

An In-depth Examination of an Emerging Population

Who Are These Older Adults Living with HIV



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ACRIA: AIDS Community Research Initiative of America

founded in NYC in 1991

Clinical Trials

- Antiretrovirals
- Side-effects management
- Comorbid treatments

Research on Older Adults

- Social networks
- Depression management
- Comorbidities
- Service utilization
- Accessing caregivers
- Stigma
- Spirituality

Education Health Literacy

- Staff/agency trainings on needs of aging HIV populations & those at-risk
- Local and national technical assistance & capacity building
- Continuing education credits
- Materials in several languages

Older Adults with HIV: An In-depth Examination of an Emerging Population

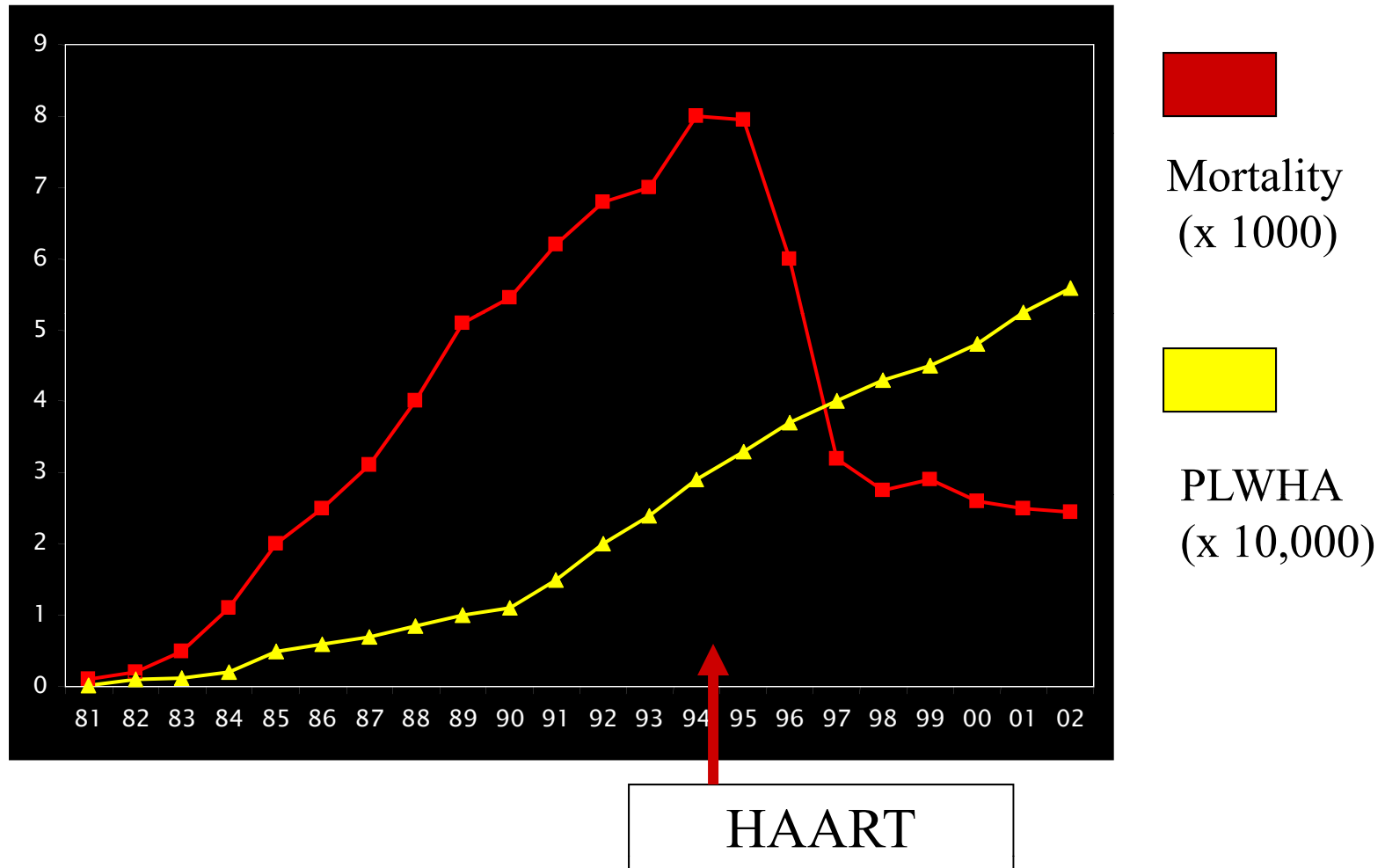
Editors: M. Brennan, S. E. Karpiak, M. H. Cantor & R. A. Shippy
Nova Science Publishers (in press, 2009)

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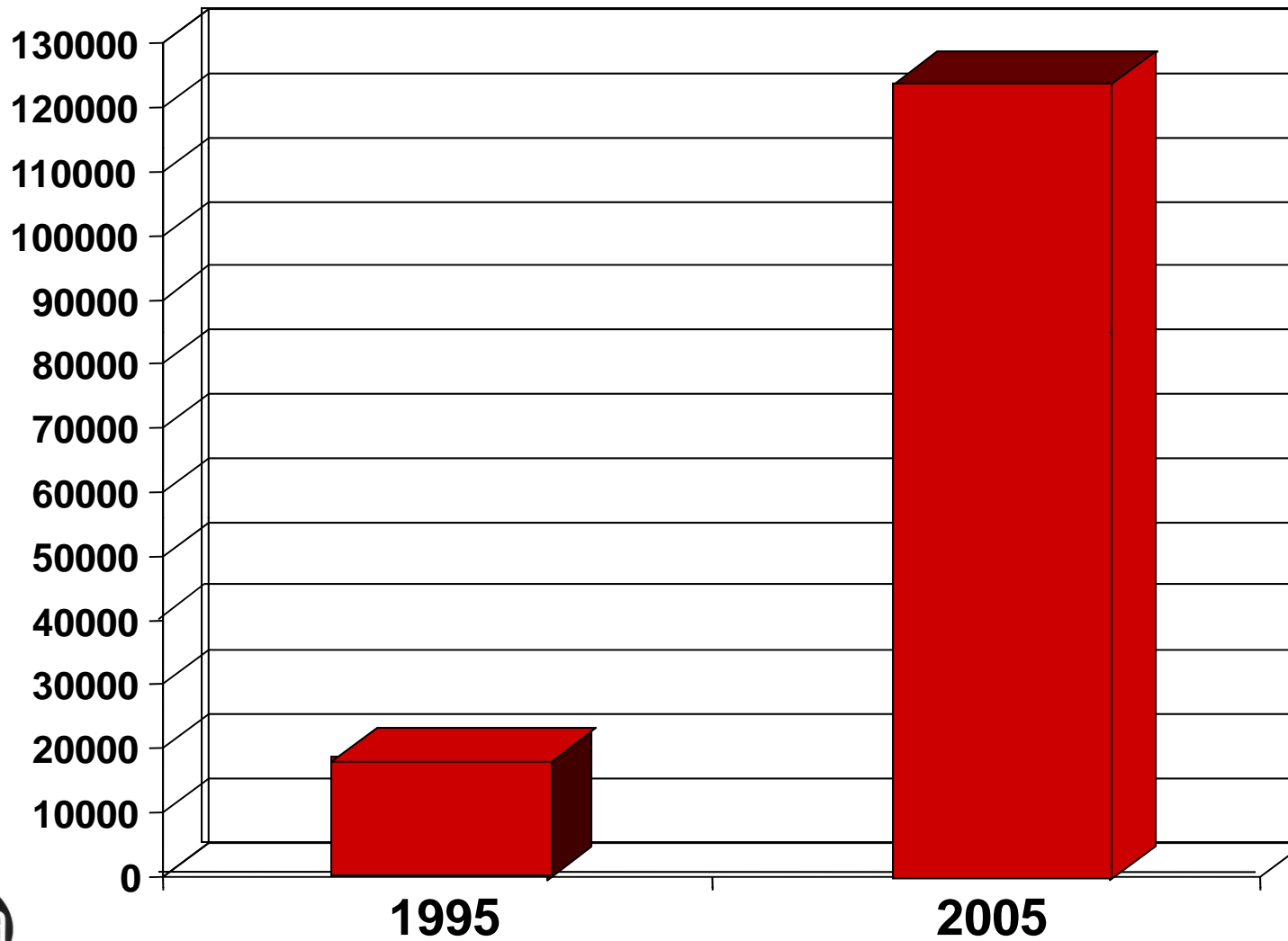
- The Emerging Population of Older Adults with HIV and Introduction to ROAH the Research Study
 - *S. E. Karpiak & M. Brennan*
- Health Status, Comorbidities, and Health-related Quality-of-Life; *R. J. Havlik*
- Mental Health; *A. Applebaum & M. Brennan*
- Substance and Alcohol Use; *A. Applebaum & M. Brennan*
- Sexual Behavior among HIV+ Older Adults; *S. A. Golub, C. Grov, & J. Tomassilli*
- HIV Stigma and Disclosure of Serostatus; *M. Brennan & S. E. Karpiak*
- Social Support Networks of Older People with HIV; *M. H. Cantor, M. Brennan, & S. E. Karpiak*
- Loneliness among Older Adults with HIV; *M. Brennan & A. Applebaum*
- Psychological Well-being; *M. Brennan & S. E. Karpiak*
- Religiousness and Spirituality; *M. Brennan*
- Aging with HIV: Implications and Future Directions; *S. E. Karpiak & M. Brennan*
- About the Authors
- Appendix: Methodology of the ROAH Study



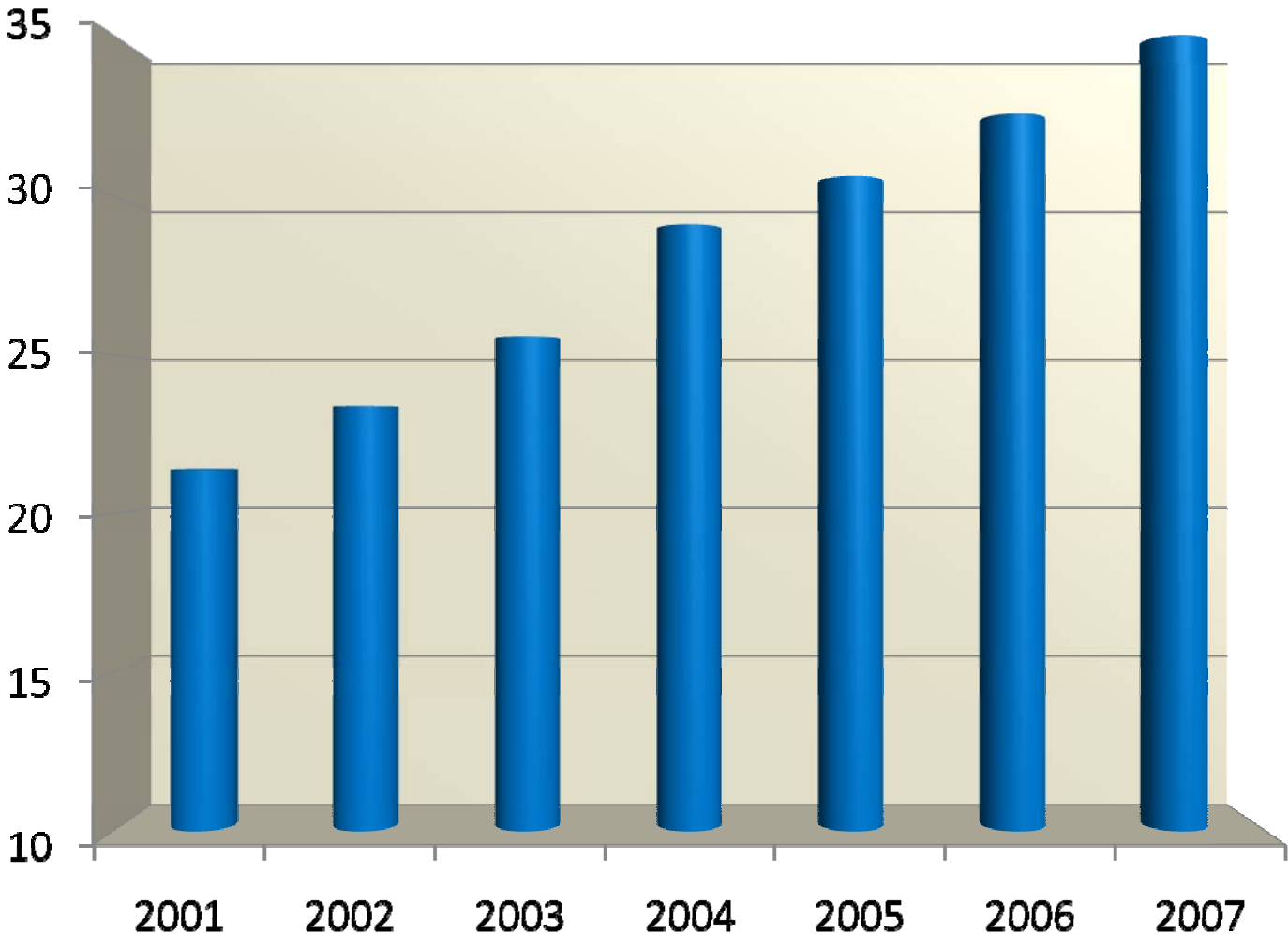
Impact of HAART



USA AIDS Cases Over Age 50 - CDC

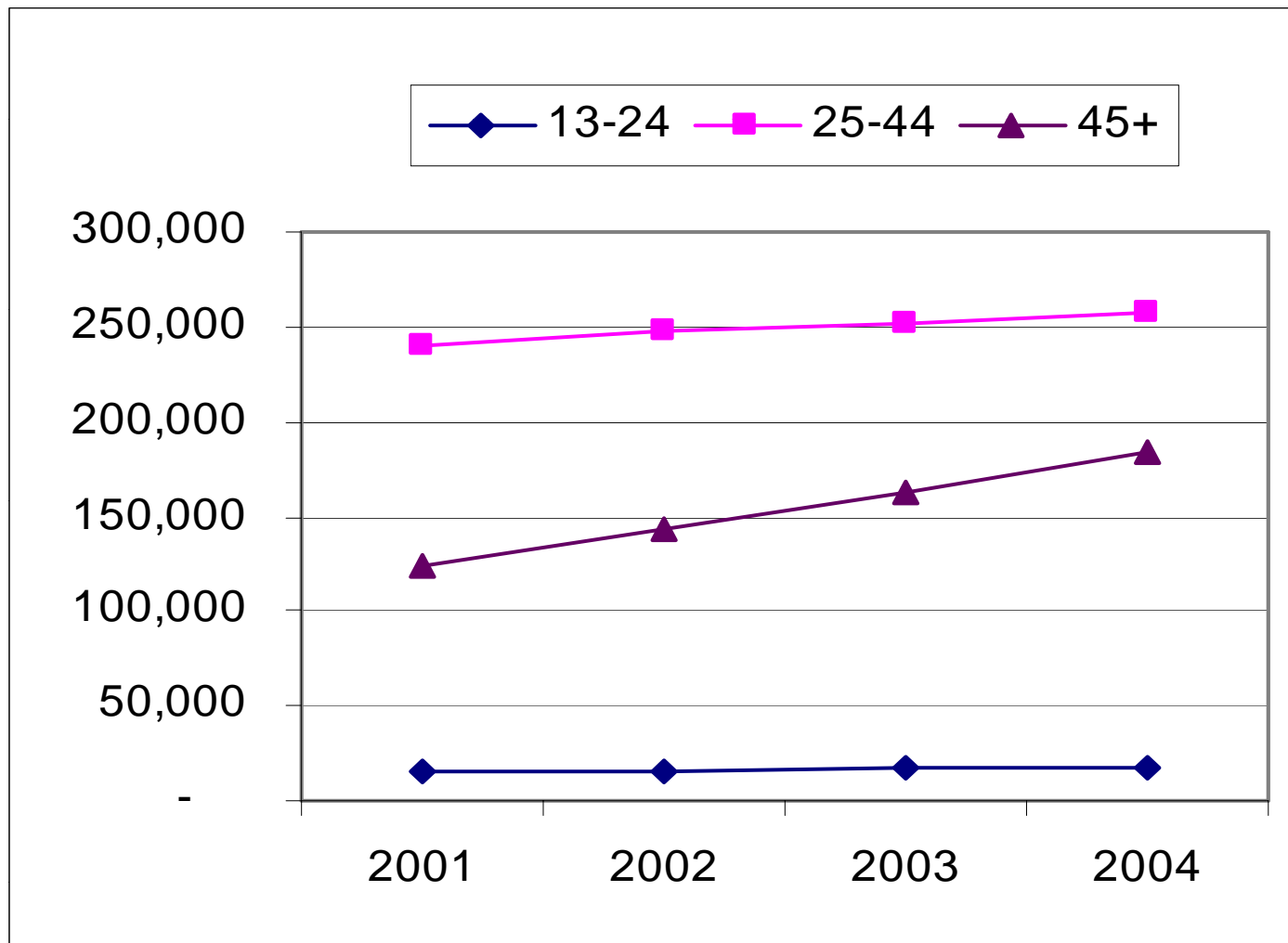


Percent of PLWHA in NYC 50 Years and Older (NYCDOH)



Estimated Number of Persons

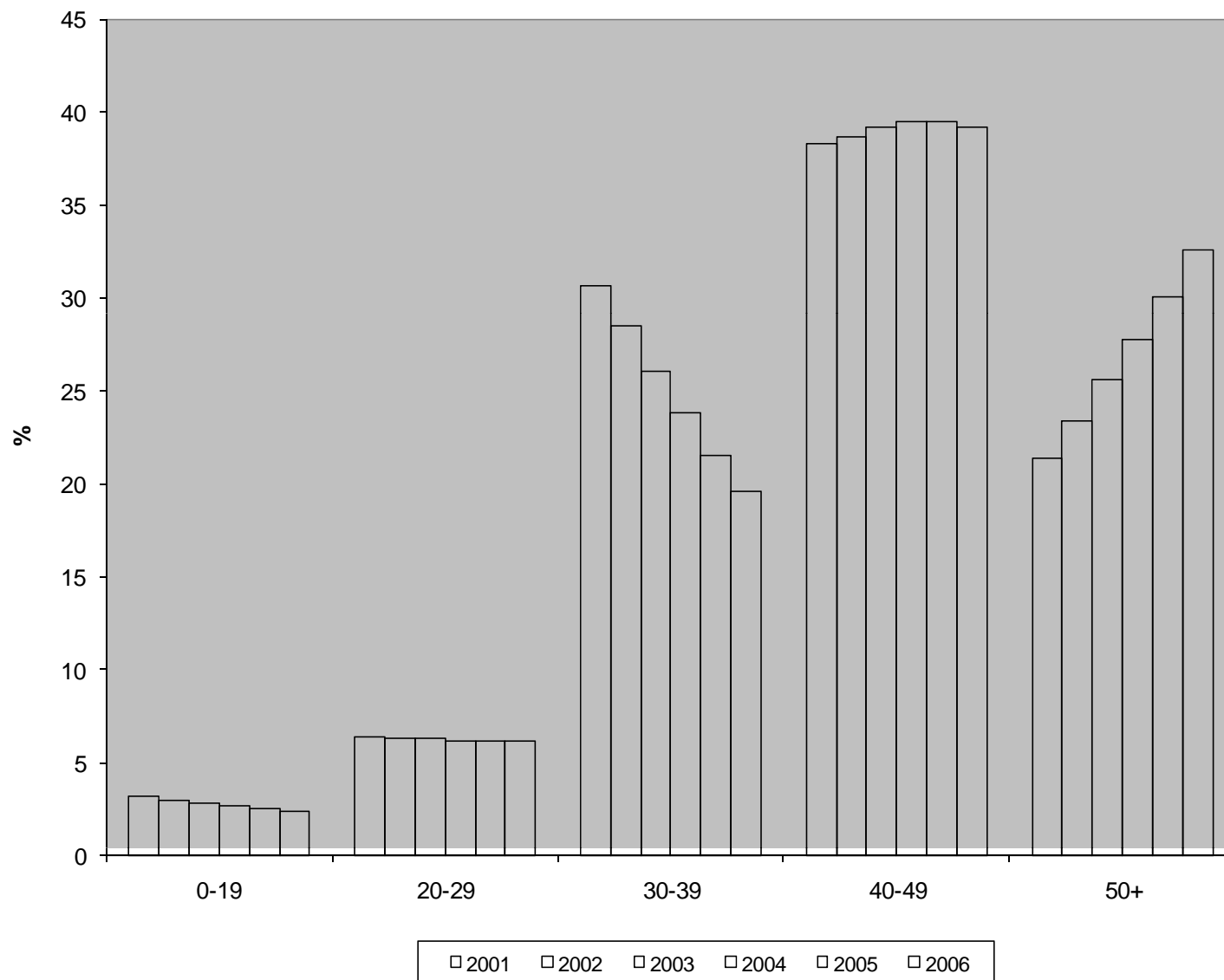
Living with HIV/AIDS - Diagnosis by Age, 2001-2004 *



*CDC HIV/AIDS Surveillance Report, 2004

% People Living with HIV/AIDS in NYC by AGE

NYCDOH 2006



New York City is the US HIV Epicenter

Today in NYC there are
approximately

120,750

known people living with
the HIV

2007 NYC HIV Epidemiology

(NYCDOH)

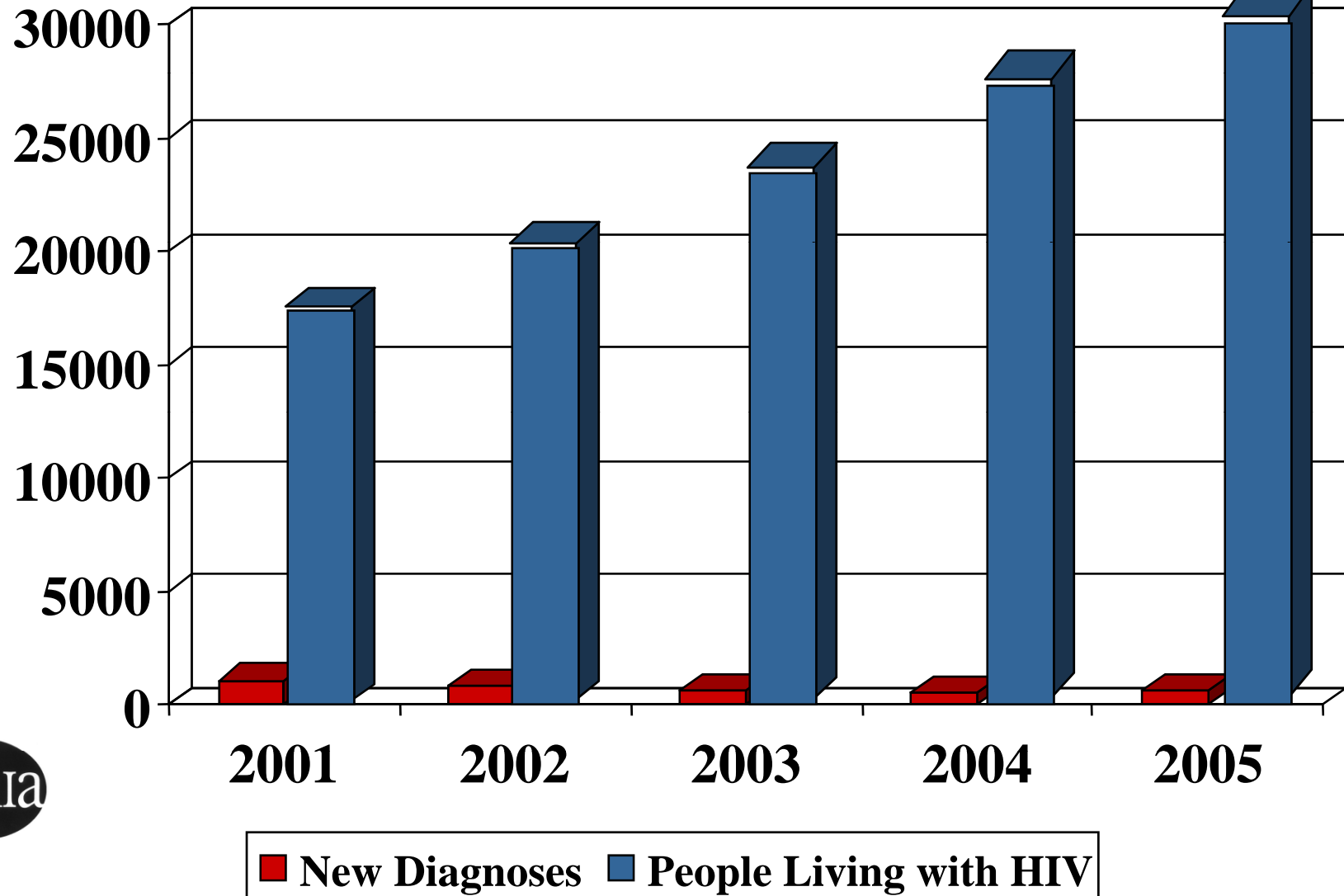
38 %

of people with HIV/AIDS in
NYC are Over 50

74 %

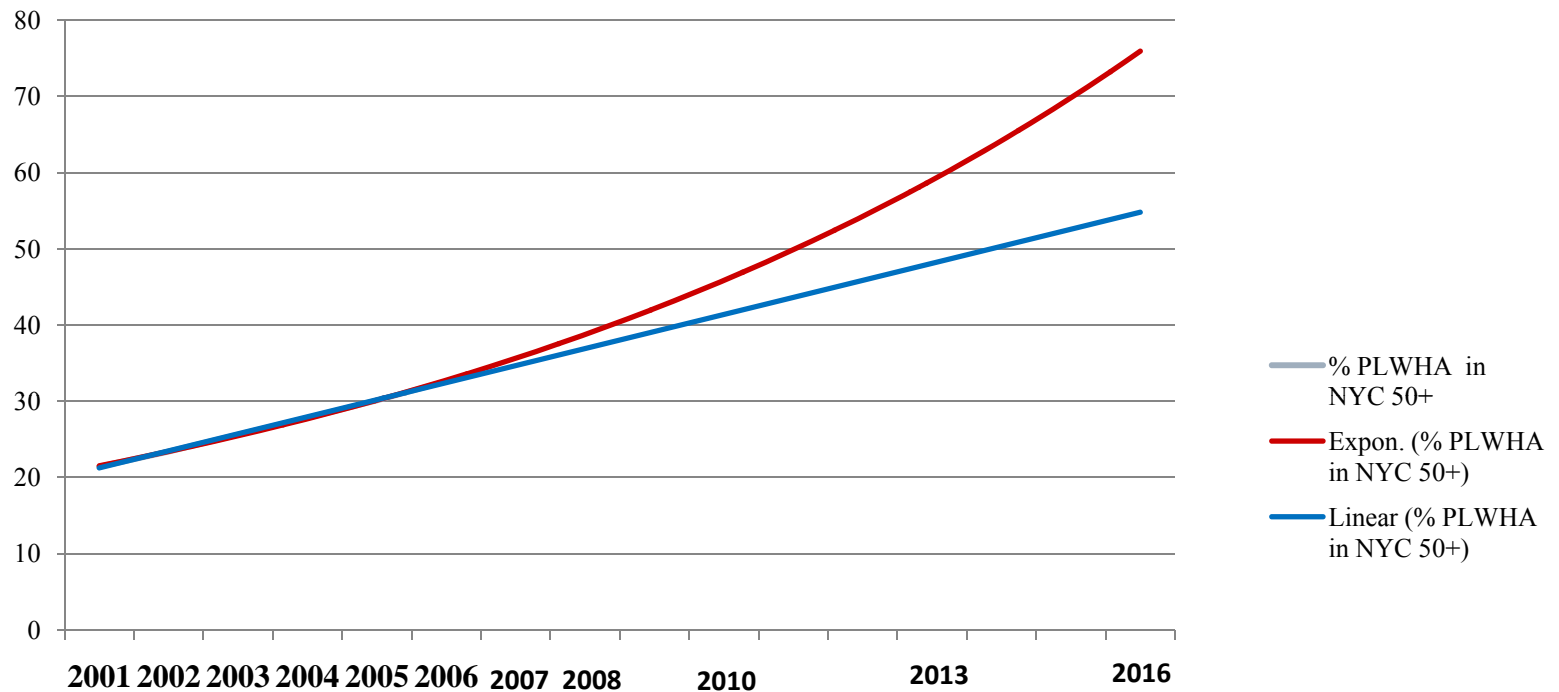
of people with HIV/AIDS in
NYC are Over 40

The Aging of the HIV NYC Population (OVER 50)



By 2013, One-half of Persons Living with HIV in NYC will be 50 Years and Older

Projected Percent of People Living With HIV/AIDS in NYC 50+



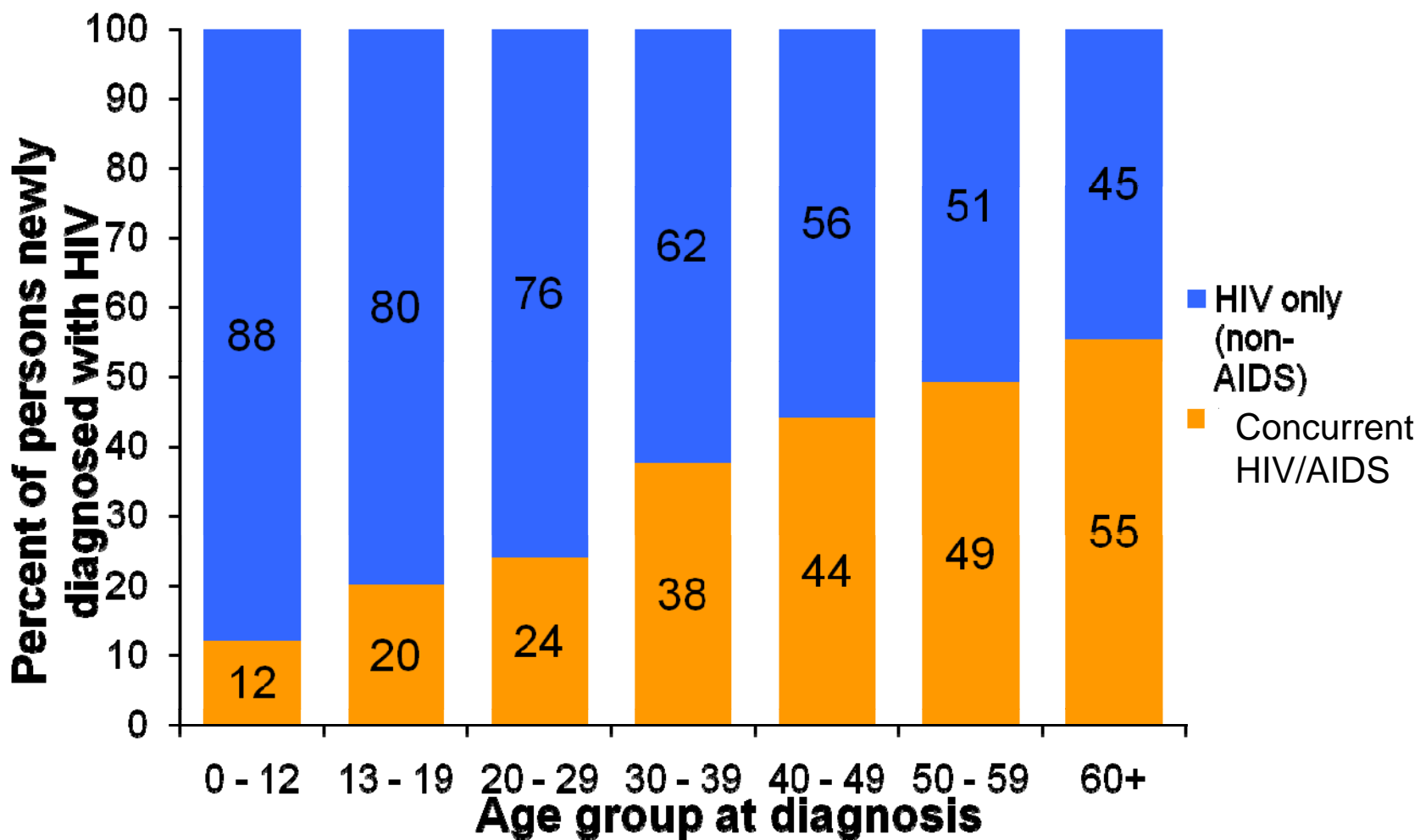
By Mark Brennan, PhD
ACRIA Center on HIV
and AGING

AIDS Cases 2006 / 07

	<u>Over 50</u>	<u>Over 40</u>
San Francisco	35 %	76 %
Los Angeles	33 %	77 %
Missouri	35 %	76 %
Illinois	32 %	74 %
Wisconsin*	38 %	
Michigan*	38 %	

* HIV/AIDS

Concurrent HIV/AIDS among persons diagnosed with HIV in 2006 by age group, United States



ACRIA: First Studies Conducted in 2004

ACRIA conducted an initial study of 150 older adults – over the age of 50 – living with HIV in NYC

That study resulted in multiple presentations, abstracts and two peer review published articles

- Shippy & Karpiak (2005). The aging HIV/AIDS population: Fragile social networks. *Aging & Mental Health*, 9(3), 246-254.
- Shippy & Karpiak (2005). Perceptions of support among older adults with HIV. *Research on Aging*, 27(3), 290-306.

Research on **O**lder **A**dults with **H**IV



Investigators
Stephen E. Karpiak, PhD
Mark Brennan, PhD
ACRIA Center on HIV and Aging

ROAH Research Collaborators/Advisory Group

Chairperson: *Marjorie Cantor, Emerita Fordham U & Brookdale Scholar*

Stephen Bailous	Office of AIDS Policy, NYC DOH
J. Bookhardt-Murray, MD	Medical Director Harlem United & AIDS Institute NYS
David Dorfman, PhD	Mt. Sinai School of Medicine
Arlene Kochman,MSW	Yale University School of Medicine
Allen Matthews, Mardi Fritz	NYC DOH
Douglas Mendez, MD	Dominican Medical Association
Peter Nwakeze, PhD	NYC Association for HIV Over 50 and Hunter College
Jeffery Parsons, PhD	CHEST & Hunter College
Cynthia Poindexter, PhD	Fordham University Graduate School of Social Service
Bobbie Sackman, MSW	NYC Council of Senior Centers, Director of Public Policy
J. Edward Shaw	NYC Commission on AIDS
J. Lee Westmaas, PhD	SUNY, Dept of Psychology
Desieree Byrd, PhD	NeuroAIDS, Mt Sinai
Richard Havlik, MD	NIA/NIH Section Chief



ROAH's Data Dissemination Includes

- 1. Publications in Peer Reviewed Journals**
- 2. Book Chapters**
- 3. Symposia at the**
 - ❖ **Gerontological Society of America**
 - ❖ **American Psychological Association**
 - ❖ **American Public Health Association**
 - ❖ **New York State Society on Aging**
- 4. Invited Presentations at Medical Schools and Academia including**
 - ❖ **Columbia University**
 - ❖ **Washington University**
 - ❖ **New York University**
 - ❖ **Johns Hopkins**
 - ❖ **Mt. Sinai**
 - ❖ **Oxford University**
 - ❖ **University of Maine**
- 5. Collaborative Efforts: NYU School of Nursing, Chelsea-Westminster Hospital in London, Fordham University, Hunter College (CHEST)**

ROAH Modules

Demographics

Sexual Behavior

Social Networks

Psychological Well-Being

Distress – Depression

HIV Status/Health

Religiousness & Spirituality

Loneliness Among Older Adults

HIV Stigma and Disclosure

ROAH Study Design

Purpose: A Profile

To establish empirically valid normative data describing the growing and changing population of older adults with HIV

Participants (total $N = 1000$)

NYC community-dwelling, HIV-positive adults over 50

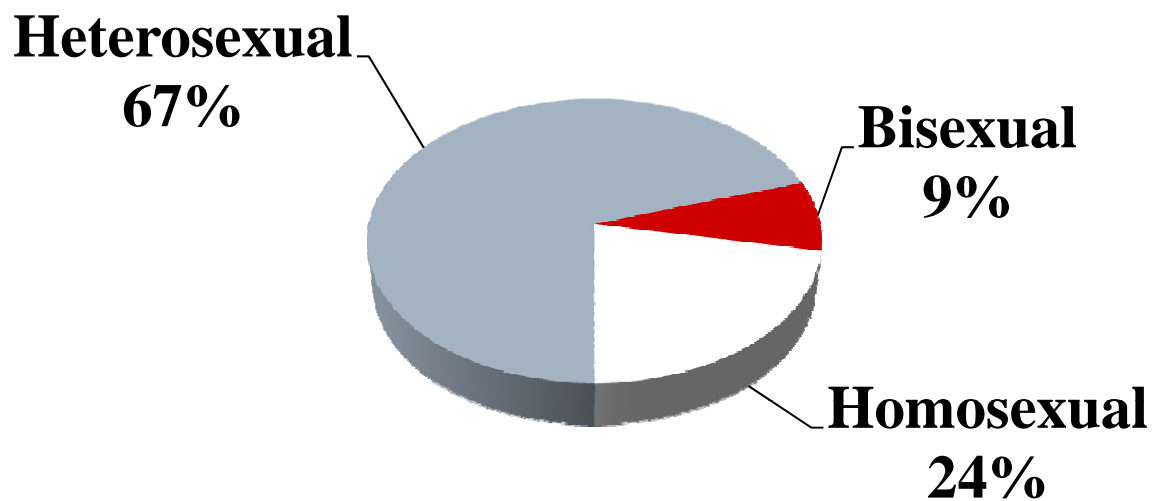
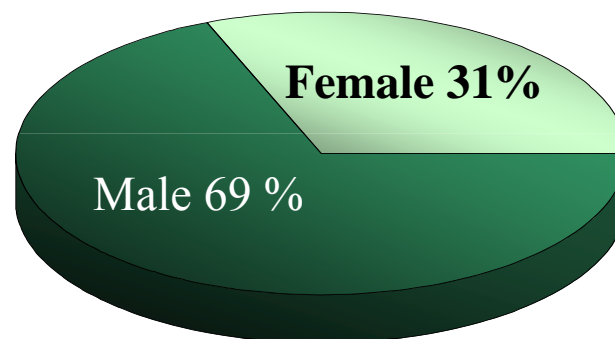
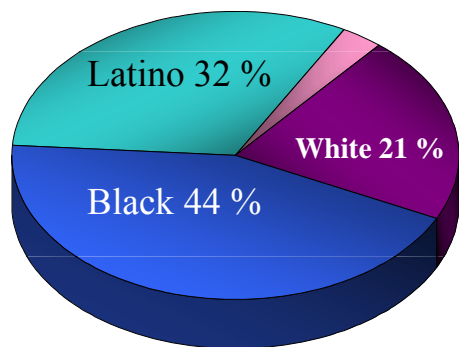
Procedure

Participants completed a self-administered survey after giving informed consent. Assessment tools include standardized tests.

HIPAA Compliant and IRB Approved

Demographics

Long-term survivors living with HIV/AIDS for 10 to 25 years



ROAH Demographics

Employment Status

▪ Working	8.3
▪ Retired	6.9
▪ Unemployed	20.1
▪ Disability	64.2

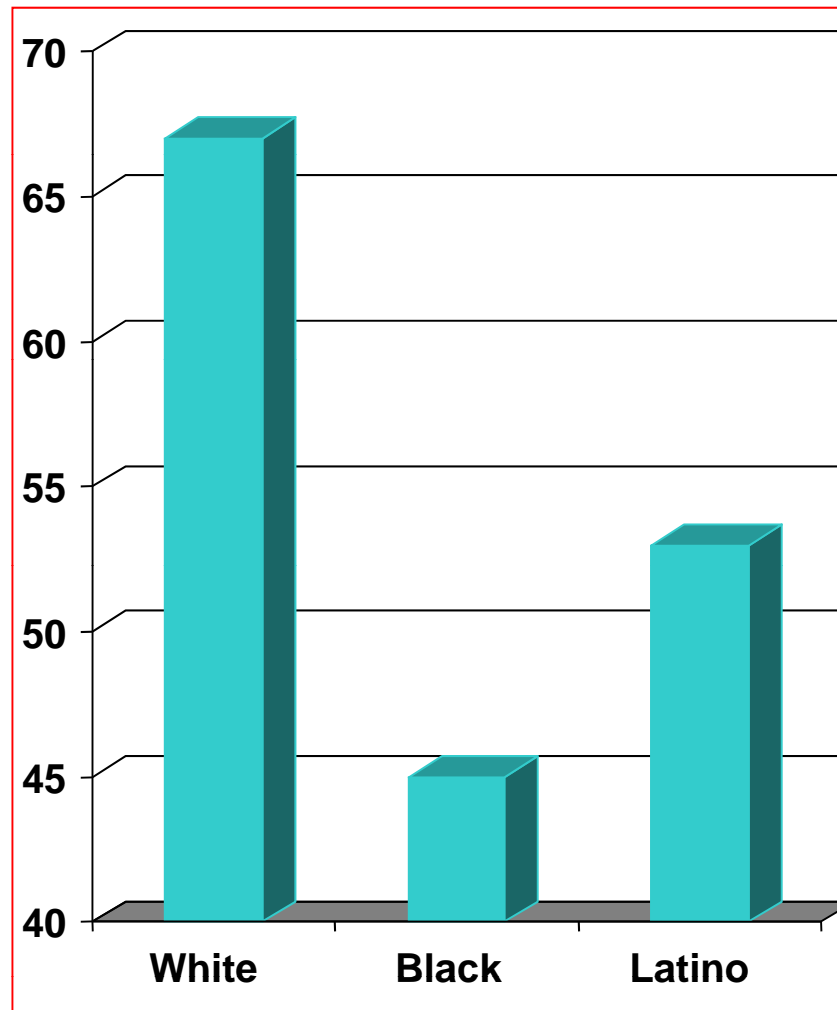
Country of Birth

▪ USA	83.5
▪ Other nation	16.5

Education

▪ Less than high school	20.4
▪ High school graduate	58.6
▪ College graduate	21.5

% with AIDS Diagnosis



ROAH HIV Care

Currently Taking ARVs

<input type="checkbox"/> Black	87.3
<input type="checkbox"/> Latino	84.8
<input type="checkbox"/> White	85.3
<input type="checkbox"/> Male	86.0
<input type="checkbox"/> Female	83.0

ROAH HIV Care

83% Medicaid Dependent

<u>Treatment facility</u>	<u>%</u>
■ Private physician	21.9
■ Public clinic / hospital	58.7
■ VA Hospital	4.9
■ ASO / day program	17.0

ROAH HIV Measures

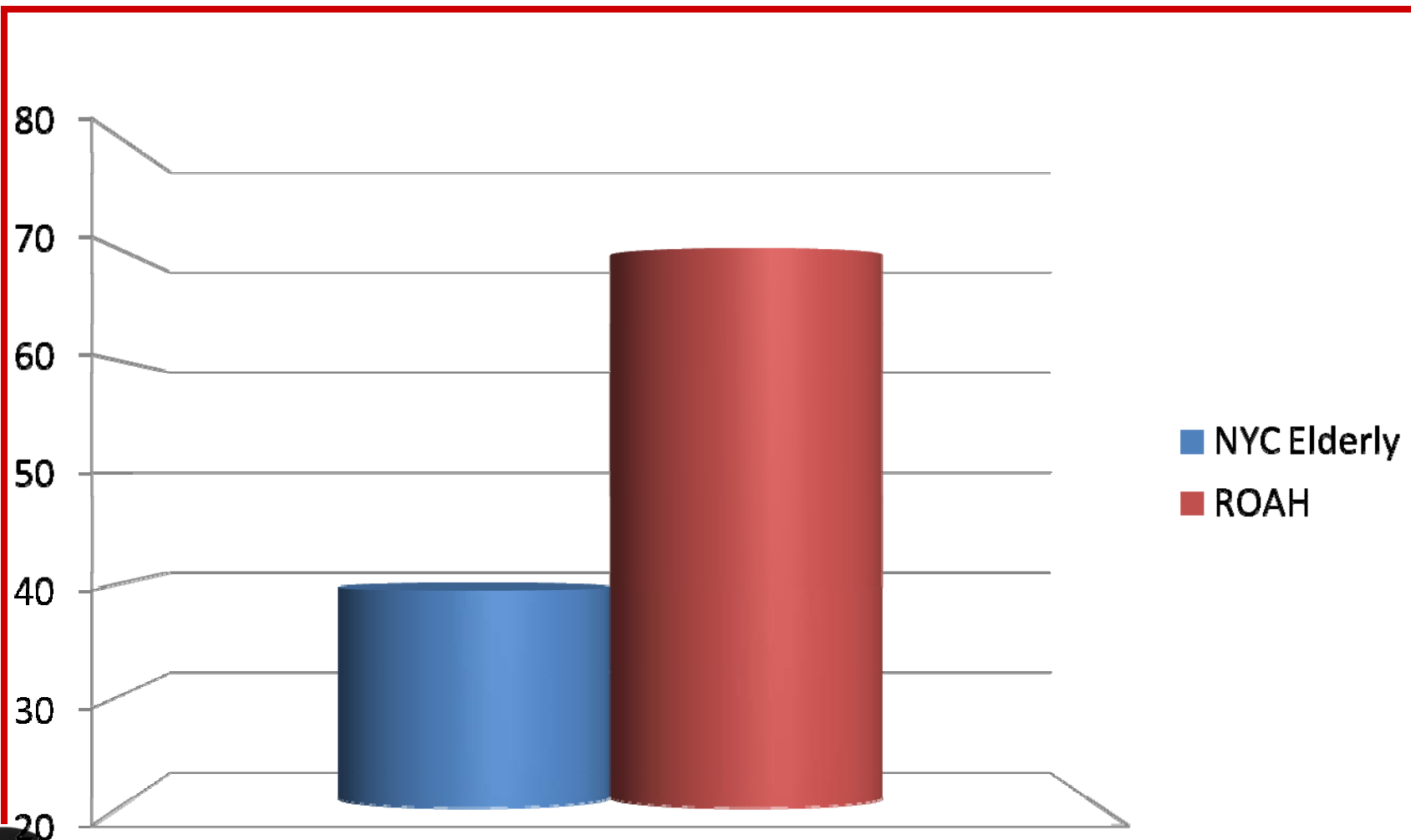
X

■ Years since diagnosis

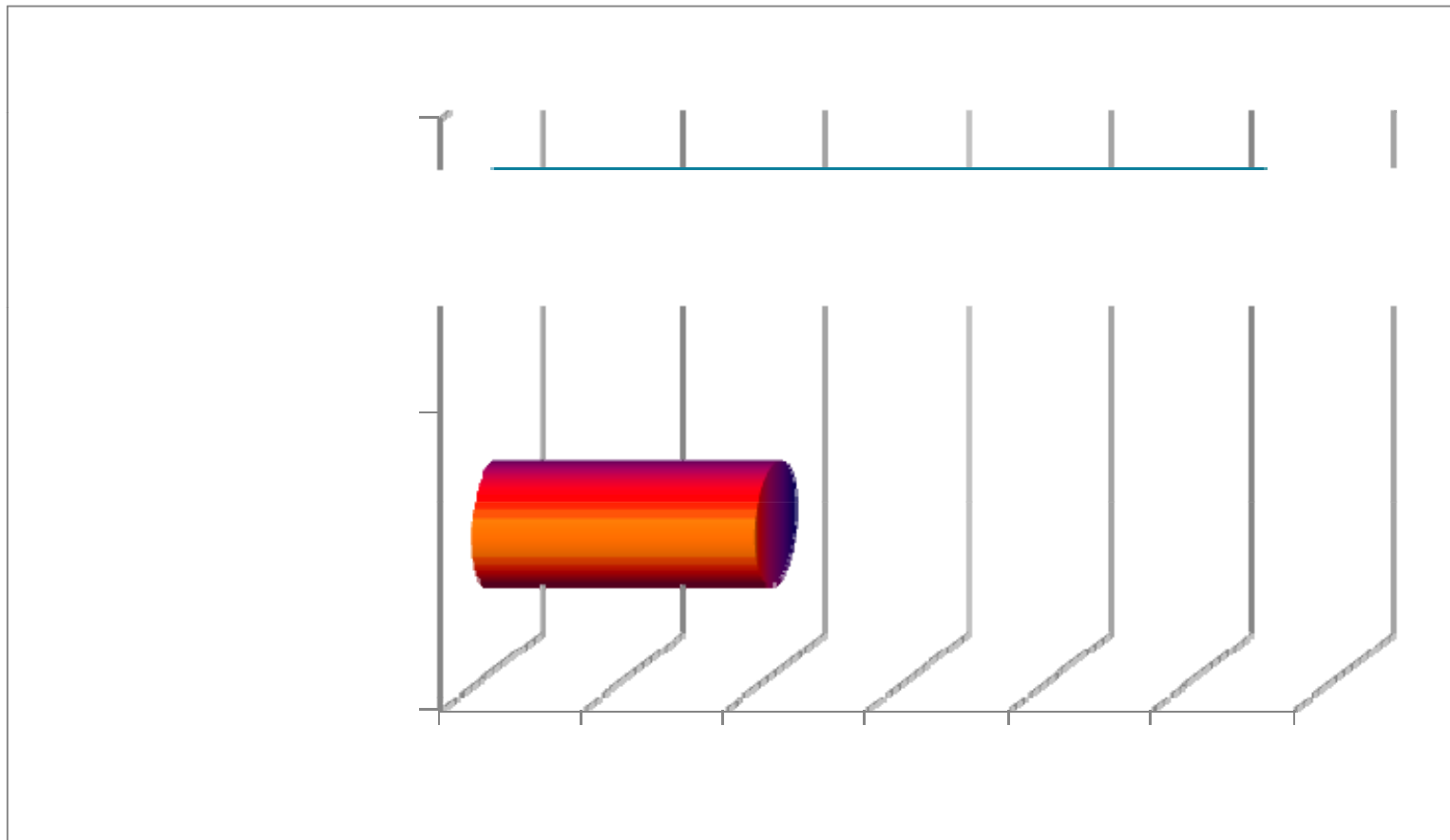
- | | |
|----------|------|
| • Male | 13.1 |
| • Female | 11.4 |
| • White | 14.9 |
| • Black | 11.8 |
| • Latino | 12.9 |

- **More than 80% rely on Medicaid**
- **54% are currently in recovery**
- **Half of their friends do not know they are HIV+**
- **Almost 70% live alone**
- **Only 15% have a spouse or life partner**

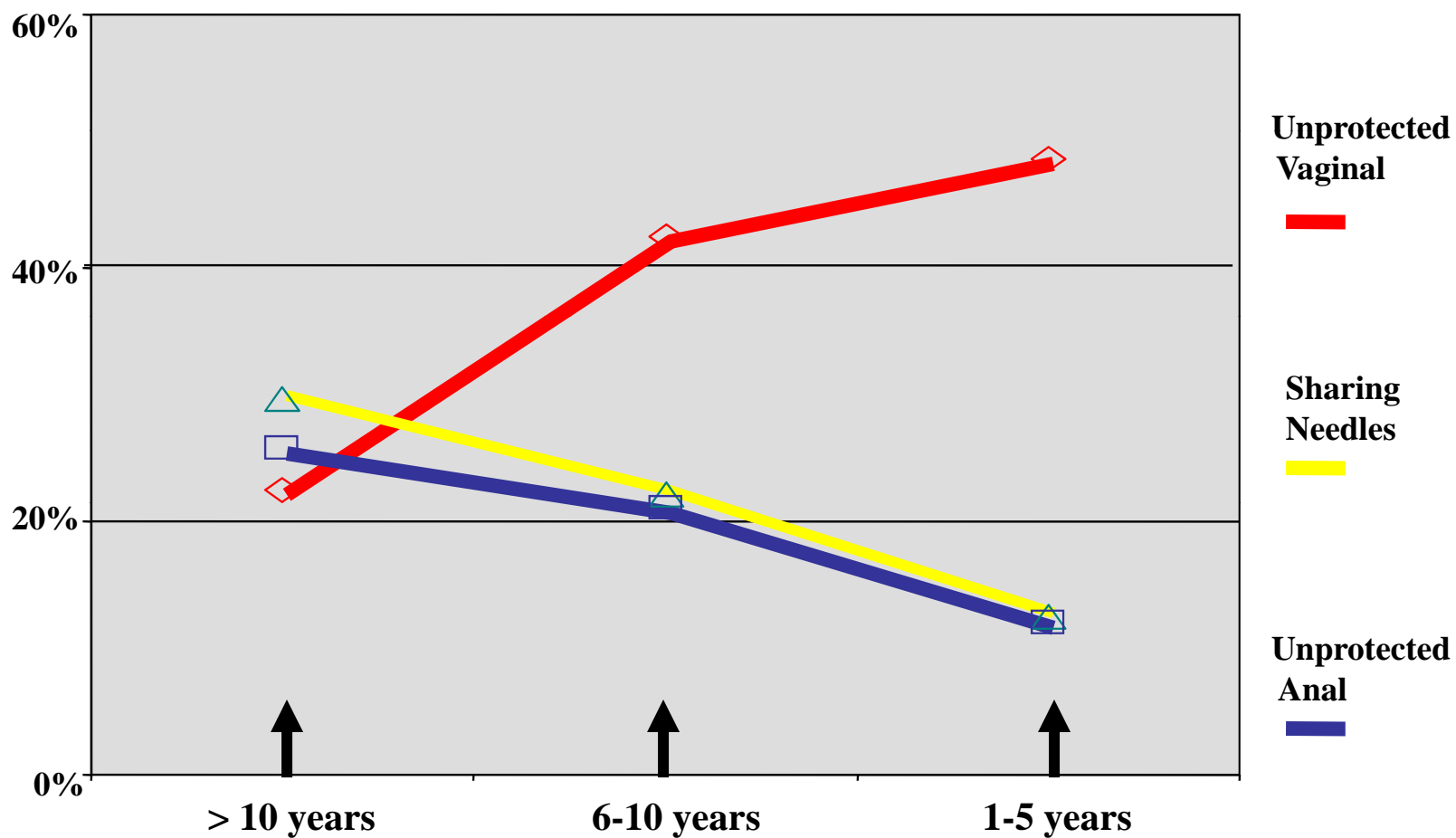
Proportion Living Alone: ROAH vs. Community-Dwelling NYC Elderly



Years Since HIV Diagnosis by LGBT Status

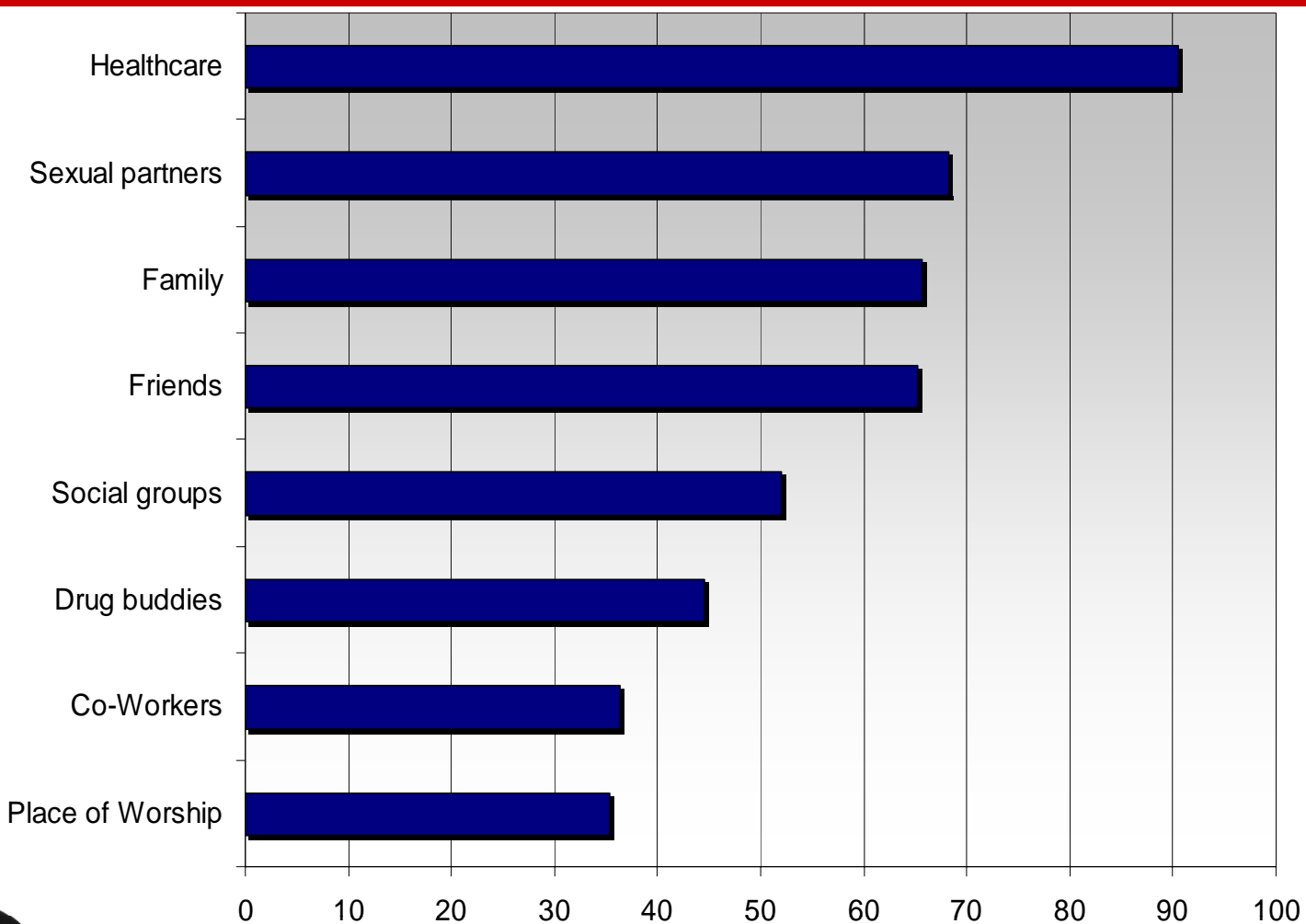


Transmission Mode in ROAH: The Changing HIV Population



Stigma

ROAH: Disclosure of HIV Status



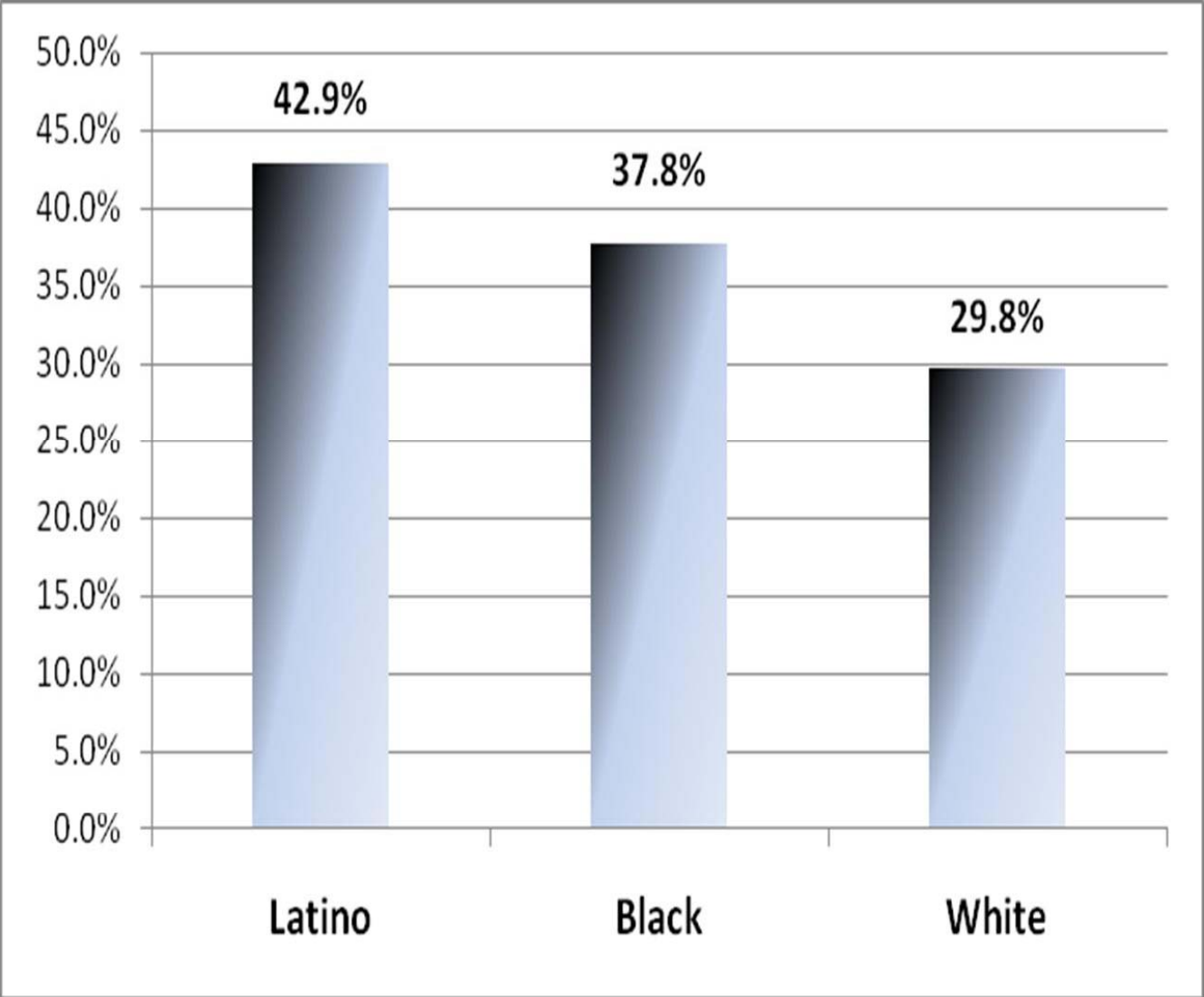


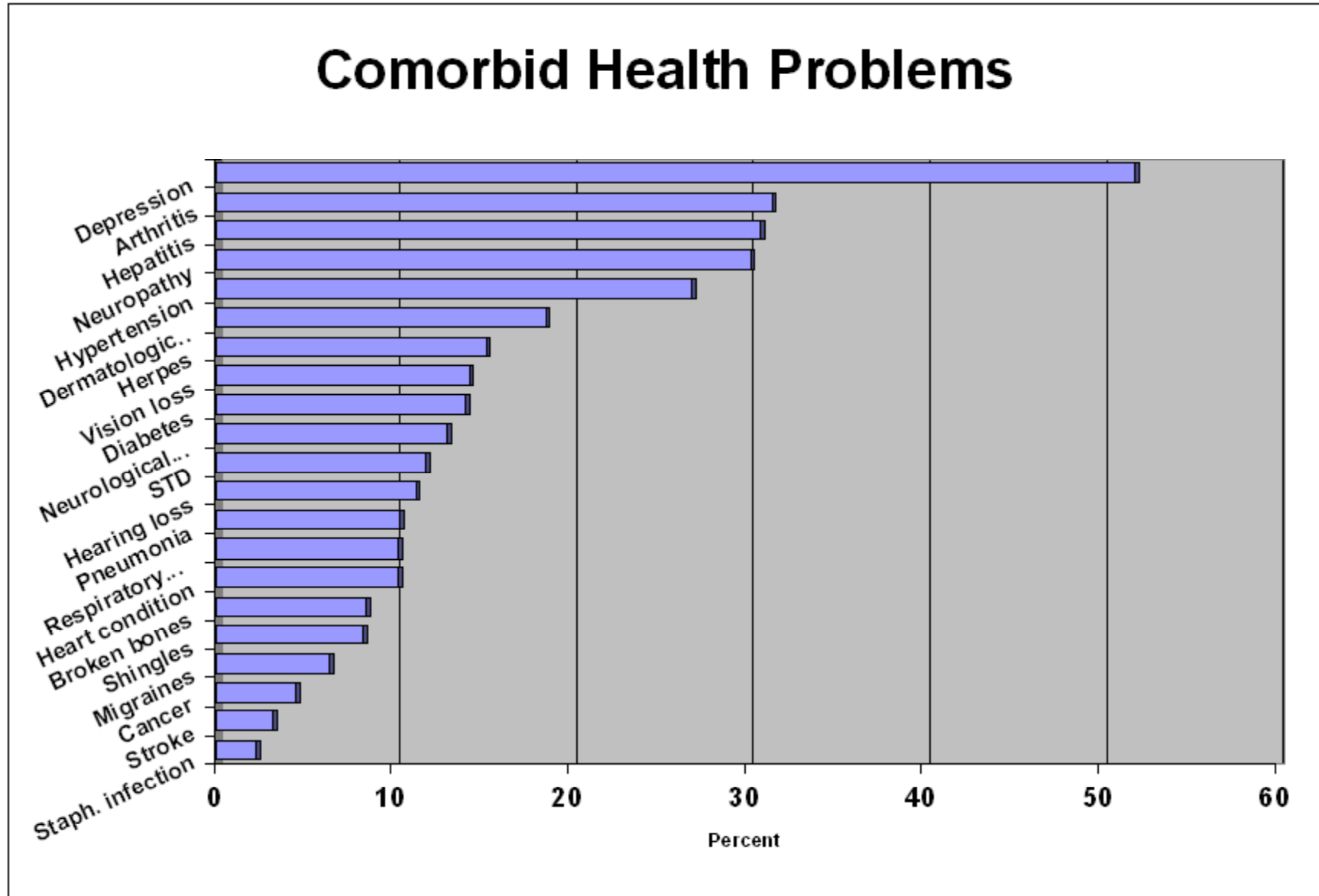
Figure 3 Proportion of Respondents Wanting to Disclose HIV Status to Others by Race/Ethnicity

Comorbidities

Richard Havlik, MD
Ret. Section Chief NIA
ACRIA Consultant and Collaborator

ROAH Self Report Data

Comorbid Health Problems



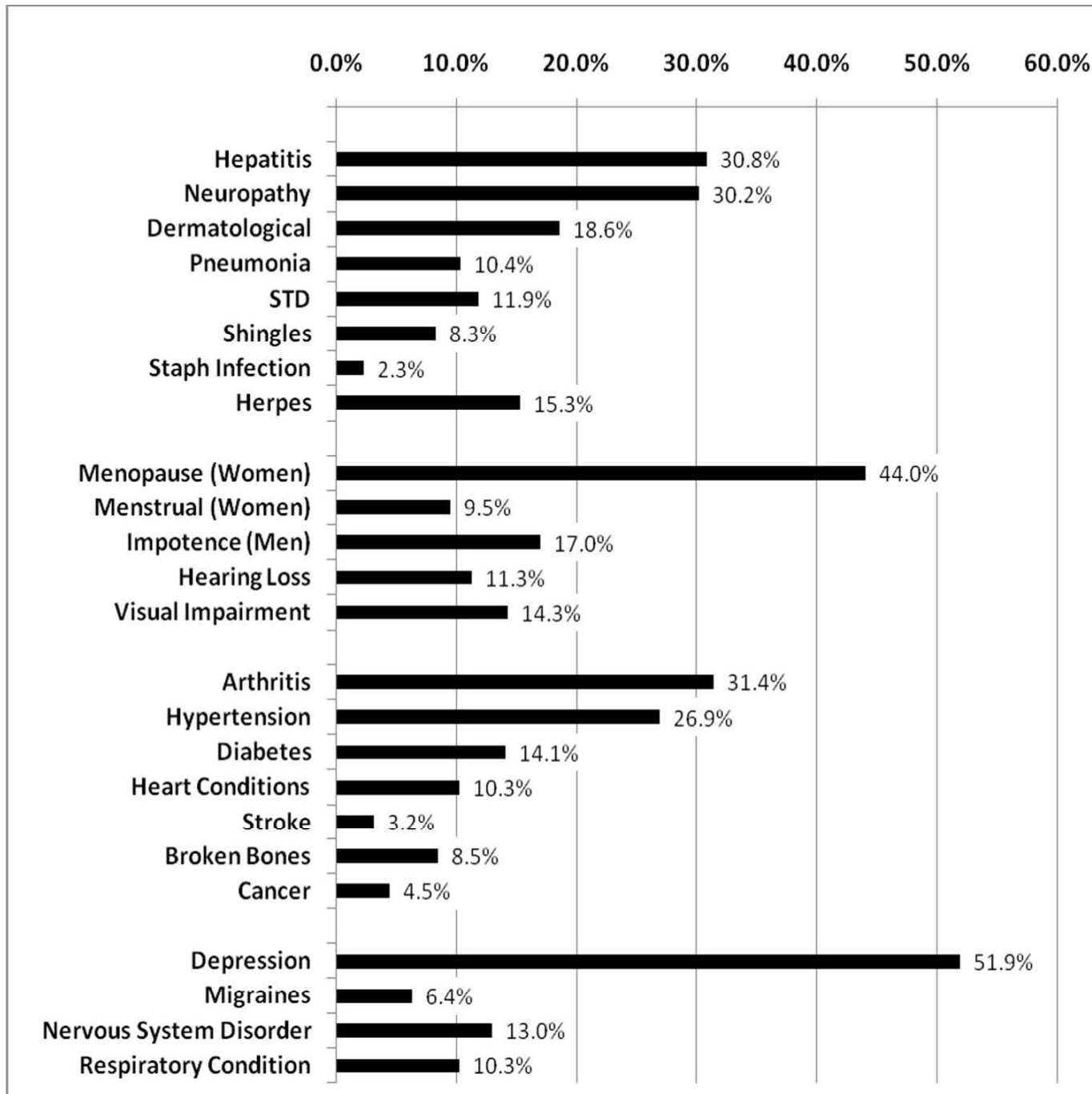
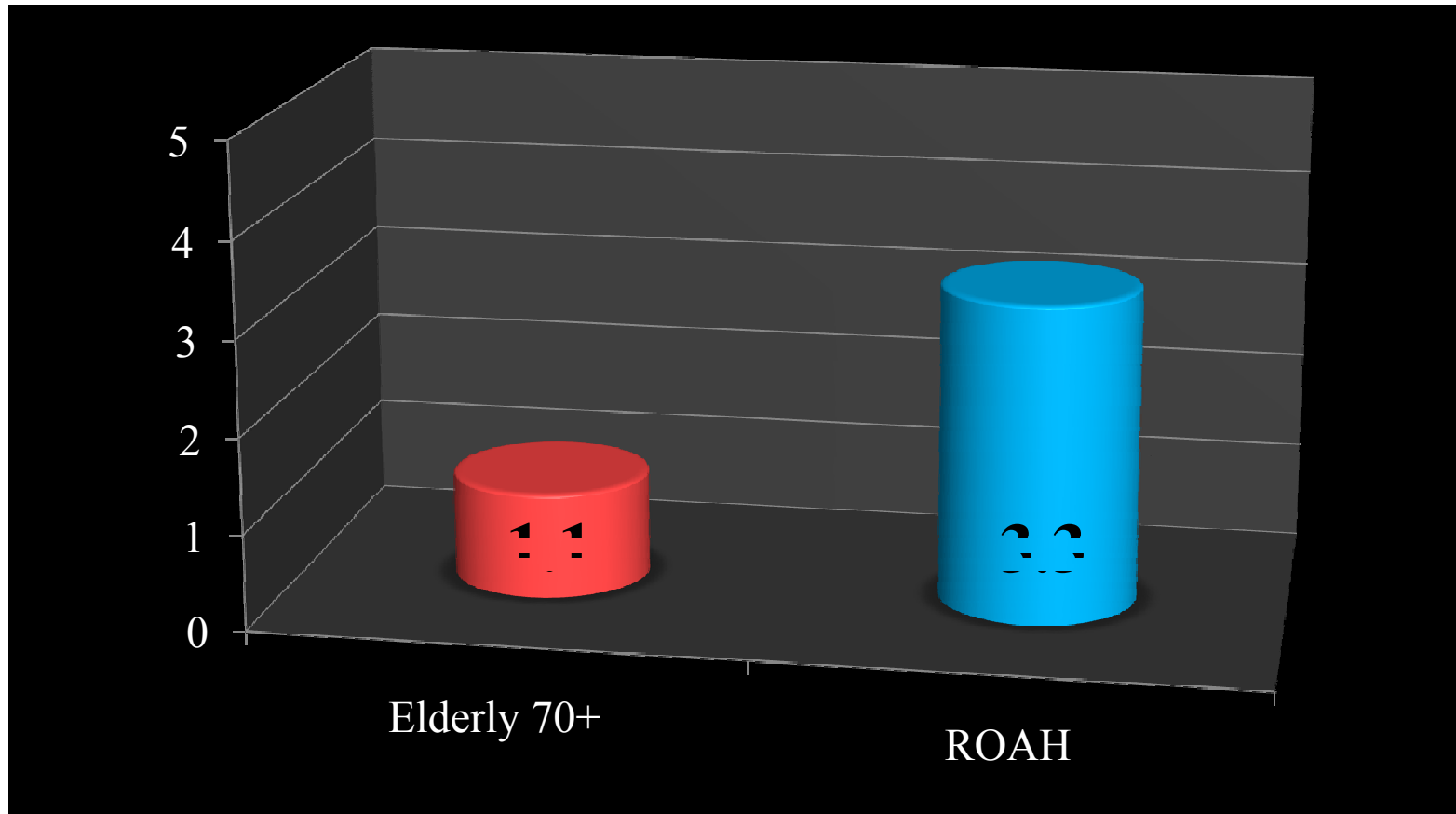


Figure 1: Prevalence of HIV-related, Age-related, Chronic, and Other Comorbidities in Older Adults with HIV

Average Number of Comorbidities



ROAH: Summary Depressive Symptoms and Comorbidities

	Significance	% No Depressive Symptoms	% Moderate Depressive Symptoms	% Severe Depressive Symptoms
Vision Loss	p<0.01	18.3	27.5	54.2
Hearing Loss	ns	28.2	21.4	50.5
Dermatological Problems	p<0.05	24.7	23.5	51.8
Heart Condition	p<0.05	26.6	20.2	53.2
Respiratory Condition	p<0.01	20.2	20.2	59.6
Stroke	p<0.05	13.8	41.4	44.8
Diabetes	ns	32.6	19.4	48.1
Broken Bones	p<0.01	19.2	33.3	47.4
Impotence	ns	29.4	21.0	49.6
Neuropathy	ns	33.5	23.6	42.9

Implication

We need to develop a more integrated approach to manage the health of those older adults living with HIV

Substance Use

ROAH: Tobacco Use

Current %

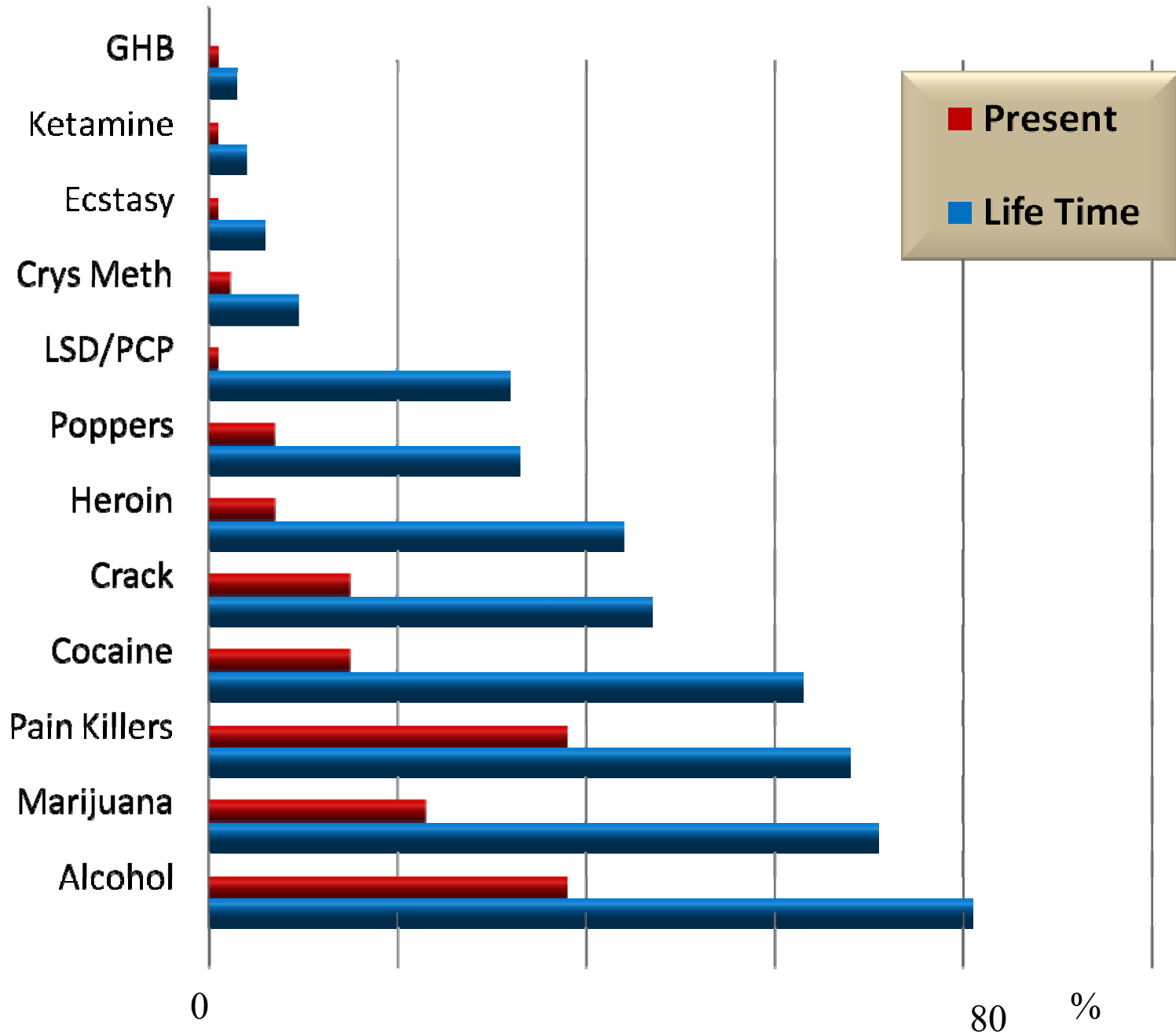
57

History %

84

ROAH: Substance Use Recovery

<u>Recovery Status of Substance Users</u>	<u>%</u>
■ Ever enrolled in 12-step	62
■ Currently in recovery	54
■ No substance use in past 3 months	48
■ In recovery for more than 1 year	44



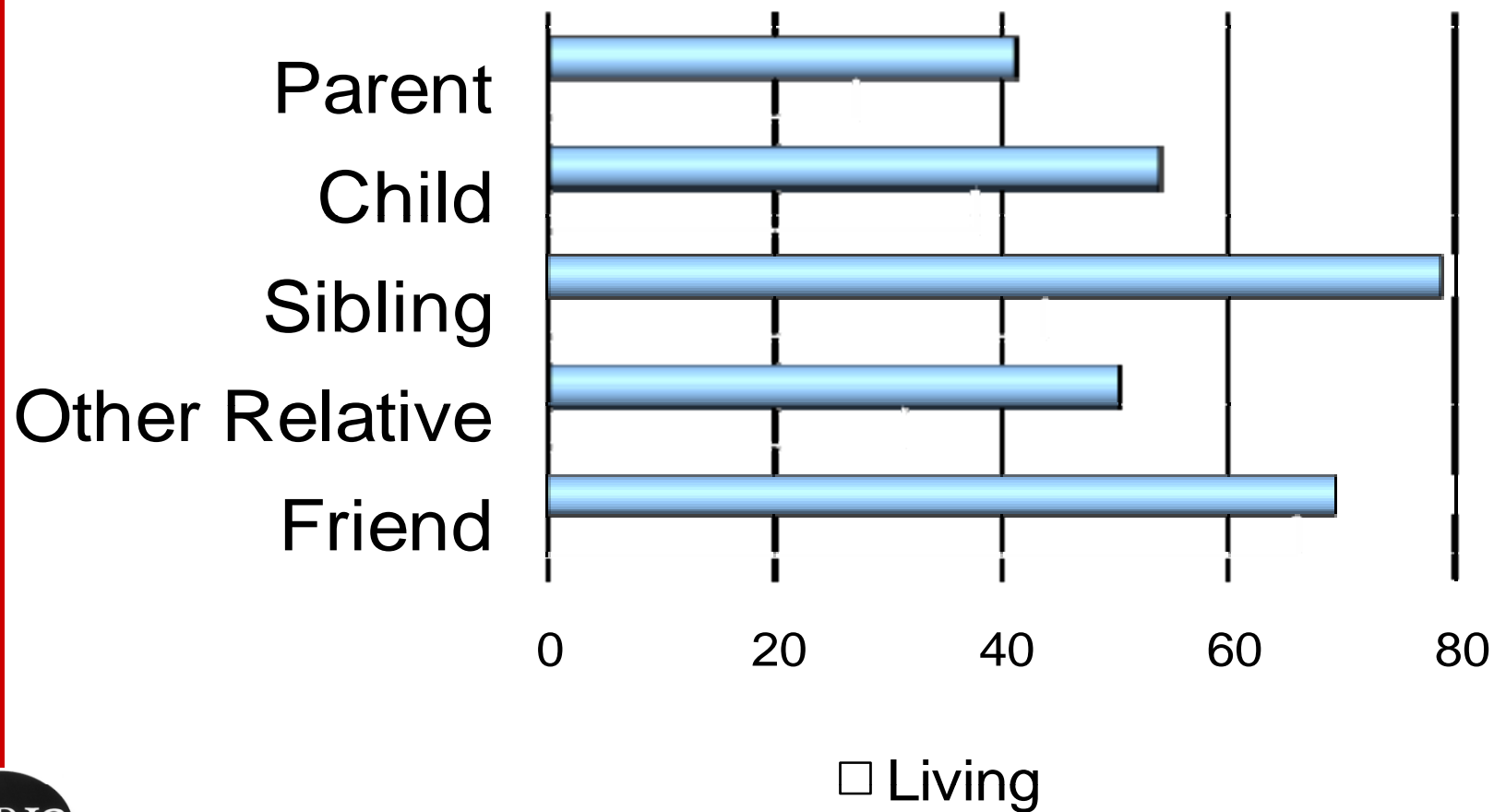
Social Networks

ROAH: Social Networks are Small and Fragile

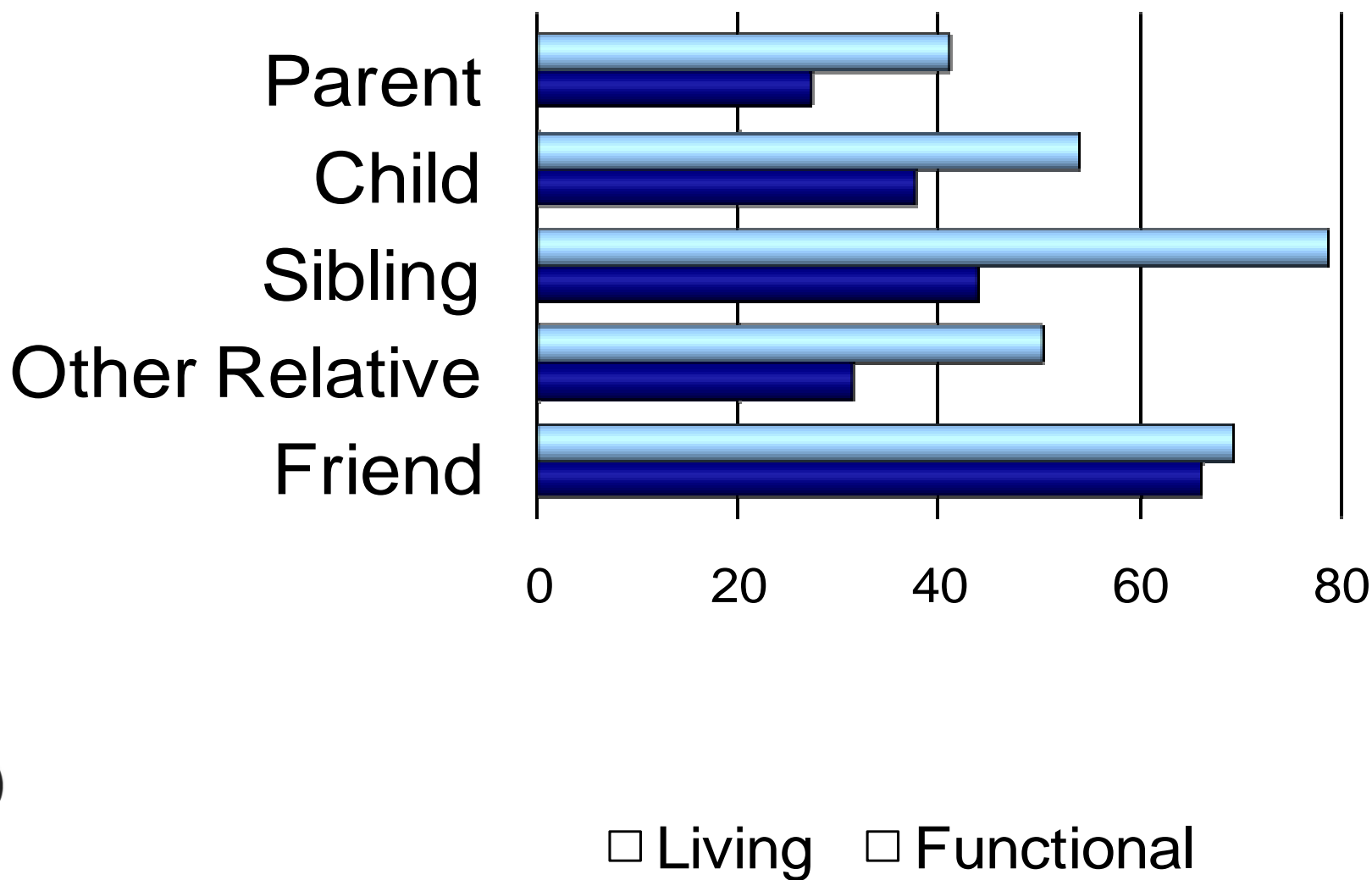
CAREGIVERS are derived from SOCIAL NETWORKS

**Social networks are a significant
healthcare
resource
300 Billion Dollars
as people age**

ROAH: Informal Network Composition



ROAH: Informal Network Composition

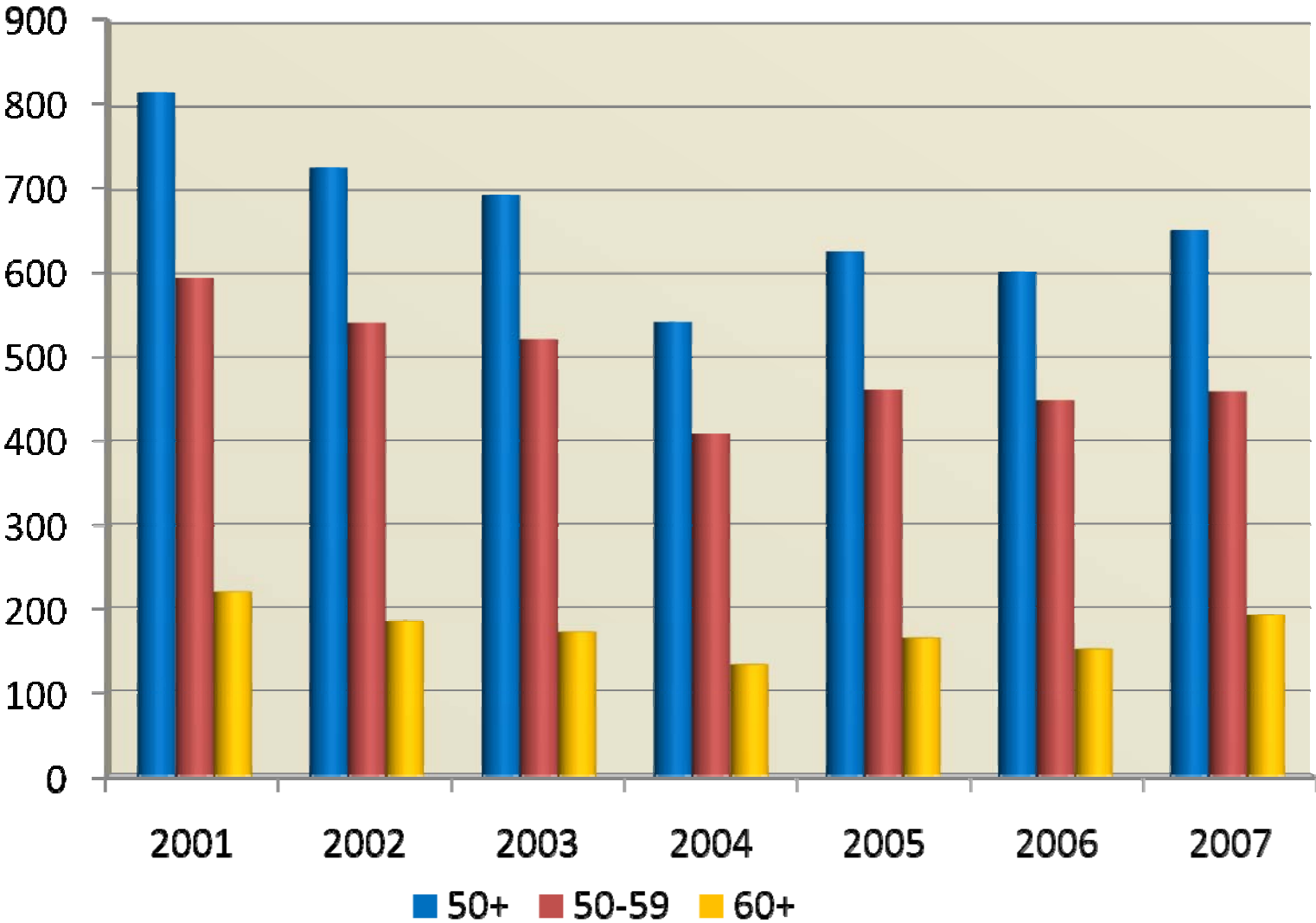


ROAH: Sexual Behavior

Center for HIV/AIDS Educational Studies
(CHEST) @ Hunter College
City University of New York
Drs. Golub, Grov, Tomaselli, Parsons



Number of New HIV/AIDS Infections in New York City



ROAH Sexual Behaviors 3MOS

<u>Number of sexual partners</u>	<u>%</u>
■ No sexual partners	43.3
■ One sexual partner	43.4
■ More than one sexual partner	13.3

<u>Sexual activity in the last 3 months</u>	<u>%</u>
■ No sexual activity	49.8
■ Oral sex	41.4
■ Vaginal sex	30.1
■ Anal sex	19.5

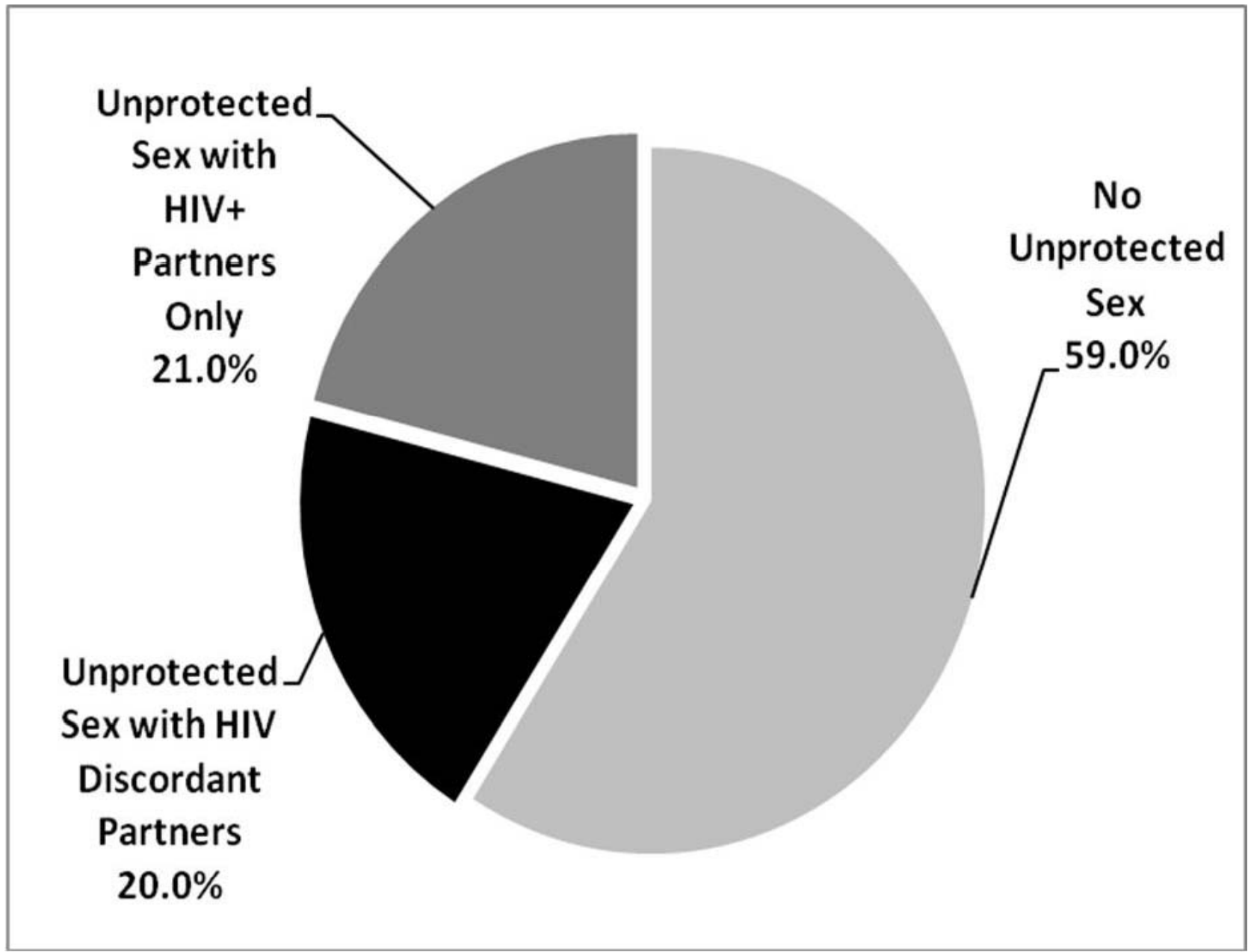


Figure 3 Unprotected Sex and Serosorting among Older Adults with HIV

ROAH: First Data on Risk Behavior in Older Adults

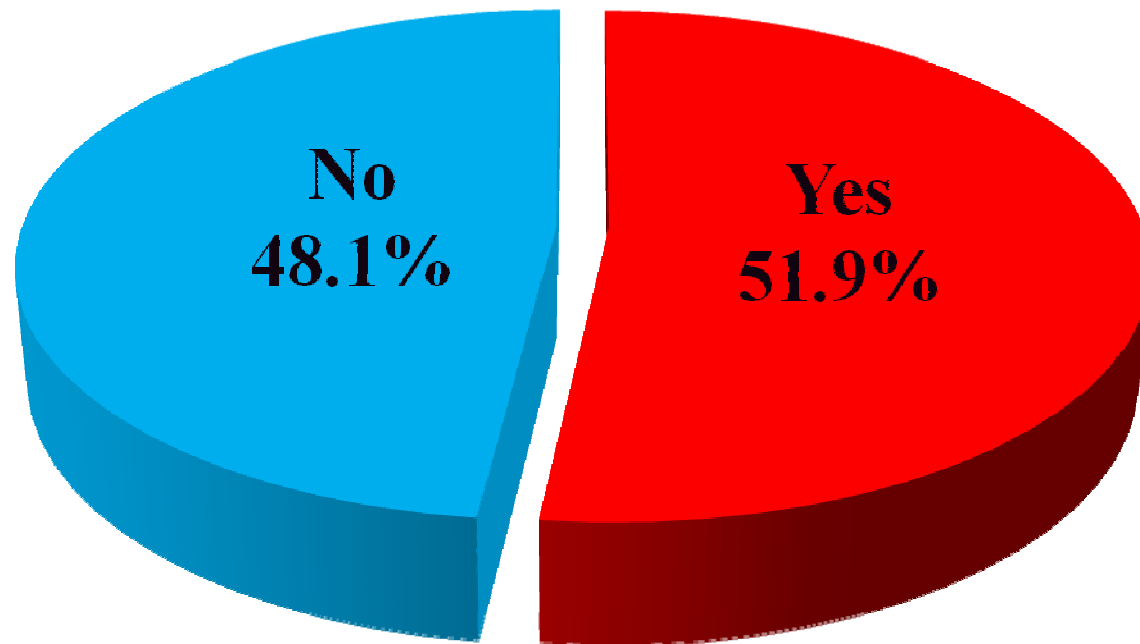
- Substance use impact - Significant
- Viagra and other ED Drugs Impact - None
- Of those who are sexually active
16% engaged in high risk sexual behavior in the
last 3 months

Depression

Depression Among PLWH

- Several studies report that depression can suppress immune responses (e.g., Tiemeier, van Tuijl, Hofman, Kiliaan, & Breteler, 2003)
- Kiecolt-Glaser and Glaser (2002) found depression to be associated with an increased inflammatory response
- Depression can contribute to neuropsychological impairment or exacerbate cognitive deterioration caused by normal aging in HIV-infected adults (Gibbie et al., 2006) , manifested by:
 - Decrements in functional ability (Activities of Daily Living)
 - Difficulty with adherence to antiretroviral therapy and other medical treatments

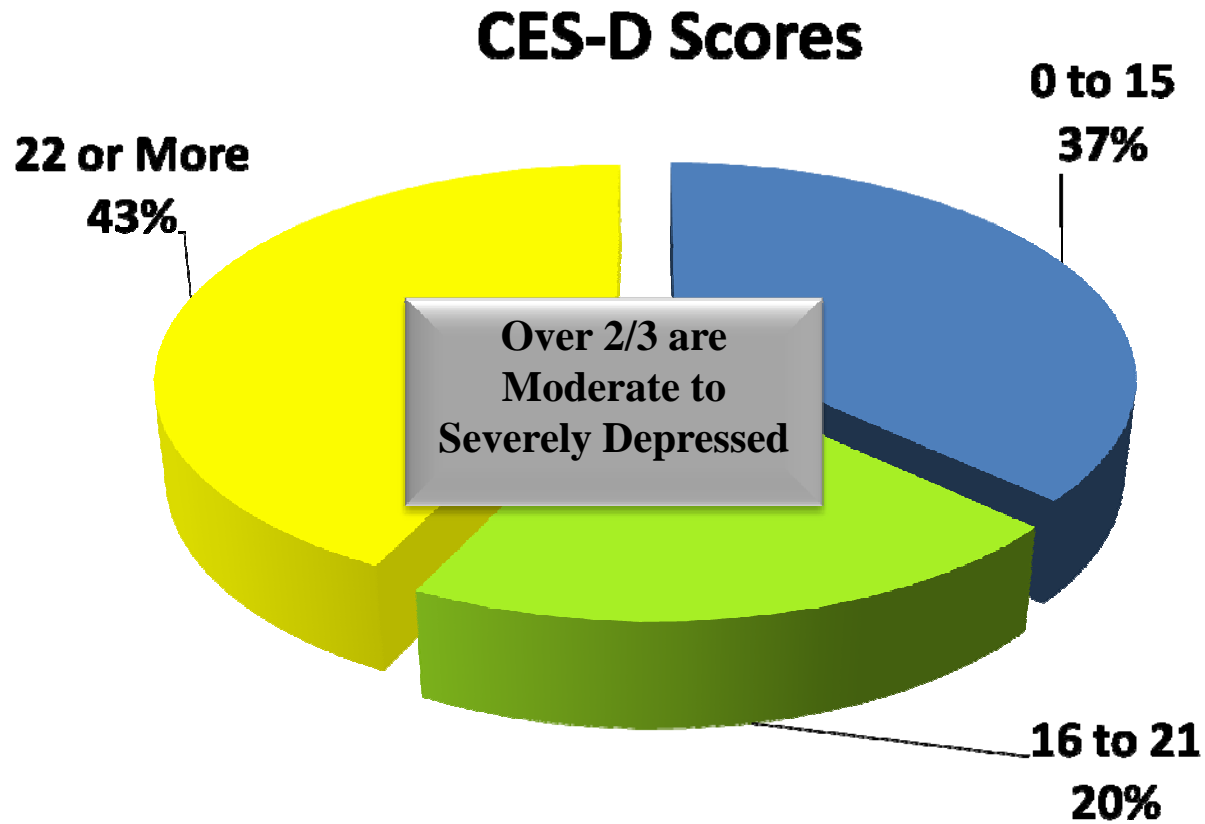
ROAH: Prior History of Depression



Depression Assessment in ROAH

- Depressive symptomatology measured with the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977)
- CES-D: 20-item self-report scale referring to symptoms experienced in the previous week; 4 items are reverse coded to prevent response-bias
- Responses scored on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time)
- Items are summed to obtain a total score with range of 0 to 60; higher scores indicate greater level of depressive symptoms ($\alpha = .90$ for ROAH sample)

ROAH: Symptoms of Depression



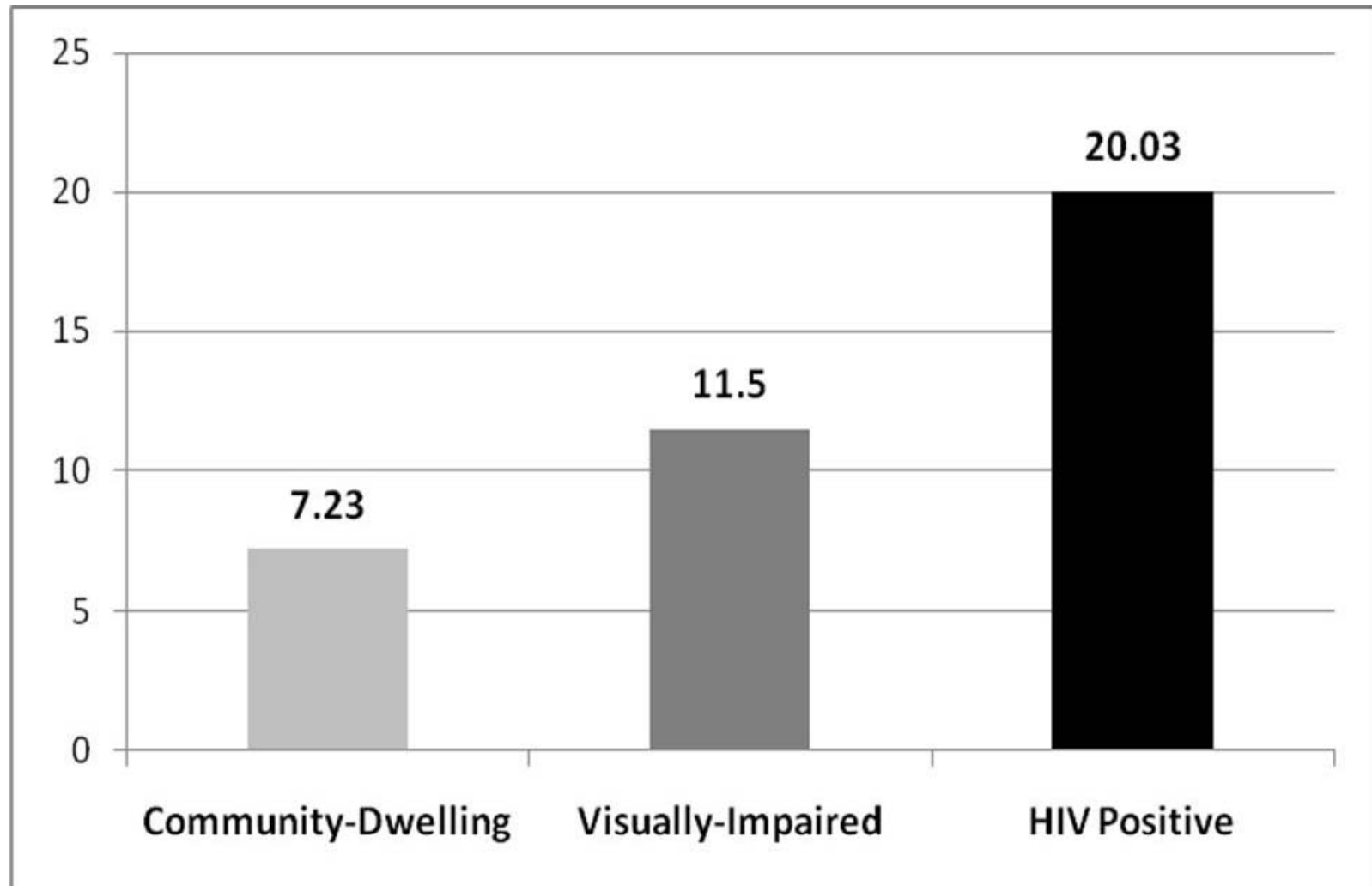
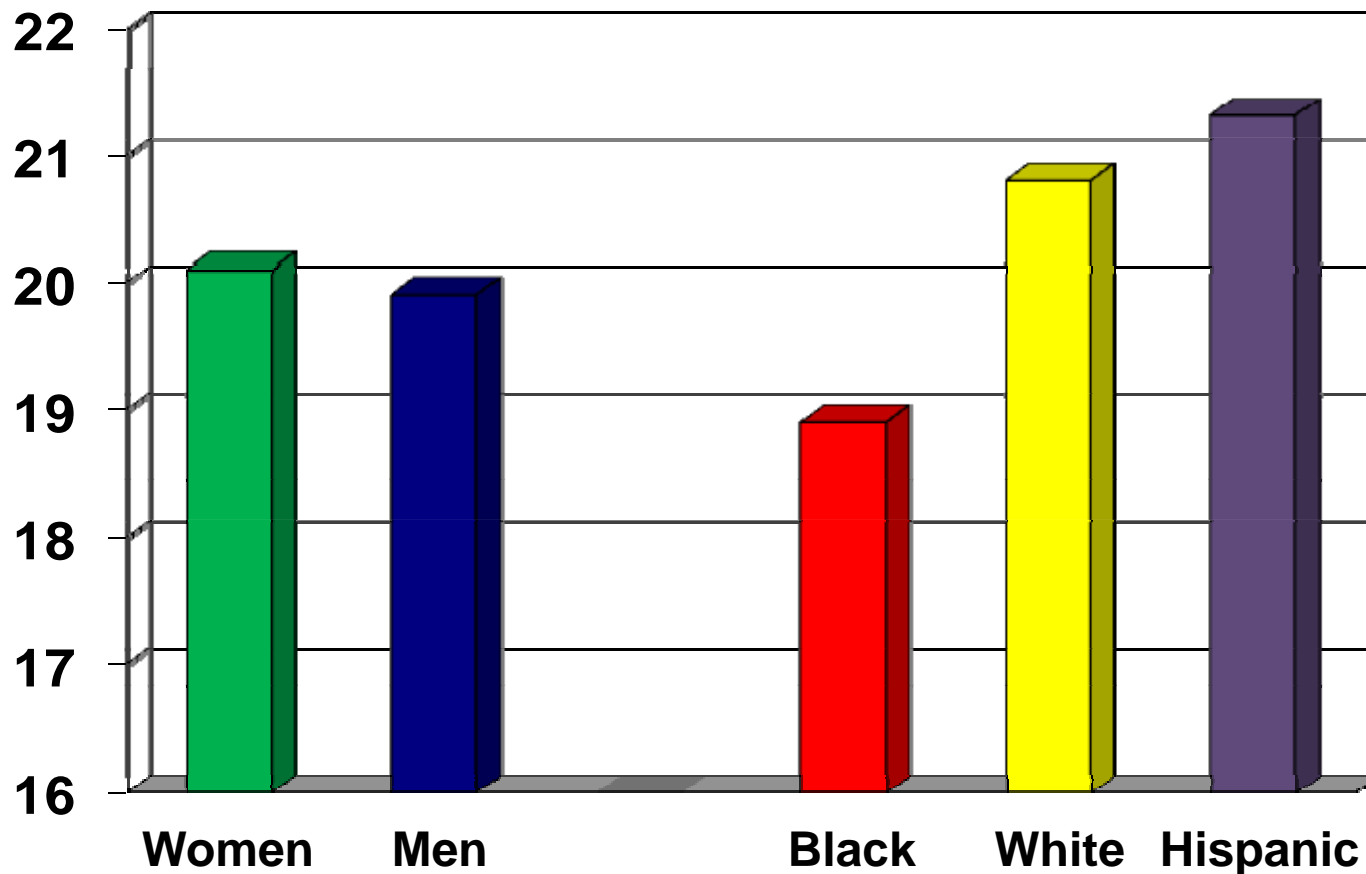


Figure 2 Comparison of Average CES-D Scores among Middle-age and Older Adults who are Community-dwelling, Visually-Impaired, or Living with HIV in ROAH. Data on Community-dwelling adults and visually impaired adults were obtained from Gump et al. (2005) and Horowitz et al. (2006), respectively.

CES-D: Level of Depression Symptoms



Health Factors Contributing to Depression for PLWH

- **PRIOR HISTORY:** major depressive disorder or significant depressive symptomatology (Harlow et al., 1991; Lyness et al., 1999; Mueller et al., 2004)
- **COMORBID PSYCHIATRIC DISORDER:** e.g., anxiety disorders, bipolar disorders, post-traumatic stress disorder (PTSD), and substance use (Pence et al., 2006; Rabkin et al., 2000; Leserman et al., 2005).
- **PHYSICAL HEALTH:** HIV symptoms, number of comorbid conditions, health-related functioning (Tostes et al., 2004; Tsao et al., 2004)

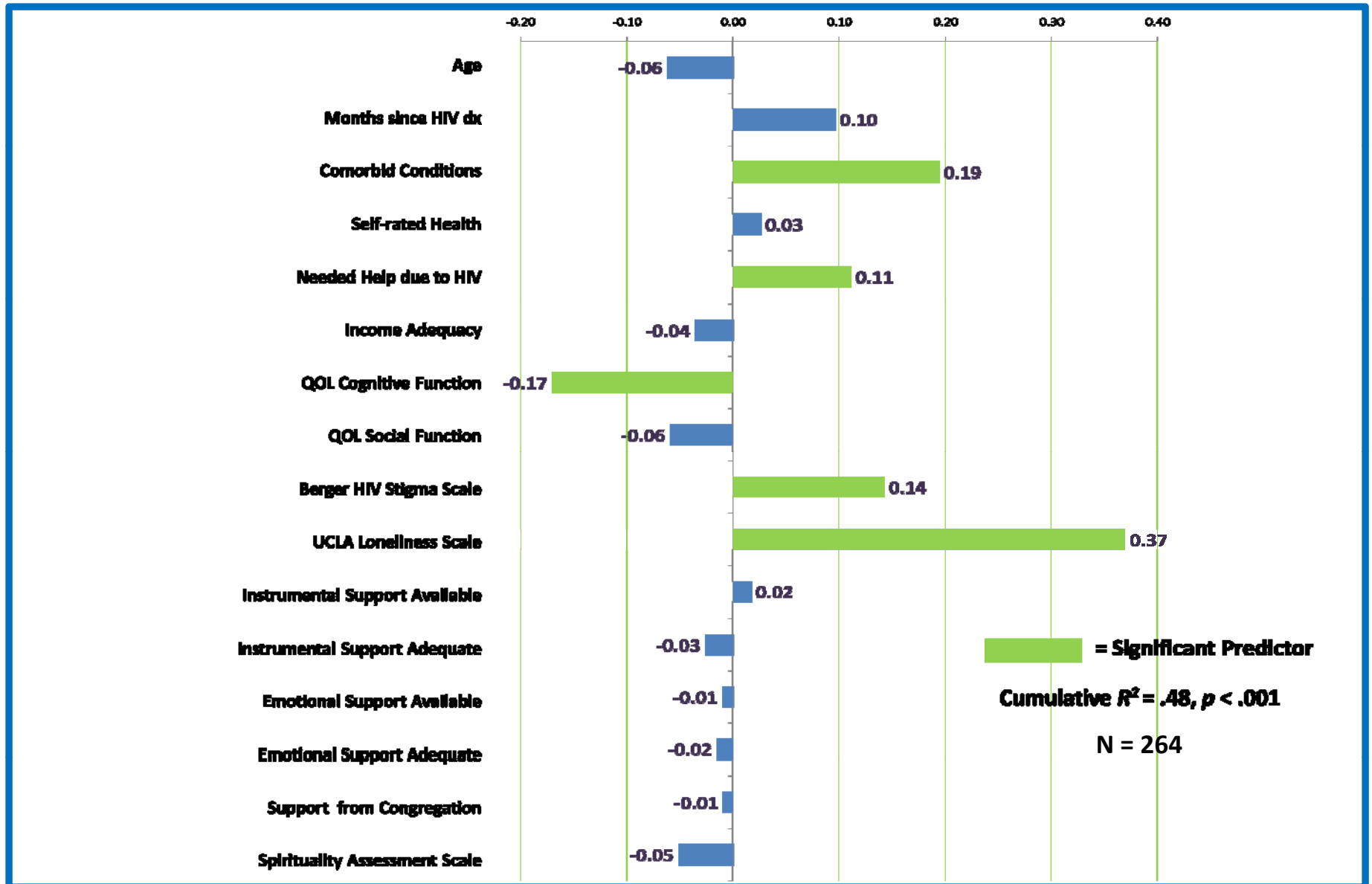
Psychosocial Factors Contributing to Depression for PLWH

- **CHRONIC STRESS:** adverse life circumstances (e.g., poverty, employment, housing, caregiving responsibilities, health care access, crime, substance use (Gurung et al., 2004; Jones et al., 2003))
- **HISTORY OF TRAUMA/ABUSE** (e.g. sexual abuse, physical abuse, or both; childhood physical neglect; childhood emotional neglect; Leserman et al., 2005)
- **HIV STIGMA:** present regardless of age, gender, or sexual orientation, and particularly demoralizing among persons who have contracted HIV but are not a member of a high-risk group (e.g., women; Stanley, 1999).

Additional Psychosocial Factors & Depression

- **LONELINESS:** among older adults with HIV, increased loneliness has been associated with higher levels of depression (Vance, 2006)
- **SOCIAL ISOLATION:** a diagnosis of HIV can also lead to social isolation due to:
 - Self-isolation for self-protection (Emlet, 2006)
 - Rejection from members of the social network due to HIV diagnosis or because of other behaviors associated with HIV infection (e.g., IV drug use, homosexuality; Flowers et al., 2006; Lichtenstein et al., 2002; Mayers & Svartberg, 2001; Trzynka & Erlen, 2004)

Predictors of CES-D Scores Among Older Women with HIV: Health & Psychosocial Stressors



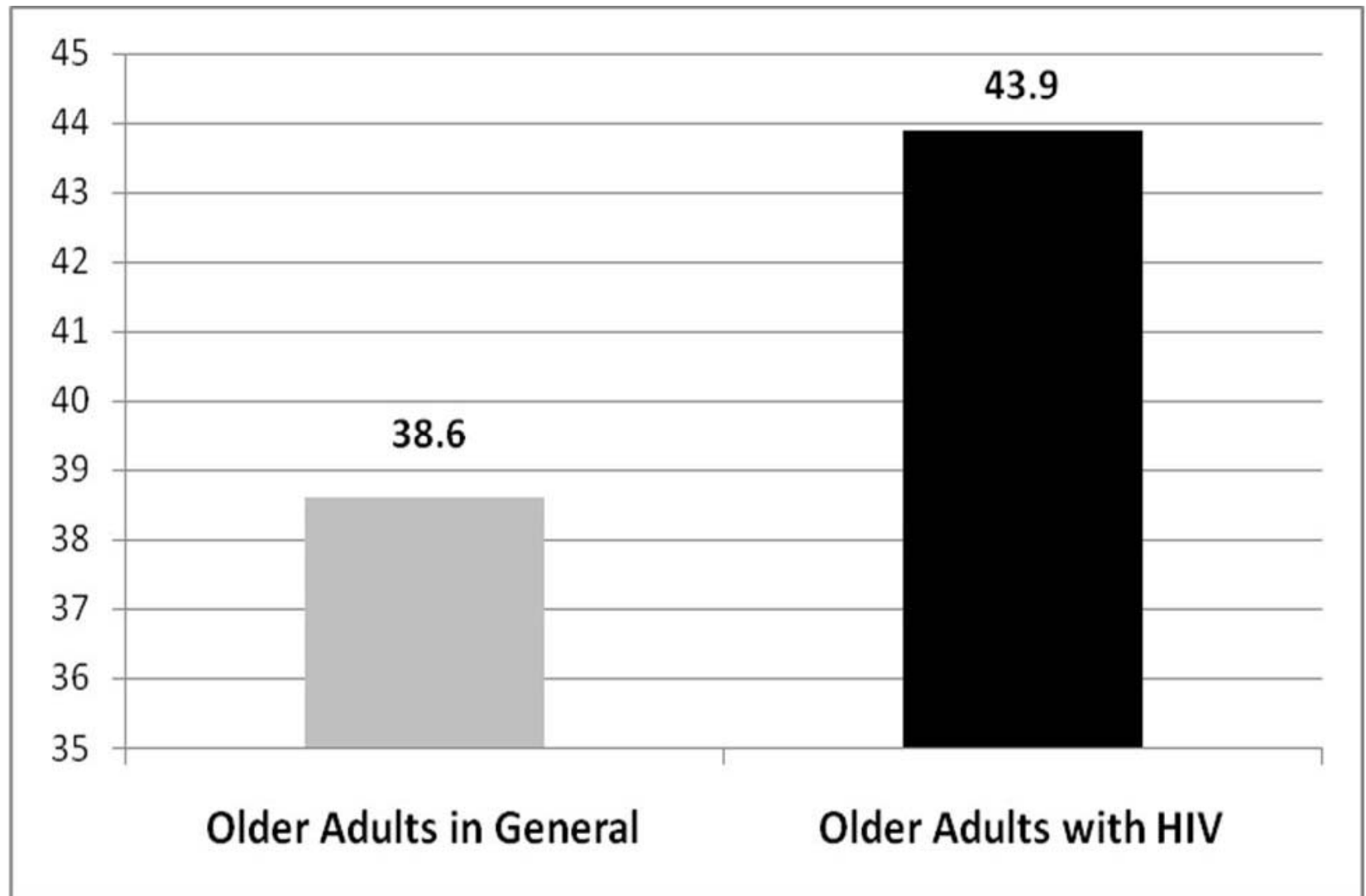
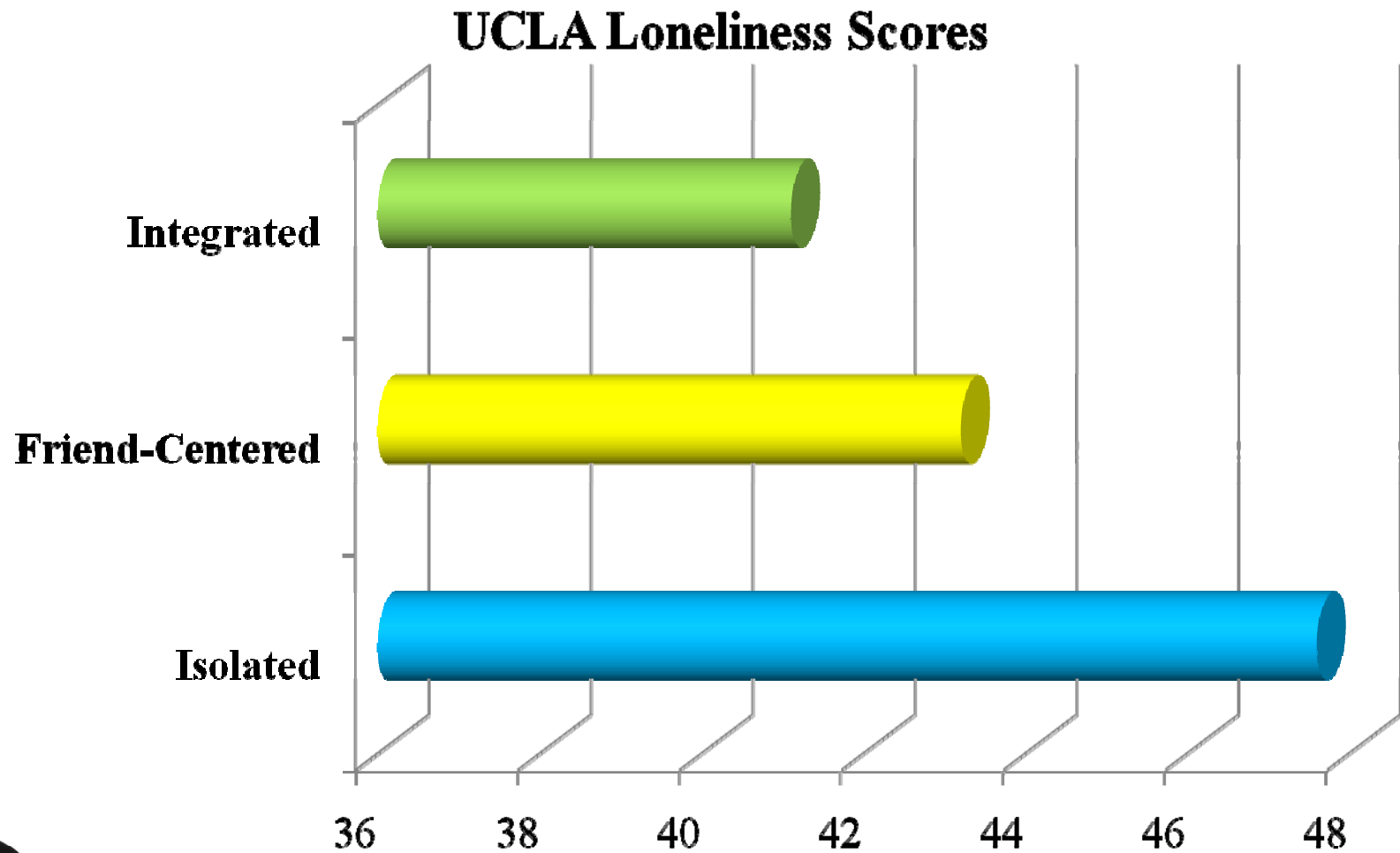


Figure 1 Comparison of UCLA Loneliness Scale Scores between Older Adults with HIV and Community Dwelling Elderly as reported in Adams et al. (2004).

ROAH: Loneliness and Social Network Type



Implications of ROAH Study

Over 2/3 of the study group had moderate to severe depression

Depression Causes Non-Adherence to ALL Medication including HIV Meds

Although in Medical Care Their Depression Remains Unmanaged

Loneliness and HIV-Related Stigma Explain Depression Among Older HIV-positive Adults (in press)

Grov, Golub, Parsons, Brennan, Karpiak

Center for HIV/AIDS Educational Studies and Training (CHEST)

and

AIDS Community Research Initiative of America (ACRIA)



**ACRIA Study Using the
MacArthur Model
as an
Intervention for Depression**

Marlena Vega, PhD
Study Clinician

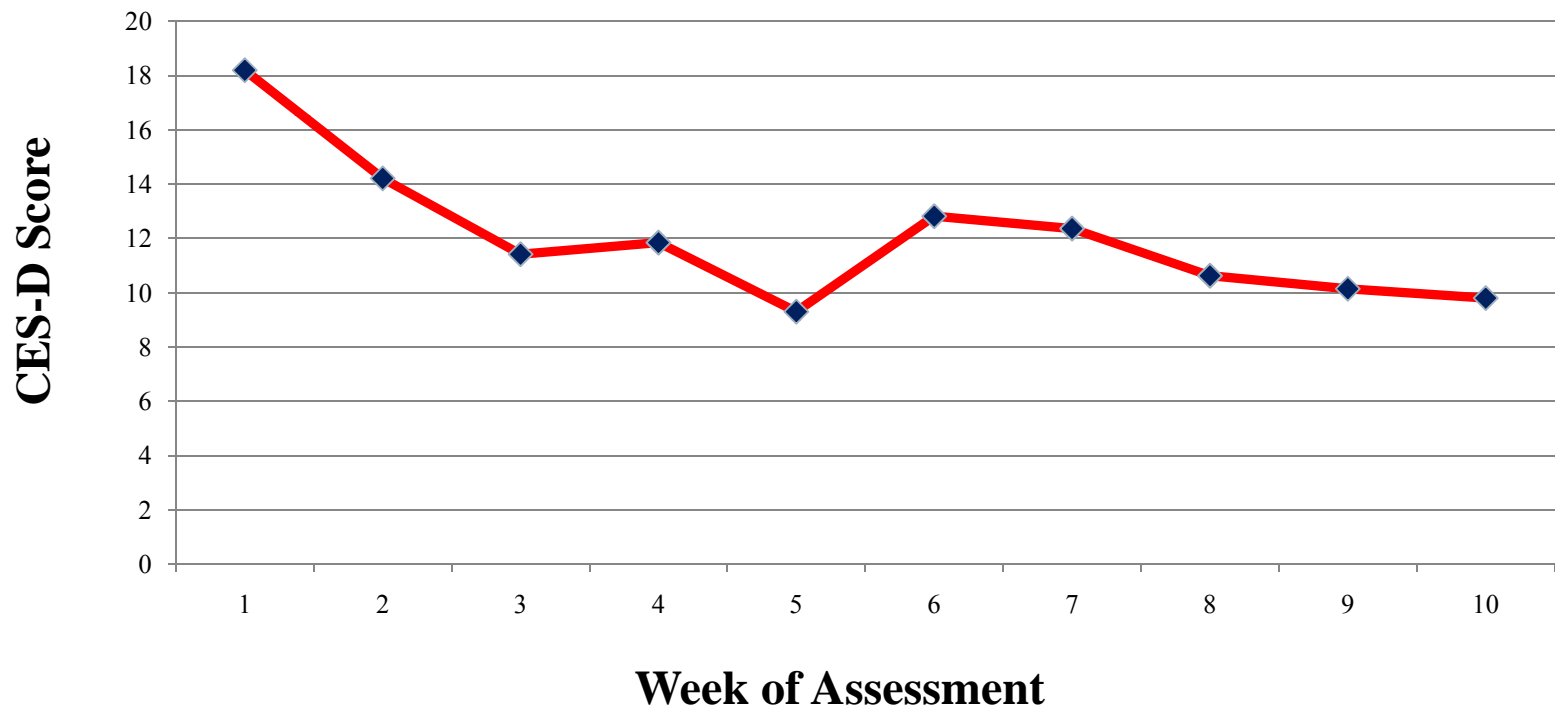
acria

Funded by the Robert Mapplethorpe and Keith Haring Foundations

ACRIA Study Using the MacArthur Model Intervention for Depression

- Patients screened for depression using the PH Q-9
- Positive screens referred to primary care/psychiatrist for evaluation
- Confirmed cases of depression receive treatment as usual (i.e., medication, individual therapy and/or group therapy)
- Care Manager (mental health clinician) makes weekly telephone calls to support patients in treatment
 - Call is simple: “Hi, How are you” etc....
 - Periodic rescreen with PHQ-9 to assess treatment progress
 - Problems that emerge during call are referred to mental health provider

Interim Follow-up Results



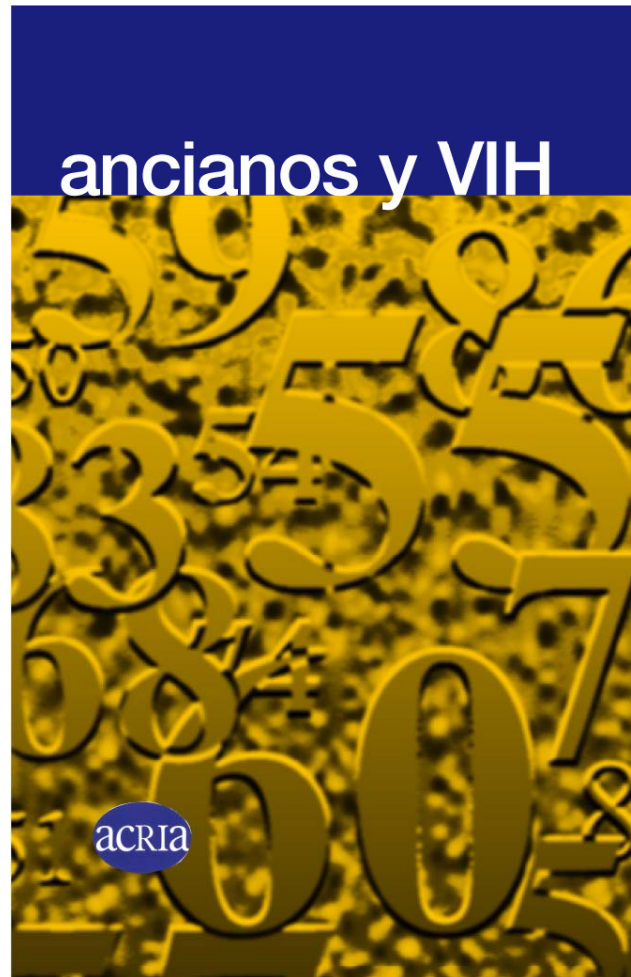
- Change in CES-D Scores Over 20 Weeks; All weeks significantly lower than baseline

Targeting Older Adults

- ACRIA is the first agency to develop comprehensive materials targeting older adults.
- Trainings have been developed to target those who provide services to older adults, as well ASO staff.

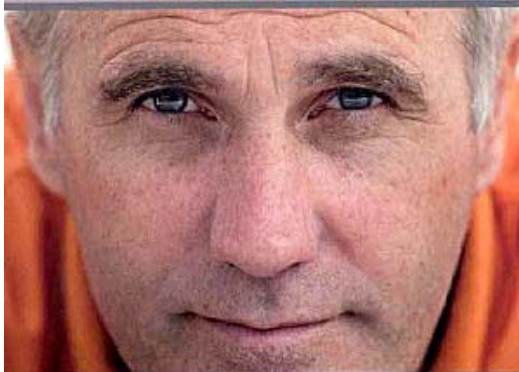
Contact Luis Scaccabarozzi (LScaccabarozzi@acria.org)
Director ACRIA HIV Health Literacy Program (HHLP)

ACRIA's HIV Older Adults Booklet



Today 70% of NYC residents living with HIV/AIDS are over 40 and 32% are over age 50.

The Greying of HIV

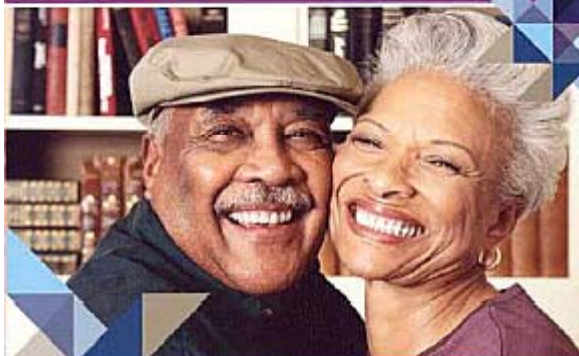


FREE TRAINING for Social Service and Healthcare Providers, and Peer Educators

This growing population of older adults with HIV is often isolated and depressed, bearing the double stigma of HIV-phobia and ageism. As they age they may be cut off from the services they need. Older adults rarely hear about HIV, and even more rarely about how they can protect themselves.

The AIDS Community Research Initiative of America (ACRIA) and the Council of Senior Centers and Services (CSCS) is offering a citywide HIV training program funded by the New York City Council. These free trainings will help senior service providers address HIV prevention issues and understand better the needs of those aging with HIV.

HIV doesn't care how old you are...



More than 2 out of 3 people living with HIV in NYC are over 40, and 1 in 3 are over age 50.

For info

Karol Mas
Council on
(212) 388

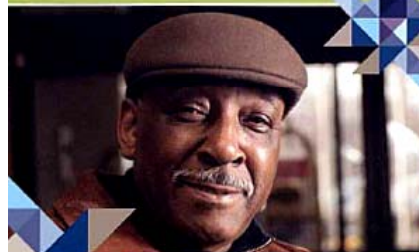
Stop HIV/AIDS



Some say HIV's only for young folks.

City
Hygiene

Think you're too old for HIV?



Think again.

One in every six new cases in NYC is found in people over 50.



Funded in whole by the New York City Department of Health and Mental Hygiene, the New York City Council Older Adults Initiative, the umbrella for the trainings being offered, is the result of a collaboration of the City Council Committee on Aging, Maria del Carmen Arroyo, Chair; and the City Council Committee on Health, Joel Rivera, Chair.

You've lived too long to believe that nonsense.

Get tested for HIV.

**Conózcalo. Combátalo.
Derrótelo.**

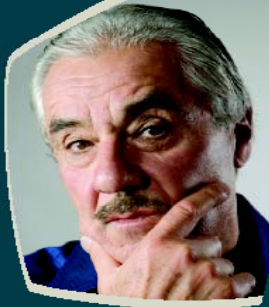
**Detenga el
SIDA.**



**Learn It. Fight It.
Defeat It.**

Funded in whole by the
Department of Health and Mental Hygiene

**Knowledge
Stops AIDS**



Funded in whole by the New York City
Department of Health and Mental Hygiene

**Your Community
Needs Your Wisdom to...**

**Stop
HIV/AIDS**



**Su Comunidad
Necesita de su Sabiduría**

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Department of Health and Mental Hygiene

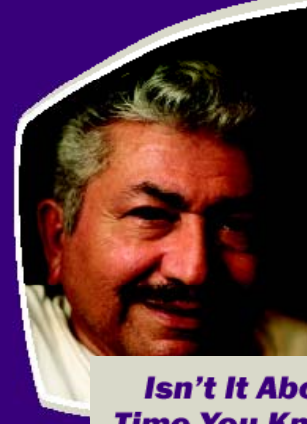
**Para Detener el
SIDA**



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**¿No es hora de que
conozca la verdad**

**SOBRE EL
VIH?**



**Isn't It About
Time You Knew...**

**The Truth
About HIV**



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ROAH Collaborative Efforts Include:

- Center for HIV Educational Studies and Training (CHEST)
- NYU School of Nursing
- Fordham University, Dept. of Economics
- Syracuse University, Dept. of Sociology
- Columbia University School of Social Work
- University of Alabama
- Chelsea Westminster Hospital, London UK (Dr. Youle)
- American Academy of HIV Physicians
- University of Ohio at Miami
- American Geriatrics Society

There are multiple
publications/abstracts/chapters published,
in press and submitted
based on the ROAH data set.

Contact Dr Stephen Karpiak at
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or any inquiries