

# The impact of COVID-19 on PLHIV Survey

**napwha** national association of people with HIV australia

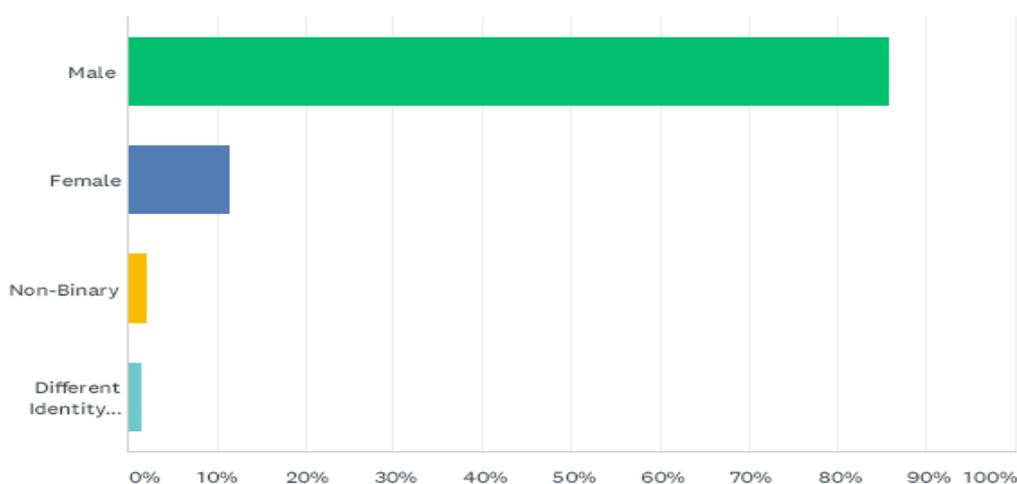
## Background

In April 2020, at the height of COVID-19 in Australia NAPWHA sought to connect directly with community to gather information on the impact of COVID-19.

**147** people living with HIV responded to the survey. This provided valuable information on location, age, gender identity, number of co-morbid conditions, experiences with virtual telehealth, views on COVID-19 and respondents most pressing needs.

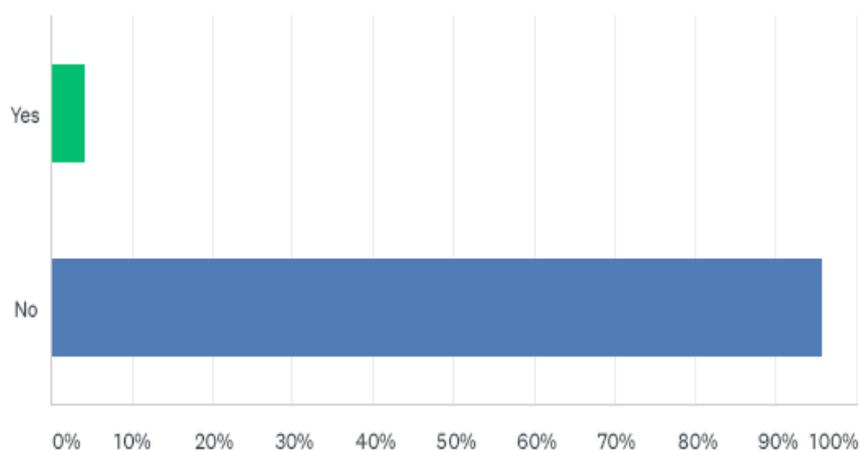
## Q1: Gender & Identity

Of the **147 people** who participated **85.71% (126)** identified as **Male**, **11.56% (17)** identified as **Female**, **2.04% (3)** identified as **Non-Binary**, and **1.36% (2)** selected **Different Identity**.



Respondents were asked if they identified as trans/ gender diverse/ genderqueer/ not cisgender.

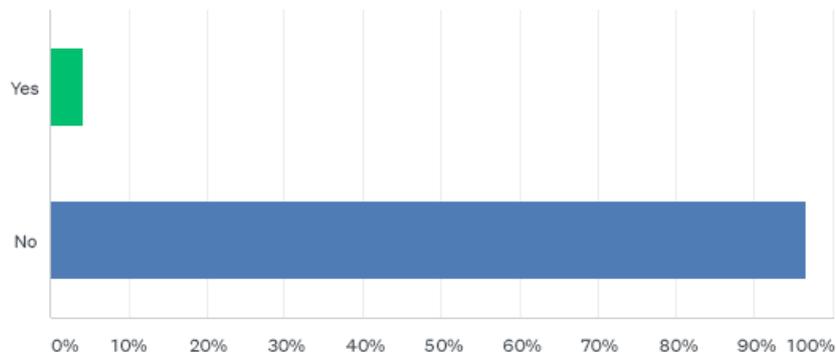
**4.08% (6)** Participants selected **Yes**, **95.92% (141)** specified **No**



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## Q2: Do you Identify as Aboriginal or Torres Strait Islander?

4.14% (6) of the 146 respondents to this survey identified as Aboriginal or Torres Strait Islander

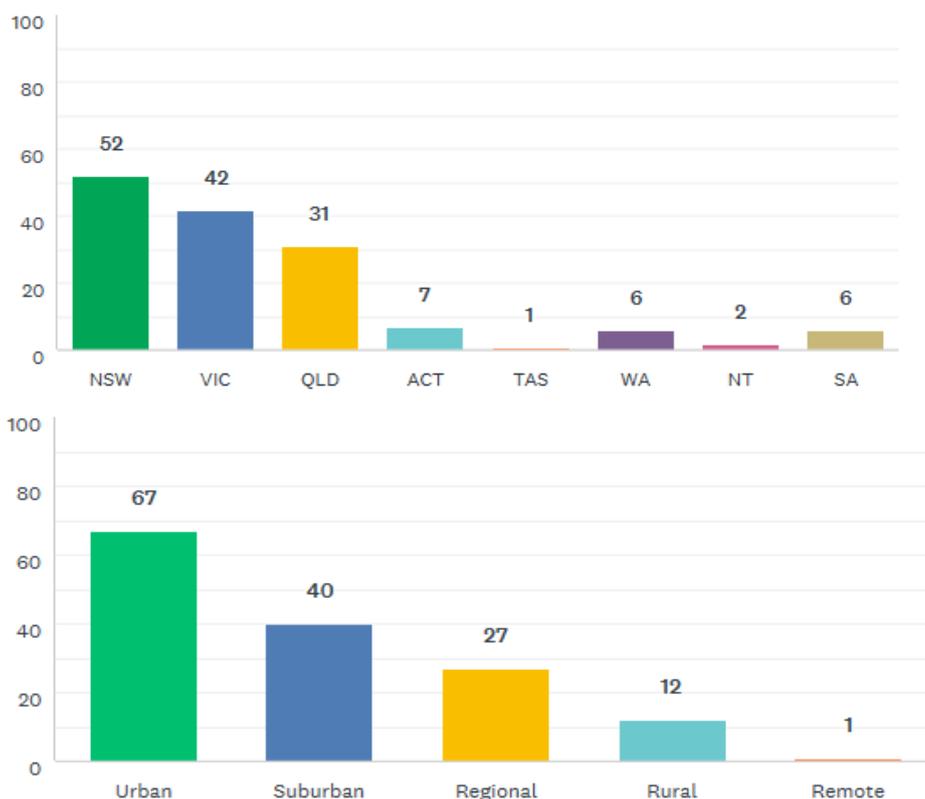


## Q3: What ethnicity do you identify as?

Of the 132 people who answered this question- 119 identified as either Australian, Anglo or European, 3 identified as Asian, 2 identified as Mixed Race, 1 identified as Aboriginal/ South Sea Islands, 1 identified as Māori, 1 identified as Indian, and 5 did not want to specify.

## Q4: Location

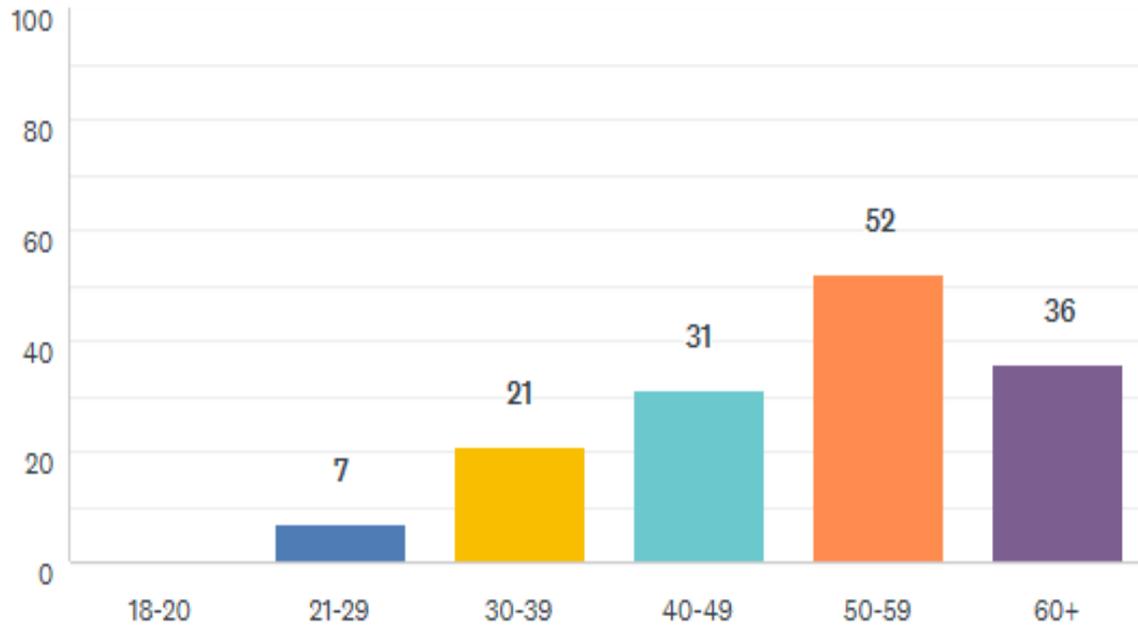
147 people answered this series of questions about the spread across the jurisdictions and whether they were located in Urban environments or more Regional places.



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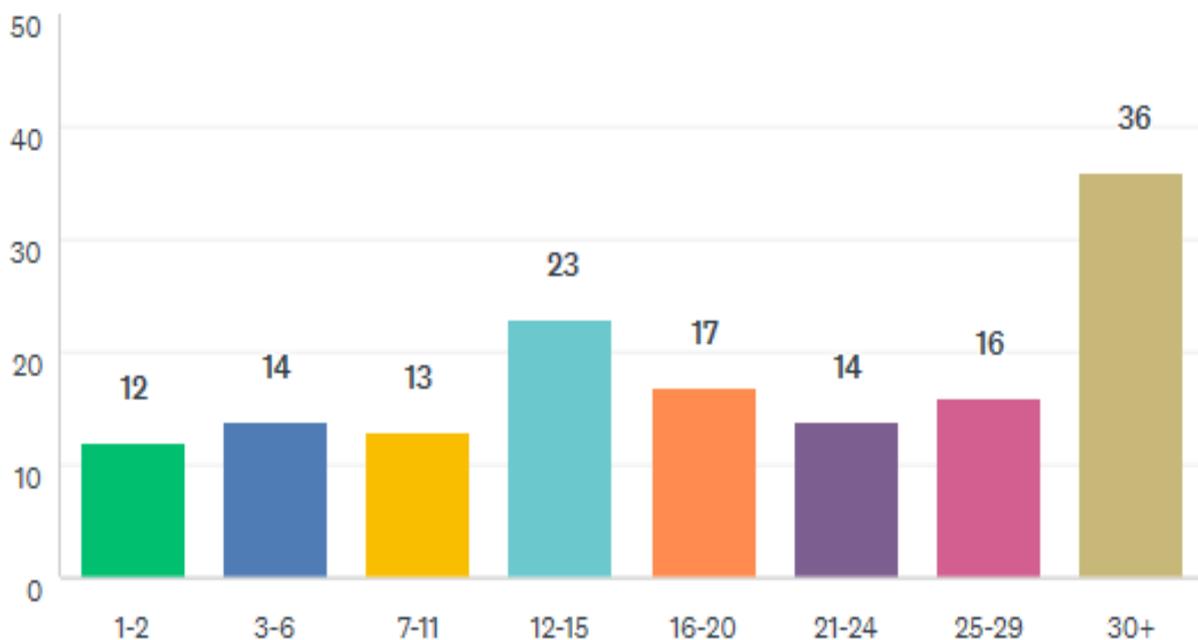
## Q5: Age

147 people responded to this question



## Q6: Years since HIV diagnosis

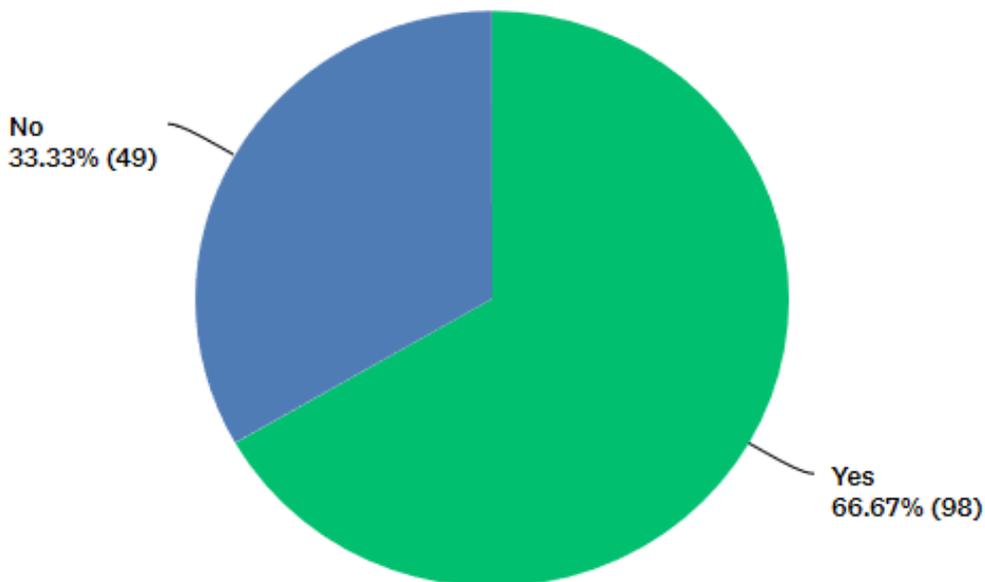
145 people answered this question and 2 people preferred not to disclose.



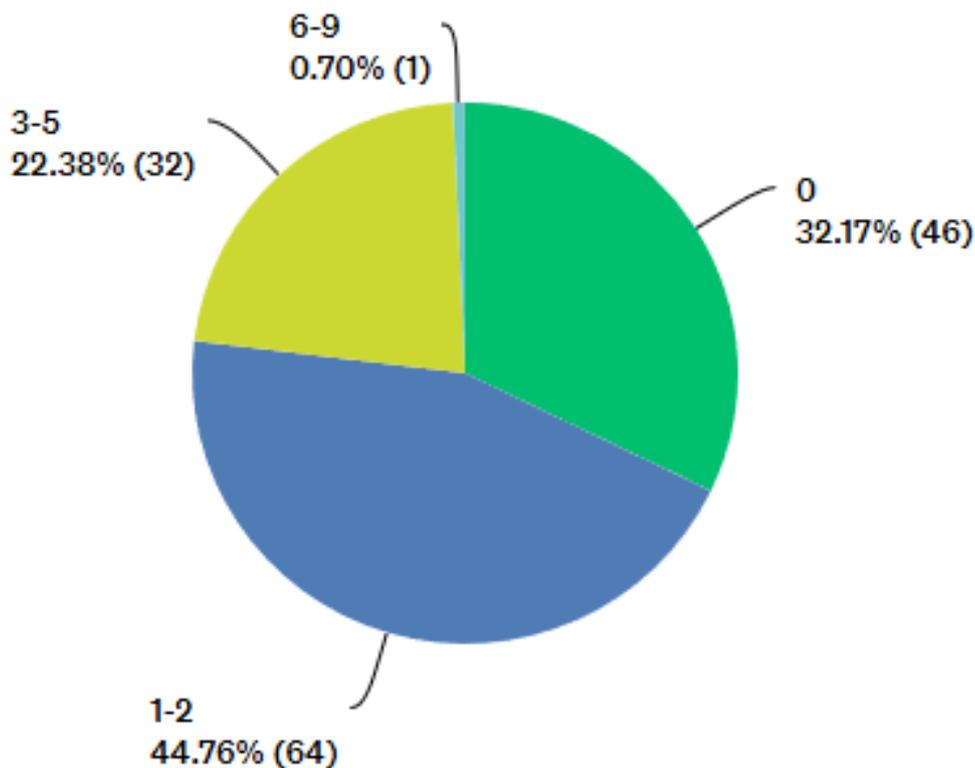
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## Q7: Co-morbid conditions

The first question asked broadly whether survey participants had co-morbid conditions. **147** people responded to this question.



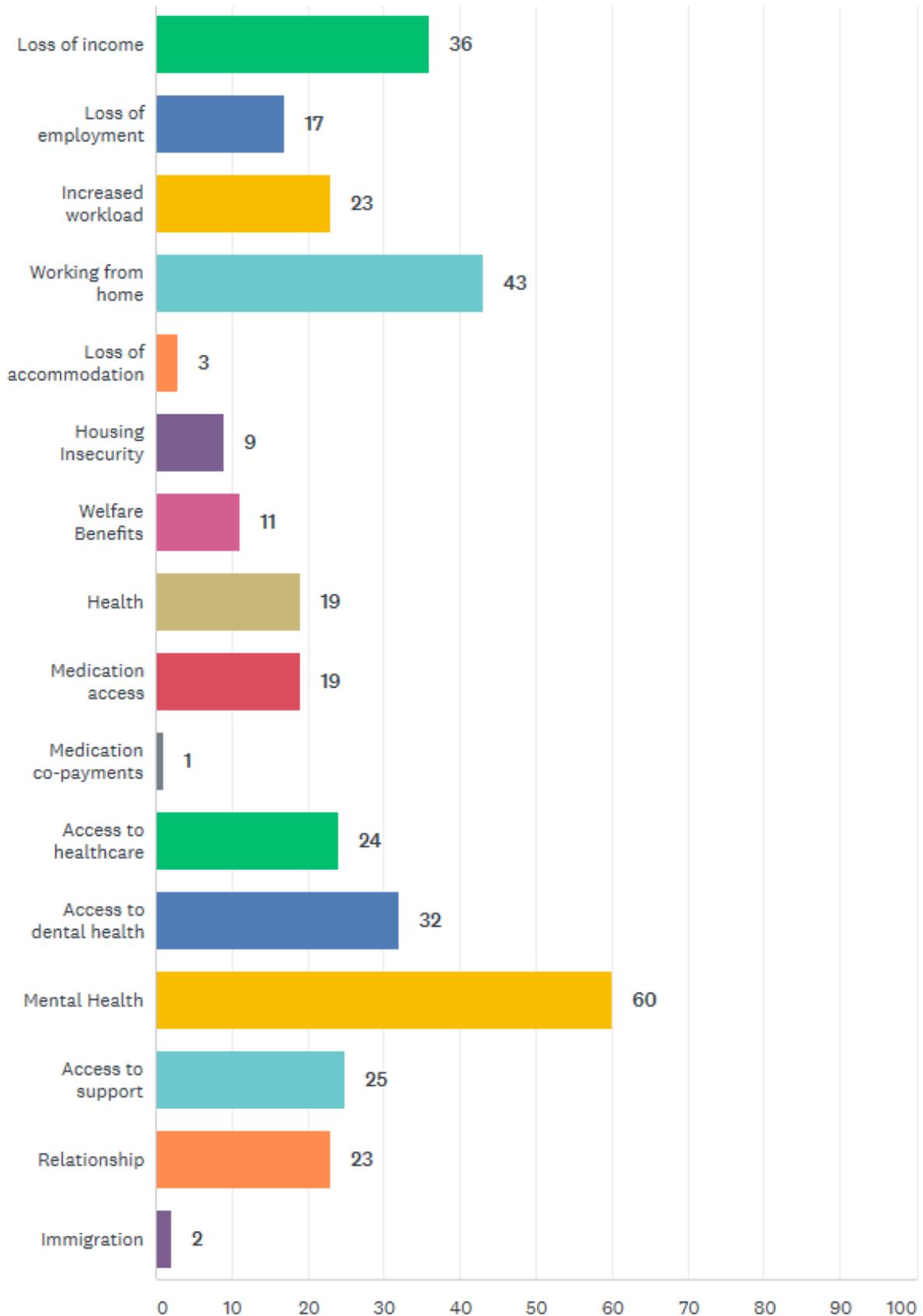
The second part of the question asked respondents to specify roughly how many co-morbid conditions they live with. **143** responded to this question.



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## Q8: How has COVID-19 impacted you?

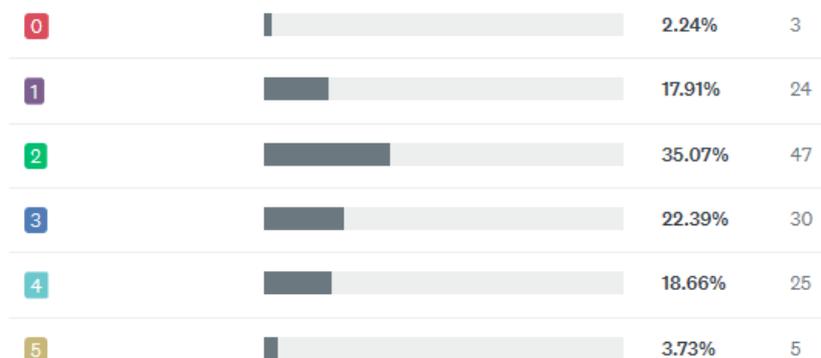
125 participants completed this question asking them to select categories that applied.



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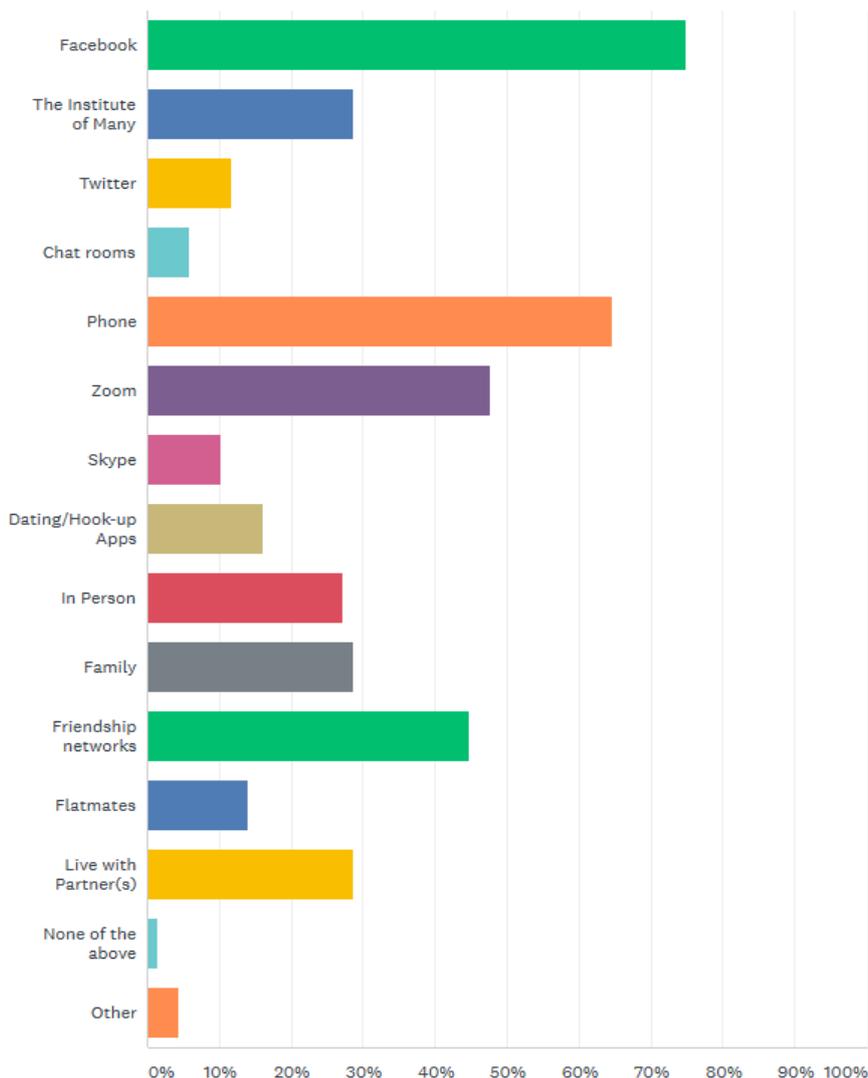
## Q9: How connected are you keeping?

134 people responded. This was measured on a sliding scale with 0 being **Not at all** and 5 being **Extremely**



## Q10: How are you maintaining Social Connection during COVID-19?

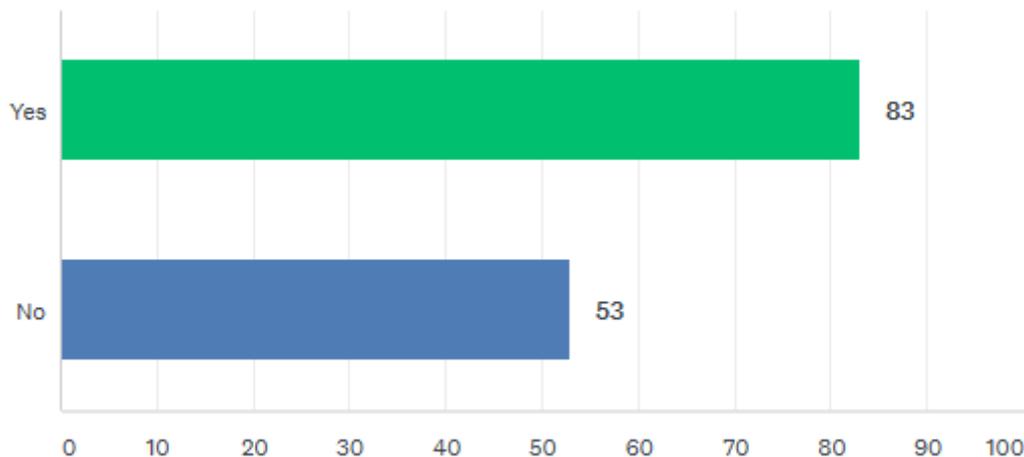
This question asked participants to record any that applied to their situation. 136 people responded



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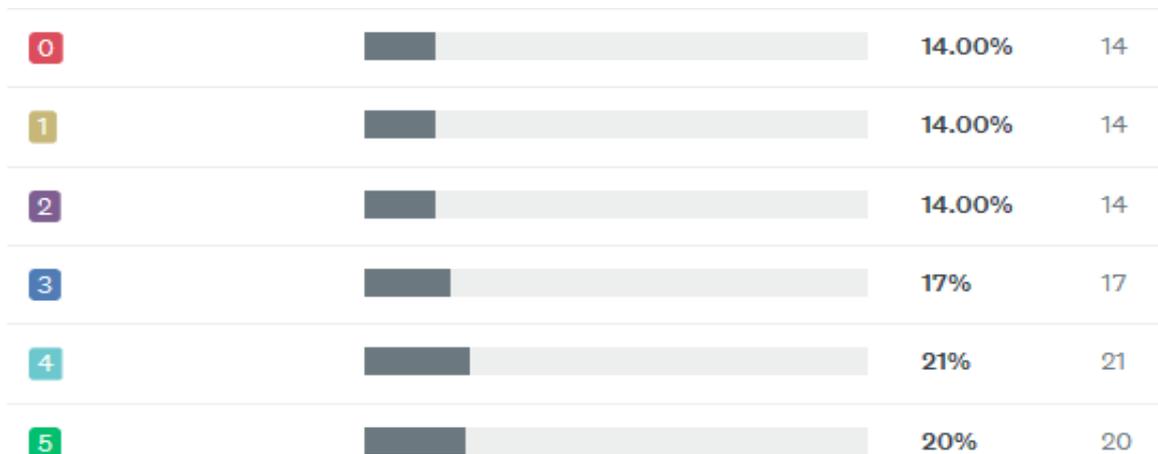
Q11: Have some or all of your Medical appointments been moved to telehealth (Skype, Phone, Zoom)?

136 participants answered this question



Q12: How satisfied have you been with your telehealth appointments?

100 participants answered this question, with the scale of: 0 being **Not at all** and 5 being **Extremely**.



Q13: Feedback for Telehealth / Virtual medical appointments (a snapshot)

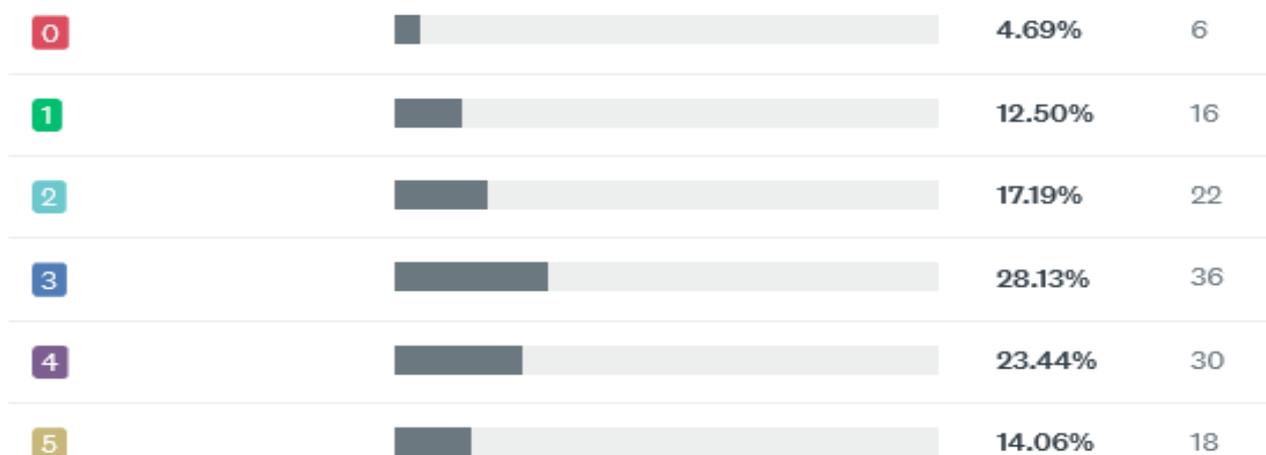
- These are generally so much more convenient and easier to manage - but this is based on preexisting relationship with health care provider. Maybe hard to establish relationship through telehealth.
- They seem very brief compared to face to face. I'm not able to go into as much detail as I would like.
- I feel there is less space to talk about things that are happening, and it becomes more of a checklist-based conversation.
- A sensible stop-gap but they cannot compare to face-to-face.

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- Not really. I live west of the appropriately named Great Dividing Range, so services are limited here.
- Video link would have been better than phone appointment, was not offered as an option.
- Yes, what a great system. Why isn't this part of the medical system permanently?
- I can't see my usual S100 prescriber in Sydney who I have seen for 28 years. I also like to get my pathology and other tests done when I see him so these have been delayed until I can travel again.
- It's really hard to get your point of view across over the phone.
- It's really not possible to address physical health problems over Telehealth. Doctors do not have enough time nor enough concentration to address all issues brought up during Telehealth.
- My psychologist wants virtual appointment, but it is my sole breach of isolation so need to pay for some human interaction.

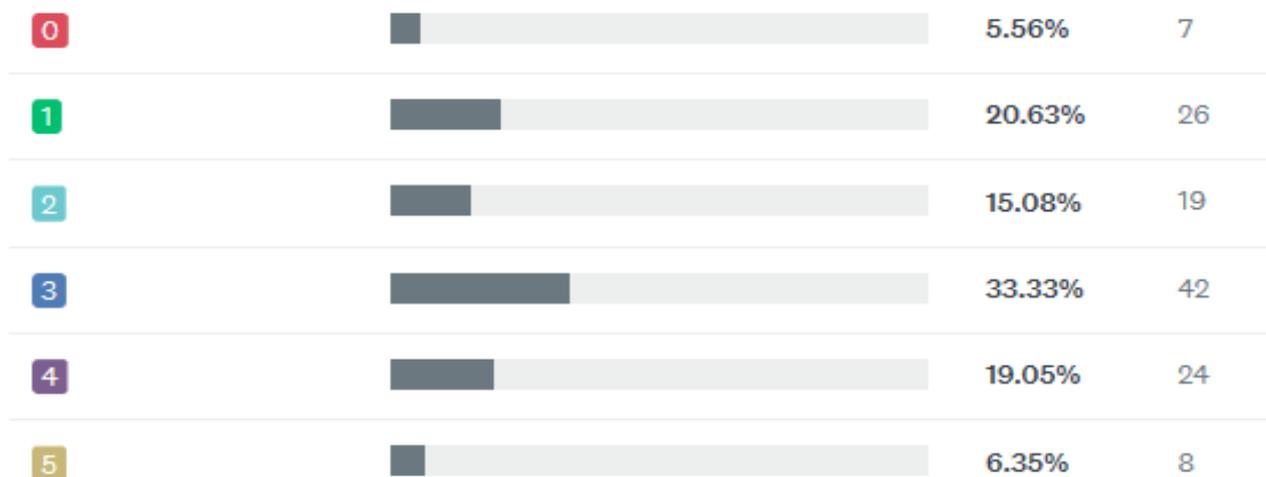
### Q14: Has COVID-19 affected how you are currently feeling?

128 people completed this question with the scale 0 being **Not at all** and 5 being **Extremely**



### Q15: How do you feel about COVID-19 in relation to yourself?

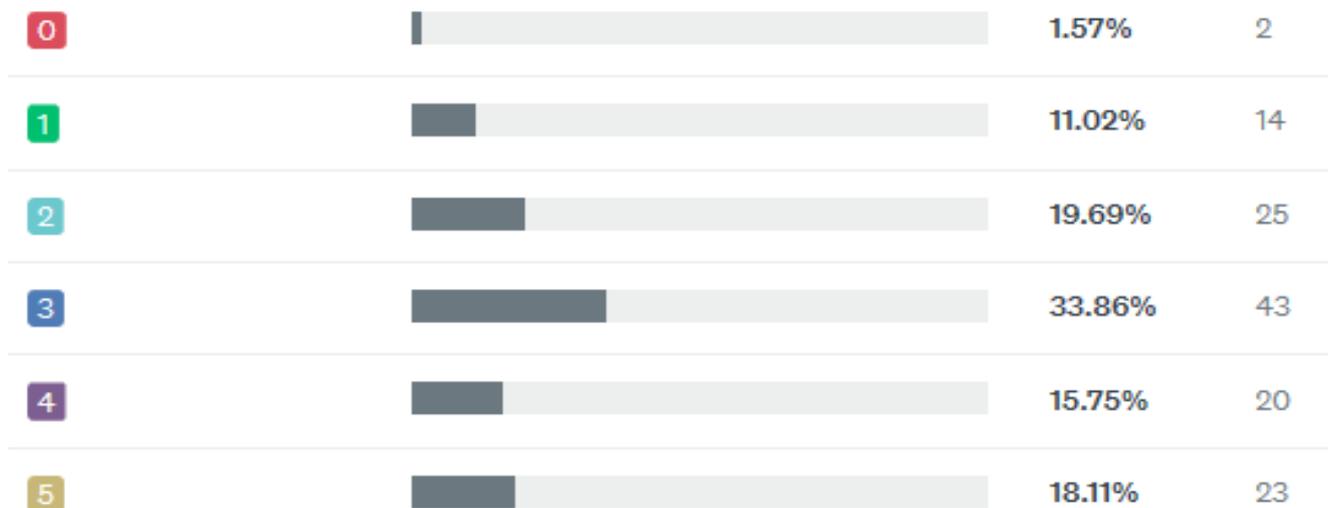
128 people responded with the scale of 0 being **Not concerned at all** and 5 being **Extremely concerned**



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### Q16: How do you feel about COVID-19 in relation to others close to you?

127 people responded with the scale of 0 being **Not concerned at all** and 5 being **Extremely concerned**



### Q17: Please describe your concerns (a snapshot)

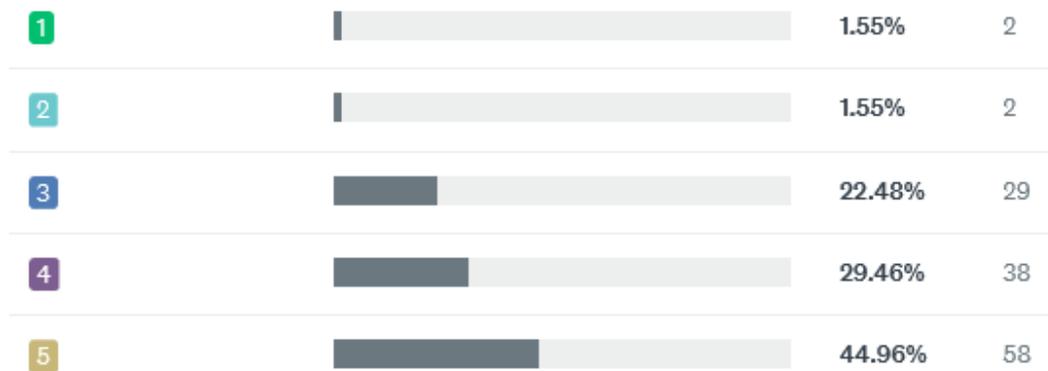
In this section there were **95 comments**, NAPWHA has gathered a broad range of the concerns and can provide the full list on request.

- No or little testing for asymptomatic people No tracking and testing of people who have recovered Community spread could increase with the lifting of restrictions
- I've lived successfully with depression for 20 years. Covid19, and the uncertainty and social media misinformation, have exacerbated my depression
- Australia has done well. I fear complacency and a significant 2nd wave. Most of my friends and myself are sticking to the rules - but if they are re-imposed after some relaxation that will be tough.
- Missing company and a chat
- As I'm still working as an outreach worker for vulnerable people living with HIV, I am careful and concerned every day. I also worry about my flatmate, she has an auto-immune disease.
- Daughter has a chronic illness and I have several chronic illnesses, it's difficult to assess risk to be honest.
- I have a low CD4 count, my partner also; my partner recently recovered from PCP and has some lung scarring. His parents who live close by are elderly with health issues. We all feel that we are at a higher risk than the general public.
- We have had no feedback about how many people that are HIV+ have contracted COVID-19, how they coped with it, are we more or less likely to die from it?

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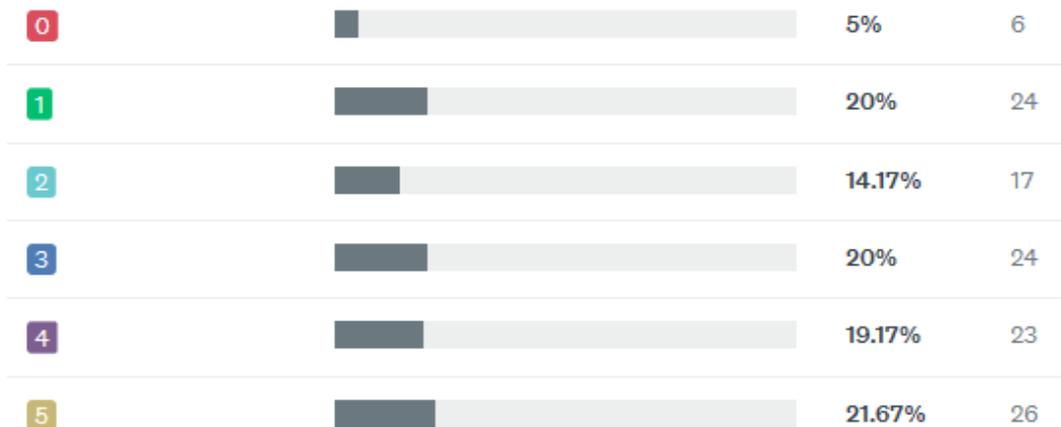
### Q18: How informed do you feel about COVID-19

129 people completed this question with the scale 0 being **Not at all** and 5 being **Extremely**. (No respondents selected the 0 value.)



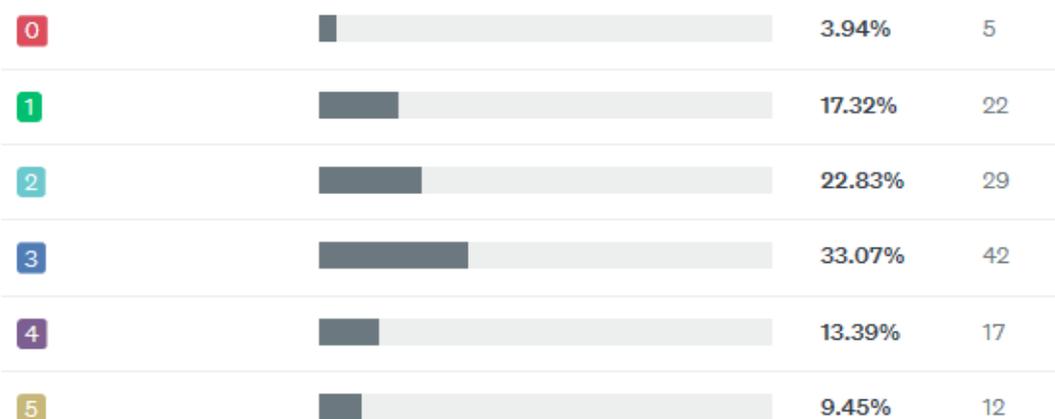
### Q19: Has Physical Distancing impacted your mental health?

120 people completed this question with the scale 0 being **Not at all** and 5 being **Extremely**



### Q20: How supported are you feeling?

127 people completed this question with the scale 0 being **Not at all** and 5 being **Extremely**



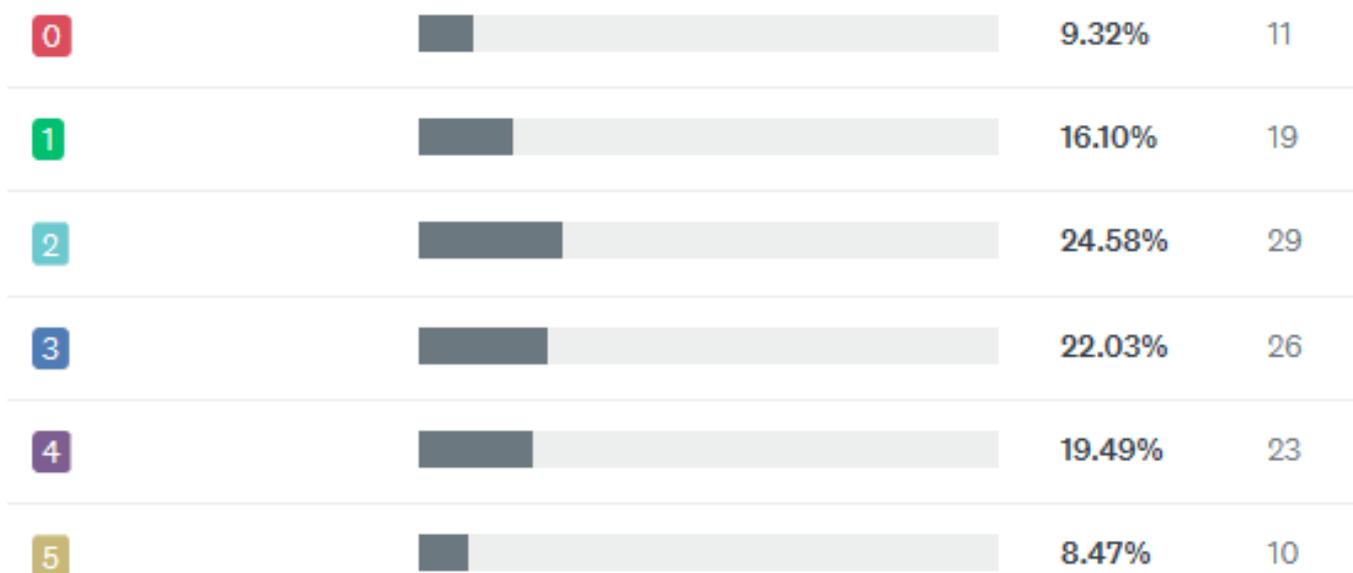
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### Q21: What could be done to better support you? (a snapshot)

- When I lost my job, I was very stressed about my situation as a NZ citizen living in Australia with no access to benefits. If I didn't get another job, I would have had to move back to NZ. I think the Australian government could really take a step back and re-evaluate their decision to lock Kiwis out of financial support here.
- It is a hard time, I don't know what more could be done in person, but I would appreciate access to a zoom session for HIV poz people as my area does not have a support group at all.
- A return to regular health care. Appointments made and kept with the public dental health system as well as a broadening of services offered to HIV positive people in the sexual health clinics. Especially in those parts of the state that don't have many S100 prescribers.
- Financial aid to see Dr. and access to mental health practitioners.
- Safe housing.
- More Virtual Meeting opportunities
- Government subsidy for mental health consultations, as I've already used my 10 x sessions
- Some peers to communicate with.
- More information from the immigration on how covid19 affects the invitation of temporary/permanent residency

### Q22: How are you feeling about your future?

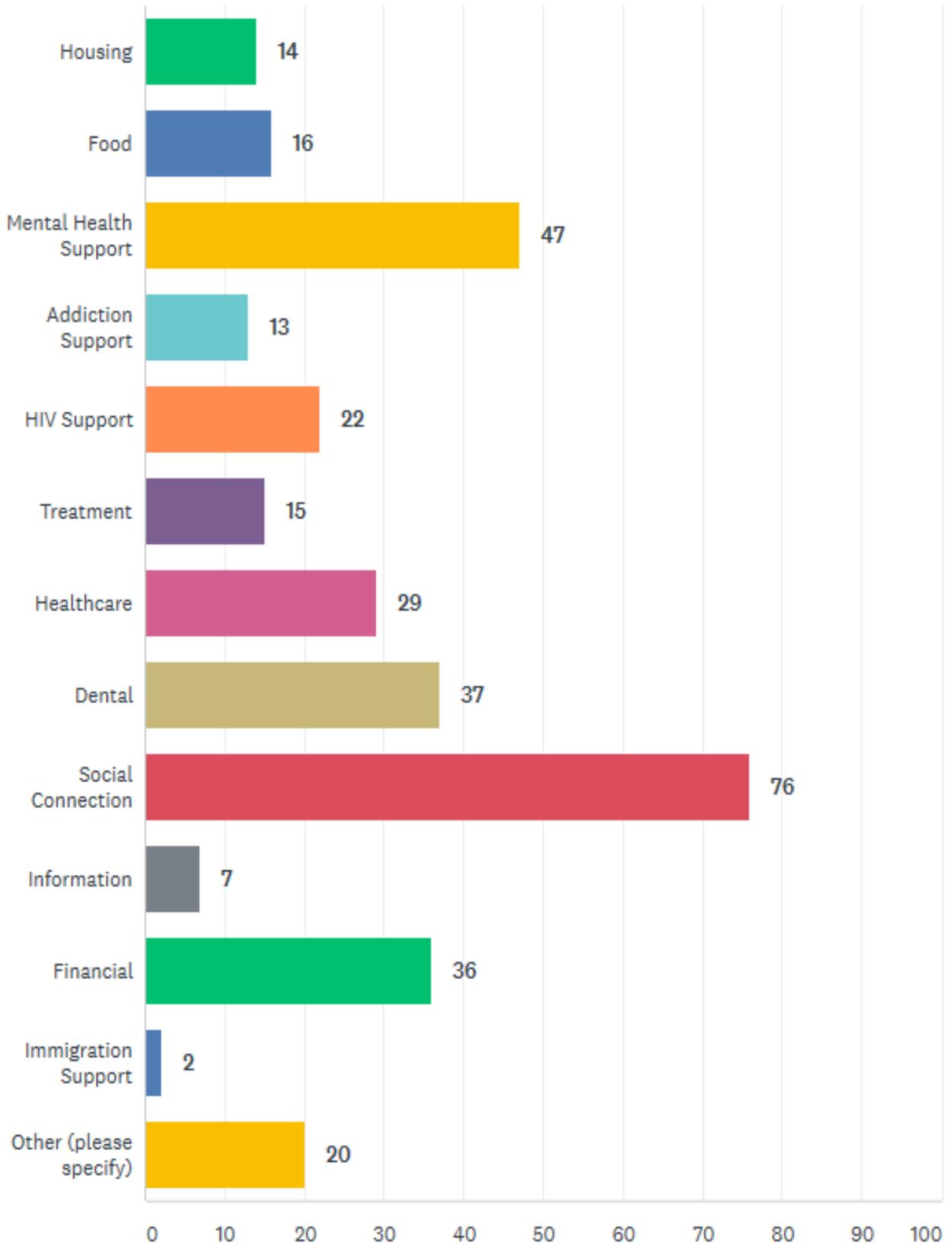
127 people completed this question with the scale **0** being **Optimistic** and **5** being **Fearful**. We wanted to measure people's optimism about their post-COVID-19 lives, given the level of uncertainty and the impact on things like social relationships and job security.



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### Q23: What are your most pressing needs?

121 participants completed this question.



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## Specific Comparisons from the data

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NAPWHA checked for differences in responses from the survey participants across two comparisons: the number of years since HIV diagnosis and residence in urban/suburban or non-urban settings (regional, rural, and remote).

The limited size of survey participants (147) and having optional questions precludes the calculation of statistical significance.

## Years since HIV diagnosis: Under 12 years vs. Over 12 years

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The vast majority of respondents to this survey had been living with HIV for longer than 12 years (**73.1%**).

### Location:

- People living with HIV for longer than 12 years were more likely to live in Rural, Regional or Remote settings.

### How has COVID 19 impacted on you:

- People living with HIV for under 12 years were more likely to have their accommodation impacted by COVID-19, reporting loss of accommodation or precarious or unstable accommodation.
- People living with HIV for under 12 years were more likely to report impacts on their social connectedness.
- People living with HIV for more than 12 years were more likely to report impact on their mental health and access to support.
- People living with HIV for longer than 12 years were more likely to report reduced access to dental health care.

### How are you maintaining social connection:

- People who have been living with HIV for less than 12 years were more likely to use social media and online mechanisms for connection (Facebook, Twitter, Chat rooms) though they were both using The Institute of Many the same amount as a place for connection.
- People who have been living with HIV for less than 12 years were more likely to report engaging in in-person social connection, and the use of Dating/ hookup apps to stay connected.
- People living with HIV for longer than 12 years were more likely to report phone use as a source of connection. This tracks with information coming from community engagement and peer workers from places like Living Positive Victoria & BGF demonstrating that broad trends in moving to online platforms for support can create barriers for ageing populations.

### Telehealth:

- People living with HIV for over 12 years were more likely to report dissatisfaction with telehealth which may be consistent with their reporting an increased number of co-morbid conditions and more complex health needs.

### How do you feel about COVID-19 in relation to yourself/others and emotional wellbeing:

- People living with HIV for over 12 years reported higher rates of personal concern over COVID-19, but their counterparts had higher rates of concern for others close to them.

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- People living with HIV for under 12 years were more likely to report that COVID-19 had serious impact on how they were currently feeling and their mental health. They also were more likely to show an increased level of apprehension about their future post-COVID-19.

### Most pressing needs:

#### People who have been living with HIV for less than 12 years (30 responses):

- Mental Health Support (16.67% vs 9.89%)
- Housing (43.33% vs 37.36%)
- HIV Support (26.67% vs. 15.38%)
- Food (16.67% vs. 12.09%)
- Treatment (20% vs. 9.89%)
- Healthcare (26.67% vs. 23.08%)

#### People who have been living with HIV for more than 12 years (91 responses):

- Addiction Support (13.19% vs. 3.33%)
- Dental Support (32.97% vs. 22.33%)
- Social Connection (65.93% vs. 53.33%)

## Location: Urban & Suburban vs. Regional, Rural & Remote

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The majority of participants in this survey lived in an Urban or Suburban setting (72.79%) compared with Regional, Rural & Remote (27.21%)

### Co-Morbid conditions:

- People living in Regional, Rural and Remote setting were more likely to be living with co-morbid conditions when comparing the number of respondents. (72.50% vs. 64.49%)

### How has COVID 19 impacted on you:

- People living in Regional, Rural and Remote were more likely to experience loss of employment and an impact on their Pension or Welfare benefits.
- People living in Regional, Rural and Remote setting were more likely to have their access to support, healthcare and medication impacted.
- People living in Urban & Suburban settings were more likely to have impacted accommodation (loss of accommodation or precarious or unstable accommodation.)

### Social Connection:

- Regional Rural & Remote participants were more likely to have lower ratings for their sense of connection.
- Regional, Rural & Remote people were more likely to use twitter, in-person connections, and family to stay connected. They also were more likely to use the phone as a primary mechanism for connection.
- Urban & Suburban respondents were more likely to use Dating/Hookup apps, Skype, and Zoom for Social Connection.
- Urban & Suburban people were more likely to live in shared accommodation.

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## Telehealth:

- People living in Rural, Regional or Remote settings were more satisfied with the use of telehealth appointments.

## How do you feel about COVID-19 in relation to yourself/others and emotional wellbeing:

- People living in Urban & Suburban settings were more likely to experience a higher impact of COVID-19 on how they are currently feeling. But in the section where they were asked how they feel about COVID-19 in relation to themselves and those close to them people in Rural, Regional & Remote settings had a higher level of concern.
- People in Urban & Suburban areas were more likely to have had COVID-19 impact on their mental health.
- People in Rural, Regional & Remote settings were more likely to express fear or uncertainty for their future post COVID-19.

## Most pressing needs:

### Urban & Suburban (87 responses):

- Food (14.94% vs. 8.82%)
- Addiction Support (12.64% vs. 5.88%)
- Social Connection (64.37% vs 58.82%)

### Regional, Rural & Remote (34 responses):

- Mental Health (41.18% vs. 37.93%)
- Dental (38.24% vs. 27.59%)
- Financial (32.35% vs. 28.74%)
- Information (8.82% vs 4.60%)
- Healthcare (29.41% vs. 21.84%)
- Treatment (14.71% vs. 11.49%)
- Housing (14.71% vs. 10.34%)

## Acknowledgements:

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Ted Cook & Liz Duck-Chong for their guidance and expertise.

The Institute of Many

Positive Life NSW, Living Positive Victoria, Queensland Positive People, POWA, Positive Life SA, BGF

Positive Women Victoria, TASCAHRD, Positive Lives Tasmania, NTAC, Meridian