

Perspectives from the Front Lines: Encouraging Community Engagement in the Performance of Research at the Intersection of HIV and Aging

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Keywords: HIV, Aging, Community, Engagement

The devastating losses of the early AIDS epidemic fueled an urgency and purpose that led to historic collaborations between people living with HIV (PLWH), HIV clinicians and researchers. This unprecedented effort led to significant advances best manifested by the rapid development and testing of highly effective antiretroviral treatments (ART) for HIV/AIDS. ART saved lives and is the primary reason we have an epidemic dominated by older PLWH. U.S. statistics from 2015 demonstrate that 38% (171,172) of PLWH were aged 50-54, 29% (131,430) were 55-59, 18% (81,438) were 60-64 and 16% (70,644) were 65 years and older(1). Current estimates suggest that by 2030 64-73% of PLWH will be aged 50 years or older(2)(3). Notable examples directly catalyzed by PLWH (i.e. the community based advocacy group ACT UP) include accelerated access to ART, studies evaluating combination therapy (no previous precedent at the FDA), and research on ART adverse effects(4). However, the hopefulness that community members experienced from those monumental successes has faded.

Given the history and effectiveness of community partnerships, researchers at the intersection of HIV and aging should be eliciting and embracing community input. Yet, a gap persists between the needs that older PLWH voice (what will happen to me when I cannot care for myself, I'm waiting to die) and the research being pursued(5). HIV research institutions do invite community stakeholders to the table but involvement is often superficial leaving advocates feeling unheard, unvalued, and fearful that the answers to their research priorities will not come in their lifetime. Specific examples generated by the authors who consist of PLWH and researchers include: 1) development of novel and innovative strategies of HIV care and support services that purposefully address aging needs, 2) studies that focus on quality as well as length of life and address factors that negatively impact aging (i.e. depression, isolation, substance use, etc.), and 3) the long term effects of ART in older adults. Additionally, many older PLWH do not have a platform as they are too frail, sick, mentally and physically impaired or disabled and are the "new silent majority".

Challenges exist to improving community collaboration in research, but they are not insurmountable (Table 1). In this letter, we advocate for the implementation of community engagement from preconception to study implementation, data interpretation

and dissemination in HIV and aging research. This will represent a change in the current research culture and practice but it is the authors' collective opinion this is worth the time and effort. As was the case for inclusion of sex as a biologic variable, we expect this change will only come if required(6). Thus, we challenge funders, publishers and conference organizers to not only ask researchers in the fields of HIV and geriatrics/gerontology to thank community participants in presentations and publications but require documentation of community engagement throughout the research process. We believe these practices will lead to meaningful community engagement in the leadership of groups that fund and conduct research, in the committees that approve research and ultimately result in broad and innovative advances in the science and care of older PLWH. Older adults dominate the current epidemic; many feel abandoned by the community, providers, researchers, and healthcare institutions and some fear that change will come too late for them.

ACKNOWLEDGEMENTS:

In memory of Spencer Cox and the numerous other community members who, suffering and feeling abandoned, chose death over life(7).

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Table 1: Barriers, root causes and facilitators of meaningful community engagement of older PLWH

Barriers	Possible Root Causes	Proposed Facilitators
<p style="text-align: center;">Advocacy fatigue and disinterest</p>	<ul style="list-style-type: none"> • PLWH are not well educated about current issues and/or are intimidated by research • “Retired” older advocates and a shortage of younger advocates interested in aging • Internal and external stigma attached to aging • Perception by younger advocates that aging is not their problem 	<ul style="list-style-type: none"> • Ongoing development and dissemination of education programs to educate the community about HIV and aging <i>and</i> about the performance of research • Develop and provide community advocacy training or mentorship • Develop community programs that target issues of community ageism

<p style="text-align: center;">Lack of community diversity and representation</p>	<ul style="list-style-type: none"> • Advocates skew to being healthier and high functioning - resulting in lack of input from medically and socioeconomically disadvantaged PLWH • Ciswomen, transwomen and transmen have different challenges and different barriers to participation 	<ul style="list-style-type: none"> • Educate a broader community population on the issues around HIV and aging • Design specific engagement strategies that allow participation of hard to reach populations and people with comorbidities <i>Examples include town halls, home-based visits, engagement with churches and other local organizations.</i> • Provide accommodations to persons unable to travel due to medical co-morbidities <i>Examples include phone or video chat participation, surveys sent to the home with pre-paid return envelopes and incentive included.</i> • Encourage HIV clinicians to advocate for PLWH without a platform
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<p>Community engagement at all levels of research is not routine</p>	<ul style="list-style-type: none"> • Researchers do not know how to meaningfully engage the community • Community input is time consuming • Community input may not be perceived as valuable • Community engagement is not required for most research grants • Community members are often not part of the evaluation process (i.e. not members of review committees) 	<ul style="list-style-type: none"> • Provide education to researchers in communicating across different levels of expertise and education • Create easy to access opportunities for researchers to engage the community • Require documentation of community engagement in grants, posters, presentations and publications • Invite experienced community members to contribute in a greater way in grant and publication review
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