

## NEGC QILC

April 29, 2011

*Participants: Dr. Maddy Martin, (Dr. Wendy Smith, Caroline Bowman, Mary Ann Gordon), Kit McCormick, Dr. Harvey Levy, Dr. John Moeschler, Monica McClain, Dr. Mark Korson*

### To Do Items

- Dr. Moeschler to follow up on next steps re: accreditation of PI (performance improvement) CMEs
- Do we want to ask families whether what they are getting out of the clinic is what they really need?
- Address whether clinics will drill into data for PKU and MCAD
  - Review measures included in charter
- Develop parallel sheet for Galactosemia
  - Group to be established

### Recap

- Face to face in February, Webinar in March
- Focus for today is reporting on how it's going
- Review of Plan – Do – Study – Act (PDSA) process

### Group Review

- Any changes to the data collection tool
  - Dr. Martin: Manipulates it a bit to fit what's needed. Some parts are not needed for her, but that's okay as it may serve the needs of other groups. Overall, forms are fine.
  - Dr. Smith: Forms work fine, clarifications helped.
  - Ms. Gordon
    - Do we want to capture planning uses of the form – are we using this as a static event or a focus on a process (e.g. are you planning a school or home visit)?
      - A: Focus is on capturing the event.
  - Dr. Levy
    - Asked for clarification on his and Dr. Waisbren's role. We should talk with Leah Hecht, who is primarily responsible for organizing patients and who could take the lead on collecting the information.
    - Are we thinking about the collection of outcomes information for each practice?
      - Dr. Moeschler: We are thinking about it; first stages are to start the process of collecting information on how things are being done. As the work gets more advanced, we will learn more

- Dr. Smith: Issue of long term outcomes and role of different groups in this area. It's great that we are looking at process and LTFU is looking at outcomes, so there's a potentially good match. Collecting some of the outcomes information along the way is a good idea, though it just scratches the surface. Would be helpful to link in data collected from LTFU.
  - Dr. Levy: Collection of data should go hand in hand with practice. Used example of heterozygous 985 and different degrees of MCAD as measured by different levels of C8; therefore it is very important to put it together. So we could work more collaboratively with the newborn screening data. However, this has been a challenge in the past.
    - Dr. Smith: Current project is focused more on the process of work rather than outcomes. However, future iterations of this process may focus more on the outcomes area.
    - Dr. Moeschler: we are currently getting some relevant information (e.g. height/weight) that could be used towards this end.
    - Dr. Martin: Once we get beyond MCAD and PKU and into more rare conditions, it will be very helpful just to see the basic management procedures that people are using as this information is quite scarce.
    - Dr. Korson: if the challenge is time and resources to enter data, why is that easier to do in Region IV?
      - Dr. Levy: They have a strong history of grants.
      - Dr. McClain: Other clinics have to pay fees to participate.
    - Dr. Moeschler: As we go into the next application process (Dec. 2011), we'll have a better understanding of what is and is not being done and the kinds of data that will be needed.
    - Dr. Levy: noted that there are some outcomes collected in the checklist
  - Dr. Korson
    - Very quick to go through – makes you do things that you really should be doing anyway (e.g. averaging levels). For the most part, very useful.
  - Dr. Phornphutkul
    - Team really liked it – was a reminder of things we should be doing but which sometimes, when clinic is busy, they realize there are certain aspects that have not been discussed recently.

- Did implementation affect workflow
  - Dr. Korson (uses ECW data system)
    - Complements what should be happening – instead of eyeballing figures, will calculate numbers. Links in with current template work.
    - Hard to do at the time if it's a very busy clinic day. If a regular clinic day, then it's easy to complete.
    - Dr. Moeschler: Who touches the data form?
      - Primarily just Dr. Korson.
  - Dr. Martin (uses EPIC and multiple other systems)
    - Challenge has been to better integrate the forms into the practice. Developing self-reminders to ensure better utilization.
    - Positive: forms help to remind about certain aspects of care. Using the note section quite a bit.
    - Negative: requires a little extra chunk of time at the end of the day
    - Dr. Martin is the only person to touch the form (until a nurse practitioner comes on board)
    - Even though some of the newborn screening information is hard to find, it is helpful to have.
    - Looking at funds for a database just for their division
      - Dr. Moeschler: may be helpful to have a conversation with Patrick Miller to facilitate data exchange
  - Dr. Smith (EPIC)
    - Had already done the basic templating; new forms have suggested additions to the template
    - Done at the end of clinic with team. Everyone checks off what they did; reviews high points / discussion points, Caroline will review to make sure everything is completed. That way, there's just a very brief period of time per form.
    - Even though they are electronic, it has been helpful to be able to write down additional information on the form is a reminder for additional steps to take
    - The only thing that takes longer is the initial newborn screening information.
      - With new diagnoses, newborn screening information is going right in.
      - It's been helpful to have the information in one spot. Also helpful to be able to see changes over time.
  - Dr. Phornphutkul
    - Took a little time to finish the top part to start, but as they follow up, it will likely be less of an issue.
  - Dr. Burke
    - Using tool reminds her to look at different aspects. Question about use of Dr. Waisbren's project.
    - Question about ID numbers at the top.
      - A: Up to the person completing the form

- Lessons in patient care learned
  - Dr. Korson
    - Supports acquisition and retention of specific data
    - Helps standardize approach with patient with a particular disorder. May look at transferring information to clinic template form so that the data could be used by other sources.
  - Dr. Martin
    - Commented on improvements in standardization of care
  - Dr. Smith
    - Commented on improvements in standardization of care
    - Noted overlap in what everyone does – for example, each person’s role in transition
  - Dr. Phornphutkul
    - Good reminder to talk about items that have not been discussed in a long time.
  - Dr. Burke
    - No issues raised.
- Insights by the team
  - Ms. Gordon: Some things we do consistently and well, but other things that are not a part of the process. So we need to look at whether there’s a way to do it (e.g. psych testing or developmental screening). Primarily they have not had the resources to do these in the past.
  - Dr. Martin
    - None at this time.
  - Dr. Korson
    - None at this time
  - Dr. Phornphutkul
    - Helps individuals to see role very clearly,
- Family perspectives on the process
  - Ms. Bowman
    - Families are not directly aware of the forms as these are completed after clinic
  - Ms. Gordon
    - Keeps us more on task to help us not forget certain pieces. She does regularly check in with families re: their questions, and will follow up with team to ensure family questions are answered.
  - Dr. Martin
    - Nothing specific at this time
  - Dr. Korson
    - Families are generally not aware. Will mention it if families ask generally about current research in PKU
  - Dr. Levy



- Dr. Korson: has changed practice in the sense that additional questions are asked. However, it has not affected the types of tests ordered. He also noted that many clinics that serve patients with PKU who do not have metabolic specialists may use this form and therefore follow practices as outlined in the form.
- Dr. Smith: noted Mountain States experience and emphasis on collecting data rather than dictating protocol.
- Dr. Phornphutkul: we are likely to be asked more and more about our data. So it is helpful to act proactively. At the end of the day, she hopes to improve the care she provides. There is the danger of not thinking and following a protocol given the lack of training / specialists.
  - Re: IRB – given variance of approaches in each clinic, how can we make sure that the data can be retrieved and utilized in a scientific way?
- Dr. Moeschler: Focus should be on how you keep score. How do we keep score without disturbing the feel/approach?
  - Discussion tabled for a time. Emphasis will be on keeping the current flow of activities, NEGC will further pursue development of an electronic repository.

### Data Report Out

- Aha – Wendy noted that the number of visits that Maine serves is on par with Boston
- See spreadsheet.
- Frequency of Conditions (in order of frequency)
  - Dr. Martin: Hyperphe/PKU, other abnormal screenings, MCAD
  - Dr. Smith: Hyperphe/PKU, then (MCAD, VLCAD, Galactosemia on similar levels)
  - Dr. Phornphutkul: Hyperphe/PKU, other abnormal screenings, children with developmental delay
  - Dr. Burke: PKU, VLCAD, MCAD (though less follow up),
- What next for expanding the conditions? Options...
  - Dr. Smith: pick 2
  - Dr. Korson: Consider picking a group with similar characteristics
  - Dr. Phornphutkul: Consider Galactosemia

### Next Steps

- Drill into data for PKU and MCAD
  - Review measures included in charter
- Develop parallel sheet for Galactosemia
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### Wrap Up

- Location was in general preferred

- Agenda Time: seems to fit the need
- Start time is good from a travel perspective