

IRB/REB Workgroup Meeting

January 24, 2008

Present

Pat Alt, Towson, MA
Margaret Butler, Houston, TX
Vivian Carter, Tuskegee, AL
Amy Davis, Boston, MA
Linda Delaney, Marion, AR
Ramona Fillman, Honolulu, HI
Anthony Fleg, Chapel Hill, NC
Carolina Gonzalez-Schlenker, Madison, WI
Loretta Heuer, Grand Forks, ND
Lucie Levesque, Kingston, ON, Canada
Mary Ann McDonald, Durham, NC
Patrick McShane, Woodbridge, VA
Maghboeba Mosavel, Cleveland, OH
Lisa Moy, Seattle, WA
Dianne Quigley, ?, MA
Menraj Sachdev, San Francisco, CA
Nancy Shore, Portland, ME
Doe West, Framingham, MA
Kristine Wong, Seattle, WA
Bernard Young, Cincinnati, OH

Welcome and Introductions

Call participants briefly introduced themselves and shared what the weather was like. (Please see the updated biosketches for information on members.)

Kristine welcomed participants to the IRB/REB workgroup conference call. This workgroup is a partnership between Community-Campus Partnerships for Health (CCPH) and the Tuskegee University Bioethics Center (Bioethics Center). The conference calls will be co-facilitated by Kristine Wong from CCPH and Vivian Carter from the Bioethics Center.

Kristine gave a brief introduction about CCPH. Community-Campus Partnerships for Health (CCPH) is a nonprofit organization that promotes health (broadly defined) through partnerships between communities and higher educational institutions. Founded in 1996, CCPH is a membership based organization with a growing network of over 1,700 communities and campuses across North America that are collaborating to promote health through service-learning, community-based participatory research, broad-based coalitions and other partnership strategies. Kristine serves as the Program Director and is currently working with community partners to increase their capacity to work with academic institutions and mentor one another. She also oversees and implements community-based participatory research (CBPR) initiatives and trainings.

Vivian Carter, co-facilitator for the IRB/REB workgroup, is from the Tuskegee University Bioethics Center. The Bioethics Center was established in 1999 as a part of the national apology made by President Clinton for the Syphilis Study conducted in 1932-1971 by the United States Public Health Service. The mission of the Bioethics Center is to promote diversity in the field of bioethics; conduct research on bioethics specifically for poor and underserved populations; provide educational resources to students, researchers, and the community; provide training programs; and advocate public policy which will improve health and healthcare.

Workgroup Orientation

Kristine briefly reviewed the workgroup expectations (see handout). The estimated time commitment is ~5-10 hours per month and members are asked to attend at least 80% of the monthly calls. Calls are on the 4th Thursday of every month and the call-in number will remain the same. If members are unable to attend a call, feedback/comments on materials would be appreciated via email or phone. Members should feel free to join the call late or leave the call early due to schedule conflicts. Kristine clarified that any workgroup documents should be considered confidential until the group has finalized them (or approved them for dissemination).

The IRB/REB workgroup was an outcome of the IRB and Research Ethics Call Series hosted by CCPH and The Bioethics Center in 2007. The Call Series reviewed the function and purpose of an IRB, the importance of the non-affiliated (community) IRB member, CBPR proposals and the human subjects review process, development of an independent community IRB, and IRB reform. The Call Series was well attended and results from an evaluation survey indicated a need to develop training materials/curriculum for IRBs about CBPR and how to review CBPR protocols. There was an overwhelming response to CCPH's IRB/REB workgroup call with ~100 persons indicating interest. The outcomes of this workgroup are not limited to the development of curriculum. Kristine thought it might be beneficial to articulate the workgroup's goals and then determine appropriate outcomes.

Discussion

The workgroup reviewed the intended outcomes and specific goals (see handout).

Discussion followed on the definition of CBPR. Points included:

- CBPR brings dignity back to the community.
- Defining key elements of what this group defines as CBPR is important to have a cohesive effort in the development of the curriculum.
- Funders have their own definition of CBPR, which may differ from the community's definition.
- A key element of CBPR is the dissemination of the research findings to the community.
- CBPR may contain different levels of community involvement.
- CBPR is a continuum.
- The committee (see below) should articulate the pros/cons of having a specific definition of CBPR.

- The workgroup's definition of CBPR should include language on action-research.

A committee was formed to draft the workgroup's definition of CBPR. A draft will be sent for the full workgroup's comments prior to the next call. Committee members are: Carolina, Anthony, Mary Ann, and Vivian.

Kristine clarified that the CBPR curriculum and format will be generated by the workgroup.

Menraj asked for input regarding IRB reviews for international research. Maghboeba said her CBPR in South Africa was impacted more by bureaucracy rather than an IRB's opposition to CBPR.

Carolina and Dianne suggested adding the rationale of using CBPR to the workgroup goals. They will share this information via the listserv. Kristine added that the IRB/REB workgroup listserv should be used as a way to share resources and materials among each other as relating to the curriculum/training.

Maghboeba thought it would be helpful to survey institutional IRBs to determine what format and content would be most appropriate. A committee was formed, including Maghboeba, Nancy, and Pat. (Note: After the meeting, Amy Davis expressed interest in joining this committee as well).

Vivian thought that one of the outcomes of the curriculum/training that this group comes up with could be the development of a cadre of trainers that could implement the training/curriculum. Nancy added that our efforts could be in collaboration with PRIM&R. Another workgroup member added that community partners also need education on the IRB process.

Wrap-Up

Kristine closed the call by reviewing the action items generated during the meeting (i.e., the subcommittees that have been formed), and asked members to share their thoughts about the call.

The next call is: Thursday, February 28, 2008, 12pm PST/3pm EST.