

NEGC Metabolic Clinics QI Learning Collaborative Planning Group

May 5, 2010

1 PM to 3 PM via webinar

Call Summary

Participants:

- Peter Antal, NEGC
- Carl Cooley, Center for Medical Home Improvement
- Bob Greenstein, UConn Medical School
- Mark Korson, Tufts
- Jeanne McAlister, Center for Medical Home Improvement
- Monica McClain, NEGC (new Project Manager)
- Patrick Miller, NH Institute on Health Policy & Practice
- John Moeschler, NEGC
- Karen Smith, NEGC
- Wendy Smith, Maine Medical
- Susan Waisbren, Children's Boston

Missing:

- Harvey Levy, Children's Boston
 - Maddy Martin, UMass Med School (Worcester)
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To Do Items

- **Wendy:** write up content re: PKU for checklist mock up (annotate Mountain States information) and send to John by May 14
- **Mark:** write up content re: MCAD for checklist mock up (annotate Mountain States information) and send to John by May 14
- **Susan:** review Mountain States info for PKU/MCAD regarding psychosocial factors and send to John by May 14
- **John:**
 - Send mountain states info to Wendy, Mark and Susan asap
 - begin writing checklist mock up using info from Wendy and Mark
- **Patrick:** edit checklist mock up into electronic compatible format
- **John and/or Monica** initiate conversation with Roger Eaton and Anne Comeau, after May 21 re: how projects could complement each other

Intro and overview

- Bob Greenstein is joining for the first time.
- Items to be included in binders (will be provided at May 21st meeting) will include:
 - Minutes from April 2nd meeting
 - Slides from today

- Mock up checklist developed by Carl and Jeannie
- Complete care plans from Mountain States
- Case definitions / diagnostic criteria developed by NYMAC
- Recap or “roadmap” (see John’s slides)
 - Wendy Smith participated in effort by Mountain States collaborative to produce care pathways for all 28 nbs conditions; these are now up on their website (though may not be used in clinics yet). http://www.msgrcc.org/nbs_outcomes_materials_v2.html
 - Enthusiasm was generated to adapt materials/process to our own regional project.
 - We are using Learning Collaborative methodology, facilitated by Carl and Jeannie.
 - NEGC is providing support (including financial), not defining the aim or scope.
 - Planning group meeting #1 was on April 2nd; today is #2.
 - Meeting of *expert panel* (planning group + others) will be on May 21st in Burlington, MA.
 - John envisions learning collaborative process going through next year, possibly another year.

Aims and checklists

- It’s up to the group to decide what it aims to do and how to accomplish it.
- “Straw man” drafts of aims, developed by Carl and Jeannie, were presented for the group to discuss and revise (see John’s slides): Broad Aim (Charter); Focused Aim (Clinic); Focused Aim (Child).
- Sample checklists were provided for discussion purposes.
 - One prepared by Carl and Jeannie
 - Top half is generic; bottom half is condition specific
 - One prepared by Wendy and Peter (galactosemia)
 - Looked at disease specific care plan from Mountain States

Discussion regarding checklist

- The group decided to use checklist to *track* what they do per visit, not entering all the points like the Mountain States’ care pathways .
 - i.e. check off if a test was done on that visit, not enter actual test result
 - clinic could go back and get that information if it wanted
- Some data points, however, would be included, generally dates.
 - These could potentially be used later to do a more focused study.
 - Nice compromise between intensive detail and something too generalized
- Checklist should be one page and simple, more likely to be sustainable.
 - Assumption is that there will be several iterations
 - John provided sample of the 1 page “pink form” being used by QI group.
 - captures a lot of info but takes only minutes to complete
 - format developed, after workflow analysis, to be converted into electronic database (by Patrick Miller)

Discussion regarding aims

- All agreed with broad aim.
- Group discussed focused aim re: clinic (see slides)
 - Consensus was to implement incrementally:
 - **Stage 1:** PKU & MCAD (time to set up the system and “work out the kinks”)

- Start date June 1st
 - **Stage 2:** conditions associated with newborn screening
 - Start date depends on stage 1
 - **Stage 3:** expanded list (based on what is learned in stage 1 & 2)
 - Start date TBD
 - Clinicians need to be ahead of the learning collab in case they are ready to go with more
 - Need to front load with enough conditions to make sure system is working or not
 - Begin now to prep for conditions after Stage 1
 - MCAD is representative so other similar conditions will be relatively easy to roll out.
 - Eventually it may be easier to gather data on 100% of children (so clinicians don't have to remember who is in target group and who isn't).
 - Group discussed importance of including some psychosocial factors (such as IQ).
- Group discussed focused aim re: child (see slides)
 - If aim re: clinic is done well, there isn't really a need for aim re: child as clinic goals should produce positive outcomes for children.
 - May want to include spot on checklist for qualitative data re: barriers to completing form
 - No transportation, no insurance, no show (could be a box to check and/or note)

Agenda development for May 21st

- Clarify using checklist vs. care pathway; determine a name for them
 - Will have two examples to share
- Determine how to develop them
 - Since it will be web-based eventually, HIE perspective should be included in development.
- Determine what data points to collect and when (when visit scheduled or actually occurs?)
- Determine timeline for turnaround
- Determine measures of improvement
 - 1st measure could potentially be how many checklists are completed
 - Start with performance indicators
 - Performance measures could come from analysis of dates of when things were done
- Begin to develop list of conditions for Stage 3
 - Clinicians should present lists of what they are following; others can be added
 - Some conditions only have annual visits; new patients would be seen more frequently.
- Identify metabolic teams to participate
 - need to have incentives to participate; why would they come; we should craft the message
 - use Metabolic Consortium meeting in Nov 2010 for launching/recruiting/learning
- What support is needed between meetings next year?
 - Develop work plan for 2010-2011
 - Have draft of timeline for experts to react to
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Discussion regarding QI and LTFU project compatibility

- Anne Comeau, NENSP, expressed an interest in knowing more about how this project compares to her LTFU project in which similar data is collected Jill Shuger, HRSA, is also interested.
 - Are we replicating what is already happening? Should we be coordinating?

- Reactions include:
 - This project is focused on improving clinical services at the point of care – high quality of care perspective; Anne is interested in the data itself – public health perspective.
 - Anne is interested in the data our checklists will be ascertaining; we anticipate that it will be complementary to hers.
 - Projects focus on different aspects of the same thing, “starting at opposite ends of the same tunnel”.
 - It is important that everyone knows what is happening; there needs to be agreement at the highest level; Learning Collaborative needs to be very clear to Anne.
 - It is important that Sara Copeland and Jill Shuger understand similarities and differences.
 - Need to coordinate so clinicians aren’t asked to double enter data

- Consensus: John and NEGC staff (Monica, Patrick, Peter) will arrange to meet with Anne and Roger Eaton after the May 21st meeting