

Dispensing of HIV medications at community pharmacies in NSW

Implementation Survey Report – February 2016

Background: From 1 July 2015, people living with HIV have had the choice whether to collect their HIV medications from a hospital pharmacy, a local community pharmacy (chemist), or order from an online pharmacy and have them delivered. This was an important change which removed a barrier to people with HIV accessing treatment more conveniently, and to remaining motivated and staying on treatment. In the lead-up to the roll-out of HIV community dispensing, Positive Life surveyed people with HIV to assess if they would use chemists to dispense HIV medications, and if not, what their reasons were. People with HIV were again surveyed several months post-implementation of the scheme to gather feedback on their experiences and to identify problems and improve community dispensing access and efficiency.

Summary Analysis: Overall, the choice of having medications dispensed by a community pharmacy has been embraced by people living with HIV, who have expressed high levels of satisfaction with the scheme and convenience and improved service as the key advantages. Some implementation issues remain, however, which have impacted on overall satisfaction and take up of community dispensing. Concerns about privacy and disclosure of HIV status also remain for people with HIV, particularly in rural and regional locations.

The survey has shown just more than 40% of respondents living with HIV are already utilising community pharmacy to have their medications dispensed, and more than half of those who have not utilised community pharmacy to date intend to in the future. For those who do not intend to utilise community pharmacy, hospital pharmacies remain more convenient or privacy/disclosure concerns are overriding issues.

Of those people with HIV who have utilised community pharmacy, satisfaction is high and dissatisfaction very low, with minimal variation between people with HIV living in Sydney and those in rural and regional locations.

Pharmacists have been key to the experience of HIV community dispensing and to high levels of satisfaction with the scheme. Almost 95% of people with HIV who responded to the survey said they have found their pharmacist to have been helpful and supportive and just more than half said they would feel comfortable talking with their pharmacist about how their experience could have been improved. The survey revealed, however, that implementation issues related to the supply of HIV medications to community pharmacy by wholesalers, and therefore on-supply to people with HIV has been problematic and has impacted on satisfaction. Key to these concerns has been pharmacist's difficulties sourcing all HIV medications, which has meant some people with HIV have not been able to collect all their medications from the one place at the one time. This has impacted on convenience, and caused some people with HIV to resort to a hospital pharmacy to have their medications dispensed.

Recommendations: That

- 1) issues related to the supply of HIV medications to community pharmacy by wholesalers, and which impact on-supply to people with HIV be communicated to those able to positively influence those issues, and those issues be considered as a matter of priority and resolved as soon as possible;

- 2) results of the survey, particularly as they relate to high uptake of community dispensing and high levels of satisfaction by people with HIV be communicated to pharmacists, health departments and others with an interest in the community dispensing scheme;
- 3) the preference of some people to collect their HIV medications from a hospital pharmacy be acknowledged, and that the choice of where to collect medications be retained for all people living with HIV, wherever they reside in the state;
- 4) the availability of community dispensing of HIV medications continue to be communicated to people with HIV and, in particular, people from culturally and linguistically diverse backgrounds in languages other than English, non-identifying men who have sex with men, and heterosexuals;
- 5) a 'safe place' type scheme be considered to enable people with HIV to identify community pharmacies who dispense HIV medications and who are sensitive to the privacy and disclosure concerns of people with HIV;
- 6) particular consideration be given to the privacy and disclosure concerns of people with HIV in rural and regional locations and how these might be addressed;
- 7) survey responses collected from people with HIV who reside in locations other than NSW, the ACT or an unknown location be provided to positive living organisations in those other locations to allow for local consideration; and
- 8) all survey responses be provided to the National Association of People With HIV Australia (NAPWHA) for consideration as part of the national survey on community dispensing of HIV medications to be undertaken by that organisation.

The Survey: Survey Monkey was used to develop a short survey comprising 27 questions and which took between five and ten minutes to complete. The survey was open between 19 October and 19 November 2015. The survey was promoted through Positive Life member and service provider networks, Facebook and Twitter, the Positive Life web site and Grindr. The survey was also promoted by NAPWHA. A total of 289 people responded to the survey.

Promotion of the survey by NAPWHA inadvertently led to responses being received from people who do not reside in NSW, and because this was not anticipated, the question which asked for the respondent's postcode was not a required answer. Overall, of the 289 responses received, 45.1% were from NSW/ACT and a further 24.3% were from unknown locations. All other responses were from locations other than NSW/ACT, most notably Victoria (13.2%) and Queensland (11.8%). For the purposes of analysis, this report excludes all responses from jurisdictions other than NSW, and people who reported being HIV negative or HIV-unknown, but retains responses when the location is not known.

Males were overrepresented (98.5%) and females were underrepresented (1.5%). There were no Transgender or Intersex respondents. There was an overrepresentation of Gay Male/Homosexual respondents and an underrepresentation of Heterosexual (2.2%) and Bisexual respondents (5%). The survey was distributed by PozHet and Multicultural HIV and Hepatitis Service (MHAHS). Paper survey responses from MHAHS clients will be fed into the NAPWHA Survey to be conducted in early 2016. Ninety-five (71.4%) respondents were born in Australia and a further twenty-two (16.5%) were born in New Zealand or the United Kingdom. The number of non-Australian born respondents was low. Employment/unemployment status, age distribution, sources of health care and length of time taking HIV-medications, were representative.

Key Findings:

- 1) The choice of having HIV medications dispensed by a community pharmacy has been embraced by people living with HIV:
 - 50% of respondents said they collect their medications from a hospital pharmacy (Q12) for reasons including supply issues with community pharmacy, convenience of hospital pharmacy, proximity of hospital pharmacy to health care providers, and privacy (Q13).
 - 41.2% of respondents said they collect their medications from a community pharmacy (Q12) primarily because of the convenience of doing so, but also improved service (Q13).
 - 2.9% of respondents said they order their medications from an online pharmacy and have them delivered (Q12), primarily because they are not a permanent resident (Q13).
 - 5.9% of respondents said they collect their medications from another source, primarily The Albion Street Centre (Q12).
- 2) Of those people with HIV who have utilised community pharmacy, satisfaction is high and dissatisfaction very low, with minimal variation between people with HIV living in Sydney and those in rural and regional locations:
 - 62% of respondents rated their experience ‘very satisfied’ (Q15)
 - 13.9% of respondents rated their experience ‘satisfied’ (Q15)
 - 1.3% of respondents rated their experience ‘dissatisfied’ (Q15)
 - 3.8% of respondents rated their experience ‘very dissatisfied’ (Q15)
 - on a scale of 1 to 5, where 5 was the most satisfied, the average overall rating was 4.29, Sydney only average rating 4.38, and rural and regional only average rating 4.20 (Q15).
- 3) Of those people with HIV who haven not utilised community pharmacy to date, more than half intend to in the future:
 - 58.8% of responses said they collect their medications from other than a community pharmacy (Q12)
 - 57.7% of respondents who have not utilised community said they plan to. (Q14).
- 4) For those who do not intend to utilise community pharmacy, hospital pharmacies remain more convenient or privacy/disclosure concerns overriding:
 - see answers to question 14.
- 5) Pharmacists have been key to the experience of people with HIV of community dispensing and to high levels of satisfaction with the scheme:
 - 93.3% of respondents said their pharmacist had been helpful and supportive (Q18)
 - 55.6% of respondents said they felt comfortable talking to the pharmacist about their experience of community dispensing (Q21).
- 6) Implementation issues related to the supply of HIV medications to community pharmacy by wholesalers, and therefore on-supply to people with HIV has been problematic:
 - see answers to questions 19 and 20.

Demographics of people who responded to the survey:

- **Jurisdiction** – 45.1% (130) of people who responded to the survey live in NSW and a further 24.3% (70) skipped the question which asked for their residential postcode. The survey inadvertently drew responses from States and Territories other than NSW. All but NSW and location unknown responses were excluded from final analysis.
- **HIV Status (Question 1)** – of the 200 respondents who live in NSW or at an unknown location, 78.5% (157) reported being HIV-positive. 9.5% (19) reported being HIV-negative, 8% (16) reported being HIV Unknown, and a further 4% (8). All but responses from people who reported

being HIV-positive were excluded from the final analysis.

Demographics of PLHIV respondents from NSW or unknown location: Of the 157 respondents who reported being HIV-positive and who live in NSW or an unknown location:

- **Age (Question 8)** – The majority were aged in the range 45-54 (37%, 51); similar numbers were aged in the range 35 to 44 (18.1%, 25), and 55 to 64 (21%, 29); 14.5% (20) of respondents were aged in the range 25 to 34; 4.3% of respondents were aged in the range 35 to 74; 4.3% of respondents were aged in the range 18 to 24; one respondent (0.7%) was aged 75+. Nineteen respondents skipped the question.
- **Gender (Question 2)** – the majority of respondents were male (135, 98.5%) and only two respondents (1.5%) were female. No respondents reported being transgender, intersex or other. Twenty respondents skipped the question.
- **Identity (Questions 3 and 4)** – the majority of respondents identified as ‘gay male or homosexual’ (123, 88.5%), none identified as ‘lesbian or homosexual’, seven (5%) identified as bisexual, three (2.2%) as heterosexual or straight, and four (2.9%) as queer. Of the respondents who identified differently, one identified as ‘MSM’ and another as ‘gay/trans’. Eleven respondents skipped the question.
Only two respondents (1.5%) identified as Aboriginal, and a further two (1.5%) preferred not to say. The majority of respondents identified as neither Aboriginal nor Torres Strait Islander (132, 97.1%). Fourteen respondents skipped the question.
- **Country of origin (Question 5)** – the majority of respondents were born in Australia (95, 71.4%). Twelve and ten respondents were born in New Zealand and the United Kingdom respectively, and further small numbers of respondents (not more than 3) were born in the United States of America, Austria, China, Cyprus, India, Indonesia, Iraq, Japan, New Zealand, Peru, Philippines, South Africa, and Thailand. Twenty-four respondents skipped the question.
- **Language spoken at home (Question 6)** – the majority of respondents speak English at home (130, 94.9%). A further one respondent each speaks Arabic, Chinese, French, Spanish, Tagalog, Thai and Turkish. Twenty respondents skipped the question.
- **Income source (Question 7)** – the majority of respondents reported being employed (92, 65.71%). A further 17.1% (24) reported receiving the Disability Support or Aged Pension; five respondents (3.57%) each reported receiving Unemployment Benefit, Student Benefit, or are supported by their partner, spouse or friend. Of those respondents who reported another main source of income, several reported being self-funded retirees, or a mix of income sources. Seventeen respondents skipped the question.
- **Location (Question 9)** – 76% of respondents to the survey were resided in the Sydney statistical division. The remainder were resided in regional and rural locations.

HIV Health care (Questions 10 and 11): Of the 157 respondents who reported being HIV-positive and who live in NSW or an unknown location:

- Sexual health or HIV specialist services were the primary source of HIV health care (67, 51.9%); a further third reported their main source of health care being a GP s100 prescriber (43, 33.3%); and 6.2% reported their main source of HIV health care as a hospital doctor.
- Of the 8.5% (11) of respondents who reported a mixed source of health care, a large number reported the Albion Street Centre.
- The majority of respondents reported they have been taking HIV medications for 3+ years (90, 70.3%); 15.6% reported taking HIV medications for 1 to 3 years; and 14.1% for less than 12 months.

Dispensing of HIV Medications: Of the 157 respondents who reported being HIV-positive and who live in NSW or an unknown location:

- **Where do you get your HIV medications (Questions 12, 13 and 14)** – half of responses to

question 12 reported collecting medications from a hospital pharmacy (68, 50%); 41.2% (56) reported collecting medications from a community pharmacy; 2.9% (4) reported buying medications online; and a further 5.9% (8) reported other. Of those who reported they get their medications from another source, most reported The Albion Centre.

When asked the reasons why they get their medications from the source they do:

- those who reported hospital pharmacy indicated various reasons including supply issues with community pharmacy, convenience of hospital pharmacy, proximity of hospital pharmacy to health care providers, and privacy.
 - those who reported community pharmacy indicated various reasons, but primarily convenience.
 - those who reported online pharmacy indicated convenience as well as not being a permanent resident.
- When those respondents who indicated they had not used a community pharmacy were asked if they intended to, 55.7% (41) responded they did intend to and 42.3% (30) responded they did not.
 - **Experience of community pharmacy (Question 15)** – asked to rate their experience of obtaining their medication from a community pharmacy, a majority (62%, 49) of respondents said they were very satisfied, a further 13.9% (11) said they were satisfied. 19% (15) respondents said they were neither satisfied nor dissatisfied. A small number of respondents said they were either dissatisfied (1.3%, 1) or very dissatisfied (2.8%, 3). Some variation was seen when comparing respondent's experience of community pharmacy between Sydney and rural/regional locations, however, these variations were minor and based on small sample sizes.
 - **Receiving medication by mail (Questions 16 and 17)** – few respondents reported pharmacists offered to send their medications in the mail (5.7%, 4), and when medications were delivered, delivery times were generally not acceptable – 63% (17) responded no when asked if the delivery time was acceptable.
 - **Support and help from pharmacist (Question 18)** – a large majority of respondents reported their pharmacist had been helpful and supportive (93.3%, 70).
 - **Pharmacist's experience (Questions 19, 20 and 21)** – mostly positive, some neutral and some negative responses were received when the question "how do you think the experience was for the pharmacist, and did they say anything positive or negative?" was asked:
 - Examples of positive responses were:
 - “Switching from the hospital to the local chemist has been 100% positive. They are friendly and ... focussed on providing good customer service – it is a totally different experience with the hospital.”
 - “The pharmacist and her staff have been very polite, supportive and I have been very pleased.”
 - “Supportive attitude. Handled discretely.”
 - “They were very positive and helpful.”
 - Examples of neutral responses were:
 - “Same as any other transaction.”
 - “Cannot say what he thought, but he had clearly had some training or guidance with respect to his manner in dealing with me.”
 - An examples of a negative response was:
 - “Negative, ordering my gay drugs is challenging for them.”

Asked if they could suggest ways their experience could have been improved, respondents particularly highlighted supply issues.

Typical responses included:

- “Wholesalers need to be able to supply chemists all medication.”
- “Make sure the nominated Community Pharmacists can provide all of the drugs, not just some.”

- "If I had known that one of my pills was not going to be available from a community pharmacy I would not have stressed over 'coming out' to the pharmacist."

Asked if they felt comfortable talking to the pharmacist about their experience, 55.6% (25) of those who responded said yes, while 44% (20) said no. Responses included:

- "We have a relationship of trust."
- "Usually other customers around – no privacy."

- **Privacy and Disclosure (Question 22)** – asked if privacy or disclosure had been an issue for them, 68.7% (68) said no and 31.3% (31) said yes. Some variation in responses was seen when comparing Sydney to rural/regional responses – a larger proportion of respondents from rural/regional locations responded privacy or disclosure had been an issue for them.

Yes responses included:

- "Stigma of HIV makes discretion very important to me."
- "...living in a small community ... there is the ever present problem of the wrong people finding out and making work difficult. Has been an issue in the past that I don't wish to relive."
- "My HIV status is an intensely private issue and I prefer to strictly control disclosure where possible."
- "It always has been, and always will be. My experience of people's discretion in this area is poor to outrageous."

No responses included:

- "Why should disclosure be an issue these days? Guys need to 'man up' about this issue and stand up for themselves. This is 2015 and this is just a chronic disease. Stop being to 'TIM' about the whole bloody thing and get on with it."

- **Information on community dispensing (Questions 23, 24 and 25)** – asked where they had heard about the implementation of community dispensing, respondents gave a range of responses which indicated sources including communications from positive living organisations, social media sources, health care providers, and hospital and community pharmacies.

Of the 44.3% (51) of respondents who said they had read information on community dispensing on the Positive Life NSW web site, 39.4% (28) said the information was very helpful, 32.4% (23) said the information was helpful, 19.7% (14) were neutral on the information, 1.4% (1) said the information was unhelpful, and 7% (5) said the information was very unhelpful. Five of the six respondents who said the information was 'unhelpful' or 'very unhelpful' gave comments which did not relate to the Positive Life information itself.

'Very helpful' responses included:

- "Very clear and precise in what you need to do, and what to expect."
- "[It] was a great reference and also allowed me to advise POZ friends too."
- "If I hadn't read the web site I wouldn't have known about the consent form. My GP did not have the consent form so the fact that I could provide one was great."
- "No jargon, just facts easily presented."

'Helpful' responses included:

- "Fairly clear to read through, could be added to for more benefit for a more diverse range of readers than it seems to be aimed at ..."

'Unhelpful' responses included:

- "I don't read websites ... does anyone?"

Authors: Lance Feeney, Policy Advisor and Scott Harlum, Communications and Policy Officer.

Date: 5 February 2016

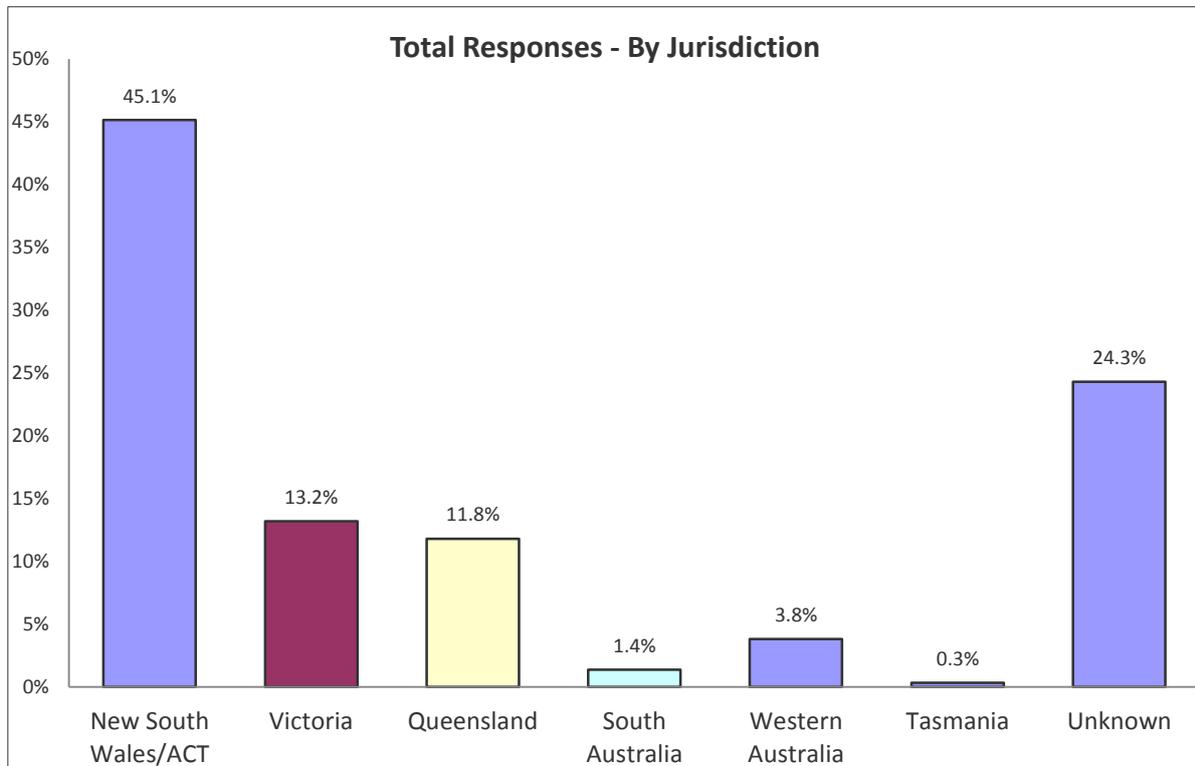
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Author: Communications & Policy Officer

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Survey Results

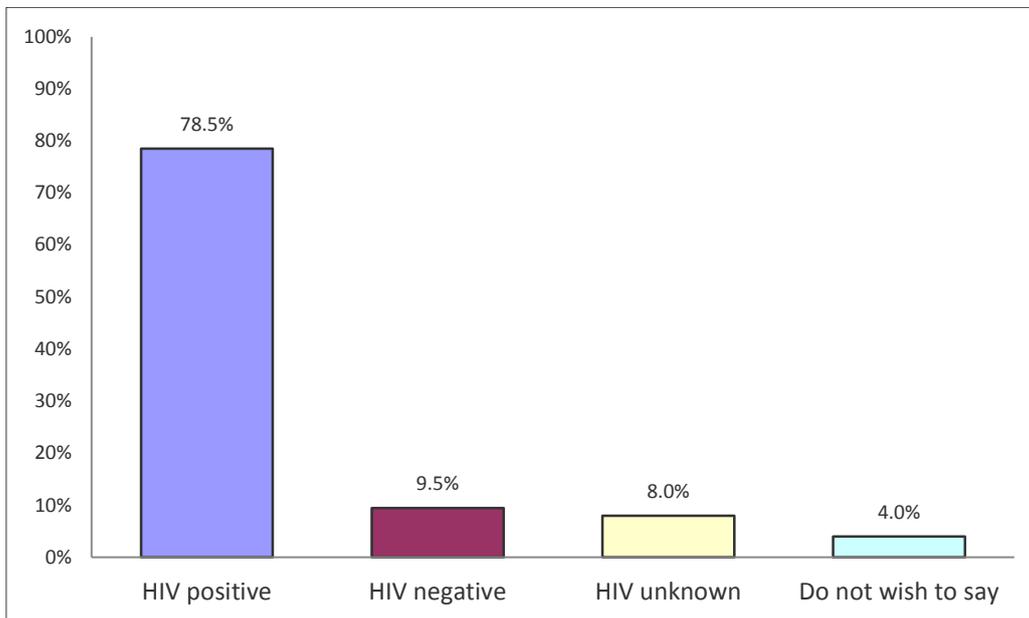
Total responses – by State or Territory



	Response Percent	Response Count
New South Wales/ACT	45.1%	130
Victoria	13.2%	38
Queensland	11.8%	34
South Australia	1.4%	4
Western Australia	3.8%	11
Tasmania	0.3%	1
Unknown	24.3%	70
answered question		288
skipped question		1

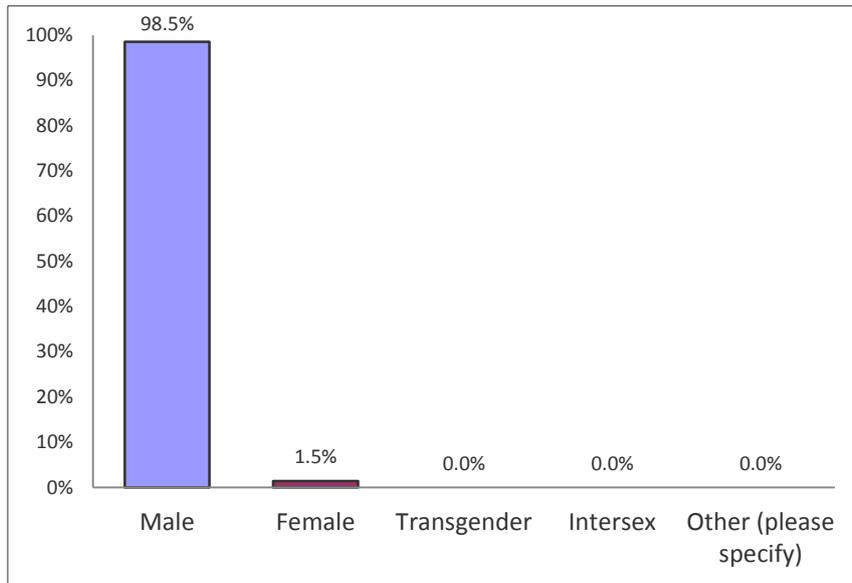
New South Wales, Australian Capital Territory and Unknown responses

1. What is your HIV status?



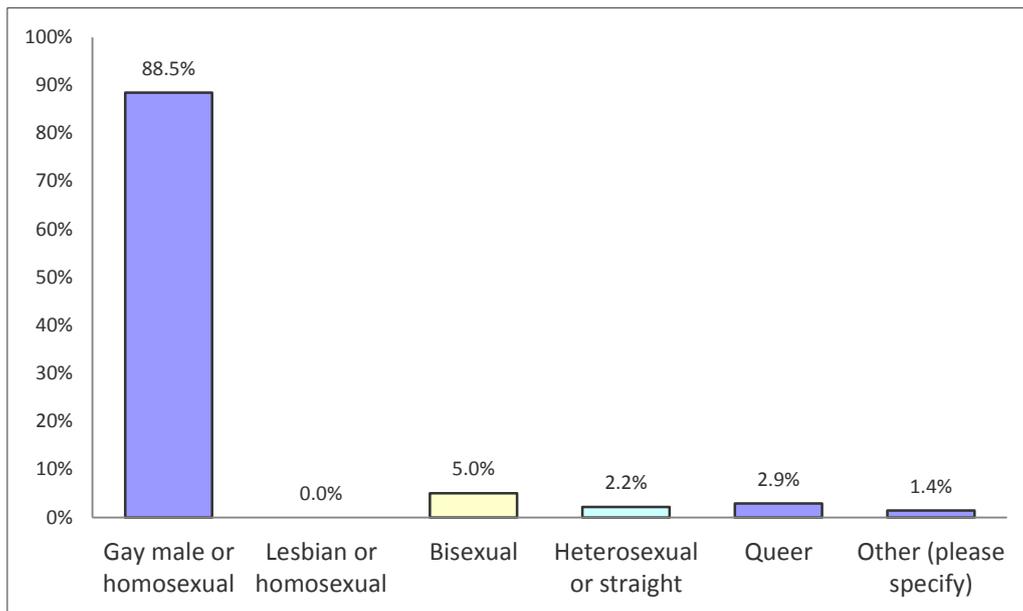
	Response Percent	Response Count
HIV positive	78.5%	157
HIV negative	9.5%	19
HIV unknown	8.0%	16
Do not wish to say	4.0%	8
answered question		200
skipped question		0

2. What is your gender?



	Response Percent	Response Count
Male	98.5%	135
Female	1.5%	2
Transgender	0.0%	0
Intersex	0.0%	0
Other (please specify)	0.0%	0
<i>answered question</i>		137
<i>skipped question</i>		20

3. How do you identify?



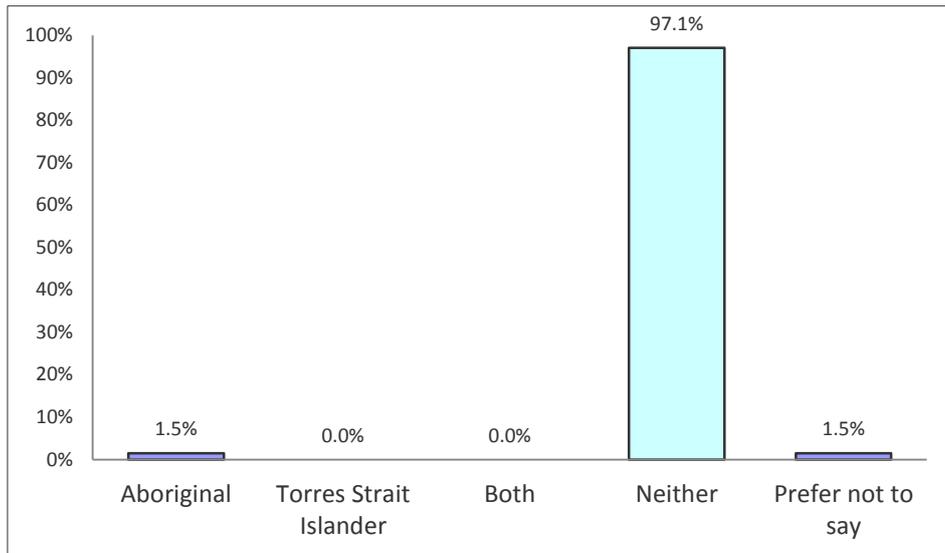
	Response Percent	Response Count
Gay male or homosexual	88.5%	123
Lesbian or homosexual	0.0%	0
Bisexual	5.0%	7
Heterosexual or straight	2.2%	3
Queer	2.9%	4
Other (please specify)	1.4%	2
answered question		139
skipped question		18

Other responses:

MSM.

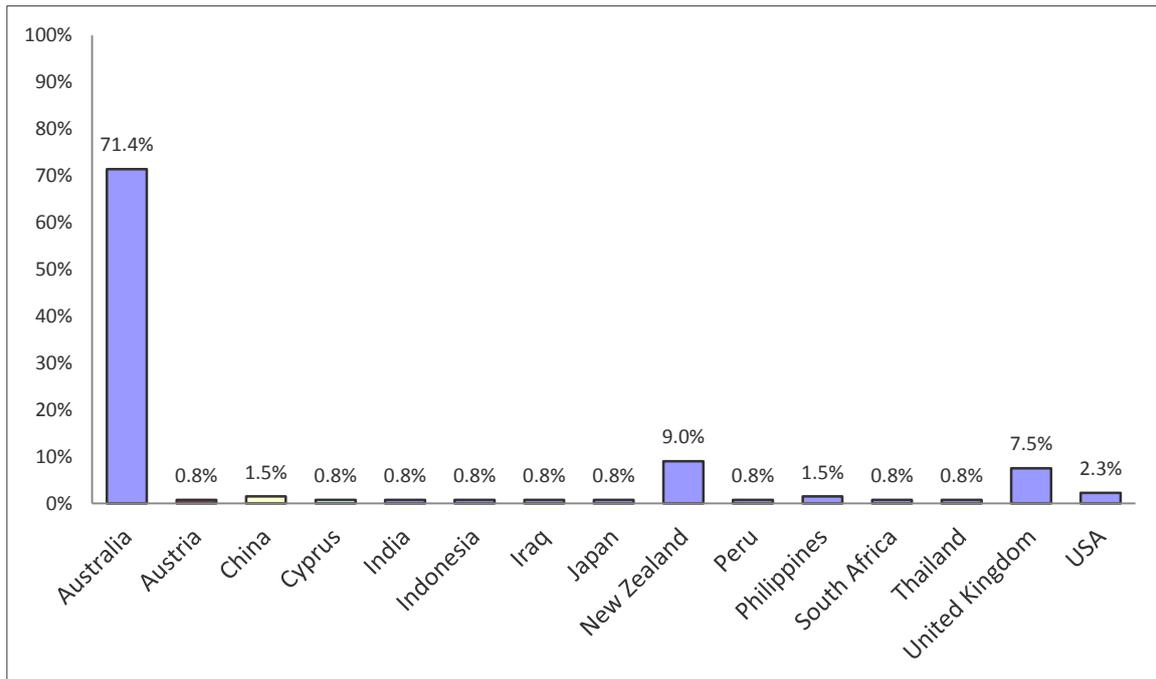
Gay/Trans.

4. Are you Aboriginal or Torres Strait Islander?



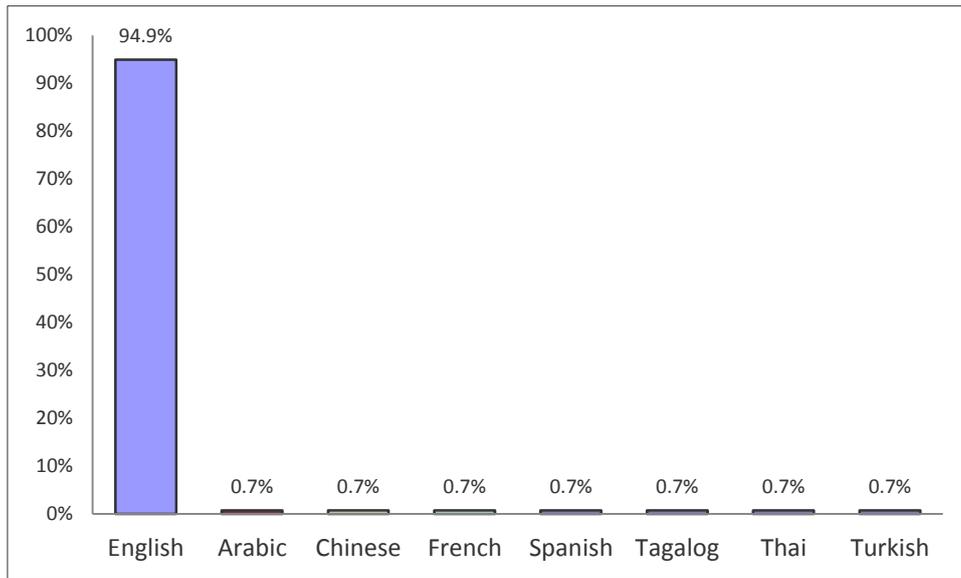
	Response Percent	Response Count
Aboriginal	1.5%	2
Torres Strait Islander	0.0%	0
Both	0.0%	0
Neither	97.1%	132
Prefer not to say	1.5%	2
answered question		136
skipped question		14

5. In what country were you born?



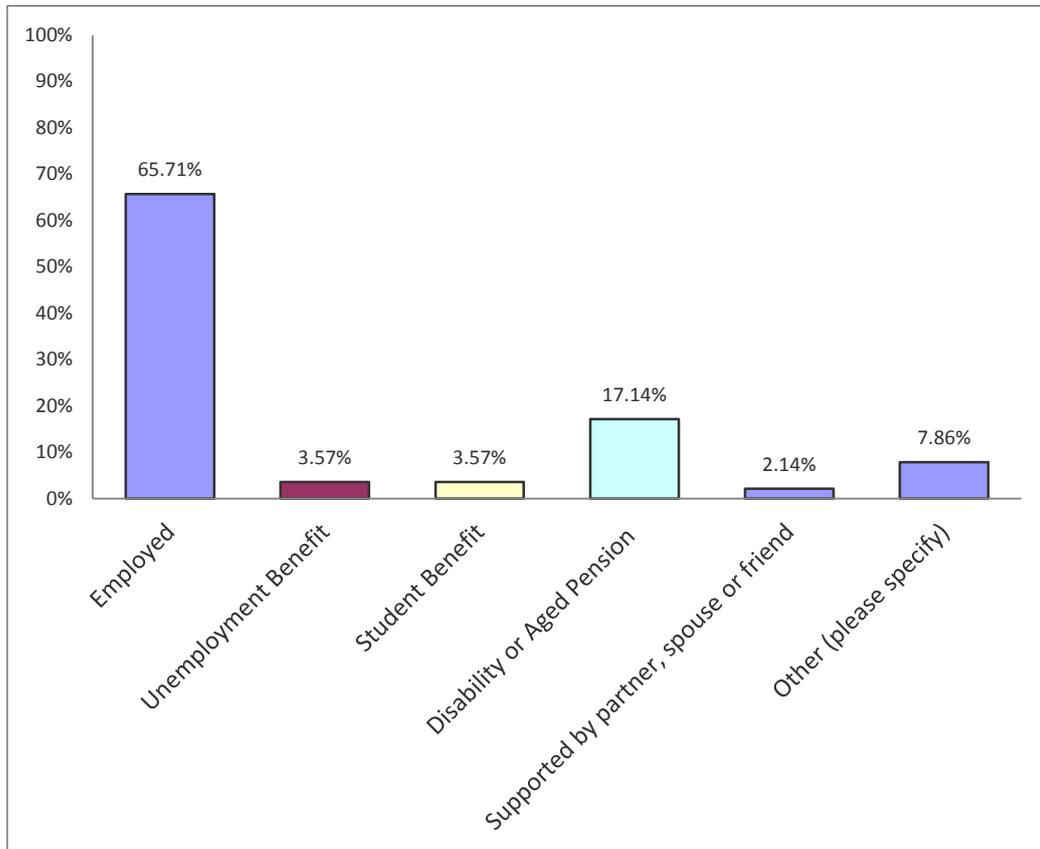
	Response Percent	Response Count
Australia	71.4%	95
Austria	0.8%	1
China	1.5%	2
Cyprus	0.8%	1
India	0.8%	1
Indonesia	0.8%	1
Iraq	0.8%	1
Japan	0.8%	1
New Zealand	9.0%	12
Peru	0.8%	1
Philippines	1.5%	2
South Africa	0.8%	1
Thailand	0.8%	1
United Kingdom	7.5%	10
USA	2.3%	3
answered question		133
skipped question		24

6. What is the main language spoken at home?



	Response Percent	Response Count
English	94.9%	130
Arabic	0.7%	1
Chinese	0.7%	1
French	0.7%	1
Spanish	0.7%	1
Tagalog	0.7%	1
Thai	0.7%	1
Turkish	0.7%	1
answered question		137
skipped question		20

7. What is your main income source?



	Response Percent	Response Count
Employed	65.7%	92
Unemployment Benefit	3.6%	5
Student Benefit	3.6%	5
Disability or Aged Pension	17.1%	24
Supported by partner, spouse or friend	2.1%	3
Other (please specify)	7.9%	11
answered question		140
skipped question		17

Other responses:

Returning to part time employment & part DSP.

Self-funded retiree, plus part time work and part Aged Pension.

Part time work & part DSP.

Self-funded retiree.

Retired.

Business Owner.

Self-funded retired.

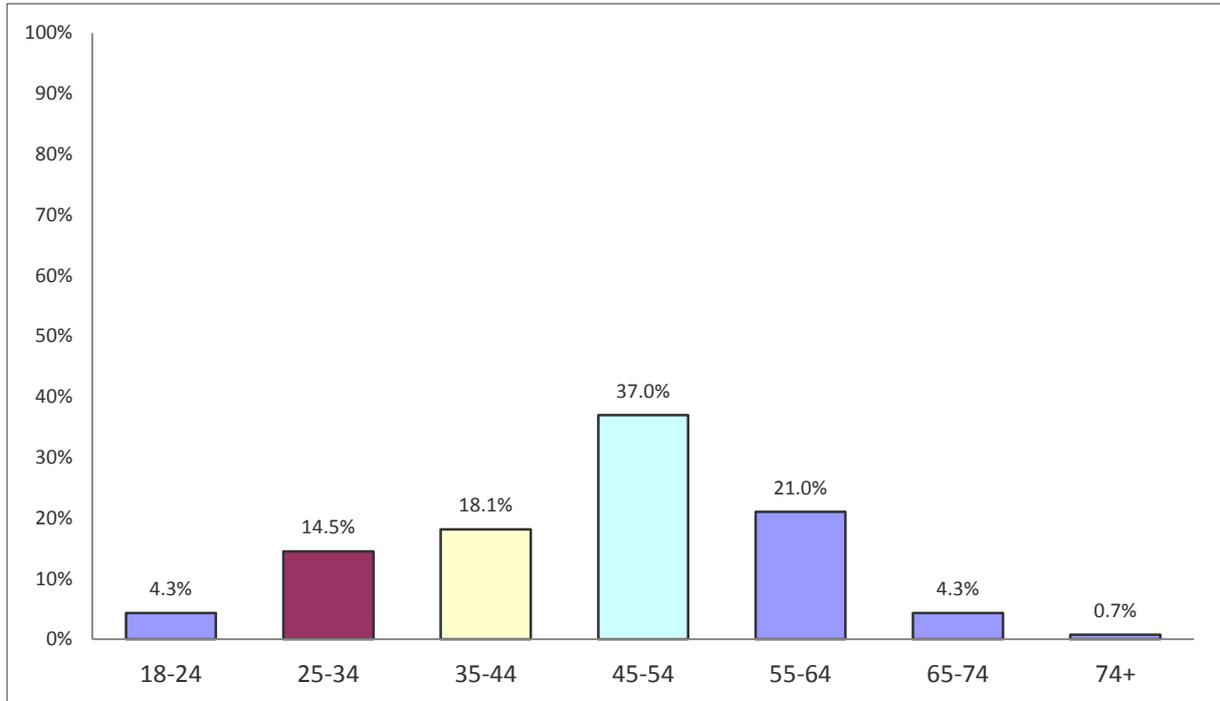
Self-employed.

Foreign disability pension only (no centre link connection at all).

Between jobs - living off savings.

Student visa.

8. What is your age?

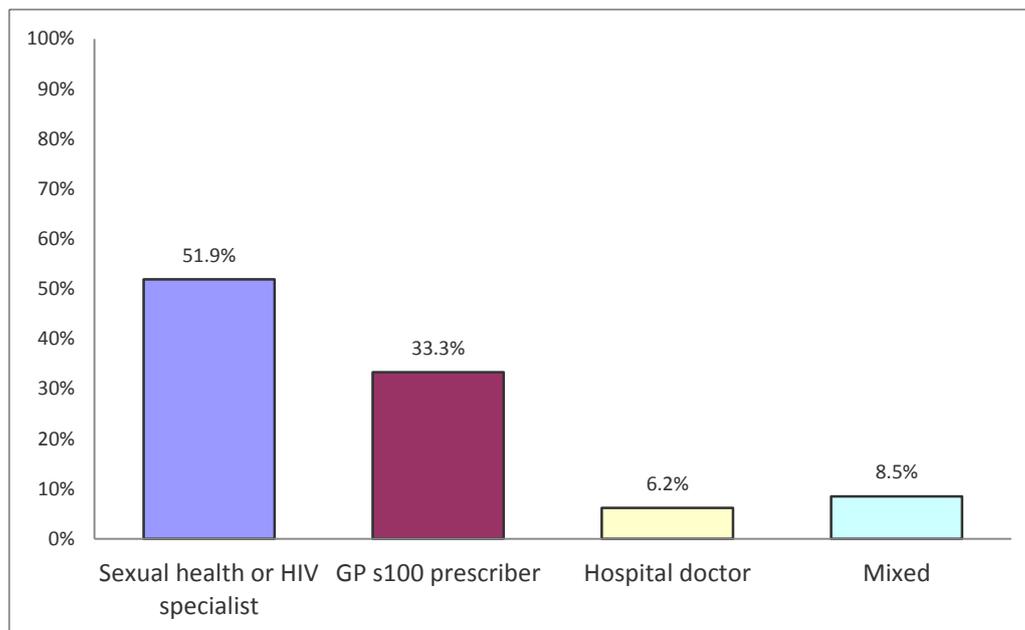


	Response Percent	Response Count
18-24	4.3%	6
25-34	14.5%	20
35-44	18.1%	25
45-54	37.0%	51
55-64	21.0%	29
65-74	4.3%	6
74+	0.7%	1
answered question		138
skipped question		19

9. What is your residential postcode?

	Response Percent	Response Percent
Sydney	76%	76%
Illawarra	23%	2%
Hunter		5%
Richmond Tweed		4%
Mid-North Coast		3%
Northern		0%
North Western		1%
Central West		2%
South Eastern		5%
Murrumbidgee		0%
Murray		1%
Far West		0%

10. What is your main source of HIV health care?



	Response Percent	Response Count
Sexual health or HIV specialist	51.9%	67
GP s100 prescriber	33.3%	43
Hospital doctor	6.2%	8
Mixed	8.5%	11
answered question		129
skipped question		28

Mixed responses:

Neurologist & S100 prescriber

HIV Specialist & GP S100 prescriber

Albion Centre

Albion Street on a specialised basis. E.S.D. Burton St is my G.P. Dr Meredith who competently handles all G.P. and HIV issues as they arise. Psychiatrist in Edgcliffe handles all my mental health requirements.

HIV Specialist at sexual health clinic (RNSH), and also S100 GP practice

S100 prescriber and Neurologist

HIV Specialist/Hospital Doctor

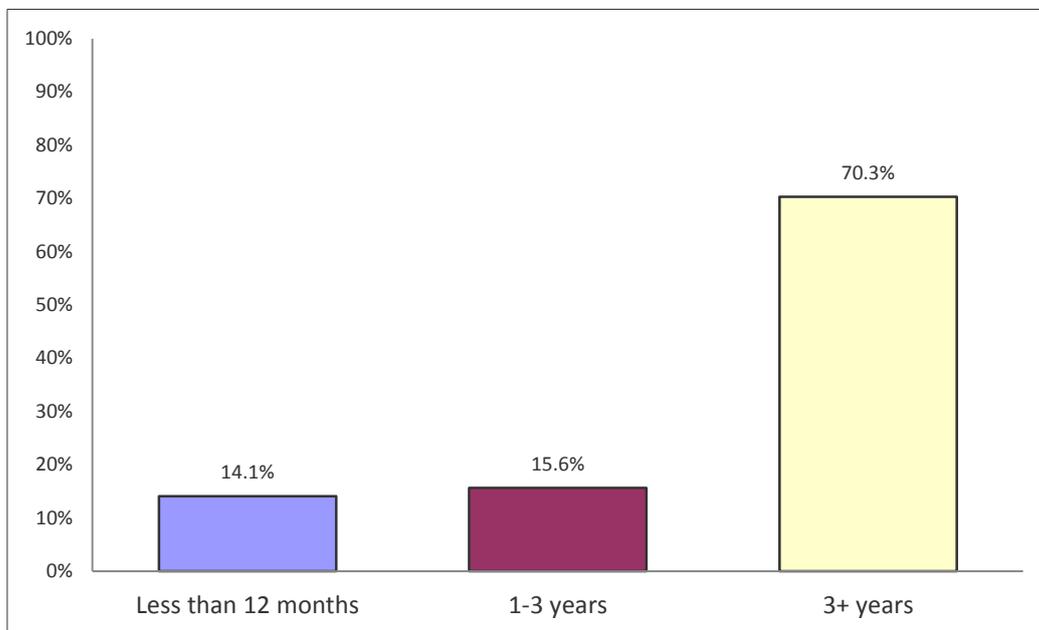
HIV specialist and s100 prescriber

s100 prescriber and sexual health clinic at hospital

Non s100 GP + HIV specialist

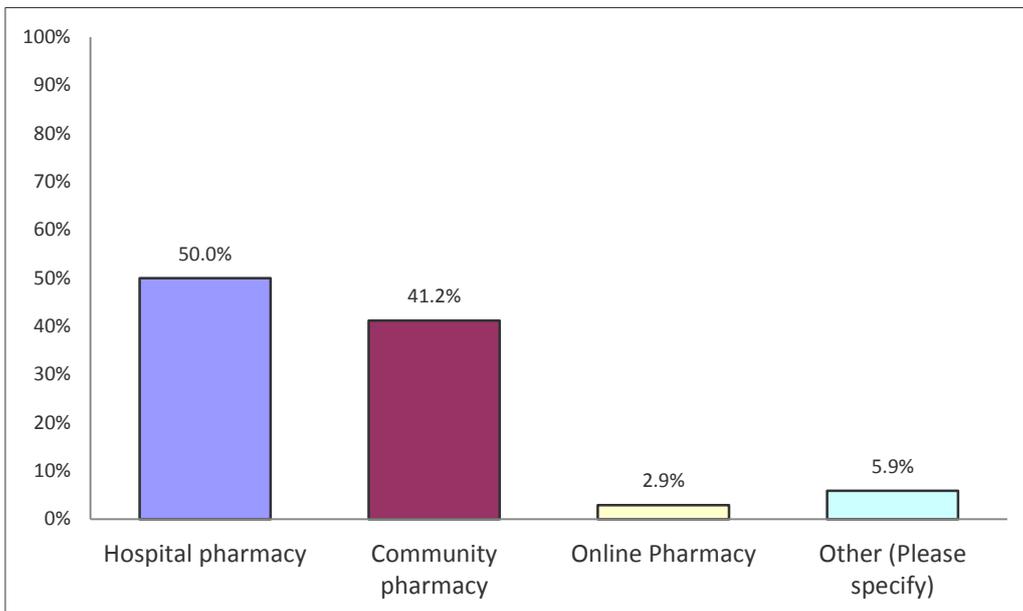
Sexual health / ID consultant / GP s100 prescriber

11. How long have you been taking HIV medicines?



	Response Percent	Response Count
Less than 12 months	14.1%	18
1-3 years	15.6%	20
3+ years	70.3%	90
answered question		128
skipped question		29

12. Please tell us where you get your HIV medications? (respondents could select more than one response)



	Response Percent	Response Count
Hospital pharmacy	50.0%	68
Community pharmacy	41.2%	56
Online Pharmacy	2.9%	4
Other (Please specify)	5.9%	8
answered question		136
skipped question		21

Other responses:

Hospital pharmacies with enormous agitation until two weeks ago, when I used a local pharmacy.

In past hospital at present on a trial at GPs.

Albion Street Clinic who will mail to me.

Albion St Pharmacy.

Albion St.

Albion Street Clinic.

Albion St.

Albion St.

Currently or in the past? I have just had my first experience with a community pharmacy, but for almost 12 years I was only able to get them at a hospital pharmacy.

13. Please tell us briefly why you get your medication from the source you do (hospital, community or online):

Mixed Hospital and Community Pharmacy:

Hospital originally because only option, now community as more convenient and not sure where to or how to do online.

Hospital because it was only choice until recent.

Local pharmacy in Penrith is open 24 hours, but they are pretty incompetent. Had to go to hospital pharmacy once because they dispensed the ARTs they ordered for me to someone else.

Convenience.

Preference.

Hospital Pharmacy:

Unfortunately for my community pharmacy can't find generic brands so cost for them is high. So I still go to hospital.

Satisfied with service and convenience of Albion Street pharmacy, so continued there.

At this stage my family community pharmacy (chemist) Bill Warner is unable to source HIV medication in without incurring significant cost as there is no generic brands which would be of cost benefit to his small business. Which I completely understand. I have used him for 15 years for all of my other medication needs, and have a long established relationship in medication dispensing.

Because they are close, convenient, confidential and efficient.

Worried about stigma/discrimination.

It is convenient, I could go to my local pharmacy but Albion Street is closer.

Availability.

I attend the RPA sexual health clinic and walk across the road to the RPA Pharmacy. I also live a 5 min walk around the corner.

It has always been this way for me. Convenient.

I park for work underneath the Sydney hospital so the pharmacy is very convenient.

Haven't gotten around to changing to using a community pharmacist yet.

I use the hospital Pharmacy because I tried my local chemist who was on the community dispensing list. They told me they could give me some my drugs but not all as they did not have a contract the company that supplies one of my drugs so I figured I may as well get the lot from the hospital pharmacy as I had to go there for that one anyway.

Community pharmacy is my preference, but it doesn't stock my medication.

Understood that this was only place could get them.

As I worked in the CBD I picked them up for the past 7 years from Sydney Hospital. Now due to being open on weekend I (as of October 2015) use a chemist which is easier to access.

They are the only dispenser in this area.

It is convenient. ACON collect on my behalf and this very convenient.

Because I always have, and my Doctor is there. I do however get them sent to a closer clinic. I

would like them online and posted out.

Privacy concerns.

Initially that was the only way I could get meds. Apart from one horrible experience, the hospital has a wonderful pharmacist who goes out of her way to be helpful.

Convenience. Close cooperation b/w Sexual Health Clinic & Hospital Pharmacy run by same Area Health Service.

Routine and privacy.

It's not in the village I live in and one of just many patients so not the fear of confidentiality. Plus the Dr is at the hospital that writes the script and I pick it up at the same time as seeing the Dr.

It's been the only place I can get it from.

Convenience, good customer service.

Hospital pharmacy staff are not judgemental and a hospital pharmacy is more anonymous.

Discrete service.

It has been the only source that I could get them from. I have also ordered from a community pharmacy but had to wait over night as the did not stock it.

Security, confidentiality and choice.

Private.

Quarterly blood test and checkup.

Free.

Cost is subsidised.

There isn't any other place to get our medications but our local hospital as we live in a small town.

Close to week discreet.

I tried to go to a community pharmacy, only to be told that one of my 3 pills is not available through their wholesalers.

Confidential .

I can pick them up while there for other appointments.

One medication is not available at the community pharmacy.

Last Rx still had a pre July 1 Rx to fill so took to hospital pharmacy.

Always have from the beginning.

Phone ahead to get it ready Used to workers.

Until now only option .

I assumed this was the only place I could get them coz when I asked my Dr if I can collect these from my local pharmacy he said no.

Convenience, reassurance of the knowledge of a specialist pharmacist.

Did not know of other options.

Close to work and clinic I go to.

St Vincent's.

Anonymous.

More privacy .

Nothing local in my postcode do hospital same distance as community pharmacy.

It was the best option for me, they really help with my meds.

Because my treating doctor is working in the sexual clinic in the hospital .

It is easy and safe .

Sydney Sexual Health Centre is where I was referred to when I was diagnosed. I'm unsure where else my medication is available and how easy it would be to access at other places.

Community Pharmacy:

Easiest.

It's close to home. I don't really need any medical advice - I speak to my Dr about that, so it's just about opening hours and being able to access it easily.

Convenient .

It is much easier to collect from a pharmacy.

convenience of location convenient opening hours existing relationship with pharmacy .

Easier at my local pharmacy. I can order repeats online to be dispensed.

Convenience.

Convenience, close to home and I can get my HIV meds and other scripts at the same time.

Next to my GP.

Location.

Convenience. One stop for all meds.

More convenient, less waiting times. I can pick up anytime of the day.

Convenient, close to home and less hassle .

Proximity to home – prefer not having to go to Albion St – easier – medication is accessible – pharmacy is accepting (but had to be 'educated' re disclosure) - no queues - SMS reminder service - friendly staff.

Ease of access, after hours service and being able to get my meds as a part of everyday life.

Cute pharmacist.

I have to get many medicines for multiple chronic illnesses, so it makes my life so much easier getting them at the same time from my local pharmacy.

Finally I no longer have the inconvenience of only being able to get my meds from the Hospital Pharmacy.

Convenient location.

Convenience.

Convenience.

That is where my doctor is.

Geographical convenience.

Convenience.

I did get from Hospital Pharmacy but have changed. To my Chemist.

More convenient.

Use to get them posted to me from Albion Centre Pharmacy - excellent service, but that has stopped, now using a small local pharmacy, some teething problems with them actually getting the meds but hopefully that will improve as they get more experience.

It is now super convenient, before the hospital pharmacy was 35klm away, now the next suburb

Convenience.

Convenience.

Convenience.

I have negotiated with my local pharmacy. This has been great as they are located on my way to and from work and are open longer hours than the hospital pharmacy is.

Convenience of location.

too difficult to arrange at canberra hospital poor parking, walk from car park to pharmacy then have to pay at emergency then have to walk back to pharmacy then walk back to car park its ridiculous.

Convenient.

Convenience.

it's more convenient, hours are better and I can get it quickly while having lunch.

They are open longer hours.

Convenient.

Convenience, local to home, extended opening hours, and great friendly attentive service.

Convenience.

Ease of collection eg: Weekends and Evenings.

Convenience .

It's convenient, I get all my meds (HIV and non HIV from the same place. I get to form an ongoing relationship with my pharmacist.

I used to get them at Albion Street. I just get my first Rx filled at a community pharmacy in Enmore where my GP is. In the future I plan to fill them at a pharmacy on Campbell n Bourke near my flat.

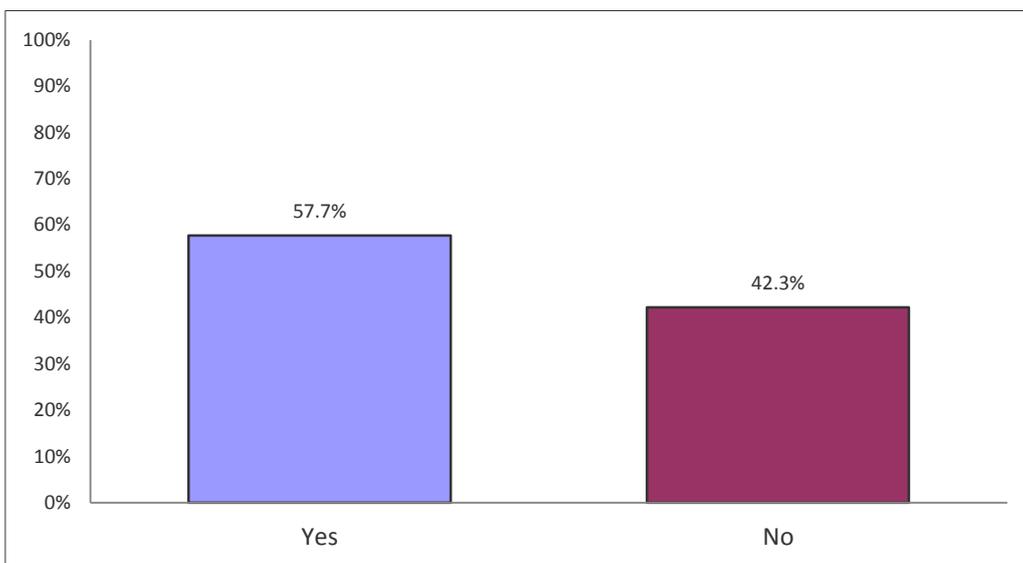
So great finally getting it from local pharmacy easy convenient.

Online Pharmacy:

Not a permanent resident.

Being employed it is far simpler ordering them online and having them delivered. Picking them up previously from a hospital pharmacy was a nightmare, the hospital pharmacy didn't even stock the medications which meant they couldn't be picked up the same day as the script which was a nightmare for anyone that had a job.

14. If you have not had your medications dispensed through a community pharmacy (chemist) do you plan to?



	Response Percent	Response Count
Yes	55.7%	41
No	42.3%	30
responses		71

Please tell us why or why not:

Why:

If my pharmacist can work their costs yes I would, as I get all my health related medications from them for the last 15years. It would then be even more convenient I just go once and collect them all at the same time.

Next time I am going to be courageous and give it a go.

I have checked out my pharmacy and they can do this with advance notice.

It will be more confident to pick up all my medications in one place and the hospital pharmacy on average takes. 20-40 minutes which is and always has been unacceptable

I would like to for the convenience but see my experience/response in the previous question

If they can start stocking my medication.

I tried to obtain meds through a recommended pharmacy in the area hover it proved very difficult so I stuck with the hospital pharmacy in the end.

It will be more convenient

The hospital where I have been getting my medication are very rude to me. They keep changing the rules on how I get my medication, I am starting to have memory problems. I come away feeling humiliated. They also still charge me for my medication.

Much more convenient and no waiting, it's also not an issue having to travel to the city to get them.

MSHC has an indiscreet waiting area and times to dispense take around 15mins to 30mins from the time you present your script. Stigma and convenience are important factors which would lead me to choose a community based dispensary.

It's closer to home & more convenient.

If I get all my meds at the community pharmacy

More convenient

Convenience

Easier

I would love to only because I work 9 to 5 and don't have time to go to a hospital and be there for 2hrs

Convenience

Easier

It would be convenient in my case because my main concern is the confidentiality of my condition as advised by the head of a certain position to be discreet about it because there are still people around in the hospital that stigmatised people with HIV

Only if it was more convenient than visiting the Sydney Hospital (ie closer to work or home, not much information required or many processes to go through)

It is much more convenient.

So I don't have to travel 30kms

big issue is only one pharmacy in Canberra stocks the meds

Community pharmacy after the trial I'm on comes to an end

Why?: Closer to home. Saves postage costs for clinic. Why not?: More paper work for my doctor. Disclosure - although I'm not sure that's really an issue after using same pharmacy for 20 odd years.

I am assuming it's quicker and less stigma

More discreet and people don't know what you are getting

I am making the arrangements to do so currently.

Why not:

Not immediately (see above) but may at some future time.

I will continue with existing system until Albion Street changes.

Not comfortable with the local pharmacy.

Don't know any.

I get my medications collected through ACON and see no reason to change.

I don't want it known in my community (chemist) that I am HIV positive. I've used this Chemist for over 10 years and I don't want the stigma.

I don't see the need to.

Possibly in future if my living / working circumstances change. At the moment, Hospital Pharmacy dispensing quite convenient, except for parking issues.

Small community and I do not wish my status to be inadvertently made known public or I may find myself without a job.

My local pharmacist belongs to a religious group that would not accept this and generally I would feel reluctant and uncomfortable to go to local pharmacies as I would be the only HIV person they would have dealt with and I would feel I would not be treated well.

Confidentiality issues in Local area Chemists.

Privacy concerns as they are handed over by retail staff not the actual pharmacist

Living in a small town does not help keep our HIV+ status private.

Don't feel it would be discreet, concerns on status or someone I'm now seeing the meds

Works fine as is.

It is just more convenient to go to the hospital pharmacy. when I go in for a check up

More privacy at the hospital

Nothing close to me

No need too

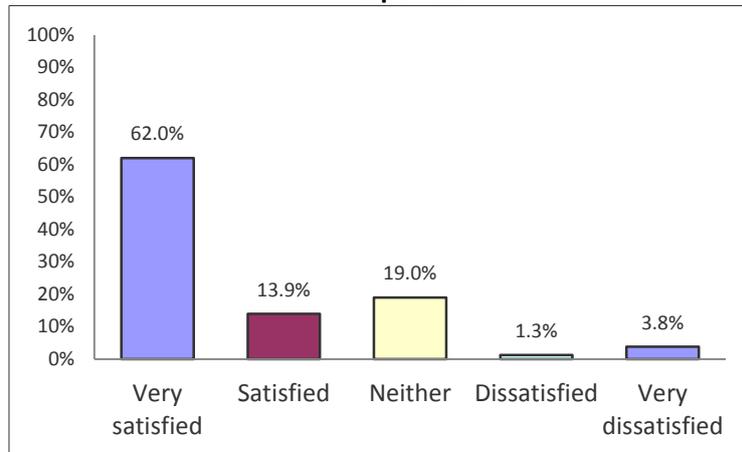
Online pharmacy far easier.

Well, my Chemist refuses point blank to consider the idea. He was more concerned who would pay for my meds if I unexpectedly passed away.... I am better to stay with Albion street for this reason and those listed in Q 13.

Feedback has seemed like it is too difficult.

15. If you have obtained HIV medication from a community pharmacy, please rate your experience?

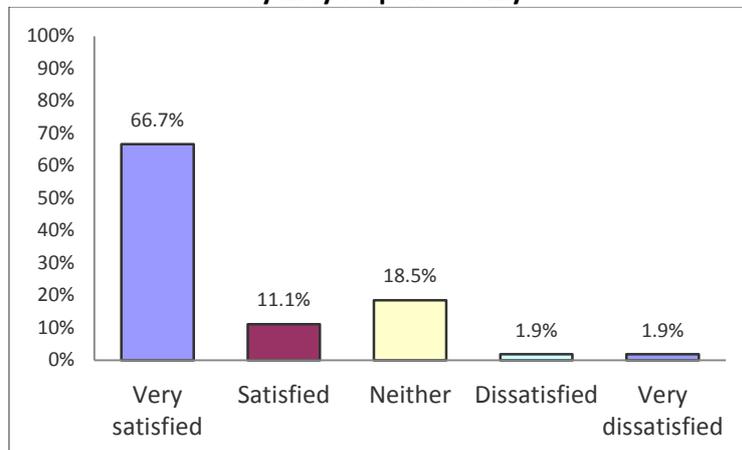
All responses



	Response Percent	Response Count
Very satisfied (5)	62.0%	49
Satisfied (4)	13.9%	11
Neither (3)	19.0%	15
Dissatisfied (2)	1.3%	1
Very dissatisfied (1)	3.8%	3
answered question		79
skipped question		78

Average rating = 4.29

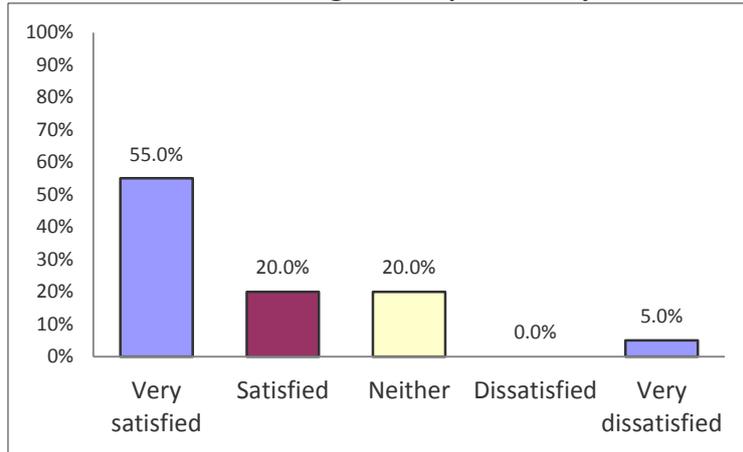
Sydney responses only



	Response Percent	Response Count
Very satisfied (5)	66.7%	36
Satisfied (4)	11.1%	6
Neither (3)	18.5%	10
Dissatisfied (2)	1.9%	1
Very dissatisfied (1)	1.9%	1
responses		54

Average rating = 4.38

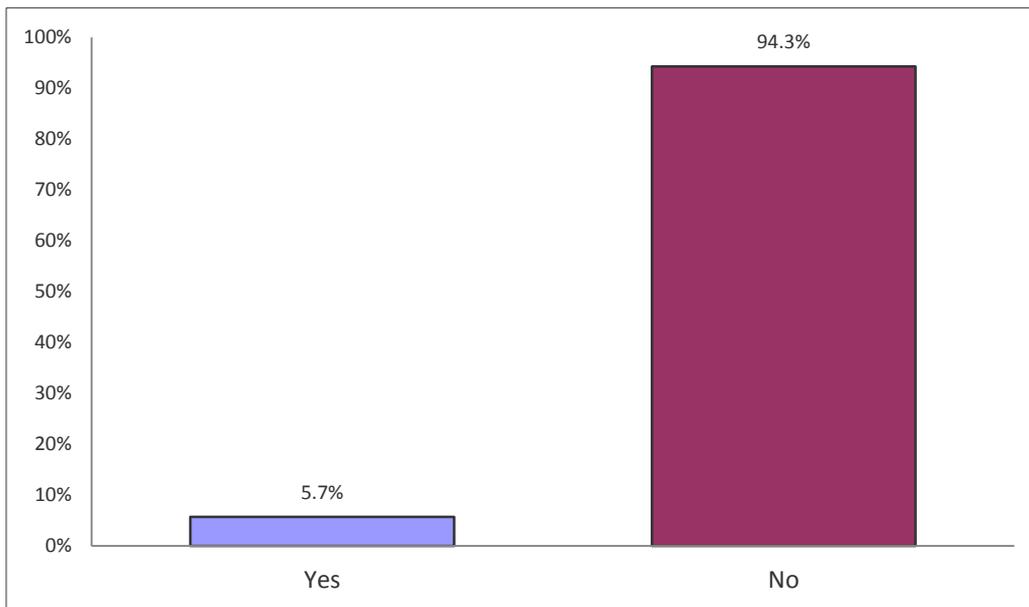
Rural and Regional responses only



	Response Percent	Response Count
Very satisfied (5)	55.0%	11
Satisfied (4)	20.0%	4
Neither (3)	20.0%	4
Dissatisfied (2)	0.0%	0
Very dissatisfied (1)	5.0%	1
responses		20

Average rating = 4.2

16. Did the pharmacist offer to send your medication in the mail?



	Response Percent	Response Count
Yes		4
No		66
	answered question	70
	skipped question	87

Comments:

I don't think I would want my medication mailed unless it was guaranteed not to be mis-delivered or indiscreetly packaged.

I did not request this.

Not necessary.

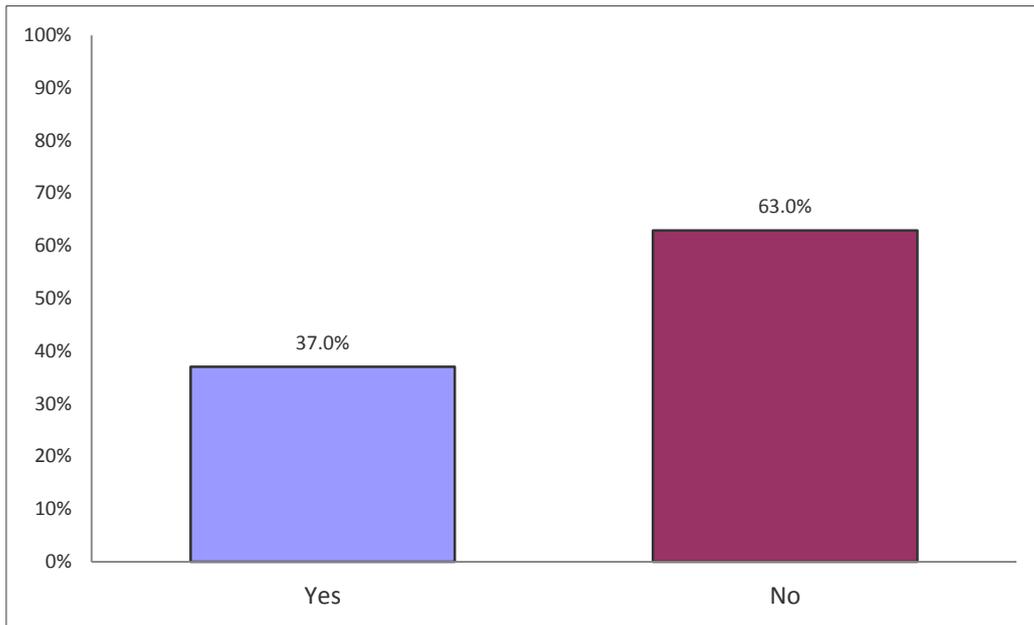
I live very close.

But I did not ask as it is so convenient to drop by.

Not necessary.

Take too long.

17. If you had your medications delivered was the delivery time acceptable?



	Response Percent	Response Count
Yes	37.0%	10
No	63.0%	17
answered question		27
skipped question		130

Why or why not:

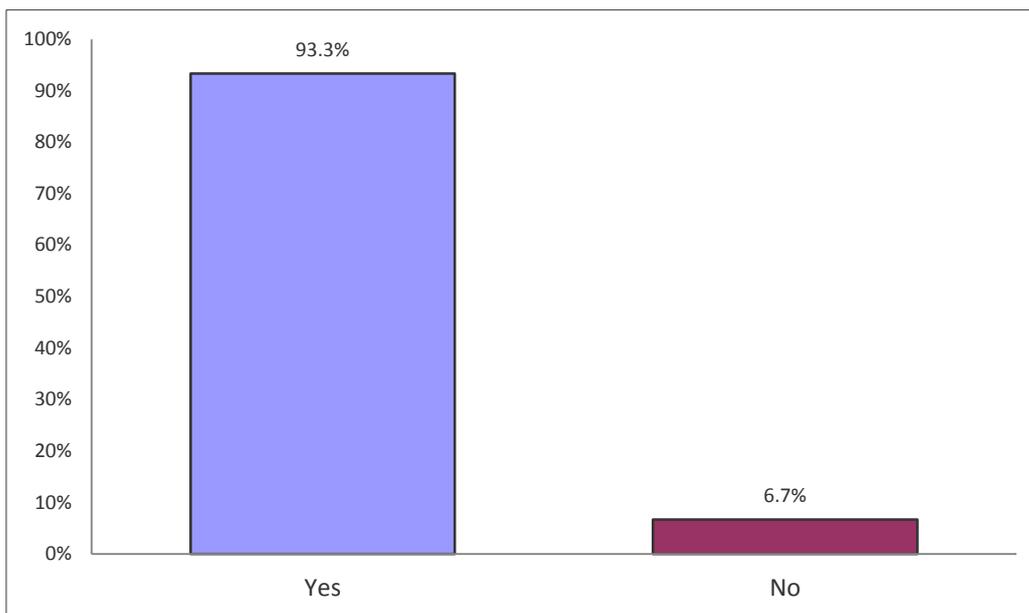
Pharmacist placed my meds on their scheduling system. I was texted when my supplies were running low and asked if I wanted more ordered.

did not offer as more convenient to pickup.

I didn't have them delivered. Where is the "not applicable" button?

Not sure if delivery late.

18. Was the pharmacist helpful and supportive?



	Response Percent	Response Count
Yes	93.3%	70
No	6.7%	5
answered question		75
skipped question		82

19. How do you think the experience was for the pharmacist, and did they say anything positive or negative?

They were pleasant and helpful

Negative, ordering my gay drugs is challenging for them.

same as any other transaction

Normal

They are working hard to deliver this service to myself and others. Only time will tell

They have researched to cost to them and the impact of the cost to their small family business and at this point in time they can not offer it. They have explained their undertakings at each stage that they have been able to update me if they can deliver or not.

It was a little odd for me to ask the chemist, however they quickly put me at ease, and explained how simple it all was.

I cannot say on their behalf

Switching from the hospital to the local chemist has been 100% positive. They are friendly and cry focussed on providing good customer service - it is totally different to my experience with the hospital.

I didn't speak with them myself I had a councillor pick them up but they were very helpful

Informative for them in understanding the supply issues/ delivery time frames and helpful for me

in understanding the actual cost of the drugs and the financial implications for the pharmacy

Seems good.

Blakes Pharmacy are FAB.

Fine, they were very keen to make it as convenient and easy as possible for me.

Nothing negative was said. He was very informative.

Jenny (part owner) Danks Street Pharmacy is very proactive and asked me prior to October 1st if I could provide her any information in advance to make it easier for me.

Mentioned some supply issues.

Very good, supportive group of people.

Pharmacists experience ok, no different than any other dispensing experience, as professional as usual.

They are all learning also : I've been very relaxed talking about my conditions and they've apologised when delays have occurred in procuring my prescriptions. The experience has been a positive learning one all round.

Difficulties in delivery and supply time and inconsistent information from different pharmacies.

Easy.

Straightforward and happy to help. A great pharmacy who do everything they can to be of help to me.

Agreed it was helpful to provide this service.

She had a greater understanding of the state government co-payment situation after I had informed her.

Yes they were positive and helpful.

No different to having non-HIV scripts filled. No problem.

The pharmacist was very obliging and helpful.

Very supportive .

Absolutely nothing but warm friendly professionalism.

Had to do some research to find suppliers but tried to be helpful & efficient.

Good. Extremely supportive.

Supportive attitude. Handled discretely.

Very professional and helpful. Outlined delivery times to pharmacy.

I think it has been a positive thing for the Pharmacist.

The pharmacist and her staff have been very friendly polite supportive and I have been very pleased.

They were fine.

Pharmacist was brilliant. Both asked questions as to how I found my meds. They'd not dispensed before and where really professional. Fantastic even!!

My local pharmacist knows my situation and looks after me.

Very positive, very helpful and very satisfied.

Professional.

Seemed happy to assist me.

Positive helpful suggestions absolutely no drama.

Brilliant and totally professional. Blakes Pharmacy normalizes having HIV like any other chronic condition.

They were happy to get their own processes organized for it.

Positive.

Great, she asked if I wanted all refills at that time. I didn't even know I could do that, so I got 4 months at once.

Cannot say what he thought, but he had clearly had some training or guidance with respect to his manner in dealing with me.

Positive, no problem at all.

My pharmacist refuses to stock my Meds. I'm not upset by this. I do prefer the expertise from Albion Centre.

It took several attempts to get my local pharmacy to actively participate but they are now very much on board.

I can't read her mind, and she was her normal and efficient self.

Know only HIV positive.

20. Can you suggest any ways your experience could have been improved?

The ordering process needs to be simplified. The pharmacy needs some basic education around HIV.

The PGA needs to work closely with NSW health and pharmaceutical companies to assist private operators who don't belong to a chain.

Make sure the nominated Community Pharmacists can provide all of the drugs not just some.

Wholesalers need to be able to supply chemists all medication.

The pharmacy being informed on how the dispensing works .

Just knowing my medication is available at my nearest pharmacy would make it much more convenient.

I don't really know of a pharmacy where I feel that I wouldn't be judged.

If I had know that one of my pills was not going to be available from a community pharmacy I would not have stressed over "coming out" to the pharmacist.

They said I need a new script.

Better information from the Health Dept to the pharmacy so they didn't have to hear about first from me.

As stated more information required on the co-payment abolishment scheme.

It was a long weekend and the on duty pharmacist though helpful had some problems with supply and procedure, possibly in need of training around HIV med dispensing.

Pricing consistency. Delivery time for all medications could be no more than 48 hours from the

time of handing in the script

Only have to get the co-signed form done once.

ACT pharmacies still charge dispensing fee. Next time I'll go to Queanbeyan which is unfortunate because the pharmacist I went to is very helpful.

Involve more pharmacies

The pharmacist should have been prepared to be informed how to Bill - once the medications became free to access

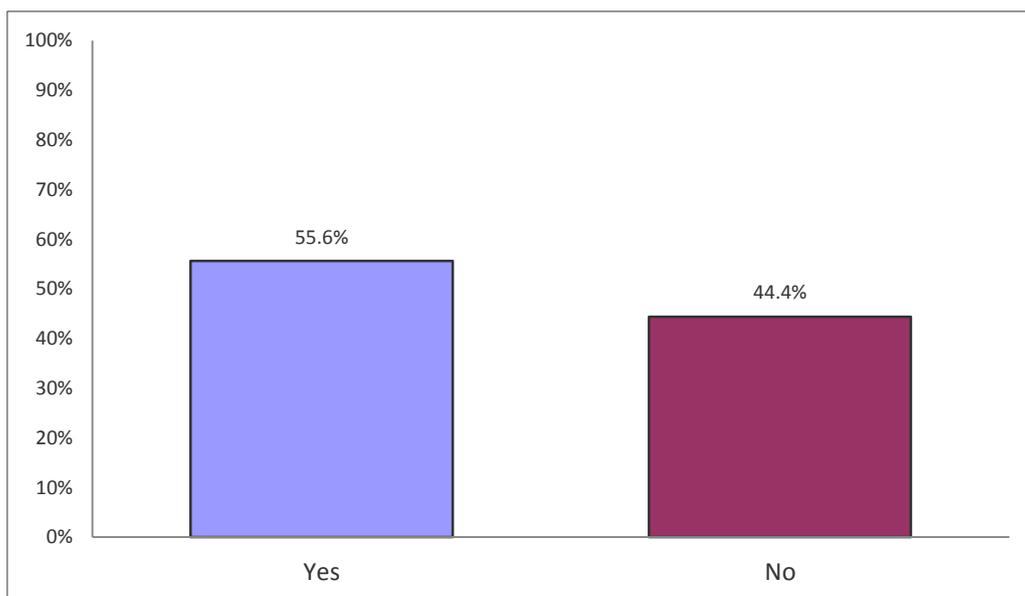
If they could afford to keep the meds stocked then the delay could have been avoided

The unnecessary bold HIV and S 100's labels should be removed, or the medications should be stored where the labels cannot be clearly read by ALL customers in the dispensary area of the pharmacy.

A list of community chemist that are willing to get the meds in.

Why I have to buy online I got in Hiv in Australia. I think not fare for me.

21. Would (or did) you feel comfortable talking to the pharmacist about how your experience could have been improved?



	Response Percent	Response Count
Yes	55.6%	25
No	44.4%	20
answered question		45
skipped question		112

Why or why not:

HIV drugs are not gay drugs.

We have a relationship of trust

Blakes are very understanding and I think all pharmacies are as confused as we are

The senior pharmacist was incredibly keen, caring and helpful.

Usually other customers around - no privacy

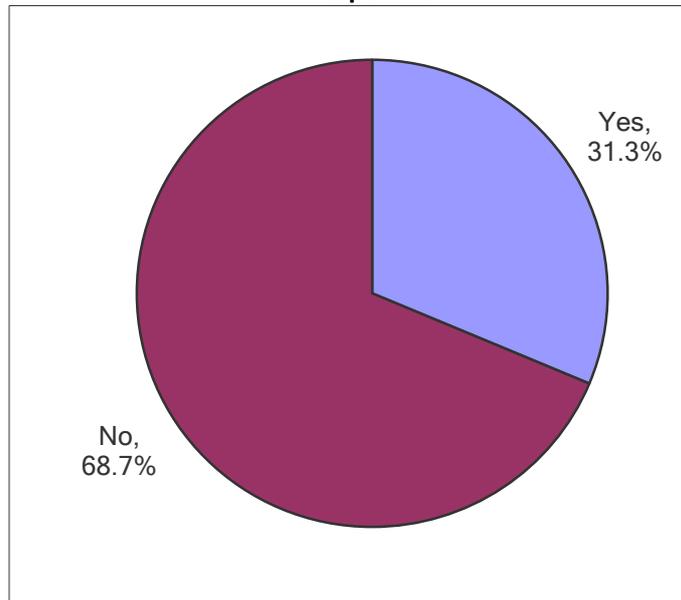
I understand the issue for the pharmacist trying to run a business

Because the stigma that still exists for positive people is only rammed home when they have to watch their meds picked from a clearly marked section of medications on shelves in the dispensary.

Already talk with doctors about this they said aids drugs only for Australian.

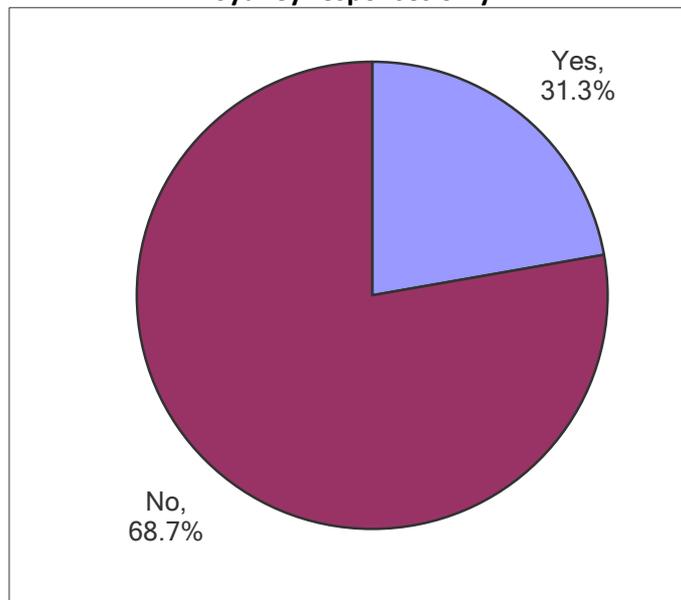
22. Was privacy and disclosure an issue for you?

All responses



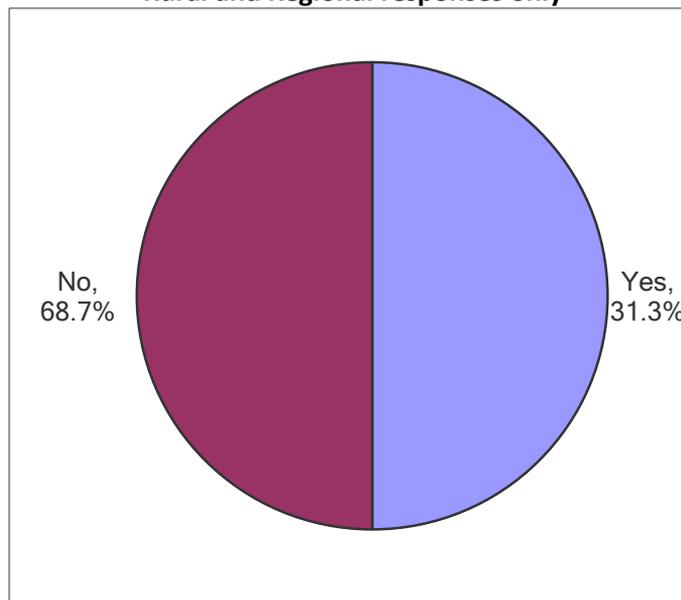
	Response Percent	Response Count
Yes	31.3%	31
No	68.7%	68

Sydney responses only



	Response Percent	Response Count
Yes	22.2%	16
No	77.8%	56

Rural and Regional responses only



	Response Percent	Response Count
Yes	50.0%	12
No	50.0%	12

Why ('yes' responses):

At the time I was more ashamed of my status. Now I am not shameful of my status.

Stigma of HIV makes discretion very important to me.

They're always discrete.

It was not in the pharmacy but rather in the sexual clinic I. The nurse who picked up the medications from the hospital based pharmacy handed to me the medications with a loud and clear voice, 'here is your medications'. I felt embarrassed and it was not taken into considerations that the people that visit the clinic are all not all diagnosed with HIV. It can potentially cause anxiety,

Yes living in a small community. There is the ever present problem of the wrong people finding out and making working difficult. Has been an issue in the past, that I don't wish to relive.

Living in a small area there are actually people that I went to school with working in the hospital pharmacy which was extremely awkward, online pharmacy is much easier & less stressful.

I prefer pharmacists don't blurt out "here's your HIV meds" if others are in the store. I chose the timing of my initial visits so we could talk without other customers being in the shop

Being known in the Entertainment industry causes some concern.

Local pharmacy in a suburb of Wollongong.

My HIV status is an intensely private issue and I prefer to strictly control disclosure where possible. This was possible in this particular pharmacy setting and I spoke directly to the pharmacist or pharmacy staff.

They were very helpful keeping it private.

It always has been, and always will be. My experience of people's discretion in this area is poor to outrageous.

Why ('no' response):

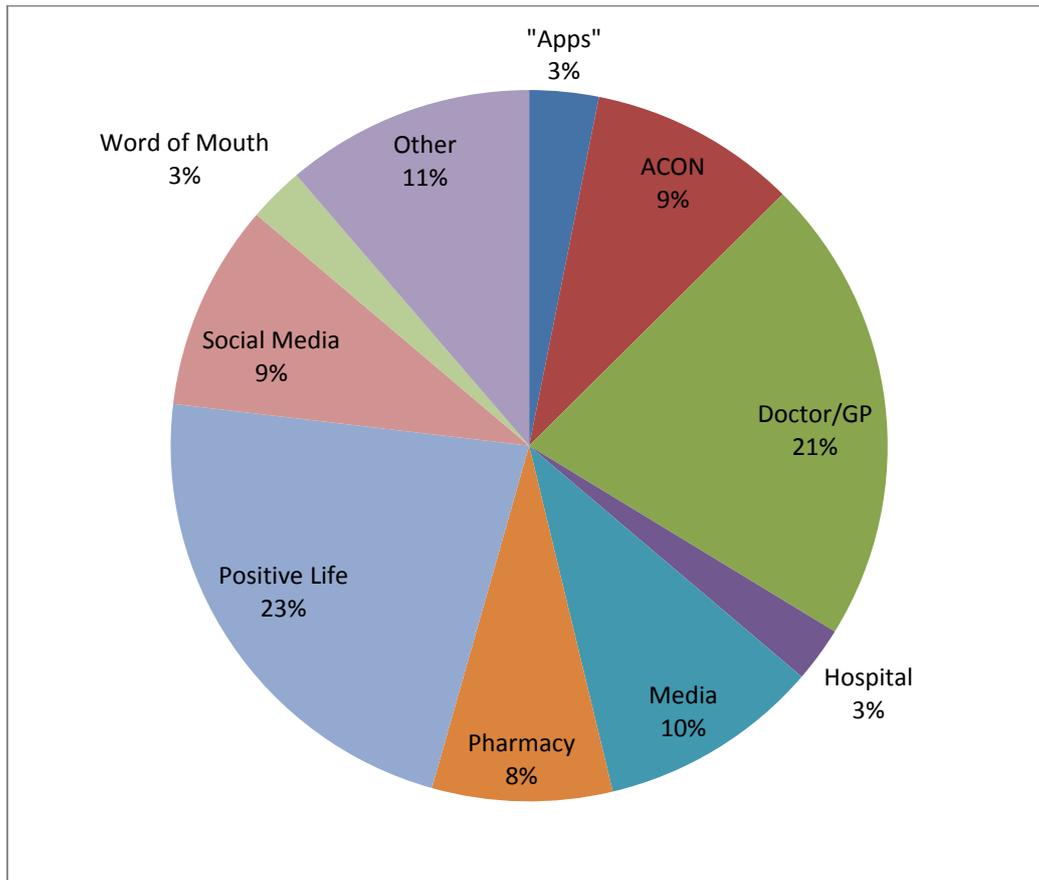
He's been my pharmacist for since 2000, and I have an amazing relationship with him. In regards to my health/medication needs

I knew this was an HIV friendly pharmacy. I would not choose my local pharmacy.

Why should disclosure be an issue these days? Guys need to 'man up' about this issue and stand up for themselves. This is 2015 and this is just a chronic disease. Stop being so 'TIM' about the whole bloody thing and get on with it

I don't understand.

23. Where have you heard about HIV medication becoming available from community pharmacies?



From my GP.

My doctor.

TIM on Facebook .

Gay paper.

Doctor .

Around town.

PositiveLife updates and it has been a work in progress for over a decade. As well as NSW Health.

HIV Organisations and notice in regular (community) pharmacist.

From GLTBIQ press, Positive Life and NSW Health updates, ACON.

Facebook.

From Positive Life & gay press.

Hospital pharmacy.

ACON, Positive Living, Positive Life, BGF, Press releases, Health NSW website.

ACON.

Positive Life.

Positive Life emails.

Positive life. Doctor.

Friends and my HIV specialist.

Through the health clinic at Short St.

Sexual Health - Social Worker .

Through Worker at ACON

Pozhet and Karumah Positive life.

Online.

Positive Living & ACON Northern Rivers emails.

No.

Was advised by the pharmacy at the hospital that would be the case.

Hospital pharmacy.

The hospital told me, then I sent an email to a local pharmacy chain to see how it would work, then I dropped into the local pharmacy.

Positive life NSW emails.

Community health centre Albury and ACON rep.

I was sent an email from the Bobby goldsmith foundation who organised for my medication to be free and cover the charge.

Media.

Gaydar.

Doctor.

My GP.

Talkabout, PositiveLife, BGF newsletters, ACON newsletters.

At the hospital pharmacy via posters.

Online support group on Facebook TIM.

LGBTQI press, Positive Life.

Work.

Positive Life, SX, SSO, GP, Sydney Morning Herald, The Telegraph, friends.

Positive life on Facebook.

TIM Facebook page.

I didn't know this.

Hospital pharmacy initially .

Online only .

Grindr ad .

ADSL mobile apps .

Doctor.

Online.

News, Facebook, friends, GP.

Doctor.

Papers Online The pharmacy .

Positive Life NSW.

Positive Life, TIM and Health Dept memo.

From my local pharmacy.

I work at ACON.

Positive Life NSW in the first instance then other agencies later on.

Tim and my doctor.

I work at ACON, as such kept up to date with topic .

Poz life.

From my doctor .

From my s100 GP and Albion Street Clinic.

From advertising in Sydney HIV magazine.

Positive Life SX.

Serafim .

From you.

Positive Life and my GP.

Online.

Positive Life NSW.

My doctor and on Facebook.

from the people at Albion St Pharmacy.

Clinic.

I the press , BGF, ACON and Positive life NSW.

it was everywhere FB, Positive Life, my clinic.

My GP Prescriber & then my previous supplier (Albion Centre Pharmacy).

HIV Dr, acon, social media, gay press.

News outlets.

Specialist.

Treating doctor.

All the usual publications like yours. It has been promoted well.

Aids action council Canberra.

ACON brochures.

AAC.

BGF mail.

Positive Living and ACON.

Doctor .

Sexual health clinic.

Positive Life.

Positive Life and my Doctor.

Everywhere - at the community pharmacy mainly - they had a sign up before it happened.

AIDS ACTION COUNCIL newsletter.

PLNSW.

Community, TIM, friends, etc

My local GP.

Clinic, Positive Life & local HIV support group.

Gay press.

Positive Life.

Albion Street Centre.

Doctor .

Didn't Know .

I believe I received an email from BGF as well as ACON.

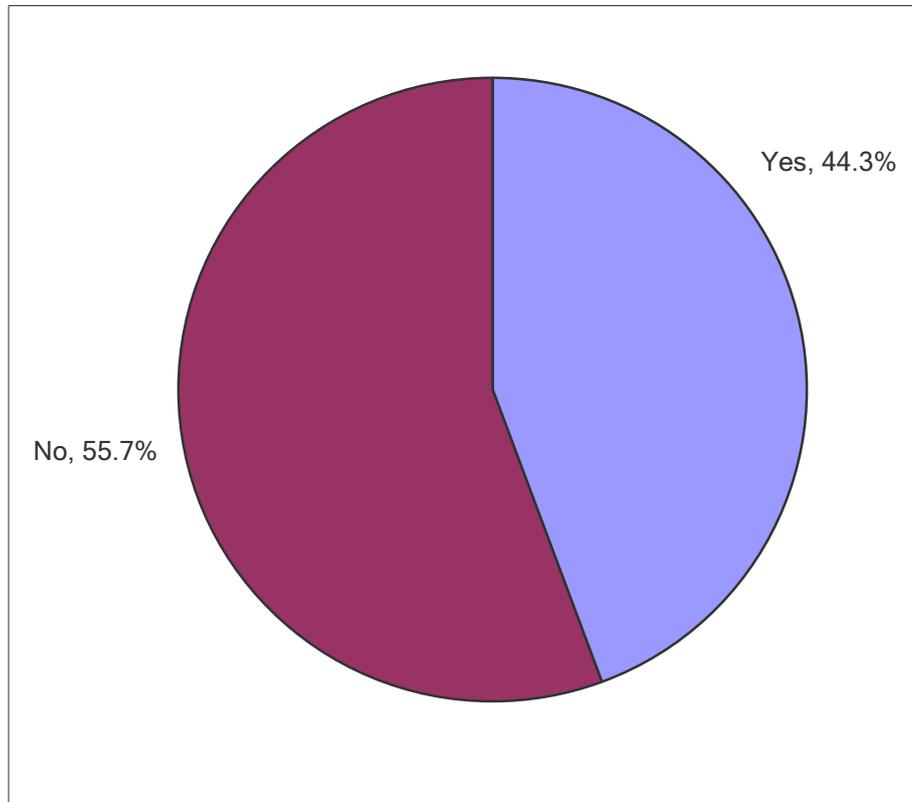
Life Mail.

Peer 2 peer and Facebook.

I heard about it from my workplace. And then from my HIV specialist. I also work in the sector, so it was a common topic talked about there.

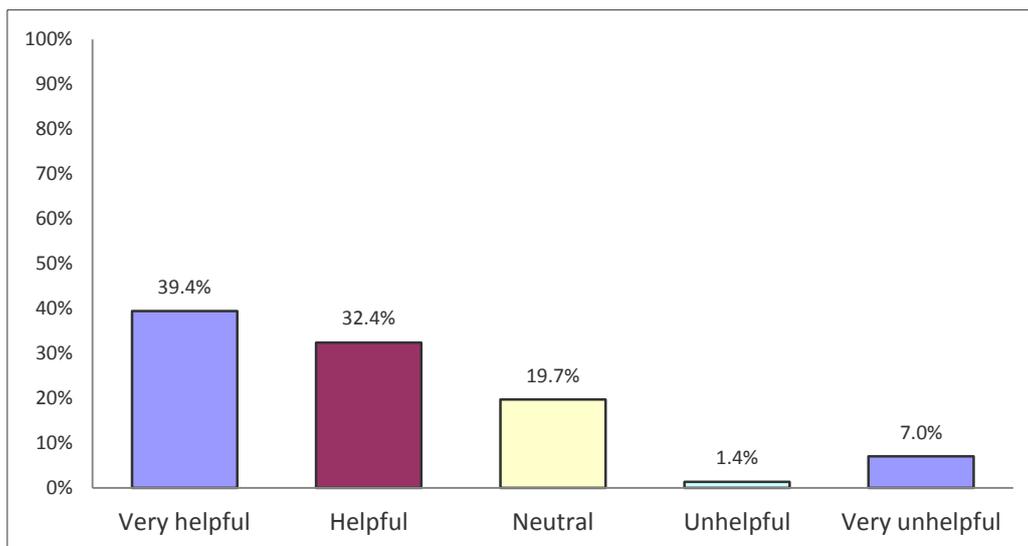
Doctors.

24. Have you read the information about getting HIV medication from community pharmacists on the Positive Life NSW web site?



	Response Percent	Response Count
Yes	44.3%	51
No	55.7%	64
<i>answered question</i>		115
<i>skipped question</i>		42

25. If so, was the information:



	Response Percent	Response Count
Very helpful	39.4%	28
Helpful	32.4%	23
Neutral	19.7%	14
Unhelpful	1.4%	1
Very unhelpful	7.0%	5
answered question		71
skipped question		86

Comments:

Very Helpful:

Very clear and precise in what you need to do, and what to expect.

It is clear and precise, give you the layout of the land. My only recommendation is to coordinate with the eligible community pharmacies and look at how they can deliver HIV Meds easier and in a cost effective manner that is not so prohibitive to them, especially if you use one chemist for all your other medications.

It outlines all the steps

Was a great reference and also allowed me to advise POZ friends too.

It was clear and understandable

No jargon, just facts easily presented.

It alerted me to the changing way I could receive my meds and that I no longer had to go and clog up the hospital health system.

If I hadn't read the website I wouldn't have known about the consent form. My GP did not have the consent form so the fact that I could provide one was great

Easier

Helpful:

Fairly clear to read through, could be added to for more benefit for a more diverse range of

readers than it seems to be aimed at..

I already knew about it so it was more just a confirmation of what PLNSW had told me.

There had been unconfirmed talk about this from by BGF case worker- so good to read it in print

Helped me work out which pharmacies were on board

It made me confident to try the option. However, I looked for information from a pharmacist's point of view, as I would like to encourage my family chemist of many years to adopt the practice, and I wanted to do some research before raising the issue with my chemist first.

Neutral:

Happy to continue with current means of accessing.

I don't read websites...does anyone?

Not Applicable.

Already knew about it.

Unhelpful:

Pointless if your pharmacist refuses point blanc to entertain the idea through fear that I may pass away and leave them with huge debt... I am happy with Albion Centre.

Very unhelpful:

Na.

I have seen the advertising.

Don't know.

I didn't read it there.