

What lifelong really means: adults born with HIV

Allison Agwu, MD ScM, FAAP FIDSA

Professor, Pediatric and Adult Infectious Diseases

Director, Pediatric Adolescent HIV/AIDS Program and Accessing Care Early Clinic

Johns Hopkins School of Medicine, Baltimore, Maryland, USA

July 19th, 2021

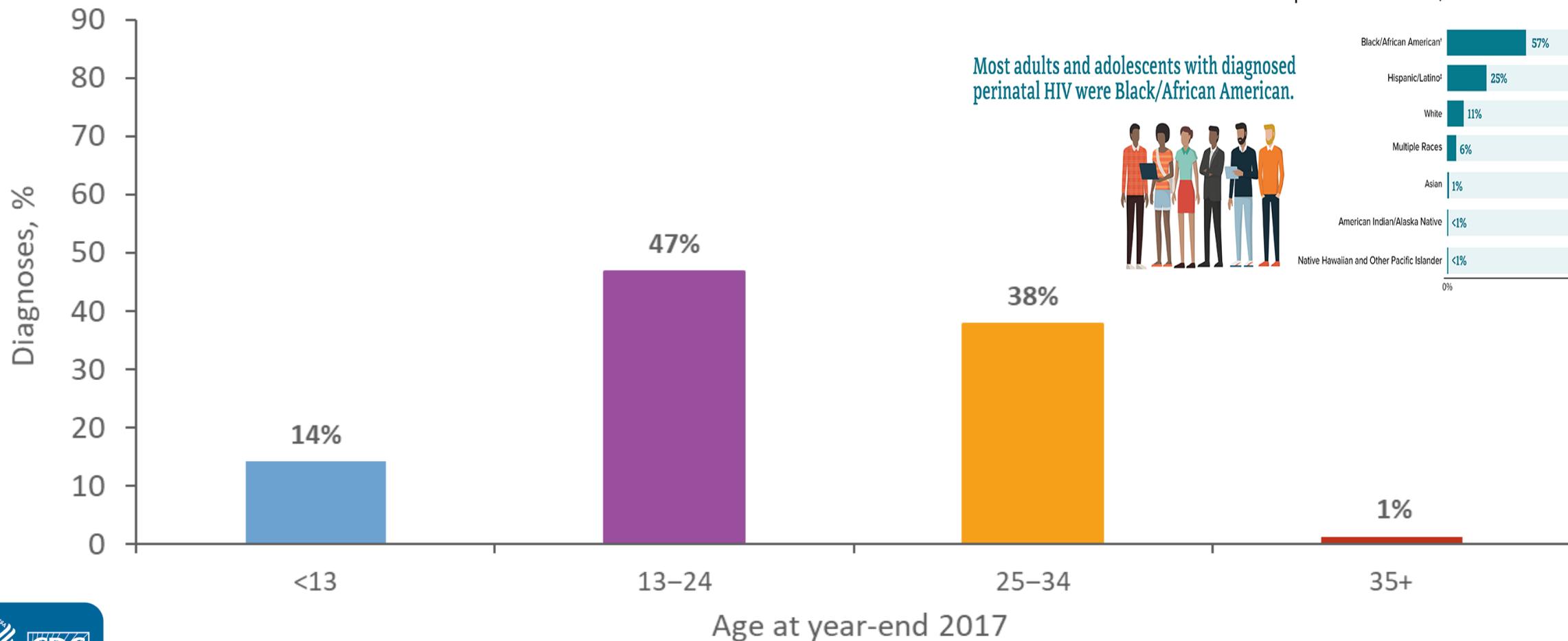
Disclosures

- Gilead scientific advisory board, site investigator under clinical research contract managed through JHU
- Merck scientific advisory board, consultant, site investigator under clinical research contract managed through JHU

Objectives

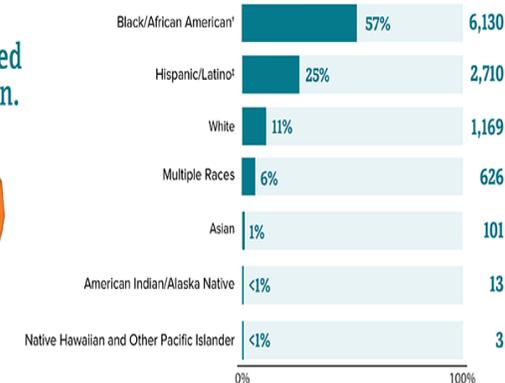
- Review the epidemiology of adults living with perinatally acquired HIV
- Highlight unique developmental, neurocognitive, biologic, psychosocial and societal factors and sequelae over the life course
- Discuss clinical, research, and societal needs to optimize outcomes

Age Distribution of Persons Living with Diagnosed Perinatally Acquired HIV Infection, Year-end 2017—United States and 6 Dependent Areas (N = 11,924)

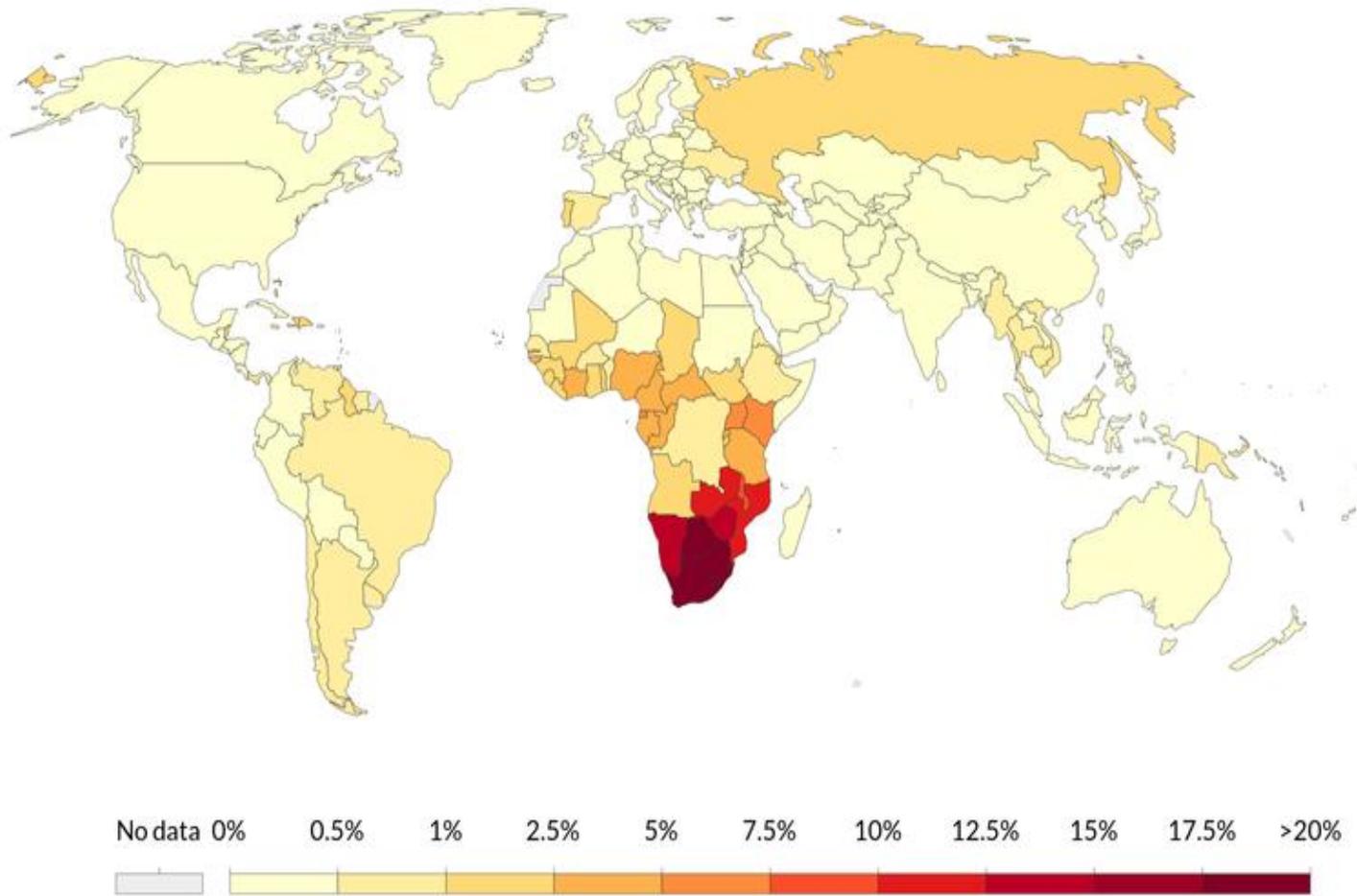


Total Number of Adults and Adolescents With Diagnosed Perinatal HIV in the US and Dependent Areas, 2018*

Most adults and adolescents with diagnosed perinatal HIV were Black/African American.

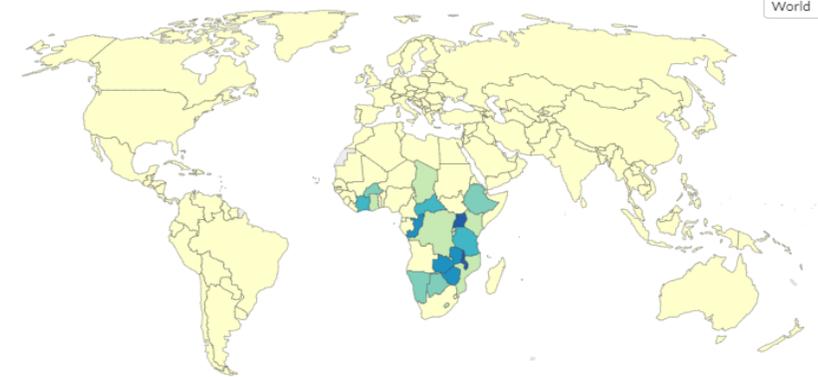


Share of the population 15-49 living with HIV, 2017



Source: Institute for Health Metrics and Evaluation (IHME)

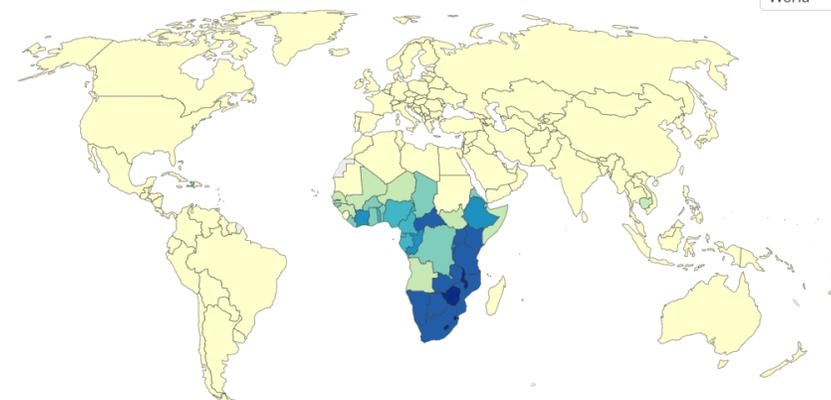
Share of children under five years old with HIV, 1990



Source: IHME, Global Burden of Disease

OurWorldInData.org/hiv-aids • CC BY

Share of children under five years old with HIV, 2000



Source: IHME, Global Burden of Disease

OurWorldInData.org/hiv-aids • CC BY

Many adults born with HIV are thriving.....

Health | Nation & World

First wave of babies born with HIV nearing 30

Originally published October 9, 2010 at 6:15 am | Updated October 9, 2010 at 8:16 am



Chanel Scott, left, and Lafayette Sanders, of Philadelphia, were both infected with HIV at birth. Both of them have died, too. Scott is a college sophomore; Sanders is a brand rep for a... [More](#)



As We See It: Wisdom and the Unique Experiences of Women Born with HIV

In honor of National Women and Girls HIV/AIDS Awareness Day (#NWGHAAD), The Well Project is excited to host an important discussion on the experiences of women born with HIV. We invite all people living with HIV, providers, and allies to join us for this necessary conversation.

Wednesday, March 10, 2021 | 12:30 PM - 2:00 PM EST

Saidy Brown @saidy_brown
 HIV might have changed my life, but I never would have allowed it to limit me. I am still standing. I am still alive. I am queening. I am no victim. I am an #HIVictor 🍷❤️



- CO-HOSTS**
 - Porchia Dees
 - Ieshia Scott
- SPEAKER**
 - Allison Agwu, MD, ScM
- PANELISTS**
 - Kalee Garland
 - Grissel Granados
 - L'Orangelis Thomas
 - Zora Voyce



"I really want people to reconsider what living with HIV means," she said from her hospital bed two days after her operation. "If anyone is proof that you can live a lifetime with HIV, that is myself. I've been living with HIV for 35 years -- pretty much the length of the epidemic in the United States."



2021 to sign up for updates!

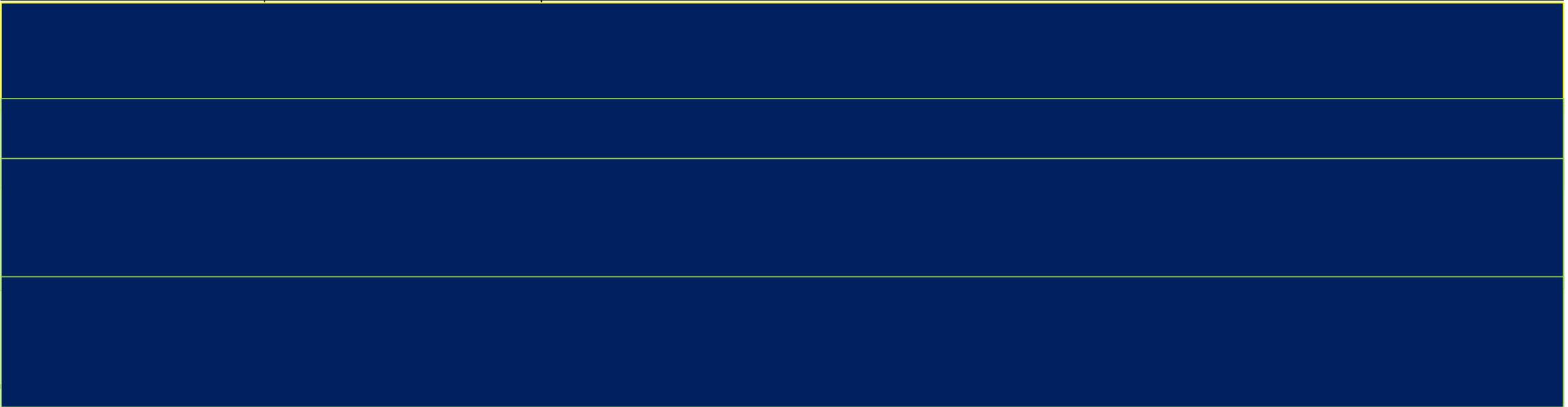


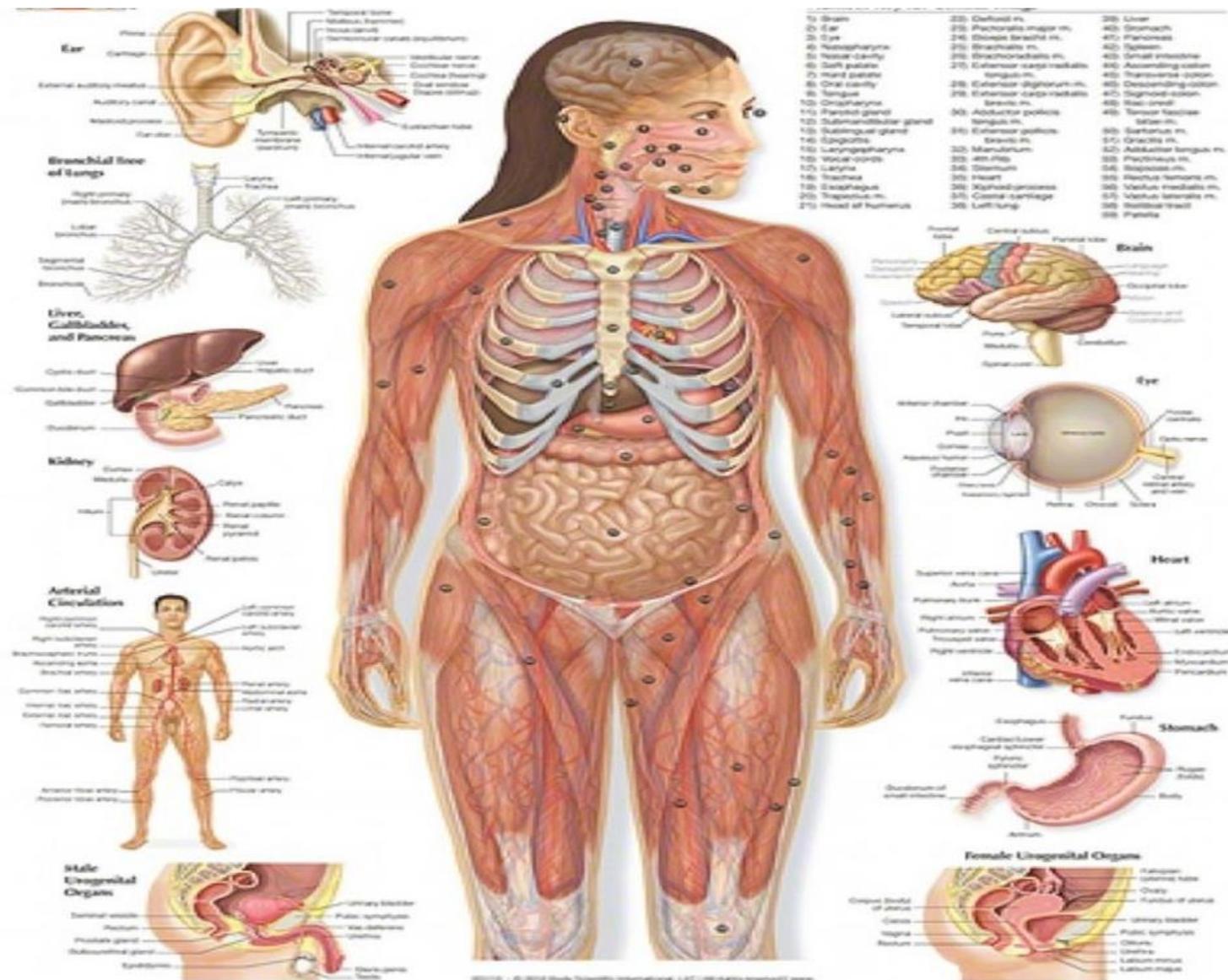
Life course perspective for adults born with HIV

	2 nd Decade 10-19 years
	
Life events	School Trade School/College Employment Parent/guardian loss
Self-management	Parental/caregiver involvement wanes
Disclosure	Disclosure (to self) Disclosure to others
Stigma	Internal and external stigma



	2 nd Decade 10-19 years	3 rd Decade 20-29 years	4 th Decade 30-39 years	5 th Decade 40-49 years	≥6 th Decade ≥50 years
					
Treatment and Treatment-related Factors					
Antiretroviral treatment	Simple regimens* Increased responsibility of ART	Simple regimen Increased complex regimens due to development of resistance Full responsibility of ART	Simple regimen Increased complex regimens due to development of resistance Full responsibility of ART		

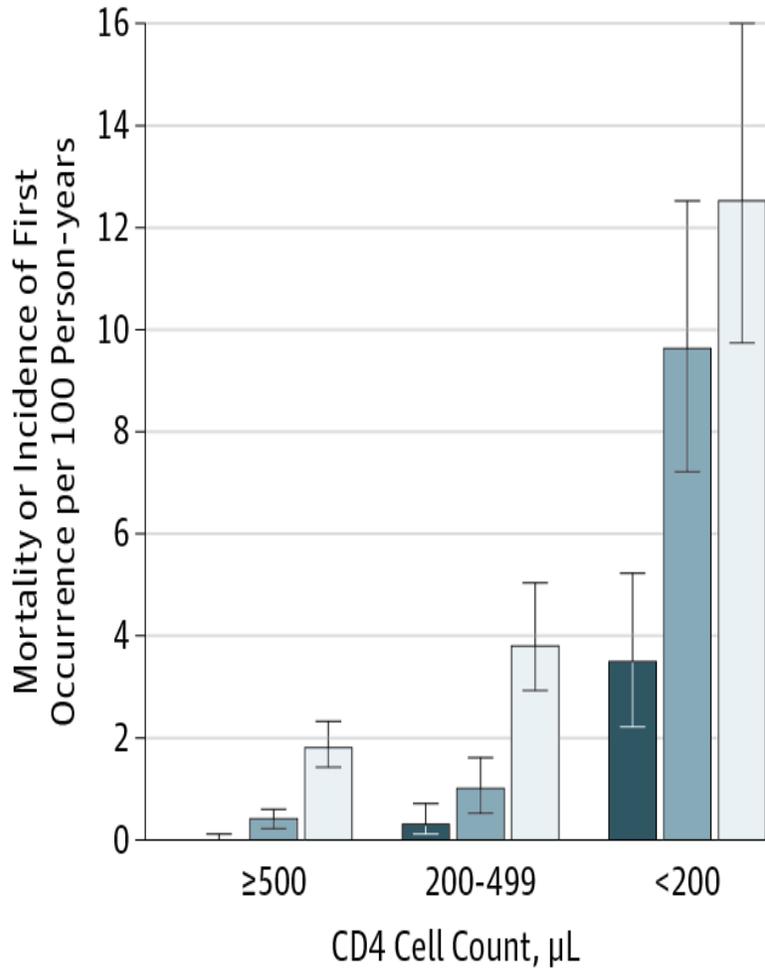




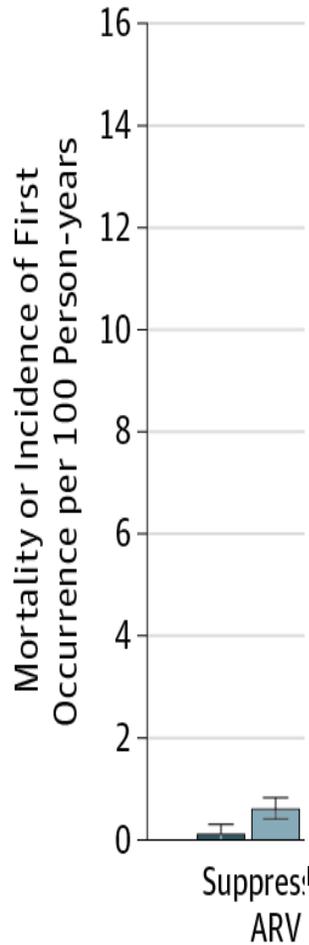
How will adults born with HIV infection be impacted?

Long-term morbidity of HIV +/- ART

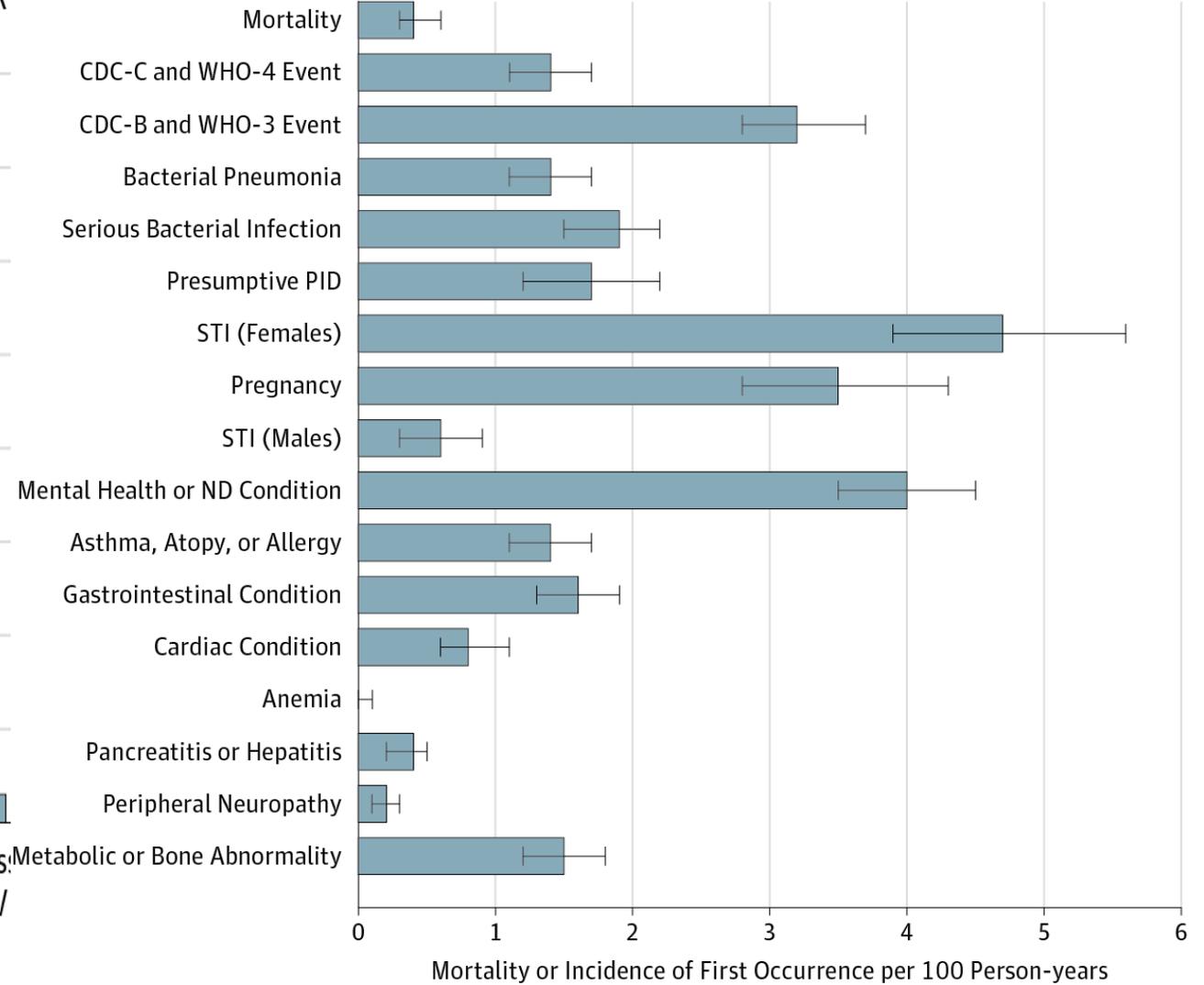
A CD4 cell count



B Viral load and ARV



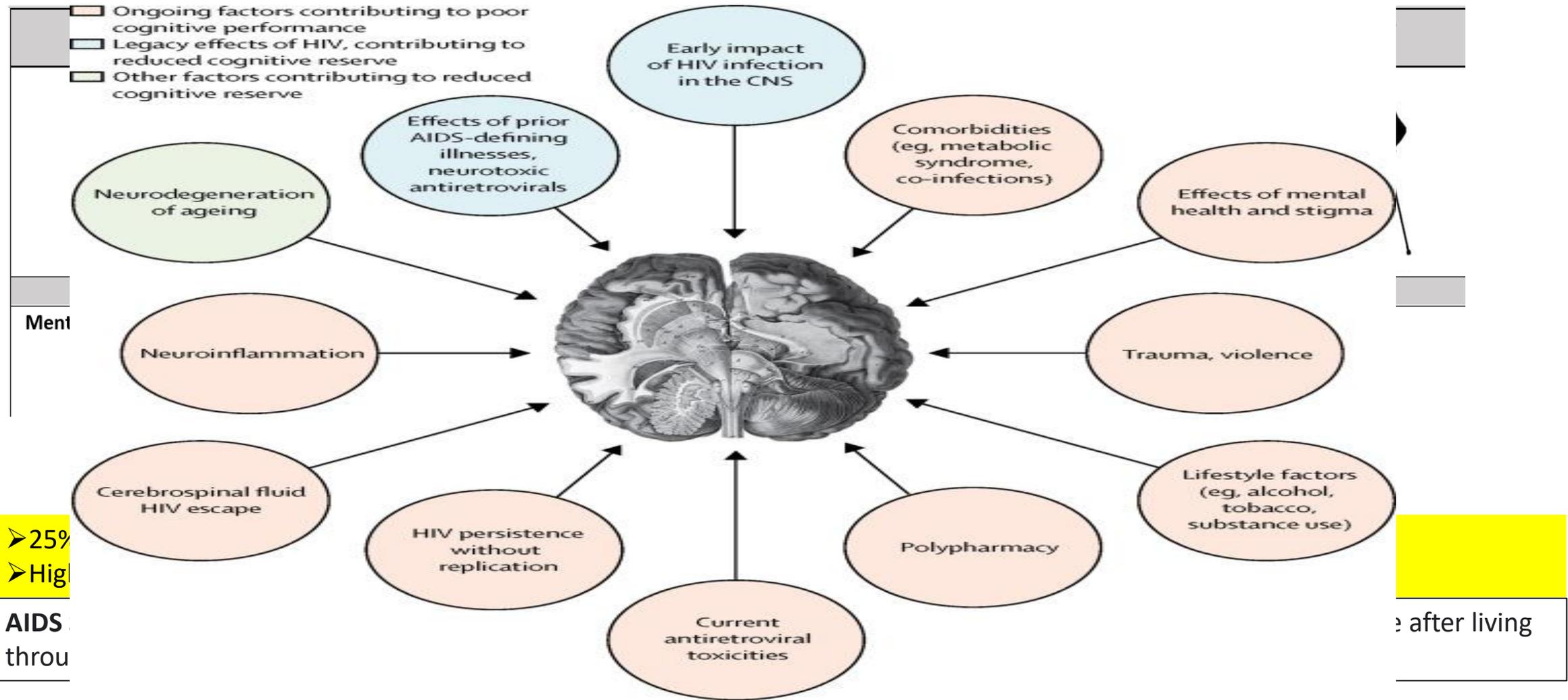
Clinical Event



Consequences of lifelong HIV:



Mental health in adults born with HIV



Sexual and reproductive health for adults born with HIV

	2 nd Decade 10-19 years	3 rd Decade 20-29 years	4 th Decade 30-39 years	5 th Decade 40-49 years	≥6 th Decade ≥50 years
					
Sexual and Reproductive Health					
Sex/reproductive	Sexual and gender identify evolving; Sexual activity often commences Risk reduction	Secondary Prevention Child bearing Risk reduction	Secondary Prevention Child bearing Risk reduction	Secondary Prevention Risk reduction	

	2 nd Decade 10-19 years	3 rd Decade 20-29 years	4 th Decade 30-39 years	5 th Decade 40-49 years	≥6 th Decade ≥50 years
					
Future Clinical and Research Focus					
Treatment	Developing ideal treatment dosing regimens and formulations	Minimizing polypharmacy, optimizing ART, minimizing drug interactions			
	Long acting antiretroviral therapy, non-ART treatment strategies, HIV cure				
Comorbidities	Longitudinal studies on HIV comorbidities and early biomarkers of organ/systemic dysfunction, prevention strategies				
	Impact of customized mental health screening and interventions				
	Minimizing cognitive dysfunction				
Secondary prevention	Early initiation of Sexual risk reduction and safer sexual conduct education Prevention of development of risk behaviors (e.g., smoking, substance use)	Intensified sexual risk reduction education Prevention/reduction of risk behaviors (e.g., smoking, substance use)	Screening for co-morbidities Risk reduction (e.g., smoking cessation)		

How will we know about emerging morbidity?

- Voices of adults born with HIV
- Case reports/series
- Observational data
- Longitudinal cohorts
 - Current cohorts*
 - PHACS (AMP Up)
 - leDEA
 - NA-ACCORD
 - UK cohorts
 - COHERE
 - Others
- Modeling studies
 - CEPAC

	ESLD		ESRD					
	Diagnosis (n=347)	No diagnosis (n=34657)	Diagnosis (n=387)	No diagnosis (n=35365)	Diagnosis (n=255)			
	63 (18%)	16 641 (48%)	124 (32%)	16 344 (46%)	94 (37%)			
	144 (41%)	12 474 (36%)	160 (41%)	13 042 (37%)	101 (40%)			
	106 (31%)	4528 (13%)	80 (21%)	4835 (14%)	41 (16%)			
	34 (10%)	1014 (3%)	23 (6%)	1144 (3%)	19 (7%)			
	298 (86%)	27 354 (79%)	334 (86%)	27 974 (79%)	178 (70%)			
White	25 075 (42%)	692 (49%)	13 429 (46%)	193 (56%)	14 560 (42%)	207 (53%)	15 022 (42%)	30 (12%)
Black	21 658 (36%)	534 (38%)	10 831 (37%)	123 (35%)	11 693 (34%)	108 (28%)	11 452 (32%)	205 (80%)
Hispanic	7 683 (13%)	111 (8%)	3 106 (11%)	20 (6%)	4 379 (13%)	43 (11%)	4 756 (13%)	12 (5%)
Other	3 033 (5%)	44 (3%)	1 308 (4%)	10 (3%)	1 269 (4%)	7 (2%)	1 333 (4%)	1 (0%)
Unknown or missing	2 646 (4%)	24 (2%)	494 (2%)	1 (0%)	2 756 (8%)	22 (6%)	2 802 (8%)	7 (3%)
HIV transmission risk								
MSM	31 370 (52%)	742 (53%)	16 103 (55%)	193 (56%)	17 514 (51%)	180 (47%)	17 114 (48%)	67 (26%)
IDU	6 885 (11%)	204 (15%)	2 971 (10%)	44 (13%)	4 231 (12%)	97 (25%)	3 912 (11%)	52 (20%)
Heterosexual contact	15 397 (26%)	343 (24%)	7 559 (26%)	84 (24%)	9 224 (27%)	73 (19%)	9 065 (26%)	108 (42%)
Other, unknown, or missing	6 443 (11%)	116 (8%)	2 535 (9%)	26 (7%)	3 688 (11%)	37 (10%)	5 274 (15%)	28 (11%)



*not all inclusive; each has limitations

Yusuf. Expert Review of Anti-Infective Therapy. Sep 2020; CDC. Pediatric HIV Surveillance 2018; Althoff et al Lancet HIV 2019

What else do we need to be doing?

- Be intentional
 - Ask specific relevant questions
 - No assumptions
 - Examine differences
 - Include adults born with HIV
- Optimize mental health, reducing stigma
- Address issues including and beyond HIV
- Predict, identify and prevent comorbidities
 - biomarkers, surrogates
 - screening tools
 - HIV as a risk factor for earlier screening?
 - address modifiable risk factors
- Optimizing care models
 - Implementation science
- Education
- **Targeted Funding**

Don't Just Survive....Optimize!



"My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humor, and some style."

Maya Angelou

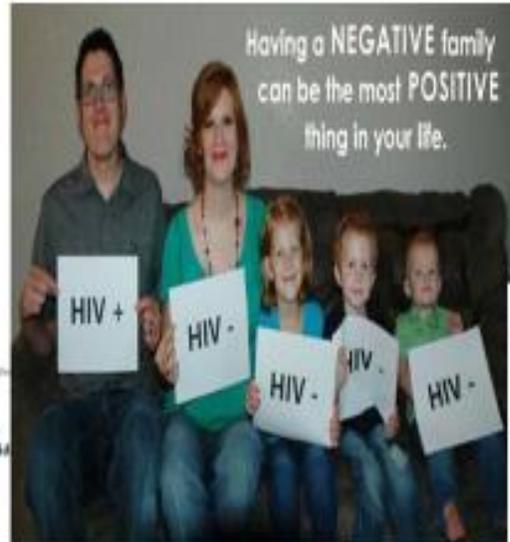
Conclusion

- Individuals born with HIV are surviving into adulthood
- Awareness of potential impact of lifelong HIV is key
- Must specifically consider these individuals in research, clinical care, advocacy and best practices

Health | Nation & World

First wave of babies born with HIV nearing 30

Originally published October 9, 2002 at 8:57 am | Updated October 9, 2002 at 8:58 am



David B. Clark, MD, and Elizabeth Landon, of Fogarty Institute, are interviewed with HIV at birth. Both are awarded the 2002-2003 Distinguished Achievement Award for their work.



Soidy Brown
 @soidybrown
 HIV might have changed my life, but I never would have allowed it to limit me. I am still standing. I am still alive. I am queening. I am no victim. I am an #HIVictor 🏆❤️

WATCH!
Women's Advocacy and Treatment Coalition on HIV

As We See It: Wisdom and the Unique Experiences of Women Born with HIV

In honor of National Women and Girls HIV/AIDS Awareness Day (#NWGHAAD), The Well Project is excited to host an important discussion on the experiences of women born with HIV. We invite all people living with HIV, providers, and allies to join us for this necessary conversation.

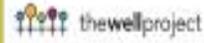
Wednesday, March 10, 2021 | 12:30 PM - 2:00 PM EST

CO-MOISTS:
 Porchelle Doss, Leahle Scott, #Hoon Agwu, MD, MS, LICP

SPEAKER:
 #Hoon Agwu, MD, MS, LICP

PANELISTS:
 Kaitie Cantwell, Gisele Hernandez, L'Orangelle Thomas, Zena Voyce

2021 to sign up for updates!

 thewellproject



and the many many more.....