

Implementing Research on Older Adults with HIV in Your Community

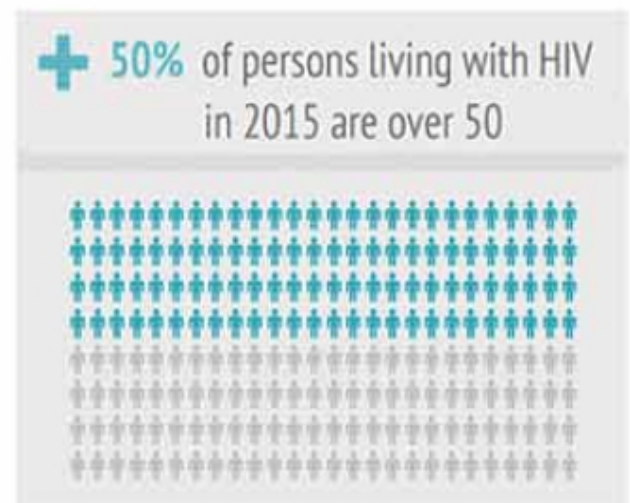
The Aging Growing HIV Infected Older Adult Communities

Those with an HIV/AIDS diagnosis prior to the mid-90s faced a rapid and at times miserable death due to the total collapse of the immune system. They exhibited rarely seen AIDS-related diseases such as PCP, Kaposi's sarcoma, dementia, lymphoma, and toxoplasmosis. Death was due to one or more of these morbidities which could not be effectively managed due to the collapse of the immune system. When these infections spread to different organ systems the course is most often fatal.

Today in 2015, almost 35 years since the HIV epidemic was recognized, it is estimated that half of all people living with HIV (PLWH) in the USA are age 50 and older. This is the result of effective anti-retroviral treatments which were first available in the mid-90s. We are witnessing the graying of the HIV epidemic, a prospect few would have imagined during the first 15 years of the HIV epidemic when death was an almost inevitable outcome following diagnosis. In the USA almost 700,000 people have died from AIDS. It would be akin to all the residents of Baltimore, MD dying.

In cities across the USA more than half of their HIV populations are 50 years and older. The words "accelerated aging" are often used to describe the older adult with HIV. This descriptor is in part premised on data that shows these older adults are developing illnesses typically associated with aging at an earlier age than would be expected.

Increasingly providers of clinical care for PLWH are spending less time managing HIV drug resistance and associated short term toxicities and



more time managing age associated illnesses. No one would argue that the HIV population in the US, and globally, is aging primarily due to the effectiveness of ART which prevents the collapse of the immune system. Older adults with HIV (defined here as those 50 years and older) exhibit a significantly higher frequency of multimorbidity which is defined as having two or more chronic diseases. These non-AIDS associated illnesses include cardiovascular disease, cancers, renal disease, osteoporosis, liver disease, and neurocognitive disorders. They occur in HIV-infected people who are on ART.

This change in the present and predicted clinical status of those living with HIV is causing an inexorable shift in the health management of those infected with HIV. Clinicians cannot use viral load numbers and CD4 counts as proxies for the management of the health of their HIV infected patients.

The Impact of ROAH

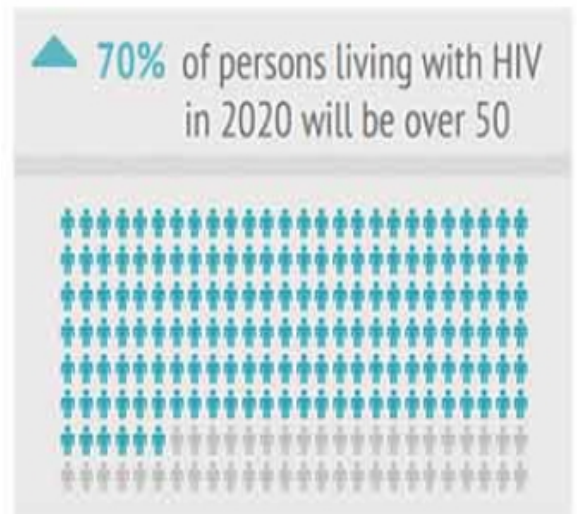
Achieving optimal health outcomes for the older adult HIV populations is the goal of our proposed research collaboration. It is 10 years since ACRIA launched its comprehensive study ROAH – Research on Older Adults with HIV. This study sampled 1,000 New York City older adults with HIV. These data became a catalyst for bringing HIV and aging onto radar screens locally, nationally and globally by focusing on the psychosocial characteristics of the emerging populations aging with HIV.

ROAH showed that older adults were challenged by continued toxic effects of stigma as evidenced by 3-5 times higher rates of depression as well as markedly increased levels of loneliness and social isolation. Fewer than 20% are partnered and 70% lived alone. The vast majority are Medicaid dependent and are not employed. Their social support networks are not adequate to meet the twin challenges of aging with HIV. Many remain connected to their respective religious congregations but do not disclose their HIV status.

ROAH fueled multiple research and training efforts. These include:

- Collaborative research papers, abstracts and presentations, including 3 International AIDS Conference Satellites (Melbourne, Washington D.C. and Vienna) and 3 New York City HIV and Aging Conferences.
- Evidence base for 8 years of NYC Council funding for HIV Prevention Programs for older adults
- Support for National Training & Technical Assistance (NOAH) on Aging and HIV.
- ROAH positioned ACRIA to advance HIV and aging policies at local, state, national, and international levels.
- ROAH was the basis for The White House Conference on HIV & Aging, 2 U.S. Congressional hearings, and ongoing advocacy with the CDC, NIH, & UNAIDS.

- ACRIA's research was part of the impetus for the NIH HIV & Aging Working Group.
- As a model ROAH has been used in Canada, the U.K, Brazil, Uganda, and South Africa.
- ROAH allowed ACRIA to join in a collaborative effort with the American Academy of HIV Medicine and the American Geriatrics Society to provide guidelines for the clinical management of older adults with HIV and the clinical resource website HIV-Age.org.
- ROAH data was the basis for developing publications for older adults with HIV that assists them in engaging health issues.
- ROAH data informed the development of 30+ curriculum modules on issues related to HIV & Aging.
- ACRIA's training center has conducted hundreds of programs on HIV & Aging throughout all NYC districts, statewide as well as nationally in 10 cities.



- The Age is Not a Condom social messaging campaigns reflects ROAH findings.
- ROAH provided preliminary data to inform the implementation of the Community PROMISE DEBI for older adults in high HIV prevalence areas throughout New York City.

The Launch of ROAH 2.0

On this 10th anniversary of the original ROAH study (2005-2006) we are launching an extension of that effort entitled [ROAH 2.0](#). The goal is to inform the care and support services provided to older adult HIV-infected populations. As they age the burden of disease increases for the older adult with HIV. They along with their care providers confront the challenges of managing multiple chronic conditions and HIV. Among these communities are the long term survivors of the epidemic who were diagnosed with HIV before 1996. The [ROAH 2.0](#) Survey will assess psychosocial factors which impact health outcomes and the well-being of the older adult. The Survey questions will be derived from established survey tools used by researchers. This assures content validity as well as proving comparative data from other studies that used the same survey components.

These include (but are not limited to):

- Demographics
- Depression
- Stigma
- Loneliness
- Function (ADLs IADLs)
- Social Network Support
- Service Utilization
- Substance Use
- Sexual Health
- Barriers to Care
- Resilience
- Medical/Health Information

While the [ROAH 2.0](#) Survey Tool will include self-reported queries regarding health particulars the [ROAH 2.0](#) effort is aimed at pairing the Survey Responses with the clinical record for each study participant. This is the first effort that recognizes that health outcomes are impacted not only by

primary medical care management, but rather a series of interactions with those psychosocial characteristics of the patient – the older adult living with HIV.

This effort to assemble both clinical and psychosocial data is being made a reality in New York City due to our collaborative work with colleagues in HIV and Geriatrics at the Weill Cornell Medical College. Selected data from the electronic clinical health records will be accessed and linked to survey data in [ROAH 2.0](#). This linking of clinical and psychosocial variables will allow for a level of analyses never previously achieved.

We plan to establish [ROAH 2.0](#) as a longitudinal cohort wherein data can be collected in subsequent waves (for example every 5 years) which will enable us to monitor this population as it ages into the 6th, 7th and 8th decades of life.

ACRIA seeks to expand [ROAH 2.0](#) to additional sites as collaborators and funding are identified. We know that the extent and quality of available medical and social support services can vary significantly based on geographic location. For example one difference can be dependent on whether a state has embraced ACA funding including the expansion of Medicaid support. We are already actively seeking additional support and welcome any other collaborators and funders. In addition to NYC, we are actively targeting Atlanta/GA, Chicago, San Francisco, Los Angeles, New Orleans/Baton Rouge, San Juan, Houston, Miami/Ft. Lauderdale, and Washington DC as other potential sites. A Foundation grant has been submitted to conduct ROAH 2.0 in Chicago, collaborating with the Howard Brown Medical Center, the Center on Halsted and AIDS Foundation of Chicago. ACRIA is actively engaged in negotiations with Emory University Medical Center to conduct ROAH 2.0 in Georgia with a focus on urban/rural comparisons

ROAH 2.0 in San Francisco

The epidemiology of San Francisco provides a rich research environment for [ROAH 2.0](#) as well as the historic significance of the city in the HIV epidemic. In 2013 surveillance data shows that more than 50% of San Francisco's PLWH population is age 50 and older.

San Francisco HIV Surveillance Data

	2013	
	Number	(%)
Gender		
Male	14,638	(92)
Female	906	(6)
Transfemale ²	357	(2)
Race/Ethnicity		
White	9,760	(61)
African American	2,038	(13)
Latino	2,795	(18)
Asian/Pacific Islander	894	(6)
Native American	90	(1)
Other/Unknown	324	(2)
Age in Years (at end of each)		
0 - 12	3	(<1)
13 - 17	4	(<1)
18 - 24	138	(1)
25 - 29	459	(3)
30 - 39	1,869	(12)
40 - 49	4,778	(30)
50+	8,650	(54)

Our primary collaborator(s) in the San Francisco community will be responsible for assembling the local focus groups (supra) and conveying the group's responses to the research team in order to adjust as needed the ROAH 2.0 Survey tool. After IRB approval the collaborators will be responsible for recruitment and ROAH 2.0 administration.

We estimate by power analyses the need to recruit 250-300 older adults from the San Francisco community.

ACRIA's commitment to the San Francisco/Bay Area is evidenced by its placement of staff locally. ACRIA has a local capacity building and technical assistance program in the SF/Bay Area and has conducted multi-day trainings with local medical and non-medical HIV & Aging service providers. Additionally, ACRIA has established strong relationships with local experts and key agencies and institutions.

Collaborating With ACRIA

ACRIA's Research staff has a history of multiple successful collaborative research efforts which include:

- New York University College of Nursing, Hartford Institute for Geriatric Nursing, New York, NY
- New York University, Center for Health, Identity, and Behavior & Prevention Studies, New York, NY
- HIV and Geriatrics Departments, Cornell Medical Center, New York, NY
- SUNY Downstate Medical Cntr, the Brooklyn NIH WIHS (Women's Interagency HIV Study) Cohort.
- GMHC, New York, NY
- SAGE, New York, NY
- Chelsea Westminster Hospital in London, UK
- London School of Tropical Medicine, UK
- Fordham University, NY, NY
- Medical Research Council and Uganda Virus Research Institute

- University of New England, New South Wales, Australia
- University of Witwatersrand, South Africa
- The Center on Halstead, Chicago, IL
- Indiana University, Bloomington, IN
- Syracuse University, Syracuse, NY
- Amida Care, New York, NY
- Albert Einstein College of Medicine, Bronx, NY
- American Academy of HIV Medicine, Washington, D.C.
- American Geriatrics Society, NY, NY

ACRIA's research staff brings to this collaborative effort [ROAH 2.0](#) a critical mass of research experience on the issue of HIV and Aging. The two primary research scientists, Drs. Karpiak and Brennan-Ing, have together 20 years' of experience conducting research on this issue (see listing of publications and invited presentations) and are recognized as leaders in this research area. Both are on faculty at New York University College of Nursing with cumulatively over 60 years of extensive rigorous research experience.

- Dr. Karpiak was on faculty at Columbia University Medical School for 25 years conducting cutting edge research in neurobiology and immunology funded by NIH and NSF and was a consultant for WHO in Geneva. He shifted his efforts to HIV/AIDS by becoming a Program Director at AIDS Project AZ and then was the Executive Director for an agency that developed congregate housing for the homeless with HIV in AZ. Upon returning to NYC he was the Executive Director for an agency that advocated and conducted research on LGBT seniors. He joined ACRIA in 2002, supervising their clinical trials program, and conducting preliminary research that led to his launch of ROAH in 2005. In 2009 ACRIA received a special recognition award from the US Surgeon General for ROAH. He is a member of the UN Committee on Aging, and the HIV-AGE Consensus Project a collaboration with the American Academy of HIV Medicine and the American Geriatrics Society.
- Dr. Brennan-Ing, a skilled gerontologist, joined ACRIA in 2007 after 11 years as a researcher in visual impairment and dual sensory loss at Lighthouse International. He is a Fellow of the Gerontological Society of America and convenes GSA's interest group on HIV and Aging, a member of the American Psychological Association Divisions 44 (LGBT Issues) and 20 (Adult Development and Aging) and Chair-Elect of APA's Committee on Sexual Orientation and Gender Diversity, a member of the American Society on Aging's LGBT Aging Information Network Leadership Council, on the NIH Working Group on HIV and Aging, and Consulting Editor for Methods and Statistics for *Gerontology and Geriatric Education*.
- Richard Havlik, M.D., retired Laboratory Chief of the National Institute of Aging (NIH) has been ACRIA's clinical consultant and collaborator since 2009.
- Liz Seidel MSW is a member of the ACRIA research team. She has been Project Director on 2 major research efforts as well as the primary Evaluator for ACRIA's extensive local and national education and capacity building programs.

ACRIA Provides: ACRIA will have done the critical development work needed to assure the scientific integrity, content and validity of [ROAH 2.0](#). It represents ACRIA's investment of an estimated \$ 201,000.00 in resources.

- The [ROAH 2.0](#) Survey tool represents the enormous experience of ACRIA research staff and reflects the input of [ROAH 2.0](#)'s National Research Advisory Committee (see listing below) and four focus groups in New York City (one of which is in Spanish only). A parallel effort identified the clinical data which if available will be linked to the responses in the [ROAH 2.0](#) survey. The choices of clinical data variables reflects the collaborative efforts of Cornell (HIV and Geriatrics) Medical Center and ACRIA

research staff. The [ROAH 2.0](#) Survey tool is constructed using REDCap. Survey data will be captured in REDCap as well. REDCap is widely used in the academic research community. It was developed by the informatics core at Vanderbilt University with ongoing support from NCCR and NIH grants. The REDCap Consortium is a collaborative, international network of more than 900 institutional partners in over 70 countries, with more than 100,000 total end-users employing the software for more than 100,000 ongoing research studies. REDCap is a PHP-based system, developed by Vanderbilt University and currently managed and updated through a national consortium that supports the rapid setup of secure, Web-based study-specific database systems and associated forms. It provides full field validation capabilities (customized to each study), import/export (including export to common statistical packages such as SAS, SPSS and Excel), and file upload/management functions. It includes a complete suite of features to support HIPAA compliance, including a full audit trail, user-based privileges, and integration within institutional servers.

- ACRIA can provide all needed texts to describe the background and details of the [ROAH 2.0](#) research effort. This text will facilitate the rapid completion of all applications made to Foundations or other entities for support of [ROAH 2.0](#) in your community.

Funds Needed to Conduct ROAH 2.0 in San Francisco

ACRIA with designated local collaborators will join efforts to achieve local/foundation support for ROAH 2.0. Local focus groups (e.g. local CABs) and an associated IRB application will be needed. The 2 or 3 focus groups comprised of older adults with HIV, including long-term survivors and local stakeholders will validate the content of the ROAH 2.0 Survey instrument and allow for any city specific changes that need to be made. We estimate that \$50,000.00 dollars will be needed to conduct the focus groups and IRB approval process and begin initial recruitment and data collection for 75 participants. An additional \$75,000 will allow for completing recruitment (~N=300) and data cleaning and validation and generating an Executive summary report for dissemination. ACRIA has a full time staff person (Hanna Tessema MPH) in San Francisco which will facilitate this process.

The ROAH 2.0 Research Advisory Committee Members

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