



**AUSTRALIAN
FEDERATION OF AIDS
ORGANISATIONS INC.**
ABN 91 708 310 631

PO Box 51
**Newtown NSW
2042 AUSTRALIA**

Ph +61 2 9557-9399
Fax +61 2 9557-9867

Email afao@afao.org.au

Internet <http://www.afao.org.au>

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Senate Select Committee into Medicare
Parliament House
Canberra, ACT, 2600

Dear Senators

I am writing to convey the full support off the Australian Federation of AIDS Organisations (AFAO) for the submission concerning proposed changes to Medicare placed before you by the National Association of People Living with HIV/AIDS (NAPWA).

The Australian Federation of AIDS Organisations is the peak body for Australia's community-sector response to the HIV/AIDS epidemic. We are charged with representing the views of our members, comprised of the AIDS Councils in each state and territory, the National Association of People Living with HIV/AIDS, the Australian Illicit and Injecting Drug Users League and the Scarlet Alliance.

NAPWA's submission on the proposed changes to Medicare was developed with our close support and co-operation and we commend the submission for your close consideration.

Yours sincerely

Don Baxter
Executive Director

napwa

ABOUT NAPWA

National Association of People Living with HIV/AIDS

- Established in 1988 to be the national advocacy body for people living with HIV/AIDS
- NAPWA is the peak non-government organisation representing people living with HIV/AIDS in Australia

Membership

- State and Territory PLWHA organisations

Objectives

- To provide national PLWHA advocacy, policy advice, and representation
- To provide issues coordination and community consultation
- To provide organisational support and capacity building for members

**Submission to the Senate Select Committee on Medicare
and Committee on the Health Legislation Amendment
(Medicare and Private Health Insurance) Bill 2003**

National Association of People Living with HIV/AIDS

July 2003

BACKGROUND: PRINCIPLES OF PUBLIC HEALTH CARE

The following submission to the Senate Select Committee on Medicare and the Committee on the *Health Legislation Amendment (Medicare and Private Health Insurance) Bill 2003* should be read against the following core principles which NAPWA holds to be the basis of an enlightened, effective and modern public health care system.

- All Australians have the right to access an appropriately-funded public health care system, including: visits to a doctor or specialist; hospitalisation; palliative care; access to best-practice medicines and medical technologies and drugs which may enhance quality of life or prevent the onset of illness or progression of disease.
- This right to access must hold for all Australians, regardless of income, health status, gender, race or other social, political or cultural differences.
- It is in the best interests of our community and society at large to have a health care system which ensures the best possible well-being of all its citizens.
- The appropriate source of funding for this system is the taxation system.
- Recognising access to universal health care as a principle also means necessarily acknowledging the social and economic limitations which already affect the uptake of health services: limit-factors like race, language barriers, gender, geographical location, age and poverty.

- Best-practice public health, including the prevention of transmissible diseases, and the prevention of other illnesses or conditions (such as heart disease, diabetes or cancer), overwhelmingly confirms that investment in a robust public health system can avert the unnecessary spending of health dollars on preventable illness or disease further down the track.
- A compassionate approach to public health must also take account of those people living in Australia who may not have access to Medicare, by supporting some access to urgent and life-saving treatments for this group of people.

Structure of the submission

As the peak body representing people living with HIV/AIDS at the level of national health policy, NAPWA is well-placed to consider how people with HIV are affected by the current system, and how proposed changes to Medicare arrangements are likely to affect peoples' daily lives, and health outcomes.

We will focus on the following areas

- Current cost burdens of people living with HIV: an outline of the demographic
- Bulk-billing arrangements
- Geographical issues
- Disadvantaged groups of people living with HIV/AIDS
- Co-ordinated care
- Access to private health insurance
- HIV and families

1. CURRENT HEALTH STATUS, HEALTH ISSUES AND COST BURDENS OF PEOPLE LIVING WITH HIV: AN OUTLINE OF THE DEMOGRAPHIC

1.1 HIV and its treatment

There are about 14,000 people living with HIV/AIDS in Australia, and new infections in some states are increasing. The *HIV Futures III Survey*¹ of more than 950 Australians living with HIV/AIDS provides some invaluable data on the circumstances, health, and lifestyles of positive people. About 71 percent of those surveyed were taking some form of antiretroviral treatment. Antiretroviral treatment has extended the lives of many people living with HIV/AIDS, allowing HIV positive people to re-enter the workplace, education, and the social and economic fabric of the nation.

However, treatments for HIV raise a number of increasingly complex health management issues for many HIV positive people, some of which may require at any time acute, short-term or ongoing hospitalisation, drug treatment or other medical interventions. Some of these include:

- **Acute toxicities** from antiviral therapy which may require hospitalisation. Admissions to acute care in HIV are now most notably associated not with opportunistic illness or infection, but with antiviral toxicities which require hospitalisation, such as reactions to treatments.
- **Chronic side effects of antiretroviral therapy**, which may affect peoples' ability to work full time, or their capacity to fully participate in daily activities (e.g. chronic nausea, diarrhoea, or liver complications). Many of these side effects may require a person to seek additional professional health care advice, which may range from

¹ Grierson J, Misson S, McDonald K, Pitts M and O'Brien M. (2002) *HIV Futures III: Positive Australians on Services, Health and Well-Being*. Monograph Series no. 37, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

specialist medical advice, to ancillary health support, such as seeing a dietitian or massage therapist.

- **Neurological, psychological and psychosocial effects** of living with HIV, which may require interventions from drug treatment to counselling, to psychiatric assessment and support
- **Long-term toxicities** of HIV treatments, which can lead to chronic health problems like lipodystrophy (distortion in distribution of body fat and the functioning of the metabolic system); elevated cholesterol and triglycerides factors for heart disease (requiring regular monitoring and sometimes, medical intervention); loss of bone density; diabetes; and organ problems such as chronic inflammation of the liver.

Available treatments do not prevent all HIV positive people from becoming ill. Positive people with AIDS, or low CD4 counts, may also find themselves facing the costs of ongoing prophylactic treatment such as Bactrim to prevent *pneumocystis carinii pneumonia*, or acute treatment or even hospitalisation arising from opportunistic illness.

Finally, there are a range of other illnesses and conditions which people may have concomitant to HIV infection. According to *HIV Futures III*, 38.1 percent of respondents reported having a major, complicating health condition. The most common of these was hepatitis C (9.9 percent of respondents), followed by cardiovascular disease (4.6 percent), asthma (3.6 percent), and hepatitis B (3.0 percent).²

HIV Futures III showed that 27.5 percent of respondents had been prescribed medication for depression, a similar proportion (27.4 percent)

² Ibid. p. 10.

had been prescribed medication for anxiety, and 3.4 percent were taking anti-psychotic medication.³

1.2 Work, income, poverty, and family

HIV Futures III shows that that, despite wide variances in the individual circumstances of HIV positive people, the nature of living with a chronic illness sees many people clustered in low income groups.

In total, over **30 percent** of positive people are reported to be **living below the poverty line**⁴. This includes a substantial number of people who are actually in some form of paid work. Among those employed in paid work, an alarming 10.5 percent remained below the Henderson Poverty Line. Over 50 percent of people who responded to the survey were living on government benefits or pensions.

The mean weekly income for all respondents was \$437.25, and the median income \$340. The total mean expenditure of respondents on medication per week, including complementary therapies, was \$27. Nearly 30 percent of respondents indicated they had some difficulties paying for their medical services, slightly more (35 percent) for prescribed medication, and 37.2 percent had some problems paying for food.⁵

Some of these issues are exacerbated among HIV positive people who have dependent children. 50.2 percent of the women in the survey reported they had dependent children.⁶ Fortunately, due to advances in HIV treatment, very few women reported that their child or children were HIV positive. However, mean and median weekly incomes for positive

³ *ibid.* p. 62.

⁴ *Ibid.* p. 103.

⁵ *Ibid.* p. 104.

⁶ McDonald K, Misson S and Grierson G. (2002) *Juggling with HIV: The Intricacies of Positive Women's Lives Today*. Monograph Series no. 38. The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, 2002, p. 71.

women were substantially lower (\$351.70; \$330) than for positive people overall⁷, and, alarmingly, 27.0 percent of women in paid work lived below the poverty line. 60 percent of the women nominated paying for medical services as “a little difficult” (30 percent); or “very difficult (29.1 percent).⁸

1.3 Implications for access to medical services

Overall, the picture of positive people is of an extreme range of circumstances, from serious and life-threatening illness, through to well-managed disease encroaching little on peoples’ lives.

However, the picture shows unambiguously that this is a group of people in the double-bind of often having the highest health-care needs to manage their illness, and at the same time, being concentrated at the low end of the income scale.

Of particular concern are the group of HIV positive people on low incomes, but who do not hold a Commonwealth Pensioner Concession Card or Health Care Card. We believe it is this group, already finding meeting their health care costs a considerable burden, who will be most dramatically affected by the Government’s proposed new Medicare package.

1.4 Costs of medical management of HIV: some figures

Following are some case studies of the expenditures faced by people living with HIV/AIDS, receiving various levels of income, on essential drugs and medical management.

The examples are concerned only with **costs incurred directly in addressing mental and physical health issues**. They do not factor in expenditure on items which have what could be described as having a

⁷ Ibid. p. 104.

⁸ Ibid. p. 109.

secondary but still significant impact on an individual's health such as housing, food, transport, leisure and other support.

The costs of living with HIV are highly variable, depending on individual and often fluctuating health conditions, but also on attitudes to particular kinds of treatments. The costs here represent variations on some 'typical' health care expenses likely to be faced by HIV positive people, including prescription HIV antivirals, over-the-counter pharmaceuticals (such as those used to manage diarrhoea, the most common drug-related side effect), other script drugs (for the management of side effects, opportunistic infections, prophylaxis, or depressive illness), dietary supplementation, as well as other therapies often sought like massage or acupuncture for stress or pain management.

Basis for the case studies

The prescription drugs and over-the-counter medicines here are based on the management of common HIV-related problems, like infections, or drug side effects ranging from nausea and diarrhoea, to peripheral neuropathy or haematological changes. The diet supplementations are based on standard combinations recommended by a HIV-experienced dietitian practicing in Melbourne, used by many Section 100 prescribers as an essential allied health service. Prices for over-the-counter are retail prices referenced from a pharmacy in Darlinghurst, Sydney. Vitamin prices sourced from the AIDS Council of NSW discount vitamin service. Gap fees are representative fees for a 45-minute consultation, as charged by a Sydney-based high-caseload HIV practice which no longer bulk-bills its patients. None of the case studies here include private health insurance, an issue which this submission will consider in Section 2.5. These case studies also assume a person has not yet reached the Safety Net threshold for that year.

Additional burden of proposed increases to pharmaceutical co-payments

The following case studies also need to be read in light of proposals to increase co-payments for prescription drugs listed on the Pharmaceutical Benefits Scheme. Managing HIV entails not simply managing the virus itself, but managing a complicated array of possible infections and illnesses arising as a result of immune damage. Treatments used to reduce HIV may also have substantive side effects which themselves require management with prescription drugs. The result is that for many people with HIV, there is a substantially high use of prescription medications than is usual for some other chronic illnesses.

In addition, the severity of both side effects, and the need to treat or prevent opportunistic infections, tends to increase according to disease progression. It is in the group of people with the lowest CD4 counts that the most severe clinical effects of HIV are experienced. This is also the group of people least likely to be able to participate in full-time paid work. NAPWA submits, therefore, that a combination of changes to Medicare bulk billing arrangements, and increased co-payments for prescription drugs could be a potentially disastrous combination for those people most incapacitated by their HIV infection.

CASE STUDY 1

A HIV positive man in his late 30s, stable HIV viral load, a good CD4 count, taking a standard-of-care triple combination of three antiretroviral drugs, and in full-time paid work. Without private health insurance.

MEDICAL EXPENSE	PERSONAL COST PER MONTH
3 prescribed HIV antivirals	\$55.50 (@18.50)
Other prescription drugs: <ul style="list-style-type: none"> • atorvastatin (protease-inhibitor associated cholesterol) • metoclopramide (controlling nausea) 	\$23.10 (@ maximum PBS) \$23.10 (@maximum PBS)
1 doctor's visit: long consultation, gap fee	\$12.50 (gap fee)
Non-prescription pharmaceuticals: Imodium (diarrhoea): as needs use Metamucil (diarrhoea) Analgesics (pain management) Nicotine replacement therapy (quitting smoking)	\$11.00 (retail) \$16.00 \$12.00 \$90.65/28 patches 14mg
Massage	\$60.00
Supplementation and dietary needs: Fish oil supplementation (triglyceride control, dietitian prescribed) Standard multivitamin (dietitian prescribed) Vitamin E 500 IU	\$18.00 \$13.00 \$15.00
Other expenditures: gym membership (classes for managing emerging lipodystrophy)	\$65.00
TOTAL MONTHLY COST	\$414.85

CASE STUDY 2

HIV positive woman, long-term infected, highly treatment-experienced, with unstable viral load and a declining CD4 count, working part-time, does not qualify for Commonwealth Concession Card or Health Care Card.

MEDICAL EXPENSE	COST PER MONTH
4 prescribed HIV antivirals	\$74.00 (@18.50 per script)
Other prescribed medications: <ul style="list-style-type: none"> • sulfamethoxazole (PCP prophylaxis) • metformin (treatment for type-2 diabetes, due to HIV-associated lipodystrophy) • acyclovir 	\$9.50 (@ PBS) \$15.60 (@PBS) \$23.10 (@ maximum, PBS)
2 doctor's visit: long consultation	\$25.00 (gap fees)
Non-prescription pharmaceuticals: <ul style="list-style-type: none"> • Clotrimazole (treatment of chronic thrush) • Claratyne (management of recurrent sinusitis) • Analgesic relief for menstrual cramps • Imodium (diarrhoea): daily 	\$30.00 per month (3 courses) \$21.05/pack 40 \$6.95 \$30.00
Supplementation and dietary needs Multivitamin supplementation (Swiss Women's) Sustagen powder prescribed, 1 kg tin per week for weight gain Psyllium husks dietary fibre	\$13.00 \$94.00 (@23.50 ea) \$5.00
TOTAL MONTHLY COST	\$347.20

CASE STUDY 3

A person with HIV, not currently experiencing major HIV-related illness, but unable to work full-time due to mental health issues, and major long-term side effects of treatment (severe neuropathy; severe neutropenia; extensive lipoatrophy and wasting).

MEDICAL EXPENSE	COST PER MONTH
3 prescribed antiretroviral drugs	\$55.50
2 visits to doctor	\$25 (2 x \$12.50 gap fee)
Other prescribed drugs: SSRI (depression) Metoclopramide (nausea) Panadeine Forte (pain control for neuropathy) Filgrastim (treating neutropenia: Section 100)	\$23.10 \$9.00 (PBS plus premium) \$9.00 (@ PBS) —
Supplementation and diet needs Ensure Plus, 2 x 250ml tetrapak per day Multivitamin CoEnzyme Q10 (mitochondrial damage)	\$108.00 (@ \$.180/pack) \$13.00 \$27.00
Other health costs: Acupuncture for pain management	\$100.00
TOTAL MONTHLY COST	\$369 .60

CASE STUDY 4

**HIV positive person, unable to work due to serious HIV illness,
receiving Disability Support Pension.**

MEDICAL EXPENSE	COST PER MONTH
5 prescribed antiretroviral drugs	\$18.50 (@ \$3.70)
2 visits to doctor	Bulk billed
Other prescription drugs: <ul style="list-style-type: none">• Bactrim• Clarithromycin for MAC• Panadeine Forte• Nausea drugs• Fluconazole	\$18.50 (@ \$3.70)
Non-prescription pharmaceuticals: <ul style="list-style-type: none">• Dermatologically approved dry skin products (wash; moisturiser; shower oils)	\$35.00
TOTAL MONTHLY COST	\$72.00

2: THE PROPOSED LEGISLATION AND CHANGES TO MEDICARE ARRANGEMENTS

Many people with HIV have reacted to proposed changes to Medicare bulk billing arrangements with alarm and trepidation.

These changes would be most likely to affect those people with HIV who currently struggle to meet their health care needs, and those of their families and dependents, on already limited incomes, but who do not have or qualify for a Commonwealth Pensioner Concession or Health Care Card.

The effect of any increase in the costs associated with primary health care can be magnified in people with HIV, because of the exceptionally high number of expensive medications required for its routine management, and the extensive number of medications which can be needed for symptomatic illness. The situation is further compounded because of the chronic nature of HIV, and the need for regular monitoring and treatment adjustment. HIV positive people need disproportionate access to medical services. People with complicated situations, such as hepatitis C co-infection, may also have a particularly high need for health care services, medications, and complementary therapies.

2.1 The General Practice Access Scheme (GPAS)

NAPWA welcomes and endorses moves to preserve and support bulk-billing for patients with health-care cards.

The decline in bulk-billing rates more generally has affected HIV positive people already, in that many general practitioners who treat a high caseload of HIV positive people have now ceased bulk-billing for all

patients. NAPWA now has a number of notifications of positive people switching from doctors after years of long-term care, to see practitioners who do bulk-bill, because they simply cannot afford the gap fee. It may be particularly difficult for people whose week-to-week cash income is limited, with fixed expenditures to be met, to meet this gap fee, particularly if it increases continuously.

However, changes in bulk-billing arrangement will also substantively affects people who have low or medium incomes, but who have high numbers of visits to their GPs, as can happen periodically in the course of HIV illness – for example, when people start or change treatments; when people need close monitoring for toxicity; for pregnant women or women planning pregnancy; for people who have other cyclical or chronic health conditions.

NAPWA is deeply concerned that the General Practice Access Scheme is a voluntary scheme. It would be our concern that large numbers of doctors may choose not to participate in the scheme. The Australian Medical Association has already expressed doubts that the GPAS will be sufficiently attractive to large enough numbers of doctors to stem the flow away from bulk billing. A low uptake would have particularly worrying consequences for consumer choice and access to health care, particularly in rural or regional areas, or other areas where access to health care is already geographically or otherwise limited.

In particular, a low registration for the GPAS could have dramatic consequences for HIV positive health care card holders in situations where a sole local GPAS provider may NOT be able to prescribe Section 100 drugs, that is, the HIV antivirals. In rural, regional and remote areas, access to general practitioners able to prescribe HIV antivirals is already extremely limited. For example, there is only one general practitioner in

the entire state of Tasmania who can prescribe Section 100 HIV antivirals. This is a situation repeatedly found in other areas of rural and regional Australia. It would be an unacceptable situation that the right of HIV positive people, as of all people, to exercise their choice as consumers of health care was to be further limited.

A low or inequitably distributed uptake of the GPAS will also affect those positive people on low incomes. The reality is that low-income earners may have access to only limited amounts of available cash. Faced with a gap fee, people in this situation may choose to delay or curtail necessary or urgent visits to their doctors.

Should it not find widespread favour with GPs, the General Practice Access Scheme is likely to result in inequitable access to the health care system, with real consumer choice being effectively limited to those areas with high populations, who are already at an advantage in terms of wider access to healthcare choices.

2.2 Burden for low income earners

Data from the *HIV Futures III* survey suggests that substantial numbers of HIV positive people have an income significantly below the Australian mean. NAPWA is concerned that the current proposal, while acknowledging the particular needs of Commonwealth Pension and Concessional Health Care Cards, risks exposing low-income earners to potentially unregulated doctors' fees. We recognise that under the current system, fees are technically uncapped and unregulated. In practice, however, the scheduled fee and bulk billing rebate have largely operated as a de facto 'floor price', discouraging significantly higher fees being widely charged. However, we believe the current proposals could see widespread increases in doctors' fees for two reasons:

- 1) By providing a further 'signal' that the government has limited its commitment to universal and accessible health care as a core principal through the Medicare system
- 2) An electronic card-swiping system would replace the old claims system, meaning that the Medicare rebate proportion of the fee will not be charged and then reimbursed later, as is the current system. Whilst this is likely to be extremely convenient for patients with ongoing cash-flow problems, it has been suggested it may also make it 'psychologically' more palatable for doctors to charge higher consultation fees.

Low to middle income earners are a group which already shoulders a substantive burden of the cost of Medicare, paying not only through the tax system, but also often paying out to meet rising private health insurance premiums, and with many already paying gap fees where bulk-billing is not offered. The Australian Council of Social Services points out that the \$2.2 billion private health insurance rebate scheme has not eased the pressure on the public health system, despite the projections and hopes for the scheme – and noting that at least half of the rebate this year will go to the 20 percent of Australians in the highest-income earning tax bracket.

In particular, these changes are likely to induce real financial stresses for those families where one or both parents may be HIV positive, and one or more of the children may also be HIV positive. Families in these situations are already struggling to meet basic health care needs. We believe these families must be protected from the potential for higher fees for routine doctors' visits, or changes which may potentially further curtail their choices in terms of access to doctors. Indeed, it is often families where one or more members are affected by HIV who may be less likely than, for example, HIV positive gay men, to live close to a range of high-quality HIV-experienced services.

NAPWA believes the proposed changes to the Medicare arrangements would risk further isolating this already isolated group of health consumers.

2.3 Compromising best-practice HIV clinical management

Best practice in HIV medicine suggests that regular monitoring, discussion with and contact with a General Practitioner is the cornerstone of appropriate clinical management of HIV infection. Effective monitoring and appropriate testing can lead to the much more effective and appropriate use of the high-cost Section 100 antiviral treatments. Regular monitoring may also identify changes in a person's clinical situation (declining CD4 counts; rising viral loads), which would suggest that a person could be at potential risk of developing an opportunistic infection or condition, and even requiring hospitalisation. Acute care in a hospital, including treatment with Section 100 medications, represents a high cost to both the individual, and to the community.

It is therefore counter-intuitive to introduce changes to current arrangements for health care delivery which could militate against the messages stressed about best practice clinical care.

For many people with HIV, there will be times where clinical best practice will dictate a much higher level of engagement with health services than is usual. People starting or changing their antiviral drugs, experiencing symptomatic illness for the first time, who are pregnant, who have been diagnosed late in infection, who have other co-infections such as hepatitis, or who are experiencing major mental health issues are among those likely to have an increased number of GP visits. The Medicare system must offer protection to these people. Already, anecdotal evidence suggests that in some cases, low income earners may postpone visiting their doctor, particularly if they are experiencing a 'cash-flow' crisis (for example, waiting to be paid).

In addition, certain aspects of HIV management require prompt, professional recognition of emerging symptoms, or signs of acute problems such as an acute opportunistic infection, or an acute onset of reaction to an antiviral treatment or other drug.

Allergic reaction to the antiviral drug abacavir, for example, occurs in about 4 percent of people who take it.⁹ Abacavir hypersensitivity, left undiagnosed, can quickly and rapidly represent a major health crisis, and can be in some circumstances fatal. It is vital that early symptoms and signs of acute abacavir hypersensitivity are recognised and managed, by immediate cessation of drug, and administration of any necessary emergency treatments. However, in its earliest phases, abacavir hypersensitivity may show up only with non-specific signs, such as tiredness or headache. Prescribing information about the management of abacavir stresses that the patient sees their GP immediately, even if these signs seem non-specific.¹⁰

NAPWA opposes any changes to Medicare arrangements which would increase the likelihood that low-income earners may decide, under such circumstances, not to visit their GP, due to the potential cost of such a visit. We urge the Senate to recognise that these proposed changes have the potential to work counter to best practice principals of preventative medicine and clinical management.

Another area of in which we believe the changes to Medicare arrangements are likely to compromise best-practice clinical management is in terms of side effects experienced by people using HIV antiviral treatments.

Some long-term side effects of HIV can be insidious in their onset and presentation. However, studies have identified that, for gay men in their 40s

⁹ Abacavir prescribing information, MIMS, 1 November, 2002.

¹⁰ *ibid*

and 50s, long-term use of protease inhibitors may increase cholesterol and triglycerides, putting this group in a higher risk category for heart disease.¹¹

Managing this problem may require a higher than usual amount of contact with a primary health provider, and increased ongoing vigilance. In addition, the range of medicines which may be required, as well as any other recommendations such as supplements prescribed by a dietitian, might substantially add to financial burden for HIV positive people.

Again, we stress that these changes have the potential to reduce the number of times people on low incomes in particular, may access their primary health care provider. This may increase peoples' risk of developing ongoing major health problems as a result of HIV treatment.

2.4 Implications for co-ordinated care

HIV clinical management has come to justifiably place great emphasis on the value of a co-ordinated approach to clinical care. The problems of HIV clinical management may give rise to the need for positive people to access a broad range of services and expertise which cannot solely be provided by a single General Practitioner.

This range includes:

- referral to specialist services (e.g. HIV immunology);
- referral to other specialist services for management of complicated side effects (e.g. endocrinology; cardiovascular);
- specialist management of major complicating co-infections or conditions (hepatitis C, HIV-related cancers);
- counselling or support around drug and alcohol issues;
- specialist management of pregnancy for HIV positive women;

¹¹ Friis-Moller N et al. Exposure to HAART is associated with an increased risk of myocardial infarction: The DAD study. Tenth Conference on Retroviruses and Opportunistic Infections, Boston, abstract 130, 2003.

- pain management;
- palliative care;
- counselling, psychotherapy or psychiatric support for HIV-related psychosocial problems or psychiatric problems.

While most people with HIV receive basic primary care in general practice, it is unrealistic to expect that any GP, no matter how experienced in HIV clinical care, can provide the full repertoire of expertise to deal with complex and complicated issues in HIV.

For this reason, HIV practitioners, allied health care workers, and the affected community, have stressed the clinical value of co-ordinated approaches to care, where case management is shared across those medical disciplines, and other areas of health care which reflect the breadth of individual patients' needs. Unlike many medical conditions, there is no single 'blueprint' for managing HIV.

This has been the theory underpinning the Enhanced Care Project running in New South Wales. In the Enhanced Care model, project officers are attached to high-caseload, busy general practices, to help develop Care Plans for patients with complex needs, and ensure these patients are fed back into the range of additional medical, allied health or support services which reflect their extra-clinical needs.

The Enhanced Care project was developed in recognition of the fact that so-called 'secondary' health issues actually have a direct link to clinical outcomes (e.g. compliance to HIV medications; safe sex; side effect management; the ability to return to the workforce; management of complicated co-infections; management of drug and alcohol problems).

By necessity, the Enhanced Care model encourages a targeted approach to health care, but for some people, may result in recommendations which are likely to increase their need to access various parts of the health care system. For example, people may be referred into allied health care services, such as acupuncture for pain management, or use of a dietitian, which may greatly improve health outcomes, but which may temporarily necessitate greater personal costs in meeting health care needs. Added to proposed increases in PBS co-payments, for example, and to potentially increased or unregulated gap fees, the cost of dietary supplements for weight-gain or cholesterol management, or alternative approaches to pain management such as acupuncture or physical therapies, may become simply unaffordable, and the patient may have to 'choose' between one or another aspect of his or her overall care strategy.

These proposed changes to Medicare are at odds with this over-arching philosophy of health care, and NAPWA urges the Senate to recognise the long-term gains to the health care system which can be achieved by enhancing primary health care.

2.5 Private health insurance

NAPWA agrees that private health insurance is an important element of a robust healthcare system, providing an important complement to the public system. However, private health insurance cannot in our view be seen as a way of remedying gaps or deficiencies in the universal provision of public health care for Australians. We point out that the following issues present some barriers to the equitable access to private health insurance for people with HIV.

- Historically, many people with HIV have assumed that exemptions under the Disability Discrimination Act in relation to the provision of life insurance to people with HIV (effectively preventing them from

purchasing it) have also applied more broadly across the insurance spectrum. On this basis, many people have assumed they are not eligible for private health cover, when in fact, they are. This is an 'information gap' which needs to be closed.

- People with HIV who have incomes greater than \$50,000 may also find themselves in a peculiar bind in a system which tends toward a greater focus on private health insurance. It is economically rational, on the one hand, to take out private health insurance, in that it reduces their tax burden. However, it is the public health system, not the private health system, which will meet the majority of their health care needs, and yet it is to the private and not the public system that their money is directed. This seems a peculiarly illogical situation, in that it is a perverse incentive for better-off HIV positive people to fund a system which does not meet their needs, arguably at the expense of the public system, which does.
- To take out private health insurance, a person with HIV may need to disclose their status or have their health investigated should a claim be made in the first 12 months. Insurers may reserve the right not to pay cover in the first 12 months for people with pre-existing illnesses or conditions. Fear of discrimination as a result of disclosure remains a real concern and issue for many people with HIV. According to the *HIV Futures III Survey*, 22 percent of all respondents indicated they had received less favourable treatment in relation to insurance in general, 15 percent of these cases occurring in the last two years.¹²

In addition, for many people with HIV, private health insurance represents an expense which they are simply unable to afford. 70 percent of those surveyed for *HIV Futures III* did not have private health insurance.¹³

¹² Grierson et. al. op. cit. p. 111.

¹³ Ibid. p. 111.

NAPWA submits that arrangements to improve access to private health insurance, while welcome, are not a substitute for a well-funded public health care system, including and especially, measures to increase rates of bulk-billing not just to protect the needs of those with Pensioner Concession or Health Care Cards, but those living with long-term chronic illness on low incomes.

2.6 Disincentives to return to the workforce

With often greatly improved health prognoses, many people with HIV are now looking to return full or part time to the workforce. Many HIV positive people have been out of the workforce for some years, and returning to work presents a unique set of challenges.

In addition, the sometimes cyclical or fluctuating nature of HIV-related illness can militate against immediate return to highly-paid, demanding full-time positions, particularly for people who have been seriously unwell or who have not worked for long periods of time. However, it is in their best clinical interests, and greatly in the interests of the nation, that they do re-join the workforce.

For many of these people, a part-time or low-paid position would represent an income which nonetheless means they would no longer be entitled to a Health Care Card or Pensioner Concession Card. This group of people would now be faced with meeting a fairly substantive health care burden, including increased co-payments, and potentially much more limited access to bulk billing.

NAPWA believes that the changes proposed to the Medicare arrangements could have the real effect of forcing people to remain on Disability Support, rather than return to work, and have a significant proportion of income lost to

increased health care costs. They represent a disincentive, in some cases, to consider or re-enter the workforce. This is in the interests of neither the HIV positive individual, nor the government.

SUMMARY

NAPWA submits that:

- the appropriate national public health policies depend on a commitment to a universally accessible, well-funded public health care system;
- this should be funded principally through the taxation system;
- people with HIV, particularly those on low incomes and with families, are likely to be adversely affected by proposed legislative changes to bulk-billing arrangements;
- people with a high need for health care services, prescription drugs, and allied health care are likely to be adversely affected by these proposed changes;
- this could compromise access to appropriate clinical and allied health care for people with HIV;
- HIV positive people in rural and regional Australia may find their health care options limited if there is no local Section 100 Prescriber who is also a participant in the voluntary General Practice Access Scheme;
- fear of shouldering an increased health care cost burden on a low or limited income may present a powerful disincentive for some HIV positive people to return to work;
- that private health insurance should be seen as an adjunct to, not a substitute for, a viable, appropriately funded health care system
- rebates for consultations to doctors should be increased to the level appropriate to reflect the real costs of providing clinical care.