Minimizing the Burden of Cancer in the United States:
Goals for a High-Performing Health Care System

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Abstract: Between 1991 and 2015, the cancer mortality rate declined dramatically in the United States, reflecting improvements in cancer prevention, screening, treatment, and survivorship care. However, cancer outcomes in the United States vary substantially between populations defined by race/ethnicity, socioeconomic status, health insurance coverage, and geographic area of residence. Many potentially preventable cancer deaths occur in individuals who did not receive effective cancer prevention, screening, treatment, or survivorship care. At the same time, cancer care spending is large and growing, straining national, state, health insurance plans, and family budgets. Indeed, one of the most pressing issues in American medicine is how to ensure that all populations, in every community, derive the benefit from scientific research that has already been completed. Addressing these questions from the perspective of health care delivery is necessary to accelerate the decline in cancer mortality that began in the early 1990s. This article, part of the Cancer Control Blueprint series, describes challenges with the provision of care across the cancer control continuum in the United States. It also identifies goals for a high-performing health system that could reduce disparities and the burden of cancer by promoting the adoption of healthy lifestyles; access to a regular source of primary care; timely access to evidence-based care; patient-centeredness, including effective patient-provider communication; enhanced coordination and communication between providers, including primary care and specialty care providers; and affordability for patients, payers, and society. CA Cancer J Clin 2019;69:166-183. © 2019 American Cancer Society.

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Introduction

Between 1991 and 2015, cancer mortality rates declined by 26% in the United States.1 This dramatic decline in mortality rates reflects improvements in the delivery of cancer prevention, screening, treatment, and survivorship care.1 Although there has been significant progress, cancer outcomes in the United States vary substantially among populations defined by race/ethnicity, socioeconomic position, health insurance coverage, and geographic area of residence.

The human cost of these cancer disparities is high. Approximately 610,000 Americans will die from cancer in 2018; at least one-quarter of these cancer deaths could have been prevented if all Americans had access to and opted to use existing effective cancer prevention, screening, and treatments that are already used by many.2 Multiple factors are associated with disparities in cancer outcomes, including patients having less than optimal interactions with the health care system and structural inequalities in social, economic, and physical environments where patients live. Historically, racial/ethnic minorities, the poor, and the uninsured are less likely to receive evidence-based cancer prevention and screening, and they are more likely to be diagnosed with advanced disease.3,4 Racial/ethnic minorities, the poor, and the uninsured are less likely to receive effective cancer treatment5,6
and have poorer survival after diagnosis.\textsuperscript{5-8} A substantial proportion of insured Americans are underinsured, and their access to high-quality care is also limited. These underinsured populations are also less likely to receive evidence-based preventive care and, when diagnosed with cancer, they are less likely to receive optimal care, including cancer surgery, radiation therapy, and systemic therapies, and they have poorer survival after a cancer diagnosis.\textsuperscript{3,9,10} Although some disparities in cancer care by race are decreasing, disparities by socioeconomic status and state of residence are increasing.\textsuperscript{11}

The Institute of Medicine defined the goals of high-performing health systems as providing safe, effective, patient-centered, timely, efficient, and equitable health care to all patients.\textsuperscript{12} This article is part of the Cancer Control Blueprint series,\textsuperscript{13} which identifies opportunities for improving cancer control to reduce disparities in the burden of cancer morbidity and mortality in the United States. Prior articles have described the extent of disparities,\textsuperscript{14} and highlighted opportunities to improve cancer prevention,\textsuperscript{15} screening,\textsuperscript{16} and cancer survivorship care.\textsuperscript{17} Herein, we synthesize published research to describe cancer care delivery in the United States, including cancer prevention, early detection and diagnosis, treatment, survivorship, and end-of-life care; provide an overview of the US health care system; and identify goals for a high-performing health care system to reduce disparities in the burden of cancer in the United States. These goals for a high-performing health care system can also inform efforts to reduce disparities in the burden of illness in the United States more broadly.

### Delivery of Cancer Control Services in the United States

In this section, we describe access to and delivery of health care across the cancer control continuum in the United States. We then discuss measures of realized access to care, health care quality, recent trends in the costs associated with cancer in the United States, and the factors associated with growth in spending.

### Access to Health Care Throughout the Cancer Control Continuum

In the landmark Institute of Medicine report \textit{Access to Health Care in America},\textsuperscript{18} access to health care was defined as “the timely use of personal health services to achieve the best possible health outcomes.” This definition encompasses both the ability of individuals to obtain needed medical services and the potential for those medical services to improve health. Although there is a tendency to think about access to care for treatment of disease, access to health care is essential throughout the cancer control continuum, including primary care, with providers who discuss cancer risk factors and encourage healthy lifestyles, implement cancer screening, ensure early recognition of and timely response to symptoms, encourage adherence to medical treatments, and coordinate survivorship care (Fig. 1). Access to palliative care is increasingly recognized as an important component of high-quality care at the time of diagnosis as well as at the end of life.

Multiple factors are associated with access to care. They broadly fall into societal, health care system, and provider issues and patient factors. Despite tremendous advances in medical therapies, inadequate coordination of care and care transitions remains a serious problem that threatens access to high-quality care and can increase health care costs. As illustrated in Figure 2, there are multiple potential breakdowns in health care delivery throughout the cancer control continuum. Cancer screening and diagnosis generally begin with a primary care provider and referral to a specialty care provider, such as a radiologist, gynecologist, or gastroenterologist. Diagnostic evaluation of a symptomatic patient or an abnormal screening test result also requires referral to a specialist. If a diagnosis of cancer is confirmed, additional referrals to cancer specialists, such as medical oncologists, radiation oncologists, urologists, and surgeons, may be required. Virtually all patients with cancer have multiple appointments with multiple providers for workup and treatment. After completion of treatment, patients should receive coordinated survivorship care in multiple settings, including specialty and primary care.\textsuperscript{17}

Health care providers and practices can be affiliated with multiple hospitals, networks, and insurance plans, but not necessarily with each other, and these affiliations can change over time. Importantly, care is not explicitly coordinated across these multiple insurers, plans, hospitals, and practices, and medical records and patient data can reside in multiple places without integration. Despite ongoing efforts to improve health information technology
infrastructure, this lack of coordination can result in duplication of services, overuse of ineffective care, underuse of effective care, and misuse of health care services. Lack of coordination and continuity also may contribute to health disparities.

Some access issues are related to geography. For some people who live in rural areas, the availability of services is often limited. It is not unusual for them to have to travel long distances for health care. Some state-by-state differences in access to care throughout the continuum reflect state-level policies. Features of Medicaid, the state-federal health insurance program for low-income persons, vary by state, including Medicaid reimbursement to providers in relation to other payers, program use of case management and managed care, and income eligibility thresholds for Medicaid insurance coverage.

Patient characteristics associated with less access to health care broadly include minority race/ethnicity, living in poverty, having limited education, or lacking experience in navigating the health care system. The poor and the uninsured very often simply cannot afford health care. These groups are at greater risk of poor health outcomes, including poorer survival and higher mortality rates than their counterparts with health insurance, even after considering other risk factors. Evidence consistently shows that having and maintaining health insurance coverage is a strong patient-level predictor of having a usual source of health care, receipt of recommended preventive services, and diagnosis and effective treatment of chronic conditions. Logistic issues also can interfere with the ability to obtain cancer care, especially among the poor. For example, access to care is limited when patients cannot obtain daycare for their children, when they lack transportation to and from the health care provider, and when they are unable to take time off from work because of a lack of paid or unpaid sick leave.

**Quality of Care Throughout the Cancer Control Continuum**

Central to the consideration of access to care is ensuring that patients have access to the highest quality of care. Evidence-based clinical guidelines define the elements of high-quality care. Numerous organizations publish clinical guidelines covering many aspects of cancer care, from prevention, to screening, and treatment of cancer. The most influential guidelines for cancer screening and prevention are authored by the US Preventive Services Task Force and by the American Cancer Society. The most influential guidelines for cancer treatment, surveillance, and follow-up care are authored by the National Comprehensive Cancer Network (NCCN), an organization of 27 National Cancer Institute-designated comprehensive cancer centers. These guidelines are published at NCCN.org. They are commonly used to define quality cancer care for providers and payers.

The NCCN gathers committees of experts to review the published literature and write guidelines for cancer prevention, screening, treatment, and survivorship care. The NCCN process involves a review of the published literature and a consensus recommendation. Because the quality of published clinical data varies, strength of study design and endpoints are taken into consideration and discussed in each recommendation. In general, the order of evidence about treatment effectiveness, from

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**FIGURE 2. Potential Breakdowns in Coordination in Health Care Across the Cancer Control Continuum.**

- Lack of risk assessment and behavior counseling
- Lack of screening recommendation
- Lack of follow-up abnormal findings
- Underuse, overuse, and misuse of effective treatment(s)
- Lack of coordinated survivorship care
- Lack of coordinated palliative care
- Lack of early inclusion of palliative care
strongest to weakest, used in consensus recommendations is prospective randomized controlled trials, nonrandomized controlled trials, and observational studies, including prospective cohorts, case-control studies, cross-sectional studies, and case series.

Choosing Wisely is another attempt to bring attention to the problem of waste in health care testing and treatment; the American Board of Internal Medicine launched the Choosing Wisely Campaign in 2012. The American Society for Clinical Oncology (ASCO) also identified limiting prostate cancer screening in men without symptoms and a short life expectancy and 9 other common, cancer-related interventions that physicians and patients should question.

First on the ASCO list is the use of anticancer treatment for solid tumors in the absence of strong evidence supporting clinical value. Patients with metastatic terminal cancer may receive third-line, fourth-line, and even fifth-line chemotherapy. Survival benefits for a fourth-line or a fifth-line of chemotherapy after other regimens have failed are modest at best, and the potential for harm from therapy can be greater than the potential for benefit. A full discussion of the potential benefits and harms of therapy is an especially important area for informed decision making. Other measures on the ASCO list of interventions to question include the overuse of expensive antiemesis medicines; the use of multiagent chemotherapy when data demonstrate an equivalent or better outcome with single-agent therapy; the overuse of advanced imaging, especially positron emission tomography (PET) scanning; and the use of targeted therapy in the absence of data to show that the tumor will respond.

Importantly, the measurement of quality requires understanding and measuring the health care associated with good health outcomes as well as bad health outcomes. Interest in measuring and improving the quality of health care has a long history. In a landmark 1966 article, Donabedian proposed using the triad of structure, process, and outcomes to evaluate the quality of health care. The structure component refers to qualifications of providers as well as the physical and organizational context of care delivery and infrastructure. Examples of structural measures can be related to the use of electronic health record (EHR) systems for identifying patients for smoking-cessation counseling, tracking and following patients who have abnormal screening results, and ensuring that patients complete guideline-consistent treatment(s) and return for routine survivorship care after treatment completion. The process component refers to interactions between patients and health care providers in the delivery of care, including prevention, screening, treatment, survivorship, and end-of-life care. Process measures are generally evidence-based or evidence-informed, and they relate to the proportion of eligible patients who received a certain type of care. Ideally, data for quality measurement are readily available, and quality measures reflect an aspect of care that is actionable by providers. Examples of process measures are the proportion of age-eligible women who received mammography screening or the timing and receipt of specific treatment(s) based on stage at cancer diagnosis and patient characteristics. Outcomes can be measured for patients and populations more broadly and generally reflect the results of process measures. Outcomes can be intermediate measures, such as emergency department or hospital admissions for patients receiving outpatient chemotherapy, or longer term, more comprehensive measures, such as survival and mortality rates. Increasingly, measures of patient experience are incorporated into quality-of-care measurement by collecting information directly from patients about their perceptions about the care they received and their experiences with health care providers.

Quality measures can be used in quality-improvement efforts and accreditation. They can also be used in payment, as described in the section below on the US health care system. Development and stewardship of quality measures can be initiated by professional organizations, such as the National Committee for Quality Assurance (NCQA), the Joint Commission, and ASCO. For example, the NCQA developed the Healthcare Effectiveness Data and Information Set, which comprises standardized performance measures widely used by health plans for quality improvement. The American College of Surgeons Commission on Cancer (CoC) has broad-based, ongoing quality improvement efforts in more than 1500 hospital-based, accredited cancer care programs. As part of these efforts, the Commission on Cancer establishes quality standards and routinely measures care quality, uses data to monitor treatment patterns and outcomes, and develops interventions to improve cancer control delivery. Its Cancer Program Practice Profile Reports program currently uses more than 20 quality measures. ASCO has also been active in promoting high-quality, evidence-based cancer care through its clinical practice guidelines and its National Quality Oncology Practice Initiative. Quality measures are evaluated and endorsed by NCQA and the National Quality Forum. The National Quality Forum-endorsed measures are most commonly used in public and private payment, as described below (see Quality in Value-Based Payment Models).
To date, most quality measures are process measures. Ideally, better performance on process measures reflects better outcomes, but they are not always explicitly linked. Some quality measures are based on a rigorous evaluation of clinical evidence, whereas others are consensus based. Approaches to quality measurement have been criticized for not incorporating or adjusting for or considering patient and provider characteristics that may influence the delivery of health care. In addition, the services that are included in “quality care” can represent the receipt of a specific service or aspects of that service, rather than the quality of the service provided. For example, the Mammography Quality Standards Act has required the inspection of mammography equipment and mammography clinics since 1995. Inspections assess calibration of the mammography machines, record keeping, notification, and some outcomes but do not directly assess the accuracy of mammogram reading. Alternatively, other quality measures, such as cervical cytology quality measures, do report accuracy based on correlation of cytology and biopsies.

Other challenges associated with quality measures and reporting are data infrastructure requirements and provider burden. As noted in an NCCN meeting summary about quality measurement, reporting may require information from multiple data sources, with elements that do not reside in structured fields. Lack of interoperability, especially across EHR systems with various reporting mechanisms and capabilities, is a hindrance to quality assessment.

Health Care Costs Associated With Cancer in the United States
Cancer is one of the most expensive medical conditions in the United States. The societal cost of cancer care is increasing. Cancer incidence increases with age, and the US population is both aging and growing. Between 2010 and 2020, the cost of cancer care in the United States is projected to increase by 27%, from $124.6 billion to $157.8 billion, based only on US population growth.

Many factors are associated with increasing costs, in addition to population growth. Historically, inpatient hospitalizations have been the major driver of cancer costs. Recent trends, such as greater treatment intensity, where more patients who have cancer are now treated with more agents and for longer periods of time, increasing use of supportive agents and advanced imaging, and the increasing cost of cancer drugs, will accelerate growth in the cancer cost burden. More than one-half of newly approved cancer drugs have list prices of $100,000 or more annually. Substantial costs are for the treatment of patients with advanced disease and at the end of life, in whom large variations in treatment patterns and costs of care, even for similar patients, suggest that there are many unrealized opportunities to improve care delivery.

The rising costs of cancer care have important implications for patients with cancer and their families. Patients who have health insurance face increasing out-of-pocket cost-sharing because of higher deductibles, copayments, and coinsurance rates. The patient share of some treatment costs often ranges from 20% to 30%. For many patients with $100,000 in annual treatment cost, the $20,000 to $30,000 out-of-pocket cost each year can be unaffordable. Patients who do not have health insurance may be responsible for the entire cost associated with treatment. The median monthly price of many cancer drugs is approximately double the median monthly household income in the United States. Thus, patients with cancer and their families are increasingly experiencing medical financial hardship associated with cancer. Health care for illness and related income losses because of employment changes as a result of illness are a leading cause of personal bankruptcy, especially for cancer survivors. Problems paying medical bills can cause emotional distress and force many patients to delay or forgo potentially lifesaving medical care. Medical financial hardship is associated with adverse health outcomes for cancer survivors, including poorer quality of life and worse survival. The medically underserved, including racial/ethnic minorities, the poor, and the uninsured, are most likely to experience medical financial hardship associated with cancer care.

The US Health Care System and Models of Care Delivery
In this section, we provide an overview of the US health care system and health insurance coverage and more specifically describe models of health care delivery and cancer care. We also discuss other efforts to promote value in cancer care. The US health care system in general is discussed because, as described above, cancer control spans the gamut of health care from counseling regarding healthy behaviors, assessment of cancer risks and preventive interventions, screening, diagnosis, treatment, survivorship, and end-of-life care. Some of the most effective cancer control interventions, including counseling regarding healthy habits and preventive care, are provided within primary care by health care providers (physicians, nurses, physician assistants, and health educators). Other cancer control interventions addressing high-quality cancer screening, treatment, survivorship, and end-of-life care require effective coordination and transitions between primary care and specialty care providers.
Overview of the US Health Care System

In 2016, US health care spending was $3.35 trillion, approximately 17.8% of the gross domestic product. US health care spending as a portion of gross domestic product is nearly twice that of other high-income countries. The high cost is partly because the United States leads the world in the speed with which it adopts innovative new therapies and offers state-of-the-art health care. In addition, the prices for the same health care services are higher in the United States than in most other developed countries. Another major reason is that the provision of health care in the United States is far from organized. It is decentralized and fragmented, with insurers, both public and private, operating independently of each other. There are a large number of health insurance companies, not including the federal Medicare program and other public programs. Health insurance, like other types of insurance, has the primary function of protecting individuals against unexpected financial risk. Unlike most other developed countries, the United States does not provide universal health insurance coverage to its citizens. Insurance coverage differs substantially in the United States by age group, as illustrated in Figure 3. The federal Medicare program provides insurance coverage for greater than 94% of Americans aged 65 years and older and those who qualify for Social Security disability. Many also have supplemental private coverage from prior employers as part of retirement benefits or purchase supplemental private coverage separately. Some Medicare beneficiaries with low income also receive coverage from the Medicaid programs. These patients are also referred to as “dually eligible” and are shown in Figure 3 as “Medicare + public” coverage.

Of the adult population younger than 65 years, about two-thirds have private health insurance coverage, which is mainly employer-based. A small proportion of the younger population receives coverage through the Medicare program because of permanent disability. Almost 20% of adults younger than 65 years have some form of public insurance coverage, usually state-based Medicaid. Medicaid programs for the younger low-income population vary tremendously by state. There are state-level differences in who is eligible, what services are covered, and how much providers are reimbursed. In 2017, state Medicaid eligibility thresholds ranged from 18% of the federal poverty level (FPL) to 221% of the FPL. The 2017 FPL was $20,780 for a family of 3. In the states with the lowest eligibility threshold to qualify for Medicaid coverage, a family of 3 must have an annual income of less than $3740.

Across all ages, about 28.5 million Americans were uninsured at any point during the year in 2017. The vast majority of uninsured are adults aged 18 to 64 years. As noted above, research has consistently shown that the uninsured have poorer access to care, lower receipt of evidence-based cancer screening and treatment, and worse health outcomes. However, even those with health insurance may experience barriers to high-quality care because of: 1) high annual premiums; 2) high deductibles, which patients must pay out of pocket before insurance coverage begins; and 3) high cost-sharing for specific covered services, including copayments, which are fixed amounts, and coinsurance, which is a percentage of the total cost of a service. Insured patients with higher deductibles and cost-sharing are more likely to delay

![Figure 3. Health Insurance Coverage for Adults in the United States, by Age Group.](image-url)
or forgo care, including necessary care, which can result in more emergency room use and hospitalizations. For example, women enrolled in high-deductible health insurance plans experienced delays in diagnostic imaging for breast cancer, receipt of biopsy, diagnosis, and initiation of treatment compared to similar women enrolled in low-deductible health insurance plans.

Recent trends of increasing patient cost-sharing with higher deductibles, copayments, and coinsurance rates mean that increasing proportions of Americans with health insurance are not able to access health care. This phenomenon of having health insurance coverage but being unable to access care or delaying care because of cost is known as being underinsured. It is estimated that as many as one-quarter of Americans who have private insurance through an employer are underinsured.

The Patient Protection and Affordable Care Act and Health Insurance Coverage

The Patient Protection and Affordable Care Act, more commonly known as the Affordable Care Act (ACA), is legislation that was enacted on March 23, 2010. It represents one of the biggest changes in health care delivery in the United States since the establishment of the Medicare and Medicaid programs in 1965. Some aspects of the ACA are related to having access to specific services, including the introduction of essential health benefit standards and the elimination of copays, deductibles, and coinsurance for preventive services, including cancer screening tests, that receive an A or B effectiveness rating by the US Preventive Services Task Force.

Significant components of the ACA address the availability of and access to health insurance coverage, including introduction of the Health Insurance Marketplace, which allows individuals to enroll in private plans; elimination of preexisting condition exclusions; and elimination of lifetime and annual coverage limits. There is also dependent coverage expansion, which allows young adults to remain covered under a parent’s private health insurance up until age 26 years and the expansion of Medicaid eligibility to 138% of the FPL for low-income adults with and without children in some states. As of November 2018, 36 states and the District of Columbia have adopted Medicaid expansion under the ACA.

Since 2014, patients with cancer and survivors in expansion states were more likely to be insured, have access to care, and be diagnosed at an earlier stage of disease than those in nonexpansion states. There is little research to date explicitly evaluating the effects of Marketplace coverage, essential health benefits, or elimination of preexisting coverage exclusions on access to care or health outcomes for cancer survivors. However, dependent coverage expansion as part of the ACA in 2010 was associated with improved access to some preventive services and earlier stage at diagnosis in young adults.

State Medicaid programs also vary in administration, with differences in covered services, provider reimbursements, integration of case management, and structure and financing of care (ie, fee-for-service and managed care). Evidence is accumulating that some of the historical disparities for minority, low-income, and rural populations have been reduced in Medicaid expansion states, with little change in disparities in nonexpansion states. These findings suggest that state-by-state differences in health disparities may increase in some cases.

Although Medicaid programs do provide for increased access and can be better than no insurance, the availability of Medicaid insurance does not eliminate health disparities, and, in some situations, outcomes in the uninsured and Medicaid insured populations are similar. However, because some cancer registries record only the last known type of insurance coverage, the interpretation of the role of Medicaid coverage is complex. As much as 57% of patients with newly diagnosed cancer who have Medicaid coverage enrolled at or after their cancer diagnosis. In many cases, insurance coverage would not have been available before the cancer diagnosis for these patients, and, as a result, they may not have been able to access a usual source of primary care, effective cancer prevention and screening, and services for symptom evaluation. Thus, patients who gain Medicaid coverage only after a cancer diagnosis may be more similar to patients who remain uninsured at diagnosis, attenuating any benefits of insurance coverage on stage of disease at diagnosis. Compared with those who have continuous Medicaid coverage before and after diagnosis, those who gain coverage only after cancer diagnosis are less likely to receive definitive surgery and more likely to disenroll within a year of diagnosis. These patients with cancer who do not have continuous Medicaid coverage may be less likely to complete recommended treatment and to have access to high-quality survivorship care, which also may be related to poorer observed survival for those with discontinuous rather than continuous Medicaid coverage. In addition, individuals who have Medicaid coverage are poorer and are more likely to be adversely affected by social determinants of health than individuals who have private insurance coverage. Medicaid reimbursement is usually lower than reimbursement from other insurance types. As a result, many health care providers do not accept Medicaid. This almost certainly contributes to poorer outcomes. Thus, limitations in current data and confounding by socioeconomic status may underestimate the positive impact of Medicaid coverage.
Models of Health Care Delivery in the United States: Moving From Volume to Value

There is a movement toward the development and testing of different models of health care delivery in the United States to improve the quality of care and patient outcomes while reducing or maintaining the costs of care. These efforts to improve the value of health care build on a long history of evaluating the cost-effectiveness of specific health interventions. Historically, health care has used a fee-for-service model, which reimburses providers for each service delivered to patients. The fee-for-service model provides incentives for greater volume of services without consideration of quality of care, patient outcomes, or cost of care. Because providers are reimbursed for every service, they have low risk in relation to the value of care provided under the fee-for-service model (Fig. 4). In addition, provider reimbursement is generally based on the complexity of health care services, meaning that specialty care has been reimbursed at a higher rate than primary care. The fee-for-service model is thought to be associated with greater numbers of health care services, higher health care costs, and greater use of technology and specialty care. Higher intensity health care may not be equivalent to higher quality care or improved patient outcomes, may be wasteful, and, in some situations, may be harmful.

Fee-for-service is the traditional Medicare payment model. A key aspect of fee-for-service thought to play an important role in rising costs of health care, especially for cancer, is prescription drug reimbursement. Oncologists and hospital outpatient departments purchase infusion chemotherapy, biologics, and other drugs that are later administered to patients in their offices. Reimbursement formulas for infusion drugs under Medicare are based on the average sales price (ASP) plus a percentage of the ASP add-on for each drug, to help compensate for administrative complexity and clinic overhead. Because the percentage add-on is proportional to the underlying ASP for different drugs, the add-on reimbursement is larger for more expensive drugs. This ASP reimbursement structure has been associated with the increased use of higher cost chemotherapies for patients with newly diagnosed lung cancer. Efforts are ongoing to modify Medicare reimbursement for prescription drugs, both infusion and oral drugs, in attempts to address rising costs.

Starting in the 1970s, health maintenance organizations (HMOs) financed and structured health care quite differently compared with the fee-for-service model. These plans assumed responsibility for all health care for a defined population of patients for a specified period of time as well as financial responsibility for providing that care. HMOs are private plans that are paid a capitated rate, meaning that there is a fixed fee for each patient in their defined population. HMOs are generally primary care focused, with a more limited network of specialist providers and facilities. Primary care providers can also serve in a gatekeeper role; patients generally require primary care referrals to obtain specialty care. This financial structure does not reward service volume but, instead, incentivizes improving the coordination of care, eliminating duplication of services, and reducing medical errors and hospitalizations that might have been prevented with effective primary care. Many HMOs have invested heavily in EHRs and other information technology infrastructure. Some researchers have expressed concerns that capitation may result in provider incentives to limit care or avoid patients who have complex or expensive medical conditions. Managed care has grown in employer-sponsored insurance and state Medicaid programs. Nearly 33% of Medicare beneficiaries are enrolled in Medicare Advantage plans, which are private plans paid with capitated rates. With capitated payment, HMOs have increased provider risk and have a greater focus on value (Fig. 4).
Pay-for-performance programs, episode-based payments, and bundled payments are other approaches to payment. Early pay-for-performance programs provided bonuses or incentives for meeting or exceeding goals for specified quality measures. Some of these programs also imposed penalties for failing to meet quality goals. The underlying assumptions of these programs were that improving performance on specified measures would be associated with overall improvement in patient outcomes. Throughout the 2000s, several private insurers implemented pay-for-performance programs, and public payers sponsored several demonstration projects. Findings on the effectiveness of pay-for-performance programs have been mixed. Most of the quality measures used by these programs were process measures and did not necessarily drive quality improvement in patient outcomes. More recently, pay-for-performance programs have addressed spending goals as well as quality metrics.

Episode-based or bundled payments provide a fixed payment amount for a specific combination or bundle of related services across health care settings for a specified episode or period of time. Episodes are usually triggered by a health event or type of care (eg, orthopedic injury, chemotherapy). As with other approaches to improving the value of care, the goals of bundled payments are typically related to better care coordination and eliminating duplication of services and the use of ineffective services. Definitions of the duration of episodes (eg, 2 weeks, 6 months), included services, and payment amounts are generally data driven. Although bundled approaches incentivize the coordination of care between providers within a bundle, they do not address the quality of care outside of bundled services and may lead to more bundles that a given patient may experience. Pay-for-performance and bundled payments have greater focus on value than the fee-for-service model and result in greater financial risk for providers.

The patient-centered medical home (PCMH), frequently referred to as “the medical home,” is a primary care model that was developed in 2007. The PCMH model of care is based on the formation of care teams, measurement of quality, enhanced access, provision of care coordination, and changes in payment to provide incentives to provide higher quality care at lower cost.

The accountable care organization (ACO) is a care-delivery model that was developed by the Centers for Medicare & Medicaid Services (CMS) for use in the Medicare program. In it, a group of primary care clinicians or primary care and specialty clinicians, usually in partnership with a hospital system, organizes and is accountable for services provided to a defined population of Medicare fee-for-service beneficiaries. ACOs are based on pay-for-performance models and are required to report more than 30 quality metrics. Patients can still seek care from other providers, and physicians are still paid on a fee-for-service basis. ACOs also are eligible for shared savings if they meet quality metrics and achieve savings compared with the expected costs of care for their defined population. They can participate in 1 of 3 payment tracks: “upside” risk only, in which they can share in any savings but do not share in losses, or 2 other tracks that have 2-sided risk, in which ACOs share savings as well as losses. Tracks with 2-sided risk have higher potential gains for shared savings.

Many of these payment and health care delivery models are being conducted by the CMS Innovation Center, which was created by the ACA. Goals of the Innovation Center are to address the “triple aim” of improving health care: better quality, better health, and lower cost. This triple aim is consistent with other private efforts to improve health care by focusing on the value of care provided rather than the volume of services. Newer models being tested include value-based payment models and alternative payment models (APMs) and feature greater provider accountability for a higher quality of care based on specified quality metrics and costs of care.

In 2015, the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA), (H.R. 2, Pub.L. 114–10, congress.gov/114/plaws/publ10/PLAW-114publ10.pdf) authorized changes in Medicare reimbursement of physicians to further move from the fee-for-service model and offer incentives to provide high-quality, cost-effective care with a strong focus on value. Physician practices are required to report quality metrics and to demonstrate meaningful use of EHRs as a structural quality measure. The MACRA established 2 payment tracks to be implemented over time. One track is a modification within the existing fee-for-service system that adjusts physician payment upward or downward based on performance against defined quality-of-care categories. This track is referred to as the merit-based incentive payment system (MIPS). Ultimately, a MIPS score will be based on performance on quality measures, adoption and use of health information technology, clinical improvement (ie, coordination, health equity, telehealth), and controlling costs. The second track requires participation in any of several advanced alternative payment models. Participation in an ACO is an example of an advanced alternative payment model.

CMS set Medicare payment goals of linking fee-for-service to quality and alternative payment models. By the end of 2018, it is projected that 90% of Medicare fee-for-service payments will be linked to quality, and one-half of all Medicare payments are in an alternative payment model. The evolution of health care payment toward value rather than volume is expected to continue.
Concerns have been raised about the potential adverse effects of value-based payment models for patients with complex medical needs and patient groups that have been historically medically underserved, including racial/ethnic minorities, dual-eligible Medicare-Medicaid beneficiaries, and the poor.\textsuperscript{100,101} Social determinants are strongly associated with health outcomes.\textsuperscript{100,101} Value-based payment models could lead to improvements in the quality of health care and reduce health disparities if the main source of poor patient outcomes is the delivery of poor-quality medical care. However, if the main source of poor outcomes and health disparities is outside of provider control and, instead, is related to factors other than quality of care, providers may become reluctant to care for medically complex patients and the medically underserved out of fear of losing bonuses and incurring penalties. Early evaluations suggest that both the quality of care delivery and patient factors are associated with poor outcomes.\textsuperscript{101} Increasingly, federal, state, and commercial models of care are explicitly addressing social determinants of health.\textsuperscript{102,103}

Models of Oncology Care Delivery

As noted above, there is substantial variation in patterns of cancer care and spending in the United States,\textsuperscript{104} especially for patients with advanced disease.\textsuperscript{47,48} Developing care delivery models that focus on oncology has been a priority, and several models have been piloted.\textsuperscript{105} Most oncology models have focused on the medical oncologist, and especially on patients receiving chemotherapy.\textsuperscript{45,106,107} They share the goals of improving care coordination and reducing spending by avoiding preventable emergency room visits and hospitalizations.

Between 2009 and 2012, UnitedHealthcare (UnitedHealth Group Inc, Minnetonka, Minnesota) piloted an episode-based payment model in 5 volunteer oncology practices.\textsuperscript{108} Oncologists were paid a fixed payment for a defined time period or for an episode of care for patients with breast, colon, or lung cancer. Episode durations were defined based on cancer type, stage, and tumor characteristics and ranged from 4 months for stage IV colon cancer to 12 months for stage III estrogen receptor-negative/progesterone receptor-negative breast cancer with human epidermal growth factor receptor 2 overexpression. Chemotherapy and other systemic antineoplastic treatments were reimbursed separately at the ASP with no add-on (ie, additional physician reimbursement) to remove incentives to deliver more chemotherapy and more expensive chemotherapy. Additional case management support was provided to participating practices, as was feedback on cost and quality measures. Compared with similar patients in a national registry, patients in the episode model had a 34% reduction in predicted total medical costs without large differences in quality measures. Costs associated with hospitalizations and emergency department visits were significantly reduced in practices in the model, but unexpectedly, chemotherapy costs were 179% higher than predicted. Nonetheless, results of this pilot suggest that care delivery innovation presents an opportunity to reduce oncology care costs.\textsuperscript{108}

The PCMH model described above has been adapted to oncology. The oncology medical home was developed initially in 2012 based on pilot programs in New Mexico.\textsuperscript{109} The CMS Innovation Center sponsored the Community Oncology Medical Home (COME HOME) model in 7 volunteer oncology practices.\textsuperscript{110} It included patients with solid tumors who were enrolled in Medicare, Medicaid, or commercial insurance. Model components included care coordination, increased access to providers through call lines and extended hours, and evidence-based diagnosis and treatment pathways. Participation in the COME HOME model was associated with decreased spending and fewer hospitalizations in the last 30 days of life for Medicare beneficiaries who died.\textsuperscript{111} The model reduced costs primarily through decreasing hospital admissions and referral to emergency care.

The Patient Care Connect Program is a model of care that integrated patient navigation at 12 cancer centers in 5 states for Medicare fee-for-service beneficiaries who have cancer.\textsuperscript{112} Navigation was associated with fewer emergency department visits, hospitalizations, and intensive care unit admissions and lower costs in analyses of matched navigated and non-navigated patients.

Other models of oncology care delivery are based on clinical pathways or treatment pathways.\textsuperscript{113,114} These models include evidence-based treatment options based on details about the cancer type, stage, and other clinical characteristics, especially for the most common cancers. They may also include information about recommended dosing and treatment sequencing. Early retrospective evaluations of receipt of pathway-consistent treatment for non-small cell lung cancer or colon cancer in EHRs or claims data suggest that patients who received pathway-consistent treatment had outcomes similar to those of patients who did not receive pathway-consistent care, and with lower costs.\textsuperscript{113,114} However, because studies conducted with claims data do not contain information about patient characteristics associated with both receipt of treatment and outcomes, including stage, response to prior treatment, functional status, and comorbidity, findings can reflect healthier patient selection into treatment pathways (selection bias).

An early example of a prospective treatment pathways model study is the Anthem Cancer Quality Program (Anthem Insurance Companies, Inc, Indianapolis, Indiana), which that began in 2014 and is being conducted in commercially insured individuals and Medicare...
Advantage beneficiaries.\textsuperscript{105,115} Patients with colon, breast, and non-small cell lung cancer who are receiving chemotherapy in more than 500 practices in 10 states are included. Treatment pathways were developed with physician input and incorporated clinical benefit, survival, quality of life, and treatment toxicity. Oncologists received per-member, per-month financial incentives to coordinate care for their patients on disease-specific treatment pathways. Findings have not yet been published. Concerns have been expressed about patient access to treatments and the transparency of the process for recommending specific treatments within pathways models,\textsuperscript{116} especially with the growth in pathway vendors. To address these concerns, ASCO has developed criteria for the evaluation of pathways, including clinician involvement in their development, being evidence-based, transparency of development, stakeholder input, integration into EHR systems for decision support, and analytics for ongoing quality improvement.\textsuperscript{116,117}

In 2016, the CMS Innovation Center launched the oncology care model (OCM) in 178 volunteer oncology practices and several commercial payers across the United States.\textsuperscript{118} The OCM focuses on patients with cancer who are undergoing systemic treatment and contains care coordination elements of PCMHs and a form of bundled payments from an episode-based model within the fee-for-service setting.\textsuperscript{119} Features of the OCM include patient navigation, care plans, round-the-clock patient access to clinicians, and guideline-based care. Six-month episodes are triggered by the receipt of chemotherapy, and patients who continue to receive chemotherapy after 6 months start a new 6-month episode. The OCM requires practices to report data on quality metrics. Structural quality metrics address the integration of EHRs and the certification of meaningful use. Process metrics are related to adherence to guideline therapy and safety, and clinical outcome metrics are related to cancer outcomes, unexpected hospitalizations, or emergency room visits. OCM practices receive an additional per-patient, per-month payment for each Medicare beneficiary on active therapy in each episode month. There is also the potential for pay-for-performance, in which the practice can receive a bonus if there is a reduction in the overall costs of care compared with historic spending benchmarks and if quality metrics are fulfilled.

Similar to the other value-based payment models, the OCM also has 1-sided and 2-sided risk arrangements, or tracks. In the 1-sided track (“upside” risk only), a practice that has expenditures lower than targets can share in the savings; however, if its expenditures exceed targets, then the practice is not responsible for additional costs. The 2-sided risk arrangement will produce greater potential gains in shared savings to encourage participation and will be phased in over time. As noted above, and consistent with previously cited model tests, savings are anticipated to derive from decreases in preventable emergency department visits and hospitalizations, more efficient use of laboratory tests and advanced imaging, better supportive care, and improved coordination of end-of-life care. The OCM qualifies as an APM under the MACRA.

To date, only preliminary findings from value-based models focusing on cancer care are available. The UnitedHealthcare, Patient Care Connect Program, and COME HOME models were associated with lower total costs in volunteer oncology practices,\textsuperscript{108,111} but the underlying reasons for increased chemotherapy costs in the UnitedHealthcare model are unclear. Lack of explicit coordination between primary care and specialty care providers in these oncology treatment models may adversely affect fully integrated survivorship care and longer term patient outcomes. In addition, the effectiveness of general value-based payment models may differ by cancer site or component of the cancer control continuum. For example, primary care-based models might be especially effective in providing cancer screening for healthy populations, but whether that same model is equally effective for patients who develop rare, poor-prognosis cancers requiring highly specialized care is unknown. Understanding the effects of different value-based payment models throughout the cancer control continuum will be an important area for future evaluation and research.

**Quality in Value-Based Payment Models**

Value-based payment models increasingly require measurement and reporting of the quality of care at the practice, hospital, health plan, or other organizational level. As discussed above, quality of care is generally evaluated in relation to structural, process, and outcome measures. Examples of these measures used in payment are listed in Table 1. Patient experience measures are incorporated into quality-of-care measurement, in which information is collected directly from patients about their perceptions regarding the care they received and their satisfaction with their health care experiences and health care providers. For example, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys include ratings of Medicare care providers (eg, hospitals, physicians) as well as health plans and prescription drug plans. The Medicare Health Outcomes Survey (MHOS) contains a patient-reported outcomes measure, a reflection of health status, used by Medicare Advantage plans. In addition to reporting information publicly, the CMS uses MHOS scores for calculating quality bonus payments in the Medicare Advantage Star Ratings program. Survey data from both the CAHPS and MHOS have been linked to Surveillance, Epidemiology, and End
Results cancer registry data to facilitate research addressing patient experiences and health-related quality of life, respectively.\textsuperscript{120,121}

Other Efforts to Promote Value in Cancer Treatment

Value in the context of health care refers to the relationship between benefits and harms of treatment(s), health outcomes, and the costs of care. ASCO defines value as clinical benefits, side effects, and improvements that affect a patient’s symptoms or quality of life from the perspective of cost.\textsuperscript{122,123} Multiple professional societies have developed value frameworks to assess the value of cancer treatment regimens and communicate their results, including ASCO,\textsuperscript{122,123} the NCCN,\textsuperscript{124} a network of National Cancer Institute-designated cancer centers, and the European Society for Medical Oncology.\textsuperscript{125} The Institute for Clinical and Economic Review generates a “value-based” price for specific treatments, and the Drug Pricing Lab at Memorial Sloan Kettering Cancer Center developed the Drug Abacus,\textsuperscript{126} an online tool to incorporate user perspectives on treatment toxicity and novelty compared with existing treatments along with population burden of disease, cost of drug development prognosis, and unmet needs.

All of these frameworks and tools take into account the clinical utility of prescription drugs for the treatment of advanced disease and in the adjuvant setting.\textsuperscript{127} These frameworks are designed to help physicians and other providers, as well as the patient and family, have a structured

\begin{table}
\centering
\caption{Examples of Quality Metrics Across the Cancer Control Continuum}
\begin{tabular}{|l|l|l|l|}
\hline
\textbf{MEASURE TYPE} & \textbf{RELEVANT COMPONENT OF THE CANCER CONTROL CONTINUUM} & \textbf{MEASURE} & \textbf{DESCRIPTION} & \textbf{SETTING} \\
\hline
Structure & All & EHR meaningful use & Use of certified EHR technology (eg, electronic prescribing); ensuring that it provides for the electronic exchange of health information to improve the quality of care; and submission of information on quality of care and other measures & APMs \\
Process & Prevention & Monitoring physical activity & Evaluation of physical activity & Medicare Advantage \\
Screening & Breast cancer screening & Proportion of age-eligible women who received mammography in past 2 y & HEDIS \\
Screening & Colorectal cancer screening & Proportion of age-eligible men and women with a colonoscopy in the past 10 y, sigmoidoscopy in the past 5 y, and/or a stool test in the past y & HEDIS \\
Treatment & Chemotherapy for colon cancer & Adjuvant chemotherapy is recommended or administered within 4 mo (120 d) of diagnosis for patients aged <80 y with AJCC stage III (lymph node-positive) colon cancer & NQF; CoC \\
Treatment & Surgery for colon cancer & At least 12 regional lymph nodes are removed and pathologically examined for resected colon cancer & NQF; CoC \\
Treatment & Radiation therapy for breast cancer & Radiation therapy is administered within 1 y (365 d) of diagnosis for women aged <70 y receiving breast-conserving surgery for breast cancer & CoC \\
Survivorship & Smoking cessation & Smoking-cessation counseling recommended to smokers/tobacco users in past y & QOPI \\
Outcome & Treatment & Emergency department visits & Admissions and emergency department visits for patients receiving outpatient chemotherapy & OCM \\
Outcome & Intensive service use at the end of life & Chemotherapy, intensive care unit admission within 2 wk of death & QOPI \\
Patient experience & Treatment & Communication & How often did drug therapy team explain things in a way that was easy to understand & CAHPS \\
\hline
\end{tabular}
\footnotesize{Abbreviations: AJCC, American Joint Committee on Cancer; APM, alternative payment model; BMI, body mass index; CAHPS, Consumer Assessment of Health Providers and Systems; CoC, Commission on Cancer; EHR, electronic health record; HEDIS, Healthcare Effectiveness Data and Information Set; NQF, National Quality Forum; OCM, Oncology Care Model; QOPI, Quality Oncology Practice Initiative.}
\end{table}
discussion regarding the value of specific treatments. They can also help third-party payers and policy makers understand the value of cancer treatment options. The President’s Cancer Panel report Promoting Value, Affordability, and Innovation in Cancer Drug Treatment emphasized the importance of these goals. 128

Efforts to promote high-value care can also focus on health insurance benefit design. Within most types of health insurance, patient copays and coinsurance are based on the underlying price of the prescription drug or treatment, with patients responsible for greater cost-sharing for more expensive treatments, regardless of their effectiveness. However, as noted above, higher patient cost-sharing is associated with worse treatment adherence, which also has adverse effects for emergency room use and potentially preventable hospitalizations. Instead, plan benefit design and patient cost-sharing can be structured to incentivize patients to use treatments with the highest value, measured in terms of effectiveness, rather than cost alone. For example, high-value treatments might be available to patients with no or low cost-sharing, even if they are expensive. Lower value treatments might have higher cost-sharing, even if they are relatively inexpensive. Because cost-related treatment nonadherence disproportionately affects populations that are already economically disadvantaged,129-133 targeted interventions may be necessary to improve health outcomes and potentially decrease long-term medical costs.

Goals for Delivery of High-Quality Care Throughout the Cancer Control Continuum

American health care costs have been rising for years. Aging of the “baby boomers” will accelerate this growth in the costs of health care. Despite these high costs, the health of the population and, for purposes of this article, the health of the population in relation to cancer control is suboptimal, and disparities are pronounced. Health care in the United States is not optimally effective, timely, efficient, or equitable.

The ACA included numerous provisions that were intended to alter our national system of how we provide care, including steps to encourage innovation in health care delivery.73 These provisions were designed, in part, to shift payment models toward a greater focus on value and to help reduce the cost of care, which, in turn, would allow insurance coverage expansions to be affordable.
Expanded health insurance coverage options, with approximately 20 million newly insured Americans, are associated with improved access to a usual source of care, preventive services, and cancer screening. Expanded insurance coverage is also associated with improvement in some outcomes, such as earlier stage of disease at diagnosis, although data are only more recently available to evaluate some of these outcomes. Other patient provisions, such as the introduction of essential health benefit standards and the elimination of preexisting condition exclusions and lifetime and annual coverage limits, have not been fully evaluated. For a variety of reasons, payment provisions have had only modest effects and, to date, have been insufficient to alter substantially the nation’s health care spending trajectory. Although the ACA has had success in expanding insurance coverage to millions of Americans, it has also been criticized as focusing too much on approaches to payment and coverage without meaningfully altering how health care is actually provided. Many new payment models are still being tested. A central challenge for the future of the health of Americans is designing and implementing a system of care that provides adequate access to high-quality health care for all Americans while promoting innovation and contributing to slowing the growth of health care costs.

Evidence clearly demonstrates that enhanced prevention is an efficient and effective way to reduce our nation’s cancer burden. Universal access to a trusted and regular source of primary care increases the likelihood that an individual will be aware of personal risks, receive lifestyle counseling, and be up to date with recommended preventive care, including cancer screening (Fig. 5). In addition, primary care systems can provide life coaching, chronic disease management, and appropriate referral for diagnostic and specialty care and can share in survivorship care. However, currently, there are many potential breakdowns in the delivery of primary and specialty care.

A health care system that minimizes the burden of cancer in the United States would ensure the timely receipt of effective preventive, chronic, and acute health care services. Critically, health care would be affordable for patients and their families, so that a diagnosis of cancer would not result in financial ruin. Health care would also be affordable for health care payers, employers states, the federal government, and society more broadly. Such a health care delivery system would feature coordination, communication, and smooth transitions between primary care and specialty care providers and between patients and providers to ensure that care aligns with patient values and goals. It would also promote the early involvement of palliative care, especially for patients with advanced disease. Finally, as shown in the center of Figure 5, a high-performing health care system would consider these features in the organization and delivery of care. It could use the health insurance benefit structure, including deductibles, copays, and coinsurance, to minimize patient barriers to receiving effective, high-value care. It would also implement value-based payment models structured to reward high-quality care for all patients, with incentives to reduce health disparities within and between practices. As summarized in Table 2, each of these goals of a high-performing health system is relevant throughout the cancer control continuum.

| GOALS FOR A HIGH-PERFORMING HEALTH SYSTEM | RISK ASSESSMENT AND PREVENTION | RECOMMENDATIONS FOR REGULAR SCREENING | TIMELY FOLLOW-UP OF ABNORMAL FINDINGS/EARLY-STAGE DIAGNOSIS | EFFECTIVE TREATMENT, INCLUDING PALLIATIVE CARE | COORDINATED SURVIVORSHIP CARE | COORDINATED END-OF-LIFE CARE |
|-------------------------------------------|---------------------------------|--------------------------------------|-------------------------------------------------|---------------------------------|-----------------------------|-------------------------------|
| Encourage adoption of healthy lifestyles  | X                               | X                                   | X                                               | X                               | X                           | X                             |
| Provide access to a regular source of primary care | X                               | X                                   | X                                               | X                               | X                           | X                             |
| Facilitate timely access to evidence-based care | X                               | X                                   | X                                               | X                               | X                           | X                             |
| Promote patient-centeredness, including effective patient-provider communication | X                               | X                                   | X                                               | X                               | X                           | X                             |
| Enhance coordination and communication between providers | X                               | X                                   | X                                               | X                               | X                           | X                             |
| Ensure affordability for patients, payers, and society | X                               | X                                   | X                                               | X                               | X                           | X                             |
Although the goals of a high-performing health care system are relatively clear, the path to achieving these goals is not. Although it is beyond the scope of this Cancer Control Blueprint article to explore the complex and politically charged question of the optimal method for designing our payment system, viewing our health care system through the lens of patients with cancer and their families helps to define principles that can be used to assess health care system design options. No American should develop cancer, suffer needlessly, or die prematurely because they cannot access the care they need. Health care should be accessible, affordable, administratively simple, and based on evidence, and payment must be linked to the right incentives, as measured by the achievement of optimal outcomes with appropriate resource utilization. Ensuring that all individuals can access high-quality care is critical, a vital attribute to judge the effectiveness of a delivery and payment system. As illustrated throughout this Cancer Control Blueprint series, much is already known about how to reduce the burden of cancer, but without a national investment and commitment to transforming our health care system, many people will not benefit from the progress we have already made, let alone the innovations and breakthroughs that are yet to come.

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