



May 26, 2010

The Honorable Kathleen Sebelius
Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

RE: OCIO-9994-IFC

Dear Secretary Sebelius:

I am pleased to submit the following comments on behalf of the National Coalition for Cancer Survivorship and twelve million cancer survivors in the United States, many struggling to find affordable health insurance coverage. In the preamble to the interim final rules regarding preexisting condition exclusions, lifetime and annual limits, rescissions, and patient protections, the Departments of Health and Human Services, Labor, and Treasury note that the interim final rules have as their primary beneficiaries "... people who generally already have some type of illness, injury or disability." This set of regulations will provide important relief to cancer survivors. Many have been unable to obtain insurance because of preexisting conditions, triggered annual or lifetime caps because of intensive and costly care, or the rescission of insurance coverage.

Preexisting Condition Exclusions

Those who have been diagnosed with cancer are at significant risk of exclusion from insurance coverage altogether or are subject to condition exclusions. The consequences for adults include job lock, where cancer survivors remain in their jobs to retain health insurance coverage despite the drawbacks of their current employment, or decisions to forgo necessary cancer care because of lack of insurance. For teens, the effects of preexisting condition exclusions can also be devastating. Many survivors of childhood cancer experience long-term effects of their cancer treatment, including some that are serious and require significant follow-up care. These teen and young adult survivors may find that care is out of reach because they are uninsurable, even through their parents' insurance coverage.

The recently released regulations on dependent coverage provide significant relief to teens and young adults by providing coverage up to age 26 for many of them through their parents' health insurance. The interim final rules would provide potential relief to another young survivor group by extending preexisting condition protections to those under age 19 who are enrolled in certain insurance plans and policies.

The interim final rules make clear that the preexisting condition protections will not apply to individual policies that are considered "grandfathered." The preamble includes advice to families who are currently enrolled in individual grandfathered plans to drop that coverage and seek coverage through an individual plan that is not grandfathered and that would be subject to preexisting condition rules. This counsel to

families and teens is useful, but it underscores the need for an aggressive consumer education program to explain the provisions of the Affordable Care Act that are soon to be implemented and to provide concrete advice to permit appropriate utilization of the Act's benefits. We appreciate the ongoing consumer education efforts of the departments and also pledge to undertake our own efforts aimed at cancer survivors. However, creative and constructive advice from the departments, such as that included in the interim final rules, will be necessary to fully publicize the Affordable Care Act's protections for consumers.

Rescissions

The preamble to the interim final rules cites findings from Congressional investigations that cancer patients, who may require expensive therapy, are among those frequently targeted for rescissions of coverage. The Affordable Care Act and the final interim rules offer important protections to cancer patients, who will no longer be subject to rescissions because the cost and intensity of their care attract the attention of their insurer and prompt an inappropriate rescission. The rules provide concrete and useful examples of what does and does not constitute "fraud or an intentional misrepresentation of material fact" that would support a rescission.

Annual Limits

We commend the departments for developing a transition to the elimination of annual limits beginning in 2014 by increasing incrementally the minimum annual limits from 2010 to 2014. As the preamble notes, however, some cancer patients are among those consumers with exceptionally high costs of care. A cancer patient undergoing aggressive multidisciplinary care, including surgery, chemotherapy, and radiation therapy, could easily hit the minimum annual limits included in the interim final rules.

We recommend that these limits be increased. Because relatively few consumers will hit annual limits – although a larger proportion of cancer patients than patients with most other serious illnesses – the cost of increasing the limits will likely have a relatively small impact on premiums.

Patient Protections

The departments provide persuasive justification for the rules governing the right to designate a primary care physician, choose a pediatrician as primary care physician, and access emergency services at in-network rates. As the departments note, these patient actions can contribute to improvement of the quality of care, enhanced patient compliance with care, and coordination of complex care. The Affordable Care Act provides additional opportunities for demonstration projects to test care planning and care coordination beyond the modest but important efforts addressed in the interim final rules, and we urge the departments to take full advantage of these opportunities to enhance delivery of health care.

We appreciate the opportunity to offer comments on these interim final rules, which offer special protections to cancer survivors and others with serious and life-threatening illnesses.

Sincerely,



Thomas P. Sellers, MPA
President and CEO
11-year Cancer Survivor

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