

# CASE STUDIES

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### Case Presentation: Community Engagement for the HapMap Project in Nigeria

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#### Background:

#### Nigeria and the Community of Abu-Alamu:

Nigeria, located on the Western coast of Africa, shares borders with Benin, Niger, Chad, and Cameroon. Following sixteen years of military rule associated with widespread human rights abuses, a new constitution was adopted in 1999, representing a return to civilian government. The Nigerian population of approximately 127 million is comprised of more than 250 ethnic groups with diverse languages and faiths. Nigerians have suffered from political instability, poor economic growth, widespread poverty, and inadequate health resources. Malaria, tuberculosis, and other infectious diseases contribute to the poor health of the region. HIV/AIDS, which has been devastating for many nations in Africa, is an emerging problem in Nigeria. Illiteracy rates are high. The national literacy rate is 57%, but is significantly lower in rural areas. Unemployment continues to be a major concern. The primary occupations are small-scale trading, cattle rearing, and farming.

Ibadan, Nigeria has an estimated population of 2 million persons in its metropolitan area. The community of Aba-Alamu, in which the study is to be conducted, is a suburb of Ibadan. Over 95% of the 19,000 residents of Aba-Alamu are Yoruba. A Baale, the community leader, who is assisted by an elected community council, heads this community. The council meets once a month to deliberate on every issue affecting the community. Contact has been made with the Baale and he has expressed his readiness to meet with the research team alone and in council to discuss the development of the HapMap research project.

#### The HapMap Project:

The capacity to map the human genome has had a profound impact on biomedical research with important implications for clinical practice and public health. The development of haplotype maps of blocks of single nucleotide polymorphisms (SNPs) along chromosomes is expected to contribute significantly to the discovery of genes related to health and disease. The Haplotype Map (HapMap) Project is an international collaborative initiative funded by the National Institutes of Health in the U.S. Approximately ten ethnic and geographic populations around the world have been identified for participation in the HapMap project. Because there are differences among groups in how common some genetic variations are, researchers will find most of the genetic variations by including people from diverse ethnic and geographic populations. Considerations of risks and benefits to individuals and communities have been at the forefront of discussions about the HapMap Project, and have been incorporated into all aspects of the initiative.

The goals of the Nigerian HapMap project are to design a culturally appropriate process of community engagement for considering the risks, benefits, and relevance of developing a haplotype map of the human genome, to obtain blood samples from community members, and to develop mechanisms for ongoing community feedback regarding the haplotype mapping initiative. Strategies for community engagement include: 1) formation of a Community Advisory Board; 2)

in-depth ethnographic interviews with individuals representing diverse segments of the community; 3) a community survey; 4) formation of community working groups to assist with the identification of risks and benefits associated with participation in the haplotype map project; 5) focus groups; and 6) town meetings to provide an opportunity for further dialogue between investigators and community. Following the process of community engagement, researchers will enroll a random sample of 80 Yoruba trios (father, mother, one offspring; n=240 persons).

With the exception of geography, ethnic origins and sex, no identifying information will be collected from the research participants. In this regard, identification of individuals participating in the HapMap project is virtually impossible. Research participants will not be contacted in the future. However, strategies to provide ongoing feedback to the community about how researchers are using the HapMap and what they are learning about health and disease will be developed. Samples will be stored at the Human Genetic Cell Repository at the Coriell Institute for Medical Research in the U.S. which the NIH oversees. Cell lines created from the samples will be available for researchers from around the world to use in future genetic studies. All studies must be approved by the Institutional Review Board (IRB) of the Repository and of all participating institutions. Also, Community Advisory Boards from the participating communities will be involved in providing oversight for future studies.

### **Ethical Issues:**

In any cultural setting, genetic researchers face many ethical challenges. Those working in resource poor nations face unique ethical dilemmas because of social and structural factors influencing the design and implementation of research. Challenges surrounding informed consent may be heightened because of language barriers that diminish effective communication, particularly regarding the translation of genetic concepts. There also may be differences in beliefs about the locus of decisional authority—who is able to provide consent to participate in scientific research. Genetic research may involve family studies and this also has important implications for informed consent practices. Throughout the world, beliefs about "genes" and "genetics" interface with notions of kinship and group identity, calling attention to the complexity of issues related to individual consent and community "permission" in genetic research.

In recent years, investigators, scholars, and public advocates have addressed the issue of conducting community consultation or obtaining community "permission" for the implementation of genetic studies. Some communities have expressed serious concerns about stigmatization, discrimination, and the promulgation of negative stereotypes. The HapMap project pays serious attention to the importance of community engagement. Yet, do the strategies outlined ensure diverse community representation in dialogues about HapMap? If there are serious disagreements about community participation among diverse constituencies within the population, should the project be abandoned altogether? Or would it be ethically appropriate to proceed with the study to enable individuals who want to participate to do so? How much consensus must there be within a community for a study to proceed? Whose community voice "trumps" in the decision for community participation? How does the notion of informed consent interface with the process of community engagement?

Ethical concerns associated with the benefits and burdens of research are important to consider in the HapMap project. Although the data base created for the HapMap will be available to researchers worldwide, it is unlikely that in the near future, individuals or communities in resource poor nations will derive the anticipated benefits from future studies. What obligations do researchers have to consider how individuals and communities might benefit from the HapMap project? What strategies can be instituted to promote benefits for individuals and communities? Capacity building through education, technological resources, and health care might be considered as potential benefits to the community, but what should be given priority considering the limited funds available in most research projects, and who should be involved in the decision-making process?

Some critics of the HapMap project might argue that the attention to community engagement is only ornamental and that, for some of the communities involved-particularly communities in resource poor nations-the project represents one more instance of biomedical hegemony and exploitation. Yet, if diverse ethnic and geographic groups from throughout the world are not included in the study, the charge of exclusivity favoring "northern" populations would definitely apply. In your consideration of the medical and social benefits and risks of conducting the HapMap project, how would you argue the pros and cons of implementing the study in resource poor nations?