

Community Outreach & Listening Activities 2022

LONG TERM SURVIVORS

Thank you to Collaborating Partners

- Long Term Survivors Group
 - May 26th, 2022
 - Derrick Mapp, Council Member/ HIV Program
 - Facilitated by Kira Perez, Melina Clark, and David Jordan
- Community Engagement Committee

COLA: Limitations

- Small sample size
 - 8 participants
- Participants may not be representative of the demographics of this target population
- COVID-19
- This report gathers information about specific groups, thus data gathered is meant to provide context for the in-depth discussions/ interviews.

Overview

Mission Statement:

It is the responsibility of the COLA (Community Outreach and Listening Activities) Team to proactively gather and disseminate relevant information to and from people living with HIV and at highest risk for HIV.

- The Community Engagement Committee determines target populations for Community Outreach & Listening Activities (COLA) focus groups.
- Post merge the council has endeavored to expand COLAs to include Prevention concerns
- The purpose of COLAs are to:
 - Disseminate information about the HCPC and the HIV Consumer Advocacy Project
 - Conduct outreach to consumers of services as potential Council members
 - Provide small scale needs assessments that focus on the San Francisco EMA system of care, in particular:
 - To collect information regarding Service Prioritization from consumer of services.
 - To collect information regarding unmet needs and barriers to care
 - To solicit input and obtain feedback on the overall service needs of HIV+ individuals and communities

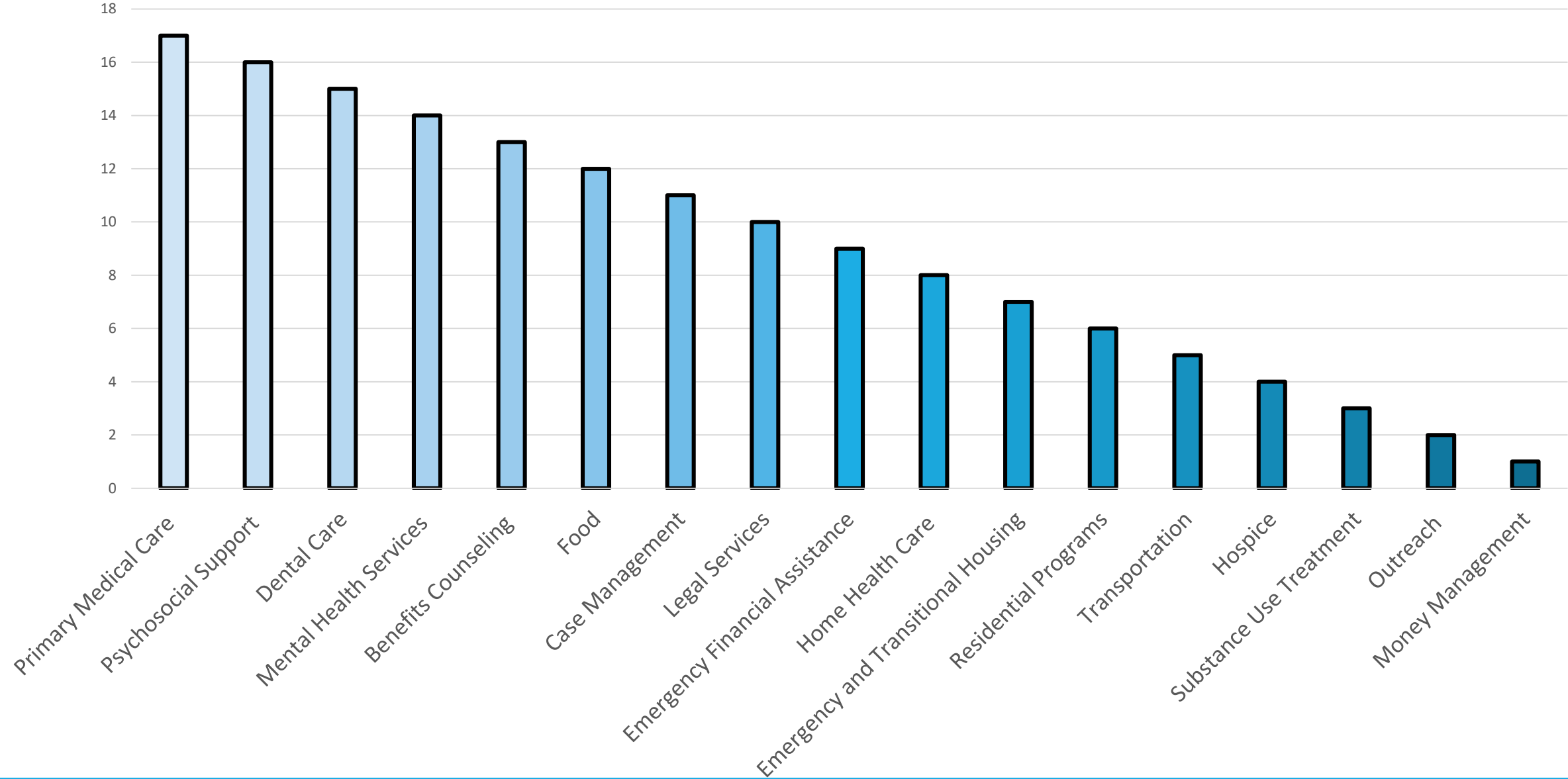
2022 COLA Results

LONG TERM SURVIVORS

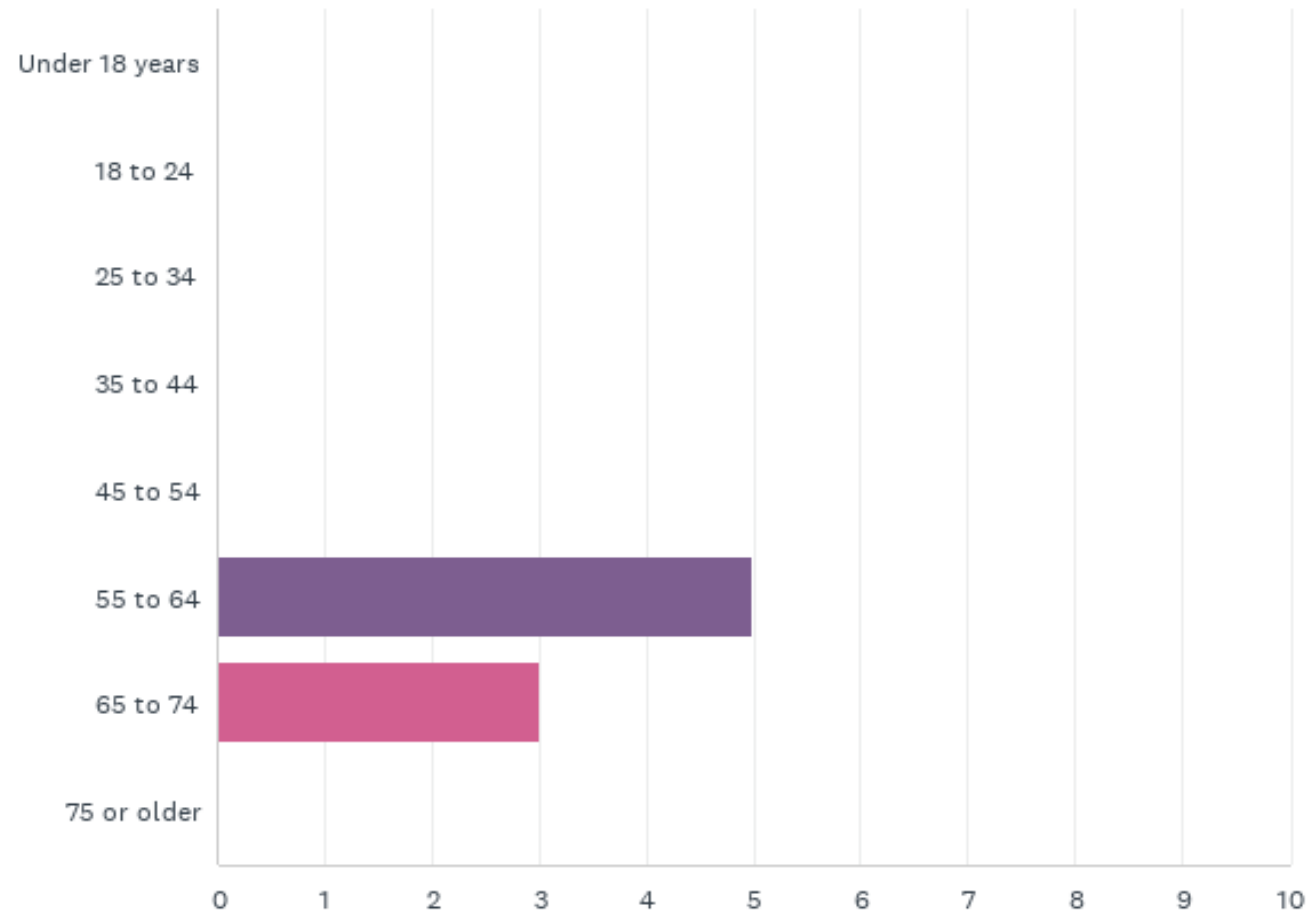
Category Ranking Results

Prioritization Exercise
Primary Medical Care
Psychosocial Support
Dental Care
Mental Health Services
Benefits Counseling
Food
Case Management
Legal Services
Emergency Financial Assistance
Home Health Care
Emergency and Transitional Housing
Residential Programs
Transportation
Hospice
Substance Use Treatment
Outreach
Money Management

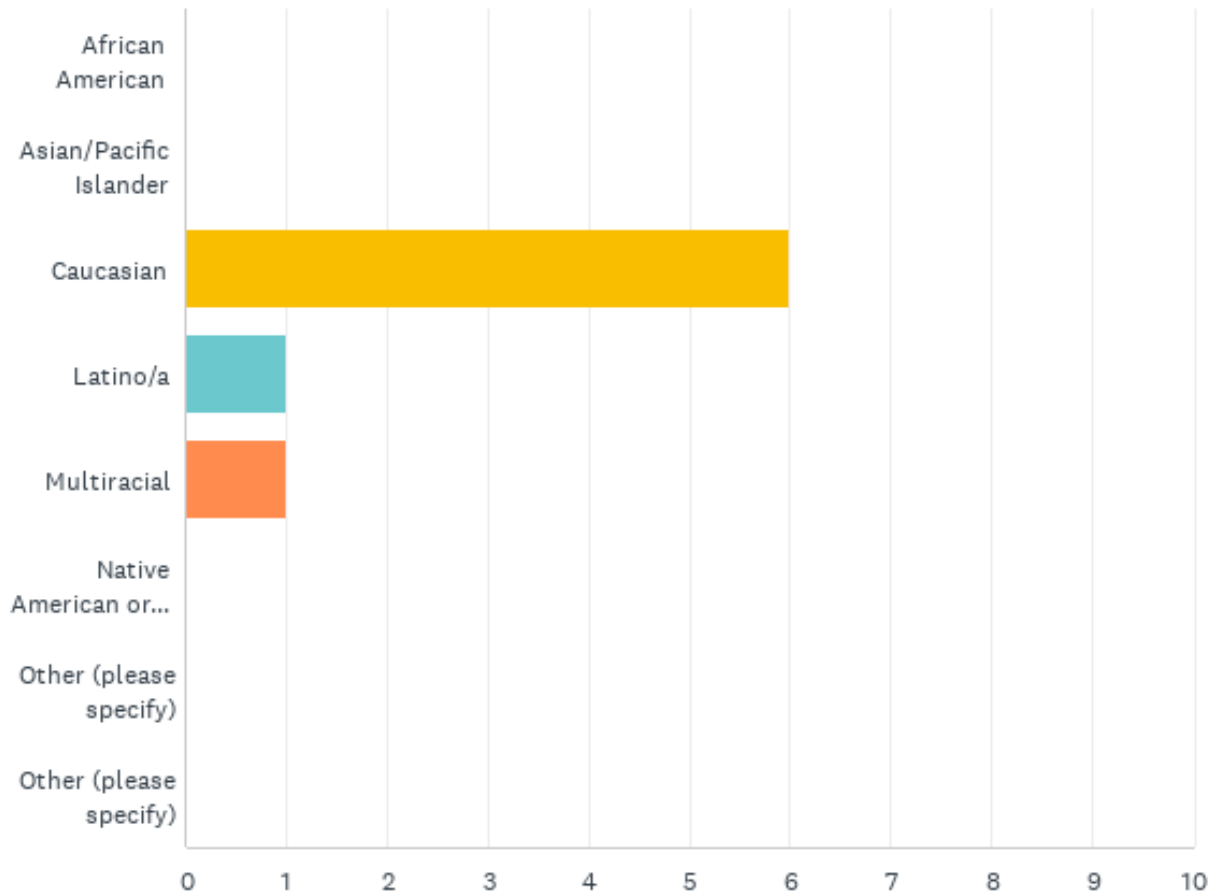
Service Category Ranking:
Long Term Survivors



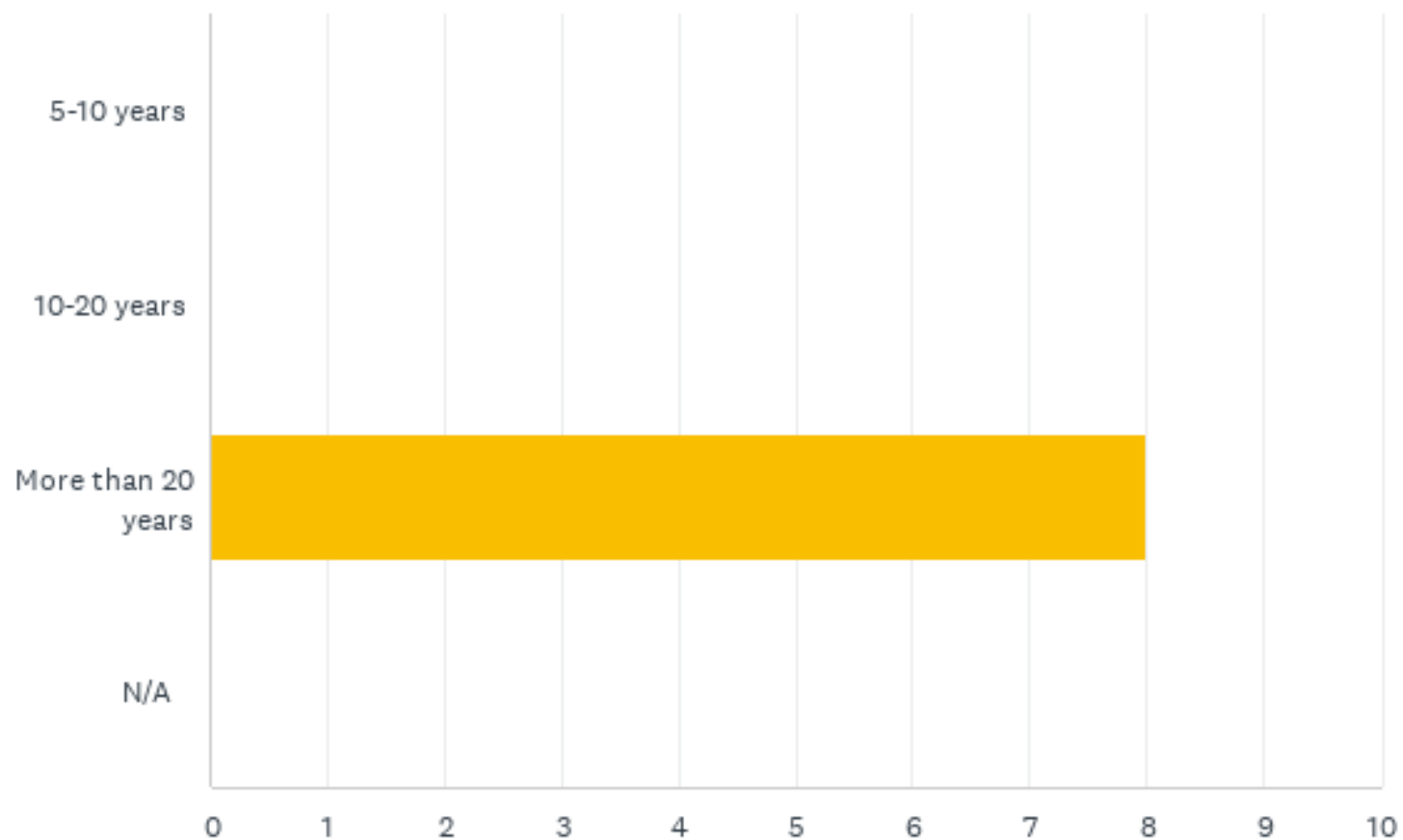
What is your age?



What is your race?



How long have you been living with HIV?



COLA Qualitative Data: Long Term Survivors

- In person surveys completed in May 2022
- Incentive: \$25 Safeway Gift Cards
- 8 participants total

Primary Medical

- Participants spoke to challenges with primary medical care, with a specific call out for integrated care.
- The discussion emphasized a conflict between HIV specific medical care and age appropriate medical care.
- There was also a concern for the loss of experienced HIV medical providers and the knowledge base they potentially take with them.

“As an older person with HIV...Integrated care is important...everyone over 65 is lumped together.”

“What if I didn’t have HIV, what about my health otherwise?”

Dental

- Described as ineffective and hard to access.
- Concerns that unauthorized procedures were taking place.

“Horrifying to be walking to payment counter between being on the chair.”

“Both times I went to UOP, they almost wiped out my bank account.”

Other themes

Housing

- Folks talked about the lack of affordable housing.
- Others brought up how important housing is for them to be able to take their medications.

“What’s affordable isn’t affordable for a lot of people.”

“If I didn’t have a subsidy, I wouldn’t have qualified for housing.”

“If you don’t have a kitchen and bathroom, you can’t take your meds on time.”

Discussion of Challenges and Barriers to Care:

What does being a long-term survivor mean to you?

What does being a long-term survivor mean to you?

- Participants spoke of their perceptions of themselves and how they may be perceived from an external perspective.
- Participants saw themselves as both leaders among the HIV+ community with knowledge and experience to share. They also shared they felt like an often overlooked and marginalized group.

“People think because HIV has been addressed and there is treatment available that it has gone away. It hasn’t, it’s become manageable not solved.”

“When you’re a long-term survivor, it’s about quality of life.”

Aging & Benefits

- Folks attempted to parse the differences between simply aging and aging with HIV.
- Benefits were a topic of concern as participants discussed how difficult it is to manage them and qualify for benefits. One person described their own situation with juggling various jobs over different periods of time, noting they can't work full-time for fear of losing their benefits.

“Is there differentiation between long-term survivors and someone aging with HIV?”

“Being able to qualify, benefits, etc...it's really frustrating.”

Conclusion

- Benefits continue to be an area of concern for long-term survivors, including anxiety around transitioning away from long-term disability benefits.
- Dental continues to be a challenging service category for many long-term survivors due to lack of ease in payment structure and lack of culturally competent care.
- Primary care is of top importance to long-term survivors, which has made the retirement/transition of physicians specializing in HIV care a stressor for this population. As well as having to differentiate ailments caused by aging with HIV or caused by simply aging.

Thank you!