

## **Metabolic Clinics QI Learning Collaborative Planning Group**

*June 16, 2010 (via webinar) 8:30 – 10:30*

Participants: Peter Antal, Carl Cooley, Bob Greenstein, Mark Korson, Jeannie McAllister, Monica McClain, John Moeschler, Wendy Smith, Susan Waisbren, Karen Smith (staff)

John provided a recap of the groups' progress to date put it in context of the overall tasks and timetable. The goal for this meeting is to finalize the PKU and MCAD data sheets and endorse the charter. Subsequent activities include piloting data sheets; learning sessions/action periods; wrap up next year.

The group discussed holding the first learning session in conjunction with the Metabolic Consortium annual meeting in November.

- Susan is tentatively planning on it if there is enough time in the agenda.
- Would all participate, or just clinicians?

### **General discussion of data sheets**

- Goals includes
  - improved outcomes
  - care plan that can be implemented and documented
  - data registry
  - software to manage registry
- This phase is to collect data on what we're doing
  - *Is it also to show improvement? Don't we want to know how patients are doing in NE?*
    - To measure this, use *consensus statement* as benchmark
  - Yes, but start with uptake – process measures
  - don't include qualitative elements at this point
- No more than 1 page
- Same layout – all need to visually appear the same
- Identifiers at top
- Enough information but not too much
- Most elements are checking yes/no, with a few hard data questions
- Using checklist as starting point, clinicians can go back and get more data if desired
- Focus on task, not person
  - genetic counseling is done by different people in different clinics
  - Keep separate record of this data element rather than asking on every data sheet
  - Develop pre-survey to participants
- Questionnaires at bottom include three tools (Uniform Assessment Method) identified by Susan
  - Adaptive Behavior Assessment System
  - BASC – Behavior Assessment in Children
  - BRIEF

### **PKU specific**

John recorded changes made to the PKU data sheet during this discussion (see revisions). Comments include:

- Phe level is the hard data element
- Clinicians track this differently (range, average, number of draws, combination); intent is to fill in what you use
- Include which lab is used
- Track methodology (filter papers, other) and units used (need to define)

### **MCAD specific**

John recorded changes made to the MCAD data sheet during this discussion (see revisions). Comments include:

- discussed timing of providing emergency protocols to family; this affects best placement on the data sheet
- Need to provide definitions (i.e. fatty acid profile)
- Discussed potential for early speech delays in MCAD
- “MCT oil” included as a reminder *not* to use it with patient (in this way the data sheet is kind of an intervention)

### **Discussion of Charter and Measures**

Jeannie led the discussion of charter/performance measures (see revisions). Discussion included the following:

#### Clinic measures

- Measure #1: ok as is
- Measure #2: need to define “complete”
- Measure #3: should be objective and quantifiable; *each section has some response?*; keep thinking about this one
- Measure #4: Carl wanted to have a way to capture improvements that weren’t anticipated; won’t be the same in every clinic; *shouldn’t clinics designate which improvements they’re looking for?* This could be added to pre-survey.

#### Patient measures

- Measure #5 and #6: check the consensus statement
  - Outcome not all under the control of the clinic but still important
  - For example, in ME capacity affects length of time
  - Could be useful for public health

### **Next steps:**

- John send email re: NICHD RFA to the group
- John make revisions on data sheets from today’s discussion
  - Wendy follow up re: PKU
  - Mark follow up re: MCAD
- Jeannie and Carl make revisions to charter/measures
- Develop pre-survey
  - Who does genetic counseling
  - What improvements are clinics looking for