

s100 Survey Report

HIV antiretroviral (ART) co-payment initiative



About Positive Life NSW

Positive Life NSW (Positive Life) is the state-wide peer-based organisation that speaks for and on behalf of all people living with and affected by HIV in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all people living with HIV, and to change systems and practices that discriminate against people living with HIV, our friends, family, and carers in NSW.

Acknowledgements

Positive Life would like to thank the community members across NSW who took the time to respond to this survey and share their knowledge and experiences freely.

Positive Life would like to acknowledge and thank the following organisations and individuals for their contributions to this study:

- NSW Ministry of Health
- Service NSW
- Survey respondents

Acknowledgement of Country

We acknowledge the traditional custodians of this land, the Gadigal people of the Eora nation of the land that we live and work on, and we pay our respects to our elders past and present. We recognise, respect and value the deep and continuing connection of Aboriginal and Torres Strait Islander people to land, community and culture. We acknowledge that sovereignty was never ceded and was and always will be Aboriginal land. The survey was completed by people on the Aboriginal lands that exist within the colonial borders of New South Wales.

Further Information

For further information on this community survey report, please contact:

Email: contact@positivelife.org.au Phone: (02) 9206 2177 or 1800 245 677 (freecall outside metro areas)

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Author: Positive Life NSW

Editor: Craig Andrews, Positive Life Communications Manager

Reviewers: Jane Costello, Positive Life Chief Executive Officer; Neil Fraser, Positive Life Deputy CEO; Bella Bushby, Positive Life Health Promotion Officer; Liz Sutherland, Positive Life Senior Policy Officer; Brent Clifton, Positive Life Treatments & Health Officer; and Louisa Wright, Positive Life Volunteer.

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Summary of Key Findings

- There were 180 respondents to the survey, living with HIV and residing in NSW.
- In total, 32.8% (n=59) of survey respondents indicated their HIV antiretroviral medication was prescribed from 'a doctor at a sexual health clinic', followed by 22.8% (n=41) by 'my GP', 20% (n=36) by an 's100 prescriber GP', 12.2% (n=22) by 'a clinician at a Public Hospital', and 11.7% (n=21) by 'a Specialist'. None of the respondents reported a nurse practitioner had prescribed their antiretroviral treatment.
- Half (50.6%, n=91) of the respondents reported obtaining their antiretroviral medication from their local chemist or pharmacy, while 42.2% (n=76) stated they accessed antiretroviral medication from 'a public hospital pharmacy'.
- Only 4.4% (n=8) of respondents had used the option of getting their prescription online.
- 'Convenience (e.g. location, familiarity with pharmacist)' was the most commonly reported (69.4%, n=125) guide for respondents when choosing a pharmacy, followed by 'trust and reputation' (36.7%, n=66), 'speed and availability of dispensing medication' (35.6%, n=64), and 'privacy' (32.8%, n=59).
- The majority (96.7%, n=174) of respondents reported collecting their own HIV antiretroviral medicines.
- Most respondents (61%, n=108) indicated they rely on healthcare providers as their main source of support to manage their health.
- There were 14.5% (n=25) of respondents who were unaware that the NSW Health co-payment waiver covers the cost of the PBS co-payment s100 HIV antiretroviral medication. Of those who were not aware of the co-payment initiative, 69.2% (n=18) believed their 'prescriber (doctor)' should have made them aware of the co-payment initiative, followed by a 'pharmacist' (23.1%, n=6).
- In total, 6.3% (n=11) of respondents were currently paying the PSB co-payment for their HIV antiretroviral medication.
- Respondents reported first hearing about the co-payment initiative through a number of sources, such as through an 's100 Prescriber GP' (19.7%, n=29), 'Positive Life NSW' (17.7%, n=26), a 'GP' (15.6%, n=23), and a 'Public Hospital Prescriber (Doctor)' (13.6%, n=20).

Summary of Key Findings

- The majority of respondents reported their response as satisfied (15.9%, n=27) or very satisfied (67.6%, n=115) when filling their prescription and accessing the co-payment initiative. The main reasons for these positive ratings included an 'easy, smooth and simple process' (n=65), 'a good relationship with a pharmacist who is knowledgeable, respectful, and aware of process' (n=30), and 'feeling grateful that it is free, as the co-payment waiver helps financially' (n=25).
- There were 7% (n=12) of respondents who identified having concerns about their privacy with the current way they access the co-payment initiative, while another 10.5% (n=18) were 'unsure'.
- In addition, 18.1% (n=31) of respondents reported ever having had issues accessing the s100 co-payment initiative for their HIV antiretroviral medication.
- Most respondents (64.9%, n=111) agreed that the s100 co-payment initiative makes it more likely they will get their medication.
- Half (50.3%, n=85) of respondents identified that their pharmacist keeps track of their s100 Patient Consent Form, followed by themselves (20%, n=34), and 29.6% (n=50) don't know who keeps track of their s100 Patient Consent Form. There were 15.2% (n=26) of respondents who agreed that keeping track of their s100 Patient Consent Form for the s100 co-payment initiative is difficult.
- Roughly one quarter (24.7%, n=43) of respondents were aware when they had reached their PBS Safety Net threshold.

Introduction

From the late 1980s through to the mid-2000s, HIV section 100 (s100) Highly Specialised Drugs HIV medications in NSW were only accessible through public hospital pharmacies. From 01 July 2015, people living with HIV (PLHIV) have had the choice to collect their s100 HIV medications from a hospital pharmacy, a local community pharmacy (chemist), some of which provide home delivery services, or to order from an online pharmacy and have them posted directly to PLHIV in NSW. This initiative removed a significant barrier to PLHIV accessing treatment conveniently, and ensured PLHIV remained motivated and adherent to treatment.

By 01 October 2015, the NSW government enacted its pre-election commitment to waive the PBS co-payment for s100 HIV medications in NSW. This meant PLHIV were no longer required to pay a co-payment for HIV medications. Instead of costing PLHIV \$41, or \$6.60 for concession card holders, for one month's worth of HIV medication, PLHIV eligible for an Australian Medicare Card (or if their country is listed within the Reciprocal Health Care Agreements with the Australian Government) received their HIV medication free of charge. Both these initiatives were well received by PLHIV.

Five years later, the NSW Ministry of Health (NSW Health) sought to understand the best way to continue the administration of the co-payment initiative into the future. In October 2020, Positive Life NSW (Positive Life) consulted with PLHIV in NSW about our experiences of the co-payment waiver via a

community survey. The survey was posted to all Positive Life full members (PLHIV) across NSW, distributed online in SurveyMonkey to all Positive Life subscribers and promoted throughout Positive Life's social media platforms, and included in our electronic bulletin.

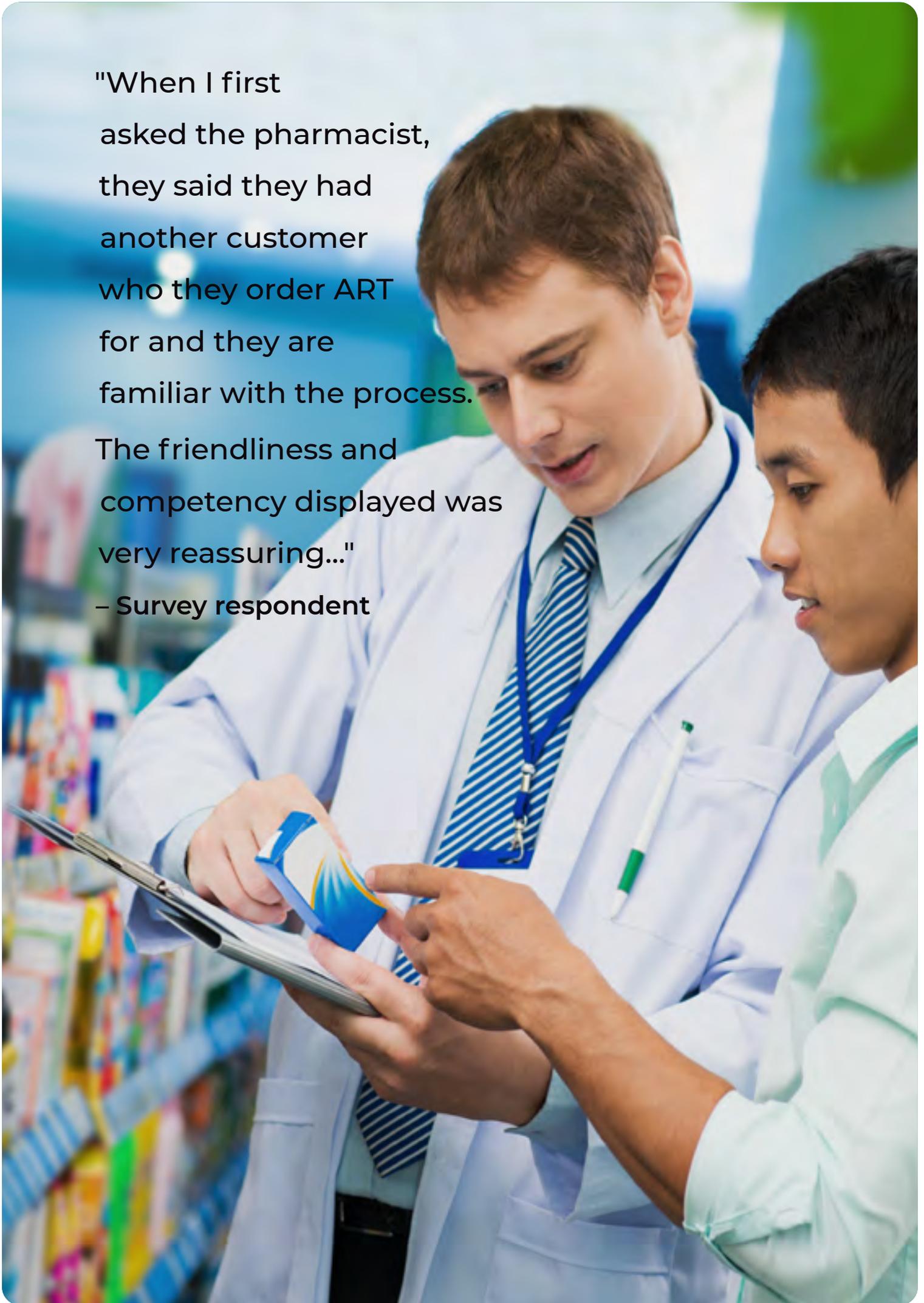
This report describes respondents' experiences of the co-payment waiver. After outlining the sample of survey respondents, the report shares survey responses regarding PLHIV experiences of s100 HIV medications in NSW including access, prescribers, collection, and experiences with ordering prescriptions online. There is discussion of respondents' preferences when choosing a pharmacy and about the respondents' main sources of support to manage their health. The report discusses respondents' reported awareness of the co-payment waiver, including their stated privacy concerns and associated issues.

Lastly, respondents' responses regarding managing paperwork such as the s100 Patient Consent Form and the PBS Safety Net threshold is discussed. Positive Life has offered some recommendations regarding the continuation of the NSW s100 HIV medication co-payment initiative, and options to improve the co-payment initiative in the future.

"When I first
asked the pharmacist,
they said they had
another customer
who they order ART
for and they are
familiar with the process.

The friendliness and
competency displayed was
very reassuring..."

– Survey respondent



Methods

In October 2020, NSW Health and Positive Life developed a survey tool (Appendix 1) to inform a project by NSW Health to understand the best way to administer the NSW co-payment initiative for s100 HIV antiretroviral medication into the future.

This survey sought to:

- Assess the awareness and use of the NSW co-payment initiative;
- Understand the variation and choice for the collection of prescribed s100 HIV antiretroviral medication; and
- Gain knowledge about community satisfaction for the initiative.

Survey Design and Recruitment

The anonymous survey was a series of quantitative and qualitative questions distributed online via SurveyMonkey to all Positive Life subscribers and promoted throughout Positive Life's social media platforms, including the agency's monthly electronic bulletin. It was also posted via Australia Post to all Positive Life Full members with a reply-paid envelope.

Responses were collected from 23 October to 16 November 2020 via 150 online surveys and 43 printed surveys; a total of 193 respondents completed returned surveys. Dissemination of the survey included promotion across our social media platforms (Facebook, Twitter, LinkedIn, and Instagram), Positive Life's October Life.mail electronic monthly bulletin, and on the Positive Life website, as well as engaging with and mobilising HIV sector

partners and local NSW sexual health clinics to promote the survey to clients and on their own social media platforms.

The survey included a total of 21 questions. Depending on the survey logic, some respondents answered only eight questions. According to SurveyMonkey, respondents completed the online survey in an average of six minutes.

The survey was divided into seven sections titled in the following order: 1) 'Let's start with your experience accessing s100 HIV medications', 2) 'Collecting your HIV medication', 3) 'Your support network', 4) 'Paying for your HIV medicines', 5) 's100 HIV antiretroviral co-payment initiative', 6) 'Your experiences accessing s100 HIV medications', and 7) 'Managing your paperwork'.

Statistical Analysis Procedure

Statistical descriptive analyses were performed using IBM SPSS Statistics version 25.¹ Thematic analysis was also used to identify patterns across the qualitative response dataset.² We coded responses by common themes and reported the themes by frequency. If applicable, some qualitative responses were recategorised into provided multiple choice responses.

This research was conducted according to the principles of Greater Involvement of People Living with HIV (GIPA) and Meaningful Involvement of People Living with HIV/AIDS (MIPA).³ Involving people with lived experience of HIV as equal partners enhances the quality and effectiveness of research and in shaping the HIV/AIDS response.

Survey Limitations/Strengths

This survey was anonymous and voluntary, and predominantly offered to Positive Life Full members. A limitation of the survey sample may be that Positive Life members have a higher level of engagement with the community of people living with HIV and a greater awareness of the s100 co-payment waiver initiative.

While the survey data offers an insight into NSW residents living with HIV and their awareness, satisfaction, and use of the NSW co-payment waiver initiative, the data should not be used to make generalisations about of all the 8,880 people living with HIV taking antiretroviral HIV medication in NSW.⁴

Demographic information of respondents such as age, gender, rural/regional location, number of years living with HIV, were not collected in this survey. This was due to the decision to avoid adding to 'survey fatigue' which is a risk for the community living with HIV, especially during COVID-19.

We were fortunate and privileged to have such passionate and engaged respondents to the survey who provided us with a wealth of information and insight in an area on which there is a paucity of data. They were open, honest, and extraordinarily generous with their time in sharing their experiences with us.

Participants

The survey was open to people living with HIV who use s100 HIV antiretroviral medications, or assist another person to obtain their HIV medications, in NSW, Australia. There were 193 people who completed this survey. For the purposes of this community report, we did not conduct analyses on data from people not living with HIV (n=11) who were carers

or sector workers who supported clients living with HIV. There were another two respondents who were not included in the final analysis due to insufficient data: one did not report their HIV status and one only completed the first question of the survey. The final reported sample was 180 respondents.

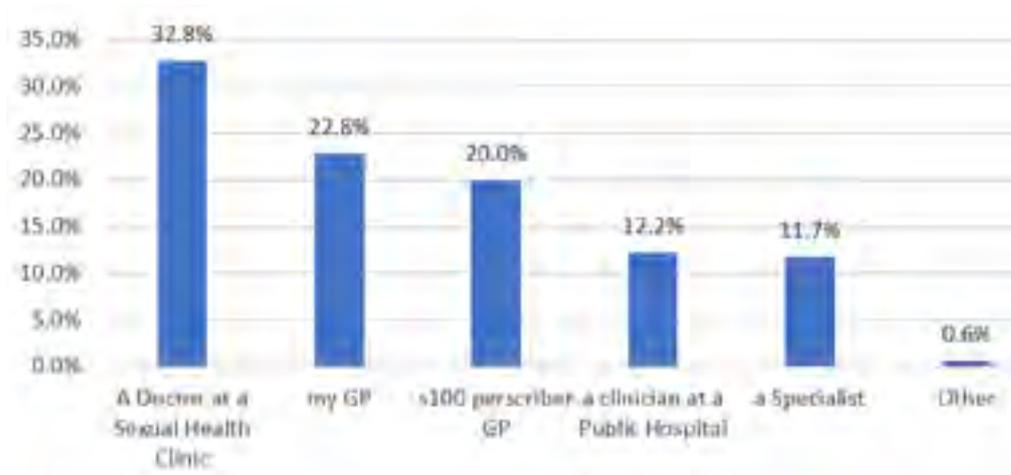
Results

Experience accessing s100 HIV medications

In total, 32.8% (n=59) of survey respondents indicated that their HIV antiretroviral medication was prescribed from 'a doctor at a sexual health clinic', followed by 22.8% (n=41)

by 'my GP', 20% (n=36) by an 's100 prescriber GP', 12.2% (n=22) by 'a clinician at a Public Hospital', and 11.7% (n=21) by 'a Specialist', see Figure 1.

Figure 1: Who prescribes your s100 antiretroviral medications?

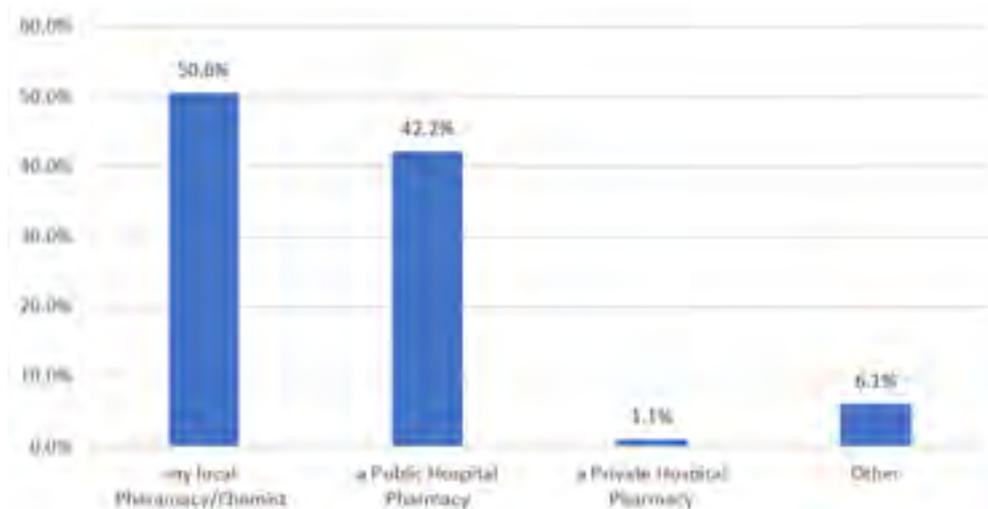


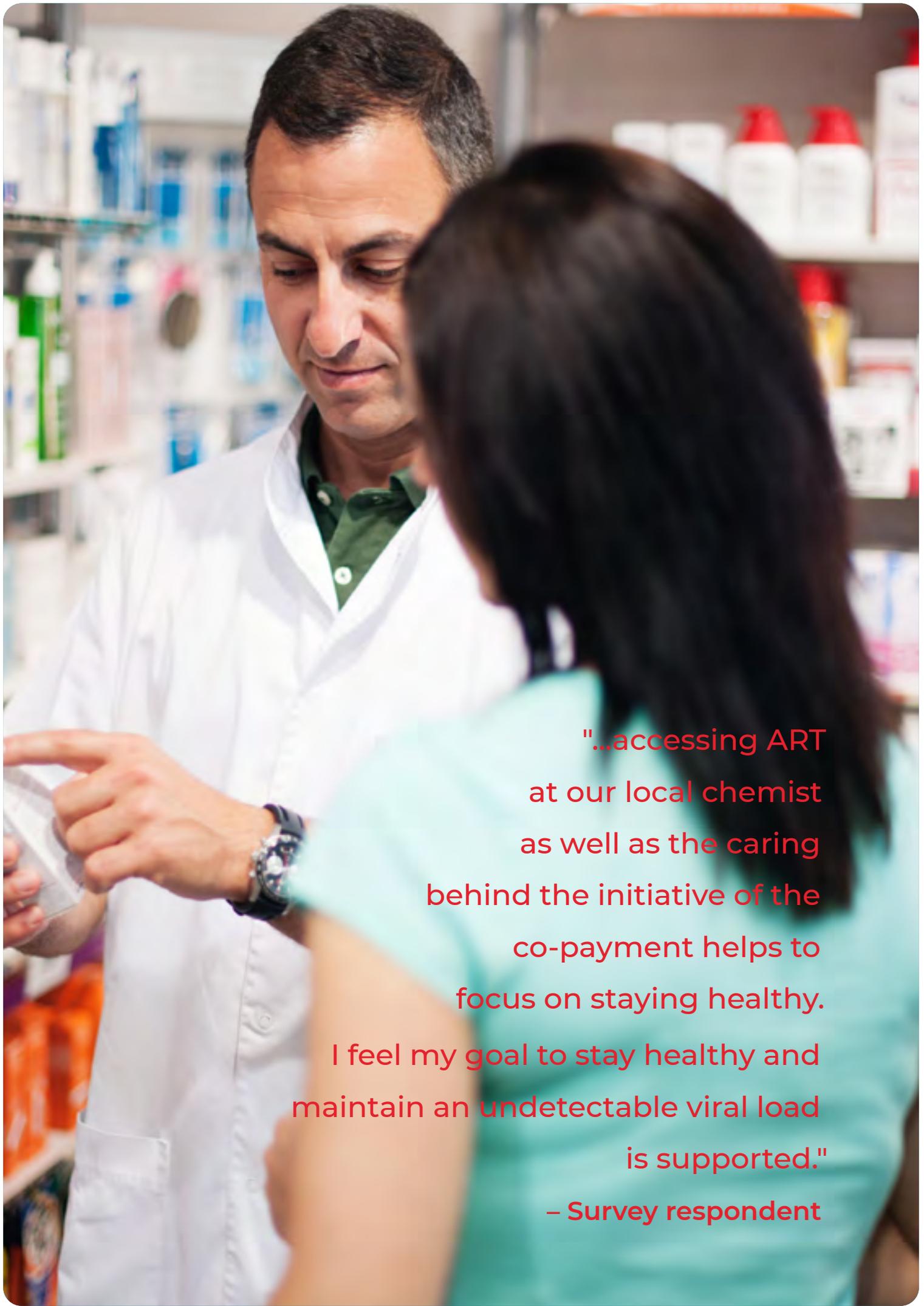
Collecting HIV medication

The majority (96.7%, n=174) of respondents collect their own HIV antiretroviral medicines. Approximately half (50.6%, n=91) of all survey respondents stated they collected their HIV antiretroviral medication from local chemists and pharmacies, including online pharmacies.

There were 42.2% (n=76) respondents who indicated they picked up their HIV medication from 'a Public Hospital Pharmacy' and only 1.1% (n=2) of respondents indicated they collected their HIV medication from 'a Private Hospital Pharmacy', see Figure 2.

Figure 2: Where do you pick up your HIV medication?





"...accessing ART
at our local chemist
as well as the caring
behind the initiative of the
co-payment helps to
focus on staying healthy.

I feel my goal to stay healthy and
maintain an undetectable viral load
is supported."

– Survey respondent

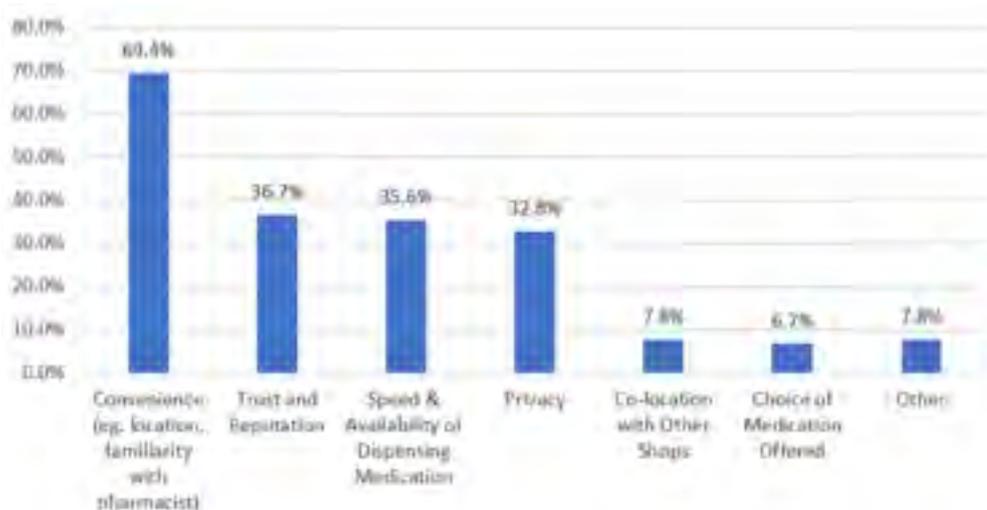
Results

Of those who responded to 'Other (please describe)' 6.1% (n=11) of respondents indicated they also picked up their medication from non-local pharmacies, had their medication delivered by post, received their medication from their s100 GP practice, or used a mixture of the provided options. In total, 4.4% (n=8) of respondents indicated they have used the option of getting their prescription online previously, and 87.5% (n=7) indicated they felt 'neutral', 'comfortable' or 'very comfortable' using this option.

Most respondents (69.4%, n=125) indicated that 'convenience (e.g. location, familiarity with pharmacist)' was what guides them when choosing a pharmacy. Other common

factors included 'trust and reputation' (36.7%, n=66), 'speed and availability of dispensing medication' (35.6%, n=64), 'privacy' (32.8%, n=59), 'co-location with other shops' (7.8%, n=14), and 'choice of medication offered' (6.7%, n=12), see Figure 3. 'Other' aspects that respondents (7.8%, n=14) indicated guided them when choosing a pharmacy included avoiding pharmacies that unfairly charged the co-payment waiver, using pharmacies that are non-discriminatory, additional services provided by the clinic or pharmacy such as postal delivery or the use of technology to manage scripts such as the Medisafe app, or having no other choice due to living in regional locations.

Figure 3: What guides you when choosing your pharmacy?

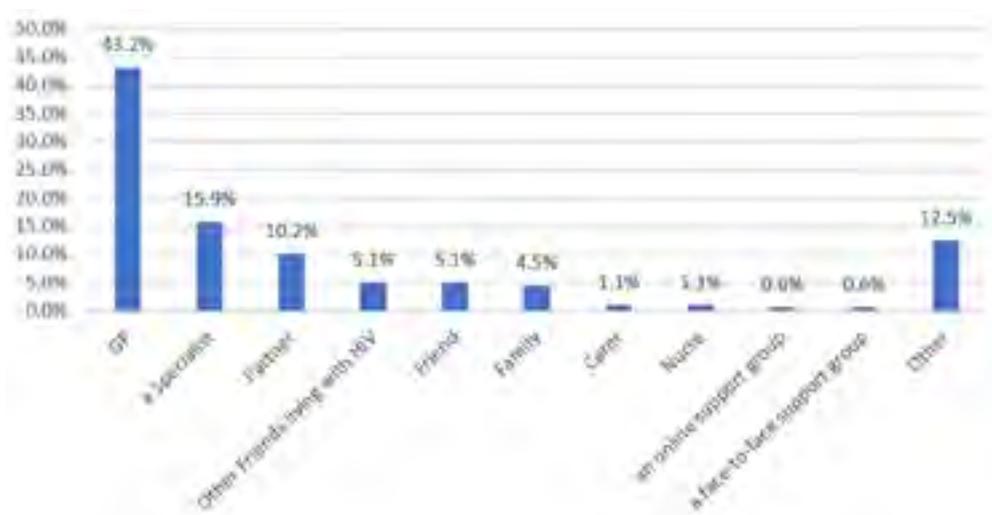


Your support network

Most respondents (61%, n=108) indicated they rely on healthcare providers as their main source of support to manage their health, such as 'my GP' (43.2%, n=76) followed by 'a specialist' (15.9%, n=28), 'a nurse' (1.1%, n=2), and 'a carer' (1.1%, n=2). This was followed by a range of familial and informal support networks (26.1%, n=46) including 'my partner' (10.2%, n=18), 'a friend' (5.1%, n=9), 'other

friends living with HIV' (5.1%, n=9), 'my family' (4.5%, n=8), 'an online support group' (0.6%, n=1), and 'a face-to-face support group' (0.6%, n=1), Figure 4. Of those respondents who listed 'Other (please specify)' (12.5%, n=22) the most common response was "myself". Other responses included 'Positive Life NSW support group', 'doctors at sexual health clinics', and one respondent stated, "No main [support] many people help".

Figure 4: My main source of support to help manage my health is:



Paying for your HIV medication

In total, 14.5% (n=25) of respondents indicated they were unaware that the NSW Health co-payment waiver covers the cost of the PBS co-payment s100 HIV antiretroviral medication. There were 6.3% (n=11) of respondents who were currently paying the PSB co-payment for their HIV antiretroviral medication. We asked these respondents why they were paying a PBS co-payment for their HIV medications and their responses highlighted confusion and misinformation about the co-payment waiver.

Some respondents indicated they didn't know about the co-payment waiver. One respondent stated that they didn't pay anything when

they picked their medication up from a public hospital pharmacy; however, after they moved to a local pharmacy, they now pay the co-payment. Some respondents indicated they pay the co-payment as they are on the disability support pension (DSP) or have a concession card. One respondent indicated they paid the co-payment due to privacy and confidentiality reasons. Of those who were not aware of the co-payment initiative, 69.2% (n=18) indicated they consider that their 'prescriber (doctor)' should have made them aware of the co-payment initiative, followed by a 'pharmacist' (23.1%, n=6).

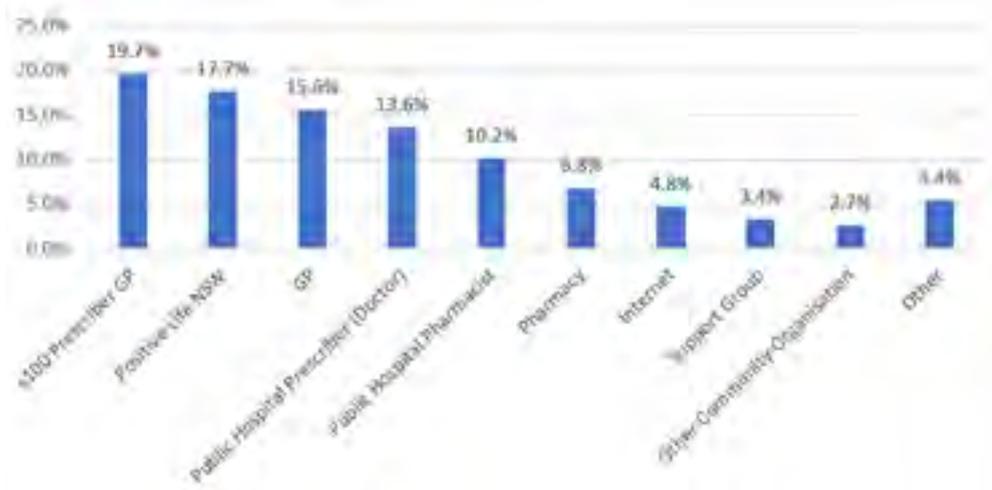
Awareness of the s100 HIV antiretroviral co-payment initiative

Respondents who were aware of the co-payment initiative (85.5%, n=148) provided a range of ways in which they first heard about the initiative. The most common was through an 's100 Prescriber GP' (19.7%, n=29), 'Positive Life NSW' (17.7%, n=26), a 'GP' (15.6%, n=23), 'Public Hospital Prescriber (Doctor)' (13.6%, n=20), 'Public Hospital Pharmacist' (10.2%, n=15), 'Pharmacy' (6.8%, n=10), 'Internet' (4.8%,

n=7), 'Support Group' (3.4%, n=5), and 'Other community organisation' (2.7%, n=4), see Figure 5. Of those who listed 'Other (please specify)' (5.4%, n=8) responses were varied. Some indicated that they had become aware of the co-payment initiative through the 2015 NSW State Election manifesto or through their work or family connections.

Results

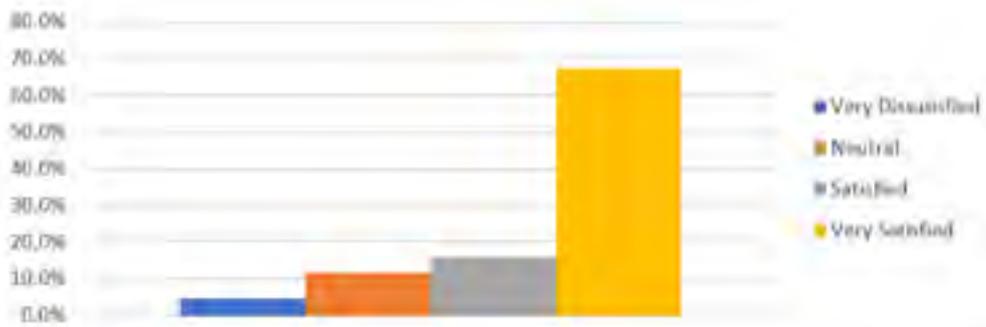
Figure 5: How did you first hear about the s100 co-payment initiative?



Your experience accessing s100 HIV medications

The majority of respondents indicated they were 'very satisfied' (67.6%, n=115) or 'satisfied' (15.9%, n=27) when filling their prescription and accessing the co-payment initiative, see Figure 6.

Figure 6: Please rate your experience of filling your prescription and accessing the co-payment initiative?



We asked respondents to explain the reason for these ratings. Table 1 represents the main themes presented by respondents (n=141).

Table 1: Respondents experiences filling prescriptions and accessing the co-payment initiative

Positive Experience	Negative Experience
Easy, smooth, and simple process (n=65)	Pharmacist not aware of the co-payment initiative. Had to educate the pharmacist/ pharmacy staff confused about process (n=9)
Have a good relationship with pharmacist who is knowledgeable, respectful, and aware of process (n=30)	Had issues in the past i.e. difficulty switching from public hospital pharmacy to community pharmacy dispensing, experienced discrimination, difficulty with picking up from public hospital pharmacy, and lack of confidentiality (n=7)
Grateful it is free, co-payment waiver helps financially (n=25)	Issue/confusion with s100 Patient Consent Form renewal (n=6)
Convenience and increased accessibility in accessing HIV medication (n=18)	Lack of pharmacies offering co-payment waiver or HIV medications issues with medication stock, chemist refuses to stock antiretrovirals (n=3)
Able to get medications on time, always in stock and pick up privately (n=7)	General confusion about co-payment (n=2)
Support from social workers and doctors such as organising waiver renewal and prescription (n=3)	Issue with GP/inconvenient to visit doctor all the time (n=2)

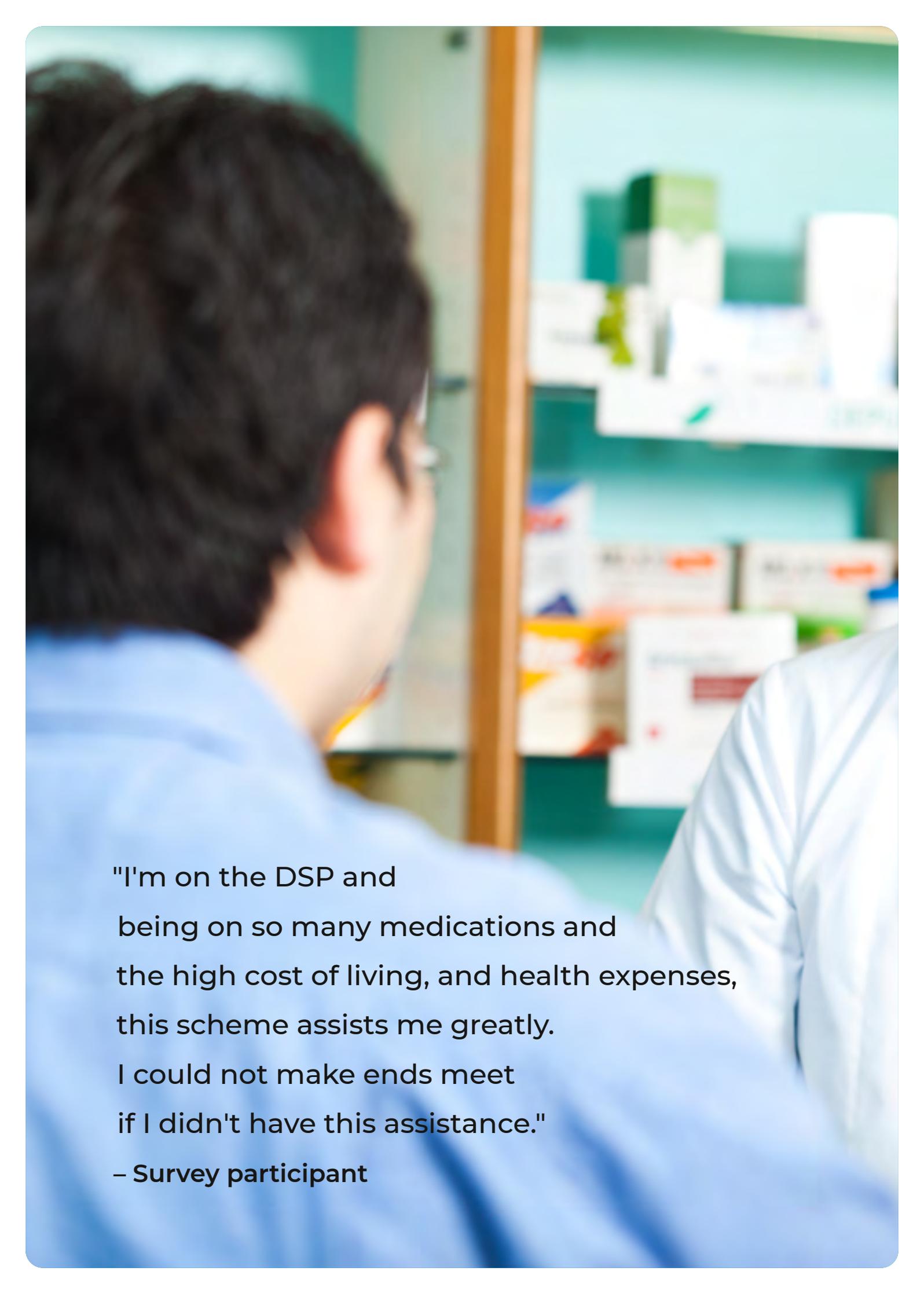
In total, 7% (n=12) of respondents indicated 'yes' to the question which asked if they had any concerns about their privacy with the way they currently access the co-payment initiative, while another 10.5% (n=18) were 'unsure'. Responses provided by these groups of respondents varied. Some reported issues with confidentiality standards in community pharmacy spaces and small rural towns. Another strong theme was uncertainty over confidentiality and who exactly has access to respondents' information. The following selected quotes illustrate these sentiments:

- *"There seems to be less confidentiality about HIV, the pharmacist talks in front of others sometimes. They might think my partner has it, but he doesn't. The less people that know the better as in the future it might cause issues with employment or insurance."*
- *"I live in a small village and the counter staff in the pharmacy are sometimes overly inquisitive about this rarely encountered subsidy arrangement."*
- *"I just don't know who may have access to my information."*

In addition, 18.1% (n=31) of respondents reported ever having had issues accessing the s100 co-payment initiative for their HIV antiretroviral medication. Responses provided included themes such as being charged the co-payment and/or being forced to pay, local pharmacies not stocking HIV medications, pharmacists not being aware of the initiative or process, issues with changing pharmacies and/or with having to organise the re-signing of the co-payment waiver annually. The following selected quotes illustrate these sentiments:

- *"Some initial issues with local pharmacy not stocking medications and trying to charge the \$41.00 p/product."*
- *"Not all pharmacists know about it. It's awkward having to explain it in the middle of the shop."*
- *"They did not know about the scheme; they did not have the valid s100 letter on file."*

Most respondents (64.9%, n=111) agreed that the s100 co-payment waiver initiative makes it more likely they will get their medication, see Figure 7.

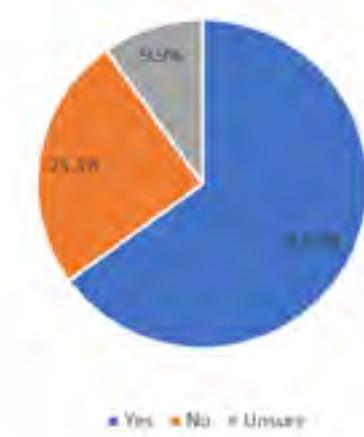
A photograph showing the back of a person's head and shoulders. They have dark, curly hair and are wearing a light blue shirt. They are looking towards a pharmacy shelf filled with various boxes of medication. The background is slightly blurred, showing more shelves and a wooden pillar. The lighting is bright and even.

"I'm on the DSP and being on so many medications and the high cost of living, and health expenses, this scheme assists me greatly. I could not make ends meet if I didn't have this assistance."

– Survey participant

Results

Figure 7: Does the s100 co-payment initiative make it more likely that you will get your medication?



Managing your paperwork

Half (50.3%, n=85) of the respondents indicated their pharmacist keeps track of their s100 Patient Consent Form, followed by themselves (20%, n=34), and 29.6% (n=50) didn't know. There were 15.2% (n=26) of respondents who agreed that keeping track

of their s100 Patient Consent Form for the s100 co-payment initiative is difficult. Only approximately one quarter (24.7%, n=43) of respondents were aware when they have reached their PBS SafetyNet threshold.

5 Significance and Conclusions

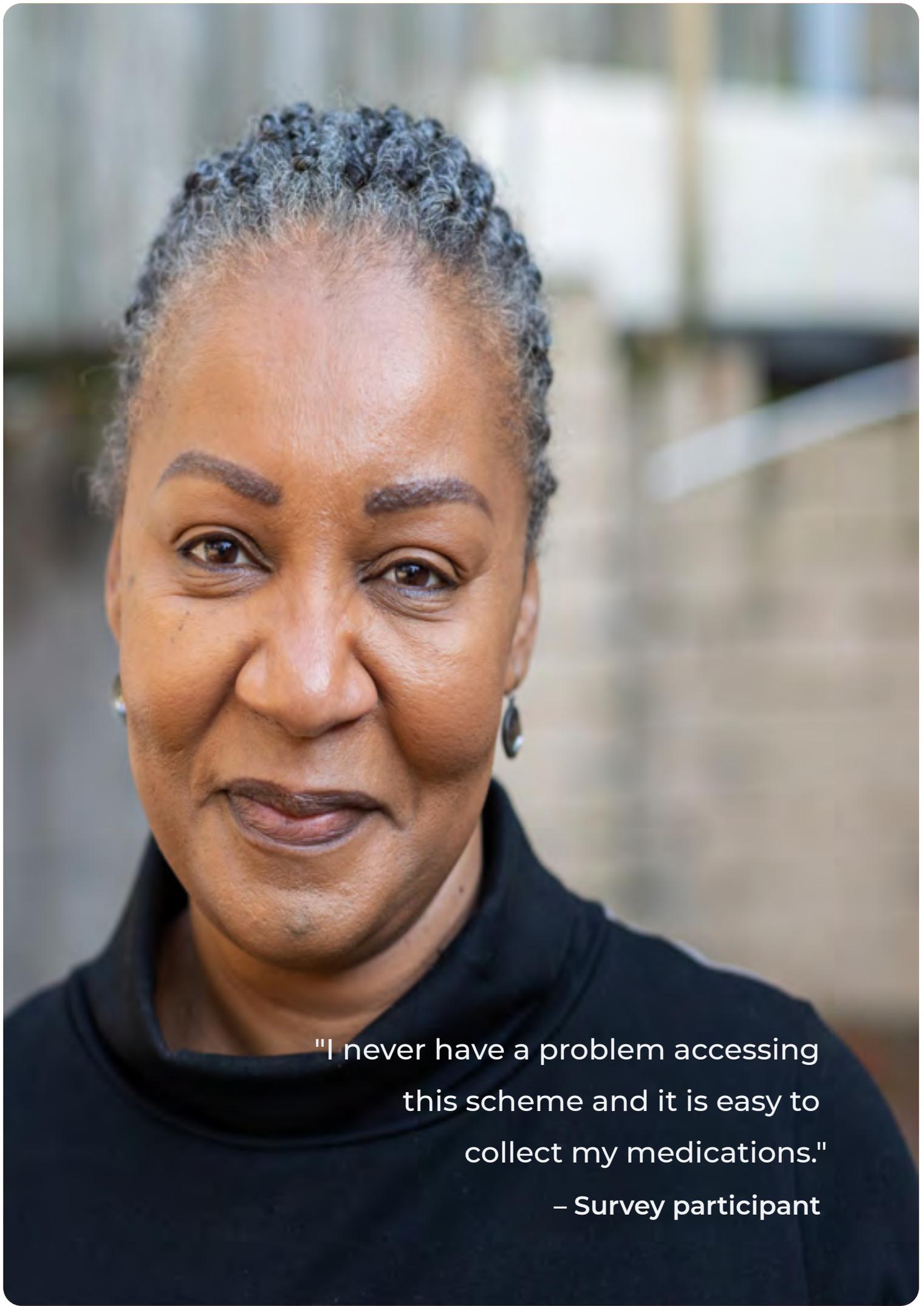
This community consultation offers insights into the way people living with HIV in NSW have experienced the co-payment waiver initiative since its introduction by the NSW Government in 2015.

The results show us that the s100 co-payment waiver initiative has been largely well communicated and received by people living with HIV in NSW. Most respondents agreed that the s100 co-payment waiver initiative reduces barriers to accessing their HIV antiretroviral medication, and qualitative insights revealed many respondents were appreciative of the initiative and felt the subsidy was supportive both financially and of their health. The majority of respondents (83.5%, n= 142), reported being 'satisfied' or 'very satisfied' with the process of filling their prescription and accessing the co-payment waiver initiative.

This small online survey highlighted that not all people living with HIV are aware of the co-payment waiver and some are unnecessarily paying for their HIV medication. In fact, 18.1% (n=31) of respondents report some issues accessing the s100 co-payment waiver for their HIV antiretroviral medication. We learned

that some people living with HIV still need to remind and educate pharmacists about the co-payment waiver. Respondents raised concerns over confidentiality and privacy with the current way the co-payment waiver is accessed, particularly within community chemists and local pharmacy settings. There were 15.2% (n=26) of respondents who agreed that keeping track of their s100 Patient Consent Form for the s100 co-payment waiver initiative is difficult. These insights tell us that we need to continue working with and supporting people living with HIV, s100 prescribing GPs and nurse practitioners, and NSW-based pharmacists and pharmacy staff, to ensure current knowledge and the process of accessing the s100 co-payment waiver is assured.

Positive Life NSW would like to thank the community members across NSW who took the time to respond to this survey. We would also like to thank NSW Health for their ongoing support in providing subsidised HIV medication to people living with HIV in NSW and their commitment to understanding the best methods to continue to administer the co-payment initiative into the future.



"I never have a problem accessing
this scheme and it is easy to
collect my medications."

– Survey participant

Recommendations

1. Increase awareness and education of the s100 co-payment waiver to people living with HIV across NSW.

- Support and advocate on behalf of people living with HIV who experience charges for HIV medications and/or issues accessing co-payment waiver.
- Maintain updated information on the Positive Life NSW website and develop resources on the co-payment waiver, including privacy and confidentiality information while continuing to promote the co-payment waiver widely to community members.
- Positive Life NSW to continue to provide information around treatment support for people living with HIV in NSW.

2. Increase awareness of the s100 co-payment waiver to NSW Health sector partners and allied health service providers.

- Partner with the Pharmacy Guild of Australia to increase awareness of the s100 co-payment waiver process, and to provide further information on privacy to pharmacies across Australia, particularly in regional and rural locations.
- Partner with the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) to engage with s100 prescribing GPs and nurse practitioners about the importance of communicating the co-payment waiver initiative to patients living with HIV.

3. Positive Life NSW to continue partnering with NSW Health to consult with community members about their experiences accessing the s100 co-payment waiver initiative.

4. Liaise with NSW Health and ASHM around the s100 Patient Consent Form.

- Partner with ASHM on s100 prescriber and nurse practitioner training to ensure that patients living with HIV are aware of the need to complete the s100 Patient Consent Form on a regular basis.
- Subject to regulatory requirements, examine the feasibility of increasing the time period for the validity of the s100 Patient Consent Form to 12 months.

5. Following the Australian Government's announcement to expand s100 co-payment waiver access to all people living with HIV who are ineligible for Medicare, to raise awareness around this policy change for people living with HIV in NSW.

7. Appendix: Survey Tool



s100 HIV ART (Co-payment initiative) survey

Introduction

Positive Life NSW invites you to participate in this survey to share your experiences as a person living with HIV (PLHIV) who uses s100 HIV antiretroviral medicines, or assists another person to obtain their HIV medications, in NSW.

Questions in this survey will focus on the NSW co-payment initiative which covers the cost of the Pharmaceutical Benefit Scheme (PBS) co-payment for s100 HIV antiretroviral medication for eligible people in NSW.

The NSW co-payment initiative on s100 HIV medications means that if you have a Medicare card, your HIV medication in NSW is completely free. Your HIV antiretroviral medications are eligible for this initiative and you therefore do not need to pay for your HIV medications at all in NSW.

Positive Life NSW will be the custodian of the data, however de-identified aggregated data will be shared with NSW Health and Service NSW to inform a project by NSW Health to understand the best way to administer this initiative in the future. There will be no changes to your eligibility for your medicines or for the co-payment initiative.

If you have questions about the survey, this initiative or your eligibility, please contact Neil Fraser, Deputy CEO or Craig Andrews, Communications Manager on contact@positivelife.org.au or call (02) 9206-2177 or 1800 245 677 (freecall outside metro)

This survey will close at 5:30pm (AEST) on Friday, 6 November 2020.

No questions are compulsory. All answers are anonymous.

You may have completed this survey online or might prefer to do so using the following link <https://www.surveymonkey.com/r/s100-Copayment> in which case you are welcome to dispose of this paperwork.

7. Appendix: Survey Tool

Let's start with your experience accessing s100 HIV medications

1. Are you a person living with HIV and taking HIV treatment? (please tick one)

- Yes
- No

2. Who prescribes your s100 HIV antiretroviral medications? (please tick one)

- my GP
 - a Doctor at a Sexual Health Clinic
 - s100 prescriber GP
 - a Nurse Prescriber
 - a Specialist
 - a clinician at a Public Hospital
 - Other (please specify)
-

Collecting your HIV medication

3. Where do you pick up your HIV medication? (please tick one)

- my local Pharmacy/Chemist
 - a Public Hospital Pharmacy
 - a Private Hospital Pharmacy
 - Other (please describe)
-

4. What guides you when choosing your pharmacy? (please select as many as apply)

- Convenience (eg Location, familiarity with pharmacist)
- Choice of medication offered
- Trust and Reputation
- Co-location with other shops
- Privacy
- speed & Availability of dispensing medication
- Other (please specify)

7. Appendix: Survey Tool

5. Who generally collects your HIV antiretroviral medicines?

(please select as many as apply)

- I do
 - my family
 - my partner
 - a carer
 - a friend
 - Other (please specify)
-

Your support network

6. My main source of support to help manage my health is: (please tick one)

- my Family
 - Carer
 - My partner
 - a friend
 - an online support group
 - a face-to-face support group
 - other friends living with HIV
 - my GP
 - a Nurse
 - Specialist
 - my local pharmacist
 - my hospital pharmacist
 - Other (please specify)
-

7. Have you used the option of getting your prescription online before?

(please tick one)

- Yes → (please go to next question)
- No → (please go to question 9)

7. Appendix: Survey Tool

8. If you have used the option to get your prescription online, how comfortable were you using this option? (please circle one)

Not Comfortable | Comfortable | Neutral | Comfortable | Very Comfortable

9. Do you know when you've reached your PBS SafetyNet threshold?
(please tick one)

Yes → (please go to question 10)

No → (please go to question 11)

10. How do you keep track?

Paying for your HIV medicines

11. Are you currently paying the PBS co-payment for your HIV antiretroviral medication (\$41 for general patients or \$6.60 if you hold a concession card)?
(please tick one)

Yes → (please go to question 12)

No → (please go to question 13)

Unsure → (please go to question 12)

12. Can you please let us know why you are paying a PBS co-payment for your HIV medications? → (then please go to end of survey)

s100 HIV antiretroviral co-payment initiative

13. Did you know that the NSW Health co-payment initiative covers the cost of the PBS co-payment for s100 HIV antiretroviral medications? (please tick one)

Yes → (please go to question 15)

No → (please go to next question)

7. Appendix: Survey Tool

14. In your opinion, who should have made you aware of this co-payment initiative?

(please tick one)

- Support Group
 - Prescriber (doctor)
 - Pharmacist
 - Other (please specify)
-

15. How did you first hear about the s100 co-payment initiative? (please tick one)

- GP
 - Support Group
 - Positive Life NSW
 - Other community organisation
 - Pharmacy
 - Friend
 - Internet
 - Public Hospital Prescriber (Doctor)
 - Public Hospital Pharmacist
 - s100 prescriber GP
 - Other (please specify)
-

Your experiences accessing the NSW co-payment initiative

16. Please rate your experience of filling your prescription and accessing the co-payment initiative? (please circle one)

Very Dissatisfied | Dissatisfied | Neutral | Satisfied | Very Satisfied

Please explain the reason for this rating?

7. Appendix: Survey Tool

17. Do you have any concerns about your privacy with the current way you access the co-payment initiative? (please tick one)

Yes → (please describe these here)

No → (please go to next question)

Unsure → (please describe these here)

18. Have you ever had any issues accessing the s100 co-payment initiative for your HIV antiretroviral medication? (please tick one)

Yes → (please describe these here)

No → (please go to next question)

19. Does the s100 co-payment initiative make it more likely that you will get your medication? (please tick one)

Yes

No

Unsure

7. Appendix: Survey Tool

Managing your paperwork

20. Is keeping track of your consent form for the s100 co-payment initiative difficult?
(please tick one)

- Yes
- No
- I don't use a consent form

21. Who keeps your Consent Form? (please tick one)

- I do
- My Pharmacist
- I don't know

Thank you for participating in this survey.

Please fold up and place in the Reply-Paid Envelope to post back to Positive Life NSW.

If you have any questions, please contact

Neil Fraser, Deputy CEO or Craig Andrews, Communications Manager

on contact@positivelife.org.au

or call (02) 9206-2177 or 1800 245 677 (freecall outside metro)

8. References

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2. Braun V, Clarke V. Using thematic analysis in psychology. *Qual. Res. Psychol.* 2006 Jul 21;3(2):77-101.
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"Both public hospital and private pharmacy promoted this initiative proactively, so I benefited from the scheme asap."

– Survey participant



Positive  Life NSW

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