# CANCER LEADERSHIP COUNCIL 

## A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS

 ADDRESSING PUBLIC POLICY ISSUES IN CANCERJune 21, 2019
Mick Mulvaney
Director
Office of Management and Budget
Russell Vought
Acting Director
Office of Management and Budget
Nancy Potok
Chief Statistician
Office of Management and Budget
Dear Director Mulvaney, Acting Director Vought, and Ms. Potok:
The undersigned organizations representing cancer patients and health care professionals are writing to express concerns about the initial steps taken by the Office of Management and Budget (OMB) to adopt a new index for inflation adjustment in programs operating under current poverty guidelines. Changing the inflation rate index may cause vulnerable cancer patients to face even greater challenges in affording their health care, addressing their food insecurity, and managing their households.

A diagnosis of cancer is life-changing, as patients make choices about treatment, initiate treatment, manage the side-effects of cancer and cancer treatment, and transition to survivorship. For many cancer patients, the side effects of cancer include financial toxicity. The financial burdens of cancer treatment include the cost-sharing patients face for their care, costs of transportation to care, costs of health care goods and services not covered by insurance, and the time lost from work. To manage these costs of care, patients rely on savings, financial assistance from families and friends, and even crowd source funding for their care. Some unfortunately face bankruptcy because of their cancer diagnosis.

Cancer patients have relied in some cases on public programs for health care access and on public programs for food and nutritional assistance critical for their treatment and recovery.

If changes are to be made to programs that operate under poverty guidelines, those changes should be an improvement of the Official Poverty Measure (OPM). The OPM is based on an old formula that is considered to underestimate the current costs of supporting a family. ${ }^{1}$ Instead of addressing the OPM, the OMB is suggesting a new inflation index that will result in lower inflation adjustments. Lower inflation adjustments will affect poverty guideline revisions and in turn weaken the important financial assistance that people with cancer receive to address their needs.

The OMB notice of May 7, 2019, asks for comments on the strengths and weaknesses of a range of indexes for the calculation of inflation but does not solicit comment on the impact of changing the Department of Health and Human Services (HHS) poverty guidelines. In identifying the inflation indexes that might be considered, OMB has stressed its role in the efficient coordination of Federal statistics. We appreciate that role for OMB, but OMB must also analyze the impact of the inflation indexes under consideration on programs operating under poverty guidelines and after receiving public comment on the potential effects of changing the poverty guideline calculation.

Although we understand the responsibilities of OMB in oversight of federal programs, we caution against changes in the statistics that are used for inflation adjustments until the impact of the changes on Americans are analyzed. For the patients we represent, the effects of these changes on their access to adequate and affordable health care must be evaluated.

We strongly recommend that OMB consider the following issues as part of its evaluation of a new index for inflation rate calculation:

- The implications of poverty line changes for Affordable Care Act premium assistance, including the magnitude of reductions in premium assistance and the number of Americans who will be affected by these reductions;
- Analysis of the impact of new methods for updating the poverty line on the calculation of the Medicare Part D low-income subsidy (LIS);
- Analysis of the number of Medicare Part D beneficiaries who will be affected by LIS changes and how the changes will affect people with cancer;
- Analysis of the number of women who would lose access to critical breast screening, diagnosis and navigation through the National Breast and Cervical Cancer Early Detection Program;
- Changes in Medicaid and CHIP eligibility standards and the effects of those changes on people with cancer, including the children with cancer who rely on Medicaid for their cancer care;
- The effects of Medicaid and CHIP eligibility changes on health care providers due to an increase in the uninsured population and in the volume of uncompensated care; and

[^0]- The impact of poverty threshold changes on nutritional programs, which may help people with cancer address food insecurity during their treatment, when good nutrition may improve treatment outcomes.

In its analysis of the impact of a new inflation rate index, OMB must consider not just the immediate effects but also the effects over two years, five years, and ten years. It is important that OMB and the public understand the cumulative impact of a change in poverty guidelines. We are concerned about the potential negative impact of this change on people with cancer in the first year and beyond.

We urge that OMB withhold any changes in the index used for inflation adjustments until the ten-year impact of such a change is evaluated and the public has an opportunity to comment on the implications of the change.

We appreciate the opportunity to comment.
Sincerely,

## Cancer Leadership Council

Academy of Oncology Nurse \& Patient Navigators
CancerCare
Cancer Support Community
Children’s Cause for Cancer Advocacy
Fight Colorectal Cancer
Leukemia \& Lymphoma Society
LIVESTRONG
LUNGevity Foundation
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
Ovarian Cancer Research Alliance
Prevent Cancer Foundation
Susan G. Komen


[^0]:    ${ }^{1}$ National Research Council 1995. Measuring Poverty: A New Approach. Washington, DC. The National Academies Press.

