

Methods for Increasing Recruitment and Retention of Ethnic Minorities in Health Research Through Addressing Ethical Concerns

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The National Institute of Health's (NIH) Revitalization Act of 1993 mandated the inclusion of women and ethnic minorities in NIH clinical research studies. By 1994, NIH had developed a set of guidelines that stated that women and members of minority groups and their subpopulations were to be included in all NIH-supported biomedical and behavioral research projects that involve human participants (Hayunga & Pinn, 1996). Despite the increase in the numbers of nonminorities involved in the collection of data in ethnic minority populations, little in the way of training has emerged to educate researchers about the communities they are entering (Cochran & Mays, 1998; Mays & Cochran, 2000).

This is unfortunate on several levels. A lack of knowledge about the historical and social context of the communities being studied robs researchers of valuable insights that should be integrated into their research endeavors. Also, being unfamiliar with the community increases the chance that research conducted with ethnic minorities may produce less benefit and have greater propensity to generate harm. Although in some instances there is little actual physical harm attributable to a particular research project, the relationship between the ethnic minority communities and the research community is harmed. This harm can occur due to perceptions arising out of historical relationships of mistrust and prior research misdeeds that derail current efforts to recruit ethnic minority respondents (Gamble, 1997; Hatch, Moss, Saran, Presley-Cantrell, & Mallory, 1993; Mays & Cochran, 1996).

This paper will focus on modules that can be incorporated into research training early in the process of conducting research in ethnic minority populations.

When and with Whom to Begin the Process

Although unrealistic, the best place to begin the process of integrating community concerns in a way that informs research activities is in the early stages of writing a grant application (Israel, Schulz, Parker, & Becker, 1998). Basically, this is because some of the suggested techniques for improving ethnic minority participation can raise project costs.

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Module 1: Ethics and Responsibility in Working with Ethnic Minority Populations

Giving serious consideration to who the stakeholders are in the research process may influence who one will decide to hire or how many indigenous community members are needed in order to reach recruitment goals. Identifying the stakeholders will also help to identify the benefits and burdens of each in the research process itself.

To understand the previous relationships among the stakeholders, it may be important to understand the complexity, needs, burdens, and benefits of ethnic minorities as participants in the research process (Buchanan, 1996; Turner Advisory Committee on Human Radiation Experiments, 1996; Wermeling & Selwitz, 1993). Many of us conduct our research under the auspices of our university or survey organization. In applying for funds we benefit from the long history and multitude of activities by our colleagues. However, we sometimes fail to recognize that, in working with diverse ethnic populations—many of whom have not had full and equal access to our university's resources, ranging from admission for their children to ease in obtaining medical care—the same organizational name that facilitates our research can carry with it more burden than benefit.

It is important as we design studies to understand not just the past history in general of a particular ethnic group but rather understand in particular the history of our own organizations in relation to the ethnic communities. There are several areas in which having an understanding of both the institution's history with the community as well as the general, overall abuses that have occurred to the ethnic population can be useful in project design. Some of these follow.

Subject Participation

If one is conducting a study of contraceptive practices, for example, there is a long and checkered history, including the testing of early oral contraceptives in Puerto Rican women (Corea, 1985; Davis, 1990). Knowing this history should lead one first to question whether one will be able to enroll and maintain Puerto Rican women successfully in this study. Is the project integrated well enough into the community that there will be strong supporters who can and will work to explain why it is important for the research project to pursue the scientific goals, in the face of this history of abuse?

Knowing the history of abuse, are there nonetheless specific benefits to Puerto Rican women that this study will bring to that population?

Hiring Staff

Often in the hiring of “indigenous interviewers” one looks for someone who is from the particular ethnic group under study. What is often overlooked is that the community is diverse and it may be difficult for one person to serve as the representative both to the research group and on behalf of the community. Rarely in interviewing such persons for jobs with projects do we try to understand who this one person can and cannot represent. Often their class background, where they have chosen to live, the churches they attend, or the social groups to which they belong will facilitate their knowledge and access to a particular segment of the community. Is that segment of the community the one that the project is most interested in recruiting? Will this person be viewed as a credible source? For example, does a university-educated ethnic minority woman of middle-class background with an MPH have much in common with poor women from the west side of Chicago attending county health clinics or Puerto Rican women in Washington, D.C., who receive care in a family planning clinic in the impoverished corridors of the city? Or would such an interviewer’s MPH, association with one of the up-scale Catholic churches, and lack of community contacts serve to *limit* whom she can reach?

Module 2: Interplay of Cultural, Racial/Ethnic, and Psychological Dynamics in Research Participation

This module focuses on volunteerism and its cultural/ethnic roots. Social science research has a long history in studies on prosocial behavior, yet little work has focused on how this varies by gender and ethnicity. Prosocial behavior typically arises from unselfish human nature or from the desire for such rewards as fame and recognition, self-fulfillment, empowerment, and the attainment of employable skills or monetary compensation. The extent to which these motivations vary by gender and ethnicity is important to the design of recruitment and retention strategies (Mays, Cochran, & Lin, 2000).

Looking at the history of volunteerism in ethnic minorities, we find that ethnic groups were historically more likely to volunteer in ethnic organizations that have benefited their ethnic groups (Gallegos & O’Neill, 1991). Appeals to ethnic group members that indicate benefits specific to their ethnic groups are more successful. There are a number of ways to accomplish this goal. In a random-digit-dialing survey we conducted of African Americans and Latino/as in South Central Los Angeles, we told participants that if they completed our survey, we would donate money to one of three organizations as an incentive for their consenting to participate. For African Americans, this included the Urban League, the United Negro College Fund, and a well-known local group. A similar list was generated for Latino/as. Even though the

mechanisms of getting a small donation to each of them would have made the study impossible, offering to contribute to a minority organization that was known for its contributions to the community was a small but effective gesture of our respect for their time.

Module 3: Culture, Gender, Age, Individual Autonomy, and Community Responsibilities

There are circumstances in which the agreement to participate in research has broad implications for the family or community. The consent and participation in research by an individual may have implications for spouses, significant others, families, or the broader community (Kuczewski, 1996), despite actions in the informed-consent process that focus only on the individual. As an ethical researcher, it may be useful to ask where those close to the participant fit into the participant’s decision-making, particularly for ethnic minority families where individualism is at times at odds with cultural values.

Often in recruitment, we ask the person to participate and expect a decision to be made immediately after our discussion. It’s a “bird-in-hand” philosophy. Yet there are times when such an approach can harm communitywide recruitment. Allowing potential respondents the time to consult with others can indirectly improve recruitment by demonstrating the project’s concern for the community. There are some segments of the ethnic minority community, particularly women, whose participation influences others to participate. It would be well worth our while as investigators to figure out those times when it would be better for participants that we wish to enroll in our study to be encouraged to consult with others first.

Module 4: The ICF (Informed Consent Form)

If researchers have engaged in many of the steps previously recommended, it will be reflected in the informed consent form. Researchers will ensure not only that their ICFs meet the legal requirements of their institution’s Institutional Review Boards (IRBs) but that they can truly discuss risks and benefits with their study participants.

Critical to the ICF is not just the preparation but the delivery of this document. Interviewer training should emphasize that a well-written ICF is an opportunity for the study to communicate with the study participant what they can gain from participation. It is also important to find a way to ensure that all passages of the ICF are at a literacy level that will enhance understanding by the study participants.

Many of us often comment that there are study nurses or particular recruiters who are excellent with the study participants. Often the reason is that these particular persons make study participants feel cared for, understood, and listened to. The more that these feelings can permeate other parts of the study, such as in administering the ICF, the greater the chance that respondents will be retained in the study and that they will act as ambassadors for their community. The ICF is one

of those tools that researchers can effectively use to convey to study participants our understanding of what they are sacrificing and how their participation will make a contribution. Taking this process seriously will increase the likelihood that they will stay and encourage others to participate.

References

- Buchanan, A. (1996). Judging the past: The case of the human radiation experiments. *Hastings Center Report*, 6 (3), 25–30.
- Cochran, S. D., & Mays, V. M. (1998). Use of a telephone interview survey to assess HIV risk among African American and Hispanic Los Angeles County residents. In *Proceedings of the 27th Public Health Conference on Records and Statistics and the National Committee on Vital and Health Statistics 47th Annual Symposium*. Washington, DC: USDHHS.
- Corea, G. (1985). *The hidden malpractice: How American medicine mistreats women*. New York: Harper & Row.
- Gallegos, H. E., & O'Neill, M. (Eds.). (1991). *Hispanics and the non-profit sector*. New York: Foundation Center.
- Gamble, V. (1997). Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*, 87, 4–9.
- Hatch, J., Moss, N., Saran, A., Presley-Cantrell, L., & Mallory, C. (1993). Community research: Partnership in Black communities. *American Journal of Preventive Medicine*, 9, 27–31.
- Hayunga, E. G., & Pinn, V. W. (1996). NIH response to researcher's concerns. *Applied Clinical Trials*, 5 (11), 59–64.
- Israel, B. A., Schulz, A. J., Parker, E.A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- Kuczewski, M. G. (1996). Recovering the family: The process of consent in medical decision making. *Hastings Center Report*, 26 (2), 30–37.
- Mays, V. M., & Cochran, S. D. (1996). Is there a legacy of Tuskegee? AIDS misbeliefs among inner city African Americans and Hispanics. In *Proceedings of the Eleventh International Conference on AIDS, Vancouver, British Columbia, Canada*.
- Mays, V. M., & Cochran, S. D. (2000). Methods for increasing the relevance of telephone and field survey research to community needs. In *Proceedings of the National Center for Health Statistics Conference on National Health Statistics*. Washington, DC: USDHHS.
- Mays, V. M., Cochran, S. D., & Lin, C. C. (2000). *Volunteering behavior of women and ethnic minorities: Implications of a legacy of discrimination and benign neglect for their participation in health research and clinical trials*. Monograph in preparation.
- Turner Advisory Committee on Human Radiation Experiments (1996). Research ethics and the medical profession: Report of the Advisory Committee on Human Radiation Experiments. *Journal of the American Medical Association*, 276 (5).
- Wermeling, D. P., & Selwitz, A. S. (1993). Current issues surrounding women and minorities in drug trials. *Annals of Pharmacotherapy*, 27 (7–8), 904–911.