Abstract: Lack of health insurance coverage is strongly associated with poor cancer outcomes in the United States. The uninsured are less likely to have access to timely and effective cancer prevention, screening, diagnosis, treatment, survivorship, and end-of-life care than their counterparts with health insurance coverage. On March 23, 2010, the Patient Protection and Affordable Care Act (ACA) was signed into law, representing the largest change to health care delivery in the United States since the introduction of the Medicare and Medicaid programs in 1965. The primary goals of the ACA are to improve health insurance coverage, the quality of care, and patient outcomes, and to maintain or lower costs by catalyzing changes in the health care delivery system. In this review, we describe the main components of the ACA, including health insurance expansions, coverage reforms, and delivery system reforms, provisions within these components, and their relevance to cancer screening and early detection, care, and outcomes. We then highlight selected, well-designed studies examining the effects of the ACA provisions on coverage, access to cancer care, and disparities throughout the cancer control continuum. Finally, we identify research gaps to inform evaluation of current and emerging health policies related to cancer outcomes.

Keywords: The Affordable Care Act, cancer, health care reform, health insurance

Introduction
Cancer is the second leading cause of death in the United States. In 2020, an estimated 1.7 million new cancer cases will be diagnosed, and more than 600,000 patients will die from cancer. Some cancer deaths can be averted by reducing risk factors, and by increasing the utilization of evidence-based screening and early detection tests, and guideline-recommended treatment. Although overall cancer incidence rates have been stable during the past several years, the number of cancer survivors in the United States continues to increase as a result of the growth and aging of the population and improvements in early detection and treatment. In 2019, there were nearly 17 million cancer survivors in the United States and the prevalence is expected to reach 26 million by 2040. Also expected to escalate is the cost of cancer care, as it is one of the most expensive medical conditions to treat.

The United States has had a substantially higher uninsured rate than other comparable industrialized countries. In 2009, 15.4% of persons of all ages, 21.1% (40.0 million) of adults aged 18 to 64 years, and 8.2% (6.1 million) of children younger than 18 years were uninsured. Most uninsured in the United States are younger, racial/ethnic minorities, and from socioeconomic disadvantaged populations. Earlier studies have demonstrated that lack of health insurance is strongly associated with having problems with access to high-quality and affordable preventive and therapeutic cancer care. For example, compared with individuals who have health insurance coverage, the uninsured are less likely to receive breast, colorectal, and cervical cancer screening; and they are more likely to have a later stage of disease at diagnosis.
Patients without health insurance who have cancer are also less likely to receive high-quality treatment and have poorer survival than those with insurance. In addition to inferior access to care and health outcomes, lack of insurance also results in high health care costs. With health care spending per capita twice as high compared with other high-income countries, the United States experiences worse life expectancy than other countries that spend far less.

Signed into law on March 23, 2010, the Patient Protection and Affordable Care Act (ACA) is the largest health care system change in the United States since the establishment of the Medicare and Medicaid programs in 1965. Its goals are to improve health insurance coverage, the quality of care, and patient outcomes, and to maintain or lower costs by catalyzing change in the health care delivery system. The implementation of the ACA can have far-reaching effects throughout the cancer control continuum, including prevention and screening, diagnosis, treatment, survivorship, and end-of-life care (Fig. 1). The ACA can affect cancer care delivery through 3 main mechanisms: 1) health insurance expansion (eg, dependent coverage expansion [DCE], Medicaid expansion, and establishment of the Health Insurance Marketplace [the Marketplace]); 2) health insurance coverage reform (eg, elimination of cost-sharing for preventive services, closing of the Medicare Part D donut hole, coverage of routine care costs during clinical trial participation, essential health benefits, elimination of preexisting condition exclusions or refusals, and elimination of annual and lifetime caps); and 3) payment and delivery system reform.

Several earlier reviews have synthesized the research findings of the effects of the ACA on various aspects of cancer care, although prior reviews were mainly based on studies published before 2017 and only focused on a single provision or a part of the cancer control continuum. With data maturation and the increasing number of well designed studies published since 2017, a comprehensive and updated synthesis of research addressing the ACA in cancer care is needed. In this article, we provide an overview of the ACA provisions and their relationship to cancer care. We first describe the ACA provisions, then highlight selected, well designed studies examining the effects of the ACA provisions on coverage and access to cancer care throughout the cancer control continuum, followed by identifying research gaps and discussing emerging policy issues.

**Health Insurance Expansion and Cancer Care**

In this section, we describe the health insurance expansion provisions of the ACA and discuss their relevance across the cancer control continuum (Table 1).

### Dependent Coverage Expansion

The DCE under the ACA was designed to improve health insurance coverage for young adults in the United States. Historically, children aged 18 years or younger were either covered through the Children’s Health Insurance Program or were eligible to be covered under their parents’ private health insurance; young adults generally lost both eligibilities upon turning age 19 years, and their main source of private health insurance coverage was through college or

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**TABLE 1. Health Insurance Expansion Under the Affordable Care Act and Access to Care Across the Cancer Control Continuum**

| COMPONENTS                  | TIME OF IMPLEMENTATION | BEFORE ACA                                                                 | AFTER ACA                                                                 |
|-----------------------------|-------------------------|----------------------------------------------------------------------------|----------------------------------------------------------------------------|
| Dependent coverage expansion| September 2010          | Young adults were eligible for coverage under their parents’ private health insurance policy until age 19 y | Young adults eligible to remain covered under their parents’ private health insurance policy until age of 26 y |
| Medicaid expansion          | January 2014            | Medicaid was restricted to low-income pregnant women and children, poor elderly, people with disabilities, and parents of poor children | Medicaid eligibility expanded to individuals with income ≤138% of the Federal Poverty Level (FPL) with or without dependent children in states that opted to expand |
| Establishment of the Marketplace | January 2014  | Nongroup private insurance was seldom available; there was no regulated marketplace; insurers could deny coverage or set high premiums for preexisting health conditions or place annual or lifetime caps on coverage, and often only cover limited services | Insurers no longer allowed to deny coverage or set higher premiums or coverage exclusions for preexisting health conditions, including cancer; income-based premium and cost-sharing subsidies for individuals with family income between 100% and 400% of the FPL |

Abbreviation: ACA, The Patient Protection and Affordable Care Act.
employment, which was susceptible to frequent transitions and was not always available or affordable. As a result, young adults had had the highest percentage of being uninsured in the United States before the ACA. According to an estimate from the National Health Interview Survey (NHIS), which is a nationally representative household survey, nearly 9.7 million (33.6%) young adults aged 19 to 25 years were uninsured in 2009. The implementation of the DCE in September 2010 allowed young adults to remain on their parents’ private insurance policy until age 26 years. By 2018, 4.7 million young adults benefited from the DCE based on an estimate from the NHIS.

Although cancer incidence is lower in young adults than in older adults, cancer is the leading cause of disease-related death among young adults in the United States. Young adulthood is an important period for certain cancer prevention behaviors, such as not initiating smoking/smoking cessation and getting the human papillomavirus (HPV) vaccination if they have not already done so. For women, cervical cancer screening is recommended starting at age 21 years. Moreover, the incidence of some cancers has been increasing since 2000 in younger populations, and less progress has been observed in cancer survival for those aged 19 to 25 years compared with children and older adults. In addition, growing evidence has shown that young adults are especially vulnerable to delays in access to cancer diagnosis and treatment, largely because of the high percentage of uninsured.

**Medicaid Expansion**

As one of the largest sources of health insurance in the United States, Medicaid provides health coverage to eligible low-income adults and children. Although there are some federal requirements, states administer plans and have considerable discretion in setting the income threshold eligibility for Medicaid. For example, in 2009, before the ACA, a parent with 2 children needed to have an annual income of about $5500 or less to be eligible for Medicaid in Texas, whereas the eligibility threshold for a parent with 2 children was approximately $33,000 in New York. Medicaid expansion under the ACA, which took effect on January 1, 2014, aimed at improving health insurance coverage for the low-income population. Before Medicaid expansion, Medicaid was restricted to low-income pregnant women and children, the elderly poor, people with disabilities, and parents of poor children. Childless adults were generally not eligible for Medicaid unless states applied Medicaid demonstration waivers to extend coverage to this population. The ACA expanded Medicaid eligibility to individuals with incomes ≤138% of the Federal Poverty Level (FPL) with or without dependent children in states that opted to expand Medicaid coverage. Although originally intended to be implemented nationwide, Medicaid expansion was allowed to proceed as a state option by the US Supreme Court in 2012. Twenty-five states and the District of Columbia adopted Medicaid expansions by January 2014; as of January 2020, 36 states plus the District of Columbia had adopted Medicaid expansion (Fig. 2). However, in states that did not expand Medicaid in 2014, eligibility limits were as low as 17% of the FPL for parents in a family of 3 in Texas.

Historically, cancer outcomes have been worse for low-income populations in the United States, and observed disparities generally widen after the introduction of new effective cancer prevention, screening, and treatment strategies largely because of the high uninsured rate among low-income populations. Therefore, improving access to insurance coverage for low-income families would be expected to improve their access to care throughout the cancer control continuum. On the basis of estimates from the NHIS, among individuals aged 18 to 64 years with family income ≤138% of the FPL, 9.7 million (26.2%) were covered by Medicaid and nearly 15.8 million (42.6%) were uninsured in 2009; 42.3 million adults would have been eligible for Medicaid in 2014 if Medicaid expansion was implemented in all states. However, under the differential state policies, 14.6 million (34.4%) low-income adults aged 18 to 64 years were left uninsured in 2014, and this number remained high in 2018 (12.6 million; 19.3%).

**Establishment of the Health Insurance Marketplace**

The Health Insurance Marketplace, also known as the Exchange, was established under the ACA to offer affordable health insurance coverage for individuals and families without employer-sponsored insurance options, with tax credit premium subsidies available for those with incomes from 100% to 400% of the FPL and cost-sharing subsidies available to those with incomes from 100% to 250% of the FPL. The Marketplace also offers health plans for small business groups with up to 50 employees. Starting in January 1, 2014, the state-based health insurance Marketplace allowed individuals and small business groups to shop, compare, and choose a plan from the Marketplace, apply for financial assistance, and purchase coverage without medical underwriting. Moreover, the ACA requires that health plans on the Marketplace cover essential health benefits, ban lifetime or annual benefit maximums, and prohibit denials or increased premiums based on preexisting conditions.

Introduction of the Marketplace can potentially free individuals from “job lock” (inability to leave a job because of loss of employer-sponsored insurance), especially for those with chronic conditions, including cancer. Cancer survivors were more likely than those without a cancer history to report job lock, which may affect their career trajectory and quality of life and impose additional economic and psychosocial burden. Those with incomes from 100% to 400% of the FPL may especially benefit from the Marketplace, given the premium and cost-sharing subsidies. On the basis...
of an estimate from the NHIS, 14 million uninsured adults with preexisting conditions in 2013 could have benefited from the establishment of the Marketplace.\textsuperscript{22}

**Health Insurance Coverage Reform**

Substantial research has shown that patient cost-sharing is negatively associated with receipt of preventive services, treatment, and clinical trial participation among individuals with private and public health insurance coverage.\textsuperscript{38} Several provisions of the ACA reduce or eliminate cost-sharing with the goal of reducing financial barriers to care. In this section, we review health insurance coverage reforms and discuss their relevance across the cancer control continuum (Table 2).

**Elimination of Cost-Sharing for Preventive Services**

Beginning September 23, 2010, the ACA required non-grandfathered private health plans (grandfathered plans are those existing before March 23, 2010 and without major changes afterward; 56\% of adults who get coverage through their jobs were enrolled in a grandfathered health plan in 2011, and the percentage gradually decreased to 16\% in 2018)\textsuperscript{39} to remove cost-sharing for: preventive services rated as “A” (strongly recommended) or “B” (recommended) by the US Preventive Services Task Force (USPSTF), Advisory Committee on Immunization Practices-recommended vaccines, and services for infants, women, and children recognized by the Health Resources and Services Administration. The Medicare program also eliminated cost-sharing starting

![FIGURE 2. Medicaid Expansion Status by State as of January 2014 and January 2020.](image-url)
January 1, 2011, for most preventive services rated as “A” or “B” by the USPSTF. Lung cancer screening for high-risk current and former smokers was covered without cost-sharing by Medicare starting February 2015. Before the ACA, fee-for-service Medicaid was required to cover certain tobacco-cessation services but generally not required to cover preventive care without copayment; Medicaid expanded under the ACA was required to cover preventive services recommended by the USPSTF and the Advisory Committee on Immunization Practices (ACIP) or supported by the Health Resources and Services Administration (HRSA) without cost-sharing.

The elimination of cost-sharing for preventive services is intended to reduce financial barriers for breast, cervical,
colorectal and lung cancer screenings, genetic counseling and testing for \textit{BRCA} mutations, HPV vaccination, smoking cessation, and obesity counseling among eligible individuals. Before this provision, out-of-pocket costs could prevent individuals from receiving these recommended services. For example, for colonoscopy, which cost >$2000 in 2008, Medicare enrollees were responsible for up to 20% of allowable charges, and the privately insured could be responsible for a range of cost-sharing.\footnote{43} According to an estimate from the NHIS, approximately 86.8 million adults covered by private insurance, 41.5 million covered by Medicare, and 10.1 million covered by Medicaid were age-eligible for at least one type of cancer screening in 2009 and could have benefited from reduced financial barriers via this provision. However, some plans do not provide coverage for diagnostic care or other follow-up services if a preventive screening shows something abnormal, and there can be complexity in distinguishing screening care from diagnostic care, which could entail substantial out-of-pocket costs.\footnote{44} For example, women may face substantial out-of-pocket costs for diagnostic mammograms after an abnormal screening test.\footnote{45}

**Closing of the Medicare Part D Donut Hole**

Medicare beneficiaries without private supplemental insurance can receive oral prescription drug coverage through Medicare Part D, in which private plans contract with the Medicare program to provide the drug benefits. The Medicare Part D donut hole, also known as the Part D coverage gap, refers to the point at which prescription drug expenses exceed the initial coverage limit of the plan but have not yet reached the catastrophic coverage level, when prescription drug costs are once again covered (Fig. 3).\footnote{46,47} Before the ACA, once in the coverage gap, patients paid 100% of their medication costs, as opposed to 25% coinsurance before the donut hole for standard plan designs and 5% after the donut hole.\footnote{46} Starting in 2011, the ACA has required incremental Part D benefit design changes annually to reduce the cost-sharing for beneficiaries while in the donut hole.\footnote{48} As of 2019, Part D enrollees pay 25% of the cost of brand-name drugs and 37% of the cost of generic drugs once in the donut hole.\footnote{48} By 2020, enrollees with standard plan designs will pay 25% of all drug costs until they reach the catastrophic coverage level.\footnote{48}

Earlier research found that about one-fourth of Medicare beneficiaries reached the donut hole in 2007,\footnote{49} of whom about 20% skipped or took less medications because of cost.\footnote{50,51} It was estimated that about 3.4 million Medicare Part D enrollees reached the coverage gap and faced the full cost of their prescriptions in 2007 who potentially could benefit from the provision.\footnote{49} Patients with cancer and survivors are more likely to reach the donut hole because they tend to have a higher need for prescription drugs than adults without a cancer history. More important, the use of orally administered, expensive anticancer medications has increased rapidly,\footnote{52} imposing a financial burden on patients. This provision also benefits those taking raloxifene or other drugs for cancer prevention. With various chronic conditions common among cancer survivors, such as cardiovascular diseases and diabetes,\footnote{53} this provision may also improve their adherence to other long-term medication use for chronic conditions.

![FIGURE 3. Medicare Part D Benefit Design Before and After the Closing of the Part D Donut Hole. Medicare Part D Benefit Design is illustrated (A) before 2011 and (B) in 2020.](image-url)
Coverage of Routine Care Costs During Clinical Trial Participation
Before the ACA, routine care costs during clinical trial participation (defined as all items and services that the payer would cover for a patient not enrolled in a clinical trial, including hospital visits, imaging, laboratory tests, and medications) were covered by Medicare but were not consistently covered by other health insurance plans under federal and state regulations. As of January 1, 2014, the ACA required private health insurance plans to cover routine care costs for clinical trials.

Coverage of routine care costs during clinical trial participation is intended to increase clinical trial enrollment overall and potentially reduce disparities in participation and improve generalizability of trial results. Because clinical trials are the gold-standard approach for testing the efficacy of new prevention, screening, and treatment interventions for cancer, enrollment and participation of eligible patients in trials is critical. Enrollment in clinical trials has played an important role in improving the 5-year survival rate to >80% for patients with childhood cancers. However, from 2000 to 2009, <5% of adult patients with cancer enrolled in clinical trials in the United States, and the high out-of-pocket costs were recognized as an important barrier, even among those with insurance coverage. In addition, vulnerable populations, such as racial/ethnic minorities, women, the elderly, and people with lower income, were less likely to enroll in cancer clinical trials.

Use of Adjusted Community Rating and Elimination of Preexisting Condition Exclusion
Before the ACA, health insurers in most states frequently priced insurance premiums based on factors such as sex, occupation, and medical history, and they could even deny coverage or decline claims for persons with preexisting health conditions. Starting January 1, 2014, the ACA has required non-grandfathered health plans to use an “adjusted community rating” to set premiums, in which they can price insurance by pooling policyholders within a geographic area into a single risk pool and set premiums based on only 4 factors: family size, age, geographic area, and tobacco use.

More specifically, the ACA prohibits denials of coverage, increases of premiums, or declining of claims for people with preexisting conditions for non-grandfathered health plans. In contrast, tobacco users may face up to 50% higher premiums (tobacco premium surcharge) than nonsmokers under the Marketplace. The use of adjusted community rating and elimination of the preexisting condition exclusion are intended to protect patients, including patients with cancer and cancer survivors, from coverage denials or substantial out-of-pocket costs. It was estimated that out-of-pocket spending would triple among those with cancer from 2014 to 2016 if preexisting conditions were excluded from coverage. Meanwhile, these provisions may also minimize the risk of job lock for patients with cancer and cancer survivors.

Payment and Delivery System Reform
The ACA also contains components that catalyze health care payment and delivery system reforms with the “Triple Aim”: improving quality of care, reducing health care costs, and improving patient outcomes. Historically, the United States has used a fee-for-service health care payment model, in which separate payments are made to providers for each individual service during the course of all treatments. The fee-for-service model incentivizes a greater volume of services, regardless of the quality and costs of care or patient outcomes. Payment reforms under the ACA seek to shift reimbursement away from traditional fee-for-service care to value-based care through better care coordination and elimination of duplicative services. Established under the ACA, the Center for Medicare & Medicaid Innovation (CMMI) has developed and tested new payment and service delivery models to evaluate results and advance best practices. Delivery models include patient-centered medical homes, accountable care organizations (ACOs), and episode-based payment models. All these types of models can affect the receipt of cancer prevention, screening, diagnosis, treatment, and survivorship care; few are specific to cancer care.

Essential Health Benefits
Beginning in January 2014, the ACA required non-grandfathered individual and small group health plans to cover 10 categories of essential health benefits, including: 1) ambulatory patient services, 2) emergency services, 3) hospitalization, 4) maternity and newborn care, 5) mental health and substance use disorder services including behavioral health treatment, 6) prescription drugs, 7) rehabilitative and habilitative services and devices, 8) laboratory services, 9) preventive and wellness services and chronic disease management, and 10) pediatric services, including oral and vision care.

Several categories of the essential health benefits are closely related to access to care across the cancer control continuum. For instance, coverage for preventive services will likely improve cancer screening, and coverage for prescription drugs will likely reduce the financial burden on patients with cancer from the high cost of medication and reduce drug nonadherence. Other health benefits, such as coverage for hospitalization, mental health, rehabilitative and habilitative services and devices, laboratory services, and emergency services, will also improve access to cancer care directly or indirectly.
Patient-Centered Medical Homes
The patient-centered medical home is a model of the organization of primary care that delivers the core functions of primary health care through a coordinated medical home. One cancer-relevant example is the Community Oncology Medical Home (COME HOME) initiative, which has been supported by Health Care Innovation Awards from the CMMI. The COME HOME initiative offers a series of services, including patient education and counseling, team-based care, and enhanced patient access, to improve the quality and outcomes of health care.

Accountable Care Organizations
Another type of service delivery model is the Accountable Care Organization (ACO), which was developed before the ACA by the Center for Medicare & Medicaid Services. An ACO is a network of physicians, hospitals, and other health care providers who share medical and financial risks by providing coordinated care to Medicare fee-for-service beneficiaries. Under an ACO, a group of providers is eligible to share the resulting savings if it meets quality standards. Although there are no cancer-specific ACOs, they may have effects across the cancer control continuum because of the substantial and growing program enrollment.

Bundled Payment Models
Another type of payment reform under the CMMI is the episode-based or bundled payment model, in which providers receive a fixed payment for all the services performed to treat a patient during a specific episode of care. The Oncology Care Model (OCM), a bundled payment model provides per-patient per-month payments over a 6-month episode while Medicare beneficiaries are receiving cancer treatment. The goal of the OCM is to incentivize better coordinated care in participating practices through patient navigation, provision of treatment summaries, and using data for continuous quality improvement. As of 2019, 176 oncology practices in 34 states that have Medicare providers and furnish chemotherapy are participating in the OCM. Participation requirements include providing enhanced services, such as patient access 24 hours a day, 7 days a week, the use of certified electronic health record technology, and the use of data to drive continuous quality improvement. The OCM was officially launched on July 1, 2016, and evaluations of the OCM and other payment models are ongoing.

Overview of Research Addressing the ACA and Cancer Care
In this section, we highlight selected, well designed studies addressing the effects of the ACA on health insurance coverage and access to care throughout the cancer control continuum and on cancer-related health outcomes.

Health Insurance Coverage Expansion
To evaluate the effects of health insurance coverage expansion provisions on insurance coverage and access to care throughout the cancer control continuum, a difference-in-differences (DID) approach has frequently been used to assess changes in study outcomes in an expansion-eligible population, or the intervention group, from the pre-ACA period to the post-ACA period, using the corresponding changes in a noneligible population as a control group. The DID approach is considered a quasiexperimental design and it incorporates any secular trends that can affect care in both the intervention and control populations (Fig. 4).

Dependent coverage expansion
Studies conducted in the general population have shown that the DCE increased health insurance coverage among young adults aged 19 to 25 years. According to an estimate from the NHIS, the percentage of uninsured adults aged 19 to 25 years decreased from 34% in 2010 to 20% in 2014. Several studies have examined the effects of DCE on HPV vaccination and receipt of Pap testing. A study based on NHIS data from 2008 to 2012 reported that the percentages of HPV vaccine initiation and completion increased 6.8 and 4.3 percentage points (ppt), respectively, among women aged 19 to 25 years; with greater increases of 7.7 and 5.8 ppt, respectively, compared with those aged 18 or 26 years. Another study using data from the 2009 to 2012 Medical Expenditure Panel Survey, a nationally representative
Several studies evaluated the effects of DCE on health insurance coverage among young adult patients with newly diagnosed cancer. Overall, DCE was generally associated with an increase in insurance coverage. For example, an earlier study using data from 2007 to 2012 in the Surveillance, Epidemiology, and End Results (SEER) cancer registry program showed that patients aged 19 to 25 years with cancer had a 1.4-ppt decrease in the percentage of uninsured and a 2.0-ppt net reduction compared with those aged 26 to 34 years after DCE. Another study using the SEER data from 2007 to 2012 found that patients aged 18 to 25 years with cancer had a 3.1-ppt net increase in the percentage of being insured compared with those aged 26 to 29 years. Another earlier study using data from 2003 to 2015 in the National Cancer Database (NCDB), a nationwide, hospital-based cancer registry, showed that private insurance among patients with newly diagnosed cancer aged 19 to 25 years increased by 0.5 per quarter after the DCE, and Medicaid coverage for those aged 19 to 25 years and 27 to 34 years increased after the 2014 Medicaid expansion.

Studies also found that DCE was associated with an earlier stage of cancer diagnosis among young adult patients. For example, a study using NCDB data from 2007 to 2012 found a 5.5-ppt decrease in late-stage (stages III/IV) cervical cancer diagnosis for women aged 21 to 25 years after the DCE and a net decrease of 7.3 ppt in late-stage diagnosis compared with those aged 26 to 34 years. By using SEER data from 2007 to 2012, another study found a 2.7-ppt increase in diagnosis at stage I disease for patients aged 19 to 25 years compared with those aged 26 to 34 years for all cancers combined. Analyses by cancer site showed that the DCE was associated with earlier stage of cervical cancer and osseous and chondromatous neoplasms at diagnosis, both of which are detectable by either screening or clinical manifestation.

A few studies focused on the effects of DCE on cancer treatment. Some of these studies suggested that DCE improved access to treatment. For example, an earlier study using NCDB data from 2007 to 2012 found an increase of 12.8 ppt in the receipt of fertility-sparing treatments among patients with cervical cancer aged 21 to 25 years and a net increase of 13.4 ppt compared with those aged 26 to 34 years. Another recent study using NCDB data from the 2007 to 2013 found that patients aged 19 to 25 years with stage IIB through IIIC colorectal cancer (CRC) were more likely to receive timely adjuvant chemotherapy, with no changes observed in the control group (aged 27-34 years). The effect of the DCE on treatment may vary by cancer type and treatment modality. For example, one study using NCDB data from 2007 to 2013 did not find any reduction in time to surgery, chemotherapy, or radiation therapy post-DCE for women with early stage breast cancer aged 19 to 25 years compared with those aged 26 to 34 years. This may be caused in part by the growing use of genetic testing in breast cancer treatment during this period, which can prolong the time between diagnosis and treatment initiation.

**Medicaid expansion**

Earlier studies conducted in the general population have shown that Medicaid expansion increased health insurance coverage among adults aged 18 to 64 years. According to an estimate from the NHIS, the percentage uninsured decreased from 20.4% in 2013, to 16.3% in 2014, and 12.8% in 2015 among adults aged 18 to 64 years.

A few studies examined the association between Medicaid expansion and smoking cessation, which is key to preventing smoking-related cancers, including those of the lung, head and neck, urinary tract, and pancreas. For example, using data from the 2011 to 2015 Medicaid State Drug Utilization Database, which included all states’ data for outpatient prescription medications (initial fills and refills) covered under the Medicaid drug rebate program, for which Medicaid serves as a third-party payer, expansion states experienced a net increase of 89 cessation prescription medication fills and refills per 100,000 nonelderly adults per quarter, or 36%, compared with nonexpansion states after the ACA.

Most earlier studies evaluating the effects of Medicaid expansion on cancer screenings focused on low-income adults, the target population of Medicaid expansion, with various findings across screening types. For example, a study using 2012 and 2016 data from the Behavioral Risk Factor Surveillance System (BRFSS), a nationwide state-based household survey, found that low-income adults in expansion states experienced greater increases in adjusted rates of self-reported colonoscopy and Pap smears compared with those in nonexpansion states, but no significant adjusted DID was observed for mammography use. Another study using 2012, 2014, and 2016 BRFSS data examined up-to-date breast and CRC screening (colonoscopy, sigmoidoscopy, or a stool test) as well as recent CRC screening. Furthermore, it classified expansion status into very early expansion states, early expansion states, and nonexpansion states. The study found that recent CRC screening significantly grew in very early and nonexpansion states, whereas no significant change was observed in early and late expansion states, and a 4.9-ppt net increase in recent CRC screening was observed in very early expansion states compared with nonexpansion states. These results suggest that...
large-scale improvements in CRC screening may take time after expansion. No net increases were observed in breast cancer screening in expansion states compared with nonexpansion states, and the authors hypothesized that the lack of increase in breast cancer screening may be attributed to widely conducted mammography support programs among uninsured low-income populations, such as the Centers for Disease Control and Prevention’s Breast and Cervical Cancer Early Detection Program.

A substantial body of research has demonstrated that Medicaid expansion is associated with coverage gains among patients aged 18 to 64 years who have newly diagnosed cancer.\textsuperscript{88-90} For example, a study using NCDB data from 2011 to 2014 found a 3.3-ppt net reduction in the percentage uninsured and an 8.8-ppt net increase in the percentage with Medicaid coverage in Medicaid expansion states compared with nonexpansion states.\textsuperscript{88} The findings were similar in another study using population-based cancer incidence data for the period from 2010 to 2014 for 40 states participating in the North American Association of Central Cancer Registries (NAACCR). The study indicated that uninsured patients decreased from 5.2% to 2.6% in Medicaid expansion states and decreased from 8.7% to 7.8% in nonexpansion states, with Medicaid expansion states experiencing a 1.3-ppt net reduction in the percentage uninsured compared with nonexpansion states.\textsuperscript{89} Another study based on SEER data from 2010 to 2014 for 13 states found a 2.4-ppt net reduction in the percentage uninsured associated with Medicaid expansion.\textsuperscript{90}

Among patients with newly diagnosed cancer, 2 of the above studies also examined the effects of Medicaid expansion on cancer stage at diagnosis. The study using NCDB data from 2011 to 2014 found a small but significant shift toward early stage (stage I) at diagnosis for cancers with evidence-based screening tests or cancers amenable to early symptom assessment, including cancers of the colorectum, lung, and female breast, melanoma, as well as pancreatic cancer, in expansion states; however, the shift was not significantly greater compared with that in nonexpansion states.\textsuperscript{88} Another study using population-based cancer incidence data from 2010 to 2014 in NAACCR reported increased early stage (stages 0 and I) diagnoses in Medicaid expansion states for most cancer types and found a net increase (0.4 ppt) in earlier stage diagnosis for all selected cancers combined associated with Medicaid expansion.\textsuperscript{89} Similarly, another study based on SEER data from 2010 to 2014 also found that Medicaid expansion was associated with a net increase in early stage (in situ, local, or regional) diagnoses of 15.4 per 100,000 population, or 6.4%, for all cancers combined.\textsuperscript{91}

Coverage gains were also observed in cancer survivors. For example, a study using data from 2011 to 2017 in the BRFSS found that the percentage uninsured among cancer survivors decreased from 13.1% to 7.7% in Medicaid expansion states between 2013 and 2014 and continued to decrease in 2015 to 5.5%. Overall, the percentage uninsured among cancer survivors decreased from 12.8% pre-ACA to 6.0% post-ACA in expansion states and decreased from 18.2% pre-ACA to 13.4% post-ACA in nonexpansion states, with a 1.8-ppt net decrease associated with Medicaid expansion.\textsuperscript{92} Similar findings were reported elsewhere, with greater declines in the percentage uninsured among low-income cancer survivors.\textsuperscript{93}

A few studies evaluated Medicaid expansion and health care delivery and affordability among cancer survivors and found that Medicaid expansion was associated with declines in problems affording care. For example, the study using BRFSS data from 2011 to 2017 found that the percentage of cancer survivors who could not afford to see a physician in the past 12 months decreased 5.6 ppt in expansion states and 2.6 ppt in nonexpansion states, resulting in a 2.9-ppt net decrease in reporting care unaffordability associated with Medicaid expansion after adjusting for sociodemographic factors.\textsuperscript{92} Similarly, another study using BRFSS data from 2011 to 2015 also found that Medicaid expansion was related to decreases in reporting care unaffordability as well as medication unaffordability.\textsuperscript{96}

Several studies also evaluated the effects of Medicaid expansion on health disparities among screening-eligible adults as well as those diagnosed with cancer. For example, the study using BRFSS data from 2012, 2014, and 2016 found that differences in CRC screening prevalence between groups with low annual income (<$25,000) and medium-to-high annual income (≥$25,000) narrowed in very early, early, and nonexpansion states, but the greatest narrowing occurred in very early expansion states.\textsuperscript{87} Another study using NCDB data from 2011 to 2014 found that the difference in the percentage uninsured between low-income (≤138% FPL) and high-income (>400% FPL) patients with cancer narrowed in expansion states, whereas it remained stable in nonexpansion states.\textsuperscript{88} The study based on NAACCR data from 2010 to 2014 found that disparities in the percentage uninsured by race/ethnicity, poverty, and rurality diminished or were eliminated among patients with newly diagnosed cancer in expansion states and remained stable among those in nonexpansion states, highlighting the promising role of Medicaid expansion in reducing disparities among sociodemographic subpopulations. Among cancer survivors aged 18 to 64 years, the study using BRFSS data from 2011 to 2017 found that the reductions in disparities of noninsurance and care unaffordability by sociodemographic factors, such as sex, income, employment, and the number of comorbidities, were larger in Medicaid expansion states than in nonexpansion states.\textsuperscript{92}

**Establishment of the Marketplace**

Current research on ACA coverage expansion and cancer care has mainly focused on DCE and Medicaid expansion,
without specifically examining the Marketplace. The findings in nonexpansion states, generally serving as the control in Medicaid expansion studies, can be used to infer the changes from the establishment of the Marketplace after the ACA implementation. For example, the study using NCDB data from 2011 to 2014 found that, in nonexpansion states, the percentage uninsured among patients with newly diagnosed cancer decreased from 9.4% to 7.7%, and the percentage covered by private insurance increased from 69.0% to 70.8%, indicating that the establishment of the Marketplace was associated with an increase in coverage.

Health Insurance Coverage Reform

In this section, we highlight selected, well designed studies that examined the effects of health insurance coverage reform on access to cancer care. We selected studies based on generalizability of findings and appropriate study design.

Elimination of cost-sharing for preventive services

Studies focusing on the elimination of cost-sharing and cancer screening showed inconsistent findings for both private insurance and Medicare beneficiaries. For example, a study using NHIS data from 2008 and 2013 found that, after implementation of the provision in 2011, the CRC screening prevalence increased by 5.9 ppt and 9.8 ppt for Medicare beneficiaries with or without private supplemental coverage, respectively. In addition, increases in mammography use were only observed among Medicare beneficiaries with private supplemental coverage but not for those without supplemental coverage. In contrast, studies based on Medicare claims data from 2009 to 2012 reported an increase in mammography uptake but little change for colonoscopy after the provision eliminating cost-sharing for preventive services. For the privately insured, inconsistent findings were also reported. For example, a study based on Medical Expenditure Panel Survey data from 2007 to 2014 showed 3.1-ppt and 4.7-ppt decreases in Pap smear and mammography use, respectively, among those who were privately insured after the provision, whereas little increase was observed in other studies.

The inconsistent findings on the cost-sharing provision and the use of cancer screening could be partially explained by the change in guideline recommendations to less frequent screening and later starting age for cervical and breast cancer screening around the same period of the ACA, which might have offset the effects of the provision. In addition, the unexpected expenses after an abnormal screening test may discourage screening and counteract the intended effects of the elimination of cost-sharing for screening services, which brought additional complexity to interpretation of the studies. The cost-sharing for cancer screenings might already have been covered before the ACA by some health plans, other screening programs, or the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. Moreover, most studies did not distinguish grandfathered policies, which were not subject to this provision, from other private plans. Screening also might not be a priority for people who just recently gained health insurance coverage. Other factors, such as limited years of data and health insurance literacy on screening, might also lead to the inconsistent findings.

Closing of the Medicare Part D donut hole

Studies conducted in the general population have found that closing the Medicare Part D donut hole reduced out-of-pocket spending for prescription drugs for Part D beneficiaries, especially for those who fell into the doughnut hole. On the basis of drug information from the Medicare July 2014 Prescription Drug Plan Formulary from the Centers for Medicare & Medicaid Services, one study projected the changes in out-of-pocket costs for existing orally administered anticancer medications before and after the Medicare Part D donut hole began closing. That study indicated that this provision would lead to a savings of approximately $2550 each year after the donut hole is fully closed in 2020; but the median annual out-of-pocket cost would still be up to $5663 across all insurance products. However, we found no studies addressing the effects of the provision to close the donut hole among patients with cancer and survivors.

Coverage of routine care costs for clinical trial participants

To date, the effects of coverage of routine care costs for clinical trial participants on trial enrollment and completion have not been evaluated directly. However, a few studies have assessed the effects of the clinical trial coverage provision in oncology on intermediate outcomes, such as health insurance clearance (a process to determine whether the patient’s health insurance qualifies for clinical trial coverage) or denial, and reported mixed findings. On the basis of data from a single clinical center, the percentage of health insurance clearance for patients with cancer who were being considered for clinical trials during 2012 through 2015 increased, and the likelihood of prolonged clearance lowered, after the clinical trial coverage provision in 2014. However, another study using data from 252 cancer research centers and community-based institutions showed that insurance denials and delays continued after the ACA provision.

Essential health benefits

To date, no studies have been conducted to examine the effects of the addition of the essential health benefits provision on cancer care.

Use of adjusted community rating and elimination of preexisting condition exclusion

To date, no studies have been conducted to examine the effects of the use of adjusted community rating and the elimination of preexisting condition exclusion on cancer care.
Studies focusing on the tobacco premium surcharge under the ACA Marketplace found a decline in insurance coverage or a lack of affordable coverage among tobacco users, whereas no significant increase in smoking cessation was observed among those living in states with a tobacco surcharge compared with those living in states with no tobacco surcharge. This may be because cessation is much more difficult as a behavior change than getting a screening test. Alternatively, putting a “price” on smoking can alleviate the guilt of engaging in it.

**Payment and Delivery System Reform**

Several studies have evaluated the effects of payment and delivery system reforms in the general population, and evaluations of outcomes and spending typically are conducted by comparing patients attributed to participating practices with similar patients treated in the fee-for-service setting before and after model implementation. However, only a few studies have examined the effects of payment and delivery system reform on access and cost of cancer care. The COME HOME model, which is a medical home program implemented in community oncology practices aimed at improving quality of care and patient outcomes and reducing care cost, is associated with lower likelihood of emergency department visits and spending for patients with any of 7 cancer types, especially at the end of life. An early evaluation of the OCM during the first performance period compared volunteer practices with propensity score-matched control practices before and after implementation using a DID approach. That study found small declines in intensive care unit admissions and emergency department use, with significantly lower use in the last 30 days of life. Spending per episode did not differ significantly. Additional evaluation of payment models and the OCM is ongoing.

**Future Research Directions for the ACA and Cancer Care**

Many studies have examined the effects of the ACA on access to cancer care, as highlighted in the sections above. Nevertheless, substantial research gaps remain. In this section, we review emerging issues and changes related to the ACA and cancer care and highlight research gaps.

**Continued Monitoring of the Effects of the ACA**

To date, research on the ACA and cancer care has mainly focused on the DCE, Medicaid expansion, and elimination of cost-sharing for preventive services on cancer care and outcomes. Few studies have assessed the effects of other provisions, such as the establishment of the Marketplace, closing of the Medicare Part D donut hole, and payment and delivery system reforms (Table 3). For example, little is known about the effects of the Marketplace, which covered about 8 to 12 million individuals each year during 2014 through 2019, on access to cancer prevention and screening, care, and outcomes. Notably, this provision is likely to have far-reaching effects for patients with cancer and survivors because ACA-compliant insurers are no longer allowed to deny coverage or set higher premiums because of their preexisting medical conditions. Future studies should

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**TABLE 3. Research Gaps in Understanding the Effects of the Affordable Care Act on Cancer Care**

| COMPONENT PROVISION | COMPONENT OF THE CANCER CONTROL CONTINUUM* |
|---------------------|------------------------------------------|
|                     | PREVENTION | SCREENING | DIAGNOSIS | TREATMENT | SURVIVORSHIP | END-OF-LIFE CARE |
| Health insurance expansion | + | + | ++ | +++ | +++ | +++ |
| Medicaid expansion | + | + | ++ | +++ | +++ | +++ |
| Dependent coverage expansion | +++ | +++ | +++ | +++ | +++ | +++ |
| Establishment of the Marketplace | +++ | +++ | +++ | +++ | +++ | +++ |
| Health insurance coverage reform | Elimination of cost-sharing for preventive services | + | + | +++ |
| Coverage of routine care costs for clinical trial participants | +++ | +++ | +++ | +++ | +++ | +++ |
| Closing of the Part D donut hole | +++ | +++ | +++ | +++ | +++ | +++ |
| Essential Health Benefits | +++ | +++ | +++ | +++ | +++ | +++ |
| Payment and delivery system reform | +++ | +++ | +++ | +++ | +++ | +++ |

*Note: + indicates the area is relatively well-studied. ++ indicates the area had been studied but the results were inconsistent, and more research are needed. +++ indicates few studies had been done.
monitor plan enrollment under the Marketplace and should examine the effects of the patient protections, including the preexisting conditions provision, on health insurance coverage, premiums, patient cost-sharing, and the ban on annual and lifetime limits.

The stated goals of the ACA are to improve health insurance coverage, the quality of care, and patient outcomes, and to maintain or lower costs. However, to date, most studies have focused on improvements in insurance coverage, prevention, screening, and stage at diagnosis, with few studies on other structure and process quality-of-care measures, patient outcomes such as treatment and survival, and costs, in part because of the limited years of data after the ACA. For example, for those provisions implemented in 2014, 5-year relative survival rates among patients who were diagnosed with cancer after the ACA are not yet available. As data post-ACA continue to mature, assessing the ACA's effects on access to cancer treatment and survival will be critical. In addition, only a few studies have focused on the ACA and genetic testing and smoking cessation to date. Ongoing evaluation will be important.

Most earlier studies focused on the effects of only a single provision of the ACA on coverage gains in the early years after implementation. Several studies have suggested that large-scale changes in care may require longer duration of implementation. Ongoing monitoring of the long-term effects of all ACA provisions will be important. In addition, understanding the differential and synergistic effects of multiple provisions is limited. One study evaluating the effect of both DCE and Medicaid expansion on insurance coverage among young adult patients with newly diagnosed cancer found that, although private insurance coverage increased incrementally after the DCE, an immediate gain in Medicaid coverage was observed after Medicaid expansion. Improvement in health insurance coverage and access to care could be caused by multiple provisions. For example, young females living in expansion states could benefit from DCE, Medicaid expansion, and cost-sharing provision at the same time and have an improved access to cervical cancer screening. Understanding how these policies interact with other social determinants of health will be an important area for study.

Health Insurance Coverage Disruptions and Shifts Under the ACA

To date, most research evaluating the effects of the ACA has focused on coverage gains, and little has examined the potential effects of the ACA on coverage disruptions, which are associated with worse access to cancer care and outcomes. Several provisions under the ACA aiming at improving coverage may also help facilitate coverage continuity.

Similarly, concerns have been raised about the coverage shifts under the ACA, as a shift in health plan may require additional enrollment process time and cause delayed or forgone care. A prior study has shown that about 50% (or 28 million adults) of adults in the United States with income below 200% of the FPL are likely to have at least one income fluctuation that will lead to a shift between Medicaid and the Marketplace within 1 year.

Health Insurance Literacy Related to the ACA

With the growing numbers of newly insured individuals under the ACA, concerns have been raised about health insurance literacy and the ACA among the reform beneficiaries. Low health insurance literacy has been shown to impede access to care in the general population. Future studies evaluating the effects of different provisions, coverage disruptions and plan shifts, and health insurance literacy and plan enrollment on access to cancer care are warranted.

Emerging Health Policy Issues

Since implementation of the ACA, emerging policy issues may challenge the observed improvements in health care. Proposed Medicaid changes such as work requirements, which impose work as a requirement of Medicaid eligibility, have been implemented or approved in 17 states as of November 2019. These changes may cause Medicaid disenrollment and impede access to care throughout the cancer control continuum. State decisions in Medicaid expansion may widen existing disparities by state expansion status in health insurance coverage and exacerbate the inequalities in access to care and cancer outcomes. A coverage gap for adults who are ineligible for Medicaid and Marketplace subsidies also remains in nonexpansion states. The emerging high-deductible health plans, which represent 30% of employer-sponsored health plans and approximately 90% of Marketplace plans in 2019, are gradually changing the US health insurance landscape. High-deductible health plans may also lead to less frequent use of cancer screening and delaying or forgoing care because of cost. Currently, only 10 states and the District of Columbia have policies that require Medicaid coverage of routine medical care costs because of clinical trial participation, potentially limiting access for patients with cancer in the remaining 40 states. Narrow networks, which were designed to control care costs through providing enrollees access only to a small set of physicians and providers, are common in the Marketplace, representing >50% of the Marketplace plans. Narrow networks may limit access to care for enrollees or impose high cost-sharing if they choose providers outside of their networks because insurance benefits under the ACA, such as annual limits on patients' out-of-pocket spending and prohibition of annual and lifetime caps, are only applied to in-network services. Short-term health plans, which do not have to cover ACA-mandated “essential health benefits,”
such as prescription drugs and preventive care, also are not required to comply with the preexisting condition provision or lifetime and annual limits. Because the ACA mandate penalty was repealed effective 2019, purchasing of short-term plans as a lower premium option is likely to increase, adversely affecting the Marketplace established by the ACA. These plans may limit access to preventive and cancer care, leading to higher risks of out-of-pocket costs burden. To understand how emerging policy issues will affect health insurance coverage and access to cancer care, ongoing surveillance of the effects of these changes on insurance coverage is needed. Future research should also focus on the subsequent effects throughout the cancer control continuum.

Conclusions
In this review, we described key ACA provisions and highlighted selected well-designed studies examining the effects of these provisions on health insurance coverage and access to health care throughout the cancer control continuum. We highlighted research gaps and discussed emerging policy issues and challenges for the ACA. Findings from earlier studies suggested that the ACA has improved health insurance coverage, receipt of prevention and screening services, and early stage diagnosis. Knowledge gaps on the effects of the ACA on access to cancer treatment and survival, quality of cancer care, and costs remain and should be addressed with the maturation of cancer data post-ACA. Furthermore, ongoing research on existing and emerging policy issues will inform future efforts to improve cancer outcomes and reduce disparities in the United States.

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References
1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2020. CA Cancer J Clin. 2020; 70:7-30.
2. American Cancer Society. Cancer Prevention & Early Detection Facts & Figures 2019-2020. American Cancer Society; 2019.
3. Miller KD, Nogueira L, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2019. CA Cancer J Clin. 2019;69:363-385.
4. Bluethmann SM, Mariotto AB, Rowland JH. Anticipating the “Silver Tsunami”: prevalence trajectories and comorbidity burden among older cancer survivors in the United States. Cancer Epidemiol Biomarkers Prev. 2016;25:1029-1036.
5. Agency for Healthcare Research and Quality. Patient-Centered Medical Home Resource Center. Accessed December 24, 2019. pcmh.ahrq.gov/page/defining-pcmh
6. Gilbert J. The Uninsured Across the OECD Countries and U.S. States. Accessed February 6, 2020. theincidentalonomist.com.wordpress/wp-content/uploads/2015/06/OECD-Uninsured.pdf
7. Cohen RA, Martinez ME, Ward BW. Health insurance coverage: early release of estimates from the National Health Interview Survey, 2009. National Center for Health Statistics, Centers for Disease Control Prevention; 2009.
8. American Cancer Society Cancer Action Network. Cancer Disparities: A ChartBook. American Cancer Society; 2009. Accessed November 29, 2019. fightcancer.org/sites/default/files/National%20Documents/Disparities-in-Cancer-Chartbook.pdf
9. Ward E, Halpern M, Schrag N, et al. Association of insurance with cancer care utilization and outcomes. CA Cancer J Clin. 2008;58:9-31.
10. Halpern MT, Ward EM, Pavluck AL, Schrag NM, Bian J, Chen AV. Association of insurance status and ethnicity with cancer stage at diagnosis for 12 cancer sites: a retrospective analysis. Lancet Oncol. 2008;9:222-231.
11. Organisation for Economic Cooperation and Development (OECD). Health at a Glance 2019: OECD Indicators. OECD Publishing, 2019. Accessed December 24, 2020. oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-19991312
12. Leopold C, Park ER, Nekhlyudov L. The impact of the Affordable Care Act on cancer survivorship. Cancer J. 2017;23:181-189.
13. Bailes JS, Kamin DY, Foster SE. The Patient Protection and Affordable Care Act: exploring the potential impact on oncology practice. Cancer J. 2010;16:588-592.
14. Collins BL, Saylor J. The Affordable Care Act: where are we now? Nursing. 2018;48:43-47.
15. Graves JA, Swartz K. Effects of affordable care act marketplaces and Medicaid eligibility expansion on access to cancer care. Cancer J. 2017;23:168.
16. Brooks GA, Hoverman JR, Colla CH. The Affordable Care Act and cancer care delivery. Cancer J. 2017;23:163-167.
17. Parikh RB, Wright AA. The Affordable Care Act and end-of-life care for patients with cancer. Cancer J. 2017;23:190-193.
18. Sabik LM, Adunlin G. The ACA and cancer screening and diagnosis. Cancer J. 2017;23:151-162.
19. Han X, Jemal A. The Affordable Care Act and cancer care for young adults. Cancer J. 2017;23:194-198.
20. Dixon MS, Cole AL, Dusetzina SB. Out-of-pocket spending under the Affordable Care Act for patients with cancer. Cancer J. 2017;23:175-180.
21. National Center for Health Statistics. Health, United States, 2008: With Special Feature on the Health of Young Adults. US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics; 2009. Accessed February 6, 2020. cdc.gov/nchs/data/hus/hus08.pdf
22. National Center for Health Statistics. Survey Description, National Health Interview Survey, 2018. Division of Health Interview Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, US Department of Health and Human Services; 2019.
23. Heron M. Deaths: Leading Causes for 2017. National Vital Statistics Reports. Vol. 68 no. 6. National Center for Health Statistics. 2019.
24. Barr RD, Ries LA, Lewis DR, et al. Incidence and incidence trends of the most frequent cancers in adolescent and young adult Americans, including “non-malignant/noninvasive” tumors. Cancer. 2016;122:1000-1008.
25. Keegan TH, Ries LA, Barr RD, et al. Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. *Cancer*. 2016;122:1009-1016.

26. Barr RD, Ferrari A, Ries L, Whelan J, Bleyer WA. Cancer in adolescents and young adults: a narrative review of the current status and a view of the future. *JAMA Pediatr.* 2016;170:495-501.

27. Kaiser Family Foundation. Medicaid Income Eligibility Limits for Parents, 2002-2019. Accessed December 24, 2019. kf.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-parents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22%22Location%22,%22sort%22:%22asc%22%7D

28. Office of The Assistant Secretary for Planning and Evaluation. The 2009 HHS Poverty Guidelines. Accessed December 24, 2019. aspe.hhs.gov/2009-hhs-poverty-guidelines

29. 111th Congress. An Act Entitled The Patient Protection and Affordable Care Act. Public Law 111-148—March 23, 2010. Accessed December 24, 2019. congress.gov/111/plaws/publ114/PLAW-111publ148.pdf

30. Rudowitz R, Artiga S, Arguello R. A Look at Section 1115 Medicaid Demonstration Waivers Under the ACA: A Focus on Childless Adults. Kaiser Family Foundation; 2013.

31. National Federation of Independent Business v. Sebelius: The Patient Protection and Affordable Care Act. *Harvard Law Review*. 2012;126:72-82.

32. Kaiser Family Foundation. Status of State Action on the Medicaid Expansion Decision, updated January 10, 2020. Accessed January 13, 2020. kf.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act

33. Kaiser Family Foundation. Medicaid Income Eligibility Limits for Adults as a Percent of the Federal Poverty Level. Accessed January 13, 2020. kf.org/health-reform/state-indicator/medicaid-income-eligibility-limits-for-adults-as-a-percent-of-the-federal-poverty-level/?currentTimeframe=0&sortModel=%7B%22colId%22:%22%22Location%22,%22sort%22:%22asc%22%7D

34. Scarinci IC, Garcia FA, Kobetz E, et al. Cervical cancer prevention: new tools and old barriers. *Cancer*. 2010;116:2531-2542.

35. Division of Health Interview Statistics, National Center for Health Statistics. Multiple Imputation of Family Income and Personal Earnings in the National Health Interview Survey: Methods and Examples. Division of Health Interview Statistics, National Center for Health Statistics; 2017.

36. Kirchhoff AC, Nipp R, Warner EL, et al. “Job lock” among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *JAMA Oncol.* 2018;4:707-711.

37. Tunceli K, Short PF, Moran JR, Tunceli O. Cancer survivorship, health insurance, and employment transitions among older workers. *Inquiry*. 2009;46:17-32.

38. Trivedi AN, Rakowski W, Ayanian JZ. Effect of cost sharing on screening mammography in Medicare health plans. *N Engl J Med*. 2008;358:375-383.

39. Kaiser Family Foundation. 2018 Employer Health Benefits Survey. Accessed December 24, 2019. kf.org/health-costs/report/2018-employer-health-benefits-survey/

40. Koh HK, Sebelius KG. Promoting prevention through the affordable care act. *N Engl J Med*. 2010;363:1296-1299.

41. American Lung Association. Medicare Coverage for Lung Cancer Screening. Accessed December 11, 2019. lung.org/assets/documents/lung-health/medicare-proposed-decision.pdf

42. Fox JB, Shaw FE. Clinical preventive services coverage and the Affordable Care Act. *Am J Public Health*. 2015;105:e7-e10.

43. Fedewa SA, Goodman M, Flanders WD, et al. Elimination of cost-sharing and receipt of screening for colorectal and breast cancer. *Cancer*. 2015;121:3272-3280.

44. Preventive vs. Diagnostic Medical Services Under the Affordable Care Act. Accessed February 5, 2020. vamedicalplans.com/2014/07/11/preventive-vs-diagnostic-medical-services-under-affordable-care-act/

45. Susan G. Komen for the Cure. Komen on the Cure. Understanding Cost & Coverage Issues with Diagnostic Breast Imaging. Accessed February 11, 2020. www5.komen.org/uploadedFiles/_Komen/Content/What_We_Do/Advocacy/komen-under-standing-cost-coverage-with-dbi-final-report.pdf

46. Centers for Medicare & Medicaid Services. Medicare & You 2019. Department of Health and Human Services; 2019. Accessed February 6, 2020. medicare.gov/sites/default/files/2018-09/10050-medicare-and-you.pdf

47. Kaiser Family Foundation. How will the Medicare Part D benefit change under current law and leading proposals? Accessed January 13, 2020. kf.org/medicare/issue-brief/how-will-the-medicare-part-d-benefit-change-under-current-law-and-leading-proposals/

48. Shrank WH, Choudhry NK. Time to fill the doughnuts—health care reform and Medicare Part D. *N Engl J Med*. 2011;364:598-601.

49. Hoadley J, Hargrave E, Juliette C, Neuman T. The Medicare Part D coverage gap: costs and consequences in 2007. Kaiser Family Foundation; 2008.

50. Soumerai SB, Pierre-Jacques M, Zhang F, et al. Cost-related medication nonadherence among elderly and disabled Medicare beneficiaries: a national survey 1 year before the Medicare drug benefit. *Arch Intern Med.* 2006;166:1829-1835.

51. Gellad WF, Haas JS, Safran DG. Race/ethnicity and nonadherence to prescription medications among seniors: results of a national study. *J Gen Intern Med.* 2007;22:1572-1578.

52. Dusetzina SB, Huskamp HA, Keating NL. Specialty drug pricing and out-of-pocket spending on orally administered anti-cancer drugs in Medicare Part D, 2010 to 2019. *JAMA*. 2019;321:2025-2027.

53. Decks L, van den Akker M, Metsemakers J, Knottnerus A, Schellevis F, Buntinx F. Chronic diseases among older cancer survivors. *J Cancer Epidemiol.* 2012;2012:206414.

54. American Society of Clinical Oncology. Affordable Care Act Provision Requiring Insurance Coverage of Clinical Trials. Accessed January 13, 2020. asco.org/sites/new-www.asco.org/files/content-files/research-and-progress/documents/affordable-care-act-clinical-trials-cover-adequacy.pdf

55. Hunger SP, Lu X, Devidas M, et al. Improved survival for children and adolescents with acute lymphoblastic leukemia between 1990 and 2005: a report from the Children’s Oncology Group. *J Clin Oncol*. 2012;30:1663-1669.

56. Institute of Medicine (US) Committee on Cancer Clinical Trials and the NCI Cooperative Group Program; Nass SJ, Moses HL, Mendelsohn J, eds. A National Cancer Clinical Trials System for the 21st Century: Reinvigorating the NCI Cooperative Group Program. National Academies Press; 2010.

57. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA*. 2004;291:2720-2726.

58. Healthinsuranc.org. Essential health benefits. Accessed December 11, 2019. healthinsurance.org/glossary/essential-health-benefits/
59. Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. J Clin Oncol. 2016;34:259-267.

60. Insperity. Adjusted Community Rating and Its Role in Health Care Costs. Accessed February 5, 2020. insperity.com/blog/adjusted-community-rating-and-its-role-in-health-care-costs/

61. US Department of Health & Human Services. Pre-Existing Conditions. Accessed February 5, 2020. hhs.gov/healthcare/about-the-aca/pre-existing-conditions/index.html

62. Friedman AS, Schpero WL, Busch SH. Evidence suggests that the ACA's tobacco surcharges reduced insurance take-up and did not increase smoking cessation. Health Aff (Millwood). 2016;35:1176-1183.

63. Glied SA, Jackson A. How would Americans' out-of-pocket costs change if insurance plans were allowed to exclude coverage for preexisting conditions? Issue Brief (Communique Fund). 2018;2018:1-9.

64. Yabroff KR, Gansler T, Bender RC, Cullen KJ, Brawley OW. Minimizing the burden of cancer in the United States: goals for a high-performing health care system. CA Cancer J Clin. 2019;69:166-183.

65. Schroeder SA, Frist W. Phasing out fee-for-service payment. N Engl J Med. 2013;368:2029-2032.

66. Center for Medicare & Medicaid Services. Innovation Models. Accessed November 1, 2019. innovation.cms.gov/initiatives/#views=models

67. Kline RM, Brown M, Buescher N, et al. The Centers for Medicare & Medicaid Services Oncology Care Model half-way through: perspectives from diverse participants. J Natl Cancer Inst. 2019;111:764-771.

68. Centers for Medicare & Medicaid Services. Oncology Care Model. Accessed February 6, 2020. innovation.cms.gov/initiatives/Oncology-Care/

69. Brooks GA, Jhatakia S, Tripp A, et al. Early findings from the Oncology Care Model evaluation. J Oncol Pract. 2019;15:e888-e896.

70. Han X, Yabroff KR, Robbins AS, Zheng Z, Jemal A. Dependent coverage and use of preventive care under the Affordable Care Act. N Engl J Med. 2014;371:2341-2342.

71. Wallace J, Sommers BD. Effect of dependent coverage expansion of the Affordable Care Act on health and access to care for young adults. JAMA Pediatr. 2015;169:495-497.

72. Lipton BJ, Decker SL. ACA provisions associated with increase in percentage of young adult women initiating and completing the HPV vaccine. Health Aff (Millwood). 2015;34:757-764.

73. Han X, Zang Xiong K, Kramer MR, Jemal A. The Affordable Care Act and cancer stage at diagnosis among young adults. J Natl Cancer Inst. 2016;108:djw058.

74. Parsons HM, SchmidtS, Tenner LL, Bang H, Keegan TH. Early impact of the Patient Protection and Affordable Care Act on insurance among young adults with cancer: analysis of the dependent insurance provision. Cancer. 2016;122:1766-1773.

75. Nogueira LM, Chawla N, Han X, Jemal A, Yabroff KR. Patterns of coverage gains among young adult cancer patients following the Affordable Care Act. JNCI Cancer Spectr. 2019;3:pkx001.

76. Robbins AS, Han X, Ward EM, Simard EP, Zheng Z, Jemal A. Association between the Affordable Care Act dependent coverage expansion and cervical cancer stage and treatment in young women. JAMA. 2015;314:2189-2191.

77. Nogueira L, Chawla N, Han X, Jemal A, Yabroff KR. Colorectal cancer among young adult patients after the dependent coverage expansion under the Affordable Care Act. J Natl Cancer Inst. Published online December 19, 2019. doi:10.1093/jnci/djz235

78. Han X, Zhao J, Ruddy KJ, Lin CC, Sineshaw HM, Jemal A. The impact of dependent coverage expansion under the Affordable Care Act on time to breast cancer treatment among young women. PLoS One. 2018;13:e0198771.

79. Sommers BD, Gunja MZ, Finegold K, Musco T. Changes in self-reported insurance coverage, access to care, and health under the Affordable Care Act. JAMA. 2015;314:366-374.

80. Miller S, Wherry LR. Health and access to care during the first 2 years of the ACA Medicaid expansions. N Engl J Med. 2017;376:947-956.

81. Cohen RA, Martinez ME. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey. 2013. National Center for Health Statistics; 2014.

82. Cohen RA, Martinez ME. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey. 2014. National Center for Health Statistics; 2015.

83. Cohen RA, Martinez ME, Zammitti EP. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey. 2015. National Center for Health Statistics; 2016.

84. Maclean JC, Pesko MF, Hill SC. The Effect of Insurance Expansions on Smoking Cessation Medication Prescriptions: Evidence From ACA Medicaid Expansions. NBER Working Paper No. 23450. National Bureau of Economic Research; 2017.

85. Koma JW, Donohue JM, Barry CL, Huskamp HA, Jarslenski M. Medicaid coverage expansions and cigarette smoking cessation among low-income adults. Med Care. 2017;55:1023-1029.

86. Hendryx M, Luo J. Increased cancer screening for low-income adults under the Affordable Care Act Medicaid expansion. Med Care. 2018;56:944-949.

87. Fedewa SA, Yabroff KR, Smith RA, Sauer AG, Han X, Jemal A. Changes in breast and colorectal cancer screening following Medicaid expansion under the Affordable Care Act. Am J Prev Med. 2019;57:3-12.

88. Jemal A, Lin CC, Davidoff AJ, Han X. Changes in insurance coverage and stage at diagnosis among nonelderly patients with cancer after the Affordable Care Act. J Clin Oncol. 2017;35:3906-3915.

89. Han X, Yabroff KR, Ward E, Brawley OW, Jemal A. Comparison of insurance status and diagnosis stage among patients with newly diagnosed cancer before vs after implementation of the Patient Protection and Affordable Care Act. JAMA Oncol. 2018;4:1713-1720.

90. Soni A, Sabik LM, Simon K, Sommers BD. Changes in insurance coverage among cancer patients under the Affordable Care Act. JAMA Oncol. 2018;4:122-124.

91. Soni A, Simon K, Cawley J, Sabik L. Effect of Medicaid expansions of 2014 on overall and early-stage cancer diagnoses. Am J Public Health. 2018;108:216-218.

92. Han X, Jemal A, Zheng Z, Sauer AG, Fedewa S, Yabroff KR. Changes in noninsurance and care unaffordability among cancer survivors following the Affordable Care Act. J Natl Cancer Inst. Published online November 5, 2019. doi:10.1093/jnci/djz218

93. Nikpay SS, Tebbs MG, Castellanos EH. Patient Protection and Affordable Care Act Medicaid expansion and gains in health insurance coverage and access among cancer survivors. Cancer. 2018;124:2645-2652.

94. Han X, Yabroff KR, Guy GP Jr, Zheng Z, Jemal A. Has recommended preventive service use increased after elimination of cost-sharing as part of the Affordable Care Act in the United States? Prev Med. 2015;78:85-91.
95. Cooper GS, Kou TD, Schluchter MD, Dor A, Koroukian SM. Changes in receipt of cancer screening in Medicare beneficiaries following the Affordable Care Act. J Natl Cancer Inst. 2016;108:dyw374.

96. Hamman MK, Kapinos KA. Affordable Care Act provision lowered out-of-pocket cost and increased colonoscopy rates among men in Medicare. Health Aff (Millwood). 2015;34:2069-2076.

97. Mehta SJ, Polsky D, Zhu J, et al. ACA-mandated elimination of cost sharing for preventive screening has had limited early impact. Am J Manag Care. 2015;21:511.

98. Hong YR, Jo A, Mainous AG. Up-to-date on preventive services under Affordable Care Act. Med Care. 2017;55:771-780.

99. Cooper GS, Kou TD, Dor A, Koroukian SM, Schluchter MD. Cancer preventive services, socioeconomic status, and the Affordable Care Act. Cancer. 2017;123:1585-1589.

100. US Preventive Services Task Force. Screening for breast cancer: US Preventive Services Task Force recommendation statement. Ann Intern Med. 2009;151:716-726, W-236.

101. Jones RM, Devers KJ, Kuzel AJ, Woolf SH. Patient-reported barriers to colorectal cancer screening: a mixed-methods analysis. Am J Prev Med. 2010;38:508-516.

102. Bonakdar Tehrani A, Cunningham P. Closing the Medicare doughnut hole. Med Care. 2017;55:43-49.

103. Unuigbe A. The Medicare Part D Coverage gap, prescription use, and expenditures. Med Care Res Rev. Published online October 18, 2018. doi:10.1177/10775871806437

104. Dusetzina SB, Keating NL. Mind the gap: prescription use, and expenditures. Med Care. 2015;53:375-380.

105. Kehl KL, Fullmer CP, Fu S, et al. Insurance clearance for early-phase oncology clinical trials following the Affordable Care Act. Clin Cancer Res. 2017;23:4155-4162.

106. Mackay CB, Antonelli KR, Bruinooge SS, Saint Onge JM, Ellis SD. Insurance denials for cancer clinical trial participation after the Affordable Care Act mandate. Cancer. 2017;123:2893-2900.

107. Kaplan CM, Graetz I, Waters TM. Most exchange plans charge lower tobacco surcharges than allowed, but many tobacco users lack affordable coverage. Health Aff (Millwood). 2014;33:1466-1473.

108. Waters TM, Kaplan CM, Graetz I, Price MM, Stevens LA, McAneny BL. Patient-centered medical homes in community oncology practices: changes in spending and care quality associated with the COME HOME experience. J Oncol Pract. 2019;15:e56-e64.

109. Colligan EM, Ewald E, Ruiz S, Spafford M, Cross-Barнет C, Parasharam S. Innovative oncology care models improve end-of-life quality, reduce utilization and spending. Health Aff (Millwood). 2017;36:433-440.

110. Cole AP, Krasnov A, Ramaswamy A, et al. Recommended cancer screening in accountable care organizations: trends in colonoscopy and mammography in the Medicare Shared Savings Program. J Oncol Pract. 2019;15:e547-e559.

111. Resnick MJ, Graves AJ, Gambrel RJ, Thapa S, Buntin MB, Benson DF. The association between Medicare accountable care organization enrollment and breast, colorectal, and prostate cancer screening. Cancer. 2018;124:4366-4373.

112. Kim H, Keating NL, Perloff JN, Hodgkin D, Liu X, Bishop CE. Aggressive care near the end of life for cancer patients in Medicare accountable care organizations. J Am Geriatr Soc. 2019;67:961-968.

113. Lam MB, Zheng J, Orav EJ, Jha AK. Accountable Care organization results in end-of-life spending among cancer patients. J Natl Cancer Inst. 2019;111:1307-1313.

114. Kaiser Family Foundation. Marketplace Enrollment, 2014-2019. Accessed December 24, 2019. kff.org/health-reform/state-indicator/marketplace-enrollment/?activeTab=graph&currentTimeframe=0&startTimeframe=5&sortModel=%7B%22sortId%22:%22Location%22%2C%22sortOrder%22:%22asc%22%7D

115. Bradley CJ, Gardiner J, Given CW, Roberts C. Cancer, Medicaid enrollment, and survival disparities. Cancer. 2005;103:1712-1718.

116. Koroukian SM, Bakaki PM, Raghavan D. Survival disparities by Medicaid status: an analysis of 8 cancers. Cancer. 2012;118:4271-4279.

117. Short PF, Graefe DR, Swartz K, Uberoi N. New estimates of gaps and transitions in health insurance. Med Care Res Rev. 2012;69:721-736.

118. Sommers BD, Rosenbaum S. Issues in health reform: how changes in eligibility may move millions back and forth between Medicaid and insurance exchanges. Health Aff (Millwood). 2011;30:228-236.

119. Kim J, Braun B, Williams AD. Understanding health insurance literacy: a literature review. Fam Consum Sci Res J. 2013;42:3-13.

120. Tipirneni R, Politi MC, Kullgren JT, Kieffer EC, Goold SD, Scherer AM. Association between health insurance literacy and avoidance of health care services owing to cost. JAMA Netw Open. 2018;1:e184796.

121. Sommers BD, Goldman AL, Blendon RJ, Orav EJ, Epstein AM. Medicaid work requirements—results from the first year in Arkansas. N Engl J Med. 2019;381:1073-1082.

122. Kaiser Family Foundation. Employer Health Benefits 2019 Summary of Findings. Accessed February 6, 2020. kff.org/health-costs/report/2019-employer-health-benefits-survey/

123. Wharam JF, Graves AJ, Landon BE, Zhang F, Soumerai SB, Ross-Degnan D. Two-year trends in colorectal cancer screening after switch to a high-deductible health plan. Med Care. 2011;49:865-871.

124. Zheng Z, Jemal A, Banegas MP, Han X, Yabroff KR. High-deductible health plans and cancer survivorship: what is the association with access to care and hospital emergency department use? J Oncol Pract. 2019;15:e957-e968.

125. Zhao J, Zheng Z, Han X, et al. Cancer history, health insurance coverage, and cost-related medication nonadherence and medication cost-coping strategies in the United States. Value Health. 2019;22:762-767.

126. American Society of Clinical Oncology. Insurance Coverage of Clinical Trials. Accessed October 7, 2019. asco.org/research-guidelines/clinical-trials/insurance-coverage-clinical-trials

127. Haeder SF, Weimer DL, Mukamel DB. Narrow networks and the Affordable Care Act. JAMA. 2015;314:669-670.

128. Pollitz K, Long M, Semanskee A, Kamal R. Understanding Short-Term Limited Duration Health Insurance. Kaiser Family Foundation Health Reform; 2018.