



January 8, 2013

Dear Dr. Cutler, Mr. McHugh and LD 1818 Workgroup members:

On behalf of the Maine Health Management Coalition and its Foundation, we are submitting the following responses and recommendations for your consideration as you revisit the final report of the LD 1818 Workgroup. As you will recall, the Coalition submitted the original legislation that resulted in the workgroup out of growing concern and frustration about the necessity of data to transform care and the inability of data users to access needed data. The Coalition's Foundation Board has been actively involved and have dedicated significant staff time and resources to participate in the workgroup and have submitted our positions to contribute to this process. We remain committed to the workgroup process and are submitting feedback on the proposed recommendations that we hope will inform decisions as they reflect carefully considered input from a broad multistakeholder group of large public and private employers, providers, unions and others.

The Maine Health Management Coalition was founded over 19 years ago with the primary function 'To assist the Members in the process of sharing and analyzing data ("Health Data"), related to the provision of health and related services to the Members, and their employees and health insurance plan participants ("Health Services")'. The Coalition now represents 65 members with over 200,000 covered lives - nearly 40% of the commercial market in Maine. The Coalition and its members have been active and engaged users of data for nearly two decades with a membership that is knowledgeable about the current environment and challenges of data access and use. Coalition members recognize and appreciate the tremendous contributions of the Maine Health Data Organization to their work while also recognizing the dramatically different market and demands for data from when the MHDO was created. The Coalition proposes that the State build on the legacy and structure of the MHDO while not limiting us to the historical design and functions. Coalition members remain committed to effective use of data to improve the value of healthcare for all stakeholders in Maine.

Providers need timely data to effectively manage their patient populations and to be accountable to and for the communities they serve. Patients need data to understand the variation in healthcare quality and costs and be educated and informed consumers who can effectively partner with their care team. Purchasers need data to ensure the care they purchase on behalf of their employees and their family members is of the highest quality and value.

The Maine Health Management Coalition (MHMC) and the Maine Health Management Coalition Foundation proposed the following priorities and aims for the development of a statewide data system to support purchasers, patients and providers in the transformation of healthcare and improvement of healthcare value at the outset of the 1818 workgroup process:

1. **A common, shared data source of integrated clinical and claims data for all parties to use** – with appropriate privacy, security and legal safeguards and role-based access – will serve as the foundation to system and payment reform. All approved users should have fair, affordable and equitable access to the data for the purposes of care improvement.
2. **A publicly governed and accountable entity should maintain the functions of the MHDO.** Public governance provides the greatest accountability and protection for data users and could provide fair and equal data access to all users.
3. **Timely access to all payer data** is necessary to support system transformation. All payer data from commercial and public payers should be available at least quarterly to users. Data on a subset of patients is insufficient to facilitate population health management. Data that is not current does not allow for effective and timely interventions to change care.
4. **Patient identified data must be included but identifiable only at the patient/provider level** to allow providers to effectively improve care for their patients. Identified data enables the combining of different data sources to allow a meaningful and longitudinal understanding of utilization, care patterns, and outcomes.
5. **Resources should be used effectively and care should be taken to avoid unnecessary duplication of data systems** and the resources needed to support them. Data is a resource that is only valuable when it is accessible and used effectively.
6. **Data users- including consumers- should have input into the structure, design, and purpose** of the state’s data systems to maximize its use for and by all stakeholders, including the public.
7. **Integrated clinical data, claims, health risk, and outcomes data is the optimal source** of information for care improvement and high value.
8. **Information created from healthcare data should be made transparent and publically available** in aggregate with the appropriate safeguards, processes, and criteria for reliability.

We believe the workgroup report and recommendations largely reflect these principles and we are in general support. However we ask that the workgroup also consider the following items:

1. **The recommendations should consider a broader range of data sources.** Recommendations acknowledge ‘several data repositories’ but only name two sources of data in the state, MHDO and HIN. Several more data sources exist including direct data from providers and other private clinical and claims data repositories and should be considered as possible partners in the Maine’s data system. The workgroup should think more broadly about options for data and data submissions.
2. **The recommendations should include an employer and/or plan sponsor on the reconstituted MHDO Board.** We support the recommendation to reconstitute the MHDO Board but the recommendations do not acknowledge the key role of employers as data users and stakeholders with strong interest in a more efficient healthcare system.

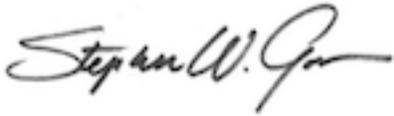
3. **Linked data should be available and identifiable for multiple purposes.** The recommendation to allow linked data only to be identifiable for linking is far too restrictive and misses the point of linking data to use the information for improvement. In fact, this restriction is in conflict with using the data for treatment, payment and operations, the recommendation directly above it, and in conflict with the recommendation in Theme 3 giving consumers access to their own information.

As stated in our original letter, we believe the Maine Health Data Organization's legal status makes it uniquely well positioned to remain the central source of data collection and management. Data submissions should be received from providers, plans, and any other entity that collects clinical, claims, health risk and functional status data, and the MHDO or its successor should continue to manage the data and serve as the primary source of integrated clinical and claims data for the state. However, we do not believe the MHDO or the Maine Quality Forum in its current or proposed state should develop redundant analytic or reporting capabilities. The purpose of the MHDO has been and should remain collecting and managing data to be used as needed for approved purposes by external parties. Each entity that requests data may have different analytic needs and objectives. It is not desirable to have the MHDO and/or MQF determining the information that is generated from the MHDO data set as it is unlikely to reflect stakeholder and user needs, may be redundant of multiple existing efforts, and runs the risk of 'politicizing' the MHDO and jeopardizing what should be a neutral source of common data. Providing data and providing analyses are separate functions and we believe strongly that **the MHDO should focus its resources on its primary mission of providing timely and reliable data to be used by entities as needed.**

Finally, in the draft report, there are repeated references to the need for data by health care providers to improve healthcare. While we strongly support this point, it is a far too narrow view of needed data uses and users. It is important that we explicitly recognize the need for other stakeholders- particularly consumers- to have access to data and information to improve their healthcare decisions. Data can and must be used for improvement and it should also be used for measurement, reporting, analysis, payment and other purposes by a variety of stakeholders. The report should reflect the need for data by multiple audiences and support for using the data for these purposes.

In the words of our Board chair, Dr. David Howes, 'The age of competing for market share by controlling access to data is over. Transparent all-payer data should be made widely available and competition should be based solely on performance'. The MHMC is committed to achieving the aforementioned principles through a redesigned data system to serve the state. We will continue to work with and through the established processes and contribute our time and perspective as both data users and Maine organizations from multiple sectors committed to the improvement of overall population health, a sustainable healthcare system and a viable economy.

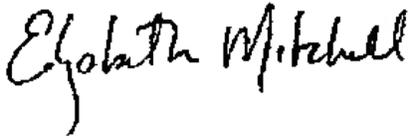
Sincerely,



Stephen Gove, Director, Maine Municipal Employees Health Trust  
Chair Maine Health Management Coalition Foundation



Laurie Williamson, Executive Director, Office of Employee Health and Benefits, State of Maine  
Chair Maine Health Management Coalition



Elizabeth Mitchell, CEO, Maine Health Management Coalition