

State of Aging with HIV National Survey

From HealthHIV

Who is HealthHIV?

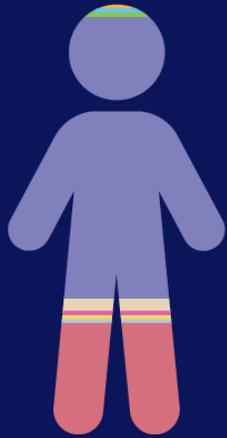
- *National Nonprofit – capacity building, training, advocacy*
- *Conducting Regular “State of” Surveys*
 - *Annually done; third national aging & HIV survey*
 - *Others: ASOs/CBOs, HCV, HIV Care, LGBTQ Health*
- *HealthHIV eNewsletter:*
 - *<https://healthhiv.salsalabs.org/signuppage/index.html>*

About the Survey

- 151 questions, open- & closed-ended
- Recruitment through HealthHIV's CRM
- Eligibility
 1. A person with HIV age 50 or older
 2. A person living with HIV For 15 or more years (to include respondents diagnosed before the first single-tab regimen introduced in 2006)
- 673 eligible respondents

Demographics

GENDER IDENTITY



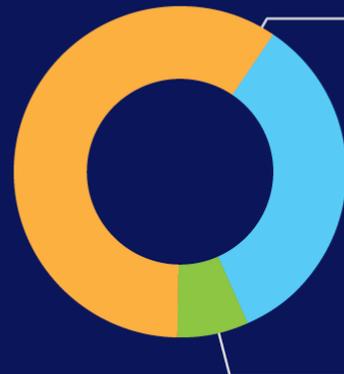
Agender	<1%
Gender Fluid	<1%
Gender Nonconforming/ Genderqueer	<1%
Man	68.7%
Nonbinary	2.6%
Other/Prefer Not to Say	1%
Transgender Man	1.2%
Transgender Woman	1.2%
Woman	26.9%

SEXUAL ORIENTATION



Asexual	1.2%
Bisexual	6.3%
Gay	51.6%
Lesbian	<1%
Other/Prefer not to say	3%
Pansexual	1.6%
Queer	4.9%
Straight	25.9%
Two Spirit	<1%

AGE



50–65 years	59%
65 or older	34%
Less than 50 but living with HIV for more than 15 years	7%

RACE AND ETHNICITY



Black	27%
Hispanic/Latinx	14%
Multiracial	7%
White	62%

- 15+ more established with education & income
- Majority White, gay-identifying cisgender men – 66% at least one post-secondary degree
- **Finances:**
 - Over 25%: > \$65,000/year
 - Nearly 50%: < \$32,000/year
 - Nearly 25%: < \$17,000/year

More than 54% of respondents had no retirement plan.

Our Word Map:

from respondents who are 50+ years of age



Key Findings

- **Multimorbidity and polypharmacy is a near-universal issue.** 2 in 3 respondents reported at least two comorbidities and 3 in 4 reported taking at least two daily medications.
- **Mental illness is on the rise.** 64% of respondents reported mental health concerns compared to less than 40% of respondents last year.
- **Retirement savings are minimal.** Half of respondents had no financial retirement plan and 4 in 5 had not saved enough for long-term care or supportive home care
- **An uncertain future looms.** There was a strong sentiment among respondents that OPWH are often forgotten and left out of the conversation around HIV care.

HIV Prevention & Persons 50+ years of age

53.3%

have been sexually active in the last year

14.2%

have been diagnosed or treated for an STI in the last year

98%

are knowledgeable about U=U

Of the

89%

living with HIV for more than 15 years

54%

have received AIDS diagnoses

Of those,

50%

received a late HIV diagnosis

- Lack of sexual health services & assumption of asexuality inhibiting important conversations:

➤ *“Once [you’re] diagnosed with HIV, [you] can’t just have sex with anyone and people aren’t very accepting of your condition if they don’t have it and it’s scary to let someone [you’re] attracted to know.”*

- No CDC recommendation for routine testing of those 65+ years of age

Comorbidities & Health

- 62% of respondents reported living with at least two comorbidities.
 - Managing comorbidities reported as a top priority
- Comorbidities less common for older adults with private health insurance

Frailty and Activities of Daily Living

1 in 4 respondents reported some level of frailty.

28% report frailty  **12.7%** need assistance with ADLs

Comprehensive Geriatric Assessments (CGA) and Frailty Index (FI) screenings are recommended for PWH starting at 50 years old, but few providers have incorporated this into standard practice.

How do you feel your health compares to people your age who aren't living with HIV?



How would you rate your overall physical health?



76.6% are taking at least one daily medication for a chronic comorbidity 

COMORBID CONDITIONS REPORTED

Anal Dysplasia	18.3%
Cancer	23.8%
Diabetes (Type 2)	17.5%
Frailty/Mobility Issues	27.9%
Hepatitis B	39.2%
Hepatitis C	14%
Heart/Cardiovascular Issues	32.3%
Hearing Problems	21.7%
Hypertension	59.9%
Hypertriglyceridemia	39.5%
Joint or Back Pain	64.4%
Kidney Disease	17.7%
Liver Disease	10.5%
Lung Disease/COPD	16.8%
Impaired Cognition	22%
Neurological Conditions/Stroke	16.8%
Neuropathy	45.7%
Osteoporosis/Osteopenia	29.3%
Periodontitis/Oral Health Issues	38.3%
Prediabetes	31.1%
Sex Drive/Libido	47.4%

Mental Health



63.6% experienced a mental health condition, including depression and anxiety

How much stress have you experienced in the last six months?



Social Support

66% participate in community groups

32% don't have anyone who takes care of them when sick or injured



7% say they have no one to call on in case of emergency

Our Data on Comorbidities & Mental Health

from respondents who are 50+ years of age

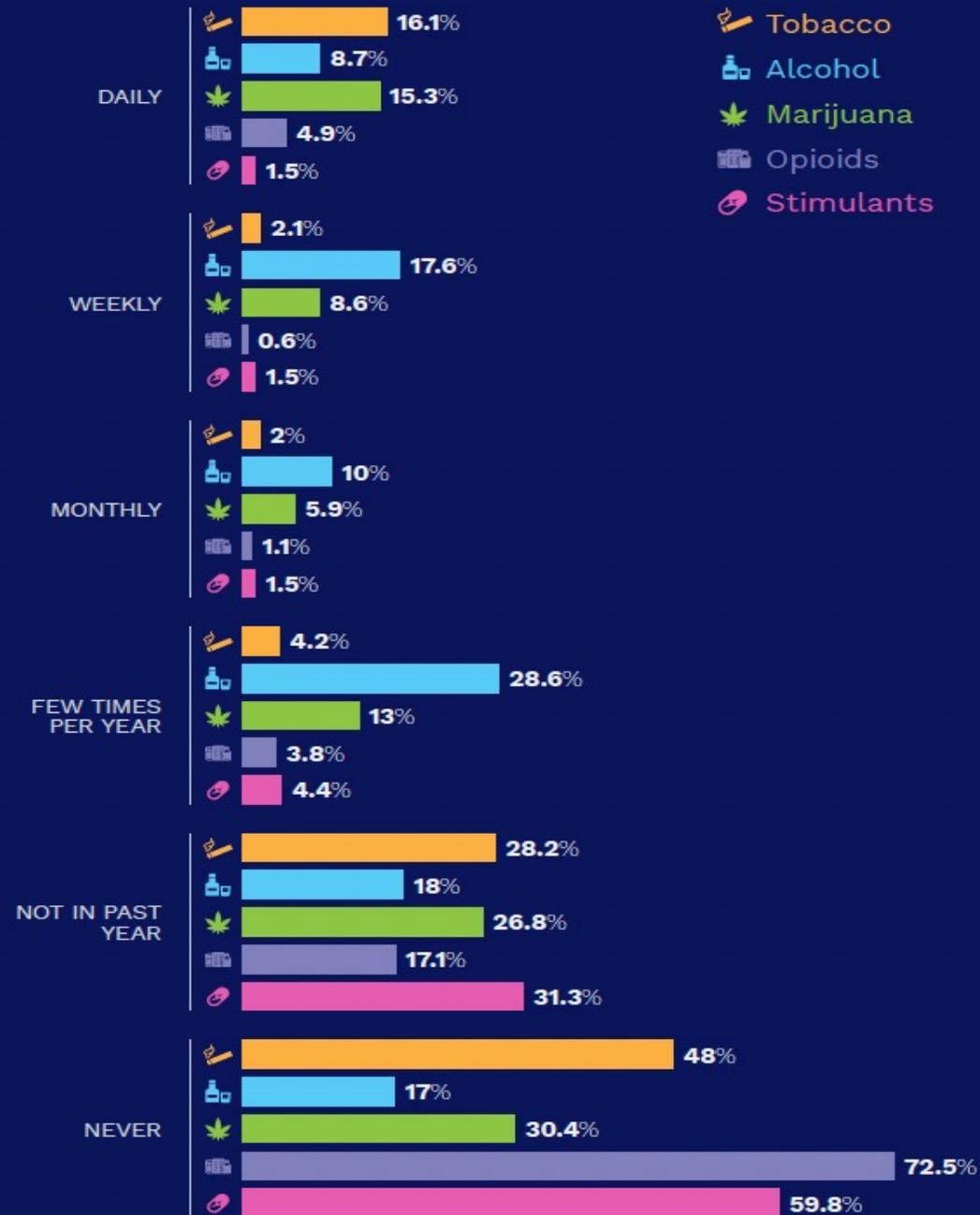
Comorbid Condition	Frequency	Percent
High blood pressure	69	53.90%
High cholesterol	53	41.40%
Lung/breathing problems	25	19.50%
Diabetes	21	16.40%
Nerve issues (epilepsy, neuropathy)	22	17.20%
Cardiac problems/heart disease	23	18.00%
Cancer	14	10.90%
Kidney problems	17	13.30%
Liver problems	12	9.40%
Don't know	4	1.70%
None of the above	20	15.60%

Percentage out of 128 respondents

Mental Health	Frequency	Percent
Depression	60	46.88%
Anxiety	54	42.19%
Post-Traumatic Stress Disorder (PTSD)	14	10.94%
Bipolar Disorder	16	12.50%
Mood Disorder	9	7.03%
Substance Use Disorder	10	7.81%
Obsessive Compulsive Disorder (OCD)	7	5.47%
Schizophrenia/Schizoaffective disorder	8	6.25%
Dementia	4	3.13%
Eating Disorder (Anorexia, Bulimia, etc.)	1	0.78%
Don't know	5	3.91%
None of the above	38	29.69%

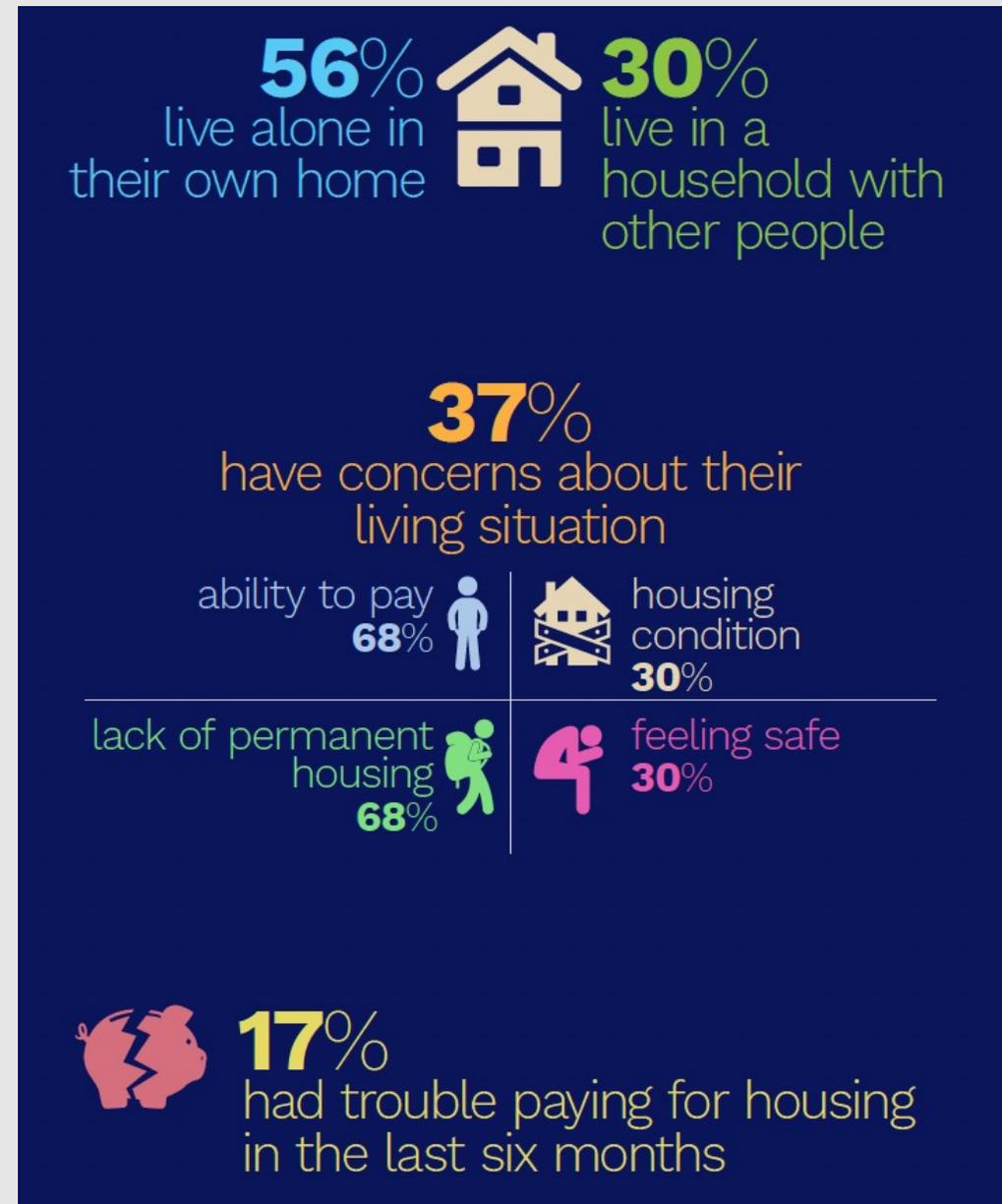
Percentage out of 128 respondents

FREQUENCY OF SUBSTANCE USE BY TYPE



Housing & Long-Term Care

- Housing was most pressing concern
- Assisted Living: How, When, Where?
 - 81% of respondents had not saved enough



Food, Nutrition, & Physical Activity

37%
engage in
regular physical
exercise



19%
are limited in
their ability to
perform
physical activity

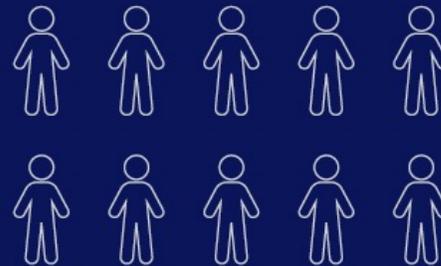
23%
had trouble
paying for
food in the
last six
months



20%
are concerned
about having
enough to eat
or where their
next meal
would come
from

Food and Nutrition

One fifth of respondents either regularly worked with a registered nutritionist or dietician or planned to see one.

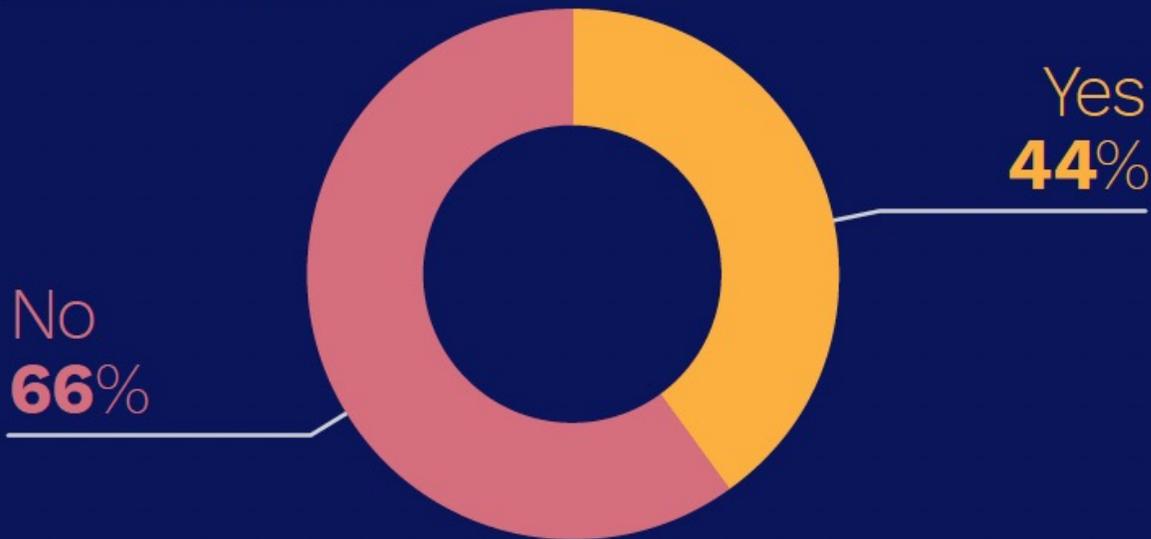


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Coordinated Care

*“Each year, my healthcare management becomes more **confusing and complicated...**”*

Do your providers coordinate or communicate with one another about your care and prevention needs?



In the past twelve months...

20%
had difficulty getting HIV medications on time

20%
had trouble getting non-HIV medications on time

28%
had to visit two or more pharmacies to fill their prescriptions

 **19%** have been referred to a outside agency for additional services

 **38%** currently receive case management services at a CBO or clinic

25% have received these services in the past

 **14%** have a peer navigator or wellness coach who connects them to services

Affording & Accessing Care

39%
access ART
through their
state's AIDS
Drug Assistance
Program (ADAP)



6%
have had to
change meds
because their
insurance didn't
cover it

What are the most common barriers you encounter when seeking healthcare?

 **25%** Cost of co-pays/co-insurance

 **24%** Long wait times

 **18%** Lack of convenient appointments

 **18%** Not able to find a provider covered by my insurance

What are the most difficult healthcare costs to cover?


25%
Co-pays/
Co-insurance


12%
Deductibles


11%
Prescriptions

Conclusions

- Building a competent workforce of HIV gerontologists is crucial to address the multifaceted issues confronting PLWH as they grow older.
- Efficient coordination of care between healthcare providers is essential to ensure that OPWH receive the comprehensive support they need.
- Addressing social determinants of health is fundamental to improve health outcomes as health extends beyond the clinic setting.
- Access to safe and stable housing is needed as fixed incomes and housing emergencies escalate for OPWH.

94% of
Respondents
Agree

There needs to be “**more representation** from the community on boards and committees that develop treatment guidelines” as well as emphasis on “**encouraging resilience and self-advocacy.**”