



## **Research Informatics Technical Policy Committee**

**Friday, February 15, 2013**

**2:00-3:00 p.m.**

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

### **Meeting Minutes**

In Attendance: R. Grossman (chair); R. Engelmann, R. Gopalakrishnan, J. Moses, D. Saner, S. Volchenbom; *Ex Officio*: S. Birz, H. Lawrence

#### **Approval of the Minutes**

The minutes from the October 19, 2012 and December 14, 2012 meetings were approved. Dr. Grossman noted that the meeting minutes from all meetings of the Research Informatics Governance Committees will be posted to the CRI website. When sensitive topics are discussed, those details will be redacted from the public minutes but included in the minutes circulated to the Committee.

#### **Affiliated Datamart Application Process**

Mr. Saner noted that at the December 14, 2012 meeting, the Technical Policy Committee defined two approved methods for providing de-identified data to individual investigators. However, the Committee also determined that providing data to datamarts incurs additional risk. One potential issue is that datamarts may already contain data that would make it possible to re-identify newly added data. In addition, datamarts are often used to redistribute data, which may allow sensitive information to leave the institution's control. Individuals who receive CRDW data, whether identified or de-identified, sign a Data Use Agreement certifying that they will use the data only for the scientific purpose outlined in the request and will share it only with scientific personnel involved in the study.

In addition to the risks of re-identification and redistribution, supplying data to datamarts raises the question of whether CRDW data should be provided to datamarts that contain unconsented patient data.

Part of the approval workflow for an Affiliated Datamart is a review and approval of its architecture by the Technical Policy Committee. Some researchers may request to receive data in an intermediate format for loading into a datamart; Mr. Saner asked the Committee whether their architecture review of such datamarts should include this intermediate format or staging area. Dr. Grossman noted that he would like the CRI to provide secure intermediate staging as an enterprise service for these datamarts.

The Committee was asked whether all Affiliated Datamarts require IRB approval. Many members present felt that they might, but that the issue should be assessed by the Data Use Committee and IRB.

The Committee recommended that the language in the Data Use Agreement currently used for individual investigators be reviewed to determine whether it should be modified when applied to Affiliated Datamarts.

Mr. Saner asked the Committee to consider the technical requirements an Affiliated Datamart should meet. Mr. Moses suggested creating a relatively short checklist of requirements, including a “sniff test” and an understanding of the datamart’s data structure, architecture, security, and technical procedures including logging and authentication. Mr. Gopalakrishnan added that many researchers author their own databases and a review could be constructed to ensure standards are met.

Mr. Saner noted that another requirement for Affiliated Datamarts is that they be housed in a “Secure Data Zone” approved by the Technical Policy Committee. Both the CRI Kenwood Data Center and the CBIS Darien Data Center are equipped with physical controls and procedures designed to ensure compliance with HIPAA. Mr. Saner asked the Committee whether any other data centers meet this requirement at this time. A discussion of Argonne Data Center and Amazon’s data centers produced some concerns, including whether the University would be able to enter a Business Associate Agreement with Amazon. The Committee determined that Darien and Kenwood are currently the only Secure Data Zones approved by the Technical Policy Committee, but that a process should be developed for evaluating other options in the future.

Mr. Saner proposed that a working group composed of members of the Technical Policy Committee, Data Use Committee, and Compliance Review Committee be convened to work through the issues presented at this meeting and prepare a proposal outlining the steps to becoming an Affiliated Datamart. All present voted to approve the creation of this working group.

The meeting was adjourned at 3:00 p.m.