

LD1818 Resolve, Voice of the Customer (VOC)

This document provides a framework for LD 1818's sub-committee work. It begins by reiterating the four key areas of the 1818 Working Group, followed by four themes that emerged from the VOC responses. It is expected that members of the 1818 Working Group will volunteer to participate in one or more of the sub-committees. There will be further discussion of this framework at the August 16th meeting.

I. 4 Key Areas of Focus for 1818 Working Group

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

II. Themes from VOC responses

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 Data Processing Structures and Protocols 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 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.

- 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 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.