Maine Health Data Organization
Board of Directors Retreat Highlights Report
June 2, 2016

These notes were taken on the spot by facilitator Craig Freshley. They are not a complete reflection of what was discussed and have not been checked for accuracy or approved by the group.

Summary of the Day’s Outcomes

- People love MHDO because of the dedication of people and the importance of the cause
  - And every day is an adventure!
- While waiting for clarity on legal implications of Gobeille decision, we will:
  - Clarify the value proposition for data submission and access
    - Ad hoc group established to work with staff to develop a strategic approach to delivering a value proposition to employers
  - Clarify and remove legal and technical barriers to voluntary data submission
  - Put in place a business associate agreement
  - Participate in discussions about national standards
  - Watch New Hampshire and consider a similar approach here in Maine
- Our priorities:
  - Manage a high-quality, comprehensive health information data warehouse
  - Promote the availability and utilization of healthcare data and information to help users improve the health of Maine people and the cost of healthcare
  - Promote the transparency and utility of healthcare cost and quality information
  - Meaningful engagement with our data providers, data users, and consumers of healthcare to understand and meet their needs
  - Support a culture of transformation in our organization and in Maine’s healthcare environment
  - Seek out opportunities to collaborate and and advance the use of health data
- It’s okay for us to release data without violating antitrust law
  - Although we might want to take some steps to better educate users
- We are on track in achieving our five-year plan
About the Meeting

Attendance

Board Members

- Lisa Harvey-McPherson (Chair), Eastern Maine Health System
- Anne Head (Vice Chair), Department of Financial and Professional Regulation, State of Maine
- Andrew Ellis, Anthem BC/BS
- Patrick Denning, Harvard Pilgrim Health Care
- James Leonard, Department of Health and Human Services, State of Maine
- Peter Gore, Maine Chamber of Commerce
- Joel Allumbaugh, Consumer
- Neil Korsen, MD, MSc, MaineHealth
- Anita M. Knopp, DC, Maine Chiropractic Association

Guests

- Deanna White, Agency Assistant Attorney General
- Katherine Pelletreau, Maine Association of Health Plans
- Shaun Alfreds HealthInfoNet
- David Winslow Maine Hospital Association

Staff

- Karynlee Harrington, Maine Health Data Organization

Facilitator

- Craig Freshley, Good Group Decisions

Agenda

9:00 AM  Opening

- Welcome – Meeting goals and introduce Craig - Lisa
- About the Meeting - Agenda and ground rules - Craig
- Warm-up exercise - Craig

9:30  Review of MHDO Statute and Recent Supreme Court Case

- Discussion of MHDO’s statutory authority – Deanna
• Discussion on ERISA and Gobeille v. Liberty Mutual Insurance Company – Deanna

10:15  **Sustainability Model**
• Presentation and discussion about various aspects of moving to a data subscription model. For each of the following topics we will first hear a presentation and then address specific issues to be resolved. – Karynlee
  1. Review of MHDO Data Users: Use, frequency, revenue generated
  2. Environmental scan of other state models
  3. Goals of a subscription model
  4. Feedback from users
  5. Overview of tactical plan to meet goals
  6. Next steps

12:15  **Lunch**

1:00  **Strategic Priorities**
• Review mission statement and strategic priorities - Karynlee
• We will discuss, revise as needed, and adopt the statement of priorities. - Craig

1:45  **Key Issues Re: Data Release and Data Submission**
• Discussion of Antitrust – Deanna
• Discussion of Voluntary Data Submissions – Karynlee

2:30  **Wrap-up**
• Review of timeline and key activities over next 12 months - Karynlee
• Summary of outcomes and next steps – Craig
• Next Regular Board Meeting - Lisa
• Closing Comments - Craig

3:00  **Adjourn**

**Ground Rules**

• Open to understanding before judgment
• Let Craig call on people to help all views be heard
• Discussion among board members and staff
• Flexible facilitation in service to the board as a whole
• Themes and conclusions now and later
• Stretch breaks enthusiastically welcomed and embraced

**What We Love About MHDO**

By way of introductions each person mentioned one thing that they love about MHDO and the following were mentioned:

• Dedication from board and staff
• Peter Gore
• Fantastic group of people to work with
• Integrity and dedication of the people
• Every day is an adventure
• Adaptability
• Like playing with data
• Being part of work that is beneficial to Maine
• Bring light to the cost of healthcare
• Shed light on the cost of healthcare

**MHDO Statutory Authority**

• The purpose of the organization of the board is to carry out policies established by the Legislature and Governor; primarily, create and maintain health information to improve the health of Maine citizens
• The board is made up of 9 providers and 9 payers (sellers and buyers)
• Each person is supposed to bring special expertise to the board from a specific area
• Board members are required to support the MHDO law
• While anti-trust laws have been in effect since 1890’s, health data is a relatively new thing and it’s a challenge to apply those anti-trust laws
• This state has made a policy decision to pursue healthcare price and data transparency
• Enabling legislation was adopted in 2003: Act to protect consumers and business owners from high health care costs – Public Law 2009
• The MHDO has authority to collect the data it needs to fulfill its statutory responsibility
• What constitutes “clinical data” is to be determined by the board
ERISA and the Gobeille Decision

About ERISA

- In 1974, ERISA (the Employee Retirement and Income Security Act) was enacted
  - This affected every “employee benefit plan,” including health plans
- ERISA supersedes any state law pertaining to a benefit plan - known as the pre-emptive clause
  - There is an exception known as the savings clause – insurance companies are covered by a state’s insurance laws
    - There is an exception to the exception – a plan itself cannot be considered an insurance company

About the Gobeille Decision

- Question: Could Liberty Mutual (an insurance company) be forced to submit its data to Vermont’s all-payer claims database?
- Liberty Mutual asked Blue Cross (who it contracted with) to turn over its data to the state, but Blue Cross refused. The state and Liberty Mutual went to court.
- At the Supreme Court, Liberty Mutual won the right to withhold data
- Decision – Vermont’s all-payer claims database is preempted because it does not have to do with ERISA plans itself – reporting data should be nationally uniform and such data should be collected by the Secretary of Labor
- So far there has been a lot of confusion about the implications of the decision
- There are implications for contracts between insurers and insured about data reporting
- States are establishing mechanisms for payers to voluntarily opt in to APCDs (All Payer Claims Databases)
- One thing for MHDO to consider is to put APCD-related laws into the insurance code, like New Hampshire is doing
- National associations of health data organizations are also working on solutions
- Comprehensive health data is much more highly valued now than a decade ago

Implications for MHDO

- Payers are telling us that they are not submitting data in light of Gobeille
- MHDO has sent a communication to payers clarifying that MHDO has authority to collect data but is suspending data collection from March 1 to October, 2016 and in October, data will have to be submitted back to March
- Some large self-insured payers have asked to continue to submit data and it’s been clarified that HIPAA does not disallow submission
  - Yet there are technical problems with accepting such data
- Nationally, we need to set up a strategy to be able to accept voluntarily submitted data
  - This might involve putting into place agreements between MHDO and data submitters
- We have also heard from self-insurers and small employers that they do not want to submit data
- At least this issue is forcing the states to come together to develop national data standards

MHDO Current Approaches
- Suspended data collection March - October
- Karynlee is continuing discussions on a national level about national uniform data collection
- We are also keeping an eye on what’s going on in New Hampshire
- We are also figuring out a way to accept voluntary data legally (and technically incorporate it)

Clarifications Related to the Gobeille Decision

- 20% to 30% of our data comes from self-insured ERISA plans (current estimate-% can fluctuate each year)
- The primary argument made by Liberty Mutual was that the data is owned by the employees
- Idea: discuss the value proposition of data submission for insurers
- The heaviest users of All Payer Claims Databases are payers – they know the value of using the data
- Speculation about resistance to providing data
  - This data is being used by “arms” within the organizations that understand the value of the data yet other “arms” do not understand this value and think differently about the issue
  - Perhaps “retribution” is happening
  - Perhaps there is a fear of legal exposure – lack of clarity about who owns the data
- APCD data is critical for public health and wonder if that has been considered in this discussion and in the courts
- Caution about assuming the extent to which users of the data necessarily value the data
- Clarified that ERISA applies to ALL employer plans, and it is insurance companies who have to follow the law
  - Individually-insured and government employees are exempt from ERISA
- Many companies self-insure for workers compensation but not for health care
- The difference between fully-insured plans and self-insured plans has to do with who accepts the risk
- Would national data collection standards require a change in federal law or would a federal rule change suffice?
  - Answer unclear
Comments About MHDO Sustainability in Light of Gobeille

- We can't just sit in a holding pattern – we need to work on multiple approaches
- The sustainability model is on a five year path towards sustainability and we need to continue on the path
- We have an obligation to continue to plan our future
- Let’s add a discussion about what MHDO can do now in light of the Gobeille decision
  - Such as helping employers understand why they should submit data

Next Steps for MHDO

Ideas

- Continue discussions on a national level about national uniform data collection
- Keep an eye on what’s going on in New Hampshire
- Figure out a way to accept voluntary data legally (and technically incorporate it)
- Understand the drivers that are encouraging submitters not to submit data
- How we think people are using our data
  - For internal planning purposes
  - For public health planning and response
  - Longitudinal research with larger clients
- Help employers understand why they should submit data
- Explore the feasibility of a business associate agreement
- Consider involving the State Employee Health Commission and other groups of employees

Clarifications

- Hospital-submitted data is not affected by Gobeille
- Tiers of self-insured companies
  - Large – purchase data that is meaningful to them
  - Medium – actively engaged with data and understand the value
  - Third Tier – not sure about how the data is helpful
- The Gobeille decision does not affect our ability to render an assessment (at least that’s the assumption we are proceeding with)

Conclusion

- Clarify the value proposition for data submission and access
  - Understand from them first: why they value this data
    - Involve large insurers and understand the value to them
Convene business to understand their perspectives on the value of health data
  - Tailored to differing size and type of submitter/user
  - Develop a "dashboard" for data presentation that is user-useful
- Clarify and remove legal and technical barriers to voluntary data submission
- Put in place a business associate agreement
- Participate in discussions about national standards
- Watch how New Hampshire is incorporating data collection laws into the insurance code, see if it works, and consider a similar approach here in Maine
- Establish a sub-group of the board to continue discussions on this
  - Members
    - Joel (convener)
    - Andy
    - Neil
    - Anita
    - Peter
  - Purpose
    - Work with staff to develop a strategic approach to delivering a value proposition to employers

**MHDO Sustainability Plans**

**Overview**

- MHDO budget: $2 million
- Several data sets available
- 5-tiered fee structure
- Over 50 commercial payers, including Medicare and MaineCare, submit data to the All Payer Claims Database
- The access fee structure has been in place for a long time

**MHDO Data Users**

- 129 data requesters over the past three years
  - These users represent about 80% of the population
- Access fees received: $728,324
- It’s very difficult to budget based on the current access fee model
- Karynlee wants to get out of the business of “building the system” and spend more time “out there” talking to users about the use of the data
- MHDO is growing capacity to provide ad hoc data – data where the requester provides parameters
• the 129 data requests, 93 are from ongoing requesters
  o This data supports a subscription model but also indicates that we have to have an alternative to a subscription model (for the 36 one-time requesters)
• Clarified that we now get Medicare data quarterly

**Proposed Future State**

• We are trying to get the right infrastructure in place so we can provide the right services that will lead to financial sustainability
• Services
  o Self service
  o Self-guided reporting
  o High level reports

**Environmental Scan**

NORC conducted an environmental scan and concluded there are four examples of sustainability models:

• Standard data extract
  o Needs development of an interactive user experience, including available metadata, data dictionaries, and data samples
  o Aligns with MHDO current and new delivery model
• Web access to data resources
  o Access to a secure portal and access to statistical software
  o Users do not have to store data, but does not preclude optional uploading of data
  o When analyses are complete, de-identified outputs are available
  o This model aligns with MHDO’s new delivery model of web access/web services
  o MHDO is currently piloting web access with one of our more sophisticated users of our claims data
• Reporting services
  o Standard reports and custom reports
    ▪ Would be good to have standard reports (developed by HSRI and NORC) available on “hot topics”
  o This model aligns with MHDO’s new delivery model web access/web services.
• Consulting services
  o Providing support to data users
  o Could be standard service for new users and/or on-demand resources
  o This model aligns with MHDO’s new delivery model of web access/web services
• Pricing structure
  o Fee-per-data-set arrangement
  o Fee-per-report arrangement
- Tiered pricing schedules based on file and/or requester types
- Annual subscriptions
- Licensing fee
- Hourly fee

**Website Presentation**

- Data should be easily available – perhaps via use of a slider
- Which payers have available data – should be easily and graphically represented
- We should provide some basic information about “what’s changed” – rather than just update the numbers
  - Examples:
    - Changes in numbers of procedures, by type
    - Opiate overdoses, by county
  - Perhaps such reports should be publicly available
    - With “greyed out” display of what could be accessed for fee

**Subscription Model**

- A subscription-based pricing model is a payment structure that allows a customer or organization to purchase or subscribe to a service or product for a specific period of time for a set price. Subscribers typically commit to the services on a monthly or annual basis.
- Goals
  - Increase the value of our products and services for existing customers
  - Acquire new customers
  - Improve the accuracy of revenue forecasting through sustainable recurring revenue growth
    - Although there is risk in getting the pricing right

**Final Comments**

- The next step will be gathering feedback from users and key stakeholders
- This wouldn’t be implemented until next fiscal year at the soonest
- This will be a different way of doing business for us
- Challenges
  - We need to figure out a way to provide data to some requesters without charge
  - We need to restructure how our asset looks on the public side
Strategic Priorities

Current Purpose and Priorities

Purpose

MHDO’s purpose is to create and maintain a useful, objective, reliable and comprehensive health information data warehouse that is used to improve the health of Maine citizens. The MHDO is the data center that is responsible for the collection, storage, management and distribution of healthcare data and information, including claims data, hospital inpatient and outpatient encounter data, hospital quality data, as well as financial and organizational data.

Priorities

1. Manage a high-quality, comprehensive health information data warehouse
2. Promote the release of healthcare data and information
3. Promote the transparency of healthcare cost and quality information
4. Support ongoing stakeholder engagement with our data providers, data users and consumers
5. Support a culture of change based on our stakeholders’ needs

Guiding Principles

Responsive and timely: Communicate data availability and manage data releases to published timeframes

Accurate: Ensure consistency and conformity of all data submissions

Accessible: Provide self-service applications where possible and remove barriers to data access

Streamlined: Build efficient processes for data collection and release; leverage national standards when available

Secure: Protect the confidentiality of personal health data – electronic threats change and systems must adapt to meet these challenges
Revised Priorities

The group had a full discussion about the priorities and revised them as follows:

1. Manage a high-quality, comprehensive health information data warehouse

2. Promote the availability and utilization of healthcare data and information to help users improve the health of Maine people and the cost of healthcare

3. Promote the transparency and utility of healthcare cost and quality information

4. Meaningful engagement with our data providers, data users, and consumers of healthcare to understand and meet their needs

5. Support a culture of transformation in our organization and in Maine’s healthcare environment

6. Seek out opportunities to collaborate and advance the use of health data

Here are some highlights from the discussion about revised priorities.

• This is a totally new organization
• Our culture has changed
  o At the policy level
  o Our reputation
  o Culture change has happened among the staff, also
• If improving the health of Maine citizens is our charge, that needs to be represented in the priorities
  o Are there specific ways or areas in which we should provide data in order to improve health of Maine people
  o We should establish metrics for measuring this
    ▪ Such as the number of ACOs who use MHDO data to improve the health of their organizations
• Supporting a culture of change applies internally and to the external world in which we exist
• Perhaps we should do an environmental scan
  o Who is in the health data space
  o Who is using our data
  o Who is in the space and not using our data
• We are taking steps to better understand why users are requesting data; how they intend to use the data. That will help us see how our data is being used to improve public health.
• Craig’s idea about priorities
  o Establish a mechanism for collection, management, and sale of data that sustains the organization and helps users improve the health of Maine people and lower the cost of healthcare
• Provide data in increasingly useful formats that showcase the value of the data
• Engage with data providers, data users and consumers of healthcare

Discussion of Antitrust

**Context and Clarifications**

- We have received several comments from data providers such that they don’t like the purpose for which the data will be used. They argue that it would be an antitrust violation.
- MHDO has countered and released the data anyway
- However, Karynlee does not think this issue will go away and there is a chance that this will get challenged in the courts
- The board needs to understand why releasing this data is not an antitrust issue
  - If there is a dispute it could potentially be appealed to this board, before going to court
- The fundamental issue that providers have is price-fixing
- The purpose of the antitrust law is to provide for competition and consumer choice
- Antitrust laws are very difficult to enforce
- It’s okay to lower a price to match a competitor but not raise a price to match a competitor (if it is an actual agreement – tacit collusion is not enough)
- Payers and providers don’t generally like price transparency because they don’t like competition

**Conclusions**

- MHDO is able to release data without violating antitrust law
- The State of Maine is not subject to antitrust laws
- If MHDO was sued, the organization and the board would be protected due to the Tort Claims Act

**Potential Approaches Going Forward**

- When payers are looking for data on each other, we may want to de-identify the payer data
- Could add an indemnity clause to the release agreement
- Could remind data users that they can’t use the data to break antitrust laws
Timeline and Next Steps

- Five years ago we established a 5-year timeline
  - It is year 4 and we are on track
  - By 2017 we expect the transition to be completed

- Over the next 12-18 months
  - New subscription model
    - Finalize recommendation
  - Hospital data
    - Launch submission portal
    - Move to quarterly releases
  - Transparency
    - CompareMaine 3.0
  - Data release rule
    - Develop and launch new data request tracking tool
    - Implement Chapter 120
  - Work related to the Gobeille decision

Closing Comments

- Recognize leadership of Karynlee and Lisa and the board
- Thanks to Deanna
- Thanks to Lisa for her skill and energy in leading the board
- Can’t believe what we’ve accomplished and it’s in large part due to the board
- We are a leader in the country
- Looking forward to sharing with this market what our data can do
- The hopeful thing about Gobeille is that it potentially advances a national solution
- Thanks to Deanna and Karynlee and the board

Board Chair Lisa Harvey-McPherson closed the meeting with these final comments

- Thanks Karynlee
- Next meeting is planned for September 1
- We are proposing a quarterly board meeting schedule, 9-12 meetings once each quarter
- Regarding Gobeille
  - Over the next 60 days we will better understand the national strategy
  - At the September board meeting we will take stock and decide our path going forward
- CompareMaine 2.0 will be released as planned in two weeks
- Thanks everyone!