

**HIV & Aging in  
Alameda County  
Oakland  
California**

Findings from

**R**esearch on

**O**lder

**A**dults with

**H**IV

2.0

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Recruitment and survey data collection was done by clinic research staff, Lance Smith and Ralph Aniciete, at HIV Services, Highland Hospital, Alameda Health System, Oakland, CA

Our thanks to ACRIA's Hannah Tessema for initiating this project in the Bay Area and to Dr. Meredith Greene for her input and support. ACRIA's Rebecca Erenrich and Liz Seidel managed the recruitment and data input.

## The ACRIA Center on Aging & HIV at GMHC

The ACRIA Center on HIV and Aging seeks to address the unique needs and challenges that older adults living with HIV face as they age. ACRIA's seminal 2006 Research on Older Adults with HIV (ROAH) Study established ACRIA as a leader in research on HIV and aging. The 2016 study ROAH 2.0 was guided by Co-Principal Investigators Stephen Karpiak PhD and Mark Brennan-Ing PhD.

The Center conducts qualitative and quantitative research to create an evidence base to advance the formulation of policy, advocacy, and program development. Through research, education, and advocacy, the Center fosters the open exchange and dissemination of information from scientific communities to AIDS service providers and older adults living with HIV. In 2017 ACRIA entered into a strategic partnership with GMHC, the world's first HIV/AIDS service organization, to create a new and innovative kind of service, research and policy organization.

Summary Reports, and slide sets based on ROAH data will be available at the **National Resource Center on HIV and Aging** ([www.AgingHIV.org](http://www.AgingHIV.org)). Launched in September of 2019 at GMHC, The National Resource Center on HIV and Aging targets the growing populations of older adults living with HIV including Long Term Survivors. The Center's goal is to inform the health choices of these older adults, together with those who provide them with needed supportive services as they age. The vetted information offered by the Center reflects the cumulative expertise of community advisors and staff from across the country. The site is dynamic, providing texts, short videos, sponsored webinars, conference summaries, slide decks, infographics, and the most current research data available. The Center, a program of GMHC, also provides an interactive National Community Map on which users can find supportive programs and conferences happening locally. This effort supports the Resource Center's mission by enhancing interactions that result in programs that meet the needs of older persons living with HIV.

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## HIV and Aging: How We Got Here

In the beginning of the AIDS epidemic in the United States, HIV infection was primarily a disease of young adults. By 1993, AIDS was among the top ten causes of death in the United States. In the last year (2019) of this decade, HIV remains a serious disease. However, unlike the first decade of the epidemic, today a HIV diagnosis is no longer the inevitable, often rapid, death sentence it once was. This reversal is a result of the extraordinary advances in HIV treatment. Today there are over 30 Anti-Retroviral Therapy (ART) drugs available, many of which offer once a day dosing with few, if any, side effects. When ART is taken daily the medication effectively blocks the HIV virus from causing the collapse of the immune system (AIDS). While HIV continues to affect people of all ages, the U.S. HIV epidemic is dominated by older adults living with HIV. Estimates based on CDC Surveillance Reports show that in 2018, over half of the estimated 1.2-1.3 million people infected with HIV in the USA were age 50 and older [1].

In every community across the USA the number of older adults living with HIV is increasing annually. In some communities that percent is now approaching 65-70%. Those increases are in part due to new cases of HIV infection among older adults but most of today's older adults living with HIV were diagnosed 10-30 years ago. They are termed Long-Term Survivors. These Long-Term Survivors may have been diagnosed with HIV before 1996, the year that ART became near universally available in the USA. These Long-Term Survivors lived through the first decades of the AIDS epidemic and may bear the marks of enduring that harsh era. Regardless of when they were infected, all people aging with HIV are coping with dual challenges: the stresses of growing older along with the challenges of living with HIV.

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## The Genesis of the ROAH Project

The genesis of this project can be traced to 2005 when ACRIA (AIDS Community Research Initiative of America), recognizing the surging numbers of older adults living with HIV and the distinctive nature of their situation, created the original Research on Older Adults with HIV (ROAH) study. The initial study, a groundbreaking look at nearly 1,000 older adults with HIV in New York City, provided a broad overview of the participants' social, psychological, and health status. A data-based book was published, as well as almost 30 peer-reviewed publications, multiple book chapters, and a myriad of abstracts and presentations. ROAH offered insights on the social connectedness, poverty, sexual behavior, substance use, HIV stigma and disclosure, spirituality, service utilization, and unmet needs of HIV-positive older adults. The study documented troublingly high rates of isolation and depression, and it showed that the older adults with HIV are experiencing a heavy burden of comorbid health conditions alongside HIV infection. The ROAH research findings received prominent international news coverage, became the impetus for the development of the largest sustained training and prevention programs on older adults with HIV in the United States (Age Is Not A Condom), led to the formation of an NIH Study Group on HIV and Aging, the White House Conference on HIV and Aging, spurred the development of a web site offering guidance on the clinical management of older adults with HIV ([www.HIV-AGE.org](http://www.HIV-AGE.org)), prompted special sessions before the US Senate and House, and inspired similar research projects internationally. More recently, in 2019, there was the launch of a National Resource Center on Aging and HIV targeting the older adult with HIV ([www.agingHIV.org](http://www.agingHIV.org)).

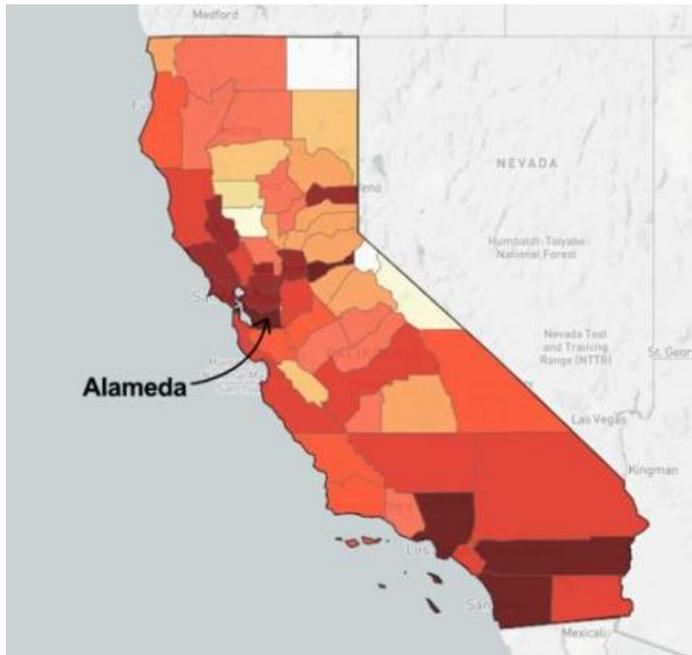
In 2015, a decade after the first ROAH effort, ACRIA researchers realized that an updated look at older adults with HIV was needed, as the growth in that population of older adults continues. In 2015, they inaugurated a successor study, the Research on Older Adults with HIV 2.0 Study (or ROAH 2.0). That effort was a multiple site research study across the United States (San Francisco, Oakland/Alameda County, Chicago, New York City and Rural Upstate New York).

## Alameda County and Oakland

The proximity of Alameda County to the resource-rich city of San Francisco provides an opportunity to compare challenges and health outcomes in two markedly different communities of older adults living with HIV.

Facts: HIV in Alameda County [2]

- Of all county residents, 0.4% are living with HIV. The majority live in the city of Oakland.
- In 2015-17, the rate of HIV diagnoses (15.2 diagnoses per 100,000 people) in Alameda County was slightly higher than the national average of 11.8 per 100,000. In Alameda County, 20% of the new HIV diagnoses were in adults age 50 and older (2014-2016).



- Similar to national trends, between 2015 and 2017 the majority of new diagnoses in the county were in men who have sex with men (MSM); 38% were in African Americans (who comprise 10% of the county), 25% each were in whites and Latinx, and 10% in Asians and Pacific Islanders.

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- HIV rates declined consistently from 2006 and 2017, especially in African Americans, particularly African American women.
  - Between 2014 and 2016, 87% of people diagnosed with HIV in Alameda County were linked to care in three months if they had labs done on the day of diagnosis. In 2016, among persons living with HIV/AIDS (PLWHA) in the county, 57.5% were retained in care, and in 2016, 68% were virally suppressed.

## Executive Summary

The data collected in this research effort aims to assess the multiple needs of the older adult community, age 50 and above, living with HIV in Alameda County, California. Of the total sample (N=198), 86% resided in Oakland. The data provided here can be used as a guide to assist in the development of needed supportive service programs and associated policies for the older adult living with HIV. Five focus groups were conducted in the Bay Area to make certain that the ROAH survey examined all characteristics that were important to the population of older adults living with HIV. Alameda County residents were represented in those groups.

Parallel to the surveyed population, this report describes primarily cisgender (i.e., not transgender) males, racially diverse, similar in age distribution of older adults with HIV in the County. Almost 53% of survey participants rate their physical health as excellent or good, nearly all participants are receiving antiretroviral therapy (ART), and over 90% report having an undetectable viral load. However, 46% report their health as fair, poor, or very poor, and many participants said their work or social lives are hampered by their health. Participants report they are confronting a spectrum of health conditions and symptoms in the past year. This data is consistent with a plethora of scientific articles exploring the intersection of aging and HIV [3-7]. Among the most common health issues were anxiety (reported by 46% of participants) and arthritis (46%), fatigue (45%), chronic pain (38%), and neuropathy (32%). Strikingly, nearly 70% are experiencing four or more coexisting medical conditions.

Participants report taking over 10 pills a day on average, including their HIV medications, other prescriptions, and over-the-counter medications. Many survey participants appear

	%
Black	46.9
White (non-Hispanic)	21.4
Latino	11.7
API	5.1
Multiracial	9.2
Other/Unknown	5.6

Age	%
50-59	57.8
60-69	30.1
70+	3.3
No Report	3

to be confronting serious mental health issues, which agrees with previous research on the mental health and psychological wellbeing of older adults with HIV [8-20]. On the PHQ-9 screen for depression, 50% scored as having severe or moderately severe depression. Another 34% screened for moderate depression. According to the PTSD checklist, 35% exhibit symptoms of post-traumatic stress disorder (PTSD). Just over a third of those who screened for PTSD and 41% of those with moderate to severe depression reported receiving no mental health care in the last year. Most (51%) reported a history of being sexually assaulted before the age of 16 and 52% have been victims of domestic violence by a partner.

On a measure of loneliness, 21% scored as “lonely” and 22% as “very lonely.” Three-quarters of participants said their needs for emotional support

are not fully met, and just over a fifth said they need “a lot more social support.” Nearly

20% of participants report use of methamphetamine, crack/cocaine, or heroin in the past 3 months. Other

challenges the participants

confront include low income,

costly housing, and food insecurity/hunger. Over 30% report hunger and additionally, 19% report food insecurity. Almost 20% report inadequate income to cover expenses. Many lack resources to help with tasks of daily living or to get needed care should they fall sick or be injured. Reported barriers to getting services include eligibility concerns, long wait times, lack of knowledge of what is available, confusing procedures for accessing services, and cost.

#### Study Participant Characteristics

- 27.2% had ever been incarcerated
- 10.6% had served in the military
- 14.8% of participants were immigrants: 66.7% of those were born in a Latin American country

## Findings for Alameda County, Oakland

In 2017 53% of the total population living with HIV in Alameda County CA were age 50 and

At Birth	%
Male	71.5
Female	28.5
Current Gender Identity	
Straight	38.3
Gay or Lesbian	34.2
Bisexual	13.3
Other (Same gender loving, queer)	14.2

older. There are over 2,626 older adults with HIV in Alameda County [2].

Epidemiological data on the prevalence of HIV in the County indicates that by 2026 another 1000 people will join the older adult with HIV population [2]. At that point in time, 63% will be ages 50 and

older. The ROAH research project in Alameda County had two phases: Initially, five focus groups comprised of older adults living with HIV in the Bay Area (San Francisco and Oakland) were held with various sub-populations of older adults with HIV: gay male Long-Term Survivors, African Americans, Asian and Pacific Islanders, Spanish speakers, and Transgender people (A summary of the focus group findings can be found in Appendix A). These focus groups informed refinements and additions to the survey questions developed for use in multiple cities. Next, older adults with HIV were recruited to take a 70-page survey through agencies, clinics, and other venues known to serve people living with HIV (For more about the study's methods, see Appendix B). This report presents an overview of the characteristics and challenges of the older adult living with HIV in Alameda County.

We begin with a look at the survey participants, their identities (gender identity, sexual orientation, and race) and life experiences with HIV/AIDS, including immigration, education, and incarceration. Next, we ask what services these older adults are utilizing, what needs are beginning to manifest, and what service gaps there are. In the following section, we cover the physical health of the survey participants, including measures of HIV related health and other conditions that may be affecting wellbeing. Finally, we examine the psychological, behavioral, and social situation of the survey participants, including their mental health and psychological wellbeing, feelings of loneliness, substance use, and sexual activities. We intend for this document to cast light on the status of older adults with HIV in

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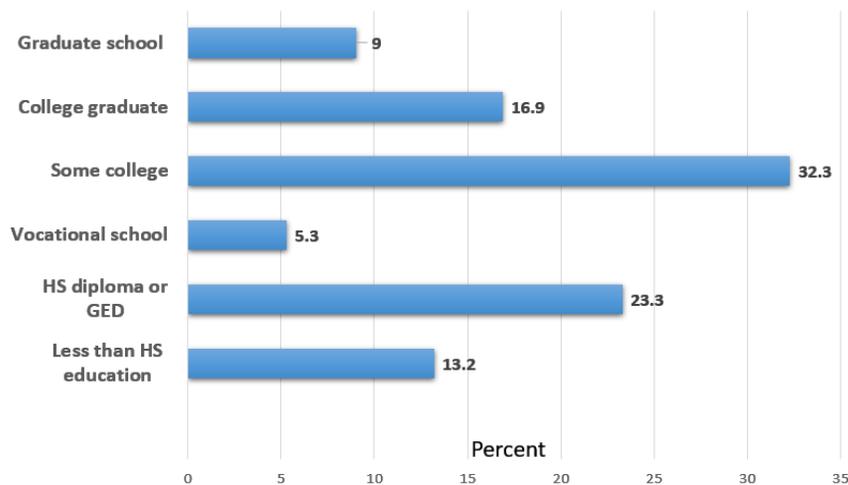
Alameda County and the city of Oakland. We hope it will provoke thoughtful conversations on the welfare of older adults with HIV, and that these conversations will in turn foster the development of programs and policy that can enhance the health and wellbeing of older adults living with HIV in Alameda County and beyond.

## A Portrait of the Participants

The study participants reflect the population of older adults with HIV in Alameda County; 22.4% of the ROAH 2.0 Alameda/Oakland sample were ages 60 or older. This parallels the HIV surveillance data from the Department of Public Health which reports that for 2016, 21.6% of all older adults with HIV were ages 60 or older [2].

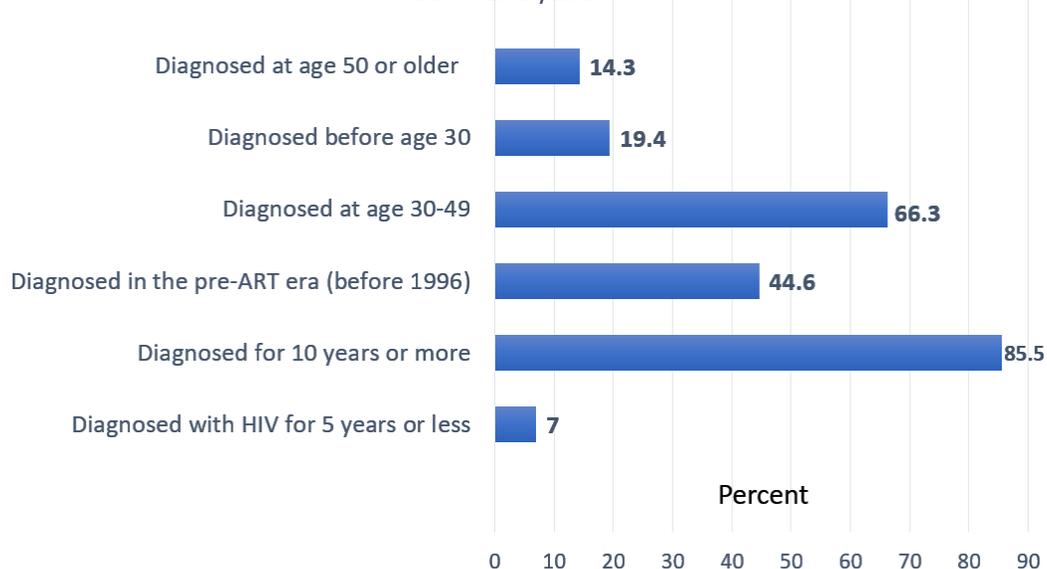
The study comprised a majority male sample with just over 60% self-defining as non-straight. There was a wide range of educational attainment with 86.8% of the participants

**Education Levels of Oakland ROAH 2.0 Sample**



**Years Since HIV Diagnosis**

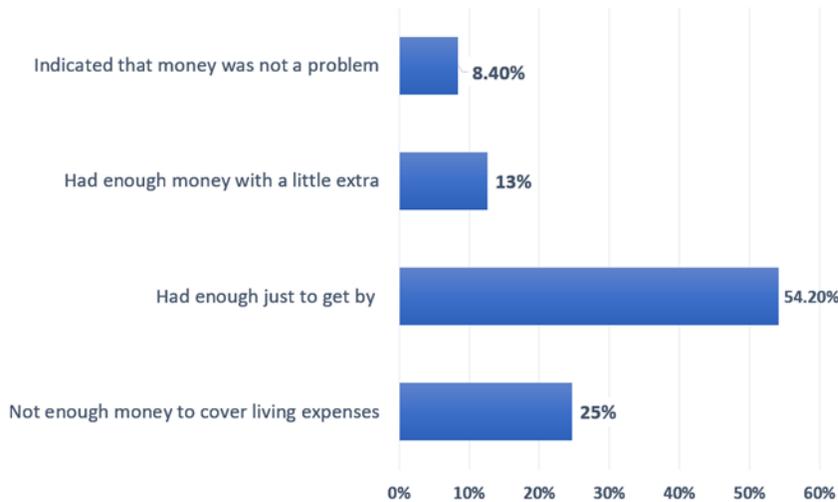
Mean = 20.6 years



receiving education of High School or above and 25.9% being college graduates.

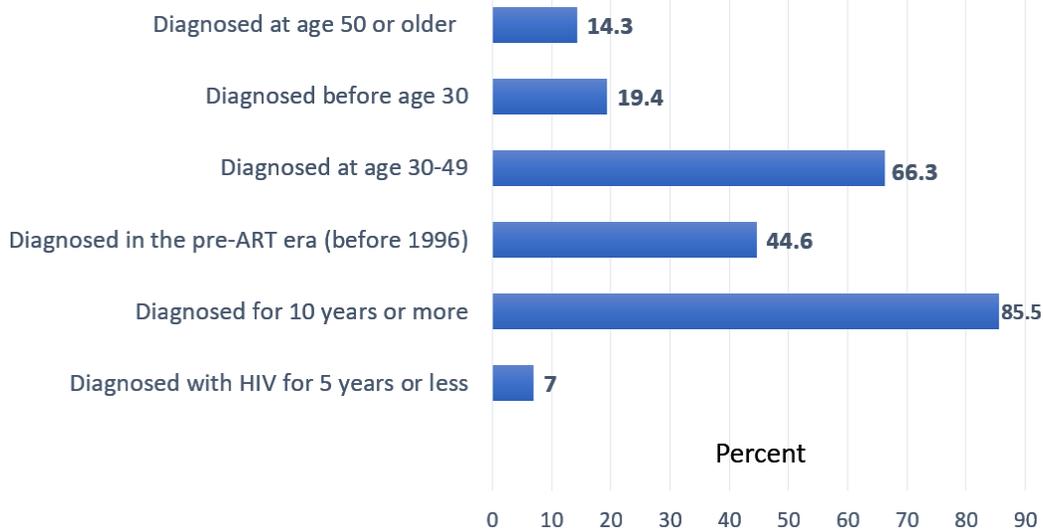
The majority of the sample reported that they contracted HIV through sexual contact which is reflective of national and international trends. The majority of those surveyed reported having their viral load under control and remaining undetectable (86.6%) and 67% having received their latest CD4 counts within the last 3 months. However, a small proportion (2.1%) had their last tests over 12 months ago. Nearly half of participants (46.3%) had

### Income Sufficiency of Oakland ROAH 2.0 Sample



### Years Since HIV Diagnosis

Mean = 20.6 years

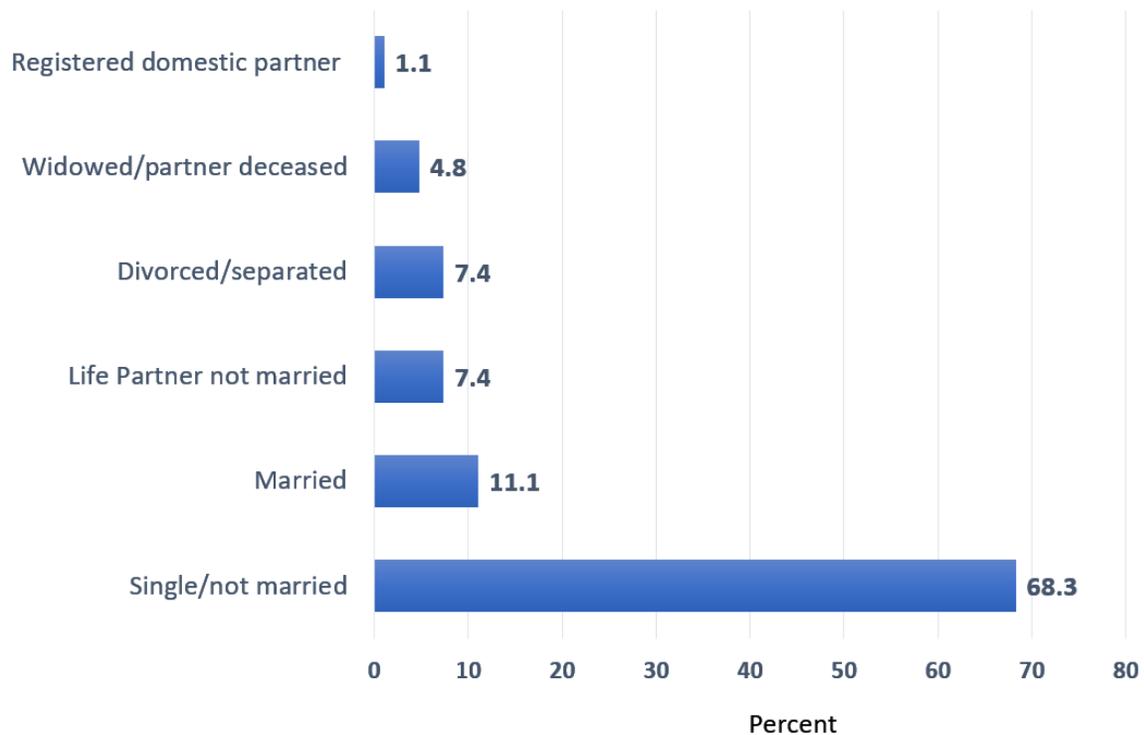


received an AIDS diagnosis in their lifetime with over a quarter (28.4%) having received this prior to 1996.

<b>Work Status</b>	<b>%</b>
On Disability	53.1
Working Full Time	12.0
Working Part Time	8.3
Unemployed	11.5
Retired	11.5

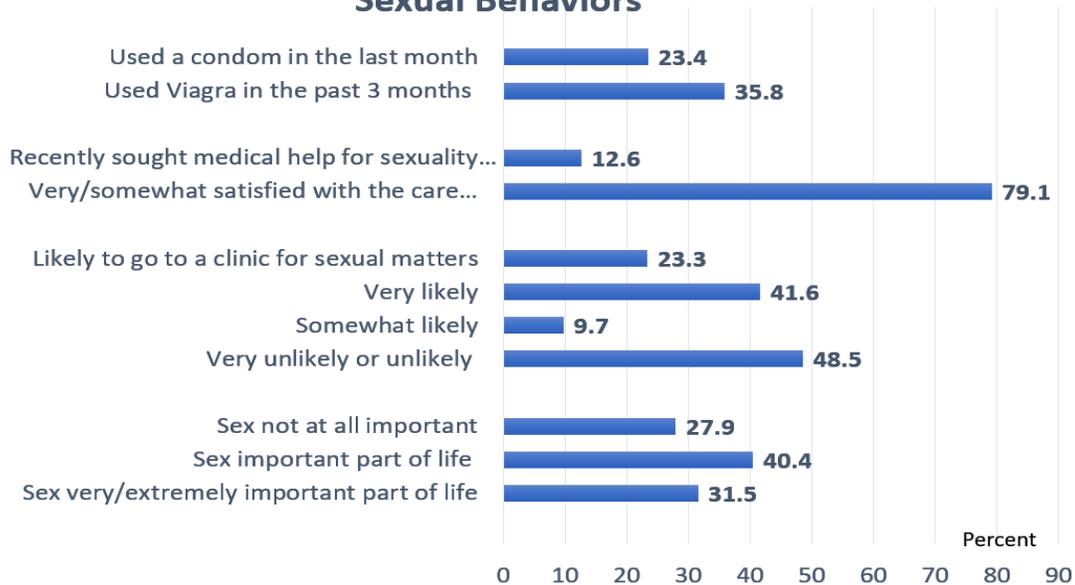
Two significant characteristics of this population emerge. One is their financial status. Almost 55% report they had *just enough money to get by* and almost one quarter (23%) did not have enough money to *cover living expenses*. For the majority, financial support is a daily challenge and therefore a source of chronic stress. The regulations that govern eligibility for health care as well as other support services place this population in a virtual bind where any

## Partnerships



desire to work is thwarted by the risk of losing health benefits and other supports. This can be seen in the data showing that only 12% work full time and 8.3% work part time. The financial stress is further illustrated by nearly two-thirds of the sample (63.6%) having experienced some form of food insecurity. Food insecurity is defined as having insufficient funds or other resources, resulting in a disruption of food intake or eating patterns. This can range from eating smaller meals to skipping meals or indeed going for sustained periods of time without eating. With nearly a third (31.3%) identifying that [21-23] they had insufficient money for food, this causes potential issues for maintaining health. The underlying cause of food insecurity is lack of employment or access to sufficient support. Both can be even more challenging for the older adult living with HIV. When there is limited or often no funds available (fiscal insecurity), health is impacted - inability to purchase over-the-counter medications, nutrition, clothing, transportation, with correlated increases in social isolation [21, 24]. Taken together, this unmet need (insufficient income) may jeopardize sustained viral suppression.

## Sexual Behaviors



The social status of this population must be underlined: over 70% are not partnered. This characteristic drives the social as well as financial isolation which many of these older adults confront. This isolation is driven by many factors, but while tolerable when younger, as they enter the 6<sup>th</sup> through 9<sup>th</sup> decades of life, this lack of partnership has an enormous impact on health status and outcomes [25, 26].

Despite the myth that older adults do not have sex [27-30], 53% of the participants reported being sexually active in the past year. Participants who reported past-year sex were asked about what kinds of sex they had and how often they use condoms when engaged in these sexual activities. Among these participants, 41%, 31%, and 26% reported having oral, anal, and vaginal sex, respectively. Most did not consistently use condoms when engaged in these sexual activities. Since 82% report having an undetectable viral load this lack of condom use may not be of large concern, except that there is the risk of transmission of other STIs. Among sexually active participants, 17% reported that their most recent sexual partner was HIV positive. Among the remainder with an HIV negative partner, 5% said they believed their partner uses PrEP Sexual health is an important part of a person's life regardless of age or HIV status [31-33]. Good sexual health contributes

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positively to the well-being and health status of all individuals [34]. This factor is illustrated by nearly 70% of these older adults with HIV reporting that sexual activity is an important or very/extremely important part of life.

## Service Use, Needs, and Challenges

To understand the needs of older adults with HIV it is helpful to begin with an understanding of their functional status – their capacity to engage in what’s often called “activities of daily living,” or ADLs, like handling chores, self-care, and errands. Participants were asked to report if they had any difficulty with these tasks and if so, to what degree. The majority (59%) of participants had trouble with at least one activity of daily living. Those participants had difficulty with an average of 3 out of 13 tasks. Many of these participants (42.7%) had difficulty with housework but a significant proportion also had difficulty with fundamental self-care activities such as getting out of bed (22.2%), bathing (21.8%) and feeding (11.7%).

Nearly all participants required some form of assistance with one or more tasks to enable them to sustain independence, health and social wellbeing. Whether it was needing help with understanding and obtaining their entitlements (75%), someone to assist them in making doctor’s visits (89.9%), help finding a job (57.9%) or general housekeeping or

personal care (75%).

Communities provide an array of services for all older adults.

### **37.3% of participants had a pet**

Of those who had pets, 78% said their pet had a positive impact on their physical health and 90% said they had a positive impact on their mental health

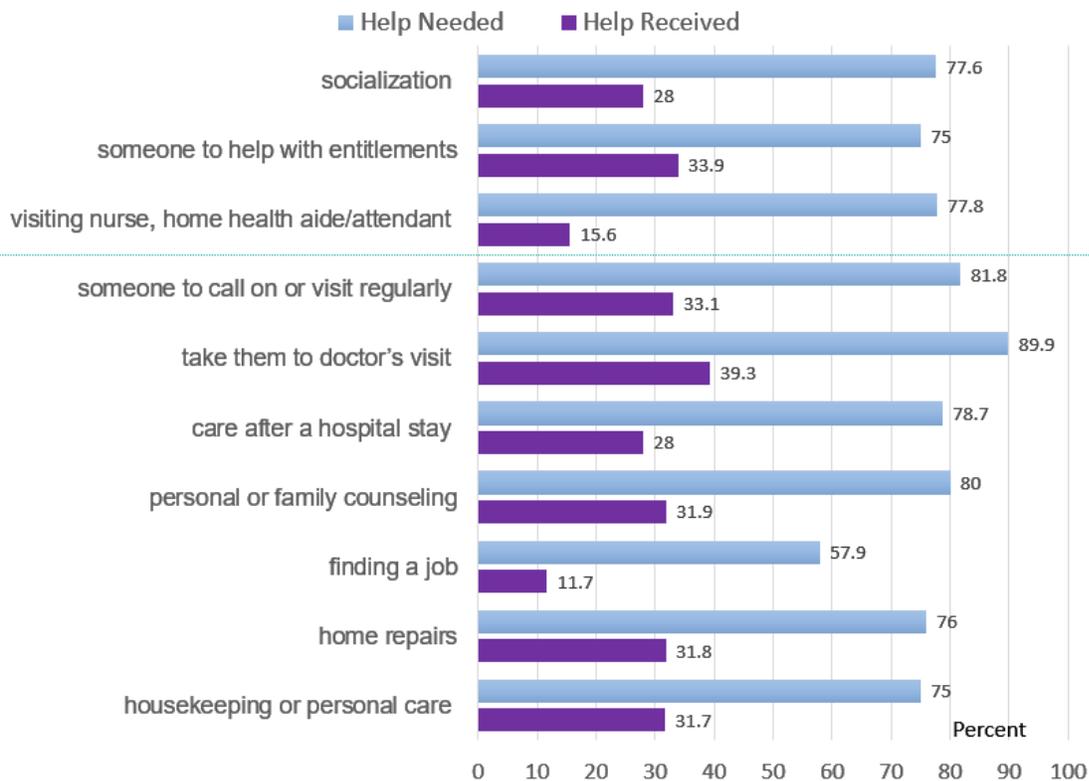
ASOs (AIDS Service Organizations) provide supportive services specific for people living with HIV. Yet older adults living with HIV encounter many challenges (disclosure issues, staff hostility, transportation etc.) when trying to engage these services [35-39]. The demands caused by HIV/AIDS increases the likelihood that social and health needs may go unmet [37].

Less than half of any identified needs were met with adequate resources. Of those needing care after hospitalization (78.7%), only 28% received any help. The post-hospitalization transition is a particularly difficult period. Without help at such a stage, re-hospitalization can occur which increases other fiscal and physical stresses [40, 41]. Benefit entitlements

can be the line between fiscal and food security and hunger or homelessness and instability [42, 43]. With only 33.9% receiving the support that they need; this highlights a significant gap that potentially impacts other aspects of the lives of those living with HIV. Similar to this, only 11.7% received the support they needed in order to find a job. Older adults find it more difficult returning to the workforce due to skills gaps as well as both institutional and individual ageism. Those with chronic conditions also find it difficult. This is further complicated when they confront health disclosure issues in the workplace [44-46].

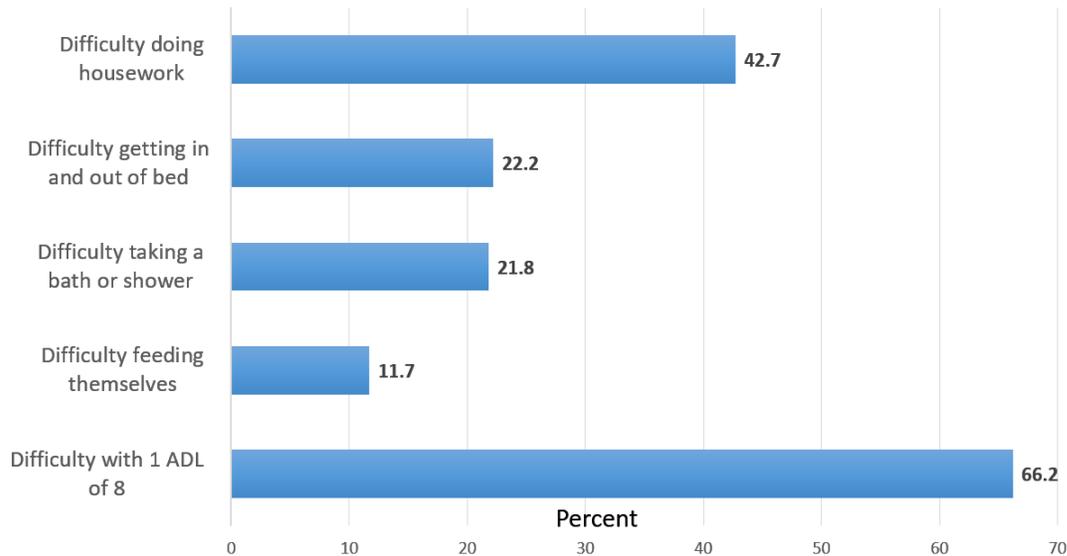
Nearly 65% were in receipt of Medi-Cal support and over 50% were receiving Medicare. Almost 30% of the sample were in receipt of Supplemental Security Income (SSI), illustrating that these are largely low-income individuals. Over 35% of the sample had qualified for SSDI, providing additional income supplements that are often the result of notable disability

### Needs/Gaps in Last Year: Oakland ROAH 2.0 Sample



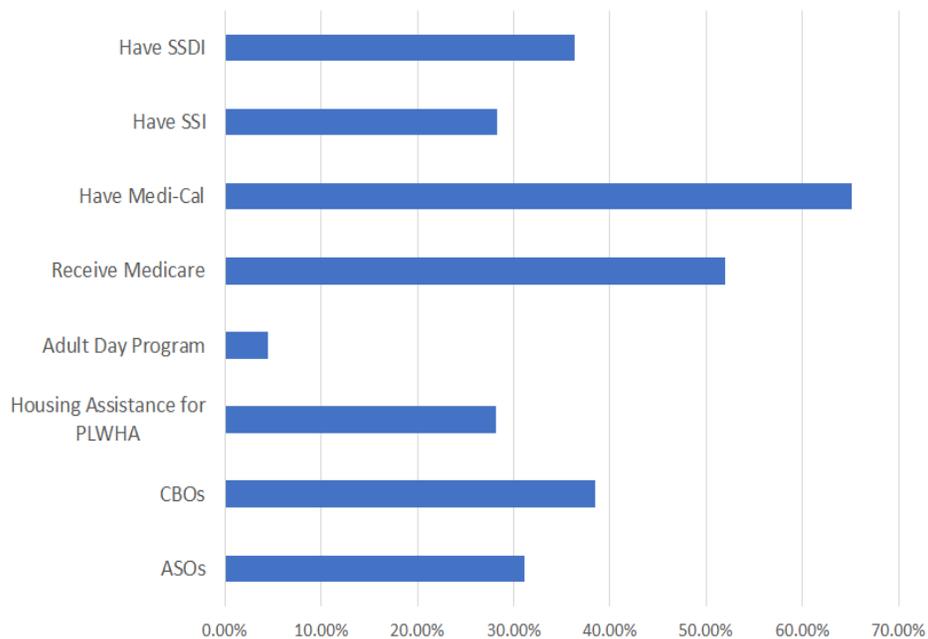
or physical restrictions. Further, when assessing housing security, nearly 30% are in receipt

### Activities of Daily Living (ADL) Oakland ROAH 2.0 Sample



of housing assistance with over 70% getting additional support from either Community Based Organizations (CBOs) or ASOs (AIDS Service Organizations). Between 30-40% of those critical psychosocial, non-medical support services, are provided by CBOs and ASOs. These Community Based Organizations are essential partners in the healthcare system [47-49]. Yet

### Use of CBO (Community Based Organizations)



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the data shows there are significant gaps in providing “wrap-around” support services. Some of this unmet need may reflect the lack of support from federal, state and local governments. These critical services are dependent on local funding which is often not stable or inadequate.

Many ADL needs could be addressed by support from family and friends and community members/entities (the social network). Here, the results underline why the need for socialization becomes critical. These unmet needs, as evidenced by the ADL data, may in part reflect the study finding that the majority of participants live alone. Living alone is characteristic of the MSM (Men who have Sex with Men) population at every age regardless of HIV status. Living alone (60.7%) also explains in part why there is insufficient income reported by this population. Nearly a third (32.3%) are receiving housing assistance to pay for their rent, and 47.3% spend more than half of their income on housing. This high demand on a limited income for rent impacts the issues of food insecurity and nutrition, lack of exercise, as well as access to socialization opportunities. Of those who did live with others, nearly half lived with a partner (42.9%) in rented accommodations (43.7%) but 14.9%, despite living with others, were not in a place of permanent housing placing them at greater risk of homelessness and other forms of insecurity.

## Medical Conditions

Over 50% of participants subjectively perceive their health as “excellent” or “good”. These older adults with HIV confront multiple health problems often characterized as multimorbidity (two or more chronic conditions). The chart below presents how many

# of Conditions	Percent
0-3	31.2
4-6	28.6
7-9	22.1
10-12	7.5
13-15	6.0
16-25	4.5

participants reported various numbers of health conditions. Only 31% of participants experience less than four coexisting medical conditions. In fact, some (4.5%) participants confronted up to 25 ailments in the past year.

The most common physical health issues include arthritis (reported by 45% of participants), chronic pain (38%) and neuropathy (32%). For the past year, hypertension was reported by 22%, nervous system disorder (18%), dermatological problems (17%), migraines, impotence,

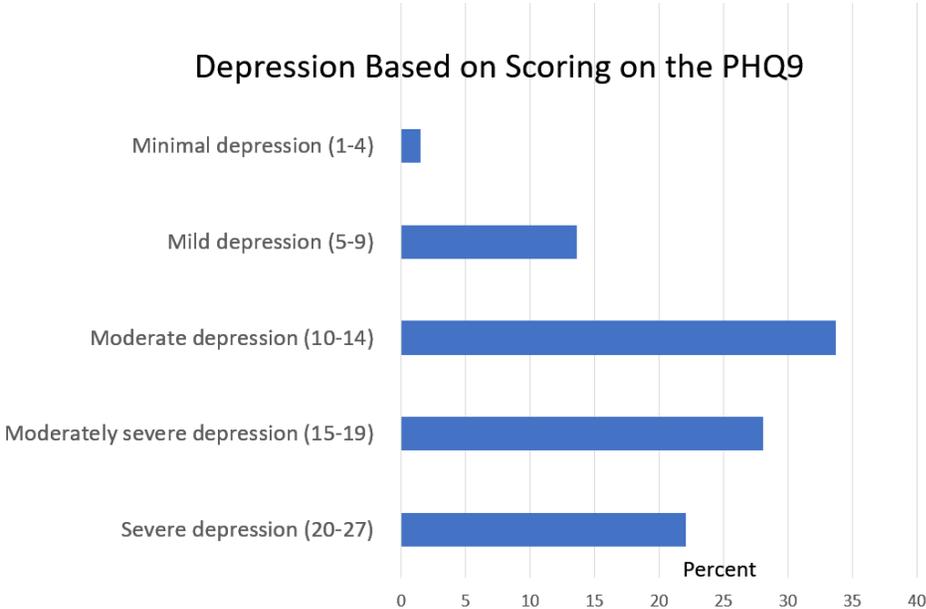
and vision loss (each reported by on average 16% of participants). Other comorbidities include cancer (11%), respiratory conditions (11%), hearing loss (11%), and hepatitis (11%).

Chronic pain was among the most reported conditions. When asked to estimate their overall level of pain, most participants reported it as “moderate”, “severe” or “very severe”. Pain interferes with work, accomplishing tasks and engaging in social activities in the great majority of participants. This is further supported by data showing that nearly a quarter (23.9%) indicated that they had been in severe or very severe pain in the last 4 weeks with 26.6% saying that the pain had interfered with normal activity to a significant degree. Conversely, only 14.5% indicated that they had not been in pain in the last 4 weeks. Pain can be a limiting factor when considering social interaction, exercise and even eating. Pain management is integral to successful health and wellbeing for all persons living with HIV, especially those over 50 years.

# Mental Health

Mental health is frequently overlooked when assessing health outcomes but is an essential part of the health and wellbeing of older adults with HIV.

Participants reported on being diagnosed with anxiety, bipolar disorder, depression or fatigue in the past year. Depression and anxiety are one of the most common health issues reported by 50% and 46% of the participants respectively, and closely followed by fatigue (45%). Bipolar disorder was reported by 14% of the participants, which like depression and anxiety levels are almost five times higher compared to the prevalence (2.8%) in the general population.



*Depression:* We asked participants to indicate whether they were diagnosed with depression during the last year. As expected, based on previous data, half of the Alameda County ROAH 2.0 participants were diagnosed with depression by a professional. Importantly, we also asked participants to complete the PHQ-9 – a valid screen of depressive symptoms in the past two weeks. PHQ-9 scores range from 0 (no depressive symptoms) to a maximum of 27 (severe depression). As can be evidenced from the data, depression is a major health issue for older adults living with HIV. The participant sample

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exhibited depressive symptoms from Minimal (1.5%), Mild depression (13.6%), Moderate Depression (33.7%), Moderately severe (28.1%) and Severe depression (22.1%). This highlights the depth of the issue and explains, in part, the high degrees of social isolation and loneliness observed in the older adult living with HIV. Nearly half of the participants had been diagnosed by a mental health professional with depression in the past, with 60% taking medication for depression.

Only a small number (12.9%) accessed medical help for sexual matters and 79.1% of those who did were satisfied with the care received. Despite low numbers of people receiving medical help, nearly three quarters (74.5%) of participants rated sex as important or very important to their life. The low usage of clinical help for sexual issues reflects the fact that almost half (48.4%) stated that they were unlikely to go to a clinic regarding sexual matters.

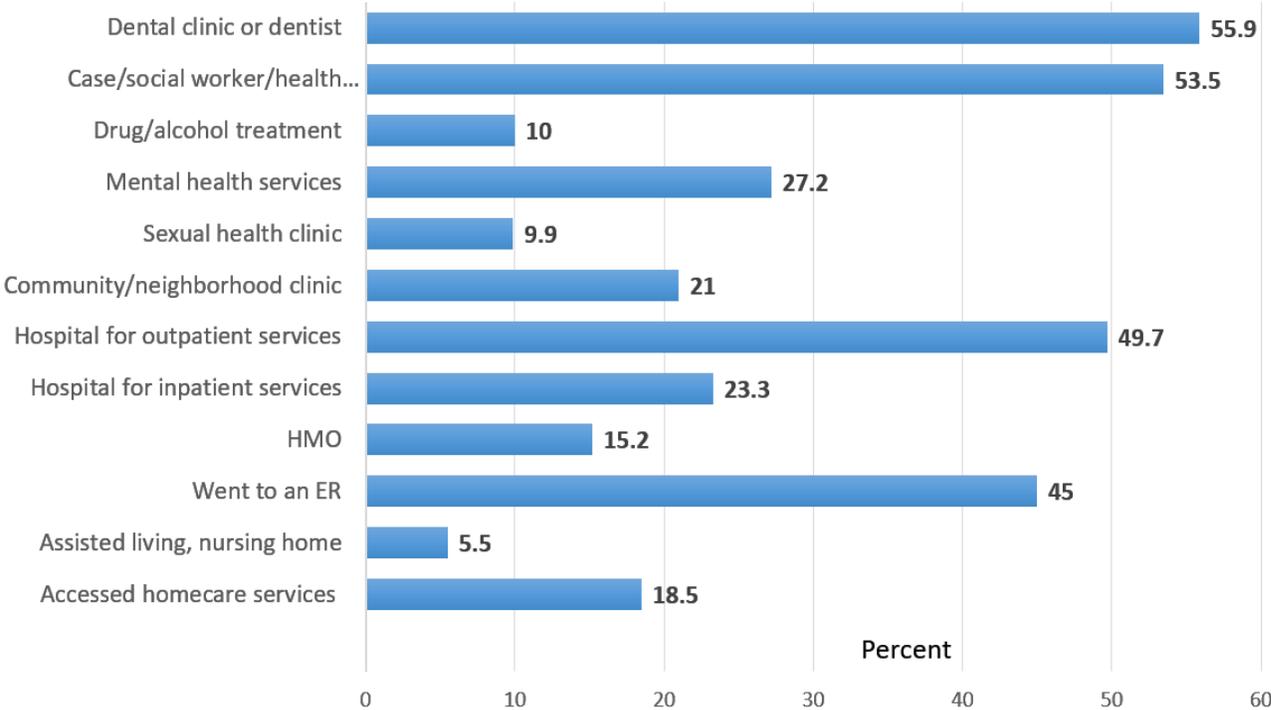
The impact of stigma can be seen in the disclosures made in the context of sexual activity. Over half (58.8%) thought that the other person may fear getting HIV from them, despite the majority (86.6%) having an undetectable viral load. This suggests that acceptance of the U=U campaign (Undetectable = Untransmittable) remains a health care challenge. Nearly half (44.3%) had disclosed their HIV status to all sexual partners with fewer having disclosed to family (37.8%) and even fewer reported having disclosed to all those they wished to (18.9%). This lack of openness and fear of disclosure is associated with increased stress levels that, when chronic, can result in multiple physiological (high blood pressure) and psychological (depression) complications [40, 50-52].

According to the screens, 35% exhibit symptoms of post-traumatic stress disorder (PTSD). Just over a third of those who screened for PTSD and 41% of those with moderate to very severe depression, reported receiving no mental health care in the last year. Most (51%) reported a history of being sexually assaulted before the age of 16 and 52% have been victims of domestic violence by a partner.

# Clinical Health Services Usage

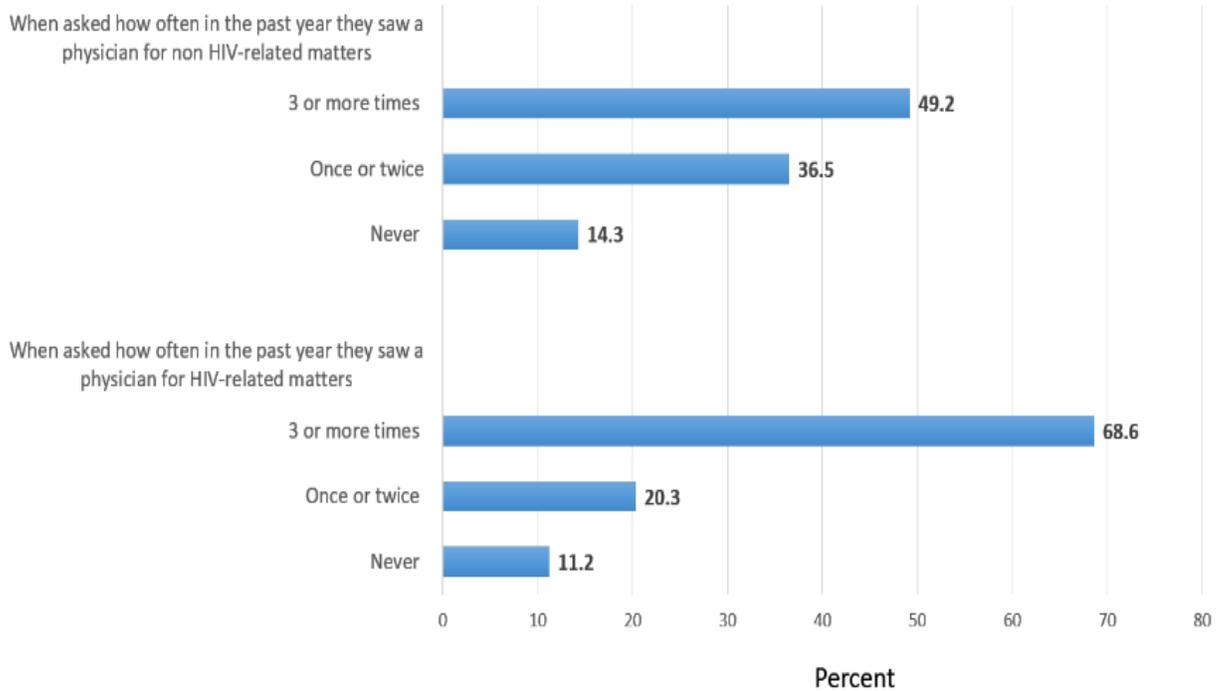
Maintaining physical health is a primary need that includes treatment and preventative services. Coordinating these services for older adults is central to achieving optimal health as they age [53-56]. Just over 56% of the sample utilized dentists with similar numbers accessing social workers (54%), hospital outpatient services (49.2%) and emergency rooms (44.6%).

**Utilization of Clinical Care: Oakland ROAH 2.0 Sample**



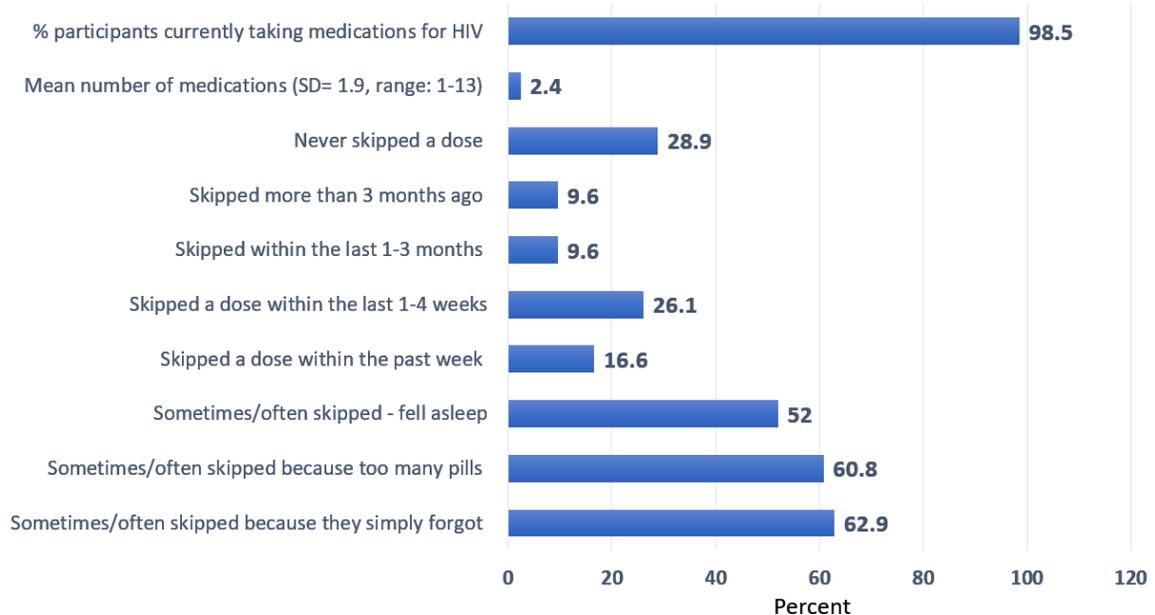
Mental Health services were accessed by 26.9% of the study sample. There was low utilization (9.9%) of substance use treatment. A similarly low (9.8%) utilization was seen for sexual health services. These numbers do not reflect whether the services were available and/or whether such services were offered by their health care policies, simply the uptake.

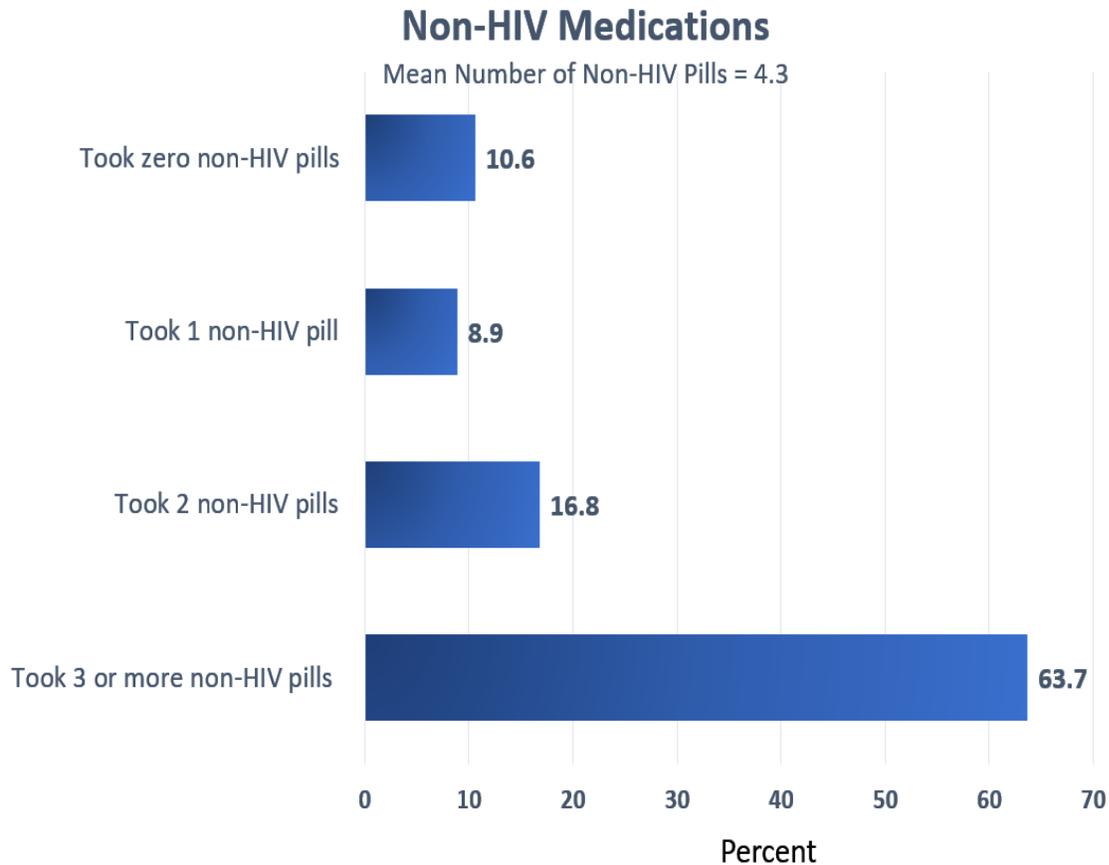
## Accessing Medical Care: HIV and Non-HIV



Nearly all of the sample population were taking medications for HIV (98.5%) with over a quarter (28.4%) indicating that they had never missed a dose. However, 52.6% had missed a

## HIV Medication Adherence

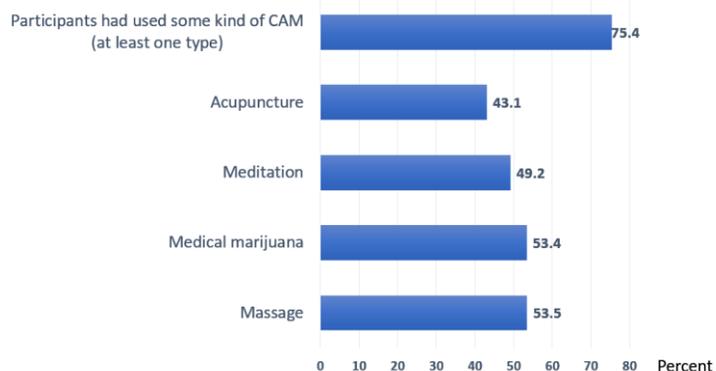




dose within the last 3 months and 9.5% in a period greater than 3 months ago. The majority of these were skipped because participants *'simply forgot'* (62.9%) closely followed by 60.8% skipping because they *'have too many pills'*. With the range of pills being between 1 and 13 (average 2.4), those with higher pill numbers were more likely to skip and therefore more likely to have greater health needs.

Over two-thirds of respondents (68.6%) saw a doctor three or more times in the past year for HIV related matters with only 11.1% stating that they had not seen a doctor for the same issues within the same 12-month period. Just over 14% said that they had not seen a doctor in the last 12 months for any non-HIV related matter and almost half (49.5%) reported they had seen a doctor 3 or more times in the past year for non-HIV related issues. This reflects many reports showing that PCPs are spending most of their time managing non-HIV related health issues [57, 58].

### USE OF CAM: Oakland ROAH 2.0 Sample



Almost three-quarters indicated that they had seen one or more practitioners of complementary and alternative medicines. The majority of these (53.4%) report using medical marijuana, mindfulness meditation (49.2%), acupuncture (43.1%) and massage (53.5%).

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## Future Directions

This study shows that access to mental health treatment is a significant problem for some older adults with HIV who live with serious mental health issues. Given the high rates of Post-Traumatic Stress Disorder (PTSD) and history of trauma, mental health providers should adopt trauma-informed therapeutic approaches. The data shows that participants evidence high rates of loneliness. This is accompanied by their need for opportunities to socialize. As many older adults with HIV in this study are challenged by high housing costs, the burden of food scarcity and hunger is also evident. Given the high levels of co-morbidity and polypharmacy in the study population, many would likely benefit from coordinated care guided by geriatric medicine's precepts. Expanding combined HIV/geriatric care programs and training HIV care providers in geriatric care principles, as well as geriatric care professionals with HIV education, may be worthy avenues for increasing access to this optimal health management approach.

## Appendix A: Focus Group

In order to investigate the experiences, challenges, strengths, and wants of older adults with HIV, multiple focus groups in the Bay Area were conducted focusing on these five sub-populations: 1) male gay and bisexual long-term survivors of HIV 2) African Americans 3) transgender persons 4) Asian/Pacific Islanders, and 5) Spanish-speaking Latinos. Findings from these focus groups informed adaptations to the Research on Older Adults with HIV (ROAH) 2.0 survey for the Bay Area and serve as an independent source of data about the older adults with HIV in the Bay Area. Almost 50 persons with HIV age 50 or over living in the Bay Area shared their perspectives on HIV and aging in November and December 2016.

### Key findings:

- Among the approaches that helped participants cope were embracing personal growth and a positive attitude, practicing self-care, viewing their lives through a religious or spiritual framework, taking on work or volunteer responsibilities that feel meaningful, and relying on social support.
- Challenges facing the participants included housing instability and poverty, loneliness and isolation, mental health problems and stress, and a range of physical co-morbidities.
- Participants requested more and different kinds of opportunities to socialize with other older adults with HIV and better access to mental health care.
- While a few participants felt confident that care would be available to them if they became sick or injured, many were uncertain and afraid of what would happen if they were no longer able to care for themselves. Several expressed reluctances or even dread at the prospect of relying on formal long-term care services.

### FACTORS FACILITATING POSITIVE AGING

**Wisdom and positive attitude:** Many participants described gaining judgment or perspective as they aged. Participants reported they had grown with the disease, found themselves, and discovered wisdom as they grew older. They shared that insight attained through hard experience helped them reject unhealthy behaviors (like drug use), embrace their own goals and dreams, discontinue pursuits they now regard as shallow and empty, and confront potentially threatening situations without fear.

For many of the participants, adopting a positive attitude was a key part of their personal development as they age. Maintaining optimism, cultivating self-esteem, and avoiding people with negative outlooks were often mentioned. An Asian/Pacific Islander group participant remarked:

*I try not to dwell on something that's a negative thing to, you know, make myself all frustrated or stressed out or things like that. I try to keep myself in a positive mood and I try to like to do for other people if I can, you know.*

**Self-care:** Eating well, exercising, avoiding illicit drug use, and taking medications as prescribed were described as important for maintaining health as one age. One participant argued:

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*Aging well is a job. It's not something that happens. You have to work out. You have to exercise; you have to eat right, keep at it.*

Having regular medical attention for HIV made some participants more aware of other medical conditions that might affect their health:

*I feel fortunate in a way to have been diagnosed with HIV because for the last, what, 35 years, some medical facility has been watching my health and I've been watching it also, you know, so I feel like I know a lot about my body.*

Religion/spirituality: Religion or spiritual practices were identified as a source of support by participants in three of the five groups (with the two exceptions being the long-term survivors and Asian/Pacific Islander groups). God was frequently described as a leader and a guiding light in participants' lives.

*I say to myself, '---, you are going to be alright, you are going to go forward, think positive and you [don't] focus on the negative.' But sometimes you get lost. You lose strength. You lose optimism. You lose faith. And faith is the last thing we have left. And without faith you cannot go on.*

Meaningful work or service: Participants described work, hobbies, and volunteerism as giving them a sense of meaning or purpose in life and thus contributing to their wellbeing. The activities participants described as providing them with meaning or motivation ranged from baking pies to running a business to caring for a terminally ill friend. One participant in the Spanish-language group said being a volunteer has been valuable because through that work, he “know[s] that [he] may be needed somehow by someone.”

Social support: Social support was more often described as inadequate, but a number of participants listed their social connections as something that facilitates aging in a positive way. Asked what makes aging with HIV easier, one African American group participant answered:

*Having strong support networks of people and friends that, that I can talk to about, you know, what I'm going through*

Several members singled out support groups and AIDS service organizations as positive forces.

*I have nine brothers, and no support from anyone. I am alone. I take it all myself, everything. The ASO is my family. I live here. I come and greet everyone. Sometimes when I am not due, I come and say, 'Hi,' and I go home happy.*

A long-term survivor group participant described his attendance at a town hall meeting organized by an advocacy organization for long-term survivors held two years ago as a revelatory experience:

*You're gonna laugh, but for me that was the first time I actually realized I'm not alone. There are a whole bunch of us out here and the stuff that we need, the stuff that we need to do for each other is new to us.*

## CHALLENGES AND UNMET NEEDS

Housing and other financial stressors: Participants in all five groups spoke repeatedly and adamantly about the difficulty of accessing or affording appropriate housing. They pointed out that adequate housing was a prerequisite for leading a healthy lifestyle and identified the tight housing market in

*San Francisco as a major stressor. Participants spoke about being forced to stay in living situations where they felt unsafe and disrespected and the difficulty of making long-term plans while living in a precarious housing situation. Inadequate income was discussed with regards to being able to afford essentials like food and housing. Participants highlighted the difficulty of living on Social Security payments or General Assistance. On the demographic survey distributed at the outset of the focus groups, 56% of respondents said they just managed to get by and 26% had not enough money. Less than a fifth of participants said money was not a problem or that they had a little extra.*

*Loneliness/isolation: Loneliness and isolation were mentioned with high frequency in the five focus groups, particularly amongst participants who were without partners or alienated from their families. Isolation was described as a paramount concern. One participant in the gay and bisexual men long-term survivor group remarked,*

*There are things that are worse than AIDS, like loneliness.*

*Similarly, a member of the transgender group said:*

*The most important thing is that it don't matter what lead up to it, it's that we need each other. We feed off each other.*

*Lack of family support contributed to isolation in several cases. Participants described being rejected by transphobic or homophobic relatives. Some gay and transgender participants also remarked on lacking children. A member of the long-term survivor's group said he missed having the support structure children can provide for older adults. A participant in the transgender group, observing that many of the group members had pets, argued that that if the group members were not transgender and straight they would have children instead of (or in addition to) animal companions, but being a trans woman in this society made parenthood unattainable.*

*Mental health and stress: Poor mental health was an often-cited challenge. Depression, post-traumatic stress disorder and substance use disorders were often mentioned as significant elements of participants' personal history. The mental health issues described were often severe. ("I guess I go into depression and I just lock myself into the room for months, probably years," one participant said.) A long history of living with HIV was described as a cause of psychological distress. For example, one member of the Asian/Pacific Islander group said:*

*Mental health is a significant issue because, you know, we've been living with this for so long. We've lived decades with this and it has ingrained itself into our system, into our brain. There is this kinda of a PTSD issue that's involved, you know.*

*Stress was another often-mentioned difficulty. It was described as a factor that accelerates aging and liable to "kill you quicker than HIV."*

*Comorbidities: Physical illness was also a frequent concern, though less often than mental health. Participants reported a spectrum of disorders, including cancers, neuropathy, edema, kidney stones, infections, and chronic pain. Others declared themselves in good health or that they felt their aging was on par with their HIV-negative friends. In two of the groups, several participants voiced the thought that HIV might make them more vulnerable to age-related disease:*

*My outside, my lab work, appears to be good, but I'm worried what's really going on in my inside.*

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*In the long-term survivors' group, some felt strongly that HIV "accelerates" aging:*

*I'm going to be 66 in January, early. I'm telling you, this is an 80-some-year-old body I'm walking around in, and all of those opportunistic infections that I've overcome have taken their toll, as does the [medications].*

#### DESIRED SERVICES/CHANGES

*Social support: Participants proposed more and different forms of social support for older adults with HIV. In the long-term survivors' group, participants were apparently aware of programs designed to provide social support, but some found them lacking. One participant spoke emphatically about yearning to be part of group involving less casual banter and more deep engagement. Another remarked that the negativity and constant complaining in existing groups for older adults with HIV was off-putting. A participant in the Asian/Pacific Islander group said he would like to see a group for older adults with HIV. Transgender group members described wanting less structured opportunities to socialize. One suggested a drop-in center for older adults with HIV, emphasizing that she wanted a place that was warm feeling and not rule bound where she could socialize casually with people like herself:*

*I don't have a problem with authority, but I've earned the right to know what I want and what I don't want, and I don't like for somebody to sit back and tell me, oh, you can't do something when I want to do something because I've earned that right to do what I want to do as long as it's not hurting anybody else. So, that's what I mean about having a place where it's not a counselor there and all that. No, I'm too old for all of that stuff. You know, go sit in a group. I've been there, done that, too old for that shit.*

#### MENTAL HEALTH CARE

*While a number of participants reported receiving satisfactory mental health care, needing and having difficulty accessing quality mental health services was a common complaint. A long-term survivor group participant described mental health services in the Bay Area as non-existent. A member of the Asian/Pacific Islander group described difficulty finding a therapist. While desire for mental health services was not universal, a member of the API group argued that members of the group might be unaware of their need for mental health treatment because they had never been screened for mental health issues.*

*A participant in the Spanish-language group recounted a hurtful encounter with a psychiatrist, who gave a glib, ageist explanation of the man's panicked feelings:*

*He said, 'Look: You are getting old and manic.'... I tell you that it left me feeling hopeless. Even now that I am telling you about it, I feel I want to cry. Because he left that wound when he told me, 'You're getting old and manic.'*

*A Spanish-speaking group participant who was generally happy with his mental health care said he wishes that there were mental health providers with specific training in the issues facing people aging with HIV.*

*Burial: Participants in the transgender and African American groups both expressed concern about how they would be buried. Lacking savings, life insurance, or family that could provide for a funeral and burial, some participants worried that their death would go un-memorialized.*

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*There should be some kind of way that you don't have to die unknown. You don't have to be found in your apartment. You can be able to be put away properly without the city taking care of you or burning you up.*

*What really hurts me is that I see a lot of these well to do lesbian and gays have their funerals and all this beauty and everything, and when it comes to us, we're thrown in the cremation bin and thrown at sea.*

## CAREGIVING

In the focus groups, time was allotted to discuss participants' anticipated needs for caregiving as they age. Many participants had little conception of what they would do should they become unable to care for themselves. A few participants felt they could rely on family or friends to care for them, and one participant was investigating long-term care insurance. Some said they would be very reluctant to accept help. A transgender group participant said:

*I have always been a very strong woman and I only... I don't ask for help even if I'm death ridden. I really would have to really, really, really be sick to ask for help because I'm very proud of who I am.*

The remaining participants who addressed this question were largely pessimistic about the options available to them. Two participants described being so fearful of old age and dependency that they preferred suicide to the available options. In-home care was considered desirable by some, but several participants felt leery of allowing a non-relative into their homes.

The long-term survivors group discussed the appeal of living with other older people, particularly others who are HIV positive and LGBT, and their fear of being isolated or forced to hide their identity if they have to live in a mainstream long-term care facility that is not sensitive to their needs.

*I'm seeing people, you know, older than myself, gay people, who are essentially returning to the closet because they don't want to be differentiated. They don't want to be distinguished as HIV [positive] or gay because they will suffer discrimination at the hands of some of these care providers. I don't want that. I want to be in a gay-friendly environment. I want to be among people of my own kind, my peers, my social comparable [sic], and I don't think I'm going to find that in a skilled nursing facility or out in the larger community.*

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## Appendix B: Methodology

ROAH 2.0 Alameda/Oakland is a mixed-methods research project including focus group participants and 198 survey participants. Inclusion criteria included being age 50 or over on the date of participation, having been diagnosed with HIV, and living or receiving services in Alameda. The study protocol and materials were approved by Alameda Health System and GMHC's Institutional Review Boards.

The ROAH 2.0 survey, crafted by the ACRIA research team and the ROAH Research Advisory Committee (see Appendix C), a team of experts on HIV and aging, was tailored to the concerns of the study population.

The next phase of the study was administration of the survey to a planned sample of 200 older adults with HIV. Participants were recruited through clinics, social service agencies, and AIDS service organizations, who posted fliers at their facilities and in some cases personally reached out to eligible individuals. (See the acknowledgements section of this report for a list of recruitment venues.) Prospective participants were invited to call a member of the research staff, who gave them a basic explanation of the study protocol and screened them for eligibility. All participants provided written informed consent and received a \$40 gift card as an incentive. Participant identity, place of residence, and age was verified by checking photo identification. Survey data collection continued through June 2019.

Survey data was entered into Qualtrics, a secure online platform for data capture, and each entry was checked for accuracy against the hardcopy survey. Survey responses were analyzed using Stata 13. Mean imputation was used for computation of scores for the Sowell Stigma Scale, PHQ9, PTSD Check List, and Ryff's Scales of Psychological Well-being. ROAH 2.0 participants' scores on the Ryff sub-scale were compared with the scores from a national sample of 1,108 community-based adults with an average age of 46. The national study used scores based on 3-item, rather than 6-item, versions of the Ryff Scales, so data reported from each sample was standardized to the same metric before analysis. Data visualization was rendered in Microsoft Excel and Tableau.

There are several limitations to this research. Convenience sampling methods were used to recruit participants. Recruitment occurred primarily through community-based organizations serving clients living with HIV, limiting generalizability to older adults with HIV in the county not connected to treatment or services: The ROAH 2.0 sample may be better connected to care or in higher need of services. Data was self-reported. Self-reported health conditions were not verified with clinical data. The survey contained several questions on sensitive topics such as substance use and trauma. To limit underreporting the survey was self-administered. Finally, the cross-sectional nature of the study limits analysis as causality cannot be inferred.

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## Appendix C: Research Advisory Council

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