# **Shared Decision Making About Screening and Chemoprevention**

### A Suggested Approach from the U.S. Preventive Services Task Force

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#### Abstract:

Shared decision making is a process in which patients are involved as active partners with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care. Shared decision making offers a way of individualizing recommendations, according to patients' special needs and preferences, when some patients may benefit from an intervention but others may not. This paper clarifies how the U.S. Preventive Services Task Force (USPSTF) envisions the application of shared decision making in the execution of screening and chemoprevention. Unlike conventional USPSTF reports, this paper is neither a systematic review nor a formal recommendation. Instead, it is a concept paper that includes a commentary on the current thinking and evidence regarding shared decision making.

Although the USPSTF does not endorse a specific style of decision making, it does encourage informed and joint decisions. This means that patients should be informed about preventive services before they are performed, and that the patient–clinician partnership is central to decision making. The USPSTF suggests that clinicians inform patients about preventive services for which there is clear evidence of net benefit, and, if time permits, about other services with high visibility or special individual importance. Clinicians should make sure that balanced, evidence-based information about the service (including the potential benefits and harms, alternatives, and uncertainties) is available to the patient if needed. For preventive services for which the balance of potential benefits and harms is a close call, or for which the evidence is insufficient to guide a decision for or against screening, clinicians should additionally assist patients in determining whether individual characteristics and personal preferences favor performing or not performing the preventive service.

The USPSTF believes that clinicians generally have no obligation to initiate discussion about services that have either no benefit or net harm. Nonetheless, clinicians should be prepared to explain why these services are discouraged and should consider a proactive discussion for services with high visibility or special individual importance or for services for which new evidence has prompted withdrawal of previous recommendations. (Am J Prev Med 2004;26(1):56–66)

#### Introduction

In 1984, the Department of Health and Human Services established the U.S. Preventive Services Task Force (USPSTF) as an independent panel of nonfederal experts that would develop evidence-based

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recommendations on clinical preventive services based on systematic reviews of published research and explicit decision rules for translating science into practice policy. At that time, the central question was whether there was high-quality evidence that showed that a preventive service improved health outcomes. Recommendations were graded according to a scheme adapted from the Canadian Task Force on the Periodic Health Examination, which focused on whether evidence existed to support performing the service as part of the periodic health examination (Table 1). Most preventive services had not been formally studied, and the USPSTF gave many "C" recommendations, indicating insufficient evidence was available to recommend for or against the service. Interventions such as mammography and hypertension screening, however, re-

Table 1. Recommendation scheme for the U.S. Preventive Services Task Force (USPSTF), 1984–1997

Category Strength of recommendations<sup>a</sup>

There is good evidence to support the recommendation that the condition be specifically considered in a

periodic health examination.

There is fair evidence to support the recommendation that the condition be specifically considered in a periodic health examination.

There is poor evidence regarding the inclusion of the condition in a periodic health examination, but recommendations may be made on other grounds.

There is fair evidence to support the recommendation that the condition be excluded from consideration in a periodic health examination.

See

related

Commentary

on page 81.

E There is good evidence to support the recommendation that the condition be excluded from consideration in a periodic health examination.

<sup>a</sup>In its early years, the USPSTF made recommendations based on the presence of evidence for or against a preventive service.

ceived "A" recommendations because formal studies showed that they improved health outcomes. Implicitly, clinicians were encouraged to promote preventive services that had been shown to improve outcomes and give lower priority to those with unevaluated health effects.

В

C

D

In the years that followed, multiple studies of prevention appeared in the literature, enabling the USPSTF to recommend a larger number of preventive services. Because these studies included more precise data on the magnitude of potential benefits and harms than had previously been available, the USPSTF was faced with answering a new and more complex question: Is the magnitude of potential benefit from a service sufficient to outweigh the magnitude of potential harm?

In time, the USPSTF encountered preventive services for which even this question could not be easily answered. The answers did not jump from the pages of clinical trials, but instead depended on the value that individual patients assigned to the potential harms and benefits. Although in some cases the USPSTF was comfortable weighing those tradeoffs based on assumptions of how most patients would value the outcomes, increasingly the USPSTF recognized that patient preferences were too variable to reach a generic determination of what was best.

To reflect its growing recognition of the complexity of its decision making, the USPSTF published a new framework for grading recommendations (Figure 1). This framework drew a distinction between the USPSTF's assessment of the quality of evidence and its subjective judgment about the degree to which benefits outweighed harms. Under this new scheme, the USPSTF assigned "C" recommendations to services thought to have small net benefit when averaged across the population. The USPSTF recognized, however, that the net benefit might be larger for population subgroups with special risk factors or for individual patients with personal preferences that differed from those of the panel. Given that recognition, the USPSTF decided not to make a generic recommendation for

"C" services, but rather to highlight that all "C" decisions are "likely to be sensitive to individual patient preferences."

Explicit language encouraging consideration and discussion of patient preferences also began creeping

into the rationale for those "A" and "B" recommendations in which the USPSTF recognized large or moderate net benefit, but also a substantial potential for harm or a significant amount of uncertainty about which screening modality was best. For instance, in 2002, the USPSTF issued a "B" recommendation for mammography screening and also recommended a conversation with women to ensure a realistic understanding of the limited absolute ben-

efit of screening in the face of potential harms.<sup>2</sup> Additionally, recommendations for colorectal cancer screening indicated that patients should be invited to participate in the process of determining which of the four available screening options was preferable.<sup>3</sup>

| four availal  | ble screening o  | options was pr  | eferable. <sup>3</sup> |
|---------------|------------------|-----------------|------------------------|
| This tre      | nd toward re     | commending      | discussions to         |
| elicit patier | nt preferences   | introduced se   | ome discomfort         |
| for the US    | PSTF. The US     | PSTF did not    | want to suggest        |
| that inform   | ning patients a  | bout the ben    | efits and harms        |
| was unnece    | essary for servi | ces in which o  | discussions were       |
| not explici   | itly recommen    | ded; rather     | it envisioned a        |
| more system   | matic process f  | or some service | es. Members of         |
| •             | -                |                 |                        |

| Quality<br>of<br>evidence | Net benefit |          |       |                    |  |
|---------------------------|-------------|----------|-------|--------------------|--|
|                           | Substantial | Moderate | Small | Zero /<br>negative |  |
| Good                      | Α           | В        | С     | D                  |  |
| Fair                      | В           | В        | С     | D                  |  |

Poor = I

**Figure 1.** Recommendation scheme for the U.S. Preventive Services Task Force (USPSTF), 1998–present. The USPSTF currently makes recommendations based on the quality of evidence and the magnitude of net benefit for a preventive service.

the Task Force disagreed about whether such discussions should be practiced for all preventive services or should be advocated for only certain services, such as those involving "close calls." Many Task Force members expressed concerns for the busy clinician who lacks the time to engage in extended discussions about every potential clinical preventive service that a patient might want. As confusion began to surround the question of whether "A" and "B" recommendations from the USPSTF meant that the preventive service was to be "performed" or "discussed," the panel decided to formulate some suggestions about how the clinician might approach discussions about screening and chemoprevention.

These USPSTF suggestions are summarized in this article, along with commentary on the current thinking and evidence regarding shared decision making between patients and clinicians. Unlike conventional USPSTF reports, this document is neither a systematic evidence review nor a formal recommendation statement. The USPSTF comes to this topic not with its customary objective of evaluating effectiveness, but rather to articulate its finding that shared decision making is a necessary tool for making recommendations to individual patients concerning interventions that have net benefit for some but not for others. This article is, therefore, a concept paper, intended to clarify how the USPSTF envisions the application of shared decision making in the execution of preventive services recommendations.

The suggestions herein were derived from a nonsystematic evidence review and an iterative dialogue between the authors of this paper and USPSTF members, experts, clinicians, and representatives from the Task Force on Community Preventive Services at the Centers for Disease Control and Prevention. Patients were not consulted directly, but their perspective was considered through examination of relevant literature. These suggestions underscore the USPSTF's growing recognition that some recommendations need to be individualized according to patients' special circumstances and preferences.

### Patient–Clinician Interactions on Screening and Chemoprevention

The USPSTF does not endorse a specific style of patient interaction, but does have suggestions for clinicians on how to interact with patients for each of its five categories (A, B, C, D, I) of screening and chemoprevention recommendations.

The USPSTF encourages clinicians to inform patients about recommended services. Ideally this means that clinicians track the "A" and "B" recommended preventive services for each patient, making sure that patients are informed that these services are recommended at given intervals. Many patients may already

be informed about these services or accept them as a routine part of the medical exam (e.g., screening for high blood pressure or obesity), making lengthy and frequent discussion unnecessary. It is prudent, however, for clinicians to be prepared to discuss the potential benefits and harms of these services if patients indicate an interest. For example, clinicians might sensibly prepare to respond to patients' concerns about the rates and consequences of false-negative Papanicolaou smears during cervical cancer screening.

For some "A" and "B" recommended services, clinicians may want to consider more discussion. For example, the USPSTF has recommended (A recommendation) that clinicians discuss aspirin chemoprevention with adults at increased risk for coronary heart disease and that adults not take aspirin prophylaxis without understanding the likelihood of specific benefits and harms.4 Patients with different values might make different decisions about taking prophylactic aspirin; thus, discussion of preferences is necessary. Similarly, the USPSTF has recommended (B recommendation) engaging women who are at high risk for invasive breast cancer and low risk for the adverse effects of chemoprevention in discussions to determine whether chemoprevention for breast cancer is appropriate.<sup>2</sup> This decision also cannot be made from existing evidence but depends on personal preferences.

A proactive approach to discussions may also be desirable for certain "C" and "I" recommended services, particularly if they have high visibility due to substantial media attention and may be on the patient's mind (e.g., prostate cancer screening) or if they have the potential to substantially affect a given patient (e.g., ovarian cancer screening in a woman who has multiple first-degree relatives with ovarian cancer). Given the demands of clinical practice, however, the USPSTF encourages clinicians to rely on clinical judgment when deciding which discussions of "C" and "I" recommendations to initiate and consider decision aids or trained assistants to help provide information about these services. Community approaches such as those suggested by the Task Force on Community Preventive Services<sup>5</sup> may also be helpful to patients in understanding the tradeoffs involved with "close call" or "uncertain" services.

Clinicians are generally under no obligation to initiate discussions of services with "D" recommendations; these are services that the USPSTF has found to be either of no benefit or potentially harmful. Nonetheless, clinicians should be prepared, with the help of decision aids and trained assistants, to explain why these services are discouraged. Clinicians should also consider a proactive discussion for services with high visibility or special importance for the individual, or for services for which new evidence has prompted withdrawal of previous recommendations. For instance, with recent evidence demonstrating the adverse effects

of hormone replacement therapy on the heart,<sup>6</sup> clinicians should consider raising the issue of the appropriateness of hormone replacement therapy with the many women who are currently receiving such chemoprevention. Clinicians may also want to proactively raise the issue of hormone replacement therapy with a woman who places special value on reducing the risk for bone fractures and wants to consider all options. In such circumstances, the woman should be fully informed of the tradeoffs between potential benefits and harms, and of her unique situation that could dictate departure from recommended practice.

Whenever decisions about preventive services must be made, the USPSTF encourages informed and joint decisions. This means that patients should be informed about preventive services before they are performed, and that the patient-clinician partnership is central to decision making. The need for this is most clearly demonstrated for "C" and "I" recommendations that require decision making because of high visibility or special importance to the individual. For such "C" recommendations, in which the average net benefit is small (e.g., osteoporosis screening in postmenopausal women aged <60 years or aged 60 to 64 years with no risk factors), patients may be aided not only by evidence-based information about the magnitude of benefit and its close tradeoff with potential harms, but also by clinician assistance in determining whether their individual risk profile and personal preferences make the net benefit positive or negative. Similarly, for "I" recommendations, in which the evidence is insufficient to recommend for or against screening (e.g., prostate cancer screening), patients may sometimes need both discussion of the uncertainty that precludes a clear recommendation and clinician assistance in determining their preference for or against action in the face of uncertainty.

One important form of informed and joint decision making is "shared decision making," in which patients are involved (to the extent that they desire) as an active partner with the clinician in clarifying acceptable medical options and in choosing a preferred course of clinical care. Although available research shows mixed results about the effect of this type of decision making on health outcomes, support for a patient–clinician partnership in decision making comes from a combination of ethical and practical arguments, which are detailed below.

#### **What Is Shared Decision Making?**

Decision making within a patient–clinician partnership has been alternately called "shared decision making," "informed decision making," "informed shared decision making," "evidence-informed patient choice," "patient centeredness," "enhanced autonomy," "relationship-centered decision making,"

"deliberative decision making," 17 "interpretive decision making," 17 and "mutual participation." 18 Whatever its name, decision making within the patient–clinician partnership universally encompasses a process in which both the patient and clinician share information with each other, take steps to participate in the decision making process, and agree on a course of action.

In some models, the process has clearly defined steps or competencies, which have been identified through focus groups or literature reviews. 9-16 In other models, the process is left to the discretion of the individual patient and clinician. 7,8,17,18 Of those models that define specific steps, many acknowledge the patient's right to relinquish the decision to the clinician and proceed in a paternalistic model, <sup>7–10,12,13</sup> several call for evidence-based presentations of information, 10-14 a few call for physicians to express their preferences, 7,16,19,20 and a few call for an explicit check of patient understanding.<sup>9,10</sup> One model acknowledges the practical limitations of medical practice<sup>10</sup> and proposes a hierarchy of decision complexity, with more complex decisions requiring a greater intensity of interaction than simple decisions.

Some confusion has surrounded the use of various terms for decision making within the patient–clinician partnership, particularly the terms shared decision making and informed decision making. Researchers, patients, and clinicians sometimes use the term informed decision making to describe both independent decision making by the patient and joint decision making by the patient and clinician.

The USPSTF, in collaboration with the Task Force on Community Preventive Services,<sup>5</sup> defines informed decision making (IDM) as an individual's overall process of gathering relevant health information from both his or her clinician and from other clinical and nonclinical sources, with or without independent clarification of values. The Task Force defines shared decision making (SDM) as a particular process of decision making by the patient and clinician in which the patient: (1) understands the risk or seriousness of the disease or condition to be prevented; (2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; (3) has weighed his or her values regarding the potential benefits and harms associated with the service; and (4) has engaged in decision making at a level at which he or she desires and feels comfortable. This process has the goal of an informed and joint decision. Thus, although the definition focuses primarily on evidence for patient involvement, the process necessarily requires clinicians to reveal their clinical reasoning and biases to facilitate a truly joint decision.

Shared decision making differs significantly from decision making under the doctrine of informed consent, which arose in the law in the mid-1970s. Although informed consent was an obvious forerunner of shared decision making, its focus in practice was on clinician

disclosure rather than on joint participation. Informed consent did mandate that patients actively express consent rather than just expressing agreement with, yielding to, or complying with proposed medical care.<sup>21</sup> Its success was measured, however, by clinician disclosures before risky procedures. These disclosures included a description of the proposed treatment, the alternatives to the proposed treatment, and the inherent risks of death and bodily injury, as well as any other information that a reasonable clinician would disclose or a reasonable patient would want to know in the same circumstance. Clinicians could forgo these disclosures if a patient did not want to be informed, if the procedure was simple with little risk, and, if (in the clinician's judgment) it was not in the patient's best interest to know.<sup>22</sup> Although patients' signatures signified their receipt of the information, little attention was given to ensuring active involvement in decision making.

Shared decision making also differs from decision making in consumerism, in which patients gather relevant information from their clinician and other sources (e.g., the Internet) and independently determine which options they prefer. In this model, the clinician's role is not to serve as a partner in decision making; rather it is to execute the selected intervention, without giving special attention to exploring the patient's understanding, values, or reasoning.

#### Why Engage Patients in Shared Decision Making?

Over the last few decades, interest in shared decision making has been growing. In a recent report, a committee of the Institute of Medicine suggested that "a patient–provider partnership is needed to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they require to make decisions and participate in their own care."<sup>24</sup> To highlight the importance of this partnership, the committee identified creating a patient–provider partnership as one of the six principal aims of the 21st-century healthcare system.

Shared decision making can be recommended on multiple grounds. From an ethical perspective, it promotes patient autonomy, protecting the integrity of the patient as an independent and rational decision maker capable of self-determination. From the interpersonal perspective, shared decision making promotes trust in the patient–clinician relationship<sup>25</sup> and may enhance the confidence of patients to participate in their health care.<sup>26</sup> From an educational perspective, shared decision making improves knowledge about screening and chemoprevention options, creates more realistic expectations about benefits and harms, and reduces the decisional conflict associated with feeling uninformed.<sup>27,28</sup> From a utility perspective, the "best choice" for decisions involving close tradeoffs can only

be made by incorporating the personal preferences of the patient.

From a health perspective, evidence that shared decision making improves health outcomes is indirect and mixed. Systematic reviews of decision aids, which are based on the tenets of shared decision making and provide patient education and values clarification, have shown no consistent demonstrable effect on health outcomes. <sup>27–32</sup> This result might have been anticipated because decision aids help patients choose among alternatives in which the balance of benefits and harms is a "close call," thereby creating an environment in which the net health benefit across a population of reasonable people who choose differently might approach zero.

Only a few studies<sup>33,34</sup> have measured adherence to a chosen course of action; such measurements could give further insight into the effects of decision aids and shared decision making. Interventions that have provided patients with training in information-seeking and negotiation skills have resulted in improvements in symptoms and physiologic outcomes.<sup>26,35–38</sup> Importantly these studies have targeted health conditions in which benefits generally outweigh harms for most individuals. Studies in which patients perceive that they negotiate a common plan with the clinician also show benefits in health outcomes,<sup>19</sup> as do studies in which patients perceive that they are active participants in decision making (regardless of their preferred role).<sup>39–41</sup>

## Do Patients Want to Be Actively Engaged in Shared Decision Making?

Patient willingness to participate is critical for shared decision making. A recent review<sup>42</sup> reported mixed interest in participation (19% to 68%), noting that patients who were younger and more highly educated showed greater interest. The authors offered possible explanations for mixed interest, including lack of a clear distinction between medical problem solving, which requires tasks for which patients are not qualified, and medical decision making, which could be shared. 43,44 The authors also noted that patients may not realize that medicine is an inexact science, believing that their clinicians prescribed the only treatment available. Other reasons for lack of interest in participation include lack of understanding that there is a decision to be made, discomfort with a new role in decision making, inexperience with clinicians employing this approach to decisions, steadfastness in preconceptions about the course of care, 43 membership in an ethnic group that does not value patient autonomy, 45,46 and fear of regret for decisions that turn out badly. Clinicians should address such concerns and misconceptions about participation in decision making before assessing patients' desire to participate.

### Are Patients Able to Engage in Shared Decision Making?

Even when patients are interested in shared decision making, inability to understand medical concepts may limit their participation. For instance, multiple studies have demonstrated that some patients have difficulty understanding risk concepts, 47–54 which calls into question their ability to accurately weigh the benefits and harms of preventive services. Low functional literacy and numeracy, each of which affects approximately a quarter of the U.S. population, 55 exacerbate these difficulties. Low literacy has been repeatedly associated with reduced health knowledge and poor outcomes. 56,57

Even patients who have good reading and numeric skills may find themselves at a loss in medical conversations. Clinicians frequently speak in a medical jargon that is inaccessible to patients. Clinicians also use ambiguous qualitative descriptions, such as "some" or "likely," which patients may interpret differently than clinicians intended.<sup>58,59</sup> Furthermore, the normal constraints of short-term memory limit patients' ability to walk away from in-depth discussions remembering all key information.<sup>60</sup>

Fortunately the number of resources available to address these problems is increasing. <sup>56,60,61</sup> These resources allow patients to privately consider complex medical information over time. <sup>29</sup> That said, it is unclear whether patients need to comprehend and remember large volumes of complex information to share decisions about screening and chemoprevention with their clinicians. The effectiveness of providing simple, focused information in concise formats to facilitate shared decision making requires further study.

## What Are Barriers to Clinician Use of Shared Decision Making?

Clinician interest is of critical importance to shared decision making, but few studies have expressly examined clinician interest in engaging patients in the decision making process.<sup>42</sup> Many have observed, however, that clinicians currently face barriers that could potentially diminish initiation of shared decision making.<sup>42,62</sup>

Even the most well-intentioned and conscientious clinicians have difficulty in engaging patients in all appropriate preventive care. With shortened office visits, primary care clinicians struggle against competing demands and opportunities to find the time for prevention. 63–66 Including patients in decision making may aggravate these struggles, resulting in reduced or delayed action as patients consider their options. Alternately, shared decision making may provide patients with skills that improve decision making and motivation across other aspects of their health care, 67 freeing up more time for prevention. The long-term effects of

shared decision making on competing clinical demands are hard to estimate and ripe for study.

The potential financial costs of shared decision making are also of concern. Lack of financial reimbursements is a disincentive to take the time to discuss topics such as breast cancer or colon cancer screening. In addition, the cost-effectiveness of such discussions has not been studied. The cost-effectiveness of shared decision making is expected to be best for decisions that are highly sensitive to patient values. 68 These decisions could be identified by formal decision analysis, <sup>69</sup> but more likely correspond to decisions for which the USPSTF has felt uncomfortable making global recommendations. A hierarchical approach to shared decision making (i.e., using shared decision making for some, but not all, decisions), as suggested in this article, might be expected to maximize the cost-effectiveness of shared decision making for preventive services.

Even when clinicians have the necessary time and financial support for shared decision making, additional barriers exist. Many clinicians lack training in the interviewing techniques needed to engage patients in decision making. The lack of accurate, organized scientific evidence about the benefits and harms of many preventive services leads to confusion about the potential benefits and harms of screening and chemoprevention services, making shared decision making more complex. When organized evidence is available, providers are often uncertain about which decisions require patient participation and about how to communicate technical concepts to patients in simple language that is accurate, balanced, and understandable.

With these barriers, clinicians (regardless of their interest) may have difficulty with engaging patients in shared decision making. Although the potential of creative solutions to increase shared decision making is uncertain, system-level changes may be worth exploring. Health plans could alter reimbursement to encourage time for shared decision making. Delivery systems could modify visit schemes to facilitate group education or promote the use of nurses or case management teams to relieve the time burden for clinicians. Health plans and delivery systems could post shared decision making materials on websites, providing decision support to both patients and clinicians. Such interventions have been shown to improve the processes and outcomes of care in chronic illness<sup>71,72</sup> and offer promise for surmounting barriers to informed and joint decisions.

### How Might Clinicians Facilitate Patient Participation in Decision Making?

Although there are distinct barriers to shared decision making about screening and chemoprevention, clinicians can facilitate this type of decision making using the techniques described below.

**Table 2.** Characteristics of an informed and joint decision

#### The patient must:

- 1. Understand the risk or seriousness of the disease or condition.
- 2. Understand the preventive service, including the risks, benefits, alternatives, and uncertainties.
- 3. Have weighed his or her values regarding the potential harms and benefits associated with the service.
- 4. Have engaged in decision-making at a level he or she desires and feels comfortable.

### Know What It Takes to Make Informed and Joint Decisions

The length of discussions about screening and chemoprevention may vary according to the scientific evidence for that service; the health, preferences, and concerns of each patient; the decision-making style of each clinician; and the practical constraints of any office visit. The measure of an informed and joint decision, however, should not vary (Table 2). A decision should be considered to be adequately informed if the patient (1) understands the risk or seriousness of the disease or condition to be prevented; (2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; and (3) has weighed his or her values regarding potential benefits and harms associated with the service. The decision should be considered jointly made if the patient and clinician participate as partners, each clarifying their knowledge and preferences for the decision.

In practice, patient participation in decision making is on a continuum, ranging from no participation to complete control of the decision. Although joint decision making may be ideal, participation should be considered satisfactory when the patient has participated at a level at which he or she desires and feels comfortable.

To facilitate patient understanding about screening and chemoprevention, the USPSTF suggests that all clinicians be prepared to respond to patients' needs for balanced, unbiased, and evidence-based information to patients. To facilitate accurate weighing of patient preferences, clinicians should contrast the rationales used by patients who decide for screening or chemoprevention and those who decide against it. Clinicians should also encourage patients to consider their own values for the potential harms and benefits associated with the decision. Ideally, clinicians would help patients to identify and overcome social, financial, or other barriers that, if absent, would alter their decision.

#### **Set Reasonable Expectations**

Patients are often eligible for more than one preventive service for which shared decision making might be a useful adjunct. Performing shared decision making for all such services in one office visit, however, is rarely feasible. Clinicians who have ongoing relationships with patients may stagger discussions across several office visits, focusing first on the issue that they and their patients mutually identify as the highest priority and deferring other discussions to a later date. The initial discussion can represent the first step in the shared decision-making process; patients can then be encouraged to review additional information at home and further consider their preferences before making a final decision at a future visit. Clinicians may also want to involve other staff in the shared decision-making process, allowing the clinician to focus on answering questions and negotiating an agreement. Other staff could spend more time with the patient on education and decision support.

#### **Consider Decision Aids**

The USPSTF suggests that clinicians consider decision aids as a way of providing information in an efficient and tailored manner. Good decision aids (e.g., pamphlets, computer programs, audio-guided workbooks, videotapes, videodiscs, decision boards, and web-based tools) can offer balanced, unbiased, and evidencebased information, in addition to values clarification,<sup>27</sup> and can be employed both within and outside the patient-clinician encounters to promote shared decision making. As previously noted, these aids have been shown to extend participation in medical decision making and enhance knowledge about the decision.<sup>29</sup> Several aids are now available commercially (www.  $health dialog.com)^{73}\, or\, through\, the\, Internet\, (www.ohri.$ ca/programs/clinical\_epidemiology/OHDEC/default. asp).<sup>74</sup>

### **Use Effective Strategies for Communicating Information**

Even when relying on decision aids, clinicians may need to answer questions, help patients clarify their thinking, and negotiate a decision. This participation requires the use of effective strategies for communicating information.

Although few studies have examined how differences in the medium of information presentation affect outcomes, some studies<sup>27</sup> have shown that the information content significantly affects the outcomes of decisions. For instance, decision aids with detail, probabilities, examples, and personal guidance are more acceptable to patients than decision aids without these characteristics. Tailored communications, which provide information specific to the individual, may also be better remembered, read, and perceived as relevant and/or credible than nontailored communications.<sup>75</sup>

Alternate presentations of the same information also yield different outcomes. For instance, the presentation of probabilities as relative risk reductions is more persuasive than presentations as absolute risk reductions; by contrast, presentations of probabilities as absolute risk reductions are more understandable.<sup>76</sup> Framing (e.g., the chance of survival vs the chance of death) also influences choices.<sup>76</sup> Because clinicians may influence patient choices, ideally clinicians would make a special effort to be aware of effective communication strategies and choose their words, as well as their nonverbal cues, carefully to avoid unintended effects on the patient.<sup>77</sup>

#### Consider a Systematic Approach

Because the evidence about shared decision making is limited and the patient–clinician partnership is complex, defining how any given interaction about screening and chemoprevention should transpire is impossible. A systematic approach, however, is likely to improve the quality of interactions and provide the foundation for systematic study of patient–clinician interactions concerning screening and chemoprevention.

Figure 2 outlines one possible approach for patientclinician interactions. This approach approximates the 5As framework (assess, advise, agree, assist, arrange), <sup>78</sup> which the USPSTF has supported for behavioral counseling interventions and which is consistent with the previous suggestions about how clinicians might interact with patients on screening and chemoprevention recommendations. The approach leads clinicians through a stepped process of assessing patients' needs for preventive services, determining their desire to be involved in decision making, conveying information on the disease and preventive services, eliciting patient values, negotiating a course of action, and delivering the preventive service. Importantly it acknowledges the characteristics of an informed and joint decision and can be adopted for the "A," "B," "C," "D," and "I" recommendations of the USPSTF. Figure 3 provides an example of how one might apply this approach for an individual patient in clinical practice.

Although not highlighted in Figure 5, an important part of this systematic approach is clear documentation of the agenda setting and decision making. Such documentation mitigates against lapses in follow-up when discussions span more than one visit, and safeguards against the potential medico-legal consequences of subsequent detection of a potentially preventable disease when discussions are delayed. What constitutes adequate documentation is something the medical and legal communities need to further explore.

#### **Conclusions**

The USPSTF places a high value on informed and joint decisions about screening and chemoprevention; such decisions are essential for making recommendations to

#### **ASSESS**

- · Patient's health needs
  - ° Acute issues
  - ° Eligibility for preventive services
- · Patient's desired role in decision making

#### **ADVISE**

- Inform the patient about recommended preventive service (USPSTF A or B)
- If time permits, inform the patient about other services (USPSTF C, D, or I) with:
  - ° High visibility
  - ° Special individual importance
- If needed, provide balanced, evidence-based information about the service:
  - ° Benefits
  - ° Harms
  - ° Alternatives
  - ° Scientific uncertainties
- If appropriate (A, B, D) make a recommendation

#### **AGREE**

- Elicit patient's values and determine preferences
- Negotiate a course of action

#### **ASSIST**

· Deliver or prescribe service

#### ARRANGE

• Follow-up or plan to revisit in the future

USPSTF, U.S. Preventive Services Task Force

Figure 2. Approach to interactions about screening and chemoprophylaxis.

individual patients concerning interventions that have net benefit for some patients, but not for others. One approach to encouraging informed and joint decisions is shared decision making. Although the effect of this approach on health outcomes is uncertain, shared decision making is supported by ethical, interpersonal, and educational considerations. Clinicians might, therefore, consider incorporating elements of shared decision making into appropriate interactions with patients about screening and chemoprevention.

Future research should address the objective impact of this approach on relevant health outcomes, consider ways to improve the feasibility of this approach in

#### A clinician approaches a 60-year-old male with diabetes and hypertension.

- ASSESS: After ensuring that the patient is up to date on his management of diabetes and
  hypertension, the clinician determines that the patient is eligible for a few preventive services, including
  chemo-prophylaxis with aspirin and screening for colon cancer, each of which receives an 'A'
  recommendation from the U.S. Preventive Services Task Force (USPSTF). The patient additionally
  wants to discuss screening for prostate cancer, for which the USPSTF has given an 'I'
  recommendation. The patient demonstrates a clear interest in being engaged in the decision making
  process.
- ADVISE: The clinician reviews the list of recommended services and advises the patient that several services warrant a shared decision making discussion to enable him to make informed choices. The clinician and patient decide to address aspirin chemoprophylaxis at this visit, arranging to return to the other topics at a follow-up visit to occur in 1 month. The clinician inquires about the patient's existing knowledge about coronary heart disease and the role of aspirin, and determines that the patient is unfamiliar with the rationale and potential risks of aspirin use. The clinician displays a decision aid that uses the patient's 5-year risk of a cardiac event to present balanced, evidence-based information about the probability of benefit from aspirin, the risk of complications, and scientific uncertainties. The clinician recommends that the patient take a daily aspirin, given the high potential for benefit compared to harm. The clinician additionally encourages the patient to review more details about this topic on a website.
- AGREE: The patient telephones the clinician 1 week later after having reviewed the website, expressing concern about hemorrhagic stroke, and asks the clinician for guidance on whether it should influence his choice. The clinician explains the types of consequences that might arise from a hemorrhagic stroke, but again encourages the patient to take aspirin given the potential for benefit that outweighs the potential for harm. The patient responds that no amount of benefit in preventing heart disease is worth an increased chance of stroke. The clinician and patient agree to defer aspirin use for now, but the clinician makes a note to return to this topic at a future visit.
- ASSIST: Not applicable since the patient wishes to defer chemoprophylaxis.
- **ARRANGE**: A decision is made to plan on addressing screening for colorectal cancer at the follow-up visit in 1 month. In preparation for this, the clinician provides the patient with an informational brochure and recommends reading on prostate cancer screening.

Figure 3. Applying a consistent approach.

current medical practice, and identify best practices in performing and teaching the shared decision-making process. Researchers should devote particular attention to measuring the effects of shared decision making for value-sensitive decisions under each of four distinct circumstances: (1) when the benefits of a preventive service clearly outweigh the harms for the majority of the population; (2) when the harms of the service clearly outweigh the benefits for the majority of the population; (3) when the balance of harms and benefits is too close to call; and (4) when there is insufficient evidence to know the balance of harms and benefits. In the latter two settings, measurement should focus on whether shared decision making improves adherence to and satisfaction with a chosen course of action. Researchers should be vigilant in measuring patients' desired and actual levels of participation in decision making, and should distinguish this clearly from their desired and actual levels of information receipt. To assess the feasibility of shared decision making in clinical practice, researchers should continue to develop and evaluate novel practice- and system-level interventions. These should be tested not only for effectiveness, but also for cost-effectiveness and practicality both within and outside the clinical arena. Details about practical, effective interventions should be made available to clinicians, health systems, educators, and researchers alike.

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