



December 9, 2013

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Dear Dr. Moyer and esteemed USPSTF panel members:

Thank you for your response to our letter dated October 12, 2013. We greatly appreciate you taking the time to consider our concerns and your acknowledgement of the importance of these guidelines for consumer access to preventive services provided under the PPACA. After considering your thoughtful letter dated November 18, 2013, we feel compelled to respond to the points made in your reply.

Regarding point 1 of your response, we appreciate your rewording of the "Patient Population Under Consideration" to clarify that the guidelines apply to women with a known mutation in the family. We request that the change states clearly that the "B grade" extends to this subset of the population. However, we remain deeply concerned about other aspects of these guidelines that will restrict consumer access to preventive services. We respectfully submit this letter, signed by members of our community, health care experts, organizations and other stakeholders, to appeal to the USPSTF to reconsider the points addressed below.

In point 2 of your response, you stated: "...women who have the diagnosis of breast or ovarian cancer, that assessment is part of disease management and is beyond the scope of this recommendation. The Task Force recognizes that genetic counseling and testing may be an important part of disease management for women who have been diagnosed. However, the Task Force's mission is to determine the evidence-base for preventive services in the general population who have no signs or symptoms of disease."

We respectfully disagree on this point. While BRCA test results can affect the surgical management of women newly diagnosed with breast cancer, it is important to recognize that BRCA testing has clinical utility for preventive services in women diagnosed with cancer, separate from and well beyond their disease management. Consequently, genetic risk assessment is still recommended for women whose personal and/or family medical history indicates a possible mutation **even after they have completed their treatment for cancer and have no evidence of disease**. These women meet the definition of having no signs or symptoms of disease.



As we previously stated, women with a BRCA mutation and a cancer diagnosis face a high risk for a second primary cancer that is unrelated to their initial diagnosis, and therefore outside of their disease management. We urge you to include them in the population under consideration. Omission of breast and ovarian cancer survivors from these guidelines is inconsistent and will negatively impact their access to care and coverage for preventive services under the PPACA.

We also respectfully disagree with point 3 of your response that states, “Individuals and populations who are at increased risk for certain cancers are addressed within the specific recommendations for those cancers.” We find this statement confusing because we could find no USPSTF breast cancer screening recommendations that include women with a BRCA mutation. We would appreciate clarification regarding where these guidelines exist. In light of the fact that the PPACA specifically cites the USPSTF guidelines for appropriate screening and preventive services, insurers may not recognize guidelines developed by other entities outside of the USPSTF.

We have already submitted separate comments on the USPSTF’s “Draft Research Plan for Breast Cancer Screening” about this topic. However, if the population under consideration remains limited to women in the general population, then the Breast Screening Guidelines will continue to exclude women with mutations under graded recommendations.

In your own words:

“As experts in primary care, we all want better screening, better treatments, and better ways to prevent breast cancer. My Task Force colleagues and I know and respect that this is an important and deeply personal topic for women, families, and communities across America. We invite you to join us in our work on this important topic.”

Given these statements, it is disappointing that these guidelines still overlook preventive services for women who are at the highest risk for breast cancer even while these services have been evaluated for the general population. It is inconsistent and confusing that the USPSTF offers guidelines for primary care providers to identify high-risk women, yet offers these practitioners no guidance for provision of preventive services to manage their risk. We urge you to provide an evaluation of preventive services for this population that is comparable to the effort afforded to women of average risk. In the absence of such guidelines these women will face significant barriers to accessing preventive services, due to gaps in primary care provider knowledge about appropriate breast cancer screening and lack of guaranteed insurance coverage for these services without co-pay or deductible as provided within the PPACA.

Thank you once again for consideration of our concerns. We respectfully request a written response that specifically addresses these remaining concerns.



Sincerely yours,

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