Susan Monarez, PhD Acting Director Centers for Disease Control and Prevention 1600 Clifton Rd NE Atlanta, GA 30333

Dear Acting Director Monarez,

For more than 25 years, the U.S. Centers for Disease Control and Prevention has held that "essential public health service #1" is to "Assess and monitor population health status, factors that influence health, and community needs and assets." Yet on Friday, January 31, 2025, without warning, explanation, or justification from CDC, major datasets developed for this very purpose became inaccessible on the CDC's website.

As members of the Advisory Committee to the CDC Director – the federal advisory committee authorized by Congress in Section 305A of the Public Health Service Act – we are writing in our individual capacities with questions about this and other unusual developments and to request that you convene the Advisory Committee, in person, as soon as possible in accordance with the requirements of the Federal Advisory Committee Act.

Datasets that are no longer accessible include critical sources of information about diseases, populations, and risk factors, including tools that allow people all across the country to understand the health of their communities. These datasets include:

- The Atlas of HIV, Hepatitis, TB, and Social Determinants of Health Data. CDC has previously stated these data are intended for "CDC staff, federal, state, tribal, local and territorial public health professionals, policymakers, community- and faith-based organization leaders, researchers, students, and those affected by HIV, viral hepatitis, STIs, and/or TB." This dataset has helped guide funding and policy decisions such as directing federal resources to rural U.S. counties with high rates of Hepatitis C among people who inject drugs, contributing to efforts to combat the national opioid crisis. An old version of the front page is archived here.
- The Social Vulnerability Index. CDC has previously stated that these data, which have been available for more than a decade, "help public health officials and local planners better prepare for and respond to emergency events with the goal of decreasing human

suffering, economic loss, and health inequities." The index has helped identify communities with barriers to maternal healthcare, enabling targeted, cost-effective solutions like expanding access to prenatal services and improving health outcomes for mothers and families. An old version of the front page is archived here.

- The Environmental Justice Index. CDC has previously stated that this index "delivers a
  single rank for each community to identify and map areas most at risk for the health
  impacts of environmental burden." This index has been used to identify communities at
  elevated risk from natural disasters so that first responders can be better prepared to save
  lives in emergencies. An old version of the front page is archived <a href="here">here</a>.
- The Youth Risk Factor Behavioral Surveillance System. CDC has previously explained that this resource "identifies emerging issues, and plans and evaluates programs to support youth health" and "gives the best picture of what is going on at national, state, and local levels." CDC has also noted previously that the data are "used by health departments, educators, lawmakers, doctors, and community organizations to inform school and community programs, communications campaigns, and other efforts." Data from this system is important to understanding the mental health challenges facing youth, including bullying and other safety issues at school. An old version of the front page is archived here.

In addition to the loss of access to these and other datasets, <u>news reports</u> have noted the removal of other websites on topics that include gender-based violence, the health challenges facing LBGTQ+ youth, racism in health, and the recommended vaccines of the Advisory Committee on Immunization Practices.

It has been reported through anonymous sources that the website changes are related to new executive orders that ban the use of specific words and phrases. But as far as we are aware, these unprecedented actions have yet to be explained by CDC; news stories indicate that the agency is declining to comment.

## Our questions include:

- 1. What was the rationale for making these datasets and websites inaccessible to the public?
- 2. What, if any, analysis of the consequences of removing access to these datasets and websites was conducted before actions were taken?
- 3. What, if any, analysis of the legal authority to make the changes was undertaken prior to their execution?
- 4. What steps are being taken to safeguard the datasets and other information removed from the websites?
- 5. When will full access to these datasets and websites be restored?

6. If there are to be changes made to the datasets and websites before reposting, what scientifically valid process will CDC follow to ensure the integrity of information used by researchers and practitioners around the country?

The CDC website states that the agency's mission is to "protect America from health, safety and security threats, both foreign and in the U.S." Congress authorized the Advisory Committee to the Director to "to advise the Director on policy and strategies that enable the agency to fulfill its mission." We ask you to provide a written response to the above questions by February 7, 2025, and convene the Advisory Committee to the Director, in person, as soon as possible in accordance with Federal Advisory Committee Act, to discuss these developments.

Thank you very much for your consideration.

Sincerely,

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