

Non government services

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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.

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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

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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.

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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 StVincent'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

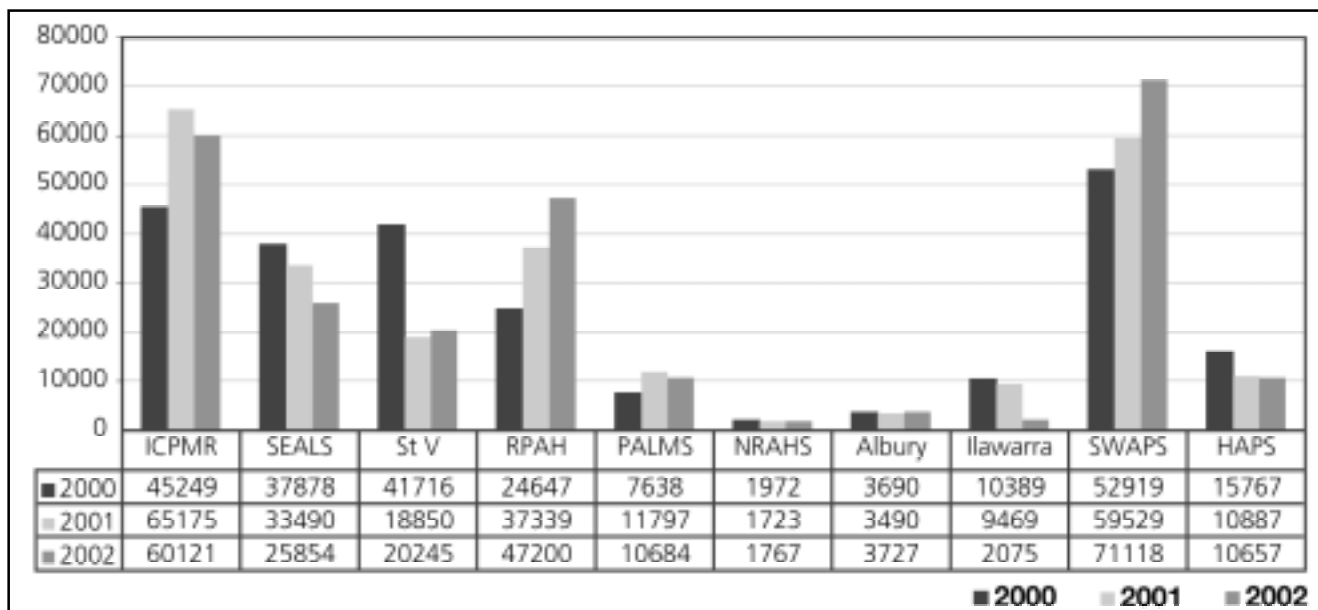
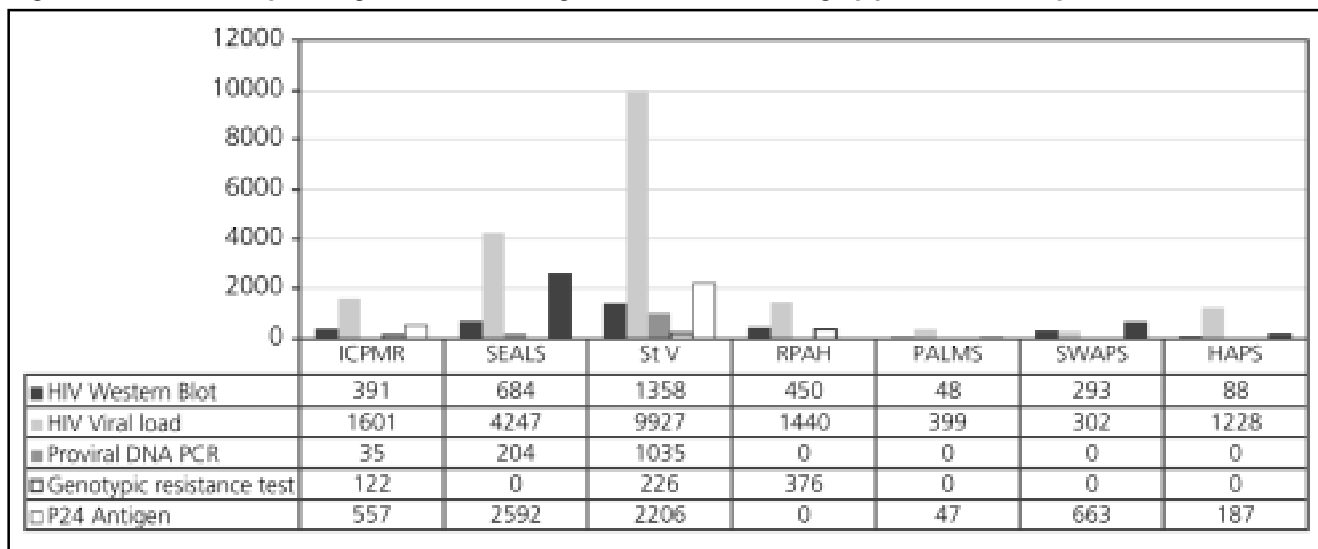


Figure 20. Confirmatory testing, viral load testing and resistance testing by public laboratory, 2001/02



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,

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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 Druitt	\$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.

