The State of Cancer Care in America 2015

American Society of Clinical Oncology
Making a world of difference in cancer care
ASCO MISSION
The American Society of Clinical Oncology (ASCO) is a professional oncology society committed to conquering cancer through research, education, prevention and delivery of high-quality patient care.

ASCO VISION
• All patients with cancer will have lifelong access to high-quality, effective, affordable and compassionate care.
• The most accurate cancer information will be available so that patients and physicians can make informed decisions about cancer prevention and treatment.
• Information we learn from every patient will be used to accelerate progress against cancer.
• Resources will exist to attract the best clinicians and investigators to provide optimal patient care and to conduct transformative research.
• ASCO will be recognized as the most trusted source of cancer information worldwide.

MEMBERSHIP
ASCO’s diverse network of more than 35,000 oncology professionals recognizes ASCO’s dedication to provide the highest-quality resources in education, policy, the pioneering of clinical research and above all, advancing the care for patients with cancer. ASCO is unique in that we are the only organization that encompasses all oncology subspecialties, allowing our members to grow from the professional and personal expertise of their colleagues worldwide and across disciplines. International members make up approximately 30 percent of the Society’s total membership and represent more than 120 countries. ASCO offers a variety of membership categories designed to fit different career stages and specific needs.

For more information about ASCO, please visit www.asco.org.

ABOUT THIS REPORT
The State of Cancer Care in America report is an annual, comprehensive look at demographic, economic, and oncology practice trends that will impact cancer care in the United States over the coming years. Published in the Journal of Oncology Practice March 17, 2015, this report also examines the growing emphasis on quality measurement and value, and the rapid expansion of health information technology. The American Society of Clinical Oncology (ASCO) publishes annual updates to this report to help the oncology community, policymakers, and others more effectively shape the future of cancer care in America.

The full text of this report and other features may be found at www.asco.org/stateofcancercare.

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A MESSAGE FROM ASCO’S PRESIDENT

In March 2014, the American Society of Clinical Oncology (ASCO) published its inaugural State of Cancer Care in America report to heighten awareness about advances in—and growing demand for—cancer care and to provide a comprehensive analysis of issues affecting patient access and delivery of cancer care in the United States. Our 2015 report continues this work by focusing on oncology practice trends and key challenges facing cancer care professionals in today’s demanding healthcare environment.

This year’s examination of current data and trends clearly shows that oncology practices in all settings continue to experience tremendous pressures and volatility in the marketplace. At the same time, advances in both cancer treatment and health information technology are spurring exciting innovations in oncology care. In addition, changes resulting from ongoing implementation of the Affordable Care Act, along with heightened concern about increasing costs, are spurring major clinical practice changes that leverage technology, support efficiency, and foster patient-centered care.

As healthcare professionals, we value evidence-based practice to ensure that all of our patients receive high-quality cancer care. The State of Cancer Care in America: 2015 provides data-driven insight—on practice trends, workforce composition, innovative care strategies, and other emerging issues—that can inform the national dialogue on what the future of the cancer care delivery system might be, and support oncology practice efforts to adapt, survive and thrive in the coming days.

We deeply appreciate the many oncology practices and researchers that helped ASCO develop this report by sharing their experiences and information, and invite all readers to join us in finding solutions to the many challenges described on the following pages.

Sincerely,

Peter Paul Yu, MD, FACP, FASCO
ASCO President, 2014-2015
Disparities in access to cancer care persist across the United States and public insurance programs should be structured to minimize barriers that contribute to this challenge.
The U.S. cancer care system remains in a state of transition.

In 2014, the United States made significant progress in cancer care as demonstrated by improvement in the five-year cancer survival rate for many cancer types and a record 14.5 million cancer survivors, as well as by the availability of 10 new drugs and several new tests for the diagnosis, treatment, or management of cancer.1 At the same time, a growing demand for cancer services, turbulence in the cancer care delivery system, and growing concerns about cost of care are creating uncertainties about the system’s capacity to continue to provide high-quality care for all patients with cancer. These factors have focused attention on the need for better definitions of value and meaningful ways to assess quality. In this second annual State of Cancer Care in America report, the American Society of Clinical Oncology (ASCO) chronicles the challenges currently facing the U.S. cancer care system. The report provides background and context to help understand what is happening today in cancer care and describes trends in the cancer care workforce and diverse practice environment that may affect cancer care in the coming years.

1. CANCER CARE IN AMERICA: A SHIFTING LANDSCAPE

The American population continues to grow and age, driving up demand for cancer services to previously unseen levels. This report includes updates on progress in the field of cancer care and on the state of cancer incidence and survival.

Progress in cancer care. In 2014, the U.S. Food and Drug Administration (FDA) approved 10 new drugs and several new tests for the diagnosis, treatment or management of cancer, and more than 771 promising therapies are in the development pipeline.2,3 Advances in treatment have produced improvements in the five-year survival rate for many cancer types, and there are now 14.5 million Americans who are cancer survivors today1—a number that continues to grow with each passing year.

Rapidly growing demand. An estimated 1.6 million new cancers were diagnosed in 2014, with growing numbers expected in future years. Demand for cancer care is being driven by newly insured patients, an aging population and long-term care needs of survivors. In 2014—the first year of the insurance mandate of the Affordable Care Act (ACA)—nearly eight million Americans registered through new insurance exchanges and millions more are gaining access to insurance through the expansion of private and governmental programs.4 As ACA implementation progresses, these numbers are expected to increase significantly.

Persistent inequities. The benefits of cancer screening and treatment advances have not been experienced evenly across racial and ethnic groups, as evidenced by differences in incidence and mortality rates. Although the Affordable Care Act has successfully expanded access to insurance and cancer care services, millions of Americans remain uninsured, while other individuals with public and private plans continue to lack sufficient coverage for high-quality cancer care.

Emerging public health concerns. This year, the ASCO report addresses two new issues with potential to influence demand for cancer services:

• Obesity. In the United States today, more than one third of adults and nearly one fifth of children are considered obese. Public health experts are concerned about a range of serious health consequences. There is mounting evidence that obesity leads to at least eight forms of cancer and affects survival.5 Obesity is responsible for more than 84,000 cancer cases annually, and this number is expected to rise substantially in future years6,7—but the link between obesity and cancer is largely unrecognized by the public.
• **Electronic cigarettes.** Electronic cigarettes are advertised to American consumers as a safe alternative to smoking—but these claims lack adequate scientific support. The U.S. Food & Drug Administration (FDA) currently only regulates electronic cigarettes marketed for therapeutic purposes, but it has proposed expanded regulations covering all electronic cigarettes. This authority is important because electronic cigarettes are becoming popular among smokers and non-smokers alike, including nearly two million U.S. adolescents. For these reasons, ASCO and public health experts support the expansion of FDA’s authority and are calling for research to assess potential direct and indirect health effects of these devices.

### 2. THE ONCOLOGY WORKFORCE

ASCO regularly monitors the size, distribution and diversity of the U.S. oncology workforce to identify trends that could affect access to care. The Society’s latest analysis identified several key issues:

- **Number of oncologists constant despite growth in demand.** In 2014, approximately 11,500 hematologists and/or medical oncologists provided care to U.S. patients with cancer, a modest 1.6 percent increase from the previous year. Altogether, more than 18,000 physicians provide oncology subspecialty patient care, including gynecologic oncology, pediatric hematology/oncology, radiation oncology, and surgical oncology. Additionally, more than three thousand advanced practice providers provide oncology care across the country, including nurse practitioners, doctors of nursing practice, and physician assistants. Advanced practice provider employment is growing rapidly, enhancing the pipeline of providers who might choose a career in oncology.

- **Aging workforce, declining interest in private or solo practice careers.** Consistent with last year’s report, oncologists are aging—with oncologists ages 65 years and older continuing to outpace those entering the field (ages 40 years and younger). Women continue to increase their share of the workforce and occupy nearly half (48 percent) of hematology/oncology fellowship slots. In contrast, the number of ethnic and racial minorities in oncology remains discouragingly low. New to this edition of the report, ASCO covers practice decisions made by new entrants into the oncologist workforce. In a 2014 survey of medical oncology fellows, a majority (55.8 percent) of respondents indicated a preference for university-based clinical practice or research, whereas 36.8 percent indicated they were likely to choose non-academic community or private practice settings. Among oncologists presently working in a practice setting, young oncologists are more likely to work in group practice and less likely to work in solo practice than their older colleagues.

- **Rural settings underserved.** Oncology continues to experience uneven geographic distribution of its workforce. Relative to where Americans ages 55 and older reside (who account for the majority of new cancer cases), Washington, DC, and Massachusetts have the most oncologists, whereas Hawaii and Nevada have the fewest. For the more than 59 million Americans living in rural areas, a diagnosis of cancer can present unique challenges to obtaining high-quality care for their disease, including long travel distances and decreased access to specialists, and state-of-the-art diagnostics, treatments and technologies. ASCO’s 2014 analysis of oncology locations identified approximately 600 hematologists and medical oncologists (5.5 percent) practicing in rural care sites.

- **States investing in outreach, monitoring workforce.** Two state-based research initiatives conducted in Iowa and Nebraska examined access in underserved areas and pointed to strategies that may serve to inform efforts in other communities across the United States. In Iowa, community hospitals and health centers in remote areas are offering cancer services by employing visiting oncologists, thereby significantly expanding patient access in the state. In nearby Nebraska, where 47 percent of residents live in rural areas and cancer is the leading cause of death, researchers found that the number of oncologists increased by 3 percent and the number of oncology nurse practitioners and physician assistants increased by more than a third (37 percent and 36.1 percent, respectively) from 2008–2012. These increases provided additional provider capacity within Nebraska—although not in rural areas.

- **Burnout a continuing problem.** A recent survey of medical oncology fellows found that more than a third of respondents experienced high levels of burnout (at least one event a week)—a rate similar to that reported among practicing oncologists.
3. THE STATE OF ONCOLOGY PRACTICE

This report highlights findings from ASCO’s third annual census of U.S. oncology practices, conducted in 2014, along with related data from other sources.

- **ASCO Oncology Census: continuing practice adaptation.** Nearly 1,000 (n=974) U.S. oncology practices participated in this year’s census study, representing more than 10,000 individual oncologists. In a continuing trend toward consolidation, one quarter of community-based practices signaled the likelihood of pursuing hospital affiliation in the next twelve months.

- **Shifts in practice staffing and administration.** The number of practices reporting multi-specialty services remained high in 2014, especially among academic and hospital-based practices. A majority (52 percent) of practices responding to the ASCO Oncology Census employed advanced practice providers, accounting for more than 2,700 advanced practice nurses and 1,100 physician assistants.

- **Practice financial health and management.** In 2014, cost and payer pressures persisted as the most pressing practice concerns, especially among physician-owned and hospital-based practices. Drug prices were also a major concern among physician-owned practices. Academic practices were primarily concerned with clinical research issues and competitive pressures.

- **Preauthorization a growing concern.** The time clinicians and their staff spend dealing with insurance companies reduces the time available for patient care and remains a burden on practices. Preauthorization—the requirement that clinicians get prior approval from patients’ insurance providers before ordering certain tests or administering certain treatments—is an area of particular concern among oncology practices. A recent survey of ASCO state affiliate organizations found that preauthorization requirements increase demands on staff time, delay or interrupt patient care, decrease patient satisfaction, and complicate medical decision making.

- **Drug shortages in cancer care.** Drug shortages remain a relatively small but persistent pressure on practices. According to a 2014 survey of oncology practices, policy changes enacted in 2011 and 2012 may have helped avert or mitigate drug shortages—consistent with findings from several recent governmental analyses. Survey respondents reported that they often address shortages by recommending different treatment regimens, working directly with manufacturers to obtain available drugs, contracting or sharing drugs available from other local providers, or contracting with other drug distributors.

- **Safe handling of chemotherapy drugs.** The regulation of chemotherapy safety often occurs at the state level, and several states have been active in recent years in developing new rules in this area. State-level efforts are typically informed by available guidelines and recommendations. In 2014, the medical oncology community worked collaboratively to develop standards and to help support communications and educational efforts with policymakers at the state level to ensure that regulations promote safety and are easily adopted when applied to the day-to-day operations of practices.

- **340B Drug Pricing Program.** The 340B Drug Pricing Program requires drug manufacturers to provide price discounts to certain hospitals and other health care facilities that qualify as covered entities. Some have questioned the rapid expansion of the 340B Drug Pricing Program in terms of both the number of eligible facilities and the number of eligible drug claims. This was a focus for both Congress and the Administration in 2014, but there has been no regulatory action to refine the program to date.
4. QUALITY AND VALUE IN CANCER CARE

Defining and delivering high-value care was a key focus across the oncology community in 2014 and will continue to dominate health reform efforts in the year ahead. Cost of care continues to drive practice and payment reform initiatives, quality measurement and improvement efforts, and a focus on data and transparency is more broadly viewed as a means of informing consumer choice.

**Focus on cost.** In the last decade, the average monthly cost of cancer treatment has more than doubled to $10,000.22 A handful of treatments now cost more than $100,000 annually per patient, and as cancer therapy moves toward use of multiple such agents, concerns about cost have grown. Payers and policymakers are focused on strategies to better define value and engage patients in selecting high-value options.

**Response to cost: targeting utilization.** Health insurers and policymakers have pursued a variety of strategies to control cost while preserving or enhancing quality. These include: administrative controls on utilization (e.g., preauthorization for costly therapies and clinical pathways), development of alternative payment models, and quality monitoring. There has also been a strong emphasis on creating more informed and value-conscious consumers.

**Quality assessment and performance improvement.** Greater availability of metrics and tools to analyze clinical data are expanding the way that oncologists learn and improve care quality. Quality measurement and improvement are central elements in virtually every payment reform model proposed this year. Notably, the Centers for Medicare & Medicaid Services—the single largest payer for health services in the United States—is increasingly expecting providers and practices to demonstrate their commitment to improving quality of care. Other organizations are also advancing national quality measurement and methods to improve performance.

**Big data.** The use of large and complex data sets to inform cancer treatment and care delivery is a growing focus. Numerous big data projects are underway among private and public organizations, including ASCO’s rapid learning system, CancerLinQ; data sharing among pharmaceutical companies through Project Data Sphere; PCORnet by the Patient-Centered Outcomes Research Institute; and several initiatives of private companies such as IBM and Optum.
5. CONCLUSION AND RECOMMENDATIONS

Although the U.S. cancer care system faces many challenges, it is capable of meeting these expectations through mobilization of cancer clinicians and researchers and the broader healthcare community in this unique time of dramatic change and significant opportunity.

Below are strategies ASCO believes can play an important role in addressing the challenges described in this report:

► Ensure all publicly funded insurance programs offer consistent and appropriate benefits and services for patients with cancer.
  • CMS should standardize benefits and other program elements across Medicare and Medicaid.
  • Congress should eliminate inconsistencies in coverage and benefits that currently exist between Medicaid patients enrolled pre- and post-Affordable Care Act and ensure that Medicaid includes coverage of clinical trials.
  • Oncology professionals should articulate the essential services any plan must include to achieve high-quality, high-value care.

► Pilot test multiple innovative payment and care delivery models to identify feasible models that promote high-quality, high-value cancer care.
  • CMS should expand its efforts to pilot alternative payment models—beyond its Oncology Care Model—to identify innovative strategies that allow practices flexibility to deliver high-quality, high-value care while containing cost.
  • Congress should provide a fair, adequate, and stable payment environment for oncology practice, including repeal and replacement of the sustainable growth rate (SGR) formula.
  • Oncology professionals should engage in testing and evaluating new payment and care delivery models and in developing measures of accountability for the care delivered.
  • Private insurers should partner with CMS, patients, and providers to test promising new payment and care delivery models so the impact of alternative strategies on the entire cancer care delivery system can be determined.

► Promote high-value care by advancing and supporting transparency and shared decision making with patients.
  • CMS should make every effort to improve its publicly released data and provide appropriate information to help the public understand the context for the data.
  • Congress should require that health information technology vendors create products that promote interoperability and enable research use of standardized data in a secure environment to advance high-quality health care.
  • Oncology professionals should discuss personal goals of care, potential treatment options, expected benefits, and the physical and financial impacts of treatment options with every patient with cancer.
  • Private insurers should ensure that publicly shared information about providers is accurate, in context, and meaningful to the intended audience.
  • Professional organizations should offer tools and information that facilitate and help routinely incorporate shared decision making into practice.

ASCO will continue to track and evaluate the ever-shifting landscape in cancer care over the coming year, will continue to support cancer care providers as they negotiate these growing pressures, and will work with policymakers and other stakeholder organizations to ensure that changes in the system support access to high-quality, high-value care for all cancer patients.
Uninsured and underinsured cancer patients continue to face delayed and restricted access to life-saving, life-extending treatments and to services that enhance quality of life.
The cancer care landscape in the United States continues to shift, with changes in demand for services, health insurance coverage, and organization of the care delivery system.

At the same time, new insights made possible by research are enabling continued progress against cancer. The availability of safer and better treatments, along with an expanded focus on value and quality of cancer care, has contributed to increasing survival rates and improved quality of life for patients living with this disease.

Despite this progress, significant challenges face the nation’s cancer care delivery system, including continued growth in demand for cancer care. In large part because of an aging population, the number of cancer cases will continue to rise, and cancer will remain a leading cause of death among adults in America. In addition, millions have gained coverage through the Affordable Care Act (ACA), which will enable greater use of cancer prevention services as well as the potential for more people to access cancer treatment. As later chapters of this report detail, the challenges are compounded by demographics of the oncologist workforce, challenges of continuity of care, and increases in the cost and complexity of delivering quality cancer care.

In this chapter of the *State of Cancer Care in America* report, ASCO surveys the current landscape of cancer patient needs, offering essential context for later chapters on the oncologist workforce, practice, value, and quality.

**PROGRESS IN CANCER CARE**

In 2014, the United States made significant progress in improving the quality of cancer care as demonstrated by growth in the number of new drugs and technologies approved by the Food and Drug Administration (FDA), improvements in the five-year cancer survival rates for many cancer types, and the increasing number of cancer survivors.

**Growing Number of New Drugs and Technologies**

People with cancer have access to a wider array of treatment options than ever before. In 2014, the FDA added 10 new drugs and biologics to its list of more than 170 approved anti-cancer agents and added nine new indications to existing drug labels (Table 1).

In 2013, the FDA established a new designation, breakthrough therapy, to recognize drugs that target serious and life-threatening conditions, and have a high likelihood of improving patient outcomes—potentially increasing the pace at which life-extending drugs will reach patients. For drugs with a breakthrough therapy designation, the FDA works with sponsors to streamline development and review of the therapy. In 2014, the FDA gave breakthrough therapy designations to 13 cancer agents. Of the newly approved drugs listed in Table 1, six had previously received breakthrough therapy designations.
The trend toward therapies that are tailored to each cancer and each patient continued in 2014. All 10 of the newly approved drugs listed in Table 1 attack cancer at the molecular level, and the use of such targeted therapies grew from 11 percent in 2003 to 46 percent in 2013.\textsuperscript{22} Drug development in oncology remains an area of high innovation; of the 771 cancer therapies now in development, 80 percent are potentially first in class, representing approaches to treating cancer that are different from any other marketed therapy.\textsuperscript{3} The development of companion diagnostics and biomarkers has also helped physicians identify which patients will benefit from these drugs, avoiding complications and expense for patients who will not benefit.

The FDA has also approved several medical devices and tests with the potential to improve patients' outcomes through early detection of cancer. In 2014, four new screening tools were approved: BRACAnalysis CDx, which detects BRCA mutations associated with ovarian cancer; Cologuard, a home-based, non-invasive colon cancer screening test that detects abnormal cells in stool specimens; Therascreen, which detects the KRAS mutation associated with colon cancer; and SenoClaire, which provides greater clarity in breast mammography without increasing radiation exposure.\textsuperscript{27} The approval of Cologuard marks a new era of regulatory collaboration and efficiency in the United States; Cologuard is the first diagnostic to receive joint approval by the FDA and by the Centers for Medicare & Medicaid Services (CMS) for coverage in the Medicare program.\textsuperscript{28}

In late 2013, the FDA also made headlines by approving four diagnostic devices for high-throughput gene sequencing, also known as next-generation sequencing.\textsuperscript{29,30} Two of these devices—Illumina's MiSeqDx Platform and Universal Kit—can be used by laboratories to develop and validate sequencing of almost any aspect of a patient's genome, thereby creating new avenues for cancer detection and selection of therapy.

**Improvements in Cancer Survival**

Scientific advancements, together with technological and practice innovations, are responsible for marked improvements in survival rates among cancer types in recent years. Today, more than two-thirds of patients (68.5 percent) live beyond five years of a cancer diagnosis.\textsuperscript{31} Patients diagnosed in 1975 had only a 49 percent likelihood of surviving five years.\textsuperscript{31} Since last year, the National Cancer Institute has reported improvements in five-year relative survival for many cancer types, notably for myeloma (from 43.2 percent to 44.9 percent) and certain forms of acute leukemia (from 28.8 percent to 30.8 percent).\textsuperscript{31}
Despite a steady decline in mortality rates, cancer accounts for nearly a quarter of all deaths in the United States. For certain cancers, mortality rates have remained steady or even increased. For example, age-adjusted mortality has been rising among patients with pancreatic cancer and men with liver cancer for decades. These mortality increases have been widely attributed to shifts in the racial and ethnic distribution of cases and associated differences in survival outcomes.

**Increasing Number of Cancer Survivors**
More than 1.6 million new cancers were diagnosed in 2014, bringing the total of Americans living with a history of cancer to 14.5 million. Figure 1 illustrates the steady growth in the number of cancer survivors over the past decade.

**RAPIDLY GROWING DEMAND FOR CANCER CARE**
As the U.S. population grows and ages, the number of people with cancer has reached a record high and will continue to grow. According to a recent study, there is likely to be a 45 percent increase in cancer incidence between 2010 and 2030, leading to increased demand for cancer care and post-treatment services. Three major trends are contributing to the increased demand for cancer care:

- **Newly insured patients.** Millions of uninsured Americans signed up for health insurance last year because of the ACA insurance mandate. At the end of the open enrollment period in March 2014, eight million people had registered through new insurance exchanges, and millions more were granted access to insurance through the expansion of private and governmental programs. The Congressional Budget Office estimated that the law would result in 12 million fewer uninsured Americans in 2014 and 26 million fewer by 2017 (Figure 2).

Included in the pool of newly insured people are cancer patients and survivors who had previously struggled to find adequate, affordable coverage because of their history of cancer. Millions of newly insured patients will require cancer and survivorship services, potentially requiring 130 additional medical oncologists by 2025 to meet the new demand. Moreover, if increasing patient access to insurance improves survival outcomes, as is projected, significant expansion in the survivor population can be expected.

- **Increasing cancer burden.** Several key demographic shifts are leading to an increased number of cancer cases. The U.S. Census Bureau projects that the number of people older than age 65 years will double by midcentury. Despite declines in smoking, these Americans remain highly vulnerable to cancer. In addition, obesity (discussed later in this chapter) is expected to cause an additional 500,000 cancer cases by 2030. And as racial and ethnic minorities continue to make up a larger proportion of the overall population, it is likely that the demographics of cancer will change as well, given the differences in cancer risk by race and ethnicity.

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**FIGURE 1**
Number of People with a History of Cancer

**Source:** SEER Cancer Statistics Review archive, National Cancer Institute

**Note:** These figures represent the number of people with a history of cancer alive in the corresponding year. Some of these individuals were cancer-free, while others still had evidence of cancer. This includes the most current year of available data, last updated September 10, 2014.

**FIGURE 2**
Insured and Uninsured Population Projections
Under the Affordable Care Act

**Source:** Congressional Budget Office, April 2014
Growing ranks of cancer survivors. Thanks to better treatments, the number of cancer survivors is continuing to increase. The American Cancer Society projects that the number of cancer survivors will increase from 14.5 million in 2014 to 19 million by 2024.1 The growing number of cancer survivors will require long-term care and monitoring to detect and treat recurrence or new cancers and manage long-term treatment side effects. They may also have ongoing financial and psychosocial needs. Although survivorship care can be offered by primary care and other providers, many cancer survivors prefer to maintain relationships with their oncologists.38 In anticipation of the challenges an increasingly stretched oncology workforce will face, ASCO has developed new resources to help providers meet patients’ cancer survivorship needs and address them through coordination among patients, oncologists, primary care physicians, and other care providers (see Box A).

SIGNIFICANT INEQUITIES IN CANCER CARE

Recent efforts to expand access to quality cancer care have made a huge difference for millions of people—but this progress is uneven. Not all Americans are benefitting equally from cancer advances, including many racial and ethnic minorities, as well as the many Americans who remain uninsured or underinsured.

Persistent Racial and Ethnic Disparities

In the United States, the benefits of cancer screening and treatment advances have not been experienced evenly across racial and ethnic groups. Cancer incidence varies by race and ethnicity, with African Americans having the highest overall age-adjusted rates and Asian Americans having the lowest (Figure 3).31 These disparities are especially dramatic for some cancers. When looking at prostate cancer risk, for example, African American men are 1.5 times as likely as white men and are 3 times as likely as American Indian men to develop the disease. In contrast, Asian and Pacific Islander populations have the highest risks for liver cancer.31 Patterns such as these are seen for many types of cancer.

Mortality rates also vary across racial and ethnic groups, independent of incidence rates. For example, although African Americans are 2.5 percent more likely to develop cancer than whites, they are 19.6 percent more likely to die as a result of cancer (Figure 3).31 These factors are more pronounced among pancreatic cancer patients, where African American men are 2.1 and 4.4 times more likely to die as a result of their cancer than white and Asian men, respectively. Asian individuals have slightly higher mortality rates for liver cancer, but the differences are less dramatic than the differences in incidence. Among cancer patients today, African American men are 27 percent more likely to die as a result of cancer than white men and African American women are 11 percent more likely to die as a result of cancer than white women.32

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**BOX A**

**ASCO’s Cancer Survivorship Compendium**

In 2014, ASCO released its Cancer Survivorship Compendium, a repository of tools and resources to help cancer care teams transition patients from active cancer care to care focused on health promotion and survivorship maintenance. Created by a group of oncology and general practice experts, the compendium identifies the key components to a successful survivorship program (e.g., monitoring for and managing psychosocial and medical late effects) and includes guidance on how to initiate or enhance a survivorship program.

Cancer disparities result from a complex mix of social, economic, and demographic factors, and they defy easy solutions. Geography, cultural practices, socioeconomic access to healthy choices, education, biology, and comorbidities are some of many factors that interact and contribute to differences in cancer incidence and outcomes across segments of the population. Major new advances that improve quality of life and survival may be out of reach for medically indigent individuals, widening the gap between what is possible and what is accessible. ASCO is working to enhance knowledge and better equip oncologists to promote more equitable access to care, most recently publishing an online educational resource addressing cancer disparities (see Box B).

### Disparities in Healthcare Coverage

People with health insurance have a better chance of surviving cancer than people who are uninsured. Insurance also promotes long-term health and financial stability among cancer survivors. Although the ACA has successfully expanded access to insurance and cancer care services, millions of Americans remain uninsured and many others lack adequate coverage for treatment and management of their cancer. Uninsured and underinsured cancer patients continue to face delayed and restricted access to life-saving, life-extending treatments and to services that enhance quality of life.

The Congressional Budget Office predicts that 31 million non-elderly residents will still lack insurance in 2024 (Figure 2). This uninsured population includes people who have elected not to purchase insurance, as well as unauthorized immigrants and people living in states not expanding Medicaid. Currently, 27 states and Washington, DC, have elected Medicaid expansion, with three additional states considering expansion. This leaves 20 states with no immediate plans to expand.

Regardless of state-level plans to expand Medicaid, access to quality cancer care will remain a challenge for Medicaid beneficiaries because of low physician reimbursement, high drug copays, and lack of access to clinical trial participation. In 2014, ASCO released a policy statement calling for broad Medicaid program reform (see Box C).

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**Online ASCO Series on Disparities in Cancer Care**

To improve awareness of care disparities among a spectrum of cancer care providers, ASCO and the LIVESTRONG Foundation have worked with a multidisciplinary planning group of 11 other organizations to develop interdisciplinary eLearning activities. Examples of online courses include:

- Disparities in Cancer Care: Do You Know…?
- Cultural Competence for Oncology Practice
- Disparities in Cancer Care: Take Action!

Oncologists, oncology nurses, and pharmacists may take these courses for continuing education credit. More information available at [www.university.asco.org/disparities-cancer-care](http://www.university.asco.org/disparities-cancer-care).

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**ASCO Calls for Medicaid Reform**

Medicaid is a vital safety net for low-income Americans with cancer. But critical Medicaid coverage gaps and restrictions prevent many patients from accessing high-quality cancer care. In November 2014, ASCO released a policy statement calling for major reforms of the Medicaid program. The recommendations highlight the urgent need to expand access to cancer care by closing major gaps in Medicaid coverage and removing barriers to key elements of quality cancer care for Medicaid enrollees.

More information available at [www.asco.org/Medicaid](http://www.asco.org/Medicaid).

According to recent reports, health insurance premiums are increasing for subsets of the population, including young, healthy individuals. As a result, some young, uninsured individuals are choosing to pay fines rather than pay for insurance. Furthermore, a growing number of plans—including Medicaid expansion programs and state health exchanges—are pursuing cost-containment measures such as tiered pricing, narrow networks, and restricted formularies, practices that may disproportionately affect patients facing costly cancer treatment. Among young and healthy individuals who do enroll in insurance, many gravitate toward high-deductible plans to lower their upfront expenses. This could prove both medically and financially catastrophic for people diagnosed with cancer.
Policy experts have questioned the adequacy of cancer benefits and oncology provider networks included under ACA exchange plans. The law mandates that certain preventive services such as breast, cervical, prostate, and colorectal cancer screening, as well as obesity and tobacco cessation counseling, be offered free of cost to patients. It also requires insurance plans to cover essential health benefits in 10 categories, the majority of which are relevant to cancer care (e.g., ambulatory care, hospitalization, and prescription drugs). However, many of the specific services and the extent of coverage included in the essential health benefits are being left to the discretion of states and payers within states and may fail to ensure sufficient coverage of cancer services. In a recent analysis of drug coverage within new plans, low-premium plans were found to be widely variable in their coverage of treatments for a sample of rare diseases. For example, pazopanib, a treatment for advanced soft tissue sarcoma, ranged from no coverage (for 40 percent of bronze plans) to top-tier formulary inclusion that requires high co-payments.

The ACA has also made it challenging for patients to access care from certain cancer care providers. In an effort to contain costs, insurers have created narrow networks of practitioners to keep insurance costs down. A growing number of cancer patients are discovering that their cancer care providers are no longer considered in-network. This is particularly concerning for vulnerable populations—including people with childhood and rare cancers—because their plans may not include clinicians with the appropriate expertise to treat their disease. In March of 2014, CMS issued network adequacy standards to help determine whether health plans offered in 2015 ACA healthcare exchanges provide access without unreasonable delay to certain health care providers, including oncology providers and hospital systems.

**Critical Role of Medicare for Patients with Cancer**

A majority (52.8 percent) of new cancers occur among Americans age 65 years and older and are therefore treated through Medicare. In 2014, the nation celebrated a significant milestone when Medicare announced it will cover routine lung cancer screening for people at high risk. Such screening has been proven effective by clinical research and is supported by evidence-based guidelines from ASCO and the American College of Chest Physicians.

However, other major Medicare challenges remain, including the continuing threat of drastic cuts to physician payments—and patient access to cancer care—because of the flawed sustainable growth rate formula. One of ASCO’s top priorities is to ensure that Medicare provides access to high-quality cancer prevention, screening, and treatment (see Box D). (For additional information about Medicare payment, see Chapter 4).

**EMERGING PUBLIC HEALTH CONCERNS: OBESITY AND ELECTRONIC CIGARETTES**

With obesity incidence rapidly rising in the United States, public health experts are concerned about a range of serious health consequences. More than 34 percent (78.6 million) of the adult population is considered obese, a percentage that has more than doubled since the 1960s. During this
Recent research has uncovered links between obesity, cancer risk, and cancer prognosis. Obesity is a risk factor for many types of cancer, including endometrial, esophageal, postmenopausal breast, and colon cancers, with as many as 84,000 cases attributed to obesity each year. If trends continue unabated, obesity may lead to an excess of more than 500,000 cancer cases by 2030. There is also mounting evidence that obesity is associated with worse outcomes for certain cancers, including breast, prostate, and colon. By one estimate, 14 percent to 20 percent of cancer-related mortality is attributed to being overweight or obese. In response to this emerging public health issue, ASCO recently launched an initiative to explore and address the link between obesity and cancer (see Box E).

Another emerging public health concern is the introduction and use of electronic cigarettes (e-cigarettes) to American consumers. Manufacturers market e-cigarettes as a safe alternative to regular cigarettes because they contain only nicotine and are not combustible. As such, they have been offered as a potential new strategy for curbing or eliminating tobacco use. E-cigarettes are becoming popular among smokers and non-smokers alike, including nearly two million U.S. adolescents. In light of this trend, some experts worry that e-cigarettes will have the undesired effect of creating new smokers. Moreover, e-cigarettes have not been adequately studied for long-term safety or for efficacy when compared with existing tobacco cessation tools. In April 2014, the FDA signaled it would pursue authority to regulate e-cigarettes, as it has over most tobacco products. ASCO and other concerned organizations have expressed support for this proposed rule.

CONCLUSION

Advances in science and technology have contributed to sustained progress in cancer prevention and treatment. In the United States, patients with a cancer diagnosis are experiencing improved survival and better quality of life. Many challenges remain, however, such as persistent disparities in access to cancer prevention and care, as well as insurance coverage, and new public health crises, such as obesity and e-cigarette use. Demand for services is likely to grow, with projected increases in cancer incidence, unprecedented numbers of survivors, and greater access to health insurance made possible by the Affordable Care Act. Additional research to better understand these challenges will help policymakers learn how to develop methods to address these issues.
Enhanced engagement of patients and improved communication and collaboration of all types of clinicians have the potential to . . . improve the quality of care and mitigate workforce shortages, especially in light of projected growth in demand.
The nation’s ability to care for an increasing number of people who will be diagnosed with cancer depends on a workforce that is sufficient in size, diversity, and geographic distribution.

The oncology workforce must also be equipped with the tools and information necessary to meet the needs of the patient population. As the U.S. population grows and changes, it is important for the cancer community to regularly consider the evolving demands for cancer services and recalibrate the resources required to address them.

This year’s ASCO report provides updated numbers on oncologists practicing in the United States, highlights information about advanced practice nurses and physician assistants, and explores trends in oncology workforce research occurring at the state level.

A SNAPSHOT OF THE FIELD

According to recent data from the American Medical Association (AMA), more than 22,000 physicians work in oncology-related specialties: medical oncology, hematology, gynecologic oncology, pediatric hematology/oncology, radiation oncology, and surgical oncology (Table 2). This report primarily focuses on medical oncology and hematology. (Medical oncologists focus on cancers that occur primarily in body organs and tissues, and hematologists focus on cancers of the blood and other types of blood diseases.) Slightly more than 14,000 physicians identify a specialty of medical oncology and/or hematology (Table 2). Among these, the number of hematologists and medical oncologists (hereafter referred to as oncologists) who cite direct patient care as their primary activity is approximately 11,700 (86.2 percent). The remaining 14 percent spend the majority

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Table 2. Numbers of Physicians in Oncology Specialties

<table>
<thead>
<tr>
<th>Oncology Specialty*</th>
<th>Masterfile</th>
<th>Physician Compare</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Number</td>
<td>Number in Direct Patient Care^</td>
</tr>
<tr>
<td>Medical Oncology and/or Hematology+</td>
<td>14,010</td>
<td>11,758</td>
</tr>
<tr>
<td>Gynecologic Oncology</td>
<td>521</td>
<td>466</td>
</tr>
<tr>
<td>Pediatric Hematology/Oncology</td>
<td>2,347</td>
<td>1,735</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td>4,781</td>
<td>4,398</td>
</tr>
<tr>
<td>Surgical Oncology</td>
<td>466</td>
<td>428</td>
</tr>
</tbody>
</table>

Sources: Physician Masterfile, American Medical Association (July 2014 update) and Physician Compare, Centers for Medicare & Medicaid Services (May 2014 update).

* Oncologists are classified according to their primary specialty designation within each data source.
+ Physicians who report Medical Oncology, Hematology/Oncology, or Hematology as their primary specialty.
^ Based on AMA Masterfile information from physicians who report direct patient care as their primary professional activity.
of their time on administration, research, and teaching, among other activities. Looking at oncologists involved in direct patient care provides a better understanding of workforce capacity. Workforce researchers have expressed concerns, however, that the AMA Masterfile may not provide the most timely information about physician activity in clinical care.58

Because claims data may be the most reliable indicator to identify physicians actively treating patients, we also used Medicare data to ascertain the number of oncologists involved in direct patient care. The Centers for Medicare & Medicaid Services (CMS) provides access to a database that includes information on all physicians who have billed for Medicare reimbursement within the previous 12 months (Physician Compare).9 Physician Compare includes unique provider numbers, specialty designations, and geographic locations of service delivery. Because the majority of cancer diagnoses are in patients age 65 years and older, virtually all oncologists treat Medicare patients. In May 2014, Medicare claims data reflected reimbursement activity by 11,530 medical oncologists and/or hematologists, up 1.6 percent from last year (Table 2).

Advanced Practice Providers Specializing in Oncology
Given the multidisciplinary and complex nature of oncology treatment, cancer care is delivered by a broad spectrum of providers in addition to oncologists, including advanced practice providers, pharmacists, nurses, and professionals providing psychosocial support. Oncology care is also delivered in different settings across the continuum of care. With an increasing focus by patients and payers on value and quality of care and concern about potential clinician shortages, policymakers are increasingly looking at team-based care. Enhanced engagement of patients and improved communication and collaboration of all types of clinicians have the potential to enable clinicians to improve the quality of care and mitigate workforce shortages, especially in light of projected growth in demand.

Advanced practice providers working in oncology include nurse practitioners, doctors of nursing practice, and physician assistants. Doctors of nursing practice/nurse practitioners have chemotherapy prescribing authority and, in 20 states, can operate as independent providers with no scope-of-practice limitations.59 Of the more than 192,000 doctors of nursing practice/nurse practitioners working in the United States, one percent (approximately 1,900) are certified in oncology.60 The physician assistant workforce is also active in oncology: of 93,098 physician assistants working in 2013, an estimated two percent worked in oncology (approximately 1,800 physician assistants).61,62 The U.S. Bureau of Labor Statistics projects that nurse practitioner and physician assistant employment will increase by 33.7 percent and 38.4 percent, respectively, from 2012 to 2022—growth rates much higher than those for the overarching labor force (10.8 percent projected increase) and physicians and surgeons (17.8 percent projected increase).63

In ASCO's 2014 census of U.S. oncology practices (discussed in greater detail in Chapter 3), practices reported widespread employment of advanced practice providers (see Appendix B). The 900 census respondents employed more than 2,700 doctors of nursing practice/nurse practitioners and 1,100 physician assistants. The majority (75 percent) of nurse practitioners, doctors of nursing practice, and physician assistants worked in academic settings, with the remainder split roughly evenly between hospital/health systems and private physician-owned practices.

50% of oncologists are over age 50

DEMOGRAPHICS OF THE MEDICAL ONCOLOGY WORKFORCE

In 2010, ASCO launched the Workforce Information System to track demographics and other workforce trends in the medical oncology community (see Appendix A). The system monitors physicians who report hematology, hematology/oncology, or medical oncology as their primary specialty in the AMA Masterfile.10 This year's data parallel those reported last year, finding that the oncology workforce is aging and shifting to include more women and, to a lesser degree, become more diverse in race/ethnicity. The 2015 report looks at these trends from new angles and introduces information on the practice preferences of oncologists entering the field.

An Aging Workforce
The oncology workforce continues to age; a steadily growing proportion (19.8 percent) of medical oncologists is nearing retirement at age 64 years or older (Figure 4). This segment of the workforce continues to outnumber oncologists entering the field—oncologists younger than age 40 years represent only 16 percent of the workforce. The median age for U.S. medical oncologists was 50 years and the average age was 53 years.10,11
of oncologists (52 years) has remained stable over the last year, although this median varies widely by state, with South Dakota and Oregon having the youngest oncologists (each with a median age of 48 years) and Delaware having the oldest oncologists (with a median age of 58 years). The median age of the overall physician population is also 52 years.\textsuperscript{10}

**Increasing Percentage of Female Oncologists**

The proportion of women in medical oncology continues to grow, with women accounting for just more than 30 percent of oncologists this year (Figure 5). This is approaching, but still slightly below, the overall figure for women in medicine (32.6 percent). Female oncologists as an overall group are younger than male oncologists (median age of 46 vs. 56 years). Of all the oncology subspecialists, pediatric hematology/oncology attracts the most women, whereas gynecologic oncology attracts the fewest.

The proportion of women in oncology fellowship programs (48 percent) is much higher than the proportion of women currently in practice and has recently surpassed medical training programs overall (46 percent; Figure 6). Within internal medicine subspecialties, oncology fellows are in the middle of the male-female distribution and closely mirror the overall percentage of women among residents and fellows.

**Gaps in Racial and Ethnic Diversity**

Diversity in the medical oncology workforce remains a challenge. For example, although the U.S. Census estimates approximately 13 percent of the population is African American, only 2.3 percent of practicing oncologists are African American (Figure 7).\textsuperscript{64,65} The rate is not much better in training programs, where only 4 percent of oncology fellows are African American.\textsuperscript{5} This figure, which lags about 2 percent behind the general population of residents and fellows, has hovered at this level for a decade. Hispanics, despite comprising 17 percent of Americans, represent only 3 percent of practicing oncologists and 5.8 percent of oncology fellows (Figure 7).\textsuperscript{11,64,65}

Increasing ethnic and racial diversity in the cancer care workforce has potential to advance cultural competency and expand access to quality care. To help advance this goal, ASCO initiated a mentorship program for medical students and residents from underserved ethnic and racial communities (Box F).
## 2. THE ONCOLOGY WORKFORCE

### Practice Choices of Fellows Entering the Oncology Workforce

A new feature of this year’s *State of Cancer Care* report is the tracking of practice decisions made by new entrants into the oncologist workforce. As part of the 2014 ASCO In-Training Exam (ITE) survey, nearly 1,400 medical oncology fellows responded to questions about preferred practice setting.

Consistent with the past five years of reporting, the majority (55.8 percent) of ITE survey respondents indicated a preference for university-based clinical practice or research, whereas 36.8 percent indicated they were likely to choose non-academic community or private practice settings.

With respect to ultimate choice of practice setting, data from the AMA Masterfile show that slightly more than 69 percent of oncologists ages 40 and under work in group practice, as compared with only 42.7 percent among those age 66 years and older (see Figure 8). Group practice in the Masterfile could include academic and hospital or health system owned practices, unlike the ITE data that distinguish among practice settings. In addition, practice setting definitions are changing considerably with practice ownership changes (further discussion in Chapter 3). Current Masterfile data also suggest that younger oncologists are less likely to choose self-employment or solo practice.

At present, the differences in terminology make it challenging to stitch together a long-range view and fully understand employment preferences of oncologists entering the field. Given concerns about workforce capacity and distribution, ASCO will continue tracking and reporting these data on an annual basis, with planned enhancements to its data collection methods. More detailed information on the oncologist practice environment can be found in Chapter 3.

### ASCO Diversity Mentoring Program

In 2014, ASCO launched the ASCO Diversity Mentoring Program, an initiative designed to encourage medical students and residents who are underrepresented in medicine to pursue careers in oncology. The program aims to help trainees prepare for the challenging field of oncology by fostering relationships with experienced oncology professionals who can provide career and educational guidance and serve as a professional resource. Thus far, more than 100 ASCO members have volunteered to be mentors, and 70 medical students and residents have requested mentors.

### FIGURE 7

**Physicians, Fellows, and U.S. Population by Race/Ethnicity**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Practicing Oncologists</th>
<th>Oncology Fellows</th>
<th>Practicing Physicians</th>
<th>All Residents and Fellows</th>
<th>U.S. Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black or African American</td>
<td>20%</td>
<td>15%</td>
<td>10%</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>10%</td>
<td>8%</td>
<td>5%</td>
<td>2%</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Sources:** Diversity in the Physician Workforce: Facts and Figures 2014, Association of American Medical Colleges, JAMA Medical Education Issue, U.S. 2010 Decennial Census

### FIGURE 8

**Distribution by Age Group for Oncologists in a Practice Setting**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Self-Employed Solo Practice</th>
<th>Two Physicians Practice</th>
<th>Group Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>40 YEARS AND UNDER</td>
<td>40%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>41-50 YEARS</td>
<td>40%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>51-65 YEARS</td>
<td>40%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>66 YEARS AND OLDER</td>
<td>40%</td>
<td>20%</td>
<td>40%</td>
</tr>
</tbody>
</table>

**Source:** AMA Physician Masterfile; Oncologists include all physicians who identify as medical oncologists, hematologists, and hematologist/oncologists.

**Note:** Included here are the 7,216 hematologists/oncologists who report their primary activity as patient care and their employment setting as: Self-Employed Solo Practice, Two Physician Practice, or Group Practice. Not included are the 4,542 hematologists/oncologists who report their primary activity as patient care and their employment setting as: Government Hospitals (1,513), Non-Government Hospital (372), Medical School (289), or Other/No Classification (2,368).
2. THE ONCOLOGY WORKFORCE

GEOGRAPHIC DISTRIBUTION

Oncology continues to experience uneven geographic distribution of its workforce. According to ASCO’s Workforce Information System (see Appendix A), more than a third of medical oncologists are located in three states (California, New York, and Texas), and a majority practice within nine states. Density calculations raise similar concerns. On the basis of the Medicare Physician Compare data, Washington, DC, and Massachusetts still hold the top spots for number of oncologists per hundred thousand residents who are 55 years of age and older; Hawaii and Nevada have the lowest concentrations, each with approximately 10 oncologists per 100,000 individuals age 55 years and older (Figure 9). U.S. residents age 55 years and older represent nearly 25 percent of the population but account for almost 77 percent of new cancer cases.65,50 Although California has the highest number of practicing oncologists of any state, the large population of individuals 55 years of age and older in the state places it in the lowest density bracket, with fewer than 13 oncologists per 100,000.

Poor Coverage in Rural Areas

For the more than 59 million Americans living in rural areas, a diagnosis of cancer can present unique challenges to obtaining high-quality care for their disease, including long travel distances and decreased access to specialists and state-of-the-art diagnostics, treatments, and technologies.12-24

Complicating these challenges is an increasingly urban physician workforce across all of medicine. Overall, 10 percent of physicians practice in rural areas; however, a recent analysis indicated that only 4.8 percent of new physicians are choosing to practice in non-urban areas.67-68

This is of particular concern in oncology, where treatment is highly specialized and often requires frequent follow-up visits to the clinic. ASCO’s analysis of oncology locations in Medicare Physician Compare identified 633 medical oncologists and hematologists (5.5 percent) practicing in rural care sites (Figure 10). Nearly three quarters of these practices (73.3 percent) have only one practice location.

Two successful state initiatives conducted in Iowa and Nebraska have addressed access in underserved areas and offered strategies that may serve to inform efforts in other communities across the United States. These are profiled in the following section entitled “Lessons from the States.”
LESSONS FROM THE STATES

The ASCO 2014 *State of Cancer Care in America* report described an ASCO–University of Iowa study on oncology practice patterns within the state of Iowa, a state where the population largely resides in rural areas. A particular strength of the study was its data source: the Iowa Physician Information System (IPIS), a statewide registry validated against national datasets and maintained through routine calls to every practice site. The registry includes information on physician practice locations and participation in visiting consultant clinics (VCCs), a program whereby community hospitals and health centers use visiting specialists to increase access to specialty care in remote areas.

In September 2014, researchers published a longitudinal analysis of medical oncologists and hematologists working in VCCs in Iowa. In 1989 (the first year of available data from IPIS), Iowa provided 778 oncology clinic days through VCC programs across the state. Over the following 23 years, Iowa significantly expanded oncology care access by opening VCC locations and increasing clinic days at existing sites. In 2011, the final year of study, more than 2,100 clinic days were recorded at 66 VCCs around the state with 95 percent of these days being offered in rural communities. Nearly half (45 percent) of Iowa oncologists and some cancer providers from Nebraska, South Dakota, and Wisconsin contributed to these VCC clinic days.

In nearby Nebraska, where 47 percent of residents live in rural areas and cancer is the leading cause of death, researchers conducted a statewide study to closely examine their oncology provider workforce. Using the Health Professions Tracking Service, a data source operated by the University of Nebraska, they collected information on physicians, nurse practitioners, and physician assistants who provided cancer services between 2008 and 2012. Over the span of the study, the number of oncologists increased by 3 percent, and the number of oncology nurse practitioners and physician assistants increased by more than one third (37 percent and 36.1 percent, respectively). These increases provided additional provider capacity within Nebraska—although not necessarily in rural areas. Despite the high proportion of rural residents in the state, approximately 80 percent of oncologists, nurse practitioners, and physician assistants work in urban areas.

Understanding workforce distribution and capacity is critical to addressing gaps in care for communities across the country. Nebraska and Iowa have invested in robust workforce monitoring systems that enable targeted programs to bridge areas of need. As states enhance their ability to collect specialist-level data on workforce and care delivery mechanisms, efforts can be better targeted to anticipate, avoid, and quickly address gaps in access.

SUSTAINING THE ONCOLOGY WORKFORCE

Oncologist Burnout

Last year’s *State of Cancer Care in America* report described the results of an ASCO survey of more than one thousand U.S. oncologists, highlighting a troubling finding: nearly half of respondents experienced some form of burnout. Burnout refers to long-term exhaustion leading to diminished interest in work and even health deterioration in some instances.

In late 2014, ASCO helped conduct a follow-up study documenting burnout experiences among oncology fellows. Of the 1,345 U.S. medical oncology fellows who participated, approximately 34 percent indicated having high levels of burnout (at least one event a week). The proportion was not significantly different from the 33.7 percent observed among practicing oncologists from the original study. Moreover, fellows’ expectations about work hours consistently underestimated levels seen in the practicing workforce. These findings suggest that fellows, already at risk for burnout while acclimating to a demanding work environment, will face additional stresses after entering the workforce.

Failing to address burnout and other quality of life issues among trainees and practicing oncologists can lead to serious workforce consequences. Oncologists experiencing such pressures may opt to reduce their patient volume or ultimately retire at an earlier age. Researchers have pointed to strategies including peer support systems, workload management guidance, and increased care coordination to prevent and address physician burnout, but they generally agree that further research and testing is needed. ASCO is exploring ways to promote provider wellness by researching burnout, career satisfaction, and quality-of-life initiatives to identify effective methods to support oncology professionals.
2. THE ONCOLOGY WORKFORCE

New Areas of Study
Current predictions of oncologist and other health care workforce shortages are challenging in the context of a rapidly shifting practice environment. New practice models emerging in response to greater emphasis on quality and value of care will have significant influence on the size, shape and capacity of the oncology workforce. Team-based care, practice transformation to better accommodate disease management and care coordination, and reaching underserved populations are all key areas of focus for ASCO in the coming year.

CONCLUSION
As the oncology community continues to be challenged by an aging workforce, uneven distribution of providers, and a dynamic practice environment, the need to explore new practice models will become increasingly important. The 2015 State of Cancer Care in America report highlights challenges posed by the demographics of the oncologist workforce, as well as the need for care coordination among specialists and across practice settings. These issues have direct implications for how practices are structured and the quality and value of care delivered. Continued close monitoring of these trends will be critical to develop strategies that enable oncology specialists to adapt and thrive in a changing world and enhance their ability to deliver high-quality cancer care.
Economic constraints, competition, growing administrative burden, and proliferation of cost containment programs are among the many pressures practices say contribute to uncertainty about their continued existence.
Oncology practices across the United States continue to experience volatility, with changes occurring in virtually every facet of the cancer care delivery system.

Economic constraints, competition, growing administrative burden, and proliferation of cost-containment programs are among the many pressures practices say contribute to uncertainty about their continued existence.

In this chapter, we highlight practice trends based on the ASCO Oncology Census. We also draw attention to two additional issues of significance for practices and the oncology marketplace:

- Efforts by several states to strengthen facility requirements for safe handling of chemotherapy in all practice settings
- Ongoing shifts in site of care, in part brought on by drug discounts available to hospitals through the 340B program

ASCO ONCOLOGY CENSUS: CONTINUING PRACTICE ADAPTATION

In 2012, ASCO began an annual oncology census to better understand and respond to economic and care delivery challenges. In addition to collecting current data on practice size, distribution of specialties, practice setting, and services, the ASCO Oncology Census captures information on how practices are adapting to today’s environment and what they anticipate in the year ahead. (See Appendix B for details.) Nearly 1,000 (n=974) U.S. oncology practices from across the country participated in this year’s Census—nearly doubling the 2013 response rate of 530 practices. The 2014 respondents served as practice homes for more than 10,000 individual oncologists (Figure 11).

974 U.S. oncology practices participated in the 2014 ASCO Oncology Census, representing 10,000 oncologists

Source: ASCO Annual Practice Census 2014

FIGURE II Distribution of Participating Census Practices
3. THE STATE OF ONCOLOGY PRACTICE

**Practice Setting**

The 2014 ASCO Oncology Census asked respondents to classify the ownership arrangements of their employment setting from among the following options:
- Physician-owned practice or group (including multisite network)
- Academic practice
- Practice, group, or outpatient department that is owned by a hospital or health system
- Government
- Industry
- Retired or temporary

*The ASCO State of Cancer Care in America* report focuses on physicians in clinical practice settings: physician-owned, academic, or hospital/health system-owned practices (Figure 12).

The total number of practices that responded to the Census increased by 83 percent from 2013 to 2014, with each clinical practice category experiencing increases: academic (78 percent increase), hospital/health system owned (185 percent increase), and physician owned (67 percent increase). The dramatic increase in hospital/health system-owned practices may indicate a migration of physician-owned practices to this arrangement. To better understand this relationship, ASCO is analyzing trends among practices that responded to multiple rounds of the ASCO census. Results are expected in 2016.

Academic practices are more evenly distributed across all census regions (Figure 13). Hospital/health system practices are more prevalent in the Midwest and physician-owned practices seem more concentrated in the South and West. Hospital/health system- and physician-owned practices are almost equally represented in the Northeast.

**SHIFTS IN PRACTICE STAFFING AND ADMINISTRATION**

**Availability of Oncology Specialties**

The number of practices reporting multi-specialty services remains high. New this year, the ASCO Oncology Census asked about internal medicine and hospitalist services; 184 respondents (19 percent) reported providing internal medicine services and 145 practices (15 percent) hospitalists. Not surprisingly, academic centers and hospitals were more likely to report specialized services (e.g., pediatric oncology and surgical oncology) than physician-owned practices (Figure 14).

**Involvement of Advanced Practice Providers**

A majority (52 percent) of practices responding to the Census (across all practice types) reported employing advanced practice nurses (primarily nurse practitioners) and/or physician assistants, with 281 practices employing advance practice nurses (29 percent), 60 employing physician assistants (6 percent), and 164 employing
individuals from both fields (17 percent). These practices employ a total of 2,752 advanced practice nurses and 1,136 physician assistants (Figure 15). The majority of advanced practice providers currently practice in academic settings. This may change, because a majority of physician-owned practices indicated they are “somewhat likely” or “very likely” to hire advanced practice nurses and/or physician assistants in the coming year. When comparing the number of oncologists at these practices with advanced practice providers, Census data revealed an average of .64 advanced practice provider per oncologist (median, .50). This is consistent with recently published data that suggest a ratio of one advanced practice provider to two oncologists across practice settings.71 Additional data about the advanced practice provider workforce are provided in Chapter 2.
Oncology practices generally provide care to patients with Medicare and private insurance, with a smaller proportion of Medicaid and uninsured or self-paying patients. The 2014 payer mix data across all practices show some subtle, but important, changes from the previous years, with a 3 percent increase in the percentage of cancer patients with both Medicare and Medicaid since 2012 (Figure 16). This is likely the result of two trends: (1) aging of the Baby Boom generation into the Medicare program and (2) states choosing to implement the Affordable Care Act’s expansion of Medicaid. Interestingly, 25 percent of respondents anticipate another increase in both Medicare and Medicaid patients in the next 12 months.

Changing Payment Models
Payment reform and the need to incentivize high-value, patient-centered care are urgent priorities for oncology providers and policymakers. The current system under which Medicare reimburses physicians for patient care has not been able to keep up with the upward cost curve and is therefore a major focus of reform as policymakers look for increasingly scarce healthcare dollars. (For additional discussion of payment reform, see Chapter 4.)

The ASCO Oncology Census asked practices about existing payment models as well as future plans for implementation of novel care delivery and/or payment models. The majority of practices reported that they continued to work in a fee-for-service environment. Other payment models selected were capitation (8 percent), episodes of care/bundling (9 percent), and other non-fee-for-service alternative payments models (11 percent). Of practices considering or implementing novel models, 36 percent reported that they had implemented or were considering a pathway adherence program and 30 percent were considering medical home programs emphasizing care coordination.

Practices indicating involvement with clinical pathway programs were asked to describe their program. Although some practices were using well-developed programs that were commercially available, many others reported using practice-developed or home-grown pathway programs. Others reported using programs mandated by specific payers. This emergence of variable pathway programs raises concern about a lack of standardization of pathway programs, which, when combined with new payer requirements, may result in increased administrative burdens for many oncology practices. (More detailed discussion on oncology pathways is available in Chapter 4.)

The ASCO Oncology Census also asked practices about their participation in accountable care organizations, which are groups of physicians, hospitals, and other health care providers that come together voluntarily to provide coordinated, high-quality care to an assigned population of patients. Current participation in accountable care organizations varies by practice setting, with 31 percent of hospital/health system-owned practices, 27.3 percent of academic practices, and 21.3 percent of physician-owned practices reporting participation (Figure 17).
The range of pressures currently facing oncology providers varies and seems to be highly dependent on practice setting (Figure 18). Academic practices indicated their top pressures are clinical research issues, staffing issues, and competitive pressures. Hospital/health system-owned practices and physician-owned practices identified payer pressures, cost pressures, competitive pressures, and drug pricing as their most important pressures in 2014. In addition, 60 respondents chose “other” and indicated electronic health records (EHRs), 340B drug pricing, hospitals, and government as the greatest pressures their practices are facing.

Two new pressures were added to the ASCO Census question on practice pressures in 2014: (1) clinical research issues and (2) access to genomic testing. Clinical research issues (not defined by the survey) were cited as a pressure by 7.4 percent of respondents and access to genomic testing was cited by 0.7 percent.

Comparing this year’s data on practice pressures with the two previous years of Census data reveals several interesting shifts (Figure 19). When the two new pressures are included in the data analyses, results indicate a notable decrease in both payer pressures (from 26.2 percent in 2012 to 21.9 percent in 2014) and cost pressures (from 24.3 percent to 17.2 percent) and an increase in pressures related to drug pricing (from 8.6 percent to 14.8 percent). When the data were analyzed without the new pressures, payer pressures rise to 24 percent of responses and drug pricing rose to 16 percent in 2014. In a recent article, oncologists in physician-owned practices cited reduced drug reimbursements from insurers as a major factor in practice sales and closures.73

Source: ASCO Annual Practice Census 2014
Note: Practices were asked to select their top two pressures.
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Respondents were also asked how likely their practices were to close, sell, merge with another practice, or purchase another practice in the next 12 months. Although the majority of the respondents to this question indicated they were unlikely to do any of these things in the next 12 months, 7 percent indicated a likelihood of closing their practice, 8 percent said they were likely to sell the practice, a notable 15 percent indicated they were likely to merge with another practice, and 13 percent said they were likely to purchase another practice.

Staffing
The number of practices that reported they were likely to lay off clinical and administrative staff in the next 12 months continued to grow (Figure 20). Notably, an increase in practices reporting layoffs was observed for every staff category with administrative staff positions reported most often as likely to be eliminated.

Conversely, greater percentages of practices reported a likelihood of hiring staff in the next 12 months. Oncology physicians were chosen as likely to hire by 46 percent of practices. Practices were similarly likely to hire certified oncology nurses (43 percent) and nurse practitioners (39 percent).

Although most practices reported they were likely to hire new staff, the number of practices reporting plans to lay off staff continues to grow each year. Practices reporting plans to increase staff seemed to be focused on hiring clinical professionals, including physicians, advanced practice providers, and oncology nurses.

Practices also anticipated growing patient volume in the next 12 months, with 71 percent of academic and hospital/health system practices and 43.6 percent of physician-owned practices expecting an increase (Figure 21).

Electronic Health Records
The use of health information technology (HIT) in oncology practices continues modest growth, with 89 percent of Census practices reporting the use of either basic or advanced EHRs. Another 6 percent reported that they will be looking to implement an EHR in the next 6 months. Only 5 percent of practices reported that they do not use electronic health records, an identical percentage to 2013. This rate of EHR adoption is slightly higher than reported across medical specialties—medical (68 percent), surgical (63 percent), and primary care (77 percent)—by the Office of the National Coordinator for Health Information and Technology. 74
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Although the adoption rate is high, frustration with the use of HIT is widespread. Several practices mentioned EHR issues as one of the pressures affecting their practice, with comments ranging from “decreased productivity because of the EHR” to the “excessive burdens of meaningful use.” A recent survey by Medscape reported that nearly a third of physicians believed that EHRs had negatively affected patient services and clinical operations.\(^7^5\)

Medicare provides incentives and payment adjustments to eligible professionals who use certified EHR technology through its EHR Incentive Program.\(^7^6\) As of December 2014, the Physician Compare database identified more than 5,000 hematologists/oncologists (46 percent) participating in the program.\(^9\)

**Clinical Trial Participation**

Participation of practices in clinical trials helps to determine the efficacy and safety of potential new cancer therapies. A majority (57 percent) of respondents indicated plans to increase the number of trials in their practice, although a smaller percentage (27 percent) reported plans to begin conducting federal trials, compared with 39 percent planning to start private clinical trials.

Large percentages of practices responded that they were unlikely to begin conducting trials, with 46 percent of practices saying this about federal trials and 39 percent about private trials. Among practices reporting likely plans to eliminate trials, 10 percent were likely to eliminate federal trials, whereas 5 percent were likely to eliminate private trials. Another 6 percent of respondents said they planned to

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eliminate all clinical trials from their practice (Figure 22). The data were more negative overall for federally funded trials than for private trials.

**PREAUTHORIZATION**

Preauthorization—the requirement that clinicians receive prior approval from patients’ insurance company before ordering certain tests or administering certain treatments—is concerning because it may result in delays to care. In addition, the time clinicians and their staff spend communicating with insurance companies reduces the time available for patient care and may hurt staff morale. Moreover, there is little evidence that these requirements improve the quality of patient care. ASCO decided to collect baseline data in the Census and add this topic to the 2015 *State of Cancer Care in America* report because of anecdotal concerns from its membership about increasing requirements for preauthorization.

A 2014 survey of state-based oncologist membership organizations affiliated with ASCO (n=36) included questions on the impact of preauthorization on oncology practice. Ninety-four percent of respondents reported that preauthorization requirements increased demands on staff time, 89 percent indicated that it delayed or interrupted patient care, 72 percent said it decreased patient satisfaction, and 64 percent reported it complicated medical decision making. In addition, nearly 70 percent reported that their preauthorization requests were often initially rejected by insurers, likely leading to appeals and additional requests.

Health information technology has the potential to facilitate communication between oncologists and insurance companies regarding preauthorization. For example, the IBM Watson computer includes a feature that allows clinicians to rapidly request and obtain preauthorization from insurance companies for treatment protocols. There is limited evidence, however, that oncology practices have been successful at realizing the potential of HIT to reduce administrative burden.

**IMPACT OF DRUG SHORTAGES ON TREATMENT**

Drug shortages remain a relatively small but persistent pressure on practices. Both the FDA and the Government Accountability Office (GAO) released reports observing that the number of new drug shortages was decreasing, although many shortages have persisted for more than one year.

In 2014, ASCO—in collaboration with the Hematology/Oncology Pharmacy Association—conducted a survey to assess the prevalence and impact of drug shortages on oncology practices (see Appendix C for additional details). When compared with a 2012 survey, it seems that policy changes enacted in 2011 and 2012 have helped avert or mitigate drug shortages. Whereas 36 percent of respondents felt that drug shortage pressures were getting better in 2012, only 10 percent report significant improvement in 2014. Nearly 70 percent of respondents in 2014 reported that shortages were “a little better” or “the same.” This is consistent with FDA and GAO observations that the total number of drug shortages (new and persisting) had plateaued.

Lack of timely communication about drug shortages is a continuing problem. Pharmacists (78 percent) overwhelmingly learned of drug shortages from distributors at the time of ordering, and most physicians (61 percent) learned of shortages from the pharmacy. The next most common method of communication is through professional societies, but only 25 percent of physicians and 45 percent of pharmacists learned about drug shortages in this way. Increased communications between professional societies and clinicians (including physicians, pharmacists, nurse practitioners, and physician assistants) about shortages may allow clinicians to mitigate any delay in treatment caused when a clinician prescribes a drug he or she does not know is in shortage. Respondents reported that they often addressed shortages by recommending a different treatment regimen (68 percent), working directly with the manufacturer to obtain any drug available (62 percent),
contracting or sharing drugs available from other providers in the region (50 percent), or contracting with another drug distributor (47 percent; Figure 23).

Addressing drug shortages takes time away from patient-focused activities. Approximately half of the respondents to the survey provided estimates of time spent on drug shortages, categorized by profession. Respondents estimated that physicians spent on average 2 hours a week dealing with shortages, although the range of time varied widely (range, 0-10 hours). Pharmacists spent more time dealing with shortages, on average more than 6.5 hours (range, 0-40 hours), whereas nurses, nurse practitioners, physician assistants, and office managers also devote time to drug shortage mitigation (2-4 hours per week on average). The burden fell most heavily on pharmacists in a hospital setting, where they spent nearly 8 hours a week on shortages. In private practice settings, the work of dealing with shortages was more evenly shared with all professionals devoting 2-4 hours a week.

SAFE HANDLING OF CHEMOTHERAPY DRUGS

The regulation of chemotherapy safety often occurs at the state level, and several states have been active in recent years in developing new rules in this area. Some states have considered adopting guidance recommended by the U.S. Pharmacopeial Convention (USP) and applying the requirements of USP Chapter 797 on sterile compounding to the physician office setting.

The application of USP 797 has raised concerns because some of the requirements in USP 797 are unnecessarily burdensome and inflexible when applied to the day-to-day operations of medical oncology practices. For example, the Maryland Legislature enacted legislation that would have required physician offices to comply with USP 797 in early 2014, but it subsequently removed the mandate because of concerns raised by the medical oncology community. Policymakers in Maryland currently are working with ASCO members and other stakeholders to draft and refine regulations that better reflect the realities of modern physician practices in the fields of medical oncology, hematology, and rheumatology.

In 2014, several states were in various stages of developing and implementing rules to help prevent occupational exposure to hazardous drugs based on recommendations published by the National Institute for Occupational Safety and Health (NIOSH). States pursuing regulations based on the NIOSH guidelines include Washington, California, and North Carolina. Currently, NIOSH is working to update its recommendations in this area, with publication of new guidance scheduled for 2015. ASCO is working collaboratively with NIOSH to provide perspectives from the medical oncology community on how best to protect its workforce while avoiding unnecessary burdens.

Perhaps the most controversial development in 2014 involved drafts posted by USP for a new proposed Chapter 800 for the handling of hazardous drugs in health care settings. ASCO provided written comments on the initial USP draft, urging USP to make extensive changes to the proposal. Given the extensive comments submitted by numerous stakeholders, USP officials decided to post a revised version on December 1, 2014, and solicit additional public comments. Comments on the second version of the draft chapter are due by May 31, 2015.

ASCO developed a task force in 2014 to develop updated guidance on the safe handling of chemotherapy drugs. In addition to developing updated guidance in this area, the ASCO task force is spearheading efforts to collaborate with other organizations that develop standards and to help support communications and educational efforts with policymakers at the state level.
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ASCO Policy Statement on the
340B Drug Pricing Program

In June 2014, ASCO released a policy statement
concerning the 340B Drug Pricing Program. The
statement recommends that policymakers focus on
meeting the original intent of the program, consider
policy changes that are consistent with the original
intent of the program, clarify ambiguous aspects of the
program, and understand and respond to the adverse
impacts that the program may have on patient access to
high-quality oncology care.

ASCO’s policy statement on the 340B Drug Pricing
Program can be found at www.asco.org/340B

340B DRUG PRICING PROGRAM

An issue that is contributing to changes in organization of
oncology practices relates to the inducements created by
the 340B Drug Pricing Program. The 340B Drug Pricing
Program requires drug manufacturers to provide price
discounts to certain hospitals and other healthcare facilities
that qualify as covered entities. Independent physician
practices are not eligible to participate in the 340B Drug
Pricing Program, but hospital-based or -owned outpatient
oncology practices may have access to 340B pricing if
the hospital participates in the program. Some practices
responding to the ASCO Oncology Census added in free text
that the 340B program is causing “the greatest pressure
your practice is experiencing currently.” When Medicare
or private insurers reimburse for drugs through the 340B
program, there is often a significant differential between
the discounted 340B acquisition cost and the payment
level. Congress intended for this differential to help
promote access to health care services for underserved and
vulnerable patient populations.

A number of stakeholders have expressed concerns
regarding the 340B Drug Pricing Program as currently
implemented. In 2011, the GAO concluded that oversight of
the 340B Drug Pricing Program by the Health Resources
and Services Administration (HRSA) had been inadequate.86
Other stakeholders have questioned whether the program
continues to meet Congress’ original vision to “stretch
scarce federal resources as far as possible, reaching
more eligible patients and providing more comprehensive
services.”87

Some have questioned the rapid expansion of the 340B
Drug Pricing Program in terms of both the number of eligible
facilities and the number of eligible drug claims.19,20,21 In 2011,
the GAO found that the number of entities participating
in 340B had nearly doubled over the previous decade,
growing from 8,605 in 2001 to 16,572 in 2011.86 In 2014, the
Office of Inspector General for the Department of Health
and Human Services examined the growth of contract
pharmacy arrangements under the 340B Drug Pricing
Program. It found that after the HRSA decision to liberalize
its policies on contract pharmacy relationships, the number
of contract pharmacy arrangements under the 340B Drug
Pricing Program increased by 1,245 percent from 2010 to
mid-2013.88

In July 2013, HRSA finalized regulatory changes to 340B
regulations that would allow program participants to
purchase orphan drugs at the program discounts for non-
orphan indications. In May 2014, implementation of
the regulation was halted by a federal court ruling that limited
HRSA’s ability to regulate.89 HRSA announced in November
2014 that it would not issue far-reaching regulatory reforms
in 2015.90 Most observers agree that any significant changes
to the program will have to come from Congress.

In response to growing concerns regarding the 340B Drug
Pricing Program, ASCO released a policy statement in 2014
(see Box G).
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CONCLUSION

The landscape of oncology practice is rapidly changing in the wake of increased demand for cancer services, financial and administrative pressures, and widespread healthcare reform. Large practices continue to grow in number as mid-size practices consolidate. Payer pressures and drug pricing pressures have increased for both hospital/health system-owned and physician-owned practices. The time clinicians and their staff spend dealing with insurance companies and drug shortages reduces the time available for patient care and remains a burden on practices. ASCO is monitoring the evolution of cancer care delivery through its annual oncology census in order to anticipate and react to practice needs and the changing environment.
A major theme of health reform has been greater patient engagement, including shared decision making about treatment options.
As the nation approaches its fifth year since enactment of the Patient Protection and Affordable Care Act (ACA), affordability of health care remains a key concern of policymakers, taxpayers, clinicians, and patients.

Although 2014 saw some slowing of healthcare expenditures, most observers do not believe these reductions will continue, and questions about sustainability of the current cancer care delivery system persist. In many ways, cancer—which consumes a large and growing portion of U.S. healthcare spending—illustrates the challenges of today's system: care fragmented across multiple providers and settings, payment structures that do not match services, and lack of clarity or communication around treatment goals and cost.

In light of these concerns, in 2014 the oncology community ramped up its search for value in cancer care, where patients receive the right treatments, at the right time, for the right price. The first section of this chapter reviews cost of care. The remaining sections review strategies for increasing the value of cancer care: (1) payment reform and new models of care, (2) creating cost-conscious consumers, (3) quality measurement (with a case study on palliative care), and (4) big data.

FOCUS ON COST

Although the United States performs well on several cancer-specific quality indicators, including cervical and breast cancer screening and relative five-year survival for breast and colorectal cancers, other Organization for Economic Cooperation and Development countries are able to achieve similar or better outcomes at a fraction of the cost. Direct medical costs of cancer care (now at $86 billion annually) are not the largest portion of U.S. healthcare spending, but they are among the fastest growing. Considering current levels of cancer incidence, survival, and cost, cancer care expenses could increase by as much as 39 percent between 2010 and 2020.

A cancer diagnosis can result in serious financial consequences for patients and their families. A 2013 study found cancer patients to be nearly three times more likely to experience bankruptcy than people without cancer. Faced with high out-of-pocket costs, some patients even decide to forgo or prematurely discontinue important cancer treatments. And financial burdens of cancer care are often felt long after active treatment. Nearly half experience problems living on their household income, and financial hardship drives non-adherence to prescribed treatment. Difficulties may extend into survivorship, with young adults experiencing wage and productivity losses after an experience with cancer. The so-called financial toxicity of cancer treatment is a major area of concern for patients and their physicians.
4. QUALITY AND VALUE IN CANCER CARE

Drug Costs
Drugs continue to be a major focus in the discussion about cost and value in cancer care, and increasingly, this is a conversation about specialty pharmaceuticals. Specialty pharmaceuticals are those that represent significant cost, require special handling, or are part of complex treatment regimens. A large number of oncology drugs fall into this category. As treatment evolves to more targeted drugs that fight specific molecular abnormalities in a patient’s tumor—and the prospect of the need for combinations of these drugs grows—concerns about affordability, both for patients and the U.S. healthcare system overall, are growing.

In the past year, alarming statistics about drug costs have emerged:
- The average monthly cost of a branded cancer treatment has more than doubled to $10,000 over the past decade.22
- Cancer drug costs are steadily increasing over time, with some approaching nearly $40,000 per patient per month in 2014 dollars.102
- Eight of the 10 most expensive drugs reimbursed by Medicare are cancer drugs (Table 3).
- Seven U.S. drugs cost more than $100,000 annually, up from only four drugs in 2010;104 four of seven of these drugs are used in cancer treatment.
- Targeted drugs are especially expensive, reaching up to $270,000 annually per patient.104
- The United States spends $37.2 billion annually on cancer drugs and supportive therapies, more than 40 percent of worldwide expenditures.22
- In 2012, spending on specialty pharmaceuticals reached $87 billion in the United States and is on track to account for 50 percent of drug spending by 2019.105
- Spending on oral oncology drugs is also growing with a 37 percent increase in average quarterly spending over five years, from $940 million in 2006 to $1.4 billion in 2011 (in 2012 dollars).106

Paradoxically, the price of a drug seems to have little relation to its demonstrated efficacy. For example, researchers point to tyrosine kinase inhibitors for treatment of chronic myeloid leukemia.104 The first-generation therapy, imatinib, increased the 10-year survival rate in chronic myeloid leukemia from 20 percent to 85 percent.107 When it was approved in 2001, it carried a price tag of $30,000. By 2012, the price had risen to between $80,000 and $92,000, despite falling development costs and an expanding patient pool. In 2006, a second-generation inhibitor, dasatinib, was approved for use in patients who become resistant to imatinib. Although this and other second-generation inhibitors have demonstrated improvement in early surrogate measures of prognosis, they have not shown an increase in long-term survival. These second-generation inhibitors range from $115,000 to $124,000 per year.104

Increasingly under fire, manufacturers have pointed out that drug prices in oncology reflect the high cost of research, a limited market for highly specialized drugs, and the need to finance future research.108 As the debate over drug prices continues, policymakers are seeking strategies for lowering cost, including value-based reimbursement, enhanced clinical guidelines to minimize variation and waste, and formation of non-profit organizations involved in the manufacturing and delivery of drugs109.

Cost of Care
Although drugs represent one of the fastest growing costs in the healthcare delivery system, they are not the largest contributor to overall spending on cancer care in the United States. UnitedHealthcare recently reported that hospitals and outpatient facilities account for more than half of spending on cancer care.110 The nearly five million cancer-related hospitalizations each year in the United States represent a cost of more than $20 billion.111 and as many as one fifth of those hospitalizations are potentially avoidable.112

The complexity of cancer care—including the need for multiple providers and specialists over the course of treatment—makes oncology especially vulnerable to fragmentation and inefficiency. Several reports point to the fragmentation of care for cancer patients, gaps in transition from treatment to survivorship, and failures in communication between multiple providers and specialists involved in a patient’s care.113-115 Apart from unnecessary or wasteful spending, poorly managed disease can lead to complications for patients, such as long-term effects from disease or treatment, disease progression, unplanned hospitalizations, and avoidable visits to the emergency room.
### Table 4. Ten Most Expensive Medicare Part B Payments for Drugs Delivered in the Physician Office and at Home

| HCPCS  | Name                  | Dose | Average Sales Price per Dosage | Total Medicare Annual Payment | FDA-Approved Indication                                                                 
|--------|-----------------------|------|-------------------------------|------------------------------|------------------------------------------------------------------------------------------
| J2778  | Ranibizumab injection | 0.1 mg | $397.26                       | $1,325,482,737               | • Macular degeneration  
|        |                       |      |                               |                              | • Macular edema  
|        |                       |      |                               |                              | • Diabetic macular edema                                                                 
| J0178  | Aflibercept injection*| 0.1 mg | $980.50                       | $1,028,454,803               | • Metastatic colorectal cancer                                                            
| J9310  | Rituximab injection*  | 100 mg | $678.70                       | $879,704,671                 | • Non-Hodgkin's lymphoma  
|        |                       |      |                               |                              | • Chronic lymphocytic leukemia                                                            
| J1745  | Infliximab injection  | 10 mg | $69.96                        | $756,940,457                 | • Crohn's disease  
|        |                       |      |                               |                              | • Ulcerative colitis  
|        |                       |      |                               |                              | • Rheumatoid arthritis  
|        |                       |      |                               |                              | • Psoriatic arthritis  
|        |                       |      |                               |                              | • Ankylosing spondylitis  
|        |                       |      |                               |                              | • Plaque psoriasis                                                                        
| J2505  | Pegfilgrastim injection*| 6 mg | $3,123.83                     | $628,741,617                 | • Neutropenia                                                                            
| J9035  | Bevacizumab injection*| 10 mg | $64.62                        | $606,329,275                 | • Epithelial ovarian cancer  
|        |                       |      |                               |                              | • Fallopian tube cancer  
|        |                       |      |                               |                              | • Primary peritoneal cancer  
|        |                       |      |                               |                              | • Cervical cancer  
|        |                       |      |                               |                              | • Colorectal cancer  
|        |                       |      |                               |                              | • Breast cancer  
|        |                       |      |                               |                              | • Renal cell cancer  
|        |                       |      |                               |                              | • Glioblastoma  
|        |                       |      |                               |                              | • Non-small cell lung cancer                                                             
| J0897  | Denosumab injection*  | 1 mg  | $14.15                        | $428,692,767                 | • Giant cell tumor of bone  
|        |                       |      |                               |                              | • Prostate cancer  
|        |                       |      |                               |                              | • Breast cancer  
|        |                       |      |                               |                              | • Bone metastases  
|        |                       |      |                               |                              | • Osteoporosis                                                                            
| J9305  | Pemetrexed injection* | 10 mg | $59.49                        | $296,412,288                 | • Non-small-cell lung cancer  
|        |                       |      |                               |                              | • Mesothelioma                                                                            
| J9041  | Bortezomib injection* | 0.1 mg | $44.89                        | $281,769,218                 | • Multiple myeloma  
|        |                       |      |                               |                              | • Mantle cell lymphoma                                                                   
| J9355  | Trastuzumab injection*| 10 mg | $78.72                        | $270,119,091                 | • Gastric or gastroesophageal junction adenocarcinoma  
|        |                       |      |                               |                              | • Breast cancer                                                                           

**Source:** Moran Company Analysis of 2013 Physician/Supplier Procedure Summary File  
**Note:** *Drugs used for treatment of patients with cancer. Pricing data reflects 4th quarter 2013 payment rates, which correspond to 2nd quarter 2013 manufacturer reports. The first column lists procedure codes from the Healthcare Common Procedure Coding System (HCPCS). The last column lists FDA-approved indications, but Medicare may also provide reimbursement for additional off-label uses.

In a 2014 *New England Journal of Medicine* Perspectives column, a general internist shared his experience coordinating care for one patient with cancer:116

Over the 80 days between when I informed Mr. K. about the MRI result and when his tumor was resected, 11 other clinicians became involved in his care, and he had 5 procedures and 11 office visits (none of them with me). As the complexity of his care increased, the tasks involved in coordinating it multiplied. I kept a running list and, at the end, created an “instant replay” of Mr. K.’s care...In total, I communicated with the other clinicians 40 times (32 e-mails and 8 phone calls) and with Mr. K. or his wife 12 times. At least 1 communication occurred on 26 of the 80 days, and on the busiest day (day 32), 6 communications occurred.

Another factor driving cost of services is the trend toward conversion to hospital-based practices. Last year witnessed a continuing trend toward affiliation and the 2014 ASCO Oncology Census reflected similar findings (see Chapter 3).
4. QUALITY AND VALUE IN CANCER CARE

The impact of this shift can be considerable; at least one analysis showed cost in hospital outpatient departments was 19 percent to 38 percent higher than cost for similar services provided in physician offices.117 Hospitals have argued the higher cost reflects the overall requirement for round-the-clock operation and other infrastructure requirements. Regardless, both the Centers for Medicare & Medicaid Services (CMS) and the Medicare Payment Advisory Commission have expressed ongoing interest in pursuing site-neutral payment policies. In a report issued in June 2014, the Medicare Payment Advisory Commission suggested options for reducing payment differentials between inpatient rehabilitation and skilled nursing facilities and signaled it would be exploring other areas where CMS should consider addressing disparity in payment.118 The 2014 Protecting Access to Medicare Act included a provision that expands the types of information CMS may consider in determining costs under the physician fee schedule, including significant difference in payment for the same service between different sites of service.119 Private payers have also begun to address this growing trend. In April 2014, the not-for-profit insurer Highmark announced that it would not pay higher chemotherapy administration fees for services rendered in hospitals.120

RESPONSE TO COST: TARGETING UTILIZATION

Health insurers and policymakers have pursued a variety of strategies to control cost while preserving or enhancing quality. These include: administrative controls on utilization (e.g., preauthorization and clinical pathways), development of alternative payment models, and quality monitoring. There has also been a strong emphasis on creating more informed and value conscious consumers. The remainder of this chapter explores the heightened efforts in 2014 to produce greater value for the nation’s investment in cancer care.

Clinical Pathways

Clinical pathways are designed to reduce costly variation in care through recommended care processes for specific clinical situations. Via Oncology, Innovent, Eviti, New Century Health, and P4 Pathways are some of the commercial developers of clinical programs and pathways in oncology. Many payers are pursuing the use of pathways because they have demonstrated the potential to yield significant savings.

▶ Use of the P4 Pathways Program in 46 CareFirst BlueCross BlueShield oncology practice sites led to $10.3 million in savings from reduced drug costs and hospitalizations—amounting to $30.9 million in savings if scaled to the entire health plan.121

▶ In a CareFirst program requiring pathways for use of granulocyte colony-stimulating factors, the plan was able to achieve a significant decrease in emergency department visits and hospitalizations for neutropenia and associated costs.122

▶ A retrospective analysis of proposed therapy for 2,544 cancer patients found that approximately 25 percent of the treatment plans did not conform to national guideline recommendations, and there was no identifiable rationale for the deviation. Deviations in care cost an average of $25,000 per patient.123

▶ A collaboration between US Oncology practices in Texas and Aetna found that use of the Innovent Oncology Program resulted in improved patient care, greater pathway adherence, and decreased costs for emergency department visits and inpatient admissions in 221 patient cases.124

▶ During 2014, WellPoint began offering monthly payments to oncologists in six states for patients treated according to recommended treatment pathways and plans to extend the program to all networks in 2015.125

Although many developers point to the fact that their programs are evidence based, there is growing concern that many commercial pathways programs fail to release information on methodology, governance, and oversight.126 Patients and physicians have voiced concerns that overly restrictive pathways may interfere with the delivery of care that is personalized and appropriate to an individual patient’s needs.127,128 Furthermore, multiple insurer requirements for disparate clinical pathways make it difficult for practices to adhere to requirements—and present a significant administration burden. Future tracking of quality and survival outcomes, in addition to pathway compliance and practice efficiency, will be important to gauge the impact of these recommended approaches on treatment decisions and care management.

Bundling and Episode Payment

Many of the payment reform models now being tested involve fixed payment for services with potential for shared savings or performance-based bonuses. Bundling or episode-based payments are common versions of this approach and have gained traction with both Medicare and private payers. The Center for Medicare & Medicaid Innovation (CMMI) is developing specialty-specific models involving episode-based payment for procedures or complex and chronic disease management, along with other innovative arrangements.129 Moving away from volume-driven incentives inherent in fee for service, bundled payment can offer a more flexible environment where practices can organize in the way that best responds directly to the needs
of their patients. However, bundled payments in oncology may expose practices to additional financial risk—especially when cancer care bundles are not adequately defined and valued. Bundled payments also introduce the potential for underutilization—a robust quality-monitoring system is vital to ensuring neither over- nor underutilization of cancer care. It is not yet clear whether widespread adoption of bundling will occur. In August, reports were published of an unsuccessful bundled payment pilot by a large network in California; contributing factors included administrative burden and inability to agree on risk and elements to be included in the bundle.\textsuperscript{130}

In 2014, the Center for American Progress (CAP) organized a consortium to develop a framework for care bundling in oncology, standardize quality measures for program evaluation, and launch a multi-site demonstration project to test the framework.\textsuperscript{131} The CAP consortium announced that initial cases would include metastatic non-small-cell lung cancer and adjuvant and metastatic colon cancer. As of December 2014, CAP had not announced the specifics of its plan; one difficulty has reportedly been challenges in defining services for inclusion in the bundle.

Private insurers are also exploring bundled payment options. During 2014, UnitedHealthcare published results of its own bundled payment pilot involving five medical groups and 810 patients with breast, colon, or lung cancer. The primary outcome measured was total medical cost per episode of care (excluding drug costs), comparing data from the sites with data in a national payer registry. Although the study reported an increase in chemotherapy drug costs of $13 million, total medical costs were reduced by $33 million when compared with projected fee-for-service expenses. There were no observed declines in quality.\textsuperscript{132} UnitedHealthcare could not draw conclusions about the reasons for the savings, although subset analyses demonstrated “statistically valid decreases in hospitalization and usage of therapeutic radiology.” Additional studies will be important to validate these findings and ascertain successful models that could be used by other practices.

**Alternative Payment Models: The Medical Home and Practice Transformation**

The medical home concept has largely been associated with primary care, but specialists are also focusing on this framework as a way to achieve better healthcare outcomes at a lower cost. Medical homes typically involve a physician-led team that takes responsibility for the full range of services patients need, including coordination of care with other providers. This approach also emphasizes the need for robust performance measurement and continuous quality improvement to assure patient safety and quality of care. Many practices are not organized to fulfill the main elements normally understood to comprise medical homes and must undergo transformation to implement what the Commonwealth Fund has identified as change concepts practices should use to become a medical home:\textsuperscript{133}

- Visible practice leaders who champion the change
- A strategy for and commitment to quality improvement
- Linking each patient/family to a specific provider
- Team-based care
- Care planning and decision support
- Patient-centered care and shared decision making
- Access to care team support after hours
- Care coordination

Many of the payment reform initiatives launched by public and private payers include medical home elements.

Practice transformation leading to better disease management and care coordination has been a major focus of the Center for Medicare & Medicaid Innovation. In its first two rounds of innovation grants, the Center has funded over $46 million in cancer projects and expects more than $95 million in savings over a three-year period.\textsuperscript{134,135} The largest oncology-related award was granted in 2012 at nearly $20 million for the Community Oncology Medical Home (COME HOME) program, a multistate oncology medical home experiment.\textsuperscript{134} COME HOME practices are focusing on comprehensive outpatient oncology care, offering extended clinic hours, patient education, medication, and inpatient care coordination. Results will be reported in 2016.

Other innovation initiatives in oncology funded through the Center for Medicare & Medicaid Innovation include:

- The Deep South Cancer Navigation Network (University of Alabama at Birmingham) is using lay health workers to decrease unnecessary hospitalization and increase patient satisfaction.\textsuperscript{134}
- The University of Virginia received more than $2.5 million for a program focusing on proactive palliative care and palliative radiation therapy for patients with advanced cancer and collection of patient-reported outcomes.\textsuperscript{134}
- The University of Pennsylvania is implementing a set of skilled home care services for patients with palliative care needs before they are eligible for hospice.\textsuperscript{134}
- University Hospitals Case Medical Center of Ohio received funding to improve care for cancer patients with complex care needs, including patients with late-stage disease or significant comorbidities.\textsuperscript{135}
In August 2014, CMS also released for public comment its proposed cancer care payment and service delivery model, the Preliminary Design for an Oncology Focused Model.\(^{136}\) The model—proposed by the Center for Medicare & Medicaid Innovation—relies on adjustments to the current fee-for-service payment system, attempting to control costs while maintaining quality of care. CMS is proposing traditional fee-for-service payments under Medicare Parts A, B, and D; per-member, per-month payments to support care transformation; and retrospective, risk-adjusted performance-based payments. Performance-based payments would be applied to a retrospective analysis of episodes of care and a practice’s ability to achieve savings relative to a selected list of measures. Episodes would begin on the date of initial chemotherapy administration—or Part D chemotherapy claim—and end six months later, or when the beneficiary dies. Per-member, per-month payment amounts would be based on the estimated practice costs of providing enhanced services in the new model, including care coordination/navigation, documentation of care plans, and 24/7 patient access to an appropriate clinician with real-time access to the practice’s medical record. The proposed demonstration would apply to all cancer types. Episodes would include all Medicare Part A, B, and D services that fee-for-service beneficiaries receive during the defined episode. CMS is assessing feedback on the proposal, and a final draft is expected in early 2015.

ASCO also released its own physician-developed detailed payment proposal in May 2014, an approach that would provide bundled payments for the comprehensive services provided in high-quality cancer care (Box H).

This past year, the Community Oncology Alliance also released a payment reform model that emphasizes practice transformation to an Oncology Medical Home (OMH).\(^{137}\) This model focuses on the following elements:

- Core quality and value measures,
- Benchmark capability to compare with peers,
- Tools and services to aid clinics in transition,
- Platform for information exchange, and
- Public and private payer models.

As part of this effort, the Community Oncology Alliance teamed with the Commission on Cancer to develop an OMH accreditation program. Applicant organizations will be reviewed based on 19 measures that promote OMH goals: (1) patient access, (2) extended or after-hours access to practice staff/providers, (3) evidence-based care, (4) comprehensive team-based care, and (5) quality improvement.\(^{138}\)

The Patient-Centered Outcomes Research Institute (PCORI), a non-governmental organization established through the ACA, is providing significant funding to explore care delivery models. As of the end of 2014, PCORI has awarded more than $50 million to cancer projects across 14 states and Washington, DC.\(^{139}\)

The patient-centered medical home (PCMH) model originally was created to enhance communication, coordination, and accountability in the primary care arena, but has also demonstrated promise in oncology.\(^{140,141}\) In 2013, PCORI granted an award to the National Committee for Quality Assurance to advance the PCMH model in specialty care.\(^{142}\) Based on standards developed in collaboration with ASCO and other specialty organizations, the National Committee for Quality Assurance created the Patient-Centered Specialty Practice Recognition Program.\(^{143}\) The model focuses on mechanisms to promote information sharing and care coordination between specialty and primary care practice—with an emphasis on organizing around the patient and their family or other caregivers.

Private payers are also pursuing the medical home model for oncology. Aetna recently announced plans to launch a pilot in January 2015 focused on patients with breast, colon, or lung cancers in Ohio, Georgia, and Texas. The insurer hopes the medical home strategy will reduce hospitalization and emergency department utilization.\(^{144}\)
Creating Value-Conscious Consumers
A major theme of healthcare reform has been greater patient engagement, including shared decision making about treatment options. Providers have focused on better communication about available therapies and their costs and benefits, often using formal treatment plans to support discussions with patients and families. Policymakers are approaching greater patient involvement by focusing on transparency in cost and providing consumer-focused information about provider practice patterns. The data released thus far, unfortunately, have limitations.

In April 2014, CMS released a public dataset of healthcare services performed by physicians and other healthcare professionals in 2012. The data included amounts charged to Medicare and payments made to providers. This disclosure—the first of its kind—was described by CMS as an effort to make the healthcare system more transparent, affordable, and accountable. Whether this strategy achieved the Administration’s goals was a topic of debate in the medical community. ASCO and other professional organizations reacted strongly, arguing that the information was released out of context and that it included numerous errors. For example, CMS bundled physician payment together with drug reimbursement, the latter being largely a pass-through. It was also not made clear that physician payments supported the entire practice and that, in oncology, the average physician supports seven to eight full-time staff members from these payments. Furthermore, the data did not capture certain structural realities of the payment system. For example, a multimillion dollar payment was attributed to one physician leader of a large clinic, when, in fact, the amount helped support drug expenses and salaries for 40 providers in that clinic. Rather than adding clarity and transparency, observers raised concerns that broad public release of information without important context may actually create more confusion about oncology for patients and their families.

In 2014, the ASCO Value in Cancer Care Task Force initiated efforts to develop a value framework designed to assess and discuss the relative value of cancer treatment options and help each physician and patient make the best possible treatment decision for each unique situation (see Box I).

ASCO Value Initiative
ASCO is developing a framework for evaluating the value of new cancer treatment regimens across three domains: treatment efficacy, toxicity, and cost. ASCO has identified three goals for its value initiative:

• Oncologists will have the skills and tools needed to assess value of interventions and use these in discussing treatment options with their patients.
• Patients will have ready access to information that assists them in selecting high-value treatments that meet their unique needs.
• Those responsible for covering the costs of cancer care will have a useful algorithm with which to define and assess the value of cancer treatment options.

Framework elements have been defined as:

• Clinical benefit: improvement in survival, time to disease progression, or quality of life, or a decrease in symptoms
• Toxicity: side effects associated with treatment
• Cost: expenses incurred by patients, society and insurers

In 2014, ASCO hosted a series of stakeholder meetings to solicit feedback on an early draft of the framework. The Society is in the process of reflecting on and integrating these diverse perspectives to ensure that the final version of the framework is responsive to patient needs and useful in the clinical setting. ASCO plans to release a revised version for broad public review and comment in 2015.

For details, please visit www.asco.org/value.
QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT

Quality measurement and improvement were central elements in virtually every payment reform model proposed during 2014, including major federal legislation to overhaul Medicare’s physician payment formula and replace the flawed sustainable growth rate (SGR) formula. While the House-passed bill (H.R. 4015) failed to pass the Senate, the legislation included provisions that:

- Emphasized quality improvement,
- Supported use of clinical data registries,
- Streamlined current federal incentive programs, and
- Encouraged provider participation in alternative payment models, including patient-centered medical homes.

The emphasis on quality is reflected in reimbursement programs recently adopted by payers—notably CMS—and provider and patient organizations. For full Medicare reimbursement, CMS now requires eligible providers to participate in the Physician Quality Reporting System (PQRS). Providers participating in PQRS have multiple routes to submit quality data to CMS, including through Medicare Part B claims, electronic health records, and CMS-approved registries. Data submissions can be made at the practice level through the group practice reporting option, an option that will become increasingly important as practices continue to consolidate. Those who did not participate in PQRS in 2014 face a two percent reduction in Medicare reimbursements on Part B physician fee schedule services in 2016. CMS is also driving increased visibility of quality assessment by making PQRS participation information publicly available through its Physician Compare website (see Chapter 2 for details about the data source).

As of December 2014, only 37 percent of hematologists/oncologists identified in the Medicare Physician Compare dataset had reported using PQRS. Practices have cited the high cost of participation, accompanied by unattractive incentive payments, and the lack of measures for oncology as reasons for the low involvement rate. However, penalties will become greater (two percent in 2016) and other programs will rely on PQRS for evaluating performance (e.g., the Value-Based Payment Modifier). Non-participating practices may reconsider as the penalties become greater.

ASCO is hoping to address the low uptake rate by enabling participation in its Quality Oncology Practice Initiative (QOPI®) to meet PQRS requirements. A provision included in the American Taxpayer Relief Act of 2012 authorized the U.S. Department of Health and Human Services to deem other registries as meeting PQRS requirements. In 2015, QOPI participants will qualify for meeting PQRS requirements.

At the national level, organizations such as the Commission on Cancer, the National Quality Forum, the Agency of Healthcare Research and Quality, and ASCO have published or endorsed metrics spanning a variety of cancer services, including treatment and procedure overutilization, palliative care, and end-of-life care. Patient satisfaction and patient-reported outcomes are also receiving attention in oncology. Additionally, individuals and institutions across the country are contributing to a growing body of research dedicated to the collection and analysis of cancer quality indicators.

The 2015 State of Cancer Care in America report illustrates progress in quality measurement and improvement, with recent efforts in an area of particular importance to cancer patients: palliative care.

Room for Improvement: Quality Measurement in Palliative Care

In a September 2014 consensus report, the Institute of Medicine evaluated the state of palliative care in the United States, identifying significant unmet need for high-quality services for patients with serious and terminal illnesses throughout the continuum of their care. Palliation encompasses many aspects of care, including pain and symptom management, psychosocial support, and end-of-life services—all areas that are important to the care of patients with cancer.
Increased focus on palliative care may contribute to advancing high-value, patient-centered care. Palliative care has been shown to improve quality of life, increase patient and caregiver satisfaction, and even lengthen survival and reduce costs in several instances. A 2014 study comparing late-stage cancer patients treated in and out of hospice found that patients receiving hospice services experienced lower rates of hospitalizations, intensive care admissions, and invasive procedures than patients not receiving these services—resulting in lower expenditures in the last year of life and savings of nearly $9,000 per patient.

A number of recent studies have focused on palliative care in the oncology setting, including several new or updated systematic reviews of the palliative care quality measurement literature. One such 2014 study identified 284 cancer-specific palliative care quality measures from 13 sources assembled between 1995 and 2012. While noting significant growth in number of quality measures, this study also mentioned gaps in data collection related to common cancer symptoms (e.g., fatigue and anorexia) and to non-physical attributes of care (e.g., emotional distress and patient/provider communication). Concerning pain management in cancer care, an updated systematic review of 46 articles published between 1994 and 2013 found that the quality of pain management had improved since 2008—but that approximately one third of cancer patients still do not receive sufficient treatment to address the intensity of their pain.

Recent findings provide evidence that enhanced palliative care improves quality of life for patients with cancer. At MD Anderson Cancer Center, researchers found that patients referred to outpatient palliative care early in the continuum of care had improved end-of-life care compared with patients with later and inpatient referral. Despite persistent and growing evidence of the benefits and improved outcomes with palliative care, performance gaps persist in this area. To raise awareness of the issue and provide a venue for discussion of successful approaches to promote palliative care, ASCO initiated the annual Palliative Care in Oncology Symposium in 2014.

To increase awareness through measurement, ASCO created a quality assessment and improvement program derived from clinical guidelines, published measures, and expert consensus. The Quality Oncology Practice Initiative (QOPI) has a module of measures devoted to end-of-life care as part of a library of more than 160 quality measures covering the broader cancer care spectrum, and a module for palliative care is currently being developed. Altogether, QOPI has more than 40 measures related to pain and symptom management, palliative care, and end of life.

As of spring 2014, QOPI practices had achieved between 69 and 85 percent concordance for selected measures of pain and symptom management (Figure 24). Constipation assessment and prescription of anti-nausea medications are areas that demonstrate continuing improvement over time. Since 2008, anti-nausea palliation scores had nearly doubled, from 44 percent to 80 percent. Constipation assessment also increased from 2008 to 2014, moving from 50 percent to nearly 70 percent. These numbers show the variability in performance among measures of pain and symptom
management and illustrate the importance of initiatives to improve quality of care in these areas.

Figure 25 features three measures from the QOPI end-of-life module. Although QOPI practices showed signs of improvement in pain management and discussions and activities related to palliative care and hospice options, hospice enrollment more than one week before death remained low.

To address areas needing improvement, ASCO established the Virtual Learning Collaborative and Quality Training Program (Boxes J and K).

Results from these ASCO programs and quality improvement programs from other organizations are beginning to enhance clinician expertise and provide models for successful strategies. In addition, payment reform approaches can provide the resources to support clinician time and attention to patient-centered improvements. Randomized controlled trials are not always feasible or viable ways to test different approaches. Greater availability of metrics and tools to analyze clinical data are expanding the way that oncologists learn and improve care quality.

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**ASCO Virtual Learning Collaborative**

In May 2014, ASCO teamed with the American Academy of Hospice and Palliative Medicine to establish the Virtual Learning Collaborative to help oncology practices enhance their delivery of high-quality palliative care services. The program consists of an online toolkit of resources and channels for practices to connect with one another to share ideas and best practices. During the initial launch that will run through 2015, a group of 24 oncology practices will participate and evaluate program activities to determine the feasibility of expanded virtual support tools covering many aspects of cancer care.

Details are available at [www.asco.org/vlc](http://www.asco.org/vlc).

**ASCO Quality Training Program**

Between October 2013 and March 2014, 15 interdisciplinary oncology teams participated in the inaugural Quality Training Program—a comprehensive education and training program that assisted the oncology teams with the design and implementation of quality improvement activities in their practice settings. In the initial round, practices sought improvements in such areas as oral chemotherapy documentation and emotional distress assessment and management for patients with cancer. On the basis of the success of the pilot, ASCO will offer the Quality Training Program to a broad audience of practices in 2015 and onward.

Program information is available at [www.asco.org/qualitytraining](http://www.asco.org/qualitytraining).
BIG DATA

Big data—the collection and analysis of large and complex data sets—has the potential to improve the quality, and thus the value, of cancer care. Big data is characterized by its volume or quantity, variety or different types and formats, and velocity or speed of accumulation.

Currently in the United States, treatment standards are determined in large part from the three percent of cancer patients who participate in clinical trials—and these patients tend to be younger, healthier, and less diverse than the overall population of cancer patients. Meanwhile, the remaining 97 percent of data on how other cancer patients respond to therapies are not available to inform patient-clinician decision making. New methods and technologies are needed to enable the cancer community to use big data to learn what is and is not currently working for the majority of patients who would not have qualified for or chose not to participate in clinical trials.

The number of organizations engaging in large-scale data efforts continues to grow. Within the pharmaceutical research and development arena, for example, companies are making unprecedented efforts to openly share data from their cancer clinical trials through the Project Data Sphere initiative. During 2014, its first year of operation, the initiative collected de-identified, control-arm data on more than 10,000 patients from more than a dozen sources. Private companies such as Cancer Outcomes Tracking and Analysis, Flatiron Health, IBM, IMS, Optum, and NantHealth are actively involved in cancer-related data initiatives. Non-profit organizations such as PCORI via PCORnet and the Commission on Cancer via the National Cancer Database are contributing their own efforts.

ASCO is playing a unique role as a specialty society interested in supporting oncology clinicians seeking assistance in measuring and improving quality and learning from the experiences of patients with cancer (see Box L on the ASCO CancerLinQ initiative).

These endeavors are in the early stages, so results are generally not yet available in the peer-reviewed literature. Future editions of this report will cover these initiatives in greater detail.

State and national governmental agencies are also substantially contributing to the big data movement. In late 2013, the Centers for Disease Control and Prevention announced its joint efforts with the Agency for Healthcare Research and Quality to enhance the National Program of Cancer Registries to better capture comparative effectiveness and patient centered outcomes data. A total of 13 states were identified for the data enhancement project. In addition, CMS has a longstanding tradition of sharing healthcare data for the purposes of establishing transparency and advancing health services research. CMS products range from provider-level datasets, including the newly released Medicare Provider Utilization and Provider Payment dataset, and cancer patient-level data when linked with the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute. The Food and Drug Administration is currently piloting elements of its Mini-Sentinel Initiative, a system intended to quickly identify and assess safety issues from real-world patients.
**CancerLinQ**

The ASCO CancerLinQ initiative will provide a cutting-edge health information technology platform to harness big data to transform how we learn from the experience of people with cancer—improving the quality and value of cancer care. CancerLinQ will securely process real-word patient data directly from electronic medical records and provide immediate quality feedback and clinical decision support to healthcare providers. At the same time, the system will analyze incoming patient characteristics, treatments, and outcomes in aggregate, leading to new insights and sweeping improvements in care.

Big data projects like CancerLinQ include strategic, technical and regulatory challenges, but ASCO has established a robust external advisory structure to guide its development. Earlier this year, the Society published a set of guiding principles that will underpin CancerLinQ:

**Stewardship**
- Stems from ethical duty to respect persons and to show consideration for all persons who might be affected by cancer
- Achieved through robust standards for collecting data that are accurate, valid, and useable for quality improvement purposes
- Encompasses application of ethical procedures for evaluating requests from researchers to use secondary redacted data; for commercial requests, requires careful consideration of balance between business necessity of commercializing knowledge and likelihood that proposed commercial use will improve health or healthcare systems
- Requires ongoing attention and willingness to adapt to changes in scientific, technologic, legal, and ethical standards upon which operational decisions are based

**Protection**
- Expresses ethical duty to prevent harm and risk to others, including patients and providers participating in CancerLinQ; special obligation to respect privacy and security of health data arises from collection of individual health information
- Supports development of strong security for data while permitting beneficial and authorized uses;
  - Data are maintained, accessed, and used in compliance with applicable law and with appropriate organizational oversight
  - Data are protected against unauthorized access and misuse at every stage
  - Standards are defined for secure collection and storage of data, response to potential security incidents, and remediation in event of deviation from standards

**Transparency and Accountability**
- Arise from ethical duty to respect persons
- Accountability to patients, participating providers, other stakeholders, and public to achieve high standards for ethical management of data
- Transparency promotes trust and willingness of providers to participate in quality-improvement activities, encourages patients to seek care from participating providers, and can speed development of science and technology from use of CancerLinQ

After having successfully created a prototype platform, ASCO has selected 15 vanguard practice sites, representing more than 350 oncologists, to contribute real-world patient data from more than 500,000 patients. ASCO will release an initial version of CancerLinQ with the vanguard practices in 2015. Information and updates can be found at [www.CancerLinQ.org](http://www.CancerLinQ.org).
CONCLUSION

The healthcare environment in the United States remains turbulent, and cost concerns have given rise to numerous experiments designed to find ways of lowering spending while preserving quality. Strategies such as specialty medical homes and bundling/episode-based payments have shown mixed results, but certain pilots have produced savings without reducing quality. With the increase of funding from the Center for Medicare & Medicaid Innovation and the Patient-Centered Outcomes Research Institute to support development of different payment models over the next five years, more data will become available that will be key to identifying successful approaches to organization, delivery, and payment for cancer care.

Creating value-conscious consumers will continue to be a major focus of payers, with emphasis on patient engagement in treatment decisions and expanded public information about provider quality and cost. Providers need to be actively engaged to assure performance measures and payment models support appropriate clinical care—and to convey accurate information to patients and families.

Large data sets hold promise for speeding scientific progress and providing greater insight into the value of individual treatment options. The challenge lies not in accumulating massive amounts of data, but rather in distilling these data into information that is accurate, meaningful, and readily accessible to providers, patients, and other stakeholders.
Disparities in access to cancer care persist across the United States and public insurance programs should be structured to minimize barriers that contribute to this challenge.
The U.S. cancer care delivery system remains in a highly volatile state, experiencing many of the disruptions taking place in the broader medical community.

Economic, policy, and technology changes are strong catalysts for many of the trends observed over the past year, including shifts in site of practice, emergence of new care delivery models, and growing concerns about cost of care. ASCO’s analysis of the state of cancer care has revealed a number of positive trends, such as increased survival rates and innovation in healthcare delivery, as well as more concerning trends, such as continuing disparities in access to cancer care, narrowing provider networks, aging of the oncology workforce, and continued migration of services away from community practices.

Anticipated oncology workforce shortages have not yet occurred, but this may be a result of delayed retirements, shifts in practice site, or involvement of advanced practice providers—or because of overall reductions in healthcare spending and utilization seen in the past couple of years. This is an area that will require continued monitoring.

Although practices in the 2014 ASCO Oncology Census reported a small increase since 2013 in the number of patients covered by Medicaid, the anticipated major surge in the number of insured cancer patients—especially those funded through state Medicaid programs—has not been observed. This may be related to insufficient time for newly insured patients to present with a cancer diagnosis. Other coverage-related changes are more apparent: narrowing provider networks, increasing patient responsibility for cost of care, and growing administrative requirements such as preauthorization for drugs and/or services. As cost concerns escalate, payers are putting heavy emphasis on performance-based payments, and many are building their own quality measurement programs in selected disease areas, especially in cancer.

Both practices and payers are responding to continued system challenges, such as fragmentation of cancer care across multiple providers and settings, barriers to access, payment structures that do not match services, and lack of clarity or communication around treatment goals and cost. Strategies include adoption of innovative payment models, expanded use of team-based care, practice transformation to medical home structures, emphasis on shared decision making, and rural outreach initiatives. The impact of these strategies remains to be seen and will be important to monitor in the coming year.

The following are strategies ASCO believes can play important roles in addressing the challenges described in this report:

- **Ensure all publically funded insurance programs offer consistent and appropriate benefits and services for patients with cancer.** The Affordable Care Act has extended coverage to millions of Americans but, as is clear from this report, there remain significant disparities in access to care across the country, including among Medicaid patients. Currently, 67.9 million Americans—approximately one fifth of the U.S. population—are enrolled in Medicaid, including those added under the Affordable Care Act expansion. Of these, an estimated 2.1 million are cancer patients or cancer survivors. Yet studies show that Medicaid patients often do not receive
5. CONCLUSION AND RECOMMENDATIONS

the same quality of cancer care as patients with private insurance, and have substantially increased risks of presenting with advanced-stage cancers at diagnosis, when treatment is less likely to be effective.\textsuperscript{42,64} Disparities in access to cancer care persist across the United States, and public insurance programs should be structured to minimize barriers that contribute to this challenge.

- **The Centers for Medicare & Medicaid Services (CMS)** should standardize benefits and other program elements across Medicare and Medicaid.
- **Congress** should eliminate inconsistencies in coverage and benefits that currently exist between Medicaid patients enrolled pre- and post-Affordable Care Act and ensure that Medicaid includes coverage of clinical trials.
- **Oncology professionals** should articulate the essential services any plan must include to achieve high-quality, high-value care.

Pilot test multiple innovative payment and care delivery models to identify feasible models that promote high-quality, high-value cancer care. Current payment systems do not support many of the elements required to achieve improved health outcomes, enhanced patient experience, and lower cost. These aims for all of health care are especially critical in oncology, where care is complex and delivered by multiple providers across many care settings. Many new promising models have been proposed, but there is limited evidence as to their feasibility or impact.

- **CMS** should expand its efforts to pilot alternative payment models—beyond its Oncology Care Model—to identify innovative strategies that allow practices flexibility to deliver high-quality, high-value care while containing cost.
- **Congress** should provide a fair, adequate and stable payment environment for oncology practice, including repeal and replacement of the sustainable growth rate (SGR) formula.
- **Oncology professionals** should engage in testing and evaluating new payment and care delivery models and in developing measures of accountability for the care delivered.
- **Private insurers** should partner with CMS, patients, and providers to test promising new payment and care delivery models so the impact of alternative strategies on the entire cancer care delivery system can be determined.

- Promote high-value care by advancing and supporting transparency and shared decision making with patients. Most innovation initiatives either underway or being proposed include emphasis on engaged and informed patients. CMS and other payers are sharing information about provider quality and cost, but as noted earlier in the report, some of the information is out of context or inaccurate. Other efforts are focused on promoting shared decision making, informing patients about their treatment options, discussing how those options can support personal patient goals, and understanding the physical and financial costs of each option. The engaged patient is critical to successful outcomes and to providing high-value care.
- **CMS** should make every effort to improve its publicly released data and provide appropriate information to help the public understand the context for the data.
- **Congress** should require that health information technology vendors create products that promote interoperability and enable research use of standardized data in a secure environment to advance high-quality health care.
- **Oncology professionals** should discuss personal goals of care, potential treatment options, expected benefits, and the physical and financial impacts of treatment with every patient with cancer.
- **Private insurers** should ensure that publicly shared information about providers is accurate, in context, and meaningful to the intended audience.
- **Professional organizations** should offer tools and information that facilitate and help routinely incorporate shared decision making into practice.

ASCO will continue to track and evaluate the ever-shifting landscape in cancer care over the coming year, will continue to support cancer care providers as they negotiate these growing pressures, and will work with policymakers to ensure that changes in the system support access to high-quality, high-value care for all patients with cancer.
APPENDIX A: ASCO Workforce Information System (Methodology)

ASCO created the Workforce Information System (WIS) to assemble current data on the U.S. oncologist supply and compare those data to the latest cancer epidemiology. For purposes of the WIS, oncologists include those who report a primary specialty of medical oncology, hematology, or hematology-oncology.

The WIS provides a data collection and analysis process that is composed of three sections: workforce supply, new entrants, and cancer incidence and prevalence. Tabulations of the number of oncologists in the United States are derived from the American Medical Association Physician Masterfile and the Centers for Medicare & Medicaid Services’ Physician Compare dataset.45,47 Demographic data on practicing oncologists come from the Masterfile. Geographic analyses of oncologists’ practice locations are conducted using Physician Compare and U.S. Census data.67

Information on fellows and residents in the oncology workforce pipeline come from published sources such as the Journal of the American Medical Association. The WIS compares the characteristics of these oncologists with those of all physicians and tracks emerging trends in the physician training pipeline.

Incidence and prevalence estimates are published by the American Cancer Society and National Cancer Institute.

In January 2014, ASCO released the third edition of WIS, and a subsequent article in Journal of Oncology Practice published key findings.68 To download the full report, visit www.asco.org/wis.

APPENDIX B: The ASCO National Oncology Census (Methodology)

The ASCO established the National Oncology Census (Census) to capture comprehensive, timely data that helps characterize oncology practice in the United States. Begun in 2012, the Oncology Census collects information about oncology services and specialties, practice settings, staffing and mergers, payer mix, patient volume, and practice pressures. ASCO is using these data to understand practice demographics and their needs so that ASCO may adapt to the changing environment and be supportive of oncologists’ interests.

Launched in May 2014 and closed in August 2014, the latest Oncology Census represents 974 practices representing over 10,000 oncologists. In 2012, ASCO had 632 practices participate with 5,018 oncologists participate compared to 530 practices and 8,011 oncologists in 2013.

During its open period, ASCO mailed over 2,600 letters to both verified and unverified practice addresses identified through ASCO’s membership database, ASCO State and Regional Affiliate organizations’ membership lists, and through the Medicare Physician Compare data. The Physician Compare dataset includes data on all physicians who have billed Medicare in the previous 12 months.

The Oncology Census collects one response per practice. Of the people who completed the Oncology Census, 581 responders were MDs or DOs, and 173 responders were practice administrators, office managers, practice supervisors, or those in similar occupations. The remaining 220 responders were a mix including Advanced Practice Nurses and Physician Assistants. Practices were asked to select the most appropriate ownership type for their practice: academic, physician-owned, or hospital/health system-owned. Responders included 420 physician-owned practices, 362 hospital/health system-owned practices and 192 academic practices. On the basis of this response rate, it is possible that ASCO does not have information from smaller practices as well as large academic institutions.

APPENDIX C: ASCO/Hematology/Oncology Pharmacy Association Drug Shortages Survey (Methodology)

An online 13-question survey tool with multiple choice and short answer questions was administered for six weeks to U.S. ASCO and Hematology/Oncology Pharmacy Association members and non-members. ASCO and Hematology/Oncology Pharmacy Association members received links to the survey via email and both organizations provided links to the survey tool in newsletters and other communications aimed at, but not exclusive to, members; 257 individuals responded.
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www.cancerprogress.net
Progress timeline of milestones for nearly 20 cancers and all types of patient care

ASCO Guidelines  
www.asco.org/guidelines
Information on ASCO clinical practice guidelines, Provisional Clinical Opinions and guideline endorsements

Cancer.Net  
www.cancer.net
Comprehensive information on more than 120 cancer types and cancer-related syndromes

ASCO in Action  
ascoaction.asco.org
News, advocacy, and analysis on cancer policy from ASCO

Clinical Cancer Advances  
www.cancerprogress.net/cca
ASCO’s annual report on progress against cancer

Conquer Cancer Foundation  
www.conquercancerfoundation.org
An organization working to create a world free from the fear of cancer by funding breakthrough research, sharing leading-edge knowledge, and improving the quality of care and access to care
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