

HIV/AIDS Care and Treatment Services Needs Assessment



This report was written by Jill Hardwick and Ruth Cotton. Isla Tooth documented the workshop discussions and assisted with the collation of the submissions. Stephen Ryan from Hades and Associates provided some assistance with data preparation.

Cover illustration:

A group art piece by residents of The Bridge. Individually painted and glazed tiles produced as part of the weekly Art Group based at The Bridge, a residential service for people living with HIV related dementia and other complex needs.

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Advisory committee

An Advisory Committee was established to guide this service and needs assessment. The members of the Committee are listed below:

Dr Roger Garsia, (Chair), Director of HIV Services, Central Sydney Health Service and also Chair of the NSW Ministerial Advisory Committee on HIV and Sexually Transmissible Diseases

Peter Todaro, HIV/AIDS Coordinator, Central Sydney Health Service

Dr Marilyn McMurchie, General Practitioner

Dr Michael Boyle, Director, Immunology & Infectious Diseases Unit, John Hunter Hospital

Stevie Clayton, CEO, AIDS Council of NSW, replaced by Mr Alan Brotherton, Director of Clinical Services, AIDS Council of NSW

Levinia Crooks, Executive Officer, Australasian Society for HIV Medicine

Antony Nicholas, Executive Officer, PLWHA (NSW)

Kim Stewart, Associate Director, AIDS/Infectious Diseases Branch, NSW Health

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Marlene Velecky, Senior Policy Analyst, HIV and Sexually Transmissible Infections Unit, AIDS/Infectious Diseases Branch, NSW Health.

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The members contributed to discussions at monthly meetings and provided comments on drafts of the report, for which we are very grateful.

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Abbreviations

AMS	Aboriginal Medical Service	IGCAHRD	Intergovernmental Committee on AIDS, Hepatitis C and Related Diseases
ANCAHRD	Australia National on AIDS, Hepatitis C and Related Diseases	MAHS	Macquarie Area Health Service
ACON	AIDS Council of NSW	MHAHS	Multicultural HIV/AIDS and Hepatitis C Service
ADAHPS	AIDS Dementia and HIV Psychiatry Services	MNCAHS	Mid North Coast Area Health Service
ADC	AIDS Dementia Complex	MWAHS	Mid Western Area Health Service
AIDS	Acquired Immunodeficiency Syndrome	NEAHS	New England Area Health Service
AIDB	AIDS/Infectious Diseases Branch	NCHECR	National Centre in HIV Epidemiology and Clinical Research
AHS	Area Health Service	NRL	National Serology Reference Laboratory, Australia
ALOS	Average Length Of Stay	NSAHS	Northern Sydney Area Health Service
ASC	Albion Street Centre	NRAHS	Northern Rivers Area Health Service
ASHM	Australasian Society for HIV Medicine	NUAA	NSW Users and AIDS Association
BGF	Bobby Goldsmith Foundation	OOS	Occasions Of Service
CAS	NSW Ministerial Advisory Committee on AIDS Strategy	OATSIH	Office of Aboriginal and Torres Strait Islander Health
CCAHS	Central Coast Area Health Service	PEP	Post Exposure Prophylaxis
CHC	Community Health Centre	Pozhets	Positive Heterosexuals
CHS	Corrections Health Service	PLWHA	People living with HIV/AIDS
CSAHS	Central Sydney Area Health Service	POW	Prince of Wales
DADHC	Department of Ageing, Disability and Home Care	RDF	Resource Distribution Formula
DOCS	Department of Community Services	RMIT	Royal Melbourne Institute of Technology
DRG	Diagnosis Related Group	RNS	Royal North Shore
DSP	Disability Support Pension	RPA	Royal Prince Alfred
ED	Emergency Department	SESAHS	South Eastern Area Health Service
EPC	Enhanced Primary Care	SHIP	Sexual Health Information Project
FPA	Family Planning Association	SSHC	Sydney Sexual Health Centre
FTE	Full Time Equivalent	STIs	Sexually Transmissible Infections
FWAHS	Far West Area Health Service	STV	St Vincent's
GMAHS	Greater Murray Area Health Service	SWSAHS	South Western Sydney Area Health Service
GPs	General Practitioners	SAHS	Southern Area Health Service
H2M	HIV, Hepatitis C and Mental Health Service	TGA	Therapeutic Goods Administration
HAHS	Hunter Area Health Service	TRAIDS	Transfusion Related AIDS and Infectious Diseases Service
HOIST	Health Outcomes Information Statistical Toolkit	WAHS	Wentworth Area Health Service
HIV	Human Immunodeficiency Virus	WDP	Workforce Development Program
IAHS	Illawarra Area Health Service	WSAHS	Western Sydney Area Health Service
IBAC	Immunology B Ambulatory Care		
ICD	International Classification of Diseases		
ID	Infectious Diseases		

Executive summary

1.1 Background and approach to project

Background

This project aims to determine the extent to which the needs of PLWHA have changed since the previous review reported in 2000 and on the basis of these needs make recommendations regarding the strategic framework for providing HIV care and treatment services and service models for the next triennium (see terms of reference in Appendix A).

Approach

Because of the broad scope of this project and the relatively short time frame, the following approach was adopted:

- a proforma was sent out to all Area Health Services and other (non health) government and non government organisations seeking data on the utilisation of their services. In this initial phase there was also a call for submissions (a guide to the preparation of submissions and an example of one of the proformas is also included in Appendix B)
- a series of seven half-day workshops with key stakeholders was conducted for the following groups of people:
 - staff of Level 5/6 services and other relevant services (mental health, palliative care, drug and alcohol, sexual health, health promotion)
 - staff of Level 4 and below services in metropolitan Areas and staff from other services such as drug and alcohol, mental health, sexual health, health promotion
 - HIV/AIDS coordinators
 - laboratory staff
 - staff of non government organisations
 - general practitioners
 - PLWHA.

1.2 Summary of key findings

Epidemiology

- In NSW at the end of 2003, there had been 13,235 HIV infections diagnosed, 5,325 AIDS diagnoses, 3,532 AIDS deaths and there were an estimated number of 9,703 people are living with HIV infection.
- The highest number of HIV notifications in NSW was in 1987 when there were 1646 cases. Since that time the numbers have decreased steadily to 337 cases in 2001. There was a slight rise in 2002 to 387 cases and this upward trend has continued in 2003 with 412 new HIV notifications.
- The number of newly reported HIV cases is highest among homosexual-bisexual men. Between 1993 and 1997, the male homosexual group represented 68% of total new HIV infections and the heterosexual group was 12% of the total. Between 1998 and 2002, the male homosexual group comprised 63% of new HIV infections and the heterosexual group was 17% of the total.
- Newly diagnosed cases of HIV are concentrated in the areas of South Eastern Sydney and Central Sydney. These are the Area Health Services of residence for 62% of cases diagnosed in the five year period, 1998 to 2002.
- The number of newly diagnosed cases of HIV who speak a language other than English is increasing as a proportion of the total. In the period 1991–1995 they represented 5% of the total number of new cases, in the period 1996–1999 this figure increased to 11%, and for the three years 2000–2002, it was 17%.
- There is good evidence that most STIs act as a co-factor in the transmission of HIV. Almost all State/Territory health jurisdictions reported an increased number and population rate of diagnosis of syphilis and gonorrhoea in the last few years. In Sydney, newly acquired infections were reported among homosexually active men at Levels that had not been seen in the recent past.

Executive summary

- If it is assumed that the number of notifications will continue to increase slightly over the next five years and that there will be around 35 deaths annually, there will be an additional 2000 PLWHA in NSW in 2008, or between 11,500 and 12,000 in total.

Service utilisation

- There has been a significant (66%) decline in patients with HIV/AIDS admitted to NSW public and private hospitals over the past five years.
- Despite the reduction in the number of admissions over the last five years there has not been much of a decline in length of stay for patients who are admitted for longer than one day with average length of stay remaining at around 11.5 days for the last four years.
- The Area Health Services with Level 4 HIV/AIDS services have increased their share of HIV/AIDS patients from 11% in 1999/2000 to 18% in 2001/02 despite the decline in HIV/AIDS inpatients overall. The share of HIV/AIDS bed days in these Areas has increased from 9% to 15% of the State's total. The largest increase has occurred in the Area Health Service of Northern Rivers.
- There is no data source that provides a reliable, detailed and complete picture of the activity of non admitted services, despite the fact that this is the setting where care and treatment of most PLWHA currently occurs.
- In the absence of data on the utilisation of non admitted services, it was decided that the pattern of expenditure on s100 drugs for HIV would provide an indication of where PLWHA were receiving non admitted services from. SESAHS has the highest expenditure on these drugs – \$25m or 66.5% of the total cost of s100 drugs for people with HIV.

Issues and Implications for service delivery

- **Shift from inpatient to ambulatory care.** The data on the utilisation of inpatient services shows the dramatic decline in their use over the past five years, mainly as a result of effective treatment regimens that are available on a non inpatient basis.
- **Poor quality of data on the utilisation of non admitted services.** There is a need to more accurately measure non admitted activity so that it is possible to ensure:

- service activity is able to be monitored and comparisons can be made between Areas
- resource allocation reflects the relative utilisation of admitted and non admitted care
- Areas are funded equitably.
- **Inadequate services in some Areas.** Areas that have recently had an increase in the numbers of people diagnosed with HIV/AIDS such as SWSAHS, NRAHS, MNCAHS and other Areas which have staff recruitment and retention problems such as GMAHS and FWAHS, have difficulty providing basic HIV care and treatment services.
- **Patient complexity and the need for integrated services.** Most submissions commented on the increased complexity of HIV patients. This patient complexity refers largely to co-morbidities and other associated problems such as depression, cognitive impairment, dual diagnosis (HIV, hepatitis, STI, mental health and drug and alcohol) and behaviour, anxiety and adjustment disorders. In addition there are side effects of treatment and physical problems associated with ageing. The problems/co-morbidities of many PLWHA require that HIV services are well integrated with other services, especially mental health and drug and alcohol services.
- **Duplication of services, competitiveness, poor communication.** Comments about service duplication, competition and poor communication between services, unclear referral pathways in high prevalence Areas were made in submissions from Area Health Services as well as non government organisations.
- **Access to some services such as allied health, dental, highly specialised drugs is an issue.** Also some population groups – people from a CALD background, Aboriginal and Torres Strait Islander people, inmates of correctional facilities, people in rural Areas – have reduced access to services.
- **Supported accommodation.** The respective roles of the NSW Department of Health, Department of Disability and Aged Care, Department of Housing in providing supported accommodation is not always clear. This is an issue that needs to be resolved as changes occur in the nature of the progression of HIV/AIDS so that it now resembles a chronic disease, resulting in an increase in the need for a range of supported accommodation services. This clarification

of roles and responsibilities should include the other supported accommodation services providers, namely non government organisations.

- **Increasing prevalence of PLWHA with ADC and other neurological complications.** People with ADC are now living an average of 44 months after diagnosis; approximately four times longer than they were in pre-HAART times, when the average life expectancy was only six months after ADC diagnosis.
- **Distribution and number of GPs.** The maldistribution and lack of GPs with s100 prescribing rights for antiretroviral treatments was highlighted in submissions, especially outside SESAHS.
- **Post Exposure Prophylaxis.** Post exposure prophylaxis (PEP) with antiretroviral medications and counselling has been offered in NSW to persons at risk for HIV exposure through sexual activity or injecting drug use since 1999. It has been proven to be very effective, however Areas should also ensure that there are clear guidelines for clinicians regarding compliance with recommended prescribing and followup protocols and PEP policies and procedures need to be reinforced in Emergency Departments in hospitals.
- **Low risk HIV antibody testing.** A number of the submissions were concerned about the extent of low risk testing that occurs among surgical and obstetric patients. It is estimated that only about 1% of the total number of samples sent for an HIV test, are positive. Despite the decline in the number of newly infected cases, the number of HIV antibody tests continues to increase from 149,000 in 1996/97 to 253,000 in 2001/02. Thus substantial savings could be made by targeting the request for testing to high risk individuals.

1.3 Proposed strategic directions

1. **Continue to endorse the planning principles outlined in the previous Review of HIV/AIDS Care and Treatment Services**
2. **Recognise the changing treatment pattern of HIV/AIDS, in particular the shift from inpatient to ambulatory care**

Priority areas for action

- Data on the cost of inpatient services is currently available and AHS should be required to monitor their inpatient utilisation and justify their inpatient allocation against this utilisation. Ideally funds would be allocated to both inpatient and non inpatient services on the basis of the relative utilisation but consistent and comparable data on non inpatient services are not available.
- Role delineation guidelines should be reviewed and the service descriptions changed to reflect the pattern of treatment and care for people with HIV so that there is less emphasis on admitted services and more emphasis on non admitted services. Core allied health services need to be identified and links to mental health and drug and alcohol should be noted.

3. **Articulate models of HIV/AIDS service delivery in Areas with a high, moderate and low prevalence of PLWHA**

Priority areas for action

- NSW Health should define models of care for high, moderate and low prevalence Areas in collaboration with AHSs, non government organisations and GP representative bodies such as ASHM and HIV/AIDS research organisations.
- An ongoing joint planning forum of SESAHS and CSAHS should be established to ensure services are well coordinated between the two Areas especially on the boundary where there is a concentration of PLWHA. Non government organisations must also be partners in a joint planning activity of this nature.

4. Develop mechanisms to enhance the integration and coordination of services

Priority areas for action

- Policy linkages and service agreements need to be developed between HIV services, Mental Health and the Alcohol and Other Drugs Programs, resulting in services that are delivered in a more holistic way.
- Some services especially oral health services and counselling services are not readily available for PLWHA in some Areas. Strategies need to be developed in collaboration with the Oral Health and the Mental Health Branches as well as the non government organisations, to determine how these services can be made more accessible and/or more effective for PLWHA.
- The feasibility of establishing new HIV services such as treatment for metabolic conditions such as lipodystrophy and lipoatrophy needs to be explored.
- Roles and responsibilities of all the main providers – specialists, GPs, sexual health services, non government organisations – need to be clearly defined, referral protocols and lines of communication clearly established. It may be appropriate to develop service agreements between these key providers based on these policies and procedures.
- To avoid duplication of services and to ensure a better continuum of care, a policy of case management for people with complex needs should be developed. This is especially relevant in the inner city where patients seek services across Area borders from both SESAHS and CSAHS.

5. Improve access to some services and for some population groups

Priority areas for action

- NSW Health should continue to pursue negotiations with the Australian Government regarding access to services for those without a Medicare card.
- Continued access to confidential and free HIV testing at sexual health centres is vital to ensure that risk populations have low threshold access to screening.
- Services need to be mindful of the need to balance the expectations and values of a diverse range of clients groups, in order to ensure a culturally appropriate service and ongoing access for all affected. This may require specific values training or

promotion strategies, or demographically targeted services, according to the population characteristics of PLWHA in the Area.

- Areas with large Aboriginal populations such as CSAHS, WSAHS, NEAHS and FWAHS need to have adequate sexual health services to facilitate a reduction in STIs and hence avert the increased risk of transmission of HIV to this population.
- Staff in specific HIV services and mainstream services (government and non government) need to have access to cultural awareness training, adhere to confidentiality protocols, and be trained to be non discriminatory and non judgmental.
- NSW Health needs to continue negotiations with the Australian Government to increase community access points for highly specialised drugs.

6. Develop and implement strategies that maximise people's access to PEP

Priority areas for action

- All Areas, but SESAHS in particular, should develop and implement strategies which direct people seeking PEP to their local services – rather than to a central site such as St Vincent's. Areas should also ensure that there are clear guidelines for clinicians regarding compliance with recommended prescribing and followup protocols. Such strategies will minimise costs and reduce inappropriate subsidy of treatment for out of Area patients. Areas may also wish to consider implementing strategies to review cases for which PEP is prescribed prior to dispensing a full month's supply of treatment.
- PEP policies and procedures need to be reinforced in Emergency Departments in hospitals.

7. Develop a supported accommodation strategy

Priority areas for action

- Commence inter-agency discussions to clarify further the respective roles and responsibilities of government and non government organisations in the provision of supported accommodation services for PLWHA. These discussions would involve the State government departments of Health, Housing, DADHC, the Australian government and non government organisations.

- Develop a supported accommodation strategy which ensures an adequate range of services across the spectrum of need, plans for projected need over the next five to ten years and is based on an agreed delineation of roles of responsible agencies.

8. Maintain funding for statewide services

Priority areas for action

- Articulate the criteria for defining and funding a statewide service. These criteria would provide a basis for the identification of services that may be eligible for funding, and for future performance monitoring.
- Monitor and evaluate the performance of these services regularly to establish their continued relevance for funding as a statewide service.
- Develop service agreements with these statewide services that include performance measures.
- Evaluate the HIV Dental Program for its effectiveness and in collaboration with the Oral Health Branch determine whether it would be more appropriate to move towards an oral health service model incorporating prevention and health promotion.
- NSW Health needs to follow up and obtain details about the number of HIV-related autopsies provided by the Institute with a view to assessing whether it should continue to be funded as a statewide service.

9. Address maldistribution and increase number of s100 accredited GPs

Priority areas for action

- Explore with ASHM the options for improving the number and distribution of s100 prescribers.

10. Develop strategies to improve GPs knowledge of HIV medicine

Priority areas for action

- Explore strategies to address this issue with ASHM and other relevant organisations such as the Royal Australian College of General Practitioners, and the Australasian College of Sexual Health Physicians.

11. Foster partnerships between AHS and non government organisations

Priority areas for action

- Identify the range of mechanisms needed to ensure adequate and appropriate involvement from non government organisations in the planning and development of services.
- Review existing service agreements with non government organisations to ensure they are adequate in the delineation of services to be provided and the specification of linkages with relevant services.

12. Continue support for workforce development

Priority areas for action

- Area Health Services should develop workforce strategies that complement their HIV service model and clearly identify the skills they are aiming to develop or enhance among their staff.
- To help address the challenge of retaining a community care workforce, non government organisations should explore the potential of offering shared traineeships in HIV community care under the newly revised National Community Training Package as well as the scope for increased use of Australian Government traineeships supported by on the job training and competency assessment.

13. Evaluate some specific laboratory issues

Priority areas for action

- Assess the issues defined above to facilitate the more cost effective provision of HIV/AIDS laboratory services.

14. Enhance utilisation data and service monitoring

Priority areas for action

- The Minimum Data Set currently being trialled in SESAHs needs to be evaluated to assess its applicability to other Areas and to non government organisations and to determine the feasibility of extending it to other Area Health Services and to non government organisations.
- A monitoring framework with standard performance indicators needs to be developed to allow an annual review of the activity of all HIV/AIDS services across all Area Health Services.
- A similar monitoring framework is needed in the non government sector so that data definitions and activity measures are standardised across the sector.
- The proposed enhanced laboratory surveillance system needs to be evaluated.

2 Introduction

2.1 Background

New HIV therapies have resulted in fewer AIDS deaths and reduced demand for HIV/AIDS inpatient care. However increased longer term survival of people living with HIV/AIDS (PLWHA) together with new cases each year, has increased the overall prevalence of PLWHA. This trend has resulted in the ongoing demand for non inpatient specialist hospital services, and an increasing demand for mental health services, drug and alcohol services, community home nursing, GP services, counselling and peer support, supported accommodation and respite care. At the same time there has been an increased demand for complex pathology services related to monitoring the effect of drug therapy and significant costs associated with routine HIV antibody testing for all surgical patients, regardless of risk.

NSW Health is responsible for statewide policy and strategic planning, determining priorities for HIV/AIDS care and treatment, identification of minimum service requirements for Areas, and monitoring service provision. Area Health Services are responsible for the planning, coordination and provision of local HIV/AIDS health promotion, care, treatment and support services. Additional health promotion, care, treatment and support services are provided by specialist community based non government organisations. There is constant pressure on NSW Health and on the Areas and non government organisations to find the right balance between spending on preventative services such as health promotion and spending on treatment services.

NSW Health released a report on the Review of HIV/AIDS Care and Treatment Services in May 2000. This current project aims to determine the extent to which the needs of PLWHA have changed since the previous review reported in 2000 and to use these needs to make recommendations regarding the strategic framework for providing HIV care and treatment services and service models for the next triennium. It is intended that the findings inform reorganisation and realignment of HIV care and treatment services where appropriate based on identified and emerging needs. That reorganisation and realignment would occur within existing resources (see terms of reference in Appendix A).

To determine the needs of PLWHA and to formulate options for the future organisation and delivery of services the following tasks have been undertaken:

- an overview of the epidemiology of HIV/AIDS
- a review of relevant policy and planning documents and reports from NSW Health, Australian Government Department of Health and Ageing
- a select literature review of the evidence in relation to models of care and treatment for PLWHA
- a broad profile of HIV/AIDS services in metropolitan and rural Area Health Services in NSW in terms of the services provided and the model of service delivery
- a description and analysis of the utilisation of statewide HIV/AIDS services including Sydney Children's Hospital Paediatric HIV Service, Haemophilia Counselling Service, Multicultural HIV/HCV Service, Workforce Development Project, ADAHPS, NSW Infection Control Resource Centre, NSW 24-Hour Needlestick Injury Hotline
- an analysis of the current utilisation of inpatient and non inpatient services over the last two to five years in Area Health Services with Level 5/6 HIV/AIDS services including details of patient casemix complexity, number of sameday admissions, cross Area flows etc
- an analysis of the current utilisation of inpatient and non inpatient services over the last two years in Area Health Services with HIV/AIDS services below Level 5 including details of patient casemix complexity, number of sameday admissions, cross Area flows etc
- an estimate of future projections of HIV/AIDS services which take into account the potential effect of current and emerging HIV treatments
- an analysis of trends in the utilisation of services and models of care of non government organisations
- a review of the role of GPs in the provision of HIV/AIDS services
- a review of workforce issues for Area Health Services and non government organisations in the provision of HIV/AIDS services

- an examination of arrangements for access to highly specialised drugs and the identification of options for improving access
- an analysis of trends in the utilisation and cost of Post Exposure Prophylaxis and the identification of options for improving access
- an analysis of the utilisation and capacity of laboratory services to undertake HIV antibody testing, viral load testing/PCR, viral resistance testing, other HIV-related testing and the identification of options to streamline AIDS program funding for this testing
- an examination of recent reviews of health promotion and the identification of opportunities for the integration of health promotion with treatment, care and support
- a broad appraisal of the range of support services including dementia care, case management, day services, housing/accommodation and dental services, in terms of their capacity, use and appropriateness of model of care.

2.2 Approach to this project

Because of the broad scope of this project and the relatively short time frame, which was interrupted by the Christmas/January holiday period, the following approach was adopted. Instead of the usual individual consultations at the beginning of the process, time was spent developing a proforma, which was sent out to all Area Health Services and other (non health) government and non government organisations seeking data on the utilization of their services (see Appendix B). In this initial phase there was also a call for submissions (a guide to the preparation of submissions and the proforma is also included in Appendix B).

Then in the second and third week of February 2004 there was a series of half-day workshops with key stakeholders.

The purpose of the workshops was use the expertise of invited participants to assist the consultants in:

- reviewing trends from relevant service utilisation data, and issues and themes raised in submissions
- identifying key areas of change in the needs of PLWHA since 2000
- exploring the implications of these changes, especially in terms of options for the reorganisation and realignment of HIV care and treatment services.

There were seven workshops in total held for the following groups of people:

- staff of Level 5/6 services and other relevant services (mental health, palliative care, drug and alcohol, sexual health, health promotion)
- staff of Level 4 and below services in metropolitan Areas and staff from other services such as drug and alcohol, mental health, sexual health, health promotion
- HIV/AIDS coordinators
- laboratory staff
- staff of non government organisations
- general practitioners
- PLWHA.

It was proposed that the maximum number of participants at each workshop would be 20. Invitations were sent out by the AIDS/infectious Diseases Branch (AIDB) of NSW Health.

All Area Health Services responded to the survey of services and call for submissions in addition to a number of other government and non government organisations. The extent of the response is shown in Table 1.

Table 1. Response to survey and call for submissions

Organisation	Survey	Submission
Area Health Service		
WSAHS	+	+
WAHS	+	+
SWSAHS	+	+
SESAHS	+	+
NSAHS	+	
CSAHS	+	+
CCAHS	+	+
HAHS	+	
IAHS	+	
FWAHS		+
MWAHS	+	
MAHS	+	
NEAHS	+	+
NRAHS	+	+
GMAHS	+	+
MNCAHS	+	
MWAHS	+	+
SAHS	+	+
Corrections Health		+
Statewide Services		
Multicultural HIV/HCV	+	+
Albion St Centre	+	+
Ankali	+	
ADAHPS		
NGOs		
PLWHA NSW		+
The Haven	+	+
Stanford House	+	+
Positive Support Network Inc	+	
ACON	+	+
NorthAIDS	+	
BGF		+
People with Disability Inc		+
ASHM		+
Foley House		+
Haemophilia Foundation	+	+
Other		
RACGP – Michael Kidd		+
St Vincent's Reference Laboratory for HIV/AIDS		+
DADHC		+
DOCS		+
Corrective Services		+
Housing		+

An Advisory Committee was established to guide the service and needs assessment. The Committee was chaired by Dr Roger Garsia, Director of Clinical HIV Services at RPA and also Chair of the NSW Ministerial Advisory Committee on HIV and Sexually Transmissible Diseases. Members of the Committee represented the NSW Health Department (AIDS and Infectious Diseases Branch), non metropolitan HIV/AIDS services, non government organisations, the HIV/AIDS Coordinators, PLWHA, the Australasian Society for HIV Medicine (ASHM), and General Practitioners. The names of Committee members are provided at the beginning of this report.

The Advisory Committee met at key stages of the project, including to review the methodology, the preliminary findings and strategic directions, and the draft report.

3.1 Australian Government

Australia's first National HIV/AIDS Strategy was released in 1989. This Strategy had a number of distinctive features, among them the notion of partnership – between governments, affected communities, researchers, educators and health professionals – and the adoption of innovative education and prevention initiatives as a means of preventing the spread of the virus. These features were retained in both the second (1993/4 to 1995/6) and third (1996/7 to 1998/99) Strategies. The third Strategy emphasised the need to link and integrate related responses in an effort to sustain and maximise the population health benefit.

The current National HIV/AIDS Strategy (2000) consolidates and extends this emphasis on integration and more effective links with related programs and policies. The central elements of Australia's response to HIV/AIDS in the five years to 2003/04 are as follows:

- a national strategy approach
- an enabling environment
- non partisan political support
- health promotion and harm minimisation
- the partnership approach
- the involvement of affected communities
- linked strategies.¹

This fourth strategy has five priority areas to guide implementation:

- an enabling environment
- HIV/AIDS related health promotion, including disease prevention
- treatment, care and support
- research
- international assistance and cooperation.

Under **treatment, care and support** some of the challenges identified include:

- the development of a coordinated continuum of care which is integrated and client oriented
- ensuring access to approved therapies and monitoring tools, such as viral load testing
- extending access to antiretroviral drugs beyond hospital pharmacies and in rural and remote communities
- supporting GPs and sexual health physicians in rural and remote communities
- ensuring access to mental and other health services.

¹ According to the Strategy, the other population health initiatives that have a bearing on the health and wellbeing of people living with and affected by HIV/AIDS are: the National Drug Strategic Framework 1998-99 to 2002-03; the National Indigenous Australians' Sexual Health Strategy 1996-97 to 1998-99; Building on Success 3, the Australian Government's response to Towards a National Strategy for HIV/AIDS Health Promotion for Gay and Other Homosexually Active Men; the National Mental Health Strategy; the National Suicide Prevention Strategy; Healthy Horizons: a Framework for Improving the Health of Rural, Regional and Remote Australians 1999-2003; and Health of Young Australians: A National Health Policy for Children and Young People.

3.2 NSW Government

NSW Health last undertook a review of its HIV/AIDS care and treatment services in 1998. The report from this review (NSW Health 2000) made a number of recommendations in the following areas:

- service utilisation monitoring
- maintenance of current 5/6 hospital services
- a stronger focus on ambulatory and community based services
- a review of the AIDS Resource Allocation Formula
- promotion of the use of case management and coordinated care models
- the need for better home support for PLWHA
- better access to dental services
- the adequacy of current referral arrangements between public sector services and GPs and between HIV services and mental health services and HIV services and drug and alcohol services
- the role of the AIDB in planning of HIV/AIDS services.

Many of these issues are still relevant today as only some of the recommendations have been implemented.

In 2000 the NSW Ministerial Advisory Committee on AIDS Strategy (CAS) prepared *Statement of Strategic Directions*, the main purpose of which was 'the creation of a framework which promotes the improvement of health through measures that prevent the transmission of HIV and reduce the impact of HIV within the community.' The Statement identifies emerging challenges and outlines clear strategic directions for future action. The strategic directions for the future in relation to treatment, care and support services are:

- development by the partnership (government, community organisations, the medical and scientific communities and PLWHA) of triennial care and treatment plans
- promotion of data standardisation for all aspects of HIV related service delivery
- development of sentinel indicators of changes in demand for clinical care
- development of strategies to maintain a core of clinical expertise in hospital and community settings
- ongoing monitoring of utilisation and morbidity data and guidelines for monitoring and allocation of resources.

The Statement also identified the roles and responsibilities of the Australian Government, State, Area Health Services, community based and non government organisations, and local authorities and proposes strategic directions in relation to education and prevention, research, funding and monitoring and evaluation as well as to treatment care and support.

This current HIV/AIDS Care and Treatment Services and Needs Assessment is being undertaken at the same time as a review of the NSW HIV/AIDS Health Promotion Plan, and a review of the AIDS Program Resource Distribution Formula. Findings from all of these projects will form the basis of the next triennial NSW HIV/AIDS Strategy.

Epidemiology, HIV treatment, profile of PLWHA and projections

4

4.1 Epidemiology

4.1.1 Definition of HIV and AIDS

The Human Immunodeficiency Virus (HIV) attacks the human immune system, leaving infected individuals vulnerable to chronic, progressive illness, opportunistic infections and cancers. Once those infected with HIV cross a certain medically defined threshold, they are described as having Acquired Immunodeficiency Syndrome (AIDS).

The virus spreads as infected body fluids – blood, semen, vaginal fluids and breast milk – pass from one person to another through for example, unprotected sexual intercourse, shared needles or vertical transmission from mother to child (in vitro, during delivery or through breast feeding). At present there is neither a vaccine to prevent HIV infection nor a cure for AIDS, however it is entirely preventable.

4.1.2 Number of new HIV infections, AIDS diagnoses and AIDS deaths

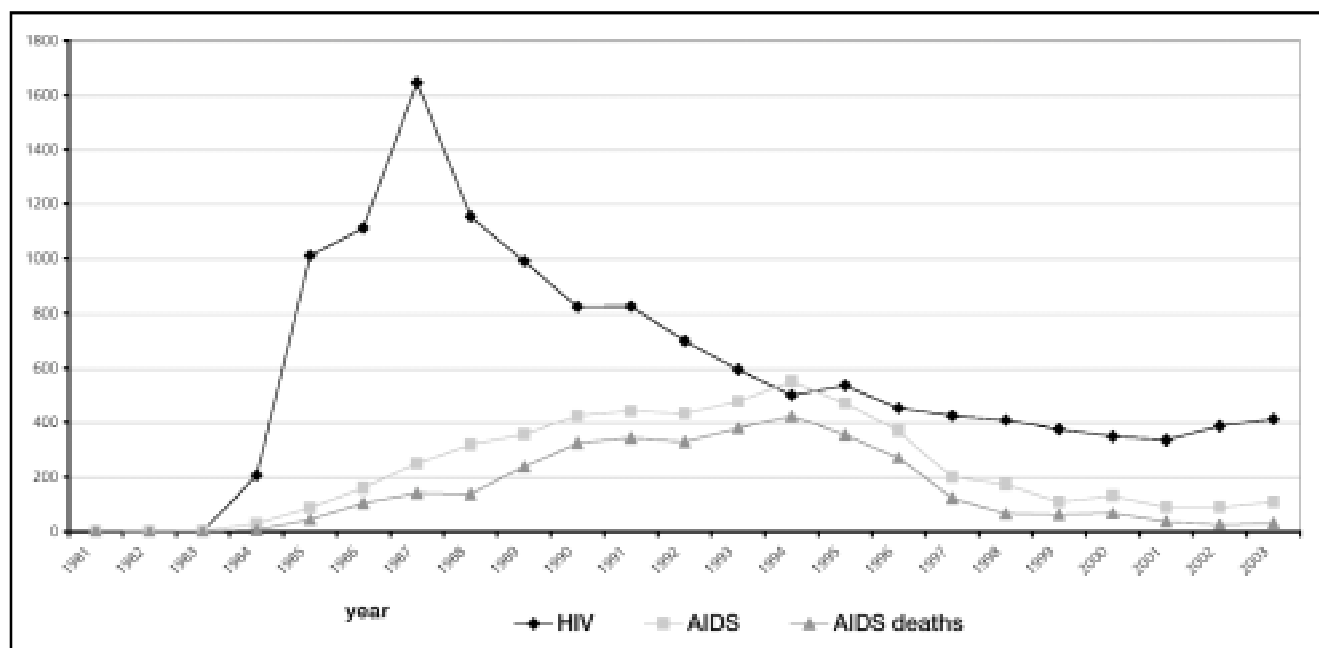
According to the National Centre in HIV Epidemiology and Clinical Research's *Annual Surveillance Report 2003*, (NCHECR 2003) there had been 19,674 HIV infections diagnosed in Australia at the end of 2002, and an

estimated 13,120 people were living with HIV infection. The per capita rate of HIV infection is highest in NSW with 5.8 diagnoses per 100,000 over the last five years followed by Victoria with 3.8 per 100,000, then the Northern Territory and Queensland – both with 3.3 per 100,000 – then the Australian Capital Territory (2.5 per 100,000), Western Australia (2.4 per 100,000), South Australia (2.0 per 100,000), Tasmania (0.7 per 100,000).

In NSW at the end of 2003, there had been 13,235 HIV infections diagnosed, 5,325 AIDS diagnoses, 3,532 AIDS deaths and an estimated number of 9,703 people are living with HIV infection. Figure 1 shows the trend in the number of notifications of HIV, AIDS and AIDS deaths by year in NSW from 1981–2003.

The highest number of HIV notifications in NSW was in 1987 when there were 1646 cases. Since that time the numbers have decreased steadily to 337 cases in 2001. There was a slight rise in 2002 to 387 cases and this upward trend has continued in 2003 with 412 new HIV notifications. The peak of the epidemic in terms of AIDS diagnoses and AIDS deaths was in 1994 when there were 552 and 424 cases respectively. By comparison in 2003, AIDS diagnoses were 112 and AIDS deaths were 31.

Figure 1. Notifications of HIV, AIDS and AIDS deaths by year, NSW, 1981–2003

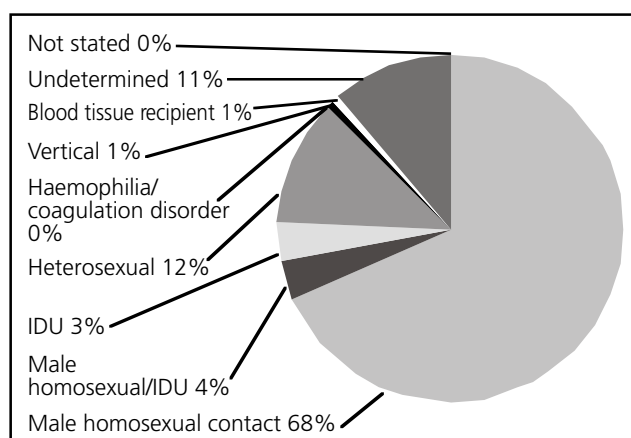


Source: NSW Health Notifiable Diseases Database

4.1.3 Risk exposure category

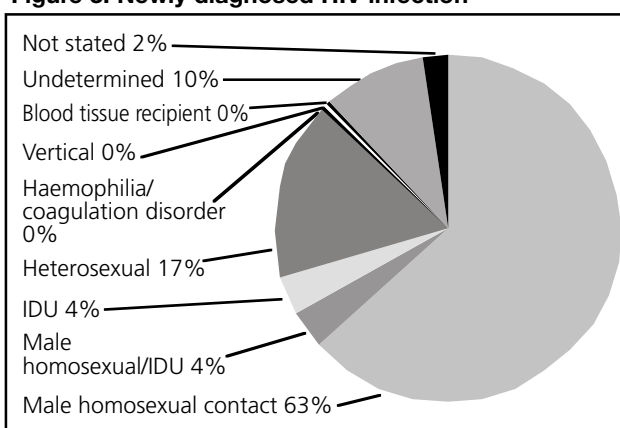
The number of newly reported HIV cases is highest among homosexual-bisexual men although this number has been generally declining since 1993² from 424 cases to 246 cases in 2002 (Table 2). The next largest group is the heterosexual group and even though the numbers have remained relatively stable over this 10 year period (see Table 2), this group has increased as a proportion of the total newly reported infections from 9% in 1993 to 15% in 2002. Figures 2 and 3 show the proportion of cases in each exposure category for two five year periods from 1993–1997 and from 1998–2002. During the first period, the male homosexual group represented 68% of total new HIV infections and the heterosexual group was 12% of the total. In the second five year period, the male homosexual group comprised 63% of new HIV infections and the heterosexual group was 17% of the total.

Figure 2. Newly diagnosed HIV infection by exposure category, NSW, 1993–1997



Source: NSW Health Notifiable Diseases Database

Figure 3. Newly diagnosed HIV infection by exposure category, NSW, 1998–2002



by exposure category, NSW, 1998–2002

Source: NSW Health Notifiable Diseases Database

See Table 2 for the actual numbers in each category.

4.1.4 Area of residence

Newly diagnosed cases of HIV are concentrated in the areas of South Eastern Sydney and Central Sydney. These are the Area Health Services' of residence for 62% of cases diagnosed in the five-year period, 1998–2002. The remaining 38% are scattered throughout the remaining 15 Area Health Services, in particular Northern Sydney (7%), Western Sydney (7%), South Western Sydney (6%), Hunter (2%), Northern Rivers (2%), Illawarra (2%) and Wentworth (2%). The Areas of Central Coast, Greater Murray, Mid North Coast, Mid Western and New England each had 1% of newly diagnosed cases and there were 5% of cases for which the Area Health Service of residence was undetermined or unstated (see Figure 4).

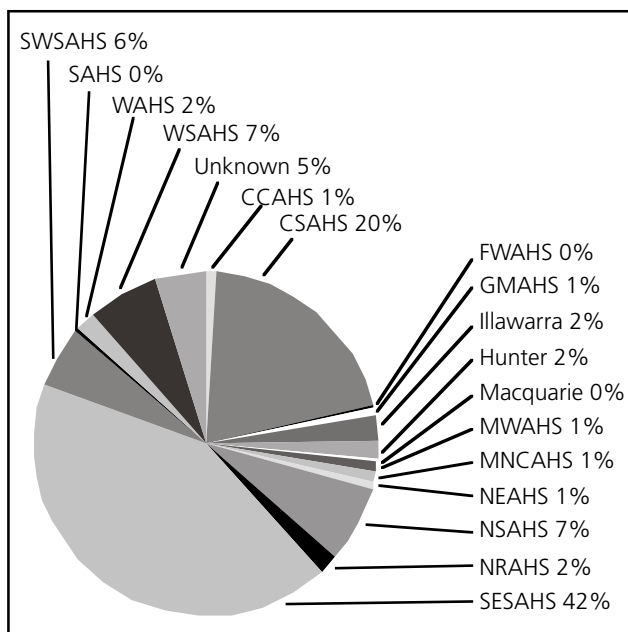
Table 2. Number of newly diagnosed HIV infections in NSW by year and risk exposure category

Risk exposure	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Male homosexual-bisexual	424	346	365	299	285	246	246	230	211	245	278
Male homosexual-bisexual and IDU	12	24	24	14	17	16	14	8	18	12	8
Injecting drug use	20	18	20	17	11	9	12	20	18	8	12
Heterosexual	55	61	65	58	62	89	57	59	56	56	63
Haemophilia–Coagulation disorders	0	0	1	0	0	0	0	0	0	0	0
Blood tissue recipient	3	7	2	4	1	0	1	0	0	0	0
Vertical	3	7	5	2	1	2	1	2	0	1	2
Undetermined and not stated	77	39	56	59	50	41	44	31	34	65	49

Source: NSW Health Notifiable Diseases Database, 29 April 2004.

² 1993 is the earliest year for which the number of 'undetermined' is at a reasonable level ie 13%. Before 1993 the proportion of 'undetermined' sometimes was as high as 33%.

Figure 4. Newly diagnosed HIV infection by Area Health Service of residence, NSW, 1998–2002

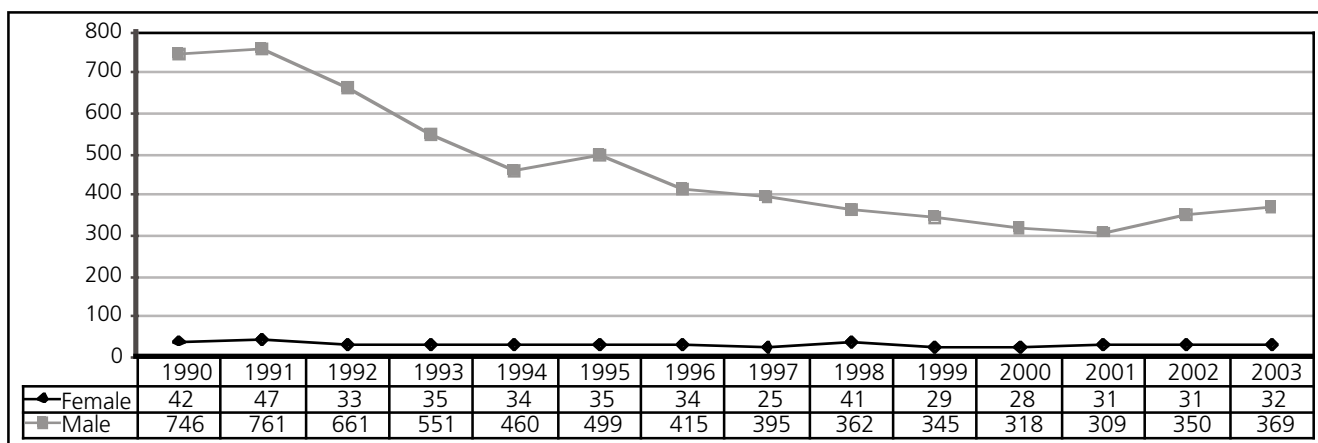


Source: NSW Health Notifiable Diseases Database

4.1.5 Gender

Women represent only a small number of the total number of newly diagnosed HIV infections (see Figure 5). However they are increasing as a proportion of the total. Between 1990 and 1994 they were 5.7% of the total number of new infections, this increased to 7.5% in the period 1995–1999 and was 8.9% for the four years 2000 to 2003. NCHECR's Annual Surveillance Report 2003 reports that an increasing number of HIV diagnoses among women was associated with heterosexual contact in a high prevalence country or heterosexual contact with a partner from a high prevalence country in sub Saharan Africa or Asia (NCHECR 2003:20).

Figure 5. Newly diagnosed cases of HIV infection by gender, NSW, 1990–2002



Source: NCHECR (2003) and NSW Health Notifiable Diseases Database for 2003 data

4.1.6 Age

At the time of HIV diagnosis, the majority of people (39%) are in the 30-39 year age group. Another 29% are in the 20-29 year age group and 20% in the 40-49 year age group.

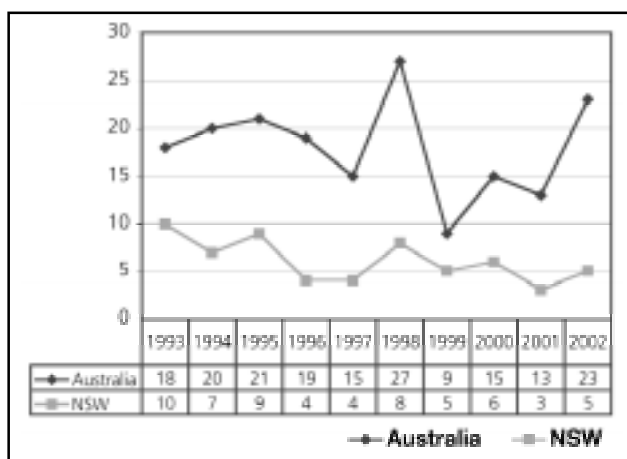
4.1.7 People from culturally and linguistically diverse backgrounds

The number of newly diagnosed cases of HIV who speak a language other than English is increasing as a proportion of the total. In the period 1991–1995 they represented 5% of the total number of new cases, in the period 1996–1999 this figure increased to 11%, and for the three years 2000–2002, it was 17%. These people tend to present at services later than the English speaking population (NCHECR, 2003). Of the 537 people who spoke a language other than English (LOTE) and were newly diagnosed with HIV between 1991 and 2002, 221 (41%) were exposed to HIV through heterosexual contact compared to 14% of all newly diagnosed cases of HIV in this category for this same period (NSW Health Notifications data). This proportion has increased over time: the proportion of heterosexual notifications that spoke a LOTE at home was 52% of notifications between 1996 and 1999 and between 2000 and 2002, this proportion increased to 78%.

4.1.8 Aboriginal and Torres Strait Islander People

Nationally between 1993 and 2002, 180 HIV diagnoses and 69 AIDS diagnoses were notified among Aboriginal and Torres Strait Islander people. Exposure to HIV was attributed to an almost equal proportion of heterosexual (37%) and male homosexual (36%) contact. A higher proportion of HIV diagnoses were associated with injecting drug use (20%) in Aboriginal and Torres Strait Islander people compared to 4% in non Indigenous people (NCHECR, 2003). Figure 6 shows the number of newly diagnosed HIV infections for the Indigenous population nationally and for NSW. The sharp increase in 2002 nationally was mostly related to an increase in notifications in Western Australia.

Figure 6. Newly diagnosed HIV infection in the Aboriginal and Torres Strait Islander population by year for NSW and Australia



Source: NCHECR (2003)

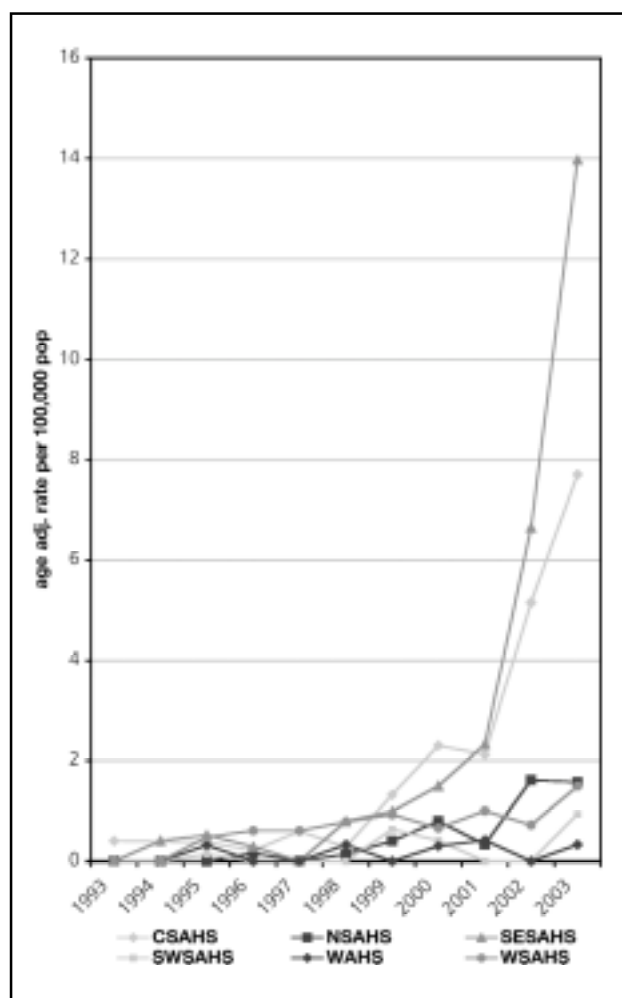
4.1.9 Other sexually transmissible infections

There is good evidence that most STIs act as a co-factor in the transmission of HIV. Increases in the rates of STIs also indicate that people at risk may be becoming less vigilant about always adopting safe sex practices.

Almost all State/Territory health jurisdictions reported an increased number and population rate of diagnosis of syphilis in 2002 compared to 2001. In Sydney, newly acquired infections were reported among homosexually active men at Levels that had not been seen in the recent past (NCHECR 2003).

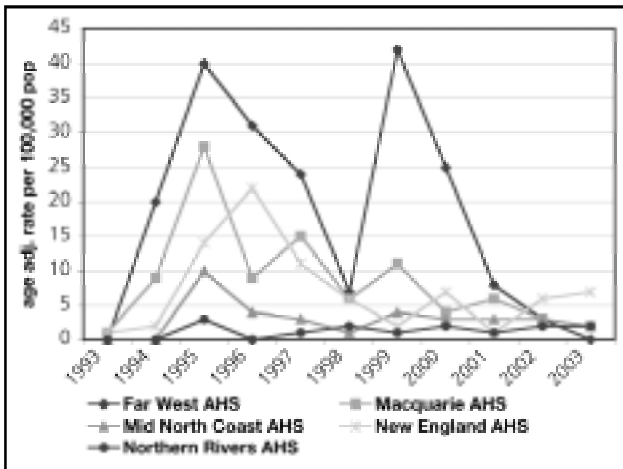
Figure 7 shows the rate of syphilis notifications in metropolitan Area Health Services for the last 11 years. There has been an alarming increase in the age adjusted rate per 100,000 population in the last few years in South Eastern and Central Sydney. Figure 8 shows the trend in rates over the last 11 years in selected rural Area Health Services. These rates are much higher than in the metropolitan Areas but the numbers are much lower because of their smaller population. The Far West and New England stand out in particular. Both Areas have a high proportion of Aboriginal people living within their boundaries.

Figure 7. Syphilis notifications by metropolitan Area Health Service by year



Source: NSW Health Notifiable Diseases Database

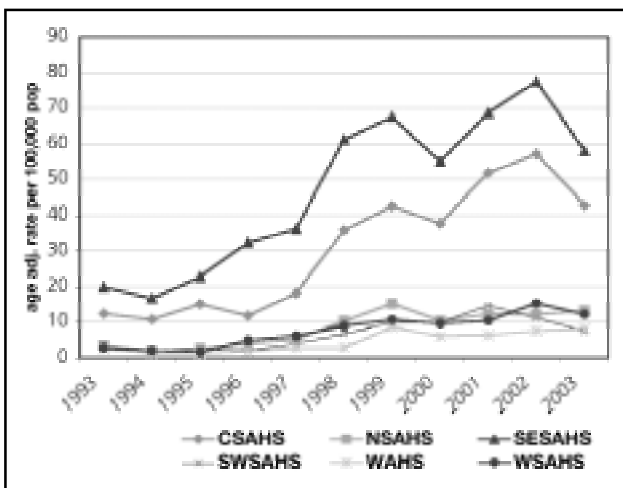
Figure 8. Syphilis notifications by selected rural Area Health Service by year



Source: NSW Health Notifiable Diseases Database

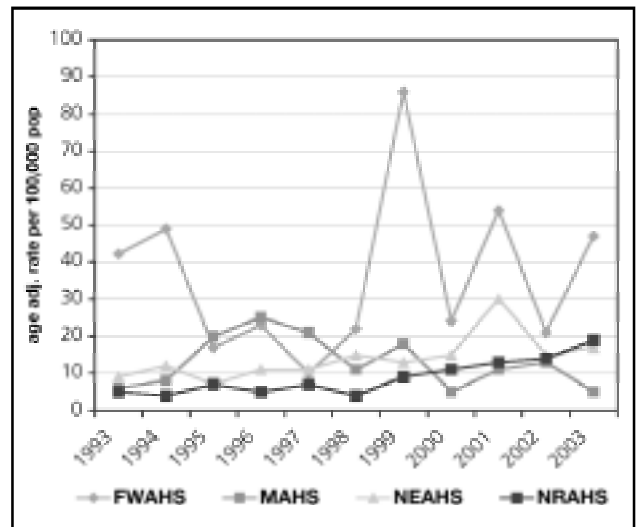
Gonorrhoea surveillance data provide another indication of a possible increase in sexual risk behaviour among gay and other homosexually active men in Australia. Figures 9 and 10 show notifications for gonorrhoea over the last 11 years by metropolitan and rural Area Health Service. Again South Eastern Sydney and Central Sydney stand out in the metropolitan area and the Far West, New England and Northern Rivers stand out in the rural areas.

Figure 9. Gonorrhoea notifications by metropolitan Area Health Service by year



Source: NSW Health Notifiable Diseases Database

Figure 10. Gonorrhoea notifications by selected rural Area Health Service by year



Source: NSW Health Notifiable Diseases Database

4.2 HIV treatment

The mid-nineties saw the introduction of the use of highly active antiretroviral therapy (HAART), which has significantly altered the course of HIV infection. HAART consists of treatment with combinations of drugs from three different classes, although not necessarily one drug from each class. Long term suppression of HIV replication occurs in about 60% of people who commence triple combination therapy (Orth, Hoy, Fitzgerald et al 2001). The consequent reduced viral load produces strong immune recovery in most patients. However the long term duration of the response in those who achieve viral control is not known nor is it known whether drug resistance and loss of efficacy will emerge. Most of the drugs have significant side effects and require complex dosing schedules, making adherence (a major determinant of resistance) an issue of concern. Long term survival may result in chronic drug toxicity and metabolic problems such as lipodystrophy, lipoatrophy, hyperlipidaemia, insulin resistance and hepatic mitochondrial toxicity (International AIDS Society – USA Panel, 2000).

It is estimated that almost nine out of ten (86%) of NSW PLWHA have taken antiretroviral drugs at some stage, with 73% using them currently (Grierson and Misson 2002).³ Of those who are currently taking antiretrovirals, 42% report that their health has improved; 42% also report that they experience side effects including diarrhoea, nausea, lipodystrophy, fatigue/lethargy and neuropathy. Almost three quarters (72%) report difficulties in taking their medication, the most common difficulty being to remember to take their medication on time. Those NSW PLWHA who are currently using combination therapy have done so for an average of four years and 11 months and 43% of them have taken a break from antiretrovirals at some stage.

4.3 Profile of PLWHA

4.3.1 Demographic, social and economic

In the HIV Futures study (Grierson and Misson 2002) the age of NSW respondents ranged from 23 to 70 years with an average age of 43.9 years. The NSW cohort of PLWHA had been seropositive for 10.5 years compared to 9.5 years nationally.

Thirty seven per cent have a major health condition other than HIV/AIDS including cardiovascular disease, diabetes, hepatitis B (HBV), hepatitis C (HCV) and asthma. One quarter (25%) of respondents from NSW reported having been diagnosed with a mental illness. For 80% of these people the diagnosis was depression. Eleven per cent indicated that they had been diagnosed with HCV.

Fifty nine per cent of the NSW sample had used marijuana in the last 12 months; 44% had used amyl, 33% ecstasy, 24% viagra, 22% speed (not injected), 12% speed (injected), 15% cocaine (not injected), 4% cocaine (injected), 9% LSD, 9% steroids (injected), 6% GHB/GBH/Fantasy, 3% methadone, 3% homebake, 2% heroin. Despite this usage, most PLWHA from NSW said they were not concerned about the amount of drugs they took.

Over half (51%) of NSW PLWHA were not in paid employment and of those working, 62% were full time. Nearly half of the working group reported that their capacity to perform their work duties is affected by having HIV/AIDS – they tire quickly, work fewer hours, or have difficulty concentrating.

Given the large number of PLWHA who are not in paid employment, it is not surprising that 45% of respondents reported that their main source of income is a government benefit, pension or social security payment. Just under half of respondents reported annual incomes below \$20,000 and 23% of Sydney PLWHA and 39% of rural PLWHA were living below the poverty line.

The majority of NSW respondents live in Sydney (80%). A third own or are purchasing their own home, 44%

³ This estimation is based on a major survey of HIV positive people, known as the HIV Futures survey – a self complete, mail back questionnaire obtaining information on demography, accommodation, health and treatments, services and organisations, sex and relationships, employment, recreational drug use and finances. Although recruitment to this study was voluntary, comparisons were made to the Australian HIV Surveillance Report and the data were weighted to conform with the demographic profile of that report so that the results reported accurately represent the Australian population of PLWHA.

rent privately (although a large proportion of these would be on a Disability Support Pension (DSP) and publicly subsidised in private rental accommodation under the Department of Housing's SAS-5 program), 11% live in public housing, 5% live rent free and 4% live in community housing. Forty eight per cent of NSW PLWHA live alone.

Over one third (35%) of NSW PLWHA had experienced discrimination when attending a medical service because of their HIV status, with 14% having experienced such discrimination in the last two years. This discrimination took the form of avoidance, confidentiality problems, being treated last, additional infection control, refusal of treatment, being rushed through, harassment and abuse. PLWHA from rural NSW were significantly more likely to have experienced discrimination at a medical service at some time than those from Sydney. Eleven per cent of PLWHA in NSW had also received less favourable treatment due to their HIV status in relation to accommodation and 18% had been discriminated against in relation to employment.

4.3.2 Changes in the needs of PLWHA

Due to the efficacy of HAART, PLWHA are living longer. They often have a number of co-morbidities, which are either pre-existing, associated with their treatment, or acquired as part of the progress of their HIV infection, general lifestyle factors, or the ageing process. They may also have socio-economic problems related to their HIV status as described above. Many of the submissions to this service and needs assessment refer to the 'increased complexity of HIV patients'. This patient complexity refers largely to these co-morbidities and other associated problems as well as the fact that PLWHA are now treated mostly in ambulatory settings (outpatients, day treatment areas, community health services, sexual health services, GP surgeries), which is very different to when HAART was not available. Pre-HAART, the pattern of illness associated with HIV was very different to now. Simply expressed it was as follows: contraction of HIV, period of up to 10 years of being relatively well, contraction of an AIDS defining illness, death. There was often not the time for the same number of co-morbidities to occur, there were none of the side effects associated with HAART and people with an AIDS defining illness were largely treated as inpatients because of the severity of their problems.

PLWHA vary along a continuum from those who are coping well, are in the workforce and living independently without any support, to those who have some or many of the co-morbidities/problems described above, and who require various Levels of home and community support. Some people on this continuum may need short term or medium term accommodation during difficult periods but many of these people may be able to return to independent living. There are also a small number of PLWHA on this continuum who have many problems such as other physical health problems, dual and triple diagnoses (HIV, mental health, drug and alcohol issues), co-infection with the hepatitises are at risk of other STIs, self harm, non adherence to medication, homelessness and unemployment. As a result these people are often seen to lead a 'chaotic lifestyle'.

At the end of the continuum there are people with AIDS dementia complex (ADC) who require 24 hour supported accommodation and in some cases, containment. Due to a very significant improvement in survival times following HAART, people with ADC are now living an average of 44 months after diagnosis of ADC – approximately four times longer than pre-HAART times (ADAHPS, 2003). Consequently there is an increase in the total numbers of people with ADC and therefore increasing numbers requiring higher Levels of care, in particular supported accommodation.

The Advisory Committee to this project was asked to estimate the number of PLWHA at various stages along this continuum. They estimated that the majority (maybe 70%) of PLWHA live independently in the community, are working and mostly only require regular monitoring. Another 29% have a greater need for services and this group becomes increasingly more complex. Included in this group are those on social security, who require more complex clinical care and generally benefit from a multidisciplinary response. Included in this group also are those in the 'chaotic lifestyle' category. The number of people with ADC is only small (approximately 1%), but because they are a growing group, their needs for supported accommodation are an important and significant issue. It is these 30% of people who probably consume the most time and resources of the health and non government HIV service providers.

4.4 Projections

In the last five years, there have been between 350 and 400 new HIV notifications each year (see Appendix C). Over the same five-year period the number of deaths have been between 70 and 26 a year. As discussed in section 4.1.2 the number of new notifications declined since the last review from 405 in 1998 to 337 in 2001 and then increased to 387 in 2002 and 412 in 2003. If it is assumed that the number of notifications will continue to increase slightly over the next five years and that there will be around 35 deaths annually, there will be an additional 2000 PLWHA in NSW in 2008, or between 11,500 and 12,000 in total.

MHAS estimate that treatment and care services in NSW will continue to experience demand from PLWHA with complex cultural and linguistic needs over the next five years, particularly from people born in Asia and sub Saharan Africa arising from HIV prevalence patterns overseas, immigration patterns and on-going mobility to and from areas of higher HIV prevalence.

Current services

5

5.1 Overview of current service arrangements

5.1.1 Roles and responsibilities

NSW Health has responsibility for statewide strategic planning of HIV/AIDS care and treatment services, which includes determining policies and priorities, identification of minimum service requirements for Areas and the monitoring of planning and service provision. Area Health Services are responsible for the planning, coordination and provision of local HIV/AIDS health promotion, care, treatment and support services. Additional health promotion, care, treatment and support services are provided by specialist community based non government organisations.

5.1.2 Funding

Up until 1997/98, Australian Government funding to the States under the National HIV/AIDS Strategy was tied to expenditure on HIV/AIDS services. Subsequently specific HIV/AIDS funding has been rolled into the broader Public Health Outcomes Funding Agreements (PHOFA) to give the States greater flexibility in its application and to shift the focus from inputs/processes to outcomes. NSW Health has maintained dedicated HIV/AIDS funding and annually allocates over \$72m to Area Health Services and non government organisations to provide HIV/AIDS services.

This funding is allocated to Area Health Services on the basis of the HIV/AIDS Resource Distribution Formula. This formula is currently under review. Included in this funding is an allocation of \$5.5m to some Area Health Services to provide statewide services, discussed in section 6 of this report. Nearly \$14m are allocated to non government organisations by a separate process. Non government organisations also provide statewide services (listed in Table 4 below) and they are funded centrally by NSW Health, while those which provide services within a particular Area Health Service are funded by that Area.

Table 3. AIDS funding to Area Health Services

Area Health Service 2002/03	Budget Allocation
CSAHS	10,212,104
NSAHS	3,946,531
WSAHS	4,442,708
WAHS	1,528,846
SWSAHS	2,446,900
CCAHS	984,403
HAHS	3,219,330
IAHS	1,311,975
SESAHS	25,301,811
<i>Total metropolitan AHS</i>	<i>53,394,609</i>
NRAHS	1,384,607
MNCAHS	840,698
NEAHS	583,990
MAHS	317,425
MWAHS	568,642
FWAHS	255,880
GMAHS	530,431
SAHS	508,364
<i>Total rural AHS</i>	<i>4,990,037</i>
Total all AHS	58,384,646

Source: NSW Health, AIDB Branch

Table 4. Non government organisation funded through the AIDS budget, 2002/03

Non government organisation	Annual Grant 2002/03
ACON	6,140,800
NCHECR	100,000
National Centre for HIV Studies	118,800
NUAA	973,300
Pharmacy Guild of Aust	1,770,200
PLWHA NSW Inc	434,900
Total grants for statewide NGOs	9,538,000
CCAHS	
Positive Support Network	38,000
CSAHS	
Family Planning NSW	417,300
Haemophilia Soc NSW	73,100
Leichhardt WHC	45,000
Stanford House Inc	141,100
The Gender Centre	207,800
W.H.O	101,910
HAHS	
ACON	102,700
Karumah Day Centre	115,300
IAHS	
Healthy Cities Illawarra – AIDS TF	24,700
NAHS	
NorthAIDS Inc	62,160
SESAHS	
ACON	248,100
ASHM	183,600
BGF	949,450
CRC Justice Support Inc	58,700
Eastern Suburbs Community Youth Association	18,630
Foley House Inc	872,300
Gamma	13,700
Gay & Lesbian Counselling Service of NSW	4,500
Luncheon Club	42,000
Youth Accommodaton Association	215,900
SWSAHS	
Cabramatta Community Centre	72,200
WAHS	
FPA – Warehouse	135,100
WSAHS	
ACON	81,800
The Haven	69,100
Total NGOs funded by AHS	4,294,150
Total all NGOs	13,832,150

Source: NSW Health, AIDB Branch

NSW Health has also funded Aboriginal sexual health projects since 1989/90. The Australian Government Office for Aboriginal and Torres Strait Islander Health (OATSIH) began contributing Special Funding for this purpose at the start of the *National AIDS Strategy 1993/94 to 1995/96*. In 2002/03 NSW Health received \$1,736,000 from OATSIH, NSW Health exceeded this allocation by contributing approximate additional funding of \$2,809,268 to Aboriginal sexual health. See details of this funding in Appendix D.

NSW currently has a large and advanced network of Aboriginal sexual health programs. This has been achieved through an effective partnership with the Aboriginal Health & Medical Research Council of NSW (AH&MRC). The implementation of the Aboriginal sexual health projects was based on the assessment of sexually transmissible infection (STI) and HIV rates; population distribution; and geographical coverage.

In total there are 40 Aboriginal sexual health projects in NSW, with an equal ratio of Aboriginal Community Controlled Health Services (ACCHS) and Non Government Organisations (NGO) to Area Health Services (AHS) projects.

The key objectives of the Aboriginal sexual health projects are to work with sexual health services and ACCHS to:

- assist in reducing the incidence of sexually transmissible infections (STI), HIV and hepatitis C virus (HCV) within local Aboriginal communities
- minimise adverse impacts of HIV, HCV and STIs by providing culturally appropriate services, support and education to the different target groups within the local Aboriginal communities
- improve the quality of life, life expectancy and reduce geographical isolation of HIV positive Aboriginal people through adequate treatment, care and support.

To ensure the success of the Aboriginal sexual health program in NSW, the AIDS/Infectious Diseases Branch (AIDB) continues to fund and establish additional initiatives including:

- a state-wide support network for the Aboriginal sexual health workers
- network training and development projects
- funding for workforce development

- specific funding for care and treatment at Redfern AMS
- the distance learning package for a *Diploma of Community Services (Case Management)* with a focus *Aboriginal Sexual Health Studies at the AH&MRC*
- the NSW Aboriginal and Torres Strait Islander Sexual Health Implementation Advisory Committee
- the NSW Sexual Health Implementation Plan for Aboriginal and Torres Strait Islander People.

5.1.3 Services

The Department of Health's role delineation guidelines (NSW Health 2002) describe six Levels of HIV/AIDS services (see Appendix E for details).

Seven hospitals (St Vincent's, Prince of Wales, Royal Prince Alfred, Westmead, John Hunter, Royal North Shore and Liverpool) located in six Areas (SESAHS, CSAHS, WSAHS, NSAHS, Hunter, SWSAHS) provide designated AIDS services (ie they are in Areas with Level 5/6 services – the highest Levels – as described in the role delineation guidelines). These hospitals have specialist multidisciplinary teams with experience and training in HIV. They accept referrals from Areas with lower Levels of service, they have specialist outpatient services; some have specialist community based HIV services and are involved in research and health care worker education.

All other Areas have services up to Level 4 which means that they have medical expertise in the management of HIV and related diseases, health promotion and education programs and a Level 3 Sexual Health Service.

A number of services also provide statewide HIV/AIDS functions – these include Sydney Children's Hospital Paediatric HIV Service, the Multicultural HIV/HCV Service, Workforce Development Program, the NSW Infection Control Resource Centre, the NSW 24 hour Needlestick Injury Hotline at Albion Street Centre, the AIDS Dementia and HIV Psychiatry Service (ADAHPS), the HIV/AIDS Dental Program, the Transfusion Related AIDS and Infectious Diseases Service (TRAIDS), and the Institute of Forensic Medicine.

Non government organisations have a major role in providing a range of services to PLWHA including information, counselling, care coordination, supported accommodation, peer support, volunteers and community services.

General Practitioners (GPs) have an increasing role in providing primary care as people with HIV/AIDS are living longer and more effective treatments become available. Antiretroviral prescribing rights are available to GPs trained in HIV medicine. Most Areas have at least one GP with these prescribing rights.

While antiretroviral therapy can be prescribed in the community (ie by GPs), the patient then has to attend a hospital pharmacy to obtain supplies. This is a requirement of the Australian Government, which funds these drugs under the Highly Specialised Drugs Program.⁴

Level 5/6 services

Level 5/6 HIV services in the six Areas listed have a variety of different service configurations. This difference is strongly related to the numbers of PLWHA living in the Areas. SESAHS and CSAHS have the most highly specialised services and it is estimated that these Areas have the highest prevalence of PLWHA.

There are no reliable data on the current distribution of PLWHA. However the NSW Health Notifiable Diseases Database data shows where people lived when they were first diagnosed with HIV. In the last five years 88% of new HIV diagnoses were in the metropolitan Area Health Services of SESAHS (42%), CSAHS (20%), NSAHS (7%), WSAHS (7%), SWSAHS (6%), WAHS (2%), Hunter (2%) and Illawarra (2%) (see Figure 4). Some people will have moved since their initial diagnosis and there is anecdotal evidence that there has been a movement of PLWHA to the MNCAHS and the NRAHS, but these numbers are relatively small. NRAHS estimates that there are about 300 PLWHA in the Area and MNCAHS estimates that they have about 70 people.

⁴ The Australian government provides funding to the States and Territories under section 100 of the National Health Act 1953, for certain drugs for chronic conditions which, because of their clinical use or other special features, are restricted to supply through hospitals having access to appropriate special facilities.

Current services

If it is assumed that the total number of PLWHA in NSW is between 7,779 and 9,703⁵ and if 62% live in SESAHS and CSAHS, there should be somewhere between 4,822 and 6,015 PLWHA in those two Areas. In addition to the number of people who live in SESAHS and CSAHS, PLWHA from other metropolitan AHSs travel to SESAHS or CSAHS for their treatment and care so it is not unexpected that there are more specialised HIV services in these two Areas.

South Eastern Sydney

Most of the specialised HIV services in SESAHS are concentrated in the northern sector of the Area around St Vincent's, Prince of Wales and Sydney Hospitals. They consist of designated specialist admitted services at St Vincent's and Prince of Wales, specialist outpatient clinics and a range of other ambulatory care services. There are palliative care beds at Sacred Heart Hospice. In addition there are specialist sexual health services attached to Sydney Hospital. St George Hospital has a specialist HIV inpatient and outpatient service and a sexual health service. Details of the services are given in Appendix F.

Due to the changing needs of PLWHA, a number of services have recently been established or enhanced to meet these needs – an Area HIV neuropsychology service, St Vincent's Community Health has a multidisciplinary team of nurses (including mental health nurses) and allied health staff who currently provide services to 86 HIV clients, two thirds of whom are co-infected with HCV or have mental health problems. H2M, the HIV, HCV and Mental Health Service, was established 16 months ago and provides GPs in the Darlinghurst area with access to mental health assessments. Albion Street Centre (ASC) has established a designated STI service to address the rising incidence of STIs in ongoing and new clients, particularly the diagnosis and treatment of gonorrhoea and syphilis. ASC also provides outreach nutrition and psychology services to patients of local GPs and, in the case of nutrition, to HIV non government organisations.

There are an estimated 14 GPs in private practice with s100 prescribing rights in the Area and there are four high caseload practices in the Darlinghurst locality.

For details of HIV/AIDS services in SESAHS, see Appendix F.

Central Sydney

Central Sydney's HIV/AIDS services are concentrated mainly in the eastern sector of the Area, around Royal Prince Alfred (RPA) Hospital. There are four designated HIV/AIDS beds in the Immunology ward of RPA and inpatients have access to a range of allied health services, palliative care and consultation/liaison psychiatry services. PEP is offered through Emergency Departments in all hospitals in the Area.

A 12-bed unit called the Bridge provides 24 hour supervised high Level nursing care for patients with dementia who can no longer live alone or whose carers can no longer cope.

Ambulatory services include a day treatment area in RPA where patients are admitted on a day only or drop in basis, outpatient clinics, community nursing, palliative care. There is an HIV Community Health team based at Redfern Community Health Centre which has three main components – Positive Central which is an allied health team that also provides case management and care coordination, Positive Heterosexuals, a statewide peer education and support service for positive heterosexuals and their partners and families and the Sanctuary – a complementary therapy centre staffed mainly by volunteers.

The HIV Community Mental Health Service is staffed by two nurses who provide case management for PLWHA who also have a mental illness as well as education and health promotion for staff and patients of mental health facilities.

The CSAHS Sexual Health Service is located in Marrickville and provides outreach clinics in Newtown, Canterbury Hospital, Rozelle Hospital and RPA Mothers and Babies Hospital. This service has a strong GP education focus.

There are four GPs in the Area with s100 prescribing rights.

For details of HIV/AIDS services in CSAHS, see Appendix F.

⁵ There are different estimates of the number of PLWHA in NSW. At the end of 2003, NSW Health Notifications data showed that there were 9,703 people who were HIV positive in NSW and that this has increased from 9322 at the end of 2002. The NCHECR (NCHECR 2003) have adjusted the data for multiple reporting and they estimate that there were 7779 HIV positive people in NSW at the end of 2002.

Other Areas with Level 5/6 services

The other Area Health Services with Level 5/6 HIV/AIDS services are NSAHS, WSAHS, Hunter and SWSAHS. All these Areas have a lower prevalence of PLWHA than SESAHS or CSAHS. HAHS estimated that it had around 200 PLWHA in 2000; SWSAHS estimate that there are approximately 350 PLWHA living in the Area. None of these Areas have hospitals with designated HIV/AIDS beds although they have specialist medical and nursing staff with expertise in HIV/AIDS. At the main hospitals in each of these Areas – Royal North Shore, Westmead, John Hunter and Liverpool, there are specialist HIV outpatient clinics (either dedicated HIV clinics or immunology or infectious diseases clinics). PLWHA have access to counselling services and psychiatry services, allied health services – dietetics, social work, physiotherapy, occupational therapy. Each of these Areas has a sexual health service.

For more details, see Appendix F.

Level 4 services

Level 4 or below services are offered in all Area Health services in NSW other than the six identified as Level 5/6 Areas. The Level 4 or below Areas have a lower prevalence of PLWHA. Of these lower prevalence Areas, Northern Rivers Area Health Service has the largest number of PLWHA and staff estimate that they have around 300 PLWHA within their boundaries. Mid North Coast estimates that there are around 70 PLWHA living there. Greater Murray is currently providing services to 31 HIV positive clients. Macquarie estimates that it has nine HIV positive clients and FWAHS estimates that it has about four.

The services available for PLWHA in these low prevalence Areas consist of a range of general inpatient, outpatient and community services. Antiretroviral treatment for HIV is available either from sexual health services in these Areas which have sexual health physicians either on staff or who visit from the metropolitan Area, or from GPs with s100 prescribing rights. The number of GPs with s100 prescribing rights varies by Area (see section 7).

For details of services available in each Area, see Appendix F.

5.2 Utilisation of services

5.2.1 Overall pattern of utilisation of admitted services

There has been a significant decline in patients with HIV/AIDS admitted to NSW public and private hospitals. However, depending on the data source used, the number of HIV/AIDS separations and bed days is different.

FlowInfo, a database derived from the NSW Inpatient Statistics Collection, only records a patient's diagnosis at the Level of Diagnosis Related Group (DRG) so it is only possible to identify patients with an HIV DRG from this database. The Health Outcomes Information Statistical Toolkit (HOIST)⁶ database, on the other hand, also contains data from the NSW Inpatient Statistics Collection which allows identification of diagnosis at the International Classification of Diseases (ICD) Level.⁷ When patients are selected from HOIST with an HIV ICD code, more patients are identified. This occurs because there are more patients with an HIV ICD code than there are patients in HIV DRGs. The reason for this is that patients are assigned to HIV DRGs only if their HIV/AIDS is the main reason they are in hospital. So for example, a patient admitted for treatment of an AIDS defining illness will be assigned to a HIV DRG. However an obstetric patient with HIV who is admitted for the delivery of the baby, would have an HIV ICD code but will not be allocated to an HIV DRG. Rather they will be allocated to an obstetric DRG because the delivery is the main reason they are in hospital.

Table 5 shows that there has been a comparable decline in inpatients with HIV over the last five years regardless of whether the data source is FlowInfo or HOIST.

⁶ HOIST provides access to most of the datasets relevant to population health, including NSW Health data collections covering: notifiable (communicable) diseases, cancer, births, birth defects, dental health, hospital inpatient statistics, emergency department presentations, and population-based survey data, as well as data sourced from the Australian Bureau of Statistics and other environmental and social data.

⁷ DRGs are determined on the basis of the number and combination of ICD codes assigned to each patient on discharge. In other words, they are a summary of the patient's multiple ICD codes.

Table 5. Separations and bed days for people with an HIV diagnosis by year and data source

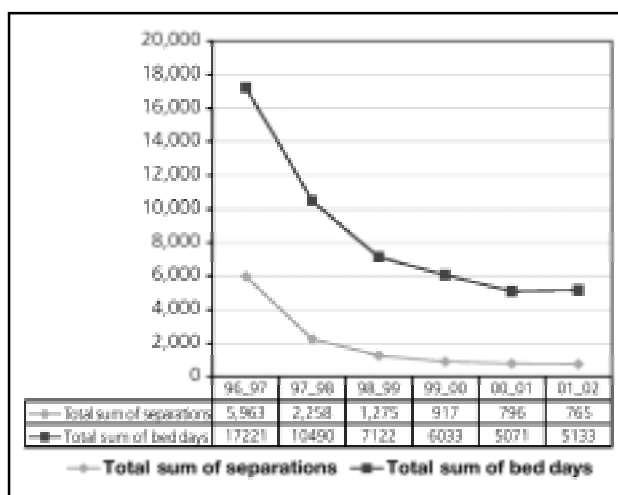
Year	FlowInfo (DRGs only)				HOIST data*			
	Separations	Annual % change	Bed days	Annual % change	Separations	Annual % change	Bed days	Annual % change
1996/97	5863	–	17221	–	–	–	–	–
1997/98	2258	-61.5	10490	-39.1	–	–	–	–
1998/99	1275	-43.5	7122	-32.1	3051	–	16219	–
1999/00	917	-28.1	6033	-15.3	2541	-16.7	14312	-11.8
2000/01	796	-13.2	5071	-15.9	2331	-8.3	12906	-9.8
2001/02	765	-3.9	5133	+1.2	–	–	–	–

*All separations where any of either the principal diagnosis or the other listed diagnoses were categorised using ICD-10-AM codes B20, B21, B22, B23.0, B23.8, B24, Z21 or R75 or had HIV AR-DRGs (version 4.1): S60Z, S61Z, S62Z, S63A, S63B, S64A, S64B.

The analysis that follows is based on FlowInfo data only because time did not permit analysis of data from both data sources. However, a cursory look at the HOIST data showed that many of the patients with HIV ICD codes ended up in DRGs that seemed related to their HIV status. Further analysis of these data are required to fully understand why some patients were assigned HIV DRGs and others were not and the extent to which patients with HIV are in hospital for reasons other than their HIV status.

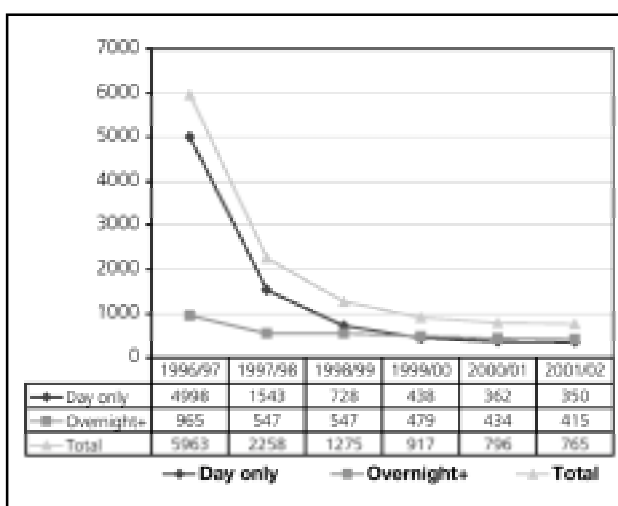
Figure 11 shows the trend in the number of separations and beddays for HIV patients in NSW public hospitals over the last five years. Figures 12 and 13 show these same data broken down into day only and non day only (ie overnight +) separations and beddays. Day only separations have declined dramatically from 4998 separations in 1996/97 to 350 in 2001/02. In 1996/97, they represented 84% of total separations but by 2001/02 they were only 46% of total separations.

Figure 11. Trends in numbers of separations and bed days for HIV patients in NSW hospitals, 1996/97 to 2001/02



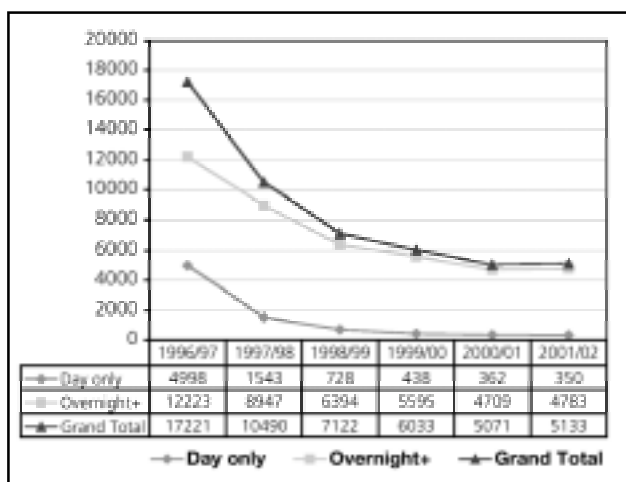
Source: FlowInfo

Figure 12. Trends in the number of HIV separations by type



Source: FlowInfo

Figure 13. Trends in the number of HIV bed days by type



Source: FlowInfo

Despite the reduction in the number of admissions over the last five years there has not been much of a decline in length of stay for patients who are admitted for longer than one day (see Table 6) with average length of stay remaining at around 11.5 days for the last four years.

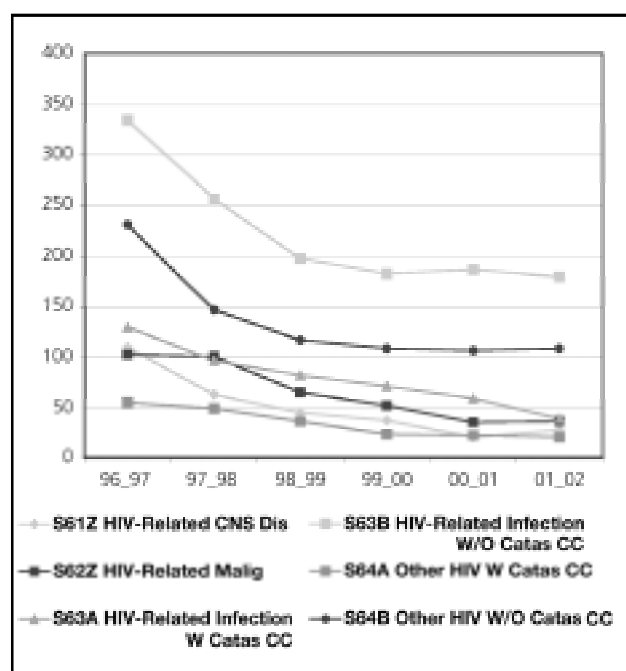
Table 6. Average length of stay for non day only (overnight+) HIV patients by year

	Non day only Overnight+		
	Separations	Bed days	Average LOS
1996/97	965	12223	12.7
1997/98	715	8947	12.5
1998/99	547	6394	11.7
1999/00	479	5595	11.7
2000/01	434	4709	10.9
2001/02	415	4783	11.5

Source: FlowInfo

The decline in separations has occurred in all types of HIV diagnoses. Figure 14 shows the decline in separations by DRG. They have all decreased at much the same rate. HIV related infection with and without complications and co-morbidities is the most common reason for admission for someone infected with HIV. This is followed by HIV related malignancy.

Figure 14. Trends in number of separations by AN-DRG, 1996/97 to 2001/02

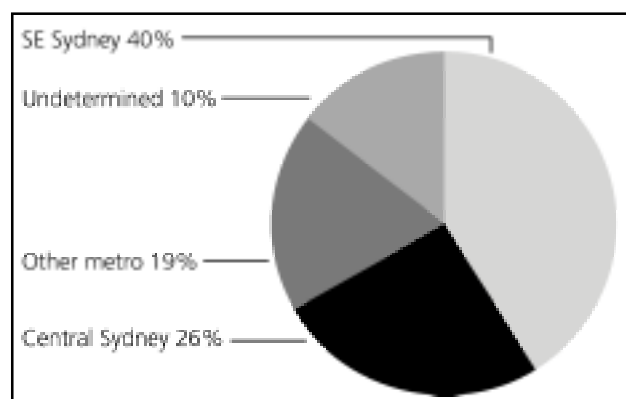


Source: FlowInfo

The Area of residence of patients is shown in Figure 15. It is very similar to the distribution of notifications of newly diagnosed cases of HIV (Figure 4) with 40% of patients admitted to hospital in 2001/02 living in SESAHS; 26% living in CSAHS; 19% living in other metropolitan Area Health Services and 15% living in rural Area Health Services.

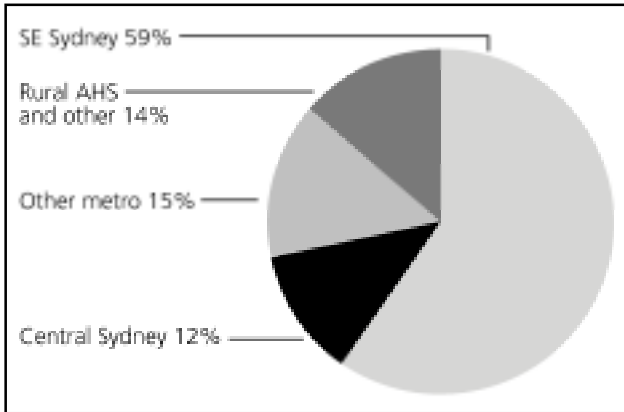
Figure 16 shows the Area Health Services where the patients were treated: 59% were treated in SESAHS, 12% in CSAHS, 15% in other metropolitan hospitals and 14% in rural and other (private and interstate) hospitals. Most of the patient flows are from CSAHS to SESAHS.

Figure 15. Area of residence of HIV patients, 2001/02



Source: FlowInfo

Figure 16. Area of treatment of HIV patients, 2001/02



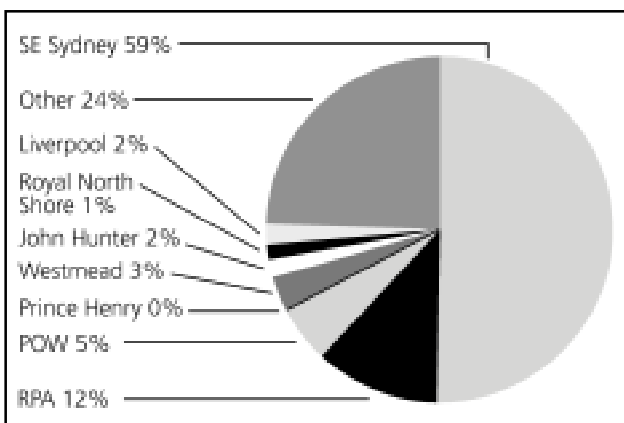
Source: FlowInfo

5.2.2 Area Level 5/6 Hospitals

Share of HIV/AIDS patients

In 2001/02 the Level 5/6 hospitals accounted for 76% of NSW's HIV admitted patients (Figure 17) and 71% of NSW's HIV bed days. This picture has changed slightly in the last three years from 82% of the total HIV/AIDS admitted patients and 76% of the total bed days in 1999/00 but the change may not be statistically significant because the numbers of patients is relatively small (Table 7). St Vincent's treats approximately half of the State's total HIV admissions and around 40% of the total HIV bed days.

Figure 17. Distribution of HIV/AIDS admissions to NSW hospitals 2001/02



Source: FlowInfo

Table 7. Number of HIV/AIDS separations and bed days in Level 5/6 hospitals in the last three years

	1999/2000		2000/2001		2001/2002	
	Separations	Bed days	Separations	Bed days	Separations	Bed days
St Vincents Public	473	2647	323	1753	384	2061
RPA	104	742	134	538	90	507
POW	87	367	64	418	40	468
Westmead	31	249	20	134	26	210
Royal North Shore	20	265	14	136	10	103
John Hunter	17	238	10	129	13	181
Liverpool	18	89	46	330	16	132
Total level 5/6 hospitals	750	4597	611	3438	579	3662
Level 5/6 as a % of total NSW	81.7	76.2	76.8	67.8	75.6	71.3
Total NSW	917	6033	796	5071	765	5133

Source: FlowInfo

Average length of stay

Average length of stay for HIV/AIDS patients (excluding day only patients) has been fairly stable for the past three years at St Vincent's. It has declined at RPA and RNS. It has increased quite markedly at POW but this relates entirely to the closure of PHH and the transfer of specialist admitted HIV services to POW. John Hunter also has a longer average length of stay, probably reflecting the admission of palliative care type patients (Table 8).

Table 8. Average length of stay for HIV/AIDS patients (excluding day only) at Level 5/6 hospitals by year

Hospital	Average length of stay (days)		
	99/00	00/01	01/02
St Vincent's Public	11.5	10.3	11.2
RPA	12.8	9.4	9.0
POW	12.2	15.2	21.4
Westmead	10.9	6.7	12.5
Royal North Shore	15.4	12.1	11.3
John Hunter	14.8	12.9	16.3
Liverpool	9.9	15.9	9.9
Total all NSW hospitals	11.7	10.9	11.5

Source: FlowInfo

Patient flows

Table 9 shows the flows of patients and bed days out of and into Level 5/6 Areas. SESAHS is the biggest net importer of HIV/AIDS patients and beddays and CSAHS is the biggest net exporter. Thirty one per cent of patients treated in SESAHS are from out of the Area. Most of CSAHS residents who are treated outside the Area go to SESAHS hospitals, especially St Vincent's. Many of these flows would be regarded as 'natural flows' because the highest concentration of HIV infected residents in CSAHS is in Newtown, which is on the border with SESAHS. The only other Level 5/6 Area which has a net inflow of patients is WSAHS. Most of these inflows come from WAHS and SWSAHS.

5.2.3 Level 4 and below admitted services

The Area Health Services with Level 4 HIV/AIDS services have increased their share of HIV/AIDS patients from 11% in 1999/2000 to 18% in 2001/02 despite the decline in HIV/AIDS inpatients overall. The share of HIV/AIDS bed days in these Areas has increased from 9% to 15% of the State's total. The largest increase has occurred in the Area Health Service of Northern Rivers (Table 10).

The proportion of the State's HIV patients admitted to Level 4 hospitals in Level 5/6 Areas has remained constant over the last three years at about 7% and 14% of bed days (Table 10).

Average length of stay for patients in Level 4 Areas has increased over this period from 7.6 days to 8.6 days (Table 11). However this fluctuation could be due to a small number of patients who may be admitted for long periods of time for sub acute care.

Three quarters of PLWHA who were residents of Level 4 Areas were treated in their own Area of residence in 2001/02 (Table 12). Two Areas (Mid North Coast and Mid Western) were totally self sufficient in the provision of inpatient care for their HIV/AIDS inpatients. Northern Rivers had the largest number of PLWHA requiring admission and the biggest outflow of patients to other Areas. Most of these outflows were to Queensland, with a smaller number going to SESAHS and CSAHS. All SAHS admissions were to the ACT and FWAHS admissions were to South Australia. Illawarra outflows were all to SESAHS.

Table 9. Net inflows and outflows of HIV/AIDS patients and bed days in Level 5/6 Areas, 2001/02

AHS	No. of residents of each Area admitted to a hospital in any Area		No. of patients treated in hospitals in each Area		Net outflows		Net inflows	
	Separations	Bed days	Separations	Bed days	Separations	Bed days	Separations	Bed days
CSAHS	196	908	92	380	104	528	–	–
SESAHS	315	2052	457	3013	–	–	142	961
NSAHS	32	555	18	260	14	295	–	–
WSAHS	22	166	31	244	–	–	9	78
HAHS	14	193	13	181	1	12	–	–
SWSAHS	31	194	18	143	13	51	–	–
Total	610	4068	629	4221	–	–	–	–

Source: FlowInfo

Current services

Table 10. Number of HIV/AIDS separations and bed days in Level 4 Areas compared to Level 5/6 hospitals and non 5/6 hospitals in Level 5/6 Areas by year

Area	1999/00		2000/01		2001/02	
	Separations	Bed days	Separations	Bed days	Separations	Bed days
Wentworth	3	25	12	83	4	34
Central Coast	7	41	10	80	6	33
Illawarra	8	68	13	94	20	80
NCH	1	3	5	56	0	0
Corrections Health	0	0	0	0	0	0
Northern Rivers	22	134	9	80	46	187
Mid North Coast	14	69	3	16	14	49
New England	2	5	5	37	3	7
Macquarie	6	23	6	15	9	28
Mid Western	14	43	12	16	4	11
Far West	0	0	0	0	0	0
Greater Murray	3	23	3	16	3	49
Southern NSW	1	14	6	23	0	0
Private	14	56	7	33	4	41
Interstate	6	61	22	247	22	247
Total Level 4 Areas	101	565	113	796	135	766
Level 4 as % of total	11.0%	9.4%	14.2%	15.7%	17.6%	14.9%
Total non 5/6 hospitals in Level 5/6 Areas	66	871	72	837	51	705
Non 5/6 hospitals in Level 5/6 Areas as a % of total	7.2%	14.4%	9.0%	16.5%	6.7%	13.7%
Total Level 5/6 hospitals	750	4597	611	3438	579	3662
Level 5/6 hospitals as a % of total	81.8%	76.2%	76.8%	67.8%	75.7%	71.3%
Total	917	6033	796	5071	765	5133

Source: FlowInfo

Table 11. Average length of stay for HIV/AIDS patients (excluding day only) at hospitals in Level 4 and below hospitals by year

Average length of stay (days)			
Hospital	99/00	00/01	01/02
Wentworth	8.3	8.1	8.5
Central Coast	5.9	9.8	6.4
Illawarra	8.5	8.4	8.5
NCH	3.0	18.0	0.0
Corrections Health	0.0	0.0	0.0
Northern Rivers	6.6	9.9	6.2
Mid North Coast	7.9	5.3	9.8
New England	4.0	7.4	2.3
Macquarie	3.8	2.5	3.1
Mid Western	10.7	5.0	8.0
Greater Murray	7.7	5.3	24.0
Southern NSW	14.0	3.8	0.0
Private	11.5	7.5	13.3
Interstate	12.0	14.2	14.2
Total	7.6	9.0	8.6

Source: FlowInfo

Table 12. Net inflows and outflows of HIV/AIDS patients and bed days in Level 4 Areas, 2001/02

	No. of residents of each Area admitted to a hospital in any Area		No. of patients treated in hospitals in each Area		Net outflows		Net inflows	
	Patients	Bed days	Patients	Bed days	Patients	Bed days	Patients	Bed days
AHS								
Wentworth	9	84	6	33	3	51	-	-
Central Coast	14	193	13	181	1	12	-	-
Illawarra	25	171	20	80	5	91	-	-
Northern Rivers	63	315	46	187	17	128	-	-
Mid North Coast	14	49	14	49	-	-	-	-
New England	6	31	3	7	3	24	-	-
Macquarie	11	30	9	28	2	2	-	-
Mid Western	4	11	4	11	-	-	-	-
Far West	2	20	-	-	2	20	-	-
Greater Murray	7	128	4	49	3	79	-	-
Southern	4	93	-	-	4	93	-	-
Interstate	-	-	-	-	-	-	19	247
Total	159	1125	119	625	40	500		

Source: FlowInfo

5.2.4 Non admitted services

There is no data source that provides a reliable, detailed and complete picture of the activity of non admitted services, despite the fact that this is the setting where care and treatment of most PLWHA currently occurs.

The main source of data on non inpatient services is the Department of Health Reporting System (DOHRS). This provides data on the number of clients and occasions of service (OOS). The problem is that there is no standardisation of data definitions and as a result there is inconsistency in the nature of reporting. Sometimes an occasion of service refers to a patient's attendance at a service ie the visit; at other times it refers to the number of consultations per visit, so if a patient sees the doctor, the nurse and the social worker then that is counted as three OOS. Sometimes client telephone calls are counted, sometimes not. Even if data definitions were standardised, there is the problem that an occasion of service can vary so much in terms of time and resources used eg one patient can see a health professional for 10 minutes while another patient may have an hour-long consultation. So one OOS is not the same as another in terms of resources used.

Many sexual health services use a database called the Sexual Health Information Project (SHIP) to manage activity data, however data definitions are not standardised between Areas. Further not all Sexual Health Services record their activity using the SHIP database and for many of the services who do use it, the data is incomplete.

Due to the resource implications – both for the state and GPs – there is also limited capacity to obtain and analyse data relating to the treatment of PLWHA by GPs. ASHM is beginning to collect data from the s100 prescribers and the NCHECR has for some years collated and analysed data on the clinical profile of clients as part of a national observational study which includes some of the major NSW practices.

The non inpatient data that has been submitted for this project in response to the questionnaire, is used in the mapping or description of services to give some indication of their size. These data have also been used to provide an indication of the trend in the Level of activity for that service over time. However such data are not necessarily an accurate indicator of need because activity is often determined by the capacity of the services and not the actual demand.

A summary of the activity of non admitted services that was supplied from each Area Health Service to this project is provided in Appendix F.

5.2.5 s100 drug utilisation data

In the absence of data on the utilisation of non admitted services, it was decided that the pattern of expenditure on s100 drugs for HIV would provide an indication of where PLWHA were receiving non admitted services from. Table 13 shows the Level of expenditure on s100 drugs for HIV by Area Health Service. Figure 18 shows this cost as a proportion of the total cost by Area Health Service.

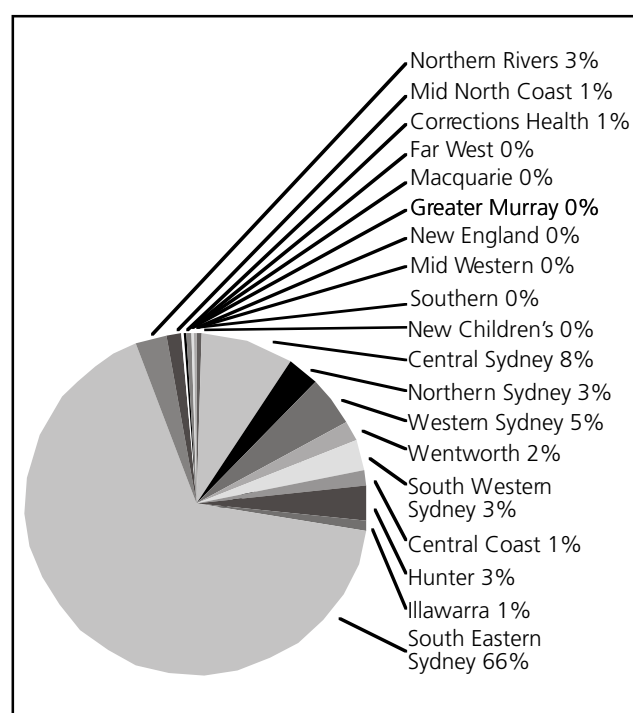
SESAHS has the highest expenditure on these drugs – \$25m or 66.5% of the total cost of s100 drugs for HIV. This is higher than the proportion of PLWHA estimated to live in SESAHS and reflects the flow of PLWHA to SESAHS for treatment, especially to the high caseload HIV GPs. In CSAHS, the cost of s100 drugs for PLWHA is \$3m or about 8.5% of the total. This is less than the proportion of PLWHA estimated to live in CSAHS (20% in Figure 4) and the proportion of HIV inpatients admitted to CSAHS hospitals (12% in Figure 17) and probably reflects the fact that many of the PLWHA in CSAHS live close to the Area's border with SESAHS and attend the more prevalent HIV GP practices in SESAHS.

Table 13. Expenditure on s100 drugs for HIV by Area Health Service, 2002/03

Area Health Service	Expenditure on s100 drugs for HIV (\$)	% of total
Corrections Health	195,992	0.5
New Children's	53,718	0.1
Central Sydney	3,179,967	8.5
Northern Sydney	1,192,136	3.2
Western Sydney	1,802,890	4.8
Wentworth	645,266	1.7
South Western Sydney	1,157,259	3.1
Central Coast	557,008	1.5
Hunter	1,258,832	3.3
Illawarra	329,979	0.9
South Eastern Sydney	25,017,304	66.5
Northern Rivers	1,188,925	3.2
Mid North Coast	551,082	1.5
New England	104,800	0.3
Macquarie	65,877	0.2
Mid Western	58,297	0.2
Far West	26,097	0.1
Greater Murray	179,774	0.5
Southern	61,037	0.2
Total	37,626,243	100

Source: NSW Health, AIDB

Figure 18. s100 drug costs for HIV by Area Health Service as a proportion of the total, 2002/03



Source: NSW Health, AIDB

See Table 13 for actual expenditure by Area Health Service.

5.3 Issues and implications for service delivery

A number of key issues emerge from the utilisation data and/or were raised in the submissions and workshops that have implications for the future delivery of services.

5.3.1 Shift from inpatient to ambulatory care

The data on the utilisation of inpatient services shows the dramatic decline in their use over the past five years, mainly as a result of effective treatment regimens that are available on a non inpatient basis. Even though the available data on non inpatient services does not show a corresponding increase in utilisation, other information such as the fact there is an increasing prevalence of PLWHA, that 73% of PLWHA are on antiretroviral therapy which requires regular monitoring as well as the incidence of co-morbidities among PLWHA, suggests there would have been a significant increase in the use of ambulatory services, if data on the use of all these services by PLWHA was available.

An analysis of Area funding plans suggests that there has not been a similar shift in resources from inpatient to ambulatory settings to reflect this change in focus. It is not clear whether the lack of a shift is related to the Resource Distribution Formula (RDF) that is used to allocate funds to Areas or to rigidities that exist in the Areas. The submission from CSAHS seems to suggest that the reason is an outdated RDF:

“Due to historical funding models at the state Level there has been a tendency to under-resource community services and over resource inpatient services.”

CSAHS (2004:19)

However the Department has used the formula for redistribution of AIDS Program funds between Areas for some time; and Areas have never been directed by the Department regarding the proportion of funds to be allocated to different Areas of service delivery. Those types of decisions have historically been regarded as the responsibility of Areas based on their knowledge of shifts in demand and needs for services.

Service delivery implications

Data on the cost of inpatient services is currently available and services should be required to monitor their inpatient utilisation and justify their inpatient allocation against this utilisation.

Role delineation guidelines should be reviewed and the service descriptions changed to reflect the pattern of treatment and care for people with HIV so that there is less emphasis on admitted services and more emphasis on non admitted services. Core allied health services need to be identified and links to mental health and drug and alcohol should be noted.

5.3.2 Poor quality of data on the utilisation of non admitted services

Section 5.2.4 described the problems with current data on the utilisation of non admitted services by PLWHA. Given that most of the care and treatment occurs in the ambulatory setting, the absence of useful data in this area means that it is impossible to compare service activity between Areas and to ensure that the formula for the equitable allocation of funding to Areas includes an adequate weight for non inpatient activity and patient flows for non inpatient activity between Areas. SESAHS is currently trialling a Minimum Data Set that should ensure standardisation of service and data definitions and provide a clearer and more accurate picture of non admitted service utilisation by PLWHA.

Service delivery implications

There is a need to more accurately measure non admitted activity so that it is possible to ensure:

- service activity is able to be monitored and comparisons can be made between Areas
- resource allocation reflects the relative utilisation of admitted and non admitted care
- Areas are funded equitably.

The Minimum Data Set (MDS) currently being trialled in SESAHS may provide a template that can be rolled out to other Areas.

5.3.3 Inadequate services in some Areas

This issue of an imbalance in the allocation of resources between inpatient and non inpatient services is less of an issue in Areas that have only recently had an increase in the numbers of people diagnosed with HIV/AIDS such as SWSAHS, NRAHS, MNCAHS or Areas such as the GMAHS and FWAHS which have problems providing basic HIV care and treatment services.

South Western Sydney

SWSAHS estimates that there are over 350 PLWHA living there (SWSAHS 2004:1). Bigge Park Centre (BPC), the only sexual health service in the Area, is also the only place where s100 drug treatment is prescribed.⁸ There are currently 140 PLWHA who seek care and treatment from BPC.

The client base at Bigge Park differs from the demographic profile of PLWHA in Australia generally. Of the 140 patients who regularly seek care at BPC, approximately 50% come from culturally and linguistically diverse backgrounds (CALD) with over 30 countries represented and a significant proportion from South East Asia.

The most likely mode of transmission of HIV for people from a culturally and linguistically diverse background is heterosexual contact or is not declared. There are many complex issues associated with the provision of care to such a diverse group. The CALD client is more likely to present in the later stages of the infection – often with an AIDS defining illness. Together with issues of disclosure, shame and embarrassment relating to sexuality, and privacy concerns the time demands made on the service are increased. Other issues such as contact tracing are also made more complicated by these concerns and the difficulties associated with the client for whom English is not their first language.

Some clients have no access to Medicare, are unwilling to provide their Medicare card (for confidentiality reasons), and/or have immigration problems. BPC therefore absorbs pathology and other related costs associated with most patients' care (including viral load testing, drug resistance testing and drug Level testing). This has placed a great strain on the BPC's budget. While under no obligation, all Areas have discretionary capacity to determine the extent to which they will fund health care services, including treatments, for Medicare

ineligible patients. It is not reasonable for the NSW AIDS Program funding formula to accommodate the needs of Medicare ineligible patients in the absence of any Australian funding for them.

The increasing numbers of clients attending BPC (they estimate that the HIV positive client numbers will grow by about 25 per year) compounded by the difficulties associated with the characteristics of the client group, and the fact that there is only one treatment service in an Area of nearly 800,000 people means that the services are not adequate. BPC estimate that there needs to be a second sexual health service or an outreach service at Campbelltown. Options for the most appropriate model of care need to be defined and evaluated but inevitably more resources and funding are required if the Area also determines to maintain the current range of services.

Northern Rivers

NRAHS is located on the far north of the State covering an area of 24,555 square kilometres and is projected to have over 300,000 people by 2006. It is estimated that there are approximately 300 HIV positive individuals in the Area most of whom have moved there since their HIV was diagnosed, so the Northern Rivers is not identified in the notifications data as their Area of residence. Based on the notifications data alone, the Northern Rivers would have less than half this number of HIV positive individuals.

Only one part time GP offers prescribing of antiretroviral drugs so treatment of PLWHA occurs primarily out of the sexual health service, SHAIDS (Sexual Health and AIDS Service), which has 1.5 sexual health physicians and provides an outreach clinic to Tweed Heads once a week. At least two other GPs with s100 prescribing rights have stopped prescribing antiretroviral treatment in the last six months. Lack of support is cited as the main reason why the GPs have stopped being s100 prescribers.

NRAHS currently has funding for three years from the Australian Government's Enhanced Primary Care (EPC) Program where case workers coordinate and liaise with GPs and other service providers to assist with care plans and case conferencing to improve care and support for PLWHA. However funding has not increased to cover costs and now, 18 months into the project, it is no longer adequate to support two case workers.

⁸ The one known s100 GP prescriber is not actively involved in HIV care.

Current services

Similarly staffing Levels at SHAIDS has decreased because designated AIDS funding has not covered cost increases (suggesting that the Area views the AIDS Program as the sole source of funds for HIV services, rather than as a contribution toward the cost thereof). NRAHS no longer has a health promotion officer, sex worker support position or funding to enable backfilling for clinical or counselling staff when they take leave.

Resource constraints are a significant issue in this Area where there has been a steady in-migration of PLWHA and where it is known that at least 55 PLWHA seek care and treatment outside the Area.

Greater Murray

This Area covers an area of 113,854 square kilometres. The Sexual Health Service is the main source of care and treatment by PLWHA in this Area as there are no GP s100 prescribers. Sexual health services are at three locations in the Area but there are no locally based sexual health physicians. A specialist visits from Sydney and spends five hours at two locations every fortnight and currently sees 30 HIV patients a month. He spends an average of 30 minutes with each HIV client per month.

These services are not adequate for treatment of PLWHA especially those with complex needs. Also the situation is not sustainable because it means that the visiting specialist does not have enough time for the HIV clients let alone people from other priority groups; and there is no mechanism for enhancing the capacity of local GPs to enable routine primary health care of PLWHA.

Far West Area Health Service

This Area is over ten times the size of the Northern Rivers covering an area of 270,000 square kilometres. Sexual health services are provided from four hub locations (Lightning Ridge, Bourke, Broken Hill and Wentworth/Dareton). At each hub there is a sexual health nurse who is supported by sexual health specialists from the Sydney Sexual Health Centre via a Service Agreement. These specialists provide a clinic at each of the four sites every two months. The current cost of providing this service exceeds the Area AIDS Program allocation. Yet the size of the Area and the geographic distances involved make it necessary to have these decentralised hub services. There are no GP prescribers and the number of GPs in the Area has been reduced by more than half in the last 10 years (FWAHS, 2004:2). This area also has a high proportion of

Aboriginal people and the highest rates of STIs in NSW, as seen in section four.

Different models of HIV service delivery are appropriate depending on the client and service characteristics of the Area – whether the Area has a high or low prevalence of PLWHA; the number of GPs and GP prescribers; the geographic size of the Area; the characteristics of the HIV positive population including the numbers of people from a culturally and linguistically diverse background, the number of people who are heterosexual, the number of women etc; the availability of other services such as allied health; the presence of non government organisations providing other forms of support.

Service delivery implications

NSW Health needs to define key aspects of service models for high, medium and low prevalence Areas.

Each Area needs to articulate their preferred and most realistic model of care for their Area based on available resources, identify the current gaps and propose a strategy for how they could achieve their preferred model. There may be other risk factors such as proportion of people from a culturally and linguistically diverse background, proportion of Aboriginal and Torres Strait Islander people. These other factors may dictate the nature of the services offered and whether the emphasis should be on prevention or care and treatment.

In rural Areas the Sexual Health Services and the way they are integrated are the focal point for HIV services. These services need to be funded adequately to ensure they can fulfil their range of responsibilities.

All Areas – particularly low prevalence Areas – need to carefully examine the extent to which they have established relationships with GPs with a view to engaging GPs to provide primary care for PLWHA with specialist support by either local or visiting clinical experts.

5.3.4 Patient complexity and the need for integrated services

Most submissions commented on the increased complexity of HIV patients. As discussed in section 4.3.2 this patient complexity refers largely to co-morbidities and other associated problems such as depression, cognitive impairment, dual diagnosis (HIV, hepatitis, STI, mental health and drug and alcohol) and behaviour,

anxiety and adjustment disorders. In addition there are side effects of treatment such as lipodystrophy and lipoatrophy, other metabolic conditions, cardiovascular problems, oral health problems. And because of the increased patient longevity, problems associated with ageing also become relevant.

NSAHS commented in its survey of services, that the increased demand in HIV patients will “not be in the numbers...but the complexity both medically and psychologically of this population. Over the past few years the psychosocial needs of clients are more complex and time consuming than in previous years. This is unlikely to change over the next five years” (NSAHS 2004).

The problems/co-morbidities of many PLWHA require that HIV services are well integrated with mental health and drug and alcohol services however the overwhelming response from health professionals is that support from these service streams is fragmented. This lack of support is related to the competing demands and limited resources for these services and their incapacity to extend their services to PLWHA. However there is also a perception among some health professionals that both these services are reluctant to deal with PLWHA. The ‘silo’ mentality restricts the provision of services across programs, and a difference in the fundamental basic principles on which a service operates affects its ability to be integrated with another service.

Most mental health services do not treat personality disorders, anxiety disorders and some depressions so many of the services required for many PLWHA are not available from most mainstream mental health services.

There are a variety of HIV mental health models operating in CSAHS and SESAHS. In Central Sydney there is an HIV funded consultation-liaison psychiatry service with strong links to the neuro-psychology service, an HIV mental health service, an outreach sexual health clinic in Rozelle Hospital; in SESAHS there is H2M, a mental health nurse on STV's community health team, a psychology service at Albion Street and an HIV funded Area neuro-psychology service (see Appendix F for details). An evaluation of these services is needed to determine which are most effective. As there are no specialised HIV mental health services in other Areas, the most appropriate model of care needs to be defined.

Service delivery implications

HIV service infrastructure needs to accommodate the requirements of women, heterosexuals, people from a CALD background and Aboriginal and Torres Strait Islander people.

The provision of mental health services required by some HIV patients – counselling, treatment for depression and personality disorder – needs to be addressed.

The mental health and drug and alcohol service requirements and a preferred model of care for PLWHA need to be clearly articulated for high, medium and low prevalence Areas.

Policy linkages need to be developed between HIV services, Mental Health and the Alcohol and Other Drugs Programs.

5.4.5 Duplication of services, competitiveness, poor communication

Comments about service duplication, competition and poor communication between services, unclear referral pathways in high prevalence Areas were made in submissions from Area Health Services as well as NGOs.

Patient complexity and the multiple services involved in a person's care demands that referral pathways are clear, service linkages are adequate and the continuum of care between services and across professional disciplines is seamless. Clear roles and responsibilities for all service providers, especially the roles of medical specialists, GPs and sexual health services, will be important in facilitating continuity of care. Lines of communication need to be clearly articulated; protocols need to be established to indicate when referral to a specialist is appropriate and when the patient will be referred back to the GP for ongoing care.

There seems to be a general consensus that clients with complex needs, especially those with drug and alcohol and/or mental health problems, would mostly benefit from having some form of case management/care coordination. Case management/care coordination is also important for medication adherence. The NRAHS and ACON EPC projects have provided an opportunity for case management. ADAHPS also provides a case management model.

There has been no systematic policy of case management for PLWHA so it has not been widely

practiced. The reluctance for case management is related to the lack of clarity around what it is; who should do it and which clients should have it.

ADAHPS (2001) defines case management as a range of functions including:

- assessment to establish an individual's needs
- planning to ensure service provision is co-ordinated
- linking with services to ensure needs are met
- monitoring to become aware of any changes
- regular review to ensure services remain responsive to changing needs.

The most important criteria used to identify an appropriate case manager seem to be the ability and willingness of the person to undertake the job. Successful case management depends on clear negotiation and understanding of each service provider's roles and responsibilities, shared goals for the client and ongoing communication.

Service delivery implications

Roles and responsibilities of service providers need to be clearly defined, referral protocols and lines of communication clearly established.

To avoid duplication of services and to ensure a better continuum of care and medication adherence, a policy of case management for people with 'complex needs'⁹ should be adopted.

The concentration of services on the CSAHS and SESAHS border and the use of services in both Areas by some people point to the need for good case management to avoid over-servicing and patient 'shopping'.

Joint planning of all HIV services across both CSAHS and SESAHS seems a logical extension of a cross Area policy of case management. Planning by both Areas jointly for the whole inner-eastern city area could help overcome the problem of duplication and poor communication between services.

Non government organisations needs to be partners in both joint planning activities and ongoing management to enable comprehensive development of services.

5.3.6 Access

Allied and other related health services

The patient complexity described above means that PLWHA need access to a range of allied and other related health services especially dental, nutrition, psychology, physiotherapy, podiatry. Special funding for HIV dental services was available to some Areas – SESAHS, CSAHS, NRAHS and MNCAHS. This funding was never meant to cover all the dental costs of PLWHA. Rather it was to supplement publicly funded services and so it is not surprising that it was never adequate to cover demand. The high prevalence Areas of SESAHS and CSAHS have dedicated HIV allied health services but other Areas have to rely on mainstream services to meet this need and there may be long waiting periods.

Highly specialised drugs

Antiretroviral drugs for PLWHA prescribed under section 100 of the National Health Act 1953, are restricted to supply through hospitals having access to appropriate special facilities. This requirement to obtain drugs from hospitals was cited by many of the submissions as being inconvenient for many PLWHA, especially those in rural Areas. Some pharmacies at RPA and STV are open after hours on some nights making it more convenient for people who work; and CSAHS provides an outreach pharmacist service to one high caseload GP practice within its boundaries. The recent trial, which made drugs available from some community pharmacies, was claimed to be a success in many of the submissions. However one of the rural Areas expressed concern about the feasibility of this approach in low prevalence Areas where the pharmacy may be caught with expensive drugs that they cannot use if a patient's treatment requires changing to a different drug.

People from culturally and linguistically diverse backgrounds

In section 3, PLWHA from a culturally and linguistically diverse background tend to be late presenters. Late presentation has a significant impact on treatment options and efficacy. These people may be legally resident in NSW but are not eligible for Medicare because of the nature of their bridging visa, or they may not have a resident visa. Migration, largely business and family reunion from high prevalence countries in South East Asia, continues to increase. Also migrations, largely

⁹ 'Complex needs' in this context means the need for an array of often quite different services ranging from medical to psychosocial to behavioural to cultural.

humanitarian, have increased from sub Saharan Africa where there are massive HIV epidemics.

It is essential that these people receive treatment for public health reasons however ineligible immigrants are not a State responsibility and the Australian Government has recently refused a consensus proposal from all States and Territories to fund services for these people. Consequently it is left to the discretion of Areas whether they provide treatment, in the absence of appropriate funding from the Australian Government.

Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people are often reluctant to use mainstream health services because they may not provide services that are culturally appropriate. So in addition to care and treatment services provided by sexual health services, which identify Aboriginal people as a key target population, AIDB gives the Redfern AMS specific care and treatment funding to provide assistance in the management of HIV positive clients who may have other complex issues.

Proposed activities for this funding include:

- assistance in providing intensive interventions to Aboriginal people living with HIV/AIDS who may have other complex issues such as: hepatitis C & B, mental health, homelessness, injecting drug use, compliance to treatments, and serious physical illness
- provision of appropriate Aboriginal carers to Aboriginal people living with HIV/AIDS who may have other complex issues, on a part-time basis
- provision of ongoing training and support to the part-time carers.

Inmates of correctional facilities

Currently there are 37 inmates with HIV/AIDS and they are spread throughout the correctional system across NSW. Six of these inmates are Aboriginal and 8 are from CALD backgrounds. The major risk for HIV transmission in correctional facilities is drug injecting practices – sexual risk is relatively less important than for those in the wider community.

The main challenges for the Corrections Health Service (CHS) include the following:

- to offer specialist services at numerous sites, which are geographically isolated and have a highly mobile population with complex health needs
- to offer specialist services in the context of broader sexual health and harm minimisation services (including PEP)
- to manage HIV/HCV co-infection.

Rural Areas

There are a number of access issues that specifically pertain to rural Areas. These are:

- distance to services and often a lack of public transport
- recruitment and retention of GPs generally – not just GP prescribers
- recruitment and retention of staff to public sector health services
- professional isolation of staff
- some Areas have no HIV non government organisations within their boundaries so no local access to peer support and advocacy
- HIV patients have reduced access to clinical trials.

Service delivery implications

The increasingly complex issues surrounding the PLWHA population means that strong clinical leadership is required. There needs to be a strengthening of links between designated HIV/AIDS services and Areas with non designated services. The opportunities to be gained from telehealth need to be explored.

Continued access to confidential and free HIV testing at sexual health centres is vital to ensure that people from priority risk populations and populations that already experience service access difficulties such as those from CALD backgrounds, have minimal barriers to screening.

Strategies to recruit and retain GPs in rural Areas are discussed in section 7.

6

Statewide services

NSW Health allocates \$5.5m a year to a number of services to provide statewide or supra-Area functions. These services include:

- AIDS Dementia and HIV Psychiatry Service (ADAHPS)
- Multicultural HIV/AIDS and Hepatitis C Service
- Paediatric HIV Service at Sydney Children's Hospital
- Albion Street Centre (ASC) – NSW Needlestick Injury Hotline, NSW Infection Control Resource Centre, NSW HIV/AIDS Information Line, NSW Needle Clean Up Hotline, NSW Post Exposure Prophylaxis (PEP) Hotline, NSW HIV and Hepatitis C Reference Library, Ankali
- HIV/AIDS Dental Program
- Sydney Sexual Health Service – Clinical Advice Hotline and Panel for the Management of People who Risk Infecting Others with HIV
- Sydney Hospital – post registration nursing courses
- Transfusion Related AIDS and Infectious Diseases Service (TRAIDS)
- HIV, Sexual Health and Hepatitis C Workforce Development Program
- Positive Heterosexual Service
- Institute of Forensic Medicine.

6.1 AIDS Dementia and HIV Psychiatry Service (ADAHPS)

The most significant statewide service in terms of funding is the AIDS Dementia and HIV Psychiatry Service (ADAHPS), receiving approximately half of the \$5m allocated to statewide services each year from the Department of Health's AIDS budget.

ADAHPS was funded in 1995 to assist in meeting the complex needs and issues related to AIDS Dementia Complex (ADC) and/or HIV Psychiatric Conditions (HPC). Two Area Health Services – CSAHS and SESAHS – undertook to auspice the service. SESAHS has the responsibility for ensuring coordination of the service; developing a tertiary service that includes a multidisciplinary outreach team known as ADAHPT; providing hospice respite and step down beds; and

ensuring mental health inpatient and ambulatory care. Sacred Heart Hospice provides step down, respite and hospice care, and Caritas Centre (at St Vincent's Hospital) provides inpatient and non inpatient psychiatric assessments, treatment and care. Cahill 17, also at St Vincent's Hospital, provides supervision on a case by case basis. These services are funded from tertiary funds allocated to St Vincent's Hospital.

CSAHS developed a residential facility – the Bridge, a 12-bed facility including one respite place. The Bridge, located in the Sydney suburb of Glebe, is the residential component of ADAHPS, offering long-term placement in a facility staffed with trained nurses 24 hours a day. The Bridge also offers a rehabilitation program facilitating short term placements for clients who, following intensive support, are able to live in their own communities. CSAHS has contributed additional funds to the Bridge and provides psychiatric and community allied services support.

ADAHPS aims to strengthen the capacity of local services to manage HIV positive persons with complex needs: cognitive impairment related to HIV infection such as ADC, mental health issues, homelessness or unsuitable accommodation, substance abuse and challenging behaviours. The ADAHPS model of service provision is based on the philosophy that the majority of people with complex needs can be treated and supported in their own community by local services. ADAHPS offers assessment and assistance when the situation is too complex for local services to manage alone. ADAHPS aims to assist the reorientation of services to better cater for clients with complex needs by promoting a case management model of service provision. The model of case management advocated by ADAHPS encourages the active participation of the client, in conjunction with their carers, in identifying their needs and establishing their goals. ADAHPS does not directly provide case management – rather the designated ADAHPT worker assists the local worker, who is the primary case manager, in an ongoing capacity to coordinate a client's care.

All referrals to ADAHPS are channelled through the AIDS Dementia and HIV Psychiatry Team (ADAHPT), the outreach component of the service. ADAHPT comprises:

Table 14. Number of new registrations/referrals to ADAHPT service

	1995/96	1997	1998	1999	2000	2001	2002	2003 (Jan-June)
Referrals	3	36	28	38	81	43	61	17
Registrations	3	25	18	34	61	39	53	16

Source: ADAHPS (2003)

the team leader – a Clinical Nurse Consultant with extensive mental health and HIV experience, a Clinical Nurse Specialist in mental health; a Senior Social Worker; a Clinical Psychologist; a Welfare Officer; and a full-time Administration Officer. ADAHPT can provide a range of services designed to assist service providers in managing clients with complex needs in their local areas. The services include the following:

- consultation
- assistance with assessment and diagnosis
- co-case management
- information
- education and training
- peer support
- advice about how to reorientate service delivery to better meet the needs of clients
- community care packages
- residential placements – either long term or short-term rehabilitation
- referral to tertiary services for step down, respite or inpatient care.

Table 14 shows the number of new clients and referrals to ADAHPT since its inception in 1995/96. The sharp increase in referrals and registrations in 2000 reflect the widening of the referral criteria to accept 'complex' clients and not just those diagnosed with ADC.

The Area of residence of ADAHPT clients is shown in Table 15. A third of referrals live in SESAHS, a quarter in CSAHS, 10% in the Northern Rivers, 7% in the Greater Murray, 4% in each of the Illawarra, NSAHS, SWSAHS, and 3% in WSAHS. Two clients were referred from the MNCAHS in 2002/03, and one each from the MWAHS, NEAHS and WAHS. It is truly a statewide service with referrals from most Area Health Services.

Table 15. Area health service of residence of referrals to ADAHPT, 2002/03

Area Health Service	No. of referrals	% of total
Central Sydney	24	25.0
Corrections Health	3	3.1
Greater Murray	7	7.3
Illawarra	4	4.2
Mid North Coast	2	2.1
Mid Western	1	1.0
New England	1	1.0
Northern Rivers	10	10.4
Northern Sydney	4	4.2
South Eastern Sydney	32	33.3
South Western Sydney	4	4.2
Wentworth	1	1.0
Western Sydney	3	3.1
Total	96	100.0

Source: ADAHPS (2003)

The type of accommodation of ADAHPT clients in 2003 is given in Table 16. Forty per cent of the clients are in supported accommodation – either the Bridge, BGF House, Floating Care (see details for the latter two in NGO section), at home but in receipt of HACC services, brokered care or both. Of the other 60%, the majority is in Department of Housing accommodation or a private house or flat.

Table 16. Accommodation of ADAHPT clients in 2003

Type of accommodation	No. of clients	% of total
Supported accommodation	33	40
Housing Department	21	26
House or flat	16	21
Hostel	4	5
Relatives/friends	1	1
Other	3	3
Not known	4	4
Total	82	100

Source: ADAHPS (2003)

The High Supervision Unit (HSU) is the acute medical specialist unit set up for the care and stabilisation of HIV positive clients with, or thought to have, a diagnosis of ADC who have an acute behavioural disturbance.

Table 17 shows the number of admissions to the HSU for the three years, 1999/00, 2000/01, 2001/02.

Table 17. Number of patients admitted with a diagnosis of AIDS dementia, ALOS and bed days in the HIV ward, St Vincent's Hospital, 1999–2002.

Year	ADC Admissions	ALOS	Bed days
99/00	41	12.5 days	511
00/01	52	6.0 days	312
01/02	34	11.5 days	390

Source: ADAHPS (2003)

Sacred Heart Hospice provides inpatient care to clients who require step down care following stabilisation of an acute phase of their illness. Additionally, clients who require respite or short-term admission of up to approximately twelve weeks for stabilisation of behavioural, social and/or environmental problems may also use the service.

Table 18. ADAHPT client admissions to Sacred Heart Hospice 1999–2002

Year	Patients	Admissions	Bed days	ALOS
1999	18	29	926	32
2000	6	9	371	41
2001	13	21	671	32
2002	12	17	932	55

Source: ADAHPS (2003)

Reasons for admission were primarily for respite in 1999 and by 2002 they were for long-term care and placement. Bed days have increased from 2000 so that in 2002 they were back to 1999 Levels, but with fewer numbers of patients and admissions. In July 2003, one patient had been on the ward in excess of a year waiting for a vacancy at the Bridge, another patient had also been there for over a year.

Caritas Centre (mental health inpatient facility of STV Hospital) provides admissions for clients with acute behavioural disturbance associated with HIV related psychiatric conditions including those requiring a secure contained environment. Additionally Caritas, through the consultant psychiatrist, provides support and consultancy to ADAHPT for community clients with HIV related psychiatric conditions on a local and statewide outpatient basis.

The service provides for PLWHA who have developed psychiatric illnesses as well as those with pre-existing psychiatric illnesses who have become HIV positive. Inpatient admissions of known HIV patients with diagnosed mental illness for 1999 to 2002 are shown in Table 18.

Table 19. Psychiatric In patient admissions of patients with concurrent HIV 1999–2002

Year	No of Admissions	No of Patients	Bed days	ALOS
1999	6	6	126	21
2000	5	5	75	15
2001	4	3	119	30
2002	3	3	63	21

Source: ADAHPS (2003)

The Bridge is the only residential facility of its type providing 24 hour supervised care and high support to people living with HIV and complex needs. Service capacity has peaked and bed availability is infrequent with lengthy waiting lists. The respite bed is usually used for carer respite and has limited use for clients seeking longer term housing arrangements. Of the 12 residents in the Bridge in at July 2002, approximately 50% were residents for two years or more and 25% has been residents for over four years. The length of stay continues, as life expectancy continues to increase with treatment success. Residents have high Levels of medication compliance (>95%) as staff administer medication and residents are monitored closely for changes in medical condition. The table below demonstrates increasing bed utilisation. Bed capacity rose from seven beds available in 1998 to 12 beds in 2002 due to increasing demand.

Table 20. The Bridge: Bed Day Utilisation 1998 to 2002

Year	Long Term Bed days	Short Term Bed days	Respite Bed days	Day only Bed days	Total
98-99	1960	514	173	–	2647
99-00	1983	436	145	8	2572
00-01	2798	645	78	40	3561
01-02	3216	730	153	45	4099

Source: ADAHPS (2003)

However, more places are needed urgently. In June 2002 there were nine clients officially on the waiting list and more who were eligible but were not placed on the list because they had no chance of getting a place. Two clients on the Bridge waiting list were in Sacred Heart at a much higher cost per day (\$544 compared to \$220 at the Bridge).

6.2 Issues and implications for service delivery

6.2.1 Role of NSW Health in providing supported accommodation

The respective roles of the NSW Department of Health, Department of Disability and Aged Care (DADHC), Department of Housing in providing supported accommodation is not always clear. NSW Health has been moving towards a position where it does not provide the buildings ('bricks and mortar') for this type of care (as evidenced by its closure, or transfer to the Australian Government, of State-run nursing homes) but rather it provides support in the form of medical, nursing, and allied health care from community health services or funding for brokered care packages. DADHC provides HACC services but the eligibility criteria are complicated and there are some population groups, especially the younger disabled, who are either too complex or too different for these services and find it hard to access them.¹⁰ It is not clear when it is Health's responsibility to provide brokered care packages or when it is DADHC's responsibility to provide HACC services. Department of Housing generally provides the bricks and mortar of accommodation services, with the patient support provided by Health or DADHC or both.

The provision of the Bridge facility by NSW Health is an unusual situation. It was available initially because the building was left vacant by the transfer of the Children's Hospital to Westmead and residual funds were available from a trust which had been established to make *ex gratia* payments to people with medically acquired HIV. At the time HAART for PLWHA was only just becoming available and the implications for long term survival of these people was not known. NSW Health continued to accommodate the growing needs of this group of patients because people with AIDS had had a relatively short survival time and people who developed ADC usually only lived for about six months after diagnosis. At present PLWHA who are receiving treatment are living much longer, including those with ADC, and therefore requiring supported accommodation for longer periods and for a variety of reasons, not just because they have ADC. Also because of the success of the treatment, numbers of PLWHA are increasing.

¹⁰ In recognition that some PLWHA are appropriately assisted through HACC, DADHC has recently funded a 12-month project aimed at increasing access to HACC services for PLWHA. This project is nearing completion (DADHC submission, 2004)

HIV/AIDS is now more like other chronic diseases and PLWHA should be eligible to access the range of services from the Australian government (nursing homes) and other State government departments (DADHC, Housing) that other people with a chronic condition and resulting disability, are eligible for. However access to these services is not readily available. This reduced access by PLWHA to these mainstream services is probably related to the fact that HIV/AIDS services have always been specifically funded. Also, the majority of people who use these mainstream services, namely the aged population, tend to have different needs from PLWHA. PLWHA may require a higher Level of support than is available in most nursing homes or HACC services. They are mostly younger and often physically much fitter and so require a different range of services. Furthermore, as the HIV Futures studies have shown, PLWHA frequently face discrimination from many of the mainstream health and welfare services.

Nevertheless it seems time for a rationalisation of the full range of supported accommodation for PLWHA, including that which is provided by the non government sector, so that the services for PLWHA are in line with services provided for other disabled groups.

Service delivery implications

The change in the nature of the progression of HIV/AIDS so that it now resembles a chronic disease, together with an estimated increase in the need for a range of supported accommodation services, suggests that there should be clarification of the respective roles and responsibilities of all the government departments who have or should have a part to play in the delivery of support and accommodation services to PLWHA – Australian Government Department of Health and Ageing, NSW Departments of Ageing, Disability and Home Care, Housing and Health. This clarification of roles and responsibilities should also include the other supported accommodation services provided by the non government organisations (see section 8).

6.2.2 Increasing prevalence of PLWHA with ADC and other neurological complications

In the post HAART era, there are increasing numbers of clients with milder dementia symptoms and fewer clients with more severe dementia symptoms. However the more severe clients are on treatment and living longer

with fewer opportunistic infections and with more time to develop a greater number of other clinical and mental health issues. People with ADC are now living an average of 44 months after diagnosis; approximately four times longer than they were in pre-HAART times, when the average life expectancy was only six months after ADC diagnosis (ADAHPS 2003:5).

ADAHPS (2003) has estimated the numbers of PLWHA with ADC and other neurological conditions in 2007. Based on current living AIDS case figures, it is estimated that by 2007, 5% to 10% of living AIDS cases (approximately 90 cases) will have severe ADC requiring heavy community support; 10% to 15% (another 90 cases or approximately 180 cases in total) will have significant ADC requiring some community support, 15% to 20% (another 90 cases or approximately 270 cases in total) will have any form of ADC and 30% to 60% (approximately 540 cases in total) will have neurological complications of HIV disease. Based on these projections, it is expected that the increase in ADAHPS clients will be as high as 20%.

Service delivery implications

The projected increase in people with ADC and other neurological conditions means that there is a need for more supported accommodation places now and in the future. The people requiring supported accommodation is also widening to include not just those with a diagnosed mental health or cognitive impairment but also a proportion of those with drug and alcohol issues. ADAHPS (2003) estimates that there needs to be:

- more places available at the highest level of support (ie, six to 10 extra places made available by 2007 at a level of support similar to current provision at The Bridge)
- the Intensive HIV Supported Accommodation Project (see NGO section for details) currently has four places. If the evaluation of this service is seen as successful, it should be expanded up to an expected extra six places by 2007
- ADAHPT brokered care established as a formal option (up to 20 places by 2007).

The increasing numbers of HIV cases with complex needs suggests that the ADAHPT may need to be enhanced in the next five years.

6.2.3 ADAHPS model of care

This service was one of the most consistently praised by many of the submissions, especially its way of operating – ie supporting the local services to provide care and support for people with HIV who have complex needs – and its approach to case management.

Service delivery implications

The success of the ADAHPS model of care to other forms of service delivery for PLWHA needs to be assessed in terms of its applicability for other services, especially its definition of and approach to case management.

6.3 Other statewide services

6.3.1 Multicultural HIV/AIDS and Hepatitis C Service (MHAHS)

The Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) received \$502,000 in 2003/2004 from NSW Health to empower people with HIV/AIDS and/or HCV from culturally and linguistically diverse backgrounds to access better health care, support and information. The service also assists mainstream health services to respond appropriately to the needs of these individuals and communities. MHAHS provides services in three areas:

- care and support
- education and prevention
- advocacy and training.

The service employs 76 casual bilingual/bicultural workers (two FTE) called co-workers from 20 different language groups, who provide emotional and social support to PLWHA from CALD background. They provide multilingual information on living with HIV/AIDS, advocacy and referral and a liaison service for HIV/AIDS clinicians to assist in the case management of CALD PLWHA by providing cultural input. These co-workers also assist with strategies in community development, health promotion and ethnic media campaigns.

There have been between 20 and 30 referrals to the service each year for the last three and a half years (Table 21). In the two years 2001 and 2002, there were a total of 117 HIV notifications in NSW who spoke a language other than English at home. It would therefore appear that referrals to MHAHS care and support service are about half of these CALD HIV notifications.

Table 21. MHAHS: referrals and occasions of service by year

	2000/01	2001/02	2002/03	July to Dec only 2003/04
Referrals	30	28	21	15
OOS	4354	5566	4966	2439

Source: MHAHS

MHAHS estimate that they see about half of the new HIV notifications from a CALD background. It estimates that treatment and care services in NSW will continue to experience demand from PLWHA with complex cultural and linguistic needs over the next five years, particularly from people born in Asia and sub Saharan Africa.

Service implications

The emerging trend of increasing numbers from a CALD background needs to be closely monitored, especially as these people are often late presenters.

The co-worker model is unlikely to be sustainable in the context of increasing numbers of people from a CALD background presenting with HIV. It is essential that mainstream and HIV services are supported by MHAHS to develop their capacity to meet the needs of PLWHA from CALD backgrounds.

HIV and mainstream services need to be aware of and sensitive to the needs and circumstances of this group (this is discussed in section 9.2.2 in the context of workforce issues).

6.3.2 Paediatric HIV Service at Sydney Children's Hospital

The Paediatric HIV service, based at Sydney Children's Hospital receives \$360,000 per annum to provide multidisciplinary clinical and psychosocial support to families with children affected by HIV.

The Paediatric HIV team consists of a CNC, social worker and an infectious diseases staff specialist. The services provided include:

- home visiting (three to four per month)
- family support groups (10 children per session, six sessions per year)
- counselling
- case conferences (10 –15 per year)

Statewide services

- disclosure
- support to school and childcare settings (five to six visits per year)
- clinic review (16 children per month)
- linking and liaising with community service providers
- education to health care workers and community services (six to eight sessions per year).

The team also organises and coordinates Positive Kids camps twice a year (10 children per camp). Camp Goodtime is held once a year and over 60 children and their families attend.

In the past HIV infection has occurred in infants and children as a result of the medical use of blood and blood products. Such transmissions have not occurred in Australia since 1984. Recently, mother-to-child transmission has been the predominant method of exposure to infants. In the last 10 years this form of transmission has occurred on 24 occasions (Table 22).

Between 1996/97 and 2001/02 only a small number of children were admitted to hospital for an HIV/AIDS related illness. The Children's Hospital at Westmead had 28 HIV/AIDS separations over the last six years; at Sydney Children's Hospital (SCH) there were seven separations. Total HIV/AIDS beddays for children aged 0–14 years over this period were 194 days (Table 23).

Many of the new families seeking services from SCH or in consultation with SCH staff are from CALD backgrounds, usually African or Asian. These families have tenuous residency status, may be on a temporary protection visa, are visiting workers, students or here illegally and are therefore ineligible for funded health service delivery in accordance with the policies of the Australian Government. While there are public health and humanitarian benefits from providing services to ineligible persons, the lack of Australian Government funding means that Areas will need to assess each case on its merits with regard to making available treatment and service provision free of charge.

Service implications

There has been a decline in the number of children being born with HIV/AIDS in the last 10 years from seven children in 1994 to one child in 2002. With new treatments, there are fewer hospital admissions. However there is still a need for specialised paediatric services because despite the reduction in new cases, there are still a number of children living with HIV/AIDS.

There is an increase in families from CALD backgrounds seeking services. Often it is not the child who has HIV/AIDS but rather their parents and they are seeking support for their children. The NSW Health Department should liaise with the Department of Community Services regarding appropriate services to meet the needs of such children, as it is not an appropriate role for the service to assume within its existing allocation.

6.3.3 Albion Street Centre (ASC) – four telephone services, Infection Control Resource Centre, HIV and Hepatitis C reference library and the Ankali Service which has a supra-regional role

The ASC receives almost \$600,000 a year to provide four toll free telephone services – NSW Needlestick Injury Hotline, NSW HIV/AIDS Information Line, NSW Needle Clean Up Hotline, NSW Post Exposure Prophylaxis (PEP) Hotline; the Infection Control Resource Centre and a HIV/HCV reference library.

The **NSW Needlestick Injury Hotline** (NSIH) offers a coordinated approach to the provision of information, support and referral for health care and paramedical workers who sustain a needlestick injury and/or occupational exposure to blood and body fluids in the workplace. The team of nurses and medical officers based at the ASC is able to provide: risk assessment; management strategies; documentation; post-exposure prophylaxis information; counselling support; referral (a database of regional services is available for referral purposes). The NSIH has operated since 1995 and calls to the phone line have remained relatively stable since that time.

Table 22. Number of cases of HIV infection via vertical transmission by year

Risk exposure	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
Vertical transmission	3	7	5	2	1	2	1	2	0	1

Source: NSW Health Notifiable Diseases Database

Table 23. Number of separations and beddays in HIV DRGs for children aged 0–14 years by hospital and year

Hospital	1996/97		1997/98		1998/99		1999/00		2000/01		2001/02		Total	
	Separations	Bed days	Separations	Bed days	Separations	Bed days	Separations	Bed days	Separations	Bed days	Separations	Bed days	Separations	Bed days
Private Day Hospitals	2	2	0	0	0	0	0	0	0	0	0	0	2	2
Lismore Base	1	4	0	0	0	0	0	0	0	0	0	0	1	4
Nepean	0	0	0	0	0	0	0	0	1	1	0	0	1	1
Sydney Childrens	4	13	0	0	0	0	0	0	0	0	3	5	7	18
Childrens Hospital Westmead	2	9	8	29	12	64	1	3	5	56	0	0	28	161
Mount Druitt	0	0	0	0	1	8	0	0	0	0	0	0	1	8
Total	9	28	8	29	13	72	1	3	6	57	3	5	40	194

Source: FlowInfo

Table 24. Needle Clean Up Hotline Calls by Area Health Service by Year

Suburb/Area Health Service	2000	2001	2002	2003	Total
Cabramatta	139	131	59	64	393
Central Coast	211	234	152	160	757
Central Sydney	227	266	133	147	773
Far West	1	1	0	5	7
Greater Murray	12	25	4	17	58
Hunter	173	161	120	111	565
Illawarra	36	25	31	29	121
Macquarie	28	55	34	28	145
Mid North Coast	47	51	42	52	192
Mid Western	33	41	27	25	126
New England	25	9	9	2	45
Northern Rivers	31	38	23	18	110
Northern Sydney	34	48	24	30	136
South Eastern Sydney	161	264	193	213	831
South Western Sydney	104	127	80	53	364
Southern	5	5	9	8	27
Wentworth	49	69	52	30	200
Western Sydney	171	185	126	112	594
Total	1487	1735	1118	1104	5444

Source: ASC

The **NSW HIV/AIDS Information Line** provides information to the public and HCW on a wide range of issues. Calls to the 1800 number can only be made from outside the metropolitan area and only 20% of calls in 2002 and 24% in 2003 were made using the 1800 number. The majority of callers (72% in 2002 and 70% in 2003) are male.

The **Needle Clean Up Hotline** was started in 1997 at the request of the NSW Health Department to meet the following objectives:

- to provide a single accessible telephone service to which all concerns about discarded needles and syringes can be referred

Statewide services

- to provide callers with an opportunity to express their concerns and to give them advice and information to help them resolve them
- to provide a standardised process for registering complaints about discarded syringes or the needle and syringe exchange program and to promptly refer complaints to the appropriate agency
- to collect data about the perceived problem of discarded syringes which can be used to inform the response of local agencies.

The **PEP Hotline** is a 24 hour service which is answered by the ASC Information Line during information Line operation hours. After hours it is answered by Link Paging and referred to the HIV treatment service operated by St Vincent's Hospital staff. The Hotline was established as part of a PEP promotion campaign to selected groups at epidemiologically increased risk of HIV infection.

Table 25. PEP Hotline calls by AHS by year

Area Health Service	2001	2002	2003	Total
Central Coast	6	3	5	14
Central Sydney	98	77	99	274
Far West	–	–	–	–
Greater Murray	–	2	–	2
Hunter	6	8	7	21
Illawarra	4	3	2	9
Macquarie	3	3	–	6
Mid North Coast	4	1	6	11
Mid Western	1	2	1	4
New England	3	1	1	5
Northern Rivers	8	4	12	24
Northern Sydney	28	30	37	95
South Eastern Sydney	233	197	152	582
South Western Sydney	11	19	16	46
Southern	2	1	1	4
Wentworth	6	2	2	10
Western Sydney	21	15	18	54
ACT	4	2	3	9
Other Australian State	11	4	5	20
International	1	–	1	2
Unknown	90	39	24	153
Total	540	413	392*	1345

Source: ASC

*Data for 2003 is incomplete.

Established in 1995, the aim of the **NSW Infection Control Resource Centre** (NSW ICRC) is to provide an expert reference service in accordance with NSW Health Department directives, guidelines, policies and regulations. This service is available to all health care workers in NSW, irrespective of their geographic location or Level of infection control knowledge or expertise.

A team of experienced and qualified infection control personnel staff the NSW ICRC. The Centre is unique in Australia and works collaboratively with the infection control staff of the NSW Health Department, the Australian Infection Control Association (AICA) and the NSW Infection Control Association Inc.

Current activities of the ICRC:

- Telephone information service (1200 calls in 2002; 3286 in 2003).
- Video and CD Rom lending library (66 titles; 292 loans in 2002; 372 loans in 2003).
- Quarterly Newsletter (In-Control) (current circulation 3000).
- Resource packages– information sheets on key topics.
- Six double-sided A4 information sheets developed (on Infection Control; Hand Washing and Hand Hygiene; Needlestick Injuries; Cleaning Health Care Facilities; MRSA Information Sheet for Staff; and MRSA Information Sheet for Patients).
- Seven hand washing posters developed (over 8000 distributed).
- Posters on Standard and Transmission-based Precautions are being designed to be distributed in 2004.
- Comprehensive list of NSW Health Circulars and Information Bulletins relating to Infection Control updated quarterly and published in In-Control.
- ICRC website.
- Infection control audits as requested by facilities and private practices.
- Expert advice to health care facilities, health care providers and NSW Department of Health.
- Membership of expert committees.
- Development, dissemination and evaluation of Core Competencies for Sterilisation.
- NSW Needlestick Injury Hotline – coordinate, staff, maintain database.

- Maintain current collection of all policies, circulars, guidelines, standards, regulations and legislation pertaining to Infection Control practice in NSW. Interpret this information for health care workers and stakeholders.
- Education courses:
 - Management of Needlestick Injuries and Other Exposures (two day, bi-annual).
 - Infection Control for Cleaners of Health Care Facilities (half day, bi-annual).
 - Introduction to Infection Control for Dental Assistants (one day, quarterly).
 - Introduction to Infection Control Nursing (one day, quarterly).
 - NSW Ambulance Service new recruits (eight sessions a year for 200 new officers).
 - Cleaning Sex-On-Site Venues (twice yearly for ACON).
 - Individual education sessions as requested from health workplaces.
 - Mobile education to rural areas ("roadshows") on specific topics.

The **NSW HIV and Hepatitis C Reference Library** provides a reference service for both Albion St Centre staff and external users throughout NSW. External users include health care workers, researchers, students and clients. Over 600 Inter Library Loans to external users are provided each year at no cost.

The Library is also a key member of the HIV/AIDS Library Network, which also includes libraries from FPA Health, ACON, and the National Centre in HIV Social Research. The Network provides cataloguing records to RMIT publishing. The records are combined to form the HIV/AIDS database. This database is published on RMIT's AUSTHEALTH database, which is available on subscription.

The **Ankali Project** provides emotional and social support to PLWHA, their partners, families and carers, through the use of trained and supported volunteers. The Project operates with approximately 120 volunteers at any one time. Volunteers are recruited and trained by the Project and receive ongoing support and supervision through weekly, compulsory, support groups which are coordinated by the professional staff. Volunteer attrition

is very low, with over 40% of volunteers having been with the Project for seven years or more.

The volunteer project is Sydney based and provides services to clients throughout the metropolitan area as follows:

- South Eastern Sydney (46%)
- Central Sydney (40%)
- Northern Sydney (2%)
- Western Sydney (5%)
- South Western Sydney (2.5%).

The Project also provides client services in Wentworth Area Health Service (2.5%) and a telephone based service to clients in the Mid Western Area Health Service (1%) and Southern Area Health service (1%).

These demographics mirror the general demographics of the HIV diagnoses throughout the metropolitan area (ie South Eastern Sydney 29.9%:

- Central Sydney 13.8%
- Northern Sydney 5%
- Western Sydney 3.1%
- South Western Sydney 2.8%).

From this it would appear that the Project reaches similar proportions of PLWHA in each Area Health Service.

The Project also provides advice and support to community groups and professionals in non-metropolitan areas, on matters relating to emotional and social support of PLWHA provided by volunteers. In the past year the Project has provided such support to staff and community groups in the New England and the Northern Rivers Area Health Services. Individuals from non-metropolitan areas attend the Project's volunteer training programs in order to be able to provide a version of the Project's model of care in their own area.

In addition to the volunteer project, the professional staff also provide limited therapeutic and welfare counseling, and a referral service to other agencies, and these services are available to all clients of the Project.

At any one time between 100 and 120 clients use the service.

Service implications

This suite of statewide information and advice services provides very important infrastructure and support to the HIV/AIDS prevention initiatives and care and treatment services. They also have broader applicability in that they have now incorporated hepatitis C into their service. The infection control resource, that may have been set up initially in relation to HIV, is now the State's expert reference resource on this issue and available to all health care workers in NSW, irrespective of their geographic location or field of specialty.

6.3.4 HIV/AIDS Dental Program

PLWHA tend to have more oral health problems than the HIV negative population for a number of reasons:

- A diminished immune system can hasten the course of oral disease.
- Some of the medications used by people with HIV may cause decreased salivary flow, which is known to contribute to rampant caries.
- A particularly severe form of periodontal disease – necrotising ulcerative periodontitis – appears to be unique to those people with compromised immune systems.

As a result of this increased risk of oral health problems, HIV positive people should ideally have a dental check up every six months. Individuals with HIV can protect themselves not only with routine examinations, but also by brushing and flossing regularly, not smoking and limiting their alcohol intake (Rosenstein 2004).

An amount of around \$268,000 is allocated each year to SESAHS (STV Hospital), CSAHS (United Dental Hospital), NRAHS and MNCAHS to provide HIV dental services. This funding was never meant to cover the cost of all the dental needs of PLWHA in these Areas but rather it was meant to supplement public dental services to improve access for PLWHA.

Most of the submissions raised access to dental services as a major issue. Public dental services have such long waiting lists generally that this specific AIDS funding has not been sufficient to meet the dental needs of all PLWHA.

Service delivery implications

Oral health is a major issue for PLWHA: problems need to be identified and treated early to reduce their impact. Even though some problems are caused by bacterial infections (periodontal disease), caries resulting from a dry mouth can be prevented by the use of fluoride and good oral hygiene. Symptoms of dry mouth can be treated using simple measures such as artificial saliva products or sugar free citrus candies. It seems that maybe the AIDS funding allocated to already under-funded public dental services, could be better spent on preventative measures such as oral health promotion or even the distribution of effective saliva-producing toothpastes.

6.3.5 Sydney Sexual Health Centre

Sydney Sexual Health Centre (SSHC) is one of the oldest and largest sexual health services in the country. It used to receive funding for supra-Area service delivery because three quarters of its clients came from outside SESAHS. However with the development of sexual health services in all Area Health Services, this out-of-Area client base is declining. The SSHC does however provide statewide services in the form of a clinical advice hotline (ie to clinicians seeking advice regarding the management of STIs and of issues such as counselling and contact tracing) and the Director chairs the Department's advisory panel on the management of persons who knowingly place others at risk of infecting others.

6.3.6 Sydney Hospital

Sydney Hospital provides a series of post registration nursing courses – infection control, HIV and sexual health for which statewide funding is contributed from the AIDS Program.

6.3.7 Transfusion Related AIDS and Infectious Diseases Service (TRAIDS)

TRAIDS is a statewide service located within Western Sydney providing support, counselling and information to people with medically acquired HIV and hepatitis C. It was established in 1986 and extended its role to people who have medically acquired hepatitis C in 1994. The majority of HIV clients of this service are long term survivors. They are experiencing health problems as well as coping with treatment side effects. Increasingly the burden of care is falling on family members or in

some cases their ageing partners. Access to community support in the home, particularly respite, personal care and transport are common requests from these clients.

6.3.8 HIV, Sexual Health and Hepatitis C Workforce Development Program

Funding support for workers in both government and non government settings to access training and development activities is available through the NSW Health Workforce Development Program (WDP), which supports the payment of registration, travel, and accommodation costs for staff. The issue of funding for relief/replacement staff remains a critical one especially for smaller agencies and workplaces. Currently \$252,000 per annum is given to this program from the AIDS budget.

More details about this program are given in section 9.2.1.

6.3.9 Positive Heterosexual (Pozhet) Service

This newly recognised statewide service is to receive \$180,000 in funding in 2004/05. Staffed by 2.6 FTE, this service provides statewide peer support and education for men and women living heterosexually with HIV/AIDS, and their partners, families and friends. It has a statewide free call number and phone counselling and information is offered. There is a monthly newsletter and outreach services are provided to clients and staff in rural Areas.

6.3.10 Institute of Forensic Medicine

No information or data was made available to this Review about this service, which is currently funded as a statewide service to provide a centralised autopsy service for HIV/AIDS related deaths.

Service delivery implications

NSW Health needs to follow up and obtain details about the number of HIV-related autopsies provided by the Institute with a view to assessing whether it should continue to be funded as a statewide service.

6.4 Concluding comments

There has been a rationalisation of statewide services since the last review. Four services that were recognised as statewide services at that time are no longer in this category – St Vincent's Hospital allowance for the pre-eminent clinical role of its HIV/AIDS service, Sydney and Parramatta Sexual Health Services, the RPA Haemophilia Counselling Service.

The current statewide services all appear to genuinely provide a statewide role, or at least a supra regional role to Areas seeking their services. Based on epidemiological trends, the services that are expected to experience increases in demand in the next five years are ADAHPS, the HIV Dental Program, the Multicultural HIV/AIDS and Hepatitis C Service and Pozhets. The AIDB proposal to introduce service agreements/memoranda of understanding between the statewide services and NSW Health will make funding and accountability of these services more transparent in the future.

7

General practitioners

7.1 Services

The active involvement of GPs in the care and treatment of PLWHA, especially in high prevalence areas, has been a feature of the Australian response to HIV. The role of the GP can encompass HIV testing and diagnosis, pre- and post-test counselling, the development and implementation of treatment plans with the patient, prescription of s100 drugs, ongoing monitoring of treatments, referral to specialists and in some cases, shared care with them.

Financing arrangements can affect the provision of medical services. The Australian Government is mainly responsible for paying benefits for services provided by private medical practitioners (GPs and specialists), operating through Medicare which is administered by the Health Insurance Commission (HIC). The State government provides public hospital medical care (inpatient and outpatient) funded under Australian Government/State Health Care Agreements.

As the pattern of disease has changed with better treatments, the role of the primary HIV care provider has become even more important for PLWHA. People with HIV report wanting to access care from GPs and get most of their care, treatment and information on HIV from them. GPs are carrying a substantial burden of care provision especially in moderate and high prevalence areas. With the increase in numbers of PLWHA who are living longer and experiencing the development of age-related and HIV-associated conditions, the need is heightened for a skilled primary care practitioner who is aware of the potential for additional complications as a result of HIV. This shift in responsibility for the clinical care of many PLWHA has not been reflected in Levels of resourcing or support for GPs.

The Report on the Review of HIV/AIDS Care and Treatment Services in NSW (2000) describes GP involvement in HIV/AIDS care as falling into one of three categories:

- The 'specialist' HIV GP, who has a high volume of HIV/AIDS patients,¹¹ is an accredited highly specialised drugs provider, and initiates and directs treatment. These GPs are usually responsible for the bulk of a patient's management and are concentrated in high prevalence areas. A patient will generally only be referred to hospital specialists if complexities arise or where particular diagnostic tools or treatment modalities are only available in the hospital setting.¹² The extent of ongoing liaison with hospital based specialists varies somewhat between GPs, but is generally much less than for other diseases or conditions, given the Level of specialisation of these GPs.
- The accredited, highly specialised drugs prescriber who manages a smaller number of HIV/AIDS patients (in some cases only two or three), and who more frequently refers to or consults with specialist services.
- The GP who provides non HIV-related primary care to PLWHA, in consultation with specialist HIV services, with the latter providing all HIV/AIDS related care and treatment. These GPs have not sought antiretroviral prescribing rights.¹³

There are many challenges in the management of HIV-infected patients.¹⁴ The patient needs to be well informed about the nature of the disease and its treatment. The clinician also has a role in exploring a range of psychosocial and sexuality issues. The quality of the doctor-patient relationship is central to the successful long term management of HIV. It needs to involve an effective, collaborative therapeutic relationship, thorough on-going assessment and education, provision of information and referral, and effective medical

¹¹ Large inner Sydney HIV practices report having caseloads of between 1200 and 1600 HIV/AIDS patients. While the majority would be seen for all their care, a substantial proportion of patients is seen occasionally as they live elsewhere.

¹² This includes access to some clinical trials, although some trials are also run in general practice settings.

¹³ NSW Health: Report on the Review of HIV/AIDS Care and Treatment Services in NSW (2000) pp. 119-120.

¹⁴ Orth D, Hoy J, Fitzgerald W et al. (2001) 'Primary care management of HIV disease' in Dore G, Grulich A, Hoy J et al (eds) HIV/Viral hepatitis, ASHM.

intervention. Offering frequent and/or long consultations may be appropriate at various points in the patient's care and the provision of an after hours contact number may be required in some circumstances.

In addition, being an s100 prescriber is complex and demanding. It means keeping up to date and informed about the initiation and management of antiretroviral therapy (including knowing and recognising side effects, adverse reactions, toxicity) as well as associated issues such as infection control.

7.2 Antiretroviral prescribing rights

NSW Health funds the Australasian Society for HIV Medicine (ASHM) to administer the NSW s100 Prescribers Project. ASHM represents medical practitioners, health care workers and others working in the HIV and related diseases sector. Under the s100 Prescribers Project, ASHM provides:

- training to general practitioners and sexual health registrars to equip them to become accredited HIV s100 prescribers
- training to accredited GPs and sexual health physicians and registrars to enable them to maintain their prescribing rights
- basic training to GPs and others who want to familiarise themselves with, or update their existing knowledge of HIV medicine, but not to a Level of expertise leading to HIV s100 prescribing
- a range of other information and education activities, including facilitating accreditation of HIV training for vocational registration with Medical Colleges.

7.3 Utilisation

There is very little available data on visits to general practitioners by PLWHA. As part of ASHM's registration of s100 prescribers, it asks doctors to complete a questionnaire about their practice. Of the 130 s100 prescribers of antiretroviral drugs, 76 responded to this questionnaire in 2002. It is important to note that of the 76 prescribers in this sample, 58% are general practitioners and 38% are specialists, most notably sexual health physicians.

Table 26 shows the number of patients with HIV/AIDS seen by those prescribers on average each week by Area Health Service where the prescriber practices. Taking the mid point of each of patient number category and multiplying by the number of prescribers in that category, it is possible to estimate the total number of PLWHA that those 76 prescribers see on average each week. On this basis these 76 prescribers saw on average over 700 PLWHA each week in 2002.

Table 26. Number of patients with HIV/AIDS seen per week by s100 prescribers, 2002

	Number of patients with HIV/AIDS seen per week								Total
	1 or less	2-5	6-9	10-14	15-19	20-29	30 or more	not known	
CCAHS	0	1	0	1	0	0	0	0	2
CSAHS	2	3	0	1	0	0	1	0	7
HAHS	0	0	0	0	1	0	0	0	1
IAHS	0	0	0	1	0	0	0	0	1
MAHS	0	1	0	0	0	0	0	0	1
MNCAHS	3	2	1	0	0	0	0	0	6
MWAHS	1	1	0	0	0	0	0	0	2
NEAHS	0	0	0	0	0	0	0	1	1
NSAHS	2	1	1	2	0	0	0	0	6
NRAHS	0	2	3	0	1	1	0	0	7
SESAHS	2	4	2	1	0	0	10	0	19
SWSAHS	1	0	0	0	0	0	0	2	3
SAHS	5	2	0	0	0	0	0	0	7
WAHS	1	0	0	1	0	0	0	0	2
WSAHS	0	3	0	1	0	0	0	0	4
Other	1	2	2	0	0	1	1	0	7
Total	18	22	9	8	2	2	12	3	76

Source: ASHM

7.4 Issues and implications for service delivery

7.4.1 Distribution and number of s100 prescribers

The lack of GPs with s100 prescribing rights for antiretroviral treatments was highlighted throughout this service and needs assessment, especially outside SESAHS.

Currently there are up to 130 accredited s100 prescribers, including GPs and sexual health physicians. Not all of them are actively using their prescribing rights. Initially, in the early 1990s, considerable effort was made to recruit and accredit GPs across the state as part of a strategy to ensure PLWHA had access to an HIV accredited primary care practitioner close to where they lived. By 1997, however, more than half of the trained GPs in rural areas had not had need to use their HIV prescribing rights and approximately half of these had seen no patients with HIV. Consequently this group of general practitioners had let their knowledge lapse. (NSW HIV Prescribers Project 1997 – report to the Steering Committee on maintenance of prescribing rights).

The situation remains much as it was reported in 2000. Specialised, high volume HIV practices are largely located in the Darlinghurst area and this is where the highest numbers of prescribers are. In most other parts of the state, there are relatively few GPs with an interest in HIV medicine. There is an urgent need for more accredited prescribers in CSAHS, especially in the Newtown area, to cater for the primary care needs of growing numbers of HIV positive people. The Northem Rivers is struggling to retain sufficient prescribers. At least one rural area reported that it is almost impossible to retain an accredited GP unless they are part of a sexual health service.

In the western Sydney metropolitan areas there has been limited uptake of, or interest in, HIV management by GPs. Care is provided by one to two general practitioners and via public out-patient clinics and sexual health services.

Initiatives by the Australian government aimed at promoting group practices has led to the growth of multi-practitioner practices where practice management is provided by a management company. Many do not easily provide continuity of care and appointments with a designated practitioner. Routine HIV care cannot be

provided in these settings as access to s100 drugs is limited to accredited providers, and prescriptions for these drugs cannot be provided, even for maintenance therapy, by colleagues who are not HIV accredited.

7.4.2 Practice viability

The nature of consultations for people with HIV (ie frequent and long) is not conducive to optimum fee generation. In practices with low to medium caseloads of people with HIV, it is easy to spend large amounts of time for no financial return, with an adverse influence on the rest of the practice. Scrutiny from the Health Insurance Commission regarding non-standard practice profiles is also a deterrent for some GPs.

The Level of the Medicare rebate is seen by many GPs as inadequate. This is the case even given provision for extended consultations and from 1999, the Enhanced Primary Care Medicare Benefits Schedule (EPC MBS) which came into effect as a part of the Federal Government's Enhanced Primary Care Package. The cost of providing quality general practice is considered by many GPs to have risen at a greater rate than the rise in rebates available through bulk billing.

The financial disincentive for GPs to bulk bill works against people with HIV, many of whom are on benefits. As patients move from pensions or benefits back into the workforce, their access to bulk billing is likely to be further eroded. Even the larger HIV focused group practices in inner city Sydney are finding the maintenance of bulk billing difficult and most are introducing charges at some level. It is a particular problem in rural areas¹⁵ where the lack of bulk billing GPs is widespread and not restricted to HIV management. Especially in areas where there are general GP shortages and variable availability of peer/specialist support, there is little incentive to become involved in HIV medicine. This may become a key issue in quality of care and may result in increased pressure on public health services.

Given the complexity of this still-emerging field of medicine, the concentration of PLWHA in inner Sydney, and the relatively small numbers overall, it is not feasible to expect significant numbers of GPs across NSW to maintain interest and/or skills in HIV medicine. At the

same time, wherever they live, PLWHA need affordable access to specialised treatments via a skilled primary care provider. Greater efforts are needed to use existing resources better (both public and private) to achieve this.

7.4.3 Maintaining s100 accreditation

There are constant demands on s100 prescribers to refresh their knowledge, both in order to maintain their prescribing rights, and keep abreast of changing protocols and treatment issues in a very complex area. This necessitates attending regular (mainly ASHM) education and training sessions. Because of the specialist nature of these sessions they are usually not provided locally for many of the prescribers and those from rural areas incur travel, accommodation and/or locum costs to attend. For GPs with a small HIV patient load, it may not be financially worthwhile for them to maintain their prescribing rights.

Support to prescribers to attend training or participate in other support initiatives is limited. ASHM has limited funding to make this training available in rural areas; likewise not all Areas are able to assist their local GPs with Workforce Development Grants. It is most cost effective to conduct training in Sydney as it provides access to more trainers and more prescribers. However, it is the rural and remote prescribers who need training and support and who have least access to it. ASHM recognises that new formats (such as videoconferencing) need to be developed to reduce costs, while maximising participation. At the same time, it considers that computer and web based initiatives are unlikely to replace face-to-face activities.

Divisions of General Practice also have a role in providing support and training opportunities for GPs, whether they are s100 accredited or simply see occasional patients with HIV/AIDS. However the current Divisional structure is not supportive of GPs with an HIV patient caseload or interest. The prevalence of HIV is too small to sustain an interest in HIV in every Division, requiring rather a supra-regional service that can focus on HIV. This has never been funded, despite early hopes, and ASHM has to a large extent filled the gap. However, resources limit what ASHM can provide, and how, including in relation to administering standards for training.

¹⁵ The Hunter, Central Coast and Illawarra also report a decline in bulk billing GPs.

7.4.4 GP access to a range of medical, allied health and other services

GPs need support from a range of medical, allied health and other services to care and treat PLWHA in the community. These services include specialist HIV/AIDS services; sexual health services; drug and alcohol services; mental health services; cardiac services; diabetes services; dermatology services; dental services; services of a dietician, psychologist, podiatrist; fitness/exercise classes; accommodation. As for the 2000 Review, GPs expressed frustration with accessing public health services on behalf of their patients, and at least one large inner city practice is providing some of these services in-house on a paying basis.

Because of diverse service needs, some PLWHA may need a case manager to coordinate these services. The GP or his/her staff, in many ways, is the ideal person to undertake this role. While the GP can make use of care planning and case conferencing, rebate numbers under the EPC MBS, this can be a very time consuming task and assumes the GP is, and remains, familiar with those services provided by other agencies. An evaluation of the EPC MBS (Australian Department of Health and Ageing, 2002) recommends that a new MBS EPC item should be created to encourage the development of care plans for patients who have chronic conditions and potentially complex needs and risk factors. This would be known as the Disease/Medical Management Plan or Assessment Item, and would be particularly relevant to GPs with HIV caseloads.

The ACON Enhanced Primary Care Project has project staff coordinating access to external services from within GP surgeries across SESAHS, as well as providing some direct services to address psychosocial issues. The highest levels of GP satisfaction reported in a 2002 evaluation (National Centre in HIV Social Research, 2002) related to the counselling and referring role that project officers fulfilled. A similar project operates effectively from the NRAHS, though resources have curtailed its reach. Other models such as in CSAHS, where a pharmacist and allied health staff have been placed in a busy HIV practice, and the H2M service in SESAHS, also appear to be very effective and appreciated by GPs.

7.4.5 Relationships between GPs and public sector services

The relationship between Australian Government funded GPs and State funded public health services can also be complicated. Establishment of Divisions of General Practice have provided a vehicle for AHSs to work with GPs as a group to improve continuity of care and a more coordinated approach to key health priorities. The effectiveness of such collaboration varies. At the practitioner level, public health services have an obligation to liaise with GPs in the interest of 'good medicine' for the patient. When this fails to occur, or does so only sporadically, GPs can feel they are being made a convenience of rather than being treated as an integral part of care provision.

The relationship between GPs who prescribe s100 drugs and specialist HIV/AIDS services provided in the public sector are more significant than the traditional GP-specialist relationship because of the key role the GPs (particularly 'specialist' GPs) play in the management of PLWHA. The 2000 Review report documented the type of communication issues that have occurred (primarily in inner Sydney) and identified a lack of clarity in the nature of the shared care arrangement between the specialist services and the GP. No formal protocols appear to have been put in place, for instance to provide guidance on when referral is indicated. Consultations for this project suggested that little has changed, particularly around clinical trials, competition for the same patients, and hospital discharge summaries. Relationships of any kind, including professional ones, work if there is sufficient incentive for both parties, and a will to make them work. While systems and protocols can assist (eg as for discharge summaries), most is a matter of professional willingness and this cannot be compelled.

There also needs to be a good relationship between GPs and the sexual health services (where relevant). In some situations such relationships are not fostered by the sexual health services on the one hand, or sought by the GPs on the other.

When the network of sexual health services was extended across NSW in the early 1990s with AIDS Program funding, the intention was that they should provide a focus for HIV care and treatment, especially in lower to medium prevalence areas, and complement services provided by private GPs. There are some challenges associated with providing ambulatory care

routinely through these facilities. Examples include irregular availability of a sexual health physician in smaller services and poor linkages with the client's regular GPs left to manage the situation in between visits; competitiveness rather than collaboration between sexual health services and local GPs as patients seek more of their generalist care from public services.

At the same time, there are some very positive examples of GPs and sexual health physicians sharing care, and GPs doing sessions in sexual health service clinics, both to extend capacity and provide more accessible services out of larger centres. Evidence of good relationships might include regular liaison between public and private services, referral from GPs for sexual health issues and contact tracing, possibly the provision of joint clinics, and GP participation in case conferences and learning opportunities. CSAHS and SESAHS have made significant efforts to actively engage GPs in HIV medicine.

Service delivery implications

While AHSs already have formal linkages with local Divisions of General Practice, further attention needs to be given to consolidating and extending functional relationships between health services and GPs in regard to HIV medicine. Practical initiatives might include identifying GPs with an interest in HIV medicine and providing opportunities for learning, support and networking; facilitating continuity of care between admitted and non admitted services and GPs; and facilitating access for patients to relevant public health services (eg hospital admissions, mental health, drug and alcohol etc).

There is a need to articulate and formalise an integrated GP/sexual health service model for primary care for PLWHA appropriate to lower and moderate prevalence areas. Examples already exist that could provide the basis for development of a model which involves elements such as:

- targeted recruitment of GPs to become (or continue as) s100 providers in the context of an AHS strategy to improve access to primary health care for PLWHA
- contracting GPs to work on a sessional basis in the sexual health service, including in outreach clinics
- appropriate specialist supervision and peer support for GPs

- networking links to Level 5/6 hospital specialist services and to a high HIV volume general practice in a high prevalence area, for day-to-day assistance and referrals. The availability of telemedicine
- referral of patients back to general practice (the contract GP and/or other local GPs) for the patient's general primary care needs
- travel and accommodation assistance for participating GPs to attend training to maintain accreditation
- adequate funding of sexual health services to enable them to fulfill these roles
- the changing nature of the epidemic and the profile of PLWHA means that more GPs will need to have a basic understanding of HIV medicine, and/or be able to access information, relevant services and expert advice. This raises the question of whether a greater range of strategies needs to be initiated to support GPs in acquiring this expertise. Strategies might involve the Royal Australian College of General Practitioners incorporating HIV medicine in its Training Program, and ASHM broadening the range of courses it offers
- the possible necessity for ASHM to review its approaches in light of the challenges of retaining s100 prescribers. A greater range of formats for provision of GP training is required especially for regional activities. There may be funding implications for ASHM which need to be addressed in the context of putting in place a more robust HIV treatment and care strategy for moderate prevalence areas
- models currently in place or being developed to support GPs in gaining access to mental health, drug and alcohol, allied health and other services for their patients need to be extended if found to be effective in the longer term,¹⁶ especially in moderate and high prevalence areas. There will be resource implications if effective, sustainable services are to be ensured
- existing models of shared care for other chronic conditions need to be reviewed for their potential application to HIV medicine. In particular attention should be given to the relationship between the GP and specialist (clarification of respective roles and referral protocols) and the adequacy of Medicare rebates for care coordination.

¹⁶ The ACON Enhanced Primary Care Project is currently being re-evaluated to work out the best model for future service provision.

7.5 Access to highly specialised drugs

The location of access points for highly specialised drugs prescribed by GPs is determined by Australian Government legislation. For the majority of people with HIV, the need to make a separate journey to a hospital pharmacy to collect s100 drugs (as is currently required) results in lost time, potential employment difficulties, and also increases the likelihood of compliance problems and interruptions to therapy, due to running out of medication outside hospital pharmacy hours. A successful community pharmacy pilot showed that a community pharmacy program was both feasible and highly valued by people with HIV and AIDS. NSW Health has submitted a proposal to the Australian Government Highly Specialised Drugs Working Party for the differential listing of HIV HSDs. The Working Party has subsequently initiated a stakeholder consultation process in response to that proposal. Differential listing would enable dispensing of the drugs via both community and hospital pharmacies, thus enhancing access options for PLWHA.

Under current arrangements, it has been reported that maintenance of stock by hospital pharmacies can be an issue in some areas and notice of orders needs to be given. If this is a result of real constraints on hospital purchase capacity, then patients would benefit from being made aware of this, either directly by the pharmacy or via their health care providers. Mechanisms can be put in place to reduce waiting times and ensure supply at appropriate times. These can occur within the current s100 guidelines.

HIV/AIDS advocacy organisations have identified hospital pharmacies as services where PLWHA are likely to identify discriminatory, judgmental staff attitudes and breaches of confidentiality. This has implications for workforce training and is discussed further in that section.

Issues relating to drug access are and will continue to be important. This will be increasingly so as the number of people using HAART and the length of time they survive increases.

In addition, the access issue is integrally linked with the above in relation to the listing of new therapies as they emerge.

Service delivery implications

There will be a need for the NSW Department of Health to continue negotiations with the Australian Government to increase access points for highly specialised drugs.

Hospital pharmacies especially in moderate prevalence Areas, need to have mechanisms in place, consistent with s100 guidelines, to reduce waiting times and ensure supply at appropriate times.

Hospital pharmacies in all Areas need to ensure staff are trained to provide confidential, non-judgmental services to PLWHA.

Non government services

8

Non government services continue to have a critical role in meeting the needs of PLWHA. Professional services with a brief specific to PLWHA grew from the community activism of the 1980s, which in turn helped shape public opinion about HIV/AIDS in a positive way and reduce discrimination. Without such services, which are also a vehicle for volunteer and charitable community engagement, many people would have died in poverty, without basic dignity.

Non government services pride themselves on being trusted by and accessible to their target population. Where clients have anxieties or concerns about approaching some government services or departments, NGOs can pave the way for easier access.

As many non government services have a client advocacy role, they operate across the boundaries of a wide range of government services. With this broader perspective, they are well placed to identify gaps and inconsistencies. Thus they can be a force for better integration and coordination of all services.

8.1 Overview of non government services

Non government services specific to PLWHA range from organisations with statewide roles (in NSW) and often multiple functions – eg ACON, PLWHA (NSW), the Haemophilia Foundation NSW, and NUAA – to small, specific purpose organisations such as positive living/wellness centres and supported accommodation services.

The statewide NGOs mentioned above have a number of commonalities in terms of role and function, although their target populations differ. All have strong advocacy, information, education, prevention, peer support and client referral roles.

In addition, ACON provides a broad range of care, coordination and support type services. These include:

- providing HIV treatments information to HIV positive people
- community care services through the Community Support Network
- counselling

- in-surgery coordination and support to GPs
- crisis accommodation for people at risk of homelessness in six properties in Sydney
- housing support, advice and advocacy
- support to families affected by HIV
- transport services through volunteers.

Each statewide organisation has different target populations. ACON describes itself as based in the gay, lesbian, bisexual and transgender communities with a central focus on HIV/AIDS. PLWHA is a consumer advocacy and empowerment group for PLWHA. The target population for the Haemophilia Foundation is people living with HIV and haemophilia. NUAA's target population is people who use illicit drugs and are at risk of blood borne infections.

The Bobby Goldsmith Foundation (BGF) provides welfare services to PLWHA from throughout NSW including financial assistance, financial counselling, interest free loans, positive employment support, and referral advice. Its AIDS Program funding is used for the provision of supported accommodation, and brokered community care and tenancy maintenance support via the Floating Care Initiative.

The following are smaller specific purpose non government services which are funded through the AIDS Program to provide supported accommodation and associated services to PLWHA (eg outreach to former residents, information, education etc). They are:

- Stanford House
- NorthAIDS Des Kilkeary Lodge
- Foley House Inc.

Foley House Inc is funded to provide medium term supported accommodation to persons at risk of acquiring or transmitting HIV within a harm minimisation framework. Its clientele are primarily injecting drug users who are generally excluded from access to supported accommodation because of their ongoing drug use; and only a small proportion currently and historically are PLWHA.

Non government services

In addition, there are four Positive Living Centres (PLCs), which variously provide social support, information and education, complementary therapies, meals and learning opportunities. They are:

- Positive Support Network Inc
- Karumah Inc (Day Centre)
- ACON Sydney Positive Living Centre
- NorthAIDS Myrtle Place Wellness Centre.

The Western Suburbs Haven is funded for social support by WSAHS (in which it is more akin to a PLC).

In relation to the terms of reference for this needs assessment, it is the services provided by NGOs relating directly to referral, treatment, care and support (including accommodation) that are within our scope. The review of the HIV/AIDS Health Promotion Plan will be examining issues relating to education, prevention and health promotion.

This following section reviews a range of services provided by NGOs, consistent with the terms of reference:

- primary care coordination
- counselling
- supported accommodation
- peer support
- volunteers and community services.

8.2 Primary care and coordination

As described at the beginning of this chapter, NGOs have an important role in providing information and referral advice to clients as a first point of call. They are well placed to identify gaps in services, and issues of service responsiveness and failure to meet a client's needs.

ACON in particular has been actively extending its role in treatment and care over recent years. Its long established Treatments Information Project, through Treatment Officers delivering services in Sydney and more recently in the Northern Rivers, provides information, support, resources and referral to HIV positive people to assist them make informed decisions about treatments. Increasingly, the Treatment Officer is seen as part of a collaborative partnership with the patient and the GP.

The introduction in 1999 by the Australian Government of the EPC MBS items for general practice was recognised by ACON as having the potential to provide a platform from which ACON and other NGO and allied health care services could form effective partnerships and deliver more comprehensive care planning and coordination for clients who attend general practices. The intended effect was to better integrate the services of GPs and NGOs, and therefore, improve services to target groups.

The ACON Enhanced Primary Care Project provides project officer(s) to work with GPs to enhance integration and coordination of care with a range of services, as well as provide direct services to clients to address psychosocial issues. Such a service is particularly useful for clients with complex needs. However the coverage of surgeries is limited due to limited resources. The first evaluation of the project (National Centre in HIV Social Research, 2002) identified a number of issues which are being/have been addressed. A subsequent evaluation will provide a sound basis for decisions about the effectiveness of the model, any enhancement or extension of their coverage and the best place to locate responsibility for such coordination.

ACON has also identified a need for stronger care coordination after discharge from hospital. Currently, ACON may not reach discharged PLWHA for some time, when their vulnerability to isolation, recurrence of illness and possible readmission is increased. In SESAHS, a GP liaison position undertakes some of this role, which inevitably is complex because of the number of providers involved.

8.2.1 Issues

A number of issues arise as ACON and potentially other NGOs increase their role in treatment and care in inner Sydney. With the plethora of existing treatment and care services, there is the risk of additional players further complicating inter-service communication and coordination. They may take over the role of another service which is ineffective or cause territorial conflict – both wasteful of resources. This is not to suggest the role is not appropriate, but rather to emphasise the need for clarity about the location and definition of responsibility, and mechanisms for communication and collaboration.

A related issue is the health care worker status of NGO staff. Doctors in particular are reluctant to communicate patient information in writing to NGO staff as they are unsure about confidentiality and record keeping provisions. This limits the potential effectiveness of NGO staff.

Service delivery implications

As some NGOs extend their role in treatment and care, clarity is needed about congruence of this role with their organisational purpose, as well as about the unique contribution such activity makes to the overall mix of services. This is particularly important in high prevalence areas.

Standard operating procedures also need to be developed to facilitate communication and exchange of patient information between health care providers and NGOs with a recognised care and treatment role.

- psychosocial issues associated with HIV transmission and diagnosis, especially in light of the reported increase in HIV risk behaviours and infection rates
- the relation between STIs, multiple sex partners, and increased HIV transmission requiring increased attention to sexual health of clients
- health implications of co-infection (HIV and HCV), with clients experiencing difficulties in juggling the various treatments, discriminating symptoms and the impact of health maintenance on their lives.

Service delivery implications

Access to medium term counselling appears to be an emerging need and priority, with links to prevention. Further work needs to be done to confirm priority target groups for such counselling, to determine the most effective means of delivering counselling, and the most appropriate organisations to be responsible. It will also be important to have clear protocols to guide referral to and exit from counselling.

8.3 Counselling

ACON provides the only community-based counselling service in NSW. The other major HIV specific counselling service is that provided by the Albion Street Centre through its Psychology Unit, which is a statewide service. However all specialist sexual health services have counselling staff with the expertise to support PLWHA and people at risk of infection.

8.3.1 Issues

Service providers consistently reported difficulties in obtaining access to counselling for clients for other than short term crisis situation. Waiting times and reduced intake Levels mitigate against early intervention.

The need was identified for longer term counselling, for PLWHA suffering from trauma or complex conditions, and to prevent serious psychological morbidity.

Access to counselling services generally was identified as an issue in moderate to lower prevalence areas.

Emerging influences that are increasing the complexity of counselling services include:

- high psychiatric co-morbidity, increased drug and alcohol use, changing patterns in drug use, and the psychosocial issues of an ageing, HIV positive population

8.4 Supported accommodation

8.4.1 Services

As people with HIV are living longer and growing older, and a small but growing proportion of them are in need of higher Levels of care, the demands on supported accommodation services are changing and growing.

Over the course of the epidemic, AIDS Program funding has been provided to (mostly) NGOs to assist them to respond to needs for step down care, respite, and crisis accommodation. Limited provision has been made for a small amount of medium and longer term supported accommodation. Along with home-based care, these services are essential features of the HIV/AIDS continuum of care.

The respective roles of NSW Health, the Department of Housing and the Department of Ageing, Disability and Home Care (DADHC) in the provision of supported accommodation have been clarifying over time. Broadly, the delineation involves Housing providing 'bricks and mortar' of accommodation services, with client support provided by Health or DADHC or both.

In the initial response to the service needs of PLWHA early in the epidemic, NSW Health provided funding for both physical infrastructure and staffing/operations

Non government services

in order to get services on the ground quickly. Those funding arrangements continue for a number of NGOs providing supported accommodation.

At the same time, successful partnerships have evolved in the housing/supported accommodation area, such as between the NSW Department of Housing, its Office of Community Housing and NSW Health – particularly via ADAHPS, ACON and BGF. These have operated for many years to extend and ensure access to community based accommodation, including supported accommodation. However, much more remains to be done to improve PLWHA access to mainstream client support provided by DADHC, in line with the provision of supported accommodation services for other disability groups. This is discussed in the next section.

In its *Housing Strategy for People with HIV/AIDS* the NSW Department of Housing (1996) sought to build on and enhance the housing available to people with HIV/AIDS. The Department provides subsidies for private renters through the Special Assistance Subsidy – (specifically aimed at PLWHA seeking to rent in the private market), access to public housing on a priority basis, and independent and community – managed housing. Public housing provides a range of supported housing over 26 properties that involve PLWHA within their target groups. For example, Bobby Goldsmith House (the property) is jointly owned by the Department of Housing and BGF. Through ACON's community housing association, SWISH, crisis accommodation and (brokered) support for people at risk of homelessness is provided through six properties in inner Sydney.¹⁷

The partnerships have been characterised by considerable flexibility in responding to the changing needs of people living with HIV/AIDS. For example, the Department of Housing, through the Office of Community Housing, and NSW Health, jointly fund the Floating Care Initiative administered through BGF, and the number of leases has been extended to 25 following a positive evaluation.

Table 27 lists all NGO-AIDS Program funded supported accommodation. Some are also supplemented from charitable funding and the use of volunteers. Some NGOs are also in partnership with the Department of Housing and/or Office of Community Housing.

To gain a complete picture of all specifically funded supported accommodation in NSW, mention needs to be made of two other important services.

The Bridge is not run by an NGO but is a service of CSAHS. A nursing home type service, it is the only residential facility of its type. It provides 24 hour supervised care and high support to PLWHA with complex needs. There are 12 beds, 11 of which are long term residential and one is for respite care.

The Intensive HIV Supported Accommodation Project (ISHAP) is being currently funded through ADAHPS as a four – bed pilot project for one year. It is a response to the identified need for another option in the HIV supported accommodation continuum of care. The project targets HIV positive and complex clients who cannot live independently but do not require 24 hour nursing care. It is one step down from the Level provided by the Bridge, yet a higher intensity of support than at BGF House. Some of the Bridge clients, once needs have stabilised, could move into this lower support option which would free up some Bridge vacancies for clients who currently need the highest Level of support.

The project is a venture between a local housing association (SWISH) funded by the Office of Community Housing, and ADAHPS.

8.4.2 Provision of support services

The earliest models of supported accommodation encompassed both the physical facility and the support in one service. In these models, support is attached to the facility where the client is housed, and in the main is provided by employed staff. While some supported accommodation services still operate on this model, new models have emerged with greater scope for flexibility in both the type and range of support provided to the client, the Level of support and its duration.

An example is the Care Package model such as the Floating Care Initiative where tenancy is managed by a housing association and support workers provide practical and emotional support. This also includes ADAHPS brokered care arrangements where support care is purchased for a client when the usual, appropriate agencies are not available and case management ensures care is coordinated.

¹⁷ ACON classifies this service as a housing resource rather than supported accommodation as such.

This flexible layering of additional support components on a baseline Level of support enables PLWHA to live in the community longer (including in community tenancies specifically for supported accommodation). It also provides an opportunity to access services and funding from a variety of sources, such as the Home and Community Care Program (HACC), Community Options Programs, and NSW Health (eg for specific community health services, and/or brokerage of private services and care packages).

Support components may include community nursing care, personal care, cleaning/home help, meals/shopping/food preparation, transport and accompanying to appointments, and allied health services. Community nursing care is generally provided by AHS community health or Sydney Home Nursing Services. Allied health services can be provided by AHS community services, and Positive Living Centres may provide complementary therapies such as massage. AHS community health services in the high prevalence areas receive AIDS Program funding for community nursing and allied health services for this target population.

ACON's Community Support Network continues to provide practical community care services, using volunteers, to PLWHA in the Sydney, Western Sydney and Hunter regions. Services include cleaning/home help, meals/shopping/food preparation, and brokerage to HACC – funded transport organisations.

Many PLWHA receiving community health and other support services live in their own homes rather than in supported accommodation as such.

HACC provides some of the home care support needed by PLWHA but they offer only basic care and maintenance services 'designed to assist in meeting the physical, psychological, daily living and social needs of people with disabilities'. Service providers report that it continues to be difficult to obtain HACC and Community Options services for most PLWHA, often but not always because of their Level of need. A number of other private agencies provide home care and support services, and where brokerage funds are available, these may be used for PLWHA.

8.4.3 Issues

Service capacity and type of service

As HIV becomes a chronic manageable disease, the lengthening survival times of PLWHA requiring progressively higher Levels of care has brought supported accommodation services for those who can no longer live independently to capacity limit.

A majority of submissions identified the need for additional longer term supported accommodation, and associated community care, in the general context of severe pressure on existing accommodation and care providers. Recurring themes were blockage of beds (such as in hospice palliative care), clients staying in crisis accommodation much longer than is normal, services at full capacity, a shortage of community care packages for care in the home,¹⁸ and the non-availability of options such as nursing homes or hostels.

More specifically, many submissions identified PLWHA with ADC, and substantial physical, cognitive and neurological impairment as a group that is increasingly difficult to cater for within the existing supported accommodation provisions. The Bridge is the only PLWHA – specific nursing home type service available, and it is at full capacity. Nursing homes are not currently an option due to patient age limitations, staff fears of contagion, lack of skills, and concerns about loss of staff. This is despite substantial efforts having been made by hospice staff in education and support of nursing home personnel. Brokered and community support is costly and hard to sustain for this client group. ADAHPS has provided evidence of need for an additional six to ten extra places by 2007 at the highest Level of support.

Key issues for this high dependency group are the increasing need for services for them, the lack of access to mainstream nursing home services, the appropriateness (or otherwise) of the mainstream model, and the responsibility of the Australian Government for ensuring access of this client group to an appropriate model and Level of care.

The ISHAP pilot is one response to the need for more service options at the high end of the continuum of care – between The Bridge and BGF House. ADAHPS has

¹⁸ Lack of community care packages was identified as a gap in SESAHS, CSAHS, NRAHS, also SWSAHS, WSAHS and Wentworth to a lesser extent.

Non government services

provided evidence to support an increase from four to seven beds for that service by 2007, if the service model is evaluated to be achieving its objectives. It is expected that as service capacity is increased, and models of care are developed which better match client need, then beds will be gradually freed up for more appropriate use. This will relieve pressure on the sector overall, and allow services to provide the Level of care they were set up to provide.

PLWHA with dual/triple diagnoses

PLWHA with a combination of HIV, drug and alcohol problems and mental illness continue to present challenges for supported accommodation services, especially those staffed to provide support at the lower end of the spectrum. Issues include the Level of staff coverage, the adequacy of staff skills in dealing with challenging behaviours, and staff and volunteers at risk of assault and injury.

As identified elsewhere, there is a need for effective case management for this group, with access to appropriate community health services. At the statewide and AHS Levels, there is no policy umbrella to integrate HIV, mental

health and drug and alcohol, to model a comprehensive and linked continuum of care across the programs.

In view of this emerging need and the limited resources available, it seems appropriate for NSW Health to review the extent to which it should continue to provide funds from the AIDS Program to Foley House which targets persons who are not PLWHA.

Equity of access

In the outer metropolitan and rural areas, there are virtually no supported accommodation options (or specific funding) for PLWHA at all. SWSAHS, WSAHS, Wentworth, NRAHS and MNSAHS are particularly affected. Any client requiring supported accommodation has to be moved to an inner metropolitan area. In addition, many clients relocate to isolated rural areas only to find no homecare, transport or community support, and difficulties accessing what mainstream services may exist.

Access to mainstream services/role delineation between government agencies

Collaboration between government departments and

Table 27. AIDS Program Funded Supported Accommodation Services provided by NGOs

Organisation	Name of service	Type of service	Location/AHS
Bobby Goldsmith Foundation	Bobby Goldsmith House	Ten units. 24 hour care. Medium to long term accommodation & support to clients with medium support needs. Provides a higher level of care than Floating Care Initiative.	Surry Hills/SESAHS
Bobby Goldsmith Foundation	Floating Care Initiative	Up to 25 leases. Medium to long term accommodation and support for PLWHA with lower level support needs. Tenancy managed by a housing association (funded by Office of Community Housing) and linked to support services coordinated through case management or brokerage.	Most tenancies in inner Sydney.
Stanford House	Stanford House	4 short term beds. Short stay (up to 1 month), respite and drop-in. No night staff.	Stanmore/CSAHS
NorthAIDS	Des Kilkeary Lodge	8 short term beds. Respite, step down/step up care, in 2-4 week stays.	Dee Why (NSHS)
ACON (Hunter)	Hunter Supported Accommodation	Supported accommodation options brokered from private businesses, for complex clients. Care is coordinated with local services, CSN and/or brokered from private services.	HAHS
Foley House Inc	Foley House	Medium term supported accommodation (6 beds) for clients at risk or acquiring and/or transmitting HIV and other BBVs.	Surry Hills /SESAHS

NGOs in the housing sector has been generally productive, and the Department of Housing has contributed to assisting PLWHA with low to moderate needs for supported accommodation. There appears to be agreement that PLWHA with needs at the higher end of the supported accommodation spectrum are a health responsibility. Nevertheless, NSW Health continues to fund the accommodation component of some smaller NGO providers at the lower support end. These services were originally set up in a climate where temporary medical needs were common such as for step down care following discharge from hospital. With significant treatment advances, this situation has changed and there is some indication that some services may be meeting needs which are not HIV-related, including homelessness and prison discharge. In this context, the role of providers at the lower support end may require reconsideration as part of a statewide planning process. For people requiring higher Levels of support an untested and unresolved issue is whether responsibility rests with the Australian Government or the State government.

In respect of community care, the record is less encouraging. The Department of Ageing, Disability and Home Care is responsible for administering HACC and the Community Options Program. It is recognised that HACC meets basic needs for community care and does not provide for high support needs. Evidence from consultations for this project indicate that even when PLWHA are eligible for these services, it continues to be very difficult to obtain access. It is not clear to this consultancy whether this difficulty is a resource issue in the face of too many competing demands, an unwillingness to take on a new client group which has, to date, been able to access alternative funding sources, a lack of knowledge and confidence around infection control and occupational health and safety issues, a conflict of values, or a mix of all these factors. The fact that the chaotic lifestyles of some of this group can present significant challenges for staff, may well be another factor. The impact of this could be managed with effective case management.

The NGO *People with Disability Australia Inc* reported on its involvement in the HACC HIV Project, which sought to increase access of PLWHA to mainstream HACC services. The experience of the project worker was a lack of consistent understanding and acceptance across the HACC sector of the right of PLWHA to access such services, and how to achieve

this. There were notable exceptions to this approach. They included where HACC services have or are developing relationships with HIV service providers, where leadership has been shown by local HACC services in affected areas such as South Eastern Sydney and in particular sectors with services based around flexible models such as brokerage. This principally includes Community Options services, some of which were reported as being able and willing to develop constructive relationships with HIV and mental health services and to offer a range of complementary services.

It is understood that the integration of PLWHA into existing health care delivery systems occurred as early as 1992 in San Francisco due to reduced AIDS funding. That a situation exists in NSW where parallel systems continue to be maintained in some areas suggests that there are systemic issues needing to be addressed. While recognising the complexity of issues involved, the fact remains that many PLWHA who are eligible for mainstream community support services are not receiving them. The mainstream health workforce has by and large accepted its responsibility to provide services to PLWHA. Greater efforts are needed in the community services area.

An issue more directly related to housing assistance, but with implications for the health of PLWHA is the Department of Housing's planned review of its Special Assistance Subsidy – Special (SASS). This has been pending for some time and causing considerable anxiety among PLWHA, many of whom have been long term recipients of this private rental assistance.

Longer term viability

NGOs (especially the smaller ones) are reportedly experiencing cost increases which in some cases, are said to be affecting the viability of their services. Government funding has not kept pace with increases in insurance premiums, wage and salary determinations, or the cost of rental. In addition, the environment for charitable fundraising and volunteerism is increasingly challenging.

Coordination of assessment and placement

The need has been identified for better coordination of assessment and placement to ensure clients are placed in the most appropriate accommodation. The key need appears to be a mechanism by which accommodation services can communicate about placement referrals.

Service delivery implications

Fundamental planning principles in supported accommodation should be that:

- there is an adequate range of viable supported accommodation options across the continuum of care spectrum and these should target HIV-related priority health needs
- while it is recognised that the majority of services will be in the high prevalence area of inner Sydney, and that high dependency services are most likely to be located there, moderate prevalence areas also need access to supported accommodation options closer to where PLWHA live¹⁹
- there is access to a range of flexible mechanisms for providing support as the needs of individual PLWHA change with progress of their condition.
- assessment of PLWHA for placement in supported accommodation is coordinated so that clients are provided with the most appropriate set of arrangements to meet their needs
- provision of support services for PLWHA is progressively integrated into the existing health and community care delivery system, particularly at the lower end of the support spectrum. Collaborative partnerships and transitional arrangements will be necessary to facilitate this. In particular, substantial investment in training of mainstream services will be required.

The application of these principles has implications for:

- reviewing the Levels of supported accommodation currently being provided to ensure that the target population of each service is clearly defined as part of a statewide planning process, that access to the range of services is coordinated and that services have the financial and workforce capacity to match the Level of care they are contracted to provide
- developing models for ensuring access to supported accommodation in moderate prevalence areas
- maintaining access to a flexible range of funded mechanisms for providing support (including care packages, brokerage) to complement mainstream services

- initiating discussions involving the State government departments of Health, Housing, DADHC, the Australian Government and non government organisations regarding the range of options for increasing access to community care services for clearly identified groups within the target population, in a measurable way. Developing a realistic transitional plan, including a risk management strategy to ensure service access and quality
- creating links with specific mainstream service providers such as Alcohol and Other Drug, Mental Health, CALD, Aboriginal Medical Services, General Practitioners and Community Health Services, particularly where links will support a person remaining in their own home or within the same locality.

Other implications for service delivery are:

- the need to review the accommodation places at the high dependency end of the continuum of care; in view of expected increases in demand. The requirement for an additional 10 places at the Bridge Level of support by 2007 has been projected²⁰
- the need to create additional places with an intermediate Level of support somewhere between the Level of support offered by the Bridge and Bobby Goldsmith House. If successful, the Intensive HIV Supported Accommodation (IHSAP) Project, should be expanded depending on need, probably by up to six to eight places by 2007²¹
- the need to review the entry criteria at the lower end to ensure that the limited AIDS Program funding is directed to health need for supported accommodation only and is not bridging gaps that are the responsibility of other sectors such as the Departments of Housing or Corrective Services, or where other sources of funding are accessible such as in the case of rural residents qualifying for an Isolated Patients Allowance
- clients with dual and triple diagnoses, behavioural issues and complex needs will continue to be a challenge to the care system, especially the mainstream system. The use of targeted resources

¹⁹ ACON's Hunter Supported Accommodation project provides one potential model.

²⁰ South East Health, NSW Health, CSAHS: AIDS Dementia and HIV Psychiatry Services Continuum of Care Project, July 2003 p. 6.

²¹ South East Health, NSW Health, CSAHS: AIDS Dementia and HIV Psychiatry Services Continuum of Care Project, July 2003 p. 6.

(such as for case management and brokered care) may always be needed to some degree to allow for rapid responses and to reduce the impact such clients have on proximate staff and services

- development of a mechanism for coordinating assessment and placement of PLWHA in supported accommodation.

The above issues and principles require a range of actions as discussed below.

Considering the identified demand for higher Levels of supported accommodation and the range of resources already funded through the AIDS Program, there is significant potential for meeting existing and future needs through a reconsideration of the resources currently available and improved planning for service delivery.

On the basis of feedback provided to this Needs Assessment on supported accommodation and current needs, it is recognised that best outcomes for the client base will only be achieved if all supported accommodation services including the NGO administered Stanford House, NorthAIDS, Foley House and BGF supported housing services are considered holistically in a statewide context together with the Area administered supported accommodation and related services. For this reason it is important that AIDS/Infectious Diseases Branch, as the funding body, takes steps in the immediate future to review all existing supported accommodation services and seek direction on the configuration of services that would best meet both short and long term priority client needs.

As it is recognised that statewide planning provides a basis for delivering appropriate and coordinated services, a statewide planning process should also be initiated to clarify the role of each of the various housing components on the basis of statewide priorities and identify criteria for entry to services, exclusions to entry and appropriate linkages between services. The plan should in particular identify systems for achieving coordinated and integrated selection processes for access such as through a 'single point of entry selection committee'.

It is acknowledged that the contributions of a range of individuals and services would strengthen the content of

a statewide plan. For this reason it would be appropriate that a statewide forum is held to explore issues and future directions for providing supported accommodation for people with HIV infection.

8.5 Peer support

Peer education and support play a fundamental role in HIV prevention and health promotion strategies. In relation to treatment and care, Positive Living Centres (as outlined earlier in this section) can play an important part in maintaining social and peer support for PLWHA. They provide opportunities for social interaction, and variously information and education, complementary therapies, referrals, meals and learning opportunities. In addition, some supported accommodation services also provide drop-in facilities and outreach for ex-clients. PLCs generally rely heavily on volunteers.

PLCs sometimes provide a 'portal' through which PLWHA with complex conditions may receive help with identifying their service needs. Issues arise if staff and volunteers lack appropriate skills and information, or linkages with relevant services are inadequate.

Information provided in the surveys and submissions to this project indicates that over recent years, with low Levels of funding and possibly changes in their clientele as more PLWHA have returned to employment, some PLCs may be at risk of losing their focus. Issues they face include clarifying their role and target group, extending operating hours, adequacy of funding, retention of volunteers, the range of services provided, and linkages with other community organisations.

ACON has been actively involved in 'rebuilding the Sydney PLC' and in so doing, reportedly providing something of a model for such services. It has a large and growing client base and an active pool of volunteers. A rehabilitation approach is incorporated via a self funding catering business which provides additional income opportunities and workplace skills for PLWHA.

The lack of peer support opportunities in moderate prevalence areas has been identified as a gap.

Service delivery implications

While PLCs have a key role to play in facilitating peer support for PLWHA, it is important for parent organisations to be clear about the specific needs for peer support, its Level of priority and how it is best provided, funded and sustained. ACON may be in a position to assist any smaller NGOs that are seeking to resolve such issues.

Consideration should also be given to options for incorporating a stronger rehabilitation approach in PLCs, encompassing areas such as re-establishing independent lifestyles, self-management (eg medication adherence), re-entering the workforce, and re-building relationships. Appropriately skilled staff and volunteers, with explicit linkages to related services need to be part of such a model.

8.6 Volunteers and community care services

- All NGOs use volunteers to assist in service provision to a greater or lesser extent, in a wide range of ways.
- Many reported finding it increasingly difficult to recruit and retain sufficient numbers. For example, reliance by ACON's Community Support Network (CSN) on volunteers is critical for provision of home care and support shifts. Influencing factors include the epidemic moving from a crisis to a longer term maintenance phase, as well as increasing numbers of clients with challenging behaviours and multiple needs. Nonetheless, CSN maintains an active volunteer workforce of 110 and growing, and BGF and PLWHA NSW continue to provide significant services using volunteers.

Service delivery implications

While most NGOs are seeking to address this issue and are putting different strategies in place, all are at different stages. Sharing learning across organisations about effective strategies, and NGO leadership giving this issue high priority is critical to future service provision.

Cross service issues

9.1 Health promotion in clinical settings

A review of the NSW HIV/AIDS Health Promotion Plan 2001–03 has been commissioned separately from this needs assessment. To complement that review, however, the terms of reference for this project require an examination of collaborative approaches to ensure gaps in health promotion in clinical settings are covered.

9.1.1 Linkages with the NSW HIV/AIDS Health Promotion Plan 2001–2003

A key point made in the Plan²² is that in addressing the needs of people with HIV/AIDS, health promotion needs to recognise the divergent experiences of people with HIV/AIDS. Factors such as treatment history, year of diagnosis, individual prognosis, and individual outlook must also be taken into account in planning health promotion programs, in addition to cultural and linguistic background, level of engagement with the gay community, gender, sexuality and age.

As already shown in this report, the availability and efficacy of HAART and the subsequent changes to the expected pattern of illness have resulted in significant changes in the needs of people living with HIV/AIDS. The goals of the NSW HIV/AIDS Statement of Strategic Directions of minimising HIV transmission, enhancing and maintaining the health of HIV infected people, and minimising the personal and social impact of HIV infection continue to be fundamental to health promotion.

The Plan outlines a number of implications for health promotion that flow directly from therapeutic developments. These implications mean that the separation between treatment and care and prevention and health promotion is far less distinct than a decade ago. In overview, some of the implications are:

- high levels of treatment failure arising from problems with medication adherence
- the development of antiretroviral drug resistance, leading to some people with HIV/AIDS running out of treatment options and experiencing HIV disease progression
- serious antiretroviral treatment related toxicities and abnormalities, affecting not only health but also self-image and self-esteem
- the development of ageing-related conditions as people with HIV live longer; HIV increases the risk of some conditions such as cardiovascular disease
- the fact that long term continuous treatment with current antiretroviral agents is not likely to be possible for many people, with consequences for their approach to their condition, alternative approaches to treatments, their health and lifestyle
- the complexity of the interaction of treatments and infectivity, and implications for prevention
- the complexity of treatments and the need to support people with HIV/AIDS with accessing the latest information, supporting their compliance and assisting them to manage side effects
- the need to address issues associated with extended life expectancy and living long term with HIV (eg financial planning, workforce entry and re-entry, relationships, parenting, social support).

Other issues not so directly related to the changes flowing from treatment advances but relevant to planning health promotion interventions include:

- managing the effects of mental illness such as long term depression
- the high incidence of smoking among people with HIV. HIV aggravates the effect of respiratory disease
- co-infection with hepatitis C
- the link between risk behaviour, sexual health and use of illicit drugs
- increasing rates of HIV transmission, and of sero-conversion close to time of infection
- the special needs of population groups that may find accessing HIV care and treatment services difficult, such as Indigenous people and those from CALD communities
- in lower-moderate prevalence areas particularly, access to local data to inform health promotion planning

²² NSW Health: NSW HIV/AIDS Health Promotion Plan 2001–2003.

Cross service issues

Such issues highlight the need for health promotion programs in which increased attention is given to the psychosocial issues associated with HIV transmission, and to supporting PLWHA in making informed decisions about their treatments, and more resourceful behavioural choices, as well as managing their health for the long term.

All of these implications add up to the need to bring health promotion more firmly into the lives of people living with HIV, not only to minimise the personal and social impact of HIV, but also to assist them achieve health and well being to the highest Level possible in their circumstances. As treatment and care providers (especially GPs, nurses and allied health staff, and sexual health services) interact closely with people with HIV/AIDS, there is often the strong basis of a trust relationship for the provider to take opportunities with patients/clients for information, education, health promotion, encouraging self management, or referral.

Prevention of HIV transmission is also critical. Treatment and care services have an important and often under-recognised role to play in minimising HIV transmission through helping individuals address the determinants of vulnerability. Counselling, case management, support and/or treatment for issues such as problematic alcohol and other drug use, mental health issues, or domestic violence are important components of an effective prevention program and can help to avoid re-admission to services. Examples referred to elsewhere in this report that facilitate referral especially from GPs include the H2M service, the Enhanced Primary Care Project in SESAHS and NRAHS, the neuropsychology assessment service for GP use in SESAHS and CSAHS.

Open communication and interaction between providers from the various areas to share knowledge and expertise is often the first step in narrowing the gap between health promotion and treatment and care. Certainly communication is vital to facilitate referral. However, because of the changes outlined earlier in both the natural history of HIV and the profile of the affected population, the concept of integrating health promotion and treatment, care and support is beginning to mean much more.

A key feature of some of the more innovative approaches to integration is collaborative partnerships (often across government and non government sectors) aimed directly at increasing access to existing services, providing new services that the individual providers alone could not have done, or building the capacity of existing providers to take on health promotion.

Extending the role of treatment and care health professionals can be problematic. They already have demanding workloads; are pressed for time in delivering their own core services; and have not been trained in health promotion. (The pressures facing GPs in particular (financially and time-wise) have been described in Section 6). Nevertheless, by way of example of what can be done:

- SESAHS provides workforce development in health promotion for staff in clinical settings, and CSAHS has special initiatives to support its s100 prescribers and other GPs with HIV caseloads in a range of ways.
- A program to build the STI/HIV/HCV health promotion capacity of the NGO youth service accommodation and support workforce is run by SESAHS.
- When a need for education and information becomes evident in a palliative care inpatient setting, the CNC for HIV palliative care, Sacred Heart Hospice may refer the patient to a sexual health service, or liaise with the co-case manager, or provide education directly.
- A rehabilitation program for PLWHAs with long term illness called 'Switched on Living' is run by allied health staff at St Vincent's Hospital.

Examples of collaborative partnerships to provide new or expanded services include:

- SESAHS, CSAHS and NGOs collaborating on the STIGMA project, a partnership between the public health units, sexual health physicians and NGOs to implement strategies to minimise the spread of STIs and HIV among gay men. This program is being evaluated
- collaboration between a psychiatric hospital and sexual health service for the provision of sexual health clinics on site is demonstrated by Rozelle Hospital and the CSAHS Sexual Health Service

- a nutritional education program for PLWHAs, with five outreach clinics at high caseload GPs and NGO services, plus a subsidised vitamin supplement service is run by the Nutrition Clinic, Albion Street Clinic.

Examples of physical integration include:

- co-location of HIV health promotion and the Area sexual health service in CSAHS
- co-location of Positive Central, Positive Heterosexuals (Pozhet) and the Sanctuary, a CSAHS venue for PLWHA providing mixed services ranging from support and treatment to prevention activities.

The way some services are experimenting with new ways of working across traditional boundaries to meet new needs is encouraging and provides valuable examples for others.

Service delivery implications

There is an identified need for additional health promotion services directed to PLWHA aimed at strengthening personal capacity for healthy choices, lifestyle management, coping with a chronic illness and rehabilitation. AHSs and NGOs need to review the scope for achieving a more holistic approach by reorienting and/or expanding existing services, building the capacity of providers in key service areas and improving linkages and coordination.

Taking into account the innovation that is already occurring, there is a need for AHSs and NGOs to identify, individually and together, opportunities to further integrate health promotion in clinical settings. Such integration should be linked directly to specific objectives (eg increasing access to services, extending existing service provision, providing new services to meet identified needs, building capacity of providers).

9.2 Post Exposure Prophylaxis

Post exposure prophylaxis (PEP) with antiretroviral medications and counselling has been offered in NSW to persons at risk for HIV exposure through sexual activity or injecting drug use since 1999 (NSW Circular 99/31, 1999). NSW was among the first health jurisdictions in the world to recommend the use of PEP as a component of the range of HIV prevention strategies. Areas are required to fund PEP from within their existing AIDS Program allocations – a strategy

which should be feasible given the reduction in demand for admitted services thus freeing resources previously allocated to those services. Prescribers of PEP were encouraged to refer their patients to an observational study with two arms: a clinician collected data arm and a patient interview arm, coordinated by the NCHECR and the National Centre in HIV Social Research (NCHSR) respectively to assist with monitoring the utilisation of the therapy and to contribute to the body of evidence on its efficacy.

St Vincent's Hospital is the largest provider of PEP and since 1999 has provided PEP to its resident gay population and also the transient gay population who require care following a possible or actual exposure to HIV. The need for PEP is predominantly a weekend or 'after-hours' phenomenon. The initial risk assessment and PEP starter-pack provision occurs in the hospital Emergency Department (ED). Patients who access PEP through the hospital ED receive follow-up care through the PEP clinic, which is based within the hospital's Immunology & Infectious Diseases Ambulatory Care Unit.

The model of care employed results in a minimum of nine occasions of service (OOS) per patient over a time period of six months. PEP provision at St. Vincent's Hospital has grown over time from 89 presentations or 801 OOS in 2000/01 to 175 presentations (1575 OOS) in 2002/03. Within the St Vincent's Hospital PEP cohort (550 PEP presentations to date) there has been no sero-conversions to HIV. In addition to the ED and PEP clinic service, St Vincent's has elected to operate the after hours component of the statewide 1800 PEP NOW help-line. This advertised 24-hour service offers risk assessment, triage, referral and health promotion services to any caller who thinks he or she may have had a non-occupational exposure to HIV. St Vincent's Hospital, in their submission to this Review, raised their concern about the increasing cost of this service.

PEP appears to be very effective in preventing infection with HIV and there is evidence to prove that it is cost-effective. (Pinkerton et al 2004). Areas, other than SESAHS and CSAHS, expressed concern in their submissions that the constant turnover of staff in ED make it difficult to ensure that all staff are aware of the Department of Health's guidelines on PEP. As early receipt of PEP is an important predictor of effectiveness, EDs need to be appropriately organised so that access to

PEP is not delayed. Education campaigns should emphasise the importance of prompt prescription (Poynten, Zheng, Smith and Grulich 2003).

Service delivery implications

All Areas, but SESAHS in particular, should develop and implement strategies which direct people seeking PEP to their local services – rather than to a central site such as St Vincent's. Areas should also ensure that there are clear guidelines for clinicians regarding compliance with recommended prescribing and followup protocols. Such strategies will minimise costs and reduce inappropriate subsidy of treatment for out of Area patients. Areas may also wish to consider implementing strategies to review cases for which PEP is prescribed prior to dispensing a full month's supply of treatment.

PEP policies and procedures need to be reinforced in Emergency Departments in hospitals.

9.3 Workforce issues

9.3.1 Provisions for workforce development

Staff in both AHS and NGO HIV/AIDS care and treatment services in NSW currently have access to a broad range of internal and external workforce development opportunities. To varying degrees according to local priorities, they are supported in accessing these. Each AHS and NGO has a set of HIV workforce development needs and challenges that are unique to its situation. Service history, roles; responsibilities, and capacity; local epidemiology; and the balance and mix of professional groups are factors which influence the local workforce development response.

Local workplace strategies including staff, unit and team meetings, project planning and monitoring groups, and other internal mechanisms provide opportunities for structured and non-structured workplace learning and development related directly to service provision, as do opportunities for acting in higher duties and placements, visits or exchanges with other agencies. Additionally, interagency links and networks may also offer support in work-based problem-solving and learning.

Provision of more formalised learning and development for the care and treatment workforce currently is currently provided for by a range of Area-based and non government agencies. Chief among these is the

Australasian Society of HIV Medicine (ASHM) which offers training-room based and self-directed learning packages in a broad range of content from prescription of s100 specialised drugs to topics like co-infection with hepatitis C, HIV-related dementia, and HIV and sexual health.

Funding support for workers in both government and non government settings to access such training and development activities is available through the NSW Health Workforce Development Program (WDP) which supports the payment of registration, travel and accommodation costs for staff. The arrangements are different for each sector.

In addition to providing funding support for its target group to access training and development opportunities, the WDP offers guidance on curriculum development and provides leadership and support in the development of innovative, multi disciplinary learning activities and curricula.

Under the WDP, all AHSs have an allocated workforce development budget set by NSW Health and provided on a yearly basis. This is managed by the HIV Coordinator in each AHS and is to cover WDP development and training costs in HIV, sexual health and hepatitis. How each AHS interprets this, and makes decisions (eg about travel, per diems, accommodation costs), and manages criteria for applications and funding varies widely. Few service areas have the benefit of a dedicated program such as this.

WDP funding to AHSs targets (a) staff who work in that AHS (b) staff in other government agencies where appropriate, and (c) health professionals in private practice (eg GPs accessing ASHM training) within that AHS.

Workforce development funding and support for staff and volunteers in NGOs is managed centrally by the WDP. While seen as a welcome and generous support provision, the major barrier to NGO staff accessing this funding is (as for AHS staff) the back-filling of their positions while away at the training.

9.3.2 General workforce issues

A recurring theme in many submissions was that as a result of static funding, and in the face of increasing award wage Levels, the ability of services to maintain Levels of service to people living with HIV/AIDS is

reducing as the number and range of staff declines. Some services have begun to reassess the way they operate and how the reach of their services can be extended by working differently rather than increasing staff. For example, the Psychology Unit of the ASC provides statewide training workshops for health care workers. The greater use of nurse practitioners in sexual health has also been suggested. At the same time, there will always be a need for HIV expertise in the health system, and for specific positions to encourage access by at-risk target groups that may not use health services.

A number of AHSs and NGOs supplied strategic service plans to the project, most of which included strategies to ensure staff accessed professional development, and kept their skills and knowledge up to date. Particular attention appears to be being given by some Areas to the Aboriginal sexual health workforce. However, there was little if any indication that AHSs or NGOs had broader strategies in place to address workforce issues relating to recruitment and retention of an adequate workforce. CSAHS was the only AHS to refer to a workforce strategy per se; development of this is in process. There is a sense of powerlessness on the part of some services as dedicated AIDS Program funds shrink and the priority of HIV/AIDS is seen to reduce in the face of other health system pressures.

In some services in high prevalence areas, fatigue and burn out as staff continue to deal with a long running epidemic in a maintenance phase is reportedly affecting the size and quality of the workforce. Rural areas and low-moderate prevalence areas have particular difficulties recruiting and retaining staff with the relevant expertise. In addition to the workforce challenges commonly faced by rural health services, added difficulties accrue because HIV is a specialist area in itself and expertise is scarce. Funding often only allows part time positions (often less attractive to prospective applicants) and may be time limited because of its project or pilot nature. Professional development is also more costly to provide in rural areas.

The changing profile and needs of people living with HIV/AIDS has implications for maintaining and extending the expertise of health care professionals in HIV. This expertise is at risk of diminishing in medical and nursing inpatient services in some facilities as fewer people present for care. At the same time, in outpatient and ambulatory settings (especially in high prevalence areas) staff need expertise to manage the increasing complexity

of health issues that patients experience – not only HIV, but also ageing, cardiovascular disease, hepatitis C and mental health.

Practically every service area is affected. Hospice staff, for example, are challenged by chronically complex long stay clients and by the need to prepare patients for return to supported accommodation or independent living following admission for respite, medication stabilisation or palliative rehabilitation. As the numbers of people with HIV/AIDS from CALD backgrounds increase in some Areas, staff need to have the skills and competencies to ensure services are accessible to them. In this context, the potential has been noted for tension between immigration policy and public health policy and the need for staff to be skilled to manage this.

The reorientation of services also has implications for workforce development. As health promotion is increasingly incorporated into clinical settings, staff used to practising on a clinical/ individual patient model would benefit from upskilling and reorientation to a population health model. A related example is dental services, where greater use of oral hygienists has been identified as the model of service provision becomes more prevention oriented.

Staff attitudes to people living with HIV/AIDS and also to people who use illicit substances are extremely important in maintaining an accessible, non discriminatory service. HIV/AIDS advocacy organisations report increasing numbers of cases of disclosure, breaches of confidentiality, refusal of service, and lack of professional assessment and judgment in relation to providing services to this target population. It is a particular issue of concern in relation to some hospital pharmacies, where PLWHA have to go to collect their antiretroviral medication. Continuing to address sensitivity and awareness training needs, especially in mainstream health and other relevant services will be important.

As services for people living with HIV/AIDS are increasingly integrated into the broader health and community services system, workforce development and support in regard to HIV/AIDS will be required as a key component of any major initiative if it is to succeed. The number of people living with HIV/AIDS in the community who require increasing Levels of support heightens the need for specialised training for staff in government and non government agencies dealing with this group, particularly in mental health and dementia. Relevant

Cross service issues

non-NSW Health services such as nursing homes, and other NSW government services such as HACC, the NSW Department of Community Services, and the NSW Department of Housing are examples.

NGOs are also affected by static funding and may be less able than AHSs (due to their size and more limited focus) to absorb the impact of increases in awards. NGOs providing supported accommodation, where the shortage of places means clients stay longer than normal, or there is pressure to take people with very challenging behaviours, have particular workforce support and development needs. Often the Level of skill required in these situations is considerable, and the working conditions and salary Levels provide insufficient incentive to attract and retain staff.

Recruiting and retaining staff for the provision of cost effective community care continues to be a challenge. One submission suggested that this could be addressed at least in part through offering shared traineeships in HIV community care under the newly revised National Community Training Package.

The issue of funding for relief/replacement staff remains a critical one especially for smaller agencies and workplaces.

Service providers note the impact that the reduction in volunteers (discussed also in Section 7) is having on service provision, especially the capacity of some NGOs to respond in a timely and effective way. This is of great concern to NGOs, though it is not clear to what extent strategies are being developed to address the problem.

The type of workforce development programs and the limited range of providers is an issue being addressed in the WDP Strategic Plan 2004–2006. With most of the funding still going to support off-site classroom-based training, the WDP considers much more remains to be done to legitimise other non-training based initiatives. Examples include using WDP funding for structured placement programs in suitable services to achieve professional and organisational goals; or for mentoring schemes, site visits, or learning circles. Some submissions also raised concerns about the inflexibility of the current range of learning models.

Workforce issues specific to general practitioners are covered in Section 6. Most AHSs are aware of the importance of GPs in the service continuum and have varying arrangements to keep them linked in with public health services.

Service delivery implications

As AIDS Program funding is likely to continue to be static at best, and as AIDS Program funding was always intended as a contribution only towards Areas meeting service delivery responsibilities to PLWHA, AHSs need to consider how to leverage that funding so best use can be made of the specialist HIV/AIDS workforce. This may involve a comprehensive reassessment of the roles and functions of that workforce and even of some specific services. At a minimum, opportunities need to be identified for upskilling mainstream staff, and better integration of specialist HIV/AIDS functions into the broader health system. High and moderate prevalence Areas would benefit from development of HIV/AIDS workforce strategies.

While having the flexibility to provide for the development of its workforce in response to unique local circumstances, it is important for AHSs and NGOs to regularly review and assess the implications for workforce development of the changing profile and needs of people living with HIV/AIDS. The priorities and content of workforce development plans will need to be adapted accordingly. Depending on local circumstances, areas for consideration include:

- maintaining expertise in medical and nursing inpatient services (where this is at risk of being lost)
- ensuring staff in outpatient and ambulatory settings have skills to manage the increasing complexity of presentations, including ageing PLWHA and those with co-morbidities
- ensuring staff are able to provide services that are friendly and accessible to people from CALD backgrounds
- exploring opportunities to upskill staff in a population health model of service delivery where this offers efficiencies and longer term health gains
- continuing to ensure all services know about and adhere to confidentiality protocols and are non-discriminatory and non-judgmental. This particularly applies in situations such as hospital pharmacies, and to population groups that are doubly marginalised such as Indigenous people, injecting drugs users
- ensuring staff in supported accommodation services have skills to manage clients with challenging behaviours

- maintenance and support for volunteer workforces.

The workforce component of strategies aimed at integrating HIV service provision into both the broader health and the community services delivery system need to be part of this periodic review.

An enhanced range and mix of partnerships across WDP providers would strengthen the sustainability of the NSW approach to HIV workforce development. Likewise use of a greater range of non-classroom based learning models needs to be fostered, both to improve learning experiences and outcomes and minimise the implications for backfilling and relief.

To help address the challenge of retaining a community care workforce, NGOs could explore the potential for offering shared traineeships in HIV community care under the newly revised National Community Training Package, as well as scope for increased use of Australian Government traineeships supported by on the job training and competency assessment.

10 Laboratories

10.1 Principles

The first National HIV/AIDS Strategy in 1989 provided the framework for HIV testing in Australia. The four basic principles, which guide HIV testing in Australia, are that:

- voluntary testing with counselling and confidentiality is fundamental to Australia's HIV/AIDS response
- testing should be of the highest possible standard
- testing is accessible to those at highest risk of HIV infection
- testing policy is critical to determining the extent and location of HIV infection in the community (IGCA 1992).

In 1998 the HIV Testing Policy Working Party (ANCARD/IGCARD 1998) extended these principles with the following additional points:

- testing should be voluntary and follow specific informed consent, with the results remaining confidential
- the current policy concerning circumstances in which compulsory or mandatory testing, is appropriate ie these circumstances should be strictly limited to special, clearly sanctioned situations and undertaken in an ethical and effective manner
- voluntary, compulsory and mandatory testing should all be accompanied by appropriate pre-test information and post test counselling
- testing policies and practices must comply with relevant federal and State/Territory anti-discrimination legislation and other law
- anonymous de-linked testing may be considered in special circumstances for research purposes
- public health legislation may need to be amended to incorporate these principles
- effective practical remedies should exist for unauthorised HIV testing, eg a medical ombudsman or health complaints authority
- testing does not diminish the need for standard precautions in handling and body fluids in all health care settings

- HIV testing must be accurate in identifying the presence or absence of infection
- the availability of confidential HIV testing has led to an improved understanding of HIV epidemiology, allowing appropriate education and prevention programs to be established
- consistent with all publicly funded programs, testing should be carried out in a cost effective manner.

10.2 Services and utilisation

HIV antibody testing

HIV antibody testing is not listed on the Medicare Benefits Schedule (MBS) so even though any laboratory authorised by the NSW Department of Health can perform these tests and raise a charge for the service, they are performed primarily by public laboratories free of charge to the patient. Authorised private laboratories do perform these tests for insurance and immigration purposes, for which they levy a charge. Reference ie confirmatory, testing is restricted to public laboratories; and not all laboratories which are authorised to perform reference testing are funded for that purpose.

Laboratories authorised to perform HIV testing are required to meet certain criteria related to accreditation, compliance with algorithms recommended by the National Serology Reference Laboratory (NRL), and participation in the NRL quality assurance program.

The public laboratories in NSW funded through the AIDS program budget to perform these tests are:

- St Vincent's Hospital Reference Laboratory
- South Eastern Area Laboratory Services (SEALS) with laboratories at POW, St George and Sutherland
- ICPMR at Westmead Hospital
- Immunology laboratory at RPA Hospital
- South Western Area Pathology Service (SWAPS) at Liverpool Hospital
- Pacific Laboratory Medicine Services (PALMS) at RNS Hospital
- Hunter Area Pathology Service (HAPS) at John Hunter Hospital

- Illawarra Pathology (IPath) at Illawarra Hospital
- Lismore Base Hospital
- Albury Base Hospital.

Positive and indeterminate samples are referred to one of the four funded reference laboratories – STV, SEALS, ICPMR, RPAH – or to one of three other authorised laboratories – SWAPS, PALMS, HAPS – for confirmatory testing. These confirmatory tests include the HIV Western Blot, Proviral DNA PCR and the p24 antigen. Figure 19 shows the volume of these tests in 2001/02 at these laboratories.

Viral load testing

Plasma viral load estimates provide the strongest long-term prognostic information for HIV patients. The plasma viral load is a measure of the balance between the amount of HIV produced each day and the amount of HIV cleared by the immune system. The reference laboratories all perform viral load testing (HIV RNA). Viral load testing is on the MBS so private laboratories can undertake this form of testing, but only two of them actually do as these tests require sophisticated technology and a special environment and most private laboratories are generally not set up to perform them. Laboratories performing viral load testing are required to participate in the Therapeutic Goods Administration (TGA) approved National Serology Reference Laboratory, Australia (NRL) quality assurance program and be capable of providing a turnaround time of 10 days (although an earlier result would be desirable). These requirements with the conservative MBS rebate would likely be a disincentive for private laboratories to perform the test.

Resistance testing

Drug resistance testing is used in cases of treatment failure to optimise therapeutic regimens, pregnant women and also to monitor the transmission of drug resistance in newly identified cases of HIV infection. Resistance testing is expensive (\$250–\$400 per test) and is currently not specifically funded. One cost control strategy employed by a major laboratory is to restrict access to resistance testing to patients managed by a hospital HIV physician or those co-managed with primary care providers in the community.

Therapeutic drug monitoring

Interest in therapeutic drug monitoring (TDM) in the management of HIV infection has increased in recent years (Pierce 2003). TDM measures the Levels of drug in the bloodstream, detects the extent of drug clearance, and can identify absorption problems among other things. Therefore it can be used to maintain drug exposure or overcome virological breakthrough (if drug exposure is too low) or toxicity (if drug exposure is too high). However, there is a lack of evidence to support its use and so it has not been introduced into routine clinical practice. Only two or three laboratories in the whole of Australia perform TDM.

Utilisation

Figure 19 shows the number of antibody tests performed by public laboratories over a three year period. Even though the total number of tests only increased by 5% from 241,865 in 2000 to 253,448 in 2002, there has been a big increase (41%) in the number of tests since the last review – 148,500 tests performed in 1996/97. There is also a significant variation at individual laboratories from one year to the next. For example, the number of tests at STV reduced by half from 42,000 in 2000 to 20,000 in 2002 while tests at SWAPS increased from 53,000 in 2000 to 71,000 in 2002. This variation is largely driven by the referral patterns of the private laboratories to these public laboratories.

Figure 20 shows the number of confirmatory tests, viral load tests and resistance tests performed in public laboratories. The four reference laboratories perform the bulk of all confirmatory testing. STV does more diagnostic confirmatory tests (western blot) because of the large number of newly identified cases of HIV infections. STV also performs more than double the viral load testing done at SEALS and more than four times the amount done at ICPMR and RPAH. RPAH does more of the resistance testing than any other laboratory.

Figure 19. Number of HIV antibody tests performed by public laboratory by year

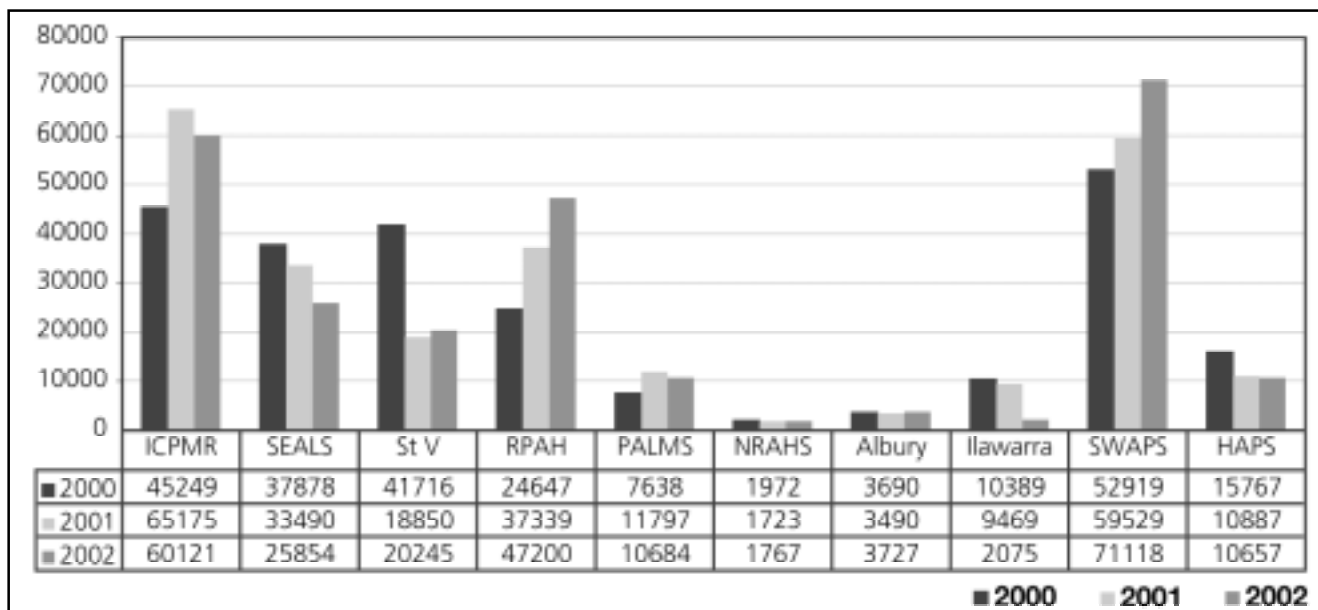
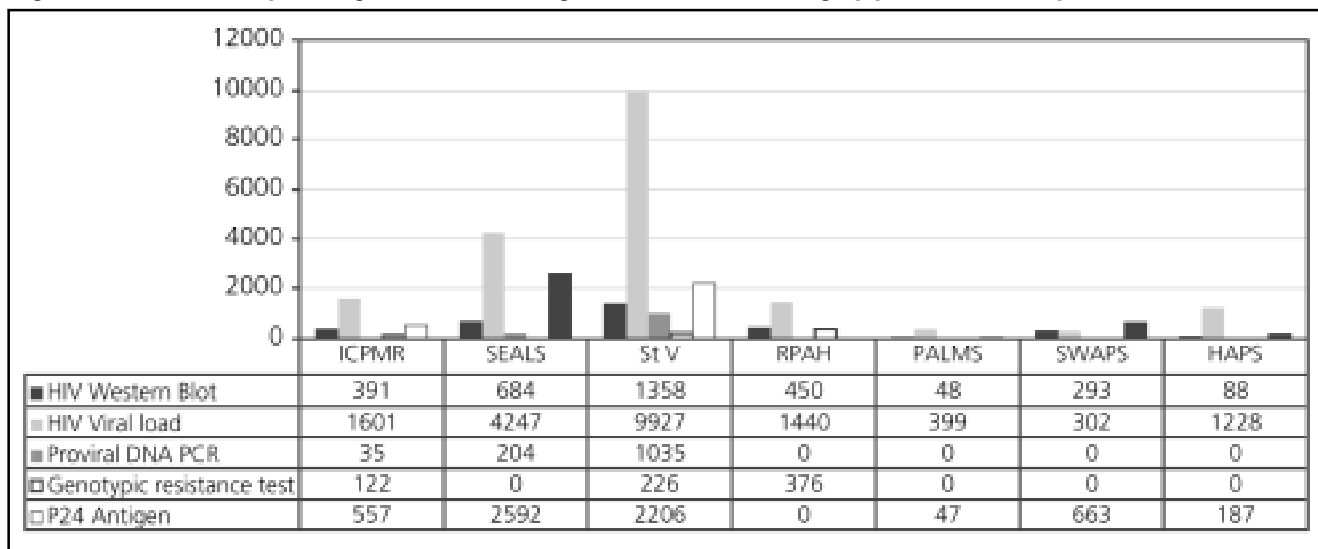


Figure 20. Confirmatory testing, viral load testing and resistance testing by public laboratory, 2001/02



10.3 Funding

Funding allocations to each of the public laboratories to cover the cost of HIV antibody testing and an amount for reference testing is given in Table 28.

Table 28. Funding allocation to public laboratories by year

	2000/01 \$	2001/02 \$	2002/03 \$	2003/04 \$
ICPMR*	434,000	382,797	436,020	448,915
SEALS*	436,000	381,629	397,479	383,154
St Vincent's*	395,000	368,567	304,819	273,932
RPAH*	169,000	204,958	237,451	283,199
PALMS	142,000	58,504	66,476	67,328
NRAHS (Lismore)	19,000	15,181	13,314	12,395
Albury Base	25,000	28,326	25,650	24,823
Illawarra	80,000	79,610	71,091	44,680
SWAPS (South Western)	217,000	405,086	395,116	422,429
HAPS (Hunter)	128,000	120,711	97,584	84,147
TOTAL	2,045,000	2,045,370	2,045,000	2,045,000

* Includes reference test allocation

The method of funding laboratories has changed since the last review. Instead of funding on the basis of the number of HIV antibody tests performed in 1993/94 and a set fee per test, funding is now based on a formula that redistributes the existing designated allocation for testing. The formula partly (40%) reflects the previous year's activity and partly reflects the actual Level of funding that the laboratory received in the previous year (60%). So for example, if a laboratory's basic screening activity represented 25% of the State's total basic screening activity last year, then it would receive 25% of 40% of the State's total laboratory budget. The other 60% of its budget would be the same proportion of the State's total laboratory budget that it received in the previous year. Thus no laboratory can receive less than 60% of what they received in the previous year, even if they did no tests at all!

10.4 Issues and implications for service delivery

10.4.1 Low risk HIV antibody testing

A number of the submissions were concerned about the extent of low risk testing that occurs among surgical and obstetric patients. It is estimated that only about 1% of the total number of samples sent for an HIV test, are positive. Despite the decline in the number of newly infected cases, the number of HIV antibody tests continues to increase from 149,000 in 1996/97 (NSW Health 2000) to 253,000 in 2001/02. Thus substantial savings could be made by targeting the request for testing to high risk individuals. However, it is less clear how this can be achieved.

One approach would be to enforce the principles of the testing policy by introducing standard protocols in all surgical and obstetric settings. These protocols would require a thorough assessment of the risk of the patient having HIV and it would demand that testing be voluntary and follow specific informed consent, with the results remaining confidential. There would need to be an assurance that testing would be accompanied by appropriate pre-test information and post test counselling. Currently there is much anecdotal evidence that these principles are not being followed. It seems that many surgical and obstetric patients are not aware that an HIV test has been requested on their behalf as in many instances it forms part of a standard surgical or antenatal screen.

Another option is to charge the surgical and obstetric departments of hospitals for all the low risk HIV tests that their clinicians request. This may not be easy to introduce because the request for the test probably emanates from the clinician's rooms and it may not be easily attributed to a specific hospital (ie where the patient is to undergo surgery or give birth). However if some form of monitoring system is established, which includes a requirement that there be some form of evidence that a full risk assessment for an HIV test has been done, it should be possible to move towards a more targeted approach to testing only high risk individuals and also enable the billing of the request for the HIV test to the appropriate hospital. One of the concerns raised by the clinicians attending the laboratories workshop as part of this service and needs assessment was the medico-legal implications of denying the request for an HIV test.

A more direct way of making savings to the AIDS budget would be to shift the cost of these low risk tests to the Australian Government by lobbying for HIV screening tests to be listed on the MBS. This approach would make savings to the AIDS budget but would not necessarily reduce the overall cost of testing nor provide any incentive to cease low risk testing. In fact the number of tests requested would probably increase. The difference would be that the cost of the test would be incurred directly by the Australian Government. But presumably the Australian Government would adjust the amount of funding under PHOFA to accommodate this change, so the AIDS budget would end up being reduced because the original PHOFA allocation would be reduced commensurate with this shift in responsibility. Furthermore, the listing of standard HIV testing on the MBS would mean that private laboratories would start doing these tests and strategies would need to be developed to support the very important surveillance function now performed by the public laboratories.

The current formula approach primarily shifts funds between Areas based on standard testing volume fluctuations which are in large part determined by contractual arrangements public laboratories have with private laboratories, rather than actual need. It would be reasonable for the Department to consider, as part of the review of the AIDS Program RDF, an approach which identifies those laboratories which perform reference and other complex testing and determines an allocation for that purpose. Areas would then have the flexibility to determine from within their total AIDS Program allocations funds which might be deployed to laboratories which perform standard HIV testing.

The Department's review of laboratory services generally may also have implications for decisions regarding which public laboratories will be identified for funding for reference and other complex testing.

Service delivery implications

There needs to be some attempt to reduce the rate of low risk testing to allow for funds to be re-allocated for the provision of higher priority HIV services. All options discussed above should be evaluated.

10.4.2 Combination antibody/antigen assays

More recently a new generation of test has become available enabling the detection of HIV antigen (direct detection of virus) and antibody combined in a single test. Specimens found to be initially reactive undergo complex confirmatory and supplemental tests ('reference' tests) to distinguish true infection from non-specific reactivity (false positives).

The application of the combination test has reduced the pre-seroconversion 'window period' by an estimated three to five days therefore improving the likelihood of detecting earlier events during primary infection. However the cost of these tests is about one quarter to one half as much again as the standard antibody test.

Due to the high number of new infections identified by the laboratory at St Vincent's Hospital, it was one of the first laboratories to evaluate and implement routine screening with the combination test. Since its implementation in February 2003, there have been more than 15 cases of acute infection (antigen only) that may have potentially been missed if antibody (alone) screening was used. However not all laboratories performing HIV testing use these tests, as they are not routinely recommended by the NRL. Wider implementation of such testing technologies is a matter for consideration by the NRL and other appropriate stakeholders as part of the planned review of the current national HIV Testing Policy.

Service delivery implications

NSW Health should advise the Australian Government that the feasibility and cost implications of making it mandatory for combination antibody/antigen assays to become the standard HIV screening test, is an issue that should be reviewed as part of the HIV Testing Policy.

10.4.3 Funding

Viral load testing and resistance testing

Viral load testing is the only form of HIV testing that is listed on the MBS. Yet the technology required to undertake this form of test and the size of the rebate has meant that it is rarely performed in private laboratories. The bulk of viral load testing is done in the four reference laboratories and HAPS (Figure 19) and generally no cost is recouped. However, the reasons for

this should be more closely examined. If a patient is referred by a GP, and it seems that most PLWHA receiving treatment have a GP, then it seems that it should be possible to claim the cost of the test from Medicare. As public laboratories are not specifically funded to perform viral load tests from the AIDS budget, it seems that there is potentially scope to recoup some of these costs from Medicare, especially as this is an area where an increase in testing is expected in the future as the numbers of PLWHA grow and live longer.

Another area where testing numbers are expected to increase is resistance testing. This form of testing is expensive, as discussed above, but there is no specific funding for it. As the numbers of PLWHA on HIV treatment increase and are on treatment for longer periods, the more they will need resistance testing. It seems that if HIV screening could be targeted to high risk cases only, the surplus funding could be re-distributed to fund resistance testing and TDM in the short term. In the longer term, if the evidence for this became available and it was introduced into routine clinical practice, it should be considered for funding via Medicare.

Service delivery implications

The trend in viral load testing, resistance testing and TDM needs to be projected and decisions made about whether these tests need to be specifically funded. Options for billing Medicare for viral load testing by public laboratories need to be explored.

Timing of funding allocation

Under the current arrangements, AIDS laboratory funding occurs on an annual basis by redistributing the historical allocation for standard testing. Figure 18 shows how the number of tests done at individual laboratories varies quite dramatically from one year to the next. The clinicians at these public laboratories say that this is determined by the referral patterns of the private pathology laboratories that collect the original specimens and then send them to one of the public HIV testing laboratories. As mergers and take-overs of these private companies occur, they may refer tests that they are not equipped or allowed to perform to a different public laboratory. This means that quite large numbers of specimens can be moved from one public laboratory to another over short time periods. At the laboratories workshop, conducted as part of this service and needs

assessment, the clinicians questioned whether it would be possible to receive their funding on a quarterly basis to try to compensate for this variation in workload.

Another way of reducing this variation would be to restrict the number of laboratories who could do this form of testing and direct private laboratories to the public laboratories that they should use for these tests. Alternatively, public laboratories could stop accepting requests for standard HIV testing referred by private laboratories. A referral system, based on geographical boundaries, is the type of arrangement that would allow the management of workload at public laboratories so that it is not left to the whim of the private sector.

Service delivery implications

The feasibility of a referral system to public laboratories for HIV testing based on geographical boundaries needs to be explored. This approach may be difficult because of the expansive capture net of private pathology collection centres. Another option may be for public laboratories to negotiate contractual arrangements with private laboratories where a service agreement defines the volume of activity for a specified period.

The implications of funding laboratories on a quarterly basis for their HIV testing also needs to be examined.

10.4.4 Importance of enhanced laboratory surveillance

Currently the NSW public laboratories involved in HIV testing play a key role in the notifications of new cases of HIV infection. Currently STV Hospital notifies the majority of new cases in NSW (40%) and Australia (30%).

NSW Health collates the notifications data and forwards it to the NCHEHR which compiles annual national surveillance reports. The existing notification system includes provision by the clinician who ordered a test which returned a positive result of data relating to the demographic characteristics of the newly diagnosed person. Clinicians are requested to provide advice on history of previous negative tests as a means of identifying incident cases.

Some stakeholders have argued that there would be benefit in establishing a comprehensive sentinel program

Laboratories

for laboratory surveillance that monitors the trends of recently acquired infections in populations at risk of HIV using recently introduced testing technologies and disperses the surveillance data in a timely manner that enables a quick response to changing patterns.

STV Hospital Reference Laboratory in their submission to this service and needs assessment proposed a research program to develop a comprehensive sentinel program for laboratory surveillance. It includes the development of a number of key elements:

- Evaluation of laboratory markers including the routine application of testing strategies with the ability to determine whether an individual having recently been diagnosed with HIV infection has been infected recently.
- Research and development of other laboratory markers of HIV incidence. Such laboratory markers could potentially be applied to related diseases such as hepatitis C infection.
- Surveillance of transmission of antiretroviral resistance in newly identified cases of HIV infection. All patients with laboratory evidence of recent infection eg indeterminate laboratory test profile typical of recent infection would undergo genotypic resistance testing to determine whether resistant HIV has been transmissible . Monitoring transmissible resistance is relevant to ongoing patient management
- Surveillance of HIV subtype secondary to the identification of the antiretroviral resistance profile to monitor trends of transmission of HIV infection from geographically distinct populations.

Service delivery implications

The surveillance program proposed by STV Hospital Reference Laboratory needs to be evaluated relative to other priorities in the provision of HIV/AIDS services.

11.1 Continue to endorse the planning principles outlined in the previous Review of HIV/AIDS Care and Treatment Services

The planning principles outlined in the report Review of HIV/AIDS Care and Treatment Services in NSW (NSW Health 2000) remain relevant and should be formally re-endorsed by the NSW Department of Health.

These principles are listed below:

1. All Area Health Services are responsible for the planning and coordination of HIV/AIDS care and treatment services within their Area. The planning and delivery of services to be consistent with the role delineation for HIV/AIDS services and sexual health services.
2. The AIDS/Infectious Diseases Branch has responsibility for the development of statewide strategic planning, policies and priorities for HIV/AIDS care and treatment services, identification of minimum service requirements in Areas, and the monitoring of planning and service provision in Areas.
3. Due to the changing nature of the epidemic and evolving patterns of health care need, service planning to be regularly reviewed on a statewide and Area basis to determine whether the capacity and utilisation of services remains appropriate in relation to demand that the range of health related need of PLWHA are being adequately met. The location of services to maximise accessibility by taking account of the demographic distribution of the target populations.
4. All health services involved in the care and treatment of persons with HIV/AIDS have an important role in preventing the further spread of infection. Preventive measure to be an integral component of all care and treatment services.
5. HIV antibody testing to be available in all Areas through a range of public and private sector outlets (eg sexual health clinics and general practitioners). Pre and post-test counselling to accompany all HIV antibody testing.
6. Continuity of care to be ensured through the use of mechanisms such as case management to coordinate and integrate a range of services.
7. Health care services to be sufficient to meet the Level of demand.
8. The type of service provided to match and be appropriate to the Level of care needed.
9. Service delivery models to enhance quality of life and be responsive to the medical and psycho-social needs of patients/clients. Health services to assist clients in gaining access to the range of 'non-health' services such as housing and welfare.
10. People with HIV/AIDS to have access to quality health care on an equitable and non-discriminatory basis.
11. Services delivery models to be responsive to the health care need and socio-economic situations of particular groups of clients (eg gay and other homosexually active men, injecting drug user, Aboriginals, people of CALD background, heterosexuals, women, children and adolescents, transfusion recipients and people with haemophilia).
12. People with HIV/AIDS to be encouraged and assisted, where appropriate, to access rehabilitation services to maximise their opportunity to fully participate in all aspects of society, including employment. Care and treatment services to promote the maximum degree of independence appropriate for a person's situation and be appropriate to a wellness model of service provision to reflect the increasingly chronic nature of HIV.
13. Care and treatment to be provided on an ambulatory or home care basis to the maximum extent which is clinically appropriate. Only when alternate care options do not suffice are persons to be admitted to acute care beds. The use of day only, respite, step-down, long-term, palliative, ambulatory and home based care options to be maximised in preference to use of acute care beds, where clinically appropriate.

Proposed strategic directions

14. HIV/AIDS care and treatment planning to continue to make use of mainstream health services so as to provide for a comprehensive range of needs. The merits of the relative mix of mainstream and specialist services to reflect local needs, the prevalence of HIV/AIDS in the Area Health Service and the infrastructure of health services.
15. Services designated to perform statewide or supra-Area roles to focus on needs beyond the Area Health service in which they are located. In addition to providing services to clients from out-of-Area all statewide services to have appropriate referral and discharge practices, good networks and communication channels and assist other Area to develop capacity and self-sufficiency as appropriate.
16. No one type of service model will be effective for all needs in all Area Health Services.
17. All Areas to continue to provide a minimum Level of HIV/AIDS services, consistent with the role delineation of services.
18. Service delivery models to be cost-effective.
19. Public sector programs and services to actively engage the contribution of the private sector and non government organisations. Consultations with relevant organisations to occur to ensure new proposals are complementary and eliminate duplication. In particular, the active involvement of general practitioners in HIV care to continue to be promoted.
20. The planning and delivery of HIV/AIDS care and treatment services to reflect a partnership between government, community organisations, health professionals, people living with HIV/AIDS and other affected people.

11.2 Recognise the changing treatment pattern of HIV/AIDS, in particular the shift from inpatient to ambulatory care

PLWHA are now treated mostly in ambulatory settings (outpatients, day treatment areas, community health services, sexual health services, GP surgeries). The number of inpatient admissions has decreased dramatically in the last five years but there has not been a similar shift in HIV/AIDS resources from inpatient to ambulatory settings within Area Health Services to reflect this change in focus.

Priority areas for action

Data on the cost of inpatient services is currently available and AHS should be required to monitor their inpatient utilisation and justify their inpatient allocation against this utilisation. Ideally funds would be allocated to both inpatient and non inpatient services on the basis of the relative utilisation but consistent and comparable data on non inpatient services are not available.

Role delineation guidelines should be reviewed and the service descriptions changed to reflect the pattern of treatment and care for people with HIV so that there is less emphasis on admitted services and more emphasis on non admitted services. Core allied health services need to be identified and links to mental health and drug and alcohol should be noted.

11.3 Articulate models of HIV/AIDS service delivery in Areas with a high, moderate and low prevalence of PLWHA

The number of PLWHA in NSW is estimated to be about 8,500. Although the actual distribution is unknown, it is estimated that the majority (around 5,000) live in inner Sydney in CSAHS and SESAHS so most services and resources are focused there. Elsewhere, prevalence can be described as moderate to low, with some Areas having distinctive characteristics. For instance, NRAHS and to a lesser extent MNCAHS and WAHS are experiencing lifestyle migration of PLWHA, increasing numbers and subsequent pressure on services. Other Areas have high Indigenous populations (FWAHS, CSAHS, WSAHS and NEAHS) who are more at risk of becoming infected with HIV because of their high rates of STIs, and/or people from CALD backgrounds (SWSAHS, CSAHS).

There is a need to define models of care for high, moderate and low prevalence Areas that reflect the significance of GPs, sexual health services, various mainstream health services, non government services and that specify particular features, such as the importance of health promotion in clinical settings, to enable the identification of where specialised funding for HIV services should be

maintained and where services for PLWHA should be part of the mainstream.

The concentration of specialised HIV/AIDS services in SESAHS and CSAHS (especially on the boundary) carries particular challenges and risks in relation to maintaining the optimal mix and distribution of services, especially as the needs of PLWHA change. A mechanism is needed that facilitates the planning and coordination of services in this inner city area in response to these changing needs

Priority areas for action

Define models of care for high, moderate and low prevalence Areas in collaboration with AHSs, non government organisations and GP representative bodies such as ASHM and HIV/AIDS research organisations.

An ongoing joint planning forum of SESAHS and CSAHS should be established to ensure services are well coordinated between the two Areas especially on the boundary where there is a concentration of PLWHA. Non government organisations must also be partners in a joint planning activity of this nature.

11.4 Develop mechanisms to enhance the integration and coordination of services

There have been a number of changes in the nature of the progression of HIV/AIDS and the complexity of managing fluctuating and multiple health issues for PLWHA means that it is important that services are integrated and coordinated.

The changing natural history of HIV/AIDS and profile of the PLWHA population suggests that HIV/AIDS increasingly resembles a chronic disease, affecting people across a progressively increasing lifespan.

Management of HIV has become more complex. A significant number of PLWHA have co-morbidities and other associated problems such as depression, cognitive impairment, dual diagnosis (HIV, hepatitis, STI, mental health and drug and alcohol) and behaviour, anxiety and adjustment disorders as well as side effects of treatment such as lipodystrophy and lipoatrophy, other metabolic conditions, cardiovascular problems, oral health

problems. Because of the increased patient longevity, ageing is becoming a relevant factor. Consequently PLWHA need access to a range of health services – mental health services, drug and alcohol services, oral health services, nutrition, psychology, physiotherapy, podiatry services in addition to specific HIV services. Access to these services by PLWHA is often limited.

Patient complexity and the multiple services involved in a person's care demands that referral pathways are clear, service linkages are adequate and the continuum of care between services and across professional disciplines are seamless. It seems that some clients with complex psychosocial needs, especially those with drug and alcohol and/or mental health problems, would mostly benefit from having some form of case management/care coordination, subject to individual agreement.

Priority areas for action

Policy linkages and service agreements need to be developed between HIV services, Mental Health and the Alcohol and Other Drugs Programs, resulting in services that are delivered in a more holistic way.

Some services especially oral health services and counselling services are not readily available for PLWHA in some Areas. Strategies need to be developed in collaboration with the Oral Health and the Mental Health Branches as well as the non government organisations, to determine how these services can be made more accessible and/or more effective for PLWHA.

The feasibility of establishing new HIV services such as treatment for metabolic conditions such as lipodystrophy and lipoatrophy needs to be explored.

Roles and responsibilities of all the main providers – specialists, GPs, sexual health services, non government organisations – need to be clearly defined, referral protocols and lines of communication clearly established. It may be appropriate to develop service agreements between these key providers based on these policies and procedures.

To avoid duplication of services and to ensure a better continuum of care, a policy of case management for people with complex needs should be developed. This is especially relevant in the inner city where patients seek services across Area borders from both SESAHS and CSAHS.

11.5 Improve access to some services and for some population groups

People from CALD backgrounds

In recent years there has been an increase in new HIV notifications for people from a CALD background, most notably people from sub Saharan Africa and Asia. Many of these people are married or bisexual men, therefore potentially increasing the risk of transmission to women. They may be illegal immigrants or on temporary protection visas, may not have a Medicare card and may present late for testing. The cultural and language issues together with their immigration status may be barriers to these people accessing services.

Indigenous Australians

There has been a rise in STIs in recent years and Indigenous Australians are at greater risk of acquiring a STI than the non-Indigenous population. As STIs are a co-factor in the transmission of HIV, Indigenous Australians are therefore at greater risk of HIV because of their exposure to STIs. These people are also at risk for other reasons – high rates of incarceration and injecting drug use.

People living in rural Areas

People living in rural Areas may have reduced access to services because of physical distances, lack of public transport, fewer specialist services, lack of bulk billing and general pressures on the rural health workforce. The HIV Futures study has shown that PLWHA in rural areas are more likely to be living in poverty and to face discrimination when seeking treatment from local health services.

Highly specialised drugs

Antiretroviral drugs for PLWHA prescribed under section 100 of the *National Health Act 1953*, are restricted to supply through hospitals having access to appropriate special facilities. This requirement to obtain drugs from hospitals is inconvenient for many PLWHA, especially those who are working or live in rural Areas. The recent trial, which made drugs available from some community pharmacies, was claimed to be a success.

Priority areas for action

NSW Health should continue to pursue negotiations with the Australian Government regarding access to services for those without a Medicare card.

Continued access to confidential and free HIV testing at sexual health centres is vital to ensure that risk populations have low threshold access to screening.

Services need to be mindful of the need to balance the expectations and values of a diverse range of clients groups, in order to ensure a culturally appropriate service and ongoing access for all affected. This may require specific values training or promotion strategies, or demographically targeted services, according to the population characteristics of PLWHA in the Area.

Areas with large Aboriginal populations such as CSAHS, WSAHS, NEAHS and FWAHS need to have adequate sexual health services to facilitate a reduction in STIs and hence avert the increased risk of transmission of HIV to this population.

Staff in specific HIV services and mainstream services (government and non government) need to have access to cultural awareness training, adhere to confidentiality protocols, and be trained to be non-discriminatory and non judgmental.

NSW Health needs to continue negotiations with the Australian Government to increase community access points for highly specialised drugs.

11.6 Develop and implement strategies that maximise people's access to PEP

Post exposure prophylaxis (PEP) with antiretroviral medications and counselling has been offered in NSW to persons at risk for HIV exposure through sexual activity or injecting drug use since 1998.

PEP appears to be very effective in preventing infection with HIV and there is evidence that it is cost-effective (Pinkerton et al 2004). However the constant turnover of staff in the Emergency Departments of hospitals, other than in the high prevalence Areas of SESAHS and CSAHS, make it difficult to ensure that all staff are aware of the Department of Health's guidelines on PEP access to drugs

Priority areas for action

All Areas, but SESAHS in particular, should develop and implement strategies which direct people seeking PEP to their local services – rather than to a central site such as St Vincent's. Areas should also ensure that there are clear guidelines for clinicians regarding compliance with recommended prescribing and followup protocols. Such strategies will minimise costs and reduce inappropriate subsidy of treatment for out of Area patients. Areas may also wish to consider implementing strategies to review cases for which PEP is prescribed prior to dispensing a full month's supply of treatment.

PEP policies and procedures need to be reinforced in Emergency Departments in hospitals.

11.7 Develop a supported accommodation strategy

As people with HIV are living longer and growing older, a small but growing proportion of them are in need of higher Levels of care. AIDS Program funding has been provided to (mostly) NGOs to assist them to respond to needs for step down care, respite, and crisis accommodation. Limited provision has been made for a small amount of medium and longer term supported accommodation. The majority of submissions identified severe pressure on existing accommodation and care providers, especially for longer term accommodation and for PLWHA with substantial physical, cognitive and neurological impairment. PLWHA with dual/triple diagnosis continue to present challenges especially for those services staffed to provide support at the lower end of the spectrum.

Specific AIDS program funding was allocated to CSAHS to establish the Bridge. This residential facility provides 24 hour supervised care and high support to people living with HIV and complex needs. However, the capacity of this service has peaked and bed availability is infrequent with lengthy waiting lists. AIDS program funding also pays for some forms of brokered support to enable PLWHA to remain living in independent accommodation in the community.

The respective roles of NSW Health, the Department of Housing and the Department of Ageing, Disability and Home Care (DADHC) in the provision of supported accommodation are gradually being

clarified. Broadly, the delineation involves Housing providing the 'bricks and mortar' of accommodation services, with client support provided by Health or DADHC or both. Successful partnerships have evolved in the housing/supported accommodation area, such as between the NSW Department of Housing, its Office of Community Housing, NSW Health, ACON and BGF. However, much more remains to be done to improve PLWHA access to mainstream client support provided by DADHC, in line with the provision of supported accommodation services for other disability groups. (The Human Services Executive Officers' Group may be the appropriate forum for the clarification of the roles and responsibilities, at least of the State government departments.)

Priority areas for action

- Commence inter-agency discussions to clarify further the respective roles and responsibilities of government and non government organisations in the provision of supported accommodation services for PLWHA. These discussions would involve the State government departments of Health, Housing, DADHC, the Australian government and non government organisations.
- Develop a supported accommodation strategy which ensures an adequate range of services across the spectrum of need, plans for projected need over the next 5–10 years and is based on an agreed delineation of roles of responsible agencies.

11.8 Maintain funding for statewide services

There has been a rationalisation of statewide services since the last review. Four services that were recognised as statewide services at that time are no longer in this category – St Vincent's Hospital allowance for the pre-eminent clinical role of its HIV/AIDS service, Sydney and Parramatta Sexual Health Services, the Haemophilia Counselling Service.

The current statewide services all appear to genuinely provide a statewide role, or at least a supra regional role to the Areas seeking their services. They either provide the basic infrastructure on which the provision of HIV/AIDS services rest (Albion St telephone lines, library and infection control resource centre; the Sydney Hospital post registration nursing courses, the WDP,

Proposed strategic directions

the Paediatric HIV Service) or else they offer a service to meet the needs of a new and emerging trend (ADAHPS, MHAHS, Pozhets, HIV Dental Program). This statewide services program needs to be retained because the services it funds fulfill very important functions in a cost effective manner.

The program needs to be reviewed regularly to ensure that the services funded under its auspice remain relevant. A statement of the criteria that determine the eligibility of a service to become a statewide service is needed so that it is possible to monitor the performance of the statewide services against these criteria and to enable the identification of services that should be nominated for funding from this source.

The HIV Dental Program needs to be evaluated and an assessment made as to whether the model of service provides sufficient access and is cost effective.

Priority areas for action

- Articulate the criteria for defining and funding a statewide service. These criteria would provide a basis for the identification of services that may be eligible for funding, and for future performance monitoring.
- Monitor and evaluate the performance of these services regularly to establish their continued relevance for funding as a statewide service.
- Develop service agreements with these statewide services that include performance measures.
- Evaluate the HIV Dental Program for its effectiveness and in collaboration with the Oral Health Branch determine whether it would be more appropriate to move towards an oral health service model incorporating prevention and health promotion.
- NSW Health needs to follow up and obtain details about the number of HIV-related autopsies provided by the Institute with a view to assessing whether it should continue to be funded as a statewide service.

11.9 Address maldistribution and increase number of s100 accredited GPs

As the nature of HIV has changed with better treatments, the role of the primary HIV care provider has become even more important for PLWHA. People with HIV report wanting to access care from GPs and get most of their care, treatment and information in relation to HIV from them. GPs are carrying a substantial burden of the care provision especially in moderate and high prevalence areas. With the ageing of the HIV positive population, and development of associated health conditions, the need is heightened for a skilled primary care practitioner who is aware of the potential for additional complications as a result of HIV.

Currently in NSW there are up to 130 accredited s100 prescribers of antiretroviral drugs, including GPs and sexual health physicians. Not all of them are actively using their prescribing rights. Specialised, high volume HIV practices are largely located in the Darlinghurst area and this is where the highest numbers of prescribers are. In most other parts of the state, there are relatively few GPs with an interest in HIV medicine. The Northern Rivers is struggling to retain sufficient prescribers. In WSAHS there are only one or two general practitioners with s100 prescribing rights.

There are constant pressures on s100 prescribers to refresh their knowledge, both in order to maintain their prescribing rights, and keep abreast of changing protocols and treatment issues in a very complex area. This necessitates attending regular (mainly ASHM) education and training sessions. Because of the specialist nature of these sessions they are usually not provided locally for many of the prescribers and those from rural areas incur travel, accommodation and/or locum costs to attend. For GPs with a small HIV patient load, it may not be financially worthwhile for them to maintain their prescribing rights.

Significant effort is required to increase the number of s100 GP prescribers in some Areas.

Strategies may include:

- targeted recruitment of GPs to become (or continue as) s100 providers in the context of an integrated GP/sexual health service model for primary care for PLWHA appropriate to lower and moderate prevalence areas

- a greater range of training formats, especially for rural and regional areas
- financial assistance to attend education sessions
- support such as case management services, access to mental health, drug and alcohol and allied health services
- medical specialist support with clear referral protocols and good communication.

Priority areas for action

Explore with ASHM the options for improving the number and distribution of s100 prescribers.

11.10 Develop strategies to improve GPs knowledge of HIV medicine

Given the complexity of this still-emerging field of medicine, the concentration of PLWHA in inner Sydney, and the relatively small numbers overall, it is not feasible to expect significant numbers of GPs across NSW to maintain interest and/or skills in HIV medicine. At the same time, wherever they live, PLWHA need affordable access to specialised treatments via a skilled primary care provider. Greater efforts are needed to use existing resources better (both public and private) to achieve this.

Divisions of General Practice also have a role in providing support and training opportunities for GPs. However, the current Divisional structure is not supportive of GPs with an HIV patient caseload. The prevalence of HIV is too small to sustain an interest in HIV in every Division, requiring rather a supra-regional service that can focus on HIV. This has never been funded, despite early hopes, and ASHM has to a large extent filled the gap. However, resources limit what ASHM can provide.

Priority areas for action

Explore strategies to address this issue with ASHM and other relevant organisations such as the Royal Australian College of General Practitioners, and the Australasian College of Sexual Health Physicians.

11.11 Foster partnerships between AHS and non government organisations

Non government organisations are very significant in the provision of care and treatment services for PLWHA. Some of these organisations perform a statewide role – ACON, PLWHA (NSW) the Haemophilia Foundation, NUAA – in their provision of advocacy, information, education and peer support.

Others provide more specific services such as positive living/wellness centres, supported accommodation services, and non health services such as financial counselling, employment services.

These organisations are critical to the network of services for PLWHA and many services are unique to this sector. As the problems of PLWHA increase and become more varied, the non government organisations are a critical part of a patient's continuum of care.

Therefore they need to be an integral part of a patient's care plan as well as being involved in the overall planning of services not only because they are a key provider but also because they represent the main forum for consumer input and participation.

Priority areas for action

Identify the range of mechanisms needed to ensure adequate and appropriate involvement from non government organisations in the planning and development of services.

Review existing service agreements with non government organisations to ensure they are adequate in the delineation of services to be provided and the specification of linkages with relevant services.

11.12 Continue support for workforce development

Currently \$250,000 is allocated from the AIDS Program budget to the WDP to support the payment of registration, travel and accommodation costs for workers in government and non government services to access training and development opportunities.

The changing profile and needs of PLWHA has implications for maintaining and extending the expertise of health care

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professionals in the provision of HIV services. This applies in different ways to high prevalence Areas as well as moderate and low prevalence rural Areas. All staff need to be aware of cultural and confidentiality issues and to be non discriminatory in their service delivery. The non government sector relies heavily on a volunteers, and this workforce needs to be maintained and supported. The non government sector also has problems recruiting and retaining a community care workforce because of limited training opportunities.

For all these reasons it is essential that workforce development opportunities continue to be supported.

Priority areas for action

- Area Health Services should develop workforce strategies that complement their HIV service model and clearly identify the skills they are aiming to develop or enhance among their staff.
- To help address the challenge of retaining a community care workforce, non government organisations should explore the potential of offering shared traineeships in HIV community care under the newly revised National Community Training Package as well as the scope for increased use of Australian Government traineeships supported by on the job training and competency assessment.

11.13 Evaluate some specific laboratory issues

A number of issues need to be explored to understand the extent of their impact on the future provision and cost of HIV laboratory services. They include:

- an evaluation of the options to reduce the rate of low risk testing
- a request that ANCARD and IGCARD undertake a cost-benefit analysis of the new combination antibody/antigen assays with a view to changing the National HIV Testing Policy
- an estimate of the projected demand for and cost of viral load testing and the impact on the public laboratories' workload and costs
- a review of the options to cushion the effect of private laboratories moving large numbers of requests for tests from one public laboratory to another, without any warning.

Priority areas for action

Assess the issues defined above to facilitate the more cost effective provision of HIV/AIDS laboratory services.

11.14 Enhance utilisation data and service monitoring

The lack of data on the utilisation of non inpatient services makes it very difficult to monitor the activity of these services, to make comparisons between services and to allocate resources in an equitable manner between inpatient and non inpatient services.

Data are needed to enhance this monitoring function, to assist in the planning of services and to ensure transparency in resource allocation.

An enhanced laboratory surveillance system has been proposed by STV Hospital Reference Laboratory so that in the event of, for example, an outbreak in HIV notifications, a more timely response will be triggered.

Priority areas for action

- The Minimum Data Set currently being trialled in SESAHS needs to be evaluated to assess its applicability to other Areas and to non government organisations and to determine the feasibility of extending it to other Area Health Services and to non government organisations.
- A monitoring framework with standard performance indicators needs to be developed to allow an annual review of the activity of all HIV/AIDS services across all Area Health Services.
- A similar monitoring framework is needed in the non government sector so that data definitions and activity measures are standardised across the sector.
- The proposed enhanced laboratory surveillance system needs to be evaluated.

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A

Appendix A. Terms of reference

1. Review activity and trends in Level 5/6 admitted and non admitted care services at St Vincent's Hospital, Darlinghurst; Liverpool Hospital; Prince of Wales Hospital; Royal Prince Alfred Hospital; Royal North Shore Hospital; Westmead Hospital; and John Hunter Hospital over the last two to five years. This should include an assessment of cross-Area flows and number and location of existing Level 5/6 admitted care facilities.
2. Consider trends in utilisation data if available, and comment on the appropriateness of models and use of services currently funded under state-wide arrangements including Sydney Children's Hospital Paediatric HIV Service, Haemophilia Counselling Service, Central Sydney Area Health Service – Multicultural HIV/HCV Service, Workforce Development Program, ADAHPS, NSW Infection Control Resource Centre and the NSW 24-Hour Needlestick Injury Hotline.
3. Review the activity/trends over the last two years and commenting on the appropriateness of the models of care of other admitted and non admitted care services in South Eastern Sydney, Central Sydney, South Western Sydney, Western Sydney, Hunter, Wentworth, Illawarra, Central Coast and all rural Health Services, paediatric HIV services and palliative care services.
4. Review trends over the last two years and commenting on the appropriateness of models and use of non government admitted and non admitted care services in NSW (including counselling, case management, peer support, step down/supported accommodation, home-based and primary care).
5. Comment on availability and use of support mechanisms for community based care provided by general practitioners, including systems of support. Recommend strategies to improve these systems.
6. Examine workforce issues for Areas and non government services, including capacity, experience and workforce development.
7. Examine the potential effect of current and emerging HIV drug treatments and treatment uptake on the Levels of admitted and non admitted care for the next five years (ie to 2008).
8. Examine arrangements for access to highly specialised drugs and identify options for improving access within the policy framework of the Highly Specialised Drugs Program.
9. Analyse utilisation trends/access to Post Exposure Prophylaxis drugs and expenditure and make recommendations on future directions regarding access.
10. Examine the collaborative approaches to ensure gaps in health promotion in clinical settings are covered. Identify linkages with the HIV/AIDS Health Promotion Plan and opportunities for integration of health promotion and treatment, care and support where they intersect.
11. Examine workforce development strategies within care and treatment services and recommend further direction of workforce development training to ensure the workforce can respond to changing needs.
12. Examine data on use and capacity of laboratory services for sexually transmissible and blood-borne viruses (specifically HIV screening; viral load testing/PCR for HIV, HCV and STDs; viral resistance testing; other HIV-related testing) and identify options for reorganisation of access to AIDS funded testing to target groups.
13. Examine specific services for people with HIV infection (including dementia/complex care needs and case management, housing/accommodation and dental services) in terms of their capacity, use and appropriateness of models and make recommendations on future directions.
14. Review existing planning principles and options for consideration by NSW Health for re-organisation and further development of HIV/AIDS care and treatment services over the next five years (to 2008).

15. Options for reorganisation and redevelopment of care and treatment services should address Level 5/6 admitted and non admitted care services; statewide services; Level 4 and below admitted and non admitted care services including specialist sexual health, paediatric HIV services and palliative care services; non government admitted and non admitted care services (including counselling, peer support, step down/supported accommodation, home-based and primary care); community-based care provided by general practitioners; arrangements for access to highly specialised drugs; laboratory services; and autopsy services.
16. Report on at least two occasions prior to presentation of a final report to an Advisory Group which includes representatives of NSW Health (Director, AIDB); high HIV prevalence Area/s; affected communities (nominees of ACON and PLWHA NSW Inc); a rural and a metropolitan AIDS Coordinator, a high caseload general practitioner; the Ministerial Advisory Committee on AIDS Strategy and a low HIV prevalence Health Service.

B Appendix B. Proforma and guide to submissions

HIV/AIDS services in area health services

This survey is being conducted as part of the HIV/AIDS Care and Treatment Services Needs Assessment in NSW. This project has been contracted to Hardwick Consulting and Mandala Consulting by the AIDS/Infectious Diseases Branch of NSW Health.

The aim of this survey is to obtain factual information about the services provided by Area Health Services for people with HIV/AIDS. It is one element of an information gathering exercise that also includes a call for submissions and a series of workshops. This survey relates to designated HIV/AIDS inpatient and outpatient services as well as related services such as sexual health, drug and alcohol, mental health, palliative care and health promotion. It may be necessary to consult with staff in these related services about the programs offered and the extent of use of these services by people with HIV/AIDS. Information is also being sought from HIV/AIDS statewide services, other government organisation such as Housing and DADHC, non government organisations and GPs (s100 prescribers), but where there are collaborative activities in place, please mention these.

Please complete this electronically and return to Jill Hardwick: jhar6964@bigpond.net.au by Friday, 23 January 2004. You are welcome to provide as much detail as you consider relevant, and expand the cells as required. Attachments and supporting documents (eg Annual Reports) are also welcome and they can be emailed or mailed to Jill Hardwick at 6 Toxteth Road Glebe, NSW 2037. If you have any questions, please call Jill Hardwick on 02 9660 5668.

Name of area health service:

Person responsible for coordinating this response:

Position: _____ **Contact number:** _____ **Date:** _____

Question 1

Does the Area Health Service have an HIV/AIDS plan or strategy? If so, could you please name the document(s) here, indicating dates/period for which they are current. Could you also email or post a copy of the document(s) to Jill Hardwick, 6 Toxteth Road, Glebe, NSW 2037.

Question 2

What specific HIV/AIDS services does the Area provide? Please list them below.

2.1 Hospital inpatient²³

Hospital name	Level of service (4, 5/6)	Number of beds (if designated)

2.2 Ambulatory²⁴

2.2.1 Outpatient clinics

Hospital name	Name of clinic eg Immunology, Haematology	Frequency of clinic each week or month	Number of occasions of service on average per clinic	Number of occasions of service per annum for the last three financial years		
				2000/01	2001/02	2002/03

²³ Details about the number of inpatients with HIV/AIDS and their utilisation of hospital inpatient services is being obtained from the Inpatient Statistics so these questions just relate to the nature of the facilities themselves.

²⁴ These are the services where demand is increasing most and is also the area where there are limited data. Hence the more detailed questions especially the request for data. It would be really appreciated if detail on client numbers could be provided. If actual numbers are not available, some qualitative comment on estimated proportional increases or decreases or trend patterns would be helpful.

2.2.2 Day treatment areas

Hospital name	Number of chairs/beds	Comments including some detail on the most common reason for admission

2.2.3 Hospital based allied health (HIV/AIDS specific counselling, psychology, dental, dietetics, pharmacy, physiotherapy)

Hospital name	Services available	Service detail eg the frequency of its provision, number of clients per clinic	Number of occasions of service per annum for the last 3 financial years, if available		
			2000/01	2001/02	2002/03

2.2.4 Other hospital based

Hospital name	Services	Comments

2.3.5 Sexual health services (STI and HIV specific)

Name of service	Specific services available	Occasions of service per annum for the last 3 financial years		
		2000/01	2001/02	2002/03

2.3.6 Community health services

Name of community health centre	Services available	Number of occasions of service per annum for the last 3 financial years		
		2000/01	2001/02	2002/03

2.3.7 Health promotion in clinical settings

Service where health promotion activity occurs	Nature of health promotion activity	Explain the integration between health promotion in clinical settings and the care, treatment and support services for PLWHA

Question 3

What *other services provided by your Area Health Service* are used by people with HIV/AIDS in your Area?

Name of service eg Mental Health, Drug and Alcohol, Palliative Care	Details of specific services used by people with HIV/AIDS	HIV/AIDS occasions of service per year for the last three financial years			Estimate of HIV/AIDS occasions of service (OOS) as a % of the service's total OOS		
		2000/01	2001/02	2002/03	2000/01	2001/02	2002/03

Question 4

Does the AHS have any programs/initiatives for people from a culturally and linguistically diverse background (including Aboriginal and Torres Strait Islander people) with HIV/AIDS? If so, please describe briefly:

- what services are actually provided
- how are the services provided (eg outreach, partnership with another organisation, employment of special health workers eg Aboriginal Sexual Health Workers)
- the Area or locality served
- funding source and whether funded on a short term or recurrent basis.

Question 5

What is your overall assessment of the adequacy of current services and the capacity of these services to meet the needs over the next five years? More generally, where do you assess the main increases and decreases in demand for HIV/AIDS services (government and non government) to be?

NSW HIV/AIDS Care and Treatment Services Needs Assessment

Guide to the preparation of submissions

The NSW Department of Health has commissioned a HIV/AIDS Care and Treatment Services Needs Assessment. The full terms of reference are given in the Attachment. The project is being conducted on behalf of the Department by independent consultants, Hardwick Consulting and Mandala Consulting.

Submissions are being sought from key stakeholders – Area Health Services, HIV/AIDS statewide services, other (non health) government organisations, non government organisations and GPs. These submissions will be one of the main ways for stakeholders to contribute to the project. In addition, the consultants will conduct a series of workshops to canvass views and issues and will undertake a survey of services to obtain factual information about the range of services provided for people with HIV/AIDS.

This guide aims to assist in making submissions. Below is a list of specific issues that you may wish to address. Some organisations making submissions may wish to concentrate on particular areas. There is no need for submissions to cover each of the issues that appear below. In addition, this list of issues is not intended to be definitive. Please feel free to structure your submissions in any way you wish, but remember that the scope of the project is defined by the terms of reference.

Do not forget to provide your name, organisation's name and full contact details including email address, when lodging your submission.

Submissions should be sent electronically to:
Jill Hardwick: jhar6964@bigpond.net.au

or by mail to:
Jill Hardwick
Hardwick Consulting
6 Toxteth Road
Glebe NSW 2037

The closing date for receipt of submissions is Friday, 23 January 2004.

Background

The purpose of the project is to determine the extent to which the needs of PLWHA have changed since the previous review reported in 2000 and to use these needs to make recommendations regarding the strategic framework for providing HIV care and treatment services and service models for the next triennium. It is intended that the findings will inform reorganization and realignment and of HIV care and treatment services where appropriate based on identified and emerging needs. That reorganization and realignment will occur within existing resources.

The implementation of the recommendations of the needs assessment will occur in the context of significant changes in the NSW health system arising from the review of NSW Health (ie the Areas and the Department) by the Independent Pricing and Review Tribunal and the Review of Functions of the NSW Department of Health.

The findings of the needs assessment, along with the recommendations of the review of the NSW HIV/AIDS Health Promotion Plan and the Review of the AIDS Program Resource distribution Formula will inform development of the next NSW HIV/AIDS Strategy.

In May 2000 NSW Health released the most recent *Report on the Review of HIV/AIDS Care and Treatment Services in New South Wales*. That Report detailed 35 major recommendations having considered the following issues in depth:

- developments in HIV/AIDS care and treatment
- HIV prevention efforts
- service demand (actual and projected)
- Level 5/6 admitted and non admitted care services
- services performing statewide functions
- community based and supported housing services
- counselling services
- the role of the general practitioner
- access to highly specialised drugs
- HIV-related pathology patterns
- case management and care coordination
- AIDS program funding and performance measures
- the role of the NSW Department of Health.

A major catalyst for the 2000 Review was the availability of new HIV therapies and their expected impact in reducing AIDS deaths and demand for HIV/AIDS inpatient care. In subsequent years this reduced demand for inpatient care has continued. Increasing long-term survival of people living with HIV/AIDS (PLWHA) and consistent new annual cases of HIV infection have increased the number of PLWHA in NSW. This increase has impacted the demand for additional community based service delivery. This ongoing trend is demonstrated by:

- a significant decline in demand for admitted acute and non-acute treatment services including a reduction in demand for palliative care services
- relatively consistent demand for non admitted specialist hospital services
- anecdotal advice that community home nursing services are increasingly requested for clients with challenging behaviours as a result of either HIV-related dementia or other cognitive impairment; pre-existing mental health and/or personality disorder problems; pre-existing alcohol and other drug problems
- increased demand for complex pathology services related to monitoring the effect of drug therapy
- a high proportion of care being provided in general practice which increases demand for appropriate community-based liaison and support services and referral pathways
- an increase in demand for mental health and drug and alcohol services – both for referral for assessment and co-management of patients
- an increase in demand for supported accommodation and respite services related to the increase in neuropsychiatric, other mental health and drug and alcohol problems
- the absence of Medicare funding for HIV antibody testing and no mechanism for restricting expenditure on that testing to high risk populations rather than routine testing of surgical patients and pregnant women, regardless of risk assessment
- the need for a source of funds for highly specialised drugs which are used for post-exposure prophylaxis (PEP)

- increased complexity of HIV/AIDS health promotion programs targeting priority populations
- increased pressure on the balance between funding directed to HIV/AIDS health promotion versus clinical services.

While demands on some local services have declined, there are a number of statewide services that have encountered increasing demands. In particular with an increased number of PLWHA with dementia or mental illness or challenging behaviours for other reasons, the statewide AIDS Dementia and HIV Psychiatric Service (ADAHPS) continues to support people with complex needs and encounters ongoing demand for services it is largely unable to provide.

Also of importance with PLWHA living longer in the community setting, are either supported housing services or community services which enable PLWHA to be maintained in their own homes.

Scope of the project

The project has a broad scope and includes the following services types:

- Level 5/6 admitted and non admitted care services
- Level 4 and below admitted and non admitted services, including care provided in specialist sexual health care services, drug and alcohol services, paediatric HIV services and palliative care
- non government admitted and non admitted care, (including counselling, supported accommodation, home-based and primary care)
- community based care provided by GPs
- access to highly specialised drugs
- laboratory services.

Specific issues to be addressed in submissions

1. Service needs

- 1.1 To what extent do the current range of services (including both service type and geographic distribution) adequately meet the care and treatment needs of PLWHA? Where are the gaps?
- 1.2 What models of service delivery will most effectively meet the care and treatment needs of persons with HIV/AIDS? Are these models currently being used either in Australia or internationally, and if so, what is the evidence for their effectiveness?
- 1.3 What role should other clinical services, such as drug and alcohol, sexual health, immunology and infectious diseases, have in meeting the care and treatment needs of PLWHA?
- 1.4 What role should non government organisations/ community based organisations have in meeting the care and support needs of PLWHA?

2. Service capacity

- 2.1 Do existing services meet the care and treatment needs of PLWHA? Does anything need to change to better meet these needs?

3. General practitioners

- 3.1 Is there adequate support and education for general practitioners providing community based care to PLWHA? If not, what measures need to be taken to address this issue?
- 3.2 Do GPs have access to adequate systems of support for PLWHA? How could access to these support mechanisms be improved?
- 3.3 What changes are required to sustain you and the services you are providing?

4. Workforce issues

- 4.1 Do you foresee any issues relating to the availability of an adequate workforce to provide services for PLWHA in government or non government organisations?

5. The effect of potential advances in HIV/AIDS drug treatments

- 5.1 What effect do you believe potential advances in HIV/AIDS drug treatments will have on the Level of demand for admitted and non admitted care and treatment services over the next five years?

6. Highly specialised drugs

- 6.1 Do people with HIV/AIDS have problems in accessing highly specialised drugs? If so, what problems do they experience?
- 6.2 What options are there for improving access?
- 6.3 Are there specific issues related to access to Post Exposure Prophylaxis drugs?

7. Laboratory services

- 7.1 What is the appropriate role of public sector laboratories in HIV/AIDS related testing?
- 7.2 What is the appropriate role for private sector laboratories in HIV/AIDS related testing?
- 7.3 In what ways do public sector and private sector laboratories need to inter-relate in regard to HIV/AIDS related testing?
- 7.4 Are volumes of HIV/AIDS related testing at public sector laboratories sufficient to maintain quality?
- 7.5 What trends are there in demand for diagnostic tests to support developments in HIV/AIDS drug treatments? What implications, if any, does this have for the current public sector laboratory infrastructure?
- 7.6 What options for reorganisation of testing and its funding should the project consider?

8. Specific services

- 8.1 Is current access to specific services such as dementia/complex care, case management, housing/accommodation, dental services adequate? Are these services for which demand will increase over the next five years? What needs to be done to ensure the adequacy of their future provision?
- 8.2 Comment on the collaborative approach to health promotion in clinical settings. Are there any gaps? Can you identify any opportunities for better integration between HIV/AIDS health promotion and treatment, care and support services?

9. Statewide services

- 9.1 How effective and accessible are the HIV/AIDS statewide services?
- 9.2 How can statewide services be most effectively provided to rural Areas?

10. Options for reorganisation and redevelopment

- 10.1 How would you like to see HIV/AIDS care and treatment services reorganised or redeveloped so they better met the needs of PLWHA?
- 10.2 In Area Health Services with comparatively low prevalence, should any specific changes be made to current services?

Attachment

Terms of reference

17. Review activity and trends in Level 5/6 admitted and non admitted care services at St Vincent's Hospital, Darlinghurst; Liverpool Hospital; Prince of Wales Hospital; Royal Prince Alfred Hospital; Royal North Shore Hospital; Westmead Hospital; and John Hunter Hospital over the last two to five years. This should include an assessment of cross-Area flows and number and location of existing Level 5/6 admitted care facilities.
18. Consider trends in utilisation data if available, and comment on the appropriateness of models and use of services currently funded under state-wide arrangements including Sydney Children's Hospital Paediatric HIV Service, Haemophilia Counselling Service, Central Sydney Area Health Service – Multicultural HIV/HCV Service, Workforce Development Program, ADAHPS, NSW Infection Control Resource Centre and the NSW 24-Hour Needlestick Injury Hotline.
19. Review the activity/trends over the last two years and commenting on the appropriateness of the models of care of other admitted and non admitted care services in South Eastern Sydney, Central Sydney, South Western Sydney, Western Sydney, Hunter, Wentworth, Illawarra, Central Coast and all rural Health Services, paediatric HIV services and palliative care services.
20. Review trends over the last two years and commenting on the appropriateness of models and use of non government admitted and non admitted care services in NSW (including counselling, case management, peer support, step down/supported accommodation, home-based and primary care).
21. Comment on availability and use of support mechanisms for community based care provided by general practitioners, including systems of support. Recommend strategies to improve these systems.
22. Examine workforce issues for Areas and non government services, including capacity, experience and workforce development.
23. Examine the potential effect of current and emerging HIV drug treatments and treatment uptake on the Levels of admitted and non admitted care for the next five years (ie to 2008).

Appendix B. Proforma and guide to submissions

24. Examine arrangements for access to highly specialised drugs and identify options for improving access within the policy framework of the Highly Specialised Drugs Program.
25. Analyse utilisation trends/ access to Post Exposure Prophylaxis drugs and expenditure and make recommendations on future directions re access.
26. Examine the collaborative approaches to ensure gaps in health promotion in clinical settings are covered. Identify linkages with the HIV/AIDS Health Promotion Plan and opportunities for integration of health promotion and treatment, care and support where they intersect.
27. Examine workforce development strategies within care and treatment services and recommend further direction of workforce development training to ensure the workforce can respond to changing needs.
28. Examine data on use and capacity of laboratory services for sexually transmissible and blood borne viruses (specifically HIV screening; viral load testing/PCR for HIV, HCV and STDs; viral resistance testing; other HIV-related testing) and identify options for reorganisation of access to AIDS funded testing to target groups.
29. Examine specific services for people with HIV infection (including dementia/complex care needs and case management, housing/accommodation and dental services) in terms of their capacity, use and appropriateness of models and make recommendations on future directions.
30. Review existing planning principles and options for consideration by NSW Health for re-organisation and further development of HIV/AIDS care and treatment services over the next five years (to 2008).
31. Options for reorganisation and redevelopment of care and treatment services should address Level 5/6 admitted and non admitted care services; statewide services; Level 4 and below admitted and non admitted care services including specialist sexual health, paediatric HIV services and palliative care services; non government admitted and non admitted care services (including counselling, peer support, step down/supported accommodation, home-based and primary care); community-based care provided by general practitioners; arrangements for access to highly specialised drugs; laboratory services; and autopsy services.

Appendix C. Notifications of HIV, AIDS and AIDS deaths by year, NSW, 1981-2003



Year	HIV		AIDS		AIDS Deaths	
1981	2	0.0%	1	0.0%	1	0.0%
1982	1	0.0%	1	0.0%	0	0.0%
1983	2	0.0%	3	0.1%	1	0.0%
1984	206	1.6%	30	0.6%	6	0.2%
1985	1009	7.6%	91	1.7%	46	1.3%
1986	1108	8.4%	162	3.0%	108	3.1%
1987	1645	12.4%	250	4.7%	143	4.0%
1988	1152	8.7%	324	6.1%	139	3.9%
1989	990	7.5%	356	6.7%	238	6.7%
1990	828	6.3%	426	8.0%	326	9.2%
1991	824	6.2%	442	8.3%	344	9.7%
1992	699	5.3%	431	8.1%	329	9.3%
1993	592	4.5%	482	9.1%	378	10.7%
1994	504	3.8%	553	10.4%	423	12.0%
1995	534	4.0%	475	8.9%	355	10.1%
1996	449	3.4%	370	6.9%	272	7.7%
1997	424	3.2%	204	3.8%	125	3.5%
1998	405	3.1%	178	3.3%	69	2.0%
1999	375	2.8%	117	2.2%	64	1.8%
2000	350	2.6%	133	2.5%	70	2.0%
2001	337	2.5%	92	1.7%	38	1.1%
2002	387	2.9%	92	1.7%	26	0.7%
2003	412	3.1%	112	2.1%	31	0.9%
Total	13235	100.0%	5325	100.0%	3532	100.0%

Source: NSW Health Notifiable Diseases Database, 6 May 2004

D Appendix D. OATSIH funding for Aboriginal sexual health projects and NSW AIDS Program funding for Aboriginal services

2002/03 NIASHS – OATSIH special funding program Aboriginal sexual health projects funded by OATSIH with NSW Health top-up

Non Government Organisations	Recurrent funding
Redfern Aboriginal Medical Service	\$149,300
NSW Aboriginal Health & Medical Research Council	\$46,200
ACON (AIDS Council of NSW)	\$169,200
Awabakal Newcastle Aboriginal Co-op	\$49,900
Biripi Aboriginal Corporation Medical Service – Taree	\$49,900
Bourke Aboriginal Health Service	\$24,400
Bulgarr Ngaru Aboriginal Medical Service – Grafton	\$49,900
Coomealla Health Aboriginal Corp – Dareton	\$43,165
Daruk Aboriginal Medical Service – Mt Drutt	\$49,900
Durri Aboriginal Medical Service – Kempsey	\$49,900
Katungul Aboriginal Corporation – Narooma	\$49,900
Pius X Aboriginal Medical Service – Moree	\$49,900
South Coast Medical Service – Nowra	\$49,900
Walgett Aboriginal Medical Service	\$61,900
Wellington Aboriginal Medical Service	\$49,900
Sub Total	\$943,265
Area Health Services	
Macquarie Area Health Service	\$42,560
Central Coast Area Health Service	\$44,000
Southern Area Health Service	\$44,400
Greater Murray Area Health Service	\$68,160
New England Area Health Service	\$96,000
Western Sydney Area Health Service	\$44,000
Illawarra Area Health Service	\$62,218
Mid North Coast Area Health Service	\$38,000
Northern Rivers Area Health Service	\$76,000
Central Sydney Area Health Service	\$64,600
Mid Western Area Health Service	\$42,000
South Eastern Sydney Area Health Service	\$60,065
South Western Sydney Area Health Service	\$44,000
Far West Area Health Service	\$79,000
Sub Total	\$805,003
TOTAL (recurrent allocations)	\$1,748,268
OATSIH contribution	\$1,736,000
Balance – NSW Health top-up	(\$12,668)

**Appendix D. OATSIH funding for Aboriginal sexual health projects
and NSW AIDS funding for Aboriginal services**

2002/03 NSW AIDS Program funding (State contribution)

Projects	2002/03 Funding
Balance - NSW Health top-up to OATSIH Funds	\$12,668
AH&MRC additional funding for:	
Diploma Coordinator	\$35,800
Aboriginal Sexual Health Training Development Project	\$80,000
One Network Development Project @ MNCAHS	\$80,000
Specific care and treatment funds to Redfern AMS	\$26,100
A number of small one-off projects allocated as part of the EOI process for the NSW HIV Health Promotion Plan	\$177,500
NSW ASHAC Support	\$20,000 (approx)
Annual Sexual Health Workers Network Training Meeting	\$15,000 (approx)
Clinical & PCR/NAA – services support	\$20,000 (approx)
Project coordination	\$37,000 (approx)
Funding of NSP specifically targeting Aboriginal & Torres Strait Islander Populations	\$600,000 (approx)
Aboriginal HIV/AIDS Client Special Support	\$140,000 (approx)
% of general Sexual Health, AIDS and Hepatitis C funding targeting Aboriginal & Torres Strait Islanders based on 2.05% of the population of NSW	\$1,510,000 (approx)
Total	\$2,754,068

E Appendix E. Role delineation guidelines

Sexual health services

Level	Description
1	Emergency services provide assessment, treatment and appropriate referral by RN or Medical Practitioner with limited training in STD/HIV. Quality assurance activities. Access to identified sexual health services. Level 1 Pathology. Provide health information through pamphlets and other media. Interpreters as per Circular 94/10. Needle and Syringe Program secondary outlet.
2	As Level 1 with designated clinic sessions run by a Medical Officer with recognised qualifications (assessed by Area/hospital credentialing committee) in sexual health or a GP with training in sexual health and an experienced RN. Limited outreach facility (contact tracing, education). Links with and consultation and referral to and from GPs; other specialist medical services; HIV/AIDS service, community, women's and Aboriginal health services. On site microscopy. One to one patient education.
3	As Level 2 plus specialist Medical Officer with recognised qualifications in sexual health and a multidisciplinary team, including counsellors and nurses with experience and training in sexual health available. Access to CNC experienced in sexual health is desirable. Sexual health promotion and education programs planned, monitored, implemented and evaluated in liaison with health promotion service. Access to a range of specialist medical services (eg gynaecology, colposcopy, dermatology, immunology, infectious diseases). Link with sexual assault services. Formal links with GPs through Division of General Practice, HIV/AIDS service, community, women's and Aboriginal health services. Access to Level 4 Pathology Service. Formal interagency collaboration with relevant Area government and NGOs. Formal quality assurance program.
4	As Level 3 plus formal link with specialist medical services. Provides professional development, including GP training and support. May undertake research. Multidisciplinary sexual health promotion programs with evaluation and monitoring of those programs. Formal link with health promotion service and HIV/AIDS service.
5	As for Level 4 plus medical team comprising Medical Officers with recognised qualifications in sexual health and clinics in relevant specialty areas such as dermatology and colposcopy. Clinical and sexual health promotion research and professional development programs.

HIV/AIDS

Level	Description	Minimum Level of Support Services							
		Path	Phar	Diag/ Imag	NMed	Anaes	ICU	CCU	Op/s
1	Limited range of community services provided by non-specialist staff in consultation with GPs. Access to specialised community health services for consultation and referral. Quality assurance activities. Interpreters as per Circular 94/10. Provide health information through pamphlets and other media. Needle and Syringe Program secondary outlet.	Not applicable							
2	As Level 1 plus access to HIV testing, multidisciplinary health, sexual health, or community HIV clinic staff providing a range of assessment, home care, counselling, information, education and prevention programs. Counselling and support services by a range of disciplines. Link with sub acute and palliative care beds.	Not applicable							
3	As Level 2 with access to inpatient beds managed by physician or Medical Practitioner with training in HIV Medicine. Has experienced RNs. Formal quality assurance program. Access to sexual health and/or community HIV clinic desirable. Support services as for Level 3 General Medicine.	3	3	3	–	2	3	3	2
4	As level 3 with formal links between hospital and community support services including home care and respite care and at least Level 3 Palliative Care Services. Management by physicians or Medical Officer experienced in the management of HIV and related diseases. Support services as for Level 4 General Medicine. Health promotion and education programs planned, monitored, implemented and evaluated in liaison with Health Promotion service. Formal links with GPs through Divisions of General Practice; Level 3 Sexual Health Service. Formal interagency collaboration and relevant Area government and NGOs. If there is a designated unit, a NUM and RNs with post basic qualifications is desirable.	4	4	4	–	4	4	4	2
5	As Level 4 with specialist multidisciplinary team with experience and training in HIV, including allied health professionals and social workers. Management by specialist immunologist or infectious diseases physicians. Participates in research, community education and professional development programs and consultative outreach programs. Strong link with Level 5 Palliative Care Service. Community support program including formal link with home and voluntary NGOs. Facilities for ambulatory and same-day admitted care. On site specialist medical staff in areas such as neurology, oncology, psychiatry, respiratory and gastroenterology. Accepts referrals from lower levels. Specialist O/P Clinic. Access to CNC experienced in HIV is desirable. Level 4 Operating Suite, other support services as for Level 5 General Medicine.	5	5	5	4	4	4	4	4
6	As Level 5 plus nominated Director of Infectious Diseases/HIV/AIDS Inpatient and Community Services. May have designated Unit. May provide State referral role. Formal teaching and research role. Level 6 Operating Suite, other support services as for Level 6 Immunology.	6	6	5	5	5	5	4	6

F

Appendix F. HIV/AIDS services in Area Health Services

South Eastern Sydney Area Health Service

Service	Description	Size/frequency of service/utilisation			
St Vincent's					
Inpatient services	Designated beds	22 bed ward shared with Gastroenterology. HIV/AIDS patients vary from 6 to 12 at any time.			
	Palliative care beds at Sacred Heart Hospice		2000/01	2001/02	2002/03
		No. of pts	62	62	50
		Median LOS	12	13	14
	No. of patients who stayed > 90 days	3	5	4	
Non Inpatient services					
Immunology B Ambulatory Care (IBAC)	Chairs and beds to treat opportunistic infections, provide prophylaxis treatment, blood transfusions, chemotherapy; there is also a procedure room, negative pressure room	6 chairs and 2 beds			
	Specialised HIV medical outpatient clinics	30 clinics per month			
	HIV psychiatry clinics	4 clinics per month			
	Dental service	4 days per week 1164 occasions of service in 2002/03			
	Allied health – social workers, dietician, psychologist, physiotherapists, pharmacist	5 days per week			
	PEP clinic, PEP Hotline, Statewide 24 hours/day HIV treatment support service, STI screening, HIV screening		2000/01	2001/02	2002/03
		Assessment and management of patients requiring PEP	397	797	1102
	Health promotion – safe sex, drug and alcohol, Quit smoking, STI advice and prevention, HIV treatment adherence support and advice.				
HIV Neuro-psychology Service	This service is based at St Vincent's (STV) but is an Area wide service. Referrals come from STVs inpatient and outpatient services, STV's community health, H2M, ASC and POW hospital.				
St Vincent's Community Health	A multidisciplinary team of nurses, occupational therapists, physiotherapists, social workers, podiatrists, mental health nurses who provide a range of services to PLWHA including assessment and assistance with ADL, palliative care, medication and health monitoring, case coordination, GP liaison.	There are 86 clients being seen by this service: 30 have HIV only; 11 have HIV and HCV, 3 have HIV and mental health problems; 10 have HIV, HCV and mental health problems.			
H2M (HIV, HCV and Mental Health Service)	This service provides several GP s with access to mental health assessments for people infected with HIV or HCV. Assessments are conducted by a CNC, clinical psychologist or psychiatrist. Treatment is offered for anxiety and depressive disorders.	5 days per week 160 clients have been seen since the service began 16 months ago.			

Appendix F. HIV/AIDS services in Area Health Services

Service	Description	Size/frequency of service/utilisation			
Prince of Wales					
Inpatient services	Designated beds	10 beds shared with ID and Immunology			
Non Inpatient services					
Day treatment	Chairs and beds to provide IV therapy; procedures	3 chairs and 1 bed			
Outpatient services	HIV medical clinics Psychiatry clinic Social work, dietetics, pharmacy	2 clinics per week 1 clinic per week On demand			
Albion Street Centre (ASC)	ASC is an ambulatory/outpatient facility of the POW hospital, providing HIV/AIDS and HCV and sexual health care. Multiple concurrent clinics are conducted 5 days a week including medical clinics, nursing clinics, nutrition clinics, sexual health clinics (focused on HIV infected clients and those at risk of acquiring HIV), psychology service, social work service, pharmacy service. There is a 2 bed, 2 chair facility for day treatment and procedures including liver biopsy, blood transfusion, lumbar puncture, IV administration. ASC provides outreach nutrition and psychology clinics in high caseload GP practices and HIV non government organisations.	Occasions of service			
		Clinical Unit	2000/01	2001/02	2002/03
		Medical/ Nursing	20,138	19,159	20,044
		Psychology	6,740	7,288	6,905
		Nutrition	780	793	942
	Pharmacy	21,620	24,543	25,485	
Sydney Hospital					
Sydney Sexual Health Centre	Sydney Sexual Health Centre (SSHC) provides a tertiary referral service for people with sexually transmitted diseases. Services include screening, vaccination and management of sexually transmitted infections including HIV and Hepatitis A, B and C, education, individual and couple counselling and a needle and syringe program. The centre also provides professional training for health care workers.	2000/01	2001/02	2002/03	
		Total clients	6906	7368	7874
		Total attendances	17113	17898	18243
		Total OOS	73827	81835	87305
		Total HIV clients	170	187	194
	Total HIV attendances	963	855	931	
Kirketon Road Centre	Located in Sydney's Kings Cross, the Kirketon Road Centre (KRC) is involved in the prevention, treatment and care of HIV/AIDS and other sexually transmitted infections among "at risk" youth, sex workers and injecting drug users. KRC provides medical, nursing, counselling and social welfare services. KRC also operates comprehensive needle/syringe, outreach and methadone access programs.	Clients attending sexual health/HIV service	2041	1830	1908
		OOS for above clients	11,441	11,828	10,432
St George					
Inpatient services	No designated beds				
Outpatient services					
Waratah clinic	HIV multidisciplinary (medical, nursing, social work) outpatient clinic	2000/1	2001/2	2002/3	
			5895	2778	
Sexual health clinic		970	940	967	
		OOS	4800	4907	5023

Central Sydney Area Health Service

Service	Description	Size/frequency of service/utilisation			
Inpatient services	Designated beds at RPA and Concord Palliative care at RPA and Concord The Bridge – provides 24 hour supervised high level nursing care for clients capable of living within a shared facility who can no longer live alone or whose carers can no longer cope.	4 beds at RPA 2 beds at Concord (shared with Immunology) 12 beds including 1 respite (increased from 7 beds in 1999)			
Allied Health	Physiotherapy, occupational therapy, dietetics, social work available from RPA and Concord Hospitals				
Non inpatient services					
Day treatment	15 chairs/beds at RPA		2000/01	2001/02	2002/03
		Day stay	151	68	83
		HIV Drop In	100	127	74
Outpatients clinics at RPA	There are 6 clinics a week that HIV+ people can attend. The specific HIV clinics are: HIV Immune Monitoring clinic HIV Tues am clinic HIV Tues pm clinic HIV Haemophilia clinic (30 patients with HIV) offered every 2nd month		2000/01	2001/02	2002/03
		Immune monitoring OOS	1275	1209	1317
		Tues am OOS	944	1054	1023
		Tues pm OOS	406	410	352
		HIV Haemophilia OOS	97	82	88
HIV Consultation/ Liaison Psychiatry	This service is based at RPA and consists of a part time psychiatrist, psychiatry registrar and clinical psychologist and provides psychiatric assessment and management for patients referred from CSAHS HIV/AIDS service. Psychiatric care is provided for approximately half of the residents of the Bridge. A small number of referrals come from CS Mental Health. The service has links with neuropsychology services in CSAHS.	In the second 6 months of 2003, this service provided care and assessment for 24 medically admitted patients, 65 non admitted patients (at an average of 4 OOS each), and 6 residents of the Bridge (between 6 and 12 OOS each in 6 months).			
Palliative Care	The CSAHS Palliative Care Service provides a comprehensive integrated service and sees patients in hospital, at clinics and at home.	HIV OOS 2000/01	HIV OOS 2001/02	HIV OOS 2002/03	
		28	22	21	
CSAHS HIV Community Health	This service is based at Redfern CHC and consists of • Positive Central • Positive Heterosexuals • Sanctuary Positive Central is an Area wide community based HIV allied health team comprising 7.5 FTE – physiotherapists, occupational therapists, social workers, dieticians. Positive Heterosexuals (Pozhets) is a statewide service and consists of 2.6 FTE who provide peer education and support to positive heterosexuals and their partners and families. They have a statewide free call number and offer phone counselling and information. They also have a monthly newsletter and they provide outreach services to clients and staff rural Areas. The Sanctuary is a complementary therapy centre staffed by 1.0 FTE and volunteers. It provides massage therapy, shiatsu, yoga and other complementary therapies.		2000/01	2001/02	2002/03
		Individual OOS	2703	3454	4049
		Group OOS	1427	1431	1534

Appendix F. HIV/AIDS services in Area Health Services

Service	Description	Size/frequency of service/utilisation			
HIV Community Mental Health	Two nurses (CNC and CNS) provide case management for people with HIV and a mental illness. They also provide education and consultation for people at risk of HIV in mental health settings and to staff of mental health services.	July to Dec 2003			
		No. of clients	52		
		No. of OOS	591		
Community nursing		Sept 02 to Aug 03			
		OOS	836		
PEP	PEP is offered through Emergency Depts in all hospitals in the Area.	In the last three years PEP has been prescribed to 171 patients.			
Sexual Health Service	Service located at Livingstone Rd in Marrickville. Provides outreach clinics at Newtown, Canterbury Hospital, Rozelle Hospital, RPA Women's and Babies. Health promotion workers are collocated with the sexual health service. Sexual health service has a strong GP education focus.		2000/01	2001/02	2002/3
		Total clients	1753	1858	2284
		Total OOS	5701	5664	6988
		Total HIV clients	119	125	231
		Total HIVOOS	510	550	958
		HIV clients for HIV management	26	30	51
	HIV management OOS	339	375	461	
Drug and Alcohol	Counselling is available to PLWHA through the HIV Mental Health team and the Area Drug Health Services.	In 2003, 29 PLWHA were seen and treated by the Area Drug Health Services.			

Northern Sydney Area Health Service

Inpatient:

Number of designated HIV beds: Nil

Number of chairs/beds for day treatment: 3

Non inpatient:²⁵

Service	2001	2002	2003
Outpatients			
HIV clinic three times/week	1697	2396	2150
Psychiatric consult clinic	45	50	40
Massage clinic (discontinued Jan 04)	192	384	384
Allied Health			
Counseling	527	540	492
Pharmacy (treatments)	158	123	162
Psychiatry	~ 45	~ 50	~ 40
Dietetics	10	10	12
Community Health			
Clinic 16 – home treatments, consults, psych social support	70	81	87
NorthAIDS	25	28	30
Northern Sydney Home Nursing	27	16	12
NSH Sexual Health (RNS and Manly)			
Total clients	2115	2582	2826
Total OOS	5311	6695	8348
Total HIV clients	49	64	79
Total HIV OOS	209	457	690
HIV clients for HIV management	22	22	19
HIV management OOS	–	–	–

²⁵ All figures are for occasions of service (OOS) unless otherwise stated.

Western Sydney Area Health Service

Inpatient:

Number of designated HIV beds: 4

Number of chairs/beds for day treatment: 2

Non inpatient:²⁶

Service	2001	2002	2003
Outpatients			
Infectious diseases twice weekly 13 people per clinic	-	-	-
Immunology	692	635	614
Allied Health			
Social work	-	-	5-6 clients/week
Dental	-	-	6 per year
Other			
Mental health	-	-	-
Drug and alcohol	-	-	-
Palliative care	-	-	-
Parramatta Sexual Health Service			
Total clients	3821	4018	4222
Total OOS	9825	9362	9075
Total HIV clients	106	101	112
Total HIV OOS	1040	809	788
HIV clients for HIV management	-	-	-
HIV management OOS	-	-	-
Luxford Sexual Health Service			
Total clients	244	280	300
Total OOS	500	612	629
Total HIV clients	5	7	10
Total HIV OOS	27	49	77

²⁶ All figures are for occasions of service (OOS) unless otherwise stated.

Hunter Area Health Service

Inpatient:

Designated HIV beds: Nil

Chairs/beds for HIV day treatment: 6

Non inpatient:²⁷

Service	2001	2002	2003
Outpatients – Immunology and ID			
Medical	185	387	447
Nursing	n/a	182	296
Allied Health			
Dietetics	24	17	28
Social work	n/a	n/a	251
Physiotherapy	n/a	n/a	240 ²⁸
Occupational therapy	n/a	n/a	n/a
Hunter Sexual Health			
Total clients	–	–	–
Total OOS	4510	5326	5176
Total HIV clients	–	–	–
Total HIV OOS	29	36	39
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–

South Western Sydney Area Health Service

Inpatient:

Number of designated beds: 2

Chairs/beds for day treatment: 1

Non inpatient:²⁹

Service	2001	2002	2003
Outpatients			
Bigge Park Centre HIV clinic	1800	2500	2000
Bigge Park Centre Counselling	476	410	546
Bigge Park Sexual Health Service			
Total clients	–	–	–
Total OOS	4495	6394	12447
Total HIV clients	–	–	–
Total HIV OOS	–	–	–
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–

²⁷ All figures are for occasions of service (OOS) unless otherwise stated.

²⁸ Group fitness class.

²⁹ All figures are for occasions of service (OOS) unless otherwise stated.

Wentworth Area Health Service

Inpatient:

Number of designated HIV beds: Nil

Number of chairs/beds for day treatment: Nil

Non inpatient:³⁰

Service	2001	2002	2003
Katoomba Sexual Health Service			
STI OOS	1035	961	979
HIV OOS	688	592	578
Nepean Sexual Health Service			
STI OOS	3802	4048	3935
HIV OOS	688	424	424
Hawkesbury Sexual Health Service			
STI OOS	550	675	676
HIV OOS	73	89	69

Central Coast Area Health Service

Inpatient:

Designated HIV beds: Nil

Non inpatient:³¹

Service	2001	2002	2003
Central Coast Sexual Health			
Total clients	1243	1353	1619
Total OOS	3734	4213	5048
Total HIV clients	72	68	72
Total HIV OOS	8809	657	583
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–
Other			
Psychologist	119	54	55
Dental	n/a	n/a	n/a
Nutrition	n/a	n/a	n/a
Social work	n/a	n/a	7
Oncology	n/a	n/a	1

³⁰ All figures are for occasions of service (OOS) unless otherwise stated.

³¹ All figures are for occasions of service (OOS) unless otherwise stated.

Illawarra Area Health Service

Inpatient:

Designated HIV beds: Nil

Non inpatient:³²

Service	2001	2002	2003
Sexual Health Service			
Port Kembla and Shoalhaven combined			
Total clients	1547	1611	1547
Total OOS	3289	3411	2895
Port Kembla			
(HIV testing and treatment including s100, counseling) OOS	377	201	97 ³³
Shoalhaven (HIV testing and treatment including s100, counselling) OOS	83	107	100
Other			
Port Kembla			
Pharmacy	No data	No data	No data
Dental			
Shoalhaven			
Pharmacy			
Dental			
Referrals to AOD, mental health, palliative care	No data	No data	No data

³² All figures are for occasions of service (OOS) unless otherwise stated.

³³ Data not up-to-date.

Northern Rivers Area Health Service

Non inpatient:³⁴

Service	2001/02	2002/03
Outpatients – Lismore Base – no designated HIV clinic	High caseload	
HIV (SHAIDS, Tweed, Byron, Ballina, Grafton CHC		
Clients	277	355
OOS	1559	2509
STI		
Clients	1030	1470
OOS	2346	2082
HCV		
Clients	47	41
OOS	188	196
Total		
Clients	1354	1866
OOS	4093	4787
Dental – Area		
Client numbers	88	97
OOS	281	298
NSP OOS	19,385	19,729
Number of needles	521,495	560,613

³⁴ All figures are for occasions of service (OOS) unless otherwise stated.

New England Area Health Service

Non inpatient:³⁵

Service	2001	2002	2003
Outpatients			
Chest clinic	–	–	4
Allied Health			
Dental clinic	4	1	0 ³⁶
Pharmacy Tamworth	15	15	15
Pharmacy Armidale	28	4	22
Counselling	14	0	0
Other			
Mental health	6	7	2
Palliative care	1	1	0
Drug and alcohol	n/a	n/a	n/a
Sexual Health			
Bligh Street Clinic			
Total clients	691	771	732
Total OOS	1743	1735	1992
Total HIV clients	22	14	18
Total HIV OOS	215	110	225
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–

³⁵ All figures are for occasions of service (OOS) and they equate to attendances. They do not include phone calls unless the patient is a registered patient.

³⁶ Funding ceased in 2002.

Mid North Coast Area Health Service

Non inpatient:³⁷

Service	2000/01	2001/02	2002/03
Outpatients			
Port Macquarie Community Health – clinic 33 HIV specialist clinic	101	96	108
Coffs Harbour Health Campus – clinic 916 HIV specialist clinic	61	72	87
Hospital Based Allied Health			
Manning Base Dental, dietetics, pharmacy, occupational therapy, psychology	Increase in demand for dental and pharmacy	Increase in demand for dental and pharmacy	Increase in demand for dental and pharmacy
Port Base Dietetics, pharmacy, occupational therapy, psychology	Increase in demand for pharmacy	Increase in demand for pharmacy	Increase in demand for mental health, pharmacy
Kempsey District Dental, dietetics, pharmacy, occupational therapy, psychology	Demand for dental and pharmacy	Increase in demand for pharmacy	Increase in demand for dental and pharmacy
Coffs Harbour Dental, dietetics, pharmacy, occupational therapy, psychology	Increase in demand for dental and pharmacy	Increase in demand for dental and pharmacy	Increase in demand for dental, dietetics and pharmacy
Other (including mental health, drug and alcohol, sexual assault, Aboriginal health, health promotion, nutrition/dietician, community nursing, diabetes)			
Taree Community Health	11	26	39
Port Macquarie Community Health	8	22	35
Kempsey Community Health	3	5	8
Coff's Harbour Community Health	12	35	49
Taree Sexual Health (2 days/week)			
Total clients	–	–	–
Total OOS	1981	1023	1612
Forster Sexual Health (2 days/week)			
Total clients	–	–	–
Total OOS	416	676	624
Coffs Harbour (5 days/week)			
Total clients	–	–	–
Total OOS	1196	1360	1784
Port Macquarie/ Kempsey SHS (not fully operational)			
Total clients	–	–	–
Total OOS	149	163	237

³⁷ All figures are for occasions of service (OOS) unless otherwise stated.

Macquarie Area Health Service

Non inpatient:³⁸

Service	2000/01	2001/02	2002/03
Hospital based service Pharmacy			Approx. 9 patients receive their drugs through Dubbo Base pharmacy
Macquarie Sexual Health			
Total clients	9	n/a	7
Total OOS	86		45
Total HIV clients	–	–	–
Total HIV OOS	–	–	–

Mid Western Area Health Service

Non inpatient:³⁹

Service	2000/01	2001/02	2002/03
Mid Western Sexual Health			
Total clients	–	–	–
Total OOS	714	1227	1457
Total HIV clients	–	–	–
Total HIV OOS	21	43	40
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–

Greater Murray Area Health Service

Non inpatient

Service	2000/01	2001/02	2002/03
Greater Murray Sexual Health			
Total clients	–	–	–
Total OOS ⁴⁰	n/a	4147	5827

³⁸ All figures are for occasions of service (OOS) unless otherwise stated.

³⁹ All figures are for occasions of service (OOS) unless otherwise stated.

⁴⁰ OOS refers to attendances. They do not include consultations by allied health staff or referrals to drug and alcohol, mental health, pharmacy etc. Some phone calls are included.

Southern Area Health Service

Non inpatient:⁴¹

Service	2000/01	2001/02	2002/03
Southern Sexual Health (6 sites)			
Total clients	–	–	–
Total OOS ⁴²	2180	2058	2331
Total HIV clients	17	19	18
Total HIV OOS	100	102	101
HIV clients for HIV management	–	–	–
HIV management OOS	–	–	–

Far West Area Health Service

Non inpatient:⁴³

Service	2000/01	2001/02	2002/03
Far West Sexual Health (4 sites)			
Total clients	–	–	–
Total sexual health nurse OOS	–	–	784
Total HIV clients	–	–	–
Total HIV OOS	–	–	12
Number of OOS provided by Sydney Sexual Health OOS to HIV clients	–	–	70
SH attendances at ED (excl. BHBH)	–	–	214
SH attendances to BHBH ⁴⁴	–	–	Not known but estimated to be over 600

⁴¹ All figures are for occasions of service (OOS) unless otherwise stated.

⁴² Refers to individual OOS.

⁴³ OOS in FWAHS refer to clinic attendances.

⁴⁴ A large number of people go to BHBH Emergency Dept for conditions that would be treated by a GP or a Sexual Health clinic in other Areas. GPs in Broken Hill are limited in number and many of them have closed their books to new patients. None of them bulk bill. None of the four Sexual health services in the FWAHS have a medical officer on staff, only a visiting specialist to each hub once every two months.

Corrections Health Service

In NSW there are 28 correctional centres, nine juvenile justice centres, police cells, transitional centres and court complexes that house inmates and juvenile detainees. Currently there are 37 inmates with HIV/AIDS and they are spread throughout the correctional system across NSW. Six of these inmates are Aboriginal and eight are from CALD backgrounds. The major risk for HIV is drug injecting practices – sexual risk is relatively less important than for those in the community.

Services for sexual health, HIV/AIDS and blood-borne viruses are funded solely by the NSW Health AIDS Budget. This budget originally (1991) funded a service model for mandatory HIV screening on entry into the correctional system. This model of screening was replaced by a comprehensive targeted screening program.

Corrections Health Service offers two specialist on-site clinics per month (at Silverwater and Long Bay Complexes). These clinics are part of a comprehensive service provided by the Sydney Sexual Health Service through a funded Memorandum of Understanding (MOU) between South Eastern Sydney Area Health Service and Corrections Health Service, which has been in place since April 2003. Other components of this MOU are telephone support for CHS staff, and clinical assessment of inmates residing at remote correctional centres.

A statewide network of public health/sexual health nurses provides ongoing monitoring and support to inmates with HIV/AIDS. This network is supported by the Clinical Nurse Consultant Sexual Health (CHS).

All inmates can access sexual health services through the Targeted Screening Program within the Population Health Clinical Stream. Those diagnosed as HIV positive are offered care and treatment (as listed above). The Targeted Screening Program assesses risk and appropriate testing for a range of bloodborne viruses and sexually transmissible infections.

Inmates requiring low-dependency hospital management are admitted to B Ward at the Long Bay Hospital. Those requiring more intensive care are admitted to local community-hospitals, or if classified as high-security will be admitted to 'The Annex' at the Prince of Wales Hospital.

CHS does not have specific HIV/AIDS allied health services, although there is enhanced access to dental services within CHS.

Corrections Health Service does not currently have a community health service, however a Drug summit funded project (the Correctional Centre Release and Treatment Scheme) is trialling community interventions for a limited number of inmates pre- and post-release. This is not HIV specific, but this co-ordinated care model could be applied for HIV positive inmates, pre-release.

There is currently no funding for health promotion to Corrections Health Service. Limited funding is currently provided to the Department of Corrective Services HIV Health Promotion Unit.

Public Health Network staff (CHS) do provide some health education through group work and through individual clinical interaction.

Mental Health and Drug and Alcohol services are available to all inmates, with HIV positive inmates offered priority access. CHS also utilises the services of ADHAPT.

