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AMERICAN CANCER SOCIETY CANCER ACTION NETWORK

## EXECUTIVE SUMMARY

## Introduction

This report presents findings from a major nonpartisan study examining how families affected by cancer fared in the health care system prior to enactment of the Affordable Care Act. The American Cancer Society Cancer Action Network (ACS CAN) commissioned Lake Research Partners and Bellwether Research \& Consulting to conduct a survey May 21 - June 2, 2010 among a nationally representative sample of 1,011 adults age 18 and older who say they or a member of their household has cancer or a history of cancer.

The survey looks at the difficulties that people with cancer faced in accessing and affording lifesaving care in the broken health care system. The survey was fielded barely two months after the March 23 signing Affordable Care Act into law - a time when nearly every major provision of the law had yet to take effect. The survey found that families affected by cancer faced mounting challenges in paying for needed health care and other basic necessities such as food and heat, underscoring the need to implement the Affordable Care Act to ensure that it works for people with cancer.

The survey also found that while most families affected by cancer lack awareness of key provisions of the new law, they strongly support those provisions after being informed about them. The vast majority of respondents believe it is important for the president and Congress to increase the federal investment in groundbreaking cancer research, which is critical to continuing our progress against a disease that will kill nearly 570,000 people in America this year.

ACS CAN, the advocacy affiliate of the American Cancer Society, is the leading voice of patients in the effort to improve access to quality health care nationwide. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority, and gives ordinary people extraordinary power to fight cancer by providing them with the training and tools they need to make their voices heard. Visit us at www.acscan.org.

## Summary of Key Findings

High health costs jeopardize the ability of families affected by cancer to afford the care they need.
Half of families with someone under 65 with cancer ( $49 \%$ ) say they have had difficulty affording health care costs, such as insurance premiums, co-pays, and prescription drugs, in the past two years.

High health costs also prevent people with cancer and their families from affording basic necessities. In the past two years, nearly one-third of families with someone under 65 with cancer (30\%) have had trouble paying for basic necessities or other bills, and $23 \%$ have been contacted by a collection agency. About one in five ( $21 \%$ ) has used up all or most of their savings, and one in six (18\%) has incurred thousands of dollars of medical debt.

Affordability of care is a major issue for people under 65, and for those most in need. As a result of costs, one in three individuals under age 65 diagnosed with cancer ( $34 \%$ ) has delayed needed health care in the past 12 months, such as putting off cancer-related tests or treatments, delaying cancer-related checkups, not filling a prescription, or cutting pills. Of those currently in active cancer treatment, one in three (33\%) has put off some type of health care in the past year due to costs.

People with cancer and their families struggle to stay insured. One in three families (34\%) with someone under age 65 with cancer say that person has been uninsured at some point since their diagnosis.

The costs of coverage continue to rise. Four in 10 families ( $42 \%$ ) with insurance say their premiums and/ or co-pays have increased in the past 12 months for the family member with a cancer diagnosis, and one in four ( $25 \%$ ) says his or her deductible has gone up.

Many doctors are not talking to patients about pain, anxiety, and other issues relating to quality of life. More than one-third of people with cancer or a history of cancer (36\%) say their doctor never talked with them about ways to relieve pain that may occur during or after treatment, and 42\% say their doctor did not regularly ask them about stress, depression, anxiety, or other emotional concerns related to having cancer.

Cancer patients and survivors show little familiarity with but strong support for Affordable Care Act provisions. Although families affected by cancer may have had a particularly strong motivation to pay attention to the health care reform debate, many lack awareness about fundamental provisions in the law. Once they learn of these provisions, more than $80 \%$ express support for each.

Cancer patients and survivors strongly support federal funding for cancer research. A large majority of respondents ( $89 \%$ ) thinks it is important that the president and Congress increase funding for cancer research and programs. By a large margin, they say they would be more likely (65\%) to vote to re-elect an elected official who advocates for cancer research and programs. Finally, $87 \%$ of respondents support increasing the federal tobacco tax to pay for cancer-related research and programs.

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## Insurance Status for People Diagnosed with Cancer

(Under age 65)

Q: Right now, (are you)/(is your [RELATIONSHIP]) covered by any form of health insurance or health plan, or (do you)/(does he/she) not have health insurance at this time?

Q: IF INSURED: Since (you were)/ (your [RELATIONSHIP] was) first diagnosed with cancer, has there ever been a time when (you/he/she) had to go without health insurance, even if it was just for a short time?


## Reasons for Being Currently Uninsured (Under age 65)



## Increasing Costs of Coverage

Q: IF INSURED: In the past 12 months, has the cost of (your)/(your [RELATIONSHIP's]) insurance gone up, either in premiums or copays?

Q: IF INSURED: In the past
12 months has (your)/(your [RELATIONSHIP's]) deductible
 gone up?


Total
Under 65

## Difficulty Affording Coverage Outside of Employer-Sponsored Insurance



## AFFORDABILITY <br> OF CARE

## Difficulty Affording Health Care in Past Two Years

All people diagnosed with cancer


In active treatment
50\%

Under 65 years old

## 49\%

Women

## Difficulty Affording Health Care in Past Two Years



## The Impact of Cancer on Financial Security



## Delayed Health Care Because of Cost



## Delayed Health Care Because of Cost (Service Specific)

Q: (Have you)/(Has your [RELATIONSHIP]) done any of the following because of the costs involved?



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## Problems with Insurance Coverage

insurance coverage of cancer treatment and care, such as the plan not paying for care or paying less than expected, reaching the limit of what the plan would pay, delaying or skipping treatment because of insurance issues, or wanting to see an out-ofnetwork doctor.


## Under 65



## QUALITY OF LIFE AND FOLIOW/UP CARE

## Pain Management

Total
Q: After (your/your relationship's) cancer diagnosis but before treatment, did a doctor or another person on the medical team talk with (you/your relationship) about ways to help relieve pain that (you/he/she) may have during or after cancer treatment?

Under 65


## Quality of Life

Q: After (your/your relationship's) cancer diagnosis but before treatment, did a doctor or another person on the medical team ask (you/your relationship) what is most important to (you and your family) (her/him and her/his family) in terms of quality of life during and after treatment?

Total


Under 65


## Quality of Life <br> (Emotional Side Effects)

Total
Q: After (your/your relationship's) cancer diagnosis but before treatment, did a doctor or another person on the medical team talk with (you/your relationship) about ways to help with the emotional effects of cancer and treatment, such as stress, depression, or anxiety?


Under 65


## Quality of Life (Physical Side Effects)

Q: After (your/your
relationship's) cancer
diagnosis but before
treatment, did a doctor
or another person
on the medical team
talk with (you/your
relationship) about
ways to help with the
physical side effects of
cancer and treatment,
such as fatigue and
nausea?


Under 65
Q: After (your/your relationship's) cancer diagnosis but before treatment, did a doctor or another person on the medical team talk with (you/your relationship) about ways to help with the physical side effects of cancer and treatment, such as fatigue and nausea?

## Discussion of Emotional Effects of Cancer

Total
Q: During and after treatment, did (your/ your relationship's) doctor or another person on the medical team regularly ask (you/your relationship) if (you were/he/she was) having any stress, depression, anxiety, or other emotional concerns related to the cancer?


Under 65


## Treatment for Emotional Effects of Cancer

> Q: If you have had emotional concerns as a result of having cancer, did a member of the medical team provide (you/your relationship) with information, care, or a referral for treatment for any of these emotional concerns related to cancer?


Under 65


## Summary of Care

Q: Did (your/your RELATIONSHIP's) doctor ever give (you/your relationship) a written summary of care? This would include information like (your/ your RELATIONSHIP's) diagnosis, (you/your RELATIONSHIP'S)
treatments, symptoms or side effects, and recommendations for follow-up care after treatment?

Total


Under 65


## ATITUDES TOWARD THE AFFORDABLE CAREACT

## Awareness of Affordable Care Act Provisions (All Respondents)



## Awareness of and Support for Affordable Care Act Provisions (All Respondents)



## When Do You Expect Most Provisions to Take Effect?



## CANCER RESEARCH EUNDING

## Importance of Increasing Funds for Cancer Research



## Government's Role in Fighting Cancer



## Would You Be More or Less Likely to Vote to Re-elect a Candidate Who Advocated for Cancer Research and Programs?



## Views on Increasing the Federal Tobacco Tax to Fund Cancer Research and Prevention Programs

Q: Would you support or oppose increasing the federal tobacco tax as a way to:


## Methodology

Lake Research Partners and Bellwether Research \& Consulting conducted the survey May 21 - June 2, 2010 among a nationally representative sample of 1,011 adults age 18 and older nationwide who say they or a family member living in their household has cancer or a history of cancer. The survey was administered online using KnowledgePanel ${ }^{\oplus}$, Knowledge Networks' probability-based panel (see www.knowledgenetworks.com/ganp). Knowledge Networks is the only Internet-based survey research company that randomly recruits participants using RDD and address-based probability sampling. Those without Internet access or hardware are provided both for participation on the panel. Panel members were screened for the presence of someone in the household with cancer or a history of cancer. Data from all responses, including those who did not qualify, were weighted to CPS benchmarks to reflect the overall U.S. population. The margin of sampling error for the survey is $\pm 3.1$ percentage points. The sampling error is larger for smaller subgroups within the sample.

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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 by providing them with the training and tools they need to make their voices heard. For more information, visit www.acscan.org.

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