

Values of Older Adults Related to Primary and Secondary Prevention

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Prepared by:

Minnesota Evidence-based Practice Center
Minneapolis, Minnesota

Investigators:

Mary Butler, PhD, MBA
Kristine M.C. Talley, PhD, RN
Rachel Burns
Alex Ripley
Alex Rothman, PhD
Paul Johnson, PhD
Rosalie A. Kane, DSW
Robert L. Kane, MD

Evidence-based Practice Center Director:

Robert L. Kane, MD

Task Order Officer:

Therese Miller, DrPH

Medical Officer:

Tracy Wolff, MD, MPH

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Cynthia Boyd, MD, MPH
Johns Hopkins Medicine
Baltimore, MD

Floyd J. Fowler, Jr., PhD
University of Massachusetts
Boston, MA

Dennis McCullough, MD
Dartmouth Medical School
Hanover, NH

Technical Expert Panel:

The authors also thank the following Technical Expert Panel members for their time and expert guidance.

Howard Leventhal, PhD
Rutgers, The State University of New Jersey
New Brunswick, NJ

Susan Curry, PhD
University of Iowa
Iowa City, IA

Judith Hibbard, DrPH
University of Oregon
Eugene, OR

Michael LeFevre, MD
University of Missouri
Columbia, MO

Erica Breslau, PhD
National Cancer Institute
Bethesda, MD

Rosanne M. Leipzig, MD, PhD
Mount Sinai School of Medicine
New York, NY

Structured Abstract

Objectives: To inform the U.S. Preventive Services Task Force deliberations on recommendations around preventive care for older persons by assessing how older adults value the potential benefits of clinical preventive services, what attitudes older adults have about potential harms of clinical preventive services, how older adults understand the balance of risks and benefits of clinical preventive services, and how clinicians should engage in shared decisionmaking related to clinical preventive services for older adults.

Data Sources: We searched Ovid MEDLINE, the Cumulative Index to Nursing and Allied Health Literature, PsychINFO, the Cochrane Database of Systematic Reviews, and EconLit databases, and consulted with experts in the field.

Review Methods: We selected English-language articles on preferences, lay understanding, choice behavior, patient/provider relationships, and shared decisionmaking regarding primary and secondary prevention that focused on a population aged 65 years and older.

Results: Very little literature exists addressing older people's perceived benefits and harms of preventive services, their decisional balance, and shared decisionmaking for preventive services. The literature identified in this review yielded a broad range of perceived benefits and harms for primary and secondary prevention, differing by those who had or had not received preventive services, the disease addressed by the intervention, and age group (e.g., the young old versus the old old). The values older adults placed on clinical preventive services were similarly variable and resistant to generalization. The literature on shared decisionmaking for preventive services for older adults demonstrated favorable response to such interventions and no indication whether older adults as a group have a different level of interest compared to other age groups. Not every older adult wants to engage in shared decisionmaking in the same way; clinicians need to determine how much an individual patient wants to be involved in his or her own screening choices. The studies largely used qualitative or descriptive analysis methods with small purposive samples.

Conclusions: People's values for preventive services and their attendant benefits, risks, and harms reflect all sorts of inputs, including prior experiences, habits, strengths, and other idiosyncrasies. This individual variation makes generalizations dangerous. Patient-centered care may not always require shared decisionmaking; clinicians need to better understand how patients value their own role in clinical decisionmaking. Future research is needed in the field covered by this review, including exploration of differences between age groups within the older adult population, tools to measure values and preferences, and identification of what helps and hinders older adults' ability to engage in shared decisionmaking.

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Executive Summary

Introduction

Prevention implies a future orientation. By engaging in preventive actions, individuals attempt to affect the likelihood of developing a health problem, delaying the development of a health problem, or reducing the severity of the health problem when it develops. An investment in preventive care today is expected to change a person's future health trajectory.

At first glance, how expected trajectories impact how various preventive actions are viewed by older adults may seem relatively straightforward. Older persons have shorter life expectancies and hence may view the likelihood of benefit differently from younger people. The differences in perceived possible benefits between the age groups would logically lead to differences in how the age groups value preventive services. Organizations like the U.S. Preventive Services Task Force (USPSTF), charged with making recommendations about preventive services, would likely want to consider the values older people place on various preventive activities as part of the process of formulating recommendations.

Setting out to understand how older people value preventive services raises a number of questions regarding how age should be viewed and considered in clinical context. One question is how we determine age. Typically, age is assessed in terms of chronological years since birth; however, gerontologists measure age in terms of the force of mortality, the likelihood of dying. The gerontological definition of age gives great weight to factors like illness, health status, and physical and cognitive function. An example of the importance of the difference between the definitions can be found in research by Gerstorf and colleagues,¹ who found that decline in life satisfaction in old age is more predictive of death than chronological age itself.

When we talk about older people's attitudes to prevention, the chronological and gerontological definitions of age take on special salience. In fact, shorter expected life spans, increased comorbidities, and competing causes of death can be present in a variety of populations and may affect their preferences for preventive services in ways similar to the older adult. So chronological age may not be the best indicator for differences in attitudes and preferences for preventive care.

Another question is how aging shapes beliefs about preventive services. Understanding the role of aging requires separating intertwined themes: intergenerational differences from intragenerational differences, and the influence of historical forces. Some differences in beliefs about preventive services may occur because people of one generation hold different social values than those of the following generation, perhaps, in part, influenced by their experiences growing up (e.g., the Great Depression). Alternatively, people in a given cohort may change their values as they age, perhaps as a function of their life experiences or their changing physical state. Cross-sectional comparisons of people at a single point in time cannot separate these effects.

Generational differences in aging also bring up the issue of the age span encompassed in the term "older adult." Given that the age range within this segment of the population covers 30 years and ages 65 and older, the term does not accurately reflect the heterogeneity of the older adult population. Neugarten first coined the term "young-old," the age group 55 to 75 years, to differentiate from the "old-old" those older adults who are younger, generally healthier,

relatively free from traditional work and family responsibilities, and socially and politically active. So, the developmental spectrum of aging has enormous variation, and individuals may not place such emphasis on decreasing life expectancy until their later years of aging.

Yet another question lies in the role of differences between people at the individual level in shaping beliefs about preventive services. An aphorism familiar in geriatrics is that age is a useful predictor for groups but very poor for predicting individual outcomes.² Hence, one might expect considerable variation in attitudes and opinions among older persons.

Just as gerontological and chronological age definitions distinguish clinical and lay perspectives of age, there are factors that differentiate clinical and lay perspectives of preventive services at the individual level as well. Clinicians characterize a preventive service by whether it avoids disease, identifies disease at early stages, or reduces the negative impact of an established disease. Patients may characterize preventive services using different qualities. For example, preventive services can differ by the patient's anticipated effort and/or burden. Some preventive actions require considerable discomfort (e.g., colonoscopy); others are simple and relatively painless (e.g., immunizations); still others require sustained behavior change (e.g., diet). Other factors such as time, money, cultural beliefs, and pain can also influence an individual's attitudes about and preferences for a preventive behavior.

This project was requested by the USPSTF because clinical preventive services are increasing in importance as the U.S. population ages. However, there are challenges in evaluating the evidence for preventive services in older adults and in applying the evidence to developing recommendations specific to older adults; perceived benefits and harms may differ from the general population due to decreasing life expectancy, increasing comorbidities, and competing causes of death in older adults. A specific challenge is determining when the net balance of perceived benefits and harms turns negative; that is, when do the harms begin to outweigh the benefits? One important consideration is how patient values affect the determination of benefits and harms of clinical preventive services.

Uncertainty is a critical issue facing patients and providers in deciding a course of action for prevention. There is uncertainty regarding the potential benefits and harms an older person may receive from any particular preventive service. There is also uncertainty regarding the place of a particular preventive service, or the array of preventive services, within the context of other health concerns older persons may face. Such uncertainty may arise from the physiology of aging, the presence of a single chronic illness or multiple conditions, or the risk for mortality. The presence of uncertainty amplifies the importance of understanding values and preferences, because those values and preferences may end up mattering more, potentially driving the choices in directions different from what would have transpired in the case of certainty.

To the extent that there is uncertainty regarding medical outcomes and variability in how people value different outcomes, there is a growing need for decisionmaking processes that are more attentive to the needs and values of the patient. Recent decades have witnessed a decided shift in the philosophy of care away from a model of professional dominance to one of patient-centeredness.³ A hallmark of this approach is the concept of shared decisionmaking. Shared decisionmaking is viewed as vital when no particular course of action presents itself as a prevailing option.⁴

The enthusiasm for shared decisionmaking is worth closer examination. Although studies have shown that patients often make very different clinical decisions when given full exposure to the

risks and benefits of alternative treatments for a given disease, it is not altogether clear just how much older patients want to be the locus of decisionmaking, or how well some can process complex information surrounding choices.

The aim of this review is to provide to the USPSTF a compendium of general information that can be used as a resource when the Task Force is deliberating recommendations on preventive care for older persons and the decision to engage or not engage in a preventive behavior.

Key Questions and Conceptual Model

The following key questions are the basis for this review.

- KQ1. How do older adults value the potential benefits of primary and secondary clinical preventive services, including reductions in morbidity and mortality, improvements in quality of life, maintenance of independence, and functional ability? Does cognitive ability or functional limitation affect how older adults value the potential benefits?
- KQ2. What attitudes do older adults have about potential harms of clinical preventive services?
- KQ3. What value do older adults place on the receipt of clinical preventive services?
- KQ4. How do older adults understand the balance of risks and benefits from clinical preventive services?
- KQ6. How should clinicians engage in shared decisionmaking related to clinical preventive services in older adults?

We approached the key questions through the rubric of shared decisionmaking, rather than through any particular psychological or behavioral model. The conceptualization acknowledges the overarching context of experience, individual attributes, information, and environmental factors that contribute to the development of individual preferences and attitudes. Essentially, the older adult has values, preferences, and attitudes toward the preventive services and the outcomes and harms these preventive services may provide. The older adult, through cognitive and emotional processes, then develops a net balance of benefits and harms, in which a negative benefit is possible if the benefits are outweighed by the harms. These same values, preferences, and harms impact the desire for, and process of, shared decisionmaking with providers.

Methods

The review focuses on older adults' perceptions of, preferences for, and attitudes about prevention. Preferences for the actual services, such as whether patients prefer colonoscopy or fecal occult blood tests for colon cancer screening, is outside the scope of this review. The review also does not address the evidence for preventive services' effectiveness. Community-dwelling adults ages 65 years and older are the population of interest. We were specifically instructed not to examine literature on younger groups with the goal of extrapolating the findings to older persons. We were unable to locate empirical literature to guide "adequate representation" of older persons to judge applicability of the prevention literature.

Our search process varied from a traditional systematic literature review process, as databases are not well indexed for "soft" topics such as values and preferences. We augmented traditional

search practices with multiple, iterative searches of the literature as material was reviewed and possible new searches were suggested. We conducted electronic searches of Ovid MEDLINE, the Cumulative Index to Nursing and Allied Health Literature, PsychINFO, the Cochrane Database of Systematic Reviews, and EconLit. Searches were conducted on keywords such as “preferences” or “lay understanding.” We also used search terms that captured qualitative research techniques and search terms that captured the patient/provider relationship and processes involved in shared decisionmaking, such as “choice behavior,” “patient/provider relationship,” and “shared decisionmaking.” The literature was focused with MeSH terms that identified primary and secondary prevention, and limited to the English language and ages 65 years and older. We identified longitudinal studies on aging and national panel surveys that would allow for examining differences in attitudes and preferences based on age, and searched the literature for any related articles. Literature searches were conducted from inception of the database to between mid-October 2009 and March 2010. Supplemental hand searches were also conducted, and experts in the field were polled for relevant articles.

Results

Though initial searches yielded thousands of articles, few matched our criteria, and fewer still directly targeted the questions of interest. We identified 28 studies related to older people’s perceived benefits and harms of preventive services and their decisional balance. We also identified two studies that examined shared decisionmaking interventions for preventive service decisions by older people. These studies largely used qualitative or descriptive analysis methods with small purposive samples. The majority of the citations located during preliminary searches were discarded because the minimum age of the population was set much lower than 65 years. Investigated populations tended to be those targeted for a particular preventive behavior, such as women aged 40 years and older for breast cancer screening. Moreover, when study populations contained some individuals aged 65 years and over, older adults were often not adequately represented or distinctions between younger and older participants were not made. The studies that remained addressed populations that were generally white, educated, female, and had a higher income.

This literature set can only be considered a sampling of articles that may contain information regarding perceived benefits, risks, harms, or other factors that may contribute to the formation of preferences. Such concepts are often examined within a multitude of health behavior topics but are not aggregated as such. What is clear from the literature is the lack of focused attention on the specific topic of older adults’ perceptions of preventive care, particularly those adults within the oldest-old age categories.

Given the above, the reader is cautioned to avoid drawing sweeping conclusions from this literature set.

Key Question 1: How Do Older Adults Value the Potential Benefits of Primary and Secondary Clinical Preventive Services?

Nineteen studies identified the perceived benefits of primary and secondary preventive services and behaviors.

Perceived benefits for primary prevention. The three studies in this area dealt with influenza

and pneumococcal disease vaccination. Identified perceived benefits are largely related to expected improvements in health state, such as avoiding influenza or other respiratory illness, and are interpreted differently by those who have and have not been vaccinated; those who are vaccinated tend to associate more health-state benefits with vaccination than those who have not been vaccinated.⁵⁻⁷

Perceived benefits for secondary prevention. The four studies in this area dealt with cancer screening and dementia screening. The identified perceived benefits tend to focus on both health-state outcomes and psychological benefits derived from peace of mind stemming from knowledge of test results and believed absence or reduction of risk for the problem.⁸⁻¹¹

Primary prevention and perceived risk. In general, older adults in these studies did not believe themselves to be at risk for serious complications associated with influenza or pneumococcal disease, regardless of immunization status.⁵⁻⁷ Older adults viewed their independent status and active engagement as evidence of good health status⁵ and believed that other behaviors, such as diligent self-care⁶ and good nutrition habits,⁶ were effective in reducing risk. Interestingly, one study found the perception among older adults that health providers demonstrate an ageist attitude with blanket recommendations for vaccination based on age to be a prominent theme.⁶

Secondary prevention and perceived risk. More articles, seven in all, addressed perceived risk rather than perceived benefits in the literature on secondary prevention. Three articles indicated that participants felt that there was no need to screen for breast cancer if one felt healthy.^{8,12,13} Age appears to be a factor in personal risk perception for developing cancer in four articles.^{11,14-16}

Key Question 2: What Attitudes Do Older Adults Have About Potential Harms of Clinical Preventive Services?

Perceived harms for primary prevention. The three studies in this area dealt with influenza and pneumococcal disease vaccination. Older adults who have not been vaccinated tend to perceive the vaccine as more harmful than those who have been vaccinated.^{5,6} Specific perceived harms identified in this literature were clinical in nature and focused on side effects.⁵⁻⁷ In one study, older people who were vaccinated tended to counterbalance perceived harms of influenza vaccinations across multiple time periods.⁵

Perceived harms for secondary prevention. The eight studies identified in this area dealt with cancer and dementia screening. Perceived clinical harms associated with screening behaviors were fear of the test,^{8,13} pain,¹¹ discomfort,¹³ side effects,¹⁷ and a view that treatment would be worse than living with the disease.¹⁸ Psychological harms were similar for breast and colon cancer screening.^{8,9,11-13,17,18}

Dementia screening had unique perceived harms. These included social stigma, emotional and practical hardships, and loss of independence if diagnosed with Alzheimer's disease.¹⁹

Key Question 3: What Value Do Older Adults Place on the Receipt of Clinical Preventive Services?

Primary prevention. No studies were found that directly addressed this area. Four related studies indicate that some older adults have positive attitudes toward physical activity.²⁰⁻²³

However, we were unable to find literature to inform our understanding of how older people view the role of physical activity counseling by their health providers, or how they view the receipt of clinical preventive services for primary prevention in general.

Secondary prevention. The four studies identified in this area dealt with cancer screening. Two studies indicated that the value of breast cancer screening is unclear to people who are unwilling to risk losing feeling healthy should cancer or some other diagnosis be discovered.^{8,12} Skepticism of medical recommendations and a sense of civic obligation were also implicated as factors that affect one's decisions to engage in breast cancer and colon cancer screening, respectively.^{8,24}

One study directly asked how older people view preventive services.¹⁰ The researchers interviewed 116 residents of a North Carolina long-term care facility's independent living quarters regarding their attitudes and beliefs about cancer screening. Of particular note is that 50 percent of participants felt that other health issues are more important than cancer screening, although older people with a history of cancer were less likely to express this opinion. Interestingly, the percentage of older adults reporting that they, personally, would continue prostate, breast, and colon cancer screening for as long as they live was larger than the percentage who agreed that everyone should get screened for these cancers as long as they live. This suggests that attitudes toward cancer screening can differ across screening targets (self versus others).

Key Question 4: How Do Older Adults Understand the Balance of Risks and Benefits From Clinical Preventive Services?

Two articles were located that provided some insight into how patients understand balance. In one study, individuals valued screening outcomes, especially mortality reduction, more than process features of the test when stating their preferences for a colon cancer screening procedure.²⁵ Likewise, another study, using focus groups, found that participants valued test sensitivity more than discomfort during a test procedure.¹⁷ Little is known about how the benefits and harms of preventive behaviors are balanced by older adults and influence behavioral decisions. There is a scarcity of theory/models available to guide this work.

Issues of valuing prevention. Several leading decisionmaking models relevant to health decisions are detailed in Chapter 4. Issues that come to bear on aging and the value of prevention include: understanding the goals of prevention, such as successful aging; the processes of proactive coping, and selective optimization and compensation; heterogeneity in elderly populations and preventive services; and competing demands created by comorbidity, multimorbidity, and habits. Understanding can be gained through many disciplinary lenses, including health psychology models, economic theory, decision theory, and decision analytics; behavioral economics examinations of bounded rationality, use of heuristics, and cognitive biases; and socioemotional selectivity theory. Response shift phenomenon may interfere with accurate measurement of study outcomes.

Key Question 5: How Should Clinicians Engage in Shared Decisionmaking Related to Clinical Preventive Services in Older Adults?

Two articles evaluated shared decisionmaking interventions for preventive services for older

adults. There is nothing in these studies to indicate whether older adults have a different level of interest in engaging in shared decisionmaking. Even though neither study included all the essential elements of shared decisionmaking, they were able to influence patient decisions. That is, improved knowledge led to a reduction in the number of older men receiving prostate-specific antigen (PSA) screening²⁶ and increased older men's preference for colorectal cancer screening.²⁷ Both studies used research assistants to implement the interventions, suggesting shared decisionmaking can be provided by someone other than the physician and still influence choices. The outcome measures focused on improving knowledge about the disease being screened, the benefits and risks associated with the screening procedure, and concern about developing the disease. Missing were outcomes related to decision quality (i.e., decisional conflict and congruency of patients' decisions with their values). Another important outcome omission was the lack of followup on actual screening behavior.

Older people appear to respond favorably to shared decisionmaking interventions, and participation in shared decisionmaking interventions increased older people's awareness of the opportunity to share their decision with their care providers. Interventions with just a few shared decisionmaking elements change older people's knowledge on disease, risk perception, and motivation to engage in behavior change. Older people may prefer more time in the encounter to discuss their individual circumstances to provide a tailored recommendation. However, it appears life expectancy may not be an important factor for some older adults, and some would prefer to not discuss life expectancy with their provider. Clinicians need to determine how much the patient wants to be involved with decisionmaking.

Issues of shared decisionmaking. Theories of medical decisionmaking are evolving and the current emphasis is on empowering patient involvement through shared decisionmaking. While this idea has strong face validity and is congruent with optimizing patient autonomy, there is little empirical evidence to guide its implementation as it relates to preventive services for older adults. There appears to be agreement that shared decisionmaking does not need to occur in all clinical encounters. It is most appropriate to use when there is more than one reasonable treatment option or when there is considerable uncertainty about the strength of evidence for a given screening option (as is the case with PSA screening). Challenges with implementing shared decisionmaking arise from a lack of consensus on what elements should be included in the process, on relevant outcome measures, when to incorporate decision aids, and when shared decisionmaking should expand beyond the patient-physician dyad to include other health care professionals or be offered at the population level through public health promotions. Other concerns include how to adequately represent risk to older adults in ways that develop accurate knowledge and the provider's role in shared decisionmaking.

Discussion

Preferences are not stable over time, and may not be elicited as much as constructed. Cognitive, emotional, and relationship factors contribute to how preferences are shaped. Given this, providers need to be sensitive to unintentional undue influences on the patient's preferences.

Both aging and prevention are challenging, complex topics. Taken singularly, they often do not lend themselves to simple solutions based on one easily defined mechanism. Together they create a complex system and a decisionmaking environment that requires acknowledging complexity and the challenge of balancing multiple inputs, attentional demands, and choices

among an array of possible actions. It is, in other words, a domain that is ripe with uncertainty.

Simply put, peoples' values for preventive services and their attendant benefits, risks, and harms reflect all sorts of inputs. People bring their past, beliefs, prior experiences, habits, strengths, and personal idiosyncrasies with them as they age. This individual variation makes generalizations dangerous.

Patient-centered care may not always require shared decisionmaking; clinicians need to better understand the appropriate role for patients in deciding their own role in decisionmaking. The congruence of decisionmaking philosophies across groups, much less individuals, is a conversation that should continue, given the underdeveloped nature of this area. We should not assume too much.

Future Research Recommendations

There has been little work regarding preferences in the arena of preventive care, and there is no strong body of evidence informing the topic of how older people value preventive services. In fact, the field is underdeveloped, and much of the available information is in the form of indirect evidence. The overwhelming majority of the current literature on preferences is disease-specific and treatment focused, and does not directly address aging and its effect on preferences for preventive health. Nor has a community of colleagues fully formed to address the topic directly. Similarly, older adults are poorly represented in the shared decisionmaking literature, and this area too is underdeveloped. Other, more specific suggestions are listed below:

- Research that examines differences between the age groups within the older adult population, particularly the oldest old, is strongly needed. Similarly, it is also important to understand how prevention preferences change over time. This includes whether and how prevention values and practices change as middle-aged adults transition to older ages, as well as how preferences change as people advance from young-old to oldest-old.
- Continuing research into tools to measure values and preferences is critical to the field. We support Smith and Ubel's call for expanded research into both decision-based utility methods, such as stated preferences, and subjective well-being, as well as for measurement tools that are more sensitive to health changes and less biased.²⁸
- Furthermore, we need to understand how the presentation of the number of choice options or number of potential side effects impacts decisionmaking through potential for cognitive biases and other heuristics.
- Older adults are also poorly represented in the shared decisionmaking literature. Although shared decisionmaking is an evolving concept, work in this field is progressing. Most decision aids were developed for younger populations and address disease treatment rather than preventive services. Future research needs to investigate how well these decision aids work for older adults.
- Future researchers need to identify what facilitates and hinders older adults' ability to engage in shared decisionmaking.
- Future research needs to determine if relevant outcome measures, such as improvement in patient knowledge of the benefits and harms of preventive services and realistic expectations of outcomes, benefits and harms, certainty of choice, feelings of being informed, and being clear about values, are also valid and reliable for older people.

- The decisional conflict scale needs to be validated with older adults. Outcomes for decisional quality need to measure consistency between eligible patient treatment uptake rates and the underlying distribution of patients' informed values and make sure there is no unresolved decisional conflict.^{29,30}
- Further synthesis reviews for preferences by disease or function may assist the field with aggregating what information is currently available in the literature. Restricting searches to relatively easily defined search scope and algorithms, such as is found with strictly defined diseases or functions, would make it easier to locate relevant articles. Most of the articles located for this review were only indirectly related, but useful nonetheless. Pulling articles together across disease categories, and linking them together with searchable keywords, would help avoid inefficient use of research resources.

Chapter 1. Introduction

Overview

Prevention implies a future orientation. By engaging in preventive actions, individuals attempt to affect the likelihood of developing a health problem, delaying the development of a health problem, or reducing the severity of the health problem when it develops. An investment in preventive care today is expected to change a person's future health trajectory.

At first glance, how expected trajectories impact how various preventive actions are viewed by older adults may seem relatively straightforward. Older persons have shorter life expectancies and hence may view the likelihood of benefit differently from younger people. The differences in perceived possible benefits between the age groups would logically lead to differences in how the age groups value preventive services. Organizations like the U.S. Preventive Services Task Force (USPSTF), charged with making recommendations about preventive services, would likely want to consider the values older people place on various preventive activities as part of the process of formulating recommendations.

Setting out to understand how older people value preventive services raises a number of questions regarding how age should be viewed and considered in clinical context. While a full discourse on life course theory and development or the discipline of gerontology is not possible here, a select set of issues is quite germane to the topic and deserves brief consideration as we examine these questions.

One question is how we determine age. Typically, age is assessed in terms of chronological years since birth; however, gerontologists measure age in terms of the force of mortality, the likelihood of dying. The gerontological definition of age gives great weight to factors such as illness, health status, and physical and cognitive function. An example of the importance of the difference between the definitions can be found in research by Gerstorf and colleagues,¹ who found that decline in life satisfaction in old age is more predictive of death than chronological age itself.

When we talk about older people's attitudes about prevention, the chronological and gerontological definitions of age take on special salience. In fact, shorter expected life spans, increased comorbidities, and competing causes of death can be present in a variety of populations and may affect their preferences for preventive services in ways similar to the older adult. So chronological age may not be the best indicator for differences in attitudes about and preferences for preventive care.

Another question is how aging shapes beliefs about preventive services. Understanding the role of aging requires separating intertwined themes: intergenerational differences from intragenerational differences, and the influence of historical forces. Some differences in beliefs about preventive services may occur because people of one generation hold different social values than those of the following generation, perhaps, in part, influenced by their experiences growing up (e.g., the Great Depression). Alternatively, people in a given cohort may change their values as they age, perhaps as a function of their life experiences or their changing physical state. Cross-sectional comparisons of people at a single point in time cannot separate these effects.

Generational differences in aging also bring up the issue of the age span encompassed in the term

“older adult.” Given that the age range within this segment of the population covers 30 years and ages 65 and older, the term does not accurately reflect the heterogeneity of the older adult population. Neugarten first coined the term “young-old,” the age group 55 to 75 years, to differentiate from the “old-old” those older adults who are younger, generally healthier, relatively free from traditional work and family responsibilities, and socially and politically active. So, the developmental spectrum of aging has enormous variation, and individuals may not place such emphasis on decreasing life expectancy until their later years of aging.

Yet another question lies in the role of differences between people at the individual level in shaping beliefs about preventive services. An aphorism familiar in geriatrics is that age is a useful predictor for groups but very poor for predicting individual outcomes.² Hence, one might expect considerable variation in attitudes and opinions among older persons.

Just as gerontological and chronological age definitions distinguish clinical and lay perspectives of age, there are factors that differentiate clinical and lay perspectives of preventive services at the individual level as well. Clinicians characterize a preventive service by whether it avoids disease, identifies disease at early stages, or reduces the negative impact of an established disease. Patients may characterize preventive services using different qualities. For example, preventive services can differ by the patient’s anticipated effort and/or burden. Some preventive actions require considerable discomfort (e.g., colonoscopy); others are simple and relatively painless (e.g., immunizations); still others require sustained behavior change (e.g., diet). Other factors such as time, money, cultural beliefs, and pain can also influence an individual’s attitudes about and preferences for a preventive behavior.

This project was requested by the USPSTF because clinical preventive services are increasing in importance as the U.S. population ages. However, there are challenges in evaluating the evidence for preventive services in older adults and in applying the evidence to developing recommendations specific to older adults; perceived benefits and harms may differ from the general population due to decreasing life expectancy, increasing comorbidities, and competing causes of death in older adults. A specific challenge is determining when the net balance of perceived benefits and harms turns negative; that is, when do the harms begin to outweigh the benefits? One important consideration is how patient values affect the determination of benefits and harms of clinical preventive services.

Uncertainty is a critical issue facing patients and providers in deciding a course of action for prevention. There is uncertainty regarding the potential benefits and harms an older person may receive from any particular preventive service. There is also uncertainty regarding the place of a particular preventive service, or the array of preventive services, within the context of other health concerns older persons may face. Such uncertainty may arise from the physiology of aging, the presence of a single chronic illness or multiple conditions, or the risk for mortality. The presence of uncertainty amplifies the importance of understanding values and preferences, because those values and preferences may end up mattering more, potentially driving the choices in directions different from what would have transpired in the case of certainty.

To the extent that there is uncertainty regarding medical outcomes and variability in how people value different outcomes, there is a growing need for decisionmaking processes that are more attentive to the needs and values of the patient. Recent decades have witnessed a decided shift in the philosophy of care away from a model of professional dominance to one of patient-centeredness.³ A hallmark of this approach is the concept of shared decisionmaking. Shared

decisionmaking is viewed as vital when no particular course of action presents itself as a prevailing option.⁴

The enthusiasm for shared decisionmaking is worth closer examination. Although studies have shown that patients often make very different clinical decisions when given full exposure to the risks and benefits of alternative treatments for a given disease, it is not altogether clear just how much older patients want to be the locus of decisionmaking, or how well some can process complex information surrounding choices.

The aim of this review is to provide to the USPSTF a compendium of general information that can be used as a resource when the Task Force is deliberating recommendations on preventive care for older persons and the decision to engage or not engage in a preventive behavior.

Key Questions

The following key questions are the basis for this review.

- KQ 1. How do older adults value the potential benefits of primary and secondary clinical preventive services, including reductions in morbidity and mortality, improvements in quality of life, maintenance of independence, and functional ability? Does cognitive ability or functional limitation affect how older adults value the potential benefits?
- KQ 2. What attitudes do older adults have about potential harms of clinical preventive services?
- KQ 3. What value do older adults place on the receipt of clinical preventive services?
- KQ 4. How do older adults understand the balance of risks and benefits from clinical preventive services?
- KQ 5. How should clinicians engage in shared decisionmaking related to clinical preventive services in older adults?

Conceptual Model

We approached the key questions through the rubric of shared decisionmaking, rather than through any particular psychological or behavioral model. **Figure 1** provides a conceptual model that illustrates the flow of the key questions. The model acknowledges the overarching contextual factors that contribute to the development of individual preferences and attitudes, such as experience, individual attributes, information, and environmental factors. Essentially, the older adult has values, preferences, and attitudes toward preventive services and the outcomes and harms these preventive services may provide. The older adult, through cognitive processes, then develops a net balance of benefits and harms, in which a negative benefit is possible if the benefits are outweighed by the harms. These same values, preferences, and harms impact the desire for, and process of, shared decisionmaking with providers.

While at first the conceptual model would seem to neatly fit into a strictly rational cognitive model of decisionmaking, it should be noted that decisions are not made in a vacuum, and contextual factors can impact the decision process at any time point. Likewise, nonrational processes, such as affective responses, social cues, and habits, may also come to bear in decisionmaking. Older adults will also have attitudes about the uncertainties themselves that are inherent in the decisionmaking process.

Scope of the Review

It is important to note that the focus of this review is on the perceptions, values, preferences, and attitudes of older adults about prevention. This review does not address the evidence for the effectiveness of the preventive services. The population of interest is community-dwelling adults ages 65 years and older. The review does not examine issues around advanced directives or end of life care.

Clinical Preventive Services of Interest

No preventive service was specifically excluded from the review. The USPSTF recommendations for screening and prevention in older people provided the basis for the report focus. These include counseling for tobacco use, healthy diet and exercise, aspirin therapy for people at increased risk for coronary heart disease, lipid management and hypertension management for at-risk patients, ultrasonography for abdominal aortic aneurysm, and screening programs for mammography, colorectal cancer, diabetes, and osteoporosis. The topics addressed cover a wide range of activities. Some involve single actions; others require sustained patterns of behavior.

While attending to the USPSTF's concerns for prevention for older adults, we also did not specifically exclude any particular primary or secondary prevention service. We included as services of interest preventive services recommended by the American Geriatric Society, including screening for depression, fall risk, obesity, alcohol abuse, skin cancer, hearing and vision impairment, elevated serum c-reactive protein in persons with coronary artery disease risk factors, cognitive impairment, glaucoma, abnormal thyroid stimulating hormone levels in women, and daily multivitamin use.³¹

Concepts/Topics of Interest

The variables of interest are an individual's attitudes, values, and preferences for outcomes related to preventive care. Preferences in health services imply a summary evaluation of the desirability of an object and are analogous to the concepts of "utility" in economics and "attitude" in psychology. Preferences themselves are also usually relative, in that one prefers something over something else. How older individuals establish preferences for health outcomes for potential utilization of clinical preventive services is influenced by their personal health priorities and lifestyle goals, their beliefs regarding their risk for developing a particular health condition, and the mental models they hold for both the condition in question and their personal definition of "successful aging." Though each individual assigns personal meaning to the notion of successful aging, definitions are multifaceted and encompass features such as good physical, psychological, social, and functional health and life satisfaction (see Chapter 4 for further discussion). Therefore, we included improved health states as a potential benefit, risk for unnecessary treatment as a potential harm, the psychological benefit of receiving an "all clear" signal after screening, and the cost of anxiety as potential outcomes of interest. We did not focus on preferences for the actual services, such as whether patients prefer colonoscopy or fecal occult blood tests for colon cancer screening.

Primary and secondary prevention differ on a number of dimensions, such as purpose and how the preventive services are engaged in over time. These differences could have implications for

the value associated with the behaviors in these categories. Accordingly, we distinguish between primary and secondary preventive behaviors in the discussion of each key question.

Primary prevention is defined as prevention aimed at avoiding developing a disease. The use of drug therapy to control identified risk factors for a disease in order to prevent the disease from occurring, such as hypertension or lipid management drug therapy to prevent cardiovascular disease, is also classified as primary prevention for the purposes of this report. Secondary prevention is defined as the early detection of a disease before signs or symptoms are evident.

Organization of the Report

We follow the introduction with a brief section on the methods used to locate and evaluate relevant literature. Results of the literature searches are broken into two chapters. Chapter 2 covers the first four key questions and the literature regarding values and preferences for perceived benefits, harms, and preventive services. Chapter 3 covers the last key question and the literature regarding shared decisionmaking. Each of these chapters begins with the empirical literature available to directly answer the key questions, and follows with a discussion of related theories and issues. These discussions are intended to help expand the reader's conceptual understanding of the topic and provide a possible starting place for a conceptual framework. The discussion is not meant to be, and indeed cannot be, exhaustive. Our goal is to stimulate curiosity about the larger context of values and decisionmaking, introduce important concepts, and raise questions regarding the limitations of some commonly held views.

Methods

Search Process

Our search process varied from a traditional systematic literature review process, as literature databases are not well indexed for “soft” topics such as values and preferences. We also noted during exploratory literature searches a paucity of studies specifically designed to address the key questions. We therefore augmented traditional search practices with multiple, iterative searches of the literature as material was reviewed and possible new search courses were suggested.

We included both electronic and manual searches. Electronic searches were conducted in the standard health and health behavior databases of MEDLINE, the Cumulative Index to Nursing and Allied Health Literature, PsychINFO, and the Cochrane Database of Systematic Reviews. We also searched EconLit for relevant behavioral economic literature on preferences and decisionmaking. Supplemental hand searches were conducted from article references and grey literature searches were independently carried out via the Internet.

Traditional search strings that rely on MeSH terms are neither sensitive nor specific for the topic of interest. For example, one related systematic review with highly focused, testable key questions had a documented hit ratio of approximately 1 out of 20,000 articles. Rather, we used key words which reflected the psychosocial and behavioral economic categories that best captured the topic content, including such terms as “preferences” or “lay understanding.” We also used search terms that captured qualitative research techniques, such as “focus group” or “interview,” to check for literature that described held beliefs, values, and preferences. We

explored the literature through MeSH terms, such as “health behaviors,” “attitude to health,” and “patient acceptance of health care.” Key question 5 required search terms that captured the patient/provider relationship and processes involved in shared decisionmaking, such as “choice behavior,” “patient/provider relationship,” and “shared decisionmaking.” The literature was focused with MeSH terms that identified primary and secondary prevention (“primary prevention,” “preventive medicine,” “mass screening,” “geriatric assessment,” “preventive health service”) and limited to “English language,” “human,” and “ages 65 and older.” We were specifically instructed not to examine literature on younger groups with the intent of extrapolating the findings to older persons.

Traditional inclusion/exclusion criteria used in a linear deductive screening method were not appropriate for this project. We instead ran multiple iterations of literature screening, abstracting, and new searches using new potential key words derived from the literature to make use of both inductive and deductive reasoning. We also identified longitudinal studies on aging and national panel surveys that would allow for examining differences in attitudes and preferences based on age, and searched the literature for any related articles. Articles were also contributed from personal files of the authors, members of the Technical Expert Panel, and other experts in the field who were invited to identify relevant literature. Articles were not excluded based on country or setting. The retained literature was transferred to an EndNote library, where it was maintained and screened for duplication. Literature searches were conducted from inception of the database to between mid-October 2009 and March 2010.

Article Assessment and Applicability

Wide ranges of study designs that used either quantitative or qualitative methods were included in the core literature because relevant randomized control trials and quasi-experimental studies were minimally available. Initial screening was based on a title and abstract review of the article. Further screening examined the research design, methodology, and the study population. Patient population inclusion criteria were community-dwelling adults aged 65 years and older. If there was no evidence that the mean age distribution was sufficiently over 65 years, the article was generally excluded. However, this eligibility criterion was used more loosely as a guideline rather than a strict decision rule, due to the nature of the report. A select few articles were passed to the full team for discussion if the report included an interesting finding or perspective. Researchers separately reviewed and rated the literature.

Literature examining the topic of self-care that focused on disease self-management was excluded. The topic of adherence to treatment or disease management programs among older adults was also excluded. Finally, the topic of care seeking was excluded due to the reactive rather than preventive nature of the research.

Researchers independently abstracted the literature for information regarding relevant study objectives, design, population, quality, and outcomes. The research team members met biweekly to review and revise the extraction and presentation of included articles in detailed evidence tables. Tables were organized by systematically comparable features.

Each study was rated for quality based on the research design, methodology, and the age of the study population as it applied to the key questions. At least two reviewers assessed the quality of all included studies.^{32,35} However, given the nature of the literature available to address how prevention is valued by older people, traditional measures of study quality proved difficult to

apply. As such, no studies were excluded based on quality measures.

Articles with a high degree of applicability included those that met the age requirement and addressed decisional analysis concepts and factors influencing the decisionmaking process as a whole. Articles with a mean age distribution over 65 years that included younger age groups were also included, but applicability to older patient populations, particularly the oldest old patient, is unknown. We were unable to locate empirical literature to guide an understanding of what “adequate representation” of older persons would be to judge the applicability of the prevention literature.

Chapter 2. Values, Attitudes, and Preferences

Review of the Empirical Literature

Overall, we identified only 28 studies related to older people's perceived benefits and harms of preventive services and their decisional balance. Almost all articles documented studies that were not specifically designed to answer this review's key questions; however, they did provide information that offered some insights into the questions. These studies largely used qualitative or descriptive analysis methods with small purposive samples. **Table 1** provides details on the included studies.

Though initial searches yielded thousands of articles, few matched our criteria, and fewer still directly targeted the questions of interest. The majority of the citations located during preliminary searches were discarded because the minimum age of the study population was set much lower than 65 years, generally because the study target was the preventive behavior and not the population (e.g., women aged 40 years and older for breast cancer screening). Moreover, when study populations contained some individuals aged 65 years and over, older adults were often not adequately represented or distinctions between younger and older participants were not made. The studies that remained addressed populations that were generally white, educated, female, and had a higher income. However, even with the thousands of articles that were screened, there will be many thousands more that were missed due to the inability to build a search algorithm that efficiently captures the literature. This set of 28 studies should be considered at best a sampling of what may be available in the literature.

The articles discussed in this report come largely from the health psychology and decision analysis literature. There is little overlap between these two areas in the identified articles. Articles from the health psychology literature focus largely on identifying the perceived benefits, risks, and psychological harms of various preventive behaviors but do not examine people's overall preferences or decisions. Though some of the identified studies and their hypotheses were derived from psychological theories, such as the health belief model or the theory of planned behavior, many of the studies were atheoretical or exploratory. Moreover, shared decisionmaking was largely neglected in this portion of the literature. Conversely, the identified decision analysis literature focused largely on stated preferences, discrete choices, and probability tradeoffs related to the clinical benefits, harms, and various aspects of "cost" associated with preventive behaviors. This body of work also explores how individuals weigh various aspects of a behavior and how these weights influence decisionmaking. Relative to the health psychology literature, discussion of shared decisionmaking was more prominent in this body of literature. Thus, the health psychology and decision analysis literatures focused on divergent aspects of older adults' valuation of preventive services and behaviors. While these two literatures remained distinct in the identified sources, they collectively provide a necessary and more nuanced depiction of older adults' valuation of preventive behaviors and services.

This literature set can only be considered a sampling of articles that may contain information regarding perceived benefits, risks, harms, or other factors that may contribute to the formation of preferences. Such concepts are often examined within a multitude of health behavior topics but are not aggregated as such. What is clear from the literature is the lack of focused attention on the specific topic of older adults' perceptions of preventive care, particularly those adults

within the oldest-old age categories.

Another issue is disease focus. If the sample patients were older, articles were often about disease treatment. If the literature dealt with prevention, samples were often composed of patients aged 40 to 64 years, as this is the age group that is typically targeted by preventive services.

Given all of the above, the reader is cautioned to avoid drawing sweeping conclusions from this literature set.

As mentioned in Chapter 1, primary and secondary prevention differ on a number of dimensions, such as purpose and temporal application. These differences could have implications for the value associated with the behaviors in these categories. Accordingly, we distinguish between primary and secondary preventive behaviors in the discussion of each key question. Though both primary and secondary preventive behaviors are represented in the identified citations, the majority of the articles consider secondary preventive services. Of these, breast cancer and colorectal cancer screening were the most frequently studied. The few primary prevention studies that were identified dealt largely with vaccination or physical activity.

Key Question 1: How Do Older Adults Value the Potential Benefits of Primary and Secondary Clinical Preventive Services?

Nineteen studies identified the perceived benefits of preventive services and behaviors for influenza vaccinations (three studies), physical activity (two studies), breast cancer screening (four studies), colorectal cancer screening (four studies), general cancer screening (five studies), and dementia screening (one study). **Table 1** provides details of the included studies.

Perceived benefits in primary prevention. Information regarding older adults' perceptions of the benefits of primary preventive behaviors comes from three studies on vaccination: two qualitative studies conducted within the United Kingdom^{5,6} and one cross-sectional survey conducted within the United States.⁷ This small literature suggests that the perceived benefits of vaccination are largely related to expected improvements in health state, such as avoiding influenza, and are interpreted differently by those who have and have not been vaccinated. Specifically, those who were vaccinated tended to view vaccination as effective,⁶ believe that the influenza vaccine will reduce the number and severity of colds and influenza bouts,^{5,6} and believe that it is the best way to prevent disease.⁷ Conversely, individuals who had not been vaccinated tended to believe that influenza is best prevented by other means (e.g., healthy lifestyle),⁷ and focused on the harms perceived to be associated with vaccination (see key question 2).^{5,6} It should be noted that these studies measured participants' perception of benefits after the behavior was determined.

Perceived benefits in secondary prevention. The extant literature on benefits associated with secondary preventive services is relatively more diverse, although still very limited and based largely on qualitative studies. The perceived benefits that have been identified tend to focus on both health-state outcomes, such as early detection and decreased likelihood of mortality, and psychological benefit derived from the peace of mind that stems from knowledge of test results and believed absence or reduction of risk for the health problem.

Cancer screening. When considering cancer screening as a general topic, the majority of older adults in one study believed that the benefits of cancer screening are immediate, as evidenced by

their disagreement with the statement that cancer screening takes several years to benefit a person.¹⁰ They also believed that they would live long enough to accrue benefits of cancer screening.¹⁰ It should be noted that participants aged 85 years and older in that study were less likely than their younger counterparts to believe that they would live long enough to benefit from screening.¹⁰ Beliefs in this study were measured by survey items. Specific benefits were not defined for participants; rather participants were free to consider any number or type of benefit when responding. For colorectal cancer, screening was viewed in one study from the United Kingdom as a chance to perform a civic duty.⁸ Another perceived benefit of screening for colorectal cancer is that it permits early diagnosis, which is perceived to be beneficial because the disease is treatable if detected early. However, the authors noted that many participants were unaware of this fact, or that precancerous polyps could be removed as a preventive measure.⁹ Early detection and decreased odds of mortality have also been identified as a benefit associated with breast cancer screening.¹¹ Specifically, perceiving early detection of breast cancer and lowered odds of mortality as benefits of mammography screening predicted adherence to mammography screening guidelines.¹¹

The literature also suggests that screening may be a means used to avoid the feared possibility of developing cancer. Dassow found that older women perceive colon cancer to be a severe disease and that perceived severity of colon cancer was associated with screening behavior.³⁹ Similarly, Black et al¹¹ found that people who readily brought to mind an image of themselves with a debilitating health condition (e.g., being a stroke victim) and were motivated to avoid this imagined situation were more likely to adhere to screening guidelines.¹¹ Black et al suggest that since mammography screening is a preventive behavior, screening acts as an avenue through which one protects oneself from becoming this feared, unhealthy possible self. The authors also note that having a feared health-related possible self is more likely in younger women. Since there were proportionally more younger women (aged 50 to 69 years) in the sample, the authors suggest that the younger women in the sample may have driven this finding. This finding was not analyzed by age and no statistical tests were run to test this prediction. Thus, caution must be exercised when generalizing the results to all age groups.

Dementia screening. Older adults also derive psychological benefit from dementia screening because they report a desire to know of any developing mental health problems.¹⁹ Older adults also view early detection of Alzheimer's disease as beneficial because it allows time to make financial, legal, and health care plans if necessary.¹⁹

Germane to the topic of benefits is perceived risk. Preventive services are valued because they aim to prevent, or reduce the impact of, a health problem. Accordingly, value cannot be associated with a preventive service if there is no risk for developing the health problem. Perceived risk is defined as one's perceived likelihood of experiencing the adverse state in question. We incorporated details on perceived risk into key question 1 because perceived risk can be conceptualized as the likelihood of achieving the benefit associated with the preventive behavior (i.e., avoiding an adverse health state).

Perceived risk in primary prevention. The small literature available on older adults' risk perception and vaccination indicates that, in general, a number of older adults do not believe themselves to be at risk for serious complications associated with influenza, regardless of immunization status. It appears that they do not see themselves as being at risk for dying of influenza,⁵ of catching influenza,⁶ or suffering serious complications if they do contract it.⁶ Similarly, a single study indicated that older adults do not see themselves as being at risk for

contracting pneumococcal disease.⁷ Studies examining the prospective relationship between older adults' perception of risk for disease and the decision to be vaccinated were not located.

Self-assessed health status is linked to perceived risk in two studies.^{5,6} Older adults viewed their independent status and active engagement as evidence of good health status,⁵ and good health,⁵ diligent self-care,⁶ and good nutrition habits⁶ were perceived to reduce risk. Interestingly, Evans et al⁶ found the perception that health providers demonstrate an ageist attitude with blanket recommendations for vaccination based on age to be a prominent theme.

In terms of the complex primary preventive behavior of exercising to prevent falls, participants of the sole identified study rarely thought that they were at risk for falling and associated falling with older individuals.³⁴ Accordingly, they were generally not motivated to exercise purely to prevent falls. However, past experience did seem to play a role in risk perception. Those who had fallen in the past were more likely to acknowledge the risk for future falls and engage in exercise to prevent falls.³⁴

Perceived risk in secondary prevention. More articles addressed perceived risk than perceived benefits in the literature on secondary prevention. Three articles indicated that participants felt that there was no need to screen for breast cancer if one felt healthy.^{8,12,13} Over 80 percent of participants in the study by Lewis et al believed that they would die from a disease other than cancer.¹⁰

Age appears to be a factor in personal risk perception. Two studies found that older women see themselves as less likely than their peers to develop breast cancer than did women younger than age 70 years.^{11,14} Similarly, older age cohorts (ages 64 to 75 years) were less likely to perceive personal comparative risk for colon cancer than those younger than age 55 years.¹⁵ That is, they believed that they were less likely to develop the disease than their peers of the same age and sex. Similarly, people older than age 70 years were more likely to perceive lower risk for developing cancer when considering absolute risk (i.e., their risk for developing cancer without reference to other individuals).¹⁶ Interestingly, age did not appear to be a factor in people's ability to perceive absolute risk.^{14,15} However, there was inconsistency in the links between age factors and screening behaviors. One study found that increasing age was correlated with decreasing breast cancer screening,¹¹ while Dassow found no difference in screening behavior by age.³⁹

There were also inconsistent links between perceived susceptibility or risk and screening behaviors. Katapodi et al did not find that comparative risk assessment predicted breast screening behavior.¹⁴ However, colon cancer screening behavior was predicted by perceived susceptibility in Dassow's study.³⁹

The concept of worry is similar to risk. Benyamini et al³⁸ found that worries about cancer and health were lowest among people with a vicarious experience of cancer due to relationships with people diagnosed with cancer, compared to worries held by cancer survivors or people with no relevant experience of cancer. Interestingly, cancer-related worries predicted checking for bodily signs of cancer only in individuals who had never had personal or vicarious experience with the disease,³⁸ which may suggest a possible moderating effect for the relationship between perceived susceptibility and screening behaviors. Han et al¹⁶ also found evidence of an age factor here as well, in that older ages, especially those older than age 70 years, predicted lower cancer-related worry.

Valuation of quality of life versus length of life. We attempted to address older adults' perceptions of benefits more broadly through literature that assessed how older adults view quality of life, length of life, and the decisional balance or potential tradeoff between them. Again, articles that were directly related to preventive services and older adults were rare; only one article was located⁴¹ (**Table 3**).

Literature for disease management or treatment is often only peripherally related to prevention services and preventive behaviors since it is grounded in an experience of a known disease. Even further afield is literature for advanced disease stages. However, we included such articles since they can provide some insight into the larger question of how older adults might view the costs, burden, or investment of preventive care efforts and relate them to the possibility of gaining some extension of life length in return. The disease states included prostate cancer⁴² and general cancer patients.⁴³

Among 459 patients with advanced cancer aged 26 to 89 years (median age, 60 years), 55 percent equally valued quality of life and length of life, 18 percent preferred length of life, and 27 percent preferred quality of life. Higher preference for quality of life was associated with older age ($P=0.001$).⁴³

Two studies used time tradeoff measures to evaluate preferences.^{41,42} Time tradeoff measures assume that decisionmaking involves a tradeoff between something now and something later, and that a decision reflects the decisionmaker's time preferences. When asked hypothetical questions about time preferences, framing effects were found. Prostate cancer patients given the impersonal versions of time tradeoff scenarios were more likely to order three health state scenarios "appropriately," by degree of dysfunction, and were more willing to trade quality of life for length of life than patients given personal versions.⁴² However, no relationship was found between the stated time preferences for quality of life versus length of life and adherence to medication regimes for primary prevention.⁴¹

Quality-adjusted life years (QALYs) are a common metric in health economics that combine a patient's attitude about length of life and quality of life into a single number. There is a considerable body of literature using QALYs; however, given that the number is a combination, there is little information that can be teased out regarding how the person determines the decisional balance. We were unable to locate any qualitative literature that explored the process for older adults regarding preventive services.

Cognitive ability/functional limitation. We were unable to locate any studies that pertained to differences in preventive service valuation that either addressed or controlled for cognitive ability or functional limitations.

Other cross-cutting themes. A point of interest is how well an older person's perceived risk concurs with risk estimates established through epidemiologically sound research methods. Cornford⁵ suggests that lay perceptions of risk for influenza do not map to epidemiologically established risk factors. Rutten and colleagues⁴⁰ found evidence of an age factor here as well; increasing age is associated with lower accuracy in estimating evidence-based cancer risk. The question remains as to whether this is due to cohort effects or the increased proportion of respondents with lower numeracy skills or mild cognitive impairment.

Key Question 2: What Attitudes Do Older Adults Have About Potential Harms of Clinical Preventive Services?

The harms associated with preventive behaviors and services identified in the literature fall into two categories—clinical harms and psychological harms. See **Table 4** for a summary of the findings.

Primary prevention. As with perceived benefits, older adults who have and have not been vaccinated for influenza differ in their beliefs about the harms of the vaccine. Two studies indicate that those who have not been vaccinated tend to perceive the vaccine as more harmful than those who have been vaccinated.^{5,6} Specific perceived harms identified in this literature were clinical in nature and focused on side effects, such as sore arms,⁵ developing influenza,^{5,7} frequent colds,⁵ and feeling generally unwell.^{5,6}

Cornford⁵ found that older people who have been vaccinated tend to counterbalance perceived harms of influenza vaccinations across multiple time periods. Specifically, side effects experienced after a vaccination in one year would be balanced against experiencing no side effects in other years. Possible lay explanations for side effects included coincidence, in which case the individual suspended judgment, or differences in the viral strain upon which the vaccination is based.

Secondary prevention. Perceived clinical harms associated with screening behaviors were fear of the test,^{8,13} pain,¹¹ discomfort,¹³ side effects,¹⁷ and a view that treatment would be worse than living with the disease.¹⁸ The psychological harms associated with breast and colon cancer screening were similar and included embarrassment,^{9,11,13,18} disgust at the idea of handling stool,⁸ fear of results or diagnosis,^{9,12,13,17} fear of unrelated diagnoses that are incurable,¹⁷ and worry.¹¹

Dementia screening had unique perceived harms. These included social stigma, emotional and practical hardships, and loss of independence if diagnosed with Alzheimer's disease.¹⁹

Key Question 3: What Value Do Older Adults Place on the Receipt of Clinical Preventive Services?

Though identifying the perceived benefits and harms associated with a preventive behavior is useful, benefits and harms are not necessarily weighted equally in the formation of global evaluations, and this weighting differs across individuals. For instance, though both persons X and Y identify embarrassment as a harm associated with colon cancer screening, embarrassment might play a major role in shaping person X's negative global evaluation of the screening, whereas person Y's global evaluation of colon cancer screening might be positive and influenced minimally by embarrassment. To circumvent this issue, some researchers have considered older adults' global evaluations of preventive services. Models provide little insight into how specific beliefs coalesce to form a global evaluation. Assessing global evaluations provides a different perspective from those that have been considered in key questions 1 and 2, and offer the possibility of triangulating evidence. Unfortunately, most of the empirical evidence focuses on older adults' evaluations of specific benefits and harms. The extant studies that assess global attitudes toward preventive behavior use one of two techniques, proxy measures or bipolar adjective scales, to explore older adults' global assessments of various preventive behaviors. Proxy measures, such as intention to be screened, are behaviors or beliefs that permit the inference of global attitude. Bipolar adjective scales have respondents indicate where their attitude falls along a continuum that is anchored by two opposing adjectives (e.g., harmful-beneficial). Coincidentally, identified studies of the value of primary prevention used bipolar scales, while proxy measures were used for secondary prevention studies. **Table 5** provides a

summary of the findings.

Primary prevention. Of five articles addressing physical activity for older people, only one was conducted in the United States.²² Four used bipolar scales in their survey methodology.²⁰⁻²³ Collectively, this set of four studies indicates that some older adults can have positive attitudes toward physical activity.²⁰⁻²² Attitudes toward physical activity appear to increase as one gives more consideration to and becomes more engaged in physical activity.^{20,21} Evidence regarding the ability of attitudes to predict intention and actual level of physical activity is mixed.²⁰⁻²³

We were unable to find literature to inform our understanding of how older people view the role of physical activity counseling by their health providers. However, Weeks and colleagues suggest that understanding the life history of the older person can help providers improve older adults' participation in physical activity.³⁵ Identified themes that influenced physical activity participation in their qualitative study of 24 older people included intergenerational influences, establishment of early physical activity patterns, family transitions over the life course, and changing health status over time and future health concerns.³⁵

Secondary prevention. The scant evidence available for global assessments of secondary prevention is mixed. Many of the women who did not adhere to mammography screening guidelines and were interviewed by LaPelle and colleagues were skeptical of medical recommendations.²⁴ Likewise, the value of breast cancer screening is unclear to people who are unwilling to risk losing feeling healthy should some diagnosis be discovered. This doubt regarding the value of breast cancer screening when one does not feel unhealthy was found in a small sample in the United Kingdom of mostly white, white collar, or professional people, and a second of Mexican immigrants.^{8,12} Conversely, Lewis and colleagues reported that the majority of older adults in their sample had positive attitudes toward cancer screening, as indicated by the general consensus that they would continue cancer screening despite discomfort.¹⁰ Interestingly, the percentage of adults reporting that they, personally, would continue prostate, breast, and colon cancer screening for as long as they live (72 percent colon, 83 percent breast/prostate) was larger than the percentage who agreed that everyone should get screened for these types of cancer as long as they live (55 percent colon, 63 percent breast/prostate).¹⁰ This suggests that attitudes toward cancer screening can differ across screening targets (self versus others). Some evidence from the United Kingdom suggests that the decision to complete a fecal occult blood test is shaped by a sense of civic responsibility or obligation.⁸ It is unclear whether this sense of obligation creates a positive attitude toward the test or if this sense of responsibility trumps personal attitudes.⁸

The Lewis study perhaps most directly speaks to the question of how older people view preventive services, and it bears more detailed reporting. The researchers interviewed 116 residents of the independent living quarters of a long-term care facility in North Carolina regarding their attitudes and beliefs about cancer screening. **Table 6** is a reproduction of a table that provides the percentages of older adults who reported statements regarding various potential attitudes toward cancer screening later in life. Of particular note is that 50 percent of older people felt that other health issues are more important than cancer screening, although people with a history of cancer were less likely to express this opinion (36 percent). However, the population of the study should not be considered representative of the general population.

Other cross-cutting themes. Force of habit as a prompt for behavior is seen in both primary and secondary prevention behaviors. As noted above, Weeks and colleagues found that the

establishment of early physical activity patterns was identified as an important influence for physical activity behavior later in life.³⁵ Likewise, Schonberg et al found that the largest proportion of women endorsed habit as an essential/very important factor in the decision to get mammography screening.³⁶

Key Question 4: How Do Older Adults Understand the Balance of Risks and Benefits From Clinical Preventive Services?

Little is known about how the benefits and harms of preventive behaviors are balanced by older adults and influence behavioral decisions. Indeed, there is a scarcity of theories and models available to guide this work. Only three studies were identified that contributed to any understanding. Findings are summarized in **Table 7**.

Lewis and colleagues' work provides an insight into the decisional balance process; 62 percent of older participants believed that their own life expectancy was not important to the decisionmaking process regarding cancer screening.¹⁰ Furthermore, 48 percent preferred not to discuss life expectancy with their physicians. There were no differences in the finding between those older than age 85 years and those younger than age 85 years, or between those who have previously had cancer and those who have not had cancer experiences. Those with a cancer history were in fact more likely to consider screening even if their physician recommended against it. However, 11 percent had decided to stop screening entirely.

Two studies explored this process from a decision science perspective. In one study, individuals valued screening outcomes, especially mortality reduction, more than process features when stating their preferences for a colon cancer screening procedure.²⁵ Specifically, participants were willing to accept longer test duration, greater risk for complications, mild pain, and different bowel preparation procedures in exchange for a reduction in mortality.²⁵ Likewise, van Wagner and colleagues, using focus groups, found that participants valued test sensitivity—which relates to benefits through a stronger likelihood of identifying a disease state, if one exists, at the risk for more false-positive findings—over discomfort during a test procedure.¹⁷

Issues of Valuing Prevention

This section is intended to expand conceptual understanding of values and preferences of older adults, and to provide one possible beginning of a conceptual framework. The discussion is not meant to be exhaustive. Our goal is to stimulate curiosity about the larger context of values and decisionmaking, introduce important concepts, and raise questions regarding the limitations of some commonly held views.

Goals of Prevention: Successful Aging

Older adults' evaluations of, and participation in, preventive health reflects their underlying reasons, current understandings, and motivations. What one hopes to achieve or avoid through preventive services is an integral part of the decisionmaking process. Moreover, different functions or behaviors may be differentially important to older adults, who may therefore be particularly interested in incorporating those particular prevention behaviors they feel will protect the needs or functions that they most value. Though the specific benefits achieved by a health behavior are varied, many of the benefits appear to fall under the superordinate category

of striving toward successful aging. One may predict that older adults are striving to age successfully. Accordingly, older adults' views of what it means to age successfully may shape their evaluations of preventive services.

Successful aging has been defined in a variety of ways. Models of successful aging often favor a biomedical or psychosocial perspective.⁴⁴ Biomedical models of successful aging emphasize longevity, the absence of disease, and good physical and cognitive functioning.⁴⁴ In contrast, models with a psychosocial perspective emphasize satisfaction with one's current and past life, social engagement, and personal growth. Rowe and Kahn distinguished between "usual aging" and "successful aging."⁴⁵ Individuals in the former category show the epidemiologically expected age-related decline in physical health and cognitive functioning, whereas those in the latter category show little or no evidence of the expected decline. According to this perspective, the three central components of successful aging are the absence of disease and disease risk factors, maintenance of physical and cognitive functioning, and engagement with life.⁴⁵

Investigating older adults' perspectives on successful aging yields what they consider to be normative and exceptional health states. Consideration of these perspectives provides a distinction between the health changes that older adults will tolerate and those they may strive to prevent. For example, having lower expectations of aging is associated with placing less importance on seeking health care for age-related issues, such as walking more slowly, having trouble sleeping, and experiencing joint aches.⁴⁶ According to research done in men with osteoarthritis, older men are more likely than their younger counterparts to view osteoarthritis as a normal part of aging and to endorse the view that one should expect to live with some pain and experience some impairment in walking ability as one gets older.⁴⁷

Moreover, older adults' views of successful aging often differ from those of researchers.⁴⁸ It is important to consider these definitional differences because older adults form their evaluations of preventive services from the vantage point of their own unique perspectives. One major point of divergence between these two groups is that older adults' definitions of successful aging are more multifaceted than those of researchers. When asked to consider the features central to successful aging, older adults include items that agree with theoretical definitions of successful aging, such as freedom from disease and good physical, psychological, functional, and social health; however, they also include more nuanced items, such as a sense of humor, sense of purpose, productivity, and contribution to life.^{44,48} Research done with focus groups of older adults indicates that a strong spiritual life, travel, and not taking medication are also associated with aging successfully.⁴⁹

Quality of life versus length of life. Another point of particular divergence between researchers and lay perspectives on aging is that older adults reduce the emphasis and value placed on longevity. More than 90 percent of the 1,890 respondents to the survey by Phelan et al considered maintaining good health until close to death as important (rather than neutral or unimportant), whereas less than 30 percent rated living for a very long time as important.⁴⁸ However, extending assumptions regarding older adults' choices regarding quality of life and length of life universally can be very misleading. As was seen in the study by Lewis and colleagues, stated choices are not always objectively logically consistent,¹⁰ and proffered justifications can be highly individualistic, based on the person's experiences of meaningful life and life fulfillment.⁵⁰

Nor is it necessarily appropriate to assume that observable health status is always an accurate

proxy for estimating another person's quality of life. Covinsky and colleagues⁵¹ found that disagreement between an older patient's health status and self-assessed global quality of life was common among a group of 493 cognitively intact patients ages 80 years and older. So while health status may function as a proxy for quality of life at the population level, it is inappropriate to use it as such at the individual level.⁵¹

Selective optimization and compensation. As the body of work in the area of successful aging has developed, interest has shifted to include articulating a formal definition of successful aging, along with delineating the processes that underlie successful aging.⁵² A widely cited process model in this area is the "Selective Optimization with Compensation" (SOC) model.⁵³ The SOC self-management model describes the ways that individuals successfully adapt to developmental changes in order to reach their goals. Though it is a lifespan model, SOC has been applied most frequently to the older population because of the functional impairments that frequently occur in this population. According to the SOC framework, older adults who age successfully achieve a positive net balance between gains and losses as they age. The cornerstone of the SOC model is the notion that older adults create environments that are conducive to goal achievement and successful aging. This model posits that individuals prioritize their goals and commit to them accordingly (selection). This prioritization process becomes particularly important when resources begin to decline, as they tend to do as one ages. Individuals then optimize the resources that they have in order to facilitate the achievement of a goal. Optimization of resources can include learning new skills and using one's energy. As resources decline, one may compensate for these declines using a variety of strategies. For example, individuals may use a wheelchair to compensate for lost mobility.

The goals discussed in the SOC model are determined subjectively. That is, each individual selects goals that are important to the development or maintenance of his or her own life satisfaction. Thus, the SOC model is flexible in that it can account for the different paths taken to achieve life satisfaction. This model has been empirically supported, though some strategies may become more difficult or infrequently used as one ages (see Ouwehand et al⁵² for review). The model has been criticized for being reactive and neglecting to recognize proactive coping as a path to successful aging.⁵² Incorporating proactive coping, which involves identifying stressors at an early stage, into the SOC model would be congruent with valuing preventive health measures.

Proactive coping. Proactive coping involves using a future oriented and proactive approach to anticipate and avoid or moderate life problems, which one would conceivably employ in pursuit of successful aging goals. While proactive coping has yet to be tested for preventive behavior in the older population, one randomized controlled trial has examined proactive coping in a sample of 191 adults ages 50 to 70 years with type 2 diabetes residing in the Netherlands.⁵⁴ Proactive coping was more predictive of successful weight loss maintenance and self-management at 12 months than either intention or self-efficacy.

Heterogeneity

Understanding how older people value health services is made more complex with the presence of heterogeneity. Heterogeneity enters into deliberations through multiple sources. In this section we expand on the concept of heterogeneity in the older population that was briefly touched on in the introduction. Heterogeneity applies in terms of the elderly designation as a whole and the

realization that each older person has a unique collection of life experiences that shapes his or her beliefs.

Heterogeneity in the older population. Currently, heterogeneity in this population is most commonly recognized through designation of three groups based on age (young old, old old, and oldest old).⁵⁵ Physical and cognitive function may be more important than chronological age in affecting attitudes toward prevention.

Though gender differences in behavior were not frequently addressed in the identified literature, older men and women differ in their perceptions of health. For instance, gender differences in self-assessments of health have been identified. Specifically, men tend to show greater decreases in self-assessments of health over time than women.⁵⁶ Though these distinctions highlight heterogeneity, diversity within the older population is not developed in the literature. Amongst other issues, the range of evaluations of preventive behaviors that exists within the older population is not fully understood or appreciated.

The heterogeneity in beliefs and attitudes toward preventive behaviors within the older population was touched upon during key question discussions. For instance, within the older population, variance exists in the extent to which health is viewed as a moral issue.^{57,58} One's stance on this issue has implications for one's response to health promotion.⁵⁸ There is also variance in levels of positive and negative affectivity and optimism and pessimism. These variances are associated with health-relevant outcomes, such as self-rated health, life satisfaction, and somatic depression.⁵⁹ It is unclear whether these age differences in beliefs are the result of a life span effect, a cohort effect, or an interaction of the two.

Similarly, economics accord particular importance to individual differences in impatience, risk aversion, and anxiety, which shape individual preferences toward preventive behaviors.⁶⁰ How much people value the present more highly than the future (impatience), prefer to avoid risk, and experience high levels of distress from uncertainty about outcomes are combined into the preference decision.⁶⁰

Heterogeneity has also been acknowledged through the development of patient archetypes. The term *archetype* is used here to label a specific cluster of key characteristics that pertain to a particular health state. For instance, diabetes archetypes are based on characteristics such as readiness for behavior change and attitudes toward diabetes.⁶¹ Health care providers can classify patients by archetype and tailor health messages appropriately.⁶¹ Similarly, patient adaptation to diabetes can be modeled to identify “best practice patients” and archetypes of “inefficient patients.”⁶²

Multimorbidity. Multimorbidity is the simultaneous occurrence of two or more chronic medical conditions within an individual.⁶³ More than 65 percent of adults aged 65 years and older are living with at least two chronic conditions.⁶⁴⁻⁶⁸ This number is projected to grow due to increased life expectancy and medical advances allowing longer life with chronic conditions.^{69,70}

Multimorbidity is germane to a discussion of older adults' evaluations of preventive services for several reasons. Not only is this state prevalent in the population, but also the many facets of multimorbidity, including concerns surrounding complex treatment, competing outcomes, psychological well-being, and disease burden, coalesce to create heterogeneous patient perspectives that undoubtedly influence the decisionmaking process.

Older patients with multimorbidity have unique needs that must be supported by providers and

the health care system. Older patients with multimorbidity desire conveniently accessible care, clear communication of treatment plans (including prevention), continuing relationships with providers, and assistance from a single coordinator who facilitates prioritization of competing demands. These patients also express a desire for a warm provider who acknowledges the dynamic and unique nature of their health.⁷¹

The treatment of one condition often conflicts with the treatment of another, or elicits side effects that can be treated. It is often impossible for all desired outcomes to be concurrently recognized, especially without intensifying or complicating treatment.⁷² Older patients with multimorbidity and their providers thus endeavor to balance the competing outcomes that accompany these conditions. Inherent in the balancing process is prioritizing outcomes and treatments. Given the unique priorities of each individual, calls have been made for patients' values and preferences to be the context in which treatment decisions are made.⁷²⁻⁷⁴

Empirical work has produced some rudimentary insights into how older adults think about and manage competing outcomes. For instance, evidence suggests a positive association between the number of compound effects (i.e., number of interferences between treatments and/or symptoms) and disease burden.⁷⁵ However, older patients may not recognize or credit the interactions among treatments.⁷² Data gathered from focus groups of adults aged 65 years and older who were taking at least five medications indicated that participants rarely acknowledged interactions between treatments. However, participants did view the benefits and side effects of their medications as competing outcomes and cited medication side effects as important influences in their medical decisionmaking processes.⁷²

The same study also provides insight into the decisionmaking strategies used by these patients. Though participants described their conditions and treatments in the context of specific diseases, when explicitly asked to consider tradeoffs associated with competing outcomes, their decisionmaking appeared to be guided by global, rather than disease-specific, concerns. Global concerns included survival and maintenance of physical function.⁷² Moreover, when asked about hypothetical medical situations that involved a tradeoff, they preferred the treatment that aligned with the outcome that was most subjectively desired.

Having to weigh the competing outcomes associated with multimorbidity also appears to affect provider decisionmaking. Physicians play an important role in the encouragement and implementation of preventive care in older adults. Though little is known about how multimorbidity influences physicians' advocacy of preventive services to older adults, in one study physicians primarily considered whether the patient will live long enough to benefit from screening when deciding whether to recommend colon cancer screening to adults aged 75 years or older.⁷⁶ Multimorbidity, along with chronological age and functional status, are factored into this calculation.

In addition to creating complicated decisionmaking situations, multimorbidity also elicits particular psychological experiences that may influence preferences and attitudes toward preventive services. Empirical evidence indicates that multimorbidity in older adults is linked to quality of life outcomes, such as self-perceived health status and life satisfaction. Specifically, a study of adults aged 65 years and older who had, at a minimum, concurrent diagnoses of depression, diabetes, and osteoarthritis found that higher levels of morbidity, as well as factors such as low levels of physical functioning, little knowledge about medical conditions, and being male, were associated with lower self-perceived health status.⁶⁴ Similarly, Stalbrand and

colleagues' examination of a cohort of 80-year-old Swedes found that individuals with at least two chronic diseases who had experienced at least seven different generic symptoms (e.g., nausea, fatigue, coughing) in the past 3 months had lower life satisfaction compared to those who had fewer chronic diseases and more symptoms, those with fewer chronic diseases and fewer symptoms, and those with the same number of chronic diseases and fewer symptoms.⁷⁷

In an attempt to distinguish between the psychological and physiological impacts of multimorbidity on quality of life outcomes, Nobrega and colleagues surveyed older adults who had at least one chronic illness. In this study, all participants were asymptomatic, free of complications, and were not experiencing any lifestyle or cognitive impairments.⁷⁸

Multimorbidity was assessed with the Cumulative Illness Rating Scale-Geriatric Version (CIRS-G), which accounts for both severity and number of morbidities. Quality of life was self-reported and was assessed separately for each of several domains of life (e.g., psychological, physical). The researchers found a negative correlation between scores on the CIRS-G and self-rated quality of life in physical domains. The negative correlation between CIRS-G scores and quality of life in psychological domains was marginally significant. Additionally, there were positive associations between self-perceived health status and quality of life in physical, psychological, and environmental domains. The authors concluded that mere knowledge that one has chronic medical conditions influences self-rated quality of life.

Heterogeneity of preventive services. Preventive services characteristics are not homogeneous. Some preventive acts, such as immunizations, are simple. Some are more complex, requiring sustained changes in behavior over time. Some behavior changes, such as smoking cessation and exercise, incur benefits even in older people. Some screening tests require a drop of blood, while others require sedation, such as colonoscopy. Primary prevention may have a different salience from secondary screening. Some effects of prevention are immediate (e.g., immunization). Others take a long time to produce a benefit. Whether a person receives benefits from still other preventive behaviors may never be certain. Similarly, preventive behaviors differ in the patient's level of independence (e.g., lifestyle changes versus clinical procedure), the amount of clinician involvement (e.g., prescriptions/referrals versus counseling), and frequency (e.g., once a year versus daily).

For example, because it is simple, brief, and requires little preparation, uptake of vaccinations may be as easily affected by the location of vaccination services (e.g., vaccines offered at a neighborhood grocery store) as a person's beliefs. However, other preventive behaviors, such as undergoing a colonoscopy, require much preparation and time, and are more invasive. It is likely that these types of behaviors are driven more strongly by one's evaluations of the service and its associated costs and benefits. Similarly, some preventive actions, such as beginning a regular exercise regimen, involve lifestyle changes that require a continuous series of choices and actions in changing environments. These types of preventive behaviors must be maintained on a daily or weekly basis and thus substantially differ from preventive behaviors that are undertaken annually, such as mammography screening.

Reason-Based Health Decisionmaking Models

As mentioned previously, researchers and health providers have approached understanding people's health beliefs and behaviors through psychological and decision analysis disciplines. Each applies a particular nuance to their conceptualizations and interpretations. The following

section provides a brief survey of the more commonly used models and approaches in each discipline that were found in the literature.

Health psychology models. Several health psychology models have been posited to facilitate the understanding of health-related behaviors. Specifically, they provide insight into how and why individuals come to participate or not participate in preventive services. These models have been extensively studied in many contexts and with many populations, including older adults and preventive health behaviors.^{21,23} The cornerstones of these models are identification of the psychological processes that are believed to underlie health-related behaviors and/or stages leading to behavioral change or action. Some models combine both of these approaches. Though these models have evolved and generally come to include factors such as demographics and individual differences, only the most central elements of these models will be highlighted here.

Among the most influential psychological models of health behavior change are the self-efficacy theory, the health belief model, and the theory of planned behavior (and its precursor, the theory of reasoned action). Self-efficacy is the belief that one is capable of carrying out specific actions in order to achieve a goal.⁷⁹ According to the self-efficacy theory, individuals are more likely to be motivated and to engage in a behavior if self-efficacy is high.⁷⁹ Self-efficacy is derived from a variety of sources, including personal experience with mastery or success, seeing the behavior modeled, social persuasion, and physiological signals.⁷⁹ The theory of planned behavior is conceptually related to self-efficacy theory in that it includes the construct of perceived behavioral control.⁸⁰ Perceived behavioral control is the perceived ease or difficulty of performing a behavior. Specifically, the theory of planned behavior purports that behavioral intention, or behavioral readiness, is a function of one's attitude toward the behavior, social norms, and perceived behavioral control. Finally, the health belief model proposes that perceived susceptibility, perceived severity of a condition and its consequences, perceived barriers, and perceived benefits of adopting a behavior coalesce to produce the likelihood that one will engage in a particular health behavior.⁸¹ Self-efficacy, perceived control, cues to action, and other processes have been incorporated into this model as mediating processes.⁸²

The common sense model of illness representation adds to this set of psychological process models by considering both the perceived reality of a health threat and one's emotional reaction to the threat.^{83,84} One's unique representation, or mental model, of the threat depends on how the individual perceives five attributes—the identity (or label), timeline, cause, controllability, and consequences of the threat. Representations guide how one copes and appraises the outcomes of action paths.

Stage models, such as the transtheoretical model⁸⁵ and the precaution adoption model,⁸⁶ delineate stages that individuals move through as they perform health behaviors. These models assert that individuals move from being either unaware of a behavior or not considering changing to contemplating the behavior, from which point they proceed to take action and maintain the behavior. The transtheoretical model includes a preparation stage in which individuals prepare to take action, and discusses processes that facilitate movement through the stages, such as self-efficacy, weighing of pros and cons, and temptation.⁸⁵ Empirical evidence supports the usefulness of matching the contents of health messages to a target's behavioral stage.^{87,88}

In summary, health psychology models help describe the internal psychological states and processes associated with health behaviors and were designed with the purpose of identifying leverage points at which interventions could be aimed to facilitate whatever is deemed a better or

healthier action. Values, attitudes, perceived benefits and harms, and risk assessments are integral to the models. However, a general critique of the literature is that the link between internal states and processes and external actions are often missing or tenuous. Furthermore, there is always the question as to the ethical basis for health interventions when considering patient agency; that is, a patient's ability to act with authority for oneself.

Decision analysis. Decision analysis in medicine is a quantitative discipline that derives from decision theory, which is based on mathematics, ethics, game theory, and economics.⁸⁹ Decision theory uses expected utility theory and describes rational decisionmaking under conditions of uncertainty.⁹⁰ The decision choice environment is characterized as involving uncertainty, incorporated through probabilities for each possible health outcome, and the individual's preference for the outcomes. More will be said about people's ability to understand probabilities in the upcoming section on issues in shared decisionmaking.

With regard to measuring preferences, decision analysis uses stated preferences—what the individual claims is the value of the object—rather than traditional economics' revealed preferences, the value that is revealed through an object's price. The choice conditions are presented as discrete choices, such as treatment versus no treatment for a given disease condition, or preferences for one form of screening test versus another (e.g., colonoscopy or fecal occult blood test).²⁵ Choices can be framed as time tradeoff choices, in which the individual indicates the tradeoff they are willing to accept between living with a particular health condition and the risk they would accept to have their health restored.

Another preference measurement technique is probability tradeoff. In contrast to the stated preference technique, which generally employs formal decision analysis methods, probability tradeoff models take the perspective of the patient standing at a particular decision node.⁹¹ In these simulations, the stated efficacy of a treatment is systematically varied until the patient switches his or her treatment preference. In these cases, patients are expected to intuitively handle the probability and uncertainty inherent in the choices.

Man-Son-Hing and colleagues compared decision analysis modeling using decision tree analysis with the probability tradeoff technique for 49 patients enrolled in a randomized controlled trial examining the efficacy of aspirin therapy for primary prevention of vascular events (myocardial infarction [MI] and stroke) in older adults aged 65 to 85 years (mean age=71 years).⁹² They found that major stroke was the least desirable health state, followed by MI, minor stroke, major bleeding, and "taking a pill every day." Furthermore, 40 of 42 patients were willing to take aspirin for a smaller reduction in the risk for stroke compared with MI. However, patients using the probability tradeoff technique indicated that they were willing to take aspirin for a smaller risk reduction for both MI and stroke than patients indicated through decision analysis techniques. In fact, treatment recommendations were discordant between the two techniques for between 38 and 62 percent of the participants. Finally, 30 of 42 participants (43 percent) reported that they were more likely to base a future decision on whether to take aspirin on the probability tradeoff exercise, five patients (17 percent) preferred the decision analysis approach, and 12 patients (40 percent) equally weighted the two approaches.

Regardless of the stated preference or probability tradeoff technique used, the result is a preference that is without explication of the underlying calculus the person employs, whether rational or intuitive. Some researchers have attempted to extend understanding of the approaches by using qualitative methods.^{17,93} Perhaps the greatest benefit these approaches provide is an

explicit, systematic tool for patients to use in decisionmaking situations, guiding them to think carefully about the uncertainties and tradeoffs inherent in preventive services choices.^{60,91}

Cautions for economic perspectives. There are two concepts in particular for which the reader is advised to retain a healthy skepticism with regard to employing economic theory-based preference research. The first concept is time preference, or intertemporal choices. As stated previously, time preference assumes that a person generally prefers something now rather than something later, and requires a tradeoff to accept a time delay. Whether this is an accurate reflection of the processes employed in making preventive health decisions is open to debate. For example, Chapman and colleagues found that time preferences had little relationship to actual adherence to hypertension or cholesterol-lowering medications.⁴¹

The second concept is utility theory, upon which the majority of stated preference approaches and QALYs are based. As mentioned in the results section of key question 4, QALYs combine the patient's attitude about both quality of life and length of life into one number. The method itself derives from both utility theory and time preferences and essentially asks, "How do you feel about a year with a medical condition compared with the two extremes of perfect health or death?" However, the realism of utility theory is debatable, suggesting that utility depends on framing and context. For example, personal versus impersonal framing affected patient preferences for health states related to prostate cancer.⁴² Therefore, caution must be exercised when considering these research findings because the results may be strongly influenced by the type of research methodology used. That is, stated preferences could be the product of actual preferences and/or the way that the question is framed. This issue is applicable to any type of research methodology that involves stating preferences or ratings, and is best countered by gathering behavioral data about actual choices.

More challenging is the perspective from which the older adult views the preference question. Individuals are often inaccurate in predicting how they will feel in the future as their reference points change.⁹⁴ Thus, one's place along this health continuum can have implications for how one perceives and evaluates current and possible future health states. For instance, Winter and colleagues found that older adults with lower levels of physical functioning reported more years of desired life in worsening hypothetical health scenarios than older adults with higher levels of physical functioning.⁹⁴ The authors concluded that impaired physical functioning places individuals at a reference point that allows them to more finely distinguish between these worsening states and death. The distinction between the worsening states and death was less refined for higher functioning participants. Thus, the population in which utility is measured is very important.

Even within a population with personal experience with a medical diagnosis, utility is subject to wide variations in responses. While statistical means can always be calculated for a population, the variation in time tradeoff utility identified by patients can span the entire choice range of 0 to 1. For example, Chin et al found much variation existed in the utility that patients with diabetes placed on complications, such as lower leg amputation.⁹⁵ There is a real problem with using population-level utility scores as a proxy for an individual patient's self-identified utility, or more simply put, the patient's own values.

In summary, careful attention should be paid to the base assumptions and techniques applied to elicit preferences. While arguments have been made that subjective well-being, based on real experiences, is a better methodology,⁹⁶ others suggest that subjective well-being is also beset

with problems and call for more research into developing new tools that are more sensitive to change and less subject to bias.²⁸

Psychological attitude research versus decision analysis preference research. Though both psychology and economics are interested in the ways in which people evaluate health states, health behaviors, and health services, the two disciplines differ in their conceptualization and measurement of evaluations. In psychology, evaluations are conceptualized as attitudes that can be measured with Likert rating scales. Economics focuses on measuring preferences by having individuals choose and rank scenarios that systematically differ in features, such as price or time investment. Both attitudes and preferences have been used to study older adults' valuation of preventive behaviors and services. Though these two measurement strategies can yield the same conclusion, they can also render divergent information. For instance, in a direct comparison of attitude and preference measurement strategies in the context of HIV testing procedures, Phillips and colleagues found that the attitude measurement strategy was more conducive to halo effects—a cognitive bias in which the perception of a particular object is influenced by previous value perceptions—and the strategies differed in their conclusions of how particular attributes of the test (e.g., price, location, counseling) were valued.⁹⁷

Other Decisionmaking Mechanisms

Behavioral economics. Behavioral economics developed as a field to modify standard economic theory by describing the behavioral bounds on rationality, willpower, and self-interest that constrain people's economic decisions. Practitioners in the field integrate insights from psychology and cognitive science with economics with the hope of building more realistic models of human behavior that incorporate social, cognitive, and emotional factors.

It should be noted that behavioral economics is an active field with healthy debate on theoretical and methodological fronts, which fall outside the scope of this brief overview. However, the existence of such a debate is present in the fact that two of the three articles identified that used these methods, while focused on older adults' preferences for preventive services, were methodological in nature.^{92,98}

Herbert Simon coined the term “bounded rationality” to describe human limits to information processing and problem solving.⁹⁹ Very simply, there is only so much time and so much brain power a person can employ toward decision processes. When the complexity of a problem breaches the bounds on rationality, or when conserving cognitive resources, people use heuristics. Heuristics are the common sense, experience-based methods, often called “rules of thumb,” that are used in problem solving and learning.

Heuristics have generally been regarded as a second-best way to process information and something to be avoided if greater information processing capacity becomes available. However, Gigerenzer and Brighton provide a counterview to the “Homo economicus” view of standard economic theory with their “Homo heuristicus,” which views “human nature as based on an adaptive toolbox of heuristics rather than on traits, attitudes, preferences, and similar internal explanations.”¹⁰⁰ They detail decisional environments in which different “less is more” heuristic models, such as “take the best” (ignoring cues), tallying (ignoring weights), or ignoring dependencies, outperform complex models in prediction. Complex mathematical models may better describe the observed data (i.e., provide a better fit), but people make decisions in order to make choices about future health behaviors, and predictive models for decision processes may be

more germane to the purpose.

Framing is another theme in behavioral economics. In this case, framing refers to the mental and emotional filters people develop from personal experience, anecdotes, cognitive biases, and other mental processes, and apply to situations to formulate understanding and responses.

The work by Arana and colleagues¹⁰¹ provides one example where both heuristics and framing were applied to understand the decision processes with which people valued health care programs for older people in the Canary Islands. They theorized that valuation involves the interplay between two paradigms: valuation by calculation and valuation by feelings. They found in a survey of 550 adults that the use of simplifying heuristics increased when the emotional intensity state of the participant was high. Their findings also support the notion that use of heuristics increases as decisional complexity increases.¹⁰¹

Socioemotional selectivity theory. Socioemotional selectivity theory, developed by Carstensen, suggests that the reduced life expectancy due to aging is a constraint that induces older adults to shift priorities from future-oriented information gathering goals to present-oriented emotion regulatory goals.¹⁰² These age-related shifts influence cognitive processing and lead to a “positivity effect,” a disproportionate emphasis on positive information in older adults’ attention and memory, which supports a state of well-being. Socioemotional selectivity theory has been tested within the context of health care decisions and has demonstrated age differences in decision processes. Older adults reviewed a greater proportion of positive choice criteria, were more positive in their recollections, and showed more positive emotional responses when making choices for themselves or another person of similar age than younger adults.¹⁰³ Older adults demonstrated a shift to information-processing goals when making a health care decision for a young person. This perspective of the younger person was made at an emotional cost; in these situations the older adults reported a decline in positive emotions. Younger adult performance was not influenced by the age of the person for whom they were making a decision. They reviewed equal proportions of positive and negative material and experienced a decline in positive emotions, regardless of who they were choosing for.

The shift from future-oriented goals to present-oriented emotion regulatory goals could have important implications for preventive services and related shared decisionmaking processes. For example, the noted age factor in personal risk perception could perhaps be explained by socioemotional selectivity theory. It is also interesting to speculate how the findings of Lewis and colleagues might be interpreted using the theoretical underpinnings of socioemotional selectivity theory. Perhaps some of the noted inconsistencies in the reported statements might resolve under such scrutiny.

Habits. Factors other than benefits and harms can influence one’s intention to perform and the actual performance of a preventive behavior. This point is highlighted in many health psychology models and theories and is supported by empirical literature. (See the section on health psychology models). It appears that habit and early experience may influence older adults’ engagement in preventive health behaviors. For instance, factors influencing older adults’ participation in physical activity include parental modeling of physical activity into older age and establishment of physical activity habits early in life.³⁵ Similarly, older women who recently had been screened reported that habit strongly influenced their decision to receive mammography screening.³⁶

Response Shift

Quality of life is an important outcome for older adults to assess within the context of preventive services. Some researchers suggest that measurement of quality of life is problematic because the assessment tools assume that patients have the same perspective of their disease and a static evaluation for their assessment of quality of life across time. That is, the patient's internal standard of measurement does not change. Response shift is defined as a psychological phenomenon, a shift in one's internal standard of measurement or how one values different health states, resulting from coping with a health condition.¹⁰⁴

One study examined the response shift phenomenon in an older population. Razmjou et al used a "then-test" study design, which asks participants to complete a second set of quality of life instruments from the perspective of how they would have perceived themselves to be before their surgery, in a study of 236 patients receiving total knee replacement surgery.¹⁰⁵ They found that the magnitude of response shift increased over time, from 6 months to 1 year post-operation, for the Short Form (36-item) Health Survey physical and mental component scores. Controlling for response shift uncovered a statistically significant change in mental health improvement.

Chapter 3. Shared Decisionmaking

Review of Empirical Literature

The literature search identified only two studies that examined shared decisionmaking interventions for preventive service decisions by older people. In addition to the literature identified for Chapter 2, three additional articles were identified that informed the review regarding shared decisionmaking. These studies also largely used qualitative or descriptive analysis methods with small purposive samples.

Key Question 5: How Should Clinicians Engage in Shared Decisionmaking Related to Clinical Preventive Services in Older Adults?

Definition and key elements of shared decisionmaking. Shared decisionmaking is defined as the process by which practitioners and patients reach health care choices together.³⁰ It is an evolving concept with no agreed upon operational definition. We compiled a list of key elements of shared decisionmaking based on a review of 161 articles containing definitions by Makoul and Clayman¹⁰⁶ and work done on the Ottawa Decision Support Framework.³⁰ We used this list of key elements to evaluate the comprehensiveness of the shared decisionmaking interventions we found on preventive services in older adults. These elements are summarized in **Table 8**.

The Ottawa Decision Support Framework, available at <http://decisionaid.ohri.ca/odsf.html>, provides a description of the shared decisionmaking process and relevant outcome measures, and expands the process to include a role for health care professionals beyond the patient-physician dyad.³⁰ The Ottawa Decision Support Framework suggests that during the shared decisionmaking process, practitioners must assess the patient's decisional needs and decision quality and provide decision support. Decisional needs include decisional conflict (uncertainty about the course of action to take when choice among options involves risk, loss, regret, challenge to personal life or values), knowledge of the health condition, expectations of the treatment outcomes, values, support, and resources. A patient's decisional needs will affect decision quality. The goal is to reach a high-quality decision, one that is informed with the best evidence and based on the patient's values. When assessing decision support, the practitioner provides facts about the treatment choices and probabilities associated with treatment outcomes and clarifies the patient's decisions, needs, and values. Decision support can be provided with clinical counseling, decision aids, and coaching. Additionally, the practitioner must monitor and facilitate progress of the patient's final decision.

Outcomes of shared decisionmaking. Shared decisionmaking interventions need to measure relevant outcomes. Good outcomes related to decisional needs include improved knowledge, improved realistic expectations of outcomes, including benefits and harms, improved certainty of choice, improved feelings of being informed, improved feelings of being clear about values, and decreased decisional conflict. Decision quality outcomes include consistency between eligible patient treatment uptake rates and the underlying distribution of patient's informed values.

Intervention studies. We found two articles on shared decisionmaking interventions for

secondary preventive services for older adults. These studies looked at prostate-specific antigen (PSA) screening for prostate cancer²⁶ and colorectal cancer screening.²⁷ Each intervention took a different approach to shared decisionmaking, contained different elements of shared decisionmaking, and had different outcome measures. See **Table 9** for a summary of the shared decisionmaking elements included in the interventions. See **Table 10** for a summary evidence table of included studies.

Study 1. Frosch et al²⁶ compared the influence of usual care and three different shared decisionmaking interventions on men's decision to undergo PSA screening for prostate cancer. The three shared decisionmaking interventions involved: 1) attending a 30-minute lecture and discussion about the risks and benefits of PSA screening, 2) watching a shared decisionmaking video, and 3) watching the video and attending the lecture and discussion. While the shared decisionmaking interventions all used a different format, the same elements were included in each intervention (i.e., define/explain problem; present screening options; discuss benefits, risks, and costs; and assess patient values and preferences). The type of shared decisionmaking intervention influenced older men's decisions to receive PSA testing. The percentage of men selecting to have subsequent PSA screening was 97.7 percent in the usual care group, 82.2 percent in the lecture and discussion group, 60 percent in the video group, and 50 percent in the video and lecture/discussion group. Older men attending both the video and lecture/discussion session had the highest prostate cancer knowledge scores.²⁶ The study findings also indicate that older men want to engage in shared decisionmaking with health care providers.

Compared to participants in the usual care group, participants in any of the shared decisionmaking interventions (video, discussion, or video plus discussion) were less likely to choose PSA screening and had less concern about prostate cancer, higher knowledge scores on PSA screening and prostate cancer, and lower confidence in their decision regarding PSA screening. While it may seem counterintuitive that these men would have lower confidence in their screening decision, the authors of the original article conclude that the shared decisionmaking interventions challenged their pre-existing perception that PSA screening was a simple and definitive way to alleviate concerns about prostate cancer. Instead, the men learned that a positive screening test led to complex decisions about how to proceed with cancer screening. This finding underscores the importance of assessing personal preference when choosing between uncertain outcomes. The men in the shared decisionmaking interventions were also more likely than those in usual care to want to share their decision with their physician (46 percent in usual care group, 54 percent in discussion group, 66 percent in video group, and 70 percent in video plus discussion group). Men in the shared decisionmaking interventions were also more likely than those in the usual care group to say that they would select watchful waiting over surgery or radiation if they were subsequently diagnosed with prostate cancer (35 percent in usual care group, 81 percent in discussion group, 72 percent in video group, and 67 percent in video plus discussion group). In summary, no matter the format of the shared decisionmaking intervention, men who engaged in shared decisionmaking made different choices about PSA screening, had higher knowledge about PSA screening and prostate cancer, were more likely to want to engage in shared decisionmaking with their physician, had less concern about prostate cancer, and would choose different treatment options if they were diagnosed with prostate cancer. This study did not use a physician in the shared decisionmaking intervention, demonstrating that parts of this process can be delegated, especially in situations where there is significant uncertainty in the evidence to support a preventive service.

Study 2. Pignone et al²⁷ conducted a quasi-experimental study to determine if older men change their preference for the type of colorectal screening procedure based on what type of information was presented. The three colorectal cancer screening options included: 1) annual fecal occult blood tests, 2) flexible sigmoidoscopy every 5 years, or 3) annual fecal occult blood tests with flexible sigmoidoscopy every 5 years. The first stage of information described the different test procedures, the second described the test performance, and the third discussed hypothetical out-of-pocket costs associated with each testing option. The percentage of participants selecting the fecal occult blood test after stage 1 was 45 percent, after stage 2 was 36 percent, and after stage 3 was 53 percent. The percentage of participants selecting the fecal occult blood test and flexible sigmoidoscopy after stage 1 was 38 percent, after stage 2 was 47 percent, and after stage 3 was 31 percent. The patients' choice of which screening option to select changed based on the type of information they were provided. When they were provided with information about the test procedure, most preferred the fecal occult blood test alone. When they received information about the test performance (efficacy at detecting colorectal cancer), most preferred the fecal occult blood test combined with flexible sigmoidoscopy. However, when presented with cost data, most went back to preferring fecal occult blood test screening alone.

When older men are presented with efficacy and cost information for colorectal cancer screening choices, cost was a stronger influence on their decision. Items not affecting the screening choice included knowing someone close to you that had colorectal cancer, perception of risk, concern about the seriousness of colorectal cancer, education, race, age, or insurance status. The reasons for making their choices were also identified. Those who preferred to have both tests cited increased effectiveness at detecting colorectal cancer. Those preferring the fecal occult blood test alone indicated that the test was easier to perform, could be done alone, and was less expensive. Those preferring flexible sigmoidoscopy indicated that it was easier to perform and viewed it as a more effective test. Receiving knowledge about the risks and benefits of colorectal cancer screening increased the participant's desire to receive screening. This intervention focused on increasing patient knowledge about the risks for colorectal cancer, benefits of screening, and describing the screening options, their efficacy, and cost. The information was provided by a research assistant and there was no followup on actual screening behavior.

In summary, very few intervention studies focus on shared decisionmaking as it relates to preventive health services for older people. There is nothing in the literature to indicate that older adults have a different level of interest in engaging in shared decisionmaking. Even though neither study included all the essential elements of shared decisionmaking, the interventions were able to influence patient decisions. Both studies used research assistants to implement the interventions, suggesting shared decisionmaking can be provided by someone other than the physician and still influence choices. The outcome measures focused on improving knowledge about the disease being screened, the benefits and risks associated with the screening procedure, and concern about developing the disease. Missing were outcomes related to decision quality (i.e., decisional conflict and congruency of patients' decisions with their values). Another important outcome omission was the lack of followup on actual screening behavior.

Older people's preferences for and experiences with shared decisionmaking encounters. A few articles described older adults' preferred role in shared decisionmaking. In a telephone survey of 200 women ages 65 years and older about screening mammography decisions, around half of the respondents indicated that they wanted to make the final decision about screening mammography (ages 65–79 years: 50.5 percent; ages ≥80 years: 46.6 percent), and the rest were

equally split among wanting to make a shared decision (ages 65–79 years: 28 percent; ages ≥80 years: 21.4 percent) and wanting the doctor to make the final decision (ages 65–79 years: 21.5 percent; ages ≥80 years: 32.0 percent).³⁶

Seventy percent of the older men engaged in a clinical trial comparing different shared decisionmaking approaches for PSA screening felt positive about participating in the shared decisionmaking interventions. The shared decisionmaking interventions also influenced older men's desire to share their PSA screening decision with their primary care provider. Those in the shared decisionmaking group were more likely to want to share their screening decision with their physician than those in the usual care group.²⁶

Older adults at high risk for cardiovascular disease who completed a consultation containing elements of shared decisionmaking reported a change in emotions, thoughts, perceived knowledge related to health and risk, and readiness to change their lifestyle.¹⁰⁸ These participants indicated that the physician's professional competence, communication, and the doctor-patient relationship contributed to having a positive experience during the consultation. They also indicated that the consultation could have been improved by increasing the number of opportunities to contribute their personal perspectives to the consultation, having more time for the consultation, and tailoring the information to their personal situation.¹⁰⁸

Other insights. The literature identified for this review offers some insights into how clinicians should engage in shared decisionmaking regarding clinical preventive services. **Table 11** provides a brief summary. Specifically, older adults in the study reported that life expectancy is not an important factor in their decision and would prefer to not discuss life expectancy with their provider.¹⁰

Second, older adults may need to be provided with more information about the screening process and the benefits and risks associated with it. In particular, older adults need to know the benefits and risks for people of their specific age group. Evidence suggests that some older adults have little knowledge about colorectal cancer,⁹ the benefits of screening for it,⁹ and what the screening procedure entails.¹³

Finally, health care provider encouragement seems to play a part in patients' decisions to engage in both primary and secondary preventive services. The likelihood of receiving an influenza vaccination shot,^{6,7} mammography,¹¹ or screening for colorectal^{9,13,109} or prostate cancer³⁷ is related to health care provider encouragement and prompts. Interestingly, health care providers' general prevention orientation may also play a role, especially when it comes to primary, complex behaviors. Among women reporting provider encouragement for physical activity, those who had providers who encouraged additional preventive behaviors were more likely to engage in regular physical activity than women who reported no additional provider encouragement.¹⁰⁹ However, conflicting evidence indicates that older patients do not necessarily adopt provider encouragement and opinions. Adult women aged 65 years and older are more skeptical than younger age groups of breast cancer screening recommendations,²⁴ and older adults interviewed by Lewis et al reported that they would consider cancer screening even if their physician recommended against it.¹⁰

In summary, older people appear to respond favorably to shared decisionmaking interventions, and participation in shared decisionmaking interventions increased older people's awareness of the opportunity to share their decision with their care providers. Interventions with just a few shared decisionmaking elements can change older people's knowledge on disease, risk

perception, and motivation to engage in behavior change. Older people may prefer more time in the encounter to discuss their individual circumstances to provide a tailored recommendation. There are no studies investigating the influence caregivers or family members may have on an older person's desired role in shared decisionmaking.

Issues of Shared Decisionmaking

As in Chapter 2, this section is intended to expand conceptual understanding of shared decisionmaking, and to examine possible conceptual frameworks. The discussion is not meant to be exhaustive. Our goal is to stimulate curiosity about the larger context of values and decisionmaking, introduce important concepts, and raise questions regarding the limitations of some commonly held views.

Typology of Shared Decisionmaking

Not every clinical encounter needs to involve shared decisionmaking. The USPSTF “believes that clinicians generally have no obligation to initiate discussion about services that have either no benefit or net harm.”¹⁰ However, the USPSTF encourages clinicians to engage in shared decisionmaking 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.”¹⁰ Whitney et al⁴ argue that the degree to which patients' preferences are considered and their role in the decisionmaking process is determined by the type and number of treatment options available for a given health situation. Health care providers need to recognize this distinction and take different approaches to engaging patients in medical decisionmaking. Some medical decisions have only one reasonable treatment option, while others offer two or more reasonable choices.

Whitney et al⁴ proposed a typology for medical decisionmaking based on the type of decisions available. The four types of decisions health care providers can facilitate include: 1) clinician directed, 2) patient controlled, 3) clinician controlled, and 4) shared decisionmaking. The first three involve situations where only one reasonable treatment choice is available. For example, the only reasonable treatment for a melanoma tumor is excision, and it would be unwise for the patient to reject this treatment, given the benefits of excision far outweigh the future potential of harm. In cases where there is only one reasonable treatment option, decisional priority is generally held by the clinician. When a patient listens, asks questions, understands, and agrees with the clinician's decision, the interaction is agreeable, even though the decision was directed by the clinician. In this situation patients can make an unwise decision by refusing the recommended treatment or by insisting on a useless intervention. In this instance, the interaction is unilateral and the decision is controlled by the patient. In the case where a clinician insists on his or her recommendation (e.g., if the physician refuses to prescribe an antibiotic for a viral infection), the interaction is unilateral and clinician controlled. Only when there are two or more reasonable treatment options can shared decisionmaking occur, in which decisional priority is shared, the interaction is collaborative, and the patient takes an active role in the process. **Table 12** summarizes this proposed typology and terminology of medical decisions.

It should be noted that the number of choices can itself be an issue of perception. To some people, no treatment is always an option. Regarding preventive services, all services would fall into the category of two or more potential choices.

Risk Perception in Shared Decisionmaking

Risk and benefit information are often presented numerically in a shared decisionmaking context, yet most people have a poor understanding of probability, causation, and risk.¹¹¹ People with different levels of numeracy may benefit from different risk communication methods.¹¹² Adults aged 60 years and older were found to have significantly lower ability to correctly read numbers from graphs and lower ability to identify the essential point of the risk information presented than younger adults.¹¹³ Presenting information using natural frequencies, or counts of occurrences that preserve the base rate, has been found to improve older adults' understanding of medical screening information.¹⁰⁷ However, 44 percent of older adults with low numeracy skills were unable to accurately complete the task; the proportion improved to 14 percent with the inclusion of icon arrays.¹⁰⁷ Icon arrays, which display natural frequencies using visual arrays, have been shown to produce adequate knowledge across numeracy levels.¹¹³ However, participants across all levels of numeracy rated tables as the most effective, trustworthy, and scientific visual display.¹¹³ Thus, there is still a need for better tools and guidance from providers to help older adults develop accurate knowledge of risks.

The Provider and Shared Decisionmaking

There are also two major concerns regarding the provider's role in shared decisionmaking that deserve consideration. The first concern involves the potential unexamined assumptions and biases that a provider may bring to a shared decisionmaking event. Epstein and Peters¹¹⁴ quote Thaler and Sunstein's "libertarian paternalism" as the current ethos guiding public health policy.¹¹⁵ Libertarian paternalism is a paternalism that does not require coercion, but instead suggests that leaders should influence patients' preferences to achieve desired goals, while leaving the ultimate choice to the individual. The shadow of this ethos is seen in the literature as the assumption that once the patient understands what the researcher or provider knows about the health benefits and risks of preventive services, then collaborative decisionmaking will lead to a consensus agreement that will necessarily be the "right" decision. Bioethics does not require that patients make "good" decisions; it simply requires that they receive adequate and comprehensible information to satisfy informed consent in order to make an uncoerced decision.¹¹⁶ Leaving aside the question of whether or not such decisions are the "right" ones, fairness would suggest that providers involved in shared decisionmaking should be as aware of their own assumptions, biases, previous experiences, and strengths and foibles as is expected of the patient.

The second major concern is also related to unexamined assumptions. The stated purpose of shared decisionmaking is to empower patients to participate in the decisionmaking process, in this case regarding preventive services. The first decision patients need to make is to what extent they wish to engage in shared decisionmaking. Some studies report that older adults are more likely to delegate decisionmaking to the physician.^{117,118} Physician-patient covenants¹¹⁹ and the obligation of nonabandonment of the patient by the physician¹²⁰ make the case that the patient's preference to participate in choosing a preventive service course, or alternatively, preferring to delegate such choice to the physician, is a viable preference. Providers need to examine their own motivations regarding shared decisionmaking and assure themselves that the motivation does not stem from the desire to shift the burden of dealing with the uncertainties of health care decisions onto the patient.

Theories of medical decisionmaking are evolving and the current emphasis is on empowering patient involvement through shared decisionmaking. While this idea has strong face validity and is congruent with optimizing patient autonomy, there is little empirical evidence to guide its implementation as it relates to preventive services for older adults. There appears to be agreement that shared decisionmaking does not need to occur in all clinical encounters. It is most appropriate to use when there is more than one reasonable treatment option or when there is considerable uncertainty about the strength of evidence for a given screening option (as is the case with PSA screening). Challenges with implementing shared decisionmaking arise from a lack of consensus on what elements should be included in the process, on relevant outcome measures, when to incorporate decision aids, and when shared decisionmaking should expand beyond the patient-physician dyad to include other health care professionals or be offered at the population level through public health promotions.¹²¹ Other concerns include how to adequately represent risk to older adults in ways that develop accurate knowledge, and the provider's role in shared decisionmaking.

Chapter 4. Conclusion

Bringing Preferences and Shared Decisionmaking Together

Preferences are not always stable over time. Epstein and Peters give a thoughtful commentary in which they point out that patient preferences may not be elicited as much as constructed, particularly in situations that are unfamiliar, have high stakes, or are uncertain, “with potential outcomes that have not been considered or cannot be imagined.”¹¹⁴ Yet, this is precisely the context for which medical shared decisionmaking is most advocated. Epstein and Peters state that cognitive, emotional, and relationship factors can impact how patients construct their preferences, citing framing effects (e.g., presenting information in positive or negative terms), information overload, the role of emotions in cognitive executive functions, and the patient-provider relationship. The literature on selective optimization and compensation theory, socioemotional selectivity theory, and response shift that was discussed previously is consistent with the factors raised by Epstein and Peters. As was mentioned previously, the use of stated preference and probability tradeoff techniques has been found to be a helpful process to participants as they deliberate on the health choices available.^{91,97}

Preference instability has been documented in the literature. One study examined whether older adults’ preferences for future attempts at life-sustaining treatment change over time in a consistent and predictable manner. Community-dwelling older adults older than 60 years with advanced cancer, heart failure, or chronic obstructive pulmonary disease were interviewed every 4 months for 2 years.¹²² Thirty-five percent of participants had inconsistent preference trajectories (e.g., becoming more or less willing over time) when asked to trade high-burden therapy for prolonged life; the proportions increased to 48 percent when participants were asked to risk physical disability, and 49 percent when participants were asked to risk cognitive disability.¹²² Those with variable health states were more likely to have inconsistent trajectories, although participants with stable health states also commonly demonstrated inconsistent trajectories. The finding that trajectories were unstable in both directions is particularly noteworthy.

Preventive services may seem to represent a relatively tame scenario for preferences, compared to high-stakes health situations or questions regarding life-sustaining treatments. However, it should be noted that the oldest old are the least represented group in prevention literature, but the fastest growing demographic group of older adults. The level of uncertainty they face regarding the potential benefits and harms of preventive services is certainly not trivial. As mentioned in previously, providers need to be aware of their role in the shared decisionmaking process in order to avoid unintentional undue influence on the patient’s preferences.

Recommendations for Future Research

There has been little work regarding preferences in the arena of preventive care, and there is no strong body of evidence informing the topic of how older people value preventive services. In fact, much of the available information is in the form of indirect evidence. Older adults are also poorly represented in the shared decisionmaking literature. The following sections discuss potential research topics that would help develop our understanding in these areas.

Values, Attitudes, and Preferences

The overwhelming majority of the current literature on preferences is disease specific and treatment focused, and does not directly address aging and its effect on preferences for preventive health, either for primary or secondary prevention. Nor has a community of colleagues fully formed to address the topic directly. What literature currently exists tends to focus on the young old.

Given the more than 30-year span that covers the aging community, research that examines differences between the age groups within the older adult population, particularly the oldest old, is strongly needed. This research needs to take into account both the possibility of differences that arise between one age cohort versus changes that occur over time as people move from middle age to young-old age to the oldest ages. This would help focus efforts on age groups that are based on evidence rather than a socially constructed chronology. For example, it may be that the young-old have more in common with the generally healthy middle-aged than the old-old with regard to prevention, and certainly the frail old.

One other important question that needs attention is whether research in a patient-centered environment would differ from research in a professional-dominant environment. This research area is primed for consumer stakeholder involvement in research planning to assure that the questions asked, and the outcomes measured, represent how older adults approach and measure questions of value and preference. Given the heterogeneity of the older adult population, it is likely that the only valid way of using preference research in preventive services is through eliciting individual preferences in individual decisionmaking processes.

Continuing research into tools to measure values and preferences is critical to the field. We support Smith and Ubel's call for expanded research into both decision-based utility methods, such as stated preferences, and subjective well-being, as well as for measurement tools that are more sensitive to health changes and less biased.²⁸

Further synthesis reviews for preferences by disease or function may assist the field by aggregating what information is currently available in the literature. Restricting searches to a relatively easily defined search scope and algorithm, such as the type found with strictly defined diseases or functions, would make it easier to locate relevant articles. Most of the articles located for this review were only indirectly related, but useful nonetheless. Pulling these together across disease categories, and tying them together with searchable keywords, would help future researchers avoid inefficient use of research resources.

Shared Decisionmaking

Although shared decisionmaking is an evolving concept, work in this field is progressing. The most developed areas are on decision aids that can be used during shared decisionmaking.¹²³ However, most of these decision aids were developed for younger populations and address disease treatment rather than preventive services. Future research needs to investigate how well these decision aids work for older adults making decisions about prevention services. Decision aids should account for lower health literacy and numeracy found in this population¹²⁴ and provide balanced and accurate information that will help older adults make choices that reflect their goals and concerns. Resources for developing decision aids are available from the Ottawa Hospital Research Institute (<http://decisionaid.ohri.ca/odsf.html>) and from the Dartmouth-

Hitchcock Medical Center's Center for Shared Decision Making (<http://www.dhmc.org>). International standards for the development of decision aids have also been developed and should be used to guide the creation of decision aids relevant to older adults' preventive services.¹²⁵

Other researchers are beginning to investigate ways to support health care professionals in shared decisionmaking.¹²⁶ Future researchers need to identify what facilitates and hinders older adults' ability to engage in shared decisionmaking. The limited evidence we found suggests that older adults are willing to engage in shared decisionmaking.²⁶

Researchers are also beginning to develop and validate relevant shared decisionmaking outcome measures.¹²⁶ Future research needs to determine if these measures are also valid and reliable for older people. The Ottawa Decision Support Framework describes types of relevant outcomes. Outcomes related to decisional needs should demonstrate improvement in patient knowledge of the benefits and harms of preventive services and realistic expectations of outcomes, benefits and harms, certainty of choice, feelings of being informed, and being clear about values. Decisional conflict should be decreased. The decisional conflict scale needs to be validated with older adults.¹²⁷ Outcomes for decisional quality need to measure consistency between eligible patient treatment uptake rates and the underlying distribution of patients' informed values and make sure there is no unresolved decisional conflict.^{29,30}

To date, most of the shared decisionmaking literature has focused on the physician-patient dyad. Several lines of research are needed to improve our understanding of this dynamic. Research regarding the influence caregivers or family members may have on an older person's desired role in shared decisionmaking would be useful. It is also important to understand how physician framing (how the physician presents information verbally) shapes preferences.

Researchers are beginning to explore how to use other health care professionals (i.e., nurses and social workers) in the process.¹²⁶ Older people experiencing multimorbidity and functional limitations make good candidates for interventions that expand shared decisionmaking beyond the physician-patient dyad. The scant literature that we identified indicates that older people generally want more time to discuss their individual health needs with providers and want these needs to be considered in health care decisions.¹⁰⁸ Given the limited time physicians have available for patient consultation, these interdisciplinary shared decisionmaking interventions may provide a more cost effective way of providing information when there is uncertainty in the decisionmaking process. The two studies we found on shared decisionmaking interventions in older adults did not involve the physician and demonstrate that part of shared decisionmaking interventions (i.e., provision of knowledge on the risks/benefits provided by a given preventive service) can be provided by other health care professionals and still influence patient decisions. However, research that would inform a physician as to whether a patient's preference is "good" or "bad" is still vital.

Conclusion

Both aging and prevention are challenging, complex topics. Taken singularly, they often do not lend themselves to simple solutions based on one easily defined mechanism. Together they create a complex system and a decisionmaking environment that requires acknowledging complexity and the challenge of balancing multiple inputs, attentional demands, and choices among an array of possible actions. It is, in other words, a domain that is ripe with uncertainty.

Simply put, peoples' values for preventive services and their attendant benefits, risks, and harms reflect all sorts of inputs. People bring their past, beliefs, prior experiences, habits, strengths, and personal idiosyncrasies with them as they age. This individual variation makes generalizations dangerous.

Patient-centered care may not always require shared decisionmaking; clinicians need to better understand the appropriate role for patients in deciding their own role in decisionmaking. The congruence of decisionmaking philosophies across groups, much less individuals, is a conversation that should continue, given the underdeveloped nature of this area. One should not assume too much.

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Figure 1. Conceptual Model

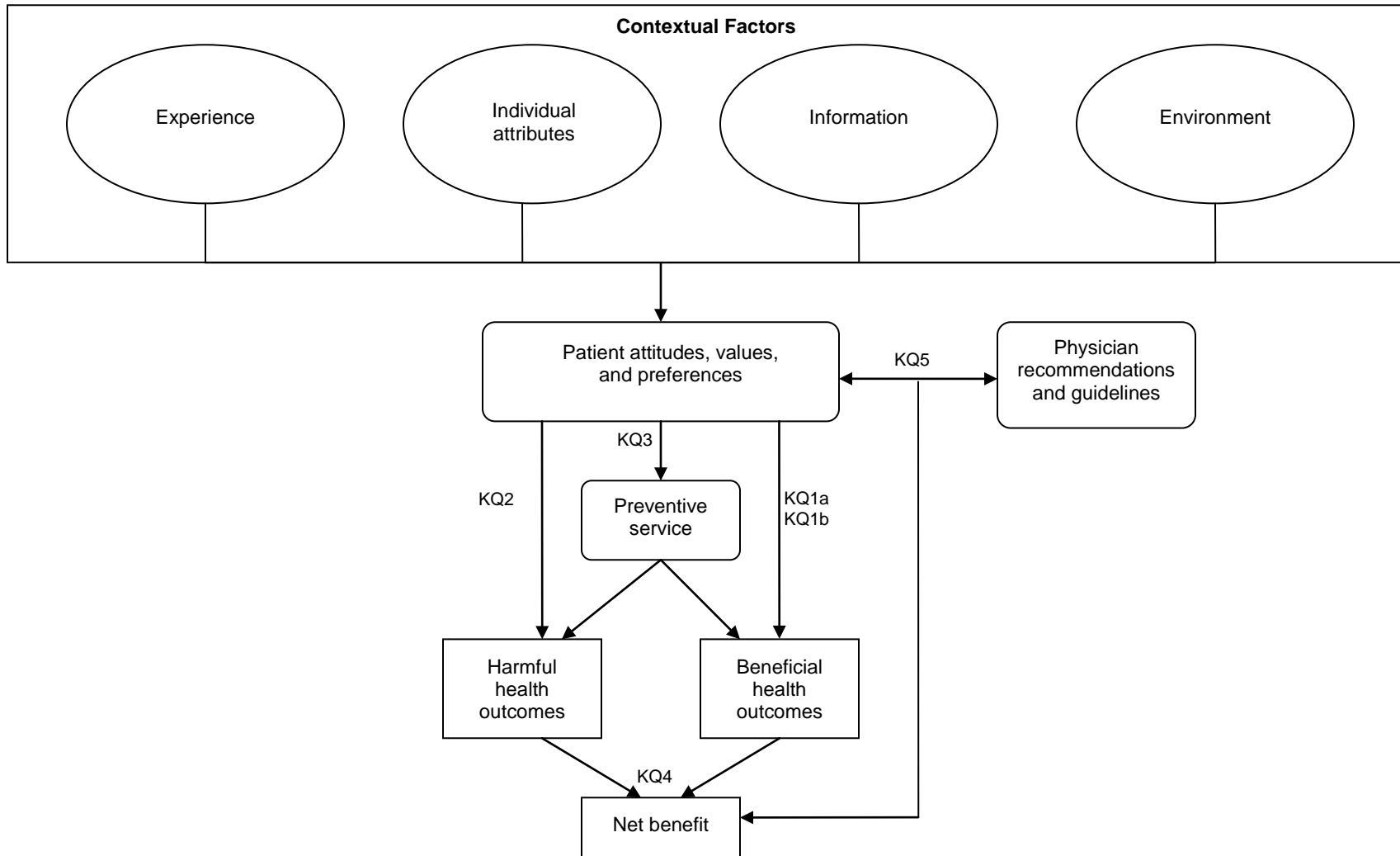


Table 1. Summary Evidence Table for Literature on Values, Attitudes, and Preferences

First Author, Year, Study Location	Relevant Study Aim	Sample	Age	Design/Methods/Models	Relevant Measures
Vaccinations					
Cornford, 1999 ⁹ United Kingdom	Examine beliefs about influenza vaccination in at-risk older patients	N=50 Vaccinated and not vaccinated in previous year; 70% female; generally low to middle class suburban residents	Mean age: 81 yrs; range, ≥75 yrs	Semi-structured interviews Lay perspective	Beliefs about influenza vaccination; “what is health?”; and self-assessed health status
Santibanez, 2002 ⁷ United States	Identify knowledge, attitudes, and beliefs that facilitate or are barriers to influenza or pneumococcal vaccination	N=1,007 English or Spanish speaking; western or central Pennsylvania; cognitive impairment, primary care patients; 95% white; 57% lower income; 90% less than college graduates	Mean age: 74.6 yrs; range, ≥66 yrs	Computer-assisted telephone interviews Theory of Reasoned Action (Triandis model)	Beliefs about prevention of influenza and pneumonia; attitudes toward vaccination; knowledge of pneumonia vaccination; attitudes toward simultaneous influenza and pneumonia vaccination
Evans, 2007 ⁶ United Kingdom	Investigate lay beliefs about influenza and influenza vaccination in older people	N=54 Random sample of survey responders; South Wales	Age range: ≥65 yrs	Narrative interviews Lay perspective	Beliefs about influenza immunization; perceived risk; self-assessed health status
Physical Activity					
Courneya, 1995 ²⁰ Canada	Examine stage of readiness for physical activity	N=288 Members of community center; 62% female; 69% high school graduates	Mean age: 71 yrs; range, ≥60 yrs	Survey*	Bipolar adjective scales (i.e., beneficial/harmful)
Estabrooks, 1999 ²¹ Canada	Examine relationship of group cohesion to attitude toward exercise	N=179 Volunteers from the Centre for Activity and Aging; 73% female	Mean age: 67 yrs; range, ≥65 yrs	Survey	Bipolar adjective scales (i.e., beneficial/harmful)
Gretebeck, 2007 ²² United States	Assess intention and self-reported physical activity	N=1,141 Retirees of midwest university receiving health benefits; 54% female	Mean age: 76 yrs; range, 65-98 yrs	Survey	Bipolar adjective scales (i.e., harmful/beneficial)
Horne, 2009 ³⁴ United Kingdom	Identify beliefs that influence uptake and adherence to exercise for falls prevention	Focus Groups: N=87 Interviews: N=40 36% South Asian; 64% female	<u>Focus Groups</u> Mean age: 65.7 yrs; range, 60-70 yrs <u>Interviews</u> Mean age: 64.8 yrs; range, 60-70 yrs	Focus groups and interviews	Beliefs that influence uptake of exercise for falls prevention; history of falls
Lucidi, 2006 ²³ Italy	Assess factors predicting physical activity attendance	N=1,095 Italy; exercise class members	Mean age: 69 yrs; range, 65-90 yrs	Survey	Bipolar adjective scales (i.e., beneficial/harmful)
Weeks, 2008 ³⁵ Canada	Identify overarching factors that influence participation in physical activity among seniors	N=24 English or French speaking; ambulatory outside home; community-based organizations; 82% female; 88% high school graduates	Age range: ≥64 yrs 42% 64-74 yrs 29% 75-84 yrs 17% ≥85 yrs	Structured interviews Thematic analysis Life course perspective	Barriers; facilitators; perceptions of physical activity; current activity level
Breast Cancer					
Black, 2001 ¹¹ Canada	Explore contribution of self-concepts to older women’s adherence to mammography screening behavior	N=210 Women; modal education college; modal income \$40-\$60K; 98% white; recruited from social or religious groups	Mean age: 67 yrs; range, 50-75 yrs 40% ≥69 yrs	Self-administered questionnaire/Quantitative PRECEDE Model (Green 1991) Health Belief Model Self Theory (Markus 1986)	Self-concept/possible selves; reinforcing factors; enabling factors; adherence to recommended screening guidelines

Table 1. Summary Evidence Table for Literature on Values, Attitudes, and Preferences

First Author, Year, Study Location	Relevant Study Aim	Sample	Age	Design/Methods/Models	Relevant Measures
Borrayo, 2001 ¹² United States	Understand how cultural beliefs about breast cancer influence screening behavior	N=34 Women of Mexican descent; Dallas and Fort Worth, Texas; 44% high school graduates; 50% below federal poverty line	Mean age: 62 yrs; range, 49-81 yrs	Qualitative Focus group interviews (open-ended) Grounded theory	Beliefs about causes/nature of breast cancer; breast screening habits
Katapodi, 2009 ¹⁴ United States	Describe perceived breast cancer risk and inaccurate risk perceptions	N=184 Women; West Coast metro area; never had cancer; 57% nonwhite; 32% earn >\$40K; 92% high school graduates	Mean age: 47 yrs; range, 30-84 yrs 33% 50-69 yrs 6% 70-85 yrs	Telephone questionnaire/quantitative Precaution adoption model (optimism bias) Social learning	Comparative perceived risk; verbal (i.e., absolute) perceived risk; objective risk; screening behavior
LaPelle, 2008 ²⁴ United States	Explore rationales used by women overdue for breast cancer screening, and relate rationales to stages of readiness	N=22 Primary care patients; East Coast; no mammography in past 27 months; 85% white; 67% high school graduates	Mean age: 61.5 yrs; range, 45-77 yrs Stratified by age (49-54, 55-64, 65-77)	Scripted interviews and surveys, administered in focus groups or via telephone depending on participant preference; focus groups answered personal questions during followup call Grounded theory Precaution adoption model (social learning, stage-based)	Attitudes toward mammography, breast cancer, and medical recommendations
Schonberg, 2007 ³⁶ United States	Examine factors influencing older women's mammography screening decisions	N=200 Academic primary care clinic patients; English speaking; 66% white; 84% high school graduates	Age range: ≥65 yrs Stratified by age (65-79, ≥80)	Telephone survey	Factors influencing decision to get screened; screening history
Colorectal Cancer					
Beeker, 2000 ⁹ United States	Identify older adults' attitudes, beliefs, and behaviors about colorectal cancer screening	N=14 Focus groups; 10-11 people per group; urban Kansas, Georgia, or Pennsylvania; private insurance or Medicare; naive and screened	Age range: ≥50 yrs Stratified by age (50-64, ≥65) and gender	Focus groups Behavioral science theory	Knowledge, attitudes, and beliefs about colorectal cancer and screening
Chapple, 2008 ⁵ United Kingdom	Examine factors affecting uptake of fecal occult blood test screening	N=44 White; 50% female	Age range: ≥58 yrs 68% ≥65 yrs	Interviews	Reasons for not bring screened for colorectal cancer
Feeley, 2009 ¹³ United States	Identify barriers and facilitators for colorectal cancer screening	N=103 New York; primary care patients of large managed care organization; most previously screened; 95% white; 70% earn <\$35K; 96% high school graduates	Mean age: 63 yrs	Focus groups Self-efficacy theory	Attitudes toward colorectal cancer screening
Hay, 2006 ¹⁵ United States	Examine relationship between colon cancer beliefs and perceived risk; assess predictors of comparative + absolute risk perception	N=2,949 HINTS survey (national probability survey)	Mean age: 64 yrs; range, 45-74 yrs 32.3% 65-≥75 yrs	Survey Quantitative	Perceived comparative risk; perceived absolute risk

Table 1. Summary Evidence Table for Literature on Values, Attitudes, and Preferences

First Author, Year, Study Location	Relevant Study Aim	Sample	Age	Design/Methods/Models	Relevant Measures
van Dam, 2010 ²⁵ Netherlands	Assess how procedural characteristics of colorectal cancer screening determine preferences, and how they are weighed against benefits	N=710 Population registry; Netherlands; naive and screened	Mean age: 61 yrs; range, 50-75 yrs	Survey Discrete choice experiment	Preference for scenario: screening pain, risk of complications, screening location, preparation, duration of procedure, screening interval, risk reduction of cancer-related death
von Wagner, 2009 ¹⁷ United Kingdom	Examine information needs and patient preferences for CT colonography vs. colonoscopy	N=26 Asymptomatic volunteers from general population; 38% female; predominately white; 80% university degree	Mean age: 64 yrs	Focus groups	Risks and side effects
Prostate Cancer					
Oliffe, 2006 ³⁷ Australia	Describe patients' perspectives of being screened and subsequently diagnosed with prostate cancer	N=35 Anglo-Australian men	Age range: 46-87 yrs	Qualitative design using ethnographic in-depth, semi-structured interviews, participant observation	Patient experiences with screening and diagnosis of prostate cancer
Cancer (General)					
Benyamini, 2003 ³⁸ United States	Assess extent to which having cancer affects perceptions of and reactions to current symptoms/diseases in older adults	N=108 Community-based older people; predominantly white, affluent, and well educated (Rutgers aging and health study)	Mean age: 77-78 yrs	Interviews Common sense approach to illness model (Leventhal)	Vicarious experience with cancer; direct experience with cancer; health perceptions; health behaviors; reactions to arthritis
Dassow, 2005 ³⁹ United States	Measure women's screening beliefs about colon cancer, breast cancer, and osteoporosis	N=125 Women; primary care patients; practice-based research network (Kentucky); 94% white; 71% high school graduates	Mean age: 65 yrs; range, ≥52 yrs	Mail survey/quantitative (32% response rate)	Beliefs about colon cancer, breast cancer, and osteoporosis severity and susceptibility; ability to obtain screening (self-efficacy); screening behavior
Glasgow, 2000 ¹⁸ United States	Examine relationships among barriers to breast and Pap screening services	N=522 Women; HMO patients; Portland, Oregon; no screening within last 2-3 yrs; 60% any college; 81% white	Mean age: 60 yrs; range, 52-69 yrs	Survey/quantitative Empirical basis (social cognition)	Barriers to mammography and Pap screening
Han, 2006 ¹⁶ United States	Examine how perceived ambiguity about cancer prevention recommendations relates to perceived preventability, cancer risk, and cancer-related worry	N=3,375 No history of cancer (HINTS survey)	Age range: ≥40 yrs Stratified by age 18.1% 60-69 yrs 15.8% ≥70 yrs	Survey interviews/quantitative Decision theory (ambiguity)	Perceived preventability of cancer; perceived cancer risk; cancer-related worry; perceived ambiguity of cancer prevention recommendations
Lewis, 2006 ¹⁰ United States	Assess older adults' perspectives about continuing cancer screening later in life	N=116 Community based; North Carolina; low barriers to health care; 100% white; 78% female; 83% college graduates (100% high school)	Mean age: 81.6 yrs; range, 70-96 yrs	Interviews Informed decisionmaking criteria (Braddock)	Attitudes toward cancer screening; attitudes toward continuing cancer screening later in life

Table 1. Summary Evidence Table for Literature on Values, Attitudes, and Preferences

First Author, Year, Study Location	Relevant Study Aim	Sample	Age	Design/Methods/Models	Relevant Measures
Rutten, 2009 ⁴⁰ United States	Compare state-of-science evidence for colon, skin, and lung cancer with public perceptions	N=5,586 (HINTS survey)	Age range: ≥18 yrs Stratified by age	Interview survey	Beliefs about prevention, detection, and survival for lung, colon, and skin cancer
Dementia					
Boustani, 2008 ¹⁹ United States	Measure primary care patients' attitudes about dementia screening	N=315 Convenience samples; clinic patients; English speaking; no dementia or mental illness; Indiana, North Carolina; 70% female; 44% black; 39% high school graduates	Mean age: 72.8 yrs; range, ≥65 yrs	Questionnaire Exploratory factor analysis	Attitudes toward dementia screening

*Note: There were issues with the response rate.

Abbreviations: CT = computed tomography; HMO = health maintenance organization; HINTS = Health Information National Trends Survey; yrs = years.

Table 2. Older Adults' Perceptions of Benefits and Risks of Preventive Actions Reported in Studies

Prevention Action	Older Adults' Perceived Benefits and Risks
Flu vaccination	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • Reduced number and severity of colds and influenza-like illnesses.⁵ • Vaccinated individuals were more likely to perceive vaccination as the best way to prevent the disease.⁷ • Immunized individuals were more likely to perceive vaccine as effective.⁶ <p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Few considered themselves at risk, due to independent and active engagement self-assessed health status, regardless of vaccination status.⁵ • Vaccination side effects were interpreted differently between vaccinated and non-vaccinated individuals.⁵ • Unvaccinated individuals believed they were at low risk for the disease.⁷ • Few considered themselves at risk, due to good health status, diligent self-care, and good nutrition.⁶ • Considered recommendations for vaccination based on age to be ageist attitude.⁶
Pneumococcal vaccination	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • Vaccinated individuals were more likely to perceive vaccination as the best way to prevent the disease.⁷ <p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Unvaccinated individuals believed they were at low risk for the disease.⁷
Physical activity	<p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Rarely acknowledged risk for falling.³⁴ • Associated falling with older people.³⁴ • Those who had fallen were more likely to acknowledge risk for future falls.³⁴
Mammography screening	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • Feared health-related possible self and perceived self-efficacy in that fear domain predicted screening*.¹¹ <p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Did not see a need for screening if one feels healthy.¹² • Age inversely predicted perceived comparative risk for developing breast cancer, but not absolute risk perception.¹⁴
Colorectal cancer screening	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • Generally believed that colorectal cancer is treatable if found early.⁹ • Fulfilling civic duty.⁸ • Perceived severity related to colon cancer screening**.³⁹ <p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Did not feel at risk because they felt healthy.⁸ • "No reason to go, I'm in good health."¹³ • Persons ages 65-74 years were less likely to perceive relative risk than persons ages 45-54 years. No age difference in ability to perceive absolute risk.¹⁵ • Perceived susceptibility predicted colon cancer screening**.³⁹
General cancer screening	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • 87% believed they will live long enough to accrue screening benefit.¹⁰ • 75% believed that the benefit from cancer screening is immediate. Persons ages ≥85 years were more likely than those ages 70-84 years to believe that they would not live long enough to benefit from screening.¹⁰ • 81% believed that they would die of a disease other than cancer.¹⁰ <p><u>Perceived Risks</u></p> <ul style="list-style-type: none"> • Cancer and health worries were lowest for vicarious experience (vs. survivors and non-survivors).³⁸ • Monitoring for bodily signs was similar and highest in both cancer experience groups (vicarious and survivors).³⁸ • Worrying was only related to monitoring for those with no experience with cancer.³⁸ • There was more arthritis vigilance among those who had direct or vicarious experience with cancer.³⁸ • There was more vigilance for ambiguous symptoms among those with direct experience with cancer.³⁸ • Self-efficacy predicted breast cancer and bone density screening**.³⁹ • Older age (especially ≥70 years) predicted lower perceived preventability, lower perceived risk, and lower cancer-related worry.¹⁶ • Increased perceived preventability reduced ambiguity aversion. Ambiguity aversion increased with cancer worry. Perceived ambiguity about cancer prevention recommendations increased with cancer worry and perceived risk.¹⁶
Dementia screening	<p><u>Perceived Benefits</u></p> <ul style="list-style-type: none"> • Screening beneficial because participants would like to be aware of any developing memory problems and early detection improves treatment and allows for planning.¹⁹

* Increasing age correlated with decreasing screening adherence. Perception of susceptibility was significant for ages 50-69 years but not 70-75 years.

** Age not related to screening behaviors.

Table 3. Summary Evidence Table for Literature on Quality of Life Versus Quantity of Life

First Author, Year	Relevant Study Aim	Sample	Age	Design/Methods/ Models	Measures	Findings
Chapman, 2001 ⁴¹	Evaluate relationship between time preference scenarios and preventive health behaviors requiring up-front cost for long-term benefit	Hypertension: N=195; 65% female Cholesterol: N=169; 49% female	Hypertension: mean age: 79 yrs; range, 62-97 yrs Cholesterol: mean age: 67 yrs; range, 36-85 yrs	Hypertension: individual structured interviews, chart review Cholesterol: questionnaire, chart review Time tradeoff preferences	Hypertension adherence: self-report, pill count, blood pressure measures Cholesterol adherence: self-report, most recent low-density lipoprotein level	No relationship between time preferences and adherence to medication for hypertension or hypercholesterolemia medication
Chapman, 1998 ⁴²	Evaluate impersonal and personal time tradeoff scenarios for differences in willingness to trade quality of life for longevity with poor health due to prostate cancer	N=59 Patients with prostate cancer	Mean age: 71 yrs	Questionnaires Time tradeoff preferences	NR	Framing effect; patients using impersonal time tradeoff version were more likely than those using personal version to “order the three health states appropriately” and be “more willing to trade off length of life for quality of life”
Meropol, 2008 ⁴³	Evaluate the weight cancer patients place on quality of life and length of life	N=459 Patients with advanced cancer	Mean age: 60 yrs; range, 26-89 yrs	Survey	Sociodemographics; physical and mental health states; quality of life/length of life values; communication preferences; cancer-related distress	Older age associated with preference for quality of life vs. length of life

Abbreviations: NR = not reported; yrs = years.

Table 4. Older Adults' Perceptions of Harms of Preventive Actions Reported in Studies

Prevention Action	Older Adults' Perceived Harms
Flu vaccination	<p><u>Clinical Harm</u></p> <ul style="list-style-type: none"> • Perceived side effects: painful arm, feeling unwell, having more colds or severe influenza after vaccination.⁵ • Vaccination side effects were interpreted differently between vaccinated and non-vaccinated individuals.⁵ • Developing influenza after vaccination.⁷ • Adverse reactions.⁷ • Those who had never had the vaccine and those who had been vaccinated in the past but had defaulted were more likely to believe that the vaccine had serious side effects.⁶ <p><u>Psychological Harm</u></p> <ul style="list-style-type: none"> • Few considered themselves at risk, due to independent and active engagement self-assessed health status, regardless of vaccination status.⁵
Pneumococcal vaccination	<p><u>Clinical Harm</u></p> <ul style="list-style-type: none"> • Adverse reactions.⁷
Mammography screening	<p><u>Clinical Harm</u></p> <ul style="list-style-type: none"> • Pain.¹¹ <p><u>Psychological Harm</u></p> <ul style="list-style-type: none"> • Harm and fear most likely reasons for not planning on screening.¹¹ • Unlikely to risk feeling ill by seeking to discover breast cancer through screening.¹²
Colorectal cancer screening	<p><u>Clinical Harm</u></p> <ul style="list-style-type: none"> • Negative attitudes toward screening procedures.⁹ • Fear of test (22.1%)*¹³ • Discomfort (21.3 %)*¹³ • Side effects of test, such as radiation or perforated bowel.¹⁷ <p><u>Psychological Harm</u></p> <ul style="list-style-type: none"> • Negative attitudes toward screening procedures.⁹ • Subject matter embarrassing or private.⁹ • Avoidance of learning diagnosis.⁹ • Disgust at idea of handling stools.⁸ • Fear of colonoscopy.⁸ • Embarrassment (15.1%)*¹³ • Fear of results (14.3%)*¹³ • Test could lead to diagnosing unrelated and benign condition, or serious condition with no cure.¹⁷ • No benefit to early diagnosis.¹⁷
General cancer screening	<p><u>Clinical Harm</u></p> <ul style="list-style-type: none"> • Pessimism/misinformation (e.g., "cure is worse than disease") for both Pap and mammography screening.¹⁸ <p><u>Psychological Harm</u></p> <ul style="list-style-type: none"> • Embarrassment/mistrust for both Pap and mammography screening.¹⁸
Dementia screening	<p><u>Psychological Harm</u></p> <ul style="list-style-type: none"> • Stigma of screening.¹⁹ • Suffering from screening.¹⁹ • Impact of screening on patients' independence.¹⁹

* Reported percentages = # of times that barrier was mentioned / # of times any barrier was mentioned x 100.

Table 5. Value Placed on the Receipt of Clinical Preventive Services By Older Adults

Prevention Action	Value
Physical activity	<ul style="list-style-type: none"> • Generally, sample had positive attitude toward physical activity.²⁰ • Attitude became more positive with increased activity (not clinical setting, no physician recommendation).²⁰ • Social cohesion positively related to attitude toward exercise (not clinical setting, no physician recommendation).²¹ • Global attitude linked to physical activity (not clinical setting, no physician recommendation).²² • Attitude partially contributed to predicting activity; perceived behavioral control and self-efficacy were stronger predictors (not clinical setting, no physician recommendation).²³ • "Must account for past experiences, life transitions, and future concerns when trying to understand factors that influence participation in physical activity." Subthemes include intergenerational influences, establishment of early physical activity patterns, family transitions over the life course, changing health status over time, and future health concerns.³⁵
Mammography screening	<ul style="list-style-type: none"> • Do not see a need for screening if one feels healthy.¹² • Unlikely to risk feeling ill rather than healthy (i.e., no symptoms and no cultural beliefs to support) by seeking to discover breast cancer through screening.¹² • Persons ages ≥65 years were more likely than those ages 49-64 years to be against screening mammography.²⁴ • Persons ages ≥65 years more likely than those ages 49-64 years to be skeptical of medical recommendations.²⁴ • Habit, reassurance, and history of breast disease were essential factors in decision to receive mammography screening.³⁶
Colorectal cancer screening	<ul style="list-style-type: none"> • Reasons to get screened include knowing someone with cancer, being a "good citizen," and encouragement from others.⁸ • Reasons to avoid screening include feeling healthy and fear of outcome.⁸
General cancer screening	<ul style="list-style-type: none"> • 62% believed their own life expectancy was not important for decisionmaking.¹⁰ • 48% preferred not to discuss life expectancy. There was no difference between those younger than 85 and those 85 and older. There was no difference between those that previously had cancer and those that did not.¹⁰ • 11% had decided to stop screening entirely.¹⁰ • 43% would consider getting screened even if their physicians recommended against it.¹⁰ • Those with cancer history were more likely to consider screening even if their doctor recommended against it.¹⁰

Table 6. Attitudes About Continuing Cancer Screening Later in Life

Statement of Attitude	Number in Agreement (%)		
	All Ages (n=116)	>85 yrs (n=36)	Cancer* (n=45)
I will likely die of some other disease besides cancer.	86 (81)	29 (80)	33 (73)
I will continue cancer screening no matter how uncomfortable the tests are.	84 (77)	28 (78)	35 (77)
I plan to get screened for colon cancer for as long as I live.	76 (72)**	22 (61)	33 (74)
I plan to get screened for breast/prostate cancer for as long as I live.	85 (83)***	29 (80)	40 (88)
I will consider getting screened for cancer even if my doctor recommends against it.	47 (43)	19 (53)	26 (58)†
It takes several years for cancer screening to benefit people.	28 (25)	10 (29)	13 (29)
I will not live long enough to benefit from cancer screening tests.	15 (13)	10 (28)†	5 (11)
I will not get cancer screening even if my doctor recommends it.	4 (4)	1 (3)	1 (2)
Cancer screening is not worth the trouble.	3 (3)	1 (3)	1 (2)
Everyone should get screened for colon cancer for as long as they live.	64 (55)	22 (61)	31 (69)†
Everyone should get screened for breast/prostate cancer for as long as they live.	73 (63)	23 (64)	41 (91)†
Screening for cancer in people older than age 70 years may waste health care time and money.	34 (30)	12 (34)	10 (22)
As people get older, other health issues are more important than cancer screening.	56 (50)	18 (50)	16 (36)†
People who live in nursing homes should not get cancer screening.	30 (26)	9 (25)	9 (21)
People older than age 70 years who are totally dependent on someone else for daily functions (such as eating, bathing, and toileting) should not get cancer screening.	50 (44)	15 (43)	18 (40)
People with Alzheimer's disease or dementia should not get cancer screening.	51 (44)	18 (50)	18 (41)

* Participants reporting previous diagnosis of cancer other than skin cancer.

** n=105.

*** n=102.

† p<0.05.

Table 7. Decisional Balance of Benefits and Harms

Prevention Action	Decisional Balance
Colorectal cancer screening	<ul style="list-style-type: none"> • Bowel preparation, risk reduction of cancer-related death, and length of screening interval influence preference for type of procedure.²⁵ • Required a 1% reduction in relative risk for cancer-related death for each additional 10 minutes of test duration; 5% to be exposed to small complication risk; 10% to accept mild pain; and 32% to use extensive bowel preparation.²⁵ • 80% valued test sensitivity over physical comfort during the testing procedure when forming a preference for a test procedure.¹⁷
General cancer screening	<ul style="list-style-type: none"> • 62% believed their own life expectancy was not important for decisionmaking.¹⁰ • 11% had decided to stop screening entirely.¹⁰ • Those with cancer history were more likely to consider screening even if their doctor recommended against it and were less likely to think that other health issues were more important than cancer screening.¹⁰

Table 8. Summary of Key Shared Decisionmaking Definitions*

Essential Elements	Ideal Elements	General Qualities
Define/explain problem	Presentation of unbiased information	Deliberation/negotiation
Present options	Reach mutual agreement	Flexibility/individualized approach
Discuss benefits, risks, costs	Present evidence	Information exchange
Explication of patient values/ preferences	Define roles (desire for involvement)	Involves at least two people Middle ground
Discuss patient ability/self-efficacy		Mutual respect
Presentation of doctor knowledge/ recommendation		Partnership Patient education
Check/clarify understanding		Patient participation
Assess level of uncertainty in decision or decisional conflict		Process/stages
Make or explicitly defer decision		
Ensure decision is congruent with patient's values and goals		Patient participation
Arrange followup		

* Based on Makoul and Clayman¹⁰⁶ and the Ottawa Decision Support Framework³⁰.

Table 9. Shared Decisionmaking Elements Included in Intervention Studies

Decisionmaking Element	Frosch et al, 2001²⁶	Pignone et al, 1999²⁷
Essential Elements		
Define/explain problem	Present	Present
Present options	Present	Present
Discuss benefits, risks, costs	Present	Present
Patient values/preferences	Present	Present (participants asked why they preferred the option they selected)
Discuss patient ability/self-efficacy	Present	Not present
Doctor knowledge/recommendation	Not present, performed by research assistant	Not present, performed by research assistant
Check/clarify understanding		Present
Assess level of decisional conflict		
Make or explicitly defer decision		
Ensure decision is congruent with patient's values and goals		
Arrange followup		
Ideal Elements		
Unbiased information	Present	
Mutual agreement		
Present evidence	Present	Present
Define roles (desire for involvement)	Present	
General Qualities		
Deliberation/negotiation		
Flexibility/individualized approach		
Information exchange	Present	Present
Involves at least two people	Present	Present
Middle ground		
Mutual respect		
Partnership		
Patient education	Present	Present
Patient participation	Present	Present
Decision Aids		
	None used	Simple flip charts on risk, benefit

Table 10. Summary Evidence Table for Literature on Shared Decisionmaking

First Author, Year, Study Location	Relevant Study Aim	Sample	Age	Design/Methods/Models	Relevant Measures
Cancer Screening					
Frosch, 2001 ²⁶ United States	Evaluate the most effective means to present information and guidance about PSA testing to patients	N=176 Men from the Health Appraisal Screening Program in the Department of Preventive Medicine	≥50 yrs	Intervention 2x2 factorial comparison of discussion and video formats; questionnaire Logistic regression	Participant ratings of interventions; concern about prostate cancer; personal or family/friend history of cancer; participant opinion of who should choose medical treatments for patients: doctor only, patient only, or both; whether participant requested a PSA test; participant confidence in personal decision about PSA testing
Pignone, 1999 ²⁷ United States	Measure patient preferences for various screening methods	N=148 No previous history of colon cancer; 58% female; 52% white; 43% black; 53% had not completed high school	Range: 50-75 yrs	Survey	Participant preference for colorectal cancer screening method (before and after information was given); reasons for preference; perception of personal risk for colorectal cancer; perception of seriousness of colorectal cancer as a disease; personal or friend/family experience with colorectal cancer; past discussion of colorectal cancer screening
Cardiovascular Disease Prevention					
Galesic, 2009 ¹⁰⁷ Germany	Explore the efficacy of icon arrays in explaining medical risk, and whether they affect perceptions of risks and benefits of treatment	Sample 1: N=59 49% female; 57% high school or lower education; 43% college education Sample 2: N=112 57% female	Sample 1: range, 62-77 yrs 49% 62-69 yrs 51% 70-77 yrs Sample 2: range, 26-35 yrs 63% 18-25 yrs 37% 26-35 yrs	Icon arrays questionnaire	Accuracy of risk understanding; accuracy of understanding of screening benefits
Kehler, 2008 ¹⁰⁸ Denmark	Explore and analyze the experiences of preventive consultations in patients at high cardiovascular risk	N=12 Patients at increased risk for cardiovascular disease; 83% male	Mean age: >57.8 yrs	Individual, semi-structured interview conducted within 2 weeks of preventive consultation Grounded theory	Participant experiences and expectations following preventive consultation regarding cardiovascular disease
General					
Greenlund, 2000 ¹⁰⁹ United States	Explore whether provider prevention orientation influences women's preventive practices	N=119 Female primary care patients; Washington; HMO; naive and previously screened, 88% white; 91% high school graduates	Range: 50-80 yrs 60% ≥60 yrs 31% ≥70 yrs	Telephone survey Quantitative Empirical basis	Provider encouragement and engagement; physical activity; postmenopausal hormone use; fecal occult blood test; flexible sigmoidoscopy

Abbreviations: HMO = health maintenance organization; PSA = prostate-specific antigen; yrs = years.

Table 11. Patient Preferences and Perceptions of Decisionmaking

Prevention Action	Factor/Source of information
Flu vaccination	<ul style="list-style-type: none"> • Individual prompt from general practitioner was the most significant motivator.⁶ • Those who had not been vaccinated reported that their physician did not recommend it.⁷
Pneumococcal vaccination	<ul style="list-style-type: none"> • Those who had not been vaccinated reported that their physician did not recommend it.⁷
Physical activity	<ul style="list-style-type: none"> • Provider encouragement of preventive measures correlated with women's report of regular physical activity.¹⁰⁹
Mammography screening	<ul style="list-style-type: none"> • Physician recommendation, but not family history, predicted screening.¹¹ • Those aged 65 years or older were more likely than those aged 49-64 to be skeptical of medical recommendations.²⁴ • 60% reported that a physician's recommendation was essential or very important in their decision to get mammography screening.³⁶ • 16% said that a family member's recommendation was essential/very important.³⁶ • 17% reported that a friend's recommendation was essential/very important, but 31% reported that a friend's experience with breast cancer was essential/very important.³⁶
Colorectal cancer screening	<ul style="list-style-type: none"> • Reported little or no information from physicians (although important source) or mass media.⁹ • Reputation (bad) of the tests.¹³ • The likelihood of having had fecal occult blood test or sigmoidoscopy examination was related to provider encouragement for those procedures, but not related to greater encouragement for other preventive measures.¹⁰⁹ • Age was positively associated with provider encouragement for flexible sigmoidoscopy.¹⁰⁹
General cancer screening	<ul style="list-style-type: none"> • 62% believed their own life expectancy was not important for decisionmaking.¹⁰ • 48% preferred not to discuss life expectancy. There was no difference between those younger than 85 and those 85 and older. There was no difference between those that previously had cancer and those that did not.¹⁰

Table 12. Proposed Typology and Terminology of Medical Decisions

Number of Choices	Preference Sensitive	Process			Outcome
		Decisional Priority	Patient Role	Interaction	Type of Decision
1	No	Usually clinician	Listen, ask questions, understand, and agree	Agreeable	Clinician directed
1	No	Usually patient	Insist on disfavored alternative (including nontreatment)	Unilateral	Patient controlled
1	No	Usually clinician	Object (unsuccessfully) to plan	Unilateral	Clinician controlled
2 or more	Yes	Usually patient	Active or shared	Collaborative	Shared