

Othink Consulting

# Queensland Positive People's Engagement with PLHIV



Queensland Positive People

INCLUSIVE, INNOVATIVE HIV SERVICES

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## Developed by Queensland Positive People

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# EXECUTIVE SUMMARY

**In 2021, Queensland Positive People (QPP) engaged QThink Consulting to design a project that sought to capture the perspectives of people living with HIV (PLHIV) in Queensland.**

This project focused on the range and quality of positive people's engagement with QPP programs and services. The project also included a quality of life tool (i.e. PozQol) to gain further insights into the social, functional, psychological and physical health needs of PLHIV across the state.

This report reflects the views of the largest sample of PLHIV ever collected in Queensland, with over 170 individual responses representing more than a dozen priority groups and communities.

Based on these responses, this report concludes that most PLHIV in Queensland:

- Believe that QPP generally involves community members in its work
- Think that QPP advocates for a diversity of PLHIV
- Feel that QPP values their lived experience, works to empower community members and brings positive people together
- Enjoy a generally good quality of life compared to national averages

However, inquiring into agency engagement also revealed that positive people in Queensland:

- Who are women, heterosexual or regionally located find overall agency engagement and service options could be improved
- Want expanded social support, peer networking and educational programs
- Report lower-than-average quality of life concerning their relationships and sense of belonging

This report provides granular detail to corroborate these findings. Based on these discoveries, the report proposes eight recommendations to improve the range and quality of QPP's engagement with PLHIV.

It is never straightforward for an organisation to open itself to external review. Such an undertaking can be a challenge for staff and management but, ultimately, it is an opportunity to improve. To their credit, QPP's staff, management and directors were highly supportive.

They helped tailor the process to a Queensland context and were willing to listen to what PLHIV had to say. As a result, they have set a high bar for agencies that want to understand better the needs of the people they serve.

This report was only possible with the help of many individuals. In particular, we would like to thank Melissa Warner, Chris Howard, Glenn Ryall, Adam Finch, Jennifer Power, the QPP Consumer Advisory Group, the Board of Directors, staff members and partner agencies.

We'd like to thank every person living with HIV who participated in the project for their cooperation, time and expertise.

*Brent Allan*

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Qthink Consulting  
May 2022

# WHY AN ENGAGEMENT PROJECT?

**As a peer-led HIV organisation, Queensland Positive People (QPP) recognises the centrality of the positive voice and the importance of the lived experience of HIV. We are committed to the Meaningful Involvement of People with HIV (MIPA) and recognise that PLHIV are central to the HIV response.**

In alignment with MIPA principles, QPP acknowledges the importance of listening to the diverse voices of PLHIV to help shape the development, implementation and evaluation of our prevention, treatment and support programs.

Last year marked 40 years since HIV/AIDS was first identified and 32 years since QPP was established. Much has changed over this time for people with HIV, including effective treatment and prevention and improved life expectancy.

However, despite advancements, we have also seen a divergent epidemic with higher numbers of diagnoses among women, First Nations people, young people and people from culturally and linguistically diverse backgrounds. In addition, there remain a number of challenges for people with HIV, such as the pervasive nature of HIV stigma, social isolation and ageing with HIV, to name a few.

While QPP has implemented community engagement initiatives in the past, QPP felt it was time to embark upon a significant community engagement survey to assess how well QPP is engaging with the diverse community of people with HIV across the state.

Ensuring we put MIPA principles in action and at the core of what we do, we wanted to know who we are serving well, who we need to serve better, what is working well, what is not and what we can do better.

The findings and recommendations of this report provide invaluable insight and will help inform QPP's strategic and operational planning and service delivery priorities to ensure they align with community needs.

QPP will commit to the further development of the report recommendations with QPP's Community Advisory Group (CAG) and other PLHIV representative groups to help inform service development and ensure that services align with community needs.

QPP will provide updated information on the actions and progress in relation to each of the recommendations detailed in the report. It is important to QPP that community are informed of progress and that we remain transparent and accountable. We want you to know your voices have been heard.

*Melissa Warner*

**Melissa Warner (she/her), CEO**  
Queensland Positive People

**Ensuring we put MIPA principles in action and at the core of what we do, we wanted to know who we are serving well, who we need to serve better, what is working well, and what we can do better.**

# + KEY FINDINGS

## QPP'S WORK & SERVICES

- Most people believed that QPP involves community members in its work and values their lived experience
- Many people were unsure what services QPP offers but most agree that they are respectful and non-discriminatory
- Some others expressed a desire for expanded social support services

## ADVOCACY & REPRESENTATION

- People expressed a desire to be more involved with QPP and the HIV response, as well as for education and training
- Many noted a lack of visible HIV advocates in Queensland and thought that QPP could do more to empower positive people to self-advocate
- People were unsure about how to provide feedback to QPP and whether a diversity of positive people are represented internally at the agency

## AGENCY ENGAGEMENT

- The report indicates that QPP engages very well with people of colour and gay and bisexual men
- It also suggests that QPP needs to improve its engagement with straight people and people who live rurally and regionally
- Engagement practices with a handful of groups, such as First Nations and transgender and gender diverse people, require further investigation

## QUALITY OF LIFE

- People reported a good quality of life on par with national averages, except in regards to how HIV affects their relationships and social wellbeing
- While there is some concern around HIV and ageing, most people feel able to manage their health
- People were especially concerned about disclosure and HIV stigma and reported feelings of fear, loneliness, isolation and self-stigma

# RECOMMENDATIONS

1

## DEVELOP A COMMUNITY ENGAGEMENT STRATEGY

**This report shows that QPP can improve engagement with several communities. QPP should consider developing a Community Engagement Strategy that outlines how the agency will improve its engagement, support and service provision for PLHIV, especially those from disengaged communities.**

### 1.1. PROVIDE SUPPORT FOR DISENGAGED PLHIV

This report identifies QPP's engagement with regional and rural people, straight people, and women as needing improvement. QPP should explore how best to support positive people who belong to these groups.

### 1.2. INVESTIGATE ENGAGEMENT WITH UNDERREPRESENTED PLHIV

There were few First Nations people, transgender and gender diverse people, asylum seekers and refugees, incarcerated people or under 25s in the survey. QPP should consider alternative consultation mechanisms to evaluate engagement with these communities and groups.

### 1.3. ESTABLISH POPULATION-SPECIFIC REFERENCE GROUPS

As part of an engagement strategy, QPP should consider establishing population-specific advisory or reference groups for under-engaged or under-represented groups, especially women and straight people living with HIV.

2

## PROVIDE MORE SUPPORT SERVICES

Survey participants expressed a strong desire for community, education and support services. QPP should consider maintaining and expanding the support services it provides, as well as evaluating the efficacy of existing services.

### 2.1. EXPAND SERVICE DELIVERY OPTIONS FOR REGIONAL & RURAL PLHIV

Positive people living in rural and regional areas face considerable isolation and loneliness. Therefore, QPP should consider investigating additional viable service delivery options to promote engagement and encourage service use.

### 2.2. EXPAND EDUCATION & HEALTH PROMOTION

The survey data reveals the corrosive impact of stigma on positive people's quality of life. For instance, PLHIV in Queensland fear rejection due to their status and how HIV limits their relationships. As part of an expanded service suite, QPP should consider disclosure and stigma resources and support.

3

## RE-EXAMINE FUNDING STRATEGY

The report reveals a tension between what PLHIV in Queensland expect of their HIV agency and the type of funding QPP receives. As a result, QPP should re-examine potential funding avenues, especially those the agency can use to fund additional support services.

## 4

## EMPOWER COMMUNITY ADVOCATES

Around 1 in 3 people thought that QPP can improve how much it empowers people living with HIV to advocate for themselves. At the same time, interviewees noted a lack of HIV activists and role models in Queensland. QPP should consider a long-term program that aims to support, up-skill and empower positive people.

## 6

## BUILD MEMBERSHIP & VOLUNTEERISM

Membership and volunteer drives represent an opportunity for PLHIV to be more involved in Queensland's HIV response and learn about what QPP does.

### 6.1. OFFER VOLUNTEERING OPPORTUNITIES

People who took part in the 1-1 interviews expressed a desire to participate in education and outreach programs as volunteers but felt there were few opportunities available. Therefore, QPP should consider offering volunteering opportunities at multiple levels of the organisation to empower PLHIV and promote engagement.

## 5

## IMPROVE COMMUNICATION

One theme throughout this report is a general lack of knowledge about QPP's work. This included things such as what QPP does, what services it offers and who it services. For this reason, QPP should examine how it can raise awareness about what it does and the services it offers.

### 5.1. EXPLORE ALTERNATIVE COMMUNICATION METHODS

In the open-ended responses, people noted that QPP lacked a presence in their community, and contacted them infrequently or only via one method (e.g. emails). QPP should explore other ways of reaching out to positive people to encourage their greater involvement.

## 7

## PLAN FOR AN AGEING POPULATION

The number of older PLHIV is expected to increase as time goes on. Further, this report found strong links between older PLHIV, disability and potential for social isolation. Therefore, QPP should consider planning for the care and support of ageing PLHIV.

## 8

## DEVELOP RECOMMENDATIONS WITH COMMUNITY

The previous seven recommendations are provisional suggestions based on information collected for the report. In line with MIPA principles, QPP should co-design, develop and implement these recommendations in close collaboration with impacted communities.

# Queensland



It is estimated that there are over 5,500 people living with HIV across Queensland.

Approximately 50% of people living with HIV live in regional and rural areas.



PLHIV

Transgender and gender diverse people, non-binary, fluid identities are not well published

**20%**  
heterosexual – around 10% males and 10% females

**5%**  
men who have sex with men and injecting drug use



**75%**

men who have sex with men

## New infections of HIV reported in Queensland in 2018

- 80%** 20-50 years of age
- 50%** over 50 years of age
- 10%** First Nations
- 1%** PLHIV under 18 years



**70%**  
Australia

- 6%** South-East Asia
- 4.7%** North-West Europe
- 4.1%** New Zealand
- 2.9%** Sub-Saharan Africa



# WHO ANSWERED THE SURVEY?

## HIV IN QUEENSLAND

According to the 2018 *HIV in Queensland* report, around 5,500 people live with HIV in the state. The report also found that 1 in 3 new cases were recently acquired. At the same time, the Kirby Institute's 2021 Annual Surveillance report showed that the overall notification rate is declining.

*HIV in Queensland 2018* showed that the largest number of new cases were from metropolitan hospitals and health Services (63%), followed by the Gold Coast (13%) and Cairns (9%). People aged 20-50 account for 67% of all new diagnoses. In particular, people aged 20-29 accounted for 1 in 3 of all new cases of HIV in Queensland.

In 2018, more than 90% of new HIV diagnoses were men. This included men who have sex with men (60%), straight men (15%), injecting drug users (10%) and a low number of cases where the circumstances of transgender and gender diverse people were unknown. This means that (mostly straight) women make up just under 10% of new diagnoses.

Further, the *HIV in Queensland 2018* report found that First Nations men had the highest notification rate of new diagnoses, followed by non-Indigenous men, First Nations women, and non-Indigenous women.

Finally, the Kirby Institute's 2021 *Annual Surveillance* report found that 24% of new HIV cases in the state were first diagnosed overseas. Similarly, the *HIV in Queensland* report found that most newly diagnosed people were born in Australia (69.2%), followed by South-East Asia (6%), Europe (4.7%), New Zealand (4.1%) and Sub-Saharan Africa (2.9%).

People who responded to the survey were typically cisgender gay men aged 30 and over. They were primarily Anglo-Australians born in Australia who live in metropolitan Queensland. Most were diagnosed with HIV after 1996. These characteristics make the sample roughly comparable to the wider population of PLHIV in Queensland.

Most people reported regulated drug use, with a significant portion reporting unregulated drug use. Most had no experience in the sex work industry. Similarly, most people who responded do not live with a disability, but a significant portion does. Finally, very few people had experience with jails or prisons.

The most common educational qualifications were certificates, diplomas and bachelor's degrees. Nearly everyone who responded took home under \$100,000 a year, with a large number earning \$45,000 or less. Interestingly, just under 1 in 2 people were not current service users with 71 people (43%) never having used a service before.





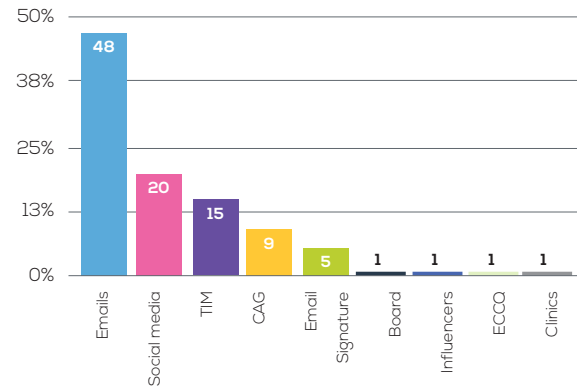
**This report suggests that PLHIV in Queensland are especially vulnerable to loneliness and isolation, and survey participants expressed a strong desire for community, education and support services. QPP should consider maintaining and expanding the social services it provides, as well as evaluating the efficacy of existing services.**



**This outcome suggests a core group of QPP clients are engaged with and receptive to the organisation, which bodes well for engagement and further investigations.**

Fig1

Survey collectors with one or more responses



(Percentages calculated from 171 responses)

## SURVEY RECRUITMENT

QPP invited HIV positive people living in Queensland to participate in the survey via direct communication, social media promotion, HIV groups and strategic partnerships with community members, service providers and health organisations (see Figure 1).

The most successful recruitment method by a significant margin was emails, which returned 83 responses (48%). Social media posts attracted 35 responses (20%), The Institute of Many (TIM) 26 responses (15%) and the staff email signature eight responses (5%).

The QPP Board, community influencers, Ethnic Communities Council Queensland (ECCQ) and sexual health clinics collected one response each (1% respectively). See Figure 1 for a breakdown of survey collectors with one or more responses.

Nearly half of the recruitment methods did not return any responses at all. These include the Queensland Council for LGBTI Health (QC), the Queensland Injectors Health Network (QulHN), Hepatitis Queensland (Hep QLD), other non-government organisation (NGO) partners, academic researchers, 100 general practitioners (GPs) and the QPP website.

In other words, 4 of the top 5 recruitment methods involved QPP connecting directly with positive people in Queensland. This outcome suggests a core group of QPP clients are engaged with and receptive to the organisation, which bodes well for engagement and further investigations.

At the same time, most recruitment methods external to the organisation did not yield any responses. Therefore, it may be worthwhile to build working relationships with key partners to reach more PLHIV in the state. QPP can apply this information in the future to design more effective recruitment strategies.

## DEMOGRAPHIC CHARACTERISTICS

### AGE AND TIME OF HIV DIAGNOSIS

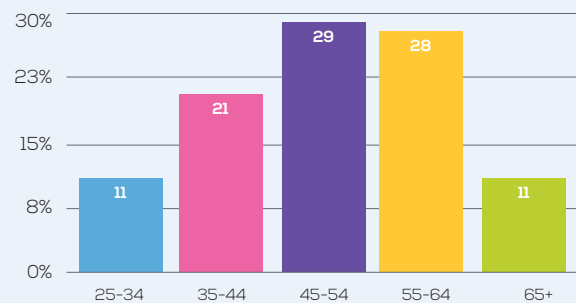
People who responded to the survey were mostly aged 30 years and over. Interestingly, there were no people under the age of 25. However, there were 19 people (11%) aged 25-34, 36 people (21%) aged 35-44, 50 people (29%) aged 45-54, 48 people (28%) aged 55-64 and 18 people (10%) over 65 (see Figure 2).

Most people were diagnosed with HIV after 1996. Forty-four people (26%) were diagnosed with HIV between 1981 and 1996, 55 people (32%) between 1996 and 2008, and 67 (39%) people since 2008. Four people (2%) declined to answer and 1 person skipped the question (see Figure 3).

Given that the average age trends older, it is interesting to note the high number of people (67 in total) who were diagnosed with HIV in 2008 or later. This group of people were distributed evenly across most demographic characteristics, for example, age and educational attainment.

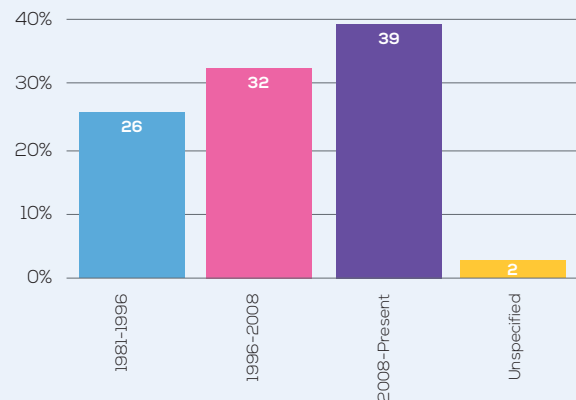
However, 2 things stand out. Firstly, nearly half the straight people in the survey fall into this group of most recently diagnosed. Secondly, 28 of them (44%) were not service users. This last point is on par with the number of non-service users in the survey overall, discussed below.

Fig 2 Age



(Percentages calculated from 171 responses)

Fig 3 Time of Diagnosis



(Percentages calculated from 169-171 responses)

**Again, the people who responded were largely endosex (i.e. not intersex). Respondents include 160 endosex people and two intersex people, with 9 people declining to answer.**



## GENDER AND SEXUALITY

The large majority of respondents were men. Of 171 people, 145 (85%) were men, 23 (13%) were women and one (1%) was non-binary. Two people (1%) declined to specify their gender (see Figure 4).

Most people were also cisgender. When asked to indicate their experience of gender, 148 (86%) indicated they are cisgender, 6 (3%) reported being non-binary, and one (~1%) was a brotherboy. Fourteen people declined to say (4%) and 2 people skipped the question.

There is a discrepancy here regarding the number of non-binary people in the survey. This is likely due to different individual understandings of what 'non-binary' means. What is important is that there were at least 6 gender diverse people in the survey.

Further, most people in the survey identified as gay. Breaking down the responses, 122 people (71%) were gay, 26 (15%) were straight and 16 (9%) were bisexual. Seven people (4%) declined to specify their sexuality (see Figure 5).

Finally, the people who responded were also largely endosex (i.e. not intersex). Respondents include 160 endosex people (94%) and 2 intersex people (1%), with 9 people (5%) declining to answer.

## ETHNICITY AND MIGRATION

The majority of respondents were born in Australia. One hundred and twenty people who responded (70%) were born in Australia, 46 (27%) migrated to Australia, and 3 (2%) sought asylum or refuge. Two people (1%) did not provide information about their relationship to Australia (see Figure 6).

Eighty-two people (49%) recorded their ethnicity as Oceanian (i.e. from Australia, New Zealand or greater Oceania). Seventy-four people (44%) recorded theirs as European, 11 (7%) as Asian, 4 (2%) as African, 4 (2%) as South American, 2 (2%) as North American and 1 (1%) as Middle Eastern (see Figure 7).

Fig 4 Gender

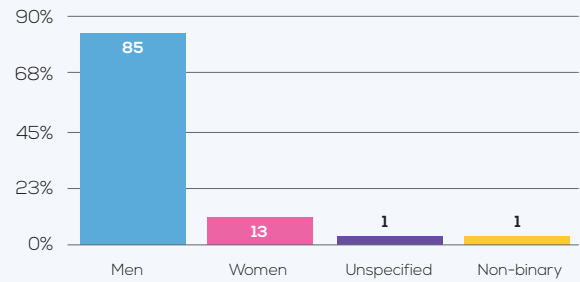
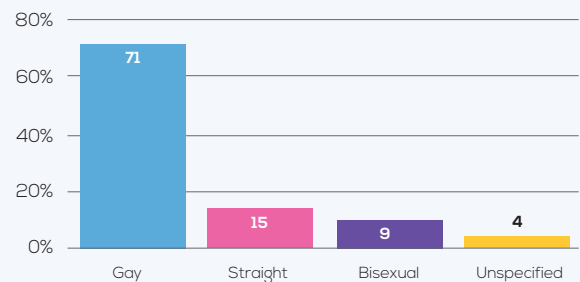
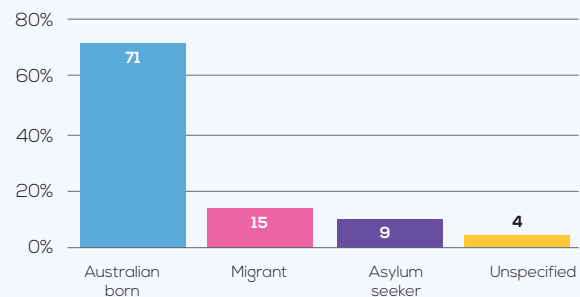


Fig 5 Sexuality



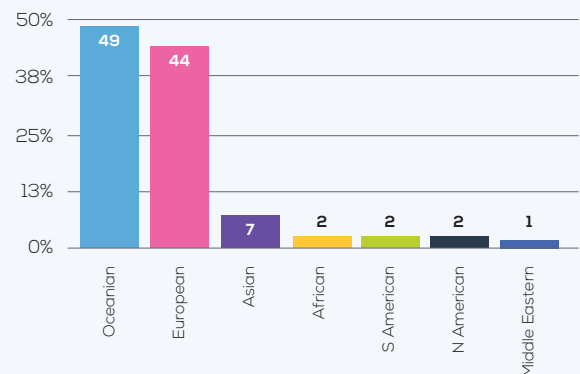
(Percentages calculated from 169-171 responses)

Fig 6 Relationship to Australia



(Percentages calculated from 171 responses)

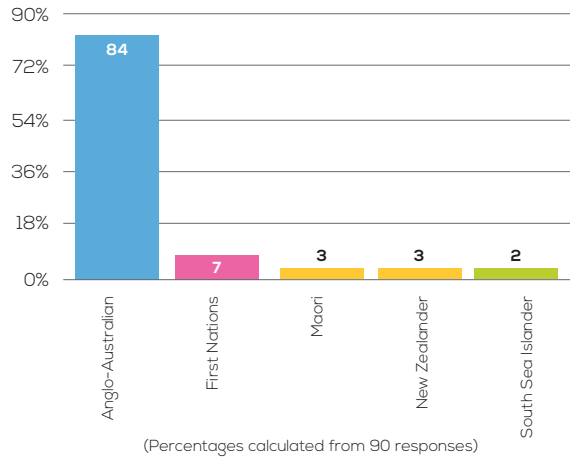
Fig 7 Global cultural and national backgrounds



(Percentages calculated from 169 responses)

Breaking down local ethnicity, 76 people (84%) indicated that they were Anglo-Australian. Six people (7%) recorded their background as First Nations, 3 (3%) as Maori, 3 (3%) as New Zealander and 2 (2%) as Pacific South Sea Islander (see Figure 8).

**Fig 8** Local cultural and national backgrounds



Additionally, 23 people were English, 16 were Scottish, and 11 were Irish. There were 4 German, Filipino, and Italian people respectively, and 3 Welsh people. Similarly, there were 2 Chinese, Dutch, Indonesian, South African, Austrian, and Zimbabwean people each.

Finally, at least one Argentinian, El Salvadorian, Peruvian, Lithuanian, Cambodian, Thai, Polish, Greek, Sri Lankan and Vietnamese person responded to the survey.

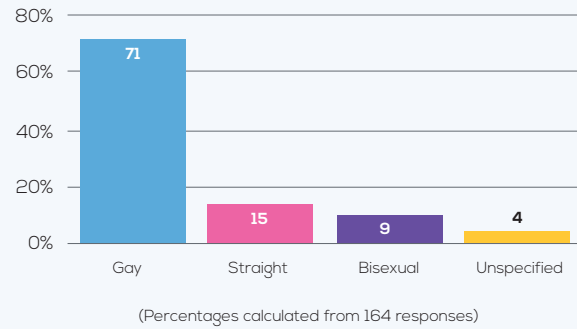
The numbers for these ethnicity questions do not necessarily represent individual people since the survey allowed people to indicate more than one background at a time. Instead, this data provides a rough overview of the survey's cultural, national and ethnic composition.

## REPORTED DRUG USE

Most people reported drug use of one kind or another. One hundred and twenty-three people (74%) said they would consume regulated drugs (such as alcohol and tobacco) in a given year.

A further 58 (35%) said they would typically use unregulated drugs (such as cannabis or MDMA). Thirty-three (20%) said they would usually use neither, 7 (4%) did not answer, and 5 people skipped the question (see Figure 9).

**Fig 9** Drug use



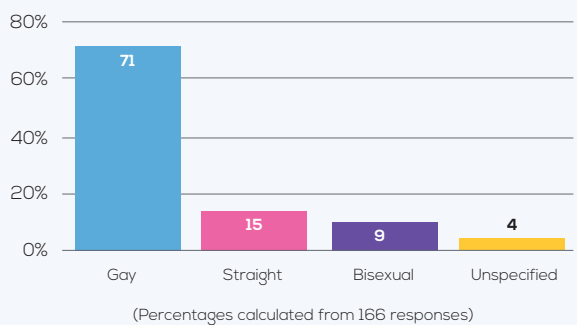
## SEX WORK EXPERIENCE

The majority of respondents had never worked in the sex work industry. One hundred and thirty-six people (82%) said they had never worked as a sex worker, 24 (14%) said they had in the past, 5 (3%) declined to answer, and 6 people skipped the question.

## ABILITY AND DISABILITY

Most people who responded to the survey do not live with a disability, but a significant number do. One hundred and nine people (66%) said they live without disability, 48 people (29%) reported a disability of some kind and 8 people (5%) declined to answer (see Figure 10).

**Fig 10** Ability



Of the 48 people with a disability, 38 (79%) specified their disability in an open text field. Half of these responses described mental health issues, especially anxiety and depression, while the other half described physical disabilities that were often related to living with HIV.

## CARCERAL EXPERIENCE

Most people in the survey said they had no experience with jails or prisons. One hundred and fifty-two (92%) said they had never been in either, while 9 people (5%) said they had been in one of them in the past. Five people (3%) declined to provide an answer.

## EDUCATION AND INCOME

Nearly everyone in the survey had at least a high-school education or higher. Twenty-five people (15%) had a high school education, 36 people (22%) held certificates and 33 people (20%) had diplomas.

Thirty-seven people (22%) had a bachelor's degree, 21 (13%) had a master's degree, and 5 (3%) had a doctoral degree. Five people (3%) reported they did not complete high school and 4 (2%) declined to answer (see Figure 11).

Further, most people reported taking home \$65,000 or less. Nineteen people (11%) said they make under \$18,000 per year, 46 people (28%) said they earn up to \$45,000, and 27 (16%) said they earn up to \$65,000.

In the higher income brackets, 25 people (15%) reported they earn between up to \$85,000 per year, 20 (12%) said they make between up to \$120,000, and 5 (3%) said they earn up to \$180,000. Five more (3%) said they earn more than this, while 19 (11%) did not specify their income (see Figure 12).

## GEOGRAPHY

Most people in the survey live in urban areas of Queensland. Some live in places like Cairns, Townsville and Mackay. Still, the highest concentration of people who supplied their postcode live in inner Brisbane, the Gold Coast and the Sunshine Coast (see Figure 13).

One hundred and twenty-three (75%) reported that they live in a metropolitan area, while 34 (20%) said they live in a regional area. Three people (2%) were uncertain, 3 people (2%) did not answer and 8 people skipped the question (see Figure 14).

Fig 11 Educational attainment

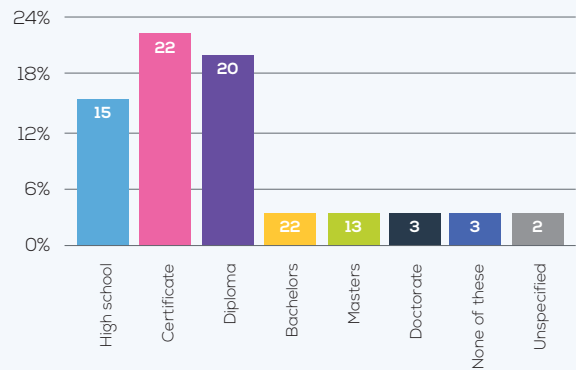
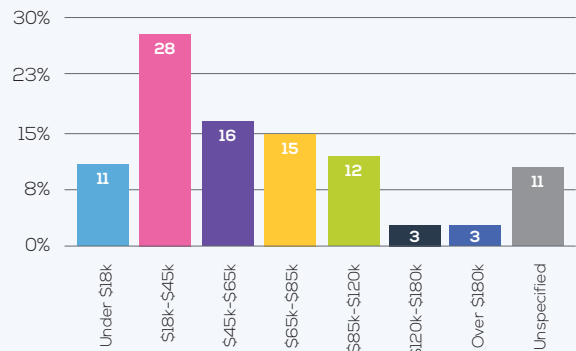
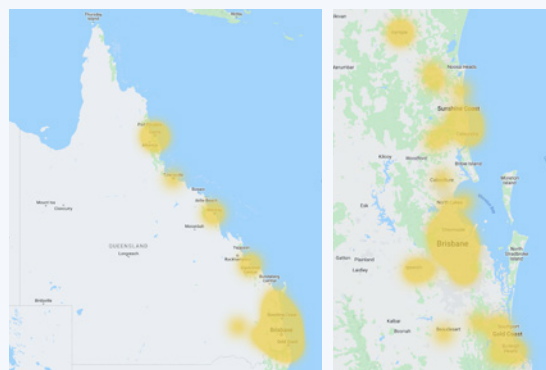


Fig 12 Income



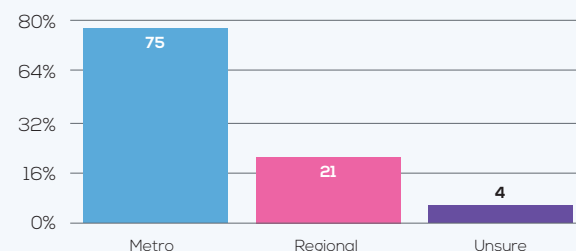
(Percentages calculated from 166 responses)

Fig 13 Geographic distribution (heat map)



(Queensland from 100km and 20km, map data © Google 2022)

Fig 14 Geographic distribution



(Percentages calculated from 163 responses)

## QPP SERVICE USE

Interestingly, most people in the survey were not current service users, with 71 people (44%) saying they had never used a QPP service before. Ten people (6%) indicated that they were not aware of any QPP services in their area.

However, 31 (19%) had participated in a Brisbane Barbecue group and 24 (15%) had been to the Planet Positive Brisbane event. Twenty-two people (13.5%) said they had used case-management support, while 17 (10%) said they had used peer navigation services. A further 13 people (8%) had used the RAPID clinic and 12 (7%) had used the HOPE Fund.

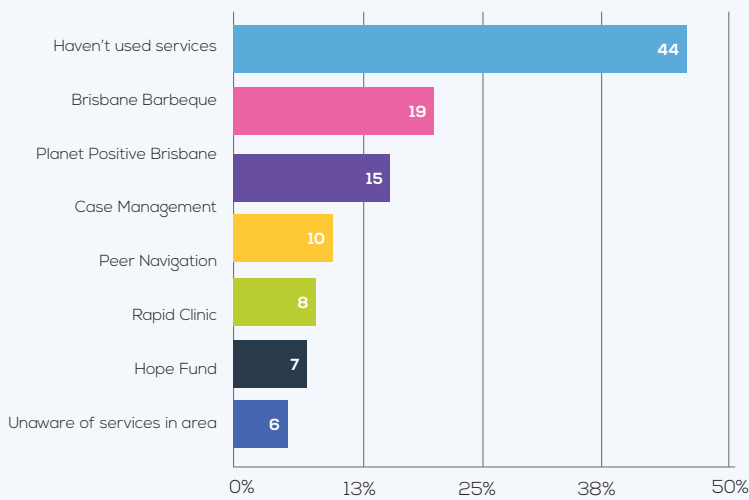
Eight people (5%) indicated they had engaged with either the Gold Coast Social Group or the Women's Group. Seven (4%) said they were involved with the Mature Age Long Term Survivors' Group. Five (3%) said they had gone to the Cairns Coffee Club.

Four people (2%) reported going to the Multicultural Group and the Positively Well Workshop each. Three (2%) said they had engaged with the AWARE Newly Diagnosed Group Workshop. Two people (1%) each indicated they had used the HIV Emergency Treatment Fund and the Rockhampton Social Group.

At least one person (less than 1%) said they had gone to the First Nations Residential Workshop, the LatinX Group, Planet Positive Cairns, the Positive Change for Positive People Workshop, the Swahili Group, Wide Bay Social Group and the Positively Quitting Fund each respectively.

Five people (3%) declined to specify if they had used a service and 8 people skipped the question (see Figure 15).

**Fig 15** QPP service use (10 users or more)



(Percentages calculated from 163 responses. Percentages do not add up to 100% since people could select multiple services)

**Interestingly, most people in the survey were not current service users, with 71 people (44%) saying they had never used a QPP service before.**





Most people thought that QPP brings positive people together and empowers them. However, there is still a desire for improvement in these areas.

# WHAT DID PEOPLE HAVE TO SAY?

## OVERVIEW

**Generally speaking, most people in the survey believed that QPP involves community members in its work. People rated engagement with gay and bisexual men, gender diverse people, sex workers and First Nations people very highly.**

However, they indicated that QPP needs to improve its engagement with straight and regionally located people. They further suggested that the agency doesn't engage as often or as well with incarcerated people and under 17s as it could.

Most people found the diversity within the organisation acceptable and its advocacy efforts adequate. The vast majority of respondents also felt that QPP valued their lived experience as people living with HIV.

Similarly, most people thought that QPP brings positive people together and empowers them. However, there is still a desire for improvement in these areas.

Moreover, most people in the survey reported a generally good quality of life with scores comparable to national averages. However, they reported a lower than average quality of life regarding their relationships, social support and their sense of belonging.

This finding reveals the corrosive impact of HIV stigma on positive people's quality of life, highlighting it as a leading concern among positive people in Queensland.

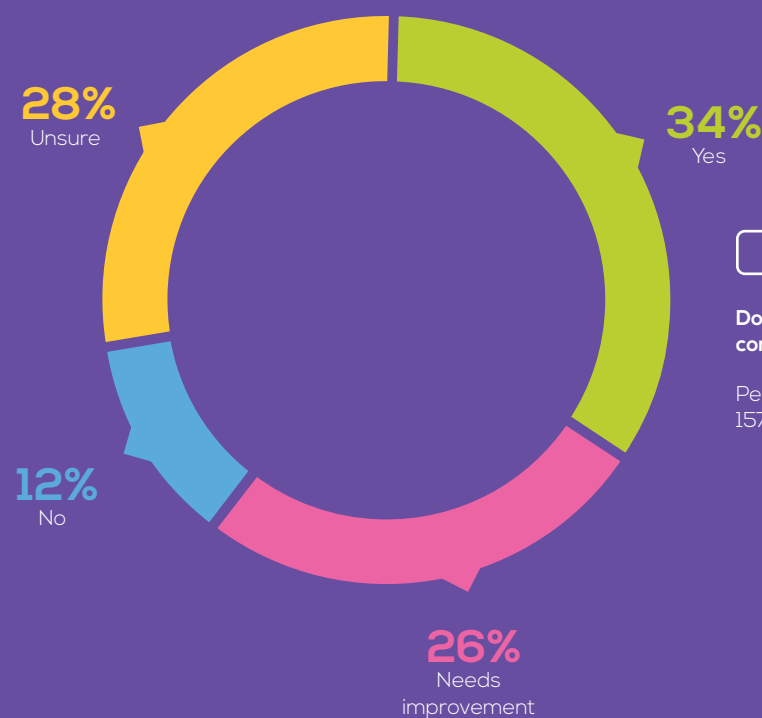


Fig14

**Do you think QPP involves community members in its work?**

Percentages calculated from 157 responses

# COMMUNITY ENGAGEMENT

## OVERALL ENGAGEMENT

When investigating agency engagement with PLHIV, a good place to start is by asking whether the agency involves them in the first place. By examining overall perceptions, the survey also provides clues for how well the agency engages communities and groups with few members.

Promisingly, most people in the survey thought that QPP involves community members in its work. Specifically, 53 people (34%) said that QPP involves community members, 41 (26%) stated that it does this but that this involvement needs improvement, 19 (12%) said that it does not, and 44 people (28%) were unsure (see Figure 14).

When asked which communities QPP typically involves, 97 respondents (61.78%) stated gay and bisexual men. Fifty-four people said gender diverse people (35%), 51 said sex workers (32%) and 50 said First Nations people (32%).

Further, 46 people (29%) indicated that QPP tends to involve over 55s and drug users, 44 (28%) said low-income earners, 42 (27%) said straight people, 40 (25%) said people of colour, 38-39 (24%) said people with a disability, 18-30s and migrants, 37 (23%) said women and girls and 33 (21%) said regional and remote people.

In comparison, a smaller number of people said that QPP typically involves asylum seekers and refugees (15%), incarcerated people (15%) and under 17s (10%). A minority (1%) of people who answered the question said that QPP involves none of the above (see Figure 15).

This means that 3 in 5 participants (60%) believed that QPP tends to involve community members, especially gay and bisexual men, gender diverse people, sex workers and First Nations people. Conversely, respondents thought that QPP involves asylum seekers and refugees, incarcerated people and under 17s significantly less often.

## QUALITY OF ENGAGEMENT

The above gives us an impression of which groups QPP tends to involve and how often, but it's also essential to understand the quality of this engagement. For this reason, we asked people in the survey how well QPP engages with their own communities and groups.

Most people (~75%) thought that QPP's engagement with gay and bisexual men, gender diverse people, people of colour, 18-30s and sex workers is very good or good. Further, many people (~60%) thought that QPP's engagement was very good or good with all remaining groups except straight people and regional people (see Figure 16).

Fig 15

Which communities do you think QPP typically involves in its work?

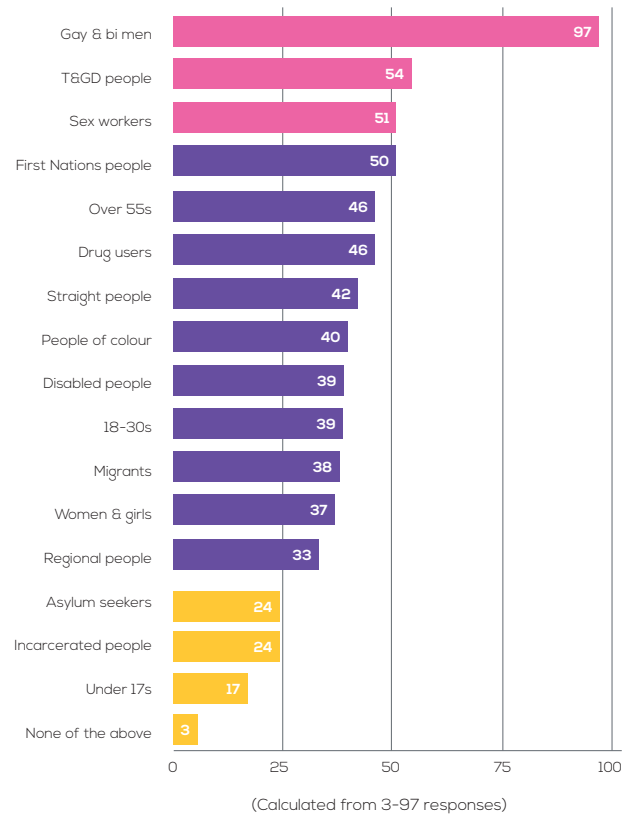
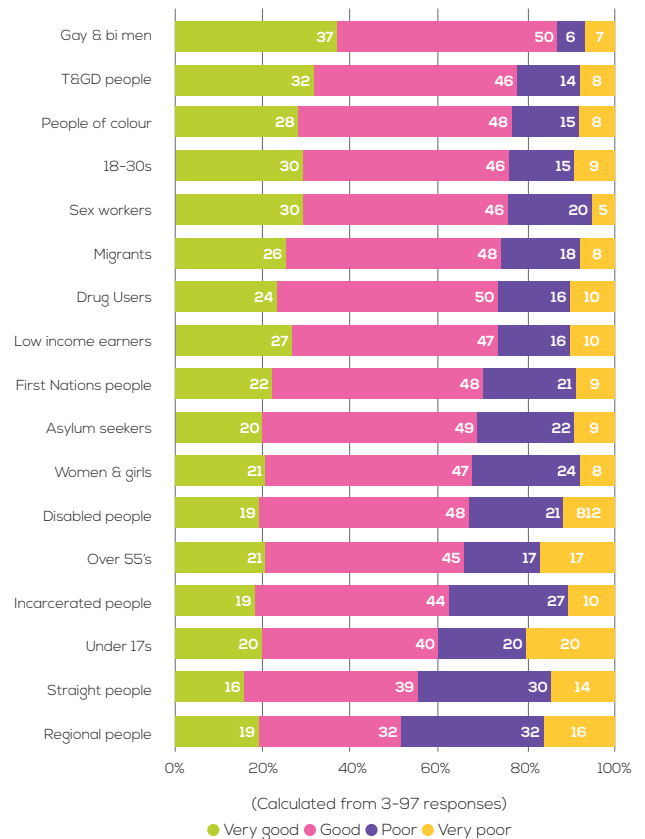


Fig 16

How well do you think QPP engages with these communities? (Ranked)





Combining this with the data from the previous section suggests that QPP may not often engage with asylum seekers but that engagement is adequate when it does. It also suggests two further things.

Firstly, it suggests that while QPP does involve straight and regional people, the quality of this engagement could improve. Secondly, that QPP doesn't engage as often or as well with incarcerated people and under 25s as it could.

Approaching engagement as service provision, 87 people (55%) thought that QPP's services were respectful and non-discriminatory, and 27 (17%) agreed but indicated a need for improvement. A small minority of 7 people (4.46%) thought the services were discriminatory, while 36 people (23%) were unsure (see Figure 17).

## DIVERSITY

Most people in the survey indicated that they think there is an acceptable level of diversity within QPP as an organisation and in its advocacy and resource development. However, there was also a high number of uncertain responses.

When asked whether a diversity of HIV positive people are represented at QPP, 43 people (27%) thought there was, and 35 people (22%) said there was but indicated a need for improvement. Twenty-six people (17%) believed there was no diversity in representation and 53 (34%) were unsure (see Figure 18).

Further, 64 people (41%) said that QPP advocated for a diversity of HIV positive people, and 36 people (23%) agreed but indicated a need for improvement. Thirteen people (8%) thought that QPP did not advocate for a diversity of positive people, while 44 (28%) were unsure (see Figure 19).

Finally, 42 people (27%) thought that QPP involves a diversity of HIV positive people in resource development. However, a further 39 (25%) agreed while also indicating a need for improvement.. Nineteen people (12%) thought that QPP does not do well in this area, and 57 people (36%) were unsure (see Figure 20).

Overall, people felt approximately the same regarding diversity within QPP and resource development. However, they were significantly more optimistic about the agency's advocacy efforts, with 3 in 5 believing that QPP did well or well with some need for improvement.

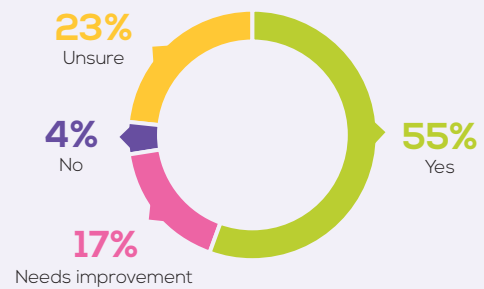


Fig 17

Do you think QPP deliver respectful and nondiscriminatory services?

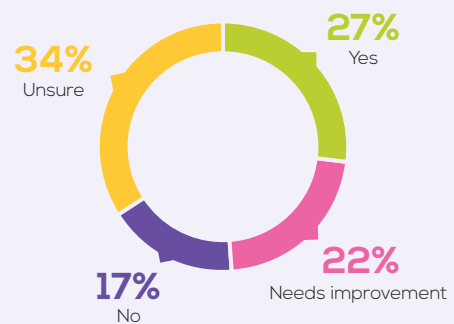


Fig 18

Do you think a diversity of positive people are represented at QPP?

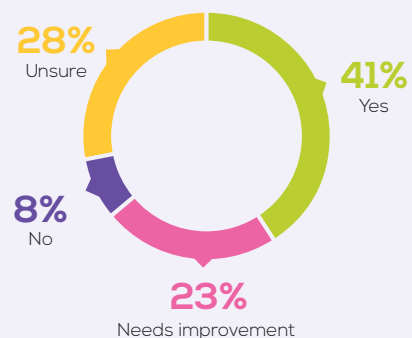


Fig 19

Do you think QPP advocates for a diversity of positive people?

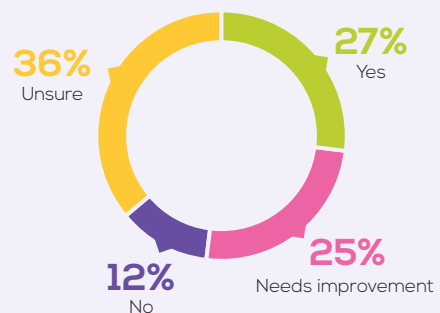
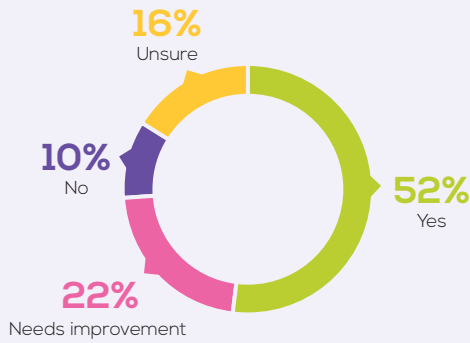


Fig 20

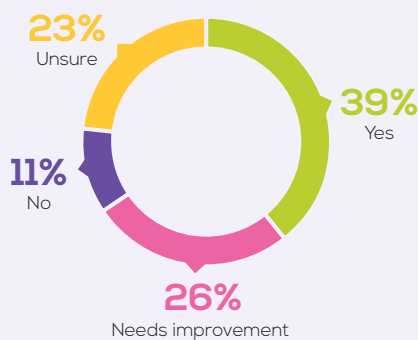
Do you think QPP involves a diversity of positive people when developing its resources?

● Yes ● Needs improvement ● No ● Unsure  
(Percentages calculated from 157 responses)

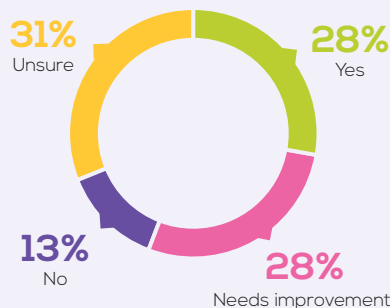




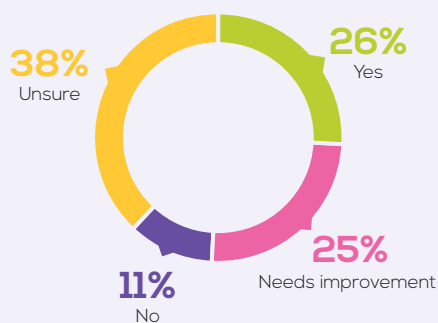
**Fig 21** Do you think QPP values the lived experience of positive people?



**Fig 22** Do you think QPP listens to positive people and acts on their input?



**Fig 23** Do you think QPP encourages positive people to participate in decision making?



**Fig 24** Do you think QPP provides avenues for feedback and criticism?

● Yes ● Needs improvement ● No ● Unsure  
(Percentages calculated from 157 responses)

## RESPONSIVENESS

The vast majority of respondents felt that QPP valued their lived experience as people living with HIV. A slightly smaller but significant number also thought QPP acts on their input.

Specifically, 81 people (52%) said that QPP values the lived experience of positive people. Thirty-five (22%) agreed but said there was a need for improvement, while 16 (10%) disagreed entirely. Twenty-five people (15%) were unsure (see Figure 21).

Similarly, 62 people (39%) thought that QPP listens to positive people and acts on their input. A further 41 (26%) agreed but said there is a need for improvement, 18 (11%) disagreed with the statement, and 36 (23%) were unsure (see Figure 22).

This means that nearly 3 in 4 people thought that QPP values HIV positive people's lived experiences. People were slightly less positive and more uncertain about QPP listening to positive people. However, around 3 in 5 still agreed with the statement.

## DECISION MAKING AND ACCOUNTABILITY

Generally speaking, most people in the survey thought that QPP engages people living with HIV in decision making and provides avenues for feedback.

When asked about decision making, 44 people (28%) thought that QPP encouraged positive people to participate in relevant processes. The same number of people agreed but said that there is a need for improvement. Twenty people (13%) thought that the agency did not do this and 49 (31%) were unsure (see Figure 23).

Further, 41 people (26%) said that QPP provides avenues for feedback and criticism and 39 (25%) agreed but indicated that this needs improvement.

Eighteen (11%) said that the agency does not do this well and 59 (38%) were unsure (see Figure 24).

In these answers, roughly as many people think that QPP performs well in these areas as those who think it needs to improve. Further, the number of uncertain respondents is larger than either of these groups on their own.

# COMMUNITY AND CAPACITY BUILDING

Most respondents thought that QPP helps bring positive people together and empowers them to self-advocate. However, there is a strong desire for improvement in both areas.

Forty people (25%) thought that QPP helps bring positive people together. A further 55 (35%) agreed but believed that the agency needs to improve in this area, while 28 (18%) said that it does not help at all. Thirtyfour (22%) were unsure (see Figure 25).



**Fig 27** Summary of agency engagement (Ranked)

Do you think QPP values the lived experience of positive people?



Do you think QPP delivers respectful and non-discriminatory services?



Do you think QPP listens to positive people and acts on their input?



Do you think QPP advocates for a diversity of positive people?



Do you think QPP helps bring positive people together?



Do you think QPP involves community members in its work?



Do you think QPP encourages positive people to participate in decision making?



Do you think QPP empowers positive people to self-advocate?



Do you think QPP involves a diversity of positive people when developing its resources?



Do you think QPP provides avenues for feedback and criticism?



Do you think a diversity of positive people are represented at QPP?



● Yes ● Needs improvement ● No ● Unsure  
(Percentages calculated from 157 responses)

Forty-three people said that QPP empowers positive people to self advocate. Forty-five (29%) agreed but flagged a need for improvement and 16 (10%) disagreed with the statement. A final 53 (34%) were unsure (see Figure 26).

In contrast to every other question in this part of the survey, people who thought QPP needed to improve in these areas were the largest group. In other words, more people felt improvement was necessary than were satisfied with the status quo.

## UNCERTAINTY IN ENGAGEMENT QUESTIONS

A significant number of people were uncertain about the agency engagement questions. Between 25 and 59 people (16% and 38% respectively) indicated that they were unsure about a given query (see Figure 27 for a summary of these responses).

People were relatively more confident that QPP values the lived experience of people living with HIV and that the agency helps bring them together. However, people were most uncertain about possible avenues for feedback and whether the organisation involves positive people in resource development.

The question with the highest number of uncertain responses was, 'Do you think QPP provides avenues for feedback and criticism?'. Of the 59 people who were unsure in their answer, 27 (45.76%) had never used a QPP service, while 4 people (7%) indicated that QPP did not offer services in their area. This trend held throughout the uncertain responses, and the percentages were higher in some cases.

Looking at the same question, 27% of uncertain people lived regionally. This was another trend throughout the engagement questions. For example, around 35% to 40% of all regional people in the survey were unsure about the self-advocacy, resource development and feedback questions.

## QUALITY OF LIFE (POZQOL)

**PozQol is a tool to measure positive people's quality of life that we added to the survey as an optional section. Approximately 145 people answered these questions, making this the most significant PozQol sample ever collected in Queensland.**

This section is subdivided into psychological, functional, health, and social areas. The first section is the 'psychological domain' which looks at a person's mood and outlook about their life and future.

Roughly 9 in 10 people indicated that they enjoy life and feel in control. They generally feel good about themselves and are optimistic about their future to some degree. See Figures 28, 29, 30 and 31.

The second section is the 'functional domain', which is about a person's independence and living with HIV. Around 1 in 3 people said that HIV doesn't prevent them from doing things, doesn't limit their opportunities in life or wear them out at all. See Figures 32, 33 and 34.

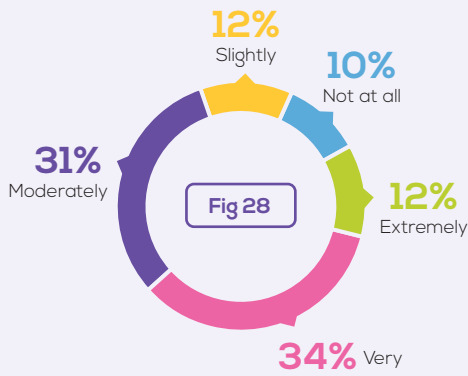
The third section is the 'health domain', which focuses on health management and health-related concerns. Responses to this section were marginally less favourable: most people indicated at least some level of worry about their health.

Interesting, while there was a relatively low number of highly concerned people, there was a substantial increase in the number of people who were extremely worried about HIV and ageing. See Figures 35, 36 and 37.

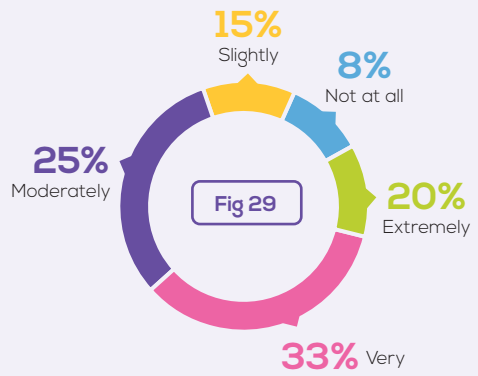
The fourth and final section is the 'social domain', which asks about relationships, support and a positive person's sense of belonging. The responses in this area were significantly less favourable than all of the previous ones.

Around 1 in 3 people said they felt a sense of belonging with the people around them. However, this means that 2 in 3 people indicated they lack this sense of belonging, with 15% saying that this lack is 'extreme'. See Figure 38.

Moreover, around 1 in 4 people indicated a powerful feeling that HIV limits their relationships, though nearly as many said that it does not affect their relationships at all. Still, altogether 113 people (88%) felt that HIV limited their relationships to some extent. See Figure 39.

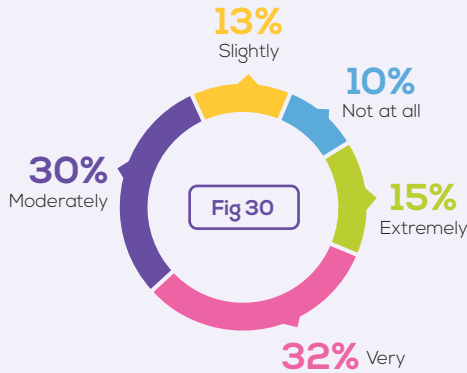


I am enjoying life

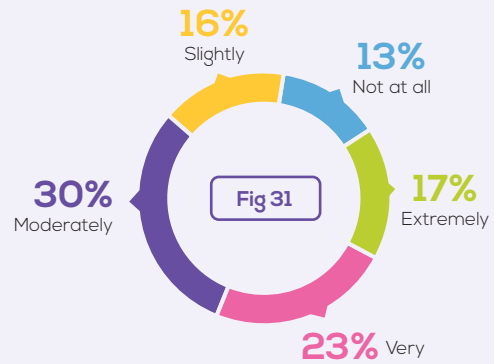


I feel good about myself as a person

(Percentages calculated from 144-145 responses)

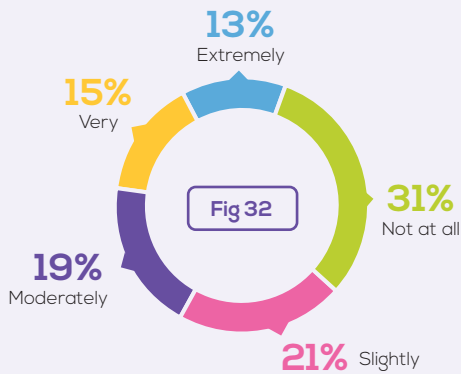


I feel in control of my life

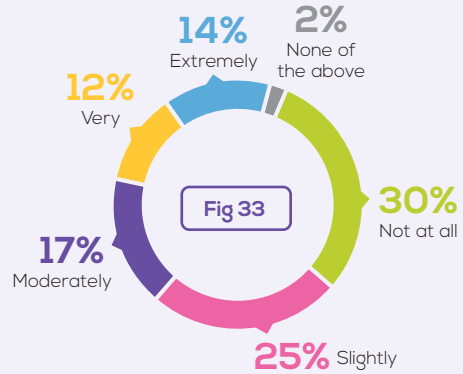


I am optimistic about my future

- Extremely
- Very
- Moderately
- Slightly
- Not at all

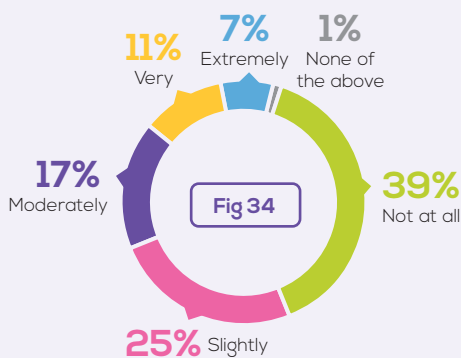


I feel that HIV prevents me from doing as much as I would like

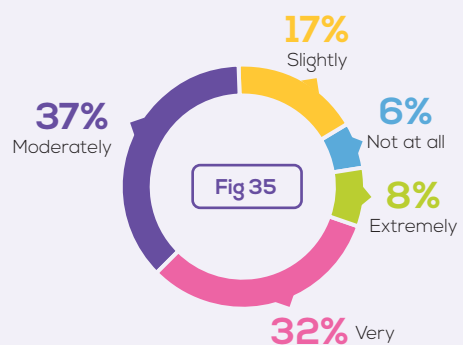


Having HIV limits my opportunities in life

(Percentages calculated from 145 responses)



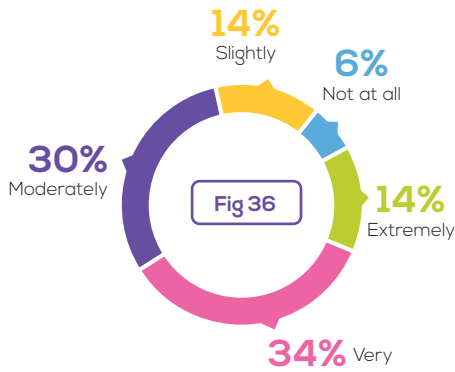
Managing HIV wears me out



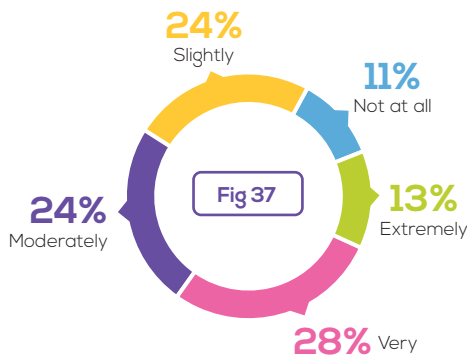
I worry about my health

(Percentages calculated from 144-145 responses)





I worry about the impact of HIV on my health



I fear the health effects of HIV as I get older

(Percentages calculated from 144-145 responses)

Strikingly, 9 in 10 said they were afraid to some degree that people may reject them on learning they have HIV. Seventy people (49%) or nearly half of people who answered the question said they were very or extremely apprehensive about social rejection due to their HIV status. See Figure 40.

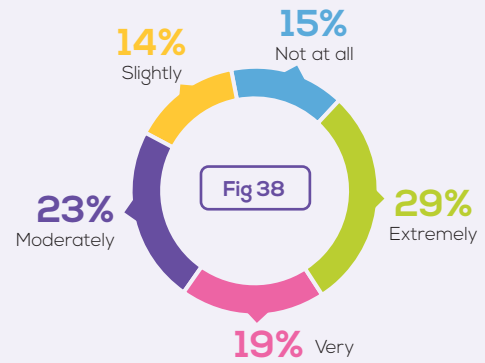
Broadly speaking, the survey found that people generally reported a good quality of life. For instance, the average PozQol score from this survey is equivalent to the national average found in HIV Futures 9.

However, what stands out is that people in this survey reported a lower-than-average quality of life in the social domain. See Figures 41 and 42.

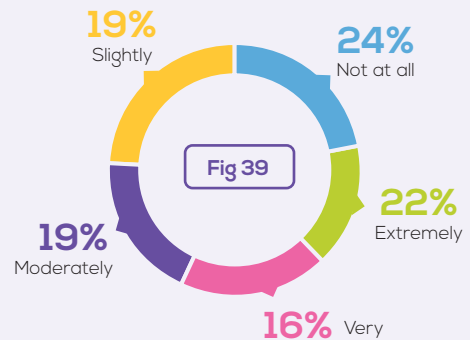
This paints a unique picture of the quality of life for people living with HIV in Queensland. These results suggest that they generally enjoy life and are optimistic about the future. Further, while there is some concern around HIV and ageing, most people feel able to manage their health.

However, when compared to their peers across the country, positive people in Queensland are quite worried about rejection due to their HIV status and how their status may limit their social relationships.

This data reveals the corrosive impact of HIV stigma on positive people's quality of life and highlights it as a leading concern in Queensland. It also suggests that they are especially vulnerable to loneliness and isolation.



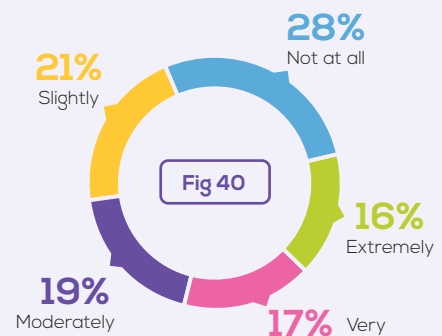
I lack a sense of belonging with people around me



I feel that HIV limits my personal relationships

(Percentages calculated from 145 responses)

See Figures 43 and 44 for a ranked summary of the PozQol questions. These summaries are divided according to positively and negatively worded questions for clarity.



I am afraid that people may reject me when they learn I have HIV

## OPEN-ENDED RESPONSES

Those who responded to the survey had the opportunity to leave comments and reflections on the content of the survey and the survey itself. Ninety-seven people provided an open-ended response, while 74 skipped the question.

Half of the responses were comments on the survey itself, such as the wording of questions or how applicable they were to a person's particular situation. However, most of these were not relevant to QPP's community engagement.

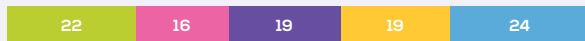
We classified 8 of these as 'affirmations' based on tone and theme. These comments were positive and supportive of QPP and its work. For example:

- 'QPP does a fantastic job [...] they give me strength and if I need it they will support me to the best they can.'
- 'I only engaged in QPP for a few months [...] but they have continued to engage with me and check on my welfare. I really appreciate having a support network.'

Fig 41

Do you think QPP helps bring positive people together?

### Queensland



### HIV Futures 9



● Not at all ● Slightly ● Moderately ● Very ● Extremely

Fig 42

Do you think QPP empowers positive people to self-advocate?

### Queensland



### HIV Futures 9



● Not at all ● Slightly ● Moderately ● Very ● Extremely

(Queensland percentages calculated from 145 responses; HIV Futures percentages calculated from 847 responses)

Fig 43

PozQoI (Negatively worded items, ranked)

### Managing HIV wears me out



### Having HIV limits my opportunities in life



### I feel that HIV prevents me from doing as much as I would like



### I worry about the impact of HIV on my health



### I lack a sense of belonging with people around me



### I fear the health effects of HIV as I get older



### I worry about my health



### I feel that HIV limits my personal relationships



### I am afraid that people may reject me when they learn I have HIV



● Not at all ● Slightly ● Moderately ● Very ● Extremely

Fig 44

PozQoI (Positively worded items, ranked)

### I feel good about myself as a person



### I feel in control of my life



### I am enjoying life



### I am optimistic about my future



● Not at all ● Slightly ● Moderately ● Very ● Extremely

(Percentages calculated from 144-145 responses)

- 'I think QPP provides quality services based on its funding.'
- 'While I have never needed to access it, QPP is a valuable service for the HIV community and should continue.'

Several people also took the opportunity to name specific QPP staff members and thank them for their work in these responses.

We categorised a further 13 responses as 'critiques'. These comments were explicitly critical of the agency and its work. They typically mentioned a lack of outreach, presence or service provision. For example:

- 'QPP is invisible to me. I never hear from them or of them. I don't know what they do.'
- 'QPP is not on my radar, my experiences have been poor... I haven't engaged with QPP for over a year and don't see that changing.'
- 'QPP has no presence for me in community [...] who do they serve?'
- 'After 30+ years as an HIV+ person, I am contacted more by Posnet in Sydney than by anyone in Qld.'

We classified a further 33 responses as 'observations' since they tended to be more neutral and were framed as factual statements. While not discreetly critical, these comments also mentioned a lack of knowledge about QPP and its work. For example:

- "I'm not fully aware of all the services QPP offers. I saw social events listed in this survey I didn't have a clue existed."
- "I ticked a lot of not sure because the only contact I have with QPP is their emails."
- "Other than the odd social event I don't know what QPP does."
- "When you live 350 km from the closest area where QPP operate it's hard to calibrate many answers."
- "As someone living in regional Queensland I am really unsure what QPP does for me as most of the communication and services appear metropolitan focused."
- "I've only had one experience with QPP and it was successfully dealt with having moved here two years ago from NSW, but I'm regional and there's nothing out here."

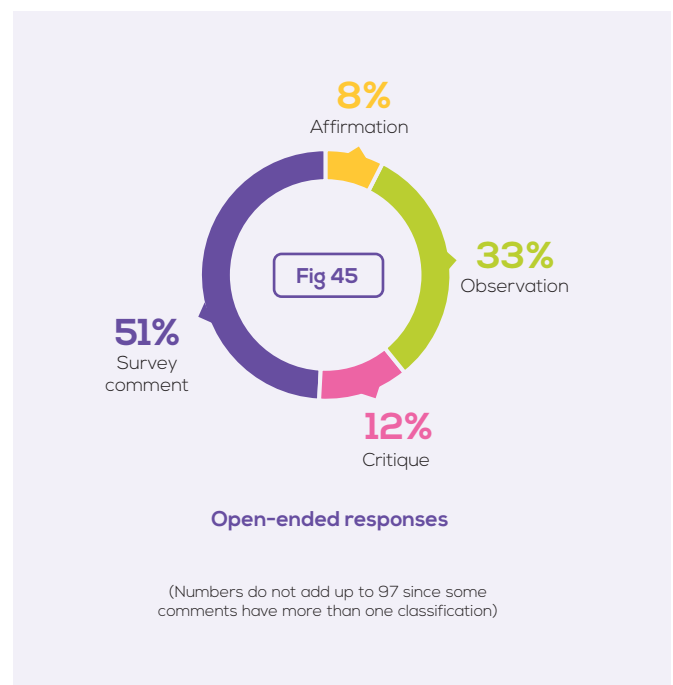
See Figure 45 for a breakdown of the open-ended responses.

Another way of examining these comments is to look at the most common words and how frequently people used them, which tells us what people were generally concerned about. For example, 'services' appeared in 18% of all open text responses, 'community' in 13% and 'support' in 13%.

The longest and most detailed response explicitly addressed these themes: 'I think that 'we're not funded for that' is not a good enough response to the lack of provision of services that include well-being [...] well-being and connection to others is vital for us and QPP really lacks in that area.'

The open text responses suggest that QPP usually engages with positive people quite well. However, they also indicate a disconnect between the agency and some groups (especially those in regional areas) and that people living with HIV in Queensland are especially eager for social services.

Please note that some of the comments in this section have been lightly edited for brevity and clarity.



# 1-1 INTERVIEWS

**To better understand why people answered the way they did, we conducted a series of 1-1 interviews with people living with HIV in Queensland. QPP offered people a \$50 gift voucher as an honorarium for their time and expertise.**

QPP nominated 14 people representing a number of different communities. Unfortunately, 2 people withdrew from the process, and 3 did not respond to the invitation to participate. In the end, we interviewed 9 people over a month.

The interviewees expressed a strong desire to maintain and expand social services, either as social activities or educational events. Similarly, many of them expressed a desire to participate in education and outreach programs as volunteers. However, they felt that there were little to no opportunities available.

They indicated a strong sense that the general public in Queensland has a poor understanding of HIV in 2022. For example, they felt that there is only limited awareness about the effectiveness of antiretrovirals (ART), preexposure prophylaxis (PrEP) and the Undetectable = Untransmittable (U=U) message.

Many reported high levels of fear, loneliness, isolation and self-stigma. Every interviewee discussed disclosure as a pressing issue they face. They described a high level of uncertainty and a lack of confidence and skills regarding disclosing their status to friends, family and the public.

At the same time, interviewees also noted a lack of publicly HIV positive activists and role models. As a result, some expressed an interest in mentoring and leadership initiatives to help build individual confidence and encourage community-led advocacy.

Some people we interviewed connected this perceived lack of visibility to QPP specifically. For example, some expressed a sense that QPP is not as 'out and proud' as it could be and that they 'wouldn't be able to pick a board or staff member out of a crowd.'

Finally, there was limited awareness across the interviewees about what services QPP offers, especially regarding community and social support. For example, one person asked whether QPP 'even has a logo?' while another expressed the view that QPP was 'an arm of the Queensland Health Department'.

The 1-1 interviews suggest that positive people in Queensland are personally invested in the HIV response and want to be more involved. However, HIV stigma, a dearth of community advocates and a lack of knowledge about QPP's work create a challenging environment for disclosure and public engagement.



People of colour, gay and bisexual men, sex workers and migrants rated QPP's engagement with their communities quite highly. In addition, drug users, low-income earners, 25-30s, over 55s and disabled people rated agency engagement with their own communities relatively highly.





# WHO SAID WHAT?

## OVERVIEW

The previous sections have told us what people who responded to the survey thought about QPP's engagement generally. This section delves deeper and interrogates what people from particular communities thought about agency engagement with their community.

People of colour, gay and bisexual men, sex workers and migrants rated QPP's engagement with their communities quite highly. In addition, drug users, low-income earners, 25-30s, over 55s and disabled people rated agency engagement with their own communities relatively highly.

Women, straight people and regional people rated engagement with their communities much more critically than average. Further, there were very few people from some groups in the survey, such as First Nations people, transgender and gender diverse people, asylum seekers and refugees, incarcerated people and under 25s.

## GROUP PERCEPTIONS

Figure 16 (above) illustrates overall perceptions of QPP's engagement with particular communities. In addition, however, the survey data allows us to look at how people from those communities rated engagement with themselves and their close peers.

Ideally, we want to see a very close similarity between the overall perception and the in-group perception of agency engagement. When displayed in a bar chart, the bars in each column should match, or the in-group perception should be more positive.

In this regard, 4 groups rated agency engagement with their community as high or higher than the overall perception: people of colour, gay and bisexual men, sex workers, and migrants. See Figures 46, 47, 48 and 49.

Based on the in-group assessment, we can confidently say that engagement with the gay and bisexual men is very good or good based on the in-group assessment. However, while the results of the other groups indicate good engagement, keep in mind that some of them have relatively fewer members in the survey.

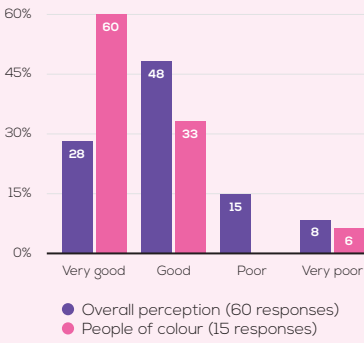
Drug users, low-income earners, 25-30s and over 55s also rated agency engagement with their respective communities similar to the overall perception. While these were still generally positive, they were less favourable than the above 4 groups. See Figures 50, 51, 52 and 53.

Based on these figures, we can be confident that QPP's engagement with drug users, low-income earners and over 55s is generally good. Over 55s and 25-30s were slightly more critical than the overall perception but agreed that engagement was good.

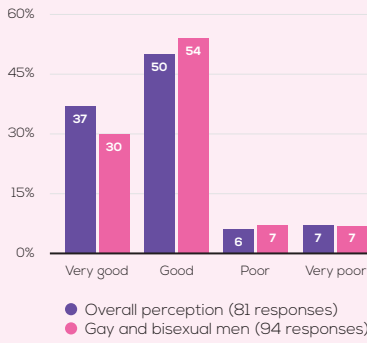
Disabled people, women, straight people and regional people tended to evaluate engagement with their communities more harshly than the overall perception. See Figures 54, 55, 56 and 57.

This trend is relatively minor for disabled people, with a slight increase in people rating engagement as poor or very poor. However, it is more pronounced for the other groups. For example, women were more likely to report poor agency engagement.

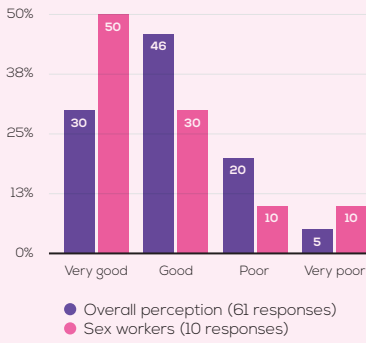
**Fig 46** People of colour



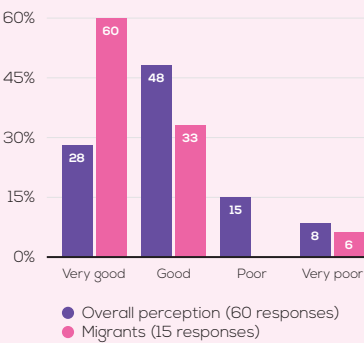
**Fig 47** Gay and bisexual men



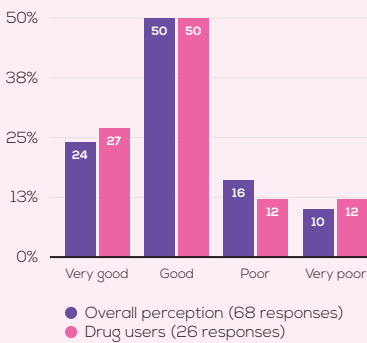
**Fig 48** Sex workers



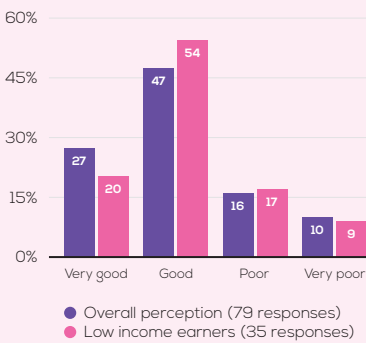
**Fig 49** Migrants



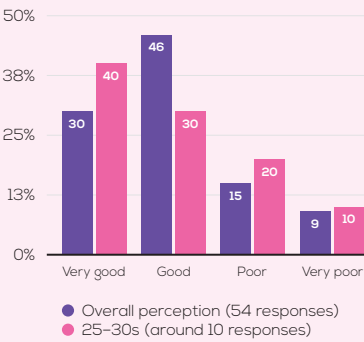
**Fig 50** Drug users



**Fig 51** Low-income earners

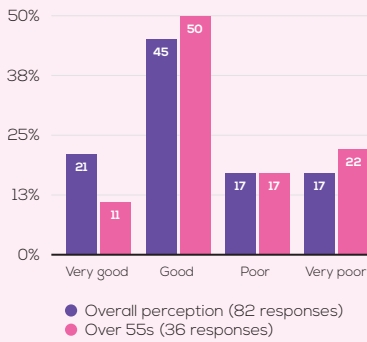


**Fig 52** 25-30s\*

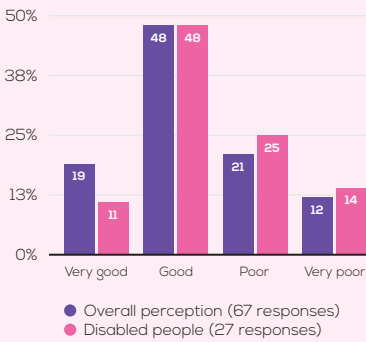


\* (This age group shifts from 18-30s in the previous section to 25-30s here since there were no under 25s in the survey)

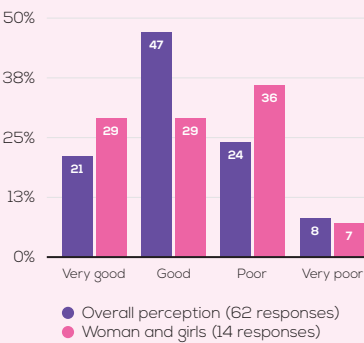
**Fig 53** Over 55s



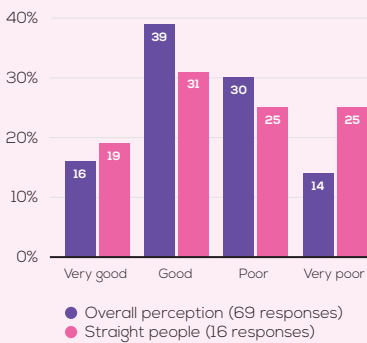
**Fig 54** Disabled people



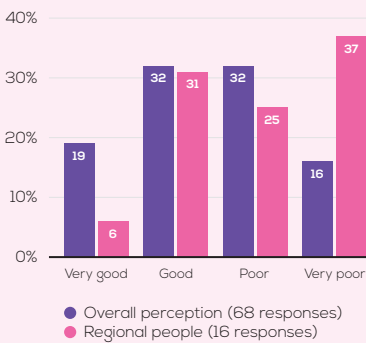
**Fig 55** Women



**Fig 56** Straight people



**Fig 57** Regional people



Significantly more straight people and regional people rated QPP's engagement with them and their peers as very poor. Regional people reported the lowest level of very good engagement and the highest level of very poor engagement.

The above data suggests that engagement with most groups is generally good. For example, most people of colour, gay and bisexual men, sex workers, drug users and low-income earners reported very good or good agency engagement. Around 75-80% of members of these communities ranked engagement as very good or good.

People aged 18 to 30 in the survey rated engagement with their groups more harshly than average, but around 3 in 5 still reported very good or good engagement. People in the survey tended to be older and there were no under 25s, suggesting that QPP can improve engagement with younger people living with HIV.

Over 55s and disabled people provided a very similar response when asked about engagement with their communities. This is partly because over half (58%) of disabled people in the survey were also over 55, which may speak to the concerns around HIV, health and ageing in the PozQol data.

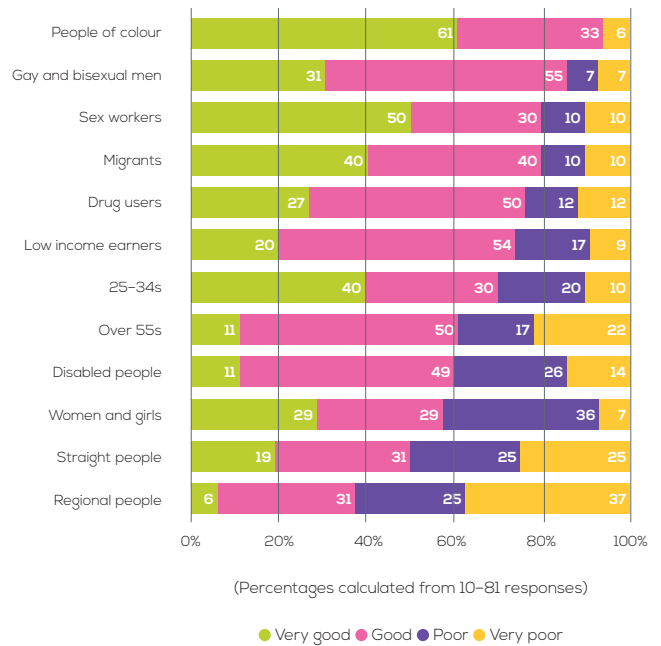
A slim majority of women reported very good or good engagement with their group. However, 4 in 10 women in the survey indicated that agency engagement with women was poor or very poor. This strongly suggests that QPP can improve engagement with this group.

Most straight people and regional people in the survey indicated that agency engagement was poor or very poor. Around 1 in 2 straight people and regional people negatively assessed agency engagement with their groups.

Tellingly, most people in the survey ranked the quality of engagement with these groups the lowest overall, and members of these cohorts did the same. This is a clear indication that QPP can improve engagement with these groups.

See Figure 58 for a ranked summary of agency engagement as reported by a given community. This does not include First Nations people, transgender and gender diverse people, asylum seekers and refugees, incarcerated people or under 25s due to the small numbers of these communities in the survey.

**Fig 58** How well do you think QPP engages with your own community? (ranked)



## CASE STUDY: Women

**There were 23 women (13% of responses) who had notably more positive than average responses. In fact, a higher proportion of women answered 'yes' to each of the agency engagement questions compared to other respondents.**

However, they were most critical about whether QPP involves community members in its work and whether an adequately diverse range of people is represented at QPP. Finally, women were most unsure about whether QPP provides avenues for feedback and criticism.

This paints a nuanced picture of QPP's engagement with women. It is clear that women generally hold QPP's work in very high regard. But, at the same time, they harbour scepticism about community involvement, internal representation and avenues of communication.

This may seem somewhat contradictory. However, one interpretation is that women do not feel personally represented at QPP and are unsure how to consult with the agency. This nuance suggests that women feel personally under-engaged in QPP's work but value its overall mission.

## CASE STUDY: Straight people

**There were 26 straight people in the survey (15% of responses). They were more positive on most questions, though slightly less than women. Interestingly, straight people were most critical and most unsure of the same questions as women.**

This is partly because most straight people in the survey were also women, which may explain some overlap. However, the answers of the few straight men living with HIV who responded are also informative.

For example, straight men were also critical of internal representation and unsure about avenues of communication. Additionally, they were also critical of the idea that QPP brings positive people together.

Further to this last point, the PozQoI data shows that straight men were particularly concerned with disclosure and stigma. Half of them said they were extremely worried about rejection when disclosing their HIV status and lacked a sense of belonging.

This all suggests that, like women, straight people do not feel represented internally and may lack the knowledge necessary to consult with the agency on issues that affect them. Additionally, straight men living with HIV appear particularly concerned about stigma and isolation.

## CASE STUDY: Regional people

**In contrast to women and straight people, the 34 regional people in the survey (20% of responses) were significantly more critical of every agency engagement question on average.**

Generally speaking, they were most critical regarding whether QPP involves community members in its work and whether a diversity of positive people are represented at QPP. Further, they were somewhat critical of the idea that QPP brings positive people together and most unsure about avenues for feedback.

This trend suggests that, as with women and straight people in the survey, regional people do not feel adequately represented within QPP and are uncertain how to approach the agency to provide feedback.

Additionally, it is fairly straightforward to conclude that regional people feel under-engaged by the agency, given that more than half of them in the survey had never used a QPP service before.



# GLOSSARY

## CISGENDER

Describes a person whose sense of personal identity and gender corresponds with the gender they were assigned at birth. Contrast with: transgender and gender diverse people.

## ENDOSEX

A term that describes a person whose sexual characteristics match the typical expectations of male or female bodies. Contrast with: intersex.

## GIPA & MIPA PRINCIPLES

Starting as GIPA (the Greater Involvement of People living with HIV/AIDS) in 1994, MIPA (Meaningful Involvement of People Living with HIV) principles involve the recognition of the contribution of PLHIV and encourage their involvement in the HIV response.

## INTERSEX

Refers to people born with sexual characteristics that don't fit medical and social norms for female and male bodies.

## NON-BINARY

Refers to any gender or experience of gender which is neither male nor female. The term includes, for example, genderqueer, gender-fluid and agender people.

## PEOPLE LIVING WITH HIV (PLHIV)

The common term for HIV positive people which is often abbreviated to PLHIV.

## POZQOL

The PozQoL Scale is an empirically validated quality of life scale for people with HIV developed by the Australian Research Centre in Sex, Health and Society (ARCSHS), the National Association of People with HIV Australia (NAPWHA), Living Positive Victoria (LPV), Positive Life NSW (PLN), Queensland Positive People (QPP) and ViiV Healthcare.

## REGULATED & UNREGULATED DRUGS

For this survey, regulated drugs refer to controlled substances such as alcohol, tobacco and amyl nitrites. Unregulated drugs refer to other substances such as cannabis, cocaine, GHB, ketamine, and MDMA. This is only a rough distinction since each state and territory regulates drugs differently.

## TRANSGENDER AND GENDER DIVERSE PEOPLE

Denotes or relates to a person whose gender expression differs from their assigned gender at birth. The term includes transgender and gender diverse people men and women as well as non-binary people.



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