# RESHAPING RESEARCH

A Guide to Integrating Cultural Considerations into Research

## Module 2: Engaging the Community

Case Center for Reducing Health Disparities

## 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

# Acknowledgements

# 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 methodology in relation to their target population.  This enables researches 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

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:

| Awareness | This section will encourage you to assess your personal awareness of the information and how it relates to your role as a researcher. |
| --- | --- |
| Knowledge | 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. |
| Skill | 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. |

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 2: Engaging the Community

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

➤ Define community engagement.
➤ Identity methods to effectively approaching communities of interest.

## INTRODUCTION

Community engagement has become an important ethical requirement for research due to the growing recognition that communities can suffer research related harms and explotitation.[1,2] However, despite the recognition of its importance, guidance on community engagement strategies for researchers remains underdeveloped.[3,4] Community engagement in research can enhance a community's ability to address its own health needs and health disparities issues while ensuring that researchers understand community priorities.[3,4,5] 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.[12, 15, 16] This module will explore strategies to appropriately identify and engage communities of interest.

## DEFINING COMMUNITY

The term "community" differs according to who is asked to define it and the purpose for which it is being defined. The definition varies across individuals, cultures, disciplines, and institutions. There is no standard definition of a community. Community has primarily been used to describe interactions among individuals in geographic terms. However, this may not always be the case. Although, people may live in close proximity to one another that may not necessarily be reflective of a community. People may differ with respect to values and other cultural characteristics that are more relevant to the social aspect of community.[2, 3, 5] The social and political networks that link individuals an community organization can define a community, as well.[2,3,9] In addition, people may have their own sense of community membership in which the defining feature can be seen as the common identity shared among members of the same group. Therefore, an individual may belong simultaneously to different religious, vocational, racial or ethnic communities.[2,9]

Even though community is determined largely by shared traditions and values, communities are not static and may accommodate multiple and even conflicting interpretations of their own traditions and values. Individuals who do not belong to a particular community may also define community differently than those who are a part of the community.[2,3,4] It is important for researchers to gain an understanding of the communities that they belong to and whom they are interested in working with. For example, researchers without prior experience of conducting research in American Indian communities may be unaware of the critical role of, or efforts required in, developing and maintaining trust. Many American Indian communities have been analyzed, stereotyped, and exploited by outside groups. This has resulted in uneasiness with nontribal members. Many American Indians are often suspicious of unfamiliar individuals who come to their community and want to conduct research.[7]  Studies have shown that mistrust of the health care system is a common barrier to participation in research among minority groups. Therefore, it is important that researchers engage with the community and build a strong relationship with its members.

## ENGAGING THE COMMUNITY

Despite common misconceptions, community members want to participate in research. They are interested in research studies taking place in their community, and they are interested in being included in the research process. Linking the term "community" to "engagement" serves to broaden the scope. It shifts the focus from the individual to the collective. This focus encourages inclusiveness that ensures consideration is given to the diversity that exists within any community.[3,8] **Community Engagement is the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.**[9] Community engagement is an ongoing process. It involves interacting with the community of interest and maintaining bi-directional relationships beyond the completion of the research study.[2,9] Collaboratively working with the community and its members is necessary in order to conduct quality research and improve health outcomes. In recent years, community engagement has been essential to programs addressing smoking cessation, obesity, cancer, heart disease, and other health concerns.[2,3,9] The benefits of community engagement also include improved community health outcomes, increased accrual rates, reduced health disparities, and increased success rates of research studies.[3,6]

The major goals of community engagement are to: [9]

- ✓ Build trust.
- ✓ Enlist new resources and allies.
- ✓ Create better communication.
- ✓ Improve overall health outcomes as successful research projects evolve into lasting collaborations.

Community engagement is a core element of any research effort involving communities. Often times, researchers develop studies based on their own personal interests instead of exploring the interests and needs of the community. Researchers must become part of the community and community members need to become part of the research team. Researchers must also be responsive to the needs of that community as defined by the community itself.[2, 3, 9] Meaningful community engagement extends beyond physical involvement. It includes involving the community in generating ideas and decision making processes. Community members are very knowledgeable of the assets, strengths, and needs of their community. Researchers should respect this knowledge and value the contributions they have to offer. Researchers must respect, listen to, and learn from community members. An absence of mutual respect and co-learning can result in a loss of time, trust, resources, and, most importantly, effectiveness.[4,9] Community engagement can take many forms and covers a broad range of activities. These examples are explained in **Figure 2.**

### FIGURE 2: APPROACHES TO COMMUNITY ENGAGEMENT

(Adapted from "Effective Engagement: building relationships with community and other stakeholders")

| Informing | Consulting | Involving |
|---|---|---|
| • Educating the community on current regulations that are in place to protect human research paticpants. | • Consult the community as part of a process to develop research protocols, or build community awareness and understanding. | • Involve the community through a range of mechanisms to ensure that issues and concerns are understood and considered as part of the research process. |

| Collaborating | Empowering |
|---|---|
| • Collaborate with the community by developing partnerships to formulate options and provide recommendations. | • Empower the community to make decisions and to implement and manage change. |

   Effectively engaging the community requires researchers to learn about community's history and identify community members, leaders, stakeholders, and local businesses within that particular setting. This will begin the process of understanding more about the key issues that are impacting community members and what should be the research focus. Researchers and practitioners need to understand the cultural dynamics of specific groups and institutions in order to build relationships, identify ways to collaborate, and build respect and trust.[2,6,8,9] For example, research often involves people from universities or medical institutions working with community groups in areas labeled as "low income" or "at risk." Acknowledging diversity in background, experience, culture, income, and education and examining how society produces privilege, racism, and inequalities in power should be central to the process of community engagement. This approach can help researchers better understand and address the root causes of health issues.[2, 8, 9]

Sullivan et.al (2001) conducted a qualitative study to understand the experiences of community members and researchers in community-based research projects conducted in Seattle, Washington. Respondents reported that often research captures only the negative aspects of their communities rather than the positive aspects. Some individuals also felt that researchers only had an interventionist perspective and were only focused on trying to "fix" people and communities rather than working with communities to identify and build on strengths.[10] By focusing and building upon the strengths and assets of the community, researchers can uphold its history and accomplishments. Researchers should approach communities, and its members, in a positive manner that is respectful and demonstrates the desire to form meaningful, genuine, and bi-directional relationships. To obtain a deeper insight into the community of interest, researchers should understand the culture of the community. Culture shapes how individuals and groups relate to each other, how meaning is created, and how power is defined. It also shapes ideas about partnership, trust, and negotiation.[6,9] When a researcher is new to the community, members of that particular community may only provide minimal information. In most communities, there is reluctance to share cultural secrets and vital information may be withheld. Researchers gain trust as they strive to become familiar and actively engaged with the community.

Researchers should become familiar with the socioeconomic and political context of potential participants prior to the implementation of the research study.[3,6,14] Understanding the community and developing alliances with key leaders helps to build a cooperative and collaborative environment. To assist in this process, researchers are encouraged to identify and interact with "community insiders." Community insiders are typically individuals who are very knowledgeable about that community. They can also serve as experts in the social meaning of diseases and can help researchers identify relevant issues, causal mechanisms, and implementation of acceptable interventions. Behaviors that appear chaotic and irrational to outsiders may seem rational and normal to the insider. This is due to the social meanings of events often understood best within the context of the history of a community. Members of that particular community are best capable of evaluating and communicating that meaning.[1,2,6] Establishing relationships with community members enables researchers to gain trust and break down barriers to research participation.

Among many racial and ethnic populations, there is a strong belief that researchers only conduct "helicopter research." Helicopter research is the notion that researchers literally or figuratively fly into communities, administer surveys, collect data, and leave-never to be heard from again by the community.[11] In order to prevent this from occurring, researchers are encouraged to maintain relationships before, during, and following the research study. Community engagement requires a substantial amount of trust, time and resources. Most importantly, community engagement must be carefully planned with the intent to create long-term, uplifting changes within the community. Researchers must be patient, committed, and open to developing authentic relationships. Culturally competent researchers are aware of the importance of engaging the community and seeking the input of residents, leaders, and key stakeholders. Furthermore, they have the ability to integrate this information in each step of the research process in a culturally appropriate manner. Researchers who integrate cultural competency are actively involved in identifying the needs, assets, and barriers of their population of interest. Cultural competence requires more than understanding a group of people or conducting a study that only minimally meets the needs of the community.

## Module 2: Review

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|---|---|
| **Awareness** | <ul><li>Think about the communities you belong to. How do they influence your role as a researcher?</li><li>Are you familiar with the various neighborhoods and communities surrounding your institution?</li><li>How do you select communities you are interested in working with or recruiting from?</li><li>Currently, what are your approaches to engaging communities in research?</li></ul> |
| **Knowledge** | <ul><li>The term "community" differs according to who is asked to define community and the purpose for which it is being defined and varies across individual, cultures, disciplines, and institutions.</li><li>Community engagement is a vital component in conducting quality research and involves not just working in communities, but working <u>with</u> communities.</li><li>Effective community engagement and relationship building requires a substantial amount of trust, time and resources.</li></ul> |
| **Skill** | <ul><li>Prior to developing a study, ask members of the community of interest how they define their community. Inquire about the strengths, challenges and needs of the community.</li><li>Implement the 5 approaches to community engagement when working with communities of interest (inform, consult, involve, collaborate and empower).</li><li>Maintain relationships before, during, and following the research study.</li></ul> |

Center for Reducing Health Disparities

# Module 2: References

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## 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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