

## Learning Collaborative Planning Group

*April 2, 2010*

### Discussion Overview

Participants: Peter Antal, Carl Cooley, Mark Korson, Harvy Levy, Maddy Martin, Jeanne McAlister, Kit McCormick, Patrick Miller, John Moeschler, Karen Smith, Wendy Smith, Susan Waisbren

Missing: Bob Greenstein

Organization of the Material Below: To Do Items, Outline of the Discussion, Background Discussion, Mountain States Review, What Do We Want to Focus On, Next Steps, Referred Resources, Meeting Evaluation

#### **To Do Items**

- Karen to get updated clinic list (DONE)
- Peter to create basic forms using Mountain States info. Follow up with Wendy and Maddy to update
- John to look at funding issues and possibility of extending Expert panel meeting into June (DONE – Not possible)
- Summarize Notes, refine charter, purpose to review documents, endorse charge and prepare for may 20/21 meeting, mocked up checklists
- Some base definitions to prepare as background information for the Expert Panel group

#### **Outline of the Discussion**

- Introductions to the Group
  - Overview of mission
  - Highlighting issues of good health care, overall challenges to the health care system, issues of fragmentation, and implications for effective health care
- Overview of Learning Collaborative Model
  - Need for a charter (purpose / activities)
  - Expert panel to vet framework / changes – best ideas, put together change package
  - Team formation (meetings and action periods (testing and action with patient / family next day)
  - Learning Sessions
  - Activity Period
    - Plan, Do, Study, Act
  - Importance of a Learning Advisor (what is the measure set? Pathways used? How are you going to test it?)
- Lessons Learned from Mountain States

- Realities of applying a new system

## **Background Discussion**

### *Structure of Healthcare*

- Primary Elements
  - Funding
  - Human element
  - Data
- Provision of health care, based on factors of:
  - Design
  - Execution
  - Cost
- Fundamentals of Improvement
  - Will, Good Ideas, Effective Execution
- Why test changes
  - Increase belief, predict how much improvement, learn how to adapt change, evaluate costs and side effects
- Note discussion on Evidence/Eminence/ Practice- Based medicine – there have been a number of different terms used over time which deal with a central core concept: how to improve care and patient outcomes.

### *Notes on the Learning and Implementation Process*

- How do we take what exists and better apply it?
  - Take out biases and variables between practices and test the intervention (not the site)
  - Within the learning environment, we pull out samples from each area and expose with the group for review
- If there are certain aspects that should be standard across providers, we want to figure out how to minimize variability
  - Note challenge in documenting changes in impact of care given low number of patients... so we may need to look at additional variables of care
- As we move forward it will be important for us to discuss barriers to implementation
  - Time, money, system of effort that is not always logical (billing / time / resource scheduling). So we should track reduction of barriers
- Need to focus on process vs. product; how do we facilitate the work?

### *Why Do This?*

- Our focus is on health care quality improvement, so how can we do this? (assumption: we need data to prove work)
  - What is our charge?
    - Identify and provide the best care we can provide for patients

- Set a tone to see patients and do a better job
- What should our focus be?
  - Center on Staff Person or Clinic
- What are our resources?
  - NEGC funding
  - Committed staff from a variety of disciplines
  - Registry
  - Pooled skills
- What kind of data do we need to move forward? What are the basic elements which need to be tracked for each condition?
- Of note, most (all?) of us have already been involved in improvement work before, we are just using different code words. We are basically talking about a collaborative effort to gather information in a systematic way that will help us improve patient outcomes
- We need to think through, rather than throw resources at the problem

### **Review of Mountain States Process**

- Noted that there was a minimum set of information to collect for tracking information in the long term
- The focus is on reviewing what needs to be done at each site, not necessarily how to do it.
  - E.g. sites might collect information on days old, when treatment started, growth parameters, evidence of genetic counseling. However, we would not prescribe how they should be collecting this information (emphasis on information collection rather than a how to manual)
- Sites did not have to do everything, they were provided a reminder (a list of outcomes they were looking for)
- Some sites driven by bare minimum, some by best practice
- Even though they are collecting different data, at similar points, staff able to compare similar information across regions

### **What Do We Want to Focus On?**

#### *Background Discussion*

- This group's task is to create some parameters on what will be accomplished by the Learning Collaborative
- Customer is the clinic: what do you need to improve your care?
  - We don't want to start with a blank slate.... How can we be flexible and customize what clinics currently do?
- Do we want to approach this broadly or specifically focus on selected disorders?

- If we don't do it all...then the rare disorders will not get followed up on.... May lead to confusion about what things to follow up on
- We need to learn what's involved in setting up the system... what's too onerous?
  - Some are just now moving into an electronic system (can't do data entry for 3 separate systems!)
  - Some systems could be used to export data for use in other systems
- How functional will the information be? Will we be able to look at regional data
- In terms of scope, what is the basic minimum set (we can all agree on?) What is our wish list?
- Challenges to Address
  - Lack of personnel; burdening day to day work of the clinic
  - Need to establish a working document for standards of care
  - Need to establish a systemic collection of information
  - How to mesh IT capacity with data entry and reporting needs
    - May be possible to track all conditions if it is just a checklist to track on existing practices
  - Overall, how to apply real world given the sometimes rare interaction with infants / families.....what is the gap between doable and optimum ?
  - How / When do we coordinate with LTFU efforts in the region?
    - Keeping in mind: LTFU national work in the future: so many different clinics reporting information in so many different ways... impossibility of clinics collecting all that information
    - If the network is going to get a LTFU started, it will need information from a collaborative
      - Note challenges of LTFU; some evidence that 30% of patients are not being followed up on
    - We should consider that registries, by themselves, can have limited use / value.
      - Note cardiology, hematology example – need for funding for data processes
      - We need funding to do what these other groups do
      - Note NICHD money to do a regional approach
    - How can we get all the relevant partners to share information to make this work?
    - We need to be sure that we are not duplicating efforts between the registry and LTFU work in the region.

### *Scope*

- What are we doing here? Create better practice? Joint data collection? What's our product?
- Do we try to do everything first or start small?
  - The focus should be on achievable outcomes... What is the minimum standard on what we can all live with and agree on.

- Idea of building success into the effort.. Keep things simple and build incrementally over time.
- Our first step will be to get a baseline of where we all stand
  - This should be in the form of a standardized checklist for all the clinics (e.g. are we collecting the newborn lab level, doing confirmatory testing, when developmental testing was done)
  - This provides an opportunity to compare and learn from other clinics (need the baseline data to do this)
- Once a baseline is done and a roadmap exists which points to the types of data that we do have we'll be in a better position to seek out grant funds for a more expanded effort and a potential retrospective research study.

### *Creation of Condition Specific Checklists*

- Will all conditions be tracked?
  - We will start with the conditions currently listed in the Mountain States work. Checklists will include some universal data like birth date, clinic visit date
- Will we be collecting and inputting data on patient level information for all conditions?
  - No. Our goal will be to collect "Checklist" data. Eg. For each patient/condition type a pink sheet will be generated which lists the different types of information that are normally to be collected. The clinician would check off those items that were done.
  - Potentially part of the New England "pink sheet" project
- Creating the Checklist
  - Envision one page checklist for clinic coordinator / dietician – one week ahead of time... part of packet used as part of clinics.... Could be used fairly readily
  - Add check boxes / radio buttons, staff hand it along with chart, doc fills out
    - Some categories may be diagnosis specific
  - Checklist Issues
    - When does it need to happen?
    - Who enters?
    - Where is it stored?
    - Who processes the information
- Potential Indicators of quality healthcare
  - For Confirmations: where born, when screening done?
  - Did you say no to any testing in the hospital?
  - Was testing for everyone or selective?
  - How often seen patients (not always consistent across providers)?
  - Are clinics doing the checklist?
  - Did developmental testing get done at right time (6 months) in right way?
- Challenges
  - Concerns about work-flow effects and barriers.
  - Need a universal system to hold the data

- Need someone to enter the data into a universal system
- How do we ensure quality assurance in data entry?
- Can all NE hospitals be on the same system?
  - Can we avoid duplication of tasks (clinical notes and “data sheets”)?
  - MMC, BCH, DHMC, Vermont all on the same vendor, what do we do with those that are not using same vendor?

## **Next Steps**

### *Expert Panel*

- Who should participate in the Expert Panel?
  - Potential Participants
    - Group representation; family/consumer, dietician, public health, dietician, office manager, health policy funders, pediatrician
    - Individuals: Janet Thomas, Celia Kay, Sarah Copeland, Jill Shuger, Laura Pickler
  - Considerations
    - We should focus on care within the clinic first and start small given the fact that we don’t have resources to record and track a broad array of information for each patient (so potentially delay involvement of lab people, public health people, others as we cannot yet follow up on all of their prospective interests)
    - We can’t separate clinical care from outcome however, so we need to be mindful of when we will expand membership of the expert panel / learning collaborative to include those with a joint interest and stake in patient outcomes
    - At this stage, importance should be placed on having members that are thoughtful, will read the charter and come prepared
- How can we prepare for the expert panel meeting?
  - Need to start with some basic level information to facilitate better conversation
- What is the role of the Expert panel
  - One role will be agree to the list of conditions to be included in the checklist
- What happens after the Expert Panel meets?
  - Use constituency attending metabolic consortium meeting; have them review work of the expert panel... use time at the consortium meeting to discuss project in more detail

### *Other Considerations*

- Importance of bringing in public health and newborn screening program
  - Are we doing the same thing? If we can do work together, then ACMG and others may be more interested in funding
- Would be nice if all the NE hospitals were on the same system.. note conjoining in 3-5 years for EMR between agencies: Children's is on EPIC, Dartmouth, Fletcher Allen, Maine Med, Elliot (electronic in summer)

### *Need for More Information*

- Janet Thomas's work on care pathways – how's the implementation / integration going?
  - It's unclear how much they have moved forward in this area.

### **Resources Referred to During Discussion**

- Groupman's book: How Doctor's Think...
- Article: Cottage industry to postindustrial care: notes implications of fragmentation of services

### **Meeting Evaluation**

- What worked well (site, food, process)
  - Good location, early, support, good discussion
  - Availability of previous night stay
  - Try for a one day meeting: either Thursday or Friday
- Concerns going forward
  - None specifically identified other than an interest to make sure that, what we task group members with is achievable and can be integrated into existing reporting structures with minimal impact on staff time.
- What would people change?
  - Need copies of Mountain states info
- Next steps: note 31<sup>st</sup> deadline of the grant
  - May 5<sup>th</sup> planning meeting ok: 1-3 via Webex
    - Harvey can call in