VII. Recruitment

In working with genetic researchers, community organizations can play an important role in recruiting participants for a study. The work of community organizations can be particularly important for studies that target racial or ethnic groups where distrust of medical research is significant or for studies involving a rare disease or with highly specific eligibility criteria. How organizations can best facilitate recruitment depends on both the nature of the organization and the design of the study. In cases where an organization has members or clients that match the eligibility requirements of a study the organization may be able to simply provide those individuals with a description of the study and contact information for the researchers. In such cases an organization can also work to ensure necessary follow-up contact for both participants seeking research results and researchers seeking additional samples. Many organizations also post descriptions of ongoing studies on their websites, allowing interested users to compare studies and contact researchers on their own. Alternately, organizations can provide a link to the NIH’s Clinical Trials website, which provides a searchable list of ongoing genetic studies, along with other non-genetic studies.

In cases where recruitment is required from outside of an organization’s membership, an organization can organize public forums where information on the study can be presented to interested community members. Organizations can also assist researchers in designing culturally sensitive presentations or advertisements for the study as well as in reaching out to influential local political or religious institutions. In situations where community members are reluctant to participate in a study, either due to mistrust or cultural barriers, community organizations can be vital in effectively
communicating accurate information about the study and the benefits and risks it poses. For instance, in recruitment for the African American Hereditary Prostate Cancer (AAHPC) Study a variety of local African American community organizations worked with researchers to both distribute information about the study and identify eligible families. Often the simple affiliation of a respected community organization with a genetic study can significantly allay community reservations. However, organizations must be cognizant that in actively endorsing a study they may communicate to the community a belief in the likelihood of a positive outcome.

In some cases community organizations may also play important roles in conducting a genetic study. Many types of genetic research rely on ascertaining both DNA samples and personal health information from participants. Community organizations with experience providing health or patient services may be able to assist researchers in collecting samples and health information. Based on their experience with the community, they may also be able to inform researchers of the most culturally appropriate way to collect samples or request personal and health information. Where a study requires travel or a significant time commitment community organizations can also provide participants with assistance either in reaching the location of the study or in alleviating work or childcare responsibilities. This may be particularly important for studies conducted in poor or rural communities where participants may not be able to easily take time off from work or access to transportation. In communities where members speak a different language than do researchers, community organizations can also be essential in translating between participants and researchers. Translation may be necessary for both informing participants about the study and ascertaining their consent.
and in terms of collecting personal and health information from participants. Effectively translating for a genetic study usually requires translators to be adequately familiar with the science related to the study as well as the specific details of the study itself.

**Readings**

The following are examples of community organizations that are involved in recruitment:
- FORCE [http://www.facingourrisk.org/]
- Foundation Fighting Blindness [http://www.fightblindness.org/]
- Genetic Alliance [http://www.geneticalliance.org/]
- National Organization for Rare Disorders [http://www.fightblindness.org/]
- National Tay-Sachs and Allied Diseases Association [http://www.ntsad.org/]
- NCI’s CARRA Program [http://carra.cancer.gov/]

NIH, Clinical Trials [http://www.clinicaltrials.gov/] provides a searchable list of ongoing genetic studies, along with other non-genetic studies.

NIH, National Human Genome Research Institute and Howard University, National Cooperative Study of Hereditary Prostate Cancer in African-Americans [http://www.genome.gov/10002040] provides information on the AAHPC Study, including who is being recruited and how.

Royal (1999) explores the implications of racial congruence between researchers and subjects for recruitment in genetic research.

**Further Readings**

Baker (1999) examines levels of distrust for medical research among different minority groups.
Duran (1998) discusses obstacles to the recruitment of Hispanics into medical research.
Fouad et al (2000a) discuss the importance of racial/ethnic concordance for the recruitment of African Americans into medical research.
Hughes et al (2004) discuss the significance of racial/ethnic concordance in recruitment for hereditary breast cancer research.
Kaback (2001) reviews the development and success of Tay-Sachs screening programs in the Jewish community.
Royal et al. (2000), Hughes et al. (2004), and Patterson et al. (2005) provide examples of recruitment strategies used in cancer genetics studies. Shavers, Lynch, and Burmeister (2002) and Roberson (1994) summarize the effect of past medical experience on minority recruitment within medical research in general. Stevens, Shi, and Cooper (2003), Cooper-Patrick et al. (1999) and Brach and Fraser (2000) examine the effect of racial/ethnic concordance in health care generally. Williams et al. (2000) provide an example of recruitment strategies used in a hypertension genetics study.