

# Consumer Needs Survey Comments

## Positive Comments

- All good.
- Every question I've had, I've asked. Thanks so much.
- I am glad that in the healthcare sector, physicians are more "comfortable" dealing with patients.
- I am happy to say that I am blessed living with HIV so many years.
- I am very grateful for the kindness and attention shown.
- I am very happy with myself cause this medication is working for me and I'm so happy thank you so much and I'm not scared for anyone to know that I'm HIV. I'm blessed God bless you all.
- I feel very fortunate to have the best possible doctor and access to the best medication. Due to my 30+ years of living with HIV/AIDS I am disabled and live on social security. I am thankful that I can occasionally access assistance as a low income person.
- I have been diagnosed now for 35 years. i am so glad all these wonderful tools, like places such as Hope & Help are now available for people that need them. When I started I was told, that day, I had 6 months to live but fortunately for me I am an RN and could find education and treatment options even back then. And have gone from vomiting almost every day for years on AZT. To now a beautiful 1 pill a day.. My t-cells have always been good > 400. so please keep these places going. ... we need them
- I thank God everyday for people like you all that are there to help.
- It's a difficult life to live and turns your entire universe upside down. The financial and medical support does make it more feasible to get by in an already complicated situation.
- I've been learning how to deal with having HIV, its hard because some people are out here to judge you. But I continue to do what I need to do to live my life and not care about what others think.
- Ryan white and the services they provide for are why I am able to remain healthy without these services, I believe I would not be alive today. I am so grateful!
- Thank you for all you do for so many.
- Thank you for all you do!
- Thank you for doing this. It's not for us if it doesn't include us.
- Undetected. Yay. Thanks
- What you are doing is already wonderful! Thank you!
- With medical attention, I feel happy and I know that by taking care of myself, I'll live many more years without having to receive an AIDS diagnosis.
- I thank God for the health care professionals in my life currently. I went threw hell and back before GOD bringing the right people into my life. Why are we as HIV Clients having to fight our health care professionals because they thing they are mighty & Powerful with threats & Punishments that aren't in there power to hand

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out? Secret shoppers need to be placed in all agencies & graded on their performances, including management.

- I have been living well with the HIV Virus for the past 28 years and have always been healthy and undetectable for more than 26. Taking medications as prescribed
- I thank God for the medication, it's keeping me alive!
- HIV support groups are very helpful.
- Todo por el momento marcha muy bien, la atención por parte del centro de salud es excelente! Gracias por todo el apoyo! (Everything is going very well at the moment, the care from the health center is excellent! Thanks for all the support!)
- Good
- You guys and gals nurses, dr., etc. are doing a great job and I really appreciate everything.
- I'm ok with my own skin I grew to love me & I can actually say I'm stronger than ever!
- I was diagnosed in 1998. I have been coming here since 98. I think the services have become better and more streamlined over time.

### Other Comments

- I have been HIV positive for over 30 years. And hope and help has been with me the entire time. At times it's embarrassing to still be going to them. But I have no choice because I do not have insurance. My prior employer did not offer insurance. And now I'm a self-employed artist and still do not make enough money to purchase my own insurance.
- I have been one of the lucky ones. I have watched multiple friends die since I was diagnosed in 1992. This July will mark 30 years that I have been living with this disease. I wished I was able to share my status with others but my last job I was not allowed to come back after the pandemic. I know that this was due to my HIV status. My upper management made comments "you just need to take care of your health" I never received a bad review in my close to 12 years working for Landry's. This was a move to stop having to pay for my insurance.
- I have been diagnosed + for HIV going on 37 years. I have never been diagnosed with AIDS or ARC for over 30 years my CD4 count has been anywhere from 700-1100. My viral load is always undetectable. What would happen if I stop taking HIV medication?
- More information on Medication to stay Healthy
- My confidentiality!
- Need eyes checked

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- No thank you
- Normal
- People are still confused regarding REAL knowledge of HIV (contracting and living with same). This includes those actually diagnosed with HIV. Improper knowledge of HIV leads to FEAR. Correct knowledge and understanding leads to better management of the all person's involved.
- Relieve the stigma that HIV makes you "DIRTY". HIV and AIDS are NOT interchangeable terms
- To find a cure.
- recommendations for longevity
- Care at VA except dental
- I have had HIV since 1998.
- When i found out i was HIV positive. there were no resources to go to for help. i had to use google to find a place to get checked and start treatment. once i found a place then there was help.
- Thank you for asking.....
- There needs to be support when someone finds out they are positive.
- Do to my HIV status. I take my life and health seriously.
- I was diagnosed in 2009. I have received the care I need, but I am also independent enough to manage my care, because I have almost 20 years in health care. This is not true for many HIV+ people. Services that help them are important.
- Nothing
- We (HIV patients) should be able to get inexpensive life insurance as people who are smokers, diabetic , etc.
- I think a lot of people think that HIV is done, is not a threat, or don't care. The commercials shown on TV are wonderful as they do help remind people HIV is still present and new drugs that keep it from spreading as in the past
- I wish there was help with vision care
- Just understand yourself that the condition will be there all the time, just follow up on your doctor care.
- I'm very particular about who I share my information with...cause in a perfect world we would all get better and get along accepting people for who they are and not separating them according to health issue cancer,hiv,diabetes etc.
- Rent is very high and assistance definitely welcome. Cost of food is getting very expensive. Physical activity assistance is needed with gym. Need an advocate to help with meal preps. Healthy lifestyle advocate.
- I like to obtain 2 or 3 times a year to visit the doctor to check or evaluate the condition.
- Nothing at this time, thank you

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- Me gustaría recibir las ayuda o algún seguro se salud que cubra más medicamentos (I would like to receive help or some health insurance that covers more medications)

### Negative Comments

- All care is needed not just my top 5 especially care that they don't seem HIV worthy to pay for but you are still sick or have illness like myself with my walking which has me not being able to balance or stand for long periods of time. Education of all that are Case management hired. MORE Food, independant & clothing options.
- Earlier help for medical assistance and food medications insurance made easier to get
- At the facilities. Waiting time sometimes it takes forever. usually spent like 2 hours waiting to get done.
- Following up on patients mental health would be my biggest thing to say. I went into a very dark place when I found out my results and I don't feel like I could talk to other about how I felt because they aren't going what im
- HIV patients need a Seccion 8 Program in Florida so we can concentrate on our health instead of our living situation. There is a program called HOPWA where they help you with your rent but it has to be an emergency and you have to provide many many documents proving the emergency. We the patients have emergencies on a daily basis. We need a program that can give us peace of mind when it come to our living situation. It's not about living for free, it's about feeling safe and having a secure roof under our heads. This program exist in Puerto Rico and the main requirement is that you be in a treatment program among other documents required and you pay according to your income. Hope you take this in consideration. This is the biggest problem we face beside having the disease.
- Help finding a partner who understands your situation and does not discriminate
- I don't know how to tell my teenage kids. It haunts me everyday.
- I feel alone and rejected.
- I just want access to care
- I need assistance to pay for my psychiatric medications.
- I used to get food vouchers but later told I don't qualify because of income. I live in Florida with has become the most expensive state to live in. By the time I pay outrageous rent etc....little money left.
- I want the food cards to come back for everyone

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- I wish the Orlando, Florida Overall Case managers took their jobs more seriously. They are very forgetful & take things as a joke. If we pulled or lowered their salaries, it wouldn't be a joke then. Get more involved with your clients. Clients shouldn't be afraid to voice their opinions to their Case managers without feeling retaliation is coming or worse. Case managers need to remember they aren't gods & finding isn't their personal monies, keeping in mind YOU also can be in these situations too. We need better care, More options, FOOD avail for ALL that might need it and not having certain people decide the fate of OUR community, especially if you aren't HIV+. Thanks
- "I would like less bloodwork and less paperwork. HIV people have to do so much of both.
- Avg. 2 hours paperwork per visit
- Avg. 12 vials of blood per visit"
- I would like to say I don't want nobody know I have HIV If they know I'm done.
- It bothers me knowing that colon rectal cancer is prevalent in men with HIV yet we can't get any assistance on the co-pay to have a colonoscopy done to remove cancerous lesions that have been in your body for 5 years
- Many of us do not know how to fill out the government paperwork they send you this all at once a year. When they do send it you can never get ahold of your peer specialist what are they called? They used to have case management. Then they took most of them away I got somebody to fill out the paperwork. If you answer the right questions you don't need help??? It does not make sense that people asked him questions and figure you don't need help anymore. It's hard for me to fill out paperwork from the government cuz I do not know how to do it! Wish this was fixed.!
- Need referrals to drs and non would take my case cause I'm HIV we need a better group of physicians. The pharmacy you recommended is screwing up meds till the pointy that I run out and haven't received them. I'm pretty much over this and looking to go elsewhere
- Patient assistance programs are great in helping people receive medications! But the upkeep of eligibility of the different programs is a bit challenging. One missed phone call or the wrong date in your calendar can easily make it a struggle to receive medications.
- People living with HIV need support groups. Most support groups are 25 30 and under most people living with HIV or over 30 40 50 60 we need support teams for those groups! We have a support group that welcomes everybody but there's only once a month
- Privacy and compassion are two things that can be improved on at AHF. The front desk experience is too familiar and privacy isn't respected as much as it should be.
- The cost of medication is so ridiculous it would be easier to maintain therapy if it was affordable.

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- There needs to be more service for LONG TERM HIV PEOPLE.
- Those having a chronic illness, such as HIV/ AIDS. I think life insurance should be offered or at least in somerray have a provider that can assist and/or direct them to a company that will cover the patient for life insurance such as an addition to the Ryan White/ ADAP program.
- Very little coordination with help with obtaining medication to help with consistency and cost of medication.
- Vision care is important and needed
- When you ask questions of clients listen to their responses and not just of those who completed the surveys.
- With the cost of housing going up in Florida and the current state of the pandemic. I have concerns of where I will be living within the next 12mo and how I will be able to afford it!
- Sex shops, book stores, sex clubs should shut down as they provide promiscuity and unprotected environments that I feel are some of the route causes for gay men getting HIV.
- There needs to be more services for the aging HIV population. Seriously.
- Many services unobtainable due to agency staff mismanagement and unwillingness to help
- I need 2 specialized surgeries and can't find doctors who cover it
- The facilities that provide healthcare need to be more attentive to patient privacy. Crowded waiting rooms and staff turnover creates a concern with privacy.
- Have better access to housing doctors when you are 1st diagnosed
- I think help with housing is important for someone living with hiv to have that stability where he or she can take care and do all the things needed to be healthy with hiv. Employers still have questioners asking if you have hiv listed u set disabilities... so I think we get discriminated against and it's hard to maintain good jobs where we can pay rent. That's why I think a better housing assistance plan should be in affect with less strict criteria and with case workers that actually want to help you and are understanding of your needs and no judging you for needing help.
- I feel like I am living a lie I'm functioning under false pretenses that my life is OK when it's not. I have to stay within parameters that limit me from having a full life. It's a lonely form of suffering.
- Hard to get help we need. Case managers are overwhelmed. Lots of loopholes. We just want medicine to live. Healthcare and support services
- Mayor accesibilidad y coordinacion para referidos de otros servicios de salud.(Greater accessibility and coordination of referrals for other health services).
- Had to wait many many months to get help from a mental health counselor after the case manager requested help. I think I had to wait 4 to 6 months.

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- Facilities that offer healthcare should be more discreet with patients and information
- Just difficult to get scheduled to see a doctor or get a referral to see a doctor.

### Agency Kudos

- I would like to thank Hope and Help, Ryan White and ADAP for everything that is made possible for me to continue living in a healthy matter. My case worker Norm is very helpful. The staff at Hope and Help are always caring and professional. Many blessing to the future years to come.
- I would no be alive today is not for Ryan White ADAP services. Diagnosed 1996.
- Pleased with staff at Comprehensive Health Care
- Pleased with the staff at Comprehensive Healthcare.
- Thank you C.H.C
- The case worker Annai Centola is a model employee and a life saver for my father.
- When I moved to Orlando I had the fortunate luck of getting Norm Gentry as my case manager. He is beyond excellent and don't know what I would have done or would do without him. He is a great asset to Hope and Health and for people living with HIV.
- I am serviced with Project Response. They are good. They have explained and have a STD/STI center which is great for the community but I wish they offered activities for a chance to socialize with others who have HIV.
- Excellent service provided by all at Project Response. Thank you.
- Thank you CHC!
- I love you all at comprehensive health care
- I have been HIV positive for over 30 years, have had my ups and downs, but otherwise doing pretty good. I am truly blessed that I can live a pretty normal life and am so grateful and appreciate all the assistance Hope and Help has provided me and the care from my doctors.
- Norman Gentry with Hope and Help in Orlando is a true asset to our community. He is amazing. He is always happy and cherrie even hen I am down. He is very resourceful in that he does whatever he can do to assist his clients. Both my partner and myself have Norm. Norm is ALWAYS available and if he can't anger the phone he calls you back as soon as possible. I have no problems talking to Norm about anything. He is very receptive Ms does not judge at all. Norm has gone out f his way to help me and I truly appreciate all he has don for me all these years. Norm is truly an asset to the community upon which he serves. Thank you Norm from my heart for all that you have done for me!

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- I would like to say thank you to hope/help center staff specially my case manager who continue keeping me in life.
- I thank God for Hope and Help and staff in the office and Case Manager Norman. The staff are always pleasant to talk to on the phone and in person. Dr. Robert Rowe is an awesome doctor and takes his time and gives his concern to what ever health issue is needed. Thank you Hope and Help for being there for so many of us in need.