

CTSA Strategic Goal Committee Four:
Enhancing the Health of Our Communities and the Nation

Attendees: A. West, Emory; P. Greenland, Northwestern; M. Helfand, OHSU; H. Selker, Tufts; J. Sachs, NCRR; M. Goode, Texas; DJ McCloskey, NCRR; S. Aguilar-Gaxiola, University of California-Davis; L. Michener, Duke University; B. Moquin, NCRR; T. Concannon, Tufts; S. Pauker, Tufts, B. Strom, University of Pennsylvania.

Meeting Summary

I. Strategic Goal 4A: Community Engaged Research Workgroup

The Workgroup has had a number of prescribed deliverables related to community engaged research best practices. One key deliverable associated with the Workgroup, is the generation of a database of researchers located all over the country. Recently the Workgroup met to discuss the creation of a network of networks that would emanate from the database of researchers. Access to information about researchers doing similar work could potentially lead to collaborative efforts and enhance the impact of projects at the national level. Next steps for the Workgroup include taking a leadership role and helping to coordinate connections between researchers at a national level. A proposal will be submitted for a national conference led by Workgroup members. Dr. Greenland will draft the proposal for an R-13 grant, with a plan for the conference to take place next year. The proposal will be shared among Workgroup members.

II. Strategic Goal 4B: Comparative Effectiveness Research Workgroup

The co-covener(s) of each deliverable workgroup provided a status update regarding their respective deliverables.

4B-1 CER Capacity and Needs Assessment

The comparative effectiveness research capacity and needs assessment has been conducted. Thirty-three of thirty-nine institutions responded to the survey. Respondents of the assessment were either PIs or designated by the PIs to answer the assessment. Drs. Ford and Pincus compiled a summary of the assessment. Respondents were provided a list of activities and then were asked to identify their level of a given activity at their institution. In every area of CER, at least 75% of the CTSA institutions reported some activity. Respondents were also asked about training activities and where they see the need to expand the activities. Additional questions included open-ended questions about how respondents would allot one million dollars

designated for comparative effectiveness research activities. The CTSA institutions were asked where they felt they needed to increase their capacity to conduct research. There were five common areas checked: use of electronic health records for CER (53%), clinically based registries for CER (50%), clinical trials in CER (38%), long term observational cohort studies for CER (34%) and use of practice based research networks (31%).

4B-2 White Paper

Deliverable Workgroup 4B-2 was charged with developing a white paper regarding how the CTSA Consortium can act as a portal to facilitate CER for ICs, other federal agencies, outside stakeholders, and the healthcare system. The capacity and needs assessment completed by Deliverable Workgroup 4B-1, helped to power the analysis for the white paper. Dr. Selker, spoke about the research infrastructure that is already in place and its adaption to CER. He also elaborated on the training centers in place such as the T32 centers. Of the 25 that currently exist, 25 are associated with CTSA's. Many of the CTSA's through other efforts, have data to conduct CER. These data could be shared among centers. Next steps for the Deliverable Workgroup include sending out the white paper to the entire Workgroup to ensure the CTSA aspect is well represented in the paper.

4B-3 CER Methods

The 4B-3 Deliverable Workgroup is evaluating the training and methodologic areas pertinent to CER and the methodologic needs for clinical trials and practices. In looking at methodologic research needs, the questions are: what needs to be further developed to conduct CER and how can training parameters be expanded for CER? Three main categories of outcome studies and health services, evidence synthesis and clinical trial design and practice have been defined. However, the existing methodologies have not been tuned up to conduct CER. The principles of CER are in the process of being defined. In re-visiting what needs to happen to methodologies to make them useful for comparative effectiveness research, it is helpful to think of the characteristics of CER and contrast them with methodologic areas. This process may involve looking at patient centered care, issues of individualized results of research and developing methods for making research applicable to individuals. This process may also require surveying the research cycle and identifying and refining topics of meaningful research. It is likely necessary to strengthen linkages in the research cycle and connecting multiple researchers and identifying the methodology for linking researchers. The goal is for the 4B-3 Deliverable Workgroup to have a draft of CER methods by September.

4B-4 Networking Activities

Deliverable Workgroup 4B-4 discussed the two primary areas of activity the Workgroup is engaged in. The Workgroup is presently planning for two face-to-face meetings to facilitate networking of participants in CER. A supplemental award has been submitted to fund these meetings as well as the activity of the Workgroups. The Workgroup should be notified about the funding on October 1, 2009. The Networking Workgroup is linking with the Informatics Key Function Committee to establish ways to collaborate. The next teleconference of the Workgroup will occur in mid to late July.

Action Items:

1. Share White Paper with entire Strategic Goal Committee for review purposes.

Next meeting: July 27, 2009 at 11 AM ET