CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS ADDRESSING PUBLIC POLICY ISSUES IN CANCER

October 21, 2011

Donald M. Berwick, M.D.
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Room 445-G
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

RE: CMS-9982-P and CMS-9982-NC

Dear Dr. Berwick:

The undersigned organizations of the Cancer Leadership Council (CLC), representing cancer patients, physicians, and researchers, appreciate the opportunity to comment on the proposed rule on the Summary of Benefits and Coverage and the Uniform Glossary and the accompanying templates, instructions, and related materials. We applaud the Departments of Health and Human Services, Labor, and Treasury for their work to develop a summary of benefits and coverage (SBC) that "accurately describes the benefits and coverage under the applicable plan or coverage." We understand that the Departments have adopted the SBC recommendations of the National Association of Insurance Commissioners (NAIC), developed through a working group process that included diverse stakeholders.

The SBC is a document of critical importance to the successful implementation of the Affordable Care Act, as it will provide uniform, standard information about health plans to plan enrollees and those shopping for coverage. We appreciate the significant challenges associated with developing a four-page, double-sided SBC that can be understood by consumers, and we commend the work to date. In the comments below, we recommend some additions to the SBC, including three new coverage examples. We make these recommendations with the understanding that incorporating new information will require streamlining or elimination of information in the draft SBC. This represents a daunting challenge, as the proposed SBC is concise and focused on critical consumer information.

CONTACT: 2446 39TH STREET NW · WASHINGTON, D.C. 20007
Phone: 202-333-4041 · www.cancerleadership.org

Coverage Examples

The Departments are to be commended for including "Treating breast cancer" as one of the three coverage examples in the SBC. We understand that coverage examples have been shown to be effective in assisting consumers in understanding in concrete terms what plans will cover, what they will not, and the cost-sharing responsibilities of patients. Coverage examples may also trigger: 1) a consideration by individuals of their own risk factors and 2) a well-informed evaluation of health care needs. Because of the value of the coverage examples, we urge the Departments to include three additional examples, to the limit of six that was previously set.

We recommend that the Departments consider additional coverage examples that would permit analysis of: 1) the medical needs of children with genetic diseases, chronic conditions, or life-threatening illnesses like cancer, 2) the services and goods, including care in a clinical trial, for those cancers where the treatment options may be limited and the treatment pathways unclear, and 3) the health care needs of those who have undergone intensive treatment for a disease or condition and require aggressive and long-term monitoring and follow-up care. The last group would include survivors of many forms of cancer, as well as those who have been treated for a number of other serious and life-threatening illnesses. We propose that the coverage examples include an additional line in the "You pay" category for the cost of out-of-network care. We appreciate the difficulty of estimating this cost, but inclusion of the line in the coverage examples would heighten consumers' awareness of their potential financial exposure.

Inclusion of a coverage example related to children and young adults will permit analysis of cost-sharing in family coverage, as compared to an individual plan.

Premium Information

The CLC recommends that information about premiums or cost of coverage for policyholders and group health plan enrollees be included in the SBC. Although this language is not required by the statute, we support its inclusion in the SBC, as proposed by NAIC. Premium information will assist consumers in making informed decisions about the value of the health coverage they will be purchasing, compared to its cost. Combined with more coverage examples, this information will empower consumers to more accurately evaluate their own health care needs and the cost of purchasing appropriate coverage.

Glossary

We recommend the addition of a number of terms to the glossary of health insurance and medical terms. These additions are intended to equip enrollees and plan applicants to make informed comparisons among plans for coverage of effective and high-quality cancer care, as well as care for other serious and life-threatening illnesses. The glossary terms we recommend would permit evaluation of plans for their coverage of the drugs

and biologicals that are a cornerstone of cancer care, multi-disciplinary care that is routinely required by cancer patients, and clinical trials that may represent the only treatment option for many cancer patients.

The following terms should be added to the glossary:

- Prescription drugs –preferred brand, non-preferred brand, generic
- Prescription drug tiers
- Specialty drugs
- Formulary
- Drugs and biologicals – self-administered prescription drugs and physician-administered drugs
- Participating providers
- Network
- Out-of-network provider
- Preexisting Condition
- Clinical Trials – routine patient care costs
- Diagnostic tests --to inform treatment decision-making and treatment monitoring

There should be a clarification and comparison of the terms "participating and non-participating," "preferred and non-preferred" and "network and out-of-network" providers so that consumers can understand the costs and benefits of each. We also recommend that the current glossary entries for "co-insurance" and "co-payment" be included in a general entry for cost-sharing. There is significant confusion among consumers – those who are insured and applicants for coverage – regarding co-insurance and co-payments, and the glossary might be effective in addressing this lack of clarity by more clearly comparing and contrasting these terms.

Making the SBC Available to Consumers

The undersigned organizations have a long history and continued active involvement in the distribution of educational materials to consumers, and that experience informs our advice about distribution of the SBC. Although most organizations are increasingly utilizing electronic media for the distribution of educational materials, that method of distribution cannot be an exclusive solution. The organizations' experience is confirmed by national surveys that describe serious limits to ready access to the internet for many Americans. Experience and research combine to suggest that the SBC must be available in electronic form but also available in printed format that can be distributed by mail upon request.

Require All Plans to Provide the SBC

We are mindful that plans that are governed by the Employee Retirement and Income Security Act (ERISA) are required to provide a summary plan document (SPD), describing covered benefits and enrollee rights and responsibilities, to enrollees. The typical SPD – lengthy, complex, and written at first-year college reading level – would not permit easy comparison of the plan it describes with those described by a summary of benefits and coverage. As a result, the typical SPD would not fulfill the goals of the summary of benefits and coverage.

We recommend that all plans be required to provide the SBC; in the case of ERISA plans, the SBC should be separate and distinct from the SPD. We acknowledge that there is a cost to plans and plan sponsors associated with the development of the SBC, but on a system-wide basis that cost is limited. If the cost is estimated on the basis of a covered life, it is only a fraction of a dollar per covered life.

Effective Date

We advise that the SBC requirement be imposed on March 23, 2012, or as soon as possible after that date. We are suggesting some flexibility because we have proposed specific revisions – the addition of coverage examples and expansion of the uniform glossary – that should be incorporated in the SBC, and we understand these changes cannot be accomplished without some review and action by the Departments. The addition of coverage examples, of critical importance for better understanding of insurance options and purchase, will require substantial modification of the SBC if the form is to remain a four-page, double-sided document. Insurance issuers and plan sponsors deserve predictability in terms of the requirements imposed on them. A modest delay in effective date would be acceptable for the sake of a stronger SBC and predictable requirements for issuers and plans.

***

We appreciate this opportunity to comment on the SBC and uniform glossary. We urge the Departments to institute a process for ongoing evaluation of the SBC, and we stand ready to assist in SBC review by bringing to this task the expertise of our professional patient service and education teams and patient advocate members.

Sincerely,

Cancer Leadership Council

American Society for Radiation Oncology
American Society of Clinical Oncology
Cancer Support Community
The Children's Cause for Cancer Advocacy

CONTACT: 2446 39TH STREET NW · WASHINGTON, D.C. 20007
Phone: 202-333-4041 · www.cancerleadership.org

Fight Colorectal Cancer
International Myeloma Foundation
Kidney Cancer Association
The Leukemia & Lymphoma Society
LIVESTRONG
Lymphoma Research Foundation
Multiple Myeloma Research Foundation
National Coalition for Cancer Survivorship
National Lung Cancer Partnership
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Prevent Cancer Foundation
Sarcoma Foundation of America
Susan G. Komen for the Cure Advocacy Alliance
Us TOO International Prostate Cancer Education and Support Network

CONTACT: 2446 39TH STREET NW · WASHINGTON, D.C. 20007
Phone: 202-333-4041 · www.cancerleadership.org