



Antiretroviral co-payments
for people with HIV in NSW.

January 2013

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A time for review

Summary & Recommendations

Financial stress and the patient co-payment for medicines are a significant barrier to uptake, maintenance and adherence of ARV medication by people with HIV. People with HIV (PLHIV) also experience higher rates of multi-morbidity and the management of multiple chronic health conditions is associated with higher out-of pocket health spending.

As people struggle to balance the financial burden of medical and health-related cost with other living expenses, decisions about treatment uptake, maintenance and adherence are negatively impacted. HIV and non-HIV disease progression, poorer health outcomes and increased risk of transmission of HIV, result. In 2011, 330 people were newly diagnosed with HIV infection in NSW¹. The lifetime cost of each new infection is estimated to be approximately \$749,000 (for NSW this would translate into a \$247,000,000 cost for 330 new HIV infections, if current infection rates continued.

If treatment uptake and adherence levels are to be significantly improved, financial barriers to starting and continuing treatment need to be urgently addressed. There is a compelling individual and public health case for the NSW Government to consider waiving ARV co-payments for people with diagnosed HIV in NSW. This measure would reduce financial stress, HIV transmission, long-term public health expenditure and improve health outcomes.

If treatment uptake for all of the 10,170 people with known HIV in NSW was increased to 90% by 2015 (the target set under the NSW HIV Strategy 2012-2015) we estimate that the annual cost of waiving ARV co-payments would be less than 5 million dollars.

We consider there is a strong case for the government to consider waiving co-payments for antiretroviral medication. Administratively, it may be simpler to waive the co-payment for all ARV medications. However, a means test for people who are earning less than \$60,000 per annum or similar could also be considered. This group would include those working part-time, self-funded retirees and people on pensions and social security payments. We estimate the cost of waiving co-payments to this group at approximately \$1.2 million annually.

We also believe that S100 prescribers potentially have a helpful role to play in assessing whether individual patients should be granted exemption from ARV co-payments at any particular period.

It should also be noted that the Bobby Goldsmith Foundation (BGF) in NSW currently operates a scheme for clients that specifically assists PLHIV with their medication costs. The overall number of 900 clients receiving this assistance has been reported and these clients are registered within the agency as welfare recipients.

While this scheme is a critical support to these clients, Positive Life NSW notes that it is a scheme that is limited to only BGF clients, which excludes a significant number of other PLHIV in NSW that could be under financial pressures or hardship. It has been reported through various services and

¹ 2012, NSW HIV Strategy 2012-2015: A New Era NSW HEALTH, p7

clinics that the number of PLHIV who are working but on lower incomes and those who are not eligible for the concessional rates of co-payments and other health care card benefits are a group of the population who are most vulnerable. Those who are on ARVs and are having financial difficulties may simply choose not to go on treatment – or to go off treatment – or to interrupt treatment until they have funds available.

The BGF scheme is also currently funded through private sources of funds, and this could prove unsustainable for the charity, placing a significant number of clients at risk of losing this support in the future.

We would also note that Positive Life NSW does not believe it is reasonable or feasible to ask BGF to be the only solution to the issues related to medication co-payments and long term ARV maintenance. A particular point is that people may not be willing to go on to ARV treatment if this means seeking charity, and/or accessing welfare services.

Positive Life NSW considers that the waiving of patient co-payments for ARV medicines for those people who are experiencing financial stress is a highly cost effective strategy to reduce HIV transmission, reduce morbidity and public health expenditure for this population.

Currently in other jurisdictions (WA, NT, and the major Sexual Health clinic in Victoria) the co-payment charges are waived and supported through the respective health system. In the United Kingdom, Canada, and in various US states with large numbers of PLHIV, there is now public health funding providing free access to ARVs to all HIV positive patients.

Trends in the contemporary setting of managing HIV at an individual level, as well as governmental responses aimed at reaching targets to increase the number of people with HIV on treatment and achieving viral suppression are including free access to ARV treatments in their strategic responses. This is now considered to be a crucial incentive and a cost effective intervention for HIV public health programs, and sustainable implementation plans for growing PLHIV populations living longer.

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Antiretroviral co-payments for people with HIV in NSW

A time for review

Issue addressed

This discussion paper examines the relationship between patient co-payments, levels of ARV treatment uptake and adherence to antiretroviral (ARV) treatment and other medications for people with HIV in NSW.

This submission addresses the deleterious individual and public health impacts that medicine co-payments have on ARV treatment uptake. For those already on ARV treatments, ARV co-payments can adversely impact on the capacity of some individuals to pay co-payment fees over time. This in turn impacts on treatment being maintained appropriately, leading to the development of ARV resistance and / or, ultimately, to ARV treatment failure. For people who have decided to initiate treatment, including those with higher CD4 counts, co-payments can be a barrier to treatment uptake in the first place, particularly for people on lower incomes.

The paper calls for waiving antiretroviral co-payments. This measure, if adopted, would ease financial stress and improve uptake and adherence of antiretroviral medications by people with HIV and help achieve NSW HIV Strategy 2012-2015 targets.

Positive Life NSW argues that the cost of not being on ARV treatment – both the individual and public health costs – are far greater than the cost-effectiveness of waiving co-payments, especially in the context of the defined numbers and projections of the NSW population of people living with HIV.

Background

Promoting HIV treatment uptake, making access to treatment easier and supporting treatment adherence are key to achieving the NSW HIV Strategy 2012-2015 goals. The Strategy states that *“If ARV treatment uptake and adherence by people living with HIV is to be increased, then some significant disincentives to commencing and staying on HIV treatment need to be removed”...“The financial cost of taking HIV treatments is a real barrier to starting and continuing treatment for many people. Cost can relate to travelling to a hospital pharmacy, losing time from paid employment, and the cost of patient’s co-payments for ARV and non-ARV prescribed drugs”.*

1) There are around 10,170 people who know they are living with HIV in NSW², with another estimated 25% who are undiagnosed.

2) Financial stress and adherence

Patient co-payments and individual financial stress have been identified as a barrier to antiretroviral adherence. Research conducted at St Vincent’s Public Hospital in Sydney and reported in 2012 found that of the 335 out-patients attending the HIV clinic at St Vincent’s Hospital between November 2010 and May 2011, 65 patients (19.6%) stated that it was difficult or very difficult to

² 2012, NSW HIV Strategy 2012-2015: A New Era NSW HEALTH, figure 2: The NSW “HIV Treatment Cascade”, Unpublished analysis by the Kirby Institute for Infection and Immunity in Society, p9

meet pharmacy dispensing costs, (14.6%) reported that they had delayed purchasing medication because of pharmacy costs and (9.0%) reported that they had ceased medication because of pharmacy costs.

Of the 65 patients with difficulty meeting pharmacy costs, (29%) had ceased medication verses (4.1%) of the remaining 270 patients. In addition, (5.7%) stated that it was difficult or very difficult to meet travel costs to the clinic. Treatment cessation and interruption were both independently associated with difficulty meeting both pharmacy and clinic travel costs³.

We note that treatment adherence in this study context is underlining the critical factors behind treatment failure, or loss to follow up of patients. The factors and barriers which contribute to treatment failure are often captured under the clinical description of “non-adherence”.

3) Rates of employment for people with HIV in NSW

*Futures Six*⁴ reports that while (37.4%) of survey respondents worked full-time, (62.6%) were either not working/retired/‘home duties’ (22.9%), working part-time (17.3%), unemployed (9.2%), a student (2.7%) or other (10.4%)⁵.

Data from the *Sydney Gay Community Periodic Survey 2012 (SGCPS)*, suggests higher levels of employment in New South Wales with (59.6%) of HIV-positive respondents to the survey reporting being employed full-time.

The SGCPS also reported (11.5%) of HIV+ respondents being employed part-time, while (7.3%) nominated ‘Other’ as a source of income⁶. It would be reasonable to speculate that those who are employed part-time are likely earning lower net incomes (less than \$40,000 per annum). Although some would be employed in high paying roles, they would conceivably be in a minority. The category of “Other” is thought to include self-funded retirees and those drawing down other income and assets, or being supported by a spouse/partner. Neither of these groups of people would necessarily be eligible for a Health Care Card and would be required to pay the full patient co-payment⁷ for ARV and other medications – despite having significantly less income.

14.7% of HIV-positive respondents (*SGCPS*) reported receiving a pension or social security payment. They would be eligible for a Health Care Card (HCC) and concession⁸. 4.1% reported being unemployed and 2.9% reported being a student and also eligible for a HCC⁹.

³ J McAllister et al 2012, Financial stress is associated with reduced treatment adherence in HIV-infected adults in resource-rich settings. *HIV Medicine* (2012)

⁴ The latest ARCSHS Futures report available, Futures 7 will be reported in 2013

⁵ J Grierson et al 2009, HIV Futures Six – making positive lives count, p49 table 55 Employment Status

⁶ Iryna Zablotska, 2012, Kirby Institute. Analysis of Sydney Gay Periodic Survey 2012 - requested by Positive Life NSW

⁷ From 1 January 2013, the patient co-payment was increased to \$36.10 for most PBS medicines

⁸ From 1 January 2013, the patient concessional co-payment was increased to \$5.90 for most PBS medicines

⁹ Iryna Zablotska, 2012, Kirby Institute. Analysis of Sydney Gay Periodic Survey 2012 - requested by Positive Life NSW

4) Multi-morbidity

Higher rates of multi-morbidity are experienced by people with HIV when compared to the general population. Nearly half (46.1%) of respondents to *Futures Six* indicated that they had a major health condition other than HIV. The most common conditions were mental health [anxiety/depression (44.6%) with 28.6% having taken prescribed medication in the last six months], hepatitis C (13%), cardiovascular disease (10%) and diabetes (4%)¹⁰.

These conditions - in many cases - require clinical management with multiple medications and regular ongoing clinical monitoring. In addition, prophylaxis for the control of viral, bacterial and fungal infections (e.g. herpes simplex/zoster, Toxoplasmosis, Cryptococci) as well as anti-depression/anxiety medication and medication to control treatment related side-effects are also frequently required.

Multi-morbidity is associated with higher out-of-pocket health care related spending and reduced employment rates. Employment continues to present challenges for HIV- positive people. While the need for financial security are critical factors in wishing to be in paid employment, the management of HIV and a other chronic health conditions can prove to be substantial barriers to obtaining and retaining employment¹¹.

The management of chronic disease is associated with varying and potentially severe economic consequences for individuals and their households, particularly due to the financial burden associated with medical and health-related care. Australian research has found a positive relationship between the number of chronic health conditions and out-of-pocket spending on health. People with multiple chronic conditions also tend to be on lower incomes¹².

5) Factors impacting on treatment uptake and adherence

The need to purchase multiple HIV and other prescribed medications, forces people with HIV on low incomes to balance the purchase of treatment and living expenses. Decisions will potentially impact on adherence¹³. For people with HIV who are receiving multiple individually-formulated antiretroviral medications, the co-contribution payment can become quite a substantial expense.¹⁴ People on low incomes frequently also report mental health and drug and alcohol issues¹⁵. They may choose to buy recreational drugs and alcohol before prescribed medication¹⁶. They may also not fully grasp the health benefits of adherence to ARV and other prescribed medication and become

¹⁰ J Grierson et al 2009, *HIV Futures Six – making positive lives count*, other health conditions p9

¹¹ J Grierson et al 2009, *HIV Futures Six – making positive lives count*, Employment p48

¹² I McRae et al 2012, *Multi-morbidity is associated with higher out-of-pocket spending: a study of older Australians with multiple chronic conditions*, Australian Journal of Primary Health - CSIRO Publishing

¹³ J McAllister et al 2012, *Financial stress is associated with reduced treatment adherence in HIV-infected adults in resource-rich settings*. *HIV Medicine* (2012)

¹⁴ J Grierson et al, *Tracking Changes, Tracking the Experiences of Starting and Switching Highly Active Antiretroviral Therapy in Australia* P47

¹⁵ J Condon 2012, ACON Treatment Officer

¹⁶ Ibid

increasingly at risk of developing other more serious health conditions - which then require more intensive clinical intervention and perhaps admissions to hospital¹⁷.

People under financial stress report delaying and starting treatment later than clinical guidelines recommend¹⁸. They also may choose a 'one pill once a day combination' for financial reasons. These treatment regimens are not always clinically optimal and can lead to future treatment failure and the need for subsequent switches to ARV combinations comprising more multiple medications within the first year to achieve and maintain viral suppression¹⁹.

6) Treatment breaks

Futures Six reports that (38.1%) of those currently using HIV treatment had taken a break at some point in time. Of these, about a quarter (24.7%) had taken their most recent break in the two years prior to the survey and (12%) in the previous one year. The mean length of break was ten months with a median of four months and a mode of three months (16.6%)²⁰. The reason for taking the break fell within two major categories: lifestyle and clinical reasons²¹. Of those citing lifestyle reasons for a treatment break, (8%) cited the *financial burden as becoming too heavy*²². Of those citing a clinical reason, (7.4%) provided *drug resistance developed* as the reason and (15.4%) provided *recommended by my doctor*, as the reason.²³

Less than ideal adherence can lead to treatment resistance, cross resistance and treatment failure which further reduces treatment options and the need for more complex regimens. More complex treatment regimens result in a further cost to people with HIV, placing a further financial burden on those least equipped to pay.

7) HIV treatment and transmission

Recent studies have found that ARV treatment dramatically reduces the risk of transmitting HIV to others.^{24 25} In Australia, modelling by researchers at the Kirby Institute has estimated the contributions to new HIV transmission across the HIV positive population by several significant sub groups.²⁶

Within NSW - PLHIV on ARV therapy with suppressed viral load (An estimated 32% of the total NSW PLHIV population), have a limited contribution to new HIV infections estimated to be 1.5%²⁷. In contrast, the estimated 25% of the total PLHIV population that does not know their positive status contributes to an estimated 48.4% of new HIV infections. Also significant is the estimated 43% of

¹⁷ Ibid

¹⁸ Ibid

¹⁹ Ibid

²⁰ J Grierson et al 2009, *HIV Futures Six – making positive lives count*, Treatment breaks p22

²¹ Ibid

²² Ibid

²³ Ibid

²⁴ HTPN 052

²⁵ 2012, NSW HIV Strategy 2012-2015: A New Era NSW HEALTH, 2.1 Advances in HIV treatment, 2.2 Treatment as prevention p8

²⁶ D Wilson 2012, Estimated Contributions to New HIV Transmissions

²⁷ Ibid

new infections that are occurring by those with diagnosed HIV with an unsuppressed viral load, and which has been estimated to be 50.1% of the HIV-positive population in NSW.

8) The number of items (HIV medications) dispensed per person in NSW

Most respondents to the 2011 *Tracking Changes* study reported currently taking a HIV regime of three ARV agents. Overall, those on ARV therapy took between one and seven ARV agents, though most took between two and four agents.²⁸

Table A lists the number of ARV agents currently being taken in Australia²⁹

| Number of Antiretroviral Agents | Frequency | Percentage of those currently taking ARV treatment |
|---------------------------------|-----------|--|
| One | 1 | 0.5 |
| Two | 10 | 4.5 |
| Three | 189 | 85.9 |
| Four | 16 | 7.3 |
| Five | 3 | 1.4 |
| Six | 0 | 0 |
| Seven | 1 | 0.5 |

Recently, St Vincents Hospital (SVH) Outpatient Pharmacy conducted a 'snapshot summary' of dispensing patterns. They believe this snapshot to be representative of all people with HIV accessing the SVH pharmacy. Within the group reviewed, patients were taking an average of 2.4 items³⁰ with about 20% taking one item and 35% taking 2 items. The remaining 45% were taking 3 or 4 items³¹.

The Albion Centre Outpatient Pharmacy has also reviewed HIV dispensing patterns for 2 months in later 2012: 1,573 patients were dispensed antiretroviral scripts.

Of these:

24% of patients were dispensed one individual item (e.g. 3-drug fixed dose combination pill)

47% of patients were dispensed two items

22% of patients were dispensed three items

7% of patients were dispensed more than 3 individual items.³²

²⁸ J Grierson et al Dec 2011, *Tracking Changes*, Tracking the Experience of Starting and Switching Highly Active Antiretroviral Therapy in Australia, La Trobe University p 24

²⁹ Ibid

³⁰ An 'item' can be a single ARV drug; or a co-formulated combination of two ARV drugs in a single tablet; or a co-formulated combination of three or more ARV drugs in a single tablet. For the purpose of estimating costs for filling prescriptions, one item equals one co-payment charge to the patient.

³¹ S.Bridle, Manager Outpatients Pharmacy, St Vincents Hospital Darlinghurst NSW, 2013

³² M Graham, G Cabrera, D Smith. Audit of antiretroviral medications dispensed at the Albion Centre Pharmacy between September 2012 and October 2012.

9) Patient co-payments

From 1 January 2013, the patient co-payment was increased to \$36.10 for most PBS medicines and to \$5.90 if people have a concession card.

10) Cost of ARV and non-ARV medication

Table 1 illustrates the cost that would be faced over a 12 month period by people taking a range of ARV and non-ARV medications. The figures are based upon the patient co-payment cost for ARV medication - which is currently \$36.10 for two months' supply of ARV medications and \$36.10 for one month supply of non-ARV medication. Some patients under certain circumstances may be eligible for an authority prescription which allows for greater quantities of medication to be dispensed per co-payment).³³

| Yearly cumulative <u>full</u> co-payment cost of ARV and non-ARV medications ³⁴ | | | | | | | | | | |
|--|---------------|---------------|---------------|---------------|---------------------|---------------|---------------|----------------|----------------|----------------|
| ANTIRETROVIRALS | | | | | NON-ANTIRETROVIRALS | | | | | |
| | 1x SCRIPT | 2x SCRIPT | 3x SCRIPT | 4x SCRIPT | | 1x SCRIPT | 2 SCRIPTS | 3x SCRIPTS | 4x SCRIPTS | 5x SCRIPTS |
| JAN | 36.10 | 72.20 | 108.30 | 144.40 | | 36.10 | 72.20 | 108.30 | 144.40 | 180.50 |
| FEB | | | | | | 72.20 | 144.40 | 216.60 | 288.80 | 361.00 |
| MAR | 72.20 | 144.40 | 216.60 | 288.80 | | 108.30 | 216.60 | 324.90 | 433.20 | 541.50 |
| APR | | | | | | 144.40 | 288.80 | 433.20 | 576.60 | 722.00 |
| MAY | 108.30 | 216.60 | 324.90 | 433.20 | | 180.50 | 361.00 | 541.50 | 722.00 | 902.50 |
| JUN | | | | | | 216.60 | 433.20 | 649.80 | 866.40 | 1083.00 |
| JUL | 144.40 | 288.80 | 433.20 | 576.60 | | 252.70 | 504.40 | 758.10 | 1010.80 | 1263.50 |
| AUG | | | | | | 288.80 | 577.60 | 866.40 | 1152.20 | 1444.00 |
| SEP | 180.50 | 361.00 | 541.50 | 722.00 | | 324.90 | 649.80 | 974.70 | 1296.60 | 1624.50 |
| OCT | | | | | | 361.00 | 722.00 | 1083.00 | 1444.00 | 1805.00 |
| NOV | 216.60 | 433.20 | 649.80 | 866.40 | | 397.10 | 794.20 | 1191.30 | 1588.40 | 1985.50 |
| DEC | | | | | | 433.20 | 866.40 | 1299.60 | 1732.80 | 2166.00 |
| Total | 216.60 | 433.20 | 649.80 | 866.40 | | 433.20 | 866.40 | 1299.60 | 1732.80 | 2166.00 |

³³ Marissa Graham, Senior Clinical Pharmacist, Albion Street Centre 2013 – reports that NSW hospitals are currently charging general patients \$28.90 per ARV item for two months' supply. In line with Commonwealth increases, co-payments will go to \$36.10 and \$5.90 on-line claiming of s100 items becomes operational. Each site will commence claiming at different dates throughout 2013 resulting in price differences at the different hospital sites during this time. In NSW – when a 4 month script is provided by a doctor, a patient would expect to pay one co-payment on the first 2 months supply, then another co-payment on the remaining two months supply.

³⁴ See Multi-morbidity p2

Table 2 illustrates the cost that would be faced over a twelve month period by those on a range of ARV and other medications who are eligible for a concession. The figures are based upon the 2013 patient co-payment cost of ARV medication which has risen to \$5.90 for two months' supply of ARV medications and \$5.90 for one month supply of non-ARV medication (some patients under certain circumstances may be eligible for an authority prescription).³⁵

| Yearly cumulative <u>concessional</u> co-payments costs for ARV and non-ARV medications ³⁶ | | | | | | | | | | |
|---|--------------|--------------|---------------|---------------|---------------------|--------------|---------------|---------------|---------------|---------------|
| ANTIRETROVIRALS | | | | | NON-ANTIRETROVIRALS | | | | | |
| | 1x SCRIPT | 2x SCRIPT | 3x SCRIPT | 4x SCRIPT | | 1x SCRIPT | 2x SCRIPT | 3x SCRIPT | 4x SCRIPT | 5x SCRIPT |
| JAN | 5.90 | 11.80 | 17.70 | 23.60 | | 5.90 | 11.80 | 17.70 | 23.60 | 29.50 |
| FEB | | | | | | 11.80 | 23.60 | 35.40 | 47.20 | 59.00 |
| MAR | 11.80 | 23.60 | 35.40 | 47.20 | | 17.70 | 35.40 | 53.10 | 79.80 | 88.50 |
| APR | | | | | | 23.60 | 47.20 | 70.80 | 94.40 | 158.00 |
| MAY | 17.70 | 35.40 | 53.10 | 79.80 | | 29.50 | 59.00 | 88.50 | 118.00 | 147.50 |
| JUN | | | | | | 35.40 | 70.80 | 106.20 | 141.60 | 177.00 |
| JUL | 23.60 | 47.20 | 70.80 | 94.40 | | 41.30 | 82.60 | 123.90 | 165.20 | 206.50 |
| AUG | | | | | | 47.20 | 94.40 | 141.60 | 188.80 | 236.00 |
| SEP | 29.50 | 59.00 | 88.50 | 118.00 | | 53.10 | 106.20 | 159.30 | 212.40 | 265.50 |
| OCT | | | | | | 59.00 | 118.00 | 177.00 | 236.00 | 295.00 |
| NOV | 35.40 | 70.80 | 106.20 | 141.60 | | 64.90 | 129.80 | 195.70 | 259.60 | 324.50 |
| DEC | | | | | | 70.80 | 141.60 | 212.40 | 283.20 | 354.00 |
| Total | 35.40 | 70.80 | 106.20 | 141.60 | | 70.80 | 141.60 | 212.40 | 283.20 | 354.00 |

11) The Safety Net³⁷

The safety net does not provide sufficient assistance to people with HIV on lower incomes. It can typically take several months before the Safety Net threshold is reached, which can mean that some individuals struggling with low incomes may decide not to start treatment (or to cease their ARV treatment), because financially they cannot sustain several months of co-payments until the Safety Net threshold is reached.

On 1 January 2013, the Safety Net threshold changed from \$1,363.30 to \$1,390.60. The Safety Net threshold for concession card holders is \$354.00. After reaching the Safety Net threshold, patients pay for further PBS prescriptions at the concessional co-payment rate (\$5.90) and concession card holders are dispensed PBS prescriptions at no further charge for the remainder of the calendar year. A Safety Net Entitlement Card or Safety Net Concession Card can be issued by the pharmacist once the threshold is reached.

People with HIV taking multiple HIV and non-HIV medications are required to purchase s100 items from a hospital outpatient pharmacy and other non-s100 medications from a community pharmacy.

³⁵ Ibid

³⁶ See Multi-morbidity p2

³⁷ Reduces the cost of prescription medicines for individuals and families once the PBS Safety Net threshold has been reached

The requirement to obtain dispensing records from all pharmacies during a calendar year before a pharmacist can issue the entitlement card can be onerous. Community pharmacies provide electronic dispensing records, however hospital pharmacies have varying systems, and they are not linked to community pharmacy records. Patients therefore need to manage two record cards to track their spending and satisfy any threshold claim. Feedback from people with HIV suggests that few patients understand the Safety Net system. It is also likely that many reach the Safety Net threshold late in the calendar year and believe that the time taken for the collection of dispensing records and application for a Safety Net Card outweighs the limited financial benefit.

The tables at **Attachment 1** show the cumulative monthly cost of combinations of two and three ARV medications and multiple non-ARV medications (where no concession is claimed and the co-payment is \$36.10). Two months' supply of ARV medication can be dispensed and one month's supply of non-ARV medications for each co-payment. The graphs also show the time of the year when the Safety Net threshold has been reached and people become eligible to claim a concession co-payment of \$5.80 per item.

12) Annual cost estimates for ARV Patient Co-payments for NSW population with HIV

The following tables estimate the annual cost burden for ARV co-payments for the NSW population with HIV in relation to eligibility/ineligibility for a Health Care Card. Each table provides an estimate of cost, based upon 3 ARV items being the average³⁸. The data used in the tables is based upon the total number of people who know they have HIV in NSW (10,170)³⁹; 100% treatment uptake; eligibility or non-eligibility to a Health Care Card (based on analysis of self-reported employment/income status of HIV+ respondents to the Sydney Gay Periodic Survey 2012; and Concession and non-concessional patient co-payment amounts of \$36.10 or \$5.90.

- **Table 3** estimates the total annual full co-payment costs for ARV medication in NSW where there is no eligibility to a Health Care Card)
- **Table 4** estimates the total annual co-payment costs for those who are employed and on low incomes or receiving income from another sources (e.g. self-funded retirees drawing down superannuation) and ineligible for a Health Care Card)
- **Table 5** estimates the total annual co-payment cost for ARV medication where people are eligible via (pension/social security payments) for a concession.
- **Table 6** aggregates the above data and estimates the total annual ARV co-payment costs for the 10,170⁴⁰ people in NSW. The table estimates the total cost of ARV co-payments if treatment uptake levels are 70%, 80% and 90% for the NSW population with known HIV.
- **Table 7** estimates the annual cost of ARV co-payments for the 20%-30% of people living with HIV who are yet to be diagnosed and treated with ARV therapy. It estimates the cost for uptake levels between 70 and 100%.

³⁸ See Table A

³⁹ 2012, NSW HIV Strategy 2012-2015: A New Era NSW HEALTH, figure 2: The NSW "HIV Treatment Cascade", Unpublished analysis by the Kirby Institute for Infection and Immunity in Society, p9

⁴⁰ Ibid

Table 3

Annual estimated cost of ARV Patient Co-payment (\$36.10 per prescription) for - NSW PWHIV employed full-time and not eligible for a Health Care Card)

| | NSW Population with known HIV (10,170) | Total annual patient co-payment cost of 3.0 ARV prescriptions \$649.80 |
|--|--|--|
| Employed full-time (59.6%)⁴¹ | 6,061 | \$3,938,437 |

Table 4

Annual estimated cost of ARV Patient Co-payment (\$36.10) for - NSW PWHIV employed part-time, self-funded retiree and receiving income from other sources (not eligible for concession and arguably low income)

| | NSW Population with known HIV (10,170) | Total annual co-payment cost of 3.0 ARV prescriptions \$649.80 |
|---|--|--|
| Employed part-time (11.5%)⁴² | 1,169 | \$759,616 |
| Other source of income (7.3%)⁴³ | 742 | \$482,151 |
| Total of part-time and Other (18.8%) | 1,911 | \$1,241,767 |

Table 5

Annual estimated cost of ARV Concessional Patient Co-payments (\$5.90) for - NSW PWHIV who are eligible for a Health Care Card via (pension/social security, student, unemployed etc.)

| | NSW Population with known HIV (10,170) | Total annual co-payment cost of 3.0 ARV prescriptions \$106.20 |
|--|--|--|
| Pension/ Social Security (14.7%)⁴⁴ | 1,495 | \$158,769 |
| Student (2.9%)⁴⁵ | 295 | \$31,329 |
| Unemployed (4.1%)⁴⁶ | 417 | \$44,285 |
| Total Concession Card holders (21.7%) | 2,207 | \$234,383 |

⁴¹ See Rates of employment for people with HIV in NSW p2

⁴² ibid

⁴³ Ibid

⁴⁴ Ibid

⁴⁵ ibid

⁴⁶ Ibid

Table 6

The yearly estimated cost of ARV co-payments for 10,170 people with HIV in NSW - where people are prescribed an average of 3 ARV items (estimates are made for 70%, 80%, 90% and 100% treatment uptake).

| Employed | 70% treatment uptake | 80% treatment uptake | 90% treatment uptake | 100% uptake |
|-----------------|----------------------|----------------------|----------------------|--------------------|
| Full-time | \$2,756,905 | \$3,150,749 | \$3,544,593 | \$3,938,437 |
| Part-time/other | \$869,236 | \$993,413 | \$1,117,590 | \$1,241,767 |
| Concession | \$164,068 | \$187,506 | \$210,944 | \$234,383 |
| Total | \$3,790,210 | \$4,331,669 | \$4,873,128 | \$5,414,587 |

Table 7

Annual cost of ARV co-payments for the 20%-30% of people living with HIV were they to be diagnosed and treated with 3 ARV items (70 – 100% treatment uptake)

| Undiagnosed and untreated | 70% treatment uptake | 80% treatment uptake | 90% treatment uptake | 100% uptake |
|---------------------------|----------------------|----------------------|----------------------|-------------|
| 20% of 10,170 | \$780,042 | \$866,333 | \$974,625 | \$1,082,917 |
| 30% of 10,170 | \$1,137,063 | \$1,299,500 | \$1,461,938 | \$1,624,376 |

13) Life-time cost of each HIV diagnosis

The Australian Department of Immigration and Citizenship provided notes for guidance to medical officers of the Commonwealth of Australia on the financial implications and consideration of prejudice of access to services associated with HIV/AIDS. The guidelines provide tables of costing for different clinical categories of HIV and AIDS, and the average health cost per year. These costs include the cost of medication and clinical management (comprising consultations and diagnostic tests). For people with HIV on first or second line therapy, the average annual cost per year is estimated to be \$13,800 - \$16,300. For those on third-line therapy the annual cost is estimated to be \$19,000 per year.⁴⁷

If the median age at diagnosis is 34⁴⁸ years and the average life expectancy is to 80 years, most people diagnosed with HIV will live an average of a further 46 years from time of HIV diagnosis. The life-time cost of each new HIV diagnosis can therefore be estimated to be between \$634,800 and \$749,800 for people on first or second line therapy. For those on third line therapy, the cost is estimated to be \$874,000.

⁴⁷ See:

http://www0.health.nsw.gov.au/resources/publichealth/infectious/diseases/hiv_aids/hiv_surveillance_data_2_011.pdf

⁴⁸ NSW Health 2012, Demographic comparison by risk exposure group,

http://www0.health.nsw.gov.au/resources/publichealth/infectious/diseases/hiv_aids/hiv_surveillance_data_2_011.pdf

14) Summary & Recommendations

Financial stress and the patient co-payment for medicines are a significant barrier to uptake, maintenance and adherence of ARV medication by people with HIV. People with HIV also experience higher rates of multi-morbidity and the management of multiple chronic health conditions is associated with higher out-of pocket health spending.

As people struggle to balance the financial burden of medical and health-related cost with other living expenses, decisions about treatment uptake, maintenance and adherence are negatively impacted. HIV and non-HIV disease progression, poorer health outcomes and increased risk of transmission of HIV, result. In 2011, 330 people were newly diagnosed with HIV infection in NSW⁴⁹. The lifetime cost of each new infection is estimated to be approximately \$749,000 (for NSW this would translate into a \$247,000,000 cost for 330 new HIV infections, if current infection rates continued.

If treatment uptake and adherence levels are to be significantly improved, financial barriers to starting and continuing treatment need to be urgently addressed. There is a compelling individual and public health case for the NSW Government to consider waiving ARV co-payments for people with diagnosed HIV in NSW. This measure would reduce financial stress, HIV transmission, long-term public health expenditure and improve health outcomes.

If treatment uptake for all of the 10,170 people with known HIV in NSW was increased to 90% by 2015 (the target set under the NSW HIV Strategy 2012-2015) we estimate that the annual cost of waiving ARV co-payments would be less than 5 million dollars.

We consider there is a strong case for the government to consider waiving co-payments for antiretroviral medication. Administratively, it may be simpler to waive the co-payment for all ARV medications. However, a means test for people who are earning less than \$60,000 per annum or similar could also be considered. This group would include those working part-time, self-funded retirees and people on pensions and social security payments. We estimate the cost of waiving co-payments to this group at approximately \$1.2 million annually.

We also believe that S100 prescribers potentially have a helpful role to play in assessing whether individual patients should be granted exemption from ARV co-payments at any particular period.

It should also be noted that the Bobby Goldsmith Foundation (BGF) in NSW currently operates a scheme for clients that specifically assists PLHIV with their medication costs. The overall number of 900 clients receiving this assistance has been reported and these clients are registered within the agency as welfare recipients.

While this scheme is a critical support to these clients, Positive Life NSW notes that it is a scheme that is limited to only BGF clients, which excludes a significant number of other PLHIV in NSW that could be under financial pressures or hardship. It has been reported through various services and clinics that the number of PLHIV who are working but on lower incomes and those who are not eligible for the concessional rates of co-payments and other health care card benefits are a group of the population who are most vulnerable. Those who are on ARVs and are having financial difficulties

⁴⁹ 2012, NSW HIV Strategy 2012-2015: A New Era NSW HEALTH, p7

may simply choose not to go on treatment – or to go off treatment – or to interrupt treatment until they have funds available.

The BGF scheme is also currently funded through private sources of funds, and this could prove unsustainable for the charity, placing a significant number of clients at risk of losing this support in the future.

We would also note that Positive Life NSW does not believe it is reasonable or feasible to ask BGF to be the only solution to these issues related to medication co-payments and long term ARV maintenance. A particular point is that people may not be willing to go on to ARV treatment if this means seeking charity, and/or accessing welfare services.

Positive Life NSW considers that the waiving of patient co-payments for ARV medicines for those people who are experiencing financial stress is a highly cost effective strategy to reduce HIV transmission, reduce morbidity and public health expenditure for this population.

Currently in other jurisdictions (WA, NT, and the major Sexual Health clinic in Victoria) the co-payment charges are waived and supported through the respective health system. In the United Kingdom, Canada, and in various US states with large numbers of PLHIV, there is now public health funding providing free access to ARVs to all HIV positive patients.

Trends in the contemporary setting of managing HIV at an individual level, as well as governmental responses aimed at reaching targets to increase the number of people with HIV on treatment and achieving viral suppression are including free access to ARV treatments in their strategic responses. This is now considered to be a crucial incentive and a cost effective intervention for HIV public health programs, and sustainable implementation plans for growing PLHIV populations living longer.

15) Further information on this submission

For further information on this submission, please contact Lance Feeney on (02) 9206 2074 or email lancef@positivelife.org.au

16) Acknowledgement

National Association of People with HIV Australia (NAPWHA) for their assistance in preparing this submission.

Marissa Graham, Senior Clinical Pharmacist, The Albion Centre

Sylvia Bridle, Chief Pharmacist, St Vincents Hospital

Jae Condon, Team Leader Newly Diagnosed Priority Service, ACON

Iryna Zablotska, Senior Lecturer, Kirby Institute

David Riddell CEO Bobby Goldsmith Foundation

John McAllister, St Vincents Hospital, Sydney

Alexandra Stratigos, HIV/AIDS Legal Centre Inc.

ATTACHMENT 1

Chart A and B show the cumulative monthly cost of combinations of ARV medications and non-ARV medications where there is no eligibility for a concession. It also shows the month when the Safety Net threshold is reached.

Cumulative monthly cost of ARV combinations and non-ARV medications

PBS Safety Net = \$1,390.60



