Report of the LD 1818 Work Group

To Evaluate Options and Actions Available to Improve the Availability Of and Access To Health Care Data and to Examine the All-payor Claims Database system in Maine

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I. Executive Summary

TO BE DETERMINED BY CHAIRS

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II. Introduction from the Chairs

The cost of health care is having a stifling effect on Maine's workers, families, taxpayers, and economy. Public and private health care costs continue to grow more rapidly than those in other sectors. These obligations are crowding out our capacity to invest in other public goods (education, infrastructure) and to grow our economy.

The health care system in the United States, and in Maine, is less efficient than those in other developed countries. If we could achieve the efficiency of these health systems – or even in the best systems within in the United States – we could eventually lower health costs by 15% to 30% in Maine, with no sacrifice in quality.

In order to accomplish this efficiency, our health system needs the capability to observe and measure its value (defined as favorable outcome achieved per dollar spent); to become, as the Institute of Medicine has described, a *continuously learning health system*. This capability can only be achieved through the judicious and widespread use of health data.

Maine is ahead of most states in its ability to analyze the performance of the health care system based on the health data we currently collect. However, there is considerable room for improvement. This report, the product of a multi-stakeholder workgroup created through *Resolve Chapter 109 (2011), Resolve to Evaluate the All-Payer Claims Data System for the State (Resolve)*, explores the current state of health data arrangements in Maine and makes recommendations for continued improvement.

The State of Maine has been a leader in the collection of health data to facilitate analysis of the state health care costs. The Maine Health Data Organization (MHDO), a State agency, was

created in 1995 by the Legislature to maintain the first all-payer claims data base (APCD) in the United States. This database includes claim records from most medical treatments that are provided to Maine citizens and that are paid for by private and public insurers. The Maine Health Data Organization also collects inpatient and outpatient encounter information on all episodes of care provided by Maine's hospitals and ambulatory surgical centers, as well as summary level financial and quality information provided by Maine hospitals. These data, termed *administrative* as opposed to *clinical* data, have proven immensely useful in the analysis of provider and health system performance.

The data enables the examination of care patterns and costs in the State. Maine employers in particular, as funders of health care, have used this information to identify high cost providers, high cost conditions, and the effects of employer-based wellness interventions on the cost of health care for their employee population. One analysis of the cost of health care in Maine, done for the Dirigo Health Agency's Maine Quality Forum, illuminated the impact of avoidable complications of chronic illness on the total costs of care in Maine. That report has led to policies promoting the adoption of "best practices" among primary care providers in Maine. Other analyses have advanced understanding of the use of expensive hospital emergency room care by different groups; provided comparative data that have helped hospitals to advance value-based purchasing; and shown different patterns in Maine and two comparison states in service use and cost through a first of its kind tri-state variation study.

The demand for these data from business, government, insurers, health care providers, and health analysts, has been high and will only increase in the future. It is fair to say that the MHDO struggled to meet these demands on a timely and convenient basis in the past. There were reliability and timeliness issues with the availability of both claims data (particularly those from Medicare and Medicaid) and hospital inpatient and outpatient data. As a result, in 2011, proposed legislation (LD 1467) was originally submitted to completely revamp the

MHDO operations. The bill was modified and led to Resolve Chapter 109 (2011), which called for the establishment of a Work Group led by the Department of Health and Human Services to evaluate and report on options to "improve the availability and access to health care data." The Resolve identified four areas for evaluation:

1. Review the current structures of and relationships among the Maine Health Data Organization, the Maine Health Data Processing Center and Onpoint Health Data in order to evaluate the timeliness and effectiveness of the data received;

2. Review the current purposes and uses of the data and limitations on access to the data and considering additional uses for the data and changes that might be necessary to achieve and facilitate additional uses;

3. Consider federal and state privacy and security laws regarding the use and release of protected health information, including policy and technical changes needed to allow increased access to protected health information and the feasibility of those changes; and

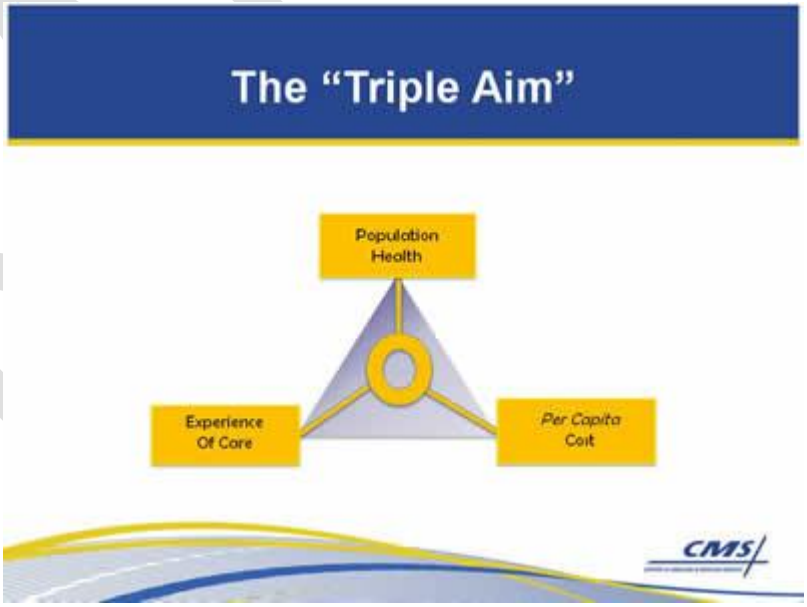
4. Consider the availability of the data, the most appropriate sources of the data and the cost of providing the data.

Resolve Chapter 109 was later amended (LD 1818) to provide the Work Group additional time to complete its work. (See Appendix A for the Resolve; a complete record of committee meetings and documents is available at *http://www.maine.gov/hit/ld_1818/index.html*).

The Work Group convened in April 2012 and met at least monthly through the remainder of the year. The Group was led by elected Co-Chairs Dr. Josh Cutler and Colin McHugh. The Group accepted the working principle that health system reform and improvement depends upon the ability to objectively analyze the system's performance in terms of cost and quality. Such analysis relies, in turn, on the maintenance of accurate and timely administrative and clinical health data that is accessible (with strict safeguards and confidentiality requirements) to patients, providers, purchasers, payers, and researchers.

The Work Group recognized that the path to the desired state requires broad consumer and stakeholder participation, and therefore issued a "Voice of the Customer" (VOC) survey in late spring. The VOC process led to several presentations and thoughtful discussions between the Work Group and experts in the health care data and claims field, including health services researchers, hospital and health system representatives, physicians, payers, public agencies, individual consumers, and employers.

What the Work Group heard above all else is that stakeholders are eager to gain access to timely and accurate health care data, including claims and clinical data, in order to move forward from the current state of our health care system towards meeting the goals of the Triple Aim (improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations).



The Triple Aim recognizes the necessity to move away from paying providers for the volume of services provided and migrating toward paying for value and quality outcomes. At the core of this payment reform initiative is patient-centered health care and provider accountability. The model requires providers to assume greater accountability for the cost and quality of services provided and rewards improved health outcomes and efficiencies. Payers and providers need to have health care data to monitor performance and make educated decisions to strive toward meeting the goals of the Triple Aim.

III. Voice of the Customer (VOC)

Although the LD 1818 Work Group represented a variety of interests, the Group believed that it was important to have input from additional stakeholders. As mentioned above, the Group issued an electronic survey in late spring to 140 groups and individuals, requesting that stakeholders answer three questions keeping in mind the four issues from the Resolve:

1. Which *Needs* and *Expectations* are being met by existing processes, relationships, and structures as it relates to the use of health care data?
2. Which *Needs* and *Expectations* are NOT being met by existing processes, relationships, and structures as it relates to the use of health care data?
3. What are the desired future uses of clinical and/or administrative claims data that are being considered?

See Appendix B for a summary of the 90+ VOC comments. The complete record, including presentations and papers submitted as part of the process, can be seen at *http://www.maine.gov/hit/ld_1818/index.html*).

Four major themes emerged from the results of the survey. The Group formed subcommittees, chaired by Work Group members, to address the four themes:

- Theme 1: Establish multi-stakeholder directed Data Governance Structures that optimize the collection, processing, and distribution (accessibility) of health care data. (Dr. Josh Cutler, Chair)

- Theme 2: Implement technically-sound and scalable Data Processing Structures and Protocols that permit timely, accurate, and cost effective submission and dissemination of pertinent health care data (administrative and clinical). (Karynlee Harrington, Chair)

- Theme 3: Balance Consumer Privacy considerations regarding the safeguarding and disclosure of Protected Health Information (PHI) with the societal imperative to drive higher quality and more affordable health care. (Colin McHugh and Dawn Gallagher, Co-Chairs)

- Theme 4: Establish mechanisms to ensure that consumer/stakeholder engagement and feedback is requested and prioritized to ensure value is being derived from health care data. (Christine Torraca, Chair)

Subcommittees were asked to identify barriers to achieving each "theme" along with the opportunities and anticipated benefits associated with the opportunities. Recommendations were then developed by the subcommittees and fed up to the full Work Group. (Note: The recommendations of the subcommittees are not consensus statements of the full Work Group. The recommendations did, however, help inform Work Group discussions.) Subcommittee minutes and documents are available on line at *http://www.maine.gov/hit/ld_1818/index.html*.

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IV. The Resolve - Four Evaluation Areas and Summary Findings

After the work of the subcommittees concluded, the full Work Group held discussions and formulated responses to the four questions raised in the Resolve:

1. Review the current structures of and relationships among the Maine Health Data Organization, the Maine Health Data Processing Center and Onpoint Health Data in order to evaluate the timeliness and effectiveness of the data received;

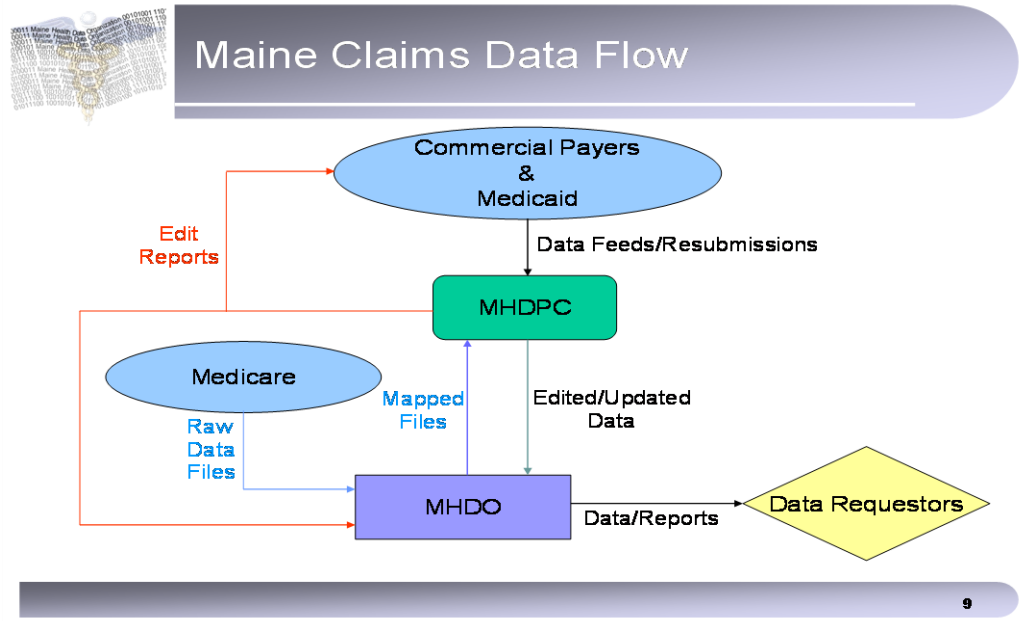
As background, the MHDO maintains administrative, financial, and some limited clinical health data for use in policy development; adopts rules governing data collection, public access, sanctions for failure to comply, fee schedules and assessments on health care facilities, payers, and third party administrators; and timely respond to requests for data. The MHDO furnishes reports on quality of care and price comparisons which are publicly accessible on the MHDO website. The MHDO also maintains the following databases:

- Hospital inpatient
- Hospital outpatient
- Hospital emergency department
- Non-hospital ambulatory services (1990 – 2004)
- Hospital financial
- Hospital organizational
- Quality data

Question No. 1 was raised to address concerns identified in 2009 and 2010. By the time the Work Group was formed in early 2011, the MHDO Board initiated action to improve organizational effectiveness, produce timely and accurate data, and plans for achieving

performance improvements including restructuring the MHDO board. Between December 2011 and December 2012, the MHDO was able to bring its APCD up to date, including data from the two public payers and commercial data. MHDO has developed a comprehensive plan to maintain its current level of performance into the future, including upgrading its technical infrastructure. This LD 1818 report will describe the past or "as-is" governance structure, and insight into the improvements made, or under consideration by, the MHDO Board.

The following diagram depicts the existing relationships of three key health data organizations: Maine Health Data Organization (MHDO), Onpoint, and the Maine Data Processing Center (DPC). It is important to note that the diagram reflects a structure that is being eliminated and replaced with a new more efficient model.



The MHDO and Onpoint were permitted by statute in 2001 to form a non-profit corporation, the Data Processing Center (DPC) to create a publicly available claims dataset.[1] The DPC has

[1] The claims dataset is described in MHDO Rule Chapter 243: dhttp://www.maine.gov/sos/cec/rules/90/90/590/590c243.doc

two primary funding sources: 60% from the MHDO and 40% from Onpoint. This funding supports the DPC's efforts to collect Medical, Rx, Dental Claims and Enrollment from over 100 Commercial payers and third party administrators (TPA); aggregation of millions of records; implementation of several layers of quality checks to ensure accuracy and quality; and creation of a completed, "ready-to-go" dataset for the MHDO. This work is currently done by Onpoint staff with funding from the DPC to provide an optimal data set for transmission to the MHDO and to serve as a technical liaison to both parties. DPC governance is provided by the DPC Board, consisting of MHDO Board members from various constituencies including Payers, Providers, Consumers, Employers, and MHDO and Onpoint leadership. The DPC Board oversees DPC activities related to data completeness, data quality, timeliness, and financial oversight. The table below outlines the roles and responsibilities of the MHDO and Onpoint.

Onpoint Health Data	MHDO
Payer communication, on-boarding	Rulemaking – data collection, release
Payer registration – initial, ongoing	Payer compliance
Secure upload and PHI encryption	Submitter role – Medicare (including mapping to APCD format), MaineCare
Data collection, validation in conformance with state regulations	Loading, warehousing data
Data specs, submission schema, reporting systems maintenance	Extracts to approved users
Master Person Index	Administrative – fee assessment to payers/providers, users; board support
Master Provider Index	
Extract preparation – qtrly to MHDO	

(A detailed analysis of factors impacting APCD timeliness and recommendations for improvement provided by Onpoint to the MHDO is included in Appendix C.)

While it is important to note the historical structure of health care data governance, it is more important to talk about the transformation of the MHDO governance and structure. In late 2010, Deloitte, a private consulting firm, was hired to assess MHDO's current claims data processing efforts. The Deloitte report sought to address basic questions about the current workings of MHDO and identify the barriers to timely provision of claims data to stakeholders. The report also provided a set of recommendations for improvement on three components—Process, Technology and People.

The Deloitte report found an organization where most of the staff was focused on day-to-day maintenance and operations tasks. There were no fully articulated processes related to testing and quality assurance that would allow issues to be discovered and resolved in a timely manner. The data architecture was not tuned to provide the full ranges of capability to its users. Most of its leadership policies were ad hoc and not geared to support MHDO data processing and growth needs.

The report recommended that MHDO create a leadership structure with clear roles and responsibilities to improve its decision making processes. It advised MHDO to establish principles and guidelines for the creation of data models along with metrics that monitor, measure adherence to, and can be used to enforce these metrics. The Report concluded that these recommendations would enable MHDO to better govern and support data management practices and policies. The complete Deloitte report can be read at the MHDO website at *http://mhdo.maine.gov/imhdo/_pdf/MHDO_Assessment%20Final%2012-05- 2010.pdf*.

Since the writing of the Deloitte report, and more recently since the Work Group initiated its evaluation efforts, the MHDO has embarked on a comprehensive plan to improve its performance and better meet the needs of data requestors and submitters. The MHDO Board adopted a new strategic vision and a set of business imperatives to guide MHDO to the future state. The new strategic vision is stated below followed by the six business imperatives set forth by the MHDO Board and the current status of the six imperatives.

The pillars of the new vision include:

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

Specifically, the MHDO Board set forth the following business imperatives:

- *Restructuring* to significantly reduce number of board members while retaining stakeholder diversity and balance;
- *Recommitting* to maintaining the agency's independent status;
- *Refocusing* attention on improvements in the current data transformation process using the State's RFP process to secure a new data contract;
- *Enhancing* communication with partner agencies, stakeholders and end users;
- *Appointing* an interim executive director; and
- *Initiating* a search for permanent executive director.

The MHDO Board is implementing these business imperatives. The existing MHDO Board structure, created by State law in 1995, consists of 21 members from the public and private sectors. Over the years, the Board's ability to function and move the MHDO forward was hampered by the size of the Board. Over the past year, MHDO has held two retreats where the Board agreed to reduce the size of the Board to between 7 and 11 members to help achieve

their goal of having a nimble, responsive, and appropriately engaged board of directors. The LD 1818 Work Group supports the reconstitution of the MHDO Board, with increased emphasis on its public role. (See Appendix D for a summary of planned improvements that was presented to the Work Group.)

In early summer 2012, the MHDO issued a Request for Proposal (RFP) for a "highly robust and secure data warehouse" built on an architecture that can support high volumes of multiple data files at rapid speeds; a set of common data structures that are available for third party use; and a system that supports web access to data and reports. MHDO envisions supporting web access will help create a shared utility that will provide value for multiple entities.

The MHDO has selected a vendor and, as of early February 2013, is in the negotiation phase with the vendor. As recommended by the Deloitte Report, and affirmed by the MHDO Board, MHDO will execute a service level agreement that specifies the levels of security, performance, and operation with measurable targets that show the level of the vendor's performance, accompanied by penalties for non-compliance.

MHDO will delineate roles and responsibilities, including the requirements that the vendor:

- Work collaboratively with MHDO to implement the Board's priorities;
- Convert the MHDO data into the new warehouse structure;
- Provide a "dashboard" view of the warehouse in real time to MHDO staff showing compliance, efficiency, load, and query information;
- Test processes to make changes to the system as needed; and
- Maintain documentation and tools to allow MHDO staff to operate the system.

As part of the reconstituted governance and data warehouse changes, the contract with the new vendor will be directly with MHDO. The Board of directors of DPC has agreed to dissolve the non-profit DPC corporation in 2013.

The MHDO's latest release of claims data contains complete data sets from private payers and Medicaid through September 2012, and from Medicare through 2010 (which is the most current data available through Medicare). It marks the first time that the most current Medicare and Medicaid data have both been available in the data set. This high-quality and complete data will prove extremely useful to identify areas of cost savings and quality improvements.

The MHDO members of the LD 1818 Work Group acknowledge that considerable work remains to be done. The Work Group is pleased with the work completed by the MHDO in the past year. The Work Group believes that the MHDO Board should be held accountable for delivering on the promise of its new vision and business imperatives through disciplined execution of its plans and robust stakeholder involvement. The Work Group recommends that the MHDO include progress made and actions that will continue to accomplish the recommendations included in this LD 1818 Report, in the MHDO annual report to the legislature.

2. Review the current purposes and uses of the data and limitations on access to the data and considering additional uses for the data and changes that might be necessary to achieve and facilitate additional uses;

A. The Policy Case for Linking Claims and Clinical Data

Analysis of payment alone is not sufficient for a complete view of the value that the payers of health care – who are ultimately the wage earners and taxpayers of the state – are getting for their investment. Although claims analysis is useful for observing the *processes* of care, it is not adequate for evaluating the *outcomes* of care. For this, clinical data in addition to

administrative data are necessary. This report briefly reviews the classification and types of quality data to understand their use in health system performance analysis.

Quality measurement is concerned with three domains of measurement: structure, process, and outcome.

- Structural quality measures describe attributes of providers (hospital bed size, number of primary care physicians in a geographic area).
- Process measures describe the components of an encounter between a provider and a patient (tests ordered, medication prescribed).
- Outcome measures describe the effect of care on aspects of patient (or population) well-being, such as survival, return to function, or state of control of a chronic illness.

Administrative data, such as claims data, can provide insights into payments, utilization, and care processes and are valuable to the extent that adherence to certain processes (timely intervention for heart attack treatment, for example) is associated with improved outcomes (lower mortality rate in heart attack patients). However, outcomes data, which is arguably the most useful quality information, is not available in administrative data sets. The MHDO and the Maine Quality Forum have collected some clinical process and outcome measures from hospitals for several years, as have other public and private entities including the federal Centers for Medicare and Medicaid Services (CMS) and Leapfrog (a national hospital health and safety group). These data have described hospital performance on healthcare-associated infection and other aspects of patient safety. The data have shown a relationship between adherence to recommended "best practice" care processes and better outcomes. Reporting on these processes and related outcomes has been done on a hospital level; processes (derived from administrative and clinical data bases) and outcomes for populations of individual patients (derived from clinical data bases and registries) have not been linked. When Maine's all payer claims database (APCD) was organized, there were no good ways of collecting large amounts of

clinical outcomes data for populations. Now, however, with the development of electronic health records and clinical outcomes registries, it is feasible to describe health outcomes in large populations of patients.

There is considerable evidence and expert opinion that the marriage of cost data with outcomes data makes robust analysis of the overall performance of health care providers and of the value of health care in Maine possible. Dr. John E. Wennberg, a noted health services researcher and founder of the Dartmouth Atlas of Health Care, which catalogs variations in care processes in the United States using Medicare claims analysis, wrote *"Claims data need to be augmented by critical information extracted from patient records and obtained directly from patients."*[2]

The limitations of claims data alone to evaluate provider quality was demonstrated in a study showing that hospital performance on process measures reported by Medicare in its consumer-facing Hospital Compare website were only modestly correlated with outcomes (mortality rates).[3] In a Brookings Institution review of the role of clinical data registries in care improvement, the following statement was made: *"Registries can play an important role in better health care performance measurement. To achieve this, clinical data from registries must be integrated with claims data to create a hybrid database that can be used to improve care and, in turn, calculate more valid and comprehensive measures of the quality and cost of medical care."*[4]

Michael Porter of the Harvard Business School, who has written extensively on value in health care, states, *"The only way to accurately measure value… is to track patient outcomes and costs*

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[2] Wennberg JE, Fisher ES, Skinner JS. Geography and the Debate over Medicare Reform. Health Affairs 2002; W96 – W114.

[3] Werner RM, Bradlow ET. Relationship Between Medicare's Hospital Compare Performance Measures and Mortality Rates. JAMA 2006; 296 (22): 2694 – 2702.

[4] How Registries Can Help Performance Data Improve Care. Engelberg Center for Health Care Reform at Brookings, 2010, Accessed at http://www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf61984.

longitudinally."[5] Similarly, in a critique of Great Britain's National Health Service approach to measuring quality, Mountford and Davie found that quality reports have had:

> *[a] focus on process and proxies, not on outcomes that matter to patients. To date, the dominant focus of quality measurement and reporting has been on processes and inputs to care, not on patient-relevant outcomes. Process measures can have advantages. For example, they are often easier to measure than outcomes, they require less risk adjustment, and there are many examples in which a favorable patient outcome has resulted despite a defective process (or in which an unfavorable outcome has followed a faultless process). However, undue focus on process and proxy measures can have serious and often surprising consequences. Patients may have worse outcomes as a result. For example, higher mortality in high-risk patients with type 2 diabetes was associated with aggressive intervention to achieve normal glycated hemoglobin levels.* [6]

A large body of evidence now supports the limitation of administrative data alone to describe or even drive improvement in health care.[7]

B. <u>The Current State of Claims and Clinical Governance</u>

Having reviewed the classifications and types of quality data, this report now moves to the current state of governance structures for claims and clinical data:

- Claims data are kept in the all-payer claims database (APCD) managed by the MHDO, an independent State agency governed by a board of directors, representing both public agencies and private entities. MHDO has the authority to require hospitals and payers to submit claims and quality data. By statute, MHDO also has authority to compel

[5] Porter ME. What is Value in Health Care. N Engl J Med 2010; 363:2477 – 2481.
[6] Mountford J, Davie C. Toward an Outcomes-based Health Care System. JAMA 2010; 304,(21): 2407-2408.
[7] See Hammill BG et al.Incremental Value of Claims Data beyond Clinical Data in Predicting 30-day Outcomes after Heart Failure Hospitalization. Circ Cardiovasc Qual Outcomes, 2011 Jan 1;4(1):60-7. See also Farmer SA, et al. Tension Between Quality Measurement, Public Quality Reporting, and Pay for Performance. JAMA 2013; 309(4):349-350)

submission of clinical data from providers, and there are precedents for collecting and housing data at MHDO.

- Clinical data is held in several repositories and owned and supervised by the providers who generate it. "Real-time" hospital and provider clinical data are often submitted to what is called the "Health Information Exchange" (HIE). In Maine, many hospitals and providers participate in the HIE by becoming customers of a non-profit company, HealthInfoNet, that operates the State's HIE. HealthInfoNet is governed by the company's Board of Directors. The HealthInfoNet exchange is voluntary, and its current framework does not provide a mechanism to compel submission of clinical data nor does it have authority to release data unless permitted by its customers.

Electronic health records (EHR) carry with them the potential for reporting massive amounts of clinical data, much of which is in the category of outcomes. Population disease registries maintained by providers and health information exchanges (HIE) such as Maine's HealthInfoNet have demonstrated and exploited the potential of EHR to collect clinical information from large populations to be used for quality analysis and care improvement. A next logical step in creating the toolset necessary for development of a *learning health system* for Maine is building the capability of linking these clinical data with administrative data already in place in the MHDO.

Considerable pressure already exists for providers to engage in care improvement initiatives driven by the use of cost and quality data. The Maine State Employees Health Commission has been an innovator in the development of incentives for its members to choose higher value providers. Medicare, through its Shared Savings, Bundled Payment, and medical home programs, has offered providers the opportunity to share in the savings generated by providing high quality care at a lower cost. MaineCare has established a patient-center medical home and is also developing a Value-Based Purchasing program. The Maine Health Management

Coalition has provided its member employers with tools for assessing health care costs and quality and helped guide their employees in making rational value-based choices for their care.

Improvement in the availability of administrative data, broadening the range of clinical quality measures, and developing safe and reliable rules governing the linkage of these two types of health data would allow the assessment of both quality and cost by all Maine stakeholders. This sets the stage for providers to continuously improve, for consumers to make better informed decisions, and for payers to derive value from Maine's health care system.

The value of integrated claims and clinical data was recognized and emphasized by several respondents to the "VOC" survey. Select survey responses include:

> *" Data needs to be aggressively used by all appropriate parties to improve the delivery of health care, and therefore made available by a public entity with appropriate governance and safeguards to as many qualified users as possible who will work to improve the health and safety of Maine people."*
>
> *"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. "*

Although there was consensus on the value of linking the claims and clinical data, the challenge for the Work Group was establishing processes and mechanisms that should be used to accomplish the linking.

Throughout the course of stakeholder discussions there was a recurring theme regarding the importance of providers and consumers having equal access to data. One VOC respondent expressed, "*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.*" Similarly, one VOC respondent stated*, "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 issue of having access to health data must be balanced with privacy issues. As one VOC respondent pointed out, "*While there may be value to expanding uses of the MHDO database or to linkage with other databases, these decisions should be made with patient's rights at the fore."* Another respondent stated*," There are lots of questions about crossing the line between de- and identifiable data. We [health systems] want to maintain control of clinical PHI. Careful assessment of what provider organizations are compelled to do vs. doing it voluntary [is necessary].*"[8]

Surmising that neither the market nor the government can provide the perfect solution, it is suggested that the combined effort of both public and private resources continue. In fact, MHDO has contracted with HealthInfoNet to test the feasibility and costs of linking administrative and clinical information. This pilot should inform next steps concerning the technical requirements, cost details, and optimal governance of these potential new capabilities.

C. Improve and Facilitate Health Data Uses—Maine Quality Forum

Question 2 also asks the Group to examine current health data uses and to look at ways to facilitate improved and expanded uses.

Although the MHDO collects a wide array of health care data and has general responsibility for its provision, analytical work on the data is conducted in collaboration with State agencies. For

[8] Brackets added to complete thought.

example, Maine's CDC and MaineCare, within the Department of Health and Human Services perform analytic services unique to their authority.

Recognizing the need for population health analytics, in 2003, Maine established the Maine Quality Forum (MQF) as a function under the Dirigo Health Agency. The MQF's primary purposes, assigned in the enabling legislation, include:

- Research dissemination on quality, evidence-based medicine, and patient safety to promote best practices which MHDO must use as the basis of MHDO rules;
- Coordinate with the MHDO the collection of health care quality data in the State, to minimize duplication and burden on the providers of data;
- Work collaboratively with the MHDO and providers to report in useable formats health care quality information to consumers, purchasers, providers, insurers and policy makers;
- Make available information on quality of services on a publicly accessible website and conduct educations campaigns;
- Conduct technology assessment reviews to guide the use and distribution of new technologies; and
- Promote the adoption of electronic health information technology.

Together, MHDO and MQF have developed a data base of clinical measures, including outcome and process measures, that has advanced the public's understanding of care quality in Maine's hospitals. These measures include process and outcome indicators in areas such as heart disease, pneumonia, and healthcare-associated infection.

The MQF has analyzed and reported on health care variation in utilization, quality, and cost using data from MHDO data bases. It has published an annual report on the incidence and efforts at control of health care associated infections since 2008 (using MHDO quality data); commissioned and supervised a study of health care cost drivers in Maine in 2009 (using the all payer claims data); and reports on its website on variations in care patterns among Maine's healthcare service areas (using hospital discharge data) – see the MQF website at *http://www.mainequalityforum.gov/*. These and other MQF projects have informed health policy development in State government and in the private sector.

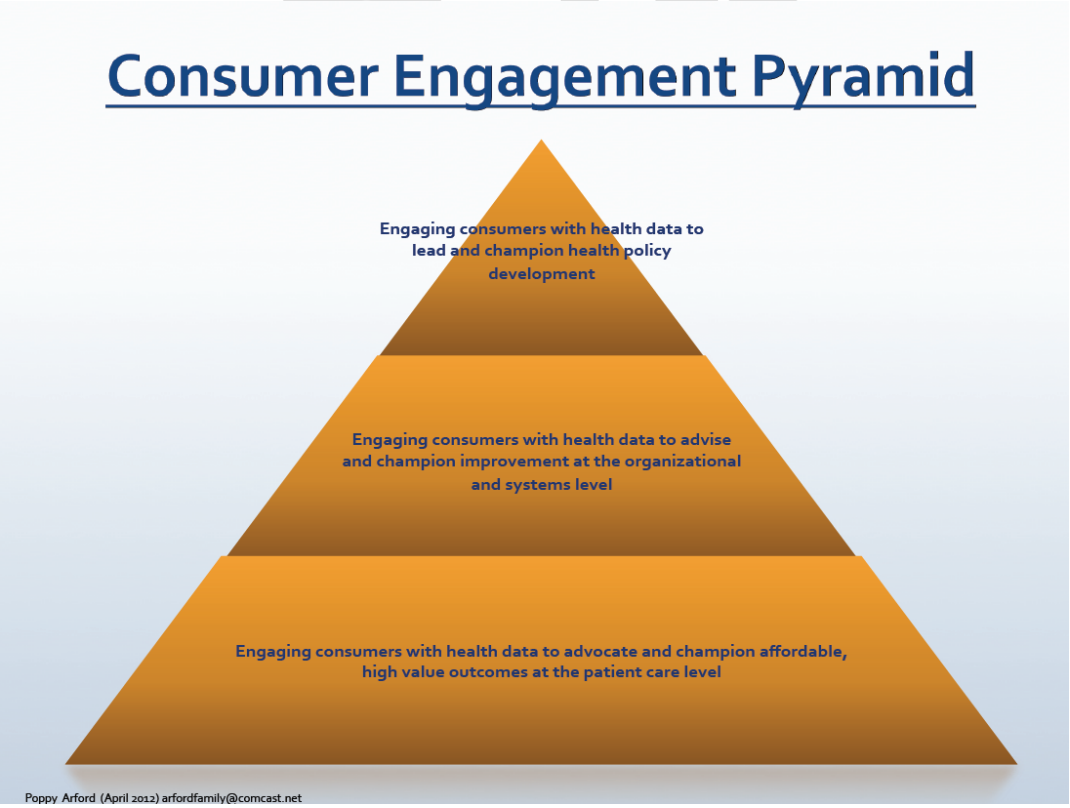
The Maine Quality Forum is a function of the Dirigo Health Agency. The current funding mechanism for the Dirigo Agency will cease at the end of 2013. The Dirigo Agency anticipates, and the MQF Board supports, funding the operations of the MQF through State Fiscal Year 2015 with existing reserves. (That proposal is in the current budget process in the legislature.)

The Work Group believes that now is the opportunity to repurpose the work of the MQF in a manner that preserves this important and unduplicated capability within State government. The functions that the MQF currently performs, especially those done in collaboration with MHDO, will still be needed in the future. The Group believes that the MQF could be relocated within the MHDO (conditioned on funding and based on an analysis of efficiencies to be gained by having administrative oversight by the MHDO, and current and future staffing needs). In addition to sustaining the ability of the MHDO to perform data analysis on its administrative and quality data sets, incorporating MQF would provide guidance to MHDO on choices of indicators collected under MHDO Chapter 270, *Uniform Reporting System for Quality Data Sets*; on the development of reports for the public and consumers regarding health care providers; and on the use of linked clinical and administrative data for these reports. The MQF Advisory Council has provided, and could continue to provide, a portal for public input into this guidance. Dirigo board agreed to fund the work of the MQF for the next biennium.

D. Active Consumer Engagement

Establishing mechanisms to ensure consumer engagement is critical to meeting the goals of the Triple Aim. It is important to develop a consumer engagement structure that can change and adapt as the field changes and adapts. One VOC respondent succinctly stated, *"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."*

One of the four themes emerging from the VOC survey was the need to establish mechanisms to ensure that consumer/stakeholder engagement and feedback is requested and prioritized, and to ensure that value is being derived from health care data. The subcommittee charged with addressing this theme developed and built a consumer engagement pyramid to illustrate the link between consumer engagement and the development of health policies:



The subcommittee then formulated three recommendations to improve on the current state:

- Clarify the role of government, relative to non-governmental entities, of the respective contributions to the creation of health care data bases and reporting;
- Build on current mechanisms that engage consumers with multi-level domain-specific stakeholder groups to gather input and feedback, discuss opportunities for engagement and education, and continuously improve the current state; and
- Establish a process of accountability and transparent processes for the stakeholder input system aligned with the data governance structure, with the ultimate goal being multi-stakeholder collaboration to ensure the greatest value is derived from this work.

The subcommittee concluded that to promote efficiency and meaningful outcomes for stakeholders, there needs to be an ongoing forum for various other advisory groups to report activities and coordinate efforts including articulated goals against which its effectiveness can be evaluated on a regular basis.

3. Consider federal and state privacy and security laws regarding the use and release of protected health information, including policy and technical changes needed to allow increased access to protected health information and the feasibility of those changes;

Personal Health Information, which can be a component of clinical and claims information, is governed under federal and State laws. The federal HIPAA law limits the disclosure of identifiable health information to treatment, payment and operations of the health care practice, and a few other specific purposes. There are more restrictive federal laws governing personal health information related to substance abuse. The general rule is that unless allowed under these laws, disclosure is not permitted. Since clinical data bases and registries, including a health information exchange such as that operated by HealthInfoNet, contain some protected health information (PHI), protection of patient privacy is of utmost importance.

The LD 1818 Work Group asked the Legal Work Group (attorneys and health information privacy experts convened by the Health Information Technology Steering Committee of the Office of the State Coordinator for Health Information Technology) to provide information and guidance on this issue.

In August 2012, the Legal Work Group provided a summary analysis of federal and State laws pertaining to HIPAA, Substance Abuse and Alcohol Abuse, Mental Health, HIV and how the MHDO, HealthInfoNet and the Health Information Exchange are affected by the laws. The following chart summarizes federal and State privacy laws and rules:

	General PHI (non-sensitive)	PHI Mental Health	PHI Federal Substance Abuse Program	PHI HIV
Informed Consent	Disclosure Allowed	Disclosure Allowed	Disclosure Allowed	Disclosure Allowed
Treatment Payment Operations	Allowed for TPO	Allowed for payment; T+O are restricted + vary for agency vs. clinician	Only with patient consent	Allowed for direct treatment
Public Health	Allowed when required by law	Restricted; can disclose to DHHS in limited circumstances	No exception listed; LWG opinion patient consent required	Allowed when required by law
Fund Raising	Allowed for entity	Consent required	No exception listed; LWG opinion patient consent required	Statute is silent; LWG opinion use requires consent
Research	Restricted	Restricted; limited exceptions	Restricted	Restricted; researchers can't re-disclose
Marketing	Consent required	Consent required	Consent required	Consent required

A full copy of the LWG report and supporting documents is contained in Appendices F and G.[9]

State laws and rules cannot contradict federal laws and rules. The federal Substance Abuse laws are very inflexible and would require considerable efforts at the federal level to make changes to the laws. HIPAA, even though it is a federal law, allows states some flexibility in how they enforce certain elements.

The State has the ability to amend Maine laws to allow "increased availability and access" to protected health information, and MHDO has the authority to change its rules (subject to the Administrative Procedures Act). Any such amendment to Maine law should be done in the context of the protections afforded by HIPAA.

Considerable VOC feedback was provided by various stakeholders as it relates to the broadening of access to healthcare data, including the following competing comments:

> *"While there may be value to expanding uses of the MHDO database or to linkage with other databases, these decisions should be made with patient's rights at the fore. Often those doing the hard work of providing us with healthcare get so excited about increasing efficiency or improving coordination of care that patient notice, privacy and consent can get lost."*
>
> *"As patient advocates and defenders of personal privacy, we urge continual focus and commitment to privacy, confidentiality and security. Patient rights must be the highest priority in Maine's electronic health information system, and we hope the State will continue to demonstrate meaningful commitments to patient privacy."*
>
> *"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."*

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[9] Many LWG members stated that they viewed the scope of the LWG as providing a factual review of the current federal and state laws and rules governing protected health information (PHI). In that respect, the LWG did not make what might be termed "subjective" recommendations. Rather, the LWG provided an analysis that was factual in nature.

"Health care providers need data with personal health information in a HIPAA compliant way so they can use it to improve care for those patients they are treating. Right now we have providers willing to take responsibility for the quality and cost of their patients and they don't have good data readily available. I hear words like "betrayal" and "tying our hands behind our backs" from providers."

As evidenced by the selected comments above, it is clear that the sharing of personal health information will bring forth significant policy discussions. The Work Group is not putting forth specific changes to Maine law to allow increased access to personal health information. However, the comprehensive review completed by the LWG will certainly guide future directions relating to expanded access to personal health information.

4. Consider the availability of the data, the most appropriate sources of the data and the cost of providing the data.

Question No. 4 was not discussed in detail, as the Group did not have sufficient time to gather and analyze all of the sources of data and the costs of providing the data at the level necessary to make an informed presentation.

Given the relative small size of Maine, competing data and reporting structures may pose undue costs to system stakeholders and unnecessary fragmentation of the overall system. As one VOC respondent stated, *"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."*

Avoiding fragmentation and duplication of effort, and not paying for the same data in multiple ways is critical because whether the submitting or receiving entities are public or private, they all face funding challenges. To that end, the Work Group supports an examination of data sets currently reported to the various entities to determine the value of the data and whether the data submissions are efficient and avoid duplication; the cost of providing the data; and an

analysis of funding sources. The Work Group believes that the following statement should guide efforts to address these issues:

> ***Maine needs to think strategically about the data we really need compared to the data we now collect and the costs of collecting that data; sustainable financial business models that are efficient and avoid fragmentation and duplication while providing the best value for the data; and how to best use the data to improve quality and health outcomes***.

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V. Next Steps

When the full Work Group reconvened to discuss the four sets of subcommittee recommendations, there was not consensus that the LD 1818 Report should contain specific recommendations for legislation. The Group believes that we need to move forward and that path requires both short and longer term steps. Some preliminary steps should be taken in 2013 to set several improvements in motion while knowledgeable stakeholders further examine and refine actions based on emerging technology, policy developments. This course ensures that we take actions that are needed today, while recognizing that health care data needs and technology will continually evolve.

The following steps are already underway or under serious consideration in existing organizations. The Work Group wishes to express its support for:

1. Continuing the work underway by the MHDO Board to implement its new vision and business imperatives by a Board that is held publically accountable for a disciplined execution of its plans with robust stakeholder involvement. Over the past two years, the MHDO Board has transformed itself into a smaller, yet much more responsive and accountable board. The joint Committee for Health and Human Services Committee, has the authority under Resolve, Chapter 109 (2011) to report out legislation amending the MHDO statute (created in 1995) to reflect this transformation to a modern-day Board structure that will meet the future needs of the State's health care data organization.
2. Making efforts in 2013, under the aegis of a reconstituted Maine Health Data Organization, to study viable financial models, protocols, data management, privacy, and encryption that lead to improved efficiency for current data submitters and standards for the use of linked databases (in which MHDO is involved).

3. Closely monitoring the current terms of the contract between MHDO and HealthInfoNet in order to determine the feasibility of linking administrative claims and clinical data at an affordable cost. The monitoring and examination should be conducted by a group of knowledgeable stakeholders that understand the myriad of issues posed in this report. The MHDO should report back to the legislature on the results of this pilot.

4. Conducting a collaborative strategic examination on the health care data we really need compared to the data we now collect, and the costs of collecting that data; sustainable financial business models that are efficient and avoid fragmentation and duplication while providing the best value for data; and the best ways for using the data to improve quality and health outcomes.

5. Collaborating between MHDO and Maine's Office of the State Coordinator for HIT to leverage public funding under sources such as the federal Health Information Technology Act and the Medicaid Meaningful Use Program that provide federal public funding to promote the use of electronic health records and access to health care data and reporting systems which improve the efficiency and quality of health care and move toward achieving the Triple Aim.

6. Conditioned on funding and based on an analysis of efficiencies to be gained by having administrative oversight by the MHDO, and current and future staffing needs, repurposing positions within the Maine Quality Forum (MQF) to support the development of health information technology improvements. These would include ongoing data projects with a focus on quality improvement across the Maine health care delivery system, and those that leverage existing and future data assets of the APCD, and active consumer engagement.

After the completion of these “next step” items, further legislation may need to be considered to more fully inform ensuing policy discussions, modify existing laws, as well as implement new laws and rules.

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VI. Conclusion

The experience of our Work Group has illustrated the importance of health data in Maine, and the passion and interest that its collection and use evoke among wide audiences in Maine. We wish to acknowledge and thank all of the groups and individuals who have contributed their ideas and time to this effort.

Maine has been in the forefront of the country in its health data collection and use. But the field is changing, as new technologies and practices enabling the linking of claims and clinical data become more widespread and practical. Maine needs to keep its leadership position, and to reap the benefits in terms of better and more affordable health care. This is an issue that justifies continued public attention in the coming years.

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Appendix A: Resolve Establishing Work Group

RESOLVE Chapter 109, LD 1467, 125th Maine State Legislature
Resolve, To Evaluate the All-payor Claims Database System for the State
HP1076, on - First Regular Session - 125th Maine Legislature

Sec. 1 Creation of working group. Resolved: That the Department of Health and Human Services, referred to in this resolve as "the department," shall establish and convene a working group to evaluate options and actions available to improve the availability of and access to health care data and to examine the all-payor claims database system in the State; and be it further

Sec. 2 Membership. Resolved: That the Commissioner of Health and Human Services shall invite 17 persons to participate in the working group, as follows:

1. Two representatives of health insurance carriers;
2. Two representatives of health care providers, one member representing hospitals and one member
3. Two representatives of employers, one member representing a statewide health management representing physicians; coalition and one member representing a statewide chamber of commerce;
4. One representative of consumers;
5. One expert in both state and federal privacy laws;
6. One representative of the Maine Health Data Organization;
7. One representative of the Maine Health Data Processing Center;
8. One representative of Onpoint Health Data;
9. One representative of the Department of Administrative and Financial Services, Office of Information Technology
10. One representative of HealthInfoNet;
11. One representative of the MaineCare program within the department;
12. One representative of the federal Medicare program;
13. One representative of the Office of the Attorney General; and
14. One representative of the Maine Quality Forum; and be it further

Sec. 3 Cochairs. Resolved: That the members of the working group shall select 2 of the members to serve as cochairs; and be it further

Sec. 4 Evaluation. Resolved: That the working group shall consider changes to the State's allpayor claims database system to improve the availability of and access to health care data by:

1. Reviewing the current structures of and relationships among the Maine Health Data Organization, the Maine Health Data Processing Center and Onpoint Health Data in order to evaluate the timeliness and effectiveness of the data received;RESOLVE Chapter 109, LD 1467, 125th Maine State Legislature Resolve, To Evaluate the All-payor Claims Database System for the State HP1076, on - First Regular Session - 125th Maine Legislature, page 2
2. Reviewing the current purposes and uses of the data and limitations on access to the data and considering additional uses for the data and changes that might be necessary to achieve and facilitate additional uses;
3. Considering federal and state privacy and security laws regarding the use and release of protected health information, including policy and technical changes needed to allow increased access to protected health information and the feasibility of those changes; and
4. Considering the availability of the data, the most appropriate sources of the data and the cost of providing the data; and be it further

Sec. 5 Funding and staffing. Resolved: That the department shall provide staffing assistance to the working group through contracted professional services and shall seek outside nonstate funding to support staffing services and administrative costs for the working group. If adequate funding is not obtained, the working group may not convene or incur any expenses; and be it further

Sec. 6 Report. Resolved: That, by January 31, 2012, the department shall report the recommendations based on the findings and conclusions, determined by vote, of the working group, along
with any recommended implementing legislation, to the Joint Standing Committee on Health and Human Services.

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Appendix B: Themes from Voice of the Customer Exercise

Theme 1: Establishing multi-stakeholder directed Data Governance Structures that optimize the collection, processing, and distribution (accessibility) of health care data.

- 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.
- Management of the APCD and other data sets by state government through the independent agency structure and governed by a multi-stakeholder board.
- 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.
- 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.
- 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.
- The focus should be on developing a combined data warehouse to which appropriate entities have access for approved purposes to improve the health of Maine people
- Data needs to be aggressively used by all appropriate parties to improve the delivery of health care, and therefore made available by a public entity with appropriate governance and safeguards to as many qualified users as possible who will work to improve the health and safety of Maine people.
- There is still no "all payer" database available. We need commercial, Medicaid, and Medicare claims data combined in a usable data warehouse
- Integrated clinical data, claims, health risk, and outcomes data is the optimal source of information for care improvement and high value.
- Information created from healthcare data should be made transparent and publically available in aggregate with the appropriate safeguards, processes, and criteria for reliability.
- Lots of questions about crossing the line between de- and id-data. We want to maintain control of clinical PHI. Careful assessment of what provider organizations are compelled vs. doing it voluntary.
- In theory, we would be interested in seeing the full MHDO data. When we get data from CMS, we get patient identifiable information. One thing that would need to be

considered is the ability to get identifiable data from public DB. This MHDO is good for benchmarking purpose. You would need to address timeliness and PHI. Particularly timeliness. We would hope for monthly feed and then turn it around within 24 hours.

- There must be careful evaluation of the roles of the actors—state has regulatory requirements; I think it is the ultimate response of the providers to have and use the tools with appropriate regulatory oversight. There is a public perception and costs considerations. State agencies have tried to keep the people within the regulatory boundary but not regulate how you deliver the care. This can get the state pretty close to regulating how you deliver the care.
- One of our most significant challenges is that HIN does not own the data. Issue is we have privately owned data, and within partnership the question of appropriate data use that benefits all and does not threaten anybody. We are focusing on E H R being the source of the clinical data. By the end of next year we will have over 95% of the Hospital (and their providers) data set. The ambulatory is taking a little longer. We are focusing heavily on FQHCs. We are the first HIE in the country nearing public health profiles (CDC) by running our data through systems including the federal POPHealth. All data is de-Id. We will be able to send data to Maine CDC.
- Multiple issues are data warehouses that are cropping up. And then we have the APCD. We need to catalog this and the legislature is aware of all of these cropping up.

Theme 2: Implementing technically-sound and scalable <u>Data Processing Structures and Protocols</u> that permit timely, accurate, and cost effective submission and dissemination of pertinent health care data (administrative and clinical).

- 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.
- Medicare data is not available in a timely/usable manner
- Data available for the patient origin report is often not timely
- Hospital Cost web-site is not maintained and up to date,
- Problems with the quality of the Maine Care data made some of it unusable, resulting in only getting old data (2006) for other pieces. Delays in the availability of the discharge data are a constant frustration. The process of resulting the data and getting waivers for public use was time-consuming and caused a few other delays.
- The data is not very useful without Medicare and MaineCare data. To the extent that this is in the control of MHDO, a quicker turnaround time for updates is needed.
- The procedure for ordering data from the Maine Health Data Organization was fairly easy, however after several different runs, the data was still unusable.
- Data dictionaries are hard to find. Needed some assistance to find the right reports and

files.

- The complex role of data submitters is not well understood by health data stakeholders. There are significant costs and limitations to what can be provided and when.
- Ensure a feedback mechanism through which submitters can verify their own data, as it exists as the output of the APCD.
- A data submitters working group should be convened to help develop common data collection standards and procedures including what should be collected, how often, and the best approaches to continuous improvement of data quality.
- There is substantial cost associated with providing health data. In Maine, one of our Plans estimates the cost of programming a single change to a single data element, and there are several thousand across multiple platforms, at $10,000. These operational costs are in addition to the annual assessments paid by carriers and providers that, along with modest income from data sales, fund the MHDO.
- There are systemic limitations to claims data in terms of both accuracy and timing that need to be acknowledged and understood.
- Not real time – only 50% of claims are adjudicated within one month of service provided, additional 35% in second month. The current release schedule of 90 days after close of quarter already requires monthly submissions from carriers.
- Limited outcomes data such as labs and radiology results.
- Lack of costs data at the claims/service level for capitated services or other special payment arrangements such as bundled payments or DRG payments.
- Data accuracy – up-coding, bundling and unbundling number to process a claim. Therefore, submitters should only be required to pass through the NPI submitted on the claim.
- NPI issues – NPI not available for all servicing providers on claims, NPI "confusion" between individual practitioners and billing practices, inaccurate NPIs on claims. Carriers may not need an NPI.
- Support broad based agreement among the states on a consistent set of data elements and formats for collection. Greater harmonization will enable increased automation through system programming increasing timeliness and efficiency. From a research and data integrity perspective, it also allows better comparisons across states, regions and populations.
- Data submissions from carriers should be limited to those elements utilized by carriers for the payment of claims. Seek out the best access point for additional data. For example, carriers do not typically need the middle initial of a provider's name in order to pay claims. It makes more sense to collect this information directly from providers. For non-payment essential fields, submitters should be only required to pass through what the provider submits and not be required to interpret, correct or enhance provider submitted fields.
- Health Plans need comprehensive, clear and detailed messaging around which fields are

causing their files to fail and why. The current data submission system is iterative and uses a serial editing process causing timely and expensive delays and an enormous volume of unnecessary communication. If problems can be addressed and understood simultaneously then increased efficiency could be realized, and the time and expense for all could be better managed.

- Expedite the data submission process by identifying all the issues with a data file at once. Upon submission, carriers should quickly receive one report back detailing all the errors or problems with their data files. In this way, multiple issues can be addressed simultaneously and much more quickly, reducing resources and time required for the DQ Pass to be achieved. Where automated error messages frequently generate questions, messages should be revised to better explain the error.
- Changes to thresholds need to be systematized so that they are set with input from submitters and occur on a predictable annual schedule with adequate notice. The current approach relies heavily on the subjective views of a few and needs to be formalized. In this way, agreements from previous years can be formally tracked and recorded and all parties are saved the unnecessary hassle and additional expense of repeating requests and justifications. From a data quality perspective, thresholds of 100% are not realistic and have no place in the data submission standards.
- In cases where there are systemic issues that prevent the meeting of particular thresholds, then a permanent waiver or twelve month waiver period would be appropriate. It is resource intensive to have to reapply for the same waiver repeatedly. When a systemic issue will not change, Maine's approach of allowing adjustments month by month, rather than for a longer period should be altered to save time and resource expense for all. An example of this could be ancillary coverage, which rarely if ever has a billing provider; if the industry practice does not include use of a billing provider, why not permanently except this type of file from this requirement instead of requiring an annual renewal of a variance?
- Other efficiencies could be achieved by experimenting with ideas such as advance applications for threshold adjustments, so the new standard would already be in place when a file is submitted. Additionally, better files could be maintained about why and when different carriers requested adjustments. This would allow easy renewals without a new application process each time. Our plans report that NH has permitted advance threshold adjustments but Maine has not. Further, Maine requires that carriers "prove" there's still a problem each time. A better balance must be struck between Maine's desire to require carriers to provide the highest standard of data and the cost, use of limited IT resources and burden to everyone (not just the plans) associated with doing so.
- Maine should consider whether there are some data elements that are more important than others. Prioritizing data elements would help the parties focus on those that are most important. Health information is needed by different constituents and different

delivery rates. Patient data most frequent, analytical/financial data less frequently.

- There are several issues similarly impacting most if not all of member plans. In these cases where there seems to be an industry wide challenge, Maine should seek to explore ways of addressing these problems using a centralized approach. For example, several plans are facing challenges around the provision of prescriber identification data. Can a solution be devised where Plans pass through to the MHDO what they receive on claims and the MHDO or their vendor crosswalks that information to a centralized database they maintain from the PBMs? This is a far more practical approach than asking all submitters to develop separate and expensive solutions to a similar problem. This is not to say that we take the increase in assessments that would result from an approach like this lightly, but rather, that we recognize the value of having one system funded by all assessment payors collectively. For each submitter to fund a "fix" would be impractical, cumbersome, and unnecessarily expensive.
- Clinical data integrated with claims data to support ongoing care process improvement and efficiency efforts
- Inclusion of Medicare and Medicaid data that are up to date and accurate
- Pharmacy and BH data is inconsistent across payers.
- The hardest part of the quarterly reporting process is to line up the charge systems data lined up with event of care. Who, what diagnosis, and which are multiple systems in the hospital.
- Important to have a master provider and patient index (slide 8). MHDO's RFP is around master patient and provider index. So we need to make sure that we don't duplicate efforts and systems.
- Provider centric data is insufficient to provide the type of data needed to parse into episodes. For example, coronary at hospital; what we didn't know was who went to rehab or nursing home or saw PCP twelve times in the next year.

Theme 3: Balancing <u>Consumer Privacy</u> considerations regarding the safeguarding and disclosure of <u>Protected Health Information (PHI)</u> with the societal imperative to drive higher quality and more affordable health care.

- Expansion raises the potential for poor policy decisions to be made about patient privacy, confidentiality, consent, notice, and control.
- Medical information is arguably the most personal and private source of data about us as individuals. In our work on health information technology, we continue to come back to the importance of informed consent. Fundamentally and consistently, patients should be aware of and have an opportunity to decide who has access to their medical information. That includes testing, diagnoses, treatment notes, payment and billing information, and anything else that is personally identifiable.
- Both doctors and patients worry that their medical data will not be adequately protected. They have good reason for concern. The familial, financial and professional

ramifications of inappropriately exposed health information could be devastating. And the larger and more comprehensive these databases become, they not only arguably become more valuable to patients, health professionals and administrators, they also become more vulnerable to thrill hackers, those seeking to commit medical identity theft, unscrupulous employees, and others.

- Concern about inadequate sharing or protection of health information can also lead patients to put off seeking care – leading to potential health consequences for that individual and fiscal costs for the rest of us. Imagine discriminatory review by insurance companies or potential employers so they can avoid paying for people who might be expensive to insure or employ.
- While there may be value to expanding uses of the MHDO database or to linkage with other databases, these decisions should be made with patient's rights at the fore. Often those doing the hard work of providing us with healthcare get so excited about increasing efficiency or improving coordination of care that patient notice, privacy and consent can get lost.
- As patient advocates and defenders of personal privacy, we urge continual focus and commitment to privacy, confidentiality and security. Patient rights must be the highest priority in Maine's electronic health information system, and we hope the State will continue to demonstrate meaningful commitments to patient privacy.
- We need to be very careful in protecting personal health information. However, we also need to be very vigilant about making sure data is being used to improve the health of Maine people.
- 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.
- Access to PHI data (by appropriate sources and with appropriate protections) to support ongoing projects.
- Health care providers need data with personal health information in a HIPAA compliant way so they can use it to improve care for those patients they are treating. Right now we have providers willing to take responsibility for the quality and cost of their patients and they don't have good data readily available. I hear words like "betrayal" and "tying our hands behind our backs" from providers
- Within PCPs we may be able to only look at 10-15% of population. We cannot look at population data from a longitudinal basis because of the lack of data. Though I believe we need to be absolutely careful of PHI, the overall public good requires us to identify and implement standards so we can have PHI, have it timely, and need access to the PHI in the APCD. We will not be able to do the work that needs to be done if we do not do this.

Theme 4: Establishing mechanisms to ensure that consumer/stakeholder engagement and feedback is requested and prioritized to ensure value is being derived from the APCD.

- Simple straight forward information that is important for patients making a choice of healthcare providers is important.
- Make consumers more aware that the data is available, and make it free to healthcare consumers. Media attention and/or information given out at facilities would help. Make available data simple to understand and easily accessible. Consumers do not understand terms like "4 infections per 1000 patient days". Put it in an easily searchable format online.
- My use would be for personal use and to help consumers to make wise choices of providers for themselves. My consumer advocacy groups would also use the data to help consumers. Publication of data is also an incentive to facilities and providers to a improve quality and safety in their practices. When public data is available to all, then it makes healthcare providers accountable and transparent. Public pressure is often what it takes to motivate improvement.
- User friendly websites that can be found through key word searches on the internet would be useful. I would like to see those providing health insurance or medical services sending people diagnosis specific information and helpful hints. Also referral information should be available for an individual's primary health provider when a new diagnosis is given. For most people where they are first told that they have a medical problem is a "teachable moment".
- Everything! I want to know who, what, where, when, and why! Then I want to know how much it is going to cost me out of my own pocket. I am a thorough healthcare consumer. I question what medication I am being given, the pros and cons of this medication vs. another and the most effective form of delivery. When tests are ordered, I want to know why and what information is going to be learned. I will refuse anything I do not feel is appropriate and am lucky to have a provider who works with me.
- I am a true fan of online resources, reliable and proven ones. My provider is also an excellent resource. There are many community resources that I am lucky to know about as a result of working in mental health and now a community health center.
- The process has varied depending on what information I was seeking. Sometimes I have been successful and sometimes I have had to change what I was looking for in order to find any success at all.
- I am, once again, shocked to find that the two hospitals in my area are some of the most expensive in the state. I have had some of the procedures listed on this site. It makes me feel like my insurance company was swindled and, in return, so was I in terms of the co-pays I had to pay out of my own pocket!
- There are too many people who need services and the wait for appointments is too long. Health literacy is a huge factor. Materials are written far above the level of the

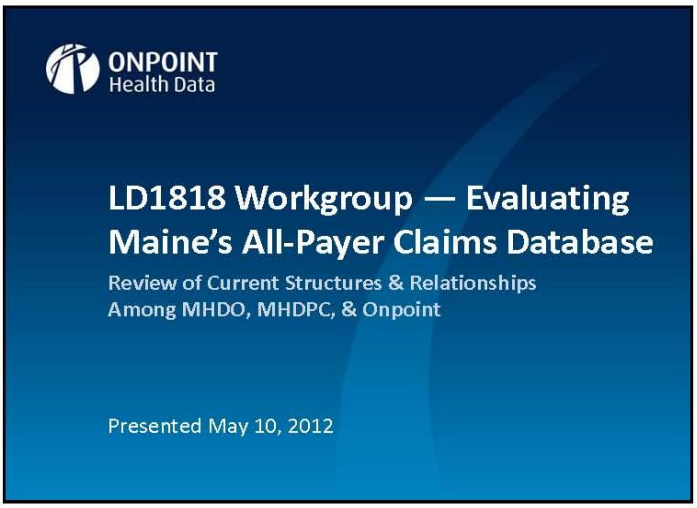
education of the people served so they cannot benefit. Many cannot read at all. Creating a health navigation or patient advocacy program within the MaineCare system is ESSENTIAL not optional! The people served by this program, for the most part, are not good healthcare consumers but are some of the biggest consumers of healthcare!

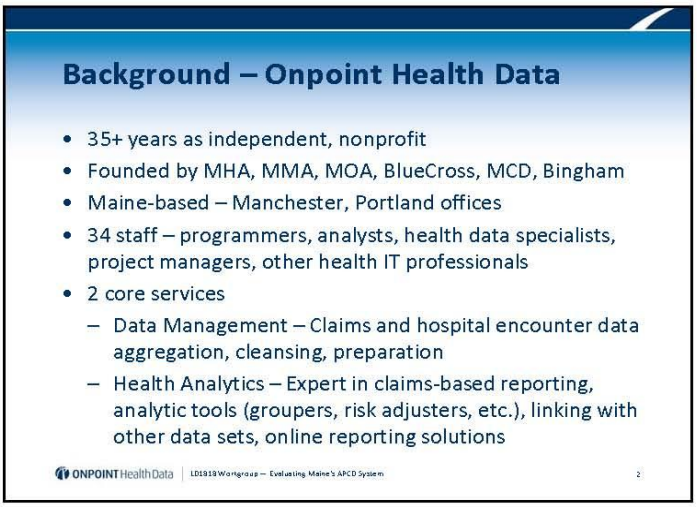
- Knowing there is a physician/clinic available 24/7 if I need care, to include but not limited to an E.R.Knowing that person has access to my medical record.
- Whether my care is covered by my insurance. If I have no insurance, cost of care. If I have no insurance, will I receive care
- Health status measures, rates of hospitalizations, emergency room visits, some interest in quality of care related measures, county, public health district and state levels, oral health, mental health, physical health.
- Discharge database (inpatient and outpatient), emergency room visits database, All Payor Claims database, Quality of care (HAI) data.
- Possible analysis of integrated care grantees
- Possible analysis of payment reform grantees
- More clinically relevant, real-time data that goes beyond claims
- Providers are going to need timely access to clinical data going into the future
- Clinical and Administrative data are going to have to be integrated in the future
- Consumers need a reliable source of information/data when they are choosing where to get their healthcare. Public reports on healthcare acquired conditions, such as HAIs and medical errors, ulcers, falls and other problems are extremely limited in the State of Maine. I was asked recently to provide reports from my state to the NEVER and CU groups. The sentinel events report was outdated and inaccurate, the HAI report was mostly process measures and only CLABSI and MRSA screening compliance results were available, and there were no detailed reports on other preventable errors or injuries and readmissions
- There is currently no detailed public data available to consumers on specific surgical complications for specific procedures. SSI on only Abdominal Hysterectomies and Colon surgery will be required by the Feds this year. This is extremely limited information. Patients should be able to access information on their specific condition, at their preferred Hospital, and find out exactly how many SSIs there were in the previous year. Patients are expected to trust and rely on their doctor's or Hospital's word that "there aren't that many". While that may be comforting to some, an educated consumer would want to confirm that for their own safety.
- Data on other preventable medical and surgical errors, adverse events and HAIs should also be available to healthcare consumers. I can get more information on a car service business than I can from my local hospital
- There is no ability to match up claims data with other increasingly available data (e.g. clinical, health risk, functional status, etc.) and
    - used by providers for improving care for patients for whom they are responsible

    - used by purchasers and the public (using de-identified data) to help assess the value of the care they are receiving and to help guide people where they can receive the best value care
- Health care providers need to focus on improving the health of people. This includes health risks like smoking, nutrition, exercise, etc. that put people at risk for future problems as well as how they are functioning in life (i.e. fulfilling roles and responsibilities at home, in the community, at work, and in leisure time). These will be measured in the future and if combined with claims and clinical data can give health providers a better picture of how to improve the health and quality of life of the people they are responsible for. By also making this de-identifiable data available, it helps to find and publicize best practices, helps providers see how they are doing and could do better, and allows people to make choices of which providers they would like to go to.
- Meaningful cost of care data to support employees and families in the purchasing decisions
- Transparency into hospital costs to allow for assessment of systemic "right sizing" based on community capacity and fixed cost analyses
- Transparency into critical quality measures such as sentinel events by hospital
- I hope that we address in the 1818 group whether this web information should continue to be posted, or is it duplicative of payer info.? We have approximately 20 more to post.
- In Maine very little done to data set to make it valuable to users. Other states do that. Small health systems would have a hard time putting this together. What additional things could we do to make data set more user friendly. The MHDO RFP moves us in the right direction—it could do value added and save money. One of the frustrations is that different organizations use different approaches and tools which make it more difficult.
- We should consider financial incentives for the use of the systems. We do something to move that work flow. Policy is probably what is needed to change.
- How do you bring the consumer into the equation to give them value? That should be a recommendation from this group and that is perhaps another committee.

DRAFT

Appendix C: Factors Influencing All Claims Payer Database Timeliness





1

Background – Onpoint Health Data

- Clients
  - Data Management
    - All-Payer Claims Database – ME (MHDO), NH (DHHS/Ins. Dept.), VT (Dept. of Financial Reg.), MN (Dept. of Health)
    - Hospital Encounter – NH (DHHS)
  - Health Analytics – VT (Dept. of Financial Reg., Medicaid, Blueprint for Health), NH (Medicaid), ME (State of Maine Employees, ME CDC, Mercy, MaineHealth, Franklin, other provider organizations)

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Background – Onpoint Health Data

- Track record of leadership, innovation
  - First of its kind, multi-payer claims database for MHMC
  - Data/analytic support for Wennberg / Dartmouth Institute variation work
  - Creation of first multi-state APCD database to support regional variation
  - Partnered in development of HealthInfoNet

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Roles & Functions in Developing, Maintaining ME's APCD

- Two partners in Maine Health Data Processing Center (a public-private partnership)
  - **Onpoint** – Technical partner; brought experience developing a multi-payer claims database
  - **MHDO** – Regulatory partner; brought statutory authority, rulemaking experience in the collection and release of hospital data

Roles & Functions in Developing/ Maintaining Maine's APCD

Onpoint Health Data	MHDO
Payer communication, on-boarding	Rulemaking – data collection, release
Payer registration – initial, ongoing	Payer compliance
Secure upload and PHI encryption	Submitter role – Medicare (including mapping to APCD format), MaineCare
Data collection, validation in conformance with state regulations	Loading, warehousing data
Data specs, submission schema, reporting systems maintenance	Extracts to approved users
Master Person Index	Administrative – fee assessment to payers/providers, users; board support
Master Provider Index	
Extract preparation – qtrly to MHDO	

Impact of Other Organizations on Performance & Timeliness

- Organizations impacting APCD timeliness

Organization	APCD Role	Target
Payers	Extract enrollment, claims from data warehouse to Onpoint	30 days + 15-day grace period
Aggregator (Onpoint)	Intake, standardize, QA data; extract to MHDO	30 days
Regulator (MHDO)	Load/QA extract, prepare for release	15 days
Total		90 days

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Impact of Other Organizations on Performance & Timeliness

- Current availability of data through MHDO

Payer	From	Through	Target	Status
Commercial	Q1, 2003	Q4, 2011	Q4, 2011	On time for the last 18 months
MaineCare	Q1, 2003	Q3, 2010	Q4, 2011	Molina implementation caused problems with eligibility, other data; corrected files expected soon
Medicare	Q1, 2003	Q4, 2006	Q4, 2010	07/08 in house; mapping complete; currently receiving test files

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Impact of Other Organizations on Performance & Timeliness

- **Payers** – Issues impacting timeliness, performance
  - Percent files overdue (past 30-day deadline): 36%

File Type	% Late Q3 2011	% Late Q4 2011
Eligibility	34%	32%
Medical	53%	47%
Rx	42%	34%
Dental	35%	27%

  - Percent of files failing Onpoint DQ/validation edits: 37%

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Impact of Other Organizations on Performance & Timeliness

- Direct vs. indirect interface with payer
  - Commercial plans – Direct, no delay
  - Government – Indirect, multiple parties involved; causes delay
    - MaineCare – MHDO as liaison
    - Medicare – MHDO as submitter
      - » Application, DUA process
      - » Mapping, programming to APCD format
      - » Available once/year, Final Action Files

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Impact of Other Organizations on Performance & Timeliness

- **Aggregator (Onpoint)** – Issues impacting timeliness, performance
  - Downstream from submitters – Issues that impact them impact Onpoint, too
  - Volume of small payers – 50-lives threshold
  - Last minute requests – Short-circuiting processes
  - Indirect relationships
- **Regulator (MHDO)** – Issues impacting timeliness, performance
  - Resource constraints

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Factors Impacting Quality, Timeliness, & Output

- Data collected
  - Eligibility – Medical, pharmacy, and dental
  - Medical claims
  - Pharmacy claims
  - Dental claims
- Collection frequency
  - Monthly for 66% of companies (including MaineCare)
  - Quarterly for 20% of companies
  - Annually for 14% of companies (including CMS)

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Factors Impacting Quality, Timeliness, & Output

- Volume

Metric	ME	NH	VT	MN
Submitters	149	71	77	78
Data volume/year	175M	115M	70M	525M
Files processed/month	400	175	200	200
Data types	EMPD	EMPD	EMP	EMP
Public payers – Medicaid	X	X	X	X
Public payers – Medicare	X			X

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Factors Impacting Quality, Timeliness, & Output

- Administrative data set – Volume, diags, $; no outcomes
- Delays with government claims data
- Excluded activity
  - Uninsured, workers' compensation, VA
  - Outcomes/results from testing
  - Premium information, capitation/admin. fees, etc.
- Payer compliance with state rules
  - Acceptance criteria
  - Data quality edits

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Factors Impacting Quality, Timeliness, & Output

- Lack of standards
  - Non-standard ways of processing, storing data by payers
  - Challenges
    - Master Provider Index – NPI took effect in '07; not fully or consistently implemented by submitters
    - Master Person Index – Encryption of PHI, inconsistent population of key identifiers (e.g., SSN)
    - Hospital owned practices – Billing at tax ID, provider-based reimbursement rules
    - Bundled billing – Loss of service-level detail

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Factors Impacting Quality, Timeliness, & Output

- Infrastructure
  - Processing capacity – More than 100M claims and eligibility records per month
  - Performance – Manage and warehouse more than 10TB of APCD data on state-of-the-art Oracle databases and advanced Storage Area Networks
  - Security – Encryption technologies at both the file and field levels plus advanced firewall capabilities to ensure HIPAA compliance

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Potential Changes to Improve Timeliness, Reliability, & Quality

- Reduce volume of submitters
  - Smaller submitters – Quarterly, annual filers
  - Dental submitters – Few requests for data
- Shift organization roles, free up resources
  - Streamline/simplify MHDO compliance process
  - Establish a direct relationship with MaineCare
  - Outsource Medicare mapping, integration

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Potential Changes to Improve Timeliness, Reliability, & Quality

- Enhancing database as analytic resource
  - Increased value-add – Elements/flags, groupers
  - Consolidation claims
  - Increase data scrubbing
- Improve MPI
  - Person – Advanced clustering, improving quality of underlying elements
  - Provider – Intake of provider files, adding street address, adding physician-to-group crosswalk

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Potential Changes to Improve Timeliness, Reliability, & Quality

- Harmonization efforts with other states
  - Demand for regional comparative analysis
  - Can't track patients from state to state
- Linking with other data sets
  - HealthInfoNet – Clinical outcomes, other
  - Hospital encounter
  - Birth, death, immunization registries

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Potential Changes to Improve Timeliness, Reliability, & Quality

- Rule changes
  - SSN threshold increased
  - Expanding from *residents only* to *residents + policies written*
  - ICD-10 conformance
  - Provider file and/or street address submission

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Questions or Follow-Up?

Contact:

Jim Harrison, President/CEO

Onpoint Heath Data

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207-430-0682

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www.OnpointHealthData.org

Appendix D: Maine Health Data Organization Program

1/24/2013

Maine Health Data Organization

MHDO's Role and Functions in Developing, Maintaining and Distributing an All Claims All Payer Database

Presentation to LD 1818 Workgroup
May 10, 2012

Anne L. Head, Vice Chair, MHDO Board of Directors

1

History of Maine Health Data Organization

- **Maine Health Care Finance Commission (MHCFC)**
- Independent executive agency charged with hospital rate setting and cost containment, repealed by Maine Legislature in 1995
- **Maine Health Data Organization (MHDO)**—established in 1996
- Successor agency to MHCFC with responsibility for maintaining multiple financial and clinical databases established during MHCFC years;
- Independent executive agency with 15 member board representing consumers, providers, payers and state;
- With enforcement authority to compel reporting by providers and payers

2

1

- **Maine Health Data Processing Center (MHDPC)—**
- Public-private partnership established in 2001, designed to provide data processing services in partnership with MHDO.

3

- MHDO All Payer/All Provider Claims Database (APCD)
- Established by MHDO in 2003 as "first in nation" APCD, intended to capture claims data from:
- All payers including commercial carriers and public payers (Medicaid and Medicare)
- In partnership with DPC/Onpoint.

4

- APCD contains:
  - Paid medical, dental, pharmacy claims files for all covered services rendered to publicly (Medicare Part A, B, C, D and Medicaid) and privately insured Maine residents
  - Eligibility / membership files
  - Health care service provider files
  - Standard format utilized:
    - HIPAA standard codes
    - HIPAA transaction set data elements

5

- **APCD Data Collection**
  - The first step of the process is **data collection** from source system.
  - Medicare data is sent to MHDO by Center for Medicare and Medicaid (CMS).
  - The Medicaid data is sent to MHDO by Office of MaineCare Services (OMS).
  - Commercial claims data is sent to Onpoint by all payers who have 50 or more members in Maine. Onpoint combines the data from each of these sources and sends it to MHDO. This data is then made available to consumers and stakeholders.

6

- **Data Transformation**
- **Medicare Data**
- The Medicare data is purchased by MHDO from CMS and received annually. There is 2-3 year delay in availability of data from CMS. The most current data MHDO has received is for year 2008. It is currently in the data transformation process.
- Medicare data received by MHDO is converted into a format that is compatible with commercial claims data and sent to Onpoint. The goal is to complete this conversion in about 7 days; however it is dependent on MHDO receiving the data in correct format. Once the data is received by Onpoint, it is merged with other commercial claims and Medicaid data. Onpoint requires 30 days to complete its processing. Once the combined data is received by MHDO, it needs another 30 days to make it available for reporting and to other stakeholders.
- This process is different from commercial because CMS sends the Medicare data in a format that is different than commercial claims data structure. MHDO converts into a commercial consistent format before sending this to Onpoint.

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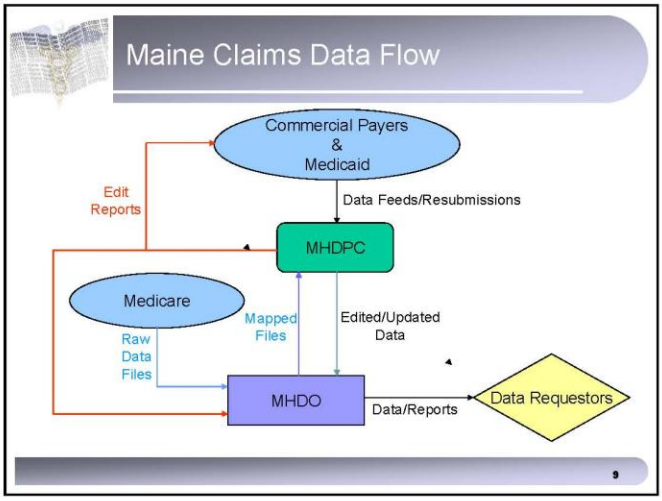
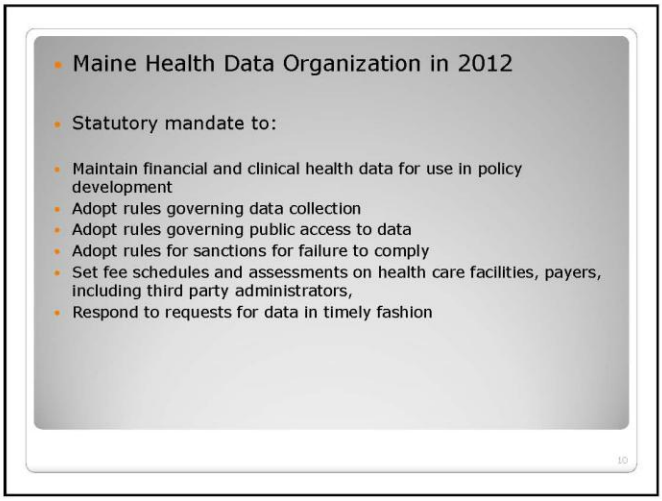
- **Medicaid Data**
- Medicaid claims data is sent by OMS through one of two paths to MHDO for transformation.
- 1/2003-8/31/2010 OMS to Muskie to MHDO to Onpoint
- 9/1/2010 and after—Unisys/Molina/DHHS to Onpoint
- Once the data is received by MHDO it is converted into a format that is compatible with commercial claims data. Once the conversion is complete the data is sent to Onpoint. MHDO's goal is to complete this conversion in 7 days. Once the data is received by Onpoint, it is merged with other commercial claims and Medicaid data. Onpoint requires 30 days to complete its processing. Once the combined data is received by MHDO, it needs another 30 days to make it available for reporting and to other stakeholders.

8


Maine Claims Data Flow
Commercial Payers & Medicaid
Data Feeds/Resubmissions
Edit Reports
MHDPC
Medicare
Mapped Files
Edited/Updated Data
Raw Data Files
MHDO
Data/Reports
Data Requestors
9


Maine Health Data Organization in 2012
Statutory mandate to:
Maintain financial and clinical health data for use in policy development
Adopt rules governing data collection
Adopt rules governing public access to data
Adopt rules for sanctions for failure to comply
Set fee schedules and assessments on health care facilities, payers, including third party administrators,
Respond to requests for data in timely fashion
10

- Produce clearly labeled and easy to understand reports reflecting quality of care and price comparison that are publicly accessible on MHDO website
- 21 member board (5 current vacancies) 5 MHDO subject matter staff, 4 State Office of Information Technology technical staff
- MHDO Databases in addition to APCD
  - Hospital inpatient
  - Hospital outpatient
  - Hospital emergency department
  - Non-hospital ambulatory services (1990 – 2004)
  - Hospital financial
  - Hospital organizational
  - Quality data

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- **Future Vision of MHDO**
- Recent board retreats have culminated in plans for:
  - Restructuring to significantly reduce number of board members while retaining stakeholder diversity and balance;
  - Recommitment to maintaining agency's independent status;
  - Refocusing attention on improvements in the current data transformation process using state RPF process;
  - Enhanced communication with partner agencies, stakeholders and end users;
  - Immediate appointment of an interim executive director;
  - Initiation of search for permanent executive director.

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- Organizations that impact MHDO's performance
- MHDO Critical Partners
  - **Commercial carriers**—provide timely, accurate claims data submitted to Onpoint pursuant to submission schedule
  - **Onpoint/DPC**—accepts commercial claims data, processes it in a timely manner and retransmits data to MHDO, according to mutual agreement between the two organizations.
  - **Office of Information Technology**—provides expert project management support and systems support for technical projects. OIT staff and MHDO staff work in close collaboration and partnership on all projects.

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- **Department of Health and Human Services, Office of MaineCare Services (Medicaid)**

Data Flow summary:

1/2003-8/31/2010 OMS to Muskie to MHDO to Onpoint
9/1/2010 and after—Unisys/Molina/DHHS to Onpoint

Federal CMS (Medicare)

Claims data is purchased by MHDO and is mapped and coded by MHDO/OIT staff before transmitting it to Onpoint for editing. There is typically a two year lag time on Medicare data. Additional resources of MHDO, Onpoint and OIT have been deployed to expedite more current data being made available to end users.

14

- Factors impacting quality, timeliness, and output of APCD components

  - Difficulties encountered in obtaining Medicare claims data and transforming the data into usable format for inclusion in the APCD. It is hoped that once 2008 data already obtained is mapped and coded, the process for 2009/10 Medicare data will be expedited.
  - Difficulties understandably encountered by DHHS/MaineCare in terms of quality and accuracy of data has caused delays throughout the balance of the data transformation process. It is hoped that issues causing delays will be resolved shortly.

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Appendix E: Inventory of Engagement Mechanisms

Maine Quality Counts - Consumer/Patient Engagement Framework

Patient/Consumer Interest	Patient/Consumer Role	Options for Involvement	Supports Needed	Key Characteristics/ Skills
Level A: • Improve one's own health • Improve health of family member	Active partner in care	• Engage in self-management, goal-setting • Participate in shared decision making • Participate in Living Well program • Participate in support group • Participate in health-related social networking site • Know how to access your medical records and make changes if required • Increasing progression on the Behavior Engagement Framework • Use of personal health record or other tracking	• Evidence-based guidelines on recommended treatments, goals (e.g. Pathways) • Living Well program (group, online) • Information on action steps, trusted support programs • Information on how to access health records and how to make changes/edits	• Self-awareness re: personal role in managing health • Ability to identify, communicate treatment preferences • Willingness to communicate with care team • Ability to track and organize personal health records and information

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Patient/Consumer Interest	Patient/Consumer Role	Options for Involvement	Supports Needed	Key Characteristics/ Skills
		tools		
Level B: • Get information to make informed choices about care	Active partner in care	• Access GetBetterMaine website and other info on health care quality, costs • Help others access information • Understand issues of healthcare safety and advocate with providers to adhere to safety guidelines	• Trusted information on health care quality & costs • Resources to answer questions	• Desire to seek out information • Ability to distinguish between valid & erroneous information sources • Ability to discuss choices, ask questions
• **Level C:** • Work with others to help improve their health	Peer supporter	• Serve as Living Well instructor • Serve as peer-to-peer support, mentor • Understand Behavior Engagement Framework and how you can assist others with specific behaviors • Serve as patient navigator in your health care system	• Training programs • Peer support • Patient navigation training	• High degree of empathy • Good communicator • Ability to maintain confidentiality
Level D: • Work directly with health care providers to help improve the	Practice Change Advisor	• Work with primary care practice redesign team ("Practice Partner") • Serve on health care	• Training programs (e.g. mtg facilitation, leadership,	• Commitment to improve care and value team goals over individual interests • Ability to maintain

DRAFT

Patient/Consumer Interest	Patient/Consumer Role	Options for Involvement	Supports Needed	Key Characteristics/ Skills
delivery, quality, experience of care		Patient Advisory Council (e.g. for primary care practice, hospital) • Participate in provider committees	knowledge, QI methods) • Peer support & coaching	confidentiality • Desire to gain knowledge re: health care quality • Comfortable articulating patient insights & bringing patient feedback to improvement team • Receptive to views of others • Good communicator
Level E: • Work with stakeholders to drive system, policy, payment changes to transform care	Policy advisor, champion for change	• Serve on QC Board • Serve on QC Consumer Advisory Council • Serve on HIN Consumer Committee • Get involved in meetings with local providers • Participate on State Workgroups • Participate in local community forums on healthcare quality and cost	• Training programs (e.g. mtg facilitation, leadership, knowledge, QI methods) • Peer support & coaching	• Commitment to improve care and value team goals over individual interests • Foundational understanding of health care quality • Ability to seek out & synthesize information on complex topics • Receptive to views of others • Excellent communicator • Ability to problem-solve in inclusive manner that addresses issues from myriad of perspectives

DRAFT

Defining Consumer Representation

The inclusion of consumer representatives is crucial to ensuring that your Alliance's efforts and end-results meet the needs of the consumers in your community. Consumer representatives also can serve as agents of change, working alongside other stakeholders to advance the goals of the Alliance. To effectively engage consumers in the work of AF4Q, Alliances should seek out groups that truly represent consumers. Sometimes the lines appear blurry and it may seem like a health plan, employer group, or even a provider organization could serve as a consumer representative. While they may aim to speak for consumers and patients, these representatives have additional interests to consider, as with any stakeholder group, and cannot be regarded as authentic consumer voices. The definitions below are meant to assist you as you work to ensure that your Alliance includes genuine consumer representatives.

Definition of an Individual Consumer
A consumer is an individual who has significant personal experience with the health care system, either as a patient or caregiver. A consumer draws upon these experiences to enrich Alliance initiatives. While there is great value in engaging consumers and patients, most individual consumers lack the ability to influence and communicate with a large network or constituency. Engaging both individual consumers and consumer representatives is recommended.

Definition of a Consumer Representative (also called Consumer Advocate)
Consumer representatives/advocates are individuals who work at nonprofit, mission oriented organizations that represent a specific constituency of consumers or patients. What distinguishes consumer advocates from other Alliance stakeholders is their primary emphasis on the needs and interests of consumers and patients. Another important characteristic of consumer advocates, compared to other stakeholders, is they typically do not have a financial stake in the health care system.

The greatest strength of consumer advocates is they are a trusted source of information in your community. Unlike individual consumers, they speak from a global perspective and have experience representing the diverse needs and wants of groups of consumers and patients. They also have networks to empower and mobilize the community using email lists, websites, meetings, newsletters and conferences to share information and messages. And most consumer advocates have established relationships with the media, policy makers and elected officials they can leverage to support the Alliance.

Examples of Consumer Advocacy Organizations:

- Organizations serving specific constituencies such as women, children, older adults, minority patients and workers, such as the YWCA, AARP, NAACP and AFL-CIO.
- Disease specific organizations, such as the American Cancer Society, American Diabetes Association, American Heart Association and the National Kidney Foundation.
- Faith-based organizations, such as churches, mosques and synagogues.
- Broad-based or policy-focused organizations, such as Citizen Action, Consumers Union, League of Women Voters and Literacy Councils.

For assistance identifying the most appropriate consumer representatives to engage in your Alliance, contact Jennifer Sweeney at the National Partnership for Women & Families (NPWF) at 202-986-2600 or Jsweeney@nationalpartnership.org. For more information on effectively supporting consumer participation in the Alliance, visit www.qualitycarenow.org

The National Partnership for Women & Families provides technical assistance for *Aligning Forces for Quality*, a national initiative of the Robert Wood Johnson Foundation.

Appendix F: Legal Work Group Report

LEGAL WORK GROUP (LWG) PRESENTATION TO THE L. D. 1818 (CHAPTER 109) WORKING GROUP
August 16, 2012
INTRODUCTION

This document summarizes the work of the Legal Work Group (LWG) in response to a request by the LD 1818 Working Group about Protected Health Information (PHI). Specifically, the LWG was tasked with helping inform the Working Group on one of the four issues included in LD 1818:

> 3. Considering federal and state privacy and security laws regarding the use and release of protected health information, including policy and technical changes needed to allow increased access to protected health information and the feasibility of those changes;

This documen f
Presentation; Rules; and V. Conclusion.

I. Background

Among other provisions, the 2009 HITECH Act created three initiatives: 1) The establishment of the federal Office of the National Coordinator for HIT; 2) The Medicare HIT Meaningful Use (operated and governed by CMS); and 3) The Medicaid Meaningful use Program (governed at the State Medicaid level with 100% federal funds for MU payments and 90% federal funds for State administration of the program).

The ONC required States that wanted to participate in the ONC initiatives, to establish an Office of the State Coordinator for HIT to oversee state HIT activities. In addition to the OSC, the ONC signed contracts with an entity within each state and provided funding to establish and operate a Regional Extension Center (REC). The RECs sign-up hospitals, and up to 1,000 primary health care professionals and entities, to implement an electronic health record (E H R) and participate in a health information exchange (HIE). In Maine, the ONC contract is with HealthInfoNet that established Maine's REC. HIN also used its exchange which had already been established as part of a pilot program in the mid-2000s as the HIE.

In 2010, the OSC was established by Executive Order (EO), which also named HIN's HIE the "HIE" under the ONC initiative. The OSC is now housed in DHHS. It is advised by a HIT Steering Committee (HITSC), an approximately 17 member Committee of stakeholders established in EO. The HITSC first established the Legal Work Group (LWG) in 2010 to help inform them on privacy issues. The LWG was again reconvened in 2012

for two purposes, one of which falls under the purview of the 1818 group--To help inform the 1818 Group on the question about Increasing Access to PHI. (The second purpose is to draft definitions and roles and responsibilities of a State Designated HIE which will be submitted for HITSC for discussion and a report to the OSC). The LWG has approximately 12 members, comprised of lawyers and other professionals from the State, healthcare organizations, consumers, and others.
With this background in mind, the LWG is making its initial report to the 1818 Working Group. Many LWG members believed it was important to state that they view the scope of the LWG as providing a factual review of the current federal and state laws and rules governing PHI. Then, if the 1818 Working Group desired to have specific scenarios examined, the LWG would provide a legal analysis of the specific scenarios. In that respect, the LWG would not make what might be termed "subjective recommendations." Rather, its analysis would be "objective and factual" in nature.
It is a challenge to inventory, analyze and report on laws and rules that govern PHI. They have been developed in a piecemeal fashion, and terms and definitions vary by law and rule and even in conversation. For example, some laws may use the term disclose while others use release or use. For these reasons, the documents being presented are an attempt to provide in the least complex way, a very complex subject.

II. Organization of Presentation

This presentation consists of several documents, including this summary document, definitions document, and several graphics and spreadsheets.
Since this presentation revolves around "protected health information" (PHI) it is useful to define that term. The term PHI is from HIPAA requirements to protect all "individually identifiable health information" which is demographic data that relates to:

- The individual's past, present or future physical or mental health or condition;
- The provision of health care to the individual, or the past, present, or future payment for the provision of health care to the individual; and
- That identifies the individual or for which there is a reasonable basis to believe can be used to identify the individual.

Individually identifiable health information includes many common identifiers (e.g., name, address, birth date, Social Security Number).

1. Graphic and Detailed Grids (Spreadsheets). The graphic and spreadsheets are grouped into four categories of PHI: General Health (termed non-sensitive PHI); and Mental Health, Substance and Alcohol Abuse, and HIV (these three are termed sensitive PHI). The reason the LWG chose these categories is because for the most part, federal and state laws and rules treat

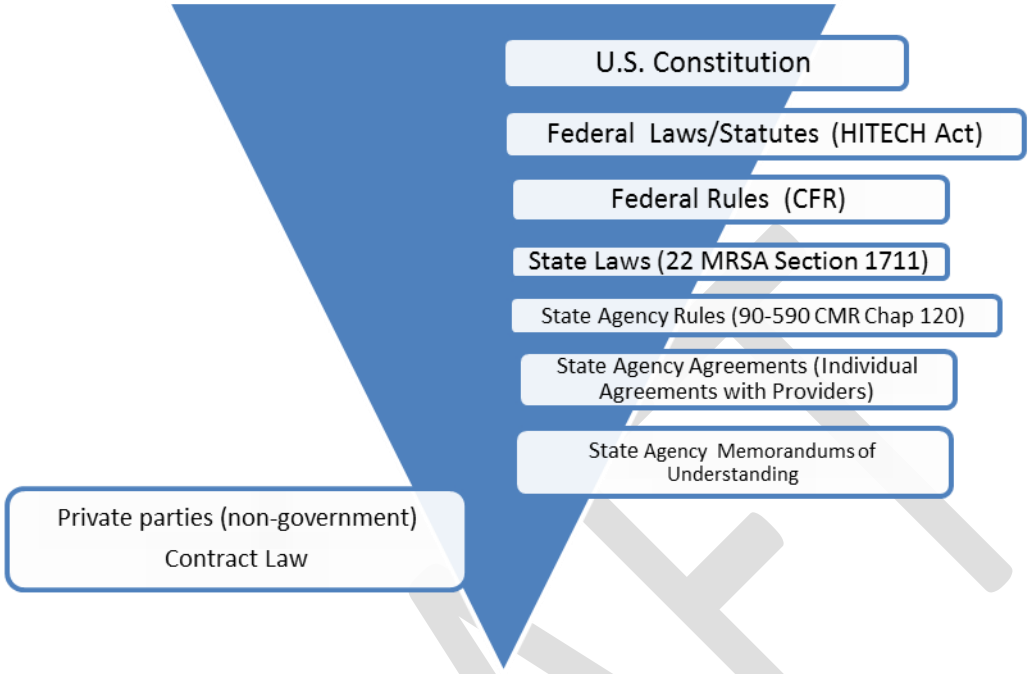
PHI differently based on which one of these categories the PHI falls under. Then, the four categories of PHI are further delineated by the category of use: Informed Consent, Treatment, Payment and Operations (TPO); Public health; Fundraising; Research; and Marketing, because federal and state laws and rules treat PHI differently based on use.

2. Inverted Pyramids -- This is a very high level graphic that displays each of the four categories of information (columns) and the six basic uses of information (rows). "Allowed" disclosure of PHI is at the top of the inverted pyramid, moving down to the "restricted" disclosure and finally the bottom of the pyramid which is "prohibited" without patient consent. (Note: This document is intended as the general rule. It does not depict the exceptions to the general rule.)

3. Detailed Grid – This spreadsheet builds on the inverted pyramid document. The spreadsheet has two tabs: 1) Detailed (General Health, SA, and HIE) and MHDO and HIN/HIE; and 2) Detailed_MH (Shown under separate tab because Maine law differentiates between MH agencies and professionals who may provide MH services as part of their practices).

For each of the four pyramids, it "drills down" to show the federal and the State laws and rules that govern each categories of information (General Health, Mental Health, Substance and Alcohol Abuse, and HIV), and within the category, the laws governing each of the six types of information. It provides a brief summary of the applicability and a cite to the law. In addition, there is a column that is color coded to show "allowed" disclosure as green; "restricted disclosure" as yellow; and "prohibited without consent" as red. (Note: The color coding is intended to show the general rule. There are likely exceptions to the rule.)

III. Hierarchy of Laws



This diagram shows the hierarchy of law. Generally speaking, federal statutes (laws passed by Congress) and federal rules (Federal Agencies, under the authority of their federal statutes, make rules which generally apply across the board to all states), trump state statutes (laws passed by state legislature) and state rules (state agencies, under the authority of their state statutes, make rules which generally apply across the board to all citizens/entities within their state). That is, if a federal rule contradicts a federal law, the law supersedes the rule. If a state law contradicts a federal law or federal rule, the federal law/rule supersedes the state law. If a state rule contradicts a state law (or a federal law/rule) the state law (or federal law/rule) supersedes the state rule. Some federal laws and rules permit states to ask federal agencies for a waiver, exemption, or federal agency action or permission to depart from the general law or rule. Absent that, it takes "an act of Congress" to change a federal law. To change a federal rule would require the federal agency to change the rule. State laws must be changed by legislatures; state rules must be changed by state agencies.

Some federal laws/rules preempt state laws/rules altogether. This means that states must follow only the federal laws/rules and cannot make their own state laws/rules. Some federal laws/rules permit states to layer their own state laws/rules on top of the federal laws/rules, as long as the state law/rule is not inconsistent. For example, let's say that a federal environmental law states that the EPA must make a rule that is protective of shore land development. The EPA makes a rule in accord with APA provisions, that preclude a person from building a factory within say, 50 feet of a large river. The EPA law and rule allow states to provide more protection. So a state passes a

law that prohibits development within 75 feet. The state law is legal because it provides more protection. (A state could not pass a law that only provides a 25 foot protection.) Federal rules must be made according to the federal Administrative Procedures Act (APA), and state rules according to the Maine APA. The APA governs the process and requires agencies to provide notice, allow comments, and to follow designated timelines. In Maine there are two types of rules: 1) Technical which allows the agency head to adopt and implement the rule; and 2) Major Substantive, which allows the agency head to provisionally adopt the rule but requires the rule to go to the Maine legislature and follow the legislative bill process where the legislature may vote to adopt, modify or not-adopt the rule. If the legislative votes to adopt the rule, the rule goes into effect. If the legislature modifies the rule, the modified rule goes into effect. If the legislature votes not to adopt the rule, the rule is void.
Statutes (laws) and adopted rules may be challenged in court. Federal rules are generally challenged in federal court; state laws and rules challenged in state court.
In addition to statutes and rules, agencies may make policies and practices outside the APA process. These policies and practices do not have the same force of law as laws (statutes) passed by the legislature or agency rules adopted under the APA. Agencies may also enter into contracts (enforceable under contract law), agreements (somewhat similar, but sometimes less formal than contracts) and memorandums of understanding (more of agreed upon expectations between the parties). The diagram above places these types or arrangements below that of laws and rules.
Entities that are non-government (private parties), must abide by federal and state laws and rules. In addition, contract and other types of laws provide supplemental legal parameters.

IV. Current Federal and State Laws and Rules

1. HIPAA

HIPAA is a federal law, that is supplemented with federal rules. It is the federal umbrella that governs all four categories of PHI. (General Health, Mental Health, HIV, SA) Having said that it only applies to what are called “covered entities.” (health plans either individual or group plans that provide or pay medical care costs; health care clearinghouses which are entities that standardize formatting which covers billing services, repricing companies, community health management information services, value-added networks if they perform the standardizing services; and every health care provider regardless of size; AND who electronically transmit data). When PHI is used or disclosed to an entity that processes claims, data analysis, utilization review, and billing for covered entities, the entity is a "business associate" (BA) and requires a BA agreement (BAA) which requires the BA to comply with HIPAA.

The use or release or disclosure of de-identified data is not restricted under HIPAA which basically only covers PHI. If PHI is encrypted in a manner proscribed under HIPAA, or consists of a limited data set, or deemed de-identified by a statistician, it can be disclosed without consent.

HIPAA allows states to enact laws and rules that provide more protection than HIPAA. In addition, HIPAA permits states to have what is termed "contrary" laws for limited purposes such as laws requiring providers to report public health types of info, or a law requiring health plan reporting, such as for financial audits and for management. Changes to HIPAA statutes require an act of Congress.

2. Substance Abuse and Alcohol Abuse (Part 2)

In addition to HIPAA, the federal Substance Abuse and Alcohol Abuse (SAA) laws and rules govern SAA PHI. The federal SAA laws and rules preempt state law and rules. This means that states must follow the federal law and rules for Substance Abuse and Alcohol Abuse PHI. In addition to this federal requirement, Maine has laws and rules that state Maine must follow the federal law and rules. Changing the federal laws or rules around SA PHI would be the most difficult of any of the four categories. State laws and rules would also need changing.

3. Mental Health

Other than HIPAA, there are few federal laws and rules on mental health PHI. (Mental Health providers who participate in Medicare, are subject to federal Medicare Communities of Practice (CoPs) governing the privacy and confidentiality of patient information.) Maine does have state laws and rules, and those laws distinguish mental health agencies/professionals licensed by the State as MH providers from health care agencies/professionals who may provide MH services as part of their practices. MH providers have more restrictions on MH PHI than health care providers. Since MH PHI is governed by State laws and rules, from a legal standpoint changing them would be easier than attempting to change federal law or rules. Also note that Maine has had a series of consent decrees that would need to be considered.

4. HIV

Other than HIPAA, there are very few federal laws and rules on HIV. Maine state laws and rules govern HIV PHI, which are summarized in the HIV grid.

5. Maine Health Data Organization (MHDO)

HIPAA laws do not apply because MHDO is not a covered entity nor is it a business associate. Maine's Attorney General's office has advised MHDO that they are a Public Health Authority (PHA), a term created in HIPAA that allows providers and hospitals to submit PHI to the PHA.

MHDO is an independent State agency which means it is not an executive department agency (such as Department of Transportation, Taxation, DHHS). MHDO is governed by a board (consisting of representatives of public and private entities) under the auspices of being a comprehensive health database to improve the health of Maine people.

MHDO has rulemaking authority, some of which are technical rules while others major substantive.

MHDO collects data on claims and finance (per rule, claims data) and in/outpatient, and specific quality indicators (per rule, clinical data). By statute, MHDO, under its vendor Onpoint, sends algorithms to payors who run their provider's data through the algorithm and then submit it to Onpoint who encrypts further and then sends it to MHDO. In this respect, it may be a double encryption.

MHDO must make some de-identified information available to the public and post it on the Web. In addition, entities may request data (in writing per MHDO rules) and requests are approved by Board. Data provided may be unrestricted (receiver may further disclose) or restricted (no further disclosure allowed) depending on the type of data. Most MHDO work is done under provider agreements governed by MHDO rules.

MHDO laws and rules generally do not permit the MHDO to disclose/release PHI. Unless the encryption that MHDO has performed is considered to make the data non-PHI, it is most likely that the MHDO law and certainly, MHDO rules would need to be changed, to allow the MHDO to release PHI.

6. HealthInfoNet and its Health Information Exchange

There are no specific federal laws on HIEs in terms of releasing PHI. There are a few State laws and rules that discuss the term "State Designated HIE" (SDHIE). Currently, by Executive Order, HIN's HIE serves this capacity.

HIN is currently a non-profit non-governmental entity governed by a Board of Directors. It primarily deals in clinical data, and while neither HIN nor its HIE are covered entities, they are considered a Business Associate under HIPAA and enter into BAAs with covered entities. From a practical standpoint, HIN and its HIE are affected by HIPAA law. They also fall under General Health, Mental Health, Substance Abuse and HIV laws and rules.

Since HIN and its HIE are neither federal nor state agencies, they do not have rulemaking authority nor governmental enforcement authority. They have a practice of negotiating private agreements with providers that govern the exchange and release of PHI.

A State law enacted in 2011 (arising from work performed by the LWG), allows the exchange of PHI data as long as the HIE has an opt-out for general health information

and an opt-in for sensitive health information (MH, SAA, and HIV). HIN's HIE follows this opt-out and opt-in practice.

V. Conclusion

The LWG appreciates the opportunity to provide this legal review of PHI laws and rules. Should the LD 1818 Working Group decide to consider different scenarios, the LWG is prepared to provide further review and reporting on changes that would be required based on the scenarios presented.

DRAFT

DEFINITIONS AND GLOSSARY OF TERMS
For LWG Presentation to LD 1818 Working Group
August 16, 2012

1. **HIPAA definitions:**

Business associate: (1) Except as provided in paragraph (2) of this definition, business associate means, with respect to a covered entity, a person who:

(i) On behalf of such covered entity or of an organized health care arrangement (as defined in §164.501 of this subchapter) in which the covered entity participates, but other than in the capacity of a member of the workforce of such covered entity or arrangement, performs, or assists in the performance of:

(A) A function or activity involving the use or disclosure of individually identifiable health information, including claims processing or administration, data analysis, processing or administration, utilization review, quality assurance, billing, benefit management, practice management, and repricing; or

(B) Any other function or activity regulated by this subchapter; or

(ii) Provides, other than in the capacity of a member of the workforce of such covered entity, legal, actuarial, accounting, consulting, data aggregation (as defined in §164.501 of this subchapter), management, administrative, accreditation, or financial services to or for such covered entity, or to or for an organized health care arrangement in which the covered entity participates, where the provision of the service involves the disclosure of individually identifiable health information from such covered entity or arrangement, or from another business associate of such covered entity or arrangement, to the person.

(2) A covered entity participating in an organized health care arrangement that performs a function or activity as described by paragraph (1)(i) of this definition for or on behalf of such organized health care arrangement, or that provides a service as described in paragraph (1)(ii) of this definition to or for such organized health care arrangement, does not, simply through the performance of such function or activity or the provision of such service, become a business associate of other covered entities participating in such organized health care arrangement.

(3) A covered entity may be a business associate of another covered entity. § 160.103

Direct treatment relationship *means a treatment relationship between an individual and a health care provider that is not an indirect treatment relationship. § 164.501*

Disclosure *means the release, transfer, provision of, access to, or divulging in any other manner of information outside the entity holding the information. § 160.103*

De-identified health information *is health information that does not identify an individual and with respect to which there is no reasonable basis to believe that the information can be used to identify an individual. Information can be de-identified using statistical methods (45 C.F.R. § 164.514(b)(1) or by removing specific information set in the HIPAA rules (45 C.F.R. § 164.514(b)(2).*

Health care operations means any of the following activities of the covered entity to the extent that the activities are related to covered functions:

(1) Conducting quality assessment and improvement activities, including outcomes evaluation and development of clinical guidelines, provided that the obtaining of generalizable knowledge is not the primary purpose of any studies resulting from such activities; population-based activities relating to improving health or reducing health care costs, protocol development, case management and care coordination, contacting of health care providers and patients with information about treatment alternatives; and related functions that do not include treatment;

(2) Reviewing the competence or qualifications of health care professionals, evaluating practitioner and provider performance, health plan performance, conducting training programs in which students, trainees, or practitioners in areas of health care learn under supervision to practice or improve their skills as health care providers, training of non-health care professionals, accreditation, certification, licensing, or credentialing activities;

(3) Underwriting, premium rating, and other activities relating to the creation, renewal or replacement of a contract of health insurance or health benefits, and ceding, securing, or placing a contract for reinsurance of risk relating to claims for health care (including stop-loss insurance and excess of loss insurance), provided that the requirements of §164.514(g) are met, if applicable;

(4) Conducting or arranging for medical review, legal services, and auditing functions, including fraud and abuse detection and compliance programs;

(5) Business planning and development, such as conducting cost-management and planning-related analyses related to managing and operating the entity, including formulary development and administration, development or improvement of methods of payment or coverage policies; and

(6) Business management and general administrative activities of the entity, including, but not limited to:

(i) Management activities relating to implementation of and compliance with the requirements of this subchapter;

(ii) Customer service, including the provision of data analyses for policy holders, plan sponsors, or other customers, provided that protected health information is not disclosed to such policy holder, plan sponsor, or customer.

(iii) Resolution of internal grievances;

(iv) The sale, transfer, merger, or consolidation of all or part of the covered entity with another covered entity, or an entity that following such activity will become a covered entity and due diligence related to such activity; and

(v) Consistent with the applicable requirements of §164.514, creating de-identified health information or a limited data set, and fundraising for the benefit of the covered entity.
§ 164.501

Health plan means an individual or group plan that provides, or pays the cost of, medical care (as defined in section 2791(a)(2) of the PHS Act, 42 U.S.C. 300gg–91(a)(2)).

(1) Health plan includes the following, singly or in combination:

(i) A group health plan, as defined in this section.

(ii) A health insurance issuer, as defined in this section.

(iii) An HMO, as defined in this section.

(iv) Part A or Part B of the Medicare program under title XVIII of the Act.

(v) The Medicaid program under title XIX of the Act, 42 U.S.C. 1396, et seq.

(vi) An issuer of a Medicare supplemental policy (as defined in section 1882(g)(1) of the Act, 42 U.S.C. 1395ss(g)(1)).

(vii) An issuer of a long-term care policy, excluding a nursing home fixed-indemnity policy.

(viii) An employee welfare benefit plan or any other arrangement that is established or maintained for the purpose of offering or providing health benefits to the employees of two or more employers.

(ix) The health care program for active military personnel under title 10 of the United States Code.

(x) The veterans health care program under 38 U.S.C. chapter 17.

(xi) The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) (as defined in 10 U.S.C. 1072(4)).

(xii) The Indian Health Service program under the Indian Health Care Improvement Act, 25 U.S.C. 1601, et seq.

(xiii) The Federal Employees Health Benefits Program under 5 U.S.C. 8902, et seq.

(xiv) An approved State child health plan under title XXI of the Act, providing benefits for child health assistance that meet the requirements of section 2103 of the Act, 42 U.S.C. 1397, et seq.

(xv) The Medicare+Choice program under Part C of title XVIII of the Act, 42 U.S.C. 1395w–21 through 1395w–28.

(xvi) A high risk pool that is a mechanism established under State law to provide health insurance coverage or comparable coverage to eligible individuals.

(xvii) Any other individual or group plan, or combination of individual or group plans, that provides or pays for the cost of medical care (as defined in section 2791(a)(2) of the PHS Act, 42 U.S.C. 300gg–91(a)(2)).

(2) *Health plan excludes*:

(i) Any policy, plan, or program to the extent that it provides, or pays for the cost of, excepted benefits that are listed in section 2791(c)(1) of the PHS Act, 42 U.S.C. 300gg–91(c)(1); and

(ii) A government-funded program (other than one listed in paragraph (1)(i)–(xvi) of this definition):

(A) Whose principal purpose is other than providing, or paying the cost of, health care; or

(B) Whose principal activity is:

(1) The direct provision of health care to persons; or

(2) The making of grants to fund the direct provision of health care to persons. § 160.103

Indirect treatment relationship means a relationship between an individual and a health care provider in which:

(1) The health care provider delivers health care to the individual based on the orders of another health care provider; and

(2) The health care provider typically provides services or products, or reports the diagnosis or results associated with the health care, directly to another health care provider, who provides the services or products or reports to the individual. § 164.501

Marketing means:

(1) To make a communication about a product or service that encourages recipients of the communication to purchase or use the product or service, unless the communication is made:

(i) To describe a health-related product or service (or payment for such product or service) that is provided by, or included in a plan of benefits of, the covered entity making the communication, including communications about: the entities participating in a health care provider network or health plan network; replacement of, or enhancements to, a health plan; and health-related products or services available only to a health plan enrollee that add value to, but are not part of, a plan of benefits.

(ii) For treatment of the individual; or

(iii) For case management or care coordination for the individual, or to direct or recommend alternative treatments, therapies, health care providers, or settings of care to the individual.

(2) An arrangement between a covered entity and any other entity whereby the covered entity discloses protected health information to the other entity, in exchange for direct or indirect remuneration, for the other entity or its affiliate to make a communication about its own product or service that encourages recipients of the communication to purchase or use that product or service. § 164.501

Payment means:

(1) The activities undertaken by:

(i) A health plan to obtain premiums or to determine or fulfill its responsibility for coverage and provision of benefits under the health plan; or

(ii) A health care provider or health plan to obtain or provide reimbursement for the provision of health care; and

(2) The activities in paragraph (1) of this definition relate to the individual to whom health care is provided and include, but are not limited to:

(i) Determinations of eligibility or coverage (including coordination of benefits or the determination of cost sharing amounts), and adjudication or subrogation of health benefit claims;

(ii) Risk adjusting amounts due based on enrollee health status and demographic characteristics;

(iii) Billing, claims management, collection activities, obtaining payment under a contract for reinsurance (including stop-loss insurance and excess of loss insurance), and related health care data processing;

(iv) Review of health care services with respect to medical necessity, coverage under a health plan, appropriateness of care, or justification of charges;

(v) Utilization review activities, including precertification and preauthorization of services, concurrent and retrospective review of services; and

(vi) Disclosure to consumer reporting agencies of any of the following protected health information relating to collection of premiums or reimbursement:

(A) Name and address;

(B) Date of birth

(C) Social security number;

(D) Payment history;

(E) Account number; and

(F) Name and address of the health care provider and/or health plan.

§ 164.501

Protected health information means individually identifiable health information:

(1) Except as provided in paragraph (2) of this definition, that is:

(i) Transmitted by electronic media;

(ii) Maintained in electronic media; or

(iii) Transmitted or maintained in any other form or medium.

(2) Protected health information excludes individually identifiable health information in:

(i) Education records covered by the Family Educational Rights and Privacy Act, as amended, 20 U.S.C. 1232g;

(ii) Records described at 20 U.S.C. 1232g(a)(4)(B)(iv); and

(iii) Employment records held by a covered entity in its role as employer.

§ 160.103

Public health authority *means an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate. § 164.501*

Required by law *means a mandate contained in law that compels an entity to make a use or disclosure of protected health information and that is enforceable in a court of law.Required by law includes, but is not limited to, court orders and court-ordered warrants; subpoenas or summons issued by a court, grand jury, a governmental or tribal inspector general, or an administrative body authorized to require the production of information; a civil or an authorized investigative demand; Medicare conditions of participation with respect to health care providers participating in the program; and statutes or regulations that require the production of information, including statutes or regulations that require such information if payment is sought under a government program providing public benefits. § 164.501*

Research *means a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge. § 164.501*

Treatment *means the provision, coordination, or management of health care and related services by one or more health care providers, including the coordination or management of health care by a health care provider with a third party; consultation between health care providers relating to a patient; or the referral of a patient for health care from one health care provider to another. § 164.501*

Use *means, with respect to individually identifiable health information, the sharing, employment, application, utilization, examination, or analysis of such information within an entity that maintains such information. § 160.103*

2. **42 CFR Part 2 definitions:**

Alcohol abuse means the use of an alcoholic beverage which impairs the physical, mental, emotional, or social well-being of the user. 42 C.F.R. § 2.11
Drug abuse means the use of a psychoactive substance for other than medicinal purposes which impairs the physical, mental, emotional, or social well-being of the user. 42 C.F.R. § 2.11

Disclose *or* ***disclosure*** *means a communication of patient identifying information, the affirmative verification of another person's communication of patient identifying information, or the communication of any information from the record of a patient who has been identified. 42 C.F.R. § 2.11*

Federal assistance. An alcohol abuse or drug abuse program is considered to be federally assisted if:

(1) It is conducted in whole or in part, whether directly or by contract or otherwise by any department or agency of the United States (but see paragraphs (c)(1) and (c)(2) of this section relating to the Veterans' Administration and the Armed Forces);

(2) It is being carried out under a license, certification, registration, or other authorization granted by any department or agency of the United States including but not limited to:

(i) Certification of provider status under the Medicare program;

(ii) Authorization to conduct methadone maintenance treatment (see 21 CFR 291.505); or

(iii) Registration to dispense a substance under the Controlled Substances Act to the extent the controlled substance is used in the treatment of alcohol or drug abuse;

(3) It is supported by funds provided by any department or agency of the United States by being:

(i) A recipient of Federal financial assistance in any form, including financial assistance which does not directly pay for the alcohol or drug abuse diagnosis, treatment, or referral activities; or

(ii) Conducted by a State or local government unit which, through general or special revenue sharing or other forms of assistance, receives Federal funds which could be (but are not necessarily) spent for the alcohol or drug abuse program; or

(4) It is assisted by the Internal Revenue Service of the Department of the Treasury through the allowance of income tax deductions for contributions to the program or through the granting of tax exempt status to the program. 42 C.F.R. § 2.12(a)

Patient identifying information *means the name, address, social security number, fingerprints, photograph, or similar information by which the identity of a patient can be determined with reasonable accuracy and speed either directly or by reference to other publicly available information. The term does not include a number assigned to a patient by a program, if that number does not consist of, or contain numbers (such as a social security, or driver's license number) which could be used to identify a patient with reasonable accuracy and speed from sources external to the program. 42 C.F.R. § 2.11*

Program director *means:*

(a) In the case of a program which is an individual, that individual:

(b) In the case of a program which is an organization, the individual designated as director, managing director, or otherwise vested with authority to act as chief executive of the organization. 42 C.F.R. § 2.11

Records *means any information, whether recorded or not, relating to a patient received or acquired by a federally assisted alcohol or drug program. 42 C.F.R. § 2.11*

Treatment *means the management and care of a patient suffering from alcohol or drug abuse, a condition which is identified as having been caused by that abuse, or both, in order to reduce or eliminate the adverse effects upon the patient. 42 C.F.R. § 2.11*

3. **22 M.R.S. §1711-C definitions:**

Disclosure means the release, transfer of or provision of access to health care information in any manner obtained as a result of a professional health care relationship between the individual and the health care practitioner or facility to a person or entity other than the individual. 22 M.R.S. §1711-C(1)(B).

Health care information means information that directly identifies the individual and that relates to an individual's physical, mental or behavioral condition, personal or family medical history or medical treatment or the health care provided to that individual. "Health care information" does not include information that protects the anonymity of the individual by means of encryption or encoding of individual identifiers or information pertaining to or derived from federally sponsored, authorized or regulated research governed by 21 Code of Federal

Regulations, Parts 50 and 56 and 45 Code of Federal Regulations, Part 46, to the extent that such information is used in a manner that protects the identification of individuals. The Board of Directors of the Maine Health Data Organization shall adopt rules to define health care information that directly identifies an individual. Rules adopted pursuant to this paragraph are routine technical rules as defined in Title 5, chapter 375, subchapter II-A.

"*Health care information*" does not include information that is created or received by a member of the clergy or other person using spiritual means alone for healing as provided in Title 32, sections 2103 and 3270. 22 M.R.S. §1711-C(1)(E).
Health care practitioner means a person licensed by this State to provide or otherwise lawfully providing health care or a partnership or corporation made up of those persons or an officer, employee, agent or contractor of that person acting in the course and scope of employment, agency or contract related to or supportive of the provision of health care to individuals. 22 M.R.S. §1711-C(1)(F).

4. **MHDO**

22 MRSASection 8702. DEFINITIONS

2. **Clinical data.** "Clinical data" includes but is not limited to the data required to be submitted by providers and payors pursuant to sections 8708 and 8711.
4. **Health care facility.** "Health care facility" means a public or private, proprietary or not-for-profit entity or institution providing health services … licensed by DHHS, but not pharmacies.
.
4-A. **Health care practitioner.** "Health care practitioner" has the meaning provided in Title 24, section 2502, subsection 1-A.

90-590 Chap 120: release of data
2. Definitions:
B. Clinical Data. "Clinical data" mean health care claims, hospital, non-hospital health care facility data, quality data, and all other data as described in 22 M.R.S.A. Secs. 8708, 8708-A, and 8711.

E. Disclosure. "Disclosure," with respect to clinical, financial, or restructuring data, means to communicate information to a person not already in possession of that information or to use information for a purpose not originally authorized. For example, to inform a person of the identity of a previously unnamed patient is to "disclose" clinical data not already in that person's possession with respect to the patient.

G. Financial Data. "Financial data" means information collected from data providers pursuant to Chapter 300 of the MHDO rules, *Uniform Reporting System for Hospital Financial Data*, that include, but are not limited to, costs of operation, revenues, assets, liabilities, fund balances, other income, rates, charges and units of services.

H. **Health Care Claims Data**. “Health care claims data” means information consisting of or derived directly from member eligibility, medical claims, pharmacy claims, and/or dental claims files submitted by health care claims processors pursuant to Chapter 243 of the MHDO’s rules, *Uniform Reporting System for Health Care Claims Data Sets*. “Health care claims data” do not include analysis, reports, or studies containing information from health care claims data sets, if those analyses, reports, or studies have already been released in response to another request for information or as part of a general distribution of public information

J. Health Care Facility. “Health care facility” means a public or private, proprietary or not-for-profit entity or institution providing health services and which is licensed by State.

K. Health Care Practitioner. "Health care practitioner" means physicians and all others certified, registered or licensed in the healing arts, including but not limited to, nurses, podiatrists, optometrists, pharmacists, chiropractors, physical therapists, dentists, psychologists and physicians’ assistants as defined in 24 M.R.S.A., chapter 21. "Health care practitioner" also includes licensed clinical social workers as defined in 32 M.R.S.A., chapter 83 and marriage and family therapists and professional counselors as defined in 32 M.R.S.A., chapter 119.

L.. Hospital Data. "Hospital data" means information consisting of or derived directly from hospital inpatient, outpatient, emergency department, or any other derived data sets filed or maintained pursuant to Chapter 241 of the MHDO’s rules, *Uniform Reporting System for Hospital Inpatient and Hospital Outpatient Data Sets*. "Hospital data" do not include analysis, reports, or studies containing information from hospital data sets, if those analyses, reports, or studies have already been released in response to another request for information or as part of a general distribution of public information by the MHDO.

N. **MHDO Records**.

1. "MHDO record" means any item of data stored in written, printed, graphic, or electronic form that is either:

(b) filed with the MHDO or its designee by a data provider in accordance with a requirement of statute, rule or MHDO order;

(d) contained in a final MHDO report, analysis, study, data compilation, decision, rule, or order;

2. "MHDO record" does not include any of the following:

(b) draft documents of any kind, including unsigned or incomplete memoranda, decisions, rules or other papers; nor

(c) reports studies, analyses, or data compilations that have not yet been reviewed for public release pursuant to section 9 or 10.

R. Privileged Medical Information. "Privileged medical information" means information other than hospital, non-hospital health care facility, or health care claims data that identify individual patients and that are derived from communications that:

1. were made for the purpose of diagnosis or treatment among a provider of health care, persons assisting the provider or patient, and a patient;

2. were made for the purpose of payment of health care services among a provider of health care, a health care claims processor, and a patient;

3. were not intended to be disclosed except to persons necessary to transmit or record the communication and persons participating in the diagnosis, treatment, or payment; and

4. have not been previously disclosed to the general public.

U. Release. To "release" data is to make it available for inspection and copying to persons other than the data provider.

90-590 MAINE HEALTH DATA ORGANIZATION, Chapter 125: HEALTH CARE INFORMATION THAT DIRECTLY IDENTIFIES AN INDIVIDUAL

C. **Direct Identifier**. "Direct identifier" means any information that discloses the identity of an individual. A case or code number used to create anonymous or encrypted medical data for research purposes is not a direct identifier

3. Identifying Information

Data elements determined to be direct identifiers of individuals include the following:

A. Patient's Name;
B. Names of Patient's Family Members;
C. Insured's Name;
D. Patient's or Insured's Address;
E. Patient's or Insured's Telephone or FAX Numbers. Includes both home and work numbers;
F. Patient Control Number. A unique alphanumeric number assigned by a health care provider to facilitate retrieval of individual financial records and posting of payment;
G. Medical Record Number. A number assigned to the patient's medical/health record by the provider;
H. Patient's Account Number. A unique number used by a health care provider or supplier to identify an individual's case records and for posting payment;
I. Patient's or Insured's Social Security Number;

J. Insured's Unique Health Insurance Identification Number;
K. Insured's Unique Health Insurance Certificate Number;
L. Patient's Medicare/Medicaid Health Insurance Identification Number;
M. Patient's Federal Employees Compensation Act Number;
N. Patient's or Insured's Credit Card Number;
O. Patient's or Insured's Bank Account Number;
P. Patient's or Insured's Operator's License Number;
Q. Patient's or Insured's Vehicle Registration Number;
R. Patient's or Insured's Vehicle License Plate Number;
S. Patient's or Insured's Vehicle Identification Number;
T. Patient's or Insured's Finger or Voice Prints;
U. Patient's or Insured's Photographic Images;
V. Patient's Pilot Medical Certificate Number;
W. Patient's Maine Department of Corrections Inmate Identification Number;
X. Patient's or Insured's Medical Device Identifiers and Serial Numbers; and
Y. Any other unique number, characteristic, code or information that is a direct identifier.

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Appendix G: Matrix of Laws for Protected Health Information

MATRIX OF LAWS FOR PHI			
	GENERAL HEALTH		
CATEGORY OF INFO.	Allowed Restricted Prohibited	Federal Law	Maine Law
Applicability		HIPAA rules include a security rule and a privacy rule for "covered entity (CE)." (45 C.F.R. § 164.302); (45 C.F.R. §§ 164.n104, 164.500). CE is a "health plan" (individual or group plans that provide or pay medical care costs), health care clearinghouse (entities that standardize formatting (covers billing services, repricing companies, community health management information services, value-added networks if they perform the standardizing services), and every health care provider regardless of size AND who electronically transmits data). Covered entity is permitted, but not required to use and disclose PHI w/o consent to 1) individual; 2) TPO; 3) Opportunity to agree or object; 4) incident to otherwise permitted use and disclosure; 5) public interest and benefit activities; and 6) limited data set for research, public health or operations. When PHI is used or disclosed to entity that processes claims, data analysis, utilization review, and billing, the receiving entity is a "business associate" and requires a BA agreement (BAA). Expanded under ARRA/HITECH Act, to a BA with access to covered entity's PHI is bound by same HIPAA provisions as covered entity. (42 U.S.C. §17931(a)) Generally, whenever using, disclosing, or requesting PHI, a covered entity must make reasonable efforts to limit PHI to the minimum necessary to accomplish the intended use. (45 C.F.R. §164.502(b).	Health Care Facilities (22 M.R.S. §1711-C(1)(D)); Health Care Practitioners (22 M.R.S. §1711-C(1)(F). Note: Maine's Privacy laws were written before federal privacy laws. Terms such as use or disclosure and release add ambiguity when trying to compare federal and state law. HIPAA law preempts state law, but allows states to have laws that provide more protection or laws that are termed "contrary" such as laws requiring provider to report public health types of info, or a law requiring health plans to report info for financial audits and for management.
Treatment, Payment, Operations	A	Entity with PHI can disclose to a receiving entity with a direct treatment relationship to patient; an entity with a direct treatment relationship can use PHI for treatment, payment, and operations purposes. (HIPAA / 45 CFR 164.502(a)(1)(ii)).	Health Care Facilities and Health Care Practitioners can disclose PHI to another Health Care Facility or Practitioner for diagnosis, treatment, or care of individuals (22 M.R.S.A. §1711-C(6)(A)); can disclose for payment (22 M.R.S.A. §1711-C(6)(L).
Public Health	R	Can disclose minimum amount of PHI necessary to Public Health Authority authorized by law to collect PHI for the purpose of preventing or controlling disease, injury, disability (HIPAA / 45 CFR 164.512(b)(1)(i)); can rely on PHA's finding of minimum amount necessary (45 CFR 164.514(d)(3)(iii) (A)); no patient authorization is needed.	Can be disclosed to gov't in order to protect the public health and welfare when reporting is required or authorized by law (22 M.R.S. §1711-C(6)(E))

Research	**R**	Can disclose with IRB approval (45 CFR 164.512(i)(1)(i)) to prepare for research if PHI is not removed from covered entity (45 CFR 164.512(i)(1)(ii)); Limited data sets may be disclosed under data use agreements (45 CFR 164.514(e)).	Can disclose PHI to IRB-approved researchers, FDA clinical trials without patient authorization; researchers may not redisclose identifiable PHI (22 M.R.S. §1711-C(6)(G). Other research requires patient authorization (22 M.R.S. §1711-C(3),(3-A), (3-B)); max duration of authorization: 30 months
Fundraising	**R**	45 CFR 164.501(6)(v) includes fundraising for benefit of covered entity as "operations" use; disclosure of demographic info & dates of care is allowed to BA or institutionally related foundation for fundraising purposes (45 CFR §164.514(f)).	Law does not expressly address; therefore disclosure to persons other than patient for fundraising is prohibited; practitioners interpreted law to allow internal use for fundraising and for provider entities to directly solicit donations from patients but not from other persons; LWG opinion is that internal fundraising use doesn't constitute a disclosure.
Marketing	**P**	Covered entities can't use PHI for marketing without patient authorization (45 CFR 164.501, 508(a)3	Requires patient authorization (22 M.R.S. §1711-C(8))
SUBSTANCE ABUSE (Providers receiving federal assistance)			
CATEGORY OF INFORMATION	**A, R, P**	**Federal Law**	**Maine Law**
Applicability		In addition to HIPAA, SA laws apply only to drug or alcohol abuse (DAA) info obtained by "federally assisted" DAA for diagnosis/treating/making referral DAA. 42 C.F.R. § 2.12(a)(ii); Federally assisted means: (1) conducted in whole or in part, directly or by contract or otherwise, by any dept/agency of US; (2) carried out under a license, certification, registration, or other authorization under Medicare; (3) methadone treatment; (4) dispense a controlled substance for DAA; (5) supported by US agency (i) by federal financial assistance not used directly pay for SAA diagnosis, treatment, or referral activities; or (ii) by State/local gov through general or special revenue sharing or other forms of assistance, receives Federal funds which could be (but are not necessarily) spent for the alcohol or drug abuse program; or (iii.) IRS allowing income tax deductions for contributions/ tax exempt status . 42 C.F.R. § 2.12(b)	Federal law governs (22 M.R.S.A. 1711-C(11)), but State licensing rules also apply; 14-118 CMR Chap 5, Section 15.2.2 and 18.4 (SA licensing rules)
Treatment, Payment, Operations	**R**	Only with patient consent (allowed: § 2.33; specific form of consent required: § 2.31) or for medical emergencies (42 CFR § 2.51)	22 M.R.S.A. §1711-C(11) states if there is another law, that law governs. So federal rule controls.
Public Health	**R**	Disclosure and use are allowed for gov't audit & evaluation of the program (42 C.F.R. § 2.53(a)); Auditors can disclose only that PHI necessary for audit or evaluation purposes (42 C.F.R. § 2.53(c)(4)).	22 M.R.S.A. §1711-C(11) states if there is another law, that law governs. So federal rule controls.
Research	**R**	Allowed if "required determination" (complex and lengthy process) is made under 42 C.F.R. § 2.52 by the substance abuse program director. Researchers may only disclose PHI back to program where PHI originated (42 C.F.R. § 2.52(b)).	22 M.R.S.A. §1711-C(11) states if there is another law, that law governs. So federal rule controls.
Fundraising	**P**	Rules are silent, given that intent of law is to prohibit use & disclosure except when specified (42 C.F.R. § 2.3(b)); LWG opinion is that fundraising use or disclosure would require patient consent.	22 M.R.S.A. §1711-C(11) states if there is another law, that law governs. So federal rule controls.

Marketing	**P**	Prohibited without patient authorization (42 U.S.C. §290ee-3, 42 U.S.C. §290dd-3; 42 C.F.R. Part 2)).	22 M.R.S.A. §1711-C(11) states if there is another law, that law governs. So federal rule controls.
HIV			
CATEGORY OF INFORMATION	**A, R, P**	**Federal Law**	**Maine Law**
Applicability		There is no specific federal HIV law. HIPAA rules for General Health apply.	Applies to any person or entity with HIV PHI (5 M.R.S. §19203)
Treatment, Payment, Operations	**R**	Entity with PHI can disclose to a receiving entity with a direct treatment relationship to patient; an entity with a direct treatment relationship can use PHI for treatment, payment, and operations purposes. (HIPAA / 45 CFR 164.502(a)(1)(ii)).	HIV test results can only be disclosed to entities designated by patient (5 M.R.S. §19203); health care providers may not disclose HIV PHI without patient authorization (statute 5 M.R.S. §19203-D(1)); doesn't preclude disclosure of other PHI (5 M.R.S. §19203-D(1)(B)). (Note: There are a few exceptions that permit disclosure in very limited situations)
Public Health	**R**	Can disclose minimum amount of PHI necessary to Public Health Authority authorized by law to collect PHI for the purpose of preventing or controlling disease, injury, disability (HIPAA / 45 CFR 164.512(b)(1)(i)); can rely on PHA's finding of minimum amount necessary (45 CFR 164.514(d)(3)(iii) (A)); no patient authorization is needed.	Notifiable diseases, which includes HIV, must be reported to DHHS (statute 22 M.R.S.A §822); and DHHS rule 10-144 C.M.R. Chapter 258(2)(I)) and some very limited exceptions that would permit disclosure such as abuse, organ & tissue donation, etc.
Research	**R**	Can disclose with IRB approval (45 CFR 164.512(i)(1)(i)) to prepare for research if PHI is not removed from covered entity (45 CFR 164.512(i)(1)(ii)); Limited data sets may be disclosed under data use agreements (45 CFR 164.514(e)).	Can disclose to researchers; researchers can't subsequently disclose (statute 5 M.R.S.A. §19203-D(3);
Fundraising	**R**	45 CFR 164.501(6)(v) includes fundraising for benefit of covered entity as "operations" use; disclosure of demographic info & dates of care is allowed to BA or institutionally related foundation for fundraising purposes (45 CFR §164.514(f)).	5 M.R.S. §§ 19203 - 19203-D prohibit fundraising use & disclosure without patient authorization.
Marketing	**P**	Covered entities can't use PHI for marketing without patient authorization (45 CFR 164.501, 164.508(a)(3)).	Prohibited without patient authorization (Statute 5 M.R.S. §19203; 5 M.R.S.A. § 19203-D)

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	MHDO		
CATEGORY OF INFORMATION	**A, R, P**	**Federal Law**	**State Law**
Applicability		HIPAA laws do not apply because MHDO is not a covered entity. Maine's Attorney General's office has advised MHDO that they are a Public Health Authority, a term created in HIPAA that allows providers and hospitals to submit PHI to the PHA. (45 CFR 164.512(b) and 160.103).	MHDO is independent State agency (22 M.R.S. §8707(3)) governed by board; has rulemaking authority; most MHDO work done under provider agreements governed by MHDO rules. (90-590 CMR Chapter 120, §9 (D)). General notion is comprehensive health database to improve health of Maine people. Collects data on claims and finance (per rule, claims data) and in/outpatient, and specific quality indicators (per rule, clinical data). By statute, MHDO, under its vendor Onpoint, sends algorithm to payors who run their provider's data through algorithm and submit to Onpoint who encrypts further and sends to MHDO. (Rule, Chapter 243) In effect, double encryption. Must make info available to the public. In addition, entities must request data in writing per MHDO rules, and requests are approved by Board. Data provided may be unrestricted (receiver may further disclose) or restricted (no further disclosure allowed) depending on the type of data.
Treatment, Payment, Operations			Under Public Access (22 M.R.S.A.) Board must release information upon request and on web (quality measures) except privileged medical information and confidential information which can only be released if individual patients are not directly or indirectly identified through a reidentification process; additional protective protocols apply.
Public Health			There is an exception to the confidentiality law for Public Health Studies (including research) or when data is used only for verification or comparison of health data and Board finds that adequate protections exist.
Research			There is an exception to the confidentiality law for Public Health Studies (including research) or when data is used only for verification or comparison of health data and Board finds that adequate protections exist.
Fundraising			Not allowed
Marketing			Not allowed
	HIN's HIE		

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	A, R, P	Federal Law	State Law
CATEGORY OF INFORMATION			
Applicability		No specific federal law on HIEs. HIN / HIE is not a covered entity--it is a Business Associate under HIPAA and enters into BAAs, so from practical standpoint, is affected by HIPAA law.	SDHIE created by Executive Order. Confidentiality Statute covers SDHIE even though SDHIE not defined in law. (22 §1711-C.) No rulemaking authority. Practice is private agreements with providers govern exchange/release.
Treatment, Payment, Operations			May disclose w/o authorization if HIE has opt-out for general health information (HIE does have opt-out); based on this opt-out, may disclose for quality assurance, utilization review, billing and collection, regulatory or licensing authority; For MH and SA, HIE is opt-in. Only patients who opt-in for MH have their MH PHI disclosed. Currently, even if patient has opt-in for SA, HIN blocks SA PHI.
Public Health			May disclose to protect the public health and welfare when required or authorized by law
Research			By practice, they do not disclose for research
Fundraising			By practice, they do not disclose for fundraising.
Marketing			By practice, they do not disclose for marketing

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