

## Board of Directors Retreat Highlights

June 5, 2014, 9:00am-3:00pm, Finance Authority of Maine, Augusta

### Recap of the Last Year

Karynlee presented a summary of accomplishments and challenges of the past year followed by some brief comments.

- Accomplishments
  - There is so much going on. We have accomplished a lot.
  - Core Work
    - Drafted PHI bill and got it passed
    - Secured access to Medicare data on a quarterly data
    - Rule changes to Chapter 10, 270, 241, 243
      - Worked with stakeholders before drafting
    - Established several user groups
      - Payer User Group
        - Representation from over 50 health plans
      - Super Data User Group
        - Huge variety of stakeholders from all sectors
        - We have learned
          - that how people use the data really informs how to structure the data
          - the value of aligning names of providers (people call providers so many different things)
        - These users are helping us make this data more reliable and more useful than it has ever been
      - Consumer User Group
        - Assisting with the Transparency Grant deliverables
        - Might make sense to continue such a group over the long run

- Established a formal communication plan
    - Now releasing NPI
    - Have replaced encrypted member ID values that are more simple
    - Release files are being delivered to users via secure download
    - Working with the Data User Group to establish metrics for data quality
      - Our goal is to have a transparent set of metrics
      - The metrics will establish
        - acceptable level of completeness
        - validation for identifying duplicate records
        - and several other standards
    - Have established an external quality assurance process for all data streams
  - Transformation Work
    - Enhanced data submission portal
    - All data is now off the state servers
    - Working towards a master provider index
      - Working with several partners to minimize redundancy
    - CMS Grant
      - Interim site is up and running
        - Outpatient procedures (about 200)
        - Only includes procedures by facility professionals
      - We are working on improvements to the methodology
    - Working on data management and governance policy
- Challenges
  - Documentation - Inconsistencies because of the difficulty of updates given that there are different stewards of data
  - External communications
  - Balancing timeliness and accuracy
  - Working in parallel spaces: day-to-day and building new
  - Balancing multiple priorities
- Comments
  - It's been a good year
  - Instead of "end state" use the term "future state"
  - The user groups are really helping to make this work relevant
  - Karynlee has transformed this organization

## Goals Clarification

Early in the meeting the group reviewed the goal that was adopted by the MHDO Board on June 7, 2102, as follows:

*To be a data provider to our clients and the public that is:*

- ***Responsive and timely:*** *clearly communicating to our clients what data are available and managing data release to published timeframes.*
- ***Accurate:*** *ensure consistency and conformity of claims submissions*
- ***Accessible:*** *providing self-service applications where possible and removing barriers to data access.*
- ***Streamlined:*** *building efficient processes for data gathering and release.*
- ***Secure:*** *protecting the confidentiality of personal health data – electronic threats change and systems must adapt to meet these challenges.*

Later in the meeting, there was general consensus on adding the following:

- ***Responsive:*** *providing data and services that are responsive to client and public needs.*

## Statute Review

Assistant Attorney General Deanna White provided an overview of statutes that govern the MHDO, which was followed by some brief comments and discussion.

### Presentation

- The Legislature and Governor can change the statute whenever they want and have expanded MHDO's statutory authority several times
- Chapter 1683 of Maine Statute is the core enabling statute for MHDO
- Statutes are fairly prescriptive about how MHDO must operate and what it must do
- In 2001, The Maine Health Data Processing Center was established
  - In order to process "claims data"
- In 2003, there was a mandate added regarding quality data and consideration of health care consumers

- Up to this point the data was used mostly for and by professionals
- Now, “the public” is added
- Several reports are now mandated for public use
- At this point, practitioners were required to provide information about their prices
- In 2009, a provision was added to address “public transparency” and provisions were added regarding data from several new sources of several new types, but do not prescribe how to do it.
- Deanna’s interpretation:
  - MHDO is mandated to collect “whatever data you need” in order to produce and publicize certain reports identified in section 8712.
  - “Claims data” and “clinical data” are terms of art and are not defined in the statute. Rather, the statute prescribes resulting reports and mandates that MHDO collect information to support the specific reports.
- Guidelines are prescribed for linking and leveraging existing data sources.
- MHDO is mandated to ensure that data is available in the public domain.

### Questions/Comments

- Thanks for such a clear explanation
- How does the potential sun setting of the Maine Quality Forum affect our work
  - It doesn’t really affect what we do – our mandates remain
  - It may result in fewer resources for us
- What does the legislation say about how MHDO will be funded?
  - MHDO gets funded mostly from fees and assessments
  - We expect to balance sale of data and assessments
  - There are caps on the rate at which assessments may increase
  - There are several other “rules” in the statute
  - we also have the ability to apply for grants
- Discussion about funding
  - The best way to bring in more revenues is to bring in more users
  - We are required to do analysis but don’t want to duplicate what others are doing
  - Clarified that hospital inpatient data populates MONAHRQ

## Types of Data we Collect

Karynlee clarified the types of data that MHDO deals with followed by some brief comments.

### Clarifications

- “Clinical Data” is defined in Chapter 120 of our Rules
- Claims Data
  - Types
    - Medical
    - Pharmacy
    - Dental
  - Sources
    - Commercial
    - Medicaid
    - Medicare
  - Restricted and unrestricted data
    - Restricted data
      - Restricted data includes date of birth and town of residence
      - The entity requesting the data must state the purpose
      - Must be reviewed by a committee prior to release
      - Staff ultimately have the decision about what restricted data to release although they must consider the committee recommendation
    - Because of LD 1740, we will likely have to change Chapter 120 of the Rules
    - It is critical that the release process be totally transparent
- Hospital Encounter Data
  - All hospitals, all encounters
  - Same definitions and protocols for Restricted data as described above
  - Practitioner identifiable data elements for restricted hospital inpatient data
  - Unrestricted hospital outpatient data
  - Restricted hospital outpatient data
  - Practitioner identifiable data elements for restricted hospital outpatient data
- Hospital Health Care Quality Data
- Hospital financial data
- Organizational data

## Comments/Questions

- MHDO is working with Muskie to develop a list of all available data
- Even with restricted data, the results of diagnostic tests are not available
- Just because we have authority to collect several types of data, doesn't mean that MHDO has all such data
- Most data is available in aggregate and by payer
- The Super Data User Group is helping to improve technical quality
- There is a quality improvement cycle for all user groups
- Both payers and hospitals are required to validate data
  - If they have data that is required but don't provide it, that is a compliance issue
  - In some cases, MHDO sets validation thresholds
  - In other cases, the payers set validation standards and explain those in the notes
- Clarified that the website should let the public know what restricted data is available

## Presentations

- Barbara Sorondo, MD MBA, Director -EMMC Clinical Research Center
  - Introduction
    - Very experienced with several sets of health care related data
    - Interested in using data to improve quality and improve the patient experience
  - Current projects
    - Bangor Beacon Community
      - Focused on Triple AIM
        - Also tried to improve the patient experience
      - We blended 3 different sources of data
        - HER
        - HIN
        - Patient Reported
      - We used these data sources to evaluate interventions
      - Limitations
        - Lacked time-sensitive claims data
        - Lack of patient crosswalk
          - Not enough information about each patient
        - Inability to identify financial impacts of interventions

- Solutions
  - Prospective cohorts
    - Don't need to know patient names and other details
    - The most important thing as a researcher in this field is to learn how to de-identify patient information
  - Focused on high risk, high cost patients
  - Used a control group and an intervention group
  - Collected patient supported metrics every 6 months
  - We were able to demonstrate that intervention group costs declined
- Finding
  - For every dollar spent in care management, we saved over 3 dollars in health care costs
  - Also analyzed cost per case at two hospitals
- Multi-Institutional Regional Collaboration for Quality Improvement
  - Provided a “dashboard” of data for providers
  - Data was even provided for providers who were competing against each other
  - Were able to demonstrate that quality can be improved just by working together
  - Due to lack of patient crosswalk, we were unable to demonstrate cost savings
- High Value Health Care Collaborative
  - National project with multiple partners
  - Merges
    - Claims data
    - Clinical Data
    - Patient Reported Measures
  - The patient crosswalk is developed by a third party and the data is reported de-identified
  - Standardization is very difficult
  - Preliminary results: improvements in patient experience, improvement of quality, reduction Medicare payments
- Triple AIM +
  - Improve quality
  - Reduce Costs
  - Improve Patient Experience
  - Improve Provider Experience

- Questions/Comments
  - Regarding Beacon reporting back to the practices, what components of information were required to report back to the practices?
    - Needed to know which patients were matched with which providers
  - Regarding the High Value Health Care Collaborative, what were the elements of data required to do the patient crosswalk
    - Patients need to be linked to providers, but then de-identified right after the crosswalk is established
  - Regarding Reports such as Diabetes Intervention Results, who should be able to see the data
  - Clarified that collecting the data requires a high level of patient trust
  - Clarified that with regard to ACO's, patient information is linked to providers but the patient has an opportunity to opt out (actually two opportunities)
- Devore Culver, CEO- HealthInfoNet
  - HealthInfoNet
    - Operates primarily in the primary care space
      - Specialists have been slow to come to the table
    - About 90% of Maine citizens have something in the Exchange
    - 13m messages arriving in the exchange per month
    - We spend a great deal of time and money standardizing content
  - About this presentation
    - Not giving opinion about public policy
    - Dev is drawing on 30 years of experience
  - The Fundamental Challenge
    - Make the case that the public interest exceeds the individual interest
    - Three key questions
      - Does the interest of the public require identification?
      - Is there another way to identify patient information?
      - What is the value proposition that compels the public interest?
  - The role of the patient
    - HealthInfoNet has done considerable public engagement in large part because they are aggregating data across sources
    - HealthInfoNet has learned that educating residents is imperative
    - Engaging the patient in how things are set up is really important
    - Data being held in a public space by a public entity is of considerable concern to the public



- If you implement an opt-out strategy, please don't do it through the provider
      - This would confuse the public
  - Do not underestimate costs of integrating clinical and claims data
    - HealthInfoNet spends \$5.5m to \$6m per year
  - Claims data and clinical data are really different types of data
  - Patient Identify
    - There are ways to reveal patient identity without asking for patient identity
  - The competitive market place for clinical data
    - This is a very fast moving market place with lots of private players
    - MHDO will have competition
    - You must have a business plan
  - Comments/Questions
    - Emphasis on the point about competition
      - The clinical data space is highly competitive
    - Those who find HealthInfoNet most useful are those who review and update it daily
    - There are big holes in the data – for instance there are several difficulties associated with the fact that HealthInfoNet does not include much data from specialists
    - There was a successful pilot project between MHDO and HealthInfoNet
- Jim Leonard, Deputy Director- MaineCare
  - Introduction
    - The Office of the State Coordinator and HealthInfoNet formed a legal work group who identified that mental health and HIV data were missing
    - Because we recognized that this missing data was really important and because we were committed to a collaborative process, we were able to achieve a good result: inclusion of this data, albeit by opt-in
    - The MHDO info and the HIN info could together provide the fuel to achieve the State of Maine goals
  - Focus ongoing discussions on data use, access, and control - not ownership
  - MaineCare data provides several use cases from which we can learn

- Michael DeLorenzo, Ph.D., Director of Health Analytics-Maine Health Management Coalition
  - Clinical Data defined
    - It need not include everything in a patient's chart
    - We need to talk through this and make decisions about what it means
  - Linking clinical and claims data is a different issue from releasing PHI
  - There are so many benefits to linking clinical and claims data, it is inevitably going to happen. The questions are:
    - How governed?
    - Who managed by?
    - How it will be done?
  - These questions will best be answered in a multi-stakeholder setting
  - The article (by Safran, et. al.) provided by Jim is really great in identifying the challenges and how to address them
  - There may be ways to combine data with specific authorities, with specific uses in different places – it need not be all in one place controlled by one entity
  
- Jeff Austin, Vice President of Government Affairs and Communications-Maine Hospital Association
  - Two biggest concerns
    - MHDO taking this on at this time
      - We want MHDO focused on other more important things that the Legislature and hospitals want MHDO to do, for instance, such as comparative cost data
      - Focus on cost and do it well
      - This is not a comment on whether or not this is a good idea, it's a comment on timing and priorities
    - Having a rule in place (such as about covered entities), needs to be rooted in defensible public policy
      - Patients understand sharing clinical data to improve their care – they are less likely to approve sharing their data for other purposes
      - There will need to be increased public awareness and public understanding for the need for clinical data sharing
      - Absent solid public policy with widespread support, MHA is not likely to spend a lot of capital to support clinical data sharing and may in fact spend political capital to oppose such activities

- Andrew McLean, Deputy Executive Vice President-Maine Medical Association
  - Echo challenges and concerns raised thus far
  - We are not enthusiastic about expanding MHDO activities to clinical data in large part because we are concerned about the additional burden it would place on medical providers
  - Worst fear is that something that the MHDO does will result in a medical support professional extracting something from a medical record and sending it to MHDO
  - Comments
  
- Comments and Clarifications
  - What would it take for MHA to support MHDO handing clinical data?
    - MHDO complete it's other more important stuff
    - Better define how "it" will work
  - What is the specific MMA concern about extracting information from medical records to provide to MHDO
    - Purely administrative burden
  - There is no intention to use the provider space for MHDO opt-out
  - LD 1740 was originally opt-out like HealthInfoNet but then it was taken out

## Release Updates

Karynlee provided the following update.

- Context
  - If we find that there are issues after a release, we might release a new file to users
  - In instances when a mistake is made by a payer, a patch file might be issued
  
- Going Forward
  - We are communicating a schedule to users that identifies all types of releases and the schedule
  - As board members, we should know the lingo
  - Clarified that "a patch" is used to fix a very specific error in a previous file

## Linking Claims Data and Clinical Data - Discussion

### **1. Where (and how) does this fit among all other MHDO priorities, if at all?**

- To answer this question, we need to establish how MHDO will participate in these activities?
- Several board members generally support expanding the scope
  - We have achieved a great deal in line with our strategic vision and should continue our transition to a new type of organization - That means beginning to expand our scope now even though we have not completed all previously-identified tasks
- Concerns about expanding scope:
  - MHDO has more important priorities.
    - Provide claims data
    - Provide pricing information
    - Patient access to data
  - We need to define “this.”
  - We need to better understand current and emerging private sector activity.
- Straw Poll: Are we in favor of continuing to play an active role in pursuing the linkage between clinical and claims data to meet our defined mission?
  - “Active role” means
    - we acknowledge the need for a linkage
    - take steps to define “clinical data” and explore how it might be done
    - and does not necessarily mean we are in favor of collecting new data
  - Results
    - All board members in favor except David Winslow of MHA.

### **2. What do we mean by “clinical data” and what does it mean to “link” it?**

**Or**

**What process should we use to define “clinical data?”**

- Ideas for what “Clinical Data” means
  - Collected in a clinical setting by a health care provider

- Has quantitative characteristics
  - Such as a value
  - The value could be “yes” or “no” and could refer to behaviors or risk factors
- Limited to what we already have
- Health outcomes (observations)
  - Did the person get better?
  - Was the surgery successful?
- Patient generated health data (patient reported)
- Information that would inform future changes in practice, generally
- Need first to decide who we are defining the data for
- The way that the statute defines clinical data
- Quality data
- Don't use the term “clinical data” but instead, describe it by sources
- Build the uses
  - Let data collection (or reporting) be driven by most needed uses
- Ideas for how it would be “linked”
  - Collect information based on use cases (what the market says they need to do their work), but NOT fully comply with all that the statute asks us to do
  - Provide the data in a way that others can link it
  - MHDO should not collect the data but might prescribe, in our rules, that such data be reported to another entity
  - We should not say that we should not collect data
- Ideas on how to proceed
  - Charge the MHDO or someone to research how others define “clinical data”
  - Learn about what's going on in the private sector
  - Establish a multi-stakeholder group to develop a recommendation for the board
- Conclusion
  - Establish a multi-stakeholder group to
    - Identify use cases
    - Learn about what's going on in the private sector
    - Develop recommendations to the board

- Establish the group’s charge, timeline, and composition at the next board meeting
  - Karynlee and the Exec. Committee will draft
    - Consider limiting membership to board members
    - Consider the context of other core key deliverables we are responsible for
    - Consider the financial implications and funding of this work
    - Convene the group ASAP and ask for their work to be completed by September, 2014
- Karynlee will approach Maine Health Access Foundation for a potential grant to fund this work

**3. What needs to happen to play an active role in pursuing the linkage between clinical and claims data**

- a. Inventory and inform the Board about how data is currently used
- b. Define the role of “the State” (the role of MHDO)
  - i. To what extent should we exercise our control over clinical data and claims data? This should be reflected in a new rule
  - ii. To what extent should MHDO actually have access to the data
  - iii. Consider lessons from “meaningful use”
- c. Establish some principles, such as:
  - i. we minimize burden of data-submitters
  - ii. it is not our intention to undermine the effectiveness of HealthInfoNet or patient trust in HealthInfoNet
- d. Engage the public
  - i. Define MHDO role re: public education
  - ii. Clarify the patient role in data ownership
  - iii. Establish a communications plan for informing the public
  - iv. Build and maintain trust with the patient
  - v. Patient education
    - 1. How this benefits the public
    - 2. How patient privacy will be protected
- e. Establish new sources of clinical data

- f. Get going on developing legislation for January, 2016
- g. Explore opportunities for partnerships with national efforts that could lead to funding

### Linking Claims Data and Clinical Data - Immediate Next Steps

- Develop a timeline for all next steps (identified above) over the next few years
  - To be developed by the Executive Committee for consideration at the next board meeting
- Wait until recommendations from the clinical data definition group (due by September, 2014 – see conclusion in discussion item #2, above) and then decide the specifics of how to proceed with each of the above listed ideas.
  - Let the use cases drive how we proceed on these other fronts
- Maybe later
  - Hold a public input session and then draft a rule based on input

### Next Board Meeting

- No meeting in July
- The next meeting will be in August

### Closing Comments

- Very productive day
- This was a great day – appreciated the legal brief
- Very productive day
- Very productive – good conversation
- I have a potential use case
- Leadership and facilitation of this meeting was excellent
- Excited that we are in the midst of this important work
- Good meeting – good, safe conversation
- Glad we are keeping a good vision of the future
- Really appreciate that we can talk about this constructively
- Today went so much better than I thought it would be
- Big sigh
- Found this to be very helpful, informative and respectful