

National Advisory Council for Human Genome Research

19 May 2008

Concept Clearance for Request for Applications (RFA)

A Data Analysis Center for the Minority Action Plan and Research Training Programs

Purpose: NHGRI Staff propose a new solicitation for a Data Analysis Center that would be responsible for collecting and analyzing outcomes data for the Minority Action Plan.

Background: The NHGRI Plan for Increasing the Number of Underrepresented Minorities Trained in Genomics and ELSI Research (<http://www.genome.gov/10001707/>) was developed in 2002 with the goal of increasing the number individuals from underrepresented minority (URM) populations who are trained to pursue research in the fields of genomics and ELSI research. The plan was based on five principles: (1) underrepresented communities must be involved; (2) opportunities must be available at all career levels; (3) programs must be anchored in institutions involved in genome and ELSI research; (4) involving and training minority individuals must be a goal for all parts of the NHGRI programs; and (5) the plan must have achievable goals, measurable outcomes, appropriate reviews and undergo evaluation. The Plan was approved by National Advisory Council for Human Genome Research in May 2002. At the same time, a subcommittee of Council was impaneled to provide oversight of the program and advice to NHGRI regarding progress. The subcommittee includes Council members, as well as additional experts who have track records in training or are interested in the research training of URM populations.

Projects in which NHGRI had a significant investment were considered ideal laboratories for this initiative. Thus, it became mandatory for large-scale sequencing centers, Centers of Excellence in Genomic Science (CEGS), and databases to respond to this initiative. Because we were not sure what would work best, grantees were allowed to propose programs that worked well in their research environment. The types of projects ranged from K-12 curriculum development to the support of postdoctoral fellows and faculty. Because training grants represented another opportunity for increasing the number of individuals from URM populations participating in genomic and ELSI research, research training grants were offered supplements to enhance their recruitment and training of individuals from URM populations.

Starting in the Fall of 2003, the MAP grantees have met annually to review progress, share information and discuss issues of common interest. The members of the Council subcommittee also attend this meeting to provide feed-back to the grantees and to the NHGRI staff. In February 2007, we convened a meeting of the training coordinators because we felt there were day-to-day issues with running this type of program that could benefit from this group discussing common interests. The second meeting was held in February 2008 and it is anticipated that these too will become annual meetings. Summaries of these meetings can be found at: <http://www.genome.gov/14514219#2>.

The imprimatur of the advisors has been evident in their suggestions that research training be encouraged at the undergraduate levels and above and that the amount of

funds allotted to new MAP programs be limited to \$300,000 direct cost. The advisors also strongly recommended that an evaluation program be established to assess whether NHGRI is progressing toward its goal of increasing the number of individuals from URM populations participating in genomics and ELSI research. While the individual programs have always been strongly encouraged to have evaluation and tracking processes in place, this has not been done systematically and it is difficult to compare data among programs. During the last year, the grantees have begun discussions about common data elements to be collected on individual participants in order to collectively assess progress. However, it is important to monitor the quality of the input data, to have objective assessments of the results, and to develop reports for the overall program.

Proposed Research Scope and Objectives: In preparation for this initiative, the MAP grantees have been involved in an exercise in which they have agreed upon the types of data that should be collected on participants to benchmark progress and to demonstrate that participants are on a path that leads to a career in genomic sciences and ELSI. The proposed Data Analysis Center (DAC) would create a centralized database for deposition of the MAP data that would then be the source of all data analysis. The DAC would analyze these data annually, make presentations at the annual MAP meeting, make periodic progress reports to the National Advisory Council for Human Genome Research, and provide written reports to NHGRI. However, in order to have quality reports, it is necessary that there be some quality control of data collected by and put into the database by MAP grantees. It would therefore also be important for DAC personnel to work with MAP grantees to collect complete and accurate records and to develop reliable procedures for tracking participants once they complete the program.

Overview of the DAC responsibilities:

- Work with MAP grantees to refine data elements to be collected on each participant.
- In collaboration with MAP grantees, help define strategies for long-term tracking of MAP participants.
- Work with MAP grantees to ensure that only quality data are collected and submitted to the database.
- Develop a database that can receive data from the MAP grantees and allow MAP grantees to have access to their data only.
- Ensure the confidentiality of information put into the database.
- Develop a variety of analyses and reports for presentation to MAP grantees, advisors, National Advisory Council on Human Genome Research and NHGRI staff.

Mechanism of Support: The DAC will be supported through the U01 Cooperative Agreement mechanism. A total cost of \$400,000 per year for each of five years will be set aside for this initiative. Only one award will be made.