Chapter 4

Cancer

Cancer is a leading cause of death in the United States (second only to heart disease), accounting for more than one in four deaths nationally and more than an estimated 1500 deaths every day.[1] Many cancer deaths can be prevented: for example, all deaths related to cigarette smoking (estimated to be more than 180,000 in 2004) could be prevented.[2,3] About one-third of the half million cancer deaths expected in 2004 could be prevented by adopting a healthy

*Insufficient evidence means that we were not able to determine whether or not the intervention works.

The Task Force approved the recommendations in this chapter for reducing exposure to ultraviolet radiation in 2001–2002. The research on which the findings are based was conducted prior to July 2001. This information has been published in the MMWR Recommendations and Reports series [2003; 52(no. RR-15):1–12] and the American Journal of Preventive Medicine [2004; in press]. The Task Force considered the evidence on effectiveness of interventions to increase informed decision making in cancer screening in 2003, and this information has been published in the American Journal of Preventive Medicine, 2004;26(1):67–80.

diet, maintaining a healthy weight and increasing physical activity,[2–6] reducing heavy drinking, and other changes in lifestyle. Cancers related to exposure to infectious diseases, such as hepatitis B or human immunodeficiency virus (HIV), can be prevented through vaccines or behavior change.[1] Regular screening by healthcare professionals can also detect certain cancers early in their course, thereby increasing the likelihood of successful treatment.[7–13]

Systematic reviews for the *Community Guide* explore many population-based interventions that can help reduce the incidence of, reduce the consequences of, or improve decisions about cancer. This chapter includes reviews about (*1*) reducing skin cancer by limiting exposure to ultraviolet (UV) radiation and (*2*) promoting informed decision making about cancer screening. Chapter 7 (Oral Health) finds that evidence was insufficient to determine whether community approaches to detecting oral and pharyngeal cancers improve outcomes. Other chapters evaluate approaches to improving health by increasing the number of people who quit smoking and reducing the number who start (Chapter 1, Tobacco); increasing physical activity (Chapter 2, Physical Activity); and increasing coverage with vaccines including the hepatitis B vaccine (Chapter 6, Vaccine-Preventable Diseases). Systematic reviews for the *Community Guide* are also underway on population-based approaches for increasing use of effective cancer screening, reducing obesity, improving nutrition, reducing the number of HIV-infected people, and reducing abuse of alcohol.

PREVENTING SKIN CANCER BY REDUCING EXPOSURE TO ULTRAVIOLET RADIATION

Skin cancer is the most common type of cancer in the United States.[14] The two most common types of skin cancer—basal cell carcinoma and squamous cell carcinoma—both respond well to treatment. Melanoma, the third most common type of skin cancer, is much more likely to be fatal. Estimates for 2004 indicated that more than 1 million people would be diagnosed as having basal cell or squamous cell carcinoma, and approximately 2300 deaths from both cancers combined were predicted. In contrast, an estimated 55,100 diagnoses of melanoma will account for 7910 deaths—more than three-quarters of all skin cancer fatalities.[1]

Reducing the Risk of Skin Cancer

Preventable risk factors for skin cancer include excessive exposure to UV radiation, especially during childhood and adolescence. Sunlight is the primary source of UV radiation. (Sunlamps and tanning beds are other sources.) People with high levels of exposure to UV radiation are at greater risk for all

three major forms of skin cancer, and approximately 65%–90% of melanomas are caused by UV exposure.[15] Exposure to UV radiation during childhood and adolescence plays a role in the future development of both melanoma and basal cell cancer.[16–21] The risk of developing melanoma is strongly related to a history of one or more sunburns (an indicator of intense UV exposure) in childhood or adolescence.[17,22–24] Sunburns during these periods have also recently been found to increase the risk of basal cell carcinoma.[19,20]

Moles are an important risk factor for skin cancer, and most moles develop during childhood. Sun exposure in childhood may heighten the risk of melanoma by increasing the number of moles.[23] Sun protection during childhood may therefore reduce the risk of melanoma in adulthood.[25,26]

"Sun-protective" behaviors that reduce skin cancer risk include limiting or minimizing exposure to the sun during peak hours (10 A.M. to 4 P.M.), when UV rays are more intense; wearing protective clothing; and using appropriate sunscreen protection. As noted in more detail below, however, sunscreens may not protect against melanoma, should not be used as the sole method for skin cancer prevention, and should not be used as a means to extend the duration of UV exposure.

Environmental factors can also affect the amount of UV exposure. These include proximity to the equator; high altitude; low levels of cloud coverage (which can allow up to 80% of UV rays to penetrate the atmosphere); the presence of materials that reflect the sun, such as pavement, water, snow, and sand; exposure to the sun around midday; and spending time outside in the spring or summer.[27,28]

OBJECTIVES AND RECOMMENDATIONS FROM OTHER ADVISORY GROUPS

Two goals of *Healthy People 2010*[29] are to (*1*) increase to 75% the proportion of people who use at least one of the following protective measures that may reduce the risk of skin cancer: avoid the sun between 10 A.M. and 4 P.M., wear sun-protective clothing when exposed to the sun, use sunscreen with a sun protection factor (SPF) of 15 or higher, and avoid artificial sources of UV light; and (*2*) reduce melanoma deaths to less than 2.5 per 100,000 people.

Recommendations for sunscreen use, including recommended public health strategies, are available from the International Agency for Research on Cancer (IARC).[30] Specifically, because the relationship between sunscreen use and melanoma is complex, the IARC recommends that sunscreens not be used as the sole method for skin cancer prevention and not be used as a means to extend the duration of UV exposure.

The Centers for Disease Control and Prevention (CDC) recommends that schools engage in skin cancer prevention activities.[31] The U.S. Preventive

Services Task Force found insufficient evidence to determine whether clinician counseling was effective in getting patients to change their behavior and thereby reduce skin cancer risk.[32]

METHODS

Methods used for the reviews are summarized in Chapter 10. Specific methods used in the systematic reviews of interventions to prevent skin cancer through reducing exposure to UV radiation have been described elsewhere.[33] An example of the kind of conceptual model we used to guide our reviews is presented in Figure 4–1, which shows the analytic framework for the reviews of mass media campaigns to reduce UV exposure and increase sun-protective behaviors. These reviews used the key health outcomes (e.g., sunburn or nevi [moles]) and sun-protective behaviors of limiting or minimizing exposure to the sun during peak hours (10 A.M. to 4 P.M.), wearing protective clothing, and seeking shade to measure the success of programs and policies and to support recommendations. Changes in knowledge, attitudes, or intentions were not used to support recommendations.

ECONOMIC EFFICIENCY

A systematic review of available economic evaluations was conducted for each of the two recommended interventions, and no economic evaluations were found for either one. The methods used to conduct those economics reviews are summarized in Chapter 11.

RECOMMENDATIONS AND FINDINGS

Interventions in Specific Settings

Many skin cancer prevention activities are carried out in specific settings. These settings are often convenient ways of organizing intervention activities for specific interveners and target populations.

We reviewed six interventions carried out in specific settings. Four were educational and policy interventions—in child care centers, primary schools, secondary schools and colleges, and recreational and tourism settings—and two were programs—in outdoor occupational settings and in healthcare system and provider settings.

Most sun-safety programs have been evaluated in formal educational settings. Such settings facilitate integration of skin cancer education into existing learning situations as well as supporting policy and environmental interventions.

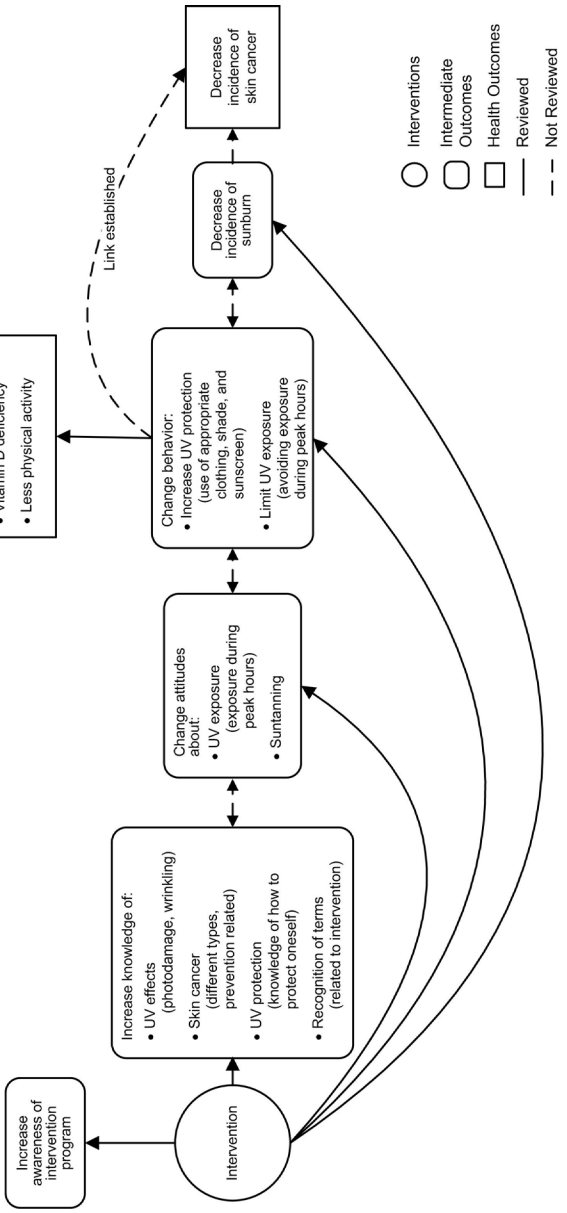

Figure 4–1. Analytic framework illustrating the conceptual approach used in the systematic review of mass media campaigns to reduce ultraviolet (UV) exposure and increase sun-protective behaviors.

Educational and Policy Interventions in Primary Schools: Recommended (Sufficient Evidence of Effectiveness) for Improving Children's "Covering-Up" Behaviors

Interventions in primary schools promote sun-protective behaviors among children in kindergarten through eighth grade. These interventions include at least one of the following activities: providing information to children (through instruction, small media education, or both); influencing children's behavior (e.g., modeling, demonstration, or role playing); attempting to change the knowledge, attitudes, or behavior of caregivers (e.g., teachers or parents); and environmental and policy approaches (e.g., providing sunscreen, increasing availability of shade, or scheduling outdoor activities to avoid hours of peak sunlight).

Effectiveness

- Educational and policy interventions in primary schools are effective in improving children's sun-protective behavior of covering up.

Applicability

- These findings should be applicable to most school-age children.

Students spend a large part of their day in school or in school-related activities during hours of peak ultraviolet (UV) light. Children are more receptive than adolescents to practicing sun-protective behaviors and are more amenable to parents' or other adults' instruction. Primary schools are therefore more likely than high schools to have success with sun-protection programs.

The findings of our systematic review are based on 20 studies.[34–53] An additional five studies[54] were identified but did not meet our quality criteria and were excluded from the review. Eight reports provided additional information on studies already included in the review.[55–62] Many of the reports included several intervention arms and multiple behavioral outcomes.

These studies examined improvements in four sun-protective behaviors: (*1*) covering up (wearing hats, long-sleeved clothing, or pants); (*2*) using sunscreen; (*3*) avoiding the sun (seeking shade, rescheduling activities, not going out in the sun during peak UV hours); and (*4*) composite behaviors (a combination of at least two of the above behaviors). We found consistent improvement in covering-up behaviors but not in any of the other three behaviors.

Intervention activities used included didactic classroom teaching, didactic teaching using sunscreen samples, interactive class and home-based activities, health fairs, an educational picture book, teaching by medical students, interactive CD-ROM multimedia programs, and peer education. Relatively few studies included environmental or policy approaches.

Study design markedly affected changes in study outcomes. For sun-avoidance behaviors, we found a median change that ranged from 4% (for concurrent comparison groups) to 16% (for before-and-after measures). For covering-up behaviors, the median change ranged from 25% (concurrent comparison) to 70% (before-and-after). For sunscreen use, the median change ranged from 17% (concurrent comparison) to 34% (before-and-after). The improvement in covering-up behaviors was consistent and large enough for the Task Force to recommend educational and policy interventions in primary schools as an effective approach for preventing skin cancer.

In general, these interventions also improved knowledge and attitudes related to sunscreen use and to skin cancer prevention. Evidence was insufficient to determine the effectiveness of interventions to improve other sun-protective behaviors because of inconsistent results. Evidence was also insufficient to determine the effectiveness of interventions in primary schools to change policies and practices or health outcomes based on small numbers of studies and limitations in their design and execution.

These findings should be applicable to most school-age children. Studies were conducted in geographically diverse areas including Arizona, North Carolina, Canada, France, and Australia. Most studies were conducted among primarily white populations.

We found no information on other potential benefits of these interventions, such as reduction in the risk of overexposure to heat. One paper reported on the potential harm of transmitting lice via hats or other clothing and found that hats were not a major factor in transmission.[63]

We did not find any economic evaluations of these interventions.

A potential barrier to implementation of educational and policy interventions in primary schools might be concerns of parents or teachers that these changes will lead to reductions in physical activity. Parents or teachers may also be concerned that covering up will lead to wearing of gang insignia, although this is perhaps less of a concern in primary schools than in secondary schools. (Until recently, California schools did not permit students to wear clothing such as hats because of concerns about gang affiliation. Now students in California can wear hats.)

In conclusion, available studies provide sufficient evidence that interventions in primary schools are effective in improving covering-up behavior. Evidence was insufficient to determine effectiveness in improving the other two sun-protective behaviors (i.e., using sunscreen, avoiding the sun) because of inconsistent evidence; evidence was also insufficient to determine effective-

ness in decreasing sunburns. These findings should be applicable to most school-age children.

Educational and Policy Interventions in Recreational and Tourism Settings: Recommended (Sufficient Evidence of Effectiveness) for Improving Adults' Covering-Up Behaviors

Interventions in recreational and tourism settings involve efforts to promote the sun-protective behaviors of adults, children, and their parents. These interventions include at least one of the following: providing information to children and adults (i.e., through instruction, small media education, or both); activities intended to change the knowledge, attitudes, beliefs, or intentions of children and adults; additional activities to influence the behavior of children and adults (such as modeling, demonstration, or role playing); and environmental or policy approaches, including providing sunscreen or shade or scheduling outdoor activities to avoid hours of peak sunlight.

Effectiveness

- Educational and policy interventions in recreational and tourism settings are effective in increasing adults' sun-protective behavior of covering up.
- We found insufficient evidence to determine the effectiveness of the interventions in reducing sunburn in adults or children.

Applicability

- These findings should be widely applicable to adults in most settings.

Domestic and international travel has increased substantially over the past decade, particularly among overseas vacationers traveling from temperate climates to regions where the UV level is high.[64] Participation in outdoor leisure activities has also increased, resulting in increased exposure to sunlight, which appears to increase the risk of melanoma.[65] Recreational and tourism settings are therefore important sites for sun-protection programs. In such settings, skin cancer education can be integrated into existing recreational or tourism activities, and supportive policy and environmental interventions can also be implemented.

The findings of our systematic review are based on 11 studies[66–76] that evaluated the effectiveness of reducing UV exposure through educational and policy interventions in recreational and tourism settings. We identified two other reports[77,78] that did not meet our quality criteria and were excluded from the review. Another five reports[79–83] provided additional information on studies already included in the review.

Intervention activities for both children and adults included interactive sun-protection education activities (stories, games, puzzles, stamps, arts and

crafts); activities to promote sun-safe environments; a UV-reduction curriculum at poolside; home-based activities for children and their parents; brochures to help educate participants about the prevalence and severity of skin cancer, the effects of the sun on the skin, or sun-protective measures; a sun sensitivity assessment, photographs providing examples of sun damage to skin, and suggestions on reducing unprotected UV exposure; and peer-leader modeling by lifeguards, informational posters and fliers, posters listing goals, and a "commitment raffle" to influence the sun-protective behaviors of children and adults.

The outcomes examined were similarly wide-ranging, and included changes in parent-reported sun-protective behaviors among children (using sunscreen; seeking shade; wearing a hat, shirt, or other protective clothing; and composite behaviors); incidence of children's sunburns; children's degree of tanness; adult sun-protective behaviors; incidence of adult sunburn; and adult information-seeking behaviors, follow-up study participation, knowledge, attitudes, beliefs, or intentions; as well as sun-protective measures and environmental supports reported by parents at outdoor recreational centers or swimming pools.

The adult sun-protective behavior of wearing protective clothing (hat or shirt) increased by a median of 11.2% (interquartile range, 5.1% to 12.9%) in five arms of three reports. This increase is the basis for recommending use of this intervention. Three other outcomes were evaluated, but none provided sufficient evidence to determine the effectiveness of the intervention: the evidence of effectiveness in reducing the adult incidence of sunburn and increasing children's sun-protective behaviors was inconsistent and, although children's sunburn decreased in two arms of one report by about 41.2%, the single study did not provide sufficient evidence for a recommendation.

We also measured several outcomes that would not, by themselves, form the basis for a recommendation. Five arms from four reports showed a 9.8% increase in children's sunscreen use and a 15.4% increase in composite sun-protective behaviors. We found inconsistent effects on adults' information-seeking behavior; follow-up study participation; knowledge; attitudes or beliefs; or intentions. Available reports also demonstrated inconsistent effects of the intervention on sun-protective measures and environmental supports at outdoor recreational centers or swimming pools.

These findings should be applicable to a wide variety of settings and populations. Studies were conducted in Australia, England, Hawaii, Southern California, Virginia, and New England. Study participants' ages ranged from 6.5 to 79 years (median 31.5 years). Most of the reports that identified race or ethnicity were conducted with a predominantly white population; three reports involved Hawaiian or Asian/Pacific Islander populations. Of the reports

that identified gender, most studies were conducted among predominantly female populations. Annual household income of study participants ranged from $20,000 to greater than $90,000. Only one study reported educational level; in this study, 88% of the participants were high school graduates.

The studies in this review did not include information on other potential benefits or harms of these interventions. Benefits may include reaching populations not otherwise exposed to skin cancer prevention and reducing the risk of overexposure to heat and UV radiation that comes from over-reliance on sunscreen. Potential negative effects include reduction in outdoor physical activity.

We did not find any economic evaluations of educational and policy interventions in recreational and tourism settings.

Potential barriers to implementation include the limited time that recreational center staff may have to implement the special activity component of an intervention[69] and limitations imposed by swimming class schedules.[68] Additionally, some in the tourism trade might worry that sun-safety concerns could adversely affect their business and would therefore be unwilling to partner in these efforts.

In conclusion, the Task Force recommends educational and policy interventions in recreational and tourism settings on the basis of sufficient evidence of effectiveness in improving the adult sun-protective behavior of covering up. Evidence was insufficient to determine the effectiveness of the intervention in reducing sunburns in adults and children, because results were inconsistent (adults' sunburns) or too few studies were available (children's sunburns). Available reports also demonstrate evidence of effectiveness of the intervention in changing children's sun-protective behaviors, including sunscreen use and composite sun-protective behaviors; these, however, are not outcomes that form the basis for a recommendation. These findings should be applicable to a wide range of settings and populations.

Educational and Policy Interventions in Child Care Centers: Insufficient Evidence to Determine Effectiveness

Interventions in child care centers involve efforts to promote the sun-protective behaviors of children under five years of age. These interventions include at least one of the following: providing information directly or indirectly to the children (through instruction or small media education); additional activities to influence children's behavior (modeling, demonstration, or role playing); activities intended to change the knowledge, attitudes, or behavior of teachers, parents, and other caregivers; and environmental or policy approaches

(such as providing sunscreen and shade or scheduling outdoor activities to avoid hours of peak sunlight).

Effectiveness

- We found insufficient evidence to determine the effectiveness of educational and policy interventions in child care centers in reducing children's adverse health effects or changing children's behavior related to sun exposure, in changing caregivers' behavior related to sun exposure, or in changing policies and practices in child care centers.
- Evidence was insufficient because of the small number of studies, lack of relevant outcomes, and inconsistent results.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Much of lifetime sun exposure occurs in childhood.[84,85] Sun exposure varies among infants and preschool-age children and is largely dependent on the discretion of parents and other adult care providers. Studies have found that parental protective behaviors often depend on whether the child tends to sunburn and that parents most often rely on sunscreen for protection.[86–91] As children progress from infancy to childhood, increased mobility and a greater tendency to play outdoors often lead to increased UV exposure.[92]

Child care centers also represent an important, although often missed, opportunity to reduce children's UV exposure by providing shady play areas or scheduling outdoor activities during non-peak UV hours.[93]

The findings of our systematic review are based on two studies.[93,94] Two additional studies were identified but did not meet our quality criteria and were excluded from the review.[95,96] One report evaluated the "Be Sunsafe" curriculum (interactive classroom and take-home activities that promote covering up, finding shade, and asking for sunscreen) but did not evaluate behavioral or policy outcomes. The other study used a workshop for staff, an activity packet for parents, and a working session to develop skin protection plans for centers to focus on increasing application of sunscreen, scheduling activities to avoid peak sun, increasing availability of shade, and encouraging children to play in shady areas and to wear protective clothing. This study did not show statistically significant effects on policy outcomes or measures of children's behavior. Although both studies showed generally consistent and statistically significant improvements in knowledge, the small number of studies, with inconsistencies in results and few measures of key outcomes, provided insufficient evidence to determine the effectiveness of this intervention.

Because we could not establish the effectiveness of this intervention, we did not examine situations where it would be applicable, information about economic efficiency, or possible barriers to implementation.

The reviewed reports did not include information on other potential benefits of these interventions, such as reduction in the risk of overexposure to heat, or on potential harms, such as reduction in outdoor physical activity or transmission of lice via hats or other clothing.

In conclusion, the Task Force found insufficient evidence to determine the effectiveness of educational and policy interventions in child care centers in reducing children's adverse health effects or changing children's behavior related to sun exposure, changing caregivers' behavior related to sun exposure, or changing policies and practices in child care centers. Evidence was insufficient because of (*1*) limitations in the design and execution of available studies, (*2*) small numbers of qualifying studies, (*3*) variability in the interventions evaluated, (*4*) very short follow-up times, and (*5*) little substantial or statistically significant improvement in outcomes other than knowledge and attitudes.

Educational and Policy Interventions in Secondary Schools and Colleges: Insufficient Evidence to Determine Effectiveness

Interventions in secondary schools and colleges are potentially important, because adolescents and young adults are more likely to be exposed to UV radiation than younger children and are less likely to adopt sun-protective behaviors; parents and caretakers have less influence in promoting sun protection; and high schools and colleges can provide an infrastructure to support intervention activities. Some data indicate that, although young people know about the potential dangers of unprotected sun exposure, as adolescents they are likely to engage in high-risk behaviors; this presents a unique challenge to health educators.[97–99] Overall, sun-protection programs have reported more success in improving sun-protective practices for infants (provided by parents) and among younger children but less success among adolescents.[98] As primary school children transition to secondary schools, efforts to establish sun-protection education, supportive environments, and policies are difficult to sustain effectively.[100]

Effectiveness

- We found insufficient evidence to determine the effectiveness of interventions in secondary schools or colleges in changing behavior or reducing adverse health effects related to UV exposure.
- Evidence was insufficient because of limitations in the design and execution of available studies, small numbers of qualifying studies, variability in interventions and evaluated outcomes, and short follow-up times.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Interventions in secondary schools and colleges involve efforts to promote sun-protective behaviors among adolescents and young adults. These interventions include at least one of the following: providing information to adolescents and young adults through instruction, small media, or both; activities to influence the behavior of adolescents and young adults, such as modeling, demonstration, or role playing; activities intended to change the knowledge, attitudes, or behavior of caregivers (i.e., teachers or parents); and environmental and policy approaches (e.g., providing sunscreen and shade, or scheduling outdoor activities to avoid hours of peak sunlight).

The findings of our systematic review are based on 13 reports[51,101–112] on the effectiveness of educational and policy interventions in secondary schools and colleges. We identified four additional reports,[49,50,113,114] but they did not meet our quality criteria and were excluded from the review. Intervention activities used in these studies included didactic classroom teaching combined with some interactive classroom- and home-based activities; Internet-based activities; small media; and provision of sunscreen samples, extra class credit, or money. One study used a strategy of information dissemination and support of school staff to facilitate policy implementation.

Only four reports (six intervention arms) examined changes in sun-protective behavior or policy, and each report measured different sun-protective behaviors (amount of time spent in the sun, sunscreen use, measure of a composite behavior, and self-reported practices). The inconsistency of the interventions undertaken and outcomes measured did not allow us to determine the effectiveness of the interventions.

We did not conduct formal quantitative analyses of the intermediate outcomes of knowledge, attitudes, or intentions. Nine intervention arms generally showed an increase in knowledge as a result of the intervention. Seven intervention arms measured attitudes and beliefs, with inconsistent results, and seven measured intentions (the majority of which looked only at the intention to use sunscreen); these results were also inconsistent.

Because we could not establish the effectiveness of this intervention, we did not examine situations where it would be applicable, information about economic efficiency, or possible barriers to implementation.

In conclusion, the Task Force found insufficient evidence to determine the effectiveness of interventions in secondary schools or colleges to reduce adverse health effects or to change behavior related to UV exposure. Evidence was insufficient because of (*1*) limitations in the design and execution of available studies, (*2*) small numbers of qualifying studies, (*3*) variability in interventions and evaluated outcomes, and (*4*) short follow-up times.

Programs in Outdoor Occupational Settings: Insufficient Evidence to Determine Effectiveness

Programs in outdoor occupational settings promote sun-protective behaviors among workers. These interventions include at least one of the following: providing information to workers (instruction, education through small media, or both); additional activities intended to change the knowledge, attitudes, beliefs, intentions, or behaviors of workers (i.e., modeling or demonstration); and environmental or policy approaches, including providing sunscreen and shade.

Effectiveness

- We found insufficient evidence to determine the effectiveness of interventions in outdoor occupational settings in reducing UV exposure and promoting sun-protective behaviors.
- Evidence was insufficient because too few reports were available, and those reports provided inconsistent results.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

The receipt of information about preventing skin cancer is crucial for outdoor workers in the United States. According to the Census Bureau, over 8% of the U.S. national workforce (over 9 million workers) works primarily outdoors, in such occupations as construction, farming, forestry, fishing, land surveying and mapping, gardening, groundskeeping, mail delivery, and amusement park or recreational center attendants.[115] From both scientific and programmatic perspectives, occupational settings are ideal sites for sun-protection programs. High rates of nonmelanoma (basal cell and squamous cell) skin cancer have been found among occupational groups that work outdoors, and these rates are significantly associated with cumulative UV exposure.[116,117] Outdoor workers may receive up to six to eight times the dose of UV radiation that indoor workers receive.[117] A recent Canadian survey[118] found low levels of sun protection among outdoor workers: 44% seek shade, 38% avoid the sun, 58% wear a hat or protective clothing, and 18% to 23% reported using sunscreen while at work. Because outdoor workers receive intense, prolonged exposure to the sun and are at increased risk of developing squamous cell cancer, interventions that educate these workers and modify their work environment are well suited to the workplace and could provide substantial benefit.

The findings of our systematic review are based on eight studies that evaluated the effectiveness of interventions in outdoor occupational settings.[68,72,82,121–125] Three reports provided additional information on studies already included in

the review.[79,80,119] Another three reports were identified but did not meet our quality criteria and were excluded from the review.[77,120,126]

The reports in our review involved numerous intervention activities: providing sun-safety training to workers, sun-protection and skin cancer education sessions and skin exams by a physician, promoting covering-up behaviors, role modeling by lifeguards or aquatics instructors, providing sun protection products to outdoor workers (e.g., sunglasses, brimmed hat, and sunscreen), using educational brochures designed for men over the age of 45 and a body chart for self-assessment of pigmented lesions to educate male workers about skin cancer, and use of environmental supports (sunscreen dispensers and shade structures) to promote sun-protective behavior.

The reports also evaluated a variety of outcomes: changes in sun-protective behaviors and UV exposure, incidence of sunburn, knowledge, attitudes or beliefs, and environmental policies at pools. The reports provided insufficient evidence to determine the effectiveness of the intervention in increasing the sun-protective behaviors of covering up or seeking shade, or in decreasing the incidence of sunburn and UV exposure, because of inconsistent results and the limited number of studies that measured outcomes that could form the basis for a recommendation. Three arms from two reports examining sun protection demonstrated desirable effects of the intervention on sun-safety measures and environmental supports (provision of sunscreen dispensers and portable shade structures) at recreational centers and swimming pools. Six arms from five reports demonstrated inconsistent effects on knowledge, and five arms from four reports demonstrated inconsistent effects on attitudes or beliefs.

Because we could not establish the effectiveness of this intervention, we did not examine situations where it would be applicable, information about economic efficiency, or possible barriers to implementation.

Reviewed studies did not include information on other potential effects of these interventions. Other positive effects might include reaching populations who are not otherwise exposed to skin cancer prevention and reducing the risk of overexposure to heat. Potential negative effects of the intervention might include worker requests for reduction in time spent working outdoors.

In conclusion, available reports provide insufficient evidence to determine the effectiveness of interventions in outdoor occupational settings in reducing UV exposure and promoting sun-protective behaviors because of too few reports and inconsistent evidence. Although available reports show that the intervention is effective in improving some sun-protective measures and environmental supports at outdoor recreational centers and swimming pools, this does not necessarily result in decreased UV exposure or better health.

Programs in Healthcare System and Provider Settings: Insufficient Evidence to Determine Effectiveness

Interventions to reduce UV exposure and promote sun-protective behaviors can take place in healthcare settings (e.g., pharmacies, drugstores, clinics, physicians' offices, and medical schools) or can target healthcare providers (e.g., physicians, nurses, physicians' assistants, medical students, and pharmacists). In our systematic review, we included studies of interventions promoting primary prevention among populations at average risk for skin cancer. Studies usually included at least one of the following: (*1*) activities aimed at providers to increase knowledge or change attitudes and intentions, to increase positive role modeling for patients and clients, or to increase counseling behaviors or information provision to patients and clients or (*2*) activities placed within a healthcare setting to promote increased knowledge and improved attitudes and intentions about sun-protective behaviors among patients and clients, to promote provision of information about skin cancer to patients and clients, and to increase sun-protective behaviors among patients and clients. Our review did not evaluate interventions that focused on early detection of skin cancers or on interventions intended for people who are thought to be at higher than average risk of skin cancer, such as people who have already been diagnosed with one skin cancer.

Effectiveness

- We found insufficient evidence to determine the effectiveness of programs in healthcare system and provider settings in reducing clients' UV exposure or increasing their sun-protective behaviors.
- Evidence was insufficient because of inconsistent results among studies that evaluated these outcomes.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

People in the United States make an average of 1.7 visits to primary care providers annually,[127] and surveys consistently show that healthcare providers are a trusted and important source of health information. For these reasons, healthcare providers and systems have a special opportunity to affect population knowledge, attitudes, and beliefs about reducing UV exposure and increasing sun-protective behaviors. Through increasing knowledge, changing attitudes and intentions, role-modeling behaviors, and even establishing policies, healthcare providers and healthcare settings can greatly influence the behavior of the people who use their services.

According to the U.S. Preventive Services Task Force (USPSTF),[32] evidence was insufficient to recommend for or against regular counseling by primary

care clinicians to decrease sun exposure, avoid sun lamps, use sunscreen or protective clothing, or practice skin self-examination. Our review expands on that of the USPSTF by evaluating a broader range of providers and by including system approaches not limited to providers.

The findings of our systematic review are based on 11 reports[61,128–137] on the effectiveness of interventions oriented to providers and healthcare systems. An additional nine reports[56,129,138–144] were identified but did not meet our quality criteria and were excluded from the review. One report[145] provided additional information on a study already included in the review.

The target audiences of the reviewed interventions were diverse, as was the content of the interventions and the media by which they were delivered. Studies targeting healthcare providers evaluated brief educational sessions for physicians and house staff in a large urban teaching hospital; evaluated a didactic skin cancer prevention module aimed specifically at nurses; provided a skin cancer prevention curriculum for medical students; taught physicians through a triage curriculum (teaching providers when to act on symptoms presented by patients, when to reassure patients, and when to track patients' conditions) how to implement and manage basic skin cancer control practices; used the Internet to train physicians, medical students, and house staff about skin cancer; taught medical students about skin cancer control and then sent them to elementary school classrooms to teach schoolchildren about skin cancer control; and used videotapes and role-modeling training procedures to teach and encourage pharmacists to engage their clients in more skin cancer control behaviors.

Studies oriented to clients in healthcare settings used community drugstores to promote the message of appropriate sunscreen use and the concept of *sun protective factor* (SPF); used a physician's waiting room to recruit and educate people about the importance of sunscreen; and tested the effects of different message content and sources of messages on client behaviors.

Only two of the studies in our review assessed the outcomes of reducing UV exposure or increasing sun-protective behaviors, and results were inconsistent in direction and statistical significance. Because of the small number of studies and inconsistency in the findings, the evidence was insufficient to determine whether or not programs in healthcare and provider settings are effective in reducing exposure to UV radiation or increasing sun-protective behaviors. Measurements of provider behaviors were diverse in type and inconsistent in direction and statistical significance. None of the studies in the review reported on behaviors or exposures among clients, only on behaviors of providers toward clients. Several but not all reviewed studies showed improvements in intermediate outcomes, such as changes in knowl-

edge, attitudes, beliefs, and intentions of providers. Studies measuring client knowledge, attitudes, beliefs, or intentions tended to show results in the desirable direction, although they did not consistently reach a level of statistical significance.

Because not enough reviewed studies measured changes in the behaviors or health outcomes on which we could base a recommendation, and those that did showed a lack of consistency in results, evidence was insufficient to determine the effectiveness of programs in healthcare system and provider settings in reducing clients' UV exposure or increasing their sun-protective behaviors.

Because we could not establish the effectiveness of this intervention, we did not examine situations where it would be applicable, information about economic efficiency, or possible barriers to implementation.

In conclusion, evidence was insufficient to determine the effectiveness of interventions in healthcare settings or for healthcare providers in reducing UV exposure or increasing sun-protective behaviors because of lack of measurement of key behaviors and health outcomes among clients and lack of consistency in results.

Interventions in Diverse Settings

Mass Media Campaigns Alone: Insufficient Evidence to Determine Effectiveness

Mass media campaigns promote sun-protective behaviors, generally in geographically defined communities. They provide information through mass media (e.g., television, radio, newspapers, magazines, and billboards), small media (e.g., brochures, flyers, newsletters, informational letters, and posters), or both. Mass media have been widely used in public health programs to address behavioral risk factors and are a recognized vehicle for reaching wide audiences, particularly for the purpose of raising awareness and concern about an issue.

Effectiveness

- We found insufficient evidence to determine the effectiveness of mass media campaigns alone in promoting sun-safe behaviors or reducing ultraviolet (UV) exposure.
- Evidence was insufficient because of limitations in the design and execution of available studies, the small number of available studies, and variability in interventions and outcomes evaluated.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Several mass media campaigns to prevent and control skin cancer were conducted in the United States over the past decade, including campaigns by the Skin Cancer Foundation (http://www.skincancer.org), the federal government (http://www.chooseyourcover.gov), the American Academy of Dermatology (http://www.aad.org), the American Cancer Society (http://www.cancer.org), and the Weather Channel (http://www.weather.com). These campaigns were launched because of the reported success of Australia's regional programs, which rely heavily on mass media.[146] Ours is the first systematic review of the effectiveness of such campaigns.[147]

The findings of our systematic review are based on three reports[148–150] on the effectiveness of mass media campaigns without other activities in reducing exposure to UV radiation or increasing sun-protective behaviors. An additional seven reports[151–157,157a] were identified but did not meet our quality criteria and were excluded from the review. One report[158] provided additional information on a study already included in the review. We reviewed interventions that included any effort using mass media alone or mass media in combination with small media, with the aim of changing the knowledge, attitudes, beliefs, intentions, or sun-protective behaviors or health outcomes of children or adults. We only reviewed reports that allowed evaluation of the effect of mass media alone on behavior change. Studies that included mass media as part of multicomponent programs are also evaluated in this chapter (see Community-wide Multicomponent Programs, Including Comprehensive Community-wide Interventions).

The reviewed interventions included a three-segment television program emphasizing early detection and the dangers of sun exposure and sunburn; the use of a CD-ROM–based information kiosk housed at sites accessible to the public; media reporting of skin cancer advisories in the form of a UV index; and a rating of sunlight intensity coupled with recommendations for appropriate sun-protective measures. Reported results of these interventions either did not address the outcomes we wanted to measure or did not allow us to separate the specific effects of mass media alone. Thus, these studies provide insufficient evidence to determine the effectiveness of mass media approaches in promoting sun-safe behaviors or reducing UV exposure. All three reports, however, found that mass media campaigns tended to show increases in some aspects of knowledge.

Because we could not establish the effectiveness of this intervention, we did not examine situations where it would be applicable, information about economic efficiency, or possible barriers to implementation.

The studies in this review did not include information on other potential effects of the intervention. Some authors, however, have cited a concern that a

primary prevention campaign may result in increased unnecessary excisions of benign skin lesions.[159]

In conclusion, we found insufficient evidence to determine the effectiveness of mass media interventions alone in changing sun exposure behaviors. Evidence was insufficient because of limitations in the design and execution of available studies, the small number of qualifying studies, and variability in the interventions and outcomes evaluated.

Interventions Oriented to Children's Parents and Caregivers: Insufficient Evidence to Determine Effectiveness

Interventions for parents and caregivers involve activities that primarily promote sun-protective behaviors for children under their care. A caregiver is defined as a nonparental adult (e.g., professional nannies, mother's helpers, babysitters, grandparents, or other family or household members) who assumes responsibility, at least part-time on a regular basis, for the care of at least one child. Occupational or volunteer caregivers such as lifeguards, teachers, coaches, or scout leaders were not included here, but were included in our review of interventions in outdoor occupational settings and in recreational and tourism settings (see Educational and Policy Interventions in Primary Schools, Educational and Policy Interventions in Recreational and Tourism Settings, and Programs in Outdoor Occupational Settings).

Interventions for parents and caregivers include at least one of the following: providing information to parents or caregivers and the children under their care (through instruction, small media education, or both); activities intended to change the knowledge, attitudes, beliefs, intentions, or behavior of parents or caregivers and the children under their care (i.e., modeling, demonstration, or role playing); or environmental or policy approaches, including provision of sunscreen or shade, or scheduling of outdoor activities to avoid hours of peak UV radiation.

Effectiveness

- We found insufficient evidence to determine the effectiveness of interventions for parents or caregivers in reducing UV exposure or increasing sun-protective behaviors.
- Evidence was insufficient because too few reports were available and available reports showed inconsistent evidence.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

Parents and caregivers play an important role in protecting children from UV radiation. In addition to directly reducing children's UV exposure, parents and

caregivers can support sun-protective behaviors by incorporating preventive behaviors into family routines and by serving as role models for the children under their care. Parental beliefs about and involvement in disease prevention are important components of successful skin cancer prevention programs for children, especially young children. Parents control family resources and activities, and the availability of sunscreen and protective clothing.[160]

Children are more likely to use sunscreen if their parents do,[90,161] but this tendency has not been shown with other sun-protective behaviors. Some parents know the risks of skin cancer but do not realize that children are at risk.[86,87] Some parents believe a suntan is a sign of good health; others use sunscreen on their children as their only or preferred skin cancer prevention measure,[91] even when other methods (e.g., shade, appropriate clothing) are available. Sometimes parents apply sunscreen on their children incorrectly and inconsistently[30,162,163] (e.g., only after a child has experienced a painful sunburn). Reports of high sunburn rates among youth[164,165] highlight the need for better education of parents and caregivers about appropriate sun-protective behaviors.

The findings of our systematic review are based on nine reports that evaluated the effectiveness of interventions directed to parents or caregivers in reducing UV exposure.[68,69,71,73,74,166–169] Three additional reports were identified but did not meet our quality criteria and were excluded from the review.[54,77,157] Four reports provided additional information on studies already included in the review.[79,80,170,171]

The reports in our review used numerous activities and evaluated a variety of outcomes in one or both parents and their children. No reports evaluated outcomes among other caregivers. Studies used interactive sun-protective activities (stories, games, puzzles, stamps, arts and crafts) and environmental supports (e.g., providing sunscreen, shade, and signage); educational materials or presentations; a UV exposure-reduction curriculum at poolside; home-based activities for parents and children; giving new mothers sun-protective guidelines, postcard reminders, sunscreen samples, baby sun hats, and sun umbrellas; point-of-purchase prompts and discount coupons for children's hats and sunscreen; and a combination of focused behavioral strategies and community-wide publicity campaigns to change the attitudes and behaviors of parents and their children.

The reports showed insufficient evidence to determine the effectiveness of the intervention in changing parental sun-protective behavior, parental UV exposure, children's sun-protective behavior, children's UV exposure, and the incidence of children's sunburn because too few reports were available (parents' UV exposure and incidence of children's sunburn) or results were in-

consistent (parents' sun-protective behavior, children's sun-protective behavior, and children's UV exposure).

Effects of the intervention on parental knowledge, parental attitudes or beliefs, and parental intentions were inconsistent. Effects on children's attitudes or beliefs were desirable and consistent (median increase of 67.6%), as were parent-reported sun-protective measures and environmental supports at outdoor recreational centers or swimming pools (median difference, a 1.3 increase in score using a scale from 0 to 4), but neither of these outcomes, by itself, would have supported a recommendation.

Because we could not establish the effectiveness of this intervention, we did not examine situations in which it would be applicable, information about economic efficiency, or possible barriers to implementation.

We identified other potential effects of interventions for parents or caregivers, but further evaluation is needed to determine if these effects are important. Interventions for parents or caregivers may reduce the risk of overexposure to UV radiation that comes from overreliance on sunscreen. Additionally, a reduction in UV exposure could be associated with reductions in cataract formation. Potential negative effects of the intervention include vitamin D deficiency and reduction in outdoor physical activity.

In conclusion, available reports provide insufficient evidence to determine the effectiveness of interventions for parents or caregivers in reducing UV exposure or increasing sun-protective behaviors. Evidence was insufficient because of too few reports or inconsistent evidence. Additionally, although the following are not outcomes on which we would base a recommendation, the reviewed reports demonstrate that the intervention led to some improvements in children's attitudes or beliefs as well as in sun-safety measures and environmental supports at outdoor recreational centers and swimming pools.

Community-Wide Multicomponent Programs, Including Comprehensive Community-Wide Interventions: Insufficient Evidence to Determine Effectiveness

Multicomponent sun-protection programs aim to achieve behavioral changes among the people in a defined geographic area (e.g., counties, states, countries). Some are relatively modest efforts, such as combining a setting-specific program with a community-wide mass media or small media effort, whereas others are multilevel and comprehensive, involving entire communities, schools, workplaces, healthcare and recreation settings, mass media, and other

organizations. In addition to education, these programs may also include significant efforts to institute sun-protection policies and structural supports.

Programs like these have been in place for two decades in Australia, with the longest-standing and most commonly cited ones being the Slip! Slap! Slop! and SunSmart campaigns in Victoria.[146] Two U.S. programs, the Safe-Sun Project in New Hampshire[55,57] and the Falmouth Safe Skin Project in Massachusetts,[168] have used similar strategies on a smaller scale.

Effectiveness

- We found insufficient evidence to determine the effectiveness of community-wide multicomponent programs that include comprehensive community-wide interventions in reducing UV exposure or increasing sun-protective behaviors.
- Evidence was insufficient because of inconsistent results.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

We defined *community-wide multicomponent programs* as those that used combinations of individually directed strategies, mass media campaigns, and environmental and policy changes in an integrated effort in a defined geographic area (city, state, province, or country). Such programs are usually delivered with a defined theme, name, logo, and set of messages[146] and sometimes also incorporate setting-specific strategies. We included studies in this review if they occurred in a defined geographic area and had at least two components and two settings. We defined *comprehensive community-wide interventions* to be multilevel (i.e., those that include multiple individually directed, setting-specific, and community-wide components), addressing a substantial proportion of the population in a defined area, and lasting longer than one year.

The findings of our systematic review are based on eight reports[57,168,172–177] that evaluated the effectiveness of multicomponent and comprehensive community-wide interventions in reducing UV exposure or increasing sun-protective behaviors. An additional five studies[178–182] were identified but did not meet our quality criteria and were excluded from the review. Another 22 reports[42,55,56,62,146,147,183–198] provided additional information on studies already included in the review.

Of the seven multicomponent studies that measured covering-up or sun-avoidance behaviors, four showed generally positive outcomes, one showed an increase in risk behaviors, and two others showed essentially no change. Results of comprehensive community-wide programs were generally more positive. All three such studies showed desirable changes in covering-up or

sun-avoidance behaviors. These results, all from Australia, are promising but by themselves still provide insufficient evidence to determine the effectiveness of the interventions because of the small number of studies and limitations in study design and execution. Furthermore, available evidence (which comes mostly from sustained programs in Australia, a country with high skin cancer rates) may or may not generalize to the United States, where skin cancer is a less prominent public health concern and the population includes a higher proportion of dark-skinned individuals who are at lower risk of developing skin cancer.

Studies that evaluated self-reported sunscreen use generally reported increased sunscreen use. Many of the comprehensive community-wide studies evaluated changes in school and government policy and changes in the environment. These studies generally showed positive outcomes (e.g., an increase in the number of sun-safe policies in schools or governments, an increase in the number of stores with available low-cost sunscreen, or an increase in the amount of information and the number of posters provided). The effects on the knowledge, attitudes, and beliefs of adults and children were inconsistent.

Because evidence was insufficient to determine effectiveness, we did not fully evaluate situations in which these interventions would be applicable. It should, however, be noted that the most promising results of the available studies are from three long-term, intensive interventions in Australia. The context in which those studies occurred may differ in some important ways from the U.S. context: in some studies the mass media component was heavily subsidized, the incidence and risk of skin cancer are higher in Australia than in the United States, and UV exposure on average is probably higher in Australia than in the United States. Any of these factors might affect the extent to which these results may or may not be applicable in the United States.

Because we could not establish the effectiveness of this intervention, we did not examine information about economic efficiency or possible barriers to implementation.

The studies included in this review did not address potential harms of reducing UV exposure, such as an increase in the incidence of vitamin D deficiency or reduction in physical activity.

In conclusion, available studies provide insufficient evidence to determine the effectiveness of community-wide multicomponent programs in reducing UV exposure or increasing sun-protective behaviors because of inconsistent results. Evidence was also insufficient to determine the effectiveness of comprehensive community-wide programs to reduce UV exposure or increase sun-protective behaviors because of the small number of studies and limitations in their design and execution.

CONCLUSION: SKIN CANCER

This first part of the chapter summarizes Task Force conclusions and recommendations for preventing skin cancer by reducing exposure to ultraviolet (UV) radiation. To reduce exposure to UV radiation, the Task Force recommends educational and policy interventions in primary schools and in recreational and tourism settings. Evidence was insufficient to determine the effectiveness of educational and policy interventions in child care centers, secondary schools, or colleges in reducing exposure to UV radiation. Evidence was also insufficient to determine the effectiveness of programs in outdoor occupational settings, for parents and caregivers, or in healthcare systems and provider settings; of mass media campaigns alone; or of community-wide multicomponent programs (including comprehensive community-wide interventions) in reducing exposure to ultraviolet radiation.

Details of these reviews have been published[33,199,200] and these articles, along with additional information about the reviews, are available at www.thecommunityguide.org/cancer.

PROMOTING INFORMED DECISION MAKING FOR CANCER SCREENING

There was a time when doctors told their patients what tests to have or what procedures to undergo, and patients generally followed their doctors' advice. In twenty-first-century health care, the belief that "the doctor knows what's best" is being supplanted by a belief that patients must be increasingly involved in the decisions made about their care. Two principal approaches to helping clients make decisions about whether to be screened for a disease, have a test, or be treated are informed decision making (IDM) and shared decision making (SDM). Informed decision making interventions should help an individual to understand the nature of the disease or condition being addressed; to understand the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; to consider his or her preferences as appropriate; to participate in decision making at a personally desirable level; and either to make a decision consistent with his or her preferences and values or to defer a decision to a later time. Shared decision making is one type of IDM, which occurs in the clinical setting. Based on the work of the U.S. Preventive Services Task Force (USPSTF),[201] we have defined SDM as occurring when a patient and his or her healthcare provider(s), in the clinical setting, both express preferences and participate in making treatment decisions. We have defined an IDM intervention as any intervention in a community or healthcare system that promotes IDM, including SDM.

Informed decision making can apply to a range of cancer screening decisions. It sometimes applies to tests that have uncertain effects on health out-

comes. Providers and individuals are often compelled to consider such tests because (*1*) the screening test is highly publicized or widely available; (*2*) the test addresses a critical public health problem for which no good alternative prevention or treatment exist; or (*3*) public interest in the test is strong. At times, when publicity fails to fully inform the public about the potential risks and benefits of a given screening test, IDM and SDM interventions can help put potential risks and benefits in context.

Prostate-specific antigen (PSA) testing for prostate cancer is a relevant example. Prostate cancer is the most commonly diagnosed cancer in men other than non-melanoma skin cancer,[1] and the PSA screening test is widely recommended and available.[202] This has led to considerable public interest in the test. However, the effectiveness of PSA screening in reducing cancer morbidity and death is uncertain, and the diagnostic testing and treatment that follow PSA testing may involve important risks.[203,204] Moreover, some of the diagnostic testing may be unnecessary because it results from a false positive screening test or identifies a cancer that would never have become apparent during the individual's lifetime. As a result of these complexities, the balance of the benefits and harms of PSA screening is unclear. Individuals considering PSA screening may find IDM to be an important aid in understanding the benefits, risks, and uncertainties of this screening method, which can help them make an informed choice. In addition, IDM might be applicable to other high-profile cancer screening issues, such as spiral-computed tomography for lung cancer or pelvic ultrasound for ovarian cancer. The importance of IDM for cancer screening tests of uncertain benefit is likely to increase as more and more cancer screening tests become available.

Informed decision making can also apply to tests with proven benefit. Scientific studies have shown that some screening tests produce greater benefit than harm for populations. As a result, these tests are widely recommended. For example, the USPSTF recommends mammography every one to two years for women over 40, because this screening test has been found to reduce breast cancer mortality.[205] However, the benefit among women in their forties is smaller than for older women, and the balance of benefits versus harms increases with age. Women need to be aware of the potential harms, which include false positive test results and unnecessary anxiety, biopsies, and costs from false test results. Nonetheless, the magnitude of the benefit is relatively small; scientific discussion continues about how conclusively the benefit has been proven; the procedure is inconvenient; and the test produces a moderately high rate of false positive results requiring follow-up, for which women should be prepared. For these reasons, balanced information on the benefits and harms should be provided to the public.[205,206]

In addition, for a growing number of healthcare conditions, people must choose among two or more equally valid screening regimens. For example,

the recommended interval for cervical cancer screening may be yearly or less frequently (e.g., every two or three years), and older women may safely discontinue use of the test.[13,207] Colon cancer screening can be performed in a variety of ways (fecal occult blood testing, sigmoidoscopy, or colonoscopy)[208] but the relative merits of each method vary, as do the values individuals place on these relative merits.[208,209] An example of an Internet-based tool intended to promote IDM for colorectal cancer screening, including the pros and cons of different screening options, can be found at http://www.med.unc.edu/medicine/edursrc/colon.htm.[210]

We conducted a systematic literature review to assess whether or not IDM interventions in the area of cancer screening have been effective in helping individuals (*1*) increase their understanding of the cancers and the screening tests, (*2*) participate in IDM at a comfortable level, or (*3*) reach decisions consistent with their preferences and values, or if the interventions have been effective in changing healthcare or provider systems or policies to promote greater use of IDM and SDM.

In choosing which health or public health programs to pursue, the goal of making decisions consistent with individuals' values and preferences may conflict with other important social goals (such as improved population health or rational allocation of resources). Goals may include providing treatments that produce the greatest likelihood of good outcomes for the greatest number of individual patients while considering the best available science, rational allocation of societal resources, and organizational financial impact, as well as the need to respect individual autonomy. Decision makers must make trade-offs among such competing goals when choosing which clinical or public health interventions to support. Our review sought to clarify what is known about the likely outcomes of programs to promote IDM about cancer screening so that decision makers can compare the results of these programs with those of other alternatives. For example, some interventions might lead to more rational decisions about prostate cancer screening that may or may not save lives. On the other hand, good conceptual bases and some empirical evidence suggest that informed and involved individuals are more likely to adhere to treatment recommendations[211,212] and less informed patients may have poorer outcomes. Better-informed patients may therefore have more autonomy *and* better health.

OBJECTIVES AND RECOMMENDATIONS FROM OTHER ADVISORY GROUPS

Informed decision making is a broad and growing topic. The *Healthy People 2010*[29] goals shown in Table 4–1 touch on some aspects of IDM.

The USPSTF, which has published a paper clarifying how it envisions the application of SDM in the execution of screening and chemoprevention,[201]

Table 4–1. *Healthy People 2010*[29] Objectives Relevant to Informed Decision Making Interventions

Objective	*Population*	*2010 Objective*
Increase the proportion of persons appropriately counseled about management of menopause (females aged 46–56 years) (Objective 1–3h)	Women	Developmental
Increase the proportion of physicians and dentists who counsel their at-risk patients about tobacco use cessation, physical activity, and cancer screening (3–10)	All	Varies by provider type and health area
Increase the proportion of healthcare organizations that provide patient and family education (7–7)	All	Developmental
Increase the proportion of patients who report that they are satisfied with the patient education they receive from their healthcare organization (7–8)	All	Developmental
Increase the proportion of health-related World Wide Web sites that disclose information that can be used to assess the quality of the site (11–4)	All	Developmental
Increase the proportion of persons who report that their healthcare providers have satisfactory communication skills (11–6)	All	Developmental

does not endorse a specific style of decision making but does encourage informed and joint decisions.

In addition to the summary of our systematic review provided in this chapter, we have published an extended discussion of the conceptual aspects of IDM and SDM, along with details of the systematic review[213] (also available at www.thecommunityguide.org/cancer).

METHODS

Methods used for the reviews are summarized in Chapter 10. Specific methods used in the systematic reviews of IDM and cancer screening have been described in detail elsewhere.[213] In our systematic review of IDM interventions for cancer screening, we assessed the extent to which these interventions have been tested and the extent to which potential outcomes have been evaluated empirically. We limited our inquiry to IDM outside of the individual clinical encounter (i.e., excluding SDM) in the areas of prevention and early detection. The USPSTF has published on SDM in the clinical encounter.[201]

Although IDM is relevant to many treatment and prevention topics, we limited this review to cancer screening because different prevention topics may raise unique questions.

The proposed outcomes on which recommendations are based in this review (i.e., knowledge, participation, and consistency with values) differ from

those typically identified in *Community Guide* reviews[214] in that they are not health outcomes or established proxies for health outcomes. However, for this novel public health intervention, we considered informed and participatory decisions consistent with preferences and values to be of value by themselves, regardless of whether or not they lead to better health. Since some informed and participatory decisions may not result in better health, we decided that we could not logically require that an intervention result in decisions that are consistent with individuals' preferences and values and also require better health as an outcome.

ECONOMIC EFFICIENCY

A systematic review of economic evaluations is conducted for each recommended intervention in a topic area. Because the Task Force found insufficient evidence to determine if the one intervention reviewed in this area—IDM interventions to promote cancer screening—is effective, no systematic review of economic evaluations was conducted.

RECOMMENDATIONS AND FINDINGS

This section presents a summary of the findings of the systematic review conducted to determine the effectiveness of IDM interventions in promoting skin cancer screening.

Informed Decision Making Interventions to Promote Cancer Screening: Insufficient Evidence to Determine Effectiveness

Informed decision making interventions occur in communities or healthcare systems and help an individual to understand the nature of the disease or condition being addressed; to understand the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; to consider his or her preferences as appropriate; to participate in decision making at a personally desirable level; and either to make a decision consistent with his or her preferences and values or to defer a decision to a later time.

Effectiveness

- Almost all studies reported increases in knowledge, improved perceptions of risk, or both.
- Evidence, however, was insufficient to determine the effectiveness of IDM interventions in helping individuals participate in IDM at a comfortable level or reach decisions consistent with their preferences or values.

- Evidence was also insufficient to determine the effectiveness of IDM interventions in changing healthcare or provider systems or policies related to IDM or SDM.
- Evidence was insufficient because of the small number of studies measuring relevant outcomes and inconsistent results among studies.
- Insufficient evidence means that we were not able to determine whether or not the intervention works.

The findings of our systematic review are based on 11 reports[210,211,215–223] that provided information on 15 independent intervention arms. Two additional reports[224,225] provided information on studies already included in our review. Of the 15 intervention arms, 10 addressed prostate cancer screening, 3 addressed colorectal cancer screening, and 2 addressed mammography screening. Most studies were directed to clients in clinical settings.

The studies in our review examined several different approaches to providing the information on which informed decisions could be based. Client-oriented interventions used small media alone (including videos, brochures, or written materials; some of the written materials were customized to individual needs and circumstances), one-on-one education (by itself or supported by computer-generated decision aids to help people make choices among options), or small group education. The only provider-oriented intervention we reviewed included aspects of provider education and reminders.

Thirteen of the study arms measured patients' knowledge, beliefs, or perceptions about the risk or natural history of the disease or about the performance of the preventive service. The evidence showed effectiveness in improving these outcomes: almost all of the available studies reported increased knowledge, increased accuracy of beliefs and perceptions, or both. Some but not all of the more intensive interventions produced larger effects.

One study showed self-reported increases in preferences for SDM. Three reports showed increases (of unstated size) in individual or patient participation in decision making. Only a single study reported on whether participation was consistent with expressed preferences for level of participation (i.e., primarily by the patient, primarily by the physician, or shared). That study showed that people in an intensive intervention group were no more likely to adopt a level of participation consistent with pre-intervention preferences than those in a less intensive intervention group. Only a single study measured any outcome related to whether intervention preferences were acted upon; it showed that only 19% of patients who received an intensive intervention actually chose a screening strategy at their next office visit that was consistent with the most highly rated strategy identified during the intervention. The results, therefore, provided insufficient evidence to determine whether IDM interventions resulted in participation in decision making

with which the patient was comfortable or decisions consistent with patient values and preferences.

Results of the interventions on screening outcomes were mixed, but effect sizes were generally small. Of the studies of prostate cancer (for which there is no consensus about whether screening provides a net benefit), eight allowed for calculation of percentage point changes in testing and showed a median 8 percentage point decrease (range, 47 percentage point decrease to 14 percentage point increase). Two more prostate cancer studies showed statistically significant decreases in self-reported preferences for screening. Of the five studies of colorectal cancer or breast cancer (where consensus is greater about the benefits of screening), four allowed calculation of the proportion of patients accepting screening after the intervention and showed a median 6 percentage point increase in screening (range, 2 percentage point decrease to 14 percentage point increase). Only the 14 percentage point increase was reported to be statistically significant. The other study showed generally small and nonsignificant increases in intentions to be screened.

Evidence was also insufficient to determine whether IDM interventions increase implementation of policies that promote and facilitate IDM (e.g., increasing time for or reimbursement of providers who participate in SDM or hiring or training non-physician staff to help facilitate SDM); improving providers' knowledge and motivation, attitudes about, and intentions to perform SDM or their participation in SDM; or improvements for clients resulting from changes in provider and healthcare system approaches.

Because we could not establish the effectiveness of IDM interventions, we did not examine situations in which they would be applicable, information about economic efficiency, or possible barriers to implementation.

We considered whether IDM interventions might have negative effects on individuals or community members (e.g., confusion, frustration, positive or negative effects on other preventive care), on healthcare systems or providers (e.g., effects on clinic efficiency), or on whole communities (e.g., adverse effects of competing or contradictory clinical and community approaches). None of the reviewed studies provided information about any of these possible effects.

In conclusion, current evidence was insufficient to determine whether IDM interventions resulted in participation in decision making at a comfortable level or in decisions consistent with patient values and preferences. This insufficiency of evidence applied to individuals in healthcare settings and community members outside of healthcare settings. Evidence was also insufficient to determine whether IDM interventions were effective in changing the

knowledge, attitudes, or behaviors of healthcare providers or the policies of healthcare systems. On the other hand, these interventions generally improved knowledge, beliefs, risk perceptions, or a combination of these.

CONCLUSION: INFORMED DECISION MAKING

The finding of this review—that available evidence was insufficient to determine the effectiveness of interventions to promote IDM—does not mean that the interventions do not achieve their objectives. Both IDM and SDM are important emerging trends, and additional studies of these interventions should be conducted. Limitations, costs, uncertainties, and trade-offs should be studied empirically and should be considered when choosing interventions. However, hypothesized costs, barriers, or trade-offs should not limit additional exploration of IDM.

Several criteria may make IDM interventions of higher priority for research and practice, make the provision of more information appropriate, or both. These include:

- High interest in the test(s) in the community or among individuals, especially if combined with uncertainty about effectiveness, uncertainty about the balance of benefits and harms, unavailability of balanced information (e.g., knowing the pros but not the cons of a particular screening test), or high complexity of trade-offs.
- Low demand despite known effectiveness.
- High variability in values or preferences.
- High-stakes issues (e.g., more common or serious conditions; more costly, complex, or dangerous consequences of screening).

This second section in the chapter summarizes Task Force conclusions about IDM interventions. The Task Force found insufficient evidence to determine the effectiveness of IDM interventions in promoting understanding of cancer screening, facilitating participation in decision making about cancer screening at a level comfortable for individuals, or encouraging individuals to make cancer screening decisions consistent with their preferences and values. Details of this review have been published[213] and this article, along with additional information about the reviews, is available at www.thecommunityguide.org/cancer.

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