
Getting to Zero Initiative

HIV and Aging
Needs Assessment Report
2022



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Introduction

In May 2022, the Santa Clara County Getting to Zero (SCCGTZ) Initiative was awarded a competitive grant by the California Department of Public Health (CDPH) to launch its first-ever HIV & Aging program. Given that people aging with HIV were identified as a priority population with a current unmet as shown by local epidemiologic data, this program will serve individuals living with HIV (PLWH) who are age 50 and older (50+) and who live or work in Santa Clara County (SCC).¹ In recent decades, the many past successes related to HIV prevention, care, and biotechnology included expansion of available treatment options, rapid initiation of antiretroviral processes (Rapid ART) and case management. These successes contributed to an overall decrease in HIV incidence as well as a shift in the average age of PLWH in SCC.¹ Specifically, while most *new* HIV diagnoses are generally observed to occur within the 24-44 age group, a majority of *existing* PLWH are within the 45-64 age group.¹ This aligns with the plethora of existing literature that confirms the significant and positive role of nationally recommended HIV treatment and care strategy implementation in improving the quality and length of life for PLWH. These shifts in the average age of PLWH in SCC are also especially important to note as they demonstrate a greater need to reduce the percentage of people who receive a late diagnoses, many times due to delayed linkage to care, which within SCC are highest among those who are 40 years of age or older.¹ Finally, national projections indicate that the percentage of PLWH50+ will increase from 50% in 2015 to 70% in 2030.² These projections are expected to align at the local-level given the HIV prevalence in SCC.¹ Thus, there is a need to ensure that the aging population living with HIV in SCC has access to appropriate and tailored resources and services to manage their holistic health and well-being.

Research suggests that people aging with HIV may experience unique health needs as a result of chronic HIV-related infections that require medical treatment.³ Aging with HIV is characterized by multimorbidity and polypharmacy, which is strongly influenced by chronic infection with HIV.⁴ Due to the chronic exposure to antiretroviral therapy (ART), medical experts especially consider patient mental health, geriatric syndromes, and physical activity to avoid the adverse effects associated with ART.⁵ This is especially true for people who had exposure to the early ART medications which were harsher on the body and could have amplified impacts among longer term survivors of HIV.⁶ Further, there are social factors that can influence the quality of life among this population - such as age-related stigma, isolation, loneliness, and lack of social support - all of which can prevent older adults from seeking or staying in care.

HIV & Aging Program Overview

The HIV & Aging program aims to address clinical and non-clinical care gaps for PLWH50+ in SCC which include, but are not limited to, routine clinical assessments and follow-up, expansion of referral systems for geriatric medicine and specialty providers, and linkage to community resources through case management. The program will also focus on building SCC provider

knowledge and skill capacity to provide care to PLWH50+ through trainings that address the conditions of aging. The program will serve anyone who meets eligibility criteria while ensuring prioritization of those who have fallen out of or have never been in care. Please see Appendix A for a Logic Model which outlines our program activities and projected short, medium and long-term outcomes in detail.

Needs Assessment Aims

The purpose of this needs assessment was to understand the perspectives and experiences of PLWH50+, specifically with regard to accessing clinical and non-clinical services in SCC and any barriers or facilitators in doing the same. To ensure resource alignment with community needs, the results directly informed HIV & Aging program development and implementation in SCC.

Methods

Design

This was a qualitative needs assessment conducted using semi-structured, key informant interviews between September and November 2022. In this report, we share and interpret our findings in the context of existing literature and recent local needs assessments that were conducted among PLWH50+ in SCC. Specifically, the SCCGTZ team referenced results from a recent Ryan White quantitative needs assessment (see Appendix B) administered between June – September 2022 among 80 Ryan White clients aged 50+ to identify areas for program alignment and mutual collaboration.

The Ryan White program also provides clinical and non-clinical services, and eligibility entails having an HIV or AIDS diagnosis, living in SCC, and meeting specific financial requirements – the program is the payor of last resort for those who do not qualify for health insurance. Given the significant overlap in participants across both needs assessments, we reviewed and discussed relevant results from the Ryan White assessment regarding the same clinical and non-clinical services provided by the HIV & Aging program in SCC.

This assessment was exempt from Institutional Review Board (IRB) review. All participants reviewed and signed an informed consent form prior to participating.

Participant Eligibility and Recruitment

All PLWH50+ who are living or working in SCC were eligible to participate in the needs assessment. This eligibility criteria were aligned with HIV & Aging program eligibility to ensure participant representation from communities that would ultimately be served through this program. We used a convenience and snowball sampling approach to recruit participants through flyers, telephone calls, email announcements, program newsletter advertisements, and word-of-mouth.

Data Collection

Instrument

The semi-structured interview guide was informed by CDPH grant requirements and an exploratory literature review pertaining to the clinical and non-clinical needs of PLWH50+. The interview guide included open and closed-ended demographic questions, such as age, gender identity, sexual orientation, and highest level of educational attainment. It also included open-ended questions that addressed the aims of this needs assessment. These questions asked about participant life experiences and their perception of their (1) length of life; (2) biological health; (3) mental health; (4) cognitive effectiveness; (5) social competence; (6) productivity; (7) personal control; and (8) life satisfaction. The questions also asked specifically about participant experiences, including any barriers and facilitators to accessing clinical and non-clinical services, such as HIV treatment and care, case management, dental, hearing and vision, and support services. The interview guide contained a total of 16 questions which included 10 demographic questions and sub-questions for probing.

The key informant interviews were conducted between September and November 2022 virtually via Zoom software technology. While participants had the option to select between in-person or virtual format for their interview, all opted to participate virtually. The interview times ranged between 45 and 60 minutes in duration and were audio-recorded. The SCCGTZ team conducted interviews until saturation was reached.

Data Analysis

Completed interviews were first transcribed verbatim and de-identified by the SCCGTZ team. Team members then reviewed and coded the transcripts for themes independently and then compared them to ensure inter-rater reliability. The transcripts were then thoroughly reviewed in Microsoft Word and coded to identify emerging themes. We used a deductive approach for coding which consisted of highlighting sections, phrases or sentences that described the overall content of each response. Themes were derived by grouping similar codes together into categories that aligned with the semi-structured interview guide.

Results

Participant Characteristics

A total of 12 participants were included in this needs assessment. The average age was 61 years old, and the age range was between 50-71 years of age. Most participants were male (58%), and two-thirds (67%) identified as gay. One fourth (25%) identified their race as White and one fourth (25%) of the participants identified their ethnicity as Hispanic or Latinx – the race and ethnicity categories were mutually exclusive. When asked about their highest level of education, 33% had a bachelor's degree and 25% had equal to a high school degree. Half (50%) of the participants were employed at the time of this needs assessment, 75% were single and 67% were currently enrolled in the Ryan White program. See Table 1 below for a detailed

breakdown of participant characteristics. These data are aligned with the overall population of PLWH50+ in SCC where all (100%) individuals are within the 50-79 age range, and most are male (69%), White (44%) and Hispanic/Latino (31%).¹

Variable		Responses n=12
Age (in years)	Average	61
	Min	50
	Max	71
Gender Identity	Male	58.3%
	Female	16.7%
	Transgender	25%
Sexual Orientation	Gay	66.7%
	Heterosexual	16.7%
	Bisexual	8.3%
	Something else	8.3%
Race/ Ethnicity	White	50%
	Hispanic/Latinx	25%
	Black or African American	25%
Highest Level of Education	≤ High school degree	25%
	Associate degree	8.3%
	Some college	25%
	Bachelor's degree	33.3%
	Master's degree	8.3%
Currently Employed	No	50%
	Yes	50%
Marital Status	Single	75%
	Divorced	16.7%
	Domestic Partnership	8.3%
Current Ryan White Client	Yes	66.7%
	No	25%
	Unsure	8.3%

Table 1. Participant Characteristics from the GTZ HIV & Aging Needs Assessment.

Emerging Themes and Subthemes

Our results included three emerging themes – perceptions of aging, access to services, and perceived gaps and barriers – with subthemes described within the sections below.

Perceptions of Aging

Within this first theme, perceptions of aging, participants shared their reflection on their life experiences from the perspectives of length of life, biological life, mental health, cognitive effectiveness, social competence, productivity, personal control, and life satisfaction. A subtheme included feelings of isolation in the realm of mental health and social competence.

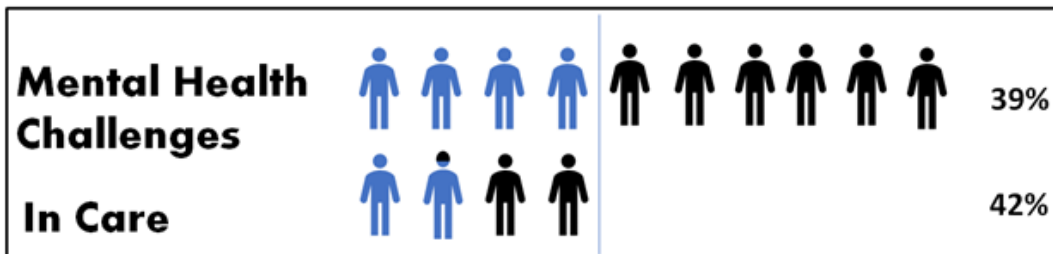
Below are the perspectives of two participants who shared how living with HIV/AIDs, the COVID-19 pandemic, and aging impacted their mental health.

“It’s already super isolating being a senior anyway... I try to stay close to my support groups which the county provides and belong to two or 3 of them and just try to stay connected with people that are dealing with that I’m dealing with. COVID adds more loneliness and isolation.”

“It’s a lonely place, even more so since covid. Its taking a toll on my health. I’m isolated, even if no disease involved, seniors are forgotten about. Very isolated, very lonely, very sad, even more so because of covid.... After 40 years of tv that show that if you’ve been on your medication, you can’t transmit HIV, people still stigmatize, and it seems like HIV is being pushed to the side so it’s pretty isolating.”

This finding is echoed by the recent Ryan White needs assessment which found that 39% of participants reported experiencing one or more mental health challenges including anxiety (23%), depression (23%), and isolation (13%), and an additional 7% reported that they are unsure if they have mental health challenges. More than half (58%) of participants who reported mental health challenges had never received care for their conditions (Figure 1).

Figure 1. Mental Health challenges and engagement in care among participants of the RW Needs Assessment (Appendix B).



Access to Services

Within this second theme, access to services, participants shared their experiences accessing services in SCC. These services included PrEP/PEP, STI/HIV testing, HIV treatment and care, case management, linkage to care, telehealth, mental health care, dental hearing or vision and support services. Subthemes included long wait times for HIV treatment and care and out of office referrals for several services. Most participants had trouble reaching their case managers and recommended extensive and up-to-date case management trainings as a result.

Below are the perspectives of two participants who voiced their experiences with case managers.

“Awful, [retracted] is off their game and have had problems with their managing of health care... they don’t try to go outside the box which creates a brick wall. For instance, needed hearing aids, but [retracted] said we don't provide that. Also needs

glasses and [retracted] said they don't do that. Routine case management is very poor. They are the providers of last resort. Takes months to receive what's needed."

"Non-existent, have a case manager I've never met him, through the [retracted]. They are probably one of the poorest excuses I've ever seen for such an organization. My case manager I haven't spoken to him once. I've never met him in person I have no idea what he looks like. I'd research about resources I needed myself. Once left a message for caseworker and it was 3 weeks before they returned the call."

These findings were also supported by the Ryan White needs assessment where case management is a standard service for all Ryan White clients. Clients may have a non-medical case manager, a medical case manager, or both depending on their needs. However, just 44% of those surveyed reported accessing non-medical case management in the prior year and 40% reported accessing medical case management. When asked about challenges accessing services, one participant reported challenges accessing medical case management noting that staff treatment did not meet their expectations.

Perceived Gaps and Barriers

The third emerging theme is participant perceived gaps and barriers in accessing services in SCC. Subthemes include limited vision and specialty services and food basket quality.

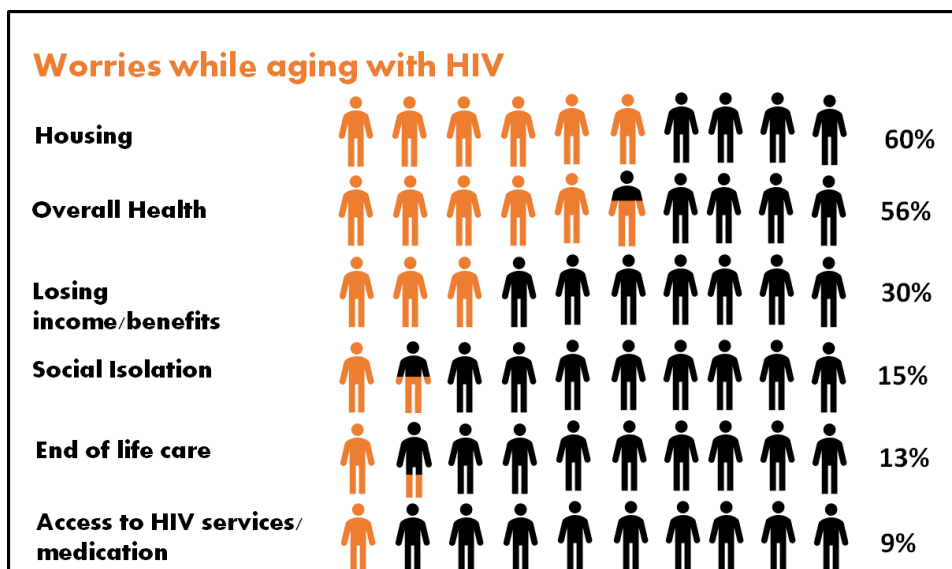
Below are the perspectives of participants who shared their experiences with the food basket and accessing specialty services.

"I've been complaining about the food basket for two years now ever since we started the COVID thing ...and I don't know if you know but people with HIV shouldn't need anything I'll be it's not good for anybody but it's even worse for us ...they really need to tighten up on the food and provide us with better quality and not stuff that's dying on the vine"

"Can't just see your doctor tomorrow, there's a huge wait. Huge wait at [retracted] it can be 12, 14 hrs. It would take 4 months to get booked to see doctor. Rarely receive neurological assessments as routine primary care every now and then receive mental health questionnaire. Routine STI tests because I request it."

These findings were further illuminated by the Ryan White needs assessment where several participants provided feedback about food services. Ryan White clients with unmet food needs have access to a food basket that provides grocery pick up twice a month. Improvement recommendations included having more variety in food options (n=2), offering pre-prepared meals that can be reheated (n=1), having consistent food pickup on assigned days (n=1), offering clients the option of independently picking out their food (n=2), inclusion of more meat in the food basket (n=1), and offering a care package when picking up food (n=1). Over half of Ryan White participants also indicated that housing (60%, 33/55) and losing income and benefits (30%; 17/55) were their greatest concerns (Figure 2).

Figure 2. *Greatest worries while aging with HIV among participants of the RW Needs Assessment (Appendix B)*



Discussion and Recommendations

While the findings presented in this report highlight several opportunities to strengthen mental health, social support and case management services in SCC through the HIV & Aging program, it is important to also acknowledge the positive experiences reported by our participants. Understanding these positive experiences will enable SCCGTZ to identify current efforts that are working well and sustain them, such as the availability and accessibility of clinical services including STI/HIV testing, linkage to care, HIV treatment and care and dental services. The recent uptick of telehealth services has provided patients with an alternative format to connect with their health care provider and receive care, most participants preferred in-person clinic or hospital visits when seeking care. This section will first discuss the aforementioned areas of opportunity followed by participant positive experiences to inform our recommendations.

Increasing Need for Geriatric Mental Health Services and Social Support

Our findings have important implications for the current mental health challenges faced by PLWH50+. In learning from the experiences and perspectives of SCC community members, we found that PLWH50+ often experience feelings of social isolation and loneliness and that these experiences of isolation have been exasperated by the COVID-19 pandemic. Furthermore, the stigmatization of HIV serves as an additional barrier faced by this community in fostering social support networks. The need for greater mental health services is also supported by an evaluation of the Golden Compass Program, a comprehensive program for older adults living with HIV in San Francisco, which also found a greater need for mental health services among their participants.⁷ Social support groups have been cited as a potential solution to combatting

feelings of isolation in the aging population.⁸ Creating group activities for this community can serve as a potential source of social support for older adults living with isolation. A systematic review conducted on social aspects related to older adults living with HIV found that fostering social support networks can help foster resilience in the HIV and aging community.⁹

Specialized Case Management for Aging PLWH

Undesirable experiences with case management were strongly voiced among our participants. Case management is a crucial aspect of addressing the unique and multifactorial needs of the aging population. A study analyzing the service delivery systems of the Older Americans' Act and the Ryan White CARE Act found that an increased emphasis must be placed on adequate training of professionals linking patients to social services such as social work and case managers to help educate these professionals on issues such as ageism and to also train them to serve as advocates for the communities they are serving.¹⁰ Comprehensive case management has also been shown to have a profound impact on improving health outcomes for geriatric patients. In a randomized control trial, it was found that elderly patients who received comprehensive case management had an improved mental and physical function.¹¹

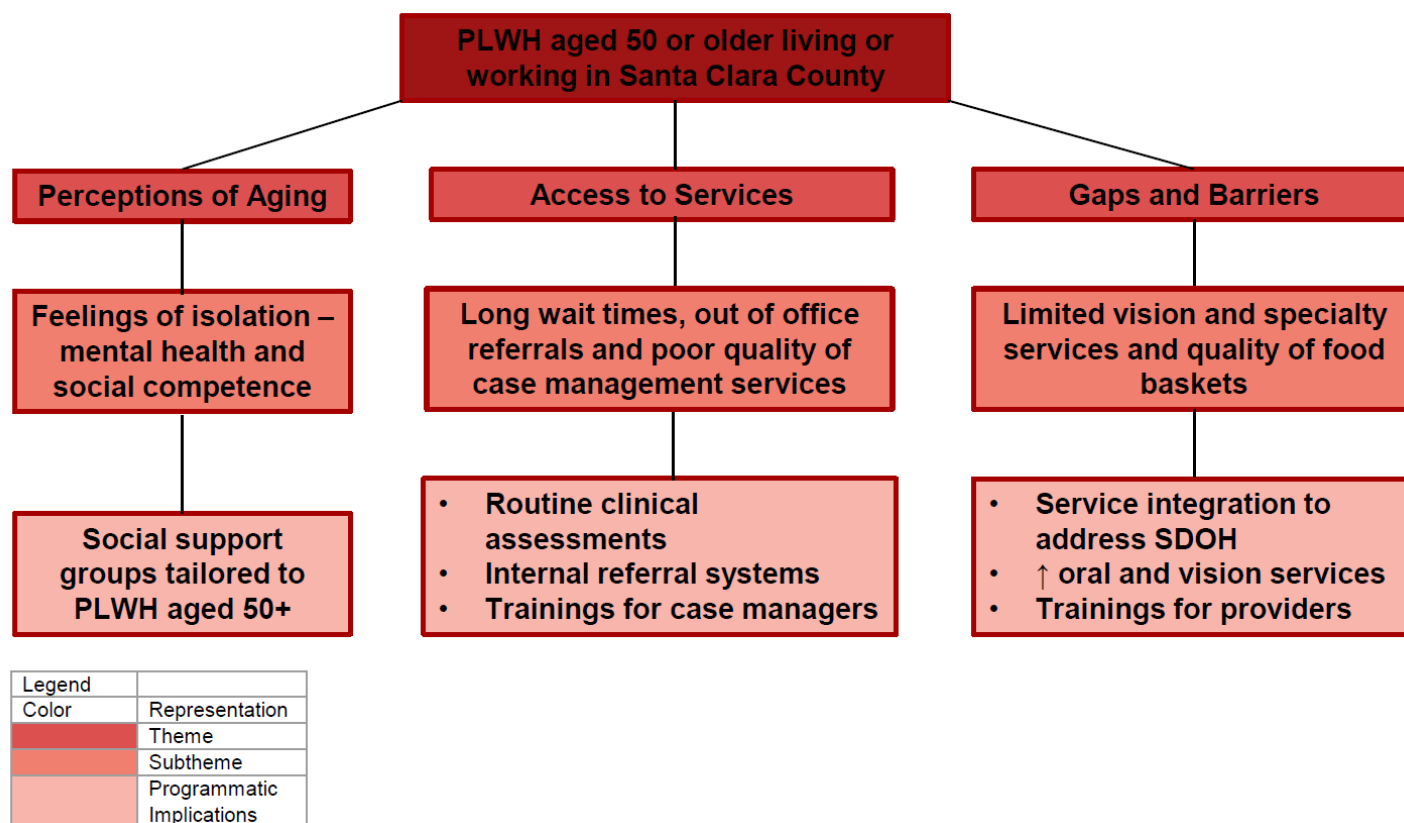
Integration and Prioritization of Health Services for the Aging PLWH

Integration of services including addressing social determinants of health such as access to food and housing was also a need voiced by participants. Providing comprehensive care and integrating geriatric and HIV networks of service was offered as a key system levels recommendation in building a care model for aging PLWH.¹² We recommend regular evaluation for psychosocial factors that can impact health during regular geriatric screenings which can also be modified to cater to the unique health needs of aging PLWH.¹³

Programmatic Implications

The population of aging PLWH is steadily rising and current HIV care models should align to better address the biopsychosocial needs of this population. Key programmatic implications from our assessment included the expansion of clinical services for aging PLWH such as increasing access to oral and vision services. Furthermore, health care systems can be educated to better address the needs of PLWH. Some examples include provider trainings and modifications of routine geriatric screenings for aging PLWH. Similarly, non-clinical services can be expanded and modified to address unique psychosocial barriers through creation of social support groups to address feelings of isolation and loneliness. Furthermore, case management services can be improved to include trainings for case managers to facilitate linkage to services in non-stigmatized and approachable manner. The emerging themes and programmatic implications are further depicted in Figure 3 below.

Figure 3. Depiction of the HIV and Aging Needs Assessment themes that emerged and the programmatic recommendations from each.



Participant Positive Experiences

Participants volunteered positive feedback about their overall life experiences and services within SCC. This feedback will further encourage our program to sustain those activities and services which have been well-received by our community.

“I’m so satisfied its amazing, I didn’t expect to live this long period. here I am. [retracted] years old and strong.”

“I have no problem accessing it, I’ve had the same doctor for 30 years more than 30 years so I have no problem accessing HIV care [...]. I see my HIV doctor twice a year right now, and that pretty much directed by the fact that I had to have my reports done every 6months for Ryan White, qualifications for ADAP. my meds are refilled every month, I see my doctor ever 6 months, and I schedule my next appointment when I finish my appt so I always leave with the next appt scheduled [...].”

“Had phone and zoom appts with doctor and it’s fine. Like to go in person so that you can ask questions and its harder for them to escape.”

“Everything being online is convenient, pretty much everything is set up through online system, so modern technology.”

“Dental- [retracted], have fabulous dentist, pay 5 dollars to see dentist and get all sorts of stuff including implants. goes twice a year.”

Strengths

We identify several strengths of our assessment. First, our participants included a diverse group of community members who would be eligible for the HIV & Aging program once launched. Second, our qualitative design for gathering data was rich and allowed us to gain an understanding of how community members perceive the services being provided to them and where there may be gaps in service delivery from our program. This provided substantial context to recent quantitative self-report survey data that was collected by the Ryan White program, especially since a majority of our participants were enrolled in the Ryan White program. Third, our findings are practical and can be utilized to launch, enhance and expand the aging services provided by SCCGTZ to better address the needs of aging PLWH. Finally, this needs assessment report serves as a baseline to compare future assessments for a greater understanding of the impact of the HIV & Aging program overall.

Limitations

We acknowledge the fact that a majority of our participants were Ryan White participants and may have participated in the Ryan White needs assessment. The alignment seen between both assessment reports could be attributed to this fact. Given this, our results may lack perspectives from individuals who receive services elsewhere. However, this presents an opportunity to conduct more robust and mixed-methods needs assessments in the future to ensure representation of people enrolled in the HIV & Aging program who may also be receiving services from a variety of locations in SCC, including but not limited to, Ryan White providers.

Conclusion

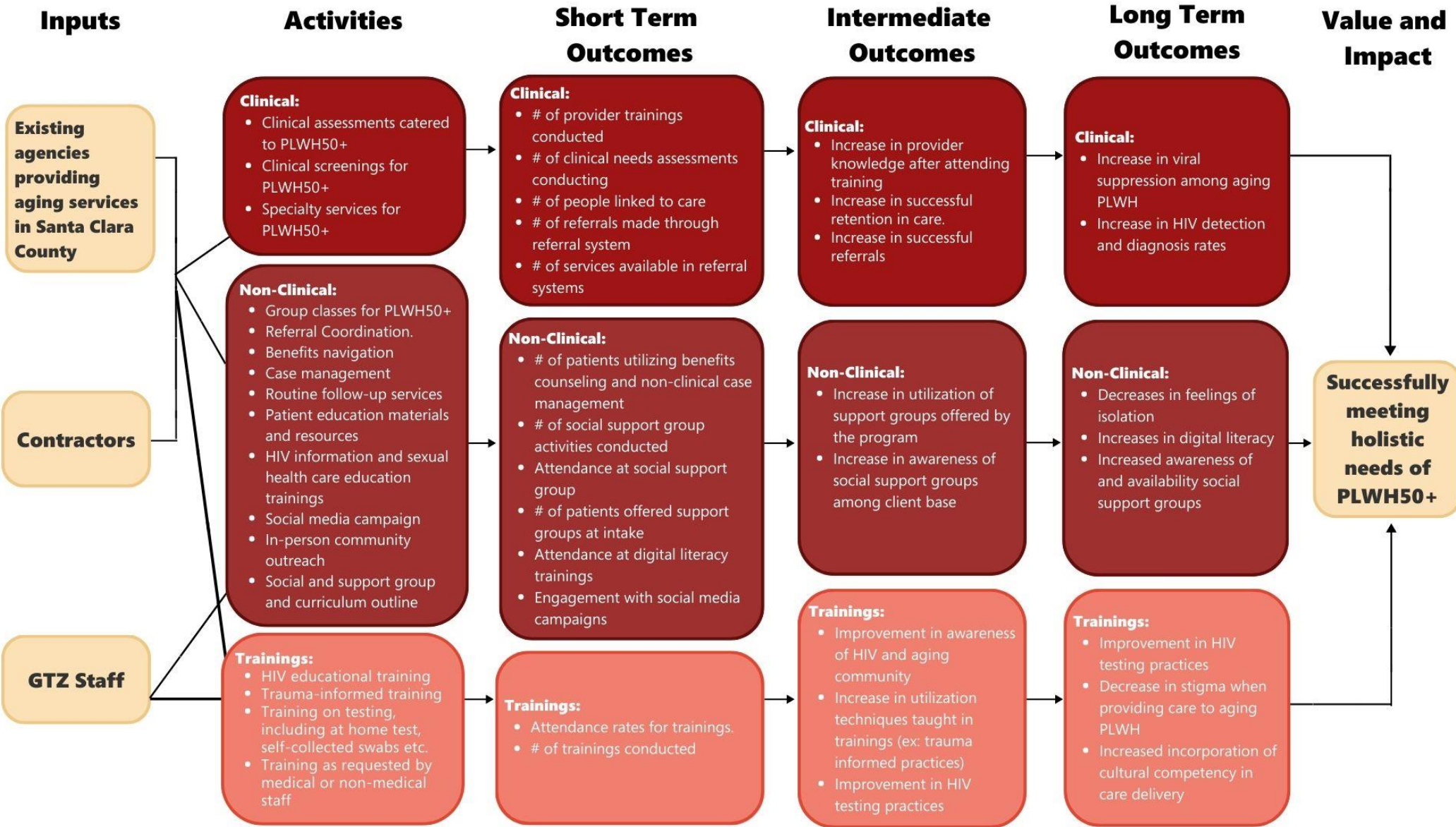
Results from this assessment highlighted key priority areas for the HIV & Aging program to further support PLWH50+. The Santa Clara County Getting to Zero Initiative is recommended to utilize these results and recommendations for HIV & Aging program development, implementation and future evaluations.

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Appendix A – Program Logic Model



Appendix B – Ryan White Needs Assessment Methods and Participant Characteristics

Ryan White Needs Assessment Aims:

This was a targeted needs assessment aimed to assess the experience of aging PLWH50+ who received RW services in Santa Clara County in terms of utilization of and engagement with care, satisfaction with care, appropriateness of care, access to care and unmet needs.

Design

This was a quantitative cross-sectional survey conducted among RW clients aged 50 and older. Active RW clients who were 50 years of age or older during 2022 were included in the assessment. The survey tool was developed based on a literature review of needs assessment for RW clients and the specific health care and support needs of aging PLWH. The tool was reviewed by the HIV Commission Care Committee and RW subrecipients for completeness and appropriateness.

Data collection and sampling:

The structured survey was programmed in Qualtrics and administered by a RW subrecipient to eligible clients who receive case management and food services from the RW program. RW Clients 50+ were invited to participate in the survey at their different touchpoints and interactions with THT whether by phone, in person visits, food pickups and home visits. All surveys were anonymous.

Client eligibility in the survey was determined ahead of time when possible. The surveys were administered through tablets (provided by the HIV commission on loan). In addition, clients were provided the link to the survey which they could fill on their own mobile devices or desktops at home. The survey was available in both English and Spanish.

For clients with literacy or sight limitations, staff at the subrecipient’s office offered to read the survey aloud and fill in the client’s responses on the tablet. Target sample size was 80 respondents. Data collection went from June 6 to September 16, 2022. In total, 61 clients were surveyed.

Participant Characteristics

Variable		N	(%)
Gender Identity	Male	45	76 %
	Female	14	22 %
	Other	1	2 %
Age	50-59	27	47 %
	60-69	24	41 %
	70-79	7	12 %
Ethnicity	Hispanic/Latinx	26	46 %

	Non-Hispanic/Latinx	28	49 %
	Decline to Answer	3	5 %
Race	Caucasian/White	30	51 %
	African American/Black	11	19 %
	Asian/Pacific Islander	4	7 %
	Native American or Alaskan Native	3	5 %
	Other	7	12 %
	Decline to Answer	4	7 %
Sexual	Heterosexual	26	44 %
Orientation	Gay	25	42 %
	Bisexual	5	8 %
	Decline to Answer	3	5 %
Housing Status	Stable Housing	38	68 %
	Temporary Housing	8	14 %
	Unstably Housed (Homeless)	7	13 %
	Other	3	5 %

