

LEGISLATIVE AGENDAS: FEDERAL



2019 Federal Agenda



Major Campaigns

Appropriations for Cancer Research & Prevention – Support substantial funding increases for research at the NIH and NCI and prevention at the CDC, including cancer registries, Breast and Cervical Cancer and colorectal cancer funding.

Access to Care (private health insurance, ACA, Medicare and Medicaid, Drug Costs) – Support and advance policies that preserve protections for cancer patients and survivors and that promote access to adequate and affordable health insurance coverage, cancer prevention screening and services. Monitor and respond to policy proposals that endanger access to affordable, adequate coverage. Promote access to affordable and comprehensive coverage and low out of pocket costs for the most vulnerable, including seniors and low-income cancer patients, survivors, and those at particular risk of cancer. Support legislative and regulatory changes to lower the price of prescription drugs, reduce patient out-of-pocket costs, and maintain access to affordable lifesaving drugs and therapies for cancer patients.

Patient and Survivor Quality of Life – Support House and Senate passage of Palliative Care and Hospice Education and Training Act (PCHETA), legislation to facilitate access to palliative care and coordinated care management for cancer patients and survivors.

Cancer Prevention and Early Detection – 80 Percent Colorectal Cancer Screening Rate– Support the Removing Barriers to Colorectal Cancer Screening Act to remove Medicare patient cost-sharing requirements for colonoscopy with polyp removal.

Ending Death from Cervical Cancer Worldwide - Support the integration of HPV vaccination and cervical cancer screening & treatment into existing global health programs.



2019 Federal Agenda

Emerging Campaigns & Other Federal Legislative Priorities

Breast Cancer Screening—Support the Breast Density and Mammography Reporting Act. Legislation that would establish an evidence-based process to give women information about the potential impact that breast density has in masking breast cancer, and to encourage new research to better understand breast density and its impact on breast cancer screening.

Childhood Cancer – Support funding increases for the Childhood Cancer STAR Act, which advances pediatric cancer research and increases transparency/expertise for pediatric cancer research at the NIH.

Clinical Trials – Support increased research funding, and better patient access to clinical trials.

Diagnostic Reform – Support assertion of FDA authority over laboratory developed tests (LDTs).

Disparities – Support initiatives in research, prevention, detection, and provision of patient services to reduce disparities in cancer that will lead to healthier outcomes for cancer patients and survivors.

FQHCs – Support yearly funding for Federally Qualified Health Centers (FQHCs) in the appropriations process and work to ensure that mandatory FQHC funding under ACA is continued.

Healthy Eating and Active Living – Support implementation of quality nutrition standards for food served in schools and menu labeling standards to combat obesity.

Oral Chemo Parity – Support legislation to provide coverage for oral chemotherapy drugs with the same out of pocket cost sharing as chemotherapy drugs administered intravenously (IV) by a physician.

Patient Navigation – Support efforts to increase the availability of patient navigators for people with cancer.

Skin Cancer – Support efforts to reduce skin cancer through better regulation of indoor tanning devices.

Tobacco Control – Support advancement of tobacco regulation at the FDA and maintain FDA's statutory authority over all tobacco products, including cigars and electronic cigarettes, and support and increase the funding of the CDC Office on Smoking and Health tobacco prevention and cessation activities.

Preserving Access to Affordable, Quality Health Coverage



Background

Individuals with pre-existing conditions such as cancer need access to comprehensive and affordable health care services. Prior to 2014, insurers could deny coverage to an individual with cancer or charge more for coverage. Now, because of the health care law, people with cancer and survivors are protected against insurance denials due to a pre-existing condition.

However, ACS CAN is concerned that over the past year, policymakers and the administration have taken several legislative and regulatory actions that could make it harder for individuals with pre-existing conditions to obtain health insurance coverage that is adequate, affordable, and available, thereby jeopardizing access to life-sustaining care.

Repealing the Individual Mandate Penalty

In December 2017, Congress enacted the Tax Cut and Jobs Act, which among other things, repealed the individual mandate penalty as of January 1, 2019. The Congressional Budget Office (CBO) estimated that repealing the mandate penalty would result in 13 million Americans losing coverage by 2027 and would increase premiums in the individual market. ACS CAN opposed repealing the individual mandate penalty because it would eliminate a key incentive for individuals to enroll in comprehensive health insurance coverage. Without the requirement to purchase insurance, healthy people tend to avoid buying coverage until they need it, leaving insurance plans to cover a sicker population and driving up costs for everyone in the health care system.

Expanding Short-term, Limited Duration Insurance

In August 2018, the administration issued a final rule that would expand access to short-term, limited duration (STLD) health insurance. ACS CAN is concerned that these policies are exempt from important consumer protections, such as prohibitions on lifetime and annual dollar limits, limits on the use of preexisting condition exclusions, and the prohibition on charging people based on their health history.

Without these protections, individuals could find themselves enrolled in policies that fail to provide coverage of medically necessary services. The Urban Institute estimates that enactment of the STLD final rule would increase the number of people without comprehensive coverage by 2.6 million in 2019 and could drive up premiums for people in the individual market.

Cutting Navigator Funding

In July 2018, the administration announced that it intended to significantly reduce funding to Navigators who provide outreach, education, and enrollment assistance to consumers to enroll in Marketplace or Medicaid coverage. The administration intends to reduce funding by 84 percent compared to 2016 funding levels. Navigators would also be required to inform individuals about Association Health Plan (AHP) and STLD coverage options – options that likely provide less comprehensive coverage. The concern is that cutting Navigator funding could significantly reduce the number of individuals who enroll in Marketplace coverage.



Preserving Access to Affordable, Quality Health Coverage

(Continued)

Encouraging Association Health Plans

In June 2017, the administration finalized a regulation that would expand access to AHPs. ACS CAN has long been concerned about AHPs because these plans are not subject to many of the consumer protections provided in the individual and small group markets – like the requirement that plans provide access to Essential Health Benefits (EHBs). These plans tend to attract younger and healthier individuals, leaving older and sicker individuals in the ACA-compliant individual and small group markets. The final rule estimated that 4 million individuals would choose to enroll in AHPs, of which 3.6 million would be dis-enrolling from other (possibly more comprehensive) coverage. This could drive up premiums in the individual market and could leave millions of Americans without comprehensive health insurance coverage.

Cumulative Impact

The cumulative impact of these proposals jeopardizes a cancer patient's access to the kind of care they need and undermines the stability of the individual insurance market. For example, the Urban Institute estimated the combined effort of eliminating the individual-mandate penalty and finalizing the STLD rule as proposed would increase ACA-compliant plan premiums by an average of 18.3 percent in the 45 states that do not already prohibit or limit these plans.

ACS CAN Policy

Adequate, affordable, and available health insurance coverage is critical for individuals with cancer and survivors. ACS CAN calls on policymakers to support public policies that:

1. Provide cancer patients and survivors access to affordable, comprehensive health care;
2. Stabilize the individual and small group markets; and
3. Protect patients from discrimination against pre-existing conditions.

To that end, ACS CAN supports establishing reinsurance programs, limiting the availability of expanded short term, limited-duration insurance policies, and increasing funding for navigators.

Funding for Cancer Research- NIH & NCI



Background

The National Cancer Institute (NCI) is one of 27 institutes and centers within the National Institutes of Health (NIH). The mission of the NCI is to lead, conduct, and support cancer research activities across the nation. For the last 50 years, every major medical breakthrough in cancer can be traced back to the NCI and NIH.

Cancer continues to take a tremendous toll on our nation. Almost 1.7 million Americans will be diagnosed with cancer in 2018 and more than 600,000 will die from this devastating disease. That means that as a country we lose more than 1,645 Americans every day to cancer. Recent estimates also show that cancer costs the U.S. economy more than \$216 billion annually in direct treatment costs and lost productivity.

However, because of previous investments in cancer research there is hope. Today, we have more than 15.5 million American cancer survivors and we are in the midst of a quarter century of sustained declines in cancer mortality. From 2006 through 2015, the rate of new cancer cases fell by more than 1 percent each year. Research advances over the past two decades have significantly improved how many cancers are prevented, diagnosed, and treated.

What You Need to Know

With increases in federal investment in medical research over the last three fiscal years and the passage of the 21st Century Cures Act that included funding for the National Cancer Moonshot Initiative, Congress has illustrated its bipartisan support for cancer research. These increases for medical research were meant to address years of flat or cut funding, put cancer research back on track and spur additional progress – all toward the end of putting the country on the path toward finally defeating this disease.

With nearly \$1.7 billion for the National Cancer Moonshot Initiative, to date Cures has allowed the NIH to fund 142 new Cancer Moonshot awards. These awards are helping “leverage advances in immunotherapy, understand drug resistance and develop new technologies to characterize tumors and test therapies,” according to the NIH. Cures is also enabling NIH to begin to reverse the more than decade long trend of young researchers leaving their careers and their research behind due to a lack of resources.

Additionally, the support provided to the NIH by Congress has led to job growth and increased economic activity in every state. More than 80 percent of federal funding for the NIH and NCI is spent on biomedical research projects at local research facilities across the country. According to United for Medical Research, in 2017, the NIH provided \$26.1 billion in funding to scientists in all 50 states. This funding supported more than 400,000 jobs nationwide and produced almost \$69 billion in new economic activity. Lastly, please consider:



Funding for Cancer Research- NIH & NCI

(continued)

- Despite recent increases and new funding through Cancer Moonshot, the increased cost of research and the constant dollar loss of funding due to inflation continue to impact the NIH and NCI. Based on inflation, NIH and NCI purchasing power has declined 11 percent and 16 percent, respectively, since 2003 and subsequently, the pace of investment in cancer research has slowed.
- We are at a point where advancements in research are saving more lives than ever and it's critical that we keep this momentum going forward. To continue the progress that has led to medical breakthroughs for treatment and therapies, NIH and NCI need an increased, predictable, and sustained federal investment.
- Congress needs to provide NIH with at least \$41.6 billion in FY19, including \$6.5 billion for the NCI in Fiscal Year 2020.

The Bottom Line

Please support a FY 2020 Increase of \$2.5 billion for NIH and a \$378 million increase for NCI



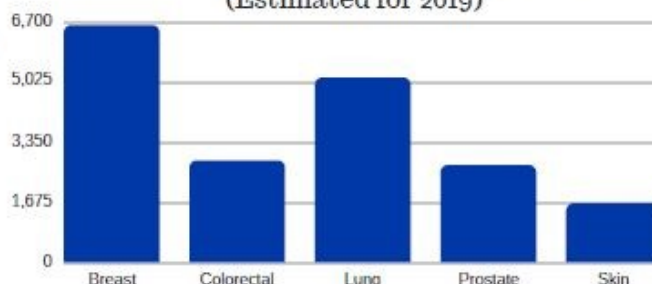
Massachusetts

2019 Cancer Research Facts and Funding

This year in Massachusetts

- 40,020 estimated new cancer diagnoses
- 12,420 estimated deaths due to cancer

Snapshot of New Cancer Cases by Type
(Estimated for 2019)



In the United States

- 1.76 million estimated new cancer diagnoses
- 606,880 estimated deaths due to cancer

1 out of every 5 deaths will be caused by cancer

FY2018 Funding Research in Massachusetts

- Total NIH State Funding: **\$2,887,150,148**
- Total NCI State Funding: **\$413,402,184**
- NCI Designated Cancer Centers in Massachusetts: 2

FY2017 NIH and State Economic Impact

- 32,788 jobs in Massachusetts supported by NIH funding
- **\$6.353 billion** created in new economic activity based on NIH funding

Massachusetts Research Accomplishments

Glioblastomas are the fastest-growing type of brain cancer and are typically treated with surgery, radiation, and chemotherapy. Unfortunately, these therapies usually do not completely cure glioblastomas and recurrence is highly likely.

Recently, scientists have been investigating the role that the PRMT5 protein plays in tumor growth. While scientists knew that higher levels of PRMT5 were linked to cancer, the exact mechanism by which PRMT5 was stimulating cancer growth was unclear. With the support of NCI funding, researchers at the Massachusetts Institute of Technology (MIT) discovered that PRMT5 regulated tumor cell growth via a process known as gene splicing. When the researchers blocked PRMT5, they discovered that the tumor cells stopped growing. The discovery could lead to the development of new therapies for this highly deadly cancer.



Removing Barriers to Colorectal Screenings Act

Bill Number:

Sponsors:

Congressman Leonard Lance [R-NJ-7] and Congressman Donald M. Payne [D-NJ-10]
Senator Sherrod Brown [D-OH] and Senator Roger Wicker [R-MS]

Background

Colorectal cancer is one of the few cancers that can be completely prevented through screening. Polyps, or abnormal precancerous growths, can be detected during the screening process and entirely removed, thereby stopping any cancer formation. Regular screening is the most effective way of detecting precancerous growths and early colorectal cancer. Cancers that are found at an early stage can be treated more easily, and lead to greater survival.¹ Yet colorectal cancer remains the second leading cause of cancer death in men and women combined in the U.S.² This year approximately 145,600 Americans will be diagnosed with colorectal cancer and over 51,000 of them will die from the disease. The majority of those diagnosed will be Medicare beneficiaries. Although incidence and mortality rates are steadily declining each year in adults 55 years of age and older, thanks, in part, to increased screening rates, we must continue to address the obstacles that prevent Americans from getting screened.

Research shows that out-of-pocket costs to patients creates financial barriers that discourage the use of recommended preventive services, ^{3,4,5} particularly for those with lower incomes. Medicare beneficiaries can be particularly vulnerable to cost sharing, as approximately 34 percent of Medicare beneficiaries are under 200 percent of the federal poverty level (FPL)⁶ and are on limited incomes. Barriers to preventive care lead to poorer health outcomes and increased health care costs.

What You Need to Know

Approximately 90 percent of all individuals diagnosed with colorectal cancer at an early stage are still alive five years later, which means that a colonoscopy can literally save a person's life when a polyp is found and removed.⁷ Colonoscopy has an A-rating from the United States Preventive Services Task Force (USPSTF), requiring most private insurers to provide *screening* colonoscopies for individuals between the ages of 50 and 75 without cost sharing. However, regulations currently require Medicare beneficiaries to pay a 20 percent coinsurance for colonoscopies if a polyp is removed. This loophole places an unfair financial burden on Medicare beneficiaries, but not adults with private insurance, for this life-saving screening.

When a Medicare beneficiary goes in for a screening colonoscopy they are led to believe there will be no copays. However, if a polyp is detected and removed during the procedure, the patient may wake-up from the procedure with a surprise bill. Colorectal cancer is unique in that a person can be spared a cancer diagnosis if a polyp is found early and removed. Unfortunately, Medicare beneficiaries continue to receive bills for the 20 percent coinsurance – a lot of money when you are on a fixed income. A colonoscopy with polyp removal could cost a Medicare beneficiary as much as \$350, depending on the removal procedure and facility used.⁸ Out-of-pocket expenses for Medicare beneficiaries can be important deterrents to screening.

Removing Barriers to Colorectal Screenings Act



(continued)

Fixing the Medicare loophole for polyp removal during a screening colonoscopy is critical for many reasons:

- An estimated **\$14 billion is spent annually** on colorectal cancer treatments in the U.S, with projections increasing to **\$20 billion by 2020**, with Medicare bearing as much as half of the cost.⁹
- Treatment costs for an individual with stage IIB colorectal cancer could **exceed \$240,000 a year**.¹⁰
- Preventing colorectal cancer through polyp removal or catching cancer at an earlier stage saves lives and can reduce costs for the Medicare program.
- A recent study estimated that **58 percent of all colorectal cancer deaths in 2020 will be due to “non-screening”** – this means that thousands of colorectal cancer deaths could be avoided if people are screened according to ACS and USPSTF recommendations.¹¹
- Cost sharing for polyp removal during a screening colonoscopy may discourage patients from getting their screening altogether.

ACS CAN's Position

ACS CAN supports the **Removing Barriers to Colorectal Cancer Screening Act**. Eliminating the surprise bill associated with polyp removal during screening colonoscopy could increase the number of Medicare beneficiaries being screened for this devastating disease. Passing the **Removing Barriers to Colorectal Cancer Screening Act** would eliminate the unexpected cost, and remove the financial disincentives that prevent people from getting this life-saving cancer screening. By passing this Act, Congress would help increase screening rates among seniors and reduce death and suffering from colorectal cancer.

Please cosponsor H.R.1670/S.668 the Removing Barriers to Colorectal Cancer Screening Act!

¹American Cancer Society. Cancer Prevention & Early Detection Facts & Figures 2017-2018. Atlanta: American Cancer Society; 2017.

²American Cancer Society. Cancer Facts and Figures 2019. Atlanta: American Cancer Society; 2019.

³Solanki G, Schauffler HH, Miller LS. The direct and indirect effects of cost-sharing on the use of preventive services. *Health Services Research*. 2000; 34: 1331-50.

⁴Wharam 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: 865-71.

⁵Trivedi AN, Rakowski W, Ayanian JA. Effect of cost sharing on screening mammography in Medicare health plans. *N Eng J Med*. 2008; 358: 375-83.

⁶The Henry J. Kaiser Family Foundation. Distribution of Medicare beneficiaries by federal poverty level. Published March 2016. Accessed January 2018. <http://kff.org/medicare/state-indicator/medicare-beneficiaries-by-fpl/?currentTimeframe=0>.

⁷American Cancer Society. Cancer Facts and Figures 2019. Atlanta: American Cancer Society; 2019.

⁸Cost estimates provided by The American Gastroenterological Association.

⁹Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst*. 2011; 103(2):117-28.

¹⁰The American Cancer Society Cancer Action Network. *The costs of cancer: addressing patient costs*. Published April 11, 2017. Accessed January 2018. <https://www.acscan.org/sites/default/files/Costs%20of%20Cancer%20-%20Final%20Web.pdf>.

¹¹Meester RGS, Doubeni CA, Lansdorp-Vogelaar I, et al. Colorectal Cancer Deaths Attributable to Nonuse of Screening in the United States. *Annals of epidemiology*. 2015;25(3):208-213.e1. doi:10.1016/j.annepidem.2014.11.011.

COLORECTAL CANCER AND MEDICARE: THE COSTS



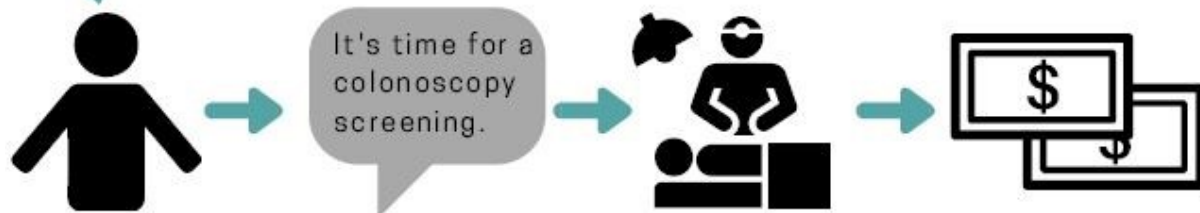
Colorectal cancer is one of the few cancers that can be prevented through screening. Yet, colorectal cancer remains the second leading cause of cancer death in men and women combined in the U.S.

145,600

Americans will be diagnosed with colorectal cancer and over **51,000** of them will die from the disease this year.

An estimated **\$14 BILLION** is spent annually on colorectal cancer treatments in the U.S., with projections increasing to **\$20 BILLION BY 2020**. Medicare will bear as much as **\$7 BILLION**.

The majority of those diagnosed will be **Medicare beneficiaries**.



When a Medicare beneficiary goes in for a screening colonoscopy, they're led to believe there will be no copays. However, if a polyp is detected and removed during the procedure, the patient could wake-up from the procedure with a surprise bill (as much as \$365). **For an individual on a fixed income, the possibility of paying the 20 percent coinsurance can be a deterrent to getting screened.**

Despite colonoscopy receiving an A-rating from the U.S. Preventive Services Task Force, **58% of all colorectal cancer deaths in 2020 will be due to "non-screening."**

Over \$240,000 a year is how much the treatment costs are for an individual with stage IIB colorectal cancer.

Preventing colorectal cancer through polyp removal or catching it at an earlier stage saves lives and can reduce costs for the Medicare program.

ACS CAN supports H.R. 1570 and S. 668 - **the Removing Barriers to Colorectal Cancer Screening Act**, sponsored by Representatives Donald Payne, Jr. (D-NJ-10) and Rodney Davis (R-IL-13) and Senators Sherrod Brown (D-OH) and Roger Wicker (R-MS).

Palliative Care and Hospice Education and Training Act



Background

Palliative care improves quality of life, enhances patient and family satisfaction with care, and controls costs for the rapidly expanding population of individuals with serious illness or multiple chronic conditions. In 2000, less than 25% of U.S. hospitals had a palliative care program, compared with 75% in 2015. Yet, not all these programs have in place the interdisciplinary team necessary to provide comprehensive, high-quality palliative care. At the same time, palliative care is increasingly being provided in community settings. This growth comes in response to the increasing numbers and needs of Americans living with serious or complex chronic illnesses and the realities of the care responsibilities faced by their families. Palliative care is a relatively new medical specialty, and more must be done to ensure patients and providers understand its benefits and that an adequate, appropriately trained workforce is available to provide the pain and symptom management, intensive communication and level of care coordination that addresses the episodic and long-term nature of serious and complex chronic illness.

Bill Summary

PALLIATIVE CARE AND HOSPICE EDUCATION CENTERS

Establishes Palliative Care and Hospice Education Centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support the training and retraining of faculty; support continuing education; provide students with clinical training in appropriate sites of care; and provide traineeships for advanced practice nurses.

PHYSICIAN TRAINING

Authorizes grants or contracts to schools of medicine, teaching hospitals and graduate medical education programs to train physicians (including residents, trainees, and fellows) who plan to teach palliative medicine. Such programs will provide training in palliative medicine through a variety of service rotations, such as consultation services, acute care services, extended care facilities, ambulatory care and comprehensive evaluation units, hospice, home health, and community care programs. Programs will be required to develop specific performance-based measures to evaluate the competency of trainees.

ACADEMIC CAREER AWARDS

Establishes a program to promote the career development of physicians who are board certified or board eligible in Hospice and Palliative Medicine and have a junior (non-tenured) faculty appointment at an accredited school of medicine. Eligible individuals must provide assurance of a full-time faculty appointment in a health professions institution and commit to spend a majority of funded time teaching and developing skills in interdisciplinary education in palliative care.

WORKFORCE DEVELOPMENT

Establishes fellowship programs within the new Palliative Care and Hospice Education Centers to provide short-term intensive courses focused on palliative care. Supporting the team approach to palliative care, the fellowships will provide supplemental training for faculty members in medical schools and other health professions schools, including pharmacy, nursing, social work, chaplaincy and other allied health disciplines in an accredited health professions school or program (such as a physician assistant education program) so providers who do not have formal training in palliative care can upgrade their knowledge and skills for the care of individuals with serious or life-threatening illness as well as enhance their interdisciplinary teaching skills.

CAREER INCENTIVE AWARDS

Provides grants or contracts for eligible health professionals who agree to teach or practice in the field of palliative care for at least 5 years. Eligible individuals include: advanced practice nurses, social workers, physician assistants, pharmacists, or students of psychology who are pursuing a doctorate, masters, or other advanced degree with a focus in palliative care or related fields in an accredited health professions school.



Palliative Care and Hospice Education and Training Act

(Continued)

NURSE TRAINING

Creates special preferences in existing nurse education law for hospice and palliative nursing, in education, practice and quality grants, workforce development, and nurse retention projects.

PALLIATIVE CARE EDUCATION AND AWARENESS

Provides for the establishment of a national campaign to inform patients, families and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness. Directs the dissemination of information, resources and materials about palliative care services to health professionals and the public in a variety of formats, in consultation with professional and patient stakeholders.

ENHANCED RESEARCH

Directs the National Institutes of Health to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illness.

Eliminating Death from Cervical Cancer

ACS CAN's Vision -- With modest, focused resources, death from cervical cancer can be eliminated worldwide, through human papillomaviruses (HPV) vaccination combined with simple, inexpensive, evidence-based screening and treatment. Cervical cancer is largely preventable and treatable. We know what to do. We know how to do it. And the world can afford it. With nearly 90 percent of deaths from cervical cancer occurring in low-and middle-income countries (LMICs), cervical cancer deaths can be dramatically reduced by providing HPV vaccination and cervical cancer screening and treatment services to girls and young women.

Prevention by Vaccination

- Virtually all cervical cancers are caused by HPV. By protecting individuals and building population-immunity, HPV vaccination can prevent most cervical cancers before women and girls become infected with the HPV virus.
- The HPV vaccine is safe. Available since 2006, more than 200 million doses have been administered worldwide with no serious vaccine-attributable adverse impacts.
- The HPV vaccine is effective and life-saving. Extensive studies demonstrate that the two most common vaccines are 90 percent effective against 70 percent of cervical cancer-causing HPV types.¹
- HPV vaccines are affordable and cost-effective. At \$4.50 per dose in many LMICs, HPV vaccination is one of the most cost-effective cancer prevention methods according to the World Health Organization (WHO), the leading global authority on health, and other global health experts who characterize it as a “best buy” in virtually all LMICs, including those with high incidence of cervical cancer.²

Eliminating Death from Cervical Cancer



(Continued)

Preventive Screening and Treatment

While the primary objective of HPV vaccination is to prevent cervical cancer in the first place, we must have effective and affordable screening and treatment options for women who are already infected with the HPV virus.

Even invasive cervical cancer can often be successfully treated if detected at an early stage. With access to screening and treatment options, the estimated five-year net survival from cervical cancer is now between 60 and 70 percent in many high-income countries. Therefore, women, regardless of vaccination status, should receive screening and treatment of precancerous lesions.

The lab-based Pap test, central to reducing incidence and mortality in higher-income countries, is not easily implemented in LMICs that lack the necessary laboratory capacity and supporting logistics. Therefore, the WHO recommends alternative but very effective screening and treatment methods specifically for LMICs. These include:

Visual Inspection with Acetic Acid (VIA) – WHO recommends this screening strategy in LMICs where resources are limited. It can be successfully performed by non-physician providers. The VIA test is based on application of diluted acetic acid (vinegar) to the cervix during examination. Abnormal cervical tissue appears white after application. The advantage of this method is that it is inexpensive and abnormal tissue can be found and treated in a single visit to the clinic.

Pre-cancer treatment – Abnormal precancerous cervical changes discovered during screening can be treated by means of one of several low-cost methods including³:

- Cryotherapy, which destroys cells with extreme cold. According to WHO guidelines, cryotherapy is the treatment of choice in LMICs, because of its ease of use and lower price. However, a reliable supply of gas (generally nitrous oxide) can be difficult, especially in rural areas.
- Thermo-coagulation, by contrast, destroys cells with heat and uses electricity to generate temperatures of 100–120 °C. It is also safe, low-cost, has high client acceptance levels and can be used in low-resource clinical settings.
- Loop electrosurgical excision procedure (LEEP), which removes abnormal tissue with a wire loop heated by electric current.

Promising alternative tests also exist for future use in LMICs. For example, the HPV DNA test requires a machine to analyze samples from the cervix and test for the presence of HPV infection. By enabling women to collect their own cervical samples, the test can facilitate screening in women who would not have otherwise been screened because of culturally conservative customs. The cost of the test and follow-up care following a positive test remain issues to be addressed with the use of this test.

Broadening Success

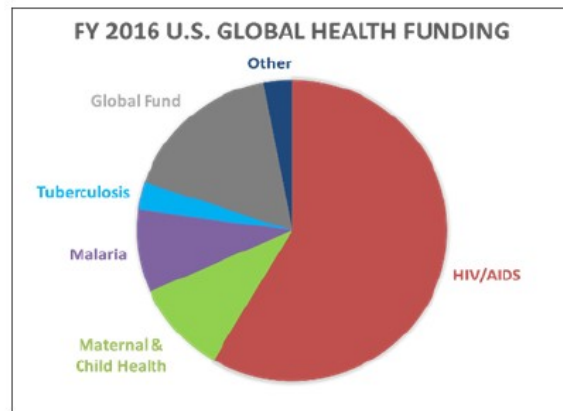
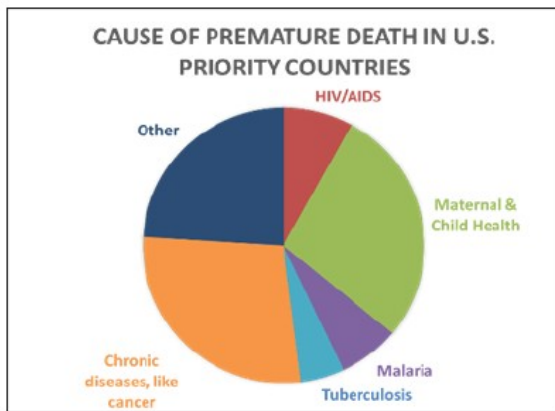
HPV vaccination as well as screening and treatment programs in Africa, Asia, and Latin America have shown that these procedures work in low-resource settings and have the potential to significantly reduce mortality. For instance, an assessment of VIA screening by primary health workers in India showed a 31 percent reduction in cervical cancer mortality.⁴ Forty-four LMICs (including many high-prevalence countries in Africa and Asia) have introduced the HPV vaccine on a national or pilot basis, and 53 have introduced new screening and preventive treatment programs on a pilot or early nationwide basis. However, few LMICs have achieved high rates of coverage. A study of HPV immunization programs in 64 countries found that coverage of females averaged only 2.7 per-cent in less developed regions.⁵ HPV vaccination and cervical cancer screening and treatment programs can be effectively integrated into existing in-country health and education programs.

Eliminating Death from Cervical Cancer

(Continued)

The Challenge

U.S. Government (USG) supports health programs in many LMICs, in part, to save lives, promote economic development and advance U.S. interests. Unfortunately, the current funding is not well aligned with the actual causes of death in those countries that the USG supports. As evidenced in the charts, while more than a quarter of deaths in those priority LMICs is from chronic diseases, such as cancer, virtually no funding is provided to prevent those deaths. As stated earlier, HPV vaccination and cervical cancer screening are proven effective strategies to eliminate deaths from cervical cancer. USG assistance to help end cervical cancer deaths would begin to address this disparity between the causes of death and the focus on global health funding.



The Strategy Going Forward

ACS CAN calls on Congress to direct U.S. global health appropriations to support a campaign to eliminate death from cervical cancer. Funds should be used to:

- Scale-up vaccination, screening and treatment services for girls and women, beginning in high-prevalence, lower-income countries.
- Continue innovation and sharing of lessons learned to strengthen and expand current programs, especially in high-prevalence, lower-income countries.
- Track progress and encourage accountability with agreed-upon progress indicators, monitoring and evaluation.

¹ http://www.who.int/vaccine_safety/committee/GACVS_HPV_statement_17Dec2015.pdf

² <https://openknowledge.worldbank.org/bitstream/handle/10986/22552/9781464803499.pdf?sequence=3&isAllowed=y>

³ http://apps.who.int/iris/bitstream/10665/94830/1/9789241548694_eng.pdf?ua=1

⁴ <https://www.ncbi.nlm.nih.gov/pubmed/24563518>

⁵ [http://thelancet.com/journals/langlo/article/PIIS2214-109X\(16\)30099-7/fulltext](http://thelancet.com/journals/langlo/article/PIIS2214-109X(16)30099-7/fulltext)

Global Impact of Cervical Cancer (HPV)

We can end death from cervical cancer.

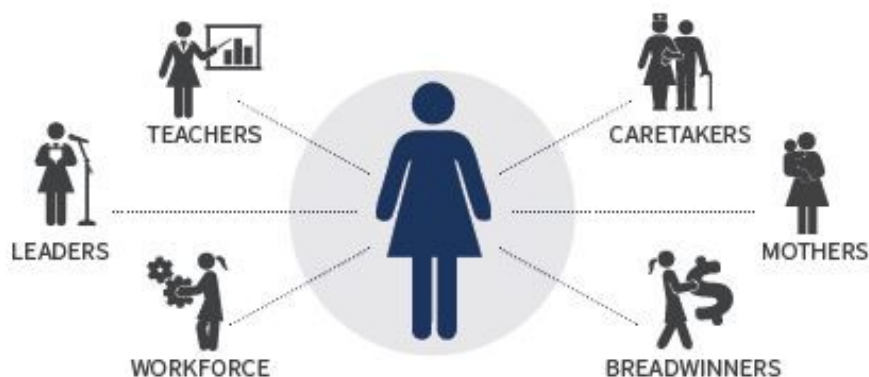
Ninety percent of all cervical cancer deaths occur in low- and middle-income countries. Cervical cancer is the leading cause of cancer deaths among women in 38 of these countries, mainly in sub-Saharan Africa.



At the current rate, deaths from cervical cancer will rise nearly 66 percent by 2030.



Women are essential to the development and well-being of our communities.
No woman has to die from cervical cancer.



We can end death from cervical cancer.

Despite the 527,600 new cases of cervical cancer every year, U.S. global health funding ignores the problem.



LESS THAN 1/2 OF 1% OF FUNDING GOES TOWARD CERVICAL CANCER ANNUALLY.⁴

Death from cervical cancer is preventable through vaccination, screening and treatment.

The World Health Organization reports that the tools to prevent cervical cancer deaths are cost-effective forms of cancer prevention.⁵



We can prevent a young woman from dying from cervical cancer for less than the cost of a pair of jeans!

\$13

TO FULLY IMMUNIZE
A GIRL⁶

+

\$20

TO SCREEN AND
TREAT A WOMAN⁷

What can we do?

Advocate for scaled-up vaccination, screening and treatment services.



Support the integration of HPV vaccination and cervical cancer screening and treatment into existing U.S. global health programs.



Visit acscan.org/globalcervical to join us.



SOURCES:

1. <https://www.acscan.org/policy-resources/global-impact-cervical-cancer>
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LEGISLATIVE AGENDAS: STATE





Massachusetts – State Agenda

An Act empowering health care consumers

S.561 – Sen. Brendan Crighton & H.969 – Rep. Jen Benson

As consumers are asked to be more savvy health care shoppers, they can only do so with accurate information. While the cost of a drug varies significantly depending on the source, consumers who are increasingly facing co-insurance (rather than a fixed co-pay) must know the cost of a drug before they can choose the plan that best meets their needs. Without this information, consumers may pick the wrong plan, unnecessarily increasing their cost and likelihood that they forgo needed medications. This bill would ensure that all the necessary cost and utilization management information is available to consumers when they choose their health plans.

An Act regulating flavored tobacco products

S.1279 – Sen. John Keenan & H.1902 – Rep. Danielle Gregoire

As Big Tobacco continues to target kids with their sweet, candy flavored, yet still addictive and harmful products, a priority bill would ban the sale of flavored tobacco products, including e-cigarettes in the Commonwealth. Flavored products are clearly designed to hook a new generation of kids on Big Tobacco's deadly products.

An Act relative to tobacco premium ratings

H.964 – Rep. Lori Ehrlich

Would prohibit insurers from charging higher premiums for tobacco users. Current law provides for the Commissioner of the Division of Insurance to decide each year whether to allow tobacco as a rating factor. Tobacco users should not be punished for an addiction made worse by the tactics of Big Tobacco! Instead, we should ensure they have access to the evidence-based tools needed to help them quit.

An Act protecting youth from nicotine addiction

S.1606 – Sen. Harriette Chandler & H.2436 – Rep. Marjorie Decker

The rapid rise in the number of youth who use tobacco products is a public health crisis that threatens to erode decades of progress made in reducing tobacco use and nicotine addiction. Massachusetts currently collects sales tax on e-cigarette/vape products, but not excise taxes. This bill would add an excise tax of 75% of wholesale to these products, increasing their prices and making them harder for young people to afford. Additionally, regularly increasing the price of cigars and cigarettes is one of the most effective ways to help smokers quit and prevent kids from starting. This bill would also increase the tax on cigarettes by \$1, bringing it up to \$4.51, and increase the tax on cigars from 40% of wholesale to 80%. History and evidence shows that this will reduce the smoking rate, saving some of the more than \$4 billion in health care costs annually attributed to tobacco use in Massachusetts, and save lives.

Massachusetts—State Agenda



An Act to provide Medicaid coverage for tobacco cessation

S.704 – Sen. Jason Lewis & H.1129 - Rep. Christine Barber

MassHealth enrollees are more likely to need cessation support, given their economic status and higher likelihood of tobacco use. After Massachusetts led the nation in 2006 by including a comprehensive tobacco cessation benefit within all MassHealth plans, there was a significant uptake of individuals using the evidence-based cessation treatments. This led to reduced smoking rates, improved health outcomes, and decreased medical costs in the first two years. This bill seeks to expand access to the program by allowing trained and approved dentists and behavioral health practitioners to provide cessation counseling as recommended by the CDC.

An Act reducing tobacco sales to minors

S.976 – Sen. Jason Lewis & H.1951 – Rep. John Lawn

By raising the age of sale for tobacco products from 18 to 21 last session, we made significant progress in our work to prevent youth from becoming addicted to nicotine. But we can't stop there. This bill would require retailers to check for identification for anyone purchasing tobacco products, including e-cigarettes. The bill also increases penalties on retailers for selling these products to minors.

An Act relative to expanding access to healthy food choices in vending machines on state property

S.1290 – Sen. Jason Lewis

Traditional vending machines sell snacks and beverages high in sugar, trans fat, saturated fat, and salt, with little nutritional value. This bill would improve access to healthy foods and beverages by requiring vending machines on public property (like in public buildings, parks, and recreation centers) to include healthy options.

An Act to promote healthy alternatives to sugary drinks

S.1291 - Sen. Jason Lewis & H.2529 - Rep. Kay Kahn

Sugary drinks contribute to obesity, which has been associated with an increased risk of cancer development and recurrence, as well as decreased risk of survival, for many cancers. Sugary drinks are the leading source of added sugar and one of the leading sources of calories in American diets. About 50 percent of the population consumes at least one sugary drink each day, with about 10 percent of youth consuming three or more. Nearly 40 percent of all added sugars come from sugary beverages. This bill would place an excise tax on sugary drinks that contain added sugar to reduce consumption.

An Act relative to fail first and patient safety

S.1235 - Sen. Julian Cyr & H.1853 - Rep. Jen Benson

Fail First prevents patients from accessing the treatment prescribed by their health care provider by making them first try and fail on one or more alternative drugs. Fail First can make patients sicker by delaying access to the most effective treatment. The time spent on trying and failing one or more medications can lead to disease progression and increase health care costs. This bill would ensure Fail First protocols are based on clinical guidelines and provide for a transparent exceptions and appeals process for health care patients and providers.



Massachusetts—Budget Priorities

Tobacco Cessation and Prevention Funding: ACS CAN will advocate for a minimum of level funding for the states' tobacco cessation and prevention program in the Department of Public Health.

Breast and Cervical Cancer Screening: ACS CAN will advocate for sufficient funding for the Breast and Cervical Cancer Early Detection and Treatment Programs to meet the continually changing demand.

Prostate Cancer Education, Awareness and Research: ACS CAN will advocate for continued funding for a prostate cancer education, awareness and research program within the Department of Public Health.

Pediatric Palliative Care: ACS CAN will advocate for continued funding for a pediatric palliative care program within the Department of Public Health.

For more information, contact:

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The American Cancer Society Cancer Action Network (ACS CAN) is making cancer a top priority for public officials and candidates at the federal, state and local levels. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions that will reduce the cancer burden. As the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN is critical to the fight for a world without cancer. For more information, visit www.fightcancer.org

Massachusetts How Do You Measure Up



MASSACHUSETTS

How Does Your State Measure Up?

The 16th edition of How Do You Measure Up?, along with this one-page summary, illustrates how your state stands on issues that play a critical role in reducing cancer incidence and death. The goal of every state should be to achieve "green" in each policy area delineated in the report. By implementing the solutions set forth in the report, state legislators have a unique opportunity to save lives, save money and fight back against cancer. How does your state measure up?

To read this report online, please go to: www.acscan.org/measure

Number of Areas that Met Green Benchmarks: **6 of 9**



Performance Area

- G** Green represents a state has adopted evidence-based policies and best practices
- Y** Yellow indicates moderate movement toward the benchmark
- R** Red shows where states are falling short

Access to Care

State Decisions on Increasing Access to Health Care Through Medicaid Up to 138% FPL

- G** State has broadened Medicaid eligibility, covering individuals under 138% FPL

State Appropriations for Breast and Cervical Cancer Screening Program - Fiscal Year 2017-2018

- R** State appropriations for the program are less than 33% of the CDC award – 26% of the CDC award

Quality of Life

Establishing a Palliative Statewide Expert Advisory Council

- G** Passed ACS CAN model legislation or similar legislation with main components of model legislation

2018 Pain Policy in the States

- Y** 50%-80% match to model policy

Prevention

2018 State Cigarette Excise Tax Rates, \$3.51 per pack

- G** Above the national average of \$1.75 per pack

Smoke-free Legislation at the State Level

- G** 100% smoke-free in non-hospitality workplaces, restaurants and bars

Fiscal Year 2018 State Funding for Tobacco Control, \$3.7 million annually – 5.6% of CDC recommended spending

- R** 1-24.9% of the CDC recommended funding level

Medicaid Coverage of Tobacco Cessation Treatments (Traditional Medicaid)

- G** Individual, group, and telephone counseling and all seven FDA-approved tobacco cessation medications covered for all enrollees

State Laws Prohibiting Minors from Using Tanning Devices

- G** State law prohibiting tanning for minors (under age 18) with no exemptions

2018





Massachusetts How Do You Measure Up

HOW DO YOU MEASURE UP?

A Progress Report on
State Legislative Activity
to Reduce Cancer
Incidence and Mortality

Number of Areas that
Met Green Benchmarks:

6 of 9



MASSACHUSETTS

ACS CAN

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard. For more information, visit www.acscan.org.

BLUEPRINT FOR LEGISLATORS

For the sixteenth year, ACS CAN has published a blueprint for state legislators on how to save more lives from cancer. Framed entirely on evidence-based policy approaches, How Do You Measure Up? provides an outline of what states can do to reduce the cancer burden and provides a snapshot of how states are progressing on critical public health measures.

HANGING IN THE BALANCE

This year's report includes a special section that will become a reoccurring feature of the How Do You Measure Up? Report. The new "Hanging in the Balance" section will shed light on a timely topic each year. This year the section details how policies aimed at combatting opioid addiction in Massachusetts impact cancer patients and survivors' access to pain treatment. View the pain report card online: www.acscan.org/painreportcard.

CALL TO ACTION

The data in this year's edition of How Do You Measure Up? show that there is still much public policy work to be done to achieve our mission of eliminating suffering and death from cancer. It is estimated that nearly 1.7 million people in the United States will be diagnosed with cancer in 2018 and more than 600,000 people will die from the disease this year alone. ACS CAN is dedicated to ensuring that lawmakers enact state health policies that help prevent cancer and save lives.

In many cases, it costs the state little or nothing to do the right thing. In most cases, these solutions will save the state millions and perhaps billions of dollars in health care costs and increased worker productivity. If you want to learn more about ACS CAN's programs or inquire about a topic not covered in this report, please contact the ACS CAN State and Local Campaigns team at measure@cancer.org. You can also visit us online at www.acscan.org.



Flavored Tobacco Products and Youth



The Problem:

Big Tobacco is targeting youth with flavored tobacco products. This year Big Tobacco will spend an estimated \$125.1 million in Massachusetts marketing their addictive and deadly products. Products that come in array of kid friendly candy and fruit flavors such as cherry, grape jelly, cotton candy, piña colada, cinnamon roll, popcorn, and appletini, all sold in colorful packaging that is designed to attract tweens and teens. In fact, as of 2014 there were nearly 8,000 different flavors of e-cigarettes on the market. ⁱ

What We Know:

- Nationwide, nearly 81% of youth ages 12 to 17 who had ever used a tobacco product reported that the first product they used was flavored. ⁱⁱ
- Here in Massachusetts, 80% of high school students who currently use tobacco report using a flavored tobacco product in the last 30 days. ⁱⁱⁱ
- Youth who use e-cigarettes may be more likely to smoke cigarettes. ^{iv}
- Youth who regularly use tobacco report that flavoring is a leading reason for using a range of tobacco products. ⁱⁱ

80% of Massachusetts high school students who currently use tobacco report using a flavored tobacco product in the last 30 days.

The Solution:

Prevention is critical. ACS CAN supports a comprehensive approach to tobacco control aimed at protecting our kids from all tobacco products. Regular and significant tax increases, smoke-free workplace laws, and a well-funded evidence-based tobacco control program are the most effective ways to reduce tobacco use. Making flavored tobacco products, including mint, wintergreen, and menthol flavors, unavailable for purchase in Massachusetts will complement the effect of these policies.

ⁱ Campaign for Tobacco Free Kids <https://www.tobaccofreekids.org/problem/toll-us/massachusetts>

ⁱⁱ Truth initiative <https://truthinitiative.org/sites/default/files/Truth-Flavors-Fact-Sheet.pdf>

ⁱⁱⁱ Massachusetts Department of Public Health <http://makesmokinghistory.org/wpcontent/uploads/2018/08/SurveyQuestionsForSchools2018.pdf>



Tackling Tobacco Use in Massachusetts

The Toll of Tobacco in Massachusetts

The use of tobacco products remains the nation's number one cause of preventable death. Tobacco use is responsible for nearly 1 in 5 deaths nationwide.

In Massachusetts:

- An estimated 9,300 adults die each year from smoking.ⁱ
- 13.7% of adults and 6.4% of high school students smoke.ⁱ
- 20.1% of high school students use e-cigarettes.ⁱ
- 2,100 kids under 18 become new daily smokers each year.ⁱ
- If smoking continues at the current rate among youth, 103,000 of today's kids will die prematurely from smoking.ⁱ
- In 2019 an estimated 5,150 will be diagnosed with lung cancer and 2,920 will die from the disease.ⁱⁱ
- 28.1% of all cancer deaths in the state are attributable to smoking.ⁱ

The Cost of Tobaccoⁱ

Tobacco-related illnesses are expensive and harmful for all of us. In Massachusetts, smoking is estimated to cost \$4.08 billion in direct health care costs, including \$1.26 billion in Medicaid costs. Additionally, Massachusetts experiences \$2.4 billion in smoking caused productivity losses annually.

The Solution: Prevention is Critical

ACS CAN supports a comprehensive approach to tobacco control aimed at protecting our kids from all tobacco products. Regular and significant tax increases, comprehensive smoke-free laws, and a well-funded evidence based tobacco control program are the most effective ways to reduce tobacco use. *An Act protecting youth from nicotine addiction* supports this comprehensive approach by:

- Adding an excise tax of 75% of wholesale to e-cigarettes. Currently e-cigarette products have no excise tax at all. This is inconsistent with the way we treat cigarettes, cigars, and other tobacco products. Taxing them at 75% of wholesale will bring them to near parity with cigarettes.
- Increasing the tax on cigarettes by \$1.00. Massachusetts' low youth cigarette smoking rate is due in part to its pattern of consistently raising cigarette taxes every few years. We have not raised the cigarette tax since 2013. It's time.
- Increasing the tax on cigars to 80% of wholesale. Cigars, currently taxed at 40% of wholesale, are still in kids' price range. Cigars come in many flavors attractive to kids and are sold at low prices. Taxing these cheap cigars at the more appropriate rate of 80% of wholesale will help make them less attractive to young people.

ⁱ Campaign for Tobacco Free Kids. The Toll of Tobacco in Massachusetts. Updated November 15, 2018 https://www.tobaccofreekids.org/facts_issues/toll_us/Massachusetts

ⁱⁱ American Cancer Society. Cancer Facts & Figures 2019. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-andstatistics/annual-cancer-facts-and-figures/2019/cancer-facts-and-figures-2019.pdf>

Massachusetts Health Plan Transparency



The Problem

The process of finding out if a healthcare plan will cover a specific type of medication is a daunting one. The process of finding out how much the monthly out-of-pocket cost would be to the patient when choosing a new healthcare plan can be an impossible one.

For a cancer patient, buying a health plan that covers the drugs they need at a cost they can afford has a direct impact on their ability to effectively fight and beat their disease. Even with health insurance, cancer care can be very costly, especially if a patient buys a plan that does not cover their drug or covers the drug at a cost they find out after the fact, that they cannot afford.

Cancer medications are increasingly being placed on the highest cost sharing tier of prescription drug formularies, and this tier is often being assigned a coinsurance. In other words, the patient has to pay a percentage of the negotiated rate of the drug. The problem is, patients do not know the negotiated rate. So, if a cancer patient is shopping for a health plan and finds their drug listed on the formulary with a 30% coinsurance, they have no idea if that 30% translates into a dollar amount that is affordable to them. If you're a patient needing to know if you'll be able to afford your prescription drug AND your rent payment, or your drug AND groceries for your family that month, you'd have no way to find out what 30% means in terms of your family budget.



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@ACSCANMA



The Solution

Currently information about what prescription drugs a health insurance plan will cover, and what the patient's out-of-pocket costs will be, can be difficult to find during open enrollment and is sometimes password -protected until a consumer elects a plan.

The American Cancer Society Cancer Action Network (ACS CAN) supports consumer access to:

- ~ Health care plan prescription drug information before a plan is purchased, including
 - ~ the list of drugs covered
 - ~ the cost to the patient in real dollars,
 - ~ and any steps a patient must take in order for it to be covered by the plan.

ACS CAN also supports ensuring that this information is available:

- ~ In the same way across all health care plans to ensure that consumers can easily compare plans
- ~ and in an easily accessible manner via website and a toll-free number.

Health Plan Transparency = Better choices, better coverage, and better care for cancer patients.