



**LIVESTRONG** CANCER POLICY PLATFORM  
GLOBAL, FEDERAL AND STATE

**LIVESTRONG**

**LIVESTRONG** serves people affected by cancer and empowers them to take action against this disease that is now the world's leading cause of death. Founded as the Lance Armstrong Foundation in 1997 by cancer survivor and champion cyclist Lance Armstrong, the organization is now known publicly by its powerful brand—**LIVESTRONG**—and is a leader in the unified global movement on behalf of the 28 million people around the world living with cancer today. Originating with the iconic yellow wristband, **LIVESTRONG** has become a symbol of hope and inspiration to people affected by cancer around the world. Since inception, the organization has raised more than \$400 million for the fight against cancer. For more information visit [LIVESTRONG.org](https://www.livestrong.org).

## **A Message from our President and CEO**

At **LIVESTRONG**, our mission is to inspire and empower people affected by cancer. We do this by working to transform cancer care and policy and by fighting for people affected by cancer around the world. Most importantly, we strive to give cancer survivors hope. Hope that cancer does not have to be a death sentence and hope that survivors can live well beyond cancer.

For more than a decade **LIVESTRONG** has supported survivors, their families, caregivers, health care providers and anyone who is touched by cancer. We've made a tremendous amount of progress, but it is not nearly enough. In 2010 cancer became the leading cause of death worldwide, claiming more lives than AIDS, tuberculosis and malaria combined. We must continue to fight.

We started off as a small foundation in 1997 to help testicular cancer survivors. Through the tremendous assistance of our supporters, we've expanded from helping a few hundred people our first year to helping millions of survivors today. Our focus has shifted from testicular cancer to all forms of the disease. Our scope has broadened from addressing cancer in Texas and the United States to taking our cause global.

One of our goals has been to amplify the voices of the 28 million cancer survivors around the world. To that end, in 2009, **LIVESTRONG** supported Lance Armstrong, our founder, in his return to professional cycling to help raise awareness about our **LIVESTRONG** Global Cancer Campaign and the global burden of this disease.

We have always focused on the survivor—providing resources, education and direct, one-on-one support. But over the years we've learned that to help the individual, often you must effect policy change. This is the most effective way to help the most people.

That is why we advocate for key policy initiatives locally, nationally and globally. Our goals are to develop navigation services for new patients and survivors, including a navigation center at our headquarters in Austin, Texas; we'll keep fighting, nationally and internationally, to improve patient care and make cancer a priority in places where it's not; and we'll develop new ways to make cancer research more patient centered.

In the next year, we have a unique opportunity to change the face of this disease forever. In September 2010, the Clinton Global Initiative's focus was on cancer. The United Nations is sharpening its focus on finding approaches and solutions to non-communicable diseases including cancer. And we are now armed with the economic data we need to convince our world leaders of the toll cancer is taking on our global financial systems and on each and every nation. Now is the time to transform the way cancer is viewed and treated, from every level—state, national and global.

With the **LIVESTRONG** Cancer Policy Platform, you will learn how we believe we can transform the way the world fights cancer. We hope you'll join us.

**LIVESTRONG,**



Doug Ulman  
President and CEO,  
**LIVESTRONG**





## EXECUTIVE SUMMARY

LIVESTRONG supports key policy initiatives at the global, federal and state levels to improve the lives of people affected by cancer. We advocate that:

### **Global Policy Initiatives**

- All countries should develop and adopt national cancer plans.
- Funding for cancer research, prevention and treatment should be a priority.
- Multilateral organizations must integrate non-communicable disease targets into global health planning.
- Governments should support efforts to reduce cancer stigma.
- Universal access to cancer medications and care should be recognized as a human right.

### **Federal Policy Initiatives**

- All people living with cancer should have access to patient-centric quality cancer care.
- We must provide systems of support for people affected by cancer.
- We must inform and engage patients in order to enhance outcomes.
- The U.S. must invest in 21<sup>st</sup> century research and a learning health care system.

### **State Policy Initiatives**

- States should ensure the new federal health care reform law is enacted effectively.
- States should strengthen tobacco control measures, including smoke-free workplace laws and tobacco taxes.
- States should develop patient-centric electronic health information networks with a focus on improved individual and population health.
- States should pursue innovative funding measures to increase investments in cancer research and programs.
- States should prioritize the delivery of effective cancer pain relief and palliative care, including increased access to hospice.



LIVESTRONG CANCER POLICY PLATFORM  
GLOBAL PRIORITIES



## ALL COUNTRIES SHOULD DEVELOP AND ADOPT NATIONAL CANCER PLANS

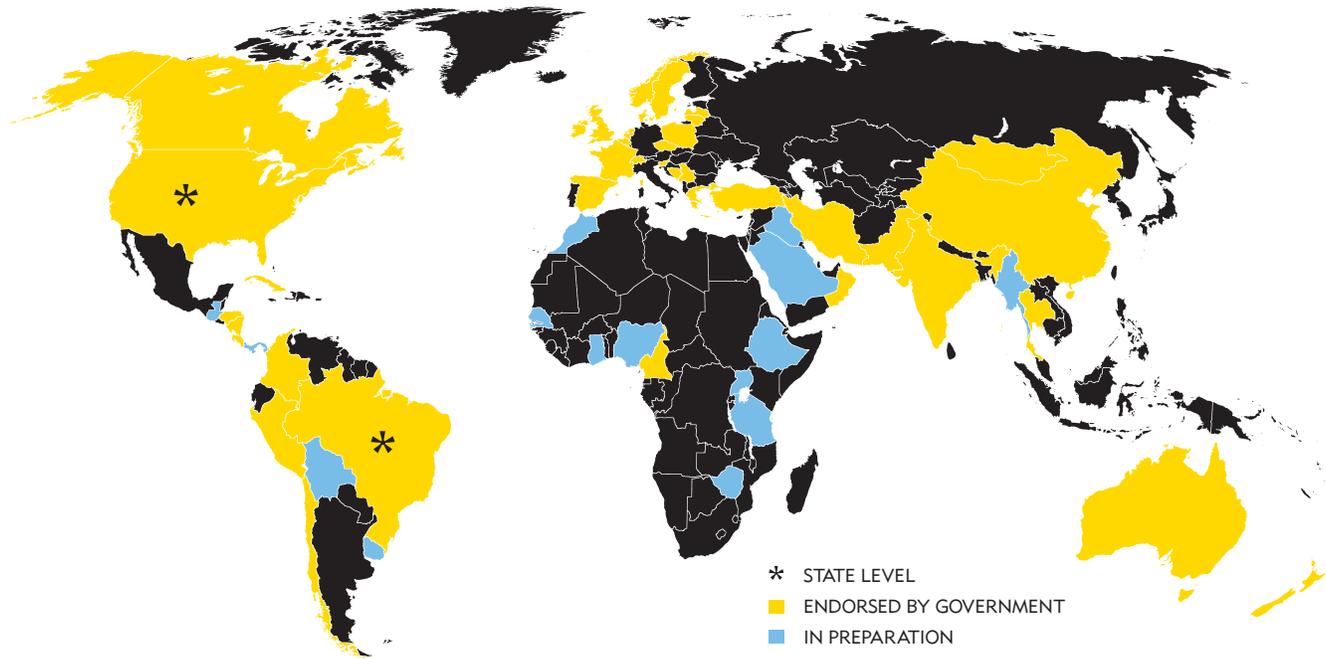
Every government should develop and adopt a national cancer plan—a coordinated strategy, goals and timeline for addressing the burden of the disease within their borders. Effective cancer control planning can lower cancer incidence and mortality and improve the lives of cancer patients.

A national cancer control plan creates a system for the coordinated use of evidence-based strategies to fight cancer. An effective plan will outline the country's specific cancer burden, the key stakeholders for implementation, the specific strategies for implementation, metrics and milestones for success and an outline for how the plan and its outcomes will be communicated. Objectives should be integrated across government sectors and national health priorities to maximize coordination and limit vertical policies or programs.

Cancer control planning allows countries to strategically address the challenge of cancer by making the best use of available resources, avoiding duplication and tailoring their approach to the specific needs of their populations. Planning should include evaluating various evidence-based strategies for prevention, early detection, diagnosis, treatment, survivorship and palliation and choosing approaches that are both high impact and affordable.

While cancer control planning can be an effective tool in maximizing and coordinating resources, many countries have yet to begin creating a national cancer control plan. By engaging multiple public and non-governmental stakeholders, countries can ensure sustained commitment and resources for cancer control. Every country, regardless of resource level, should develop a plan, tailored to its specific needs and infrastructure.

### COUNTRIES WITH NATIONAL CANCER CONTROL PLANS



## FUNDING FOR CANCER RESEARCH, PREVENTION AND TREATMENT SHOULD BE A PRIORITY

Funding for cancer research, prevention and treatment should be prioritized as a public health investment that will yield significant future savings. Greater public and private investment is needed to close the gap between current spending and the considerable financial burden of cancer borne by countries worldwide.

Cancer is currently responsible for one out of every eight deaths around the world annually. Cancer kills more people each year than AIDS, tuberculosis and malaria combined.

The global economic cost of new cancer cases in 2009 was more than \$305 billion (U.S.). However, funding to fight cancer has not kept pace with the growing cost of this disease. For example, despite the massive burden caused by non-communicable diseases (NCDs), in 2006–07, the World Health Organization (WHO) allocated only 12 percent of its budget to these diseases (including cancer). Center for Global Development estimates that less than 3 percent of global development assistance for health in 2007 was directed to non-communicable diseases including cancer. By some 2007 estimates, cancer received less than \$20 million of nearly \$22 billion in available funding.

The situation is particularly dire in the developing world. In 1970, only 15 percent of new cancer cases occurred in the developing world. Currently, over half of new cancer cases and almost two-thirds of cancer deaths now occur in low-income and middle-income countries, and the burden is expected to grow: By 2030, it is estimated that 70 percent of the global cancer burden will be borne by the developing world. Despite this fact, less than 5 percent of the world's resources are currently going to fight the disease in these countries. Immediate and sustained investment is necessary before the cost in human lives and the destruction of health systems become unbearable.

Effective and affordable interventions exist for countries at all stages of development.

Recent technological and policy breakthroughs make now the time to focus on cancer. With adequate funding this impending tidal wave can be alleviated.

By investing now in research, prevention, treatment and survivorship, we can save significant future cost—a cost that will only grow as the burden of cancer increases.

We must act now.

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“We cannot allow chronic diseases to even further amplify the health challenges faced by developing countries, especially when we know the solutions.”

— Ban Ki-moon, Secretary-General, United Nations

## MULTI-LATERAL ORGANIZATIONS MUST INTEGRATE NON-COMMUNICABLE DISEASE TARGETS INTO GLOBAL HEALTH PLANNING

Investments in essential public health infrastructure and education can have an impact on both non-communicable and communicable diseases. Multilateral organizations must integrate non-communicable disease (NCD) targets in global health planning to underscore the urgent need for governments, the international development community and philanthropic organizations to commit resources to meet the health needs of developed and developing countries alike.

In 2008, 38 million people died from the four main NCDs: cardiovascular diseases, diabetes, cancers and chronic respiratory diseases. This represents 60 percent of all deaths in the world—80 percent of which occurred in low-income and middle-income countries.

In 2009, the World Economic Forum (WEF) ranked chronic diseases as the third most likely risk to occur and the fourth most severe in its economic impact. WEF estimated that the severity of economic loss caused by chronic diseases would be surpassed only by a potential oil and gas price spike, retrenchment from globalization or asset price collapse. Furthermore, both the likelihood and severity of economic impact for chronic diseases are steadily increasing. In 2010, WEF updated its global risk assessment matrix, highlighting chronic diseases as one of three trends that have “the potential for wider systemic impact,” which is exacerbated by “greater resources constraints or short-term thinking.” The global burden of NCDs has the potential to limit productivity and economic growth nationally, regionally, and internationally. In 2010, **LIVESTRONG** released a report with American

Cancer Society citing that the global productivity lost from premature cancer-related deaths and disability in 2008 amounted to \$895 billion or 1.5 percent total global gross domestic product.

Currently, development policy around NCDs is often based on the assumption that the incidence of these diseases is limited to the rich or the elderly. Unfortunately, this assumption is incorrect; in fact, the poor often bear the double burden of both infectious and chronic disease. In addition, the cost of treatment and/or care for those with chronic diseases often causes a poverty trap for both individuals and their extended families.

The United Nations General Assembly recently took an important step to protect global health by voting to hold the first-ever summit on the threat posed by NCDs to low- and middle-income countries. The summit, involving heads of state, will be held in New York City in September 2011.

The summit will bring together public health experts and government officials from around the world to assess the dangers posed by NCDs and to develop a strategic response. To bring about real change that saves lives and improves global health, it will be critical that strategies for addressing non-communicable diseases are integrated into efforts to strengthen health systems, reduce poverty and enhance sustainable development.

By incorporating NCD targets into global health planning, we have the opportunity to stem the tide of an impending epidemic.

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“[C]hronic diseases are no longer just a medical or a public health problem. They are a development problem, and they are a political problem. The pressure not to make the right decisions will be enormous.”

—Margaret Chan, MD, Director-General, World Health Organization

## GOVERNMENTS SHOULD SUPPORT EFFORTS TO REDUCE CANCER STIGMA

Cancer patients and survivors deserve to live, and die, with respect and dignity, not stigmatization because of their disease.

The vast burden and impact of cancer around the globe is undeniable. As the incidence of cancer grows expeditiously, the stigma associated with cancer often acts as a barrier to treatment, leading to both increased incidence and mortality. Unfortunately, this stigma is pervasive—existing across countries, cultures and communities. Its origins are many: misinformation, lack of awareness, deeply ingrained cultural myths and fear. Many people believe that “cancer is not something to be talked about,” and quite often, that “cancer is a death sentence.”

This stigma is problematic because it often frames cancer patients as having done something to deserve developing the disease and it deeply affects the daily lives of those who have it. Many are judged negatively by family and friends, lose sources of income, are

socially isolated or, in extreme situations, are ostracized from their communities, left to suffer or die alone. These types of beliefs commonly lead to later-stage diagnosis and poorer prognosis, and in places where the stigma is severe enough, soaring mortality rates.

By directly combating this stigma and creating an arena for cancer survivors to share their experiences, we can increase awareness about cancer, remove barriers that prevent access to care and begin to change the course of this disease. Civil society organizations, in particular those serving cancer patients or survivors, have a unique role to play in empowering people affected by cancer and improving awareness about the disease.

Efforts to reduce stigma should be supported through the implementation of educational programs and awareness-building efforts, creation of support systems for patients and families and a health system that supports compassionate end-of-life care.

## UNIVERSAL ACCESS TO CANCER MEDICATIONS AND CARE SHOULD BE RECOGNIZED AS A HUMAN RIGHT

People are dying from cancer around the world for one simple reason—they are poor. Cancers that have largely become either preventable or treatable for those with means are still killing those without resources to fight the disease. While more than 50 percent of new cancer cases now occur in the developing world, almost two-thirds of cancer deaths occur there. And yet less than 5 percent of global cancer control resources are spent fighting cancer in these countries.

Drug pricing is prohibitive for most underserved populations. Working in collaboration with producers and delivery systems is imperative for significant improvement in care services.

No one should have to suffer from pain related to cancer. If we applied what we know now, cancer survivors around the world could receive the pain relief they need. We need balanced policies that ensure adequate access to pain medications while minimizing opportunities for abuse.

We must treat access to care as a basic human right—whether rich or poor, people affected by cancer deserve care and support. This should include not only access to chemotherapy, radiotherapy and/or surgery, but also information, education, pain control and the physical, practical and emotional support necessary to meet the needs of cancer survivors.

Like other diseases such as drug-resistant TB or HIV/AIDS, cancer traditionally has been viewed as too complicated to be treated. Historically, regimens were too complex, patients were uncooperative and treatment was viewed as a bad choice for resource allocation. We now know that these barriers can be overcome and people in even the most remote and challenging settings can receive the care they deserve.

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“I believe in health care as a human right. The fight for health care is a human right. The goal of preventing human suffering must be linked to the task of bringing others—many others—into a movement for basic rights.”

—Paul Farmer, MD, PhD, Co-founder, Partners in Health and Deputy UN Special Envoy for Haiti



LIVESTRONG CANCER POLICY PLATFORM  
FEDERAL PRIORITIES



## ALL PEOPLE LIVING WITH CANCER SHOULD HAVE ACCESS TO PATIENT-CENTRIC QUALITY CANCER CARE

Quality cancer care means ensuring that people living with and beyond cancer have access to patient-centered care and treatment that has been proven successful and is appropriate for the individual.

### **Insurance**

While important, health insurance coverage is not, by itself, adequate to ensure delivery of health care. Evidence-based disease prevention services should be provided as a standard component in every individual health care plan. Access to these services must not be effectively denied through unnecessary financial burdens, obstructive administrative rulemaking, geographic location or lack of qualified providers for these services.

### **Coordinated Care Delivery**

We must take full advantage of what we already know about delivering high-quality cancer care. National policies should support coordinated care among the various health care providers, focusing on each patient's overall dignity, health and well-being. Measuring and publicly reporting the use of best practices and/or quality of performance will drive improvement in the quality of care for cancer patients and survivors, while also providing them vital information for informed decision making.

### **Survivorship Care**

Treatment summaries and survivorship care services should be adopted as standard practices in comprehensive care, and national policies should support delivery of these services in community settings. Cancer survivors and caregivers should be engaged as active partners in their care strategies and provided with sufficient information to best navigate challenging decisions and to facilitate meaningful discussion with physicians.

### **Health Disparities**

Some racial and ethnic populations carry a disproportionate burden of poor quality cancer care in the United States—even after adjusting for socioeconomic factors. Adolescent and young adult cancer survivors face additional issues, including fertility, education and career challenges. A "one-size-fits-all" approach to cancer care does not adequately address the needs of a diverse population. Continued support in programs that give these underserved populations greater access to health care, education and care delivery in a culturally sensitive and competent manner will maximize our investments in serving these populations.

## WE MUST PROVIDE SYSTEMS OF SUPPORT FOR PEOPLE AFFECTED BY CANCER

The experiences of cancer and survivorship are not the same for everyone, though there is one prevalent common denominator: regardless of individual differences in diagnosis and treatment, all those affected by cancer find that the disease touches all facets of one's life. Thus a comprehensive care system must address the very real physical, emotional and practical needs of all people affected by cancer.

### **Patient Navigation**

Cancer patients and their families routinely report difficulty in coping with the diagnosis of cancer and the confusing maze of treatment and care. A comprehensive set of navigator tools should be provided by care systems and communities to support services across the cancer continuum from prevention and early detection through treatment and survivorship.

### **Psychosocial Support**

The current health care infrastructure lacks adequate psychosocial support delivery mechanisms, and appropriate insurance coverage for such services in this area is often abysmal or nonexistent. Psychosocial interventions and clinical management are absolutely critical to the quality of life of cancer patients and survivors. Providers of cancer care should adopt models to address these needs and incorporate psychosocial management services as an integral part of treatment.

### **Pain Management**

The appropriate management of symptoms is not only central to quality of life, but also has implications for the efficiency of the health care system. Palliation is a critical dimension of health care, and all patients should have access to practitioners skilled in appropriate palliative therapies. Comprehensive hospice and end-of-life care should be addressed to meet the needs of patients and families facing late stages of cancer. Balanced regulatory policies should be enacted to reflect the need for these services.

### **Employment Concerns**

Many cancer survivors require some accommodations to continue working throughout their treatment. Employers should implement cancer disease management programs among their employees as components of their overall health programs. These programs should include information regarding the increased risk of employment discrimination that affects people with cancer. Procedures should be established within diverse patient care settings to better inform patients/survivors and their caregivers about available legal and regulatory protections and resources.

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“In communities of low socioeconomic status, patient navigation has proved to be an effective intervention in promoting screening, timely diagnosis and treatment of cancer.”

— Harold P. Freeman, MD, President and Founder of the Ralph Lauren Center for Cancer Care and Prevention

## WE MUST INFORM AND ENGAGE PATIENTS IN ORDER TO ENHANCE OUTCOMES

Informed patients are knowledgeable about best cancer care strategies, from risk reduction and early detection through treatment and care. They participate with their care team in identifying all options and managing health strategies that are right for them.

### **Education, Prevention and Early Detection**

We must take advantage of what we already know about preventing and controlling cancer and support the implementation of a national infrastructure to provide these services consistently. We need unified national policies to reduce the use of tobacco products and promote healthy lifestyle choices that include proper nutrition and physical activity. In addition, education and awareness efforts must be linked with screening, early diagnosis and treatment. We need to invest in more research that addresses risk reduction, prevention, screening and early detection to stop cancer in its earliest stages.

### **Clinical Trials Research**

It is estimated that approximately 20 percent of cancer patients qualify for clinical trials, yet only 3–5 percent of adult patients actually enroll in a trial. As we enter the era of personalized medicine, it is increasingly important to ensure that cancer patients who are likely to respond to new drugs targeted to alterations in their cancer have awareness and access to these drugs. We need to provide resources to ensure that our research agencies like the NIH and FDA improve clinical trial design for “likely responders” to new drugs and that our health care system provides access to these drugs as potential options for patients.

### **Patient-Centered Outcomes Research**

Comparative clinical effectiveness studies evaluate the impact of various medical interventions on patient outcomes. Ready access to evidence about the effectiveness, benefits and risks of different treatments, better enables patients to make informed decisions with their health care providers. We need a transformed and modernized health care infrastructure that addresses patient-reported needs and outcomes while providing patients with evidence-based information on their treatment options, medical benefits, risks and the costs of these options.

## THE U.S. MUST INVEST IN 21<sup>ST</sup> CENTURY RESEARCH AND A LEARNING HEALTH CARE SYSTEM

A “learning health care system” is supported by an interoperable information technology infrastructure that virtually links patients, doctors, researchers and policymakers. This new system fills in knowledge gaps, transforming generalized strategies for care into actualized patient-centric care.

### **Research Funding**

While the U.S. needs a national, long-term commitment to increased investment in cancer research, funding alone is not sufficient to ensure transformation to a 21<sup>st</sup> century research system. Our current research infrastructure is fractured among patients, clinicians and researchers. The federal government needs to fund and conduct more coordinated research inclusive of the patient’s role and ensure that this research translates from bench to the bedside and back to the bench in a seamless feedback loop.

### **Personalized and Precise Medicine**

The hallmark of personalized medicine is to get the right treatment to the right patient at the right time. This will require evolving our current practice of intuitive medicine, based more on symptomatic diagnosis and clinical training, to precision medicine, based on molecular classification of cancer and targeted treatment. We need a national initiative for innovative technologies that support molecular-based clinical decision aids, patient awareness and engagement, and regulatory and reimbursement environments allowing development of paired diagnostics and treatments.

### **Electronic Health Information Exchange**

Electronic health information exchange is a foundational component for coordinated care, improved outcomes, enhanced value and patient-centered participation. Standardized and uniformly utilized electronic health records would support initiatives in research, early detection, treatment and survivorship and should be a national priority. In addition, patient safety, privacy and control of personal health information are pivotal components necessary to building a national Health Information Technology (HIT) framework.

### **Learning Health Care System Infrastructure**

We need an integrated and interoperable health care system capable of providing care, measuring quality, supporting innovation and allowing transparent, real-time data acquisition and analysis to continue to improve care. The system should adapt to an increasing role for patient input and patient-centered care driven by outcome-based and performance-based models of care delivery.

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“It is impossible to imagine a high-performing U.S. health care system that does not take full advantage of the computing technology that has transformed virtually every other aspect of human endeavor.”

—Dr. David Blumenthal, MD, National Coordinator for Health Information Technology

LIVESTRONG CANCER POLICY PLATFORM  
STATE PRIORITIES



## STATES SHOULD ENSURE THE NEW FEDERAL HEALTH CARE REFORM LAW IS ENACTED EFFECTIVELY

The historic passage of federal health care reform legislation in 2010 has provided a golden opportunity to positively impact the lives of people affected by cancer. Provisions in this law were based on the understanding that those who lack health insurance or who are underinsured have higher cancer mortality rates than those who have insurance that adequately provides access to consistent and quality care. This new law potentially provides access to health insurance for 32 million Americans who would otherwise remain or become uninsured.

Key provisions within this law seek to address many issues commonly faced by those affected by cancer. These measures include putting an end to discrimination by insurers against those with preexisting conditions and removing arbitrary annual and lifetime caps on health insurance benefits. In addition, routine costs associated with clinical trials, which can save lives and improve the quality of care for many others must now be covered by health insurance plans. And young adults faced with a cancer diagnosis—a demographic that has long been underserved within the previous health insurance system—can now be covered under their parents' insurance policy until their 26th birthday.

Over the past several years, many states already have enacted laws addressing health insurance issues contained within the recently passed federal legislation. For example, more than half of the states in the U.S. have passed laws requiring health plans to cover routine costs associated with clinical trials. States also will play a key role in expanding Medicaid and establishing health insurance exchanges that will provide coverage for millions of Americans. But to enact the provisions contained in the new federal law, states must create the rules and necessary regulations. This process cannot go unmonitored or left to develop without the voices of those affected by cancer.

**LIVESTRONG** encourages all state policymakers to actively and effectively engage cancer survivors and other stakeholders, specifically state Comprehensive Cancer Control Coalitions, as they write the rules and regulations that will implement the federal health care reform law at the state level. These individuals hold a wealth of knowledge, acquired through their unique experiences with cancer, that can help shape effective policies that will keep with the spirit of the federal law.

## STATES SHOULD STRENGTHEN TOBACCO CONTROL MEASURES, INCLUDING SMOKE-FREE WORKPLACE LAWS AND TOBACCO TAXES

Smoking-related illnesses claim more than 440,000 lives annually in the U.S. Almost one out of every three cancer deaths in the U.S. — 160,000 people a year — is the result of tobacco use. The U.S. Surgeon General released a report in June 2006 that clearly states there is no risk-free level of exposure to secondhand smoke. These facts and statistics leave no room for debate: It is in the public's best interest to be protected from all environmental tobacco smoke. Fortunately, a growing number of states and communities have passed comprehensive smoke-free workplace laws. Because states play a critical role in tobacco control, **LIVESTRONG** encourages all states to pass similar laws to ensure everyone's right to breathe clean air.

Raising tobacco taxes is another tobacco control strategy that creates a double benefit for states. Increased tobacco taxes create much-needed revenue and are proven to reduce smoking, which in turn saves lives. On April 1, 2009, the federal cigarette tax increased by 62 cents to \$1.01 per pack after Congress passed legislation to expand the children's health insurance program. The average

state cigarette tax is \$1.45 per pack and ranges from a high of \$4.35 in New York to 17 cents in Missouri.

Currently, nearly every state is facing severe budget shortfalls, forcing legislators to make tough decisions about raising revenue and cutting certain programs including health care and education. According to Campaign for Tobacco-Free Kids:

- Higher tobacco taxes have proven to be a reliable and predictable source of significant and immediate new revenue for the states. The declines in tobacco use also will produce considerable health care savings.
- Increasing tobacco prices by raising tobacco taxes is one of the most effective ways to reduce tobacco use, especially among youth.
- Majorities of voters of all political persuasions and demographic groups support increasing tobacco taxes.

**LIVESTRONG** strongly supports increases to state tobacco tax rates to fund public health programs and reduce the number of smokers.



"The debate is over. The science is clear. Secondhand smoke is not a mere annoyance but a serious health hazard."

—Richard H. Carmona, MD, MPH, FACS, 17th Surgeon General of the United States

## STATES SHOULD DEVELOP PATIENT-CENTRIC ELECTRONIC HEALTH INFORMATION NETWORKS WITH A FOCUS ON IMPROVED INDIVIDUAL AND POPULATION HEALTH

Adoption and use of Health Information Technology (HIT) and electronic health records have the potential to improve quality of patient care, prevent medical errors, increase the efficiency of clinical communication, reduce unnecessary or repeated tests and their associated costs, provide patient access to care summaries, improve population health and personalize a patient's care delivery. The 2009 federal stimulus bill directed funding toward state Health Information Exchanges and commits more than \$20 billion toward physician adoption of certified electronic health records.

States have a responsibility to ensure electronic health information is collected and exchanged in a responsible and trusted manner, one that protects the privacy and confidentiality of the patient, while also ensuring the information is utilized to benefit individual, public and population health.

Health Information Exchanges should prioritize collaboration with public health agencies and disease registries, including cancer registries, to improve real-time data collection and provide a more accurate understanding of the public health profile of the state. State health agencies should coordinate planning and governance of Health Information Exchanges with input from patient communities.

In addition, because of the potentially positive impact electronic health information applications may have on the health of economically disadvantaged populations and other populations with health disparities, states should prioritize programs to leverage use of this technology in these populations.

## STATES SHOULD PURSUE INNOVATIVE FUNDING MEASURES TO INCREASE INVESTMENTS IN CANCER RESEARCH AND PROGRAMS

Aside from a \$1.2 billion injection of funding for cancer research at the National Institutes of Health (NIH) in the 2009 federal stimulus bill, federal funding for cancer research and programs has been virtually flat for the past several years. Fortunately, cancer advocates in some states are taking matters into their own hands and pushing their elected officials to increase investments in cancer research and programs at the state level.

In 2007, the Texas Legislature passed—and Texas voters approved—a landmark \$3 billion bond initiative to establish the Cancer Prevention and Research Institute of Texas (CPRIT). This ten-year effort is expected to distribute \$300 million in grants annually to expedite innovation in cancer research and prevention in the state of Texas. The Institute is also responsible for implementing the Texas Cancer Plan, which is the blueprint for state cancer prevention and control programs. The push for the initiative started at the grassroots level, spurred by patient advocates and cancer survivors. CPRIT is now up and running in Texas and began awarding its first research and prevention grants in 2010.

A similar effort is underway in California. During the next statewide election, California voters will have an opportunity to vote in support of the California Cancer Research Act—a citizen’s ballot initiative that would create a trust fund to provide grants and loans for research on prevention, diagnosis, treatment and potential cures for cancer and other tobacco-related diseases. Funds also would be used for tobacco prevention and cessation programs administered by the state of California. If the measure is approved at the polls, the initiative will be funded by a \$1-per-pack increase to the state tobacco tax and is expected to raise approximately \$800 million annually for these programs.

The research funded by these investments has the potential to uncover lifesaving treatments. Additionally, the research programs promise to generate a positive economic impact for states. According to a recent Families USA study, every \$1 million NIH invested in biomedical research generated an average of \$2.21 million in new state business activity.

**LIVESTRONG** supports the efforts in Texas and California and encourages other states to consider similar solutions to invest in cancer research and programs.

## STATES SHOULD PRIORITIZE THE DELIVERY OF EFFECTIVE CANCER PAIN AND PALLIATIVE CARE, INCLUDING INCREASED ACCESS TO HOSPICE

Pain is one of the most common and feared symptoms of cancer. Cancer survivors may experience both acute and chronic pain following their treatment. State laws, regulations and guidelines – such as drug control laws and health professional regulations – can encourage or impair the quality of pain management.

Many states have established prescription monitoring programs to help reduce the amount of pain medication diversion that occurs when prescriptions are obtained illegally for non-legitimate reasons. Although prescription monitoring programs may help spot problem pharmacies and deter “doctor shopping,” they may also unintentionally cause delay for people with cancer who need to receive legitimate prescription medications on a regular and timely basis. Doctors also may be hesitant to prescribe appropriate medication for patients if they feel they could be “marked” as over-prescribing pain medication.

Care must be taken to ensure that monitoring programs allow cancer patients access to legitimate prescriptions for pain management. The Pain and Policy Studies Group at the University of Wisconsin has reviewed each state’s pain-related laws and developed criteria to evaluate how well each state is able to achieve a balanced pain policy.

In addition to facing unmitigated pain, facing the possibility of death from cancer is also difficult. Fortunately, palliative care programs and hospice are effective options to address physical and emotional pain and suffering when the goal changes from cure to comfort.

Palliative care includes recognizing and treating the physical, emotional, social, spiritual and practical concerns of a survivor at any stage of living with cancer or other life-limiting diseases, from the time of diagnosis throughout the survivor’s life. Recent studies have even demonstrated that effective palliative care programs not only improve quality of life, but can extend life.

Hospice provides invaluable care and support services for people with terminal illnesses, focusing on relief from pain and symptoms. These programs, often run by hospitals or private care organizations, may provide services on an inpatient or outpatient basis.

A handful of states mandate coverage of hospice services for private insurance plans and most, but not all, states’ Medicaid programs cover hospice services. Medicare typically covers the supplies and services related to a terminal illness; however, copayments among plans vary. Based on the evidence, states should ensure that:

- There is universal access to hospice and palliative care services.
- Services are regulated and licensed to provide adequate care.
- Health insurance plans and Medicaid cover hospice care.
- Assistance is provided for those who are in need of hospice services but unable to pay.

To learn more about **LIVESTRONG** programs and initiatives, and to download the full **LIVESTRONG** Cancer Policy Platform: Global, Federal and State, visit **LIVESTRONG.org**.

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