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## Epidemiology and Implementation of Cancer Prevention in Disparate Populations and Settings

Ana Maria Lopez, MD, MPH<sup>1</sup>, Lauren Hudson<sup>2</sup>, Nathan L. Vanderford, PhD, MBA<sup>2</sup>, Robin Vanderpool, DrPH<sup>2</sup>, Jennifer Griggs, MD, MPH<sup>3</sup>, and Mara Schonberg, MD, MPH<sup>4</sup>

<sup>1</sup>Sidney Kimmel Cancer Center, Thomas Jefferson University, Philadelphia, PA

<sup>2</sup>University of Kentucky Markey Cancer Center, Lexington, KY

<sup>3</sup>University of Michigan, Ann Arbor, MI

<sup>4</sup>Beth Israel Deaconess Medical Center and Harvard Medical School, Boston, MA

### Abstract

Successful cancer prevention strategies must be tailored to support usability. In this article, we will focus on cancer prevention strategies in populations that differ by race and ethnicity, place and location, sexual orientation and gender identity, and age by providing examples of effective approaches. An individual may belong to none of these categories, to all of these categories, or to some. This intersectionality of belonging characterizes individuals and shapes their experiences. Even within a category, broad diversity exists. Effective cancer prevention strategies comprehensively engage the community at multiple levels of influence and may effectively include lay health workers and faith-based cancer education interventions. Health system efforts that integrate cancer health with other health promotion activities show promise. At the individual physician level, culturally literate approaches have demonstrated success. For example, when discussing cancer screening tests with older adults, clinicians should indicate whether any data suggest that the screening test improves quality or quantity of life and the lag time to benefit from the screening test. This will allow older adults to make an informed cancer screening decision based on a realistic understanding of the potential benefits and risks and their values and preferences. Addressing individual and health system bias remains a challenge. Quality improvement strategies can address gaps in quality of care with respect to timeliness of care, coordination of care, and patient experience. The time is ripe for research on effective and interdisciplinary prevention strategies that harness expertise from preventive medicine, behavioral medicine, implementation science, e-health, telemedicine, and other diverse fields of health promotion.

### INTRODUCTION

The prevention of cancer is informed by epidemiologic data that effectively map the cancer problem by defining its characteristics and location. In this process of uncovering cancer's footprint, epidemiologists identify associations between risk factors and the disease.<sup>1</sup>

Successful cancer prevention strategies must be tailored to the population and the individual to improve usability.

In this article, we will focus on cancer prevention strategies in populations that differ by race and ethnicity, place and location, sexual orientation and gender identity, and age. An individual may belong to none of these categories, to all of these categories, or to some. It is this intersectionality of belonging that characterizes individuals and shapes their experiences. The individual lives in multiple, overlapping realities with different levels of privilege. How these factors “add up” is the result of a complex interplay between longstanding societal power imbalances resulting in discriminatory practices that yield favor or disfavor. These four threads of identity are not comprehensive. They provide a lens through which we may understand the link between epidemiology and the development of effective approaches for cancer prevention. Even within a thread, there may exist broad diversity related to multiple social factors.

We intentionally avoided the term “vulnerable” in this article. Although this term is often used to refer to those “at risk for worse outcomes,” it is our assertion that the people and populations addressed in the following sections are often the most resilient. Although cancer outcomes are indeed alarmingly poor among marginalized populations and historically invisible groups of people, the attribute of “vulnerability” is often an inaccurate misnomer that we avoided and recommend avoiding.

## **ADDRESSING AND OVERCOMING DISPARITIES IN CANCER PREVENTION IN RACIALLY AND ETHNICALLY DIVERSE POPULATIONS**

### **Race and Ethnicity**

We understand that race and ethnicity have generally been used to define characteristics of a population. Race generally has been used in relation to biologic and physical attributes and ethnicity to cultural factors. Over time, our understanding of race has moved away from that of an immutable biologic attribute.<sup>1</sup> We recognize that these categories, which are largely developed for data collection by federal agencies, may homogenize populations, making it more difficult to identify actionable priorities.<sup>2</sup> Still, health data continue to be collected with race as an independent factor. Recognizing the interdependence of both race and ethnicity on lived experience,<sup>3</sup> we will use the term race/ethnicity in this article. When referring to the work of others, we will use the descriptor as used in their text.

### **Epidemiology**

Scientific knowledge begins with identifying data gaps. In 1973, the United States instituted a cancer registry system, the Surveillance, Epidemiology, and End Results (SEER) Program, to collect cancer incidence and survival data to better understand the cancer burden in the United States. Data are collected by age, gender, place, race, and ethnicity. Over time, the data collection sites have expanded. Currently, SEER covers more than one-quarter of the population in the United States.<sup>4</sup> Although initially thought to be over-representing urban populations, SEER has expanded to include Kentucky, Iowa, and Georgia, increasing generalizability. SEER data contribute to the Annual Report to the Nation on the Status of

Cancer that is jointly issued by the Centers for Disease Control and Prevention, the North American Association of Central Cancer Registries, the American Cancer Society, and the National Cancer Institute (NCI). The report<sup>5</sup> underscored the benefit of early detection for cancer survival.

## Cancer Prevention

**Cancer prevention behaviors**—A review of national data reveals differences in cancer incidence and cancer outcomes by race/ethnicity. For example, black men experience a higher incidence of cancer compared with white men. Black women experience a lower incidence of cancer compared with white women. When looking at cancer related mortality, both black men and women fare more poorly than white men and women despite overall recent improvements in cancer health outcomes.<sup>4</sup>

Cancer prevention behaviors may improve early detection and decrease cancer mortality and may be impacted by social factors. Socioeconomic status can impact access to health insurance, access to health care, and the ability to prioritize health among competing survival priorities (e.g., paying for rent, paying for food, or paying for health care).<sup>6</sup> Given the complex history of race/ethnicity in our country, other substantial cultural factors that may specifically interrelate with race/ethnicity in the achievement of cancer prevention behaviors are mistrust of the health care system and fear of prejudice.<sup>7</sup>

**Cancer prevention strategies**—Insofar as the diagnosis of cancer results from an interplay of biology (the genome), environment (exposures), and social factors (e.g., socioeconomic status, education, language, culture, literacy, and numeracy), strategies in these areas may contribute to cancer prevention behaviors and cancer health outcomes.

Effective cancer prevention approaches can take place at the community and health system level by engaging communities directly. Beyond community outreach, programs that fully engage community participation and leadership in the development, implementation, and assessment of cancer prevention strategies are likely to be of greatest long-term impact.<sup>8</sup> These successful programs engage communities as “resident experts” in their health and health care needs. Community interventions that partner with promotoras/promotores or other professional or lay health workers or advisors can effectively bridge the medical profession and the community. These models improve cancer health outcomes by providing culturally literate and linguistically competent cancer health education for prevention and screening.<sup>9–12</sup>

The first step for most successful cancer prevention efforts is education. Education itself is an independent protective factor favoring health.<sup>13</sup> An educational intervention delivered in a location convenient to the community (e.g., church, community center, or school), in a culturally literate and linguistically competent manner (in a way that it can be easily understood), and in a manner that makes it easy to accomplish the cancer prevention behavior yields a successful intervention. The combination of outreach, education, access to screening, increased referrals to screening, and lay workers to facilitate the process can begin to close the gap in early detection of cancer.<sup>14</sup> Education includes addressing health literacy and numeracy, both independent adverse risk factors for health outcomes.<sup>15</sup> Given

the difficulty of transportation in some urban settings and the substantial geographic barrier in rural and frontier settings, telehealth and mobile health technologies may serve to facilitate cancer prevention behaviors.<sup>15,16</sup>

Individuals may access health care through multiple touch points. Large health systems may integrate cancer prevention strategies into overall population-based health promotion strategies. For example, patients may access the health care system for a flu vaccine and be reminded of colorectal screening or be provided with access to a colorectal screening test.<sup>17</sup> In an earlier example, in 1993, WISEWOMAN (Well-Integrated Screening and Evaluation for Women Across the Nation) reached women simultaneously for cancer and cardiovascular disease screening.<sup>18</sup> Integrating access to prevention and health promotion supports the health of the population.

Although much of health care takes place outside of the individual physician's office, the individual physician's recommendation impacts patient behavior.<sup>19</sup> A physician's culturally literate approach can support patient cancer screening behaviors.<sup>20</sup> Similarly, greater awareness of clinician bias and its inhibition of cancer screening behaviors is important to uncover, address, and improve.<sup>21</sup>

## Summary

Race/ethnicity impacts cancer prevention behaviors and contributes to delays in detection and to worse cancer health outcomes. Effective strategies must engage the community directly from program development, implementation, and assessment. The role of lay health workers in supporting cancer prevention has been well documented and should be considered. Health system efforts that integrate cancer health with other health promotion activities show promise. At the individual physician level, culturally literate approaches have demonstrated success. Addressing individual and health system bias remains a challenge.

## THE CHALLENGE OF CANCER PREVENTION IN RURAL POPULATIONS

As described earlier, cancer disparities present across different sectors of our society, including varying age groups, racial and ethnic populations, individuals of differing gender and sexual orientations, and as outlined in this section, rural communities. Although rural residents overall experience a lower age-adjusted incidence of new cancer cases, they have notably higher premature mortality rates in all age groups, which directly correlates with a decrease in life expectancy.<sup>22</sup> Rural residents, in particular, are 8% more likely to face mortality when diagnosed with preventable and screenable malignancies such as lung, colorectal, prostate, or cervical cancer.<sup>23</sup> This cancer statistic is especially true in the rural Appalachian communities of eastern Kentucky. Statistically speaking, eight of the 10 U.S. counties with the greatest decrease in life expectancy are in Appalachian Kentucky, and some of the highest lung, colorectal, and pancreatic cancer incidence and mortality rates in the nation are found in eastern Kentucky.<sup>21,24</sup>

## Drivers of Rural Cancer Disparities

Cancer disparities in rural communities, including in Appalachia, may be caused by a variety of contextual, environmental, cultural, socioeconomic, and behavioral reasons.<sup>25</sup> For example, rural residents are more likely to have higher rates of tobacco use, poor diet, and physical inactivity.<sup>26–29</sup> They also have lower rates of cancer screening and HPV vaccination.<sup>27,28</sup> Economically, rural residents are more likely to be low income and experience higher poverty levels, which in turn may circumvent needed cancer screenings or treatments due to limited health insurance coverage and financial insecurity.<sup>26,27</sup> Many rural areas across the United States are also recognized as health care professional shortage areas for primary care, dentistry, and mental health.<sup>30</sup> Similarly, specialized oncology care services are extremely limited in their options; only 3% of oncologists actually practice in rural areas.<sup>26</sup> Rural-residing individuals may also have lower levels of education, which may impact health literacy and cancer information-seeking behaviors.<sup>27</sup> In Appalachia, cultural beliefs and practices such as fatalism and storytelling may reinforce negative perceptions of cancer prevention and treatment among familial and social networks.<sup>31,32</sup> Topographically, rural areas may have mountainous or desert terrain that makes it difficult to create dependable roadways to take patients from their homes to distant clinical care as well as implement technologic advancements such as broadband and connected health programs.<sup>27,28,33</sup>

## Innovative Rural Cancer Control Initiatives

In an attempt to close the cancer disparities gap between rural and urban regions, one NCI-designated cancer center in particular has dedicated itself to positively impacting cancer outcomes in its primary rural catchment area. Specifically, the University of Kentucky Markey Cancer Center (MCC) and its investigators have embedded innovative outreach programs within rural communities across Kentucky, with a specific focus on Appalachian Kentucky. MCC has created numerous rural-focused initiatives that aim to increase community engagement and capacity building focused on local cancer control while highlighting community strengths and assets, improve outcomes across the cancer care continuum, and alleviate the burden of cancer on individuals, families, and communities.<sup>28</sup> Herein, we describe several examples of these innovative rural cancer initiatives.

## Faith Moves Mountains

As described earlier, the rates of cervical cancer incidence and mortality in rural Appalachia are significantly higher than non-Appalachian communities.<sup>24,34</sup> To address this public health concern, Faith Moves Mountains was developed as a community-based, faith-centered intervention program designed to educate and encourage Appalachian women to receive Papanicolaou (Pap) tests.<sup>34</sup> Utilizing the church's community presence in rural areas, pastoral leaders, vital motivational and uplifting impact, and cadre of parishioners, Faith Moves Mountains successfully and positively educates women ages 40–65 about the importance of Pap tests and how to obtain screening services.<sup>34</sup> The findings of the initial study showed that women who received the Faith Moves Mountains intervention were greatly influenced by the cancer information presented; 17.6% received Pap tests after program completion.<sup>35</sup> Given the success of Faith Moves Mountains, the faith-based

initiative has been recognized by NCI's Research-Tested Intervention Program and has been expanded to address breast and colon cancer screening, tobacco cessation, healthy living, and diabetes prevention and control among rural Appalachian communities.<sup>29</sup>

### 1–2–3 Pap

Previous research suggests that rural communities experience an undue burden of HPV-related cancers,<sup>36</sup> including Kentucky, which leads the nation in the incidence of HPV-related cancers.<sup>37</sup> Moreover, national data suggest that adolescents from rural communities are less likely to receive the HPV vaccine.<sup>38,39</sup> These trends are likely present among young adult women in rural areas eligible for catch-up vaccination.<sup>40,41</sup> As a result, 1–2–3 Pap is a program designed to encourage young adult women in Appalachian Kentucky to complete doses two and three of the three-dose series. After the first HPV dose is administered, the patient is shown a health communication video describing the effects of cervical cancer screening and proper vaccination on sexual and overall health, along with a provision of cues to action and strategies to overcome barriers to vaccine series completion.<sup>41</sup> The intervention's messages were designed from the prospective of rural young adult women and showcased local community influencers, such as a local media personality, a nurse practitioner, and young women from Appalachia.<sup>40,41</sup> In addition, the HPV vaccination intervention was delivered in community settings such as local festivals, Walmart, work sites, and community colleges. The results of the program showed that young adult women were almost three times more likely to complete the HPV vaccination series after receiving the culturally tailored intervention compared with women who received standard of care.<sup>41,42</sup> 12–3 Pap has subsequently been included in NCI's Research Tested Intervention Program and disseminated across Kentucky, West Virginia, and North Carolina.<sup>43</sup> Partnerships established as part of 1–2–3 Pap have led to additional HPV vaccination research projects in rural Kentucky, including school- and pharmacy-based interventions.<sup>44,45</sup>

### Rural tobacco control

In general, rural areas see higher rates of youth and adult smoking rates compared with urban areas,<sup>25,46,47</sup> which likely play a role in the elevated rates of lung cancer observed in rural communities.<sup>23,24</sup> Kentucky ranks second in the nation for the percentage of the adult population that smokes; notably, 25% of adults in the state identify as smokers. This number is partially driven by the 31% of males and 27% of females in Appalachia who consider themselves smokers.<sup>29</sup> Understanding the behavioral and cultural factors that influence why youth begin using tobacco is an important step at devising effective tobacco control interventions. For example, impulsivity, low delay discounting behaviors, and having a parent or friend who smokes are associated with an increased risk of smoking among Appalachian youth.<sup>48</sup> Data establishing these particular risk factors were collected within the community through the innovative use of a mobile laboratory that parked at accessible public locations such as Walmart parking lots.<sup>48</sup> A targeted 6-week web-based voucher reward system intervention strategy has been used to successfully reduce smoking behaviors in this population; the average number of cigarettes smoked per day by the intervention group at the end of the treatment dropped from 11.3 to 6.0. This study was also tailored to overcome internet connectivity barriers facing many rural residents, namely investigators



provided loaner equipment to greater than 95% of the participants so that they could access the internet from home due to the lack of broadband service in their rural neighborhoods.<sup>49</sup>

Faith-based smoking cessation interventions that educate users on the physiologic aspects of nicotine dependence are also effective at lowering tobacco use among rural residents. Using lay health advisors in rural Appalachian churches to deliver a 12-week evidence-based smoking cessation program has been shown to be effective at reducing smoking rates by leveraging sociocultural factors to improve the cultural salience of the program.<sup>29</sup>

Ultimately, these examples speak to the need to create culturally sensitive tobacco control interventions that take into account the specific needs, barriers, and ideologies of rural residents.

### **New Opportunities to Reduce Cancer Disparities**

Although educating the general public about cancer prevention and screening is paramount, providing support and continued education for rural health care systems and local health care professionals is of equal importance. With medicine being an ever-changing field, staying up to date on the cutting-edge techniques and treatments is in the best interest of the patient, the caregiver, and the professional. As such, the MCC has created a network of 19 cancer care centers across the state of Kentucky, 14 of which are in the center's primary rural catchment area of eastern and central Kentucky.<sup>28,50</sup> The MCC Affiliate Network (MCCAN) provides guidance, assistance, and support as local hospitals work to provide quality cancer care within their community. This statewide effort encourages health care professionals to participate in cancer committees, tumor boards, and continuing education offerings. From 2013 to 2017, MCCAN's continuing education service has provided training to over 1,600 health care professionals (e.g., physicians, nurses, social workers, and dietitians). In addition to increasing access to quality treatment, MCCAN sites also participate in community-based cancer screening initiatives. An example of this outreach is Mamm's Day Out, which offers free or low-cost breast cancer screenings on Saturday mornings for women who are unable to receive a screening due to work or financial restraints. Since 2014, 244 women received mammograms at 15 different Mamm's Day Out events held at the MCC. Nearly 90 additional women have been screened at other MCCAN hospitals in rural central Kentucky and Appalachian Kentucky. Working with affiliate sites represents a substantial opportunity for academic cancer centers to implement cancer control activities within rural, low-resourced service areas and thus reduce the cancer disparities in these areas.

### **Summary**

Overall, the cancer disparities between rural and urban areas in Kentucky and elsewhere across the United States have the potential to be remedied with culturally designed, place-based cancer control programs. However, this reduction is not going to be the result of just one community outreach program or research study or a single continuing education seminar. It is going to take the invested efforts at multiple levels of influence and among all involved (i.e., patients, caregivers, health care professionals, and community stakeholders) to make a sustainable difference. Innovative programs (conducted in collaboration with rural

communities) that focus on increasing education about and access to cancer preventive services can positively influence related outcomes. By encouraging the strong sense of community, rural patients can also find a support network through faith-based cancer education interventions. Finally, health care networks like MCCAN support hospital staff in rural areas, thus elevating the cancer treatment they provide, and such networks can also be leveraged to implement cancer prevention and control initiatives in rural communities.

## **EPIDEMIOLOGY AND IMPLEMENTATION OF CANCER PREVENTION IN SEXUAL AND GENDER MINORITIES**

### **Epidemiology and Cancer Burden**

Members of the lesbian, gay, bisexual, transgender, and queer communities, as well as others who identify as sexual and gender minorities, bear a disproportionate burden of cancer. Multiple factors contribute to this burden, including a high prevalence of risk factors such as smoking and obesity,<sup>51</sup> higher likelihood of exposure to HPV,<sup>52</sup> and lower uptake of prevention services. Exclusion from cancer prevention outreach campaigns as well as negative experiences with the health care system all increasingly widen inequities in cancer prevention.<sup>53</sup> Knowledge gaps among health care providers, barriers erected by health care policies, gaps in insurance coverage,<sup>54</sup> and lack of prevention guidelines specific for sexual and gender minority communities have further hampered progress in cancer prevention.<sup>55</sup>

Two additional factors have impeded progress in cancer prevention in sexual and gender minorities. The first is a historical lack of research funding in this area. The second is lack of data collection regarding sexual orientation and gender identity in health care and public health settings.

### **Cancer Prevention Strategies**

Using the framework from the ASCO Position Statement,<sup>55</sup> which laid out approaches for reducing cancer health disparities among sexual and gender minorities, the following is a proposed set of strategies that can be leveraged specifically to close gaps in cancer prevention among sexual and gender minorities. These address patient, provider, policy, quality improvement, and research strategies.

We begin by advocating for the use of culturally competent care of members of lesbian, gay, bisexual, transgender, and queer communities. As in the ASCO Position Statement, we use here the Joint Commission definition of cultural competence (<http://www.jointcommission.org/lgbt/>), which requires that providers and the organizations in which they work (1) value diversity, (2) practice self-awareness and self-assessment of their own biases, (3) manage the “dynamics of difference,” (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of individuals and communities served.

Interventions to reach people who are eligible for specific risk-reduction and secondary prevention programs must be deployed in a thoughtful way to have the greatest impact. Educating people about risk reduction strategies in community settings and patients in



primary care offices requires that program developers be aware that not all people are in heterosexual, cisgender relationships. Creating programs that are developed specifically for lesbian, gay, bisexual, or transgender communities and working with members of those communities appear to be more effective than nontailored programs.<sup>56</sup>

For programs that are publicized using broadcast media, inclusive language for such campaigns as tobacco prevention and cessation, HPV immunization, exercise and other wellness programs in and out of the workplace, as well as health insurance expansion opportunities will increase the effectiveness of such programs without compromising their effectiveness in heterosexual, cisgender populations.

Education of the health care workforce is also critical. Gaps in knowledge among physicians regarding cancer risk factors were recently identified through a survey of oncologists from NCI-designated cancer centers.<sup>57</sup> The respondents expressed high levels of interest in receiving education regarding the health needs of sexual and gender minority patients. It is likely that gaps in knowledge among all clinicians, not only physicians, impede the delivery of high-quality cancer prevention. If cancer epidemiology and the prevention needs of sexual and gender minorities were to be incorporated as part of the training curriculum of health care providers, missed opportunities for prevention would be less likely to occur. We recommend that all health care personnel who interact with patients receive training on how to work with people of diverse sexual orientation and gender identities. Continuing education, whether done at each facility or at the level of state or national societies, is warranted to close gaps in preventative care.

Policy solutions include ensuring that discrimination against sexual and gender minorities does not occur. To receive preventive services, people must be able to seek care and follow-up of symptoms and abnormal screening tests in a safe and welcoming environment without fear of systematic discrimination. There is ample evidence that members of lesbian, gay, bisexual, transgender, and queer communities have difficulty accessing health care<sup>58,59</sup> and that even once they do so, their experiences may be fraught with challenges not experienced by their heterosexual, cisgender counterparts. In other words, provider education can address the barriers that patients face to only a partial extent if the health system itself does not support patient and family-centered care. The Joint Commission requires that hospitals prohibit discrimination on the basis of personal characteristics, including sexual orientation and gender identity. As of this writing, however, only 22 states have legislation protecting patients from physician discrimination on the basis of sexual orientation and only 14 from discrimination on the basis of gender identity.

## Summary and Future Directions

Two final implementation strategies that will address the gap in cancer prevention are quality improvement strategies and expansion of research in the area of sexual and gender minority cancer prevention. Both require systematic collection of sexual orientation and gender identity from all patients in research studies, including population health studies and clinical trials as well as in clinical settings, as recommended by the National Academy of Medicine.<sup>53</sup> Clearly, both discrimination on the basis of sexual orientation and gender identity as well

as collection of patient-reported information on this information must be addressed simultaneously if patients are to feel confident that they are safe.

Quality improvement strategies are indicated to first measure and then address gaps in quality of care with respect to timeliness of care, coordination of care, and patient experience. Closing such gaps in communities that have faced barriers to receipt of care or discrimination when seeking cancer prevention services would be a major stride forward in cancer prevention.

Finally, the time is ripe for research on effective and interdisciplinary prevention strategies that harness expertise from preventative medicine, behavioral medicine, implementation science, e-health, telemedicine, and other diverse fields of health promotion.

## SCREENING IN THE GERIATRIC POPULATION: TIMING IS EVERYTHING

### Epidemiology

The population of adults age 65 and older is rising and the risk of cancers such as breast, colorectal, lung, and prostate cancer increases with age.<sup>60</sup> The most common cancers diagnosed in men are prostate, lung, and then colorectal cancers, and in women, they are breast, lung, and then colorectal cancers, with the most lethal cancers being lung, then prostate or breast (depending on sex), and then colorectal cancers.<sup>61</sup> Screening tests are available to help identify each of these cancers early, with the goal of reducing cancer morbidity and mortality. However, few trials of cancer screening tests included older adults, especially those with comorbidity. Therefore, the effect of screening on reducing cancer mortality in older adults is often uncertain. Meanwhile, there are risks to screening, such as anxiety, complications from unnecessary diagnostic tests, and overdiagnosis (detection of tumors that otherwise would not have caused morbidity and/or mortality during an individual's remaining life span) leading to overtreatment.<sup>62,63</sup> Overtreatment is concerning because burdens of cancer treatment increase with age. Due to the uncertain benefits and the potential for harm, guidelines and experts increasingly recommend that screening decisions for older adults consider the lag time to benefit from the test, patient life expectancy, risk of disease, and their values and preferences.<sup>64–66</sup>

### Cancer Prevention Rationale

The lag time to benefit from a cancer screening test is the time between screening (when complications/harms are most likely) to the time when improved health outcomes (e.g., extended survival) are seen.<sup>65</sup> Based on a meta-analysis of the randomized controlled trials of mammography screening, the lag time to benefit from mammography is estimated to be 10.7 years (i.e., it takes 10.7 years before one breast cancer death is prevented among 1,000 women screened). Similarly the lag time to benefit from colorectal cancer screening is estimated to be 10.3 years.<sup>67</sup> From randomized controlled trials of prostate cancer screening with the prostate-specific antigen blood test, the lag time to benefit is estimated to be 10 years,<sup>68–72</sup> and that of lung cancer screening with low-dose CT is estimated to be 6 years.<sup>73,74</sup> If an older adult is unlikely to live longer than the lag time to benefit from a screening test, then that screening test may only cause harm.

Several tools are now available to help clinicians estimate patient life expectancy and to help them decide if a patient is likely to live long enough to have a chance of benefiting from screening (i.e., is the patient's estimated life expectancy longer than the estimated lag time to benefit from the screening test?). The Lee and Schonberg prognostic indices (available at [www.ePrognosis.org](http://www.ePrognosis.org)) consider a patient's age, sex, body mass index, function, mobility, history of comorbid disease (e.g., cancer, diabetes, emphysema, and/or heart failure), smoking history, hospitalizations, and/or perceived health and estimate mortality risk over 10–14 years.<sup>75–77</sup> Adults with greater than 50% risk of mortality within 10 years based on their score on these indices are considered to have an estimated life expectancy of less than 10 years and thus may be unlikely to benefit from most cancer screening tests. Walter and using data from 1997 U.S. life tables (and updated using 2008 data) calculated the upper, middle, and lower quartiles of life expectancy for U.S. adults age 70 or older stratified by sex and age.<sup>66,78</sup> They recommended that clinicians estimate whether a patient is in the top, middle, or lower quartile of health for his/her age group and then refer to the stratified life tables to estimate patient life expectancy. Cho et al expanded on this approach by further stratifying life expectancy estimates by patient race and comorbidity in addition to age and sex.<sup>79,80</sup> For example, based on Cho's calculations, a 75-year-old white male with congestive heart failure has a life expectancy of 5.8 years, whereas a 75-year-old white male with no comorbidities has a life expectancy of 12.8 years.<sup>79</sup> These tools were designed to help inform but not replace clinical judgment in estimating patient life expectancy.

In terms of individualizing cancer risk, increasingly there are online tools available to help estimate absolute risk of breast,<sup>81</sup> prostate,<sup>82,83</sup> colorectal,<sup>84</sup> and lung cancer<sup>85,86</sup> in the next 5–10 years based a patient's risk factors. However, most of these risk models were developed with few adults age 75 or older and may overestimate risk in older adults, especially those with comorbidities. For example, the widely used Gail Breast Cancer Risk Assessment Model overestimates breast cancer risk by 10% to 30% in women age 75 or older.<sup>87</sup> However, these risk models may still be useful in helping older adults get a better sense of their absolute risk of a specific cancer to inform cancer screening decisions.

## Decision Aids

Increasingly, patient decision aids are also available to help older adults weigh the benefits and risks of screening and elicit their values and preferences. For example, a pilot study of a mammography screening decision aid for women age 75 or older found that the decision aid (available online)<sup>88</sup> led to older women being more informed about the pros and cons of mammography screening, to more discussion with primary care providers, and to fewer intending to be screened.<sup>89</sup> Similarly, a decision aid on colorectal cancer screening for adults age 70 or older led to more appropriate screening behaviors in older adults.<sup>90</sup> These decision aids will soon be available on ePrognosis.<sup>88</sup> Although we are not aware of decision aids designed specifically for older adults for prostate or lung cancer, there are general decision aids available to help inform older adults about the benefits and risks of these screening tests.<sup>91–97</sup>

Although decision aids may help inform patients, many patients still want to discuss the decision of whether to continue screening with their doctor. However, doctors report feeling

ill prepared to engage older adults in shared decision-making around when to stop screening, especially because these discussions may lead to sometimes uncomfortable discussions about patient life expectancy. When discussing cancer screening tests with older adults, clinicians should indicate whether any data suggest that the screening test improves quality or quantity of life and the lag time to benefit from the screening test. Older adults are more receptive to hearing that a test is unlikely to help them live longer than hearing that they may not live long enough to benefit, a more negative message.<sup>98</sup> It may also be helpful to discuss the harms of screening and that the harms are often immediate. Older adults should then be asked how they view the potential benefits and harms of the screening test, so that their values and preferences are considered. To help clinicians with these discussions, Dr. Schonberg is currently developing scripts and strategies on discussing stopping cancer screening with older adults, which are available on request.<sup>88</sup>

## Summary

Ideally, older adults would be permitted to make an informed decision about whether to be screened for cancer based on a realistic understanding of the potential benefits and risks and their values and preferences.

## CONCLUSION

This article shares cancer prevention considerations across four population settings. Each lens represents a perspective through which we may become more adept and literate at interpreting and valuing difference and resilience in our patients and their communities. Effective cancer prevention and early detection approaches tailored to the population needs may ultimately yield the ephemeral promise of greater health.

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### PRACTICAL APPLICATIONS

- Social factors impact health in an intersectional manner such that people who are members of more than one marginalized group (e.g., race, ethnicity, gender identity, etc.) experience cumulative, rather than additive, effects of these factors.
- Effective cancer prevention strategies engage the community as “resident experts” of their own health.
- Rural residents experience lower age-adjusted cancer incidence, yet higher premature mortality; culturally tailored, community-engaged interventions are effective in addressing these disparities.
- Although there are regulations in place to prevent hospitals from discriminating on the basis of sexual orientation and gender identity, at the time of this writing, less than half of the states protect patients from physician discrimination on sexual orientation and only 14 from discrimination on the basis of gender identity. +• When discussing cancer screening tests with older adults, clinicians should help patients weigh the benefits and risks of screening in relation to their life expectancy and risk factors for cancer and elicit patients’ values and preferences.