Measuring Shared Decision Making in Practice: Priorities from the 2012 Dartmouth Summer Institute for Informed Patient Choice

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Abstract: *Objectives:* The Dartmouth Summer Institute for Informed Patient Choice (SIIPC) seeks to prepare the next generation of scientists to investigate problems and solutions in the field of patients' health care decision making. The theme of the 2012 SIIPC was, "Measuring Shared Decision Making in Practice".

Methods: Twenty-five content experts in shared decision making and measurement presented the state of the science. Using a modified nominal group technique, 115 attendees from seven countries identified measurement priorities and proposed solutions for measuring shared decision making in clinical practice.

Results: Participants identified six priorities for measurement: 1) a clear and measurable definition of shared decision making; 2) decision quality measures for audit, feedback, and public reporting; 3) measures that are acceptable to clinicians; 4) measures that are meaningful to patients; 5) consensus on a standard minimum data set; and 6) actionable information for organizations and policy makers. Potential barriers and proposed solutions are presented.

Conclusions: Use of sustainable, standard shared decision making measures capable of providing timely, actionable insight into patient-provider communication and decision processes is a first step in increasing awareness.

Practice implications: Increased public awareness and additional training for clinicians are priorities for measuring shared decision making in clinical practice.

Keywords: Decision Quality, informed patient choice, measurement, shared decision making.

1. INTRODUCTION

The Dartmouth Summer Institute for Informed Patient Choice (SIIPC) is held annually by the Dartmouth Institute for Health Policy and Clinical Practice. Founded in 2007 by Drs. Hilary Llewellyn-Thomas and Annette O'Connor, the overall goal of the SIIPC is to identify and mentor the next generation of scientists who are prepared to investigate basic and applied problems in the field of patients' health care decision making - with a particular emphasis on the provision of decision support (DS) using patients' decision aids (PtDAs).

Each year, the planning committee identifies a scientific theme in the field of DS/PtDAs, and invites faculty who are world leaders in the thematic area to identify the current state of the science and emerging opportunities, and outline how best to prepare the next generation of scientists to seize those opportunities. Fellows and attendees of the SIIPC join in discussion with faculty and engage in directed activities to address pressing concerns.

The 6th Annual SIIPC was held from July 9-11, 2012, with a theme of "Measuring Shared Decision Making in Practice". The theme was largely motivated by the need for measures that can evaluate the impact of shared decision making (SDM) and the use of PtDAs. This paper summarizes the discussions and work group activities of the 2012 SIIPC, and can be used as an agenda for researchers, clinicians and policy makers who are interested in advancing measurement of shared decision making in clinical practice.

2. METHODS

2.1. Institute Agenda

The Institute agenda incorporated essential elements of health care delivery science with didactic, multi- and interdisciplinary presentations by 25 local, national and international innovators of shared decision making measurement. Participant engagement activities were

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Table 1. Priorities for measuring shared decision making in clinical practice.

Priority	Barriers	Proposed Solutions
Clear and measurable definition of shared decision making	Language, goals and indicators may vary across disciplines	Different language may be used, however essential elements should include: engaged communication between patient and clinician; and eliciting the patient's medical goals and lifestyle preferences to come to an informed, values-based choice.
Decision quality measures for audit, feedback, and public reporting	Methodological challenges and lack of clear linkage to health outcomes.	Short term: SURE scale screen Long term: develop taskforce charged with analysis of multidisciplinary theories to arrive at consensus.
Measures that are acceptable to clinicians	Constraints in both clinical practice and medical education limit the time, tools, and incentives for effectively teaching, providing, and measuring shared decision making.	Provide educational programs for SDM across curricula. Provide fiscal and legal incentives for clinicians who engage and demonstrate proficiency in SDM.
Measures that are meaningful to patients	Need to define what is meaningful to patients? Underserved groups and patient proxies need to be included. Language can be a barrier between clinicians and patients.	Create a Meaningful Use Requirement that includes SDM. Radically re-envision the EMR to include bi-directional use for/by patient & clinician Increase patient voice for health care decisions.
Consensus and standardization of a minimum data set	Differing priorities across stakeholder groups. Clear and meaningful outcomes must be identified to address the heterogeneity of systems and contexts.	Create a panel of diverse stakeholders to assess measures already in use and identify gaps. Publish a consensus statement promoting a minimum SDM data set.
Actionable information for organizations and policy makers	Competing priorities and current culture. Lack of data on costs and impact on workflow.	Determine important outcomes and report on cost and impact of SDM across systems and payment structures. Process mapping to understand and model costs. Public and provider education initiatives.

included across 15 sessions that focused on: 1) State of the Science: Measurement of SDM and Decision Quality; 2) SDM Measurement in Healthcare Systems: U.S.& Beyond; 3) SDM Data Collection and Use: Routing Care and Public Reporting; 4) Patient-Centered Co-Design of Care: Lessons for Shared Decision Making; and 5) SDM Measurement: Defining the Path Forward.

2.2. Participant Procedures

On the first day of the institute, participants engaged in a modified nominal group technique [1] to identify the top priorities by posing answers to the following question: "What is the most important priority or key issue around measurement that will accelerate the broad adoption of shared decision making in clinical practice?"

During the second day, breakout groups were organized and led by pre-identified faculty moderators. Participants were asked to self-assign to priority topic areas ensuring that participants were personally and professionally motivated to engage in the topic of discussion. The breakout groups were allowed 1 hour and 15 minutes to accomplish three tasks using a structured format: 1) Define the priority; 2) Identify barriers/challenges; and 3) Propose solutions.

On the final day of the institute, representatives from each priority group reported the results to the attendees. A

panel of six experts (representing patients/consumers, clinicians and policymakers) reacted to the reports and provided initial commentary. The institute fellows then engaged in an institute-wide discussion to expand and refine their final measurement priority reports.

3. RESULTS

A total of 115 individuals from seven countries attended the SIIPC 2012. Participants included primary care and specialty clinicians, health outcomes researchers, shared decision making educators, health coaches, healthcare lawyers, graduate students, patient advocates, and patient representatives. More than 80 topics were generated as potential SDM measurement priorities by the attendees; results from the nominal group ranking exercise identified the top six priorities (Table **1**). Highlights from the group work, including barriers and potential solutions for the priorities are described in detail. The ordering of the priorities reflects the order of presentations at the Summer Institute.

3.1. Definition of Shared Decision Making with Clear Goals and Measurable Indicators

This group had 19 participants and 2 moderators. A standard definition of shared decision making has the

benefits of: 1) creating consistency across clinical implementation and research measurement projects, 2) engaging diverse groups of stakeholders (patients, clinicians, researchers, policy makers), and 3) supporting priority-setting by institutions. More than 40 definitions of "shared decision making" are available in the published literature and many SDM definitions share similar elements. The workgroup borrowed heavily from Charles, 1997 [2] in drafting a shared decision making definition as:

"An interactive process of communication between patient and provider with the goals of –

1) providing evidence-based clinical information on risks and benefits of options;

2) eliciting patient values and preferences; and

3) making a decision based on the informed patient's preferences."

Getting agreement on the language of SDM will have inherent barriers, and there was some discord even among the workgroup. Failure to adequately communicate and promote what researchers and practitioners mean by shared decision making is a potential barrier. For example, clinicians may not fully understand the ethical precept of the term "shared decision making" confusing it with, "I talk to my patients every day", or they may respond, "Who has time given my busy clinic schedule" [3]. Also, goals and indicators may vary by across disciplines (e.g. clinical, research, legal, health policy professionals may have different perspectives on SDM).

By day three, most participants agreed that the language used to define shared decision making and the associated goals and indicators may vary depending on the situation. However, there was general consensus on the essential elements of shared decisionmaking, including engaged communication between the patient and clinician to evaluate the patient's medical goals and lifestyle preferences to make an informed choice [4].

3.2. Decision Quality Measured for Audit, Feedback, and Public Reporting

This group had 12 participants plus a moderator. Decision Quality was defined as the degree to which patients are a) well-informed about treatments that are clinically appropriate and b) receive treatments that are congruent with their goals and values [5]. As the purpose of shared decision making is to improve the quality of medical decisions, generating consensus on the essential components of a high-quality decision will facilitate standardized measurement of shared decision making.

Decision quality measures can play a role in accountability, generate public awareness, and inform and change clinical practice. Some methodological challenges to establishing measures for decision quality include: lack of consensus, need to reconcile divergent theories, and challenges to assessing values congruence. Further challenges include lack of clear linkage to health outcomes and other measures (e.g. cost, mortality, adverse events), as well as time and fiscal constraints [5, 6].

The group generated some solutions that include both short-term and long-term efforts. In the short-term, the SURE test (a 4-item validated version of the Decisional Conflict scale [7]) can be rapidly implemented as a generic screener to measure decision quality. While the SURE scale has the advantage of generalizability, it may be limited as a detailed measure for decision quality.

A long-range solution could include a taskforce with a broad range of stakeholders charged with analysis of multidisciplinary theories and measures towards comprehensive consensus on measurement of decision quality. As initial consensus is reached, long-term efforts to identify champions in the field and adopt a change theory can begin to identify opportunities for incentives at the institutional level. Finally, infrastructure that allows for ongoing audit, feedback, and public reporting can provide adaptable and sustainable processes of measurement.

3.3. Acceptability of Measures to Clinicians

This priority workgroup included 13 participants and two moderators. Clinician buy in and acceptability of measures are essential elements for shared decision making in practice. Significant barriers to implement shared decision making in clinical settings include the lack of resources for clinicians to be able to effectively diagnose both a patient's disease and their informed preferences when two or more treatment options are available [8]. Current constraints in both clinical practice and medical education limit the time, tools, and incentives for effectively teaching, providing, and measuring shared decision making as a clinical skill [9]. Meanwhile, progress in medical science leads to more situations where two or more "medically-appropriate" options are available. This necessitates a shift in traditional clinical decision making that recognizes the role of two experts in the decision-making process; the clinician (*i.e.* clinical evidence) and the patient (*i.e.* informed preferences).

Proactive approaches to successfully adopt this shift from informed consent to informed choice currently vary by practice, institution, system, country, and culture [10-12]. Many systems face time and fiscal constraints that challenge even the skilled clinician in their ability to fully inform patients, assess which risks/benefits patients value most, and reach a well-informed shared decision. Across these challenges, it is important that the essential measures of shared decision making are acceptable to clinicians in terms of cost, time, limited need for any additional training, minimal increased burden, and defined paths for reimbursement. A key consideration is whether the measure provides information that is of value to clinicians in their practice.

Addressing these challenges requires measurement strategies that extend across the care pathway. The three most often reported facilitators of engaging clinicians in shared decision making are: provider motivation, positive impact on the clinical process, and patient outcomes [9, 13]. Programs in decision support as a clinical skill should be included in the medical training curriculum and accreditation review.

The electronic medical record (EMR) may provide additional opportunities to enhance provider acceptance of SDM measures. Making patients' decision aids available within the EMR may reduce the time clinicians have to spend addressing misconceptions and can also provide the clinic with needed decision support tools while simultaneouly providing measurement. Lastly, and perhaps most importantly, legislative and reimbursement changes are essential to provide fiscal and legal support for clinicians who demonstrate high-quality shared decision making with their patients.

3.4. Meaningfulness of Measures to Patients

The eight-person workgroup plus a moderator defined this priority area as the need to create measures of shared decision making that are meaningful to patients. The need for measures that are meaningful to patients was considered an essential element of ensuring that shared decision making is consistently integrated across all aspects of the process - from its ethical motivation, rigorous research methods, and evidence-based clinical practice interventions, to measurement and continual optimization.

The top barriers reported by the group included the need to: 1) give voice to all types of patients (e.g. representativeness of underserved groups) and other decision makers (e.g. caregivers, legal proxies); 2) maintain a clear, shared language between clinicians and patients; 3) identify methods for assessing which measures are meaningful; and 4) optimize meaningful measures that are feasible within clinicians' work flow and patients' life flow.

To address these barriers, the workgroup's solutions focused on increasing the patient voice towards "shared" priority-setting, re-envisioning the electronic medical record, and creation of a meaningful use requirement. The first solution addressed the challenge of determining what is "meaningful" by increasing the patient voice early in the processes of research, intervention, measurement, and implementation. This solution includes increased use of existing approaches (e.g. community-based participatory research, stakeholder members on advisory committees, qualitative pilot studies, formal usability/accessibility assessments, user-centered studies, etc.) and development of novel approaches for rapid feedback within electronic medical records and measurement systems.

The second solution addressed the need to streamline usability within clinicians' work flow and patients' life flow by radically re-envisioning the potential of the electronic medical record. Through bi-directional design for, and use by, patients and clinicians, shared decision making tools and measures could be optimized in the EMR to provide, "the right care, to the right patient, at the right time" [14]. Finally, the panel proposed creating a Meaningful Use Requirement for shared decision making that maintained a shared language (e.g. asking patients: What are your health care goals? or, What is most important to you in this decision?) and requiring documentation of patient responses.

Patients not only have the right to make an informed choice, they have a responsibility to participate in their health care decision making. Engaged patients are essential to drive the improvement of SDM measurement [15, 16].

3.5. Consensus and Standardization of a Minimum Data Set

This group had seven participants plus a moderator. Creating a common measurement tool and data set with the minimum information is necessary to show the impact of shared decision making on health outcomes. Establishing a minimum data set for SDM would allow for comparisons across institutions/systems/countries, isolation of performance indicators that underlie results, creation of a unified voice for SDM, and increased sense of information and ownership for all stakeholders. However, three main barriers were identified. First, differing priorities across stakeholder groups must be addressed to achieve consensus on a set. Second, to develop an efficient and effective instrument, clear and meaningful outcomes must be identified. Third, successful and sustainable implementation must include both standardized components and flexible components to address the heterogeneity of systems and contexts.

To address these barriers, a panel of diverse stakeholders should pool measures already in use, identify gaps, and assess the strengths and weaknesses of available instruments. Then, the stakeholder panel could be convened to generate consensus around a set of measures and publish a consensus statement promoting a minimum data set. The design approach should be practical and allow for at least some customization.

3.6. Actionable Information for Organizations and Policy Makers

This group had nine participants plus a moderator. The priority was defined as, "better utilization of SDM will lead to more value for society; better service for patients; better physical and mental health for the population; and better financial health for businesses". In order to bridge the gap between the efficacy demonstrated by SDM in dozens of research trials and the lack of widespread dissemination and implementation, the group focused on the role of organizations and policy makers in setting the context for and promoting SDM.

The group highlighted several challenges. Current medical culture, provider training and education often lack attention to core competencies of SDM. For example, medical training prioritizes knowledge and skills needed to make a correct medical diagnosis, but this alone is insufficient without attention to determining the treatment that is most aligned with a patient's preferences. There is often a chasm between what providers think their patients want and what is truly important to patients [17, 18]. Furthermore, an individual patient can have preferences for treatments and outcomes that change over time. This means that getting the medical diagnosis correct is not the full measure of quality care. When thought of this way, getting a patient's preference diagnosis correct is no less daunting than getting the medical diagnosis correct [19].

The lack of data to guide treatment decisions or other care decisions is another key barrier. Many chronic conditions require treatment decisions that medical science

has not yet addressed. For example, the most effective interval between physician visits is unknown for patients with congestive heart failure or chronic obstructive pulmonary edema. In both of these cases, getting only the medical diagnosis correct will not provide sufficient information to arrive at a treatment plan. Additional barriers include competing priorities and the considerable impact on workflow that solutions to these issues may require.

One solution recommended by the group is that organizations and policy makers ensure that providers know how to communicate with patients in a manner that encourages SDM. Training providers to arrive at just the medical diagnosis is no longer adequate. Providers need to know how to get the preference diagnosis correct. After all, providers are often asked, "What would you do if it was you?" Provider training should include skills on: 1) recognizing a choice situation; 2) appreciating patient expertise; 3) eliciting patient knowledge and preferences; 4) explaining common treatment options and common Frequently Asked Questions (FAQs); and 5) incorporating the informed patient's preferences into treatment planning.

Organizations and policy makers are also concerned with the costs and financial consequences of SDM. The lack of data on the costs and consequences of implementing SDM is another a key barrier. While the utilization of decision aids to encourage SDM has been associated with many positives for patients -- including increased knowledge scores, more accurate risk perception, and more explicit values clarification [20] -- implementation has direct, indirect, and opportunity costs. A subgroup analysis of 11 trials suggests that informed patients might be less likely to use expensive invasive treatment options. This finding suggested the use of decision aids might be associated with reduced healthcare spending for payers [21].

DISCUSSION AND CONCLUSION

Discussion

A common theme that emerged from the Institute was the need for increased awareness of shared decision making as a standard in clinical practice and in public health. Institute participants listed a broad array of different issues that would advance the field and identified six topics as priorities. These priorities focus on having clear definitions of SDM and decision quality, and generating consensus on a core set of measures that are meaningful to key stakeholders, including patients, providers and policy makers.

The Institute led to several projects seeking to advance these priorities. A recent systematic review by one of the authors (TW) and colleagues of the costs and spending associated with decision support interventions found the quality of economic analyses to be low to moderate and the risks of bias in the studies to moderate to high [22]. The authors reaffirmed the benefits of SDM and the ethical rationale for informing patients of their treatment options and called for caution regarding promises of systematic savings from the use of decision support interventions.

Second, another author (KS) has worked with the National Cancer Institute (NCI) to launch the NCI Grid

Enabled Measures (GEM) Shared Decision Making Measures project. In this project, the NCI hosts a website that encourages users to upload their measures, define key constructs and then rate measures. The end result is a living repository for measurement that can be used to try to promote standardization and harmonization of measures (https://www.gem-beta.org/).

Third, one author (AH) received a grant from the Department of Health and Human Services (DHHS) to develop and test an integrated system of patients' decision aids and quality measures that are meaningful, usable, and timely. This project convened a multidisciplinary stakeholder panel to identify meaningful and shared decision support language, tools, and measures by integrating research methods from decision support, informatics, and implementation sciences. Results will be applied in a practical example to assess whether an online suite of patients'/families' decision aids for dementia care can a) extend access of timely decision support tools into the community, b) provide tailored support at each decision point across chronic care management, c) assess decision quality measures in real-time, and d) feedback responses into the electronic medical record. Successful completion will provide a model of patient-centered interdisciplinary research methods, and a model of Internet-delivered decision support and quality assessment measures.

Fourth, the High Value Healthcare Collaborative (HVHC) received a $26 million award from the Center for Medicare and Medicaid Innovation (CMMI, award 1C1CMS331029) to implement shared decision making processes, tools and measures across 15 member organizations for patients with diabetes or congestive heart failure and patients considering hip, knee, or spine surgery. Dartmouth serves as the facilitator and data convener for HVHC member organizations, which collectively serve a market of more than 70 million people across the United States. The goal is to achieve a healthcare cost savings of $64 million over three years, largely through reduced utilization and costs that have been shown to occur when patients are engaged and empowered to make health care decisions based on their own values and preferences.

Practice Implications

Shared decision making is a key component of patient-centered care, and increasingly a priority for health care systems. For example, in the United States, shared decision making is a prominent feature in patient-centered medical homes and accountable care organizations, and patient and family engagement in healthcare decisions has been identified as one of six national health priorities [23]. In the United Kingdom, shared decision making, as encompassed in the mantra of "nothing about me, without me," has been adopted as core part of government health policy [24].

It is axiomatic that people manage what they measure, and incentives to deliver high quality care need to include high-quality measures that assess whether care meets informed patients' preferences. With the development of standard definitions, minimal use requirements, timely dissemination strategies, and meaningful reporting strategies, these measures will provide clinicians with a "patient

preference lab report" detailing the patient's understanding of the clinical information, clarity about how they personally value the trade-offs in risks/benefits, strength of preference for each treatment option, and access to the resources needed to successfully complete the chosen treatment option [25]. Clinicians will have the information they need to tailor consultations to address any gaps in information comprehension, uncertainty about risks/benefits, correctly diagnose the individual patient's informed preferences to ensure the right care is delivered to the right patient at the right time.

High-quality, standardized, practical measures of shared decision making in practice may also have implications for hospital quality assurance efforts to improve meaningful informed consent, and to reduce medical errors involving overuse of treatments that informed patients may not prefer, and underuse of treatments that patients may not be fully informed about [26].

Finally, at the population-level, measurement of shared decision making may help to improve equity of care. While variations in the utilization of many treatments have been observed (e.g. age, gender, and geographic differences in the use of surgical *versus* non-surgical management of back/hip/knee pain), measures of shared decision making may help identify whether these variations are warranted or unwarranted [26]. Specifically, measures of patients' level of engagement in the decision-making process, comprehension of the clinical information, clarity about how the risks/benefits matter to them personally, and overall decision quality may help to identify the distributions of patients' well-informed, values-based health care decisions. There may be areas where high-quality decisions produce warranted variations in utilization of particular therapies, allowing resources to be shifted to areas with lower-quality shared decision making and unwarranted variations.

Conclusion

The workgroups of the SIIPC 2012 identified six priorities in creating and implementing successful tools for measuring shared decision making in practice, and summarized the current barriers and possible solutions for development and dissemination of SDM measures. Across priority topics, the faculty and participants identified shared needs for clear definitions, multidisciplinary approaches, and early engagement of stakeholders including patients, clinicians and policy makers. They also called for increased use of health information technology, integration of measures into existing care pathways, resources for medical education, and supportive legislation. Effective shared decision-making measures will be essential to facilitate ongoing monitoring, reporting, and continual improvement of quality clinical care decisions in order to ensure that all patients receive care that meets their informed preferences.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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