit and retain research participants.

- ✓ **Involve members of the targeted population and the local community in the recruitment process.**
 - Involve community members in the recruitment process.
 - Community members can provide great insight on how to recruit individuals from a specific community. They can also assist in the decision-making process.
 - Although, they can provide assistance in identifying potential participants, keep in mind that community members should be involved in all aspects of the research process.
- ✓ **Ensure that members of the research team have the necessary skillset and training to recruit minority participants.**
 - Research staff members should have the appropriate interpersonal skills to approach and communicate with individuals of various cultural backgrounds.
 - Racial and ethnic matching of project staff and prospective participants may be beneficial in the recruitment process. However, recruiter experience and community ties are also important attributes.⁶
- ✓ **Be familiar with the community “hot spots.”**
 - Go where the people are.
 - This may include churches, grocery stores, academic institutions, shopping centers, barbershops, beauty salons, local coffeehouses, libraries, community events, health fairs, and neighborhood centers.
- ✓ **Build Relationships.**
 - Building rapport with individuals directly from the community will help you in your efforts to build trust and recruit participants.
 - Contact local leaders, residents, and reach out to predominately minority fraternities and sororities to assist with education and recruitment.
 - Schedule meetings and/or send letters explaining the study and its benefits on an individual and community level.
- ✓ **Advertise, Advertise, Advertise!**
 - Develop culturally appropriate research materials (study flyers, brochures, TV ads, radio ads).

RECRUITMENT & RETENTION KEY STRATEGIES

- Ensure that materials are translated into the appropriate language.
- Use images that are reflective of the target population.

✓ **Conduct Community Presentations.**

- Do not rely solely on distributing flyers and brochures. There is power in face-to-face conversations.
- Present your study to the community and allow individuals to ask questions and provide feedback on how you can increase participation.

Retention Strategies

✓ **Keep communication clear and open.**

- Clearly reiterate the details of the study.
- Be readily available to answer questions as they arise. Throughout the study, ensure that participants understand their role and feel comfortable with the process.
- Communicate your long-term commitment to the individual and community.
- Send out newsletters that report the progress of the study.

✓ **Be mindful of issues related to childcare, work schedules, phone number or address change and transportation.**

- Research participants have a life outside of being a part of a study. Be prepared to have a plan in place to address issues that they may encounter.

✓ **Tell participants that they are appreciated.**


- Thank research participants for the time and effort and the contribution that they are making to the field of research and to their community.

✓ **Provide participation incentives and tokens of appreciation.**

- Research participants have a vital role in a research study. Incentives are a great way to show that you are appreciative of their time and efforts.
- Incentives should be appropriate for the target population (i.e. study specific items or gas/grocery gift cards). Consider asking a community advisory board to assist with selecting possible incentives.
- Whether incentives are given during or following a study, they should be distributed in a timely manner.
- Send participants small tokens of appreciation that will remind them of the study (i.e birthday cards, refrigerator magnets, pens).

MODULE 4: REVIEW

Module 4: Review

<h3>Awareness</h3> 	<ul style="list-style-type: none">■ Be aware of your personal strengths and challenges as it relates to participant recruitment and retention.■ Identify your level of comfort with engaging in conversations with people of various cultural backgrounds.■ Think about your current recruitment tools and resources. What changes, if any, do you feel should be made in order to improve participant recruitment?
<h3>Knowledge</h3> 	<ul style="list-style-type: none">■ Recruitment is the dialogue which takes place between an investigator and a potential participant prior to the initiation of the consent process.■ Barriers to participation can be categorized into 4 areas: participant barriers, researcher barriers, protocol/eligibility barriers, and funding barriers.■ The adoption of successful recruitment and retention strategies is important throughout the entire research process.
<h3>Skill</h3> 	<ul style="list-style-type: none">■ Start the process early! Engage in conversations with community residents before recruiting for a research study.■ Everyone on the research team plays an important role in participant recruitment and retention. Discuss individual and intuitional strengths and weaknesses with your colleagues. Then, as a group identify strategies appropriate to your target population.■ Include members of the target population in your recruitment and retention plan. They can assist you in identifying the best strategies to use based on your research study.

MODULE 4: REFERENCES

Module 4: References

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FOR ADDITIONAL INFORMATION

For Additional Information

The Case Center for Reducing Health Disparities offers seminars, trainings, and presentations to researchers associated with Case Western Reserve University, including affiliated hospital staff, trainees, and community-based investigators. These trainings review key steps in conducting culturally competent research. This includes assisting researchers in the process of integrating cultural considerations into developing research questions, study design, data collection, analysis, and dissemination of findings. The purpose of these trainings is to increase researcher's knowledge, skill, and confidence in engaging and meeting the needs of culturally and linguistically diverse populations.

For more information about the Reshaping Research guide or our cultural competency trainings, please contact:

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