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## Healthcare Reform Affects Cancer on Many Fronts

More coverage for treatment and prevention planned

**S**ophia Smith, PhD, MSW, was diagnosed with Hodgkin lymphoma at age 16 years. Years later, after giving birth to twins, she was diagnosed with breast cancer—possibly the result of previous radiation treatments.

Knowing the importance of health insurance, Dr. Smith chose jobs where she always would have coverage despite her cancer history—first at a large corporation (IBM) and now as a postdoctoral fellow in cancer care quality at the University of North Carolina at Chapel Hill.

Dr. Smith understands firsthand how lucky she is to have always had health insurance. A National Cancer Institute-funded study she conducted 5 years ago as a doctoral candidate at Duke University in Durham, North Carolina, added to the large body of evidence regarding the struggles cancer patients have faced for years.

She found that of 886 non-Hodgkin lymphoma survivors, 10% were denied healthcare insurance, 11% did not change jobs for fear of losing their healthcare insurance, and 3% lost their insurance—all directly related to having cancer.

After the passage of the federal Patient Protection and Affordable Care Act (PPACA) in March, however, those sta-

tistics are expected to change dramatically—most notably through the elimination of pre-existing condition exclusions and rescissions of coverage due to cancer.

### Provisions of the PPACA

“It’s a sea change in terms of all but eliminating discrimination against people just because they have cancer,” says John Seffrin, PhD, CEO of the American Cancer Society (ACS) and its Cancer Action Network. “The law is not perfect, and we have a lot of work to do with respect to implementation. But for the first time in my lifetime, we have the opportunity to build a much, much better healthcare system,” he says.

At least 160 provisions within the PPACA directly affect cancer patients in some way, he notes. The ACS estimates that the provisions, when implemented, will save a minimum of an additional 8400 lives that would have been lost to cancer per year. Dr. Seffrin adds that 8400 is a conservative estimate because it does not take into account life savings that will occur when the preventive services outlined in the law are more widely available and better used.

Five years ago, the ACS board decided to shine a light on the broken healthcare system, declaring that a new system had to create care that was affordable, available, adequate, and administratively simplified. The PPACA has provisions that address each of those areas. Although coverage of people with pre-existing conditions is not required until 2014, the insurance industry is already voluntarily cooperating with the spirit of the law, Dr. Seffrin notes. Removal of both lifetime and annual insurance caps—which have proven financially devastating to many cancer patients—will occur in 2014.

### Prevention and Education

The PPACA’s focus on preventive services is also seen as a crucial step toward improving cancer prevention and early detection (see “Key Provisions Affecting Cancer Patients and Survivors”). “The new prevention platform is critical,” Dr. Seffrin says. “We have no choice economically but to find ways to keep people healthy longer.” He cites a Milken Institute report that says a 10% reduction in the cancer mortality rate would equate to a \$4.4 trillion savings.<sup>1</sup>

In addition, physicians have been limited in terms of the patient education and prevention activities they provide because of lack of insurance coverage for such services; however, now that all US Preventive Services Task Force services with an “A” or “B” rating are covered and all out-of-pocket

- costs for these services will be eliminated, many more patients are likely to undergo screening examinations.

Further, the PPACA paves the way for increased participation in cancer clinical trials by requiring insurance coverage of standard patient care costs associated with the trials. With that key barrier eliminated, cancer research leaders are optimistic that adult patient participation in clinical trials (currently around 3% to 5%) will begin to grow.

### What It Means for Personalized Medicine

For proponents of personalized medicine, passage of healthcare reform legislation was reassuring.

“Originally, we were concerned that comparative effectiveness research—which is a large part of the reform



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—Amy Abernethy, MD

effort—would lock us into a 1-size-fits-all paradigm,” says Edward Abrahams, PhD, president of the Personalized Medicine Coalition (PMC), based in Washington, DC. “But we were very pleased that the law recognizes the principles of personalized medicine in improving science. Comparative effectiveness won’t just be comparing the red pill versus the blue pill to find out what works better at a lower cost.”

The PMC represents a broad coalition of interests that seek to advance the understanding and adoption of personalized medicine concepts and products. The organization notes that the new law will support personalized medicine through its comparative effectiveness provisions by:

- Including primary research on molecularly informed trials in the research agenda;
- Ensuring that research recognizes potential patient differences, including genetic and molecular subtyping;
- Improving the quality of science generated by comparative effectiveness research, incorporating new information and technological information into its studies, and reviewing and updating evidence as necessary and outlining what future research is needed to address perceived gaps;
- Incorporating research on patient preferences in the scope of work, including patient quality of life and physician choice; and
- Creating an independent research methods committee that includes experts in molecular diagnostics.

Although these provisions will help support personal-

ized medicine, the major barriers to the field remain—namely, lack of reimbursement for companion diagnostics, which are the hallmark of personalized medicine because they link therapy to a subset of the population, Dr. Abrahams notes. As a result, PMC continues to advocate for reimbursement.

According to Amy Abernethy, MD, associate director of Duke Comprehensive Cancer Center in Durham, North Carolina, the new law provides “incredible opportunities” in the fields of comparative effectiveness, health information technology, access to care, and personalized medicine.

Now that clinical decision makers have “multiple tools in their toolbox,” comparative effectiveness enables them to decide what the most appropriate tool is and when it should be used, she notes. That is a different approach from what the research community does now, which is to give a tool every chance to work and compare it to a less effective option.

“Randomized, controlled clinical trials are expensive and leave out many people we take care of, such as the elderly and people with comorbidities,” Dr. Abernethy says.

In addition to traditional, randomized clinical trials, researchers will now need all the elements of health information technology to gather appropriate data for comparative effectiveness research, she adds.

### Accountable Healthcare Organizations

Another important component of reform is the accountable healthcare organization (ACO), which comprises healthcare delivery networks of primary care physicians, 1 or more hospitals, and subspecialist groups that are formed to provide care to specific patient populations. Still in the demonstration phase, ACOs aim to improve efficiency and rein in costs, and networks would receive bonuses for providing high-quality, low-cost care.

“ACOs look a lot like managed care, but they’re more sophisticated, and we have to look at how to reblend care when we have a responsibility across the patient population,” Dr. Abernethy says. “If done well, the system will be more patient-centric, but the challenge is how to blend it into an American culture of capitated care while also building the scientific agenda.”

Although no one knows for sure whether the new PPACA provisions will truly control healthcare costs, many are hopeful. “If we’re diligent and careful and ... ask what’s best for the patient, then we’ll end up with something that’s light-years better than what we now have,” Dr. Seffrin concludes.

*Editor’s Note: Next month, CancerScope will look at health information technology’s role in healthcare reform.*

### Reference

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# Key Provisions Affecting Cancer Patients and Survivors

Among some of the most important provisions in the Patient Protection and Affordable Care Act affecting the cancer community are:

## Immediate Investments

- Immediate access to coverage for uninsured people with a serious pre-existing condition through high-risk pools.
- No lifetime limits for all plans; annual limits will be phased out by 2014.
- No rescissions except in the case of fraud or intentional misrepresentation.
- Coverage of preventive health services.
- Dependent coverage extended until age 26 years.
- Reduction in Medicare Part D prescription drug coverage gap (the “doughnut hole”).

## Disease Prevention and Early Detection

- Guarantees coverage and eliminates out-of-pocket costs for US Preventive Services Task Force prevention services with an “A” or “B” rating and mammography coverage for all women aged 40 years and older.
- Establishes a National Prevention Interagency Council and Strategy.
- Establishes a fund to be administered through the Department of Health and Human Services (HHS) to provide for expanded and sustained national investment in prevention and public health programs.
- Grants funding for state, local, and community-based prevention programs and services.
- Strengthens the primary care workforce through student financing; additional primary care residency programs; and training in cultural competency, prevention, and public health.
- Greatly increases community health center funding.

## Administrative Simplicity

- Develops and encourages the use of uniform explanation of coverage documents and standardized definitions.
- Assists consumers with coverage appeals and educates consumers on their rights and responsibilities.

## Quality of Life for Cancer Patients and Survivors

- Reauthorizes HHS’s Patient Navigator Program, which assists patients in maneuvering through the healthcare system and provides outreach and education.
- Requires commercial health plans and the Federal Employee Benefits Plan to cover patient care costs associated with participation in clinical trials that are approved or funded by a vari-



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The PPACA will help provide insurance coverage for uninsured individuals and will protect coverage for those being treated for cancer as well as cancer survivors.

- ety of federal agencies.
- Requires the HHS secretary to establish national priorities and plans to improve the quality of healthcare, including care coordination and chronic disease management.
- Authorizes an Institute of Medicine conference and report on pain management and an enhanced grant program to improve health professionals’ ability to assess and appropriately treat pain.
- Provides training grants in family medicine, general internal medicine, general pediatrics, physician assistantship, and geriatrics, giving priority to programs that apply team-based approaches to care.
- Expands career development awards to advanced practice nurses, clinical social workers, pharmacists, and psychologists.

Source: American Cancer Society Cancer Action Network

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