



RESEARCH INFORMATICS GOVERNANCE COMMITTEE

Thursday, January 16, 2014

KCBD 10th Floor South Conference Room

3:00-4:00pm

Meeting Minutes

In attendance: R. Grossman (chair), S. Badlani, J. Cunningham, D. Edelson, C. Gilliam, M. Hanzal, C. Ostapina, L. Ross, J. Solway, W. Stadler, S. Volchenboun, E. Yablonka *Ex Officio* S. Birz, T. DeNormandie, H. Lawrence, P. Martinov, C. Pike

Minutes Approval

Minutes from the November 7, 2013 meeting were approved.

PCORI Update

Dr. Badlani provided a brief overview of the PCORI grant received by nine Chicagoland institutions, including the University of Chicago. The purpose of the PCORI grant is to connect clinical databases between institutions to create a research database of one million patients, which is to be used to study three types of disease: obesity-related diseases, common diseases (anemia and asthma), and rare diseases (C. diff infection and sickle cell disease). This grant presents many technical challenges in combining data from different institutions with different EMR systems, and requires that strict six-month milestones be met.

Dr. Badlani asked who the main technical person working on this will be, in light of Don Saner's departure. Dr. Grossman noted that Don was included on the grant at 10 percent effort, and suggested hiring a person solely to work on PCORI.

Ms. Hanzal asked whether PCORI is classified as quality or research. Dr. Badlani clarified that it is research. Ms. Hanzal noted that she would make sure the Office of Legal Counsel is aware.

Data Stewardship Committee Update

Dr. Cunningham provided an update on the Data Stewardship Committee (DSC). The DSC has been tasked with creating a set of policy recommendations for data stewardship in the BSD. Their interviews are complete and they expect to have policy recommendations to the Dean in early February. These guidelines will focus around institutional expectations for PIs regarding protection of data, including issues of implementation.

Dr. Stadler asked whether the DSC has engaged University IT, and Dr. Cunningham clarified that Klara Jelinkova (Senior Associate Vice President and Chief Information Technology Officer) is a member.

CRI Committee Updates

In the last meeting of the Governance Committee, it was agreed that Committees reporting to the Research Informatics Governance Committee should report regularly at meetings of the Research Informatics Governance Committee. At this meeting, the chairs of the Data Use Committee and Compliance Review Committee made brief updates.

Data Use Committee

Dr. Edelson reported that the Data Use Committee met seven times in 2013. Their major accomplishments included developing and updating a Data Use Agreement, creating policies and procedures for CRDW use, facilitating the fulfillment of 146 data requests, and beginning to collect additional data such as turnaround time. They are currently engaged in developing a chargeback process for CRDW services.

Dr. Stadler asked if the Office of Clinical Research has been engaged to ensure that the processes developed are compatible, and Dr. Edelson clarified that the OCR is represented on the Data Use Committee.

The Committee discussed faculty/PI perceptions of the CRDW's accessibility and the potential effects of the proposed new chargeback model. Volchenboun noted that he has met with similar groups at other institutions to study their methods for applications, chargeback, triage, and storage, and that the CRI's new proposed system is in line with these practices. The Committee agreed to discuss the issue in further detail at the next meeting and to potentially create an ad hoc committee around the topic.

Compliance Review Committee

Mr. DeNormandie reported that the Compliance Review Committee met nine times in 2013. Their work has been devoted to re-evaluating a set of approved procedures in order to improve them and apply best practices. They will continue to review procedures until all have been improved, update procedures as policies change, and review the CRI's security metrics. Mr. DeNormandie noted that the Compliance Review Committee is a technical committee (as opposed to a high-level policy-making committee).

Ms. Ostapina noted that the BSD Security Policies are being removed from the HIPAA website and replaced with a link to the UCM Security Policies. The CRI security procedures are based on the BSD Security Policies.

Informatics Priorities for 2014-15

Dr. Grossman initiated an open discussion to determine informatics priorities for the BSD in the next year. He noted that a conversation like this should occur each year, and that it should include discussion of how the BSD can organize to support the goals that are chosen. He reminded the committee that the creation of smaller “ad hoc” committees is one potential tool for this support.

Dr. Grossman noted that as CRIO, one of his priorities would be organizing for the University’s success in meeting the required milestones of the PCORI grant.

Dr. Stadler suggested considering which other enterprise or enterprise-like systems should be incorporated into the CRDW – for example, tissue databases, imaging, and clinical trials management systems. This includes determining which systems should be prioritized, how they should be incorporated, and whether tools need to be evaluated for long-term viability.

Ms. Hanzal suggested an ad hoc committee be formed to discuss the creation of a de-identified datamart and requested to be a part of that group.

Dr. Ross noted that the CTSA grant has been restructured with three main priorities (subject recruitment, electronic health records, and federated IRBs). While it is not yet clear how these elements will interact, RFAs will be released soon and some can be expected to have a significant informatics component. Dr. Stadler noted that the PCORI grant similarly focuses on connecting EHRs between institutions, that having a functioning CRDW already is a strong position for the BSD, and that integrating other datamarts into the CRDW could fall under this umbrella as well. Dr. Cunningham agreed that grant funding will likely be available for this type of activity, as well as for linking electronic health records with biorepositories.

Dr. Edelson asked about the status of a de-identified datamart and portal for self-service data retrieval. The CRI’s self-service portal will be a priority in the first half of 2014, with the main potential barrier being regulatory issues. Dr. Volchenbom noted that he visited Loyola recently and their goal is for 85 percent of data retrieval to be self-service. He added that Loyola’s program benefited from strong physician-led support to refine data types and standardize naming conventions in a reliable, peer-reviewed way.

Ms. Hanzal asked how potential costs, in both human and financial capital, should be incorporated into this discussion. Dr. Stadler noted that putting a prioritized list through the budget process would be the next step.

The committee reviewed their list of potential areas of focus:

- PCORI grant
- CRDW and integration of other enterprise systems (e.g. TRIDOM)

- De-identified datamart and self-service data portal
- Biospecimens
- Imaging
- Developing a CRDW-EIA interface that will allow the BSD to work effectively with the hospital
- CTSA as related to informatics
- Risk reduction (including having more researchers on secure infrastructure and designing services to reduce overall risk to the BSD)
- Improving clinical trials informatics (including Velos)
- Molecular diagnostics and computing over cell-based imaging, to integrate basic research/discovery with diagnostics
- Beagle transition

Dr. Grossman noted that we must prioritize this list and that we would return to this task at the next meeting. Dean Gilliam suggested separating scientific questions from regulatory and compliance issues, and consulting other groups on the prioritization of scientific questions. Dr. Cunningham invited Dr. Grossman to the next meeting of the Research Advisory Committee for feedback on scientific priorities.

The committee concluded the meeting by noting that all members should be involved in prioritizing, and others including the Informatics Oversight Committee and the Research Advisory Committee should play a part as well.

The meeting was adjourned at 4:00pm.