CLOSING GAPS IN CANCER SCREENING:

Connecting People, Communities, and Systems to Improve Equity and Access

A REPORT TO THE PRESIDENT OF THE UNITED STATES
FROM THE PRESIDENT'S CANCER PANEL

THE PRESIDENT'S CANCER PANEL

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This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and
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Dear President Biden,

The President's Cancer Panel is most appreciative of your ongoing dedication to ending cancer as we know it. We know that cancer is a deeply personal issue for you and your family, as it is for too many Americans. As we conclude the year-long observance of the National Cancer Act's 50th anniversary, we applaud the investments in research and cancer control over the past five decades that have led to tremendous progress against cancer, including substantial declines in cancer mortality. At the same time, we are keenly aware that there remains so much more to be done. In this report, the Panel focuses on one area requiring urgent attention: improving the uptake of cancer screening.

Throughout much of 2020, as the United States and the rest of the world focused on combatting the COVID-19 pandemic, our country experienced an alarming drop in cancer screenings. The postponement and cancellation of cancer screening is projected to result in thousands of excess cancer-related deaths. This sobering figure highlights the life-saving power of cancer screening and the need to correct the misperception that it is "elective." Underutilization of screening before, during, and beyond the pandemic is a problem that must be addressed. **We know that cancer screening saves lives. The challenge at hand is to ensure that screening is prioritized and easily accessible to *all* Americans, now and in the future.**

Gaps in cancer screening uptake—both before and during the pandemic—mean that too many Americans are enduring aggressive treatment for or dying from cancers that could have been prevented or detected at earlier stages. These gaps exacerbate the already heavy burden of cancer experienced by many communities of color, socially and economically disadvantaged populations, and families with hereditary cancers.

In 2020–2021, the President's Cancer Panel chose to investigate and identify opportunities to address these gaps in cancer screening. To this end, the Panel convened a series of meetings on cancer screening, gleaning insights from noted experts in the fields of breast, cervical, colorectal, and lung cancers. **Informed by these experts, the Panel concluded that more effective and equitable implementation of existing evidence-based cancer screening modalities and guidelines represents a significant opportunity to reduce the burden of cancer and accelerate the decline in cancer deaths**. In this report, we share with you recommendations to achieve four critical goals for connecting people, communities, and systems to improve equity and access in cancer screening. Implementation of the Panel's recommendations by stakeholders across the National Cancer Program will improve communication, facilitate equitable access, promote team-based care, and harness technology to support patients and providers.

Mr. President, the time to stem this tide is now. Your Cancer Panel respectfully shares this report and our recommendations for your urgent consideration, as a catalyst for action across the cancer enterprise at this critical time. We can and must improve uptake of cancer screening for all Americans, and we must effect meaningful change well before the next milestone anniversary of the National Cancer Act. Too many American lives depend on it.

Sincerely,

John P. Williams, MD

Edith P. Mitchell, MD

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EXECUTIVE SUMMARY

Cancer screening has been shown to save lives and reduce the burden of cancer. However, gaps in cancer screening mean too many in the United States are unnecessarily enduring aggressive treatment or dying from cancers that could have been prevented or detected at earlier, more easily treated stages. This includes disproportionate numbers of socially and economically disadvantaged populations and many at elevated risk for cancer due to inherited mutations in cancer susceptibility genes. This avoidable burden of cancer imposes a heavy physical, emotional, and economic toll on individuals, families, and communities around the country. It also has broader economic implications, reducing workforce productivity and adding unnecessary strain to the healthcare system.

In 2020–2021, the President's Cancer Panel held a series of meetings on cancer screening, with a focus on breast, cervical, colorectal, and lung cancers. **The Panel concluded that more effective and equitable implementation of cancer screening represents a significant opportunity for the National Cancer Program, with potential to accelerate the decline in cancer deaths and, in some cases, prevent cancer through detection and removal of precancerous lesions**. While continued research undoubtedly will lead to improvements in cancer screening in the coming years, meaningful gains can be made through better application of existing evidence-based modalities and guidelines.

PART 1
Cancer Screening in the United States: Challenges and Opportunities

Cancer screening has reduced the burden of cancer in the United States, but screening uptake has been incomplete and uneven. Furthermore, many people do not receive timely follow-up care after an abnormal screening test result, which undermines the effectiveness of screening. People without a usual source of care or health insurance, individuals with low income or low educational achievement, recent immigrants, individuals living in rural or remote areas, and members of some racial/ethnic minority groups are among those who experience disparities in cancer screening and follow-up care. Barriers to screening—which vary among individuals, communities, and healthcare settings—must be addressed to ensure that the benefits reach all populations.

PART 2
Taking Action to Close Gaps in Cancer Screening

In this report, the Panel identifies four critical goals for connecting people, communities, and systems to improve equity and access in cancer screening. Implementation of the Panel's recommendations to achieve these goals will improve communication, facilitate equitable access, promote team-based care, and harness technology to support patients and providers.

GOAL 1: IMPROVE AND ALIGN CANCER SCREENING COMMUNICATION

The public and healthcare providers alike need accurate, digestible, and actionable information about cancer screening. Lack of knowledge and misconceptions about screening have been reported among many populations with low rates of cancer screening, including racial/ethnic minority groups, individuals with low income or low educational achievement, and populations with low access to healthcare.

Recommendation 1.1: Develop effective communications about cancer screening that reach all populations.

A renewed commitment to effective, targeted communications about cancer screening is needed to ensure that screening reaches all populations. **Large and small organizations—including federal, state, and local government agencies; national advocacy organizations; healthcare systems; and community organizations—should develop and implement communications campaigns focused on cancer screening**. These campaigns should emphasize the benefits of cancer screening—including improved prognosis associated with early detection and, in some cases, prevention of cancer—and the importance of regular screening. Communications about cancer screening should be developed and disseminated in ways that empower people to apply information to make decisions about their health and increase the likelihood they will adopt proven interventions. Targeted messaging is needed for each cancer type for which screening is available. These messages should be tailored to different populations, as needed, and designed to help individuals overcome identified barriers to optimal cancer screening.

Recommendation 1.2: Expand and strengthen National Cancer Roundtables that include a focus on cancer screening.

The Panel believes that the National Roundtable model provides an ideal framework for bringing stakeholders together and addressing gaps in cancer screening and follow-up care, including inequities experienced by various sociodemographic groups. The American Cancer Society (ACS), Centers for Disease Control and Prevention (CDC), and other key partners should invest resources to expand the National Roundtable model to increase coordination and promotion of high-quality cancer screening. **New roundtables that include a strong focus on screening should be created for breast cancer and cervical cancer. Financial support for the National Colorectal Cancer Roundtable and National Lung Cancer Roundtable should be increased to allow important work on colorectal and lung cancer screening to continue and expand their reach to communities with low rates of screening and follow-up care. National Roundtables should make health equity and alignment of messaging about cancer screening and cancer screening guidelines high priorities**. Roundtable membership should represent the geographic, socioeconomic, and racial/ethnic diversity of the United States to ensure that the voices and perspectives of all populations inform activities and messaging.

GOAL 2: FACILITATE EQUITABLE ACCESS TO CANCER SCREENING

Inadequate access to healthcare services due to geographic, financial, or logistical challenges is a commonly cited barrier to cancer screening. Fear of judgment, apprehension about potential diagnoses, cultural factors, lack of trust in healthcare systems, and structural racism also can deter people from seeking or receiving recommended care. These barriers contribute to the lower rates of cancer screening initiation and recommended follow-up observed among many.

Recommendation 2.1: Provide and sustainably fund community-oriented outreach and support services to promote appropriate screening and follow-up care.

Accessing and navigating healthcare systems can be daunting, particularly for populations that are medically underserved. Community health workers (CHWs) have invaluable expertise on the culture and life experiences of their communities, making them effective liaisons between those communities and healthcare systems. CHWs can perform a range of activities to promote cancer screening and appropriate follow-up care, facilitate access, and address inequities. **Healthcare systems and health plans should establish CHW programs to reach the people in the communities they serve and ensure that those eligible receive appropriate and timely cancer screening and follow-up care. Healthcare systems and health plans should provide training directly or through partnerships with other organizations to ensure that CHWs have the knowledge and skills needed to do their jobs**. To date, most CHW programs have been funded through short-term grants or contracts, which creates instability that undermines cultivation of meaningful relationships with communities, community members, and healthcare systems. **Healthcare systems and health plans should establish sustainable funding for CHW programs to ensure they meet their full potential**.

Recommendation 2.2: Increase access to self-sampling for cancer screening.

Self-sampling approaches can increase access to cancer screening for people who live long distances from medical facilities, have difficulty attending appointments, or are uncomfortable in medical settings or with medical procedures used for other screening approaches. For any screening done via self-sampling, patients who receive an abnormal result need to receive follow-up care at a healthcare facility. Screening, including screening with self-collected samples, is effective only if those screened receive appropriate and timely follow-up care.

Stool-based tests have been integrated into U.S. colorectal cancer screening guidelines; however, despite evidence they can increase screening uptake, they are underused. **Healthcare providers should promote stool-based tests as an option for colorectal cancer screening, particularly for people who are hesitant or unable to undergo colonoscopy. In addition to offering colonoscopy, healthcare systems and health plans should distribute**

stool-based tests to individuals due for colorectal cancer screening as part of a systematic, organized effort to increase appropriate screening.

Human papillomavirus (HPV) self-sampling has not been approved for use in the United States, although it has been used effectively in other countries. Evidence suggests that HPV self-sampling could help reach U.S. women who are underscreened for cervical cancer. **The Panel encourages HPV test manufacturers to participate in validation efforts and pursue regulatory approval for HPV self-sampling strategies. The U.S. Food and Drug Administration (FDA) should prioritize review of the evidence supporting HPV self-sampling to ensure that it is available to women in the United States as soon as possible.** If HPV self-sampling is approved by the FDA, U.S. cervical cancer screening programs, including state and federal programs, should use HPV self-sampling to extend the reach of cervical cancer screening.

GOAL 3: STRENGTHEN WORKFORCE COLLABORATIONS TO SUPPORT CANCER SCREENING AND RISK ASSESSMENT

Providers play an essential role in patients' decisions about whether and when to be screened for cancer. However, competing demands make it difficult to thoroughly address each patient's needs within the limited time available during an appointment, particularly in the primary care setting in which most decisions about cancer screening are made.

Recommendation 3.1: Empower healthcare team members to support screening.

Team-based care has the potential to improve implementation of cancer screening. **Healthcare systems and medical offices should set up systems and processes that allow all members of the healthcare team to promote and implement cancer screening programs or practices**.

Payment policies can facilitate or restrict team-based care. Medicare coverage for lung cancer screening currently requires that the ordering physician or qualified nonphysician practitioner conducts a counseling and shared decision-making visit with the patient. This requirement places the burden of shared decision-making on the provider, introducing a bottleneck that results in a barrier to this new, lifesaving screening modality. If physicians can share the decision-making process with other team members, they will be able to implement lung cancer screening recommendations more broadly. **The Centers for Medicare & Medicaid Services (CMS) should modify its coverage requirements to allow additional members of physician-led healthcare teams to conduct shared decision-making for lung cancer screening**.

Recommendation 3.2: Expand access to genetic testing and counseling for cancer risk assessment.

Individuals at elevated risk for cancer due to their personal or family history or because they harbor mutations in cancer susceptibility genes may benefit from earlier, more frequent, or enhanced cancer screening or other risk-reducing interventions. Currently, most people with mutations in cancer susceptibility genes are never identified or are not identified until after they are diagnosed with cancer. Providers should regularly collect thorough family and personal health histories to determine whether their patients should undergo genetic testing for cancer risk genes.

Some payors require consultation with a certified genetic counselor or medical geneticist prior to genetic testing. Unfortunately, this policy creates an unnecessary barrier that results in fewer appropriate tests performed and longer turnaround times. **Providers should be enabled to offer genetic testing with informed consent. Payors should eliminate requirements for pretest counseling by a certified genetic counselor or medical geneticist**. Training and continuing education on genetics and genetic testing are critical to ensuring that providers are prepared to discuss various facets of genetic testing both before and after a patient undergoes testing. **Training and residency programs, professional societies, guideline makers, and other organizations should expand opportunities for training and education on genetics, genetic testing, and interpretation of genetic testing results**.

Genetic counselors are important members of the healthcare team. Most private insurers will reimburse certified genetic counselors who provide counseling services for people who meet personal and family history criteria for testing. However, genetic counselors are not recognized as healthcare providers by CMS, which means that they cannot be reimbursed directly through Medicare. **Legislative changes should be made so that genetic counselors are recognized as healthcare providers by CMS**. This would allow genetic counselors to contribute their specialized knowledge and skills to medical teams working to deliver high-quality care to patients at elevated risk for cancer and other diseases.

GOAL 4: CREATE HEALTH INFORMATION TECHNOLOGY THAT PROMOTES APPROPRIATE CANCER RISK ASSESSMENT AND SCREENING

Providers and patients alike are faced with more information than they can process in a reasonable amount of time. Health information technology (IT) has potential to help providers, patients, and healthcare systems quickly access and effectively use clinical knowledge and patient-specific data. Suboptimal application of the evidence-based clinical practice guidelines—including guidelines for cancer risk assessment and screening—is a critical problem that should be addressed through health IT.

Recommendation 4.1: Create computable versions of cancer screening and risk assessment guidelines.

Before being incorporated into health IT tools—including clinical decision supports (CDS)—clinical guidelines must be converted into a format that can be fully interpreted and executed by a computer. Currently, each health IT developer using a guideline independently renders a computable representation. Public availability of all cancer risk assessment, screening, and follow-up guidelines in a computable format would promote broader, more consistent, and faster implementation. **Research funding organizations with an interest in healthcare quality and implementation—including the Agency for Healthcare Research and Quality (AHRQ), CDC, National Institutes of Health (NIH), ACS, and others—should fund development of computable guidelines for cancer risk assessment and screening**. This could be done through grants to guideline organizations, researchers, or collaborative teams. **CDC and AHRQ should consider investment in dedicated programs to support creation of computable guidelines relevant to risk assessment, screening, and follow-up care for cancer and other diseases**. Computable guidelines should be shared through public resources, such as the AHRQ CDS Connect Repository, to facilitate their dissemination and use.

Recommendation 4.2: Create and deploy effective clinical decision support tools for cancer risk assessment and screening.

CDS can help providers and patients access and integrate clinical knowledge and patient-specific data to guide care. CDS may be particularly beneficial for primary care providers, who are expected to address a wide range of issues within a limited time during appointments, and providers in settings with limited financial resources. To be effective, CDS must deliver the right information in the right formats through the right channels to the right people at the right times in clinical workflows. **Electronic health record (EHR) vendors, healthcare organizations, and research funding organizations—including AHRQ, NIH, CDC, and private foundations—should prioritize support for development and evaluation of standards-based, interoperable CDS for cancer risk assessment and screening**. CDS should be integrated with EHRs to optimize workflow, facilitate data exchange, and avoid duplicate data entry. **EHR vendors should include CDS for cancer risk assessment and screening in standard EHR systems and make it as easy as possible for CDS developed by others to be integrated with the EHR**. To this end, it is critical that EHR vendors and IT developers continue to pursue interoperability of health IT systems.

PART 3
Conclusions

More effective and equitable implementation of cancer screening can save lives and reduce the burden of cancer. Implementation of the goals and recommendations put forth in this report will help optimize cancer screening through better communication about cancer risk and screening, enhanced access to care, and more efficient application of evidence-based screening guidelines. The Panel urges all stakeholders—healthcare providers, healthcare systems, payors, community and patient advocacy organizations, government agencies, and individuals—to work together to close gaps in cancer screening and ensure that the benefits reach all populations.

PREFACE

The President's Cancer Panel was established in 1971 by the National Cancer Act (P.L. 92-218) and is charged with monitoring the progress of the National Cancer Program—which includes all public and private activities focused on preventing, detecting, and treating cancers and on cancer survivorship—and identifying barriers to reducing the burden of cancer. The Panel investigates topics of high importance to the National Cancer Program for which actionable recommendations can be made. Information is collected through workshops, discussions with subject matter experts, and review of peer-reviewed and gray literature. Findings and recommendations are compiled in reports to the President of the United States.

For its 2020–2021 series, the Panel focused on uptake of cancer screening. The Panel convened the Working Group on Cancer Screening During the COVID-19 Era to inform the planning of five virtual, public workshops. The first four workshops each focused on a specific cancer type: lung, colorectal, cervical, and breast. The final workshop explored innovations with potential to improve cancer screening. All workshops engaged a range of stakeholders, including patients, patient advocates, healthcare providers, academic researchers, oncologists, health economists, statisticians, and intellectual property specialists, as well as representatives from healthcare systems, federal agencies, media outlets, insurance companies, and the biopharmaceutical industry.

Cancer screening has contributed to substantial reductions in cancer deaths in the United States over the past few decades. Despite its well-known benefits, uptake of cancer screening is incomplete and uneven. Rates for lung cancer screening—which has been recommended by the U.S. Preventive Services Task Force (USPSTF) for less than 10 years—are particularly low. While rates for breast, cervical, and colorectal cancers are higher, they are still well below targets. Furthermore, many people who receive an abnormal screening result do not receive recommended follow-up care in a timely fashion. Gaps in screening and receipt of follow-up care are even more pronounced in some sociodemographic groups, including people who do not have a usual source of healthcare or adequate health insurance, have low education or income, live in rural or remote areas, and/or are members of some racial/ethnic minority groups.

The Panel concluded that closing these gaps through more effective and equitable implementation of cancer screening is a significant opportunity for the National Cancer Program, with potential to accelerate the decline in cancer deaths and, in some cases, prevent cancer through detection and removal of precancerous lesions. Many trends in the U.S. healthcare system—including expanding access to high-quality health insurance, the shift toward value-based medicine, increased adoption of telehealth, and a commitment to data sharing and interoperability of health information systems—have potential to support cancer screening, but these efforts are not sufficient. Targeted actions at the national and local levels are needed to empower the American people and healthcare providers to seek and promote cancer screening.

In this report, the Panel presents strategies for closing gaps in cancer screening. These include efforts to increase overall rates of appropriate screening and follow-up care, as well as actions to ensure that the benefits of cancer screening reach all populations and communities. While this report is presented to the President of the United States, the recommendations also are for the diverse stakeholders that make up the National Cancer Program. By implementing the Panel's recommendations, these stakeholders—large and small, public and private, national and local—will connect people, communities, and systems to ensure the benefits of cancer screening reach all populations.

PART 1

Cancer Screening in the United States: Challenges and Opportunities

Cancer Screening in the United States: Challenges and Opportunities

An estimated 3.2 million U.S. cancer deaths have been averted since 1991 because of improvements in early detection and treatment, as well as reductions in smoking. However, cancer continues to be a major public health problem in the United States, with 1.9 million new cancer cases and more than 600,000 cancer deaths expected in 2021.[1] In addition to the toll cancer imposes on individuals, families, and communities, cancer deaths cost the United States over $90 billion per year in lost earnings.[2]

Cancer screening has been shown to save lives, but there currently are significant gaps in screening uptake and timely receipt of follow-up care after an abnormal screening test result, including among many populations that often are medically underserved. **The President's Cancer Panel has determined that more effective and equitable implementation of cancer screening represents a significant opportunity for the National Cancer Program, with potential to accelerate the decline in cancer deaths and, in some cases, prevent cancer through detection and removal of precancerous lesions**.

This report focuses on the four cancers—breast, cervical, colorectal, and lung—for which the U.S. Preventive Services Task Force (USPSTF) recommends screening for eligible individuals.[3-6*] Several other organizations also issue screening guidelines for these cancers (Table 1). While there are differences in details among guidelines—for example, related to recommended age at initiation, frequency of screening, and/or screening modality—guideline organizations are united in their belief that regular and appropriate cancer screening helps save lives. Most cancer screening guidelines are for people at average risk of cancer, with eligibility often based primarily on age. Lung cancer screening, however, is recommended based on smoking history. There also are screening recommendations tailored to those at high risk for breast or colorectal cancer based on personal or family history of cancer. Cancer screening guidelines are for asymptomatic individuals; any person experiencing symptoms consistent with cancer should follow up with a healthcare provider for a diagnostic workup.

Screening Reduces the Burden of Cancer

Cancer screening tests have been available for cervical, breast, and colorectal cancers for decades. Lung cancer screening via low-dose computed tomography (CT) has been recommended since 2013. Uptake of these tests has had a measurable impact on mortality and, in some cases, incidence of these cancers:

- **Breast cancer**—Screening mammography, along with advances in treatment, substantially contributed to the 50 percent reduction in breast cancer mortality in the United States between 1975 and 2012.[7]

* Currently available screening tests for other types of cancer have not been shown to reduce deaths from those cancers. Source: Centers for Disease Control and Prevention. Screening tests [Internet]. Atlanta (GA): CDC; [updated 2020 July 29; cited 2021 March 31]. Available from: https://www.cdc.gov/cancer/dcpc/prevention/screening.htm

SCREENING DURING A PANDEMIC: LESSONS LEARNED FROM COVID-19

Rates of cancer screening plummeted in the spring of 2020 when many healthcare services were suspended due to the coronavirus disease 2019 (COVID-19) pandemic. This sparked concern within the cancer community about the impact of missed and delayed diagnoses, with estimates that there would be nearly 10,000 excess deaths from breast and colorectal cancers in the United States over the next 10 years. While most facilities and patients have resumed screening, rates continue to fluctuate and remain below prepandemic rates. The full impact of COVID-19 on cancer screening and subsequent diagnoses and deaths is still being assessed, but the COVID-19 crisis provides several lessons for cancer screening:

- Cancer screening is an essential healthcare service. Decisions to delay or forgo screening should only be made when the risks clearly outweigh benefits.
- Clear and accurate communication is needed to guide screening during healthcare system disruptions.
- When screening capacity is limited, high-risk individuals should be identified and prioritized.
- Telehealth and self-collection may enable screening for certain cancers with minimal physical contact with healthcare settings.

Sources: Sharpless NE. Science. 2020;368(6497):1290. Available from: https://www.ncbi.nlm.nih.gov/pubmed/32554570; Mast C, et al. Delayed cancer screening—a second look. Epic Health Research Network [Internet]. Verona (WI); EHRN; 2020 Jul 17 [cited 2021 Oct 2]. Available from: https://ehrn.org/articles/delayed-cancer-screenings-a-second-look; Mast C, et al. Cancer screenings are still lagging. Epic Health Research Network [Internet]. Verona (WI); EHRN; 2021 Jun 9 [cited 2021 Oct 6]. Available from: https://ehrn.org/articles/cancer-screenings-are-still-lagging

- **Cervical cancer**—Screening using the Papanicolaou test (Pap smear) and, more recently, human papillomavirus (HPV) testing has been largely responsible for the 58 percent drop in cervical cancer incidence and nearly 60 percent reduction in cervical cancer mortality between 1975 and 2017 in the United States.[8]
- **Colorectal cancer**—Rates of colorectal cancer incidence and mortality have declined by more than one-third over the past 30 years, a trend that has been credited to expansion of screening.[9,10] It is estimated that about two-thirds of colorectal cancer deaths in the United States could be avoided through screening.[1,11,12] Most colorectal cancer screening in the United States is done via colonoscopy, though other visual tests (e.g., sigmoidoscopy) and stool-based tests (e.g., fecal immunochemical test [FIT]) also are available.

- **Lung cancer**—Although it is too soon to assess the impact of lung cancer screening at the population level, the U.S. National Lung Cancer Screening Trial determined that annual low-dose computed tomography reduced lung cancer mortality by 20 percent in high-risk individuals.[13] Trials in other countries have yielded similar outcomes.[14]

Cancer Screening Uptake Is Incomplete and Uneven

Despite the established benefits of cancer screening, there are significant gaps between recommended screening and screening uptake (Figure 1). Rates are particularly low for lung cancer, in large part because screening has only been recommended since 2013. Colorectal cancer screening has increased in recent years, but continued momentum is needed to achieve target rates. While rates of breast and cervical cancer screening are higher, they have plateaued over the past 20 years, leaving many without the benefits of screening. Furthermore, many people at high risk for cancer due to their personal or family history are not being identified or offered appropriate high-risk screening (e.g., initiation at an earlier age, more frequent screening, different screening modality). Cancer screening effectiveness depends on timely follow-up care and diagnostic resolution after an abnormal screening test result.[15] There currently are insufficient data on follow-up for abnormal lung cancer screening results, but gaps in follow-up have been documented for mammography, Pap and HPV tests, and stool-based tests.[16]

TABLE 1. Cancer Screening Guidelines

Cancer Type	Organizations Issuing Screening Guidelines
Breast	American Cancer Society American College of Obstetricians and Gynecologists American College of Physicians American College of Radiology and Society of Breast Imaging American Society of Breast Surgeons National Comprehensive Cancer Network U.S. Preventive Services Task Force
Cervical	American Cancer Society American College of Physicians U.S. Preventive Services Task Force
Colorectal	American Academy of Family Physicians American Cancer Society American College of Gastroenterology American College of Physicians National Comprehensive Cancer Network U.S. Multi-Society Task Force for Colorectal Cancer U.S. Preventive Services Task Force
Lung	American Academy of Family Physicians American Association for Thoracic Surgery American Cancer Society American College of Chest Physicians National Comprehensive Cancer Network U.S. Preventive Services Task Force

Note: This list may not be comprehensive. Organizations are listed only if they develop their own guidelines. Organizations that endorse the guidelines of another organization are not listed. **Sources:** American Cancer Society. American Cancer Society guidelines for the early detection of cancer [Internet]. Atlanta (GA): ACS; [updated 2020 Jul 30; cited 2021 Feb 26]. Available from: https://www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html; Oeffinger KC, et al. JAMA. 2015;314(15):1599-614. Available from: https://www.ncbi.nlm.nih.gov/pubmed/26501536; Smith RA, et al. CA Cancer J Clin. 2019;69(3):184-210. Available from: https://www.ncbi.nlm.nih.gov/pubmed/30875085; The American College of Obstetricians and Gynecologists. Breast cancer risk assessment and screening in average-risk women. Practice Bulletin Number 179 [Internet]. 2017 [cited 2021 Nov 9]. 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Available from: https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/cervical-cancer-screening; American Academy of Family Physicians. Clinical preventive service recommendation: colorectal cancer [Internet]. Leawood (KS): AAFP; [cited 2021 Nov 2]. Available from: https://www.aafp.org/family-physician/patient-care/clinical-recommendations/all-clinical-recommendations/colorectal-cancer-adults.html; Wolf AMD, et al. CA Cancer J Clin. 2018;68(4):250-81. Available from: https://www.ncbi.nlm.nih.gov/pubmed/29846947; Shaukat A, et al. Am J Gastroenterol. 2021;116(3):458-79. Available from: https://www.ncbi.nlm.nih.gov/pubmed/33657038; Qaseem A, et al. Ann Intern Med. 2019;171(9):643-54. Available from: https://pubmed.ncbi.nlm.nih.gov/31683290; National Comprehensive Cancer Network. Colorectal cancer screening [Internet]. Plymouth Meeting (PA): NCCN; [cited 2021 Jun 4]. Available from: https://www.nccn.org/guidelines/guidelines-detail?category=2&id=1429; Provenzale D, et al. 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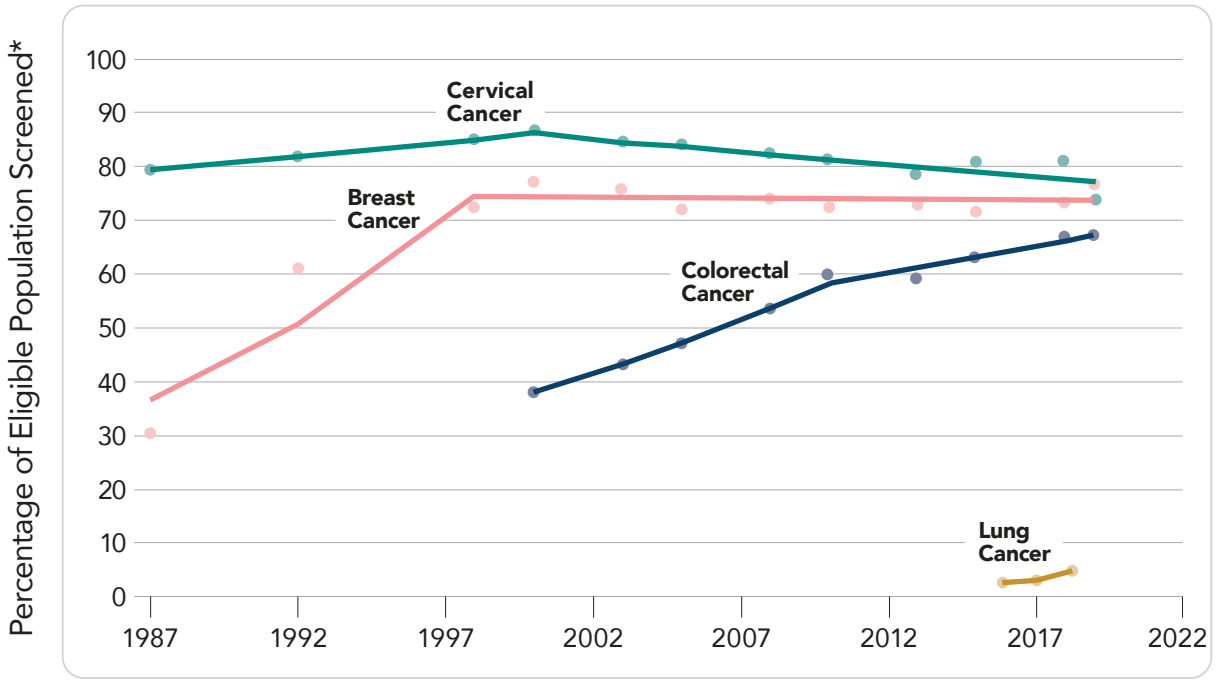
FIGURE 1. U.S. Cancer Screening Rates



***Breast cancer:** Percentage of females aged 50–74 years who have had mammography within the past 2 years. **Cervical cancer:** Percentage of females aged 21–65 years who are up to date with cervical cancer screening. For 2013 and before, up to date with cervical cancer screening was defined as having a Pap test within the past 3 years. For 2014–2018, up to date was defined as having a Pap test within the past 3 years for women aged 21–65 years, or, for women aged 30–65, having an HPV test with a Pap test in the past 5 years. **Colorectal cancer:** Percentage of adults aged 50–75 years who are up to date with colorectal cancer screening. Before 2016, up to date was defined as having fecal occult blood test (FOBT) every year, a sigmoidoscopy every 5 years in combination with FOBT every 3 years, or a colonoscopy every 10 years. Since 2016, up to date has been defined as FOBT or fecal immunochemical test (FIT) every year, fecal DNA testing at least every 3 years, CT colonography every 5 years, flexible sigmoidoscopy alone every 5 years or every 10 years in combination with yearly FIT, or colonoscopy every 10 years. **Lung cancer:** Proportion of adults who have been screened for lung cancer using low-dose CT in the past year among those who are aged 55–80 years who have smoked for 30+ pack-years and who currently smoke or have quit within the past 15 years. **Source for breast, cervical, and colorectal cancers:** Centers for Disease Control and Prevention, National Center for Health Statistics. National Health Interview Survey. Weighted regression lines are calculated using the Joinpoint Trend Analysis Software, Version 4.8 April 2020, National Cancer Institute. Available from http://progressreport.cancer.gov. **Source for lung cancer:** Fedewa SA, Kazerooni EA, Studts JL, et al. State variation in low-dose computed tomography scanning for lung cancer screening in the United States. J Natl Cancer Inst. 2021;113(8):1044-52. Available from: https://www.ncbi.nlm.nih.gov/pubmed/33176362

Although there are differences among cancer types, the following factors are associated with lower rates of screening or follow-up after abnormal screening test result among age-eligible adults across multiple cancers:[9,17-21]

- No usual source of healthcare
- Uninsured or underinsured status
- Recent immigrant status
- Less than high school education
- Low income
- Younger age
- American Indian/Alaska Native, Asian, Black, or Hispanic race/ethnicity
- Residence in a rural or remote area.

Numerous barriers to cancer screening—including the initial screening test and follow-up care after an abnormal screening test result—have been documented for both patients and providers. Patients report lack of awareness or understanding, concerns about the cost of screening or follow-up care,

discomfort with screening or follow-up procedures, lack of trust in providers, belief that screening is not a priority, stigma, and fear of cancer diagnosis or cancer treatment.[22-28] Logistical challenges—such as lack of time due to competing personal demands, lack of paid time off work, availability or cost of transportation, and dependent care—also play a role for some patients.[22-28] Some eligible patients also say their providers have not recommended cancer screening.[22-28] Provider barriers to cancer screening include lack of familiarity with guidelines, challenges identifying eligible patients, insufficient time to discuss screening, disagreement with or skepticism about screening guidelines, challenges conducting shared decision-making (particularly for lung cancer), and anticipated burden of managing abnormal results.[23,29,30]

Equitable Cancer Screening Must Be a Public Health Priority

Screening tests for breast, cervical, colorectal, and lung cancers can detect cancer at earlier stages when it is more likely to respond to treatment and, in some cases, can prevent cancer through detection of precancerous lesions. Gaps in cancer screening must be closed to realize its full potential. Efforts to close these gaps and equitably implement cancer screening in the United States must go beyond the initial screening test; to complete the screening process, individuals also must receive all recommended follow-up care for abnormal screening test results and receive a definitive diagnosis and action plan (e.g., return to regular screening, increased surveillance, cancer treatment). All too often, populations that are medically underserved have lower rates of cancer screening and follow-up care, putting them at greater risk of late-stage cancer diagnoses and death. Inadequate risk assessment also means that many people at high risk of cancer are not identified or given the opportunity to benefit from more intensive screening.

In this report, the President's Cancer Panel sets forth four goals to optimize evidence-based cancer screening in the United States. The recommendations for achieving these goals acknowledge the importance of clear and actionable information for empowering patients and providers, the need to facilitate easy access to screening services, and the opportunity to improve systems to make screening more efficient and equitable. The Panel's recommendations and some of the stakeholders responsible for implementing them are detailed in the following section of the report and summarized in Appendix B. The Panel urges all stakeholders—from large national organizations and agencies to small community groups—to work together to achieve the full promise of cancer screening.

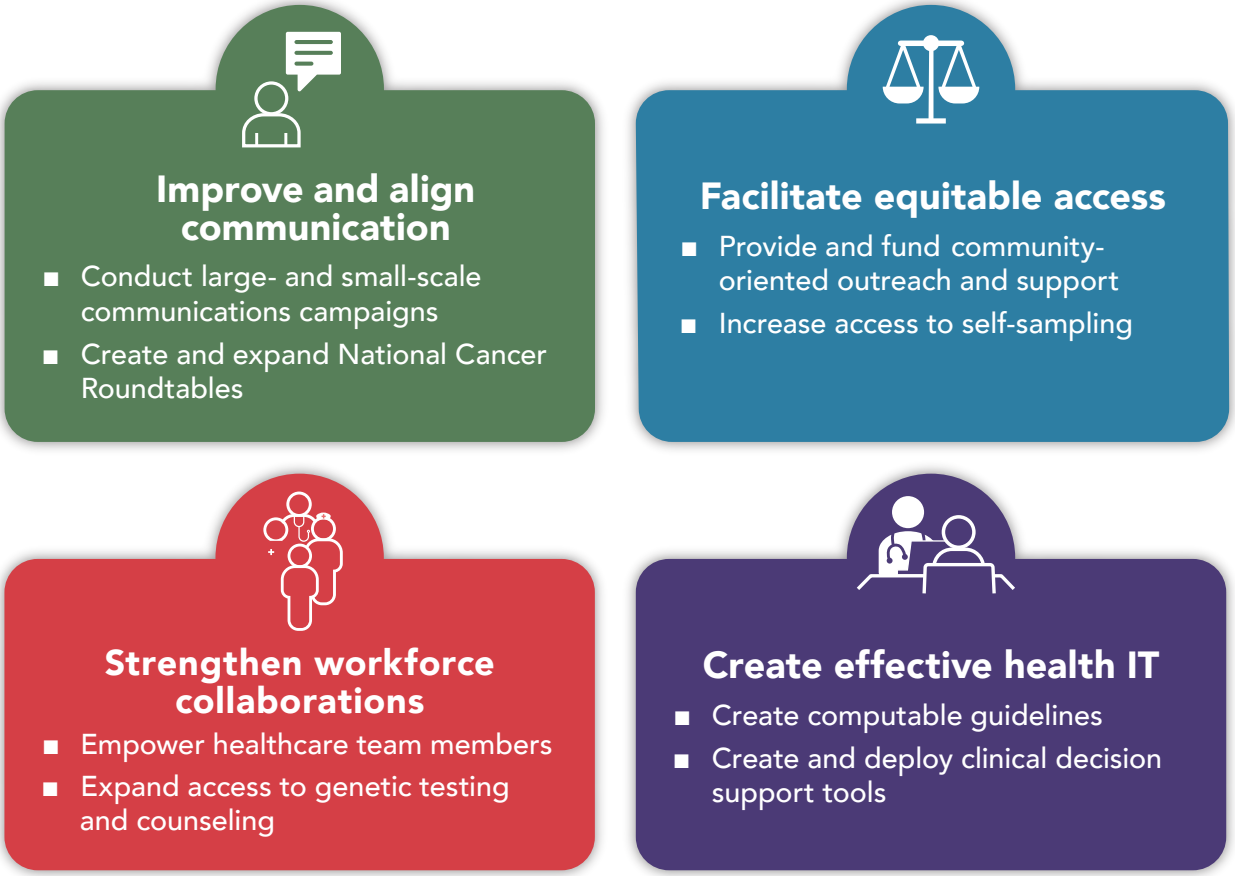
PART 2

Taking Action to Close Gaps in Cancer Screening

Taking Action to Close Gaps in Cancer Screening

Cancer screening has the potential to save lives and reduce the burden of cancer on individuals, families, communities, and the nation. While many in the United States benefit from cancer screening, too many are left behind, resulting in unnecessary suffering and death. Strategies and tools needed to address the current gaps in cancer screening and follow-up care after an abnormal cancer screening test result are available, but they must be innovatively and collaboratively applied to equitably reach all populations. In this report, the Panel identifies four critical goals for connecting people, communities, and systems to improve equity and access in cancer screening (Figure 2). Implementation of the Panel's recommendations will improve communication, facilitate equitable access, promote team-based care, and harness technology to support patients and providers.

FIGURE 2. President's Cancer Panel Goals and Recommendations



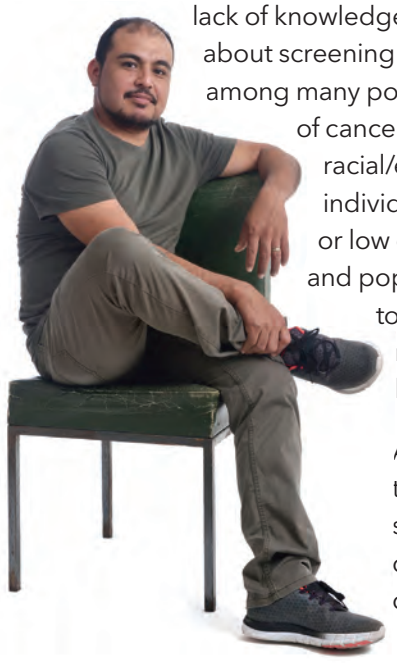
GOAL 1:
Improve and Align Cancer Screening Communication

General awareness of cancer screening in the United States is high, and a large proportion of people believe regular screening is important and can save lives.[31] A substantial portion of Americans undergo regular screening for cancer, leading to the early detection of many cancers and precancers. Despite this, many people are missing out on the benefits of cancer screening. Although many factors influence screening uptake, understanding the benefits and options for screening and knowing how to access it are critical. **The public and healthcare providers alike need to have accurate, digestible, and actionable information about cancer screening**.

Recommendation 1.1

Develop effective communications about cancer screening that reach all populations.

Communications campaigns and education have increased awareness of cancer screening, particularly for more established screening tests for breast, cervical, and colorectal cancer screening. However, lack of knowledge and misconceptions about screening have been reported among many populations with low rates of cancer screening, including racial/ethnic minority groups, individuals with low income or low educational achievement, and populations with low access to healthcare (e.g., living in rural/remote areas, lacking health insurance).[32-34]



A renewed commitment to effective large- and small-scale targeted communications about cancer screening is needed to ensure that screening reaches all populations. **Communications about cancer screening should be developed and disseminated in ways that empower people to apply information to make decisions about their health and increase the likelihood they will adopt proven interventions**. Use of a four-part health literacy framework has been suggested to guide health communications about screening (Figure 3).[35]

Communications should emphasize the benefits of cancer screening—including improved prognosis associated with early detection and, in some cases, prevention of cancer—and the importance of regular screening. Targeted messaging is needed for each cancer type for which screening is available. These messages should be tailored to different populations, as needed, and designed to help individuals overcome identified barriers to optimal cancer screening.

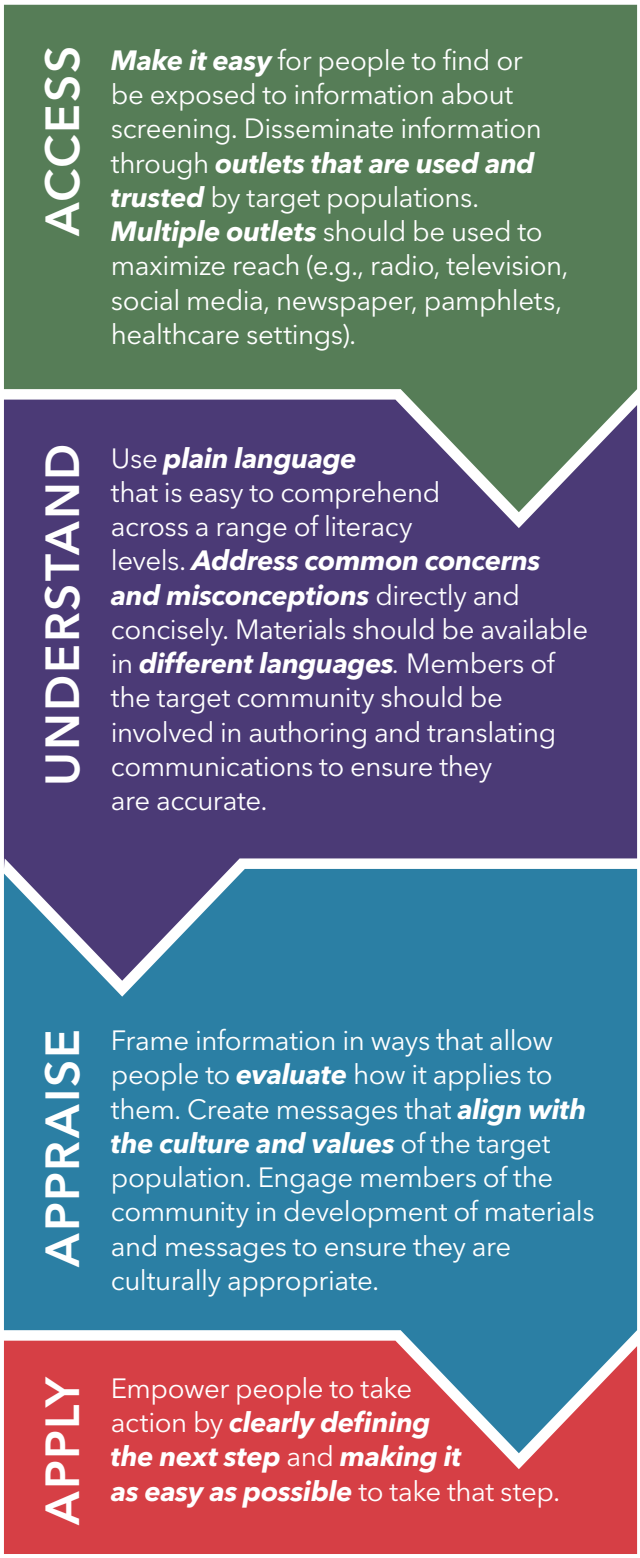
General Cancer Screening Messages

- ***Cancer screening saves lives and reduces the burden of cancer.*** Cancer screening can identify cancer at earlier stages when it is easier to treat and when treatment is more likely to be effective. In some cases, screening tests can even prevent cancer through detection of precancerous lesions.
- ***Regular screening and follow-up for abnormal screening results are essential***. To achieve the full benefits of cancer screening, screening tests must be performed at recommended intervals (e.g., annually, every 3 years) and recommended follow-up for abnormal screening test results must be received in a timely manner.

Breast Cancer Screening Messages

- ***Women should undergo regular screening in accordance with any of the major guidelines***. Differences in breast cancer screening guidelines with respect to age at initiation and screening

FIGURE 3. Health Literacy Framework



Source: Best AL, et al. J Cancer Educ. 2017;32(2):213-7. Available from: https://www.ncbi.nlm.nih.gov/pubmed/28275965

interval for women at average risk of breast cancer[4,36,37] have resulted in confusion among the public and providers.[38,39] However, adherence to any of the major screening guidelines is expected to reduce the risk of death from breast cancer.[40]

- ***Risk assessment for breast cancer should be done for all women by age 25***. Women at high risk of breast cancer may benefit from earlier initiation of screening and enhanced screening with magnetic resonance imaging in addition to mammography; however, risk assessment and supplemental screening currently are underutilized.[41] Providers should assess risk based on family and personal history. Genetic testing and counseling should be offered to those at risk of inheriting mutations in cancer susceptibility genes and supplemental screening recommended as appropriate.

Cervical Cancer Screening Messages

- ***HPV testing is a highly effective option for cervical cancer screening***. The annual Pap test has been the mainstay of cervical cancer screening for more than 50 years; however, guidelines have evolved over the past few decades. Women now have the option to be screened via Pap test or using the more sensitive HPV test, either alone or in combination with the Pap test. Screening intervals have been extended to 3 years for Pap tests and 5 years for HPV testing with or without a Pap test. Inadequate adherence to current guidelines has been documented, in part due to the mistaken belief that HPV testing is less effective than the Pap test.[42]
- ***Cervical cancer screening should continue through age 65 and sometimes beyond***. Major guidelines recommend that cervical cancer screening begin at 21 or 25 years of age (depending on the guideline) and continue through age 65. However, compared with younger women, fewer women between 51 and 65 years of age are up to date for cervical cancer screening.[17] Screening also may be indicated for women older than 65 if they have not been adequately screened or if they have been recently treated for a precancerous lesion.

Colorectal Cancer Screening Messages

- ***There are multiple effective options for colorectal cancer screening, including noninvasive stool-based tests***. Major guidelines recommend either direct visualization tests (e.g., colonoscopy, flexible sigmoidoscopy, virtual colonoscopy) or stool-based tests (e.g., FIT, FIT-DNA) for colorectal cancer screening. Nearly 90 percent of colorectal screening in the United States is being completed through colonoscopy,[43,44] likely because many providers believe colonoscopy is the best colorectal cancer screening modality.[45,46] While colonoscopy is an excellent option for colorectal cancer screening, stool-based tests offer some logistical benefits over colonoscopy, and there is no evidence they are less effective than colonoscopy for people at average risk. Survey data show that many people would select a stool-based test over colonoscopy if given the choice,[47] and offering stool-based tests can increase rates of colorectal cancer screening.[48]
- ***Colorectal cancer risk is increasing among younger adults. Colorectal cancer screening should begin at age 45 for average-risk individuals***. Incidence rates of colorectal cancer in individuals aged 65 and older have been falling since the 1990s, largely due to increased screening. However, rates of colorectal cancer have been increasing among younger adults, including those younger than 50 years of age.[9] It is projected that colorectal cancer will become the leading cancer-related cause of death for those 20 to 49 years old in the United States by 2030.[49] This trend has led guideline makers, most recently USPSTF,[5] to recommend that colorectal cancer screening begin at age 45 rather than age 50.
- ***Risk assessment for colorectal cancer should occur by age 20***. Individuals at high risk for colorectal cancer—such as those with Lynch syndrome or other inherited cancer syndromes—may benefit from earlier and/or more frequent screening; however, risk assessment for colorectal cancer and inherited cancers is underutilized.[50] Providers should regularly collect a comprehensive family and personal history to assess colorectal cancer risk beginning by age 20 since initiation of screening is recommended at this age for some high-risk individuals.[51] Genetic testing and counseling should be offered to those at risk for inherited cancer syndromes and supplemental screening recommended as appropriate.

Lung Cancer Screening Messages

- ***Lung cancer screening is available and can save lives***. Lung cancer screening—first recommended by USPSTF in 2013—is relatively new. Lack of public awareness and lack of provider familiarity with guidelines have been identified as key

TARGETING HEALTHCARE PROVIDERS

Healthcare providers play a critical role in people's decisions to be screened for cancer. However, guidelines frequently are updated based on new evidence and evaluation, which makes it challenging for providers to stay up to date on all guidelines relevant to their practice. Communications campaigns targeted to various types of providers are needed to ensure that current guidelines are disseminated, understood, and adopted. These campaigns should be carried out by professional societies, public health organizations, and healthcare systems. Education and training in key areas also will help providers assess cancer risk and appropriately promote screening for their patients (see *Education and Training for Healthcare Teams* on page 28).

Source: Peterson EB, et al. Prev Med. 2016;93:96-105. Available from: https://www.ncbi.nlm.nih.gov/pubmed/27687535

barriers to lung cancer screening.[23] In addition, many people hold fatalistic beliefs about lung cancer, viewing the disease as untreatable.[52] Thus, communications campaigns should focus on increasing familiarity with lung cancer screening and its potential to reduce mortality.

- ***Lung cancer screening can benefit current and former smokers***. Lung cancer screening currently is recommended for adults aged 50 to 80 years based on smoking history (e.g., at least a 20-pack-year history of smoking). The stigma surrounding smoking and lung cancer may hinder some eligible people from pursuing lung cancer screening. Communications campaigns with targeted empathic messages may help overcome this stigma. Messages and decision aids tailored based on current smoking status also may resonate better with people eligible for lung cancer screening.[53]

Large and small organizations—including federal, state, and local government agencies; national advocacy organizations; healthcare systems; and community organizations—should develop and implement communications campaigns focused on cancer screening. Organizations with a strong national presence—such as the Centers for Disease Control and Prevention (CDC) and American Cancer Society (ACS)—are well positioned to deliver messages to the broader public and healthcare providers. Healthcare systems should conduct both large- and small-scale information campaigns tailored to the populations they serve.

Regional and local advocacy organizations also can play very important roles in ensuring that messages are accessible, appropriate, and actionable for the people in their communities.

Recommendation 1.2

Expand and strengthen National Cancer Roundtables that include a focus on cancer screening.

The most effective way to improve cancer screening in the United States is through coordinated national efforts that involve all stakeholders. The National Roundtable model provides mechanisms to accomplish this. The first cancer roundtable—the National Colorectal Cancer Roundtable (NCCRT)—was cofounded by ACS and CDC in 1997 with the primary goal of increasing colorectal cancer screening rates among eligible U.S. adults. A key feature of NCCRT then and now is the involvement of organizations and individuals from numerous sectors that work together to address barriers to screening. A notable achievement of NCCRT is the *80% by 2018* initiative launched in 2014 to activate organizations to invest in colorectal cancer screening. More than 1,800 organizations participated in the initiative; more than 350 organizations reported reaching the 80 percent goal, and hundreds of others reported increased colorectal cancer screening rates. National colorectal cancer screening rates increased from about 65 percent to nearly 70 percent over the course of the campaign. To build on the momentum created by *80% by 2018*, NCCRT has launched *80% in Every Community* to address disparities in cancer screening and follow-up care in racial/ethnic minority, low-income, and rural communities.[54-56]

Based on the success of NCCRT, ACS partnered with many organizations and companies to form roundtables for HPV vaccination, patient navigation, and lung cancer (Table 2). The National Lung Cancer Roundtable (NLCRT) addresses various aspects of lung cancer screening, including shared decision-making, implementation of screening programs, access to high-quality screening, and delivery of tobacco cessation treatment in the context of lung

cancer screening. NLCRT has issued proposed quality metrics for lung cancer screening programs[57] and a call for improved electronic health record (EHR) tools to support screening programs.[58]

The Panel believes that the National Roundtable model provides an ideal framework for bringing stakeholders together and addressing gaps in cancer screening and follow-up care after an abnormal screening test result, including inequities experienced by various sociodemographic groups. Roundtables are well positioned to identify and amplify high-priority messages about cancer screening to providers and the public using modern communications platforms. ACS, CDC, and other key partners should invest resources to expand the National Roundtable model to increase coordination and promotion of high-quality cancer screening.

New roundtables that include a strong focus on screening should be created for breast cancer and cervical cancer. Financial support for the NCCRT and NLCRT should be increased to allow important work on colorectal and lung cancer screening to continue and expand their reach to communities with low rates of screening and follow-up care. The roundtable for cervical cancer should coordinate with the National HPV Vaccination Roundtable given their overlapping interest in cervical cancer prevention.

National Roundtables should make health equity and alignment of messaging about cancer screening and cancer screening guidelines high priorities. Roundtable membership should represent the geographic, socioeconomic, and racial/ethnic diversity of the United States to ensure that the voices and perspectives of all populations inform activities and messaging. NLCRT should implement a large-scale campaign, similar to *80% by 2018*, to raise awareness of and commitment to lung cancer screening.

TABLE 2. Current National Cancer Roundtables

Roundtable	Year Established	Goal(s)
National Colorectal Cancer Roundtable	1997	Increase the use of proven colorectal cancer screening tests among the entire population for whom screening is appropriate.
National HPV Vaccination Roundtable	2014	Raise HPV vaccination rates and prevent HPV cancers in the United States.
National Navigation Roundtable	2014	Achieve health equity and access to quality care across the cancer continuum through effective patient navigation.
National Lung Cancer Roundtable	2017	Reduce lung cancer incidence and mortality in the United States through coordinated leadership, strategic planning, advocacy, and action.

Sources: National Colorectal Cancer Roundtable. Home page [Internet]. Atlanta (GA): American Cancer Society; [cited 2021 Jun 9]. Available from: https://nccrt.org; National HPV Vaccination Roundtable. Home page [Internet]. Atlanta (GA): American Cancer Society; [cited 2021 Oct 2]. Available from: https://hpvroundtable.org; National Lung Cancer Roundtable. Home page [Internet]. Atlanta (GA): American Cancer Society; [cited 2021 Oct 2]. Available from: https://nlcrt.org; National Navigation Roundtable. Home page [Internet]. Atlanta (GA): American Cancer Society; [cited 2021 Oct 2]. Available from: https://navigationroundtable.org

ENSURING COST IS NOT A BARRIER TO SCREENING

Access to cancer screening, follow-up testing, and treatment should not depend on a patient's ability to pay. Lower rates of cancer screening and recommended follow-up care have been linked to lack of health insurance and underinsurance. The Panel believes that all people in the United States should have access to high-quality health insurance, and safety net programs must be created to ensure that out-of-pocket costs do not deter people from receiving recommended care, regardless of insurance status. Provisions of the Affordable Care Act—including the expansion of Medicaid in many states and elimination of cost-sharing for preventive services for private insurance plans, Medicare, and many people covered by Medicaid—have increased access to health insurance and reduced financial barriers to cancer screening. There is evidence that these changes are helping to narrow cancer-related disparities experienced by some sociodemographic subpopulations.

Despite widespread coverage without cost-sharing for cancer screening tests, cost may continue to pose a barrier for some patients. In some states, individuals with traditional Medicaid coverage may have a copay for preventive services such as cancer screening. In addition, patients often must pay out of pocket for follow-up testing, including diagnostic services and additional surveillance. This can be particularly problematic for colorectal cancer screening. Patients initially screened for colorectal cancer using a stool-based test must undergo colonoscopy if they receive an abnormal result. While the cost of the stool-based test would be fully covered, patients often must pay a deductible or copay for the subsequent colonoscopy, despite the fact that the colonoscopy is needed to complete the screening process. Out-of-pocket costs or perceived costs also have been cited as barriers to receipt of recommended follow-up for other cancer types. The Panel supports efforts—including legislation—to ensure that cost-sharing for cancer screening or additional surveillance and recommended diagnostic services after an abnormal cancer screening test does not deter patients from receiving these services. In this regard, the Panel applauds Congress for passing the Removing Barriers to Colorectal Cancer Screening Act in December 2020, eliminating cost-sharing for Medicare patients if polyps are identified and removed during a screening colonoscopy.

Programs such as the CDC National Breast and Cervical Cancer Early Detection Program and Colorectal Cancer Control Program have helped make cancer screening and follow-up care more accessible for low-income people. The National Breast and Cervical Cancer Early Detection Program serves more than 300,000 women a year through direct provision of Pap tests, HPV tests, mammograms, magnetic resonance imaging, clinical breast exams, and diagnostic services. The Colorectal Cancer Control Program partners with healthcare systems that serve high-need populations to help implement evidence-based interventions to increase colorectal cancer screening; the program currently works with state health departments, universities, tribal organizations, and other organizations in 20 states. CDC should continue to evaluate these programs and consider the potential need for similar programs to address other cancers, such as lung cancer. Resources should be provided to ensure that these programs meet the needs of their target populations.

Sources: Durham DD, et al. Cancer Epidemiol Biomarkers Prev. 2016;25(11):1474-82. Available from: https://pubmed.ncbi.nlm.nih.gov/27803069; Sabatino SA, et al. MMWR Morb Mortal Wkly Rep. 2021;70(2):29-35. Available from: https://www.ncbi.nlm.nih.gov/pubmed/33444294; Zhao J, et al. CA Cancer J Clin. 2020;70(3):165-81. Available from: https://www.ncbi.nlm.nih.gov/pubmed/32202312; Rosso R. U.S. health care coverage and spending. Washington (DC): Congressional Research Service; 2021 Jan 25. Available from: https://fas.org/sgp/crs/misc/IF10830.pdf; Gan T, et al. J Am Coll Surg. 2019;228(4):342-53 e1. Available from: https://www.ncbi.nlm.nih.gov/pubmed/30802505; Lyu W, et al. Med Care. 2019;57(3):202-7. Available from: https://www.ncbi.nlm.nih.gov/pubmed/30624303; Biddell CB, et al. J Womens Health. 2021;30(9):1243-52. Available from: https://pubmed.ncbi.nlm.nih.gov/33851854; Tejeda S, et al. J Womens Health. 2013;22(6):507-17. Available from: https://pubmed.ncbi.nlm.nih.gov/23672296; 116th Congress (2019-2020). Removing Barriers to Colorectal Cancer Screening Act of 2020, H.R.1570. (2020 Dec 10). Available from: https://www.congress.gov/bill/116th-congress/house-bill/1570; Centers for Disease Control and Prevention. National Breast and Cervical Cancer Early Detection Program (NBCCEDP) screening program summaries: national aggregate, five-year summary: July 2015 to June 2020 [Internet]. Atlanta (GA): CDC; [updated 2021 Sep 21; cited 2021 Sep 30]. Available from: https://www.cdc.gov/cancer/nbccedp/data/summaries/national_aggregate.htm; Centers for Disease Control and Prevention. Colorectal Cancer Control Program (CRCCP) [Internet]. Atlanta (GA): CDC; [updated 2021 Feb 3; cited 2021 Oct 1]. Available from: https://www.cdc.gov/cancer/crccp/index.htm

GOAL 2: Facilitate Equitable Access to Cancer Screening

Inadequate access to healthcare services due to geographic, financial, or logistical challenges is a commonly cited barrier to cancer screening.[22,23,25,28] Fear of judgment, apprehension about potential diagnoses, cultural factors, lack of trust in healthcare systems, and structural racism also can deter people from seeking or receiving recommended care.[23,25,27] **These barriers contribute to the lower rates of cancer screening initiation and recommended follow-up observed among many populations in the United States**; people without a usual source of care or health insurance, individuals with low income or low educational achievement, recent immigrants, individuals living in rural or remote areas, and members of some racial/ethnic minority groups are among those who experience disparities in cancer screening and follow-up care.[17,18,59]

Factors that undermine equity and access must be addressed to optimize cancer screening in every community in the United States. The prevalence and impact of these barriers vary among communities, and solutions should be tailored to each situation. Supportive local, state, and federal policies are needed to ensure that effective strategies can be implemented.

Policy makers, healthcare systems, health plans, and communities must work together to identify and address other barriers to make it as easy as possible for people to receive recommended cancer screenings and follow-up care after abnormal screening test results. Some solutions may be relatively straightforward. For example, extended and flexible appointment hours may help reach people whose jobs or caregiving responsibilities make it difficult to attend

TELEHEALTH

The challenging circumstances of the COVID-19 pandemic have demonstrated the feasibility and benefits of telehealth for a variety of health services. Telehealth can be used to support some aspects of cancer screening, such as consultation before colonoscopy, shared decision-making for lung cancer screening, facilitation of self-sampling for colorectal or cervical cancer screening, risk assessment, genetic counseling, and discussion of results and next steps. The Panel supports the calls by the National Academies of Sciences, Engineering, and Medicine and numerous medical societies and professional organizations to extend coverage for telehealth services, including audio-only services, which make telehealth more accessible to those without broadband access.

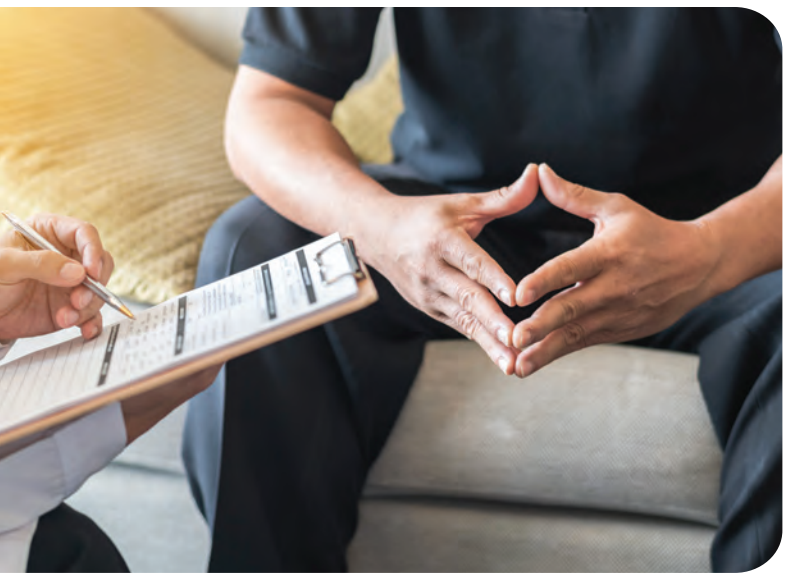
Sources: National Academies of Sciences, Engineering, and Medicine. Implementing high-quality primary care: rebuilding the foundation of health care. McCauley L, Phillips RL Jr, Meisnere M, Robinson SK, editors. Washington (DC): The National Academies Press; 2021. Available from: https://www.nap.edu/catalog/25983/implementing-high-quality-primary-care-rebuilding-the-foundation-of-health; American Society of Clinical Oncology. ASCO interim policy statement: telemedicine in cancer care. Alexandria (VA): ASCO; 2020 Jul 23. Available from: https://www.asco.org/sites/new-www.asco.org/files/content-files/advocacy-and-policy/documents/2020-ASCO-Interim-Position-Statement-Telemedicine-FINAL.pdf; Adirondacks ACO, et al. Letter to: The Honorable Mitch McConnell (Majority Leader, United States Senate), The Honorable Nancy Pelosi (Speaker, United States House of Representatives), The Honorable Charles Schumer (Minority Leader, United States Senate), The Honorable Kevin McCarthy (Minority Leader, United States House of Representatives). 2020 Jun 29. Available from: https://connectwithcare.org/wp-content/uploads/2020/06/Post-COVID-Telehealth-Priorities-Group-Letter-FIN.pdf

appointments during traditional hours. More screening locations (including mobile units), transportation assistance, and telehealth (see ***Telehealth*** on page 17) may help those who live long distances from or have difficulty traveling to health centers. The Panel has determined that community-oriented outreach and engagement and increased use of self-sampling also will improve access to screening and follow-up care, particularly for populations less likely to be up to date for cancer screening.

Recommendation 2.1

Provide and sustainably fund community-oriented outreach and support services to promote appropriate screening and follow-up care.

Accessing and navigating healthcare systems can be daunting, particularly for populations that are medically underserved. Community health workers (CHWs)—sometimes called community health navigators, promotoras de salud, or other names—serve as liaisons between communities and healthcare systems or services with the underlying goals of improving access and promoting equity. CHWs do not provide clinical care and generally do not hold another professional license. The defining feature of CHWs is their invaluable expertise on the culture and life experiences of the populations they serve. Although they perform some overlapping roles, CHWs are distinct from nurse navigators, social workers, medical assistants, or patient navigators that hold a professional degree.[60] Unlike CHWs, many nurse or patient navigators work primarily within healthcare systems and focus on coordination of care for patients with complex needs (e.g., active cancer treatment, organ transplantation).



Their connection to their communities makes CHWs uniquely poised to understand and help address the diverse barriers facing populations with low cancer screening rates. **The Community Preventive Services Task Force found strong evidence that interventions engaging CHWs are effective and cost-effective for increasing screening for breast, cervical, and colorectal cancers (programs for colonoscopy were actually found to be cost saving).**[61,62] **A body of evidence also is emerging for lung cancer screening.**[63] CHWs can work both within communities and within healthcare systems. They can perform a range of activities to promote cancer screening and receipt of appropriate follow-up care (Figure 4), including:[60]

- Cultivate relationships between healthcare systems and community organizations.
- Interact with people in trusted community settings.
- Encourage people to establish relationships with healthcare providers.
- Provide culturally appropriate information to increase awareness and understanding of cancer risk and screening.
- Promote appropriate cancer screening.
- Identify and reach out to established patients who are due or overdue for cancer screening.
- Identify individual barriers to cancer screening and follow-up care (may include basic needs such as food and housing).
- Facilitate access to services and resources (e.g., financial, transportation, dependent care) needed to overcome barriers to care.
- Provide informal counseling and social support.
- Assist with care coordination.
- Advocate within healthcare systems for individual and community needs.

Healthcare systems and health plans should establish CHW programs to reach the people in the communities they serve (see *CHWs: Connecting People to Care* below) and ensure that those eligible receive appropriate and timely cancer screening and follow-up care. Regardless of whether they are working in the community or the clinic, CHWs must be trusted members of the community and have a strong understanding of the social, economic, and cultural issues that affect people's desire and ability to obtain healthcare. CHWs should be treated as respected members of healthcare teams and compensated in a timely and fair manner. Healthcare systems should solicit input from CHWs on ways to better reach and serve their target populations. CHWs should have multiple modes of communication available (e.g., in-person, telephone/telehealth, text message) to facilitate frequent and convenient interactions with community members.

To date, most CHW programs have been funded through short-term grants or contracts, which creates instability that undermines cultivation of meaningful relationships with communities, community members, and healthcare systems. **Healthcare systems and health plans should establish sustainable funding for CHW programs to ensure they meet their full potential.** No single funding

strategy will be effective in every situation, and a single program may use multiple funding sources. Programs must be tailored to community needs and resources, as well as to state and local policies and regulations. CHW programs may be particularly useful in settings that serve low-resource populations, including Federally Qualified Health Centers.[64,65] In all settings, CHW services should be made available regardless of a person's insurance status. Options for consideration include:[66-68]

- ***Healthcare system operational funds***— Healthcare systems or providers can use operational funds to finance CHWs in the absence

CHWs: CONNECTING PEOPLE TO CARE

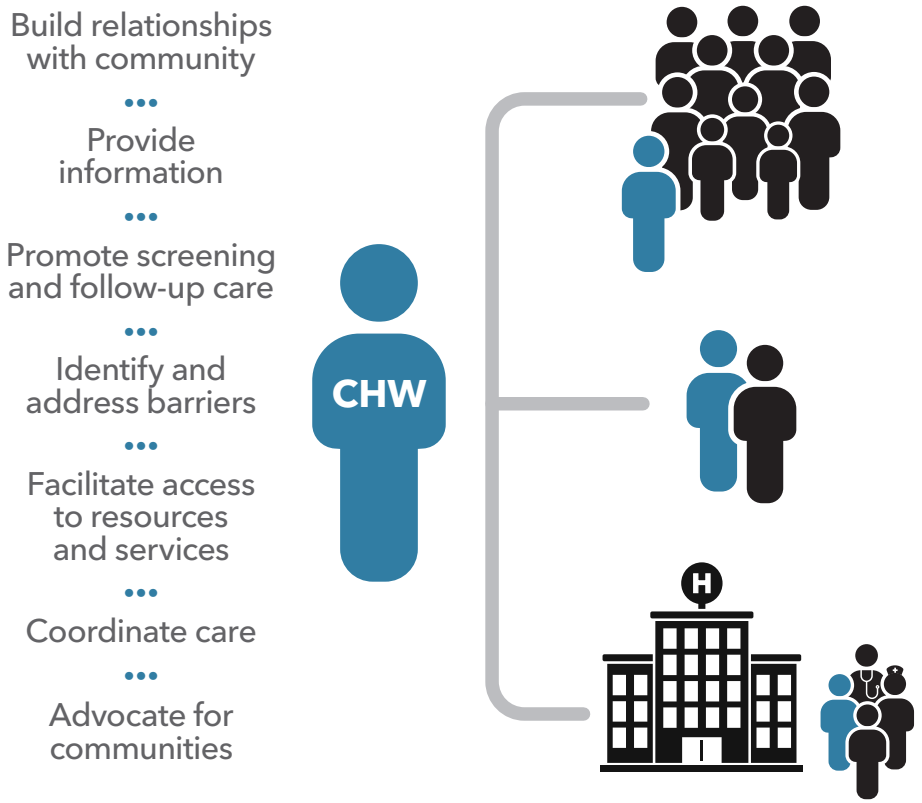
People without a usual source of medical care are among the least likely to be up to date on recommended cancer screenings. The Panel supports the recent recommendation made by the National Academies of Sciences, Engineering, and Medicine that payors assign a primary care provider for enrollees who do not declare a usual source of primary care and use this assignment for payment and accountability measures. CHWs could help health plans and healthcare systems cultivate relationships with populations who historically have been difficult to reach and retain.

Source: National Academies of Sciences, Engineering, and Medicine. Implementing high-quality primary care: rebuilding the foundation of health care. McCauley L, Phillips RL Jr, Meisnere M, Robinson SK, editors. Washington (DC): The National Academies Press; 2021. Available from: https://www.nap.edu/catalog/25983/implementing-high-quality-primary-care-rebuilding-the-foundation-of-health

of direct reimbursement or provide supplemental funding based on the expectation that CHW programs will pay for themselves. For example, CHWs can help increase utilization of preventive and primary care services and reduce the volume of uncompensated care through better disease detection and management as well as linking patients with health insurance and other financial resources.

- ***Health plan funds***—Some states have incorporated CHWs into their Medicaid Managed Care Organization contracts for specific services. Health plans also may fund CHWs through administrative or quality improvement funds.
- ***Public health organizations***—Many local health departments use CHWs to engage their communities. In general, these CHWs have been funded through disease-specific grants or initiatives, which undermines stability. State health departments could establish long-term funding to allow local health departments to build and maintain relationships with community organizations and CHWs.
- ***Reimbursement for CHW services***—Fee-for-service is the dominant reimbursement model in the United States, although an increasing number of providers are participating in alternative payment models that tie reimbursement to quality and value. Within the fee-for-service realm, a 2014 Centers for Medicare & Medicaid Services (CMS) rule change opened the door to Medicaid reimbursement for preventive services provided by CHWs as long as those services are recommended by a physician or other licensed practitioner.[69] Multiple states are pursuing one or more mechanisms to utilize this funding route; however, the challenges and limitations of CHW reimbursement within the fee-for-service model—including the need to clearly define eligible patients and services and substantial

FIGURE 4. CHW Roles and Activities



STOOL-BASED TESTS FOR COLORECTAL CANCER SCREENING

Stool-based tests provide a noninvasive way to screen for colorectal cancer or precancerous polyps. The fecal immunochemical test (FIT) and guaiac fecal occult blood test (gFOBT) detect traces of blood in the feces. The FIT-DNA test (or multitargeted stool DNA test) checks both for blood and DNA mutations linked to abnormal cells. All major U.S. colorectal cancer screening guidelines include stool-based tests as an effective screening option, although stool-based tests must be done more frequently than colonoscopy. If a stool-based test yields an abnormal result, a follow-up colonoscopy must be done in a timely manner to complete the screening process and reduce colorectal cancer incidence and mortality.

Source: San Miguel Y, et al. Gastroenterology. 2021;160(6):1997-2005 e3. Available from: https://www.ncbi.nlm.nih.gov/pubmed/33545140

administrative burden—make it unlikely that this model will provide sufficient coverage for CHW programs. The role of CHWs as community liaisons capable of addressing medical and sociocultural barriers is more suited to emerging value-based payment models that incentivize team-based care.

Healthcare systems and health plans should provide training directly or through partnerships with other organizations to ensure that CHWs have the knowledge and skills needed to do their jobs. CHW training should impart a working knowledge of cancer screening—including different test options and eligibility criteria—as well information about institutional systems and both institutional and community resources available to help overcome common barriers. Training also should enhance communication, teaching, counseling, advocacy, and organizational skills. Programs should check the requirements for CHW training and certification in their states; many states have or are pursuing legislation related to CHWs.[70] Importantly, training should be affordable and accessible for potential CHWs.

Recommendation 2.2

Increase access to self-sampling for cancer screening.

There are tools for two cancers that allow screening to be done using self-collected samples (see *Stool-Based Tests for Colorectal Cancer Screening* above and *HPV Self-Sampling for Cervical Cancer Screening* on page 23). Currently, stool-based tests are integrated into U.S. colorectal cancer screening guidelines. HPV self-sampling is utilized in other countries and has potential to expand the reach of cervical cancer screening in the United States; however, it has not yet been approved by the U.S. Food and Drug

Administration (FDA). The Panel supports expansion of both self-sampling approaches.

Self-sampling can increase access to cancer screening for people who:

- Live long distances from medical facilities that provide in-office screening
- Have difficulty attending appointments due to transportation challenges or work/caregiving responsibilities
- Are uncomfortable in medical settings or with healthcare providers
- Prefer to avoid the colon-cleansing prep and invasive nature of colonoscopy (for colorectal cancer)
- Prefer to avoid pelvic exams (for cervical cancer—e.g., due to history of sexual trauma or cultural/religious preference).

Stool-based tests for colorectal cancer and HPV self-sampling both can be done in the clinic setting or at home. Use of these sample collection tools in the clinic allows cancer screening to be done in the offices of providers who do not perform colonoscopies or pelvic exams. This may help improve access to screening for people living in rural or remote areas with limited access to specialists who often perform these services. At-home sample collection also provides an option for those who cannot or prefer not to be screened in person. The value of stool-based tests has been reinforced during the COVID-19 pandemic. Self-sampling provided a way to continue colorectal cancer screening when people were unable or unwilling to visit clinics in-person. Stool-based tests also could be used to triage higher-risk patients to colonoscopy, allowing optimal use of in-demand resources and limiting in-person visits to those patients most likely to benefit.[71,72] For both stool-based tests and HPV self-sampling, patients who receive an abnormal result need to receive follow-up care at a healthcare facility (e.g., colonoscopy after abnormal stool-based test result). Screening, including screening with self-collected samples, is effective only if those screened receive appropriate and timely follow-up care.

There is evidence that self-sampling can increase rates of screening. Several studies including in Federally Qualified Health Centers, which often have lower-than-average colorectal cancer screening rates have linked active distribution of stool-based tests to increased completion of colorectal cancer screening.[48,73-75] A meta-analysis from studies conducted in several countries found that offering the option of HPV self-sampling can increase cervical cancer screening uptake by about twofold.[76,77]

Stool-based testing is underused in the United States. Stool-based tests—including FIT and FIT-DNA—are available for use in the United States and included in all major colorectal cancer screening guidelines.[5,78,79] Although stool-based tests are effective, cost-effective, and associated with higher screening uptake,[75] they account for only a small proportion of colorectal cancer screening in the United States.[43] This is likely in part due to the fact that many providers consider colonoscopy to be superior to stool-based tests despite no evidence to support this.[43,45] **Healthcare providers should promote stool-based tests as an option for colorectal cancer screening, particularly for people who are hesitant or unable to undergo colonoscopy. In addition to offering colonoscopy, healthcare systems and health plans should distribute stool-based tests to individuals due for colorectal cancer screening as part of a systematic, organized effort to increase appropriate screening.**

Research supports HPV self-sampling in the United States. HPV self-sampling has been adopted as part of cervical cancer screening programs in other countries[80,81] and has shown promise for reaching individuals who do not participate in regular screening.[82] Research has found that U.S. women—including women underscreened for cervical cancer—consider self-sampling to be an acceptable, or even preferable, option for cervical cancer screening.[83] Given that more than half of

HPV SELF-SAMPLING FOR CERVICAL CANCER SCREENING

HPV testing is more accurate and reliable than cytology-based testing (Pap smears) for cervical cancer screening, leading many guideline makers to recommend primary HPV testing alone or HPV testing in combination with cytology. In the United States, samples for HPV testing currently are collected by a clinician during a pelvic exam. Research has shown that the accuracy of HPV tests done with self-collected samples is similar in most cases to those done with samples collected by a clinician; however, self-sampling for HPV testing has not yet been approved for use in the United States.

Sources: Gupta S, et al. Front Public Health. 2018;6:77. Available from: https://www.ncbi.nlm.nih.gov/pubmed/29686981; Arbyn M, et al. BMJ. 2018;363:k4823. Available from: https://www.ncbi.nlm.nih.gov/pubmed/30518635

new cervical cancer cases in the United States are among women who have never been screened or are infrequently screened, there is a critical need for new strategies to reach this population. Lack of regulatory approval of HPV self-sampling in the United States is a critical barrier to its implementation in cervical cancer screening that needs to be addressed. The National Cancer Institute's "Last Mile" Initiative—a public-private partnership that is conducting a clinical trial to validate HPV testing with self-collected samples for cervical cancer screening in the United States—will be coordinated with the regulatory process and help drive progress in this area.[84] **The Panel encourages HPV test manufacturers to participate in validation efforts and pursue regulatory approval for HPV self-sampling strategies. The FDA should prioritize review of the evidence supporting HPV self-sampling to ensure that it is available to women in the United States as soon as possible.** If HPV self-sampling is approved by the FDA, U.S. cervical cancer screening programs, including state and federal programs, should use HPV self-sampling to extend the reach of cervical cancer screening.

Self-sampling has potential to extend the benefits of cancer screening, particularly to those who cannot or do not want to participate in traditional screening. While self-sampling empowers patients, it should not be viewed as a replacement for regular provider visits. It is essential that individuals performing self-sampling for both stool-based and HPV tests are connected with a healthcare provider or system that will answer questions, provide results, and be accountable for facilitating next steps in the case of an abnormal result (e.g., diagnostic studies, treatment, surveillance, increased screening frequency). As culturally competent community liaisons, CHWs should be involved in this process, particularly for individuals who do not have an established relationship with a healthcare provider. CHWs can help develop culturally and linguistically appropriate instructions, provide support for patients with questions or concerns, and facilitate access to follow-up care in the case of abnormal results.

GOAL 3:
Strengthen Workforce Collaborations to Support Cancer Screening and Risk Assessment

Providers play an essential role in patients' decisions about whether and when to be screened for cancer. However, competing demands make it difficult to thoroughly address each patient's needs within the limited time available during an appointment, particularly in the primary care setting in which most decisions about cancer screening are made. There is a growing recognition that providers cannot do it all on their own. It is well established that multidisciplinary teams support delivery of high-quality care and reduce burnout among primary care providers.[85] **Team-based care has the potential to improve implementation of cancer screening. To accomplish this, supportive policies and a commitment to team-based care approaches are needed**.

A team-based approach allows functions to be distributed across multiple people, creating opportunities for each team member to contribute to patient care. The ideal size and makeup of healthcare teams depend on several factors, including the clinical setting; the healthcare needs, demographics, and sociocultural features of the population being served; and assets of the community. Team members can include primary care providers (physicians, physician assistants, nurse practitioners), specialists, nurses, medical assistants, office staff, care managers, CHWs, genetic counselors, social workers, behavioral health specialists, laboratory staff, and others (Figure 5). Patients—along with family members and caregivers involved in their healthcare and everyday lives—also are key team members and should be treated as such.

Recommendation 3.1

Empower healthcare team members to support screening.

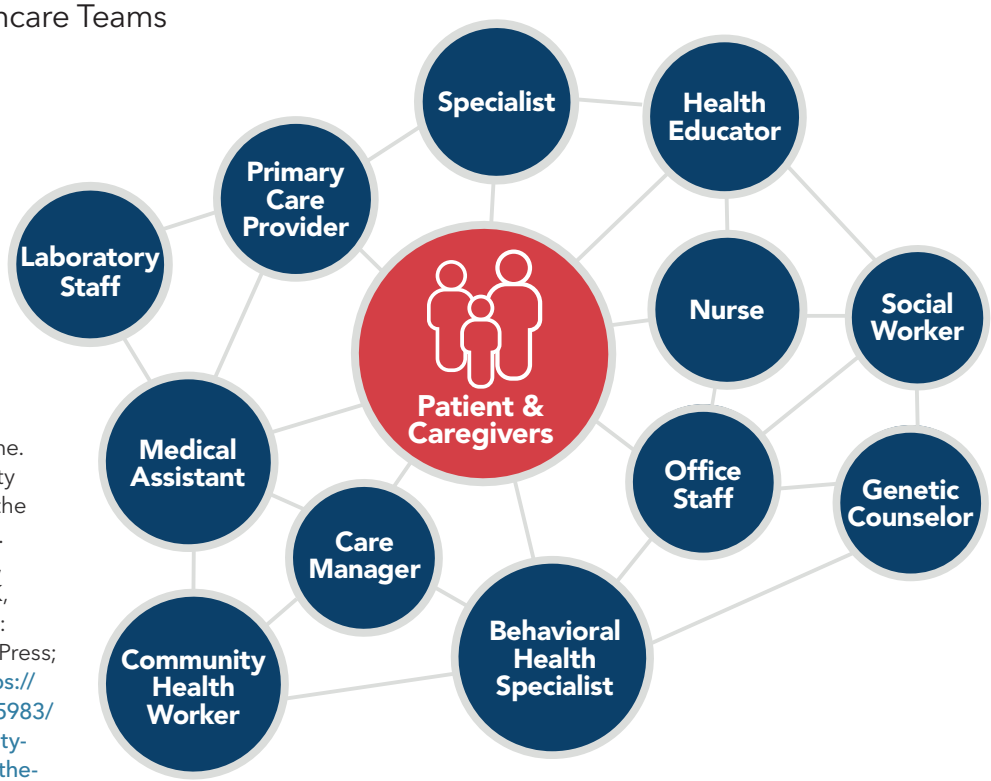
Healthcare systems and medical offices should set up systems and processes that allow all members of the healthcare team to promote and implement cancer screening programs or practices. Nurses, medical assistants, and office staff can collect family and personal health history (including smoking history), identify patients potentially eligible for cancer screening, initiate conversations about screening, and help coordinate recommended follow-up care. CHWs can connect people to healthcare and help identify and address barriers to cancer screening and follow-up care (see Recommendation 2.1) and respond to questions and concerns in culturally competent ways. Nurses or other team members can receive training to discuss tobacco cessation options with patients eligible for lung cancer screening who are active tobacco users.

Building and maintaining strong teams requires buy-in from team members and organizational leadership. This may include investment of resources and a commitment to fostering a culture of teamwork. Roles of team members must be clearly defined and communication channels established to ensure seamless integration and optimize clinical workflows. Information technology systems should be developed and used to facilitate communication

and hand-offs among team members (see Goal 4). Team effectiveness should be evaluated regularly and improvements made as needed. Efforts should be made to create teams that represent the diversity of populations being served to help with cultural competency and improve health equity.

Payment policies can facilitate or restrict team-based care. Value-based payment models may be better able than traditional fee-for-service models to support team-based strategies to deliver high-quality care. It also is important that all members are empowered to apply their skills and training. Medicare coverage for lung cancer screening with low-dose computed tomography currently requires that the ordering physician or qualified nonphysician practitioner (e.g., physician assistant, nurse practitioner) conducts a counseling and shared decision-making visit with the patient.[86] This requirement places the burden of shared decision-making on the provider, introducing a bottleneck that results in a barrier to this new, lifesaving screening modality.[87] Primary care providers play a central role in recommending lung cancer screening to their patients; however, while shared decision-making is valuable, it is unrealistic to expect primary care providers to have the time and resources to individually and effectively perform this task with all patients eligible for lung cancer screening. Other team members can be incorporated into shared decision-making—including discussion of the benefits and potential harms of lung cancer screening with low-dose CT—if they are provided with appropriate training and access to patient decision aids. If physicians can share the shared decision-making process with other team members, they will be able to implement lung cancer screening recommendations more broadly. Use of technologies such as telemedicine or chatbots to support shared decision-making also may help increase access to screening. **CMS should modify its coverage requirements to allow additional members of physician-led healthcare teams to conduct shared decision-making for lung cancer screening.** Doing so would remove a barrier to screening and allow teams to more easily deliver high-quality, guideline-based care.

FIGURE 5. Healthcare Teams



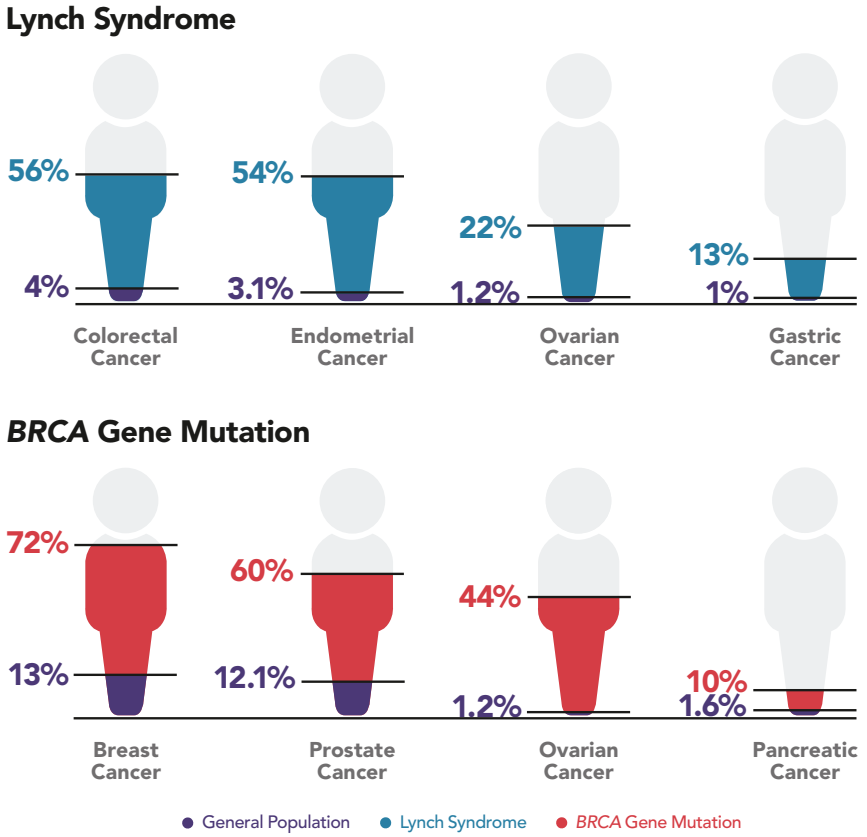
Adapted from: National Academies of Sciences, Engineering, and Medicine. Implementing high-quality primary care: rebuilding the foundation of health care. McCauley L, Phillips RL Jr, Meisnere M, Robinson SK, editors. Washington (DC): The National Academies Press; 2021. Available from: https://www.nap.edu/catalog/25983/implementing-high-quality-primary-care-rebuilding-the-foundation-of-health

Recommendation 3.2

Expand access to genetic testing and counseling for cancer risk assessment.

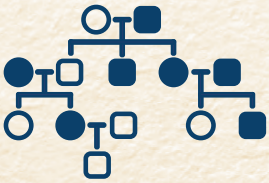
Most cancer screening guidelines are intended for populations at average risk for cancer; however, some people are at elevated risk for cancer due to their personal or family history or because they harbor mutations in cancer susceptibility genes. These people may benefit from earlier, more frequent, or enhanced cancer screening or other risk-reducing interventions.[51,88-90] It is estimated that 10 to 15 percent of cancers result from inherited mutations, also called germline mutations.[91-93] For example, Lynch syndrome, which is characterized by mutations in DNA mismatch repair genes, and mutations in *BRCA1* and *BRCA2* dramatically elevate risk for multiple cancers (Figure 6).[90]

FIGURE 6. Increased Cancer Risk with Inherited Mutations in Cancer Susceptibility Genes



Note: For General Population, percentages shown are average lifetime risk of being diagnosed with the designated cancer type. For Lynch Syndrome and *BRCA* Gene Mutation, percentages represent the highest published estimated risk; risk varies based on the gene and mutation. **Sources:** National Cancer Institute. Surveillance, Epidemiology, and End Results Program DevCan database: SEER 21 incidence and mortality, 2015-2017, with Kaposi sarcoma and mesothelioma. Bethesda (MD): NCI; 2021 Apr. Available from: https://seer.cancer.gov; National Cancer Institute. Genetics of colorectal cancer (PDQ): health professional version [Internet]. Bethesda (MD): NCI; [updated 2021 Jul 7; cited 2021 Nov 5]. Available from: https://www.cancer.gov/types/colorectal/hp/colorectal-genetics-pdq; National Cancer Institute. Genetics of breast and gynecologic cancers (PDQ): health professional version [Internet]. Bethesda (MD): NCI; [cited 2021 Nov 5]. Available from: https://www.cancer.gov/types/breast/hp/breast-ovarian-genetics-pdq; Nyberg T, et al. Eur Urol. 2020;77(1):24-35. Available from: https://www.ncbi.nlm.nih.gov/pubmed/31495749; Pilarski R. Am Soc Clin Oncol Educ Book. 2019;39:79-86. Available from: https://www.ncbi.nlm.nih.gov/pubmed/31099688

GERMLINE GENETIC TESTING FOR PEOPLE DIAGNOSED WITH CANCER



The time of a cancer diagnosis is an opportunity to determine whether patients carry inherited, or germline, mutations that increase risk of other cancers. Many cancer patients have their tumors sequenced to inform cancer treatment planning, including potential use of precision therapies that target specific mutations. Performing germline genetic testing for hereditary cancer predisposition genes in concert with tumor sequencing can provide additional information on genetic risk with implications for the patient's treatment and future cancer screening and surveillance. Studies of germline genetic testing in cancer patients have documented clinically actionable findings that were missed by tumor sequencing.

Results of germline genetic testing also have implications for family members. If a cancer patient is found to harbor a cancer-associated germline variant, cascade testing of family members can help identify other carriers. This may lead to increased screening adherence, enhanced screening, or other risk-reducing interventions.

The Panel supports assessment of eligibility for germline genetic testing for all people diagnosed with cancer. If variants of concern are identified, cascade testing of family members should be offered.

Sources: Samadder NJ, et al. JAMA Oncol. 2021;7(2):230-7. Available from: https://www.ncbi.nlm.nih.gov/pubmed/33126242; Lincoln SE, et al. JAMA Netw Open. 2020;3(10):e2019452. Available from: https://pubmed.ncbi.nlm.nih.gov/33026450

Currently, most people with mutations in cancer susceptibility genes are never identified or are not identified until after they are diagnosed with cancer (see ***Germline Genetic Testing for People Diagnosed with Cancer*** above).[94,95] It is estimated that among women who have not been diagnosed with breast cancer, fewer than 10 percent of *BRCA* mutation carriers have been identified, and at least 10 million high-risk women have not received recommended genetic testing for breast cancer risk genes.[96,97] Men harbor *BRCA1/2* mutations as frequently as women, but male carriers are identified at an even lower rate.[98] For Lynch syndrome, more than 800,000 individuals remain undiagnosed.[50] Providers should regularly collect thorough family and personal health histories to determine whether their patients should undergo genetic testing for cancer risk genes. Collection of this information should start before age 25 so that genetic testing can be recommended and any supplemental screening initiated according to the guidelines. If genetic testing is warranted, providers should provide information on risks and benefits, as well as the implications and limitations of genetic testing, so that patients can make informed decisions about undergoing genetic testing to identify germline mutations in cancer susceptibility genes.

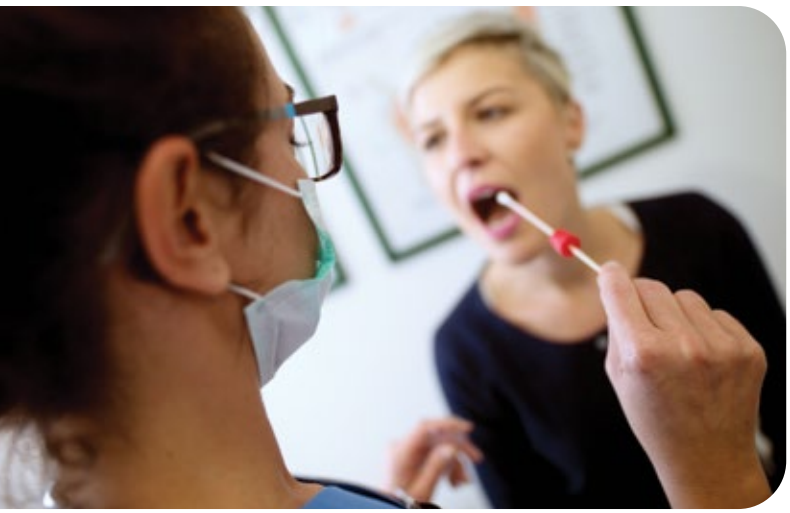
As demand for hereditary cancer genetic testing has increased, some payors have mandated consultation with a certified genetic counselor or geneticist prior to genetic testing to minimize inappropriate testing. Unfortunately, this policy creates an unnecessary barrier that results in fewer appropriate tests performed and longer turnaround times; racial/ethnic minority populations are disproportionately affected.[99] The Panel believes the harms of limiting access to genetic testing far outweigh the risks of genetic testing without prior access to a certified genetic counselor. Healthcare providers manage a range of tests and information, and many are fully capable of determining eligibility for and conducting informed consent prior to genetic

EDUCATION AND TRAINING FOR HEALTHCARE TEAMS

All members of the healthcare team—physicians, nurse practitioners, physician assistants, nurses, CHWs, behavioral health experts, patient navigators, and others—must have the knowledge and skills to effectively recommend and discuss appropriate cancer screening. Although the depth of knowledge needed varies depending on their role, all members of the team should learn about:

- Cancer risk assessment, including the role of pathogenic variants in cancer susceptibility genes
- Cancer screening modalities and guidelines, including benefits and potential harms of screening
- Management of cancer screening results, including recommended follow-up care in the event of an abnormal screening test result
- Shared decision-making, including discussion of benefits and potential harms of cancer screening and genetic testing
- The role of stigma and inherent bias in healthcare and strategies to overcome them
- The importance of cultural competency
- Effective use of telemedicine
- Functioning as part of a team.

Training and education on cancer screening and related topics should take place across the career continuum. Postgraduate training programs (e.g., medical schools, nursing schools) should include these topics in curricula. Residency training programs and certification boards should prioritize knowledge related to cancer risk reduction and screening. Professional societies, guideline makers, and other organizations should develop continuing medical education courses to ensure that team members maintain and increase competencies in these areas throughout their careers. These topics also should be covered as part of certification programs and on-the-job training for nonprovider team members (e.g., CHWs). Healthcare systems and medical offices also can increase the knowledge and competencies of team members in these areas through quality improvement initiatives.



testing. **Providers should be enabled to offer genetic testing with informed consent. Payors should eliminate requirements for pretest counseling by a certified genetic counselor or medical geneticist.** This will optimize patient access to appropriate genetic testing and promote access to supplemental screening if warranted. It also will allow certified genetic counselors to focus on patients with the highest need, particularly those found to have pathogenic variants in cancer susceptibility genes or complex genetic situations. Allowing providers to order genetic tests should not reduce patient access

to genetic counselors; any patient who prefers to speak to a genetic counselor before or after genetic testing should be able to do so. Providers who are uncomfortable discussing genetic testing should refer their patients to a genetic counselor.

Training and continuing education on genetics and genetic testing are critical to ensuring that providers are prepared to discuss various facets of genetic testing both before and after a patient undergoes testing (see *Education and Training for Healthcare Teams* on page 28). Some primary care providers report lack of confidence in interpreting and discussing genetic test results with patients.[100] However, studies have shown that targeted education can increase knowledge and confidence in this area.[101] **Training and residency programs, professional societies, guideline makers, and other organizations should expand opportunities for training and education on genetics, genetic testing, and interpretation of genetic testing results.** Well-designed clinical decision support (CDS) tools also can help identify patients eligible for genetic testing and assist with management of results (see Goal 4).

Importantly, providers should have established relationships with genetic counselors so that timely follow-up appointments can be made for patients with complex results or additional questions. The demand for genetic counselors is high and will undoubtedly continue to rise as the availability and uptake of genetic testing for various diseases increase. There currently is a shortage of certified genetic counselors involved in direct patient care,[102] and the Panel heard many accounts of long waits for appointments with genetic counselors. The numbers of genetic counseling programs and trainees have been increasing steadily over the past several years,[103] though supply has not yet met the rapidly expanding patient demand. The interorganizational Genetic Counselor Workforce Working Group[104] should continue its work to ensure that a robust and well-trained genetic counselor workforce is available to meet the needs of patients in the emerging genomic era of medicine. Counseling via telemedicine should be used as needed to increase access in rural/remote areas and avoid delays based on availability of in-person appointments.

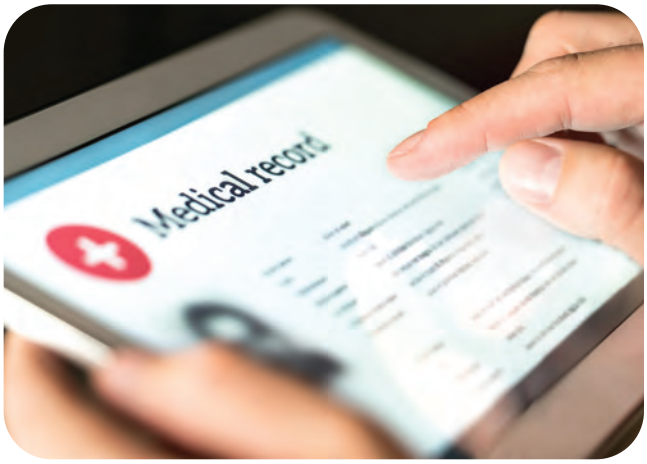
Most health insurers cover genetic counseling for people who meet personal and family history criteria for testing. Most private insurers will reimburse certified genetic counselors who provide this service; however, genetic counselors are not recognized as healthcare providers by CMS, which means that they cannot be reimbursed directly through Medicare.[105] **Legislative changes should be made so that genetic counselors are recognized as healthcare providers by CMS.** This would allow genetic counselors to contribute their specialized knowledge and skills to medical teams working to deliver high-quality care to patients at elevated risk for cancer and other diseases. This issue has gained the attention of some lawmakers, resulting in the introduction of the Access to Genetic Counselor Services Act in the U.S. House of Representatives in 2019[106] and reintroduction in both the U.S. House of Representatives and U.S. Senate in 2021.[107,108] The Panel urges Congress to take up this issue and amend the Medicare program to provide direct coverage for services provided by genetic counselors.

GOAL 4:
Create Health Information Technology that Promotes Appropriate Cancer Risk Assessment and Screening

Health information technology (IT) involves the processing, storage, and exchange of health information in an electronic environment. Examples of health IT include electronic health records (EHRs), personal health records, electronic prescribing systems, clinical decision support (CDS), and computable guidelines.

The vast and rapidly expanding body of health-related data creates challenges. **Providers and patients alike are faced with more information than they can process in a reasonable amount of time. Health IT has potential to help providers, patients, and healthcare systems quickly access and effectively use clinical knowledge and patient-specific data**. Massive investments in health IT have led to nearly universal implementation of EHRs in U.S. hospitals and medical practices;[109,110] however, the benefits for clinical care have fallen short of expectations.[111] Additional investment and commitment are needed to create more effective health IT systems and tools—including but not limited to EHRs—to facilitate high-quality personalized care.

Suboptimal application of the evidence-based clinical practice guidelines—including guidelines for cancer risk assessment and screening—is a critical problem that should be addressed through health IT. Machine-interpretable representations of clinical guidelines—or computable guidelines—could be used to create health IT tools, including clinical decision support (CDS), that allow providers and patients to quickly determine what care is recommended based on patient-specific factors. Cancer screening is particularly well suited to benefit



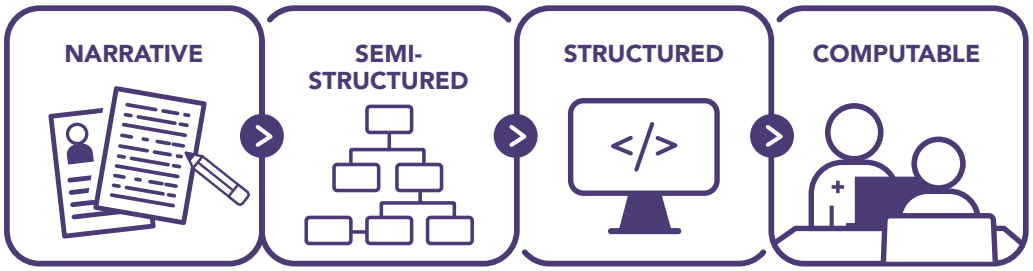
from health IT, including computable guidelines and CDS, for multiple reasons:

- ***Screening eligibility should be widely and repeatedly assessed***—Virtually all adults will be eligible for screening for one or more cancers over the course of their lives. Screening tests must be repeated on a regular basis to improve outcomes. Furthermore, recommendations must be revisited repeatedly because each person's risk factors (e.g., family history, smoking history)

CANCER SCREENING AND GENETIC TESTING RECOMMENDATIONS MAY BE AFFECTED BY:

- Age
- Sex
- Family health history
- Smoking status/history
- Screening history
- Past screening test results
- Genetic testing results (for screening).

FIGURE 7. Development of Computable Guidelines



Adapted from: Boxwala AA, et al. J Am Med Inform Assoc. 2011;18:i132-9. Available from: https://www.ncbi.nlm.nih.gov/pubmed/22052898

and health history (e.g., diagnoses, results of prior screening tests) change over time and guidelines are updated based on new evidence. Algorithms that can be run automatically and modified as guidelines evolve would help providers and healthcare systems more quickly and efficiently mine records to identify patients eligible or overdue for screening.

- ***Screening guidelines are increasingly complex***—Many factors are taken into account when assessing screening eligibility (see *Cancer Screening and Genetic Testing May Be Affected By* on page 30). Guidelines are likely to become increasingly complex as guideline makers incorporate additional factors (e.g., breast density for breast cancer) that help determine an individual's cancer risk. In some cases, patients and providers also must weigh the pros and cons of different modalities available to screen for a given cancer (e.g., colonoscopy and FIT for colorectal cancer). The recommended frequency of screening often differs based on the screening modality and individual factors. CDS can integrate person-specific information from multiple sources and present it to patients and providers in ways that facilitate assessment and shared decision-making.
- ***Screening is a multistep process***—A provider recommendation for cancer screening is only the first step. Cancer screening often includes additional appointments at outside facilities. Timely follow-up, additional testing, and/or a modified schedule for future screening may be needed based on the result of each screen. Management of abnormal results in turn requires consideration of additional clinical guidelines and care recommendations. Health IT tools can be used to monitor initiation and completion of the screening process, as well as receipt of follow-up care, for individuals and groups of patients. CDS can incorporate multiple sets of screening and follow-up guidelines to ensure seamless care management. Health IT also can facilitate communication and handoffs among healthcare team members.

The Panel recommends creation of computable guidelines for cancer screening and use of these guidelines to create CDS for cancer risk assessment, screening, and follow-up care.

Recommendation 4.1

Create computable versions of cancer screening and risk assessment guidelines.

Cancer risk assessment, screening, and follow-up guidelines are issued by several organizations (Table 1) and are disseminated in narrative form to healthcare providers and systems through publication in peer-reviewed journals, organizational websites, and professional societies. **Before being incorporated into health IT tools—including CDS or oth er tools—narrative guidelines must be converted to a more structured format (Figure 7)**. For automated tools, computable

guidelines—a format that can be fully interpreted and executed by a computer—must be created. Currently, each health IT developer using a guideline independently renders a computable representation. This duplicative process is an inefficient use of resources that must be repeated every time guidelines are updated and can result in unintentional variability in guideline interpretation and implementation.

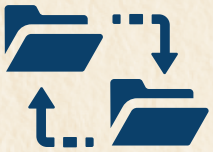
Development of health IT tools would be more efficient if all cancer screening guidelines were publicly available in a computable format. Computable guidelines created using open-access data standards, such as Fast Healthcare Interoperability Resources (FHIR),[112] are platform agnostic and could be readily used by health IT developers to create tools to support clinicians, healthcare systems, and patients. Tools could include CDS (see Recommendation 4.2), as well systems for quality measurement and reporting, generation of case reports, and creation of population registries. In addition to saving resources, the availability of computable guidelines would promote broader, more consistent, and faster implementation of cancer screening guidelines.

Standards, methods, and tools for translating guidelines to computable formats are actively being developed and refined (see *Data and Exchange Standards* on page 33).[112-114] Creation of computable guidelines requires the expertise of a variety of informaticians capable of translating technical medical information into advanced logic that can be understood by computer systems. Ideally, informaticians would interface with guideline makers, clinical domain experts, and health IT developers to ensure that the programmed terminology and logic are accurate as well as usable and valid for downstream applications. Proactive collaboration between informaticians and guideline makers during the guideline development process can help identify unintentional gaps or lack of clarity in recommendations; addressing these issues through an iterative process can both strengthen the recommendations and facilitate translation to a computable form.

Resources are needed to support these collaborations and catalyze generation of computable guidelines for cancer risk assessment and screening. Guideline makers with access to the necessary resources and expertise should incorporate creation of computable guidelines into their guideline development process. However, the Panel recognizes that many guideline-making organizations currently do not have the expertise or resources to make their guidelines computable.

Research funding organizations with an interest in healthcare quality and implementation—including the Agency for Healthcare Research and Quality (AHRQ), CDC, National Institutes of Health (NIH), ACS, and others—should fund development of computable guidelines for cancer risk assessment and screening. This could be done through grants to guideline organizations, researchers, or collaborative teams. Alternatively, computable guidelines could be directly created through targeted initiatives of federal agencies (see *Making Cancer Screening Guidelines Computable* on page 34). **CDC and AHRQ should consider investment in dedicated programs to support creation of computable guidelines relevant to risk assessment, screening, and follow-up care for cancer and other diseases**. Computable guidelines should be shared through public resources, such as the AHRQ CDS Connect Repository, to facilitate their dissemination and use.[115,116]

DATA AND EXCHANGE STANDARDS



Widespread development and adoption of data standards are essential to achieve interoperable healthcare systems and facilitate development and implementation of computable guidelines, CDS, and other tools that can be used across different settings and platforms. Data standards define the data to be collected as well as terminologies to represent those data and methods for encoding the data for transmission.

The Fast Healthcare Interoperability Resources (FHIR) standard has gained traction as the preferred standard for healthcare data. FHIR is built on modular components called resources that can be assembled in different ways. These resources are developed and refined by expert work groups in an open and transparent process. The FHIR Clinical Guidelines Implementation Guide—also referred to as Clinical Practice Guidelines (CPG)-on-FHIR—describes a standard approach and methodology for how to use FHIR to develop computable representations of narrative clinical guidelines that can be used to create CDS and other tools. While not yet comprehensive or fully refined, FHIR is a promising foundation for data sharing and interoperability.

FHIR resources have been and continue to be developed for areas relevant to cancer screening, including family history and genomics. Health IT developers should continue to expand FHIR through development of additional standards needed to support creation of interoperable CDS for cancer risk assessment and screening. Areas of high priority include smoking history and documentation of cancer screening results, including laboratory test and pathology results. Developers of EHRs, CDS, and other health IT tools should use FHIR standards whenever possible to facilitate data sharing and interoperability; when standards are not available, developers should work with the FHIR standards community to develop consensus-based data elements.

The Substitutable Medical Applications and Reusable Technologies (SMART) App Launch Framework allows third-party apps to be integrated seamlessly with any compatible EHR system, creating opportunity for large and small health IT developers alike to create tools to meet the needs of diverse end users. The number of compatible systems undoubtedly will grow, as the Office of the National Coordinator for Health Information Technology (ONC) 21st Century Cures Act Final Rule issued in 2020 requires EHRs to be enabled with FHIR and SMART App Launch Framework capabilities that are to be certified; the Rule also adopted the United States Core Data for Interoperability standards to promote interoperability.

Sources: HL7 International. HL7 FHIR [Internet]. Ann Arbor (MI): HL7 International; 2019 Nov 1 [cited 2021 Sep 20]. Available from: https://www.hl7.org/fhir/summary.html; HL7 International. FHIR clinical guidelines implementation guide [Internet]. Ann Arbor (MI): HL7 International; [updated 2021 Feb 11; cited 2021 Sep 20]. Available from: http://hl7.org/fhir/uv/cpg/index.html; HL7 International. SMART App Launch Framework [Internet]. Ann Arbor (MI): HL7 International; 2018 Nov 13 [cited 2021 Sep 21]. Available from: http://www.hl7.org/fhir/smart-app-launch; Office of the National Coordinator for Health Information Technology. Fed Regist. 2020 May 1;85:25642–961. Available from: https://www.federalregister.gov/d/2020-07419; Institute of Medicine. Patient safety: achieving a new standard for care. Washington (DC): The National Academies Press; 2004. Available from: https://www.nap.edu/catalog/10863/patient-safety-achieving-a-new-standard-for-care

MAKING CANCER SCREENING GUIDELINES COMPUTABLE

The CDC Division of Cancer Prevention and Control has launched an initiative to develop computable guidelines, CDS tools, and quality measures to enable improved adherence to cervical cancer screening and follow-up guidelines. As part of this effort, USPSTF guidelines for cervical cancer screening and other guidelines for management of abnormal screening results are being translated to a computable format using the CPG-on-FHIR standard. The team has interfaced with USPSTF and other guideline makers to ensure guideline representations are accurate. Once completed, the computable guidelines developed through the initiative will be publicly available through the AHRQ CDS Connect Repository.

Sources: Centers for Disease Control and Prevention. Adapting Clinical Guidelines for the Digital Age [Internet]. Atlanta (GA): CDC; [updated 2021 Jul 8; cited 2021 Oct 2]. Available from: https://www.cdc.gov/csels/phio/clinical-guidelines/index.html; HL7 International. FHIR clinical guidelines implementation guide [Internet]. Ann Arbor (MI): HL7 International; [updated 2021 Feb 11; cited 2021 Sep 20]. Available from: http://hl7.org/fhir/uv/cpg/index.html

Recommendation 4.2

Create and deploy effective clinical decision support tools for cancer risk assessment and screening.

CDS can help providers and patients access and integrate clinical knowledge and patient-specific data to guide care (see *Tools to Facilitate Clinical Decision-Making* on page 36). CDS tools are not intended to replace provider judgment or patient decision-making; rather, they are intended to inform and facilitate care. Effective CDS would help alleviate the pressures on providers; they may be particularly beneficial for primary care providers, who are expected to address a wide range of issues within a limited time during appointments, and providers in settings with limited financial resources (e.g., Federally Qualified Health Centers, private practices). Automated CDS also could help reduce the impact of provider bias and ensure that cancer risk assessment is completed and screening recommendations are delivered to all populations.

Most EHR systems employ CDS to some extent, often through best practice alerts to providers. While these alerts can improve the safety and quality of care, low-quality alerts can lead to alert fatigue and even interfere with patient care.[117] To effectively improve care, CDS must follow the Five Rights model: the right information must be delivered to the right people in the right formats, through the right channels, and at the right times in the clinical workflow (Figure 8).[118] The key to good CDS begins with the right information; CDS must integrate patient-specific information with evidence-based guidelines (see Recommendation 4.1) and clinical best practices. Usability is key to the success of CDS. CDS for providers must be seamlessly integrated into clinical workflows and provide information in concise, understandable, and actionable formats. CDS also can be created to help inform patient decision-making and allow patients to securely share personal information with healthcare providers as desired; it is critical that information and questions included in patient-facing tools are presented in language that is easy to understand and apply.

Currently, many healthcare organizations develop and implement their own CDS in parallel, resulting in redundant effort and expense. Progress in development and adoption of standards for clinical data, data exchange, and CDS is providing

opportunities to create a collection of shareable, scalable CDS that can easily be implemented or adapted for use in a variety of healthcare settings, including large healthcare systems and small independent practices.[119, 120] Health IT developers should use available standards (see *Data and Exchange Standards* on page 33) to the extent possible and build on the knowledge generated through development and implementation of earlier CDS. Evaluation of CDS is needed to measure impact on health outcomes, quality of care, safety, cost, patient satisfaction, and physician productivity. The results should inform improvements in systems and processes to maximize benefit for patients, providers, and healthcare systems.

CDS can be created by EHR vendors, healthcare systems, or third parties, such as academic researchers, patient advocacy organizations, or professional societies. Collaborative approaches that include multiple stakeholder groups and perspectives also may be beneficial. **EHR vendors, healthcare organizations, and research funding organizations—including AHRQ, NIH, CDC, and private foundations—should prioritize support for development and evaluation of standards-based, interoperable CDS for cancer risk assessment and screening.** The reach of CDS would improve if developers shared code for their tools. This would provide opportunity for institutions with fewer resources—including small practices or healthcare settings with limited resources—to insert existing tools into their EHRs and customize them to meet their needs. The Panel encourages sharing of CDS, such as through the AHRQ CDS Connect Repository;[115] sharing should be a prerequisite for any CDS created using public funds.

FIGURE 8. Five Rights of Clinical Decision Support

Source: Sirajuddin AM, et al. J Healthc Inf Manag. 2009;23(4):38-45. Available from: https://www.ncbi.nlm.nih.gov/pubmed/19894486

CDS should be integrated with EHRs to optimize workflow, facilitate data exchange, and avoid duplicate data entry. **EHR vendors should include CDS for cancer risk assessment and screening in standard EHR systems and make it as easy as possible for CDS developed by others to be integrated with the EHR.** To this end, it is critical that EHR vendors and IT developers continue to pursue interoperability of health IT systems (see *Data Sharing and Interoperability* on page 37).

TOOLS TO FACILITATE CLINICAL DECISION-MAKING

CDS tools of different types are being developed by various groups. These tools vary in their design, complexity, and focus but share the goal of increasing high-quality care. The Penn Medicine Nudge Unit leverages insights from behavioral economics and psychology to design, implement, evaluate, and disseminate "nudges" that change the way information or choices are presented to steer decision-making toward evidence-based care. Nudges are codesigned with frontline clinicians, healthcare system leadership, and patients, then implemented and evaluated in clinical settings. The Unit has created numerous nudges for clinicians and patients. One EHR-based active choice nudge that prompted medical assistants and physicians resulted in increased physician ordering of colonoscopy and mammography.

CDS also can facilitate integration of patient-generated health data with clinical data and practice guidelines to help providers and patients make decisions about genetic testing, cancer screening, and other care. MeTree—which was developed with funding from the Department of Defense and the National Human Genome Research Institute Implementing Genomics into Clinical Practice (IGNITE) consortium—is a family and personal health history collection and CDS tool that can be integrated with EHR systems that support the SMART-FHIR standard. This web-based, patient-facing tool collects information on diet, exercise, smoking, and clinical history, as well as family health history related to numerous health conditions, including several cancers. This type of patient-reported information is often not present in EHRs or is not in structured or standardized formats. Giving patients the opportunity to enter information beforehand can increase the quantity and quality of data compared with what usually is collected during a primary care visit. Based on the information entered, MeTree provides clinical decision support for hereditary cancer syndromes as well as other cancers and diseases. A large, multi-institutional study of MeTree in diverse primary care populations found that nearly half of participants met criteria for more intensive risk management for one or more conditions. This illustrates the importance of systematic risk assessment in primary care settings and the feasibility of using standards-based tools to support data collection and clinical decision support.

Sources: The Nudge Unit. Home page [Internet]. Philadelphia (PA): Penn Medicine; [cited 2021 Sep 25]. Available from: https://nudgeunit.upenn.edu; Hsiang EY, et al. JAMA Netw Open. 2019;2(11):e1915619. Available from: https://pubmed.ncbi.nlm.nih.gov/31730186; Orlando LA, et al. BMC Health Serv Res. 2020;20(1). Available from: https://pubmed.ncbi.nlm.nih.gov/33160339

DATA SHARING AND INTEROPERABILITY

Lack of EHR interoperability is cited as a key shortcoming by providers. To be maximally effective, health IT systems must be able to communicate, exchange data, and use the information that has been exchanged without special effort by the recipient. This includes the need for structured data exchange of pathology and test results coming from laboratory information systems. This free flow of information will support continuity of care for patients who receive care in different healthcare systems or facilities. Access to comprehensive, longitudinal patient data is particularly relevant for cancer screening because the eligibility for and benefits of cancer screening often depend on a patient's medical history, including the results of past tests. The President's Cancer Panel supports the ongoing work of the Office of the National Coordinator for Health Information Technology to increase interoperability as well as reduce the regulatory and administrative burden of EHRs for clinicians, hospitals, and healthcare organizations.

Sources: National Academy of Medicine. Taking action against clinician burnout: a systems approach to professional well-being. Washington (DC): The National Academies Press; 2019. Available from: https://www.nap.edu/25521; Office of the National Coordinator for Health Information Technology. Fed Regist. 2020 May 1;85:25642-961. Available from: https://www.federalregister.gov/d/2020-07419; Office of the National Coordinator for Health Information Technology. Strategy on reducing regulatory and administrative burdens relating to the use of health IT and EHRs. Washington (DC): ONC; 2020 Feb. Available from: https://www.healthit.gov/topic/usability-and-provider-burden/strategy-reducing-burden-relating-use-health-it-and-ehrs; Office of the National Coordinator for Health Information Technology. Trusted Exchange Framework and Common Agreement [Internet]. Washington (DC): ONC; [cited 2021 May 14]. Available from: https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement; Office of the National Coordinator for Health Information Technology. About ONC's Cures Act Final Rule [Internet]. Washington (DC): ONC; [cited 2021 May 14]. Available from: https://www.healthit.gov/curesrule/overview/about-oncs-cures-act-final-rule

PART 3

Conclusions

Conclusions

Screening for breast, cervical, colorectal, and lung cancers has been shown to save lives and reduce the burden of cancer. However, gaps in cancer screening mean too many in the United States are enduring aggressive treatment for or dying from cancers that could have been prevented or detected at earlier stages with screening. This includes disproportionate numbers of socially and economically disadvantaged populations and a large percentage of those with hereditary cancers. This avoidable burden of cancer imposes a heavy physical, emotional, and economic toll on individuals, families, and communities around the country. It also has broader economic implications, reducing workforce productivity and adding unnecessary strain to the healthcare system.

The President's Cancer Panel has determined that more effective and equitable implementation of cancer screening represents a significant opportunity for the National Cancer Program, with potential to accelerate the decline in cancer deaths and, in some cases, prevent cancer through detection and treatment of precancerous lesions. All stakeholders, large and small, need to take collaborative action to optimize cancer screening through better communication, access, and implementation.

Communication. Improvements in dissemination of guidelines and best practices for cancer risk assessment and screening are needed. More effective communications campaigns and educational strategies are essential to ensure that the public and healthcare providers have sufficient knowledge about cancer risk factors, screening benefits, and key eligibility criteria. The existence of multiple guidelines, changes in guidelines, and the evolution of screening modalities can cause confusion about screening. Coordination among stakeholders—including guideline makers—would facilitate alignment of key messages and development of strategies to promote screening. Communications campaigns must be tailored to reach and resonate with populations that may have different values, priorities, and cultural and communication norms, and, sometimes, different languages. Alignment of larger stakeholders with smaller, community-embedded organizations will facilitate delivery of effective messaging to populations experiencing gaps in cancer screening.

Access. Steps must be taken to ensure that every person in the United States has access to high-quality cancer risk assessment, genetic testing and counseling, cancer screening, and follow-up care. Legislative and policy changes have helped address insurance and cost issues, but this is often not sufficient. Community-oriented outreach and support services are needed to identify and address the social, cultural, economic, and logistical barriers that deter people from seeking out, initiating, and completing cancer screening and receiving recommended follow-up care in the case of an abnormal screening test result. Self-sampling approaches also should be pursued to extend the reach of cancer screening.

Implementation. Better implementation of screening guidelines will allow healthcare providers and systems to identify eligible people, make appropriate recommendations, and guide patients to complete all recommended screening and follow-up in a timely manner. Changes are needed to make it as easy as possible to support cancer screening. Well-rounded healthcare teams are needed to meet patients' needs effectively and efficiently, and all team members must be empowered to use the full extent of their skills and training. Improved health IT is needed to help healthcare teams apply the growing and increasingly complex set of cancer risk assessment and screening guidelines so they can deliver the right care to the right people at the right time. The technology needed to create these tools is available; steps must be taken to adapt and apply it more uniformly within our healthcare system.

The Panel urges all stakeholders—healthcare providers, healthcare systems, payors, community and patient advocacy organizations, government agencies, and individuals—to work together to close gaps in cancer screening and ensure that the benefits reach all populations. Improved early detection and prevention of cancer through screening will reduce the burden of the disease on individuals, families, communities, and the nation.

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APPENDIX A:
Workshop Dates and Roster of Participants

Meeting Date	Location
October 26 and October 28, 2020	Virtual Meeting
November 2 and November 4, 2020	Virtual Meeting
November 9 and November 10, 2020	Virtual Meeting
November 16 and November 18, 2020	Virtual Meeting
February 11, 2021	Virtual Meeting

Meeting Participants	Affiliations
Members of the Working Group on Cancer Screening During the COVID-19 Era	
Al B. Benson, III, MD, FACP, FASCO	Northwestern University Feinberg School of Medicine
Durado D. Brooks, MD, MPH	Exact Sciences
Haywood Brown, MD	University of South Florida
Lisa Carter-Harris, PhD	Memorial Sloan Kettering Cancer Center
Eva L. Cruz-Jove, MD	Senos Puerto Rico
Anjelica Davis, MPPA	Fight Colorectal Cancer
V. Paul Doria-Rose, DVM, PhD	National Cancer Institute
Chyke A. Doubeni, MBBS, MPH	Mayo Clinic
Tamika Felder	Cervivor
Francisco Garcia, MD, MPH	Pima County, Arizona
Michael K. Gould, MD, MS	Kaiser Permanente Bernard J. Tyson School of Medicine
Kevin S. Hughes, MD, FACS	Massachusetts General Hospital
Steven H. Itzkowitz, MD	Mount Sinai Hospital Icahn School of Medicine
Janie M. Lee, MD	University of Washington School of Medicine
David Lieberman, MD	Oregon Health & Science University Portland VA Medical Center
Thomas S. Lorey, MD	The Permanente Medical Group, Kaiser Permanente Northern California

Meeting Participants	Affiliations
Folasade P. May, MD, PhD, MPhil	UCLA Health
Worta McCaskill-Stevens, MD	National Cancer Institute
Olufunmilayo I. Olopade, MD, FACP	The University of Chicago Medicine
Rakesh R. Patel, MD	Good Samaritan Hospital
Rebecca B. Perkins, MD	Boston University School of Medicine Boston Medical Center
Sandhya Pruthi, MD	Mayo Clinic
Mitchell D. Schnall, MD, PhD	University of Pennsylvania Perelman School of Medicine
Richard C. Wender, MD	University of Pennsylvania Perelman School of Medicine
Nicolas Wentzensen, MD, PhD, MS	National Cancer Institute
Douglas E. Wood, MD	University of Washington
Other Meeting Participants	
Carolyn R. Aldigé	Prevent Cancer Foundation
Deborah Arrindell	American Sexual Health Association
Ashish Atreja, MD	Mount Sinai Health System
Tracy A. Battaglia, MD, MPH	National Navigation Roundtable
Elise Berman, MD	Fairfax Radiology Centers
Jay Bhatt, DO, MPH, MPA	University of Illinois at Chicago School of Public Health
Jessica L. Bienstock, MD, MPH	Johns Hopkins University School of Medicine
Kathleen Biesecker	CVS Health
Otis W. Brawley, MD, MACP, FASCO, FACE	Johns Hopkins University Bloomberg School of Public Health
Melissa F. Buffalo, MS	American Indian Cancer Foundation Meskwaki Nation
Diana Buist, PhD, MPH	Kaiser Permanente Washington Health Research Institute
Christian Cable, MD	Baylor Scott & White Medical Center
Ruth C. Carlos, MD, MS, FACR	University of Michigan
Tanner Caverly, MD	University of Michigan Medical School/Ann Arbor VA Center for Clinical Management Research
David Chambers, PhD	National Cancer Institute

Meeting Participants	Affiliations
Peter W. Chauncey, MSPH	PWC Solutions, LLC
David Chelmow, MD	Virginia Commonwealth University School of Medicine
Joseph Chin, MD, MS	Centers for Medicare & Medicaid Services
Doug Clarke, MD, MBA	Centers for Medicare & Medicaid Services
Sarah Coles, MD	American Academy of Family Physicians
Gloria D. Coronado, PhD	Kaiser Permanente Northwest Center for Health Research
Katherine Crew, MD	Columbia University Herbert Irving Comprehensive Cancer Center
Andrew Crighton, MD	CEO Roundtable on Cancer Project Data Sphere
Angela Criswell, MA	GO2 Foundation for Lung Cancer
Barbara Crothers, DO	Joint Pathology Center, Uniformed Services University of the Health Sciences
Katherine Dallow, MD	Blue Cross and Blue Shield of Massachusetts
Roslyn Y. Daniels	Black Health Matters
Paul DePriest, MD	Baptist Memorial Healthcare Corporation
L. Allen Dobson, Jr., MD	Community Care of NC, Inc.
Joelle T. Fathi, DNP, RN, ARNP, CTTS	University of Washington
Kathleen A. Fennig, MSN	Wright State University Boonshoft School of Medicine
Lisa Flowers, MD	Emory University School of Medicine
Holly B. Fontenot, PhD, RN/NP	University of Hawaii at Manoa School of Nursing
Mary E. Freivogel, MS, CGC	Invitae
Ann M. Geiger, PhD, MPH	National Cancer Institute
Venus Ginés, MPH	Día de la Mujer Latina
Richard Guido, MD	University of Pittsburgh Medical Center Magee-Womens Hospital
Samir Gupta, MD	Department of Veterans Affairs San Diego Healthcare System
Heather Hampel, MS	The Ohio State University
Daniel F. Harris, MD	Mid-Atlantic Permanente Medical Group

Meeting Participants	Affiliations
Todd G. Hartley	WireBuzz
Ernest T. Hawk, MD	The University of Texas MD Anderson Cancer Center
Candace Henley, CPN	The Blue Hat Foundation
Ronda S. Henry-Tillman, MD	University of Arkansas for Medical Sciences Winthrop P. Rockefeller Cancer Institute
Aimee C. Holland, DNP, WHNP-BC, FNP-C, FAANP	University of Alabama at Birmingham School of Nursing
Judd Hollander, MD	Thomas Jefferson University
James A. Hotz, MD, MACP	Albany Area Primary Health Care
Warner K. Huh, MD	University of Alabama at Birmingham
Thomas F. Imperiale, MD	Indiana University School of Medicine
Rachel Issaka, MD, MAS	University of Washington Fred Hutchinson Cancer Research Center
Louis Jacques, MD	ADVI
Gregory K. Jenkins, MD	Baptist Memorial Health Care Corporation
Kim M. Johnson, MD	Susan G. Komen
Leah Johnson	Epic
Djenaba Joseph, MD, MPH	Centers for Disease Control and Prevention
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APPENDIX B:
President's Cancer Panel Goals and Recommendations

Goal/Recommendation	Responsible Stakeholder(s)
GOAL 1: IMPROVE AND ALIGN CANCER SCREENING COMMUNICATION	
Recommendation 1.1: Develop effective communications about cancer screening that reach all populations.	
Develop and implement communications campaigns focused on cancer screening.	Centers for Disease Control and Prevention State health departments National advocacy organizations (e.g., American Cancer Society) Healthcare systems Community organizations
Recommendation 1.2: Expand and strengthen National Cancer Roundtables that include a focus on cancer screening.	
Create National Cancer Roundtables for breast cancer and cervical cancer that include a strong focus on screening. Increase financial support for the National Colorectal Cancer Roundtable and National Lung Cancer Roundtable.	American Cancer Society Centers for Disease Control and Prevention
Make health equity and alignment of messaging about cancer screening and cancer screening guidelines a high priority for National Roundtables.	National Roundtables
GOAL 2: FACILITATE EQUITABLE ACCESS TO CANCER SCREENING	
Recommendation 2.1: Provide and sustainably fund community-oriented outreach and support services to promote appropriate screening and follow-up care.	
Establish community health worker programs to reach people in communities and ensure those eligible receive appropriate and timely cancer screening and follow-up care.	Healthcare systems Health plans State health departments
Establish sustainable funding for community health worker programs to ensure they meet their full potential.	Healthcare systems Health plans State health departments
Provide training, directly or through partnerships with outside organizations, to ensure community health workers have the knowledge and skills necessary to do their jobs.	Healthcare systems Health plans State health departments

Goal/Recommendation	Responsible Stakeholder(s)
GOAL 2. FACILITATE EQUITABLE ACCESS TO CANCER SCREENING	
Recommendation 2.2: Increase access to self-sampling for cancer screening.	
Promote stool-based tests as an option for colorectal cancer screening.	Healthcare providers
Distribute stool-based tests to individuals due for colorectal cancer screening as part of a systematic effort to increase appropriate screening.	Healthcare systems Health plans
Participate in validation efforts and pursue regulatory approval for HPV self-sampling strategies.	HPV test manufacturers
Prioritize review of the evidence supporting HPV self-sampling.	U.S. Food and Drug Administration
GOAL 3: STRENGTHEN WORKFORCE COLLABORATIONS TO SUPPORT CANCER SCREENING AND RISK ASSESSMENT	
Recommendation 3.1: Empower healthcare team members to support screening.	
Create systems that allow all healthcare team members to promote and implement cancer screening programs or practices.	Healthcare systems
Modify requirements to allow nonphysician members of physician-led teams to conduct shared decision-making for lung cancer screening.	Centers for Medicare & Medicaid Services
Recommendation 3.2: Expand access to genetic testing and counseling for cancer risk assessment.	
Enable providers to offer genetic testing with informed consent. Eliminate requirements for pretest counseling by a certified genetic counselor or medical geneticist for coverage of genetic testing.	Health plans
Expand provider training and education on genetics, genetic testing, and interpretation of genetic testing results.	Medical training and residency programs Professional societies Guideline makers
Allow CMS to recognize genetic counselors as healthcare providers.	U.S. Congress

Goal/Recommendation	Responsible Stakeholder(s)
GOAL 4: CREATE HEALTH INFORMATION TECHNOLOGY THAT PROMOTES APPROPRIATE CANCER RISK ASSESSMENT AND SCREENING	
Recommendation 4.1: Create computable versions of cancer screening and risk assessment guidelines.	
Fund development of computable guidelines for cancer risk assessment and screening.	Agency for Healthcare Research and Quality Centers for Disease Control and Prevention National Institutes of Health Private research funding organizations (e.g., American Cancer Society)
Consider investment in dedicated programs to support creation of computable guidelines relevant to risk assessment, screening, and follow-up care for cancer and other diseases.	Centers for Disease Control and Prevention Agency for Healthcare Research and Quality
Recommendation 4.2: Create and deploy effective clinical decision support tools for cancer risk assessment and screening.	
Prioritize support for development and evaluation of standards-based, interoperable clinical decision support for cancer risk assessment and screening.	EHR vendors Healthcare systems Agency for Healthcare Research and Quality Centers for Disease Control and Prevention National Institutes of Health Private research funding organizations
Include clinical decision support for cancer risk assessment and screening in standard EHR systems and make it easy for clinical decision support developed by others to be integrated into EHR systems.	EHR vendors

CMS = Centers for Medicare & Medicaid Services
EHR = Electronic health record
FDA = U.S. Food and Drug Administration
HPV = Human papillomavirus

APPENDIX C: Acronyms

Acronym	Definition
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
CDS	Clinical decision support
CHW	Community health worker
CMS	Centers for Medicare & Medicaid Services
COVID-19	Coronavirus disease 2019
CPG-on-FHIR	Clinical Practice Guidelines-on-Fast Healthcare Interoperability Resources standard
CT	Computed tomography
EHR	Electronic health record
FDA	U.S. Food and Drug Administration
FHIR	Fast Healthcare Interoperability Resources
FIT	Fecal immunochemical test
gFOBT	Guaiac fecal occult blood test
HPV	Human papillomavirus
IGNITE	Implementing Genomics into Clinical Practice consortium
IT	Information technology
NCCRT	National Colorectal Cancer Roundtable
NIH	National Institutes of Health
NLCRT	National Lung Cancer Roundtable
ONC	Office of the National Coordinator for Health Information Technology
SMART	Substitutable Medical Applications and Reusable Technologies
USPSTF	U.S. Preventive Services Task Force

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