



## RESEARCH INFORMATICS GOVERNANCE COMMITTEE

*Thursday, May 9, 2013*

*KCBD 10<sup>th</sup> Floor South Conference Room*

*3:00-4:00 p.m.*

### **Meeting Minutes**

In attendance: R. Grossman (chair); J. Cunningham, D. Edelson, C. Gilliam, M. Hanzal, J. Solway, W. Stadler, S. Volchenboun *Ex Officio*: S. Birz, H. Lawrence, C. Pike, D. Saner

### **Minutes Approval**

The March 7, 2013 meeting minutes were approved.

### **CRI Organizational Update**

Dr. Grossman updated the Committee on recent changes to the CRI's organizational structure. Dr. Volchenboun is now Director of the CRI. Dr. Grossman remains the Chief Research Informatics Officer (CRIO) and is also Director of the BSD's Initiative in Data Intensive Science. Plamen Martinov has been hired as the CRI's Director of Systems and Security. One of Mr. Martinov's priorities is leading the effort to migrate systems and labshare data from Prudential to Kenwood Data Center, with 48 of 75 labshares transferred so far. Dr. Grossman requested that any concerns from faculty regarding the migration be directed to Dr. Volchenboun.

### **Methodology for De-Identifying Data**

Mr. Saner explained that the U.S. Department of Health and Human Services recommends two methods of de-identifying data for the purpose of clinical research. The first method is Safe Harbor, which redacts the identifying elements that constitute PHI. For research requiring more granular dating of events, the method of Expert Determination allows dates to be provided if they are obfuscated in one of two ways: either shifted on a per-patient basis by a random number between 0-364 or provided as "days since birth" without the date of birth. The Research Informatics Technical Policy Committee has reviewed and approved these methods on a technical level, and the CRI now seeks the approval of the Governance Committee to use these two methods to provide de-identified data to BSD researchers.

The Committee voted to approve the use of these two methods as outlined above in a manner consistent with HHS Guidelines.

### **De-Identified Data Mart**

Dr. Grossman is seeking the Governance Committee's approval to create a de-identified Datamart and allow access to researchers, with the following safeguards: data would be de-identified in the manner described above; requests for access would be evaluated and approved by the Research Informatics Data Use Committee; users would receive education and sign a Data Use Agreement certifying that they will not attempt to re-identify data; and additional monitoring of user activity would be added over time.

The Committee was supportive of this concept but raised questions including the following: the specific criteria that the Data Use Committee will use to evaluate the merit of requests for access; whether and under which circumstances non-BSD faculty and/or non-PIs would be allowed access; the details of the necessary education and monitoring; and the makeup of the Data Use Committee and whether it should include more faculty members.

The Committee concluded that the members are supportive of the principle of this request, but will require further detail before voting to approve.

*The meeting was adjourned at 4:00 p.m.*