

U.S. Cancer Registries, Constrained by Trump Policies, to Recognize Only ‘Male’ or ‘Female’ Patients

Scientists and advocates for trans rights say the change will make it much harder to understand cancer diagnoses and trends among the trans population.

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The top authorities of U.S. cancer statistics will soon have to classify the sex of patients strictly as male, female, or unknown, a change scientists and advocates say will harm the health of transgender people, one of the nation’s most marginalized populations.

Scientists and advocates for trans rights say the change will make it much harder to understand cancer diagnoses and trends among the trans population. Certain studies have shown that transgender people are more likely to use tobacco products or less likely to receive routine cancer screenings — factors that could put them at higher risk of disease.

The change is a consequence of Trump administration policies recognizing only “male” and “female” sexes, according to cancer researchers.

Scientists said the change will affect all cancer registries, in every state and territory, because they receive federal funding. Starting in 2026, registries funded through the Centers for Disease Control and Prevention and the National Cancer Institute [will categorize cancer patients](#) as male, female, or not stated/unknown. And federal health agencies will receive data only on cancer patients classified that way.

Registries [currently specify](#) whether a cancer patient’s sex is “male,” “female,” “other,” various options for “transsexual,” or that the patient’s sex is not stated or unknown.

President Donald Trump in January issued an [executive order](#) stating that the government would recognize only male and female sexes. Cancer registry officials said the federal government directed them to revise how they collect data on cancer patients.

“In the U.S., if you’re receiving federal money, then we, essentially, we weren’t given any choice,” Eric Durbin, director of the Kentucky Cancer Registry and president of the North American Association of Central Cancer Registries, told KFF Health News. NAACCR, which receives federal

funds, maintains cancer reporting standards across the U.S. and Canada.

Officials will need to classify patients' sex as unknown when a "patient's sex is documented as other than male or female (e.g., non-binary, transsexual), and there is no additional information about sex assigned at birth," the new standard says.

Missing the Big Picture

Researchers said they do not have high-quality population-level data on cancer incidence in transgender people but had been making inroads at improving it — work now at risk of being undone.

"When it comes to cancer and inequities around cancer, you can use the cancer registries to see where the dirtiest air pollution is, because lung cancer rates are higher in those areas. You can see the impact of nuclear waste storage because of the types of cancers that are higher in those ZIP codes, in those areas of the country," said Shannon Kozlovich, who is on the executive committee of the California Dialogue on Cancer.

"The more parts of our population that we are excluding from this dataset means that we are not going to know what's happening," she said. "And that doesn't mean that it's not happening."

For decades, cancer registries have been the most comprehensive U.S. surveillance tool for understanding cancer incidence and survival rates and identifying troubling disease trends. Each year, cancer cases are reported by hospitals, pathology labs, and other health facilities into regional and statewide cancer registries. The compiled data documents cancer and mortality rates among regions, races, sexes, and age groups.

Two federal programs serve as the top authorities on cancer statistics, with information on tens of millions of cases. The CDC's National Program of Cancer Registries provides funding to organizations in 46 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and the U.S. Pacific Island territories. Its data represents [97% of the U.S. population](#). The National Cancer Institute's Surveillance, Epidemiology, and End Results program, known as SEER, collects and publishes data from registries covering [nearly half](#) the U.S. population.

The information published by cancer registries has led to changes in treatment and prevention, and the enactment of other policies designed to reduce diagnosis rates and mortality.

For example, data collected by cancer registries was essential in identifying [rising rates of colorectal cancer](#) among people [younger than 50](#). As a result, U.S. guidelines [now recommend](#) that adults start screenings at age 45 rather than 50.

States have enacted their own measures. Lara Anton, spokesperson for the Texas Department of State Health Services, said epidemiologists with the Texas Cancer Registry in 2018 found that the state had the nation's highest incidence rates of hepatocellular carcinoma, a liver cancer more common in men than women. The Cancer Prevention and Research Institute of Texas [initiated a](#)

[statewide effort](#) aimed at reversing rising rates of liver cancer. The Texas Cancer Registry joined SEER in 2021.

“Once a cancer patient is entered into a cancer registry, we follow those patients for the rest of their lives. Because we really need to know, do patients survive for different types of cancer and different stages of cancer?” Durbin said. “That’s incredibly important for public policies.”

The North American Association of Central Cancer Registries maintains national standards outlining what kind of data registries collect for each diagnosis. It develops the list in partnership with the CDC, the National Cancer Institute, and other organizations.

For any given patient, under NAACCR’s standards, Durbin said, registries collect more than 700 pieces of information, including demographics, diagnosis, treatment, and length of survival. CDC and NCI-funded registries must specify the sex of each patient.

The NAACCR definitions and accompanying data standards are designed to ensure that registries collect case data uniformly. “Everyone essentially follows the standards” that NAACCR develops, Durbin said. Although registries can collect state-specific information, researchers said they need to follow those standards when sending cancer data to the federal government.

In an emailed statement, Department of Health and Human Services spokesperson Andrew Nixon said, “HHS is using biological science to guide policy, not ideological agendas that the Biden administration perpetrated.”

‘Backwards’ Progress

NAACCR routinely publishes updated guidelines. But the change to the “sex” category to remove transgender options in 2026 was an emergency move due to Trump administration policies, Kozlovich said. She was among a group that had pushed for changes in cancer data collection to account for sex and gender identity as separate data points.

According to an [analysis of CDC data](#) by the Williams Institute at the UCLA School of Law, 2.8 million people age 13 and older identify as transgender.

Scientists and trans rights advocates said in interviews that there are troubling signs that may make transgender people more likely to develop cancer or experience worse health outcomes than others.

“Without evidence of our health disparities, you take away any impetus to fix them,” said Scout, executive director of the LGBTQIA+ Cancer Network.

A study published in 2022 found that transgender and gender-diverse populations were [two to three times](#) as likely as cisgender people to report active use of cigarettes, e-cigarettes, or cigars. Tobacco use is a leading cause of cancer and death from cancer.

A [Canadian study](#) concluded in 2019 that transgender patients were less likely to receive recommended screenings for breast, cervical, and colorectal cancers. And a [2023 study](#) from researchers at Stanford Medicine found that LGBTQ+ patients were nearly three times as likely to experience breast cancer recurrence as cisgender heterosexual people.

Scarlett Lin Gomez, an epidemiologist at the University of California-San Francisco and the director of the Greater Bay Area Cancer Registry, said that for at least 10 years the NCI had been interested in improving its ability to monitor cancer burden across patient populations with different sexual orientations and gender identities. Cancer registries are a logical place to start because that is what they're set up to do, she said.

There's been "slow but good progress," Gomez said. "But now we've completely, personally, I think, regressed backwards."

The decision not to capture transgender identity in cancer patients is just one change registries have confronted under the Trump administration, according to scientists leading surveillance efforts and state health agencies. An HHS mandate to reduce spending on contracts led to funding cuts for cancer registries in NCI's SEER program. Scientists said CDC funds for registries haven't been cut; however, the White House's proposed fiscal 2026 budget aims to eliminate funding for the National Program of Cancer Registries.

Among the Trump administration's other actions targeting trans people are canceling research grants for studies on LGBTQ+ health, dismantling the National Institutes of Health's office for sexual and gender minority health, and [stopping specialized services](#) for LGBTQ+ youth on the 988 national suicide prevention hotline.

Without data, researchers can't make a case to fund research that may help trans patients, Gomez said. "It's erasure."

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