

## Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection: Workshop Summary

### DETAILS

116 pages | 6 x 9 | PAPERBACK  
ISBN 978-0-309-39101-6 | DOI: 10.17226/21892

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# Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection: Workshop Summary

Erin Balogh, Margie Patlak, and Sharyl J. Nass, *Rapporteurs*

National Cancer Policy Forum

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*Washington, DC*  
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This project was supported by Contract No. HHSN261200900003C and Contract No. HHSN2632012000741 (Task Order No. HHSN26300052) between the National Academy of Sciences and the Centers for Disease Control and Prevention and the National Cancer Institute/National Institutes of Health, respectively, and by the American Association for Cancer Research, American Cancer Society, American Society for Radiation Oncology, American Society of Clinical Oncology, American Society of Hematology, Association of American Cancer Institutes, AstraZeneca, Bristol-Myers Squibb, Cancer Support Community, CEO Roundtable on Cancer, EMD Serono, Helsinn Healthcare SA, LIVESTRONG Foundation, National Comprehensive Cancer Network, Novartis Oncology, Oncology Nursing Society, and Pfizer Inc. Any opinions, findings, conclusions, or recommendations expressed in this publication do not necessarily reflect the views of any organization or agency that provided support for the project.

International Standard Book Number-13:

International Standard Book Number-10:

Digital Object Identifier: 10.17226/21892

Additional copies of this workshop summary are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; <http://www.nap.edu>.

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Printed in the United States of America

Suggested citation: National Academies of Sciences, Engineering, and Medicine. 2016. *Cancer control in low-resource areas: Cancer prevention and early detection: Workshop summary*. Washington, DC: The National Academies Press. doi: 10.17226/21892.

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This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

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Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this report was overseen by **VIVIAN W. PINN**. She was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the rapporteurs and the institution.



## ACKNOWLEDGMENTS

Support from the many annual sponsors of the National Cancer Policy Forum is crucial to the work of the Forum. Federal sponsors include the Centers for Disease Control and Prevention and the National Cancer Institute/National Institutes of Health. Non-federal sponsors include the American Association for Cancer Research, American Cancer Society, American Society for Radiation Oncology, American Society of Clinical Oncology, American Society of Hematology, Association of American Cancer Institutes, AstraZeneca, Bristol-Myers Squibb, Cancer Support Community, CEO Roundtable on Cancer, EMD Serono, Helsinn Healthcare SA, LIVESTRONG Foundation, National Comprehensive Cancer Network, Novartis Oncology, Oncology Nursing Society, and Pfizer Inc.

The Forum wishes to express its gratitude to the expert speakers whose presentations helped examine the issues of cancer prevention and early detection in low-resource areas. The Forum also wishes to thank the members of the planning committee for their work in developing an excellent workshop agenda.

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## ACRONYMS

ARGO	African Research Group for Oncology
CBE	Clinical Breast Exam
c-CARE	Cancer Community Awareness Access Research and Education
CDC	Centers for Disease Control and Prevention
DALY	disability-adjusted life year
ECHO	Extension for Community Healthcare Outcomes
FCTC	Framework Convention on Tobacco Control
FETP	Field Epidemiology Training Program
HDI	Human Development Index
HPV	human papillomavirus
IARC	International Agency for Research on Cancer
IOM	Institute of Medicine
NCD	noncommunicable disease
NCI	National Cancer Institute
NCPF	National Cancer Policy Forum
NIH	National Institutes of Health
PLANET	Plan, Link, Act, Network with Evidence-based Tools
USAID	U.S. Agency for International Development
VIA	Visual Inspection with Acetic Acid
WHO	World Health Organization





## INTRODUCTION<sup>1</sup>

Though cancer was once considered to be a problem primarily in wealthy nations, low- and middle-income countries now bear a majority share of the global cancer burden, and cancer often surpasses the burden of infectious diseases in these countries. Effective low-cost cancer control options are available for some malignancies, with the World Health Organization (WHO) estimating that these interventions could facilitate the prevention of approximately one-third of cancer deaths worldwide (WHO, 2015b).<sup>2</sup> But these interventions remain inaccessible for many people in the world, especially those residing in low-resource communities that are characterized by a lack of funds—on an individual or a societal basis—to cover health infrastructure and care costs, said Greta Massetti, associate director for science in the Division of Cancer Prevention and Control at the Centers for Disease Control and Prevention (CDC). As a result, worse cancer outcomes are more common in low- and middle-income countries compared to high-income countries. Disparities in cancer outcomes can also be found in high-income countries—communities within wealthier nations can experience worse cancer outcomes, especially if they have challenges accessing cancer prevention and cancer care services.

Few guidelines and strategies for cancer control consider the appropriateness and feasibility of interventions in low-resource settings, and may undermine the effectiveness of these efforts. For example, interventions that are designed for high-resource settings may not account for important considerations in low-resource settings, such as resource constraints, infrastructure requirements, or whether a community has the capacity to deliver downstream cancer care. Patients in resource-constrained communities continue to face delayed diagnoses of cancer, potentially resulting in the diagnosis of later stage cancers and worsened patient outcomes. In addition, social stigmas, geopolitical issues, and cultural norms may limit access to cancer care in certain communities. These factors—combined with issues such as cost and infrastructure—are important considerations when developing cancer control programs for low-resource areas.

Recognizing the challenges of providing cancer care in these settings, the National Cancer Policy Forum (NCPF) of the National Academies of Sciences, Engineering, and Medicine developed a workshop series examining cancer care in low-resource communities: the first workshop focused on cancer prevention and early detection and was held on October 26 and 27, 2015, at the Academies in Washington, DC. The second workshop—planned for November 14 and 15, 2016, in Washington, DC—will focus on cancer treatment, palliative care, and survivorship care.

The following is a summary of the first workshop, *Cancer Care in Low-Resource Areas: Cancer Prevention and Early Detection*, which featured invited presentations and panel discussions on topics including

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<sup>1</sup> The planning committee's role was limited to planning the workshop. The workshop summary has been prepared by the rapporteurs as a factual account of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They should not be construed as reflecting any group consensus.

<sup>2</sup> Cancer prevention efforts discussed at the workshop included tobacco control; obtaining a healthy diet, weight management, and physical activity; cancer vaccines, early detection, and screening for cancer; and experimental approaches (see section on Cancer Prevention Efforts in Low-Resource Areas).

- Global cancer trends and geographic disparities in cancer control and outcomes, the rising burden of cancer in low-resource areas, and the gap between what is known about cancer prevention and what is accessed by low-resource communities.
- An overview of sociocultural and political challenges to providing cancer prevention programs in low-resource areas.
- Strategies for supporting effective cancer prevention and risk reduction, detection and diagnosis in low-resource settings, and lessons learned from applying those policies and programs to communities throughout the world.
- Key gaps in the evidence base on ways to improve cancer outcomes for patients in low-resource populations, and how to address those gaps.

This report is a summary of the presentations and discussions at the workshop. A major goal of the workshop was to facilitate discussion and encourage workshop participants to share ideas about how to improve cancer prevention and early detection among low-resource settings throughout the world. By including a dual emphasis on domestic and international experiences, workshop participants had the opportunity to discuss what has worked well for specific low-resource settings, to describe some of the challenges that workshop participants have faced and how they have been overcome, and to consider whether similar interventions could be applicable in other settings. Although communities will have unique factors that will need to be considered when implementing cancer prevention efforts, the planning committee thought this framing could be helpful so that international experiences have the potential to inform domestic efforts to improve cancer prevention and early detection, and for domestic experiences to inform international efforts. In addition, workshop presentations and discussions provided an opportunity to discuss the evidence base that can be leveraged to support future policy development, as well as providing a better understanding of challenges and lessons learned when implementing cancer prevention and early detection programs. A broad range of views and ideas were presented and a summary of suggestions for potential actions from individual participants is provided in Box 1. The workshop Statement of Task can be found in Appendix A and the Workshop Agenda can be found in Appendix B. The speakers' presentations (as PDF and audio files) have been archived online.<sup>3</sup>

### **BOX 1**

#### **Suggestions Made by Individual Workshop Participants**

#### **Advocacy**

- Develop global cancer prevention goals (similar to the United Nations' Millennium Development Goals). (Pace)
- Persuade policy makers of the benefit of cancer prevention programs by informing them about the costs of inaction. (Bhadelia)
- Advocate for cancer prevention programs using national and local champions. (Dorotheo, Khleif, Oluwole)
- Ensure that cancer screening programs are linked with adequate cancer treatment. (Khleif, Oluwole, Scarinci, Stevens)

<sup>3</sup> See <http://iom.nationalacademies.org/Activities/Disease/NCPF/2015-OCT-26.aspx>.

- Advocate for broad-based prevention programs that have the potential to reduce the burden of multiple noncommunicable diseases (NCDs), including cancer. (Knaul)
- Collaborate with the advocacy community, cancer survivors, and health care providers to counter the fear and stigma associated with cancer in many cultures. (Massetti)

### **Program Planning, Implementation, and Funding**

- Develop comprehensive cancer plans in low-resource areas that address how to provide care across the cancer continuum and consider health systems issues (e.g., stewardship, financing, delivery, resource generation, and evidence building). (Knaul)
- Prioritize according to what programs will have the greatest impact. (Brawley)
- Create an organized population-based approach when developing cancer screening programs. (Saraiya)
- Invest in the “best buys” in cancer screening and prevention based on the population-attributable fractions and the return on investment. (Massetti, Saraiya, Stevens)
- Maximize resource utilization by conducting multiple screenings within the same program, rather than devoting a program to screening for a single type of cancer. (Bialous, Kingham)
- Involve primary care providers throughout the cancer care continuum (Bialous)
- Use community-based participatory research and build community-based coalitions to plan, develop and implement cancer prevention programs in low-resource areas (Baskin, Palafox)
- Seize opportunities within the Affordable Care Act to engage community health workers in the provision of cancer prevention. (Baskin)
- Increase efforts to reach rural communities for cancer prevention efforts. (Baskin)
- Request that a portion of the international funds low- and middle-income countries receive be designated for cancer and other NCDs. (Bialous)
- Leverage partnerships to improve funding for prevention of NCDs, including cancer. (Trimble)

### **Research and Evaluation**

- Identify the essential factors for effective cancer prevention interventions in low-resource settings. (Massetti)
- Stress the importance of collecting baseline and outcomes data for cancer control programs to evaluate their success, and to determine future funding and policies. (Castilla)
- Include sociocultural variables in data collection efforts to determine if programs are reaching underserved groups. (Tsu)
- Conduct disease surveillance in a more systematic fashion, and improve the collection of information on NCDs, including cancer, throughout the world. (Saraiya, Trimble)
- Conduct more research on cultural adaptations of theoretical models of behavior change. (Scarinci)

### **Infrastructure**

- Develop cancer screening tests that are feasible in low-resource settings.

(Kingham, Schmeler)

- Build infrastructure for cancer prevention programs by bundling interventions and screening services, and by sharing resources, including partnering with organizations focused on other disease areas to offer the full spectrum of preventive health. (Masseti)
- Build up health systems prior to implementing cancer prevention and screening programs, including necessary pathology services. (Castle, Pace)
- Rely more on nurses and other mid-level care providers to perform certain medical tasks traditionally provided by physicians. (Tsu)
- Maintain and improve investments in infrastructure and ensure opportunities for evaluation and quality metrics. (Masseti)

### **Education**

- Inform communities about the benefits of screening in the absence of symptoms, which can be a relatively new concept for some communities. (Saraiya)
- Address social and cultural issues, such as cancer myths or stigmas, before starting a national or regional screening program. (Khleif)
- Understand the subpopulations experiencing high cancer burdens in order to focus cancer prevention efforts on what would help them most. (Scarinci)
- Have a foundational knowledge of the history and culture of the communities in which cancer prevention programs will be implemented. (Palafox)
- Improve clinician training on providing care in low-resource communities. (Paskett)
- Train and increase reliance on local community health care workers in cancer prevention and screening programs. (Castle, Kingham, Schmeler)

### **Communication**

- Communication needs to be culturally sensitive and developed with input from the community. (Dorotheo, Knaul, Paskett)
- Tap new forms of communication, such as social media, in cancer prevention efforts. (Oluwole, Palafox)
- Ensure that cancer prevention messaging is accurate and reflects what is known and what is not known. (Brawley)
- Build trust in the communities by cultivating and maintaining relationships with its residents and having a plan that moves towards social justice and health equity. (Palafox)

### **Tobacco Control Efforts**

- Make evidence-based tobacco control policies a larger component of international cancer prevention efforts. (Bialous, Bollyky, Eriksen)
- Build a clearinghouse of information to help countries network to prevent tobacco industry interference. (Bialous)
- Develop political leadership and anticipate tobacco industry actions to improve the success of anti-tobacco efforts, including more proactive legal approaches. (Dorotheo)
- Integrate tobacco cessation services in cancer screening programs. (Bialous)

## **CANCER TRENDS**

A number of cancer trends were described and discussed at the workshop, including the rapidly increasing burden of cancers in low- and middle-income countries, disparities in cancer burden and access to care, and how realigning financial support for global health based on the burden of the disease could help improve care and health outcomes.

### **Rapidly Rising Cancer Burden**

Thomas Bollyky, senior fellow for global health, economics, and development at the Council on Foreign Relations, noted the current crisis in low- and middle-income countries in regard to the burden of noncommunicable diseases (NCDs), including cancer.<sup>4</sup> In 2013, about one-fifth of all NCD deaths in these countries were due to cancer (Council on Foreign Relations, 2014). Between 1990 and 2013, deaths from NCDs in low- and middle-income countries increased 53 percent, he reported, which is about twice the rate of population growth (Bollyky and Andridge, 2015). The rate of death and disability from NCDs is also increasing much faster than the rates of decline of communicable diseases. For example, between 1990 and 2010, the percentage change in disability-adjusted life years (DALYs) in low-income countries ranged from nearly 30 percent for cervical cancer to more than 120 percent for breast cancer; at the same time, DALYs for all communicable diseases declined 14 percent (Bollyky and Andridge, 2015). “These are faster rates than you would expect merely from population growth and the changing demographics of these countries,” Bollyky said. Lisa Stevens, the deputy director of the Center for Global Health at the National Cancer Institute (NCI), added that the reduction in infection-related cancers worldwide are being offset by increases in cancers linked to reproductive, dietary, and hormonal factors (Bray et al., 2012). She reported that the 12.7 million cases of cancer that occurred globally in 2008 were expected to rise to 22.2 million cases by 2030 (Bray et al., 2012).

The increase in NCDs in low-income countries is occurring 300 percent faster than the decline from communicable diseases, Bollyky said (Council on Foreign Relations, 2014). Otis Brawley, chief medical officer for the American Cancer Society, added that worldwide, cancer now kills more people than malaria, tuberculosis and HIV combined (ACS, 2015b). Vivien Tsu, associate director of the PATH Reproductive Health Global Program, noted that deaths from cervical or breast cancers in low- and middle-income countries are now greater than those due to pregnancy and birth, which traditionally have been leading causes of death among women in these nations (Pace and Katz, 2015).

### **Differences in Cancer Burdens Among Low- and High-Resource Countries**

Several speakers noted that the incidence of and health outcomes from cancer diagnoses in low- and middle-income countries differ from those in high-income countries, as well the age of populations affected. Stevens reported that when cancer trends are categorized according to a

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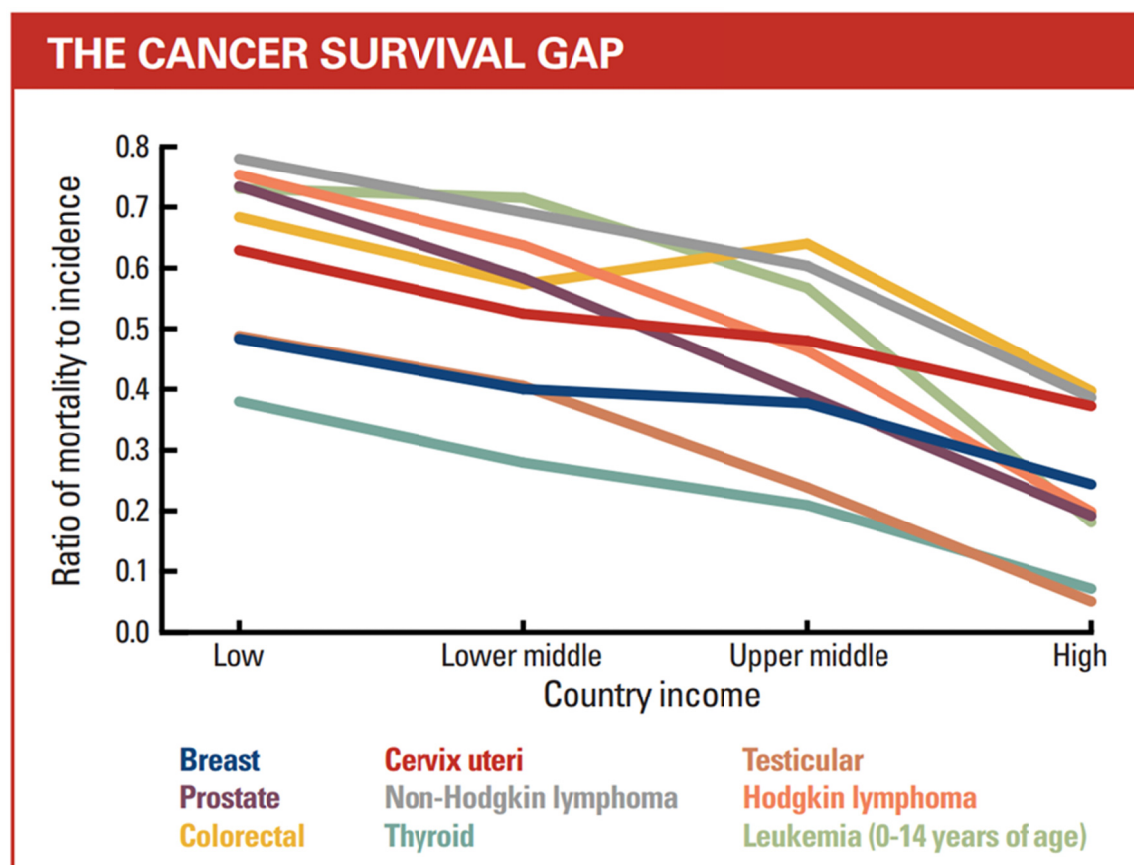
<sup>4</sup> Although the World Health Organization specifies cancer as a noncommunicable disease, there are some cancers—such as cervical, stomach, and liver cancers—in which infections are known to play a role in their development (WHO, 2015a).

country's Human Development Index (HDI),<sup>5</sup> the most prevalent cancers in the highest index countries are breast, lung, colorectal, and prostate cancers, comprising 50 percent of all cancer cases. Prevalent cancers in middle-HDI countries include esophagus, stomach, and liver cancers, all of which are infection-associated cancers. In countries with the lowest HDI, cervical cancer is the most prevalent cancer (Bray et al., 2012).

Felicia Knaul, director of the Miami Institute for the Americas at the University of Miami, stressed that cancer is different in low- and middle-income countries, with the opportunity to survive largely defined by income. For example, she said that nearly 90 percent of childhood leukemia patients in Canada survive, whereas only 10 percent do in the poorest countries (Knaul et al., 2011). "Although cancer is a disease of both rich and poor, it is the poor who increasingly suffer," she emphasized, calling this inequity "the cancer divide." Massetti added, "The current reality both globally and within the United States is that many people don't have equal opportunity to [access] the best quality cancer care, and one of the main determinants of disparities in cancer is the country per-capita income." She said that variation in cancer survival is linked to national wealth, including gross domestic product, total national expenditure on health, and the level of investment in health technology, such as screening, diagnostic, and treatment technologies (see Figure 1). The cancer incidence-to-mortality ratio becomes smaller as countries increase in wealth, creating disparities related to country income (IARC, 2012).

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<sup>5</sup> The HDI is a summary measure of average achievement in key dimensions of human development: living a long and healthy life, being knowledgeable, and having a decent standard of living (<http://hdr.undp.org/en/content/human-development-index-hdi>; accessed March 7, 2016).



**FIGURE 1** The cancer survival gap for various cancers. People with cancer who live in higher-income countries are often less likely to die from their cancer, compared to people who live in lower-income countries.

SOURCE: Massetti presentation, October 26, 2015. From Enserink, 2011. Reprinted with permission from the American Association for the Advancement of Science.

Massetti added that 80 percent of the cancers in low-income countries present at a stage when cures are impossible and palliative care is the only available treatment (see Table 1) (International Prevention Research Institute, 2013). But “income doesn’t tell the whole story,” Stevens said, because some high-income countries, such as Spain, France, the United States, and Australia, have shown a decrease in breast cancer death rates over time, despite increases in breast cancer incidence. However, other high-income countries, such as Japan, Korea, and Singapore, have not had similar reductions in breast cancer mortality rates (IARC, 2012). Understanding the reasons for these differences in mortality rates could help inform subsequent cancer prevention and early detection efforts.

**TABLE 1** Cancer Case Fatality Rates by World Bank Income Group

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SOURCE: Massetti presentation, October 26, 2015, and International Prevention Research Institute, 2013.

Although most cancer deaths occur in older adults in wealthy nations, in low- to middle-income countries, the mortality rates for cancers are rising in younger populations. Bollyky said that in many low- and middle-income countries, including those in sub-Saharan Africa and South Asia, most of the death and disability from NCDs, including cancer, occurs in the working age population (those under age 60) (Council on Foreign Relations, 2014). Knaul added that approximately two-thirds of breast cancer diagnoses in low-income countries occur in women less than 55 years of age; for example, in Latin America, 62 percent of all breast cancers occur in women younger than 55 years, but in high-income countries, only one-third of breast cancer diagnoses are made in this age group. According to Knaul, the majority of this disparity is due to younger population distributions; however, part of the disparities seen in cancer burden among younger populations in low-income countries and in Latin America cannot be accounted for and need to be better understood.

Stomach cancer is the third leading cause of cancer mortality globally, despite it being relatively rare in Western nations, said Douglas Morgan, director for Latin America Sites at the Vanderbilt Ingram Cancer Center (WHO, 2015b). Stomach cancer is especially common in Latin America, Eastern Asia, and Eastern Europe. Morgan said the burden of stomach cancer is particularly high in Honduras; in some years, stomach cancer is the number one cause of adult male mortality, and one quarter of these patients are under age 55 (Dominguez et al., 2013). He added that in the United States, the incidence of stomach cancer in minority populations is nearly twice as high as in white populations (NCI, 2016a).

Tsu said that the number of breast cancer deaths in 1990 was greater in high-income nations compared to low- and middle-income countries. However, breast cancer deaths are expected to only slightly increase in high-income countries by 2030, while in low- and middle-income countries, they are expected to substantially increase to nearly double the expected deaths in wealthier countries (IARC, 2012; Pisani et al., 1999). In addition, the number of deaths from cervical cancer in low- and middle-income countries is expected to be seven times greater than for high-income nations by 2030. Cervical cancer is currently the leading cause of cancer death among women in sub-Saharan African countries, Bollyky said. Cervical cancer, childhood leukemia, and other largely preventable or treatable cancers are more likely to be fatal in low- to

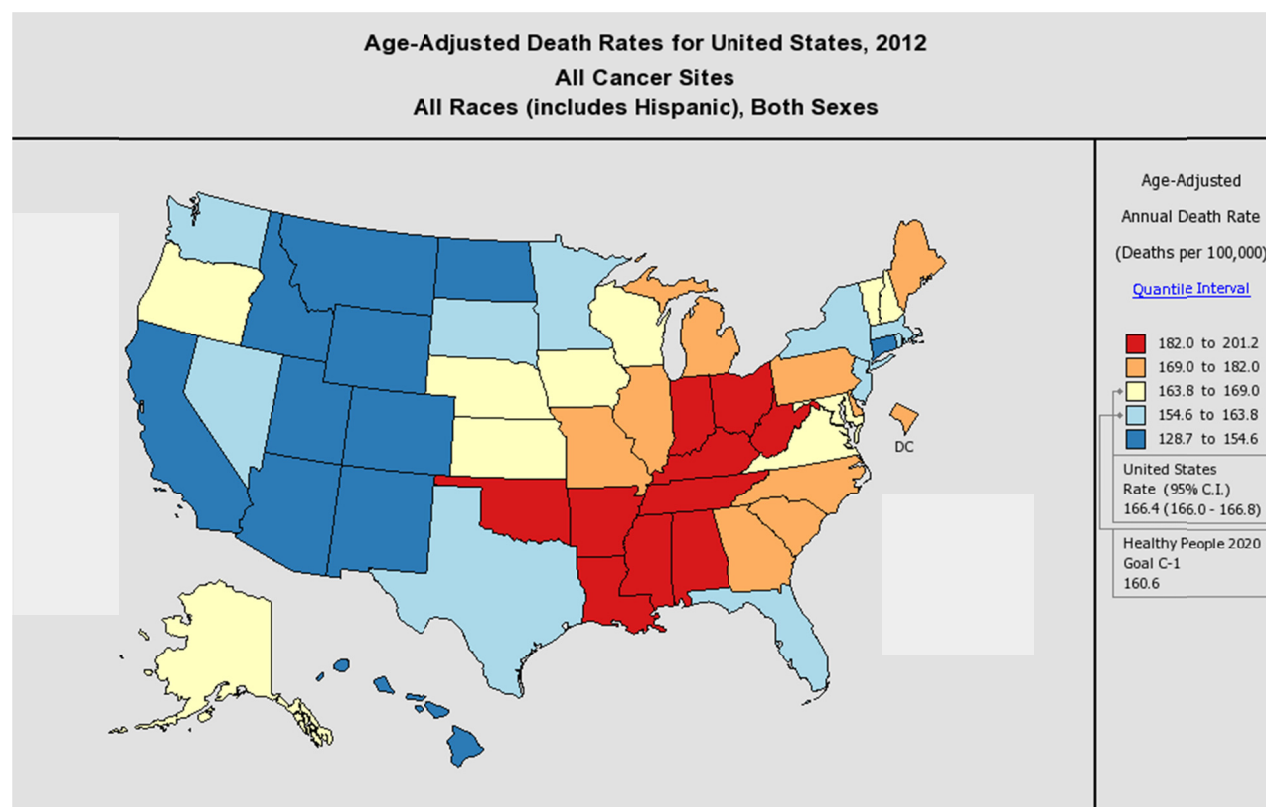


middle-income countries than they are in wealthier nations (ACS, 2015b; International Prevention Research Institute, 2013).

Stevens also pointed out that countries with the greatest incidence of breast cancer are often not the ones with the greatest breast cancer mortality, especially in Africa where breast cancer incidence tends to be low, but breast cancer mortality is high (IARC, 2012). This could be due to low-income countries not having the financial resources to link breast cancer treatment to incidence, or higher income countries conducting more breast cancer screening that detects the cancer at an earlier, more treatable stage. Stevens added that in the United States, 90 percent of breast cancers are diagnosed at an early stage, whereas 76 percent of breast cancers in India are diagnosed when they are locally advanced or metastatic (Moss, 2008; NCI, 2007).

### **Differences in Cancer Burdens in the United States**

Cancer burdens also vary by region in the United States, said Monica Baskin, associate professor in the division of preventive medicine at the University of Alabama at Birmingham. She presented U.S. cancer death rates by state, which indicate that portions of the midwest and south have higher cancer mortality rates than other regions of the country (see Figure 2). “This Deep South region has an unequal burden of cancer,” she stressed. Samir Khleif, director of the Georgia Regents University Cancer Center, also noted that even within a single state—Georgia—there can be major disparities in cancer incidence and mortality. “We have a tale of two Georgias. We have Atlanta and we have outside of Atlanta,” he said. The counties that make up the greater Atlanta region have the best cancer outcomes in the state and are also more urbanized and economically advantaged compared to the other portions of the state, he said. Other areas in Georgia have incidence-to-mortality ratios that are greater than the national average for lung, colorectal, breast, cervical, prostate, and oral cancers. The cancer incidence-to-mortality ratio is also much higher for African Americans than for whites in Georgia for all cancer sites (Wagner et al., 2012).



**FIGURE 2** Age-adjusted annual death rates from cancer in the United States, 2012.

SOURCES: Baskin presentation, October 26, 2015; NCI and CDC, 2015.

Khleif said that African American women in Georgia have nearly the same incidence of breast cancer as white women, but they are 49 percent more likely to die from it, mainly due to being diagnosed at a later stage (Markossian and Hines, 2012). Similarly, African Americans in Georgia have a 40 percent increased risk of being diagnosed with late-stage colorectal cancers compared with whites, as well as an increased risk of death from colorectal cancers (Hines and Markossian, 2012). Khleif added that African American men in Georgia are also nearly twice as likely to be diagnosed with prostate cancer than white men, and are 2.5 times more likely to die of prostate cancer than white men (Davis et al., 2012; Steenland et al., 2011).

In addition, Isabel Scarinci, associate director for Globalization and Cancer at the University of Alabama at Birmingham Comprehensive Cancer Center, noted that subpopulations in the Mississippi Delta region experience worse cancer outcomes. She reported that the national cervical cancer mortality rate is 4.1 per 100,000 women, but among African American women in the Mississippi Delta region, it is 8.6 per 100,000 women. However, Scarinci noted that the cervical cancer mortality rate for all women in the Mississippi Delta is 3.4 per 100,000, which conceals the extent of the burden in cervical cancer mortality among women in the Mississippi Delta. She added that “the burden of cervical cancer in this country is now limited to what we call pockets, that is, Pacific Islanders, the Mississippi Delta, the [Mexican] border, Appalachia, and [Native American populations].”

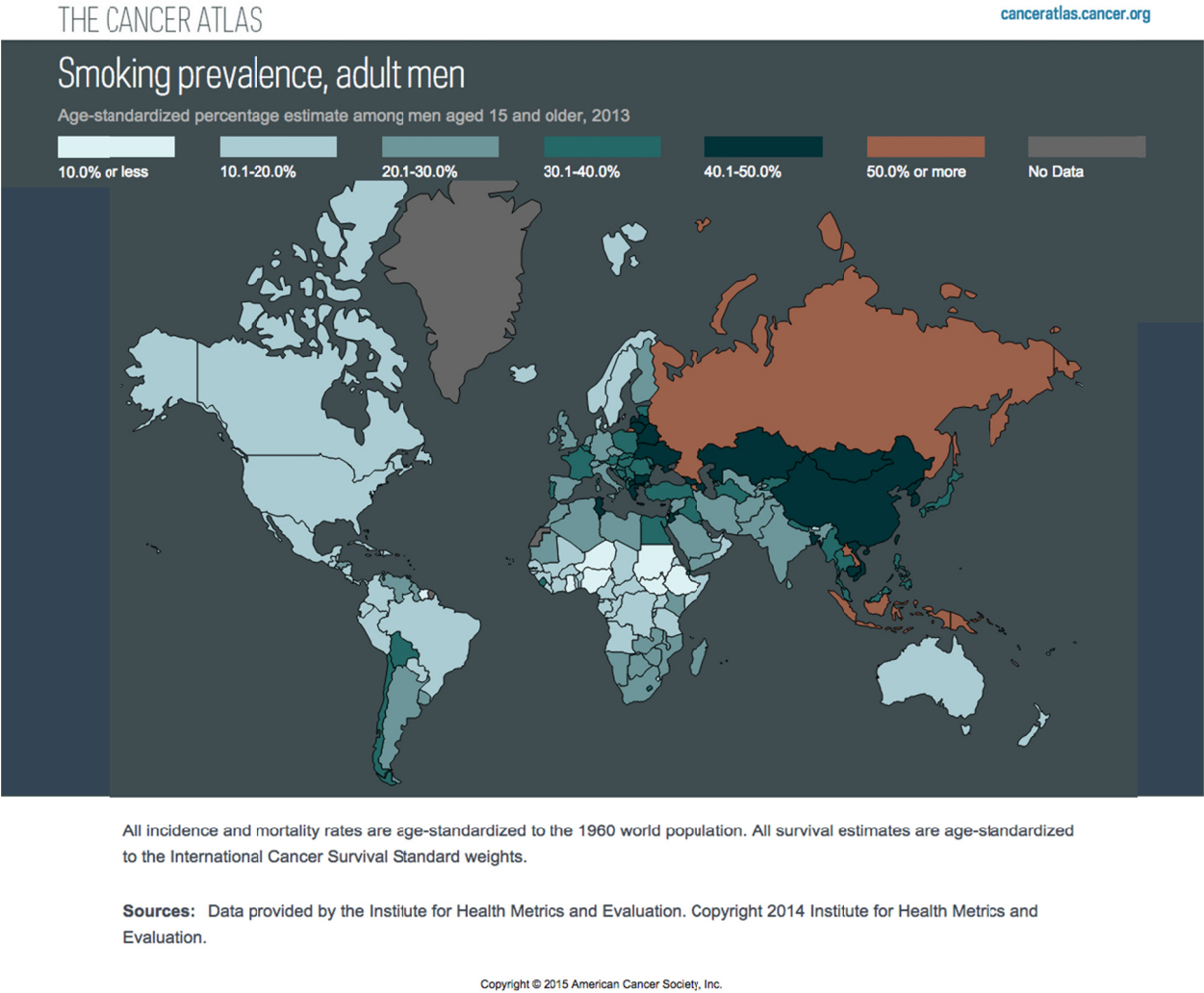
Electra Paskett, director of the division of cancer prevention and control at Ohio State University, reported that in the Appalachian region of Ohio, only about one-quarter of women

aged 50 to 74 have received a mammogram in the past year. As a result, breast cancer is more likely to be diagnosed at a later stage compared with urban women, she said (Katz et al., 2015).

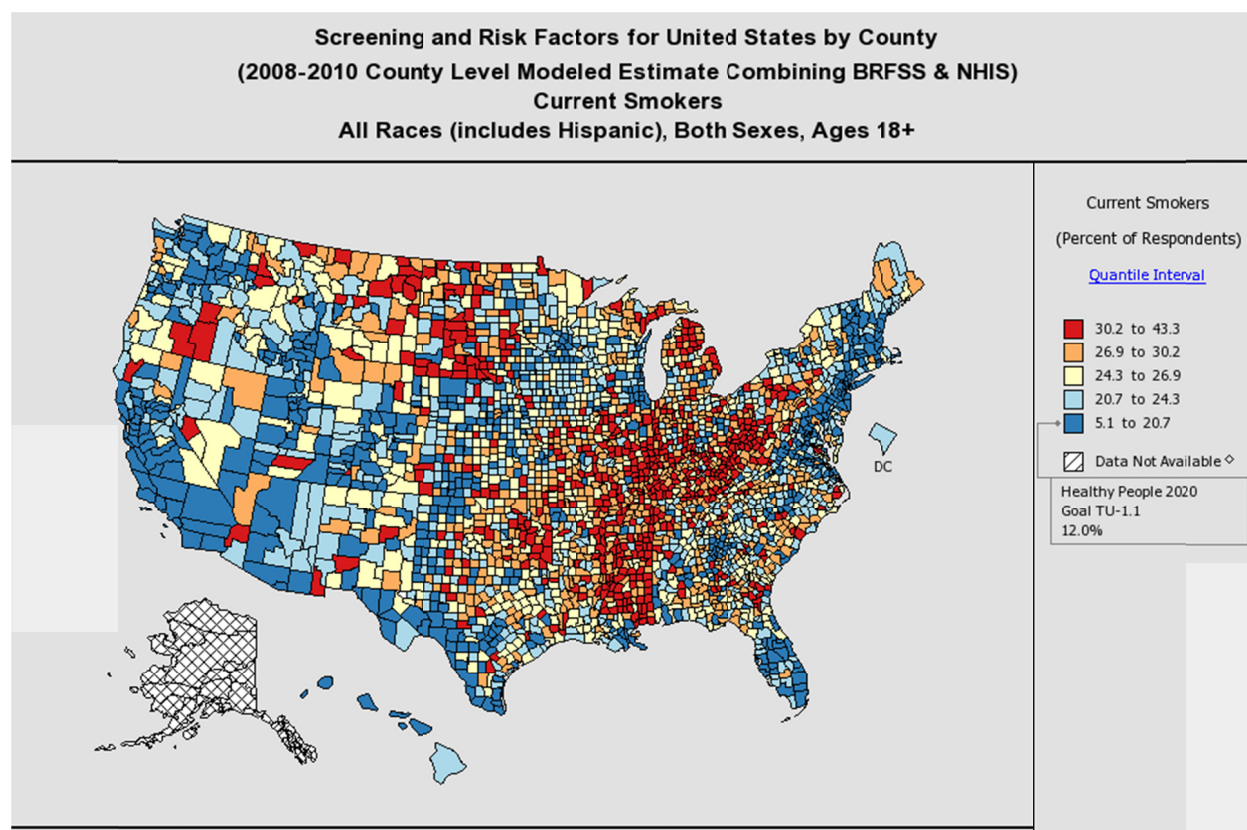
### **Causes of Cancer Disparities**

A number of factors contribute to the disparities in cancer burden and the types of cancers experienced in low-resource areas, both domestically and abroad said Paskett (ACS, 2015a; WHO, 2010). Causes of cancer disparities can include insufficient health insurance or funds to cover health care costs, both on an individual or country-level basis, as well as a lack of education and health literacy, inaccurate cultural beliefs about health, language differences, and other social and cultural factors, which are discussed in more detail in the section on “Sociocultural Challenges in Low-Resource Areas.” Cancer risk factors—such as tobacco and alcohol use, unhealthy diet and a lack of physical activity, as well as some infections—are another reason for disparities in cancer outcomes (WHO, 2015b).

Some risk factors linked to cancer, such as tobacco use or residing in an urban area with greater pollution, have markedly increased in low- to middle-income countries. Urbanization in Africa and Asia is especially increasing rapidly, according to Bollyky, with many people residing in cities that have a limited health infrastructure and greater prevalence of ambient pollution and other modifiable cancer risks (United Nations, 2015). Worldwide tobacco use has nearly doubled between 1970 and 2000; while developed countries are experiencing declines in tobacco consumption, aggregate consumption has increased 70 percent among developing countries over these 30 years (Food and Agriculture Organization of the United Nations, 2003). According to WHO, tobacco use is the most important risk factor for cancer; tobacco causes around 20 percent of global cancer deaths and around 70 percent of global lung cancer deaths (WHO, 2009, 2015b). Differences in smoking by region that are seen both globally and in the United States help to explain differences in the prevalence of lung and other smoking-related cancers, Massetti said (see Figures 3A and 3B). For example, Khleif reported that smoking is especially prevalent in Jordan, with approximately 70 percent of males and 20 percent of females 18 years and older having smoked in the past 30 days. He added that the smoking rate is 11.5 percent among 13- to 15-year-olds. Nearly 80 percent of the population is exposed to secondhand smoke. Michael Eriksen, dean of the School of Public Health at Georgia State University, said that the decrease in mortality in non-smoking-related cancers that has been achieved in Poland in men aged 35 to 69 years has been superseded by a dramatic increase in smoking-related cancers during the same time period. “To have these tobacco-caused cancers exceed all other cancers on our watch is really a collective embarrassment,” he said.



**FIGURE 3-A** Smoking prevalence among adult men aged 15 and older, 2013.  
SOURCES: Massetti presentation, October 26, 2015; ACS, 2014. Reprinted by the permission of the American Cancer Society, Inc. All rights reserved.



**FIGURE 3-B** Estimate of current adult smokers in the United States by quartile ranking.

NOTE: BRFSS = Behavioral Risk Factor Surveillance System; NHIS = National Health Interview Survey.

SOURCES: Massetti presentation, October 26, 2015; NCI and CDC, 2015.

Being overweight or obese is also a risk factor for certain cancers. Baskin said that obesity is estimated to contribute to 20 percent of all cancer deaths (more information on obesity and cancer can be found in the workshop summary *The Role of Obesity in Cancer Survival and Recurrence* [IOM, 2012]). Wendy Demark-Wahnefried, associate director of Cancer Prevention and Control at the University of Alabama in Birmingham, reported that worldwide in 2008, 35 percent of adults were overweight, and 11 percent were obese; these figures have doubled since 1980. Although starvation is one of the most pressing global health issues, she noted that 65 percent of the world's population now resides in countries where obesity and being overweight kills more people than being underweight. However, Bollyky said the burden of adult obesity in low-income countries is still only 5 percent (Institute for Health Metrics and Evaluation, 2014b).

Baskin added that several factors are contributing to the unequal cancer burden in the U.S. Deep South, including higher rates of obesity and tobacco use; limited physical activity; diets replete with fried foods, big portions, and limited fresh produce; lower household incomes; and limited access to health care facilities, especially among rural communities. All of these factors are known to increase the risk of cancer (CDC, 2015a,b,c; Shikany et al., 2015). Paskett added that inadequate breast cancer screening occurs in Appalachian communities in Ohio because of a number of barriers to care, including a lack of health insurance, poor health literacy, mistrust of the medical system, concerns about costs and the need to travel, and gender roles

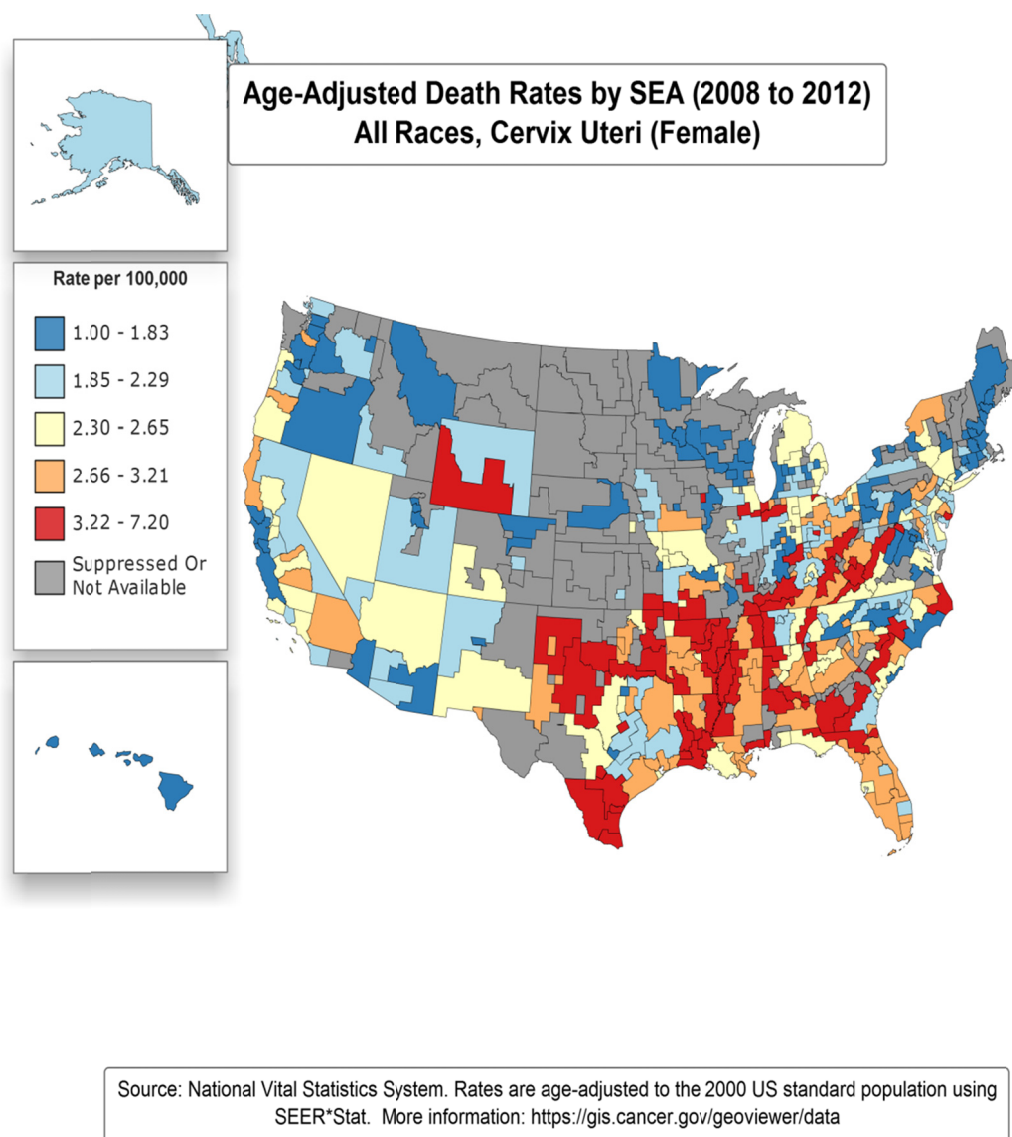
(e.g., women may be expected to prioritize taking care of children and domestic responsibilities and neglect taking care of themselves).

Disparities in cancer outcomes are also seen with cervical cancer. Vaccines for human papillomavirus (HPV) that are available today can prevent more than 70 percent of all cervical cancers. Precancerous conditions and early-stage cervical cancers that do develop can be detected with inexpensive and easily administered Pap smear tests. Cervical cancers can often be caught early and treated effectively because it takes about 10 years to progress from preinvasive disease to cancer, providing a long time window for interventions, said Kathleen Schmeler, associate professor of gynecologic oncology at the MD Anderson Cancer Center. However, about 13,000 new cases of cervical cancer and 4,000 deaths occur in the United States per year. In low- and middle-income countries, cervical cancer is the first or second leading cause of cancer death among women, causing more than 400,000 deaths per year (IARC, 2012; Siegel et al., 2015; Torre et al., 2015). Eighty-five percent of cervical cancer deaths occur in low- and middle-income countries; the prevalence of cervical cancer varies globally from less than 9 cases per 100,000 women in North America, Australia, and much of Europe to between 33 and 87 cases per 100,000 women in many countries in Africa and Latin America.

Although the United States has one of the lowest rates of cervical cancer globally, Schmeler pointed out that cervical cancer is highly prevalent in certain pockets of the United States. Massetti added that cervical cancer death rates vary substantially even by U.S. county: “These geographic disparities and outcomes are really often a reflection of disparities in access to health services,” she said (see Figure 4). She noted that urban areas tend to have better access to health care and better quality care than most rural areas, but even within most urban environments there are pockets that have shortages of health professionals, hospitals, and clinics, usually in high-poverty areas. Impoverished populations may also lack education, and there may be cultural and language barriers that impede access to cervical cancer screening and treatment services. In addition, those services may be inaccessible due to a lack of insurance coverage and inadequate income to cover health care costs, Massetti said.

One U.S. area that lacks access to cervical cancer screening is along the Rio Grande Valley between Texas and Mexico, where 90 percent of the population is Hispanic and 40 percent live below the poverty line. In a four-county region there, less than 5 percent of women are receiving cervical cancer screening, and if a precancerous or cancerous condition is detected, most of these women—who are uninsured or underinsured—have limited access to treatment for preinvasive disease. Consequently, cervical cancer rates are 31 percent higher in this region than the rest of Texas. Even Houston has large disparities; Schmeler said that when she was invited to give a talk to a parent–teacher organization at a local school less than 10 miles from MD Anderson Cancer Center, many women said they had not been screened for cervical cancer, and almost none had vaccinated their children against HPV. “Down the street from MD Anderson we have similar problems to what we see in Latin America and Africa,” she said.





**FIGURE 4** Cervical cancer death rates by state economic areas (SEA), 2008-2012.  
SOURCES: Massetti presentation, October 26, 2015; National Vital Statistics System, 2012.

Knaul also noted geographic disparities in Mexico with regard to breast cancer diagnosis. In some poor municipalities in the southern portion of the country, as many as half of women with breast cancer are diagnosed with Stage IV (metastatic) disease, a rate that is five times that of wealthier regions. Overall, only 5 to 10 percent of women are diagnosed with Stage I or precancerous disease, and Knaul said that breast cancer is the second leading cause of death in Mexican women aged 30 to 54 (Knaul et al., 2014). Knaul added that although the Mexican government now covers the costs associated with breast cancer treatment, there are still barriers to breast cancer treatment. These barriers include a lack of access to breast cancer screening and diagnosis, as well as costs associated with cancer treatment that are not covered (e.g., transportation for radiation therapy and chemotherapy, caregiving responsibilities, and lost income associated with treatment). “Even if I have all of the treatment in the world and it is all covered, if I am not effectively working on the earlier detection and effective diagnosis aspects,

then what I am doing as a policy maker is overinvesting in treatment to some extent,” Knaul said.

She noted that only one in five women in Mexico between the ages of 40 and 69 reported having received a clinical breast exam or mammogram in the past 12 months in 2012, with women in the highest income bracket being three times more likely to have received breast cancer screening than those in the lowest income bracket (Instituto Nacional de Salud Pública, 2012). Half of women diagnosed with breast cancer reported problems with receiving medical attention in the diagnostic process at the primary care level, including not receiving a clinical breast exam or information in their routine annual exam about breast cancer, and physicians not valuing the importance of the signs and symptoms that the women reported (Knaul et al., 2008).

Inadequate breast cancer screening and early diagnosis is also problematic in Jordan, Khleif reported. Most breast cancers (70 percent) were diagnosed as Stage III or IV in this country between 2000 and 2003. He attributed that late diagnosis to a number of cultural factors, including a lack of education about breast cancer and a number of misconceptions, including that cancer is contagious, incurable, or caused by witchcraft.

### Potential Impact of Prevention

Daniel Masys, affiliate professor of biomedical and health informatics at the University of Washington School of Medicine, noted that to combat the worldwide disparities in cancer depends not so much on fundamental breakthroughs in science, but more on “shrinking the gap between what we know and what we do.” Scarinci agreed, adding that the 2002 President’s Cancer Panel report concluded that this discovery/delivery disconnect is a key determinant of the unequal burden of cancer (Freeman et al., 2002). In addition to closing the discovery/delivery gap, Massetti noted that low-resource settings may need to tailor cancer prevention and early detection programs—or consider alternative approaches—due to resource constraints, health system factors, the fit within a community’s cultural context, or other considerations.

Massetti stressed that 30 percent of cancer deaths globally are due to leading preventable risk factors such as obesity, lack of physical activity, tobacco and alcohol use, exposure to radiation and other carcinogens, and some infections (WHO, 2015b). As mentioned previously, tobacco use is the most important risk factor for cancer worldwide, and is responsible for approximately 20 percent of global cancer deaths and 70 percent of global lung cancer deaths (WHO, 2009, 2015b).

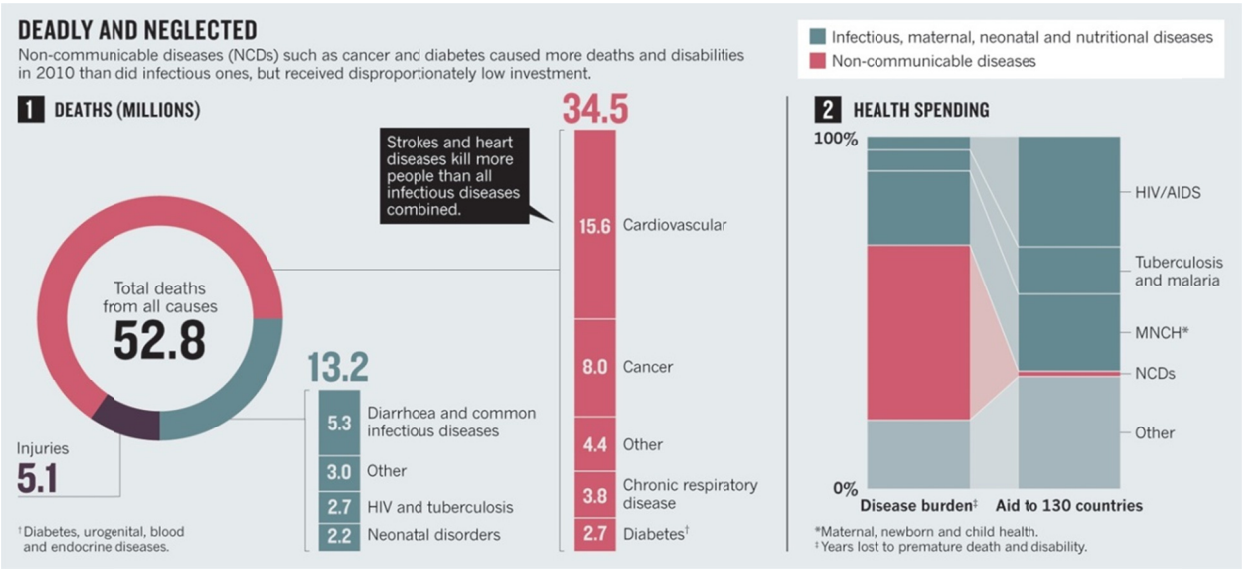
Morgan said that about one-quarter of cancers in low- and middle-income nations are due to infections such as *Helicobacter pylori*, which can cause stomach cancer; HPV, which can cause cervical, anal, throat, and penile cancer; and the hepatitis B and C viruses, which can cause liver cancer. Most of these cancers could be prevented with vaccines and antivirals. In high-income countries, in contrast, only about 7 percent of cancers are due to infections (de Martel et al., 2012; Plummer et al., 2015).

Bollyky estimated the number of lives that could be saved globally if there was a greater effort to apply known, effective prevention efforts in low- and middle-income countries. Based on the expected growth of populations and the rates of cervical cancer in the 49 countries that the United States targets for its global health funding, if cervical cancer rates were brought down to that of high-income nations by 2025, approximately 120,000 deaths from cervical cancer could be avoided from 2014-2025 (Council on Foreign Relations, 2014). Bollyky said a similar analysis indicates that 170,000 deaths from leukemia could be avoided over 10 years. “That’s a pretty good return on investment in comparison to some other global health programs,” Bollyky said.



He noted that although health spending in low- and middle-income countries has tripled over the past 20 years, spending remains insufficient. “All the governments of sub-Saharan Africa [combined] spend about as much on health as the government in Poland,” Bollyky said. He added that “all the governments of low- and middle-income countries spend less than the governments of the United Kingdom, France, Germany, and Canada combined,” which is significantly less spending per capita on health when one considers that the population of all the governments on the high-income side amount to 300 million people versus the 5.7 billion people residing in the low- and middle-income countries (Institute for Health Metrics and Evaluation, 2014a). Stevens added that average annual per-capita spending on health in low-income families is \$22, versus more than the \$4,000 spent in high-income nations (The World Bank, 2016).

Bollyky also said that U.S. global health funding has not addressed the changing burden of disease in low- and middle-income countries, especially the fact that cancer and other NCDs are major causes of deaths in these countries. Most of the global health budget is still allocated toward HIV, maternal and child health, and family planning. In 2013, the United States spent \$10.8 million on NCDs globally, which amounts to about one-fifth of a cent for every dollar spent on global health aid (Council on Foreign Relations, 2014). The very small fraction of funding for global NCDs—in comparison with their burden on health—was also emphasized by Fabio Almeida, assistant professor of human nutrition, foods, and exercise at Virginia Tech (see Figure 5).



**FIGURE 5** Death and disability due to noncommunicable disease outnumber those due to infectious disease, but receive a disproportionately low investment of health spending globally.  
SOURCES: Bollyky presentation, October 26, 2015; Gostin, 2014, reprinted by permission from Macmillan Publishers Ltd.

Bollyky described the potential economic impact of greater funding for NCDs. For the 49 countries on which the United States spends \$5 million or more in global health aid per year, NCDs comprise nearly 30 percent of the health burden of those aged 59 and younger. This burden is six times higher in these countries than the burden of HIV, and is nearly twice as high as the burden of malaria and tuberculosis combined. Given that the bulk of the cancer burden

occurs in people aged 35 to 55 in middle- and low-income countries, the economic losses tied to such cancers is substantial, Bollyky added. “These are working-age people, parents, heads of households. Given the scale at which this is happening, it reverberates out through health systems and economies,” he said. He added that experts estimate that NCDs will cause more than \$21 trillion of economic losses between now and 2030 (Bloom, 2011).

Massetti said a substantial portion of the economic costs due to cancer can be averted by investing in cancer prevention, early detection, and treatment. “Population-based cancer prevention is not just about health, but about savings,” she stressed. Cost-effective strategies to address common cancer risk factors such as tobacco use, alcohol abuse, unhealthy diet, and physical inactivity in low- and middle-income countries would cost \$2 billion per year (U.S. dollars)—a small amount compared to the costs incurred by the total disease burden, she said. For example, in developing countries, cervical cancer screening techniques that require little laboratory infrastructure, such as simple visual inspection of the cervix with acetic acid or DNA testing for HPV in cervical cell samples, cost less than \$500 per year of life saved. Massetti added that in general, cancer prevention is far more cost-effective than treatment.

## **SOCIOCULTURAL CHALLENGES IN LOW-RESOURCE AREAS**

When developing programs aimed at advancing cancer prevention and control in low-resource settings, speakers stressed the importance of understanding contextual issues within communities, and addressing sociocultural challenges that can influence program effectiveness. Tsu defined cultural factors as beliefs, customs, practices, and behaviors shared by a group. Social factors can include education, income and occupation, ethnicity, race, religion, political affiliation, and geography. “We know that health issues reflect a complex interaction between biological factors, the health system, and individual factors. Many of those individual factors are governed by social and cultural kinds of issues,” she said. She added that sociocultural factors are important determinants of health, but can also influence how communities perceive health interventions and can determine their effectiveness.

Tsu described the ecological model for health interventions, which state that health behavior is influenced by individual, interpersonal, community, institutional, and political factors. Health interventions tend to be most effective when they address these multiple levels of influence (Sallis et al., 2008). For example, her international cervical cancer prevention programs included teams that involved an anthropologist, epidemiologist, sociologist, and economist, as well as clinicians. In different settings, she added that other specialists may also be necessary: “Sometimes it is easier to change the technology than it is to change the culture. Culture is strongly seeded, and sometimes you have to recognize that there may be another way to go about this to do what you are trying to achieve.” Implementing a cancer prevention program may be challenging because it requires addressing strongly held cultural beliefs, Tsu said. For example, “in the HPV vaccine world, there were big concerns that the vaccine would encourage more risk-taking by young adolescents,” Tsu said. “Fortunately there have been lots of studies in the last seven or eight years to show that is not at all true. Sometimes it is even the reverse; the education around the vaccine may encourage more careful behavior.”

Several speakers mentioned a number of sociocultural challenges in low-resource communities, including

- Lack of education, cancer myths, and stigma;

- Religious beliefs and outlook;
- Language barriers and a lack of trust;
- Built environment challenges, including a lack of transportation and limited access to power, water, and other resources; and
- Challenges in obtaining a healthy diet.

In addition, specific challenges arise when providing women's health care, including sexual and fertility beliefs and mores, body image issues and modesty, and gender expectations.

### **Lack of Education, Cancer Myths, and Stigma**

Tsu noted that because cancer is considered to be fatal by many people in low-resource communities, this leads to a high degree of fear about cancer and a lack of understanding of the disease process. A lack of education can compound the fears that cancer stirs. "People who have limited access to information about biomedical processes find cancer quite mysterious, which always heightens the sense of fear and uncertainty," she said. There is often a fear that cancer is contagious, she noted, and a lack of awareness that some cancers can be prevented. Prevention interventions in general can be a hard sell, Tsu added, because many cultures are not future oriented and have a hard time grasping the long time lag for many prevention benefits. "You are telling people to do something now, like give their 12-year-olds an HPV vaccine for something that they have never seen occur before the age of 40 or 50 years. If their immediate need is food on the table, then it is difficult to say 'do these preventative measures that will pay off in 20, 30, or 40 years,'" Tsu said.

A survey conducted in Jordan found that many people believed cancer was contagious, and could be caused by envy, witchcraft, or cell phones. In addition, a sizable portion surveyed thought there was no cure for cancer (Ahmad et al., 2011). All these beliefs are major impediments for people seeking cancer care, Khleif stressed. "If you take these beliefs into account, why would Jordanians even think of having an early cancer detection attempt?" he said, noting that some people may not see the benefits of early cancer detection because they don't believe cancer can be cured, and they believe they will be shamed and shunned by their friends and relatives due to their cancer diagnosis. Khleif said the stigma of cancer was so prevalent that many would not use the word "cancer": "Anyone who talked or mentioned that word was looked upon as being against society," with a majority of cancer patients at the Jordanian cancer center he worked in not realizing they had cancer. Instead, they believed they had inflammation or some other disease that needed treatment. "The inability to mention the word 'cancer' is a major impediment to doing prevention and early detection. When you view cancer as a monster that you don't know anything about, it is very difficult to even start talking about what you can do for early detection and prevention," he said.

To counter the myths, taboos, and stigmas about cancer in Jordan, Khleif and others developed a cancer truth campaign. This campaign began by changing the name of Jordan's Hope Center, which was devoted to treating cancer patients, to King Hussein Cancer Center. "We put the word 'cancer' on every single wall of that building so everyone who comes through the doors will know that they have cancer," he said. The campaign also made a major effort to normalize the word cancer by having festivals, lectures, and other activities affiliated with the cancer center. "We broke the taboo so people at least could start talking about cancer," Khleif said. They also started a national cancer awareness program using trained educators for

underserved communities, including refugee camps, schools, villages, and other remote areas. The program partnered with several communities and organizations and provided access and navigation services for cancer prevention and early detection. Although there was initial public and media resistance to the campaign, within a year or two, several articles came out in the Jordanian press that were positive about the campaign and how it had changed people's attitudes on cancer by clearing up misconceptions about the disease and making them more open to talk about cancer in public.

Cancer myths can also be prevalent in certain populations in the United States, Khleif said. Among the common misconceptions are that cancer is contagious and caused by the devil, you have no control over your cancer risk, yet your beliefs and attitude can help beat cancer if you develop it, and that if a close relative has cancer, you will most likely develop the same cancer.

Loyce Pace, health policy director of the LIVESTRONG Foundation, added that LIVESTRONG conducted person-on-the-street interviews to gather beliefs about cancer about 10 years ago. "From Italy to India, you had the same myths—cancer is a death sentence; it is caused by witchcraft, or by being hit in the chest when you are a young girl. We need to know what beliefs we are dealing with when we are going into these settings—that is a fundamental piece to advancing screening, early detection, and prevention, as well as treatment and support," she said.

Scarinci noted that when she started working to prevent cervical cancer in low-resource communities in the southern United States, she saw that there were widespread misperceptions among Latinos and African Americans about the causes of cervical cancer. She added that even Scarinci's own mother, who is Brazilian, insisted that bruises could cause cancer. "If I did a clinical trial with a million people to prove to her that bruises do not cause cancer, she would ignore everything because I challenge a core belief.... We need to not only identify the factors that cause cancer, but to understand how people make meaning of those so we can intervene," she said.

## **Religious Beliefs and Outlook**

An individual's religious beliefs and outlook on life can influence opportunities to deliver cancer prevention. For example, Tsu reported that fatalism—or the general belief that all events are predetermined by fate—can be problematic to cancer prevention efforts. In health, fatalism results in negative or passive attitudes regarding preventive health practices and disease outcomes, such as not taking an active role in the care and protection of one's own health, Tsu said (Espinosa de Los Monteros and Gallo, 2011). Ethnicity, religion, and social status can influence the intensity and extent of fatalism, or "the sense that you have no power over your life; therefore, you must accept whatever happens to you," Tsu said. In breast and cervical cancer, fatalism can affect a woman's willingness to seek cancer screening or to accept treatment. Such fatalism can be especially difficult to counteract if cancer survivors are rare or not visible within a community, Tsu noted. Khleif added that religious beliefs that are embedded within many societies may deter people from seeking cancer screening or care, and addressing these beliefs can be critical to the success of cancer prevention programs.

## Language Barriers and Lack of Trust

When people residing in low-resource areas have a different language or ethnic background than that of their clinicians, there can be language and cultural barriers that impede the understanding of cancer prevention, and influence the effectiveness of cancer prevention efforts. But even if the same language is spoken, there can be a lack of trust, especially if there is a history of cultural trauma, which can be a major barrier to participation in cancer prevention efforts, said Neal Palafox, professor of family medicine and community health at the University of Hawaii's John A. Burns School of Medicine. He works with U.S.-affiliated island communities in the Pacific, including American Samoa, Guam, and the Marshall Islands. These communities have a history of colonization by major powers, such as France, Great Britain, Japan, Spain, and the United States. That history has had long-lasting effects on the indigenous people, whose ancestors inhabited and owned the islands collectively before colonization, he noted.

Despite being a numerical majority, indigenous people are often economically disadvantaged because of changes to their land rights and economy due to colonization, Palafox said. He added that the colonizers also introduced many new life-threatening diseases to the islanders, but the resources to treat these diseases tend to be unequal: "In many of the areas I work, the standards of health are never equal or accessible in equal amounts for the people who are the colonizers and the people who have been colonized," Palafox said.

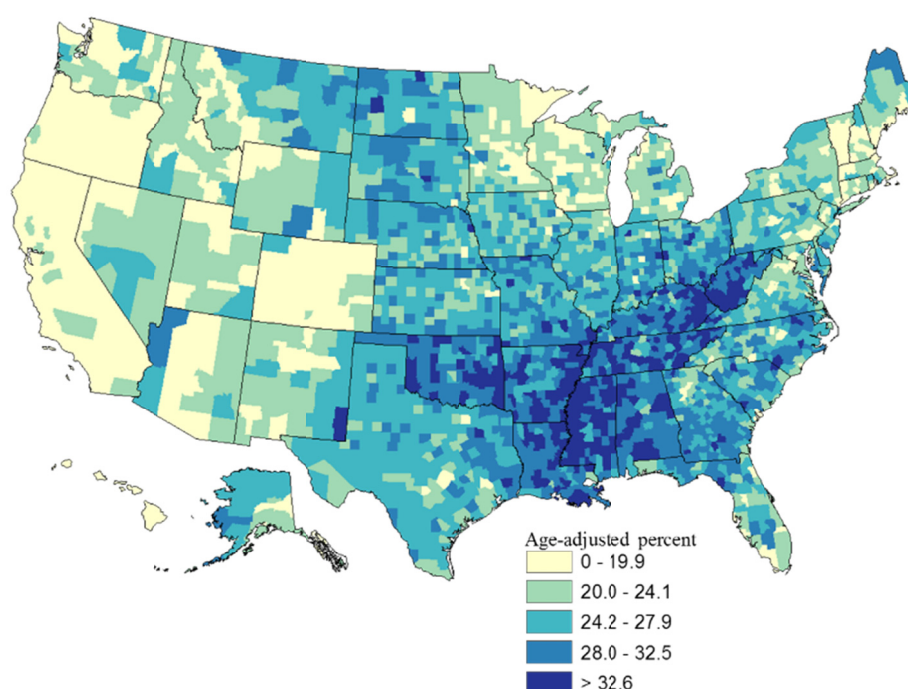
He also pointed out that indigenous people, even though they are often several generations removed from the trauma of colonization, still experience that trauma in their collective memory, akin to how African Americans have the collective memory of the trauma of slavery in their past. The Pacific Islands have also experienced a lot of nuclear testing, which Palafox said makes them to be more susceptible to cancer, and has, in some cases, forced indigenous inhabitants to move to new locations.

All these factors foster a lack of trust between indigenous people and non-indigenous medical personnel, Palafox said. "Cultural trauma transmits through generations and affects relationships. Trust has been violated ... and the collective identity has been strengthened and formed by things that perhaps may have been negative," Palafox said. "These kinds of things don't wash out over time." Consequently, health care workers in the area need to be sensitive to this cultural trauma and work hard at building trust in island indigenous communities, he said.

## The Built Environment and Geographic Challenges

Several aspects of geography and the built environment can make cancer prevention efforts challenging, both in international low-resource settings, as well as within the United States. For example, Palafox noted the extreme isolation of island communities can make the logistics of accessing preventive cancer care difficult. Similarly, Doyin Oluwole, chief executive officer of the Global Health Innovations and Action Foundation, noted that in Zambia it was difficult to access some parts of the country due to bad roads, which was a challenge in implementing a cervical cancer prevention program. Certain rural communities can experience isolation and transportation difficulties that can impede their access to care. Paskett said the social isolation in Appalachia can cause loneliness that fosters smoking, overeating, and drinking, which can increase the risk of certain cancers. "Place does get under the skin," she said.

Rural areas may also lack safe areas in which to walk or exercise, which can lower cancer risk, Baskin noted. “There are few parks and recreational facilities, or when they exist they may be a significant distance away from where individuals live and be difficult to access,” she said. She added that the built environment is not as conducive to physical activity in many rural areas because of limited connectivity. “When city centers are connected to houses, schools, and so forth you are more likely to walk to get places, but when you have sidewalks that go nowhere or no sidewalks, people are less likely to get out and be physically active,” she said. In addition, many rural areas have highways as the connectors, but the high speed and noise of the cars and trucks on these highways make them unsafe to use as walking or biking corridors. Baskin added that the prevalence of inactivity is increased in most rural geographic regions of the United States, compared to what is seen in urban areas (Reis et al., 2004) (see Figure 6). These rural challenges to receiving preventive cancer care are significant in the United States, given that between about one-fifth of the U.S. population resides in rural areas, Paskett stressed (U.S. Census Bureau, 2012).



**FIGURE 6** Age-adjusted county-level estimates of leisure-time physical inactivity among adults aged  $\geq 20$  years in 2011.

NOTE: The map does not take into account rates of occupational physical activity.

SOURCES: Baskin presentation, October 26, 2015; CDC, 2015b.

### Challenges in Obtaining a Healthy Diet

Unhealthy diets are prevalent in certain geographic areas or cultures, several speakers said. Baskin noted that populations in rural areas in the Deep South tend not to eat fresh fruits and vegetables, which can lower cancer risk, and instead consume large portions of fried foods and other foods that can increase cancer risk. The culture of these communities also tends to

emphasize large portion sizes at family meals, which can foster obesity, another risk factor for certain cancers. She added there also can be limited access to affordable foods, with only small grocery stores or convenience stores nearby. These stores tend to offer a limited selection of fresh fruits and vegetables and are more expensive. Two recent studies found U.S. southern cooking is replete with added fats, fried foods, eggs, organ and processed meats, and sugar-sweetened beverages. Such a diet boosts the risk of developing several chronic diseases, including cancer (Seguin et al., 2014; Shikany et al., 2015). “In terms of the culture related to eating healthy, there are a number of challenges that individuals who live in these rural communities might face,” Baskin said.

Low-resource communities living in large urban areas have their own challenges in accessing healthy food, as many reside in what are known as “food deserts.” These areas, though populated with convenience stores and small groceries, lack large supermarkets or farmers’ markets, which sell fresh produce, Paskett noted.

### **Challenges in Providing Women’s Health Care**

Tsu noted that a number of misconceptions about how cancer is tied to sexuality can greatly affect women’s willingness to seek prevention or treatment for gynecological or breast cancers. For example, she noted strong beliefs in many places that cervical cancer is due to promiscuity. In communities with these beliefs, women are less likely to participate in cancer screening or even treatment due to concerns about being stigmatized or blamed for their cancer.

Concerns about loss of sexual function or desirability, especially the loss of breasts, can also make women avoid breast cancer detection and forego life-saving treatment, Tsu said. Others may not give their children HPV vaccines that can prevent cervical cancer because of a concern that it might make them take sexual risks or affect their fertility. Even though there are no fertility risks linked to such vaccination, Tsu addressed this concern in the educational materials she provided about the vaccine. “That is a legitimate question that people have and we have to address it actively,” she said.

Tsu added that modesty concerns can prevent women from being examined by a health care clinician, especially a male provider. In Kenya, for example, nurses were trained to do visual inspections of the cervix, but about one-third of these nurses were men. “In small communities where you knew the man and he knew you and your family, this was a huge limiting factor,” Tsu said. Khleif noted that in Jordan, women are often uncomfortable sharing their gynecological and breast cancer symptoms with a male doctor, are concerned about their family embarrassment, a lack of male approval, have little faith in efficacy of modern medicine, and are more likely to trust traditional healers in their community (Abu-Helalah et al., 2015; Daher, 2012).

Cultural expectations for women can also be challenging when delivering cancer interventions. “In many societies, women in their mid-adult years have little power to act on their own behalf,” Tsu said. They may need permission from their husbands or fathers to get health care services, and they often are expected to put the needs of their family before their own, which delays or prevents them from seeking the care they need. Women are less likely to have access to economic resources for travel to screening or follow-up care. “When we think about all these social issues—age, gender and social position—all of them combine in a perfect storm to really disadvantage women in their mid-adult years,” Tsu said.

Knaul gave an example of a Mexican woman who had a breast cancer the size of a grapefruit but did not seek care until lymphedema prevented her from moving her arm. She was being treated in a hospital that was not covered by the social insurance program she had because she couldn't pay the transportation costs, nor could she leave her children in the care of her partner because he had recently abandoned her. "This is a typical story I hear repeatedly and is why women do not want to go to find out if they have breast cancer and why they don't want to have a Pap smear," Knaul said. "Over and over women tell me they are encouraged not to do so by their male partners, and in some cases, by their mothers-in-law." Knaul said one well-educated, professional Mexican woman who lived in Miami and had two children was abandoned by her husband when she had a double mastectomy because he told her she was no longer useful. "This machismo is one of the biggest barriers to any of the work we are doing on early detection or treatment," Knaul said.

The traditional expectation that women have sole responsibility for the care of their children is another impediment for women seeking cancer care, she added, as well as an inability to take time off from their jobs. "They neglect themselves and don't get checked because they think only of work or have no one to leave their children with," she said. Mexico reimburses all medical costs associated with breast cancer treatment, but not the costs incurred due to loss of work, childcare, or transportation costs. Such costs combined with the high expenses of health care for those uninsured or underinsured is another major barrier to preventive health, Tsu stressed.

## **CANCER PREVENTION EFFORTS IN LOW-RESOURCE AREAS**

Several workshop speakers described their experiences delivering preventive cancer care and discussed potential opportunities to help reduce the cancer burden in low-resource areas, both currently and in the future. Several types of interventions were described, including

- Behavioral modification programs to lower risk factors for developing cancer;
- Cancer vaccines for infection-related cancers;
- Cancer screening and detection programs that can diagnose precancerous conditions and cancers at an early stage, when they are more likely to be effectively treated; and
- Antibiotic and antiviral drugs that might prevent cancers linked to infections.

Several workshop speakers reported on how these interventions can lower cancer risk and discussed their efforts to apply these preventive measures to low-resource areas.

### **Behavior Modification Programs**

Massetti emphasized that almost a third of cancer deaths globally are due to leading preventable risk factors like obesity, lack of physical activity, tobacco use, and alcohol use. "It is far easier and more effective to prevent cancer than to treat it," Massetti said. Workshop speakers described interventions that are targeted at modifying behaviors that are associated with increased cancer risk. Specifically, several workshop speakers described opportunities to reduce the use of tobacco products, to improve access to healthy diets high in fruits and vegetables and low in animal fats, and to encourage physical activity and weight management.



## *Tobacco Prevention and Cessation*

Eriksen reported that tobacco is the leading cause of cancer and nearly all lung cancer globally, making tobacco use the most preventable cause of cancer worldwide (Eriksen, 2015). Experts estimate that more than 6 million people died early and unnecessarily because of their tobacco use, Eriksen said (WHO, 2011). U.S. deaths from lung cancer equal that of breast, colon, prostate, and pancreatic cancer combined, he added (ACS, 2015a). Bollyky said that of all the behaviors linked to NCDs, smoking is the most likely to cause premature adult deaths. “We do very little on tobacco control internationally and we certainly can do more,” he said. Massetti added that despite known programs and policy measures that can decrease tobacco use, “they are not used or they are not applied consistently in low- and middle-income countries. Instead, cigarettes have become more affordable in these countries.”

Most of the harm from tobacco comes from combusted smoke, but smokeless tobacco can also cause cancer, and is prevalent in certain communities, especially in Southeast Asia, Eriksen noted (Sinha et al., 2015). He added that smokeless tobacco is used in at least 70 countries by more than 300 million people. In addition to causing oral cancers, smokeless tobacco can cause cancers of the pharynx, larynx, esophagus, and stomach. An ongoing debate is the public health impact of electronic cigarettes, which provide non-combusted nicotine vapor and are increasing in use, Eriksen noted.

Stella Bialous, associate professor in residence at the University of California, San Francisco, School of Nursing, said that although there is now a low prevalence of tobacco use globally among women relative to men, data in many countries, particularly in low- and middle-income nations, are finding that smoking rates in girls aged 13 to 15 are higher or equal to boys. “I hope 20 years from now we are not talking about the increasing prevalence of smoking among women, because this is where we can and should do something about all tobacco-related cancers and diseases. This is our opportunity and either we’re going to continue to make a big investment to keep it at this low level in women, or we’re going to really miss the boat,” she said. She added that although smoking prevalence in both sexes is on the decline globally, because of population growth there is an increasing number of smokers worldwide.

One global effort to counter the increase in tobacco use is the WHO Framework Convention on Tobacco Control (FCTC),<sup>6</sup> an international treaty finalized in 2005, Eriksen said. Of 194 WHO member states, 180 have ratified the FCTC, with a notable exception being the United States. The FCTC provides guidelines and a foundation for countries to implement and manage tobacco control efforts, including specifying measures to assist in the country-level implementation of effective interventions to reduce the demand for tobacco.

Eriksen noted that the FCTC specifies four main types of evidence-based, anti-tobacco policy measures: taxes on tobacco products, bans on tobacco advertising, clean indoor air laws, and graphic warning labels on tobacco products (more information on tobacco control and cancer prevention efforts can be found in the workshop summary *Reducing Tobacco-Related Cancer Incidence and Mortality* [IOM, 2013]). Smoking rates have rapidly declined in countries that have undertaken these anti-tobacco policy measures, according to Eriksen. For example, “for every 10 percent increase in price, there’s a 4 to 7 percent decrease in consumption,” he said.

Eriksen added that the most effective tobacco control strategies are policies rather than treatment programs, and that these policies are inexpensive and can be implemented equally well

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<sup>6</sup> See <http://www.who.int/fctc/en> (accessed January 18, 2016).

in low- and high-resource settings. Ulysses Dorotheo, director of the Framework Convention on Tobacco Control Program at the Southeast Asia Tobacco Control Alliance, described several tobacco control efforts in Box 2.

## **BOX 2**

### **Anti-Tobacco Efforts in Guam and the Philippines**

Ulysses Dorotheo, director of the Framework Convention on Tobacco Control Program at the Southeast Asia Tobacco Control Alliance, reported on some of the anti-tobacco efforts in Guam and the Philippines. Guam passed a law in 2010 that increased taxes by \$2 per pack, with nearly three-quarters of that tax revenue allocated for the U.S.-wide Healthy Futures Fund designated for tobacco, alcohol, and drug prevention, health promotion, and tobacco cessation; 15 percent of revenues were earmarked to the Guam Cancer Trust Fund; and 1 percent of revenues were allocated to fund the Guam Cancer Registry. Dorotheo noted that this law resulted in linking for the first time a tobacco tax to sustainable local funding for health care and prevention in Guam (Steger et al., 2010).

Critical advocates for this bill were those in the health community, especially physicians and cancer patients and their families, he said. Physicians appeared en masse during public hearings and provided written and verbal testimony about the evidence linking tobacco to cancer and other diseases. In addition, cancer patients and their families spoke at the public hearings and to the media about their struggles with cancer, giving a compelling human face to the issue, Dorotheo noted.

The Philippines in 2012 also passed a “sin tax” on cigarettes. This tax reform law was 20 years in the making, Dorotheo reported, and uses most of the tax income to support its national health insurance program, attainment of Millennium Development Goals, and health awareness programs. Twenty percent is earmarked for medical assistance and health facilities’ enhancement. When the sin tax was first collected, both the Philippine Departments of Finance and of Health experienced a doubling of their budgets, Dorotheo noted, calling the tax a win for finance, public health, and the poor. “It was the largest Department of Health budget they had ever had in Philippine history,” he said. The number of families enrolled in health insurance programs for the poor increased from around 5 million before the bill was instituted to nearly 15 million (WHO, 2015c).

Prior to the passage of the sin tax bill, the tobacco industry waged extensive media campaigns in which they argued that raising tobacco taxes would adversely affect tobacco farmers, destroy the local tobacco industry, reduce government revenues, and increase unemployment. They also argued that the bill would increase smuggling and illicit trade, and negatively impact the poor. The Department of Finance refuted these arguments with their own statistics. “Finance people speaking on behalf of the health sector actually refuted the tobacco industry,” Dorotheo said. But editorials and articles in support of the tobacco industry significantly outnumbered those in favor of the sin tax, with many of the information cut and pasted from industry publications. Consequently, promoters of the bill used social media to expose the biased reporting in traditional media. “Facebook was our battleground to try to get the public aware and support the sin tax,” he said.

The main message spread via social media was that the sin tax was an anti-cancer tax so if a Senator was against the tax then he could be labeled being anti-health, Dorotheo said. Simple infographics also showed the impact of tobacco on health.

In addition, at congressional and other public hearings, epidemiologists and physicians spoke on behalf of the tax, as well as patients with laryngeal and other cancers caused by tobacco. “One of the huge factors for moving this forward was getting the doctors involved,” Dorotheo said.

The costs of some of these policy measures, such as warning labels, are borne by manufacturers, while other measures, such as taxes on tobacco products, generate income, or in the case of clean indoor-air laws, save money on maintenance costs. For example, the United States receives billions of dollars in revenue from state and federal tobacco taxes.

Eriksen said that the total annual cost of delivering core population-based tobacco control measures in all low- and middle-income countries is estimated at only \$600 million U.S. dollars, or the equivalent of 11 cents per person (Eriksen et al., 2015). Globally, \$10.74 is generated per smoker from tobacco taxes. However, Eriksen said that the international community provides only about a penny per person to fund tobacco control efforts globally, most of which comes from private foundations, rather than from development agencies or from the domestic budgets of low- to middle-income countries, who, on average, spend even less than a penny per person.

### *Smoke-Free Environments*

Several governments have instituted smoke-free environments, but more effort could be made in this regard, Bialous said. “Every primary health clinic or hospital in the world should be smoke free but they’re not,” she said. Schmeler added that MD Anderson Cancer Center recently adopted a policy that prohibits all new employees from smoking and requires that new employees be tested to confirm that they comply with the no smoking policy. However, Eriksen said he opposed the policy of not hiring smokers, because smoking is an addiction that is difficult to overcome and often begins during teenage years. “Seventy percent of smokers would like to quit, so to further discriminate against them because they have an addiction is a wrong policy,” he said.

Bialous noted that when WHO passed a policy of not hiring smokers, the organization also provided smoking cessation support for those employees who wanted to quit. The University of Alabama at Birmingham also offered cessation assistance when it banned smoking among its employees, Scarinci noted, and recently started charging employees who are tobacco users an extra \$50 on their health insurance premiums. Dorotheo noted some local governments offer initiatives to not hire smokers, while offering employees cessation services. He said this is being done to “encourage them to walk the talk and give the public a really good example of what a government official should be doing, rather than promoting tobacco with his or her actions.” Some local governments have even turned entire cities into smoke-free zones. In addition, there is a directive for the police force in the Philippines that they not be seen smoking in public when they are in uniform. “There is a move to de-normalize smoking, but at the same time not to criminalize the smokers because they are victims of the tobacco industry,” he said. China also prohibits communist party officials from smoking in public, Eriksen added.

Scarinci pointed out that smoking was once considered a glamorous pursuit by women until Brazil instituted a federal smoke-free policy indoors. “It’s amazing to see in a country that big how quickly social norms change because of legislation and regulation, which has had a huge impact in changing behaviors,” she said. Bialous added that Argentina is making significant progress with smoke-free legislation, and is moving toward becoming 100 percent smoke-free

nationwide. Knaul noted that the National Institutes of Health (NIH) campus did not go smoke free until around 2008—more than 50 years after the 1964 Surgeon General’s report documented the health hazards of smoking.

### *Graphic Warning Labels*

More than 1 billion people now live in countries that require graphic warning labels or plain packaging for tobacco products, Eriksen said. Some of these warning labels take up as much as 85 percent of the space on the packaging, while others constitute a much smaller percentage of package space. FCTC requires that tobacco product warnings cover at least 30 percent (and preferably 50 percent) of the visible area on a pack of cigarettes. Examples of these graphic labels include a picture of lungs blackened by tobacco smoke, or faces that have been damaged by oral cancers, and often use plain packaging and drab colors. The intent of implementing packaging requirements is to decrease the appeal of smoking and increase quitting, said Eriksen. The United States has not yet instituted graphic warning labels, due to legal battles that the tobacco industry has waged.

### *Countering Tobacco Industry Efforts*

Eriksen said that legal and public relations mechanisms are often used by the tobacco industry to oppose any country attempting to implement tobacco control policies. “Governments must be alert to tobacco industry’s undue influence,” he said, noting that in addition to litigation, tobacco companies donate generously to homeless shelters and the arts, among other societal endeavors, to help improve their image and win their lawsuits. He stressed, “It’s not just money but more political will that’s needed to launch what we know works. You need to have a willingness to stand up to [the political resistance] that’s in place in a country. The advocacy that exists, the lawyers that are available to help defend countries against these assaults by tobacco companies, all go into that mix.”

Bialous noted the FCTC specifies: “In setting and implementing their public health policies with respect to tobacco control, Parties shall act to protect these policies from commercial and other vested interests of the tobacco industry in accordance with national law.” This section of the FCTC also states “there is a fundamental irreconcilable conflict of interest between the tobacco industry and public health,” she said (WHO Framework Convention on Tobacco Control, 2008). But nearly half of all the countries that signed the FCTC treaty have not implemented measures to protect against tobacco industry interests, such as banning the industry from subsidizing vaccination or other health programs, and other conflict of interests, Bialous reported. “Countries need a lot of help still to find out what we need to do to stop tobacco industry interference,” she said. One positive example is the recent ban in Mauritius of Corporate Social Responsibility donations by tobacco industries, as well as code of conduct guidelines for civil service employees and elected officials that a few other countries have developed. “There are many good examples, but we need a lot more. We cannot have only half of the countries doing something because we need all of them to do something,” she said.

Dorotheo agreed that successful anti-tobacco efforts require political leadership, as well as anticipating the tobacco industry at every step. He suggested “stepping up our game” and being on the offensive rather than the defensive (i.e., suing tobacco companies more so they have fewer legal resources to devote to litigating against anti-tobacco policies). Bialous noted that

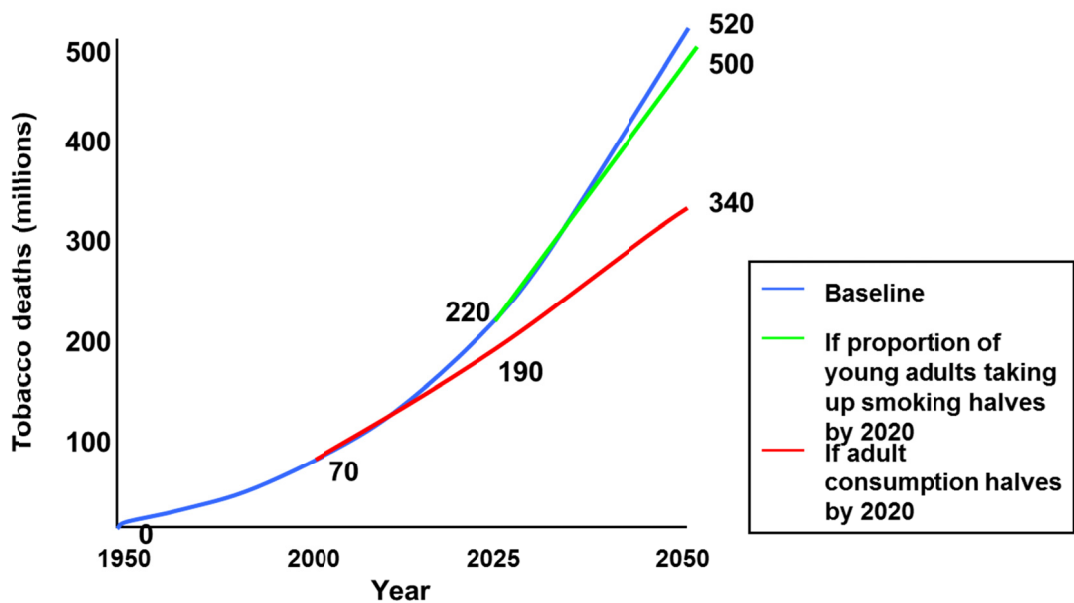
tobacco companies have multiple layers of arguments they use to counter tobacco legislation, and although they may vary which of these arguments to use in specific countries, worldwide they are often the same arguments. “It’s the same bag of tricks no matter where in the world it is,” she said. Because their strategies do not vary globally, she suggested improving networking within and between countries so there is something akin to a clearinghouse of responses to industry that any country could use.

Dorotheo also stressed the importance of sharing information on the impact anti-tobacco legislation has had to counter some of the myths the tobacco companies are propagating. For example, when Tonga tried to increase taxes on tobacco products, the British American Tobacco company claimed that when Hong Kong did something similar, there was an increase in illicit trade without a significant decrease in the use of tobacco. But when Hong Kong was contacted about this, that information was refuted, and after acquiring the correct information, Tonga increased their tobacco tax. “It’s important to share information,” he said.

Dorotheo said anti-tobacco programs also require partnerships with local leaders and harnessing the power of social media when communities cannot afford large anti-tobacco media campaigns. He also suggested collecting data to show the effects of efforts on tobacco use and disease.

### *Smoking Cessation Programs*

Bialous suggested more effort be made to promote smoking cessation programs, which have been shown to work and be cost-effective, she said. “We have more research coming out about the benefits of cessation on survival rates for cancer, so we have to provide it to those who are already addicted or sick,” she said (Dobson, 2015). She noted that unless current smokers quit, tobacco-related deaths will increase dramatically over the next 50 years (see Figure 7). She stressed that the FCTC recommends educating health care professionals about smoking cessation and having it incorporated into primary health care services, as well as setting up easily accessible quitlines and providing access to low-cost pharmacological therapy. Smoking cessation education for nurses need not be extensive, Bialous added. An online training program on smoking cessation for nurses in China used minimal resources and was successful, she reported (Sarna et al., 2016).



**FIGURE 7** Estimated cumulative tobacco deaths from 1950 to 2050 with different intervention strategies. SOURCES: Bialous presentation, October 26, 2015; World Bank, 2016.

Bialous suggested integrating tobacco cessation with cancer screening programs by asking all patients if they smoke, and offering cessation therapy if they respond affirmatively. She noted that many health professionals are reluctant to talk to their patients about quitting smoking, but that reluctance is unwarranted because many people have managed to quit with interventions, support, and health professional advice. Smoking cessation can be promoted in a number of health care settings, including primary care sites as well as clinics for maternal and child health, tuberculosis, and HIV, she said. Bialous stressed that nurses are widespread resources who can provide education on smoking cessation. “All they have to do is talk to patients about it, refer them to a quitline or cessation clinic, and recommend a smoke-free home,” she said.

*Physical Activity*

Almeida reported that physical activity can lower the risk of developing breast, colon, and other cancers by 20 to 30 percent, although that figure varies by cancer type (Kruk and Czerniak, 2013). He noted that researchers have postulated several mechanisms for how physical activity reduces cancer risk, including its influence on reducing fat deposits, decreasing certain hormones, improving immune function, reducing inflammation, and possibly reducing insulin resistance (Steindorf et al., 2013). “We have more and more data suggesting the importance of physical activity to cancer risk,” he said. Almeida added that independent from physical activity, sedentary behavior also influences cancer risk.

Almeida reported that both the American Cancer Society and the American Institute for Cancer Research have recognized the importance of physical activity for cancer prevention and both have devised guidelines (Kushi et al., 2012) (see Table 2). In addition, the Community Preventive Services Task Force developed The Community Guide and the NCI developed the PLANET (Plan, Link, Act, Network with Evidence-based Tools) publication, both of which detail how to promote physical activity (Community Preventive Services Task Force, 2016; NCI, 2016b).

**TABLE 2** Physical Activity Recommendations for Cancer Prevention

American Cancer Society	American Institute for Cancer Research
<ul style="list-style-type: none"><li>• Adults – 150 minutes of moderate or 75 minutes of vigorous physical activity per week</li><li>• Children and Adolescents – 1 hour of moderate or vigorous physical activity per day</li><li>• Limit sedentary behavior</li></ul>	<ul style="list-style-type: none"><li>• Be physically active for at least 30 minutes every day</li><li>• For maximum health benefits, 60 minutes or more of moderate or 30 minutes or more of vigorous physical activity per day</li><li>• Limit sedentary behavior</li></ul>

SOURCE: Almeida presentation, October 26, 2015.

The Community Guide suggests goal setting, self-monitoring, building social support, behavioral reinforcement, problem solving, and relapse prevention. It also recommends social support interventions in community settings, including creating buddy systems, walking groups, and social support contracts to increase accountability, as well as enhancing school-based physical education, especially instructional strategies to increase physical activity and lesson plans that incorporate fitness and circuit training activities. The guide also recognizes the importance of targeting multiple sectors in the community to promote physical activity, and to encourage the development of environmental policies, such as zoning regulations, building codes, and city planning, that foster built environments conducive to physical activity and active lifestyles. Such measures include walking trails and connected sidewalks, landscaping that enables physical activity, and exercise facilities (Community Preventive Services Task Force, 2016).

The PLANET publication recommends programs that have multiple supervised exercise sessions (e.g., weekly, biweekly, monthly) of 60 to 90 minutes, group meeting sessions of 60 minutes, telephone support calls, interactive technologies, intervention materials (e.g., videos, workbook, flyers, pamphlets), and community campaigns, including advertising in multiple media outlets, holding press conferences, implementing worksite programs, improving website exposure, and using trusted figures (e.g., health care professionals, ministers) to implement public health education programs.

But as Almeida noted, program recommendations from both these sources are heavily resource intensive and may not be feasible for low-resource communities, both in the United States and throughout the world. “The key challenge is to balance what works with what is feasible, given the available resources of the places we are going to be working with, and the needs of these local communities and target audiences,” he said. For example, before instituting a physical activity program in Brazil, Almeida and his colleagues first had to address more pressing problems in their target community, such as a lack of electricity, water, and sanitation.

“Those basic needs trump anything else that as a public health practitioner or researcher we might come in with,” he said.

When planning physical activity programs, Almeida employs an Integrated Research–Practice Partnership, which involves fitting effective interventions with delivery sites by working collaboratively with the communities in which the intervention is planned. These collaborations enable the development of practical interventions that can be easily adopted and implemented, can be sustained over time, and are designed to reach a large and representative sample of the intended population. Programs should also demonstrate their effectiveness in fostering and maintaining those changes, Almeida said.

Partners in such collaborations can be health departments, community organizations, or state and federal governmental agencies. “The idea is that together we match evidence-based interventions to the resources available—we determine what the best fit is between what is recommended and what can be done,” he said. Sustainability is a big issue, he noted, because often programs depend on the financial resources of a research grant, which eventually expires.

One of the programs in Brazil that Almeida and his colleagues developed was a program promoting physical activity for older adults. The researchers worked with the local health department and various community health agents across the city of Santa Catarina to develop and implement walking groups. Early on, it became apparent that in certain parts of the city these programs were not getting off the ground because a lack of cooperation of key power brokers—drug lords who determined access to the areas in which the walking groups were planned. Community health agents who worked for the city and lived in the community worked with these individuals to gain access to the walking areas so the programs could be implemented in these neighborhoods.

Demark-Wahnefried asked how Almeida conveyed the importance of physical activity to the communities being targeted with exercise promotion programs. Almeida responded by noting that evidence can play an important role, and cited a recent paper that estimated that worldwide physical inactivity causes 9 percent of premature mortality (Lee et al., 2012). Such information can motivate people to exercise. But he added that “If literacy levels are an issue, you just talk about how if you move a little more, if you have a more active lifestyle, you’re going to have all of these different types of health benefits.”

### *Multilevel Programs for Health Promotion, Cancer Prevention, and Early Detection*

Some cancer prevention programs for low-resource communities apply multiple interventions, including physical activity, diet, weight management, as well as participation in cancer screening programs. These multilevel programs aim to lower cancer risk and improve health outcomes in general. One of these multilevel programs that Baskin described is the Deep South Network for Cancer Control.<sup>7</sup> This 15-year collaboration among academic researchers, health care professionals, local leaders, and community volunteers from Alabama and Mississippi aims to eliminate cancer-related health disparities by conducting community-based participatory education, training, and research. A major part of this program has also been cancer outreach and screening so that individuals are aware of the cancer prevention guidelines and recommendations. Community members are connected with opportunities to be screened, as well

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<sup>7</sup> See <http://www3.ccc.uab.edu/index.php/community-outreach/deep-south-network-for-cancer-control> (accessed January 18, 2016).



as opportunities for treatment if needed, Baskin said. The Network also promotes health behaviors, such as weight management, a healthy diet, and physical activity. Training is provided to individual community members to increase their capacity to maintain cancer prevention efforts in the long term.

Baskin noted that a large portion of the Network's NCI funding during its first 5 years was devoted to identifying community leaders and individual partners, and providing training on the specific interventions offered in the program, as well as cancer prevention and control. "That's been the cornerstone of what we do and allowed us to build trust over the past 15 years to deliver some very intensive interventions more recently," she said. The Network also chooses evidence-based community strategies for weight management and adapts them so they are more likely to be feasible and effective when implemented by community health workers, as opposed to academic specialists who conducted the original research on the strategies. "The DASH [Dietary Approaches to Stop Hypertension] trials, the Weight Loss Maintenance Trial, and others had all the bells and whistles and a lot of funding, but they were fundamentally different in terms of who was delivering the interventions," Baskin said (Appel et al., 1997; NIH, 2011). "We chose to adapt them so they could be delivered by our non-professional community health advisors and staff within each of the counties in which we worked."

The Network embedded its weight management program within a larger multilevel intervention that included farmer's markets, community gardens, and park improvements, all of which made it easier for participants to exercise and have access to healthy foods. Using CDC's recommended community strategies to prevent obesity as a basis, the Network met with their community advisory board and developed a list of different strategies that their local organizations could use to help promote physical activity and healthy eating within their communities, Baskin said (Khan et al., 2009). The Network then awarded mini-grants to local communities to help them implement these strategies (i.e., grants to expand farmers' markets and community gardens, as well as coupons and other incentives to facilitate the purchase of fresh fruits and vegetables). Network grants also funded park improvements, such as mile markers for walking and jogging trails, as well as an indoor, air-conditioned walking trail that community members could use during the hot summer months.

Initial findings on a weight loss intervention combined with the various community strategies suggested clinically significant weight loss at 6 months, as well as improvements in waist circumference, blood pressure, and lipids, Baskin reported. "We're using individual volunteers and lay health providers from the community to deliver the curriculum and they are getting success comparable with some of these other trials," she stressed. "We found community-based participatory research methods were associated with a significant reach of this target population that has historically been hard to reach. And we've shown that these multilevel interventions for cancer prevention can be effectively implemented by non-professional local staff and volunteers," she said. To help ensure sustainability of the program, "once the grant runs out," the researchers provide local community organizations with curriculum manuals, Baskin added.

Baskin suggested increasing efforts to target rural communities for cancer prevention research and practice. "We can take advantage of community engagement to develop and implement programs that meet the unique needs and resources of rural communities," she said, adding "we can also seize opportunities within the Affordable Care Act to engage community health workers ... in the provision of preventive services."

Khleif reported on another multifocal cancer prevention program he developed at the Georgia Regents University Cancer Center. It is located in a low-resource and underserved county in Georgia, where approximately half of county residents are African American and one-quarter have incomes below the poverty level. The county ranks 135th out of 159 in health outcomes, Khleif noted. He and his colleagues created a program called Cancer Community Awareness Access Research and Education (c-CARE),<sup>8</sup> initially to reduce the burden of cancer within the area the hospital serves in a sustainable, collaborative, and community-based manner with the hope of eventually extending its reach to other parts of Georgia and beyond.

The long-term goal of c-CARE is to reduce new cases and deaths from largely preventable cancers in populations who have low access to health care and face health care disparities. It hopes to achieve this reduction by addressing the cultural stigma and mythology surrounding cancer, improving cancer knowledge, and better aligning care with cancer prevention guidelines, as well as expanding access to services. More specifically, c-CARE:

- Trains community-based trainers to deliver evidence-based, culturally competent cancer education to improve health literacy;
- Provides access to high-quality prevention and early detection services;
- Assists with patient navigation;
- Shares information about community resources (medical and non-medical); and
- Measures changes in knowledge, attitudes, beliefs, and cancer health behaviors.

c-CARE's initial focus has been lung cancer prevention and early detection among African Americans. Seven of c-CARE's programs are faith based, four operate in community clinics, and one is housed in a community center. c-CARE is expanding into 24 additional communities in Georgia, as well as into 2 underserved communities in Jordan and Lebanon. "We are developing the infrastructure, but then we are leaving them alone," Khleif said. "It's very sustainable."

## **Cancer Vaccines**

Several vaccines that offer some protection from cancer are currently available, including vaccines for HPV to prevent cervical cancer and vaccines for the hepatitis B virus to help prevent liver cancer. The presentations at the workshop focused on HPV vaccination, as cervical cancer is one of the leading causes of death of women in many low-resource communities.

Without a vaccine, more than three-quarters of people will be infected with HPV, which is a sexually transmitted virus. Most women will clear HPV infections, but a small percentage will go on to develop preinvasive cervical cancer, which can develop into cervical cancer if left untreated, Schmeler reported. She noted that there are three vaccines for HPV; their effectiveness in preventing cervical cancer is greater than 90 percent in those not previously infected with the virus (CDC, 2012). The vaccines, which are considered very safe, need to be given prior to the onset of sexual activity to prevent infection by HPV (Scheller et al., 2015; Slade et al., 2009). Massetti said that across the globe, the target group for HPV vaccination is usually young adolescent girls, although it is also recommended for boys in the United States and a few other countries. Complete vaccination requires three doses over 6 months.

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<sup>8</sup> See <http://www.gru.edu/cancer/ccare> (accessed January 18, 2016).

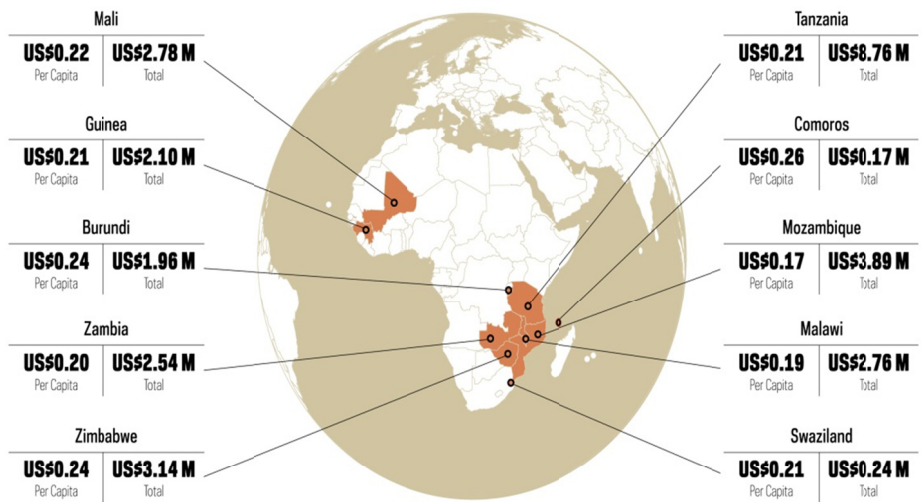
Due to the high cost of HPV vaccines, the first countries to introduce them were high-income countries. Middle- and low-income countries started to introduce HPV vaccines 3-6 years later, many with the help of Gavi, the Vaccine Alliance,<sup>9</sup> which aids the delivery of vaccines for children to countries with low resources. By mid-2013, 45 countries had introduced HPV vaccination.

“The investment in vaccination is really key, and many low- and middle-income countries have not embraced it as much as they could, especially given the cost of screening,” said Mona Saraiya, associate director of the Office of International Cancer Control at CDC. Countries eligible for support from Gavi, the Vaccine Alliance, are most likely to benefit from the HPV vaccine, according to Saraiya. She noted that with such support, Rwanda has achieved high coverage with the HPV vaccine, but many middle-income nations that receive no vaccine subsidies are waiting for the costs of these vaccines to decrease. “They are only in the pilot phase and have not been able to scale up as much,” she said.

Massetti said, “There are still tremendous missed opportunities to make this life-saving vaccine available to many countries where cervical cancer still causes thousands of deaths.” She added that cervical cancer prevention programs can be very affordable interventions (see Figure 8). Oluwole reported on a successful HPV vaccination program in Botswana (see Box 3).

Cervical cancer prevention programs are very affordable.

Estimated annual average cost (in USD) per capita of a comprehensive cervical cancer prevention program in the ten countries with the highest estimated age-standardized cervical cancer mortality rate (world) in 2012



THE CANCER ATLAS

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**FIGURE 8** The affordability of cervical cancer programs, total and per capita, in African countries. SOURCES: Massetti presentation, October 26, 2015; ACS, 2014. Reprinted by the permission of the American Cancer Society, Inc. All rights reserved.

<sup>9</sup> See <http://www.gavi.org> (accessed January 18, 2016).

### **BOX 3**

#### **Cervical Cancer Vaccine Program in Botswana**

Doyin Oluwole, chief executive officer of the Global Health Innovations and Action Foundation, reported on Pink Ribbon Red Ribbon's<sup>a</sup> efforts to institute a human papillomavirus (HPV) vaccination program in Botswana. Cervical cancer was the most common newly diagnosed cancer in women in Botswana in 2012, and nearly one-third of Botswana women are afflicted with it, she noted. There were numerous challenges to developing an HPV vaccination program, she said, including competing priorities with overworked Expanded Program of Immunization staff, who were more focused on other childhood immunizations, and a lack of a national injection safety policy. Other challenges included inadequate vaccine stock management, delays in rolling out the single-use syringe in the country, and difficulties securing financing to procure the HPV vaccine at affordable prices, because Botswana was not eligible for financial support from Gavi, the Vaccine Alliance.

But Oluwole and her colleagues took advantage of numerous opportunities when developing the vaccination program, she said. These opportunities included government commitment and leadership support from the Minister of Health. The Ministry of Health was well respected in the community, had solid oversight over the health programs, and allocated funds for the training of health workers administering vaccines that were used for the HPV program, she said. Also, because the country has a 95 percent enrollment of girls in primary school, "it was a good opportunity for us to catch the 9- to 13-year-olds in a school-based program," Oluwole said. The country had a high prevalence of HIV infection, which she said could be seen as a detriment. But the program capitalized on it by convincing the Permanent Secretary of the Ministry that HPV vaccination was also a big opportunity to help reduce spending for treatment of cervical cancer that would likely develop 10 or more years later, Oluwole said. "This was the breaking point because it made sense to him," she said.

Funding for the vaccines was still needed, but public-private partnerships such as the Pink Ribbon Red Ribbon helped the program find a vaccine manufacturer who would agree to donate a number of doses of the HPV vaccine as part of a demonstration program. To help ensure the success of that program, Pink Ribbon Red Ribbon also sought and received funding from other private and governmental organizations for the entire spectrum of preventive cervical cancer services, including for the "see and treat" approach and training and resources to improve cervical cancer detection, diagnosis, and treatment. The program also received funds to do a baseline analysis of data systems for cervical cancer.

Although the HPV vaccination program was school based, it was also offered to the 2-5 percent of girls aged 9 to 13 years who were not enrolled in school, but were seen regularly by other facilities, such as infectious disease centers. After the Minister of Health agreed to a one-year demonstration project in one district, more than 2,000 girls were fully vaccinated with three doses in 2013. After a consultant recommended that the demonstration project continue for another year, the Minister of Health gave approval for the vaccination program to be extended, saying, "We cannot go back—communities are demanding services." As Oluwole stressed, "The voice of the people is always very important."

By 2015, more than 95 percent of the target population was vaccinated in Botswana, nearly 14,000 women were screened for cervical cancer, and nearly 4,000 women were treated for precancerous lesions, Oluwole reported. The government of

Botswana now fully owns and leads the HPV vaccination program as part of its national cervical control plan, and HPV vaccination is fully embedded into its national Expanded Program on Immunization. To carry out the program, there is a dedicated national program manager funded by the government of Botswana. The national cervical cancer control program is embedded in the national budget, and an evaluation of the first few years of the program will be used to plan for the next 5 years, with support by the U.S. National Cancer Institute, Oluwole noted.

The rollout of the HPV vaccination program was not without challenges, however, including claims on social media that the program was sterilizing the girls. Members of the Botswana Parliament had to make an effort with their constituents to debunk this myth, Oluwole said.

<sup>a</sup> <http://pinkribbonredribbon.org> (accessed January 18, 2016).

Schmeler reported that HPV vaccination in the United States is recommended for girls and boys between ages 11 and 12, yet the HPV vaccination rate in this country is only 60 percent for the first dose, and 40 percent for all three doses. This is in contrast with the U.S. hepatitis B vaccination rate of more than 90 percent, and the 70 percent HPV vaccination rates in Australia, Canada, and the United Kingdom. Khleif noted that only 18 percent of eligible children in southern Georgia have been vaccinated with the HPV vaccine, and he said that the poor penetrance of the vaccine in this area is largely due to religious and cultural beliefs, as well as misinformation about the vaccine and cervical cancer. According to Schmeler, the biggest challenge to HPV vaccination in the United States is a lack of school-based vaccination programs. “The countries that have shown these huge successes in high vaccination rates vaccinate the kids through the schools,” she said.

The combination of HPV vaccination and cervical cancer screening has reduced U.S. cervical cancer deaths by 70 percent, according to Schmeler. Saraiya noted that the HPV vaccine has been so successful in reducing the incidence of cervical cancer in Australia that the country is considering a recommendation to limit cervical cancer screening to once or twice in a woman’s lifetime.

## **Early Detection and Screening for Cancer**

A number of workshop speakers described opportunities for cancer screening and early detection, including those for cervical, breast, colorectal, and stomach cancer. Saraiya suggested that the “best buys”<sup>10</sup> for cancer screening in low- and middle-income countries include screening programs for cervical and colorectal cancers, but there is ongoing debate about whether screening for breast cancer is cost-effective (WHO, 2010). She added that screening for stomach cancer is another “best buy” in countries in Asia that have low resources and high incidence, and screening for oral cancers is warranted among heavy tobacco smokers and those with other risk factors. She suggested several elements of a successful screening program, including:

<sup>10</sup> Best buys are defined as highly cost effective interventions that are also feasible and appropriate to implement given a health system’s resource constraints (WEF and WHO, 2011).

- A stable budget sufficient for ongoing costs of all of the services required to deliver the program;
- A central administration with responsibility for screening, policy, and coordination of all elements in the screening process. A public policy should be documented in the law that specifies who is eligible for screening, what the protocol for screening is, and how often screening should occur;
- A registry for screening results that is audited for quality assurance;
- Evidence-based training standards, clinical practice guidelines, and performance indicators;
- Education programs for the general public and health care professionals;
- Mechanisms to identify and recruit disadvantaged persons among target populations; and
- Substantial information technology infrastructure to support the program.

Several workshop participants reported on their experiences applying early detection and screening for cancer in low-resource communities. Some programs had a single-cancer focus (e.g., breast, cervical, or colorectal cancer), while other programs were multifocal and not limited to cancer.

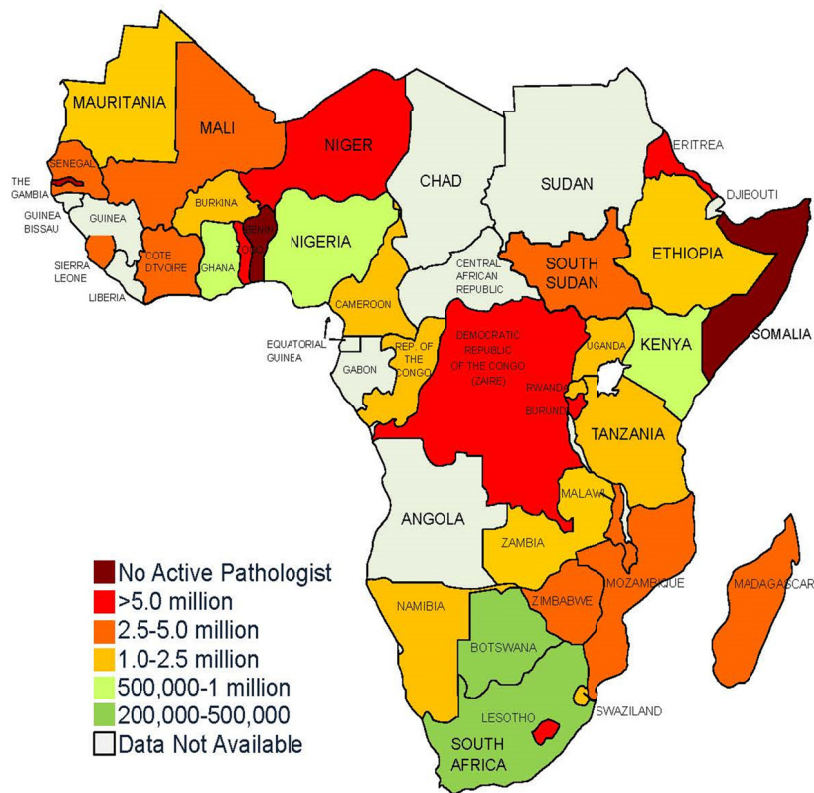
### *Cervical Cancer*

Schmeler noted that some people have suggested more effort be devoted to developing and implementing HPV vaccination programs rather than screening programs for cervical cancer and she suggested that HPV vaccination needs to be the primary goal of cervical cancer prevention programs. But she stressed that in countries such as the United States, as well as some low- to middle-income countries in which HPV vaccination rates are not 100 percent, screening will still be needed. She suggested screening will also be needed even in those countries with good vaccination rates to detect those cancers that develop due to HPV infections occurring prior to the advent of HPV vaccines. “We have got two or three generations of women for whom the vaccines were not available and these women still need screening,” she said.

U.S. cervical cancer prevention and screening may require three clinical visits. The first visit is for a Pap test to detect cervical abnormalities and, for women over 30, testing for presence of HPV (CDC, 2015d). If the Pap test is abnormal, patients return for a more intensive examination of the cervix (colposcopy) and cervical biopsies. If significant abnormalities or precancerous lesions are detected on the biopsies, patients return for a third visit in which the abnormal tissue is either surgically removed or destroyed with freezing (cryotherapy) or with electrical or laser treatments.

“The challenge with this is you need pathology and lab services at each step and skilled gynecologists, nurse practitioners, or family physicians. This is not [always] feasible in low-resource settings and often has problems in high-resource settings,” Schmeler said. She noted the paucity of pathologists in Africa where, in many places, there are none of these specialists, or one pathologist per 200,000 to more than 5 million people (see Figure 9; by contrast, the United States has one pathologist per 19,000 people) (Adesina et al., 2013). “It is really not possible for these pathologists to be doing three steps for our screening process,” Schmeler said. “They need to do everything—the autopsies, biopsies for other cancers, et cetera. To be looking at cervical biopsies using our existing system is really not feasible.” The same is true for many parts of

Central America, she added. “A classic finding for anyone who has worked there is to walk into the pathology lab and find stacks of dried out Pap tests,” she said. “The women have been screened technically because they have had a Pap test, but no one has read the Pap test, the Pap tests end up being such poor quality that they are not helpful, or it takes months to get in touch with the women or they are unable to come back for the next step.”



**FIGURE 9** The availability of pathologists is limited in many parts of Africa.  
SOURCES: Schmeler presentation, October 26, 2015; reprinted from *Lancet*, Adesina et al., 2013, with permission from Elsevier.

An alternative to the Pap test is the use of vinegar to stain the cervix and reveal abnormal tissue, which turns white with vinegar. This procedure, called Visual Inspection with Acetic Acid (VIA), had been highly successful in low- to middle-income countries, Schmeler said. VIA is a low-cost intervention that can be performed by primary health care workers and can be combined with treatment in a single visit. In India, this “see and treat” intervention led to a 31 percent decrease in deaths from cervical cancer, Schmeler reported (Shastri et al., 2014). But although this screening has also worked well in other areas, it has high false-positive results leading to overtreatment, increased costs, and concern on the part of patients, she said.

Researchers at Rice University have developed another low-cost “see and treat” approach to cervical cancer screening that they hope will have fewer false positives. This method uses an inexpensive high-resolution microendoscope, a build-your-own computer kit, and a dye that generates high-quality images of the cervix on a computer screen. This system enables

practitioners to make similar assessments of cervical lesions that a pathologist would make on cervical biopsies, but in real-time, so the patient can be treated simultaneously if the need arises. “It is an easy procedure which will eliminate all those extra steps that aren’t available in low-resource settings,” Schmeler said. The test could be done by community health care workers, she added, and though it originally required a laptop, it now can be done using a smart phone. Schmeler is currently conducting tests of this cervical cancer screening method in Brazil, Houston, and El Salvador. In Brazil, practitioners are administering the screening to women in rural areas via a mobile van that travels to their communities.

Tsu pointed out there is a new *careHPV* test that can be used with vaginal specimens that women can collect themselves. This HPV self-test might overcome women’s modesty concerns in some communities, because “women who do not want to be examined can take the sample themselves and hand it over to a health worker who can then return it to the lab for testing,” Tsu said. There were concerns that a self-test may raise other modesty barriers: “We go in and usually the doctors at the top level say that women would never accept this because they would never be comfortable [gathering their own specimens due to concern over touching their own genitals]. Then we would go in the next day and talk to the community and the women would say that it sounded like a great idea to them,” Tsu said. She added that in her experience in a number of countries, 85 to 90 percent of women accept the test. Those that do not use the test are more concerned that they will not perform the test properly or that it might hurt them, rather than modesty concerns. “You have to show them the sample brush so they can feel how soft it is, etc.” Tsu said. Tsu added that when appropriately used, the *careHPV* test could make collection in remote communities possible by reducing travel and cost barriers.

Saraiya reported on efforts of using HPV self-tests and other tests to improve cervical cancer screening in the U.S.-Affiliated Pacific Islands and Jurisdictions. She said that these regions have lower cervical cancer screening coverage than that of the U.S. mainland (about 30-55 percent versus 83 percent) and higher cervical cancer incidence (about 20.6 diagnoses of cervical cancer per 100,000 women versus 9.9 diagnoses per 100,000). Screening in the Pacific islands is supported by several U.S. programs, including CDC’s National Breast and Cervical Cancer Early Detection Program and the Health Resources and Services Administration’s Community Health Centers program (see Box 4 for an overview of CDC’s cancer prevention and control programs),<sup>11</sup> but despite the investment, coverage remains low, Saraiya noted. She and others are developing a demonstration project for the area, which will “get these programs speaking to each other,” she said. The project’s aim is to show the feasibility of using VIA, HPV testing, or HPV self-tests to improve screening.

**BOX 4**  
**Overview of the Cancer Prevention and Control Activities**  
**at the Centers for Disease Control and Prevention**

Mona Saraiya, associate director of the Office of International Cancer Control at the Centers for Disease Control and Prevention (CDC), provided an overview of the four major cancer prevention and control activities that CDC undertakes nationwide as well as in U.S. territories and Native American tribes. Saraiya stressed that the planning for each of these CDC programs relies on health economics research, and uses such research to estimate the cost of

<sup>11</sup> See <http://www.cdc.gov/cancer/nbccedp/>; <http://bphc.hrsa.gov/about> (accessed January 18, 2016).



cancer to society, to determine the value of cancer interventions and programs, and to project future costs of cancer treatment and care, Saraiya noted. The four programs include

- The National Breast and Cervical Cancer Screening Program, which has provided more than 12 million screening exams. Saraiya said that CDC plans to increase population-level screening rates, aided by the Affordable Care Act, which increased access to screening exams. Studies found that women screened in this program receive timely diagnoses and follow up treatment, when necessary, that met preestablished program guidelines (Bernard et al.; Richardson et al., 2010).
- The Colorectal Cancer Control Program is one of the few organized colorectal cancer screening programs in the United States that places a major emphasis on ensuring quality, according to Saraiya. To improve screening rates, all 31 grantees are partnering with health systems to implement priority strategies. Six grantees are also being funded to support direct screening for low-income adults aged 50 to 64.
- The Comprehensive Cancer Control Program supports robust state-, tribal-, and territorial-wide coalitions, supports early detection and treatment activities, and addresses public health needs of cancer survivors. The Comprehensive Cancer Control Program also plans and implements policy, systems, and environmental changes that emphasize primary prevention of cancer, and promotes health equity as it relates to cancer control. The past few years, the program has focused on increasing HPV vaccination rates in partnership with state immunization groups, Saraiya pointed out.
- The National Program of Cancer Registries operates in 45 states, Puerto Rico, and U.S. territories in the Pacific Islands. The United States is one of the few countries globally that has nearly 100 percent population coverage in its cancer registries. CDC plans to increase completeness, timeliness, and usefulness of registry data, Saraiya reported.

“This is an example of how some of the things we have learned globally have been applied domestically,” she said. But she noted that CDC’s global efforts are limited by congressional mandates that dictate using domestic funds only for domestic programs. She suggested there be strong consideration for allocating a proportion of CDC’s domestic budget for global work. Saraiya also reported on a program that CDC and NCI have with the Thai government to conduct cervical cancer screening. Thailand has universal coverage for such screening and has introduced HPV testing in one province, which they are currently evaluating. CDC is offering technical assistance. Oluwole reported on the successful implementation of a cervical cancer prevention and treatment program in Zambia (see Box 5).

**BOX 5**  
**Cervical Cancer Prevention and Treatment in Zambia**

Doyin Oluwole, chief executive officer of the Global Health Innovations and Action Foundation, said that cervical cancer is the most common cancer in Zambian women, and Zambia has the highest rate of cervical cancer deaths in the world. Forty percent of Zambian women with late-stage cervical cancer are less than 35 years of age, Oluwole noted. Zambia also has a high rate of HIV infection, with nearly 10 percent of Zambian women over the age of 15 infected with the virus.

Oluwole noted numerous challenges to combating cervical cancer in Zambia, including a lack of access to quality advanced cancer care and funds to pay for it, as well

as a lack of information about cancer. There are pervasive myths and stigmas about those with the cancer; a common belief is that cancer is not preventable and that anyone who develops it has a death sentence. People with cancer in Zambia tend not to seek care in hospitals until their cancer is advanced beyond being treatable, which perpetuates the myth that the cause of death is the hospital care that individuals receive, Oluwole said. Many think cervical cancer is caused by evil spirits, and that one shouldn't associate with women who have it. Consequently, "a lot of women will keep things to themselves and not come out for treatment at the stage when they could be helped," she said. A lack of health care resources compounds the problem: with a population of 13 million, Zambia only has one cancer treatment center.

Oluwole and her Pink Ribbon Red Ribbon colleagues found that the biggest health care priorities in Zambia were maternal and child health and HIV, which were seen as being crisis-level health problems. The country had no national strategy or roadmap for cancer control, which was mainly driven by nongovernmental organizations, she said. Cervical cancer fell under the domain of two recently formed ministries, the Ministry of Health and the Ministry of Community Development, Mother, and Child Health. These ministries were in the midst of determining their responsibilities when Pink Ribbon Red Ribbon proposed to support Zambia's cervical cancer control program. There was no national cervical cancer control program, nor was there funding for such a program at that time. She said it was challenging to access some parts of the country due to bad roads.

But there were also opportunities in Zambia, including that the First Lady, the Minister of Health, and the Permanent Secretary of Health were all physicians in obstetrics and gynecology "who knew the implications of cervical cancer and what needed to be done," Oluwole said. There was a high level of support for a cervical cancer prevention and screening program at the upper echelons of government, including the President, the Minister of Health, the First Lady, and the spouse of the Vice President, and the U.S. Ambassador was also supportive. In addition, there was support from nongovernmental agencies such as Project Concern International, Palliative Care Association, Breakthrough Cancer Trust, and others, as well as from public-private partnerships, such as Pink Ribbon Red Ribbon.

The cervical cancer prevention and screening program was able to build on the HIV control programs and clinics established with foreign and national government support. In addition, the Zambian government paid for cervical cancer screening with VIA and treatment of precancerous lesions detected (via cryotherapy or surgery) for any woman who could access it. Training and technical capacity was available at the Center for Infectious Disease Research of Zambia and at the Cancer Diseases Hospital. The U.S. Centers for Disease Control and Prevention also supplied some technical support.

With these resources, Zambia decided to scale up its "see and treat" program for cervical cancer. Merck donated HPV vaccines and the Komen Foundation provided the funds to enable an HPV vaccination program. In addition, there was air transport of supplies and equipment to hard-to-reach areas. Between 2012 and 2014, nearly 34,000 girls were vaccinated against HPV, and about 155,000 women were screened for cervical cancer, out of which approximately 12,000 were treated for precancerous lesions.

Breast Cancer

Stevens said that early detection and effective treatment are both essential to improving breast cancer outcomes (Berry et al., 2005). “To save lives, screening programs must be linked to timely, effective treatment,” she stressed. She noted that the International Agency for Research on Cancer (IARC) reviewed the evidence and concluded that mammography screening reduces breast cancer deaths in women ages 50 to 74, and that such screening can be cost-effective in countries with a high incidence of breast cancer. But there is limited evidence to suggest that mammography is cost-effective in low- and middle-income countries, the agency concluded (Lauby-Secretan et al., 2015). In addition, the WHO Global Status Report in 2010 found that although mammography is a “best buy” and saves lives in women aged 50 to 70 and could alleviate 19 percent of the breast cancer burden, this intervention is often not possible in low- and middle-income countries, due to its implementation costs and the limited feasibility of treatment in such countries, Stevens reported (WHO, 2010). “Early detection strategies are needed to improve breast cancer outcomes, but we need to do additional research to determine what is going to work in both low- and middle-income settings,” Stevens said.

Scarinci said that the Breast Health Global Initiative developed guidelines for international breast health and cancer control that make recommendations based on the resources available (Anderson et al., 2008) (see Table 3). “This model is great for those of us who work in other countries,” she said, adding that it was quite helpful for her when developing her program in Brazil. The American Society of Clinical Oncology uses the same framework for primary and secondary prevention of cervical cancer guidelines, Scarinci added. Peter Kingham, assistant professor of surgery and director of the Global Cancer Disparity Initiatives at Memorial Sloan Kettering Cancer Center, agreed that “these guidelines are fantastic.” But he added that “Implementing them is really the challenge.”

**TABLE 3** The Breast Health Global Initiative Guidelines for International Breast Health and Cancer Control—Early Detection

	Level of Available Resources			
	Basic	Limited	Enhanced	Maximal
Public education and awareness	Development of culturally sensitive, linguistically appropriate local education programs for target populations to teach value of early detection, breast cancer risk factors, and breast health awareness	Culturally and linguistically appropriate targeted outreach/education encouraging CBE for age groups at higher risk administered at district/provincial level using health care providers in the field	Regional awareness programs regarding breast health linked to general health and women’s health programs	National awareness campaigns regarding breast health using media

Detection methods	Clinical history and Clinical Breast Exam (CBE)	<ul style="list-style-type: none"><li>• Diagnostic breast U.S. +/- diagnostic mammography in women with positive CBE</li><li>• Mammographic screening of target group</li></ul>	<ul style="list-style-type: none"><li>• Mammographic screening every 2 years in women ages 50-69</li><li>• Consider mammographic screening every 12-18 months in women ages 40-49</li></ul>	<ul style="list-style-type: none"><li>• Consider annual mammographic screening in women 40 and older</li><li>• Other imaging technologies as appropriate for high-risk groups</li></ul>
Evaluation goal	Breast health awareness regarding value of early detection in improving breast cancer outcome	Downsizing of symptomatic disease	Downsizing and/or downstaging of asymptomatic disease in women in higher yield target groups	Downsizing and/or downstaging of asymptomatic disease in all risk groups

SOURCES: Stevens presentation, October 26, 2015; Anderson et al., 2008.

Khleif reported on his efforts to develop a program to reduce breast cancer morbidity and mortality in Jordan by detecting breast cancer at earlier stages when it is more amenable to treatment. The program chose this goal rather than implementing a wide-scale breast cancer screening program, because the country did not have the financial resources to conduct such screening, he said. The Jordan Breast Cancer Program started in 2006 and its objectives were to:

- Increase public awareness and education;
- Improve availability and accessibility of screening services across Jordan;
- Establish national unified protocols and guidelines that cover all processes of a comprehensive early detection and screening program;
- Improve health care personnel education and training; and
- Evaluate the quality of the program by creating a breast cancer registry and analyzing the data collected.

Khleif stressed that the program was built “from the bottom up,” with its first focus being advocacy and building awareness in the community, which it viewed as the cornerstone on which to develop capacity and services. The program to date has installed 35 mammography units across various sectors of the country and developed 2 mobile mammography units that can be used in remote areas. Radiologists and radiation technologists were also trained because when the program began, there was only one radiologist who was certified to perform mammograms. Data collected from Jordan’s King Hussein Cancer Center found that when the program began in 2006, nearly 70 percent of breast cancers were diagnosed as late-stage cancers (Stage III or IV); by 2013, that percentage was reduced to approximately 40 percent.

*Colorectal Cancer*

Kingham noted that colorectal cancer is the third most common cancer in males and females and the third most common cause of U.S. cancer deaths. This cancer can be prevented or diagnosed at an early stage by detecting and removing precancerous growths (polyps) or early

cancers with a colonoscopy procedure. Several studies have shown the effectiveness of screening for polyps and colorectal cancer in reducing the death rate from this cancer with a number of methods, including colonoscopy and fecal occult blood testing combined with sigmoidoscopy, Kingham reported (Lieberman, 2009; Loberg et al., 2014; Shaukat et al., 2013; Winawer et al., 1993; Zaubert, et al., 2012). Such screening has also been shown to be cost-effective, he noted. “There is a huge amount of evidence and data that show this screening can be successful,” he said.

Despite those data, compliance with colorectal screening is suboptimal in the United States, Kingham noted. It also varies from county to county, Massetti added. Colorectal cancer screening is recommended for those older than 50 years, but one-third of the people in that age group in the United States report they have never undergone such screening, he said. “My colleagues in Nigeria, who are fighting to get colonoscopies approved for their new government insurance system, cannot believe that there are Americans who have an opportunity to be screened who don’t take advantage of it,” Kingham said. Barriers to increasing the rate of colonoscopies include its inconvenience, especially its cumbersome and time-consuming bowel prep. “Nobody likes taking a half a day off of work to do the bowel prep and then the next day off to have a colonoscopy done,” he said. Some people also find the procedure itself uncomfortable or lack access to it or information about it, he noted. Some patients report that they had little knowledge about colorectal cancer, that physicians did not explain screening to them, and that they have a fear of the health care system, Kingham said.

To better align colorectal cancer screening with recommended guidelines among African Americans, a program in a public hospital in the Bronx used patient navigators, streamlined the referral network so that patients diagnosed with colorectal cancer could be seen directly by gastroenterologists and surgeons, and simplified a fact sheet that they used to explain to patients why they were being screened and what a positive result meant. Despite the fairly small number of interventions instituted, there was a drastic drop in the amount of patients who missed their colonoscopy appointments: Kingham noted that the rate fell from 67 percent to only 5 percent. “It is possible to overcome these barriers,” he said (Kanna et al., 2007).

Paskett reported on another successful colorectal cancer screening program in Delaware. This program focused on improving colorectal cancer outcomes in African Americans, who are much more likely to be diagnosed with late-stage colorectal cancers than whites in the state, she said. The program has what she called a “top down and bottom up” approach in which objectives were to not just improve colorectal cancer screening rates among African Americans, but also to ensure timely resolution and treatment when a cancer is diagnosed. The screening program used a patient navigator for screening and care coordination, as well as case management for abnormal results. The screening expenses for underinsured patients are reimbursed, and there is reimbursement of up to 24 months of cancer treatment for this population. Underserved populations were engaged and recruited for screening, Paskett said.

When the screening program began in 2001, 48 percent of African Americans older than age 50 had received colorectal cancer screening, compared to 58 percent of whites older than age 50 who had received colorectal cancer screening. By 2009 this disparity in screening disappeared, with nearly three-quarters of both populations reporting that they had undergone such screening. This resulted in a 235 percent increase in local-stage diagnoses in African Americans, as well as closing the colorectal cancer incidence gap and a near closing of the mortality gap between African Americans and whites in Delaware. The program fostered a 42 percent drop in colorectal cancer mortality in African Americans in the state (Grubbs et al.,

2013). By providing universal screening and therapy access, Delaware decreased overall deaths from colorectal cancer by 20 percent over 10 years, Paskett said.

Colorectal cancer is also a major cause of cancer deaths globally, and the rate of this cancer is rising dramatically in low-income countries, according to Kingham. Saraiya pointed out that most colorectal cancer screening programs in the world are not organized, nor is there uniformity in the type of screening recommended. In Europe most organized screening programs use noninvasive colorectal screening tests, such as blood and stool tests, rather than colonoscopies, she said. Even countries that have organized screening, such as France, have poor uptake of them, she added. “There’s a real opportunity to make an impact with colorectal cancer screening,” she stressed. Kingham pointed out the need to develop colorectal screening tests that work in low-resource environments. “It is hard to think that colonoscopy is going to be the answer for most low- and middle-income countries,” he said. To try to counter the large disparity in colorectal cancer outcomes in patients in West Africa compared to those in the United States, Kingham and a Nigerian colleague formed the African Research Group for Oncology (ARGO) (see Box 6).

# **BOX 6**

## **African Research Group for Oncology**

Peter Kingham, assistant professor of surgery and director of the Global Cancer Disparity Initiatives, described the African Research Group for Oncology (ARGO). ARGO is a consortium of five hospitals, all of which are located in Nigeria, except for New York’s Memorial Sloan Kettering Cancer Center, home institution of Kingham. The consortium has a database and tissue bank that enables ARGO’s goal of conducting research on colorectal cancer screening in Nigeria, with the ultimate objective to improve treatment of colorectal cancer in that country. ARGO developed standard operating procedures for colorectal cancer screening, which it plans to review once it has analyzed data collected on the first 200 patients, Kingham reported. The consortium also plans to initiate some therapeutic trials based on chemotherapy and surgery to see if it can improve outcomes. ARGO has recently branched out to include breast cancer screening.

ARGO initially focused on improving training of Nigerian medical staff, many of whom travel to Memorial Sloan Kettering Cancer Center, where they attend classes, pathology training sessions, research conferences, or observe operations, rounds, team management of patients, and data management. ARGO also offers postgraduate classes in Nigeria, including one on colorectal cancer this past spring in which approximately 120 Nigerian physicians from throughout the country attended.

ARGO’s baseline analysis of its patients screened for colorectal cancer found that the median age of being diagnosed with colorectal cancer is 55, about 15 years younger than in the United States. Most patients report having blood in their stool, with nearly one-quarter experiencing this for more than 6 months, and weight loss. Most patients presented with metastatic disease. The outcomes were very poor—only 62 percent survived 6 months and 48 percent survived a year after diagnosis.

ARGO strived to improve those outcomes by first determining through research who should undergo colorectal cancer screening. Due to a lack of financial and logistical resources, it was unrealistic to screen every person over the age of 45 or 50 in Nigeria. Using the symptoms reported by the patients who underwent screening, the consortium developed a probability model that determined which patients over age 45 with rectal bleeding should be considered high risk and undergo a colonoscopy. (Because of the

cultural resistance to colorectal cancer screening using stool samples, the local physicians and community health workers did not think these tests would be accepted by Nigerians; thus, the consortium declined to use this screening tool.)

The consortium is still attempting to overcome many barriers to colorectal cancer screening in Nigeria, including a lack of funds. “In Lagos it costs a thousand dollars for a colonoscopy, which is totally impractical for 99.9 percent of the population,” Kingham noted. He reported that there is now a government-run insurance system that covers about 15 to 20 percent of the population. “Our hope is that colonoscopies will be covered by that insurance, and that the number of Nigerians who have the plan grows,” he said.

ARGO is also researching how to improve geographic access to colonoscopies, and trying to expand the number of physicians capable of performing them in Nigeria. Mostly surgeons conduct colonoscopies in the country, Kingham noted. He added that in most of the countries in sub-Saharan Africa, there are no medical oncologists or radiation oncologists that treat solid tumors. Instead, for breast, cervical, colorectal, gastric, or other solid tumors, surgeons are relied on to not only remove the cancer, but also to prescribe chemotherapy and treat any complications that arise.

ARGO advertises on television and the radio to raise awareness of colorectal cancer and the importance of addressing rectal bleeding. “A large part of this has to be education and cultural acceptance,” he said. One patient who was diagnosed with an early-stage colorectal cancer now advocates for ARGO in the community. “We need to develop advocates like this for community awareness because most Nigerians think that if you have colon cancer you shouldn’t go to the hospital because you are going to die,” Kingham said, adding, “Given the survival curves that [belief] is pretty much true, so until we identify more patients who have earlier stages and have survived, it is going to take a long time until patients are willing to come into the hospital even to accept treatment.”

## *Lung Cancer*

There was some discussion on whether lung cancer screening should be implemented, both in high-income as well as low- and middle-income countries. Some people voiced the concern that such screening could potentially deter tobacco cessation efforts. Eriksen noted a recent publication that interviewed current smokers who were offered lung cancer screening about their attitudes about smoking cessation (Zeliadt et al., 2015). The study found that approximately half of those interviewed described mechanisms in which screening lowered their motivation to undergo smoking cessation. As an analogy, Almeida noted that he has observed that doing well on a cardiac treadmill test can be a disincentive for cardiac patients to be more physically active, because individuals may perceive they are at low risk for a cardiac event (Almeida et al., 2015). But this lack of motivation can be countered by referring all cardiac patients who undergo a stress test, including those with negative results, to an exercise program, he said.

Bialous noted that “there is an increased call to make sure any lung cancer screening is attached to a cessation intervention.” She added that tobacco use causes more deaths from heart disease than lung cancer, so a negative lung cancer screen does not reveal all the life-threatening effects of smoking on the body. She suggested that if such screening is done, it should always be linked to information on and access to smoking cessation programs. Massetti said that Medicare requires that smoking cessation be provided in order to cover the costs of lung cancer screens,

and she added that “there’s a lot around lung cancer screening intervention and implementation we need to understand better since [CT screening for lung cancer is] such a new technology.”

## Experimental Approaches

The discovery that *H. pylori* plays a role in the development of stomach cancer has led to the drug and vaccine development research that aims to target this microbe in an effort to prevent stomach cancer. These experimental interventions are currently undergoing clinical trials, Morgan reported. Researchers are conducting large studies in China and Korea on whether the use of antibiotics to rid the stomach of *H. pylori* infection can prevent stomach cancer. Several studies have suggested that this intervention can significantly lower the incidence of stomach cancer in Asian populations, but it is not known whether these results are applicable to other populations, and whether the eradication of *H. pylori* is long lasting, Morgan said. He also noted concerns that this prevention approach might lead to the development of antibiotic resistance or adverse changes in the microbial flora that might increase the risks of developing esophageal cancer, obesity, or other conditions. But this should not deter research in this area, Morgan said: “We need to move forward with the science, but with a certain level of caution.”

Morgan conducted an *H. pylori* eradication trial in Latin America using community-based recruitment. He tested three different antibiotic regimens, but found no major differences among them and an overall recurrence rate of *H. pylori* stomach infections of 11.5 percent. However, the recurrence rates varied widely by country and site, with younger women of childbearing age much more likely to experience recurrence. These women are at the least risk for stomach cancer at this age, Morgan noted. The findings suggest “a one-size-fits-all intervention may not be the best, and we need to be a little bit wiser about how we do this,” he said.

Researchers have suggested that other drugs, such as a drug approved to treat African sleeping sickness (eflornithine), might help prevent stomach cancer by countering some of the compounds *H. pylori* generates in the gut, Morgan added (Chaturvedi et al., 2015). Researchers are currently testing whether prophylactic treatment with eflornithine can prevent colon cancer recurrence, Morgan noted, and added that a number of other potential drugs might be tested to see if they can prevent stomach cancer from developing in high-risk populations.

Researchers are also testing an *H. pylori* vaccine to see if it can prevent stomach cancer. A large study in China with children found that a vaccine against *H. pylori* had efficacy of about 72 percent for preventing infection, Morgan said, but the study seemed to indicate waning efficacy of the vaccine 3 years after it was administered (Zeng et al., 2015). “We still have a ways to go, but it’s one step forward after a decade of silence,” he said.

Morgan mentioned briefly another potential intervention for early detection of stomach cancer—the use of regular endoscopy to detect precancerous lesions or stomach cancer at an early stage. He is working on developing an ultra low-cost endoscopy system that should cost about \$2 per use and is disposable (Caprara et al., 2015).

## LESSONS LEARNED

Several speakers at the workshop presented the lessons they learned from their experiences in developing and implementing cancer prevention programs in low-resource areas. The lessons learned focused on several main themes:



- The role of policy and advocacy for cancer prevention and anti-tobacco efforts;
- How to plan and implement cancer prevention programs;
- Funding and infrastructure for cancer prevention efforts; and
- Education and communication.

## **Advocacy**

Prior to implementing cancer prevention strategies in low- and middle-income countries, several workshop participants stressed the efforts they and local leaders made to advocate for their programs among relevant government officials, as well as in the communities they served. Oluwole noted, “Government needs to own the process. Sustainability depends very much on how government owns and leads and fully commits to delivering the program and scaling it up.” Paskett agreed: “The interventions need buy-in from policy makers as well as community members.” Scarinci added that “whatever group we work with needs to make an investment in the program because if not, there is no ownership and sustainability.”

Oluwole also said that once communities in Botswana saw how successful nearby cancer screening programs were, they put pressure on their local governments to offer these programs. “Because other districts were asking or demanding services, government could no longer pull back and had to [reallocate] resources and ask for additional resources to expand into these districts,” she said. “Local grassroots efforts are critical to a successful program or to get governments to adopt a program,” Oluwole concluded.

Afsan Bhadelia, research associate in global health and social medicine at the Harvard T.H. Chan School of Public Health, said there are compelling arguments to convince policy makers of the need to take action, including informing them about the costs of inaction—both the monetary and non-monetary impacts of inaction on families, caregivers, and society at large. Pace agreed, adding that “I like to say you pay now or you pay later, take your pick. It is probably going to be more expensive later. Health is an investment.” Bollyky also said that there is a strong economic rationale to invest in cancer prevention in low-resource areas: It does not make sense to allocate money to enable young people to survive HIV, malaria, and childbirth only to see the same population succumb to cancer. “The fact that we are spending billions of dollars to address one set of preventable, treatable diseases and watching them succumb to another set of preventable, treatable diseases seems like poor economic stewardship,” he said. “If we care about them for these other conditions, it is really hard to understand why we don’t care about them for [cancer],” Bollyky said. Luis Miguel Castilla, the Peruvian ambassador to the United States, noted that the prevalence of cancer can also strengthen advocacy efforts for cancer prevention efforts: “Cancer can touch any person, any household. It does not discriminate in any sense and you need to prevent it.”

When advocating for cancer prevention programs with government officials, Knaul suggested stressing to them the benefits that the program will have beyond cancer. “It’s an easier sell when you demonstrate that the program will also be good for their institute or ministry or for the work that the education ministry or the ministry for women is undertaking. You can get a much bigger bang for your buck by taking advantage of what we can do for something like breast cancer, because it will generate positive externalities for other programs in other areas,” she said.

Several participants suggested involving all stakeholders in advocacy and program development efforts. “Always make sure you have the right people in the room,” Almeida said.

“Sometimes we have had the self-appointed community leaders in the Brazilian communities we’ve worked with, but they might not really be the community leaders we needed,” he said. Scarinci added: “A lot of times we focus so much on the target audience that we forget there is a whole infrastructure there. You need to have the input of the community and all the stakeholders when you develop your interventions.” Castilla suggested broadening the stakeholders to include the U.S. Agency for International Development (USAID), the U.K. Department of International Development, the World Bank, and other organizations “so they can add to this conversation and we are not seen as competitors, but complementary to the work they are doing.”

Bialous suggested broadening stakeholder involvement in anti-tobacco advocacy efforts by including the health care professions and their organizations, such as the Oncology Nursing Society and oncology medical associations. “We need to get cancer societies and professionals a lot more involved in advocating for taxation and price increases on tobacco products that can generate funds for all the other cancer control measures we need,” she said.

Several workshop speakers also stressed using national and local champions to advocate for cancer prevention programs. “Key opinion leaders have to be part of this,” Khleif said, and suggested involving public role models. King Hussein and Queen Noor of Jordan, for example, championed his cancer awareness campaign, and King Hussein was part of the press conferences and events linked to the campaign. Oluwole noted that the First Ladies of the countries in Africa with whom she has worked have been extremely effective national champions for her programs. “In Africa, a First Lady is regarded as the mother of the nation. When she speaks, people listen. When she comes out, other people come out,” she said. For example, Pink Ribbon Red Ribbon asked the First Lady of Tanzania to lead a cervical and breast cancer screening campaign in 2013. Oluwole said that due to her involvement, approximately 11,000 people attended the event and more than 3,800 women were screened for cervical cancer and more than 5,200 for breast cancer.

Members of the executive and legislative branches of government can also be effective advocates, Oluwole and Dorotheo said. Dorotheo related his experience in Cambodia trying to pass an anti-tobacco law, which sat on the docket for 10 years because several lawmakers had relatives who owned tobacco companies. But once the Prime Minister quit smoking and made it a priority to have an anti-tobacco policy, then the bill moved forward with unanimous support from lawmakers. “Even though we have the evidence, at the end of the day, you need political champions to push this through,” he said.

Local cancer survivors can also have a big impact on advocacy efforts, several participants stressed. For example, a nurse screening patients for cervical cancer in Zambia was herself screened and found to have preinvasive cervical cancer, which was successfully treated. “She was able to talk to the women because she herself had been through it and the women identified with her because she was one of them. Her experience motivated others to be screened,” Oluwole said. Saraiya added that husbands and other men are important stakeholders—they can play a role in the success of cancer screening for women because in many low-resource countries, their acceptance of screening is needed for women to access a screening program.

Several workshop speakers highlighted the importance of primary care clinicians and community health workers as advocates for cancer prevention and early detection. Saraiya said that frontline providers also play a large role as champions for programs: “Their recommendations on vaccination are really key.” Dorotheo added that the health community—

and particularly physicians—were critical advocates for Guam’s anti-cancer tax. He said they appeared en masse during public hearings and provided written and verbal testimony.

Paskett stressed the importance of having local and national champions spread accurate information. “Nurses and teachers are respected opinion leaders in Appalachia, but they don’t always have the correct information, and at least in our communities, [some] are anti-vaccine,” she said. Brawley agreed, adding that inaccurate or inappropriate health messaging can dilute the impact of cancer prevention information that communities need to hear. “We need to apply scientific orthodoxy and be careful about communicating the truth,” he said. He also described the challenge of tailoring appropriate health messaging to community resources and infrastructure: for example, messaging about prostate cancer screening would be inappropriate if a country does not have the health care professionals (e.g., urologists and oncologists) available to conduct this screening or to treat individuals identified by screening with prostate cancer.

Several participants said that advocacy efforts would be greatly enhanced if cancer prevention was seen as a global goal that all countries should strive to meet. Pace noted that just as there are global development goals (e.g., the United Nations Millennium Development Goals),<sup>12</sup> there could be global cancer prevention goals. “These global goals are developed so that we can try to develop solutions across our silos, not just within the health sector, but also [addressing] economic and environmental issues,” Pace said. “The global cancer issue is bigger than everyone in this room, so we need to look outside of where we usually work to address the problem.” Bhadelia agreed: “We have been very narrow in our discussion and it would be valuable to take a step back and think about broader common-cause platforms. How can cancer fit into the health coverage agenda? What targets can be established at the global, regional, and national levels for meeting the goal of reducing one-third of premature mortality from NCDs?”

Castilla added that universal health care coverage is one of the goals set by the United Nations 2030 Agenda for Sustainable Development. Knaul said that WHO defines universal health coverage as when “all people have access to the health services they need (prevention, health promotion, treatment, rehabilitation, and palliative care) without the risk of financial hardship when paying for them.” Knaul added that the Pan American Health Organization is considering whether efforts to advance universal health coverage in the Americas should include cervical cancer screening as a covered benefit. “I think cervical cancer screening would be a good indicator of universal health coverage,” Knaul said. She added, “If we can get cancer care in low- and middle-income countries onto the universal health coverage bandwagon, we will have won a lot of ground.” Castilla stressed that if countries meet the objective of providing universal health coverage, they should also ensure that such coverage is sustainable. “There’s nothing worse than giving someone a service and then taking it away,” he said. Edward Trimble, director of the Center for Global Health at the NCI, added that it is also important to make sure that quality cancer care is provided under a universal health coverage program. “We have to make sure we build in the metrics for quality because we do not want to be paying for bad care,” he said.

### **Program Planning and Implementation**

Several participants described elements that had been important for successful cancer prevention programs they had worked with, including

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<sup>12</sup> See <http://www.un.org/millenniumgoals> (accessed January 21, 2016).

- Developing a comprehensive and pragmatic plan;
- Being culturally sensitive;
- Integrating and synergizing with other medical services; and
- Monitoring a program's effectiveness.

### *Comprehensive Plan*

Saraiya suggested having an organized population-based approach when developing cancer screening programs. She noted that such programs in Europe usually have taken about 10 years to plan, pilot, and implement. Saraiya suggested to “start small and scale up regularly.” Knaul noted that “If we can scale up models by inserting them into health care reforms, we will very quickly expand.” Saraiya agreed, adding that “Universal coverage for clinical preventive services makes a huge impact.”

Khleif said that in low-resource countries, developing the capacity to provide treatment and palliative care for cancer is as important as prevention and early detection, and suggested developing these programs in parallel. However, he added that resources for developing comprehensive cancer care across the continuum of prevention, early detection, diagnosis, treatment, rehabilitation and survivorship, and palliative and end-of-life care is often lacking. He said that policy makers and program planners have to decide how resources will be allocated between cancer prevention and cancer treatment. “Are you going to be treating some patients and paying for Avastin, or are you going to do Pap smears for the whole country? These were some of the questions that we grappled with and we had to make a plan that could be comprehensive enough to take all these matters into account,” Khleif said.

Knaul suggested that comprehensive cancer care plans in low-resource countries address not only how to provide care across the cancer continuum, but also consider health system issues, such as stewardship, financing, delivery, resource generation, and evidence building. Such complex planning is challenging, she said, but “I do believe very strongly that this is not too much to ask from low- and middle-income countries.” Knaul added that she recently wrote an article to aid decision makers in this complex planning. “You have to be both an optimist and an optimist when working on cancer in these countries,” Knaul said. Oluwole added: “Despite the huge challenges in combating cancer in low-resource centers, I am convinced that the health system issues can be overcome if we apply proven, simple, cost-effective interventions that give hope to families and show them that a cancer diagnosis is not necessarily a death sentence and that cancer can be prevented.”

When conducting cancer control program planning, Stevens suggested considering the population-attributable fraction, which is an indirect measure of the impact of a potential prevention program.<sup>13</sup> Such measures can suggest which prevention programs are “best buys” for low-resource communities or countries. Brawley said it is important to prioritize according to what programs will have the greatest impact on patient outcomes, and noted that “cancer is a very emotional issue and we do need to be emotional about it and develop a fire in the belly to actually attack it. But we also need to be rational in our approach or else we will fail.” He added, “We need to focus on the ‘low-hanging fruit,’ the things that will save the most lives.” A

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<sup>13</sup> The World Health Organization defines population-attributable risk fraction as “the proportional reduction in population disease or mortality that would occur if exposure to a risk factor were reduced to an alternative ideal exposure scenario (e.g. no tobacco use)” (WHO, 2016).

participant from the Southeast Asia Tobacco Control Alliance stressed that graphic warning labels on tobacco products are an example of a low-hanging fruit in the cancer prevention arena.

Scarinci highlighted the importance of understanding the subpopulations experiencing high cancer burdens and focusing efforts to address these issues. “At the community level, there is sometimes a lack of clear definition or understanding of subpopulations experiencing high burden of disease. Especially in low- and middle-income countries when we do research projects, people expect we are going to work in the whole country. But in a large country like Brazil, that is impossible so it is very important to focus on the subpopulations that experience high burden of disease,” she said.

Prior to implementing cancer prevention programs, Khleif suggested planning for their continuity: “Sustainability must be considered from the onset and public–private partnerships are going to be extremely important, particularly for financial sustainability.”

Scarinci pointed out that although it is important to follow clinical practice guidelines when planning a cancer prevention program, it is also important to recognize that “a lot of these guidelines have been based on the science—what it should be—without taking into account availability of resources.” She suggested there be more involvement of targeted populations in the development of interventions. In addition, Scarinci noted that before expectations for a program are created, there should be an understanding of the infrastructure, political will, opposition forces and allies, and hidden agendas in the communities in which the program will be implemented. Khleif said that addressing social and cultural issues, such as cancer myths or stigmas, is also necessary before starting a national or regional screening program.

### *Cultural Sensitivity*

Several speakers stressed the importance of being culturally sensitive and partnering with community members when developing and implementing cancer control programs in low-resource areas, because any disease prevention effort is performed in a cultural context. “Being global means it is less ‘them’ and more ‘we,’” Pace said.

Palafox suggested building trust in the communities served by cultivating and maintaining relationships with its residents and having a plan that moves toward social justice, such as achieving health equity. He stressed that participatory community engagement in research and cancer prevention programs means that the community has equal power. “I would go as far as to say they should be able to trump you at any time,” he said. Quoting a native Hawaiian woman, Palafox said: “Above all else, indigenous research or health care models should be about healing and empowerment. It should involve the return of dignity and restoration of sovereignty, and it should bring colonized communities one step further along the path of self-determination. We should think on these factors as they apply to our own research, and if and when we decide to proceed, we should do so humbly, in an effort to serve.” Baskin added that “many times, we have had to step back” to address community needs prior to implementation of a cancer prevention program.

Palafox suggested having a foundational knowledge of the history of the communities in which cancer prevention programs will be implemented. That foundational knowledge includes knowing the history of colonization and other cultural traumas experienced by the communities, as well as understanding one’s own cultural bias. “In order to understand someone else’s culture you have to know your own culture,” as that cultural bias acts as a lens that affects how one views another culture, Palafox said. Baskin agreed, adding, “You need to understand your own

bias to be able to understand and listen to what the community is talking about.” That understanding may require modifying one’s expectations of what a program will do, she noted, or modifying the program itself. “We are influenced by and influence others through our cultural background and experiences,” Scarinci stressed. For example, she noted that rural populations are often termed “hard to reach.” However, she stressed that “they are hard to reach from our perspective. But they have always been there and we are the ones [who are] hard to reach for them.” Paskett added, “Show genuine concern and [communities] will come.” Palafox said that often when people refer to indigenous communities, they refer to cultural deficits rather than assets. “We need to rearrange that and talk about cultural assets and protecting indigenous health,” he said. “It is about celebrating who they are and not the science that I bring in or the institution that I bring in. It is about how I bring out their indigeneity and promote their self-efficacy and not my ability to give them the latest science.”

Several presenters suggested working with community-based coalitions to plan, develop, and implement programs in low-resource areas. For example, in the U.S.-affiliated Pacific Island communities, local cancer coalitions each built their own cancer control plan, as well as a regional plan that builds on the economies of scale. This community-based effort resulted in changing tobacco policies and standards for breast and cervical cancer care in the region, as well as in the creation of a cancer registry.

Tsu suggested starting any cancer control program by conducting qualitative research that identifies potential factors and concerns that the population will have and developing a conceptual framework, such as an ecological model, to guide the questions that are posed to community members and how the information is collected. She also suggested searching the published literature for relevant information. “There is a wealth of literature available already that can be helpful as we try and design interventions that will work in these diverse cultures,” she said.

Massetti asked whether it might be helpful for cancer control programs to speak with physicians and other health care professionals who are representative of the communities. Tsu responded that often it is difficult to find such health practitioners, and said that when they are available, they may have greater education and income compared with other people in the community, which may create some cultural distance that may need to be overcome.

### *Integration and Synergy*

Several participants noted the benefits of integrating cancer prevention programs with other medical services, including primary care, and ensuring that efforts among health care and community organizations are synergistic. Pace said that “people are more than their diseases, so the more we can focus on strengthening health systems and thinking holistically about how we approach all of this is essential.” Saraiya suggested “packaging interventions more” and going beyond cancer as a sole focus. Instead cancer control programs could be broadened to include primary care providers and interventions that lower risk for a number of NCDs, including cancer, heart disease, and diabetes. “There is the opportunity with primary care to think about the other risk factor reductions rather than having a siloed approach,” she said. Saraiya also noted that most organized screening programs are successful because they can leverage the primary care health system as opposed to specialists.

Bialous also highlighted the need to involve primary care providers throughout the cancer care continuum. If a patient visits a primary care provider for one screening, for example, she

said it is an opportunity to see what other care needs may be appropriate at that same visit. Loyce agreed, noting that prevention programs can be designed to try and “catch people when they come in the door for HIV screening or treatment, so they leave with an understanding of whether or not they have precancerous cells for cervical cancer or other risk factors for other noncommunicable diseases,” she added. Oluwole pointed out that the cervical cancer screening programs Pink Ribbon Red Ribbon helped develop in Africa also provided other medical services women needed so “that the single day they have devoted to health care can be maximized.” In addition, Bialous added that primary care involvement is also important when patients undergo outpatient cancer treatment, “because if there is a complication, that will [often] be the first point of entry to get back into health care.”

Almeida added that increasing physical activity, having a healthy diet, and following other health-promoting behaviors reduce the risks of developing multiple NCDs. “So when community-wide campaigns focus on multiple components, they also tend to be more successful,” he said. Knaul agreed, suggesting programs promote prevention and healthy lifestyles that can reduce the risk factors for cancer as well as other diseases. Knaul also suggested harnessing the synergy that occurs when both disease-specific priorities, such as breast cancer screening, are tackled along with more generalized systemic gaps, such as the adverse stigma associated with women’s cancers in certain communities. She noted that this synergy enables program providers to accomplish more when the same resources can tackle multiple health issues simultaneously. “We need to bridge disease divides using a lifecycle response, exploit existing platforms, and avoid the false dilemma of disease silos,” Knaul stressed.

One participant added that economies of scale can be leveraged when multiple screenings are conducted by the same program using some of the same resources and infrastructure. In India, Saraiya said that breast, oral, and cervical cancer screening are conducted under the same program. Morgan said the mobile screening vans that his program uses to perform endoscopies for gastric cancer potentially could be used to conduct cervical cancer screening. Kingham agreed that much could be gained by performing screening for more than one cancer and he said that the ARGO program, which initially focused on colorectal cancer screening, has recently expanded into breast cancer screening and plans to eventually include cervical cancer screening in its program. But he stressed the need to stay focused and small to grow successfully. “We are slowly bringing more people into the infrastructure we have built because otherwise it is pointless to just focus on one cancer,” he said. Sally Cowal, senior vice president of Global Health at the American Cancer Society, added that there is a new coalition of pathologists just forming that plans to work in six countries in Africa.

A number of participants stressed the importance of linking cancer screening and diagnosis to cancer treatment, so that if cancer is detected, there are resources and facilities to treat it. “We’ve found that as we try and increase our screening rates for cervical cancer, [oftentimes] there isn’t anyone to treat the preinvasive disease, never mind the invasive cancer or the palliative care,” Schmeler said. Saraiya added, “How can we think about investing in screening from an organized perspective if we don’t have the linkages to treatment?” Oluwole noted that many countries have substandard cancer treatment centers, so helping to build the capacity for cancer care is critical to the success of cancer screening programs. Another participant added, “it is not screening until you complete the care.”

There was some disagreement among a few of the workshop participants about whether it is appropriate to conduct cancer screening if there are inadequate resources to provide cancer therapy. Knaul suggested conducting screening and early detection even if there are not

sufficient treatment resources because “denying people information about the fact that they have a disease means denying a country a voice to do something toward getting the resources to have that treatment and the right to health.” Cowal agreed, adding, “We won’t begin to overcome stigmas and denial and raise awareness in communities until we have some screening. It is a way to build advocacy in communities for greater access to care and treatment.” But Scarinci noted that this places low-resource providers in a difficult position: “I cannot ethically tell a woman that she has breast cancer and there is nothing I can do for her.” Khleif added that “My fear is that if we screen people and diagnose them and then do not do anything about it, it will reinforce [the belief] that cancer is a death sentence.”

Kingham noted that the ARGO program provides both surgical treatment and chemotherapy for patients diagnosed with cancer, but lacks outpatient palliative care, which most of the individuals diagnosed require. Oluwole noted that Pink Ribbon Red Ribbon usually tries to only provide screening programs in countries that can also provide treatment. But in Zambia’s cervical cancer program, so many women were identified with precancerous and low-grade lesions who needed surgery that treatment needs outpaced the surgical capacity. “We became the problem of our own success. Women started to complain, ‘You asked us to come for screening and now we have to wait 6 months to get care. Suppose we develop invasive cancer before you are ready for care?’”

### *Monitoring*

Castilla stressed the importance of collecting baseline and outcome data for cancer control programs for evaluation purposes and to determine future funding and policy efforts. He noted that by monitoring Peru’s cancer control program, “we have the relevant information for appropriate policy making, which is essential. Resources are always insufficient so we need to allocate them wisely and learn what works and what does not work.” Tsu added the importance of including sociocultural variables in data collection efforts to ascertain if programs are reaching underserved groups. Trimble stressed the importance of linking appropriate data sources for monitoring cancer programs: “We need to make sure our cancer registries are linked to the vital registries, the death registries of the countries we work with and help them set up unique personal identifier numbers.” He added that with the widespread use of mobile phones globally, “it is not acceptable that anyone is lost to follow-up. We need to make sure we can link these databases.”

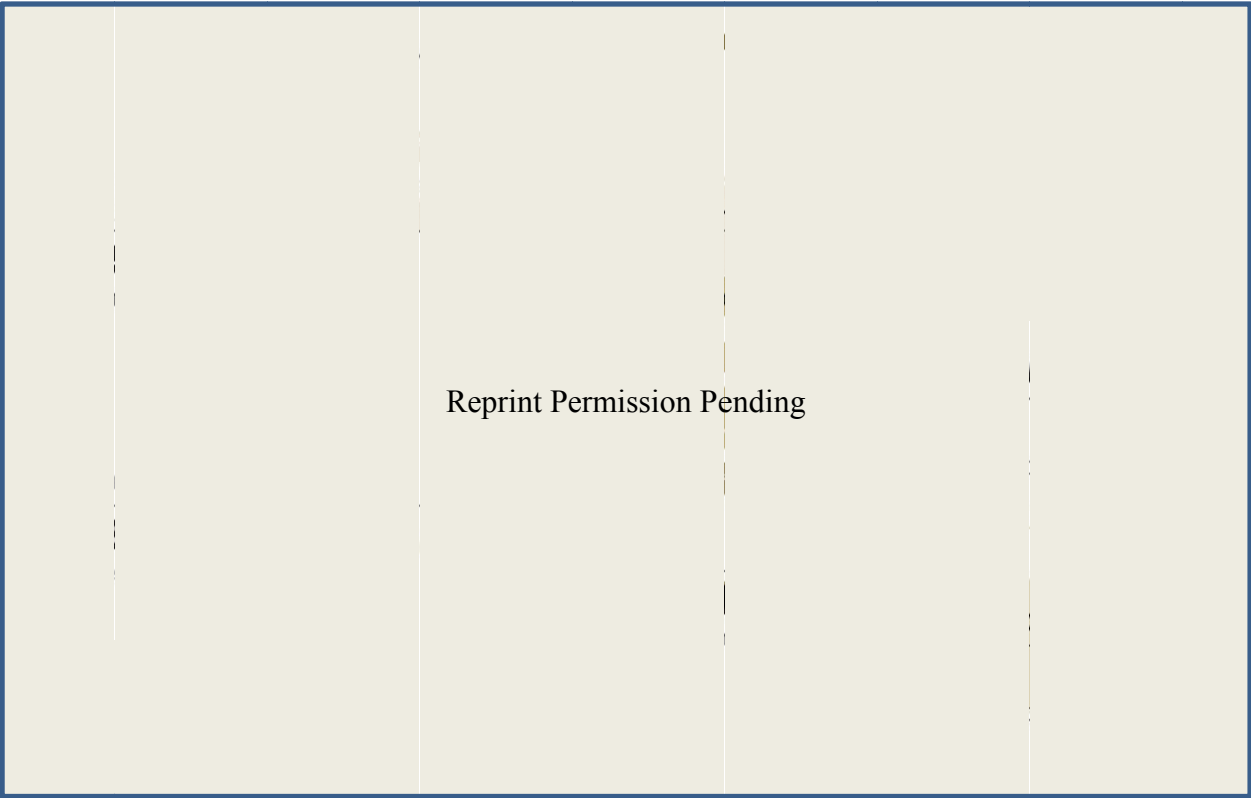
Khleif noted that the King Hussein Cancer Center cancer registry is integrated into Jordan’s national cancer registry, which is a high-quality registry established with the help of the NCI. Kingham noted that the data ARGO collects on its cancer patients is not integrated with the data collected by the Nigerian Ministry of Health, which collects cancer data from only three or four of its major health centers. ARGO has expressed interest in sharing its data with the Ministry, but Kingham noted that it is reluctant to do so because it is still collating its colorectal data and “there is a lot of politics about who has data and where it is coming from.”

Saraiya said that U.S. cancer registries do not collect high-quality data on where people are born, which is important information because immigrant populations share part of the cancer burden in the United States. She suggested capturing treatment patterns and surveillance data in immigrant populations to help assess the quality of cancer care and outcomes within various programs. Morgan added that there are more than 50,000 immigrants from Mexico and Central America in the United States, but current surveillance systems in this country are not set up to



collect data on them: “As we move to develop population-based cancer registries in Mexico and Central America I think that [data from U.S. immigrants] will be informative. For first generation immigrants, what we’ve learned south of the border has immediate implications for at least the Hispanic/Latino populations that we serve up north and certainly vice versa. We need to leverage the science.” He noted that studies suggest Hispanics have an increased incidence of stomach and cervical cancers in the United States compared to other populations.

Saraiya said that “we need to think about surveillance in a more systematic fashion, whether it is cancer registries, leveraging other registries to collect cancer data, and registries for screening.” She also suggested strengthening vital statistics as well as incidence-based registries. Globally there are very limited surveillance systems for cancer and other NCDs, according to Saraiya. “If we don’t invest in these systems immediately we are not going to really know the burden of this problem,” she said. Cancer registries can also indicate changes over time and whether programs implemented have been successful. But as illustrated in Figure 10, in most parts of the world, especially sub-Saharan Africa, Asia, and Latin America, there is a lack of cancer registries or even vital statistics registries. For example, only 8 percent of Latin American countries have cancer registries, and only 25 percent have vital statistics registries that include cancer incidence and mortality data.



**FIGURE 10** Global status of cancer registration and vital registration.  
SOURCES: Saraiya presentation, October 26, 2015; American Cancer Society.

To improve the collection of cancer data throughout the world, IARC created the Global Initiative for Cancer Registry. The objectives are to create Centers of Excellence, to increase support for countries to start or maintain cancer registries, and to analyze and disseminate their data, Saraiya reported. “There is not enough investment in cancer surveillance,” she said. She

added that many countries want 100 percent population coverage; however, this may not be realistic and it may be more feasible to focus on particular sentinel sites where there can be high-quality data associated with interventions.

One economic analysis suggests it costs approximately \$60 to \$250 per cancer diagnosis to maintain a cancer registry. Palafox added that it costs much more than that in the remote and isolated Pacific Islands. CDC recently created a cost assessment tool that can assess the cost to maintain a cancer registry in a variety of country contexts and estimate the resources needed to establish, improve, or expand a cancer registry (CDC, 2015e). This information can be used to advocate for and effectively allocate resources to improve and sustain cancer surveillance, Saraiya said.

CDC is currently conducting pilot studies of this tool in Barbados, Colombia, India, Kenya, and Uganda (Tangka et al., 2015) and has found that most cancer registries are funded by their host institutions, such as universities, ministries of health, or cancer centers, and that most of the costs of a cancer registry are related to labor and data collection. “With electronic data reporting, you will see a significant efficiency in the future,” Saraiya noted. Shared infrastructures can also lower the costs of running a cancer registry, she added, noting that Barbados has a population-based, NCD-based disease registry, which is operated by the Chronic Disease Research Centre of The University of the West Indies on behalf of the Barbados Ministry of Health. This registry has substantially reduced its costs for cancer surveillance by using the same building and personnel to register data on both cancer and cardiovascular disease.

## **Funding**

Several participants noted the importance and difficulty of acquiring sustainable funding for cancer control programs in low- to middle-resource settings. “The expectation that the shift from acute to preventive and chronic care will occur with virtually no support from the international community is unrealistic,” Bollyky said. He added that several international programs, such as Pink Ribbon Red Ribbon, are aimed at supporting the transition to improved emphasis on NCDs. “They are limited to just a small number of countries, but the shift in international support is happening now. Instead of looking at what these populations and governments can do, we need to think about what we can do to support them. I think we can do a lot more,” he added. Another participant agreed, saying, “While donor funding is doing wonderful support of some surveillance systems, and cervical cancer screening and treatment, it is quite limited in terms of support for the large infrastructure for a variety of other activities. It does need to come from another player and the U.S. government or some other organization or nation needs to step up to the plate.” Saraiya added, “A little goes a long way for global health compared to domestic health.” Knaul observed, “Cancer is different in low- and middle-income countries,” and in many of these countries there are opportunities to intervene in “relatively inexpensive ways to move along the curve and flatten those survival lines.”

Bialous suggested that low- and middle-income countries might be more assertive in requesting that a portion of the international funds they receive be designated for cancer and other NCDs. “I would love to see the governments of these countries go back to the agencies and say, ‘This is wonderful support you are giving us, but we want to include NCD prevention in the aid package,’” she said. She also suggested that reputable scientific organizations could write an open letter to development agencies specifying the need to have funding for NCDs. “This will get somebody to pay attention because it carries weight and brings a unified voice. We need to

be a little louder and find our assets—who people listen to,” she said. But Pace noted that there is the fear that advocating more aggressively for funding to combat NCDs “may be sort of robbing Peter to pay Paul. There is a fear that they won’t be able to do some other things if they ask for money in one area because they’ll be told the pie is only so big. If we go and demand money for cancer and other NCDs, does that mean we get less for HIV and some of these other diseases that are still a problem for us?” she asked.

Trimble emphasized the importance of public–public partnerships because “it is time we unleash the full power of USAID and CDC on cancer and NCDs. We have to figure out how best to do that. We know that no one institution can tackle this issue.” He added that the NIH-wide implementation science program announcement makes it clear that global health studies “are of great value to NIH and the NCI,” he said. In addition, the NCI has a Request for Proposal to build a consortia of cancer centers, both from the United States and other countries, to work together in a country or a region on cancer control and treatment or treatment of other NCDs “because we think it is important for people to break down the silos and work together,” he said.

Trimble also stressed the value of public–private partnerships as a source of funding for global health endeavors. He noted that NIH has allocated \$30–\$50 million over 5 to 7 years for validation studies of novel technologies. The funding requires that applicants have partners with expertise in global health, cancer, engineering, and business “because we want to make sure the products that are developed and shown to be effective are ready to be marketed at low cost,” Trimble said.

Castilla noted that Peru created its first national cancer control plan in 2005 with aid from all over the world, including from the NCI and other international institutions. But Peru’s finance ministry did not initially offer any financial backing for the program, despite evidence that early detection and prevention programs were needed for this nation, because about three-quarters of all cancers are diagnosed at an advanced stage in Peru. Such costly programs require public resources, Castilla said, but those resources were scarce in Peru.

Peru recently instituted performance-based budgeting, he reported. Such budgeting is based on the relationship between program funding levels and expected results from that program, with activities that have a higher probability of generating a result being more likely to be financed. Program administrators can use performance-based funding to manage more cost-efficient and -effective budgeting outlays. “Making sure there is appropriate financial allocation is essential,” Castilla said.

After intensive monitoring that indicated the success of Peru’s cancer control program, Castilla said the country ensured the program’s sustainability by passing a law that protected funding for cancer prevention, early detection, and treatment. In addition, the law allocated a budget for the program that is sufficient to sustain it until 2018. “This signals to the society, the public, and private sectors that our government is taking this seriously,” he said.

One participant suggested taxing tobacco products to generate revenue for cancer control programs, and noted that the Thai Health Promotion Foundation is funded by a 2 percent surcharge on tobacco and alcohol. That tax generated \$120 million per year, which is used to fund prevention and community programs. The sin tax on tobacco in the Philippines supports universal health care coverage, which covers 70 percent of the population and includes coverage for catastrophic diseases such as cancer. Castilla noted his concern that if taxes are raised too high on tobacco products, “then it becomes easier for individuals to smuggle cigarettes from neighboring countries, so it is a trade-off.” He suggested tobacco taxes might only work in nations that have good law enforcement and controlled borders, “but for many countries in the

world, Peru included, our borders are very porous and there is a lot of contraband. If you were to increase tremendously the price of cigarettes through taxes to discourage their consumption, you would have entry of illegal cigarettes.”

## **Infrastructure**

Khleif stressed that for cancer screening programs to be successful, they need an appropriate infrastructure, including workforce and workforce training, equipment and maintenance plans, information systems and data accessibility, supportive policies, and funding. Philip Castle, executive director of the Global Coalition against Cervical Cancer, stressed building up health system infrastructure prior to implementing cancer prevention programs. “We can do a lot with cervical cancer because we have great tools, but you are not going to do it even with the simplest program without good pathology, good clinical labs, surgery, etc. It is not [exciting] to talk about building good clinical and pathology labs, but it is critical.” He added that cancer registries depend on adequate pathology capacity: “We are going to be in the dark until we address those basic health care needs. We have to move the clinical lab and pathology ... into global access.” Schmeler agreed, noting that cervical cancer prevention programs in Africa have been challenged by infrastructure constraints, including very few pathologists per capita in many countries (see Figure 9).

Tsu suggested relying more on nurses and other providers to perform certain medical tasks traditionally performed by physicians. She noted that cervical cancer screening programs in low-resource areas have relied on nurses to perform colposcopies and cryotherapy on detected precancerous lesions. “We need to rely on these mid-level providers because there aren’t [enough] doctors and specialists. There are many things that well-trained people can do without having specialty training,” Tsu said.

Others suggested the training of and reliance on local community health care workers, often as educators, advocates, and navigators for patients. Kingham recounted the importance of community health workers in his cancer screening program in Nigeria. Given the lack of health care professional staff, “Relying on community health workers is the only way that we can move forward.” Castle added that a lot of screening in low-resource areas happens out in the community rather than in clinics: “If we are going to implement screening for secondary prevention or downstaging of cancers, we have to move it out. It has to be done through community health workers.” He noted that there are 25,000 midwives in Vietnam and these women provide most of the primary care to women in the country. He suggested that the Ministry of Health in Vietnam could use midwives to collect Pap smears while they are out working in the community, and suggested integrating existing community health workers into cancer prevention programs.

Schmeler stressed that patients are more likely to trust and listen to someone from their peer group, so community health care workers play an important role in traditionally marginalized communities, such as in Mexican communities along the Texas border. Paskett added that when she delivered programs to primarily African American, low-resource communities in the southern United States, she collaborated with community health workers who provided input to advisory boards and conveyed the cultural concerns of the communities involved in the cancer prevention efforts. “Religion and heritage were very important to these communities, so we included references to them in what we were trying to deliver about health,” she said.

Paskett also relied on members of the community as patient navigators in cancer screening programs. These individuals worked with patients who were referred for colonoscopy, as well as those who received positive screening results to ensure they received appropriate follow-up care by providing reminders, coaching, and transportation when needed. For example, a patient who presented with rectal bleeding discussed this with a patient navigator. The navigator coached him over a number of phone calls about the importance of receiving a colonoscopy, how to schedule the appointment, and suggesting he use his sick leave to take a day off from work for the screening. The navigator explained the preparation steps for the colonoscopy and drove him to the facility where the colonoscopy was performed. “He had a big polyp that was removed and the cancer was prevented,” Paskett said. In the month of March, her program performed 50 colonoscopies. “The gastrointestinal doctors could not believe how good the prep was and we had nobody cancel because we had a navigator who contacted them,” she said. Tsu added that the patient navigators with whom she worked in a breast cancer program in Peru helped women make their way through a fragmented health care system and made sure they received proper diagnosis and treatment.

Knaul produced a training manual and scheme for community health workers, both professional and lay, when she implemented a cancer screening program for Mexican communities. The training is certified by the National Institute of Public Health of Mexico, and those who complete it receive a diploma. More than 16,000 community health workers, professional health workers, nurses, and physicians have undergone such training. She also trains the trainers of the community health promoters, providing both print materials and online materials and interactive courses. Her evaluation of the Train-the-Trainer model found that individuals who went through the program, both professional and lay health promoters, had significantly improved knowledge and comprehension regarding breast cancer screening. These health workers were able to perform a clinical breast exam and also understood the risk factors for breast cancer and its treatment. “We concluded that there was significant potential for involving community health workers in the early detection and management of breast cancer,” she said. Based on her experience working with community health workers on a cancer prevention program in low-resource communities in the southern United States, Baskin also concluded that “a multilevel intervention for cancer prevention can be effectively implemented by non-professional local staff and volunteers.”

Scarinci stressed the importance of community health care workers implementing disease prevention in a culturally relevant way and providing a link between the community and health care and social services. But she added that there are often no established standards for lay community health workers. She is working on a project in Brazil that includes a behavioral analysis component to try to narrow down the essential skills for effective community health workers. She added that lay community health workers are a recognized part of the health care team, they live in the community they serve, and are paid for their work in Brazil. There is some movement to have similar recognition of community health workers and reimbursement for their services with the Affordable Care Act, according to Scarinci, but she said that currently “peer health educator” is not a recognized and reimbursable profession in the U.S. health care system. Scarinci said such reimbursement is critical, however; she noted that her previous work with volunteer community health workers has not always been successful.

Part of the infrastructure requirements for some communities, especially those in rural areas, is the ability to provide transportation to clinics or other places where medical services are provided, some speakers noted. One of Paskett’s programs provided buses to transport women to

receive cancer screening. “When we first started we realized the women didn’t even know how to get to the medical clinic to get a mammogram,” she said. Some of the programs provided gas vouchers for participants unable to pay their transportation costs. In another of her programs, a van was outfitted with mammography equipment and traveled to remote Amish communities. The vans also provided transportation to follow-up care if needed. “The women said nobody has ever come and done this for them and they cried when we left,” Paskett said.

Baskin noted that to effectively target diffusely spread communities in rural areas, she and her colleagues created projects that are county-specific and have a regional staff person. They then identified a central community-based organization, such as a church or school system, and found a location that would draw in the most individuals for weekly or bimonthly classes. “By having a staff person who lives in the community, they are very familiar about where people go to congregate, what’s an easier location to reach,” she said. She added that staff and volunteers also make home visits, which involves a lot of travel expenses that need to be reimbursed.

One of Paskett’s programs in Appalachia is located in a food desert because it did not have a grocery store that provided fresh produce in the area. This made it hard for participants in the program to follow healthy diet recommendations. Consequently, part of the infrastructure Paskett and her colleagues put in place was a grant that enabled them to teach how to establish a community garden and grow, prepare, and preserve fresh fruits and vegetables. “We wanted to increase year-round access to fruits and vegetables as well as raise awareness about the role of nutrition in preventing cancer,” Paskett said.

Cost was still a major barrier to individuals participating in many of the communities in which Paskett has worked. She tried to overcome this barrier by helping communities write grants to secure funding for the costs of screening or treatment. For example, a community coalition she helped to establish received funding from the Governor’s Office of Appalachia Community Investment Fund, which enabled free cervical cancer screening and treatment. The coalition also negotiated with pharmaceutical companies for free or reduced-cost breast cancer drugs, when needed. In addition, the coalition secured local physicians willing to donate their time to provide colposcopies, and found donated locations in which the procedures were performed. “The coalitions that we work with have been extremely successful. We have helped them write over 33 community grants and acquire half a million dollars to do projects. We do not get a penny of that—we just help them write those grants,” Paskett said. She noted that the coalitions are staffed primarily by community health care providers, such as nurses and administrators from local health departments.

## **Education**

Several participants stressed the importance of education and awareness on all levels, from community participants, to community health workers, to professional medical providers. Oluwole noted that the African cervical cancer prevention programs provided information on HPV vaccination to both the community and the providers that served them, and trained health workers on cervical cancer prevention.

Morgan noted that the stomach cancer control program in Central America was successful in part because of collaborators in that region that conducted public health campaigns about the risk of stomach cancer. “In the mountainous areas of western Honduras, for example, the message has gotten out in terms of stomach cancer being a common and serious cancer, and

that has led to individuals sometimes seeking screening or at least having a low threshold for the uptake of certain cancer control programs,” he said. Paskett described a community education program that included a colon cancer awareness month and “Wellness Wednesdays,” in which a physician was available in a grocery store to talk with shoppers about nutrition and a chef taught people how to prepare healthy meals. The program also trained medical students and others to guide a scripted walk through an inflatable colon, and showed a video of a colonoscopy being performed.

Saraiya said that the idea of screening when one lacks symptoms is a relatively new concept for some low- or middle-income countries, and some programs may need to educate the communities they serve on “why you would get screened if you are not currently sick,” she said. “Education is critical,” Castilla said, adding that in Peru and other low- to middle-income countries, there is a lack of information on what cancer is, what causes it, and how it can be prevented or detected. Bhadelia added that educating the media about cancer can be helpful.

Paskett suggested that physicians be better educated on providing care in low-resource communities. “I teach medical students, but they get only one lecture on the social determinants of health by me and they need more. You need to know the culture and the history and what you are approaching. Anybody in any aspect of biomedical research science or health care needs to take a class, not just one lecture,” she said.

Medical professionals in low- and middle-income areas also may need more education and training from others outside their communities to adequately conduct cancer control programs, several participants noted. Presenters reported on a few programs aimed at providing such education and training. Saraiya discussed CDC’s domestic Epidemic Intelligence Service,<sup>14</sup> which offers a 2-year, postgraduate fellowship on applied epidemiology. Those eligible for the program include physicians, doctorate-level scientists, and other health care professionals, she said, and the fellowships can help them acquire cancer surveillance and policy development skills.

CDC has also helped to establish 65 Field Epidemiology Training Programs (FETPs)<sup>15</sup> throughout the world that have trained more than 3,100 graduates from 72 countries, with 80 percent working in their home governments, many in leadership positions. FETPs train public health personnel in applied epidemiology and provide subject matter experts for Ministries of Health, in order to support epidemiologic services at the national and local levels. Participants of FETPs acquire expertise on building and evaluating reliable surveillance systems, conducting research activities on high-priority public health problems, and improving communications and networking within the country. FETP trainees include physicians, laboratory workers, nurses, pharmacists, and scientists. They are given closely supervised, on-the-job, competency-based training in both the classroom and in the field.

FETP started to focus on NCDs in 2010 in five countries, said Saraiya. Curricula include general information on chronic diseases, as well as information on tobacco and cancer. The program provides mini-grants to support mentoring of field work, which has increased interest in NCDs, Saraiya said. However, she said some countries do not have enough mentors on chronic diseases.

Schmeler discussed the Extension for Community Healthcare Outcomes (ECHO),<sup>16</sup> a telementoring training program established in 2003 to expand the capacity and provide best

<sup>14</sup> See <http://www.cdc.gov/eis> (accessed January 21, 2016).

<sup>15</sup> See <http://www.cdc.gov/globalhealth/healthprotection/fetp> (accessed January 21, 2016).

<sup>16</sup> See <http://echo.unm.edu/about-echo> (accessed January 21, 2016).

practice care for common and complex diseases in rural and underserved areas. “The idea is to de-monopolize knowledge from places like big cancer centers like MD Anderson and get this information to the communities and to the providers in the communities that need it,” she said. The program originally was developed to counter the problem that many patients in rural areas cannot travel to university-based specialists and many rural providers did not think they had sufficient training to offer certain treatments. The program provides weekly teleconferences in which local providers from the community present cases, histories, lab results, treatment plans, and challenges. These providers then receive feedback from a university-based specialist, as well as 15-minute teaching sessions that enable them to get the continuing medical education credits needed to maintain their certification. This program was found to be as effective at delivering care to hepatitis C patients in rural communities as a university-based clinic, with equal cure and adverse event rates. In addition, patients reported improved satisfaction with the telementoring program that enabled them to receive care from their local physicians, Schmeler noted (Arora et al., 2011).

Schmeler applied ECHO telementoring to the cervical cancer prevention program that serves women near the border of Texas and Mexico, and with funding from the Cancer Prevention Research Institute in Texas. The program also provides hands-on training for some of the providers in the Rio Grande Valley in colposcopy and techniques for removing precancerous cervical lesions. She also established two other ECHO projects: one for cervical cancer prevention and treatment programs in Latin America that is conducted in Spanish, and another for breast and cervical cancer treatment programs in Zambia and Mozambique. “What has been really amazing is how many people show up every week,” Schmeler said.

## Communication

Communication plays a critical role in the success of cancer control programs in low-resource settings, several presenters stressed. As in previously described examples, many suggested the most inspiring messages about cancer prevention come from cancer survivors, especially those whom have benefited from the services a program is trying to promote. Such real-life stories are especially important to counter the notion in many low-resource settings that cancer is always a death sentence, Pace said. Thus, cancer survivors telling their stories are essential to inspiring others to participate in cancer prevention activities. Pace added that LIVESTRONG has a communications toolkit that can be used to help dispel misconceptions about cancer.

Brawley stressed that communication about cancer needs to be both honest and accurate. “We in medicine need to talk about what it is we know, what it is we do not know, and what it is we believe, and label them accordingly,” he said. “We need to be open and honest with both the news media as well as with public health and political officials who determine where money is spent so that money is spent in the wisest possible way.” Pace added: “We are not terribly consistent in what we say, especially in the global cancer space, so media, policy makers, and the public are confused. I would make a plea for us not to just shout from the rooftops, but for us to do so in a way that we are holding hands. Do not make the message so fractured that people do nothing.” She noted that often there is conflicting or inaccurate information that rapidly spreads on social media.

Dorotheo suggested that messaging be culturally sensitive. “In the Philippines we call our tobacco tax a sin tax, but in other countries it is called a health tax. The reason we do that is



because we are primarily a Christian nation and we think of tobacco as a vice, so this labeling helps reinforce the idea that people should not be smoking because there is a large religious influence in the country,” he said. Culturally sensitive images in communication materials are also important, said Knaul. Commonly distributed brochures for breast cancer include images of women who look like “young white Barbies with beautiful little breasts.” But Knaul noted that the women she works with are “60 percent overweight, dark brown, and large breasted. They have breastfed for many years so when they see the picture of the ‘Barbie,’ that doesn’t look anything like them.” Knaul said they do not respond well to this visual messaging: “The real message we are giving them [with these brochures] is ‘if you don’t look like a Barbie, you are not what you are supposed to be.’”

Bialous cautioned that communications should be vetted with the targeted audience to ensure there is good community-based support for the messaging. “You have to carefully consider the community context and make sure it doesn’t backfire,” she said. Schmeler added that the HPV vaccine should have been marketed as an anti-cancer vaccine, rather than one that can prevent a sexually transmitted infection. “If we had really pushed it as an anti-cancer vaccine from the beginning, I think we would have had much higher acceptance of it and avoided a lot of the problems with it being associated with a sexually transmitted infection,” Schmeler said. Paskett added, “We need to take the message to the people, but the message has to be developed with input from the people.”

Several speakers noted social media and cell phones can provide new avenues for communication. But Paskett noted that the digital divide has not been overcome in many communities, especially in rural areas that lack good Internet access. She recounted the difficulties in teaching people in Appalachia how to access an Internet-based intervention when she was unable to access a reliable Internet connection. Not everyone can afford cell phones, she added. “Those barriers make people who you are trying to help less receptive to what you are trying to do,” she said.

Palafox noted that many people in the Pacific Islands move frequently between the islands and mainland United States, and they stay in touch with friends and family through Facebook. Thus, social media is a communication avenue that can be used for cancer prevention interventions if social media platforms are appropriate for the targeted community. Tsu noted that access to the Internet is still a big challenge in many places in Africa, where it tends to be limited to urban areas and among those who can afford access. But she added “there is a lot of hope from the increasing use of mobile phones. It is amazing how quickly this technology is spreading and there is hope that they can help overcome some of the barriers we have encountered, but they have to be used in a careful way,” she said.

In addition to tapping new forms of communication, Oluwole suggested using more traditional avenues of communication, such as hair salons, barbershops, churches, and government pamphlets. Knaul said she asked that the manuals the Mexico government provides as part of its social welfare program to include information on breast cancer screening.

## RESEARCH

Several workshop participants suggested various avenues for research relevant to cancer prevention, screening, and early detection, including

- How to provide interventions in rural areas;

- How to engage in community-based, participatory research;
- Applicability of models of behavior change among those with a high burden of disease;
- The links among physical activity, a sedentary lifestyle, and cancer; and
- How to use new, low-cost technologies that might better enable screening programs in low-resource communities.

Baskin suggested that more research be conducted on prevention projects in rural areas: “There’s very limited published research targeting cancer prevention in rural communities domestically or internationally, so we need to do more work in this area.” She added that the research should address sustainability over time and long-term impacts of various programs. In addition, Baskin suggested research is needed on the key factors necessary to support programs with limited traditional resources, such as access to primary care and cancer centers. Paskett agreed, and noted that “rural populations in general are understudied.”

Baskin stressed the importance of conducting community-based participatory research. Such research involves topics that are important to the community, with the aim of combining knowledge with action and achieving social change to improve community health and eliminate health disparities. “Academic researchers as well as community members are in this fight together and are equitably talking about the issues we need to focus on and ideal approaches,” Baskin said. Community-based participatory research employs community members who agree to be a link to researchers. Community partners also help collect and interpret the data, she added. Baskin noted that despite working in a rural area among a number of disenfranchised, low-resource communities, by conducting community-based participatory research, she and her colleagues were able to complete a study on weight management with an exceptionally high retention rate of 99.5, 98.5, and 75 percent at 6, 12, and 24 months, respectively. In addition, another ongoing project has met more than 50 percent of its targeted enrollment of 450 cancer survivors and family members and has had an average retention of 98 percent among counties reaching the initial follow-up period. The cancer survivors are being recruited by local community health advisors who are volunteers, as well as by local part-time paid staff who are employees of the university conducting the research and also live in the communities in which the research is conducted. “People talk about African Americans or people living in rural areas as being hard to reach, but we have not experienced that,” she said.

Scarinci noted that few studies validate theoretical models of behavior change among populations experiencing a high burden of disease, particularly in behavioral science, where most of the models have been developed and tested. She suggested it may be warranted to conduct more research on appropriate cultural adaptations, but also questioned whether these cultural adaptations “are part of the house structure or are window dressings. Do we need another randomized trial with another population to prove that it works? I don’t know,” she said.

Almeida called for more research on the links among physical activity, sedentary activity, and cancer risk. Those links are better established among more prevalent cancer sites, such as breast or colon, but for most cancer sites they remain unknown, he said. Many cancer researchers see the need for a large clinical trial that can assess the importance of exercise and diet for cancer prevention across multiple cancer sites, akin to Diabetes Prevention Program, which found that lifestyle changes or treatment with metformin effectively delayed diabetes in a diverse population of overweight or obese American adults at high risk of diabetes (DPPOS, 2016). He added that research is also needed to determine the type, dose, and timing of physical

activity required to help prevent cancer. Most research on physical activity has been conducted in middle- to high-income populations in wealthier nations. More studies or evaluation tools are needed that clarify which of those interventions are applicable to low-resource settings, Almeida said, but little funding exists for these types of analyses.

Schmeler suggested more development and testing of novel cancer screening techniques for low-resource settings that do not require a lot of infrastructure and specialized skills. Trimble noted he is currently investigating whether there are cancer diagnostics that can be linked to smart phones. “There is a whole host of potential things that are out there that we are very excited about, but they need to be validated and then integrated into the health care system,” he said.

## **WRAP-UP**

Massetti closed the workshop with an overview of the six themes she took away from workshop presentations and discussion:

- Cultural context;
- Essential ingredients for interventions in low-resource settings;
- Investment in what is effective;
- Leveraging infrastructure and existing investments;
- Partnerships; and
- Sustainability.

She stressed the importance of understanding cultural similarities and differences, including the fear and stigma attached to cancer in many cultures. To counter these cultural beliefs and show the benefits of cancer control programs, practitioners need to engage or create an advocacy community that relies on partnerships with community advocates and survivors and health care providers. Stories from cancer survivors can “put a human face to cancer,” she stressed.

Better understanding is needed of the essential ingredients necessary for effective interventions in low-resource settings, Massetti said. She said important factors include what conditions need to be in place to be maximally effective, how well a program fits within the cultural and historical context, whether there is political and social will to advocate for the program and make it happen, and whether there is a health care infrastructure, including pathologists to diagnose and practitioners to treat those with positive screens, to support the program.

Investing in what works involves choosing the “best buys” in cancer screening and prevention based on the population-attributable fractions and the return on investment, Massetti stressed. “We need to do better at getting the data so we can help make the case that there is a return on investment,” she said. Surveillance and registries are critical to understanding where and how to invest resources and cancer prevention, she added.

The infrastructure needed for programs to be effective can be built by bundling interventions and preventive screening services and sharing resources, perhaps combining with partners focused on other disease areas to offer the full spectrum of preventive health, Massetti added. Building workforce capacity and community health worker networks “is not just saying which physicians are in which resource settings, but is also about expanding our concept of what

we mean by health care providers and how primary care physicians, specialty care physicians, community health workers, nurses, midwives, and everyone in between can to work together.” Massetti noted the debate on whether cancer prevention should be offered when adequate cancer treatment or palliation is not available. “That dialogue needs to continue and we need to think that through,” she said.

Massetti stressed that cancer control programs in low-resource settings cannot be undertaken without partnerships. These programs need to engage the local community as well as engage cross-sector and cross-disciplinary partners. “We need to think outside of just the health sector. If we are thinking about HPV vaccination, we need to think about education because boys and girls who need to be vaccinated go to schools. We also need to take it to the business sector and try to make a business case for cancer prevention,” Massetti said. She also called for building on existing networks.

Massetti pointed out that many speakers noted the need for programs to be sustainable and suggested there be more investments in infrastructure and more opportunities for evaluation and quality metrics “because it is those data that drive the ability for communities to make their own case.” She stressed that “You cannot start a program and ignore what it is going to look like 5 or 10 years from now because that does a disservice to communities when we cannot think about how they can take ownership and run with whatever is established in their context,” Massetti stressed.

Massetti finished her wrap-up by noting that the NCPF will be hosting a second workshop on cancer care in low-resource settings on November 14 and 15, 2016, in Washington, D.C. This workshop will focus on cancer treatment, palliative care, and survivorship care.

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## Appendix A

### Statement of Task

Ad hoc committees will plan and host a series of two 2-day public workshops to examine policy issues pertaining to the cancer care continuum in low-resource areas, both domestic and international.

The first workshop will focus on cancer prevention and early detection, while the second will focus on cancer treatment, palliative care, and survivorship care in low-resource communities. The workshops will feature invited presentations and panel discussions on topics that may include

- An overview of disparities in cancer control and outcomes, accounting for cultural and political barriers to access as well as resource constraints
- The current evidence base and strategies to support effective cancer prevention and risk reduction, diagnosis, and treatment in low-resource settings
- Key gaps in the evidence base and the challenges and opportunities to address those gaps to improve cancer outcomes for patients in low-resource populations
- Potential action steps for effectively applying the available evidence on cancer prevention, diagnosis, and treatment in resource-constrained communities
- Principled evaluations of successes and failures in cancer control efforts in low-resource settings, which could serve as models for how to develop effective and affordable cancer control

The committee will develop the agendas for the workshop sessions, select and invite speakers and discussants, and moderate the discussions. Individually authored workshop summaries of the presentations and discussions at the workshops will be prepared by a designated rapporteur in accordance with institutional guidelines.

## Appendix B

### Workshop Agenda

**October 26, 2015**

**7:30 am Registration and Breakfast**

**8:00 am Welcome from the National Cancer Policy Forum (NCPF)**

Michael Caligiuri, Ohio State University, NCPF Chair

**Overview of the Workshop**

Greta Massetti, Centers for Disease Control and Prevention, Planning Committee Co-Chair

Kathleen Schmeler, University of Texas MD Anderson Cancer Center, Planning Committee Co-Chair

**Overview of Global Trends in Cancer Prevention and Screening**

Lisa Stevens, National Cancer Institute

**8:40 am Session 1: Challenges and Opportunities in Prevention, Control, and Early Detection of Cancer in Low-Resource Settings**

*Moderator: Dan Masys, University of Washington*

**Speakers:**

- Thomas Bollyky, Council on Foreign Relations
- Mona Saraiya, Centers for Disease Control and Prevention
- Doyin Oluwole, Global Health Innovations and Action Foundation
- Kathleen Schmeler, University of Texas MD Anderson Cancer Center

**Panel Discussion**

**10:30 am Break**

**10:40 am Session 2: Sociocultural Considerations in Advancing Cancer Prevention and Control in Low-Resource Settings**

*Moderator: Lori Hoffman Hogg, Department of Veterans Affairs*

**Speakers:**

- Vivien Tsu, PATH, University of Washington
- Electra Paskett, Ohio State University
- Neal Palafox, University of Hawaii
- Felicia Knaul, University of Miami

**Panel Discussion**

**12:45 pm      Lunch Break**

**1:30 pm      Session 3: Cancer Prevention: Tobacco Control**

*Moderator: Greta Massetti, Centers for Disease Control and Prevention*

Speakers:

- Stella Bialous, University of California, San Francisco
- Ulysses Dorotheo, Southeast Asia Tobacco Control Alliance
- Michael Eriksen, Georgia State University

**Panel Discussion**

- Session speakers and Isabel Scarinci

**3:15 pm      Break**

**3:30 pm      Session 4: Cancer Prevention: Addressing Other Risk Factors and Emerging Issues**

*Moderator: Wendy Demark-Wahnefried, University of Alabama at Birmingham*

Speakers:

- Monica Baskin, University of Alabama at Birmingham
- Fabio Almeida, Virginia Tech
- Doug Morgan, Vanderbilt Ingram Cancer Center

**Panel Discussion**

**5:15 pm      Wrap Up Day 1**

**October 27, 2015**

**7:30 am      Registration and Breakfast**

**8:00 am      Session 5: Screening and Early Detection in Low-Resource Settings**

*Moderator: Kathleen Schmeler, MD Anderson Cancer Center*

Speakers:

- Samir Khleif, Georgia Regents University Cancer Center
- Isabel Scarinci, University of Alabama at Birmingham
- Peter Kingham, Memorial Sloan Kettering Cancer Center

**Panel Discussion**

**9:45 am      Break**

**10:00 am      Session 6: Stakeholder Perspectives**

*Moderator: Afsan Bhadelia, Harvard University*

Speakers:

- Mona Saraiya, Centers for Disease Control and Prevention
- Ted Trimble, National Cancer Institute
- Otis Brawley, American Cancer Society
- Luis Miguel Castilla, Embassy of Peru
- Loyce Pace, LIVESTRONG Foundation

**Group Discussion**

- 11:30 am      Workshop Wrap-Up**  
Greta Massetti, Planning Committee Co-Chair
- 11:45 am      Adjourn**