Report to the Maine Health Data Organization Board of Directors

From the Maine Health Data Organization Subcommittee on Consumer Information

September 5, 2013

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I. Background

The purpose of the Maine Health Data Organization (MHDO) is to create and maintain a useful, objective, reliable, and comprehensive health information database that is used to improve the health of Maine citizens. In response to recommendations included in the report of the multistakeholder group convened by the Maine Legislature to evaluate the All-Payer Claims Database (APCD) pursuant to Resolve Chapter 109 (2011), ("the L.D. 1818 Workgroup"), the MHDO Board of Directors established the MHDO Subcommittee on Consumer Information on April 3, 2013 (the "Consumer Subcommittee" or the "Subcommittee" or "Advisory Committee") to develop and provide recommendations to the MHDO Board at the Board's retreat in August 2013. The Subcommittee report date was later rescheduled for the September MHDO Board meeting.

The Charge of the Consumer Subcommittee is as follows:

- Review MHDO's HealthCost tool for functionality and user friendliness and make recommendations for improvement
- Create a comprehensive and specific list of what information is available to consumers from MHDO
- Develop recommendations for a low cost awareness campaign to educate Maine people about the value of what is currently available through MHDO
- Consider appropriate next steps for the Board to advance the goals of consumer education and engagement at no additional cost to the agency

II. Advisory Committee Members

In April, the MHDO Board appointed the members of the Consumer Subcommittee representing a multi–stakeholder composition of providers, employers, consumers, and health plans. The members of the Subcommittee are:

- Poppy Arford, (Co-Chair) Consumer
- Andy Ellis, (Co-Chair)
 Anthem Blue Cross and Blue Shield
- Lisa Harvey-McPherson
 Eastern Maine Healthcare Systems
- Tom Hopkins University of Maine System

Staff to the Subcommittee: Karynlee Harrington, Maine Health Data Organization

III. Issues Considered by the Advisory Committee and Related Recommendations

A. LD 1818 Voice of the Customer Feedback

The Subcommittee reviewed the report of the LD 1818 Workgroup with special attention to the "Voice of the Customer" section compiling public comments solicited by the workgroup. Of the comments pertaining to consumer use and access to health information, several motifs emerged. The subcommittee referred to these themes and areas of interest, as outlined below, throughout their work.

- 1. Accurate, timely information that is easy to understand in order to make informed choices about personal healthcare, and foster transparency and accountability on the part of healthcare providers.
- 2. Improving the experience of users accessing data through the HealthCost website.
- 3. Avoiding duplication of existing data resources.
- 4. Broadening awareness of the availability of data from the APCD

For further information see A. LD 1818 Resolve, Voice of the Customer (VOC) in the Supporting Documents section.

B. Consumer Definitions

The Subcommittee discussed the importance of defining the term healthcare "Consumer" as this was considered a basic component of the subcommittee's charge. Accordingly, the following definition was drafted and revised by the Subcommittee to aid in the understanding of its recommendations.

Consumer: Healthcare consumer describes anyone who may utilize healthcare goods and services.

The subcommittee also reviewed related terms including consumer representative and consumer engagement. For further information on these terms see E. Healthcare Consumer Descriptions in the Supporting Documents Section.

Additionally, although the focus of the Subcommittee charge was on consumer access to and use of MHDO data the subcommittee discussed and acknowledged the multi stakeholder (i.e. providers, researchers and other users) interest in improved web access to MHDO data.

C. Overview of Information and Resources Currently Available to Consumers

The Subcommittee reviewed information and resources currently available to consumers through the MHDO's website. Currently consumers have access to:

HealthCost

Average Statewide Procedure Payments and Charges - Provides statewide charge and payment information across all insurance carriers and all medical providers for 29 of the more common "shopable" procedures in the following categories: imaging, preventive health, radiology and surgery. Included are amounts for the professional (provider) portion and for the facility (e.g. hospital) portion of a procedure.

Each procedure has a histogram- A histogram is a graphical display of data. This graph represents the distribution of dollars paid for each patient encounter where the procedure occurred.

Procedure Payments for the Insured - Provides an estimate of total dollars paid by specific commercial health insurance companies at various facilities in Maine for 29 of the more common "shopable" procedures in the following categories: imaging, preventive health, radiology and surgery.

Estimated Procedure Charges for the Uninsured - Provides an estimate of the median charge at various facilities in Maine for 29 of the more common "shopable" procedures in the following categories: imaging, preventive health, radiology and surgery.

MONAHRQ (My Own Network, Powered by the Agency for Healthcare Research and Quality)

Hospital Quality Ratings - Consumer can compare hospitals in the State of Maine to assess level of quality.

- Ratings for the Public
- Detailed Quality Statistics

Hospital Utilization - Consumer can compare Maine hospitals by the number of patients they treat for different medical conditions and procedures.

Map of Avoidable Hospital Stays - Consumer can map and compare counties by rates of potentially avoidable hospital stays. Compare cost savings from reducing avoidable stays

County Rates of Hospital Use - Consumers can map and compare counties by rates of inpatient medical conditions and procedures.

Hospital Financial/Organization Data

Hospital Financial Data- Annual Summaries of hospital financial data from 2007 through 2011, as reported by Maine's 39 non-governmental hospitals. Profitability, Liquidity, Capital Structure, Asset Efficiency, and other common ratios are also provided in the reports.

Link to IRS 990 Forms posted on DHHS website

Hospital Organizational Data- Reports on major structural changes relevant to the restructuring of hospitals and their parent entities in Maine. Including organizational charts depicting the organizational structure and relationships, in terms of ownership, control, and membership, and the individual corporate tax status, tax identification number, and functional description, among the persons and health care facilities owned by or affiliated with the hospital and parent entity.

External Reports –

Below are the examples of reports and analyses that used data from the MHDO:

- Healthcare Associated Infections in Maine, 2013 Annual Report prepared by Dirigo Health Agency/Maine Quality Forum.
- Maine Health Management Coalition / Onpoint Health Data: Hospital Cost Comparison, January 2013.
- Analytic Models to Identify Patients at Risk for Prescription Opioid Abuse published in The American Journal of Managed Care, Vol. 15, Issue 12, December 2009, Pages 891-906.
- <u>All-Payer Analysis of Variation in Healthcare in Maine</u>, Conducted on behalf of Dirigo Health Agency's Maine Quality Forum & The Advisory Council on Health Systems Development April, 2009.
- <u>The Epidemiology of Case Fatality Rates for Suicide in the Northeast</u> from the Harvard School of Public Health, Boston, MA. Published in the Annals of Emergency Medicine, Vol. 43, Issue 6, June 2004, Pages 723–730.
- Management of Adult Splenic Injury: A 20 Year Perspective as presented at the 83rd Annual Meeting
 of the New England Surgical Society, September 2002.
- <u>Decreasing Incidence of Burn Injury in a Rural State</u> published in Injury Prevention, Vol. 6, Issue 4, 2000, Pages 259-262.

In addition, the Subcommittee reviewed websites published by other states including the New Hampshire Healthcost site (www.nhhealthcost.org), non-governmental organizations including the Maine Health Management Coalition GetBetterMe site (http://www.getbettermaine.org) and the member-facing websites and portals of certain health insurance carriers. The Subcommittee noted aspects of each resource that could enhance the functionality and user experience of the MHDO's online resources. Examples of such aspects include:

- More procedures listed
- More information about each procedure included (i.e. volumes at each facility, potential cost shares for members)

- Links to provider websites embedded with procedure information
- Ranking systems for quality of care (i.e. "low, good, better, best" designations)

The Subcommittee discussed improvements that would be practical for the MHDO to pursue, as well as areas where other entities might be better positioned to assist consumers. Ultimately, the Subcommittee agreed that adding information on as many procedures (i.e. Colonoscopy) and services (i.e. Office visit) as possible to the HealthCost website would add significant value for users.

During the course of their work an opportunity was identified to apply for a grant from the federal government for monies to fund improvements to health cost access and transparency for consumers. The Subcommittee strongly supported an application for funds to expand the HealthCost website including the number of procedures listed. The MHDO staff developed a proposal, which was submitted for consideration by the full MHDO Board, then for approval by the Governor in late July. The Subcommittee was tasked with considering the cost of improvements and the ongoing exploration of additional funding sources (i.e. grants) is advised. For further information on see D. Information on the application for "Grants to States to Support Health Insurance Rate Review and Increase Transparency in Health Care Pricing, Cycle III" in the Supporting Documents section.

Regarding the provision of a more detailed cost calculator tool for the insured population, it is important to understand that carriers, who have access to current pricing arrangements, benefit designs, and deductible applications, are in a better position to serve this specific consumer need. Furthermore, the major carriers operating in Maine, including Aetna, Anthem, Harvard Pilgrim, and Cigna are offering or in process with rolling out web based cost calculator tools for their members (For further information see F. Examples of Carrier Cost Calculator Tools in the Supporting Documents section). The Subcommittee views this as an area where MHDO may align with the LD 1818 "Voice of the Customer" themes and avoid duplication of effort.

It was noted that the availability of cost calculators might change as the carriers' tools evolve in the marketplace. As such an ongoing assessment of the cost calculator tools available to the insured population in Maine seems appropriate.

D. Functionality and User Friendliness of HealthCost Tool

The Subcommittee reviewed the current resources and tools available to consumers through the HealthCost website with online demonstrations and explanations from members and MHDO staff. Several themes emerged from this review as consensus views of the Subcommittee. The committee agreed that:

- The website is challenging to navigate as it requires a number of decisions (clicks) and inputs before specific cost information is obtained.
- As the purpose of the website is to engage users with relevant and meaningful cost information, the absence of prices being displayed for some of the insured

procedures (resulting from low volume of the procedure claims reported by a carrier or plan type) is problematic. It will potentially result in disappointed and/or frustrated users. The reputation of the website may also be diminished as a result of the missing information and a remedy would be advisable.

• The separation of quality and cost information on the website makes it more difficult for users to utilize both types of information when making decisions.

The Subcommittee also worked with MHDO staff to roll out an online survey for users of the HealthCost website to gather feedback on the functionality and user friendliness of the HealthCost tool. Preliminary results of the survey are included with this report and generally align with the same themes that emerged from the Subcommittee's review. For further information see B. MHDO HealthCost Survey and C. MHDO Health Cost Survey Results in the Supporting Documents section

E. Expanding Public Awareness of MHDO HealthCost Website and Resources

The Subcommittee engaged in brainstorming sessions to identify ways to expand public awareness of the MHDO and the HealthCost website resource.

One idea that was offered was to follow the example of the Centers for Medicare and Medicaid Services (CMS) by releasing some quantity of data without cost to the public. With the recent release of IP and OP hospital charge data to the public by Medicare, there was significant media interest created. The Subcommittee felt that a similar release of data by the MHDO might create similar media interest and drive attention to the unique resources of the MHDO. There was consensus around the idea that MHDO data sets might be used by researchers and the public (i.e. entrepreneurs) in new ways that could ultimately benefit consumers, the encouragement of such activity by offering free data may be worthwhile.

The Subcommittee also discussed ways to leverage existing opportunities to raise awareness by partnering with organizations working to improve healthcare in Maine. A few such opportunities were identified including;

1. Choosing Wisely®, an initiative of the ABIM Foundation, is a nationwide campaign to engage physicians/health care providers and patients in conversations to help patients make smart and effective care choices. Leading medical specialty societies, along with Consumer Reports, have joined Choosing Wisely and the Quality Counts organization is leading the Choosing Wisely® campaign here in Maine. Relevant to the HealhCost website expansion and future public awareness work, the Choosing Wisely® "5 Questions to Ask your Doctor" information sheet includes the question "How much does it Cost." The committee concurred that providing a link to Quality Counts along with information on Choosing Wisely® in Maine and the procedures involved would be advisable. For further information see G. Choosing Wisely® in Maine Hand out, and H. Choosing Wisely® "5 Questions to ask your Doctor" Sheet in the Supporting Documents section.

- 2. The newly enacted legislation L.D. 990 will require healthcare providers to "make available written information on health claims data that may be obtained through the publicly accessible website of the Maine Health Data Organization." (For further information see I. LD 990 "An Act To Require Public Disclosure of Health Care Prices" in the Supporting Documents section). The Subcommittee viewed this requirement as an opportunity to work with providers and consumers to expand awareness of MHDO resources. Possibilities include;
- Providing offices with cards and other information on the MHDO website
- Providing e-notes and other information for provider based patient portals
- Working with providers to identify the common procedures for the listing of prices as additionally required by the statute.

F. Recommendations: Next Steps to Advance Consumer Education and Engagement

In the context of the discussions outlined above, and in response to the LD 1818 themes, the Subcommittee identified the following next steps to advance the purpose of the MHDO.

LD 1818 Theme #1: Provide more accurate, timely information that is easy to understand in order to make informed choices about personal healthcare, and foster transparency and accountability on the part of healthcare providers.

RECOMMENDATIONS:

- Expand master list of the initial 29 procedures to the grant funded 200, and as many as possible thereafter with all payer and provider claims data.
- Include the Choosing Wisely® in Maine focus area procedures:
 - o Imaging (EKGs, stress tests, cardiac catheterization
 - o Imaging tests (CT scan, MRI) for low back pain
 - o Imaging tests (CT scan, MRI) for uncomplicated headaches
 - o Bone-density (DEXA) scans for low-risk women
- Link and integrate information on health care quality and cost including MONAHRQ, Chapter 270 quality data and GetBetterMe.
- Provide linkages to discount or low cost drug resources and explore feasibility of providing public access to comparative drug cost information.
- Explore the inclusion of Medicare and Medicaid data into the MHDO HealthCost website and identify options for such expansion.
- Explore and consider potential website improvement funding sources (i.e. grants)

LD 1818 Theme #2: Improve the experience of users accessing data through the HealthCost website.

RECOMMENDATIONS:

- Provide user-friendly explanations and definitions of health cost and consumer related terms on HealthCost web page.
- Offer a HealthCost site user feedback function (i.e. survey) to support relevant and meaningful public engagement with health cost information, and to assess consumer education needs in regard to cost and quality information.
- Re-evaluate, modify, and improve methodologies for determining average payments of procedures for the insured population.
- Re-evaluate methodologies for presentation of pricing for uninsured.

LD 1818 Themes #3 and #4: Broaden awareness of the availability of data from the APCD and avoid duplication of existing data resources.

RECOMMENDATIONS:

- Designate and expand website information clearing house role including:
 - o Linkage with carrier cost calculator tools and cost information resources
 - o Explore and provide alternative resources for insured population if and when access to cost calculator information is not provided by their carrier(s).
 - Collaborate on and support LD 990 including requirement to educate consumers about MHDO HealthCost website cost assessments and information.
- Expand public awareness campaign in alignment with "Transparency in Health Care Pricing, Cycle III" grant identified processes and programs.
- Evaluate potential awareness campaign linked to public data release (i.e. recent CMS
 Inpatient and Outpatient hospital charge data releases) including the possibility of
 broader public data access through free release of limited data sets, or public access to
 standard queries of APCD. This evaluation should consider the context of ongoing
 transformation activities.
- Collaborating with and link to other state and regional health data and analysis efforts (i.e. HP 1123, SIMS)

IV. Supporting Documents

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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 of 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

- 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. <u>Themes from VOC responses</u>

Theme 1: Establishing multi-stakeholder directed <u>Data Governance Structures</u> 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.

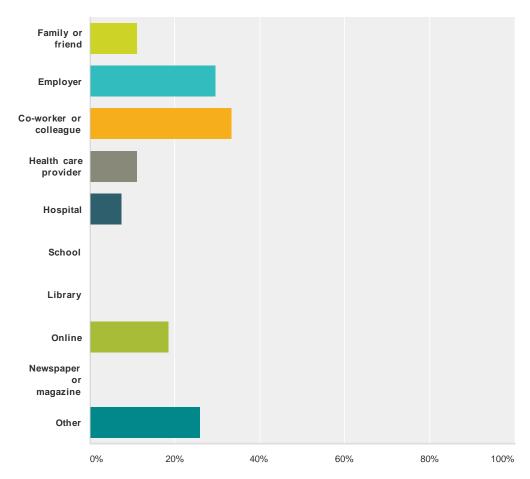
- Expansion raises the potential for poor policy decisions to be made about patient privacy, confidentiality, consent, notice, and control.
- Medical information is arguably the most personal and private source of data about us as individuals. In our work on
 health information technology, we continue 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.

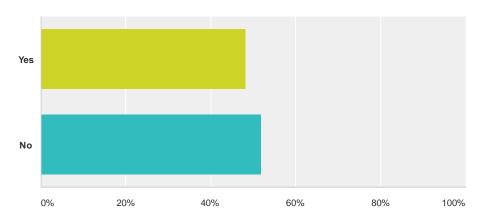
- Data on other preventable medical and surgical errors, adverse events and HAIs should also be available to healthcare consumers. I can get more information on a car service business than I can from my local hospital
- There is no ability to match up claims data with other increasingly available data (e.g. clinical, health risk, functional status, etc.) and
 - o 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.

Q1 Where have you heard about the MHDO HealthCost website? (Please check all that apply.)



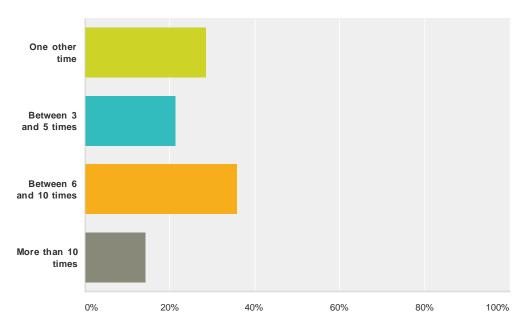
Answer Choices	Responses	
Family or friend	11.11%	3
Employer	29.63%	8
Co-worker or colleague	33.33%	9
Health care provider	11.11%	3
Hospital	7.41%	2
School	0%	0
Library	0%	0
Online	18.52%	5
Newspaper or magazine	0%	0
Other	25.93%	7
Total Respondents: 27		

Q2 Is this your first time using the HealthCost website?



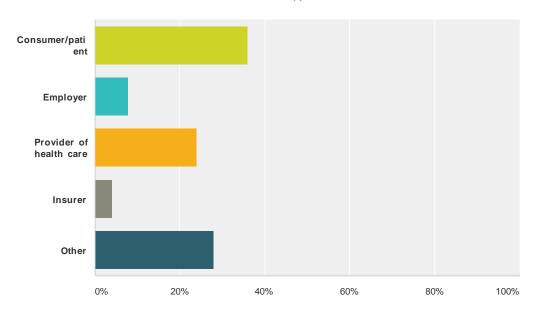
Answer Choices	Responses
Yes	48.15% 13
No	51.85% 14
Total	27

Q3 If not, how many times have you used the site in the past 12 months?



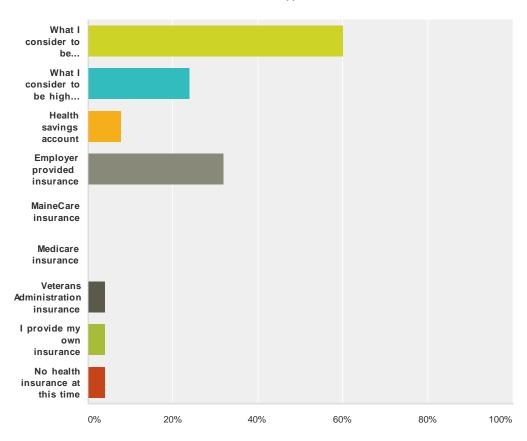
Answer Choices	Responses	
One other time	28.57%	4
Between 3 and 5 times	21.43%	3
Between 6 and 10 times	35.71%	5
More than 10 times	14.29%	2
Total		14

Q4 How would you best describe yourself? (Please select best fit for today's use of the site.)



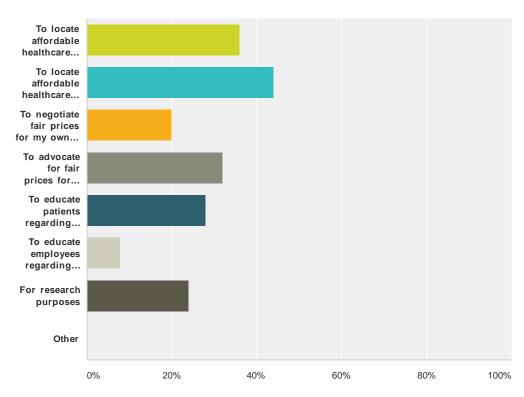
Answer Choices	Responses
Consumer/patient	36%
Employer	8%
Provider of health care	24%
Insurer	4%
Other	28.00%
Total	2:

Q5 Which options best describe your current health insurance? (Please check all that apply.)



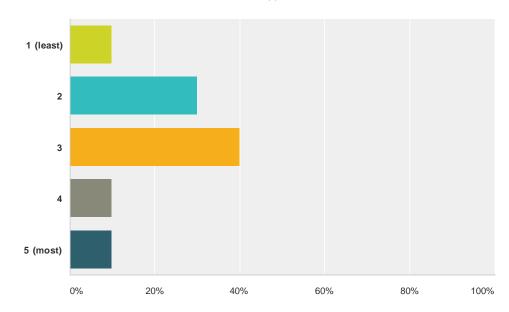
Answer Choices		Responses	
What I consider to be comprehensive insurance (covers medical, behavioral health, prescriptions, vision and/or dental)	60%	15	
What I consider to be high deductible insurance	24%	6	
Health savings account	8%	2	
Employer provided insurance	32%	8	
MaineCare insurance	0%	0	
Medicare insurance	0%	0	
Veterans Administration insurance	4%	1	
I provide my own insurance	4%	1	
No health insurance at this time	4%	1	
Total Respondents: 25			

Q6 How will you be using the information? (Please check all that apply.)



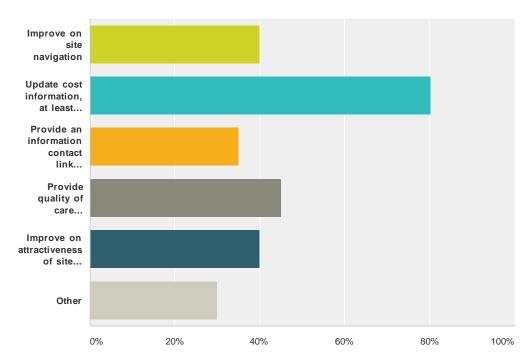
Answer Choices	Responses	
To locate affordable healthcare for myself	36%	9
To locate affordable healthcare for others	44%	11
To negotiate fair prices for my own health care services	20%	5
To advocate for fair prices for other people's health care services	32%	8
To educate patients regarding their health care costs	28.00%	7
To educate employees regarding their health care costs	8%	2
For research purposes	24%	6
Other	0%	0
Total Respondents: 25		

Q7 Overall, using the rating range of 1 to 5, with 1 being least and 5 being most, please indicate how useful the health cost information was today.



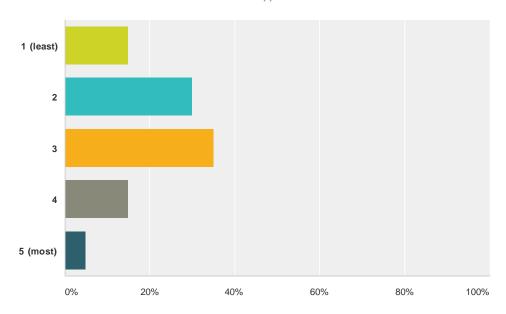
Answer Choices	Responses	
1 (least)	10%	2
2	30%	6
3	40%	8
4	10%	2
5 (most)	10%	2
Total		20

Q8 What changes would you make to improve the site's usefulness? (Please check all that apply.)



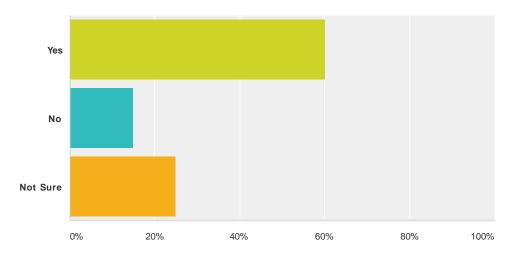
Answer Choices	Responses	
Improve on site navigation	40%	8
Update cost information, at least every 6 months	80%	16
Provide an information contact link for every provider site listed	35%	7
Provide quality of care information related to the procedures listed	45%	9
Improve on attractiveness of site appearance	40%	8
Other	30%	6
Total Respondents: 20		

Q9 Overall, using the rating range of 1 to 5, with 1 being least and 5 being most, please indicate how satisfied you are with today's HealthCost website experience.



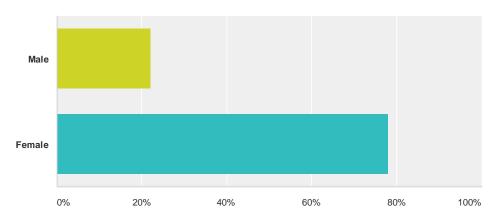
Answer Choices	Responses
1 (least)	15% 3
2	30% 6
3	35% 7
4	15% 3
5 (most)	5% 1
Total	20

Q10 Would you recommend the HealthCost website to someone else?



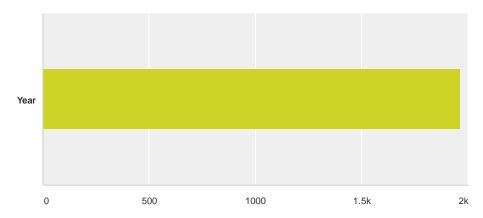
Answer Choices	Responses
Yes	60% 12
No	15% 3
Not Sure	25% 5
Total	20

Q11 Please indicate your gender.



Answer Choices	Responses	
Male	22.22%	4
Female	77.78%	4
Total	1	18

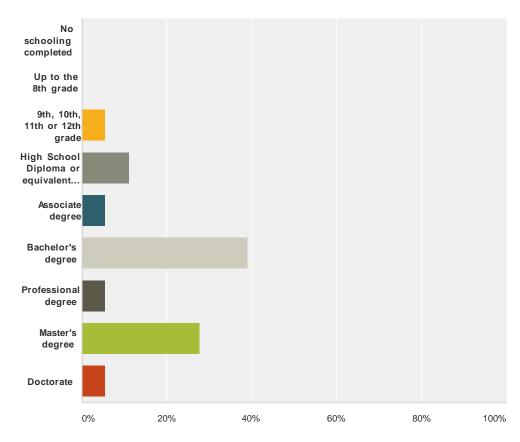
Q12 Please provide the year you were born.



Answer Choices	Average Number	Total Number	Responses
Year	1,963.06	35,335	18
Total Respondents: 18			

Q13 Please provide your zip code.

Q14 Please check the highest level of school or degree you have completed.



Answer Choices	Responses	
No schooling completed	0%	0
Up to the 8th grade	0%	0
9th, 10th, 11th or 12th grade	5.56%	1
High School Diploma or equivalent (GED)	11.11%	2
Associate degree	5.56%	1
Bachelor's degree	38.89%	7
Professional degree	5.56%	1
Master's degree	27.78%	5
Doctorate	5.56%	1
Total	·	18

Project Abstract

State of Maine Data Center Enhancement to Improve Health Cost Transparency

The Health Insurance Rate Review Grant Program: Grants to States to Support Health Insurance Rate Review and Increase

Transparency in Health Care Pricing, Cycle III, Funding Opportunity Number: PR-PRP-13-001

Project Director: Karynlee Harrington

Organization: Maine Health Data Organization Mailing Address: 102 SHS, Augusta, ME 04333-0102 Physical Address: 151 Capitol Street, Augusta, ME, 04333

Phone: 207-446-0890 Fax: 207-287-6732

Karynlee.Harrington@maine.gov

http://mhdo.maine.gov/imhdo/index.aspx

The Maine Health Data Organization (MHDO) is proposed as the lead agency for Maine's Rate Review Cycle III grant to enhance their existing Data Center. The Maine Legislature established MHDO in 1996 as an independent executive agency to create and maintain a useful, objective, reliable and comprehensive health information database that is used to improve the health of Maine citizens. MHDO created the nation's first All Payer Claims Database (APCD) and has been collecting medical, pharmacy and dental claims data from public and private insurers since 2003 and makes those data publicly available while protecting individual privacy. MHDO is able to obtain these data expeditiously since public and private insurers are required by state law to submit these data. MHDO currently provides data on quality of care and price comparisons through its publicly accessible HealthCost and MONAHRQ web pages. As described more fully in the proposal, Maine has a strong history of public/private collaboration in health care improvement initiatives. By communicating and working together MHDO and these groups are able to leverage each other's work and avoid duplication of effort.

Building upon the existing functionality of the HealthCost and MONAHRQ websites, and taking advantage of a new data warehouse infrastructure under development, MHDO intends to use grant funding to further integrate its cost and quality data to provide more comprehensive and useful information to consumers and other key stakeholders online. Specifically, MHDO intends to:

- 1) Increase the number of "shopable" procedures available online from 30 to at least 200
- 2) Incorporate quality data from MONAHRQ with cost data
- 3) Link and integrate other information on health care quality to cost information
- 4) Evaluate the inclusion of Medicare and Medicaid data on the cost website
- 5) Re-evaluate, modify, and improve methodologies for determining average payments of procedures for the insured population
- 6) Re-evaluate methodologies for presentation of pricing for uninsured
- 7) Evaluate links and integration with other efforts in Maine involving health data and commercial plans' cost calculators and price information
- 8) Evaluating linking to or incorporating prescription drugs pricing information
- 9) Incorporate more powerful tools for online analysis
- 10) Improve accessibility for mobile devices so that MHDO and other health organizations can more easily develop apps leveraging MHDO data
- 11) Improve user interface and usability of site
- 12) Provide appropriate tools and data as separate paths on the site for researchers, employers, providers, consumers and other stakeholders
- 13) Improve web IT infrastructure to make site more modular and flexible, supporting ease of change in the future
- 14) Evaluate and potentially build infrastructure to support national claims and hospital encounter data sets
- 15) Create web application programming interfaces (APIs)

- 16) Improve communication and outreach to the public to raise awareness of MHDO as a resource for health cost and quality data
 - a. Awareness campaign
 - b. Develop a mechanism for website user feedback
- 17) Collaborate with other state and regional health data and analysis efforts
- 18) Work collaboratively with stakeholders to better respond to their needs for data and transparency

The State of Maine is requesting \$2,621,098 to complete this ambitious agenda.

Healthcare Consumer Descriptions

Healthcare Consumer

This term describes anyone who may utilize healthcare goods and services.

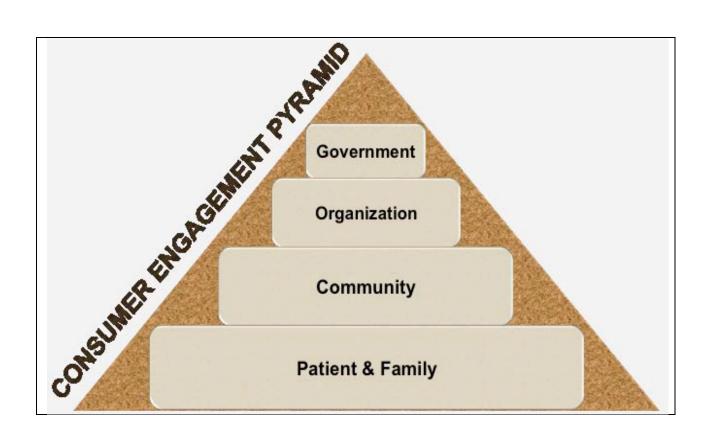
Healthcare Consumer Representative (i.e. Advisors, Board members)

This term describe both independent and organizational consumers who are committed to providing the consumer perspective in multi stakeholder settings. They may not be an employee or business associate of a provider, payer, or regulator entity. Furthermore;

- Organizational consumers are employees or business associates of a consumer organization whose primary mission is to advance the interests of healthcare consumers.
- Independent consumers have significant personal experience as a healthcare consumer and are not employees or business associates of a consumer organization. When they represent consumers on one or more bodies they may be referred to as independent consumer advocates.

Healthcare Consumer Engagement

This term describes the activation of consumers at multiple levels within the healthcare system. The following "Consumer Engagement Pyramid" identifies four levels of engagement; Patient and Family, Community, Organization, and Government.



Examples of Healthcare Consumer Engagement

Consumer Engagement at the individual Patient and Family level:

Patients and providers engage in a shared decision making conversations that include the Choosing Wisely© 5 Questions to ask your Doctor.

Consumer Engagement at the Community level:

Community members engage as organizers of fundraisers to provide dental care to residents of local homeless shelter.

Consumer Engagement at the health systems Organization level:

Parents of pediatric practice patients engage as members of the practices Patient Advisory Group to improve their children's experience and the quality of care provided.

Consumer Engagement at the Government level:

Maine people serve as consumer representatives on health care policy Boards at the state level to bring the consumer perspective to the multi stakeholder leadership arena.

EXAMPLES OF CARRIER COST CALCULATOR TOOLS

1. AETNA

Link to Aetna's instructional video for Member Payment Estimator tool:

http://www.aetnatools.com/?video=video5

2. HARVARD PILGRIM

Link to information on Harvard Pilgrim member Payment Calculator Tool, which is scheduled for release this fall, called "Now iKnow.":

 $\underline{https://www.harvardpilgrim.org/portal/page?_pageid=213,246822\&_dad=portal\&_schema=PORTAL$

Link to a promotional "Now iKnow" Video:

http://yww.brainshark.com/hphc/vu?pi=zEszlCBJuzEB1z0&intk=290708429

3. ANTHEM

Link to video of the Anthem "Estimate your cost" tool available to members through their My Anthem portal:

https://wpetutorial.jellyvision-conversation.com/?id=anthemBCBS&go=TT

Link to Anthem video for members entitled "Health Care Budget Basics by Joey":

https://www.insidemyplan.com/page.aspx?QS=2e4c31a3756cb940453830c819f764a1d2d411 19e90f32a6f6a9e8df257831fc&j=31942853&s=1535871588&id=20130604_AF_ABCBS&s d=20130604

4. CIGNA

Link to Cigna cost of care calculator course for providers, which gives information and instructions for use of this tool:

https://secure.cigna.com/app/provider/help/CostofCareEstimatoreCourse.pdf

Note: This document is designed to offer examples of carrier cost calculator tools and not to provide a comprehensive review of Carrier cost tools.

Choosing Wisely in Maine



<u>Choosing Wisely®</u> is an initiative of the <u>ABIM Foundation</u> to help physicians/health care providers and patients **engage in conversations** about the overuse of tests and procedures and support physician/health care providers efforts to help patients make smart and effective care choices.

Recognizing the importance of physicians/health care providers and patients working together, leading medical specialty societies, along with <u>Consumer Reports</u>, have joined Choosing Wisely to help improve the quality and safety of health care in America.

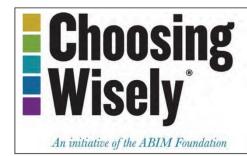
As part of Choosing Wisely, each participating medical specialty society has created lists of <u>"Five Things Physicians/Health Care Providers and Patients Should Question"</u> that provide specific, evidence-based recommendations physicians and patients should discuss to help make wise decisions about the most appropriate care based on their individual situation.



5 Things Maine Providers and Patients Should Question

Through the guidance of the Choosing Wisely in Maine Leadership Group composed of physicians and other providers, consumers, employers, payers and other key stakeholders, *Choosing Wisely in Maine* has identified these focus areas:

- 1. <u>Cardiac imaging (EKGs, stress tests, cardiac</u> catheterization) for patients at low risk for heart disease
- 2. Imaging tests (CT scan, MRI) for low back pain
- 3. Antibiotics for upper respiratory infections
- 4. <u>Imaging tests (CT scan, MRI) for uncomplicated</u> headaches
- 5. Bone-density (DEXA) scans for low-risk women
- 6. <u>Sleeping pills or sedatives (e.g. benzodiazepines) for</u> insomnia, agitation, or delirium in older adults
- 7. Opioids or butalbital as pain medications for treating migraine headaches



ConsumerReportsHealth



5 QUESTIONS to Ask Your Doctor Before You Get Any Test, Treatment, or Procedure

- 1 Do I really need this test or procedure? Medical tests help you and your doctor or other health care provider decide how to treat a problem. And medical procedures help to actually treat it.
- What are the risks? Will there be side effects? What are the chances of getting results that aren't accurate? Could that lead to more testing or another procedure?
- Are there simpler, safer options? Sometimes all you need to do is make lifestyle changes, such as eating healthier foods or exercising more.
- What happens if I don't do anything? Ask if your condition might get worse or better if you don't have the test or procedure right away.
- How much does it cost? Ask if there are less-expensive tests, treatments or procedures, what your insurance may cover, and about generic drugs instead of brand-name drugs.

Use the **5 questions** to talk to your doctor about which tests, treatments, and procedures you need — and which you don't need.

Some medical tests, treatments, and procedures provide little benefit. And in some cases, they may even cause harm.

Talk to your doctor to make sure you end up with the right amount of care — not too much and not too little.



http://consumerhealthchoices.org/campaigns/choosing-wisely/



CHAPTER

JUNE 21, 2013

332

BY GOVERNOR

PUBLIC LAW

STATEOF MAINE

IN THE YEAR OF OUR LORD TWO THOUSAND AND THIRTEEN

S.P. 335 - L.D. 990

An Act To Require Public Disclosure of Health Care Prices

Be it enacted by the People of the State of Maine as follows:

Sec. 1. 22 MRSA §1718-A is enacted to read:

§1718-A. Consumer information regarding health care practitioner prices

Each health care practitioner, as defined in section 1711-C, subsection 1, paragraph F, shall maintain a price list of the health care practitioner's most frequently provided health care services and procedures. The prices stated must be the prices that the health care practitioner charges clients directly, when there is no insurance coverage for the services or procedures or when reimbursement by an insurance company is denied. The prices stated must be accompanied by the applicable standard medical codes listed by diagnosis. For purposes of this section, "frequently provided health care services and procedures" means those health care services and procedures that were provided by the health care practitioner at least 50 times in the preceding calendar year. Health care practitioners shall inform clients about the availability of the price list and provide copies of the price list upon request. Health care practitioners shall make available written information on health claims data that may be obtained through the publicly accessible website of the Maine Health Data Organization established pursuant to chapter 1683. This section does not apply to pharmacists.

- Sec. 2. 24 MRSA §2987, as enacted by PL 2003, c. 469, Pt. C, §30, is repealed.
- Sec. 3. Effective date. This Act takes effect January 1, 2014.