

The federal government will stop collecting data on LGBT seniors—bad news for their health

April 4 2017, by Brandon Brown

You've likely read the front-page news about accessible gender-neutral bathrooms. This has gained attention, not only as a human rights issue, but also a political one.

What we don't usually read is that LGBT populations face stigma and discrimination in employment and health care, as well as significant health disparities. Recent moves by the Trump administration, though, mean that these health questions will be more difficult to discern.

Information on civil rights and LGBT issues [has been removed](#) from the White House website. And, on March 20, the U.S. Department of Health and Human Services proposed to eliminate LGBT elders from [critical national surveys](#), including the [National Survey of Older Americans Act Participants \(NSOAAP\)](#). LGBT people will continue to lose presence in data, as sexual orientation and gender identity will not be collected in the 2020 census. Data from both surveys are directly used in health policy decision-making.

The sharp move to remove collection of LGBT elder data from these surveys removes the group's voice from federal funding input. But my main concern as a public health practitioner is the potentially devastating impact on their health. Without knowing how health services are rated by consumers and how effective they are, LGBT elders and other vulnerable populations may not be able to maintain their independence

and receive the myriad benefits provided by Title III services. As a result, they could face additional health disparities.

What we don't know

March 27 through 31 was [National LGBT Awareness Week](#). LGBT stands for lesbian, gay, bisexual and transgender, but the LGBT umbrella includes many other sexual and gender minorities, such as queer, intersex and asexual. Each year, the [National Coalition for LGBT Health](#) hosts activities nationwide to improve and increase awareness of LGBT health issues.

It's ironic that this event would coincide with the decision not to collect data on these communities. The NSOAAP survey programs on aging are funded by Title III of the Older Americans Act. They report on how well programs funded by the federal government meet their legislative goals. These data are needed to provide performance outcomes for state and area agencies on aging and local service providers.

The U.S. population is aging, with baby boomers being [between ages 52 and 70](#). By 2050, more than 40 percent of all people in the U.S. will be over age 45 and more than 25 percent [over age 60](#).

Why should we worry about LGBT elders in particular? Data are lacking, but [recent research](#) shows LGBT older adults are both resilient and at-risk, with [higher rates](#) of disability, cardiovascular disease, depression and social isolation than non-LGBT adults of similar ages. In addition, cardiovascular disease is seen mostly among older adults, but [few studies include LGBT adults](#), further adding to the list of what we don't know. Many studies also have age restrictions when measuring sexual orientation. This further limits the possibility to identify disease disparities among older LGBT adults.

HIV affects everyone – young and old, LGBT and non-LGBT. Yet, when one thinks about HIV, one does not immediately move to association with seniors. But [half of all HIV-positive people](#) in the U.S. are older than 50, and HIV accelerates the aging process. Indeed, one group often overlooked in HIV testing outreach [is seniors](#). While half of all deaths of HIV-positive individuals are due to AIDS, half are caused by other age-related conditions and [simultaneous illness, or comorbidities](#), such as cardiovascular disease, lung disease and cancer.

Despite our knowledge of the relationship between HIV and aging, there is a scarcity of information on older adults, particularly [older LGBT adults](#). This dearth of data is why perhaps there is an interest in studies related to HIV/AIDS and Aging by [the National Institutes of Health](#). Sadly, the current administration has proposed [significant cuts](#) to NIH AIDS funding, which will hinder data collection and progress toward an AIDS-free generation.

Most people likely don't think about seniors as being at risk for HIV infection, but seniors are sexually active. People over 50 may have similar risk factors to those under 50, such as unprotected sex and multiple sex partners, but may be less aware of their risk. Health care professionals, too, may underestimate older patients' risk for HIV, leading to [missed opportunities for HIV prevention](#). This means that people over 50 are more likely to be diagnosed with HIV later in the course of the disease, with [missed opportunities](#) to connect early to HIV care. Some older adults may actually be at an increased risk for getting HIV – for example, vaginal thinning and dryness in older women can make HIV transmission easier. This is in addition to generally lower immune response due to aging.

Few surveillance systems collect data on gender identity, sex anatomy or sexual behaviors, although the Centers for Disease Control and Prevention's [Behavioral Risk Factor Surveillance System](#) does ask about

sexual behaviors related to HIV transmission. Sadly, only some states utilize it.

And HIV isn't the only pressing health concern for LGBT elders. [One survey of the transgender community](#), released during this year's LGBT Awareness Week, found that three-quarters of respondents contemplated suicide, over two-thirds had depression or anxiety disorder and many experience stigma, isolation and abuse. While this report focused on the transgender population, 20 percent were over age 50, and the T in the LGBT may be at highest risk.

These survey outcomes are particularly relevant to LGBT seniors, as they may have less access to care for depression and anxiety, more isolation due to deaths of partners and friends and, importantly, may face abuse in care if not measured by national surveys.

More data needed

For these reasons, we need to include data from LGBT elders [in national surveys](#). Like all elders, they deserve our time and respect, and we should make sure they receive adequate services from hospitals, community centers and caregivers. Without the data to illustrate service provision, we will not know if they are receiving services, if they are satisfied with the services or how effective the services are.

With these data, we can design interventions to reach LGBT elders with services, as well as alter services to provide the highest standard of care to LGBT elders.

We can start this process by letting people know that LGBT people exist and surveying them like we do all other people. Young LGBT people grow up to be older LGBT people, and that older LGBT people have some specific [health](#) needs that are distinct from those of non-LGBT

people.

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