NAACCR Institutional Review Board (IRB)
Conference Call Summary
April 24, 2009 at 11:30 AM ET and 10:30 AM CT

Present: John Fulton (Chair) Susan Carozza, Won Silva, Deirdre Rogers, Tara Hylton, Will Athas, Suzanne Hornbeck

NAACCR Staff: Royale Anne Hinds, Betsy Kohler

Absent: John Morgan, Maria Schymura, Vivien Chen, Linda Muul, Jack Finch

Agenda Items

1. a. A quorum was established for the meeting.
   b. John Fulton welcomed Suzanne Hornbeck, the IRB's newest member. He gave a brief introduction describing her job as a grants coordinator at Susan G. Komen in New Jersey. She is a lobbyist on Capitol Hill. She has done some grant reviews, but has not worked on an IRB previously.

2. Royale Anne Hinds reported on the minor changes that were made over the last six months to the NAACCR IRB Guidelines. They include membership updates and updated forms.

3. No Expedited IRB reviews were completed during the past six months. There are no outstanding reviews at this time.

4. There are five CINA Deluxe applications that have been approved to use NAACCR data, but the IRB applications have not been received. Aruna Babu has not responded to email requesting an update. Tara Hylton informed the group that Aruna Babu has been out of the office on maternity leave. Tara will forward the email to Aruna to find out the status of her data request. Howe and Goodman are not being completed because funding is not available. McCarthy and Huang have recently been approved, so we expect to receive IRB applications soon.

5. The annual progress reports section of the agenda shows 16 projects that had activity in the last six months. Royale Anne Hinds explained the annual monitoring forms are only reviewed by the Chair if changes to the protocol have taken place. If there were any problems encountered, such as loss of data or breach of confidentiality, there would be a review by the entire Board. If data was lost, it would be a considerable problem. An emergency IRB meeting would need to be held.

6. Won Silva asked if there is a written policy on data security. Is the data encrypted while it is used locally? John Fulton responded that NAACCR should have a policy on data security, though the IRB could have standards on data security also. Each IRB application has information on data security, which should be reviewed. The group feels that laptops and shared drives are not acceptable to put data on. NAACCR should have a policy that researchers sign before getting data. The IRB could make sure that the data security policy is signed.

Royale Anne and Betsy will research and send information to the NAACCR IRB to review. NAACCR has a report on data security on the website which will be forwarded to the group. John feels that the IRB needs to review the data security policy on a regular basis because of constant changes. Won Silva suggested having IT people also sign the data security policy, so everyone is responsible.

Upcoming Call Information

1. The next meeting will be held Friday, October 16, 2009 at 11:30 AM Eastern, 10:30 AM Central, 9:30 AM Mountain, and 8:30am Pacific.
2. John thanked everyone for joining the call.