ISP

INCLUSIVE SCIENCE PROGRAM

RURAL HEALTH RESEARCH TOOLKIT

A resource for researchers in the design and conduct of research focusing on rural communities

UNC

SCHOOL OF MEDICINE

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I. Introduction

Recruiting and retaining diverse participants in clinical research continues to be a major barrier to addressing today's pressing health concerns and health disparities. The Inclusive Science Program (ISP) at the North Carolina Translational and Clinical Sciences (NC TraCS) Institute promotes the inclusion of diverse populations across the life course in clinical and translational research, with particular emphasis placed on groups that have been historically underrepresented in research or who experience significant health disparities in North Carolina. Our goal is to provide investigators with access to experts, resources, and educational opportunities that enhance their ability to engage diverse study populations in clinical and translational research.

Rural populations experience significant health disparities in comparison to their urban and suburban counterparts and are also less likely to be included in research. This toolkit was developed to aid researchers in their design and conduct of research that focuses on rural communities. While this toolkit focuses on North Carolina, we hope the information provided will give researchers initial guidance and resources necessary to implement best practices in formulating research questions, developing protocols and recruitment and retention strategies, and engaging rural communities in the research process. This toolkit is not intended to be a comprehensive source of information; we encourage researchers to explore the additional resources listed throughout.

II. What is "Rural"?

"Rural" means different things to different people. Most commonly used as a descriptor of a given geographical area, the term "rural" is often defined based on population size, population density, or population commuting patterns. For many residents of rural areas, however, rurality is also a social identity. This section of the toolkit provides an overview of the different ways in which "rural" can be operationalized. The definitions provided below are not exhaustive; ultimately, researchers should select the definition that best fits their research aims.

A. Rural as a Geographic Area

Traditional categorizations of geographical areas focus on population density, population size, geographical location, and/or proximity or distance from employment and other services or resources. The federal government alone uses at least fifteen different definitions of rurality, and applies these definitions at different levels (e.g., county, Census tract, zip code). These definitions typically focus on population size, population density, or commuting patterns with little to no regard for other characteristics. For example, the Census Bureau defines two types of locales: "Urban Areas" which include 50,000 people or more, and "Urban Clusters" with between 2,500 and 50,000 people.[1] The Office of Management and Budget (OMB) defines geographic areas as Metropolitan (50,000+ people), Micropolitan (10,000-49,999 people), or neither. In both cases rural is defined, by default, as non-Urban Areas, non-Urban Clusters, non-

Metropolitan, and non-Micropolitan areas. Thus, rural is often defined as "not urban" or the absence of urbanicity.

The OMB and Census Bureau definitions are often criticized for failing to capture the complexity of rurality. They do not distinguish rural from suburban, and may mask rural pockets within larger metropolitan areas—for example, the OBM definition classifies the Grand Canyon as non-rural because it is located in a metro county. Other definitions, like the Rural-Urban Commuting Area (RUCA) Codes and the Rural-Urban Continuum Codes (RUCC) developed by the Economic Research Service of the U.S. Department of Agriculture (USDA-ERS), offer more nuanced definitions of rurality.[2] For example, RUCAs use the Census Bureau's Census-tract based classification of urbanized areas and urban clusters, but also incorporate information on daily commuting patterns.

The specific definitions mentioned above represent only a few of the many definitions in use. State entities often create their own definitions. For example, the North Carolina Chamber of Commerce and NC Rural Center use the definition of 250 people per square mile to differentiate between rural and urban counties.[3] The fact that there are multiple definitions of rurality can lead to confusion: some areas may be rural according to one definition and urban according to another, and the degree or even direction of rural-urban disparities can change depending on the definition used. It is important that researchers be aware of various definitions, be thoughtful and deliberate in the definition chosen for their work, and, to the extent possible, use well-established definitions to facilitate comparisons across different bodies of research.

B. Rural as a Social Identity

Rurality represents more than just the number or density of individuals residing within a geographic location; it can also be viewed as a social identity like race, ethnicity, sexual orientation, gender identity, citizenship status, class, etc.[4,5] Similar to other aspects of identity, rural culture and the rural social identity may influence how people view themselves, how they are treated by others, and their risk and resilience factors for health outcomes. People living in rural settings often consider themselves to have values or ways of living that distinguish them from their (sub)urban counterparts and can be subject to assumptions and stereotypes.[6,7,]

Rural identity intersects with other aspects of personal identity. In a recent analysis of U.S. Census data, the Pew Research Center found that racial and ethnic diversity is increasing more rapidly in urban and suburban counties than in rural counties.[8] Rural counties also contain a higher share of older Americans, and a smaller share of young adults, than do urban or suburban areas. Researchers should carefully consider the multiple and intersecting aspects of identity that their research participants hold, as this is a critical step in both building trusting relationships between researchers and community members and in better understanding the complex dynamics that underlie persistent health disparities.

C. Demography of Rural North Carolina

As of 2010, North Carolina had the second largest rural population (3.2 million) after Texas (3.8 million).[9] Fourteen of the 100 counties in the state have no urban areas at all.[10] Most of the entirely rural counties in North Carolina are located in the Western (mountain) and Eastern (coastal plains) parts of the state. Still, the relative proportions of rural vs. urban populations in North Carolina are changing. Two out of every three North Carolinians now live in an urban area according to the U.S. Census Bureau, a major change for a state that was majority rural until 1990. Although the change from rural to urban represents a significant shift for the state, with implications for everything from transit planning to politics, North Carolina's densest urban areas still remain substantially less dense than in many other states.

Additional Information and Tools:

- *The Health Resources and Service Administration: Defining Rural Population*
  Provides an overview of key definitions of rurality used by federal agencies.
  https://www.hrsa.gov/rural-health/about-us/definition/index.html

- *The Rural Health Information Hub: What is Rural?*
  Provides an overview of rural definitions and related terminology, produced by the Rural Health Information Hub (a program of the Federal Office of Rural Health Policy)
  https://www.ruralhealthinfo.org/topics/what-is-rural

- *Carolina Demography*
  A program of the Carolina Population Center at UNC-Chapel Hill, providing analysis of demographic trends in North Carolina
  https://www.ncdemography.org/

- *What Unites and Divides Urban, Suburban, and Rural Communities*
  Survey results from the Pew research Center's analysis of political, social, and demographic trends in rural, suburban, and urban communities across the United States
  https://www.pewsocialtrends.org/2018/05/22/what-unites-and-divides-urban-suburban-and-rural-communities/

III. Underrepresentation of Rural Communities in Research

Rural residents participate in research at lower rates than urban or suburban residents.[11,12] Barriers to rural residents' participation in research include geographic distance, geographic isolation, misperceptions of research, lack of opportunities for research participation, and stereotyping or misperceptions on the part of researchers. Another potential issue that underlies the limited representation of rural populations is a lack of local infrastructure and resources for conducting research, particularly at the population level, in rural communities. This issue may exist in parallel with disparities in access to healthcare. For example, analyses of the geographic

distribution of clinical trial sites have found that sites tend to be clustered in urban areas where there is also a significant concentration of healthcare and social services facilities.[13]

One way to address the underrepresentation of rural populations in research is to establish collaborations between community-based/grassroots organizations and more resourced entities (e.g., large healthcare facilities). These partnerships can cultivate mutual benefit in terms of goals and research outcomes. Community-based organizations can provide expertise and insight on the social, environmental, historical and individual-level factors that influence research participation. Research centers and healthcare facilities can provide infrastructure and necessary resources for conducting research. The use of telehealth and other electronic methods for engaging rural populations may further alleviate barriers related to geographic isolation, travel time by research staff to the community, or lack of transportation—thereby enhancing the participation of rural communities in research.

IV. Rural Health Disparities

Rural populations in the US experience significant health disparities compared to urban populations, and these disparities exist across all stages of the life course. In recognition of the scope and severity of these disparities, the National Organization of State Offices of Rural Health recommended that Healthy People 2030 adopt a separate category (Rural Health) to establish goals and objectives for decreasing and ultimately eliminating disparities based on geographic location (rural and urban).The following content highlights some of the major health disparities that exist between rural and urban areas.

A. Physical Health and Mortality

The all-cause mortality rate (defined as the number of deaths per 100,000 people) is higher in rural areas than in urban areas. This disparity has been increasing over time, and is most pronounced in southern part of the United States. This disparity—and its regional variation—is likely due to the complex interplay of a number of trends, included increases in obesity-related diseases, the opioid crisis, and changing social and economic conditions and healthcare infrastructure.[14]

Though infant mortality has declined in the United States, rates continue to be higher in rural areas than in urban areas (and higher among Black women than non-Hispanic white women, regardless of rurality).[15] The leading causes of infant deaths also vary by rural/urban status: compared with urban counties, rural counties report lower infant mortality rates due to low birthweight, but higher mortality rates due to congenital malformations, sudden infant death syndrome, and unintentional injury.

People living in rural settings generally have worse physical health outcomes compared to those in non-rural communities.[16] They suffer disproportionately from preventable illnesses and from chronic conditions such as diabetes, hypertension, COPD, and arthritis, and obesity. In North

Carolina, residents in rural counties have higher percentages of residents with Type II diabetes, cardiovascular disease, and other chronic diseases.[17] Most of the NC counties designated as primary care shortage areas, behavioral health shortage areas, or dental shortage areas are also categorized as rural.[18]

B. Unintended Injuries and the Opioid Epidemic

Deaths from unintentional injury are substantially higher in rural areas than in urban areas.[19] This may be due in part to greater risk of death from motor vehicle crashes and opioid overdoses, and because the distance between healthcare facilities and trauma centers limits rapid access to specialized care for injured persons in rural areas.

Rural communities have been hit hard by the opioid epidemic, with the rate of drug overdose deaths in rural areas now surpassing that of urban areas.[20] The dynamics of this epidemic among rural communities are complex and multifaceted, with research suggesting that rural populations are less likely to have access to health insurance and to evidence-based prevention and treatment programs.

C. Cancer

People living in nonmetropolitan areas of the US experience higher death rates from all cancers combined than persons living in metropolitan areas—even though the overall incidence of cancer in rural areas is lower. Additionally, between 2006 and 2015, the annual death rates for all cancer sites combined decreased at a slower pace in nonmetropolitan areas compared to metropolitan areas.[21] Incidence rates of cancers that can be prevented by regular screening, such as colorectal and cervical cancers, are also higher in rural areas.

Beyond cancer mortality disparities, rural communities experience significant disparities across the cancer control continuum (access, prevention, detection, diagnosis, treatment, survivorship).[22] For example, rural women may be less likely to receive follow-up testing after receiving abnormal screening results. Rural communities also experience disparities in financial burden related to cancer care and treatment.[23]

E. Behavioral and Mental Health

Rural areas generally have higher rates of health risk behaviors (e.g., cigarette smoking, physical inactivity during leisure time, lack of seat belt use) than urban areas. According to data from the Behavioral Risk Factor Surveillance System, residents of metropolitan counties are more likely to report current nonsmoking, normal body weight, and adherence to physical activity recommendations as compared to residents of nonmetropolitan counties.[24] Each of these health behaviors is linked to chronic disease risk.

Disparities in mental health outcomes echo those seen in physical and behavioral health. While the prevalence of mental health disorders does not appear to differ significantly between rural and urban areas,[25] suicide rates are consistently higher among rural residents.[26] Available

evidence suggests that this geographic disparity is due to more limited access to mental health services in rural areas and, perhaps even more importantly, a higher case-fatality rate for suicide attempts in rural areas due to more widespread use of firearms.[27,28]

F. Variation Within Rural Populations

Simply looking at health disparities between rural and urban residents can mask disparities *within* rural populations. Data from the Behavioral Risk Factor Surveillance System indicates that, compared to rural non-Hispanic white adults, rural American Indians/Alaskan Natives, non-Hispanic African Americans, and Hispanics are more likely to report fair or poor health, be obese, and to report difficulty seeing a health care provider due to cost.[29] It is critical that

Spotlight on American Indian Health in North Carolina

In considering health disparities and health determinants in rural North Carolina, researchers should note regional overlaps and intersections between rural and American Indian/Indigenous identities. North Carolina is home to the largest American Indian/Alaska Native population east of the Mississippi River and one of 15 states with a population of greater than 100,000 residents.

There are eight state-recognized tribes in North Carolina representing over 220,000 American Indian/Alaska Native residents, making up 2.3% of the state population in 2015. Lumbee is the most commonly-reported tribal affiliation in North Carolina; indeed, almost 4 out of 5 individuals nationwide who identify as Lumbee reside in North Carolina. A large majority of North Carolina's American Indian residents live in counties also considered rural, with a large concentration in Robeson and Hoke counties, and another large cluster in Swain and Jackson counties. Researchers looking to engage with these communities should work closely with the several groups and organizations representing North Carolina tribes, which can be found on the website of the North Carolina Department of Administration.

American Indian residents in North Carolina face substantial health disparities in key health indicators. Compared to non-Hispanic whites, American Indians in North Carolina are twice as likely to die of unintentional motor vehicle injury and five times as likely to die of homicide. These disparity ratios should be considered alongside broader data trends of higher injury-related mortality in rural areas.

Social Determinants of Health
American Indians in North Carolina have higher rates of poverty, a higher proportion of households on food stamps/SNAP benefits, lower household income, and are more likely to be uninsured than their white counterparts. Researchers should consider these determinants when examining access to healthcare and health infrastructure in rural communities with significant proportions of American Indian residents.

researchers consider the substantial heterogeneity among "rural residents," both in terms of risk and protective factors, when designing, conducting, and interpreting health disparities research.

Additional Information and Tools:

- *2017 Rural Health Snap Shot NC Rural Health Research Program*
  Compares national urban and rural communities in key indicators related to population characteristics, mortality, health behaviors, clinical care, and health insurance.
  https://www.shepscenter.unc.edu/wpcontent/uploads/dlm_uploads/2017/05/Snapshot2017.pdf

- *Rural Health Information Hub: Rural Health Disparities*
  Compendium of resources for data on rural health disparities
  https://www.ruralhealthinfo.org/topics/rural-health-disparities/resources

- *Proposed Rural-Specific Objectives for Healthy People 2030*
  Lists the proposed rural-specific objectives for Healthy People 2030 from the National Organization of State Offices of Rural Health
  https://nosorh.org/wp-content/uploads/2019/02/HP-2030.pdf

- *UNC American Indian Center*
  University-wide public service Center designed to advance leadership in American Indian Scholarship and Research, engagement with and service to Native populations, and enrichment of campus diversity and dialogue.
  https://americanindiancenter.unc.edu/

- North Carolina Commission of Indian Affairs
  Created 1971 by the North Carolina General Assembly to respond to the requests of concerned American Indian citizens from across North Carolina. Provides information on tribal communities across the state.
  https://ncadmin.nc.gov/about-doa/divisions/commission-of-indian-affairs

V. Social Determinants of Health in Rural Communities

Social determinants of health refer to the conditions in which people are born, grow, live, work, and play. They include factors such as neighborhood physical environment, education, and employment status. Differences in social determinants of health likely underlie many of the health disparities observed in rural communities.

A. Geographic Isolation and Transportation

Geographic isolation can be a barrier to accessing services and goods necessary to promote or maintain health.[30,31] The impacts of geographic isolation can be amplified in rural areas that have limited transportation options. Lack of access to personal vehicles and the costs of long-distance travel may also impede access to care and participation in research studies. These difficulties can result in delayed, deferred, or missed care, and may also make it more challenging to access other health-promoting resources such as nutritional/healthy food options, gyms, bike lanes, and walkable areas.

C. Environment

Rural communities are impacted by various environmental factors (e.g., exposure to hazardous substances in the air, water, soil or food; natural and technological disasters; and occupational hazards).[32] Many industries common in rural areas, like mining and concentrated animal feeding operations (CAFOs), bring their own dangers and environmental impacts. These industries are often located in disproportionately socioeconomically disadvantaged and minority communities, thus further compounding ongoing disparities in health and wellbeing.[33,34] In North Carolina, researchers have found that hog CAFOs are significantly more likely to be located in counties with greater proportions of minority residents.[35,36]

The economic, health-related, and environmental effects of climate change are also unevenly distributed. North Carolina coastal areas, located in the eastern region, are at increasing risk of catastrophic flooding due to the effects of climate change.[37] Still, the relationship between rural residence and environmental quality is not always consistent: some evidence suggests that while water quality is higher in more urban areas, air quality is better in rural areas.[38]

D. Economy

Major economic disparities exist between rural and urban areas. Over half of non-core counties are persistent poverty counties where 20% or more of the population has lived in poverty over the last 50 years.[39] The rural unemployment rate has declined steadily since 2010, though it has not fully recovered from the Great Recession. While it is comparable to urban areas (4.2% vs. 3.9%, as of 2018), vast variability exists in specific locales.[40]

Economic determinants of health can be uniquely nuanced in rural areas, in that these areas may feel the impact of the gain or loss of new companies and industries differently than urban areas. Many companies in rural areas have been impacted by rapid technological advancements and increased automation; however, workforce development opportunities in rural areas have not kept pace. These changes have resulted in workers commuting into urban areas for work and longstanding rural residents having to leave their communities or face unemployment and poverty.

In North Carolina, the average per capita income in 2018 was approximately $46,117, while rural per capita income lagged at $37,575.[41] The poverty rate in rural NC is 18.3% compared to

12.9% in urban areas of the state. Only 45% of rural-metropolitan county residents and 39% of non-metropolitan rural county residents earn a living wage – compared to over half of both urban and suburban residents.[42,43]

E. Education

Rural/urban disparities exist across educational levels.[44] While the percentage of people completing higher levels of education is increasing in all areas, there are significant differences between rural and non-rural areas in key indicators of educational attainment. In North Carolina, these disparities include attainment of college-and-career ready scores in reading and math and post-secondary enrollment.[45] Rural communities may also experience *brain drain,* whereby students or professionals leave the area for educational or professional reasons and do not return.[46]

F. Healthcare

Rural residents generally have more limited access to quality healthcare, including primary care, and higher rates of uninsurance.[47,48] Rural communities in North Carolina, and nationwide, have also struggled with hospital closures and provider shortages that exacerbate disparities in access to care. Over one hundred and fifty rural hospitals have closed since 2005, with most closures concentrated in the South. As of 2017, metropolitan counties in North Carolina had almost 3 times the supply of physicians as rural counties, and shortages in almost every type of provider persist across rural areas of the state (according to the interactive NC Health Professions Data System).

F. Community Trauma

Historical trauma—or the cumulative emotional and psychological harm that persists across generations—can have a profound influence on health, and may be particularly relevant in rural areas due to legacies of enslavement and oppression, forced assimilation or relocation, loss of land rights, and destruction of cultural practices.[49,50] Other types of trauma may be rooted in current experience. For example, fear of detention or deportation related to immigration and mass incarceration can also impact rural communities by influencing the health of further marginalized groups (e.g., immigrants and African Americans) through increased stress, limitations on economic opportunity, and more.

Additional Information and Tools:

- *Rebuilding the Unity of Health and the Environment in Rural America*
  Workshop summary from the Roundtable on Environmental Health Sciences, Research, and Medicine convened by the Institute of Medicine
  https://www.nap.edu/catalog/11596/rebuilding-the-unity-of-health-and-the-environment-in-rural-america

- Achieving Rural Health Equity and Well-Being
  Workshop summary from the Roundtables on Population Health Improvement and Promotion of Health Equity, convened by the National Academies
  https://www.nap.edu/catalog/24967/achieving-rural-health-equity-and-well-being-proceedings-of-a

- *North Carolina Social Determinants of Health Map*
  Interactive map providing data on social determinants of health across North Carolina
  https://nc.maps.arcgis.com/apps/MapSeries/index.html?appid=def612b7025b44eaa1e0d7af43f4702b

VI. Ethical and Regulatory Issues

A. Inclusion of Rural Populations in Research

The exclusion or under-representation of rural communities in health research runs counter to the principle of justice, one of the three key principles of the Belmont Report.[51] According to this principle, the selection of research subjects should be scrutinized to ensure that certain groups of people are not selected purely because of their "easy availability, their compromised position, or their manipulability." Selection of research subjects should instead be driven by the problem being studied and handled in a way that minimizes the possibility of coercion or exploitation of the individuals or communities involved. Further, selection of research subjects should be designed to minimize the possibility of undue, excess, or unfair burden on the people/groups who participate and to ensure the fair distribution of benefits. Findings from research conducted in urban communities may not necessarily generalize to rural communities. Thus, ensuring that the benefits of health discovery reach all people demands that rural communities be active partners in research.

B. Research Impact and Resource Sustainability

People in rural communities may be inclined to participate in research primarily as a means to obtaining access to healthcare that would otherwise be unavailable or unattainable. Researchers should consider the ways in which the introduction of these resources may be coercive. Researchers must also be mindful of sustainability issues as they relate to the project's end and its effect on the study participants and their community.[52] Before embarking on a given project, researchers should consider how they will help sustain the resources that their research introduces.

C. Ethics of Communication: Literacy, Language and Culture

While communities of color are still generally underrepresented, rural areas are increasing in racial, ethnic, and linguistic diversity.[53] It is the research team's responsibility to ensure that these communities understand what research participation entails. Excluding participants solely because they do not speak English should not be considered an adequate justification.

Investigators should give thought to the amount of time needed to communicate the study purpose, procedures, risks, benefits, and participant rights. As with all study communications, language and literacy level are important considerations. If a study design is particularly complex, researchers may explore using multi-stage, tiered, or layered approaches to obtaining consent.[54,55] These types of approaches can make the consent process easier for participants and can allow participants and research teams to build trust and rapport.

D. Protection of Communities

There is a growing literature suggesting that investigators consider the protection of *communities* in addition to individuals.[56,57] This consideration may be especially important when working with small rural communities. One potential source of harm to communities may derive from the way in which research conducted in rural communities is presented. Researchers should consider the ways in which dissemination of results that show poor outcomes in rural communities, if not done carefully, may result in further harm to that community – for example, though community job loss, increased insurance rates, loss of tourism dollars, stigmatization, or discrimination against communities. Use of community-engaged approaches to research (See Recruitment and Retention Best Practices: Community Engagement) is one way to minimize community harm.

E. Privacy & Confidentiality

Maintaining privacy or confidentiality may be particularly challenging when conducting research in rural communities.[58,59] Rural communities often have close social networks, and in some communities, residents know many of the details of each other's lives. Those close relationships can be leveraged to establish rapport and credibility for a research project if the appropriate gatekeepers or community leader are approached with a commitment to adhering to the principles of community engagement. However, close relationships within a community can also make it difficult to maintain study confidentiality.

Beyond person-to-person interaction, confidentiality can sometimes be compromised based on someone being seen entering or exiting a research site or having their car spotted outside of a building. Thus, investigators should be thoughtful about protecting the privacy of participants when planning the logistics of data collection.

Though community-engaged approaches can enhance the overall success of a research project, the inclusion of community members in study implementation (e.g., staff, administrators, interviewers, clinicians) should be handled in a way that does not compromise the confidentiality of participants. All persons involved in research should be trained to maintain the confidentiality of study participants. Some institutions have created training specifically for the community members to meet the required Human Subjects Research training.

Investigators who receive funding from the National Institutes of Health (NIH) can apply for a Certificate of Confidentiality, which provides an additional layer of protection for participants' data by ensuring that researchers cannot be forced to disclose information about study participants.

VII. Methodological Considerations

A. Study design

A traditional clinical trial with placebo and intervention arms may be unappealing to potential participants because they fear "missing out" on the treatment if randomized to the control condition. Other trial designs (e.g. cross-over, stepped-wedge, and others) that increase access to a treatment intervention may prove to be more palatable to a specific community. Establishing communications and partnerships with community members early can help researchers strategically anticipate and address specific design issues.

The use of very limiting inclusion/exclusion criteria is another potential methodologic concern. Researchers should carefully consider their inclusion and exclusion criteria—particularly the way in which their criteria affect generalizability—and balance methodological rigor with the flexibility necessary for recruiting from populations that face significant barriers.

B. Analytic Issues

One of the most pressing concerns for rural health researchers is the statistical challenge associated with small sample sizes.[60] Current statistical techniques are often unstable or imprecise with small samples. Many recent advances in multivariate analytics require large samples, state-of-the-art research designs, and rigid design parameters that are often unattainable when targeting smaller populations. Small sample sizes can also preclude the use of multivariate and/or multi-level statistical models. Some proposed innovations in statistical methodologies for the design and analysis of small sample data include using research designs and analytic methods that maximize statistical power (e.g., dynamic wait list research design, Bayesian methods, matching and imputation).[61]

Researchers should also consider the possibility that commonly-used statistical techniques may not translate well to rural health research. For example, a recent brief from the NC Rural Health Research Program at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill argues that rural health data often contains more extreme values than urban health data.[62] Because of this, relying on statistical averages without also considering the data range can obscure important information.

Additional Information and Tools:

- *Improving Health Research for Small Populations*
  Workshop summary, including annotated bibliography, from the National Academies' Committee on National Statistics and Board on Health Care Services
  https://www.nationalacademies.org/our-work/improving-health-research-on-small-populations-a-workshop

VIII. Recruitment and Retention Best Practices

Thoughtful engagement with the target community—from question formulation and study design to the communication and dissemination of study findings—is critical to the successful recruitment and retention of study participants.[63] Many of the common principles and approaches applied to engaging other underrepresented populations (e.g. Latinos, African Americans, LGBTQ+ communities, etc.) can also be applied to research with rural populations.

A. Research Design and Implementation

Recruitment and retention can be impacted by study design and implementation strategies. Researchers should anticipate possible barriers to participation (e.g., location of study visits, transportation, timing of study events) prior to study implementation, and identify ways to address these barriers for potential participants (e.g., transportation vouchers, child care).

In some cases, researchers can inadvertently create or reinforce barriers to recruitment through their perceptions of communities as "hard-to-reach."[64] This term implies that there are fundamental qualities of certain groups that make it more difficult to recruit and retain them in research. Instead of viewing some populations as "hard-to-reach," researchers should instead consider how and why these populations might be "hardly-reached"—that is, how does the design and implementation of research create obstacles to participation that are unequally distributed across groups? [65] Efforts to address the challenges that potential rural participants may face in engaging in a research study can enhance trust and rapport between researchers and community members, thereby improving recruitment and retention and strengthening community-researcher collaborations.

B. Cultural competence, cultural humility, and team diversity

Cultural competence refers to the capacity for people to increase their knowledge and understanding of cultural differences, the ability to acknowledge cultural assumptions and biases, and the willingness to address those biases. Establishing cultural competency about the community one seeks to engage can significantly impact recruitment and retention success. However, some literature suggests that traditional approaches to cultural competence can actually promote stereotyping and reinforce the (incorrect) notion that culture is a static concept that one can "master."[66] Recent literature suggests that researchers instead adopt a stance of cultural *humility*. Cultural humility is an on-going process of self-reflection and self-critique

through which an individual examines their own beliefs and cultural identities while learning about the culture of another person or group of people.[67,68] The overarching principle is that research teams should become knowledgeable about the culture, context, and history of the communities with whom they conduct research.

Assessing a research team's readiness to engage vulnerable and/or underrepresented populations, including rural populations, is an important preparatory step for successful study recruitment and retention. Some tools (e.g., Cultural Competence Assessment Instrument, Look Different's Implicit Association Tests, Project Implicit) can be adapted to assess a person's or team's readiness to engage in research with rural populations. Team diversity, specifically the inclusion of researchers who identify similarly to the target population, is also particularly important for projects working with historically under-engaged populations.[69]

C. Community Engagement

Principles of community engagement underlie the best practices for recruitment and retention of rural participants. These principles promote relationship and trust-building by centering the real voices of the community throughout the research process. These approaches can range from the development of a community advisory board (CAB) to the implementation of community-based participatory research (CBPR), community-engaged research (CEnR) or participatory action research (PAR). Note that CBPR, CEnR, and PAR are approaches rather than specific methodologies, and can be applied to qualitative, quantitative, and mixed-methodology research.

D. Communication and Dissemination of Research Findings

Best practices for dissemination include using participants' preferred language, avoiding scientific jargon, and identifying venues/modes for dissemination that are frequently used by community members. In rural settings, where challenges related to broadband access or other communications technologies may exist, researchers may need to think creatively about how best to communicate findings to study participants. Research teams should also consider their use of different messengers; in many under-represented groups, including rural communities, it may be important to engage community leaders in dissemination efforts. Where possible, investigators should incorporate the feedback from dissemination activates into subsequent research protocols and/or discuss community feedback in research products (e.g., journal articles, broadcasts). It is also becoming more common to recognize community members' contributions to the design and implementation of a study by including them as authors on manuscripts or as co-presenters at conferences.

Research with underrepresented populations has often been framed from a deficit model, which focuses attention on a community's problems and poor outcomes rather than its assets and strengths. Among rural populations, this model reinforces the perception that poor outcomes are the result of features of the community or population itself, rather than the result of a complex set of economic, social, environmental, and political factors.[70] This type of negative framing has been cited as a potential barrier to study participation. More importantly, it perpetuates stereotypes that that only serve to harm rural communities and their residents. Thus, investigators

should give critical attention to the framing of their research narratives when approaching these communities and when disseminating findings.[71]

Additional Information and Tools:

- *Inclusion of Special Populations in Clinical Research*
  Journal article, publicly available through PubMed Central, detailing key considerations for inclusive research
  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6410628/

- *Dissemination of Rural Health Research: A Toolkit*
  Toolkit produced by the Rural Health Research Gateway to assist researchers with development of dissemination products for rural health research
  https://www.ruralhealthresearch.org/toolkit

- *Cultural Competence Assessment Instrument (CCAI)*
  Tool to assess level of cultural competence and readiness to engage in research with culturally diverse populations, produced by the Center for Capacity Building on Minorities with Disabilities Research
  https://ccbmdr.ahslabs.uic.edu/wp-content/uploads/sites/5/2014/04/CCAI.pdf

- Look Different's Implicit Association Test
  Short quiz designed to assess implicit bias related to gender, race, and sexual orientation
  http://www.lookdifferent.org/what-can-i-do/implicit-association-test

- The Community and Stakeholder Engagement (CaSE) Program at NC TraCS
  Program of the North Carolina Translational and Clinical Sciences Institute to promote and support community-engaged approaches to clinical and translational research, boost public trust in health research, and build capacity for researchers and communities to engage in academic-community partnerships
  https://tracs.unc.edu/index.php/services/engagement

IX. Data Sources

Robert Wood Johnson Foundation: County Health Rankings and Roadmaps
https://www.countyhealthrankings.org/

Rural-Urban Communizing Area Codes
https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes/

US Census Bureau Urban & Rural Definitions and Data
https://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural.html

US Census Bureau Geography Program/Interactive Maps
https://www.census.gov/programs-surveys/geography/data/interactive-maps.html

Centers for Disease Control and Prevention: Rural Health
https://www.cdc.gov/ruralhealth/index.html

Health Resources and Services Administration: Rural Health
https://www.hrsa.gov/rural-health/index.html

USDA: Atlas of Rural and Small-Town America
https://www.ers.usda.gov/data-products/atlas-of-rural-and-small-town-america/go-to-the-atlas.aspx

X. General Information on Rural Health, Rural Research, and Rural Populations

Rural Health Research Gateway
Center for Rural Health
University of North Dakota
https://www.ruralhealthresearch.org/

Rural Health Research Support Network
Clinical and Translational Science Center
University of New Mexico
https://hsc.unm.edu/research/ctsc/rhrsn/index.html

Rural Health Information Hub
University of North Dakota
https://www.ruralhealthinfo.org/

Federal Office of Rural Health Policy
Health Resources and Services Administration
US Department of Health and Human Services
https://www.hrsa.gov/rural-health/index.html

National Organization of State Offices of Rural Health
https://nosorh.org/

National Rural Health Association
https://www.ruralhealthweb.org/

North Carolina-Specific Information Sources

North Carolina Office of Rural Health
North Carolina Department of Health and Human Services
https://www.ncdhhs.gov/divisions/orh

North Carolina Health Atlas
North Carolina State Center for Health Statistics
North Carolina Department of Health and Human Services
https://schs.dph.ncdhhs.gov/data/hsa/

Rural Health Initiative
Mountain Area Health Education Center (MAHEC)
https://mahec.net/innovation-and-research/research/rural-health-initiative

NC Rural Health Research Program
Cecil G. Sheps Center for Health Services Research
University of North Carolina at Chapel Hill
https://www.shepscenter.unc.edu/programs-projects/rural-health/

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