

Dispensing of HIV medications at Community Pharmacies in NSW

Positive Life Survey Report

Background - The Federal Minister for Health, the Hon. Peter Dutton MP announced that from 1 July 2015, people with HIV (PLHIV) will be able to access HIV medication from community pharmacies. In preparation for the roll-out of the new policy, Positive Life NSW surveyed people with HIV in NSW about whether they would use a community pharmacy to collect their HIV medicines and if not, what their concerns might be.

Summary Analysis - Nearly two thirds of respondents (64.84%) to the community dispensing of HIV medication survey said they would consider collecting HIV medications from a chemist and a little less (61.92%) said that it was the easiest way to collect their HIV medication. However, the proportion of PLHIV choosing to use a chemist for HIV dispensing may be higher than the survey indicates. PLHIV employment data (SGCPS 2012) suggests that the proportions of PLHIV in NSW who are employed, is higher than the percentage of survey respondents and it would be reasonable to speculate that more than 2/3 of PLHIV in NSW may switch to a chemist for HIV dispensing services after 1 July 2015.

However, approximately one third of the community pharmacy survey respondents had significant concerns about privacy and confidentiality when using chemists for HIV dispensing services. Some PLHIV also had concerns about the expertise of chemist staff in relation to the provision of advice and support for HIV medication related side-effects and drug interactions. Addressing these issues via community education and chemist workforce training programs will be crucial to improving community understanding and confidence in the professional services provided by chemists and to increasing confidence in community HIV dispensing uptake by PLHIV in NSW.

Recommendations:

- 1) Support community understanding of the transition from hospital based HIV medication dispensing to chemist dispensing
- 2) Work with the Access to HIV Treatments Working Group to implement a smooth transition from hospital based dispensing of HIV medication to include chemist dispensing of HIV medication
- 3) Develop a communication strategy for PLHIV on the benefits of local chemist access to HIV treatments that:
 - Describes the process of community dispensing of HIV medications in NSW after 1 July 2015
 - Addresses concerns about the privacy and confidentiality in chemists, in particular local pharmacies in outer suburban and regional/rural areas of NSW, and provides information about the management of privacy in chemists; and access to complaint and dispute resolution processes
 - Provides information on alternative postal delivery options
 - Ensures messaging is consistent for all PLHIV, including heterosexual, Aboriginal and CALD PLHIV populations
- 4) In partnership with ASHM, communicate with GP s100 prescribers about changes in pharmacy access and transitioning PLHIV on treatment to chemist dispensing
- 5) Work with PLHIV, relevant HIV service providers (HARP Units) and the Pharmacy Guild NSW to identify chemists in key locations and identify information and workforce development needs

- 6) In partnership with: ASHM; the NSW Ministry of Health; and the NSW Pharmacy Guild, lead workforce development opportunities and increase information and knowledge skills of chemist staff about HIV treatments and privacy and confidentiality concerns
- 7) Work with the Albion Centre to transition EMA clients to community pharmacy or hospital pharmacy dispensing of HIV medication
- 8) Monitor barriers to PLHIV (BGF clients) receiving financial assistance for the purchase of HIV medications at chemists
- 9) Implement a community survey in 2015 to identify transition concerns and barriers to HIV dispensing services in NSW

The Survey - Survey Monkey was used to develop a short community survey and assess community attitudes to HIV dispensing in chemists. The survey comprised 21 questions, was targeted at people with HIV in NSW and was completed in less than two minutes. It was open for approximately one month; the survey started collecting responses on the 27th September 2014 and closed on the 26th October 2014. There were 504 respondents, representing approximately 4.75% of the estimated NSW population with diagnosed HIV completed the survey. The survey link was distributed through the Positive Life membership, service provider networks, Lifemail (eNewsletter) Facebook, Twitter, website, Gay News Network (SX online) and Grindr. Weekly email reminders and advertising on Grindr were the most successful promotional strategies.

Key Findings:

- 1) The survey sample was:
 - Gay Males were over represented (85.59%) and people who identify as Heterosexual were underrepresented (6.92%)¹.
 - An over representation of PLHIV who are receiving a Disability Support or Aged Pension (39.77%), and an underrepresentation of PLHIV who are employed (48.99%)².
 - There was an overrepresentation of BGF clients. 26.80% of respondents were receiving financial assistance for the purchase of HIV, medications from BGF. BGF reports approximately 1200 active clients which is 11.2% of the NSW population with diagnosed HIV
 - The spread of other demographic data (age, area of residence, and percentage of CALD respondents) is representative of the HIV epidemic in NSW
- 2) 64.84% of respondents stated that they would consider collecting HIV medication from a community pharmacy, with convenience (evening and weekend access), better service and continuity of care (HIV and non-HIV medications) being major considerations and reasons
- 3) Of the 35.16% who said no to collecting HIV medication from a community pharmacy, when asked their reasons for continuing to collect HIV medications from either a hospital/clinic pharmacy or EMA, more than half (53.64%) were concerned about other people knowing their HIV status, while quarter (25.83%) stated that the current arrangement worked for them, and 20.53% stated that they collected HIV drugs after seeing the doctor. Additional concerns included: delays due to the

¹ The Annual Surveillance Report 2013 (Kirby, UNSW.) reports that – In 2008-2012, 67% of new diagnoses occurred among men who have sex with men, 25% were attributed to heterosexual contact, 2% to injecting drug use and exposure was undetermined in 6%

² In comparison, the Sydney Gay Community Periodic Survey 2012 reports the following employment data for PLHIV: 59.6% working full-time; 11.5% working part-time; and 14.7% receiving a Pension/Social Security, while 2.9% were students, 4.1% were unemployed and 7.3% were self-funded retirees

need to pre-order medications through a chemist; potential issues for BGF clients receiving financial assistance for the purchase of HIV medications; concerns about increased costs at chemists generally; and the levels of experience of chemists when dispensing HIV s100 drugs

- 4) When asked what they would need to improve confidence in using a chemist to collect HIV medications, the majority (82.13%) required reassurance that their privacy and confidentiality would be maintained, while about 40% required information about how dispensing would work, and a quarter wanted information about HIV/non-HIV drug interactions. There were other suggestions which included: the need for a privacy booth or privacy screen; the need for acceptance and non-discriminatory behaviour by chemist staff; convenience of location and opening hours; and the need for confidence in knowledge of HIV medication, side-effects and drug interactions by chemist staff.
- 5) Respondents were then asked what would be the easiest way to access HIV medications. The majority (61.92%) said community pharmacy. This percentage is slightly lower than the percentage stating they would consider using a community pharmacy. 30.81% said that a Hospital Pharmacy would be easiest, and 19.77% chose the EMA scheme.
- 6) The proportion of PLHIV choosing to use a chemist for the dispensing of HIV medications may be higher than the proportion indicated by the survey (62-65%). This is because proportions of PLHIV in NSW who are employed are reported to be higher (SGCPS 2012) and it would be reasonable to assume that a higher percentage than the survey indicates may switch to a community pharmacy for HIV dispensing services after 1 July 2015.
- 7) A summary of survey findings can be found at the end of this report.

Demographics of PLHIV completing the online survey (Questions 1 to 11)

- **HIV Status** - The majority of survey respondents were HIV-positive (79.56%), however 13.10% were HIV negative, 3.57% were HIV status unknown, and 3.77% did not wish to disclose.
- **Gender** - The majority of respondents were male (94.52%), however 5.48% were female
- **Identity** - The majority of respondents were Gay male or Homosexual (85.59%). 6.92% identified as straight or Heterosexual and 6% identified as Bisexual. 0.74% identified as Intersex. The proportion of respondents who identified as Aboriginal was 2.93% and 1.76% did not wish to disclose.
- **Country of origin** - A majority of respondents were born in Australia (71%), with New Zealand and the UK being the next largest groups (0.06%) respectively, followed by Europe (0.04%). There were small numbers of respondents from Asia/South East Asia (7), Africa (9), North America (4) and other (14).
- **Language spoken at home** - A majority of respondents spoke English at home. Other languages spoken at home including: Arabic, Bengali, Cantonese, Chinese, Filipino, French, German, Hindi, Italian, Kiswahili, Korean, Luo, Ndebele, Portuguese, Spanish, Swedish and Tagalog
- **Income Source** - Nearly half (48.99%) were employed (38.04% full-time and 10.95% part-time). 39.77% were receiving a Disability or Aged Pension, and 4.9% were receiving Unemployment Benefit. 3.75% were supported by a partner, spouse or friend
- **Age** - Respondents ranged in age from 18 to more than 75, with the majority (40.35%) aged 45 – 54 and a quarter (25.65%) aged between 55 to 64 years.
- **Residential Area** - More than three quarters of respondents lived in the Sydney metropolitan area (67.72% in inner Sydney and 3.75% in Western Sydney). The next largest group lived in the Northern Rivers (6.92%) and Central Coast and Newcastle Areas (6.34%). Smaller number of respondents lived in Southern NSW and the ACT, Western NSW the Illawarra and South Coast and Hunter and New England Areas.

Healthcare (Question 12 and 13)? More than half (53.03%) sourced their healthcare from a Sexual Health or HIV Specialist s100 prescriber, while about one third (32.85%) used a GP/s100 prescriber and 14.12% sourced HIV health care from a Hospital s100 doctor/specialist. The majority (76.66%) had been prescribed cART for three years or more, however 15.56% had been prescribed cART for one to three years and 6.92% for less than 12 months. Less than 1% (0.86%) were not taking cART (A summary of the demographic profiles and tables can be viewed in the Appendix).

Enhanced Medication Access (EMA) Scheme (Question 14 and 15)? The Enhanced Medication Access (EMA) Scheme was promoted by PLNSW, the Albion Centre and other HIV Services in NSW. In August 2014, 355 (or 3.35% of the NSW population with diagnosed HIV) were enrolled in EMA and high levels of service satisfaction were reported in two consumer evaluations. Respondents to this survey were asked if they had heard about (EMA) and results were approximately evenly split, with 49.28% stating yes and 50.72% saying no. 9.91% of survey respondents had enrolled in EMA and this percentage is higher than the percentage of PLHIV in NSW who have enrolled in the scheme.

Attitudes to using a community pharmacy for cART dispensing (Question 16, 17 and 18)? Respondents were asked “when community dispensing of HIV medication begins on 1 July 2015, would you consider collecting your HIV drugs from a community pharmacy”. Nearly two thirds (64.84%) said yes and 35.16% said no. Most respondents who said yes cited convenience as the reason for using a community pharmacy. However, there were other reasons given, both positive and negative. They included, positive reasons (other):

Evening and weekend access

Better service and advice at community pharmacy

I trust my community pharmacy and have a closer bond with them than Hospital Pharmacy staff

Continuity of care with pharmacist/staff

A more normal environment

Already accessing non-HIV medications at community pharmacies

Length of waiting time at Hospital Pharmacy

Disclosure - by virtue of having to attend a hospital pharmacy, you may as well wear a hat that says HIV+ as you wait

Hospital Pharmacy staff ask too many intrusive questions

Hospital pharmacies are time consuming and confronting

I live in a small country town and it's easier for the PBS

Negative reasons (other):

I live in a rural/remote town

I worry about others finding out about my HIV status

For those that answered no (35.16%), they were then asked their reasons for not using community pharmacy and continuing to collect HIV medications from either a hospital/clinic pharmacy or EMA. More than half (53.64%) were concerned about other people knowing their HIV status at a community pharmacy, while a quarter(25.83%) stated that the current arrangement worked for them, and 20.53% stated that they collected HIV drugs after seeing the doctor. Other comments included:

Community Pharmacy will have to pre-order drugs - delay

Issues with BGF funding medications at community pharmacy

Concerns about increased cost at a community pharmacy

I am accessing ART via drug trial

Hospital pharmacy is experienced with s100 drugs and community pharmacy is not so experienced

I wish to collect drugs from my doctor

Everyone knows everyone else in rural areas and it is better to collect meds from a hospital pharmacy in a nearby town

I am not able to be reassured that anonymity would be maintained. In rural or small communities it is completely unrealistic to suggest that this would occur as a certainty

Further analysis of respondents who said no to using a community pharmacy revealed the following findings: 63% resided in the Greater Sydney and 37% in Regional NSW. Of the respondents from Greater Sydney who said no, the reasons were: concern with disclosure (49%), can collect their HIV drugs when seeing the doctor (31%) and the current arrangement works – convenience (20%). For those respondents who lived in Regional NSW, 57% had concerns about people knowing their HIV status, 39% were happy with the current arrangement, and only 5% collected HIV drugs when seeing the doctor.

What would you need from a community pharmacy/pharmacist to feel confident about using the service (Question 19)? Respondents were asked what they might need from a community pharmacist/pharmacist to feel confident about using the service. The majority (82.13%) required reassurance that their privacy would be maintained, while about 40% (39.48%) required information about how dispensing is going to work and just over a quarter required information about drug interactions (HIV and non-HIV medications). Other comments included:

Medication on the shelf and no waiting for a day to get them in

BGF ability to fund the cost of drugs, and ease in working with BGF and getting drugs in time

No extra charges

Recourse if privacy violated

Unless there is a private booth, community pharmacies cannot guarantee total privacy from other nearby customers

I am not 'out and proud' about my HIV status in most circumstances

How reliable will the medication deliveries to the chemist be?

Information about their acceptance of HIV patients

A huge counter with privacy screen

I live in a suburb where attitudes to HIV are negative and retrograde

Pharmacy with extended opening hours

Convenient location

Community pharmacists are not familiar with HIV ARVs and may be unaware of drug-drug interactions. They will also be unaware of the common side-effects (esp. those not mentioned in the product information for the drug).

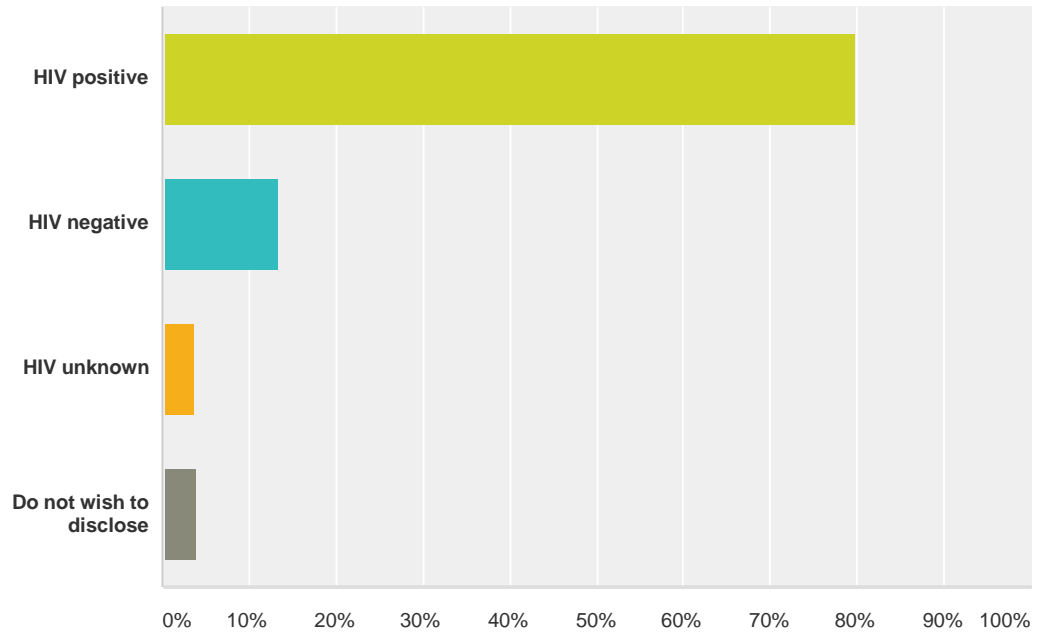
Preferred way to access HIV medications (Question 20)? Survey respondents were asked what would be the easiest way to access HIV medications. The majority (61.92%) said community pharmacy, 30.81% said Hospital Pharmacy, and 19.77% chose the EMA scheme.

BGF assistance (Question 21)? When then asked whether respondents were receiving financial assistance for the purchase of HIV medications from BGF, 26.80% said yes and 73.20% said no.

Survey Results

HIV Status

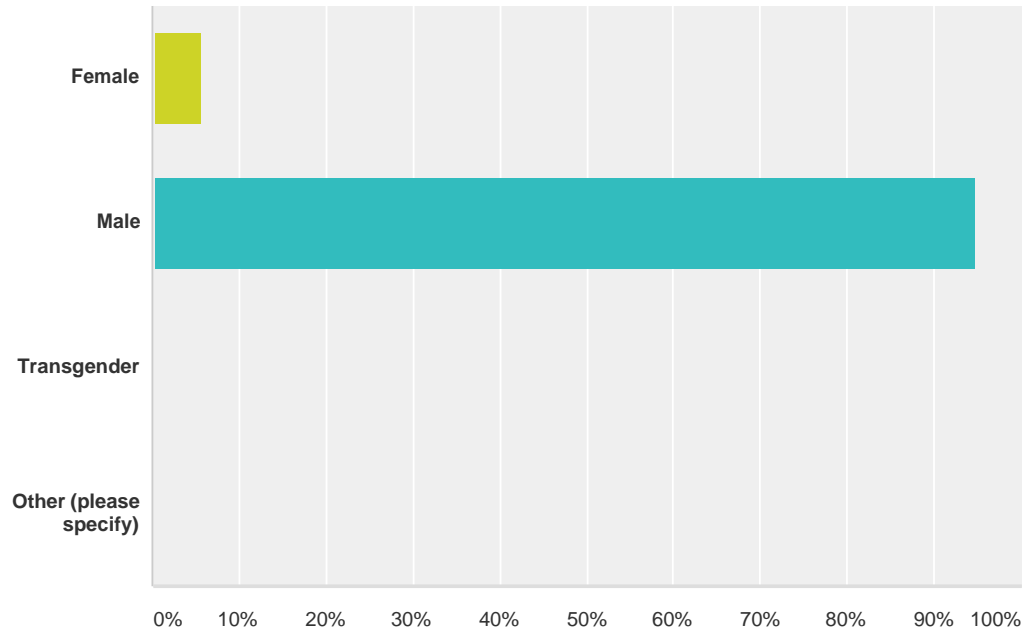
Answered: 504 Skipped: 0



Answer Choices	Responses	
HIV positive	79.56%	401
HIV negative	13.10%	66
HIV unknown	3.57%	18
Do not wish to disclose	3.77%	19
Total		504

Q2 I identify my gender as:

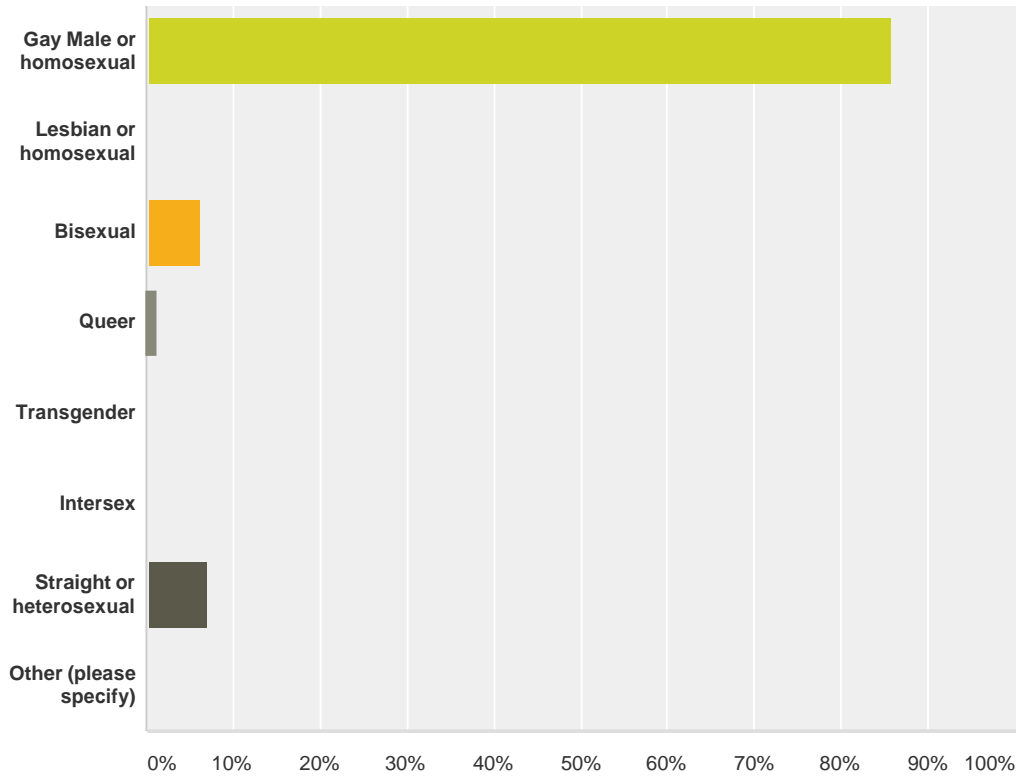
Answered: 347 Skipped: 157



Answer Choices	Responses	
Female	5.48%	19
Male	94.52%	328
Transgender	0.00%	0
Other (please specify)	0.00%	0
Total		347

Q3 Do you consider yourself to be:

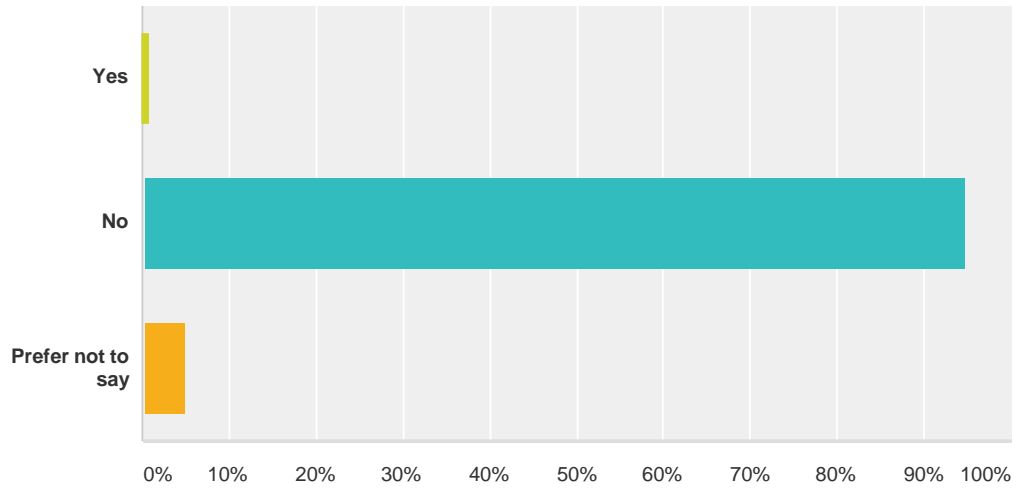
Answered: 347 Skipped: 157



Answer Choices	Responses	
Gay Male or homosexual	85.59%	297
Lesbian or homosexual	0.29%	1
Bisexual	6.05%	21
Queer	1.15%	4
Transgender	0.00%	0
Intersex	0.00%	0
Straight or heterosexual	6.92%	24
Other (please specify)	0.00%	0
Total		347

Q4 Are you intersex?

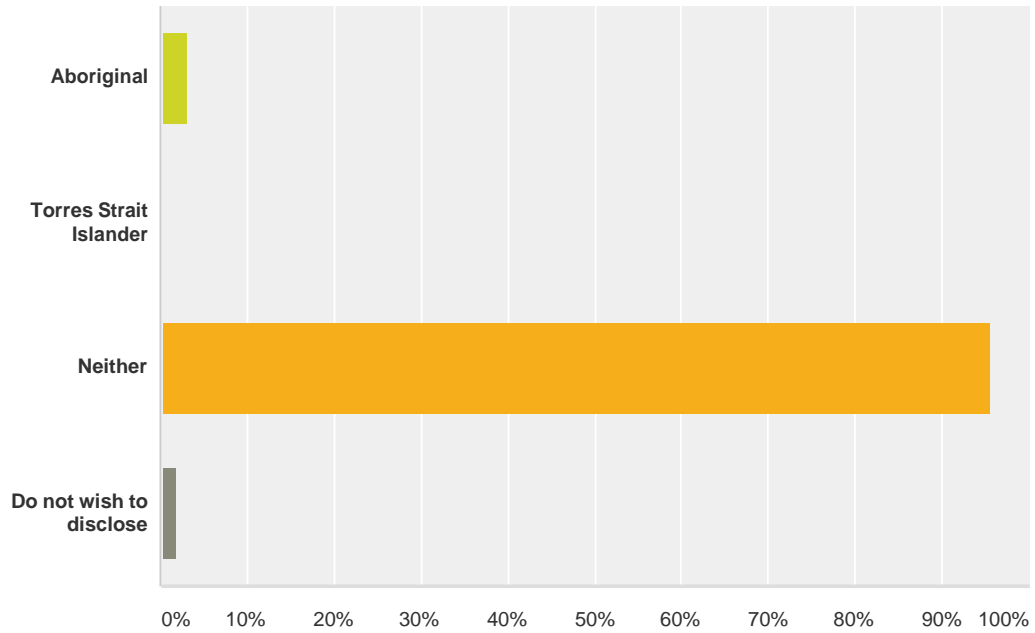
Answered: 272 Skipped: 232



Answer Choices	Responses
Yes	0.74% 2
No	94.49% 257
Prefer not to say	4.78% 13
Total Respondents: 272	

Q5 Aboriginal and Torres Strait Islander

Answered: 341 Skipped: 163

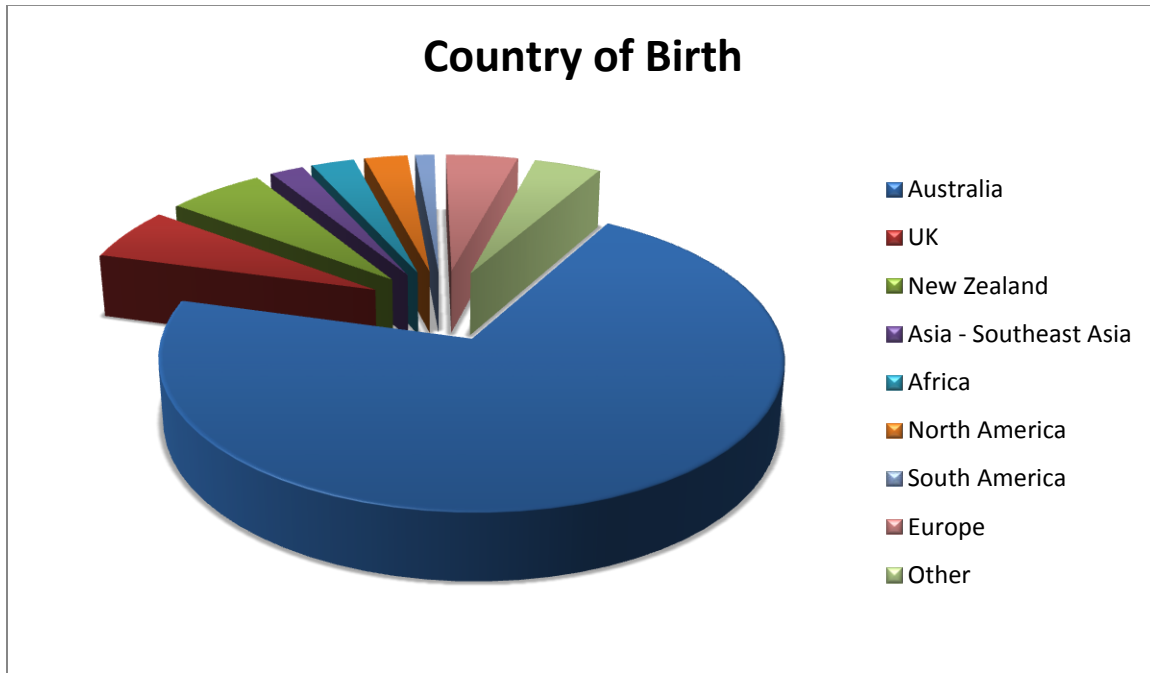


Answer Choices	Responses	
Aboriginal	2.93%	10
Torres Strait Islander	0.00%	0
Neither	95.31%	325
Do not wish to disclose	1.76%	6
Total		341

Q6 In which country were you born?

Answered:
337
Skipped:
167

239 Australia
20 UK
20 New Zealand
07 Asia/Southeast Asia
09 Africa
09 North America
04 South America
15 Europe
14 Other

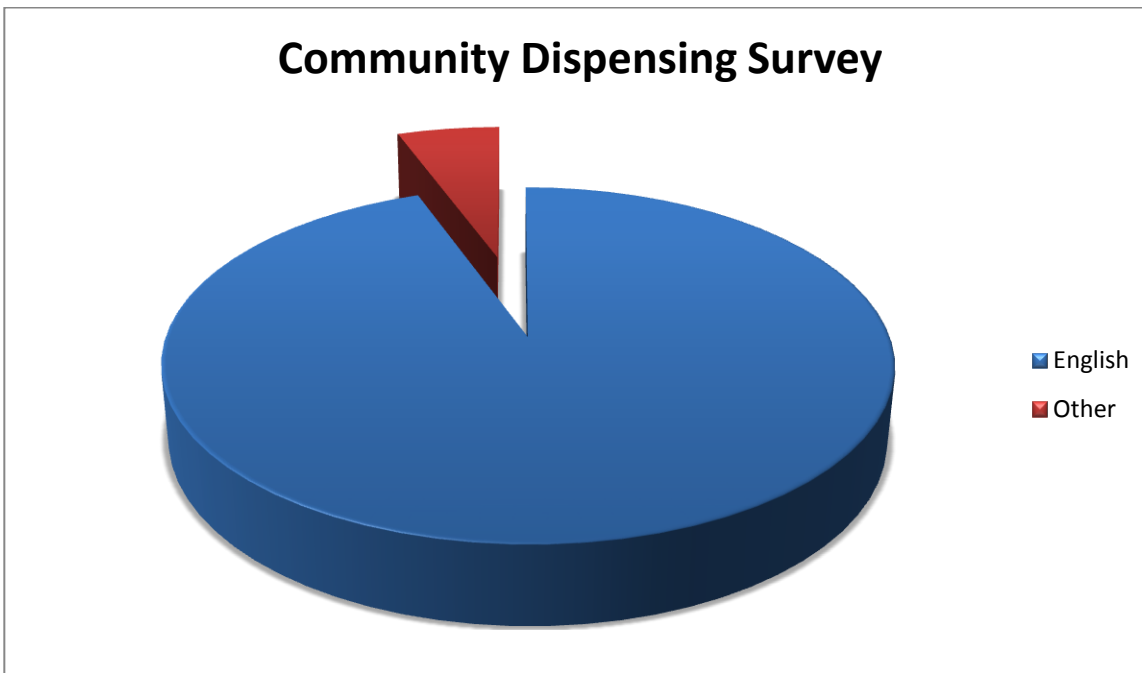


Q7 What is your first language spoken at home?

Answered: 341 Skipped: 163

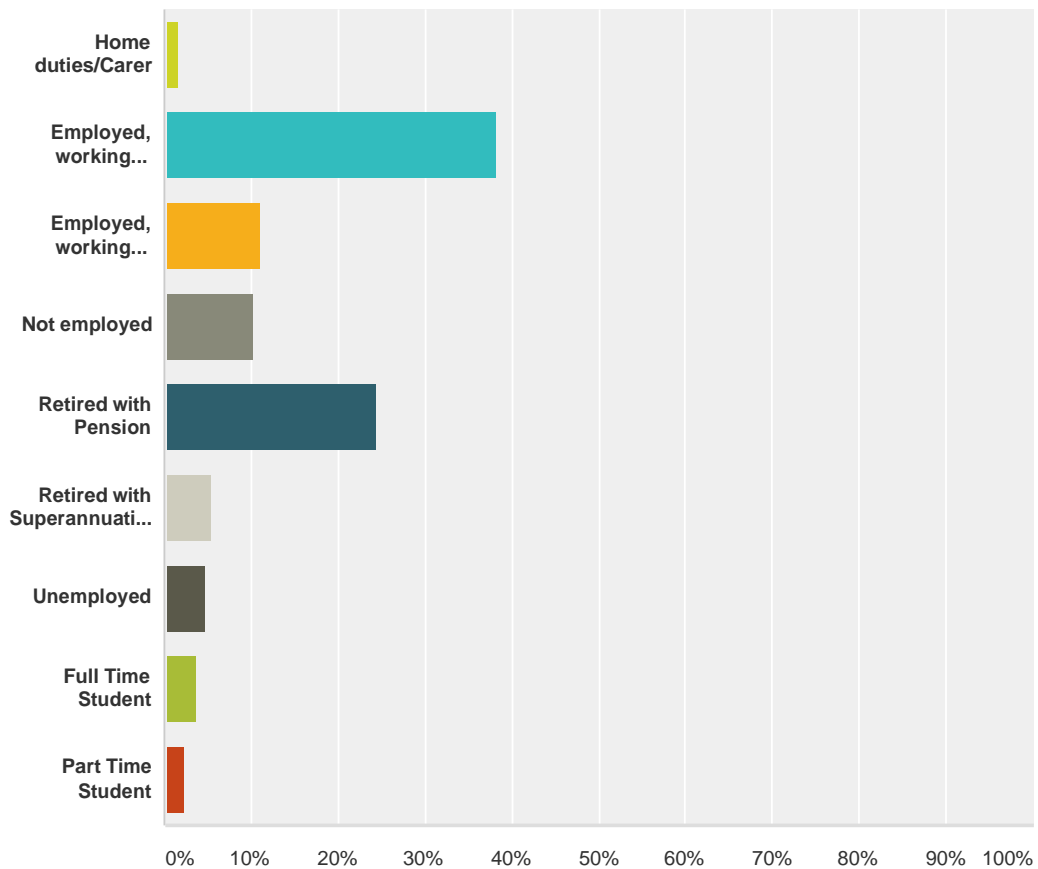
322 English

19 Other languages including: Arabic, Bengali, Cantonese, Chinese, Filipino, French, German, Hindu, Italian, Kiswahili, Korean, Luo, Ndebele, Portuguese, Spanish, Swedish and Tagalog



Q8 Which of the following categories best describes your employment status?

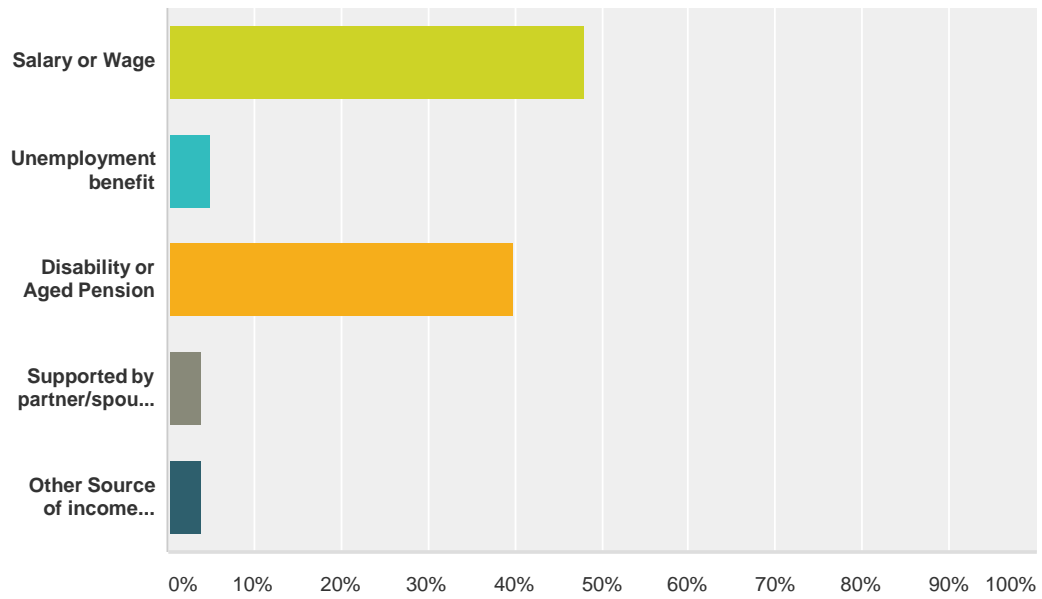
Answered: 347 Skipped: 157



Answer Choices	Responses
Home duties/Carer	1.44% 5
Employed, working full-time	38.04% 132
Employed, working part-time	10.95% 38
Not employed	10.09% 35
Retired with Pension	24.21% 84
Retired with Superannuation/savings	5.19% 18
Unemployed	4.61% 16
Full Time Student	3.46% 12
Part Time Student	2.02% 7
Total	347

Q9 Income source

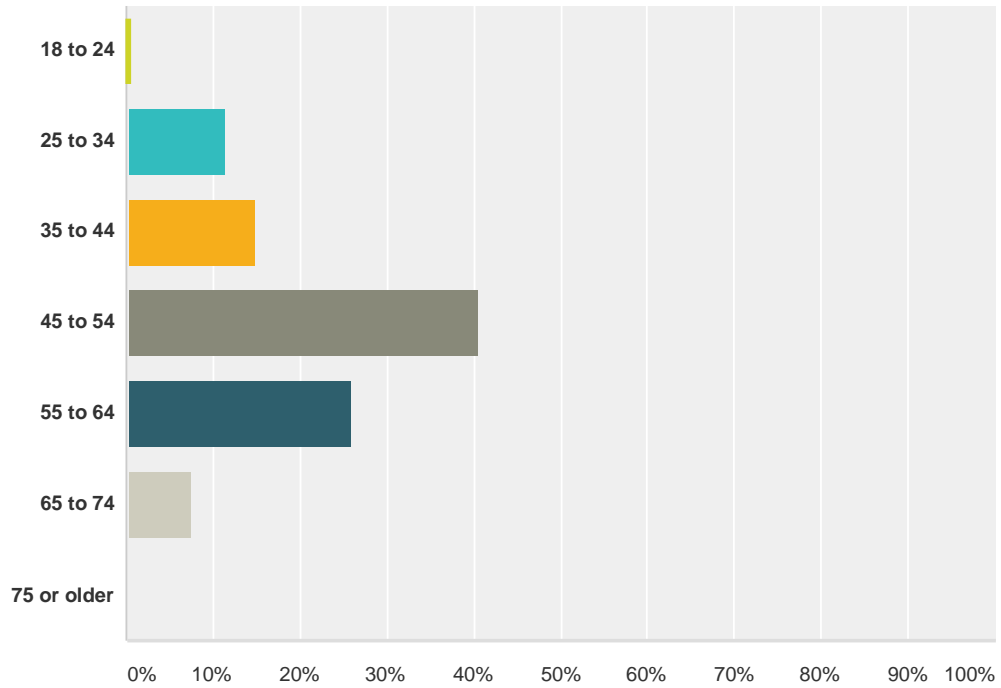
Answered: 347 Skipped: 157



Answer Choices	Responses
Salary or Wage	47.84% 166
Unemployment benefit	4.90% 17
Disability or Aged Pension	39.77% 138
Supported by partner/spouse/friend	3.75% 13
Other Source of income (please specify)	3.75% 13
Total	347

Q10 What is your age?

Answered: 347 Skipped: 157

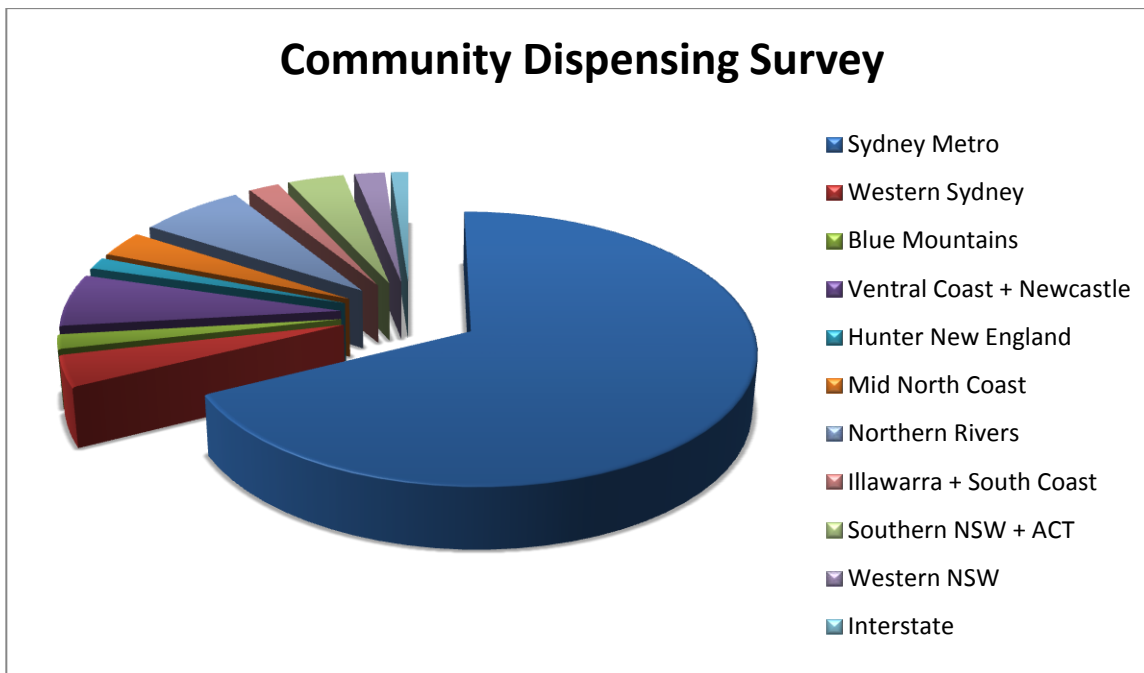


Answer Choices	Responses
18 to 24	0.58% 2
25 to 34	11.24% 39
35 to 44	14.70% 51
45 to 54	40.35% 140
55 to 64	25.65% 89
65 to 74	7.20% 25
75 or older	0.29% 1
Total	347

Q11 What is your residential postcode?

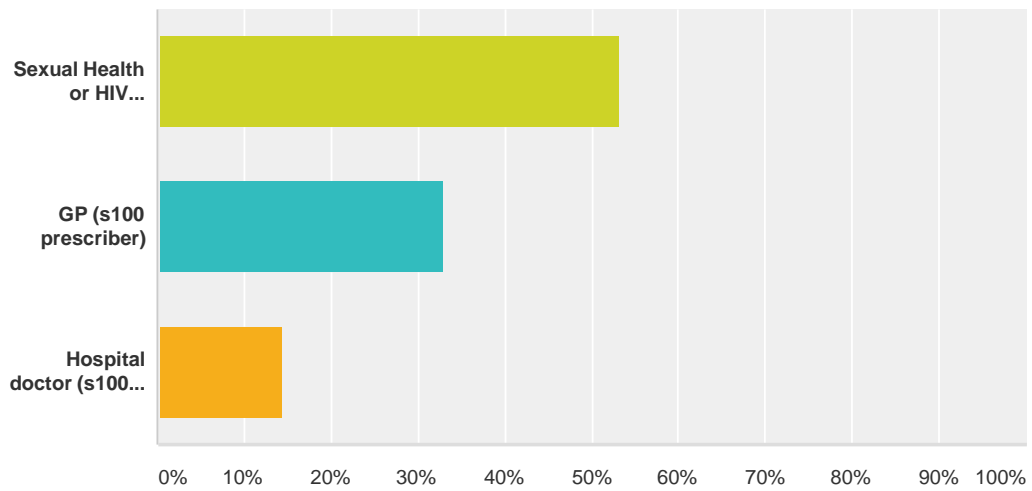
Answered: 347 Skipped: 157

Sydney metro = 235 (67.72%)
Western Sydney = 13 (3.75%)
Blue Mountains = 6
Central Coast and Newcastle = 22(6.34%)
Hunter New England = 5
Mid North Coast = 11(3.17%)
Northern River 24(6.92%)
Illawarra and South Coast = 7
Southern NSW and ACT = 13(3.75%)
Western NSW = 7
Interstate = 4



Q12 Where do you get your main source of HIV health care from?

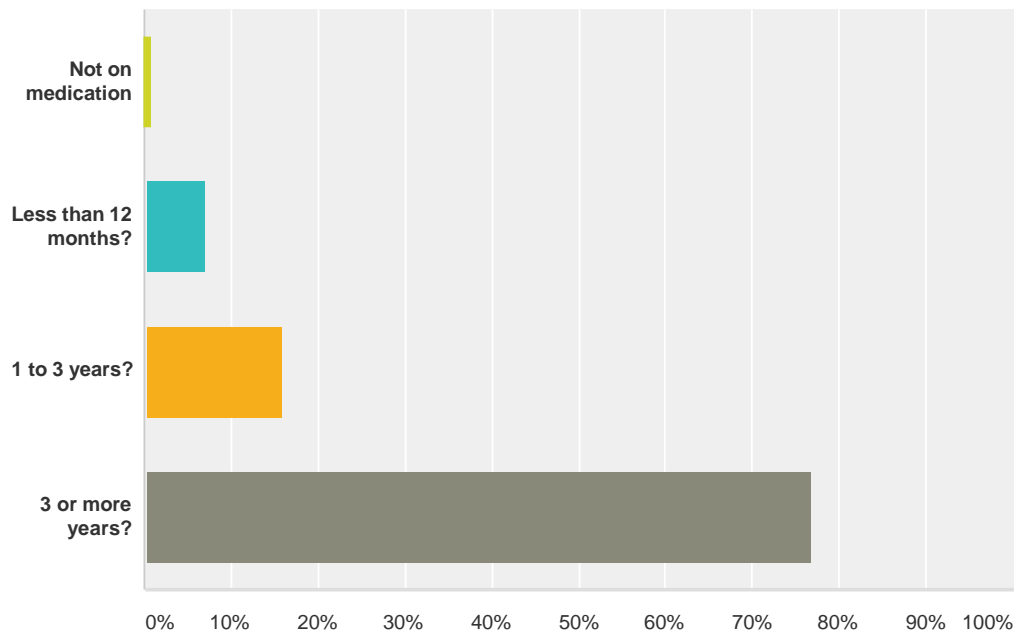
Answered: 347 Skipped: 157



Answer Choices	Responses
Sexual Health or HIV Specialist (s100 prescriber)	53.03% 184
GP (s100 prescriber)	32.85% 114
Hospital doctor (s100 prescriber)	14.12% 49
Total	347

Q13 How long have you been prescribed HIV medicines?

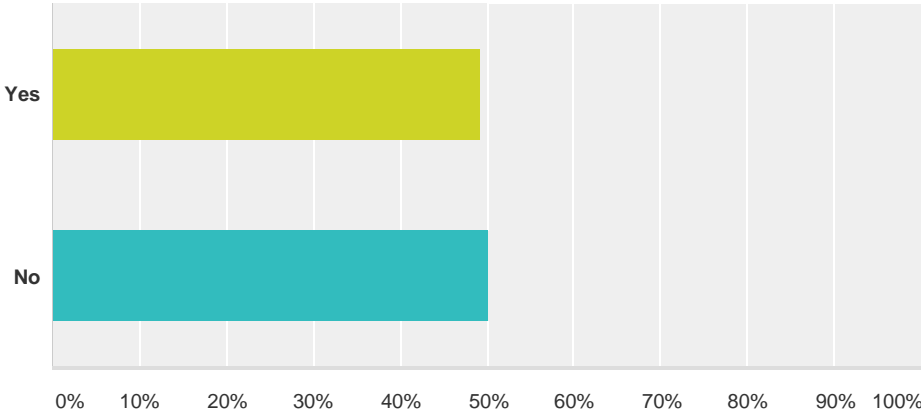
Answered: 347 Skipped: 157



Answer Choices	Responses
Not on medication	0.86% 3
Less than 12 months?	6.92% 24
1 to 3 years?	15.56% 54
3 or more years?	76.66% 266
Total	347

Q14 Have you heard about the Enhanced Medication Access Scheme (EMA)

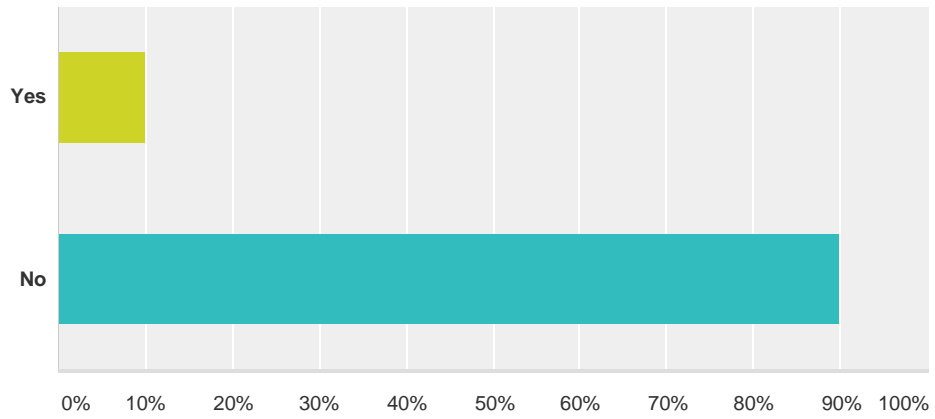
Answered: 347 Skipped: 157



Answer Choices	Responses
Yes	49.28% 171
No	50.72% 176
Total	347

Q15 Have you enrolled in the EMA Scheme?

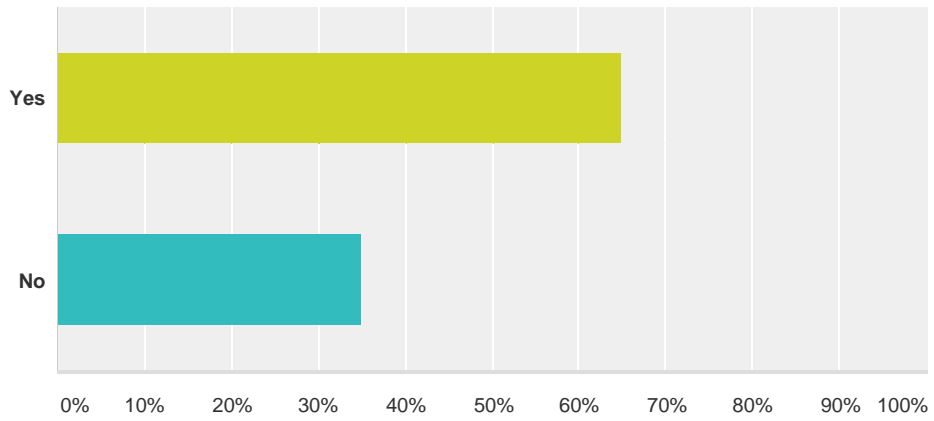
Answered: 343 Skipped: 161



Answer Choices	Responses
Yes	9.91% 34
No	90.09% 309
Total	343

Q16 When community dispensing of HIV medication begins on the 1 July 2015, would you consider collecting your HIV drugs from a community pharmacy?

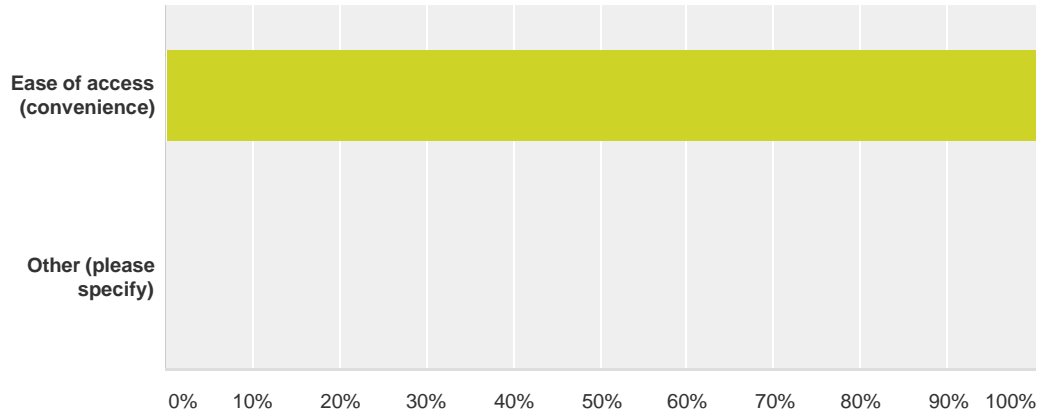
Answered: 347 Skipped: 157



Answer Choices	Responses
Yes	64.84% 225
No	35.16% 122
Total	347

Q17 If yes, what are your reasons for collecting your HIV drugs from a community pharmacy?

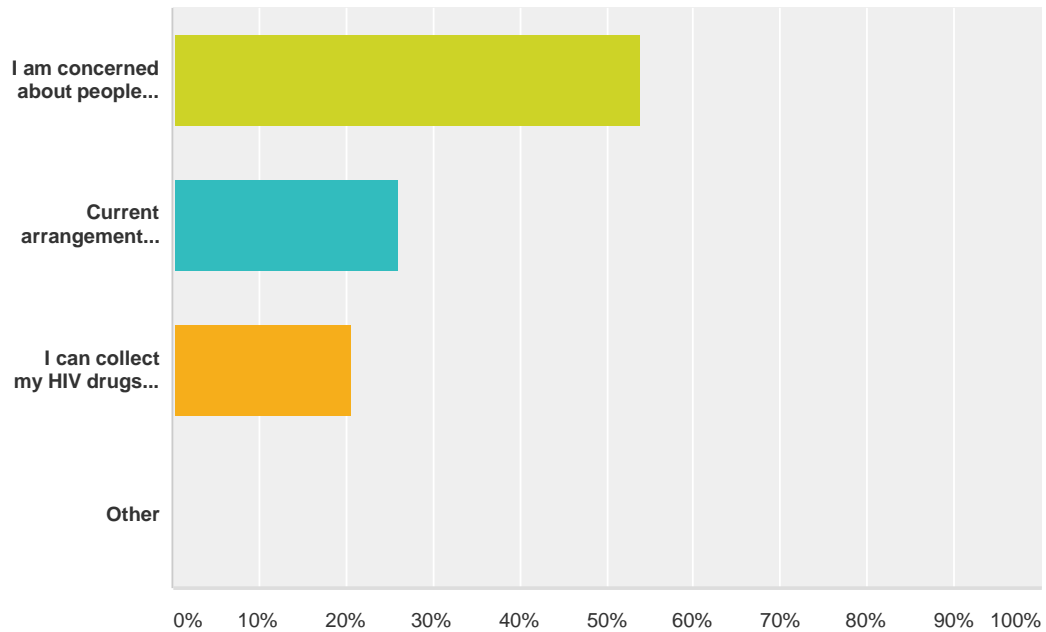
Answered: 217 Skipped: 287



Answer Choices	Responses
Ease of access (convenience)	100.00% 217
Other (please specify)	0.00% 0
Total	217

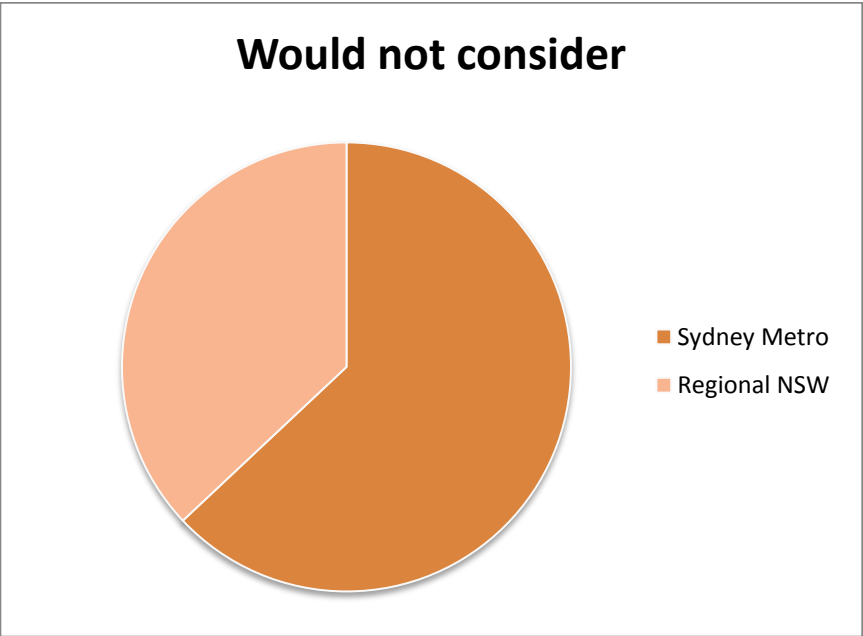
Q18 If no, what are your reasons for continuing to collect your HIV medications from a hospital/clinic pharmacy or EMA?

Answered: 151 Skipped: 353



Answer Choices	Responses	Count
I am concerned about people knowing my HIV status at a community pharmacy	53.64%	81
Current arrangement works for me (convenience)	25.83%	39
I can collect my HIV drugs when I'm seeing the doctor	20.53%	31
Other	0.00%	0
Total		151

Further analysis of respondents who said no to Question 16 by region



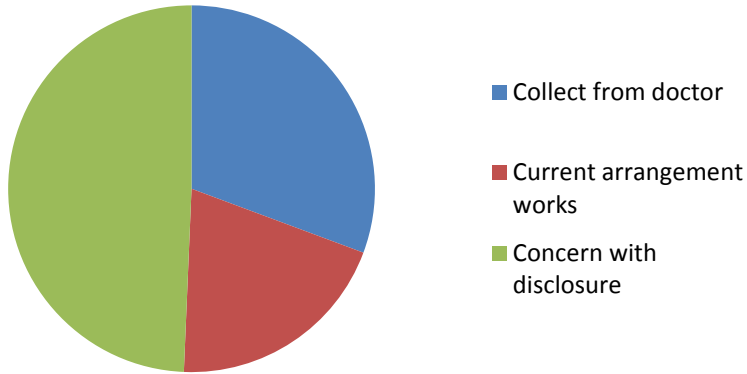
No = 122 respondents

63. % Sydney Metro (75 respondents)

37. % Regional NSW (47 respondents)

(Interstate respondents not included)

Greater Sydney - Reason for No



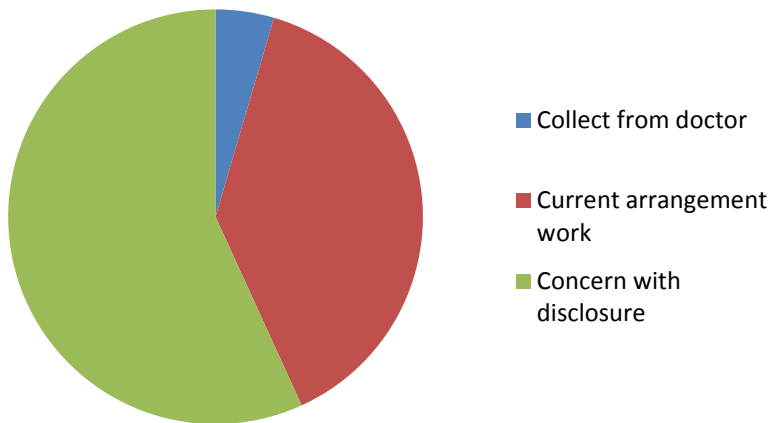
Greater Sydney – Reason for no

31% Collect from doctor

20% Current arrangement works

49% Concern with disclosure

Regional NSW - Reason for No



Regional NSW – Reason for No

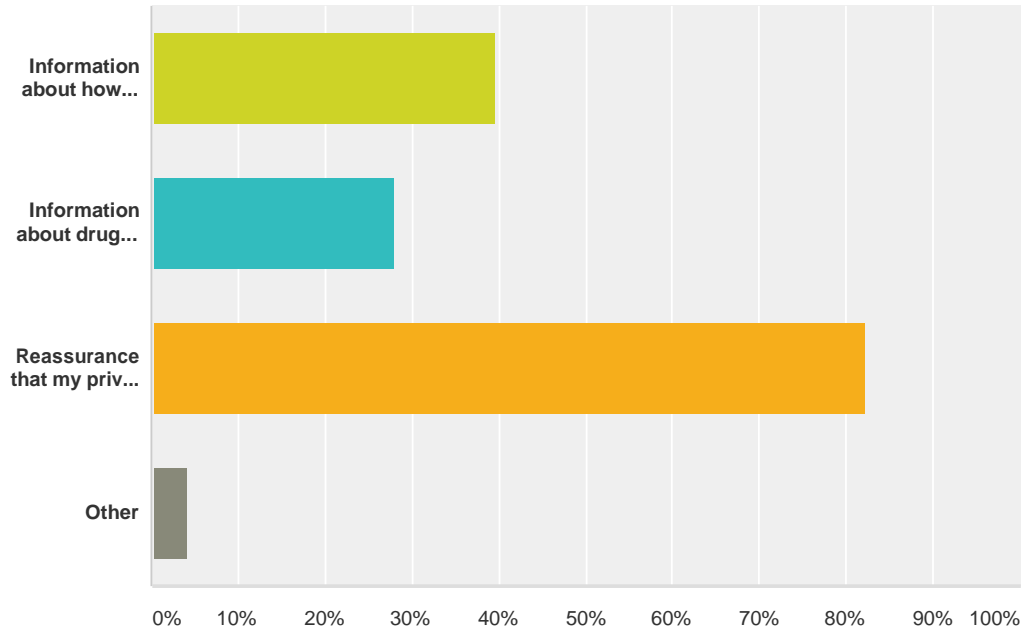
5% Collect from doctor

39% Current arrangement works

57% Concern with disclosure

Q19 What do you need from a community pharmacy/pharmacists to feel confident about the service you receive?

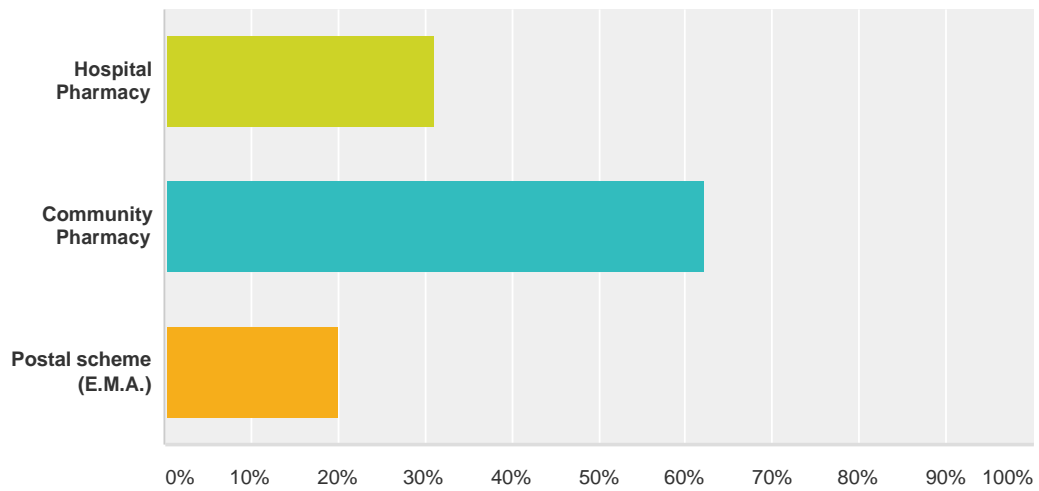
Answered: 347 Skipped: 157



Answer Choices	Responses
Information about how dispensing is going to work	39.48% 137
Information about drug interactions (HIV and non-HIV medications)	27.67% 96
Reassurance that my privacy will be maintained	82.13% 285
Other	4.03% 14
Total Respondents: 347	

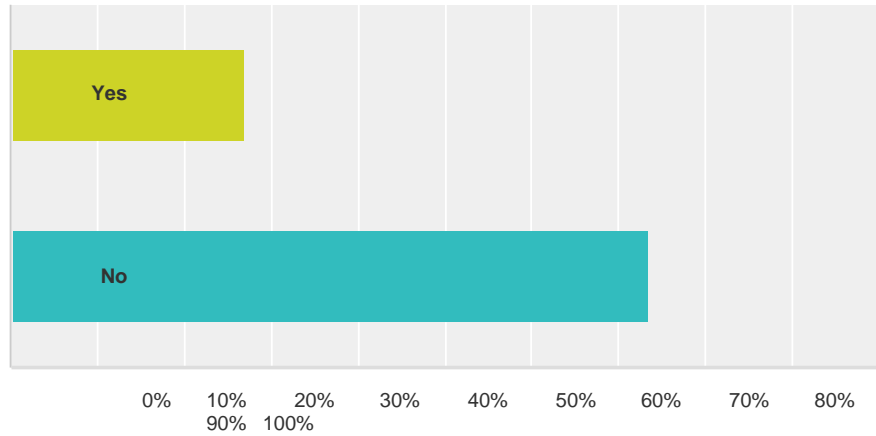
Q20 What would be the easiest way for you to access your HIV medications?

Answered: 344 Skipped: 160



Answer Choices	Responses
Hospital Pharmacy	30.81% 106
Community Pharmacy	61.92% 213
Postal scheme (E.M.A.)	19.77% 68
Total Respondents: 344	

Q21 Are you receiving financial assistance from BGF or elsewhere to assist with the purchasing of HIV medications?



Answer Choices	Responses
Yes	26.80%
No	73.20%
Total	