

HIV Populations in Australia:

Implications for access to services and delivery

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Key points

- The HIV-positive population in Australia is growing. People living with HIV (PLHIV) are surviving longer and getting older on average.
- There is an increased emphasis on managing side effects and long-term toxicity, as well as co-morbidities related to ageing. The mental health demands of PLHIV are also emerging as significant.
- Among PLHIV, there are three main categories relevant to medical service demands: those not on antiretrovirals, those who are stable on treatment, and those with complex treatment demands.
- The majority of PLHIV who are relatively stable on treatment are accessing antiretroviral therapy through HIV GPs or HIV specialists. Meanwhile, the small group with complex treatment demands require specialist care (provided mostly by HIV specialists) and occasional acute inpatient or ambulatory care.
- Difficulty in accessing prescriptions for antiretroviral and other drugs varied according to the number of pick-up points, and across 'area type' – capital city/inner suburban, outer suburban, regional centre, and rural.
- Who PLHIV access for HIV-related management as opposed to general healthcare varied across states and territories, and across 'area type'.
- Other service demands of PLHIV are significant – and services are accessed through both HIV community organisations and other organisations/services.
- Looking at service access and delivery requires a particular approach to characterisation of key sub-populations – as the focus is not simply on analysing populations at risk but on the nature and shape of specific interactions and interventions.
- Key sub-populations are identified as:
 - long-term positive (mostly gay and homosexually-active men)
 - newly positive (mostly gay and homosexually-active men)
 - late presenters (particularly from culturally and linguistically diverse backgrounds)
- General patterns can be drawn out in how underlying health, social, cultural and economic issues inter-relate with service demands in these sub-populations.
- Two important emerging issues are potential changes in the patterns of geographic location of the HIV-positive population, and changes in how and what type/style of services are accessed or wanted.
- The key issue remains tailoring medical and other service delivery to individuals. This will require a balance between expanding access to mainstream services, and developing or supporting the capacity of HIV-specific services in particular areas.
- Further research is required in relation to emerging trends and projections in the HIV-positive population, and the implications for service planning and delivery.

Introduction

The HIV response in Australia is now close to 30 years old. In this context, it is timely to take stock of the current situation for people living with HIV in Australia, in order to best target, and consider models for, service delivery. This requires looking not only at the current and future healthcare demands of PLHIV, but as Grierson, et al, write: 'appreciating the range of ways in which HIV has an impact on people's lives allows a more considered approach to the building and maintenance of services.' (Grierson et al 2006: xv)

This report aims to focus on the following:

- outlining key trends in the HIV-positive population
- summarising treatment, healthcare and other service demands
- analysing and assessing sub-populations
- applying this analysis in relation to access to services and current/future demands in service delivery
- making comment on future directions for research and analysis that are suggested by undertaking this work

The report contains a new analysis of data from HIV Futures 5 – the fifth in a series of anonymous cross-sectional surveys of samples of people living with HIV/AIDS in Australia.¹ The Positive Health, Straightpoz and Health in Men studies were also utilised, as were reports on epidemiological and behavioural surveillance from the National Centre in HIV Epidemiology and Clinical Research and National Centre in HIV Social Research.

Key trends

At the end of 2007, the estimated number of people living with HIV (PLHIV) in Australia was 16,692. While the rate of new HIV infections was declining prior to 1999, it has increased each year since then, predominantly amongst men who have sex with men. Meanwhile, the number of AIDS diagnoses has remained steady. (NCHECR 2008: 7 and 10)

The following sections summarise and outline the key trends in the HIV positive population in Australia.

Ageing

The increasing availability and effectiveness of combination antiretroviral therapy (cART) has had a major impact on the health of those infected with HIV – in relation to disease progression and health maintenance. The median survival period among people diagnosed with AIDS increased from 19 months prior to 1998 to 69 months in 2002. (NCHECR 2008: 28) The HIV-positive population in Australia is surviving longer and getting older on average. The ageing of the HIV positive population is also related to age at HIV infection.

¹ HIV Futures 5 was completed by 982 positive people. This sample is approximately 6.4% of the estimated HIV positive population, and is broadly representative of the demographics of this population.

The median age of men at AIDS diagnosis increased from 37 prior to 1999 to 44 in 2007, and from 33 to 43 in women. (NCHECR 2008: 35) In Futures 5, on average HIV-positive women were five years older than in the previous study in 2003 – with an average of 45 years. (Grierson et al 2007: 23) The median age of new diagnoses increased amongst men from 31 in 1998 to 35 in 2002, and from 19 to 37 amongst women. (NCHECR 2008: 46)

As Dr Darren Russell from Cairns Sexual Health Service points out: ‘an increase in incidence (new infections), coupled with better treatments, means that the total population is increasing. This has real impacts on services.’ (interview December 5, 2008)²

Complications, co-infections and co-morbidities

The increasing availability of antiretroviral drugs (now at least 20 drugs in five classes) and the simplification of treatment regimens have had a significant impact. However, managing side effects and long-term toxicity are ongoing and important concerns. With long-term treatment increasing, there is also more attention being paid to co-morbidities related to ageing.

While there is some uncertainty about the relative contribution of HIV disease or antiretroviral therapy to morbidity, increased rates of hyperlipidaemia, heart disease, diabetes and bone disease are seen in HIV-infected individuals. There are also increased rates of diseases often associated with ageing, including arthritis and dementia. Other significant co-morbidities are related to malignancies and liver disease. Darren Russell from the Cairns Sexual Health Service predicts that two important growing areas of healthcare demand for HIV are ‘chronic health conditions and non-AIDS serious events – cardiac, renal, hepatic, smoking-related – as well as co-infection with hepatitis B and C – for treatment, monitoring, transplant.’ (interview December 5, 2008)

Significant numbers of people living with HIV also report viral hepatitis infection. Over one quarter had at some point had hepatitis A, and nearly one quarter had at some point been diagnosed with hepatitis B. The estimated prevalence of hepatitis C amongst respondents was 11.3%. (Grierson et al 2006: 6-7) Younger PLHIV were more likely than older to have had hepatitis C, whereas older PLHIV were more likely to have had hepatitis A or B. (Pitts et al 2005: 463)

Geographic location

Some differences are emerging between states and territories, with NSW having a relatively stable rate of new HIV infections between 2003-2007, while other states recorded increases, particularly Queensland and Victoria. While Victoria recorded a stable population in 2006-2007, it has seen steady increases since 1999. (NCHECR 2008: 7)

² A small number of semi-structured interviews were conducted with key stakeholders from the healthcare and community sectors related to HIV in order to draw out key themes to assist in data analysis.

In Futures 5, the state/territory location of respondents was collected³, along with 'area type' – capital city/inner suburban, outer suburban, regional centre, and rural. The majority of HIV positive people in Australia live in capital cities and inner suburban areas. However, significant percentages of respondents live in regional centres – particularly in Queensland (34.9%) and NSW (19.9%). The outer suburbs of major cities are also important – with up to 20% of respondents living in these areas across the states and territories. (See Table 1)

Table 1: Response rate for each state/territory by area type

Area type	State/territory (percent)								Total
	ACT (n=17)	NSW (n=478)	VIC (n=218)	QLD (n=129)	SA (n=45)	WA (n=55)	TAS (n=9)	NT (n=5)	
Capital city/inner suburban	88.2	61.2	76.3	36.4	73.3	78.2	66.7	100	63.6
Outer suburban	11.8	7.5	11.6	19.4	15.6	12.7	0	0	10.7
Regional centre	0	19.9	7.0	34.9	4.4	3.6	0	0	16.7
Rural	0	11.3	5.1	9.3	6.7	5.5	33.3	0	9.0

The centralised location of populations of gay and homosexually-active men (particularly in Sydney) has assisted in service access and delivery. However, there has been an increasing focus in the HIV sector on service delivery for those living in rural/regional areas, and for populations which are more geographically dispersed – e.g. Aboriginal and Torres Strait Islander (ATSI) people, culturally and linguistically diverse populations, and positive heterosexual men and women. ATSI people in particular are more likely to live in non-metropolitan areas; 54% live in rural or remote areas, compared with 20% of the Australian population in general. (Commonwealth of Australia 2005: 7) Other specific challenges have arisen in relation to particular geographic areas – e.g. concerns about infections related to travel between Papua New Guinea and the Torres Strait islands and Cape York.

Important emerging questions relate to how the ageing of the HIV-positive population, and other economic and social trends, are influencing the location of the population, and therefore service demands.

Mental health

The mental health demands of PLHIV are increasingly significant. The prevalence of depression amongst HIV-infected individuals is generally higher than in un-infected. Major risk factors include an AIDS-defining illness, older age and social isolation. Mania, hypomania and psychosis also occur more frequently. (Workman 2004: 239-240) In Futures 5:

- 43% reported having been diagnosed with a mental health condition, predominantly depression and anxiety
- 28.5% reported having taken medicines prescribed for depression in the last six months
- 25.7% reported taking medication for anxiety in the past six months
- 4.6% reported taking anti-psychotic medication. (Grierson et al 2006: 9-10)

³ The largest number of responses was from NSW (473) followed by Victoria (204). The response rates from the ACT, Tasmania and the Northern Territory were too small to conduct any meaningful analysis (all n<30).

Almost 20% of HIV-positive men included in the Positive Health study had consistently sought mental health services in the previous 12 months, and another 45% had sought some medical treatment or counselling for mental health problems. (Fogarty, et al, 2006: 12) The National Association of People Living with HIV/AIDS (NAPWA) argues that as PLHIV live longer with HIV and treatments, anxiety about resistance and the long-term effects is increasing. (2007: 18) Rob Lake from Positive Life NSW raises concerns about possible rates of suicide – ‘who knows what we would find if we looked back at AIDS deaths’. (interview December 3, 2008)

In addition, coping with neurological conditions, particularly AIDS dementia complex, presents challenges for PLHIV. Jo Watson, Executive Director of NAPWA, says:

It's becoming clear that case management in the future is going to have to include assessment of neuro-cognitive issues. It's not necessarily AIDS dementia, depression or anxiety, but can be about mild deficits and tracking these to see if they change. It's hard to tell what is drug-related, what is the disease, what are just normal processes of stress and ageing, and clinicians aren't well set-up to deal with this right now. (interview, December 2, 2008)

In Futures 5, 48% of respondents reported confusion/memory loss in the preceding 12 month period. (Grierson et al 2006: 5)

Summary of service demands

HIV treatment demands

The number of PLHIV on cART nationally is estimated to have increased from 5757 in 2000 to 9463 in 2006. (Falster et al 2008: 144) Other estimates put the current total at 9933, up from 7173 in 2007. (NCHECR 2008: 32) In Futures 5, 85.2% of respondents had used antiretrovirals at some point, and 75.5% were currently on treatment. (Grierson et al 2006: 16)

Between 1999 and 2006, the proportion of patients with an undetectable viral load – a sign of successful treatment – increased in NSW from 67% to 87%, in Victoria from 39% to 88% and in Queensland from 51% to 90%. (Falster et al 2008: 144) In the Positive Health study conducted between 2002-2005, the percentage of HIV-positive men who reported an undetectable viral load rose from almost 60% to over 70%. Only a minority (12%) reported having a detectable viral load at every interview. Maintenance of CD4 cells is a sign of immune system preservation. While CD4 counts decreased over time, there was also a decrease in clinically low CD4 counts, and a greater proportion maintained stable or high counts. (Fogarty, et al, 2006: 14 and 30)

Despite the overall success of antiretroviral therapy, the health demands of PLHIV are still significant. In Futures 5, 44% rated their health as good and 24.1% as excellent, compared with the Australian population norm of 86.6% rating their health as good, very good or excellent. In addition, 31.9% rated their health as fair or poor. (Grierson et al 2006: 3)

Around a fifth of respondents reported being diagnosed with an AIDS-defining illness at some point, with 14.3% having been diagnosed in the last one or two years. Almost 30% of respondents indicated having experienced an HIV-related illness at some point. In addition, large numbers reported experiencing conditions commonly associated with HIV infection in the last 12 months (e.g. low energy/fatigue – 91.8%, diarrhoea – 66.6%, sleep disorder – 65.8%, nausea or vomiting 48.1%). (Grierson et al 2006: 5) These conditions are also related to the side effects of cART – which were reported by 29.7% of those on treatment, and were the most common reason for switching drug regimens. (Grierson et al 2006: 18 and 20)

Because of the success of treatment, patients are remaining on at least three drugs for longer periods. In Futures 5, 50.3% of those taking cART had been on treatment for at least seven years. (Grierson et al 2006: 19) This has increased attention on the short- and long-term toxicity of antiretroviral drugs – leading to recommendations to delay treatment until CD4 cells fall below 350 cells/ μ L in asymptomatic patients and to simplify effective regimens. (Pierce, 2004: 59) Resistance in long-term treatment is also an increasing concern. Respondents in Futures 5 had used between one and 26 combinations of drugs, with the median being three.

Darren Russell from Cairns Sexual Health Service points out that treatment in general has been simplified, but that other complexities are emerging: 'the plethora of treatments makes treatment decisions more difficult for doctor and patient. The decision to start treatment is still a difficult one, and the question of *when* to start treatment remains controversial.' (interview December 5, 2008)

Accessing prescriptions

In terms of cART, respondents in Futures 5 nominated multiple points at which they accessed prescriptions: 43.8% of respondents through GPs as part of the s100 prescribing scheme⁴, 36.9% through an HIV specialist in an outpatient clinic, 21.8% through a doctor at a sexual health clinic, 4.5% from an HIV specialist as an inpatient, and only 2% from another GP. 17.5% of respondents had accessed treatment through a clinical trial in the last two years. (Grierson, et al, 2006: 29) (See Table 2)

Table 2: Person who prescribes antiretroviral drugs (multiple responses)

Who prescribes drugs	n	%	% of total cases
HIV GP/s100 prescriber	336	40.0	46.3
Other GP	15	1.8	2.1
Outpatient clinic HIV specialist	269	32.0	37.1
Inpatient HIV specialist	32	3.8	4.4
Doctor at sexual health centre	155	18.4	21.4
Somebody else	28	3.3	3.9
Other doctor	6	0.7	0.8

Overall, respondents were most likely to be prescribed antiretroviral drugs by their HIV GP/s100 prescriber or by a doctor at an outpatient clinic. When we examine the proportion of respondents within each 'area type' that nominate each prescriber category, 'doctor at a sexual health clinic' nominated by only 14% of those in inner city locations, around 30% for those in outer suburban areas and regional centres and by 43% of those in rural areas. Also, prescription by HIV GP/S100 Prescriber varies, with 50% of those in the inner city nominating this source, 36% in outer suburban areas, 40% in regional centres and 43% in rural areas. (See Table 3)

Table 3: Percentage of respondents within each area type nominating specific cART prescribers (multiple prescriber responses permitted)

Who prescribes drugs	Area (%)			
	Capital city/inner suburban	Outer suburban	Regional centre	Rural
HIV GP/s100 prescriber (n=333)	50.2	36.3	40.3	43.3
Other GP (n=15)	2.7	2.5	0.8	0
Outpatient clinic HIV specialist (n=266)	37.4	38.8	37.0	32.8
Inpatient HIV specialist (n=32)	4.2	5.0	5.9	3.0
Doctor at sexual health centre (n=152)	13.5	30.0	31.9	43.3
Somebody else (n=28)	4.2	6.3	2.5	1.5
Other GP (n=15)	2.7	2.5	0.8	0
Other doctor (n=6)	1.3	0	0	0

⁴ As part of this scheme, GPs complete training to achieve accreditation to prescribe antiretroviral drugs in the community.

Respondents from Western Australia and Queensland were the least likely to receive their prescriptions from an HIV GP/s100 prescriber. In WA, respondents were most likely to receive their prescriptions from an outpatient clinic (75%). In Queensland, respondents were most likely to receive their prescriptions from either an outpatient clinic or a sexual health centre. No respondents from WA stated that they were prescribed drugs at a sexual health centre.⁵ (See Table 4)

Table 4: Percentage of respondents within each state/territory nominating specific cART prescribers (multiple prescriber responses permitted)

Who prescribes drugs	State/territory (%)						
	ACT	NSW	VIC	QLD	SA	WA	TAS
HIV GP/s100 prescriber (n=329)	53.8	48.6	52.6	32.3	61.8	20.5	42.9
Other GP (n=15)	0	1.9	3.2	0	5.9	2.3	0
Outpatient clinic HIV specialist (n=265)	30.8	37.4	26.6	38.5	29.4	75.0	57.1
Inpatient HIV specialist (n=32)	0	4.7	3.9	3.1	14.7	2.3	0
Doctor at sexual health centre (n=152)	23.1	19.0	29.2	34.4	5.9	0	0
Somebody else prescribes drugs (n=28)	0	4.4	1.9	3.1	2.9	11.4	0
Other doctor (n=6)	0	0.3	2.6	1.0	0	0	0

Medical service demands

Demand for medical services among PLHIV now varies across particular groups. There are three main categories which are relevant to medical service demands:

- those not on antiretrovirals: in Futures 5, 24.5% were not on treatment (although of these nearly 40% had been in the past)
- those who are stable on treatment: 66.5% had used only one combination of cART in the last year and 21.2% had used two
- those with complex treatment demands: although difficult to quantify, 2.8% of respondents felt that they had only one treatment option left, while 3.4% thought they had none. These respondents had tested positive on average in 1989. (Grierson, et al, 2006: 20-22)

Demand also varies over time within these groups. Those not yet requiring treatment or those stable on treatment require regular monitoring, with episodic service demands related to illness, toxicity or treatment failure. The majority of PLHIV who are relatively stable on treatment are accessing cART through HIV GPs or HIV specialists. Meanwhile, the small group with complex treatment demands require specialist care (provided mostly by HIV specialists) and occasional acute inpatient or ambulatory care.

⁵ Trish Langdon from the WA AIDS Council points out that there is no stand-alone sexual health service in Perth. While treatment needs are met elsewhere, she argues that this creates a gap in terms of addressing sexual health needs in an integrated way, particularly for homosexual men. (interview January 14, 2009)

HIV-related management vs. general healthcare

HIV GPs were nominated as the key physician for most respondents in management of their HIV (43.2%) and also for general medical treatment (46.7%). HIV specialists were the primary provider for 32.8% in relation to HIV management, but only 13.8% in relation to general health care. Other GPs were utilised by 25.1% for general treatment, but only 4.4% for HIV management. (Grierson, et al, 2006: 32)

There is some variation in who is accessed for HIV-related management and general healthcare across states and territories.

Excluding the Northern Territory (which had a very low response rate), respondents in Futures 5 from Queensland and WA were less likely than those from other states to see an HIV GP or s100 prescriber for HIV-related treatment. Queenslanders were more likely to see a doctor at a sexual health clinic than respondents from other states. West Australians were more likely to visit an outpatient HIV specialist than respondents from any other states ($p < 0.001$). (See Table 5)

Excluding the Northern Territory, respondents in Futures 5 from Queensland and WA were less likely to visit their HIV GP or s100 provider for general medical care than respondents from other states and the ACT. Over 50% of respondents in the ACT, NSW, Victoria and South Australia indicated that they would visit their HIV GP or s100 provider for general medical care. In Queensland, respondents were more likely to seek general medical care from another GP or a doctor at a sexual health service. (See Table 6)

Table 5: Use of HIV-related medical services by state/territory

Physician used for HIV-related treatment	State/territory (%)								Total
	ACT	NSW	VIC	QLD	SA	WA	TAS	NT	
HIV GP/s100 prescriber (n=392)	57.1	48.9	46.5	30.0	55.0	28.8	37.5	20.0	44.7
Other GP (n=34)	0	3.9	5.0	3.3	5.0	1.9	0	0	3.9
Outpatient HIV specialist (n=281)	28.6	29.7	27.0	35.8	30.0	63.5	50.0	20.0	32.0
Inpatient HIV specialist (n=4)	0	0.5	0.5	0	0	0	12.5	0	0.5
Doctor at sexual health centre (n=147)	14.3	14.8	19.5	29.2	5.0	1.9	0	60.0	16.8
Other doctor (n=3)	0	0	1.0	0.8	0	0	0	0	0.3
Other (n=16)	0	2.3	0.5	0.8	5.0	3.8	0	0	1.8

$\chi^2 (42) = 103.958, p < 0.001$

Table 6: Use of services for general medical treatment (not HIV) by state/territory

Physician used for general medical treatment	State/territory (%)								
	ACT	NSW	VIC	QLD	SA	WA	TAS	NT	Total
HIV GP/s100 prescriber (n=412)	60.0	50.1	53.1	31.0	53.7	36.0	50.0	20.0	47.6
Other GP (n=210)	13.3	24.9	19.6	31.9	22.0	24.0	37.5	0	24.2
Outpatient HIV specialist (n=122)	13.3	13.0	10.8	13.8	19.5	32.0	12.5	20.0	14.1
Inpatient HIV specialist (n=2)	0	0.5	0	0	0	0	0	0	0.2
Doctor at sexual health centre (n=90)	6.7	8.9	12.9	18.1	2.4	0	0	60.0	10.4
Other doctor (n=16)	6.7	0.9	2.6	4.3	0	2.0	0	0	1.8
Other (n=14)	0	1.6	1.0	0.9	2.4	6.0	0	0	1.6

$\chi^2 (42) = 80.900, p < 0.001$

These differences across the states and territories seem to correlate with differences in the spread across 'area type' location, as noted above. There are other differences related to area type.

Across all area types, those in the outer suburbs were the least likely to visit an HIV GP for HIV-related medical care (27% compared with 52% for those residing in inner suburban areas). People in outer suburban, regional and rural areas were also more likely than those in the capital city/inner suburban areas to access specialist HIV care at a sexual health clinic. Those in inner suburban areas were more likely to have visited an HIV GP (66%) than an outpatient clinic (42%). People from the outer suburbs were more likely to have visited a HIV specialist at an outpatient clinic (47%) than a HIV GP (40%). (See Table 7)

- Those living in outer suburban areas were the least likely to see their HIV GP for general medical treatment (29% compared to 34% for those in rural areas). People in outer suburbs, regional centres and rural areas were more likely than those in inner suburban areas to receive general medical care at sexual health centres. (See Table 8)

Table 7: Primary physician seen for HIV-related medical services by area type

Physician used for HIV-related treatment	Area (%)				Total
	Capital city/inner suburban	Outer suburban	Regional centre	Rural	
HIV GP/s100 prescriber (n=394)	52.1	27.1	31.5	36.4	44.6
Other GP (n=34)	4.3	3.1	3.4	2.6	3.9
Outpatient HIV specialist (n=283)	30.1	43.8	31.5	32.5	32.0
Inpatient HIV specialist (n=5)	0.7	0	0.7	0	0.6
Doctor at sexual health centre (n=148)	10.3	24.0	31.5	27.3	16.8
Other doctor (n=3)	0.5	0	0	0	0.3
Other (n=16)	2.0	2.1	1.4	1.3	1.8

$\chi^2 (18) = 70.442, p < 0.001$

Table 8: Primary physician seen for general medical treatment (not HIV) by area type

Physician used for general medical treatment	Area type (%)				
	Capital city/inner suburban	Outer suburban	Regional centre	Rural	Total
HIV GP/s100 prescriber (n=415)	56.6	28.7	31.5	33.8	47.4
Other GP (n=213)	19.2	36.2	31.5	33.8	24.3
Outpatient HIV specialist (n=122)	14.5	13.8	12.3	13.0	13.9
Inpatient HIV specialist (n=2)	0	0	1.4	0.0	0.2
Doctor at sexual health centre (n=93)	6.6	17.0	19.2	15.6	10.6
Other doctor (n=16)	1.4	3.2	3.4	0.0	1.8
Other (n=14)	1.6	1.1	0.7	3.9	1.6

$\chi^2(18) = 87.751, p < 0.001$

These differences may be related to geographic accessibility of HIV GPs and specialists. However, it is also possible that people living with HIV in rural areas prefer to travel to regional centres or cities for all their medical treatment rather than see the local GP. This may be for reasons of confidentiality and/or to ensure quality of care.

Positive women are more likely to live in outer suburban areas, and women are generally less likely than men to access services through an HIV GP for both HIV treatment and general medical treatment. Over half saw different doctors. (Grierson, et al, 2007: 11) This may be due to the focus of HIV-specific services on gay men's health, concern about confidentiality and different needs in relation to reproductive health. (Thorpe, et al, 2008: 547 and 550)

In relation to ageing, a higher percentage of people over 50 see outpatient HIV specialists for general medical treatment ($p < 0.05$) and for HIV-related treatment ($p < 0.001$). While a slightly higher percentage of people 35 or under will use a doctor at a sexual health centre for general and HIV-related treatment. (Table 9 and Table 10)

Table 9: Primary physician seen for HIV-related medical services by age group

	Age (%)					Total
	<= 35	36 - 40	41 - 45	46 - 50	51+	
HIV GP/S100 prescriber (n=394)	46.6	40.3	55.1	49.7	35.4	44.7
Other GP (n=34)	1.5	5.0	5.9	4.8	2.3	3.9
Outpatient HIV specialist (n=283)	27.8	30.9	24.1	27.9	43.6	32.1
Inpatient HIV specialist (n=5)	0.8	0	0.5	0	1.2	0.6
Doctor at sexual health centre (n=146)	19.5	20.9	12.8	17.6	14.8	16.6
Other doctor (n=3)	2.3	0	0	0	0	0.3
Other (n=16)	1.5	2.9	1.6	0	2.7	1.8

Table 10: Primary physician seen for general medical treatment (not HIV) by age group

	Age (%)					Total
	<= 35	36 - 40	41 - 45	46 - 50	51+	
HIV GP/S100 prescriber (n=416)	47.0	44.9	55.2	53.3	40.6	47.7
Other GP (n=211)	25.8	26.5	21.3	20.4	26.8	24.2
Outpatient HIV specialist (n=122)	9.8	11.0	13.1	12.0	19.7	14.0
Inpatient HIV specialist (n=2)	0.8	0	0	0	0.4	0.2
Doctor at sexual health centre (n=91)	12.1	12.5	7.7	10.8	10.2	10.4
Other doctor (n=16)	3.8	1.5	1.1	2.4	1.2	1.8
Other (n=14)	0.8	3.7	1.6	1.2	1.2	1.6

Finally, in terms of specialist care of co-morbidities, the only data available relates to hepatitis C. In many cases, the primary HIV doctor remains the most common point of care for co-morbidities (e.g. 61.3% of those monitoring and managing hepatitis C). However, specialist care is also often accessed (e.g. 17.4% saw a separate hepatitis C doctor or specialist). A significant proportion (25.8%) of those co-infected with hepatitis C reported that HIV community services did not meet their needs – because of lack of understanding of hepatitis C or IDU issues, or fear of disclosure. (Grierson et al 2006: 7-8)

Gaps and barriers

Zablotska reports that HIV-positive homosexually-active men in the Positive Health study expressed a need particularly for HIV-experienced doctors, antiretroviral prescribers, dentists and hospital pharmacies. (2008: 25-26) According to NAPWA, the highest scored areas of demand amongst PLHIV in their 'audit' of service demands are GP care and hospital services (including specialist and ambulatory services and counselling). Respondents reported a lack of HIV-experience GPs and s100 prescribers as key barriers to service access, particularly in regional and rural areas. (2007: 20) Jo Watson from NAPWA notes that there is a need to consider a range of ways of providing services:

I have a lot of people saying that they are still waiting for community pharmacies to dispense their drugs rather than public hospitals, that they don't want to come in for monthly check-ups when they don't need them just to get a script, that they've left the 'gay ghetto' and don't want to travel back to access care unless the HIV specialist is required for a particular issue, and that if they need to see another specialist then why can't a GP write the referral? (interview, December 2, 2008)

In the Positive Health study, participants did not consider distance to services, confidentiality or referral mechanisms as major issues of concern, but did note availability of appointments, inadequate opening hours and costs of some services (particularly dental care) as barriers. (Zablotska 2008: 25-26)

In Futures 5, around 70% of respondents stated that they had to travel to more than one place to collect all their prescription drugs (including both antiretroviral and other drugs).

Just over 17% had to travel to three or more places. Most people stated that travel was 'not at all difficult', although 38% of those who responded to the question about difficulty stated that it was 'somewhat' or 'very difficult' for them to collect their prescriptions. This percentage increased with people's distance from the city. Approximately 50% of people living in rural areas stated that it was somewhat or very difficult for them to collect their prescriptions, compared with 33% in the inner suburbs, 43% in the outer suburbs and 46% in regional centres. (See Table 11)

Table 11: Difficulty of getting prescription by area type

	Area (%)			
	Capital city/inner suburban	Outer suburban	Regional centre	Rural
Not at all difficult (n=442)	67.0	57.5	53.8	50.0
Somewhat difficult (n=230)	29.0	35.0	37.6	43.8
Very difficult (n=38)	4.0	7.5	8.5	6.3

Respondents were asked to note the postcode of their place of residence and the postcode of the doctor they see for HIV related treatment. The distance between these two postcodes was calculated.⁶ Interestingly, the median distance travelled was higher for those living in outer suburbs than those living in regional centres. This may be because those in outer suburban areas have the option of travelling to their preferred provider, even if they are located some distance away. By comparison, those in regional areas may have less choice of provider and so travel to the nearest sexual health clinic, outpatient clinic or GP. Not surprisingly people in regional centres and rural areas had the greatest distance to travel to access their main HIV healthcare provider, with over 17% of people in regional and rural areas travelling more than 100km. Over a third of people in rural areas travelled over 50km. (See Table 12)

Table 12: Distance travelled to see main doctor for HIV treatment

	Median distance travelled (km)	Minimum (km)	Maximum (km)	% who travel more than 20km	% who travel more than 50km
Capital city/inner suburban	3.14	0*	120.12	2	<1
Outer suburban	12.46	0	90.47	29	5
Regional centre	4.71	0	1411.93	36	23
Rural	35.60	0	1324.14	62	35

*a zero distance is recorded if the respondent's doctor is located in the same postcode as their residential address

In general, high degrees of satisfaction have been found with existing services provided by HIV-experienced doctors. (Grierson et al 2006: 25) In the Straightpoz study of HIV-positive

⁶ This analysis showed that there were 14 participants who travelled more than 500kms to visit their HIV GP or ≤100 prescriber. Eight of these were from rural areas or regional centres. The remaining six lived in inner or outer suburban areas and it appeared that their doctors were located in different states or territories to their residential location. This may be due to the respondent recently moving, or having moved cities since diagnosis. These six cases were excluded from the analysis, along with one other extreme outlier.

heterosexuals and their HIV-negative partners in NSW, most participants reported satisfaction with their HIV doctor/specialist, whose advice they trusted and followed. They were much less satisfied with health professionals working outside the field of HIV, and had trouble finding a suitable GP. (Persson 2008: 28) This points to the need for capacity-building and sensitisation associated with any 'mainstreaming' of medical services for PLHIV.

Other service demands

Porcino and Leach list the main types of home-based and community-based services needed by and provided for PLHIV in Victoria as:

- home-based nursing care
- other home-based care services
- peer support and contact
- supportive counselling
- housing services
- positive health promotion
- support with prevention
- systemic advocacy
- information and referral
- community development
- social supports (2007: 25-26)

In Futures 5, respondents had used the following support services most in the last six months: PLWHA organisation (22.7%), HIV peer support officer (12.3%), and hospital social worker/counsellor (11.6%). (Grierson et al 2006: 32) In an 'audit' of service demands amongst PLHIV, NAPWA notes that after medical care, most demands were related to income support, housing and employment. PLHIV accessed services through both 'mainstream' and HIV-specific organisations. (2007: 19 and 27) Respondents in Futures 5 utilised HIV community organisations for treatments advice, social contact and financial assistance, while they tended to access other organisations for pharmacy services, transport, housing assistance, mental health and employment services. (Grierson et al 2006: 33) Older PLHIV (over 50) were less likely to make use of services than younger PLHIV, and were less likely to use services at non-HIV organisations. (Pitts et al 2005: 463) A large percentage of PLHIV also accessed complementary therapies (76.5% in the last six months), sourced most commonly from health food shops, private practice or AIDS community organisations. (Grierson et al 2006: 12) There is some variation across area type as to what services were accessed. (See Table 13)

Table 13: Percentage of respondents within each area type using specific services in the past six months (multiple service responses permitted)

	Area (%)			
	Capital city/inner suburban	Outer suburban	Regional centre	Rural
HIV GP/s100 (n=550)	65.8	39.8	44.6	52.4
Dentist (n=402)	46.3	35.9	35.0	38.1
HIV specialist in outpatient clinic (n=396)	41.7	46.6	40.8	40.5
Other GP (n=394)	37.2	45.6	50.3	53.6
Doctor at a sexual health clinic (n=228)	18.3	34.0	35.7	32.1
PLWHA organisation (n=222)	25.2	26.2	20.4	14.3
Other doctor (n=139)	15.5	14.6	14.6	9.5
Hospital social worker (n=136)	13.2	17.5	19.1	10.7
HIV peer support group (n=129)	13.0	24.3	12.7	7.1
AIDS organisation support worker (n=118)	10.8	14.6	17.2	13.1
Other (n=114)	12.7	11.7	10.2	11.9
HIV organisation clinic (n=111)	12.2	12.6	12.1	7.1
HIV peer support officer (n=108)	10.7	20.4	12.7	3.6
AIDS org social worker (n=98)	9.0	14.6	14.0	8.3
Employment agency (n=69)	7.3	5.8	7.0	9.5
HIV specialist as inpatient (n=61)	6.7	7.8	5.1	6.0
Liver specialist (n=46)	4.5	4.9	5.7	6.0
IDU organisation (n=17)	1.7	2.9	2.5	0
Hepatitis C organisation (n=15)	1.2	1.0	3.8	1.2

In Futures 5, one third of respondents identified unmet demand in relation to services – most common of these needs were peer support groups (10.7%), financial assistance (6.5%) and services for PLHIV in rural, regional and outer suburban areas (4.4%). (Grierson et al 2006: 34) In the Positive Health study of HIV-positive homosexually-active men, less than half expressed a need for other community-based or social services. Of those who did, the most common were income support, access to peer groups and financial planning. (Zablotska 2008: 26) NAPWA notes a high degree of ‘service shortage’ issues expressed by PLHIV, particularly in smaller capital cities and regional areas. Key areas of demand were mental health and counselling services, oral health services and specific supported accommodation services for positive people. (2007: 27) Rob Lake from Positive Life NSW says: ‘The main needs are psycho-social and providing less intensive health management. It’s about looking at continuum of care and how to respond at particular points in people’s lives.’ (interview December 3, 2008)

The data above on services accessed and identified gaps is important, but it doesn’t give a full picture as to whether those who need services are actually accessing them or whether these services are meeting needs. For these reasons, it is important to explore the key sub-populations of PLHIV in Australia, and how underlying health, social and economic factors may influence treatment, medical and other service demands.

Key sub-populations

Priority populations

In Australia, much attention has been paid to ensuring that the experiences, culture and demands of those affected by HIV are central to service development and delivery. Initially this was focussed on the prioritised affected communities of men who have sex with men, injecting drug users and sex workers. However, over time more attention has been paid to the diversity within and interaction between these populations, as well as other sub-populations with specific demands and concerns.

The national HIV/AIDS strategy (Commonwealth of Australia 2005b) identifies the following as priority populations:

1. Gay and other homosexually active men
2. Aboriginal and Torres Strait Islander people
3. People who inject drugs
4. People in custodial settings, including young people in detention
5. Sex workers
6. People from Culturally and Linguistically Diverse (CALD) backgrounds

This prioritisation is linked to concerns about prevalence (gay and homosexually active men), concerns over increasing rates of new infections or diagnoses (gay and homosexually active men, CALD and custodial settings), and concerns about potential for increased rates of infection (Aboriginal and Torres Strait Islander people and sex workers).

While this categorisation of populations is useful and necessary, it can miss the diversity within these populations. The latter is particularly important in terms understanding patterns of service need and usage.

For instance, concerns have arisen about the rate of infection in ATSI people, particularly since 2002. (Commonwealth of Australia 2005: 9) It is clear, however, that patterns of infection within this population are related to interactions with other priority populations – particularly gay and homosexually active men and injecting drug users, as well as those in custodial settings. New diagnoses in the ATSI population are significantly associated with homosexual contact (37%). In addition, the percentage of new infections attributed to injecting drug use increased from 3% in 1992-1998 to 18% in 2002-2007 – compared with a stable 3% in the non-indigenous population. (NCHECR 2007: 8 and 24) From 1998-2007, around 8% of diagnoses in Australia were related to people with a history of injecting drug use. Over half of these also reported homosexual contact. (NCHECR 2008: 23) It should be noted, however, that a significant percentage of new diagnoses in the ATSI population are related to heterosexual contact (34%). (NCHECR 2007: 24) This is another example of diversity within this priority population.

In applying this analysis to service demands, it may be important to support some population-specific services, but also integration with other services aimed at gay and

homosexually active men and injecting drug use, as well as sensitisation of HIV, sexual health and mainstream (particularly rural) health services. In designing a response in terms of service delivery, it is also important to acknowledge that the numbers of people involved is still relatively small. In the nine years from 1997, 190 diagnoses occurred in the ATSI population. In 2006, 19 people were diagnosed. (NCHECR 2008: 24)

In another example, 'people from CALD backgrounds' is a difficult population to analyse, in that it encompasses a large amount of diversity in culture, location, social experience, etc. Some cultural, national and/or linguistic groups are more likely to suffer from geographic and social isolation. As will be shown below, some common characteristics emerge when one looks at the issues of patterns of barriers and access to service delivery. While CALD-specific services may be needed in some areas, there is a similar need to consider sensitisation and integration with the HIV, sexual health and mainstream health service delivery. Again, the numbers are relatively small. As one indication, between 2004 and 2007, 216 new diagnoses occurred nationally amongst people who reported speaking a language other than English at home. (NCHECR 2008: 42)

Overall, if the focus is on addressing service access and delivery, there is a need to take a different approach to characterisation of key sub-populations – as the focus is not simply on analysing populations at risk but on the nature and shape of specific interactions and interventions.

While keeping in mind that the aim remains promoting the fullest possible access to services which meet the demands of all affected by HIV, the characterisation of key sub-populations below is intended to focus attention on the most common patterns in relation to service access. This leads on to a discussion of how services might be targeted to achieve the broadest reach within these populations, while ensuring that the demands of other specific populations (such as women, heterosexual men, Aboriginal and Torres Strait Islanders) are also addressed.

Key sub-populations

Long-term positive (mostly gay and homosexually-active men)

The first key sub-population is made up of people who have been living with HIV over a long period – the majority of whom are gay and homosexually-active men. Of all AIDS diagnoses (an indicator of long-term infection) in 2003-2007, 58% were related to male homosexual contact. (NCHECR 2008: 11) Pitts, et al, reported on the previous Futures survey that 22% of respondents were aged over 50, and that of these 90% reported being infected through male homosexual or bisexual contact. (2005: 462)

In line with general patterns of location for homosexual and bisexual men, this population is located predominantly in NSW and in urban areas. At the end of 2006, 68% of all HIV infections among gay and homosexually-active men had occurred in NSW. There are around two thirds more HIV-positive men in NSW than in Victoria and Queensland combined. In every state except Queensland, most homosexual or bisexual men live in the capital cities. (Prestage et al 2008: 97 and 101) A postcode analysis of men reporting homosexual or other

same-sex identity, experience or desire in Sydney indicated that the population is concentrated within clear geographic boundaries (inner east and inner west) with smaller proportions living elsewhere. (Maddedu et al 2006, 39) However, this population is relatively more dispersed in other cities which do not have the same gay community, cultural and social centre as Sydney.

As outlined above, this population includes a large percentage of those who are stable on treatment, with a relatively small number requiring complex or acute care. Rob Lake from Positive Life NSW says:

It is becoming clearer that there is a core group of older people living longer with HIV at the 'crunchy' end of health impact and socio-economic issues with retirement, possibly also isolation and long-term psychological issues. Then there is a much larger group who are doing ok with medication and management, are probably working but have high needs at particular points – clinical issues or with life stresses like relationship break-up. The issue is how to keep those people well. (interview December 3, 2008)

Care demands for the long-term positive population of gay and homosexually-active men are predominantly met by HIV GPs and specialists, and access to these has historically been facilitated by the geographic location of much of this population. However, this population is increasingly marked by the complexities associated with ageing and a range of treatment, healthcare and other service demands.

In terms of other groups within the long-term positive population, treatment, healthcare and support demands may differ slightly. Women are estimated to make up only 8% of the HIV positive population, but it is important to consider the specific demands of women in relation to long-term HIV infection. While attention to date has focussed on reproductive health, issues of increasing concern in an ageing HIV positive population relate to the health of women post-menopause. For those infected with HIV through injecting drug use, higher rates of hepatitis C infection complicate long-term care and support demands, as well as treatment (e.g. liver toxicity with long-term cART). These populations do not tend to congregate in particular geographic areas, and also access healthcare outside of HIV specific services.

Newly positive (mostly gay and homosexually-active men)

Of newly acquired HIV infections in 2003-2007, 82% were attributed to male homosexual contact. (NCHECR 2008: 11) Again, in line with general patterns of geographic location for gay and homosexually-active men, this population is predominantly located in urban areas. This population is relatively younger than the population outlined above, and relatively more healthy. However, it requires additional support to cope with new diagnosis, including peer support, education, and counselling. NAPWA notes the success of support programs for the newly-diagnosed. (2007: 33)

This population is likely to include more people who are not on treatment. However, medical service demands may initially be high due to clinical assessment/investigation and laboratory testing requirements, and possible treatment initiation. Care is likely to be provided

predominantly by HIV GPs and specialists, as the geographic location of this population is again likely to match the overall demographics of homosexual and bisexual men.

In terms of other groups within this population, additional support and services are likely to be necessary for injecting drug users to assist with health maintenance and initiation of treatment if necessary (particularly in terms of co-infection with hepatitis C). Those in custodial settings may additionally require attention in relation to prevention through safe sex and injecting practices.

Late presenters (particularly from CALD backgrounds)

Late presentation is an important and growing issue for service delivery. In general, 55% of all cases have undiagnosed HIV infection until the time of AIDS diagnosis. This is up from 38% in 1998-2002. (NCHECR 2008: 29) A large percentage of late presentation is related to heterosexual transmission. Only 9% of newly *acquired* infections in 2003-2007 were attributed to heterosexual contact, compared with 21% of newly *diagnosed* infections. Of all AIDS diagnoses in 2003-2007, 68% were related to heterosexual contact. (NCHECR 2008: 8 and 11)

In 2003-2007, 60% of cases of HIV infection attributed to heterosexual contact involved people from high-prevalence countries and their partners. The per capita rate of diagnosis of HIV and AIDS in people born in countries in sub-Saharan Africa was at least five times higher than those born in Australia. (NCHECR 2008: 8) Korner notes the association of late diagnosis with being born in Asia, and the incidence of AIDS-defining illnesses (e.g. tuberculosis and cryptococcosis) being higher in those born in Africa and Asia. (2007: 169)

The communities of concern vary state by state. In Victoria, the focus has been on those from the Horn of Africa (Sudan, Somalia, Ethiopia and Eritrea), Arabic-speaking and Vietnamese communities. (McNally and Dutertre 2006: 9) In NSW, Cambodian and Thai communities have also been a focus. The experiences, current circumstances and location, and thus demands of these communities vary. However, there are some commonalities.

The CALD population is more likely to be socially and economically disadvantaged. Some communities may be grouped together. Sonny Williams from PLWHA Victoria points out: 'The African communities affected by HIV here tend to live close together, some in the inner city and housing commission areas'. (interview December 9, 2008) However, the CALD population is more geographically dispersed. This may make access to HIV-specific services more difficult. It also raises the need for HIV experience/expertise outside of these services. Late presenters tend to be diagnosed outside of HIV-specific services, as a result of becoming ill or screening related to pregnancy. Korner notes that some participants (particularly heterosexuals) in a study on CALD in Sydney reported that they were not promptly tested for HIV, despite presenting with serious infections. (2007: 171-172)

There are some similarities between the issues facing the CALD population and Aboriginal and Torres Strait Islander people – particularly in terms of the interaction of HIV infection with existing health disparity, other economic and social disadvantage, and relative geographic isolation and cultural differences which may limit access to appropriate and effective services. Late presentation is also a feature of HIV diagnosis in this group.

Overall, some individuals within the key sub-populations identified here will be more 'high-end' users of medical or other services than others, but the important thing is to look for general patterns in terms of how underlying health, social and economic issues inter-relate with service demands in these sub-populations.

HIV and socio-economic disadvantage

According to the Ottawa Charter for Health Promotion, the fundamental conditions and resources for health include:

- shelter
- education
- food
- income
- social justice and equity (WHO 1986)

Adverse social and economic circumstances have adverse health impacts. This is important in considering how the underlying health issues of those more socially and economically disadvantaged may be exacerbated by HIV, or how this disadvantage may relate to their ability to access services.

Adverse social and economic circumstances may increase HIV risk in particular ways (including lower levels of education or turning to risk behaviours such as injecting drug use). However, it is not clear in general in Australia that socio-economic disadvantage makes people more likely to acquire HIV. This is a growing area of debate internationally. In many resource poor countries, the relatively richer and better educated can be more likely to acquire HIV in the early stages of an epidemic, with urban location, mobility, disposable income and longer lifetimes contributing. (Gillespie et al 2007)

So while socio-economic disadvantage may not be an issue across the board at the time of diagnosis (aside from amongst late presenters in CALD or indigenous populations), there is evidence that it may become so over time. NAPWA notes the additional financial burdens associated with HIV, including increased medical expenses and reduced capacity to work. Stress over financial issues also compounds adverse health effects of HIV. (2007: 18-20)

Economic issues

HIV and treatment appear to have significant impacts on the ability of PLHIV to work. Just over half of respondents in Futures 5 were currently employed. Of these 34.1% were in full-time work and 17.1% in part time. Others described themselves as unemployed (10.7%) or retired (19.8%). Nearly a quarter said that of the continuing impact of HIV on their work was that their career ended or that they stopped work. 14.4% had had to stop work because of the impact of cART. Nearly half had stopped work at some point because of HIV. (Grierson et al 2006: 55) Older PLHIV were less likely to be in paid employment, and in full-time employment than younger PLHIV. (Pitts et al 2005: 463) Levinia Crooks from the Australasian Society for HIV Medicine (ASHM) says:

Financial issues are real – and mostly related to ability to work. This may partly be about physical issues, but may also be because they should really be on old age pension, or because they have become de-skilled from being out of the workforce, or because they have become so used to their lives circulating around their health and unused to functioning in other environments. (interview December 4, 2008)

When not working, 71.6% of respondents were on government benefits, social security payments or a pension. In general, 45.7% nominated these payments as their primary source of income. (Grierson et al 2006: 57 and 61) NAPWA notes that welfare reforms have put more emphasis on individuals moving into employment, and that workforce participation requirements do not adequately recognise the episodic nature of HIV illness. (2007: 25)

The median weekly in-hand income of respondents in Futures 5 was \$400. Over one quarter of PLHIV were living below the poverty line.⁷ These people were generally more likely to be unemployed, on benefits, on a sole income, and in poor or fair health. (Grierson et al 2006: 61-64) More women than men were living below the poverty line – 34.5% compared to 20.1%. (Grierson et al 2007: 20) Older PLHIV were more likely to be below the poverty line, and their median income was lower. (Pitts et al 2005: 464)

In Futures 5, 73.4% either owned, were purchasing their own home or were living in private rental accommodation. Around 15.6% were living in public housing. 84.2% said that their current accommodation was suitable. Of those who said it was unsuitable, 27% gave expense as the reason. (Grierson et al 2006: 54) Respondents who lived alone were no less likely than those who lived with others to feel their accommodation was unsuitable for their current needs. However, those living alone were less likely to own, or be paying off, their own home.

NAPWA argues that emergency and respite housing is a critical area of need. (2007: 24) With the ageing of the HIV population, access to aged care, independent living units and public housing are likely to become a larger issue in decades to come. Sonny Williams from People Living with HIV/AIDS Victoria argues that: 'A key need will be retirement accommodation and nursing homes, and their ability to deal with the HIV positive population'. (interview December 9, 2008) More broadly, Rob Lake from Positive Life NSW says: 'It won't work to create a whole new HIV and ageing sector, and a range of solutions might be necessary aside from residential aged care, like access to long-term secure rental housing.' (interview December 3, 2008)

Low income makes it harder for PLHIV to pay for basic items like food, clothing, utilities and rent. In Futures 5, people living alone did not report finding it more difficult than those living with others to meet housing costs. However, they were significantly more likely to report that they found it 'very difficult' to meet the costs of utilities and food. The health impacts of this may exacerbate medical service demands.

⁷ The quarterly Henderson Poverty Line has been used, as published by the Institute of Applied Economics and Social Research.

Of those living below the poverty line, one quarter rated paying for medical services as very difficult, while others noted difficulty in meeting co-payments for medication and other prescribed medication. (Grierson et al 2006: 65) In Futures 5, respondents reported spending an average of \$10 per week on antiretroviral medication and \$10 per week on other medication.⁸ This was similar across all area types. Those earning less than \$500 per week reported finding it more difficult to meet the costs of co-payments for HIV/AIDS medication and the cost of general medical services. (See Table 14 and Table 15)

Table 14: Reported difficulty meeting costs of co-payments for HIV medication according to weekly income

	Weekly income (percent)		
	\$500 or less	\$501 or more	Total
Not difficult (n=346)	53.3	72.6	60.7
A little difficult (n=176)	36.5	21.9	30.9
Very difficult (n=48)	10.3	5.5	8.4

$$\chi^2(2) = 21.198, p < 0.001$$

Table 15: Reported difficulty meeting costs of medical services

	Weekly income (percent)		
	\$500 or less	\$501 or more	Total
Not difficult (n=392)	44.4	66.3	54.1
A little difficult (n=219)	33.3	26.3	30.2
Very difficult (n=114)	22.2	7.5	15.7

$$\chi^2(2) = 43.330, p < 0.001$$

People living alone were significantly more likely to report that they found meeting the cost of medical services 'very difficult'. NAPWA also notes that even for those with a low-income Health Care Card, multiple prescriptions (even when subsidised) create pressure. The costs of dental care are also an additional burden. (2007: 23 and 30) The costs of consultations and tests may also be a factor outside HIV-specific services.

Access to effective healthcare in the CALD population has other socio-economic barriers, including medicare ineligibility for some. Trish Langdon from the WA AIDS Council argues that while the numbers affected by ineligibility for medicare may not be large, this remains a significant issue: 'People who are here on temporary visas or student visas may find themselves HIV positive and be here for a number of years, during which they need to start treatment. This is a complex problem for service providers.' (interview January 14, 2009) People in the CALD population may also have restricted work conditions under particular visas, and be working in more physically demanding unskilled jobs. (Korner 2005: 2)

⁸ Both of these were calculated with one extreme value excluded.

Social or cultural issues

All of this has impacts on the range, variety and intensity of medical and other service demands of PLHIV. In Futures 5, those below the poverty line tended to utilise more services available through HIV organisations and other services. This is most likely exacerbated by differences in health maintenance behaviour.

In Futures 5, those who rated their health better overall were more likely to indicate that they had engaged in health improvement strategies – most commonly healthy eating and spending time with friends and family. Those who rated their well-being as better had engaged in exercise, healthy eating, spending time with friends, family or pets, and relaxation. (Grierson et al 2006: 10) Management of a range of co-morbidities and complications, particularly those associated with ageing, is increasingly focussed around lifestyles choices such as stopping smoking, low-fat eating and exercise. An unanswered question is who does better in relation to self-management of HIV. However, socio-economic disadvantage is generally associated with increased engagement in risk behaviours associated with diet, exercise and smoking and substance abuse. (Turrell et al 2006: 133-137)

Other social differences can create particular barriers to effective medical and other service delivery. For instance, amongst the CALD population, these include:

- language barriers
- lack of familiarity with system of care and referral
- ability to absorb information and deal with medical terminology
- women's reliance on husbands for assistance/permission to access services
- lack of understanding about the difference between HIV and AIDS. (Korner 2005: 2-3)

In terms of the latter, diagnosis may be interpreted differently by those from resource-poor countries, where HIV survival rates are much lower. (Korner 2007: 175) Diagnosis in this population is particularly sensitive in that it often occurs at a time of health crisis, and is initiated by someone other than the patient. (Korner 2007: 171)

Social support is identified as a key factor in health maintenance. NAPWA writes that 'personal' needs rate highly with PLHIV – 'notions of closeness and connection through peer support and social participation opportunities'. (2007: 19)

This social support and participation may be harder for marginalised communities to access. Korner notes that individuals in the CALD population can experience difficulties making decisions about lives within an unfamiliar culture, without close friends to confide in. Cultural differences also play a part through beliefs about morality and deviance, and fear of stigma within communities. (Korner 2005: 2-3) On a positive note, Korner found that many participants felt that living in Australia offered them more privacy and confidentiality than they would have had in their country of birth. This positive feeling was mitigated, however, by uncertainty about immigration status and the possibility of deportation. (2005: 3-4)

One general indication of social support and connectedness is whether PLHIV live alone or with others. In Futures 5, 44% of respondents stated that they currently live alone. The

remainder lived with a partner/spouse, family, children, friends/flatmates or combinations of these.⁹ People living alone were more likely than those living with others to 'agree' or 'strongly agree' that they 'don't enjoy things like they used to' and that 'they have lost interest in other people' ($P<0.01$). People living alone were also more likely to state that they 'don't feel it's worth going on' ($p<0.05$), although this was a small number of people overall.

People who lived alone were significantly less likely than those living with others to state they received a lot of support from a partner or spouse ($p<0.001$). Among people who lived with others, partner/spouse was the most commonly cited source of support. For people living alone, health care workers, close friends and peer support groups were the most commonly cited sources from which people receive a lot of support (although less than half of people living alone attended groups). By comparison, people living with others were more likely to attend a peer support group (only 43% stated this was not applicable to them, compared to 55% of people living alone). People living alone were less likely to have support from their parents (significantly more people living alone than with others stated parental support was not applicable to them, $p<0.001$). People living alone were also less likely than those living with others to state that they received support from positive friends ($p<0.01$). (Table 16 and Table 17)

Table 16: People living alone: support received from others

	Perceived level of support (percent)				
	a lot	some	a little	none	NA
Health care workers	47.1	29.3	18.3	3.7	1.7
Close friends	41.9	26.5	17.4	7.4	6.9
PLWHA groups	30.1	7.5	4.1	3.1	55.2
Positive friends	23.6	29.1	19.7	12.1	15.5
Siblings	23.0	16.3	18.6	23.0	19.1
Parents	22.5	9.3	12.4	16.1	39.6
Family	16.3	21.3	17.3	14.5	30.6
Doctor	15.7	15.9	13.4	16.7	38.4
Pets	15.0	15.8	18.7	18.1	32.4
Counsellor	13.5	17.6	24.6	20.5	23.8
Other friends	12.5	27.9	26.9	19.7	13.0
Partner/spouse	9.9	2.7	1.9	4.3	81.2
Volunteer carer	5.5	3.6	2.9	13.8	74.2
Religious/spiritual adviser	4.9	3.3	4.6	12.8	74.4
Kids	4.2	1.3	2.1	6.8	85.6

⁹ This did not differ substantially across states and territories. People living in outer suburban areas were slightly less likely to live alone than those living in inner suburban, rural or regional areas.

Table 17: People living with others: support received from others

	Perceived level of support (percent)				
	a lot	some	a little	none	NA
Partner/spouse	60.0	9.1	2.7	1.5	26.6
Health care workers	48.5	30.2	16.2	2.9	2.3
Close friends	45.8	30.7	13.2	4.4	5.9
Positive friends	32.8	28.7	17.1	6.8	14.6
PLWHA groups	31.4	13.2	7.7	4.7	43.0
Parents	30.0	17.6	11.4	16.7	24.3
Siblings	24.9	23.1	16.0	19.7	16.4
Pets	22.1	19.1	16.9	17.9	24.1
Family	17.6	21.0	13.2	14.6	33.5
Other friends	12.9	30.7	28.7	15.1	12.5
Doctor	12.7	17.5	10.6	19.5	39.6
Counsellor	10.8	19.6	19.4	22.0	28.1
Kids	8.1	3.3	2.9	4.5	81.2
Religious/spiritual adviser	6.3	5.3	3.0	14.4	70.9
Volunteer carer	4.5	3.5	3.3	16.3	72.4

The range of services accessed in the past six months by people who live alone was not noticeably different to that of people who live with others. However, people living alone were more likely to be a client or user of HIV/AIDS services ($p=0.05$) – particularly for financial assistance ($p<0.01$).

Among people aged over 50, those who lived alone were significantly less likely than those who lived with others to receive support from positive friends ($p<0.001$) and slightly less likely to say they receive support from close friends (42% of people living alone stated they received a lot of support from close friends compared to 52% of people living with others).

The social support needs of older, long-term HIV-positive people (most of whom are gay and homosexually-active men) are likely increase as this population ages. Individuals in this population are potentially more likely to be affected by the intersection of a range of factors, including the effects of long-term HIV infection and/or toxicity related to long-term treatment, economic disadvantage and associated adverse health impacts. Social isolation may also become more pronounced.

In the Private Lives study – a large survey of gay, lesbian, bisexual, transgender and intersex (GLBTI) people conducted in 2005 – respondents reported turning to a range of sources of emotional support, as well as health information and advice. GLBTI friends rated most highly, and in most cases higher than biological families. A similar pattern is evident in who participants turn to for health information and advice. However in times of sickness, relatives (biological family) or partners were rated higher. (Pitts et al 2006: 12) Older men may become more isolated in terms of social support to deal with HIV as biological family

and/or partners pass away. This has an impact in terms of other service needs, as well as medical service usage in as much as these people may access doctors for some degree of social support/contact. The insight from Private Lives above is also relevant to younger positive gay and homosexually-active men in relation to how patterns of identity and community connectedness may be changing over time.

There is broader evidence that stigma and discrimination undermine social support and participation, and are barriers to service access. In Futures 5, 27.2% said that they had experienced less-favourable treatment at a medical service – most commonly including infection control, avoidance and confidentiality problems. (Grierson et al 2006: 68) In addition, 6.8% reported less favourable treatment in relation to housing. In addition, Jo Watson from NAPWA says:

Policy issues confronting this population right now are about criminalisation and legal issues intersecting with public health. This population is quite concerned and uneasy about their status and what their rights are – especially across different legislative arrangements. (interview, December 2, 2008)

Peer support may help to counteract the impact of stigma and discrimination. However, there is an increasing need to adapt services and messages for different sub-populations – who experience life, identity and HIV in different ways. Rob Lake from Positive Life NSW reflects:

Peer support is still important – people may understand this differently though, and not engage consistently. They may just drop through occasionally to see ‘how I am tracking compared to people like me’. We need to look at adjusting models for peer support to make them relevant to targeted groups. (interview December 3, 2008)

Sonny Williams from PLWHA Victoria points to the need to gather more knowledge about how peer support needs are changing:

We are looking at revisiting where the community is located, and what their access points are for services. We have a core group who are high-end users of services but we service only 20% or so of the positive population in Victoria. We want to know where people are at in their lives. Where are the ‘working well’ and what do they want from us? (interview December 9, 2008)

In terms of how central HIV is to identity in the HIV positive population, nearly half of positive people in Futures 5 considered their HIV status an important, but not essential aspect of their identity. Meanwhile 17% considered it essential. It is not clear how this might influence patterns of service access, as it did not vary greatly across different groups of PLHIV based on sexuality, gender, having had an AIDS-defining illness, use of antiretrovirals or partner sero-status. (Grierson et al 2006: 42) In general though, Levinia Crooks from ASHM argues:

The types of treatment we used to have led to a very medicalised focus in management, and real difficulties in incorporating that into a normal life. The lived

experience of HIV now can be much more about living life, rather than living with HIV. (interview December 4, 2008)

So while the ongoing importance of HIV overall within the identity of PLHIV supports the need for maintaining HIV-specific medical and other targeted services, this may begin to shift over time, and may not always be so important for other populations such as CALD or women – as noted above, fear of stigma or the association of HIV services with the gay community can be barriers.

Location

Socio-economic issues are particularly relevant to service access and delivery in terms of how this influences where positive people live or where they may move in future.

In Futures 5, people living in capital city/inner suburban areas had a slightly higher median income (\$500) than those in outer suburban (\$380) or regional centres (\$330) or rural areas (\$300). Rising housing costs are likely to mean that more PLHIV are less able to afford to live in inner suburbs. As a reflection of this, in Futures 5, a slightly higher percentage of people 35 or under lived in outer suburbs. (See Table 18)

Table 18: Area type by age

	Age (percent)					Total
	<= 35	36 - 40	41 – 45	46 - 50	51+	
Capital city/inner suburban (n=610)	70.4	67.8	65.2	64.4	56.8	63.7
Outer suburban (n=102)	15.5	11.2	9.3	9.6	9.6	10.7
Regional centre (n=159)	12.0	16.1	14.2	16.5	21.1	16.6
Rural (n=86)	2.1	4.9	11.3	9.6	12.5	9.0

In this context, access to transport may be an important issue in terms of accessing appropriate services. Nearly three quarters of respondents in Futures 5 owned their own car, and 76.2% had easy or very easy access to public transport. However, 11.1% said that access to public transport was very difficult, and 12.6% said it was difficult. (Grierson et al 2006: 54) Women may find it difficult to travel longer distances, particularly if they have children. (Thorpe et al 2008: 550)

Having access to a car did not appear to influence whether respondents found it difficult or not to collect their prescriptions. However, those who stated that accessing public transport to or from their home was easy were significantly more likely to state that it was not at all difficult for them to collect their prescriptions ($p < 0.001$). Those with more limited access to public transport had greater difficulty collecting their prescriptions. (Table 19)

Table 19: Difficulty of getting prescription according to difficulty accessing public transport to and from home

Difficulty getting prescription filled (percent)	Public transport difficulty			
	Very difficult	Difficult	Easy	Very easy
Not at all difficult	46.8	46.0	59.6	74.7
Somewhat difficult	40.5	51.7	36.0	20.8
Very difficult	12.7	2.3	4.4	4.5

$\chi^2(6) = 48.143, p < 0.001$

Location – particularly in rural/regional or outer suburban areas – is important in terms of easy access to appropriate services. Possible changes in the location of the HIV positive population may have an impact on service access/delivery.

Projections

The two most important issues for the HIV-positive population in relation to service access and delivery are potential changes in the patterns of location of this population, and potential changes in how and what type/style of services are accessed or wanted.

Today's population of long-term positive (mostly gay and homosexually-active men) is ageing. For lifestyle and economic reasons, those who are stable on treatment may choose to live further away from the HIV-specific services predominantly based in the inner cities. Prestage, et al, have noted what could be a shift in the population of homosexual and bisexual men from NSW to Queensland. (2008: 101) Jo Watson says: 'The 'sea change' is huge in this population. The northern rivers, central and south coast of NSW are swelling. And those regional areas are struggling to deal with those demands.' (interview, December 2, 2008) Sonny Williams from PLWHA Victoria agrees: 'There has been quite a move out of Melbourne out towards the Macedon ranges – like there was in Sydney towards the Blue Mountains'. (interview December 9, 2008) Already in Futures 5, a slightly higher percentage of people over 50 lived in regional centres or rural areas. (Figure 18)

In this context, the emphasis shifts to the general health management of this population, particularly in relation to diseases associated with ageing. This may point towards the need to develop HIV expertise within the general healthcare system (or specialist areas like cardiology) in particular regional areas where this population may choose to live. This may also be related to whether the 'sea change' phenomenon is more generalised, in which case it will influence more general patterns of health care delivery in regional areas.

Long-term positive people will continue to have episodic need for acute and ambulatory care, and some will continue to have complex treatment and healthcare demands which are best met in HIV-specific services. However, as people surviving on treatment over the next 5-10 years are going to be on simplified treatments which aim to minimise toxicity and side-effects, the demands for HIV-specific services may change over time.

It is also important to note that today's long-term positive population of gay and homosexually-active men has a specific history in relation to HIV. The experience of the early epidemic in Australia, with the push to develop specific HIV services and the involvement of a mobilised community, has conditioned the type and style of healthcare services which are expected and seen as necessary.

As the long-term positive population is progressively replaced by those without this historical experience, it is interesting to speculate as to how these expectations may change. Jo Watson from NAPWA says:

This group is not as 'out' or as engaged with the community support structure and not necessarily wanting to be seen as a group needing anything. So they are more vulnerable in some ways to deal with future challenges. Our whole construct as a sector will have to adapt. The other group of new infected will have better clinical management and drug options, with longer life expectancy – and we will need to

adjust services for a group who will be healthier for longer and may access services through general rather than specialist care. (interview, December 2, 2008)

From an epidemiological perspective it seems clear that there will be a continuing increase in HIV infections among gay and homosexually active men nationally over the next 5-10 years. However, there may be state-based differences.¹⁰ This means that the sub-population of newly infected (mostly gay and homosexually active men) is likely to remain a key priority. Rob Lake from Positive Life NSW points out: 'More attention is being paid to the ageing population, but there are also young gay men and heterosexual women being diagnosed, and culturally we need to make sure that there are services that work for them too.' (interview, December 3, 2008)

In terms of late presenters, it is unclear how prevalence will develop in CALD populations. Concerns over infections relating to high-prevalence countries in sub-Saharan Africa may dissipate over time as migration patterns change and communities have lived longer in Australia, but this will vary based on the communities of concern in each state. For instance, AIDS incidence increased in people born in North Africa/Middle East and Asia between 2003-2007, compared to the previous four years. This contrasts with a decrease related to other regions, including Sub-Saharan Africa. (NCHECR 2008: 12) One important question is what will happen in terms of patterns of late presentation among gay and homosexually-active men.

¹⁰ Based on mathematical modelling, NCHECR has predicted a decrease in NSW notifications among men who have sex with men (from 303 in 2006 to ~266 in 2015), and increases in Victoria (from 234 in 2006 to ~406 in 2015) and Queensland (from 122 in 2006 to ~146 in 2015). (NCHECR 2008b: 7)

Changes?

The analysis outlined above adds to existing reviews of the demands of people living with HIV in terms of service delivery. Porcino and Leach note that:

Today's people with HIV may require assistance in a much wider range of areas: with understanding the myriad of treatment options, with managing drug toxicities, with occasional acute care, with the challenges of ageing, with co-morbidities' management, with mental health, drug and alcohol, welfare and social support issues, etc. (2007: 14)

Treatment has allowed a greater number of PLHIV to maintain their health with relatively basic support from health services. However, others still require episodic acute care or more intensive support to deal with treatment side effects, toxicities and resistance. Levinia Crooks from ASHM argues:

Access to generalised healthcare is becoming more important. The care of certain people with HIV has become quite routine, and we need to look at new ways of monitoring stable patients through GPs, with streamlined referrals on for care and complex issues as necessary. (interview December 4, 2008)

Finding the right balance between HIV-specific services, and 'mainstreaming' or utilising other specialist care, is informed by an analysis of the sub-populations involved.

As PLHIV live longer and the length on treatment has increased, their lifetime demands are expanding and becoming more complex. All of this points to the need for attention to be paid to the development of a range of appropriate services, but also to service coordination and referral. This is relatively more easy to achieve and support within centralised HIV-specific or hospital-based services. HIV prescribers and other GPs may require extra support to understand the emerging variety of demands of and services available for PLHIV.

The key issue remains tailoring service delivery to individuals. The range of other service or social support demands which may be required by PLHIV varies widely and will change over time. It is likely that addressing demands will require a combined approach of expanding access to mainstream services (e.g. housing, income support), and developing or supporting the capacity of HIV-specific services to provide a greater range of tailored services (e.g. targeted mental health services). The balance between these will also vary according to the local context in each state and territory, and the particular sub-populations involved. For instance, Trish Langdon from WA AIDS Council says:

In WA we have been talking a lot about mainstreaming, up-skilling other services to be able to provide services to HIV-positive people. Because the numbers here are lower, there is less momentum for creating HIV-specific aged care or mental health services. We are less bothered by who provides the services, just that they are the best possible. (interview January 14, 2009)

In any case, systems of service delivery will require ongoing attention to ensure that gaps and overlaps are minimised.

Implications for future research

In undertaking this report, ARCSHS has been pleased to note the amount and variety of data available in Australia to assist in this analysis. However, important gaps in the research are also emerging – particularly in relation to emerging trends and projections in the HIV-positive population. These have important implications for ongoing analysis and recommendations to assist in service planning and delivery.

An important gap in the data relates to how often and at what intervals PLHIV utilise medical services. This would help to understand to what degree healthcare demands are regular or episodic – as well as how this may vary across sub-populations and according to different health states.

There is also a particular need for attention to be paid to trends such as the ageing of the HIV-positive population in Australia – how this process is influencing the experience of living with HIV, as well as patterns of service use/demand. This is related to generational shifts which seem to be occurring in the social experience and cultural/community characteristics of the population of gay and homosexually-active men, and to the growing diversity of the HIV-positive population.

None of the existing studies or datasets provide sufficient evidence concerning those people living with HIV who have complex needs. These will include people who face significant social and economic challenges. PLWHA who are in short term or sheltered housing, those who have significant mental health issues and those who have drug and alcohol dependencies will continue to require high levels of support and are clearly under-represented in the current evidence base.

Shifts in the geographic location of the HIV-positive population are an important related indicator. These are hard to track overall, without characterising specific sub-populations – long-term positive, newly diagnosed, late presenters, as well as ‘generations’ or ‘cohorts’ within these (e.g. older long-term positive people or specific CALD communities).

Exciting opportunities exist to expand on and develop the analysis contained in this report into the future, in order to support the aims of providing the appropriate, accessible and best quality care and support to HIV positive people in Australia.

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Key stakeholders

Levinia Crooks, Chief Executive Officer, Australasian Society for HIV Medicine, interview December 4, 2008.

Rob Lake, Chief Executive Officer, Positive Life NSW, interview December 3, 2008.

Trish Langdon, Executive Directory, Western Australian AIDS Council, interview January 14, 2009.

Dr Darren Russell, Director of Sexual Health, Cairns Sexual Health Service, interview conducted via email December 5, 2008.

Jo Watson, Executive Director, National Association of People Living with HIV/AIDS, interview December 2, 2008.

Sonny Williams, Executive Officer, People Living with HIV/AIDS Victoria, interview December 9, 2008.

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