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FINAL REPORT

The Practice and Impact of Shared Decision-Making

**A Study Conducted by
The Shared Decision-Making Study Group
for the Dirigo Health Agency's Maine Quality Forum**

**Submitted to:
Maine's Joint Standing Committee on Health and Human Services
and the Joint Standing Committee on Insurance and Financial Services**

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FINAL REPORT

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■ BACKGROUND

The 124th Maine State Legislature adopted a Resolve requesting the Maine Quality Forum (MQF) to study the issue of shared decision-making.¹ (See APPENDIX A for the full text of the Resolve.)

Specifically, the Resolve required the MQF to establish an advisory group to consider:

- The appropriate preference-sensitive health care services for use in a shared decision-making program and an accepted protocol for shared decision-making
- The availability of approved patient decision aids relating to each health care service and the effectiveness of patient decision aids
- The payment method to be used by health insurance carriers and public programs to reimburse for services provided by a shared decision-making program
- The appropriate incentives to encourage use of a shared decision-making program by providers and patients
- Evidence-based studies that evaluate shared decision-making
- Any barriers to implementation of a shared decision-making program

In September 2009, the MQF established a Shared Decision-Making Study Group in accordance with the composition required in the Resolve. Nominations were solicited from MaineCare, the Maine Health Data Organization, the Maine Hospital Association, the Maine Medical Association, and the Maine State employee health insurance program. In addition, the MQF solicited participation from legislators, researchers with an interest in shared decision-making, and practitioners and consumers involved in preference sensitive care.

■ WHAT IS SHARED DECISION-MAKING?

The Study Group spent considerable time establishing a working definition for shared decision-making based on the literature and current practice, which could guide its work. While definitions vary, researchers generally agree that three essential factors must be present for a process to be considered *shared decision-making*:

- The patient is faced with two or more treatment options with no clear best choice in terms of survival, outcome, or functionality
- The patient's own preferences and values drive decisions
- The patient and clinician share information with each other, take steps to participate in the decision, and agree on a course of action based on the patient's preferences²

Shared Decision-Making versus Informed Decision-Making

The term *shared decision-making* is often mistakenly used interchangeably with *informed decision-making* – a broader term referring to patients becoming more knowledgeable about their health care and treatment decisions in general.³ The distinction is an important one worth reinforcing. Shared decision-making occurs in cases where a patient's *values and preferences* are the determining factors in deciding between two or more medically reasonable alternatives. Informed decision-making, on the other hand, is

an effort to advance a patient's understanding of the *science-base* for choosing one treatment option over the other.

Shared decision-making refers to a *process* of interaction to better match a patient's preferences with the treatment he or she receives. The process connects the clinician's understanding of the risks, benefits, and uncertainties of each treatment option with the patient's goals, preferences and life values. Since by definition there is no *best* treatment choice in cases where shared decision-making is used, the process relies on the experience and expertise of both parties to find a mutually satisfactory decision.

Decision aids, including videos, interactive web programs, or printed material, may be used as an adjunct in shared decision-making. Aids are intended to provide objective and easy to understand information about treatment options, the likely physical and emotional consequences of each option, and their potential harm and benefit. Aids may also include tools to assess personal values and preferences. Decision aids help ground but are not a replacement for direct conversation between a clinician and patient to determine the preferred course of action. The field of shared decision-making is evolving and likely will be shaped by the emergence of new technologies that change the nature of the clinical-patient encounter. For example, the use of other real-time interfaces other than in-person visits may shift how decision aids are used or how shared decision-making occurs between clinician and patient.

■ MAJOR FINDINGS

The Study Group relied on the literature and subject matter experts to inform their understanding of the use and impact of shared decision-making in Maine and nationally. A full description of the research upon which major findings are based can be found in the SUPPLEMENT to this Report. Following are findings specific to the questions raised by the Maine State Legislature in its Resolve:

1. The Study Group believes that shared decision-making applies to all preference sensitive conditions where patients are faced with two or more treatment options with no clear best choice. Research found many models of shared decision-making in use, some more comprehensive than others, with no nationally accepted protocol. In defining an accepted model, the Study Group believes that an ideal shared decision-making process includes:
 - A real time interaction between patients and their clinicians
 - Clarification of patient values and preferences
 - Balanced information and education about treatment options
 - Supportive guidance through the decision process
2. No nationally recognized body currently exists to certify and/or oversee the use of decision aids and their effectiveness varies. The Affordable Care Act does authorize the adoption of standards for the certification of decision aids. No timeframe for implementation has been identified.

3. While advocating for reimbursement of shared decision-making, the Study Group identified multiple challenges to its implementation. First, no standard exists for defining what constitutes an acceptable shared decision-making process which must be present in order to be reimbursed. Second, no national or local codes exist to document that the process took place. Third, there is incomplete evidence on the differential payment that should be received for implementing shared decision-making and who should be eligible for such payments.
4. Reimbursement would be a clear incentive to promote the use of shared decision-making. Also, recognizing the practice of shared decision-making within pay for performance programs may raise the profile of shared decision-making and properly acknowledge its place in clinical practice. This could be done through use of the standardized quality measure for shared decision-making adopted by the National Committee for Quality Assurance. Further examination could also be given to modifying benefit design by creating consumer incentives to participate in the ideal process of shared decision-making.
5. There is evidence that shared decision-making leads to higher quality of care as measured by patient engagement and positive experience of care. Shared decision-making focuses on situations where there is no best clinical choice. The risks and benefits of each choice can only be weighed within the context of a patient's own preferences and values. When effectively provided, shared decision-making provides the opportunity and structure for patients to receive and understand objective information on treatment options along with the risks and benefits of each, and to select the option that best matches their preferences. Studies show that patients do better when they are actively involved in these decisions. The alternative to shared decision-making is a return to a paternalistic system where choices are governed by the preferences and values of clinicians and not those of the patient who must live with the consequences.
6. The evidence is insufficiently strong to promote shared decision-making on the basis of saving costs. Presently, findings from randomized clinical trials are the most credible bases for determining potential cost savings from the introduction of shared decision-making practices. Findings from these studies indicate that the impact of shared decision-making on cost is inconclusive. Four aspects of existing studies are especially troubling when trying to determine cost impact. First, studies necessarily provide a very controlled environment for testing the process and targeting patients who are most likely to benefit from the intervention. Secondly, studies do not fully account for all costs associated with shared decision-making, including the cost of the shared decision supports and tools, identifying, screening and contacting patients, training clinicians, and the additional time required by health care workers to incorporate shared decision-making into the patient encounter. Thirdly, cost savings identified through clinical studies do not examine a long enough time horizon to understand whether patients subsequently change their mind and later opt for more expensive procedures, whether substitution effects occur, and the appropriateness of service use on long term outcomes. Finally, clinical studies involving decision aids are subject to potential bias if conducted by the developer of those aids.
7. The lack of reimbursement to adequately fund the time and resources needed to implement shared decision-making is the most frequently raised barrier to its implementation. The Study Group found that other factors also serve as deterrents to its full adoption. There are no national standards for shared decision-making leading to substantial variation in its effectiveness. Up until now, there has been no nationally

recognized body authorized to certify shared decision-making aids, further complicating a categorical endorsement of the concept. Outside of the controlled setting of clinical trials, there is no standardized documentation that would allow its use and impact to be routinely assessed.

■ CONCLUSIONS AND RECOMMENDATIONS

The Study Group found sometimes conflicting and inclusive evidence about the value proposition for promoting shared decision-making. While seen as the right thing to do, they found no unequivocal impact on improved outcomes or reduced costs. Yet, several recent developments are likely to address those factors seen as contributing to shared decision-making's mixed results: the lack of a nationally recognized certification process; insufficient funds to adequately invest in the training and infrastructure to support shared decision-making; and adequate methods for monitoring its effectiveness.

The Affordable Care Act requires the Secretary of Health and Human Services (HHS) to “establish a National Quality Strategy to improve the delivery of healthcare services, patient healthy outcomes and population health.” Under the leadership of the National Quality Forum, the National Priorities Partnership, a multi stakeholder group, proposed that the National Strategy focus on six areas around which targeted and collective action could lead to dramatic change: patient and family engagement, population health, safety, care coordination, palliative and end of life care, and overuse. In its roadmap for improving patient and family engagement, the National Priorities Partnership has advocated greater support for and use of shared decision-making.

The Affordable Care Act also calls for the implementation of a national Shared Decision-Making Program designed to support patients and providers in incorporating patient preferences and values into treatment decisions. Key components of the program include:

- The adoption of standards for certification of decision aids
- Funding to support the development and adoption of decision aids
- The creation of Shared Decision Making Resource Centers to provide technical assistance to health care providers, disseminate best practices on the use of decision aids, and promote adoption of these tools
- Dissemination of best practices and research on the implementation and effective use of patient decision aids
- Grants to health care providers for the development, use, and assessment of certified shared decision-making aids for preference sensitive care
- Funds to support the development of measures to assess the effectiveness of shared decision-making tools

Proposal for a Maine-Based Demonstration

It is within the context of these national developments that the Study Group recommends that Maine build on the expertise and experience of the Maine provider and research community in promoting shared decision-making in the State. The Study Group recommends that a Maine-based demonstration be designed to leverage employer and payor interest with the applied expertise of Maine providers to address

key issues that remain unanswered and which are critical to the advancement and spread of shared decision-making in Maine:

- *Identify the true cost of implementing shared decision-making, including costs related to the purchase and/or development and updating of decision-aids, provider training, and provider time required to participate in shared decision-making and to document the encounter*
- *Design mechanisms to track short and long term patient reported outcomes (e.g., satisfaction, regret) and use of services*
- *Determine the feasibility, effectiveness, and efficiency of embedding shared decision-making into the provision of health care*
- *Develop methods for reliably identifying clinically appropriate patients for shared decision-making*
- *Identify strategies for engaging patients in shared decision-making to extent that they desire*
- *Assess the use of non-physician personnel and technology in shared decision-making*

It is anticipated that the Maine Quality Forum will direct the demonstration under the guidance of a Shared Decision-Making Pilot Design/Implementation Work Group. The MQF is expected to seek external funding to help support the design, implementation and evaluation of the demonstration.

RESEARCH SUPPLEMENT

■ BACKGROUND

The 124th Maine State Legislature authorized the Maine Quality Forum (MQF) to convene a Study Group to examine the benefits and use of shared decision-making.¹ In its Resolve, the Legislature requested the Study Group to consider:

- The appropriate preference-sensitive health care services for use in a shared decision-making program and an accepted protocol for shared decision-making
- The availability of approved patient decision aids relating to each health care service and the effectiveness of patient decision aids
- The payment method to be used by health insurance carriers and public programs to reimburse for services provided by a shared decision-making program
- The appropriate incentives to encourage use of a shared decision-making program by providers and patients
- Evidence-based studies that evaluate shared decision-making
- Any barriers to implementation of a shared decision-making program

This RESEARCH SUPPLEMENT reviews the research conducted by the Study Group that formed the basis of its FINAL REPORT to the Legislature

Approach to Work

In addressing the issues raised in the Resolve, the Study Group undertook three major activities:

- ***Review of evidence-based literature*** – The Study Group compiled and synthesized findings from research on shared decision-making. While much has been written on the practice, the Study Group focused its review on scientific clinical trials comparing the impact of shared decision-making to usual care of a control group.
- ***Presentations by subject matter experts*** – The Study Group heard from clinicians and consumers who practice shared decision-making, sponsors of pilots who are testing real world implementation, and researchers who study its impact.
- ***Survey of Maine providers and payors*** – To inform its understanding of the current and proposed use of shared decision-making in Maine, a survey was administered to major health systems, hospitals, provider groups and payors.

Findings of their research are presented under three major headings: Current State of Practice and Initiatives; Challenges to Implementation; and Impact on Cost and Quality. The Study Group's work also was informed by the federal Triple Aims of improving the experience of care, improving the health of populations, and reducing per capita costs of healthcare.

■ CURRENT STATE OF PRACTICE AND INITIATIVES

Nationally

Spurred by the consumer advocacy movement of the 1970s, the former paternalistic attitude that only clinicians know what is best for their patients has given way to a recognition that patients have a critical role to play in their medical care. Nowhere is that role greater than in conditions for which there is no single best medical approach to treatment. Such areas, often referred to as *preference sensitive care*, include but are not limited to certain decisions about managing early stage cancers, symptoms of menopause, and back pain, where patient values and goals should govern treatment decisions. The Dartmouth Institute for Health Policy and Clinical Practice defines preference sensitive care as those “treatments that involve significant tradeoffs affecting the patient’s quality and/or length of life. Decisions about these interventions – whether to have them or not, which ones to have – ought to reflect patients’ personal values and preferences, and ought to be made only after patients have enough information to make an informed choice.”⁴

Nationally, there are limited data about the extent to which shared decision-making is incorporated into current medical practice since the process is not reimbursed and not typically documented by providers. One researcher, through a review of office visit audio tapes, found surgeons more likely to engage in informed decision-making than primary care physicians. But even among surgeons, only about 10 percent fully engaged patients in decision-making.³ In another study, patients surveyed by phone were asked to recall the decision-making process about cancer screening. The majority reported a lack of involvement in decision-making. For example, only 31 percent of female patients were asked for their preferences about colorectal cancer screening. Providers recommended screenings to these patients 78 percent of the time. The study was limited by the reliance on patient recall of events.⁵ More information is needed about how shared decision-making is being practiced since no standard exists against which it may be measured. Variation in practice (and potential impact on quality and costs) can be significant - ranging from the simple viewing of a video by a patient to a systematic process of personal exchanges between a clinician and patient to clarify treatment options that best align with the patient’s preferences and values.

Despite having limited information on shared decision-making processes, we know that decision aids are growing in number and popularity. Repositories of aids can be found online for access by providers and patients.⁶⁻⁸ Some are proprietary; others exist in the public domain. No recognized process currently exists for certifying decision aids although resources are available comparing the scope and features of existing decision aids and, where available, findings from clinical trials. The Cochrane Decision Aid Registry includes all decision aids that have been subject to randomized clinical trials in which the outcomes of their use are compared to no intervention, usual care and alternative interventions.^{6†} The International Patient Decision Aid Standards Collaboration is a group of researchers, practitioners and stakeholders from around the world whose goal is to establish an internationally approved set of criteria to

[†] The Cochrane Collaboration has updated their systematic review of decision aids, now including 87 trials (32 additional trials).⁵³ Findings will be presented later this summer.

determine the quality of patient decision aids. Decision aids are rated on a number of criteria related to content, development process, and effectiveness. The Ottawa Hospital Research Institute is an online resource to help consumers and clinicians learn about decision aids and their quality. Tools and training are also available on the Ottawa site for clinicians wanting to incorporate aids in their practices.⁷ The Foundation for Informed Medical Decision-Making provides an online library of decision aids licensed and distributed by Health Dialog, Inc.⁸

The National Committee for Quality Assurance (NCQA), a leading developer of standardized measures to assess performance of the health care system, has developed a shared decision-making measure to assess a patient's satisfaction with the decision-making process in cases where there was more than one reasonable treatment option. The composite measure is based on consumer responses to the Consumer Assessment of Health Care Providers and Systems or CAHPS survey.⁹

The recently enacted Affordable Care Act[‡] calls for the implementation of a national Shared Decision-Making Program designed to support patients and providers in incorporating patient preferences and values into treatment decisions. This is a key component of the national quality improvement strategy. That strategy is built upon the “Triple Aim” framework[§] that calls for the simultaneous realization of the best care for the entire population at the lowest cost.

Key components of the national program include:

- The adoption of standards for certification of decision aids through the National Quality Forum
- Funding to support the development and adoption of decision aids
- The creation of Shared Decision Making Resource Centers to provide technical assistance to health care providers, disseminate best practices on the use of decision aids, and promote adoption of these tools
- Grants to health care providers for the development, use, and assessment of certified shared decision-making aids
- Funds to support the development of measures to assess the effectiveness of shared decision-making tools

In other states

The Study Group investigated initiatives in other states related to shared decision-making. Key among them is Washington State which, in 2007, was the first state to pass legislation formally recognizing shared decision-making in the state's laws on informed consent and encouraging collaborative efforts to develop, certify, use, and evaluate decision aids.¹⁰ The legislation authorized the Washington State Health Care Authority to conduct a demonstration pilot to study the impact of using decision aids for identified preference-sensitive health care services on health care expenditures and patient satisfaction and understanding.¹¹

[‡] The Patient Protection and Affordable Care Act is referred to herein as the ACA and is H.R. 3590.

[§] <http://www.ihl.org/IHI/Programs/StrategicInitiatives/TripleAim.htm>.

Leah Hole-Curry, Director of Health Information Technology at the Washington Health Care Authority, updated the Study Group on the four site pilot at Group Health and the University of Washington. The Study Group learned that the decision aids used in the Washington State pilot were limited to those meeting requirements and which were provided free of charge, during the pilot, by their developer and study funder, Foundation for Informed Medical Decision-Making (FIMDM) and commercial distributor, Health Dialog. At the Group Health demonstration sites, patients whose condition fell within preference sensitive care areas addressed in the pilot** were “prescribed” access to an online decision aid (typically a video) for viewing prior to an appointment with a clinician. The trigger for determining when a decision-aid is “prescribed” varied by service and condition, and was based on the discretion of the primary care provider or specialist. An electronic mail system automatically recorded when a patient completed the video – documentation that the patient had been fully informed of the risks and benefits of treatment options. An important component of the Group Health demonstration was the shared decision-making which happened with the clinician after a patient was exposed to a decision aid.

Subsequent to the presentation by the Washington Health Care Authority, the Study Group learned that three multi-disciplinary clinics were added to that State’s pilot. Independent of the pilot, Group Health decided to roll-out shared decision-making and the use of patient decision aids across several clinical domains in its 26 area medical centers. Domains include orthopedics, women’s health, heart disease, prostate cancer, and back care (Email correspondence with Leah Hole-Curry, January 13, 2011).

Some Study Group members expressed reservations about the Washington State pilot, specifically related to the advisability of commercial developers of patient decision aids serving in the role of study sponsors. This concern is reinforced by the American Medical Association which stated that “decision support tools could be created that are misleading or biased towards or against certain treatment choices, in an effort to encourage patients to choose less expensive options. Even in choosing what questions to ask, and how to ask them, it might be possible to subtly influence patient choices in an inappropriate manner. This risk makes the independence of groups creating these tools and the use of quality control measures especially important”.¹² Additionally, the Study Group expressed reservations about the adequacy of controls for selectively targeting the subset of patients for whom decision aids are most appropriate and how outcome measures will evaluate impact on costs, health services use, and efficiency.

Offsetting some of these concerns is the use of an independent evaluator for the Washington State pilot. The Study Group saw the Washington State pilot as an important contribution for helping Maine better understand how shared decision-making can be effectively implemented in clinical practice and its impact on quality.

** Preference sensitive conditions addressed in the pilot include: treatment choices for hip osteoarthritis, knee osteoarthritis, coronary artery disease, benign prostatic hyperplasia, prostate cancer, uterine fibroids, abnormal uterine bleeding, early stage breast cancer, breast reconstruction, ductal carcinoma in situ, low back pain, spinal stenosis, and herniated disc.

In Maine

To understand the use of shared decision-making in Maine, the Study Group surveyed and heard directly from local clinicians about their efforts and development plans. The survey, administered by the Muskie School to major health care providers and payors, found no organizations with institutional policies or guidelines governing the practice or payment of shared decision-making.¹³ However, “pockets” of practice were found, most notably in the areas of breast and prostate cancer treatment and bariatric medicine. More generally, survey respondents discussed the value and use of tools and techniques to solicit patient engagement in their medical treatment decisions, a process more aligned with informed decision-making.

The Study Group also learned firsthand from the Maine Medical Center Genitourinary Cancer Program about their commitment to shared decision-making in the treatment of prostate cancer patients.¹⁴ The program uses an oncology nurse to help patients navigate through the many decisions faced as part of the treatment process and to support them in living with the decision after it is made. The clinical “navigator” is an independent patient advocate working collaboratively with the patient and clinician to identify and implement treatment options meeting a patient’s preferences and values. The value of the navigator approach to shared decision-making was reinforced by a consumer and Study Group member. Time and resources required to implement the program are not reimbursable and are funded by the Maine Medical Center.

As part of its national demonstration, the Foundation for Informed Medical Decision-Making recently awarded \$185,540 to MaineHealth to help patients use decision aids, licensed and distributed by Health Dialog Inc., to make complex medical decisions in coordination with their physicians. Participants in the three year study will be identified through an electronic medical record system. Health educators located at MaineHealth’s Learning Resource Center will be available to support patients' use of these materials and answer questions.¹⁵ A major goal of the project is to learn more about how to implement shared decision-making as part of routine primary care practice.¹⁶

Another Maine-based study will directly compare different types of decision aids (decision cards versus video and/or print) as well as different approaches to integrating shared decision-making in practice (use of decision aid alone, with a navigator/coach, with a physician). Focused on shared decision-making for “low risk” prostate cancer and low back pain, this collaborative study^{††} will assess outcomes related to treatment choice, health service use, cost and cost-effectiveness.¹⁷

Several collaborators at Maine Medical Center’s Center for Outcomes Research and Evaluation have received grant support from the Maine Cancer Foundation for the development of personalized risk prediction tools. The results from the study “Predicting quality of life outcomes after prostate cancer treatment” will allow care providers and patients to better predict urinary continence and erectile function outcomes following surgery or radiation therapy treatment at Maine Medical Center. Such shared

^{††} Study collaborators include Maine Medical Center’s Genitourinary Cancer Program, Maine Medical Partners Neurosurgery and Spine programs, Maine Medical Center’s Center for Performance Improvement and Maine Medical Center’s Center for Outcomes Research and Evaluation.

information platforms will help patients make better informed and more personalized treatment decisions.¹⁸

Investigators in Maine have been involved in research on developing standards for assessing the quality of decision aids as part of the International Patient Decision Aids Standards Collaboration (IPDAS),^{19,20} assessing the impact of decision aids on multiple outcomes through the Cochrane Collaboration,^{21,22} measuring the impact of decision aids on cost,²³ and measuring the potential for bias in decision aids.²⁴

The Maine Patient-Centered Medical Home pilot offers technical assistance to support the 26 participating primary care practices in implementing patient shared decision-making for preference sensitive care (Email correspondence with Lisa Letourneau, MD, February 24, 2010). These resources are being made available to support practices in their effort to transform to a more patient-centered model of care and to meet the core expectations of the pilot.

The Maine Health Management Coalition completed Phase 1 of a two-part study to develop a research and education program for shared decision-making for minimally invasive procedures.²⁵ Funded by Ethicon Endo, a manufacturer of minimally invasive surgical equipment, the study conducted surveys and interviews with local physicians and a consumer focus group to assess the content and administration avenues for decision aids developed by Ethicon Endo. The study noted that the effectiveness of shared decision-making very much relies on changing the behaviors of physicians, staff and patients as consumers become more engaged parties in the decision-making process. A materials distribution strategy will be developed in Phase 2.

CHALLENGES TO IMPLEMENTATION

Muskie School survey respondents identified challenges to implementing shared decision-making similar to those found in the research literature. Most commonly cited challenges include:

Time – A lack of time for prolonged clinical interactions with patients is a primary concern when trying to integrate shared decision-making into clinical practice.^{26,27} Although generally considered to be a time consuming proposition, studies differ on whether shared decision-making increases the interaction time between patient and physician.^{26,27}

Provider training – Shared decision-making is a new concept for providers and has not been modeled in practices or medical schools. Physicians need training in the use of decision aids and guidance in how to initiate the process.^{27,28} They also need to differentiate shared decision-making from informed decision-making. Results from the Muskie School survey revealed that many physicians mistakenly believe they are already practicing shared decision-making with their patients when providing information on treatment options. As one respondent stated, “I am quite sure our breast surgeons use shared decision-making. They present the patients with the pros and cons of breast conservation versus mastectomy... They ... obtain informed consent at that time if the patient is ready to make a decision. Otherwise the patient is sent with reading material and will call once they have reached a decision.”

Reimbursement – With more time and resources required, providers understandably look for increased compensation when implementing shared decision-making in their practices. Nationally, there is no system of reimbursement in place.^{26,28} With the assistance of Jana Purrell, a former consultant specializing in medical coding, the Study Group examined possible codes for reimbursing time devoted to shared decision-making. The Group was advised that there are no standard or local codes specific to shared decision-making but that codes for evaluation and management may be applicable. Time-based evaluation and management codes can be used if more than half of the visit is spent in counseling and/or coordination of care. To code based on time, there must be documentation of the total time spent with the patient, the amount of time spent in counseling/coordination of care, and a detailed description of what was discussed. Alternatively, a clinician could use a general code for an evaluation and management visit if the visit also includes history taking, physical exam and medical decision-making (Email correspondence with Jana Purrell, March 29, 2010).

There is a perception among some that shared decision-making simply represents good practice and should not receive differential payment. One payor responding to the Muskie School survey noted: “Good practitioners should be discussing all treatment options and the pros/cons...with their patients already, without requiring legislative action that may have unintended consequences (i.e. more administrative procedures, reporting, paperwork, etc. for both practitioners and health plans that will increase administrative costs).”

Patient and physician challenges – Shared decision-making is only appropriate in certain circumstances even when patients have similar diagnoses. First, it applies only where there are multiple options and no best choice, such as during earlier stages of a disease process.^{‡‡} Secondly, patients differ in the extent that they want to share in decision-making, and need different levels of support to understand the choices they have in treatment and the impact of those choices on them in ways that would influence their preferences. In addition, given that shared decision-making often comes at an already stressful time for a newly diagnosed patient, some patients are challenged to take on the added responsibility of participating in their treatment choice. On the other hand, the literature is clear that the substituted judgment of the physician is not an accurate way to assess patient preference.^{29,30} The benefits of shared decision-making are enhanced when there is a decision support component – staff members whose job includes responsibility for helping patients and families to access information about their medical conditions and to help them consider their choices in the context of their values and preferences. Clinicians must be sensitive to the emotional, physical and intellectual capacity of their patients and match the level of decision-making involvement to the individual patient.³¹ While recognizing that patients have a right to shared decision-making, the process of involvement, unfortunately, often relies on the comfort level of physicians in tailoring a process to the needs of a patient. This variable process may deter clinicians from engaging in shared decision-making.²⁷ Conversely, less selective methods of choosing patients, such as automated mailings of decision aids to patients based on diagnoses recorded in their records, carries with it the risk of inappropriate patient selection. The fact that even the provision of health care information is in itself a medical intervention reinforces the need for careful patient selection, and the importance of clinical context.

^{‡‡} Evidence in favor of a certain treatment is often emphatic in later stages of a disease.

■ IMPACT ON COSTS AND QUALITY

In its Resolve, the Maine Legislature expressed specific interest in understanding the potential for shared decision-making to improve the quality of care and reduce unnecessary use of medical services. The literature generally supports the premise that shared decision-making improves quality but is mixed on the question of its impact on costs.

Quality

Most stakeholders agree that shared decision-making is “the right thing to do” because it improves care by empowering the patient to be involved in decisions. One study found that 78.5 percent of patients wanted to be involved in the decision-making process.³⁰ Many researchers have concluded “patient centered decision-making is an important component to quality of care and is closely linked to patient satisfaction”.³² Researchers with the Cochrane Collaboration, after a review of all randomized controlled trials of patient decision aids, reported that decision aids as an adjunct to shared decision-making have no impact on satisfaction with decision making.^{33,23} However, the review showed that decision aids “improve people’s knowledge of the options, create accurate risk perceptions of their benefits and harms, reduce difficulty with decision-making, and increase participation in the process.”³³ Despite null findings on satisfaction, studies find it crucial to gauge a patient's interest and ability to be involved in decision-making. Satisfaction may decrease when involvement in decision-making becomes burdensome to the patient; it may even increase anxiety.³¹

A number of studies reported beneficial health outcomes among patients after shared decision-making. Women with breast cancer, for example, tended to have improvement in overall quality of life, including fewer side effects and better physical functioning, after taking an active role in their treatment decisions.^{29,34,35} In another trial, involvement in shared decision-making improved health behaviors such as diet, exercise, smoking cessation, and alcohol consumption among women counseled in menopausal treatment options.^{36,37} These studies conclude that patients do better when they are involved in their own care. The Cochrane Collaboration, however, found conflicting evidence that patient health or adherence to chosen treatments improve after a shared decision-making process. They cited studies comparing decision aids to routine care and found no difference in how often patients followed the chosen treatment.³⁸ However, there is clear evidence that shared decision-making increases knowledge, improves understanding of risks and benefits of treatment options, increases confidence in decision-making, and results in a choice more in line with patient values.²

The Shared Decision-Making Workgroup of the U.S. Preventative Services Task Force recommends shared decision-making on several grounds: it promotes the ethical treatment of patients by protecting their autonomy; it educates patients about health information; it reduces decisional conflict; and it fosters trust in the health care provider.²⁶ For over a decade, the American Cancer Society has endorsed shared decision-making, specifically for prostate screenings and ovarian cancer.³⁹ The Society cites studies showing most patients also prefer to engage in shared decision-making rather than leave treatment decisions to their doctors.⁴⁰ With the complexity of many cancer screening recommendations, such as prostate specific antigen (PSA) screening and mammograms, the American Cancer Society endorses shared decision-making as a way for clinicians to discuss risks and benefits of screenings with patients

and arrive at a mutually agreeable decision.

Cost

Research by the Dartmouth Institute for Health Policy and Clinical Practice (formerly the Center for Evaluative Clinical Sciences) demonstrated “wide variations in what Medicare spends for services to treat chronically ill patients and that higher spending does not achieve better outcomes”.⁴¹ Findings included evidence that there are higher rates of elective invasive procedures in some regions of the country, with no improvement in quality of care or patient satisfaction with care.⁴ This is not surprising since incentives in medical practice are tied to the procedure performed and not quality.⁴² Shared decision-making offers a possibility to reduce costs associated with *preference sensitive* procedures by allowing patients a role in choosing a treatment based on their values. Studies suggest that patients, when given a choice, tend to favor less invasive procedures.^{4, 33}

The Cochrane Collaboration review concluded that rates of elective surgery, menopausal hormone usage, and prostate specific antigen (PSA) screenings were lowered as a result of shared decision-making with use of a decision aid.³³ For example, because PSA screenings will sometimes detect “low risk” prostate cancers for which there is no best decision on treatment, “watchful waiting” is often favored by patients after undergoing a shared decision-making process.⁴³ However, the impact was modest and inconsistent, with some trials finding decision aids increase breast and colorectal cancer screening rates.⁴⁴ If cancer is detected after a screening, an invasive procedure may not result in a better long-term outcome for a patient, but it will cost a great deal more.⁴² While there is no way to predict what treatment a patient will choose after participating in shared decision-making, since information will be presented impartially, evidence that aggressive procedures may decline as a result of shared decision-making is encouraging. The Washington State pilot is assessing the impact of decision aids developed by a specific vendor, so more conclusive evidence may be forthcoming.¹¹

The Lewin Group applied existing studies to estimate potential savings among Medicare patients with any of 11 conditions who used decision aids. However, their estimated savings of \$4 billion over a ten-year period assumed that there would be a co-payment penalty if patients chose a higher cost procedure where a less costly procedure was as effective. The analysis also assumed a “denial of payments to physicians and hospitals for higher-cost services performed when a lower-cost alternative of at least the same effectiveness is available”.⁴⁵

Studies on cost impact generally do not account for the increased expense of purchasing decision support tools such as interactive video disks, screening for appropriate patients, training clinicians, and implementing neither procedural changes nor the clinical time required to participate in the process. While there are ways to minimize costs by having nurses coach patients, for example, or using less costly or free tools, additional costs are likely.² Increased interaction time with physicians may also increase costs, although trials cited in the Cochrane Database of Systematic Reviews found conflicting evidence that use of a decision aid increases consultation times.⁴⁶ One study found consultations increased by six minutes when a decision aid and shared decision-making were used.⁴⁷ Another found interaction time was eight minutes shorter when similar consultation techniques were used.⁴⁸ Testing these outcomes in real world settings rather than controlled trials would help determine average consultation time for shared decision-making and how it would impact cost.

In a health coaching program, funded by Health Dialog, cost reductions of 4.4 percent were shown for patients selected for “enhanced-support”. These patients received coaching from nurses by phone, educational software, print materials and DVDs on various health conditions. Results showed a reduction in hospital admissions, emergency room visits, and surgical procedures among this population as compared to those not receiving the “enhanced-support”.⁴⁹ The results demonstrate the potential cost advantages of educating patients using decision aids. However, since patients did not consistently receive the real-time interaction characteristic of shared decision-making, more studies are warranted. In addition, this study measured outcomes after one year; it is not clear of the long-term savings associated with the interventions. The Dartmouth Institute and Maine Medical Center completed a collaborative study “Measuring the impact of a Navigator over time”. This study assessed the impact of shared decision making using a patient navigator on treatment choice and cost for men newly diagnosed with prostate cancer. This retrospective cohort analysis found that following the introduction of a dedicated prostate cancer navigator at Maine Medical Center in April 2008 men with “low risk” prostate cancer were more likely to elect active surveillance as a management option, with a trend towards less surgical and radiation therapy intervention. Not surprisingly, overall costs for active surveillance were less than for patients treated with surgery or radiation therapy. However, over the 2006 – 2009 study period, treatment costs were higher across all treatment options after introduction of the navigator, likely largely due to medical inflation. This study underscores the complexity of linking the impact of shared decision making to costs as a result of changes in patient treatment choice.⁵⁰

A recent meta-analysis of the total costs associated with shared decision-making, including the costs of developing and distributing decision aids as well as their impact on health service utilization, found that shared decision-making increased health care costs by \$164.29 per patient per year (the range was -\$298.72 - \$627.30).²³ This meta-analysis of patient decision aids did not include the trial on health coaching described above, which reported a savings of \$7.96 per patient per month.⁴⁹

Cost savings identified through clinical studies have not examined a long enough time horizon to understand whether patients subsequently change their mind and later opt for more expensive procedures or whether substitution effects occur (e.g., less invasive procedures may be accompanied by more use of other tests or clinical services) as was demonstrated in one study which tracked these outcomes.⁵¹

Although research on the subject has failed to show conclusive cost savings associated with shared decision-making, there are several other areas of promise. Some studies show patients actively involved in health-related decisions tend to have better health outcomes.^{29, 35} This could reduce the need for follow up care or more costly interventions if these findings can be demonstrated in real world practice. Shared decision-making, as a component of informed consent may also reduce malpractice and liability claims, since the creation of a collaborative partnership in decision-making may make patients feel more empowered and less likely to hold a health provider liable should a complication occur.⁵² More research is needed to prove this hypothesis.

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APPENDIX A

Legislative Resolve

SP0493, LD 1358, item 2, 124th Maine State Legislature , Amendment C "A", Filing Number S-218
'Resolve, To Study Implementation of Shared Decision Making To Improve Quality of Care and Reduce Unnecessary Use of Medical Services'

PLEASE NOTE: Legislative Information **cannot** perform research, provide legal advice, or interpret Maine law. For legal assistance, please contact a qualified attorney.

Amend the bill by striking out the title and substituting the following:

'Resolve, To Study Implementation of Shared Decision Making To Improve Quality of Care and Reduce Unnecessary Use of Medical Services'

Amend the bill by striking out everything after the title and before the summary and inserting the following:

Sec. 1 Implementation of shared decision making. Resolved: That the Maine Quality Forum shall convene an advisory group of stakeholders, including, but not limited to, representatives of MaineCare, the Maine Health Data Organization, the state employee health insurance program, health insurance carriers, hospitals, physicians, health care providers and consumers, to develop a plan to implement a program for shared decision making as a strategy to improve the quality of health care in the State and control the unnecessary use of preference-sensitive health care services. The advisory group shall consider the following issues:

1. The appropriate preference-sensitive health care services for use in a shared decision-making program and an accepted protocol for shared decision making;
2. The availability of approved patient decision aids relating to each health care service and the effectiveness of patient decision aids;
3. The payment method to be used by health insurance carriers and public programs to reimburse for services provided by a shared decision-making program;
4. The appropriate incentives to encourage use of a shared decision-making program by providers and patients;
5. Evidence-based studies that evaluate shared decision making; and
6. Any barriers to implementation of a shared decision-making program; and be it further

Sec. 2 Report. Resolved: That the Maine Quality Forum shall submit a preliminary report on the findings and recommendations of the advisory group on or before February 1, 2010 to the Joint Standing Committee on Health and Human Services and the Joint Standing Committee on Insurance and Financial

Services. Before February 1, 2011, the Maine Quality Forum shall submit a final report to the joint standing committee of the Legislature having jurisdiction over health and human services matters and the joint standing committee of the Legislature having jurisdiction over insurance and financial services matters. The joint standing committee of the Legislature having jurisdiction over health and human services matters and the joint standing committee of the Legislature having jurisdiction over insurance and financial services matters may each report out a bill to the First Regular Session of the 125th Legislature based on the final report.’

SUMMARY

This amendment replaces the bill with a resolve and changes the title. The amendment requires the Maine Quality Forum to convene an advisory group of stakeholders to develop a plan for implementation of shared decision making as a strategy for improving the quality of medical care and for controlling the unnecessary use of preference-sensitive health care services. The amendment requires the Maine Quality Forum to submit a preliminary report on February 1, 2010 and a final report by February 1, 2011 to the joint standing committees of the Legislature having jurisdiction over health and human services matters and insurance and financial services matters.

APPENDIX B

Shared Decision-Making Survey

REQUEST FOR INFORMATION

Use and Payment of Shared Decision-Making in Maine

Background

During its last session, the Maine legislature authorized the Maine Quality Forum to convene an advisory group to study the issue of shared decision-making and to make recommendations on a strategy for promoting its use in Maine. One aspect of their work is to better understand the extent to which shared decision-making is currently used in Maine and reimbursement methods that are available.

Definition

The Shared Decision-Making Study Group generally agreed that shared decision-making occurs when patients are faced with two or more treatment options with no clear best choice in terms of survival, outcome, or functionality. The following working definition has been adopted.

A decision-making process jointly shared by patients and their health care provider.

The group recognizes that other forms of enhanced decision-making exist including informed decision-making and that current terminology is imprecise. We are interested in how improved patient decisions are being supported in Maine.

Purpose of Survey

The following survey is being sent to major payers in Maine and large health systems in Maine and nationally. Information obtained from the survey will be used to assess current opportunities and barriers to implementing shared decision-making and to inform recommendations to the Maine State Legislature.

1. Person completing the survey [name, title, email address]

2. Name of organization
 - a. Name
 - b. Type
 - i. Health care provider
 - ii. Payor
 - iii. Other (please specify)

3. Does your organization have current policies or guidelines governing the practice or payment of shared decision-making?
 - a. Yes
 - b. No (Skip to Q7)

4. Are current policies or guidelines limited to specific clinical services, settings or practitioners?
 - a. Yes (please describe)
 - b. No

5. Please describe the purpose and scope of current policies or guidelines. [open text]
6. If applicable, please provide the definition of shared decision-making included in current policy or guidelines. [open text]
7. Is your organization actively considering the development of policy or guidelines governing the practice or payment of shared decision-making?
 - a. Yes
 - b. No (Skip to Q11)
8. Please describe the nature of that activity, participants, timelines, and expected products. [open text]
9. If applicable, please provide the working definition of shared decision-making that is being used in these activities. [open text]
10. Please describe any current or proposed methods that have been developed to document the occurrence of shared decision-making, such as new codes or other data entry. [open text]
11. Please describe the major barriers you see to the use and payment of shared decision-making among practitioners and patients? [open text]
12. The Shared Decision-Making Study Group welcomes your input. Please describe any legislative or other statewide action that you believe would enhance the use of shared decision-making in Maine. [open text]