#### The Time is Now! Advocating for Age-Inclusive HIV Testing Guidelines and Sexual Health

**Faculty:** Terri L. Wilder, MSW Jeffrey Kwong, DNP, MPH, AGPCNP-BC, FAANP, FAAN, ACRN

Moderator: Ronald Johnson ANAC Policy Consultant

December 7<sup>th</sup>, 2023





#### The Association of Nurses in AIDS Care (ANAC)

**Mission**: ANAC fosters the professional development of nurses and others involved in the delivery of health care for persons at risk for, living with and/or affected by the human immunodeficiency virus (HIV) and its comorbidities. ANAC promotes the health, welfare and rights of people living with HIV around the world.





**NOVEMBER 14<sup>TH</sup>-16<sup>TH</sup>**, 2024

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- Type questions in the "Question" pane of your dashboard
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#### **Learning Outcomes**

At the conclusion of today's activity, participants will be able to:

- List key components of the current CDC HIV testing guidelines, focusing on age-related limitations and their impact on older adults' access to testing.
- Describe the potential repercussions of delayed HIV detection in older adults, emphasizing its effects on quality of life and public health.
- Discuss effective strategies and approaches to advocating for the removal of the upper age limit of the CDC HIV Testing Guidelines and promoting sexual health initiatives tailored for older adults.



#### Disclosures

No one in a position to control the content for this educational activity has relevant financial relationship(s) to disclose with ineligible companies whose primary business is producing, marketing, selling, re-selling, or distributing healthcare products used by or on patients.



#### Faculty



Terri L. Wilder, MSW HIV/Aging Policy Advocate, SAGE



Jeffrey Kwong, DNP, MPH, AGPCNP-BC, FAANP, FAAN, ACRN Professor, Division of Advanced Nursing Practice, Rutgers University Nurse Practitioner, Gotham Medical Group The Time is Now!: Advocating for Age-Inclusive HIV Testing Guidelines and Sexual Health for Older Adults

> Terri L Wilder, MSW HIV/Aging Policy Advocate December 7, 2023



# Sage | Advocacy & Services for LGBTQ+Elders

## We refuse to be invisible<sup>®</sup>

# What is SAGE?

- The country's largest and oldest organization dedicated to improving the lives of LGBTQ+ older people and older people living with HIV.
- Founded in 1978 and headquartered in New York City, SAGE is a national organization that offers supportive services and consumer resources to LGBTQ+ older people, older people living with HIV, and their caregivers.







#### The CDC Should Remove Upper Recommended Age Limit for HIV Testing

Current US Centers for Disease Control and Prevention (CDC) Guidelines state:

**Screening for HIV Infection** - In all health-care settings, screening for HIV infection should be performed routinely for all patients aged 13--64 years. Health-care providers should initiate screening unless prevalence of undiagnosed HIV infection in their patients has been documented to be <0.1%. In the absence of existing data for HIV prevalence, health-care providers should initiate voluntary HIV screening until they establish that the diagnostic yield is <1 per 1,000 patients screened, at which point such screening is no longer warranted.<sup>(1)</sup>

GOAL: Have the upper age limit removed, i.e., "In all health care settings, screening for HIV should be performed routinely for all patients aged 13 year and older."

Why is this needed? Many older adults (and their providers) don't think that older people are vulnerable to HIV, yet the most recent data shows that approximately 17% of new HIV diagnoses in the United States occurred among people aged 50 years and older. 55 and older is 10%. While the CDC has not recommended routine HIV testing for adults over the age of 64, there are experts around the country who argue that HIV testing should be a routine part of healthcare for all adults, regardless of age. People over 64 are being diagnosed late...with advanced disease...and some have died.

#### This is not ok. People 65 and older should be offered HIV testing. It is an urgent situation.

## It is way more complicated

There were 3,281 new HIV diagnoses among adults 65 years and older in the U.S. (2017-2021)

I want to challenge you to not think of this as a "low number." HIV surveillance report (latest validated data from states and localities) provides data by age in 5year groups (e.g. 50-54, 55-59, 60-64, >

From: <u>https://www.cdc.gov/hiv/library/repor</u> <u>ts/hiv-surveillance/vol-</u>



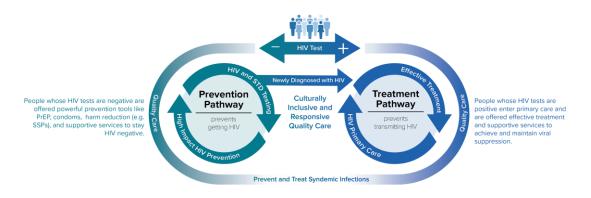
#### CENTERS FOR DISEASE<sup>TM</sup> CONTROL AND PREVENTION

Table 1a. Diagnoses of HIV infection, by year of diagnosis and selected characteristics, 2017-      2021—United States										
	201	2017		2018		9	2020 (COVID-19 Pandemic)		2021	
	No.	Ratea	No.	Ratea	No.	Rate <sup>a</sup>	No.	Rate <sup>a</sup>	No.	Ratea
Gender							·			
Male	30,444	-	29,602	-	28,809	-	24,174	-	28,304	-
Female	7,288	-	7,055	-	6,900	-	5,421	-	6,554	-
Transgender woman/girl <sup>b</sup>	651	-	661	-	692	-	676	-	811	-
Transgender man/boy <sup>b</sup>	32	-	48	-	45	-	41	-	56	-
Additional gender identity <sup>2</sup>	18	-	19	-	32	-	23	-	44	-
Age at diagnosis (yr)										
<13	105	0.2	86	0.2	57	0.1	60	0.1	53	0.1
13-14	25	0.3	20	0.2	21	0.3	12	0.1	15	0.2
15-19	1,791	8.5	1,722	8.2	1,652	7.8	1,264	5.9	1,452	6.7
20-24	6,481	29.4	6,123	28.1	5,987	27.7	4,849	22.6	5,460	25.4
25-29	7,720	33.0	7,682	32.6	7,382	31.4	6,080	26.7	6,713	30.0
30-34	5,680	25.9	5,664	25.6	5,645	25.1	5,199	22.7	6,368	27.6
35-39	4,254	20.1	4,186	19.4	4,102	18.9	3,400	15.3	4,403	19.7
40-44	2,981	15.2	2,964	15.1	2,946	14.8	2,474	12.0	3,140	14.9
45-49	2,926	14.0	2,759	13.3	2,571	12.6	2,044	10.1	2,326	11.8
50-54	2,637	12.4	2,435	11.7	2,303	11.3	1,828	8.8	2,116	10.1
55-59	1,869	8.5	1,824	8.3	1,837	8.4	1,558	7.1	1,786	8.3
60-64	1,082	5.4	1,042	5.1	1,106	5.4	879	4.2	1,095	5.2
≥ 65	882	1.7	878	1.7	869	1.6	688	1.3	842	1.5

## How is removing upper age limit related to other prevention (and care) services?

## The status neutral approach to HIV prevention and care defines the entry point to care as the time of an HIV test.

#### **Status Neutral HIV Prevention and Care**



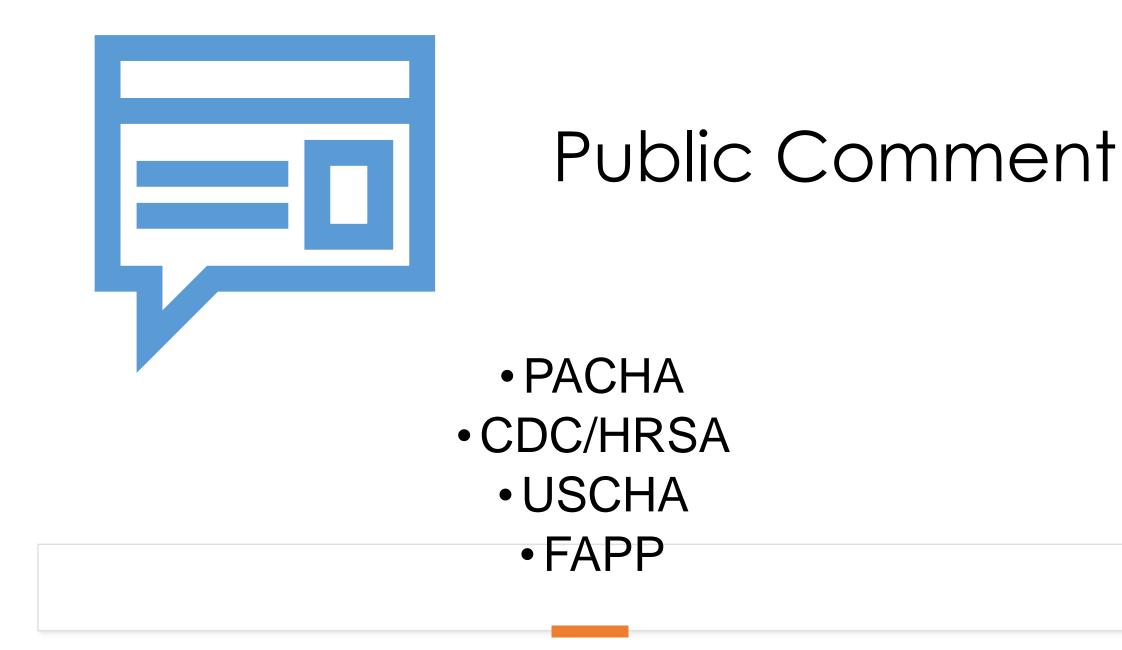
Follow CDC guidelines to test people for HIV. Regardless of HIV status, quality care is the foundation of HIV prevention and effective treatment. Both pathways provide people with the tools they need to stay healthy and stop HIV. >PEP

#### ≻PrEP

Medicare Coverage Guidelines. The federal government proposes that Medicare cover the cost of all forms of pre-exposure prophylaxis, or PrEP, to prevent HIV, including daily pills and long-acting injectables as well as the related doctor visits and screenings, such as tests for HIV and hepatitis.







#### Presidential Advisory Council on HIV/AIDS (PACHA)



#### Presidential Advisory Council on HIV/AIDS (PACHA) Resolution on Removing the Upper Age Limit of CDC Testing Guidelines

In recognition of National HIV/Aging Awareness Day, September 18<sup>th</sup>, the Presidential Advisory Council on HIV/AIDS (PACHA) stands united in our commitment to address the unique challenges faced by older adults aging and vulnerable to HIV. It is imperative that we recognize and attend to the intersecting issues of aging and HIV, ensuring that older adults receive the support, care, and respect they deserve.

Whereas, the Centers for Disease Control and Prevention (CDC) currently recommends that in all healthcare settings, HIV testing should be performed at least once as part of routine healthcare for all individuals between ages 13 and 64, and further recommends that people at heightened vulnerability to HIV acquisition ext tested for HIV at least once a vear:

Whereas, HIV acquisition is not confined to specific age groups, necessitating a comprehensive and inclusive approach to HIV testing;

Whereas, barriers to HIV testing among people over 50 include low perceived HIV risk and clinician preconceptions about older people;

Whereas, according to CDC data in 2019, 17% of new HIV diagnoses were among persons aged 50 and older;

Whereas, older people are at the highest risk of all age groups for having Stage 3 disease (AIDS) at the time of diagnosis such that in 2021, 34% of people 55 and older were diagnosed with Stage 3 disease (AIDS) at time of HIV diagnosis;

Whereas, older adults are at increased risk for immunocompromising conditions such as cancer, which can further increase risk of mortality if HIV is undiagnosed:

Whereas, the existence of an upper age limit in the CDC HIV testing guidelines may inadvertently perpetuate the misconception that older people are not susceptible to HIV acquisition and may deter healthcare providers from recommending HIV testing to this population;

Whereas, the evolving landscape of healthcare and advancements in HIV prevention and treatment underscore the importance of ensuring that individuals of all ages have equitable access to sexual health, HIV prevention, and comprehensive age-appropriate healthcare services;



September 20, 2023



## Dr Jeffrey Kwong!

## HIV Screening in Older Adults: Clinical Implications & Strategies for Improvement

#### Jeffrey Kwong, DNP, MPH, AGPCNP-BC, FAANP, FAAN, ACRN

**Professor**, Rutgers School of Nursing

Co-Medical Director, AAHIVM HIV and Aging Initiative





## Disclosures

• No Relevant Disclosures



## "He wasn't getting better"

- 75 yr old male admitted with increasing shortness of breath and hypoxia
- PMH: HTN, Type 2 DM, Dyslipidemia
- Medications: Telmisartan 80mg, Metformin 850mg BID, Atorvastatin 40mg
- Social Hx: Retired, Widowed, Lives alone

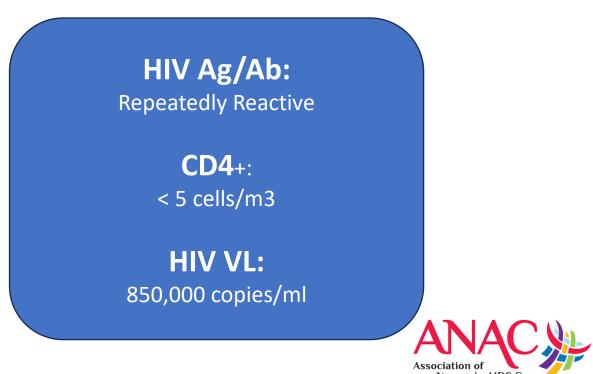


## **Hospital Course**

- CXR with RUL consolidation
- Treated with IV ertapenum and azithromycin
- Intubated due to poor respiratory status
- Transferred to higher level care
- Open lung biopsy

#### Diagnosis:

PJP Pneumonia



## "I'm so tired..."

 69 y.o. with ongoing fatigue, 15 pound weightloss

PMH: depressionMedication: sertraline 100mgSocial Hx: store clerk



## **Case Continued**

- WBC: 2.3 thousand/ $\mu$ L
- Glucose: 89 mg/dl
- TSH: 1.80 mIU/L
- CXR: normal
- Colonoscopy: + benign polyps

HIV Ag/Ab: repeatedly reactive CD4+: 230 cells/m3 HIV VL: 120,000 copies/ml

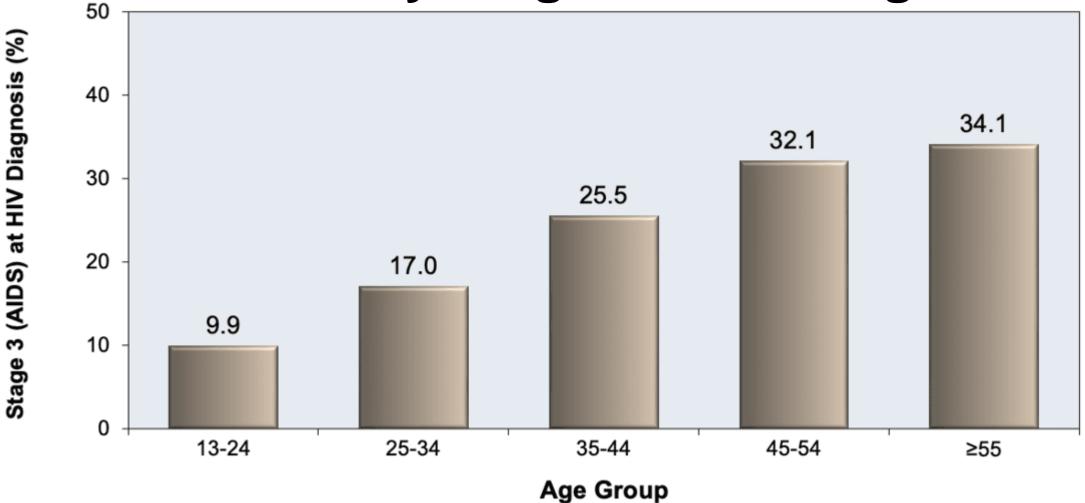
"It's not diabetes" "Your thyroid is fine" "It doesn't look like cancer..." "Are you sure you aren't depressed?"

## "New" HIV Diagnosis in Older Adults

- Identified with more advanced HIV
- Advanced untreated HIV associated with increased morbidity and mortality
- Higher risk of further HIV transmission

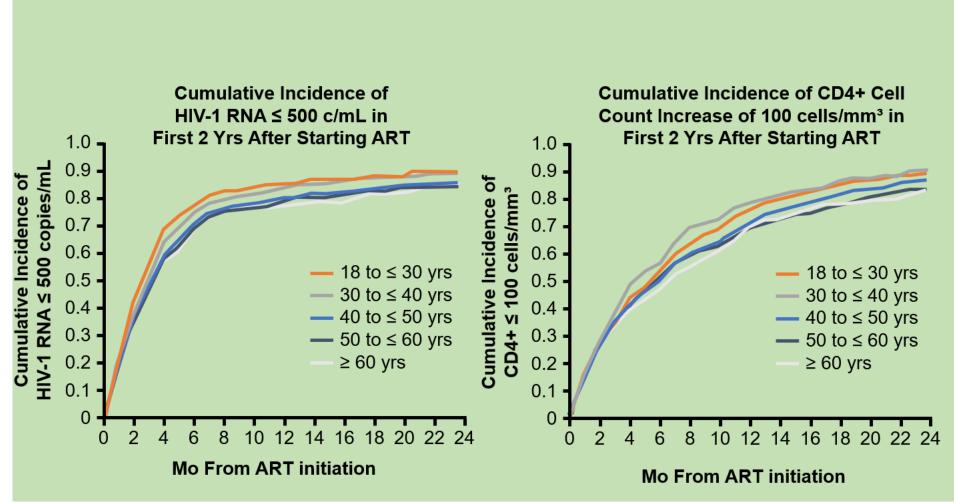


#### Percent of New HIV Diagnosis Concurrently Diagnosed at Stage 3





#### Immunologic But Not Virologic Response Decreased in Older Patients (n=12,196)







#### **Diagnose** all people with HIV as early as possible.

**Treat** people with HIV rapidly and effectively to reach sustained viral suppression.





**Prevent** new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).

**Respond** quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.



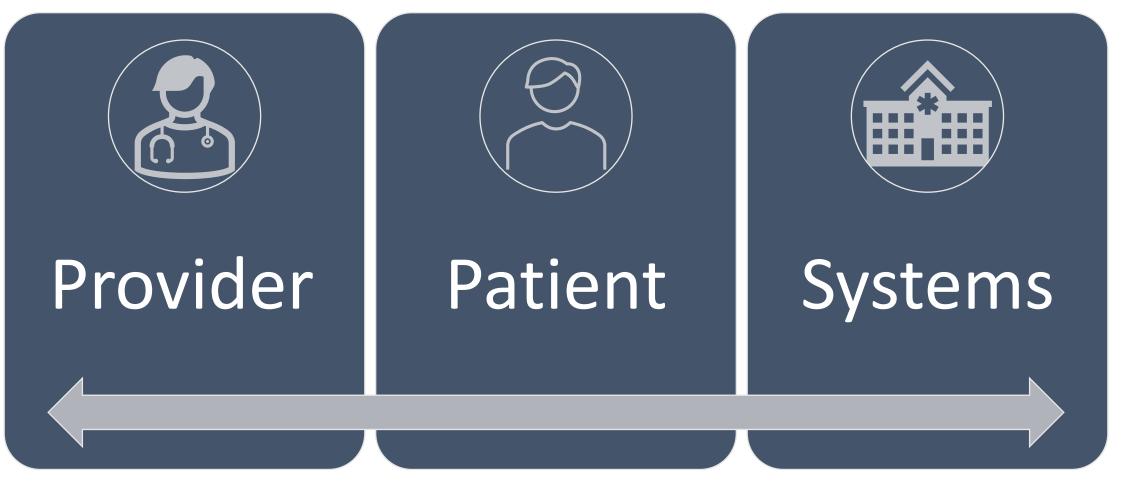


## An estimated **72.5%** of US adults had never tested for HIV.

## Almost **80%** of "never testers" were age 50 and older.

Patel SN, Emerson BP, Pitasi MA, et al. HIV Testing Preferences and Characteristics of Those Who Have Never Tested for HIV in the United States. *Sex Transm Dis*. 2023;50(3):175-179. doi:10.1097/OLQ.00000000001746

## **Barriers to Testing & Screening**





## **Provider Level Barriers**

- Competing demands
- Misconceptions and biases
- Ageism

Gott M, Hinchliff S, Galena E. General practitioner attitudes to discussing sexual health issues with older people. Soc Sci Med. 2004;58(11):2093-2103



## In a survey of older adults...

• 53% of respondents aged 65 to 74 years, and 26% of respondents aged 75 to 85 years, were sexually active

• Only 38% of <u>men</u> and 22% of <u>women</u> reported having discussed sex with a physician after age 50 years



## Are we the biggest barrier?

 17% of older adults (65-80) talked about sex with a health care provider

 However, 60% of older adults said they had to initiate the conversation



Image: creative commons



Agochukwu-Mmonu N, Malani PN, Wittmann D, et al. Interest in Sex and Conversations About Sexual Health with Health Care Providers Among Older U.S. Adults. *Clin Gerontol*. 2021;44(3):299-306. doi:10.1080/07317115.2021.1882637

#### Are we prepared?

More than half of medical, nursing, physician associate curriculums contain < 10 hours on sexual health

44% of U.S. Medical Schools lack a formal sexual health course in the curriculum

1 out of 6 nursing instructors thought students were capable of managing sexuality concerns 37.9% of OB-GYN residents felt comfortable obtaining a sexual history from a 58 y.o. transgender woman

Capiello J, Coplon L, Carpenter H. Systematic review of sexual and reproductive health content in nursing curricula. *J Obstet Gynecol Neonatal Nurs*. 2017;**46**:e157–e169 Criniti S, et al. The State of Sexual Health Education in U.S. Medicine. *Am J Sex Ed*. 2014;**9**:165–180. doi: 10.1080/15546128.2013.854007 Worly B, et al. Sexual Health Education in Obstetrics and Gynecology (Ob-Gyn) Residencies-A Resident Physician Survey. *J Sex Med*. 2021;18(6):1042-1052. doi:10.1016/j.jsxm.2021.03.005



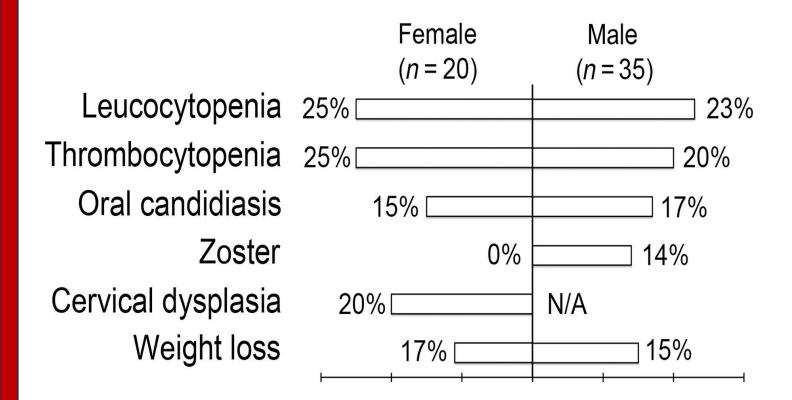
## **Clinical Presentation**

• Some conditions more common in older adults and may not prompt HIV testing.

 Older patients often perceived to be lower risk for acquiring HIV, which subsequently puts HIV lower on differential diagnosis



## **Missed Opportunities**



"This group of patients experienced a delay in HIV diagnosis despite having contact with the *healthcare system for* other co-morbidities, and even in the presence of warning signs of HIV indicator conditions...."

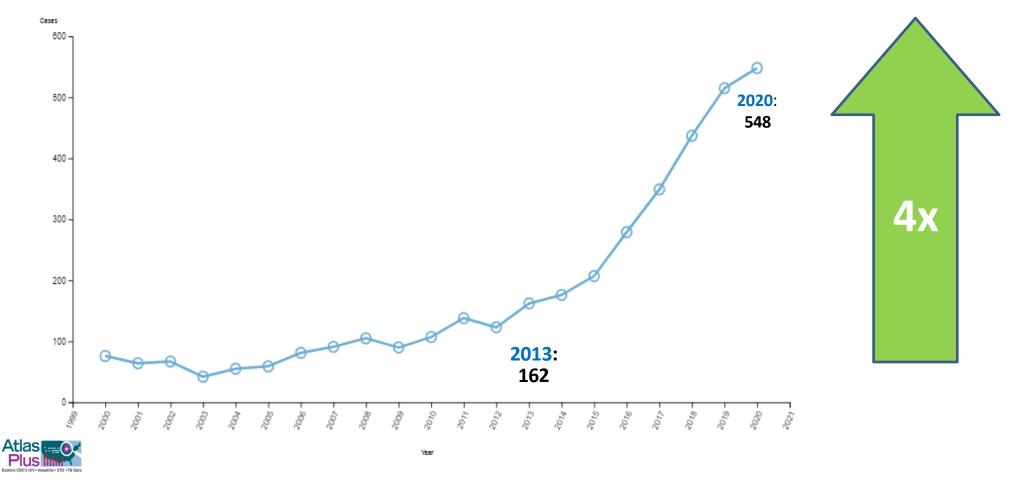
Tominski D, Katchanov J, Driesch D, et al. The late-presenting HIV-infected patient 30 years after the introduction of HIV testing: spectrum of opportunistic diseases and missed opportunities for early diagnosis. HIV Med. 2017;18(2):125–32.



## Providers don't think about HIV yet....



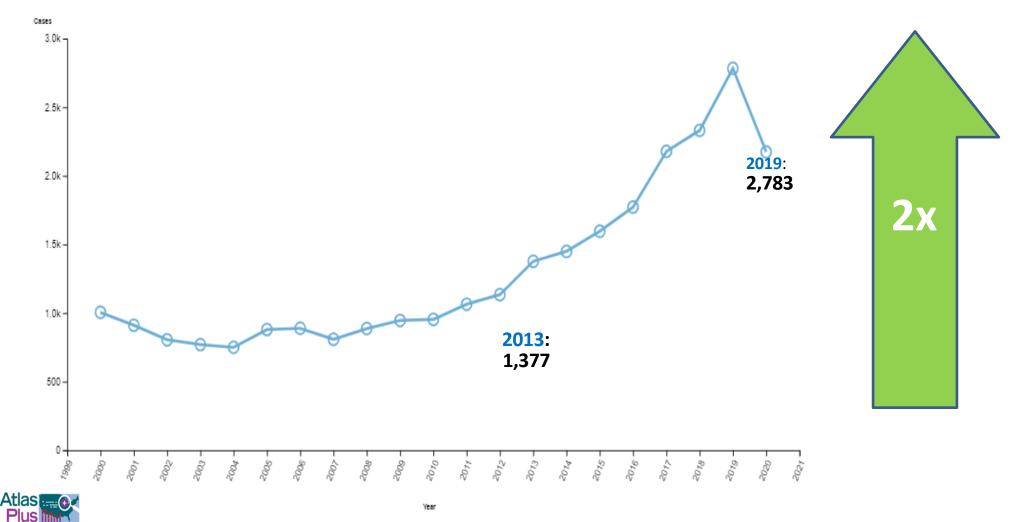
#### Primary and Secondary Syphilis | 2020 (COVID-19 Pandemic) | 65+ | All races/ethnicities | Both sexes | United States





https://gis.cdc.gov/grasp/nchhstpatlas/charts.ht ml

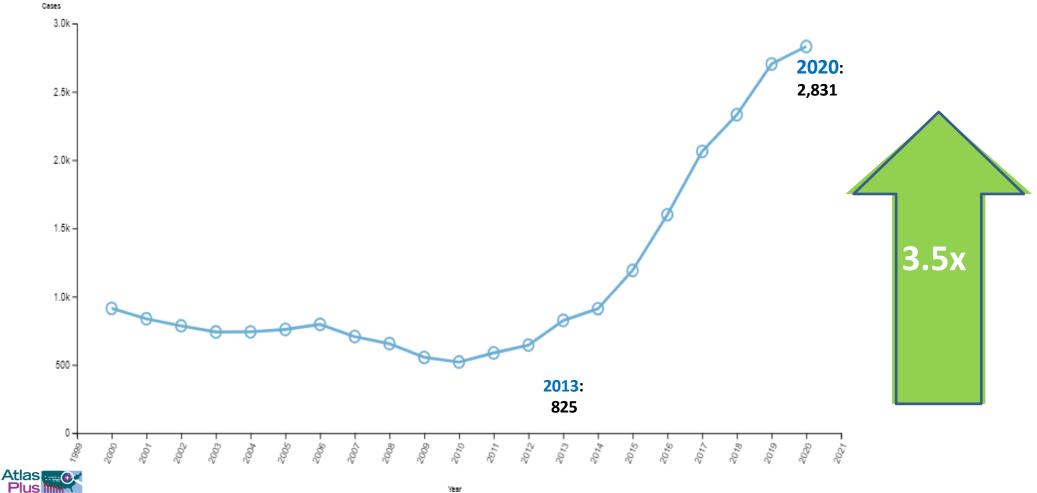
## Chlamydia | 2020 (COVID-19 Pandemic) | 65+ | All races/ethnicities | Both sexes | United States





https://gis.cdc.gov/grasp/nchhstpatlas/charts.ht

## Gonorrhea | 2020 (COVID-19 Pandemic) | 65+ | All races/ethnicities | Both sexes | United States



ASSOCIATION OF

https://gis.cdc.gov/grasp/nchhstpatlas/charts.ht ml

## **Patient Level Barriers**

- Fear
- Stigma
- Privacy concerns
- Cultural beliefs
- Inconvenience (e.g., transportation)
- Poor access to care
- Low health literacy
- Lack of communication with health care providers
- Lack of awareness or perceived risk

Youssef E, Wright J, Delpech V, et al. Factors associated with testing for HIV in people aged >=50 years: a qualitative study. BMC Public Health. 2018;18(1):1204.

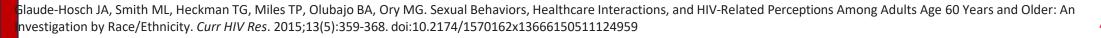




https://www.cdc.gov/stophivtogether/partnerships/toolkit/february-202-toolkit.html

## It's Not Happening...

- In a survey of older adults aged 60 and older (n=1,429)
  mean age 69.9 years
  - 83.1% visited a medical provider at least twice in the previous year
  - 49.3% engaged in sexual intercourse
  - 3% used condoms
  - 30.9% discussed sex with a medical provider since turning age 50
  - 14.2% tested for HIV
  - African Americans had greater perceived risk for HIV, they were less likely to discuss sex with a medical provider since turning age 50





## **Reasons For Patients to Seek Care and Testing**

Prompted when symptoms:

- affected ability to perform day-to-day activities
- greater severity, and occurred over a longer period
- recognition by others, such as family and friends

Bell S, Doran T, Martin F, Adamson J. Journeys to HIV testing and diagnosis among adults aged 50+ years in England: A qualitative interview study. Journal of Health Services Research & Policy. 2021;26(2):85-94



## **Systems Level Barriers**

#### Recommendation Summary

Population	Recommendation	Grade
Pregnant persons	The USPSTF recommends that clinicians screen for HIV infection in all pregnant persons, including those who present in labor or at delivery whose HIV status is unknown.	A
Adolescents and adults aged 15 to 65 years	The USPSTF recommends that clinicians screen for HIV infection in adolescents and adults aged 15 to 65 years. Younger adolescents and older adults who are at increased risk of infection should also be screened. See the Clinical Considerations section for more information about assessment of risk, screening intervals, and rescreening in pregnancy.	A

**Clinical Considerations** 

#### Patient Population Under Consideration

This recommendation applies to adolescents, adults, and all pregnant persons regardless of age. Based on the age-stratified incidence of HIV infection and data on sexual activity in youth, the USPSTF recommends screening for HIV infection beginning at age 15 years. Adolescents younger than 15 years and adults older than 65 years should be screened if they have risk factors for HIV infection.



What You Don't See Matters



Take the Test & Take the Next Step







## Moving The Needle Forward

## **Universal Testing**:

• Help clinicians not focused on HIV to consider possibility of HIV infection

### **HIV self-testing:**

• May benefit people concerned about privacy, such as people facing the double stigma of age and sexual minority status.

Justice AC et al. Delayed presentation of HIV among older individuals: a growing problem. The Lancet HIV, published online 23 February 2022.



#### TAKEMEHOME

ABOUT

#### Learn about Together TakeMeHome

Together TakeMeHome is a collaboration between Emory University, Building Healthy Online Communities, the U.S. Centers for Disease Control and Prevention, NASTAD, OraSure, and Signal.

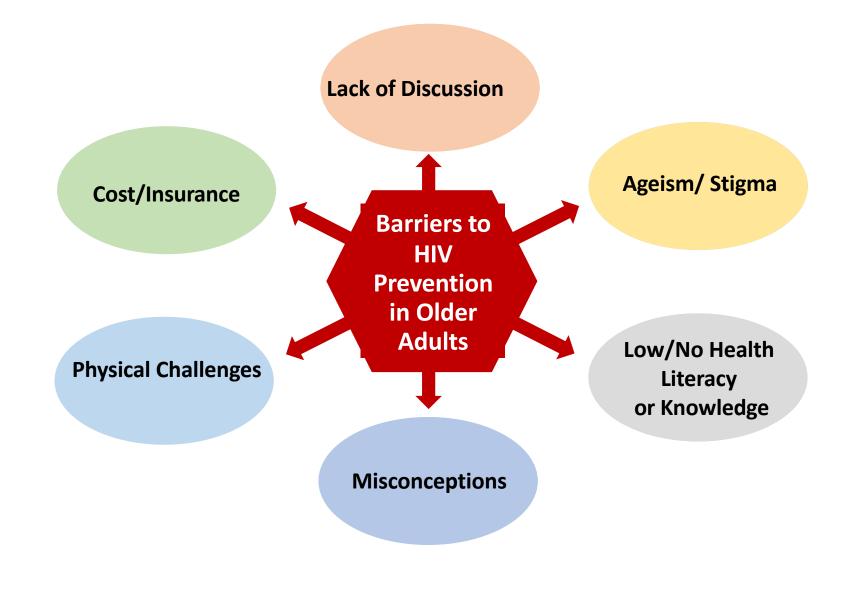






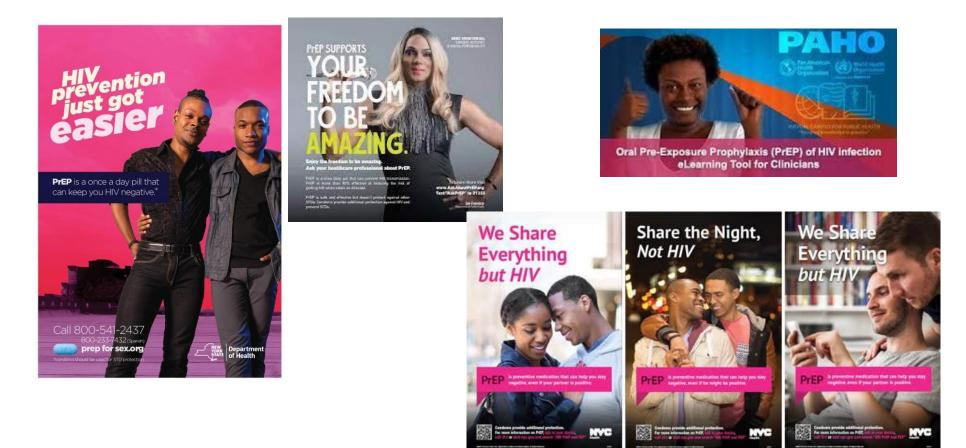








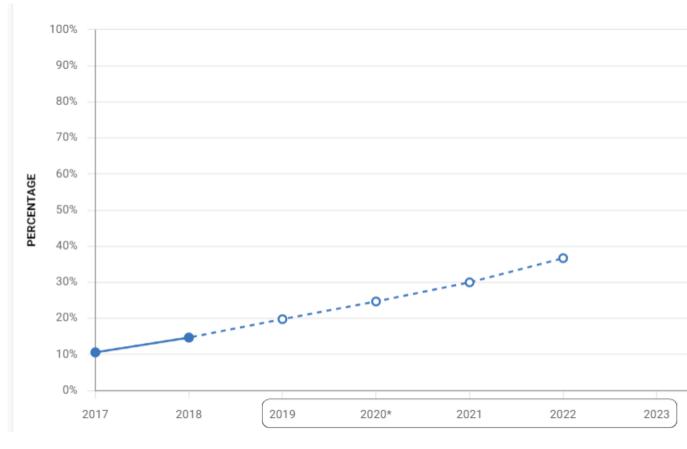
## Is PrEP right for me?





## **PrEP Use in Persons 55+**

 36.7% of persons >55 yrs with indications for PrEP were prescribed PrEP in 2022



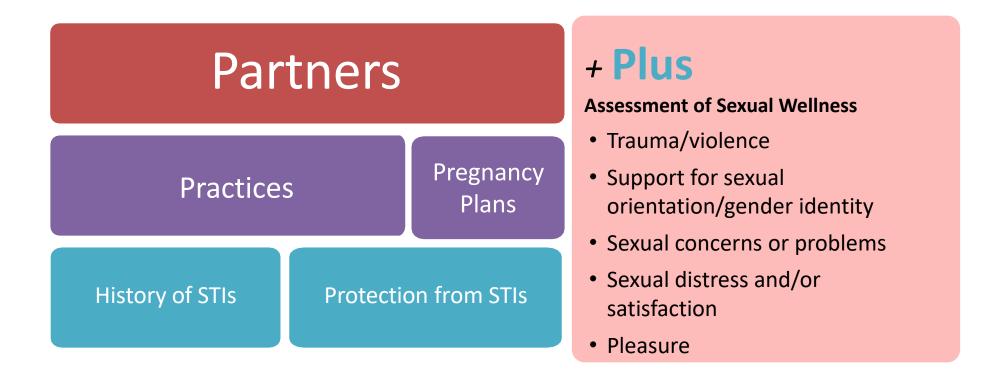


## How do you open the door?





## 6 P's Approach



Source: Rubin ES, Rullo J, Tsai P, et al. Best Practices in North American Pre-Clinical Medical Education in Sexual History Taking: Consensus From the Summits in Medical Education in Sexual Health. J Sex Med 2018;15:1414–1425.



# Approach to Older Adults and Sexual Health Concerns

- Listen
- Build trust
- Educate about normal changes
- Consider interprofessional approach
- Use inclusive language



Image source: stock image MS Powerpoint



## Key Take Aways

- Continued efforts are needed to improve HIV testing and early diagnosis in older adults.
- Normalizing conversations about sexual health and should be a part of routine care for older adults.
- Nurses play a role in educating about HIV testing, assessing candidates for HIV and STI prevention, and engaging and retaining those newly diagnosed.



# Take Action!

## Public Comment on Draft Research Plan: Screening for HIV

- The U.S. Preventive Services Task Force
- November 30, 2023, through January 3, 2024
- https://uspreventiveservicestaskforce.org/uspstf/document/draftresearch-plan/human-immunodeficiency-virus-hiv-infectionpregnant-nonpregnant-adults

## CDC HIV Testing Public Comment

Coming in 2024

## Speak Up! Raise Awareness!



Give public comment at PACHA, CDC/HRSA meetings or any other public meetings you attend.



Advocate for and develop policies and procedures in your workplace to address HIV testing (and sexual health) that is inclusive of people 65 and older.



Talk about this issue whenever you have the opportunity (team meetings, IDJC, conferences, press, etc).

## Activism is my rent for living on the planet.



66





## **Questions?**

- Terri L Wilder, MSW
- HIV/Aging Policy Advocate
- twilder@sageusa.org

#### Discussion and Q & A





