

REPORT

HIV

November 2017

National Survey of Young Adults on HIV/AIDS

Kaiser Family Foundation

Introduction

More than three and a half decades have passed since the first case of AIDS. An entire generation has been born and grown up without ever knowing a time when HIV did not exist, and they may be the first to see it end.

While there is no cure for HIV, experts say we have the knowledge and tools today that could lead to the eradication of the disease. Antiretrovirals (or ARVs), the medications used to treat HIV, work to reduce the viral load to levels undetectable by standard lab tests. Studies show that when the viral load is less than 200 copies of virus per milliliter of blood, long-term health is greatly improved and sexual transmission of the virus is extremely unlikely, if not impossible.¹

For those who do not have HIV, PrEP (short for pre-exposure prophylaxis), an FDA approved once daily pill, offers another means of protection. When taken as prescribed, PrEP is highly effective in protecting against HIV.² PrEP is also a significant advance in that it provides women with the first HIV prevention tool that they can control themselves.

To provide more insight into the knowledge, attitudes and experiences of young adults in the U.S. at this critical time in the epidemic, the Kaiser Family Foundation conducted a comprehensive nationally representative survey of 1,794 18-30 year olds between January 25-February 16, 2017. Given the disproportionate impact of HIV on Black and Latino populations, oversamples of these groups were included to provide a more in-depth look by race.

Highlights of the Survey Findings

HIV hits close to home for many young people of color.

- A majority (53%) of Black young adults say they are *personally* concerned about HIV, as do 47 percent of Latinos. By contrast, 81 percent of whites this age say HIV is not a concern for them.
- About three times as many Blacks (46%) and Latinos (41%), as whites (15%), say HIV today is a “*very serious*” issue for *people they know*. Almost twice as many Blacks (30%) as whites or Latinos (16% each) report knowing someone with HIV. One in five (20%) Blacks have a family member or close friend affected by HIV.
- A third of Black (34%) and Latino (35%) young people say they worry about getting HIV; 16 percent of whites express concern about their own risk.

Low awareness about advances in HIV prevention and treatment.

- Only 13 percent of young adults know about PrEP, the pill to prevent HIV. When prompted slightly more, though still a minority (27%), report having heard *anything* about it and most of them say “only a little;” 74 percent say they have heard “nothing at all” about PrEP.
- Among those who have heard *anything* about PrEP, only 18 percent of young adults believe it to be “very effective.” Many also doubt that all who might want PrEP could get it: 64 percent say “no.”
- While most know antiretrovirals (ARVs) improve health outcomes for people with HIV, fewer are aware of the preventative benefits of these medications. Most young adults do not know being on consistent treatment also *prevents the spread of HIV to sexual partners*. Just one in ten (11%) know modern treatments have been shown to be “very effective” – another 36 percent say “somewhat effective” – in preventing the spread of HIV.

Stigma and misperceptions about HIV persist.

- Most young people say they would be *comfortable* having someone with HIV as friends (65%) or work colleagues (66%), but when it comes to other situations, more stigma is evident. Half or more say they would be *uncomfortable* having a roommate with HIV (51%) or having their food prepared by someone with HIV (58%). Three quarters (73%) respond that are “very *uncomfortable*” having a sexual partner with HIV, another 18 percent say they would be “somewhat *uncomfortable*.”
- More than a third *incorrectly* believe HIV can be spread through everyday items, such as plates and glasses (38%) or toilets (38%). Majorities are misinformed in thinking HIV can be transmitted by spitting (54%) or kissing (58%).

HIV testing is occurring less than generally recommended.

- More than half (54%) of young adults report *never* having been tested for HIV. Nearly two-thirds (63%) say they have *never* talked with a health care provider about HIV.
- Black young adults are *more likely* – and *more recently* – to report having gotten an HIV test. One in three (34%) replied they have been tested for HIV *within the last 12 months*, compared to 16 percent of whites and 25 percent of Latinos. Overall, 61 percent of Blacks report *ever* having been tested for HIV, as compared with 42 percent of whites and 49 percent of Latinos.

Detailed Findings

HIV/AIDS as an Issue for Young Adults

Due to a combination of social inequities, and where the disease initially took hold, HIV has disproportionately affected certain groups. In 2015, Black Americans accounted for almost half (45%) of new HIV diagnoses in the U.S., while comprising just 12 percent of the population.³ Latinos are also heavily affected, accounting for 24 percent persons newly diagnosed with HIV in 2015 and representing 17 percent of the population.⁴

The uneven impact of HIV is reflected in the starkly differing views and experiences reported by those of different races. With regard to how HIV is affecting their communities, 46 percent of Black, and 41 percent of Latino, young adults say it is a “very serious” concern *for people they know*; far fewer, only 15 percent of their white counterparts say the same. Indeed, half (50%) of white young people say HIV/AIDS is “not at all” a concern for those they know, as compared to 35 percent (each) of young Black and Latino adults.

When asked *how personally concerned are you about HIV/AIDS*, 44 percent of Black, and 35 percent of Latino, young people say they are “very concerned,” as compared to just 11 percent of their white counterparts who express this degree of concern. Conversely, 61 percent of whites say HIV is “not at all” a concern for them

Black young adults (30%) are about twice as likely as whites and Latinos to report knowing *someone living with or who has died of HIV*, compared with 16 percent (each) of whites and Latinos. Twice as many Blacks (20%) as whites (8%) or Latinos (9%) say someone close to them – a family member, spouse, and/or close friend – has or had HIV.

When it comes to how worried they are about their own risk, twice as many Black (34%) and Latino (35%) young adults say they are *at least* “somewhat worried” about *getting HIV* as whites (16%). This includes 22 percent of Blacks, and 15 percent of Latinos, who say they are “very worried” about *getting HIV*. A majority (53%) of whites, by contrast, express no concern about getting HIV, with 53 percent saying they are “not at all worried.”

Gaps in Awareness about HIV Prevention and Treatment

In the five years since PrEP was approved by the Food & Drug Administration (FDA), only 13 percent of young adults know about the prevention option. When prompted, somewhat more (27%) recall having heard *anything* about the pill to protect against HIV, though most of them say “only a little.”

Among the relatively few young people who have heard *anything* about PrEP, while most think it works, just 18 percent know it to be “very effective.” Many also doubt that all who might want PrEP could get it: 64 percent say “no.”

There are also gaps in understanding of how antiretrovirals (ARVs) work. While most young adults are generally aware of the health benefits of these medications, many understate their effectiveness. Just one in

four know ARVs are “very effective” at *helping people with HIV live longer* (25%, another 57% say “somewhat effective”) and *improving the health of people with HIV* (26%, another 56% say “somewhat effective”).

While most know antiretrovirals (ARVs) improve health outcomes for people with HIV, fewer are aware of the preventative benefits of these medications. Most young adults do not know being on consistent treatment also *prevents the spread of HIV to sexual partners* (23% say “not at all effective,” and another 29% say “not too effective.”) Just one in ten (11%) know modern treatments have been shown to be “very effective” – another 36 percent say “somewhat effective” – in preventing the spread of HIV. Similarly small percentages of young people know that a pregnant woman with HIV can prevent the spread of the virus to her baby with treatment (13% “very effective,” 38% “somewhat effective”); young women, in particular Black women, are somewhat more likely to be aware of this as compared to men their age.

When asked *if someone who has HIV takes their treatment as prescribed, does this reduce the risk of passing HIV to sexual partners, or not?*, half (52%) say “no,” in spite of scientific evidence to the contrary. And, among those who know treatment reduces risk, many understate the effects. Eleven percent say these medications “significantly reduces risk,” and another 36 percent believe they “somewhat” do.

When asked about the term HIV *undetectable* – when the viral load of someone with HIV is reduced to levels that cannot be detected by standard lab tests, the goal of ARVs – 25 percent say they have *heard of it and know what it means*, another 18 percent have *heard of it but don’t know what it means*. The majority (57%) say they have *never* heard the term.

Many young adults also understate the effectiveness of condoms in HIV prevention. A third (32%) of young people believe condoms to be “very effective” in preventing HIV. When used correctly and consistently, the CDC says condoms are highly effective in protecting against HIV.⁵ One in ten (9%) think birth control pills are at least “somewhat effective” in protecting against HIV; 81 percent know they are “not effective at all.”

HIV Stigma & Misperceptions

Most young people today say they would be *comfortable* having people with HIV as friends (65%) or work colleagues (66%) but when it comes to other situations, the stigma of the disease is evident. Half or more say they would be *uncomfortable* having a roommate with HIV (51%) or having their food prepared by someone with HIV (58%). Three quarters (73%) respond that would be “very *uncomfortable*” having a sexual partner with HIV, another 18 percent say “somewhat *uncomfortable*.”

Providing insight into what may be behind the stigma, the survey also reveals a lack of understanding among some about how HIV is and is not transmitted. More than a third *incorrectly* believe there is a possibility HIV could be spread through everyday items, such as plates and glasses (38%) or toilets (38%). Majorities are misinformed in thinking HIV can be transmitted by spitting (54%) or kissing (58%).

Conversations about HIV

Young adults today say conversations about HIV, even with those closest to them, are infrequent, if they happen at all. Large majority of young people say they “rarely,” if ever, talk with family members, friends or even sexual partners about HIV. Black and Latino young adults are more likely than whites to report *at least* “sometimes” discussing HIV with family (20% and 17%, respectively, vs. 5%) and friends (31% and 19%, vs. 7%). Forty percent of Black, and 30 percent of Latino, young adults, say HIV *at least* “sometimes” comes up in conversation with sexual partners, compared with just 16 percent of whites who say it does.

HIV Testing

The CDC recommends HIV testing as part of routine health care, yet more than half (54%) of young adults say they have never been tested. Most of those who have not been tested say it is because they *don’t believe [they are] at risk* (67%), followed by a *doctor never suggested it* (41%, multiple responses were possible).

For those who have *ever* been tested for HIV, a large share say they did so because it *seemed like a good idea* (69%). Having a health care provider suggest testing was a contributing factor for many (46%, multiple responses were possible).

Black young adults are *more likely* – and *more recently* – to report having gotten an HIV test. One in three (34%) Blacks replied they had been tested for HIV *within the last 12 months*. Comparatively, 16 percent of whites and 25 percent of Latinos report having been tested as recently. Overall, 61 percent of Black young adults report *ever* having been tested for HIV, as compared with 42 percent of whites and 49 percent of Latinos.

Black young adults are also more likely to say a health care provider has suggested HIV testing. One in four (25%) Blacks report having a health care provider suggest HIV testing *within the previous 12 months*, as compared with only about one in ten whites and Latinos (8% and 14%, respectively). Analysis shows that having a health care provider suggest testing – or even having talked with them about HIV – are *more likely* to report being tested.

HIV Information Sources and Needs

Two in five (41%) of young people say they would like more information about at least one basic HIV topic asked about. For any given topic – including, how HIV is and is not spread, HIV prevention and treatment options, testing, etc. – between 19-30 percent, depending on the issue, of young adults were interested in learning more. More Black and Latino young people indicate they want to know more about HIV, across all topics, as compared to whites.

When it comes to where young people are learning about HIV the largest percentages say from school with 68 percent saying they got *at least* “some information” here, followed by online searches (64%, multiple responses possible). Almost as many cite media sources (51%) as doctors (52%) for *at least* “some” information.

Overall, more Black, and to a somewhat lesser degree Latino, young adults report turning to more resources of all kinds to learn about HIV, as compared to their white counterparts.

Health Care Access

Three quarters (78%) of young people say they accessed some type of health care setting, including private doctor's offices, health centers (including Planned Parenthood), or emergency rooms, for their own personal care in the 12 months prior (multiple responses possible). More than one in four (27%) report having been to an emergency room in the last year. Black and Latino young adults are less likely to use private doctor's offices as compared to whites.

Almost half (45%) of young adults say they have put off health care because they worried about the cost. Not having insurance was a commonly mentioned reason (27%), and more so by Black (38%) and Latino (33%) young adults. (Multiple responses possible.) Young people of color express the most worry about *paying for health care if they needed to* with 31 percent of Blacks and 29 percent of Latinos saying they are "very worried," as compared with 19 percent of whites. Majorities of all are *at least* "somewhat worried."

Methodology

The 2017 Kaiser Family Foundation National Survey of Young Adults on HIV/AIDS is based on interviews with a probability-based sample of 1,794 people between 18 and 30 years of age conducted January 25 through February 16, 2017. Interviews were administered online and by telephone in English using an instrument developed by staff at the Kaiser Family Foundation. NORC at the University of Chicago conducted sampling, interviewing, and tabulation for the survey using the GenForward panel, a representative panel of adults ages 18-30 living in the United States. The GenForward panel was built from two sample sources: NORC's AmeriSpeak Panel, a probability-based panel that uses address-based sample sourced from the NORC National Sample Frame; and the Black Youth Project panel, a probability-based address-based sample from a registered voter database of the entire United States. Panel members who do not have internet access complete surveys via telephone, and internet users complete surveys via the web (for the current survey, 1,647 participated via the web and 147 via telephone).

A random sample of 18-30 year-olds was selected from the GenForward panel, including an oversample of Black Americans and Latinos. The combined results have been weighted to adjust for the fact that not all survey respondents were selected with the same probability, to address the implications of sample design, and to account for systematic nonresponse along known population parameters. The first weighting stage addressed differences in probability of selection for the panel and to account for differential nonresponse to the panel screening interview. At this stage, an adjustment was also made to account for the oversampling of Black and Latino panelists. In the second weighting stage, the sample was adjusted to match known demographic distributions of the U.S. population ages 18-30 by age, gender, Census region, race/ethnicity, and education. Demographic weighting parameters were based on the U.S. Census Bureau's Current Population Survey. All statistical tests of significance account for the effect of weighting.

The margin of sampling error including the design effect for the full sample is plus or minus 3 percentage points. All statistical tests of significance account for the effect of weighting. Numbers of respondents and margin of sampling error for key subgroups are shown in the table below. For results based on other subgroups, the margin of sampling error may be higher. Sample sizes and margins of sampling error for other subgroups are available by request. Note that sampling error is only one of many potential sources of error in this or any other public opinion poll.

| Population | Number | Margin of sampling error |
|--------------------------------------|--------|--------------------------|
| Total Young Adults (18-30 years old) | 1,794 | ±3 percentage points |
| White Young Adults | 630 | ±5 percentage points |
| Black Young Adults | 523 | ±7 percentage points |
| Latino Young Adults | 521 | ±7 percentage points |

Please note:

- Values less than 0.5% are indicated by an asterisk (*).
- Due to rounding, percentages may not always add up to 100 percent.
- Questions are presented in the order asked; question numbers may not be sequential

End Notes

¹ Journal of the American Medical Association, July 12, 2016; New England Journal of Medicine, Sept. 1, 2016

² New England Journal of Medicine, Dec. 30, 2010; Science Translational Medicine, Sept. 12, 2012; New England Journal of Medicine, Aug. 2, 2012

³ <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-aa-508.pdf>

⁴ <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/cdc-hiv-latinos-508.pdf>

⁵ <https://www.cdc.gov/hiv/risk/condoms.html>



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