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Donald Berwick, M.D  
Administrator  
Centers for Medicare & Medicaid Services,  
Department of Health and Human Services,  
*Attention:* CMS-9982-P, CMS-9982-NC  
P.O. Box 8016,  
Baltimore, MD 21244-1850.

***RE: CMS-9982-P: Summary of Benefits and Coverage and the Uniform Glossary, and CMS-9982-NC: Summary of Benefits and Coverage and Uniform Glossary- Templates, Instructions, and Related Materials under the Public Health Service Act***

Dear Dr. Berwick:

Susan G. Komen for the Cure® (Komen) generally supports the provisions included in the *Summary of Benefits and Coverage and the Uniform Glossary, Notice of Proposed Rulemaking*, issued by the Departments of Health and Human Services, Labor, and Treasury (Departments).<sup>1</sup> These draft regulations propose requirements for the summary of benefits and coverage, under Section 2715 of the Public Health Service Act (PHS Act), as added by the Patient Protection and Affordable Care Act of 2010 (Pub. L. 111-148, as amended by Pub. L. 111-152), collectively referred to as the ACA.

Komen is the largest grassroots network of breast cancer survivors and advocates. At the heart of Komen's mission is saving lives, empowering people, ensuring quality care, and energizing science to find the cures. Since 1982, Komen has played a critical role in every major advance in the fight against breast cancer. The 2.6 million breast cancer survivors living today in the U.S. can attest to the fact that improved screening, education and outreach, treatment, and pioneering research have saved many lives. Yet, much remains to be done since, just this year alone, 230,480 new cases of invasive breast cancer are expected to occur and nearly 40,000 women in the U.S. will succumb to the disease. On behalf of breast cancer survivors those who will fight it

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<sup>1</sup> Department of Treasury, Department of Labor, and Department of Health and Human Services, *Summary of Benefits and Coverage and the Uniform Glossary, Notice of Proposed Rulemaking*, 76 Fed. Reg. 52442 (Aug. 22, 2011).

in the future, and those who love them, Komen appreciates this opportunity to provide these comments.

Section 2715 of the PHS Act directs the Departments, in consultation with the National Association of Insurance Commissioners and a working group of stakeholders, to develop standards to be used by group health plans and health insurance issuers for the development of their Summary of Benefits and Coverage (SBC) explanation that will be provided to applicants, enrollees, policyholders, and certificate holders. The intended purpose of the SBC is that it “accurately describes the benefits and coverage under the applicable plan or coverage.”

We support and applaud the goal of providing standardized formats and page limits for the SBC. A concise and easy-to-understand presentation of a plan’s benefits will facilitate the consumer’s ability to evaluate coverage and compare plans, enabling the consumer to make better decisions for themselves and their families regarding health care coverage.

These regulations are intended to help make it easier for consumers to compare policies thereby helping to reduce time and confusion during the decision-making process. The better consumers understand their options, the better decisions they can make for themselves and their families.

Komen also supports the development of a uniform glossary of health coverage and medical terms. Below we offer comments on the specific issue of the ability of the average health care consumer to comprehend and practically apply this information, which we believe is a fundamental issue that will determine the usefulness of these documents for consumers. Additionally, we offer comments on how to improve the coverage examples portion of the SBC, particularly with respect to breast cancer treatment.

#### Summary of Benefits and Coverage

We appreciate the sensitivity given to reading level and the process of collaboration that was used to solicit input in the development of the glossary. We are concerned, however, about how the requirements will be practically implemented. Our specific concern is that the instruction guide for group policies will not meet the goal of presenting information in a way that

consumers, such as breast cancer patients, can easily understand. We are concerned that the content of the text is too dense and the reading level appears to be at a level above that of the average health care consumer. After reviewing the content, it appears that only those who have completed an education at a post-college graduate level will be able to read these documents with ease. It is also well-documented that consumers have a difficult time understanding health insurance today, and low health insurance literacy rates are pervasive.<sup>2</sup> The purpose of the SBC is to provide an easy-to-read and easy-to-comprehend document that compares plans.

Specifically, we are concerned that the content is well beyond the 8<sup>th</sup> grade reading level, which is the reading level of the average adult in the U.S.<sup>3</sup> We believe that the reading level and technical vocabulary in the SBC documents will impede patients from fully comprehending their benefits and that it will cause some people to forgo reading them all together. The Departments should consider alternative communication methods to facilitate better consumer understanding of their benefits. For example, a video overview on a website would present the information in a way that would not require advanced reading skills. The Departments could also consider further focus group testing to ensure that material is better suited to general literacy levels.

### Coverage Examples

Komen supports the inclusion of up to six (6) common benefits scenarios in the SBC. Rather than the SBC simply advising consumers that the usual and customary cost will be covered, these more detailed benefits scenarios will offer specific coverage information. With breast cancer affecting 1 in 8 women in their lifetime, we are particularly encouraged that breast cancer has been identified as one of these sample benefits scenarios.

More effectively communicating coverage information in a manner that can be well understood by health care consumers is critically important. This is especially true because plans can vary significantly in cost-sharing for covered care. This was highlighted in a 2009 study that

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<sup>2</sup>See, Uniform Coverage Summaries for Consumers,” *Focus on Health Reform*, THE HENRY J. KAISER FAMILY FOUNDATION, available at <http://www.kff.org/healthreform/upload/8244.pdf>.

<sup>3</sup>See *National Adult Literacy Survey Data*, (“The average reading level in the U.S. is 8th grade, and 20 percent read at the 5th grade level or below. (*NALS data*),” cited by National Partnership for Clear Health Communication, at the National Patient Safety Foundation, “What is Health Literacy,” available at <http://www.npsf.org/pchc/health-literacy.php>.

compared plans offered in the Massachusetts Commonwealth Connector that determined that a breast cancer patient's care costs might be approximately \$7,600 under one plan, but more than \$12,000 under another plan, based on the same actuarial value and providing an equivalent level of coverage.<sup>4</sup> Consumers need to be aware that significant cost-sharing differences can exist from one plan to the next, so that they can make informed comparisons and better decisions regarding their health insurance.

When developing the specifics of these benefits scenarios, it is also important that related care, such as counseling and fertility preservation, be addressed, along with post-treatment care. We are concerned that these may not fit within the categories included in the proposed template for treating breast cancer. Komen suggests that this template be modified to include survivorship care and counseling (including care beyond general counseling and services such as genetic counseling and fertility preservation) as categories. These are also important considerations when selecting health coverage.

### Uniform Glossary

Additionally, Komen has concerns about the requirements for the glossary of insurance and medical terms. While the use of color and illustrations will help consumers compare one plan to another, the reading level is still equivalent to 12<sup>th</sup> grade or higher. We believe that the text that is permitted by the draft regulations still may be beyond the understanding of many of consumers and patients, which would be contrary to the "plain language" and "linguistically and culturally appropriate" statutory requirements included in the ACA.<sup>5</sup> To ensure that the purpose of these regulations is actually met, we recommend the Departments seek further simplification of the language in these documents.

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<sup>4</sup> See, Uniform Coverage Summaries for Consumers," *Focus on Health Reform*, THE HENRY J. KAISER FAMILY FOUNDATION, available at <http://www.kff.org/healthreform/upload/8244.pdf>.

<sup>5</sup> Department of Treasury, Department of Labor, and Department of Health and Human Services, *Summary of Benefits and Coverage and the Uniform Glossary, Notice of Proposed Rulemaking*, 76 Fed. Reg. 52449, 52454 (Aug. 22, 2011). See also, "Uniform Coverage Summaries for Consumers," *Focus on Health Reform*, THE HENRY J. KAISER FAMILY FOUNDATION, available at <http://www.kff.org/healthreform/upload/8244.pdf> ("The SBC must be brief- no longer than 4 double-sided pages according to the regulation. It must use words understandable to the average consumer and be presented in a culturally and linguistically appropriate manner. It cannot contain 'fine print.'")

Again, thank you for this opportunity to comment and share our views and concerns with the Departments on this important topic. We appreciate your taking our suggestions into consideration. If you have any questions or would like any additional information, please do not hesitate to contact me or Karen Handel, Senior Vice President, Public Policy, Komen Advocacy Alliance, at 202.654.6536 or [khandel@komen.org](mailto:khandel@komen.org).

Sincerely,

Elizabeth Thompson  
President  
Susan G. Komen for the Cure®