

# 2022 Emerging Issues

## Community Consultation and Engagement Forum Report





### **Acknowledgements**

Positive Life NSW acknowledges the support of the NSW Ministry of Health, Mr Craig Sams of Capital Workplace, Board Directors and staff of Positive Life NSW, and the resilient members of the NSW Body Positive living with HIV.

**Author:** Positive Life NSW

### **Further Information**

For further information on this community survey report, please contact:  
Email: [contact@positivelife.org.au](mailto:contact@positivelife.org.au) Phone: (02) 9206 2177 or 1800 245 677

*Images used in this publication are sourced stock photography from a collaboration between ViiV Healthcare and Shutterstock Studios 'HIV in View' which showcases empowering images of people living with HIV. They do not imply any particular HIV status, sexuality, attitudes, or behaviours.*

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A photograph showing two men in profile, facing right. They are both wearing light blue polo shirts. The man in the foreground is wearing black-rimmed glasses and has a wide, joyful smile, showing his teeth. The man behind him is also wearing glasses and is looking towards the same direction. The background is slightly blurred, suggesting an indoor setting with other people or objects.

People living with HIV from CALD backgrounds shared how language barriers confound the experience of isolation and compound the uncertainty of COVID-19 health messaging which often changed from week to week.

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## Executive Summary

The February 2022 community consultation and engagement forum (CCEF) drew attendees from the Sydney inner and outer Metropolitan areas, with 50% of attendees from a culturally and linguistically diverse (CALD) background. Over a third of the group were heterosexual men and women living with HIV, and half of the total group were men who have sex with men living with HIV. This CCEF highlighted that despite the impacts of the COVID-19 (COVID) pandemic on the lives of people living with HIV in NSW, there remains a resilience within the community and a strong desire to seek out options to move towards improving our quality of life. Impacts included isolation, fears for the future, and challenges to maintain our health and positivity.

### **Isolation and access to healthcare and social support**

Many participants living with HIV shared stories and personal experiences of the overwhelming impacts of the COVID lockdowns. These included changes to the way we interact and connect with the clinical and allied health services which sustain our lives as people living with HIV. The impact of isolation was significant for many people living with HIV. Forum attendees from culturally and linguistically diverse (CALD) backgrounds shared how language barriers further confounds the experience of isolation, compounds the uncertainty of COVID-19 health messaging which often changed from week to week, and created obstacles for people living with HIV to receive timely and appropriate health care.

### **Impacts of the known, unknown and the future**

As COVID lockdowns were extended throughout NSW, people living with HIV experienced insecurity about the impact of COVID on our HIV-related health needs, and we were forced to adjust our expectations of the future in the light of a seemingly unending worldwide pandemic. Many of us have found the past two years increasingly exhausting as the ongoing likelihood of reduced social connection continued. Some people living with HIV were stranded in Australia and could not travel back to family and support networks overseas, while others expressed increased financial uncertainty and mental-health related burdens of distress, anxiety, and depression. A small number of participants described a cautious sense of privilege, freedom and anticipation.

### **Challenges to maintaining quality of life**

During this time of COVID lockdowns, many people living with HIV expressed frustration with accessing their usual HIV s100 provider appointments, navigating the relatively new options of telehealth and accessing allied healthcare such as hydrotherapy, exercise regimens and comorbid health appointments and support. Mental health concerns were a constant theme along with the challenges of remaining positive, resilient and maintaining a good quality of life.

### **Strategies of response**

Participants were agreed around the importance of security in mitigating the impacts of the COVID pandemic on our lives as people living with HIV in NSW. Security strategies were broken down around an axis of secure housing, finances and health, with issues of dental health, healthy relationships, a reformed migration system, and end of life or pro-choice assisted dying being identified as associated with agency, reassurance and safety.

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## Discussion

ON Saturday 12 February 2022, Positive Life NSW (Positive Life) engaged and consulted with people living with HIV, about the impacts of two years of the COVID pandemic on people living with HIV navigating our own health needs and the health system. The full day program explored how attendees, all people living with HIV perceived our current quality of life, our future and the strategies or solutions that would improve our quality of life (Appendix A).

29 community members living with HIV attended the forum travelling from the Sydney inner and outer Metropolitan areas including Parramatta, Liverpool, Bonnyrigg, Newcastle and Queanbeyan regions. Half of the attendees were from a culturally and linguistically diverse (CALD) background, including spoken languages of Portuguese, Mandarin, Swahili, Arabic, Spanish. Over a third of the attendees were heterosexual men and women living with HIV, while gay and bisexual men living with HIV made up exactly half the total number. The forum was held at the Vibe Hotel Sydney on Goulburn Street, so people could easily attend the forum and access the venue via public transport (buses, trains, light rail, Uber, taxi etc.)

Craig Sams, an Indigenous Dharawal (WodiWodi) man, led the proceedings as an external facilitator, to equalise the power dynamic among peers and staff and ensure all participants, including the CEO, were free to participate in the conversation alongside the rest of the attendees. The room was laid out with

chairs surrounding large tables with the aim of encouraging inclusion, discussion and contributing to the free-flowing dynamic among all participants. Post-it notes and large sheets of paper were freely available including large markers and pens so participants could add extra thoughts, experiences and impressions (Appendix B).

The day's discussion covered a range of domains of the experiences and impacts of living with HIV throughout the COVID pandemic in NSW, in terms of access to the health system, social impacts on employment, housing and access to services, as well as psycho-social impacts for people living with HIV who are also facing or faced the potential of COVID acquisition and vaccination (Appendix A). He explored the different strategies that attendees used to maintain and enhance their own sense of safety, self-determination and self-esteem in the face of COVID threat and COVID lockdowns and ways they described their tactics to cope with and respond to the COVID pandemic.

Positive Life CEO, Jane Costello welcomed participants and opened the day with an acknowledgement of country. Mr Sams then set the scene with housekeeping, an introduction and outline for the day's discussion, and agreed and shared COVID strategies to maintain a sense of participant safety. An icebreaker followed with attendees sharing in pairs to learn more about each other and with permission introduce each other to the group.





Some people living with HIV were stranded in Australia and could not travel back to family and support networks overseas, while others expressed increased financial uncertainty and mental health related burdens of distress, anxiety and depression.



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## 1. What word/s describe your quality of life?

*"Blame shame  
HIV"*

*"Previous bad  
experiences  
worse than now  
- resilience"*

*"Worry about  
aged care"*

*"Alone,  
depressing,  
anxious, can't  
be on the go"*

*"Dental  
forced  
to make  
choices"*

*"COVID - we are  
concerned about the  
future. It impacts  
family and personal  
relationships"*

*"Positive -  
strengthened  
in relationship  
under COVID"*

*"When will we  
normalise HIV?"*

*"HIV VISA - OZ  
doesn't want  
me"*

*"Positive - comfort  
of working from  
home, saves a  
lot of time and  
expenses, time  
alone reflecting  
on one self"*

*"More negatives at  
the moment than  
positive"*

*"Changing criteria  
constantly  
for support  
and accessing  
services"*

*"DSP no longer  
has the currency  
it was"*

*"Government  
policy on the run"*

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## 2. What word/s describe your future?

*"Dealing with grief and ageing"*

*"Confused – uncertain cost of living, can't plan"*

*"Future feels great"*

*"Positive/exciting – we believe there are things to look forward to"*

*"Resilient"*

*"We have lived with a lot of death as PLHIV"*

*"Security"*

*"History and experience of living with HIV impacts"*

*"Medical care includes dental"*

*"Important people in life not here anymore – peers passing away from older age"*

*"Health conditions paradox – physical health still here"*

*"Financial security – increase government"*

*"Benefits of living authentically and benefits of disclosure"*

*"Not rich – can't take \$\$ with you – reconciled with financial state"*

*Insert in-text pull quote here.*

## Word Cloud 2: What words describe your future?



Immediately following morning tea participants were once again invited to anonymously submit, without restriction, as many times as they like to populate a second Word Cloud using the Mentimeter question 'What word/s describe your future?' A total of 73 responses were received which is just over an average of 2.5 entries per person. (Appendix B, number 2)

Once responses to this second Word Cloud were received, the facilitator posed the thought, 'If you had a magic wand, how could your life be better?' Plastic wands were distributed amongst the participants as a prop, to invite free-flowing thoughts and participants were invited to 'be as blue sky thinking as you like'. These suggestions and solutions were written down onto butcher's paper

by participants on each table. Once each table had produced their list, the group was supported to begin to distil the future issues that would impact their lives into themes and priorities until lunch was served.

After the lunchbreak, the final Mentimeter question was posed, 'What strategies or solutions would improve your quality of life?' and participants were invited to offer as many words, as many times without restriction to populate a third Word Cloud. A total of 82 responses were received which is just over an average of 2.8 entries per person (Appendix B, number 3). Again, conversation in the room was robust, comparing responses and reading out the various results as the words appearing on screen grew larger or smaller with each addition.

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### 3. What strategies or solutions would improve your quality of life?

*"Cloak of invisibility"*

*"Reform the migration system"*

*"Heal me"*

*"Take COVID away - get back to normal"*

*"Free medical for mental health: some of us are overburden by the cost of medication since we are dealing other several medical conditions"*

*"Free comprehensive dental care"*

*"Dying with dignity: having a voice of saying it's enough"*

*"Take away social, medical, social discrimination"*

*"psychologist that care and know about and not ticking boxes"*

*"Cure for HIV: End of stigma"*

*"Find someone who loves me unconditionally"*

*"Defund institutions that promote"*

*"Health systems that work"*

*"Cure HIV so I don't have to go through the need of dealing with the current migration system"*

*Insert in-text pull quote here.*

## Word Cloud 3: What strategies or solutions would improve your quality of life?



By 2pm the facilitator asked the participants to group themselves around the tables and come up with three solutions or strategies to the question *'How can Positive Life NSW support you to improve your quality of life?'* as a group. It is worth noting, by this stage of the consultation, participants had self-selected themselves into various groups that could be identified against different demographics, such as a table of participants from CALD backgrounds, a table of woman living with HIV, another table had all Asian gay-identified participants, and a fourth table formed a group of participants all over the age of 60 years.

As the discussion progressed, participants' responses, phrases, solutions and strategies referenced elements of secure housing, finances and health as ways to improve personal quality of life. Responses related to housing was expressed not only as 'secure housing', but 'permanent good housing', 'safe cleaner housing', 'more comfort at home', 'warm bathroom', 'own a house', and 'someone to do housework'. Phrases related to finances and 'financial security' included statements such as 'safety net', 'NDIS funding', 'NDIS to be easy', 'secure my employment job', 'reduced insurance

premium', 'increase DSP', 'less problem Centrelink', 'a clearer career pathway', 'funeral expenses covered', 'good financial advice', and of course 'win the lottery'. Elements expressed in terms of health included 'secure health', 'better health outcomes', 'free dental', 'free dental care', 'good health', 'mental health', 'mental health care', 'free fillers for face', 'fight depression', 'comprehensive healthcare', 'mental health meds free', and 'hiv cure' or 'hiv can be cured'. Other associated elements with health were expressed as 'aged care security', including 'assisted dying', 'pro-choice assisted dying', 'dying with dignity', while a number of participants pinpointed the need for a reformed migration system to provide them with a sense of reassurance and safety, improved health outcomes and a better quality of life.

Attendees were agreed around the broad themes and the importance of security, be it housing, financial, health as strategies to mitigate the impacts of the COVID pandemic on our lives as people living with HIV in NSW. Secure housing, reliable income support and finances, and issues of affordable dental health, healthy relationships, and end of life or pro-choice assisted dying were identified as associated with security, and a better quality of life.

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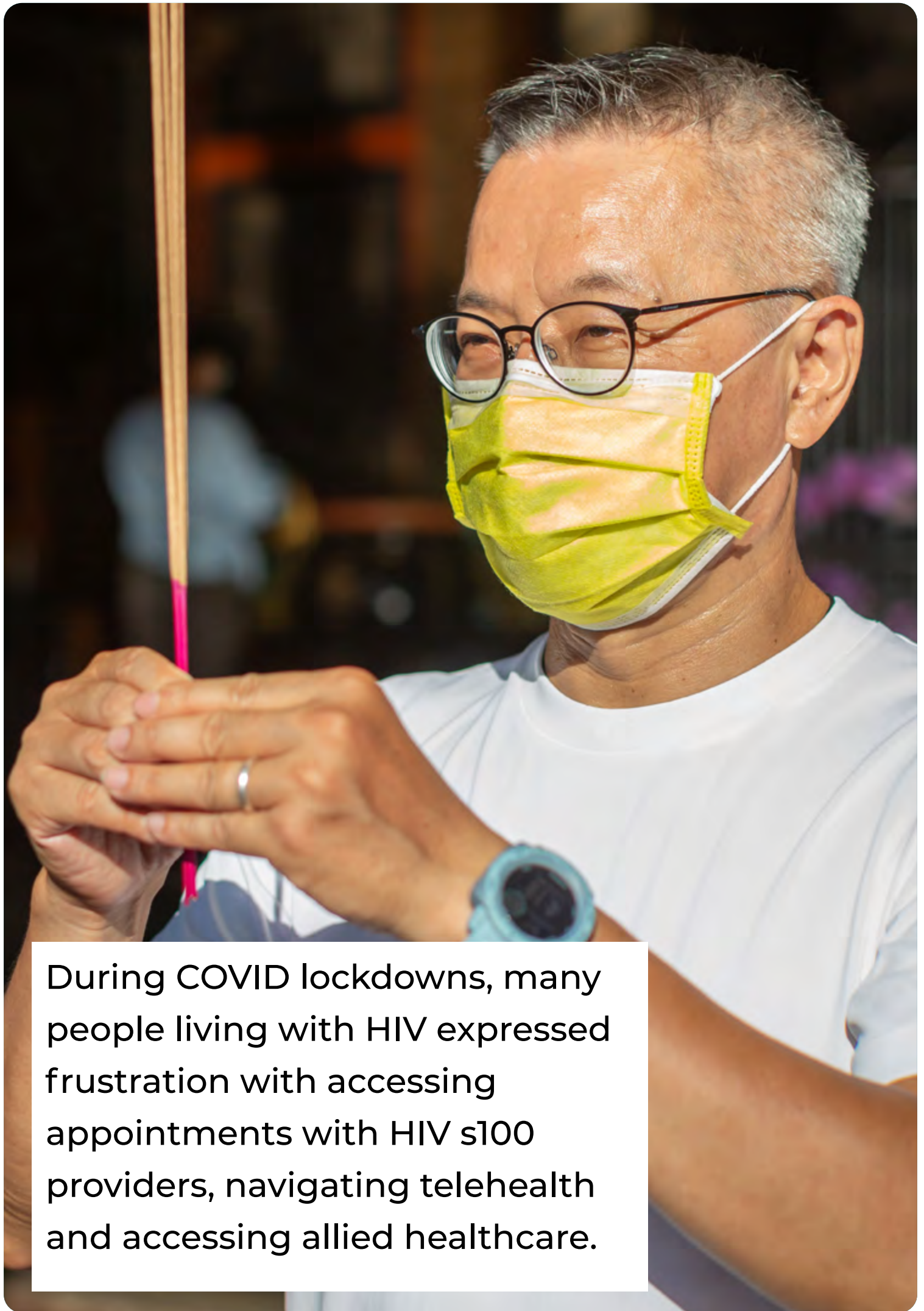
## Conclusion

The forum was an opportunity for Positive Life NSW staff, Board and forum participants to engage and consult together with people living with HIV about our perceptions of our current quality of life after two years of COVID, the future and hear various strategies or solutions that would improve our quality of life.

The forum created a safe space for community to confer and validate our experiences, reflect on the experiences of other people living with HIV recognising and acknowledging the differences between us and also the commonality

of the lived experience. It identified the variety of strategies we use to cope, manage and explore our options around isolation, connection and changes that the COVID pandemic has brought to our society.

This consultation highlighted the fact that despite the fears, threats, isolation and challenges posed by COVID, we remain engaged in our healthcare, we value the strength and connection of community, and continue to embrace the changes and choices of the past two years.



During COVID lockdowns, many people living with HIV expressed frustration with accessing appointments with HIV s100 providers, navigating telehealth and accessing allied healthcare.

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# Appendix A

## **Mentimeter Questions**

1. What word/s describe your current quality of life?
2. What word/s describe your future?
3. What strategies or solutions would improve your quality of life?

## **Forum Prompts or Questions**

1. Outline of the interaction between the COVID pandemic and navigating our health needs. Invitation of people's thoughts, experiences and impressions (Parking lots, post-it notes)
2. If you had a magic wand how could you make your life better? (Be as blue sky thinking as you like).
3. What do you think are the future issues that will impact your life as a person living with HIV?
4. How can Positive Life NSW support you to improve your quality of life?
5. Practical solutions?



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# Appendix B

## Mentimeter Comments

### 1. What word/s describe your current quality of life?

- Awkward
- Great
- Busy
- Fun
- Fantastic
- Lonely
- Really\_good
- Hilarious
- Joyful
- Full\_filling
- Exciting
- Interesting
- Varied Fluctuating Challenging
- Moderate
- Vivacious
- Good
- Worrying\_about\_covid
- What\_about\_the\_future
- Confused
- Liveable
- Unfolding
- Anxious
- Resilient
- Depressing
- Concerned\_about\_future
- Isolation
- Depressed
- Content
- Concerned
- Comfortable
- Challenging
- Feelings\_of\_isolation
- So\_over\_Covid
- Average
- Expensive\_housing\_in\_Syd
- Fluctuating
- Concern
- Busy
- Cautious
- Inquiring
- Anxious
- Stress
- Unhappy
- Trying\_to\_keep\_a\_positive
- Ok
- Happy
- Exhausting
- Frustrating
- Hungry
- Full
- Safe
- Privileged
- Improving
- Alone
- Transparency
- Satisfying
- Bad
- Burdened
- Relieved
- Aging
- Full\_on
- Turbo\_charged
- Anticipatory
- Homesickness\_overseas
- Isolation
- Covid\_worries
- Could\_be\_better
- Want\_improvement
- Quality
- Stress\_from\_parents
- Culture

Mentimeter responses have been reported here verbatim as recorded by participants.

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## Appendix B

### 2. What word/s describe your future?

- Bleak
- Good
- Hopeful
- Unknown
- Positive
- So\_bright I\_gotta Wear\_shades
- Hopeful
- Happy
- Nonplused
- Gregarious
- Unknown
- Exciting
- Colourful
- Short
- Comfortable
- Euthanasia
- Possibilities
- Freedom
- Promising
- Surprising
- Uncertainty
- Confused
- Closing
- Accept
- New
- Not\_exciting
- Anxious
- Abundant
- Open\_to\_cgange
- Uncertain
- Distressing
- Small\_hopes
- Employment
- Keeping\_hopes
- Do\_my\_best
- Time\_will\_tell
- Be\_positive
- Hopeful
- Busy
- Quiet
- Rewarding
- Greens
- Loving\_and\_loved
- Deteriorating
- Open\_to\_change
- Connected
- Climate
- Rise
- Family
- Challenging
- Fresh
- Opportunity
- Live
- Journey
- U\_never\_know
- Alien\_invasion\_from
- Annoying
- Fulfilled
- Looking\_forward
- Full\_of\_wonder
- Privileged
- Full
- Intriguing
- Interesting
- I\_don't\_know
- Relationships\_fade\_out
- Opportunities
- Financial\_uncertainty
- Climate-y\_changed
- Rewarding
- Secured Finances\_secured
- Hope
- Full\_of\_plans
- Financial\_uncertainty
- Isolation
- Choices
- Freedom
- Rockstar
- WWII
- Surrendering
- Unknown\_country
- Worry
- Financially\_insecurity
- Partner
- More\_Hugs
- Encourage\_intimate\_HUGS
- Engaging

Mentimeter responses have been reported here verbatim as recorded by participants.

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## Appendix B

### 3. What strategies or solutions would improve your quality of life?

- Secure\_housing
- Secure\_health
- Secure\_friends
- Secure\_my\_employment\_job
- Keeping\_fit
- Praying\_to\_God
- Financial\_security
- Good\_health
- Social\_connections
- Lifting\_of\_immigration\_re
- Winning\_the\_lotto
- Travelling
- Lotto
- Fulfilling\_work
- Less\_problem\_Centrelink
- COVID\_in\_the\_past
- Financial\_security
- A\_understanding\_society
- Eliminate\_guilt
- Book\_a\_cruse\_holiday
- Covid\_in\_the\_past
- Win\_the\_lottery
- Equal\_opportunities
- Physical\_Exercise
- Support\_worker\_visits
- Fight\_depression
- Moving\_to\_spain
- Better\_healthcare
- Moving\_forward
- Ambitious
- Strong\_minded
- Fido\_or\_tabby
- Mental\_health
- Free\_dental\_care
- Good\_financial\_advice
- Mental\_health
- Security
- Empowerment
- Less\_govt\_interference
- Financially\_secured
- Hiv\_cure
- Support\_Groups
- Concession\_cards
- Peace\_love\_unity\_respect
- Free\_fillers\_for\_face
- Medications\_are\_free\_real
- Drink\_less
- Healthy\_relationship
- Reformed\_migration\_system
- More\_Hugs
- More\_Vegetables
- Having\_a\_job
- mental\_health\_meds\_free
- Dying\_with\_dignity
- Warm\_bathroom
- Empowerment
- Educate\_people\_about\_HIV
- End\_the\_stigma
- Pet\_a\_cat
- Install\_a\_rheem
- Dying\_with\_dignity
- Ndis\_to\_be\_easy
- Own\_a\_house
- Make\_peace\_with\_my\_past
- Someone\_to\_do\_housework
- Pro\_choice\_assisted\_dying
- Hamsters
- Mindfulness
- NDIS\_funding
- More\_funding\_to\_pos\_life
- End\_stigma
- Health\_Insurance
- Quality\_impact\_on\_plhiv
- Assisted\_dying
- Free\_dental
- Travel

Mentimeter responses have been reported here verbatim as recorded by participants.

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## Appendix B

### 2. What words describe your future?

- Confused – uncertain cost of living, can't plan
- Family proximity
- Medical care includes dental
- Financial security – increase government financial assistance
- Employment – increase employment opportunities
- Positive/exciting – we believe there are things to look forward to
- Security
- Exciting – anything is possible
- Hope
- Resilient
- Future feels great – Authenticity impacts this outlook
- Alright – wake up thank God I'm still here
- Mental security – engaged, staying connected, artistic, movies, culture/theatre, active
- Employment – busy, housing, happy, meds/health, mental outlook
- History and experience of living with HIV impacts
- Benefits of living authentically and benefits of disclosure
- Dealing with grief and ageing
- Health conditions paradox – physical health still here
- Important people in life not here anymore – peers passing away from older age
- We have lived with a lot of death as PLHIV
- Not rich – can't take \$\$ with you – reconciled with financial state

Mentimeter responses have been reported here verbatim as recorded by participants.

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# Appendix C

## Post-It Notes Comments

### 1. What word/s describe your current quality of life?

- Confused
- COVID future – COVID impact differently
- Government policy on the run
- Isolation – what is needed for development
- Positive – strengthened in relationship under COVID
- More communication
- More negatives at the moment than positive
- Previous bad experiences worse than now – resilience
- Challenges
- Isolation positives and negatives
- Alone, depressing, anxious, can't be on the go
- Fear intimidation
- HIV & COVID
- Deep thoughts, self care, creativity, introvert, cooking
- Vaccine rollout terrible
- No early vaccine available
- MRNA too new
- Not transparent enough
- Communication of health advice
- Confused: new medications for HIV
- Hope for positivity
- HIV VISA – OZ doesn't want me
- When will we normalise HIV?
- Assumptions of stigma
- Pharmacy primary care – if you are straight you get treated differently from queer/gay doctors/clinics
- Too hard to be positive
- Gender, sex, sexuality is changing
- Mental health
- Worry about aged care
- Euthanasia laws – right to die change
- Isolation – HIV
- Stressful
- Work and COVID
- No family
- 3years overseas family
- Masks – no makeup
- Facetime
- Loss of physicality
- Blame shame HIV
- Challenging access
- Cost of living, finances
- Dental forced to make choices
- Long term effects of medication
- Changing criteria constantly for support and accessing services
- Ageing complexities
- NDIS access for WHO and WHY
- DSP no longer has the currency it was
- Challenging – concerned about COVID situation
- It is a whole new experience in our lives
- COVID – we are concerned about the future. It impacts family and personal relationships
- Positive – comfort of working from home, saves a lot of time and expenses, time alone reflecting on one self
- Isolation – caused depression/anxiety and stress
- Confused – what the future holds with the current situation we are in.

Mentimeter responses have been reported here verbatim as recorded by participants.

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## Appendix C

### 3. What strategies or solutions would improve your quality of life?

- Win the \$80 million Powerball
- To be young again
- Having nothing to worry about
- All be equal
- Find someone who loves me unconditionally
- Fix the climate!
- Get a decent erection
- Forget my worries
- Free drugs and legal
- Bigger orgasms
- Defund institutions that promote discrimination
- No more stigma
- Health systems that work
- No more HIV
- Slimmer waistline and have fabulous frocks
- Have hot sexy naked men looking at me all the time
- Win Powerball
- Private boat
- Learn how to live in the moment
- Unlimited funds
- Heal me
- Younger
- Cure HIV so I don't have to go through the need of dealing with the current migration system
- Free dental care
- Better health outcomes
- Health relationship without caring of being judged because of your HIV status
- Dying with dignity: having a voice of saying it's enough
- Free medical for mental health: some of us are overburden by the cost of medication since we are dealing other several medical conditions
- Take COVID away – get back to normal
- Create equal opportunities
- Take away social, medical, social discrimination
- Reform the migration system
- Mental health issues: psychologist that care and know about and not ticking boxes
- More understanding of Centrelink to understand and treat people correctly
- Financial security
- Cure for HIV: End of stigma
- Face to face relationships
- Help in being pointed in the right direction
- To be connected
- Healing the world
- Extra arms to do things and extra ears to listen better
- Cloak of invisibility
- HIV cure
- Endless youth fountain
- Greater level of humanity
- Social justice and equality for all
- Gender parity
- Increased compassion increased nurture
- The opportunity for all to be the best that they can be
- Appeal the health waiver
- Better health care: Dental (accesses, subsidy), Health Insurance (access and costs), Mental health (security)
- Secure housing (own/rental)
- Strong minded
- Good heart
- Full of energy
- Free comprehensive dental care
- Funded mental health with practitioner of choice
- Earlier assessment of HAND

Mentimeter responses have been reported here verbatim as recorded by participants.



Participants were agreed around the importance of security, be it housing, financial or health as strategies to mitigate the impacts of the COVID pandemic on our lives as people living with HIV in NSW.



For more information phone 02 9206 2177 or 1800 245 677 (freecall)  
or visit [www.positivelife.org.au](http://www.positivelife.org.au)