

NEGC Quality Improvement Learning Collaborative

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Background

- Intro
 - NEGC's mission focus is on access and quality; today's focus: improving quality
- Review of generalizable scientific evidence model: Attention on health care quality improvement:
 - Measures for where we start, where we go
 - Importance of understanding context: culture, ecosystem plus scientific evidence (note biases that are inherent)
 - Note the distinction between improving health care vs. health
- Presentation of road map of IHI model
 - Relevant to push from New England Metabolic Consortium
 - As a group, they haven't taken on much that was a long term collaborative group effort. The opportunity to participate in this endeavor seems to be a natural fit with their goals.
- Today's meeting builds on multiple management team meetings, as well as two planning meetings held on April 2 and May 5th

Mountain States Presentation with Janet Thomas

- Background
 - Most states have only one metabolic center per state, patients not always seen with same frequency
 - At the start of the project, most states had not implemented expanded newborn screening
 - Recognized the challenge of a lack of evidence / data to suggest efficacy of newborn screening
 - Benefited from previous collaborations: linkages already established in the region
 - Also has LTFU project
- About the Collaborative
 - Goal: document benefits of newborn screening for LTFU compared to symptomatic clinical detection
 - Did not want to dictate care, but rather establish parameters (minimal requirements)
 - More interested in long term rather than short term goals

- Started metabolic consortium in 2006
 - Includes other collaboratives
 - Characterized by excellent collaboration: sharing ER letters, resources (age specific, disease specific- will be posted on website), experiences
- About the Data System
 - Supported by Public Health - data system known as 'CHIRP' and 'NEST'. CHIRP refers to the local database in each clinic, CHIRPs feed into the central data resource (NEST)
 - Established consent process and IRB approval
 - Vital stats, birth stats, etc. all feed into NEST
 - 'Need to know' access to system
 - Data systems are web-based
 - Data capture
 - Data currently entered by grant funded staff (PRA, project mgr)
 - While information about the data elements can be found on the entry screens, no separate data dictionary exists
- Progress
 - 28 shared data sets and outcome measures identified
 - Outline of minimum treatment for conditions - data system will allow staff to assess:
 - Impact of clinic specific variations in treatment – allowing systematic studies of improvements in treatment strategies
 - Track adherence
 - Created a set of consistent developmental assessments (2, 3, 4/5, 6, 9, 18)
 - Note: they are building in outcomes assessment to identify variations
- Discussion
 - Collaborative maintained by annual meeting, and emails between
 - Erica worked on cleaning the data sets and providing other supports
 - What is the opt out rate with the consent process? Only know of 2 patients
 - Protocol includes endocrine and hemoglobinopathy; consent rate among sickle cell was much lower
 - Having consent aided the project's ability to share data across state lines
 - What problems are there in capturing neuropsych data? (people not entering, Janet noted some similar issues)
 - Insurance pays for neuropsych evals at 3 and 6 (need to have a diagnosis first)
 - It was noted that, in MA, insurance protocols have tightened up considerably – no evaluations provided for prevention
- Next Steps
 - SCID recently added at the national level, future: lysosomal disorders

Overview of LC Model for NEGC (Jeanne and Carl)

- Model for improvement (trying to accomplish, recog. Improvement, changes we can make)
- Aim: team focused

- Creation of change package (e.g. data dictionary, data sheets) to help with clinic uptake of changes
- Use packages (test, improvement, implement, measure results)
- Breakthrough Series Steps
 - Planning, charter, expert panel, learning collaborative (12 months), plan and hold learning sessions (3) and action periods (needs structure, content, process, faculty, measures, spread of tested change ideas and methods)

Charter (*Agreed Upon Language Highlighted in Yellow*)

- Overview of what it includes (issue, mission, aim, goals/measures, methods, expectations, timeline)
- **Broad aim:** *improve the health and health care of the population of individuals with inherited metabolic conditions in New England*
- **Focused aim (clinic):** *improve comprehensive clinical care for 100% children seen with PKU, MCAD by May 31, 2011 and other conditions as determined by LC participants - as a result of using, reviewing and completing a dated care checklist at ever visit thereby documenting adherence to established performance indicators for each condition*
- **Focused aim (individuals):** *100% of individuals with PKU, MCAD and other conditions receive the best agreed upon metabolic clinical care*
 - Challenges
 - May be a problem in getting all docs to agree to defining what is the best care; particularly given the lack of evidence based processes
 - With Mark, Harvey, and Wendy on the faculty, agreement may be much easier
 - How do we make the determination of improving efficiency/efficacy? System seems so big and out of control...?
 - How do we address the challenge of some children receiving suboptimum care due to structural impediments?
 - To what extent is health care delivery potentially different within this framework of service improvement from traditional primary care practices?
 - Recommendations
 - Important to score the use of the checklist and how much is complete or determine other methods for identifying issues in implementation
 - Do we want to say children or patients? (e.g. concerning moms with conditions with infants with conditions)
 - HRSA now interested in individuals over time
 - Group decided to change language throughout to reflect 'individuals'
 - Can we focus discussion around families?
 - Maybe include as part of needs statement of the charter (family centered care language)

- There is a challenge in putting it in as part of LC aims given narrow scope of what we are planning on doing during the next year
 - Timeline: charter should be focused on a 12 month period
- **Mission/Purpose**
 - *The purpose of this collaborative is to improve the health and health care of individuals with inherited metabolic conditions identified by newborn screening in New England*
- **Collaborative Expectations: Each metabolic clinic team's organization will:**
 - *Connect collaborative goals to their organization's mission related to patient quality improvement initiatives*
 - Challenges
 - Concern with organizational quality improvement goals; for example, Maine Health, Maine Med center, Maine Medical Partners – all three bodies have to approve QI practices
 - Will a dept chair object to participation? Probably if activities are not funded
 - Noted that participation will be a necessity anyway once data agreements start
 - Need to address local particularities for each clinic / sub region
 - Re: Mountain States - they haven't sought active hospital support
 - *Send two to three team members to the metabolic learning sessions and support their improvement work during interval action periods (teams include a physician leader, a family member, and another key clinic member (metabolic dietician, care coordinator, genetic counselor, other))*
 - *Support the team's participation and improvement efforts*
- **Each metabolic team will agree to:**
 - *Connect collaborative goals to their organization's strategic initiative*
 - *Perform pre work activities and measures to prepare for Learning Sessions*
 - Teams need to come with an expectation of working
 - *Everybody learns and everybody teaches* (language for this needs to be updated)
 - *Identify a physician champion to lead and oversee the team and/or a team champion to lead the team's implementation of QI initiatives*
 - Does it have to be a physician champion?
 - *Identify an organizational senior leader to sponsor the teams working in the collaborative; demonstrate that leader's commitment to supporting the success of the team and sustaining and spreading its accomplishments (senior leaders are welcome to attend at least one Learning Session).*
 - Q: How should commitment be demonstrated? A: Sign off on PSO agreement
 - *Implement changes that will lead to improvement in the practice or clinic*
 - *Consider the additional metabolic conditions that they will address*
 - *Use a registry provided by the Collaborative to track care*

- Report on each collaborative goal/ measure and share their progress and challenges with other Collaborative teams
- Participate in regular Collaborative conference calls
- **The NEGC Metabolic Learning Collaborative Planning Team will:**
 - Establish Learning Collaborative structure and process with faculty: collaborative charter, QI checklists, other quality improvement tools, learning session agendas, and evaluation
 - Establish registry function with clear completion criteria
 - Develop/expand website and post all needed and related materials
 - Create and monitor metabolic learning collaborative list serve
 - Coach and support metabolic clinics in their efforts
 - Support data reporting (this needs to be described)
 - Post data and summary reports on the NEGC secure website

Review of the PKU and HyperPhe Checklist

- See marked up document from Wendy, MS form, and new PKU form
- Introduction... it will be important to have:
 - Basic information
 - Sections: Heights and Weights, History,
 - Some information should be maintained across checklists for different conditions
- Form recommendations
 - NBS screen date (date)
 - 2nd screen date (date)
 - Diagnostic confirmation studies
 - Avg Phe level
 - Number of draws
 - Range of Phe
 - >10, 6-10. 2-6
 - Quantitative Phe (level and date)
 - Quant Tyr (level and date)
 - Urinary pteridine profile (y: normal / abnormal ; not completed)
 - Blood dihydropteridine reductase enzyme assay (y: normal / abnormal ; not completed)
 - Consider molecular analysis (y/n) -- / --
 - Early intervention
 - Change 'Labs at this OV' to Lab
 - Avg. Phe level
 - Or include recommended level of draws?
- Discussion Notes
 - Levels have to be gauged within context (e.g. if child is sick)
 - Need enough information to answer important questions

- Start with a unified care plan, then establish measures / data collection protocols
- Questions
 - Are we going to gauge our effectiveness on the completeness of each form?
 - Will we have similar performance indicators across conditions? What are they?
 - Overview of disease specific care plans, may be helpful to look at case definitions of NYMAC
 - Will we have different paper formats for tracking the information?
 - What are the measures we need? (e.g. number of draws and outcome)
 - Is there a budget for a staff person to enter information?
 - Will we track services to provide back to families?
 - What happens with intervening information (services in between clinic visits)?
 - Will reporting intervals coincide with participating institutions?
 - When do we expand to other conditions?
 - Individual clinics should have a role in what new conditions role out
 - We should be careful of independent clinics going their own way as this may defeat the purpose of the collaborative
 - This group should make the decision (as part of governance) but with input from clinics
 - **How do we improve comprehensive care by 2011 for PKU and MCAD?**
 - We are going to improve consistency of care (but clinical outcomes?)
 - Assumption that we are making is that utilizing the checklist will result in positive outcomes
 - How quickly can we turn the data around and prove anything?
 - Are we collecting data or data on the data we are collecting -> how do we move towards analyzing the data as a group?
 - To date, we've looked at existing care plans that have been vetted and are now turning this into a data dictionary.... How much can we expect... you are getting data on health care processes (some is so detailed that it won't work, so data about data), in looking at the data sheets how much information can we collect (visits data, phenyl levels, etc..) without having an excessive negative impact on workflow?
 - Needs subgroup to review and place in context of needed information and force variables so that they provide this information
 - Adapt screening protocols, specifying for age context

Review of the MCAD Checklist

- Focuses on Y/N information on existence of labs rather than collecting detailed information
- About the Labs
 - Some geared towards diagnostic / initial labs, family studies, illness at the time
 - Diet / medication
 - Counseling (what was provided to the family)

- Form Recommendations
 - Have similar look across paper and/or electronic information (same type of information in same area)
 - E.g. initial screening, newborn labs, etc.
 - Work towards establishing a trail: road to diagnosis on each form
 - Needs a data dictionary
 - Maybe add a category for healthy visit / sick visit

Goals and Measures Discussion

- *Author's Note: Due to time limitations, discussion on this section was fairly brief and needs to be continued*
- When do institutions have to report their QI? How will this coincide with our work?
- Qs about ER and hospitalization measures – is this applicable? Multiple concerns were raised by participants
 - See if there's a way to qualify the type of visits to be tracked
 - Hypoglycemia, non-responsiveness, bad events; reducing freq of critical events
- Maybe add a sustainability goal
- Measures need to be operationalized

Proposed Timeline

- June: Webinar of the planning group. Finalize the checklists for PKU and MCAD.
- Summer
 - Clinics pilot checklists over July – Sept. (targeting 25)
 - Preliminary outreach by John and others to clinics not currently represented (but who we want to participate next year)
- Sept.: planning group meeting, review pilot
- Oct: Revisions to checklists, learning collaborative process
- Begin in fall with first learning session to coincide with Metabolic Consortium (Nov.12).
 - Note that learning sessions should be 4-5 hours each.
- January 2011. Potential Planning Group meeting?
- Learning Session #2 : ??
- Learning Session #3 before May 31, 2011

Next Steps

- Define Groups and include in charter (management, planning, expert faculty, collaborative)
- Create a one page / brochure describing the learning collaborative to hand out for organizational decision makers
- Work on creating a data dictionary for the checklist

- Performance Measures need to be more clearly defined for the learning collaborative as a whole as well as for individual conditions. Once this is done, the number and type of data elements (e.g. y/n vs. detailed data) can be more clearly defined for the checklists.
- Address questions identified in the PKU checklist discussion

Review of the Meeting

- Overall, participants enjoyed the meeting and found it useful and well organized. Recommendation was made to provide better follow up processes for questions raised during the meeting that we could not get to (due to time).

Other

- Note: Jill Shuger sits on a national subcommittee overseeing data sets / improvements for LTFU; it will be helpful to keep her posted and seek feedback on our progress.