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From the Guest Editor: The Affordable Care Act and Cancer Care

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In 2017, more than 1.6 million Americans will be diagnosed with cancer and over 600,000 will die of cancer,¹ making cancer the second leading cause of death in the U.S. With the aging of the population, the number of new cancers is expected to increase to 2.6 million by 2050.² In addition, there are currently more than 15 million cancer survivors living in the U.S.³ Cancer is also costly, with \$124 billion spent on cancer care in 2010; this spending is projected to rise to \$173 billion by 2020.⁴ The substantial spending on cancer care is important both to payers (including federal and state governments who finance Medicare and Medicaid) and to patients, for whom a cancer diagnosis can substantially impact their financial well-being. Out-of-pocket spending is considerably higher for individuals with cancer than for those without cancer,^{5–7} and “financial toxicity” is now recognized as an adverse effect of cancer treatment.⁸ This burden is growing due to new cancer treatments and rising prices of existing treatments^{9,10} and because patients are paying increasing shares of total health care costs.¹¹ In 2010, about one-third of cancer survivors reported cancer-related financial problems, and those who did were substantially more likely than others to report delaying or forgoing needed care.¹² Higher out-of-pocket spending on oral cancer medications, even when monthly copays are modest, is associated with higher rates of discontinuation and nonadherence to effective therapies.¹³ And cancer can have devastating financial impact, with rates of bankruptcy for individuals with cancer 2.65 times that for others.¹⁴ Even more concerning is that bankruptcy among cancer patients is associated with a substantially higher risk of mortality.¹⁵ For these reasons, access to affordable health insurance is particularly important for individuals with a new or previous diagnosis of cancer. The high levels of spending on cancer care also underscore the need for health care delivery system reform that will help to control the growth of health care spending for cancer.

In 2010 the Patient Protection and Affordable Care Act (ACA)¹⁶ was signed into law with a goal of expanding health insurance to the more than 48 million Americans who were uninsured at the time. The ACA reflects the most substantial health insurance expansion in the U.S. since the creation of Medicare and Medicaid in 1965. The law involved an individual mandate requiring individuals without employer-sponsored insurance to purchase insurance or pay a penalty, and it created an insurance exchange where individuals could purchase insurance that covered a set of essential benefits. Subsidies were provided for households with incomes between 100% and 400% of the federal poverty level. In addition,

the law required states to expand Medicaid eligibility to include individuals and families with incomes up to 138% of the federal poverty level, although the Supreme Court later made Medicaid expansion by states voluntary (as of 2017, 31 states and Washington DC have expanded their Medicaid programs). Regulations in the ACA prohibited denying coverage to individuals due to pre-existing conditions, prohibited annual and lifetime coverage caps on essential benefits, and prohibited health plans from setting premiums based on existing health conditions. The law also allowed young adults to remain on their parents' insurance until the age of 26.

The ACA also included provisions whose goal was to make health care more affordable. Most notably, the ACA has prompted a move away from fee-for-service payments in favor of alternative payment models that seek to balance payment with accountability for high-quality care and better patient outcomes. The law created the Center for Medicare and Medicaid Innovation (CMMI) to test alternate payment models and expand them if they are successful. One such model, the Oncology Care Model,¹⁷ focuses specifically on delivery of care to cancer patients undergoing chemotherapy.

This special issue of The Cancer Journal highlights some of the provisions of the ACA that directly affect individuals with cancer. In the first paper, Sabik and Adunlin provide a systematic review of the emerging literature about the effects of the ACA on cancer screening and early diagnosis. Although the evidence is somewhat mixed to date, overall it suggests benefits of the ACA on screening and earlier cancer diagnosis that were greatest among individuals with lower levels of education and income as well as groups with the highest cost barriers to screening before the ACA. Next, Brooks, Hoverman, and Colla review the impact of the ACA on cancer care delivery, including the CMMI's efforts to expand accountable care organizations and oncology patient-centered medical homes and their implementation of the Oncology Care Model. Graves and Swartz reviewed the ACA marketplaces and Medicaid eligibility expansions as well as federal and state rules affecting Medicaid beneficiaries' access to cancer treatments. They conclude that not only have these programs helped to ensure access to cancer treatments for individuals with cancer, but regulations also expand access to clinical trials for patients in ACA health plans. Nevertheless, gaps remain—most notably the lack of coverage for individuals with low incomes living in states that did not expand Medicaid as well as restricted access to oncology experts due to narrow provider networks. Dixon, Cole, and Dusetzina review out-of-pocket spending under the ACA for individuals with cancer. They find early evidence that several provisions of the ACA, including annual caps on out-of-pocket spending for commercially-insured patients, closing the doughnut hole, and expansion of Medicaid eligibility have lowered out-of-pocket spending for patients with cancer, although gaps remain and cancer care remains unaffordable for many. Leopold, Park, and Nekhlyudov summarize ACA provisions that are most relevant for cancer survivors, including provisions that increase access to preventive care, access to high-quality and affordable care, and coverage expansions and increased affordability. Parikh and Wright summarize some of the ACA provisions that have potential to improve care for patients with advanced-stage cancers, including expanded access to hospice care, payment reform, and quality reporting for hospices. Finally, Han and Jemal summarize evidence about the ACA's impact on young adults. Research suggests that the ACA's provision allowing young adults to be covered

under their parents' insurance until age 26, which went into effect in September 2010, was associated with cancer diagnosis at earlier stage and higher insurance rates among individuals with cancer as well as higher rates of human papillomavirus vaccination and receipt of fertility-sparing treatment for cervical cancer.

Uninsurance rates in the U.S. have decreased from 48.6 million in 2010 to 28.4 million in 2016.¹⁸ Millions of Americans that were previously uninsurable due to a prior cancer diagnosis, or whose cancer care was unaffordable due to annual or lifetime limits on coverage can now obtain insurance that allows for at least reasonably affordable care. Health care spending growth has slowed in recent years¹⁹ as the delivery system shifts away from fee-for-service care towards alternate payment models that seek to reimburse for value over volume of services. Oncology providers have demonstrated enthusiasm for such models of care delivery, as evidenced by the participation of 190 practices in the CMMI Oncology Care Model—these practices include approximately 3,200 oncologists who will treat about 155,000 Medicare beneficiaries nationwide under the model.²⁰

The papers in this issue suggest good early progress towards many of the goals of the ACA for individuals with cancer, although more needs to be done to ensure that all Americans with cancer have access to affordable cancer care of high quality. Efforts to repeal and/or replace the ACA must not lose sight of that goal.

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