

NEGC Collaborative Council Meeting Summary

March 6, 2009

10:00 AM to 2:00 PM

Attendees: Roger Eaton, Anne Comeau, Carl Cooley, Leah Burke, John Moeschler, Peter Antal (staff), Amy Schwartz (staff), Karen Smith (staff)

NEGC UPDATES

- Reviewed various activities of the NEGC staff
- Discussed functions of NCC meetings with all of the regions
 - NCC now has publicity / marketing person: Kathy Beal
- *Announcement.* NEGC will be featured in Genetic Alliance webinar: "Meet Your Neighbor", on May 6th, 2009
- Discussed looking for grant-based initiatives for the work groups
 - AHRQ grant application: \$300,000 for 2 years; Health Information Technology

Follow up to Annual Meeting

Agenda / Scheduling

- Discussed ways to modify the schedule to allow for more time for discussion, and how to incorporate work group meetings into the agenda
 - Group agreed on meeting from "noon to noon", starting the Wednesday of the meeting week

Advisory Committee

- AC meeting minutes from Dec 08 were distributed
- Discussed filling the spot on the AC left open by Lou DiNicola, who left due to increased responsibilities elsewhere.

State Teams

- Reviewed discussion at the annual meeting; *do we want to go ahead with a survey to find out who key informants are and what groups already exist?*
- Discussed appropriate role for NEGC, how to structure the next steps, and potential elements of a survey

Consumer Involvement

- Reviewed discussion at annual meeting: *do we want to develop consumer advisory pool, and if so, what would its task be?*
- Discussed importance of making the work relevant to consumers, but also the difficulties involved
- Discussed structuring consumer involvement around a topic, like privacy
 - Should include consumer perspective advocating *more* privacy, not necessarily information-sharing; this voice is often not heard

Innovative Projects

- Reviewed changes proposed at Advisory Committee meeting, allowing for longer project period

NCC NATIONAL UPDATES

NBS Translational Research Network

- 13.5 million for 5 years; Mike Watson, project director

- Goal is to develop a system to collect LTFU and outcome data to evaluate success of NBS programs using organized network of clinical centers

National LTFU update

- Anne reviewed slide presentation that she gave at ACHDGDNC meeting

Emergency Preparedness

- Discussed history of emergency preparedness efforts, and where New England stands

WORK GROUPS / CONTINUATION APPLICATION

- Reviewed “Goals and Objectives” for each work group

Quality Improvement

- Group has momentum; Quality Improvement, Medical Home and Transition all overlap; Patrick Miller, consultant, is supporting database development
- Next meeting in March: setting up a database; future plan: Access meeting in 2010

Medical Home

- Work group had conference call on 3/4/09; next call in early May; face to face in Dec 09
- next steps: 1) identify additional site for pilot project now under development (Childrens’ Boston is one); 2) convene pilot sub-group to draft a communication tool for the pilot

Transition

- PKU Toolkit was distributed; successful PKU conference was held, will be replicated
- increased collaboration with Medical Home work group; expanding focus on galactosemia and social networking; expanded Teen Challenge to include leadership

Long Term Follow Up

- Hemoglobin and Cystic Fibrosis workgroups meeting; hosted Newborn Screening and Molecular Training Workshop in Nov 08
- presented about LTFU to NH, RI, ME

Quality Assurance

- Overall goals are the same, but the ways in which they are measured have changed somewhat; Roger will update worksheet and submit to Amy next Wednesday

Dissemination, Education, and Marketing

- Current project regarding special educators: will assess what they need to know to help them in their classrooms (not what they need to know about genetics)
- Discussed possible ways clinicians could do something to enhance the welfare of children in special ed settings

MEETING EVALUATION AND NEXT STEPS

- Discussed what went well and what could be better
- Identified next steps to be taken
 - Post and/or distribute NCC meeting agendas, CC minutes, AHRQ abstract
 - Follow up on Advisory Committee opening
 - Finish revisions to goals and objectives worksheet for continuation application