## Progress Against Cancer Relies Heavily on Data Collected and Shared by the Federal Government

## Disruptions or Changes to Government Data Collection and Availability Could Compromise Understanding of Disease Burden, Emerging Trends, and Effective Interventions

**WASHINGTON**, **D.C.** – February 6, 2025 – In recent days, certain widely-used government data sets have been removed or removed and later restored with redacted data on the websites of the Centers for Disease Control and Prevention (CDC) and Food and Drug Administration (FDA). There have also been reports that scientific papers from federal authors have been withdrawn from submission to research journals pending administration review.

The following is a statement from Dr. Wayne A. I. Frederick, interim chief executive officer of the <u>American Cancer Society (ACS)</u> and the <u>American Cancer Society Cancer Action Network (ACS CAN)</u>:

"Federal and state governments have long had and should continue to play a central role in data collection. Consistent, ongoing and comprehensive data collection and dissemination are instrumental in our ability to ensure we have relevant and timely information to inform the best interventions to prevent, detect and treat chronic diseases including cancer.

"ACS recently released the Cancer Statistics, 2025 report and the consumer-friendly companion, Cancer Facts and Figures report, highlighting that cancer mortality has decreased overall by 34% since it peaked in 1991, but areas of concern persist, including rising cancer incidence in women and younger adults. The Facts & Figures report and accompanying publications present the most current trends in cancer occurrence and survival, provide information on symptoms, prevention, early detection and treatment, and serve as a roadmap for the cancer research community to investigate the causes of these changes and identify solutions. This comprehensive compilation and the subsequent analysis are only possible thanks to a wide range of data provided by myriad federal and state agencies, and any restriction to gather and release these data could thwart our ability to address and reduce the cancer burden across all communities.

"In addition, ACS develops guidelines for cancer screening and prevention, informed by the latest available data and evidence, to meet the needs of clinicians, the general public, and policy. We are very concerned that the changes in data collection and dissemination have the potential to impact these efforts in the future.

"On the patient support front, ACS leads programs that touch over 100M lives annually and are planned by understanding where and how people need supportive services. Data from public sources like the Social Vulnerability Index are key to deploying the right resources to those who could benefit the most. Therefore, any barriers to accessing these data can also have repercussions on planning and deployment of support services for cancer patients and survivors.

"We are still evaluating the scope of data removal and longer-term data collection changes to understand potential implications on our ability to analyze disease burden across communities. As evidence-based organizations who rely on these data sets, ACS and ACS CAN will monitor closely the potential impact of these changes.

"ACS CAN calls on the administration to restore access to comprehensive data, refrain from changes that would lead to incomplete future data collection and commit to ensure evidence-based science can proceed without additional bureaucracy or red tape. Access to comprehensive, consistent and ongoing data is imperative to our ability to make progress to end cancer as we know it, for everyone."

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## **About the American Cancer Society**

The American Cancer Society is a leading cancer-fighting organization with a vision to end cancer as we know it,

for everyone. For more than 110 years, we have been improving the lives of people with cancer and their families as the only organization combating cancer through advocacy, research, and patient support. We are committed to ensuring everyone has an opportunity to prevent, detect, treat, and survive cancer. To learn more, visit cancer.org or call our 24/7 helpline at 1-800-227-2345. Connect with us on Facebook, X, and Instagram.

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