



## Regional Meeting Feedback

### Combined responses to open-ended questions 1 & 2

1. In your opinion, what were the most useful parts of the meeting (responses in blue)
2. In your opinion, what were the least useful parts of the meeting? (responses in black)

#### **Networking**

- Informal networking
- communication among primary care physicians, specialists & families
- Ability of workgroups to meet in person
- Parent face-to-face meeting
- Regional people together
- Meeting others in person
- Getting people from the states in the region together
- Networking during breaks
- Family meeting time
- general networking time with others
- Networking with others
- Regional collaboration
- Meeting other people with similar concerns
- Meeting people and experiencing the RC in action
- The opportunity to hold 2 impromptu sessions with EHDI folks from other states. The meeting included little info on EHDI, but we were still able to gather and use our time well.
- Interactive conversations
- Information/ideas/networking
- The mix of collaborators is fantastic; the parent and family advocates were fantastic

#### **Updates on Regional Activities**

- Updates on various projects in the region
- Update of MEMSCIS system and the MEMSCIS breakout group
- work group updates
- Program/project overviews
- updating everyone as to what has been going on in the region
- Follow-up on the endocrine project & presentations on CAH
- CAH project summary
- Hearing from each workgroup in the Region 4 regarding an update on what each group is currently working on and what they have done so far
- learning about collaborative
- Hearing subcommittee's reports/updates
- Because it was my first time, I'm glad Dr. Cameron explained the mission of the collaborative again
- Regional project presentations – would have been more useful to read a short abstract/description of the project, decide which interested in, and attend longer discussion section

### Exploring Regional Opportunities

- Exploring regional opportunities
- Possible future collaboration project presentations & breakouts;
- Exploring regional opportunities section was very different from the normal program. It was very very good!
- Research breakout groups
- Research results were interesting, but not as useful
- The breakout session after the research presentations; on Tuesday morning. The purpose/focus was not clear

### Medical Home

- How to establish care coordination for medical home
- The focus on medical home as well as the breakout sessions or possible next projects was useful.
- Care coordination
- Breakout sessions for the medical home – everybody restated the same comments that were already known
- Medical home topics are better addressed to primary care practitioners. This conference should be used for genetic related topics with a section for lab issues.
- Don't understand why the "genetics" collaborative is championing the medical home initiative- - feel we're losing site of the genetics thread throughout all the subcommittee work. I sit on EDHI workgroup and a genetics component seems totally absent to me. While I think it is great to see more "heterogeneity" in workgroup members and conference participants, I feel some of the genetics focus has been lost by going so broad. With increase restrictions on our time and travel at the state public health department level, I feel we're running the risk of loosing buy in and involvement of the public health genetics community in the future of this grant.

Medical Home Presentation and Breakout Discussion I now have a better understanding of:	Strongly/ Somewhat Agree	Don't Know/ Neutral	Strongly/ Somewhat Disagree
The National Center for Medical Home Implementation	31	3	2
Specific medical home resources and tools that are available	29	4	3
What I learned in this medical home session is useful to my work/life	26	6	3

### Workgroups

Workgroup breakout meetings; small group discussions

Opportunity to meet with my workgroup

Workgroup sessions

Workgroup meetings; it applied more specifically to my role in the collaborative

Subcommittee meeting

Concurrent Workgroup Sessions	Strongly/ Somewhat Agree	Don't Know/ Neutral	Strongly/ Somewhat Disagree
My workgroup made a lot of progress during our meeting	31	4	1
My workgroup meeting was a good use of my time	32	3	1
I am comfortable with the decisions made in our meeting	33	2	1
I have a good understanding of my workgroup's next steps	30	5	1

**General**

- Depth of knowledge I received
- Breakout sessions
- IRB help
- IBEM training
- I learned some important info regarding metabolic disorders that will assist in making me a better member of my departmental community
- Think this is a great meeting overall
- The caliber of the presenters was generally very good, as were the topics
- General sessions were very broad and not always relevant to my area in endocrine
- I thought all parts were informative and useful
- None
- Zero
- None
- Can't think of anything

**Suggestions****Meeting logistics**

- Great facility!!
- Recommend that meeting be held in a more centrally located place such as Chicago suburbs
- Consider using a travel agent
- It was somewhat difficult to get to Lansing, although the facilities were very nice
- Please notify guests if their room assignment will be changed before arrival

**Meeting organization**

- Keep people on time
  - Need a time keeper – some presenters don't understand the concept of time and amount of information
  - Put a time limit on people- if there were only allowed 15 minutes stop them
  - The AM session on 9/16 was rushed. Microphone problems caused distractions and took away from the presenters' material. Wished there was more time in the meeting for Q/A
- Sessions too long
  - Sitting and listening for 2-2 1/2 hours- would have preferred more hands-on time
- Handouts
  - It would have been nice to get the detailed agenda before the meeting
  - Please put 4 slides to a page on handouts – text on many of slide pages too small to be useful
  - Need PowerPoint on all presenters
  - It would have been nice to have a description of the goals and objectives for each workgroup in this grant cycle included in a handout packet
  - Needed a handout with summaries of what Priority 1, Priority 2, & subcommittees names and purposes with this grant cycle
- Workgroup meetings
  - I think workgroups held Wed. afternoon should not all overlap for those individuals that are in more than 1 workgroup
  - More working group time would have been useful
  - Could have used formal workgroup time on Day 1; some had to leave early so missed designated workgroup time
- Other

- All of the breakout sessions would benefit from more specific goals
- Should have brought us back together for a wrap up to go over when we are meeting next
- You should color code the name tags according to states
- Optional planned evening social time

<b>Overall Meeting</b>	<b>Strongly/ Somewhat Agree</b>	<b>Don't Know/ Neutral</b>	<b>Strongly/ Somewhat Disagree</b>
In general, the meeting was well organized	34	1	1
The two days were a good use of my time	30	1	5
I have a clear understanding of the Collaborative's accomplishments	33	1	2
I had adequate opportunities to express my views during the meeting	31	4	1
I had adequate time to talk with other attendees at the meeting	32	1	3
I learned some new ideas or concepts at the meeting	31	4	0
I will apply some of what I experienced to my work and/or family	33	2	1

### **Quality of presentations**

- Need list of all abbreviations of words
- Too many acronyms
- Michigan endocrine screening evaluations. The speaker used too many abbreviations in slides. The disease should be identified when speaking to a general audience
- I need a cheat sheet for all the alphabet labels. Please don't assume we know them

<b>Presentations</b>	<b>Strongly/ Somewhat Agree</b>	<b>Don't Know/ Neutral</b>	<b>Strongly/ Somewhat Disagree</b>
In general, the presentations were well organized	35		1
The presentation from HRSA was informative	32	3	0
The update from the National Coordinating Center was informative	31	3	1
The presentations about Exploring Regional Opportunities to Support State and National Initiatives were informative	34	1	1
I now have a better understanding of the Collaborative's workgroups	34	1	1

### **Suggested topics for future meetings**

- Discussion of how non-newborn screening genetics fits in collaborative as well as public health genetics (non-newborn screening)
- I feel that short term follow-up of metabolic NBS needs to be reintroduced. This was the only conference where issues were discussed & work was done to standardize what was being done across the region.
- More focus on clinical genetics services in the Region.
- Genetic services access in rural areas; telemedicine
- Integration of EHDI into the general topics
- Coordination & follow-up beyond clinical services
- Medical home definitions in each state and reimbursement related to care coordination
- Regional reimbursement issues for care coordination and other components

- Can we spend any time addressing solutions for the impending clinical geneticist shortage or insurance coverage for genetic services?

### **Additional comments**

- It might have been helpful to meet with people from my state – to hear updates more specific to us
- Is this a good time to have a “state” meeting since we are all together?
- Would like to meet with co-leads and others from state working with
- EHDl workgroup needs a leader who knows better about national EHDl goals and objectives & be connected with the CDC EHDl team.
- States do not necessarily have resources to implement/develop/follow models developed in other states

Administration of the Grant	<b>Strongly/ Somewhat Agree</b>	<b>Don't Know/ Neutral</b>	<b>Strongly/ Somewhat Disagree</b>
I am satisfied with MPHI's administration of the grant so far	<b>34</b>	<b>1</b>	<b>1</b>
MPHI has provided me with the assistance that I need	<b>32</b>	<b>4</b>	<b>0</b>