

**NIH/NIDDK/KUH Inter-Agency Coordinating Committee  
(IACC) Meeting**

**July 18, 2005**

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Dr. Briggs welcomed participants and indicated that this meeting would focus on questions relating to oversight of web resources that support scientific research. In addition to the usefulness of the data maintained in the research databases, she discussed some additional criteria important in their evaluation: Are the sites well constructed? Are they easily found? Can their performance be accurately assessed with web statistics tools? What are their costs?

### **Improving Website Visibility**

**Roberta Albert**

Offering suggestions for how one can promote the visibility and the prominence of a particular database, Roberta Albert who is the Web Project Team Leader at NIDDK, explained that an adequate marketing plan should be formulated and that it is useful to advertise a database in blogs, and other media like journals and television news reports. Ms Albert explained briefly how search engines rank web sites; in Google and Yahoo, the data for ranking is acquired automatically by software which determines, among other factors, the degree to which a site is linked to other sites and how often it is chosen by users conducting searches with a given term. The weight given to the number of links to other sites in the process of site ranking makes interagency coordination to ensure adequate inter-linkage of databases especially important. Other search engines are more dependent on direct submission of information by those maintaining the website. Ms Albert discussed some strategies for choosing and positioning key words in the interests of improving the ranking of a site. Search engines are also sensitive to the degree to which content is kept up to date.

### **Flybase**

**Dr. Lisa Brooks**

Dr. Brooks, who is Director of the Genetic Variation Program and Genome Informatics Program, stated that research databases are generally most appropriately supported by government and that a policy favoring integration that leads to emergence of a few major, broad databases is preferred. In her experience, a team of committed principal investigators who understand and are responsive to the needs of the community is essential in establishing and maintaining bioinformatics resources. In general, new databases should incorporate tools and approaches developed by existing ones; the generic modules for organizing biological information developed by databases like Flybase should be used in those devoted to new model organisms. She briefly discussed appropriate award and review mechanisms for bioinformatics resources.

Dr. Briggs asked who decides on the admissibility of new kinds of datasets to Flybase. Dr. Brooks said the decision might involve the convening of an expert panel and explained that it was helpful to get data structures in place early, even on an experimental basis, so that one is ready to handle large amounts of data that may become available

later on. Dr. Brooks predicted that in the future there would essentially be one overarching database for all model organisms.

### **United States Renal Data System**

**Dr. Josephine Briggs.**

Dr Briggs explained how the Annual Data Report of the US Renal Data Service had evolved over the years to a leading epidemiologic data base. Using RenDer (Renal Data Extraction and Referencing System), all interested researchers can now mine the epidemiological database; specific questions pertaining to the incident and treatment of renal disease are submitted and returned in tabular formats suitable for further analysis. The site had 60,000 unique visitors last year. Recalling Roberta Albert's discussion of how to make websites more prominent in searches, Dr. Briggs noted that searches using terms like kidney and epidemiology did not turn up the USRDS, in spite of its recognition as the leading source of information on renal disease. Dr Briggs outlined the costs of the USRDS which relies on the CMS for its data files.

Dr. Engelgau asked about procedures to ensure confidentiality of the medical data. Dr. Briggs noted that in its reports RenDer censors small cells of data to protect privacy . Some needed steps for facilitating feedback from RenDer users were discussed. Dr. Nyberg indicated that it was envisaged that the data in the NIDDK's report, "Urological Diseases in America" would also be transformed into an interactive epidemiological database.

### **Stem Cell Genome Anatomy Project**

**Dr. Arthur Castle**

In the Stem Cell Anatomy Projects, seven academic institutions maintain databases that are linked to a common portal . The project is devoted to maintaining data on gene expression in a variety of tissue-specific progenitor cells. The gene expression data is from gene expression arrays, in situ hybridization, immunohistochemistry and other methodologies . Dr. Castle explained briefly how a search might be conducted for data on the expression of a gene of interest. Although the data base allows users to access diverse kinds of data, the existence of separately maintained databases linked only by a common portal is not conducive to meta-analyses. New software now permits investigators to conduct pathway –specific rather than gene-specific searches. The cost of the seven databases and the common portal is \$200,000 and \$150,000 respectively.

Dr. Rassooly explained that it was a bit early to assess usage of the site, which has been advertised at stem cell conferences and in relevant journals.

### **Animal Models of Diabetic Complications Consortium**

**Dr. Chris Ketchum**

Dr Ketchum explained that the consortium grew out of the need for suitable animal models for diabetes complications. The AMDCC, which has developed a set of standards by which to assess the validity of the models for various complications of diabetes in

humans, seeks to facilitate the sharing of animals, reagents, and expertise in the research community. NIDDK, NHLBI, and steering and external advisory committees oversee the project whose annual budget is 4.8 million dollars. About 6% of the total budget is allotted to a dedicated informatic core (Coordinating and Bioinformatics Institute). The ongoing research activities of the Mouse Engineering and Phenotype Units are freely available on the website allowing investigators to stay abreast of newly available strains and phenotypic data. Dr. Ketchum indicated that one problem that needs to be addressed is the under reporting of negative data on the site and in peer-reviewed publications. After reviewing web traffic reports for the AMDCC site, Dr. Ketchum concluded that at present most queries seek to gain information about experimental protocols and methodology.

In the ensuing discussion, there was general agreement that the website of the AMDCC was well organized and easy to use.

### **New or planned initiatives of potential interest to NIDDK**

Dr Briggs announced NIDDK interest in an RFA directed to the new methodologies for the imaging of renal scarring.

Dr. Barouch announced two program announcements—“Pilot and Feasibility Program Related to the Kidney” and “Development of Diagnostic Screening Test for Salt Sensitivity”. Three RFAs being considered that would be of interest to the NIDDK focus on volume regulation and heart failure in humans, the management of coronary artery disease in humans, and the relationship of renal ion transport to blood pressure.

Dr. Prasad announced that NIAID was planning to issue an RFA, (Genomics of Transplantation) to identify and characterize gene polymorphisms and gene expression patterns that correlate with or predict transplantation outcomes. He also described a database maintained by the NIAID which functions as a virtual repository for reagents used in non-human primate research.

Dr Bellino of the NIA mentioned his institute’s RFA focusing on anemia in the elderly and discussed plans for an RFA on testosterone trials in aging men with some focus on urological outcomes.