

**NAACCR Institutional Review Board (IRB)  
Conference Call Summary  
April 25, 2008 at 11:30 AM ET and 10:30 AM CT**

**Present:** John Fulton (Acting Chair), Vivien Chen, Will Athas, Jack Finch, Susan Carozza, Won Silva, Deirdre Rogers

**NAACCR Staff:** Royale Anne Hinds

**Absent:** Tara Hylton, John Morgan, Bette Ann MacIntosh

**Excused:** Maria Schymura, Linda Muul

**Agenda Items**

1. a. John Fulton welcomed new members, Deirdre Rogers and Won Silva. John asked them for background information. Deirdre Rogers responded that she has not served on an IRB before, but is familiar with the function of an IRB. She has completed the IRB training and received her certificate. Won Silva responded that she does not have experience, but has been trained by her state government and is familiar with proposals. John invited members to contact him or Royale Anne if they have questions.  
b. Because Holly Howe has resigned as Executive Director, John Fulton is filling in as the Acting Chair of the IRB until a new Executive Director is hired.
2. Royale Anne Hinds reported that membership updates have been made to the IRB Guidelines and with the Office for Human Research Protections (OHRP). The Federal Wide Assurance (FWA) number was renewed until March 7, 2011.
3. Four IRB reviews were completed in the last six months, of which three were Exempt and one was Expedited. John detailed the process of IRB review. The Chair is first given the option to review each proposal. Reviews are offered to various members to review throughout the year. Completed review summary forms are sent to all Board members with a two week period to comment or ask questions. It is important that the members review the summary form to raise any questions or concerns. No concerns were raised or questions asked about the exempt or expedited IRB reviews that have been approved over the last six months, either upon completion or during today's call.
4. Jack Finch asked for clarification on the IRB's purview. John Fulton explained that the NAACCR IRB reviews proposals for the protection of human subjects. John further explained that if you were working with human subjects, a poor research design can increase the cost to human subjects.
5. The annual monitoring results show that thirteen projects are ongoing and five projects have been completed since the last IRB meeting. The completed projects had their access to the data file terminated. Some projects are nearing completion, but researchers keep access to the data file open while they submit to journals, in case changes are needed.

6. Other Business – Will Athas asked about the issues with VA reporting and how it affects the IRB. John Fulton explained that responsibility lies outside of the NAACCR IRB. The NAACCR Board of Directors and state registries are responsible for making the data available for the CINA Deluxe Data File, etc. It becomes the NAACCR IRB's responsibility to make sure the available data is used appropriately, in such a way that confidentiality is not breached. As NAACCR members, we should bring up any possible violation of the data use agreement.

Won Silva asked if another review takes place when a researcher requests an updated data set, but all other variables are the same. John Fulton explained that requesting an updated dataset does not require re-review by the IRB. But a change in protocol, such as requesting a new variable, would require IRB re-review. If new variables are used, the risk of breach of confidentiality changes and needs to be re-reviewed.

Vivien Chen asked about the "Expected Completion Date" on the table of annual progress reports. Royale Anne Hinds explained the table shows the date the researcher gave as their expected completion date during their last annual monitoring. This date is not verified until the current year's annual monitoring process is completed.

### **Upcoming Call Information**

1. The next meeting will be held Friday, October 17, 2008 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 and welcomed the new members to the IRB.