

# NOTES

## Genetic Expertise Workgroup Friday, August 7<sup>th</sup>, 2009 12 p.m. ET/11 a.m. CT

### Roll Call & Introductions

*Cindy Cameron*

In attendance: Nancy Mendelsohn (MN), Dianna Dummitt (IL), Nancy Leslie (MN), Renee Temme (MN), Cathy Wicklund (IL), Cindy Cameron (R4), Jodi Griffin (R4), Brianne Dzwonek (R4)

Sent regrets: Jacqueline Noonan (KY), Edith Chernoff (IL), William Rhead (WI) and Debra Sowell (KY)

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### Review of the Genetic Specialists Survey

*Nancy Mendelsohn*

Content review

- Questions on this survey are a combination of: 1) workgroup discussions at the May 1<sup>st</sup> meeting in Chicago, 2) a survey on medical geneticists work models by ACMG in 2003, and 3) an interview survey of geneticists in four cities by ACMG with results unpublished.
- METHODOLOGY QUESTIONS:
  - Response rates for surveys? Is calling the best route?
    - Typical seems to be around 20% - workgroup would like higher return
    - Wicklund believes phone surveys will be best route
  - How many would be surveyed?
    - Regional survey of seven states, with at least 3 centers in each state; less than 30
  - N. Leslie would like to see the questions sent out a head of time so that the participant can prepare information
    - We could come up against data that is from legitimate database tracking or just the participants best guess figures
  - Make sure the survey is not too long or complex so that we can get a reasonable response
  - May need to have multiple people from each center surveyed (I.e. medical geneticists and a representative from administration) because physicians may not have accurate information -- may have to call multiple times in this situation
    - One person to answer all questions would be best
- Survey Content: Question 12
  - Would like to see the question of technology attached to the goal of the group
    - How is email used? Is it to contact patients, specialists or other clinicians working to treat the patient?

- Would like to include broadband and technology capacity as a part of the technology questioning
  - Perhaps use a scale to rate importance of having technology resources available in clinic
  - Could also split the response depending on where the clinician is : home base or outreach clinic
  - Gather information, up front, on the make-up of the center
    - Number of physicians/clinicians, nurse practitioners, counselors, etc
    - Not just FTE's, but people
    - Also discussed reorganizing questions so that you could ask more about these people – how many genetic counselors do outreach, how much time do they spend doing it, etc
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### Next Steps

*Nancy Mendelsohn*

- Brianne will follow up with workgroup members who were unable to attend the call to get their feedback on the survey
- Region 4 will develop a cover letter and send to N. Mendelsohn for review
- Once feedback is provided and edits made, N. Mendelsohn and N. Leslie will pilot the survey with Region 4 staff

Other:

- Celia's region (Mountain States) is interested in this project as well and would like to partner with Region 4 – workgroup approves of the potential partnership
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### Updates:

*All members*

- “Ask the Geneticists” Project – this project is currently being taken on by ACMG on a national level and at this point this workgroup will not be moving forward.
  - Cindy and Dianna will talk soon about the grant through ARC and the potential for this group to explore funding options for more work in rural health initiatives.
  - Next meeting is September 4<sup>th</sup> however it was suggested that with the Labor Day holiday and a future conflict with the October meeting, we move the regular meetings to the **second Friday of each month**. Please respond to the email message with your preference.
  - Save the Date!  
Regional Meeting 2010, April 15<sup>th</sup> & 16<sup>th</sup> at the Henry Center in Lansing, Michigan
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Adjourned at 1:05 p.m. ET/12:05 p.m. CT